

# **PELiCaN Network**

## **Annual Report**

### **2023/24**

**Lead Clinician:** Dr Chris Kidson  
**Programme Manager:** Shelley Heatlie  
**Programme Support Officer:** Chris Williamson

## Introduction

Throughout 2023-24 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

It is with enormous pride that I reflect upon the achievements of the PELiCaN Managed Clinical Network over the previous year and celebrate the achievements of its membership.

PELiCaN has continued to grow in stature, influence, and status throughout 2023-24. Key objectives can be considered under three over-arching themes: national publication of world-leading end-of-life care service standards; prominence of voice that informs the development of the paediatric element of the National Palliative Care Strategy; championing the inviolable need for the recognition of a supra-speciality for paediatric palliative care.

We hold a privileged position to be instrumental in the development of the paediatric element of the forthcoming National Palliative Care Strategy, giving national voice to NHS delivered paediatric palliative care services. The interactions with our adult colleagues and the beneficial gains are unprecedented. We hold high membership within the overarching Steering Group; within multiple Working Groups (paediatric, bereavement and education and training, data), to comprehensively assist the policymakers of the Scottish Government to formulate the National Palliative Care Strategy.

A strategic vision for PELiCaN has been the creation of a patient specific 'end-of-life toolkit', including a revised format of Children and Young People Acute Deterioration Management (CYPADM) paperwork into digital Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) and hosting all relevant end of life documentation on an accessible confidential NHS digital platform. This would be transformative to all who endure the threat to their natural life where family time becomes a limited precious asset. Last year we continued to work on updating the paediatric 'anticipatory care plan', nationally re-branded to become the 'future care plan'. We created a national framework to guide the process of supplying a bespoke 'just-in-case-box'. It may be another daunting complex task to tackle, but the benevolent aim is to rapidly treat the emergence of refractory symptoms and safely allow families to remain at home. This is heavily dependent upon guidelines, medication supply and delivery, and training, and lends itself to the inception of a patient specific 'symptom management plan', which in turn implies the need for bespoke 'paediatric treatment escalation' plans. It is encouraging – even rewarding – to appreciate that our vision for the digital toolkit which pre-dates that defined by the National Palliative Care Strategy is perfectly aligned. We will continue to work with Scottish Government on designing and delivering this aim.

In collaboration with NHS Education for Scotland (NES), PELiCaN begun developing a 'Realistic Conversations - Goals of care' educational resource designed to help facilitate and record goals of care decisions with families. This will be a great resource for staff in Boards to support learning and facilitate further teaching.

And finally, partly funded by the Children Hospital Charity Glasgow, and in collaboration with academic colleagues from the University of York, PELiCaN begun development of a parent's experience outcome measurement (PEOM) tool for use by Boards. Data is powerful: it is anticipated that the continual use of PEOM will provide detail to future proof the work of PELiCaN. We debate the utility of nationally collecting a locally ratified minimal dataset.

I envisage new challenges for 2024-25, including increased financial pressures, imposed restraints, and uncertainty regarding the outcome of the review of the Networks. However, I am proud of the progress of PELiCaN so far, and so privileged to work alongside such a dedicated and dynamic team of professionals, who epitomise excellence and share my passion for success.

Sending my continued thanks to all PELiCaN members and the continued support from our Experts by Experience family members who continue to provide us with their first-hand experiences and knowledge.

Dr Chris Kidson

## Current Position

The Network completed 100% of all workplan service development objectives. An extension was agreed for one objective as the Goals of Care Turas development project has evolved into a joint project with NES and required more time for delivery. 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.

## Highlights

### Service Development Documents

The Network developed one 'gold standard' guidance document this year on the use of Just in Case Boxes in Scotland, a summary of this and its purpose is below:

- The purpose of this guideline and supporting documents is to improve timely access to appropriate symptom management medication if a child experiences distressing or escalating symptoms as they approach end of life. It aims to support the ability to offer a range of locations for the preferred place of care and death as is appropriate to each child's specific circumstances. Facilitating timely access to specialist symptom management has the potential to enhance patient care and aid the prevention of unnecessary crises and unscheduled hospital admissions. A launch event for this document is planned for 16<sup>th</sup> May 2024, this has been distributed to all PELiCaN members, Scottish Children and Young People's Palliative Care Network (SCYPPCN) and the Managed Service Network for Children and Young People with Cancer mailing lists.

The Network would like to thank all members who contributed to the development of our guidance documents this year, feedback has shown that they have been easy to use and useful.

## **Goals of Care Education Resources**

PELiCaN has begun work on developing a suite of education resources in collaboration with NHS Education for Scotland (NES) titled 'Palliative Care- Having Realistic Conversations for Babies, Children and Young People'. This will be constructed of six 30-minute Turas modules on the topics of Introducing Goals of Care Conversations, Introducing Future Care Planning, Introduction to Palliative Care, Shared Decision Making, Goals of Care in the Acute Setting and Goals of Care in Antenatal and Neonatal Settings. A multi-disciplinary steering group has been established and meet every six weeks to oversee development, further project groups have been established to develop module content. The draft overarching Learning Outcomes are:

- Effectively use decision aids to support effective communication and shared decision-making in practice.
- Communicate sensitively and effectively with parents/carers (children and young people where appropriate) about deteriorating health and goals of care.
- Talk about Future Care Planning informed by an understanding of ' what matters to children/young people and their families (wording for a perinatal specific version of this objective is TBC).
- Discuss the benefits and limitations of treatment in a balanced way to support informed decision making.
- Reflect on whether a good conversation has taken place.

The project groups will submit final drafts of modules to NES for development by November 2024 for a delivery date of March 2025. A launch will take place after this date.

Additionally, there will be a suite of resources produced to allow Boards to utilise learning in a small group environment looking at specific scenarios relevant to their area. These will be recorded and shared on the Turas platform to build up a further library of resources.

## **Case Based Learning Event**

In February 2024, PELiCaN hosted the first virtual case-based learning event, these will be held three times per year with presenters from Boards across Scotland. 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.

Feedback was gathered and a report can be seen in Appendix 1.

## Patient Experience Tool Development

The PELiCaN Patient/Parent Feedback Tool Project Group was formed as part of the Education and Communications Group. The purpose of the group was to create a tool for use in Boards across NHS Scotland which allows families to feedback on paediatric end of life care received. Initially the tool will only look at care in Hospital, it is hoped that other areas will be added to this in the future. PELiCaN is working with researchers from the University of York on this project, several families have been involved in the process throughout. This project has a planned delivery date of July 2024, therefore will carry into next year's business plan.

### Key deliverables

- A parent completed questionnaire of a parent and child's experience of a recent episode of hospital-based care.
- This questionnaire will be developed specifically for children and young people with a life-threatening or life-shortening condition and their parent and will be in two parts:
  - Part 1 will cover the parent and child's experience of hospital healthcare, based on the research evidence as to what matters to them.
  - Part 2 of the questionnaire will be an additional module on 'post-death care and support'.
    - this optional module will only be administered to those for whom it is relevant.
    - the content of this module will be based on PELiCaN's service development checklist on post child death care.
- Two versions of the questionnaire will be provided:
  - one for parents of younger/cognitively impaired children
  - one for parents of older children without cognitive impairments
- The questionnaire will be suitable for completion by either parent (mother or father)
- The research team will provide PELiCaN with the questionnaire as a pdf and a Word document.
  - PELiCaN can opt to convert the questionnaire to an online format.
- The research team will provide an instruction manual for Boards to accompany the questionnaire, detailing how to administer and score the questionnaire.
- The research team will provide a spreadsheet for data entry and simple analysis.

Going forward: research team will maintain contact with PELiCaN to track experiences in using questionnaires/impact of questionnaires etc.

## **End of Life Toolkit Development – Future Care Planning**

Through the year PELiCaN continued to work to review the use of the following documents: Anticipatory Care Plan (ACP) (now known as Future Care Plan), CYPADM, RESPECT and Paediatric Treatment Escalation Plan (P-TEP). Scottish Government is now looking at this piece of work at through their Future Care Planning Group, who are working to develop a digital Future Care Plan resource incorporating the aforementioned documents. PELiCaN members Katrina Marshall and Dr Jonathan Downie represent the network on this group providing a paediatric perspective to this work. PELiCaN will continue to review the Children and Young Peoples Anticipatory Care Plan template to provide a best practice view to Scottish government to inform future developments on the digital Future Care Plan System. PELiCaN will continue to contribute to this work in 2024-25.

## **Palliative Care Strategy input**

PELiCaN continues to be represented in a number of the Scottish government palliative care strategy groups; the overarching Steering Group, Paediatric Working Group, Bereavement Working Group, Education and Training Work Group and the Data Group. This project has been a considerable commitment for the clinical team this year, due to the volume of meetings and documents to be produced/reviewed. The planned delivery date of the strategy is Summer 2024. PELiCaN has met with Scottish Government colleagues in early 2024, regarding planning for taking forwards recommendations, space has been allocated on the 2024-25 business plan for further consideration and delivery of this.

## **Experts by Experience (EbE)**

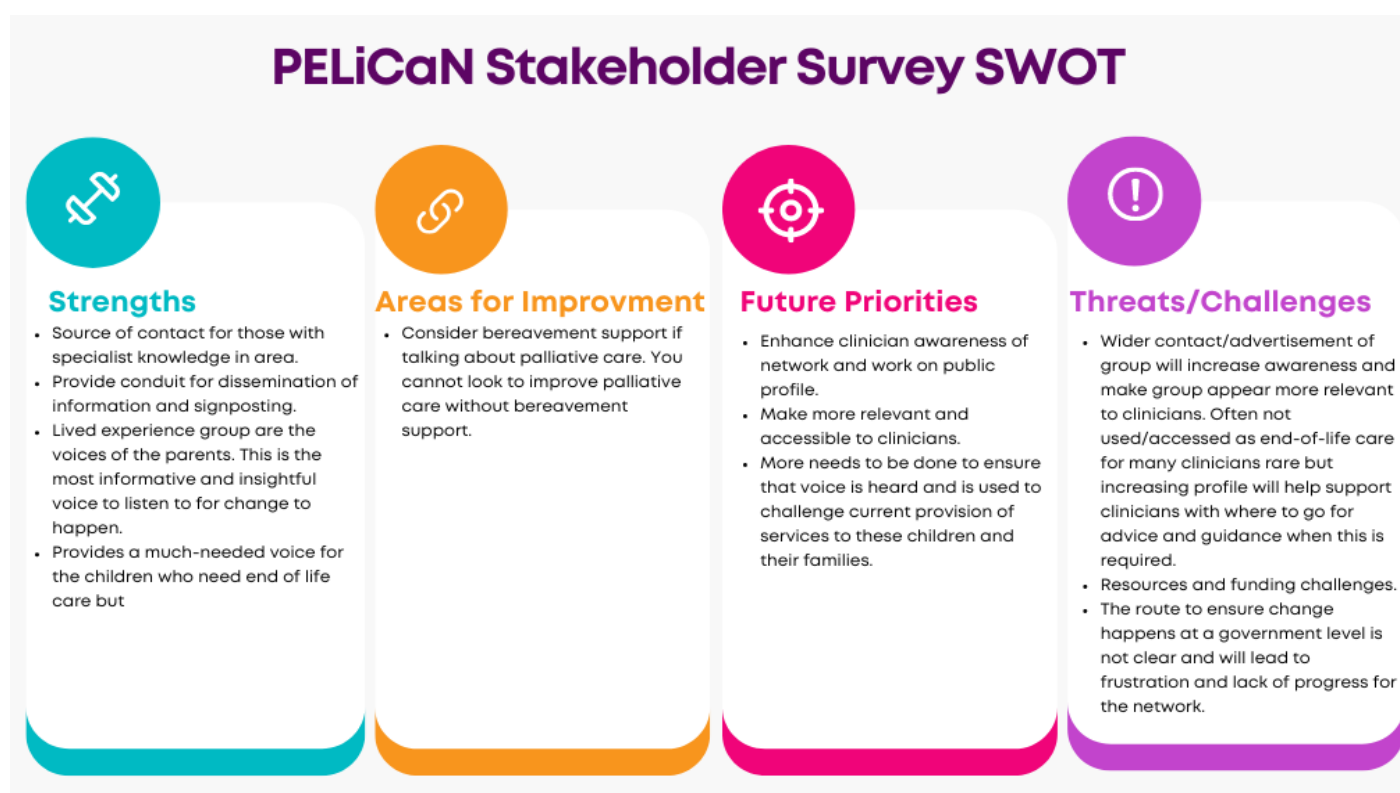
The PELiCaN Experts by Experience (EbE) family engagement group have had another productive year, members have been invited to participate in the Scottish government palliative care strategy family engagement consultation. A small focus group and a number of one-to-one interviews took place to provide feedback on what palliative care means for families. This feedback will help to shape the updated strategy. Several families also participated in the patient feedback project with the University of York, again a few one-to-one interviews took place with families from the group to inform questionnaire development. We thank all our Experts by Experience for taking part in this work this year. A review of membership will take place in 2024-25.

## Stakeholder Survey

A stakeholder survey was issued to 67 stakeholders, the response rate was 8.9%. Unfortunately, this was sent at the end of the financial year which is a particularly busy time with annual leave and heavy workload, believed to contribute to the poor response rate. A summary of key results is below.

- 50% of respondents 'strongly agree' or 'agree' that the network positively contributes to developments for children receiving end of life care.
- 74% of respondents 'strongly agree' or 'agree' that the network service development activities add value for children receiving end of life care.
- 50% of respondents 'strongly agreed' or 'agreed' that the networks education offering adds value for children receiving end of life care.
- 33% of respondents 'agreed' that the networks audit and continuous quality improvement activity adds value for children receiving end of life care.

This table includes a summary of all survey responses. However, it is acknowledged that some response views may not be relevant to the role and or remit of the National Managed Clinical Network.



An action plan will be developed with the PELiCaN Steering Group to address areas for improvement.

## Looking forward – 2024/25

The below details key service development objectives planned for 2024/25.

- Consider the recommendations from the palliative care strategy and identify any actions for the network.
- Develop gold standard guidance documents and templates for use of syringe drivers in paediatrics.
- Develop National Symptomatic Guidelines for paediatrics.
- Develop gold standard guidance documents and templates for confirmation of death competency in paediatrics.
- Deliver a suite of education resources including 'train the trainer' resources to support delivery of training on having effective goals of care conversations in all health boards.
- Deliver a patient experience outcome measurement tool in association with University of York.
- Deliver 3 case-based learning events.
- Report on impact of service development documentation.

## Finance

There was no spend on the network budget in 2023/24. All events and meetings that took place were online and no other expenses were incurred.

## Risks & Issues

There is a risk that there may be a negative impact on delivery of workplan objectives this year due to the impacts of moving to portfolios of care, potential changing of staffing etc which may result in less objectives being delivered.

There is a risk that PELiCaN may not be able to progress all workplan objectives in 2024-25 if there is a gap in Lead Clinician (LC) tenure. Due to the lack of clinical leadership and expertise as well as strategic oversight. There is also a specific risk around reputational damage due to miscommunication around the extension/recruitment process for PELiCaN Lead Clinician.



## Appendix 1- Feedback Report Case Based Learning Event - 7 Feb 2024





### Q1- Attendees Board

9-Tayside  
6- CHAS  
4- GGC  
3- Lothian  
2 – Grampian  
2- NSS  
1 – Ayrshire and Arran  
1- Lanarkshire  
1- Highland  
1- Forth Valley

#### 3. The case presented increased my learning/knowledge

[More Details](#)


 Insights





 Strongly agree	18
 Agree	12
 Disagree	0
 Strongly disagree	0



#### 4. The facilitator encouraged and supported discussions and invited questions/comments from participants

[More Details](#)

 Insights

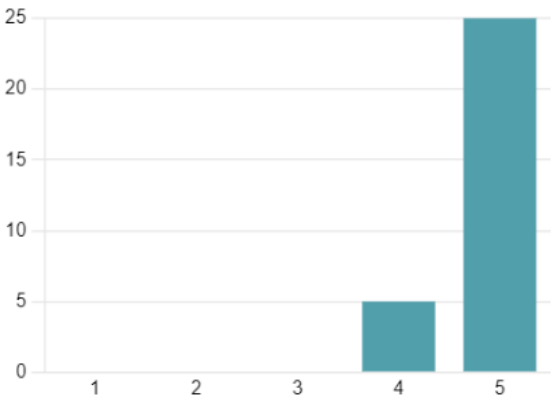
 Strongly agree	26
 Agree	4
 Disagree	0
 Strongly disagree	0



5. Rate your overall satisfaction with the session

[More Details](#) [Insights](#)

4.83  
Average Rating

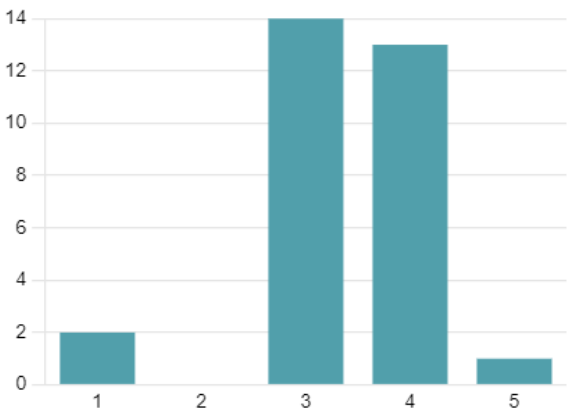


1- Very dissatisfied – 5- Very Satisfied

6. Please score your knowledge of the topic **before** the session

[More Details](#) [Insights](#)

3.37  
Average Rating

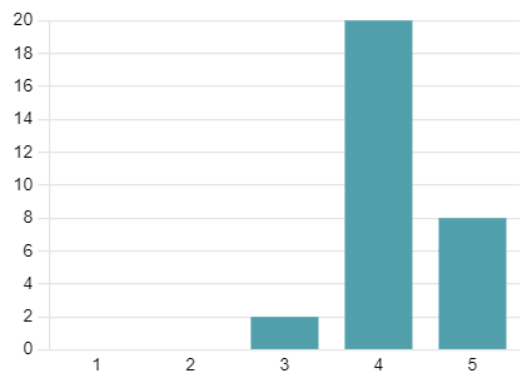


1- Very dissatisfied – 5- Very Satisfied

7. Please score your knowledge of the topic **following** the session

[More Details](#) [Insights](#)

4.20  
Average Rating



1- Very dissatisfied – 5- Very Satisfied