

PELiCaN Network

Annual Report

2024/25

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Introduction

Throughout 2024-25 the Paediatric End of Life Care (PELiCaN) Network continued to work towards supporting delivery and improving access to high quality, patient and family centred, end of life care for children and young people, regardless of age, ethnicity, or geographical location.

Lead Clinician Update

The PELiCaN network continues to thrive, grow and achieve its desired outcomes and annual work-plan objectives despite three significant pressures: the uncertain future of the Networks (NSS); awaiting the outcome of the National Palliative Care Strategy (Scottish Government), and the constraints of virtual working. Our celebrated major achievements this year has seen the completion of the parent outcome feedback tool that will inform parental opinions of evolving service need and design – a collaborative project with York University. And, in partnership with NES, the successful launch of a series of six Turas e-learning modules that cover the art of holding, documenting and sharing realistic conversations in paediatric palliative care. Our clinical education sessions hold prominence in the calendar and the breadth of hosting formal and informal multi-agency interactions (including with Police Scotland and the Scottish Ambulance Service) continues to be representative and influential. Our involvement to champion the NHS delivery of acute specialist paediatric palliative care services continues to gain traction through dialogue with Scottish ministers. We have been consulted regarding a proposed intra-hospital acute paediatric palliative care suite to ensure local plans align with national vision.

I am confident that PELiCaN will continue to prosper– at greater pace and breadth going forwards. Our foundation and prominence in the complex landscape is strong. I yearn to hold an ‘in-person’ conference to capitalise on the synergistic opportunism that materialises from a national meeting of passionate, inspiring, devoted, multi-agency, multi-disciplinary professionals. We await instruction from the National Palliative Care Strategy with eager anticipation as our consultation submission detailed the visions that we had previously contemplated developing.

‘Palliative Care’ and ‘Care at the End-of-Life’ are evolving specialities, destined to grow in complexity, acuity and demand as patients live longer with increasing healthcare needs and dependency to maintain their increasingly fragile life. Service provision is highly topical, and PELiCaN must lead to represent the views of its national multi-agency members.

Current Position

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development.

The Network completed 100% of all workplan service development priority objectives. A summary of key achievements can be seen below. The Network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate friendly practices.

The actions prioritised for PELiCaN were:

Priority Action	Progress
By 30/11/24 PELiCaN will have started work on developing gold standard guidance documents and templates on the use of Syringe Drivers in Paediatrics nationally. This will fit into the work of the National Adults group. Caroline Porter Network Lead on this.	<ul style="list-style-type: none"> Work on this project is complete; an updated paediatric syringe pump guidance document is finalised and will be published on the website.
By 31/3/25 PELiCaN will have designed an education tool/resource on completing ACP's / communicating goals of care, the vision is that this will be a 'train the trainer' which will enable learning to cascade out in Boards. This will comprise of 6 Turas modules and a suite of resources to host learning events.	<ul style="list-style-type: none"> Work on this project is complete; the 'Having Realistic Conversations in Paediatric Palliative Care' resource is now complete and ready to be launched on 13th May 2025. The work to promote this project continues into the 2025-26 workplan as agreed by SMG.
PELiCaN will complete delivery of a patient experience Outcome Measurement tool to be used in Boards. Data gathered will be owned by Boards and for Boards to follow up/respond. Annual analysis/summary of feedback any key themes should be highlighted to the network from Boards. Methods of doing this will be explored.	<ul style="list-style-type: none"> Work outlined on this project for 2024/25 business plan is complete. As agreed by SMG the roll out of this project including delivery of the pilot and full roll out in Boards continues into the 2025/26 business plan.

Highlights

Turas- Having realistic conversations in paediatric palliative care resource

Throughout the reporting period the Network continued to work to develop a suite of six new Turas e-learning modules titled 'Having Realistic Conversations in Paediatric palliative Care'. This has been a significant piece of work this year for all involved and has taken a lot of time and resource. The first task was to develop the draft scripts early in 2024, these were then sent to the development team in NHS Education for Scotland (NES) for review and build towards the end of the year. Following significant rounds of reviews, module testing and peer review the modules were signed off in March 2025. All imagery within the modules were built by the Network and added to the modules to give them a similar look and feel throughout.

Throughout the review period all final titles were agreed for the resource and individual modules, the module titles are noted below.

- 1- Introduction to paediatric palliative care
- 2- Introduction to Goals of Care
- 3- Shared decision-making in paediatric practice
- 4- Introduction to perinatal palliative care
- 5- Supporting future care planning conversations in practice
- 6- Realistic conversations in unscheduled care

A launch event was planned for 13th May 2025, there has been over 200 registrations to date. This session will be recorded and placed on the network website following the event for those who can't attend.

The Network would like to extend continued thanks to those involved in this project and to NES for their support.

Syringe pump process

Throughout the reporting period PELiCaN worked to develop a guidance document on the use of syringe pumps in paediatrics adapted from a new adult's syringe pump guideline. The adult guideline was first produced in 2011 by NHS Education for Scotland (NES) in consultation with practitioners in hospital, hospice and community settings throughout Scotland. It was then reviewed in 2023 as part of the Scottish Palliative Care Guidelines review and maintenance process.

A small, short life working group (SLWG) was established to work to review the guidance and make the necessary changes to meet the needs of our patient cohort. Once drafted the document was sent for comment by the adult's group before being sent to the PELiCaN Steering Group for ratification. No changes were made by the adult's group, and this was testament to the hard work of the SLWG in amending the original document. PELiCaN thanks all involved in this process.

This document soon be available on the PELiCaN website.

Taking a child home after death guidance

Throughout 2024-25, PELiCaN worked to update the 'Family transporting child home following death' guidance document. This guideline is for use by professionals within paediatrics where a family wish to transport their child home following their death. This could be any baby, child or young person up to the age of 18 years. The guidance was originally developed by Scottish Children and Young People Palliative Care Network (SCYPPCN) in 2017 and required updating. It was agreed by both SCYPPCN and PELiCaN that governance arrangements should be progressed within the Network due to the previous SCYPPCN Managed Knowledge Network site being shut down.

A small SLWG was set up to review this document and a final version was sent to SCYPPCN for ratification as well as the PELiCaN Steering Group. We thank all members involved for being part of this work.

The final document will be available on the PELiCaN website very soon.

Palliative Care strategy

PELiCaN continued to provide subject matter expertise to the Scottish Government Palliative Care Strategy work throughout the reporting period. The strategy consultation went live in October 2024 with a closing date of 10th January 2025. A project group was established, this brought together representatives from different Boards and Specialities, ensuring that Remote and Rural, District General, specialist and generalist views were covered. This group met every four weeks to pull together a comprehensive draft consultation response. The response highlighted areas where PELiCaN could support work or already had resources available which would aid delivery of objectives. This was a significant piece of work and took a lot of time to pull together. A final draft of the response was sent out to members and the Steering Group on 16th December for comment/ratification and was also approved by National Services Division (NSD) Senior Management Group (SMG). No changes were received, and the response was ratified and submitted on 10th January 2025.

We now await publication of the final strategy. Updated timescales for this piece of work remain unknown but PELiCaN will keep in touch with Scottish Government on this.

Case review sessions

Two case review sessions were held in the reporting period. The purpose of the events is to discuss interesting case studies with colleagues to share learning experiences. Professionals from across Scotland are invited to present a recent case where there is potential learning for all, by sharing practice in often challenging situations. Each session follows a structured format and is facilitated by a member of the Communication and Education sub-group. Presenters are invited to present their case and there is then an opportunity for a structured discussion with those attending. Confidentiality is respected, and no slides are copied or shared out-with the session. The sessions are not recorded. The sessions are intended to be respectful and non-judgemental acknowledging that presenters may feel vulnerable when presenting their cases. The aim is supported, shared learning for all.

Sessions this year were, 18th June 2024- NHS Greater Glasgow and Clyde and 19th March 2025- NHS Grampian. Both sessions were very well attended with 82 and 41 registrations respectively.

Feedback on the 18th of June session highlighted that 100% of attendees 'strongly agreed' or 'agreed' that the case presented increased their learning/knowledge and that the facilitator encouraged and supported discussions and invited questions/comments from participants. 100% of attendees rated their overall satisfaction with the session as 'very satisfied' or 'satisfied'.

Unfortunately, feedback form was not distributed for the session on 19th March 2025, however comments on the Teams channel at the end of the session suggested that professionals thought the session was very good, informative and interesting.

The next session will be in June 2025.

POEM Tool

PELiCaN continued to work with the University of York to deliver a new patient feedback tool for in hospital care. This tool is known as the 'Experiences of Hospital Care Questionnaire (EHCQ)'.

There was a slight delay in getting the final documents over to the network from the University due to a change in funding structures and the researchers time allocated to this work.

There had been some remedial works during the reporting period to refine the process down to four separate questionnaires. Two are for bereaved parents of under one-year olds and one year and older and the other two are for families where their child survived the hospital stay.

The final documents including questionnaires and an analytics spreadsheet were received early in 2025.

The Network is working with NHS Greater Glasgow and Clyde to plan for the launch of a pilot of the process in the Board area. This work is underway, and it is hoped the pilot will launch towards the end of Quarter 1 in 2025-26 reporting period.

A full admin process sits alongside the questionnaires and PELiCaN is working to refine this to suit the needs of Boards and ensure all required templates are available. Additionally, the Network will work throughout the pilot period to establish how long the process will take Boards to establish if any further efficiencies can be achieved.

All data gathered from the questionnaires is owned by Boards, and any key themes which may require a national approach to resolving will be fed back to the Network for consideration. Further work is required to establish the reporting process for this.

It is believed that once this process is fully implemented within Boards it could be beneficial to several other Networks and specialties, as it is not end of life care specific. PELiCaN would keep in contact with colleagues in York around this.

The Network would like to extend thanks to colleagues at the University of York and to those from NHS Scotland involved in this process.

Looking forward – 2025/26

Due to ongoing review of national networks, networks have only been asked to plan business as usual activity for Quarter 1, 2025/26. However, PELiCaN has a number of additional service developments which have been carried over as agreed by SMG into the 2025/26 business plan. These can be seen below.

- Launch the new PELiCaN 'Having Realistic Conversations in Paediatric Palliative Care' resource in Boards and monitor its use/impact.
- Pilot the 'Experiences of Hospital Care (EHCQ)' tool within NHS Greater Glasgow and Clyde and then roll it out within Boards.
- Continue to provide subject matter expertise to the Scottish Government Palliative Care Strategy work.

Finance

The network operated within its allocated budget in 2024/25, focusing on low-cost, high-impact activities such as virtual education and digital resource development

Risks & Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals.

Stakeholders have highlighted the importance of maintaining national coordination to sustain improvements in care. Continued support will be essential to build on existing progress and deliver future benefits

In 2024/25, Scottish Government consulted on their Palliative Care Strategy for Scotland. PELiCaN provided input to the consultation to reflect the paediatric and young person context and highlight the resources that were available through PELiCaN to support the delivery of the strategy. Publication of the strategy is still awaited but there is a concern that the strategy and its associated delivery plan may impact on the work towards the vision of PELiCaN for end of life care for children and young people.

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