



Children's Hospice Association Scotland

Sharing the Caring

RESEARCH SPECIFICATION

October 2008

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An Assessment to Identify the Future Research Priorities for the Children's Hospice Association Scotland

Copies of the final report and lay summary are enclosed as separate documents

BACKGROUND

1. The Children's Hospice Association Scotland was established in 1992 by a group of parents and professionals who wanted to develop a service to provide hospice services to families with a child or children with life-limiting conditions. It embarked on ambitious fundraising programmes and in 1996, it opened Rachel House in Kinross. In 2005, with the need for further specialised palliative care, CHAS opened Robin House in Balloch. Both hospices are purpose built, and each has 8 single rooms for children and young people, and additionally 8 rooms to accommodate their families.
2. The hospices provide the following support to families by offering:
 - Short planned breaks for the whole family or respite for the child alone
 - Emergency care in times of crisis
 - Advice and information to families and professionals
 - Outreach services
 - Bereavement support
3. CHAS developed some home care services for the Central Belt areas as well as a small home care service (CHAS at Home) in Inverness, to offer some services in the north of Scotland.
4. CHAS is a charity with 188 employees and over 800 volunteers. It has an executive Senior Management Team which reports through its Chief Executive to a board of directors – in September 2006 the Board commissioned the Cancer Care Research Centre (CCRC) at the University of Stirling to identify important areas for future research. The CCRC asked the following to participate in this study:
 - Children, young people and their families using the hospice services
 - Staff and volunteers providing the service
 - Professionals closely linked or associated with the service
5. A Delphi method was adopted to carry out the study between November 2006 – September 2007, and this resulted in 6 recommendations. In June 2008, the CHAS Board endorsed the recommendations, and agreed to commissioning specific pieces of research.
6. The Children's Hospice Association Scotland (CHAS) aims to provide the highest quality of care for children and young people in Scotland who have life limiting conditions, and support for their families.
7. CHAS is recognised by the Scottish Government Health Directorates as the national body for the provision of children's hospices in Scotland. This offers the opportunity to make a substantial contribution to research in palliative care for children and young people, both at a national and an

international level. CHAS has a growing interest in research, as was evidenced in its commissioning and subsequent endorsement of the *“Assessment to Identify the Future Research Priorities for the Children’s Hospice Association Scotland”* (Malcolm, Knighting, Forbat and Kearney, Cancer Care Research Centre, University of Stirling, 2007) Appendix 2.

8. To take forward recommendations made in the report, CHAS seeks to work in collaboration with experienced researchers to action a number of identified priorities. It is anticipated the research will commence no later than Autumn 2009, and outline applications will be submitted to the CHAS Research Advisory Committee. Following a short listing process, successful applications will be invited to develop full proposals.

AIMS AND OBJECTIVES

9. To commission discrete pieces of research to develop knowledge and evidence which will inform practice and service development, and which subsequently add to the body of knowledge in the growing area of palliative care for children and young people. The report detailing the assessment led to a number of recommendations, the two areas agreed for this current round of research are:
 - **Pain and symptom management in children and young people with life limiting conditions** – identified in the above assessment as being “a research area of central importance” in interviews with families, hospice staff and indeed professionals, especially paediatricians (Appendix 2 - page 41 and 70)
 - **Communication by hospice staff with children, young people and families about death and dying issues** (Appendix 2 - page 40 and 71)

CRITERIA FOR RESEARCH WORK

10. Successful applications for research funded with the Children's Hospice Association Scotland will

- Demonstrate how the experiences of children, young people and their families will be at the core of this research, and how they will be involved
- Demonstrate that the research team has previous experience in research with children, young people and families
- Have a UK focus, demonstrating collaboration with other children's hospices/palliative care teams
- Work within an agreed monitoring framework
- Identify recommendations for CHAS in terms of service delivery and development, if appropriate
- Demonstrate effective working within the allocated budget
- Acknowledge Children's Hospice Association Scotland on all publications, as well as ensuring co-ownership, and joint copyright on all findings

RESEARCH DESIGN AND METHODOLOGY

Proposals should clearly identify, within the application form:

- The aims of the research
- The proposed research methodology
- The method whereby ethical approval would be sought
- Whether any co-sponsorship is being sought or considered
- An outline of evidence of relevant research that has been previously undertaken by the University / Researchers, and previous experience of involving children, young people and their families in research
- An outline of evidence of work previously undertaken with hospice staff and other related health care and social work professionals
- Identification of the responsibilities of the Researcher to ensure that the design of the study complies with the Data Protection Act 1998

FUNDING / TIMESCALES

11. CHAS is not specifying a budget limit for this project in advance of receiving proposals. Bidders are to propose an appropriate amount to conduct the work carefully and thoroughly, but with a view to probity and accountability in spending money donated by the public for the benefit of children and young people with palliative care needs. The process to decide which proposal to support will include some discussion on proposed costs.
12. Funding will be available for direct costs only. Academic Institutions should note that as a charity, CHAS cannot pay full economic costs.
13. The research topics are outlined in section 2 – Aims and Objectives. It is anticipated that the initial time period for the pieces of research will be 1 year full time, or 18 months part time.
14. Further funding may be available depending on the outcomes of these initial pieces of work

APPLICATION PROCESS

15. The outline application form can be completed electronically or by hand and should be returned to Yvonne Jones, secretary to Dr P Carragher, by 5pm on 12 December 2008. The application should be in plain English and any technical terms used should be explained as clearly and as simply as possible.

Outline applications will be assessed by the Research Advisory Committee, and successful applicants will be notified.	23 January 2009
Full research proposals should be submitted.	3 April 2009
The Research Advisory Committee will assess the proposals, which will also be subject to a peer review process, and make recommendations to CHAS Board of Directors.	15 May 2009
The decision will be communicated to all applications in writing.	30 June 2009

CHAS RESEARCH ADVISORY COMMITTEE

16. The Research Advisory Committee includes representatives from both the CHAS Board, parents, and other disciplines with recognised relevant experience. This committee functions as an autonomous advisory body within the structure of CHAS. Its members are listed in Appendix 1.
17. The Research Advisory Committee is responsible for assessing projects on the basis of the criteria listed, and will make recommendations to the CHAS Board.

Appendix 1

Membership of the Research Advisory Committee

- Tabitha Bell, Director, CHAS
- Dr Peter Fowlie, Director, CHAS
- Marian Keogh, Chief Executive, CHAS

- Dr Anne Hunt, Senior Research Fellow in Paediatric Palliative Care, University of Central Lancashire
- Professor Nora Kearney, Cancer Care Research Centre, University of Stirling
- Dr Dermot Murphy, Consultant Paediatric Oncologist, Yorkhill Hospital, Glasgow
- Renee McCulloch, Paediatric Palliative Consultant, Great Ormond Street, London
- Professor Sheila McLean, Director, Institute of Law and Ethics in Medicine, University of Glasgow
- Mike Naulty, Associate Dean, School of Education, Social Work and Community Education, University of Dundee
- Professor Sheila Payne, Help the Hospices Chair in Hospice Studies, Lancaster University
- Katie Rigg, Nurse Consultant, Children's Palliative Care, Scotland
- Patrick Smith, Parent

In attendance

- Andrea Cail, Director of Service Development, CHAS
- Dr Pat Carragher, Medical Director, CHAS

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Appendix 2

Copies of the lay summary and final report of *An Assessment to Identify the Future Research Priorities for the Children's Hospice Association Scotland*, (Malcolm, Knighting, Forbat and Kearney, Cancer Care Research Centre, University of Stirling, 2007) are enclosed as separate documents.