York Health Economics Consortium

TOGETHER FOR SHORT LIVES

Economic Case Studies for Projects Funded Through the Improving Transitions for Young People Fund

Final Report

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Executive Summary

1. INTRODUCTION

Together for Short Lives (TfSL) is a UK charity for children's palliative care. In 2017, TfSL launched a funding programme called The Improving Transitions for Young People Fund. The fund supported 10 innovative projects which focussed on encouraging co-ordination between services and engagement with care professionals for young adults aged 14 to 25 years with a life-limiting or life-threatening condition, and their families. York Health Economics Consortium (YHEC) was commissioned to conduct an economic analysis of four of the projects involved in the Fund. The four projects included in the analysis were:

- Transforming transition experiences of young people in Suffolk (St Elizabeth Hospice).
- Transition Hubs (Tŷ Hafan – Hospice for children in Wales).
- Engaging GPs, Improving Outcomes (St Oswald's Hospice, Newcastle-upon-Tyne).
- Pathways Clinic (Royal Devon and Exeter NHS Foundation Trust).

The economic analysis produced an individual case study for each project, which includes a comparison of costs and outcomes of the project, and also considers the wider benefits of the services provided which are not quantifiable in economic terms. YHEC worked with the four projects over the course of the implementation period (2019 to 2021) to design and make use of the quantitative and qualitative data collection methods to inform the project analyses. The input costs associated with the project interventions were calculated using recognised unit costs, such as the Unit Costs of Health and Social Care.[1] The annual costs were calculated based on the reported inputs in the first year, costed at 2021 prices, to represent the opportunity cost to the local health economy. For each case study, a threshold analysis was conducted, to determine the point at which the intervention would be cost neutral to the local health economy.

2. SERVICE MODELS AND OUTCOMES

All four projects included bespoke services, designed to improve young people's transition experience to adult services in their local area. There were, however, some common features across the service models with regard to the approach taken and the input resources required. These were proactive co-ordination of care, a multi-disciplinary approach, opportunities for young people and families to share experiences and gain mutual support, plus training and information for health and social care staff.

While the implementation and evaluation of the projects was affected by the Covid-19 pandemic, all four projects have been able to demonstrate benefits from the new service models. These are described in detail in the individual case studies.

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[1] PSSRU: Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK.

The common themes were as follows:

- Improved co-ordination of care, identifying and responding to unmet needs of young people and their families.
- Increased satisfaction with services and awareness amongst families of the services available to support them.
- Improved wellbeing for young people (e.g. sharing common experiences with others) and their families (e.g. alleviating the stress of caring roles, preparation for bereavement).
- Improved multi-disciplinary working amongst health and care professionals involved in the young person’s care and positive feedback from health and care staff about the support provided to them by the project teams.
- Reduction in duplication of effort from staff, both in the same and also across different organisations.
- Increased familiarity with the adult hospices and staff teams, with positive comments about the likelihood of using hospices instead of hospital in the future.
- Examples of reduced use of health services by young people and their families, due to awareness of alternatives or reduced need.

3. ECONOMIC ANALYSIS

The four case studies in Sections 4 to 7 describe in detail the input resources used to deliver each project. The average annual cost per project, based on the resources used in the first year, was £49,492. The average project grant allocated by TfSL was the equivalent of £46,047 per year, so the TfSL grants more or less offset the annual costs of implementing the projects. The time periods over which the funding was granted varied from 18 to 30 months. The resources required to deliver the projects included items such as transition co-ordinator/nurse roles, clinic venues and activities, administration and project management. The economic outcomes reported include improved health and wellbeing of young people and their families, changes in healthcare and social care service use and service efficiencies. While it was not possible to measure the extent of improved wellbeing of young people and their families in terms of quality adjusted life years (QALYs) gained, the qualitative evaluation provided some evidence of these benefits. In the UK, interventions with an incremental cost effectiveness ratio of less than £20,000 per QALY are generally considered to be cost effective.[2] At an average annual cost of £49,492, the average project would need to generate approximately 2.5 QALY’s per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be ‘cost-effective’.

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[2] National Institute for Health and Care Excellence. The principles that guide the development of NICE guidance and standards. [Accessed 8.4.2022 at: https://www.nice.org.uk/about/who-we-are/our-principles].

All four projects aimed to reduce the use of health and social care services in some way, either by reducing duplication and workload for statutory services in the area, or by improving the health of the young people and their families, so that their need for services was reduced. There was some evidence from expert clinician views on what might have occurred in the absence of the transition services. This included some examples of avoided use of health services by young people and their families, which may contribute to offsetting the cost of the project to local health economies. As there was limited quantitative data to provide evidence of this impact, a threshold analysis was performed for each case study, to provide decision makers with an understanding of the resource use that would need to be avoided per year if the interventions were to be cost neutral, while at the same time improving the overall quality of care for young people. This shows that for service use with a high unit cost, such as admissions to hospital for this patient group (£8,946), only six would need to be prevented across the cohort per year for the transitions project to be cost neutral to local health economies. For service use of lower unit value, such as a consultant paediatrician appointment (£224), a much higher number (221) would need to be avoided.

4. CONCLUSION

The four projects included in this report aimed to improve the experience of young people with life limiting conditions as they transition to adult care services. There were also wider benefits to families in relation to the provision of holistic care and support for caring roles. While the implementation and evaluation of the TfSL funded projects was affected by the Covid-19 pandemic, all four projects have been able to demonstrate benefits from the new service models. The cost consequence analysis has found that these are relatively low cost interventions, which apparently generate substantial benefits for patients and families. Furthermore, there is the potential that some of the project cost could be offset by reductions in resource use elsewhere in the health and social care system, although it was not possible to demonstrate this using robust quantitative methods. The fact that all four of the projects have been successful in making the case locally for their continuation suggests that their contribution to improving the care of young people with life limiting conditions has been recognised. There were limitations to the analysis as described in Section 8.2.

Acknowledgements

YHEC would like to thank the four project leads for their assistance providing data for the analysis and the staff at Together for Short Lives for their guidance on the topic of transition for young people with life limiting conditions.

1 Introduction

Together for Short Lives (TfSL) is a UK charity for children's palliative care. The charity supports families caring for seriously ill children and seeks to build a strong and sustainable children's palliative care sector. Medical advances mean that the number of young people with life-limiting conditions is increasing. However, a lack of co-ordination between children's and adult services, and an absence of tailored support mean that these young people often move to adult services without appropriate arrangements in place.[3]

In 2017, TfSL launched a funding programme called The Improving Transitions for Young People Fund. The fund supported innovative projects which focussed on encouraging co-ordination between services and engagement with care professionals for young adults aged 14 to 25 years with a life-limiting or life-threatening condition, and their families. £790,000 was available, and 10 projects were funded to try to address problems facing many young adults who are seriously ill, when they need to transition to adult services.[4]

In addition to the evaluation that each of the funded projects was required to undertake, TfSL commissioned York Health Economics Consortium (YHEC) to conduct economic analysis for four of the projects involved in the Fund. The projects included in the economic analysis were as follows:

- Transforming transition experiences of young people in Suffolk (St Elizabeth Hospice) – the project aimed to improve the transition experience of young people in Suffolk through the provision of additional resources and enabling increased partnership working by bringing organisations together.

- Transition Hubs (Tŷ Hafan – Hospice for children in Wales) – the project aimed to provide a holistic one-stop point of contact where young adults could be supported to transition their palliative care from paediatrics to adults and receive advice and support.

- Engaging GPs, Improving Outcomes (St Oswald's Hospice, Newcastle-upon-Tyne) – the project aimed to develop and test services and systems which will enable GPs to confidently provide support in their local communities for young adults with palliative care needs. It also aimed to improve young adults' confidence in and willingness to engage with their GP.

- Pathways Clinic (Royal Devon and Exeter NHS Foundation Trust) – the project was a continuation of a multi-agency 'team around the person' model facilitated by a Transition to Adult Care carousel clinic.

The aim of the analysis was to pragmatically evaluate the economic costs and benefits of the projects, to determine the cost consequences of each project. The economic analysis produced an individual case study for each included project, which includes a comparison of costs and outcomes compared to 'standard of care', and also considers the wider benefits of the services provided which are not quantifiable in economic terms.

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[3] Together for Short Lives. Evaluation of Together for Short Lives 'Improving Transition for Young People Programme. February 2022.

[4] Improving Transitions for Young People Fund Round Two.

2 Methods

2.1 Data Acquisition

An initial review was carried out of all 10 TfSL funded projects in 2019, to ensure that the four suggested projects were the most amenable for economic analysis. We conducted a desk-top review of the information available, to assess whether the projects' scope and evaluation plans had the potential to generate data which could be used in the economic analysis. The project leads were then sent an economic analysis framework to complete. The aim of the analysis framework was to describe how the intervention was expected to lead to the proposed outcomes (theory of change), the data on costs and outcomes that would be available for analysis, and any evidence or literature which may be useful.

Following the completion of the analysis framework by the project leads, interviews were held with each project site to discuss their plans for collecting data on the costs, benefits and numbers of young people and families involved in each project. Any additional methods for acquiring data for the economic evaluation were proposed at this stage, so that data acquisition plans could be integrated into the project analyses and additional methods undertaken if necessary.

The data required for the economic evaluation was as follows:

- Costs: including project funding and health care resource use/costs.
- Benefits: including evidence of changes in health care resource use; improvements in outcomes and wellbeing for young people with life-limiting conditions; and improvements in wellbeing for carers and families.
- Uptake: including numbers of young people and carers/families receiving the interventions provided through the projects.

The project teams developed evaluation plans to observe whether the service was achieving the proposed benefits. Evaluation methods included both qualitative and quantitative approaches, including questionnaires and surveys to staff and service users, development of case studies and collection of service use and clinical data. While each project used their own bespoke data collection methods, there were some common approaches taken to collecting data on the use of services, and the health and wellbeing of young people and their families, as shown in Table 2.1.

Table 2.1: Data collection methods

Outcomes	Data collection methods
Health and social care service use	Clinical audit, system data (e.g. events in SystmOne), user feedback
Health & wellbeing	Clinician view on avoided treatment / admission / polypharmacy
Service efficiencies	Staff feedback
Outcomes	Patient narrative histories

Having discussed the data framework with the project teams in the initial stages, we continued to engage with the projects as they progressed, particularly throughout the Covid-19 pandemic. The projects supplied data on an on-going basis, and towards the end of 2021, the project teams provided any final data collected, plus their final evaluation reports.

2.2 Economic Analysis

For each project, a case study was developed, describing the input costs, the outcomes and an economic analysis. The input costs associated with the project interventions were calculated using recognised unit costs, such as the Unit Costs of Health and Social Care.[5] The annual costs were calculated based on the reported inputs in the first year, costed at 2021 prices, to represent the opportunity cost to the local health economy. This means they may not reflect exactly the costs recorded in the TfSL project documentation. The reported outcomes associated with any health and social care resource use were monetised, also using recognised national sources. These were valued at 2021 prices, to reflect the value of outcomes in the most recent financial year.

For each case study, a threshold analysis was conducted, to determine the point at which the intervention would be cost neutral to the health economy. The analyses made use of both quantitative and qualitative data provided by the projects.

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[5] PSSRU: Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK.

3 Summary Results

3.1 Service Models

All four projects included bespoke services, designed to improve young people's transition experience to adult services in their local area. There were, however, some common features across the service models with regard to the approach taken and the input resources required.

All of the interventions were designed to optimise the use of the wider multi-disciplinary team in the young person's care. In two cases this was supported by providing a 'one-stop shop' clinic approach, so young people and their families could meet with a range of health and social care professionals on the same day, in one venue. Another key feature was care co-ordination and overview of care. Two projects recruited new 'co-ordinator' roles, and for the two other projects, the co-ordination of care transition was implicit in the role of the key professionals driving the projects. Another common feature was the proactive approach, seeking information about the family's needs, how well needs were currently being met and endeavouring to meet these needs before a crisis occurred. In parallel with this, anticipatory care planning was used, to prepare in advance for situations such as the deterioration of the young person's health, or wishes for end of life care. Three of the projects provided forums for young people to come together and means for them connecting with each other which could be continued without the involvement of the project teams, such as via social media. All projects incorporated tools, guidance and training for staff, both for palliative care specialists (e.g. adult hospice staff) and generalist roles (e.g. GPs), to support them to tailor their care to the needs of young adults.

Not surprisingly the input resources needed to deliver the project features described above were also similar across the projects. Examples of the type of expenditure that the funding was used for were:

- Transition co-ordinator/nurse role.
- Administration/support worker.
- Clinicians' time and other professionals (some included in core roles).
- Venues and activities for workshops/hubs e.g. complimentary therapies.
- Project management.
- Facilitating resources e.g. phone, laptop.

3.2 Project Outcomes

The proposed outcomes resulting from the projects fell into three main categories: improved health and wellbeing of young people and their families; changes in healthcare and social care service use; and service efficiencies. Examples of each category are shown in Table 3.1.

Table 3.1: Examples of project outcomes

Category	Project outcome
Health & wellbeing	Improved health and wellbeing for children/young people and their families Fewer crises Ability of parents to work Improved experience of services, including at end of life
Healthcare and social care service use	Number of contacts with health care professionals (HCPs) e.g. consultant, GP A&E attendances Hospital admissions (unplanned), needing high level of care Length of hospital stay Treatment for anxiety & depression for family members
Service efficiencies	Saved contact time by using multi-disciplinary or group settings Avoided appointments as needs are met in other ways

At the outset of the projects, it was acknowledged that demonstrating quantitative changes such as improved health status or changes in service use would be challenging. Only one project collected data on a comparator group, using hospital data from a sample of young people transitioning to adult services in a period before the new service was introduced. Methods such as follow up surveys and case studies were used to seek evidence of the impacts of the new services. Unfortunately, the Covid-19 pandemic affected both project delivery and evaluation activity, with some project staff being re-deployed into other roles for a time, and some of the planned evaluation activities being curtailed, given the pressure on staff and services during this time. Furthermore, a health function tool used by St Oswald’s Hospice was useful for identifying needs, but did not work as expected for the purpose of monitoring changes in patient outcomes.

Nevertheless, all four projects were able to complete evaluations reporting on the outcomes of the services provided. These are described in detail in the individual case studies. The common themes were as follows:

- Improved co-ordination of care, identifying and responding to unmet needs of young people and their families.
- Increased satisfaction with services and awareness amongst families of the services available to support them.
- Improved wellbeing for young people (e.g. sharing common experiences with others) and their families (e.g. alleviating the stress of caring roles, preparation for bereavement).
- Improved multi-disciplinary working amongst health and care professionals involved in the young person’s care and positive feedback from health and care staff about the support provided to them by the project teams.
- Reduction in duplication of effort from staff, both in the same and also across different organisations.
- Increased familiarity with the adult hospices and staff teams, with positive comments about the likelihood of using hospices instead of hospital in the future.
- Examples of reduced use of health services by young people and their families, due to awareness of alternatives or reduced need.

3.3 Economic Analysis

The four case studies describe the input resources used to deliver each project, costed at 2021 prices, using recognised national sources of unit costs. The total annual cost for each project and the average for the four projects can be seen in Table 3.2. This includes the cost of the services provided and also any other costs incurred as a consequence of the project, such as input for project management. The average annual cost to the local health economy was £49,492 in the first year. Costs in subsequent years may be lower, as new ways of working become embedded, the need for project management reduces and new equipment is required only at the outset of the project. The average project grant allocated by TfSL was the equivalent of £46,047 per year, so the TfSL grants more or less offset the annual costs of implementing the projects. The time periods over which the funding was granted varied from 18 to 30 months.

Table 3.2: Average cost of TfSL funded projects

TfSL project	Annual cost	TfSL grant (equivalent per year)
St Elizabeth Hospice: Transforming Transition Experiences for Young People in Suffolk	£42,634	£41,388
Ty Hafan: Transition Hubs	£56,884	£41,472
St Oswald's Hospice: Engaging GPs, Improving Outcomes	£46,685	£44,400
Royal Devon & Exeter NHS Foundation Trust: Pathways Clinic	£51,763	£56,928
Average	**£49,492**	**£46,047**

The service evaluations have found that these are relatively low cost interventions which apparently generate substantial benefits for young people and their families. One approach to valuing these benefits is to consider the potential to improve quality of life, as measured by a quality adjust life year, or QALY. While it was not possible to measure the extent of improved wellbeing of young people and their families in terms of QALYs gained, the qualitative evaluation provided some evidence of these benefits. In the UK, interventions with an incremental cost effectiveness ratio of less than £20,000 per QALY are generally considered to be cost effective. At an average annual cost of £49,492, the average project would need to generate approximately 2.5 QALY's per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be 'cost-effective'.

All four projects aimed to reduce the use of health and social care services in some way, either by reducing duplication and workload for other services in the area, or by improving the health of the young people and their families, so that their need for services was reduced. There was limited quantitative data to demonstrate this impact, although feedback from clinicians provided some anecdotal evidence. In the absence of robust data on avoided health and social care service use, a threshold analysis was performed for each case study, to provide decision makers with an understanding of the resource that would need to be avoided if the interventions were to be cost neutral, while at the same time improving the overall quality of care for young people.

Table 3.3 shows the unit costs of the types of services included in the case studies. Table 3.4 shows the results of the threshold analysis against the average annual project cost, for a range of different service use. This shows that for service use with a high unit cost, such as admissions to hospital for this patient group (£8,946), only six would need to be prevented across the cohort per year for the transitions project to be cost neutral, while also improving the quality of care for young people and their families. For service use of lower unit value, such as a consultant paediatrician appointment (£224), a much higher number (221) would need to be avoided.

Table 3.3: Unit costs and sources

Resource use	Unit cost	Source
GP appointment	£39	PSSRU 2021
Hospital outpatient appointment	£212	PSSRU 2019: Outpatient, medical specialist palliative care attendance (adults and children)
Admission to hospital	£8,946	PSSRU 2015. Weighted average of Short illness trajectory 75% (cancer and cystic fibrosis) and Longer life illness trajectory 25% (cystic fibrosis)
Bed days	£303	PSSRU 2021. Specialist palliative care for children, average cost per bed day. Hospital specialist palliative care support
Local authority respite bed nights	£327	PSSRU 2018 short break provision for disabled children and their families, mean cost £310 per residential child night (24-hour period), uprated to 2019
Consultant paediatrician appointment	£224	PSSRU 2021 Paediatric consultant-led outpatient attendance
A&E attendance (Type 1 only)	£213	National Cost Collection 2019/20: Weighted average of Type 01 attendances
A&E attendance (All Types)	£182	National Cost Collection 2019/20: Weighted average of all A&E Types attendances
Hospice stay per night	£1,209	PSSRU 2015. Respite care at hospice for child with multiple disabilities. 15 days per year at £16,233. Uprated to 2021.
Productivity (average half-time weekly wage)	£281	Median gross weekly earnings for full-time adults working in Wales were £562.8 in April 2021. https://gov.wales/annual-survey-hours-and-earnings-2021
Invasive treatments	£1,653	National Schedule of NHS Costs 19-20. Other Respiratory Disorders with Single Intervention, with CC Score 0-4
Treatment in primary care for anxiety and depression	£132	PSSRU 2021: GP visit: 3 visits at £39 each. (One year's prescription costs for escitalopram tabs 10mg per day (BNF, 2021) 10mg per day, 28 tabs is £1.22 (£14.64 per year) Drug tariff price

Table 3.4: Threshold analysis against average project cost

Item	Unit cost	No. per year needed to be cost neutral
Admission to hospital	£8,946	6
Hospital bed days	£303	163
Invasive treatment	£1,653	30
Hospital outpatient appointment	£212	233
Consultant paediatrician appointment	£224	221
GP appointments	£39	1269
A&E attendance	£182	272
Hospice stay per night	£1,209	41
Local authority respite bed night	£327	151
Treatment for anxiety & depression	£132	375
Average half-time weekly wage in Wales	£281	176

4 St Elizabeth Hospice: Transforming Transition Experiences for Young People in Suffolk

4.1 Background

St Elizabeth Hospice is an adult hospice which has a dedicated focus on transition for young people in Suffolk aged 14 years upwards. The hospice was awarded £103,471 from Together for Short Lives (TfSL) between 1 November 2018 to 30 April 2021. The funding was to pilot a co-ordination role, working proactively with young people from 14 to 19 years to improve their readiness for transition. The project comprised:

- A multi-agency transition key worker/coordination role - enabling better care packages to be established, including day care and short breaks plus better access to the adult hospice.
- New transition tools and guidelines e.g. Bridging the Gap and Stepping Up framework, transition checklist and a care transfer document.
- Training and workshops for young people and families - covering common topics in a group setting.

St Elizabeth Hospice has been developing service provision for transition (the Zest service) since 2015, working closely with East Anglia Children's Hospice (EACH) and Ipswich Hospital for young people aged 14 to 19, pro-actively encouraging and enabling young adults to have a smooth transition into adult care.[6,7] The new co-ordination role was intended to enhance the existing service provision for transition already in place at the Hospice, working in a multi-disciplinary (MDT) way across the children's hospice, the Continuing Healthcare Team (Ipswich and East Suffolk CCG), Ipswich Hospital (East Suffolk and North Essex Foundation Trust), Suffolk County Council (Disabled Children & Young People's Services), the Neuromuscular Advisory Service and Suffolk Integrated Community Paediatric Service.

The Transition Coordinator was recruited for 22.5 hours/week, along with a Support Worker who could do delegated work in support of the Co-ordinator. Between July 2019 to July 2021, 43 young people were supported, 11 of whom had particularly focussed work, taking more time than some of the other young people. The average age was 23 (range 15-42 years). 21% of the patients using the service were aged between 14 to 18 years and the remaining 70% of patients were 19 years plus. [8]

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[6] https://www.stelizabethhospice.org.uk/zest/ accessed 4 January 2022.

[7] TfSL Improving Transitions for Young People Application Form. St Elizabeth's final bid.

[8] ZEST service review – quantitative analysis, February 2022.

The proposed benefits of the service for the young people and their families were improved overall care, removing previously reported themes of abandonment and 'falling off a cliff edge,[9] and ultimately leading to improved health and wellbeing and reduced stress amongst young people and their parents/carers. It was hoped there would also be increased confidence and greater uptake of the adult hospice as a positive place to receive care.

For healthcare professionals and organisations, there were several proposed benefits:

- A reduction in contacts from families for transition related issues not relevant to their role.
- Fewer and shorter contacts, due to a more efficient way of working.
- A clearer understanding of the transition process, through MDT working and the use of tools and guidelines.
- Reduced stress for staff wanting, but being unable, to support young people through transition.
- Reduced use of other health and social care services due to improved health and wellbeing of young people and their families.

The project team developed evaluation plans to collect data over the course of the project, in order to observe whether the service was achieving these benefits. These included a range of questionnaires for organisational and service leads, and also for families, at baseline, and after the service had been introduced. While some of these methods were deployed at the commencement of the project, the Covid-19 pandemic disrupted the ability of the project team to conduct the evaluation as intended. Furthermore, some activities ceased during the lockdown period, and young people remained under the care of the paediatric service and the children's hospice for longer than would usually be the case. The Transition Coordinator was required to return to their nursing role within St Elizabeth Hospice for a time, and was unable to work directly with families, who were shielding.[10]

Despite this, the service successfully worked with a number of families during the TfSL funding period, and a service evaluation of the Zest service was commissioned from the University of Suffolk by St. Elizabeth hospice, to obtain the views on the service from service users, stakeholders and service providers. YHEC liaised with the evaluation team to include questions relevant to the economic evaluation in the interview schedules, such as: how long staff spent supporting each young person in transition (including face-to-face/telephone contacts and non-contact time); the type of staff involved; whether they had noticed a change in the amount of time spent, or any reduction in duplication of tasks, since the Transition Co-ordinator role has been in place; and perceived benefits of the service. Questions for families focused on their perceived benefits of the service; their use of other services with and without access to the Transition Co-ordinator and whether it had helped alleviate any concerns or stress.

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[9] Analysis Framework. Transforming Transition Experiences. August 2019.

[10] March 2020 Transition Update Internal: Impact of COVID-19 on the IT4YP Pilots.

The following cost consequence analysis is based on a synthesis of the data available from the sources described, along with intelligence collected from the project lead within St. Elizabeth hospice. Any assumptions are clearly stated.

4.2 Input Costs

The input costs for the service included project management resource and the staffing costs for the Transition Co-ordinator and Support Worker. At project inception the intention was for the Transition Co-ordinator role to be 0.6 whole time equivalent (wte) Agenda for Change (AfC) Band 6. As the role developed however, there was considerable overlap with other functions at the hospice. Following implementation, the time devoted to the Transition Co-ordinator role was estimated by the staff involved to be 0.4 wte. The Support Worker was a 0.2 wte at AfC Band 3. Project development and project management was costed as one day per month for a senior manager in the hospice, estimated to be equivalent to an AfC Band 8a.

Using recognised sources of unit costs, the estimated on-going costs to the health economy to provide the management and staff involved in the service for one year are £42,634, as shown in Table 4.1. The TfSL grant was £103,471 for 30 months, equivalent to £3,449 per month, or £41,388 per year.

Table 4.1: Annual costs of the Transition Co-ordinator service

Item	Agenda for Change band	Annual cost	WTE	Total annual cost
Transition Co-ordinator	6	£80,590[a]	0.4	**£32,236**
Administrator	3	£24,396[b]	0.2	**£4,879**
Senior manager	8a	£110,377[a]	0.05	**£5,519**
Total				**£42,634**

Sources:
a) Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK. (Hospital based nurses).
b) NHS Employers. Annual pay scales 2021/22 https://www.nhsemployers.org/articles/annual-pay-scales-202122 (hourly rate has been estimated based on annual salary assuming 20% on-costs and 1573 workable hours annually). Band 3 basic pay in 2020 £20,330.

4.3 Outcomes

The proposed benefits of the Transition Co-ordinator service were improved wellbeing for young people and their families, a reduction in workload for staff involved in transition support, a reduction in duplicated work, plus the potential to reduce the use of other healthcare services.

4.3.1 Services supporting young people in transition

Three healthcare organisations provided baseline data on how much time was spent with families providing support for transition to adult services. There was an average of 13 young people supported per year (range 4 to 24). The average length of face-to-face (F2F) and telephone contacts was 60 minutes and 10 minutes respectively. Taking the averages across the responses, the findings from the questionnaires are shown in Table 4.2.

Table 4.2: Average responses from professional baseline questionnaires

Item	Average
Number F2F contacts per young person per year (average of 60 minutes each)	7 contacts
Number of telephone contacts per young person per year (average of 10 minutes each)	28
Grade of staff involved in these appointment (range: AfC Band 5 to 7)	Band 6
Grade of staff doing administration	Band 3
Average non-contact time per year (making arrangements etc) - unclear if this is clinical or administration. Assume 50/50 Band 3 and Band 6.	24 hours
Proportion of workload that could potentially be removed by the Transition Co-ordinator role (range 25%-50%)	38%

These questionnaire respondents proposed that there was the potential for 25% to 50% of their workload to be removed by the Transition Co-ordinator role. Responses to the Zest evaluation interviews with stakeholders and service providers (excluding the Zest team) also confirmed that the service was saving time for some staff, and reducing duplication. This wasn't consistently the case, however, with some saying that time spent working with families might increase, because the transition co-ordination work was identifying gaps and providing a better quality service for young people and their families. A sample of interview responses to questions on 'time spent' and 'duplication' are below:

- Yes, can save social worker time.
- In some cases, causes additional work as gaps are highlighted.
- Now spends time on planning transitions when wasn't before.
- Has helped co-ordinate – takes tasks from other staff and from families.
- Helps with more complex patients but not the less complex ones (biggest cohort).
- Yes - more to talk about with Zest starting up.
- Yes – probably a reduction.
- Reduced in some areas of work and increased in others.
- At start was additional duplication but now less.
- Unclear if families contacting for support was reducing the workload for other staff or if it just filled a gap.
- Slight reduction in duplication, which expect would increase further if role continues.
- Expect it should as when there is a query they can go straight to them rather than several other people.

4.3.2 Other benefits

The project aim was to improve co-ordination of transition and lead to improved wellbeing of young people and their families. The Zest evaluation questioned stakeholders and service providers about their perceived benefits of the service, who gave the following responses:

- Enabling young people to have the best life that they can.
- It is about maximising quality of life.
- Provides a gentler pathway to transition to adult services.
- Reduces the risk of possible gaps in services as they transfer over.
- Smoother transition and information sharing.
- Help with planning and providing information on young person's lives such as options for post-18 education.
- Saves staff time.
- Saves families time, alleviates need for parents to co-ordinate.
- Reduces duplication.
- Social aspect is beneficial for young people. Also gives parents a break. Provides psychological support.
- Social opportunity for YP.

The Zest evaluation also interviewed service users, who responded that they viewed the service as 'somewhere safe', giving families confidence and respite, and the staff were well trained to handle issues and give information on what support is available. Families described navigating the various health and social care services 'like treading through treacle' and often gave up due to the repetition of explaining their young adult's needs or due to the amount of paperwork. Most described the Zest service as their 'lifeline' and the 'light at the end of a very dark tunnel' but wished it could be developed further to provide more services. The Transition Co-ordinator provided psychosocial and wellbeing support, such as helping families liaise with continuing healthcare services, where interactions had previously proved challenging. Families also benefited from the proactive information sharing and peer support gained through the support groups and workshops, encouraging a positive self-management model.[11]

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[11] Correspondence with Project Lead at St Elizabeth's Hospice, July 2021.

The ability of better quality care to improve the health and wellbeing of young people and their families, and therefore reduce demand for health and social care services elsewhere, was highlighted as a potential benefit of the service. It was acknowledged however, that use of some services may increase, as improved co-ordination of care may identify unmet need. It was not possible to measure the use of health and social care services by young people and their families, to provide any evidence of changes in their use of these services before and after access to the transition service, so we have conducted a threshold analysis below. Some examples of services that are reported to be used by young people with life limiting conditions are as follows:

- GP appointments.
- Hospital outpatient appointment.
- Admission to hospital.
- Bed days.
- Local authority respite bed nights.

4.4 Economic Analysis

4.4.1 Value of avoided staff resource

There appears to be evidence from the evaluation findings that the workload for some health and social care staff can be reduced by the presence of the Transition Co-ordinator role. Using the two sources of baseline data shown in Table 4.2, we estimate that the average value of staff support provided for transition, for an average of 13 young people per year, before the Transition Co-ordinator role, is between £18,639 and £22,644, as shown in Table 4.3. If 38% of the reported workload per organisation providing care for young adults could be replaced by the presence of the Transition Co-ordinator role, this is a value of between £6,980 and £8,605 per year per organisation. It is important to note that these values are averages across a range of responding organisations and roles and are illustrative only.

Table 4.3: Average value of contact time for transition per year for an average of 13 young people

Source	Item	Unit cost	Cost per young person	Total cost per year (all contacts)
Baseline questionnaires	F2F contacts for 13 young people (7 contacts of 60 minutes per year, AfC Band 6)	£51 per 60 minute contact	£357	£4,641
	Telephone contacts for 13 young people (28 calls of 10 minutes per year, AfC Band 6)	£9 per call	£252	£3,276
	Administration for1 13 young people (24 hours at 50/50 AfC Band 3 and AfC Band 6)	£51 per hour (Band 6) £16 per hour (Band 3)	£804	£10,452
	Total value of support per year		**£1,413**	**£18,639**
	38% reduction in total value per year for 13 young people			**£6,980 (low estimate)**
Evaluation interviews*	**Time on transition (average of 37 hours per month across various providers – assuming AfC Band 6)**	**£51 (Band 6)**	**N/A***	**£22,644**
	38% reduction in total value per year			**£8,605 (high estimate)**

* Number of young people supported not specified.

4.4.2 Threshold analyses

As the likelihood of reducing service duplication and/or avoiding other health and social care service use is challenging to measure, we have conducted a threshold analysis on these two aspects. This estimates the number of these proposed outcomes that would need to be achieved for the service to offset some of the costs to the health economy overall.

Table 4.4 shows a threshold analysis with a range of scenarios for how many organisations would need to reduce staff workload to the extent shown, in order for the cost of the Transition Co-ordinator service to be cost neutral. This uses the low and high value estimates of time spent on transition (Table 4.3) along with the low, average and high estimates of the amount of that time that could be replaced by the Transition Co-ordinator role. This shows that a minimum of four organisations would need to reduce staff workload to the extent shown each year, in order for the Transition Co-ordinator service to be cost neutral.

Table 4.4: Number of organisations with workload to be reduced for the Transition Co-ordinator service to be cost neutral to the health economy

Item	Value	Number needed to be cost neutral
Cost of Transition Co-ordinator service per year	£42,634	
Low estimated value of staff time (£6,980) plus low proportion avoided (25%)	£4,592	9
High estimated value of staff time (£8,605) plus low proportion avoided (25%)	£5,661	8
Low estimated value of staff time (£6,980) plus average proportion avoided (38%)	£6,980	6
High estimated value of staff time (£8,605) plus average proportion avoided (38%)	£8,605	5
Low estimated value of staff time (£6,980) plus high proportion avoided (50%)	£9,185	5
High estimated value of staff time (£8,605) plus high proportion avoided (50%)	£11,322	4

Table 4.5 shows the threshold analysis for avoidable health and social care service use. The service with the greatest unit cost is an unplanned admission to hospital (£8,946). At a cost of £42,634 per year, the Transition Co-ordinator service would need to result in relatively few avoided admissions (five) for the service to be cost neutral. The lower value items (such as a local authority respite bed night), would need to see a sizeable reduction in demand to cover the cost of the service. In reality, the benefits of the Transition Co-ordinator are more likely to accrue across a range of different health and social care services.

Table 4.5: Health and social care resources to be avoided for the TfSL service to be cost neutral to the health economy

Health & social care resource	Unit cost	Source	Number avoided per year to be cost neutral
GP appointment	£39	PSSRU 2021 GP appointment 9.22 minutes average	1,093
Hospital outpatient appointment	£212	PSSRU 2019: Outpatient, medical specialist palliative care attendance (adults and children). Uprated to 2021.	201
Admission to hospital	£8,946	PSSRU 2015. Weighted average of Short illness trajectory 75% (cancer and cystic fibrosis) and Longer life illness trajectory 25% (cystic fibrosis). Uprated to 2021	5
Hospital bed days	£303	PSSRU 2021. SPECIALIST Palliative care for children, average cost per bed day. Hospital specialist palliative care support	141
Local authority respite bed nights	£327	PSSRU 2018 short break provision for disabled children and their families, mean cost £310 per residential child night (24-hour period). Uprated to 2021.	130

In reality, an economic evaluation looks not just to establish the extent of costs which need to be offset, but also at the value of the actual benefits for young people and their families. While it was not possible to measure the extent of improved wellbeing of young people and their families in terms of quality adjusted life years (QALYs) gained, the qualitative evaluation provided some evidence of these benefits. In the UK, interventions with an incremental cost effectiveness ratio of less than £20,000 per QALY are generally considered to be cost effective. At an annual cost of £42,634, the project would need to generate approximately 2.1 QALY's per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be 'cost-effective'.

4.5 Conclusion

The funding provided by TfSL has supported the introduction of a co-ordination role, to improve the care and support for young people in Suffolk during their transition to adult services. The service, which was originally intended to support young people aged 14 to 19 years, has also worked with those over 19 years, due to their previously poor experience of transition. The Transition Co-ordinator role has now been integrated into the Zest service at St Elizabeth Hospice, and the postholder provides training and support to the wider staff group, which should be of benefit to the broader caseload.[12]

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[12] Correspondence with Project Lead at St Elizabeth's Hospice, January 2022.

The estimated cost of the service model was found to be £42,634 per year, at 2021 prices. Evaluating the economic impact of the service was challenging, due in part to the complex health system within which the service operates, but also due to the effect of the Covid-19 pandemic on the planned evaluation activities. Nevertheless, there is evidence that the service has generated benefits, both to health and social care staff, and the young people and families with whom they work.

This analysis supports the assertion that the transition co-ordination service can reduce duplication of effort and reduce workload for both clinical and support staff across the multi-disciplinary team. An average of 38% of the workload of other staff/organisations was thought to be removed by the service, at a value of between £6,980 and £8,605 per year per organisation. It should be acknowledged that the improved co-ordination achieved by the service may also lead to increased demand on other services, as a consequence of identifying previously unmet need.

While the findings of the qualitative evaluation found that the service improved the health and wellbeing of young people and their families, there was no quantitative data to demonstrate that the service led to reduced demand on services as a consequence of this. The prevention of service use elsewhere is both difficult to measure and to attribute directly to the existence of the Transition Co-ordination service. The lack of robust evidence for this outcome does not, however, imply that it cannot be achieved. If this were to be the case, the relatively low annual cost of the Transition service means that only five hospital admissions per year, at an average cost for this patient group, would need to be avoided for the service to be cost neutral overall. Health and social care use of lower cost, such as hospital outpatient appointments, would need to be avoided in larger numbers. Nevertheless, the combined activities to evaluate the service show that it has improved the transition experience and give better quality care for young people and their families, at a relatively low cost per year to the health economy, with the potential for some cost offsetting in other service use.

5 Ty Hafan: Transition Hubs

5.1 Background

Tŷ Hafan is a Welsh children's charity offering a range of holistic palliative care services to children with life-limiting conditions, along with their families.[13] The hospice was awarded £62,200 from Together for Short Lives (TfSL) between 1 November 2018 to 31 May 2020. The funding was for the roll out of the Transition Hubs service, a one-stop point of contact within a local adult hospice, to support young adults with a life limiting or life threatening condition to transition their palliative care from paediatrics to adults care and receive the advice and support needed. The Transition Hub service was facilitated by a Transition Nurse and comprised:

- Joint clinics and joined up working across adult and paediatric clinicians.
- Symptom management, with clinicians able to prescribe on-site.
- Implementation of a 'Traffic Light tool' to provide essential information for acute admissions and to ensure young person's holistic needs are understood.
- End of life planning.
- Ability to access complementary therapies.
- Welfare benefit support, carers support and legal advice.
- Employment and education advice.
- Social opportunities, social media/Facebook group to enable ongoing peer support.
- Home visits to offer reassurance and support to help build confidence to access the Hubs.
- Lead consultant for follow-up and referral, plus support to establish links with other health, social care and education professionals.
- Support for admission to adult hospital wards (Transition Nurse).
- Coordinated study sessions, skills and professional development for staff.

The Hubs were developed across four geographical areas, with a Hub clinic taking place every three months in each area. Young people and their families were invited to attend, without requiring an appointment or allocated attendance time, so this intentionally did not feel like a hospital appointment.

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[13] TfSL Improving Transitions for Young People Application Form. Ty Hafan Hospice for children in Wales.

The Transition Nurse was appointed in January 2020 and over the 18 months of the project, 11 of the 15 planned Hubs were delivered. A total of 71 young people were supported during project period, with 33 (46%) aged under 18 years at time of the interventions and 38 (54%) being over 18 years, of whom 9 were aged over 25 years. There was a total of 768 interventions, giving an average of 11 interventions per family, ranging from 1 intervention to as many as 37 interventions per family throughout the project period. The Covid-19 pandemic affected the ability to deliver some of the planned activities, and for a time much of the support became virtual, with the Transition Nurse working from home to support young people remotely and promoting the use of via social media.

The proposed benefits of the service for the young people were improved overall care from multi-disciplinary (MDT) services, having appropriate services in place to meet their needs before leaving the paediatric palliative care service. The proactive planning of care and the involvement of the Transition Nurse where appropriate was anticipated to prevent avoidable deterioration of young people’s health, and the consequent need for health and social service interventions, such as inadequate symptom management leading to an acute hospital admission. The project team hoped to achieve an enduring legacy of informal communities for the young people involved, and of communities of practice for the professionals with little experience of young people in this care group.

The project team developed evaluation plans to collect data over the course of the project, in order to observe whether the service was achieving these benefits. These included quantitative and qualitative methods, such as monitoring interventions, the development of qualitative case studies to capture user experience and the use of healthcare, plus questionnaires to attendees at the Hubs, and evaluation of the staff training. The ability of the project team to conduct all of the evaluation methods was hampered by the Covid-19 pandemic. However, the project lead and Transition Nurse have been able to provide feedback from the Hub attendees and five case studies to illustrate the nature and impact of the service.

The following cost consequence analysis is based on a synthesis of the data available from the sources described, along with intelligence collected from the project lead at Tŷ Hafan. Any assumptions are clearly stated.

5.2 Input Costs

The input costs for the service included the employment of the Transition Nurse and an administrator, plus senior management support.[14] There were also costs associated with the Hubs and organising social opportunities for young people. There were no additional costs for staff involved in the Hubs, as their time was integrated into their roles caring for the young people, albeit in a different setting.[15]

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[14] Analysis Framework. Ty Hafan Transition Hubs. August 2019.

[15] Together for Short Lives Transition Awards Programme. FINAL PROJECT REPORT. Ty Hafan Hospice. December 2020.

Based on the final project budget adjusted for monthly spend,[16] and using recognised sources of unit costs, the estimated on-going costs to the health economy of the staff and activities for one year is £56,884, as shown in Table 5.1. The TfSL grant was £62,200 for 18 months, equivalent to £3,456 per month, or £41,472 per year.

Table 5.1: Annual costs of the Transition Hubs service

Item	Agenda for Change Band	Annual Cost	WTE	Total Annal Cost
Transition Co-ordinator	6	£80,590[a]	0.6	£48,354
Administrator	3	£24,396[b]	0.03	£732
Clinical supervision (shared with Ty Hafan)				£450
Management support @ 14%				£4,555
Travel expenses (staff £600 and young people £133)				£733
Hub refreshments				£167
Social opportunities				£1,333
Mobile phone				£360
Resources and information				£200
Total				**£56,884**

Sources:
a) Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK. (Hospital based nurses).
b) NHS Employers. Annual pay scales 2021/22 https://www.nhsemployers.org/articles/annual-pay-scales-202122 (hourly rate has been estimated based on annual salary assuming 20% on-costs and 1573 workable hours annually). Band 3 basic pay in 2020 £20,330.

5.3 Outcomes

The proposed benefits of the service were improved wellbeing for young people and their families, the prevention of avoidable deterioration of young people's health, and the potential to reduce the use of other healthcare services, such as admissions to hospital.

5.3.1 Use of services

While quantitative data on the use of different health services by young people and their families was not available on a cohort basis, five case studies have given examples of the types of health services that are typically used by young people with health needs and the potential impact on avoided service use resulting from the Transition Hub service. The types of service/ resource use outcomes described in the case studies are as follows:

- Prevented admission to hospital.
- Reduced length of hospital stay.
- Fewer invasive treatments for respiratory distress, due to following an end of life care plan.
- Reduction in time of staff on ward required for providing care and medical interventions.

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[16] 210106 Ty Hafan Final Budget.

- Reduced need for GP appointments.
- Reduced medication for anxiety and depression.
- Ability for parents to return to work (reduced benefits claims).
- Access to respite services enabling parents to maintain their caring role.

In some cases, where hospital admissions to adult wards have been difficult, (requiring additional staff time to calm the young person, support the family and undertake additional tests), the involvement of the Transition Nurse, coupled with the proactive planning of care passports and traffic light documents, has supported ward staff who are often unfamiliar with the specific needs of this group of young people. This reportedly resulted in quicker treatment planning and potentially shortened admissions.[17]

One case study described how the young person felt more 'confident in his new team' and has continued to engage with them. His mum highlighted that 'being under the care of the adult palliative care team' has made a significant difference to her support network and the ability to get help when she needs it, easing access to GP consultations or prescription advice. One family reported that a year on from receiving the initial input from the Transition Hub service, this has helped the young person's overall health and they now seek GP advice less than previously.

Table 5.2 shows the number of interventions and time spent by the Transition Nurse in each case study, and the reported benefits in terms of use of other services. The average number of interventions per case was 10, over 15 hours, giving an average of 1.5 hours per intervention.

Table 5.2: Number of Transition Nurse interventions and impact on use of services

Case study	Number of nurse interventions	Number of nursing hours	Impact on other resources
A	12	16	Reduced length of hospital stay. Reduced need for staff on adult ward to spend time calming and intervening with the young person.
B	6	8	Reduced need for GP appointments.
C	9	17	Fewer invasive treatments during hospital admission. Parent reduced medication for anxiety and depression and returned to work part-time.
D	17	26*	Prevented hospital admission. *This young person also received 7 hours consultant input and a 2 night stay in the hospice.
E	6	9	Parents able to maintain their caring role
Average	**10**	**15**	

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[17] Together for Short Lives Transition Awards Programme. FINAL PROJECT REPORT. Ty Hafan Hospice. December 2020.

5.3.2 User experience

The shared questionnaires to attendees at the Hubs have provided the following examples of feedback from young people and parents (summarised, not verbatim): [18]

- The range of support is great, brilliant to be able to get symptom management advice in a friendly setting but also have access to benefits advice …. The massage was a lovely touch (parent).
- It was great to be able to talk to someone who understood and didn't make me feel embarrassed about my continence issues. The advice has really helped me feel more confident about going out (young person).
- I didn't really think there was much for me to do when I left school but I realise there are opportunities out there (young person).
- The contact in between is fab it really helps us feel included and the social media pages have helped make new friends (parent).
- I really look forward to the Hub – I like the company and the chance to have a chat with people (young person).
- Coming to the adult hospice has been helpful, it is not like I expected it to be and I feel more confident now in case we should ever need to use it in the future (parent).
- Hadn't realised how anxious I was about '*young person's'* deterioration and thinking about what we wanted for his future care. Having the chance to think about end of life care planning with professionals that understood was really helpful (parent).
- So glad we came and that you convinced '*young person'* to give it a go as this is the first time he has been out of the house in months (parent).

In one case study, a young man and his parent found the Hub experience empowering and decided to brave a first visit to the hospice, generating the following feedback:

> *"First visit to Tŷ Hafan this week. First time in 5 years we have been in a swimming pool with G and first time in 5 years that I have spent the week just being his mum not his nurse, physio, carer etc…… The support we have had is tremendous. We have made wonderful friends and laughed till our stomachs hurt. Thank you all for giving us a break that we so desperately needed"*

Following this the family attended a further Hub and mum received some benefits advice whilst there. This, alongside the family feeling more confident and empowered, led mum to feel ready to go back to work after a long period off sick and concentrating on being G's carer. She identified that realising there is support to help G and the family, and that there were others in similar situations, helped her feel ready to get some normalisation into family life.

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[18] 211228 Transition qualitative feedback data for YHEC,

Feedback from another parent was as follows:

> *"The Hub is my lifeline as a mother of a child with a life-limiting condition; I don't know what I would do without them. Having everything in one place has made it so much easier for us".*

5.4 Economic Analysis

As there was little quantitative data available to monitor the impact of the service on the use of healthcare services, a threshold analysis has been performed. This considers the metrics thought to potentially be impacted by the service (e.g. unplanned admissions to hospital, bed days, GP appointments), and the amount of resource use that would need to be avoided for the TfSL funded service to offset some of the costs to the health economy overall. The opportunity cost of the health and social care resources mentioned, and the results of the threshold analysis are shown in Table 5.3.

Table 5.3: Health and social care resources to be avoided for the Transition Hubs service to be cost neutral to the health economy

Healthcare resource	Unit cost	Source	Number avoided per year to be cost neutral
Admission to hospital	£8,946	PSSRU 2015. Weighted average of Short illness trajectory 75% (cancer and cystic fibrosis) and Longer life illness trajectory 25% (cystic fibrosis). Uprated to 2021	6
Hospital bed days	£303	PSSRU 2021. SPECIALIST Palliative care for children, average cost per bed day. Hospital specialist palliative care support	188
Invasive treatment for respiratory distress	£1,653	National Schedule of NHS Costs 19-20. Other Respiratory Disorders with Single Intervention, with CC Score 0-4	34
GP appointment	£39	PSSRU 2021 GP appointment 9.22 minutes average	1,459
Treatment for anxiety & depression	£132	'PSSRU 2021: GP visit: 3 visits at £39 each. (Number of GP consultations based on: Scottish primary care consultations for depression https://www.isdscotland.org/Health-Topics/General-Practice/GP-Consultations/Health-Conditions/Depression. One year's prescription costs for escitalopram tabs 10mg per day (BNF, 2021) 10mg per day, 28 tabs is £1.22 (£14.64 per year) Drug tariff price	431
Ability to return to work	£281	Assume return to work half-time. Median gross weekly earnings for full-time adults working in Wales were £562.8 in April 2021. https://gov.wales/annual-survey-hours-and-earnings-2021	202

This shows that if the improved care resulting from the Transition Hubs service were able to prevent an unplanned admission to hospital, only six of these per year would need to be prevented for the service to effectively cover its costs within the health economy. Lower cost resources, such as hospital bed days and treatment for anxiety and depression would need to be reduced considerably to achieve a cost neutral position. In reality, the benefits of the Transition Hubs service are likely to accrue across a range of different health and social care services.

Another illustrative threshold analysis has been performed on the five case studies, where the input of the Transition nurse led to a proposed reduction in use of healthcare services. The cost of one hour of the Transition Nurse time at AfC Band 6 is assumed to be £51.[19] Table 5.4 shows the number of relevant resources that would need to be avoided in each case for the Transition Nurse time to be cost neutral to the health economy (using the unit costs in Table 5.3).

Table 5.4: Health and social care resources to be avoided for the Transition Nurse input to be cost neutral

Case study	Transition Nurse Input		Healthcare resources avoided to be cost neutral	
	Number of Hours	**Cost**	**Description**	**Number in cohort**
A	16	£816	Reduced length of hospital stay (days)	3
B	8	£408	Reduced need for GP appointments	10
C	17	£867	Fewer invasive treatments during hospital admission.	1
			Parent reduced medication for anxiety and depression	7
			Parent returned to work part-time	3
D	26*	£1,326	Prevented hospital admission *Also includes 7 hours consultant input (£861) and a 2 night stay in the hospice (£2,418). Total cost: £4,605.	0.5
E	9	£459	Parents able to maintain their caring role	N/A
Average	**15**	£765		

In reality, an economic evaluation looks not just to establish the extent of costs which need to be offset, but also at the value of the actual benefits for young people and their families. While it was not possible to measure the extent of improved wellbeing of young people and their families in terms of quality adjusted life years (QALYs) gained, the qualitative evaluation provided some evidence of these benefits. In the UK, interventions with an incremental cost effectiveness ratio of less than £20,000 per QALY are generally considered to be cost effective. At an estimated annual cost of £56,884, the project would need to generate approximately 2.8 QALY's per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be 'cost-effective'.

5.5 Conclusion

The funding provided by TfSL has supported the introduction of a Transition Hub service, working in partnership between Tŷ Hafan children's hospice and the adult hospices in four areas of Wales. The service has become embedded into the business-as-usual work of these hospices, and the main additional resource needed to ensure the Hubs run smoothly is the Transition Nurse role. This post also has a wider role supporting work with the growing cohort of young people moving from paediatric palliative care to adult care. The study skills sessions to the adult staff team involved in the care of young people has contributed to increased knowledge and confidence in managing the palliative care of life limited young people.

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[19] Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK. (Hospital based nurses).

The post has now been funded as a substantive full-time post by Tŷ Hafan, and will continue to facilitate Transition Hubs with the existing, and any newly interested, adult hospices across the south, east and west Wales area.[20]

The estimated overall cost of the service model to the health economy was found to be £56,884 per year, at 2021 prices. The evaluation activities undertaken by the team found evidence of benefit to young people and their families, and also to the services providing their care. The MDT approach forged new relationships between families and services, increasing their confidence in and likelihood of using services to support their care, and enabling them to take a proactive approach to addressing their health needs. Examples of beneficial impacts of this included improved care from the GP and a parent being able to return to work.

An evolving element of the project was the support provided by the Transition Nurse for young people requiring a hospital admission, for both planned and emergency admissions. The relationships developed at the Hubs has led to increased confidence of families to reach out to the Transition Nurse for support during acute admissions.

While there was no quantitative data to demonstrate that the service led to reduced demand on services, the qualitative data collected in the case studies provide examples of where the service has contributed to prevented or shortened admissions, avoidance of expensive and invasive treatments, and reduced need for treatments for anxiety and depression.[21] At an annual cost of £56,884, only six hospital admissions per year, at an average cost for this patient group, would need to be avoided for the Transition Hub service to be cost neutral overall to the health economy. Health and social care use of lower unit cost, such as hospital bed days or treatment for anxiety and depression, would need to be avoided in larger numbers to achieve a cost neutral position. Such healthcare avoided would not necessarily be cash releasing, rather it would contribute towards freeing up capacity for other service users. Nevertheless, the evaluation and this analysis found evidence that the service has improved care for young people and their families, at a relatively low cost per year to the health economy, with the potential for some cost offsetting in other service use.

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[20] Together for Short Lives Transition Awards Programme. FINAL PROJECT REPORT. Ty Hafan Hospice. December 2020.

[21] 211228 Transition qualitative data for YHEC.

6 St Oswald's Hospice: Engaging GPs, Improving Outcomes

6.1 Background

St Oswald's Hospice is a charitable organisation based in the North East of England, providing specialist care for adults, young people, babies and children with life limiting conditions.[22] Services include an adult inpatient unit, adult day care and outpatients, specialist short breaks and end of life care for children and young adults.[23] The hospice was awarded £110,896 from TfSL between 1 November 2018 to 30 April 2021, to develop and test systems to enable GPs to confidently provide transition support for young adults with palliative care needs in their local communities.

The key components of the service were:

- An annual outpatient multi-disciplinary team (MDT) assessment at St Oswald's Hospice for North East young adults who have palliative care needs, followed by collaborative work with each patient's GP to agree a plan of action.
- Health care planning for every young adult to be regularly reviewed/discussed with their GP.
- Education and information sessions for North East GPs.

The TfSL funded service was launched in April 2019 and was led and managed by the Consultant in Palliative Medicine at the hospice, supported by the Social Care Lead for the Children and Young Adult Service. Nursing care at each clinic was provided by members of the adult palliative care nursing team and a learning disability nurse from the Children and Young Adult team.[24] Initially the plans were for the service to work with young people aged 16 to 25 years with neurodegenerative conditions or other neuro-disability, with a view to possibly extending the referral criteria to include young people with other palliative conditions at a future date. Any professional group was able to refer to the service, via letter or phone call.

There were 13 referrals to the service, with the majority of referrals coming from either paediatricians, adult physicians or through St Oswald's Hospice.[25] Those referred were between the ages of 17 and 29 years. The higher age of the referrals was considered by the project team to be indicative of transition issues not being tackled well at the time of transition, and therefore enduring a number of years into adulthood.

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[22] St Oswald's Hospice. Trustees' Annual Report and Financial Statements for the year ended 31 March 2020.

[23] TfSL Improving Transitions for Young People Application Form. St Oswald's final bid.

[24] St Oswald's bid – Schedule 2.

[25] St Oswald's Hospice. Improving Transitions for Young People Engaging GPs: Improving Outcomes. Final Evaluation 2020.

The team identified unmet needs in all domains (health, social care, education, employment and housing etc.), although the main emphasis was on health.[26] The social worker provided ongoing needs-led care and support throughout the duration of the contact and beyond as required. The consultant played a central role in the intervention, operating as co-ordinator of a network of specialists, in conjunction with the local GP.

The aim of the service was to improve the young adults' confidence in and willingness to engage with their GP about their health needs and care.[27] The proposition was that improved engagement with and care from the patient's GP would improve the management of their condition, reduce consequent health crises, and lead to reduced demand on services such as unplanned admissions to hospital.[28]

The project team developed evaluation plans to collect data over the course of the project, in order to observe whether the service was achieving these benefits. Evaluation methods included a survey questionnaire for referring GPs and focus groups for patients and parents, extraction of clinical data and case note review. Also suggested was a narrative history of patient/family-identified needs, priorities and health-related events between each attendance.

As engagement with the service was initially slow, the number of families engaged at the start of the Covid-19 pandemic was lower than anticipated. Due to the further inhibiting effect of the pandemic, the TfSL funded service was ceased in August 2020. The remaining TfSL funds were devoted to commissioning an evaluation.[29] This evaluation used mixed methods, stakeholder interviews and comments from phone calls with patients/families, to take any lessons from the project and make recommendations for the future.[30] The clinical activity of the consultant lead continued, however, with one session subsequently included in the consultant's job plan on an on-going basis. The social worker funding was not continued, so the multi-disciplinary element of the service was not formalised. At the time of writing, the take-up of the service with the consultant was reportedly increasing.

The following cost consequence analysis is based on a synthesis of the data available from the evaluation report, along with intelligence collected from the clinical lead. The threshold analysis undertaken considers the implications of both the original planned MDT approach and also the ongoing service model provided by the consultant only model. Any assumptions are clearly stated.

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[26] St Oswald's Hospice. Improving Transitions for Young People Engaging GPs: Improving Outcomes. Final Evaluation 2020.

[27] Analysis Framework. Engaging GPs, Improving Outcomes. August 2019.

[28] Analysis Framework. Engaging GPs, Improving Outcomes. August 2019.

[29] Evaluation conducted by Barefoot Research and Evaluation.

[30] St Oswald's Hospice. Engaging GPs: Improving Outcomes. Learning and Recommendations for other services. 2020.

6.2 Input Costs

The input costs of the multi-disciplinary service included the Consultant in Palliative Medicine, plus input by the social worker and nurse. Using recognised sources of unit costs, the estimated overall costs of these roles for one year are £46,685, as shown in Table 6.1. The TfSL grant was £110,986 for 30 months, equivalent to £3,700 per month, or £44,400 per year. The ongoing scaled down service model, based on one session per week of a Consultant in Palliative Medicine only, is assumed to be £22,651 i.e. just the cost of the consultant session.

Table 6.1: Annual costs of the Engaging GPs, Improving Outcomes service

Role	Grade	Annual cost[a]	WTE	Total annual cost
Consultant in Palliative Medicine	Consultant	£226,505	0.1	£22,651
Social worker	Social worker	£79,163	0.1	£7,916
Nurse	AfC Band 6	£80,590	0.2	£16,118
Total				**£46,685**

Source:

a) Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK. (Hospital based nurses).

6.3 Outcomes

The proposed benefits of the service were improved multi-disciplinary working, improved management of the young person's condition, with a reduction in the use of other healthcare resources as a result, such as admission to hospital and GP attendances.

6.3.1 Use of healthcare resources

Although it is recognised that some admissions to hospital are appropriate, it was speculated by the clinical lead that improved health status, advanced care planning and improved knowledge and confidence of non-specialist clinicians, would increase the potential for a young person to be cared for at home, rather than be admitted to hospital.[31] This assertion was supported by the evaluation, which found that prior to the project, the approach to care was generally reactive, dealing with young people's health crises as they occurred. After the introduction of the service, there was an increased focus on preventative interventions, with the team using their specialist knowledge to intervene before situations escalated.[32] Due to the small numbers of patients involved in the service before it ceased in 2020, it was not possible to draw any meaningful conclusions from service use data. From discussion with the hospital staff involved in the young people's care, the clinical lead concluded that there was no evidence that the hospital admissions that did occur could have been managed in the community rather than in hospital.

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[31] St Oswald's Hospice. Engaging GPs: Improving Outcomes. Learning and Recommendations for other services. 2020.

[32] St Oswald's Hospice. Improving Transitions for Young People Engaging GPs: Improving Outcomes. Final Evaluation 2020.

Before commencement of the project, the number of GP appointments was a metric of interest. It was viewed that improved engagement with the GP might result in a shift of consultations from the hospital based consultant paediatrician, to the GP. Conversely, improved management of health conditions might reduce the need to consult healthcare professionals at all. There were however, no data available on the use of GP appointments and paediatricians by those referred to the service. The patient feedback to the clinical lead indicated that there was little change to consulting behaviour, with patients who already trusted and used their GP continuing to use them in a similar way, and those that did not, continuing to find support from specialist teams. It was concluded that a larger group of patients over a longer timeline would be needed to detect any shift in this type of healthcare use.[33]

6.3.2 Patient outcomes

The evaluation found that all patients who attended were keen to come again and remained positive about the service. The holistic approach to the young person's assessment identified additional needs and in particular highlighted the patient's own priorities.[34] The evaluation also reported positive mental health benefits for the young people and their families in terms of preparation for dying and pre-bereavement support.

A health function tool which measures health status using a traffic light approach was used in the first consultant appointments with the young people. This was found to be useful to screen for the level of need, and families used it as a tool in the MDT to explain the complexities of their child's care. However, while it was thought that the tool may be a way of monitoring changes, it was found to be less helpful in follow up appointments for this purpose.

6.3.3 Multi-disciplinary working

While multi-disciplinary working was a core feature of the service, the clinical lead was keen to stress that the team was 'part' of the young person's care, and any improvement in the patients' care experience was also due to the wider team involved, supported by clinical advice and education from the project MDT. The clinical lead observed this improved care in practice, exemplified by one case, where the referring GP managed the care of a young person with increasing symptoms who died unexpectedly, but their experience of care was a good experience managed well by the GP. In another example, the MDT service was actually not needed to intervene to support the GP at all. That being said, the evaluation found that the service has also provided an effective central co-ordinating role.[35]

As well as upskilling GPs, a further positive benefit was increased professional awareness of hospice as an alternative to hospital, with examples of a healthcare professionals proactively referring to the hospice where previously a hospital admission was viewed to have been likely.[36]

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[33] Correspondence with Clinical Lead, June 2021.

[34] St Oswald's Hospice. Improving Transitions for Young People Engaging GPs: Improving Outcomes. Final Evaluation 2020.

[35] St Oswald's Hospice. Improving Transitions for Young People Engaging GPs: Improving Outcomes. Final Evaluation 2020.

[36] Correspondence with Clinical Lead, June 2021.

The evaluation found that the project has created a professional peer support structure that can be accessed by medical teams affected by transition-related issues.[37] Although the TfSL funding has ceased, the Consultant in Palliative Medicine continues to work proactively in a multi-disciplinary way and has become involved in wider MDT meetings as a direct consequence of the TfSL project.

6.4 Economic Analysis

As there was no quantitative data available to monitor the impact of the service on the use of healthcare services, there was no robust evidence that the service can directly lead to reduced demand on other health care. A threshold analysis has been performed, which considers the metrics thought to potentially be impacted by the service (unplanned admissions to hospital, paediatrician appointments and GP appointments), and the amount of resource use that would need to be avoided for the TfSL funded service to offset some of the costs to the health economy overall.

The cost of the two service models (MDT and consultant only) per year is as follows:

Cost of service per year (MDT)	£46,685
Cost of consultant only	£22,651

The opportunity cost of the healthcare resources mentioned, and the results of the threshold analysis are shown in Table 6.2. This shows that if the improved care provided during transition were able to prevent unplanned admissions to hospital, only five of these would need to be prevented for the service to be cost neutral to the health economy. For healthcare resources with a lower unit cost, such as GP and paediatrician appointments, considerably more would need to be avoided to achieve a cost neutral position.

Table 6.2: Healthcare resources to be avoided for the TfSL service to be cost neutral

Healthcare resource	Cost	Source	Number avoided per year to be cost neutral	
			MDT	Consultant only
GP appointment	£39	PSSRU 2021[a] GP appointment 9.22 minutes average	1,197	581
Admission to hospital	£8,946	PSSRU 2015. Weighted average of Short illness trajectory 75% (cancer and cystic fibrosis) and Longer life illness trajectory 25% (cystic fibrosis). Uprated to 2021	5	3
Bed days	£303	PSSRU 2021. SPECIALIST Palliative care for children, average cost per bed day. Hospital specialist palliative care support	154	75
Consultant paediatrician appointment	£224	PSSRU 2021 Paediatric consultant-led outpatient attendance	208	101

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[37] St Oswald's Hospice. Engaging GPs: Improving Outcomes. Learning and Recommendations for other services. 2020.

In reality, an economic evaluation looks not just to establish the extent of costs which need to be offset, but also at the value of the actual benefits for young people and their families. While it was not possible to measure the extent of improved wellbeing of young people and their families in terms of quality adjusted life years (QALYs) gained, the qualitative evaluation provided some evidence of these benefits. In the UK, interventions with an incremental cost effectiveness ratio of less than £20,000 per QALY are generally considered to be cost effective. At an estimated annual cost of £46,685, the project would need to generate approximately 2.3 QALY's per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be 'cost-effective'.

6.5 Conclusion

The Engaging GPs: Improving Outcomes project funded by TfSL was set up to improve the support for GPs to provide appropriate transition support for young people, with the aim of improving health and wellbeing, as well as having positive impacts on healthcare service use. The estimated cost of the MDT service model was found to be £46,685 per year, at 2021 prices.

As the project ended prematurely, the planned evaluation methods did not yield the data hoped for. However, a commissioned evaluation found a number of non-monetiseable benefits, as the service positively impacted on other professionals and added value to existing provision. There was no robust evidence that the service can directly lead to reduced demand on other health care. If this were to be the case, however, the threshold analysis found that only five hospital admissions per year, at an average cost for this patient group, would need to be avoided for the service to be cost neutral overall to the local health economy. A considerable number of GP and/or consultant paediatrician appointments would need to be avoided for the opportunity costs of the service to be covered by avoided healthcare use elsewhere. Such healthcare avoided would not necessarily be cash releasing, rather would contribute towards freeing up capacity for other service users.

One of the main consequences (and benefits) of the service was the improvement in multi-disciplinary working across the range of professionals involved in the care of young people, with them being more aware of each other and of the service provided by the hospice.

Although the TfSL funded project officially ended, the activity of the main health and social care professionals involved continues, exemplified by the one session now included in the Consultant in Palliative Medicine's job plan. As the number of referrals to the consultant increases, a business case may be required to request further funding from commissioners to increase this capacity. Furthermore, the involvement of the consultant role in multi-disciplinary working (such as the cross-service Neurodisability multispecialty team) is considered to be a direct consequence of the TfSL funded project.

7 Royal Devon & Exeter NHS Foundation Trust: Pathways Clinic

7.1 Background

Royal Devon and Exeter NHS Foundation Trust provides acute, specialist and community health and care services in Exeter and across East and Mid-Devon. The Trust was awarded £113,852 from Together for Short Lives (TfSL) between 1 November 2018 to 31 October 2020, for the Pathways Clinic Service.

The service was for young people aged over 16 years with complex medical needs and their families. It involved transferring care of the young person from a paediatrician to a Healthcare for Older People (HFOP) Consultant Physician - roles which are experienced in looking after people with a range of complex needs and in discussing sensitive issues with families, such as palliative care. Their role was to take over the holistic care of the young people, in a similar manner to their paediatrician.

The service model also included a multi-agency, multi-disciplinary "team around the family" model, facilitated by a Transition to Adult Health Care Pathways Clinic. The clinic provided the young person and their family with the opportunity to meet with the professionals and specialists together, so that families could tell their story only once to all the health and social care professionals with relevant expertise.[38]

The service was designed to follow the NICE Guidelines for Transition from Children's to Adults services.[39] The consultations included:

- Changes to medication completed during clinic appointment including Complex Medication regime reconciliation (for reduction of drug errors and discrepancies).
- Opportunities for discussions about advanced care plans, reasonable adjustments, ensuring the young person was on GP Learning Disability and Local Authority Disability registers.
- Parent and/or carer rated scale of concerns for a range of biopsychosocial issues as per the NHS Health, Functioning and Wellbeing Summary Traffic Light Communication Tool.
- Feedback obtained from parents/carers to include confirmation that worries, anxieties or queries have been addressed.

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[38] TfSL Improving Transitions for Young People Application Form. Royal Devon & Exeter final bid.

[39] National Institute for Health and Care Excellence (NICE). Transition from Children's to Adults' Services for Young People Using Health or Social Care Services, Guideline 43. London: National Institute for Health and Care Excellence (NICE); 2016.

The service started in May 2019, and up to March 2020 there were 14 clinics and 39 appointments held (30 new, 9 follow-up). During the Covid-19 pandemic, the face-to-face clinics moved to a virtual arrangement, so they were able to continue the contacts with families which had been established prior to the pandemic. The named consultant and single point of contact for any concerns was continued throughout this period.[40]

The overall aim of the service was to improve holistic care for young people with complex medical needs, with one key clinician co-ordinating proactive rather than reactive care as the young people moved from paediatric to adult healthcare services. This was anticipated to improve management of health needs and prevent escalation of medical conditions to avoidable medical crises, thereby reducing demand on health services such as A&E attendances, hospital admissions, GP appointments, and polypharmacy. While the number of GP attendances were not expected to change, the quality and satisfaction was expected to improve. Furthermore, the improved service and positive impact on the young person's health was anticipated to have positive benefits for parent/carer mental health and wellbeing, potentially impacting on their ability to work if their child was healthy and not experiencing repeated health crises.

The project team developed evaluation plans to collect data on some of these metrics over the course of the project, in order to observe whether the service was achieving these benefits. The plans included using 12 months' activity data on hospital admissions, A&E attendances and Intensive Treatment Unit stays, for both the patient group and a control group (patients who transitioned before the Pathways Clinic was set up and, therefore, did not undergo a managed transition to an adult physician). To gauge the impact on young people's wellbeing, carers were invited to complete the Health, Functioning and Wellbeing Summary as part of their clinic appointment, and again six weeks later. The views on the service of health and social care professionals were obtained from an online staff survey.

The following cost consequence analysis is based on the data available from the evaluation, along with intelligence collected from the clinical lead at Royal Devon and Exeter NHS Foundation Trust. Any assumptions are clearly stated.

7.2 Input Costs

The resources required for the Pathways Clinic service included staffing (paediatric liaison and transition nurse; consultant adult physician; consultant paediatrician; administrator), plus some non-staff costs, such as meeting expenses, hoist and laptop. Based on this, using recognised sources of unit costs, the estimated on-going costs to provide the service for one year are £51,763, as shown in Table 7.1. The TfSL grant was £113,852 for 24 months, equivalent to £4,744 per month, or £56,928 per year.

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[40] Bulwer C, Heslop J, Dunlop J et al. Pathways. Transferring young people with complex needs from a Consultant Paediatrician to a Consultant Adult Physician. Royal Devon and Exeter NHS Foundation Trust/Together for Short Lives. Undated.

Table 7.1: Annual costs of the Pathways Clinic Service

Item	Grade	Annual cost[a]	WTE	Total annual cost
Paediatric Liaison and Transition Nurse	AfC 7	£96,947	0.1	£9,695
Consultant Adult Physician	Consultant	£226,505	0.1	£22,651
Consultant Paediatrician	Consultant	£226,505	0.02	£4,530
Administrator	AfC 4	£50,435	0.2	£10,087
Laptop				£1,000
Hoist				£2,500
Family involvement events				£200
Printing materials				£400
Travel and meeting expenses				£700
Total				**£51,763**

Source:

a) Jones K. and Burns, A (2021) Unit Costs of Health & Social Care 2021. Unit Costs of Health and Social Care. Personal Social Services Research Unit, Kent, UK. (Hospital based nurses).

7.3 Outcomes

The proposed benefits of the Pathways Clinic service were the improved wellbeing for young people, with a consequent reduction in the use of healthcare resources in secondary care. The data collected through the evaluation methods showed the following results.

7.3.1 Use of healthcare resources

Data analysed by the clinical lead were from the 12 month period of 1st May 2019 to 30th April 2020. The intervention group included 30 patients, with an average age of 19.7 years. The comparator group included 13 patients, with an average age of 22.7 years. There was a statistically significant difference in the age of the two groups ($p<0.0001$).

The analysis found no statistically significant difference in the number of A&E attendances, hospital admissions or length of stay between the intervention and comparator groups (p values of 0.2387; 0.6603; 0.3288 respectively). A sub-analysis tested for any differences between patients whose transition was optimal (i.e. a joint meeting before the young person reached 18 years, with the paediatrician and adult physician present) and those where the transition was delayed, so the young person’s care reverted to their GP for a time. This sub-analysis was helpful to take account of those patients who had admissions within the analysis period but prior to attendance at their first Pathways Clinic. There was no statistically significant difference found between these two groups.

With regard to polypharmacy, a benefit of joint Pathways Clinic was the ability to identify where different staff had given different doses of medications. These discrepancies could be discussed and removed to ensure consistent prescribing practice across the MDT.[41]

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[41] Communication from clinical lead, June 2021.

7.3.2 Patient outcomes

The Health, Functioning and Wellbeing scores were completed by carers as part of the first clinic review and again six weeks after the first and second appointments (eight and nine patients respectively). While there were no statistically significant changes in the scores over time, the average number of carers reporting “no concerns” increased over time, whereas the average numbers reporting “some concerns” and “serious concerns” decreased from the first appointment to the second.[42]

Parents/carers attending the clinics said they felt “supported and listened to”, “cared for and safe”, and that their issues and concerns were understood, and helpful solutions suggested.

7.3.3 Clinician views

An online survey of health and social care professionals asked about their experience of the Pathways Clinics, including the estimated time spent attending the clinic, how it compared to the time they would usually spend with young people, and whether it was an effective and efficient way of supporting young people. There were 19 responders between October 2019 and July 2020, from the following staff roles: specialist nurse (7, 36.8%), doctor (4, 21%), dietician (3 (15%), social worker (4, 21%), OT (1, 5%). The responses are shown in Table 7.2.

Table 7.2: Responses to online staff survey

Question	**Average response (n=19)**
Compared to your usual appointment, how much time did today’s appointment take out of your day? (0 = much less time; 50 = about the same; 100 = much more time)	62
How do you think that the overall amount of time you spent working with this patient and the MDT (including e.g. travel, letters and telephone calls) compared with your usual appointments? (0 = much less time; 50 = about the same; 100 = much more time)	54
On a scale of 1 to 100, was your attendance at the Pathways Clinic and effective use of your time? (10= least effective; 100 = most effective)	74
Do you think today’s Pathways Clinic improved multi-disciplinary working? (0 = no; 100 = yes)	96
Do you think that the Pathways Clinic improved patient care? (0 = definitely not; 50 = same level of care; 100 = definitely yes)	89

The responses show that while the clinic took a bit more time on a given day, the overall time spent working with young people and the MDT was much the same as with usual appointments. This suggests that the clinic approach removed some patient contact time from elsewhere in their workload, in order to make time for attendance at the clinic. The respondents thought that it was an effective use of time, improved multi-disciplinary working and improved patient care.

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[42] Bulwer C, Heslop J, Dunlop J et al. Pathways. Transferring young people with complex needs from a Consultant Paediatrician to a Consultant Adult Physician. Royal Devon and Exeter NHS Foundation Trust/Together for Short Lives. Undated.

When asked to mention three things that were good about the clinic, most replied MDT working and communication, plus patient centred care, confidence around transition and clinical excellence. The MDT approach was valued by staff, in particular the presence of a social worker at the clinics. One social worker would attend on behalf of the social work team with all of the necessary information on the cases, and report back to their colleagues. When asked ‘How do you think patient care was improved as a result of today’s Pathway Clinic’, the responses were:

- Robust handover and information sharing within the MDT (12).
- Patient and family centred approach (7).
- Providing a clear route and ongoing support into adult services (8).

7.4 Economic Analysis

As the quantitative data analysis did not show a statistically significant difference in the use of healthcare resources between the Pathways Clinic group and the comparator group, a threshold analysis has been performed. This considers the metrics thought to potentially be impacted by the service (A&E attendances, admissions to hospital, length of hospital stay), and the amount of resource use that would need to be avoided for the Pathways Clinic service to offset some of the costs to the health economy overall. The opportunity cost of the healthcare resources mentioned, and the results of the threshold analysis are shown in Table 7.3.

Table 7.3: Healthcare resources to be avoided for the Transition Clinic service to be cost neutral

Healthcare resource	Unit cost	Source	Number avoided per year to be cost neutral
A&E attendance	£82	National Cost Collection 2019/20: Weighted average of all A&E Types attendances	284
Admission to hospital	£8,946	PSSRU 2015. Weighted average of Short illness trajectory 75% (cancer and cystic fibrosis) and Longer life illness trajectory 25% (cystic fibrosis). Uprated to 2021	6
Hospital bed days	£303	PSSRU 2021. SPECIALIST Palliative care for children, average cost per bed day. Hospital specialist palliative care support [a]	171

While the project evaluation did not find any impact of reduced healthcare use, the analysis shows that if the improved care provided during transition were in fact able to prevent unplanned admissions to hospital, only six of these would need to be prevented for the service to effectively cover its costs to the health economy. Resources with a lower unit cost, such as A&E attendances and bed days, would need to be reduced considerably to achieve a cost neutral position.

In reality, an economic evaluation looks not just to establish the extent of costs which need to be offset, but also at the value of the actual benefits for young people and their families. While it was not possible to measure the extent of improved wellbeing of young people and their families in terms of quality adjusted life years (QALYs) gained, the qualitative evaluation provided some evidence of these benefits. In the UK, interventions with an incremental cost effectiveness ratio of less than £20,000 per QALY are generally considered to be cost effective. At an estimated annual cost of £51,763, the project would need to generate approximately 2.6 QALY's per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be 'cost-effective'.

7.5 Conclusion

The Pathways Clinic project funded by TfSL was set up to provide a co-ordinated transition from paediatrician to adult care physician, coupled with a multi-disciplinary clinic for families to attend. The estimated cost of the service model was found to be £51,763 per year, at 2021 prices. The Pathways Clinic service was designed to meet the gold standard for transition according to NICE guidelines and the service model was viewed by the Trust to be an improvement on the previous approach. A business case to continue the service on a recurring basis was successful.

While clinicians reported that the approach did not save overall time involved in providing care for the young people, there was consensus that the service contributed to improved patient care. The patient Health, Functioning and Wellbeing scores over time suggest that there were positive outcomes for young people and their families, although the changes observed were not statistically significant. Similarly, no statistically significant changes in healthcare use were observed between the intervention and comparator group. The lack of statistical significance may indicate that the number of study subjects in the analysis was too small to show meaningful changes. The project team also acknowledged that some admissions to hospital are appropriate. Furthermore, the young people in the comparator group were statistically significantly older than the intervention group. The project team speculated that perhaps the cases entering the Pathways Clinic service were more complex than those who declined, or who had survived several years beyond transition.[43]

As there was no evidence to show that the service can directly lead to reduced demand on other health care, a threshold analysis was performed to show how much health care would need to be avoided for the service to be cost neutral, while gaining the other non-monetiseable benefits. This found that only six hospital admissions per year, at an average cost for this patient group, would need to be avoided for the service to be cost neutral overall to the local health economy. A much greater number of A&E attendances and hospital bed days would need to be avoided for the opportunity costs of the service to be cost neutral. Any such healthcare avoided would not necessarily be cash releasing, rather would contribute towards freeing up capacity for other service users.

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[43] Communication from clinical lead, June 2021.

One of the main consequences (and benefits) of the service was the quality of patient/family centred care and improved communication between members of the multi-disciplinary team. Parents/carers reported feeling supported, listened to and cared for. Furthermore, the service required families to make fewer visits to hospital for individual consultant appointments, and demonstrated a service model that can also work in a virtual way when required.

8 Discussion

8.1 Key Points

The TfSL Improving Transitions for Young People Fund has supported 10 projects to develop and test new initiatives to improve the experience of young adults with life limiting conditions in their transition to adult services. This report has considered the input costs, outcomes and economic consequences of four of the funded projects. The cost consequence analyses are described in detail in a separate case study for each project, and give an additional perspective to the evaluations conducted or commissioned by each project and by TfSL.

The services funded by TfSL had a number of common features, such as proactive co-ordination of care, a multi-disciplinary approach, opportunities for young people and families to share experiences and gain mutual support, plus training and information for health and care staff. The average annual cost of the services provided, based on the resources used in the first year, was £49,492. This average value of the TfSL grant was £46,047 per year, so the TfSL grants more or less offset the annual costs of implementing the projects. Two of the projects were funded for 30 months, one for 24 months and the other for 18 months. The resources required to deliver the projects included transition co-ordinator/nurse roles, clinic venues and activities, administration and project management support, plus the time of non-project clinicians and therapists.

The evaluation of the projects was affected by the Covid-19 pandemic, which curtailed some of the planned evaluation activities and the ability of stakeholders to respond to requests for feedback and provide data. However, the evaluations conducted by the individual projects and by TfSL found that the services were able to improve the transition experience of services for young people and their families, with services being more tailored to young adults and their needs. The projects improved co-ordination of care, reduced duplication, multi-disciplinary working, and support for staff involved in caring for this patient group. Increased awareness and familiarity with the adult hospices was reported as a particular benefit, increasing the likelihood of families making use of these services as an alternative to hospital. The TfSL evaluation also provided valuable practical lessons for organisations involved in the process of transition with young people and their families.[44]

The projects were able to provide qualitative findings plus some limited quantitative data to inform the cost consequence case studies included in this report. The economic outcomes reported include improved health and wellbeing of young people and their families, changes in healthcare and social care service use and service efficiencies. At an average annual cost of £49,492, each project would need to generate approximately 2.5 QALY's per year across the cohort of beneficiaries, to have achieved the equivalent value in improved quality of life and be considered to be 'cost-effective'.

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[44] Together for Short Lives. Evaluation of Together for Short Lives 'Improving Transition for Young People Programme. February 2022.

There was some evidence from expert clinician views on what might have occurred in the absence of the transition service, although it was not possible to demonstrate this using robust quantitative methods. This included some examples of avoided use of health services by young people and their families, which may contribute to offsetting the cost of the project to local health economies. The threshold analyses provide decision makers with an understanding of the resource that would need to be avoided if the interventions were to be cost neutral, while at the same time improving the overall quality of care for young people. The interventions were delivered at a relatively low annual cost when compared to high value healthcare which they may prevent, such as a hospital admission, with only six hospital admissions on average per year needing to be prevented to avoid the equivalent of the project value. Service use with a lower unit cost, such as hospital outpatient appointments and A&E attendances would need to be prevented in much large numbers per year. While any prevented service use may not lead to cash releasing savings from the perspective of health and social care, it may contribute to relieving service pressures in the system.

As well as the common themes across the case studies, there were some summary findings which were specific to each project, as shown in Table 8.1.

Table 8.1: Summary findings specific to resource use in each project

Project	Summary findings
St Elizabeth's - Transforming Transition Experiences	▪ Evidence to suggest that the Transition Co-ordinator role resulted in reduced tasks for other roles and some reduction in duplication of effort across organisations. ▪ Qualitative evaluation supported the potential to reduce healthcare use.
Ty Hafan - Transition Hubs	▪ Case studies showed evidence of reduced use of health services and improved care. ▪ Transition nurse role in supporting hospital admissions on adult wards was highly valued.
St Oswald's - Engaging GPs	▪ Positive feedback on value of MDT and joint working. ▪ Patient numbers were too small to draw conclusions on healthcare use. ▪ Threshold analysis shows resource needed to be cost neutral for ongoing service model and consultant only model (as the latter has continued).
Royal Devon & Exeter NHS Foundation Trust - Transitions Pathways Clinics	▪ No statistically significant difference in use of healthcare resources when compared with a control group. ▪ Staff reported using about the same amount of time with the young people but viewed the care provided within the time available to be improved compared to before the project.

8.2 Limitation of the Analysis

There were substantial limitations to the analysis, as follows:

- Proposed quantitative data collection methods to measure use of services by young people and their families was not possible, with the exception of the Transitions Pathways Clinics. Information on changes in service use has come mainly from qualitative methods.

- It was not possible to capture quantitative data on changes in mental wellbeing of young people and their families, or the associated use of health and social care resources to treat mental health problems.

- Establishing what would have occurred in the absence of the intervention was not possible in a robust manner. The Transitions Pathways Clinics used a comparator group, although matching the comparator to the intervention group was found to be challenging.

8.3 Conclusion

The four projects included in this report aimed to improve the experience of young people with life limiting conditions as they transition to adult care services. There were also wider benefits to families in relation to the provision of holistic care and support for caring roles. While the implementation and evaluation of the TfSL funded projects was affected by the Covid-19 pandemic, all four projects have been able to demonstrate benefits from the new service models. The cost consequence analysis has found that these are relatively low cost interventions which apparently generate substantial benefits for patients and families. Furthermore, there is the potential that some of the project cost could be offset by reductions in resource use elsewhere in the health and social care system, although it was not possible to demonstrate this using robust quantitative methods. The fact that all four of the projects have been successful in making the case locally for their continuation suggests that their contribution to improving the care of young people with life limiting conditions has been recognised.