FINAL REPORT- May 2016

EVALUATION OF:

Strategic Development of Children’s Palliative Care Networks for Better Health and Care Outcomes through Improved Commissioning

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Lead: Professor Jane Coad
Professor in Children and Family Nursing
Research Team:
Dr Alex Toft; Joanne Kelly; Charlotte Clowes; Erica Brown

Children and Families Research
Coventry University
Faculty of Health and Life Sciences,
Richard Crossman Building. Coventry.
Tel: 02477 793802 Email jane.coad@coventry.ac.uk

This report is the final report- Synthesising the findings from the Year 1, Year 2 and Year 3 reports.

Project Team – Coventry University: Children and Families Research

Professor Jane Coad	Principal Investigator/Professor in Children and Family Nursing / Head of Children and Families Research (CFR)
Dr Alex Toft	Senior Research Assistant (CFR)
Joanne Kelly	Research Assistant (CFR)
Charlotte Clowes	Project Assistant (CFR)
Erica Brown	Senior Research Assistant (CFR)

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1.0 Introduction

This report is the Final Report of the evaluation of: **Strategic Development of Children's Palliative Care Networks for Better Health and Care Outcomes through Improved Commissioning** which was commissioned by the charity '*Together for Short Lives'* to Professor Jane Coad, Professor in Children and Family Nursing, and team in the centre for Children and Families Research (CFR), Coventry University.

This final report has been arranged in terms of key findings/themes. It is envisioned that this approach will allow the reader to understand the key successes and challenges including recommendations. Distinctions between regions and participants (users, providers, commissioners) will be made when required throughout.

2.0 Background

It has been estimated there are approximately 40,000 children and young people in England with life-limiting and life-threatening conditions who may require palliative care (Fraser et al, 2012). This is a small population with highly complex needs, which can make planning and commissioning services difficult. In addition, children's palliative care spans health, education and social care services. There is therefore a potential danger of negative health outcomes for these children and young people.

3.0 Aims of the Project

Together for Short Lives are working to improve the commissioning of healthcare for children and young people with life-limiting and life-threatening conditions through strong and effective strategic networks. Changes to the NHS, particularly the establishment of CCGs and the enhanced importance given to clinical networks, means that new approaches to commissioning are needed in order to deliver improved health outcomes for children needing palliative care. The Children and Family Act (2014) requires that CCGs co-operate with local authorities in ensuring that single assessments and Education, Health and Care Plans (EHCP) are put in place.

The evaluation supported the *Together for Short Lives* project researching the effectiveness of the clinical networks over a three year period. Annual reports were produced and agreed with the charity at the end of each year. Each data set was compared and contrasted to produce the final report (March 2016). The overall aim was to evaluate the successes and highlight areas for development with regards to the children's palliative care networks.

4.0 Data Collection and Analysis

The project team worked with *Together for Short Lives* to agree Terms of Reference and Reporting Structures.

Support documentation for the project including information sheets, consent forms, assent forms and survey questions and interview questions were drafted and sent to *Together for Short Lives* for the project Steering Group approval in September 2013. Minor revisions were undertaken by the research team during 2014.

4.1 Ethics

All supporting documentation including the project proposal, letters of invitation, information sheets and consent forms were submitted for ethical review to the Faculty of Health and Life Sciences Ethics Committee at Coventry University. Full approval was granted in September 2013. No participants were named in project data, and written consent was obtained from all participants. In accordance with NHS Research Ethics Guidelines, participants were provided with a Participant Information Sheet and process was fully explained before they were asked to give their written consent. The project was also supervised by Together for Short Lives Project Management Team, the Steering Group and the Advisory Board.

4.2 Methods

Year 1 took the form of online surveys constructed using Bristol Online Surveys/BOS (https://www.onlinesurveys.ac.uk/). Surveys were distributed via email using the research team and the funders extensive contact list. Questioning was developed in partnership with the funder to explore the impact of the networks in terms of: changes as a result of the networks, the overall difference the networks have made, the integration of services, the impact upon staff and training, improving services for users and how to use the networks more effectively.

During Years 2 and 3 semi-structured interviews were conducted. Participants who identified as being Service Commissioners, Service Providers or Services Users took part in a telephone interview. The interview was guided by an interview schedule agreed upon with *Together for Short Lives*, using the questionnaires as a starting point. This ensured that data collected was comparable.

Commissioners were reluctant to take part and did not attend meetings either due to a lack of time, not knowing about the network or feeling that it was not part of their role to attend. Service Users were also difficult to contact as they were rarely part of networks, as will be discussed further.

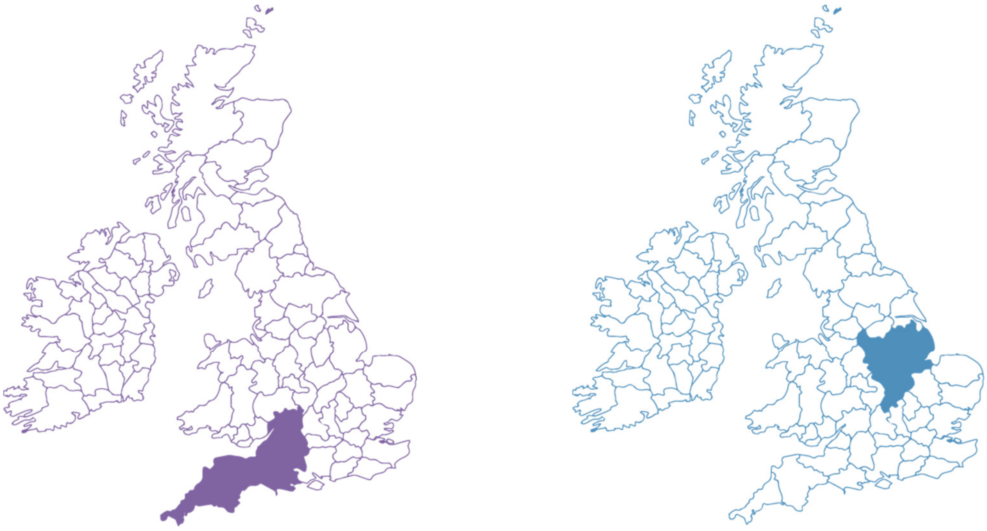
The interviews lasted between 30 and 60 minutes resulting in high quality qualitative data which was could be used in thematic analysis to create a clear narrative presentation of results and findings. Manual thematic analysis took place on all the data collection throughout years 1 to 3. This involved using the interview schedules and evaluation aims as guides and then exploring the data for recurrent patterns and themes. The findings from the three years have then been grouped together into the most salient themes in order to present a picture of the evaluation as a whole. Unlike the yearly reports which focussed upon region, this final report presents the findings and themes of the evaluation as a whole in order to give a clear understanding of the successes and challenges facing the children’s palliative care networks.

5.0 Participants

Table 1: Breakdown of survey completion.

Job Role	Surveys collected			**Total**
	Year 1	**Year 2**	**Year 3**	
Commissioners	16	NA	NA	**16**
Service Providers	12	NA	NA	**12**
Service Users	5	NA	NA	**5**
Total	**33**			**33**

Table 2: Breakdown of survey completion per region



South-West England

Commissioners: 5

Service Providers: 6

Service Users: 3

Total: 14

East Midlands

Commissioners: 11

Service Providers: 6

Service Users: 2

Total: 19

Table 3: Breakdown of interview participants.

Job Role	Interviews conducted			Total
	Year 1	**Year 2**	**Year 3**	
Commissioners	4	5	2	**11**
Service Providers	4	15	14	**33**
Service Users	6	0	1	**7**
Total	**14**	**20**	**17**	**51**

Table 4: Breakdown of interview participants per region

South-West England

Commissioners: 2

Service Providers: 2

Service Users: 3

Total: 7

East Midlands

Commissioners: 2

Service Providers: 2

Service Users: 3

Total: 7

West Midlands

Commissioners: 2

Service Providers: 7

Service Users: 0

Total: 9

South Central

Commissioners: 2

Service Providers: 3

Service Users: 0

Total: 5

London

Commissioners: 1

Service Providers: 5

Service Users: 0

Total: 6

East of England

Commissioners: 2

Service Providers: 3

Service Users: 1

Total: 6

North-East

Commissioners: 0

Service Providers: 2

Service Users: 0

Total: 2

North-West

Commissioners: 0

Service Providers: 5

Service Users: 0

Total: 5

Yorkshire and Humberside

Commissioners: 0

Service Providers: 4

Service Users: 0

Total: 4

6.0 Key findings

1. The networks are seen as places to share experiences and practices, working in a collaboration manner.
2. Real change has occurred as a result of the networks, which have acted as catalysts for change. The networks have exerted influence and been a forum for debate around new models of care and best practice.
3. Commissioners and users are not sufficiently engaged with the networks, although there is variation across the regions. Lack of commissioner engagement has detrimentally affected the impact of the networks and their ability to enact changes.
4. The networks have had limited impact on the integration of health, education and social services.
5. Those who attend meeting often find the time and costs associated with meeting attendance difficult to cover.
6. It was felt that the networks would improve with more administrative support, allowing the meetings to be focussed.
7. The networks have led to an increase in formal and informal training delivered through the networks.
8. The impact of the networks is limited due to the lack of commissioners taking part. Networks struggled to go beyond discussion and tangible changes are sometimes difficult to quantify.
9. Users and commissioners (in particular) suggested that the networks do not communicate their work effectively.
10. Practices and equipment has improved as a result of the networks. Advanced care planning and the standardization of equipment have been key achievements.

7.0 Results and Findings

7.1 Purpose of the network

Summary: The networks have helped providers and commissioners to come together and to work as a team, heightening the access to experts. They have increased consistency and raised the profile of children's palliative care. Initial engagements with commissioners have been made but change has been limited.

Although this report focusses upon evaluating the networks in terms of their successes and challenges, to frame the research, the participants were asked what they felt the purpose of the networks was.

For many of the participants consistency of care is the prime directive for the palliative care networks. Both commissioners and service providers argued that by coming together, the networks can improve care across regions. It was felt that sharing best practice and experiences would lead to all regions being raised to the highest performing region. One service user highlighted this aspect, noting that consistency of care across regions is important for families:

> *Try to raise standards across a region, ensure equity, look at what is working in other areas, map gaps in services. From a family point of view it is a huge postcode lottery. (Service User 1)*

Participants felt that end of life care is traditionally concerned with adults and that children are often not a high priority. The networks therefore, were seen as an excellent way to raise the visibility of children's palliative care and ensure that it is on the agenda. One commissioner clearly put this argument:

> *End of life is always about adults and children are piggybacking on the back of that – so the forums are all about getting children on the agenda. (Commissioner 1)*

Ultimately, the majority of the participants felt that the purpose of the networks is to facilitate change. The networks present an opportunity to encourage people to improve their service and to inspire others to change:

> *It's given a platform for people outside of the NHS to stir the pot and say we can't carry on like this. It's provided me as an advocate for children's palliative care, a platform to encourage things to move forward and created a momentum for change. (Service Provider 2)*

This is linked to the desire to change through engagement with commissioners. A number of participants argued that change and improvement was only possible through engagement with commissioners. It was hoped that in future the networks can influence the landscape for commissioning of services.

7.2 Networking and Sharing Best Practice

Summary: The networks have been framed as spaces for discussion and debate, working to change services and practices. They have allowed professionals to test ideas and to raise concerns. However, there is a concern that some work has gone no further than discussion.

Those participating in the children's palliative care networks felt that the networks provided an opportunity to network and share best practice. The networks are a place where similarly minded people interact to improve children's services. As a result people have worked together on diverse projects and with professionals they would usually not have the opportunity to work with:

> *Being able to collaborate over pieces of work. We've made some really strong links with the neonatal network and we hosted a study day at the hospice*

> *which got people here who wouldn't normally come into contact with the hospice and completely dispelled any myths they had. (Service Provider A)*

As the provider notes, such collaborative working is mutually beneficial as the partner learns more about children's palliative care. The participants gave a number of reasons as to why collaborative work is beneficial, particularly noting the fact that a shared voice or collection of similar opinions will add weight to an argument:

> *It's very useful to be able to refer to the network when trying to implement things within the organisation – it's more influential if it's come from a network rather than at department level. (Service Provider L)*

Collaborative working has also given professionals access to others who may have specific expertise that can be utilised. This supportive atmosphere was welcomed by a number of the service providers in particular who framed the networks as an expert bank of professionals to be accessed when required, as the following provided noted:

> *They give us an opportunity to network and discuss new practice that we're managing to roll out. If you get stuck with anything, then there's a list of experts that we can go to. (Service Provider I)*

The providers also noted that working in children's palliative care services could be a lonely and isolated experience. This was due to the specialist nature of the care and the limited number of professionals working in the area. Providers therefore used the networks to share concerns and experiences:

> *In palliative care you work a lot in isolation so your feel like a lone voice – by being able to get to the network you can discuss the successes and the challenges. (Service Provider 12)*

This sense of connection and shared experiences has been useful in developing care and improving policy and practice. A real and tangible example of this has been the implementation of advanced care plans. Both commissioners and service providers argued that the connectedness of the networks has led to smoother implementation:

> *Yes [in response to any direct benefits of the networks], in terms of the use of advanced care planning because we're trying to utilise those documents*

> *much earlier and with more children than perhaps we would once have done. (Commissioner C)*

It is clear that the networks are being used as places for discussion and debate. Both commissioners and providers noted that issues such as transition and the integration of health, education and social services were being raised at meetings. One commissioner discussed activities at their meetings:

> *The network has been talking about improving transition services and as a result the local practitioners have talked about how to improve the experience of young people going into the adult hospice. So we've been bringing adult professionals down to the children's service to meet the young people before they make the move. (Commissioner E)*

The picture provided here is wholly positive, however, this is variable across regions as issues such as transition and integration have not progressed past discussion as will be discussed in 6.4.

7.3 Engagement

Summary: In general the networks reported low levels of engagement from users and commissioners. Providers argued that user attendance is problematic and often not appropriate. However, engaging with commissioners has been difficult due to NHS re-structuring and demands on the time of commissioners.

Not all the networks accessed by the evaluation team were well-engaged. It would be a fair general finding that commissioners were not well engaged across most of the networks. This is a concerning findings as the networks hope to be used as a new forum for commissioning. This frustration was summarised by one provider when discussing commissioner engagement:

> *They should attend – it's meant to be commissioner focused, it's about changing the way services are delivered and that can only be done by working through commissioners. (Service Provider 8)*

A number of reasons were provided as to why commissioners do not engage with the networks. It was argued that with the re-structuring of the NHS accessing commissioners had become very difficult. The creation of CCGs in particular were noted as being one overriding reason. One service provider suggested that commissioner were not taking ownership of children's commissioning:

> *I think the new NHS has made it more difficult to do all these things [engage with commissioners] – networks will struggle because of the split between specialised commissioning and CCG commissioning – both sides can say it's someone else's responsibility. (Service Provider 8)*

The confusion about who to access for children's palliative care commissioning was noted by a number of providers. It is a very real scenario that appears to be creating a good deal of confusion amongst providers. One provider highlighted the difficulties they had faced in accessing commissioners:

> *They have so many priorities – really difficult to find a commissioner of children's services who has a responsibility for palliative care or anyone with palliative care that might consider including children. (Service Provider 9)*

The situation with regards to the engagement of service users in the networks was more complex. Commissioners in general felt that users needed to be involved in the networks. Users bring practical experiences to the networks and are involved in children's palliative care on a constant basis:

> *We do have some service users who attend sometimes; it's beneficial as they're the ones going through it. The wider commissioning network always has service providers attend and they bring so much to the table every time – they've always had an experience of it or have a view on it. (Commissioner 1)*

However, difficulties lie in the opinions put forward by the service providers who were not unanimously in favour of service user participation in the networks. User participation was seen as often being unnecessary and potentially damaging to discussion. Some providers suggested that the content of the meetings would not be understood by the users:

> *No [users don't attend]. I think it's appropriate that they know things are being done to improve their standards of care and for us to get their perspective, but it might be too much information that they might not understand. (Service Provider 7)*

One provider pushed this argument further in relation to the strategic focus of the meetings and the perceived inability of the users to engage with such material:

> *When you're talking about service design, new builds, new models of care then you need service users front and centre, but if you're struggling over a 16 page application form for specialist commissioners, I'm not sure where a service user will feel part of that. (Service Provider 2)*

This is a worrying stand-point which appears to patronise and undermine the importance of parents/carers. The suggestion is that systems or procedures are too complex for users and their families to understand. This does not seem a fair and accurate reflection as users and families live and experience the systems in place on a daily basis. As a result some networks have taken the decision not to include users in their groups, arguing that it is more constructive and powerful to seek a collective of voices from their users:

> *No [service users don't attend] – active decision – they set up own parent group [removed]– have influenced decisions. For one person to sit round the table at a network meeting and represent families is too difficult. (Service Provider 3)*

It is arguable that the networks are in fact being claimed by service providers as spaces to share best practice without user involvement or a commissioning agenda. One commissioner argued that they had not been welcomed into the networks and that commissioners were not being copied into emails and news updates

7. 4 Integration of services

Summary: There is no evidence that the networks have positive impacted upon the integration of health, education and social services. However, it is clearly an area for discussion and debate within the networks.

The integration of health, education and social services is vital in children's palliative care, particularly in relation to transition. However, improvements have tended to consist of discussion at meetings and have progressed no further. Service providers in general were not positive about service integration:

> *No, it's as appalling as it always has been. Trying to engage with the local authority commissioners has been near on impossible. Education is almost as if they don't see palliative care as part of their business at all. (Service Provider 9)*

Again, this was explained in relation to the re-structuring of the NHS and creation of CCGs. It was argued that no-one is willing to take ownership of care which crosses services and budgets:

> *No, it's still as bad as it ever was [integration of services]. I think it's because there are separate budgets and there are always arguments over whether it's a health, education or social need." (Service Provider C)*

It is clear that the participants felt that the integration and engagement across services was important. Integration would improve the networks and allow them to address issues that cross services. As previously noted, one commissioner had noted their work to link adult and children services. However, in practice some providers had worked on an individual basis with local councils to improve integration rather than using the networks, although this would be desirable:

> *Locally we've integrated with social care but I don't think as a result of the network – I've not seen any attendees at the network, but that would be*

> *useful from a funding perspective as we always get better outcomes from joint funding. (Service Provider 7)*

7.5 Costs

Summary: Organisation of time and resources was noted as being a difficult negotiation. Staff attended through goodwill and job re-allocation to cover positions when required.

There are cost implications of network participation, usually in terms of time and staffing. There were reports of providers having to stop attending meeting due to a lack of resources:

> *We just didn't have enough resources, staff left and they weren't replaced so we were struggling with staffing, so we couldn't attend the meetings for a while and then we sort of dropped of their agenda and never had any emails about new meetings, even when we were better staffed. (Service Provider C)*

Negotiating attendance is difficult and relies on goodwill on the part of managers and staff. There are no extra resources or time provided to attend meeting and as a result attendance is occasionally inconsistent. Costs were also a factor in relation to travel. A number of service providers noted that to attend meetings they had to travel long distances:

> *Travel is the biggest expense because we're up in [area East of the region] but all the West Midlands meetings are [area West of the region] centric, so that's quite a lot of travel; quite a lot of time, and an added commitment for us. (Service Provider A)*

7.6 Administration Issues

Summary: Administration support and organisation was noted as being a cause of frustration for those attending meetings. Meetings were not structured strictly enough and did not focus upon enacting change or disseminating discussions.

Linked to the issue of costs, some service providers suggested that networks needed more administration support. This was noted in relation to the focus of the meetings and those attending. One commissioner gave an example of this:

> *At the end of a meeting we agree to reconvene in two months' time and then there are a number of different people there, so we spend most of the meeting covering what happened last time for those who weren't there. (Commissioner E)*

Administration issues also link to difficulties in how the networks are organised. Commissioners argued that there needed to be stronger links between regional networks and national dissemination sources:

> *If regional leads had the opportunity to feed key messages back to a wider national network that would be quite powerful. (Commissioner F)*

Here it was felt that if good regional work could be shared nationally, this would improve care consistency.

The respondents were clear that administrative support such as the sharing of notes and good dissemination was important. However, the quotations allude to a need for a deeper understanding of the work and overall aims of the network in order to improve this aspect of the networks. For example, in order to keep meetings focussed and structured the support would need to be knowledgeable about the aims of the networks and the overall goals. It therefore may be preferable to combine the administrative role with that of an expert 'overseer'. This person could ensure practical tasks are completed (note sharing, feeding back to TfSL) but could also make sure that meeting agendas are appropriate and that progress is made through consistent meeting aims. The key frustrations from the respondents note the repetition of the meetings and the lack of forward momentum which could potentially begin to be addressed using this approach.

7.7 Training and Development

Summary: Training has occurred as a result of the networks. This has been through formal training packages delivered in conjunction with the networks by nurse specialists. However, due to the set-up of the networks and the enhanced sharing and collaboration, a good deal of training has been delivered informally.

The networks have successfully implemented training into their agendas. This has been done informally through the sharing of best practice and experiences during meetings. However there are examples of formal training being developed and delivered through the networks:

> *The clinical nurse specialists attend the network. The nurse specialists put on training 3 or 4 times a year to allow the local team to refresh their training around end of life and symptom management care. Not that many children die in our service and so you can go for long periods of time without having hands on experience. (Service Provider E)*

This has been particularly useful for staff who do not have a specialism in children's palliative care. The field is seen as being rather specialised and the networks have allowed knowledge to be shared through training for a wider audience:

> *Staff interested in palliative care have attended the study days that they've put on and that's increased their knowledge. Some of us have also done more work with the hospices because of working together through the networks. (Service Provider D)*

This has had a real benefit on children and young people and their families due to the increased knowledge of professionals. Staff have become more aware of the services available to users:

> *[We have all] Accessed training which has raised awareness. Staff are now able to refer patients on to other services which they may need. (Service Provider 13)*

7.8 Lack of Authority

Summary: Although the networks have been used to influence change, participants argued that their reach was lacking due to the non-engagement from commissioners.

Throughout the regions and amongst providers, commissioners and users, it was felt that the networks lacked the authority to make actual changes to services. In order to be successful it was argued that a higher level of authority is required in order to change the commissioning landscape. However, without the full engagement of commissioners this can never be achieved:

> *There's a lot of experience and expertise in the network but due to lack of authority, that's not being maximized. I think we really need to look into how we can utilize this expertise to influence decision making, and how this links with the NHS and other local authorities. (Service Provider A)*

The above quotation effectively summarises the frustrations that some service providers felt. Having bought together such qualified experts it was disappointing that more changes cannot be effected due to commissioner non-engagement.
This was reflected in the views of the service providers who felt that the commissioners often hold the key to change:

> *It's difficult to get the network to influence commissioners to do things differently – it doesn't have any sort of authority. (Service Provider 9)*

A number of the service providers were very pessimistic about the force of the network and the ability to make a difference. This was linked to difficulties in leadership:

> *The children's palliative care network is often just the great and the good coming together to have a moan. They don't put their energy into the right areas of work to make things start to happen, but that's partly because they aren't leaders in their own right and there isn't the resource there to make that happen. (Service Provider G)*

This is a strong comment to make as it is critical of leadership and the amount of resources the networks have at their disposal.

7.9 Communication

Summary: Communication was noted as being a weakness of the networks. Commissioners and users were interested in knowing more about the networks and often did not know about their work or existence.

Throughout the interviewing and recruitment process it became clear that the visibility of the networks was a concern. During Year 1 and 2 of the evaluation a number of the commissioners contacted had no knowledge of the networks and no involvement. This was reflected in the data collected, specifically from service users who felt that networks need to improve their routes of communication. The networks were framed as being rather insular and in-looking.

> *The networks are not good at sharing what they're doing beyond their inner circle – as a parent it would be good to know that people are thinking about doing something about it. (Service User 1)*

The same user continued this argument, suggesting that a newsletter should be distributed:

> *Communication – if there are good things going on, how about a palliative care newsletter that goes out to parents, special schools, local providers, local authorities, social care team etc.? I can't imagine there are many parents that even know there is a network. Even if parents don't want to get involved they do want to know that something is being done. And maybe even for all the different regions to see what other areas are doing. (Service User 1)*

7.10 Impact

Summary: There are examples of real impact cases as a result of the networks. These have included advanced care planning, toolkits, purple pages and the fast-tracking of equipment.

The participants in general were able to discuss the positive impact the networks have had. There are real examples of changes that had been brought about due to the network, or sped up in their implementation. The networks were noted as being instrumental in the development and implementation of advanced care plans:

> *Advanced care plans have been around for a while, but all the networks, nationally, have been very influential in driving the development of them and across the whole of the [region] we've agreed to a standardized model. (Service Provider A)*

Purple Pages and Toolkits have also been developed across a number of regions. Equipment provision has also been positively affected with a number of providers discussing successes in relation to pumps and syringe drivers. Providers argued that their adoption had been sped up as a result of the networks:

> *We started using the T34 pumps as a direct result of the network, before the rest of hospital changed over to them. (Service Provider B)*

It is important to note that the impact of the networks has been varied across the regions. Throughout the three years of data collection it became clear that whilst some networks are flourishing and are working to engage with users, providers and commissioners. However, a couple of networks are struggling to continue and are no longer able to engage with the required participants.

The greatest impact of the networks remains the ability to come together and share practice, experience and skills through the network. This aspect has led to increased knowledge, the ability to signpost to specialists and a wider understanding of children's palliative care services.

8.0 Discussion

The evaluation has focussed upon the successes and challenges of the children's palliative care networks. It has explored the impact that the networks have made across the nominated regions. Specifically, evaluation aims were met through focussing upon: the benefits, how well the networks are engaged with, the integration of services, costs, the challenges associated with the networks, training, communication issues and their overall impact.

The evaluation took place over a three year period, focussing upon different regions each year but using the same interview schedule and evaluation aims. This meant that all the data is comparable and that summaries and conclusions across the years are possible. The overarching aim of the evaluation (alongside the evaluation aims as laid out above) has been to explore whether the networks are being used effectively and whether they may be seen as alternative methods of commissioning, or at least as venues were commissioning is discussed. In this regard the networks need refocusing as the purpose of the networks appears to be unclear. There is a concern that the networks are used as meeting events for service providers. Although the respondents clearly valued this aspect of the networks it is important to note that this is not to sole purpose of the networks. Here it would be useful if the aims and objectives of the networks could be clarified for consistency.

Further thought is needed with regards to engagement of commissioners and service users. Both commissioners and users were difficult to interview due to their lack of connection with the networks and this was further reflected in the data collected from the service providers. If the purpose of the networks is to influence commissioning then it is clear that commissioners must be present. Furthermore, service users will add strength to the cases put forward as they have real experiences with services. This aspect will require a good deal of work if it to be successful, particularly in light of recent re-structuring of the NHS and the demands upon commissioners time which are being made.

A key evaluation outcome was to explore how successful the networks had been in integrating key services. The results suggest that there has been little improvement in this area, although it is an issue of discussion and an area of great frustration for those involved in the networks. It may be that with greater administration support and organisation that these issues could be rectified.

It is clear that for some service providers, the networks have been invaluable in their professional lives. Although some of the outcomes have been difficult to achieve they are debated and discussed through the networks, even if change has been slow. Furthermore, the networks have been successful in the truest sense of what a network hopes to achieve as the distance been professionals has been reduced. Professionals are now interlinked and networked.

As a result a picture of how effective the networks are and what networks should ideally look like developed.

Valued attributes of the networks:

Respondents were clear that they welcomed networks as places to *share and discuss experiences and ideas.*

Training has occurred within the networks increasing both awareness and knowledge in a specialised area.

Practice has been *standardised* through networking and collaborative working.

Specific equipment has been obtained due to the influence of the networks.

More successful networks have been involved in the *development of toolkits* and procedural changes which have improved levels of care.

Missing components of the networks:

There is very *little evidence that tangible changes in commissioning* have emerged from the networks. Although the networks have been successful in a number of other aspects, the failure to engage with commissioners combined with NHS re-structuring has made any changes in commissioning difficult to measure.

Not all parties are *engaged* with the networks. For example, some networks do not have users as part of the networks. Although respondents argued that such involvement is not appropriate for strategic meetings

Integration of services has not improved as a result of the networks. More successful networks have engaged in debate but real differences are difficult to show.

The less successful networks do not *communicate* their achievements or advertise their meetings effectively. Improving this would attract commissioners and improve overall engagement.

9.0 Recommendations

1. The overall purpose of the networks needs to be clearer. The sharing of best practice and networking with other providers appears to have overtaken the need to influence commissioning.
2. Commissioners should be part of the networks. This aspect needs further consideration. For example, commissioner's time should be utilised effectively and they should be presented with evidenced cases for change.
3. Service users should be part of the networks in some regard. Users and their families are knowledgeable and have a unique viewpoint which needs to be used when discussing care. Arguments that users do not understand or may not engage with service planning are weak.
4. Services are not well integrated. As with the engagement of commissioners, this requires further consideration to explore how to engage other services.
5. Each network needs administrative support to ensure that issues and discussions are not replicated and time is managed effectively. As noted in 7.6, this refers to practical support but could also refer to more expert support.
6. The achievements and important discussions from the networks need to be disseminated consistently and effectively. Commissioners and users are unaware of the networks to which they could be contributing.
7. The networks need to be focussed towards changing commissioning. This has become lost in the current make-up of the networks.

10.0 References

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