

# **PELiCaN Network**

## Annual Report

### 2022/23

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## Introduction

Throughout 2022-23 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

PELiCaN continues to thrive, grow and develop, driven by the passion and inspiration of its visionary devoted members of whom we are so grateful, especially when we acknowledge that key personnel are busy healthcare providers. We have had to temper our aspirations as both of the highly trained paediatric palliative care consultants have been unavailable for consultation; an issue that we felt necessary to enter on the formal NSS risk register.

This year we have managed to complete our bereavement best practice and occurrence markers work and published all associated documentation on our website. This was presented at the combined education day with the 'Children with Exceptional Healthcare Needs' NMCN. This work was prioritised in response to requests that were received at our roadshows and embraces the driving principal of 'family-centred care' and the philosophical approach of 'what matters to me'. We continue to progress with three broad themes: the core service development and the educational groups work-streams, both of which are heavily influenced by the lessons learned from within the 'Experts by Experience' parental group. Our representative pivotal role to develop the acute intra-hospital palliative clinical care service and to capitalise on our opportunity to represent our member's views on the National Palliative Care Strategy Steering Group. And to continue to build the catalogue of documents that form the often referenced 'toolbox' to make available to all care providers on a universally accessible digital platform.

Despite the universal challenges faced by clinical staff and service development managers, PELiCaN is flourishing, dynamic and pan-inclusive: the work continues to be absorbing, impressive and expansive. The goals are inviolable: we will provide the tools for all those involved in the provision of paediatric end-of-life care to help the families create a bespoke masterpiece that captures their baby's, child's or young person's 'final scene' of their natural life, and to help the families reflect upon positive memories, virtues and values.

Our determination will ensure that the next year proves to be just as rewarding.

## Current Position

The Network completed 100% of all workplan service development objectives. Extensions were agreed for two additional objectives which had not started. These will begin in 2023-24 and have been approved by the Senior Management Team.

A key development was the creation of two more 'gold standard' guidance documents which have been rolled out nationally (see more detail in highlights). The network also achieved further development of the end of life toolkit. This included work to review the use of the Children and Young People's Anticipatory Care Plan (CYP ACP), Children and Young People Acute Deteriorate Management (CYPADM) form, ReSPECT and Digital ReSPECT and also the Paediatric Treatment Escalation Plan (P-TEP). A final important piece of work was the development of a

network data group who will work to drive quality improvements in end of life care services across Scotland.

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 two 'gold standard' guidance documents this year, a summary of each and its purpose is below:

- 'Guide to Completing Effective De-Briefs Following the Death of a Child or Young Person'-This guidance document outlines the process for holding effective debriefs following the death of a baby, child or young person. The guide supports staff to reflect and recount any examples of exemplary practice of multi-disciplinary teamwork, but it equally supports them in identifying any lingering negative emotions of stress, guilt, anxiety and sadness
- 'Notifying Police and Scottish Ambulance Service of Child Likely to Die in the Community (Occurrence Markers)'- The purpose of this document is to ensure Police Scotland and Scottish Ambulance Service (SAS) are made aware of palliative patients who are vulnerable to sudden deterioration that could result in death at home and those who are actively dying and receiving end of life care (EOL care) at home, to ensure an informed and measured response to such calls. A launch event was held for this process as it would be a significant change to current process in Boards, this was attended by 122 people, and Boards have engaged well so far with adopting the guidance into local processes. The Network also worked collaboratively with Police to create an information sheet for officers on end of life choices and the occurrence marker process.

The Network gathered feedback on the impact of these documents<sup>1</sup>. A feedback link will be circulated annually, and any comments will be considered. The Network will also use the results to tailor processes when producing further guidance, for example, ensuring that members understand their responsibility to share documents with their own contacts who may not be linked in with the Network.

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

## **End of Life Toolkit Development**

Through the year PELiCaN worked to review the use of the following documents: ACP, CYPADM, RESPECT and P-TEP. A number of actions have come out of this group which will be actioned later in 2023-24 including:

- Review and update the CYP ACP template
- Create a new CYP ACP guidance document on how to complete them appropriately
- Develop appropriate education programme to go with the new ACP documentation
- Review use of CYPADM and ReSPECT forms, based on feedback from professionals and families. This may include an update of the CYPADM form
- Develop a national P-TEP form and pilot its use

Additionally, PELiCaN met with NES Digital colleagues who confirmed that Digital ReSPECT was now available for all Boards to use. There a number of early adopter Boards using the system; NHS Forth Valley, NHS Tayside, NHS Lanarkshire, NHS Western Isles and NHS Ayrshire and Arran (not all are utilising this in Paediatrics). In 2022-23 PELiCaN linked with NHS Tayside paediatric department who are testing use of the form with a number of young people who are transitioning to adults' services. They are committed to ensuring that any learning is shared.

## **Data Group Established**

There were numerous challenges in setting up a PELiCaN data group including lack of engagement, the moving landscape in terms of data gathered by Child Death Review (CDR) and clinical pressures that affected members availability to attend meetings. Despite this, the network data group have now met twice. The priority for 2023-24 will be to use feedback from the Experts by Experience (EbE) Group to drive service improvements and evidence the benefits of doing so. It was agreed that further work on producing recommendation from the PELiCaN service mapping exercise should be placed on hold until the Scottish governments' service mapping exercise is complete in 2023-24.

Through the year the Network linked closely with the CDR team who noted that their electronic data system was still not up and running. It is expected that this will be rectified in the near future and the possibility of a data sharing agreement will be investigated by the Network when this is in place. It was established that, in-line with the CDR process in England, the Scottish CDR would develop supplementary data forms which PELiCaN could support with. This is an excellent opportunity for PELiCaN to gather all necessary data and get a picture of the landscape and requirements of services across Scotland. Ensuring links with the Scottish CDR process will also support Health Board engagement and reduce duplication of effort for clinical staff. The timescales are unknown for the supplementary data forms, but the Network will keep in touch with CRD to remain informed.

## **Palliative Care Strategy input**

During the year Dr Kidson was appointed as a member of the Steering Group for the update of the national palliative care strategy, representing paediatrics. Following a number of discussions the Chairs of SCYPPCN have also been invited onto this group to broaden the voice of paediatrics in this piece of work. The group will conduct a service mapping exercise of all paediatric palliative care services across Scotland utilising the original service mapping conducted by PELiCaN in 2021-22 as a starting point. The Network are involved in development of the new service mapping tool, ensuring joined up working and that the voice of paediatrics is at the forefront.

## **Efficiencies– Education and Communication Group**

The Education, and the Communication and Engagement sub-groups were combined this year to become the Education and Communication Group. It became apparent many tasks were shared among the remit of both of these groups, so to ensure efficiencies in the ask on members time and efforts and, given the ongoing clinical pressures facing clinical staff in Boards, these groups were merged.

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

The PELiCaN Experts by Experience (EbE) family engagement group had a productive first year. There are currently eight families in the group and the network thanks our members for their support this year and going forwards. The group gathered service user feedback on 'what went well', 'what could have gone better' and 'what would families like to be available to them if it wasn't at the time of receiving end of life care'. Information gathered will be used to inform quality improvements and sharing of best practice going forwards in 2023-24 and beyond. The second half of the focus group will take place in early 2023 following this the Network will work with the EBE group to identify priority projects, once these have been identified they will be added to the revised Quality Improvement Strategy for the network.

## **Looking forward – 2023/24**

The below details key work that is planned for 2023/24.

- By 31/3/24 PELiCaN will have started work on developing gold standard guidance documents and templates on the use of Symptom Management Plans and Just in Case boxes nationally. This will fit into the PELiCaN End of Life Toolkit
- By 31/3/24 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.
- PELiCaN will continue to contribute to and advise on the work ongoing with Scottish government to update the palliative care strategy. This will include implementation of any recommendations which may be identified.
- Through 2023 PELiCaN will continue to work on establishing a role for end of life documentation by means of creating an 'end of life toolkit', this will include Digital RESPECT, CYPADM, Children and Young People's ACP and Paediatric Treatment Escalation Plans.

## **Finance**

There was no spend on the network budget in 2022/23. All events and meetings that took place were online and no other expenses were incurred.

## **Risks & Issues**

There is a risk that due to extended period of absence of both Paediatric Palliative Care Consultants in Lothian and GGC, who provide specialist subject matter expertise to PELiCaN, that progress on some workplan objectives may not be able to progress in a timely manner (service developments).

## Appendix 1 – Feedback on PELiCaN Service Development Documents

Which Document are you feedback back on	How useful did you find this document?	Did you find the guidance document easy to follow?	Is the guidance document now recognised/mentioned as part of your local process	How did you implement this guidance document into your local processes/practice?	Did you share this document with colleagues in your board who may not know about PELiCaN	If you didn't share the guidance document with colleagues - how do you plan to do this in the future? OR If you did share the document, how did you do this?	Do you have any comments on the content of the guidance document content?	How do you access the document when using it?
Clinical Lead Checklist – Post Child Death	Extremely Useful - 2	yes -3	yes -2	Used in conjunction with our local bereavement checklist	Yes-2	Emailed around relevant colleagues	Easy to use but will continue to use our local checklist as it has more detail of AHP's and shared care centres	Online -2
	Somewhat Useful- 1		I don't know -1	I will highlight this to child death lead		I will highlight this to child death lead	Useful overview	Saved copy to own files- 1
			I work in ED so some of it isnt relevant but it will be there of 'expected deaths'	I work in ED so some of it isnt relevant but it will be there of 'expected deaths'		via e-mail and weekly brief and teaching sessions	excellent and useful	
Funeral Costs in Scotland for children under the age of 18 years	Extremely Useful - 2	yes -2	yes -1	Added as link in checklist for clinicians	Yes-2	At our team meeting and will be discussed at departmental CME session as part of session on child death	It was very clear and factual	Online -1
			I don't know -1	It will be passed on at team meeting and put on our shared drive		Shared at team meeting an sent link to it electronically		Saved copy to own files- 1
Guidance for the Compassionate Reorientation of Care + Flow Chart Doc	Extremely useful	Yes	Yes	shared publication through email and discussed and operational group meetings. shared with teams likely to utilise. we have our own eol pathway (which the guideline and flow chart was adapted from) however we reference the documents in our associated guidelines section.	Yes	through operational group meetings, ward round and team meetings	easy to follow and easy for other health boards to adapt into their own area as we recognise that every are will have access to different (sometimes limited) resources to support end of life care	Online (PELiCaN website)
Raising Occurrence Markers with Police and Ambulance Service Process	Extremely Useful - 5	Yes- 5	Yes- 5	Have used this document a few times now and have found it easy to use with good communication to ambulance and police. Has made raising the alert a much easier process	yes- 4	Have emailed it around and poster up on noticeboard in office area	Easy to follow.	Saved a copy to own files-3
				Supportive Care team who would be leading on such patient's care made aware of guidance		Discussed at Supportive Care Team meeting	Very clear	Online (PELiCaN website) - 1
				the guideline was initially developed locally in NHSL so it's use has been led by the PCT locally as part of the CYPADM and EOLC planning with appropriate teams		shared with relevant teams who have patients with CYPADMs	it has proved very useful for reducing the stress around deaths at home and police/SAS involvement	
				adapted into our local guideline and referenced PELiCaN guideline. Shared the PELiCaN guideline with colleagues who are likely to utilise it: CCNS, Critical Care, CNS teams. we decided as an area that all occurrence markers/ambulance alerts would be managed through the palliative care team for the two groups of patients identified in the guideline		shared via email and discussed at operational group meetings and disussed with CDR team	it would be good (and more pragmatic) to have the forms for completion hyperlinked and formatted in to a template that can be electronically filled in.	Printed copies held locally -1
Through Colleague who was involved in development of the process	Spoke about it.	To make the forms an online form which once completed, are sent automatically to Police Scotland and Ambulance service and copied to the person completing the form or allow the forms to be accessed and edited in a single document for completing and emailing to the addresses required.						