



# Quality Account

2019/20



**Marie Curie**

Care and support  
through terminal illness

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# Introduction from the CEO and Chair of Trustees

**Welcome to our 2019/20 Quality Account, which outlines the key quality improvements we have delivered this year and the priorities we have set ourselves for 2020/21.**

We pride ourselves on delivering excellent care to people living with a terminal illness and we are always looking to find ways to develop and improve the care we offer. We believe that everyone across the UK should get the end of life care they deserve and their families should be supported through extremely difficult times.

In 2019/20 we set ourselves seven priorities, including improving the way we design our services by listening to patients and carers, improving how we learn from incidents and complaints, and developing a workforce capable of meeting the changing needs

of our patients. We made good progress in all of these areas, as you can read in the following pages. While we have been affected by the coronavirus (Covid-19) pandemic, this Quality Account does not include metrics about it unless specifically stated because our services had not been significantly impacted by the end of March 2020.

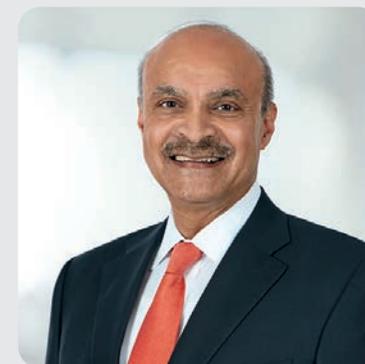
In the coming year we aim to improve patient experience by reaching out to more people for input and developing services to better meet their needs, ensure all staff are valued and feel able to contribute to improving our services, and make sure our services make a meaningful improvement to the quality of life of the people who depend on them.

Specifically, our focus will be on:

- reaching out to and involving under-represented groups
- rolling out a clinical support line
- improving our approach to whistleblowing and fostering a culture in which all staff feel safe to raise concerns
- developing and piloting our career capability framework
- participating in the Nightingale Challenge
- improving how we meet the requirements of the Accessible Information Standard
- researching a new quality of life assessment in palliative care day services.

We set these priorities prior to the coronavirus situation developing, but whether or not we are able to achieve them will be very dependent on the impact of and recovery from it.

This year's Quality Account has been prepared by our Nursing and Quality Directorate with support from the Clinical and Research teams. The Hospice and Community Leadership teams have shaped our priorities for quality improvement and have supported and empowered their teams to deliver the improvements in practice. The Board of Trustees has endorsed our Quality Account and we are able to confirm that the information contained in this document is accurate to the best of our knowledge.



Iain Crockett

A handwritten signature in black ink, appearing to read 'Vindi'.

**Vindi Banga, Chair of Trustees**



Katie Hyams/Marie Curie

A handwritten signature in black ink, appearing to read 'Matthew'.

**Matthew Reed, Chief Executive**

# Our vision and values

## Our North Star

The North Star is our long-term aspiration. It is captured in the following statement:

“Everyone will be affected by dying, death and bereavement and deserves the best possible experience, reflecting what’s most important to them. Marie Curie will lead in end of life experience to make this happen.”

## Our strategic drivers

To ensure all our work is aligned to the North Star and moving us in the right direction to achieve our ambition, we’ve defined four “strategic drivers” that underpin all our work:

- Innovation in the delivery of high-impact services.
- Developing as a thought leader.
- Becoming a flexible, efficient organisation able to adapt to local needs and changing demands.
- Driving social inclusion in all that we do.

Our North Star and strategic drivers inform our strategic initiatives (annual priorities), which in turn inform our annual business plan and feed

into directorate, team and individual objectives. This means we can see how everything we do – individually, as teams and as an organisation – is contributing towards our overall aspiration.

## Our strategic initiatives

While our four strategic drivers will be in place for the whole period of our current strategy, we have seven strategic initiatives that have been prioritised for this year. These inform our planning and budgeting and are reviewed annually:

- We will design the end of life experience to reach more people.
- We will shape systems that impact people at end of life.
- We will develop an impact-orientated organisation.
- We will put people first and develop our culture.
- We will uplift and integrate our leadership in shaping the end of life experience across society.
- We will grow our fundraising.
- We will become an efficient and effective organisation, working and co-designing services with other organisations and service users to support people in their local communities.



Kieran Dodds/Marie Curie

**Marie Curie were there for that final week, day and night. The nurses helped with the syringe driver and came out of hours – they travelled miles to get to us. They administered medication and gave a flawless service. Most importantly they gave hope in a time when most was lost. We were fortunate to have a Marie Curie nurse present with us whilst my mum drew her last breaths. I can't imagine what it would have been like without Marie Curie there by our side.”**

**Ashleigh Salter.** Ashleigh's mum Liz died in May 2019 after being diagnosed with breast 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, 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 to one or more of these areas.

## Our three quality priorities are:

- **Patient and carer experience**

Ensuring that people are treated with compassion, dignity and respect and that our services are person-centred and respond to people's individual needs.

- **Patient safety**

Improving and increasing the safety of our care and the services we provide.

- **Clinical effectiveness**

Making sure that the care and treatment we provide achieves good outcomes, promotes a good quality of life and is based on the best available evidence.



Kate Stanworth/Marie Curie

## Part 1a: Patient and carer experience

Our focus for 2019/20 around improving patient and carer experience was:

- to improve the way we design our services.

### Marie Curie Nursing Service and Hospices

#### Designing services We said we would...

Improve the way we design our services by listening to the experiences of patients and carers and building on the way we currently involve the people that use our services.

#### What we did

We have recruited new staff into our Patient and Carer Experience team who have reviewed our existing processes to identify how we can more meaningfully involve the people who use our services. We are

also updating our user involvement policy to make our guidance on this approach more consistent and to increase both the quantity and quality of user involvement across the organisation.

As well as gaining insights from our standard feedback channels, we have developed new ways to capture the experiences of people who use our services. These include running user involvement and feedback sessions within some of



Ben Gold/Marie Curie

#### Experience-based co-design

Experience-based co-design is a method that draws on the experiences of patients, carers, staff and other relevant stakeholders to identify where change is needed. It then brings staff and service users together to design and implement improvements in partnership.

our hospices and in the community, and piloting new forms of telephone survey to gather and respond to feedback.

We have also made progress towards involving people in the design of our services in a more structured and detailed way. We have launched two experience-based co-design projects that will involve patients and carers in the redesign of our day therapy services in two of our hospices.

We have also continued to work closely with Marie Curie Voices, a group of volunteers with personal experience of terminal illness, end of life care or bereavement, the majority of whom have experience of Marie Curie services. In the past year their expertise has informed and shaped services and projects within the Information and Support, Caring Services, Research and Fundraising teams, as well as the development of our charity-wide North Star and strategy.

Recruitment to the Quality Improvement Lead posts was delayed, but we have now recruited leads to each of our four geographical divisions. We have also recently appointed an Equality, Diversity and Inclusivity Lead to support our strategic driver related to social inclusion. We will build on our work with these teams to establish impact measures that we can use to measure progress against our patient and carer experience priorities for the coming year. This will be overseen by our Executive Leadership Team.

## Part 1b: Patient safety

Our focus for 2019/20 around improving patient safety was:

- to improve the way in which we learn from incidents and complaints to improve patient safety in the future
- to review and strengthen our approach to safeguarding
- to improve patient care by enabling the sharing of electronic patient records.



Brian Morrison/Marie Curie

### Marie Curie Nursing Service and Hospices

#### Incidents

##### We said we would...

Improve the way we learn from incidents and complaints to improve patient safety in the future.

##### What we did

We reviewed our incident management policy and introduced a new policy for the management of serious incidents. We are also rolling out a system for the direct reporting of incidents.

We have started serious incident panels to review all serious incidents after investigation. After the meetings, the panel writes reports that are shared across all our services so they can learn from the findings. Examples of shared learning include:

- syringe driver documentation to include checks on the site and connections every four hours
- including the date and time of the notice on engaged notices on hospice side room doors

- the development of guidelines for the use of mobility scooters in hospices.

We have also undertaken an audit of the serious incident process so that we are confident that we are following our agreed procedures.

In order to improve how we learn from incidents, we have made changes to our quarterly report, which is shared with the hospice managers and Marie Curie Nursing Service managers. We have introduced statistical

process control (SPC) charts to help us more effectively understand our data and clearly identify areas of concern. We will continue to monitor our work on the management of incidents through local governance groups, the Caring Services team management meetings and quality visits.

#### What is statistical process control (SPC)?

Statistical process control (SPC) is an analytical technique that helps understand variations in data over time. In doing so, it can guide us to take the most appropriate action. SPC is widely used in the NHS to understand whether change results in improvement.

## Safeguarding

### We said we would...

- improve our oversight of the safeguarding process
- monitor and improve staff training
- renew our policies and procedures.

### What we did

We have appointed a full-time Head of Safeguarding who will lead on the wider safeguarding agenda and strategy. We have also introduced a Safeguarding Assurance Group, chaired by the Chief Nurse and Executive Director of Quality & Caring Services, and including one of the Trustees, to ensure that safeguarding receives detailed scrutiny and governance throughout the organisation.

This group reports directly to the Executive Leadership Team and is responsible for ensuring the charity is meeting all its statutory, regulatory and legal requirements in relation to safeguarding children and

adults at risk of harm. It also ensures that all safeguarding requirements and standards set by the Board of Trustees are met.

The Safeguarding Assurance Group reports formally to the Executive Leadership Team on:

- safeguarding incidents or concerns, their impact and any actions that were taken to address them
- relevant updates on regulation that have the potential to impact the organisation
- the main risks facing the organisation and proposals to address these risks.



In terms of safeguarding training, we will be carrying out a more detailed review for all staff groups now that our recently appointed Head of Safeguarding is in post. We have started the review, beginning with level 1 safeguarding training. We have also implemented a different online course, which we are currently evaluating. The Learn Pro Safeguarding Training for our teams in Scotland has been made available on our online learning platform. Bespoke safeguarding training has also been provided to our Board of Trustees and the Executive Leadership Team.

We have reviewed our two safeguarding policies – for adults and children – and made our responsibilities for children clearer, which we have communicated across the charity. We have also started work to include the wider Charity Commission definitions and responsibilities in these policies. We have reviewed

### Exception reporting

Exception reporting is a way of flagging and escalating concerns or practice and performance that fall outside agreed levels of tolerance.

the reporting categories we use on our incident reporting system and are now able to do further analysis on the type of safeguarding concerns being raised across the organisation.

The Safeguarding Assurance Group workplan will continue to be reviewed four times a year. Progress and exceptions will be reported to the Executive Leadership Team and Clinical Governance Trustee Committee.

## Marie Curie Nursing Service and Hospices

### Patient safety

#### We said we would...

Improve patient care by enabling the sharing of electronic patient records across our nursing service.

#### What we did

As part of our Nursing Systems Transformation (NST) project, we have procured a clinical records system for the nursing service – EMIS Web and EMIS Mobile. These systems will be used by our local co-ordination centres that receive referrals and by the nurses working in people's homes.

In anticipation of rolling this system out, we have been piloting the use of electronic patient records in one of our North West England services. In this service, healthcare assistants can now access patient records on their tablet devices. They can read, and write directly in, the patient record. Once contracts have been agreed

with the providers, we can start implementing the new system across the Marie Curie Nursing Service. This work will be monitored and reported by the project team for the NST project and programme board.

#### Nursing Systems Transformation (NST)

This is a project that aims to make our hospices and community nursing service more efficient, safer and more adaptable by improving our electronic systems. It will enable a patient's healthcare records to be shared, giving all health professionals involved in the person's care the information they need to provide the right care at the right time. It will also free up nursing staff to spend more time providing care, rather than dealing with administrative tasks such as writing staff rotas.



Ben Gold/Marie Curie

## Part 1c: Clinical effectiveness

Our focus areas for 2019/20 around improving clinical effectiveness were:

- to ensure that we had a clinical workforce that is able to meet the changing needs of our patients
- to assess the validity of a new delirium assessment tool
- to build outcome measures into patient records.

### Marie Curie Nursing Service and Hospices

#### Workforce

##### We said we would...

Ensure that we had a clinical workforce that is able to meet the changing needs of our patients through workforce planning, exploring how our services are designed and adapting healthcare roles to meet patients' needs.

##### What we did

We have started the first stage of this project by developing a "career capability framework" for our clinical staff. This will allow us to clearly identify

the skills, behaviours and experience our staff require to perform each role. It will also outline the career progression routes that are open to staff, which will help us with staff recruitment and retention.

The first draft of the career capability framework was developed alongside external experts and our clinical staff. We undertook an exercise to understand current practice within the organisation and reviewed the available evidence in the nursing and medical literature.



Kieran Dods/Marie Curie

We then used an approach called "co-creation practice development methodology" to help us understand what our staff feel really matters to people at the end of their lives and what skills, values, behaviours and expertise they need to provide a service that responds to these needs. We will continue to involve our staff at each stage of development to help us make sure the framework truly captures this.

We have made good progress with the first phase of this project, although the timeline for this phase has been extended due to staff changes, a need to ensure that we were in line with our strategic priorities, and a requirement for wider engagement with stakeholders. Work will continue into next year and it will remain one of our key priorities. A steering group has been established to have oversight of the work.

#### Co-creation practice development

This is a methodology that brings people together to work toward a shared goal. In practice, this often takes the form of a collaborative workshop. We used different question-based approaches and exercises with our frontline staff at a series of workshops around the UK.

## Delirium assessment tool

### We said we would...

Assess the validity of a new delirium assessment tool for use with palliative care patients.

### What we did

We obtained NHS Research Ethics Committee approval for a validation study of a delirium assessment called the 4 "A"s Test (4AT). This study is the first to assess the validity of the 4AT for routine delirium assessment in a specialist palliative care setting. It is funded by Marie Curie Small Internal Grants Scheme at the Marie Curie Hospice, Edinburgh and the Marie Curie Hospice, Glasgow.

The study team have received training in delirium assessment from the chief investigator, Professor Alasdair MacLulich at the University of Edinburgh, who is collaborating closely with the team to ensure that the study remains on track.

Recruitment commenced in October 2019 at the Marie Curie Hospice, Edinburgh and in January 2020 at the Marie Curie Hospice, Glasgow. The team have so far recruited 81 participants across the two sites (as of 31st March 2020). The findings will be relevant to all hospice in-patient units and will inform clinical practice on delirium assessment in specialist palliative care.

### What is delirium?

Delirium, sometimes called "acute confusional state", is confusion that comes on suddenly, over a period of hours or days. It can be the result of a serious illness, infection, dehydration or medication.

Delirium is very common towards the end of life and can be very distressing for patients and those close to them. Managing delirium involves treating any causes that may be reversible, reviewing the person's medication and providing a calm, safe and reassuring environment.

## Marie Curie Hospices

### Outcome measures

#### We said we would...

Expand on our previous work on electronic patient records by building outcome measures into patient records.

#### What we did

We have made steady progress with the implementation of outcome measures within our hospices. All hospices are now collecting Phase of Illness and the Australian Karnofsky Performance Status (AKPS) scores and are at varying stages of implementing the Integrated Palliative Care Outcome Scale (IPOS). Recording this information helps our staff understand and demonstrate the impact of the care a person has received on the outcomes that matter to them.

Each hospice identified a clinical lead to drive this project and we hold a teleconference every three months to support them with implementation. We held our

#### What are patient outcome measures?

These are ways of measuring what we are trying to achieve for our patients, based on their wishes. This could include relief from symptoms, such as pain or nausea, choosing where their care is delivered, or where they die at home or in the hospice. Each patient can discuss what is most important to them in the order they wish.

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. These three outcome measures 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.

first workshop in June 2019 to promote and support the use of outcome measures, which was well received. A further workshop is planned in 2020. Our analytics team is currently working to improve how we report on the outcome measures.

Further work on outcome measures will be discussed within the services, multidisciplinary team meetings, clinical governance meetings and the Caring Services team management meeting.

## Part 1d: Next year's priorities

In this section, you can see our priorities for improvement for 2020/21, again grouped in three key areas:

- patient and carer experience
- patient safety
- clinical effectiveness.

This year we will improve patient and carer experience by reaching out to more people for input and developing services to better meet their needs. We will ensure all staff are valued and feel able to contribute to improving our services, and we will ensure our services make a meaningful improvement to the quality of life of the people who depend on them.

### Marie Curie Nursing Service and Hospices

#### Patient and carer experience

We will establish partnerships with under-represented groups to understand how we can better support their communities and reflect their experience and priorities in our work.

#### What does this mean and why is it important?

Marie Curie wants everyone affected by dying, death and bereavement to have the best possible experience, reflecting what's most important to them. More inclusive user involvement will help us to ensure that our services and strategic decisions are informed by a broad range of experiences. This will enable us to make sure our local services meet the needs of the communities they serve.

As part of this, we will work in partnership with people and communities to change the language and terminology around user involvement within Marie Curie to be more inclusive.

#### How will progress be measured, monitored and reported?

We will review what we currently know about the needs of under-represented groups, and any barriers to reaching them. We will



Kieran Dadds/Marie Curie

then use this to identify partnerships through which we can explore co-design and involvement. We will share what we learn through reports and governance meetings. We will measure the impact of any involvement activities against three core pillars: the impact on the people we involve, the impact on the specific service or project, and any wider, longer term impact.



### Patient and carer experience

We will roll out our clinical support line, offering members of the public the chance to speak to a Marie Curie nurse without a formal referral.

### What does this mean and why is it important?

In January 2019, we launched a pilot initiative through our telephone Support Line. The initiative provided callers with access to a Clinical Nurse Specialist (CNS) in palliative care who could provide information and guidance on clinical issues.

The pilot began in February 2019. Initially, there was a “soft” launch where the clinical support line was only advertised internally and staffed by the lead nurse for the pilot. Over time, more CNS staff have become involved and the service was promoted more broadly through the Marie Curie website and other digital marketing.

An evaluation was completed and, as a result of this, recommendations were made to raise awareness about the service and collect information about the design of the service and user’s experiences of it. We will use this evidence to redesign and roll out an effective, safe and cost-effective clinical enquiry service to the public.

### How will progress be measured, monitored and reported?

Callers will be offered the opportunity to give feedback directly after a call on whether they found the information useful and whether they would recommend Marie Curie, amongst some other measures. An ongoing evaluation process will be put in place.

Nurses will be supported with training and coaching so they can provide a high standard of service. Information about the volume of calls and the types of enquiries handled will be reported internally to senior

stakeholders. The service is anonymised and confidential (as the existing Support Line is), therefore patient records and information will not be accessed or updated, even if the caller is known to Marie Curie.

### The Marie Curie Support Line

The Support Line service is a free national service for anyone affected by a terminal illness – this could be someone with a diagnosis, a carer, family member or friend.

The Support Line receives in the region of 9,000 calls and 2,500 web chats per year. The team of six staff provide support and advice on a wide range of topics over the phone, via web chat, on an online community, and through social media. The existing Support Line provides emotional and practical support, a listening ear, and signposting to appropriate organisations.

## Patient safety

We will improve our training and approach to staff speaking up and whistleblowing, and foster a culture of safety and learning in which all staff feel safe to raise concerns.

### What does this mean and why is it important?

To improve staff and patient safety, it is important that staff and volunteers feel able to speak up when anything gets in the way of delivering safe, high quality care, or when it affects their experience in the workplace. As an organisation we need to be confident that we have the right leadership and a culture that places less emphasis on blame when things go wrong and more importance on openness and learning from mistakes.

We will work with staff at all levels of the organisation to ensure that the necessary training is developed and completed. We will work to show that speaking up is celebrated and used to correct problems and make

improvements that turn “good” practice into “great”.

### How will progress be measured, monitored and reported?

We have undertaken a self-assessment to provide a baseline from which we can measure our progress. Measurement against this will be overseen through the Executive Leadership Team

meetings and Audit and Risk Committee. Training numbers will be monitored through our governance meetings.

## Patient safety

We will continue to develop our career capability framework, piloting the first version of the framework before rolling out the final version across the organisation.

### What does this mean and why is it important?

We will use co-creation practice development methodology to review and refine the first version of the framework. Once finalised, the second phase of this project will involve piloting the framework in both hospice and community settings. This pilot will inform the final version of the framework that will be rolled out across our hospices and nursing service.

The career capability framework will enable us to have a clear picture of the competencies, values and behaviours we expect from all clinical roles. This will allow for a consistent approach to staff development and performance, with defined career pathways for our staff. This will contribute to staff retention, workforce design, workforce development and high-quality person-centred care delivery.

### How will progress be measured, monitored and reported?

We will evaluate the success, outcomes and impact of the project throughout. Key stakeholders will be engaged through the project steering group, which will report to the executive lead. Project milestones will be monitored through this steering group.

## Clinical effectiveness

We have signed up to the Nightingale Challenge, an initiative set up as part of the 2020 Nursing Now and International Year of the Nurse campaign. It asks all healthcare organisations to develop the next generation of the profession by providing support and mentorship to a group of younger registered nurses (aged 35 years and below).



**What does this mean and why is it important?**

Nursing leadership is key to the ongoing success of Marie Curie as an end of life charity. By creating opportunities for young, talented nurses within our organisation, we aim to not only support their personal development and increase their satisfaction with their current role, but also to inspire in them aspirations of leadership in their chosen field.

Participants will be offered a truly bespoke experience with face-to-face learning, shadowing and a dedicated mentor. They will be required to complete a project during the 12-month period that will be focussed on a local service improvement or workforce need.

In a time of significant workforce challenges and high vacancy rates across the nursing establishment, it is key that Marie Curie can demonstrate a commitment to the Nightingale Challenge

and other similar schemes. Participation will also place us in contact with similar and related organisations across the globe and potentially create new links and partnerships.

**How will progress be measured, monitored and reported?**

Evaluation of each face-to-face day will be collected along with overarching feedback of the whole project from the participants. A celebration event will be planned where participants will deliver a short presentation on their personal development and the work-based project they have completed during the challenge.

**Clinical effectiveness**

We will improve the way in which we identify and meet the information needs of people who have a disability or sensory loss in line with the Accessible Information Standard.

**Accessible Information Standard**

The Accessible Information Standard is a law that aims to make sure people with a disability or sensory loss are given information they can understand and the support they need to communicate on health issues. There are five steps to the standard:

<b>1. ASK</b>	Find out if a person has any communication or information needs due to a disability or sensory loss and, if so, what they are.
<b>2. RECORD</b>	Record those needs in a clear way that everyone agrees with.
<b>3. HIGHLIGHT</b>	Make sure that a person’s needs stand out whenever their records are checked.
<b>4. SHARE</b>	Ensure information about a person’s needs is shared with other health care providers.
<b>5. ACT</b>	Make sure that people get information that they can understand and the support they need to communicate.

**What does this mean and why is it important?**

People who have disabilities or sensory loss experience some of the poorest health outcomes and inequalities. The Accessible Information Standard sets out an approach to identifying, recording, flagging, sharing

and meeting the information and communication needs of this group. Successfully implementing the standard will help us to improve their outcomes and experiences, as well as providing safer and more personalised care.

**How will progress be measured, monitored and reported?**

We undertook an audit of how well we were performing against the Accessible Information Standard in our hospices and nursing service regions. Our quality improvement facilitators will use this to identify key

areas for improvement with each of the teams and we will undertake a follow-up audit to measure progress against our benchmark. This will be monitored through our local governance groups and Caring Services team management meetings.

We will work with our Information and Support team to increase the use of available information and explore the development of new resources to support communication, for example around sensory loss.

## Marie Curie Hospices

### Patient and carer experience

We will undertake a research project looking at a quality of life assessment in palliative care day services.

#### What does this mean and why is it important?

People attending palliative care day services have reported a positive impact on their quality of life, but there

is a lack of rigorous research evidence to support this. One of the reasons for this is that tools to assess quality of life may not capture the areas of life most valued by people who use these services.

The individualised approach to quality of life assessment that we are looking at provides a way of assessing quality of life that prioritises the areas most valued by an individual. Existing tools commonly use set questions that the person answers, which are then scored. This means that scores can be compared on the same questionnaire at different points in time. To date, no research has recommended a generic, condition-specific or individualised measure for use in palliative care.

Research is needed to compare an individualised assessment of quality of life with more traditional questionnaires in order to understand which are most helpful for use in palliative day care services. Therefore, the



Kieran Dodds/Marie Curie

aim of this study is primarily to identify the most appropriate and acceptable method of assessing quality of life among patients receiving palliative care day services. This will involve comparisons between the SEIQoL-DW (an individualised measurement tool), the MQOL (a palliative care-specific measurement tool) and the SF-36 (a generic

measurement tool) among patients receiving palliative day care services. To do this, the study will recruit 110 day service patients who will complete the quality of life measurements at two points within a three week interval.

#### How will progress be measured, monitored and reported?

We will complete a mid-point progress report and a final report at the end of the project. We will also complete an annual online Researchfish submission where we will record outputs, outcomes and the impact of the research.

**When Diana was having active treatment at the hospitals it felt like we were always chasing the next appointment and the next scan. Whereas in palliative care it's a lot less stressful. At Marie Curie we had chance to take stock. I'm so grateful that she was somewhere she could rest and have her symptoms managed and her pain kept under control. We were so lucky to have this hospice in our area."**

**William Bolger.** William's wife Diana was cared for at the West Midlands hospice before she died in March 2020

# Part 2 Quality in focus

## Our staff

Palliative and end of life care can make significant emotional and physical demands on our staff. We provide holistic support to help staff cope with the stress of work, balance the competing demands in their life and manage their financial wellbeing.

We take care to protect and support the wellbeing of our staff so they can provide the best possible care and support to patients, carers and family members. We have been developing our approach to staff wellbeing, encouraging local action in teams across the UK with expert support and services from our Human Resources team, including occupational health services.

## Mental wellbeing

Poor mental wellbeing is the most common reason for sickness absence and has therefore been the focus of

much of our HR work. We have expanded access to Schwartz Rounds, a forum for staff to discuss the emotional effects of their job, to non-clinical staff. This is in addition to the usual clinical supervision arrangements.

Staff can access a range of expert advice through our Employee Assistance Programme and a counselling service. We will be measuring the impact of counselling in the next year using comparisons of people generalized anxiety disorder (GAD) at the beginning and end. We are also promoting our critical incident debriefing services for occasions where staff or teams are significantly affected by events at work. We have introduced a new cognitive behavioural therapy (CBT) service through our occupational health provider to help staff in coping with anxiety or depression disorders.

**Schwartz Rounds** provides a structured forum where all staff, clinical and non-clinical, come together to discuss the emotional and social aspects of working in healthcare. The purpose is for people to understand the challenges and rewards of providing care, not to solve problems or to focus on the clinical aspects of patient care. Evidence shows that staff who attend Schwartz Rounds feel less stressed and isolated, with increased insight and appreciation for each other's roles.

We continue to roll out personal safety and mental health awareness training to hospices and nursing services and we have plans to do this for the rest of the organisation as well. We also provide bitesize videos via our online learning site on recognising and managing stress and we actively promote national initiatives such as Time to Talk Day. We are promoting a "day one" approach, where we refer staff to occupational health support the first day they are absent due to mental health.



Kieran Dodds/Marie Curie

Our HR team and network of anti-bullying champions respond proactively to workplace conflict and promote a zero-tolerance culture for bullying and harassment. As a Stonewall champion, we are bringing about changes that mean our employees are confident and comfortable in celebrating, sharing and promoting the diversity of our organisation.

## Physical wellbeing

In terms of physical wellbeing, we have introduced new services that offer physiotherapy and physical capability assessments for staff. We are looking at developing a service for expert

ergonomic assessment for frequent car users where required. We are working towards completing a risk assessment of immunisation against blood-borne viruses for all staff and we are preparing an organisational-wide plan to update inoculations.

## Employee Assistance Programme

The Employee Assistance Programme provides proactive, practical and emotional support to help staff manage and reduce the impact of life events, both at home and at work. It is provided through an external occupational health provider.

## Social and financial wellbeing

The social and financial wellbeing of our employees is extremely important. The majority of stress-related absence is due to issues outside of work. In order to lessen the effects of stress, we provide family-flexible policies and we are improving access to remote working technology to help staff balance life with work.

We are reviewing shift patterns to improve work-life balance and patient support. We are developing a new benefits platform that will improve access to benefits such as discount purchase schemes and bike loans. Financial advice and debt management guidance is readily available through our Employee Assistance Programme.

We have just embarked on research looking at the effectiveness of “acceptance and commitment therapy” (ACT), an intervention to support the emotional resilience of staff involved in palliative and end of life care.

## Patient and carer experience

Feedback from patients, their families and their carers is fundamental in driving improvements to our services.

People can provide feedback on our services:

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

## Patient safety

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

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 to the right shows the numbers of incidents recorded at all levels of harm in 2019/20.

## Number of patient deaths

As palliative and end of life care providers, we provide care and support to patients at the end of their life, helping them to manage their symptoms. Many of our patients are discharged home and some remain in our hospice where the patient is supported until they die.

Between 1 April 2019 and 31 March 2020, 2,085 patients died in our hospices, broken down as follows:

- Q1 – 491
- Q2 – 570
- Q3 – 534
- Q4 – 490

None of these deaths was subject to a case review or investigations.

### What do we mean by an incident?

We record anything significant that happens to a patient that could have or did lead to unintended or unexpected harm, loss or damage while under our care. This might include anything from a fall that injured the patient to a late administration of medicines that had no impact on them.

Level of harm	Total number	% of incidents
No harm – no injuries or obvious harm, loss of property or significant likelihood of service issues arising from incident.	3,394	75.52
Low harm – any incident that required extra observation or minor treatment and caused minimal harm to one or more persons receiving care.	1,087	24.19
Moderate harm – any incident that resulted in a moderate increase in treatment and that caused significant but not permanent harm.	11	0.24
Severe harm – a permanent lessening of bodily, sensory, motor, physiologic or intellectual function that is directly related to the incident and not related to the natural course of the service user’s illness or underlying condition.	2	0.04

**In the last week it became particularly hard for my dad. He needed intensive care, so having the back-up of the Marie Curie nurses made all the difference. The staff were wonderful. I honestly couldn't fault them. They came on Christmas Day, gave him a bath, put him in clean pyjamas and shaved his beard. The next day he died.'**

**Joanne Urquhart.** Joanne's father John had nursing care at home before he died in December 2018

## Part 2a: Marie Curie Nursing Service

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

### Patient experience

#### Patient and carer feedback

This year 3,505 patients and carers provided us with their feedback and comments about the Marie Curie Nursing Service via our primary satisfaction survey (see table below). We have largely maintained or improved our excellent satisfaction scores across different aspects of our services, with a slight

#### Friends and family test, Marie Curie Nursing Service

Responses	Total number	%
Likely to recommend Marie Curie	3,439	98.45%
Neither likely nor unlikely to recommend Marie Curie	25	0.72%
Unlikely to recommend Marie Curie	29	0.83%

#### What is the Marie Curie Nursing Service?

Marie Curie Nurses provide hands-on care for people living with 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 employs around 2,395 registered nurses and senior healthcare assistants working across the UK, who cared for 32,823 patients in 2019/20.

#### Patient satisfaction, Marie Curie Nursing Service

Aspect of care	2018/19 – responded “always”	2019/20 – responded “always”	Change from last year
Treated with dignity and respect	97%	97%	No change
Involved in decisions about your care	92%	92%	No change
Have up-to-date information about you	88%	89%	Up 1%
Provide support for family and friends	88%	87%	Down 1%

decrease in satisfaction in the friends and family test. We will continue to identify key themes and improvements in these areas to focus on in 2020/21.

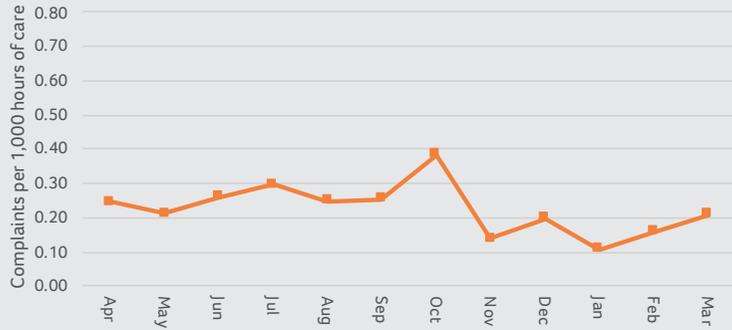
#### Friends and family test

We also ask patients and carers how likely they would be to recommend our services to their family and friends (see table above). Out of 3,493 people who answered this question, 98.45% (2018/19: 98.37%) said they would recommend the Marie Curie Nursing Service. We believe this indicates that we generally achieve an excellent level of

care, which has remained consistent over the past year.

However, a small number of people would be unlikely to recommend Marie Curie to their family and friends, and we are committed to learning from their experience and improving. In some instances, we have not been told why an individual would not recommend our services, but some of the reasons given include the organisation or reliability of our care. We will continue to monitor this measure and to make improvements in response to feedback wherever we can.

### Nursing service complaints



### Complaints

We aim to respond to 95% 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 235 complaints in 2019/20 (2018/19: 376). This significant reduction in the overall figure is for the most part due to a reduction in complaints about care not being delivered when expected (down from 124 to 37) and staff and volunteer behaviour (down from 94 to 25).

The most common complaints in the nursing service are to do with sleeping on duty, staff

attitude and care not being delivered when expected.

We responded to 79% of nursing service complaints within 20 working days and 83% within 20 working days or an agreed revised timeframe. Two complaints were escalated to the Parliamentary and Health Service Ombudsman from the nursing service. In one case we were asked to provide a further response to the family which we did and no further feedback has been received. With the other we have provided all relevant information to the Ombudsman and await further feedback from them.

### Changes made following complaints

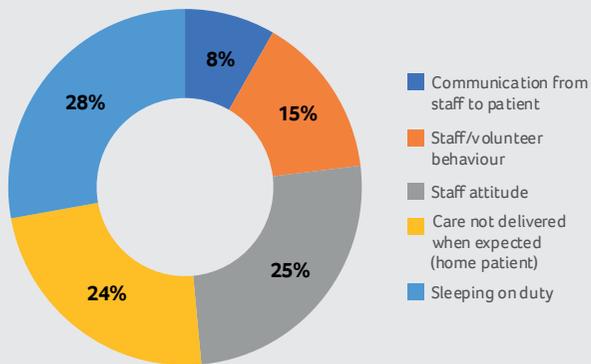
In 2019/20, we made changes in response to complaints received about our nursing service.

- We increased the knowledge and skills of our staff to improve their interactions with patients and families, as well as helping them to understand how certain conditions can affect patients. This included

specific targeted training on communication skills, documentation and managing difficult conversations.

- We improved the way that nurses are scheduled and given information on how to get to a person’s home. Nurses will now be tracked via a satellite navigation system so staff in the central office (hub) will be able to provide directions if they have difficulty finding locations. This is due to be implemented in 2020 and will be fully operational by the autumn. The start and finish times for shifts will be tracked more easily and nurses will be able to communicate with the team at the hub automatically.
- The team in the London region has developed a document called “22 Points of Proactivity” as an easy reference guide containing details of all of the essential tasks that should be completed during a visit. This has been shared with all staff and is being used as part of new staff inductions. It will be rolled out across the organisation in the coming year.

### Most common themes of complaints reported in the Marie Curie Nursing Service



## Clinical effectiveness Audit

We carried out four Marie Curie national audits of our nursing service in 2019/20, each focusing on a different aspect of our work.

Each of our 11 nursing service regions in the UK 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 2020/21 Marie Curie national audit programme will include three audits for the Marie Curie Nursing Service:

- complaints
- record keeping
- professional standards.

### Marie Curie Nursing Service audits undertaken April 2019 – March 2020

Audit	Percentage compliance across all services	Main findings or recommendations	Actions
Falls prevention and management	70	<p>All regions demonstrated staff are up to date with manual handling training. Staff were aware of what they must do in the event of a fall. However, they could not all identify the local standard operating procedure for post-fall care.</p> <p>The audit highlighted problems with access to patient notes due to the move to electronic records. Areas of low response often related to the lack of access to patient notes, which cannot be rectified directly by Marie Curie and requires work to be undertaken with the local district nurse teams.</p>	<p>Local teams will work with the local district nurse teams to manage issues relating, where appropriate.</p> <p>A falls policy, including post falls care, is currently being written. This will include requirements for assessment in the home when no records are available. Once disseminated, each area should write a local standard operation procedure for post-fall care and circulate to staff so they are aware.</p>
Record keeping	89	<p>This was a repeat of an audit last completed in 2017. There was an increase in the number of regions that scored 100% against eight of the standards compared to 2017. Against two standards there was a decrease, and six standards remained the same.</p> <p>Key areas for improvement were:</p> <ul style="list-style-type: none"> <li>• staff not reporting incidents where patient notes are not available in the home</li> <li>• the processes for disposal of notes or checklists containing patients' personal data</li> <li>• access to patient notes.</li> </ul>	<p>Regions whose scores have highlighted the need for improvement will explore the reasons for this with their teams and write action plans that they will monitor locally.</p> <p>We will continue the roll out of direct incident reporting.</p> <p>Regions will undertake work with the local district nurse teams to ensure that staff can access patient notes.</p>

### Marie Curie Nursing Service audits undertaken April 2019 – March 2020 (cont)

Audit	Percentage compliance across all services	Main findings or recommendations	Actions
Professional standards	95	<p>This audit had two parts: a self-assessment and gathering feedback from patients and carers. It was last undertaken in 2018.</p> <p>The feedback from service users demonstrated that staff are continuing to successfully convey high professional standards to patients and carers.</p> <p>The areas where staff scored the strongest were “on arrival to patients’ home” and “uniform and appearance”.</p> <p>Access to sufficient uniforms and patient notes were highlighted needing improvement for both years. Similar recommendations have been suggested, highlighting the need for implementing local action plans.</p>	<p>We agreed local action plans that will be monitored through local governance committees.</p> <p>Regions with low scores will ensure that they provide staff with an adequate number of uniforms so that they can be correctly laundered before their next shift.</p>
Accessible Information	68	<p>This audit, which was divided into two parts, has not been previously undertaken nationally in the nursing service. Part one required an assessment of systems, documents and resources, and part two was completed by each registered nurse or healthcare assistant via their tablets.</p> <p>Part one returned higher scores than part two. However, the audit tool requires changes to ensure that the data gathered is as accurate as possible.</p>	<p>Each region is encouraged to use the results of the audit to make improvements locally. This is also reflected in our priorities for next year.</p> <p>We plan to carry out this audit again in line with the requirements of the NHS contract in 2021.</p>

## Patient safety

### Incidents

The table below shows the number of incidents where duty of candour applies in each of our nursing service regions in the UK in 2019/20. There were four incidents that

resulted in moderate or severe harm in the nursing service (0.17% of all incidents).

**Incidents, Marie Curie Nursing Service, 2019/20**

	1. No harm	2. Low harm	3. Moderate harm	4. Severe harm
Central	324	17	0	1
Eastern	33	3	1	0
London	134	7	0	0
North East	697	23	0	0
North West	249	22	0	0
Northern Ireland	10	7	0	0
Scotland North	49	9	0	0
Scotland South	38	16	0	0
South East	35	8	0	0
South West	592	37	2	
Wales	51	16	0	0

### 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. They are given clear guidance on how to complete these so

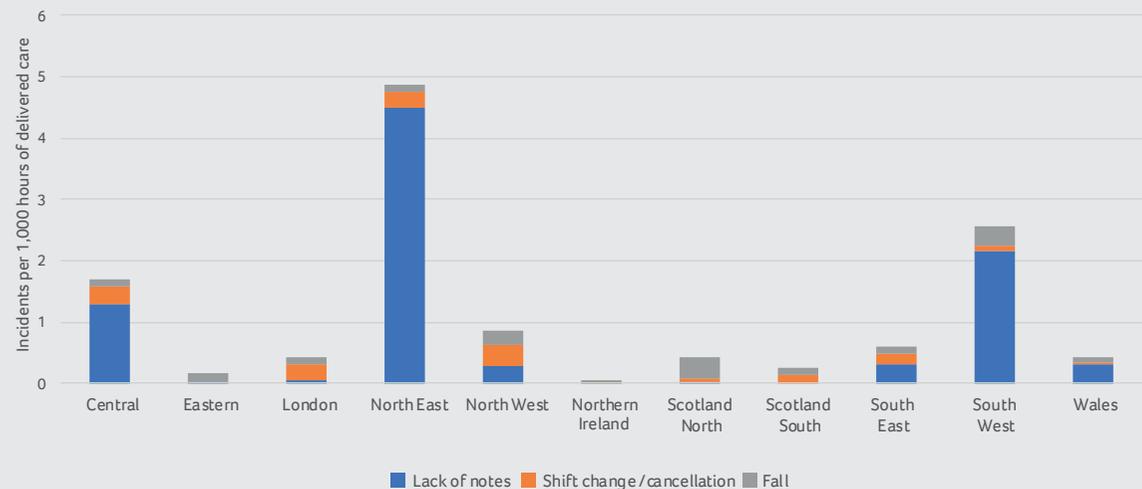
that the care they provide can be recorded by the district nurse in the patient's full record.

Lack of notes is more problematic in the North East, South West and Central regions; increasing use of electronic records by district nurses in these regions means

notes are often not left in patients' homes.

As part of the Nursing Service Transformation project, we are working to provide shared electronic records to nurses working in the community.

**Most common types of incidents reported in the Marie Curie Nursing Service**



### Shift cancellations

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. Local care co-ordination has changed the way visits are allocated, reducing the amount of shift changes or cancellations to 169 from 208 last year.

Reasons for visits being cancelled at late notice include staff phoning in sick and no other staff being available to cover their shift, staff availability being recorded incorrectly, or visits being declined because male staff have been booked and the patient was not comfortable with this.

In 103 of these incidents care was no longer required. This is often due to information not being passed on to staff that a patient has died. Most of the time this is due to the

community referral team not updating Marie Curie teams in time. If, when making a pre-visit call to a patient, the member of staff is informed that care is no longer required, a process is followed to try to re-allocate them to another patient.

### Falls

There were 172 falls in the nursing service this year. An audit on falls prevention and management was undertaken and, as a result of the findings, a short life working group has been set up lead by the Health and Safety Manager. The group will write a falls policy for the Marie Curie Nursing Service that includes post-fall care. They will also develop the requirements for falls assessment in the home when no records are available.



Philip Hardman/Marie Curie



**I was amazed when we walked through the doors of the hospice. Even though it is a clinical space, it doesn't feel it at all. It feels homely. I think that makes you feel a bit more safe and protected. Not only for the patient, but for the family as well. The staff were just fantastic. They were always there if you wanted a chat.”**

**Rachel Yates.** Rachel's father Julian died at the Marie Curie Hospice, Bradford in May 2019

## Part 2b: Marie Curie Hospices

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



Elizabeth Cuthbertson/Marie Curie

### What are Marie Curie Hospices?

There are nine Marie Curie Hospices across the UK, 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 and carer experience

#### Patient and carer feedback

This year 1,472 patients and carers provided us with their feedback and comments about our hospices across the UK via our primary satisfaction survey. Patient satisfaction with our service has remained largely constant, although some areas have seen a decrease in satisfaction as outlined in the table on the right. We will ensure that these are the focus of quality improvement initiatives over the coming year.

#### Patient satisfaction, Marie Curie Hospices

Aspect of care	2018/19 – responded “very good”	2019/20 – responded “very good”	Change from last year
Welcome into the hospice	92%	93%	Up 1%
Hospice cleanliness	92%	92%	No change
Quality of food and drink	86%	83%	Down 3%
Quality of information	86%	84%	Down 2%
Quality of care	93%	93%	No change

### Friends and family test

We also ask patients and carers whether they would recommend our services to their family and their friends (see table on the right).

Out of 1,468 people who answered this question, 99.25% said they would recommend Marie Curie Hospices (2018/19: 99.15%). Maintaining standards from the previous year, we are confident that this still represents a high level of patient and carer satisfaction.

Despite the high satisfaction level, there are a small number of people who would be unlikely to recommend Marie Curie to their friends and family. The reasons for this are not always provided to us, but we will continue to monitor this measure and to make improvements in response to feedback wherever we can.

### Friends and family test, Marie Curie Hospices

Responses	Total number	%
Likely to recommend Marie Curie	1,457	99.25%
Neither likely nor unlikely to recommend Marie Curie	6	0.41%
Unlikely to recommend Marie Curie	5	0.34%

### Complaints

We received 72 complaints about Marie Curie Hospices in 2019/20 (2018/19: 93).

We responded to 82% of hospice complaints within 20 working days and 90% of complaints within 20 working days or an agreed revised timeframe (target: 95%, 2018/19: 90.63%). There were no complaints escalated

to the Parliamentary and Health Service Ombudsman or other regulatory bodies from our hospices.

Poor communication is at the heart of most of the complaints we receive. Within our hospices, it was the main issue complained about in 2019/20.

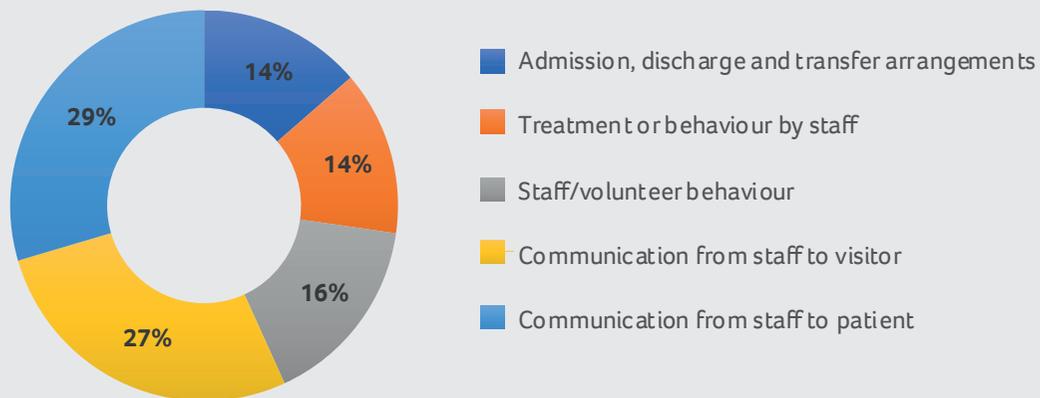


Kieran Dodds/Marie Curie

### Hospice Complaints



### Most common themes of complaints reported in Marie Curie Hospices



#### Changes made following complaints

In 2019/20 we made changes in response to complaints in our hospices, targeted at individual hospices, including:

- improved information for patients and relatives around, for example, the role and involvement of a clinical psychologist and safety procedures on the ward

- the recruitment of volunteers to work on reception to ensure adequate cover at all times
- staff reminders that if or when a patient indicates that they wish to make a complaint, this should be escalated so it can be dealt with immediately to ensure that the patient is receiving the best possible experience
- providing communication training to staff.

#### Clinical effectiveness Audit

We carried out two Marie Curie national audits of our hospices in 2019/20, each focusing on a different area of our work (see table on the next page).

Each hospice 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 2020/21 Marie Curie national audit programme

will include four hospice audits:

- care of the dying
- anticipatory prescribing
- complaints
- safeguarding.

### Hospice audits undertaken April 2019 – March 2020

Audit	Percentage compliance across all services	Main findings or recommendations	Actions
Care of the dying	89	<p>Our hospices demonstrated consistently high scores on resuscitation decisions and symptom control, as well as improved scores on the needs of families.</p> <p>Key areas for improvement were standards relating to drinking, eating and assisted hydration, where results remained similar to 2017, and recording of advance care planning. Explanations for low scores included sudden death, deteriorating state of the patient or delirium.</p>	<p>Each hospice will take a quality improvement approach and use methodologies such as the “plan, do, study, act” (PDSA) cycle to further understand the results. We will then implement actions to drive improvement in identified areas. Such improvements will be reflected in future audit scores.</p>
Bereavement	88	<p>This audit assessed us against the <i>Bereavement Care Support Standards</i> to help services determine areas for improvement. Adult and children services were audited separately, as not all hospices provide bereavement services for children. The audit highlighted a number of strengths, particularly with children’s services, which scored well in planning and resources..</p>	<p>Each service has produced an action plan which will be monitored through local governance groups.</p> <p>We are considering the implementation of a process for independent review/evaluation against these standards.</p>
Accessible information	73	<p>The overall score for this audit increased significantly since it was last undertaken in 2018 (62%) with improvements shown across all hospices.</p> <p>Key areas of improvement were better documenting of carers’ information or communication needs, and better flagging of these needs on electronic records.</p>	<p>Each hospice will use the results of the audit to assist in quality improvement work in this area.</p> <p>We will re-audit this in line with the requirements of the NHS contract in 2020.</p>
Anticipatory prescribing		<p>This audit has been delayed due to the coronavirus (Covid-19) pandemic.</p>	

NB: The third audit this year was scheduled to be on outcome measures, however we changed this to accessible information because we are currently unable to extract information about outcome measures from our electronic databases.

## Research

All of our hospices endeavour to engage in research and six of our nine hospices now have research leads or academic research fellows who oversee and encourage research in their locality. In 2019/20, 344 patients, carers or staff members have taken the opportunity to take part in research studies at our hospices.

Patients, carers and staff members appreciate the opportunity to take part in research, and we are grateful for their participation at such a difficult time. The following studies are being undertaken using a variety of research methods including feasibility studies, qualitative studies, mapping exercises and systematic reviews.

<b>Marie Curie Hospice, Belfast:</b>	<p>Quality of life assessment in palliative care day services.</p> <p>Developing and evaluating an educational intervention for the management of constipation: a feasibility intervention study.</p> <p>Developing an e-learning training resource for healthcare professionals to facilitate communication with parents on preparing their children for the death of a parent with cancer.</p>
<b>Marie Curie Hospice, Bradford:</b>	<p>Effect of disease and treatments on body image and intimate relationships of patients referred to specialist palliative care services.</p> <p>Resolving symptoms in cancer.</p> <p>Pain in advanced disease: a South Asian study.</p> <p>A multi-centre evaluation of excessive saliva management in patients with motor neurone disease.</p> <p>Accessing and delivering person-centred care in advanced non-cancer conditions: developing and piloting a support needs approach for patients with advanced COPD.</p>
<b>Marie Curie Hospice, Edinburgh:</b>	<p>Delirium assessment in palliative care: validating the 4AT delirium assessment tool in a hospice setting.</p> <p>Accessing and delivering person-centred care in advanced non-cancer conditions: developing and piloting a support needs approach for patients with advanced COPD.</p> <p>Future estimates of palliative care need in Scotland up to 2040.</p> <p>Exercise and nutritional rehabilitation in patients with cancer.</p> <p>Brief engagement and acceptance coaching in community and hospice settings.</p> <p>Developing and evaluating an educational intervention for the management of constipation: a feasibility intervention study.</p> <p>Characterisation of patients admitted to hospice in-patient unit.</p> <p>A carer intervention to improve support for patients with delirium in a palliative care inpatient setting: a quality improvement approach.</p> <p>Perspectives of palliative care nurses managing delirium in palliative care patients in the community: a qualitative study</p>

<p><b>Marie Curie Hospice, Glasgow:</b></p>	<p>Delirium assessment in palliative care: validating the 4AT delirium assessment tool in a hospice setting.</p> <p>The development of evidence-based good practice guidelines and resources to support children and young people pre-bereavement.</p> <p>Exploring the psychosocial impact of living with advanced chronic obstructive pulmonary disease of those attending two different models of palliative care services.</p>
<p><b>Marie Curie Hospice, Hampstead:</b></p>	<p>Evaluating psychological services in UK hospices: what exists, what works and what may not.</p>
<p><b>Marie Curie Hospice, Liverpool:</b></p>	<p>The study of hydration status and complex symptoms in advanced cancer using bioelectrical impedance vector analysis.</p> <p>Investigation of biological changes in urine in patients with advanced lung cancer: a pilot study.</p> <p>Changes in fat content (ketones) towards the end of life – a feasibility study.</p> <p>A feasibility randomised trial of an educational booklet to support and give practical advice to informal carers of patients with advanced cancer.</p> <p>Improving the support and management of depression for patients with advanced cancer.</p> <p>Desire for hastened death: a pilot study of specialist palliative care healthcare professional's approaches to managing desire for hastened death.</p>
<p><b>Marie Curie Hospice, West Midlands:</b></p>	<p>Developing and evaluating an educational intervention for the management of constipation: a feasibility intervention study.</p> <p>The nature of complexity in specialist palliative care referrals.</p> <p>A multi-centre evaluation of excessive saliva management in patients with motor neurone disease.</p> <p>The study of hydration status and complex symptoms in advanced cancer using bioelectrical impedance vector analysis.</p> <p>The development of evidence-based good practice guidelines and resources to support children and young people pre-bereavement.</p> <p>Costs and effectiveness of UK palliative care day services: a three-centre mixed methods study of impact upon patients and family carers.</p> <p>Roles and experiences of nurses when meeting the psychological need of patients receiving palliative care.</p> <p>Survey of psychological services in UK hospices.</p> <p>Survey exploring research environment in hospices in West Midlands.</p> <p>How confident are palliative care teams in the identification and assessment of mental health problems and risks survey.</p>

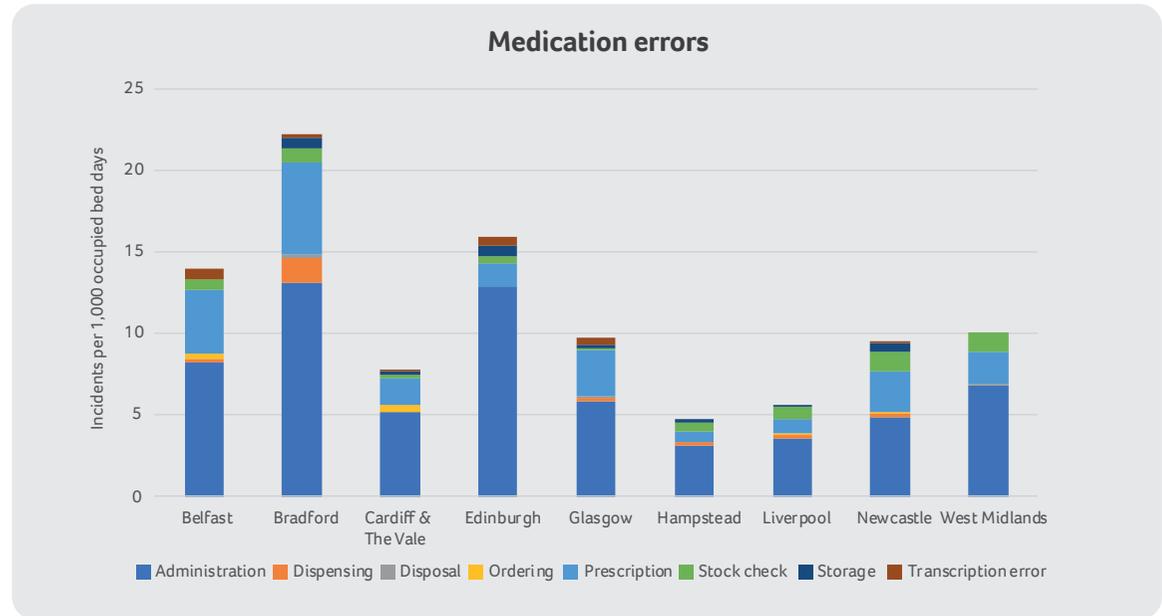
## Patient safety Incidents

The table below shows the number of incidents where duty of candour applies in our hospices in 2019/20. Overall, there were 9 incidents that resulted in moderate or severe harm throughout 2019/20 (0.43% 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.

**Incidents, Marie Curie Hospices, 2019/20**

Region	1. No harm	2. Low harm	3. Moderate harm	4. Severe harm
Belfast	90	84	1	0
Bradford	238	70	0	0
Cardiff & The Vale	113	161	2	0
Edinburgh	207	67	0	0
Glasgow	156	148	0	0
Hampstead	49	76	0	0
Liverpool	94	73	0	1
Newcastle	134	89	3	0
West Midlands	101	154	2	0
<b>Total</b>	<b>1,182</b>	<b>922</b>	<b>8</b>	<b>1</b>



### Medication errors

There were 557 medication errors over the year in our hospices (2018/19: 605). This includes administration, dispensing and prescription errors (see graph above).

All errors are discussed by senior clinicians at a regular medicines management meeting to identify any trends or themes and agree changes to systems and staff training, or other steps to reduce or mitigate the incidents.

This year in one of our hospices we launched the use of an electronic prescribing and medication administration system (ePMA) which aimed to reduce medication related incidents on the in-patient and day therapy units. The benefits of this include a reduction in time spent looking for paper medication charts (meaning faster delivery of medication), checks on whether the medication could react with other medication, allergy alerts (both increasing safety), and more legible prescriptions.

The learnings from this project will be shared across all of the hospices.

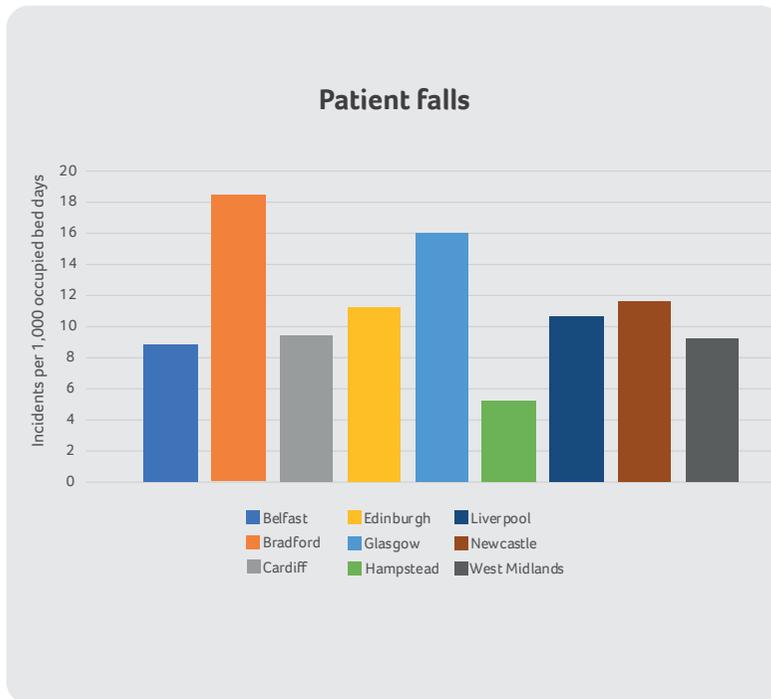
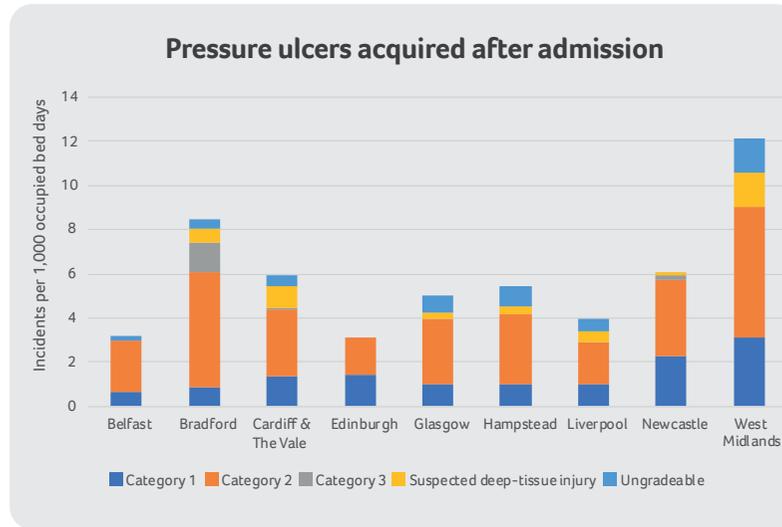
Most medication errors were administration errors and the majority were missed doses. No incidents resulted in moderate or severe harm. There is no clear reason for the variance in the number of incidents reported in the different hospices. In the next year we plan to review our data definitions to ensure that all hospices have the same threshold for reporting.

## Falls

Patient falls increased this year across our hospices – from 543 last year to 586. Five falls resulted in moderate harm to the patient and one in severe harm. In this case, the patient was transferred to hospital for further observation and x-rays.

## Pressure ulcers

We recorded 313 pressure ulcers in our hospices this year, compared to 267 in 2018/19. Most pressure ulcers recorded during admission (55%) were category 2 pressure ulcers. These have the potential to deteriorate to a more serious category 3 or 4 ulcer so our nurses ensure all possible steps to prevent a deterioration are taken, in agreement with the patient.



The West Midlands and Bradford hospices had higher rates of incidents than the others. There could be a few reasons for this. One patient could have multiple ulcers which would all be recorded separately. Patients at the end of life may chose not to be moved as regularly as we would recommend, even though they understand the risk this would pose for the development of ulcers.

The actual numbers of pressure ulcers acquired in our care are very small and our hospices carry out a review

of all pressure ulcers and complete a more detailed investigation on every category 3 or 4 pressure ulcer. This is to check if care plans were followed correctly, and whether there were any failings in the patient's care and treatment that may have contributed to the development of pressure ulcers. The results of these reviews are shared with colleagues at the lead nurses' meetings to enable lessons to be shared across the organisation. There were no failings or omissions in care leading to pressure ulcers identified this year.

## 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.

## Categories of pressure ulcer

**Category 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.

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

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

**Category 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.

## Moisture lesions

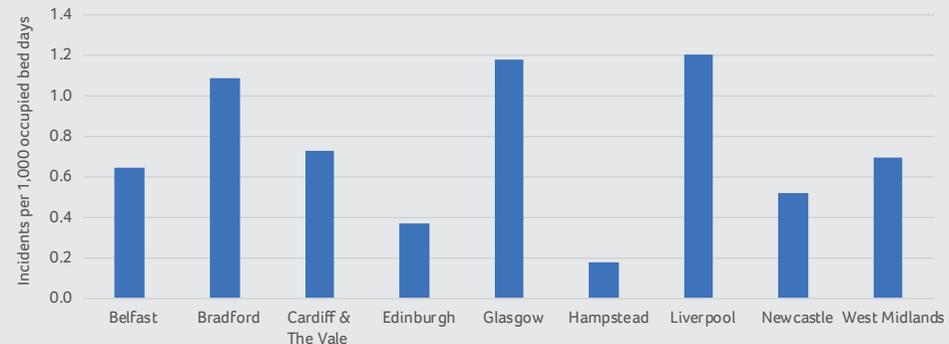
We recorded 42 moisture lesions in our hospices last year, 16 of which were acquired in our care. This is the first year we have recorded moisture lesions separately. We distinguish between moisture lesions and pressure ulcers because the prevention and management are quite different for each.

Hospices carry out a more detailed investigation on every moisture lesion to check if care plans were followed correctly, and whether there were any failings in the patient's care and treatment that may have contributed to the development of moisture lesions. The results of these reviews are shared with colleagues at the lead nurses' meetings to enable lessons to be shared across the organisation. There were no failings or omissions in care leading to moisture lesions identified this year.

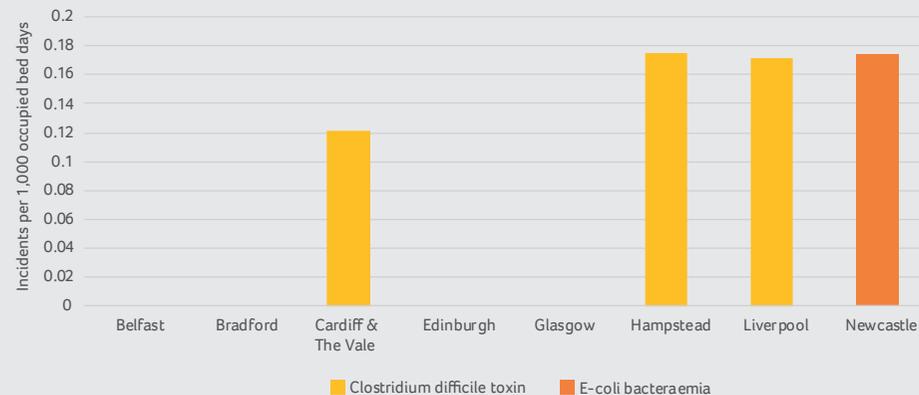
### What are moisture lesions?

Moisture lesions are caused by urine, faeces or perspiration that is in continuous contact with intact skin of the perineum, buttocks, groins, inner thighs, natal cleft or skin folds (where skin is in contact with skin).

### Moisture lesions acquired after admission



### Infection prevention and control incidents acquired in our care



## Infection prevention and control

We continue to manage incidents and the senior nurse for infection prevention and control carries out post-infection reviews of all reported incidents. Based on this initial review, a post-infection review panel is called comprising of the Medical Director, Director of Nursing, AHP and Quality, pharmacist, consultant, lead nurse and Associate Director of Nursing to complete a full review.

## Regulators

All Marie Curie services are registered with the relevant regulatory body in that country and are subject to unannounced or announced inspections carried out by the regulator for that service. We have not participated in any special reviews or investigations in 2019/20.

In England, Marie Curie is registered with the Care Quality Commission (CQC). The nursing services underwent two inspections through 2019/20 across all key lines of enquiry: caring, safe, effective, responsive and well-led. The outcomes of the inspections were:

- Eastern – good
- North East – outstanding

None of our hospices in England was inspected in 2019/20.

The Marie Curie Nursing Service in Scotland is registered with The Care Inspectorate Scotland.

Services are registered as both a care at home service and a nurse agency. This simply means that, depending on the patient's needs, care can be provided by either a healthcare assistant or a registered nurse.

The nursing service, care at home and nurse agency in Scotland South underwent one inspection in 2019/20, the outcome of this was:

- Care and support – very good
- Management and leadership – excellent

The nursing service nurse agency in Scotland North underwent one inspection in 2019/20, the outcome of this was:

- Care and support – very good
- Management and leadership – excellent

The Marie Curie Hospices in Scotland are registered with Healthcare Improvement Scotland. None of our hospices in Scotland was inspected in 2019/20.

The Marie Curie Nursing Service and Hospice in Northern Ireland are registered with the Regulation and Quality Improvement Authority (RQIA). Our Belfast Hospice was inspected in March 2020. This inspection report has not yet been published.

In Wales, the Marie Curie Nursing Service is registered with the Care Inspectorate Wales (CIW). The Nursing Service in Wales had one inspection in 2018/19. No areas of non-compliance were found (gradings are not used by the CIW).

Marie Curie Cardiff and the Vale hospice is registered with the Health Inspectorate Wales (HIW). No inspections by HIW took place in 2019/20.



Ben Gold/Marie Curie

# Part 3 Quality Account Regulations

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

- During the period 1 April 2019 to 31 March 2020, Marie Curie provided end of life care through part-NHS funded services through its nine hospices 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%. The rest is provided by Marie Curie charitable contribution.
- The income generated by the NHS services reviewed in the period 1 April 2019 to 31 March 2020 represents 98% of the total income generated from the provision of NHS services by Marie Curie for the period 1 April 2019 to 31 March 2020.
- During the period 1 April 2019 to 31 March 2020 there were no national mandated clinical audits or national confidential enquiries covering the NHS services that Marie Curie provides.
- From 1 April 2019 to 31 March 2020 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 2019 to 31 March 2020 that were recruited during that period to participate in research approved by a research ethics committee was 178.
- £88,155 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 (see the next page for details).
- 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 this 1 April 2019 to 31 March 2020.
- Marie Curie has not participated in any special reviews or investigations by the Care Quality Commission during 1 April 2019 to 31 March 2020.
- Marie Curie did not submit records during the reporting period from 1 April 2019.
- to 31 March 2020 to the Secondary Uses service for inclusion in the Hospital Episodes Statistics.
- As a healthcare provider, we use the NHS Data Security and Protection 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 2018/19, we self-assessed ourselves as compliant with all 38 mandatory assertions for charities/hospices (Data Security and Protection toolkit). We are due to submit our next assessment by 30 September 2020.
- Marie Curie was not subject to any Payment by Results clinical coding audit during 1 April 2019 to 31 March 2020.

### Commissioning for Quality and Innovation payments and goals

Service	Monetary value	Topic
Newcastle Hospice	£29,614	<p><b>Mental health wellbeing</b> Aim: to raise awareness of mental wellbeing with staff and promote the role of mental health first aiders in the workplace.</p> <p><b>Locality engagement</b> Aim: to raise awareness of the hospice and palliative care within the West End of Newcastle. To pilot strategies to engage with minority groups and to embed cultural diversity within the hospice.</p>
West Midlands Hospice	£14,474	Implementation of OACC outcome measures.
Central Region Marie Curie Nursing Service	£17,418	To deliver and embed person-centred care training to staff to encourage positive change in individuals that improves care.
South West Marie Curie Nursing Service	£15,028	Dorset: eight week reviews on CHC patients.



Layton Thompson/Marie Curie

## Statements from stakeholders

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

We are required to send a copy of our report to our Lead Commissioning Clinical Commissioning Group for their comments before publication. Their comments must be included in the published report. We also approached Marie Curie Voices, our network of volunteers with experience of terminal illness who help us improve our care.

We also approached our local Healthwatch and Overview and Scrutiny Committee and asked them to comment, but they were unable to do so in the timeframe this year.

### NHS Lincolnshire Clinical Commissioning Group

NHS Lincolnshire Clinical Commissioning Group (the commissioners) welcomes the opportunity to review and comment on the Marie Curie (the organisation) Annual Quality Account 2019/20.

The Quality Account provides very comprehensive information on the quality priorities the organisation has focussed on during the year, including:

- designing services in collaboration with patients and carers, including the redesign of day services in two hospices
- following on from the initial roll out of secure mobile devices enabling nurses to access a patient's "short care record", the past year has seen planning to enable community-based nurses to access a patient's full electronic record
- Marie Curie enhanced workforce planning using the career capability framework, which enabled

the organisation to have the right people with the right skills to deliver care in both hospices and the community.

The commissioners are particularly assured by the appointment of a Head of Safeguarding and the establishment of a Safeguarding Assurance Group as this was raised as a concern by the commissioners when reviewing the 2018/19 Quality Account.

Looking forward to the 2020/21 quality priorities, the commissioners are assured that the approach of considering all aspects of a patient's needs is continuing with:

- ensuring under-represented groups are included in a range of activities including patient and carer experience
- linking into the above, providing information in an accessible format for people with a disability or sensory loss to ensure all patients and carers are valued

- the clinical support line offering members of the public an opportunity to talk to a Clinical Nurse Specialist in palliative care without a formal referral, which will be a very good source of clinical advice
- the development of the workforce, with the organisation committing to the Nightingale Challenge which develops the next generation of nurses.

The commissioners are pleased that a number of the above align with the Lincolnshire System Quality Priorities.

The Quality Account has numerous examples of the good work undertaken by the organisation over the past year, but the commissioners believe that the Care Quality Commission inspections of the Nursing Service, rating the Eastern region as good and North East region as outstanding, are particularly noteworthy.

The commissioners would like to thank Marie Curie, who have worked very well with partners in the Lincolnshire Health System during the coronavirus (Covid-19) pandemic to ensure patients' needs are met in this challenging time.

NHS Lincolnshire CCG look 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**  
**Associate Director of**  
**Nursing & Quality**  
**NHS Lincolnshire Clinical**  
**Commissioning Group**

### **Marie Curie Voices**

We are pleased to have the opportunity of commenting on this Quality Account.

There is no dress rehearsal for a perfect death from a carer's viewpoint. We keep a promise in our hearts to learn and do everything we possibly can to be there for our loved one, whilst in that moment silently acknowledging the uncertainties we may have to face with them, perhaps not quite sure if we'll have the know-how or the physical and emotional capacity to make good on our promise.

It is particularly apposite, therefore, that we should make these comments, as Marie Curie Voices members are volunteers with direct experience of terminal illness through caring for a family member at end of life. Many of us have experienced first-hand the delivery of the services provided by Marie Curie Nurses in our homes or in one of the Marie Curie Hospices.

And our voices are heard. We are reassured that learning from the experiences of patients and families is at the heart of Marie Curie, central to its ethos and a principal policy driver. Marie Curie listens and continuously strives to lead the way in delivering outstanding palliative care. Consequently, the Voices are closely involved in how Marie Curie develops and implements quality services and we have assisted in the consultations about the North Star, other strategic developments, online information and support, bereavement services, research and new policies. This approach ensures that the views of patients, families and carers are seen as extremely important and considered at all times.

The Quality Account for 2019/20 demonstrates the comprehensive approach, through research and planning, that translates into quality care through the nursing services and the

hospices. This is impressive and something Marie Curie Voices are most proud of. We have no hesitation in endorsing this Quality Account as a fitting testament to the outstanding work of Marie Curie.

**Harry Bunch and  
Shital Bhaloo  
Members of Marie Curie  
Voices on behalf  
of the group**

## 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  
Marie Curie  
89 Albert Embankment  
London  
SE1 7TP

Email: [supporter.relations@mariecurie.org.uk](mailto:supporter.relations@mariecurie.org.uk)  
Tel: 020 7599 7294

*All images in this document were taken before PPE and social distancing measures were advised*

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](https://mariecurie.org.uk)

   [mariecurieuk](https://mariecurieuk)

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Front cover photo: Patrick Olnier/Marie Curie



Care and support  
through terminal illness