

CHILDREN'S HOSPICES ACROSS SCOTLAND

Economic Evaluation of Hospice Services

Executive Summary

JO HANLON, Senior Research Consultant
NICK HEX, Associate Director

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1. INTRODUCTION

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

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

2. METHODS

2.1 Development of the Analysis Framework

The first stage of the work was to update the analysis framework which was developed for the earlier economic evaluations. The framework describes the interventions provided by CHAS, the costs and benefits of each service, and proposes how the information will be used in the analysis, including any assumptions required. The analysis year is 2018/19, which is considered to be the latest year that reflects 'business as usual'. 2019/20 was affected by the introduction of a new clinical system and, latterly, by the impact of Covid-19.³

¹ CHAS. Clinical and Care Strategy 2019-2020.

² Hex N Hanlon J. Economic Evaluation of Hospice and Hospice at Home Services. Updated Report for 2016/17. York Health Economics Consortium. 2016.

³ In addition, most families chose to shield and not uptake services weeks ahead of the Scottish Government's advice.

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

2.2 Economic Analysis

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

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

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

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

3. IMPACT OF CHAS SERVICES

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

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

The following services are included in the quantitative analysis:

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

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

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

4. ECONOMIC ANALYSIS

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

Based on the literature evidence, the values described in Appendix A and the assumptions in Appendix B, the total estimated benefits value for one year for the services provided by CHAS in 2018/19 was over £49 million. A number of different perspectives were considered in the analysis, including the NHS and social care perspectives and the societal perspective, in the form of improved productivity due to improved mental health. Based on the assumptions used in the analysis, the estimated total benefits of CHAS services per year from these different perspectives are shown in Table 4.1.

Table 4.1: Value of benefits of CHAS Services

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

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

The results of the return on investment (ROI) calculations for CHAS services are shown in Table 4.2. This shows the ROI for each individual service and the total of all services, in four ROI scenarios:

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

Table 4.2: Estimated return on investment of CHAS Services

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

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

5. DISCUSSION

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

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

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

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

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

5.1 Other Services

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

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

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

5.2 Recommendations

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

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

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

- CHAS and statutory bodies should investigate the extent of unmet need in terms of palliative care for BCYP with life-shortening conditions and also any variation in provision across different areas of Scotland.
- The Scottish Government, Local Authorities and NHS Health Boards should consider increasing the level of statutory funding available for CHAS services, particularly given the likelihood that the services reduce the burden of health and social care resource use.
- Given the substantial involvement of volunteers, it would be useful to attempt to quantify the wider benefits for the volunteers themselves in any future economic reports.