A realist evaluation of the Care 24 Lothian service

Summary Report

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Acknowledgements

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It is beyond the scope of a summary report to present the breadth and scope of the full project report which is over 100 pages long. This summary report outlines the aims, methods and participants of the study, along with the key findings and recommendations. If you would like more information about any particular phase of the study, please contact the project team.

Background

Improving end of life care is a key component of national policy and the *Strategic Framework for Action on Palliative and End of Life Care 2016 to 2021* clearly outlines the government's commitment to increasing awareness and acceptance of the specialist palliative care needs of infants, children and young people.[1] Within this strategy, Commitment 4 focuses specifically on addressing the needs of the paediatric population and promoting the development of holistic palliative and end of life care for those aged 0-25.

Within Scotland, NHS Lothian and Children's Hospices Across Scotland (CHAS) set out to address the disparity in home-based end of life care services by developing a bespoke model of care that supports families living in Lothian to access specialist paediatric palliative and end of life care in their home if that is their wish. The service is underpinned by principles of relevant policies, standards and frameworks to ensure safe and effective person-centred care.[1-8]

The service, known as Care 24 Lothian, provides home-based end of life care for children and young people recognised as having reached the end of life stage, chosen delivery of care to be at home during this time and residing within NHS Lothian boundaries. This nurse-led service, supported by medical input as required, ensures families have 24-hour access to holistic care, advice and support during their child's end of life stage and following death. The service is delivered primarily by the Community Children's Nursing service during the hours of 08:00 until 18:00 and by CHAS (Rachel House Children's Hospice team) from 18:00 until 08:00.

Care 24 Service

The Care 24 Lothian service is delivered to children and families living within the NHS Lothian boundaries. NHS Lothian comprises the City of Edinburgh, Midlothian, East Lothian, West Lothian and covers a geographical area of approximately 700 square miles. Latest available population estimates calculated 177,000 children aged 0-18 years living within the NHS Lothian area.[9] Applying a prevalence rate of 47.2:10,000[10] indicates that there are 835 children with a life-shortening condition within the NHS Lothian boundaries who are likely to require input from palliative care services at some point over the trajectory of their illness.

Rationale for the evaluation

In 2018, NHS Lothian and CHAS commissioned a team of researchers from Edinburgh Napier University (ENU) and Edge Hill University (EHU) to undertake an independent evaluation of the Care 24 Lothian service which would explore the impact and effectiveness of the service and make informed recommendations for the future development of this unique model of care. The evaluation would assess how successful the service has been in meeting its intended aims from the perspectives of families who have accessed the service and professionals involved in its development, management and delivery.

The principal research question posed at the outset of the evaluation was:

> What are families' and professionals' views and experiences of end of life care provision for children and young people delivered through the Care 24 Lothian service?

In order to address this question, the following objectives were set:

1. To determine the extent to which Care 24 Lothian has met the intended aims as set out in the care framework and standards developed for the service.

2. To explore the value, and assess the effectiveness, of Care 24 Lothian as perceived by families who have accessed the service, including identification of any unmet needs.

3. To explore the value, and assess the effectiveness, of Care 24 Lothian as perceived by professionals who are involved in the development, management and delivery of the service, including any professional development needs, to support future workforce planning.

4. To identify what is working well, and any barriers to the service delivery, to make recommendations for broader implementation in other regions of Scotland.

5. To share learning from the evidence gathered to inform the planning and delivery of statutory and voluntary services for children and young people's palliative care.

Ethics approval

Ethics approval for the evaluation was granted by the School of Health and Social Care Research Integrity Committee, Edinburgh Napier University and the evaluation complied with research governance principles and procedures of NHS Lothian.

Methods

This evaluation was grounded in the principles of realist evaluation, a theory-driven approach to evaluating programmes and services to better understand how they operate in practice by considering the questions, 'what works, for whom, under what circumstances, and how'.[11-12] Realist evaluation typically consists of three broad phases. The first seeks to identify how the programme or service is 'meant' or expected to work in practice which is referred to as the initial programme theory (IPT). Data is gathered from a variety of sources to do this such as a review of the current evidence base and engagement with those involved in the development and management of the service. These data are then used to develop propositions or hypotheses about how the service is intended to operate. The IPT comprises propositions expressed in the form of Context-Mechanism-Outcome (CMO) configurations which examine 'how the context and mechanisms influence the outcomes of an intervention' (p. 201).[13] In the second phase, the theory is tested by gathering data that seeks to explain how the programme or service actually works in 'real life' contexts from the perspectives of those involved in its operation. Participants are invited to confirm, refute or refine the IPT about the service. In the third and final phase, the overall programme theory is refined through analysis and interpretation of the data to establish how in different contexts (C), various mechanisms (M) are triggered to generate outcomes (O). These are communicated as CMO configurations.[14] Figure 1 illustrates the realist evaluation process and sources of data and activity included within each phase of the evaluation.

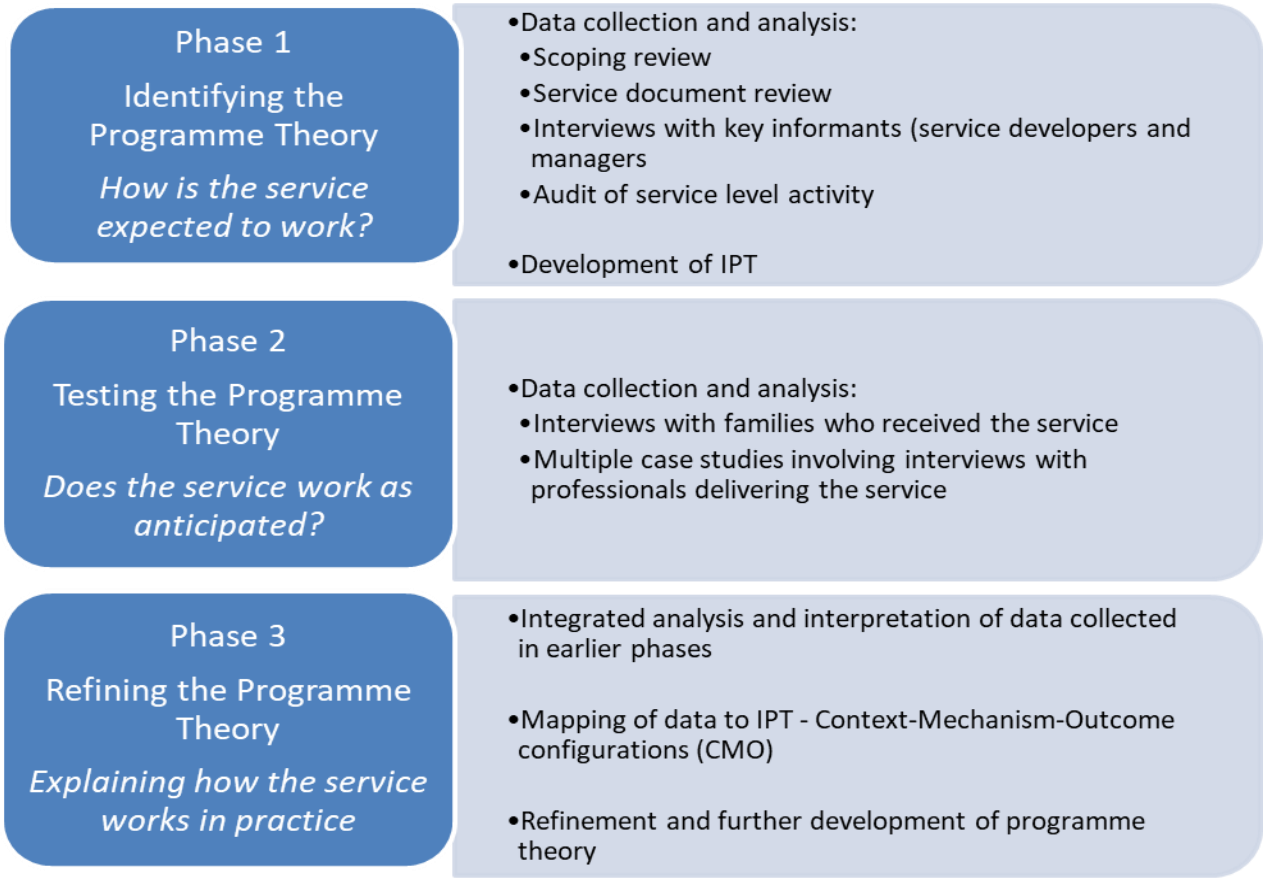

Figure 1: The realist evaluation process indicating the sources of data and activity included within each phase.

Participants

A summary of the participants included in each phase of the project is provided in table 1.

Table 1. Description of participants (n=43)

Phase	Description of Participants	Number of Participants
Phase 1: Context interviews	Service developers and managers of the Care 24 Lothian service who came from a range of medical and nursing backgrounds	6
Phase 2: Family interviews	13 bereaved parents and two adult relatives of 10 children	15
Phase 2: Case studies	Three cases studies were selected from the 10 families. **Case 1**: Lead clinician*, Lead professional**, GP, CHAS care team x 2 (medical and nursing), Palliative care specialist nurse, Community health support worker, Children's community nurse, Community staff nurse (n=9) **Case 2**: Lead professional**, GP, CCN x 2, CHAS care team, Palliative care specialist nurse (n=6) **Case 3**: Lead clinician*, Lead professional**, CCN x2, CHAS care team, Palliative care specialist nurse, Oncology consultant (n=7)	22
Total		**43**

*Lead Clinician refers to an identified clinician with overall responsibility for the child's medical care and is normally a consultant from the relevant specialty. **Lead Professional refers to an identified professional from NHS Lothian who is responsible for coordinating the service for the child or young person and their family. Typically, this is normally a member of the Community Children's Nursing Service but will be a member of the Paediatric Outreach Oncology Nursing Service for those with an oncology diagnosis.

Key Findings

The main findings will be discussed against each of the five objectives set to be addressed during this evaluation. Where relevant, illustrative verbatim quotes from participants will be provided.

OBJECTIVE 1. To determine the extent to which Care 24 Lothian has met the intended aims as set out in the care framework and standards developed for the service.

The findings from this evaluation demonstrate that the Care 24 Lothian service has been successful in meeting its intended outcomes and is highly valued by both families and professionals. The outcomes for the service, as stated in the framework document, are to provide consistent, high quality care and support to families via staff with the appropriate knowledge and expertise, and to ensure families have choice over their preferred place of care for their child's end of life care. Both outcomes were clearly met as evidenced by findings from this evaluation:

> *"We've offered choice…real choice. We're not just saying that you can die at home, but you can't really. We're making that a reality. I would say that is one of the key outcomes."* (Stakeholder P01)

> *"We have nothing, nothing but praise for everybody from start to finish. Just really, yeah, really quite something. I think the whole support at home was amazing. I think it would have been so much more different for me and my grief if [Child] died in hospital and we hadn't been given that choice, or in the hospice. Now I know some people choose to take their child into hospital and I know some people choose to take them to the hospice and that's absolutely fine but I think where I'm probably getting at is the fact that we had that choice and I will forever be grateful for that, and the support that we were given to put that in place."* (Family 6)

The Care 24 Lothian service is delivered by a team of professionals with knowledge, skills and expertise in palliative and end of life care. As evidenced throughout this evaluation, the team have provided consistent, high quality care and support to children and families, underpinned by Standard 5 (End of Life Care Plan) of Together for Short Lives core care pathway for children with LSCs[4]. The anticipatory approach to care planning and delivery has proved effective in reducing the number of contacts families make to the service out with the regular hours of 08:00 to 18:00 and,

as indicated in the service activity audit data, avoided unnecessary or emergency admissions to hospital during the time the Care 24 Lothian service was in place. This was regarded by parents and professionals as an additional benefit of the service and is communicated by one professional in the quote below:

> *"There's been a developed knowledge base around it, so that it always improves, so that it has got to this stage that this anticipatory care does support families more so that they don't have to call out of hours, or they feel supported that there is an out of hours service, however, they don't utilise…they may not have utilised it as much as they would have if we hadn't had good planning in place."* (Professional ID13)

An unprecedented increase in both the number of referrals to and the number of families accessing the service, as reported by the service management team, is an additional indicator of how effective this model of care has been. Moreover, in addition to an increase in referrals, the active promotion of Care 24 Lothian had a positive impact on the wider understanding of what palliative care teams can offer to families.

With respect to ensuring families have choice over their preferred place of care, the audit data showed that nearly all deaths occurred in the families' preferred place. There was only one exception to this where the child's condition deteriorated quickly and despite a referral to the Care 24 Lothian service being initiated, a transfer home was not managed prior to the child dying. However, in line with parents' wishes, this family were supported to bring their child home after death and with the use of mobile cooling devices were able to remain at home until the time of the child's funeral. This example reiterates the importance of timely ACP planning and some of the inherent challenges in predicting death in children with LSCs.[15-16]

In addition to the intended outcomes as set out in the service framework, there were a number of unintended yet positive outcomes. An unintended outcome, which demonstrates flexibility of the service, was how the service enabled some families to remain at home for as long as appropriate to that family before being transferred to an alternative setting of their choice in advance of their child dying. In most cases, this final choice of care setting was Rachel House. Despite current policy claiming that home is the preferred setting for end of life care and death, the evidence base surrounding this is limited.[17] There are several possible reasons for this, including a lack of services in place to support families to be at home. Current figures on place of death from birth to age 25 in Scotland indicated that 73% of deaths occurred in hospital, 21.4% at home and 5.6% in a children's hospice.[18] The Care 24 Lothian service data has shown that with adequate support available, families may choose to remain at home for end of life care but some may choose to be in an alternative place at the time of death. This flexibility to respond to changes in families' wishes surrounding

place of care demonstrates true family centredness which is at the core of the Care 24 Lothian service and an emphasis on ensuring, as much as is possible, that the end of life care wishes of families are met:

> *"We have used the service to support children to stay at home for a bit longer, although they've specified that home isn't their preferred place for end of life care. That was something we didn't really plan on but has worked quite well. So, families have identified that they want their child to die at the hospice but have said that they want to stay at home for as long as possible before that happens, and Care 24 has been used to support that, more so recently in this last year"* (Stakeholder P03)

> *"To me that was quite positive because the whole aim of palliative care is to support preferred place of care, and even though [family] wanted their child to die in the hospice, they wanted to be at home as long as possible and to make that happen was really through Care 24 Lothian."* (Case 3 P01)

OBJECTIVE 2. To explore the value, and assess the effectiveness, of Care 24 Lothian as perceived by families who have accessed the service, including identification of any unmet needs.

Families were resoundingly positive regarding the quality of end of life care and support provided by the Care 24 Lothian service. Caring, kind, knowledgeable, compassionate, sensitive, honest and supportive were identified attributes of the Care 24 Lothian team valued by families:

> *"Always compassionate...always. It felt like they really, really cared about [Child] and us."* (Family 3)

> *"But because [Nurse] was just [Nurse] and so lovely and was just so open and honest then, you know, she could have said the sky was falling down and I would have believed her, so it was that kind of relationship."* (Family 8)

Parents participating in this evaluation described Care 24 Lothian as a service characterised by compassionate, holistic child and family centred care. Parents described the importance of having a team of professionals around them who really knew their child and could tailor care to the family's unique needs and wishes at this very sensitive and emotional time. This resonates with the existing evidence base which highlights the importance of recognising parents as key partners in the wider care team responsible for providing end of life care in the home[19] and with the paediatric palliative care standards which maintain that families should be central in discussions around their child's care.[4-5] Parents also referred positively to the efforts professionals made to avoid being '*intrusive*' and ensuring a fine balance of checking in on families and giving them the privacy and space to be together as a family:

> Parent 1: *"We are quite private people and to have people in your house is quite, can be quite intrusive but they never made you feel like that did they?"*
> Parent 2: *"No they always used to say, 'we don't have to come back if you don't want us to' and 'it's entirely up to you' and they were just totally led by what we wanted. There was never any awkwardness or anything like that."* (Family 7)

Parents noted the importance of having consistency in the team around them and in being able to build trusting relationships with those delivering care to their child. They were critical on occasions where they felt there were too many different staff members visiting the home yet understanding that providing 24 hour care requires a team approach.

The importance of maintaining a parental role throughout end of life care has been identified in several studies[18-20] and parents value the opportunity to remain close to their child and participate in their care. Following Fraser and colleagues[18] review of the literature, they recommended parents are afforded choice and control over the extent to which they remain in this parental role and meet their children's care needs through to the point of death. Whilst much of the evidence in this area has focused on deaths of children in a hospital setting, the model of care adopted by Care 24 Lothian is intended to facilitate the parental role and supports parents in being able to spend time and care for their child up to and following death. Parents within this evaluation were grateful for the support they received and for the opportunity to engage in their child's end of life care with the ongoing guidance and support from the team. Moreover, there was appreciation for the sensitive and respectful manner in which both emotional and practical support was communicated to parents:

> *"I'm sure for me personally I couldn't do it without this, all the support and help, without all these people really, and they agreed to my wish to bring [Child] home, with all the help and all the equipment that we needed. They knew this is something that we wanted as a family. This is something that we're always grateful for really. The help, support, compassion, you know, the friendly staff and the knowledge that they have really. They know how to speak with you, they know how to look after [Child], you know, they know in advance what you need, they really think ahead. I really think this is something absolutely amazing to have to be able to have such a help and support for your child because you are totally broken, lost and if you have such people around you who are looking after everything, it's such a relief because you can just spend time, the precious time with your child."* (Family 3)

Having access to advice and support via the 24 hour dedicated telephone number of Care 24 Lothian was important to families. Regardless of whether or not families required assistance out with 'regular' working hours, knowing that they had access to support if needed gave them confidence to be able to remain at home. The importance of those families wishing for their child to be cared for and die at home having access to 24-hour care is supported in the literature.[21-23]

Some parents felt that adoption of a non-uniform approach by the nursing and associated staff delivering care within the home would enhance their experience of the service. Families described

one of the benefits of being at home was the fact that it was a familiar and non-clinical environment Linked to this wish for a non-clinical environment, some families made an association between nursing uniforms being worn during home visits and anxiety displayed by their child and his/her siblings. Having care provided by staff in 'non-clinical' attire was perceived as being important to families. A comparison was made between the NHS Lothian nursing team and the Rachel House care team, with the former wearing NHS nursing uniforms and the later wearing casual attire.

OBJECTIVE 3. To explore the value, and assess the effectiveness, of Care 24 Lothian as perceived by professionals who are involved in the development, management and delivery of the service, including any professional development needs, to support future workforce planning.

In addition to the points discussed above, other aspects of the service deemed effective from professionals' perspectives were the approaches taken to develop ACPs with families, the processes and procedures in place to communicate key information and patient handover at the end of shift and the efforts in advancing partnership working amongst with Care 24 Lothian team. Professionals were cognisant of the positive developments in partnership working between the two core providers since the service started and acknowledge that there is further scope for continuing to build on those partnerships:

> *"I think it's evolving. I think when I take myself back to the very early days of Care 24 Lothian, it definitely very much was or felt like a…a bit like an 'us and them', you know, 'us' I mean NHS Lothian, 'them' being Rachel House. But I think our partnership working has evolved. That's how a partnership develops. It doesn't just…you know, you don't just go walking along the street with a member of the public, holding their hand, skipping, saying everything's going to be fine. It takes time. It takes commitment. It takes mutual respect for services, you know. And I think in the early days they didn't know what we did and we didn't really understand what they did. And I think it has evolved. I definitely feel in particular with [Child], that partnership working was amazing. And then that trickled…that has trickled on to lots of different cases."* (ID3)

Professionals, both those responsible for managing and those with a role in delivering the service, identified a number of areas for future improvements to enable Care 24 Lothian to continue to provide quality end of life care. These were largely centred on the provision of medical and nursing input 24 hours a day and continued improved partnership working between the core providers of the service.

Throughout this evaluation, the importance of families developing trusting, open and supportive relationships with those providing their care has resonated clearly. It is important that both service providers, NHS Lothian and CHAS, are visible to families and have the opportunity to build such relationships. This is currently being achieved for the NHS CCN and POON staff but less so for CHAS, or more specifically, Rachel House staff:

"Sometimes the expectation is that [Rachel House] will take the on call part and do the out of hours bit but we've [Rachel House team] never actually met the child. So if the child's come from hospital and gone home but never actually been in the hospice because that's not the sort of care that the parents want, then you can be giving advice on a child and family you've never met, and if you are called out at three in the morning it's not the time to really be doing the background stuff." (Case 1 P06)

There are recognisable reasons for this, as given the success of the anticipatory approach to care, families infrequently require contact with the Rachel House team. Yet families clearly highlighted their need to have trust and confidence in the team around them which includes the staff providing care between 18:00 to 08:00. Building relationships with the complete Care 24 Lothian team, including CHAS and Rachel House staff is therefore of value and will increase the opportunities for families to engage with this aspect of the service.

Other aspects of partnership working requiring improvement include overcoming the communication challenges inherent with separate organisations delivering a joint service. These included use of incompatible email systems which can block each other's emails and means that emails are not secure when sent between the services, and different core paperwork such as medication prescribing kardexes. Similar challenges were highlighted in Bennett and colleagues[24] service evaluation with agreeing pathways and standards of care and developing joint paperwork between the hospice service and community care nursing team identified as aspects of their end of life home care service where there is capacity for improvement.

Care 24 Lothian is a nurse-led service where families can access end of life care and support 24 hours a day. The service provides a single point of contact with NHS Lothian CCN service responding to care needs from 08:00 until 18:00 and CHAS Rachel House care team covering the remaining hours. The infrequency of calls made to the service out with the NHS Lothian team's hours of care provision, as evidenced in the audit section of this report and corroborated during interviews with professionals, suggest that the current anticipatory approaches to care and symptom management planning are effective.

However, despite infrequent contact with the Rachel House team, the service must remain accessible to families and responsive to their care needs over the 24 hour day. This means having identified CHAS nursing staff, with the appropriate skills and expertise, on call when there are active Care 24 Lothian cases. These nurses must ensure they are familiar with all recent communication and care plans related to these cases. There also needs to be a second staff member available to attend should a home visit be required, with another staff member available to provide appropriate on-call cover for Rachel House. The service has, at times, found this challenging to resource. In cases

where there isn't a developed relationship between families and the CHAS Rachel House nursing team, providing telephone support can be more challenging and the advice given from CHAS staff during out of hours more cautionary as they are less familiar with the child and family:

> *"I don't know, I couldn't obviously speak for everyone as well, but I think when you've not…not so much, you know, when we're doing a lot of the advice over the phone I don't know if there's sometimes a slight inclination whether you mean to or not to sort of advise slightly more cautiously when you've never met the child or family, because actually you're kind of advising a little bit blindly and I don't know if you advise slightly more on the cautious side if that makes sense."* (ID9)

Maynard's[23] evaluation of a specialist nursing service providing 24/7 symptom management for children with LSCs also observed a reduced volume of telephone contact with the service after hours and suggested the infrequent nature of telephone calls was not related to the extent of need for the 24/7 service but rather the key issue for families was that the service was perceived as a "*lifeline*" and just knowing that it was available provided sufficient support and reassurance. Moreover, Maynard[23] suggested the anticipatory planning strategy coupled with the formal telephone contact element of the service was a critical success factor which ensure the service was sustainable. This is in contrast with the findings emerging from this evaluation as referred to earlier where families want to be familiar with the staff providing care at such a personal and emotive time. The audit data highlighted that three families who had experienced the death of their child during the night had chosen not to contact the out of hours CHAS team at Rachel House, opting to wait to speak to the NHS Lothian CCNs who they were familiar with in the morning. This may have been their choice whether or not a relationship existed, but the potential it was influenced by the lack of an existing relationship with the CHAS team is worth exploring.

Alongside nursing care, the service ensures 24 hour access to medical support. The findings suggest that access to medical advice is working largely as expected during the 08:00-18:00 timeframe as there are a number of clinicians who can be called upon including the child's medical consultant, paediatric palliative care specialists, advanced nurse practitioners and the child's GP. When there is a need to contact medics out with these hours, it can be more problematic as there is greater reliance on on-call cover. This can mean that a paediatric palliative care clinician can be on call for both Rachel and Robin House and families in communities other than Lothian. Giving support to families or other members of the Care 24 Lothian team is feasible via telephone but geographical distances can pose a challenge if a home visit is required. Given the clinical complexity of many of these children and the very specialist nature of paediatric palliative care, clinicians are not always agreeable to symptom management and treatment without having undertaken a face to face assessment of the child. This is particularly the case in situations where the clinician has little previous knowledge of the child and family. The service can find it challenging to ensure there is

capacity to respond. When a child is under the care of Care 24 Lothian it will be necessary to identify where they live and to explore options for out of hours medical support so that arrangements can be made with local service on an individual basis where necessary:

> *"Yes we need that 24-hour medical support model, it's crucial to the delivery of that type of service. The nurses need to have access to someone who can say 'yes it's okay to increase that medication' or 'yes it's okay to have no ceiling dose and to give another dose of Midazolam' And the GPs need that too."* (ID1)

The key role that GPs within primary care can play in supporting the service and the importance of continuing to engage with and involve the GPs on a more consistent basis to build capacity was recognised within the evaluation. As outlined in the quote by one professional below, it is often the GP who is the closest medical contact for a family geographically so there is merit in working in partnership with them:

> *"I think that's fine and that is actually the case that we do have medical staff on 24 hours but whether or not, do you know, we're not involving the local GPs as much as we should be, I'm not sure. I mean, I know in some areas, some that are quite remote, the plan is to get GPs on board because they may be the nearest point, you know, the nearest medical point for families."* (ID20)

The Care 24 Lothian team support children at the end of life, families, colleagues, and others. The emotional impact of this role is significant and requires access to good quality clinical supervision, debriefing and self-care.[25] Self-care is a fundamental part of palliative care practice and is required to be able to continue to deliver effective end of life care and support to others[26-27]:

> *"There's definitely something about looking after our staff. And, you know, ultimately that is what we need to do because if you don't have the staff with the right mindset on how to provide the care, then the service is going to fall on its nose instantly."*
> (Case 1 P03)

> *"I think it's such a hard thing to provide palliative and end of life care, you really need to look after each other."* (Case 2 P03)

OBJECTIVE 4. To identify what is working well, and any barriers to the service delivery, to make recommendations for broader implementation in other regions of Scotland.

There is potential for this unique and creative model of care to be extended to other regions of the country and this was supported by participants and perceived as important in terms of avoiding a 'postcode lottery' and ensuring appropriate services were in place to facilitate the provision of end of life care for children at home. Moreover, as illustrated in the following quote, families see value in promoting this model of care to others:

> *"I found it quite surprising that this service is only available in Lothian…I found that profoundly surprising. Like I said, I think that parents have no idea that their child can stay at home…and I think they should know and it's probably how to approach someone and talk about end of life."* (Family 2)

Care 24 Lothian's successful implementation was dependent on access to key resources including the CCN service, Clinical Nurse Specialist for Children and Young People's Palliative Care, POON service, Rachel House, and lead medical consultants from the Royal Hospital of Sick Children being within the region. Whilst rolling out this model of care across Scotland would help to promote equity in accessing home as the preferred place of care for end of life, it will require determining how access to these resources can be achieved in other areas, particularly those which are rural and remote.

An extensive scoping review, conducted as part of this evaluation, revealed that few similar services providing 24 hour specialist paediatric end of life care in the home have been reported in the literature. There are, however, two UK services which published their evaluations of a related model of care that is also based on 24 hour access to palliative and end of life care at home. Interesting, both of these services have reported comparable challenges to those highlighted in this evaluation. Care 24 Lothian would be ideally placed to lead on discussions with these services to jointly identify strategies for addressing such barriers moving forward.

OBJECTIVE 5. To share learning from the evidence gathered to inform the planning and delivery of statutory and voluntary services for children and young people's palliative care.

An extensive evidence base was generated from this evaluation which in addition to influencing the development of the Care 24 Lothian service moving forward, can inform best practice in children's end of life care generally. Hearing the stories of bereaved families, from the point of deciding where they wanted their child's end of life care to take place to their experiences following their child's death are of immense value and contribute to enhancing palliative care and services. Some families also spoke of a desire to share their learning with other families by developing an information pack which could be of benefit to families requiring end of life care for a child.

Two distinct organisations coming together to design, develop and subsequently deliver an integrated service is not without challenges. The Care 24 Lothian team have confronted these challenges and continued to enhance both the service and their partnership working. Whilst additional improvements would be of benefit, the service is proactive in seeking solutions and better ways of delivering care. There is merit in sharing learning around this.

Finally, it was clear from the data that despite progress over many decades, misconceptions surrounding children's hospice care continue to exist, even amongst families with a child nearing the end of life. Interestingly, a number of families taking part in this evaluation went from being fairly certain that hospice care was 'not for them' to accessing care and support from Rachel House and describing it as invaluable. Parents suggested a number of approaches to promoting Rachel House to other families and these are important to consider in order to facilitate access to palliative care services:

"So, at the time I didn't want to go to Rachel House but when I look back in hindsight it was the best thing for us. But I think I didn't know any of this stuff existed and now that I've experienced it, it's trying to get across to other parents if they'll listen, that's the thing, it's whether they want to listen to it or not, that they can actually have, like, you can make it what you want to, definitely." (Family 10)

"I think that's a big problem. I think that part of the problem that we have, and I have, is how to promote it I guess…Rachel House as a place that supports families. Because everyone has a very fixed view of what it is. People don't want to talk about it, and I really found that with [Child]'s parents. They just weren't for entertaining any conversation around that." (Case 3 P03)

Recommendations

Based on the findings from this evaluation of the Care 24 Lothian service, a number of recommendations are proposed for consideration to facilitate further development of the service and achievement of the core outcomes of the service. These are organised under the five core areas of the service that were identified and tested during the project:

Anticipatory approach to care planning and delivery

The anticipatory approach of the service is working as intended and all involved felt that this should continue as a core approach. A few areas for improvement were identified: (i) Much of the care provided to families occurs during the 'regular' working hours of 08:00 to 18:00 when the NHS Lothian staff are providing care, therefore CHAS members of the team are not as visible to families. This can have an impact on the confidence of the families to reach out for support during out of hours and on the advice that CHAS staff can provide to families on the telephone or during home visits; (ii) the involvement of other key professionals in anticipatory planning, particularly the GP, could be further developed to ensure they know the family and are better placed to provide support when needed. Several recommendations are made for consideration:

1. The anticipatory approach to care planning and delivering has proved effective and this model of care should continue to be adopted by the service moving forward.

2. To facilitate building and maintaining relationships, between families and staff which are based on trust, respect, and confidence in the service, the following strategies should be considered:

    - A joint visit to the family at an early stage by NHS Lothian and CHAS staff to introduce both sides of the service to the family and to avoid unnecessary risk for CHAS staff locating an unknown family home during out of hours if a home visit is required while the service is provided;
    - Explore how CHAS staff can have a more visible and active role with families during the regular hours;
    - NHS Lothian staff to continue to positively promote to families the specialist staff who are available to support them during out of hours as a core part of the integrated Care 24 Lothian service.

3. The service should consider ways to engage earlier with GPs working within primary care services, and so they are informed of the care and support needs of children and families and included in the anticipatory model of care.

Advance care planning

Advance care planning is an essential part of the end of life planning which is initiated by the Care 24 Lothian service if not already in place. This approach to beginning, or continuing, conversations with families is a strength of the service which all participants viewed as a pre-requisite for future care provided by the service. It was recognised that these discussions are contingent on families

being ready to have them and that a relaxed and individualised approach is needed. Several recommendations around timing of conversations and involvement of other professionals are proposed below:

4. Care 24 Lothian staff should continue to identify if an ACP is in place and to have an initial ACP conversation with families as soon as possible following referral of a child.

5. To continue with the facilitating mechanisms of relaxed and re-visited advance planning conversations to allow families to make informed decisions regarding end of life care and have a clear understanding that their decisions are not fixed and can be revised as required.

6. To continue to encourage and support clinicians who are involved in children's treatment to be proactive in having anticipatory discussions regarding end of life care with families which are written in detailed and accurate ACP documentation to ensure clear communication of care plans and family's wishes to all professionals involved in the child's care.

Service responsiveness and flexibility

The Care 24 Lothian service provides a responsive and flexible service to provide choice and individualised end of life care to children and families. This has evolved to enable families to move between care settings towards the end of life in line with their choices and care requirements. The challenge of unpredictable demand, the need for timely transfer between care setting, and ensuring sufficient 24/7 nursing care and medical support were identified and recommendations are made for future planning:

7. The Care 24 Lothian service has been successful in supporting families to move between care settings towards the end of life in line with their wishes and care requirements and should continue to facilitate this.

8. As stated in recommendations 4, 5 and 6 above, anticipatory planning with ongoing assessment and discussion with families is needed to facilitate this aspect of the service, along with good communication with all involved to facilitate planning for any change of setting for death.

Nurse-led service with 24 hour medical support available

The Care 24 Lothian service is a nurse-led service with nursing care and additional medical support available at any time of the day or night as required by families. Challenges were identified around the capacity of the service to consistently resource nursing staff 24/7 and medical cover during out of hours during peak demand given the unpredictable nature of referrals. The NHS Lothian CCN team work in pairs of an experienced and junior nurse to grow capacity by developing nursing competence and expertise in delivering community-based palliative and end of life care. There is a small team of four charge nurses who currently provide the out of hour nursing care. The Care 24 role is absorbed into their role and can result in them being called on during the night and then possibly being on shift the following day. The CHAS medical team are committed to the Care 24

Lothian service but have responsibilities across a broader geographical area and at times may be reliant on providing support by telephone for a child they have not met. The confidence of CHAS staff, and external medics such as GPs, to provide appropriate advice support is impacted by their knowledge of the child and family and may result in more cautious advice. Whilst there are plans to build capacity the following recommendations are made for consideration based on the findings:

9. To ensure families can access end of life care and support that is responsive to their needs and available any time of the day or night at home, and to meet increasing demand for the Care 24 Lothian service, consideration should be given to identifying ways to strengthen 24 hour access to specialist paediatric palliative nursing care. Strategies to achieve this may include:

- To continue the NHS Lothian CCN model of working in pairs to ensure safe and best practice which also facilitates better support for both families and staff and builds capacity.
- To explore the potential for CHAS staff to have two members of the team attending visits during out of hours to ensure safety and best practice, and to build capacity amongst other members of the team such as the CHAS at Home team.
- If the above is adopted into practice, mechanism for replacement on-call cover for Rachel House at short notice will need to be in place.
- To build capacity of prescribers with additional nurse prescribers and advanced nurse practitioners with specialist palliative and end of life care experience.
- To ensure a consistent standard of care and to advance current nursing practice, additional education is required to ensure staff have the required skills and expertise to deliver end of life care in the home setting and to build capacity within the service. A shared and team approach to learning is suggested.
- Consider the use of technology such as video conference calls (Skype® or Facetime®) to improve the level of information available for assessment and advice from the CHAS nurse on-call during out of hours.

10. Likewise, consideration should therefore be given to identifying ways to strengthen 24 hour access to specialist paediatric medical care. Strategies to achieve this may include:

- Consider the use of technology, such as video conference calls (Skype® or Facetime®), to aid assessment and symptom management, and facilitate access to specialist paediatric palliative care medical support via CHAS 24 hours a day, particularly when there are geographical distances between professionals and families.
- To facilitate medical cover across the 24 hour day when CHAS medics are unavailable, robust mechanisms for proactively communicating and engaging with other medics based in the community, at the hospital and NHS24 are needed. This can be supported by specialist advice from the CHAS medics where required.

- To establish current availability and input, a prospective audit of out of hours medical provision to the Care 24 Lothian service should be conducted to ascertain an accurate picture of the medical input out of hours.

Partnership working to deliver an integrated service

The partnership working between the teams to provide an integrated service to families is working as intended and has developed over the time the service has been in operation. Several areas for further enhancement of partnership working were identified including improving the communication between services, reviewing current documentation use to improve standardisation and that it is all fit for purpose, developing a deeper understanding of each service, and use of service level de-briefings and well-being support for staff. The recommendations are presented below for consideration:

11. Consideration should be given to maximising opportunities for enriching partnership working between the core Care 24 Lothian service providers to foster a more cohesive approach to delivering the service. Strategies to achieve this may include:

- The creation of joint posts or rotational secondments between Rachel House nursing team and the NHS Lothian CCN service;
- Adopt a partnership approach to some home visits of children and families receiving the service;
- Participation in shared learning and training amongst the teams to ensure consistent standards and approaches to care being delivered to families;
- Participation in shared learning and training amongst the teams to ensure consistent standards and approaches to care are being delivered to families;
- Arrange 'away days' or equivalent to engage in team building activities and conduct ongoing review and evaluation of service provision.

12. To have an experienced CHAS staff member at Rachel House assigned to the service as the CHAS lead when there are active cases so the lead person for out of hours is clear to the whole Care 24 Lothian service.

13. To conduct a joint review of policy and procedures to ensure the service is being delivered to the same agreed standards and the documents have incorporated any changes which has evolved since the inception of the service.

14. To conduct a joint review of all documentation to ensure that they are fit for purpose for the whole Care 24 Lothian service and establish processes that will facilitate better access to and sharing of documents across the organisations (NHS and CHAS). This would include, for example, email systems and drug prescribing Kardexes.

15. To review daily communication processes between the core providers during active cases to ensure that all staff are following the agreed processes and enhance communication.

16. To explore options such as technology use to conduct service level de-briefings following the death of a child to promote shared learning, quality improvement and support across the teams.

17. To makes links with other hospital-based services for those nearing the end of life and consider how these services might be replicated in home-based end of life care to ensure that families have the same access to service and support as those dying in hospital and address any impact of the Care 24 service on other services. Examples of services to link in with are clinical psychology, spiritual care and KINDRED.

18. To consider how to prioritise support through various evidence-based measures including self-care, debriefing and clinical supervision to support the emotional impact of providing end of life care on staff.

19. Engage in national discussions concerning the feasibility of extending this model of care to other regions in order to promote greater equity of access to end of life care at home for families across Scotland.

20. To consider the feasibility for the Care 24 Lothian CNN team adopting more casual and non-clinical attire instead of the standard nursing uniforms, as requested by families.

21. To support the development of GPS and other professionals with less palliative care experience through joint working and training, particularly on prescribing and symptom management, and for non-oncology conditions.

22. To consider supporting the request from families for them to develop an information pack of their experiences and suggestions to be shared with other parents.

Future evaluation and research

This evaluation has highlighted a number of additional areas which would be of merit to explore through research in the near future:

- A prospective audit of out of hours medical provision to the Care 24 Lothian service should be conducted to ascertain a more accurate picture of the medical input during out of hours.
- Longitudinal follow up of families who have received the service to explore longer-term impact of the experience and their perspective on the effectiveness of available post-bereavement support.
- Collaborative study with families to develop resources for families receiving end of life care at home.
- Impact and effectiveness of technology for clinical patient assessment across geographic areas or during out of hours.

Conclusions

Provision of end of life care in the preferred setting of children, young people and their families is a priority within palliative care policy and practice. Services like Care 24 Lothian are pivotal to achieving this and, crucially, in ensuring the end of life care needs and wishes of families are met. This evaluation has demonstrated that Care 24 Lothian is an effective and highly valued service which has enabled families to have genuine choice regarding place of care and has provided them with high quality end of life care and support. Parents were extremely positive in their accounts of the service and the sensitive, compassionate and expert care provided by the Care 24 Lothian team. Professionals involved in the development and delivery of the service were confident that the service has been effective in meeting its intended outcomes and in providing an expert level of palliative care within the home in a way that is family led and family oriented.

This evaluation has also shown that Care 24 Lothian offers a model of end of life care which is flexible, responsive, and driven by the unique needs of children and families. Additional enhancements are necessary to ensure the service can remain responsive to families' care needs with expert nursing input and additional medical support as required, any time of the day or night. Effective partnership working between NHS Lothian, CHAS and related agencies is essential in delivering an integrated service like Care 24 Lothian. Opportunities for strengthening partnership working have been identified and can inform the development of this service moving forward.

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A realist evaluation of the Care 24 Lothian service – Summary Report

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