hospice UK

Being curious and confident:

learning from the Hospice UK transition programme for young people with life-limiting conditions

Evaluation report

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Acknowledgements

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About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

About hospice care

Hospices seek to improve the quality of life and wellbeing of those with a life-limiting or terminal illness, helping them live as fully as they can for the time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs. Hospices are rooted in their communities they serve, with each service developed to reflect the needs and the context of its local area. Hospices provide expert care for those in need as well as their family and carers, and care is free at the point of access.

Hospice providers offer a wide range of services to people in their homes, in day services or outpatient clinics, into care homes and hospitals, and through inpatient hospice care. The majority of care provided is to people in their own homes or attending the hospice, rather than just inpatient care.

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Foreword

> *"If you don't have anything to transition into … why should I feel hopeful about that? Why should I be excited for the future?"*
>
> **Hannah Hodgson 2023**[1].

Every young person with a life-limiting condition should be able to expect to receive appropriate care and support before, during and after they transition from children's hospice and palliative care to adult services. This should reflect their individual needs and preferences.

This project had the ambition to transform 'transitional care' by using Project ECHO™ (Extension of Community Healthcare Outcomes) methodology and connecting professionals together through learning networks. It is a testament to the tenacity, expertise and focus of all of those involved, that this programme has achieved its outputs and influence despite the challenges posed by the COVID-19 pandemic. While the pandemic affected us all in different ways, it was people with complex health and care needs who were affected the most, and that includes young people with palliative care needs and those providing their care.

Therefore it is important that we celebrate the programme's many achievements which include:

- new web resources to support those caring for young people transitioning to adult services
- supporting the updating of the 'Stepping Up Guide' and other national resources, and
- deploying ECHO methodology to share learning and to build lasting networks to drive improvements in care.

Importantly, this programme has also reinforced the critical value and importance of listening to the expert voice of lived experience as a foundation for improvement projects. Listening to, and really hearing, what it is that young people moving between children's and adults' palliative care services have to say is central to how we will deliver lasting and meaningful change.

Jonathan Ellis
Director of Policy, Advocacy and Clinical Programmes
Hospice UK

1. Introduction

This report provides a summative evaluation of the impact and learning from a three- year Hospice UK transition programme that aimed to:

> *"improve the care and experiences of young adults with complex and life-limiting conditions, with a particular focus on improving the 'transition' process these young adults undergo when moving from children's to adults' palliative care services."*

The programme began in September 2019 and concluded in December 2022 (with a three month hiatus in 2020 due to the COVID-19 pandemic), and was announced at the national Hospice UK conference in November 2019. This announcement took place the week after the first patient is known to have contracted COVID-19 in China[2]. The COVID-19 pandemic significantly influenced the programme and its impact is discussed later in the report.

1.1. Why transition is important?

'Transition' describes the process of planning and moving from children's to adults' services. 'Transitional care' has been described as the 'purposeful, planned movement of adolescents, and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems'[3]. It has been described as a long and gradual process, rather than a single event[4].

The reality is that there are 'multiple and multidimensional life transitions' occurring for young people at the same time[5]. They have been described as 'health transitions' and 'developmental transitions'[6]. 'Health transitions' relate to the young person's illness and adapting to the illness. 'Developmental transitions' relate to 'employment/education, training, future planning, independence'[5] and sexuality and relationships[7]. External events may also occur such as death, loss, parental separation etc. This is alongside changes to funding, such as continuing health care and legal ages for 'consent' and mental capacity; together with the transitions for young people, parents and families, family carers and professionals. For example, in a study[5] a consultant physician highlighted that improved survival meant that he had to educate himself, change his thinking and realise he found talking about end of life care issues with young people 'very, very difficult' and had no training or help with how to address these issues with young people.

There are six 'conflicting realities' for young people and their parents/carers[8]:

1) 'planning to live and planning to die with different illness trajectories that are misaligned with adult service models;
2) 'being treated as an adult and the oldest 'patient' in children's services compared with being treated as a child and the youngest 'patient' in adult services;
3) 'being a 'child' in a child's body in children's services compared with being a 'child' in an adult's body in adult services for those with learning impairments;

4) ‘being treated by experienced children’s professionals within specialist children’s services compared with being treated by relatively inexperienced professionals within generalist adult services;

5) ‘being relatively one of many with the condition in children’s services to being one of very few with the condition in adult services;

6) ‘meeting the same eligibility criteria in children’s services but not adult services.’

> *“We parent during normal physical, social, and emotional adolescent events through the lens of cancer [9].”*

There is a need to understand the perspectives of parents and their challenges in supporting their child, their child’s development and advocating around transition alongside enabling their child to become their own advocate[9], [10].

If transitional care ‘is not well managed, adolescents with long-term health conditions sometimes fall into a gap in services, which can lead to deterioration in their health’[11]. It ‘needs to be planned for years in advance, yet planning is often poor. The reduced support then offered by adult agencies comes as a shock to many young people and their families’[12]. Most young people and their parents / carers have a negative experience of transition. They were ‘left to get on with it’, it lacked co-ordination and there was not enough preparation[10].

‘[This] can be a very worrying time for parents and carers as their child moves from familiar children’s services to adult services that are new to them’[13] and are expected to take on decision-making responsibility for themselves. The experience can be bewildering for young adults and their families – *a sense of moving ‘from the pond into the sea*’[10].National evidence shows the transition from paediatric to adult healthcare is associated with an increase in emergency hospital visits for young people with life-limiting conditions[14]. Further, costs of bad transition for young people can include ‘greater illness, adverse social and educational outcomes, and even earlier death’[12].

There is an **increasing number of young people** living with life-limiting conditions in the UK. ‘Advances in medicine and technology mean that more children with life-limiting or life-threatening conditions are living into adulthood, often with complex and unpredictable healthcare needs’[13].

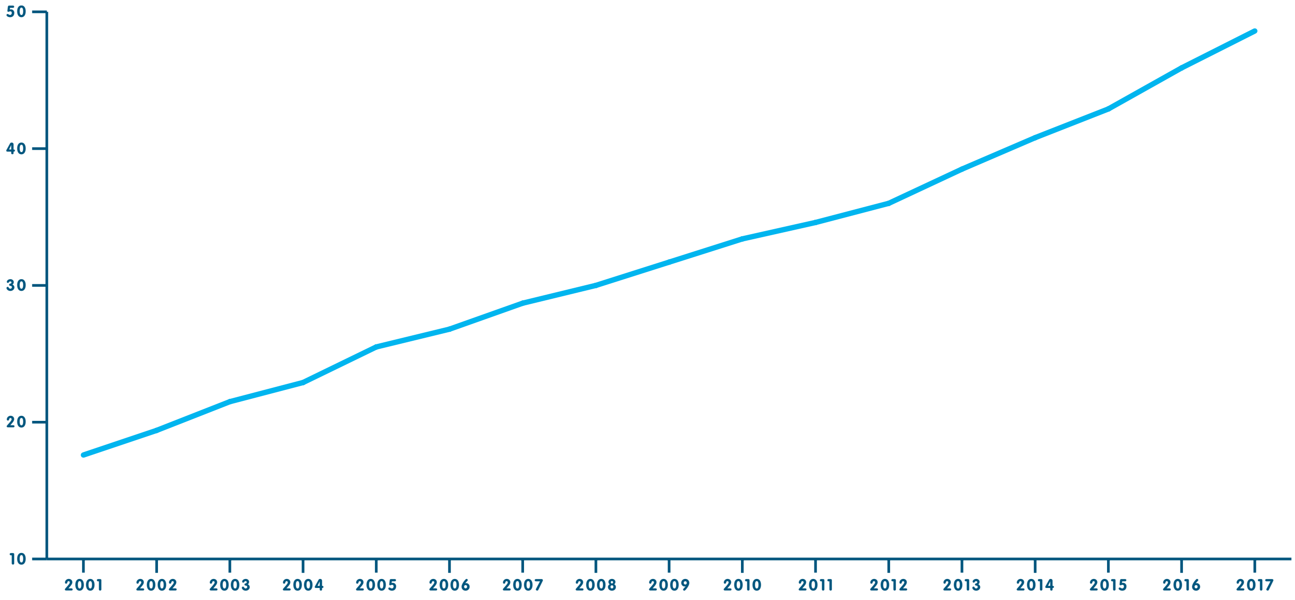

Figure 1 The proportion of 16-19 year olds with life-limiting conditions in England per 10,000 people

From: Fraser et al 2021. Estimating the current and future prevalence of life-limiting conditions in children in England[15].

There are relatively few 16 to 19 year olds with life-limiting conditions (less than half a per cent of the population), however, there has been a steep increase in numbers, a 62 per cent increase in 10 years[15] (*see Figure 1*). Alongside this increase in proportion and numbers of young people with life-limiting conditions, there is also evidence of 'increased complexity regarding the number of conditions and number of distinct main specialties of consultants involved in care'[14]. This means that service developments need to keep pace with increased demand for services.

There is some evidence and guidance on how to support effective 'transition'.
The 2012 report on transition from Marie Curie Cancer Care and Together for Short Lives[12] is clear that 'successful transition needs to address both the transfer of responsibility for young people from children's to *existing* adult social care, health and education services and the development of new adult services tailored to young people's additional needs.'

There are five overarching quality standards developed by the National Institute for Health and Care Excellence that cover the period before, during and after a young person's transition from children's to adults' health or social care services[16]. These provide useful context for the five key standards for young people with a life-limiting or life-threatening conditions developed by Together for Short Lives[13],[17]. There are seven principles of good transition in the Scottish framework for young people with additional needs[18]. There are a number of guides to support transition planning developed by Together for Short Lives and others to support the practical planning for transition generally over a period from 14 to 25 years old[13],[17].

Young adults 'have a variety of needs related to their age and development stage' so transition should consider **developmentally appropriate services**[19]. Central is 'listening to what young people and their families want. Young people have told us they find the adult services they need inadequate. They want services which enable them to lead ordinary lives, including a social life. They want a feeling of freedom and not being overwhelmed or bossed around by adults at the same time as being offered appropriate support. The young people's frustrations regarding transition are shared by their parents'[12].

Kerr et al[20] developed a conceptual integrated model in 2018 based on the experience of young people with muscular dystrophy to explain the impact of services and interventions, and to identify organisation and human factors thought to influence 'the quality, safety and continuity of care' in transition to adult services. The model includes eight 'configurations' thought to promote 'successful' transition shown in Box 1. Kerr et al recommended 'continuity of care' as an outcome measure. Their narrative highlights nuances, dependencies and importance of understanding thoughts, feelings, perceptions and belief of individual stakeholders. For example, young adults, parents/carers and service providers all had different understandings of **person-centred care** – for the young adults it was being seen as a person first, before their medical conditions.

Box 1: Eight factors influencing quality and safety of transitional care

1. Early commencement to the transition process
2. Effective communication, cooperation and commitment to joint working between children's and adults' services
3. Orientation of the young adult to adult services
4. The engagement of a transition coordinator
5. Interdisciplinary and interagency joint working
6. Developing the young adults' autonomy throughout the transition process
7. Service providers demonstrating a person-centred approach to care
8. Involvement of parents/carers.

From Kerr et al 2018: Facilitating transition from children's to adult services for young adults with life-limiting conditions[20]

Effective communication with young people and their parents/carers is central. Understanding a young person's interaction style: 'laid back', 'anxious', 'wanting autonomy' or 'socially oriented' may help personalise communication with them[19]. In addition some young people are non-verbal and/or have cognitive impairments also requiring personalisation in communication.

There are and have been strong voices highlighting the perspectives of young people. For example, Josh and his mother shared his story to develop a play and a training resource as they found that Josh's needs were too 'complex' for the hospice and dealing with transition as he became an adult[21]. Lucy Watts MBE who helped the development of the first 'Stepping Up Guide'[17] highlighted what is possible for some young people.

> *"When I was 17 the staff of the young adult* ***hospice*** *began to support me and they taught me crucial skills in self advocacy. They appreciated my desire to have my mother involved and treated me like an adult, but they understood that I was inexperienced, vulnerable, and scared. They checked to see that I wasn't overwhelmed and asked what my wishes were – for example, did I want my mother present? Would I like to speak about this without her? They saw the big picture and it helped me[4]."*

> *"Young adults aren't big children nor are they little adults; they are a unique subgroup of the population and need to be treated as such."* **Lucy Watts MBE, 2018**[4].

From a hospice perspective, in the UK a survey of staff working in hospices highlighted general differences between children's and adult hospices: children's hospices mainly 'provide short breaks and end of life care and adult hospices providing mainly symptom management, end-of-life care and day services'[22].The study found a 'mixed picture of UK hospice service provision for the growing number of young adults with life-limiting conditions.' The challenges have been identified as:

- lack of adult respite services including developmentally appropriate services;
- lack of funding and capacity;
- need for a skilled and confident workforce in adult hospices for young adults with complex life-limiting illness;
- need for more integrated provision between children's and adults' hospices.

Responders highlighted expectations of young people and their families being dashed when young people do not meet eligibility criteria for adult hospice care.

Overall, there is a lot of information and research describing the need for improvement, that some of the challenges are around having the right services, co-coordination and planning, having the right skills and confidence and engaging and working with young people and their parent carers throughout transition. There is also clear guidance on how to provide good 'transitional care'. There is a greater urgency to enable improvements with the increase in numbers of young people with life-limiting conditions.

1.2. The programme design

The inputs, outputs and outcomes are shown in the programme logic model in Appendix 1. The original proposed outcomes included:

- improving *'care outcomes for young people (and their families) when they are transitioning from children's to adults' services, thus improving their quality of life*;
- putting *'young people at the heart of the transition process and provide them with a platform to influence change, in partnership with care providers and key stakeholders*;
- empowering *'the voices of young people affected, and enable them to have more control over their futures*;
- embedding *'the Project ECHO™ approach as part of the ongoing, everyday healthcare working practice in the UK*.

The proposed outputs included:

- establishing three ECHO hubs, each creating its own transition ECHO networks which in turn would be *'hosting up to 10 meetings annually*;
- *'developing an online resource of videos, blogs, tools, how-to guides and other resources for young people and their families, as well as for the palliative and health care workforce*;
- *'hosting an online forum for young people affected (and/or dedicated ECHO network) to communicate with and support each other, help them share ideas and information, and input into the project*;
- *'evaluate the programme and produce guidelines / recommendations to extend and embed the learning and expertise gained beyond the life time of the programme and influence national agencies (e.g. NHS England and Public Heath England*[a]).

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[a] Now UK Health Security Agency and Office for Health Improvement and Disparities

The proposed activities in the original programme proposal involved:

- *'training three regional children's hospices to become transitions ECHO hubs in different regions;*
- *'engaging a Transitions ECHO Partnerships Manager for three years to champion the use of the ECHO methodology across the sector and support the stakeholders, ECHO networks and groups;*
- *'engaging health professionals via a Transitions ECHO Community of Practice to influence and drive change in paediatric care locally and nationally;*
- *'establishing a national transitions network that is designed by and reflects the views of young people living with complex conditions; and is sustainable / self-managing for the long term.*

The ECHO hubs, networks and a national transition network are central to the programme approach. ECHO is an evidence based[23],[24] 'distance education' model in which people from multiple disciplines come together as a community of practice to address a common issue or achieve a common goal. It is designed through 'hub' and 'spoke' networks, each network following specific design characteristics (*see Appendix 2 for further information*).

The overall programme approach evolved differently from initial plans, and was heavily impacted by the COVID-19 pandemic. Figure 2 provides an overview of the structures and key relationships at the end of the programme. It includes networks that were external to the programme. The figure excludes ad hoc support the team provided to individuals, including a transition ECHO network in Scotland.

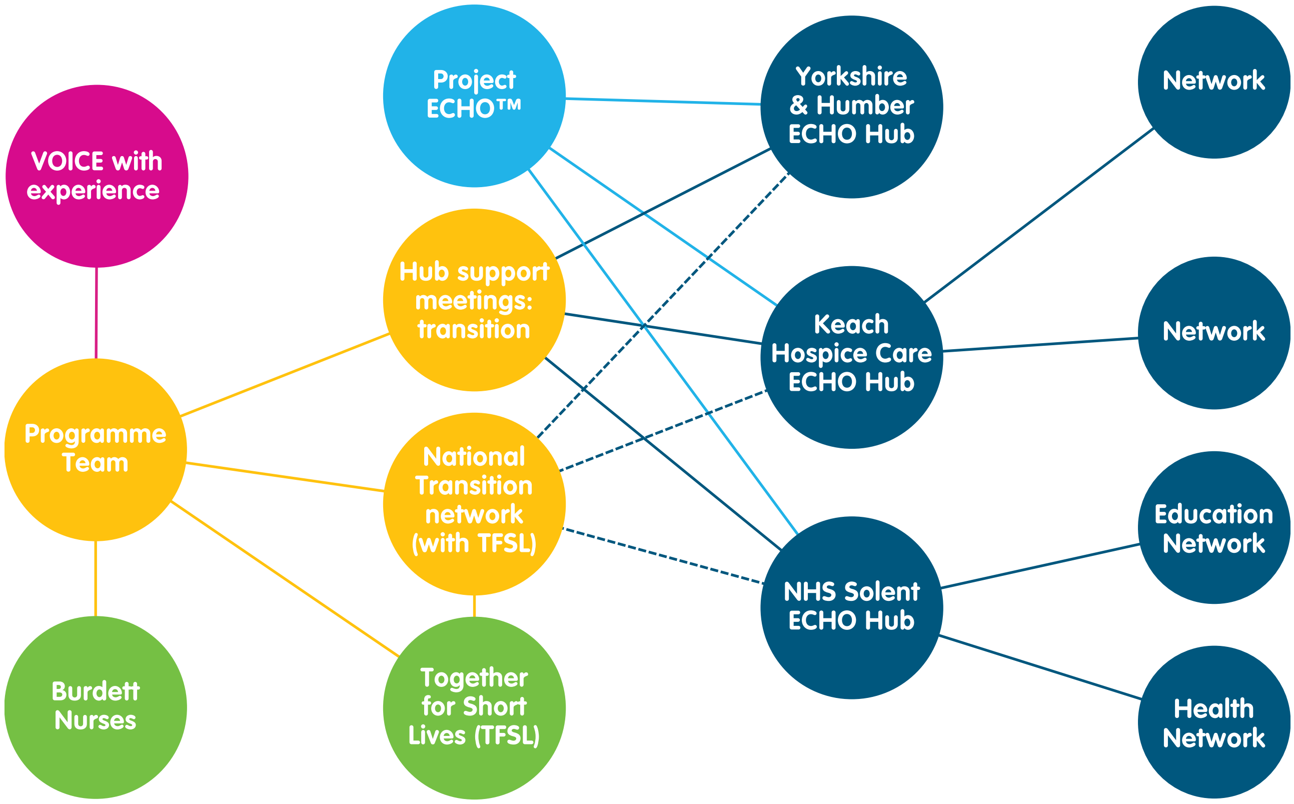


Figure 2 Programme structure and relationships

1.3. The impact of the COVID-19 pandemic

The COVID-19 pandemic had multi-layered impact on the programme, health and social care provision and life in general. For example:

- programme team (furlough, and dealing with lockdown and living in a pandemic);
- the ECHO hubs and networks (re-prioritisation to frontline work);
- transition co-ordinators (redeployment and focus on support rather than transition planning);
- young people and families (shielding, healthcare on hold, no transition planning)[25].

> *"I might possibly have a condition that is rare and undiagnosed … because of COVID a lot of the investigations and hospice care, palliative care, advance care planning has all been put on hold…* [25]*"*

The pandemic affected everything and in terms of project planning there was considerable uncertainty. For example, the project team attempted to restart the co-production of a young persons' forum in October 2020, but rising infection rates and illness put these plans on hold. To highlight this issue generally, we have included the number of people with COVID-19 in hospital as part of the programme timelines (*Figure 3*) as a proxy indicator of impact and the periods of lockdown[26],[27].
As we learn to live with COVID-19, teams are expected to catch up with the back-log of work that has been put on hold, which would include transition planning.

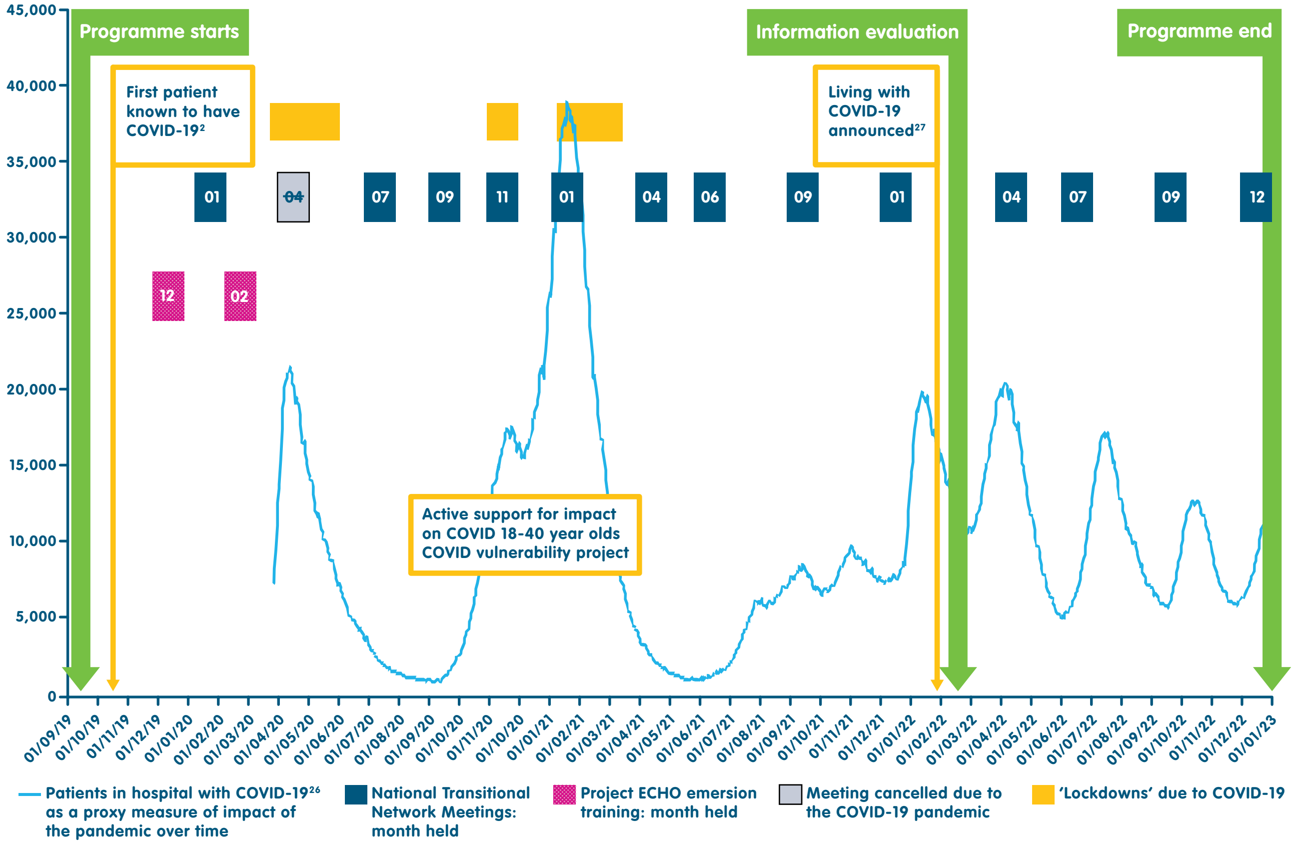


Figure 3 Programme timeline

2. The evaluation approach

The evaluation commenced towards the end of year two of the programme and had two key aims:

1) To undertake a gap analysis of the programme against its original priorities (*Box 2*) and the anticipated programme outputs and outcomes, to provide informative feedback to the programme team;

2) To provide a summative analysis of outputs, outcomes and learning from the programme, with recommendations.

The evaluator met with the team to understand the programme structure, inputs to date, reviewed programme reports and information supplied. This included meetings with the ECHO hubs and undertaking a sustainability assessment.

The informative evaluation highlighted the following areas for pragmatic focus during the final year:

- re-create opportunities to increase the VOICE of young people directly into the programme;
- celebrate progress and understand sustainability of all the networks including the ECHO hubs;
- re-create opportunities for the ECHO hub leads to meet as a collective;
- introduce feedback loops to the National Transition Network meetings and try out different approaches to managing the meetings to reinforce relationships.

At that stage, it was recognised that there were fewer ECHO networks than originally planned, no young persons' forum and no project specific community of practice. As there was a shared understanding that the COVID-19 pandemic had substantially impacted the programme, this informative feedback needed to be realistic.

In addition, we explored the potential to collect Equality Diversity and Inclusion (EDI) data in the participating networks. From a UK General Data Protection Regulation (GDPR), Hospice UK could only ask members of its own networks to supply EDI data and people directly working with Hospice UK. We did not request that the ECHO hubs provided EDI data of their attendees, in part due to their IT technical capabilities and in part due to constraints of GDPR on sharing personal data with a third party. The issues the programme faced in this area are discussed later in the report with an associated recommendation.

Box 2: Priorities for the programme, January 2022

Young people and their families to be actively engaged and feeding into the project.

- Put young people at the heart of the transitions process and provide them with a platform to influence change, in partnership with care providers and key stakeholders.
- Empower the voices of young people affected, and enable them to have more control over their futures.

In terms of the original project outcomes:

- Establish a national Transitions Network that is designed by and reflects the views of young people living with complex conditions; and is sustainable / self-managing for the long term.
- [Determine how to] Assist palliative care providers to better manage the health and social care needs of young people with complex and life-limiting conditions in their localities.
- Identify and produce recommendations for a new approach to managing the transitions process and roll these out widely via hospices and other stakeholders / partners.

In addition, there was a request made in 2021 for the programme to start collating Equality, Diversity and Inclusion data on who is engaging with the project.

2.1. The VOICE of young people

As previously highlighted, it was expected that the VOICE of young people would be integrated throughout the programme and its activity.

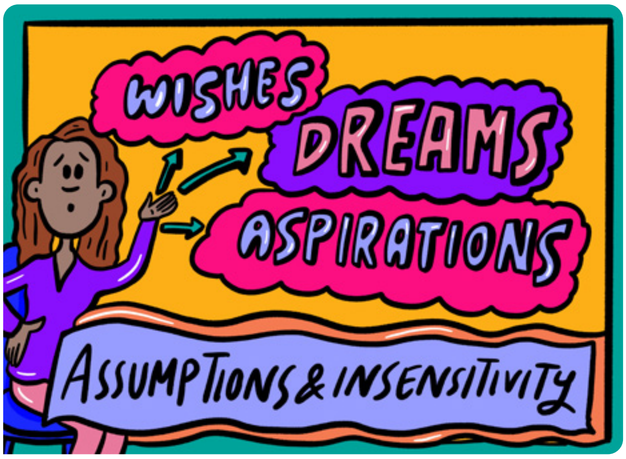
> *"nothing about us without us[44]"*

To assess how well the VOICE of young people has been integrated into the programme, the evaluation has taken into consideration both the continuum of engagement[28] and the 4Pi National Involvement Standards[29],[30]. The continuum of engagement has three levels: consultation, collaboration, and controlled or led by young people and/or parent carers. It can be applied in different situations such as direct care, service development, clinical education and training.

The 4Pi National Involvement Standards referred to throughout this report describe five components: **principles, purpose, presence, process** and **impact of involvement**. The standards create a logical framework that includes a clear consideration of equality. For example the 'principles' highlight inclusivity, non-discrimination, respect, transparency and being open-minded to cultural difference. '**Presence**' includes ensuring an inclusive approach that seeks to address inequality.

VOICE of young people in the evaluation

Two young adults (Hannah and Tom) in their 20s with lived experience of transition and hospice care co-designed the initial recommendations of the evaluation for Hospice UK, based on their experiences. The first meeting with them had a specific structure and purpose seen in Resilience Based Clinical Supervision[31]: a safe space agreement, grounding, checking in, discussion and endings. The rationale for the design was to recognise and allow for the emotional context and recognise that everyone attending the meeting were participants. The initial meeting took place in June 2022, with follow-up meetings to discuss and agree the recommendations (*Box 3*) and an artist's visual record of the discussion. Hannah continued to be actively involved in the programme, attending monthly team meetings, and led the development of specific outputs, including presenting at the 2022 Hospice UK conference.



Box 3: Key messages from Tom and Hannah, 2022

Ask me what's important to me. I want to live my life. I need things to lift me. (I have accepted I am dying).

Respite is "REALLY important" – this may include overnight stays, short breaks and proactive respite in a crisis.

"It shouldn't be so difficult" and finding out that it is not (relatively) if you have a cancer diagnosis. Some may be at an even greater disadvantage as some parts of the system feels set up to say "no" and run on appeals (e.g. continuing health care funding).

Some services avoid emotions, rather recognising and being supportive – for example: being on an adult ward for the first time, experiencing death for the first time, signing a consent form for the first time.

The materials in Dying Matters [50] are really useful and really important – having plans allows valuable resources to be directed to where they are needed.

2.2. The National Transition Network for young people with life-limiting illnesses

The evaluation applied the Health Foundation's framework of effective networks for improvement[32] to collate and assess the impact of the National Transition Network as shown in Figure 4.

The data collected included: reviewing terms of reference, meeting notes, attending network meetings, meetings with the National Transition Network's chairs, developing a specific questionnaire.

The network questionnaire was based on a thematic analysis of the content of meetings to understand the potential impact on members' knowledge about transitions. The chairs of the meeting and a couple of active members tested the draft questionnaire, including one member who is an academic. The final survey was issued to current and former members of the network, and a knowledge gathering exercise that included recipients of the bulletin. 24 out of a potential 49 people responded to the network survey (response rate of 49%) and 28 out of a potential 157 for the bulletin (18% response rate). A 50 per cent response rate is fairly typical for a survey of this nature, but means that the results may not represent everyone's perspective.

2.3. The ECHO hubs and networks

The ECHO methodology encourages ECHO hubs to evaluate their impact and progress[24]. The evaluation approach aimed to replicate this, and reviewed data provided by the ECHO hub leads, observation of ECHO network meetings and other information provided by the project team such as the bi-annual project reports of progress. The ECHO hub leads were supported to undertake a sustainability assessment using the model of sustainability[33] to support their planning for the future beyond the end of the programme.

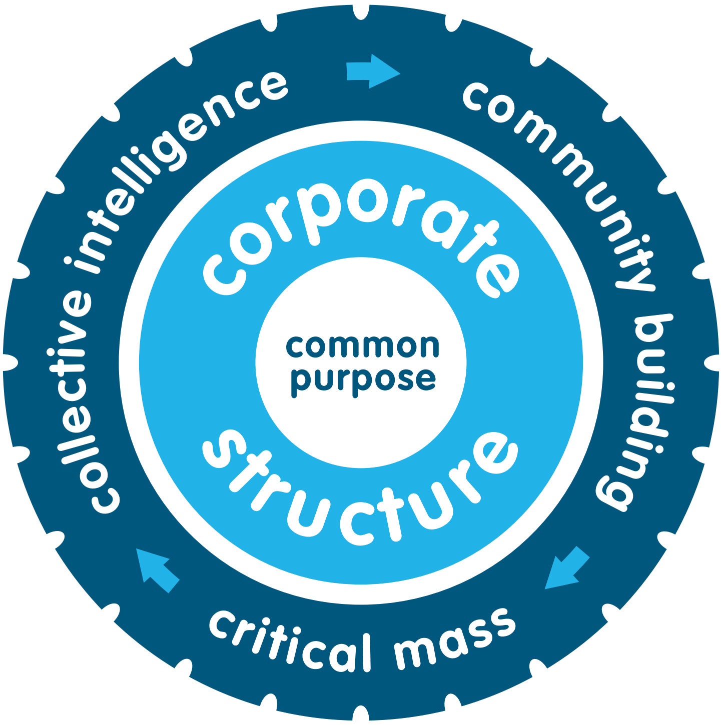


Figure 4 The 5C wheel for effective networks
Based on the original wheel developed the Health Foundation[32], 2014.

3. The programme results and outputs

The programme has had a wide range of influences and impact, both within its networks and by connecting to other networks, encouraging the participation in research and consultation in policy and other developments (Box 4).

Box 4: Summary of the programme outputs

Programme outputs

Hospice UK web resources: Transition from children's services into adulthood[34].

What does 'Transition' mean to young people? Video developed by Hannah Hodgson, featuring her friend Katherine and edited by Jon Morris[1].

Improving Transition to adult services young people's voice: 20 illustrations of Tom's and Hannah's experiences by Beci Ward[45].

Supporting Together for Short Lives' review and revision of 'Stepping Up' Transition Pathway to enable a good transition to adulthood for young people with life-limiting and life-threatening conditions[17].

Improving transition: Hearing the Voice of Young People. Live stream presentation at Hospice UK 2022 Conference[49].

Transforming Care for Young People with complex and life-limiting conditions. Poster at the Hospice UK 2022 Conference[51].

Presentation to Hospice UK Executive Clinical leads in Hospice and Palliative Care December 2022.

Publication of 12 Transition Network Quarterly Bulletins with Together for Short Lives.

ECHO Hub outputs

What do Young People with Life-limiting Conditions Want Professionals to Know about Transition? Oral presentation. 5th Maruzza International Congress, Rome[46].

Transition from Child-Centred to Adult-Oriented Services: Needs and Concerns of Parents and Carers of Young People with Life-limiting Conditions. Poster presentation 5th Maruzza International Congress, Rome.

Contribution to national guidance and research

'Whose life are They Going to Save? It's Probably Not Going to be Mine!' Living With a Life-Shortening Condition During the Coronavirus (COVID-19) Pandemic[25].

Guidance for: Paediatric to Adult Critical Care Transition[47].

Key stakeholder in the Development of the Transition of Young People into Adult Services Core Capabilities Framework by Skills for Health (to be published 2023).

Hospice UK response to proposed Disabled Children and Young People (Transitions) (Scotland) Bill[48].

3.1. The VOICE of young people

The conversations and discussions between Hannah and Tom illustrated the potential of peer support and how technology can enable people with different experiences to meet one other.

> *"I wanted to say a huge thank you for everything that you both did to ensure an amazing Transitions session at our Hospice UK Conference. Putting young people right at the centre and enabling and supporting them to deliver such a powerful session that received a standing ovation by the audience. This was months in the preparation and planning to enable three young people to attend conference with complex life limiting conditions ensuring that their needs were fully attended to and their voices heard."* **Anita Hayes, Head of Clinical Leadership. Hospice UK.**

The approach to involvement had a clear **purpose**[29] and clear **principles** in terms of creating a safe space and setting out the expectations for the collaboration. The **process** was effective and the meeting framework could be replicated. The process also recognised that time is precious, and provided a financial bursary for involvement and covered costs for the young people to attend and participate in other activities such as the Hospice UK 2022 Conference. It also allowed the idea of a young person's video[1],[34] to be heard and acted upon.

> *"It means a lot to me to be listened to, people (Hospice UK) are excited to have us giving our reflections. I don't always get that experience. I have been involved in other work where people don't want to hear as this means more work for them."* **Tom**

It will take more time and more work to realise the full potential of **impact**, i.e. the development of improved services and support for young people. The immediate response has been positive, reflecting clarity and impact of the messages (*see Box 5*). Importantly it has opened up conversations about what is possible and concerns in adult hospices, for example as highlighted in Box 6.

Box 5: Feedback from the Hospice UK 2022 Conference[49]

"The session with young people with life limiting illness, was particularly moving and thought provoking. Hearing their voice in person, seeing the films they made was powerful and a great call to adult hospices to address issues around transition. Inspirational."

"Illuminating to learn about the significant gaps in care and to hear the voices of young people effected, very powerful."

"The transition speakers were very emotive and thought provoking. It has spurred me on to look at what we do in my own organisation."

Hannah Hodgson's[1] video has raised the profile of potential inequality that depends upon diagnosis and geography. The Hospice UK Conference also showcased Sumi, a talented film maker with very restricted physical movement who interviewed a parent carer, drawing out important points from a parent carer's perspective and her struggle to access care for her daughter. This is a replicable model; young experts with experience contributing to the diversity of voices needed for '**presence**'. In terms of **presence**, the future approach needs to consider a greater diversity of voices and the experience of young adults with a range of cognitive abilities, communications requirements and culture/ethnicity, and include parent carers.

The collection of reflections build on Hannah and Tom's original key messages:

- aim high to support ambitions - 'Living Matters Now';
- ensure there is equal access to high quality care and support for everyone;
- accessing respite and short breaks and continuing health care funding are substantial challenges;
- there is a need to work across a continuum of transitional care that emphasise partnership, collaboration and commissioning to break down barriers;
- adult hospices can care for young people and adults, but we need to listen, create good environments and pay attention to emotional needs.

Box 6: Impact of the conference: sharing important questions and their answers

A consultant's question to the panel
"It feels daunting, and that our skills are ill-matched to deal with the complex needs that some young people present. What is your advice to getting our skills to the right level?"

The answer:
"We had to challenge ourselves to think differently for people with neurological problems. The symptoms are the same as our other patients. We have the skills and we can get the knowledge and understanding of what a young person needs by talking to them and/or their parents and learn from them."
Hospice UK conference[49], 2022

3.2. The National Transition Network for Young People with Life-limiting Illness

The National Transition Network evolved from the Transition Co-ordinators Network established by Shooting Star Children's Hospices. The hospice had approached Together for Short Lives and Hospice UK to take on the leadership and further develop this network, together with a bulletin which together has a reach of over 150 people. The co-chairs facilitated the agreed revised terms of reference and the handover of the chairs in January 2020.

> *"I was able to make contact with a colleague from another area to support a young adult staying for a prolonged period of time with extended family out of their usual area."*

Hospice UK and Together for Short Lives co-chaired 12 National Transition Network meetings throughout the programme, with more than 50 people attending. Only one network meeting was cancelled due to the COVID-19 pandemic, although all the meetings after the face-to face meeting in January 2020 were held virtually.

A '**shared purpose**'[32] allows a network 'to unite individuals from various organisations and professions around' this common goal, 'which fosters widespread engagement and commitment to quality improvement'. The National Transition Network's shared purpose is:

> *"To improve the transition experience of young people and their families and improve outcomes."*

The majority of the network members (86%) who responded to the network survey felt that they were clear about the network's purpose. Almost half of the network (48%) felt that they have improved their practice as a result of attending the network (*Figure 6*). Four people provided examples of how their practice has improved as a result of attending the network and these included one example of direct care, "*connections made with other professionals to work collaboratively with" and "links with the network has enabled support with funding and developing a job description" and "I am interested in the examples of technology being introduced to care. It hasn't changed my practice as such but has all helped to increase my knowledge around what is available in hospices.*" Having meetings that worked well, provided a greater opportunity for members to realise the shared purpose. Almost 70 per cent of network members felt that the meetings were of either high or very high quality.

Future meetings could reinforce the connection between the shared purpose and changes in practice or learning by encouraging feedback from meeting to meeting and small group discussion. Further, creating routine feedback in addition to chat from each meeting would have allowed chairs to develop the network.

> *"Transition nursing can be quite isolating as no one else that you work with understands what you do, so it is great to have a like-minded peer group."*

The '**corporate structure**'[32] should allow individuals to collaborate safely and in a non-hierarchical manner, while being structured and influential enough to get things done (*Figure 6*). 71 per cent of members felt they would be able to share a work-related problem or issues with others, indicating that the network provided a safe space. During the study period the chairpersons experimented with break-out rooms to encourage members to discuss and learn from each other and develop distributed connections. There was a sense of energy in the group (described as being "talkative"), a need for transition coordinators to have a peer support network, and a desire to improve transition.

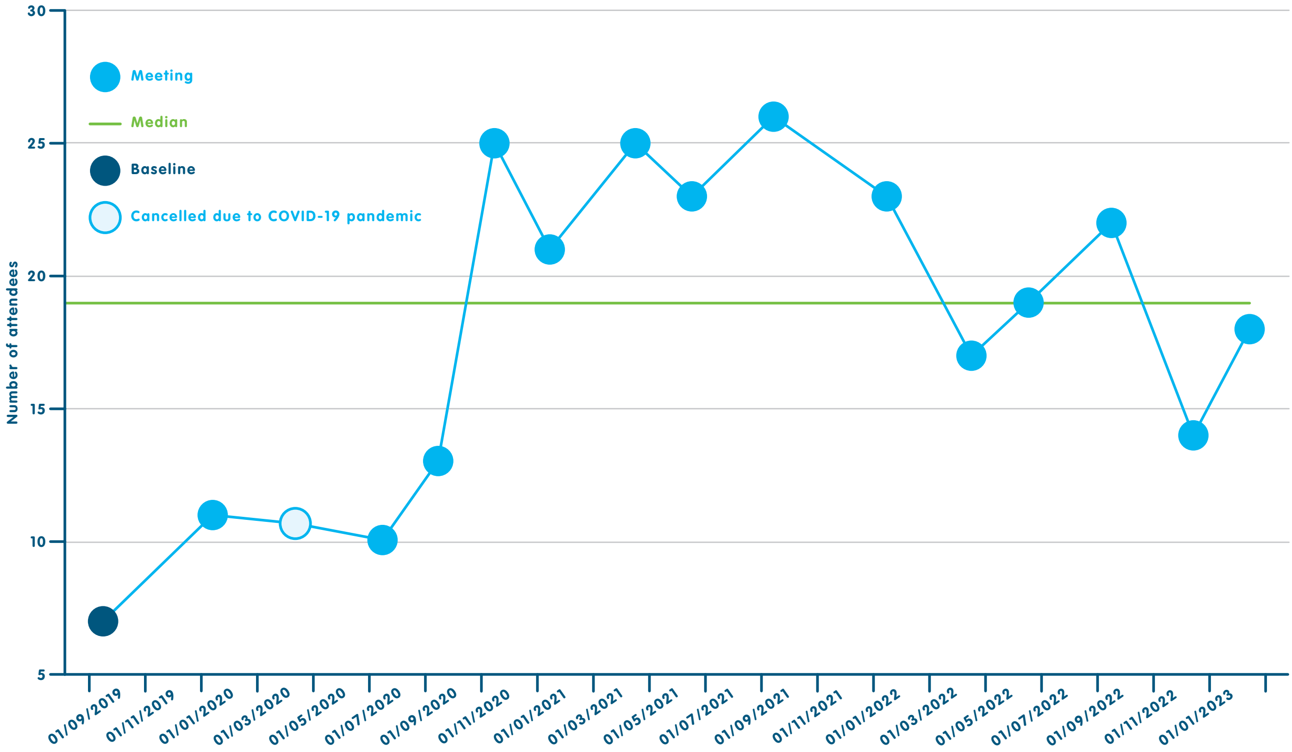


Figure 5 National Transition Network meetings: number of attendees over time

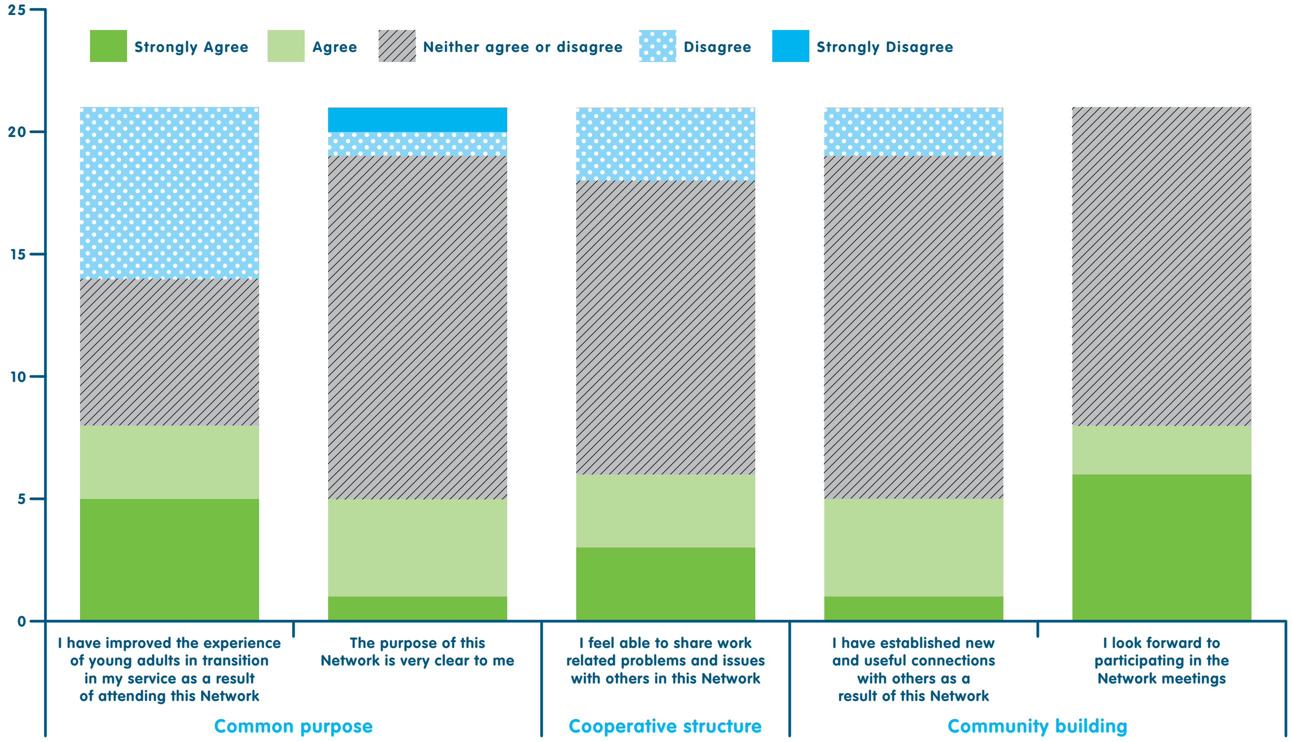


Figure 6 Impact of the National Transition Network 1

'**Critical mass**'[32] of a network reflects its ability to combine resources and voice to exert internal and external momentum. This includes the speed at which ideas and knowledge are spread among members and the external influence of the network. The joint chairs of the network successfully recruited greater attendance and membership of the network (*see Figure 5*), with key updates being shared across a wider group through the associated bulletin (which has a distribution list of over 180 members). Twenty three per cent of hospices were connected to the programme in this way and the membership reflected a range of organisations outside of hospices, so had the opportunity to exert greater influence (50% of bulletin recipients are from NHS providers). These figures provide a focus in terms of how the network could develop and communicate its collective voice through the bulletin and other communication/ influencing channels.

'**Collective intelligence**'[32] focuses on the ability of a network to develop, generate and share knowledge and ideas. A diverse range of topics were presented and discussed through the quarterly meetings (first two years) and members. Figure 7 shows how members assessed their knowledge increasing due to attending the network. They indicated the greatest knowledge gains have been around transition pathways and enabling the participation of young adults. The least strong views have been feeling up to date with policy and new funding opportunities.

'**Community building**'[32] describes how networks create a community that fosters cooperation and trust between its members. Figure 6 shows that there is a sense of people being able to establish new and useful connections as a result of attending the Network and a sense of looking forward to attending the meetings.

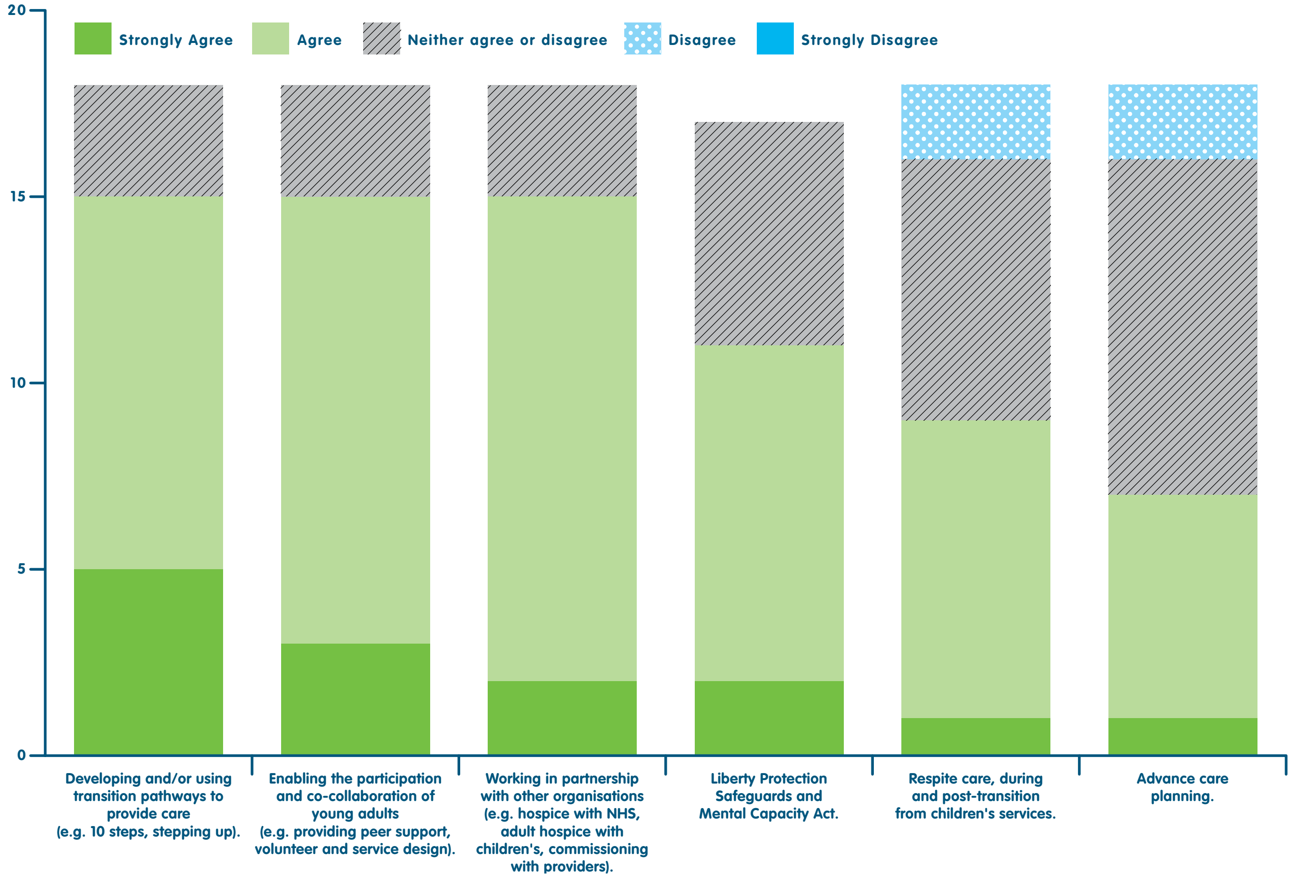


Figure 7 Impact of the National Transition Network 2: 'collective intelligence'

Overall, through the programme the National Transition Network has gained new members, and is in position to support and facilitate improvement. It has a clear focus, targeting young people who have a life-limiting illness so provides an opportunity to focus on hospice and other palliative care providers' roles in transition for this group of young adults. Historically it focused on supporting 'transition co-ordinators' but has expanded to a wider focus beyond specific roles. People attending commented that it is useful that there is a feeling of not being alone, "there is national support", "protected time", "connecting me with others in adult settings that support transition" and opportunities for "collaborative working". The feedback highlighted opportunities to improve operational aspects of the meeting and also a call for "a more frequent support group in-between more formal meetings". One person also highlighted a need for more participation of young people and carers.

> *"I think that those young people who cannot speak for themselves are particularly left out. We hear a lot from those cognitively able young people, but little from carers/ families who are representing the young person."*

In terms of **future work** and potential focus for the network, a questions was posed: *what are the biggest current challenges you face in your work with transitions at the moment?*

Figure 8 shows the summary analysis of the responses and indicates the multiple layers of challenge. At the centre is the challenge of one-to-one level of engaging with young people and their families or engaging with other professionals (which includes professionals who are nominated champions for transition in their area). At the outer layer is a need for greater national direction and supporting adherence to national guidelines.

> *"It would be a shame if Hospice UK stopped working in transitions, we need the pull from adult hospices. We would like to continue working with Hospice UK and co-chairing this Network with Hospice UK."*

The comments provide a lot of insights around these challenges. For example, in **availability of services to transition** a feeling that there is *"no recognition by other adult hospices that this in a growing emerging population with unequal access to care."* The need to develop confidence – *"we have recently had two patients transition to the adult unit of a hospice. This has been the first time that our patients have met the adult criteria. Unfortunately the adult unit is not fully confident with caring for those with complex needs and currently have staffing issues. The first patient that transitioned, they relied heavily on our team to provide care."*

Is there a need to develop a shared understanding of roles – for example: *"understanding if adult hospices are the right place for young adults who have complex needs once they are too old to receive respite care from a [children's] hospice, especially if their condition is stable."*

There is substantial geographical variation: *"wide geographical coverage of children's hospice across three counties. Adult hospice serves a more local community. Limited or no resource to support transition in adult hospices unless young person has symptom management or end of life needs.*

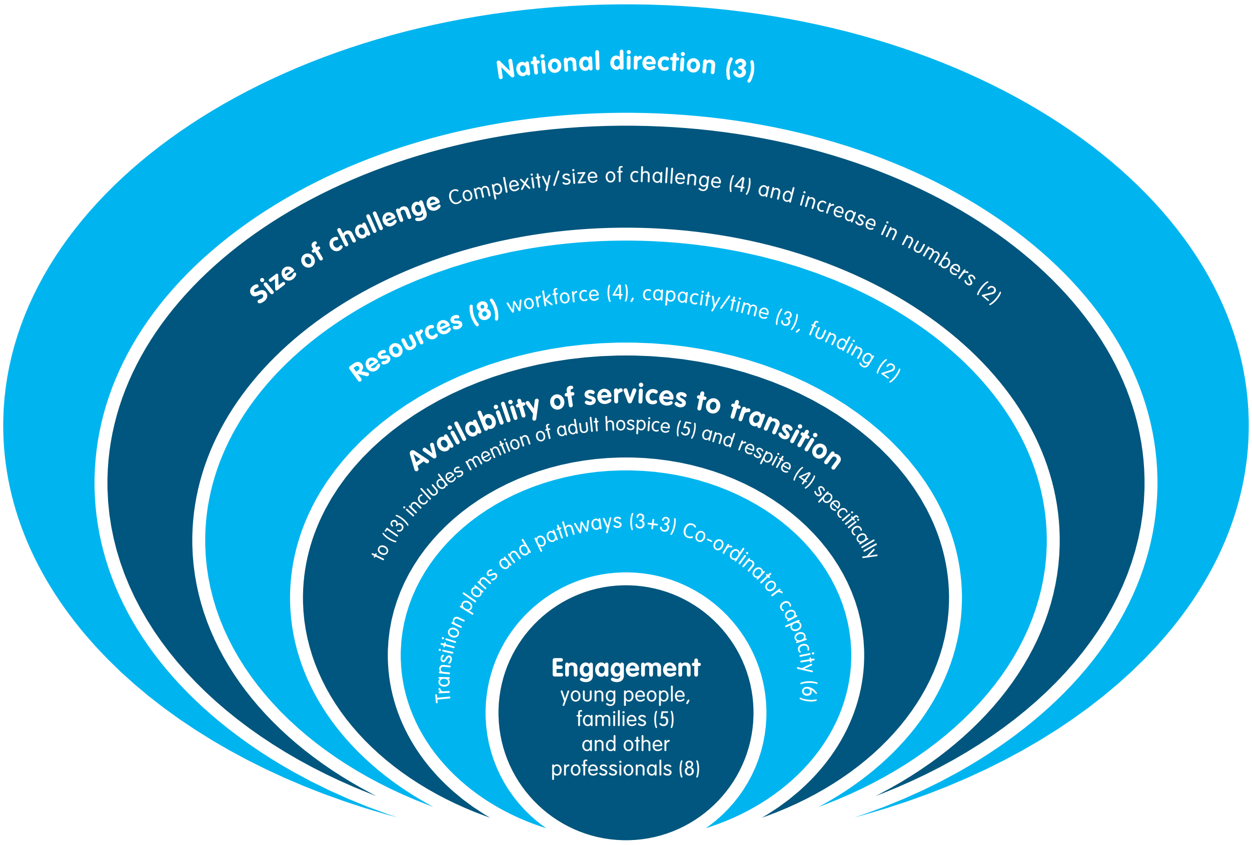


Figure 8 Biggest challenges relating to transitions identified by the wider network

Huge variability in each locality to support the needs of young people with complex care needs".

Overall the National Transition Network is in a good position to grow to become a strong voice for children's and adults' hospice and palliative care to improve transitional care for young people with life-limiting illness. There are opportunities to strengthen the network and refine its focus in the future.

3.3.The ECHO hubs and networks

The attendees for the two three-day ECHO Partner Launch training (formerly known as Immersion training) held in December 2019 and February 2020 gave positive feedback. The average scores for usefulness, relevance and interestingness were over 9 (on a scale of 1 to 10, where 10 is the maximum possible score). Feedback also indicated positivity and a feeling of connectedness.

> *"Great team thank you for a really great three days, loved meeting the other teams and I look forward to keeping in touch and seeing where we all go with this."*

> *"Thank you for the training. I'm excited to get the ball rolling with everything we have learnt."*

The table below provides a summary of the three ECHO hubs, their focus, approach and future plans.

ECHO hub	Primary focus	Key dates	Number of ECHO Networks	VOICE of young people	Followed ECHO structure	Future plans 2023	Impact on staff knowledge and practice change
Keech Hospice Care	Young people with life-limiting illness	Sept 2020 curriculum setting Nov 2020 1st session	1	Presentations at meetings and membership	Mainly	Yes	Qualitative
NHS Solent	Complex needs and life-limiting illness	Oct 2020 curriculum setting Jan 2022 launch	2 (education and health)	Presentations at meetings.	Mainly	Yes	Qualitative, some quantitative
Yorkshire and Humber Children's Palliative Care Network	Young people with life limiting illness	July 2021 curricula Sept 2021 first echo	1	Presentation at curricula setting, focus group, interview. Attendance.	Fully	Yes	Quantitative and qualitative

Keech Hospice Care

The hospice provides hospice care for children and adults living in Hertfordshire, Milton Keynes and north Bedfordshire. They have reported that they managed to provide around six ECHO sessions a year from November 2020 and planned to continue with their network into 2023. On average 16 people are attending the ECHO sessions. Over 120 people are invited to attend each network meetings that includes a ranges of stakeholders both within and beyond their geography and includes people with lived experience. For example, adults' and children's hospices, hospital trusts, people with lived experience, mental health trusts have attended sessions.

The team found the administrative burden and technology requirements to manage the networks greater than anticipated. They provided facilitated discussions after an external presentation, without a 'case study' focus with associated break-out discussion. The observed sessions had a strong focus on the voice of young people and illustrated the potential way that adult hospices can create 'pull' (See Joel's story) and the role of Peer Researchers i.e. people with lived experience being active researchers. The hospice has clear plans to continue with its transition ECHO network going forward.

> *"I don't feel ready to run breakout rooms."*

Joel's Story

Joel, an adult with Duchenne's Muscular Dystrophy reflected on his journey to move from the family home to his own accommodation with the support of a hospice social worker Kate, during an ECHO session run by Keech Hospice Care.

The session gave insight into what is possible and how adult hospices can support young people who transition from a children's hospice or those that have opted to not receive support from children's hospices.

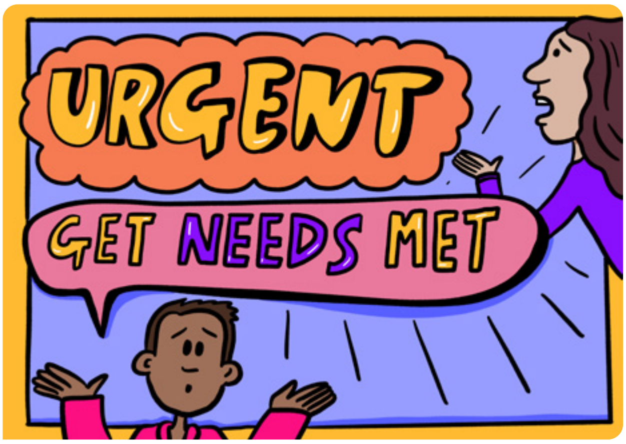
"Kate was a point of contact for me in the adult hospice during transition.

All the support I have received is as an outpatient. It started off with a lot of mental health support through creative counselling using virtual reality.

I realised I wanted to move out when I was about 20. My friends were going to university. I didn't want to be stuck with my parents. Our first point of call was the council and it was surprising that we didn't have to wait that long for a home to become available. Though there were some issues, for example as the council didn't understand my specific requirements so these weren't ready when the flat was ready. The whole process has taken about three years. Kate gave us the support we needed. We did not feel alone.

It hasn't been easy, but it is good to live in my own home. It is nice to have my friends around. I have noticed that there has been a positive change in my relationship with my parents, in particular my father. He now feels like a father, rather than my carer. This feels good."

Kate reflected that: "I learnt a lot from the process, and I thought I was an expert but I needed to learn new things and new processes. It is good to build the relationship with Joel. This means that if he ever needs the inpatient care or other parts of our service we already have the relationship with him."



Top tips

For young people (from Joel):

“Don’t feel you ‘can’t’ - don’t let your disability stop living your own life.”

For people working in an adult hospice and the council (from Joel):

“Understand and listen to my family and me, what we need and our problems.”

For people working in an adult hospice and in the council (from Kate):

“In order to get things right for a young lad aged 14-19, you need to understand what is most important to him.”

NHS Solent

NHS Solent runs mental health, community services and community hospitals in Southampton, Portsmouth parts of Hampshire and the Isle of Wight. They ran two ECHO networks – one that focused on health and the other focused on education transitions. Their evaluation of their services focused on quantitative and qualitative elements. The quantitative elements showed that nine attendees found the content of the ECHO sessions were helpful (2 ‘extremely’, 5 ‘very’, 2 ‘somewhat helpful’).

> *“Suddenly we found the right person in our staff bank. She just got it, she was great at communications, running the evaluation.”*

The team feels that the greatest impact has included the cross-fertilisation between clinical and education, for example the continence team attended the education sessions and it gave a better outlook to the complexities that families face outside of medical realms. They also highlighted the impact on a parent carer presenting their story to professionals. The discussion empowered the parent carer to feel that her daughter deserved more and she achieved getting her daughter into the education establishment.

> *“I meant to say, I’ve been telling all my colleagues to attend ECHO and a couple finally got round to it, they said it was amazing and they learnt so much!! Now planning on attending the future ones.”*
> **Text message from a Community Children’s Nurse in Southampton.**

They faced similar challenges to Keech Hospice Care in terms of the administrative and technology requirements – they highlighted the ‘case presentation’ and running virtual break-out rooms being difficult. Once they recruited the right person in their team, who had the confidence and skills, this gave the clinical leaders greater headspace to focus on the content of the meetings rather than logistics.

The observed session created debate and problem solving around barriers for improving transitional care. The team evaluated and reflected on the approach and their progress. The team highlighted that they felt that the structure of ECHO did not fit a quality improvement approach and raised the idea of running an ECHO network for parent carers.

Yorkshire and Humber Children's Palliative Care Network

The Yorkshire and Humber ECHO hub was part of a wider infrastructure of the Yorkshire and Humber Children's Palliative Care Network which meant that they could draw on skills and infrastructure to support the ECHO networks (for example project management, administration, communications, information technology and evaluation).

They developed their programme with local information on the issues facing young people. They held a focus group with young people in the process of transition, a focus group with parents (*see Box 7*) and also conducted a survey of young people at a hospice who had recently experienced transition, conversations with members of a youth group, and in transition clinics in a hospital. The network established a curriculum with more than 47 people and the sessions were evaluated according to whether the session was useful, interesting or has changed practice. All ECHO sessions were routinely evaluated by the team. The sessions generally were found to be very useful (on average 77%), interesting (on average 80%) and changed their practice [very much] (on average 36%). The session that most helped to change practice was one on transition and developmentally appropriate healthcare (*Figure 9*).

Despite a substantial risk for sustainability with the decommissioning of the Yorkshire and Humber Children's Palliative Care Network, there are clear plans in development. St Luke's Hospice (Sheffield) plans to host the ECHO hub going forward, with the same faculty providing the leadership for the programme, supported by the Project ECHO team.

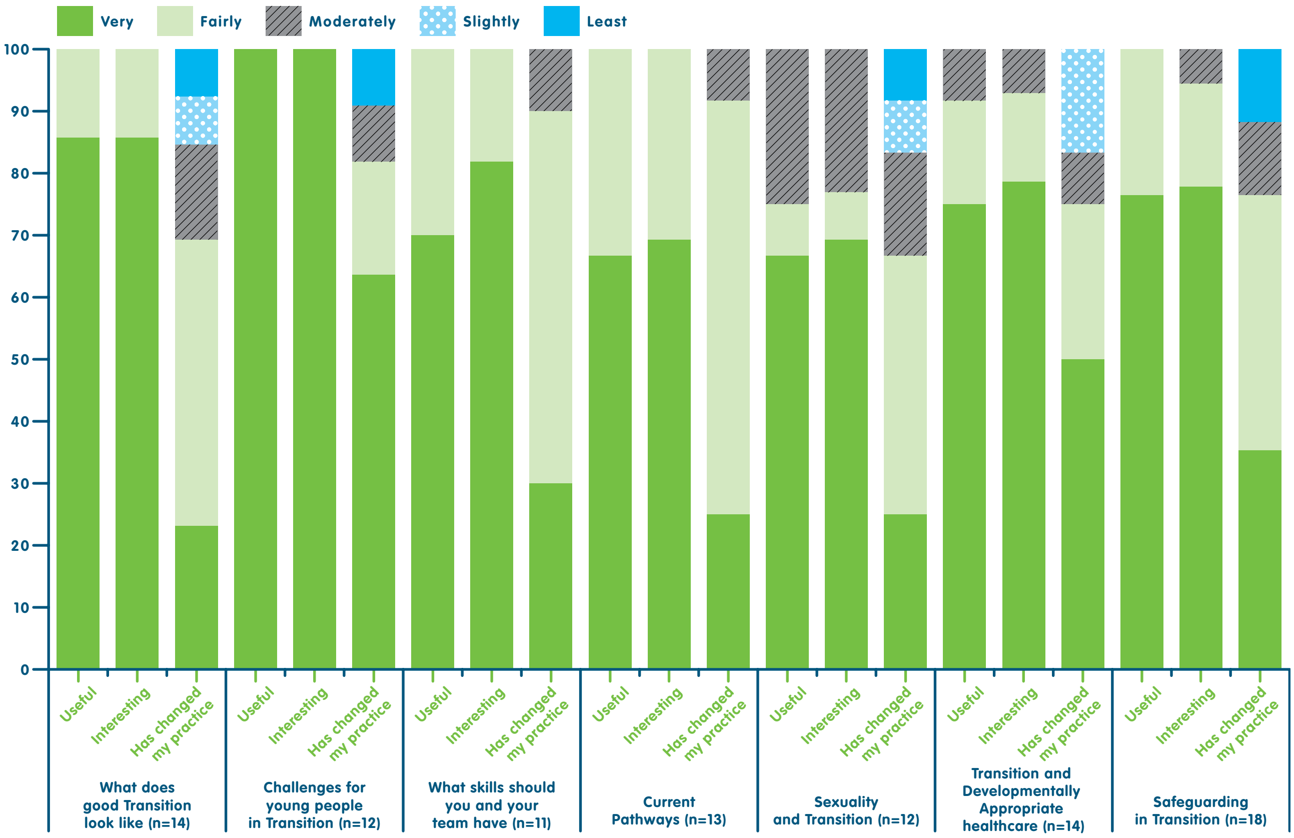


Figure 9 Impact of the transition ECHO network in Yorkshire and Humberside

Box 7: Learning from the parent focus group in Yorkshire and Humberside

One thing that would help transition:

- Family care coordinator role
- Handover for clinical teams
- Compassion, understanding and really listening
- Someone to cut through all the bureaucracy and be given the power to turn things around.

Additional ideas coming out of the focus group included the suggestion of holding parent carer specific ECHO sessions on issues such as:

- power of attorney and legal aspects relating to care in adulthood;
- induction for transition to introduce the professionals and key team;
- advocacy support services potential for holding virtual clinics and peer support clinics for staff in more remote areas or where specialists are in short supply e.g. neuro muscular specialists, a GP with special interest, specialists training consultants, virtual outreach clinics.

Overall, ECHO networks need time, and a considered approach with the right support[24,35] to enable them to realise their goals. All three networks have shown impact, learning despite the multi-layered challenges they experienced from the COVID-19 pandemic and other issues. The networks all need more time and support to realise their full potential. There is a benefit to actively supporting knowledge sharing between the networks and creating peer support. It may be interesting to explore how to integrate quality improvement into the ECHO methodology[36] and/or create ECHO networks for young people and/or their parent carers. However, if providing ECHO networks feels like an ‘add-on’ to a person’s workload then this approach to clinical education is unlikely to be sustained long term.

4. Discussion and conclusions

This programme has provided a strong narrative about what is important for young people with life-limiting conditions. It has contributed to existing evidence that networks, including ECHO networks[24] are an effective mechanism to facilitate professional learning and engagement. It reinforces the benefits of a considered and structured approach to network design, starting with a shared purpose and being curious about how and if this is being met. The ECHO networks and the National Transition Network have all benefited from including expert voices with experience of transition. The programme and this evaluation have collated knowledge about what is important, the complexity of providing good transitional care and enabling improvements. It has also surfaced potential inequality of support depending upon diagnosis (*Box 8*). The knowledge and expertise of the partnership managers has ensured that learning from the programme has influenced national policy and guidance.

Box 8: What is the level of inequality of support between different diagnoses during transition to adult orientated services?

"How many versions of myself are falling through the cracks because they don't have certain illnesses? … The thing that chatting to Kathryn [my friend who is an oncology patient with a life-limiting diagnosis] made me realise was the health inequality that myself and others with rare diseases are living through."

Hannah Hodgson, 2022[1]

However, there is a sense that the sum of the parts of the programme is not greater than whole. This is partly due to the disruption caused by the COVID-19 pandemic, for example ECHO networks generally need at least three years to realise their full impact and potential[24]. Similarly the VOICE of young people generated most momentum and influence towards the end of the programme and there was a lack of time to consolidate this into greater impact, in part due to fixed term contracts ending. Given additional time, creativity and focus, a broader 'presence'[29] with a wider diversity of 'expert voices' for 'transitional care' could also evolve and emerge.

Methodologically, a quality improvement approach could create a connection between the 'what needs improving' and 'how to provide 'transitional care' and help the practical implementation of guidance such as the 'Stepping Up' transition pathway[17]. Similarly, so could applying methodologies such as experience based-co-design and measurement for improvement that includes 'patient reported outcome measurement'[37]. The advice is[20]:

- to *'take a diagnostic approach, seeking to understand how [interventions] can most effectively work to produce important outcomes in their unique context'*;
- to recognise and address '*it is the combination and interaction of organisational and human factors to achieve a successful transition.*'

This could work well within ECHO networks. There is an approach that integrates quality improvement into the ECHO model[36] and this programme has highlighted skills and confidence needed for staff working in adult hospices, parent carers and potentially peer support for young people.

A potential future focus could be on a sub-group of young people with life-limiting illness. For example those who receive children's hospice care (or could receive children's hospice care) or have received children's hospice care. Creating '***a pull***' from adult services could focus on individual young people and the needs of all children in a geographical area.

For example, all hospices in a geographical area could collectively ensure that there is a good understanding of the numbers of young people who have already, are currently and will in the future transition to adult services. The next level of understanding is what they and their parents need in terms of support and care, during and after transition and collectively answer how these needs can be met[38]. Having a greater understanding of equality, diversity and inclusion data[39] would help this 'coalition' to understand and address areas of inequity and answer a question: who is missing out on support and services? This evidence should support a collective voice for hospices to raise the profile and champion the needs of young people with life-limiting illnesses in transition to adult services.

This geographical focus needs to build on what is known already around gaps in respite and short break care for adults, and seek to improve the evidence of impact[40], which will in turn support sustainability. There is also a need to share ideas and examples of existing sustainable models in the adult hospice section that effectively support transition and models of care for young adults, for example[41],[42] and learning from evaluation of projects, for example[43].

In order to achieve greater reach across hospices, there are opportunities to build on the National Transition Network and ECHO hubs and networks. With time this would allow them to consolidate their impact and enable further connections to the health and care sectors. For example, in England each Integrated Care System has a nominated lead for children's services which includes transition.

Curiosity and confidence is needed at all levels to realise future improvements for transition, and collective learning to demonstrate impact.

> *"Don't create a forum – create an expert advisory group and invite people to work with you on specific, well defined pieces of work where you are clear about the expected outcomes."* **Tom**

5. Recommendations

Hospice UK is in a unique position to continue to influence improvement in transitional care for young people with life-limiting illness in the UK. The following recommendations from the three-year Transitions ECHO programme aim to inform the next steps that need to be taken to improve care outcomes for young people and their families:

1.

Harness the expert voice of experience to improve transitional care.

Hannah's video creates some direct calls to action based on her and her peers' experiences.

These are:

- just ask me what is important to me and don't be afraid of the answer;
- we need respite and short breaks;
- it shouldn't be so difficult to get the help and support we need;
- there are inequalities in support and help that need to be understood and addressed.

It is recommended that work with the 'expert voices' of young people with lived experiences of 'transitional care' **continues and grows**. This isn't a small or easy undertaking to do well, and ensure that '**presence**' includes diversity of voices e.g. for those who have cognitive impairment. It is clear that young adults want help to make their voices heard in the circles that matter, to directly influence and input into discussions with care providers and decision makers. However, for each interaction it is important that there is clarity about the purpose and desired outcome, as well as influence and flexibility to run with the good ideas that emerge. Ensuring young adults with life-limiting illnesses are heard well also requires a safe space, as their experiences may have a strong emotional context.

2.

Encourage and support adult hospices to do more to support young people through transition.

The above recommendation dovetails into an apparently simple recommendation to address the challenge of: '**we need '*pull*' from adult hospices**'. This could provide a strong focal point to support transitional care for individuals, and in identifying and resolving gaps in services. There is a need to develop skills and confidence for staff working in adult hospices to care for a very different type of patient, and solutions to address the wide geographic variance in knowledge and resources. Hospices may need to form coalitions in geographical areas, making connections with partner hospices, 'expert voices' and other stakeholders, and potentially working with Integrated Care Systems in England, Health and Care boards in Scotland and Wales and Health and Social Care Trusts in Northern Ireland. Understanding who is currently receiving children's hospice care (or could receive children's hospice care), their chronological and development age, is one important starting point.

3.

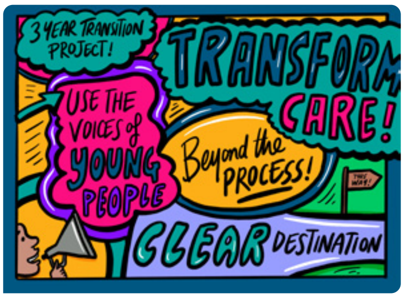
Discover more about who is missing out on care so that we can tackle unequal access.

At a basic level, many adult hospices and other services don’t know how many children and young people in their catchment area may need care now or in the future. Hospices need support to improve their access to this information, as well as their use of information technology, which varies significantly across the sector. In addition, being able to collect and analyse equality, diversity and inclusion data is crucial to informing person-centred care and identifying opportunities to improve equity of access for young people who may be missing out. This will require action to be proactive in seeking consent from young people to share their experiences and insights, and, where necessary, to anonymise individual data to analyse gaps and inform actions.

4.

Continue the Transition ECHO hubs and National Transition Network to realise their full potential.

The National Transition Network and the associated communication bulletin is an important vehicle for hospices and palliative care providers to exchange learning, ideas and provide a mechanism for peer support for those who are professional transition co-ordinators. The Transition ECHO hubs and networks are part of the collective action and need to be supported for at least another year to realise their full potential. A forum to facilitate learning across the hubs and emergent leaders from within the network to exchange learning may accelerate progress and enable curious and confident distributed leadership for change. All networks benefit from an ‘evaluation mind-set’ with the aim of continuous improvement to achieve their shared purpose. A part of being curious and confident is understanding if and how ECHO networks can be embedded as part of everyday working practice.



5.

Make sure that local health and care systems consider the needs of young people in transition to adult services.

Health and care planning decisions are now devolved to a more local level. It is important that hospices champion the needs of young people in transition to adult services as part of system-level priorities and plans. This will need hospices to have a good understanding of how to influence local systems, and the framework for transitional care that exists in national policy and guidance, so that they can encourage local health and care systems to take action.

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Appendix 1: Programme Logic Model

Aim to improve 'care outcomes for young people [with complex and life-limiting conditions] (and their families) when they are transitioning from children's to adults' services, thus improving their quality of life.

Situation/need

'In the UK at least 49,000 children and young people are living with a complex and life-limiting condition - however there are only 15 paediatric palliative care consultants to support them.

Children's hospices are crying out for solutions to the seemingly intractable problems young adults and their families face when transferring from paediatric to adult palliative care services.

Both Hospice UK and Together for Short Lives share responsibility for supporting children's hospices around the UK and we have worked closely with the charity for over a decade on various projects.'

Inputs

- Training three regional hospices to become ECHO hubs.
- Transitions Partnership Manager recruitment and support.
- The National Transition Network for young people with life-limiting illnesses.
- Transitions ECHO Community of Practice.
- Co-production and co-design with young people with experience of transition.

Outputs

- 12 community based Transition ECHO Networks, each hosting up to 10 meetings annually.
- Quarterly Newsletters.
- Online resources.
- Online forum for young people.
- New learning shared through guidelines and recommendations.

Outcomes

Improved care outcomes for young people (and their families) when they are Transitioning from Children's to adult services, thus improving their quality of life.

Empower the voices of young people affected, and enable them to have more control over their futures.

Put **young people at the heart** of the Transitions process and provide them with a platform to influence change, in partnership with care providers and key stakeholders.

Project ECHO approach incorporated into **everyday working practice**.

Proposed measures:

- Number of Transition ECHO Hubs trained in different regions of England
- Number of ECHO Networks set up
- Number of virtual ECHO Group meetings held per Network
- Number of heath professionals engaged in the Community of Practice
- Number of non-medical stakeholders engaged in the project
- Number of young people/ families engaged with the project
- Number of different resources (e.g. videos/ guides) produced for professionals and families

Appendix 2: Overview of Project ECHO™

Project ECHO™ (Extension of Community Healthcare Outcomes) is a 'distance education model' in which people from multiple disciplines come together as a group to address a common issue or achieve a common goal.

It was originally developed in the USA in 2003 as a method of treating people with hepatitis C in underserved and hard to reach populations[23]. Project ECHO has developed into a unique learning and peer-mentoring programme that exponentially increases capacity to provide high quality, specialist health care for patients in a community setting.

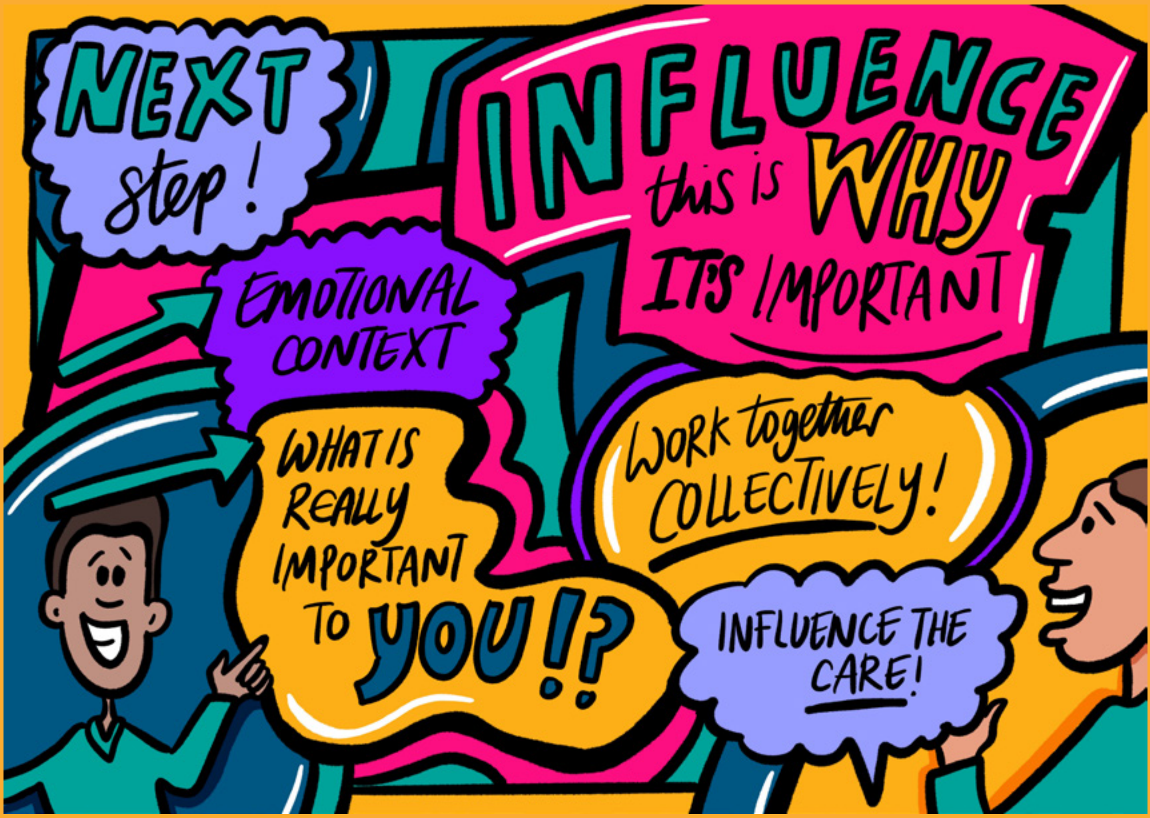
Over a series of carefully planned and facilitated virtual meetings, the group meet for case-based learning; sharing knowledge and expertise in a safe and non-hierarchical learning environment. The end result is better clinical decision making and ultimately a change in the way in which services are delivered.

At its heart is the 'hub-and-spoke' knowledge sharing model in which everyone is a teacher and a learner. The topics discussed in each Network are decided in advance by group consensus. Expertise is then shared across the Network during the virtual ECHO meetings.

Each 90 minute meeting is assisted by a trained facilitator and includes 20-30 minute teaching by the selected topic experts, anonymised patient case presentations from operational teams, best practice presentations and facilitated discussion, with IT and administration support provided by dedicated personnel.

This methodology has been shown to improve the confidence of healthcare professionals in their ability to care for people; better patient-centred decision making, peer-learning and group working.

Since its launch in 2003, the Project ECHO approach is now operating in 21 countries world-wide covering over 55 complex conditions including: cardiology, dementia care, endocrinology, ophthalmology, bone health, addiction treatment, rheumatology, and palliative care. Where Project ECHO has been introduced, waiting times to see a specialist have been dramatically reduced and health outcomes improved. There is more evidence of its impact24 and learning about how to build a successful network[35].



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