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CHILDREN'S HOSPICES ACROSS SCOTLAND

Economic Evaluation of Hospice Services

Final Report

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Contents

Executive Summary

1. INTRODUCTION

Children's Hospices Across Scotland (CHAS) is the national charity that provides hospice services for babies, children and young people with life-shortening conditions in Scotland. The care provided by CHAS is integrated across all settings, including hospice, home and hospital, combining medical intervention, nursing care, and family support for the whole family, as and when they need it, throughout their journey from referral to bereavement, or transition to adult services. CHAS provides two hospices, Rachel House in Kinross and Robin House in Balloch, which support families from all parts of Scotland. CHAS provides a home care service called CHAS at Home, with teams based at the two hospices and in Inverness and Aberdeen. The service offers nursing care in the family home to give families a break from caring for their child. In addition, CHAS provides a family support team, CHAS Care24, in-hospital services (via specialist Diana Children's Nurses and doctors in hospitals), plus collaborative arrangements with local health services where CHAS funds and embeds staff across paediatric, neonatal and community teams.[1]

In 2015, CHAS commissioned York Health Economics Consortium (YHEC) to undertake an economic evaluation of the services it provides. This work was completed in May 2016 and an updated report produced in 2018 for the 2016/17 financial year.[2] Since that time, CHAS has continued to develop new and expanded services, and CHAS has requested that the previous economic evaluation is updated. This report comprises an update of the original reports, refreshed to reflect service changes in subsequent years.

2. METHODS

2.1 Development of the analysis framework

The first stage of the work was to update the analysis framework which was developed for the earlier economic evaluations. The framework describes the interventions provided by CHAS, the costs and benefits of each service, and proposes how the information will be used in the analysis, including any assumptions required. The analysis year is 2018/19, which is considered to be the latest year that reflects 'business as usual'. 2019/20 was affected by the introduction of a new clinical system and, latterly, by the impact of Covid-19.[3]

[1] CHAS. Clinical and Care Strategy 2019-2020.
[2] Hex N Hanlon J. Economic Evaluation of Hospice and Hospice at Home Services. Updated Report for 2016/17. York Health Economics Consortium. 2016.
[3] In addition, most families chose to shield and not uptake services weeks ahead of the Scottish Government's advice.

Information gained from documentation, interviews, and CHAS activity and financial systems, was synthesised to inform a draft analysis framework for comment by CHAS. The analysis uses a number of assumptions, informing the alignment of inputs to benefits and how best to make use of the available evidence and activity data. The assumptions are based on the information obtained while developing the framework, plus literature reviewed for the previous economic reports. Where appropriate these assumptions have been updated, using expert opinion and new evidence. While this current update did not include a further literature review, a small number of additional references have been used to inform the work. The previous report, containing the references used, can be found on the CHAS website.[4]

2.2 Economic Analysis

The economic analysis combined the costs of providing the services with the activity data for each service and the value of the proposed outcomes, informed by the assumptions agreed in the analysis framework. The cost of providing CHAS services was derived from CHAS management accounts, adjusted in accordance with agreed assumptions, and apportioning the cost of support services based on the whole time equivalents of staff in each service. Proxy values for outcomes (Appendix A) were taken from nationally recognised sources such as the Unit Costs of Health and Social Care, published annually by the Policy and Social Services Research Unit, information from the Scottish Government and the Office of National Statistics.

The outputs of the economic analysis were, both in total and for individual services:

- Cost of the services provided
- Value of the economic benefits
- Net cost/saving
- Return on investment from different perspectives, including the NHS/health care system, social care and local government, societal and family perspectives.

To test the effect of any uncertainty in the base case assumptions on the ROI, some of the assumption values were varied in sensitivity analysis (Section 4.5 of the main report).

3. IMPACT OF CHAS SERVICES

During 2018/19, CHAS looked after 465 babies, children and young people (BCYP) with life-shortening conditions and their carers and families. The services provided by CHAS are complex and the framework has distilled these into categories against which economic measures could be applied.

[4] YHEC. Economic evaluation of hospice and hospice at home, Diana Children's Nurses and bereavement Services. Updated report for 2016/17. Available at: https://chas-assets.s3.eu-west 1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5d80f3bf0f7d33777a373d52/190912-YHEC2-Final-Report-2016-17.pdf

The following services are included in the quantitative analysis:

- Hospice based services: planned care and unplanned care
- Home based services: planned care and unplanned care
- Hospital based services: Diana Children's Nurses
- Family Support Service: bereavement support
- Volunteering: Home Support Service and direct care and support
- Specialist clinical support for non-palliative care clinicians
- Palliative care training

Sections 3.2 to 3.10 of the main report describe the service activity in 2018/19 and the estimated value of benefits accruing from each service included in the analysis. The proposed service benefits and the assumptions used in the 'base case' analysis can be found in Appendix B.

Some of the services that CHAS provides are not included in the analysis, due to there being insufficient data or evidence available, or because there is a chance they will double count benefits with other services included in the analysis. They are: Family Support Service (other than bereavement), Care 24, 24 hour advice line, Rainbow Room.[5] These services, and their benefits, are described in Section 3.12 of the report.

4. ECONOMIC ANALYSIS

CHAS received just over £16.5 million in income in 2018/19, of which 41.1% (6.8 million) came from the Scottish Government/NHS Health Boards and Scottish Local Authorities. CHAS total expenditure in 2018/19 was £17.9 million.

Based on the literature evidence, the values described in Appendix A and the assumptions in Appendix B, the total estimated benefits value for one year for the services provided by CHAS in 2018/19 was over £49 million. A number of different perspectives were considered in the analysis, including the NHS and social care perspectives and the societal perspective, in the form of improved productivity due to improved mental health. Based on the assumptions used in the analysis, the estimated total benefits of CHAS services per year from these different perspectives are shown in Table 1.

Table 1: Value of benefits of CHAS Services

Economic perspective	Element	Value
NHS perspective	Avoided healthcare resource use £15,673,408	£43,113,418
	Quality of life gains £27,440,010	
Social care perspective	Avoided social care resource use	£3,770,512
Societal perspective	Productivity gains	£2,455,656
TOTAL		**£49,339,586**

[5] The Rainbow Room is a private bereavement suite in each of the Hospices with a cooled bedroom for the deceased child.

The results of the return on investment (ROI) calculations for CHAS services are shown in Table 2. This shows the ROI for each individual service and the total of all services, in four ROI scenarios:

- Value of health care resource use outcomes and statutory funding only
- Value of health and social care resource use outcomes and statutory funding only
- Value of all outcomes and statutory funding only
- Value of all outcomes and total running costs

Table 2: Estimated return on investment of CHAS Services

SERVICE	ROI (Healthcare resource use outcomes)	ROI (Health & social care resource use outcomes)	ROI (All outcomes)	
	Statutory funding only	Statutory funding only	Statutory funding only	Total running costs
TOTALS (all services)	130%	185%	624%	175%

A number of sensitivity analyses were carried out to examine the effect on the results of changing assumptions or activity levels. The sensitivity analyses found that the scenarios which increase the proportion of care in the CHAS at Home service that is planned, versus unplanned, increases the ROI. This is due to the fact that the service is provided at relatively low cost, but has the potential to prevent costly healthcare use in the form of admissions.

5. DISCUSSION

CHAS services are highly valued by families and by professionals alike. When adopting a conservative approach, and accepting the limitations of the analysis detailed in Section 5.3 of the main report, the base case economic evaluation has found that CHAS services continue to generate substantial net benefits. The total costs of service delivery are calculated to be £17.9 million in 2018/19, while generating an estimated benefits value of £49.3 million. This is a return on investment of 175%, or £1.75 equivalent value for every £1 spent on service delivery, when taking a health, social care and societal perspective on outcomes.

CHAS received just over £6.8 million in statutory funding, from the Scottish Government/ NHS Health Boards and Scottish Local Authorities, which represents 38% of the 'running costs'. When considering the value of benefits generated against this funding, this an ROI of 624%, a return equivalent to the value of £6.24 for every £1 spent. Even if only the benefits attributable to avoided health and social care resource use are taken into account (i.e. direct cost reduction to the NHS and local authorities), then over £19.4 million of benefits value is estimated – a return on investment of 185% against the statutory funding received.

The benefits generated by CHAS services include cost reductions attributable to avoiding the need for BCYP and their families to use health and social care services. These can be either through avoidance of illness, or substitution of care into the hospice or hospice at home setting. Societal benefits were also identified, particularly for adult carers of children and young people with life-shortening conditions, who are able to work as a result of the support received from CHAS. The service also benefits from a significant input from volunteers, providing important additional capacity.

There are some limitations in the analysis, which are described in Section 5.3 of the main report. For example, the analysis has had to use assumptions about the extent of the economic benefits generated through CHAS services and there is no guarantee that these reflect reality. The assumptions are based on literature evidence, (mostly from the literature review for the previous economic evaluation reports) and from clinical opinion. With this in mind, the assumptions made have been conservative. Another key limitation was the need to generalise the analysis approach and to treat all BCYP and their carers and families the same way.

In conclusion, the economic evaluation supports the analysis framework's assertion that children's hospice care services can generate benefits across the health and social care system. CHAS clearly has the potential to reduce demand on the statutory sector, while also providing a choice of services for BCYP and families. Additionally, the evaluation demonstrates that CHAS has the potential to bring wider societal benefits for BCYP who need their services, their families and for volunteers.

5.1 Other services

Although the analysis year for the report is 2018/19, it must be acknowledged that the Covid-19 pandemic in 2020 has had a dramatic impact on CHAS and the services it has been able to provide. Planned hospice care was ceased for a time, with many nurses furloughed. Admissions were limited to unplanned admissions only, with the priority being of crisis and unplanned care, with the hospices providing care for symptom management; deterioration in clinical condition; care package breakdown; housing crisis or whenever a family's resilience is challenged by these unprecedented circumstances. Fundraising activities were also dramatically reduced. In response, CHAS drove forward its model of care for a virtual hospice and also increased its resource to CHAS at Home, with staff being deployed to work in people's homes to a greater extent than previously.

The Paediatric Supportive and Palliative Care Team continues to develop, providing specialist palliative care support in the Royal Hospital for Children, Glasgow (RHC). The service started in 2019/20 and is the first in-hospital team of its kind in Scotland, providing care across the paediatric spectrum, from the antenatal period up to 16 years of age.

The CHAS Strategic Plan states an intention to increase its 'digital offer' to increase access to CHAS services to those who are not able to attend the hospice.[6] The advent of Covid-19 accelerated these developments, in order to be able to provide palliative care and support to families while face-to-face services were severely curtailed. This has included many activities to replace the usual care provided in the hospices, but also to enhance the service offer from CHAS, via a virtual hospice approach.

5.2 Recommendations

A number of recommendations are proposed as a result of the evaluation:

- Providing care at home: the analyses suggests that there are opportunities to achieve greater net benefit by shifting the balance of care in the hospices to care at home. While there may be efficiencies from this service model, any future economic analysis should be careful to understand the impacts of this service delivery on children and families and not assume equivalence of outcomes.
- Virtual hospice: the developing approach to a virtual hospice has the potential to bring efficiencies to the CHAS service offer and any future economic analysis should consider the costs and benefits of this service once it is established.
- Diana Children's Nurses: the benefits value of the DCNs is lower than expected, as the numbers of BCYP seen only by the DCNs was lower in 2018/19 than in the previous year. While the data have been checked, for future analyses it may be worth reviewing the way data are recorded to ensure all DCN activity is captured, including measures to demonstrate the impact they have on the NHS colleagues with whom they work.
- Planned:unplanned bed days: the number of bed days and admissions that are classed as planned and unplanned in the Service Activity statistics appear different to the proportion of bed capacity which is used for planned and unplanned care, a view also supported by CHAS staff. As planned and unplanned care have the potential to bring different benefits to the health and social care system it would be worth considering how planned:unplanned care is categorised for any future analyses.
- Further qualitative and quantitative research could be carried out to understand the extent to which the assumptions made about the benefits of CHAS services are correct. For example, children and their families could be interviewed to understand the benefits gained or data could be collected to understand the extent to which the use of a CHAS service reduced the need to access a statutory service.
- CHAS and statutory bodies should investigate the extent of unmet need in terms of palliative care for BCYP with life-shortening conditions and also any variation in provision across different areas of Scotland.

[6] CHAS. Reaching Every Family in Scotland. Our Strategy plan for 2020 to 2023.

- The Scottish Government, Local Authorities and NHS Health Boards should consider increasing the level of statutory funding available for CHAS services, particularly given the likelihood that the services reduce the burden of health and social care resource use.
- Given the substantial involvement of volunteers, it would be useful to attempt to quantify the wider benefits for the volunteers themselves in any future economic reports.

Acknowledgements

YHEC would like to acknowledge the important contribution of the staff at CHAS in helping our understanding and providing activity and financial data. The work would not have been possible without their help.

Section 1: Introduction

1.1 CHILDREN'S HOSPICES ACROSS SCOTLAND

There are approximately 16,700 babies, children and young people in Scotland with a life-shortening condition.[7] Children's Hospices Across Scotland (CHAS) is the national charity that provides hospice services for babies, children and young people with life-shortening conditions in Scotland. The care provided by CHAS is integrated across all settings, including hospice, home and hospital, combining medical intervention, nursing care, and family support for the whole family, as and when they need it, throughout their journey from referral to bereavement, or transition to adult services. CHAS provides two hospices, Rachel House in Kinross and Robin House in Balloch, which support families from all parts of Scotland. The two hospices both have accommodation for up to eight babies, children or young people, for planned and unplanned visits, as well as residential facilities for their families. The hospices provide a combination of planned short breaks and emergency admission bed nights.

CHAS provides a home care service called CHAS at Home, with teams based at the two hospices and in Inverness and Aberdeen. The service offers nursing care in the family home to give families a break from caring for their child. In addition, CHAS provides a family support team, CHAS Care24, in-hospital services (via specialist Diana Children's Nurses and doctors in hospitals), plus collaborative arrangements with local health services where CHAS funds and embeds staff across paediatric, neonatal and community teams.[8] The CHAS Strategic Plan describes how CHAS currently provides medical, nursing and family support work, and how it plans to expand.[9] The CHAS team has the skills to look after children whose care requires a high degree of complex intervention including ventilation, parenteral nutrition, intravenous medication and peritoneal dialysis. CHAS provides support from the neonatal stage through to the end of life. The Transition Team supports young people to move into adult services. Since 2017 the upper age limit for referrals is 18 years, and for CHAS services is 21 years. Referrals can be made by health and social care professionals and families.

[7] CHAS & Public Health Scotland. Children in Scotland requiring Palliative Care (ChiSP) 3, 2020.
[8] CHAS. Clinical and Care Strategy 2019-2020.
[9] CHAS. Reaching every family in Scotland. Our strategic plan for 2020 to 2023.

1.2 ECONOMIC EVALUATION OF CHAS

In 2015, CHAS commissioned York Health Economics Consortium (YHEC) to undertake an economic evaluation of the services it provides.[10] This work was completed in May 2016 and an updated report produced in 2018 for the 2016/17 financial year.[11] Since that time, CHAS has continued to develop new and expanded services, such as CHAS into Hospital, at the Royal Hospital for Children, Glasgow, the Royal Aberdeen Children's Hospital and University Hospital Crosshouse. In addition, recruitment for a Consultant in Paediatric Palliative Medicine based at the Royal Hospital for Sick Children, Edinburgh, is currently underway. Furthermore, in March 2020, in response to the Covid-19 pandemic, CHAS launched the Virtual Children's Hospice, to continue to support Scotland's most vulnerable children and their families who are self-isolating or unable to visit one of the hospices. The plans for the service are evolving at the time of writing.

CHAS has requested that the previous economic evaluation is updated. It is also interested to understand the potential impacts of the services which are currently under development, such as the Virtual Hospice. The objectives of the work were to:

- Categorise the interventions, updating the analysis framework, including the benefits of the services currently provided.
- Obtain data to identify the costs of providing the various services and the levels of activity in 2018/19.
- Update the modelling assumptions and model the economic results, using scenario analysis to understand the impact of any uncertainty.

This report comprises an update of the original reports, refreshed to reflect service changes in subsequent years.

[10] Hex N Hanlon J. Economic Evaluation of Hospice and Hospice at Home Services. Final Report. York Health Economics Consortium. 2016.
[11] Hex N Hanlon J. Economic Evaluation of Hospice and Hospice at Home Services. Updated Report for 2016/17. York Health Economics Consortium. 2016.

Section 2: Methods

2.1 DEVELOPMENT OF AN ANALYSIS FRAMEWORK

The first stage of the work was to update the analysis framework which was developed for the earlier economic evaluations finalised in 2016 and 2018. The framework describes the interventions provided by CHAS, the costs and benefits of each service, and proposes how the information will be used in the analysis, including any assumptions required.

The analysis year is 2018/19, which is considered to be the latest year that reflects 'business as usual'. 2019/20 was affected by the introduction of the new CHAS care database and, latterly, by the impact of Covid-19.[12]

Useful documentation in the form of annual reports, service evaluations and clinical strategy and activity monitoring data from CHAS systems were provided by the Associate Director of External Affairs and the Information & Data Analyst. The Head of Financial Governance provided budgetary information and management accounts. In some cases, in order to inform allocation of activity to different elements of care, it was necessary to obtain a further breakdown of activity. CHAS staff undertook additional audit work to provide the detail required.

Stakeholder interviews were conducted with key individuals at CHAS to inform the framework and discuss any assumptions which were required. The interviewees were:

- Chief Executive
- Medical Director
- Director for Children & Families
- Head of Quality & Care Assurance

The information from the documents, data and interviews was synthesised to inform a draft analysis framework for comment by CHAS. The framework set out proposals for how the service inputs were to be costed and how the evidence of benefits would be attributed at the analysis stage. It also identified further questions arising from the data which were discussed with the project team. The analysis uses a number of assumptions, informing the alignment of inputs to benefits and how best to make use of the available evidence and activity data. The assumptions are based on the information obtained while developing the framework, plus literature reviewed for the previous economic reports. Where appropriate these assumptions have been updated, using expert opinion and new evidence.

[12] In addition, most families chose to shield and not uptake services weeks ahead of the Scottish Government's advice.

For the original economic evaluation report in 2016, a rapid literature review was undertaken, to identify evidence for the economic benefits of the services provided by CHAS. This current update did not include a further literature review, although a small number of additional references have been used to inform the work. The majority of the analysis is based on literature used in the first two reports, the references for which are contained within those reports. The latest report can be found on the CHAS website.[13]

2.2 ECONOMIC ANALYSIS

The economic analysis combined the costs of providing the services with the activity data for each service and the value of the proposed outcomes, informed by the assumptions agreed in the analysis framework. The input values were derived as follows.

2.2.1 Costs of Services

The cost of providing CHAS services was derived from CHAS management accounts. These costs were adjusted in accordance with agreed assumptions, for example to separate planned and unplanned care in the hospices and by CHAS at Home. Management costs associated with volunteering were extracted from hospice care, in order to allocate the appropriate proportion of time and cost to this activity.

To give the total costs for each service, the cost of support services (e.g. administration, property/facilities, IT, staff training), governance and also the cost of generating funds, were apportioned to each service by CHAS, based on the whole time equivalents of staff in each service.

As the analysis has been undertaken for one year only, discounting of costs and benefits values has not been necessary.

2.2.2 Proxy Values for Outcomes

To establish the values of health and social care service benefits, sources used include the Unit Costs of Health and Social Care, published annually by the Policy and Social Services Research Unit, information from the Scottish Government and the Office of National Statistics. Information from the Information Services Division (ISD) Scotland (Scottish Health Service Costs) and the Scottish National Tariff were examined for relevant information. In the main, these have not been used to value the service benefits, as the level of detail is insufficient to estimate costs of specific episodes of health and social care relevant to this economic analysis.

[13] YHEC. Economic evaluation of hospice and hospice at home, Diana Children's Nurses and bereavement Services. Updated report for 2016/17. Available at: https://chas-assets.s3.eu-west 1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5d80f3bf0f7d33777a373d52/190912-YHEC2-Final-Report-2016-17.pdf

Other values were derived from literature evidence. Values available from earlier years but not updated in the literature were uprated to 2019 values using the hospital and community health services (HSHC) index.[14] The proxy values used for each outcome are listed in Appendix A.

2.2.3 Return on Investment

The economic analysis was designed to show the following outputs, both in total and for individual services:

- Cost of the services provided
- Value of the economic benefits
- Net cost/saving
- Return on investment from different perspectives, including the NHS/health care system, social care and local government, societal and family perspectives.

Benefits were calculated and compared to the overall costs of delivering CHAS services, and more specifically to the statutory funding CHAS receives from the Scottish Government/NHS Health Boards Scottish and Local Authorities.

The return on investment (ROI) of CHAS services was calculated using the following formula:

$$\frac{\sum \text{Total benefits} - \sum \text{costs}}{\sum \text{Total costs}}$$

The ROI results were modelled for the following four scenarios to give different perspectives:

- Value of healthcare outcomes only and statutory funding only
- Value of health and social care outcomes and statutory funding only
- Value of all outcomes and statutory funding only
- Value of all outcomes and total running costs

To test the effect of any uncertainty in the base case assumptions on the ROI, some of the assumption values were varied in sensitivity analysis (Section 4.5).

[14] PSSRU. Curtis L & Burns A. Unit Costs of Health & Social Care Personal Social Services Resource Unit2019.

Section 3: Impact of CHAS Services

3.1 CHAS SERVICES

The services provided by CHAS are complex and the framework has distilled these into categories against which economic measures could be applied. The following services are included in the quantitative analysis:

- Hospice based services: planned care and unplanned care
- Home based services: planned care and unplanned care
- Hospital based services: Diana Children's Nurses
- Family Support Service: bereavement support
- Volunteering: Home Support Service and direct care and support
- Specialist clinical support for non-palliative care clinicians
- Palliative care training

Some of the services that CHAS provides are not included in the analysis, due to there being insufficient data or evidence available, or because there is a chance they will double count benefits with other services included in the analysis. These services, and their benefits, are described in Section 3.12 of the report. They are:

- Family Support Service, other than bereavement
- Care 24
- 24 hour advice line
- Rainbow Room[15]

The sections below describe the service activity in 2018/19 and the estimated value of benefits accruing from each service included in the analysis. The proposed service benefits and the assumptions used in the 'base case' analysis can be found in Appendix B. As the evidence underpinning the assumptions is largely the same as that used for the previous economic evaluations, evidence of benefits is included only where this is additional information to that included in those reports.

[15] The Rainbow Room is a private bereavement suite in each of the Hospices with a cooled bedroom for the deceased child.

3.2 HOSPICE BASED PLANNED CARE

3.2.1 Service Description and Activity: Hospice Based Planned Care

At Rachel House/Robin House, the short planned breaks element of the service provides accommodation and activities for babies/children/young people (BCYP), either accompanied by their families or on their own. The service provides individual and holistic care to BCYP, while providing parents with the opportunity to take time out from being a carer and be a parent, spending time with siblings. This helps to increase their resilience and ability to continue to provide care. Integral to planned care in the hospices is the Family Support Service, which provides activities, particularly at the end of life, including memory making, case management and support for transition. End of life care is also provided on a planned basis, including anticipatory care planning (ACP), guiding how certain situations should be medically managed and preferences around the place of care, such as a hospital, hospice or home.

Robin House also provides the Forest School, which is an approach about learning in the environment, using natural resources from outdoors to learn, explore, build, paint etc. It helps children to develop new skills, gain new experiences and supports children and siblings with opportunities to create cherished memories. It is part of the holistic service provided at the hospice and as such, may not account for separate quantifiable benefit over and above that provided by planned hospice care/short breaks. An evaluation of two Forest Schools found that they can provide learning opportunities for children who typically do not do so well in the classroom.[16] The evaluation found that they can help to increase children's confidence and improve a range of skills, such as social, communication and physical skills.

The number of babies, children and young people supported by the hospices in 2018/19 was 465 in total. For the purposes of analysis, the total number supported (465) has been adjusted by subtracting those BCYP who were seen by only the Diana Children's Nurses (36) and those who were seen only by CHAS at Home (39). The total for the purposes of estimating the benefits from planned hospice care is therefore 390 BCYP. The hospices provided 974 planned admissions over 3,483 bed nights, and 528 'day bed' admissions. The average length of stay was 3.58 days.[17] There were 820 family admissions, comprising 5,035 adult bed nights and 2,638 sibling bed nights. There were 84 BCYP who died during the year, 41 of whom died at home or in one of the hospices.

The proposed benefits of hospice based planned care and the assumptions used in the base case analysis can be found in Appendix B.

[16] O'Brien E, Murray R. A marvellous opportunity for children to learn. A participatory evaluation of the Forest School in England and Wales. Forest Research 2006. [Accessed on 27 November 2020 at: https://www.forestresearch.gov.uk/research/forest-schools-impact-on-young-children-in-england-and-wales/].
[17] HospiceUK_MemberSurvey_Scotlandv1.2 CHAS20200302

3.2.2 Modelled Outcome Benefits: Hospice Based Planned Care

The benefits attributed to hospice based planned care are from both the health and social care perspective (e.g. assumed reductions in the use of hospital stays, local authority bed nights and mental health services), and the societal perspective (e.g. improved mental health/quality of life; improvements in productivity through people being able to work).

Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from hospice based planned care is estimated to be £35,153,846. The calculations are shown in full in Appendix C. The benefits estimate comprises:

- Avoided healthcare resource use - £9,357,121
- Avoided social care resource use - £2,297,665
- Quality of life gains due to mental health improvements - £21,446,100
- Productivity gains - £2,052,960

Although short breaks may also generate quality of life gains for BCYP, no specific evidence was found to support this. It is not possible, therefore, to include a utility value for this in the calculations, making this a conservative estimate of the overall benefits gained.

3.3 HOSPICE BASED UNPLANNED CARE

3.3.1 Service Description and Activity: Hospice Based Unplanned Care

Both Rachel House and Robin House provide beds for emergency unplanned stays. These stays may be needed to provide symptom control, support for carer breakdown or while awaiting home adaptations and also to provide step down care from hospital admissions. Three of the eight beds in each hospice are generally used for unplanned admissions. These stays provide holistic care, with significant medical input and support for families to help them cope with the stress of the admission. They also potentially avoid an admission to hospital for the BCYP.

There were 122 admissions which were classed as unplanned in 2018/19. This used 492 bed nights, which accounts for 12% of total bed nights. The average length of stay 4.03 was days.[18] For the purposes of estimating costs, unplanned care is assumed to account for 35% of the resource use in the hospice. This is based on the use of the beds in each hospice, where three of the eight beds are generally used for unplanned admissions. Although this does not tally with the activity data, in which 12% of bed nights are classed as unplanned, this is suggested by the CHAS management team to be a more accurate reflection of the balance of planned versus unplanned activity. In contrast to an admission to hospital, (which is categorised as planned or unplanned for the duration), the categorisation of hospice bed nights as planned or unplanned can change over time. What starts as an unplanned admission may change to be categorised as planned bed nights, due to the length of the stay and the interventions being provided.

[18] HospiceUK_MemberSurvey_Scotlandv1.2 CHAS20200302

The proposed benefits of hospice based unplanned care and the assumptions used in the base case analysis can be found in Appendix B.

3.3.2 Modelled Outcome Benefits: Hospice Based Unplanned Care

The benefits attributed to hospice based unplanned care are from the health and social care perspective, in terms of reduced use of hospital stays, GP services and local authority bed nights.

Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from hospice based unplanned care is estimated to be £3,840,200. The calculations are shown in full in Appendix C. The benefits estimate comprises:

- Avoided healthcare resource use - £3,266,165
- Avoided social care resource use - £574,035

As acknowledged above, an unplanned admission into the hospice can change to that of a planned stay and is then categorised as such.[19] This is in contrast to the NHS approach, where an emergency admission will continue to be classified as such until the patient is discharged from hospital.

Although there are likely to be mental health benefits to parents from the availability of hospice provision in emergency situations, this has not been estimated in order to avoid potential double counting, as this benefit has been included in the analysis for planned short breaks. This may therefore be an underestimate as it will not include benefits for families of BYCP who only have unplanned stays.

3.4 CHAS AT HOME PLANNED CARE

3.4.1 Service Description and Activity: CHAS at Home Planned Care

The CHAS at Home service provides planned breaks, nursing and overnight care to support families in the home environment. The core team comprises nursing and family support with medical staff providing support. It is a small team, planning its work around availability and the families, with a Home Care Agreement setting out what the service will do. The majority of CHAS at Home care is planned, although in 2020 the proportion of unplanned care has increased due to the Covid-19 pandemic. End of life care, including anticipatory care planning, is also provided by CHAS at Home.

[19] Source: CHAS Clinical System.

195 BCYP were supported by CHAS at Home in 2018/19. There was a total of 1,205 visits for all BCYP.[20] A previous audit has found that the majority of care is planned, agreed in the previous analysis to be 80%. The analysis therefore split CHAS at Home into planned (80%) and unplanned (20%), to reflect the different resource use which may be prevented by planned and unplanned care. As most of the BCYP also make use of Rachel House and Robin House services, the economic analysis for CHAS at Home is based on the smaller number who never use the hospice facilities, in order to avoid double counting of the benefits. In 2018/19 there were 39 BCYP, who only received care from CHAS at Home,[21] equivalent to 241 visits. Planned care is 80% of this i.e. 193 visits.

The proposed benefits of CHAS at Home planned care and the assumptions used in the base case analysis can be found in Appendix B.

3.4.2 Modelled Outcome Benefits: CHAS at Home Planned Care

The benefits attributed to CHAS at Home planned care are from both the health and social care perspective (e.g. reductions in the use of hospital stays, local authority bed nights and mental health services), and the societal perspective (e.g. improved mental health/quality of life; improvements in productivity through people being able to work).

Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from CHAS at Home planned care is estimated to be £2,867,770. The calculations are shown in full in Appendix C. The benefits estimate comprises:

- Avoided healthcare resource use - £459,096
- Avoided social care resource use - £58,768
- Quality of life gains due to mental health improvements - £2,144,610
- Productivity gains - £205,296

It is important to note that this value is derived by including only 39 BCYP and their families in the analysis. It is possible that there were additional benefits from CHAS at Home interventions for the 156[22] children and young people who used both services, although it is not possible to quantify these separately. Therefore, by only including the 39 cases additional to hospice care, we have made a conservative estimate of the benefits accrued.

[20] Source: CHAS Clinical System
[21] CHAS analysis 'CHAS at Home only', November 2020.
[22] 195-39=156

3.5 CHAS AT HOME UNPLANNED CARE

3.5.1 Service Description and Activity: CHAS at Home Unplanned Care

The CHAS at Home service also provides unplanned care to BCYP in the home environment, which includes symptom control/support for carer breakdown. Medical staff provide consultations by telephone to update medication charts. Advanced Nurse Practitioners are now doing some of this work in their role as independent prescribers.

All BCYP who receive services from CHAS at Home are assumed to potentially also receive unplanned care from the service. Unplanned care is estimated to account for 20% of the service provided i.e. 241 visits for all unplanned care provided by CHAS at Home.

The proposed benefits of CHAS at Home unplanned care and the assumptions used in the base case analysis can be found in Appendix B.

3.5.2 Modelled Outcome Benefits: CHAS at Home Unplanned Care

The benefits attributed to hospice based unplanned care are from the health and social care perspective, in terms of reduced use of hospital stays, GP services and local authority bed nights.

Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from hospice based unplanned care is estimated to be £1,689,187. The calculations are shown in full in Appendix C. The benefits estimate comprises:

- Avoided healthcare resource use - £1,601,409
- Avoided social care resource use - £87,778

There are likely to be mental health benefits to parents from the availability of palliative care provision at home in emergency situations. This has not been estimated, in order to avoid potential double counting, as this benefit has been included in the analysis of other services.

It is important to note that this value is derived by including only 20% of the CHAS at home activity. It does not explicitly include the domiciliary medical visits, which may take place in addition to intervention by the CHAS at Home nursing team. The medical team reports that approximately 90% of the ‘domiciliary’ work it undertakes is considered to be unplanned or emergency, so this is a conservative estimate of the benefits accrued by CHAS services provided outside of the hospice environment.

3.6 DIANA CHILDREN'S NURSES

3.6.1 Service Description and Activity: Diana Children's Nurses

Diana Children's Nurses (DCNs) provide nursing support for BCYP in a hospital setting, as well as supporting strategic and service development to improve the quality of palliative care for BCYP in Scotland. They specialise in:

- Neonatal palliative care in NHS Lothian
- Paediatric critical care and oncology principally in NHS Greater Glasgow and Clyde
- Community liaison work across the North of Scotland, principally in NHS Grampian and NHS Highland. (Post is vacant).

In 2018/19 there were 47 new referrals received to the DCNs during the year, 11 of whom progressed to other CHAS services during the period. This number is considered to be lower than usual due to the vacant post. To avoid double counting benefits, it has been assumed that the additional benefits of the DCN Service is gained by those BCYP who did not receive other CHAS services (36 individuals).

The proposed benefits of the DCNs and the assumptions used in the base case analysis can be found in Appendix B.

3.6.2 Modelled Outcome Benefits: Diana Children's Nurses

The benefits attributed to DCNs are from the health care perspective (e.g. reductions in the use of GP appointments and hospital admissions). Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from the DCNs is estimated to be £184,107. The calculations are shown in full in Appendix C.

The estimate of economic benefits of DCNs is likely to be an underestimate for a number of reasons. The capacity of the service is reduced, due to a vacancy in the NHS Highland post. Furthermore, the number of BYCP in the analysis does not include BCYP who may have received (and gained benefit from) the service in 2018/19 but were referred prior to that period. Also, DCNs have significant input into the palliative care of many other children and young people via their input to training and policy development across the hospitals in which they are based. They train 50-60 nurses per year, in conjunction with the charity, Simba.[23] It is not possible to measure and value the benefits of this training and capacity building as part of their role, which builds the confidence and skills of colleagues in the hospital in which they work, but it should be acknowledged.

[23] Source: CHAS Chief Executive interview.

3.7 FAMILY SUPPORT SERVICES (BEREAVEMENT SERVICES)

3.7.1 Service Description and Activity: Bereavement Services

The Family Support Service offers a holistic service, working in the hospices and the community alongside clinical and other services. This includes case management, activities such as memory making, support for transition, and bereavement counselling. As many of the service benefits are considered to be integral to the care provided by the hospice and CHAS at home, the analysis for Family Support Services includes only those benefits arising from bereavement support. This includes time spent both before and after the death of the BCYP, working with the wider family to build memories and prepare for the future, as well as supporting them after the death. This can be for up to three years, through counselling, key worker support, chaplaincy and remembering days.

The additional benefits of bereavement services (over and above benefits from other CHAS services) are gained by the families of the BCYP that died in the previous year (2017/18). This was 70 families.[24] However, 120 referrals were made to the Family Support Team in 2018/19 for 'bereaved families', so 70 families may be a conservative estimate. The impact of increasing this number to 95 is tested in sensitivity analysis (i.e. half way between the service activity statistics figure of 70 families and the Family Support Team data of 120 referrals).

The proposed benefits of Bereavement Services and the assumptions used in the base case analysis can be found in Appendix B.

3.7.2 Modelled Outcome Benefits: Bereavement Services

The benefits attributed to bereavement services are from both the health care perspective (e.g. reductions in GP appointments and use of mental health services) and the societal perspective (e.g. improved mental health/quality of life; improvements in productivity through people being able to work).

Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from bereavement services is estimated to be £4,212,455. The calculations are shown in full in Appendix C. The benefits estimate comprises:

- Avoided healthcare resource use - £150,732
- Avoided social care resource use - £15,023
- Quality of life gains due to mental health improvements - £3,849,300
- Productivity gains - £197,400

[24] CHAS Service Activity Statistics 2017/18.

These benefits may be underestimated as Family Support activities other than bereavement are not included. Furthermore, the impact of bereavement services is gained from working both before and after the death of the child and it is possible that there are additional benefits prior to the death, for the families supported in 2018/19. These have not been included, to avoid potential double counting the mental health benefits for family members using other CHAS services in the same year.

3.8 VOLUNTEERING

3.8.1 Service Description and Activity: Volunteering

CHAS and children and families benefit from significant input from volunteers, providing important additional support, and bringing additional skills and experience to the care provided. The number of volunteer hours provided across all aspects of the organisation in 2018/19 was 59,310.[25] In 2019 there were 855 active volunteers [26], over 150 of whom were involved in direct clinical and care service delivery, including in children's activities, befriending, complementary therapies, hospice driving, nursing support, and sibling support. The Home Support Service provides families with practical support, like domestic tasks, support for siblings, help with homework and other things that the family has identified that they need. One volunteer supports the child with a life-shortening condition directly; others support the parents and siblings. Families talk powerfully about the difference a volunteer makes to their ability to cope and live. The service works with up to 25 families in east central Scotland. 22 volunteers participate in the service. In 2018/19, seven families were supported with 187 hours of volunteer time provided.[27] This may be an underestimate, as this is a growing service, with 18 families being supported and 966 volunteer hours in 2019/20, despite March being affected by Covid-19.

A systematic review by Candy *et al,* [28] found that families who experienced volunteer involvement during palliative care were significantly more satisfied with their care. There was evidence from one study that patients survived substantially longer if they had received home visits from a volunteer. In a study of the benefits of hospice volunteering for patients, family caregivers and volunteers, Claxton-Oldfield found that those volunteering in hospice palliative care reported benefits such as personal growth, including being able to make a difference in the lives of others.[29] This is supported by the feedback from CHAS volunteers, 24% of whom felt that their health and wellbeing has improved as a result of their volunteering.[30] Additionally, 34% reported that they have gained experience to help get a job or pursue further study.

[25] CHAS. Volunteering April 2018 - March 2019.
[26] CHAS. Volunteering April 2018 - March 2019.
[27] Communication from CHAS Information & Data Analyst
[28] Candy B, France R, Low J, Sampson L. Does Involving Volunteers in the Provision of Palliative Care Make a Difference to Patient and Family Wellbeing? A Systematic Review of Quantitative and Qualitative Evidence. Int J Nurs Stud. 2015. Mar; 52(3): 756-68.
[29] Claxton-Oldfield S. Hospice Palliative Care Volunteers: The Benefits for Patients, Family Caregivers, and the Volunteers. Palliat Support Care . 2015 Jun;13(3):809-13.
[30] CHAS. Volunteering April 2018 - March 2019.

The proposed benefits of volunteering and the assumptions used in the base case analysis can be found in Appendix B.

3.8.2 Modelled Outcome Benefits: Volunteering

The benefits attributed to volunteering are from the social care perspective, with the potential to avoid demand on an alternative social care service, in order to address the BCYP's and family's needs. Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from volunteering is estimated to be £737,243. The calculations are shown in full in Appendix C. This does not include any wider benefits that may be accrued by the volunteers themselves by participating in their voluntary activities.

3.9 SPECIALIST CLINICAL SUPPORT FOR NON-PALLIATIVE CARE CLINICIANS IN THE COMMUNITY

3.9.1 Service Description and Activity: Specialist Clinical Support for Non-Palliative Care Clinicians in the Community

CHAS works closely with a range of general practitioners across Scotland, and with NHS Ayrshire and Arran and NHS Lothian, for those who are dying at home. CHAS staff often meet with the GP along with the hospital team, advising on care and prescribing. Unfortunately there is no specific activity recorded for this. There is evidence that this kind of activity can lead to a reduction in demand on other healthcare. Youens *et al,*[31] found that patients accessing palliative care support in the community were more likely to die out of hospital. The service was associated with reduced emergency department attendances, acute care admissions, bed days, and costs over the last year of life. A study by Teo *et al,*[32] demonstrated substantial savings associated with an end-of-life programme, which introduced palliative care and care planning into a care home setting. Based on this evidence, we have agreed in the analysis framework that one admission to hospital is avoided per week as a result of the advice available to non-palliative care clinicians in the community (i.e. 52 admissions). The costs of providing this are integral to other hospice care services.

The proposed benefits of specialist clinic support to non-palliative clinicians in the community and the assumptions used in the base case analysis can be found in Appendix B.

[31] Youens D, Moorin R. The Impact of Community-Based Palliative Care on Utilization and Cost of Acute Care Hospital Services in the Last Year of Life. J Palliat Med. 2017 Jul;20(7):736-744.
[32] Teo WS, Raj AG, Tan WS et al. Economic impact analysis of an end-of-life programme for nursing home residents. Palliat Med. 2014 May;28(5):430-7.

3.9.2 Modelled Outcome Benefits Specialist Clinical Support for Non-Palliative Care Clinicians in the Community

The benefits attributed to providing clinical support for non-palliative care clinicians are from the health care perspective in terms of reductions in admissions to hospital. Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits value is estimated to be £441,350. The calculations are shown in full in Appendix C.

3.10 STAFF TRAINING

3.10.1 Service Description and Activity: Staff Training

CHAS has a role in sharing learning with other clinical and care staff in children's palliative care, both within the hospice and for non-CHAS clinicians. It is an active participant in Project ECHO (Extension of Community Healthcare Outcomes). This is a method and technology to allow professionals with expertise in palliative care to teach and cascade both knowledge and experience, so specialists are engaging with generalists (including those at remote distances), via communities of practice.[33] There were eight CHAS ECHO communities of practice by early 2020.[34] Indicative data from 2019 show that 100 non-CHAS participants attended a session over a period of five months.[35]

The ECHO sessions enable participants to bring cases and gain peer-to-peer advice and learning, with support from palliative care specialists from CHAS. An article by Arora *et al*,[36] reports on seven Project ECHO partners around the world, describing it as an effective way of disseminating the skills and expertise of palliative care specialists to frontline healthcare providers working in a range of diverse communities. The ECHO model can assist healthcare providers, medical staff, and community members to acquire new skills, competencies and best practices in palliative care. A three-year evaluation was carried out by Katzman *et al*, in relation to the use of project ECHO in pain management.[37] They found "statistically significant improvements in participant self-reported knowledge, skills and practice". Based on this evidence and supported by CHAS, we hypothesised that the provision of education by the ECHO programme has the potential to avoid hospital outpatients appointments or admissions by increasing the ability of non-specialists in community and primary care settings to care for BCYP with palliative care needs.

The proposed benefits of staff training and the assumptions used in the base case analysis can be found in Appendix B. The costs of providing this is integral to other hospice care services.

[33] CHAS Clinical and care Strategy 2019-20.
[34] Flash update ECHO year 2019.pptx
[35] Communication from CHAS ECHO Project Lead.
[36] Arora S, Smith T, Snead J *et al*. Project ECHO: An Effective Means of Increasing Palliative Care Capacity. Evidence-Based Oncology > June 2017 – Published on: June 15, 2017.
[37] Katzman JG, Comerci Jr G, Boyle JH, *et al*. Innovative Telementoring for Pain Management: Project ECHO Pain.Contin Educ Health Prof.. Winter 2014;34(1):68-75.

3.10.2 Modelled Outcome Benefits: Staff Training

The benefits attributed to staff training are from the health care perspective (e.g. reductions in the use of GP appointments and hospital admissions). Based on the proxy values in Appendix A and the assumptions described in Appendix B, the total value of the benefits from staff training is estimated to be £213,249. The calculations are shown in full in Appendix C.

3.11 OTHER ASSUMPTIONS INFORMING THE ANALYSIS

Assumptions which are specific to individual services are shown in Appendix B. Other assumptions which inform the analysis are as follows:

- Number of close family members: based on the experience of CHAS, the previous economic evaluations assumed that each BCYP treated at CHAS has on average 4.7 family members, including parents or carers and siblings. A more recent audit of CHAS systems confirmed that this remained a realistic figure. In a study of the 'spill over' effects of end of life care for older adults, Canaway *et el* advised that economic evaluations should include three 'closest individuals'.[38] Given the different patient age group involved, the previous assumption of 4.7 close individuals for BCYP appears to be reasonable, and was used in the base case analysis to assess the potential improvements in mental health quality of life which may result from CHAS services. In the sensitivity analysis, the average number of family members experiencing improvements in mental health quality of life was decreased to three per child/young person.
- Mental health benefits for close family members:
  - It is estimated that the healthcare use avoided by preventing a case of family member depression is three GP visits per year, including prescribing of antidepressants, plus 10 days sickness absence.
  - Of those family members who have avoided suffering from depression, it is assumed that half would have required greater intensity treatment from community mental health teams and would have required a further 20 days of sick leave.
- Although there are likely to be mental health benefits to parents from the availability of hospice provision in emergency situations, this will not be estimated, in order to avoid potentially double counting benefits which have been included in the analysis for planned hospice care.
- It is assumed that the activity data represents individual BCYPs and there is no double counting of outcome benefits.
- There is an assumption that the healthcare system has the capacity to provide the services which are potentially avoided by hospice care.

[38] Canaway *et al*. Close-Person Spill-Overs in End-of-Life Care: Using Hierarchical Mapping to Identify Whose Outcomes to Include in Economic Evaluations. Pharmacoeconomics. 2019 Apr;37(4):573-583

- Outcome proxy values: the values applied to the outcomes used in the analysis are derived from nationally recognised sources such as the Scottish Health Service Costs and the Unit Costs of Health and Social Care. The values used are underpinned by assumptions which are described in the table in Appendix A.

3.12 OTHER SERVICES

CHAS has a number of other services which add value to the service provision at hospice, home and hospital. We have not attempted to separately value the benefits of these services, either because they are integral to other service provision so would risk double counting, or because there are insufficient data available.

3.12.1 Family Support Services (excluding bereavement)

As described above, the Family Support Service is an integral part of the services offered by CHAS. It includes social work, end of life planning, case conferences and multidisciplinary reviews, advocacy and support with funding/housing, specialist play, chaplaincy and bereavement therapy. The service aims to enhance the lives of BCYP though fun and stimulation, as well as providing emotional and practical support for parents and support, friendship and events for siblings. The holistic nature of the service means it is hard to disaggregate the evidence and benefits of the Family Support Service from other services provided by CHAS. Consequently, many of the service benefits (with the exception of bereavement support), are considered to be included in the analyses of care in the hospice and CHAS at Home.

The Transition Team is part of Family Support Services, to provide support for young people who are approaching adulthood, and their families, so they are able to successfully transition to adult services. The team came into effect in December 2014. They work to ensure organisations are aware of the needs of this growing cohort of young people with life-shortening conditions living in the community, helping them to adapt their provision and respond appropriately to the needs of the young people.

3.12.2 Care 24

Care 24 is a collaborative approach between CHAS and NHS Lothian, which supports families wanting to be at home with around the clock end of life care. Children's community nurses are the main case holders and CHAS provides an out-of-hours service, allowing the family to directly contact nursing staff at Rachel House throughout the night between 6pm and 8am. Nursing staff are able to attend the child's home if necessary, backed up with telephone advice from the CHAS on-call medical team, who will administer medications if required.

The service has not been included in the quantitative analysis, partly as activity data were not available in an accessible format, but also because the service is a partnership with NHS Lothian, and it would be difficult to attribute the outcomes to the CHAS input as opposed to that provided by the wider team, including NHS Lothian community nurses. However, an evaluation report contains information on the qualitative benefits and also gives an indication of the potential economic benefits of the service. [39]

The evaluation found that the service was highly valued by both families and professionals, consistently providing high quality care to families. It enables families to have choice regarding place of care, with a de-medicalised death and for the wider family to be present. The anticipatory care planning approach was found to reduce the number of contacts families make to the service outside the regular hours of 8am to 6pm and also avoided unnecessary or emergency admissions to hospital, maybe to an HDU or ICU bed. In turn, avoidance of a hospital admission at the end of life could potentially avoid the need for additional childcare for other children, while parents are in hospital with their dying child.

The evaluation reported that having access to advice and support via the 24-hour dedicated telephone number gave families the confidence to remain at home. Some families reported not calling at night because they were not known to the Rachel House staff and had no previous opportunity to build a relationship with them. However, another benefit of the service was that contact with Rachel House staff dispelled their preconceptions about children's hospice care, as the service became more familiar.[40] Some families taking part in this evaluation changed their view that hospice care was 'not for them', to describing the care and support from Rachel House as invaluable. Similarly, the promotion of the service was found to improve understanding amongst families of what palliative care teams can offer. Parents valued being able to build trusting relationships with staff who really knew their child and could tailor care, involving parents as partners. The importance of partnership working with the family's GP was highlighted, especially for families remote from Rachel House or Robin House.

3.12.3 24 hour advice line

CHAS offers a 24-hour telephone advice line to families and to health and social care professionals. This is staffed by the nursing team and the on-call doctor. The service has the potential to avoid GP and hospital care, as the expertise of CHAS staff is available both in and out of hours for advice and support. This is an integral part of the CHAS service offer and the costs of providing the advice line are not separately accounted for. The new clinical system will collect more data on the use of the advice line going forward. These figures are not available for the current report, however.

[39] Malcolm C, Knighting K. A realist evaluation of the Care 24 Lothian service – Summary Report. School of Health and Social Care, Edinburgh Napier University. March 2020.
[40] Malcolm C, Knighting K. A realist evaluation of the Care 24 Lothian service – Summary Report. School of Health and Social Care, Edinburgh Napier University. March 2020

3.12.4 Rainbow Room

The Rainbow Room is a private bereavement suite in each of the Hospices, with a cooled bedroom for the deceased child. Families can use the Rainbow Room and all the hospice facilities from the day of death until the day of their child's funeral. In 2018/19, 33 BYCP and their families used the Rainbow Room, over 184 nights. There were also 23 temporary Rainbow Room nights and 50 bed nights for a temporary bereavement suite.[41] CHAS is seeing an increase in use of the Rainbow Room by families previously not known to CHAS. The expected benefits are improved ability of families to cope with their bereavement and less subsequent morbidity/depression. However, as no external, published evidence for the economic benefit of bereavement suites is currently available, the benefit is not quantified in this review. This will therefore potentially underestimate the value of the service provided.

[41] If more than one family need the rainbow room at the same time, hospice rooms are converted into a temporary rainbow room and sitting room for the family.

Section 4: Economic Analysis

4.1 SERVICE COSTS

CHAS total expenditure in 2018/19 was £17.9 million, an increase of £2.0 million on the previous year.[42] This was partly due to increased investment in nursing staff and support teams located at the hospices, with the overall cost of delivering services to BCYP and their families rising by £1.7 million from 2017/18 to £14.5 million in 2018/19.[43]

Service costs are broken down into direct costs of services provided (charitable activities), support costs, governance costs and the cost of generating funds. Table 4.1 summarises the resources expended by CHAS during 2018/19.

Table 4.1: CHAS resources expended 2018/19

Resources expended	Costs (£'000)	Percentage
Charitable activities: Hospices, CHAS at Home and Central Care Services	11,523	64.3%
Support costs: Central administrative support	3,110	17.4%
Governance costs	302	1.7%
Cost of generating funds: Fundraising, trading and investment management costs	2,979	16.6%
TOTAL	**17,914**	**100%**

In 2018/19 CHAS directly looked after 465 BCYP, giving an average cost per BCYP of £38,525 per year.

The costs for charitable activities have been split between the services included in the analysis. The costs of each service have then been adjusted with assumptions on the proportion of planned/unplanned activity and the proportion of bereavement activity as follows:

- Hospice care costs were split between planned and unplanned care using a 65:35 ratio.
- CHAS estimates that 40% of Family Support Services relates to bereavement work.
- The costs of volunteer management have been extracted from hospice care and support costs. This has increased the total costs of charitable activities to £11,585.

Table 4.2 summarises the reallocated costs for the individual services.

[42] Children's Hospice Association Scotland. Annual Report and Accounts. 31 March 2019.
[43] Children's Hospice Association Scotland. Annual Report and Accounts. 31 March 2019.

Table 4.2: Reallocated costs for charitable services 2018/19

Service	Cost (£'000)
Hospice care planned	6,236
Hospice care unplanned	3,358
CHAS at Home planned	734
CHAS at Home unplanned	183
Diana Children's Nurses	277
Bereavement services	491
Volunteer management	306
TOTAL	**11,585**

The above services do not operate in isolation and are supported by a range of essential services on a day-to-day basis. These include support costs (e.g. administration, IT, property, staff training), governance and also the cost of generating funds. The latter are included in recognition of the contribution fundraising can make to the capacity that can be delivered by CHAS.

Table 4.3 shows the final costs when these additional costs are apportioned to each of the services on the basis of employee whole time equivalents.

Table 4.3: Service costs for 2018/9, including apportioned support & governance costs and costs of generating funds

Service	Service costs	Apportioned Support Costs	Apportioned Governance Costs	Service costs including apportioned support and governance costs	Apportioned Cost of Generating Funds	Total service costs including apportioned support, governance and fundraising costs
	£000s	*£000s*	*£000s*	*£000s*	*£000s*	***£000s***
Hospice care planned	6,236	1,432	140	7,808	1,809	**9,617**
Hospice care unplanned	3,358	771	76	4,204	974	**5,178**
CHAS at Home planned	734	174	17	925	214	**1,139**
CHAS at Home unplanned	183	43	4	231	54	**285**
Diana Children's Nurses	277	62	6	345	80	**425**
Bereavement services	491	124	12	627	145	**773**
Volunteering	306	89	9	404	94	**498**
Cost of Charitable activities	**11,585**	**2,695**	**264**	**14,544**	**3,370**	**17,914**
Cost of generating funds	2,917	415	38	3,370	(3,370)	**0**
Support costs	3,110	(3,110)	0	0	0	**0**
Governance costs	302	0	(302)	0	0	**0**
Total Expenditure	**17,914**	**0**	**0**	**17,914**	**0**	**17,914**

4.2 FUNDING RECEIVED

CHAS received just over £16.5 million in income in 2018/19. Table 4.4 details the sources of income received by CHAS.

Table 4.4: CHAS incoming resources 2018/19

Source	Income (£'000s)
Donations	4,965
Legacies	3,719
CHAS trading income	480
Statutory funding: • Scottish Government/NHS Scotland £6m (including £275k for DCNs) • Local Authorities £816k (£680k for National Funding Agreement & £136k for infrastructure)	6,816
Investment income and interest	590
TOTAL	**16,570**

Statutory funding from the Scottish Government/NHS Health Boards and Scottish Local Authorities accounts for 41.1% of the incoming resources. Statutory funding provided 38% of the CHAS resources expended in 2018/19 (£17.9 million). This funding also includes £275,000 earmarked for the Diana Children's Nurses, provided by the Scottish Government.

The remaining £6,541k of the £6,816k statutory funding provides part-funding for the remaining services. When allocated to each of the service areas based on the proportion of service costs, the allocation of statutory funding per service is as shown in Table 4.5.

Table 4.5: Estimated allocation of statutory funding 2018/19

Service	Costs (£000's)	% of total costs (excluding DCNs)	Allocation of statutory funding based on % of total costs (£000's)
Hospice care planned	9,617	55.0%	3,597
Hospice care unplanned	5,178	29.6%	1,937
CHAS at Home planned	1,139	6.5%	426
CHAS at Home unplanned	285	1.6%	106
Bereavement services	773	4.4%	289
Volunteering	497	2.9%	186
Diana Children's Nurses	425	-	275
TOTAL	**17,914**	**100.00%**	**6,816**

4.3 VALUE OF BENEFITS

Based on the literature evidence, the values described in Appendix A and the assumptions in Appendix B, the total estimated benefits value for one year for the services provided by CHAS in 2018/19 was over £49 million. A number of different perspectives were considered in the analysis, including the NHS and social care perspectives and the societal perspective, in the form of longer and improved quality of life and productivity due to improved mental health. Based on the assumptions used in the analysis, the estimated total benefits of CHAS services per year from these different perspectives are shown in Table 4.6.

Table 4.6: Value of benefits of CHAS Services

Economic perspective	Element	Value
NHS perspective	Avoided healthcare resource use £15,673,408	£43,113,418
	Quality of life gains £27,440,010	
Social care perspective	Avoided social care resource use	£3,770,512
Societal perspective	Productivity gains	£2,455,656
TOTAL		**£49,339,586**

Table 4.7 shows total costs, estimated value of the outcomes and the net position for each individual service.

Table 4.7: Total costs, value of outcomes and net benefit of CHAS Services

SERVICE	Total costs	Value of outcomes					Net benefit
	2018/19	Healthcare resources	Social care resources	QALYs	Productivity	TOTAL	2018/19
Hospice care planned	£9,616,777	£9,357,120	£2,297,665	£21,446,100	£2,052,960	£35,153,846	**£25,537,069**
Hospice care unplanned	£5,178,265	£3,266,165	£574,035	£0	£0	£3,840,200	**-£1,338,065**
CHAS at Home planned	£1,139,046	£459,096	£58,768	£2,144,610	£205,296	£2,867,770	**£1,728,723**
CHAS at Home unplanned	£284,762	£1,601,409	£87,778	£0	£0	£1,689,187	**£1,404,425**
Diana Children's Nurses	£424,689	£184,107	£0	£0	£0	£184,107	**-£240,582**
Bereavement services	£772,889	£150,732	£15,023	£3,849,300	£197,400	£4,212,455	**£3,439,565**
Volunteering	£497,615	£0	£737,243	£0	£0	£737,243	**£239,628**
Support for non-specialists	£0*	£441,530	£0	£0	£0	£441,530	**£441,530**
Staff training	£0*	£213,249	£0	£0	£0	£213,249	**£213,249**
TOTALS	**£17,914,043**	**£15,673,408**	**£3,770,512**	**£27,440,010**	**£2,455,656**	**£49,339,586**	**£31,425,543**

* The costs of providing this is integral to other hospice care services.

4.4 RETURN ON INVESTMENT

The results of the return on investment (ROI) calculations for CHAS services are shown in Table 4.8. This shows the ROI for each individual service and the total of all services, in four ROI scenarios:

- Value of health care resource use outcomes and statutory funding only
- Value of health and social care resource use outcomes and statutory funding only
- Value of all outcomes and statutory funding only
- Value of all outcomes and total running costs

Table 4.8: Estimated return on investment of CHAS Services

SERVICE	ROI (Healthcare resource use outcomes)	ROI (Health & social care resource use outcomes)	ROI (All outcomes)	
	Statutory funding only	Statutory funding only	Statutory funding only	Total running costs
Hospice care planned	160%	224%	877%	266%
Hospice care unplanned	69%	98%	98%	-26%
CHAS at Home planned	8%	22%	573%	152%
CHAS at Home unplanned	1,404%	1,486%	1,486%	493%
Diana Children's Nurses	-33%	-33%	-33%	-57%
Bereavement services	-48%	-43%	1,357%	445%
Volunteering	-100%	296%	296%	48%
TOTALS (all services)	**130%**	**185%**	**624%**	**175%**
Hospice care planned, CHAS at Home planned & DCNs	133%	188%	789%	242%

The ROIs for staff training, and for providing specialist clinical support for non-palliative clinicians in the community, are not calculated, as the costs are integral to other hospice care services. The estimated value of benefits is noted in Table 4.7.

4.4.1 ROI from Statutory Funding

When considering only the statutory funding received from the Scottish Government/NHS Health Boards and Local Authorities, the overall return on investment from CHAS service outcomes was estimated to be 624% in 2018/19. In other words, for every £1 spent, one can expect a return equivalent to the value of £6.24. If only the benefits associated with the estimated avoided health care resources are considered, i.e. the value of statutory care cost offsets (£15,673,408) there is an estimated ROI of 130%. When health and social care benefits are also considered (£19,443,920), the ROI increases to 185%. This is due in part to the inclusion of benefits from the avoided local authority bed nights for children and their families, plus the support provided for siblings which may avoid the need for education welfare support.

There is considerable variation in the estimated ROI for the individual services included in the analysis. Those with the greatest estimated ROI when considering health and social care outcomes are hospice based planned care and CHAS at Home unplanned care, with estimated ROIs from the statutory funding of 224% and 1486% respectively. For hospice based planned care, the costs of providing the service are low relative to the expected alternative (e.g. acute hospital admission for BCYP, and the use of mental health services for families). Unplanned hospice care shows a good ROI, of 98%, when considering only health and social care resource use outcomes. While this is lower than hospice based planned care, this is not unexpected, as unplanned inpatient care is resource intensive, being the most expensive service relative to the number of BCYP receiving it.

The ROI from CHAS at Home planned care (22% when considering health and social care outcomes), may be underestimated, as the analysis includes only those BCYP who did not also use hospice based services. The costs of providing CHAS services in the home may be slightly underestimated due to the exclusion of medical staffing costs. However, the costs remain low compared to the potentially expensive healthcare use, such as an admission to hospital, which may be avoided by caring for BCYP at home.

The DCNs show a negative ROI of -33% against the statutory funding. This is mainly due to the low numbers of children/young people recorded as receiving only the DCN service (to avoid the risk of double counting benefits for those that access other CHAS services), and is also due to DCN vacancy. Furthermore, this does not include the significant training aspect of their role which builds skills and confidence of colleagues in the hospitals.

Bereavement services show a negative ROI of -43% against statutory funding. This is not surprising, as any avoided service use for mental health support is low cost, while the main benefit accruing from this service is the wider benefit of improved mental health. When these benefits are included, the ROIs for bereavement services increases to 1,357%. The inclusion of estimated mental health benefits also increase the ROIs of hospice planned care and CHAS at Home planned care, to 877% and 573% respectively.

It is important to note that, as there is some uncertainty in some of the estimates, and the allocation of costs to services, the ROI from individual services may vary from the values here. Hence, the overall ROI from CHAS services of 624% is the more relevant figure to consider. When the costs and benefits values of the all hospice based, CHAS at Home and DCN services are combined, this shows substantial ROIs in all four ROI scenarios.

4.4.2 ROI from Total Costs

When the value of all outcomes is compared to the total running costs of the services, the ROI values reduce, as expected. Nevertheless, there is an estimated total ROI of 175% when taking into account the value of all outcomes. The services with the greatest estimated ROI are CHAS at Home unplanned care and bereavement services, which are estimated to bring considerable benefits for the system and for BCYP and their families, at relatively low cost.

The only services returning a negative ROI are the DCNs and hospice unplanned care. However, it should be acknowledged that this evaluation has sought to model only a portion of the DCN's work, and some of the benefit of the DCNs will be reflected in the benefits attributed to the hospice planned and unplanned work. As stated above, hospice based unplanned care is resource intensive compared to other CHAS services.

4.5 SENSITIVITY ANALYSIS

A number of sensitivity analyses were carried out to examine the effect on the results of changing assumptions or activity levels. The value of outcomes and the ROIs for a number of scenarios, when considering all CHAS services and only the statutory funding, can be seen in Table 4.9.

The scenarios tested show that the results for health and social care outcomes, and for all outcomes, are not particularly sensitive to the assumptions about the number of hospital admissions which are prevented by CHAS services (scenarios a and b). While the value of a prevented hospital admission is high, the assumptions made are conservative and this therefore makes a relatively small contribution to the overall benefits total, so adjusting this up or down does not impact the ROI a great deal.

The results do show however, that the ROI is affected by the scenarios which change the proportion and type of care which is provided by CHAS at Home. Scenarios d and e show that when the proportion of CHAS at Home which is unplanned care increases, the ROI increases. This is due to the fact that the service is provided at relatively low cost, but has the potential to prevent costly healthcare use in the form of admissions to hospital. Similarly, if the number of BCYP receiving planned and unplanned care by CHAS at Home increases substantially to pick up all of those BCYP who would have received planned care in the hospice (scenario f), the ROI for health and social care outcomes increases from 185% to 247%, and for all outcomes from 624% to 686%. In this scenario, the individual ROI for CHAS at Home planned care is 841% and for CHAS at Home unplanned care is 2,206%. This large increase is due to the low costs of CHAS at Home compared to hospice care. If the number of BCYP included in the analysis of CHAS at Home is increased to include all (and not just those who received only CHAS at Home), and the number of BCYP included in hospice base care reduced to include only those who received hospice care only (121 individuals), the benefits value increases by over £2.3 million. This scenario is reflective of the potential shift in service provision from hospice to home that is currently occurring due to the Covid-19 pandemic.

The results are sensitive to the assumptions about the number of family members experiencing quality of life and mental health improvements as a result of the family using CHAS services (scenario h). When this is reduced to three family members (from 4.7), the ROI from all outcomes reduces to 478%, largely due to the reduction in value of quality of life gains from improved mental wellbeing.

When the number of family members who would have suffered from mild depression in the absence of the CHAS services is reduced from three to one (scenario i), the ROI from health and social care resource outcomes reduces to 175%, due to the reduction in avoided mental health services. There are also reductions in societal gains from a reduction in avoided sick days. The benefits still very much outweigh the costs, however.

The ROI from all outcomes reduces somewhat when the benefits value of volunteers is removed (scenario l). CHAS benefits from many volunteer hours per year, so if this is removed, the value from a societal perspective is reduced. The results are not greatly affected by removing the assumed benefits value from support for non-palliative care clinicians in the community, and from staff training.

Table 4.9: Value of outcomes and ROIs for statutory funding for different scenarios

Scenario	Value of outcomes		ROI	
	Health & social care resource outcomes	All outcomes	Health & social care resource outcomes	All outcomes
Base case analysis	*£19,443,920*	*£49,339,586*	*185%*	*624%*
a) The number of expected hospital admissions avoided is reduced by 50%.	£19,278,346	£49,174,012	183%	621%
b) The number of expected hospital admissions avoided is increased by 20%.	£19,510,150	£49,405,816	186%	625%
c) The proportion of care provided in the hospice which is planned:unplanned is varied to 80%:20%.	£17,798,120	£47,693,786	161%	600%
d) The proportion of care provided by CHAS at Home which is planned:unplanned is varied to 90%:10%.	£18,648,377	£48,544,043	174%	612%
e) The proportion of care provided by CHAS at Home which is planned:unplanned is varied to 65%:35%.	£20,637,235	£50,532,901	203%	641%
f) The number of BCYP supported just by CHAS at Home is increased substantially, such that hospice beds support only unplanned care, in the same proportion as in the base case i.e. 35% of capacity (3 beds). i.e. Of 465 BCYP supported by CHAS in 2018/19, 137 BCYP supported by hospice only, 36 by DCNs only and remaining 292 by CHAS at Home only with 65%:35% planned:unplanned care.	£23,672,866	£53,568,532	247%	686%
g) The number of avoided GP appointments for children and young people at the end of life is increased by 50%.	£19,448,834	£49,344,500	185%	624%
h) The average number of family members experiencing improvements in mental health quality of life is decreased to three per BCYP cared for by CHAS, in line with the evidence from Canaway *et al*.	£19,443,912	£39,409,468	185%	478%
i) The number of family members who would have suffered from depression in the absence of the CHAS services is reduced to one.	£18,727,585	£47,685,131	175%	600%
j) The proportion of siblings benefitting from bereavement service and therefore not requiring education welfare support is increased to 20%.	£19,463,950	£49,359,616	186%	624%
k) The number of families bereaved in 2017/18 is increased from 70 to 95. For rationale see Section 3.7.1.	£19,532,091	£50,873,007	187%	646%

Scenario	Value of outcomes		ROI	
	Health & social care resource outcomes	All outcomes	Health & social care resource outcomes	All outcomes
l) The benefits from volunteering are removed.	£18,706,677	£48,602,343	175%	613%
m) The benefits from specialist advice to non-palliative care clinicians are removed.	£19,002,390	£48,898,056	N/A	N/A
n) The benefits from staff training are removed.	£19,230,671	£49,126,337	N/A	N/A
o) The potential outcome benefits of the Glasgow hospital team are included.	£19,530,415	£49,426,081	187%	625%
p) All users of any CHAS at Home services (308)* are included in the CHAS at Home analysis and those using hospice based services only (121) are included in the hospice based analysis. *CHAS at Home number derived from total (465) minus hospice only (121) minus DCN only (36) = 308.	£17,707,845	£51,721,643	220%	659%

Section 5: Discussion

5.1 OVERALL CONCLUSIONS

As the prevalence of BCYP with palliative care needs in Scotland increases, along with a rise in the complexity of cases, it is important that there are effective and cost effective services for this group. During 2018/19, CHAS looked after 465 BCYP with life-shortening conditions and their carers and families. The services are highly valued by families and by professionals alike. This evaluation has updated previous reports in 2016 and 2018, which estimated the value of the services provided by CHAS, based on an understanding of the benefits generated for BCYP and their families.

Adopting a conservative approach, and accepting the limitations of the analysis detailed in Section 5.3, the base case economic evaluation has found that CHAS services continue to generate substantial net benefits. The total costs of service delivery are calculated to be £17.9 million in 2018/19, while generating an estimated benefits value of £49.3 million. This is a return on investment of 175%, or £1.75 equivalent value for every £1 spent on service delivery, when taking a health, social care and societal perspective on outcomes. CHAS received just over £6.8 million in statutory funding, from the Scottish Government/NHS Health Boards and Scottish Local Authorities, which represents 38% of the 'running costs'. When considering the value of benefits generated against this funding, this an ROI of 624%, a return equivalent to the value of £6.24 for every £1 spent. Even if only the benefits attributable to avoided health and social care resource use are taken into account (i.e. direct cost reduction to the NHS and local authorities), then over £19.4 million of benefits value is estimated – a return on investment of 185% against the statutory funding received.[44]

The benefits generated by CHAS services include cost reductions attributable to avoiding the need for BCYP and their families to use health and social care services. These can be either through avoidance of illness, or substitution of care into the hospice or hospice at home setting. Societal benefits were also identified, particularly for adult carers of children and young people with life-shortening conditions, who are able to work as a result of the support received from CHAS. The service also benefits from a significant input from volunteers, providing important additional capacity.

The greatest proportion of the outcomes value accrued by CHAS services is for improved mental health and quality of life. This is reflective of the fact that hospice and palliative care is providing a better patient experience and has wider benefits for their family. While this comes at a cost, there is also good evidence that the services will reduce demand on other statutory health services, while providing a more tailored and appropriate intervention for BCYPs and their families.

[44] The values in the analysis cannot be directly compared to previous economic evaluation reports, as updated benefits values have been used when new evidence and unit costs become available. In some cases these values may be lower, in order to take a conservative approach.

It has not been possible to quantify improved mental health and wellbeing for the BCYP, or any potential extension of life as a result of hospice services. The lack of published evidence on these benefits in children and young people does not necessarily mean that they do not occur. CHAS staff report observing longer than expected survival for some BCYP once transferred to the hospice environment. It is speculated that this may be due to the involvement of expert palliative care clinicians, taking a holistic approach to palliating disease; for example, by ceasing of quite toxic medications.

A further calculation has been performed, to estimate the ROI against only the income that CHAS receives via fundraising (£9,164k in 2018/19). When considering the value of all outcomes against the fundraising income, the net benefit is £40,175,586, giving an ROI of 71% for healthcare outcomes, 112% for health and social care outcomes, and 438% for all outcomes. Clearly this gives only a partial picture, in a similar way to considering the benefits against only the statutory funding. In reality, both the statutory funding and the income from fundraising are interdependent, and the ability of CHAS to provide its current services would be severely curtailed without both sources of income.

5.2 INDIVIDUAL SERVICES

The economic evaluation has estimated the cost and benefits from individual services provided by CHAS, taking account of the support services required and the distribution of clinical staff across them. It should be noted, however, that there are some uncertainties in the allocation of costs to services, and the ROI from individual services may vary from the values shown here. All hospice based and CHAS at Home services return a positive ROI against the statutory funding, this despite the analysis of CHAS at Home including only those BCYP who received only CHAS at Home services, to avoid the risk of double counting benefits accrued by care in the hospice. The largest amount of resource goes into hospice based planned care and this is the cornerstone of the services CHAS provides. Therefore for the analysis, the majority of the estimated benefits were associated with this service. The highest returns from a health and social care perspective are for planned care, CHAS at home unplanned care and for volunteering. The DCNs return a negative ROI, due to the low numbers of BCYP included in the analysis (i.e. those supported only by the DCN service). However, due to a vacancy, the service was not operating at full capacity. Furthermore, the analysis does not capture the benefits of DCN training and support for hospital based colleagues, nor does it include the care that DCNs provide to other BCYP who are not formally ‘referred’ to the service.

The ROI from the Family Support team includes the potential outcomes from bereavement support. The results show a positive ROI compared with the statutory funding (1,357%) and compared with total costs (445%). The ROI becomes negative when compared with healthcare and social care outcomes only (-43%). This is to be expected, as the principal benefit from bereavement counselling is the mental wellbeing of the recipients. While this may avoid future use of mental health services, the value of this is not estimated to exceed the cost of providing the service. It is important to note that the Family Support team provides other interventions which are not included in the analysis, so this is a conservative estimate.

At the time of writing, during the Covid-19 pandemic, the ability to provide support to clinicians in the community is important. Participation in the ECHO project enables CHAS to convey expertise to other non-CHAS settings, helping to connect teams, giving them knowledge and confidence to care for children with palliative care needs wherever they are. The estimated benefits value of providing specialist clinical support for non-palliative clinicians and for staff training are listed in the analysis. ROIs have not been calculated however, as the input costs are integral to other hospice care services. Furthermore, while there is evidence for the benefits in the literature, attribution of such benefits to this activity at CHAS is difficult to demonstrate.

For some of the services provided, such as Family Support and bereavement counselling, it is possible that alternative healthcare might not be provided if CHAS services were not available. In the absence of these services, while the costs of service provision may not be incurred, there would likely be some adverse outcomes for the BCYP and their families. Hence, the quantification here indicates a proxy value of the service in terms of the benefit generated. The value of the contribution of volunteers was estimated to be £737k in 2018/19. This does not include any wider health benefits that may be accrued by the volunteers themselves through their voluntary activities. Evidence and feedback from CHAS volunteers suggests that the emotional support and practical assistance offered by volunteers is likely to lead to mental health benefits for both the BCYPs, their families and the volunteers. These benefits are hard to measure and value, plus there is a risk of double counting, so the only benefit included in the analysis is the equivalent value of volunteer hours.

The sensitivity analyses found that the scenarios which increase the proportion of care in the CHAS at Home service that is planned, versus unplanned, increases the ROI. This is due to the fact that the service is provided at relatively low cost, but has the potential to prevent costly healthcare use in the form of admissions. The scenario which tests the impact of shifting a large proportion of care to CHAS at Home, (such that the hospice provides only unplanned care), finds a greater net benefit and ROI than the base case analysis, due to the low cost of providing these services compared to the potentially high value of the alternative healthcare. This is not entirely surprising, as hospice based care is likely to be more resource intensive than providing services in a family's home. To be able to choose 'place of death' is important however, with evidence suggesting that the transfer from hospital to hospice care for end of life can increase the likelihood of a 'good death' experience. This brings societal value for both the BCYP and their families, and may have benefits in terms of reducing future use of mental health support.

In conclusion, the economic evaluation supports the analysis framework's assertion that children's hospice care services can generate benefits across the health and social care system. In our analysis, while we are not wishing to claim that CHAS services can be delivered at a lower cost than statutory services, CHAS clearly has the potential to reduce demand on the statutory sector, while also providing a choice of services for BCYP and families. Additionally, the evaluation demonstrates that CHAS has the potential to bring wider societal benefits for BCYP who need their services, their families and for volunteers.

5.3 LIMITATIONS OF THE ANALYSIS

There are some limitations of the analysis, as follows:

- The analysis has had to use assumptions about the extent of the economic benefits generated through CHAS services and there is no guarantee that these reflect reality. The assumptions are based on literature evidence, (mostly from the literature review for the previous economic evaluation reports) and from clinical opinion. With this in mind, the assumptions made have been conservative. Some examples of the conservative approach used to carry out the analysis are:
    - Mental health QALY gains for children and young people were not included.
    - No benefits were ascribed to prolonged life for children and young people.
    - The benefits were modelled over one year only, whereas some of the benefits will last longer than one year (with the exception of the mental health QALY, which measures lifetime benefit).
    - For CHAS at Home planned care, only those children and young people who did not also use the hospices were included in the analysis.
    - The benefits of domiciliary medical support are not explicitly included as they are difficult to measure and value. It was assumed that the benefit of domiciliary medical visits is subsumed into the CHAS at Home visits and these were assumed to be for emergency care. In fact, the medical team visits may well be over and above the CHAS at Home nursing team and/or with different BCYP.
- CHAS is a complete palliative care service, offering multi-disciplinary care which is, by intention, seamless between the different component parts. This means there is a risk of double counting benefits and the assumptions made are careful not to do so. The analysis, therefore, used a conservative approach to the estimation of the benefits of CHAS services. For example, in some cases numbers of beneficiaries were minimised, such as the inclusion of benefits for BCYP who only received CHAS at Home services rather than the majority who also received hospice services.
- Where there is insufficient data or evidence available, or because there is a chance of double counting benefits, some services have not been included in the quantitative analysis.
- There is an assumption that the healthcare system has the capacity to provide the services which are potentially avoided by hospice care e.g. community mental health services exist, so the use of them can be prevented. In reality, the BCYP may merely have to manage without any care provided, and the values attributed represent a proxy value for the benefits the BCYP gain from the services.
- Benefits may be underestimated due to:
    - The outcomes from Family Support includes only bereavement services. Other activities are not included in the analysis, to avoid the risk of double counting.
    - The benefits of the 24hour advice line are not included, which has the potential to avoid use of healthcare resources when non-palliative care clinicians can access advice and clinical expertise for the care of their patients.
    - The benefits of the Care24 service are not included, which has the potential to reduce the incidence of unplanned hospital admissions and use of out of hours services.

- It was necessary to generalise the analysis approach and to treat all BCYP and their carers and families the same way. In reality it is acknowledged that there is a great deal of variation in case mix, both between BCYP of different ages and with different conditions and severity of condition.

5.4 OTHER DEVELOPMENTS

There are some issues which have a bearing on the nature of service provision in 2019/20 and into the future which merit mention, as follows.

5.4.1 Covid-19

Although the analysis year for the report is 2018/19, it must be acknowledged that the Covid-19 pandemic in 2020 has had a dramatic impact on CHAS and the services it has been able to provide. Planned hospice care was ceased for a time, with many nurses furloughed. Admissions were limited to unplanned admissions only, with the priority being of crisis and unplanned care, with the hospices providing care for symptom management; deterioration in clinical condition; care package breakdown; housing crisis or whenever a family's resilience is challenged by these unprecedented circumstances. Fundraising activities were also dramatically reduced. In response, CHAS drove forward its model of care for a virtual hospice and also increased its resource to CHAS at Home, with staff being deployed to work in people's homes to a greater extent than previously. This has been facilitated by the flexible approach to staff working arrangements already in place, whereby hospice based staff would work with CHAS at Home for a month to become familiar with the service. CHAS has also worked in partnership with the NHS and social care, looking to support with additional capacity in areas which were struggling in order to help keep children at home if possible. There may be implications for any future analysis of the activity in the current financial year, as activity data will be affected, and new ways of working may mean that not all activity is captured.

A sensitivity analysis considers an increase in the proportion of BCYP who are cared for by CHAS at Home rather than in one of the hospices. This has found that a shift to care in the home would appear to be able to maximise the use of CHAS resources. This is because the costs associated with CHAS at Home are lower than providing care in the hospices, due in part to the associated overheads that come with hospice estates. This analysis cannot, however, make the assumption that the outcomes are equivalent by providing care at home.

5.4.2 Virtual Hospice

The CHAS Strategic Plan states an intention to increase its 'digital offer' to increase access to CHAS services to those who are not able to attend the hospice.[45] The advent of Covid-19 accelerated these developments, in order to be able to provide palliative care and support to families while face-to-face services were severely curtailed. This has included many activities to replace the usual care provided in the hospices, but also to enhance the service offer from CHAS.

[45] CHAS. Reaching Every Family in Scotland. Our Strategy plan for 2020 to 2023.

A mechanism was developed to do virtual clinic visits, either with one clinician or taking a multidisciplinary team approach. Virtual visits have an advantage of being easier for families who don't need to travel and are therefore not restricted by geography. Also, staff are able to reach more families compared to the in-person visits to the hospice where the staffing ratios are higher. The team make proactive 'triage' calls to families, rather than waiting for them to call the hospice. In usual times these are conducted six-weekly and may potentially being three-monthly if one scheduled call is missed. During 2020, these have been more frequent, weekly in some cases, where that has been required and requested by the family.

A programme of activities has been offered for children and their families. While not a full day programme as in the hospice, half day sessions have been tailored to different groups, (e.g. pre-school, 8-11 years, teenagers), each with an age appropriate theme (e.g. a bear hunt for pre-school, gaming for teenagers). To simulate the hospice experience for the wider family as much as possible, takeaways and pamper packs have been provided. A virtual youth club developed as an offshoot, whereby some young people continue to meet online every second Thursday evening. This enables them to interact with other young people who they may not have encountered previously.

Other activities include:

- Virtual bereavement sessions with social workers.
- Clown Doctors' doing Zoom sessions with music therapy charity Nordoff Robbins.
- Activity packs, for very small children and their siblings to do activities such as painting and puppet making.
- 'CHAS does summer', in lieu of a summer camp, including Book Bug sessions, art and music therapy sessions.

Not only has the virtual hospice demonstrated what is possible, but there are some advantages, such as being able to 'see' more people than would be possible face-to-face, and bringing families together in a virtual environment who wouldn't usually have encountered each other in the hospice. The next stage is to evaluate the service and test the financial benefit of this approach, to assess which elements will be a valuable addition to the CHAS service offer in the longer term.

5.4.3 Paediatric Supportive and Palliative Care Team

The Paediatric Supportive and Palliative Care Team provides specialist palliative care support in the Royal Hospital for Children, Glasgow (RHC). The service started in 2019/20 and is the first in-hospital team of its kind in Scotland, providing care across the paediatric spectrum, from the antenatal period up to 16 years of age. CHAS funds a consultant, two clinical nurse specialists and a team administrator to work across wards and ensure children with a life-shortening condition consistently experience palliative and end of life care, on both an inpatient and outpatient basis.

Referrals are made either by the primary specialist team or by the paediatric intensive care unit (PICU), with approval from the primary specialist team. In the first year of the service 86 referrals were made and accepted by the team, 60% of whom were not previously known to CHAS. 27 of the referrals came from the intensive care team (19 from PICU and 8 from NICU). 90% of children/young people supported had a non-malignant condition and 85% were unstable, deteriorating or dying.[46] In the first year, 68 BCYPs (79%) were referred for anticipatory care planning and complex decision making, and end of life care provision. 82% died within a month of the referral to the team, giving an indication of the urgency of the response required by the team. The team have formalised a bereavement pathway to ensure that all families receive support following the death of their child. The team also plays an active role in education and training of other staff, in recognition of the importance of supporting clinicians to develop confidence and competence in the provision of palliative care.

CHAS also works with NHS Health Boards to part-fund consultant posts with experience and expertise in palliative care. These include NHS Grampian (0.5FTE), NHS Lothian (0.2FTE), NHS Ayrshire and Arran (0.5FTE), and NHS Greater Glasgow and Clyde (0.6FTE). Specialisms include paediatric palliative care, neonatology, paediatric oncology, general paediatrics, and neurodisability.

The proposed benefits of providing specialist palliative care input in non-palliative care environments are a contribution to improved quality of care towards the end of life, with an enhanced holistic approach which may contribute to increased quality and length of life. From a resource use perspective, this could assist earlier discharge from an intensive environment to general ward or from a general ward to home or hospice. Input from the Paediatric Team also upskills those working alongside CHAS staff, while freeing up time of the CHAS medical team for non-hospital based work.

Evidence for the cost effectiveness of this approach comes from a retrospective study by Fitzpatrick *et al*, who found that early intervention with inpatient palliative care consultation in hospital correlated with shorter length of stay, with no negative effect on mortality.[47] May *et al* observed cost savings from early palliative care consultation in hospital, arising from reduced length of stay and reduced intensity of treatment, with an estimated 63% of savings associated with shorter length of stay.[48] When the referrals received by the Paediatric Supportive and Palliative Care Team are assumed to reduce the length of hospital stays (NICU/PICU referrals by four days and general ward referrals by one day), the estimated benefits value is £371,610 over the first year.[49]

[46] NHS Greater Glasgow & Clyde & CHAS. Riyal Hospital for Children, Glasgow. Paediatric Supportive and Palliative Care Team 2019/20 ANNUAL REPORT FINAL
[47] Fitzpatrick J, Mavissakalian M, Luciani T *et al*. Economic Impact of Early Inpatient Palliative Care Intervention in a Community Hospital Setting. J Palliat Med. 2018 Jul;21(7):933-939.
[48] May P, Garrido MM, Cassel JB *et al*. Cost analysis of a prospective multi-site cohort study of palliative care consultation teams for adults with advanced cancer: Where do cost-savings come from? Palliat Med. 2017 Apr;31(4):378-386.
[49] Analysis based on extrapolated full year effect due to Covid-19 (67 referrals in 6 months, equates to 134 referrals per year).

This represents only a partial 'value' of the team. Evaluation with families refers to improving quality of life for their child, increasing control over their lives, and avoiding unnecessary hospital admissions. Professional feedback has been very positive, finding the team collaborative and supportive, while educating others about a holistic approach to the care of children and their families. These non-tangible benefits cannot easily be monetised and would be difficult to include in an economic analysis. The findings from the CHiSP Phase 3 report shows that more children die in hospitals than any other setting.[50] CHAS is therefore committed to working with hospital teams to support families wherever they are.

5.4.4 Case complexity

The ChiSP study set out to identify the number of BCYP with life-shortening or life-threatening conditions in Scotland and to describe this population in terms of their ages, conditions/diagnoses, geographic locations and ethnicity.[51] The study showed a rising trend in the numbers of BCYP with life-shortening conditions (the report uses life-limiting conditions as an umbrella term to also cover life-threatening conditions) in Scotland. Indeed, CHAS staff report that the BCYP being seen nowadays are more complex than four years ago. The 2019 Phase of Illness Study found that the proportion of BCYP whose current phase of illness is 'unstable' has increased compared to the previous year.[52]

In response, CHAS has upskilled staff, such as advanced nurse practitioners, and increased the medical staffing. In recognition of the increased complexity of cases, the value of an avoided hospital admission has been increased in this analysis, to reflect the likelihood that some of the admissions would be in critical care and not on a general ward.

5.5 RECOMMENDATIONS

A number of recommendations are proposed as a result of the evaluation:

- Providing care at home: the analyses suggests that there are opportunities to achieve greater net benefit by shifting the balance of care in the hospices to care at home. While there may be efficiencies from this service model, any future economic analysis should be careful to understand the impacts of this service delivery on children and families and not assume equivalence of outcomes.
- Virtual hospice: the developing approach to a virtual hospice has the potential to bring efficiencies to the CHAS service offer and any future economic analysis should consider the costs and benefits of this service once it is established.
- Diana Children's Nurses: the benefits value of the DCNs is lower than expected, as the numbers of BCYP seen only by the DCNs was lower in 2018/19 than in the previous year. While the data have been checked, for future analyses it may be worth reviewing the way data are recorded to ensure all DCN activity is captured,

[50] Children and Young People in Scotland with Life Limiting Conditions - Phase 3. NHS National Services Scotland (XRB17085). 15 June, 2020
[51] Fraser L, Jarvis S, Moran N, Aldridge J, Parslow R, Beresford B. Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study). University of York. November 2015.
[52] CHAS. Phase of Illness Study (SUDD) July-September 2019.

including measures to demonstrate the impact they have on the NHS colleagues with whom they work.

- Planned:unplanned bed days: the number of bed days and admissions that are classed as planned and unplanned in the Service Activity statistics appear different to the proportion of bed capacity which is used for planned and unplanned care, a view also supported by CHAS staff. As planned and unplanned care have the potential to bring different benefits to the health and social care system it would be worth considering how planned:unplanned care is categorised for any future analyses.
- Further qualitative and quantitative research could be carried out to understand the extent to which the assumptions made about the benefits of CHAS services are correct. For example, children and their families could be interviewed to understand the benefits gained or data could be collected to understand the extent to which the use of a CHAS service reduced the need to access a statutory service.
- CHAS and statutory bodies should investigate the extent of unmet need in terms of palliative care for BCYP with life-shortening conditions and also any variation in provision across different areas of Scotland.
- The Scottish Government, Local Authorities and NHS Health Boards should consider increasing the level of statutory funding available for CHAS services, particularly given the likelihood that the services reduce the burden of health and social care resource use.
- Given the substantial involvement of volunteers, it would be useful to attempt to quantify the wider benefits for the volunteers themselves in any future economic reports.

Appendix A: Outcome Proxy Values

Table A1: Outcome proxy values

Item	Source of proxy value, including assumptions	Unit value of outcome (2019)
Admission to hospital	PSSRU 2015 values, uprated to 2019. Cost of one palliative care inpatient stay for children and young people (PSSRU 2015): average for short and long illness trajectories for cancer admission (£2,495), cystic fibrosis admission (£4,195) and weighted with 7 day step down care for cardiac admission (£12,667) in ratio of 50% inexpensive to 50% expensive = total of £8,006..	£8,491
Bed days: less expensive	PSSRU 2015 values, uprated to 2019 Cost of bed day for children and young people with palliative care needs: less expensive stay e.g. local hospital for respiratory infection (£499 per day);	£529
Bed days: expensive	PSSRU 2015 values, uprated to 2019. Cost of bed day for children and young people with palliative care needs: expensive stay e.g. paediatric cardiac unit/PICU (£1810 per day).	£1,919
Bed day: average	Based on PSSRU 2015 values, uprated to 2019, average of less expensive and expensive	£1,224
Hospital outpatient appointment (England)	PSSRU 2019: Outpatient, medical specialist palliative care attendance (adults and children)	£202
GP appointments	PSSRU 2019: GP visit: £39 each, including direct care costs and qualification costs	£39
Prescribing costs at GP appointment for BCYP	PSSRU 2019. Prescription costs per consultation (actual cost)	£30.90
GP/primary care for mental health problems	PSSRU 2019: GP visit: 3 at £39 each, plus one year's prescription costs for citalopram tabs 20mg per day (BNF, 2020) £10.92 (£0.91 x 12) Drug tariff price,	£127.92
Community mental health services for depression (England)	PSSRU 2015 values, uprated to 2019. Average cost of treating a case of depression by community mental health team for adults with mental health problems. Using convention from previous PSSRU manuals - annual cost of team CMHT member (£60,645) divided by annual cases per CMHT (24) = £2526.88	£2,615
Improved mental health status	"Based on EQ-5D scores for depression severity categories: from Jia & Jubetkin 2017. EQ-5D non/minimal 0.875, EQ-5D mild depression 0.680, Therefore HR QoL is 0.195. Assume over one year. At Green Book societal value of QALY of £60,000 per QALY: 0.195 x £60,000 = £11,700."	£11,700
Local authority respite nights (BCYP)	PSSRU 2018 short break provision for disabled children and their families, mean cost £310 per residential child night (24-hour period), uprated to 2019 using NHSCII Index at 2.31%.	£317
Local authority respite nights (family)	PSSRU 2018 short break provision for disabled children and their families, mean cost £201 per family-based overnight (24-hour period), uprated to 2019 using NHSCII Index at 2.31%.	£206

Item	Source of proxy value, including assumptions	Unit value of outcome (2019)
Average of LA respite for BCYP and hospital stay	Calculated as average of LA respite night and hospital bed day	£246
Education welfare officer	PSSRU 2015: support for family, where there is child behaviour and attendance problems, including education welfare input, figure of £2,698, updated to 2018/19 using NHS Cost Inflation Index (£2,862).	£2,862
Productivity value (annual)	Median Scottish salary in 2019 £24,440. Calculated from £470 per week x 52, source: https://spice-spotlight.scot/2019/10/31/earnings-in-scotland-2019/	£24,440
Productivity (sick day)	Median Scottish salary in 2019 £24,440. Calculated from £470 per week divided by 5, source: https://spice-spotlight.scot/2019/10/31/earnings-in-scotland-2019/	£94
Value of volunteering	ONS. Changes in the value and division of unpaid volunteering in the UK: 2000 to 2015 (available at: https://www.ons.gov.uk/economy/nationalaccounts/satelliteaccounts/articles/changesinthevalueanddivisionofunpaidcareworkintheuk/2015#valuation-of-unpaid-formal-volunteering). Average value per hour based on total value (£22.62bn) and number of hours (1.93bn) in 2015 = £11.72. Updated to 2018/19 using NHS Cost Inflation Index (£12.43).	£12.43

Appendix B: Service Benefits and Assumptions Used in the Analysis

Table B1: Service Benefits and Assumptions Used in the Base Case Analysis

Service	Proposed Benefits	Assumptions (based on literature evidence and/or clinical opinion)

Hospice based: planned care	Health & social care service use:
	• Avoided hospital admissions, GP appointments, local authority respite care for children/young people.
	• Avoided costs of prescribing and other medical interventions as a result of ceasing treatments (aligned to anticipatory care planning).
	
	Other benefits:
	• Improved mental health & wellbeing for children/young people, parents and siblings able to cope, leading to:
	  ○ reduction in health care resource use for mental health for families
	  ○ improvements in productivity
	  ○ better school attendance
	A good death, in preferred place
		• The benefits for hospice care will be applied to the numbers of children/young people 'supported during the period', minus the number seen only by the DCNs (Section 2.4) and those receiving only CHAS at Home care (Section 2.3).
		• For the purposes of estimating costs, planned care is assumed to account for 65% of the resource use in the hospice. This is based on the use of the beds in each hospice (three of the eight beds are reserved for unplanned admissions). Note: although this does not tally with the activity data, in which 88% of bed nights are classed as planned, this is suggested to be a more accurate reflection of the balance of planned versus unplanned activity.
		• Half of the children/young people cared for by CHAS would experience two hospital admissions per year (average of one per child/young person). 10% of these episodes of hospital care would be prevented as a result of improved wellbeing resulting from care received during short breaks.
		• In the absence of short breaks provision, an equivalent number of bed nights in either local authority respite care or less expensive hospital stay would be used (for BCYP and family). Base case is 50:50.
		• The 'spill-over' effects of palliative care will affect all close family members (parents or carers and siblings), who will experience improved mental health quality of life as a result of the services provided.
		• For half of the children/young people admitted for short breaks, it is assumed that three family members would have suffered from depression without the increased resilience gained from access to short breaks provision. For the assumed healthcare use and sick leave for depression amongst family members, see Section 3.11 Other Assumptions.
		• One in ten families is assumed to have one parent or carer who would have had to give up paid employment due to caring duties or stress or mental health problems, if it were not for the respite care support provided.
		• 75% of the children/young people are assumed to have a sibling. 10% of those siblings are assumed to have avoided a problem at school which would have required education welfare support.
		• One admission to hospital is assumed to be prevented during the end of life period for each child and young person who died during the year, as a result of improved wellbeing due to anticipatory care planning.
		• Three GP appointments are assumed to be prevented for each child and young person at the end of life as a result of end of life care and anticipatory care planning.

Service	Proposed Benefits	Assumptions (based on literature evidence and/or clinical opinion)
		• Of the children/young people who died in the hospice or at home (and not in hospital) it has been assumed that one hospital admission would have been avoided.
Hospice based: unplanned care	Health & social care service use for children/young people: • Avoided hospital admissions/HDU beds, day care hospital attendances, GP appointments, LA respite costs, reduced length of hospital stays. Other benefits: • Prolonged life for children/young people.	• For the purposes of estimating costs, unplanned care is assumed to account for 35% of the resource use in the hospice. This is based on the use of the beds in each hospice, where three of the eight beds are reserved for unplanned admissions. Note: although this does not tally with the activity data, in which 12% of bed nights are classed as unplanned, this is suggested to be a more accurate reflection of the balance of planned versus unplanned activity. • 35% of the children/young people supported in the hospices over the year will be assumed to have received unplanned care and will accrue the following benefits: ○ One episode of hospital care prevented in 10% of cases. ○ Six fewer hospital day care attendances in 20% of cases ○ One GP appointment avoided in 100% of cases • These children/young people will accrue these benefits in addition to those arising from planned care described in Section 2.2.1 • Of the hospital admissions that are not avoided, 75% will be assumed to be less expensive hospital stays (e.g. general ward) and 25% will be more expensive hospital stays (e.g. HDU) and will be shortened by four day. • In the absence of hospice provision, an equivalent number of bed nights in local authority respite care or hospital would be used for both children/young people and their families to cover emergency situations. Base case 50:50.
CHAS at Home: planned care	Health & social care service use: • Avoided hospital admissions, GP appointments, local authority respite care for children/young people. • Avoided costs of prescribing and other medical interventions as a result of ceasing treatments (ACPs). Other benefits: • Improved mental health & wellbeing for children/young people, parents and siblings able to cope, leading to: • reduction in health care resource use for mental health for families • improvements in productivity • better school attendance	• The benefits of planned care at home are the same as for planned care in the hospice environment. • The benefits of CHAS at Home planned care will be applied to only those children/young never or rarely use the hospice facilities, in order to avoid double counting of the benefits. • For the purposes of estimating costs, the proportion of CHAS at Home activity which is planned is assumed to be approximately 80%. • Half of the children/young people cared for by CHAS would experience two hospital admissions per year (average of one per child/young person). One episode of hospital care is assumed to be prevented for 10% of the children/young people as a result of improved wellbeing resulting from care received from CHAS at Home. • In the absence of CHAS at Home provision, an equivalent number of bed nights in either local authority respite care or less expensive hospital stay would be used (100% for BCYP and 50% family).

Service	Proposed Benefits	Assumptions (based on literature evidence and/or clinical opinion)
	• A good death, in preferred place	• The 'spill-over' effects of palliative care will affect all close family members (parents or carers and siblings), who will experience improved mental health quality of life as a result of the services provided. • For half of the children/young people admitted for short breaks, it is assumed that three family members would have suffered from depression without the increased resilience gained from access to short breaks provision. For the assumed healthcare use and sick leave for depression amongst family members, see Section 3.11 Other Assumptions. • One in ten families is assumed to have one parent or carer who would have had to give up paid employment due to caring duties or stress or mental health problems, if it were not for the home care support provided. • 75% are assumed to have a sibling. 10% of those siblings are assumed to have avoided a problem at school which would have required education welfare support. • For those children/young people at the end of life who died in 2018/19, the benefits of anticipatory care planning have been included in the hospice planned care section, and not been included again for CHAS at Home planned care.
CHAS at Home: unplanned care	Health & social care service use for children/young people: • Avoided hospital admissions/HDU beds, day care hospital attendances, GP appointments, LA respite costs, reduced length of hospital stays Other benefits: • Prolonged life for children/young people	• The benefits of unplanned care at home, including availability of domiciliary medical support, are assumed to be the same as for unplanned care in the hospice environment. • The benefits of CHAS at Home unplanned care will be applied to all of the CHAS at Home unplanned activity, and not just those children/young never or rarely use the hospice facilities, as this will not risk double counting benefits in the same was as for planned care. • The proportion of CHAS at Home activity which is unplanned is assumed to be approximately 20% i.e. 241 visits. • It is assumed that half of the CHAS at Home visits over the year assumed to have been unplanned care will accrue the following benefits: o One episode of hospital care prevented o Six fewer hospital day care attendances o One GP appointment avoided • These children/young people will accrue these benefits in addition to those arising from planned care described in Section 2.3.1. • In the absence of hospice provision, an equivalent number of bed nights in local authority respite care or hospital would be used for both children/young people and their families to cover emergency situations.

Service	Proposed Benefits	Assumptions (based on literature evidence and/or clinical opinion)
Diana Children's Nurses	Health & social care service use: • Avoided hospital admissions and GP appointments. Other benefits: A good death, in preferred place.	• The additional benefits of the DCN Service are gained by those children and young people who did not receive other CHAS services (36 individuals). • It is assumed that one hospital admission is prevented during the end of life period for 10% of the children/young people receiving improved end of life care by the DCN (4 admissions). • One GP appointment is assumed to be prevented for half of the children/young people at the end of life as a result of the input to care by the DCN (18 appointments). It is assumed that half of the children/young people receiving care from the DCN were able to die in settings other than hospital, thus avoiding one hospital admission 18 admissions).
Bereavement Services	• Improved mental health & wellbeing - parents and siblings able to cope, leading to: ○ reduction in health care resource use for mental health for families ○ improvements in productivity ○ better school attendance	• The additional benefits of bereavement services (over and above benefits from other CHAS services) are gained by the families of the children/young people that died in the previous year (2017/18). This was 70 families. • The 'spill-over' effects of palliative care will affect all close family members (parents or carers and siblings), who will experience improved mental health quality of life as a result of the services provided (329 individuals). • For half of the families receiving bereavement services, it is assumed that three family members would have suffered from depression without the increased resilience gained from bereavement support. (105 individuals). For the assumed healthcare use and sick leave for depression amongst family members, see Section 2.10 Other Assumptions. • Of those family members who have avoided suffering from depression, it is assumed that half would have required greater intensity treatment from community mental health teams and would have required a further 20 days sick leave (52 individuals). • Of the 70 children/young people, all are assumed to have a sibling (70 individuals) and one in 10 of these is assumed to have avoided a problem at school which requires education welfare support (7 individuals).
Support for non-palliative care clinicians	Health & social care service use: • Avoided admission to hospital. Other benefits: • Upskilling of non-palliative care clinicians in the community. • Improved quality of care for BCYPs and ability to remain at home.	• As there is no specific activity recorded for this, we propose to assume that one admission to hospital is avoided per week as a result of the advice available to non-palliative care clinicians in the community (52 admissions). • There are no specific costs and resources identified for this activity, as it is integral to the work of the medical team. Therefore, no costs will be aligned to this activity.
Volunteering	• Improved mental health & wellbeing for families	• As we can't assume that the volunteer hours provided would have been replaced by another service, we will apply a 'value' of volunteer time to the hours of work provided.

Service	Proposed Benefits	Assumptions (based on literature evidence and/or clinical opinion)
	• Financial contribution to service provision • Increased resilience for families and increased ability to cope and live. Improved mental health & wellbeing for volunteers, plus help to gain employment or further study.	Mental health benefits to families won't be included separately as there is a risk that these will double count those mental health benefits already included in hospice planned.
Staff Training	• Sharing info and exploring children/young people with palliative care needs wherever they are. Skill up teams and give them confidence. • Spread CHAS reach, improve paediatric palliative care, give confidence to non-specialist clinicians.	• We assume additional benefits will accrue from 50% of the non-CHAS staff attending ECHO sessions (50 individuals). • Attendees have the potential to avoid one GP appointment or unplanned hospital admission as a result of improving palliative care knowledge. It is assumed that this is the case for 50% of ECHO attendees in any given year. • The avoided healthcare is split 50:50 between GP appointments and hospital admissions (25 of each).

Appendix C: Service Benefits Value Calculation Tables

Table C1: Service benefits value calculations: Hospice based planned care

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided hospital admissions due to wellbeing from respite care	39	£8,491	£331,148				**£331,148**
Avoided hospital bed nights (BCYP)	2006	£3,548	£7,114,983				**£7,114,983**
Avoided or local authority bed nights (BCYP)	2006	£317		£636,066			**£636,066**
Avoided local authority bed nights (family)	7673	£206		£1,577,900			**£1,577,900**
Improved mental health status of family members	1833	£11,700			£21,446,100		**£21,446,100**
Avoided loss of employment	39	£24,440				£953,160	**£953,160**
Avoided education welfare support	29	£2,862		£83,700			**£83,700**
Avoided use of GP/primary care for family member MH issue/mild depression	585	£128	£74,833				**£74,833**
Avoided sick days for mild depression	5850	£94				£549,900	**£549,900**
Avoided use of community mental health services	293	£2,615	£764,958				**£764,958**
Avoided further sick days for depression	5850	£94				£549,900	**£549,900**
Avoided admission to hospital at EOL due to ACP	84	£8,491	£713,241				**£713,241**
Avoided GP appointments at EOL due to ACP	252	£39	£9,828				**£9,828**
Avoided hospital admission due to BCYP dying in the hospice or at home (good death in preferred place)	41	£8,491	£348,130				**£348,130**
			£9,357,121	**£2,297,665**	**£21,446,100**	**£2,052,960**	**£35,153,846**

Table C2: Service benefits value calculations: Hospice based unplanned care

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided hospital admission	14	£8,491	£115,902				**£115,902**
Avoided hospital day care attendance	164	£202	£33,088				**£33,088**
Avoided GP appointment	137	£39	£5,324				**£5,324**
Less expensive hospital stays shortened by 1 day	102	£529	£54,181				**£54,181**
Expensive hospital stays shortened by 4 days	137	£1,919	£261,967				**£261,967**
Avoided hospital bed nights (BCYP)	788	£3,548	£2,795,704				**£2,795,704**
Avoided local authority bed nights (BCYP)	788	£317		£249,931			**£249,931**
Avoided local authority family bed nights	1576	£206		£324,104			**£324,104**
			£3,266,165	**£574,035**			**£3,840,200**

Table C3: Service benefits value calculations: CHAS at Home planned care

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided hospital admissions due to wellbeing from respite care	4	£8,491	£33,115				£33,115
Avoided hospital bed nights (BCYP)	96	£3,548	£342,002				£342,002
Avoided or local authority bed nights (BYCP)	96	£317		£30,574			£30,574
Avoided local authority bed nights (family)	96	£206		£19,824			£19,824
Improved mental health status of family members	183	£11,700			£2,144,610		£2,144,610
Avoided loss of employment	4	£24,440				£95,316	£95,316
Avoided education welfare support	3	£2,862		£8,370			£8,370
Avoided use of GP/primary care for family member MH issue/mild depression	59	£128	£7,483				£7,483
Avoided sick days for mild depression	585	£94				£54,990	£54,990
Avoided use of community mental health services	29	£2,615	£76,496				£76,496
Avoided further sick days for depression	585	£94				£54,990	£54,990
			£459,096	**£58,768**	**£2,144,610**	**£205,296**	**£2,867,770**

Table C4: Service benefits value calculations: CHAS at Home unplanned care

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided hospital admission	121	£8,491	£1,023,161				**£1,023,161**
Avoided hospital day care attendance	723	£202	£146,046				**£146,046**
Avoided GP appointment	121	£39	£4,700				**£4,700**
Avoided hospital bed nights (BCYP)	121	£3,548	£427,502				**£427,502**
Avoided or local authority bed nights (BCYP)	121	£317		£38,218			**£38,218**
Avoided local authority family bed nights	241	£206		£49,560			**£49,560**
			£1,601,409	**£87,778**	**£0**	**£0**	**£1,689,187**

Table C5: Service benefits value calculations: Diana Children's Nurses

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided hospital admission due to EOL care	4	£8,491	£30,567				**£30,567**
Avoided GP appointment	18	£39	£702				**£702**
Avoided hospital admission due to dying in non-hospital setting	18	£8,491	£152,837				**£152,837**
			£184,107				**£184,107**

Table C6: Service benefits value calculations: Family support services (bereavement services)

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Improved mental health status of family members	329	£11,700			£3,849,300		**£3,849,300**
Avoided use of GP/primary care for family member MH issue/mild depression	105	£128	£13,432				**£13,432**
Avoided sick days for mild depression	1050	£94				£98,700	**£98,700**
Avoided use of community mental health services	53	£2,615	£137,300				**£137,300**
Avoided further sick days for depression	1050	£94				£98,700	**£98,700**
Avoided education welfare support	7	£2,862		£15,023			**£15,023**
			£150,732	**£15,023**	**£3,849,300**	**£197,400**	**£4,212,455**

Table C7: Service benefits value calculations: Volunteering

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Value of the volunteer hours provided	59310	£12		£737,243			**£737,243**
				£737,243			**£737,243**

Table C8: Service benefits value calculations: Specialist support for non-palliative care clinicians in the community

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided unplanned admission to hospital	52	£8,491	£441,530				**£441,530**
			£441,530				**£441,530**

Table C9: Service benefits value calculations: Staff training

Outcome description	Data on outcome	Unit value of outcome	Value of outcomes				
			Healthcare	Social care	QALY	Productivity	TOTAL
Avoided GP appointments	25	£39	£975				**£975**
Avoided unplanned admission to hospital	25	£8,491	£212,274				**£212,274**
			£213,249				**£213,249**