

Paediatric End of Life Care Network (PELiCaN) A Proposed National Managed Clinical Network

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Background

It has been recognised across the health and care sector that broader collaboration in paediatric end of life (EOL) care is required to achieve the best possible care for patients and their families.

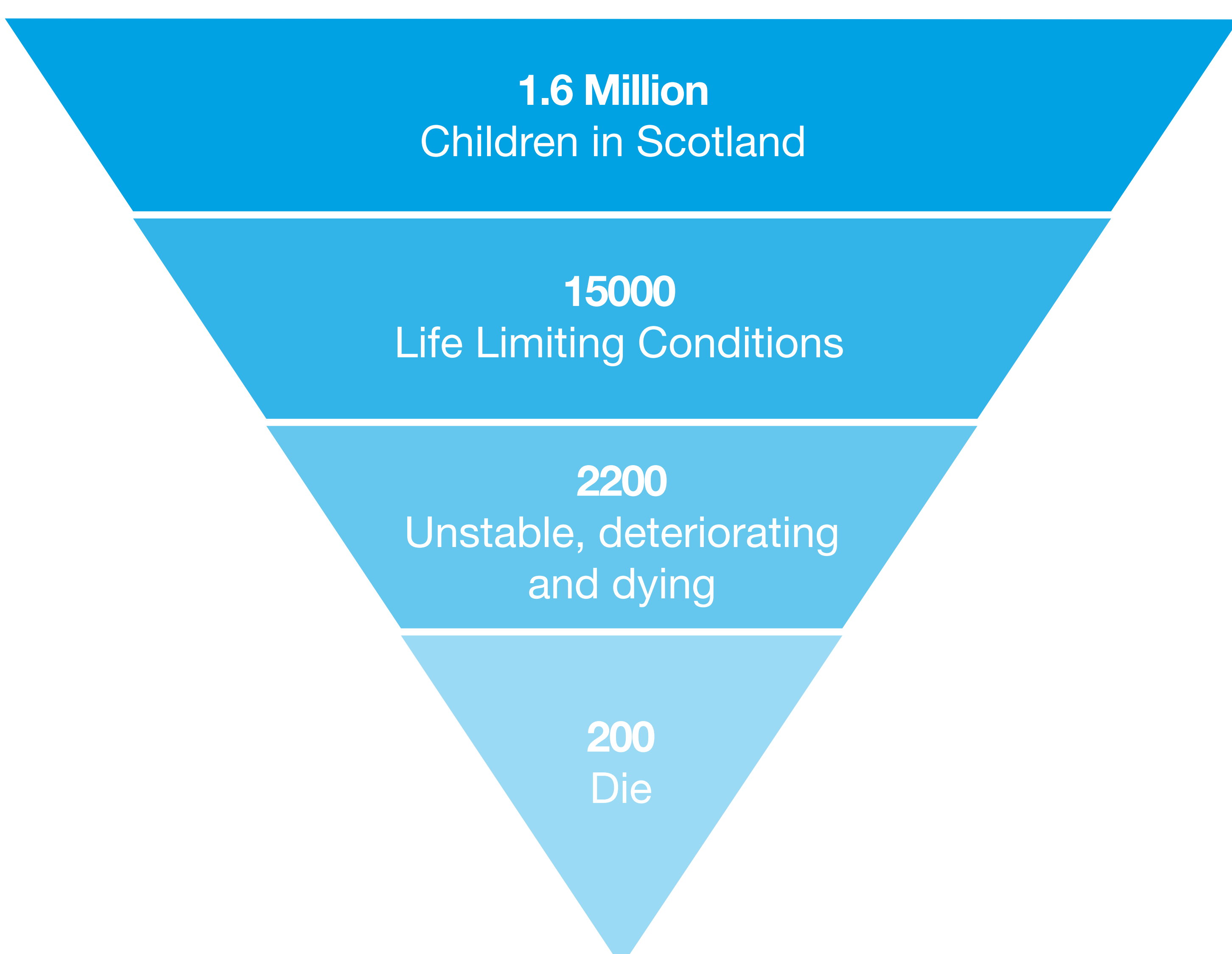
In response, National Specialist and Screening Directorate (NSD), in consultation with a wide range of stakeholders, submitted an application for a new national Managed Clinical Network focused on improving paediatric EOL care. A working group, including parents of patients, prepared the proposal for the Paediatric and Young Peoples End of Life Care Network (PELiCaN) which has since been approved for national implementation.

Challenges

There are approximately 2,200 children and young people in Scotland who have EOL care needs. There is variation in access to care, inequity and reduced choice for families and their children due to several factors:

- The number of children is small but significant. Specialist services for EOL care are not available in all locations and Scotland's geography impacts on the delivery of care in remote and rural communities.
- EOL care for children and young people requires input from a variety of care and voluntary services.
- Few professionals have specialist postgraduate training in palliative care.
- There are more children with palliative care needs who live in areas of deprivation and who are from ethnic minority backgrounds.

Children in Scotland requiring palliative care (ChiSP report) 2015



The Vision

PELiCaN aims for every child and young person that requires EOL care to have improved access to the support they need.

To achieve this, a multi-disciplinary steering group in collaboration with existing networks and organisations, will aim to:

- identify where there is reduced equity of access to care
- develop guidelines and care pathways to improve transition arrangements, support local care within national guidelines and allow every family a meaningful choice of the place of death
- engage with families as key stakeholders to identify areas for improving information
- ensure the Framework for the Delivery of Palliative Care for CYP in Scotland is achieved
- improve communication and collaboration in the work surrounding anticipatory care planning (ACP)
- develop an education programme for all members of the MDT

Measuring outcomes

Data sets will provide information at local, regional and national levels to inform planning and reduce unwarranted variation in outcomes.

The following indicators have been proposed for recording progress:

- An appropriate and timely EOL care discussion with every patient and their family.
- Family-led anticipatory care planning, including increased awareness and training in their use.
- Assessment of the potential need for emergency admission at the end of life.
- Patient-reported outcomes and experience measures.

While outcome indicators are not yet available the work toward national designation has promoted a significant level of collaboration.

Conclusion

The need for a development like PELiCaN to champion improvements in EOL care for children and young people has been evident at both a clinical practice and care policy level for some time. NHSScotland has been able to progress this work through NSD providing support for multiagency engagement and co-creation of the proposal.

