

Outcomes and Economic Evaluation of Children's Hospice Care at Home Service

Invitation to tender

June 2023

1. Introduction

This invitation to tender (ITT) invites proposals to undertake an outcome and economic evaluation of the impact of Jessie May Trust in providing children's hospice care at home. We are seeking proposals to deliver an economic evaluation of our core service in providing care in the home for children with life limiting and life-threatening conditions, in our current geography of Bristol, North Somerset, South Gloucestershire, Bath and North East Somerset, Swindon and Wiltshire.

We welcome proposals from organisations with experience in:

- Evaluating children's health related interventions
- Evaluating palliative care interventions
- Working with confidential client data

2. About Jessie May

Jessie May Trust (JMT) is a children's charity providing hospice care at home and was established by parents Chris and Philippa Purrington in 1996 after the death of their daughter Jessica May. Jessica died from a genetic condition known as severe Spinal Muscular Atrophy when she was only 4 ½ months old. Jessica was cared for by her family in her own home and died, in her father's arms at home. During one of the family's many visits to Bristol during Jessica's short life, Jessica was admitted to Southmead hospital in Bristol and the family learnt that the home support that was available in High Wycombe, where the family lived, was not available in the Bristol area. After Jessica's death the family were determined to do what they could to ensure that families in the Bristol area could access support in their own homes and the charity was officially launched in 1996.

Now known as Jessie May, our vision is that all children and young people with life-limiting and life-threatening conditions are supported to have the very best quality of life possible, and to choose to live, and to die, in their own homes with their families. We work to achieve this by making it our mission to provide the very best care and support possible, at home, for children and young people with life limiting and life-threatening conditions and their whole families, for the whole journey in life, at the end of life, and in bereavement.

Over the last 26 years we have supported hundreds of families and have a current caseload of around 90 families.

3. Background

Our nursing model is unusual in that we have an agreement with University Hospitals Bristol and Weston NHS Trust (UHBW) in which our nurses are employed by them and seconded into the charity to provide the service to JMT children and their families.

In 2022 we launched our five-year strategy, 'No Place, Like Home'. At the heart of the strategy is our commitment to support more children and their families with life-limiting and life-threatening conditions and looking at our we might replicate the Jessie May model in other areas of the South West and beyond.

We are also looking at our nursing (care) model and are currently renegotiating our contract and arrangement with UHBW.

4. Aim of the Evaluation

This is intended to be an outcome and economic evaluation which aims to understand the key outcomes associated with Jessie May's work and the economic impact of the provision of hospice care in the home.

Our aims and outcomes are outlined as follows:

Aim	Outcomes
Each child with a life-limiting condition lives as full a life as possible	<ul style="list-style-type: none"> • Increase the happiness and confidence of each child. • Increase the amount of time each child can spend safely in their family environment, including at end of life. • Increase each child's social experiences
Each family experiences as positive a life as possible	<ul style="list-style-type: none"> • Increase the confidence of parents and children to care for their child. • Increase the parents' sense of belonging to a supportive community of other parents and the Jessie May team. • Maintain the family unit by increasing parents' and siblings' resilience and reducing the medium-long term risks to their physical and mental health and well-being

For the outcome evaluation, we would like to understand the following:

- Is Jessie May meeting the aims we have set out above?
- Are there any additional outcomes of our work?
- What are the impacts of these aims on families and children?

We would like the economic evaluation to answer the following questions:

- What is the evidence for the cost effectiveness and social value provided through hospice care in the home?
- How cost effective is the provision of hospice care in the home provided by Jessie May?
- Do the outcomes associated with hospice care at home, mean that Jessie May makes cost savings for healthcare services in Bristol, North Somerset and South Gloucestershire (BNSSG)?
- Are these cost savings likely to translate to other geographical areas?

We are open to refining these questions based on your experience and approach. Your submission should clearly outline your proposed evaluation methods and how they will respond to the questions set out.

To support this evaluation, the contractor will have access to the following documents and data:

- Exported data sets from our CRM system, which monitors our patient interactions (including type of support received from JMT and the regularity of support) and communications (including missed, cancelled and rearranged visits).
- Documents outlining insights from past monitoring and evaluation activities (although the contractor should be aware that this is limited)
- Access to current information about costs of Jessie's May's services/finances
- Qualitative data relating to case studies and quotes from children and their families.
- Facilitated access to speak to children and their families who use Jessie May's services.

If your evaluation approach requires further information or data from Jessie May, please indicate this within your submission.

5. Working with the Jessie May team

The work will be managed by Daniel Cheesman, CEO of Jessie May, with input from Clare Pearce, Director of Funding Development and Andrea Choules, Director of Care (in post from June 2023) and the Quality Assurance Subcommittee at Jessie May. There will be collaboration working with partners from UHBW and with Jessie May families.

At the evaluation inception meeting, we will work with the successful contractor to refine the proposed approach and agree on the ways that we will work in partnership. We will work closely to align the evaluation with the broader evaluation activities of Jessie May.

6. Deliverables

The contractor will be expected to deliver on the following outputs:

- A workplace detailing how the work will be delivered including timescales.
- Attendance at monthly project meetings
- A short progress report in advance of each project meeting
- Ongoing updates to the key contact by email or telephone where needed and raising awareness of any risks or blocks to the work.
- A final report outlining the findings from the evaluation questions and the methodology used in an accessible format which can be feed into the overall evaluation report.

7. Timescales

Tender Process	
ITT published	07 June 2023
Deadline for submissions	14 July 2023
Interview with awarding panel	28 July 2023
Selection of contractor	August 2023
Evaluation Delivery	
Project start / inception meeting	September 2023
Monthly project meetings	Ongoing until completion
Completion of the project	End of March 2024

8. Intellectual Property

The ownership of the research material, including the final report and any data produced lies with JMT.

9. Information Sharing

To facilitate the evaluation, it is understood by all partners that information generated by the project will be shared on a regular basis with the evaluator, and information sharing arrangements will be in place from the outset of the project.

Data will be extracted from our CRM systems which monitor various aspects of JMT delivery. The evaluator will need to take steps to ensure that any sensitive data is stored securely and processed in line with GDPR.

10. Budget

The budget for this research is £20,000 including VAT where applicable. The proposal should include a comprehensive outline of costs including:

- Salary costs for each project team member to be involved in fulfilling the contract.
- Other staff costs, e.g., admin
- Fieldwork costs
- Overheads (if charged)
- Other costs (with detail)

If the allocated cost to conduct the specification exceeds £20,000 can contractors set out what is possible within budget and how much of the full specification falls outside of this amount and what the additional expenditure would add to the work.

Payments will be made according to the following schedule:

- 50% on receipt of a signed contract agreement
- 50% when the final outputs are signed off.

11. Responding to this ITT

Your submission should include:

- An outline of the proposed approach to the project and limitations

- An explanation of how the proposed approach addresses the questions set out in this ITT.
- Details of the research methods proposed.
- Indication of what data we would need to provide to answer the proposed questions.
- Indication of what data you can bring to answer the proposed questions.
- Information on how data will be analysed.
- Any proposed adjustments to the research questions
- A schedule for completing the work in line with the timescales.
- The name of the lead contact
- An initial assumption of how much Jessie May staff time might be needed to support the project and at which key points.
- Relevant experience of the organisation and individuals working on the research in terms of:
 - Working with small charities
 - Completing outcome and economic evaluations
- A detailed breakdown of the costs
- A summary of the risks associated with work and how these can be mitigated.
- Details of two references (one must be a previous research client) who can be contacted for references if appointed the contract.

Proposals will be based on a written submission (Word, PowerPoint or PDF accepted) and a subsequent interview with the awarding JMT panel.

We will assess the research bids according to the following criteria:

- The extent to which the proposal meets the brief outlined in the ITT.
- The appropriateness of the proposed methods
- The ability to meet the specified timescale.
- The contractors' experience of carrying out similar work.
- Overall value for money

Please send any clarification questions to Daniel Cheesman, CEO at Daniel.cheesman@jessiemay.org.uk by 23 June 2023.

Please send your written submission to Rebecca.sheehy@jessiemay.org.uk with 'Jessie May Evaluation Proposal' as email header by 5pm on 14th July 2023.