

School of Health and Social Care

Scoping exercise to inform the development of an education strategy for Children's Hospices Across Scotland (CHAS)

SUMMARY DOCUMENT



Children's Hospices Across Scotland



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Background

Children's palliative care¹ continues to grow as a speciality in Scotland with sustained increases in the prevalence and complexity of life-limiting conditions (Fraser et al. 2015). Education is an integral component of children's palliative care to ensure the workforce is capable and equipped with the required knowledge, skills and attitudes to deliver high quality and effective care. Policy makers and professional bodies recognise the need for and support educational initiatives within children's palliative care (Scottish Children and Young People's Executive (SCYPPEX) 2012; Scottish Government 2015; NES/SSSC 2017). This report presents findings from a scoping project examining current evidence relating to the provision of education across the United Kingdom (UK) and internationally. The overall aim of the project was to inform the development of an evidence-based and research-informed education strategy for Children's Hospices Across Scotland (CHAS).

The objectives of the project were:

1. To review the literature and evidence base pertaining to policy, practice and research in children's palliative care education.
2. To identify the current and future education, learning and continuing professional development requirements of practitioners, volunteers and professionals working across the field of children's palliative care in Scotland.
3. To provide recommendations for and contribute to the development of an evidence-based education strategy for CHAS which can inform the future service agenda and influence the delivery of a national approach to children's palliative care education, learning and continuing professional development.

Methods

Three phases of activity were undertaken to meet the above objectives. Phase 1 consisted of a scoping review of the evidence base to provide a comprehensive overview of relevant research, policy and practice pertaining to children's palliative care education (Arksey and O'Malley 2005; Levac et al. 2010). Using a qualitative exploratory design, Phase 2 involved focus group discussions and an online survey to identify the learning and development needs of hospice staff, volunteers and professionals from health, social care, education and early years services with links to children's palliative care. In Phase 3, findings from the literature review, focus groups and survey were reviewed and synthesised to propose a set of recommendations which would form the basis of an education strategy for CHAS.

¹ The term children's palliative care is used throughout this report with the understanding that it is inclusive of neonates, infants, children and young people.

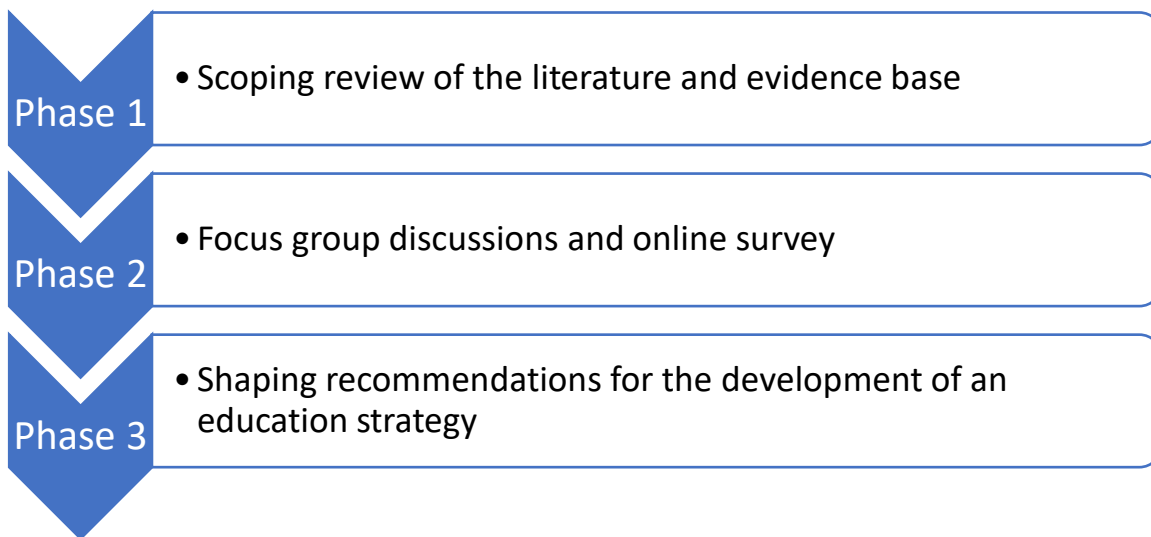


Figure 1: Methodology illustrating phases included in the project.

Key Findings and Recommendations

A scoping review of 85 papers and 35 items of grey literature was undertaken. Engagement with 79 stakeholders through focus groups (n=61) and completion of an online survey (n=18) was also completed. These stakeholders represented a wide range of services and care providers including the NHS (acute and community), children’s hospices, the voluntary sector, social care and education services.

Phase 1 Findings - Scoping Review of the Literature

The importance of education in preparing the workforce to deliver quality palliative and end of life care to children and families was evident in the papers reviewed. The agenda for children’s palliative care education has largely been informed by the development of national and international core standards and frameworks that guide best practice within palliative care. Programmes of learning should be based on these recognised paediatric palliative care competency frameworks and standards. Moreover, it is acknowledged that the care and support needs of children and families are continually changing. As they change so will the education and training needs of those who are providing their care and support. It is important that education is responsive to these evolving care needs.

Children’s palliative care is delivered by a network of service providers from health, social care, and education settings within the statutory, voluntary and independent sectors yet not all sections of the workforce were represented in the literature reviewed. The emphasis was on education requirements and initiatives for doctors and nurses working in tertiary care settings with most other disciplines, including those working within children’s hospices, currently under-represented. The growing complexity of children’s palliative care provided in the community underlines the importance of ensuring there is adequate education, training and support for this part of the

workforce. Further research to explore the education and learning needs of those delivering community-based care would be of value.

All individuals who are in contact with children with palliative care needs must have the knowledge, skills, and attitudes to do this effectively and compassionately. Across a range of settings, support staff (including reception staff, porters, ward clerks) serve a vital role in the provision of palliative care and there is a clear need to provide better training and support services for these individuals.

Education is clearly visible in recent UK policy. Commitment 3 within the *Scottish Government's Strategic Framework for Action on Palliative and End of Life Care* explicitly highlighted their support in developing a national educational framework to support workforce development in this field. In 2017, the *Palliative and End of Life Care: A framework to support the learning and development needs of the health and social service workforce in Scotland* (NES/SSSC 2017) was published. The framework is all encompassing and directed at "every worker who might come into contact with people who have palliative and end of life care needs" across a range of settings. There are four increasing levels of knowledge and skills in the framework which mirrors other tiered approaches to education within palliative care. Such approaches acknowledge the requirement for all individuals to receive education on the principles and practices of palliative care, with those individuals whose work is primarily focused on palliative care move to a specialist level of knowledge.

There was extensive evidence on the unmet learning needs of those delivering palliative and end of life care. Priority content areas included pain control and symptom management, managing palliative care emergencies, providing emotional support and bereavement care to families, end of life care planning, care of self and personal coping strategies and psychosocial skills.

Communication skills, including discussing uncertainty and poor prognosis, was the most frequently identified learning need in the literature. Whilst not all sections of the paediatric palliative care workforce or care settings were represented in the papers, in those professions and settings that were, there was clear consensus that communication was a priority content area for further education.

There is evidence to suggest that working in the field of children's palliative care has a powerful emotional impact on individuals. The literature reviewed emphasises the importance of self-care and personal coping strategies being included as part of a well-rounded curriculum. The emotional investment individuals make in delivering quality palliative care is valued and appropriate support, development and training for their role is warranted.

The principles of paediatric palliative care should be introduced at an undergraduate level and continue during postgraduate education and through continuing professional development.

Where possible, practice placements that provide opportunities for learning in a range of settings where palliative and end of life care is delivered should be promoted.

Within children's hospices and the wider field of children's palliative care, there is immense value in engaging in multi-professional education and training as this is reflective of the way that care is delivered and facilitates effective team-working and communication. However, it was also noted in the literature that it is important to maintain a balance. Whilst multi-professional education or shared learning offers benefits, education within disciplines is also important to ensure the distinct needs of each profession is addressed.

Involving children and families in the design, delivery and evaluation of education has been shown to be effective in children's hospice and wider palliative care settings and is valued by both professionals and families. The literature offers a range of approaches for engaging children and families in the training and education of those working in children's hospice and palliative care.

All education and training should be based on effective and evidence-based approaches that reflect the "real world". Effective learning methods described in the literature included experiential or "on the job learning", case-based learning, clinical simulation, reflection and small group discussions. Those approaches which aim to embed education into daily practice are deemed to be the most effective.

In addition to increasing the knowledge base and developing skills, attitudes form a core component of the palliative care curriculum. Emphasis on how the values, beliefs, attitudes, and ethics of paediatric palliative care can best be taught would be of merit.

The challenge in accessing learning opportunities in children's palliative care was acknowledged in the evidence base. Many children have complex and rare life limiting conditions which pose an additional challenge for educating the workforce. It is therefore important to maximise those opportunities for learning as they arise in practice. Education in children's palliative care should ideally be facilitated by individuals who are experts in paediatric palliative care and have experience in education and pedagogy.

Phase 2 Findings – Focus Group Discussions and Online Survey

The experiences and perspectives described by CHAS staff members and those professionals delivering children's palliative care in different services and regions in Scotland were largely homogenous. There were issues related to education that were specific to each group, however, the overall consistency in the discussions provides a strong rationale for considering a standardised and national approach to education in children's palliative care.

The underlying importance of education in enhancing the quality of care delivered to children with palliative care needs and families was compelling and resonated across the focus group discussions. Educational initiatives should be targeted at all those who have contact with children and families with palliative care needs, including individuals working in support roles and

volunteers. The level and scope of education should be dependent on an individual's role and responsibilities.

Areas identified for future learning and continuing professional development were consistent across the focus groups with the domain of communicating with children and families surfacing as one of the main priorities. There were many examples of communication skills that could be enhanced through further education, including communicating difficult information to families and providing psychosocial and emotional support. Participants acknowledged that further education on end of life and bereavement care should also be prioritised. A recurrent theme running through each of discussions was the essential requirement for self-care. The emotional impact of working with in the field of palliative care was acknowledged and an educational framework for self-care where professionals can discuss, reflect and learn from their experiences in practice is required.

Preferred learning approaches were also comparable between CHAS staff and external professionals and included case-based learning, small group learning, simulated practice and experiential learning. Participants emphasised the merit of 'learning on the job' and where possible, children's palliative and end of life care education should be integrated into everyday practice. It is important to share learning and for those who are more experienced in paediatric palliative care to support others in gaining knowledge and skills. Participants recognise that effective children's palliative care is predicated on inter-professional collaboration and team-working and support an interdisciplinary approach to palliative care education and training.

There were many similarities in the key challenges identified for children's palliative care education. Mutual challenges involved resource implications, namely time, to access training and apply learning to practice and limited opportunities for continuing professional development including an absence of postgraduate programmes that focus on children's palliative care.

Challenges specific to CHAS' workforce were also raised. A recent strategic aim within the organisation to extend their 'reach' and provide care to more babies, children and young people with palliative care needs across Scotland is advocated by its staff and volunteers. However, this expansion in the service has identified specific learning and development needs that can be addressed through a future education strategy to best support staff and volunteers in delivering care.

The focus groups generated both innovative and achievable ways in which capacity and capability for children's palliative care could be fostered through education. The potential for CHAS to lead such educational developments and serve as an expert resource to the broader children's palliative care community resonated within the discussions. Importantly, participants advocated a collaborative approach to educational developments involving partnerships with the NHS, professional bodies and higher education.

Having a strong organisational philosophy and culture of learning was identified by the participating CHAS staff and volunteers as a means of motivating and encouraging lifelong learning within the hospice. There was a clear enthusiasm amongst participants to create and nurture a culture of evidence-based learning.

In summary, the findings from this phase of the scoping exercise provides further evidence to inform the development and implementation of a comprehensive programme of evidence-based palliative care education which will meet the learning and development needs of CHAS's workforce. Such a programme would additionally be of value if it were extended to professionals working in the wide ranges of settings where children with palliative care needs and their families are cared for and supported.

Recommendations

Based on the findings, the project team proposed ten key recommendations which are detailed in the final report. An abbreviated list of the recommendations is presented in this summary document:

- The education strategy should adopt a strong philosophy and culture of learning, enquiry and evidence-based practice.
- Developing and implementing an education strategy will have resource implications and requires a dedicated learning and development team with the inclusion of expertise from both paediatric palliative care practice and higher education.
- Consider conducting a formal learning and development needs analysis on a regular basis to ensure that education and training is responsive to the changing needs of staff and volunteers. The current priority learning and development needs identified during this project should be addressed in the first instance.
- The education strategy should be cognisant of the relational and emotional context within which staff and volunteers are caring for and supporting children and families. Through evidence based educational approaches, self-care, self-awareness and resilience building should be addressed to support staff and volunteers in managing the emotional dimension of their roles.
- Consider implementing the educational strategies and approaches identified during this project in the literature review and focus group discussions.
- Consider developing formal relationships with higher education institutions to further the development and accreditation of educational courses. Specific consideration should be given to the development of an inter-professional post-graduate educational pathway in the context of advanced paediatric palliative care practice. This is important for supporting the development of future leaders in children's palliative care and promoting the creation and dissemination of evidence-based knowledge in paediatric palliative care.
- Further development and enhancement of clear career pathways for all staff groups within CHAS (newly qualified, qualified, support staff and volunteers) should be prioritised to ensure opportunity for continuing personal and professional development and progression.
- Three main populations were identified as a priority for implementing educational initiatives in children's palliative care – the public, those working in generalist roles, and palliative care specialists. CHAS are ideally placed to lead the development of such

initiatives and it is recommended that CHAS consider developing educational initiatives in partnership with key stakeholders and experts across NHS Scotland.

- Consideration should be given to maximising opportunities for building capacity and capability in the small and specialist field of paediatric palliative care, through sharing of knowledge and expertise. Suggested strategies to achieve are included in the report.
- CHAS should consider linking with higher education institutions to influence the curriculum by sharing innovative and feasible ways of integrating the concepts of children's palliative care into undergraduate education.

Conclusions

The themes identified during review of the literature were consistent with those originating from engagement with the children's palliative care workforce in Scotland. Education, learning and continuing professional development are core to developing and maintaining a workforce capable of delivering the best possible care to children with palliative care needs and their families. The findings emanating from this project contribute to the evidence base surrounding the requirement for further development of educational initiatives to enhance capacity and capability of the workforce. Moreover, they provide a strong and focused argument for the development of a comprehensive and inclusive education strategy within CHAS.

Next Steps

The overall findings of this project identified many examples of good practice in palliative care education whilst also highlighting gaps in provision. Future work in exploring families' views surrounding education provision would be beneficial. Addressing the recommendations put forward in this report to develop a robust education strategy would enable CHAS to meet the current and future educational needs of its staff. Working collaboratively with external practice partners across Scotland and beyond would enable CHAS to influence and support further development of children's palliative care education.

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**Publisher: School of Health and Social Care,
Edinburgh Napier University**

Publication date: 03.08.2018

This study was commissioned by Children's Hospices Across Scotland (CHAS).

Children's Hospices Across Scotland is a trading name of Children's Hospice Association Scotland. Scottish Charity number SC 019724