



York Health Economics Consortium

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CHILDREN'S HOSPICES ACROSS SCOTLAND

Economic Evaluation of Hospice and Hospice at Home, Diana Children's Nurses and Bereavement Services

Updated Report for 2016/17

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Executive Summary

1. INTRODUCTION

The number of children and young people in Scotland with life limiting conditions is increasing. In 2015 it was estimated that more than 15,000 children and young people up to the age of 25 were living with these conditions, with nearly 200 children and young people dying per year.

For the past decade, the Scottish Government and other stakeholders have been developing more structured policy frameworks to address palliative care in general and also specifically for children and young people. The Framework for the Delivery of Palliative Care for Children and Young People in Scotland was published in 2012, which sets clear objectives for care. The recently published Scottish Government Strategic Framework for Action on Palliative and End of Life Care has placed further emphasis on the importance of holistic palliative care for people under the age of 25.

Children's Hospices Across Scotland (CHAS) plays a central role in the delivery of palliative care for children and young people in Scotland. It provides medical and other care and support services across the care pathway for children and young people and their carers and families. This includes bereavement support for families after children and young people have died. CHAS core services are two hospices in Kinross and Balloch, a CHAS at Home service which provides support outside the hospice setting, and their increasing hospital presence including through their dedicated CHAS Diana Children's Nurses..

Despite the increased emphasis on palliative care for children and young people in Scotland, CHAS provides end of life care to around 78 people per year. This is considerably lower than the numbers of children and young people with life-limiting conditions dying each year in Scotland and indicates a potentially large unmet need.

2. METHODOLOGY

CHAS commissioned York Health Economics Consortium (YHEC) to analyse the costs and benefits of the services it provides. The first step was to understand, describe and categorise the interventions provided by CHAS, to develop an analysis framework. YHEC undertook a number of interviews with CHAS staff to understand the interventions provided and also to consider the associated costs and benefits.

Allied to this, a targeted and pragmatic review of information sources was conducted to seek more detailed evidence on the activity and costs associated with CHAS services. This was supplemented by using national data sources, such as the Units Costs of Health and Social Care, to provide estimates of the value of certain activities.

A rapid literature review was undertaken to identify the potential benefits of the services provided by CHAS. A targeted and pragmatic search was undertaken using PubMed to search MEDLINE, life science journals and online books. Relevant findings were drawn from the selected papers and recorded, with conclusions drawn on what the evidence indicates to inform the assumptions made on service benefits for the economic analysis.

The populated analysis framework was then used to analyse the evidence obtained and make assumptions about the extent of the benefits that were likely to accrue from CHAS interventions. The activity and costs data were then used to calculate estimates of effect. Benefits were calculated and compared to the overall costs of CHAS services and more specifically to the statutory funding CHAS receives from the Scottish Government, local authorities and Health Boards. The results were reported in May 2016 based on the costs and activity for the 2014/15 financial year and in this report these have been updated to take account of the 2016/17 financial year.

3. RESULTS

During 2016/17 CHAS cared for a total of 530 babies, children and young people. Of these, 421 were cared for in the two hospices, 107 of whom also received care from the CHAS at Home service. A further 24 babies, children and young people received care only from CHAS at Home and a further 85 were supported by the Diana Children's Nurses, but not referred to other CHAS services.

CHAS services were categorised into specific interventions and potential benefits and values were assigned to each. The services evaluated were:

- Hospice services (planned breaks and unplanned care);
- CHAS at Home (planned and unplanned care);
- Diana Children's Nurses;
- Bereavement services.

Although CHAS provides many interlinked services, these categories of services are those for which benefits were most readily attributable. No benefits were measured for other services such as the Transition Team, the Sleightight Service and the 24 hour advice line because they were either integral to other services or were only recently established.

The estimated benefits for one year for the services provided by CHAS were £36.7 million. A number of different perspectives were considered, including the NHS and social care perspectives and the societal perspective, in the form of improved productivity due to carers being able to work as a result of the interventions provided by CHAS. The total benefits per year break down into the following components:

Economic perspective	Element	Value
NHS perspective	Quality of life gains - £16.6 million	£32.2 million
	Avoided healthcare resource use - £15.6 million	
Social care perspective	Avoided social care resource use	£1.5 million
Societal perspective	Productivity gains	£3.1 million
TOTAL		£36.7 million

In order to understand the return on investment for each service, it was necessary to apportion the overall costs of CHAS, including support costs, to the services evaluated. The overall expenditure for CHAS was £13.147 million in 2016/17. Total funding for CHAS services was £11.183 million, of which statutory funding (from the Scottish Government, local authorities and the Health Boards) was £2.152 million.

Considering only the statutory funding, the overall return on investment from CHAS services was 1,606% in 2016/17. If only the benefits associated with the estimated avoided health and social care use are considered (£17.1 million), CHAS interventions provided a return on investment of 694%.

A number of sensitivity analyses were carried out to examine the effect of changing assumptions or activity levels. The worst case scenario considered (halving the number of hospital admissions avoided and reducing the number of family members and those experiencing mental health difficulties), reduced the benefit value to £25.9 million, while a more optimistic scenario, increased the benefit value to £36.9 million.

4. CONCLUSIONS AND RECOMMENDATIONS

The evaluation has found that CHAS services are highly cost effective in comparison with the levels of statutory funding received from the Scottish Government, local authorities and Health Boards. The service received a little over £2.1 million in statutory funding but generated more than £36 million in benefit. The estimated return on investment is 1,606%, or £16.06 equivalent value for every £1 of statutory funding spent on CHAS services. 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 £17.1 million of benefit value is estimated – a return on investment of 694%.

The economic analysis was constrained by the lack of specific evidence that could be used to model the benefits of CHAS services. This is partly due to a lack of metrics in peer-reviewed literature but also concerns about the applicability of evidence that relates to adult palliative care services, or services provided in other countries. It is hard to compare CHAS to other services as it is unique in Scotland and although children’s hospice services exist in other countries, there are bound to be differences in service provision and care pathways. The analysis had to use a number of assumptions about the extent of the economic benefits generated through CHAS services and there is no guarantee that these reflect reality. Another key limitation was the need to generalise the analysis approach and to treat all children and young people and their carers and families the same way. The analysis, therefore, used a conservative approach to the estimation of the benefits of CHAS services. 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 evaluation highlights a number of important issues and a number of recommendations are proposed:

- CHAS should consider building on the data already collected to include additional data and / or analysis, for example:
 - The breakdown between planned and unplanned care, both in the hospice and CHAS at Home;
 - The number and nature of domiciliary medical visits;
 - The proportions of different activities provided by the Family Support Service.
- 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;
- Future evaluation of CHAS services should attempt to measure quality of life for children and young people and collect evidence for prolonged life;
- A future review and evaluation of the Diana Children's Nurses service should include an assessment of the benefits in terms of avoided need for additional healthcare services. The review should be undertaken when the service has been established for a longer period and the caseload has increased;
- The Scottish Government, local authorities and 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;
- CHAS and statutory bodies should investigate the extent of unmet need in terms of palliative care for children and young people with life-limiting conditions and any variation in provision across different areas of Scotland.

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 WITH LIFE-LIMITING CONDITIONS

The national charity for children's palliative care in the UK, Together for Short Lives, defines life-limiting conditions as "those for which there is no reasonable hope of cure and from which children or young people will ultimately die prematurely, e.g. Duchenne muscular dystrophy or neurodegenerative disease" [1]. Additionally, the charity defines life-threatening conditions as "those for which curative treatment may be feasible but can fail, e.g. cancer. Both life-limiting and life-threatening conditions require palliative care support through to the end of life stage. The term 'life-limiting conditions' has been used throughout this report to cover both of the definitions.

The Children in Scotland requiring palliative care study (ChiSP) set out to identify the number of children and young people with life-limiting or life-threatening conditions in Scotland up to the age of 25 and to describe this population in terms of their ages, conditions/diagnoses, geographic locations and ethnicity [2]. The study showed a rising trend in the numbers of children and young people with life-limiting conditions (life-limiting conditions is used as an umbrella term to also cover life-threatening conditions) in Scotland. Since 2009/10, the numbers of children with these conditions has increased from 12,039 to 15,404. The highest prevalence is for children with life-limiting congenital conditions.

The ChiSP study found that on average 195 children and young people with a life-limiting condition die each year. The Children's Hospices Across Scotland (CHAS) provides palliative care for around 78 children and young people who die each year, so there is potentially a large unmet need. Children and young people with life-limiting conditions also require other specialist care both in hospital and home settings and this care may also be provided in hospices.

1.2 PALLIATIVE CARE FOR CHILDREN AND YOUNG ADULTS

The policy background that underpins the provision of palliative care for children and young adults in Scotland has developed over the last decade. In 2008 the Scottish Government published an action plan to ensure that palliative and end of life care was available to all people in Scotland with life-limiting conditions, called 'Living and Dying Well' [3]. The plan was supplemented in 2013 by a set of indicators to monitor implementation of the plan. The four indicators were:

- Increase in the number of people with palliative and end of life care needs who are identified;
- Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan;
- Increase in the number of electronic palliative care summaries accessed;
- Place of death.

A more specific response to the plan for children and young people was published in 2012 – A Framework for the Delivery of Palliative Care for Children and Young People in Scotland [4]. The Framework set out ten key objectives:

- Lead doctor and nurse for children and young person's palliative care in every health board;
- Identification of all children and young people with palliative care needs;
- Breaking bad news privately and with respect, honesty and sensitivity;
- A lead paediatric consultant for each child and young person;
- Assessment of care needs and multi-agency care plan for each child and young person;
- An agreed discharge plan for every child and young person with palliative needs in a hospital setting;
- Recognition and planning for end of life care;
- Bereavement support for families after death;
- Health boards to develop local pathways for transition to appropriate adult services;
- Education and training for all staff caring for children and young people with palliative care needs.

In November 2015, the Scottish Government Health and Sport Committee published a report on palliative care, which included specific references to children and young people [5]. It cited the World Health Organisation's (WHO) definition of palliative care for children which is:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family;
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease;
- Health providers must evaluate and alleviate a child's physical, psychological and social distress;
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited;
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

The report acknowledged the difference between palliative care for adults and for children and young people and made a number of recommendations. The Health and Sport Committee asked the Scottish Government to reflect the difference between child and adult palliative care in its Strategic Framework for Palliative and End of Life Care [4]. It also welcomed the work being undertaken by the Scottish Government and CHAS to look at how respite services for young adults can be improved and increased.

In December 2015, the Scottish Government published a Strategic Framework for Action on Palliative and End of Life Care for 2016 to 2021 [6]. In this document, the Scottish Government made a commitment to “*Support and promote the further development of holistic palliative care for the 0-25 years age group.*”

1.3 CHILDREN’S HOSPICES ACROSS SCOTLAND

Children’s Hospices Across Scotland (CHAS) is a charity that provides hospice services for babies, children and young people with life-limiting conditions and their families in Scotland. CHAS provides specialist palliative care, which responds to the needs of children and their families, to offer care and support wherever the family chooses. Families and health and social care professionals are supported by a range of specialist support across disciplines including nursing, medicine, social work, play and allied healthcare. The whole family is supported, as and when they need it, throughout their journey from referral to bereavement.

CHAS runs two hospices, Rachel House in Kinross and Robin House in Balloch, both of which 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 majority of the bed nights provided in the two hospices are for children and young people on planned short breaks, although an increasing number are being used for unplanned or emergency admissions.

CHAS also 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. Domiciliary medical services are also provided to support children and young people in their own homes or in hospital. 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 recognises that in order to reach more children with palliative need, it is important to have a visible and hands-on presence caring for children and families in hospital settings. They jointly appoint Consultant Paediatrician posts in two NHS Boards. Additionally there are three Diana Children’s Nurses embedded in NHS hospitals. These staff have been instrumental in increasing the number of children and families CHAS has supported. As well as being able to reach families that would otherwise not be known to CHAS, they have also enabled families to access additional support from other CHAS services.

An important part of CHAS’s role is collaboration with, and working alongside, professionals in the family’s community. CHAS supports the communication pathway between a child, their family and the professionals caring for them, recognising that the team is part of a bigger network of care services for children across Scotland. Clinical leadership and support are provided and expertise is shared with the teams caring for a child and their family.

CHAS provides support from the neonatal stage through to the end of life. New referrals are considered for children with life-limiting conditions from the antenatal period up to their 18th birthday, with an upper age limit of 21 years. The Transition Team supports young people to move into adult services and from 2017 the upper age limit for CHAS services is 21 years.

Decision making frameworks used at the initial referral assessment are the Together for Short Lives/Royal College of Paediatrics and Child Health (RCPCH) (2009) categories and The Spectrum of Children's Palliative Care Needs Prognosis Based Framework (2012). Referrals can be made by health and social care professionals and families.

1.4 ECONOMIC EVALUATION OF CHAS SERVICES

CHAS commissioned York Health Economics Consortium (YHEC) to understand and evaluate the economic value of the services it provides. The aim of this work was to analyse the costs and benefits of the services provided by CHAS. The objectives of the work were to:

- Describe and categorise the interventions provided by CHAS, developing an analysis framework including the costs and benefits of the services;
- Identify the costs of providing the various services provided by CHAS;
- Identify the potential benefits of the services provided by CHAS. Where appropriate different perspectives were considered, including the NHS/health care system, social care and local government, societal and family perspectives;
- Generate assumptions and model the results, using scenario and sensitivity analysis to understand the impact of any uncertainty.

This work was originally completed and reported in May 2016. This is an update to that report for the 2016/17 financial year and includes adjustments to the costs and activity levels to reflect changes in the subsequent years.

Section 2: Methodology

A mixed-methods approach was used to gather and analyse evidence for the project, including interviews with key stakeholders, data gathering, rapid literature review and data analysis. The services provided by CHAS are broad in scope and a staged approach was used to understand the services provided and the information that would be available to inform the economic analysis.

2.1 DEVELOPMENT OF THE ANALYSIS FRAMEWORK

The first stage was to design an analysis framework to describe the interventions provided by CHAS and to scope the costs and the benefits of each service. Six stakeholder interviews were held and a review of documentary evidence was undertaken to understand in more detail the nature of the services provided by CHAS, the inputs and costs, as well as the benefits that are gained from the interventions provided. Interviews were held with the following individuals:

- Maria McGill, Chief Executive;
- Pat Carragher, Medical Director;
- Babs Henderson, Associate Nurse Director for Clinical Effectiveness;
- Libby Gold, Associate Nurse Director for Care;
- Corinna Robertson, Family Support Manager;

An interview schedule was used, with questions themed on the services provided, inputs required and benefits; activity and resource information; demand and need, plus suggestions for useful contacts and references.

The interviews facilitated discussion on how to categorise the services in the most appropriate way and led to increased understanding of the nature of CHAS services. Coupled with documentary evidence on the CHAS model of care the information was synthesised to inform a draft analysis framework for comment by CHAS. Following discussion with CHAS, minor amendments were made to the framework. This was then used to guide the literature review and the analysis of the benefits and values.

2.2 DATA GATHERING

A targeted and pragmatic review of information sources was conducted to seek more detailed evidence on the activity and costs associated with CHAS services. The 2014/15 financial year activity was selected for analysis, as a full picture of cost and activity data for a complete year was available. This has been updated for the 2016/17 financial year for this report. CHAS provided a wealth of documentary evidence for review, including:

- Annual reports and activity monitoring;
- Management accounts and other detailed financial information;
- Funding applications and monitoring reports;
- Organisational structures;
- Estimates of unmet need.

In addition, CHAS provided activity data in relation to the numbers of children and young people and their families receiving services. 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 within CHAS at Home, bereavement services delivered by the Family Support Service and the distribution of the medical caseload between planned and unplanned care.

Information on CHAS expenditure was taken from the annual management accounts, with additional supporting documents provided by the finance department.

To establish the values of health and social care service benefits, national sources were used, including the Unit Costs of Health and Social Care (2016) [7], published annually by the Policy and Social Services Research Unit. 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 cost 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.

2.3 RAPID LITERATURE REVIEW

A rapid literature review was undertaken to identify the potential benefits of the services provided by CHAS. YHEC carried out a literature review in 2012 into the cost-effectiveness of services for children with life-limiting conditions, which found some evidence that home care for children with complex needs is cost-effective. A further rapid literature review was carried out to identify more recently published papers and to target more specifically the benefits of hospice and hospice at home services for children and their families, health and social care (e.g. in terms of avoided hospital admissions) and society (in terms of improved productivity).

A targeted and pragmatic search was undertaken using PubMed to search MEDLINE, life science journals and online books. The searches were conducted on 26 and 30 November 2015 using combinations of the following search terms: children; palliative care; end of life; hospice; respite; cost; benefit; bereavement support and 'good death'. 162 titles were assessed for relevance. Following screening, 14 were selected for full text review.

In addition to searching biomedical databases, the NICE NHS Evidence website was used to search for evidence on palliative care interventions for children and young people not included in peer-reviewed literature. The search was undertaken on 1 December 2015 using the terms "Children" AND "palliative care" AND "benefit". 1,328 results were generated, reducing to 276 results when filtered for the category of 'primary research/evidence summaries/policy & service development/systematic reviews' in the 'last 3 years'. A further 10 titles were included for full text review.

Relevant findings were drawn from the selected papers and recorded, with conclusions drawn on what the evidence indicates to inform the assumptions made on service benefits for the economic analysis.

2.4 DATA ANALYSIS AND MODELLING

The information on CHAS service activity and evidence from the literature review was used to formulate a set of assumptions on the nature and size of the proposed benefits for each CHAS service area. The assumed benefits were valued using national data sources.

This information was used to populate a 'calculator', which allowed the summary and detailed benefit values for each service area to be estimated. The calculator was used to aggregate the benefits accruing from each service area and model the potential outcomes for the economic analysis, in the following format:

Figure 2.1: Economic calculator

Service area	Benefit	Assumptions	Proxy value for the benefit	Number of beneficiaries in 2014/15	Overall potential benefit

A key variable in the analysis is the number of beneficiaries for each benefit. The spreadsheet allows for the number of beneficiaries and the proxy values to be varied. To understand the impact of any uncertainty in the data and the assumptions, sensitivity analysis was undertaken and variables were varied to model both the best and worst case scenarios.

Section 3: Results

3.1 ANALYSIS FRAMEWORK

The services provided by CHAS are complex and interlinked, in order to provide seamless and holistic care for children and young people with life-limiting conditions. During 2016/17, CHAS cared for a total of 530 babies, children and young people. Of these, 421 were cared for in the two hospices, 107 of whom also received care from the CHAS at Home service. A further 24 babies, children and young people received care only from CHAS at Home and a further 85 were supported by the Diana Children's Nurses but not referred to CHAS. There are a variety of different disciplines involved in the provision of care and CHAS also employs salaried staff and volunteers in roles that do not have direct contact with children and families, such as finance, HR and fundraising.

It is, therefore, difficult and somewhat arbitrary to divide the services provided into separate categories for the purpose of economic evaluation. Nevertheless, the reason for this analysis was to try to understand the potential benefits that children and families might receive from the different services provided. To that end, an analysis framework was generated to consider the different types of services and interventions provided and to map the costs and potential benefits for each.

The analysis framework attempts to distil the services into categories to describe the interventions and the potential benefits of each service element, against which economic measures can be applied. It is acknowledged that the services are not mutually exclusive and the analysis has made assumptions about the alignment of benefits to each service intervention. The analysis framework is in Table 3.1.

Table 3.1: CHAS services analysis framework

Service	Intervention	Potential benefits of the service
Hospice: planned	Planned care / respite breaks for family or child on own	<ul style="list-style-type: none"> Improved mental health & wellbeing (reduction in health care resource use, improvements in productivity, better school attendance): for children and young people, parents and siblings able to cope; Reduced demand for health and social care services for children e.g. hospital admissions.
	Anticipatory care planning	<ul style="list-style-type: none"> A good death, in preferred place; Reduced demand for health and social care services e.g. hospital admissions; Avoided costs of prescribing and other medical interventions as a result of ceasing treatments (ACPs).
Hospice: unplanned	Step down care/ symptom control/support for carer breakdown/ awaiting home adaptations	<ul style="list-style-type: none"> Prolonged life for children and young people; Reduced demand for health and social care e.g. hospital admissions/ HDU beds, GP services, LA respite costs; Improved mental health & wellbeing for parents/carers (reduction in health care resource use, improvements in productivity).
CHAS at Home: planned	Planned breaks / respite e.g nursing, overnight care, events for families	<ul style="list-style-type: none"> Improved mental health & wellbeing: for children and young people, parents and siblings; Reduced demand for health and social care services e.g. hospital admissions.
	Anticipatory care planning	<ul style="list-style-type: none"> A good death, in preferred place; Reduced demand for health and social care services e.g. hospital admissions; Avoided treatment costs (ACPs).
CHAS at Home: unplanned	Symptom control/support for carer breakdown	<ul style="list-style-type: none"> Prolonged life for children and young people; Reduced demand for health and social care services e.g. hospital admissions/ HDU beds, GP services, LA respite costs; Improved mental health & wellbeing for parents/carers.
Family Support Service (FSS)	Social work, EOL planning, specialist play, chaplaincy and bereavement therapy	<ul style="list-style-type: none"> Improved mental health & wellbeing (parents and siblings coping better – reduced days off work/reduced demand on mental health support).
Volunteering	Direct care and support roles	<ul style="list-style-type: none"> Improved mental health & wellbeing (QOL for families); Financial contribution to service provision; Societal and mental health benefits for volunteers.
Transition team (part of FSS)	Transition planning for move to adult services	<ul style="list-style-type: none"> Improved mental health & wellbeing for children and young people; Improved access to age appropriate care in the community; Families better able to cope with caring role as move beyond CHAS.
Diana Children's Nurses	Nursing support for children and young people in hospital setting Strategic / service development	<ul style="list-style-type: none"> Reduced demand for health and social care services e.g hospital admissions; A good death, in preferred place.
Sleep Tight Night Sitting service	Nursing support to the Night sitting service	<ul style="list-style-type: none"> A good death, in preferred place; Improved mental health & wellbeing for parents/carers.
24 hour advice line	Advice to families or professionals	<ul style="list-style-type: none"> Avoided GP and hospital care.

A simple theory of change was developed to underpin the economic evaluation. This assumed that children and young people referred to hospice care receive holistic care leading to a range of outcomes:

- Improved mental health and wellbeing for children and their families;
- Reduced demand for health and social care services for children and families;
- Improved productivity for families;
- A good death in preferred place.

Based on the evidence found through the literature review and the activity information from CHAS, assumptions have been made about the size of the benefits accrued from each intervention and the value associated with each benefit. Benefit values have been estimated using national sources of financial information such as the Unit Costs of Health and Social Care, published annually by the Policy and Social Services Research Unit.

Where services appear to be integral and contributing to benefits estimated for other services, such as some elements of the Family Support Service, we have not attempted to evaluate them separately. This is a conservative approach and aims to avoid double counting of benefits and value.

3.2 SUMMARY FINDINGS FROM LITERATURE REVIEW

The literature review found a range of studies and evidence available on the effectiveness and cost effectiveness of palliative care and end of life care. Many of these relate to adult services and there are relatively few that are specific to children and young people with life-limiting conditions. Furthermore, many studies are from countries outside of the UK and care must be taken in transferring findings to a UK setting. Helpfully, two recent literature reviews have been conducted in the UK, which are informative.

A literature review by Smith *et al.* [8] in 2014 found that despite wide variation in study type, characteristic and study quality, there are consistent patterns in the findings on the cost-effectiveness of palliative care interventions. Palliative care is mostly found to be less costly relative to alternative forms of end of life care, and in most cases, the difference in cost is statistically significant.

In a review of evidence on palliative care in the UK in 2015, Dixon *et al.* [9] also found palliative care to be less costly than alternative forms of end of life care. Whilst acknowledging the challenge of standard service definitions and overseas comparisons, they found evidence of savings in acute care, reduced symptom burden and increased chance of dying at home for both cancer and non-cancer diagnoses. The authors concluded that there is promising evidence that a palliative approach may be less costly, and even if it is not, it has the potential to improve outcomes for people at end of life, and their families, for little or no more cost. The study did not attempt to quantify any additional costs to carers of shifting care into the community.

In general, there is a lack of specific data or metrics in the evidence reviewed and some uncertainty about the transferability of the evidence to the Scottish children's palliative care setting. For example, where financial implications have been calculated in different healthcare systems, while the values cannot be used directly, the information has been used to inform assumptions to estimate the value of the benefits.

The specific findings from the literature review relating to each of the CHAS service areas evaluated are presented in each section below.

3.3 RACHEL HOUSE AND ROBIN HOUSE HOSPICES

3.3.1 Short Planned Breaks (including Anticipatory Care Planning)

The short planned breaks element of the service provides accommodation and activities for children and young people, either accompanied by their families or on their own. The service provides individual and holistic care to the children and young people, 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 the service is the Family Support Service, which provides activities, particularly at the end of life, including anticipatory care planning, memory making, case management and support for transition. CHAS supported 421 children and young people in its hospices during 2016/17. This included 3,211 planned children and young people bed nights and 6,640 family bed nights.

It is assumed that the benefits of short planned breaks are:

- Improved mental health and wellbeing for children and young people, parents and siblings, e.g. reduction in health care resource use, improvements in productivity, better school attendance;
- Reduced demand for health and social care services for children and young people e.g. hospital admissions;
- A good death, in preferred place;
- Avoided costs of prescribing and other medical interventions as a result of ceasing treatments via anticipatory care planning.

While the evidence review did not find evidence of the impact on the mental health of children and young people, there was evidence of the benefit to family members. In a study of the physical and psychological effects of out-of-home respite care, Remedios *et al.* [10] found that caregivers of children with life-threatening conditions had below-standard levels of quality of life compared to normative populations. Analysis showed that, following access to respite care, average psychological adjustment scores improved significantly, reducing levels of psychological distress to below typical levels. Furthermore, caregivers' average fatigue scores and mental health quality of life scores improved significantly from pre-respite levels.

NEF Consulting [11] calculated the potential financial impact of implementing the programme of short breaks. They found that the stress experienced by carers due to caring activities resulted in days off work and visits to the GP. Their calculations took account of reducing the costs of disabled children in long-term residential care (although their calculations assumed no reduction in placements for children with complex needs); reducing parental stress and hence the number of GP visits and sick days off work; and reducing the costs of educating siblings of disabled children who may have behavioural and emotional difficulties. Their evaluation found the services to be cost-benefit.

In their evaluation of family support teams, Sanderson *et al.* [12] found evidence from alternative models of care indicating that more children could be managed away from hospital inpatient facilities and/or their lengths of stay could be reduced. They also found that early recognition and management of problems associated with poor school attendance or performance by siblings can result in considerable cost savings from, for example, avoided involvement of an Education Welfare Officer.

In a systematic review of paediatric palliative care programmes, Conte *et al.* [13] observed that compared with patients receiving usual care, fewer patients in the palliative care group had hospital admissions and fewer of those with cancer had planned hospital admissions.

No specific evidence was found for the avoided costs from ceasing prescribing and other medical interventions as a result of ceasing treatments via anticipatory care planning. We have assumed that this is an integral part of the CHAS services provided and hence any such outcome will be counted in other service benefits.

It has been necessary to make a number of assumptions in order to estimate the value of the benefits accrued from the hospice short breaks service. These are:

- Half of the children and young people would experience two hospital admissions per year (average of one per child and young person). One in 10 of these episodes of hospital care would be prevented as a result of improved wellbeing resulting from care received during short breaks (42 admissions);
- In the absence of short breaks provision, an equivalent number of bed nights in either local authority respite care or hospital would be used (3,211 children and young people bed nights, 6,640 family member bed nights);
- Each child and young person supported at CHAS's hospices is assumed to have, on average, at least 4.7 family members, including parents or carers and siblings. It has been assumed that all of these individuals will experience improved mental health quality of life as a result of the services provided (1,979 individuals);
- For half of the children and 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. It is estimated that the healthcare use avoided by preventing a case of depression is three GP visits per year, including prescribing of antidepressants, plus 10 days sickness absence (632 individuals);

- 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 (316 individuals);
- 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 (42 individuals);
- Of the 421 children and young people, 75% are assumed to have a sibling (316 individuals). One in ten of those siblings are assumed to have avoided a problem at school which would have required education welfare support (32 individuals);
- 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 (78 admissions);
- Additionally, of the 78 children and young people who died in 2016/17, 31 died in the hospice or at home and not in hospital. It has been assumed that one hospital admission would have been avoided for each of those 31 children and young people;
- 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 (78 children and young people).

Proxy values have been estimated for the benefits that are produced by the service intervention. These have been estimated based on the assumptions made and have been costed using national sources cost data. The benefits of the service are valued as follows:

Table 3.2: Benefits and proxy values for short planned breaks

Benefit	Proxy value
Avoided hospital admissions for children and young people due to improved wellbeing	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 75% inexpensive to 25% expensive = total of £5,676. Uprated to 2016/17 figures using the hospital and community health services (HSHC) index: £5,752.
Avoided GP consultations for children and young people	Three GP visits (PSSRU 2016): £36 each (£108).
Avoided hospital admission due to dying at home or hospice	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 75% inexpensive to 25% expensive = total of £5,676. Uprated to 2016/17 figures using HSHC index: £5,752.
Avoided demand for local authority short break services or hospital stay	Average of local authority provided residential respite care and hospital bed night (PSSRU 2015): average of mean cost for child per night (24 hour period) = £280 and cost of hospital stay (£5956) = £2978. Uprated to 2016/17 figures using HSHC index: £3,018.
	Local authority provided residential respite care (PSSRU 2016): mean cost for family member night (24 hour period) = £188.

Improved mental health quality of life for family members	Improved mental health status £7,040 per year (based on average loss of health status in quality-adjusted life years (QALYs) for a level three mental health problem of 0.352 (Centre for Mental Health (2010)). At a cost-effectiveness QALY threshold of £20,000 per QALY, the value of health gain is £7,040 (0.352 x £20,000). This is a lifetime benefit.
Avoided use of GP consultations for family member with mental health problems	Three GP visits at £36 each (PSSRU 2016), plus one year's prescription costs for citalopram tabs 20mg per day £8.52 (total £116.52).
Avoided use of community mental health team for family member	Average cost of treating a case of depression by community mental health team for adults with mental health problems (PSSRU 2015): £2,426.42. Uprated to 2016/17 figures using HSHC index: £2,458.71.
Improved productivity from prevented sick days	Improved productivity from 10 prevented sick days for depression at median Scottish salary of £27,820 in 2016 (Office for National Statistics (ONS)). 10 days is equivalent to 1/23rd of £27,820 = £1,210.
	Improved productivity from 20 further prevented sick days for those with depression requiring further treatment, at median Scottish salary of £27,820 in 2016. 20 days is equivalent to 2/23rd of £27,820 = £2,419.
Avoided need for education welfare due to improved wellbeing of siblings	Prevented problems at school for siblings - £3,026 for involvement of Education Welfare Officer (2010/11 price inflated using HCHS Index).
Improved productivity as parent does not need to give up work	Median Scottish salary in 2016 £27,820 (ONS).

The benefits attributed to short break interventions are from both the health and social care perspective (e.g. reductions in the use of hospital services and improved quality of life) and the societal perspective (e.g. improvements in productivity through people being able to work).

Based on the assumptions above and the values in Table 3.2, the total value of the benefits from short planned breaks is estimated to be £29,391,319. The calculations are shown in full in Appendix A.

The benefit estimate comprises:

- Quality of life gains due to mental health improvements in families - £13,930,048;
- Avoided healthcare resource use - £11,418,269;
- Avoided social care resource use - £1,343,866;
- Productivity gains - £2,699,136.

Although short breaks may also generate quality of life gains for children and young people, 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 benefits gained.

Short planned breaks are the mainstay of the CHAS service, providing an opportunity for a wide range of interventions. The benefits valued here capture the contribution of various different service elements – nursing, medical support, the Family Support Service, multidisciplinary approaches to care co-ordination and anticipatory care planning. The ‘ability to cope’ is hard to quantify but is a significant factor in the mental health and wellbeing of children and young people and their families.

The assumptions and proxy values are applied uniformly across all children and young people and their families. There will, of course, be a case mix involving different children and young people at different ages and with different conditions, which means that some children and young people require much greater intervention and equally hospice care. This is one of the main limitations of this evaluation and is another reason for applying conservative assumptions.

3.3.2 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. Unplanned stays account for a smaller component of the service (estimated by CHAS to be equivalent to one of the eight beds in each hospice). These stays provide holistic care, with significant medical input and support for families to help them cope with the stress of the admission and they potentially avoid an admission to hospital.

The activity for unplanned care is a smaller proportion of the overall activity within the hospice, although according to CHAS, the proportion of care supporting emergency situations appears to be increasing. In 2016/17, the hospices provided 584 unplanned/emergency bed nights - an increase on the 184 bed nights reported in the previous year. The distinction between planned and unplanned bed nights becomes blurred, as an unplanned admission can change in terms of the interventions being provided to that of a planned stay and is then categorised as such. We have used 584 bed nights as the activity measure.

Based on the literature review, it is assumed that the benefits of unplanned hospice care are:

- Prolonged life for children and young people;
- Reduced demand for health and social care services e.g. hospital admissions / High Dependency Unit (HDU) beds, GP services, LA respite costs;
- Improved mental health & wellbeing for parents/carers.

Evidence from the literature review indicates that hospice care has been found to replace the amount of hospital inpatient care required, either by avoiding an admission altogether or by reducing the length of admissions. Pascuet *et al.* [14] found there was a significant decrease in the monthly number of inpatient days and the monthly number of outpatient days after the opening of a paediatric hospice in Ontario, Canada. Henson *et al.* [15] found that patients receiving palliative care were significantly less likely to attend the emergency department in their last month of life.

Postier *et al.* [16] found that for children with non-cancer diagnoses, use of paediatric palliative care services was associated with lower total hospital charges as compared with the period prior to using the services.

The evidence review found no studies focusing on evidence for prolonged life for children and young people resulting from palliative care. This has therefore not been modelled or valued within the analysis, although the direct experience of staff at CHAS suggests that this may be an outcome. It is speculated that this could be due to care provided by clinicians highly skilled in palliative care approaches and the reduction in use of some palliative care medications and the resulting side effects.

Again, the evidence review lacks specific metrics, so to estimate the value of the benefits accrued from the service, a number of assumptions have been made:

- CHAS has provided an estimate of the proportion of medical staff time spent working across planned and unplanned care, both in and out of the hospice environment. Unplanned care accounts for approximately 25% of medical workload in the hospices. It has, therefore, been assumed that 105 children and young people (25% of 421) were beneficiaries of unplanned care in 2016/17;
- For each of the 105 children and young people it has been assumed there would be:
 - One episode of hospital care prevented in 10% of cases;
 - Six fewer day care attendances;
 - One GP appointment avoided.
- Of the hospital admissions that are not avoided, 75% will be less expensive stays and will be shortened by one day. The remaining 25% will be more expensive stays (e.g. HDU) and will be shortened by four days;
- 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 and young people and their families (584 nights) to cover emergency situations.

The proxy values for the benefits of unplanned care, using the evidence, assumptions and national data sources, are listed in Table 3.3.

Table 3.3: Benefits and proxy values for unplanned hospice care

Benefit	Proxy value
Avoided hospital admissions for children and young people due to improved wellbeing	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 75% inexpensive to 25% expensive = total of £5,676. Upated to 2016/17 figures using HSHC index: £5,752.
Avoided hospital bed days	Cost of bed day for children and young people with palliative care needs (PSSRU 2015): less expensive stay e.g. local hospital for respiratory infection (£499 per day); expensive stay e.g. paediatric cardiac unit/PICU (£1810 per day). Upated to 2016/17 figures using HSHC index: £1,834.
Avoided hospital day care	Reduced day care costs (PSSRU 2015): average of short illness trajectory (cancer day care episode £159) and longer life illness trajectory (cystic fibrosis OP visit £150) = £154.50 x 6 = £927). Upated to 2016/17 figures using HSHC index: £939.
Avoided GP consultations for children and young people	One GP visit (PSSRU 2016): £36 each with average prescribing costs of £26.70(£62.70).
Avoided demand for local authority respite care or hospital bed night	Average of local authority provided residential respite care and hospital night (PSSRU 2015): average of mean cost for child per night (24 hour period) = £280 and cost of hospital stay (£5956) = £2978. Upated to 2016/17 figures using HSHC index: £3,018.
	Local authority provided residential respite care (PSSRU 2016): mean cost for family member bed night = £188.

Based on the assumptions above and the values in Table 3.3, the total value of the benefits from unplanned hospice care is estimated to be £2,780,417. The calculations are shown in full in Appendix A.

The benefit estimate comprises:

- Avoided healthcare resource use - £2,670,625;
- Avoided social care resource use - £109,792.

It is possible that the impact of unplanned care is underestimated, as CHAS admissions for planned breaks will, at times, transition to an unplanned continuation of the admission when a deterioration or change means it is not appropriate or possible to discharge a child or family. Additionally, CHAS mirrors the NHS approach, where an emergency admission will continue to be classified as such for as long as that care is needed.

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.

3.4 CHAS AT HOME

3.4.1 Planned Care

The CHAS at Home service provides planned breaks, nursing and overnight care to support families in the home environment. In 2016/17, CHAS at Home supported 131 children and young people and their families, providing 1,029 home care visits. An activity audit over a 16 week period showed that the majority of this care is planned (approximately 95%, since adjusted to 80%). Most of the children and young people using CHAS at Home also make use of Rachel House and Robin House services and in 2016/17 there were only 24 children and young people who never or rarely used the hospice facilities.

It is assumed that the benefits of planned services from CHAS at Home are:

- Improved mental health and wellbeing for children and young people, parents and siblings, e.g. reduction in health care resource use, improvements in productivity, better school attendance;
- Reduced demand for health and social care services for children e.g. hospital admissions;
- A good death, in preferred place;
- Avoided costs of prescribing and other medical interventions as a result of ceasing treatments via anticipatory care planning.

The evidence review found numerous studies referring to home based palliative care. Although some of these were studying adults and some were from outside the UK, there appears to be evidence that home based palliative care can both reduce the burden of symptoms and reduce costs to the health and social care system.

Vollenbroich *et al.* [17] found that involvement of a paediatric palliative care home team led to highly significant improvements in the children's symptoms and quality of life. Their research also included the views of healthcare professionals, who reported care to be improved across many areas, particularly communication and support for the families. They concluded that the intervention led to a 'substantial improvement in the experience of care' as reported both by parents and healthcare professionals.

Gans *et al.* [18] found that, for a lower cost, participation in community-based paediatric palliative care resulted in improved quality of life (such as improved sleeping, less stress) and a one-third reduction in the average number of days spent in the hospital. The analysis by Gomes *et al.* (19) showed that home palliative care more than doubled the chance of dying at home.

To estimate the value of the benefits accrued from the service, a number of assumptions have been made, as follows:

- The benefits of planned care at home are the same as for planned care in the hospice environment;
- As most of the children and young people also make use of Rachel House and Robin House services, the economic analysis for planned care has been based on the smaller number of children and young people who never or rarely use the hospice facilities, in order to avoid double counting of the benefits. This is 24 children and young people. Based on annual activity of 1,029 visits (for all children and young people), this equates to 189 visits for these children and young people;
- The proportion of activity which is planned is approximately 80%. This is 151 of the 189 visits for 24 children and young people;
- One episode of hospital care is assumed to be prevented for 10% of the children and young people as a result of improved wellbeing resulting from care received from CHAS at Home (2.4 admissions);
- In the absence of CHAS at Home provision, an equivalent number of bed nights in local authority respite care or hospital would be used in 10% of cases (15);
- Each child and young person treated by CHAS at Home is assumed to have, on average, at least 4.7 family members. It has been assumed that all of these individuals will experience improved mental health quality of life as a result of the services provided (113 individuals);
- For half of the children and young people using planned care services at home, it is assumed that three family members would have suffered from depression without the increased resilience gained from access to this provision. It is estimated that the healthcare use avoided by preventing a case of depression is three GP visits per year, including prescribing of antidepressants, plus 10 days sickness absence (36 individuals);
- 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 (18 individuals);
- 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 (2.4 individuals);
- Of the 24 children and young people, 75% are assumed to have a sibling (18 individuals). One in ten of those siblings are assumed to have avoided a problem at school which would have required education welfare support (one individual);
- For those children and young people at the end of life, the benefits have been included in the hospice planned care section, for the 78 children and young people who died in 2016/17. They have therefore not been included again for CHAS at Home planned care.

The proxy values for the benefits of CHAS at Home are the same as those for planned short breaks in the hospice and can be found in Table 3.2 above.

Based on the assumptions above and the values in Table 3.2, the total value of the benefits from CHAS at Home planned care is estimated to be £1,063,073. The calculations are shown in full in Appendix A.

The benefit estimate comprises:

- Quality of life gains due to mental health improvements in families - £794,112;
- Avoided healthcare resource use - £107,828;
- Avoided social care resource use - £7,262;
- Productivity gains - £153,870.

Although CHAS at Home may also generate mental health benefits for children and young people, no specific evidence was found to support this, so no benefits were included.

It is important to note that this value is derived by including only 24 children and young people and their families in the analysis. The evidence for improved outcomes and reduced demand on hospital services from home based palliative care is convincing. It is possible that there were additional benefits from CHAS at Home interventions for the 107 children and young people who used both services, although it is not possible to quantify these separately. Therefore, by only including the 24 cases additional to hospice care; we have made a conservative estimate of the benefits accrued.

3.4.2 Unplanned Care

The CHAS at Home service also provides unplanned care to children and young people in the home environment. The activity audit showed that this accounts for approximately 20% of CHAS at Home activity, estimated to be around 206 out of the 1,029 visits in 2016/17. The CHAS at Home team is supported by the medical team, which also provides medical support to children and young people out of the hospice environment, both at home and in a hospital setting.

It is assumed that the benefits of CHAS at Home unplanned care are:

- Prolonged life for children and young people;
- Reduced demand for health and social care services e.g. hospital admissions / HDU beds, GP services, LA respite costs;
- Improved mental health & wellbeing for parents/carers.

There is evidence that access to community based palliative care teams can lead to reduced emergency hospital admissions at the end of life. Seow *et al.* [20] found that community based specialist palliative care teams, despite variation in team composition and geographies, were effective at reducing emergency care use and hospital deaths at the end of life. The pooled relative risk of being in hospital and having an emergency department visit in late life was significantly lower for the patient group receiving home-based palliative care.

Georghiou and Bardsley [21] evaluated a Marie Curie nursing service in 2014 and found that during the last three months of life, patients spent 2.5 fewer days in hospital during the period service was being delivered. Taking account of the implications on other out-of-hospital services (e.g. GPs, community nursing) they found overall lower costs for the home palliative care group.

To estimate the value of the benefits accrued from the service, a number of assumptions have been made, as follows:

- 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;
- For the 206 CHAS at Home visits assumed to be for emergency care, it is assumed that half of the children and young people (103 individuals) would avoid:
 - One hospital admission;
 - Six fewer day care attendances;
 - One GP appointment.
- In the absence of hospice at home provision, there would have to be one local authority or hospital respite bed night needed for half of the children and young people needing an unplanned visit by CHAS at Home (103 individuals).

The proxy values for the benefits of CHAS at Home unplanned care are the same as those for hospice unplanned care and can be found in Table 3.3.

Based on the assumptions above and the values in Table 3.3, the total value of the benefits from CHAS at Home unplanned care is £1,006,485, derived from avoided healthcare resource use. The calculations are shown in full in Appendix A.

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. This additional benefit has not been estimated as the activity metrics are not clear and so this is, therefore, a conservative estimate of the benefits accrued by CHAS services provided outside of the hospice environment.

3.5 FAMILY SUPPORT SERVICES - BEREAVEMENT SERVICES

The Family Support Service is an integral part of the services offered by CHAS, working in the hospices and the community alongside clinical and other services. 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 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 are considered to be included in the analyses of care in the hospice and CHAS at home.

The exception is bereavement therapy, because this can have a lasting benefit for families that is separate from the benefits gained from hospice breaks and visits from CHAS at Home while the child or young person is alive. A significant proportion of the work of the Family Support Service team is considered to be bereavement therapy. This includes time spent both before and after the death of the child or young person, 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.

It is assumed that the benefits of bereavement services are:

- Improved mental health and wellbeing (parents and siblings coping better – reduced days off work/reduced demand on mental health support).

The impacts of bereavement support are difficult to measure, but there is some evidence of the benefits in certain circumstances. Kissane *et al.* [22] found the overall impact of family focused grief therapy, although modest, led to significant improvements in distress and depression for individuals with high baseline scores, with a reduction in distress at 13 months. They also concluded that even for families with poor relationship functioning, depression was at worst unchanged, but the benefit for families with 'intermediate functioning' was clear.

In a systematic review of controlled studies, Rowa-Dewar [23] found that that the provision of bereavement support programmes for parents with parental grief had no overall benefit, but for highly distressed mothers, psychological symptoms and marital dysfunction were significantly reduced. The conclusion was that bereavement programmes have benefit for some and that a targeted approach may therefore be the best use of resources.

To estimate the value of the benefits accrued from the service, a number of assumptions have been made, as follows:

- The additional benefits of bereavement services (over and above benefits from other CHAS services) were gained by the families of the children and young people that died in the previous year (2015/16). This was 56 families;
- Each child and young person treated at CHAS is assumed to have, on average, at least 4.7 family members. It has been assumed that all of these individuals will experience improved mental health quality of life as a result of the bereavement services provided (263 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. It is estimated that the healthcare use avoided by preventing a case of depression is three GP visits per year, including prescribing of antidepressants plus 10 days sickness absence (84 individuals);
- 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 (42 individuals);
- Of the 56 children and young people, all are assumed to have a sibling (56 individuals) and one in 10 of these is assumed to have avoided a problem at school which requires education welfare support (6 individuals);

The proxy values for the benefits of bereavement services are those used for mental health benefits and can be found in Table 3.2 above.

Based on the assumptions above and the values in Table 3.2, the total value of the benefits from bereavement services, before sensitivity analysis, is £2,186,120. The calculations are shown in full in Appendix A.

The benefit estimate comprises:

- Quality of life gains due to mental health improvements in families - £1,852,928;
- Avoided healthcare resource use - £113,054;
- Avoided social care resource use - £16,901;
- Productivity gains - £203,238.

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 2016/17. These have not been included to avoid potential double counting the mental health benefits for family members from using other CHAS services in the same year.

3.6 DIANA CHILDREN'S NURSES

The Diana Children's Nurses provide nursing support for children and young people in a hospital setting, as well as strategic and service development to improve the quality of palliative care for children and young people in Scotland. There are three Diana Children's Nurses at CHAS: based in Lothian (neonatal care), Glasgow Children's Hospital (oncology and paediatric ITU) and Inverness and Aberdeen (support in the community). They are funded by a specific grant for children with life threatening illnesses, established in memory of Diana Princess of Wales. In 2016/17, the nurses supported 143 children with palliative care needs, 58 of whom were subsequently referred to and received other CHAS services.

It is assumed that the benefits of the CHAS Diana Children's Nurses services are:

- Reduced demand for health and social care services e.g. hospital admissions;
- A good death, in preferred place.

As the Diana Children's Nurses (DCNs) provide bespoke services around the country, there is no published evidence specific to the service at CHAS. Their impact is therefore assumed to be similar to those provided by the CHAS at Home service, in line with the service objectives to increase the number of children and young people who die in preferred place and reducing hospital admissions.

To estimate the value of the benefits accrued from the service, a number of assumptions have been made, as follows:

- The additional benefits of the DCN Service is gained by those children and young people who did not receive other CHAS services (85 individuals);
- It is assumed that one hospital admission is prevented during the end of life period for 10% of the children and young people receiving improved end of life care by the DCN (8 individuals);
- One GP appointment is assumed to be prevented for half of the children and young people at the end of life as a result of the input to care by the DCN (42 appointments);
- It is assumed that half of the children and young people receiving care from the DCN were able to die in settings other than hospital, thus avoiding one hospital admission (42 admissions).

The proxy values for the benefits of Diana Children's Nurses are the same as those listed in Table 3.2 above.

Based on the assumptions above and the values in Table 3.2, the total value of the benefits from Diana Children's Nurses is £296,017. This benefit estimate is comprised entirely of avoided healthcare resource use. The calculations are shown in full in Appendix A.

The Diana Children's Nurses have significant input into the palliative care of many other children and young people via their support and input to training and policy development across the hospitals in which they are based. It is not possible to measure and value the benefits of this work but it should be acknowledged. The estimate of benefits is therefore likely to be an underestimate.

3.7 OTHER SERVICES

CHAS has a number of smaller services which add value to the overall service provision from the hospices, CHAS at Home and the Family Support Service. We have not attempted to value the benefits of these services, either because they are integral to other service provision so would risk double counting, or because they are very recently established.

3.7.1 Transition Team

The Transition Team is part of Family Support Services, funded by a Big Lottery grant for 2014 to 2019. Its purpose is to provide support for children and young people who are approaching adulthood, and their families, so they are able to successfully transition to adult services. The team came into effect December 2014 and in 2014/15 was supporting 67 young people and their families.

The aim of the Transition Team is to ensure organisations are aware of the needs of this growing cohort of young people with life-limiting conditions living in the community, helping them to adapt their provision and respond appropriately to the needs of the children and young people. The proposed outcomes of the service are proposed to be:

- Young people with life-limiting conditions will have increased opportunity for autonomy;
- Young people with life-limiting conditions have improved access to age appropriate services in their community;
- Families supporting young people with life-limiting conditions are better able to cope with their caring roles as they move beyond CHAS.

By the end of the first year of the service (December 2015), 12 young people had transitioned to adult services; five had been placed 'on hold' due to ill-health and there had been 13 deaths. During years two and three, the team is expected to support a further 27 young people over the age of 18.

The Transition Team clearly has value in supporting children and young people to live their lives to the full and transition successfully to adult services, increasing their opportunities to enjoy an independent life. It is, however, too soon to estimate quantitative benefits and values for the service, for the purpose of the economic analysis.

3.7.2 Sleptight Service

CHAS provides nursing and medical support to the Sleptight night-sitting service. This is funded and provided in partnership with the Emma Cameron Foundation and an oncology outreach nursing service. It is assumed that the support provided by the service to families has the potential to increase the chances of children and young people dying at home and also contributes to the mental health and wellbeing of parents and carers. The value of the CHAS element of this service is not included in the economic evaluation.

3.7.3 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 doctor on-call. 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, and nor is the activity measured. The additional benefits that may accrue from the advice line are, therefore, not included in the economic analysis and this may be an underestimate of the value of the overall benefits accrued.

3.8 COSTS AND RESOURCES

3.8.1 Funding

CHAS received just over £11 million in income in 2016/17 and spent more than £13 million on service provision. Table 3.4 details the sources of income received by CHAS.

Table 3.4: CHAS incoming resources 2016/17

Source	Income (£'000)
Donations	4,566
Legacies	3,478
CHAS trading income	380
Statutory funding	2,152
Investment income and interest	607
TOTAL	11,183

The bulk of the income received by CHAS is generated via fundraising, through donations, legacies, trading and associated investments. Statutory funding only accounts for 19.2% of funding received and this is primarily provided by the Scottish local authorities (£679,000) and the Scottish Health Boards (£1,035,000). The funding also includes £275,000 earmarked for the Diana Children’s Nurses, provided by the Scottish Government but allocated by the UK Government. As a proportion of the CHAS resources expended in 2016/17, (£13.147 million), statutory funding was only 16.4%. When ‘running costs’ are adjusted as described in the Chief Executive Letter 2012 [24], these total £12.231 million. The statutory funding received by CHAS in 2016/17 represented 17.6% of these ‘running costs’.

A new statutory funding agreement was agreed with the Scottish Government in 2017 that provided for greatly increased core funding of £6 million per year from 2017/18 onwards. This includes the statutory funding for Diana Children’s Nurses but CHAS will continue to receive additional funding from Local Authorities until 2019/20.

3.8.2 Service Costs

Service costs are broken down into direct costs of services provided (charitable activities), support costs and the cost of generating funds. Table 3.5 summarises the resources expended by CHAS during 2016/17.

Table 3.5: CHAS resources expended 2016/17

Resources expended	Costs (£'000)
Charitable activities: Hospices, CHAS at Home and Central Care Services	9,308
Support costs: Central administrative support	1,977
Cost of generating funds: Fundraising, trading and investment management costs	1,862
TOTAL	13,147

In order to consider the costs and benefits of the charitable activities provided by CHAS it is necessary to understand the full costs of the individual services provided, including any support costs.

The main services considered in this evaluation are:

- Hospice care planned;
- Hospice care unplanned;
- CHAS at Home;
- Bereavement services;
- Diana Children’s Nurses.

Costs for charitable activities before allocation of any support costs have been split between the main services listed, so as to reflect the true cost of each service. This takes into account the contribution of the whole staff team to the effective running of the different parts of the service, for example, medical staff who work across the hospices, CHAS at Home and the DCN service.

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 an 80:20 ratio on the advice of CHAS;
- CHAS estimates that 40% of Family Support Services relates to bereavement work.

Table 3.6 summarises the reallocated costs for the individual services.

Table 3.6: Reallocated costs for charitable services 2016/17

Service	Cost (£'000)
Hospice care planned	6,322
Hospice care unplanned	1,580
CHAS at Home	707
Bereavement services	420
Diana Children's Nurses	278
TOTAL	9,308

The support costs can be apportioned to each of the services on the basis of employee numbers. Table 3.7 shows the final costs, including apportioned support costs and also with the costs of generating funds apportioned to the services being evaluated. The latter are included, in recognition of the contribution fundraising can make to the capacity that can be delivered by CHAS.

Table 3.7: Service costs for 2016/17, including apportioned support costs and apportioned costs of generating funds

	Service costs including apportioned support costs (£'000)	Service costs including apportioned support costs and costs of generating funds (£'000)
Hospice care planned	7,516	8,996
Hospice care unplanned	1,879	2,249
CHAS at Home	813	973
Bereavement services	498	597
Diana Children's Nurses	278	333
Cost of generating funds	2,162	0
TOTAL	13,147	13,147

The £275k funding for Diana Children’s Nurses comes directly from the UK Government via the Scottish Government. This leaves £1.877 million in statutory funding that provides part-funding for the remaining services. Table 3.8 shows how these funds have been allocated to each of the service areas.

Table 3.8: Estimated allocation of statutory funding 2016/17

Service	Costs (£'000)	% of costs (excluding DCNs)	Allocation of statutory funding (£'000)
Hospice care planned	8,996	70.20%	1,318
Hospice care unplanned	2,249	17.55%	329
CHAS at Home	973	7.59%	142
Bereavement services	597	4.66%	88
<i>Diana Children’s Nurses</i>	333	-	275
TOTAL	13,147		2,152

3.9 RETURN ON INVESTMENT

The total estimated value of the benefits aggregated across all of the CHAS service areas analysed, was £36,723,432 in 2016/17. This value is well in excess of the total expenditure on CHAS services in 2016/17. It is important to consider that the value of not every service could be quantified and care has been taken not to overstate the benefits that were estimated. The time horizon for benefits gained has also been conservatively set at one year, rather than being sustained for a longer period, with the exception of mental health quality of life, which takes into account the lifetime effect.

The benefits from different economic perspectives are as follows:

Table 3.9: Estimated annual benefits from different economic perspectives

Economic perspective	Element	Value
NHS perspective	Quality of life gains due to mental health improvements in families £16,577,088	£32,189,366
	Avoided healthcare resource use £15,612,278	
Social care perspective	Avoided social care resource use	£1,477,821
Societal perspective	Productivity gains	£3,056,244
TOTAL		£36,723,432

A range of different return on investment scenarios have been considered overleaf.

When considered in the context of the statutory funding provided to CHAS, the return on investment (ROI) for the total statutory funding is 1,606%. This is calculated as follows:

$$£36,723,432 - £2,152,000 / £2,152,000 = 16.06 (1,606\%)$$

When CHAS receives £6 million per year towards running costs from statutory sources, the ROI will be 512%, calculated as follows:

$$£36,723,432 - £6,000,000 / £6,000,000 = 5.12 (512\%)$$

The return on investment if the cost of all charitable activities is included would be 295%, calculated as follows:

$$£36,723,432 - £9,308,000 / £9,308,000 = 2.95 (295\%)$$

The return on investment if the whole of the resources expended are taken into account would be 179%, calculated as follows:

$$£36,723,432 - £13,147,000 / £13,147,000 = 1.79 (179\%)$$

If only the benefits associated with the estimated avoided health and social care use are considered (approx. £17 million), CHAS interventions provided a return on investment of 694% for the statutory funding received:

$$£17,090,099 - £2,152,000 / £2,152,000 = 6.94 (694\%)$$

If only the assumed cost reduction benefits in relation to healthcare were to be included, the ROI from an NHS perspective (including only the health funding) would be 1,408%:

$$£15,612,278 - £1,035,000 / £1,035,000 = 14.08 (1,408\%).$$

If only the assumed cost reduction benefits in relation to social care were to be included, the ROI from a social care perspective (including only the local authorities' funding) would be 118%:

$$£1,477,821 - £679,000 / £679,000 = 1.18 (118\%).$$

3.9.1 Individual Services

If the estimated values for each of the service areas evaluated are compared to the estimated levels of statutory funding for each service area, summarised in Table 3.8 this shows a range of ROI figures. These are shown in Table 3.10.

Table 3.10: ROI calculations for each service area compared to statutory funding

Costs	Statutory funding (£)	Value of benefits (£)	ROI (%)
Hospice care planned	1,318,000	29,391,319	2,130
Hospice care unplanned	329,000	2,780,417	745
CHAS at Home planned and unplanned	142,000	2,069,558	1,357
Bereavement services	88,000	2,186,120	2,384
Diana Children's Nurses	275,000	296,017	8
TOTAL	2,152,000	36,723,432	1,467

3.10 SENSITIVITY ANALYSIS

The analysis above shows the intervention to be very cost effective. We can vary the assumptions made in a number of ways to allow sensitivity analysis of the impacts and costs. For example, we could assume that the intervention is more or less successful, or that the costs of implementation are higher or lower.

The following scenarios have been modelled:

- a) If the number of hospital admissions avoided is reduced by 50%, the value of avoided healthcare use reduces to £15,129,438 and the overall benefit value reduces to £36,240,592;
- b) If the average number of family members experiencing improvements in mental health quality of life is decreased to two, the value of benefits from an NHS perspective decreases to £23,722,978 and the overall benefit value decreases to £28,257,044;
- c) If the number of family members who would have suffered from depression in the absence of the CHAS services is reduced to one, the value of avoided healthcare reduces to £14,930,167 and societal benefits reduce to £1,844,075. The overall benefit value reduces to £34,829,151;
- d) If the number of hospital admissions avoided is increased by 20%, the value of avoided healthcare use increases to £15,794,455 and the overall benefit value increases to £36,905,608;
- e) If the number of avoided GP appointments for children and young people is increased by 50%, the value of avoided healthcare use increases to £15,612,311 and the overall benefit value increases to £36,723,465;
- f) If the number of siblings benefitting from bereavement services is increased to two, the overall benefit value increases to £36,732,504.

We have used the calculator to combine various scenarios and observe the effect of changing the assumptions. In the worst case scenario, (combining a, b and c above), the overall benefit value reduces to £25,895,579.

In the best case scenario, combining d, e and f above, the overall benefit value increases to £36,930,370.

Section 4: Conclusions

4.1 CONCLUSIONS

Children and young people with life-limiting conditions require intensive levels of health and social care resources throughout their lives and it is not easy to understand or quantify the benefits gained from the interventions provided. These children and young people do not recover from their conditions and the effects of caring for them can also have a significant impact on the health and wellbeing of their carers and families.

The provision of palliative care, particularly outside the remit of statutory services, is an area which lacks significant levels of research into the effectiveness and cost-effectiveness of interventions. It is, though, increasingly important for non-statutory services that provide palliative care for children and young people to be able to demonstrate the value of the services they provide.

This evaluation has attempted to develop an understanding of the benefits generated by CHAS services for children and young people with life-limiting conditions and their carers and families. Services have been categorised into different areas and potential benefits identified through a rapid evidence review.

Adopting a conservative approach and accepting the limitations of the analysis, detailed below, the evaluation has found that CHAS services are highly cost effective. The service receives a little over £2.1 million in statutory funding from the Scottish Government, local authorities and Health Boards but generates more than £36.7 million in benefit. The estimated return on investment from the statutory funding is 1,606%, or £16.06 additional value for every £1 of statutory funding spent on CHAS services.

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 almost £17.1 million of benefit value is estimated – a return on investment of 694%.

The return on investment when including the value of all benefits compared to the costs of total resources expended is 179%. When comparing to the costs of charitable activities, (£9.31 million), the return on investment is 294%.

The statutory funding received by CHAS represented only 17.6% of the 'running costs' [24], adjusted as described in the Chief Executive Letter 2012.¹ When this is increased to £6 million per year, the return on investment against statutory funding would be 512%.

¹ Based on adjusted running costs of £12,231,000.

It is concluded, therefore, that services provided by CHAS are cost effective when considering both the total resources expended and the statutory funding only.

The benefits generated by CHAS services are diverse and include cost reductions attributable to avoiding the need for children and young people 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-limiting conditions, who are able to return 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, which is not supported by statutory funding. The value of the contribution of volunteers was estimated by CHAS to be £1.1m in 2014/15, £321,028 of which has benefitted the hospice and hospice at home services. This does not include any wider health benefits that may be accrued by the volunteers themselves through their voluntary activities.

There are also quality of life gains for children and young people and their families through, for example, reductions in mental health problems through the provision of respite care. It has not been possible to quantify improved quality of life for the children and young people, 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. Indeed, such evidence does exist for adults with lung cancer [25], although this cannot be used to calculate a utility value for prolonged life, either in adults or children. CHAS staff report observing longer than expected survival for some children and young people once transferred to the hospice environment. It is speculated that this may be due to the involvement of expert palliative care clinicians; for example, by ceasing of quite toxic medications.

4.1.1 Analysis Limitations

The economic analysis was constrained by the lack of specific evidence that could be used to model the benefits of CHAS services. This is partly due to a lack of metrics in peer-reviewed literature but also concerns about the applicability of evidence that relates to adult palliative care services, or services provided in other countries. Where no peer reviewed literature was available, clinical opinion on the potential benefits observed by CHAS staff has been used to inform the assumptions made. It is hard to compare CHAS to other services as it is unique in Scotland and although children's hospice services exist in other countries, there are bound to be differences in service provision and care pathways. The analysis had to use a number of assumptions about the extent of the economic benefits generated through CHAS services and there is no guarantee that these reflect reality.

Another key limitation was the need to generalise the analysis approach and to treat all children and young people 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 children of different ages and with different conditions and severity of condition. Without carrying out a more detailed analysis of individual children and young people, it was important to be able to use robust assumptions that were generalisable across the children and young people using CHAS services.

The analysis, therefore, used a conservative approach to the estimation of the benefits of CHAS services. 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. Benefits were not quantified either because evidence was not considered strong enough to support analysis or it was impossible to isolate benefits from a specific service as opposed to the overall holistic service provided by CHAS. A conservative approach was also adopted to avoid over-stating potential benefits. For example, in some cases numbers of beneficiaries were minimised, such as the inclusion of benefits for children and young people who only received CHAS at Home services rather than the majority who also received hospice services.

Some specific 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 206 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 patients;
- The Transition Team, Sleightight service and 24 hour telephone advice line were not included in the economic analysis;
- No specific benefit or value was ascribed to the large number of volunteers who provide support to CHAS.

The largest amount of resource goes into short planned breaks and this is the cornerstone of the services CHAS provides. The majority of the estimated benefits were associated with this service. The benefit to mental health should not be underestimated, both for children and young people and their families. No QALY value was included for children and young people, as no specific evidence was found, so this could add significant value if these benefits were included in the analysis.

There may be other aspects of day-to-day care provided by CHAS that may not be captured in this analysis, especially in relation to primary care where hospice care may have the effect of reducing GP consultations. Furthermore, the Diana Children's Nurses service was only introduced in the year being reviewed and is expected to increase caseload and associated benefits over time.

4.2 RECOMMENDATIONS

The evaluation highlights a number of important issues and a number of recommendations are proposed:

- CHAS should consider building on the data already collected to include additional data and / or analysis, for example:
 - The breakdown between planned and unplanned care, both in the hospice and CHAS at Home;
 - The number and nature of domiciliary medical visits;
 - The proportions of different activities provided by the Family Support Service.
- 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;
- Future evaluation of CHAS services should attempt to measure quality of life for children and young people and collect evidence for prolonged life;
- CHAS and statutory bodies should investigate the extent of unmet need in terms of palliative care for children and young people with life-limiting conditions and also any variation in provision across different areas of Scotland.

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APPENDIX A

Benefits Values Tables

For the purpose of accuracy, figures in these tables are not 'rounded'.

1. Hospice short planned breaks

Benefit	Proxy value	Assumed activity in 2016/17	Overall value of outcome
Avoided hospital admissions for children and young people due to improved wellbeing	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 75% inexpensive to 25% expensive = total of £5,676. Up-rated to 2016/17 figures using the hospital and community health services (HSHC) index: £5,752.	42.1	£242,159
Avoided demand for local authority short break services or hospital night	Average of local authority provided residential respite care (PSSRU 2015): average of mean cost for child per night (24 hour period) = £280 and cost of hospital stay (£5,956) = £2,978. Up-rated to 2016/17 figures using the HSHC index: £3,018.	3,211	£9,690,798
	Local authority provided residential respite care (PSSRU 2016): mean cost for family member night (24 hour period) = £188.	6,640	£1,248,320
Avoided hospital admissions as a result of anticipatory care planning	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 75% inexpensive to 25% expensive = total of £5,676. Up-rated to 2016/17 figures using the HSHC index: £5,752.	78	£448,656
Avoided GP consultations for children and young people as a result of anticipatory care planning	Three GP visits (PSSRU 2016): £36 each (£108).	78	£8,424
Avoided hospital admission due dying at home or hospice	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 75% inexpensive to 25% expensive = total of £5,676. Up-rated to 2016/17 figures using the HSHC index: £5,752.	31	£178,312
Improved mental health quality of life for family members	Improved mental health status £7,040 per year (based on average loss of health status in quality-adjusted life years (QALYs) for a level three mental health problem of 0.352 (Centre for Mental Health (2010). At a cost-effectiveness QALY threshold of £20,000 per QALY, the value of health gain is £7,040 (0.352 x £20,000). This is a lifetime benefit.	1,978.7	£13,930,048

Benefit	Proxy value	Assumed activity in 2016/17	Overall value of outcome
Avoided use of GP consultations for family member with mental health problems	Three GP visits at £36 each (PSSRU 2016), plus one year's prescription costs for citalopram tabs 20mg per day £8.52 (total £116.52).	631.5	£73,582
Avoided use of community mental health team for family member	Average cost of treating a case of depression by community mental health team for adults with mental health problems (PSSRU 2015): £2,426.42. Upated to 2016/17 figures using the HSHC index: £2,458.71.	315.75	£776,338
Improved productivity from prevented sick days	Improved productivity from 10 prevented sick days for depression at median Scottish salary of £27,820 in 2016 (Office for National Statistics (ONS)). 10 days is equivalent to 1/23rd of £27,820 = £,1,210.	631.5	£764,115
	Improved productivity from 20 further prevented sick days for those with depression requiring further treatment, at median Scottish salary of £27,820 in 2016. 20 days is equivalent to 2/23rd of £27,820 = £2,419.	315.75	£763,799
Avoided need for education welfare due to improved wellbeing of siblings	Prevented problems at school for siblings - £3,026 for involvement of Education Welfare Officer (2010/11 price inflated using HCHS Index).	31.58	£95,546
Improved productivity as parent does not need to give up work	Median Scottish salary in 2013 £27,820 (ONS).	42.1	£1,171,222
TOTAL			£29,391,319

2. Hospice unplanned care

Benefit	Proxy value	Assumed activity in 2016/17	Overall value of outcome
Avoided hospital admissions for children and young people	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 75% inexpensive to 25% expensive = total of £5,676. Upated to 2016/17 figures using HSHC index: £5,752.	10.53	£60,540
Avoided use of hospital day care	Reduced day care costs (PSSRU 2015): average of short illness trajectory (cancer day care episode £159) and longer life illness trajectory (cystic fibrosis OP visit £150) = £154.50 x 6 = £927). Upated to 2016/17 figures using HSHC index: £939.	21.05	£19,766
Avoided hospital bed days (less expensive)	Cost of bed day for children and young people with palliative care needs (PSSRU 2016): less expensive stay e.g. local hospital for respiratory infection (£506 per day).	278.25	£140,795
Avoided hospital bed days (expensive/complex)	Cost of bed day for children and young people with palliative care needs (PSSRU 2016): complex/expensive stay e.g. paediatric cardiac unit/PICU (£1834 per day).	371	£680,414
Avoided GP consultations for children and young people	One GP visit (PSSRU 2016): £36 each with average prescribing costs of £26.70 (£62.70).	105.25	£6,599
Avoided demand for local respite services or hospital stay	Average of local authority provided residential respite care (PSSRU 2015): average of mean cost for child per night (24 hour period) = £280 and cost of hospital stay (£5,956) = £2,978. Upated to 2016/17 figures using HSHC index: £3,018.	584	£1,762,512
	Local authority provided residential respite care (PSSRU 2016): mean cost for family member night (24 hour period) = £188.	584	£109,792
TOTAL			£2,780,417

3. CHAS at home planned care

Benefit	Proxy value	Number of beneficiaries in 2014/15	Overall value of outcome
Avoided hospital admissions for children and young people due to improved wellbeing	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 75% inexpensive to 25% expensive = total of £5,676. Upated to 2016/17 figures using HSHC index: £5,752.	2.4	£13,805
Avoided demand for local authority short break services or hospital night	Average of local authority provided residential respite care (PSSRU 2015): average of mean cost for child per night (24 hour period) = £280 and cost of hospital stay (£5,956) = £2,978. Upated to 2016/17 figures using HSHC index: £3,018.	15.1	£45,572
Improved mental health quality of life for family members	Improved mental health status £7,040 per year (based on average loss of health status in quality-adjusted life years (QALYs) for a level three mental health problem of 0.352 (Centre for Mental Health (2010). At a cost-effectiveness QALY threshold of £20,000 per QALY, the value of health gain is £7,040 (0.352 x £20,000). This is lifetime benefit.	112.8	£794,112
Avoided use of GP consultations for family member with mh problems	Three GP visits at £36 each (PSSRU 2016), plus one year's prescription costs for citalopram tabs 20mg per day £8.52 (total £116.52).	36	£4,195
Avoided use of community mental health team for family member	Average cost of treating a case of depression by community mental health team for adults with mental health problems (PSSRU 2015): £2,426.42. Upated to 2016/17 figures using HSHC index: £2,458.71.	18	£44,257
Improved productivity from prevented sick days	Improved productivity from 10 prevented sick days for depression at median Scottish salary of £27,820 in 2016 (Office for National Statistics (ONS). 10 days is equivalent to 1/23rd of £27,820 = £1,210.	36	£43,560
	Improved productivity from 20 further prevented sick days for those with depression requiring further treatment, at median Scottish salary of £27,820 in 2016. 20 days is equivalent to 2/23rd of £27,820 = £2,419.	18	£43,542
Avoided need for education welfare due to improved wellbeing of siblings	Prevented problems at school for siblings - £3,026 for involvement of Education Welfare Officer (2010/11 price inflated using HCHS Index).	2.4	£7,262
Improved productivity as parent does not need to give up work	Median Scottish salary in 2016 £27,820 (ONS).	2.4	£66,768
TOTAL			£1,063,073

4. CHAS at home unplanned care

Benefit	Proxy value	Number of beneficiaries in 2014/15	Overall value of outcome
Avoided hospital admissions for children and young people	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 75% inexpensive to 25% expensive = total of £5,676. Uprated to 2016/17 figures using HSHC index: £5,752.	103	£592,456
Avoided use of hospital day care	Reduced day care costs (PSSRU 2015): average of short illness trajectory (cancer day care episode £159) and longer life illness trajectory (cystic fibrosis OP visit £150) = £154.50 x 6 = £927). Uprated to 2016/17 figures using HSHC index: £939.	103	£96,717
Avoided GP consultations for children and young people	One GP visit (PSSRU 2016): £36 each with average prescribing costs of £26.70 (£62.70).	103	£6,458
Avoided demand for local respite services or hospital night	Average of local authority provided residential respite care (PSSRU 2015): average of mean cost for child per night (24 hour period) = £280 and cost of hospital stay (£5,956) = £2,978. Uprated to 2016/17 figures using HSHC index: £3,018.	103	£310,854
TOTAL			£1,006,485

5. Bereavement services

Benefit	Proxy value	Number of beneficiaries in 2014/15	Overall value of outcome
Improved mental health quality of life for family members	Improved mental health status £7,040 per year (based on average loss of health status in quality-adjusted life years (QALYs) for a level three mental health problem of 0.352 (Centre for Mental Health (2010)). At a cost-effectiveness QALY threshold of £20,000 per QALY, the value of health gain is £7,040 (0.352 x £20,000). This is lifetime benefit.	263.2	£1,852,928
Avoided use of GP consultations for family member with mental health problems	Three GP visits at £36 each (PSSRU 2016), plus one year's prescription costs for citalopram tabs 20mg per day £8.52 (total £116.52).	84	£9,788
Avoided use of community mental health team for family member	Average cost of treating a case of depression by community mental health team for adults with mental health problems (PSSRU 2015): £2,426.42. Uprated to 2016/17 figures using HSHC index: £2,458.71.	42	£103,266
Improved productivity from prevented sick days	Improved productivity from 10 prevented sick days for depression at median Scottish salary of £27,820 in 2016 (Office for National Statistics (ONS)). 10 days is equivalent to 1/23rd of £27,820 = £1,210.	84	£101,640
	Improved productivity from 20 further prevented sick days for those with depression requiring further treatment, at median Scottish salary of £27,820 in 2016. 20 days is equivalent to 2/23rd of £27,820 = £2,419.	42	£101,598
Avoided need for education welfare due to improved wellbeing of siblings	Prevented problems at school for siblings - £3,018 for involvement of Education Welfare Officer (2010/11 price inflated using HCHS Index).	5.6	£16,901
TOTAL			£2,186,120

6. Diana children's nurses

Benefit	Proxy value	Number of beneficiaries in 2014/15	Overall value of outcome
Avoided hospital admissions for children and young people	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 75% inexpensive to 25% expensive = total of £5,676. Uprated to 2016/17 figures using HSHC index: £5,752.	8.5	£48,892
Avoided GP consultations for children and young people	One GP visit (PSSRU 2016): £36 each with average prescribing costs of £26.70 (£62.70).	42.5	£2,665
Avoided hospital admission due dying at home or hospice	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 75% inexpensive to 25% expensive = total of £5,676. Uprated to 2016/17 figures using HSHC index: £5,752.	42.5	£244,460
TOTAL			£296,017