Quality Account 2018–19
Our quality performance, initiatives and priorities
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1.1 Welcome to our annual Quality Account

Joint statement from our Chief Executive and the Chairman of Trustees

We are extremely proud to present our Quality Account for 2018–19. At Sue Ryder, we put our patients and service users at the heart of everything we do. We tailor our care to suit the individual needs of each person we care for and their families. We go the extra mile to find out what’s important to each person and support them to make their own choices.

Sue Ryder supports people through the most difficult times of their lives. Whether that’s a terminal illness, the loss of a loved one or a neurological condition – we’re there when it matters. Our doctors, nurses and carers give people the compassion and expert care they need to help them live the best life they possibly can.

2018–19 was the first year of our five year strategy with the aim to provide more care for more people; and we hit the ground running. We started to pilot a new approach to providing palliative care through our South Oxfordshire Palliative Care Hub and expanded our Hospice at Home services in Bedfordshire and Cambridgeshire.

We’re developing our buildings, starting at Sue Ryder Dee View Court Neurological Care Centre in Aberdeen, where we’re doubling the number of people we care for. We’ve commenced the building of a new Sue Ryder Neurological Care Centre in Lancashire with 40 rooms and four supported living apartments and increased our rehabilitative care provision at The Chantry; the Sue Ryder Neurological Care Centre in Ipswich.

And we’re helping more people to cope with bereavement through our online community and bereavement counselling online via video.

One of our key ambitions is to be an outstanding provider of care. And it’s important for us to ensure that this care stands up to the high quality measures set for us nationally and the high standards that we set for ourselves.
1.2 Our vision, mission and values

At Sue Ryder, we’re passionate about giving people the quality of care they deserve.

For us to achieve this, we have a clear vision of what we want to achieve, an ambitious mission, and operate with three corporate values.

**Our vision**

We see a future where our palliative and neurological care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

**Our mission**

Sue Ryder supports people through the most difficult times of their lives. Whether that’s a terminal illness, the loss of a loved one or a neurological condition – we’re there when it matters. Our doctors, nurses and carers give people the compassion and expert care they need to help them live the best life they possibly can.

**Our values**

1. **Make the future together** – sharing our knowledge with each other and collaborating with our volunteers, supporters and people who use our services to deliver positive outcomes.

2. **Do the right thing** – working with honesty and integrity, having courage and resilience to face the challenges in delivering our goals.

3. **Push the boundaries** – constantly looking at ways to improve what we do and how we do it, with creativity and innovation.
1.3 Our service map

Neurological care
8. The Chantry Neurological Care Centre, Ipswich
9. Cuerden Neurological Care Centre, Preston
10. Dee View Court Neurological Care Centre, Aberdeen
11. Stagenhoe Neurological Care Centre, Hitchin

Palliative care
1. Duchess of Kent Hospice, Reading, including Reading, Wokingham and Newbury community services
2. Leckhampton Court Hospice, Cheltenham, including Gloucestershire community services
3. South Oxfordshire Palliative Care Hub
4. St John’s Hospice, Moggerhanger, including Bedfordshire Palliative Care Hub
5. Thorpe Hall Hospice, Peterborough, including community services
6. Wheatfields Hospice, Leeds, including community services
7. Manorlands Hospice, Keighley, including community services

Supported living
16. Supported Living Unit, Aberdeen
17. Supported Living Unit, Ipswich

Community services
12. Angus Homecare, Arbroath
13. Stirling and Falkirk Homecare, Stirling
14. Perth and Kinross Homecare, Perth
15. Dementia Together, Suffolk

1.4 Putting our work in context

Our principles are at the heart of everything we do which enables us to provide high-quality, person-centred care, in line with the policy direction contained within the NHS Long Term Plan for England and the Health and Social Care Delivery Plan for Scotland.

Our care supports the realisation of national and local healthcare policy priorities of supporting people to live as independently as possible at home or in their local communities. Hence we have started to expand our community services and support. In South Oxfordshire we are now piloting a new approach to providing palliative care in people’s homes via our Palliative Care Hub and expanded our Hospice at Home services in Bedfordshire and Cambridgeshire.

At Sue Ryder we see the person, not the condition, which is why we are using our own Personal Outcomes Framework for people living with neurological conditions. This empowers service users to make decisions that enable them to live their lives as fully as possible. In 2018–19 we also started to explore the use of assistive and other new technologies to improve the experiences of our service users.

To enable an appropriately skilled and integrated workforce we have continued to invest in specialised training including:
- The Management of Actual or Potential Aggression (MAPA)
- EDGE (manual handling) train the trainer
- Human rights in end of life care.
1.5 Our core services and national service offer for palliative care and specialist neurological care

Specialist neurological care:
Specialist neurological care centres:
- Post-acute rehabilitation
- Slow stream rehabilitation
- Complex disability management
- Support for people with cognitive impairment and behavioural needs
- Non invasive ventilation and tracheostomy care
- Neuro-palliative care
- Therapeutic support such as physiotherapy, occupational therapy and psychological support
- Providing social and recreational activities that enhance well being and quality of life

Supported living:
- Link to centres
- Link to step up/step down

Neuro community services:
- Care at home
- Self management and preventative programmes
- Specialist day services

Palliative care:
Inpatient services:
- 24/7 admissions through a range of access points and inclusive of the ‘hard to reach’
- Beds managed by a specialist medical and nursing team
- Offering physiotherapy, occupational therapy, complementary therapies, social workers and chaplaincy
- Delivering individual programmes of care linked to personal goals and preferences

Hospice at Home:
- Domiciliary visits
- Medical and family support

7/7 CNS service:
- Community nurse prescribers
- Assessing, planning and co-ordinating care for people at home

Day therapy:
- Delivering flexible, responsive ‘packages of care’ tailored to individual need
- Outpatients
- Specific clinics, ‘drop in’ visits
- Long term conditions programmes
- Medical outpatients with interventions

Patient co-ordination:
- Palliative care co-ordination
- Delivering co-ordinated and seamless access and transition through all services and settings
- Hospital and care home in-reach service

Carer and family support:
- Bereavement, spiritual and social
- Providing access to psychology

24 hour co-ordinated palliative care advice:
- Signposting advice and guidance
- Support for individuals to signpost to the appropriate service
- Rapid response and crisis support

Befriending:
- Maximised by the use of volunteers

Bereavement services:
- Development of a ‘best practice’ bereavement model
- Providing transition for young adults.

2.1 Progress against our priorities for improvement 2018–19

Our priorities for 2018–19 were:

Priority 1: Service user experience
To ensure we are capturing personal outcomes for our neurological residents including the planned actions. To implement measuring clinical outcomes in our palliative and neurological centres.

Priority 2: Service user safety
To continue to manage the risk of harm to service users by reducing incidents. Focusing on falls, medicines and pressure ulcers in palliative and falls, medicines and behaviour that challenges in neurological. Setting local targets to achieve a year on year decrease for each site.

Priority 3: Service user effectiveness
To continue to roll out the national educational programme on human rights approach to end of life care and build a sustainable model.

Priority 4: Service user experience
To explore and utilise assisted technology to enhance residents and patient experience in our neurological and palliative centres.

Priority 5: Service user and staff safety
To embed the management strategies for behaviours that challenge our service delivery.
2.2 Priority 1

We said we would:
Ensure we are capturing personal outcomes for our neurological residents including the planned actions. Implement measuring clinical outcomes in our palliative and neurological centres.

1. To capture personal outcome measures and planned actions using existing technology.
2. To work in collaboration with our palliative and neurological services to implement validated clinical tools to measure outcomes.

We did:

1. We have continued to focus on the personal outcomes of all our residents in all our services. Various tests of change on how to capture the outcomes have been undertaken at centres, and the data collection tool has also been refined based on feedback. There is a continual focus on achieving personal outcomes with clear evidence of partnership working to achieve the best outcomes for the residents living in our care.
2. Measuring clinical outcomes started to be tested in 2018, with data being collected using the clinical outcomes tools on the UK ROC database. The aim of this is to enable services to understand changes in individual residents’ dependency levels and review effectiveness of any rehabilitation, identify if there is a need for a review of care, and to aid services to manage workforce and budget plans more effectively.

Krystle’s story

This is definitely the best place for Krystle to be.

For years we had coped with Krystle’s condition at home, it was hard, particularly because our son has Wolfram Syndrome also, but we just got on with it. Over time her condition deteriorated to the point where we couldn’t cope any longer at home and we needed help.

We looked everywhere and tried many different places to see if they could accommodate Krystle but none of them could. We wanted to find somewhere so that she could have her life back, being stuck in hospital meant she was missing out on so much.

When we found Sue Ryder it was exactly what we had been looking for. Krystle now lives in her own apartment, so she has her own space with all the home comforts she had been missing. As well as her medical needs being covered the support workers who are with her 24/7 have also helped to give her some normality back into her life – they’ve got time to have a chat, to watch TV with her, to do activities with her. She’s done things whilst she’s been at Dee View Court that she’d not been able to do for a long time, like her art.

As for us, her family, it has been completely life-changing. I can be her mum again, not just her carer. The burden of worry has been lifted off my shoulders and it is now possible to spend time together as a family. We can come and visit her and do normal, everyday things together like have dinner.

Told by Vicki, Krystle’s mum
**2.3 Priority 2**

**We said we would:**
Continue to manage the risk of harm to service users by reducing incidents. Focusing on falls, medicines and pressure ulcers in palliative and falls, medicines and behaviours that challenge in neurological. Setting local targets to achieve a year on year decrease for each site.

1. Following detailed analysis and benchmarking we are agreeing specific measurements to reduce the number of incidents that cause harm per 1000 OBDs (occupied bed days).
2. To ensure that each palliative and neurological service has a detailed quality improvement plan to achieve this.

**We did:**
In our Quality Account for 2017–18 we set ourselves a series of key priorities for improvement:

1. Falls prevention
2. Medicines management
3. Behaviours that challenge (neurological services) and
4. Pressure ulcer prevention (palliative services)

**These have been achieved through:**

**Equipment and devices:** We audit pressure relieving mattresses monthly and we have changed our maintenance contract for all equipment and formalised equipment registers.

**Documentation:** We have completed a review of policies, incident management system and processes, risk assessments and support plans at Quality (assurance) Visits and through audit.

**Data analysis:** We carry out a monthly review of data at local Quality Improvement Groups, quarterly reviews of data at each service and at Healthcare Governance Group.

**Timely review of harm:** We undertake significant event analysis for any incidents that have caused significant harm, and learning from this through local forums.

**Collaborative working:** Topic specific workstreams have been established, with membership from both palliative and neurological services. The groups aim to share best practice, share learning and embed a culture of continuous improvement in our services.

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**Michelle’s story**

**My Mum and Dad**

Sue Ryder Manorlands Hospice gave my mum and dad outreach nursing at home before needing respite care and going to the hospice to die. After my parents passed away Sue Ryder Manorlands Hospice gave us as a family support, time to grieve and also gave me and my daughter counselling for our loss.

The staff at the hospice amazed me how much they listened to my mum and dad about their wishes, their preferences and their inner feelings. Which I really think was hard for our parents to share with me and my brother so as not to cause us anymore pain. Nothing was ever too much for the staff. My mum was so violently sick with having pancreatic cancer, no medicine seemed to ease it, so the doctors and nurses agreed to put a NG tube down my mum’s nose into her stomach to drain her stomach fluids (sometimes 3 or 4 times in an hour). This was to enable my mum to still have the pleasure of eating and drinking without constantly being sick. The staff brought her ice cream anytime she asked and one night she had a cheeky glass of prosecco which she always loved.

From experience I can say when a loved one is seriously poorly, it can be a very traumatic time for all, it’s scary, overwhelming and very upsetting for everyone involved. Sue Ryder Manorlands Hospice is an amazing place with amazing staff and helped me and my family through this twice and I, as a volunteer fundraiser, will continue to give as much back to the hospice as I possibly can.
2.4 Priority 3

**We said we would:**
Continue to roll out the national educational programme using a human rights approach to end of life care and build a sustainable model.

Continue to share expertise in human rights across all neurological and palliative care centres.

**We did:**
We have continued to develop expertise on human rights at the end of life through unique training workshops. The training is designed to help staff support people with life threatening illnesses to make what can be very complex decisions. This in turn ensures care and support is truly person centred.

As well as training our own staff, the workshops are available to staff working outside of Sue Ryder such as the NHS. We now have developed a network of expert trainers in three out of four of the UK Nations: Northern Ireland, Scotland and England and to date those trainers have trained at least a further 446 health and social care professionals.

**We said we would:**
Support staff to use this approach to ensure personalised care is consistently delivered as part of end of life care delivery and demonstrate impact via local measurement tools.

**We did:**
In our analysis of the first six months of workshops, we have seen knowledge and understanding of human rights increase from 36% pre-training to 92% two weeks post-training. Confidence to use human rights in their practice and decision-making increased from 30% pre-training to 91% two weeks post-training. We receive consistently positive feedback from attendees and managers of staff who have attended.

Human rights training feedback

“I wish I had had this training years ago. It has made me more aware of the links between legislation and has given me more confidence to challenge poor practice that doesn’t take human rights into account.”

—Deputy Manager, Care Home

“I have personally spoken to a number of people who attended the training and they have spoken very highly of you and thought the day was excellent.”

—Palliative Care Social Worker, Hospice

“I thought it was an excellent study day; it really opened my eyes to a subject I had no knowledge of. Personally, I think it is essential for practitioners to understand how human rights is a key factor in helping patients and families make difficult decisions at end of life and this session really helped me understand this. It also allowed me to reflect on situations I had come across in the past.”

—Education Lead
2.5 Priority 4: To explore and utilise assisted technology to enhance resident and patient experience in our neurological and palliative centres.

**We said we would:**
Identify the assisted technology that would be appropriate for our residents and patients.

**We did:**
We collaborated with a number of universities on this topic area. We have explored potential technology appropriate for our residents and patients at one of our neurological centres. We will be developing this further in the future.

**We said we would:**
Pilot this technology and evaluate the effectiveness on resident and patient experience.

**We did:**
We met with representatives from the University of East Anglia to discuss potential collaborative work. Following discussions, the funding bid with the University of East Anglia has been successful, and this enables the evaluation study of the effectiveness of virtual reality (VR) on our residents. Key areas that we plan to examine are agitation levels pre and post VR intervention.

Sue Ryder Dee View Court has been piloting the use of VR with people with neurological conditions to see if it has any impact on health and wellbeing. Therapists at Sue Ryder say the new therapy is having a dramatic effect on those using it. They have noticed a reduction in blood pressure and pain levels for many and some were less agitated and more relaxed. The effects last for several days.

The technology is now being rolled out across Sue Ryder’s network of neurological centres across the UK.

One 65-year-old resident with MS said the virtual reality experience was “terrific” and that “It’s somewhere I could not go in a wheelchair”. The resident added: “The sea lapping at my feet feels so good, I feel like kicking off my shoes.”

Louise Torrance, Head of Care at Sue Ryder in Aberdeen, said: “Within seconds of [the equipment] being on, people were more relaxed. “About 75% of people saw blood pressure decrease – a couple increased as they were so excited. “They have got freedom as they can choose where to go. It’s something to look forward to. “It’s hugely significant. They are talking about it with other residents and their families. Once that is rolled out it will have a huge impact.”

Our initial findings are that it improves mood level, can help with pain, improves relaxation levels, and may affect blood pressure.
2.6 Priority 5

We said we would:
Embed the management strategies for behaviours that challenge our service delivery. Successfully implement an organisational training programme within our neurological centres in partnership with a specialist training provider.

We did:
We have successfully rolled out the Managing Actual or Potential Aggression (MAPA) training programme across all our neurological centres to both clinical and non-clinical staff. Initial staff training is almost complete with some neurological centres starting to roll out the refresher training on an annual basis. Our MAPA Instructors register any training they have delivered at our centres with the British Institute of Learning Disabilities (BILD) and issue BILD accredited participant certificates when staff have been trained. Our MAPA Instructors have also attended their MAPA annual update with the Crisis Prevention Institute (CPI) and a further 10 staff have been identified to become MAPA Instructors to be trained by CPI. In addition to this bespoke in-house MAPA updates have been planned for 2020 in partnership with CPI.

We said we would:
Monitor the effectiveness through incident reporting in our neurological centres.

We did:
Our incident reporting system has been updated to reflect the changes since the implementation of the MAPA training programme in our neurological centres and successfully monitors the effectiveness of our management process across the centres.

We said we would:
Explore how these strategies and training can be utilised in our palliative centres.

We did:
We explored types of behaviours that challenge through our Learning and Development Working Group and Allied Health Professional forum to ascertain issues that occur in the palliative care setting. This was also explored for our home care setting in Scotland through the Learning and Development Home Care Working Group. Case studies of identified issues of behaviours that challenge were collated to see themes that arose in these settings.

By using these identified themes we will continue to develop the appropriate training required to meet these needs.

Key themes that have emerged from the qualitative data include:
- Ability to manage difficult situations
- Increased awareness of positive behaviours and de-escalation strategies
- Reduced need for escalation and increased confidence

The following are some quotes from staff who have completed the MAPA training.

“I now know how to manage situations that may occur better and how to apply these methods in my workplace.”

“I can manage the crisis situation more confidently.”

“I will be able to efficiently employ the strategies and movements to ensure my residents’ safety.”

“A very interactive course with enough time to discuss scenarios that could potentially happen. I think the fact that instructors are familiar with clients and behaviours that can present has added to the value of the course.”
2.7 Our priorities for 2019–20 are:

Quality priorities for 2019–2020 have been developed based on themes of clinical incidences, concerns, service user feedback and consultation with staff from across the organisation.

**Priority 1: Service user experience**

*Priority for Improvement:* To work collaboratively with our staff and service users to review and enhance our approach to service user involvement and engagement for all our services.
- To implement the new models and review their effectiveness to drive quality improvement.
- To develop skills and resources in person centred engagement methods.

*How this will be monitored and measured:*
- Feedback will be monitored at service level and through corporate governance to include response rates for real time feedback.

**Priority 2: Service user safety**

*Priority for Improvement:* To strengthen shared learning across the organisation, internally and externally, with a focus on quality improvement initiatives to reduce falls, medicines and pressure ulcers in palliative and falls, medicines and behaviour that challenges in neurological.
- To share best practice across palliative and neurological services.
- Each service to demonstrate quality improvements using agreed quality improvement methodology and measure progress.

*How this will be monitored and measured:*
- Quality improvement displays in staff areas.
- Quality visits showcasing improvement and the implementation of shared learning.
- Learning for safety memos acted on.
- Incident and performance data.

**Priority 3: Service user effectiveness**

*Priority for Improvement:* To continue to enhance the care culture by using a human rights approach to end of life care and implement a sustainable model.

*How this will be monitored and measured:*
- An increase in the number of trained trainers who will ensure this work is shared across their health and social care communities across all four UK nations.
- Training compliance rates.
- An evaluation of the training as an approach for improving end of life care delivery.

**Priority 4: Service user experience**

*Priority for Improvement:* To strengthen our awareness of mental health and dementia for all our services.
- Increase our knowledge through education.
- To assess and improve the care environment.

*How this will be monitored and measured:*
- Training compliance rates.
- Quality audit and assessment of regulatory standards.

**Priority 5: Service user and staff safety**

*Priority for Improvement:* To further develop our workforce planning incorporating new models of care delivery.

To develop our leadership and management capabilities and workforce behaviours and create a culture of learning and feedback, wellbeing and safety.

*How this will be monitored and measured:*
- Annual Let’s Talk survey results.
- Training attendance rates (Leadership and Management programmes).
- Wellbeing and safety in the workplace e-learning completion rates.
- Annual Performance Review completion rates.
2.8 Statements of assurance

This section contains the mandatory statements of assurance required of all providers of NHS funded care within their Quality Account. The information provided is relevant to the services Sue Ryder provides. During the period of this report, 1 April 2018 to 31 March 2019, Sue Ryder provided NHS-funded community care services in our hospices and some care centres and NHS-funded nursing care in most of our centres. Sue Ryder had seven adult inpatient units within hospices, seven day hospices, two Hospice at Home services, four community nursing services, and four care homes with nursing (three in England and one in Scotland). In addition to these services we also delivered care within two supported living services.

Sue Ryder has reviewed all the data available to it on the quality of care in all of the above services.

The income generated by the relevant health services reviewed in year ending March 2019 represents 53% of the total income generated from the provision of relevant health services by Sue Ryder for year ending March 2019. The % statutory income received for palliative services was 38% and neurological services was 85% during the year (the total across both being services 53% for the period). During the period from 1 April 2018 to 31 March 2019 there were no national clinical audits or national confidential enquiries covering the NHS services that Sue Ryder provides.

The reports of 0 national clinical audits were reviewed by the provider from 1 April 2018 to 31 March 2019. Whilst the mainstay of national audits is directed at the hospital setting, Sue Ryder acknowledges the benefit of learning from the wider health and social care sector. Going forward the newly appointed Chief Medical Director will be reviewing relevant national audits and sharing learning across the organisation.

Sue Ryder sets an annual core audit programme that runs from April to March each year. The core audit programme is risk-driven, and for hospices and neurological care centres includes record keeping, medicines management, falls prevention, manual handling, pressure ulcer assessment and management and infection prevention and control (including environmental and hand hygiene audits).

The reports of 11 local clinical audits were reviewed from 1 April 2018 to 31 March 2019, with high compliance observed across the board. As a result of the audit programme Sue Ryder intends to take the following actions to improve the quality of healthcare provided:

- Improvements to the documentation demonstrating application of the Mental Capacity Act.
- Improved training for staff on the application of the Mental Capacity Act.
- Facilitate shared learning and spread of best practice across the organisation with the development of specialist interest groups in: falls prevention, medicines management, safeguarding and pressure ulcer care.

74 patients were recruited at Sue Ryder during the financial year 2018–19 to participate in research approved by a research ethics committee within the National Research Ethics Service.

A proportion of Sue Ryder income in the year ending March 2019, was conditional on achieving quality improvement and innovation goals agreed between Sue Ryder St John’s Hospice and Bedford CCG through the Commissioning for Quality and Innovation payment framework; NHS staff health & wellbeing: CQUIN 2017–19. Further details of the agreed goals for year ending March 2019 are available electronically at https://www.england.nhs.uk/wp-content/uploads/2018/05/staff-health-wellbeing-cquin-2017-19-implementation-support.pdf.

Sue Ryder is required to register with the Care Quality Commission and the Scottish Care Inspectorate. Conditions of registration include the management by an individual who is registered as a manager in respect of that activity at all locations and maximum number of beds for its services in the following regulated activities:

- Accommodation for people who require nursing or personal care
- Diagnostic and screening procedures
- Personal care
- Transport services, triage and medical advice provided remotely
- Treatment of disease, disorder or injury

The Care Quality Commission has not taken enforcement action against Sue Ryder from 1 April 2018 to 31 March 2019. Sue Ryder has not participated in any special reviews or investigations by the CQC during the reporting period.
2.8 Statements of assurance (continued)

Sue Ryder was not required to submit records during the period from 1 April 2018 to 31 March 2019 to the secondary uses service for inclusion in the hospital episode statistics.

Previously Sue Ryder has submitted evidence based on self-assessment information for quality and records management, assessed using the Information Governance (IG) toolkit as a ‘NHS Business Partner’. The evidence submitted was based on self-assessment for attainment level two. All organisations that have access to NHS patient data and systems are now required to publish a Data Security and Protection Toolkit (DSPT) self-assessment to provide assurance that they are practising good data security and that personal information is handled correctly. Sue Ryder has registered and completed an assessment during year ending March 2019 with 100% all standards met.

Sue Ryder was not subject to the Audit Commission’s payment by results clinical coding audit during the period 1 April 2018 to 31 March 2019.

Sue Ryder will be taking appropriate actions to improve data quality through:
• Increased awareness in the importance of reporting
• Implementation of integrated quality and improvement reporting training, including how to use our documentation templates
• Identifying trends through a balanced scorecard reporting system
• ‘Learning for safety’ memos for when systems and processes change.

During the period 1 April 2018 to 31 March 2019, 1312 Sue Ryder patients died (1288 in our palliative inpatient units and 24 in our neurological care homes). This comprised the following number of deaths which occurred in each quarter of that reporting period: [321] in the first quarter; [350] in the second quarter; [323] in the third quarter; [318] in the fourth quarter.

The deaths in our services were expected deaths, and by 31 March 2019, 0 case record reviews and 0 investigations have been carried out in relation to the deaths included above. One hospice contributed effectively to a case review as part of the Learning Disabilities Mortality Review (LeDeR) Programme. The care was commended with no recommendations for improvement.

In response to findings in the Gosport report, the following declaration identifies how staff are guided to raise concerns and speak up if they have concerns over quality of care, patient safety or bullying and harassment within the organisation.

Staff are guided to follow guidance in a revised Whistleblowing (Raising Concerns) Policy and approach their line manager in the first instance where appropriate:
1. Internal disclosure to their line manager
2. A member of the Senior Leadership Team in their area
3. A member of the People Team
4. A member of the Executive Leadership Team
5. The Chief Executive
6. The Chairman of the Trustees.

Should an internal response not address concerns, staff are guided to seek independent advice and contact the External Regulators.

2.9 Indicators for quality

Safety

Number of incidents affecting service users 2018–19

<table>
<thead>
<tr>
<th>Service user incidents &amp; harm</th>
<th>Neurological</th>
<th>Palliative</th>
<th>Homecare</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. Incidents affecting service user / clinical incident</td>
<td>479</td>
<td>538</td>
<td>1253</td>
</tr>
<tr>
<td>No. of incidents resulting severe harm</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Rate of incidents resulting in severe harm</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

Note: Severe harm relates to those recorded on DATIX as ‘permanent or long-term harm’.

Regulatory inspection results 2018–19 (April 2018–March 2019)

There have been no inspections by the Care Quality Commission in 2018–19 to any of the Sue Ryder services in England.

There have been three inspections by the Scottish Care Inspectorate in 2018–19 in Sue Ryder services in Scotland:

- May 2018: Stirling – 6 Excellent for areas inspected
- December 2018: Arbroath – 5 Very good for areas inspected
- January 2019: Dee View Court – 6 Excellent for areas inspected

Effectiveness

Healthcare Associated Infections 2018–19

Only one case of Clostridium Difficile was acquired within a Sue Ryder service and one case acquired prior to the patient being admitted to the hospice.

<table>
<thead>
<tr>
<th>Clostridium Difficile</th>
<th>2017–18</th>
<th>2018–19</th>
</tr>
</thead>
<tbody>
<tr>
<td>SR Out</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Rate per 100,000 occupied bed days</td>
<td>0</td>
<td>n/a</td>
</tr>
</tbody>
</table>

SR = Acquired within Sue Ryder
Out = Acquired external to the service
2.9 Indicators for quality

We use a number of ways to measure service user satisfaction including real-time feedback surveys. The questions we ask relate to their experience of the care and support they receive, how well they are treated by us and whether they would recommend our services to others if they needed similar care and treatment. Relatives of those people using our services are also encouraged to provide feedback particularly for service users with complex conditions or who may have communication difficulties.

Neurological care 2018–19

In our neurological centres we support people with complex conditions, many of whom have communication difficulties and therefore are not able to respond to the survey questions. To increase service user feedback we have introduced a survey for relatives to complete on their behalf. We will be reviewing other ways to support our service users to have their say.

“'The friendliness of all staff. The area is beautiful and we love to walk in the grounds. It’s close to my home. The menus are outstanding. This is like a second home to me.'

“'It’s very resident focused. I can visit at any time. The staff are exceptionally kind.'

“'Warm and friendly people, with a professional approach.'

Relatives of patients with difficulty communicating can complete a survey on their behalf.
2.9 Indicators for quality

Palliative care

"It is paradise here. Because here everyone is trying to think what they can do to help me/make things better for me. They have a different mindset of how to help people." 

"Staff are very respectful of my privacy and do their utmost to ensure dignity at all times."

"The staff are confident and very capable at what they do. They are cheerful, they laugh and you can have a chat and laugh with them. It is really cosy and almost like being at home."

"I find that they do everything they can to help you. They do everything with a smile on their face."

98% of service users in our hospices are likely or extremely likely to recommend our care to friends and family if they needed similar care or treatment.

96% of service users in our hospices feel they are always treated with respect and dignity by staff.

98% of service users in our hospices rate overall care as excellent or good.
2.9 Indicators for quality

Community, home care and supported living services 2018–19.

I look forward to the carers coming in and we have a laugh and fun.

The girls are extremely supportive, nice to have only a few girls on rota so not different people all the time who don’t know me and my family.

I get a really good service everyone is so kind and cheery.

We define a formal complaint as ‘an expression of discontent to which a response is required’. With reference to our complaints policy, the complaint is considered formal when it is received orally, in writing or electronically and cannot be resolved within 24 hours of receipt.

There were 16 formal complaints about care during 2018–2019.

The target in the complaints policy for the initial holding response to complaints is three working days. Where the complaint was initially received by a service, and where the complaint was by a named complainant, 88% were acknowledged within the timescale.

The target in the complaints policy for the final written response to a complaint is 20 working days. However, the policy does acknowledge that in some instances this is not possible. This would usually be where the investigation is complex. In these cases all services aim to maintain contact with the complainant, giving a report of progress and in all cases sending a holding reply within 20 working days. Of those complaints where the complainant requested a formal response, in 12 out of 16 instances the 20 working day target was met. Where the target time was not met, the complainant was in all cases sent a holding letter to explain the delay.

The themes from complaints are very important. They help us to learn and to improve the overall experience for individuals using our services. The number of complaints across all service areas is low, but we have reviewed those received and the following themes have been identified (please note there may be multiple issues in one complaint):

- Communication
- Staff attitudes/behaviours
- Care quality

All complaints are raised within local Quality Improvement Groups at individual services. Feedback and learning to the local teams regarding improvement measures is monitored locally.

<table>
<thead>
<tr>
<th>Complaints</th>
<th>Upheld</th>
<th>Not Upheld</th>
<th>Partially upheld</th>
<th>Ongoing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>16</td>
<td>5</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>%</td>
<td>31%</td>
<td>38%</td>
<td>25%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Formal complaints about care 2018–19.

<table>
<thead>
<tr>
<th></th>
<th>Complaints</th>
<th>Acknowledged 3 days</th>
<th>%</th>
<th>Responded 20 days</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurological</td>
<td>7</td>
<td>7</td>
<td>100%</td>
<td>7</td>
<td>100%</td>
</tr>
<tr>
<td>Palliative</td>
<td>8</td>
<td>6</td>
<td>75%</td>
<td>5</td>
<td>63%</td>
</tr>
<tr>
<td>Home Care</td>
<td>1</td>
<td>1</td>
<td>100%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>14</td>
<td>88%</td>
<td>12</td>
<td>75%</td>
</tr>
</tbody>
</table>

99% of service users in our Scottish Homecare services agreed or strongly agreed that they are respected and treated with dignity as an individual.

86% of service users in our Scottish Homecare services are likely or extremely likely to recommend our service to friends and family if they needed similar care.
3.1 Hazel and David’s story

In April, I was diagnosed with vascular dementia. I was very concerned that David wouldn’t be able to cope as my cognitive functions became impaired or to do the things I do in the home.

My GP suggested a referral to Dementia Together [which is a unique service based at The Chantry] and we felt hopeful that the service would be able to help.

When we first met Lisa, our Dementia Navigator, she spent the time to explain my condition so we could understand what lay ahead for me in the future. Lisa supported David in understanding what to look for when I may have mini-stroke episodes and this has helped him feel less anxious.

Lisa works with David to show him how to support me, explained how important our physical and mental wellbeing is for both of us and help him to be aware of his own feelings.

Lisa also advised us of the importance of having the practical and legal bits sorted out now. She helped to plan for the future including our Lasting Powers of Attorney and looking at local residential care homes.

We have been given information on other services and peer support that is available when we feel the time is right.

Lisa has given us the confidence to cope with any situation we find ourselves in and knowing that there will always be help and advice when it is needed has taken a load off our minds.

Knowledge has taken away a lot of the anxiety that we felt.

3.2 Siobhan’s story

Here Siobhan, the wife of Colin Jacobs, thanks us for all the care her late husband received at Stagenhoe in a letter she titled ‘The wonderful care of the late Colin Jacobs.’

The work you do is amazing, friendly, caring and professional. Every member going the extra mile, truly wonderful, a special team.

Never underestimate the outstanding work you all do and the impact you have on people’s lives.
3.3 Ray’s story

In September 2018, Ray sustained a severe head injury following a quad bike accident. He fell into a coma for almost nine weeks and his family were told there was little hope of him making a full recovery.

Ray was moved from the Critical Care Unit as his injury improved, but in order to progress he needed more comprehensive therapy. That was when he was referred to The Chantry for post-acute neurological rehabilitation.

Following an assessment, Ray was funded to receive daily therapy to include physiotherapy, occupational therapy and speech and language therapy over a period of eight weeks. When Ray was admitted to The Chantry, he was walking with a frame and two people and could only manage around five metres before needing support. His goals were to be able to walk independently, and regain independence to get ready in the morning, be able to cook meals at home and return to work and driving.

During his stay at The Chantry, he made such good progress that he fulfilled his therapy goals in just five weeks. Within a few days of returning home, with support from the Community Therapist Service Ray was able to walk and use the stairs unaided and returned to work running his own business.

Despite his treatment at The Chantry being complete, Ray maintains strong links with the centre due to the positive experience and the strong relationships he formed with staff members.

3.4 Five year strategy: Year one

Here’s what we achieved in the first year of our strategy to improve quality

Improving access to our care; expanding our community services:
- The pilot of the South Oxfordshire Palliative Care Hub, combining Hospice at Home services, community nursing and telephone support and advice, launched in April 2018.
- We’ve received two sources of trust funding to expand our Hospice at Home services in Gloucestershire and Cambridgeshire. As of May 2019 we’re currently recruiting to these services.

Improving the care environment; developing our buildings:
- We have begun construction of the Sue Ryder Neurological Care Centre – Lancashire. The new centre, with 40 rooms and four supported living apartments, will provide more care for more people.

Sue Ryder The Chantry is providing a new 12 week rehabilitative therapy service from three new rooms built in 2018–19. The service aims to help patients live independent lives or move them to the next stage of their recovery. Three additional beds will now be converted to offer further post-acute rehabilitation.

We’ve agreed new leases for our Northampton warehouse and an adjacent site in order to serve our expanding online retail teams and operations.

Improving access to bereavement support; growing our online support:
- We’ve exceeded our targets for the growth of the Online Community and piloted online bereavement counselling via video. Feedback from our counsellors and people using the service has been very positive.

Some of our most regular online community users are now supporting us as Online Community Champions – helping us to monitor conversations, provide support and advice and signpost others to further support.
3.5 Five year strategy: Year one (continued)

Improving the skills and knowledge of our staff; investing in education and development:
- We’ve rolled out e-learning to all colleagues and are now looking at ways to widen access to the system for our volunteers.
- We designed a leadership development programme structure and the first module of our management development programme on recruitment and selection was developed and is now being delivered. More modules for this audience are due to come online in 2019–20.
- We’ve grown apprenticeship opportunities within Sue Ryder and will be looking to provide more throughout the organisation in 2019–20.

Heidi Travis, CEO, with leaders at Sue Ryder and the build team.
3.6 Quality driven by research

Why do we need research?
Our research activity aims to support discovery and implementation of the best possible care for our patients and service users. It helps us determine which interventions and care models are best clinically and which are most cost effective. It also gives us the evidence we need to support necessary change.

As an established and respected provider of excellence in palliative and neurological care, Sue Ryder continues in its ambition to become an influential member of the wider palliative and neurological research communities. We have made strides in achieving this through actively seeking and establishing mutually supportive partnerships with our research peers, including universities and other academic institutions, the NHS, other hospices, fellow charities and the National Institute of Health Research Clinical Research Networks (NIHR CRNs). We also participate in nationwide palliative care research stakeholder consultations and have formally joined the NIHR Consortium.

We are working collectively within the organisation to embed an inclusive, well informed research culture that creates enthusiastic, research-aware staff, volunteers and service users that ultimately turns research into core business. Research working groups within palliative and neurological care are taking shape and are creating forums for generating research ideas, sharing knowledge and expertise and championing research as a core activity across Sue Ryder.

The Research Lead, along with a Research Governance Group made up of representatives from across Sue Ryder, provides expert oversight of all research activity within Sue Ryder. This ensures that our research governance is robust and meets the necessary legal, ethical and regulatory requirements that safeguard the rights, dignity and well-being of all research participants.

Research activity 2018–19

**SIP Study: Exploratory study of behaviours of patients who take their strong opioids as unmeasured sips.** This is a prospective, observational study wherein patients or relatives/carers are trained to use a simple scale to measure the mass of a bottle of the opioid before and after 2 doses of breakthrough strong opioid has been taken in unmeasured sips. Sue Ryder is working in partnership with Gloucestershire Hospital NHS Foundation Trust.

**OPEL: Optimum Hospice at Home (H@H) Services for End of Life Care, Phase 2 (Phase 1 now complete).** A 3-year mixed methods study exploring H@H care models including their impact on patient and carer outcomes; the costs and resource implications of patient care in different H@H models; experiences of patients, family carers, providers and commissioners; enablers and barriers to embedding H@H models. Sue Ryder is collaborating with the University of Kent for this research project.

**CARIAD Study:** This study aims to review the feasibility of carer-administration of as-needed subcutaneous medication for breakthrough symptoms in home-based dying patients within the UK. Participants are randomly allocated to either the ‘usual care’ or ‘new care’ group. Carers in the ‘usual care’ group are asked to call a HCP if their loved one has breakthrough symptoms. Carers in the ‘new care’ group are given training to recognise symptoms, give injections and then see if they work to relieve the symptom. They are invited to talk about how they found the study and the experience of giving injections. This study is being co-ordinated by Bangor University.

**MePFAC:** The aim of this study is to estimate the clinical effectiveness of methylphenidate versus placebo for cancer-related fatigue in patients receiving specialist palliative care. This is a prospective, randomised, double-blind, placebo-controlled trial. This study is being led by UCL.

**Leeds Cancer Pain Assessment Study:** The aim of this study is to feasibility test procedures for undertaking a simple pain assessment and a quantitative sensory testing (QST) assessment in a sample of patients with cancer pain. This study is led by the University of Leeds.

**STOIC:** This is an observational study investigating the diagnostic criteria and clinical features of opioid induced constipation in patients with cancer pain. Participants can be inpatients, outpatients, at day hospice or cared for at home. The study is being co-ordinated by the Royal Surrey County Hospital NHS Foundation Trust.

**Accessing medicines at end-of-life: a multi-stakeholder, mixed method evaluation of service provision (ActMed):** This study evaluates patient and carer access to medicines at end-of-life within the context of models of service delivery. Patients and carers (where applicable) will take part in face to face semi structured interviews at baseline and shorter interviews at week 4 and week 8. This research is being led by the University of Southampton.

**Physical activity research**

**Dementia Together Evaluation:** This evaluation aims to evaluate the outcomes of the Suffolk Dementia Together service. Sue Ryder will be working in partnership with Norfolk and Suffolk Dementia Alliance, Purple Tuesday and the University of Suffolk to offer a single point of contact for people curious or concerned about dementia, so that people only have to tell their story once. The evaluation study adopts a mixed methods approach which draws on both qualitative and quantitative frameworks to meet the aims of the evaluation. It adopts the underlying principles of highly appropriate evaluation and research methodological approaches.

**What Matters To Me Evaluation:** To explore the impact of a training programme on practitioners’ knowledge of and confidence in the use of human rights in their end of life care practice. We have also commissioned a review by the University of Birmingham to examine the literature in this field.
Annexe 1: Feedback received from our Clinical Commissioning Groups (CCGs)

Every year we share our draft National Quality Account with our service users and the local Clinical Commissioning Groups for all our services asking for their feedback and areas for improvement. We would like to share their feedback with you.

We are really grateful for the feedback we have received which is summarised below.

The feedback supports a focus on mental health and dementia awareness.

Our commitment to embedding person centred care and a quality improvement approach was well received.

The style and flow of the document and the inclusion of examples of the positive work provided by Sue Ryder services was congratulated.

There was recognition that the use of digital innovation within Sue Ryder services is in line with wider health and social care strategy, particularly that which enables people to remain independent for as long as possible.

We were asked if the quality priorities for 2019–20 apply to community settings as well as in-patient services. We were asked to provide more detail about how we will measure the outcome of dementia and mental health awareness training.

Our response to the feedback we received:

We are pleased to confirm that the priorities we have presented to improve quality, apply across all of our services, whether that be within a centre or in the community.

We will ensure that training evaluation compares staff confidence, knowledge and awareness before and after training. We will also seek feedback from our service users (or their representatives) to learn if the training has been effective.

We are really pleased to receive such positive feedback and would like to thank our commissioners for sharing their views.

Sarah Gigg
Director of Nursing

Annexe 2: Service user feedback

Feedback from a resident at Stagenhoe Neurological Centre:

My thoughts are that it is very much written from a ‘management’ point of view. So I think it may go over the heads of a lot of people. Also I am disappointed that reducing the carbon, I was disappointed that nothing was written to do about us facing the climate emergency footprint of Sue Ryder and reducing the waste and encouraging recycling.

Alex Longmore
Resident at Stagenhoe Neurological Centre

Our response to the feedback we received:

Thank you Alex for your valuable feedback and we will incorporate this into next year’s Quality Account. With regard to your comments around recycling and climate, environmental sustainability is very important to us and we will respond to you individually regarding this.

Jane Turner
Deputy Director of Nursing

Feedback from our service users from the Bereavement drop in group at Manorlands Hospice:

We are happy and agree with all the priorities listed, but our order of interest is as follows: Priority 3, Priority 4, Priority 1, Priority 2 and Priority 5. The priorities for 2019–2020 covers a wide range of interesting and valuable topics. It would be good if we could look at a list of complaints to see if a particular condition/complaint is covered.

Priority 5 is vital for staff well-being. The drop-in service and the Bereavement group is an incredibly beneficial service. It provides such a great support for family members after losing a loved one and creating a valuable environment which enables the confidence to talk to others in the same situation.

Teamwork is also important to improve the standards, as well as monitoring the issue. The drive for improvements continues to drive the developments of all services. This is essential and applies to all areas – particularly with regards to all types of care.

Training needs to be targeted to ensure effectiveness – ensuring high quality of trainers, which is vital.

Overall, Sue Ryder Manorlands already provides excellent services and it is always good to move forward – keep up the good work.

Our response to the feedback we received:

We are grateful to you all at the Bereavement drop in group at Manorlands Hospice for your valuable feedback. We are unable to share the details of specific complaints, however we can talk through themes, and will respond to you regarding this.

Jane Turner
Deputy Director of Nursing
Annexe 3: Final statement

This final statement provides assurance that Sue Ryder has fulfilled the legal requirements set out under the Health Act 2009 and the National Health Service (Quality Accounts) Regulations.

Sue Ryder are required under the Health Act 2009 and the National Health Service (Quality Accounts) Regulations to prepare Quality Accounts for each financial year. In preparing the Quality Account, we are required to take steps to satisfy ourselves that:

• The content of the Quality Account meets the requirements set out NHS Improvement and supporting guidance 2018–19.

• The content of the Quality Account is not inconsistent with internal and external sources of information including – relevant committee minutes and papers for the period April 2018 to March 2019 – papers relating to quality reported over the period April 2018 to March 2019 – feedback from commissioners.

• The Quality Account presents a balanced picture of Sue Ryder’s performance over the period covered.

• The performance information reported in the Quality Account is reliable and accurate.

• There are proper internal controls over the collection and reporting of the measures of performance included in the Quality Account, and these controls are subject to review to confirm that they are working effectively in practice.

• The data underpinning the measures of performance reported in the Quality Account is robust and reliable, conforms to specified data quality standards and prescribed definitions, is subject to appropriate scrutiny and review.

• The Quality Account has been prepared in accordance with the Quality Accounts regulations.

The Quality Account was approved by Trustees at the Health and Social Care Sub-committee on 26 June 2019.

Neil Goulden
Chairman of Trustees
26/06/2019

Heidi Travis
Chief Executive
26/06/2019
We’re there when it matters

Sue Ryder supports people through the most difficult times of their lives. For over 65 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can.

We take the time to understand what’s important to people and give them choice and control over their care. This might be providing care for someone at the end of their life, in our hospices or at home. Or helping someone manage their grief when they’ve lost a loved one. Or providing specialist care, rehabilitation or support to someone with a neurological condition.

We want to provide more care for more people when it really matters. We see a future where our palliative and neurological care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

For more information about Sue Ryder

call: 0808 164 4572
email: healthandsocialcare@suer Ryder.org
visit: www.suer Ryder.org

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This document is available in alternative formats on request.