Quality Account

2017/18

Marie Curie

Care and support through terminal illness

Contents

Kieran Dodds/Marie Curie

Introduction from the CEO and Chair of Trustees

Welcome to our 2017/18 Quality Account for England

Marie Curie is the UK's leading charity caring for people living with any terminal illness and their families.

Through our 1,403 Marie Curie Nurses in communities across England, and our five hospices in Bradford, Hampstead, Liverpool, Newcastle and the West Midlands, we provided palliative and end of life care for 25,549 terminally ill people in 2017/18.

Those people were living with conditions ranging from terminal cancer to dementia and motor neurone disease, to chronic heart or lung disease. We may have been supporting them for months following their terminal diagnosis, or for just days at the very end of their life.

But what all the care we provide has in common is our commitment to meet the highest standards of quality for our patients. Particularly, it's crucial that our services are always centred around our patients' individual needs – everything we do is to serve them and their families.

This report outlines how we've met those standards over the past year – as well as those areas where we still have improvements to make.

We believe there's much to be proud of here: levels of satisfaction among our patients, already very high, have improved across a range of measures compared to the previous year. Almost everyone we care for would recommend our services to their friends and family (99.2% for our hospices and 98.2% for our nursing services).

Meanwhile, complaints around challenging areas, such as making sure we always have nurses available when patients need them, have decreased significantly by about 38%.

Work on improving this further will continue next year, as we move towards a system of services being co-ordinated locally across England, rather than via a central hub. This represents an important change in how we organise our services and allocate nurses to patients.

We are also in a strong position to adapt to changing regulatory requirements. As of next year, our hospice services will be assessed by the acute care inspection team at the Care Quality Commission (CQC), rather than the social care inspection team.

This shift will involve meeting different standards, but it's important to make sure the unique nature of hospice care is reflected in the requirements we're being asked to meet.

As such, we have worked closely with the CQC to develop the new hospice inspectors' guide, highlighting the differences between hospice care and acute hospital care.

We hope you find this year's Quality Account for England informative and useful – and, as always, do please get in touch with us with any questions or comments you may have.

Iain Crockart/Marie Curie

Vindi Banga, Chair of Trustees

Pete Jones/Marie Curie

Dr Jane Collins, Chief Executive

Our vision and values

Our vision

A better life for people and their families living with a terminal illness.

Our mission

To help people and their families living with a terminal illness make the most of the time they have together by delivering expert care, emotional support, research and guidance.

Our values

- Always compassionate
- Making things happen
- Leading in our field
- People at our heart

Kieran Dodds/Marie Curie

Having Marie Curie Nurses looking after Dad gave us peace of mind. They were incredibly respectful of everything we had done to care for him and everything we were working towards. Looking after Dad at home meant there was always something that needed doing, and knowing Marie Curie Nurses were on their way was like the cavalry coming. It was a wash of relief."

Jane Cozens. Marie Curie Nurses cared for Jane's dad William, 84, who was living with pancreatic cancer.

Part 1 **Our priorities**

When considering the quality of our care, we look at three key areas. If these three things are as good as they can be, then we believe we will be delivering a genuinely high-quality service for the patients we care for.

When we look at potential improvements we could make to our services, we prioritise changes that we think will make a significant difference in one or more of these areas.

Our three quality priorities are:

- **Patient experience**
  How consistent and reliable has our care been, and how far has it been based around our patients' individual needs?

- **Patient safety**
  How successfully have we protected patients from unnecessary illness, injury or distress while in our care?

- **Clinical effectiveness**
  How successfully have we achieved the best possible outcomes for our patients, in line with their wishes and preferences?

In this section, we've outlined what improvements we have made in each of these areas over the last year, and what impact they had for our patients.

Ben Gold/Marie Curie

Part 1a: **Patient experience**

Our three focus areas for 2017/18 around improving patient experience were:

- consistency of care in our nursing service
- reliability of care in our nursing service
- person-centred care for patients and their families.

Consistency of care in our nursing service

We said we would...

Improve our use of technology for staff rostering and allocation to improve continuity of care.

What we did

Consulting with clinical teams, we analysed what our rostering system ideally needs to do to improve how we allocate our staff to patients. The new system will be purchased, and implementation will be underway, by the end of 2018.

This new method of allocating staff will help us send the same nurse or nurses to visit patients more consistently, providing better continuity of care and better outcomes for patients and their families.

Currently, on average, each patient in England is visited by around four different nurses (3.94) while we are caring for them and we would like to see this number reduce under the new system.

We would expect to see an improvement in patient and family experience, reflected in a reduction of complaints and an increase in positive feedback.

We are exploring other ways to improve continuity of care. For example, in London, we've piloted shared electronic records, to help ensure that even when different nursing staff are involved in caring for a patient, they still have a full understanding of the patient's needs and preferences. This information can also be shared with other healthcare staff outside of Marie Curie who are involved in caring for the patient.

What is consistency or continuity of care?
We'd like our patients to always be visited by the same nurse (or same few nurses), so the patient and their family always have familiar faces in their home. Practically, this isn't always possible, but there's more we can do to ensure it happens as often as it can.

What is reliability of care?
We want to make sure that we always have nurses available for our patients when they need them. This is challenging to achieve, but we're working hard to improve this.

What is person-centred care?
This is care based around the needs of the individual person being cared for. It means part of our nurses' job is to get to know what is important to the patient and their family, so they can care for them in the way that's right for them.

Simon Rawles/Marie Curie

Reliability of care in our nursing service

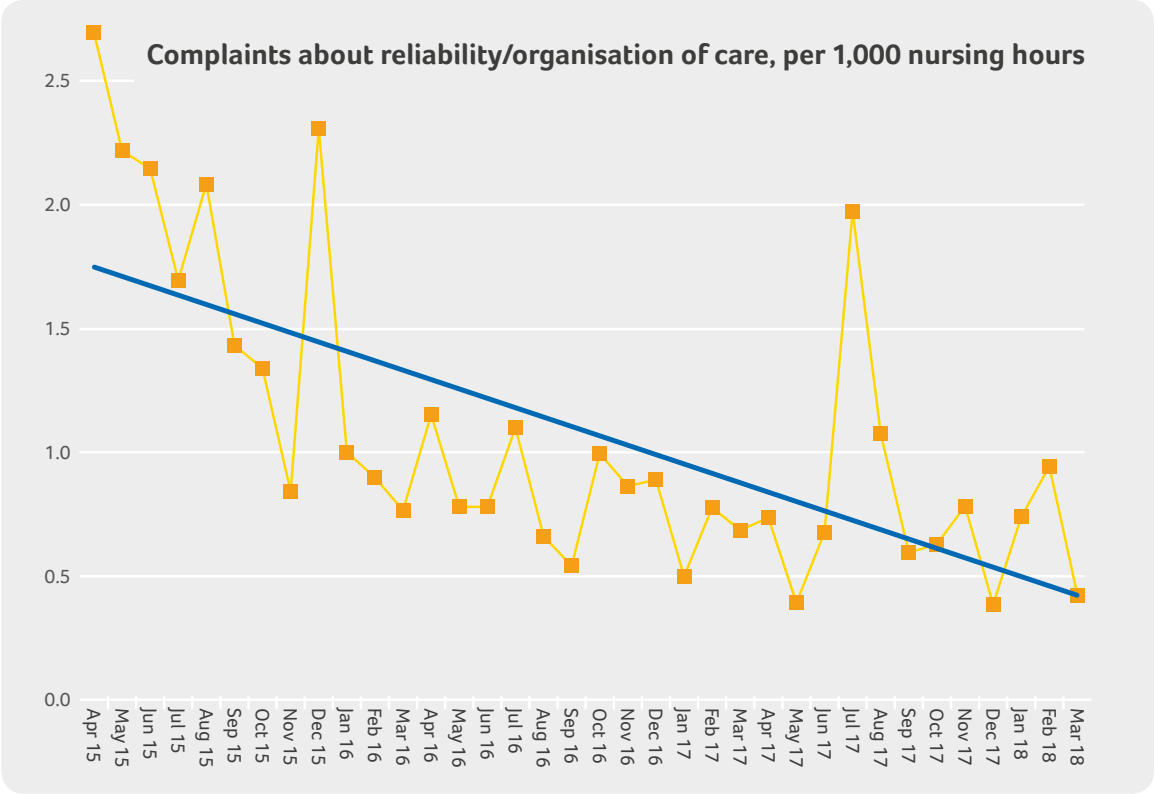
We said we would...

- improve how we share information with our NHS partners to improve reliability of care
- reduce the number of cancelled visits to patients and families.

What we did

We increased the responsibilities of our registered nurses to provide line management to a group of healthcare assistants. This has increased the capacity of our clinical nurse managers to support the senior nurses. Over the last year, senior nurses have become more involved with caseload management, working with district nurses to ensure care is prioritised for patients according to need. Line managers are working to ensure the maximum number of bookings are made for the available nursing staff.

Next year, we plan to build on these improvements by moving towards local co-ordination of our nursing service through seven hubs in England. This will enable us to use local knowledge to meet the specific needs of the area and allocate nurses more effectively.



What the data shows

Over the course of 2017/18, we've received significantly fewer complaints about reliability of care (134 compared to 215 in 2016/17), which suggests we are performing well in providing care where and when it is needed.

This is an encouraging downward trend that we expect to continue based on our plans for further improvement next year.

Person-centred care for patients and their families

We said we would...

- ensure patients are at the centre of everything we do and the care we provide
- give staff the development, training and clinical supervision they need to deliver care in this way.

What we did

Person-centred care is fundamental to the Marie Curie ethos of care and is core to our values. All our clinical staff receive specific training in how to deliver care based around the wishes and preferences of their patients, initially as part of their induction and then with further training as needed during their career at Marie Curie.

This year, we held workshops in our Liverpool and West Midlands hospices for staff on person-centred practice, open to all patient-facing staff from across Marie Curie's services and from

different disciplines, including nurses, social workers and physiotherapists.

We are also piloting an electronic record for our hospice patients entirely based around their individual needs and preferences.

The About Me care plan (example opposite) was introduced in the Marie Curie Hospice, West Midlands this year and we will review it (and potentially roll it out across other services) in the year ahead.

Ben Gold/Marie Curie

The About Me care plan

This is the template of our About Me care plan, including examples of the type of information it might record about patients' preferences and needs.

Physical	• Sophie has a lot of medications to take in the evening, so these need to be spread out (otherwise she can get sick). • Joyce has very cold feet due to poor circulation. This is normal for her but she needs to wear thick socks.
Social	• Huw can understand everything that is being said. Please speak to him normally. • Amir enjoys the peace of nature so would like to be taken to the gardens when the weather is fine.
Psychological	• Barrie is not afraid of death and welcomes talking about it. • Lawrence worries about his family more than himself and wants them to be supported as much as possible.
Spiritual	• Pat feels supported by her Catholic faith and would like to attend services in the quiet room. • Annette is a Methodist and her faith is important to her. She enjoys home visits from her Methodist minister.
Fundamentals	• John would like to have his shower before 10am. • Lawrence can only eat a soft, puréed diet. He likes yoghurts, soup and smooth mashed potatoes with gravy.
Safety	• Fatima needs oxygen to breath comfortably and must have her nasal cannula on at all times. • John has fallen twice, so he now sits on special sensory pads so we know when he starts to get up.
Family and friends	• Tony is keen for his wife to stay overnight as often as possible. • Edwin's daughter Pam visits daily and brings him to day services.

Part 1b: **Patient safety**

Our three focus areas for 2017/18 around improving patient safety were:

- pressure ulcers
- infection prevention and control
- safeguarding.

Pressure ulcers

We said we would...

Take part in the national React to Red Skin campaign, to reduce the number of pressure ulcers developed by patients in our care.

What we did

We launched the campaign in May 2017, spearheaded by our tissue viability link nurses, who specialise in skin protection.

Using the national campaign materials, we have trained our staff to recognise the development of a pressure ulcer and to intervene at an early stage. This training, including an online training package, now forms part of every nurse's induction and practice update.

We have also reviewed our pressure ulcer policy to ensure our community nurses always alert the district nurse about any pressure ulcers observed in patients' own homes. Treatment and recording of these forms part of district nurses' care plans.

What are pressure ulcers?
Also known as bedsores, these are injuries to the skin caused by prolonged pressure. They often affect people who are lying in bed or sitting for a long time.

Grades of pressure ulcer

Grade 1 – skin is intact and does not become paler when pressed. Skin may be a different colour, warmer to touch or swollen with fluid. There may be thickening of the skin which feels harder.

Grade 2 – some loss of skin which looks like a blister or graze.

Grade 3 – deep skin loss; the skin is damaged and can appear black.

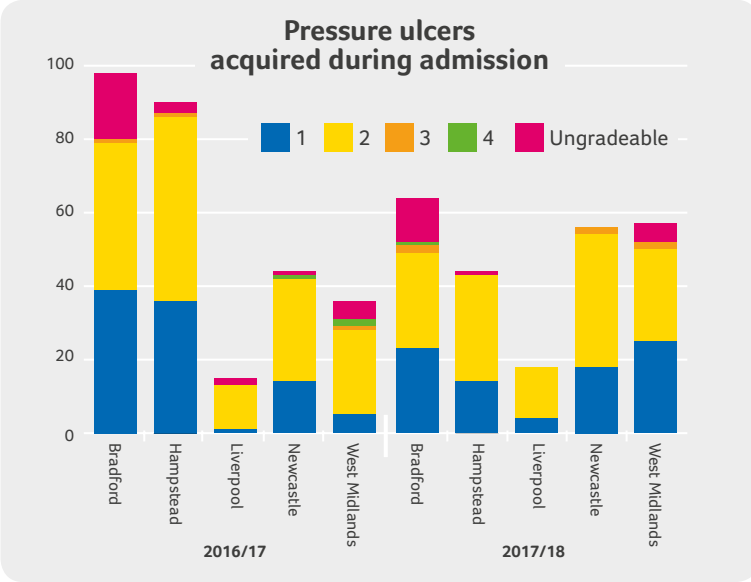
Grade 4 – there is damage to the skin and the muscle and bone underneath. At times the damage underneath the skin can cover a greater area than the skin damage on the surface.

Ungradeable – there is damage to the skin, muscle and bone underneath a scab-like covering, making it impossible to measure the amount of damage.

What the data shows

We recorded 239 pressure ulcers in our hospices in England this year, compared to 284 in 2016/17. This improvement included notable reductions in Bradford and Hampstead. Most pressure ulcers recorded during admission (54%) were grade 2 pressure ulcers. These have the potential to deteriorate to a more serious grade 3 or 4 ulcer so our nurses ensure all possible steps to prevent a deterioration are taken, in agreement with the patient.

The Director of Nursing carries out reviews of every grade 3 or 4 pressure ulcer to check if care plans were followed and whether or not there were any failings in the care and treatment the patient was given that may have contributed to the development of pressure ulcers. The reviews determine whether the pressure ulcer was avoidable or unavoidable. There were no avoidable pressure ulcers recorded this year.



Infection prevention and control

We said we would...

- continue to manage Clostridium difficile (C. diff)
- develop information on C. diff for patients and families specific to end of life
- continue to carry out post-infection reviews on C. diff infection cases as required.

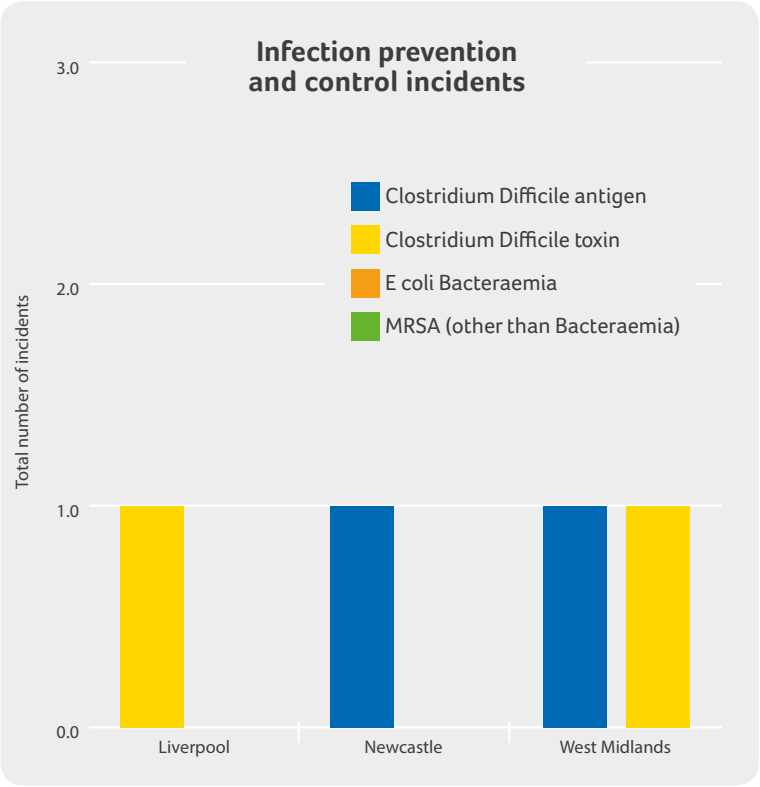
What we did

We developed an information leaflet about C. diff, working with patients to make sure the information was clear and useful. This leaflet explains the condition and what to expect, and advises families on how to keep themselves safe and well. We will review and update the leaflet if there are any changes in practice, with input from patients and families, to ensure it remains useful and understandable.

What the data shows

There were four incidents of C. diff antigen or toxin infection (2016/17: seven) across our hospices in England this year. After each incident, the Director of Nursing, supported by the specialist Senior Lead Nurse, carries out a review. Each review this year concluded that the infections were not a result of the care or treatment provided, and that high standards of clinical care were maintained in all cases.

Ben Gold/Marie Curie



What is Clostridium difficile?

Also known as C. diff, this is a bacterium that can infect the bowel and cause diarrhoea. It mostly affects people who are over 65, have been taking antibiotics or who have underlying health conditions – this describes many of the people in our care.

Safeguarding

We said we would...

Strengthen our safeguarding training and develop in-house expertise to deliver training across the organisation.

What we did

We revised our clinical induction programme. It now includes face-to-face safeguarding training to complement the existing online training. All clinical staff must attend this training.

The face-to-face training includes:

- outlining safeguarding issues staff may encounter while working in the community and hospices, including discussion around safeguarding and adults at risk, who to contact and referrals to local authorities
- an introduction to Prevent. Prevent is part of the government's strategy to tackle the problem of terrorism at its roots, by preventing people from becoming radicalised and involved in terrorism.

A safeguarding leaflet is given to all staff, including non-clinical staff, as part of Marie Curie's overall corporate induction.

Our mandatory training policy states that all staff require knowledge of safeguarding adults and children, at the appropriate level for their role. Safeguarding training is mandatory for all volunteers working in the clinical environment. We have also worked with the Home Office to train local safeguarding leads to become accredited trainers able to deliver workshops to raise awareness of Prevent.

What is safeguarding?
Safeguarding is how we make sure we are protecting the health, wellbeing and interests of vulnerable people we come into contact with, including children and young people. A collection of policies and procedures exist to help us do this.

Ben Gold/Marie Curie

Part 1c: **Clinical effectiveness**

Our three focus areas for 2017/18 around improving clinical effectiveness were:

- service compliance
- improved patient outcome measures
- quality improvement.

Service compliance

We said we would...

- deliver a compliance programme focussed on the services that need support the most
- use a range of quality measures to identify where the focus is needed.

What we did

We continued to review incidents, complaints, audit results and feedback to plan compliance visits and the areas we needed to focus on.

An example of this was the quality assurance team attending the multi-disciplinary team meeting at one of the hospices to review how this meeting was conducted. We observed the meeting could be more focussed and better prepared, and made suggestions on how to improve it.

Local teams are involved in this process of assessing the quality of their service and can then use this knowledge to drive ongoing improvements.

We will continue to review the way we assess our services, and share good practice across the organisation, to ensure we are meeting, and where possible exceeding, the standards set by our regulators.

We also invited master's students in international healthcare leadership from McGill University in Canada to carry out an independent review of our compliance programme. This led to a series of suggestions for further improvements, which we are reviewing.

What is service compliance?
Our work is regulated by the Care Quality Commission and various pieces of legislation. Our quality assurance team visit each of our services regularly (at a minimum every two years), and inspect the service, essentially in the same way that the external regulator would. This ensures both that we are fully compliant with all relevant standards and that we are well prepared for formal regulatory inspections when they happen.

What are patient outcome measures?
These are measures of what we are trying to achieve for patients through our care and in accordance with their wishes. These might include relief from pain or nausea, or being able to die at home, depending on what is most important to each individual patient.

Ben Gold/Marie Curie

Improved patient outcome measures

We said we would...

Implement a selection of recognised outcome measures focussed on symptom management and other patient needs. This will help us measure the outcomes that matter to individual patients in our day-to-day care.

What we did

We have started using three outcome measures from the Outcome Assessment and Complexity Collaborative (OACC) suite that together provide an overview of the patient's clinical status, abilities and main priorities. They complement existing measures such as user feedback and together offer the most insight into what

Outcome measures

We use three outcome measures from the Outcome Assessment and Complexity Collaborative (OACC) project, led by the Cicely Saunders Institute at King's College London.

The three outcome measures we use are:

Phase of Illness
Phase of Illness describes the distinct stage in the patient's illness.

Phases are distinguished as: stable, unstable, deteriorating, dying and deceased.

Australian Karnofsky Performance Status (AKPS)
Three aspects of the patient's overall capabilities are assessed: activity, work and self-care. The measure results in a single score between 0 and 100%, based on observations of the patient's ability to perform common tasks.

Integrated Palliative Care Outcome Scale (IPOS)
IPOS is a 10-question measure of how a patient's symptoms affect them in different respects, including physically, psychologically, socially and spiritually.

matters to the patient. Over the next year, all our hospices in England are phasing in these measures to deliver and evaluate care.

The use of these measures ensures staff are constantly focussed on each patient's individual priorities, which helps improve clinical decision-making and co-ordination of the discharge process.

The next steps will be to analyse the data gathered from across the organisation to assess how well we are meeting our patients' needs and where there is room for improvement.

Ben Gold/Marie Curie

Quality improvement

We said we would...

- develop our existing audit leads to become quality improvement leads
- support each service to develop a local quality improvement programme based on their local priorities.

What we did

Each community nursing region and hospice has a designated audit lead. They are responsible for carrying out regular clinical audits offering a detailed snapshot of what care is like at that point in time.

Because audits are spread out in time, it can be difficult to closely monitor the impact of changes through an audit programme. To supplement audits, we are introducing quality improvement projects. By continuously tracking the effect of changes, we can make sure they are genuinely improving the quality of care and not just introducing change for the sake of it.

Introducing and managing these projects will become an important part of our audit leads' roles.

We ran eight workshops to train the audit leads and other staff in quality improvement methodology. These included theory and practical sessions to equip them to run a quality improvement project.

The workshops will give staff the necessary knowledge and support to generate local quality improvement projects. They are looking at a range of topics, including improving catheter care, staff wellbeing and managing administration of medication.

We also have quarterly teleconferences with these leads to share learning and provide peer support.

Part 1d: **Next year's priorities**

In this section, you can see our priorities for improvement for 2018/19, again grouped in three key areas:

- patient experience
- patient safety
- clinical effectiveness.

Marie Curie Nursing Service

Patient experience

We will improve the way we allocate care by introducing local co-ordination centres.

What does this mean and why is it important?

Currently around half of our nursing services are co-ordinated by a central referral centre. Over this year, we plan to shift towards all of our services being co-ordinated locally by seven regional hubs in England.

We believe this approach will:

- make it easier to provide the right care at the right time
- allow us to prioritise urgent cases more effectively
- give local staff greater oversight of patients who may be receiving multiple services
- promote closer working between administrators and clinicians
- create a single point of contact in each area for referrers, patients and families.

How will progress be measured, monitored and reported?

We will measure how often a nurse can be allocated to a patient, how often a caller abandons a phone call due to waiting too long for a response and call waiting times. We will analyse this information to identify causes of any issues and inform improvements to how we work.

Other information we will gather includes referrer impact, user feedback, economic impact, and how well our hospice and nursing services work together.

Patient safety

We will improve patient care and information security. Patient information will be sent to the nurse's mobile device on the day of their visit, secured by encryption. Currently this information is delivered over the phone. They will also be sent electronic short episode of care documents to use when there are no records available in the home.

We will review how we share information with other health providers and Marie Curie staff to ensure all patient data is being shared appropriately and safely.

What does this mean and why is it important?

Patient information needs to be timely, accurate and shared with all relevant healthcare workers to make sure patients get the best care and to ensure their safety. These improvements mean we will be able to send the most up-to-date patient information securely to the nurse immediately before the shift.

The short episode of care document is used to document the care given to the patient and can now be sent electronically to other health professionals involved in the patient's care.

What are short episode of care documents?
Short episode of care documents capture basic information about patients, including their diagnosis, prognosis and needs. Our staff document the care they deliver and this is sent to the district nurse so they can maintain a complete record of care for each patient.

How will progress be measured, monitored and reported?

This will be monitored by reviewing complaints, incidents and patient experience, as well as through local governance meetings.

Marie Curie Hospices
Clinical effectiveness

We will improve and embed our electronic patient records. This will be a two-year project to standardise patient records across all services. All clinical staff will receive training in how to record data consistently and accurately under the new system.

What are local governance meetings?
Each region and hospice has a regular (monthly or quarterly) quality review meeting to highlight issues and areas for potential improvement. A range of staff from all levels are involved in the meetings.

What does this mean and why is it important?
Electronic patient records improve patient care as they enable all members of the healthcare team to access up-to-date patient records at all times. We plan to introduce a system that is easy to navigate and access for staff, so they can deliver safe, patient-centred care. Staff training will ensure the system is used correctly and that clear, high-quality, useful information is documented. We have already started to pilot this approach at the Marie Curie Hospice, West Midlands.

How will progress be measured, monitored and reported?
This will be monitored by our quality assurance team and clinical data quality committee, using spot audits. We will also monitor patient and carer feedback and experience through patient surveys, comments and complaints.

Marie Curie Nursing Service and Hospices
Clinical effectiveness

We will translate research into practice. Marie Curie is the UK's largest charitable funder of research into palliative and end of life care. The research we fund looks at how we, and other organisations, can improve the care and support they offer people at the end of their lives.

When our research, or that carried out by others, finds ways to improve care, we want to make it quicker and easier to change our clinical practice to incorporate these findings. Our research management team will use our clinical reference group, made up of clinicians of all types and levels, to introduce researched care into practice. This will ensure new best practice methods will be introduced more quickly.

We will also give all patients the opportunity to participate in research if they wish.

Katie Hyams/Marie Curie

What does this mean and why is it important?
By incorporating new research findings into how we work more frequently and rapidly, we'll improve patient care using evidence to make changes that help us better meet people's needs. This may include specific groups, such as Black, Asian and Minority Ethnic (BAME) or LGBTQ+ people, whose needs around end of life care may previously have been under-researched.

How will progress be measured, monitored and reported?
This will be monitored through local and national governance meetings identifying the number of practice changes and improvements as a result of evidence-based research. We will publish research highlights and research into practice initiatives, and share them with all staff. During compliance visits, the quality assurance team will specifically look at and review changes in practice as a result of research.

We will maximise the skills of our staff and develop them so that we can continue to provide a high standard of care.

We will:
- establish the nursing associate role within Marie Curie
- review the training and development we offer healthcare assistants to increase the types of care they can provide for patients
- evaluate the clinical nurse specialist and advanced clinical practitioner roles.

Ben Gold/Marie Curie

What are nursing associates?
Nursing associates are healthcare assistants who have received additional training to help bridge the gap between healthcare assistants and registered nurses. They will be trained to perform additional tasks, which could include administering some medications. Establishing this role is important due to the nationwide shortage of registered nurses.

What are clinical nurse specialists?
Clinical nurse specialists are senior registered nurses who have had specialist training in different branches of healthcare (in our case in palliative care). We are evaluating this role to make sure we are using these nurses in the most effective way.

What are advanced clinical practitioners?
Advanced clinical practitioners are registered nurses who have had additional training that allows them to perform some tasks beyond the normal remit of a nurse, such as prescribing some medication. We are evaluating this role to make sure we are using these nurses in the most effective way.

“Support from the hospice made all the difference. Everything I needed to support and care for Simon was there for me, and the offer was always there for all the family to chat if we needed to. You think you can cope, but I don’t know how I would have managed without their help.”

Tracey Parkes. After Tracey’s husband Simon, 51, was diagnosed with terminal prostate cancer, he received outpatient care at the Marie Curie Hospice, West Midlands, including physiotherapy and support from a social worker.

Part 2 **Quality in focus**

Our staff

Marie Curie conducts its own comprehensive staff survey every year. Findings are reported and action plans created to address any issues. Our survey covers similar topics to the NHS staff survey, for example workload, working environment, bullying and management relationships.

Palliative and end of life care are stressful, highly emotive disciplines. Our staff deal with extremely difficult cases and there is significant pressure on them to deliver exceptional care – there are no second chances to get it right when someone is dying.

As such, we place a strong emphasis on the health and wellbeing of our staff and have clear policies to support this. We have introduced mindfulness training to help staff manage stress levels and introduced bespoke coaching sessions for those who require a higher level of support.

Patient experience

Feedback from patients, their families and their carers about their experiences is fundamentally important in driving improvements to our services.

People can provide feedback on our services by:

- telephone
- completing a paper survey sent to every home nursing patient and available in each hospice room
- through our website
- completing an electronic survey via a mobile device available in our hospices.

In areas and services where feedback levels are low, we also use volunteers to proactively seek feedback from patients and families. This has resulted in a

Kieran Dodds/Marie Curie

significant increase in the volume of feedback received – for example in the Central region, this approach led to an almost 4,000% month on month increase in the number of responses received.

Patient safety

We are committed to reducing avoidable harm and improving patient safety. When an incident happens, we are open and honest, informing the patient and their family. We ensure we fulfil the duty of candour requirements.

What do we mean by an incident?
We record anything significant that happens to a patient under our care that is not part of their care plan. This might include anything from a fall which injured the patient to a late administration of medicines that had no impact on them.

The duty of candour is our statutory obligation to be open and transparent when an incident occurs. Our duty of candour policy outlines four levels of harm that can result from an incident – the duty of candour applies to all moderate and severe incidents. The table opposite shows the numbers of incidents recorded at all levels of harm in 2017/18.

Level of harm	Total number	% of incidents
No harm – no injuries or obvious harm. No loss of property. No significant likelihood of service issues arising from incident.	3,972	77.93
Low harm – any incident that required extra observation or minor treatment and caused minimal harm, to one or more persons receiving care.	1,108	21.74
Moderate harm – any incident that resulted in a moderate increase in treatment and which caused significant but not permanent harm.	17	0.33
Severe harm – a permanent lessening of bodily, sensory, motor, physiologic or intellectual function, that is related directly to the incident and not related to the natural course of the service user's illness or underlying condition.	0	0.00

Learning from deaths

As palliative and end of life care providers, we expect a significant number of patients to die in our hospices every year.

Between 1 April 2017 and 31 March 2018, 1,144 patients died in our hospices in England, broken down as follows:

Q1 — 291
Q2 — 277
Q3 — 290
Q4 — 286

None of these deaths were subject to a case review or investigation.

Ben Gold/Marie Curie

At first we were nervous about having someone we didn't know in the house, but our nurse was very good at reassuring my parents. It was amazing to have her there. It meant we could get some sleep and took the pressure off us at night. A good night's sleep makes it so much easier to cope during the day."

Amanda Stamp. Marie Curie Nurses cared for Amanda's father Gordon, 74, who had bowel and liver cancer, at home for the last six nights of his life.

Part 2a: **Marie Curie Nursing Service**

This section looks in more detail at the Marie Curie Nursing Service, across our three priorities of patient experience, patient safety and clinical effectiveness.

What is the Marie Curie Nursing Service?
Marie Curie Nurses provide hands-on care for people living with any terminal illness, usually in their own homes. Our nurses make it easier for people to be cared for at home at the end of their lives, and avoid unnecessary hospital admissions. Marie Curie has 1,403 registered nurses and senior healthcare assistants working across England, who cared for 21,602 patients in 2017/18.

Patient experience

Patient and carer feedback

This year 2,260 patients and carers provided us with their feedback and comments about the Marie Curie Nursing Service in England (see table below). We have largely maintained or improved our excellent satisfaction scores across different aspects of the experience patients have of our services.

Patient satisfaction, Marie Curie Nursing Service

Aspect of care	2016/17 – responded 'always'	2017/18 – responded 'always'	Change from last year
Treated with dignity and respect	97%	97%	No change
Involved in decisions about your care	92%	91%	Down 1%
Have up-to-date information about you	87%	87%	No change
Provide support for family and friends	95%	100%	Up 5%

Friends and family test, Marie Curie Nursing Service

Responses	Total number	%
Likely to recommend Marie Curie	2,087	98.2%
Neither likely nor unlikely	23	1.1%
Unlikely to recommend Marie Curie	15	0.7%

Friends and family test

We also ask patients and carers how likely they would be to recommend our services to their family and their friends (see table above).

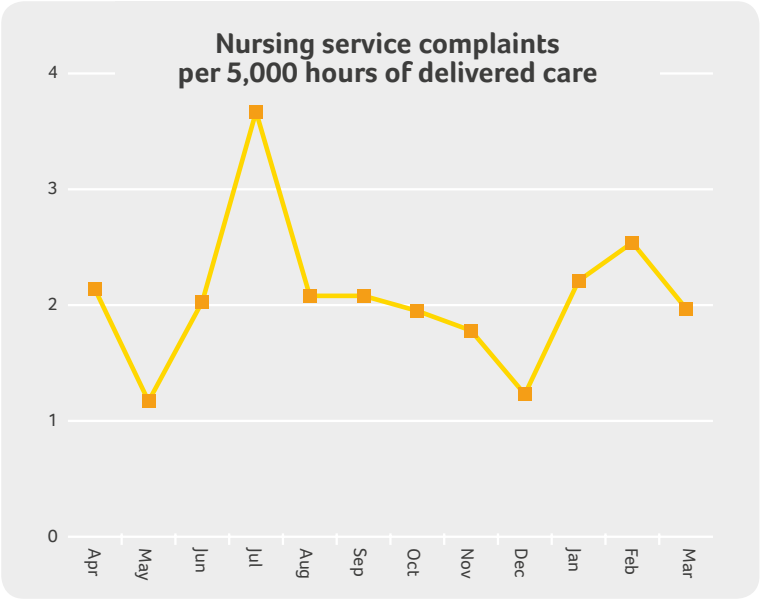
Out of 2,125 people who answered this question, 98.2% (2016/17: 98.4%) said they would recommend the Marie Curie Nursing Service. We believe this indicates an excellent level of care, even though it is a very marginal decrease from last year. We will continue to monitor this measure.

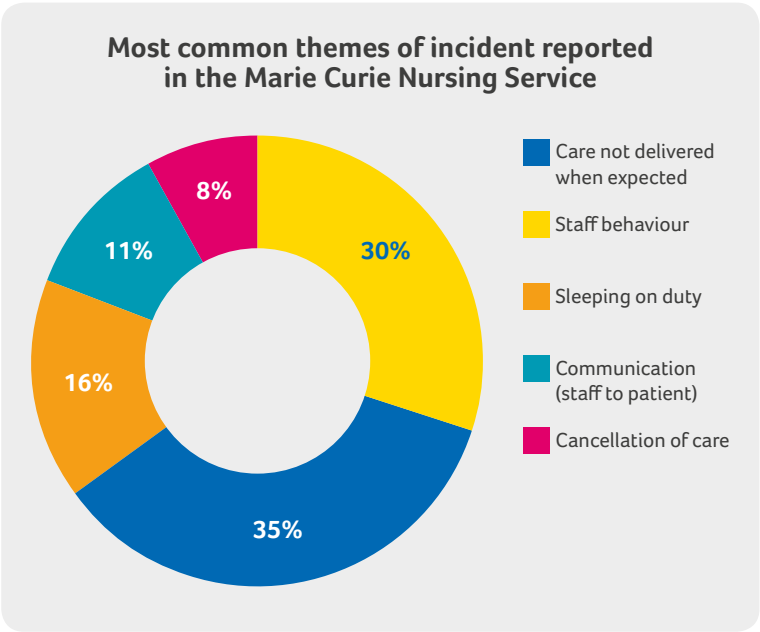
Complaints

We aim to respond to 75% of complaints within 20 working days. If it is not possible to respond to a complaint within 20 days (due to the complexity of the complaint or difficulties investigating the concerns raised), we agree a revised timeframe with the complainant.

Complainants who are dissatisfied with the outcome or handling of their complaint can refer their complaint to the relevant ombudsman or regulatory body.

The Marie Curie Nursing Service received 356 complaints in 2017/18 (2016/17: 392).





We responded to 84.5% of nursing service complaints within 20 working days (target: 75%, 2016/17: 83%). There were no complaints escalated to the Parliamentary and Health Service Ombudsman from the nursing service.

The main theme of complaints relates to the reliability or organisation of care (for example, when patients do not get care when expected or planned visits are cancelled). Changes to our services and processes over the last three years have resulted in a significant reduction in these complaints and this continued through 2017/18. The introduction of local co-ordination and electronic nurse allocation over 2018/19 should reduce this type of complaint further.

Learning from complaints

In 2017/18, actions taken in response to complaints within our nursing service included:

- training, coaching and team development days on issues such as communication and good record-keeping
- review of procedures and policies
- reminders to staff of policies, procedures, their roles and responsibilities
- clinical supervision
- case review with external agencies.

Ben Gold/Marie Curie

Clinical effectiveness

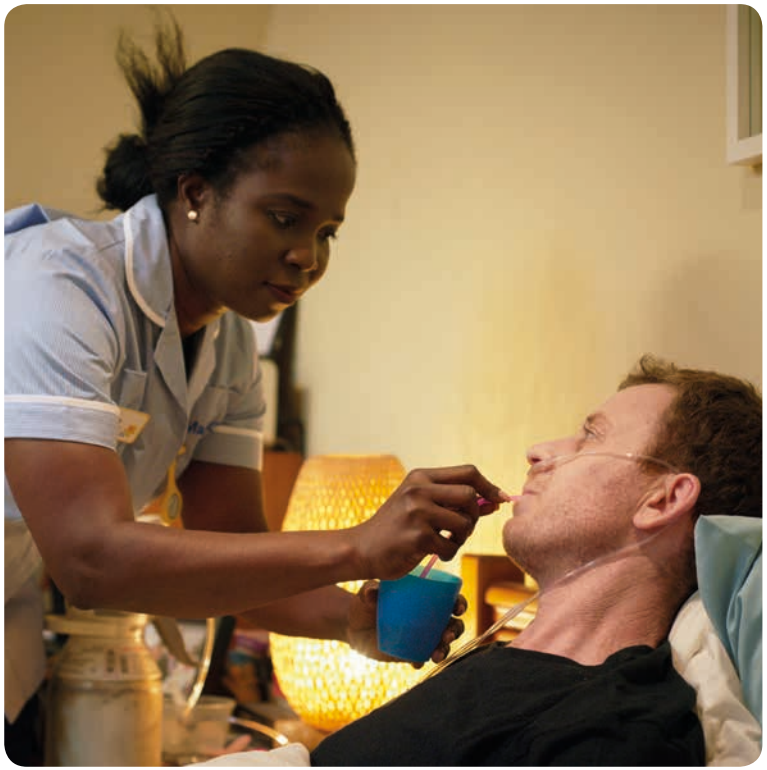
Audit

We carried out three national audits of our nursing service in 2017/18, each focussing on a different aspect of our work.

Each of our seven nursing service regions in England has an audit lead and is expected to supplement the national audit programme with locally co-ordinated audits including infection prevention and control audits.

The 2018/19 national audit programme will include four audits of the Marie Curie Nursing Service:

- complaints management
- medicines management
- safeguarding
- professional standards.



Ben Gold/Marie Curie

Nursing Service audits undertaken April 2017 – March 2018

Audit	Percentage compliance across all services	Main findings / recommendations	Actions
Professional standards	92%	The overall findings of the audit were positive, however there is scope to improve practice in some areas, which vary by region.	Some staff failed to show their ID card on arrival at the house; this is now included in induction and reinforced with staff. Information sharing and communication with NHS partners, including district nurses, needs to be improved. This will be addressed with the introduction of information sharing via the nurse's tablet as set out in our priorities for 2018/19.
Care after death	83%	Although there were some areas for improvement, overall good practice was found across the regions.	The lack of care plans provided by district nurses was an identified issue. This will be addressed with the introduction of information sharing via the nurse's tablet as set out in our priorities for 2018/19.
Documentation	88%	This was a repeat of last year's audit and although some improvements are evident, there are still some areas for improvement in relation to handover information and incident reporting.	Services were asked to assess changes in practice needed around: • recording of handover information • disposing of records in line with policy following a visit • reporting incidents where patient notes are not available in the home. These issues will be addressed with the introduction of information sharing via the nurse's mobile device as set out in our priorities for 2018/19.

Patient safety

Incidents

The table below shows the number of incidents where duty of candour applies in each of our nursing service regions in England in 2017/18. There was one moderate harm incident reported in the nursing regions (0.03% of all incidents) and no severe harm incidents.

Lack of notes

The most common type of incident reported relates to lack of access to patient notes in the home, not to direct patient care.

Staff carry short episode of care documents to complete when notes are not available and they are given clear guidance on how to complete these so that the care they provide can be recorded by the district nurse in the patient's full record.

Lack of notes is a particular issue in the north-east; increasing use of electronic records by district nurses means notes are often not left in patients' homes.

Shift cancellations

Over the year, we have made a number of changes to reduce the amount of shift changes or cancellations.

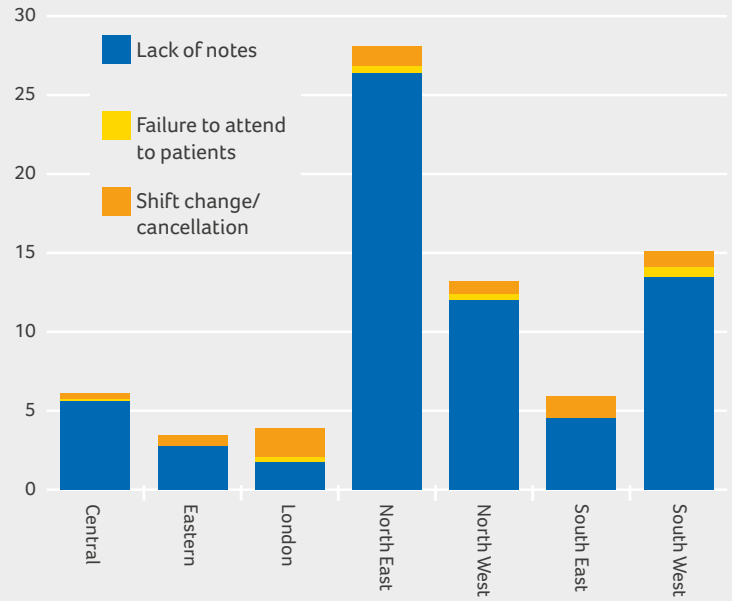
This has reduced the number of occasions on which visits were cancelled at late notice to 80, from 117 last year. We know how difficult and frustrating it is for carers when visits are cancelled at short notice and we try very hard to avoid this.

Further work is planned including local co-ordination of care, which will change the way visits are allocated. We anticipate this will continue to reduce the number of visits we have to cancel at short notice.

Incidents, Marie Curie Nursing Service, 2017/18

	No harm	Low harm	Moderate harm	Severe harm
Central	256	4	1	0
Eastern	135	9	0	0
London	151	5	0	0
North East	1105	81	0	0
North West	625	76	0	0
South East	70	1	0	0
South West	761	52	0	0

Most common types of incident reported in the Marie Curie Nursing Service



Being in the hospice was almost like going home to family. It was as if they knew Brian his whole life. Nothing was too much trouble and it felt like everybody was on our side and trying to make things as easy and peaceful as possible. It made an enormous difference compared to being on a hospital ward."

Graham Batterham. Graham's brother-in-law Brian was cared for at the Marie Curie Hospice, Hampstead, at the end of his life, after being diagnosed with terminal stomach cancer at the age of 72.

Part 2b: **Marie Curie Hospices**

This section looks in more detail at Marie Curie Hospices, across our three priorities of patient experience, patient safety and clinical effectiveness.

What are Marie Curie Hospices?
There are five Marie Curie Hospices in England, each of which provides both in-patient and outpatient care for people living with a terminal illness. Outpatient services include physiotherapy, counselling and bereavement support.

Patient experience

Patient and carer feedback

This year 1,313 patients and carers provided us with their feedback and comments about our hospices in England (see table opposite). This year, we have seen improvements to our satisfaction scores for Marie Curie Hospices across all but one category.

Friends and family test

We ask patients and carers whether or not they would recommend our services to their family and their friends (see table opposite).

Patient satisfaction, Marie Curie Hospices

Aspect of care	2016/17 – responded 'very good'	2017/18 – responded 'very good'	Change from last year
Welcome into the hospice	90%	93%	Up 3%
Hospice cleanliness	95%	95%	No change
Quality of food and drink	81%	84%	Up 3%
Quality of information	82%	88%	Up 6%
Quality of care	93%	96%	Up 3%

Friends and family test, Marie Curie Hospices

Responses	Total number	%
Likely to recommend Marie Curie	1,137	99.2%
Neither likely nor unlikely	4	0.4%
Unlikely to recommend Marie Curie	5	0.4%

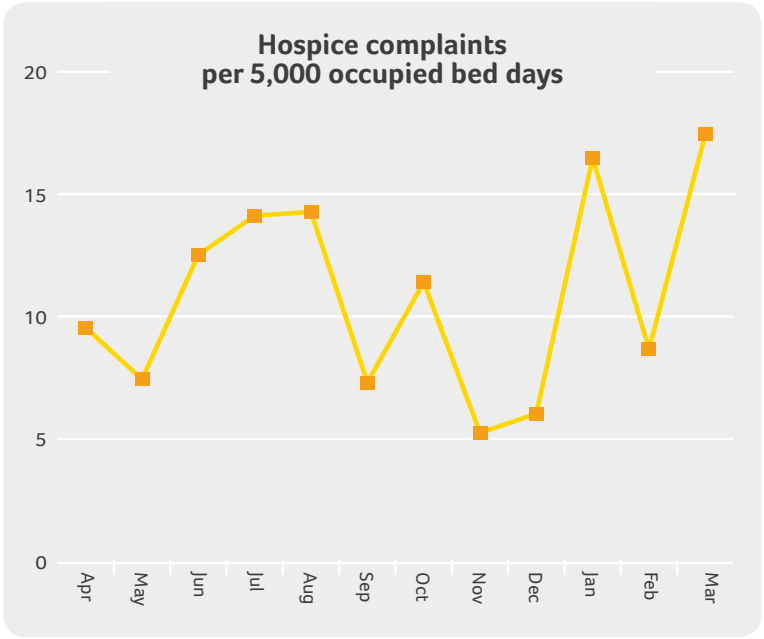
Out of 1,146 people who answered this question, 99.2% (2016/17: 99.2%) said they would recommend Marie Curie Hospices. We are delighted to have maintained this excellent level of patient satisfaction.

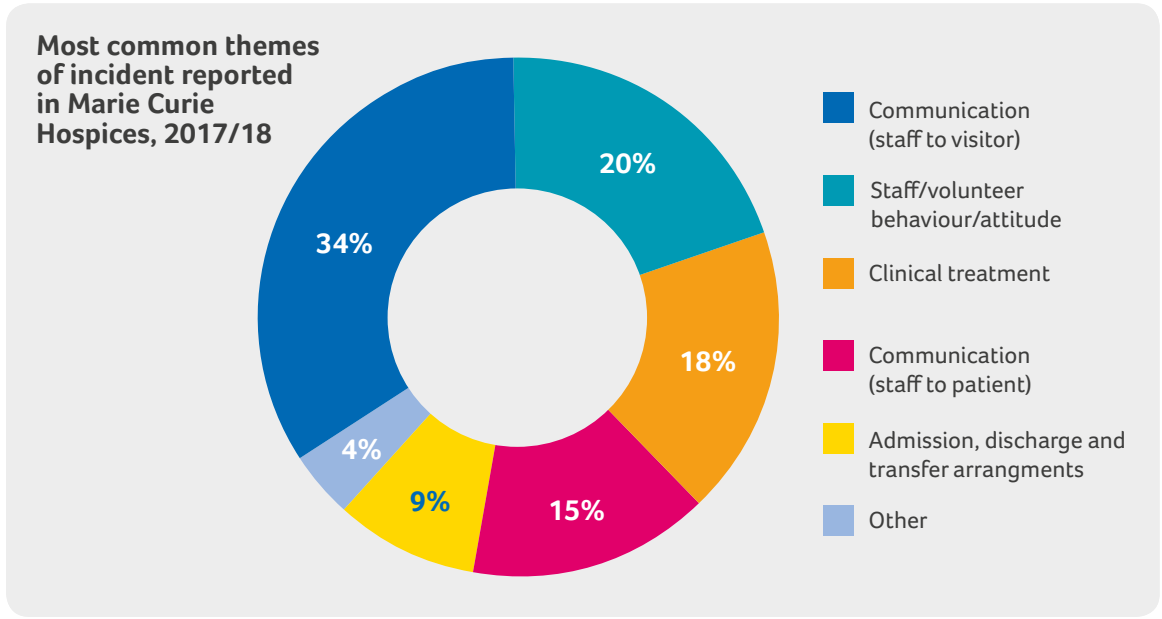
Complaints

We received 70 complaints about Marie Curie Hospices in 2017/18 (2016/17: 50).
In 2017/18, we responded to 83% of hospice complaints within 20 working days (target: 75%, 2016/17: 87%).

One complainant escalated their complaint about care and treatment at the Marie Curie Hospice, Bradford to the Parliamentary and Health Service Ombudsman. The Ombudsman did not uphold the complaint as they were satisfied that we had taken appropriate action to address a failing in communication.

Poor communication is at the heart of most of the complaints we receive. Within our hospices, it was the main issue complained about in 2017/18.





Katie Hymas/Marie Curie

Learning from complaints

In 2017/18 actions taken in response to complaints in the hospices included:

- delivering further communication skills training
- holding dignity workshops to improve the way in which staff communicate, empathise and value each patient's individual needs.

Clinical effectiveness

Audit

We carried out three national audits of our hospices in 2017/18, each focussing on a different area of our work (see table opposite).

Each service has an audit lead and is expected to supplement the national audit programme with locally co-ordinated audits including infection prevention and control audits.

The 2018/19 national audit programme will include two hospice audits:

- care at the end of life audit aligned to NICE guidance
- falls.

Hospice audits undertaken April 2017 – March 2018

Audit	Percentage compliance across all services	Main findings / recommendations	Actions
Confidentiality	81%	There was good practice in respect to confidentiality across the hospices.	National policies related to confidentiality are being reviewed as part of our normal policy review cycle.
Care at the end of life	87%	The audit demonstrates that care is provided in accordance with the latest best practice guidance from NICE. One area for improvement identified was further development of our electronic patient records to be more focussed on patient outcomes.	Developing electronic patient records is a priority for 2018/19.
Accessible information	63%	The audit results demonstrated good availability of alternative formats for information. Some areas for improvement were identified, for example how consistently we identify patients' needs for accessible information when they're first admitted.	Referral and admission documentation now includes a section on assessment of communication needs. The assessment includes the nature of support needed, and the particular format of information required. We have updated our accessible information and access to hospices policies to reflect these changes.

Research

Marie Curie employs two research fellows – one at the Marie Curie Hospice, Bradford, in partnership with the University of Leeds, and the other at the Marie Curie Hospice, West Midlands, in partnership with the University of Warwick.

The following studies are being undertaken using a variety of research methods including feasibility studies, qualitative studies, mapping exercises and systematic reviews.

Dr Bill Noble,
Executive Medical Director

At the Marie Curie Hospice, Hampstead:

- Acceptability of sedation monitoring in palliative care: patient and relative perspectives.
- Is structured monitoring of sedative use useful, feasible and acceptable for palliative care patients in a UK hospice?
- Conversation analysis of communication with the relatives and friends of patients in a hospice.

Participants across the studies include:

- 27 patients
- 30 carers
- Nine staff members and/or volunteers
- No other members of the public

No patient records have been used in any of these studies.

At the Marie Curie Hospice, Liverpool:

- The study of hydration status and complex symptoms in advanced cancer using bioelectrical impedance vector analysis (BIVA).
- Investigation of biological changes in urine in patients with advanced lung cancer: a pilot study.
- Living with advanced head and neck cancer: an exploratory qualitative study assessing experiences, unmet needs and health service usage.
- Exploring service user experiences in palliative and end of life care.

Participants across the studies include:

- 53 patients
- 18 carers
- No staff members and/or volunteers
- No other members of the public

No patient records have been used in any of these studies.

At the Marie Curie Hospice, West Midlands:

- Assessing the effectiveness and cost-effectiveness of palliative care day services.
- Developing and testing and educational intervention for the management of constipation for people in hospice: a feasibility study – mapping exercise and focus groups.
- Goal attainment study (GAS).
- Prognosis in palliative care study.
- Supporting people bereaved through advanced illness: a systematic review of the evidence and development of a core outcome set for bereavement research in palliative care.
- The experiences of volunteering in a palliative care setting.

Participants across the studies include:

- 51 patients
- Five carers
- 95 staff members and/or volunteers
- No other members of the public

Fifty-four patient records have been used as part of these studies. All patients involved have consented to the use of their records for research purposes.

Patient safety

Incidents

The table below shows the number of incidents where duty of candour applies in our hospices in England in 2017/18. Overall, there were 16 incidents resulting in moderate harm in 2017/18 (0.91% of all incidents).

All of these incidents were fully investigated. More than half of them were falls; all practical steps had been taken to support the patients, but some falls are unavoidable, particularly where the patient wants to remain as independent as possible.

There were no severe harm incidents reported in our hospices.

There were 352 medication errors over the year in our hospices in England (2016/17: 442).

This includes administration, dispensing and prescription errors (see graph opposite). All errors are discussed by senior clinicians at a regular medicines management meeting to identify any trends or themes and agree changes to systems, staff training or other steps to reduce or mitigate the incidents.

Most medication errors were administration errors and most of these were missed doses.

No incidents resulted in severe harm. Two medication incidents resulted in moderate harm.

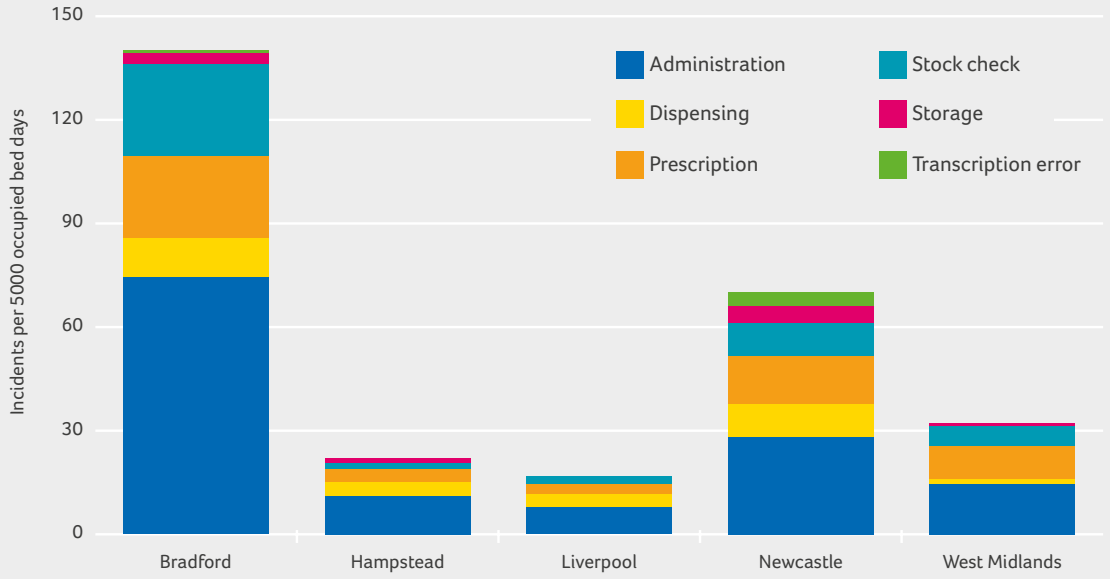
Incidents, Marie Curie Hospices, 2017/18

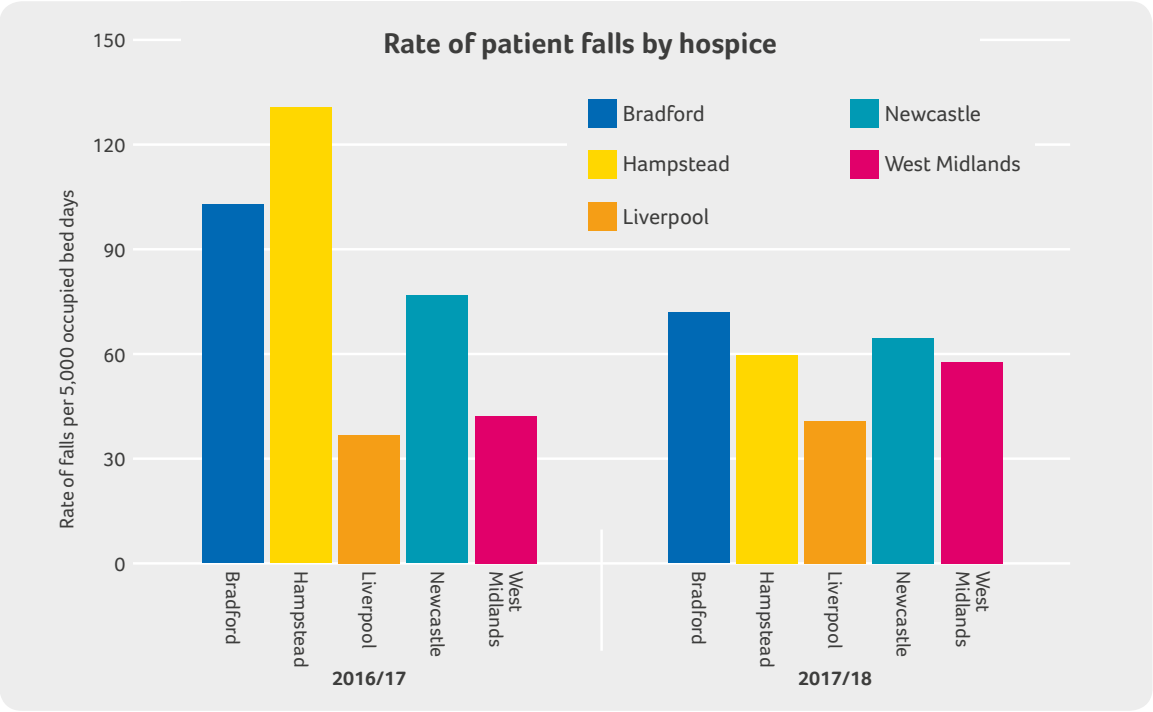
	No harm	Low harm	Moderate harm	Severe harm
Bradford	265	183	2	0
Hampstead	112	275	1	0
Liverpool	112	96	1	0
Newcastle	258	135	7	0
West Midlands	122	191	5	0

Medication errors and falls, Marie Curie Hospices, 2017/18

Hospice	Number of medication errors	Number of falls recorded
Bradford	170	63
Hampstead	39	102
Liverpool	22	58
Newcastle	86	78
West Midlands	35	71

Medication errors by hospice per 5,000 occupied bed days





Ben Gold/Marie Curie

Patient falls reduced this year across our hospices from 447 last year to 372 in 2017/18.

Ten falls resulted in moderate harm to the patient and they were transferred to hospital for further observation and x-rays. No falls resulted in severe harm.

Regulators
In England Marie Curie is registered with the Care Quality Commission (CQC) and has not participated in any special reviews or investigations in 2017/18.

Marie Curie Nursing Service
The nursing regions underwent three inspections through 2017/18 across all key lines of enquiry: caring, safe, effective, responsive and well-led. The outcomes of the inspections were:

- South West – Good
- Eastern – Good
- Central – Outstanding

No other Marie Curie nursing services in England were inspected in 2017/18.

Marie Curie Hospices
None of our hospices in England were inspected in 2017/18.

In 2018/19, the way services are inspected by the CQC is changing. Hospices will now be regulated within the healthcare framework and move from the responsibility of the Chief Inspector of Adult Social Care to the Chief Inspector of Hospitals.

Part 3 **Quality Account Regulations**

We have a legal requirement to report on the areas below:

- **During the period 1 April 2017 to 31 March 2018, Marie Curie provided end of life care through part-NHS funded services through its five hospices in England and national community nursing service.**

- Marie Curie has reviewed all the data available to it on the quality of care in all of the services detailed in the preceding section.

- **The percentage of NHS funding is variable depending on the services commissioned but on average is in the region of 47.8%. The rest is provided by Marie Curie charitable contribution.**

- The income generated by the NHS services reviewed in the period 1 April 2017 to 31 March 2018 represents 100% of the total income generated from the provision of NHS services by Marie Curie for the period 1 April 2017 to 31 March 2018.

- **During the period 1 April 2017 to 31 March 2018 there were no national clinical audits or national confidential enquiries covering the NHS services that Marie Curie provides.**

- From 1 April 2017 to 31 March 2018 Marie Curie was not eligible to participate in national clinical audits and national confidential enquiries.

- **The number of patients receiving NHS services provided by Marie Curie from 1 April 2017 to 31 March 2018 who were recruited during that period to participate in research approved by a research ethics committee was 131 patients.**

- £121,303.74 of Marie Curie income from the NHS was conditional on achieving quality improvement innovation goals through the Commissioning for Quality and Innovation payment from Clinical Commissioning Groups.

- **Marie Curie was not subject to any Payment by Results clinical coding audit during 1 April 2017 to 31 March 2018 by the Audit Commission.**

- Marie Curie Hospices and Community Nursing Services in England are registered with the Care Quality Commission. Marie Curie's registration is subject to conditions. These conditions include the registered provider, and the number of beds in our hospices, for the following:
  - accommodation for persons who require nursing or personal care
  - diagnostic and screening procedures
  - nursing care
  - personal care
  - treatment of disease, disorder or injury.

- **Marie Curie has not been subject to any periodic reviews by the Care Quality Commission during the period 1 April 2017 to 31 March 2018.**

- Marie Curie has not participated in any special reviews or investigations by the Care Quality Commission during 1 April 2017 to 31 March 2018.

- **Marie Curie did not submit records during the reporting period from 1 April 2017 to 31 March 2018 to the Secondary Uses service for inclusion in the Hospital Episodes Statistics.**

- As a healthcare provider, we use the NHS Information Governance Toolkit to ensure we follow the correct procedures for managing our information. Every year, we complete a self-assessment looking at how we manage our data. For 2017/18, our overall score was 93% and was graded GREEN: satisfactory (Information Governance Toolkit version 14.1).

Statements from stakeholders

Statements from Lead Commissioning Clinical Commissioning Groups, the Overview and Scrutiny Committee, Healthwatch and Marie Curie Expert Voices Group.

We are required to send a copy of our report to our key stakeholders for comment. These comments must be included in the published report. All received comments are published below. We also approached Healthwatch Lincolnshire and the Health Scrutiny Committee for Lincolnshire and asked them to comment, but they were unable to do so this year.

NHS Lincolnshire West Clinical Commissioning Group

NHS Lincolnshire West Clinical Commissioning Group (the commissioners) welcomes the opportunity to review and comment on the Marie Curie (the organisation) Annual Quality Account 2017/18.

The Quality Account provides very comprehensive information on the quality priorities the organisation has focussed on during the year. It is pleasing to see the organisation placed "Care" as the centre point of three quality priorities, these three care areas are:

- Consistency of Care – endeavouring to ensure that patients have the same nurse wherever possible to deliver the care. This will ensure the needs of the patient are understood and acted upon in a consistent and repeatable way.
- Reliability of Care – links into the above with Marie Curie Nurses sharing information with NHS Partners to enhance patient care and reduce the number of cancelled visits to patients and their families
- Person Centred Care – placing patients at the centre of the organisation, developing staff in delivering this and supporting staff through clinical supervision.

Looking forward to the 2018/19 Quality Priorities the commissioner is assured that the approach above is continuing with a new set of quality priorities which link into the previous year's and build upon the work undertaken, with:

- Enhancing Patient Experience further with more local co-ordination of Nursing Services. This is welcomed by the commissioner as a more local focus for the patients of the East Midlands and Lincolnshire will deliver tailored local services for the population.
- Employing technology to manage patient records using secure mobile devices. This will enable a patient's full care record to be accessed by staff, enabling real-time updating of interventions given. This will ensure timely and appropriate care is given and will enhance patient safety.
- Ensuring that research undertaken by Marie Curie or others is translated into clinical practice both quickly and safely.

The Quality Account has numerous examples of the good work undertaken by the organisation over the past year but the commissioner believes the "About Me Care Plan" on page 9 is a particularly noteworthy piece of work. The care plan encompasses the seven holistic elements of Physical, Social, Psychological, Spiritual, Fundamentals, Safety, and Family and Friends to ensure the patient's needs are met.

The commissioner cannot confirm the accuracy of the national information presented within the Quality Account but the commissioner does not have concerns with the accuracy of information submitted to the Lincolnshire specific Quality Contract Meetings. The commissioner would encourage Marie Curie to consider appendices in next year's Quality Account detailing information at either the seven regional hubs level or if possible at a county level.

The commissioner can confirm that this Quality Report has been critically appraised against the 2010 Quality Account Regulations and subsequent additions to the regulations in 2017 and 2018. The results of this appraisal have been issued to the trust.

The commissioner looks forward to working with the organisation over the coming year to further improve the quality of services available for our population in order to deliver better outcomes and the best possible patient experience.

Wendy Martin
Executive Nurse
NHS Lincolnshire West Clinical Commissioning Group

Durham Dales, Easington, Sedgefield (DDES) and North Durham (ND) Clinical Commissioning Groups

The CCGs welcome the opportunity to review and comment on the Quality Account for Marie Curie for 2017/18 and would like to offer the following commentary.

As commissioners, Durham Dales, Easington and Sedgefield Clinical Commissioning Group (CCG) and North Durham Clinical Commissioning Group (CCG) are committed to commissioning high quality services from Marie Curie and take seriously their responsibility to ensure that patients' needs are met by the provision of safe, high quality services and that the views and expectations of patients and the public are listened to and acted upon.

The CCGs felt that the report was written and presented in a meaningful way for both stakeholders and service users. To the best of the CCG's knowledge the quality account provides a good representation of the service provided across the CCGs geographical location during 2017/18.

We recognise the work that the organisation has undertaken to drive quality improvements throughout the year particularly around patient experience, clinical effectiveness and patient safety.

It was encouraging to see the work that the organisation has undertaken work in the 'React to red skin' campaign. The strengthening of Safeguarding through training which has been carried out in 2017/18 is also very pleasing.

The CCGs were pleased to see the audit programme included in the quality account and the learning which has come from incidents and complaints.

North Durham and DDES CCGs note the work that the Marie Curie are engaged in for 2018/19 around improving and embedding electronic patient records and the introduction local co-ordination centres.

The CCGs acknowledge the specific priorities set out for continued improvement in 2018/19 and look forward to seeing evidence of this through future reports to commissioners.

The CCGs look forward to continuing to work in partnership with the organisation to assure the quality of services commissioned in 2017/18.

Gillian Findley
Director of Nursing/
Nurse Advisor
North Durham and DDES CCGs

Marie Curie service user

I am a volunteer member of Marie Curie's Clinical Governance Trustees Committee (CGTC), one of two volunteers representing the service user perspective. This is the independent forum for scrutinising the governance mechanisms, quality assurance, risk management and health and safety across the charity's clinical services.

Through the Clinical Governance Trustees Committee, I have witnessed that the charity has comprehensive and robust reporting and investigation processes in place to minimise the risk of poor service to patients and their families. Where something has gone wrong, the incident is the focus of a root cause analysis process, leading to appropriate interventions to prevent re-occurrences and to spread learning throughout the organisation to drive continuous improvement.

My wife Wendy died from a brain tumour at the age of 54 after an illness of less than six months. Her end of life care was poor, with one exception – the Marie Curie nursing staff. They came into our home every night for the last seven days of Wendy's life. This was the difference between dying at home or in the local hospital.

I commend the 2018 Quality Account to you.

Peter Buckle
Volunteer member, Clinical
Governance Trustees Committee

Do you have any comments or questions?

Marie Curie is always keen to receive feedback about our services. If you have any comments or questions about this report, please do not hesitate to contact us using the details below:

The Quality Assurance Team
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89 Albert Embankment
London
SE1 7TP

Email: qualityassurance@mariecurie.org.uk
Tel: 020 7599 7294

Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit our website **mariecurie.org.uk**

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Front cover photo: Brian Morrison/Marie Curie

Marie Curie

Care and support through terminal illness