End of Life Care Annual Report 2022/23 and 2023/24

1. Executive summary

- There was a total of 397 deaths at Royal Papworth Hospital (RPH) from April 2022 to March 2024 with most deaths occurring on Critical Care in the context of withdrawal of life-sustaining treatment.

- The Supportive and Palliative Care Team (SPCT) appropriately leads on much of the work supporting end of life care across the Trust. Our goal is for all staff at RPH to be equipped and prepared to care for people as they approach the end of their life. All urgent patient referrals are seen within 24 hours and all patients are seen within priority timeframes. The overall number of patient referrals is relatively consistent each quarter (2022-24).

- The current guidance on staffing from the Royal College of Physicians (RCP) suggests that hospitals should have 1 WTE palliative medicine consultant per 250 beds. RPH has 0.3 WTE for 300 beds which is significantly under recommendation. SPCT have submitted two Authority To Invest Requests for additional medical and nursing resource to meet the palliative care service needs via the Trust operational planning process.

- End of Life care at RPH has a robust audit programme including Care in Last days of Life, NACEL (National Audit Care at End of Life), Bereaved Relatives Survey, Syringe Pump Use and Acupuncture. The Bereaved Relatives Survey was overall reassuring with some improvement noted between 2022 and 2023, but with an ongoing theme that improvement is required in communication skills. A key finding in the Audit of Care in Last Days of Life was that the use of the Personalised Care Plan for the last days of life (PCPLDL) has reduced over the last two years. The SPCT have recommended a relaunch of the PCPLDL with the aim of increasing in its use and documentation on both Lorenzo and Metavision.
  There has been a substantial change to NACEL for 2024 with a requirement to audit at least 20 deaths each quarter at RPH which is a significant increase in workload for the SPCT.

- In 2024 there was an increase in Chaplaincy support offered at RPH and Chaplaincy volunteers were welcomed back. These changes have enabled a significantly increased presence on the wards and have led to a better awareness of patients who are towards the end of life.

- A key milestone of 2023 has been the development and finalisation of a Standard Operating Procedure for the use of the PALS team regarding hospital funerals when there was no designated or discernible next of kin.

- There were 30 incidents relating to end of life over the 2-year period; syringe pumps, ReSPECT decisions and discharge planning were the main themes reported. There have been no patient complaints specifically about End of Life care within the 2-year report timeframe.

- Education continues to be a priority focus for SPCT including development of online learning and End of Life/ ReSPECT Champions, and a programme of two study days each year available for all staff, with the aim of enabling and equipping all staff to provide outstanding care to all dying patients.

2. Purpose

This paper presents a 2-year report on End of Life care at Royal Papworth Hospital, covering the time period from April 2022 to March 2024. The purpose of this report is to outline areas of good practice and improvement work undertaken by teams across the Trust.

3. Introduction

3.1 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.

In the year from 1st April 2022 to 31st March 2023, there were 203 deaths in Royal Papworth Hospital and in the year from 1st April 2023 to 21st March 2024, there were 194 deaths.

3.2 Deaths by location

Most patient deaths have occurred in Critical Care, followed by deaths on ward areas as illustrated in **Table 1** (2021 to 2024).

Table 1 – Deaths by location 2021 to 2024

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

4. Services

4.1 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 team is made up of one Band 7 Clinical Nurse Specialist (0.8 WTE) and four Band 6 Clinical Nurse Specialists (3.01 WTE). The Band 7 CNS leads the nursing team and acts as line manager for the Band 6 CNSs.
There are two junior doctors in rotating posts – a Specialist Registrar in Palliative Medicine (0.4 WTE) and an FY1 (1 WTE) and 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 – two of the CNS team are qualified in acupuncture, with another currently in training and, in addition, one of the CNS team is 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 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,

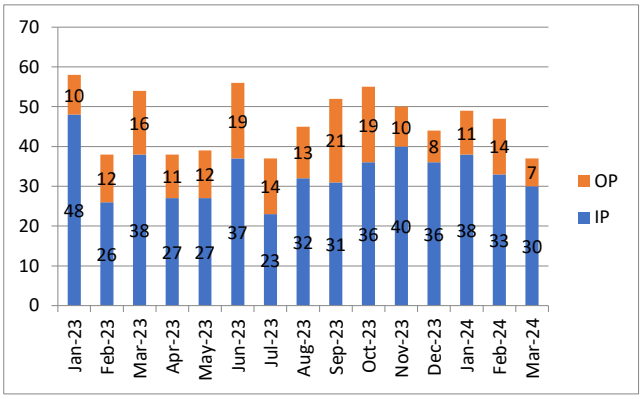
4.2 In the time frame covered by this report, SPCT has started seeing all prospective transplant patients as part of their routine assessment. Work is ongoing to assess the impact of this intervention.

There are workforce challenges for the SPCT. It is a stretch to continue to provide a 7-day face to face CNS service with only 3.89 whole time equivalent nurses. There are difficulties recruiting to palliative medicine trainee roles in the East of England deanery and, whilst we have not been without a trainee yet, this is highly likely to become a problem in the coming years unless recruitment substantially improves. Lack of a specialty trainee is a significant problem for the lone consultant, whose workload would 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. SPCT are currently working on two ATIRs – one for another band 7 CNS with an education focus and one for another 3 consultant sessions.

SPCT Referral data

Inpatient referrals are higher that outpatient referrals as illustrated in **Table 2.**

Table 2 – Referral data January 2023 to March 2024



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 number of referrals from July to September 2023.

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 23	133	22	100%	96%	100%
July to Sept 23	134	16	100%	95%	100%
Oct to Dec 23	149	24	100%	92%	100%
Jan to Mar 24	133	26	100%	96%	100%

Supportive and Palliative Care Team Objectives for 2024

1. Education:

    - Record all new starter talks for use when no one from SPCT is available to deliver teaching in person.
    - Review and develop e-learning package.
    - External study day July 24.
    - Revitalise EOL champions role.
    - Create advanced communication skills course for RPH, in collaboration with Resus team.
    - Start shadow shifts in collaboration with Arthur Rank Hospice.

2. Audit and QI activity

    - Continue with annual programme of audit.
    - Assess effect of our routine assessment of patients being considered for transplant (audit of notes, survey of transplant team).

3. Clinical

    - Offer support routinely to Ataxia-Telangiectasia patients.

- Consider offering support routinely to all ECMO patients.
- Continue up-skilling team, particularly in complementary therapies.
- Participate in Dying Matters week 2024 in order to raise profile in the trust.
- Relaunch Personalised Care plan for Last days of life
- Relaunch CCA relative information leaflet.
- Project involving use of Virtual Reality for inpatients.
- Submit business case for more CNS and consultant hours.

Usual audit programme:

Audit	Most recent audit	Re-audit due
Care in Last days of life	July – December 2023	July 2024
NACEL	June 2022	Ongoing 2024
Satisfaction survey	June 2023	June 2024
Syringe pump use	July – Dec 2023	July 2024
Acupuncture	Feb 20	Jan 2025

4.2 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 is also here to provide support to relatives and staff as well as patients.

This year has seen an increase in Chaplaincy support offered at the Royal Papworth Hospital with the move from a three to a five-day service, with a Chaplain on site each weekday. We have also welcomed back Chaplaincy volunteers and these changes have enabled us to significantly increase our presence on the wards and led to a better awareness of patients who are towards the end of life. Throughout the year we have been focusing on end-of-life care and have been involved in creating excellent hospital-led funeral provision for those without next-of-kin, including leading services at the Crematorium. We have also been involved in offering baptisms to those at the end of life (and their families as requested).
We were grateful to receive a grant from the Papworth Charity which has enabled us to purchase resources such as a memory tree, gift tags and candles. These resources have supported remembrance events in the Chapel space for a long-term patient and a member of staff who had died, along with a space for those affected by baby loss. A Chaplain attends the Trust's End of Life Steering Group and has brought patient stories to this meeting to support continuing excellent patient care. This year we have had two opportunities to teach alongside the Supportive and Palliative Care Team. These sessions have highlighted the wide range of the Chaplaincy role, the needs of patients from different faiths as they approach the end of life and raised awareness of spirituality and spiritual needs more broadly.

4.3 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 Friday, 08:30am to 4pm.
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 team and this usually includes discussing the involvement of the medical examiners, 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. The PALS team will liaise with the medical team to ensure the Medical Certificate of Cause of Death (MCCD) and Cremation forms (CF4) are completed in a timely manner, and this will be sent by them electronically to the registration office along with the Mortuary once verified by the Medical Examiner team. 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 the medical 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, although these have been slightly delayed over the last few months due to demand/disruption in the PALS team.

A key milestone of the last year has been the development and finalisation of a SOP for the use of the PALS team regarding Hospital funerals when there is no designated or discernible Next of kin (NOK) (PALS SOP 11). This was developed as sadly there has been an increase in cases where the Trust has been responsible for arranging a funeral when there is no NOK. This has also been added as an appendix to DN864 – 'Information for staff following a death' and helps give some clear guidance in how to proceed in such circumstances.

A recent concern that has arisen has been several occasions where the reporting of a death has not occurred on Lorenzo, nor the PALS team contacted to be made aware of the death. PALS produce a daily bereavement report that is taken from Lorenzo and what appears on this, alongside any notification from the relevant departments of a death, is how the team are made aware and therefore can begin the Bereavement process. Unfortunately, this has happened on a few occasions in the last three months and has provided a delay to the Bereaved loved ones in the process. The incidents are currently being investigated and amendments to procedures/process being looked at to eliminate these issues moving forward.

Looking ahead the announcement has been made that the commencement date for the statutory medical examiner system will be 9 September 2024. The PALS team liaise closely with the MEO team, and the changes are expected to involve a new MCCD document and the removal of the need for a Cremation (CF4) form. We look forward to these changes and supporting our colleagues as best possible during the transitional phase.

4.4 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.

4.5 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

4.6 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.

4.7 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 e.g., people with Cystic fibrosis or those who have had an organ transplant.

5. 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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6. Education

6.1 Online learning

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

6.2 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.

6.3 Study days

SPCT has a programme of 2 study days each year, which were initially aimed at Champions and have now been opened to all staff. They run a standard, basic course on caring for the dying patient, which will have the same content each year and which we are encouraging all staff to attend at some point. This includes input from the Chaplaincy team on caring for those with different faiths and input from PALS and the Medical Examiner's Office. There is now a second course, which will have more advanced content, and which will change each year. In July 2024, SPCT are opening this course to external delegates for the first time.

6.4 Communication skills

In February 2024, Dr Sarah Grove, palliative medicine consultant, and Annemarie Harris, chief resuscitation officer, planned and delivered a short communication skills course for the Cardiac Physiologists. This was well received – 6 attendees gave feedback (out of 16) and all rated it as 'extremely useful'. It is an aspiration to be able to provide a full-length communication skills course within RPH, open to all staff.

7. Patient feedback

In January 2022, we started giving a survey about the quality of care to bereaved relatives and carers. Our PALS team discuss this with the next of kin during their bereavement support and give surveys to those who consent to receive them. Since January 2024, we are using the quality survey generated by the National Audit of Care at the end of Life, rather than our own, but have not had any data returned from this yet.

Bereaved Relatives Survey - Summary Jan. 2022 to Dec. 2023.

The full results of patient feedback are presented at the end of this report in ***Appendix 1****, including a full list of free text feedback from the respondents.*

Conclusions
We recognise that it is a very difficult time for people when someone they love is dying and we are grateful to those people who felt able to complete this survey and give us their feedback.
There is a relatively small response rate which means there are limits on how we interpret this data.

Overall, the results are reassuring, with most feedback being good. However, there is definitely room for improvement, and the results which are unacceptable are highlighted in red in the tables in Appendix 1. We only get one chance to get this right for people and those who love them, and it is unacceptable to have even one person who felt that the care at RPH was poor.

There is some improvement between 2022 and 2023, which is most easily demonstrated in the rating of the care – all respondents rated the care as at least good in 2023 (16 outstanding, 7 excellent, 1 good and 3 left blank).

There is a theme around communication needs highlighted in this survey – some patients and carers not told they were dying when they could have been, not all patients and carers involved enough in decision-making, not all communication sensitive enough, lack of emotional support for patients and some carers feeling that they were not supported adequately after their loved one died.

Action plan
1. Continue 6-monthly study days on caring for the dying patient, with focus on communication.
2. Review relevant eLearning slides considering these results and consider updating. Action – SPCT.
3. Consider developing RPH communication skills course. Action – SPCT/ ReSPECT Steering Group.
4. From 2024, RPH will be receiving results from the NACEL audit team, which should also enable us to benchmark our data against other Trusts.

8. Incidents and Complaints

8.1 Incidents

There were 32 incidents relating to end-of-life care in this 2-year period.

- 8 were regarding syringe pumps.
- 3 were regarding ReSPECT or DNACPR decisions.
- 2 were regarding deaths not being reported to PALS.
- 2 were regarding discharge planning problems.

The remainder of incidents were isolated incidents, with no themes emerging.

Learning from incidents is shared with service partners attending the End of Life Steering Group.

8.2 Complaints
None specifically about end-of-life care in this 2-year time frame.

9. Audit

9.1 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 of Audit of Care in Last Days of Life 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 (PCPLDL) is intended to guide the healthcare professional through the different issues which need to be considered at this stage in someone's life and, unfortunately, the use of the PCPLDL has reduced over the last 2 years.
This audit indicates a clear need for a relaunch of the personalised care plan, with a focus on the need to directly address nutrition and hydration needs, including the possibility of clinically assisted hydration where appropriate.

All the patients were known to SPCT, so this audit also indicates the need for us to improve our documentation and to continue prompting treating teams to improve their documentation as well.

Recommendations
1. Review audit in detail at next SPCT team meeting planned for 20th June 2024.
2. Review PCPLDL once again to see if we can improve usability.
3. Relaunch PCPLDL with the aim of a substantial increase in its use and in documentation.
4. Explore possibility of adding extra junior doctor teaching sessions.
5. Consider targeting training to cardiology department (given the four patients admitted via PPCI route whose death was not expected).
6. Re-audit in 2024, though questions will need to be reviewed as we are already auditing for the National Audit of Care at the End of Life.

9.2 Syringe pump audit

Background
Continuous subcutaneous infusions (CSCIs) are a common way of delivering medication when people are approaching the end of their life and are no longer able to swallow tablets. As demonstrated in the audit above, there are relatively few expected ward deaths here at RPH, and so it is difficult for staff to maintain competence in this area, hence the importance of undertaking the annual audit.

Standards
1. That syringe pumps are prescribed correctly – 100%
2. Service history is up to date – 100%
3. That the syringe pump is set up within 2 hours of the prescription – 100%
4. That the T34 nursing care plan is followed and completed accurately – 100%

Sample
July – December 2023 inclusive:

Year	2018/19	2020	2021	2022	**2023**
Patients with syringe pumps	10	6	16	12	**11**

Results

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

Conclusion
This is a similar sample size to last year.
The prescribing was accurate in all cases, which is good. We noted some apparent problems with prescribing in 1 patient. Our intranet pages now include a guide on how to prescribe a syringe pump.

Our system for logging which patient has which pump was not used all the time in this audit period and this needs to be improved.

Most were set up very promptly, which is encouraging. The only cause of significant delay is the use of alfentanil, which is at times unavoidable, and is not required frequently enough to be kept as stock on the wards. All patients had PRN medication prescribed in addition to the pump so that, if there is a delay in starting the pump, this can be used to maintain symptom control.

Use of the nursing care plan was generally good. All pumps were checked regularly, even if not all within the precise mandated time frame.

Action plan

- SPCT to improve logging of syringe pumps used on equipment tracker.
- Continue to provide education to junior doctors on prescribing and use of syringe pumps.
- Highlight 'junior doctor' section on SPCT intranet pages at above teaching.
- 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 2024.

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

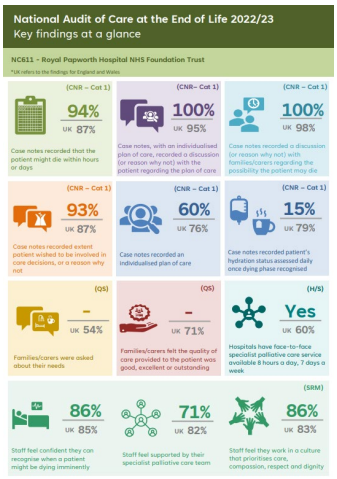
We have participated in this audit annually since 2019, apart from during Covid and 2023 for a reboot, and is an opportunity to benchmark our service against other Trusts. It consists of a case note review, a service level overview, a survey of bereaved relatives and a staff survey. However, our ability to benchmark our service is limited by the small data set that we usually provide, as we have a small number of deaths in comparison to most other hospitals. This has meant that we have had to continue to audit our own data internally, as we have found we need to review deaths over a 6-month period to have sufficient numbers to audit.

In addition, when we used their relatives' survey, it generated a complaint from a family, so we subsequently opted to use our own survey, which was only given to people who consented to receive it via our Bereavement Service.

However, there has been a substantial change to NACEL for 2024. They now require us to audit at least 20 deaths each quarter, which effectively means we are continuously auditing deaths here at RPH. This has been a significant increase in workload for SPCT, who complete this work but should mean that the data is more robust. The only concern that we continue to have 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 NACEL team has also relaxed their rules on how to administer the bereaved relatives survey, such that we can continue with our system and only send to those who consent. We are currently only using an electronic feedback option and will assess after 6 months use (in July 2024) whether we are getting adequate feedback without a paper option.

Results 2022



9.4 CCA Care of Dying Audit

Audit completed by CCA team, data taken from Metavision, initially performed in 2019 by SPCT, so this data was reaudited by CCA team in 2022, in addition to 20 new sets of notes and reaudited again in 2024 with another 20 patients. A new care plan to support care of the dying patient and withdrawal of life-sustaining treatment was introduced in 2022.

Some data were not included as a standard, but for information:

- Referral made to chaplaincy/SPCT
- Were boluses given for symptom relief?
- Were any new medications started?
- Reduction of oxygen flow.

The summary of results is included in this report in ***Appendix 3.***

Conclusion

Documentation needs to be improved, particularly regarding why bolus medication is given, and use of existing care plans would help with this.

Action plan:

- Relaunch personalised care plan for last days of life in Metavision – summer 2023.
- Ensure the care plan is discussed with junior doctors at induction.
- Review audit data collection tool to check questions are appropriate for ITU setting.
- Re-audit in 2 years.

9.5 Other

ReSPECT audit data is contained in section 9.
SPCT carries out a satisfaction survey annually which consists of positive feedback and does not require further elucidation for this report.

10. ReSPECT

10.1 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.

10.2 The issues which the ReSPECT steering group are targeting are:

- Need for ongoing education and development Trust wide
- ReSPECT is predominantly used for recording 'Not for CPR'
- An increase in ReSPECT forms 'not found' at audit when we were informed there was one.
- Although low in numbers, an increase in the number of DNACPR forms being seen at audit.

10.3 Education and development

- ReSPECT leaflets translated into 11 different languages.
- New educational resources have been added to Learnzone, including a new explainer video to introduce staff to ReSPECT.
- Ongoing junior doctor teaching, discussed at medical simulation sessions and BLS as well as at induction.
- here are now ReSPECT champions in every division, the aim of which is to disseminate information, teaching, and training.
- ReSPECT patient information has been added to consent booklets.
- Divisions have been encouraged to discuss ReSPECT in their M+M meetings.

10.4 Engagement and Leadership

- The ReSPECT steering group meetings are now held quarterly, with each focusing on an update from a different division.

10.5 Incidents

All discussed at ReSPECT Steering Group. 10 incidents in latest reporting period, main theme is around communication.

10.6 Audit summary

Data collection June 22 to December 23:

- Documented ReSPECT conversations are found in higher numbers in the following areas Critical Care, 3 South East, 3 North East during this audit cycle.
- During this auditing period we removed the 'mandatory to complete this field' option from the digital ReSPECT forms and saw a slight increase in the use of digital forms compared to previous years. This auditing period an average of 50% of forms were digital.
- Alarmingly, 4% of ReSPECT forms were not found at time of audit. This is where staff informed the auditor that a ReSPECT form was in place but when auditing no paper or digital documentation was found. The issues were immediately raised with medical teams for rectifying.
- 4% of forms were the old DNACPR document from prehospital areas, clinicians were in the process of initiating ReSPECT conversations.
- The 'Summary of relevant information' section was completed 94% of the time
- 2% of forms did not have a documented 'for CPR' or 'not for CPR' on the form.
- 58% of forms were documented 'Not for CPR', 36% 'For CPR', 6% were not found or DNACPR forms.
- The lowest compliance section over all four quarters is where clinicians input their details and those who were involved in the ReSPECT conversations.

10.7 ReSPECT Proposed Objectives for 2024/5

1. Continue development of ReSPECT champions across the trust
2. Explainer video embedded within the Trust Mandatory Training portfolio with compliance governance.
3. Development of a communications course, centred around ReSPECT
4. Improvement in senior clinical engagement (through divisional reporting every quarter).
5. Inclusion of questions about ReSPECT in "All about me" booklet used in surgery and CCA.
6. Audit of ReSPECT forms where patient is deemed not to have mental capacity.

11. 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, vice-chair is Dr Sarah Grove, Supportive and Palliative Care team consultant.

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.

12. Recommendations

There is a significant amount of quality improvement work and teaching and training taking place across Royal Papworth Hospital. . There is a clear need for ongoing education across the Trust, particularly pertaining to end of life care and communication skills, especially related to ReSPECT and advanced/ personalised care planning.

Areas for development and improvement for 2024-25:

- The Supportive and Palliative Care Team to continue current programmes of audit and education in partnership with all teams.
- Develop a communication skills course, focused on ReSPECT with Dr Sarah Grove Palliative Care and the ReSPECT Steering Group.
- SPCT to continue work to embed the ReSPECT process within the Trust in partnership with the ReSPECT Steering Group.
- SPCT to consider targeting end of life care education for the cardiology department in response to learning from deaths that were not expected via the PPCI service.
- SPCT to relaunch the Lorenzo-based Personalised Care Plan for care in the last days of life across the Trust.

  Critical Care medical and nursing leads to relaunch the Metavision-based Personalised Care Plan for last days of life following recent CCA audit of the dying patient in Critical Care presented at the End of Life Steering Group in May 2024.

Dr Sarah Grove, April 2024.

Appendix 1 - Bereaved Relatives Survey summary Jan 2022 – Dec 2023.

Results:

2022

- 179 deaths in the Trust. 120 surveys sent out. 31 returned. 25% response rate.

2023

- 198 deaths in the trust. 82 surveys sent out. 32 returned. 39% response rate.
- Total = 63 returned surveys.

Location of death in returned surveys are reported below:

	2022	2023
Critical care	16	16
Level 3	3	2
Level 4	2	4
Level 5	2	2
Unclear	8	8

1. Did staff explain person was likely to die in the next few days?

		Yes	No, could have been	No, died unexpectedly	No, didn't want to know	No, too unwell	No, other	Unsure	Left blank
2022	Patient	11	2	5	0	7	3	3	0
	Carer	18	4	5	0	0	2	1	1
2023	Patient	12	1	6					
	Carer	25	1	5					1

2. Did staff involve the patient/carer as much as they wanted in decision-making?

		Yes	No- wanted more	No – wanted less	No – not able	Unsure	Other	Left blank
2022	Patient	17	1	0	9	3	1	0
	Carer	22	4	0	5	0	0	0
2023	Patient	18			8	4	1	1
	Carer	27	3			1		1

3. Did staff communicate in a sensitive way?

		Yes - definitely	Yes – to some extent	Mixed	No, not at all	Unsure	N/A	Left blank
2022	Patient	17	4	3	1	1	5	0
	Carer	21	2	4	2	1	1	0
2023	Patient	18	3	1	1	1	8	
	Carer	19	2	1				1

4. Review of care needs

		Always	Most of the time	Some of the time	Almost never	Never	Unsure	N/A	Left blank
Adequate pain relief	2022	17	4	1			4	2	3
	2023	18	4				1	2	1
Adequate relief of other symptoms	2022	16	3				5	3	4
	2023	17	4	1			1	1	2
Support to eat	2022	13	2		1	1	3	8	3
	2023	16	1				1	7	2
Support to drink	2022	14	2	3	0	0	2	6	4
	2023	15	3					7	2
Emotional support	2022	10	3	0	3	1	4	8	2
	2023	9	3	3				10	2

		Always	Most of the time	Some of the time	Almost never	Never	Unsure	N/A	Left blank
Treated with compassion	2022	20	3	2	0	1	2	1	2
	2023	21	3	1				1	1
Spiritual/cultural needs met?	2022	11			1	2	2	12	3
	2023	11	2		1		2	9	2
Adequate privacy	2022	17	6	1			3	1	3
	2023	16	5	1	1			1	3

5. With regard to the carer

		Yes definitely	Yes, to some extent	No	unsure	Prefer not to say	N/A	Left blank
Supported after death	2022	17	7	4	0	0	1	2
	2023	19	2	1				1
Cared for compassionately	2022	23	4	2	1	0	0	1
	2023	24	3					

6. Rate the care.

	Outstanding	Excellent	Good	Fair	Poor	Unsure	Prefer not to say	Left blank
2022	8	15	0	2	1	2	0	6
2023	16	7	1					

Free text patient feedback from surveys

Not all respondents included a free text response. These answers are listed here in the time order in which we received the responses, from January 2023 onwards.

- I think they could have explained visiting times in critical wards.
- Hospital staff were brilliant.
- Long comment – in summary, care on ward not good but care on CCA very good on night of death.
- My husband had gone for a routine CT scan and was due to be admitted on 10th May but unfortunately, he passed away in the CT room. I was kept informed and was able to spend some time with my husband in ICU after his passing, as were his daughters.

- I and the family were treated like royalty. Couldn't have asked for a better place to be in the circumstances. Thank you to everybody from the cleaner to the top of the tree.
- Lots of positive comments, patient named, he would have wanted to say a big thank you to you all.
- I can't express how wonderful the care…received was, and how they were sympathetic to me as his NoK…sorry to say I left so quickly after he died that I don't think I said thank you for your care and love for…. thank you transplant consultants, ward 5 North, ICU even the lovely lady at WHSmith who gave me a tissue. You guys are amazing thank you for everything. Signed.
- A lot of positive free text including "I have nothing but admiration and grateful thanks to all those staff that have helped both my wife and I over a lot of years"
- Couldn't fault the care that dad received. The team tried everything possible to save dad. I will be forever thankful.
- Lots of positive comments, on holiday in Cambs when husband became ill and t/f to RPH "Papworth hospital is an amazing place. I cannot praise or thank staff enough for what they did and the care they showed “.
- Lots of positive comments - small minor point to raise was that husband was taken ill on Sunday evening and we did not hear a full debrief or discussion with registrar/consultant until Tuesday - However ALL staff involved were thoughtful, hardworking, and caring...
- My son never regained consciousness. He was treated with exceptional kindness and gentle respect which I can only describe as love. The support given to me, and my daughter was wonderful. No more could have been done.
- We feel that our mother was cared for some of the time… confusing that we were called, and she only had hours …
- It has been difficult to answer some of the questions because ….was unconscious the whole time he was at the RPH. However, we would like to thank the staff on CCA for the care they gave him.
- Long free text, in summary: PALS very helpful and compassionate and one particular consultant outstanding. Arrangements for moving husband near a window or visit outside never made and communication on evening of death could have been better.

All feedback was passed to the relevant wards where possible (some respondents didn’t include the ward name and the surveys were anonymous).

Named staff, including ‘the lovely lady in WH Smith’ were emailed the feedback.

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

Data from both 2022/23 and 2023/24 are included below:

Number and Location of deaths

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

Results

In 2022, 19 deaths were assessed as expected and audited and in 2023, 15 deaths were assessed as expected and audited. These were audited against all NICE quality standards.
Four deaths were not expected by the ward team, so were not audited. All were patients with pre-existing frailty admitted via the PPCI route.

Table 4 – Audit results of care against expected standards in last days of life

	Expected standard	Result 2019 N=10	Result 2020/21 N=19	Result 2021 N=19	**Result 2022 N=19**	**Result 2023 N=15**
Recognition of expected death	100%	90%	100%	100%	**100%**	**100%**
Personalised care plan completed	100%	N/A	31%	58%	**53%**	**40% (6/15)** **Of the 9 not done:** **4/9 rapid deterioration** **3/9 partial (nurse, not doctor)** **2/9 no reason**
Effective communication of expected death to pt	100%	90%	74%	79%	**79%**	**60% (9/15)** **5/6 – too unwell** **1/6 – rapid deterioration**
Effective communication with carer	100%	N/A	100%	100%	**89%**	**100%**
Daily monitoring of condition	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 due to rapid deterioration**
Evidence of discussion about CAH						**33% (5/15)** **NA 13% as above**
Evidence of daily review of hydration needs	100%	50%	89%	74%	**68%**	**40% (6/15)** **NA in 4/15 due to rapid deterioration**
Evidence of appropriate PRNs	100%	80%	74%	95%	**84%**	**87% (13)** **2/15 partial prescribing.**
Support for families before death	100%	90%	100%	100%	**95%**	**93% (14)** **1/1 not time**
Support for families after death by staff	100%	80%	84%	100%	**84%**	**100%**
Referred to SPCT		80%	95%	84%	**79%**	**100%**

Based on section in Personalised Care Plan for the last days of life for medical team to complete:

Commented [JW2]: What is PCPLDL - suggest note in full

Commented [JW3R2]: Is this Personalised care plan last days of life?

	2020/21 N=19	2021 N=19	**2022 N=19**	**2023 N=15**
PPOD documented	42%	53%	**42%**	**67% (10)**
PPOD achieved	50%	70%	**62%**	**33% (7/15)**
Review need for obs	79%	89%	**89%**	**73% (11/15)** **3/4 rapid deterioration**
Review need for bloods	89%	84%	**79%**	**53% (8/15)** **4/7 rapid deterioration**
Review medication	100%	89%	**74%**	**80% (12/15)** **3/3 rapid deterioration**
Review need for O2	79%	89%	**58%**	**40% (6/15)** **1 NA** **3/7 rapid deterioration**
ReSPECT form in EPR	79%	42%	**63%**	**67% (10/15)** **3/5 just paper** **2/5 just alert**

Based on nursing section in Personalised Care Plan Last Days of Life (PCPLDL):

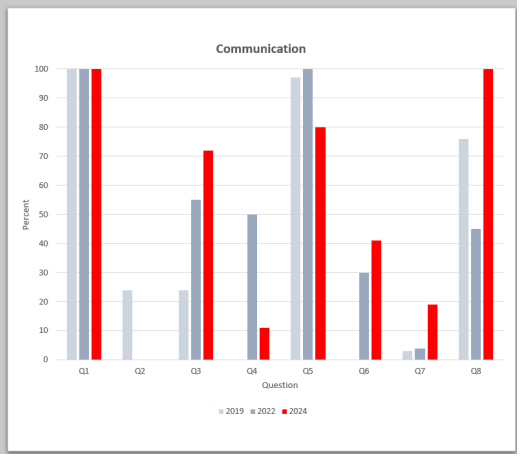
	2020/21 N= 19	2021 N=19	2022 N=19	**2023 N=15**
Regular mouth-care	68%	84%	53%	**67% (10/15)** **4/5 not time**
Bowel care	73%	89%	74%	**67%** **3/5 not time**
Bladder care	89%	89%	84%	**67%** **3/5 not time**
Personal hygiene	79%	89%	74%	**67%** **3/5 not time**
Skin integrity	89%	89%	74%	**67%** **3/5 not time**
Emotional needs	89%	100%	79%	**73% (11/15)** **1/4 not time**
Cultural/spiritual needs	58%	79%	79%	**60% (9/15)** **1/6 not time**
Regular review of symptoms	100%	100%	89%	**73%** **3/4 not time**
On CSCI? Not expected to be 100%	42%	68%	58%	**80% (12/15)**

Appendix 3 - Results of CCA Audit of Care of the Dying Patient

Communication

- Were the following discussed or offered to patient or NoK?

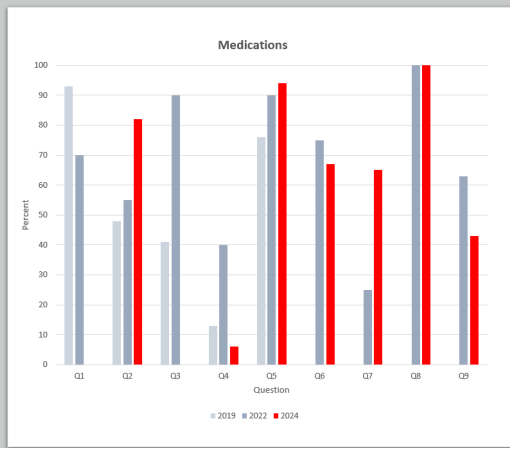
  - Q1: Diagnosis and prognosis
  - Q2: Contact preferences
  - Q3: A referral to SPCT
  - Q4: A referral to the chaplain
  - Q5: That NoK could be present during withdrawal
  - Q6: That FiO2 would be reduced to 0.21
  - Q7: Hydration & nutrition plan during withdrawal
  - Q8: Extra support or information after death



Medications

- Were the following changes to medications made during withdrawal?

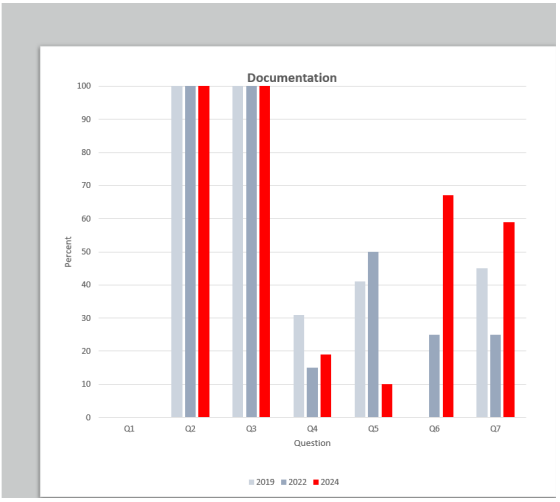
  - Q1: PRN analgesia
  - Q2: PRN anti-emetics
  - Q3: PRN meds for agitation / dyspnoea
  - Q4: PRN meds for secretions
  - Q5: Were stable opioids continued?
  - Q6: Were non-essential meds continued?
  - Q7: Were any new meds started during withdrawal?
  - Q8: Were iv boluses given for symptom relief?
  - Q9: Was a rationale for boluses or changes in infusion rates documented?



Documentation

- Were the following documented during the EoL process?

  - Q1: Standardised assessment for dyspnoea
  - Q2: Standardised assessment for agitation
  - Q3: Standardised assessment for pain
  - Q4: Assessment of hydration status
  - Q5: Assessment of religious & spiritual needs
  - Q6: Reduction of obs to 4-hourly
  - Q7: Review of relevant nursing care



Withdrawal

- Were the following carried out during the EoL process?

  - Q1: Reduction of FiO2 to 0.21
  - Q2: Neuromuscular blockers allowed to wear off prior to withdrawal
  - Q3: Non-essential meds discontinued
  - Q4: Vasoactive meds discontinued
  - Q5: Antibiotics discontinued
  - Q6: Pacing / ICD stopped
  - Q7: Blood tests stopped
  - Q8: CVVHF discontinued
  - Q9: MCS discontinued (2024 only)