Agenda Item: 7.1.2

End of Life Care Annual Report 2024/25

1. Executive summary

- There was a total of 194 deaths at Royal Papworth Hospital (RPH) from April 2024 to March 2025 with most deaths occurring on Critical Care in the context of withdrawal of life-sustaining treatment.

- The NCEPOD report 2024; 'Planning for End' contains recommendations on improving end of life care, which are detailed below. In particular, we should note the recommendation for basic care of the dying patient to be included in mandatory training.

- The Chaplaincy team has intentionally increased their presence on the wards, including CCA, which has led to an increase in the number of people they have been able to support.

- The Medical Examiner's role became statutory in 2024, with consequent changes in processes regarding issuing the MCCD and cremation forms.

- There were 17 incidents relating to end of life in this time period and 11 relating to ReSPECT forms; issues around ReSPECT and DNACPR decisions and communication were the main themes reported. There have been 6 patient complaints specifically about End of Life care within this year, with communication being a significant theme here too.

- Education continues to be a priority focus for SPCT. We were fortunate to receive funding via the ATIR (Authority to Invest request) pathway for a new band 7 (1.0 WTE) nurse. Stephen Parish was successfully appointed in August. The new role will comprise of 50% time on education 50% clinical/line management alongside existing band 7. His previous post in the team has been successfully recruited from within the trust.

2. Purpose

This paper presents an annual report on End of Life care at Royal Papworth Hospital, covering the time period from April 2024 to March 2025. The purpose of this report is to outline areas of good practice and improvement work undertaken by teams across the Trust.

3. Introduction

End of Life care is defined by NHS England as 'care in the last year of life' (https://www.england.nhs.uk/eolc/). Caring for those in the last year of their life will include holistic assessment and management of their needs, advance care planning, care in the last days of life and bereavement support. According to NICE guidance (NG142), those who may be in their last year of life include people with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are at increased risk of dying within the next 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

These criteria could refer to many of the patients we care for here at Royal Papworth Hospital NHS Foundation Trust and therefore our goal is that all staff here are equipped and prepared to care for people as they approach the end of their life.

Royal Papworth Hospital operates at the cutting edge of medicine, providing outstanding care to people from all over the UK. Many people have their lives transformed by interventions and care from this trust. However, this cannot always be the case and it is our ambition that when people die here, they continue to have the same outstanding care.

4. National picture

The national End of Life care Strategy was written in 2008 and has not been updated since. Its key areas for action were raising the profile of end-of-life care, strategic commissioning, identifying people approaching the end of life, care planning, coordination of care, rapid access to care, delivery of high quality services in all locations, care in the last days of life, involving and supporting carers, education and training, measurement and research and funding.

Marie Curie published a report on end-of-life care in 2024 which shows that there are still significant problems in all key areas from the 2008 national strategy and states

that ‘whilst the number of people who need palliative and end of life care is increasing steeply, our health and care system is already struggling to meet that demand’. This was backed up by the NCEPOD report from 2024 called ‘Planning for the End’, which I have detailed below.

In addition, a private member’s bill to make assisted suicide legal in England and Wales passed its first reading in Parliament in October 2024 and is due for its second reading soon. If this becomes law, it will fundamentally change the nature of palliative and end of life care in this country in ways which are as yet unclear.

5. Local picture

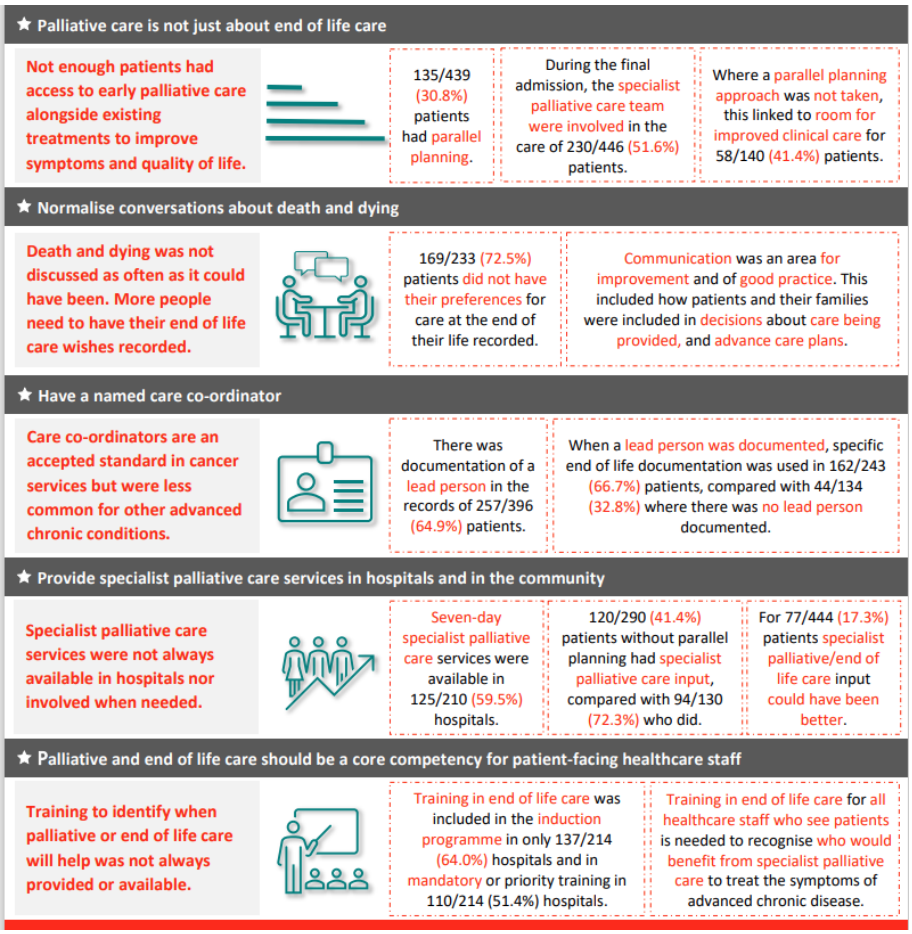
Royal Papworth hospital is an internationally renowned cardiothoracic hospital, which provides cutting edge care and surgery for patients across the UK. When compared with other more generalist hospitals, we have low numbers of deaths, particularly expected deaths. We know from our audit data that wards will only care for a small number of dying patients each year, which means that it is difficult for staff members to maintain their competence and confidence in caring for the dying patient. Caring for the dying has many facets, including excellent symptom control, emotional support for the patient and those around them, cultural and religious support and the importance of considering nutrition and hydration. This care does not end with the patient’s death – there needs to be excellent care after death for both the patient and those who love them.

It is therefore vital that we have ward staff who are able to provide this excellent care, which means an extensive programme of teaching and training. It is also vital that we have support services in place, such as the Supportive and Palliative Care team, the Chaplaincy team and the PALS team who will help and support the bereaved – this report is a summary of all such activity from 2024/25.

6. NCEOPD Report

In 2024, the National Confidential Enquiry into Patient Outcomes and Death (NCEPOD) published a report called ‘Planning for the End’, which is a review of the quality of care provided to adult patients towards the end of life. It is worth noting the main recommendations and their relevance to RPH.

The enquiry reviewed adult deaths in hospital, or within 6 months of discharge, of patients with lung cancer, liver disease, heart failure and dementia. They gathered demographic data on all deaths (16657, of which 9373 were in hospital and 7284 were at home), asked clinicians in hospitals to review 8 sets of case notes randomly selected per participating centre (701 patients) and peer reviewed in depth 350 of these, which were biased towards patients who had had hospital contact in the 6 months prior to their death. The infographic summary of notes is shown below:



Recommendations and relevance to RPH:

1. Ensure that patients with advanced chronic disease have access to palliative care alongside disease modifying treatment.
   - SPCT to consider offering palliative care review routinely to more patients e.g. those patients receiving VV ECMO support.
2. Normalise conversations about advance care plans, death and dying, including improving recognition of deterioration and dying.
   - SPCT to work with individual teams to consider trigger tools for SPCT referral.
3. Named care co-ordinator for all with advanced chronic disease
   - This is already standard practice for most teams here at RPH.

4. Provide specialist palliative care services in hospitals
    - Good SPCT nursing staffing levels now.
5. Train patient-facing healthcare staff in palliative and end of life care.
    - Aim to include palliative and end of life care training in mandatory training and induction.
6. Share existing advance care plans between all providers involved
    - Work in progress at ICS level.
7. Raise public awareness of LPAs
    - National/ICS level work, more relevant for patients with dementia than most of RPH patients.

7. Deaths by location

In the year from 1st April 2024 to 31st March 2025, there were 194 deaths in Royal Papworth Hospital.

Table 1 – Deaths by location 2021 to 2025

	2021/22	**2022/23**	**2023/24**	**2024/25**
Critical care	109 = 60%	126 = 62%	129 = 66%	**115 = 59%**
Ward	55 = 30%	58 = 29%	45 = 23%	**58 = 30%**
Cath lab	8 = 4%	13 = 6%	9 = 5%	**3 = 2%**
Theatre	10 = 6%	6 = 3%	11 = 6%	**18 = 9%**
Total	182	203	194	**194**

8. Services

8.1 Supportive and Palliative Care team

The Supportive and Palliative Care team (SPCT) inevitably and appropriately leads on much of the work supporting end of life care in the trust. The team is led by a Consultant in Palliative Medicine, who is based at Arthur Rank Hospice in Cambridge and attends RPH for 3 sessions each week, funded by a Service Level Agreement.

The rest of the team is made up of two Band 7 Clinical Nurse Specialists (1.8 WTE) and four Band 6 Clinical Nurse Specialists (3.01 WTE). One Band 7 CNS leads the nursing team and acts as line manager for three of the Band 6 CNSs. The other Band 7 CNS line manages one of the Band 6 CNSs and leads in Education for the team, with a 50% education component to their role.
There are two resident doctors in rotating posts – a Specialist Registrar in Palliative Medicine (0.4 WTE) and an FY1 (1 WTE) as well as a team secretary (0.64 WTE).

The team provides:

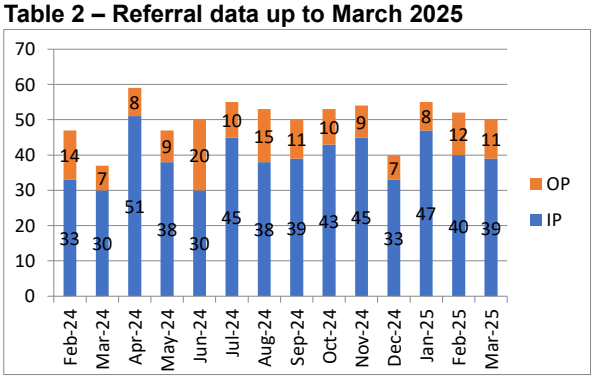
1. A 7-day face to face hospital liaison service, where patients are referred by the treating team. SPCT undertakes a holistic assessment of each patient, assessing their physical, emotional, social (including financial) and spiritual needs. The team provides advanced symptom control, emotional support for patients and their carers, future care planning, specialist discharge planning and care in the last days of life. The team refers and signposts to other services, e.g. chaplaincy, as appropriate.
2. A rolling programme of education, seeking to ensure that all staff in the trust are equipped and empowered to prevent excellent care at the end of life.
3. Provision of complementary therapy – three of the CNS team are qualified in acupuncture and two are qualified in reflexology.
4. Leadership on quality improvement activity in end-of-life care, including a programme of annual audits.
5. Out of hours consultant palliative medicine on call rota, which is staffed by the consultants from Cambridge University Hospital (CUH) and Arthur Rank Hospice and which is available to provide advice for clinical staff at RPH, CUH, Arthur Rank Hospice and in the Cambridgeshire community area.

There are workforce challenges for the doctors in SPCT. There are difficulties recruiting to palliative medicine trainee roles in the East of England deanery and we may be without a specialist trainee from September 2025 for at least a year. This is particularly a problem for the lone consultant, whose workload will then effectively double. The current guidance on staffing from RCP and the APM suggests that hospitals should have one whole time equivalent palliative medicine consultant per 250 beds. Here at RPH, we have 0.3 WTE for 300 beds, which is significantly under the recommendation and we will consider an application for more consultant hours in future years.

SPCT Referral data

Inpatient referrals are higher than outpatient referrals as illustrated in Table 2.

Table 2 – Referral data up to March 2025



Numbers of referral by month

SPCT Response times

All urgent patient referrals are seen within 24 hours and all patients are seen within priority timeframe as reported in Table 3.

The total number of patient referrals is largely consistent each quarter with exception of an increase in annual number of referrals from 549 in 2023/24 up to 617 in 2024/25.

Table 3 – Response times for patient referrals April 2023 to March 2024

	Total number of referrals	Number of urgent referrals	Percentage of urgent referrals seen with 24 hours	Percentage of total referrals seen within 24 hours	Percentage of referrals seen within priority time frame
April to June 24	156	10	100%	92%	100%
July to Sept 24	158	20	100%	88%	100%
Oct to Dec 24	147	18	100%	96%	100%
Jan to Mar 25	156	10	100%	92%	100%
Total	617				

Supportive and Palliative Care Team Objectives for 2025

Education

1. Review and develop our offer on Learnzone.
2. Investigate possibility of being included at hospital induction training.
3. Aim to include care of dying patient in mandatory training.
4. Revitalise EOLC champions role.
5. RPH advanced communication skills course.
6. Peer-learning collaboration with ARHC.

Audit

1. NACEL - monthly.
2. Last days of life –annually.
3. Syringe pump – annually.
4. Satisfaction survey – annually.
5. Complementary therapies – biennially.
6. Discharge summaries – new.
7. Transplant patients review of input – one-off.

Clinical

1. Develop tools to prompt referral to palliative care for difference service areas.
2. More palliative care access - VV ECMO patients.

3. Improve complementary therapy skills within team.
4. IPOS (outcome measures).
5. Dying matters week.
6. VR project.
7. Consider applying for more consultant hours.
8. Continue to develop links with Harefield.
9. Revitalise breathlessness clinic.
10. Consider possibility of complementary therapy clinic.

Research

1. Poster for national conference – review of transplant patient input.

Usual audit programme:

Audit	Most recent audit	Re-audit due
Care in Last days of life	July – December 2024	July 2025
NACEL	Continuous	Continuous
Satisfaction survey	June 2024	June 2025
Syringe pump use	July – Dec 2024	July 2025
Acupuncture	Feb 20	Jan 2025

6.2 Chaplaincy

Chaplaincy support is led by a Hospital Chaplain provided by Cambridge University Hospitals NHS Foundation Trust via a Service Level Agreement, with support from volunteers. They provide spiritual, religious, and pastoral care to anyone who wants this – people of any faiths or of no faith. The Chaplaincy service also provides support to relatives and staff as well as patients.

This year Chaplaincy has continued to support the Royal Papworth Hospital with a Chaplain on site each weekday, with on call provision available out of hours. In addition, five Chaplaincy volunteers each support a ward / area once a week under the guidance of the Chaplain. There has been an intentional increase in presence on CCA where a Chaplain visits most days. This has been the area most likely to contact the team for end-of-life support and the increased presence has enabled awareness of situations sooner than may have been the case previously.

Chaplaincy very much values working alongside other teams in the hospital and appreciates a positive relationship with the Supportive and Palliative Care Team, PALS and Psychological Services amongst others. With an increased presence throughout the hospital, ward staff are more aware of the Chaplaincy support that is available and offer the service to patients and their families. Much of the support requested in end-of-life situations involves religious support. This includes prayer, anointing, blessings and accessing support from a variety of faith leaders to support the individual needs. There are fewer requests for those without a faith background and the team is keen to emphasise that support is available for anyone experiencing distress, whether there is a religious need or not.

Sadly, there have been deaths of members of hospital staff this year. At these times, Chaplaincy have been involved in supporting colleagues, creating opportunities for remembrance in the Chapel space and leading services of remembrance for the hospital community.

6.3 Patient Advice and Liaison Service (PALS) – bereavement support

It is recognised that a death causes a very distressing and confusing time for family members and loved ones. The Patient Advice and Liaison Service (PALS) team ensure bereaved families are treated with dignity and respect, acting as a point-of-contact, and guiding them through the bereavement process.

The PALS team consists of a supervisor, an advisor and an administrator and their office hours are Monday to Thursday 09:00 – 16:00, with a close time of 3:30pm on a Friday.

As of 09 September 2024, the Medical Examiners process became statutory nationwide. Royal Papworth were already operating under these arrangements, however the national implementation brought with it a few changes. The most notable of these were changes to the MCCD and the extension of detail required, in addition to the abolition of the CF4 Cremation form. Our continued collaboration with the Medical Examiner Officer team has meant the transition has been seamless and disruption has been minimal.

The ‘Recently Bereaved’ leaflet is being updated to reflect the changes, the PALS Bereavement SOP’s have been reviewed (and updated where necessary) and the PALS Advisor role has been developed to merge with the Medical Examiner’s team. The PALS team continue to work closely with our ward clerks, medical examiners, medical examiner officers and in addition the mortuary team at CUH.

As of November 2024, there was a creation of a hybrid role and the “PALS Advisor” is now the “Bereavement and PALS Advisor”. This has increased the collaboration between the PALS team and the Medical examiner’s office, allowing for smoother working on RPH bereavement cases. Whilst still in its infancy, this way of working has shown positive early indications. This role now encompasses all aspects of the bereavement process. As part of this, the Bereavement and PALS Advisor also works as a Medical Examiners Officer for 16 hours a week. PALS still have oversight of the Bereavement process and assist with any aspects of this should the Advisor not be available.

The first call to the family or next-of-kin (after they are informed of the death by the medical team) is made by the PALS / MEO team and this usually includes discussing the role of the Medical Examiners Office, identifying any major concerns of the family, the potential for involvement of the Coroner’s office, advice on contacting Funeral Directors and providing details on registering the death. Additional information such as reuniting loved ones with the property of the deceased or arranging a viewing with the Mortuary are also regularly advised upon and supported with. The team will liaise with the medical team to ensure that the MCCD is

completed in a timely manner and sent to the Medical Examiners office for verification before being sent electronically to the Registrars along with the Mortuary team, enabling the deceased to be taken into the care of the Funeral Director. On occasion, there will be people who need PALS to provide assistance with payment of a funeral. This is arranged with the assistance of the Hardship fund, and, as standard, the proceeding will be attended by a representative of the PALS team.

The PALS team also offer Bereaved families the opportunity for a “Bereavement follow-up” meeting. This is an opportunity for them to meet with the medical team who took care of their loved ones and allows them the opportunity to discuss themedical journey, asking any questions to allow them to understand what happened during the patient’s stay at Royal Papworth. These letters are usually sent around 6-8 weeks following the death of a patient.

6.4 Safeguarding and Social work team
The Social Workers within this team may have a role to play in end-of life care by providing safeguarding advice regarding Adults at Risk and children, as well as providing specialist social work advice and support to patients and their families. They are available Monday – Friday from 8.00-4pm. They also ensure appropriate support for patients with Learning Disabilities and their families ensuring that reasonable adjustments are made for them.

The Safeguarding Lead may offer advice to clinicians completing a” child death review panel notification” when a child dies.

LeDeR (Learning from Lives and Deaths) is a national service improvement programme commissioned by NHS England where the death of every adult with a learning disability and autistic people is reviewed. We have a responsibility to report such deaths, although anyone can do so by following the process in the “DN864 Information for Staff following a death at RPH”

6.5 Discharge planning team
The Discharge planning team may be involved in planning discharges for patients who are dying, though this is more likely to be led by the ward team and/or SPCT

6.6 Occupational Therapy
The OT team are vital in assisting with discharges, mainly in the area of equipment provision. People who are likely to deteriorate and die at home will need specialist equipment such as a hospital bed. They and the physiotherapy team may also be involved in helping with symptom control for patients, e.g. application of TENS machine, breathlessness and fatigue management and distraction techniques.

6.7 Psychological support services.
Psychological medicine services may also play an important role in end-of-life care when there is concern that a person’s mental health is having a significant impact on their condition. This is particularly true for patients who already have an established therapeutic relationship with psychological medicine services, who offer mental

health pathways for inpatients, cystic fibrosis, organ transplant, and adult congenital heart disease within the hospital.

7. Discharge planning

SPCT tend to lead on planning discharge for patients who are rapidly deteriorating and thought to be appropriate for fast-track Continuing Healthcare funding.
As RPH has such a wide geographical reach, this involves liaising with many different Integrated Care Systems, all of which have different paperwork. A patient who is being discharged home for end-of-life care will usually also need close liaison with their GP and community nursing team, provision of anticipatory injectable medication and a corresponding local Medicines Administration Record chart, equipment such as a hospital bed and commode and referral to their local community palliative care team. SPCT coordinates all of this.

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8. Education

Education within Palliative and End of Life Care will be receiving a renewed focus moving forward following the appointment of a new CNS with 0.5 WTE dedicated to education. We have conducted a training needs analysis for palliative care education in the trust, which included a survey of staff to assess confidence in skills. Following this analysis, we are working on an education strategy.

KPI's have been developed as follows:

1) Measurement of staff confidence in providing care at the end of life.
2) Has Palliative education improved user experience?
3) Percentage or staff number receiving some sort of palliative care education or training in the previous year.

Plan and goals for education in the upcoming year are as per the SPCT team objectives listed earlier in this report.

Although the ReSPECT process is becoming more widely accepted and used, the need for education is ongoing. A variety of educational resources are available and have been updated. The availability of these has been advertised at a range of fora across the trust in order to capture all operational and clinical staff.

8.1 Learning resources

Here at RPH, we have several essential to role online packages; care of deceased patient, palliative care training and ReSPECT training.

SPCT has reviewed the current e-learning package on Learnzone and established it is infrequently accessed by staff (65 staff members over 4 years). We are reviewing the content of the elearning and exploring how we can increase

the number of staff undertaking this training. SPCT presents at induction of HCSWs and CCA staff.

ReSPECT educational resources and teaching currently available include a learnzone study package, guidance on the ReSPECT intranet page, medical and MDT simulation training sessions and teaching during basic, intermediate and advanced life support courses. ReSPECT is also discussed at student nurse forums and medical staff induction.

8.2 Champions

We use a system of 'Champions' to encourage ward staff and allied healthcare professionals to become local experts and advocates on different issues. We have a network of End of Life care champions, who have regular meetings and updates and a network of ReSPECT champions, who are encouraged to attend ReSPECT steering group and report back on work in their service areas.
There is work ongoing to develop the EOL champions role with an offer of 2 regular study days each year.
Due to the lead resuscitation officer position being vacant for several months at the beginning of 2024, the ReSPECT champions project has not made as much progress as was hoped. However, now that this position has been filled the resuscitation department will focus on developing this project and aim to increase the presence of ReSPECT champions in all areas.

8.3 Study days

SPCT has already planned two study days for the EOL Care Champions – the first will take place in April and be repeated in May 2025 and will have a simulation basis to help embed skills and knowledge. A second study day is to be held at the end of the year. In July 2024, SPCT held their first external study day, called 'Palliative care in the tertiary setting'. It was attended by about 40 people and the feedback was excellent.

Our annual, internal study day open to all staff has been renamed "End of Life Care Core study day", this ran successfully April 2025 with 21 candidates. A second study day will be running later in the year in September with a range of evolving and contemporary issues related to palliative and end of life care. This will be designed to help further knowledge of staff who have already completed the core study day.

8.4 Communication skills

We are planning a RPH communication skills course for November 2025. This planning is in its early stages.

9. Patient feedback

Since January 2024, we have been using the quality survey generated by the National Audit of Care at the end of Life, rather than our own, but had only 3 responses returned over the year. We have decided to return to sending out paper copies of the survey with space for free text responses for people to return to us here at RPH. We will then need to upload the data to the NACEL website, but we are hoping that these changes will generate more feedback.
We have not included any data here as there were only 3 surveys returned.

10. Incidents and Complaints

10.1 Incidents

There were 17 incidents relating to end-of-life care in this year, which is similar to the previous 2 years.

- 6 were regarding ReSPECT or DNACPR decisions.
- 4 were regarding problems with communication.

The remainder of incidents were isolated incidents, with no themes emerging. Thirteen were classed as 'no harm' and four classed as 'low harm'. One incident has resulted in a change in practice in how we manage care after death with a patient dies in the theatre area.

Learning from incidents is shared with service partners attending the End-of-Life Steering Group. It should be noted that there will be overlap with incidents reported via the ReSPECT steering group (see below).

10.2 Complaints

There have been 4 formal complaints and 2 informal complaints about end of life care in this time period. Four of these were about communication issues and two about discharge processes. These have been dealt with through our usual processes, and one has resulted in a significant change in practice regarding supporting loved ones after a patient dies in the theatre area.

11. Audit

11.1 Audit of Care in the Last days of life

Background

We complete an annual audit of care in the last days of life to ensure that we are providing the best possible standards of care to those patients who die here in Royal Papworth Hospital. Our audit standards are based on NICE Quality Standard 'Care of Dying Adults in the Last Days of Life' (QS144).

The full results are included in this report in Appendix 2.

Conclusions

Our demographics remain stable, with a relatively small number of expected deaths on the wards, which means that it is difficult for staff to maintain their competence and confidence in this area of care provision. Our Personalised Care Plan for the Last Days of Life is intended to guide the healthcare professional through the different issues which need to be considered at this stage in someone's life and was used more widely this year. We are making changes to improve its use and will relaunch it when these are complete.

The audit indicates a need for better spiritual and cultural awareness, so we will liaise with Chaplaincy on this issue and will plan to include education on this on our upcoming study day.

The audit indicates a need for training in the ReSPECT process on level 3 wards in particular, so these results will be presented to the ReSPECT steering group.

We continue to see that many of our patients rapidly deteriorate at the very end of their lives, so will continue to teach and train staff across the trust in how to care for people who are dying. The 3 referrals made on the day of death were all in cardiology patients, which suggests we could focus our education on the cardiology wards.

Recommendations

1. Make changes to PCPLDL to indicate that any appropriately trained clinician can complete the first part.
2. Relaunch PCPLDL once changes made.
3. Target care of the dying patient training to cardiology wards.
4. Present these results to ReSPECT steering group.
5. Re-audit 2025.

11.2 Syringe pump audit

Audit of all syringe pumps used between July and December 2024.

	2019 N=10	2020 N=6	2021 N=16	2022 N=12	2023 N=11	**2024 N = 13**
Correct prescription	90%	100%	100%	100%	100%	**100%**
Service history	100%	100%	100%	100%	82%	**100%**
Set-up <2 hours	80%	83%	94%	92%	73%	**92%**
Care plan used	80%	83%	100%	92%	100%	**92%**

This is a slightly larger sample size to last year. The prescribing was accurate in all cases, which is good. Our equipment tracking and servicing system appears to be working well.

Most were set up within 1 hour of the prescription, with only one significant delay due to nursing workload. All the patients had PRN medication prescribed, which could be used as needed pending the syringe pump being started.

Use of the nursing care plan was generally good. All pumps were checked regularly, even if not all within the precise mandated time frame. We will continue to mandate checking at 1 hour and every 4 hours thereafter as we consider this is best practice.

Action plan

- Continue with current programme of visiting wards to teach and update nursing staff, which appears to be working well.
- Re-audit annually to ensure that these standards are maintained.
- We will re-audit this in 2025.

11.3 National Audit of Care at the End of Life (NACEL)

We have participated in this audit annually since 2019, apart from during Covid and 2023 for a reboot, and is an opportunity to benchmark our service against other Trusts. It consists of a case note review, a service level overview, a survey of bereaved relatives and a staff survey. The case note review was changed substantially for 2024, resulting in the auditing of many more deaths than in previous years. This has resulted in a substantial increase in workload for the Supportive and Palliative Care team. However, it has improved our ability to benchmark our data against other services. The only concern is that most of our deaths happen on Critical Care in the context of withdrawal of life-sustaining treatment, which is no longer working, and, as such, it is difficult to audit against the criteria, which are tailored towards expected deaths on the wards. In our internal audits, we audit ward deaths and CCA deaths separately, because they are quite different situations.

The full results of NACEL 2024 are due to be published in summer 2025.

11.4 CCA Care of Dying Audit

This will be repeated in 2025 and is currently a work in progress.

11.5 Other

ReSPECT audit data is contained in section 12.

SPCT carries out a satisfaction survey annually which consists of positive feedback and does not require further elucidation for this report.

12. ReSPECT

ReSPECT stands for ‘recommended summary plan for emergency care and treatment’. This is a process which seeks to support shared decision-making between patients and healthcare professionals. It is under the auspices of the UK Resuscitation Council and the aim is that it will be used nationwide, across all trusts. We have been using ReSPECT here at RPH since 2019 and are seeing a steady increase in its use over time.

The ReSPECT steering group is chaired by Dr Dot Grogono, consultant in Respiratory Medicine, assisted by the Chief Resuscitation Officer and by 3 vice-chairs – Dr Dan Aston, consultant anaesthetist, Mr Jason Ali, consultant cardiothoracic surgeon and Dr Sarah Grove, consultant in Palliative Medicine. The steering group continues to meet quarterly and reports to QRMG. At each meeting there is a discussion of any incidents involving ReSPECT that have been raised, a summary of the rolling audit results, and a focus on one of the divisions (CCA, surgery, transplant, cardiology, respiratory medicine) who will present their report.
A segment at the National ReSPECT Leads Conference entitled 'Introducing ReSPECT in the elective surgical setting' was presented by our surgical division ReSPECT lead, which received very positive feedback from many of the delegates present at the meeting.

12.1 Incidents

During this reporting period, there have been 11 reported incidents. Of these 8 (73%) were graded as ‘No harm’ and the remaining 3 (27%) graded as low harm. The general themes of these incidents relate to patients not having appropriate ReSPECT forms on arrival at RPH or on transfer from RPH and patients having ReSPECT forms that are unclear. The use of ReSPECT forms in the ICU area has also been highlighted and is subject to an ongoing review.
In response to several incidents being reported where patients have been transferred to other hospitals without ReSPECT forms, the requirement for a valid ReSPECT form has been added to the ward nursing transfer checklist to improve our compliance with this.

12.2 Audit summary

ReSPECT forms are audited on a monthly basis by one of the Resuscitation officers checking electronic and patient forms in all clinical inpatient areas. The data are reported quarterly to ReSPECT steering group.
A total of 270 responses were collected between January and December 2024.

- 38% of forms were digital compared with 50% last year.
- No instances of unavailable/missing form (4% in 2023).

- 60% of forms indicated that the patient was ‘Not for CPR’, while 39% indicated ‘For CPR’, which is an increase.
- Only 1% of forms did not have a documented ‘for CPR’ or ‘not for CPR’ on the form. In 2023 there were 2% of forms with this problem.
- The lowest compliance over all four quarters is for the section of the form where clinicians should state details of those people who were involved in the ReSPECT conversations.
- 8% of the forms did not have section 6 completed and therefore do not state if the patient had capacity at the time of completion of the form.
- 10% of forms did not have any details about the clinician who completed it.
- In 9% of cases, staff were not aware that the patient had a ReSPECT form in place. In all cases where staff were unaware of the form, corrective actions were taken, including notifying staff and updating handover sheets

Recommendations

- Feedback of positive findings to clinical staff mean that improvements are being made and this also encourages further engagement in the ReSPECT process.
- Introduction of ReSPECT champions to increase audit capture and advocate ReSPECT to clinicians and patients.
- Encourage further engagement and ongoing learning via forums, mandatory training sessions and LearnZone with a focus on lower compliance areas.
- Target training to doctors; include how to find the form and advice on how to properly complete each section. This will be achieved by the additional training for doctors at induction (see Education above).

12.3 ReSPECT Proposed Objectives for 2025/26:

- Focused education during doctors’ induction.
- Increased frequency of audit reporting to allow rapid identification and correction of any problems
- Further development of ReSPECT champions is likely to continue in 2026.
- Develop RPH Advanced Communications Course.

13. Oversight of End of Life care

End of Life care in the Trust is overseen by the End of Life Care Steering Group. This is chaired by our Deputy Chief Nurse, Jennifer Whisken and the vice-chair is Dr Sarah Grove, Supportive and Palliative Care team consultant and clinical lead. The Steering Group meeting will be considered quorate provided a minimum of 5 members are in attendance: at least one from each of: specialist palliative care; nursing directorate; patient and carers; matrons and the directorates. Nominated deputies may attend in the absence of permanent committee group members.

The group meets quarterly and reports to the Quality and Risk committee.

14. Recommendations

SPCT

Continue teaching and training, particularly:

- Improving engagement from EOLC Champions – by end 2026.
- Communication skills course – by end 2025.
- Working to improve engagement across the trust, ideally by including care of the dying patient in mandatory training – by end 2026.
- Target education on cardiology wards based on audit results – by end 2026.

Continue participating in audit, particularly:

- focus on benchmarking against national NACEL audit results when available – by end 2025.
- Re-do CCA care of dying audit – by end 2025.

Improve access to palliative care, particularly:

- Use of area-specific ‘trigger tool’ to facilitate referral to SPCT – by end 2027.
- Routine offer of SPCT support to patients on VV ECMO – by end 2025.

ReSPECT

- Continued education, particularly in area of communication – by end 2025.
- Increase frequency of auditing and reporting – by end 2025.

Dr Sarah Grove, April 2025.

Appendix 2 Results of Audit of Care in the last days of life.

Audit of Care in the Last Days of Life 2024

Background

We complete an annual audit of care in the last days of life to ensure that we are providing the best possible standards of care to those patients who die here in Royal Papworth Hospital. We also participate in the National Care at the End of Life Audit annually, but this doesn't gather all the same data, so we have continued to collect our own, more detailed data.

Our audit standards are based on NICE Quality Standard 'Care of Dying Adults in the Last Days of Life' (QS144), which in turn is based on the 5 priorities of care outlined in the 'One Chance to Get it Right' document published by the Leadership Alliance for the Care of Dying People in 2014. These are:

- the possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly,
- sensitive communication takes place between staff and the person who is dying and those important to them,
- the dying person, and those identified as important to them, are involved in decisions about treatment and care,
- the people important to the dying person are listened to and their needs are respected,
- care is tailored to the individual and delivered with compassion with an individual care plan in place. This priority includes the fact that a person must be supported to eat and drink as long as they wish to do so, and that their comfort and dignity is prioritised.

In October 2020, we introduced a 'personalised care plan for the last days of life' (PCPLDL) for use in Lorenzo (the trust electronic patient record) which is also based on the guidance above. In November 2023 the format of the daily nursing assessment was adapted further to improve ease of use.
We audit deaths between July and December inclusive each year – we audit only expected deaths on the ward. Deaths in the Critical Care Area are audited separately.

Aims and Objectives

Our aim was to audit all expected deaths that occurred on the wards in Royal Papworth hospital between the months of July 2024 and December 2024 inclusive

and to compare them against our audit standards which are listed below and are based on NICE Guidance (QS144).

Standards

- Appropriate recognition of expected death – 100%
- Did the last phase occur rapidly (within 12 hours)? No standard, for information only
- Effective communication to patient and relative that death likely – 100%
- Daily monitoring of their condition – 100%
- Evidence of discussion about eating and drinking – 100%
- Evidence of discussion specifically about the merits of clinically assisted hydration (CAH) – 100%
- Evidence of daily review of hydration needs – 100%
- Evidence of appropriate anticipatory prescribing – 100%
- Evidence of specific support for families before and after death – 100%
- Record of 'Preferred place of death' (PPOD) – 100%
- If so, was PPOD achieved? No standard, for information only.
- Review of frequency of observations – 100%
- Review of need for routine blood tests – 100%
- Review of regular medication – 100%
- Review of need for oxygen therapy – 100%
- ReSPECT form in place on electronic patient record – 100%
- Appropriate 'as required' (PRN) medication prescribed – 100%
- Evidence of regular mouth care – 100%
- Evidence of regular bowel care – 100%
- Evidence of regular bladder care – 100%
- Evidence of regular review of personal hygiene needs – 100%
- Evidence of regular review of skin integrity – 100%
- Evidence of review of emotional needs – 100%
- Evidence of review of spiritual/cultural needs – 100%
- Evidence of daily review of symptoms – 100%

We collected information on the ages and diagnoses of the patients and in which clinical area they died.
We also recorded whether the patient had been referred to the hospital Supportive and Palliative Care team (SPCT) and, if so, how long before death, and whether a continuous subcutaneous infusion was needed. These data were collected for information only and therefore there is no standard attached.

Method

We obtained a list of all in-hospital deaths between July 2024 and December 2024 from Lorenzo and audited these using an audit tool (appendix 1). We were able to access electronic patient records via Lorenzo. All results were peer reviewed by two members of the Supportive and Palliative care team.

We recorded where the death occurred: whether it was in Critical Care area, a ward or another location. We excluded deaths on the Critical Care Unit as these are being separately audited. We then assessed from the notes whether this death should have been expected by the clinicians caring for the patient and then whether the clinical team at the time had recognised that the person was dying. In all cases where death was expected, we went on to assess against all standards.

Sample

The sample was 94 patients who died in Royal Papworth Hospital between 1st July 2024 and 31st December 2024. 54 patients died on the Critical Care Unit (CCU), 27 in ward areas and 13 in other areas.

Location of deaths

	2019	2020/21	2021	2022	2023	2024
Critical care	69 (74%)	71 (65%)	61 (64%)	53 (59%)	60 (64%)	54 (57%)
Ward	14 (15%)	30 (28%)	30 (31%)	28 (31%)	23 (24%)	27 (29%)
Cath lab	6 (6%)	3 (3%)	1 (1%)	6 (7%)	6 (6%)	2 (2%)
Theatre	5 (5%)	4 (4%)	4 (4%)	3 (3%)	5 (5%)	11 (12%)
Total	94	108	96	90	94	94

Results

27 out of the 94 deaths occurred on the general wards and, of these, 18 were assessed as being 'expected'. These were therefore audited against all standards.

The ages of the patients ranged from 52 to 91, with a median age of 79. Nine patients died of cardiac problems (an assortment of MI, aortic dissection, myocardial rupture and valvular disease) and nine of mainly respiratory problems.

	Expected standard	Result 2019 N=10	Result 2020/21 N=19	Result 2021 N=19	Result 2022 N=19	Result 2023 N=15	**Result 2024 N=18**
Recognition of expected death	100%	90%	100%	100%	100%	100%	**100%**
Personalised care plan completed	100%	N/A	31%	58%	53%	40%	**66% 12/18** **Of these 12: 3/18 nurse only 3/18 dr only**
Effective communication	100%	90%	74%	79%	79%	60%	**100%**

of expected death to patient							
Effective communication with carer	100%	N/A	100%	100%	89%	100%	**100%**
Daily monitoring of condition	100%	100%	100%	100%	100%	100%	**100%**
Evidence of discussion about CANH	100%	60%	47%	53%	58%	*Changed – see below*	
Evidence of discussion about eating and drinking						60% both 27% fluid only 13% NA	**89% both** **11% NA**
Evidence of discussion about CAH						33% NA 13%	**83%** **17% NA** **(3/18)**
Evidence of daily review of hydration needs	100%	50%	89%	74%	68%	40%	**83%** **17% NA** **(3/18)**
Evidence of appropriate PRN prescribing	100%	80%	74%	95%	84%	87% (13)	**100%**
Support for families before death	100%	90%	100%	100%	95%	93% (14)	**100%**
Support for families after death by clinical staff	100%	80%	84%	100%	84%	100%	**100%**
Referred to SPCT	No standard	80%	95%	84%	79%	100%	**89%** **(16/18)**

Based on section in PCPLDL for medical team to complete:

	Standard	2020/21 N=19	2021 N=19	2022 N=19	2023 N=15	**2024** **N=18**
PPOD documented	100%	42%	53%	42%	67%	**39%** **(7/18)** **All others unable to leave RPH**
PPOD achieved	No standard	50%	70%	62%	33% (7/15)	**57%** **(4/7)** **3/7 hospice and died before transfer**

Review need for observations	100%	79%	89%	89%	73%	**100%**
Review need for bloods	100%	89%	84%	79%	53%	**100%**
Review medication	100%	100%	89%	74%	80%	**100%**
Review need for O2	100%	79%	89%	58%	40% (	**100%**
ReSPECT form in EPR	100%	79%	42%	63%	67% (10/15) 3/5 just paper 2/5 just alert	**72% (13/18)** **100% had ReSPECT forms** **3/13 paper +alert** **5/18 only paper**

Based on nursing section in PCPLDL:

	Standard	2020/21 N= 19	2021 N=19	2022 N=19	2023 N=15	**2024 N=18**
Regular mouth-care	100%	68%	84%	53%	67%	**78% (14/18)** **4/18 not time**
Bowel care	100%	73%	89%	74%	67%	**78%** **4/18 not time**
Bladder care	100%	89%	89%	84%	67%	**89%** **2/18 not time**
Personal hygiene	100%	79%	89%	74%	67%	**100%**
Skin integrity	100%	89%	89%	74%	67%	**94%** **1/18 not time**
Emotional needs	100%	89%	100%	79%	73%	**100%**
Cultural/spiritual needs	100%	58%	79%	79%	60%	**72%** **2/18 not time**
Regular review of symptoms	100%	100%	100%	89%	73%	**100%**
On CSCI?	No standard	42%	68%	58%	80%	**61%**

Of the 5 patients who didn't have a ReSPECT form alert on the electronic patient record (EPR), four of them were cardiology patients on level 3.

Of the 3 patients who had a ReSPECT form alert as well as a paper form, but did not have a form on the EPR, two of them were cardiology patients on level 3.

Of the 18 expected deaths, in ten of them the last phase occurred rapidly (in under 12 hours). Of these ten deaths, 6 were under cardiology teams and 4 were under respiratory teams.

Discussion

The number of deaths was fairly similar to what we have seen over the last few years. The deaths occurred on 8 different wards, with a range of 1 to 3 deaths on each ward – 3 wards had 1 death, and 5 wards had 3 deaths. Some of these ward areas will work as one large team, but this still illustrates how infrequently staff here are caring for dying patients and therefore how difficult it is to maintain confidence and competence in this area.

Most of the patients (16/18) were known to the Supportive and Palliative Care team and were referred to the team from the day of death up to 13 days before death. There were 3 referrals on the day of death, all of whom were cardiology patients.

The results this year are generally better than the results of last year.

The personalised care plan for the last days of life was used in more patients (12/18), by at least one of the nursing or medical team, if not both. The purpose of this plan is to act as a guide about which issues should be considered and discussed and its use should therefore enhance the care that is given. We have made some recent adjustments to make it easier to use, and to clarify that the first section can be completed by any clinician who knows the patient and who has the authority to lead on decisions about end-of-life care. This will include the Clinical Nurse Specialists of the Supportive and Palliative Care team and should improve our documentation.

Levels of communication remain good, our levels of discussion about food and drink and clinically assisted hydration have improved, basic nursing care was well documented, as were decisions about continuing observations, medication and oxygen.

Preferred place of death was discussed with only 7 of the 18 patients and this was achieved in 4 of these. The other 3 patients who had wanted to be discharged to a hospice died in RPH before they could be transferred but the delay was always waiting for a hospice bed. Preferred place of death was not discussed in 11 patients because they were unable to be transferred out of hospital, so it was not appropriate to offer a choice which did not exist. For this reason, we need to consider whether this audit standard should be 100% for future years.

Most patients (13/18) had an assessment of their spiritual or cultural needs. Two of the five who didn't have this assessment deteriorated very rapidly so we have judged

that there was not time, but this was not the case for the other three patients, so this is an area for improvement.

All patients had a ReSPECT form completed, but not all had evidence of this on their EPR. Whether ReSPECT forms should be paper or electronic or both continues to be a difficult logistical issue to resolve, but there at least needs to be a paper form and an alert to indicate this on the EPR. This seems to be a bigger problem on level 3 wards, which gives us an indication of where to target education.

We continue to see that many of our patients deteriorate very rapidly, with 10 of the 18 having a final phase which lasted less than 12 hours. This emphasises the need for all staff to be equipped to provide excellent care for dying patients.

Conclusion

Our demographics remain stable, with a relatively small number of expected deaths on the wards, which means that it is difficult for staff to maintain their competence and confidence in this area of care provision. Our Personalised Care Plan for the Last Days of Life is intended to guide the healthcare professional through the different issues which need to be considered at this stage in someone's life and was used more widely this year. We are making changes to improve its use and will relaunch it when these are complete.

The audit indicates a need for better spiritual and cultural awareness, so we will liaise with Chaplaincy on this issue and will plan to include education on this on our upcoming study day.

The audit indicates a need for training in the ReSPECT process on level 3 wards in particular, so these results will be presented to the ReSPECT steering group.

We continue to see that many of our patients rapidly deteriorate at the very end of their lives, so will continue to teach and train staff across the trust in how to care for people who are dying. The 3 referrals made on the day of death were all in cardiology patients, which suggests we could focus our education on the cardiology wards.

Recommendations

6. Make changes to PCPLDL to indicate that any appropriately trained clinician can complete the first part.
7. Relaunch PCPLDL once changes made.
8. Target care of the dying patient training to cardiology wards.
9. Present these results to ReSPECT steering group.
10. Re-audit 2025.

Dr Sarah Grove

2nd January 2025