

# The Royal Marsden NHS Foundation Trust

RPY

# Community end of life care

## Quality Report

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# Summary of findings

## Locations inspected

Location ID	Name of CQC registered location	Name of service (e.g. ward/unit/team)	Postcode of service (ward/unit/team)
RPYX1	The Royal Marsden Community Services	Robin Hood Lane Health Centre	SM1 2RJ
RPYX1	The Royal Marsden Community Services	Green Wrythe Lane Clinic	SM5 1JF







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

# Summary of findings

## Ratings

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

# Summary of findings

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# Summary of findings

## Overall summary

Overall we rated the trust as **GOOD** for community end of life care services because:

- Staff understood and fulfilled their responsibilities to raise concerns and report incidents and near misses.
- Medicines were managed safely in relation to end of life care, including the use of “just in case” anticipatory medication to support the management of symptoms quickly and effectively.
- There was good prioritisation of the needs of patients at the end of life.
- There was a clear vision and strategy for the work of the specialist care home team (SCHT) and there was evidence of a positive impact on patients living in care homes experiencing improved end of life care as a result of supportive care home service.
- There was good multi-disciplinary working through the GSF and specialist staff were available to support the work of the community nursing teams.
- Patients were treated with dignity, kindness and compassion and there was consistently positive feedback from patients and their relatives about the service.
- Staff worked hard to ensure that patients at the end of life were given the support that they need, including staying beyond the end of their shift to make sure patients had in place what they needed.
- We observed good use of advance care planning with a uniform approach across services and adapted tools for use when patients did not have capacity and decisions were made in their best interest.

- There was a culture of quality end of life care across all community end of life care services.

However,

- It was unclear what guidance was being used to support the delivery of end of life care in patient's homes as there was no evidence based end of life care plan in use within the service.
- It was unclear how the service was monitoring a range of patient outcomes specific to end of life care when patients were supported by community nurses in their own homes.
- Staffing shortages within the community nursing teams meant that the delivery of end of life care fell to more experienced staff who had attended relevant training.
- There was no completed end of life care strategy for community end of life care implemented and the development of this service in relation to the trust-wide strategy was unclear.
- Quality measurement in relation to community end of life care services was limited and did not cover all aspects of the service. There was no clear plan for measuring or improving the quality of end of life care for patients receiving care in their own homes.
- In the absence of a community end of life care strategy and clear processes for measuring the quality of services it was unclear how specialist palliative care and end of life care input was influencing the development of services for patients receiving end of life care in their own homes.

# Summary of findings

## Background to the service

The Royal Marsden Community Services formed Sutton and Merton Community Services (SMCS) in 2011. Various community health services were provided in the London Boroughs of Sutton and Merton. From 1 April 2016 The Royal Marsden Community Services stopped providing services to Merton and formed Sutton Community Services (SCS). Our report includes data from the 12 month period leading up to our inspection which was before the disaggregation of service and contains some data relating to Merton. We have included separate data where it was available. Our site visits during the inspection were limited to Sutton only.

The Royal Marsden NHS Foundation Trust provides community end of life care services to a population of approximately 196,000 people across Sutton. End of life care is provided by community nursing teams in people's own homes. The community nursing teams operated within three integrated locality teams across the area, working alongside specialist nurses and therapy staff such as physiotherapy and occupational therapy to provide the service. The teams were aligned with GP practices across Sutton who also had been divided into three localities.

There were two strands of community end of life care: one service provided to patients in their own homes and another service provided to patients accommodated in care homes.

An end of life care supportive care home team (SCHT) was operating within the trust, with a remit for promoting end of life care in nursing and care homes; they did not provide specialist support for people in their own homes. This team was led by the palliative care nurse consultant who had responsibility for end of life care within the trust alongside the matron in palliative care and specialist consultant in palliative medicine.

Specialist palliative care input for people in their own homes was provided seven days a week by a team of specialist palliative care clinical nurse specialists from a local hospice who worked with the community nursing teams to provide specialist support. There were no community inpatient beds run by The Royal Marsden.

There had been 155 patient deaths in the community where patients and their families were supported at the end of life by the community nursing teams in the 12 months prior to our inspection. Between April 2015 and March 2016 there had been a total of 6383 patient contacts in the community for patients requiring palliative or end of life care.

In March 2015 Sutton Clinical Commissioning Group (CCG) was awarded vanguard status by NHS England for Enhanced Health in Care Homes. A vanguard site is a service that takes a lead on the development of new care models as an example to other NHS services. The end of life care (EoLC) supportive care home team (SCHT) provided by The Royal Marsden played a significant role in this development. The EoLC SCHT consisted of four whole time equivalent (WTE) clinical nurse specialists (CNS). Prior to 1 April 2016 the team provided support to nursing homes across Sutton and Merton CCGs. Since the disaggregation of Merton CCG services to another provider from 1 April 2016, the EoLC SCHT were providing support to homes in Sutton only. Following a review of the services by Sutton CCG there was an agreement to increase their remit and extend their support to include care homes including a pilot of support for learning disability care homes. The aim of this service was to effectively manage the care of people living in nursing and care homes, working closely with other healthcare professionals and GPs to ensure they received optimal end of life care. This was to be achieved through education, training, ward rounds and clinical visits within each home.

During our inspection we met with The Royal Marsden specialist palliative care team including the lead specialist palliative care consultant, the nurse consultant, the palliative care matron and members of the end of life care SCHT. We met with managers of the integrated locality teams within the community, including the divisional director and clinical director for nursing. We went on four home visits with district nurses and specialist nurses. We visited four patients in their own homes where we observed care being delivered by general community nurses. We visited one patient being cared for in a local nursing home during a visit by the

# Summary of findings

specialist palliative care nurse. We spoke with a range of community nursing staff including locality managers, nursing sisters, and more junior nurses. We met with CNS' from the end of life care supportive care home team and we spoke with CNS' from the local hospice, including the

manager of the CNS team. In total we spoke with 21 staff members. We looked at the records of eight patients identified as receiving end of life care and four 'do not attempt resuscitation' (DNACPR) forms.

## Our inspection team

**Chair:** Robert Aitken

**Head of Hospital Inspection:** Nick Mulholland, CQC

### Team Leaders

Stella Franklin, Inspection Manager, CQC

Margaret McGlynn, Inspection Manager, CQC

Michelle McCarthy, Inspection Manager, CQC

The community end of life sub team included a CQC inspector and a specialist adviser who was a practicing specialist palliative care nurse.

## Why we carried out this inspection

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

## How we carried out this inspection

To get to the heart of patients' experiences 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?

The inspection team visited the specialist palliative care team at The Royal Marsden NHS Foundation trust, spoke with specialist palliative care clinical nurse specialists from the local hospice, went on visits with community nurses to patients being cared for in their own homes. We observed Gold Standards Framework (GSF) meetings, met with members of the end of life care supportive care home (SCHT) team and visited a care home that had received support from the SCHT.

Prior to the inspection we reviewed a range of information that we held and asked other organisations to share what they knew about the trust. These included the clinical commissioning group, Health Education England, the General Medical Council, Local Authorities and local Healthwatch organisations.

During our inspection of end of life care services we spoke with 21 members of staff. We reviewed the records of eight patients and reviewed four 'do not attempt resuscitation' forms. We spoke with four patients and five relatives. We also interviewed key members of staff and held focus groups with various staff groups.

We undertook the announced inspection visit between 19 and 22 April 2016.

# Summary of findings

## What people who use the provider say

We spoke with four patients receiving care from the community nursing teams in their own homes and five relatives. People who used the service and their families said;

- “It has been a very positive experience, everyone involved has been caring, knowledgeable, compassionate and nothing has been too much trouble”.
- “We can’t praise them highly enough”.
- “They respond very quickly when we need support, even during the night.”
- “They are very caring, friendly and compassionate.”
- “They are always there at the end of the phone.”
- “They try and make sure that the same nurses come as much as possible.”

## Good practice

The end of life supportive care home team (SCHT) was a part of a Sutton CCG (clinical commissioning group) vanguard relating to improving end of life care in care and

nursing homes. Members of the SCHT were involved in developing the service and had been invited to speak about the model and share this development with other services.

## Areas for improvement

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

- The trust should ensure their audit and governance systems are effective in relation to community end of life care services.
- The trust should ensure that a clear vision and strategy is developed that incorporates all aspects of community end of life care, including the care of patient’s in their own homes.
- The trust should ensure community nursing teams have a clear, consistent approach in relation to planning care for patients that is based on national and evidence based guidance.
- The trust should ensure that a range of patient outcomes are measured and tools developed to monitor the quality of the community end of life care service as a whole.
- The trust should ensure that leadership and multi-disciplinary roles are clarified in relation to the development and improvement of community end of life care services across the trust, ensuring clarity of roles and responsibilities and how services are integrated across the trust and between service providers.
- The trust should ensure clear records of end of life care training are kept for all staff.
- The trust should review staffing levels, training and caseloads to ensure that all community nursing staff were able to participate in the delivery of end of life care.



# The Royal Marsden NHS Foundation Trust

## Community end of life care

### Detailed findings from this inspection

Good 

## Are services safe?

By safe, we mean that people are protected from abuse

### Summary

We rated safe as good because:

- Staff understood and fulfilled their responsibilities to raise concerns and report incidents and near misses. Incidents involving patients at the end of life were reported and reviewed with input from end of life care clinical specialists. Lessons were learned and communicated widely to support improvements.
- Medicines were managed safely in relation to end of life care, including the use of “just in case” anticipatory medication to support the management of symptoms quickly and effectively in the community.
- Records were kept in relation to the management of controlled drug medicines, for example logs of stocks of medicines kept in patient’s homes so that an audit trail of medicines was recorded.
- Equipment used in end of life care was monitored and maintained, including the use of syringe drivers.
- Systems were in place to protect people in vulnerable circumstances from abuse. Staff were knowledgeable about their roles and responsibilities in relation to ensuring vulnerable adults and children were safeguarded.

- There was good prioritisation of the needs of patients at the end of life and access to specialist support was available 24 hours a day, seven days a week.

However:

- 79% of nursing staff across the trust had attended syringe driver training, including those working in the community, however the trust did not have available specific data relating to which nurses working in the community had attended training updates and appropriate competency checks.

### Safety performance

- A range of safety performance was being monitored over time. For example we saw that safety thermometer information was used. The trust used the NHS Safety Thermometer to measure harm free care delivered to patients. The overall rate of harm free care across the community service between January 2015 and December 2015 was 92.3%.
- Safety performance data included information relating to urinary tract infections, falls and pressure ulcer prevention.

# Are services safe?

- There were zero never events between February 2015 and January 2016. Never Events are serious incidents that are wholly preventable.

## Incident reporting, learning and improvement

- There were no serious incidents reported for community end of life care services between February 2015 and January 2016.
- Staff delivering end of life care understood their responsibilities with regard to reporting incidents. Staff we spoke with told us that when an incident occurred it would be recorded on an electronic system for reporting incidents.
- In total there were 691 incidents within community services between October 2014 and September 2015. 63% of these related to pressure ulcers and 14% to medication errors. Incidents were reviewed by a Clinical Quality Review Group where trends and themes were identified. There were no trends or themes identified relating to end of life care in the community.
- We viewed details of one medication error relating to a patient at the end of life. We saw that the error had been thoroughly investigated with involvement from the clinical nurse director, the chief pharmacist and the palliative care nurse consultant. Specific action included liaising with the acute trust about discharge medication, reviewing documentation and recording of controlled drugs and further education and training for nursing staff. Learning was cascaded by locality managers to nursing staff in each locality team. Staff involved in the incident received feedback, including those staff reporting it.

## Duty of candour

- Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 is a new regulation which was introduced in November 2014. This regulation requires the trust to be open and transparent with a patient when things go wrong in relation to their care and the patient suffers harm or could suffer harm.
- Staff were aware of their responsibility in relation to duty of candour and being open with patients and their relatives when incidents occurred. We saw that the incident reporting forms used included a section on the

duty of candour and staff consistently told us that patients/relatives were kept informed when incidents occurred. We saw evidence of this in relation to a medication error investigation report that we viewed.

## Safeguarding

- Systems were in place to protect people in vulnerable circumstances from abuse. Staff were knowledgeable about their roles and responsibilities in relation to ensuring vulnerable adults and children were safeguarded. Staff understood what constituted a safeguarding concern and we observed staff discussing safeguarding in handovers.
- 90% of community staff had attended level one child safeguarding training, 88% had attended level three. This was against a target of 90%. Adult safeguarding training attendance was between 92 and 100% which was above the trust target.
- Members of the end of life care team for the community had attended safeguarding training relevant to their role in relation to both adult and children's safeguarding.
- There have been no safeguarding alerts or concerns raised with the CQC specific to community end of life care services.

## Medicines

- Patients in the community identified as requiring end of life care were prescribed anticipatory medicines. Anticipatory medicines were medicines prescribed in advance to ensure patients received prompt relief from pain and other symptoms.
- We visited four patients in the community who had anticipatory medicines prescribed and these were available and stored safely in their home for when they were required.
- Some members of the community nursing teams were non-medical prescribers (NMP). We spoke with one NMP who told us that they did not prescribe anticipatory medicines for patients at the end of life as this was the remit of the hospice based specialist palliative care clinical nurse specialists (CNS').
- Staff we spoke with told us that they had not experienced any difficulties in getting anticipatory medicines prescribed or in terms of their availability

## Are services safe?

from community pharmacies. Support was available from the specialist palliative care team at the local hospice where community CNS' were trained as non-medical prescribers.

- The trust had produced The Royal Marsden guidelines for symptom control which were available to community staff and GPs and were based on national guidance. For example, anticipatory medicines were prescribed for the key symptoms at the end of life including pain, breathlessness, nausea, restlessness and respiratory tract secretions.
- Prescriptions and administration records we looked at in the community were completed accurately and clearly.
- Controlled drugs (medicines controlled under the Misuse of Drugs legislation and subsequent amendments) were stored securely with appropriate records kept.

### Environment and equipment

- Community nurses we spoke with told us they were able to access equipment for patients at the end of life in the community. This included syringe drivers as well as other types of equipment to enable them to care for people safely in their homes.
- Syringe drivers were stored on site at clinic locations and we viewed up to date maintenance records for these. Staff told us they had not experienced difficulties accessing syringe drivers when they needed them and that they could access additional machines from other community locations if necessary.
- Staff told us that equipment was accessible within a few hours for patients at the end of life who were being discharged from hospital via the fast track route. The electronic system for ordering equipment ensured a quick response and a clear audit trail and teams were kept updated regarding any new equipment available.

### Quality of records

- Community nurses used both paper and electronic record systems. Information was scanned onto the electronic system, for example risk assessments and other patient information. Care plans were kept in patient's homes.

- We viewed eight care records of patients considered to be at the end of life. We found that the standard of record keeping was good. Risk assessments and summaries of care delivery were in place and records were dated and signed.
- We viewed four 'do not attempt cardiopulmonary resuscitation' (DNACPR) records. These records were completed appropriately. For example, they contained clearly documented decisions with reasoning and clinical information, were dated and signed, and included a record of discussions with the patient and their family as appropriate.
- Syringe driver monitoring forms were completed where patients were receiving medicines via a syringe driver. These forms included a record of the amount of medicine being administered and also a check of the pump and the site of the infusion.

### Cleanliness, infection control and hygiene

- We observed staff wash their hands, use hand gel between patients and comply with 'bare below the elbows' policies.
- We saw the use of personal protective equipment (PPE) when dealing with patients. Staff told us that hand gel and other equipment was available and easily accessible for their use when visiting patients in their own homes.
- We observed staff following safe infection control practices when visiting patients at home. This included the use of appropriate clinical waste disposal processes and equipment.

### Mandatory training

- The average mandatory training rate for general community nurses was 92%. Mandatory training for community nurses included information governance, basic life support and moving and handling.
- Members of the end of life care specialist care home team had undertaken training in areas such as infection control, resuscitation, infection control, and fire safety and information governance.
- Syringe driver training was mandatory for nursing staff in the community and was included as part of new nurse induction programmes. Additional training was provided as part of twice yearly in-house palliative care

## Are services safe?

days to provide updates for staff. An audit of syringe driver training attendance across the trust including community nursing showed that 79% of nurses had attended training. We viewed competency assessment templates and staff we spoke with told us that an assessment of competency was included as part of the training. However, specific data about the percentage of community nurses having attended training updates and competency assessments was not available.

- A number of more junior nursing posts were covered by bank and agency staff who may not have attended syringe driver training. Staff told us that bank and agency staff would generally not undertake end of life care visits where patients had syringe drivers in place.

### Assessing and responding to patient risk

- Staff assessed and managed patient risk as part of an ongoing holistic assessment process. We observed good use of general risk assessments for patients receiving end of life care. This included the assessment of risk in relation to nutrition and hydration, falls and the potential for pressure area damage.
- We saw that the top areas of risk for community services as a whole related to medicines and the incidents of pressure ulcers. We did not see any patients at the end of life who also had a pressure ulcer at the time of our inspection. However, there was a high incidence of pressure ulcers reported in comparison with other NHS trusts within the community adult's service.
- When a patient's condition changed information was recorded in the daily notes by nursing and therapy staff. Advice and support from the hospice specialist palliative care team (SPCT) regarding deteriorating patients was available.
- End of life care in the community was provided by general community nurses located at each of the four clinics across Sutton. Specialist palliative care was provided by the local hospice from 9am to 5pm seven days a week, with telephone advice available from the hospice inpatient unit and on-call clinical nurse specialist (CNS). A community based consultant in palliative medicine was also available to staff and patients in the community via the local hospice.

- We observed a handover in the community where patient risk was discussed, in particular around safeguarding issues and deteriorating conditions. Staff told us that discussions around risk and safety were held at all handovers.
- We spoke with relatives who were aware of how to access help and support should a patient's condition deteriorate in situations where they were being cared for at home. This included access to out of hours support. We viewed records of staff being contacted out of hours and saw that they responded quickly when patient conditions deteriorated.

### Staffing levels and caseload

- Vacancy rates for community nurses at the time of our inspection were 16%. Staff and managers we spoke with told us this was mostly due to band 5 nursing vacancies.
- Community nurses we spoke with consistently told us they felt able to prioritise end of life care within their workloads although they stated that this was sometimes more difficult at certain times of the day. For example, in the morning when visiting patients with diabetes who required insulin injections.
- The end of life care team were commissioned to deliver end of life care education and support across care homes in Sutton. The team consisted of four whole time equivalent (WTE) community clinical nurse specialists (CNSs).
- Prior to April 2016 the team had worked across Sutton and Merton and following disaggregation of the service the team was reviewed with Sutton CCG in terms of staffing and the scope of the service. As a result, a decision was made to expand the scope of the service to include nursing homes, care homes and homes for people with a learning disability in Sutton.
- Specialist palliative care provided to patients being cared for in their own homes was delivered by CNS' from the local hospice.

### Managing anticipated risks

- Patient risk assessment and screening tools were in use including those to assess nutritional risk, falls risk and risks to deteriorating health.

## Are services safe?

- Staff told us that major incident and winter management plans were in place and that patients at the end of life were prioritised.

# Are services effective?

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

## Summary

We rated effective as good because:

- All new nurses to the community attended end of life care training within the first few months of commencing in post.
- There was good training and support available from the end of life specialist care home team (SCHT) to staff working in care and nursing homes.
- The Gold Standards Framework (GSF) was used in the community and within the work of the end of life SCHT in care and nursing homes.
- There was good multi-disciplinary working through the GSF and specialist staff were available to support the work of the community nursing teams.

However:

- It was unclear what guidance was being used to support the delivery of end of life care in patient's own homes as there was no evidence based end of life care plan in use within this part of the service.
- The quality of patient a range of patient outcomes specific to end of life care for patients supported by community nurses in their own homes were not formally monitored.
- Staffing shortages within the community nursing teams meant that the delivery of end of life care fell to more experienced staff who had attended relevant training.

## Evidence based care and treatment

- The Gold Standards Framework (GSF) was in use within the service. Specialist palliative care nurses from both the community end of life care team and the local hospice would attend regular GSF meetings with GPs and community nursing teams. We saw evidence that the GSF prognostic indicator guidance was used to help identify where patients were in the last few days, weeks or months of life.
- Where patients were being supported by the end of life care team in care and nursing homes we saw a monthly

'prospective prognostic planning tool' in use to help plot changes in a patient's condition and identify a pattern of deterioration over time. This supported staff in care and nursing homes to anticipate and recognise dying and therefore plan care in the last phase of life.

- For EoLC patients in care homes, there was an individual plan of care. This was based on the Leadership Alliance for the Care of Dying People (LACDP) Priorities of Care for the Dying Person. This individual plan of care was adapted from one in use within the local hospice and within the acute trust.
- However, there was no similar individual plan of care for patients in the last phase of life in the community being cared for in their own homes that was based on national guidance or evidence based care and treatment. While we saw generic care plans in place, they did not reflect evidence based guidance around end life care such as the 'five priorities' and evidence of 'physical, emotional and spiritual' needs assessment and care planning specific to end of life care in line with national guidance. The trust states that they were planning on rolling out the hospice care planning document to provide this specific end of life care framework, however this was not evident at the time of our inspection. We saw care plans where an identified problem was recorded as a patient needing 'palliative care due to diagnosis of terminal illness' and care planning prompts were included such as 'pain management' or 'nutritional intake'.

## Pain relief

- There were tools available to assess and monitor pain and we saw these consistently in use in care and nursing homes where patients and staff were supported by the end of life care team. There was a range of tools available including those that prompted the assessment of restlessness and agitation, body language and facial expression for those patients unable to verbalise their pain. However community nursing staff delivering end of



## Are services effective?

life care in patient's homes told us they used a one to ten pain level score although didn't generally use other pain assessment tools, however they would be able to access them from specialist nurses if they needed to.

- Patients we spoke with told us their pain was well managed and that staff were quick to respond to requests for additional medicines when pain occurred. We did not see patients in pain and relatives we spoke with told us pain was well managed by the community staff as a whole.
- Where appropriate patients had syringe drivers which delivered measured doses of medicines at pre-set times. We were told that all qualified nursing staff were trained in the use of syringe drivers, however due to the volume of nursing vacancies within the community there were a number of agency staff being used who would not necessarily have attended training. Staff told us if this was the case, only senior staff who had been trained would attend to the needs of patients at the end of life.
- Staff told us there were adequate stocks of appropriate medicines for end of life care and that these were available as needed both during the day and out of hours.
- Anticipatory medicines were available in patients homes where it had been identified they may require medicines to manage their symptoms quickly in the near future. Community staff told us getting anticipatory medicines prescribed was relatively straightforward and advice was available from the specialist palliative care team at the hospice.
- Community nurses told us that prescribing of analgesia and medicines to manage other symptoms was generally carried out by the specialist palliative care team at the hospice who were quick to respond to requests for input where symptoms were an issue.

### Nutrition and hydration

- The assessment of nutrition and hydration needs were incorporated into the general nursing assessment in use in the community.
- The use of malnutrition universal screening tool (MUST) was observed as part of routine patient risk assessments. We saw that where the risk was identified as being high staff liaised with the patient's GP and

other members of the multi-disciplinary team as appropriate. MUST assessments were completed in all of the records of patients at the end of life that we reviewed.

- We saw evidence of one patient at the end of life who had experienced swallowing difficulties. Their swallowing had been assessed by a speech and language therapist (SALT), their care plan amended and daily reviews implemented by community nurses. There was an emphasis on patient choice and the use of nutrition and hydration for comfort at the end of life.

### Patient outcomes

- The end of life care team providing support to care and nursing homes provided activity data relating to key performance indicators for the service. Included in this was an ongoing audit of patient's preferred place of care at the end of life. The results showed that 80% of patients were cared for in their preferred place at the end of life.
- The quality of a range of patient outcomes specific to end of life care for patients supported by community nurses in their own homes were not formally monitored. For example, we found no evidence of monitoring the effective use of the '5 priorities of care' at the end of life for patients cared for in their own homes.
- We did not see evidence of the use of audit specific to end of life care in the community where care was delivered in patient's homes by the community nurses. We also did not see end of life care in the community included in the trust's community audit forward plan.
- The end of life supportive care home team remit included meeting with care and nursing home residents and their families to promote advance care planning for patients at the end of life.

### Competent staff

- The percentage of community staff that had received an appraisal in the last 12 months was 88.4% against a target of 85%.
- The trust ran a 'nurses new to the community development programme' that incorporated training

## Are services effective?

relating to end of life care. In addition the local hospice ran an end of life care course although we were told the most recent one had been cancelled due to poor uptake.

- Staff told us that syringe driver training would include medicines calculations and symptom management and included competency checks following the training.
- We requested data from the trust relating to the percentage of community nursing staff who had attended training relating to end of life care; however this data was not available at the time of our inspection. We were told that as part of the 'nurses new to the community development programme' end of life care issues such as advance care planning, supportive and palliative care and symptom management were covered. We saw that 10 new nurses in the community had completed the programme between November 2015 and February 2016.
- Staff we spoke with told us that senior members of the community nursing teams would generally deliver care for end of life care patients until less experienced staff felt competent and had attended training. In addition they told us that the practice nurse educator would provide training and support around end of life care issues.
- Community staff told us that ad hoc training was delivered by the palliative care nurse consultant or members of the end of life care specialist team who provided end of life care support to care and nursing homes.
- Staff we spoke with in the community demonstrated knowledge of end of life care issues and the importance of good quality end of life care for patients in the last few months or weeks of life. For example, all community nursing staff we spoke with had a good understanding of anticipatory prescribing and were able to demonstrate awareness of appropriate symptom management. However, not all community nursing staff we spoke with demonstrated an understanding of national guidance relating to end of life care. For example there was limited awareness of the five priorities of care at the end of life.
- Community palliative clinical nurse specialists (CNS) provided specialist care for patients with complex symptom management issues being cared for in their

own homes. These CNS' were contracted through a service level agreement with the local hospice. They were available to support individual patients and nurses in delivering end of life care and could provide joint visits and advice and support to the team.

### Multi-disciplinary working and coordinated care pathways

- The integrated locality teams in the community were aligned to GP Practices and worked as part of wider multi-disciplinary teams. The community nurses, specialist palliative care clinical nurse specialists (CNS) and the end of life care supportive care home team were also part of the Gold Standard Framework (GSF) for EOL care.
- The end of life care supportive care home team were part of the Royal Marsden specialist palliative care team and have close working relationships with colleagues supporting the acute and inpatient services.
- Community nursing staff had established relationships with the hospice based specialist palliative care CNS team. This included joint working through the structure of the GSF meetings and conducting joint visits where this had been identified as potentially beneficial for patients.
- One example where staff had worked to improve practice included the development of a weekly schedule that was shared across teams and organisations so that all staff had direct contact with specialists and community leads who were working or on call outside of normal working hours. Staff we spoke with told us this had improved communication and coordination outside of normal working hours.

### Referral, transfer, discharge and transition

- Patients were referred and transferred appropriately for end of life care and to their preferred place of death.
- There was a clear pathway for referral to the hospice based community specialist palliative care service and community nursing staff were able to access specialist nurses by phone if they needed advice or input about a patient.
- We were told that the specialist palliative care team from the acute trust met regularly every six weeks with the CNS from the hospice. However, meetings between



## Are services effective?

the hospice CNS and community nurses happened less regularly. Hospice staff told us they were trying to increase the regularity of meetings to further improve relationships and ensure that staff felt confident about contacting them in a timely way.

- We saw evidence of good multi-disciplinary working between services to ensure appropriate and timely transfer, discharge and transition. Staff we spoke with consistently told us that patients could be supported at home very quickly in the last days of life where they wanted to be transferred from hospital.
- Staff told us of scenarios where they had stayed beyond the end of their shift to support patients who had been discharged home from hospital at the end of life. This included providing support to the patient and their family and ensuring that appropriate equipment was in place.
- The end of life care supportive care home team provided support to care and nursing home staff and patients around good quality end of life care. The aim of this service was to reduce admissions to hospital for patients at the end of life and to improve end of life care in the patient's preferred place of care. Data showed that 80% of patients in care and nursing homes died in their preferred place of care.

### Access to information

- We saw that risk assessments and care plans were in place for patients at the end of life. Patients were cared for using relevant plans of care to meet their individual needs.
- Across the locality 'coordinate my care' (CMC) was used. This was an electronic record system where patients were supported to record their views about their future care, including where they would like to receive care. This plan was then accessible through the electronic system to doctors, nurses and emergency services to ensure the information was available to those who were involved in planning and delivering care.
- In the community paper records were kept in patient's homes and these were kept up to date during the visits

we observed. The community nursing teams used an electronic record system where paper records were scanned in once a patient had been discharged from the service.

### Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- Staff told us they undertook Mental Capacity Act (MCA) 2005 and Deprivation of Liberty Safeguards (DoLS) training as part of their safeguarding training. There was a policy available to support staff when considering MCA and DoLS along with a standard mental capacity assessment proforma.
- Staff we spoke with demonstrated some understanding of issues around mental capacity and the presumption of capacity. They were aware of the use of formal assessments and best interest decision making but told us that generally undertaking assessments was the remit of the GP in charge of the patient's care.
- Specialist nurses as part of the SCHAT used two different approaches to advance care planning, one for people with mental capacity and one for people who lacked mental capacity. This approach made it clear when mental capacity assessments were required and when and how decisions were made in the best interests of patients.
- There was a section relating to mental capacity on each Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) form, which was filled out by the doctor completing it. All of the DNACPR forms we viewed were appropriately completed and we did not see a form completed where a patient had been identified as not having capacity.
- All of the DNACPR forms we viewed included appropriately recorded discussions with the patient or their family. We viewed the results of an audit that was carried out in January 2016 where 88% of those DNACPR forms completed had included a discussion with the patient or the family members.

# Are services caring?

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

## Summary

We rated caring as good because:

- Patients were treated with dignity, kindness and compassion.
- There was consistently positive feedback from patients and their relatives about the service.
- Patients and their relatives were encouraged to share their individual choices and beliefs about their care through the use of the 'coordinate my care' record system so that this information could be shared across teams.
- Staff worked hard to ensure that patients at the end of life were given the support they needed, including staying beyond the end of their shift to make sure patients had in place what they needed.
- We consistently observed nursing staff assessing the emotional needs of patients alongside their physical needs as part of end of life care visits.

## Compassionate care

- Patients and relatives we spoke with told us that staff were professional, caring and kind. We observed care being provided and saw that patients were treated with compassion, dignity and respect.
- We observed staff caring for patients in a way that respected their individual choices and beliefs. The use of the 'coordinate my care' (CMC) record system was encouraged. This meant there was a record of patient choices and beliefs so that these were widely communicated between the teams.
- All patients and relatives told us they were highly satisfied with the quality of care they received and that staff treated them with respect and maintained their dignity.
- We heard stories of situations where staff had gone the extra mile to support patients. For example, nursing staff staying beyond the end of their shift to settle patients at home following their discharge from hospital to their

preferred place of care. One specific example included where a relative was struggling to cope so staff stayed to provide support while liaising with other services to ensure longer term support was available.

- A relative told us that their experience of the support they received from the community nursing team was a very positive one where staff were caring, knowledgeable and nothing was too much trouble.
- The trust provided an information booklet for families on 'what to do after a death at home'. Written records from one patient showed that nursing staff visited the family after the death and gave practical advice and support.

## Understanding and involvement of patients and those close to them

- All patients and family members told us they felt involved with the care delivered. For example, one family member told us staff had spent time with them to teach them about certain aspects of care so that the patient's care could be supported by their family at home. The family told us that this had reduced the number of hospital appointments the patient needed to attend and enabled them to stay at home.
- We saw that staff discussed care issues with patients and relatives and these were clearly documented in patient's notes.
- The use of the CMC record system enabled patients and their families to be involved in planning care, particularly around a patient's choice of where and how they wanted to spend their last weeks and days of life.
- Patients and family members we spoke with consistently told us that staff took the time to ask for their input and opinions about care. We saw evidence of advance care planning and staff providing support to ensure that this was carried out. We observed the use of advance care planning booklets in patient's homes where their preferences and choices were recorded.

## Are services caring?

### Emotional support

- Staff told us they felt they generally had the time to spend with patients and provide the emotional support to meet their needs, although they also told us that sometimes this required them staying beyond the end of their shift.
- We observed community nurses assessing the emotional needs of patient's at the end of life and their families as a matter of routine when visiting them at home.
- Bereavement support was provided to patients by nursing staff in the community immediately after death where nurses would undertake a visit to the family. Information about bereavement services were available. This included support from the local hospice such as counselling for families of patients who had been in receipt of hospice services.

# Are services responsive to people's needs?

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

## Summary

We rated responsive as good because:

- The trust worked closely with other providers and commissioners to plan services, for example in relation to the end of life supportive care home service.
- The trust made it a priority to promote patients' preferred place of care at the end of life.
- A recent expansion of the supportive care home service across Sutton included the development of services across all care homes and a pilot in some homes for people with learning disabilities.
- There was evidence of a positive impact on patients living in care homes experiencing improved end of life care as a result of supportive care home service.
- The trust made use of contracted interpreters to support end of life care where language barriers existed, thus taking pressure off of family members to support communication during difficult discussions.
- We observed good use of advance care planning with a uniform approach across services and adapted tools for use when patients did not have capacity and decisions were made in their best interest.
- End of life care was prioritised by community nursing staff.
- There was evidence of learning from complaints and working with other services to improve the experience of patients and their families as a result.
- Services were planned and delivered to meet the needs of patients and their relatives. Staff told us a priority was to ensure that patients were cared for in their preferred place of death wherever possible.
- Data provided by the trust showed that 83.9% patients on an end of life plan died in their preferred place of death between December 2014 and November 2015, which was better than the trust target of 80%.
- The trust used external information to plan current and future health and care needs such as Joint Strategic Needs Assessment (JSNA) and working closely with Sutton clinical commissioning group (CCG) to ensure that services meet the needs of the local population.
- The end of life supportive care home team (SCHT) worked closely with local commissioners to ensure the service was aligned with the needs of the care homes they supported. For example, the recent disaggregation of community services across Sutton and Merton saw positive developments in expanding the services across Sutton to continue a pilot of non-nursing care homes. In addition the trust had worked with commissioners to develop a pilot to carry out a scoping exercise around care homes for people with a learning disability in relation to promoting optimal end of life care.
- Staff within one of the care homes receiving support from the end of life SCHT fed back to us that they felt the service had positively impacted the end of life care of people living in their care home. Specifically they told us they felt more confident in caring for people at the end of life and more able to manage their symptoms.

## Planning and delivering services which meet people's needs

- The Royal Marsden NHS Foundation Trust provided community end of life care services to a population of approximately 196,000 people across Sutton.
- The Royal Marsden specialist palliative care team worked closely with other providers and met regularly with local commissioners and their counterparts in the local hospice to communicate issues and plan services.

## Equality and diversity

- Equality and diversity training was part of the mandatory training for all nursing staff in the community including the end of life care SCHT.
- 87% of community nursing staff had completed equality and diversity training which was below the trust target of 90%



# Are services responsive to people's needs?

- Staff we spoke with were able to demonstrate their understanding of equality and diversity. For example, one staff member told us they routinely identified patient's values and beliefs so as to ensure these were incorporated into the way they delivered care.
- Patient information and leaflets including letters to patients could be provided in a person's own language, large print for people with visual impairment or in easy read versions.

## Meeting the needs of people in vulnerable circumstances

- The trust were planning on providing learning disability awareness training for staff working within the community locality teams in 2016 and staff had already attended dementia awareness training.
- The Trust had contractual arrangements in place for telephone interpreting and face-to-face interpreting. One family member we spoke with told us that the trust had arranged for an interpreter for their relative who was at the end of life and spoke very little English. The family member was grateful that this had taken the pressure off of other relatives having to interpret.
- Specialist palliative care support for people in vulnerable circumstances was apparent through the end of life care SCHAT where the primary aim of the service was to improve end of life care for patients living in care and nursing homes. This included end of life care support for people who had dementia. In addition we saw that the trust were in the process of rolling out a pilot of support for care homes for people with a learning disability.
- Staff told us they could access support and advice from the trust's learning disability nurse or the community dementia services.
- Advance care planning was a key part of end of life care and we saw that this was prioritised in terms of training delivered to generalist staff. We also saw that tools and templates were available in the form of a booklet that staff could use to support the completion of the process with patients at the end of life and their families.
- Tools such as advance care planning and 'coordinate my care' were in place to support the care of people in vulnerable circumstances by sharing information in a way that took account of patient's beliefs and individual choices.

## Access to the right care at the right time

- Community specialist palliative care in patient's own homes was provided by the local hospice. Staff reported that this service was accessible and that hospice staff were responsive to patient's needs and the support needs of community nursing staff.
- Between November 2014 and November 2015, community nursing teams completed 100% of urgent assessments within four hours of receipt and 100% of routine assessments within 48 hours of receipt; which was better than the 95% target set by the trust.
- We did not have detailed data relating to patients with end of life care needs.
- Referrals were prioritised based on assessed patient need. Staff, patients and relatives consistently reported that the community nursing teams were able to respond quickly to end of life care issues as these were prioritised as part of daily work activities.
- The trust operated a 'T card' system where colour coded cards were used to help identify patient's with specific issues quickly. This included patient's at the end of life so that there was a visual prompt for staff in terms of managing and prioritising care.
- Patients we spoke with told us staff were responsive to their needs. We spoke with families who had accessed the service for patients at the end of life and they told us that the community nursing teams were consistently quick to respond to changing needs. For example, we viewed patient records where staff had visited a patient within 30 minutes of being called. A family member told us nursing staff had visited within an hour following a call during the night to inform them that the patient's syringe driver was alarming.

## Learning from complaints and concerns

- The Trust received 118 complaints in 2015, which covered both acute and community services. The most

## Are services responsive to people's needs?

common themes were communication, appointment delays and cancellation and attitude of staff. This data was not available specific to community services or community end of life care services.

- Staff said they referred complaints to the Patient Advice and Liaison Service (PALS) if they were unable to resolve the issue locally. Staff supported patients, their relatives or carers to make complaints if they needed help. Staff told us they received feedback and shared lessons learnt from complaints if they were about themselves or the team. Those teams that had regular team meetings said complaints were discussed and discussion took place on the learning and any changes that needed to be made.
- Complaints about the community nursing service were reported to the clinical director for nursing who worked closely with the palliative care nurse consultant. Actions were taken to ensure improvements were made in the case of complaints relating to end of life care in the community.
- Specific complaints that staff told us about relating to end of life care included those where relatives were unhappy with the coordination and delivery of care at the end of life. For example we saw that two complaints had been received in the last 12 months that involved community nursing but also other community health services. Managers told us that where other services were involved the investigation and search for resolution and learning would involve other services with the clinical director for nursing and palliative care nurse consultant meeting with other service providers to ensure learning across the services.
- In January 2016 the trust had carried out a survey of complaints, including seeking the views of complainants to identify changes and improvements to the complaints process within the trust. Recommended changes included making sure that information on how to complain was more easily accessible. All patients and their relatives we asked about the process for making a complaint said they understood how to complain but that none of them had reason to at the time of our inspection.

# Are services well-led?

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

## Summary

We rated well-led as requires improvement because:

- There was no completed end of life care strategy for community implemented and the development of this service in relation to the trust-wide strategy was unclear.
- Quality measurement in relation to community end of life care services was limited and did not cover all aspects of the service. There was no clear plan for measuring or improving the quality of end of life care for patients receiving care in their own homes.
- In the absence of a community end of life care strategy and clear processes for measuring the quality of services it was unclear how specialist palliative care and end of life care input was influencing the development of services for patients receiving end of life care in their own homes.

However:

- There was a clear vision and strategy for how the community end of life care supportive care home services were working to improve end of life care in care and nursing homes.
- There was a culture of quality end of life care across all community end of life care services.
- There was evidence that the community end of life supportive care home team engaged with other services to improve end of life care.

## Leadership of this service

- There were two strands of community end of life care: one service provided to patients in their own homes and another service provided to patients accommodated in care homes. An end of life care supportive care home team (SCHT), with a remit for promoting end of life care in nursing and care homes; they did not provide specialist support for people in their own homes. This team was led by the palliative care nurse consultant who had responsibility for end of life care within the trust alongside the matron in palliative care and specialist consultant in palliative medicine. Specialist

palliative care input for people in their own homes was provided seven days a week by a team of specialist palliative care clinical nurse specialists from a local hospice who worked with the community nursing teams to provide specialist support.

- There was a palliative care nurse consultant who was responsible for the management and leadership of the end of life care supportive care home team (SCHT) and the provision of end of life care support across the trust as a whole. The community nursing lead was the clinical director for nursing.
- The Lead Nurse for the trust had the role of maintaining an overview of end of life care at trust board level.
- We observed clear leadership from the end of life care lead and their team in relation to support for care and nursing homes. In relation to end of life care in patient's own homes we saw clear leadership from the clinical director of nursing and from team managers within community services. We saw that senior staff prioritised end of life care and that there was a commitment to good quality end of life care.
- All staff we spoke with in leadership roles had a good understanding of the importance of high quality end of life care and we consistently heard from staff that end of life care was prioritised based on patient need.
- Staff told us that specialist palliative care nurses that provided advice and support to community nurses delivering end of life care in patient's own homes were visible and easily accessible, providing leadership around specific care issues on an individual patient basis.
- However, in the absence of an end of life care strategy it was unclear how the leadership elements of the service were working together to ensure that specialist input was influencing the development of community end of life care delivery by general community nurses.

## Service vision and strategy

- The Royal Marsden NHS Foundation trust had a trust-wide strategic plan that included the development of



## Are services well-led?

integrated care models across acute, community and home settings. In addition the trust had developed an end of life care strategy where key aspects of the strategy included increasing education and training on principles of end of life care, the development of individual care plans and improving the experience of patients and carers in the last year of life. However, it was unclear how the delivery of end of life care in the community was a part of this strategy.

- When we spoke to staff about an end of life care strategy for community services they saw this as separate from The Royal Marsden strategy. An end of life care strategy was in the process of being drafted by NHS Sutton clinical commissioning group (CCG). This was based on national guidance and incorporated the work of the Royal Marsden community nursing service and the end of life care supportive care home team (SCHT).
- The vision for end of life care in relation to The Royal Marsden Community end of life care service was unclear in relation to the development of end of life care for patients in their own homes. The service received operational support from the local hospice in relation to specialist palliative care support but it was unclear how the service was planning to develop strategically. For example, the community service was run by The Royal Marsden Hospital, with operational support from the local hospice. There was no clear end of life care strategy in operation or plans evident for how the services would work together to ensure quality improvement in end of life care for patients at home.
- Staff working as part of the end of life care supportive care home team had a clear vision for supporting care and nursing home staff to ensure that patients received optimal end of life care. This service was a key component of the Sutton CCG vanguard site for 'enhanced health in care homes' and the service was achieved through education and training for care home staff, clinical ward rounds and assisting with the identification of patients at the end of life.

### Governance, risk management and quality measurement

- Community end of life care reported within the structure of the community adults service with specialist input from the palliative care nurse consultant and end of life care supportive care home team (SCHT).

- Governance arrangements were in place to enable the effective identification of risks, monitoring of such risks and the progress of action plans. There were risk registers in place for both trust wide end of life care and community adults services. We did not see specific risks identified for community end of life care, for example in relation to staffing risks identified.
- The business unit reviewed the risks on the risk register. The end of life care team fed into the clinical governance structure of the business unit and we saw evidence of governance issues and processes being discussed at the range of end of life care service meetings held. For example, trust wide end of life/palliative care incidents were a standing agenda item on the palliative care senior management meeting agendas.
- Within community services there were divisional management team meetings which fed into senior nurse meetings and cascaded into integrated locality team meetings. We viewed minutes of senior nurse meetings and saw that governance, risk management and quality measurement were discussed in these meetings, however we did not see issues specific to end of life care being minuted.
- Quality measurement within community end of life care services was limited within the trust. There was limited evidence of quality audit or focus on continuous improvement of these services delivered by generalist community nurses. We could not see evidence of how the trust ensured that appropriate specialist palliative care services influenced the development of end of life care delivery by generalist community nurses in patient's own homes. For example, in the absence of an agreed end of life care plan for use by community nurses or through the use of quality measures such as audit to monitor the quality of end of life care in this environment.
- Quality measurement within the end of life care SCHAT included the use of monthly performance monitoring data. In addition, feedback was sought from staff within the care homes the team were supporting. For example, training evaluations were completed following each training session and learning from this was used to develop the service.



# Are services well-led?

## Culture within this service

- Staff we spoke with demonstrated a commitment to the delivery of good quality end of life care. Staff told us they felt proud of the care they were able to give.
- There was evidence that the culture of end of life care was centred on the needs and experience of patients and their relatives. For example staff consistently told us they felt able to prioritise the needs of people at the end of life in terms of the delivery of care. We were given examples of where staff had gone out of their way to support patients and their families at the end of life, particularly around ensuring their choices and preferences were met.
- We observed good collaborative team working across community teams in relation to end of life care. Staff told us there were opportunities to learn and that the delivery of high quality end of life care services within the community was encouraged.
- There was a strong culture in place of enabling people to receive end of life care where they wished and we heard that teams worked together to try and ensure that patients were cared for in their preferred place of death.
- Staff said they worked well together as a team and staff morale was generally good. However staff shortages in some teams impacted on staff morale at times.
- We viewed six cards and letters sent by patients and their relatives providing feedback on the service they had received. These were very positive with praise for the staff delivering care at the end of life.
- The end of life supportive care home team remit included meeting with care and nursing home residents and their families to promote advance care planning for patients at the end of life.
- The specialist palliative care service across the trust used a number of engagement activities with patients and the public including undertaking surveys, audits and research around good palliative and end of life care.
- Specifically relating to community end of life care we saw that the End of life care supportive care home team (SCHAT) had worked extensively with the CCG (clinical commissioning groups) to engage with other local services delivering care home services in order to ensure that the end of life supportive care home service met the needs of services and individual's using the services.
- We viewed plans for the SCHAT to provide education and training in conjunction with the local hospice to raise public awareness of the issues around end of life care such as will writing and advance care planning.

## Staff engagement

## Public engagement

- Community adults nursing staff told us they did not ask patients to complete formal patient feedback forms. However, friends and family test results showed that 97% of community patients would recommend the service. The NHS Friends and Family Test (FFT) is a feedback tool used by services and commissioners to understand whether patients are happy with the service provided and whether or not they would recommend it to their friends and family. Formal patient feedback specific to end of life care in the community was not available.
- The Royal Marsden took part in national bereavement surveys for inpatient services, however they did not for community services. There was no bereavement follow up survey sent to families of people who died under the care of the community nursing service.
- 95% of staff would recommend the trust to friends and family as a place to receive care or treatment. 73% of staff would recommend the trust as a place to work.
- Staff told us they participated in regular meetings including integrated locality team meetings where information was cascaded from the trust and there was an opportunity for staff to feedback.
- The end of life care supportive care home team were part of the trust's wider specialist palliative care team. They met regularly with colleagues from the acute team, hospice based community CNS' and with community nursing colleagues.
- There was a trust newsletter that was available to all staff. Staff told us that this was generally focused on the inpatient services and would sometimes reinforce a sense of separation between the acute and community departments within the trust.

# Are services well-led?

## Innovation, improvement and sustainability

- The end of life supportive care home team (SCHT) was a part of a Sutton CCG (clinical commissioning group) vanguard relating to improving end of life care in care and nursing homes. Members of the SCHAT were involved in developing the service and had been invited to speak about the model and share this development with other services. For example, at an international London Cancer Alliance conference.
- It was difficult to see how all aspects of end of life care services worked together across the trust to improve end of life care within the community. While there were clear innovations in relation to the support for care and nursing homes, there did not appear to be clear processes for improving end of life care for patients in their own homes. For example, there were no regular meetings taking place between community nursing and the specialist palliative care teams in relation to the development of end of life care in the patient's own homes.