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Research Article

Learnings from the establishment and delivery of the UK Collaborative Paediatric Palliative Care Research Network

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Abstract

Background: There are increasing numbers of children living with conditions that may threaten or shorten their lives. While child mortality has decreased in recent decades, it is estimated 4500 infants, children and young people (0–19 years) die in the United Kingdom every year. Despite a growing increase in clinical provision, there is a clear paucity in research evidence underpinning paediatric palliative care. To support research delivery, a United Kingdom-wide network composed of paediatric palliative care-sector organisations and academics with expertise in the area was developed. The network had a clear vision of establishing partnerships between academia and services delivering paediatric palliative care that would support increased research capacity and delivery in the sector.

Objective(s): The overarching aim of the network was to deliver national high-quality research studies, education and materials, and build research capacity. Specific objectives included working closely with seven paediatric palliative care sites to develop guidance on the appropriate methods for undertaking research, the delivery of information and educational resources including a webinar series, offering of mentor opportunities, and the development of a minimum of two bids to National Institute for Health and Care Research related funding pathways.

Design: A collaborative design underpinned the network. Network activity included continued partner engagement through online meetings and newsletters, scoping activity to identify research priorities, establishment of research themes, and active engagement and support from national organisations. Patient and public involvement was core to all network activity.

Setting: Network engagement largely took place online. The network has a web page hosted on the website of the organisation Together for Short Lives.

Partners: Seven paediatric palliative care sites in England and Scotland (six hospices and one National Health Service hospital site) formed the network with input from several academic partners.

Results: The network achieved several outputs related to objectives including the submission of two National Institute for Health and Care Research applications for funding, the delivery of five educational webinars, the establishment of an online research toolkit and the development of a research nurse group.

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Conclusions: Prior to the establishment of the network, there was no national mechanism for co-ordination for research in paediatric palliative care. In bringing together seven partner organisations and clinical and research expertise, the network has supported the foundations upon which to deliver high-quality research in the sector.
Future work: Future work is required to support the sustainability of the network including obtaining necessary funding. Key learning from the network can be transferred and replicated across other contexts, including internationally. Grant applications and research themes developed as a result of the network will continue to develop and mature.
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Background

This paper reports on the key learning from the establishment and delivery of a research network funded by the National Institute for Health and Care Research (NIHR) Health Technology Assessment programme. The paper does not report an empirical study. Consequently, the authors have reported the network following guidance from the NIHR.

There are increasing numbers of children living with conditions that may threaten or shorten their lives. These conditions can be described as life-limiting or life-threatening and encompass nearly 400 individual diagnoses.[1] While child mortality has decreased in recent decades, it is estimated 4500 infants, children and young people (0–19 years) die in the UK every year.[2] Consequently, there is a significant need for evidence-informed paediatric palliative care.

Paediatric palliative care refers to the delivery of care for children with either life-limiting or life-threatening conditions. Care should follow the child's illness trajectory and, therefore, may continue from the point of diagnosis through to end-of-life care and bereavement.[3] While specialist paediatric palliative care teams in the NHS are growing, the delivery of paediatric palliative care is reliant on third-sector organisations such as children's hospices.[4] In relation to the latter, there are 53 children's hospices in the UK and more than 10 hospital-based paediatric palliative care services. In the absence of a national strategy for the development of these services, the delivery of palliative care for children has been described as 'inconsistent and incoherent'.[5] More so, inequalities relating to access to services have been evidenced, in respect of age, ethnicity, gender, diagnosis, socioeconomic status and geography.[6–9]

Despite a growing increase in clinical provision, there is a clear paucity in research evidence underpinning paediatric palliative care, with current knowledge eminence-based as opposed to evidence-based.[10] For example, the quality of evidence that informed the most recent National Institute for Health and Care Excellence (NICE) guidelines on end-of-life care for infants, children and young people was described as low or very low. NICE recommendations for research included identifying factors that support preferred place of care and place of death and managing breakthrough pain.[11] Relatedly, World Health Organization (WHO) guidelines on the management of chronic pain in children also identified significant research gaps.[12] As such, there is an urgent need to develop and improve the evidence base to inform practice guidelines and address national/international research recommendations.[13]

Remedying the paucity in evidence relies on an awareness of the contextual factors that surround the paediatric palliative care sector. For example, given the overall population size, the numbers of children receiving palliative care at any one site or with any one condition are relatively small. Consequently, there was a clear requirement to establish a UK-wide network composed of paediatric palliative care-sector organisations and academics with expertise in the area. A clear vision of the network was to create partnerships that would support the sector to increase research capacity and delivery. In doing so, the network would lay the foundations for addressing key clinical and research priorities including symptom management and outcome measurement, putting the UK at the forefront of paediatric palliative care research internationally.

To achieve this vision, the network had an overarching aim of developing a collaborative UK-wide paediatric palliative care research network that would deliver national high-quality research studies and education, and build research capacity.

Methods

The delivery of this aim was sustained by meeting a set of objectives as outlined below:

1. To work closely with seven paediatric palliative care sites (six hospices and one NHS hospital site) to develop research readiness using methods that can be scaled up to the other hospices and NHS paediatric palliative care sites. Each site was chosen to geographically represent paediatric palliative care services in England, with representation also from Scotland.
2. To deliver a series of educational webinars on the key components of research activity.
3. To establish a process by which those developing and delivering research studies can access a network of patient and public involvement (PPI) partners.
4. To offer mentor opportunities for paediatric palliative care staff interested in developing a research career to apply for fellowships, including the NIHR pre-doctoral or doctoral awards.
5. To develop guidance on the appropriate methods to undertake research in palliative and end-of-life care in children.
6. To develop a minimum of two bids for stage 2 of the NIHR commissioned call on palliative and end-of-life care

To meet the outlined aim and objectives, the following activity was undertaken using a collaborative approach.

Continued partner engagement

To support and sustain network participation (objective 1), regular meetings with all partners were held throughout the life course of the network. Each meeting allowed the opportunity to provide updates to partners and engage in key activity such as providing feedback on network outputs. To complement regular meetings, a Collaborative Paediatric Palliative Care Research (CoPPAR) network newsletter (see project documents) was also produced and sent to all partners.

Priority scoping and setting

To set the agenda for both the research and educational outputs of the network, priority scoping exercises were undertaken. The first exercise aimed to generate subject or topic areas of priority to paediatric palliative care. Clinical and academic representatives across all seven partner sites met online to generate topic areas. Those in attendance were asked ‘what topic areas would you like to see developed into a grant application’. The site ‘Mentimeter’ was used to support participation. In total, 53 topic areas were put forward. These ranged from managing agitation at end of life, to providing wider family support (please see project documents). A process of grouping topics into themes then followed. Feedback was sought from the network at this stage, resulting in a final set of three key themes.

A further exercise with clinical and academic representatives from partner sites aimed to identify areas of the research process where training and guidance was most needed. Based on findings of this exercise, a set of five educational webinars were developed and delivered alongside a set of resources that formed an online research toolkit.

Establishment of research theme groups

The identified 53 topic areas were distilled into 3 core research themes: namely, symptom management and pharmaceuticals, transition from paediatric to adult services and outcome measurement development. The purpose of the research themes was twofold. Firstly, the themes would facilitate networking and the sharing of expertise with clinicians, clinical academics and academics interested in the theme topic. Secondly, each theme would support the generation of research proposals suitable for grant submission (objective 6).

Active engagement and support from national organisations

The network partnered with two key organisations in paediatric palliative care: namely, Together for Short Lives and the Association for Paediatric Palliative Medicine. These partnerships have been integral to meeting the network objectives. For example, both organisations supported the promotion, hosting and dissemination of the educational webinar series. Likewise, the CoPPAR research toolkit has been developed and delivered in close partnership with Together for Short Lives and is hosted on their web page. Finally, the network required a physical presence or space. The CoPPAR network has its own dedicated landing page on the Together for Short Lives web page.

Patient and public involvement

Patient and public involvement was integral to the delivery of network objectives. The network maintained a close connection to an existing Family Advisory Board that represents the perspectives of parents of children and young people living with, or who have died from, a life-limiting condition. In addition to providing general oversight of the network, the Family Advisory Board and other PPI groups (‘SE England CYP PEoLC’ PPI group) directly contributed to network activity and outputs. In relation to the webinar series, the named PPI groups worked collaboratively with network partners to develop and deliver a webinar on PPI. Relatedly, PPI was key to the delivery of resources hosted on the research toolkit

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(objective 3) aimed at supporting young people and parents to engage in research. Regarding further network objectives, PPI has also played a role in the development of a funding bid.

Delivery of funds

To support research capacity-building in the sector, the network provided funding to each partner site to support network participation and research readiness. In addition, the allocation of funding to each partner site facilitated the opportunity for mentoring (objective 4).

Results

The network has achieved the following results against its objectives.

1. Development and delivery of the CoPPAR research toolkit

Hosted on the Together for Short Lives website, the toolkit offers a single point of information for users interested in paediatric palliative care research. The toolkit is designed to cater for different audiences ranging from clinical staff pursuing a research career, to parents of children with life-limiting conditions interested in engaging in sector research.

Toolkit resources include guidance on pursuing a career in clinical research, developing a research funding application and setting up a children's palliative care service as a research site. The toolkit specifically delivers to objectives 3, 4 and 5 of the network.

2. Delivery of five educational webinars

Five educational webinars were delivered across an 18-month period (objective 2) with the primary aim of making research more accessible. Topics covered were research and its value, PPI, clinical research networks, careers in paediatric palliative care and an introduction to the CoPPAR research toolkit. Each webinar was well attended, with an average of 75 registrations and 36 attending the event live. Each webinar was recorded and uploaded as a resource in the CoPPAR research toolkit.

3. Submission of funding applications

The three outlined network themes have delivered two applications for funding with further applications being developed for later funding calls. Each application addresses identified priority areas, both outlined nationally (e.g. NICE recommendations[11]) and through network activity. To date, the network has submitted one successful application to the NIHR Health and Social Care Delivery Research (HSDR) call (submitted April 2023) about transition to adult care. A further application was submitted to the NIHR Programme Grant for Applied Health Research (competition 42, July 2023) on evaluating a structured support intervention for parent carers. Both applications were developed in collaboration with CoPPAR network partners (objective 6).

4. Enhancing sector research readiness through study development and delivery

To complement the submission of funding applications for potential future research (objective 6), the network utilised resources to develop and deliver a small-scale observational study.

The study aimed to describe the doses and indications for which children are administered the drug midazolam in paediatric palliative care settings, consequently addressing a key NICE recommendation on the management of distressing symptoms such as anxiety and agitation at end of life.[11] While the study will deliver clinically relevant findings, it had a broader aim of developing research readiness by working collaboratively with CoPPAR partner organisations (objective 1).

Key markers against this aim have been the establishment of research governance procedures including research panels at partner sites. Relatedly, for some sites, participating in the study offered the opportunity to go through the process of Health Research Authority (HRA) and Research Ethics Committee (REC) approvals and governance processes. The collaborative nature of the network has been fundamental to the delivery of this objective. To complement the opportunities related to the small-scale observational study, the allocation of CoPPAR funding supported research nurse posts at several partner organisations. These posts have assisted organisations to develop their research processes while also improving connections across the sector and with local clinical research networks.

5. Development of a research nurse group

To support network mentorship (objective 4), a group was developed formed of research nurses whose posts were facilitated through CoPPAR funding. The group met every 3 months, providing the opportunity for group networking, support, mentoring and cross-setting engagement.

Discussion

Prior to the establishment of the network, there was no national mechanism for co-ordination for research in paediatric palliative care. In bringing together seven partner organisations and clinical and research expertise, the network has supported the foundations upon which to deliver high-quality research in the sector.

It is recognised that embedding a research culture into the hospice sector is critical to the continued delivery of high-quality care. Nevertheless, prior barriers included a lack of research awareness in the overall sector, exacerbated by the isolation of hospices both geographically and from established research networks and pathways.[14] Notably, being part of a research network with the opportunities for engagement presented a marked step towards promoting a research culture and developing research awareness for some partners. For example, scheduled regular online meetings reduced geographical barriers and provided opportunity for collaboration, engagement, and new insights into research and its value. Relatedly, network funding secured nurse research posts, providing an active research role and presence in several partner organisations. Consequently, engagement with the network supported partners to promote research culture in their own organisation. This was evidenced by, for instance, one partner explicitly acknowledging their engagement in the network in a report to the Care Quality Commission.

Fostering a strong research culture is also heavily reliant on organisations being in a position to actively participate in research. Importantly, organisations need to be aware of and have in place the necessary governance processes and procedures. These include a sufficient understanding of research ethical and governance procedures, the formation of research and PPI panels or groups and ensuring clinicians have undertaken training related to good clinical practice. However, a significant barrier identified in a report into hospice research engagement was a lack of understanding of such processes and procedures.[14] Therefore, a core objective of the network was to support research readiness using methods and developing learning that could be applied to the broader sector.

To support partner receptivity towards developing their research infastructure and understanding, it was necessary to offer research opportunities of clear clinical value to partners. Midazolam is a drug commonly used in paediatric palliative care settings to manage distressing symptoms such as agitation and seizures. Despite its use, evidence supporting the recommended doses and outcomes for midazolam for the management of agitation and seizures at end of life for children is limited.[11,15] Consequently, there was a clear clinical rationale to offer partners the opportunity to undertake a small-scale observational study, supported by network expertise, to describe the doses and indications for which children are administered the drug midazolam in paediatric palliative care settings. This short study successfully recorded data on > 300 episodes of midazolam prescribing in ~40 children, highlighting that it is feasible to collect data in this setting.

The setting up of a clinically relevant small-scale observational study offered network partners practical insight into research procedures and processes. For example, some partners had minimal prior experience of undergoing study HRA and REC approvals. Similarly, the collaborative nature of the network lent itself to cross-partner learning and support. Key documents and advice such as establishing research panels and processes for study approval were, for example, shared.

Supporting research readiness can also be aided by an understanding of the context in which research is taking place. A previously cited barrier to hospice engagement in research was the perceived restraints on resource and time.[14] Undertaking a small-scale observational study also provided the opportunity to develop methods of routine data collection that did not overburden clinical staff. Working closely with network partners meant such methods could be developed with consistent input, direction and testing from clinical partners. It is envisaged that these methods will be more broadly shared beyond the network.

In addition to developing network partner research readiness, CoPPAR also delivered resources and materials to promote research engagement across the paediatric palliative care sector.

Notable examples included the delivery of an educational webinar series and development of a toolkit of resources to support participation in research. These resources exist on a specific web page dedicated to research in paediatric palliative care, hosted on the Together for Short Lives charity website. The placement of resources on the website supports their accessibility to the wider sector, facilitating maximum value and impact.

Akin to supporting research readiness, the network also had a core objective related to mentorship. In bringing together several partner organisations and their staff alongside academic partners, the network created a pool of resource for those interested in, or in the early

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stages of, a clinical academic career. The use of CoPPAR funding to develop research nurse roles further supported the opportunity for mentorship and support. Beyond the network, the development of a resource specific to developing a clinical research career, available on the CoPPAR toolkit, serves to provide guidance to support sector staff.

The delivery of the network has resulted in key learning applicable beyond the remit of paediatric palliative care. The requirement for high-quality research grounded in service priorities is also recognised in, for instance, the social care sector. The Adult Social Care Committee report, for instance, explicitly calls for research into adult social care.[16] Fundamental to the achievements of the CoPPAR network has been collaboration between sites delivering paediatric palliative care and academics. There are few clear examples of initiatives that involve collaborative working with local authorities and academic institutions focused on priority-setting, education and resource development. The CoPPAR network has highlighted the benefits of such a collaborative approach to develop research awareness and provide essential networks to deliver high-quality research.

To support the evaluation of the network, partners were asked to complete an evaluation form detailing their thoughts and reflections on participating in the network. Responses were overwhelmingly positive, citing the proactive nature of the network, the benefits of collaboration, and the value of network outputs including the webinar series and research toolkit. Partners were keen to see momentum built from the network continue, with ongoing opportunity for collaboration and connection. The funding available to the partner organisations was critical to their ability to participate in this network. The benefits of establishing the network are evident in its achievements. Nevertheless, the network is in its infancy, and therefore to continue to build on the foundation will rely on opportunities for sustainable funding, which unfortunately do not exist within the NIHR structures.

In acknowledging the successes of the network, it is also important to identify areas where further development is needed. The publishing of the research toolkit represents a key achievement by offering an online presence and space for paediatric palliative care research. However, an objective of the network was to establish a process whereby PPI partners could access and engage in research studies. This objective has not yet been achieved. It is envisaged that the process will be hosted on the research toolkit landing page. Therefore, while the process itself is still under development, the foundation to deliver the objective is in place.

Equality, diversity and inclusion

The network purposely targeted an underserved group, namely, children and young people with life-limiting conditions and their families. Life-limiting conditions are more prevalent in areas of higher deprivation and in ethnic minority populations.[1] The network aimed to draw on the perspectives of parents and young people in its design and related activities. In the planned studies following the network, we will work closely with our hospices, local principal investigators and PPI groups to ensure all eligible families can access those studies following NIHR INCLUDE guidance.

Conclusion

There is an urgent need to increase the quantity and quality of research into paediatric palliative care. Addressing the paucity in research relies on acknowledging the vital role of those delivering care in the research process. The CoPPAR network has illustrated the clear benefits of funding a network that supports collaboration between organisations delivering care and research institutions. The network has achieved success in challenging previously cited barriers to research engagement, offering genuine opportunity and support to sector involvement in research. The response to the network both in terms of partner engagement and wider involvement, has demonstrated that with the right funding and support there is clear appetite for research within the sector. Additional funding is required for the network to continue.

Additional information

CRediT contribution statement

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Data-sharing statement

The network described above was not a research study and therefore no data were generated from the network.

Ethics statement

The network described above was not a research study and therefore ethical approval was not required. However, as part of the network, a small-scale observational study was undertaken. HRA and REC approvals for the study were granted on 07.06.23 by HRA and Health and Care Research Wales (HCRW) (23/NS/0057).

Information governance statement

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Disclosure of interests

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Catherine Hewitt declares membership of the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Commissioning Committee 2015–22, General Committee 2023–current, CTU SAC 2020–2.

Ian Wong declares receiving consultation fees from WHO, IQVIA, Non-executive director of Jacobson Medical in Hong Kong. He was a member of the Expert Committee on Clinical Events Assessment Following COVID-19 Immunization, Department of Health, The Government of the Hong Kong Special Administrative Region, Hong Kong Special Administrative Region, China. He is the founder and director of Advance Data Analytics for Medical Science (ADAM) Limited (HK), Asia Medicine Regulatory Affairs (AMERA) Services Limited and OCUS Innovation Limited (HK, Ireland and UK) and former Director of Therakind Limited (UK).

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List of abbreviations

HRA	Health Research Authority
HSDR	Health and Social Care Delivery Research
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
PPI	patient and public involvement
REC	Research Ethics Committee
WHO	World Health Organisation

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