Right Team Right Place

SUMMARY REPORT

An Evaluation across the Midlands of Service Development in Palliative and End of Life Care through the lens of Children and Young People and their Families

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Principal Investigators

Principal Investigator (WEST): **Dr Cheryl Adams MC BCh BSC FRCPCH, MSc (pall med)**, Consultant Community Paediatrician with a special interest in complex and palliative care, Palliative Lead for Coventry and Warwickshire, South Warwickshire Foundation Trust

Email: **Cheryl.adams1@nhs.net**

Principal Investigator (EAST): **Dr Bindu Koodiyedath MBBS, DCH, FRCPCH, DipPallMed (Diploma Palliative Medicine Cardiff).** Consultant Paediatrician/ Paediatric Oncology/Haematology and Palliative Care. Northampton General Hospital, University Hospital of Northamptonshire.

Email: **b.koodiyedath@nhs.net**

Principal Investigator (EVALUATION)) **Professor Jane Coad RSCN/RGN BSc (Hons) PG Cert. PhD. FRCN.** Professor in Children and Family Nursing, Director – Centre for Children and Young People's Health Research (CYPHR). School of Health Sciences, Faculty of Medicine and Health Sciences. University of Nottingham.

Email: **jane.coad@nottingham.ac.uk**

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Evaluation team

Professor Jane Coad RSCN/RGN BSc (Hons 1st) PG Cert. PhD. FRCN. Professor in Children and Family Nursing, Director – Centre for Children and Young People's Health Research (CYPHR). School of Health Sciences, Faculty of Medicine and Health Sciences. University of Nottingham.

Dr Susan Tomlinson BSc, Dip Psych, MSc, PGDip, PhD. Research Fellow in the School of Nursing - Centre for Children and Young People's Health Research (CYPHR). School of Health Sciences, Faculty of Medicine and Health Sciences. University of Nottingham.

Shannon Chresham-Fox BSc (Hon 1st). Research Assistant. Centre for Children and Young People's Health Research (CYPHR). School of Health Sciences, University of Nottingham. Junior Sister/Chief Nurse Fellow. Nottingham Children's Hospital, Nottingham.

Katie Green. Child Nursing Student, The Dean's Health Sciences Academic Intern (Teaching and Research), School of Health Sciences, Faculty of Medicine and Health Sciences. University of Nottingham.

Dr David Widdas. Consultant Nurse, Children with Complex Healthcare Needs
South Warwickshire University NHS Foundation Trust

Dr Emma Popejoy. Research Fellow – Centre for Children and Young People's Health Research (CYPHR). School of Health Sciences, University of Nottingham
Staff Nurse – Nottingham Children's Hospital

Professor Sarah Redsell RGN BSc, HV, PhD. Professor in Children and Young People Health Research -Centre Co-Lead Centre for Children and Young People's Health Research (CYPHR). School of Health Sciences, Faculty of Medicine and Health Sciences. University of Nottingham.

West Midlands Team

Dr Cheryl Adams Consultant Community Paediatrician with a special interest in complex and palliative care, Palliative Lead for Coventry and Warwickshire, South Warwickshire Foundation Trust

Dr David Widdas. Consultant Nurse, Children with Complex Healthcare Needs
South Warwickshire University NHS Foundation Trust

Continues >

Suzannah Davies Lead Nurse CYP palliative care, South Warwickshire University NHS Foundation Trust

Julie Redmond Community Children's Palliative Care Nurse Specialist, Coventry and Warwickshire Partnership Trust

Dr Sarah Thompson Paediatric consultant in palliative care- Staffordshire Children's Hospital at Royal Stoke

East Midlands Team

Dr Bindu Koodiyedath Consultant Paediatrician/ Paediatric Oncology/Haematology and Palliative Care Lead. Northampton General Hospital, University Hospital of Northamptonshire.

Dr Sarah Haynes Consultant Paediatric Neurodisability and Medical lead for Palliative Care Nottingham University Hospital.

Moira Flanigan Clinical Lead/ESP Childrens Paediatric Respiratory Physiotherapist, City Hospital, Nottingham.

Contents

Background Context

To be able to provide a service that is equitable and suitably staffed we first need to understand our paediatric palliative population. Fraser et al (2020) have produced very clear data and projections about the number of children/young people (CYP) with life limiting/life threatening diagnoses, showing an increase from 26.7 per 10,000 in 2001/1 to 66.4 per 10,000 in 2017/18 and projection to 84.22 per 10,000 in 20301. This is due to longer survival, which can be credited to improvements in neonatal care and ongoing integrated management of children with complex needs across health care settings including the use of technologies such as long-term ventilation. However, this group of babies, children and young people (BCYP) remain medically frail with complex health needs and a tendency to develop life-threatening complications including infections.

Palliative and end of life care is provided to BCYP with life-limiting or life-threatening conditions from diagnosis, thus representing an extremely wide range of diagnoses (in excess of 300). However, a significant proportion of BCYP with palliative and complex care needs (up to 15%) do not have a definitive underlying diagnosis and often have multiple healthcare needs, including needs related to their underlying condition, as well as palliative care needs.

Multi-disciplinary integrated care services embrace the philosophy of paediatric palliative and continuing care packages and require teams in place that are competent, responsive, and sustainable. To be delivered effectively these services should be jointly commissioned by the Integrated Care Board (ICB) and Local Authorities (including social care and education). They should be able to offer support and care for children and young people at any point from diagnosis or recognition, through active maintenance and stabilisation treatment (including that aimed at cure) to end of life care and bereavement. These services transcend diagnosis or prognosis and can be provided at any stage of a child or young person's illness (For the purposes of this specification there are three tiers of care described – please see Figure 1). This tiered view of the framework does not seek to compartmentalize but aims to join the provision into a seamless pathway. Care and support should be provided by the ***right team in the right place.*** This will ensure opportunities for support are not missed and specialist provision is targeted where needed most. This is the essence of the scope here outlined.

A truly integrated system for BCYP and their families should enable universal, core and specialist providers to work together in a coordinated way that enables accessible local support and management of everyday problems, and access to specialist services when needed. Integration of services is challenging, but the complexity of conditions and high level of care needs that many BCYP live with, often over many years, mean that services do need to use their combined workforce and resources effectively.

COVID-19 has compounded these issues, COVID-19, including Long Covid, has disrupted vital health and social care provision and changed everyone's lives. Little is known about the impact on care provision and on carers themselves who may be ill themselves or facing 'knock-on' effects of the pandemic, such as lost income. These families caring for a BCYP with a high level of healthcare needs have been bearing the brunt throughout the pandemic having to shore up gaps in care packages and losing their respite provision. These families require support from professional care teams to help them meet the full range of their BCYP's health, education and social needs.

Drawing together all the issues reported here, what is clear is that there is still a data gap in the breadth of the narrative for those children and young people and their families/carers, as identified in the Fraser at al (2020) report. This narrative needs to include the reality of the medical, technological, nursing and care needs, and the situational reality of where children with palliative care needs are managed, both geographically and physically. In addition, information is needed on which services they have access to including community respiratory physiotherapy and palliative care teams both nursing and medical and whether this support is in the community, hospice or hospital.

One way of commencing this narrative discussion would be to evaluate where these BCYP are living, whether this is hospital, hospice, community or a blend of the three across a defined geographical area. Another element would be to evaluate what ward-based scenario they would be in when they are in their baseline health status, for example Paediatric Intensive Care Unit (PICU), High Dependency Unit (HDU), Specialist ward or general paediatric ward. This would provide a virtual ward picture of the population and reflect the reality that many families have of a 'mini PICU/HDU' in their home. These two narratives, combined with 'deep dive' illustrations of BCYP and their families, would give a more rounded picture of these families' lives and close the data gap.

The Midlands, UK, is arguably a microcosm of the national picture of paediatric palliative and end of life care services and of the children, young people and the families that use these services. The Midlands has a diverse population with regards to ethnicity and socioeconomic status with issues such as geography, rurality, distance to tertiary/specialist centres and hospices comparable to the rest of the Country. They also have a variety of models for providing the medical, nursing and broader care needs. Some systems across the Midlands will have a community integrated model with 24/7 access to nursing and medical advice such as in Coventry and Warwickshire whilst others will have a less developed or less available service although the majority aim to provide medical and nursing support at home during end-of-life. However, many families lack access to 24/7 support when they are caring for their child at home.

Once the narrative of the paediatric palliative population is more rounded, then a clearer discussion of the staffing and skill mix needed to provide extended hours can commence. Currently, apart from suggestions in the broadest sense via the National Institute of Clinical

Excellence (NICE, 2019), there is no such structure which is nationally accepted as a standard. This would inform trusts, commissioners and teams of the requirements and investments needed to meet this priority area. Given this backdrop, ***The Right Team in the Right Place*** project was born.

To do this, we took a unique Midlands wide approach to scoping palliative and end of life services. Using two workforce delivery projects in the West and East Midlands, we embedded an independent evaluation (Coad et al 2023) and asked Health Care Professionals supporting BCYP with life limiting / life threatening conditions (and who may access palliative and end of life services) what has worked for them and what could be better. We will report in this summary in three parts:

PART A: An evaluation led by Coad et al. (2023) of services as viewed by health professionals caring for BCYP who had a life-limiting / life-threatening condition and their families.

PART B: Translation to clinical services in the West Midlands (Adams et al., 2023)

PART C: Translation to services in the East Midlands (Koodiyedath et al, 2023)

Overall, this project provided a unique lens of Health Care Professionals in terms of what services BCYP, and their families receive (what services look like) and the type of improvements needed (what they could look like to make it better).

Overall Aims of The Study

The agreement was to undertake an independent, evaluation across the Midlands to explore services to support development of a workforce plan to help improve the delivery of the Palliative and Continuing Care Service provided to babies, children, and young people (BCYP) and their families accessing services in both the West and East Midlands regions. To identify and capture via Health Care Professionals caring for the BCYP, how existing services and care needs are recognised and if / how are they met and what could be better. To profile service delivery and needs in a meaningful way. To provide an evidence-based vision for extended hours and staffing structures to improve the quality of care and services.

A unique Midlands-wide approach was used to scope services for the population of families with a child who has a life-limiting / life-threatening condition. Focusing on the West and East Midlands, U.K. this evaluation provides a unique lens of Health Care Professionals in terms of what services BCYP and their families receive (what services look like) and also the type of improvements needed (what they could look like to make it better). Within this the main evaluation objective was to identify the right team, at the right time and in the right place. The framework of five NHSE priority areas were of interest namely transition, education, and training for all working with BCYP, extended hours, and personalised care approaches.

The broad overall aim of the evaluation was to understand what the right team in the right place looks like to make recommendations for future service planning .

The following NHSE priority areas were included as the platform for discussion (See Section Discussion):

Area 1	**Transition Services – Improvement of handover**	**Yes**	**West/East**
Area 2	**Education and Training for Generalist Staff**	**Yes**	**West/East**
Area 3	**Education and Training for CYP Symptom management**	**Yes**	**Previously funded to East (not included specifically here)**
Area 4	**Personalised Care Approaches**	**Yes**	**West/East**
Area 5	**Extended Hours**	**Yes**	**West/East**

PART A: The Evaluation Coad et al (2023)

To meet our broad aims, we focused on two key services for BCYP with life-limiting/life-threatening diagnoses /conditions in receipt of continuing care and/or a palliative care plan in two areas for the Midlands in **(1. WEST MIDLANDS)** and BCYP with severe neurodisability and persistent or recurrent acute life-threatening respiratory disease **(2. EAST MIDLANDS)**. Whilst two areas of the Midlands in **(A. WEST MIDLANDS; B. EAST MIDLANDS)** had set regional objectives, the aim of the evaluation was to have an overall lens to data collected.

All supporting documentation including the protocol, information sheets, consent forms and audit forms were submitted and approved for ethics review to the research ethics committee at the University of Nottingham. A three-stage, deep dive approach was used across three packages:

Work Package 1 (WP1): Months 1-10. Set up and rapid review of literature

This included team set up and ethical approval via University of Nottingham (Faculty of Medicine and Health Sciences – Research Ethics Committee).

In WP1, key literature was drawn from a Rapid Review which then supported the development of the interview schedule (WP2) and survey (WP3).

Work Package 2 (WP 2): Months 3-10. Deep dive interviews in both regions

A semi-structured interview tool was developed from WP 1 data, and included questions about their teams, services they delivered, what service worked well, and what could be better. Each participant was invited to use a confidential case study approach within each interview conducted.

Data was collated using online technology from five networks in each area of the West and East Midlands **(n = 10 interviews/ 5 from each region).**

Interviews were recorded, transcribed, and destroyed after consensus and analysis.
A Framework Approach, a type of qualitative analysis that allows for flexibility and uses the same, agreed framework for each set of data (Smith & Firth, 2011) was used to analyse the interviews.

Work Package 3 (WP3): Months 4-10. Case Study Survey in both regions.

A case study, point prevalence survey approach was used to capture data from a single designated time point Using the same survey tool, data was collated from sites in the West and East Midlands.

The team supported by the wider on-site team identified, approached, and collated data from Health Care Professionals who support this group and were invited to respond using a unique BCYP Case Study approach. We aimed to collate information about care and services using the case study approach (families being captured by Health Care Professionals).

The survey (WP3) was informed by the baseline WP 1 and WP 2 work and the NHSE areas as described earlier. The survey was sub-divided into six sections comprising Background Case Information, Patient Case Information, the Health Care Professional's role, Visit Information, Time Information, and Patient Care Overview. We aimed to collect up to 100 completed case study surveys from West and East Midlands to be collated as one data set over the time frame.

We requested that Health Care Professionals collated case studies from one to three diverse BCYP and families only. The survey could be accessed using Information Technology and an interactive online platform. Following collation, 81 successfully completed surveys resulted 41 (50.62%) from the East Midlands and 40 (49.38%) from the West Midlands from the time scale August to December 2022.

Findings

Work Package 1

Following a rigorous rapid review process, we ended with 12 papers and identified only eight that could potentially contribute to a narrative account of the current state of play for research in this area. They are described in brief here.

Community settings were the predominant place of care for BCYP with life-limiting and life-threatening conditions and experiencing complex medical needs. From the rapid review no literature evidencing a standardised method to assess care service needs for BCYP with life – limiting and life-threatening conditions and their families within community settings were sourced.

However, two strands of literature providing insights into some requirements of assessment and the current challenges in coordination, care, efficiency, and equity was identified. First, three papers were identified for Health Care Professionals to use to assess specific aspects of service need. For example, The Paediatric Palliative Screening Scale (PaPaS) to identify children who could benefit from a palliative care approach (Bergstraesser et al. 2013). Earlier the Nursing-Kids Intensity of Care Survey (N-KICS) was developed to describe the intensity of nursing care for children with complex medical needs (Navarra et al., 2016). Finally, Noyes et al. (2013) developed a method to estimate population prevalence, care preferences, service costs, including cost of home-based end of life care. However, none provide a holistic measure of the needs of BCYP with life-limiting / life threatening conditions and their families or are suitable for assessing care needs in a community setting.

A small body of literature existed on the views of health care professionals on service provision to BCYP and their families. However, only one study (Law et al., 2011) focused exclusively on HCP's views was identified. Other literature (Brenner et al., 2021; Carter et al., 2012; Monterosso et al., 2007) included data from both parents and families and HCP's. Furthermore, no study could be found about HCP's experiences of service delivery, assessment of service need and service use of BCYP in the community. Nor did we identify any literature detailing the implementation of better services models for BCYP with life-limiting / life threatening conditions.

Nonetheless the identified literature provided useful insight into challenges with current assessment and allocation of care such as criteria for use, inconsistent leadership, integration of services, and collaboration and need for case management (Monterosso et al., 2007) and being reactive. As well the value of child and family-centred care and the specialist knowledge of a service manager in enhancing care was stressed (Brenner et al., 2021). In relation ideally services are commissioned by people within the community to ensure what is needed is provided (Carter et al., 2012) both BCYP families and HCP's further research is needed to identify and evaluate local service models. Discourse to understand the community setting from the HCP's perspective can support the development of an assessment instrument, evaluation of local service models and implementation of best practice on a national level.

An assessment instrument can support estimations of the funding required (Brenner et al., 2021), improve understanding of what is present and what is missing in terms of services for BCYP. In sum what services look like) and the type of improvements needed (what they could look like to make it better). The completion of a standardised assessment on diagnosis can support care and management. Specifically, to allow for planning of care and resources, improve communication, redistribution of resources to promote equity, timely resource provision that is locally and culturally appropriate, and allocation of resources across sectors and professional boundaries. Such targeted service provision may reduce family care burden, improve family confidence in the care provided, evidence equity and be person centred.

Work Package 2 and Work Package 3 (WP 2 and 3)

The interview data (WP2) and the survey data (WP 3) were obtained from Health Care Professionals representing a range of specialities across the West and East Midlands, revealed insight into their ways of working and the work context. Additionally, from both WP2 and WP3 insights into the challenges and strengths of the services on the delivery of services to BCYP with life-limiting and life-threatening conditions and their families emerged. Furthermore, glimpses into the clinical presentation, care settings, service needs, and areas of service inequities are identified.

The report is set out in key areas of learning.

What we Learned about BCYP with Life Limiting and Life-Threatening Conditions and their Families

Health Care Professionals and family / caregivers were dealing with complex medical presentations consisting of an array of symptoms and in turn demanding care needs. Symptoms range from those common across clinical populations such as nausea to life threatening cardiac events, and symptoms concerning eating and mobility that impact on functioning and quality of life. Further 52.5% BCYP cases included in WP3 experienced more than one primary diagnosis. Overall, a respiratory diagnosis was the most common followed by nervous system disorders and congenital and chromosomal conditions. The relationship of respiratory status to overall condition severity warrants further examination.

What we Learned about the Care and Services

In the East Midlands, each BCYP had on average 1.71 available services offered compared to 4.05 available services in the West Midlands. Overall, the services provided the most were clinical care (74), assessment of needs (55), co-ordination (33), psychological support, spiritual care (15), and social care (12).

As shown in Figure 2 assessment of needs was provided more frequently in the West Midlands. Additionally, in only 29.63 % (24) of cases were care service types classed as *'non-medical'* with non-medical care in the East Midlands reported less (See Figure 3).

Figure 2
Care Services

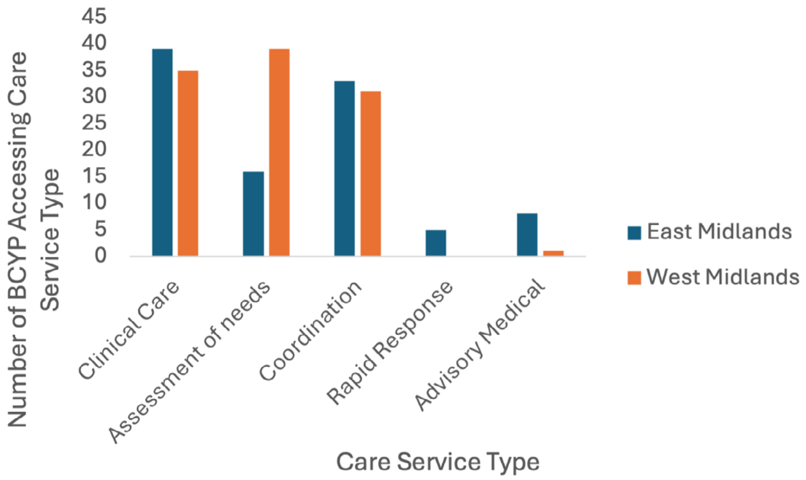
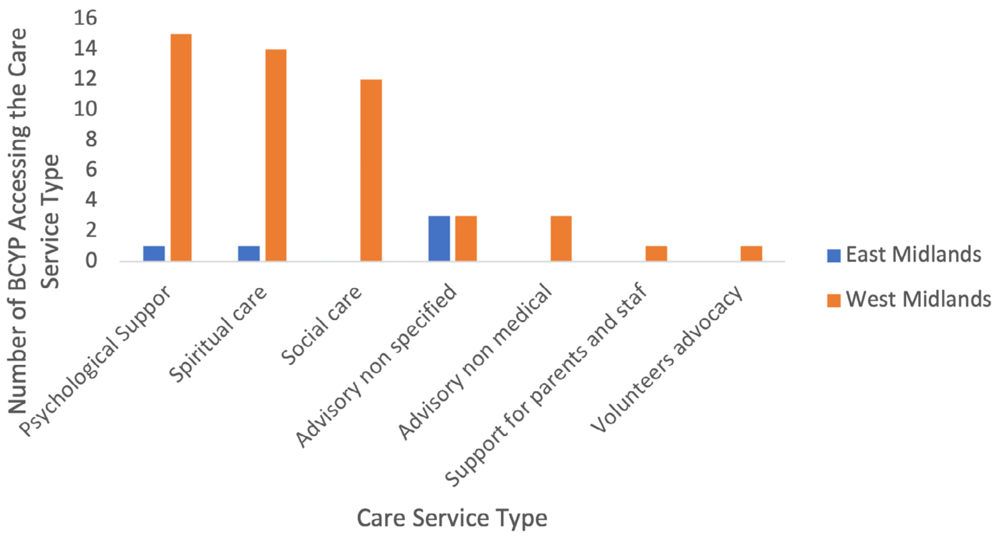


Figure 3
Additional Services



Most of the BCYP (87.65%) care took place in the home representing a heavy caregiver / parental burden as illustrated in the following quote:

> **" When we aren't there, families don't stop. They are clinical 24/7."**
>
> **(Participant 2 WM, WP2)**

Care needs required very specialised and skilled input in the home care setting. This was directly related to experience and training of the Health Care Professional, teams around the BCYP and family and access to services that were coordinated and responsive with clear channels of leadership. For example:

> **"All aspects of the child's care are managed, reviewed and co-ordinated by the palliative lead consultant".**
>
> **(Participant 76 WM, WP3)**

In many cases, the family homes had become like an extension of an acute hospital. Moreover, a high number (40%) needed to use intensive technology and/or specialist equipment with rooms in the home such as bedrooms reflecting this.

In the samples here, the patient's home was thus where Health Care Professionals in the main undertook their work. Health Care Professionals considered their role to be important in supporting care giving and for BCYP to remain at home. While use of hospice and acute ward as a care setting was low (15% of BCYP in and 9.75% respectively) support of families and Health Care Professionals at all levels and specialities was felt to vital. For example:

> **"Without carers, the child's care would be unmanageable at home and due to a breakdown in this care package, the child has been in hospital for 12 months."**
>
> **(Participant 8 EM, WP2).**

Home first, followed by hospice were preferred places for care. When acute hospital care was required both local and regional hospitals were frequently required. However, the ability to support the case is a paramount factor so wards and staffing must be suitable for BCYP needs. For example:

> **"Specialist team in underlying condition based here WM4 WP3".**

We explored what home visits entailed. While the average number of services utilised at the visit was only 1.75 and reasons for the visit 1.84 this differed between the regions being higher in each case across the West Midlands. The reasons for the visit and services used at the visit were wide and comprised medical and non- medical services. The most frequently stated reasons for the visit and services utilised are depicted in Figure 5 and 6 respectively.

Figure 5

The Reason for the Selected Consultation/Visit by Region

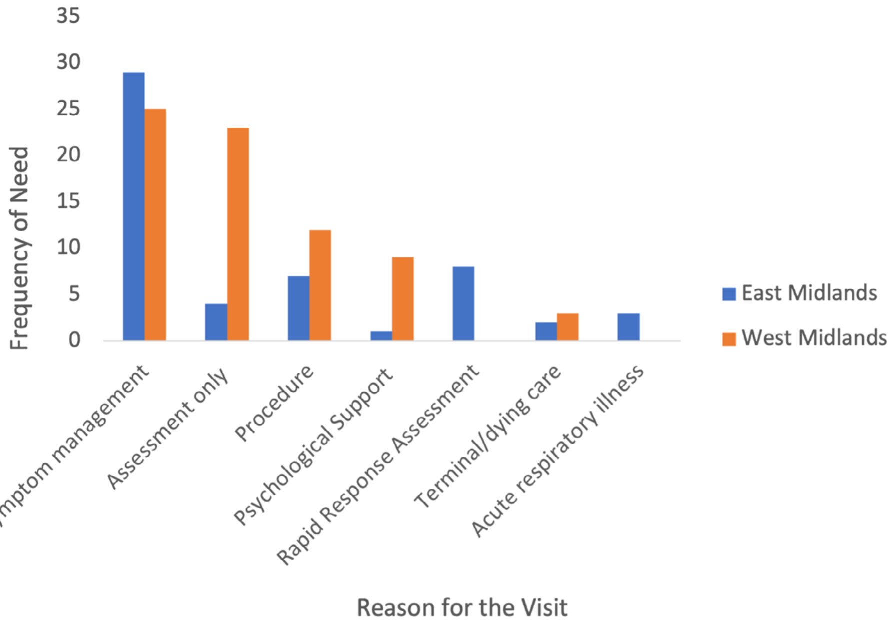
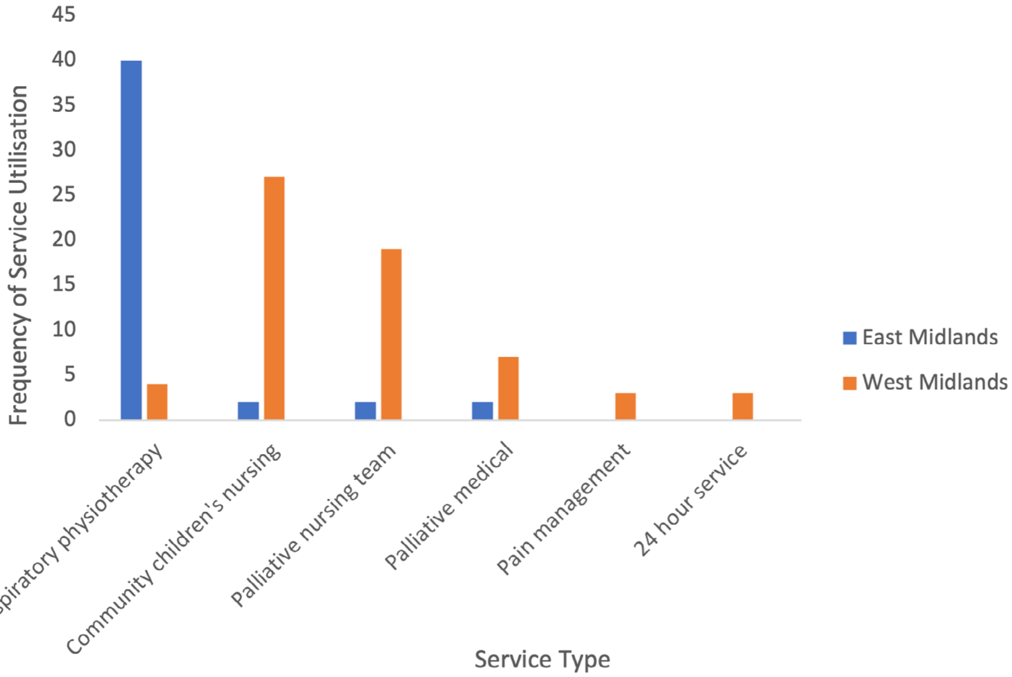


Figure 6

BCYP Type of Visits /Consultation by Region



We found that BCYP frequently utilised respiratory physiotherapy in the East Midlands whilst in the West Midlands BCYP frequently utilised Community Children's Nursing, palliative medical or nursing. Notably despite the availability and involvement of a wide range of services and Health Care Professionals responses to acute visits were people from specialised roles. Symptom management was the commonest reason for visit with assessment of needs more common in the West Midlands. The reasons for this are difference between the regions remain unknown.

We explored the ability of existing services to deliver care in the acute phase. For example, 62.55% had 70% or better functioning at the end of the acute phase of the visit compared to 41.25% BCYP experiencing 70% or better functioning at the beginning of the phase. Of 39 changes in stability from start to end, 35 were cited as improvements 14 in the West Midlands and 21 in the East Midlands. There were some regional differences in supporting stability within services with more BCYP in the East Midlands used Paediatric Intensive Care (PICU)/High Dependency Units (HDU). However, whatever services were used to intervene at a visits 'Stability' occurred across both regions.

Most of Health Care Professionals (64.1%) across the Midlands needed more time in order to deliver the 'flexible' service needed, reported as due to the complex diagnoses and accompanying symptoms. For example, the average length of time of the visit was 112.05 minutes with the range of 20 minutes to over 23 hours. 24-hour care and weekend care are needed and 50% in WP3 stated that specifying any time allocation was challenging as for one time required differs by service required. The hours and days specified varying between one and 50 hours and differing by service reflective of this. Length of time of consultation/visit is related to need which is uncertain and challenging. For example, acute visits require more time allocated for travel and administration.

Despite the ability to deliver care in the acute phase this is a limited measure of service functioning. Any change (such as retirement, sickness, budget constraints, limited recruitment) makes it challenging to sustain current services. From WP3 current large gaps and disparities in services across and between regions were identified and outlined in Table 1.

	East Midlands	**West Midlands**
Escalation Plans	83%	85%
End of Life Medical and Nursing Care	30%	95%
Palliative Care	15%	72.5%
Specialist Paediatric Provision	52.5%	95%
Rapid Response service	87.8%	35%
Respiratory Physiotherapy	97.5%	45%

Table 1: *Percentage Availability of Key Services by Region*

Insights into the work context Health Care Professionals, afterhours extended hours care, escalation plans, range of continuing care and palliative services; teamwork, end of life care were highlighted. We found that an integrated, multi-disciplinary approach is required due to the complexity of the BCYP and families. The delivery of respiratory physiotherapy, nursing and transitional care services in the East Midlands was reported as functioning well whilst palliative care services were reported positively in the West Midlands. However, the gaps in service provision for the equivalent service in each region were apparent. This included a reduction of respite care, no 24/7 cover in many areas and reduced workforce in the East Midlands. In both areas to prevent hospitalisations and to support BCYP and their families, adaptions and time flexibility was required, placing pressure on individuals and services. Services were reported to be reliant on small widespread teams, stretched and under pressure. A further highlighted need was that additional training was required and could be regionally shared more but was frequently overlooked to provide continued care to BCYP in their preferred place of care, that being their home. Funding for ongoing training and support of staff is essential so that a sustainable workforce is achieved.

What we Learned about WHO the Health Care Professionals were Supporting Care

All the Health Care Professionals clearly articulated the desire to make a difference, with many citing that they had worked with BCYP and families for long periods of time. Health Care Professionals involved with the BCYP cases ranged in experience significantly, this being from one to 15 years, with an average of 7.63.

In total 21 disciplines were being included in the teams. As illustrated in Figure 7, there were significant medical 97.44% (76), registered nursing 73.08% (57), physiotherapy 88.46% (69), and occupational therapy 75.64% (59) professionals were cited. Overall, nursing and medical services was valued the most by families. Some regional differences were observed such as more dieticians in the West Midlands. Although interesting, it was unknown in our data how and why teams had evolved in the way they had.

What was reported that the context of Health Care Professionals and impact on care theme findings reflected the skill mix required to provide responsive care to maintain the baseline health of BCYP known to these services. The Right Team was vital. Provision and access to relevant education and training was felt to be much needed in improving the skill of the team, but very limited opportunities were highlighted.

Figure 7

Professionals Supporting the Care of the BCYP and their Families

Services were led by a range of professionals Medical Consultants, Physiotherapists, Registered Nurses, Service Managers, or Extended Scope Practitioners. Dual leadership which could facilitate training was low at 11.1%. Whilst there were leads Consultants, Nurses and Physiotherapists within a service, notably there was no regional professional lead across the geographic regions for BCYP palliative care resulting in a limited regional co-ordination and join up.

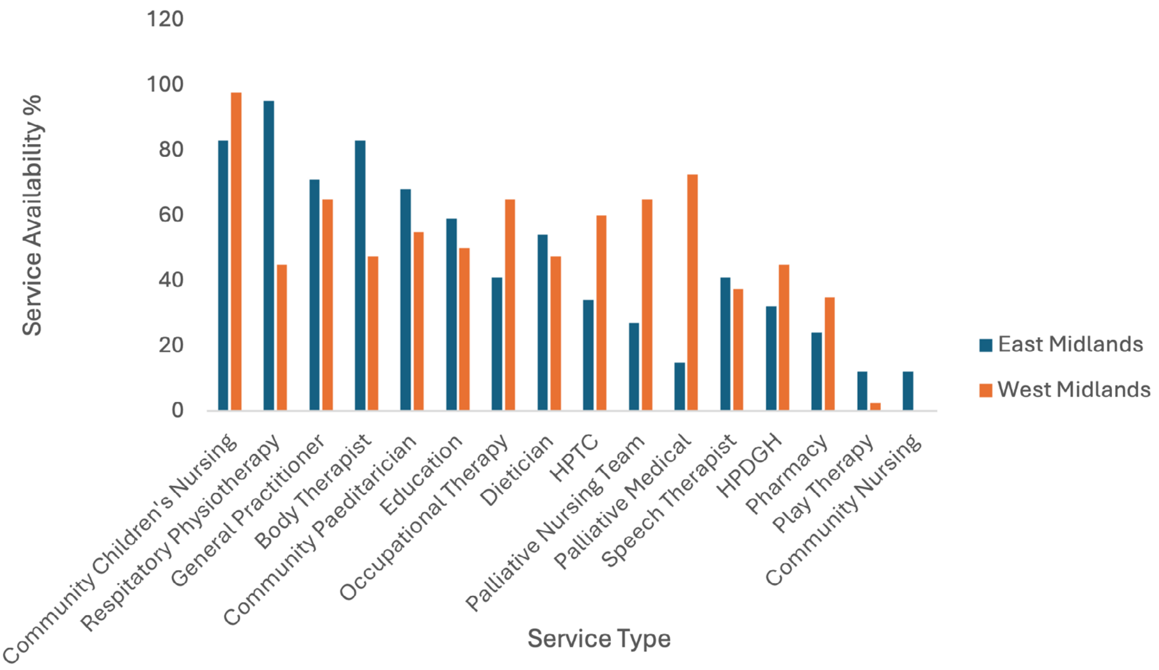
What we learned about WHAT Health Care Professionals and their Teams offered families

While availability of some Health Care Professionals was consistent across regions significant differences exist. Across both regions most BCYP had access to a Community Children’s Nurse 91.25% (73) and a General Practitioner 68.75% (55). In total, 62.5% (50) had access to a Medical Paediatrician. Differences emerged in the availability of respiratory physiotherapy, body therapy, occupational therapy, hospital paediatrician at tertiary hospitals, palliative nursing, and play therapy.

Availability of services emerged in part based on local needs meaning that delivery to BCYP and their families was inequitable as specialisms developed (See Figure 8). For example, 97.5% of BCYP cases were reported to be able to access physiotherapy in the East Midlands compared to 45% in the West Midlands. However, the service required at the visit was available in that region, for example, physiotherapy was available to respond to an acute visit in the East Midlands which was reported as making a difference in reporting hospital admissions.

Figure 8

Service Type Availability across the Midlands



The provision of services to BCYP and their families is tenuous with inadequate staffing consistently voiced. From WP2 workloads are impacted by rising patient numbers, ‘acuity’ of the conditions, and expectations to cover additional roles. Additionally, from both WP2 and WP3 the geographical areas covered impact on workloads. The extract below highlights a common response.

> **“I have a joint role as a Children’s Community Nurse N with a special interest in palliative care (SPIN nurse). I cover [named area], however as a SPIN nurse I cover the whole of my county [named].”**
>
> **(Participant 5 WM, WP2).**

We found many examples of supportive team networks around the BCYP and their families where Health Care Professionals had access to rapid referrals to experts, debriefing sessions, and peer support. This was important to Health Care Professionals. Similarly, data from WP3 highlighted that integration of health, education and social care services was needed with external and tertiary centres as this was currently inconsistent.

One aspect we explored was training. Training is vital to maintain currency of expert knowledge, delivery of effective care to BCYP and their families, and for sustainability of Health Care Professionals teams. However, there is a lack of relevant, specialist, and accessible training due to multiple factors such as high staff turnover.

> “A huge part of our service is keeping up to date and that requires training. We are not commissioned, as a service, so training is challenging – very even impossible right now!”
>
> **(Participant 9 EM, WP2)**

Whilst 50% of Health Care Professionals surveyed in WP3, had completed additional training relevant to their role it is unknown what proportion of staff are currently accessing training. Critically even when additional training had been undertaken in both regions such as prescriber there was no regional professional lead across both regions for this group.

As well interviewees considered having a diverse team with a variety of skills to meet holistic needs was also considered important a requirement. A point reiterated in WP3:

> “Working within the physiotherapy profession we only play a small part that would be most effective within the wider team that could help support more collaborative healthcare.”
>
> **(Participant 11 WM, WP3).**

The service and care requirements of this group of BCYP and their families versus the staff/skill mix available to provide a responsive and sustainable care to support them was significant. In all interviews this was reported as ‘not enough’. In terms of the Right Place services were described as stretched and the workforce similarly. The range of services and disparities across the regions demonstrated large gaps and disparities across and between services, especially in view of the increasing complexity of needs in this groups. This was compounded by the impact of COVID 19 which had in turn impacted on team delivery and subsequently on BCYP and families accessing these services. Whilst service users were not directly interviewed, Health Care Professionals reflected upon how they value continuity of care, support during out of hours, and a flexible end of life care.

Summary - PART A

The broad aim of Part A evaluation was to understand the notion of the **right team** and in the **right place**. The evaluation focused on two key regional areas (West and East Midlands) providing services for BCYP with life-limiting or life-threatening diagnoses in receipt of continuing care and/or a palliative care plan. We have conducted a robust evaluation and have highlighted the positives and avenues for where improvements could be made to improve capability, equity of outcomes, and efficiency of resources.

Key to this evaluation is that the **right team** is a team of Health Care Professionals working in partnership with BCYP and families, who have the right training and skills mix to respond to the specific symptom(s) and needs. The **right place** for care and support is in line with national policy within the UK and commitment to the preferred place for treatment or care as determined by the BCYP and families (Malcolm & Knighting, 2022). For our discussion we also found that the **right time** is when needs are flexibly met.

Key to this evaluation is that the **right team** is a team of Health Care Professionals working in partnership with BCYP and families, who respond to the specific symptom(s), uncertain needs, and their access to services. This depends on the Health Care Professional and teams – specialist numbers in post, their training knowledge, skills, and understanding and relationship with the BCYP and family.

Part B & C – TRANSLATION TO PRACTICE IN WEST & EAST MIDLANDS

While set in two regions of England this study has national implications for practice. Firstly, significant inequities between the two regions in key medical and allied health services, 24/7 end of life care, and palliative care were revealed suggesting a worsening of the situation since the work of Coad et al. (2015). These evidenced inequalities concord with Brenner (2018) who documented wide variations in access to care between and across services in Ireland.

From the data on symptom experience and escalation plans both respiratory and palliative care was required by all BCYP in the Evaluation. Concordant with Smith et al. (2022) and Wolfe et al. (2017) respiratory physiotherapy as reported in East Midlands was found to be improving functioning and stability. In the West Midlands needs were met for community nursing or palliative medical or nursing and some improvement was evident. However, this was reported as challenging in the East Midlands. Further whilst Community Childrens Nurses may be trained in palliative care (RCN, 2020) arguably specialist palliative care may support more improvement. The data set showed that availability of palliative care and respiratory physiotherapy aligned to clear leadership in both regions and further additional training opportunities.

From both regions it was clear that services must be designed provided based on estimated need from symptom patterns as well as diagnosis grouping. Professionals cannot be expected to know or support all diagnoses from the skill set of their profession. Therefore, a multi-disciplinary approach is required to support this population, maintain sustainability of community services. This we argue can facilitate equity in in service provision between and within regions.

Specifically, to support care by the right team, in the right place it is recommended that there is regional sharing of human resources knowledge and more partnership formed across and between the regions. To support this integrated care centrally coordinated under clear clinical expert leadership (Brennar et al., 2021., Carter et al., 2012., Monterosso et al., 2007) is required and according to McLorie et al. (2023) required urgently. The aim would be a local service providing 24/7 integrated care designed to improve communication, training, professional development and sharing of medical, technological, and human resources which could be evaluated for efficiency and sustainability. While an older sample and mostly experiencing cancer a “single point of access” end of life service effectively supported patients, their families and healthcare personnel (Efstathiou et al., 2020). Consequently, Single Point of Contact (SPOC) approaches should be explored and piloted.

Overall conclusions

By exploring specific focuses in both the West and East Midlands the project has provided a unique lens, via health care professionals, on what CYP using palliative and end of life services and their families feel they have currently had provided (what services look like) but also what improvements would support their needs (what they could look like to make it better).

To support care by the ***right team, in the right place at the right time,*** we recommend that there is more regional sharing and more partnership formed across and between the Midlands as a region including clinical expert leadership. Specifically, we recommend a Midlands-wide Managed Clinical Network with clear clinical leaders supported an assessment of needs standardised.

The aim would be to be provide integrated care which could improve communication, accredited nationally accessible training, and sharing of medical, nursing, respiratory physiotherapist and care resources including staff. Such a model could also support regional shared training given the extensive range of skills required to support this population growing in numbers and needs. This can support accessible and fit for purpose out of hospital provision and respite services.

This was an important evaluation with interesting results. We believe the study could act as a pilot to a national view on regional sharing as we move forward with Integrated

Care Systems seeking to improve the lives and health outcomes of this group of BCYP and families. To support sustainability of services research is needed to identify and evaluate local service models with a view to learning and implementing best practice at a national level.

References

Bergstraesser, E., Hain, R.D., & Pereira, J.L. (2013). The development of an instrument that can identify children with palliative care needs: The Paediatric Palliative Screening Scale (PaPaS Scale): A qualitative study approach. BMC Palliat Care, 12(1), 20. https://doi:10.1186/1472-684X-12-20

Carter, B., Coad, J., Bray, L., Goodenough,T., Moore, A., Anderson, C., Clinchant, A., & Widdas, D. (2012). Home-based care for special healthcare needs: Community children's nursing services. Nursing Research. 61(4), 260-8. https://doi:10.1097/NNR.0b013e31825b6848.

Coad, J., Tomlinson, S., Chresham-Fox, S., Green, K., & Redsell, S. (31st March, 2023). Right Team / Right Place Project. University of Nottingham.

Law, J., McCann, D, & O' May, F. (2011). Managing change in the care of children with complex needs: Healthcare providers' perspectives. Journal of Advanced Nursing, 6 (12), 2551-60. https://doi: 10.1111/j.1365-2648.2011.05761.

Monterosso, L., Kristjanson, L.J., Aoun, S., & Phillips, M.B. (2007). Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: Evidence to guide the development of a palliative care service. Palliative Medicine, 21(8), 689-696. https://doi:10.1177/0269216307083032

Navarra, A.M., Schlau, R., Murray, M., Mosiello, L., Schneider, L., Jackson, O., Cohen, B., Saiman, L., Larson, E.L. (2016). Assessing nursing care needs of children with complex medical conditions: The Nursing-Kids Intensity of Care Survey (N-KICS). Journal of Pediatric Nursing, 31(3), 299-310. https//:doi: 10.1016/j.pedn.2015.11.012.

NICE (2019) Recommendations | End of life care for infants, children and young people with life-limiting conditions: planning and management | Guidance | NICE Recommendation 1.5 Service deliver

Noyes, J., Edwards, R.T., Hastings, R.P. et al. (2013). Evidence-based planning and costing palliative care services for children: Novel multi-method epidemiological and economic exemplar. BMC Palliative Care 12, 18. https://doi.org/10.1186/1472-684X-12-18

Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. Nurse Research,18(2), 52-62. https://doi: 10.7748/nr2011.01.18.2.5

Smith, S., Flanigan, M., Haynes, S., Michael, A., & Wolff, T. (2022). Evaluating a community respiratory physiotherapy service for children with neurodisability. BMJ Open Quality 11(1). https://doi: 10.1136/bmjoq-2021-001683.

Wolff, A., Griffin, H., Flanigan, M., Everest, S., Thomas. D., Whitehouse, W. (2015). Development and evaluation of a community respiratory physiotherapy service for children with severe neurodisability. BMJ Qual Improvement Reports.19, 4,1. https:// doi: 10.1136/ bmjquality.u208552.w3411