

Development of a Managed Clinical Network for Children's Palliative Care – A Qualitative Evaluation

Andrew Papworth (✉ andrew.papworth@york.ac.uk)

University of York <https://orcid.org/0000-0002-3244-2634>

Lorna Fraser

University of York

Jo Taylor

University of York

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Abstract

Background Consistent evidence suggests that children’s palliative care is not equitable and managed clinical networks have been recommended as a solution. This study explored the development of a managed clinical network for children’s palliative care in England, with an aim to identify barriers and enablers of successful implementation.

Methods Thematic analysis of semi-structured interviews and focus groups with 45 healthcare staff with a role in developing the Network or in the delivery of children’s palliative care (September 2019-March 2020).

Results The study identified Network features that helped to formalise governance processes, establish training and networking opportunities, standardise practice, and improve collaboration between organisations. These include the funded Network co-ordinator, committed individuals who lead the Network, and a governance structure that fosters collaboration. However, the Network’s development was impeded by cross-cutting barriers including limited funding for the Network and children’s palliative care more generally, no shared technology, lack of standards and evidence-base for children’s palliative care, and shortage of palliative care staff. These barriers impacted on the Network’s ability to improve and evaluate palliative care provision and affected member engagement. Competing organisational priorities and differences between NHS and non-NHS members also impeded progress. Training provision was well received, although barriers to access were identified.

Conclusions Key features of children’s palliative care can act as barriers to developing a managed clinical network. Managing expectations and raising awareness, providing accessible and relevant training, and sharing early achievements through ongoing evaluation can help to sustain member engagement, which is crucial to a network’s success.

Introduction

Evidence consistently shows there is significant inequality in the provision of children’s palliative care,²⁻⁵ in part due to the patchy geographical distribution of provision,^{4 6} the differing structures and services among providers,^{3 7} and the lack of collaboration and coordination between these organisations.^{3 4 7} Establishing managed clinical networks (MCNs)⁸ for children’s palliative care has been proposed to address these issues,⁹ and to ensure specialist palliative care is available to those who need it.^{10 11}

MCNs have been established for various care pathways and medical specialties in the UK and other countries.¹² Unlike informal professional networks which are organic by nature, the key feature of MCNs is that they are formal and managed entities in which the emphasis “shifts from buildings and organisations to services and patients”,⁸ often requiring members to “surrender sovereignty’ to achieve shared objectives”.¹³

The current evidence about MCNs suggests they lead to improved care processes and clinical outcomes. A recent systematic review identified a lack of high-quality studies examining effectiveness,¹² but it also identified factors associated with positive outcomes. These are summarised in Table 1.

Table 1: Features of successful clinical networks – enablers and barriers

Enablers of clinical network success
Sufficient resources – funding, administration and human (staffing)
Availability of information and communication technologies
A bottom-up, locally driven approach to implementation
A positive, trusting culture where networks are seen as desirable and perceived to be necessary
The norms and values of the network are compatible with those of the organisations involved
Strong leadership
Inclusive membership
Engagement at different levels of the healthcare system
Evidence based work plans and projects that address issues identified by network members
Supportive policy environments
Barriers to managed clinical network success
Lack of funding and resources
Tension, distrust and competition (particularly over resources) between network members
An imbalance of power between network members resulting in competition for resource
Poor communication and unwillingness to collaborate
Lack of confidence in the ability of network leaders and managers
Lack of representation of key stakeholders in certain contexts (e.g. rural interests)
Poor record keeping and documentation
A top-down approach of network implementation

Source: Adapted from Brown et al. (2016)¹²

There is no published evidence about the implementation of MCNs for children’s palliative care. It is a comparatively new medical specialty with a small specialised workforce,¹⁴ includes third sector providers as well as NHS services,⁴ and covers a broad spectrum of diseases within a relatively small population.¹⁵ An understanding of how these distinct features may influence the implementation of MCNs is needed. This study aimed to identify the key barriers to and enablers for successful implementation of a regional MCN for children’s palliative care (‘the Network’) in England.

Methods

This two-phase study draws on process evaluation methodology¹⁶ and implementation theories, in particular Socio-technical Systems Theory (SST),^{17 18} which views the Network as a system made up of interacting sub-systems with their own unique infrastructures, cultures and goals.

Qualitative methods were employed to explore meanings, experiences and beliefs about the Network among individuals with a role in developing the Network in phase 1, and staff who work in the Network’s member organisations in phase 2. The study objectives are presented in Table 2.

Table 2: Study objectives

1	To evaluate how and to what extent the Network is being implemented across the region
2	To identify the key factors that are influencing implementation of the Network
3	To understand the role of technology (e.g. information systems) in implementing the Network
4	To ascertain what the Network means for member organisations and their staff
5	To understand the perceived impact of the Network on the delivery of palliative care.

The Network

The Network is in a large geographical region of England with a mix of dense urban and sparsely populated rural localities. The region is served by a small number of paediatric palliative care clinicians, children's hospices, tertiary centres and specialist nursing teams. The Network was established as an informal professional network and during the time of the study was transitioning into an MCN. The Network has a hub-and-spoke model,¹⁹ as seen in Figure 1.

Sample and recruitment

Phase 1 aimed to explore the perspectives of individuals involved in the Network's internal structures (e.g. executive committee) in order to understand what had been achieved so far and the challenges faced in implementing the Network. All individuals with a role in these structures were invited to take part. Fourteen of the executive committee members took part.

Phase 2 explored wider awareness of the Network and gathered perspectives about the Network's impact on changing palliative care practice. Participants worked in hub and spoke organisations but were not involved in the Network's internal structures. Organisations were purposively sampled to ensure representation from different services, particularly those not already represented in phase 1 and those on the Network's periphery, either geographically or due to limited engagement in the Network (drawing on phase 1 findings). Convenience and snowballing strategies were used to identify potential participants. We expected to recruit 20-30 participants in phase 2.

All participants received a study information sheet and provided either verbal recorded, email or written consent prior to participation.

Data collection

In phase 1 we used semi-structured (face-to-face or telephone) interviews or focus groups to collect data. In phase 2 we used semi-structured (telephone) interviews. Topic guides designed to capture implementation work, barriers, enablers and achievements in phase 1, and awareness and impacts of the Network in phase 2, were used to structure data collection. Interviews lasted approximately 20-30 minutes and were conducted by AP. AP and JT facilitated the focus groups, which were around 60 minutes long. Data were collected between September 2019 and March 2020. Focus groups and interviews were audio-recorded and all but one were transcribed intelligent verbatim for analysis. Extensive notes were made on the final interview, which could not be transcribed due to poor recording quality.

Data analysis

Data were analysed thematically in NVivo version 12²⁰ using an inductive coding process.²¹ Phase 1 data were analysed first, informing the coding and analysis of phase 2 data. Coded data were mapped to the SST framework (see Figure 2) to identify factors found to influence Network implementation, and the relationships between these. The analysis was finalised through a process of moving backwards and forwards between the factors identified and the data from both phases. AP carried out the initial coding and

analysis before AP and JT developed the themes further. The finalised themes were agreed jointly by AP, JT and LF and re-mapped to the SST framework.

Results

Thirty-three participants from 15 organisations took part in phase 1; 14 in interviews and 19 in two focus groups. Twelve participants from 10 organisations took part in phase 2 (total 45 participants from 20 organisations (see Tables 3 and 4)). The numbers in phase 2 were lower than expected; some invited participants excluded themselves because they felt they didn't know enough about the Network and we reached data saturation earlier than expected.

Table 3: Study participant numbers by organisation type

Type of organisation	Hub organisations		Spoke organisations		Total
	<i>NHS</i>	<i>Non-NHS</i>	<i>NHS</i>	<i>Non-NHS</i>	
Phase 1	5	18	8	2	33
Phase 2	3	5	3	1	12
Total	8	23	11	3	45

Table 4: Study participant numbers by professional role

Type of role	Clinical	Nursing	Management	Other	Total
Phase 1	9	8	15	1	33
Phase 2	3	3	4	2	12
Total	12	11	19	3	45

Figure 2 uses the SST framework to summarise identified factors affecting Network implementation and demonstrates their connected nature. The factors are described further below, using participant quotations to illustrate key points and relationships between factors.

Goals and metrics

Nearly all participants articulated a shared vision for the Network: to achieve equitable and high-quality children's palliative care provision and develop a 24/7 model of care. However, a small number raised concerns that the Network's goals were too broad, which one participant linked to the definition of palliative care adopted by the Network:

"[Our] definition [...] talks about [providing services] from the point of recognition of a life limiting condition all the way through to death and beyond. If you're trying to provide that for everyone [...] actually it's a massive task." P1 participant #2

Some participants acknowledged that they prioritised the care provision and future of their own organisation over the aims of the Network. Others stated the Network helped children's palliative care remain on the agenda in their organisation and secure senior buy in.

"[The Network gives] a degree of status that means it's difficult for both the trust and the commissioners to ignore." P1 participant #21

The lack of a standardised outcome measure was noted as a significant barrier to implementing the Network because it made it difficult to demonstrate the Network's worth to funders and prevented evaluation against agreed standards. It also presented challenges for the Network to agreeing how success should be measured.

People

Despite sharing the Network's vision for children's palliative care, participants varied in their awareness of the Network and its work. Several potential phase 2 participants excluded themselves from the study because they felt unable to say anything about the Network and many participants in both phases of the study were not clear about the specific purpose or role of the Network.

This uncertainty may well reflect the fact that the Network is still in its infancy, with much of the work in standardising care and developing a 24/7 specialist service yet to be achieved. However, it also reveals that not all members of the Network are working to shared goals or benefiting from the shared processes or resources that have been established.

The small number of specialist palliative care professionals and community nursing teams in the region were identified by numerous participants in phase 1 as a key barrier to the development of a 24/7 community-based service model, which was a core goal for the Network.

"There are areas of our geographical patch that don't have good access to community nursing. It's not about the skill of the people involved. It's purely about their presence, their availability." P2 participant #39

The shortage of specialist palliative care staff was recognised to be a national problem; however, there were more mixed views about whether more specialist palliative care professionals were needed, or whether the solution was about working differently to ensure community nurses and others were able to access the specialist expertise available.

Infrastructure

The limited and short-term nature of funding for the Network was identified by many as a barrier to effective implementation. The Network relied on the commitment of key individuals who were not Network funded.

"[W]e're continually having to look at getting that funding on an annual basis [and that process] takes away from the work that we're doing." P1 participant #10

Insufficient funding was a cross-cutting issue, impacting on the Network's ability to address barriers related to technology, training, service development and staffing. It also meant change was slow to be implemented and individual and organisational engagement suffered because barriers were perceived by member organisations as being too challenging to overcome.

The size and geographical diversity of the region was another important barrier. Participants from organisations on the geographical periphery of the region were concerned that the Network's resources may not reach them, and also reported difficulties engaging with meetings and events that were held centrally. Some participants were concerned that standardised care might not be appropriate for some locations with local idiosyncrasies.

The appointment of the Network's full-time coordinator was named by nearly all participants as the most important enabler for formalising the Network's governance structures and driving forward the Network's goals. The role also provides the Network with a single site of contact and liaison point to raise awareness and keep members updated.

Technology

The Network's hubs and spokes use different patient record systems and there is no technological solution to share these data. This was identified as a cross-cutting barrier to implementing the Network, impacting on its ability to improve access to specialist palliative care, increase co-ordination and collaboration between services, and impeding the Network's plans to create a specialist 24/7 service reliant on health professionals providing telephone advice or care for children they do not know.

"The classic is if the GP has started long acting morphine [and] I can't find that [in their records] because [the GP uses a different system]. You're reliant on people being able to grab you and phone you [and] it's not a robust system." P2 participant #46

Although data incompatibility is a known issue impeding joined-up care nationally, participants also stated it impeded the evaluation of the Network due to the different information that is recorded, the differences in how the same information is recorded, and the different functionalities for searching and extracting data. These issues were also highlighted in a pilot data collection process carried out by the Network to understand hospice provision. Participant feedback suggests that some organisations will find it difficult to use a standardised data collection template, and may worry that their provision is not being adequately captured. There is also a resource implication for organisations who have to manually search for information.

During this study, the Network had secured funding for a virtual community of practice focused on improving transition of children into adult services. Several phase 1 participants believed this could facilitate more accessible training, peer support and collaboration, and sharing of expertise and best practice. Although not yet implemented, this could be a potential enabler for the Network in the future.

Culture

Many participants talked about the impact of the diversity in member organisations; each has different priorities, funding structures, practices and governance processes. The differences between the NHS and hospice organisations at the centre of the Network – in terms of scale, models of care, specific populations served (e.g. different transition points into adult services, and security of funding – were specifically highlighted as a key barrier to developing a co-ordinated Network with shared governance, data, resources and care pathways. These differences also contributed to the uncertainty expressed by participants about the Network.

"I think there are issues around the definition ... you know, how the term palliative care is used in different places ... I just think that if we're talking about specialist palliative care we need to make sure we're talking about specialist palliative care consistently." P1 participant #6

As highlighted previously, the limited amount of funding for the Network was identified as a barrier to its development. For some participants, this reflected the fact that funding children's palliative care is not a priority for healthcare commissioners.

"[C]hildren's and young people's palliative care [...] hasn't been funded properly by the NHS for goodness knows how long" P2 participant #35

Several participants believed that the lack of sufficient funding for palliative care more generally placed constraints on what member organisations were able and willing to offer to the Network, in terms of sharing and expanding resources and expertise.

"One of the barriers is that there's not enough funding to go around, and then that creates challenges and competition [...] between different organisations." P1 focus group 1 participant

Processes and procedures

The study found that the Network has a clear governing structure that includes all the hub-and-spoke organisations that make up the MCN and has a more formalised approach compared with the informal network that existed previously.

"It has changed. It feels a bit more formalised now, a bit more structured; [there are] agendas and actual projects rather than just a forum that people went to." P1 focus group 2 participant

This opinion was not unanimous, however: one participant referred to the Network as a 'talking shop' and several other participants expressed concerns about the changeable and partial involvement of organisations in the Network's governance structures. Some participants also expressed uncertainty about whether the Network itself had led to formal changes in the provision of palliative care, although their beliefs about why differed.

When asked what had been achieved, many participants talked about the Network's role in setting standards for palliative care in the region, including guideline development and endorsement. However, the varied knowledge and engagement in the Network across the region is likely to affect adoption of these, and as one participant noted, there is no legal requirement or agreed responsibility that members will use them.

Training provision by the Network, which includes an annual conference and various study days, was positively evaluated by a number of participants who commented on the impact it has had on their practice, both from the training provided and the opportunity to learn from others working in children's palliative care.

However, several participants believed that the training offer was limited and needed to be expanded. There was evidence that staff in less clinical roles or those in services that provided universal services may not be benefiting, risking a widening of the skills gap between those already engaged in palliative care and the Network and others.

"I just felt it was all attended by people who were in that world. I didn't really feel it was aimed at us." P2 participant #40

Discussion

This study identified key features that aided development of an MCN for children's palliative care, i.e. having a funded Network co-ordinator, a committed leadership team, a governance structure that fosters collaboration, and a shared vision for the future. However, the study found that these features alone, which have been identified in previous research as enablers for MCN success,¹² were not sufficient to overcome the cross-cutting barriers that are impeding the Network's development. These included limited funding for the Network and children's palliative care, having no shared technology, the lack of standards and limited evidence-base for children's palliative care, and the shortage of community nursing and specialist palliative care staff. These barriers, some of which have also been identified as pertinent to adult palliative care networks,²² were found to impact on the Network's ability to agree and implement changes and evaluate success, and consequently on member engagement. Importantly, these secondary impacts were identified as additional barriers to future success.

Other research exploring implementation of new innovations also highlights the significance of first-order problems,²³ such as interoperability of information systems, and how they lead to second-order problems, such as developing work-arounds to share patient data; and third-order problems, such as member disengagement. However, it is recognised that addressing first-order problems is not always possible when implementing new practices into existing infrastructures and organisations,²³ and the cross-cutting barriers we identified are likely to hinder the development of other children's palliative care networks, certainly within countries with established healthcare systems^{12 24 25} and varying models of palliative care.²²

Understanding how these features of children's palliative care influence MCN development can nevertheless inform planning of new networks and reduce the risk of associated problems that impact on member engagement, which research consistently shows is not static and requires continuous work to sustain. The role of local champions could prove useful here, although there is a lack of research about their role in children's palliative care.

Agreeing the definition and model of children's palliative care and ensuring there is clarity about this across organisations are also essential because of the different definitions and models of care that currently exist.^{26 27} Although in this study there was a shared vision for equitable and around-the-clock palliative care across the region, there was uncertainty about what this would look like, both in terms of service provision and who would be eligible. This was in part due to the holistic definition of paediatric palliative care adopted by the Network, which whilst aligned with the World Health Organisation's definition and the holistic offering of children's hospices,²⁸ generated uncertainty about what the Network was trying to achieve. At the same time, the focus on developing specialist palliative care services led to concerns about how other palliative care provision would be captured as part of the Network, whether young adults supported by some services would be eligible for this, and the relevance of the Network's resources, e.g. training, for organisations providing universal services, such as social care and education.

In this study, training was well received by Network members and offer networks an important mechanism through which to demonstrate the value of an MCN and keep member organisations engaged and connected with one another, as well as improve clinical practice. However, networks need to ensure its training meets the diverse needs of its members and is accessible across a network.²⁹⁻³¹ Virtual learning networks (e.g. Project ECHO) could play an important role, and evaluations of adult palliative care ECHO networks have reportedly increased staff knowledge and confidence, and improvements in clinical practice.³²⁻³⁴

Robust evaluation of MCNs is particularly important because of the limited evidence in children's palliative care. However, in this study the cross-cutting barriers to developing the Network had impeded plans for evaluation, and other regions are likely to

experience similar challenges because of the lack of standards and care pathways, and the resulting lack of agreed outcomes and robust measurement tools.³⁵ There were, nonetheless, missed opportunities to demonstrate early successes, for example measuring uptake of newly endorsed guidelines. It is important that, in the absence of appropriate measurement tools, networks make use of process as well as outcome data to assess potential changes in the delivery of palliative care, and to understand issues surrounding implementation.¹⁶ Networks may also benefit from drawing on appropriate implementation frameworks to help plan and evaluate new services and practice changes.^{17 18 36-38} For example, in this study the socio-technical systems framework facilitated an understanding of the cross-cutting nature of the identified key barriers.

Study strengths and limitations

We used appropriate qualitative methods with a purposive sampling strategy to ensure a diverse sample. A clear and iterative analytical process was followed involving more than one researcher to ensure findings are credible and trustworthy.

This study focused on a single hub-and-spoke MCN for children's palliative care; therefore, findings may not be transferable to other specialties or those using other models. There was also limited representation from organisations on the Network's periphery, although concerns relating to geography were raised by participants from umbrella organisations that covered those localities.

Conclusions

Some of the key features of children's palliative care can act as barriers to early development of an MCN and to implementing practice changes. Managing expectations and raising awareness, providing accessible and relevant training, and sharing early achievements can help to maintain member engagement, which is crucial to a network's success and requires continuous attention. Robust evaluation of children's palliative care networks is also essential and should make use of process as well as outcome data to better understand issues surrounding implementation as well as potential changes in the delivery of palliative care.

Declarations

Ethics approval and consent to participate

Ethics approval for this study was obtained from the University of York's Department of Health Sciences Research Governance Committee (HSRGC/2019/352/C) and governance approval was obtained from the Health Research Authority (IRAS: 272774).

Consent for publication

All participants received a study information sheet and provided either verbal recorded, email or written consent prior to participation.

Availability of data and materials

Because individuals involved in the study could be identified through them, the datasets generated and analysed for the current study are not publicly available but are available from the corresponding author on reasonable request.

Competing interests

All three authors work for the Martin House Research Centre, which receives some of its funding from Martin House children's hospice. LF is part of the Network's Executive Committee but was not a participant in the study and did not take part in data collection or initial coding.

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Authors' contributions

AP and JT collected the data. AP carried out the initial coding and analysis before AP and JT developed the themes further. The finalised themes were agreed jointly by AP, JT and LF and re-mapped to the SST framework. AP and JT drafted the paper and LF gave final approval of the version to be published. All three authors are guarantors.

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Figures

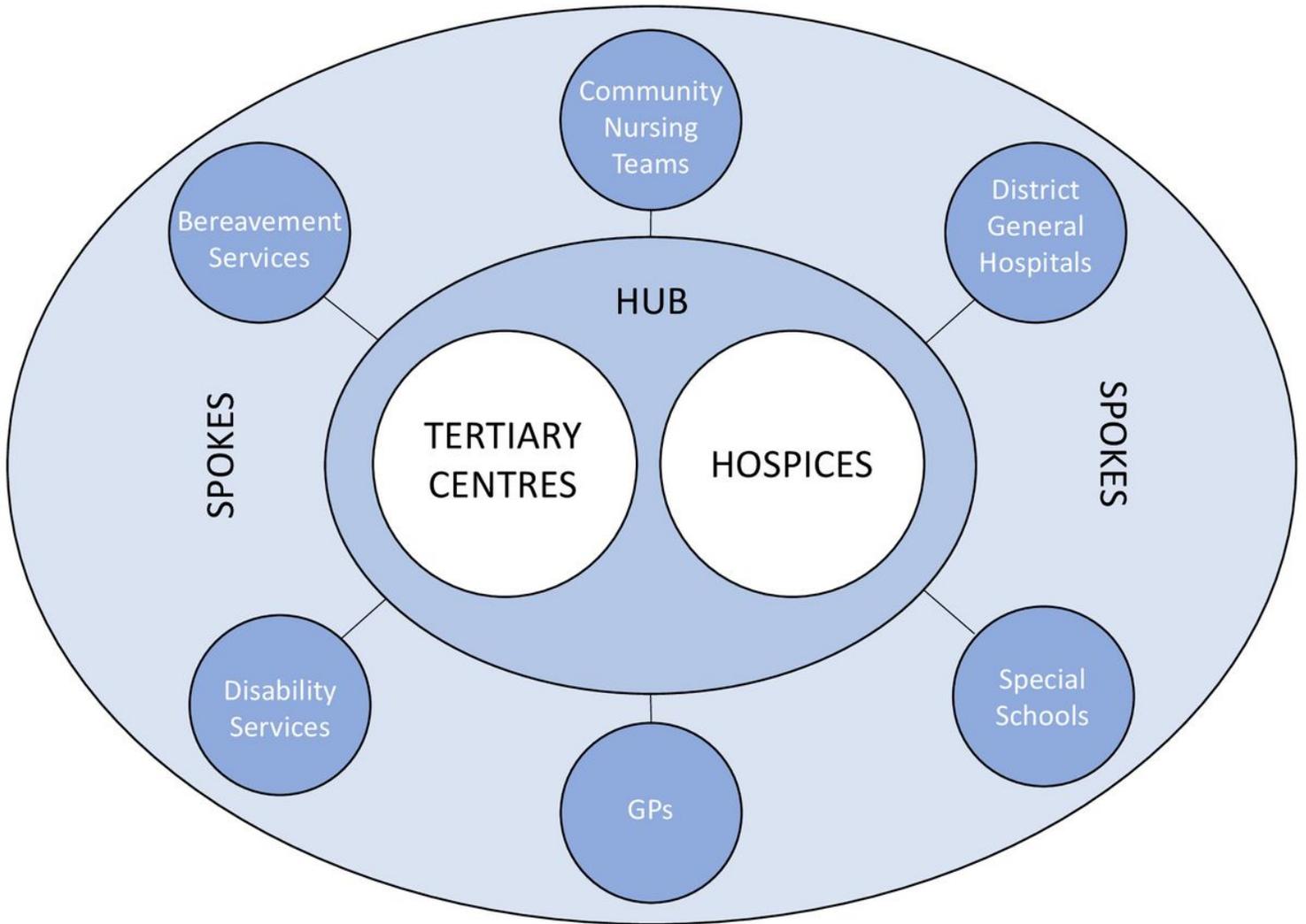


Figure 1

Schematic of the hub-and-spoke model used by the Network.

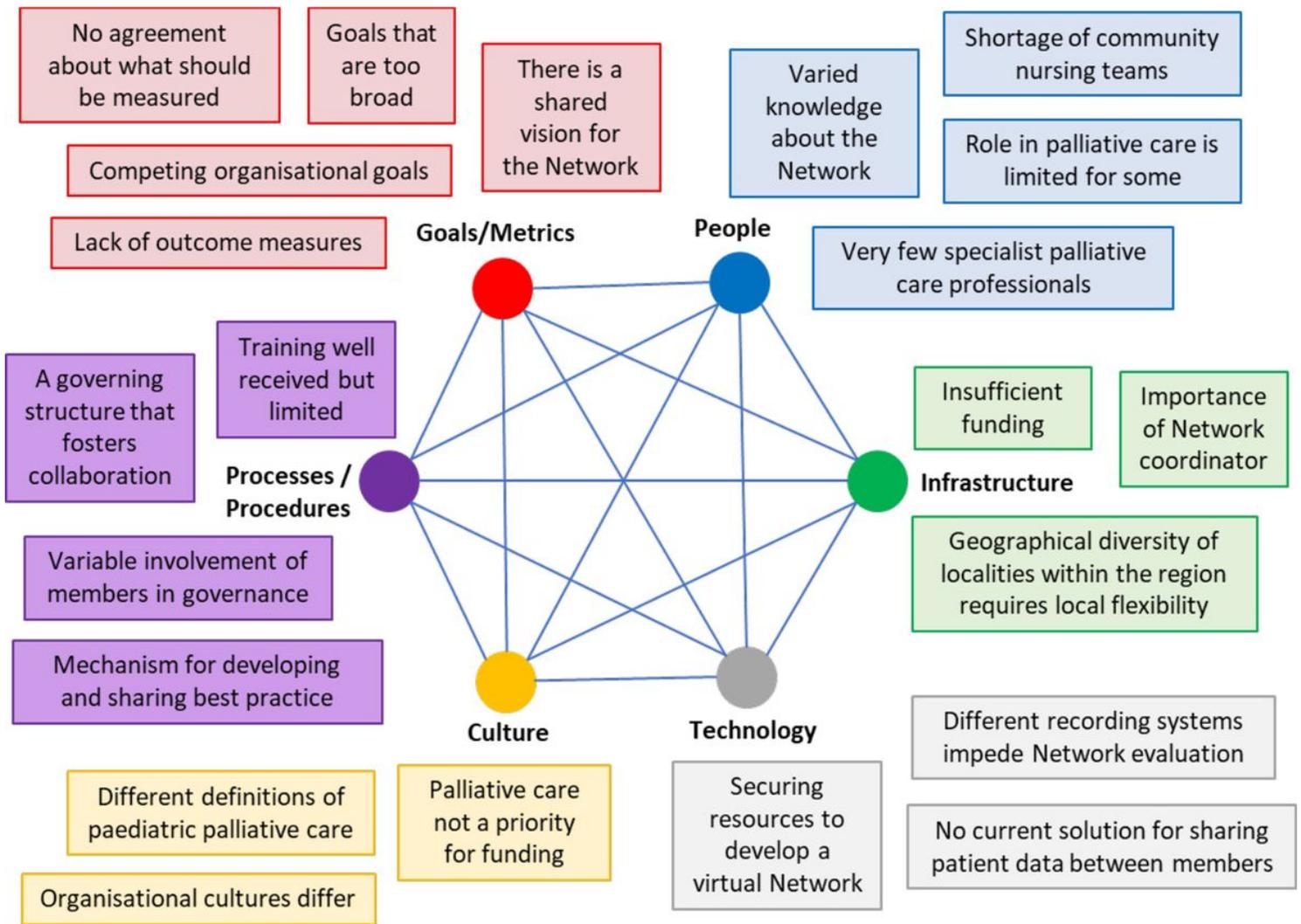


Figure 2

Factors affecting implementation of the Network Source: Adapted from Davis et al. 201417

Supplementary Files

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- [COREQChecklist.pdf](#)