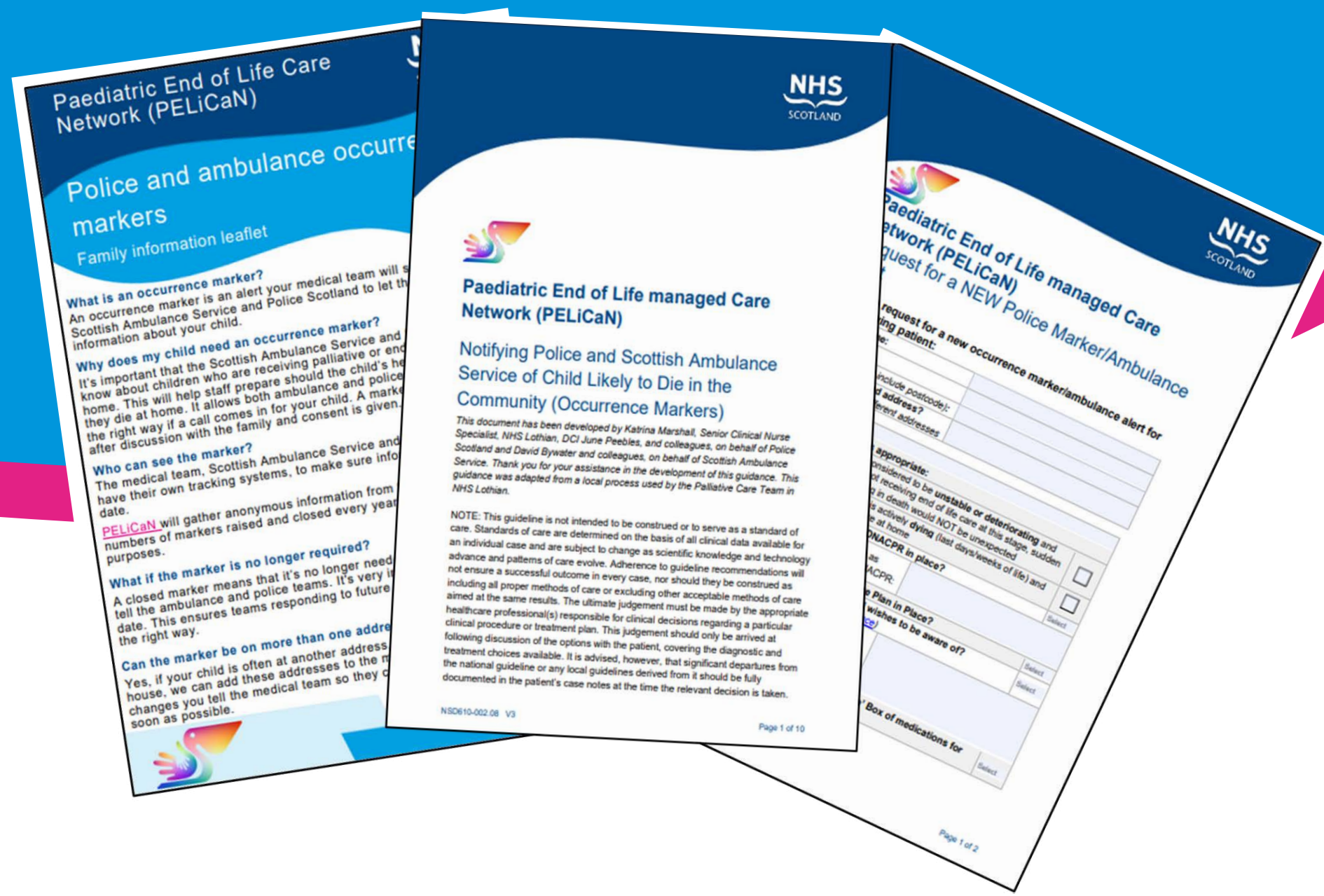


Paediatric End of Life Care Network (PELiCaN) - Police Scotland Occurrence Marker/Scottish Ambulance Service alert project



Establishing a process for sharing key information with emergency services for children who are likely to die in the community.

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Aim

The number of children living with a life-threatening/life- limiting condition (LTLLC) is increasing in Scotland.¹ As a result of medical and technology advances, children with LTLLC are surviving longer² and are requiring palliative care in the community over a longer period of time.³

PELiCaN developed a nationally consistent process to facilitate seamless integrated care between agencies for paediatric palliative care patients who identified home as their preferred place for care. This process identifies patients who are unstable/deteriorating and vulnerable to sudden deterioration that may result in death at home and patients who are ‘actively dying’ and receiving end of life (EoL) care at home. Ensuring integrated working between Police Scotland, the Scottish Ambulance Service and clinical services, a proportionate and sensitive response can be facilitated, should attendance be needed at the home of a child who has died.

This work was in response to several situations reported by health boards where there was an un-measured response by emergency services in situations where child death at home was expected leading not only to distress for families but also professionals involved.

“All children and young people with palliative care needs should be cared for and die in their preferred place of care”

Scottish Children & Young People Palliative Care Executive 2012⁴

Evidence shows that the loss of a child puts parents at greater risk of complex grief.⁵ The aim of this process is to reduce the risk of further trauma to families immediately after a child’s death by ensuring emergency services are able to use information on the child’s situation effectively and efficiently, avoiding unnecessary actions.



Methodology

An expert review group with representation from key stakeholders was formed who then followed the below process:



The national guideline was launched at a webinar of 122 delegates. The aim was to encourage boards to adopt the process into local procedures. Ultimately providing a better service to families whose child dies at home.

- The benefits of this process/guideline are:
- reduce/avoid risk of trauma
 - robust communication process and integration between services
 - more informed decision making
 - reduce risk of unnecessary transfer of patients to hospital
 - reduced fears/anxiety for families who choose for their child to die at home.
 - improved patient safety
 - whole system change to provide real choices for families to have EoLC at home

Results / Outcomes

Eight out of 14 Scottish health boards have so far adopted the process incorporating 12 of 13 Scottish Police Divisions. Work will be ongoing to ensure this process is adopted by all Board areas in the near future.

Evidence suggests positive outcomes for patients and their families. For example:

- Avoidance of unnecessary transfers of deteriorating patients by SAS by having key information in advance.
- Parental feedback which has further informed changes to the process.
- Evoke empowerment amongst families when considering EoL choices for their child. By reducing fear, as result of hearing other parent’s negative experiences.
- Consistent and robust working partnership with Police Scotland/SAS since process implemented in 2021.
- Improved patient safety.

Whilst we cannot change the outcome, for those children who are palliative, we can influence the quality of support and care provided.

Quote - “Feedback from frontline staff confirms that the markers have positively impacted their ability to provide appropriate care, ultimately improving the overall service provision for children requiring emergency assistance” Scott McKinnon, Scottish Ambulance Service (2025).

Produced by: Paediatric End of Life Care Network (PELiCaN) Managed Clinical Network, National Services Division, NSS.

Health Boards Requesting Markers

NHS Dumfries and Galloway
NHS Fife
NHS Forth Valley
NHS Greater Glasgow and Clyde
NHS Grampian
NHS Highland
NHS Lothian
NHS Tayside

Boards requesting differs to Local Authority area of residence. This is due to the location of clinical teams leading on the management of a child’s care, which may be out of their area of residence.

Local Authority Residence of Patients Where Markers Raised

Aberdeen	Renfrewshire
Angus	Scottish Borders
Argyle and Bute	South Lanarkshire
D&G	Stirling
Dundee	West Lothian
East Lothian	
Edinburgh	
Falkirk	
Fife	
Glasgow	
Midlothian	
North Lanarkshire	
Perth and Kinross	

References

¹[https://pure.york.ac.uk/portal/en/publications/children-in-scotland-requiring-palliative-care-identifying-number-Children-in-Scotland-Requiring-Palliative-Care-identifying-numbers-and-needs-\(The-ChiSP-Study\).](https://pure.york.ac.uk/portal/en/publications/children-in-scotland-requiring-palliative-care-identifying-number-Children-in-Scotland-Requiring-Palliative-Care-identifying-numbers-and-needs-(The-ChiSP-Study).)

²<https://pubmed.ncbi.nlm.nih.gov/31625623/>
Survey of paediatricians caring for children with life-limiting conditions found that they were involved in advance care planning.

³<https://bmcpalliatcare.biomedcentral.com/articles/10.1186/1472-684X-12-18>
Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar.

⁴<https://www.gov.scot/publications/framework-delivery-palliative-care-children-young-people-scotland/A-Framework-for-the-Delivery-of-Palliative-Care-for-Children-and-Young-People-in-Scotland.>

⁵<https://pubmed.ncbi.nlm.nih.gov/35610720/>
Looking back: Identifying supportive care and unmet needs of parents of children receiving specialist paediatric palliative care from the bereavement perspective.

