Guy's and St Thomas' NHS Foundation Trust

End of life care

Quality Report

Trust Office, 4th Floor Gassiot House
St Thomas' Hospital, Westminster Bridge Road
London
SE1 7EH
Tel: 020 7188 7188
Website: www.guysandstthomas.nhs.uk

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This report describes our judgement of the quality of care provided within this core service by Guy’s and St Thomas' NHS Foundation Trust. Where relevant we provide detail of each location or area of service visited.

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

Where applicable, we have reported on each core service provided by Guy’s and St Thomas' NHS Foundation Trust and these are brought together to inform our overall judgement of Guy’s and St Thomas' NHS Foundation Trust.
### Summary of findings

#### Ratings

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<td>Are services safe?</td>
<td>Good</td>
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<td>Are services effective?</td>
<td>Good</td>
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<td>Are services caring?</td>
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# Summary of findings

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End of life care Quality Report 24/03/2016
Summary of findings

Overall summary

We rated the community end of life care services at Guy's and St Thomas' NHS Foundation Trust (GSTFT) as ‘good’ overall. We found the end of life care (EOLC) team, specialist palliative care team (SPCT) and community nurses were passionate about ensuring patients and people close to them received safe, effective and good quality care in a timely manner.

During our inspection we asked the trust to gain consent from patients or bereaved relatives to speak with us about the care and support they had received from the community nursing, EOLC and/or the SPCT. We were advised that none of the five patients who were receiving care at this time were suitable to visit due to complex social circumstances and/or communication barriers; it was felt our visit would cause further distress to families and patients at a sensitive time. We were not provided with any contact details for bereaved relatives.

At the time of our unannounced inspection we followed the request up again. We were told that the trust had made a decision not to contact bereaved relatives to seek permission to provide us with contact details, therefore we were unable to evidence the views and opinions of people who had recently used the end of life care services. However we reviewed thank you cards and we witnessed staff talking about patients in a compassionate and considerate way during interactions with each other and in their description to us of how they cared for and supported patients and their families. They included patients and their families in discussions about their care and end of life plans; they considered social needs and family dynamics. Staff took conversations about prognosis, death and dying as far as was comfortable for the patient and their family; they displayed patience and understanding about how hard this dialogue could be. We were impressed that staff used other indicators to gain an understanding about the level of acceptance the patient may have. For example we observed one member of staff telling their colleagues at the weekly multidisciplinary (MDT) meeting that one of their patients was starting to accept they were dying as they noticed funeral directors information at their recent visit.

The trust responded to the independent review of the use of the Liverpool Care Pathway (LCP) for the dying patient and the subsequent announcement of phasing out the use of the LCP in July 2014. They created a document called ‘priorities of care’. 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. It was an open document so the whole MDT wrote about their interactions with the patient, any changes and the care and treatment provided, such as pain relief, symptom management and nutrition and hydration needs. Patient records/care plans were regularly updated, matched the needs of the patient at the time and were relevant to EOLC.

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 always act in the patient’s best interests should they assess the patient lacked the mental capacity to make decisions for themselves. However there was little understanding as to which forms were required to be completed and who could legally provide consent for best interest decisions on behalf of the patient.

There were regular MDT meetings to review all end of life patients who had or were being cared for using the trust’s ‘priorities of care’ or receiving palliative care services. If there was a clinically urgent case then joint visits or ad hoc meeting were organised as necessary. Incidents, complaints and concerns were also discussed at regular meetings and across the trust-wide meetings where appropriate.

Palliative and EOLC was provided by competent staff with a range of clinical and non-clinical skill mix. For example GPs, social workers and psychologists were employed by the trust as part of the team. We observed a flattened hierarchy amongst the teams. They were highly supportive of one another and open to challenge and advice on how to approach patient care and treatment. The EOLC and SPCT were highly trained and received continual consultant, doctor and pharmacy support.

The community nurses were given the confidence to care for palliative and end of life patients through training and support from the EOLC and SPCT. They were able to express their concerns if they felt out of their depth or
uncomfortable supporting patients at the end of their life. However some of the community nurses expressed a concern that sometimes there was no time for them to reflect and ‘gather themselves’ after someone dying prior to going to their next patient. Whilst most of the nurses told us it was not always necessary to take time out after a patient’s death there were occasions when “it gets to you.” The senior leaders expressed surprise that staff did not feel they could take time if they required it and assured us they would address this with local managers and team leaders.

We found the end of life care service was well led. Staff in the EOLC and SPCT spoke highly of their managers and valued their experience and the support they gave. All the staff, including those who worked part-time or had been newly recruited, told us they felt part of their team and appreciated by their colleagues. All the community staff said they felt very much part of the wider GSTFT team, one of them told us this was a positive change as they used to feel “like the poor relative” to the acute hospitals.

End of life care was a clear priority for the trust, including services provided within the community. A draft strategy to provide seamless good quality care was due to be presented to the board. The strategy had been developed in conjunction with the clinical commissioning groups (CCGs), local hospices, other hospital trusts and other organisations such as Macmillan Cancer and Marie Curie.
End of life care is provided to patients who have been identified as having entered the last twelve months of their life or less.

End of life care (EOLC) services for people living in the London boroughs of Southwark, Lambeth and Lewisham were provided by several organisations, Guy’s and St Thomas’ NHS Foundation Trust (the trust), GPs, three hospices and other organisations such as Marie Curie. The trust does not have any dedicated acute or community inpatient EOLC beds or dedicated beds at any of the three hospices.

The trust’s EOLC service is provided by two teams; the community specialist palliative care (SPCT) which was based at Guy’s Hospital and the community EOLC team which was based in locations within the clinical commissioning groups (CCG) areas of Lambeth and Southwark. These teams, although managed separately, worked together to provide community end of life care.

The community SPCT provide specialist support for people facing serious illness. They work closely with the patient’s GP, hospital doctors and district nurses to support the patient and those people who were important to them. The SPCT visit patients in their home and/or care homes and provide additional telephone support when required. They also see patients in outpatient clinics in hospital when appropriate.

The EOLC team provides support to patients and those close to them; and advises and assists the generalist community (district) nurses in the day-to-day care of patients who have entered the last twelve months or less of their life.

Our inspection team

Our inspection team was led by

Chair: Ellen Armistead Deputy Chief Inspector Care Quality Commission

Team Leader: Margaret McGlynn Interim Head of Hospital Inspection Care Quality Commission

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

Why we carried out this inspection

This was a scheduled comprehensive trust inspection.

How we carried out this inspection

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

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

During our inspection we spoke with 25 members of staff which included the trust lead for end of life care and local level service leads for SPCT and EOLC, community nurses, end of life nurses, clinical nurse specialists in palliative care (CNS), a social worker and a GP lead.

At the time of our inspection there were five patients in the community who were reaching the end of their life. We were unable to speak with any patients or their relatives as we were advised by staff that the families’ circumstances meant it was inappropriate for us to visit...
Summary of findings

patient’s in their homes to speak them about their experience of the care they receive. We asked the community SPCT matron, a EOLC nurse and the community head of nursing at the trust to seek permission from families who had previously used the service over the last year however we were not provided any details. We followed this up again on our unannounced visit and were told by the community matron that after a discussion with the deputy chief nurse they had decided not to approach any recently bereaved relatives; therefore were unable to speak directly with patients or their families who had experienced end of life care from the SPCT, EOLC team or the community nurses. To gain an understanding of people’s experience of the service we reviewed thank you cards.

We looked at three care records and a selection of thank you cards; and prior to our inspection we reviewed performance information from and about the hospital.

What people who use the provider say

We found that bereaved families and carers wrote passionately about the support they received from the EOLC and SPCT. They described staff as being ‘angels’ and as having ‘reassuring kindness’ which provided families with a ‘huge amount of support’. This was extended to the bereavement counselling support given by psychologists attached to the SPCT.

We observed from the abundance of letters and thank you cards that the SPCT and EOLC team provided a huge amount of support to families in caring for a relative dying in their own home. The letters and cards described how invaluable the support was in order to ensure the patient’s dying wishes were accommodated, many said they could not have done it without the teams’ continuous support.

Other cards told of how impressed families were with the teams’ approach. They described how the nurses were interested in the patient’s life and listened to their wishes, thoughts and concerns. Relatives and those close to them valued being involved in caring and sharing any concerns.

Another letter described the extended bereavement support they received through group counselling sessions with the psychologists in the SPCT. They said the counsellors were empathetic, understanding and provided them with tools to deal with their grief on a day-to-day basis.

Good practice

Community services had a dedicated end of life care (EOLC) team as well as a specialist palliative care team (SPCT). The SPCT supported patients who had complex illnesses and deaths and were not generally involved with patients who were dying through non-complex illnesses or old age. The EOLC team supported this patient group and the community nurses supporting them in their home.

Every day the community nurses held a safety meeting. They discussed patients who were identified as being at end of life (last 12 months or less of life) and shared any changes, issues or concerns.

The SPCTs multidisciplinary team meeting involved all members of the team who presented their patients and responded to challenges and offers of support from colleagues who may have different expertise or experiences and may help difficult or new situations.

Patient’s families and people close to them were given a leaflet that provided clear information about the dying process to help them understand the signs of a someone approaching the end of their life, why some interventions such as taking blood pressure were stopped and what to expect in the final stages of death.
Areas for improvement

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

The trust should consider training nurses in the palliative and end of life care to verify death. This would be beneficial to the bereaved as someone closely involved in their relative/friend’s death would officially verify death in a timely and sensitive manner and allow the release of the patient’s body to an undertakers within an appropriate timescale.

The trust should consider training the CNS and EOLC nurses to be independent prescribers and allow the nurses who are trained as independent prescribers to use the skills they have. This would allow patients to receive appropriate medication in a timely manner and alleviate pressure on the local and SPCT GPs.

The trust should ensure that all staff have a clear understanding of Deprivation of Liberty Safeguards (DoLS); that mental capacity is always appropriately assessed and recorded for patients who may lack capacity; and all staff know who can consent on the patient’s behalf and how this information should be recorded in patients’ records.
By safe, we mean that people are protected from abuse

Summary
End of life care services provided in the community were safe. People were protected from avoidable harm and abuse through a comprehensive safety system, and focus on openness, transparency and learning if things went wrong. Although there had been no recent serious concerns staff were aware of their responsibility to raise concerns and report incidents and near misses. The incident report information we reviewed clearly described the incident, action taken, investigation and follow up. The teams had regular meetings and any incidents, concerns and learning from them was discussed. Staff told us there was a "no blame culture" and saw incidents and concerns as a way to learn and improve safety.

Risks to patients who used the service were assessed, monitored and managed. This included signs of deteriorating health and medical emergencies. Medical records were person centred, completed by all healthcare professionals involved in their care; and the views of the patient and those important to them were fully taken into account. The ‘priorities of care’ took into account the patient’s individual prognosis and systems for reacting to critical clinical events. There were effective systems in place for prescribing and administering medicines to patients.

Staffing levels and skills mix were planned, implemented and reviewed to keep patients safe. Staff shortages were responded to quickly. There were staff vacancies within the SPCT and EOLC team. The potential for the quality of care and systems and processes to be compromised was identified on the risk register. Some specialist nurses worked bank shifts to cover gaps and some tasks were temporarily withdrawn to ease the current work load until the staff vacancies were filled. The change in service was monitored closely to ensure patients continued to receive safe and timely care.

All staff in the Specialist Palliative Care Team (SPCT) had received safeguarding vulnerable adults and safeguarding children training to an appropriate level for their role. All staff were required to complete mandatory training and the majority of staff within the SPCT had completed their training. The three members of the community EOLC team came under the community (district) nursing department. We were unable to ascertain through trust records whether the community EOLC team specifically had completed their mandatory training to the required level. Most of the team told us they had completed their training and had time to complete it.
Are services safe?

Safety performance

- The trust monitored safety performance and reported incidents to the relevant authorities. 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 requiring investigation (SIRI) in the last year.

Incident reporting, learning and improvement

- The trust had systems in place to report and record safety incidents, near misses and allegations of abuse.
- The trust reported patient safety incidents to the National Reporting and Learning System (NRLS). During the period 1 June 2014 to 16 July 2015 the trust reported 11 incidents relating to EoLC in the community. Nine of these were reported as no harm and two were recorded as low harm.
- All the nursing staff we spoke with told us there was a positive “no blame” culture for reporting incidents. Managers told us they encouraged reporting of incidents and ensured staff had time to complete incident reports. The team were keen to learn from incidents, change practice where appropriate and ensure the safety of patients. Staff told us they reported incidents or near misses when they returned to the office at the end of their working day. They were able to show us how they used the Datix incident reporting system.
- Incidents which took place within the community were contained in the community health services for adults incident report log. Managers reviewed all reported incidents and contributed to any further investigations. Staff received feedback from incidents reported.
- We reviewed information provided by the trust and noted between 1 February 2015 and 29 June 2015 there had been 18 incidents reported on Datix two of which were reported as causing harm to the patient.
- The reported incidents clearly identified the issue, outcome and learning from it. For example there was a reminder to staff about the importance of early escalation for patients who were seen to be deteriorating; a reminder to all staff about the need for communication across all the teams caring for the patient to ensure consistency in care; and contact with patients who could have been affected by a data breach when patient identifying information was left at another patient’s home.
- We reviewed meeting minutes from the 'Care in the Last Days of Life: Quality Assurance Group' which met on a monthly basis. Safety improvements were discussed using a variety of sources including incidents, complaints, safeguarding and clinical audits.
- Trust wide and local incidents and the learning from them were disseminated to staff through a number of formats, such as team meetings, emails and posters on notice boards. All the staff we saw spoke positively about the notice boards as they were able to access them easily each time they visited their office. We observed the information of the notice boards was current and up to date.
- The trust newsletter ‘Clinical Governance Quality Bulletin’ was sent out to staff on a monthly basis. This had key messages about incidents and the learning from them was shared and discussed in their own teams. Contact details were included for the adult community governance facilitator who staff could contact for support and advice.

Safeguarding

- There were arrangements in place to safeguard adults and children from abuse. Staff received safeguarding children and vulnerable adults training as part of their mandatory training. Staff received level two or three child protection training depending on their role. Training records showed that 100% of staff in the community EoLC and SPCT had completed adult safeguarding training and child protection training to a level that was required for their role.
- Staff understood their responsibilities in reporting safeguarding concerns and gave a clear account of how they would respond to hypothetical situations.
- Safeguarding referrals were considered if a patient refused care and support which was detrimental to their health. This was in line with the trust’s policy and the changes to safeguarding adult within the Care Act 2014 and the MCA requirements as part of the update. Staff were briefed about these changes through a bespoke safeguarding training update; since April 2015 just under 100 community staff had attended.
Are services safe?

- Staff could access the trust’s safeguarding policy and procedure through the intranet system. They also had access to social workers attached to the team for immediate support or to discuss any concerns.
- Nursing staff reported a close working relationship with the hospital’s community safeguarding team and gave us examples of concerns they had raised with the team to investigate. The reported incidents records showed where safeguarding concerns had been raised appropriately for a vulnerable adult living alone and recognised as dying.

Medicines

- There were arrangements in place to keep people safe and manage medicines for patients who were being cared for in their own homes.
- Patients who expressed a wish to die at home were discharged with prescribed anticipatory injectable medication and medication charts. Patients could also be discharged from the trust using a T34 syringe driver. The community nurses made up a box of the anticipatory medication to be held at the patient’s home. These were provided to patients whose condition required them. This could include going into crisis at short notice, or it may be in anticipation of serious deterioration of health. 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.
- The EOLC teams worked closely with primary care which meant that medicines were prescribed by the patient’s GP. Outside of the patient’s GPs working hours the community nursing team contacted the local GP on-call service. Nursing staff told us there were occasional issues in arranging mediation through GPs, however they told us it was usually due to miscommunication and was addressed and resolved very quickly after a conversation with the EOLC or SPCT.
- District nurses, EOLC nurses and clinical nurse specialists (CNS) undertook medicine administration and maintained syringe drivers where this was required. The syringe drivers were locked as per guidelines. This prevents other people, such as family members, altering or increasing medication doses.
- Although two CNSs and an EOLC nurse were qualified as independent prescribers they were not utilising this skill. We were told this was because it added to their already heavy workload, however it was hoped that once the teams were fully staffed they would be able to use this skill in order to provide a more responsive medicine service.
- GPs working with the SPCT discussed changes to patients’ medicines with the patient’s GP. The SPCT GPs were unable to prescribe as they did not carry the prescription pads (FP10), although there had been some discussion within the trust to change this practice so the GPs could prescribe while visiting patients in their homes. If a prescription was required urgently the GP would call the patient’s GP practice while they were visiting or return to the hospital to obtain an outpatients department prescription and take it to the local pharmacy for the patient’s relative to collect. If it was non-urgent the GP wrote to the patient’s GP and/or called them with the suggested changes.
- Community nurses used the trust medicine administration record (MAR) chart. We observed these were completed clearly and accurately, reflecting the prescribed medicines which were copied into the records and on the trust’s computer system.
- A pharmacist and a pharmacy technician had recently been recruited to work alongside the community nursing teams, initially for a one year contract. Currently all district nurses had access to the trust’s pharmacists and could contact them for any concerns. Nursing staff told us this resource was being used widely to support them with medication queries.
- Medicines were available through a local pharmacy up to 11pm Monday to Friday. Staff could obtain medicines from the pharmacy at either Guy’s or St Thomas’ hospitals if they should require it outside of these hours.

Environment and equipment

- Patients’ homes were assessed for suitability for home-nursing by occupational therapy (OT) services via social services, or from the Enhanced Rapid Response teams in Lambeth and Southwark. This ensured their home environment was suitable and safe to nurse them in.
- Patients admitted to hospital or a hospice had their home environment assessed by the hospital’s inpatient OT or local authority OT prior to being discharged. This ensured that patients were cared for in the most suitable environment with appropriate adaptations and equipment, such as a hospital style bed in a room that was easy to access.
• The trust had a collaborative system for the delivery, tracking and maintenance management of the T34 syringe drivers for use in both the acute hospitals and in the community; this was run by the medical equipment library at Guy’s hospital.
• A courier service was available between the hours of 9am to 3.30pm from Monday to Friday to deliver syringe pumps with a spare battery to patients requiring pain relief and being supported in their own home. Outside of these hours emergency pumps were kept at each district nursing base and in the palliative care on call bags; alternatively the on-call CNS could arrange collection of a pump from the equipment library and deliver it to the patient’s home.
• Emergency syringe drivers were kept at each district nursing base and in the palliative care on call bags for use outside of the equipment library hours.
• A tracking email update was produced weekly. Pumps were returned after single patient use for maintenance, however staff reported that it could be difficult to get pumps returned by families after use, even though a return envelope was provided. This meant nursing staff had to contact families to arrange for their return or collect them if more appropriate.
• The syringe drivers were all of a standardised type that conformed to national safety guidance on the use of continuous subcutaneous infusions of analgesia.

Quality of records

• We found patient's individual care records were written and well managed in a way that kept people safe. They were accurate, complete, legible and up to date.
• The trust used both electronic and handwritten notes. Staff attending to patients in the community completed a paper record which was held at the patient’s home so that everyone who visited had an up to date record of the patient's care and treatment. They also made a record of the care in their community nursing folder which was entered onto the electronic patient record in the trust's community offices at the end of their shift. This meant there was a duplication of records which staff said “was not ideal but unavoidable as other people involved in the patient’s care needed access to the patients records for continuity of care.” Staff were aware of the importance of ensuring electronic notes reflected the written records. The trust was exploring the use of portable electronic equipment so that electronic records were updated at the time care and treatment took place.
• The 'priorities of care' folder and all multidisciplinary notes were retained in one file and kept in the patient's home. Anyone involved in the patient’s care could add notes and follow the patient’s progress and the patient and those close to them were able to identify who to contact in an emergency or about any concerns.
• Patient records were kept in the patient's home until they died. The files were then returned to the office for completion and sent to the patient records department for safe keeping. At the time of our inspection there were three records of care for deceased patients being completed at the community office we visited. We observed all three were completed, concise, legible, notes were dated chronologically and the do not attempt cardiopulmonary resuscitation (DNACPR) orders were filed at the front. We found the plan was easy to navigate and track back who did what and when.
• We reviewed the three DNACPR forms in the records that had been returned to the office and 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 transferrable with the patient to their home, care/ nursing home or hospice. The patient’s GP was responsible for reviewing, amending and/or re-assessing a DNACPR directive as soon as possible after the patient was in the community setting. This ensured all interested parties fully understood the process. A GP was always the counter signatory where senior nurse had completed the DNACPR process.
• Patients with a DNACPR in place were logged onto a central computer recording system called ‘Coordinate my Care’ (CMC). Patients who had palliative care needs were identified on the computer system and all nurses were aware of the flagging system used. CMC allows other agencies, such as the ambulance service, know what the care plan and patient’s wishes are and therefore if they are called to the home can support the patient in the most appropriate way.

Cleanliness, infection control and hygiene

• We found the trust had systems in place to prevent and protect people from healthcare associated infections.
Are services safe?

- The trust has an infection prevention and control policy (IPC) and all staff received training in infection prevention and control. The staff we spoke with had a good understanding of IPC practices.
- The trust’s IPC scorecard for April 2015 to June 2015 showed community adult services had achieved an overall compliance 99% in hand hygiene and 100% for isolation and line continuing care (line insertion could not be accurately measured). IPC mandatory training was identified on this scorecard for each directorate, however it was not identified for community services. The trust’s overall score for mandatory training for this period was 74%; the trust’s target was 95%.
- Clinical staff took part in IPC training on an annual basis. At the time of our inspection 20 out of 28 SPCT staff had current training. For three staff their training was just out of date or very shortly due to be refreshed; and five members were out of date by some months or years in two cases. Records in relations to the community EOLC team showed that a senior member of staff had completed IPC training. The remaining EOLC nurses were under the community adults team and we were unable to differentiate the EOLC nurses from this information. However records showed that 82% of registered nurses in the community adults team had completed training; the trust’s target was 95% compliance.
- The EOLC and SPCT told us they had plentiful supplies of personal protective equipment (PPE) available to them at all times. They told us they always left PPE in the patient’s home for other healthcare professionals, such as Marie Curie nurses or health care assistants whenever they were employed to care for patients out of hours.

**Mandatory training**

- All staff took part in mandatory training to ensure they were trained in safety systems, processes and practices. Mandatory training details were displayed on the office notice board at the community nurse’s base we visited. Managers and the individual staff member received an alert to remind them to attend the course, they also received confirmation of the staff member booking the course and this information was entered on the staff rota.
- The adult community performance review scorecard target for staff completing mandatory training was 95%. Most of the EOLC nurses we spoke with told us they were up to date with their mandatory training modules and said they had time to complete the training. However one team member told us they had fallen behind with their mandatory training due to work load pressures. The team had achieved 76% compliance in completing all the mandatory training modules.
- The year to date average for the generalist community nurses was 87.3% which was lower than the target. Staff told us they often had difficulty taking time out to complete training as teams were short of permanent staff and very busy.
- Training records for the SPCT showed that a majority of staff had completed most of the mandatory training modules related to their role. However the way the information was presented to us made it difficult to calculate what percentage the team were compliant by.
- Conflict resolution training was available as part of mandatory training. We observed this had previously been a one off course and had recently changed to a three yearly refresher. All staff should be compliant by 1 October 2015. According to records provided by the trust none of the SPCT or EOLC team had completed the training.

**Assessing and responding to patient risk**

- End of life care advice and support was available outside of core working hours. A SPCT CNS and EOLC nurse was available on-call up to 11pm. From the 5th of October the SPCT’s over-night on-call service was restarting. One member of the community EOLC team was also available over the weekends. There was consultant support 24 hours per day seven days per week for urgent medical attention. A local hospice also provided a 24 hour telephone support line.
- Comprehensive risk assessments were carried out for people who used the services and risk management plans were developed in line with national guidance.
- Risk assessments were completed in relation to both the patient and environment. The ‘priorities of care’ plan identified nursing actions such as the patient’s comfort and wellbeing, hygiene and skin care, oral hygiene and continence needs. Review dates indicated when the patient’s needs should be reassessed to ensure appropriate care and professional support at every stage.
- The community nursing team had a daily safety briefing. This allowed the team to share information and discuss
Are services safe?

Concerns about specific patients. We observed a handover meeting and each member of the nursing team discussed patients whose health was deteriorating. This meant all the staff were aware of each other’s patients and would know how to respond to any changes. We observed staff referring to the EOLC nurse specialists if they required advice or felt the patient and family would benefit from further support from an end of life nurse specialist.

- The community nursing team had access to the community SPCT and the community EOLC team who were able to support the nurses with patients who were dying. The generalist nurses spoke highly of the support they received from these teams and said they had the confidence to call them if they had any concerns or issues.

- We observed staff handovers between the teams coming on and going off duty was timely and occurred everyday. The district nurses met daily and shared any concerns with the team, we observed them specifically talking about patients who may have deteriorated or were at end of life, they discussed referrals to the EOLC specialist nurses. The EOLC and SPCT informed the on-call OOH staff about any patient of concern and whether they expected any patients to die. These were a combination of face to face meetings, telephone conversations and emails.

Staffing levels and caseload

- The community SPCT was made up of the 1 whole time equivalent (WTE) head of nursing; 1WTE matron; 8WTE band 7 clinical nurse specialists (CNS), of which there were two vacant posts; and 3WTE band 6 CNS.

- The EOLC community nursing team had 1WTE consultant nurse; 0.8WTE EOLC practitioner; and 0.4WTE dual role specialist practitioner who, this nurse was due to become the full-time lead in the near future. We were told there was a 0.8WTE vacancy. The current size and structure of the community EOLC team was limited.

- Staffing levels had been identified as a risk that could potentially compromise achieving quality care for EOL patients and expected processes in time of high demand and/or staff absence. The staffing levels within the EOLC and SPCTs were on the risk register. The draft strategy for end of life and palliative care identified the number of staff required based on the local statistics and demographics for CCGs they serviced and therefore they knew the potential shortfall they had. There was an emphasis on staff retention and ‘growing’ their own staff to increase the number of staff in the teams.

- As a result of this band 6 CNS posts were introduced to enable the SPCT to train and develop nurses to eventually move into band 7 roles. The EOLC team’s vacant post was soon to be filled by the part-time role holder as they relinquished their community nursing responsibilities to be a full-time EOLC specialist nurse.

- Generalist community (district) nurses and the trust’s ‘@Hometeam’ supported end of life and palliative care patients across the boroughs of Lambeth, Southwark and Lewisham. There were no EOLC link nurses however there were a number of nurses that had a specialist interest in EOLC and felt confident in supporting patients at this stage of life.

- The SPCT was made up of 2WTE medical consultants; 0.8WTE trust grade doctor which was made up of two 0.4WTE GPs who were employed by the trust and worked at a GP practice in the local community outside of this time; 1WTE F2 doctor; and specialist trainee(s) which was dependent on training and service needs. The was consultant cover available 24 hours per day seven days per week, this was provided by an on-call rota system by consultants from acute hospitals and hospices.

- The SPCT was supported by a consultant pharmacist who specialised in palliative care.

- The community EOLC team received support from the trust’s community pharmacist.

- Psychologists worked alongside the SPCT. They offered psychological support to patients and those close to them, as well as staff.

- The SPCT had administrative support from a service manager and assistant service manager and receptionist/personal assistant support. All the clinical staff we spoke with talked highly of the administrative support they received.

- The SPC and EOLC community teams worked closely with primary and social care, Marie Curie and other voluntary sector agencies (none of these other providers were inspected at this time).

- The SPCT community team had 1WTE palliative care social workers attached to the team.

Case loads and staff levels and mix were reviewed regularly to ensure that patients received safe care and treatment at all times. As a result of this some of the
skills the specialist nurses had, such as prescribing, were not being utilised in order to ensure they reached more patients and could spend time supporting the community nursing teams. This did not mean that patients received poor or untimely care as their GP or consultants would be asked to prescribe any medication required.

- The average case load for a CNS was 37 patients at a time, there was usually between two and five patients coming to the end of their life at a time. Caseloads were discussed each morning, this meant staff could support one another should one of them have more patients or complex cases to see than one of their colleagues. New patients were triaged to ascertain the urgency to see them and identify any extra support required from other healthcare professionals. New cases were allocated to the lead CNS for the patient’s GP service.
- On average the EOLC team supported the community nurses with 70 patients who were identified as at end of life (less than a year of life) across the whole of Lambeth, Southwark and Lewisham. The needs of each patient were discussed at the community nurses’ safety meeting each day.
- The EOLC team and SPCT told us they were busy but felt they had sufficient time to provide a meaningful and quality experience for their patients. Senior staff acknowledged that some skills, prescribing, or training in further skills such as verifying death was not being utilised to allow the specialist nursing staff to reach more patients or spend more time supporting community nurses. We also observed many of the specialist and community nurses stayed beyond their hours in order to complete paperwork and patient’s computer records.
- It was hoped that once the two band seven CNS posts and the EOLC specialist nurse posts were staffed full-time this would alleviate any pressure and allow nurses to start to prescribe medicines when necessary and attend a course in verifying death.

**Managing anticipated risks**

- All community nursing staff were expected to adhere to the trust’s lone working policy and on-call procedures.

They each had a loan worker tracker device. This device had a GPS system to locate the individual and the ability to open a channel for the tracker call centre to listen into conversations should the member of staff find they were in a threatening situation. They could also trigger an emergency alarm if they were in immediate danger. The call centre informed the police of the situation. We observed staff being asked to test their tracker alarm so they could ensure all trackers were working.

- The SPCT or EOLC team attending patients’ homes OOHs were collected from their home by taxi. The taxi remained at the location until the member of staff had finished their visit and was ready to return home.
- The trust had a ‘no access’ policy to follow if they could not gain access to a patient’s home. This detailed the process to follow and information that should be recorded on the patients records.
- At local level community nursing teams told us they had systems in place to make sure people got visits despite bad weather. For example patients who did not need to be seen would be telephoned to check their health and welfare.

**Major incident awareness and training**

- The Trust had protocols in place to respond to major incidents and staff were of aware of escalation procedures for areas of risk. Training in ‘Resilience - Introduction to business continuity’ formed part of the mandatory training. We noted from information provided that training was planned and all staff were due to complete it by 1 October 2015. One member of senior staff from the SPCT had completed this training at the time of our inspection.
- A cascade system was in use in the event of a major incident, with staff being alerted by telephone or text, to inform them of any risks and action to take. The system was implemented effectively when a location was evacuated due to an unexploded world war two bomb being discovered on a nearby building site. All patients were seen although care was disrupted it was with minimal effect to patients.
Are services effective?

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

Summary
People in Lambeth, Southwark and Lewisham received end of life services that were assessed, planned, delivered and evaluated by highly skilled, trained and competent staff. Their care was planned and delivered in line with current evidence based guidance, standards, best practice and legislation.

The trust participated in the National Care of the Dying Audit however this did not include community services as it only relates to hospital services. At the time of our inspection the trust was in the process of auditing the standard of care for patient’s dying in the community and bereavement support.

We found the EOLC and SPCT aimed to support as many patients as possible to die in their preferred place and where this could not be achieved there was clear communication and rationale as to why. Patient’s needs were assessed on an individual and holistic basis which ensured the ‘whole person’, their social circumstances and those close to them were considered in their end of life care planning.

There was clear documentation which guided staff about having clear and open discussions in relation to the patient’s wishes, symptom management and pain control. Multidisciplinary meetings to discuss patients’ care took place and clinical staff demonstrated a clear understanding of their patients’ needs, were open to challenge and highly supportive of their colleagues in complex or difficult circumstances.

Deprivation of Liberty Safeguards (DoLS) was not always understood by the community or EOLC nurses; and mental capacity was not always appropriately assessed and recorded for patients who may lack capacity. Staff were knowledgeable about the need to act in patient’s best interest however they were not clear about who could consent on the patient’s behalf and how this information should be recorded in patients’ records.

Evidence based care and treatment
• EOLC was managed in accordance to national guidelines. Patient’s needs were assessed, their preferences were identified and holistic care was planned and delivered in line with best practice.
• The trust responded to the independent review of the use of the Liverpool Care Pathway (LCP) for the dying patient and the subsequent announcement of phasing out the use of the LCP in July 2014. They created a document called ‘priorities of care’. This personalised holistic care plan ensured the patient’s wishes were identified, their dignity was maintained, symptom control was discussed and there was consistency in care. The trust’s policy referenced ‘More Care, Less Pathway: a review of the Liverpool Care Pathway 2013’ and ‘One Chance to Get it Right 2014’. Staff spoke positively of this document as it brought the patient’s care into focus for all those involved. The trust was currently auditing the use of the document as part of their normal auditing procedures.
• The two-weekly community end of life care meeting reviewed all deaths within the community. They discussed patient outcomes, any lapses in protocols or procedures and identified good practice, staff did not report any significant concerns. This was attended by the community matron, EOLC nurse consultant, SPCT consultant and one of the community EOLC nursing leads.

Pain relief
• Patient’s pain was regularly assessed and appropriate pain relief was administered in a timely manner.
• Where appropriate patients had T34 syringe drivers which delivered measured doses of drugs at pre-set times. All qualified nursing staff were trained in EOLC and this included the use of a syringe driver and symptom control management.
• Patients, community nurses and GPs received further support, advice and guidance from the EOLC and 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

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Appropriate treatments and care, which included pain relief, nausea and vomiting. The community nurses told us they valued the support of the EOLC and palliative care teams.

- Patients in the community receiving end of life care were ultimately under the care of their GP who was responsible for prescribing medicines. The community nurses were responsible for administering any medicines prescribed.
- 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.

**Nutrition and hydration**

- Nutrition and hydration needs were identified in the patient’s care plan as part of their ‘priorities for care’ folder. Staff followed the trust’s and GMC’s guidelines for nutrition and hydration.
- Patients’ oral fluid and food intake was encouraged for as long as the patient was able to swallow. Hydration and nutritional needs were reviewed with the patient and people important to them and nurses acted on any concerns.
- The community SPCT and EOLC teams described how they supported families and those close to the patient in understanding why food and fluid intake changes for people who are in the dying phase of their life.
- Subcutaneous fluids (artificial hydration) could be administered. There are currently no universally accepted medical or nursing guidelines for the administration of subcutaneous fluids at the end of life. It is unclear whether giving parenteral fluids to people who are dying causes, rather than alleviates, symptoms therefore every case should be considered on an individual basis. Nursing staff told us they followed National Institute for Health and Care Excellence (NICE) guidance about using subcut fluids for other health conditions such as diabetes.
- The trust informed us they were continuing to develop and improve nutrition and hydration through a nutritional steering group. This group was due to be established.

**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 does not include community services as it only relates to hospital services.
- The trust were in the process of completing a full audit on the use of the ‘priorities for care’. They looked for key information such as, how and who initiated the document, conversations with patients and those close to them, who was involved in the patient’s care, response times for referral(s), GP responses, spiritual support and injectable medications being prescribed as per the guidelines. Interim audit results indicated further improvements in notifying the EOLC team through daily safety briefings held by the community nurses, providing regular feedback to the teams and continued training/joint visits. We observed a safety briefing and heard staff discuss patients who were receiving palliative or EOLC, and any patients they were concerned about could be escalated to the community EOLC or SPCT. The audit findings were fed back to the teams involved, which could include ward staff where referrals were not made in a timely or appropriate manner. The trust was planning on using the audit results as part of a process to develop an ‘out of hospital’ collaborative approach to support people who are dying in nursing/residential homes and in their own home.
- The ‘audit and service evaluation of patient discharges from the GSTFT community palliative care team’ dated September 2014 looked at the documentation of the patient discharge process and identified what happened to patients in the first six month after discharge from the SPCT. The audit showed the discharge process was generally good but things were missed usually because patients were omitted from the discharge spreadsheet. Recommendations from the audit included re-emphasising the importance of entering all the patients on the discharge spreadsheet to ensure comprehensive documentation of the discharge process; standardising terminology to give concise actions; considering ways to make key
Are services effective?

information stand out in notes; re-audit in 2015 and consider auditing reasons for re-referral. Staff were aware of the findings and were able to articulate the key messages and learning from the audit. We observed this in practice at the weekly team meeting.

- The EOLC team audited the DNACPR forms; the audit taken in May 2015 showed that 90% of patients had a completed DNACPR in their home. We were told any findings were fed back to the community nursing teams and management meetings.

Competent staff

- The EOLC and SPCT was made up of competent and highly trained individuals. A majority of the staff reported having the opportunity to develop and attend further education courses in line with their role.
- Training was provided by the SPCT and EOLC team for the wider team of community nurses, this included: a two day ‘transforming end of life care’ course, SAGE & THYME (a course in how to listen and respond to people who are distressed or concerned), simulation “one chance to get it right” training, joint visiting with role modelling and bedside teaching, and ad hoc teaching as requested.
- Members of SPCT / EOLC team have also delivered the Department of Health advanced communication skills training across the Trust
- The EOLC team provided syringe driver training, role modelling/mentoring and supported competency sign off in clinical practice and priorities for care support in practice.
- There was a transition programme for new nurses to ensure they are skilled and competent to provide generalist end of life care. They also had one to ones with the nurses to sign off the competencies.
- Community nurses were encouraged to shadow the EOLC nurse to observe difficult conversations and allow them to gain confidence in supporting patients and those close to them when discussing death and dying.
- The SPCT band 6 CNS’ were fully supported and mentored by the experienced band 7s, matron and consultant. They had competencies to complete prior to being able to work alone in the community. This was expected to take up to 18 months to complete.
- The SPCT was made up of nurses with different expertise as they had previously worked in different fields, such a heart failure or oncology. The less experienced CNSs valued the support they received from the mix of experienced senior nurses.
- The band 6 CNSs took a rotational post every six months to further their training and development. For example one of the band 6 CNS was going to work in EOLC within St Thomas’ Hospital, they told us this meant they could further their knowledge in a supportive environment due to medical and consultant support being continuously available and this would ultimately give them more confidence when working alone in the community.
- All of the community nurses have had taken part in a two day EOLC training course; day one covered syringe driver competency training, the second day included subjects such as symptom control and difficult conversations.
- The community nursing staff we spoke with told us they knew their own abilities and how to get support should they feel out of their depth when discussing EOLC with patients.
- Clinical staff received an annual appraisal of which 20 out of 22 staff had received one.
- Some staff told us that work load and lack of funding did not allow for them to participate in further courses related to their job role.

Multi-disciplinary working and coordinated care pathways

- Care was delivered and co-ordinated in a way that included all the different teams and services involved in patients’ care, such as the hospital team, community services, GPs, social workers and physiological support.
- The SPCT held a daily meeting which involved all the staff in the team. Any changes in patients’ individual needs were discussed each day together with details and needs of any new patients.
- Formal MDT meetings took place once a week. This meeting included an F2 registrar, GP (trust grade doctor), CNSs, community matron, social worker, psychologist, and an administrator. The EOLC team’s nurse consultant attended as often as work load allowed.
- We observed how the team discussed patient care, options for treatment and how this might be delivered and supported, such as support from the EOLC team or
Are services effective?

the community mental health team. Patients who had died were also discussed, the team shared the events leading up to death, the dying phase and the support offered to those close to the patient. We were impressed how every team member took part in the meeting. They presented each patient in turn, by name and without using any or many notes. They each had a thorough understanding of the patients and those close to them. They were able to recount the patient’s social circumstances, preferences and prognosis. The team was open to challenge, gave and guidance and there was genuine support for each other. They recognised their boundaries and most suitable approach for the patient. For example the team recognised that one patient appeared to be more communicative when supported by male staff. All discussions and decisions were recorded ‘live’ on the patient’s electronic record.

• We observed priorities of care records included the contact details for all the people involved in the patient’s care. This was an open document so the whole MDT could document their interactions and interventions with the patient and those close to them.

• The EOLC team spoke of good joined up working with SPCT’s CNSs. They said, “this has improved a lot and we work excellently well together. They flag up concerns with us all of the time. It improves things for the patient, the care is coordinated and under one umbrella.” They told us patients understood that they were “special” and are being looked after by a whole team although the GP has overall responsibility

• The teams spoke positively about the relationships with the local GPs. However they told us the locum GPs used by the out of hours GP service could be challenging. Staff told us as locum GPs did not have a historic relationship with the patients or their families that some of them could appear lacking in empathy. We were given an example of a locum GP visiting a house to verify the death of a patient. They were observed by nursing staff to be functional, perform the ‘task’ and leave without extending any emotional support to the bereaved relatives.

• The EOLC team, SPCT and community nursing teams worked closely with the hospices and described how they supported GPs when breaking bad news to patients in their home environment. Referral, transfer, discharge and transition

Referral, transfer, discharge and transition

• The EOLC team received referrals from hospitals, district nurses, relatives, GPs, social workers and patients in Lambeth, Southwark or Lewisham area. Anyone who was identified as approaching the end of their life and therefore likely to die within the next 12 months, including people whose death was imminent (expected within a few hours or days) could be referred to the team.

• The SPCT team told us they discharged patients from their caseload if they reached a stage where their condition although not curative was stable. They felt it was important for patients to be released from regular palliative care appointments if they did not require regular specialist support; this meant patients could normalise their life more. The patient could be referred back to the team at any time should their health deteriorate.

Access to information

• All the information needed to deliver effective care and treatment was available and accessible to relevant staff.

• Paper records were kept at the patient’s home for all people involved in the person’s care to document their actions, conversations and the patient’s wishes and outcomes. This meant all healthcare professionals involved in the patient’s care had up to date information and knew of any changes or developments in the patient’s health.

• Electronic records were updated each day when nursing staff returned to their office. The OOHe on-call nurses for the EOLC and SPCT had access to patient these records through a remote access secure on-line portal. This meant they could advise and support the care professionals or families using up to date information and without attending the patient’s home first to read the records.

• Forms were sent to the OOHe GP service so they are aware of complex patients who were dying in the community. This was documented in CMC and there was space to record whether the families were unrealistic about outcomes of the patient and likely to call an ambulance.
Are services effective?

Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- We were told all staff undertook Mental Capacity Act (MCA) 2005 and Deprivation of Liberty Safeguards (DoLS) training via e-learning as part of their mandatory training. However the records provided by the trust did not indicate these subjects were part of mandatory training and therefore we were unable to identify how many EOLC or SPCT staff had completed this training.
- We found that Deprivation of Liberty Safeguards (DoLS) was not always understood by the community or EOLC nurses; and mental capacity was not always appropriately assessed and recorded for patients who may lack capacity. Staff were knowledgeable about the need to act in patient’s best interest however they were not clear about who could consent on the patient’s behalf and how this information should be recorded in patients’ records. The trust’s procedure was to hold discussions about the patient’s welfare and mental capacity with the team, the patient’s GP and those that were close to them; other interventions could involve a GP assessment of the patient’s mental capacity.
- MCA and DoLS guidance was available on the trust’s intranet and this included a capacity assessment tool ‘determination of capacity’.
- Staff could access support and advice from the social workers in the SPCT in relation to the MCA and DoLS.
- Patients discharged from the trust’s acute hospitals to go home to die left with their ‘priorities of care’ plan and a do not attempt cardio pulmonary resuscitation (DNACPR) form. This ensured staff transferring the patient had a clear directive of what action to take should the patient need cardio pulmonary resuscitation.
Are services caring?

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

**Summary**
The community end of life care and specialist palliative teams were unable to provide us with the opportunity to either visit patients (and/or those close to them) who were being cared for by them or to provide contact details of bereaved carers who had received support from them.

At the time of our inspection there were five patients in the community who were coming to the end of their life. We were unable to speak with any of these patients or their relatives as the nursing staff in the EOLC team advised that due to the families' circumstances it was inappropriate for us to visit them to hear about their experience of the care they were receiving; this was due to their social circumstances or the need for interpreters.

We then asked the community SPCT’s matron and the nurse in the EOLC team to speak with bereaved families who had used the service over the last year. We were not provided with any details however we followed the request up again at the unannounced inspection. We were informed by the community SPCT matron that our request had been discussed with the deputy chief nurse and a decision had been made not to contact recently bereaved relatives for permission to pass their contact details to the CQC. Therefore we were unable to speak directly with people to ascertain their views. The trust did however provide us with copies of thank you cards and letters from which we have taken some quotes.

We found that bereaved families and carers wrote passionately about the support they received from the EOLC and SPCT. They described staff as being 'angels' and as having 'reassuring kindness' which provided families with a 'huge amount of support'. This was extended to the bereavement counselling support given by psychologists attached to the team.

Patients and those close to them were involved and encouraged to be partners in their care and in making decisions about any support they needed. Staff described how they provided emotional support and compassionate care while involving patients and those close to them. Our observation of the SPCT MDT meeting and community nursing safety handover indicated that staff knew individual patients, their social circumstances and family situation well, this could only have been done by spending time with the person listening and talking with them.

There was real compassion displayed between the team when sharing the patient's 'story' and much consideration given in how to support the patient in maintaining their relationships and social networks, or even trying to locate long lost family or friends.

**Compassionate care**

- Staff understood and respected patients and their family's cultural, social and religious needs. They gave us examples of things they considered when attending to patient's in their homes, such as covering or removing shoes or arranging visits (if appropriate) outside of religious festivals or prayers.
- Staff spoke compassionately about people who were dying. They understood for the patient and those close to them that time was precious and there was only one chance to get it right for everyone involved. The EOLC nurse told us they always supported a patient with any care or treatment when they visited as tasks did not have to wait until the community nurses visited. They told us everyone who was involved in the patient's care was responsible for their needs and to ensure they were comfortable.
- Staff told us how they ensured the privacy and dignity of patients was still maintained although they were being cared for in their own home, such as asking for permission to enter the room, asking if they preferred to have treatment or care with a relative or friend present.
- Thank you cards indicated that patients and those close to them thought the teams were compassionate. One letter said 'we get great comfort from the kindness and compassions shown to [name]....your kindness will never be forgotten.' Another person wrote, 'we miss our [relative] everyday but take comfort knowing we did all we could to make [their] last days full of love. Without your help this may not have been the case.'
- The SPCT counsellors, who were part of the psychological support team, were described as 'excellent, warm, friendly and empathetic.'
Understanding and involvement of patients and those close to them

- All the staff we spoke with talked passionately about understanding and involving the patients and those close to them. They gave us many examples of how they spent time understanding what was important to the patient and what they were passionate about. For example one patient was upset because they could no longer do their gardening, the EOLC team helped support the patient find a gardener which was paid for through their personal benefits budget.
- Staff talked us through how they used the ‘priorities of care’ document to discuss the patient’s needs and those close to them. They told us in light of the media coverage around the use of the LCP they spent time reassuring patients and families that although it replaced the LCP it was not the same ‘pathway’ and had addressed the concerns the enquiry had raised.
- Another member of staff told us how they involved a patient’s relative in caring for the patient. They described how they encourage carers to wash them, or massage creams into hands and feet. They also described how one patient had a little tear in their eye and how they suggested their carer wiped the patient’s eyes as it could be an intimate moment between them.
- The specialist nurses spent time with families and people close to dying patients to explain the process of death and what to expect during the dying phase. This meant they would be able to react appropriately and support their loved one through the dying phase.
- A number of thank you cards we reviewed indicated that patients were cared for in their own home surrounded by friends and family as per their wishes. Families indicated they felt supported in doing this even though some did not think they had the strength to do it.
- Another family had written to the SPCT to say how much they appreciated the staff from the first visit, they wrote ‘I loved how you spoke to my mother, treating her as a person and [being] interested in her life.’

Emotional support

- Staff understood the impact a patient’s care and treatment had on their wellbeing and those close to them. They ensured patients, their carers and those close to them had the support and strength to manage their care at home. This was monitored through regular contact and discussion. Patients and those close to them could change their mind at any time if it became to much for them to cope with.
- Staff we spoke with were conscious of who should be present to support patients and those close to them when breaking bad news. They took into consideration factors such as the most appropriate healthcare professional to speak with the patient. For example the GP or community nurse who knew the patient well and had the confidence and ability to discuss the patient’s prognosis and wishes may be more suited to talking with them than the EOLC nurse who had never met the patient before. However, if the GP or community nurse did not feel confident in breaking bad news the EOLC or SPCT led the conversation with the support of health care staff who were familiar to the family.
- The CNS and social worker made telephone contact with bereaved relatives within 14 days after their family member’s death and sometimes followed it up with a bereavement visit should they required further emotional support. They would offer to call again in a month and could refer them to voluntary organisations that specialised in bereavement support.
- The social workers supported families accessing local support services to help patients and families to come to terms with diagnosis and prognosis. This included liaising with schools so that they were aware of the child’s parent’s health. Although some of the team felt confident in breaking bad news to children on behalf of their parents they felt it was more appropriate for the parent to be honest and open with their own children and supported and encouraged them to do so.
- The SPCT offered bereavement counselling to those who required extra support. A detailed thank you letter indicated that this had been valuable support and helped the writer to understand and deal with bereavement on a daily basis. They wrote that the seven month group session had left them with the tools to deal with life and gave them hope for the future.
- We observed that staff wrote ‘died’ on the front of the patient records as opposed to R.I.P which you normally see when a patient has passed away. Using the words death, dying and died are clear to everyone and normalises talking about death; it encourages staff to use the words and talk about it in a clear way as opposed to soft phrases such as ‘nothing more we can do’ or they ‘passed’.
Are services responsive to people’s needs?

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

**Summary**

Services were organised and delivered to meet people’s needs. The importance of flexibility, choice and continuity of care was reflected in the service. Care and treatment was provided in a timely manner and coordinated with other community services and providers, which ensured patients received the most suitable care, equipment and support for them and their family’s circumstances.

We found there were open channels of communication between the trust’s community healthcare professionals and their health care colleagues within the CCGs. Community nurses felt confident in the EOLC and SPCT team’s support and guidance when supporting patients with palliative and end of life care needs. The needs of different people was taken into account when planning care and services.

Staff shared information with patients and their carers at a level and at a speed that the they could digest and accept. Staff were aware that each family responded to death and dying in a different way and therefore their approach to this had to be tailored to the individual needs of that family/community.

Complaints were responded to appropriately and staff demonstrated examples of learning and improvements to the quality of care as a result of patient’s comments or concerns.

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

- Information about the needs of the local population was used to inform how services were planned. Commissioners of the services and other stakeholders were involved in the planning.
- The EOLC and SPCT team worked closely with other agencies to ensure the healthcare needs for Lambeth, Southwark and Lewisham residents was met. The team worked closely with one of the local hospices to develop procedures and training.
- Each CNS had a portfolio of GP practices. This allowed them to build up a relationship with patients while supporting them in their own homes, build a good working relationship with their GP and have a greater understanding about the needs of the local population the practice served.
- The teams offered EOLC training to local GPs, carers and nursing staff to ensure consistency of care and support for patients across both CCGs. The GPs supporting the SPCT provided insight into delivering care in the community environment.
- The trust employed social workers within the SPCT whose role was to provide social care advice and guidance to services and support available to dying people and their families.
- Staff were aware that Lambeth and Southwark had some highly deprived areas. They also had a lot of cultural challenges which required them to work sensitively with individuals and families who were often in denial about their own or their relative’s prognosis. The community nursing teams was made up of many long-term members of staff who had a huge amount of experience in delivering care to a diverse population. All staff had attended an equality and diversity course as part of their mandatory training. The trust’s chaplaincy service provided training and advice on cultural differences, different religions etiquette and customs surrounding end of life care. The team worked together to build the trust of patients and their families on an individual basis.

**Equality and diversity**

- We found that 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 patients and carers and 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.
- Staff were aware that different cultures had a different approach to death and dying. For example some cultures were very open about discussing it while others did not discuss death at all and had a strong belief in medical cures and believed talking about death meant...
you were giving up on the person. Therefore, they approached difficult conversations about death and dying at a pace that the patient and family could understand.

Meeting needs of people with vulnerable circumstances

• A guide for people close to the dying person was available to support them in understanding how an individualised care plan could support their relative/friend. It included information such as why some tests and medications may be withdrawn, the physical changes that occur before death and what to expect when someone dies.
• A leaflet about specialist palliative care as well as a generic community services leaflet was given to patients. A leaflet to support care of patients in the last hours or days of life (priorities for care of the dying person) was being revised at the time of our inspection. The trust had recently developed a community leaflet called ‘What to do after death’.
• The EOLC and SPCT nurses were unable to verify death. They told us they thought it would be useful to be able to do this for expected deaths as they were often present and knew the family. It would allow families to make arrangements with the undertakers quickly if they wished to and alleviate pressure on the doctors’ busy workload. The nurse told us families could wait from four to six hours for a doctor to visit the home to verify death.
• The social workers in the SPCT sign-posted patients and their families in finding appropriate social support for their needs, such as benefits or accessing day care.
• Psychological support, complimentary therapies, welfare benefits advice, stress and relaxation courses, carer’s support and various tumour specific support groups were provided by appropriately trained staff at Dimbleby Cancer Care which was based in the oncology outpatients department at Guy’s hospital. This was available for anyone in the community who had been diagnosed with palliative or end of life care needs.

Access to the right care at the right time

• Anyone could refer a person living in the boroughs of Lambeth, Southwark and Lewisham who was thought to have palliative and/or end of life care needs to the trust’s EOLC or SPCT. This included healthcare professionals such as GPs and community nurses, social care, relatives and friends. The team triaged patients and all of them were seen within 24 or 48 hours depending on the urgency of their needs.
• The SPCT core working hours were Monday to Friday 9am to 5pm, they provided support to patients over the telephone and via a home visiting service. At the time of our inspection the trust had suspended 24 hour services due to a lack of staff to support the service; outside of the core hours a CNS was available on-call up to 11pm; they provided advice over the telephone and a home visit could be arranged if required. The withdrawal of the overnight service had been closely monitored to measure the impact. Hospital communications showed the overnight on-call service was re-starting on the 5th of October 2015.
• The community nursing EOLC team was available Monday to Friday from 9pm to 5pm with flexibility for long days from the nurse consultant. There was an on-call service available from 6pm to 11pm. One of the team worked bank shifts over the weekend to provide further support to patients, GPs and community nurses.
• There was consultant support twenty four hours per day seven days a week across the locality. This was provided by consultants from Guy’s and St Thomas’ and other local hospitals or hospices on an on-call basis outside of core working hours.
• A local hospice had a 24 hour helpline. They triaged the calls and directed the caller to the most appropriate support, such as the on-call CNS or the local out of hours GP service.
• Marie Curie nurses were used for overnight support for people in their homes (this provider was not inspected). However, if nurses were unavailable the commissioners of the service approved agency nurse cover.
• In Lambeth, Southwark and Lewisham an on-call GP service was used to support GP services outside of the practice’s hours. This service was covered by local doctors or locums.
• The trust was setting up a service called Pal@home to which they were currently recruiting. This service was being hosted by the hospital@home service and due to commence in December. The service would provide overnight cover. The EOLC team were working closely with the local hospice to devise training and advice for this new team.
• NICE quality standard [QS13] Published date: November 2011 stated ‘Many people receive high-quality care in
Are services responsive to people’s needs?

hospitals, hospices, care homes and in their own homes but a considerable number do not. Up to 74% of people say they would prefer to die at home, but it was found that 58% of people die in hospital. On average, people have 3.5 admissions to hospital in their last year of life, spending almost 30 days in bed in hospital. As a result national guidance was produced for all healthcare professionals in order to drive high quality care for people at the end of life. This included supporting patients to die in their preferred place of death.

- Between April 2014 to March 2015 the community SPCT supported 810 palliative patients in their home, care/ nursing home or hospice. 417 of these patients died of which 317 died outside of hospital: 77% died in their preferred place, 6% did not die where they chose, and 17% had no preference recorded.
- Between 1 Jan 2015 and 30 Aug 2015 293 new patients in the community were identified with end of life needs. 214 of these patients were supported by the EOLC community nursing team to die at home, which was the patients preferred place.
- People who may benefit from specialist palliative care are those whose symptoms cannot be managed in a timely way by their usual care team. Traditionally people associate specialist palliative care (SPC) with supporting patients with a cancer diagnosis. SPC should be available on the basis of need and not diagnosis. Between April 2014 to March 2015 the community SPCT supported 810 palliative patients in their home, care/ nursing home or hospice. 36% had non-cancer diagnosis and 64% had a cancer diagnosis.
- The EOLC team supported a similar percentage split between patients who had been diagnosed with cancer (61%) and those that had not (39%).

- We were told by a GP working for the community SPCT that GP practices were encouraged to identify patients who required palliative or end of life care early on. They searched their patient lists for those who were frail and elderly or had co-morbidities which were life limiting. This ensured discussion about the patient’s wishes, next of kin details and advanced care plans were in place; realistic and timely interventions could be made to support them in their preferred place when they neared the end of their life.
- The EOLC and SPCT worked closely with patients, families, GPs, community nursing team and other health providers in a supportive and advisory way to ensure patients received medical interventions, which historically might have meant a hospital stay, in their home environment. The community nurses we spoke with told us they felt able to discuss a patient’s decline in health with the EOLC team to ascertain whether the patient was displaying signs of coming to the end of their life.
- The trust was not currently using rapid discharge pathway however as part of the 2015/16 EOLC work plan there was an objective to develop one specifically for patients at the end of life.
- Patients identified as dying within the next 24 hours were fast tracked to receive the care and support they required with immediate effect. Twenty four hour one-to-one care was not available however patients received four visits per day from social service carers, two standard visits from community nurses who assessed the patient and their family’s need, set up syringe drivers, provided symptom advice, and arranged for Marie Curie nursing overnight, all under the support of the SPCT and/or EOLC team.
- The teams worked with an ambulance provider in order to identify appropriate options if ambulance staff were called to end of life patients. Information was shared electronically with ambulance staff so that they could identify end of life patients and provide appropriate support in their home or care home setting. This prevented the patient being transferred to hospital unnecessarily. However we were unable to ascertain whether this electronic information was available to call handlers at the time of a 999 call being made and therefore whether they would be able to support the caller in the most appropriate way (therefore whether to perform cardio pulmonary resuscitation (CPR) or not).

Learning from complaints and concerns

- End of life services received very few 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 any issues or complaints immediately and offered a face-to-face meeting with the complainant. If they found the issue could not be dealt with in this way at this stage they supported people in making formal complaints to the hospital.
Staff gave us an example of a recent complaint, the process they followed to investigate it and the learning and changes made as a result of the issue.

The team had received also complaints about some locum doctors’ brusque and clinical manner when they attended to verify death. Any concerns were reported through the hospitals incident log ‘Datix’. They were investigated and feedback given to the individuals concerned.

Are services responsive to people’s needs?
Are services well-led?

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

Summary
The trust had a clear statement of vision and values which was driven by quality care and safe practices. This had been disseminated well across the community palliative and end of life staff group. Staff were proud of their work and put the patients’ needs first, sometimes at the detriment of their own well-being; staff ‘burn-out’ was identified as a possible risk on the local risk register. We found staff were less clear as to which direction EOLC in the community was moving. However, the trust was in the process of completing a strategic review which was aimed at providing seamless care across the hospitals and in the community for patients approaching the end of their life. This included engagement with internal and external stakeholders.

The board and other levels of governance within the organisation functioned effectively and interacted with one another appropriately. There were clear structures, processes and systems. All staff at each level understood their roles and responsibility and took account of their actions.

Without exception all the staff we spoke with were proud to work for Guy’s and St Thomas’ NHS Foundation Trust. They spoke with passion and enthusiasm about the care they provided. There was a huge amount of respect between the team members and they valued the support they gave one another to provide the best possible experience for patients and those close to them. However, community nursing staff expressed some concern that they were unable to take time out between patient appointments if someone’s death had particularly upset them. Senior staff were concerned that community nurses felt this way and assured us they would address this with local managers and team leaders immediately.

GPs working in the community specialist palliative care team provided clinical oversight, immediate medical advice to nursing staff, and had an overview of how all the services supporting a patient gelled in a community setting.

Service vision and strategy
- The deputy chief nurse responsible for EOLC told us it was a priority for the trust to provide seamless care for the dying patient. The trust had recently completed a strategic workforce review for palliative and end of life care across the hospitals and community. The detailed and ambitious report was in its draft stage and due to be presented to the board. The trust’s integrated strategy involved the acute hospitals, their community services, the CCG and other local organisations such as hospices, voluntary organisations and patient/family representation. It was linked to other strategies and quality standards such as the NHS England Palliative Care Funding Review, CQC strategy, NICE guidelines and reviews such as ‘One Chance to Get it Right’ published by the Leadership Alliance for the Care of Dying People. The aim of the trust’s strategy was to provide a palliative and/or patient coming to the end of their life and those important to them with the same quality of care wherever they chose to be supported, be it at home, care/nursing home, hospice or hospital.
- Staff told us the vision for the service was to provide safe and good quality support to people dying at home every time. Each member of staff spoke passionately about ‘getting it right for the patients and family’.

Governance, risk management and quality measurement
- The community EOLC team sat within the community health services for adults. A nurse consultant had day-to-day responsibility for the team. They reported directly to the Head of Nursing Adult Community.
- The community SPCT sat within oncology and haematology services. A matron had day-to-day responsibility for the team.
- Community EOLC risks were included on the adult community risk register and the community SPCT’s risks were included on the acute oncology and haematology risk register. There were a total of four risks (two on each register) relating to the community services. The senior staff had good oversight of the risks and discussed the actions they had put in place to manage any risk to
patients or staff. Junior staff were made aware of the risks. We observed the two SPCT risks were placed on the register in 2015 and therefore relatively new, dates for review were included and progress was recorded. We were unable to identify how long the EOLC risks had been on the register as it was not presented to us in the same way.

- The community directorate had a clinical governance structure and implemented a quality agenda across the directorate. Quality and governance issues were discussed at the bi-monthly Adult Community Clinical Governance Committee (ACCGC), Community Clinical Effective Committee (CCEC), and Patient Safety Working Group (PSWG). Governance also formed part of the agenda for the directorate’s quarterly business meeting and the monthly adult services performance and governance meeting.
- We observed clear clinical oversight and involvement with patients throughout their care. Systems were in place which ensured managers understood their workforce and their workload.
- The specialist palliative care governance framework outlines the roles and responsibilities of each team. Governance was included within the weekly management meetings and on a rolling basis within the weekly team meetings.
- Clinical incidents within the SPCT were reported in their key performance indicators (KPI) scorecard. These were discussed at the performance review meetings with the directorate management team and within the SPCT’s governance meetings.
- Audits were completed to measure patient outcomes and team performance. Regular audits included DNACPR forms in patients homes, who and when a patient was recognised as dying and whether they were cared for using the ‘priorities of care’, preferred place of death and the percentage who died in their preferred place. Any learning from the audits was cascade to staff through meetings, one to one conversations and emails.
- A hospital meeting to review patient care in the last days of life, audits and actions arising met on a weekly basis and the community equivalent met on a fortnightly basis. The EOLC quality assurance group met every six weeks. This was a joint community and hospital meeting. All complaints and incidents relating to EOLC within the trust and community services were discussed at the meeting as well as policies, procedures and changes in practice. The end of life care governance committee met on a six to eight weekly basis (soon to move to four times a year) to share incidents and complaints and the outcome from them.
- Senior staff told us they felt assured that staff used the incident reporting system Datix and described their role in investigating and disseminating the outcome of any incidents or near misses.
- Inappropriate discharges were fed back to the hospital through management meetings; the palliative care matrons in the hospitals flagged incidents up to individual wards to investigate what went wrong.

**Leadership of this service**

- There were clear lines of accountability within the management teams. Whilst the teams worked in a very balanced team-orientated way, with no visible ‘pecking-order’, the managers knew what was expected of their role as a leader.
- Staff spoke of an open leadership culture within EOLC and palliative care. We observed a flattened hierarchy across the services. All staff were included in discussions and asked for their opinion, whether it was about a patient’s care, how the service should be shaped or something in relation to their personal expertise.
- The end of life and palliative care leads at a local level spoke modestly about how they led their teams and the service. However we found staff spoke more avidly about the support their managers gave and valued their experience. One member of staff said, “my manager is a role model, they look at the bigger picture, they know more than me and I can always learn from them. I can then pass this learning on.”
- All staff we spoke with felt their line managers and senior managers were approachable and supportive. Staff were aware of some of the trust’s senior leaders, particularly the Chief Nurse.

**Culture within this service**

- We found the overall the teams were very supportive of one another. They told us there was always someone to call upon should they have any concerns or queries. There was a clear sense of pride amongst staff at all levels within the end of life and specialist palliative care teams. They appeared to have a genuine respect for each other and valued each other’s experience and expertise. This allowed them to work as a cohesive team.
Are services well-led?

• Many of the staff worked longer than their contracted hours in order to ensure they had completed their administrative tasks for the day. Many of them ensured they had completed all their visits prior to returning to the office. They told us this meant many of them often worked later than they were contracted. Managers told us they often had to remind staff to ‘go home’. Although some of the community staff told us they did not receive recompense for the extra hours they worked, senior managers told us there were mechanisms in place to ensure staff were paid for their hours, or if it was a regular occurrence extra support could be obtained. Senior managers told us they would follow this up with the local managers to ensure the correct procedures were followed.

• One member of staff we spoke with said, “a year ago we [the community nursing teams] were on our knees as staffing levels were so low and experienced staff were retiring. We did a big recruitment drive, and received a lot of applications from newly qualified staff, which was unusual. We decided to take them straight from qualifying rather than them working in acute for a year. So although we have inexperienced staff they are learning faster than was expected through the mentoring and competencies system and now the workload is more manageable.”

• Other staff told us that they did not feel part of the larger trust when GSTFT first took on the community services. However, they now feel very much part of the “Guys and Tommie’s team” and no longer “like the poor relatives”.

• The GPs working with the SPCT told us although they worked with the team on a part-time basis they felt included and valued. The social workers attached to the team were also fully involved and were often sought out for their thoughts and opinions.

Public engagement

• Up until recently there had been no formal mechanisms to obtain feedback from bereaved relatives. Staff only knew how well they were doing through thank you cards, emails and ad hoc comments. In the last month a modified version of The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation Of Services) was being used to canvass views. It was too early to obtain any results at the time of the inspection.

Staff engagement

• The community teams told us they had ‘show cased’ their work by demonstrating what ‘good’ looks like to their colleagues in the acute hospitals. They have been championed by GPs, had low incidence of harm and provided considerable support to community nursing colleagues and GPs alike.

• All community nurses spent a shift in the hospital and all hospital nurses covered one shift in the community each year. This meant there was a greater understanding of each other roles and they could share their learning with other colleagues as well as put into practice any learning.

• The EOLC and SPCT engaged GPs in Lambeth, Southwark and Lewisham through training courses and creating strong links with the trust’s CNS lead.

• Staff told us there was no end of life strategy group for specifically for community nursing. The EOLC team felt having a steering group for the community setting would promote the importance of EOLC in the home setting and the development of training and competencies for nurses. However we observed that community services were included in the (draft) strategic workforce review for palliative and end of life care. This included developing the community services, staffing and training provision as part of the whole development for palliative patients and those reaching the end of their life. The leads for the community services had been involved in the development of the strategy. The staff we spoke with did not appear to be aware of how the strategy incorporated community services.

Innovation, improvement and sustainability

• The recent addition (February 2015) of local GPs working with the SPCT has improved community working. The GPs spoke positively of the union; not only has it increased the profile of EOLC and palliative care in the community which has provided a stronger professional network to assist GPs in supporting their dying patients at home, it has provided easily accessible medical advice for the trust’s CNSs, end of life nurses and nursing teams while they are working in the community.