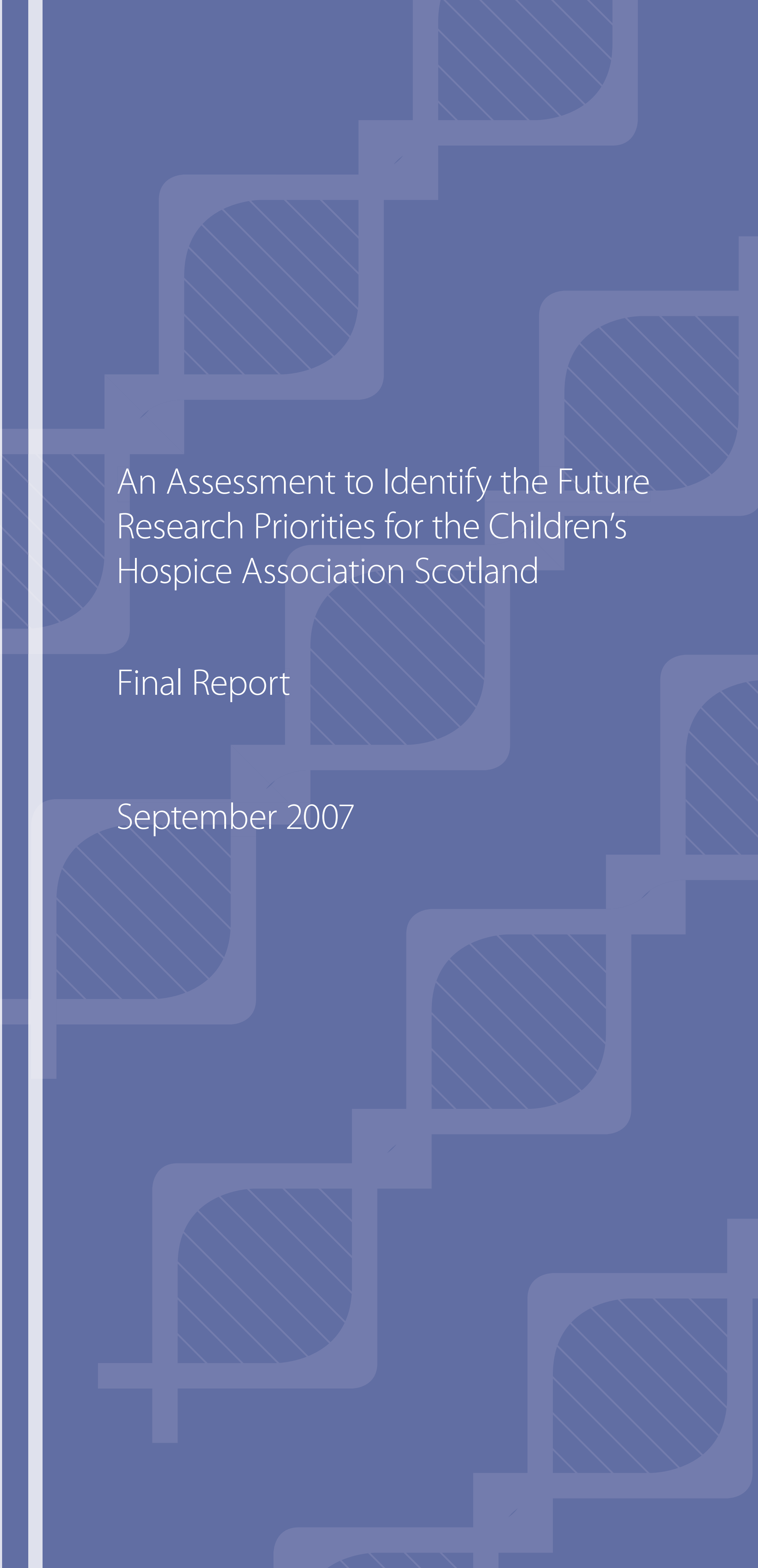

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An Assessment to Identify the Future Research Priorities for the Children's Hospice Association Scotland

Final Report

September 2007

UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

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

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EXECUTIVE SUMMARY

I. The Children's Hospice Association Scotland (CHAS) was established in 1992 and is known across the country as a charity committed to specialist caring, support and respite for children and young people with palliative care needs and their families. The primary objective of CHAS is to offer hospice services, free of charge to every child and family who needs and wants them (CHAS, 2005). CHAS has two hospices, Rachel House in Kinross and Robin House in Balloch, offers a home care service in the Central Belt area, a 24 hour telephone support and advice service and a small home care service called Rachel House at Home (RHAH) in the north of Scotland.

II. There is currently a paucity of research in children's palliative and hospice care and a recognised need to further develop an evidence base to continue to advance the field.

III. CHAS' commitment to excellence in care services is evident in their strategic objectives where they aim to develop a programme of education and research that is based around real needs of children, young people and families using the service (CHAS, 2007).

IV. A three-round Delphi survey was conducted to obtain agreement/consensus among family, staff, volunteer and professional stakeholders regarding the future research priorities for CHAS.

V. Round 1 data collection included interviews and focus groups with families (n=5), CHAS staff and volunteers (n=44) and professionals in health, social care, education, policy and the voluntary sector (n=18) between January and February 2007. From this process, fifty-six research questions in fourteen broad themes were identified.

VI. Round 2: A questionnaire containing the 56 research questions was distributed to 621 participants (families n=293; CHAS staff and volunteers n=216; professionals n=112) where they were asked to rate importance of each question using a five-point Likert scale and begin the process of consensus. Of the 621 questionnaires distributed, 274 were completed yielding a response rate of 44%.

VII. Round 2 analysis: There was a high level of consensus amongst participants. Fifty-five of the 56 research questions had a mean rating of ‘important’ or ‘very important’. The fifteen research questions rated as ‘very important’ included topics relating to hospice and respite care needs of young people, pain and symptom management, bereavement and end-of-life care, hospice awareness, supporting the wider family, medical cover in the hospice and improving access to the hospice.

VIII. Round 2 analysis: Participants were also invited to indicate how important the broad research themes were to them by rank ordering their top five choices. The top five research themes as ranked by participants were: pain and symptom management; improving access to children’s hospice care; bereavement and end-of-life care and support provided by CHAS; community care (outreach) provided by CHAS and hospice and respite care needs of young people (aged 16+).

IX. Round 3: Given the level of consensus amongst the participants only the 15 research items which were rated as ‘very important’ in the Round 2 questionnaire were included in the final questionnaire. Postal questionnaires were distributed to 247 participants (families n=87; CHAS staff and volunteers n=107; professionals n=53) where they were asked to rate the importance of each of the 15 questions. Of the 247 questionnaires distributed, 204 were completed yielding a response rate of 83%.

X. Round 3 analysis: There was a high level of consensus amongst participants. All 15 research questions in Round 3 received a mean rating of ‘very important’.

XI. In conclusion, a high level of consensus was reached amongst service users and providers with acknowledgement that all of the issues raised during this project are of high importance and merit future research. The themes of hospice and respite care needs of young people (aged 16+); pain and symptom management; and bereavement and end-of-life care and support provided by CHAS emerged as the issues of greatest importance to families, staff, volunteers and associated professionals with the relevant research questions appearing in the top five list.

XII. It is important for readers of this report to remember the research priorities were rated as important research priorities for CHAS and do not necessarily indicate that participants have concerns about these areas of the current service or are highlighting them as areas requiring immediate service improvement.

XIII. A range of research priorities have emerged from this work that may be of value for CHAS to consider when developing their research strategy for the next five years. The key recommendations which have come from research priorities are outlined below and whilst not exhaustive of the data, reflect those areas for research considered to be of the highest importance by the families, staff, volunteers and professionals who participated in the process.

Recommendation 1: Consider conducting a needs assessment of young people (16+) with life-limiting conditions from the perspective of the young people themselves, their parents and professionals. The needs assessment should consider the following issues:

- identify the care and support needs of young people from all perspectives;
- review the psychological support CHAS currently provides to young people (16+) who know they have a life-limiting condition; and
- make recommendations for staff training, development and support.

Recommendation 2: Consider conducting an assessment into pain and symptom management. The assessment should consider the following issues:

- identify the services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess their effectiveness;
- look at the practice within CHAS and how it links with other agencies/services;
- explore the main symptoms experienced by children with very rare life-limiting conditions;
- develop and evaluate improved symptom management strategies.

Recommendation 3: Consider conducting a needs assessment to identify any training and support CHAS staff would benefit from regarding bereavement care and, more specifically, how to communicate with children and their families on end-of-life issues.

Recommendation 4: Consider exploration of the other areas which were identified by participants as being research priorities. The areas include:

- supporting families who are new to the service or potential users of the service;
- spiritual and emotional care issues;
- children's education;
- support needs of the wider family;
- diversity issues;
- issues of specific relation to CHAS staff and volunteers;
- service development; and
- strategic planning issues.

Recommendation 5: The introduction of a formal research programme will require a change in thinking and practice for some within the organisation and some who use the service. It will be important for CHAS to consider opportunities to build research capacity and expertise. This could include several strategies such as:

- the recruitment of a senior academic/researcher with the appropriate research expertise to drive forward and oversee the research activities of CHAS and its external partnerships. This could be achieved through the creation of a new post within CHAS or through a consultancy agreement with an external organisation;
- explore secondment opportunities for CHAS staff to engage in the research process with external organisations; and importantly to
- explore methods of engaging with families to identify and increase their awareness and understanding of the need and future benefit of research.

Recommendation 6: Consider developing links and formal networks with other hospices in the UK, relevant academic institutions and areas of clinical excellence to encourage a collaborative approach to research.

ACKNOWLEDGEMENTS

The project team from the Cancer Care Research Centre would like to extend their thanks to all those who have contributed to this work. Thank you to all who participated, either in an interview or focus group or in the completion of the postal questionnaires. We would like to extend a special thank you to the families who met with the researcher and shared their experiences using CHAS, and their thoughts on important areas for research.

We also wish to thank members of the Project Steering Group for their expert guidance throughout the project, their time, contributions and invaluable comments which were much appreciated by the project team.

Finally, thank you to the Rachel House and Robin House staff for all their assistance with the distribution of the project questionnaires. We are especially grateful to Sue Hogg and Julie Wyllie for their advice and support at all stages of this work.

1 INTRODUCTION

The Children's Hospice Association Scotland (CHAS) was established in 1992 and is recognised as a charity committed to specialist caring, support and respite for children and young people with palliative care needs and their families. CHAS' primary objective is to offer hospice services, free of charge to every child and family who needs and wants them (CHAS, 2005). In Scotland there are an estimated 1,200 children with a life-limiting/life-threatening condition and over half will require active palliative care (CHAS, 2005). Collectively, Rachel House in Kinross, and the more recently opened, Robin House in Balloch have the capacity to provide 300 children and their families with 17 hospice nights per year. In addition CHAS also offer a home care service in the Central Belt area, a 24 hour telephone support and advice service, and a small Home Care Service called Rachel House at Home (RHaH) in the north of Scotland to offer support to families in more remote areas. Recent expansions of the service, such as the opening of Robin House, an audit which identified strengths of the service and pockets of unmet need (CHAS, 2005) and recent policy initiatives afford an opportunity to consider the future research priorities for CHAS.

In line with recent policy developments and usual practice of the Cancer Care Research Centre (CCRC), the initial proposal for this project was discussed and developed in consultation with three families who use CHAS services. Members of the CCRC team went out to visit the three families in their homes to discuss and gather their views on the proposal and proposed methods. The families all contributed to the methods and discussion of the potential participants for the project.

After a successful proposal bid, the CHAS Board commissioned the CCRC, University of Stirling to undertake an assessment to identify the future research priorities for CHAS from the perspective of its key stakeholders including children and families using the service, staff and volunteers providing the service and professionals closely linked or associated with the service. The research project was overseen by a Project Steering Group; details of the members of this group can be found in Appendix A.

2 BACKGROUND

The epidemiological, policy and social context, in which this assessment took place, will be outlined in the following section. Palliative care will be defined and the epidemiology of children in the UK with palliative care requirements outlined prior to discussing the current policy informing children's palliative care services and models of adult palliative care. The existing evidence base and current research activity in the field of children's palliative and hospice care will also be presented.

2.1 Definition of Palliative Care for Children and Young People with Life-Limiting Conditions

A widely used definition of palliative care for children and young people with life-limiting conditions provided by the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), and the Royal College of Paediatrics and Child Health (RCPCH) (ACT/RCPCH, 2003) is as follows:

'an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement.'

Within this definition, the essentiality of a holistic approach to care and one that encompasses both the child and wider family is recognised. Palliative care may be necessary for a wide range of different medical conditions. Four broad definitions of groups of children and young people with palliative care needs have been described by ACT/RCPCH (2003) and they are:

- life-threatening conditions where cure is possible but can fail (such as cancer)
- conditions where premature death is inevitable despite long periods of intensive treatment aimed at prolonging life (such as cystic fibrosis)
- progressive conditions where treatment is palliative and often extends over many years (such as muscular dystrophy)
- irreversible but non-progressive conditions causing severe disability and sometimes premature death (such as severe cerebral palsy)

2.2 Epidemiology of Children's Palliative Care in the UK

The epidemiology of children with life-limiting conditions is progressing yet sound data on prevalence rates is not available, particularly with regard to non-cancer conditions (Emond & Eaton, 2004). Data provided by ACT/RCPCH (2003) indicate that in the UK the prevalence of severely ill children with life-limiting conditions who will require palliative care is at least 12 per 10,000 children, aged 0-19 years. Using this data, it has been estimated that the prevalence of children living in Scotland with a life-limiting condition is around 1,200 and of these, over half will require active palliative care at some stage (CHAS, 2005). The incidence of cancer amongst children is increasing, and hence too the potential for increased life-limiting illness (Scottish Executive, 2005a). More precise figures are currently unavailable. Many children with life-limiting conditions are surviving longer as a result of continuous improvements and advancements in medical care. Defining prevalence rates will be essential in order to plan and develop the services this population will require in future (Davies, 2003).

The timescale for involvement of palliative care services for children and young people differs somewhat to palliative care services for adults (Emond & Eaton, 2004). The need for palliative care services may be recurrent and unpredictable for children with long-term disabling conditions, life-limiting illnesses or complex needs (DoH, 2005). This is particularly relevant for children's palliative care where it may be harder for the distinction between the curative and palliative stages of care to be made; consequently the identification of an appropriate time to initiate the involvement of palliative care services is difficult (Hynson & Sawyer, 2001). This raises additional challenges when trying to accurately define prevalence rates.

2.3 Current Health Policy Informing Children's Palliative Care Services

Current health policy outlines a clear commitment to ensuring 'every child matters' and insists that health services are patient and family focused and available to all regardless of background or circumstances (Scottish Executive, 2001; Scottish Executive, 2005b). In Scotland, following recent shifts in the provision of palliative care arising from the recommendations made in the *NHS Framework for Service Change* (Scottish Executive, 2005b), a model of health care for the management of long-term conditions has evolved. Focus is placed on the individual and their needs, making it vital for all providers of health care to work with patients and carers to ensure services, including palliative care, reflect the range of needs for individuals requiring care. A key message during the framework process was that health care should be provided in settings as local and as close to patients' homes as possible. Therefore, Care in Local Settings ensures the themes identified in the framework will be implemented in relation to a specific field (National Framework for Service Change in the NHS in Scotland: Report of the Care in Local Settings Action Team, 2005).

One such field is children with complex needs. The *Children with Complex Needs* report states that the model of care for children with complex needs should be bound by several principles: "child and family centred, offer choice, integrated and co-ordinated services and integrated planning systems and timely decision-making" (National Framework for Service Change in the NHS in Scotland: Care in Local Settings: Children with Complex Needs, 2005, p.1). Furthermore, a number of entitlements in the model of care for children with complex needs are presented, namely: "good multi-agency working to provide a more seamless service, increasing choice, high standards of care and packages of care" (National Framework for Service Change in the NHS in Scotland: Care in Local Settings: Children with Complex Needs, 2005, p.1). In relation to palliative care specifically, it is stated that all children and young people who have the need should be given access to high quality palliative care services, with a recognition that young people's palliative care needs will change as they move on from children's services. It is therefore recommended in this report that the "Managed Care Network for Children with Complex Needs should review palliative care services for children with complex needs. This should include consideration of hospice services and pain management services available to children with complex needs" (National Framework for Service Change in the NHS in Scotland: Care in Local Settings: Children with Complex Needs, 2005, p.5).

Thus, there is a need for fully integrated, multi-agency assessment of the needs of the child or young person and their families, to ensure an appropriate package of care is delivered which fully reflects where they want their care delivered (DoH, 2005). It is vital to involve the child or young person and their family in the decision-making process while developing their care package. There should also be a choice of setting where the needs of every child or young person and their family will be met, including the hospital, hospice or the home (DoH, 2005).

Children's hospice care should also be seen in the context of developing adult palliative care services. The Gold Standards Framework (GSF), for example, aims to improve the delivery and experience of palliative and supportive care in the home and community and optimise the role of GPs in facilitating this as a location of care (www.goldstandardsframework.nhs.uk). Moreover, the GSF promotes having one 'gold standard' of palliative care that is offered to all who require it.

It is recognised that children and families require a variety of palliative care services from both the statutory and voluntary sectors. Collaboration between all service providers is a necessity in order to address unmet need and to provide reliable, integrated and quality palliative care services (CHAS, 2005). In 2004, a *Framework for the Development of Integrated Multi-agency Pathways for Children with Life-Threatening or Life-Limiting Conditions* was developed by a working party comprised of the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), the Royal College of Nursing (RCN), and the Royal College of Paediatrics and Child Health (RCPCH). The objective of this framework was to provide a template to be used in the development of care pathways for children with palliative care needs and their families. It was expected that the framework would encourage partnerships between service providers, including health, social care, education and voluntary agencies and service users, in developing and evaluating care pathways for children and young people with palliative care needs and their families whilst putting the children and families at the centre of planning and delivery of their care (Elston, 2004).

With this commitment to integrated palliative care services, it will be essential for research and evaluation to be designed and undertaken within a multidisciplinary and collaborative context (ACT/RCPCH, 2003; Scottish Executive, 2005b). Davies (2006) highlights the importance of evaluating, auditing and researching the effectiveness of the ACT framework in practice from the perspectives of children and young people themselves in order to develop more effective care pathways in future.

2.4 Evidence Base and Current Research Activity in Children's Palliative Care

Clinical governance standards in the UK insist that all health care practice is firmly based on quality evidence (DoH, 1997; SODoH, 1997). Whilst research in the area of children's palliative care has increased over recent years, published research and outcome data is currently insufficient to provide the required evidence base for improving policy and practice (Cooley *et al*, 2000; Hynson & Sawyer, 2001; ACT/RCPCH, 2003; Emond & Eaton, 2004; Liben *et al,* 2007) thus demonstrating the need for a clear research agenda to address key questions. Indeed criticisms have been levied that paediatric palliative care lacks a rigorous empirical basis (Cooley *et al*, 2000), creating an opportunity to move services forward by identifying and pursuing key research topics.

As a major player in providing hospice care for children and young people with palliative care needs in Scotland, CHAS have the opportunity to define a research strategy that will facilitate the continued development and evaluation of the hospice care they provide. The Scottish government recognises the importance of involving patients and their families in both research and health service planning (Scottish Executive, 2003). Moreover, the involvement of children, siblings and parents is important in evaluating and improving the quality of services provided by children's hospices (Maynard *et al*, 2005), indicating a need to engage in research and evaluation that is inclusive in its design. Thus active participation of children, young people and families in developing the future research priorities for CHAS and engaging them in the research process is fundamental.

3 METHODS

3.1 Aim

The primary aim of this project was to identify future research priorities for CHAS that would contribute towards developing an evidence base of the hospice care they provide. The project was committed to involving service users and providers therefore the research priorities were identified from the perspectives of key stakeholder groups including children and families who use CHAS, staff and volunteers who provide the service and professionals closely associated with the service.

3.2 Project Steering Group

A steering group consisting of the CCRC project team, key representatives and service users was established to guide the project, review the methods and analysis and adopt an advisory role in monitoring progress and performance. Specific roles included contributing to the development of the data collection tools (interview schedules and questionnaires) and commenting on the final report. The steering group met at face-to-face meetings on two separate occasions, once at the beginning of the project and again towards the end of the project. Additional correspondence by email, post and telephone took place throughout the project period. Details of steering group membership are given in Appendix A.

In addition, the CHAS Board and relevant Heads of Care nominated a senior member of staff from both Rachel House and Robin House to act as the lead representative and contact person during the project.

3.3 Ethical Issues

This project involved the participation of children and families affected by a life-limiting condition and therefore it was essential the project was conducted according to sound ethical guidelines. Advice was sought from the Chair of the Local NHS Research Ethics Committee in regard to ethical approval, but as the project was classified as an *evaluation of current services*, approval was not required from the Central Office of Research Ethics Committee (COREC). The project was submitted to the Department of Nursing and Midwifery Research Ethics Committee, University of Stirling and received full ethical approval. In addition, the project was overseen by the CHAS Clinical Governance Committee who received detailed progress updates every three months.

Members of the research team were aware of the potentially sensitive and emotive nature of the conversations and correspondence with families, volunteers and hospice staff. The information and recruitment process employed ensured that participants were given clear details of the nature of their involvement and an understanding that they could leave the project at any time without giving reason. It was also ensured that participants had adequate time in which to consider their involvement and the opportunity to discuss it with others if they wished to. All participants were required to give informed written consent. Throughout the project, every effort was made to protect the anonymity of participants and confidentiality was maintained at all times.

All tapes, transcripts and questionnaires were anonymised and stored securely within the CCRC and only accessed by those investigators directly involved in the project. These will be stored for ten years in accordance with data protection law and then destroyed.

3.4 The Delphi Technique

Future research priorities for CHAS were identified during an extensive scoping exercise that adopted a quasi-Delphi technique (Chambers *et al*, 2003). The Delphi technique is a postal exercise consisting of several stages known as ‘rounds’ where a questionnaire is used to establish the views and opinions of participants so they can confirm or change their previous responses. The process normally has a number of data collection rounds and ends when participants are happy with their represented opinions and do not want to make changes or too few participants continue to respond. The first round is typically used to establish a list of topics or questions which are used in the subsequent rounds until a consensus has been reached by the group of particpants. The first round may use a quantitative approach such as questionnaires or a qualitative approach such as focus groups and interviews. The approach is well-suited to this work as it is a democratic process which is designed to produce a representative opinion with all participants having an equal say, participants can see where their thinking lies with reference to the full range of opinions of the group, and individuals have the chance to change their opinion when they have had time to reflect.

The Delphi technique has been previously applied to determine the priority areas for nursing (Barrett *et al*, 2001; Lopez, 2003; Mcilfatrick & Keeney, 2003; Bayley *et al*, 2004; Rodger *et al*, 2004), midwifery (Fenwick *et al*, 2006), and health research (Broomfield & Humphris, 2001; Zebrack *et al*, 2006; Hauck *et al*, 2007), and more specifically in identifying clinical and nursing research priorities within the domain of palliative and hospice care (Chang & Daly, 1990; Daniels & Howlett, 2001).

The Delphi procedure used for this project consisted of three rounds which are depicted in the flowchart below (Figure 1). This section of the report will describe the participant recruitment, data collection and analysis approach taken at each stage of the project as outlined in the flowchart.

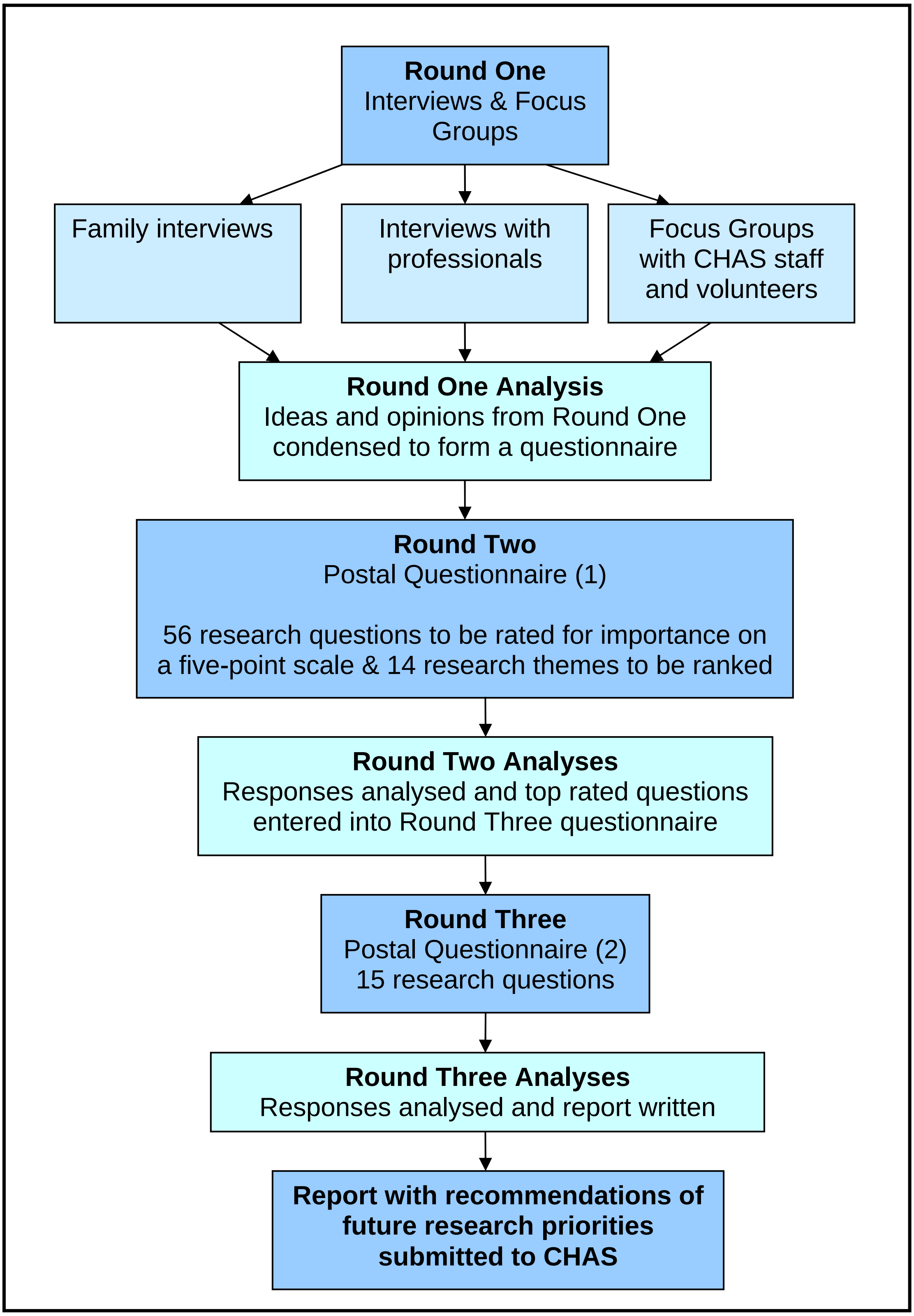

Figure 1. Flowchart of Delphi Procedure

3.5 Participants

Participants in Delphi studies are considered to be a panel of ‘experts’ and have been previously defined as a group of ‘informed individuals’ (McKenna, 1994) with ‘demonstrated knowledge about a subject and an ability to articulate a broad perspective on an issue’ (Zebrack *et al*, 2006, p.2916).

A purposive sampling strategy was employed in this project to identify participants who would hold a breadth of perspectives and opinions on the future research priorities for CHAS. The participants included families using the service, staff and volunteers operating within the organisation, professionals in health, social care and education, policy developers and representatives from national organisations in the field of palliative care. All participants invited to take part had an association with CHAS and a committed interest to the care of children with life-limiting conditions and their families. The rationale for selection of these participant groupings included their ability to consider potential research priorities from broad and diverse perspectives and experiences, thus they formed the panel of ‘experts’ within this project. Further details of the participants and their recruitment are given below separately for each Round.

3.6 Round 1 – Participant Recruitment and Data Collection

Round 1 was qualitative in nature and consisted of face-to-face interviews with families using CHAS, focus groups with CHAS staff and volunteers and telephone interviews with key professionals associated with the service. A total of 71 individuals took part in Round 1. The interview and focus group schedules were developed by the research team and then discussed and revised with the Project Steering Group. The primary objective was to gather the views and perspectives of key stakeholders involved with the CHAS service on which research issues they felt were of high priority to the future hospice care of children and families and thus CHAS should consider when developing their research agenda. Participants were asked to generate and discuss a list of research priorities. Participants were also invited to say which of the research topics they identified should be given the highest priority.

3.6.1 Family interviews

The lead representative from each of the hospices, together with their Head of Care, was asked to nominate families they felt would be suitable to invite to participate in the interviews. The aim was to gather the views of a range of families currently being supported by CHAS including new users, longer-term users and bereaved families. Three families using the services of Rachel House were suggested and included a new user (family who had recently started using Rachel House), a longer-term user (family who had used Rachel House for more than five years) and a bereaved family. As Robin House has been in operation for a much shorter period of time it was difficult to distinguish between new and longer-term users. Two families using the services of Robin House were suggested and included a family who had recently started using Robin House and a family who had been using Robin House for more than one year (Table1). It was suggested by the Head of Care that since Robin House is a relatively new service compared to Rachel House it would not be appropriate to approach any of their bereaved families to participate in the interview.

The lead representatives took responsibility for contacting the identified families and requesting their permission to be contacted by a member of the research team to discuss the project in greater detail and obtain formal consent to participate. The researcher posted a detailed project information sheet and ‘agreement to take part’ form to each of the families. Once the agreement forms were returned to the researcher, families were contacted to arrange a suitable date, time and place for the interview.

Table 1. Families participating in the focus groups (n=5)

Category	Number of Participants
Rachel House Family who recently started using Rachel House	1
Family who have used Rachel House for more than 5 years	1
Bereaved family	1
Robin House Family who recently started using Robin House	1
Family who have used Robin House for over a year	1
TOTAL	**5**

Semi-structured face-to-face interviews were conducted with the five families during January and February 2007. The interviews took place at a location chosen by the family. Four of the families requested to be interviewed in their home and one family requested the interview take place at Robin House during one of their scheduled visits. Three of the interviews were conducted with one parent present, one with two parents present and one with two parents, a sibling and the affected child present. The interviews lasted between 32 minutes and 51 minutes. Participants provided written consent for the family to take part and to have the discussion audio recorded and subsequently transcribed. The interview schedule can be found in Appendix B.

3.6.2 Focus groups

Posters were displayed at Rachel House and Robin House inviting staff and volunteers to take part in focus groups to discuss the future research priorities of CHAS. The research team requested that the lead representative of each hospice ensure as far as possible that the focus group participants would include representation from a selection of the various volunteer and staff groupings.

Four focus groups were held with CHAS volunteers and staff members during January 2007; two took place at Rachel House and two at Robin House. There were a total of 44 participants as described in Table 2 with each focus group having a minimum of nine and a maximum of thirteen participants.

Table 2. Categories of CHAS staff and volunteers participating in the focus groups (n=44)

Category	Number of Participants
Activities Team	3
Administration	5
Care Team	16
Catering	2
Chaplain	4
Maintenance and Housekeeping	5
Physiotherapy	2
Social Work	3
Volunteer	4
TOTAL	**44**

During each focus group session, participants were asked to discuss and compile a list of the future research priorities for CHAS. Once a comprehensive list had been put together and displayed on flip-charts the participants were then requested, as a group, to prioritise the top five most important research questions.

The focus groups were facilitated by a member of the research team and lasted between 55 and 70 minutes. All participants provided written consent to participate and to the audio recording and subsequent transcription of the focus group discussion. The focus group schedule can be found in Appendix C.

3.6.3 Professional interviews

In consultation with the project steering group and the lead representatives from Rachel House and Robin House, key professionals in health, social care and education were identified and invited to be interviewed. These professionals were selected on the basis that they had an association with CHAS and/or families using the service (often as referrers to the organisation) and an informed interest or expertise in the care of children with life-limiting conditions and their families. Professionals working in a range of Health Boards areas were included and there was specific inclusion of one Health Board area that has had low referrals to CHAS in the past (CHAS, 2005).

An invitation letter containing detailed information about the project and an ‘agreement to take part form’ was posted to each of the 23 identified professionals. If they wished to be interviewed as part of this assessment professionals were requested to indicate on the ‘agreement to take part form’ and return it to the research team. Of the 23 professionals initially contacted, responses were received from 21, with 16 of these accepting the invitation to be interviewed. Reasons given by the remaining five professionals for being unable to participate included long-term sick leave (n=1), peripheral involvement with CHAS (n=2) and recent retirement from their post (n=2). Both professionals who had recently retired were able to suggest alternative colleagues who were suitable to approach. Responses were received from the two alternative professionals and they agreed to participate giving a total of 18 participants in the professional category.

Participants were contacted by the researcher and asked to suggest a suitable date and time for the telephone interview to take place. Participants were then sent a confirmation letter and a copy of the interview schedule to give them an opportunity to consider their responses in advance of the interview. Table 3 details the roles of the participants involved.

Table 3. Categories of professionals participating in the telephone interview (n=18)

Categories	Number of Participants
General Practitioner	2
Paediatric, Neonatal or Palliative Care Consultant	6
Professional in Education	1
Social Worker	2
Nurse (Community and/or Palliative Care Specialists)	3
Member of CHAS Executive Board	2
Professional in Voluntary Sector	1
Policy Development (National)	1
TOTAL	**18**

During the interview participants were asked to list up to five research priorities and from these identify which they would give the highest priority or importance. Participants were also asked to discuss some of the barriers and facilitators CHAS should consider when developing their research agenda. Interviews lasted between eight and 24 minutes. All participants provided written consent to participate and to the audio recording and subsequent transcription of the interview discussion. The telephone interview schedule can be found in Appendix D.

3.7 Round 1 Analysis and Questionnaire development

Content and interpretive analysis of the Round 1 interview and focus group data was performed. Thematic content analysis is a useful approach for answering questions about the salient issues for a particular group of respondents or for identifying typical responses (Hill & Weinert, 2004). A member of the research team read through each of the transcripts to identify research questions. Some of the research questions were a direct answer to structured interview questions, which asked respondents to put forward their research priorities whereas others emerged during analysis and interpretation of the contextual data.

The key findings from Round 1 were developed into a questionnaire to allow a larger sample of participants from the key stakeholder groups to rate the importance of the research questions identified during Round 1 and begin the process of consensus. This process was accomplished through the use of a postal questionnaire. Further details of the analysis conducted for Round 1 is presented in the analysis section of the report.

A 12-page questionnaire consisting of three sections was developed from the key findings of Round 1. The first section of the questionnaire contained 56 research questions grouped under 14 broad themes. Each research question had a five-point Likert scale for rating the importance with 1 being ‘not at all important’, 2 being ‘least important’, 3 being ‘important’, 4 being ‘very important’ and 5 being ‘extremely important’.

The second section invited participants to rank the 14 research themes to identify which were the five *most* important themes in their view. Participants were asked to do this by ranking the topics from 1 to 5, with one being the most important, in their opinion. Additional space was provided to give participants the opportunity to provide additional comments or rationales for their ratings and ranking in the questionnaires if they wished to do so.

The third and final section collected demographic and contact details of the participants. Participants were asked to indicate their consent to participate in the third round by ticking a box and providing their contact details. (see Appendix E for Round 2 questionnaire)

3.7.1 Pilot study

A small pilot study was conducted prior to distribution in order to assess the face validity and reliability of the questionnaire. The pilot questionnaire was administered to the project Steering Group (n=12), the wider CCRC team (n=27) and selected academics from the Department of Nursing and Midwifery, University of Stirling with experience in Delphi research and/or questionnaire design (n=6). Respondents were requested to offer comment on the following aspects of the questionnaire:

- Instructions provided for completing the questionnaire
- Process of completing the questionnaire
- Clarity of the wording of the research questions considering both the language and meaning will require to be understood by both professional and lay participants
- Overall layout and design of the questionnaire
- Any suggestions for further improvement

The results of the pilot study highlighted minor amendments to the layout of the questionnaire and wording of some of the research questions. There was acknowledgement and agreement in the comments from the pilot respondents that any attempt to over simplify the research questions could easily go wrong and that the terms would be understood by most of the participants. Moreover, the literature recommends that when employing the Delphi technique the wording used by participants, with minor editing, should be used as much as possible (Hasson *et al*, 2000). The research team made the final decision that some simplification of terms would take place. However, where altering the terminology would potentially alter the meaning of the research questions, as set out by respondents in the first round, no changes were made.

3.8 Round 2 – Participant Recruitment and Data Collection Procedure

3.8.1 Round 2 participants

A list of potential participants for Round 2 was compiled by the research team, project steering group and other key staff in CHAS to ensure that all relevant stakeholders were contacted and offered the chance to take part in the project.

The CHAS Clinical Governance Committee requested that the twelve Child Health Commissioners (CHCs) in Scotland be included. Due to the vast number of volunteers working with CHAS the Voluntary Services Manager provided a representative sample of 50 volunteers from within the organisation. All CHAS Head Office staff and members of the Board and Sub-Committees were included. Lead representatives identified all current staff within Rachel House, Robin House and the Rachel House at Home (RHAH) service. This included representation from all staff groupings such as the care team, administration, catering, housekeeping and maintenance and the GPs providing medical cover at the hospices.

Lead representatives were also asked to identify all families currently using the CHAS service and all bereaved families supported by CHAS. Lead representatives identified a few families who were currently experiencing a difficult time and it was felt it would not be appropriate to include them in the sample. Thus a total of 106 families currently using Rachel House and 73 families currently using Robin House were contacted in Round 2.

As requested by the CHAS Clinical Governance Committee, a letter was sent to all bereaved families (families bereaved over the past five years for Rachel House) to notify them of the intention to distribute a research priorities questionnaire and give them the opportunity to opt-out should they wish. One family using Rachel House and one family using Robin House replied requesting not to be included. A total of 93 bereaved families using Rachel House and 21 bereaved families using Robin House were included.

A total of 621 participants were included in the distribution of the Round 2 questionnaire. A profile and breakdown of the participants by their category of families, CHAS staff, CHAS volunteers and Professionals is outlined in Table 4.

Table 4. Profile of participants in the distribution of Round 2 questionnaire (n=621)

% of each category in the total sample	Breakdown within each category	Number of questionnaires distributed
Families **47%**	Current users of Rachel House	106
	Bereaved families using Rachel House	93
	Current users of Robin House	73
	Bereaved families using Robin House	21
	Sub-total for families:	**293**
CHAS staff **27%**	Head Office staff	23
	Board & Committee Members	9
	Rachel House staff	77
	Robin House staff	55
	Rachel House at Home (RHaH) staff	2
	Sub-total for CHAS staff:	**166**
CHAS volunteers **8%**	Volunteers working at:	
	Rachel House	8
	Robin House	10
	Rachel House at Home	3
	Retail	5
	Fundraising	22
	Head Office	2
	Sub-total for CHAS volunteers:	**50**
Professionals **18%**	Policy makers/advisors	4
	Consultants	25
	Nurses	28
	General Practitioners	8
	Allied Health Professionals	14
	Social Work	9
	Education	9
	Voluntary Sector Representatives	3
	Child Health Commissioners	12
	Sub-total	**112**
	TOTAL:	**621**

3.8.2 Round 2 procedure

Project packs containing a cover letter, questionnaire and reply paid envelope were distributed to the 621 participants by post. The project packs were posted directly to all of the professionals and the CHCs. The CHAS Voluntary Services Manager posted the project packs to the volunteer sample. CHAS administrative staff distributed the project packs to Head Office and Board (Sub-Committee) members. Lead representatives distributed the project packs amongst staff at Rachel House and Robin House. Administrative staff at Rachel House and Robin House provided address labels for the project packs and posted them on to the families, ensuring the research team had no access to participants' personal addresses.

Participants were given two weeks to return their completed questionnaire. A reminder letter was posted to participants in the professional grouping, one week after distribution of the questionnaire. The lead representatives were responsible for reminding staff at Rachel House and Robin House to return their questionnaires. A member of CHAS' administrative staff was responsible for sending a reminder email to all Head Office staff. Families were not sent a reminder letter, as it may have been experienced as applying undue pressure.

3.9 Round 2 Analysis and Questionnaire Development

The questionnaire data from Round 2 was entered into the statistical analysis software SPSS version 14.0. Random data screening was performed on every third questionnaire entered, to ensure accuracy of data inputted. Descriptive statistics were run to provide full summaries of the participants for the total sample and each participant category and are presented in the key findings section for each round.

In Delphi studies there is little consistency in the standard statistics that are reported, or used as a cut off point for inclusion of topics in further rounds, with some researchers choosing between reporting the median or mean of participant responses. In this project the number of participants, mean and standard deviation for each research question is presented according to each theme in the key findings section. The mean, as a measure of central tendency, represents the average group opinion of the sample or participant category. For example, a mean which is close to 3 shows that the group opinion was at the 'important' level of the rating scale. The standard deviation is used to show the level of agreement of this opinion in each group as it measures the spread of the data about the mean value. The standard deviation can be useful in comparing sets of data which may have the same mean but a different range, such as a rating scale like the one used in the questionnaire of this project. If the standard deviation is low the sample are in strong agreement of the mean, whereas if the standard deviation is high there was some level of disagreement, or spread, in the opinions of the group. For example, if a mean rating of 3 *('important')* was given for a research question but it had a standard deviation of 1, this means that the individual responses of participants varied by -1 or +1 so the range of responses across the sample was from 2 ('not as important') to 4 ('very important').

A 3-page questionnaire consisting of two sections was developed from the key findings of Round 2. The first section of the questionnaire asked participants to confirm their role by ticking a box for each participant category (Family, CHAS staff, CHAS volunteer, Professional). The second section contained 15 research questions which following analysis of the Round 2 data emerged as the top priorities receiving a mean rating by the total sample of 4 or above. Each questionnaire was personalised to display the rating that each participant had given in Round 2 for the individual research questions and asked them to confirm or change their rating on the same five-point Likert scale used in Round 2 with 1 being 'not at all important', 2 being 'least important', 3 being 'important', 4 being 'very important' and 5 being 'extremely important'.

In this final round, each questionnaire was personalised to include participants' last individual response from Round 2 and were informed that the average rating given to each of the 15 questions was 4 'very important'. Participants were requested to consider the 15 research questions once again and were asked to confirm their original rating or change their response if they wished following consideration of the group response and their previous response. Space was provided for participants to comment on their responses should they wish to do so. (see Appendix F for Round 3 questionnaire)

The same postal procedure as Round 2 was followed for Round 3. Participants were given two weeks to return their completed questionnaire. Reminder letters were not sent in this round.

3.10 Round 3 - Participants and Data Collection

The primary objective of Round 3 was to obtain a group consensus on the rating of the research questions deemed as most important to CHAS following analysis of the Round 2 questionnaire data. Table 5 provides a profile of the participants who returned the Round 2 questionnaire and those who were sent and responded with the Round 3 questionnaire. Further details of the response rates are provided in the analysis section of the report.

Table 5. Response rate of Round 2 and Round 3 questionnaires

Participant Categories	**Round 2 distributed** (Number & % of the total sample)	**Round 2 response rate** (Number & % of the total sample)	**Round 3 distributed** (Number & % of the total sample)	**Round 3 response rate** (N & % of those distributed for each category)
Families	293 (47%)	92 (34%)	87 (35%)	72 (83%)
CHAS staff	166 (27%)	92 (34%)	79 (32%)	66 (84%)
CHAS volunteers	50 (8%)	31 (11%)	28 (11%)	27 (96%)
Professionals	112 (18%)	55 (20%)	53 (22%)	39 (74%)
No details given*	N/A	4 (1%)	N/A	N/A
TOTAL:	**621 (100%)**	**274 (100%)**	**247 (100%)**	**204**

* Respondents did not complete section C of the Round 2 questionnaire so we do not know which participant category they belong to.

3.11 Round 3 Analysis

The analysis for Round 3 focused on any change in the ratings of the research questions between Round 2 and Round 3, the reasons given by participants for any change, the level of consensus between the participant categories and identifying the top five research priorities for CHAS.

4 KEY FINDINGS OF ROUND 1

4.1 Identification of Research Questions

Following content analysis of the interview (n=23) and focus group transcripts (n=4) an initial list of 84 research questions or statements were identified and categorised into 14 principal themes. There was some similarity amongst a number of the research questions. Following discussion and debate amongst the members of the research team as to which research questions were similar and warranted merging with other questions, the 84 research questions were collapsed to form a final list of 56 research questions under 14 broad themes (Table 6). This is not a hierarchical list, but one which allows the best flow of ideas across the many research topics raised in the qualitative component of the project.

Table 6. Distribution of the 56 research questions identified during Round 1 in the 14 broad themes.

Themes	Number of Research Questions
Awareness of children's hospice care	3
Improving access to children's hospice care	5
Supporting families who are new to or potential users of the service	3
Community care (outreach) provided by CHAS	3
Hospice and respite care needs of young people (aged 16+)	4
Spiritual and emotional care	2
Bereavement and end-of-life care and support	8
Pain and symptom management	2
Education of children and siblings	1
Supporting the wider family	5
Diversity	2
CHAS staff and volunteers	2
Service development	11
Strategic planning	5
TOTAL	**56**

A breadth of topics for future research emerged from the interviews with key stakeholder groups and provides some insight into the areas of children's hospice care that are of high importance to families, service providers and relevant professionals. Given the diverse range of participant perspectives included, it is important to discuss each of the themes in greater detail, to provide further context regarding where the research questions and priorities originated. Some of the themes and detailed research questions contained within them were specific to certain participant groups whereas other themes were identified unanimously across all of the groups as being a priority area for future research.

Talking about research priorities is not a routine way of conceptualising the experience of CHAS. Consequently while some ideas about research were clearly articulated and worked-up in participants' speech, other ideas were less well developed. At times, themes and concerns emerged subtly in conversation about the services CHAS provides and people's responses to their role with the organisation. Research ideas were implicit within their speech, and were therefore not consciously presented or processed as research ideas. The research team's role was to identify those more subtly articulated ideas, and reflect them back to speakers within the conversation for confirmation, and to further develop them by the use of interpretative analysis of the transcribed discussions. The conversations were very different between the three participant groups. The families' research ideas were largely guided by their experiences with using CHAS. CHAS staff and professionals were much more explicit in sharing research priorities whereas families' ideas came through stronger during the interpretative analysis.

4.2 Thematic Analysis

Content analysis identified 14 themes in the qualitative data of Round 1. This section will describe the themes and provide quotes from participants to support the themes and research questions that were included in the questionnaire in Round 2.

4.2.1 Theme 1: Awareness of children's hospice care

Exploring the awareness and understanding of CHAS and children's hospices in general, and the range of services provided to children with life-limiting conditions and their families emerged as being a key research priority by all stakeholder groups. Families, hospice staff, volunteers and professionals acknowledged that many myths and misconceptions concerning children's hospices continue to prevail amongst public and professionals alike. There was recognition of the need to develop strategies that would promote a greater understanding of CHAS and assist to dispel existing misconceptions. It was felt very strongly across all of the respondent groups that actively promoting the wide range of care and support provided by CHAS was necessary to increase awareness amongst the public and professionals and thus improve access to the service, tapping into unmet need:

> *"There is a big issue in terms of getting children and families across the threshold of a children's hospice, A because of the terminology and B because of professional misconceptions or lack of education and information that professionals have about what children's hospices do…."* (Professional)

> *"I think if everybody is aware that the hospices are around….I think it's just people knowing about it more than anything and not being scared that it's some really sort of negative place where children or babies just go to die. I think trying to make sure it's a much more positive thing for the families*…" (Professional)

Conceptualising 'awareness of the hospice' thereby moves away from traditional concerns regarding the associations between hospice and death, and toward ideas where service demand and unmet need are prioritised. Further, the potential for increased donations was also cited as a potential benefit to arise from better public awareness of the organisation's services.

4.2.2 Theme 2: Improving access to children's hospice care

Families, service providers, volunteers and professionals highlighted the issue of improving access to children's hospice care as a priority area for future research. In order to improve access to the service it will be necessary to undertake some initial scoping work to form a sound evidence base of the precise requirement for children's hospice care in Scotland:

> *"The first one is to have evidence-based research about the number of families who fit our referral criteria who actually live in Scotland, a needs analysis."* (Professional)

> *"…whether this is research or analysis and scoping or audit, I mean these things sort of stray across boundaries, depends how specifically one wishes to use the word research,….there's issues around scoping unmet need…"* (Professional)

There are geographical considerations in Scotland with the need to ensure equal access to the service for children and families living in more rural and remote areas. It was acknowledged in the interview data that both hospices are located in the central belt and many families wanting to use the service will be required to travel long distances. This also raised the issue of CHAS providing community and outreach care which is discussed in detail in a later section.

The link between the level of awareness that professionals in health and social care have regarding the services CHAS provides to children and families and patterns of referral to CHAS was expressed as a research priority:

> *"so if they've got a perception that children's hospices adopt the same model as adult hospices that they are there for end-of-life care, then they (professionals) wouldn't necessarily perceive a family on their caseload would benefit from using a children's hospice, so there's work that could be done in identifying the sort of patterns of referral in terms of who refers to CHAS and who doesn't*…" (Professional)

> *"There's issues about patterns of referral to hospices, so that can be something to look at: why professionals refer, why don't they refer…"* (Professional)

Moreover, there was a clear identification that referral to the service should be made by professionals, not families, which raised the concern that professionals responsible for the care of children with life-limiting conditions may not have a clear understanding of the referral criteria. It was thought that CHAS services could be offered to families much earlier in the course of their child's illness if professionals had a clearer understanding of the referral criteria:

> *"I think more professionals should know from the beginning like, my consultant didn't offer me Rachel House, he just said we can give you help and support if you need it, and I think that it would be helpful if someone like my consultant or anybody's consultant actually visited the place and knew what it was like and knew what it could offer, or even be able to put it forward you know 'cause none of that was ever suggested when [Child] was born*…" (Family using CHAS)

> *"A lot of people still don't know who can be referred….at what stage….they're still not sure what stage of illness they can refer people at. I think that's still a problem with some consultants…"* (CHAS Staff)

> *"I'm vague about the criteria, I tend to hear about the criteria through the families because they've had experience of going through that process, rather than being clear about the criteria myself because I've had no direct information…"* (Professional)

Focus group participants discussed the value in exploring the reasons why children with certain life-limiting conditions are not being referred to and/or not accessing children's hospice services, for example cardiac anomalies, gastro-intestinal disorders and cancer. The issue of offering hospice services to children with cancer also arose during the interviews with professionals. Cancer seemed to emerge as the priority with the need to investigate where CHAS and children's hospice care fits into palliative care for cancer in children and young people in Scotland:

> *"I think there is an interesting debate about where the hospice [CHAS] fits into the services for palliative care for cancer patients."* (Professional)

> *"It [CHAS] is a valuable resource, but I think it could be a more valuable resource. I mean I work with children who are terminally ill, from a oncological point of view and almost none of my children access either of the hospices. And that would be a reflection of quite a lot of oncologists working in Scotland. And, I think that's to the detriment….maybe we could use the facilities, but they have to be used in a different way to what they've provided at the moment. I think, the fact that parents don't want to use these facilities indicates to us that they've not provided a way that's suitable for these parents."* (Professional)

> *"Well they've got their own model of care because it's a children's oncology background that I come from and they have a very, very good network of support there, they were one of the first before CHAS was funded if you like, so they've already got something in place that they'd like to use. But I think there is a big scope that these children could come here and it's just at the moment that's not really tapped into*…" (CHAS staff)

Participants also suggested exploring the reasons families choose to access or not access CHAS. There was acknowledgement that the decision to use a children's hospice is a personal one and will not be the choice of all children with life-limiting conditions and their families. However, an area for research may be to further explore how and when the offer of accessing CHAS is presented to families and how CHAS can support families in making an informed choice:

> *"We're not getting everyone…so we need to really think about why, why are we not able to access CHAS for all children and I know it's a personal thing for some families but how can we do it better? How can we sell CHAS to them? On the other hand there are a number of children that would benefit from CHAS but can't access it because of a very strict criteria."* (Professional)

> *"It was mentioned by a few people early on, very early on when it was just days or weeks. I'm sure in the hospital they mentioned getting in touch with Rachel House and I can remember thinking what on earth is that, but to be honest, my recollection of the early days even at that time is very hazy … I think the day we got the diagnosis I'm sure the consultant at the time mentioned it as well and that definitely wasn't the time to do it."* (Family using CHAS)

4.2.3 Theme 3: Supporting families who are new or potential users of the service

The issue of supporting families when they start to use CHAS or at the time they are presented with the option of using the service emerged as an area for future research from CHAS staff and families. Families described how parents often find the idea of using a hospice 'daunting' at first and preconceptions based on understandings of adult hospices prevail:

> *"But I think maybe an introduction system for new families [to an existing family] you know and once you're introduced if a parent chooses to do their own thing then that's fine, that's fair enough."* (Family using CHAS)

> *"..ideally somebody from [CHAS] would maybe come down when your child is diagnosed and sit somewhere outside the room and have a chat and say well we can help and this is how we can help instead of….that might of made a difference, well it would have made a difference, that would have been really good….I wouldn't think for a moment that that could be feasible, because*

> *although there, there are hundreds of volunteers so maybe it would be….we can help and you can come up and we'll know all about how you'll be feeling and we can talk you through it and there's always somebody to talk to, you know that kind of thing might have helped…"* (Family using CHAS)

4.2.4 Theme 4: Community care (outreach) provided by CHAS

The focus group discussions and interviews with health and social care professionals and members of the CHAS executive team highlighted community care as an important area for future research with an emphasis and recognition of the need to deliver care as close to home as possible.

Participants expressed that if CHAS is to further develop in the area of community care and extend its reach across remote and rural areas, it will be necessary to conduct a formal evaluation of what is wanted by families throughout Scotland. There is opportunity to expand on the success of local outreach respite teams recently piloted in Ayrshire and Arran and potential for local authorities, heath services and CHAS to jointly fund and further evaluate this service in the hope that it can be expanded throughout Scotland.

It was acknowledged during one of the interviews how unique and valuable CHAS' 'Home from Home' service is to families:

> *"The Home Care that I get from Rachel House, they come here to my home and they either take [Child] out or they can stay in my house if they want and I just go and, I can then forget about her for a while, you know, I know she's looked after. There were services offered to me in the past, like Lend A Hand through different charities and that as well, they, they didn't send anyone that was experienced, they didn't send anyone who was a nurse, so I had to stay at home with them, and watch, still watch [Child] even though there was someone there…, so it's something quite unique that they do when they come into your own home and look after your child."* (Family using CHAS)

Within this service, CHAS care staff visit families in their home, particularly during times of need where additional care would be welcomed such as when a parent is ill. 'Home from Home' was described by CHAS staff participating in the focus groups as being able to offer something special or different to the existing community care provided by statutory and other voluntary services. As this is a relatively new service within CHAS, there was agreement amongst the staff and volunteers that it should be an area to research and further develop.

4.2.5 Theme 5: Hospice and respite care needs of young people (age 16+)

Children with life-limiting conditions are living longer and continue to use the services of a children's hospice into their late teens and early twenties. The issue of actively preparing, planning and managing the transition to adult services was raised in the focus groups and interviews with families and professionals as being a key research priority. This raised questions around the appropriateness of children's services as a location in the midst of psychological, relational and emotional transitions occurring for young people using CHAS and their families.

Respondents discussed a needs-based approach to this issue, and the cultural shift between child and adult services:

> *"…that's one of the big issues as well, as adult hospice services are so different from children's hospice services and there's this huge big chasm in the middle where nobody is meeting the needs of this client group."* (CHAS staff)
>
> *"…transition I have to say is the really big one…so you know okay you're providing the service now, but actually what are the needs of young people, and how can that, how can those needs be best managed in a pro active way before young people in that you know no longer being eligible to attend CHAS, but actually having very little service provision elsewhere, so the transition would definitely be a big one."* (Professional)

Crucial in operationalising this research area is conducting a needs analysis from the perspectives of young people themselves, their families and the professionals involved in their care to identify support services that will be of benefit to them.

While participants acknowledged that it may not be suitable to care for young adults in a children's hospice they stressed the fact that few other services exist to meet the hospice and respite needs of this population. The importance of working in partnership with statutory and voluntary services in preparing for the transition to adult services was raised.

Identifying and meeting the support needs of young people with limited cognitive functioning emerged as specific concern from a family:

> *"One of the big issues for me is for children like [Child] who have got very complex needs and have got very complex health needs, their care and everything should be needs led and not age appropriate. To say that a child like [Child] should leave somewhere like [hospital] when they're 16 is a piece of nonsense because [Child] is never going to be 16. You know, mentally and physically is never going to be that age. So their care should be needs led and not age appropriate…"* (Family using CHAS)

Exploring the psychological support offered to young people with an awareness of their life-limiting condition to develop clear evidence of what is required and what works was raised in one of the professional interviews:

> *"I'm sure there is much more we have yet to learn about what works and what doesn't work in terms of offering good psychological support to children and young people facing these kind of issues …"* (Professional)

Recognising the lack of adequate alternatives to CHAS for the care and support of young people, discussion turned to training and development issues for CHAS staff and volunteers so they are better able to support this age group.

4.2.6 Theme 6: Spiritual and emotional care

Focus group participants discussed core elements of hospice care, being cognisant of the need for spiritual and psychological as well as physical care.

Staff focus groups identified the difficulties they face in assessing the spiritual care needs of children and families they support thus identifying an opportunity to research this area further. This was constructed as a whole-team approach to spirituality, rather than just the remit of chaplains:

> *"The thing that exercises my mind is how we spiritually assess people within CHAS and especially the children, how we assess them and how we meet their spiritual needs, given that obviously quite a lot of the children are unable to*

> *communicate, quite easily, so it would take a long time to assess them spiritually, what actually their needs are..."* (CHAS staff)

> *"But, it's quite interesting that, it's something that, you know we could maybe think about more how, how do we as a care team, you know assess, maybe not as in formally you know with a written thing, but just to get help us to find out their spiritual needs…"* (CHAS staff)

4.2.7 Theme 7: Bereavement and end-of-life care

Bereavement and end-of-life care and support emerged from staff focus group discussions and interviews with professionals. These respondents identified the opportunity to explore the wishes of families for end-of-life care as well as the decision-making process families go through related to preparing for their child's death, mirroring research in adult hospice care around preferences for where the death could take place:

> *"It would be nice to know where people want to be when their child's dying. Do they want to be in a hospice or a hospital or at home and are they getting the option? And if they're not getting the option, why not?"* (CHAS staff)

> *"….also looking at why do people use a hospice, in particular with regard to end-of-life care, and are they using it because that's where they really want to be, or because, there isn't a better service to look after them at home…"* (Professional)

A specific requirement within the area of bereavement care is to explore how hospice staff communicate with children and young people about death and dying within the context of impaired cognitive ability:

> *"There's no way we can talk to some of these children about end-of-life care or about you know just how they're feeling about it, you know what do, you know I'm sure they have some kind of idea of what's going on and what, how do they interpret that then, what are the feelings that are all around that for them and … and how do they express that, can they express those feelings, you know do we just leave them being scared?"* (CHAS staff)

> *"They're [young people] a very difficult nut to crack in that they're very withdrawn and not necessarily willing to tell you unless you're actually the one to bring it out.*

> *So we're not actually seeing these young people. But if we had a mechanism where we were actually able to get in touch with them and have some kind of plan in place that we could trial something and then if they said 'we don't actually need you' then that's fine."* (CHAS staff)

CHAS offer a bereavement suite, the Rainbow Room, to families and it is acknowledged as a unique and highly valued aspect of the service. However, there is little documented evidence on how families feel about the use of the Rainbow Room and in what ways it is of benefit to them. Staff and volunteers taking part in the focus groups felt that it would be useful to develop an evidence base of the use of the Rainbow Room as part of the bereavement support for families, for example how the use of the Rainbow Room may be of benefit to families after having a stillborn child:

> *"That's another group that we are not getting…baby units and sort of saying to parents who maybe only get a chance to be with their baby for a couple of hours but they're taken away but there is another service you know they can come here and be supported and be with their child for a week and you know but whereas at the moment they're just get to sit in a room and that's it, your baby's away…."* (CHAS staff)

4.2.8 Theme 8: Pain and symptom management

Pain and symptom management was raised by three of the medical consultants interviewed as being a research priority. There was some discussion on the challenges in assessing and managing symptoms experienced by children with life-limiting conditions, particularly those with communication and cognitive impairments. It was thought that practitioners often rely on anecdotal rather than research evidence, pointing to a clear need to develop an evidence base in symptom management of children with life-limiting conditions.

> *"Looking at particular symptoms. Because, a lot of what we do, we all do the same. But no one's actually researched it. Or written it up. If you see what I mean. So what we do, it's not evidence-based and we've almost got to the point where we can't be bothered to gather the evidence cos they're all doing it anyway."* (Professional)

Identifying the specific symptoms experienced by children with rare life-limiting conditions and the effectiveness of the current strategies used to manage their symptoms also emerged as a priority area to investigate. Parents would play a valuable role in assisting practitioners to identify these symptoms as they know their child better than anyone else and are actively involved in the day-to-day management of the child's symptoms:

> *"The other major project that I would like to see happen would be simply asking the families of children with unusual conditions, what in their experience are the main symptoms experienced by their child. Because I feel at the moment, as a clinician now, I'm handicapped when it comes to managing, for example a child with say…Tay Sachs… and I suspect that there are other symptoms like that we don't know about in rare conditions. But if we actually looked at a wide enough group of parents who had to look after a child with it, we would actually pick that up. So, I suppose what I'm thinking of, is a sort of, handbook of symptoms in rare conditions."* (Professional)

Further research into the management of pain in children with life-limiting conditions is required. One of the professionals interviewed highlighted the importance of investigating this area:

> *"…many of the children with long term conditions have pain issues…and I don't know whether CHAS is well placed to look at techniques and services and provision for pain relief?"* (Professional)

The uncertainty regarding CHAS' position in scoping pain was addressed by another respondent who felt that they, and other children's hospices, are ideally placed to undertake research in pain and symptom management:

> *"Because no other institution, it seems to me, has the distillation of a group of children who have symptoms and who have life-limiting conditions….the children's hospices have unique access to that, and I think that is potentially something very important."* (Professional)

4.2.9 Theme 9: Education of children and siblings

Community nurse, social work and general practitioner respondents articulated that the continued education of children and young people with life-limiting conditions and that of their siblings must be sustained in as normal a manner as possible. There is opportunity to research whether this is what actually happens in practice and identify whether sufficient efforts are currently made to ensure, as much as possible, the social and school inclusion of children with life-limiting conditions and their siblings. The need to continue life as normal was felt important for children returning to school after the death of their sibling. Moreover, there is opportunity to explore the relationship between the hospice and schools:

> *"One thing that's important for me is the siblings and the way the siblings are affected and I think also their education, because I am aware that sometimes it can cause issues, the schools don't like them being away so often and especially if they're nearing exam time. But again they get so much out of the hospice you know the schools are maybe not aware of what they get there and I don't think the schools are very good at giving them education programmes away with them that they can work on up there. So I feel there's a lot of work that could be done there."* (Professional)
>
> *"…the educational aspects have to be looked at depending on the specific type of illness. Yeah, just trying to I suppose keep life as normal as possible for the children overall."* (Professional)

4.2.10 Theme 10: Supporting the wider family

The care CHAS provides is family-centred and extends beyond the child to include siblings, parents and significant members of the wider family. The issue of family support was identified as a priority area for further research by two of the five families and six of the 18 professionals. In addition, issues related to CHAS supporting families were raised in all of the focus groups with CHAS staff and volunteers.

Exploring the impact of coming to the hospice on siblings and how they re-integrate into life outside of the hospice after their brother or sister passes away was raised as a priority area for research. Conducting a needs assessment to identify the specific support requirements of siblings at all stages of the child's illness including bereavement support was raised as an area worthy of investigation by professionals in health and social care.

Care of siblings emerged as an important issue for professionals and CHAS staff and volunteers; the potential for improved services to support siblings was emphasised:

> *"One thing that's important for me is the siblings and the way the siblings are affected."* (Professional)

> *"I know they're probably doing work into siblings but from where I'm sitting siblings don't always get listened to and that's probably maybe to our own limitations. The needs of the siblings, no matter what age they are."* (Professional)

> *"I think from our point of view, where do siblings fit, I would be really concerned about, because obviously they have, the family will have the care out with Robin House but again it's not the care of the siblings, it's the care of the sick child at that particular time and it's just, you know can we do more for the family group, more for the brothers and sisters?"* (CHAS staff)

During one of the focus group discussions, it was acknowledged that CHAS staff often identify specific support needs for siblings. They identified behavioural problems as one manifestation of siblings expressing their need for support. There was concern with regard to how the support need is then communicated with other agencies involved in the care of the family. Future research could focus on exploring the process for CHAS to make referrals to community services when they identify a support need of siblings:

> *"…generally they're just treated as part of the family, we're getting to know them as well as we get to know the sick child really, and its only through time that we will realize that there are problems within the families with maybe a child's behaviour, behaviour at school, how he's reacting to having a sick brother or sister, that's all time, but what do we do when we get those answers, who do we work with to help the child, not just while they're here but you know, at home, you know, programmes and things that may help if it's a bed wetting problem because they're not getting the attention from mum and dad because of mum's care for the sick child. What do we put on for support on that, follow it through into the community or we might find that some families do have help."* (CHAS staff)

There was discussion amongst staff and volunteers regarding how gender mediates the experience of using and working at CHAS. Respondents spoke of the specific support needs of male family members, and it was acknowledged that previously it has been difficult to attract more men to work at Rachel or Robin House particularly on the care and support team. It was felt that having men present on the staff team encourages fathers to engage with CHAS more, so increasing the gender diversity of the team will be important in supporting the families holistically:

> *"…because I have a group of bereaved parents and, traditionally, it's really hard to engage the men in that, I have no difficulty in getting the mothers to come but I have got a group of men who have asked specifically for the opportunity to meet as a group of men and I am not a man [laughs]…"* (CHAS staff)

The wider issue of how CHAS supports male family members including fathers and grandfathers was raised as an area for future research by CHAS staff and volunteers and by two of the families. Research would identify their specific support needs, including bereavement care, and gaps in service provision:

> *"even without looking at the male members of the care team, sometimes the fathers feel at a loose end…"* (CHAS staff)

> *"…what they can do about that I don't know… it must be very, very difficult to get male members of staff but that's one of the reasons that [Father] doesn't go up a lot he says because it's very female orientated and then he says 'and all you women sit and chatter about is your kids'. You just sit and talk about them all the time. I think well, what else is there to do, because your life is just so consumed by this wee person, especially if it's another parent in the same situation then that's what you're going to talk about. But [Father] says that it's too female orientated."* (Family using CHAS)

> *"I think a lot of men find it very uncomfortable to talk about their child who's very sick…because I think, and I don't think that I'm saying anything that's not been said in the past about, I think that mums do cope much, much better because they need to because they're doing the care and they're doing everything all the time. I think that dads find it much more difficult to cope with the long term illness of your child, the fact that probably somebody you know that are going to die which is a really, really difficult thing to cope with, I think maybe more so for men.*

> *So maybe that is something that they [CHAS] could think about…..”* (Family using CHAS)

Research reflecting the support needs of other key family members and carers was also raised as important for CHAS to consider:

> *“….impact on the wider family…I am always struck by the impact on grandparents who not only are mourning the loss of a grandchild, but they are also then trying to support their own child….”* (Professional)

4.2.11 Theme 11: Diversity

Diversity emerged as a key issue for further research by staff and volunteers participating in the focus groups which was strongly articulated as a core area for development. In addition to gender diversity in the staff team and diagnostic diversity, as discussed above, the need to explore ethnicity and culture was also raised. Research priorities could identify how CHAS could encourage and promote diversity amongst the staff and volunteers within the organisation. Moreover, exploring how families from a range of minoritised ethnic groups and cultural backgrounds perceive CHAS and how these features mediate bereavement care needs emerged as a priority research question:

> *“I think that cultural diversity’s very important”* (CHAS staff)

> *“And I think that comes back to the other thing about access for different cultures…”* (CHAS staff)

Staff raised concerns about their own levels of knowledge regarding different faith and cultural groups’ rituals around death and burial, identifying a priority to research and develop services to meet the needs of all potential service users:

> *“the Rainbow Room….it’s just the kind of cultural thing and they, within 24 hours you know that they kind of bury or cremate and, and the whole nature of how does that affect a bereavement process in comparison to a family who has had that time to actually be with a child to gradually let go, to read their child a story, that kind of thing after the child has died and, and time that people have and it just seems, and like I say it’s a very limited experience but it just seems from*

> *what I've seen that you know it makes a big difference as to how that bereavement process is …"* (CHAS staff)

4.2.12 Theme 12: CHAS staff and volunteers

There were a few areas of specific concern to staff and volunteers within CHAS that were raised during one of the focus groups. Participants recognised the emotional challenges and demands of caring for children with life-limiting conditions and their families and the potential long-term effects this could have on their personal health and well-being. It was thought that particularly busy periods within the service or times when staff are responsible for caring for very sick or very aggressive children often coincide with periods of high levels of staff sickness. Participants acknowledged that the stress encountered when trying to provide quality care and meeting high expectations of families during stressful periods could have negative effects on the health and well-being of staff, particularly in the long-term:

> *"They [periods of high stress] come in bursts. But I feel personally that the bursts are becoming more and more regular and also the only way in my head that I can sort of put it over to somebody who doesn't work with it is if somebody says to you here's £150 get us a really nice buffet that's got to impress everybody and a week later they give you £50 saying I want exactly the same, it doesn't work."* (CHAS staff)

Therefore, a valuable area for research would investigate the impact of stress on staff and volunteers as well as evaluating the effectiveness of the support mechanisms and coping strategies (both individual and as an organisation) currently in place.

There was considerable debate over the current ethos of CHAS. Focus group participants discussed how, when CHAS was a new service, staff inductions were very much centred on the ethos of the organisation and the family-centred approach to hospice care. Recent staff inductions have focused more on how the organisation operates and on policy and procedures with far less emphasis on the ethos of CHAS:

> *"…When I first started and I started when Rachel House opened its doors, before any families were in and the ethos.. the team were very much aware of the ethos of CHAS and it was drummed into us about the family-centred and the whole importance of making it you know supportive care, a family-centred environment and taking your time and things and I'd like research to be done to find out what*

> *people think the ethos of you know, we've lost the ethos, the importance of you know, it seems to have dispersed into the, I don't think that we hold it as strongly."* (CHAS staff)
>
> *"…yes more of the tick box, this is what we expect of you from the care plans and things like that but when it comes to the actual ethos, spiritual side of things, I think that's where it's changed…"* (CHAS staff)
>
> *"I think we felt that through our induction, when we all started, before it opened, we had 5 weeks of intense, and part of that was to get to know every area of CHAS.….Well I think the difference is what it means is we felt part of a huge team, we felt so involved in it, whereas new, new people coming in are part of this team, but you know … and I think that's something that maybe needs to be looked at, I think we really do need to give them a wee bit longer…"* (CHAS staff)

A related research topic would be to evaluate whether current induction programmes meet staff needs and how staff inductions impact on staff and volunteer sense of belonging within CHAS as a growing organisation.

4.2.13 Theme 13: Service Development

Eleven research questions were categorised under the theme of *service development*. The majority of these research questions were put forward by the professional stakeholders and are specifically aimed at increasing the evidence base to further develop the hospice services CHAS provides. They covered ideas which would be of benefit to hospice providers nationally, in developing systems, structures and an evidence base for service delivery.

Longitudinal research was considered important, developing an evidence base for the provision of hospice services for families who access them compared to those who do not, over the long term.

The development of collaborative relationships with other service providers, particularly paediatric wards and community services to identify ways to promote and encourage a greater emphasis on the active planning of end-of-life care and palliative care emerged as research priority. Closely related to that, determining the level of medical service provision required in a children's hospice emerged as a research priority in Scotland and nationally. Exploring ways to provide additional medical cover in the hospice setting, working in partnership with the physicians who are responsible for the medical care of children using CHAS, may facilitate medically fragile or unstable children to continue to be cared for in the hospice instead of being transferred to hospital:

> *"…being able to provide services for children, in the hospice situation in a … at the moment the hospice situation in Scotland, and I'm not sure about in England, 'cause I know that in England they quite often have resident medical staff, of one sort or another, but both of the hospices in Scotland are, are basically served by Primary Care or by NHS 24, and that's not conducive to keeping unstable children there. And therefore I think what might facilitate and might be part of a, a research base would be how, how to actually provide adequate care in a hospice situation for children with adequate medical cover and I do think that's an issue within the hospice situation in Scotland."* (Professional)

One of the research questions focused on expanding the service to new groups of children and families. Health professionals and CHAS staff felt it was important to identify the support needs of families of neonates with palliative care needs and to explore the possibility of CHAS proving this support in future:

> *"We don't really know again what the role for hospices would be in terms of neo-natal units…and it would be interesting to try and talk with neo-natalogists more, identify the numbers; is there a role for CHAS in this? Is there not a role for CHAS?"* (Professional)

4.2.14 Theme 14: Strategic Planning

Research priorities related to *strategic planning* were identified exclusively during interviews with professional stakeholders. *Strategic planning* refers to a focus on broad palliative care issues at a national level, such as models of hospice care, integration of CHAS within the wider children's palliative care network, role of CHAS within the provision of palliative care services for children with cancer, and the establishment of a collaborative system for conducting research in the field. All require the development of collaborative partnerships locally and nationally to facilitate the development of best practice in children's hospice care:

> *"…research aimed at the integration of a children's hospice within the wider children's palliative care network or arena locally, and how you develop that, that integration and make that happen…and what are the sort of barriers to developing an integrated service…"* (Professional)

> *"…I think that, any such research in that area would be, need to be done with the NHS in some way, I think it would not just be about the services CHAS offers. Or whether CHAS could be willing to fund and participate in some analysis of palliative care and options for children in Scotland. It's certainly an area that I think needs continuing work specifically in the field of cancer."* (Professional)

> *"Review different models of children's hospice care and ways of working and why, what are the, what are the benefits both in terms of quality and cost?"* (Professional)

A number of ideas offered such as defining strategies to ensure quality of access to children's hospice services suggested a research priority around developing a Gold Standards Framework (GSF) for children's palliative care services. The GSF sets out guidelines to facilitate high standards of care for people requiring supportive/palliative care. It is based on an evidence-based approach to palliative care provided to adults in community setting. Developing a child GSF could involve exploring the lessons learned from the recent national implementation of the adult framework :

> *"Trying to find a gold standard for services to children across Scotland…with a gold standard framework or a SIGN guideline or something that some people have to take credence over…."* (Professional)

5 KEY FINDINGS OF ROUND 2

5.1 Participant Response Rate and Demographics

Of the 621 participants invited to participate in Round 2, 274 returned a completed questionnaire, yielding a response rate of 44%. An additional two questionnaires were received following the requested reply date and were not included in the data analysis due to time constraints of the project. There was representation across all of the participant groups with completed questionnaires as illustrated in Table 7 below. In addition, four respondents returned a completed questionnaire but did not indicate to which participant category they belonged. Questionnaire data from these four respondents was included in the overall analysis of the total sample but not in the inter-group analysis. The highest response rate was from CHAS volunteers with 62% returning completed questionnaires. The lowest response rate was from the families with 31% returning completing questionnaires.

Table 7. Number of Round 2 questionnaires distributed and returned by participant category

Participant Categories	Number of Round 2 questionnaires distributed (N & % of total sample)	Round 2 response rate (Number & % of respondents for each category)
Families	293 (47%)	92 (31%)
CHAS staff	166 (27%)	92 (55%)
CHAS volunteers	50 (8%)	31 (62%)
Professionals	112 (18%)	55 (49%)
No details given *	N/A	4
TOTAL:	**621 (100%)**	**274 (44%)**

* Respondents did not complete section C of the questionnaire so we do not know which participant category they belong to

Participants provided details of their relationship with CHAS in the third section of the questionnaires. Tables 8 to 11 provide the breakdown of demographic data provided for each of the four participant groups (families, CHAS staff, CHAS volunteers, and professionals).

Table 8. Round 2 Participant Demographics: Families (n=92)

Families use of the CHAS service Families were asked: *‘Which of the following best describes your family’s use of CHAS? Please tick all boxes that apply.’*	**N ***
We attend Rachel House	43
We attend Robin House	22
We use the RHaH Service	8
We use CHAS family bereavement support	29
We no longer need services of CHAS	6
We currently use other services	8
Missing data	1
How long families have been using CHAS Families were asked: *‘How long has your family been using or had previously used the services of CHAS.’*	**N (%)**
Less than 1 year	17 (19%)
1-2 years	15 (16%)
3-5 years	24 (26%)
6-8 years	14 (15%)
9 years or more	18 (20%)
Missing data	4 (4%)

* May include more than one response if a number of services were being used by families.

Table 9. Round 2 Participant Demographics: CHAS staff (n=92)

CHAS Staff *Staff were asked to 'indicate their current role' from a list of roles and teams that are available in CHAS.*	**N (%)**
Care Team (including AHPs)	41 (45%)
Activities Team	4 (4%)
Social Work	2 (2%)
Chaplains and Bereavement Support	3 (3%)
GPs	4 (4%)
Maintenance, Housekeeping, Catering	8 (9%)
Administration	22 (24%)
Board and Sub-committees	7 (8%)
Missing data	1 (1%)
CHAS Staff *Staff were asked 'what length of time have you been in the position/role indicated?'*	**N (%)**
2 years or less	42 (46%)
3-5 years	21 (23%)
6-8 years	12 (13%)
9 years or more	13 (14%)
Missing data	4 (4%)

Table 10. Round 2 Participant Demographics: CHAS volunteers (n=31)

CHAS Volunteers Volunteers were asked to *'indicate the area(s) you volunteer in.'*	**N (%)**
Rachel House	7 (23%)
Robin House	4 (13%)
RHAH	2 (7%)
Fundraising and Retail	16 (52%)
Other	2 (7%)
CHAS Volunteers *Volunteers were asked 'what length of time have you been in the position/role indicated?'*	**N (%)**
2 years or less	8 (26%)
3-5 years	10 (32%)
6-8 years	6 (19%)
9 years or more	6 (19%)
Missing data	1 (3%)

Table 11. Round 2 Participant Demographics: Professionals (n=55)

Professionals Professionals in health, social care, education and the voluntary sector were asked to *'indicate your role.'*	**N (%)**
Policy developer/advisor	2 (4%)
Consultants	10 (18%)
Nurses	21 (38%)
GPs	5 (9%)
AHPs	5 (9%)
Social Work	3 (5%)
Education	3 (5%)
Voluntary Sector Representatives	2 (4%)
Child Health Commissioners	4 (7%)
Professionals Professionals were also asked to *'indicate your employer or Health Board.'*	**N (%)**
Ayrshire and Arran	1 (2%)
Dumfries and Galloway	6 (11%)
Fife	5 (9%)
Forth Valley	6 (11%)
Grampian	2 (4%)
NHS Greater Glasgow and Clyde	13 (24%)
Highland	3 (5%)
Lanarkshire	3 (5%)
Lothian	7 (13%)
Orkney	1 (2%)
Tayside	1 (2%)
Western Isles	1 (2%)
Other (ie. in a national or policy role)	3 (5%)
Missing data	3 (5%)
Professionals *Professionals were asked 'what length of time have you been in the position/role indicated?'*	**N (%)**
2 years or less	4 (7%)
3-5 years	9 (16%)
5-8 years	10 (18%)
9 years or more	25 (45%)
Missing data	7 (13%)

5.2 Round 2 - Questionnaire Analysis

Analysis of the Round 2 questionnaire data revealed a high level of consensus or agreement on the rating of the research priorities amongst participants. With the exception of one of the 56 research questions included in the questionnaire, the mean or average scores for rating of the questions were 3 ‘important’ and 4 ‘very important’.

This section of the report will present the top 15 research questions as rated by the total sample of participants during completion of the Round 2 questionnaire. The top 15 research questions are those that received the highest mean rating of 4 ‘very important’. The five most important research questions and the five least important research questions for both the total sample and each participant category are also presented. Please note that for simplicity the CHAS category has been collapsed to include staff and volunteers and will be referred to as CHAS staff in this section.

Table 12 shows the top 15 rated research priorities for the 274 participants who completed a Round 2 questionnaire. There was a high level of consensus in terms of the importance of these research questions with all 15 research questions having received a mean rating of 4, ‘very important’. The top research priority was related to investigating current pain and symptom management strategies and assessing their effectiveness (Q8.30) and was very closely followed by a needs assessment of young people with life-limiting conditions (Q5.15) as there were negligible differences in their mean ratings.

Further detailed statistical analysis of the research questions by total sample and participant categories is included in Appendix G.

Table 12. The top 15 research questions for the total sample of participants (n=274) in Round 2. (Means and standard deviations (SD) are presented.)

Research Theme	Research Questions	Mean (SD)
Pain and symptom management	identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are (Q8.30)	4.35 (0.97)
Hospice and respite care needs of young people (aged 16+)	Find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals (Q5.15)	4.34 (0.95)
Hospice and respite care needs of young people (aged 16+)	review the psychological support CHAS provides to young people (16+) who know they have a life-limiting condition and make recommendations for staff training and development (Q5.18)	4.25 (0.96)
Bereavement and end-of-life care and support	explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues (Q7.27)	4.24 (0.99)
Bereavement and end-of-life care and support	find out what families want from the CHAS service with regard to end-of-life and bereavement care (Q7.21)	4.23 (1.03)
Pain and symptom management	identify the symptoms experienced by children with very rare life-limiting conditions to develop management and control strategies (Q8.29)	4.22 (1.03)
Hospice and respite care needs of young people (aged 16+)	find out the specific care needs of young people (16+) with limited cognitive abilities (learning, understanding, communicating)? e.g. how will their care needs change during the transition to adult services (Q5.16)	4.17 (1.04)
Awareness of children's hospice care	identify ways to promote awareness of CHAS and the wide range of services it offers to children and families (Q1.3)	4.13 (0.95)
Service development	explore ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital (Q13.45)	4.10 (1.02)
Hospice and respite care needs of young people (aged 16+)	explore ways CHAS could work together with other services (health, social care, voluntary etc.) to meet young people's needs for the transition to adult services (Q5.17)	4.08 (1.02)
Community care (outreach) provided by CHAS	work together with local services to review and develop outreach respite teams across Scotland which would allow more families to access CHAS services within their own homes and/or communities (Q4.14)	4.06 (0.92)
Improving access to children's hospice care	find out the number of children in Scotland with palliative care needs and the number of children who meet CHAS' current referral criteria (Q2.4)	4.06 (1.00)
Supporting the wider family	find out what the needs of siblings (brothers and sisters) are throughout each stage of a child's illness including bereavement support (Q10.32)	4.05 (0.91)
Community care (outreach) provided by CHAS	find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by CHAS (such as the home from home service) (Q4.12)	4.03 (0.89)
Improving access to children's hospice care	find out the reasons why professionals refer or do not refer children and families to CHAS (Q2.5)	4.01 (0.88)

To illustrate how the individual groups of participant (families, CHAS staff and professionals) rated the research questions in Round 2 and to reflect any differences in perspective between these groups, Table 13 details the top five rated research questions, in order of importance, and Table 14 details the bottom five rated research questions by participant category. It is important to reiterate that whilst the term 'bottom' is used to indicate those research questions that received the lowest rating by participants, this does not in any way imply that they are not of importance. All items in the bottom five received ratings of 2 'least important' or 3 'important' and there was only slight variation between the participant groups in the research questions which received the lowest rating.

Questions related to pain and symptom management were rated as two of the top five research priorities for families and the top priority area for research by CHAS staff. Interestingly, pain and symptom management did not appear in the top five research questions within the professional category especially given the fact that this research issue emerged from professional participants in the Round 1 interviews. The research questions related to exploring the needs of young people with life-limiting conditions was the only question to appear in the top five for all three categories of participants. Additionally, CHAS staff and professionals rated reviewing the psychological support provided to young people and making recommendations for staff training and development as a priority. Bereavement and end-of-life issues did appear in the top 5 list for all participant groups but with minor variation as families and CHAS staff prioritised looking at the needs of CHAS staff regarding bereavement and how to communicate with children and families on these issues whereas the professionals prioritised finding out what families want from the service with regard to end-of-life and bereavement care.

The bottom five research questions, as shown in Table 14, were similar across the three participant groups and a number of the questions could be addressed as service development issues such as Q3.10 (pilot a 'buddy system' where a new family is paired with an existing family), Q3.11 (explore the role of volunteers in increasing awareness amongst families who are potential users of CHAS) and Q13.51 (evaluate how families value the hydrotherapy service and the benefits received by the child/young person). There was minor variation across the participant categories in their perception of the least important research questions.

Table 13. TOP 5 research questions for each of the three participant categories.

	Families (N=92)	Mean (SD)	CHAS (N=123)	Mean (SD)	Professionals (N=55)	Mean (SD)
1	identify services, techniques and provisions available to relieve pain and other symptoms in children with LLCs and assess how effective they are (Q8.30)	4.49 (0.70)	identify services, techniques and provisions available to relieve pain and other symptoms in children with LLCs and assess how effective they are (Q8.30)	4.35 (1.05)	find out the needs of young people with LLCs from the viewpoint of young people themselves, their parents and professionals (Q5.15)	4.44 (0.81)
2	explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues (Q7.27)	4.39 (0.89)	find out the needs of young people with LLCs from the viewpoint of young people themselves, their parents and professionals (Q5.15)	4.31 (1.03)	find out what families want from the CHAS service with regard to end-of-life and bereavement care (Q7.21)	4.31 (0.94)
3	find out the needs of young people with LLCs from the viewpoint of young people themselves, their parents and professionals (Q5.15)	4.38 (0.82)	identify ways to promote awareness of CHAS and the wide range of services it offers to children and families (Q1.3)	4.29 (0.91)	work together with local services to review and develop outreach respite teams across Scotland which would allow more families to access CHAS services within their own homes and/or communities (Q4.14)	4.29 (1.03)
4	identify the symptoms experienced by children with very rare LLCs to develop management and control strategies (Q8.29)	4.37 (0.77)	review psychological support CHAS provides to young people who know they have a LLC and make recommendations for staff training and development (Q5.18)	4.24 (0.98)	find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by CHAS (such as the home from home service) (Q4.12)	4.24 (0.79)
5	explore ways to provide additional medical cover so children whose condition is fragile/medically unstable can be cared for in hospice instead hospital (Q13.45)	4.36 (0.79)	explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues (Q7.27)	4.21 (0.96)	review the psychological support CHAS provides to young people who know they have a LLC and make recommendations for staff training and development (Q5.18)	4.24 (0.96)

Table 14. BOTTOM 5 research questions for each of the three participant categories.

	Families (N=92)	Mean (SD)	CHAS (N=123)	Mean (SD)	Professionals (N=55)	Mean (SD)
1	CHAS to establish a collaborative system for conducting research in the field of children's palliative care involving statutory and voluntary services, and academic institutions (Q14.56)	3.27 (1.12)	evaluate how families value the hydrotherapy service and the benefits received by the child/young person (Q13.51)	3.14 (1.12)	develop and test standards of care specific to children and families that chaplains can use as none currently exist (Q6.20)	3.15 (1.16)
2	identify ways for CHAS to encourage/promote diversity amongst staff and volunteers (e.g. ethnicity, gender) including recruitment to the organisation (Q11.37)	3.27 (1.08)	conduct an action research project aimed at the integration of CHAS within the wider children’s palliative care network exploring barriers to integration and how the regional area is proactive in terms of its children’s palliative care provision (Q14.53)	3.11 (1.17)	test the possibility of offering services of the Rainbow Room to families after having a stillborn child (Q7.26)	3.09 (1.25)
3	find out whether the educational needs of children and siblings using the CHAS service are being met, and if not how this can be improved (Q9.31)	3.23 (1.14)	test the possibility of offering services of the Rainbow Room to families after having a stillborn child (Q7.26)	3.06 (1.28)	pilot a ‘buddy system’ where a new family is paired with an existing family (Q3.10)	2.96 (0.93)
4	explore the role of volunteers in increasing awareness amongst families who are potential users of CHAS (Q3.11)	3.18 (0.93)	explore the role of volunteers in increasing awareness amongst families who are potential users of CHAS (Q3.11)	2.98 (0.99)	evaluate how families value the hydrotherapy service and the benefits received by the child/young person (Q13.51)	2.89 (1.02)
5	pilot a ‘buddy system’ where a new family is paired with an existing family (Q3.10)	2.78 (1.14)	Pilot a ‘buddy system’ where a new family is paired with an existing family (Q3.10)	2.67 (1.05)	explore the role of volunteers in increasing awareness amongst families who are potential users of CHAS (Q3.11)	2.89 (0.95)

5.2.1 Round 2 Participant Comments

Participants were invited to provide comments or explanations on their ranking of the top five themes or on any other section of the questionnaire. Thirty-one participants provided comments with 21 (68%) being comments of a general nature. For example, participants often included acknowledgement that each and every theme is of great importance thus making it difficult for them to prioritise. Many felt that all of the research questions included in the questionnaire were worthy of future investigation. Families often used this section as an opportunity to commend CHAS on the invaluable care and support they receive from them. One family suggested that an additional area for CHAS to consider as a research priority is the difficulty or challenges in meeting the care and support needs of children and families in situations where there has been a parental divorce or separation.

A few staff and volunteers included comments on their questionnaires that some of the research questions were, in their opinion, currently being addressed elsewhere or already sufficiently addressed by CHAS. The process undertaken in this project involved including all of the research questions or ideas raised by participants during the Round 1 interviews and focus groups as items in the questionnaire. Participants completing questionnaires in the subsequent rounds may hold a different opinion or have a greater awareness of the current areas being addressed by the organisation. However, it was not for the researchers to make this judgement but rather to ensure that all views and perspectives of participants were included in the questionnaire and put forward to be rated by others.

Participants provided explanations or rationale on their ranking of the research themes. Three families explained how the themes they ranked as being their top five preferences often related to their personal circumstances at the time.

5.3 Ranking Of Themes

Participants were asked to consider the 14 research themes and rank order those which they felt were the five most important themes (Table 15).

Table 15. The top five research themes as ranked by the total sample (n=265)*

Ranking	Research Theme	Number of Responses (%)
1	Pain and symptom management	60 (23%)
2	Improving access to children's hospice care	50 (19%)
3	Bereavement and end-of-life care and support provided by CHAS	43 (16%)
4	Community care (outreach) provided by CHAS	35 (13%)
5	Hospice and respite care needs of young people (aged 16+)	25 (10%)

* Nine participants did not complete the ranking section of the questionnaire.

'Pain and symptom management' was ranked as the first preference by 23% of participants. 'Improving access to children's hospice care' was ranked as the second preference by 19% of participants. 'Bereavement and end-of-life care and support provided by CHAS' was ranked as third preference by 16% of the participants. The theme ranked fourth preference was 'community care (outreach) provided by CHAS' by 13% of participants and the theme ranked fifth preference was 'hospice and respite needs of young people (aged 16+)' by 10% of participants.

The priority ranking of the themes is closely related to the priority rating of the research questions. It is interesting to note that 12 of the 15 (80%) research questions put forward for inclusion in the Round 3 questionnaire originated from within the top five ranked themes.

5.4 Analysis Strategy for Development of Round 3 Questionnaire

After all the initial descriptive statistics had been run for each theme the data was reviewed to identify which research questions would be included in the Round 3 questionnaire. The analysis strategy included the following steps:

1) *Review the range of means for the total sample across the 56 research questions*

Rating scale	Number of mean ratings
(1) Not at all important	0
(2) Least important	1
(3) Important	40
(4) Very important	15
(5) Extremely important	0

The above table demonstrates that the most frequent mean rating across the 56 research questions in the Round 2 questionnaire was (3) 'important'. It was interesting to note that there were no research questions rated as 'not at all important' or 'extremely important' by the total sample, although there were some individual participant ratings at these levels.

2) *Review the ranking of the themes for the total sample across the 14 themes*

The top ranked theme was Theme 8 *pain and symptom management*. The research questions within this theme were rated at the level of 'very important' (4) or 'extremely important' (5).

3) *Agree a cut-off point for research questions to be entered into the Round 3 questionnaire*

As the table above demonstrates the majority of the ratings were at the level of 'important' (3) so it was agreed that a cut-off group mean of 'very important' (4) would be used to identify those research questions to be included in the Round 3 questionnaire. This resulted in 15 research questions being put forward to gain further consensus from the participants.

4) *Confirm the total sample mean ratings were representative of the participant categories*

To ensure that the total sample ratings were reflected in the different participant categories of families, CHAS staff, CHAS volunteers and professionals the means for each research question were reviewed by participant category. All participant categories had a typical mean rating of 4 for each of the 15 research questions; in the few cases where it was lower the mean rating for the participant category was not less than 3.75 which was an acceptable variation. This analysis confirmed that highest rated 15 research questions were representative of the total sample and all participant categories.

5) *Consensus of agreement on items for Round 3 questionnaire*

To review the consensus level the team reviewed the frequencies for each research questions to look at the percentage of the total sample who had rated the research questions at a 4+ mean level. There are no agreed upon levels for consensus so the team defined positive consensus as 70% or more participants rating at 4 or above. All 15 items had a consensus level of 74-86% across the sample.

6 KEY FINDINGS OF ROUND 3

This section of the report will present the participant response rate and demographics for Round 3, and analysis of any change in the ratings of the research questions between Round 2 and Round 3, the reasons given by participants for any change, the level of consensus between the participant categories and identifying the top five research priorities for CHAS.

6.1 Participant Response Rate and Demographics

An increase in response rates was observed between rounds with 204 of the 247 participants returning a completed questionnaire in Round 3, yielding a response rate of 83%. Once again there was representation across all of the participant groups as demonstrated in Table 16 below.

Table 16. Response rate of Round 3 questionnaires

Participant Categories	Round 3 distributed (Number & % of the total sample)	Round 3 response rate (N & % of those distributed for each category)
Families	87 (35%)	72 (83%)
CHAS staff	79 (32%)	66 (84%)
CHAS volunteers	28 (11%)	27 (96%)
Professionals	53 (22%)	39 (74%)
No details given*	N/A	N/A
TOTAL:	**247 (100%)**	**204**

Questionnaire Analysis – Round 3

The results following analysis of the Round 3 questionnaire were very similar to the results from Round 2 with a high level of consensus amongst participants as to which research questions should receive the greatest priority. In Round 3, the mean ratings for the 15 research questions remained at 4, ‘very important’. Participants once again rated pain and symptom management strategies and the needs assessment of young people with life-limiting conditions as the priority research questions. Slight changes in the mean rating after Round 3 meant that there was an exchange with the research question to ’find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals’ moving to the top position and the research question to ‘identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are' closely followed in second position. Table 17 details the top 15 research questions from both questionnaire rounds.

Table 17. The mean ratings and standard deviation (SD) of the top 15 research questions for the total sample in Round 2 (n=274) and Round 3 (n=204), ordered by Round 3 means.

Research Theme	Research Questions	Round 2 Mean (SD)	Round 3 Mean (SD)
Hospice and respite care needs of young people (aged 16+)	Find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals	4.34 (0.95)	4.49 (0.76)
Pain and symptom management	Identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are	4.35 (0.97)	4.45 (0.83)
Bereavement and end-of-life care and support provided by CHAS	Explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues	4.24 (0.99)	4.41 (0.75)
Hospice and respite care needs of young people (aged 16+)	Review the psychological support CHAS provides to young people (16+) who know they have a life-limiting condition and make recommendations for staff training and development	4.25 (0.96)	4.31 (0.78)
Pain and symptom management	Identify the symptoms experienced by children with very rare life-limiting conditions to develop management and control strategies	4.22 (1.03)	4.30 (0.92)
Service development	Explore ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital	4.10 (1.02)	4.28 (0.94)
Hospice and respite care needs of young people (aged 16+)	Find out the specific care needs of young people (16+) with limited cognitive abilities (learning, understanding, communicating)? e.g. how will their care needs change during the transition to adult services	4.17 (1.04)	4.26 (0.88)
Community care (outreach) provided by CHAS	Work together with local services to review and develop outreach respite teams across Scotland which would allow more families to access CHAS services within their own homes and/or communities	4.06 (0.92)	4.23 (0.85)

Bereavement and end-of-life care and support provided by CHAS	Find out what families want from the CHAS service with regard to end-of-life and bereavement care	4.23 (1.03)	4.22 (0.86)
Community care (outreach) provided by CHAS0.83	Find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by CHAS (such as the home from home service)	4.03 (0.89)	4.22 (0.86)
Awareness of children's hospice care	Identify ways to promote awareness of CHAS and the wide range of services it offers to children and families	4.13 (0.95)	4.18 (0.86)
Supporting the wider family	Find out what the needs of siblings (brothers and sisters) are throughout each stage of a child's illness including bereavement support	4.05 (0.91)	4.16 (0.84)
Improving access to children's hospice care	Find out the number of children in Scotland with palliative care needs and the number of children who meet CHAS' current referral criteria	4.06 (1.00)	4.15 (0.91)
Hospice and respite care needs of young people (aged 16+)	Explore ways CHAS could work together with other services (health, social care, voluntary etc.) to meet young people's needs for the transition to adult services	4.08 (1.02)	4.11 (0.87)
Improving access to children's hospice care	Find out the reasons why professionals refer or do not refer children and families to CHAS	4.01 (0.88)	4.07 (0.88)

The top five research priorities for CHAS at the conclusion of the Delphi process are presented in Table 18. The research questions included in the top five are similar to the top five research questions following Round 2 with the exception that in Round 3, the research question to 'identify the symptoms experienced by children with very rare life-limiting conditions to develop management and control strategies' ranked one place higher at fifth, with the research questions to 'find out what families want from the CHAS service with regard to end-of-life and bereavement care' dropping to sixth.

Table 18. Top five research priorities for CHAS at the end Round 3 (n=204)

Research Theme	Research Questions	Mean (SD)
Hospice and respite care needs of young people (aged 16+)	Find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals	4.49 (0.76)
Pain and symptom management	Identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are	4.45 (0.83)
Bereavement and end-of-life care and support provided by CHAS	Explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues	4.41 (0.75)
Hospice and respite care needs of young people (aged 16+)	Review the psychological support CHAS provides to young people (16+) who know they have a life-limiting condition and make recommendations for staff training and development	4.31 (0.78)
Pain and symptom management	Identify the symptoms experienced by children with very rare life-limiting conditions to develop management and control strategies	4.30 (0.92)

6.1.1 Round 3 Participant Comments

Participants were invited to provide comments or explanations on any changes they made to a question's rating in the Round 3 questionnaire. Thirty-two participants provided comments. Similar to the comments made in Round 2, a number of participants stressed the difficulty in rating the questions as they were all considered to be priorities for future research. Four participants noted that their ratings remained unchanged to those made in the previous questionnaire. Four participants explained how their changes to the rating of questions were a result of their increased awareness and appreciation of the issue. As in the Round 2 comments, families explained how their ratings related to their personal circumstances at the time.

7 DISCUSSION

In this project the current salient issues perceived by families, hospice staff, volunteers and associated professionals as being the research priorities for CHAS were identified. It is important for readers of this report to remember that these research priorities were rated by participants for their importance as future research priorities for CHAS. This does not necessarily indicate that participants have concerns about these areas of the current service or are highlighting them as areas requiring immediate service improvement. The rationale for the research priorities in each theme has been presented in the interview section of the report which provides further understanding of why participants may have raised certain issues. The Delphi methodology also dictates that any topic raised in the interview round is submitted to the questionnaire rounds to enable the larger group of participants to have their opportunity to rate its importance. It is necessary to acknowledge the challenge participants faced in rating the research questions. As many of the participants commented throughout the process, all the research questions are of a high importance and should be considered by CHAS when developing their research programme. This need to consider carefully the next steps in taking forward the research priorities is also demonstrated by the high level of consensus which was reached amongst the different participant groups in prioritising the extensive list of research topics.

Following two rounds of Delphi questionnaires, a list of 15 research questions emerged as the most important future research priorities for CHAS. From this list, the top five research priorities were highlighted (Table 18, pg 67). These five research questions and the broader themes under which they were categorised will be discussed first followed by a summary of the remaining 10 priority research questions which were also clearly identified by the key stakeholders as areas CHAS should focus future research on.

7.1 Hospice and Respite Care Needs of Young People (Aged 16+)

The research question rated overall as the highest priority in this project was question 5.15 (find out the needs of young people (16+) with life-limiting conditions from the viewpoint of the young people themselves, their parents and professionals). Moreover, the four research questions categorised within this theme all appeared in the final table of fifteen questions and were rated as 1st, 4th, 7th, and 14th. Issues related to the care and support of young people emerged from the focus groups and interviews conducted in Round 1. In addition, question 5.15, as described above, was the only research question to appear in the top 5 list for all three participant groups, further demonstrating its importance. It is therefore imperative for a needs assessment that actively seeks the views of young people and involves them in the planning of hospice services be considered. With earlier diagnosis and improved clinical management, children with life-limiting conditions are living longer thus the numbers of young people with palliative care needs will continue to increase. These young people will be required to move from children's services, which will probably have cared for them since the beginning, to adult services. This will require forward planning to identify specific issues related to the transition to adult services and ensure the care needs of this population are adequately supported. Transition will form a particular challenge for children with cognitive and severe neurological impairments. Thornes (2001) recommends that those responsible for commissioning palliative care services should undertake a local needs assessment for their population of young people with life-limiting conditions and encourage involvement from the young people. CHAS are aware of the issues related to transitional care and are committed to developing a care model with active involvement from young people and their families (CHAS, 2007).

A review of the psychological support CHAS provides young people emerged as a research priority for all participants and was one of the top five research questions for CHAS staff and professional participants. There is recognition that the psychological needs may not be adequately addressed and moreover, that professional staff and clinicians require additional training to meet the very unique care and support needs of this group (Thornes, 2001). This issue was raised as a research priority with both CHAS staff and health and social care professionals, recognising the need for further staff training and development in this area so that they are better able to meet the unique support needs of young people with life-limiting conditions.

Planning for transition to adult services will not be unique to CHAS and is expected to be an issue that all children's hospices in the UK will need to confront in the near future. Other hospices will be developing their own ideas and approaches but it is an opportunity for CHAS to take the lead and undertake joint research activities. Moreover, within Scotland, statutory services and agencies will also be confronted with the issue of transition to adult services and all parties may benefit from working in partnership to plan, deliver and evaluate care services for young people.

7.2 Pain and Symptom Management

Pain and symptom management emerged as being a research area of central importance and was ranked as the top theme by participants in this project. The two research questions categorised within this theme, question 8.29 (identify the symptoms experienced by children with very rare life-limiting conditions to develop management and control strategies) and 8.30 (identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are) were rated by participants in the final Round 3 questionnaire as 5th and 2nd, respectively. Analysis of the qualitative interviews provided insight into where the research questions were generated. Pain and symptom management issues emerged from interviews with professionals, specifically from the paediatric consultants. However, when looking at the top five research questions within each of the three participant categories, pain and symptom management issues were rated highest by families and CHAS staff who perceived this area as being of extreme importance.

It is not surprising that the issue of pain and symptom management would be a strong theme within the study. The concern of family members that their loved one may suffer pain is common concern throughout palliative care. Pain and symptom management is also an important issue for the professionals working in the field. These two factors would make pain and symptom management an important issue in any study. The importance of this theme to families, CHAS staff and professionals in the current study demonstrates the importance of research which can improve techniques and share expertise across professional boundaries. There is a paucity of published research regarding the management of physical symptoms in children's palliative care, particularly for children with a non-cancer diagnosis. A review of children's palliative care literature conducted by Cooley *et al.,* (2000) demonstrated the lack of evidence-based management of some of the most common symptoms (pain, constipation, seizures, respiratory symptoms). Pain may be one of the most common symptoms experienced by children with a life-limiting condition, yet there is evidence in the scientific literature to say it is still often poorly managed (Watterson & Hain, 2003). In their recent review, Liben *et al.,* (2007) discussed some of the explanations underlying the limited outcome data relating to the management and control of symptoms and the effectiveness of these interventions in caring for children with life-limiting conditions which include “the small numbers of children to be studied in any one institution, the lack of standardised measurement scores for pain and quality of life in young children, and the fact that the need for such research in children’s palliative care has only been recognised in the past few years” (p.3).

In the absence of research evidence, clinicians and carers are required to rely on anecdotal evidence based on their recent or past experiences (Cooley *et al.*, 2000). This was acknowledged by one of the consultants interviewed during Round 1 of the project highlighting the requirement of clinicians, including those working within the hospice setting, to use their expertise in this specialised area to document and evaluate their practice. Moreover, the inclusion of the child and his/her parents, who are the experts when it comes to knowing the symptoms and identifying any changes in those symptoms, would be advantageous. ACT/RCPCH (2003) highlight the ‘evaluation of therapeutic approaches to symptom management so that new guidelines can be evidence based and existing ones can be modified as necessary’ as a priority area for research to facilitate evidence based practice in this field.

7.3 Bereavement and End-Of-Life Care and Support Provided by CHAS

Exploring the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues emerged as the 3rd most important research question and finding out what families want from CHAS with regard to end-of-life and bereavement care emerged as the 9th most important research question overall.

Developing effective and innovative approaches to engaging with children, young people and families to assess their needs and to evaluate the extent to which they are being met is an identified strategy within CHAS (CHAS, 2007). Including both children and adolescents in research projects and actively seeking their views on care issues which concern them allows the collection of valuable data that will contribute towards planning and delivering children’s end-of-life care and, more importantly, promotes their autonomy and independence (Davies *et al.*, 2005). In the past, research in sensitive and emotional areas such as end-of-life care has often been conducted without including the child’s perspective. However, there is growing evidence that children and young people wish to be active participants in decisions affecting their care and this includes end-of-life decisions (Hinds *et al.*, 2004).

The quality of care received has important implications for family and siblings following death and bereavement. As described in a review by Liben *et al* (2007) “the death a child affects the physical and psychological well-being of family members for the rest of their lives, and events that occur around the time of death, both positive and negative, are highly important” (p.3). Outcome data is needed in end-of-life care for children to clearly define what children and families perceive to be a ‘good’ death (Emond & Eaton, 2004). Moreover, additional research is needed to support siblings and families throughout their bereavement.

Exploring the needs of hospice staff with respect to communicating with children and families about death and dying issues emerged as a priority area for research. As a child’s level of understanding regarding their condition will be dependent on their age and development this poses particular challenges to care providers. CHAS staff identified communicating end-of-life issues with young people to be particularly complex and would welcome further exploration of this area.

7.4 Improving Access to Children’s Hospice Care

Research to identify strategies to promote awareness of CHAS and the wide range of services it offers to children and families emerged as 11th in the final list of 15 research questions in Round 3. Promoting awareness of CHAS to both professionals and the public was acknowledged by all stakeholder groups as fundamental in improving access to hospice services.

Research priorities identified that relate to improving access to children’s hospice care included (i) epidemiological studies to accurately define the incidence and prevalence of children in Scotland with palliative care needs and (ii) the number of those children who meet CHAS’ current referral criteria. Statistical evidence to demonstrate such figures are currently being drawn from other sources (ACT/RCPCH, 2003) and applied to the Scottish population (CHAS, 2005). Accurate data on the number on children with complex needs, of which children with life-limiting conditions will be included, are not currently available (National Frame National Framework for Service Change in the NHS in Scotland Care in Local Settings: Children with Complex Needs, 2005). Thus there is a need to determine precise and up-to-date figures of the number of children throughout Scotland who require hospice services.

It is important that all professionals who refer to the service and all potential referrers have an accurate understanding of CHAS' referral criteria. Moreover, professionals need to be aware of the wide range of services CHAS offers to families including bereavement support. Research questions in this area were raised by all stakeholder groups thus clearly suggesting its importance. The literature also provides evidence to support this as an area requiring further investigation. A recently published service evaluation which aimed to identify and utilise families' views to improve children's hospice services revealed that families wanted professionals to have greater awareness of the roles of children's hospices (Maynard *et al*, 2005). The families also wished for earlier referral to the hospice and linked professional's limited awareness and reluctance to refer as a barrier to early access to the service.

Professionals may not refer to children's hospices because they perceive them to be similar to adult hospices and this assumption presents another barrier to families being referred to a hospice (Hynson & Sawyer, 2001). Moreover, professionals may not be aware of the variety of medical conditions and specific timing that referrals can be made often resulting in children being referred much later in the course of their illness. Specific reference to children with cancer has been documented in the literature and supported by the findings of this work. A postal survey of 632 paediatric oncologists to examine hospice referral patterns and locate barriers to referral, showed that continued cancer therapy was cited as the most common reason for not making a referral and was significantly higher when the hospice did not admit children receiving chemotherapy (Fowler *et al.*, 2006). An additional question categorised under the theme of *strategic planning* that did not appear in Round 3 list of research questions, however relates to children with cancer and highlights the need to identify where the hospice movement in Scotland fits with services of palliative care for this population.

The findings from this project highlight the scope to broaden hospice care to populations such as neonates with palliative care needs and their families and explore the possibility of CHAS offering this support. Perinatal and neonatal hospice care is a newly developing area (Ramer-Chrastek & Thygeson, 2005) providing opportunity for CHAS to further explore and develop services to support these families.

7.5 Community Care (Outreach) Provided by CHAS

Community care (outreach) is an area of the service CHAS is further developing with the aim to have a ‘CHAS at Home’ model in place by 2010 (CHAS, 2007). The findings of this assessment indicate that conducting a needs analysis to determine what families across Scotland want with regard to home care services provided by CHAS would be beneficial. Current health policy is dedicated to shifting the balance of care provision from hospitals and institutions to homes and communities (Scottish Executive, 2005b). With both hospices located in central Scotland, families, particularly those living in the more rural and remote areas of Scotland, are currently required to travel some distance to their respite. Home care is valued by those families currently using it and it would be worthwhile to further explore what home care services these families would like CHAS to provide.

A Big Lottery palliative care initiative recently piloted in Ayrshire and Arran Health Board where outreach respite services are provided to families who may otherwise not be able to access CHAS has recently come to the end of its funding. These outreach teams have proved successful and a valuable service which is making a real difference to families has involved. A priority research question which emerged in this project is for CHAS to work together with local services to review, further develop and expand these outreach respite teams across Scotland, which would allow even more families to access CHAS services within their own homes and/or communities. Children’s palliative care services are currently provided by the NHS, hospices, social care, education services and the voluntary sector. To provide integrated and co-ordinated community care, it is essential that there is collaboration and partnership working between all agencies involved in the care of children with life-limiting conditions and their families (National Framework for Service Change in the NHS in Scotland: Care in Local Settings: Children with Complex Needs, 2005; Danvers *et al.*, 2003).

7.6 Other Research Priority Areas Identified

In addition to the items discussed above, two further questions made up the list of 15 most important research questions which were: (i) supporting siblings throughout the child’s illness and during bereavement and (ii) exploring ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital.

The impact of the child's illness and death on siblings is immense and requires the psychological, spiritual and emotional support needs of siblings to be assessed and addressed. In doing this it is important to gather the sibling's perspectives. As explained by Davies *et al.* (2005) in an evaluation of a children's hospice program, *"without addressing children's perspectives directly, we are denying them their right to a voice and, furthermore, are missing out on much valuable information they have to offer"* (p.252).

It was clear throughout this process and at all stages of the Delphi assessment the extent to which participants found it difficult to prioritise the research questions. This is despite explanation by research team that the aim of the assessment was to reduce the list of 56 research questions and attempt to pull out the *most* important ones or the priority areas. The challenge participants faced in doing this was evidenced by the fact that 55 of the 56 research questions were rated as a mean of 3, 'important', or 4, 'very important', with only one research question having a mean of 2, 'least important'. This result demonstrates that there is a breadth of areas that were deemed by the participants as being research priorities for CHAS to investigate. It is important to emphasise the range of research questions identified in this process and the importance participants placed on each question, which was clearly explained in the reporting of the qualitative interview and focus group data in Section 5.2. A number of examples and extracts from interviews were given to support participants' selection of each research question. Moreover, all topics would contribute to the advancement and improvement of palliative and hospice care of children and their families.

7.7 Overview Of Research Potential

The priority areas for research identified in this work are similar to those recently reported in the literature (Liben *et al.*, 2007; ACT/RCPCH, 2003). In their review paper, Liben *et al.* (2007) conclude that there are more questions than answers in the field of children's palliative care and provide examples of basic questions such as: how to best control symptoms such as pain and fatigue; how to communicate with children and appropriately involve them in decision-making; and how to provide care that reduces the suffering of the bereaved. The similarity of the key questions between Liben *et al.*'s review and this project for CHAS provides further evidence of the importance of the research priorities highlighted in this report and its timely nature.

There are, however, a number of different approaches that CHAS could take in addressing the issues as not all would require a piece of empirical research. Some of the issues would be opportune areas for service development through internal audit, evaluation of practice or even dissertation topics for staff and practitioners interested in pursuing post-graduate study or continuing education. Whilst some topics would be suitable for independent research, others may benefit from the involvement of an external agency or academic institution and/or collaboration with other children's hospices in the UK who may well be confronted with similar issues. During telephone interviews conducted in Round 1, professionals were asked to identify some of the key challenges or barriers and some of the key facilitators that CHAS should be aware of. This allowed professionals, many of whom with previous experience in undertaking and evaluating research to share their knowledge and ideas. The barriers and facilitators are presented in Appendix H.

It would be valuable to investigate what research is currently going on within the UK with reference to children's palliative and hospice care. Colleagues from ACH who were interviewed as part of this assessment, were happy to share information that they had regarding various centres and teams across the UK that are currently active in children's palliative care research. This information is given in Appendix I. Regardless of the precise approach undertaken to address the priority areas for research identified in this project, the result would be further contribution to the development of an evidence base in children's hospice and palliative care and delivery of children's hospice services that are underpinned by robust and valid research.

8 LIMITATIONS

This project intended to gather the views and perspectives of a range of key stakeholders including children and families who use CHAS, staff and volunteers who work within the organisation and professionals with experience and expertise in the care of children with life-limiting conditions. It proved difficult, however, to include the views of children; both the child with a life-limiting condition and any siblings, in the research process. Despite the researchers inviting and encouraging children to be present during the interviews and to contribute to the discussion in generating ideas for research, only one of the five interviews was conducted with the parents, affected child and sibling present. In the remaining four interviews, parents opted to be interviewed without their children being present. This was often for logistic reasons mainly the fact that parents requested the interview to take place during the daytime when the children were at school. In a further attempt to include children's perspective, the researchers posted the interview schedule out in advance to give families the opportunity to discuss the issues together so the parent/s could then bring the views of their entire family to the interview. During subsequent rounds, the researchers once again requested that the views of all family members were included in questionnaire responses but this would have been done at the discretion of the families involved.

An additional challenge was framing the research questions in a way that they would be understood by the very diverse sample of participants. Using the Delphi technique meant ensuring, as far as possible, that the wording of research questions put forward by participants in the first round was used with only minor editing (Hasson *et al.*, 2000). Similarly, in trying to identify the research priorities for CHAS from the views and perspectives of families, staff, volunteers and professionals, the researchers have to accept all of the topics put forward by the participants as valid areas for future research. So whilst some readers who hold greater awareness or understanding of the wider field of children's hospice and palliative care may question the focus of some of the topics, or have knowledge that the issues are currently being addressed elsewhere be it nationally or internationally, the researchers had to incorporate all topics into the questionnaire for rating by the whole sample.

The primary aim in carrying out this project was to generate questions for future research from the viewpoint of key stakeholders. It is important to acknowledge that conducting a thorough review of what is going on elsewhere, nationally and internationally, will be necessary. However, given the need for an increased evidence base in children's palliative care (ACT/RCPCH, 2003) and the broad research agenda in this field (Emond & Eaton, 2004) it is likely that valid research in any of the issues identified during this project will be beneficial. The development of links with other hospices, agencies and academic institutions in conducting collaborative research to investigate some of the priority areas will be advantageous.

9 CONCLUSIONS AND RECOMMENDATIONS

This project set out to explore the future research priorities for CHAS from the perspective of its key stakeholders. As stated at the beginning of the discussion section it is important for readers of this report to remember the research priorities were rated as important research priorities for CHAS and do not necessarily indicate that participants have concerns about these areas of the current service or are highlighting them as areas requiring immediate service improvement. A range of research priorities have emerged from this work that may be of value for CHAS to consider when developing their research strategy for the next five years. The key recommendations which have come from research priorities are outlined below and whilst not exhaustive of the data, reflect those areas for research considered to be of the highest importance by the families, staff, volunteers and professionals who participated in the process.

9.1 Research areas identified as being of the highest priority

Recommendation 1: Consider conducting a needs assessment of young people (16+) with life-limiting conditions from the perspective of the young people themselves, their parents and professionals. The needs assessment should consider the following issues:

- identify the care and support needs of young people from all perspectives;
- review the psychological support CHAS currently provides to young people (16+) who know they have a life-limiting condition; and
- make recommendations for staff training, development and support.

Recommendation 2: Consider conducting an assessment into pain and symptom management. The assessment should consider the following issues:

- identify the services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess their effectiveness;
- look at the practice within CHAS and how it links with other agencies/services;
- explore the main symptoms experienced by children with very rare life-limiting conditions;
- develop and evaluate improved symptom management strategies.

Recommendation 3: Consider conducting a needs assessment to identify any training and support CHAS staff would benefit from regarding bereavement care and, more specifically, how to communicate with children and their families on end-of-life issues.

9.2 Other important areas for research

Recommendation 4: Consider exploration of the other areas which were identified by participants as being research priorities. The areas include:

- supporting families who are new to the service or potential users of the service;
- spiritual and emotional care issues;
- children's education;
- support needs of the wider family;
- diversity issues;
- issues of specific relation to CHAS staff and volunteers;
- service development; and
- strategic planning issues.

9.3 Building research capacity within CHAS

Recommendation 5: The introduction of a formal research programme will require a change in thinking and practice for some within the organisation and some who use the service. It will be important for CHAS to consider opportunities to build research capacity and expertise. This could include several strategies such as:

- the recruitment of a senior academic/researcher with the appropriate research expertise to drive forward and oversee the research activities of CHAS and its external partnerships. This could be achieved through the creation of a new post within CHAS or through a consultancy agreement with an external organisation;
- explore secondment opportunities for CHAS staff to engage in the research process with external organisations; and importantly to
- explore methods of engaging with families to identify and increase their awareness and understanding of the need and future benefit of research.

Recommendation 6: Consider developing links and formal networks with other hospices in the UK, relevant academic institutions and areas of clinical excellence to encourage a collaborative approach to research.

As children's palliative care is an emerging field, the current evidence base is not sufficient to adequately support policy and clinical practice (ACT/RCPCH, 2003). Thus there is a crucial need to increase the existing evidence base through valid research so that palliative care services can be designed, delivered and evaluated on the basis of robust scientific evidence. This will contribute to ensuring the best possible quality of life for children with life-limiting conditions and their families. In addition, it will allow CHAS, as a small Scottish charity, to be leaders in the advancement of children's hospice and palliative care. The recommendations detailed above address the key research priorities identified during this project. It is hoped that the findings from this work will provide a useful template from which CHAS can develop their research agenda.

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11 APPENDICES

Appendix A - Names and job titles of the Project Steering Group

Name	Job Title	Organisation
Rev. Robert Allan	Chaplain	Rachel House, CHAS
Nicky Bridges	Community Children's Nurse	NHS Greater Glasgow and Clyde
Chris Brodie	Team Leader, Children and Disability Team	Stirling Council
Angela Davidson	Family using CHAS	
Sue Hogg	Depute Head of Care	Rachel House, CHAS
Dr. Pat Jackson	Consultant Paediatrician	NHS Lothian
Anne Mitchell	Volunteer	Rachel House, CHAS
Struan McCallum	Board Member	Care Commission
Anthea Morley	Family using CHAS	
Richard Morley	Family using CHAS	
Dr. Dermot Murphy	Consultant Paediatric Oncologist	NHS Greater Glasgow and Clyde
Julie Wyllie	Depute Head of Care	Robin House, CHAS
Dr. Liz Forbat	Senior Research Fellow	Cancer Care Research Centre, University of Stirling
Dr. Katherine Knighting	Research Fellow	Cancer Care Research Centre, University of Stirling
Dr. Cari Malcolm	Research Fellow	Cancer Care Research Centre, University of Stirling

Appendix B: Family interview schedule

INTERVIEW SCHEDULE (Family/Children)

An Assessment to Identify the Future Research Priorities for the Children's Hospice Association of Scotland (CHAS)

<u>What do we mean by 'research priorities'?</u>

The researcher will first describe what we mean by 'research' and discuss some of the benefits of CHAS being active in research and development.

1. **Can you tell me a little bit about your family and about their experiences in using CHAS (Rachel House, Robin House, RHAH)?**

2. **Do you know of any research that is currently going on or that has recently taken place within CHAS? If so, please tell me about the research?**

3. **Is there anything that is special about the services CHAS offers? Is there anything that stands out as being different or unique compared to other respite or hospice services available?**

4. **What could CHAS do differently? or better?**

5. **Based on your recent experiences with CHAS what do you think are some of the important areas for CHAS to research over the next five years?**

   Let's try to put together a list of five questions related to respite and hospice care needs of children and families who use CHAS?

   From this list of five questions, can you select the most important one?

   From this list of five questions, can you select the least important one?

Thank you for taking the time to answer these questions.

Appendix C: Focus group schedule

FOCUS GROUP SCHEDULE (CHAS staff/volunteers)

An Assessment to Identify the Future Research Priorities for the Children's Hospice Association of Scotland (CHAS)

What do we mean by 'research priorities'?

The researcher will first define the term 'research' (i.e. developing and testing new knowledge or information, evidence-based practice, could be audit, evaluation or surveys) and discuss the benefits of CHAS being active in research and development (i.e. to further develop and enhance the hospice care they provide to children and families)

Thinking about your recent experiences working for or volunteering with CHAS (Rachel House or Robin House, RHAH etc.):

Are you aware of any research currently going on or that has recently taken place within CHAS? If so, please describe the research? How did you hear about it?

What are some examples of the services that CHAS provides best? What is different about the services CHAS provides compared to other palliative care services available?

Where are some areas for improvement within CHAS/CHAS' services? Can you think of a more interesting or beneficial way of doing …….?

What in your opinion are some of the areas CHAS should conduct research in?

What are some of the barriers for CHAS conducting research?

Thinking about some examples of research questions:

Let's try to put together a list of 10 priority questions relating to palliative and respite needs of the children and families who use CHAS that you think are particularly important for future research to be conducted on?

From this list of # priority questions, can we select the top five?

Thank you for taking the time to answer these questions.

Appendix D: Professional telephone interview schedule

TELEPHONE INTERVIEW SCHEDULE

An Assessment to Identify the Future Research Priorities for the Children's Hospice Association of Scotland (CHAS)

During the telephone interview you will be asked the following questions. In advance of the interview, you are asked to read these questions and note any answers you may want to give the researcher on the form. Please note your identity will be protected at all stages of the research project. You do NOT need to answer every question.

1. **Please describe your relationship or association with CHAS?**

2. **Are you aware of any current or recent research taking place within CHAS?**

3. **What do you know about research that is currently/recently going on within the wider field of hospice and respite care for children with life limiting conditions?**

4. **Are you aware of any potential barriers or constraining factors to CHAS conducting research? If so, what are these barriers?**

5. **Are you aware of any factors that could facilitate or promote CHAS to increase their research capacity? If so, what are these facilitators?**

6. **Please list below up to *five* questions or challenges relating to the hospice and respite needs of children with life limiting conditions and their families that you believe are of particular importance and that CHAS therefore should conduct future research on?**

1)
2)
3)
4)
5)

7. **If I had a pot of money to give to you today that could be spent on conducting one area of research or one research project what, in your opinion, should it be?**

8. **Do you have any additional comments or general statements you would like to make on the future research priorities for CHAS?**

Thank you for taking the time to answer these questions.

Appendix E – Round 2 Questionnaire

Identifying Future Research Priorities for CHAS

This project is being carried out by a team from the University of Stirling, to help CHAS identify their future research priorities. We recently interviewed families using CHAS and staff, volunteers and professionals who work with CHAS to find out what research questions they felt were important for CHAS to consider. Whilst we recognise that all of the research questions identified are important, the purpose of this questionnaire is to ask a larger number of people who are involved with CHAS to help us narrow down and identify which research questions are the 'most' important ones.

You may choose to participate in the project or not, and may answer only the questions you feel comfortable with. If you do not wish to participate, you may simply return the blank questionnaire. If you do participate, completion and return of the questionnaire indicates your consent in the process. The questionnaire has 3 sections and should take about 30 minutes to complete. All your responses will remain anonymous.

Instructions for completing the questionnaire

Section A

This section contains the 56 research questions identified in the interview phase of the project. As stated above, these have all been put forward as important areas for research and this questionnaire gives you the opportunity to tell us what your preferences are.

When completing section A, for each question, please circle the number on the scale to indicate how important you think the research question is. An example of how to complete each question is given below:

Part 1 **Thinking about *pain and symptom management* in children and young people how important do you think it is for CHAS to:**

		not at all important	*least important*	*important*	*very important*	*extremely important*
1.	evaluate current methods used to assess pain in children?	1	2	[✓ 3]	4	5

Section B

This section lists the 14 broad research topics included in the questionnaire. We would like you to identify the top five topics you think CHAS should consider as their research priorities. Please rank them in order from 1 to 5 with 1 being the topic you think is most important for CHAS to research first.

Section C

To help us identify the different priorities of people involved with CHAS it would be helpful for us to know something about the people completing the questionnaire. This section asks some questions about your role/relationship with CHAS and some personal details. It will be removed from the questionnaire upon receipt by the researchers and stored securely in a separate location from the questionnaire. This section will also ask you to indicate if you agree to receive the second and final questionnaire in this project.

Please complete all 3 sections and return in the pre-paid envelope by Friday 8th June, 2007.

If you have any questions or queries about the questionnaire or project , please contact Dr. Cari Malcolm, from the Research Team, on 01786 849260 or email cari.malcolm@stir.ac.uk

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SECTION A

For EACH of the 56 following questions, please circle ONE number on the scale to indicate how important you think the question is as a future research priority for CHAS with 1 being 'not at all important', 3 being ‘important’ and 5 being 'extremely important'.

Topic 1 Thinking about *children’s hospice care* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
1.	find out what the public and professionals (doctors, nurses, social workers, teachers etc.) understand about CHAS and the service it provides to children and families?	1	2	3	4	5
2.	explore the meanings the public and professionals associate with the term 'children's hospice'?	1	2	3	4	5
3.	identify ways to promote awareness of CHAS and the wide range of services it offers to children and families?	1	2	3	4	5

Topic 2 Thinking about *improving access to hospice care* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
4.	find out the number of children in Scotland with palliative care needs and the number of children who meet CHAS’ current referral criteria?	1	2	3	4	5
5.	find out the reasons why professionals refer or do not refer children and families to CHAS?	1	2	3	4	5
6.	find out what professionals know and understand about CHAS’ referral criteria?	1	2	3	4	5
7.	explore the reasons why a family chooses to use or chooses not to use hospice services?	1	2	3	4	5
8.	explore the reasons why children with **cancer** and their families are **not** being referred to or are choosing **not** to use CHAS?	1	2	3	4	5

Topic 3 Thinking about *CHAS supporting families who are new to the service*, or are potential users of the service, how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
9.	explore the ‘fixed ideas’ families hold about using a children’s hospice before they visit Rachel/Robin House, and how this compares to their future visits?	1	2	3	4	5
10.	pilot a 'buddy system' where a new family is paired with an existing family?	1	2	3	4	5
11.	explore the role of volunteers in increasing awareness amongst families who are potential users of CHAS?	1	2	3	4	5

Topic 4 Thinking about *community care (outreach)* provided by CHAS how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
12.	find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by CHAS (such as the Home from Home service)?	1	2	3	4	5
13.	identify how the ‘*Home from Home’* service CHAS provides differs or compares to the care currently provided by other community services?	1	2	3	4	5
14.	work together with local services to review and develop outreach respite teams across Scotland which would allow more families to access CHAS services within their own homes and/or communities?	1	2	3	4	5

Topic 5 Thinking about *hospice and respite care needs of young people (aged 16+)* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
15.	find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals?	1	2	3	4	5
16.	find out the specific care needs of young people (16+) with limited cognitive abilities (learning, understanding, communicating)? e.g. how will their care needs change during the transition to adult services?	1	2	3	4	5
17.	explore ways CHAS could work together with other services (health, social care, voluntary etc.) to meet young people's needs for the transition to adult services?	1	2	3	4	5
18.	review the psychological support CHAS provides to young people (16+) who know they have a life-limiting condition and make recommendations for staff training and development?	1	2	3	4	5

Topic 6 Thinking about the *spiritual and emotional care* CHAS provides to children and families how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
19.	evaluate whether spiritual/emotional care provided by CHAS staff is adequate, consistent and effective?	1	2	3	4	5
20.	develop and test standards of care specific to children and families that chaplains can use as none currently exist?	1	2	3	4	5

Topic 7 Thinking about the *bereavement and end-of-life care and support* CHAS provides to children and families how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
21.	find out what families want from the CHAS service with regard to end-of-life and bereavement care?	1	2	3	4	5
22.	explore how families make decisions when planning end-of-life care?	1	2	3	4	5
23.	explore the reasons why families may choose to use CHAS for end-of-life care rather than use other services or remain at home?	1	2	3	4	5
24.	explore the impact of cultural differences on the bereavement process of the family and their support needs?	1	2	3	4	5
25.	explore how families feel about the experience of using the Rainbow Room (bereavement suite)?	1	2	3	4	5
26.	test the possibility of offering services of the Rainbow Room to families after having a stillborn child?	1	2	3	4	5
27.	explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues?	1	2	3	4	5
28.	identify ways to ensure the continued role of community professionals (e.g. social workers, community nurses) when a child and family come to the hospice at the end-of-life stage?	1	2	3	4	5

Topic 8 Thinking about *pain and symptom management* in children and young people how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
29.	identify the symptoms experienced by children with **very rare life-limiting conditions** to develop management and control strategies?	1	2	3	4	5
30.	identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are?	1	2	3	4	5

Topic 9 Thinking about children and young people's *education* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
31.	find out whether the educational needs of children and siblings using the CHAS service are being met, and if not how this can be improved?	1	2	3	4	5

Topic 10 Thinking about CHAS *supporting the wider family* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
32.	find out what the needs of siblings (brothers and sisters) are throughout each stage of a child's illness including bereavement support?	1	2	3	4	5
33.	explore the process for CHAS to make referrals to community services when they identify a support need of siblings?	1	2	3	4	5
34.	find out what the support needs of men (e.g. fathers, grandfathers, uncles) are during a child's illness and through bereavement?	1	2	3	4	5

35.	find out what the support needs of the extended family (e.g. grandparents) and close friends are, and explore how these needs are being met?	1	2	3	4	5
36.	explore how CHAS staff can support and empower parents in their contact with other services e.g. help with accessing equipment?	1	2	3	4	5

Topic 11 Thinking about the issue of *diversity* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
37.	identify ways for CHAS to encourage/promote diversity amongst staff and volunteers (e.g. ethnicity, gender) including recruitment to the organisation?	1	2	3	4	5
38.	explore how people from a range of cultures and ethnic groups perceive CHAS and identify their support needs?	1	2	3	4	5

Topic 12 Thinking about issues specifically related to *CHAS staff and volunteers* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
39.	investigate the impact of stress and the effectiveness of current coping strategies among CHAS staff and volunteers?	1	2	3	4	5
40.	evaluate whether current induction/orientation programmes meet staff needs and how it impacts on their sense of belonging within a growing organisation?	1	2	3	4	5

Topic 13 Thinking about CHAS and *service development issues* how important do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
41.	identify ways to promote and encourage a greater emphasis on active planning of end-of-life care and palliative care for children amongst other service providers (e.g. children’s hospital wards and community services)?	1	2	3	4	5
42.	conduct a study to measure the quality of life and experiences of a child/young person and their family attending a children’s hospice compared to one who doesn’t have that opportunity?	1	2	3	4	5
43.	evaluate the policies and procedures in place to address infection control issues within the hospice?	1	2	3	4	5
44.	find out what day-to-day medical cover is required in a children’s hospice?	1	2	3	4	5
45.	explore ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital?	1	2	3	4	5
46.	find out how knowledgeable GPs and paediatricians are with children’s palliative care issues?	1	2	3	4	5
47.	identify ways to support families who want to express concerns about the CHAS service?	1	2	3	4	5
48.	identify ways CHAS staff can share their expertise in children’s palliative care with professionals?	1	2	3	4	5
49.	explore the possibility of CHAS supporting professionals in the community/health service who are caring for children with palliative care needs in isolation and would benefit from peer support or clinical supervision?	1	2	3	4	5

50.	identify the support needs of families of neonates (newborn babies) with palliative care needs and the possibility of CHAS providing this support?	1	2	3	4	5
51.	evaluate how families value the hydrotherapy service and the benefits received by the child/young person?	1	2	3	4	5

Topic 14 Thinking about CHAS and *strategic planning* issues how <u>important</u> do you think it is for CHAS to:

		not at all important	*least important*	*important*	*very important*	*extremely important*
52.	review different models of children’s hospice care and the benefits of each in terms of quality of care and cost?	1	2	3	4	5
53.	conduct an action research project aimed at the integration of CHAS within the wider children’s palliative care network exploring barriers to integration and how the regional area is proactive in terms of its children’s palliative care provision?	1	2	3	4	5
54.	identify where the hospice movement in Scotland fits into services of palliative care for children with cancer?	1	2	3	4	5
55.	explore the lessons learned from the implementation of the Gold Standards Framework (GSF) for adult palliative care in the community to initiate the development of a GSF for children’s palliative care services?	1	2	3	4	5
56.	CHAS to establish a collaborative system for conducting research in the field of children's palliative care involving statutory and voluntary services, and academic institutions?	1	2	3	4	5

SECTION B

Listed below are the 14 research topics included in the questionnaire. We would like you to identify your top five topics by placing a number from 1 to 5 in the boxes on the right. For example, put the number 1 in the box next to the area which is your first preference, 2 in the box next to your second preference, 3 in the box next to your third preference, and so on until you have identified your top five. Please leave the other boxes empty.

Awareness of children’s hospice care ☐
Improving access to children’s hospice care ☐
Supporting families who are new users or potential users of the CHAS service ☐
Community care (outreach) provided by CHAS ☐
Hospice and respite care needs of young people (aged 16+) ☐
Spiritual and emotional care provided by CHAS ☐
Bereavement and end-of-life care and support provided by CHAS ☐
Pain and symptom management ☐
Education needs of children and young people ☐
Supporting the wider family ☐
Diversity ☐
Issues specific to CHAS staff and volunteers ☐
Service development issues ☐
Strategic planning issues ☐

If you would like to provide comments or explanations for your top five choices above, or for any other section of the questionnaire please tell us here.

SECTION C – Personal information and consent

These questions will help us to know something about the person completing the questionnaire, in terms of your family and how you use the CHAS service (Part 1), or your role working with CHAS (Part 2). If you do not want to answer any of the questions in this section please just put a line through it so we know that the question has not been missed. Please respond to the questions by putting a tick (✓) in the appropriate box or by writing in the spaces provided.

Please remember to complete Part 3 after completing either Part 1 or Part 2.

Part 1: Information from families who use, or have used, the CHAS service

1. **Which of the following best describes your family's use of CHAS?** (check all boxes that apply):

   ☐ we attend Rachel House

   ☐ we attend Robin House

   ☐ we use the Rachel House at Home (RHAH)

   ☐ we use CHAS family bereavement support

   ☐ we no longer need the services of CHAS

   ☐ we currently use other services

2. **How long has your family been using, or had previously used, the services of CHAS**?

   ☐ less than 1 year ☐ 1-2 years ☐ 3-5 years ☐ 6-8 years ☐ 9 years or more

3. **If you have a child or children currently using CHAS, please tell us a bit about them.**

Sex	Age	Medical Condition/Diagnosis

4. **If you have a child or children who previously used CHAS but have since passed away, please tell us a bit about them.**

Sex	Year Child Passed Away	Medical Condition/Diagnosis	Did you use the services of the Rainbow Room?

5. **Please tell us who in your family uses, or have used the services of CHAS in the past and please remember to include yourself:**

   ☐ sibling 5 years or younger

   ☐ sibling 6-14 years

   ☐ sibling 15 years and over

   ☐ mother

   ☐ father

   ☐ aunt/uncle

   ☐ grandparent

   ☐ step-parent

   ☐ other (please state)________________________

   ☐ carer

   ☐ foster parent

Please turn over page to complete Part 3

Part 2: For CHAS staff, volunteers and other professionals working with CHAS

1. **Please complete the section which best describes your association/link to CHAS. Are you currently a:**

   A. **Member of CHAS staff** - please indicate your place of work **and** your role:

   Place of Work: ☐ Rachel House ☐ Robin House ☐ Rachel House at Home
   ☐ Head Office ☐ Other (please state)____________________

   Role: ☐ Care Team ☐ Activities Team ☐ Housekeeping
   ☐ Maintenance ☐ Catering ☐ Administration
   ☐ Fundraising ☐ Retail ☐ CHAS Board
   ☐ Other (please state)________________________________

   B. **Volunteer with CHAS** - please indicate the area(s) you volunteer in:

   ☐ Rachel House ☐ Robin House ☐ Rachel House at Home
   ☐ Fundraising ☐ Retail ☐ Head Office
   ☐ Other (please state)____

   C. **Professional in health, social care, education, voluntary sector** - please indicate your role **and** your employer or Health Board:

   Role/Job Title: ____

   Health Board: ____

2. **What length of time have you been in the position/role indicated in question 1?**

   ☐ 2 years or less ☐ 3-5 years ☐ 6-8 years ☐ 9 years or more

Part 3: Participating in the final round of the study

We will be sending out a second questionnaire that will contain the research questions that were most highly rated in this questionnaire. You will see what everyone said about each question and have the opportunity to confirm your first rating of that question or change it. The final report will include the responses to both questionnaires but the questions that have the highest rating from the second questionnaire will be those considered the most important for CHAS to act on in the immediate future.

If you are happy to receive the second and final questionnaire in this study please tick (✓) the box below and provide your name and a contact address to which the questionnaire should be sent.

☐ I **AGREE** to receive the second and final questionnaire on the future research priorities for CHAS.

Name (of person who completed this questionnaire): ____

Relationship to Child using CHAS (for family members): ____

Contact address: ____

____POST CODE_____________________

Email: ____

Thank you for taking the time to respond.
Please return the completed questionnaire to Cari Malcolm in the pre-paid envelope provided
by **Friday 8th June 2007**.

Appendix F – Round 3 Questionnaire

SPSS Ref: ID:

Cancer Care Research Centre
Linking reality with science

Identifying Future Research Priorities for CHAS

CHAS
Children's Hospice Association Scotland
Sharing the Caring

Instructions for Completing the Final Questionnaire

1. Personal Information

To help us identify the different research priorities of those involved with CHAS it would be helpful for us to know something about the people completing the questionnaire. Please **tick one box below** to tell us who you are:

☐ **Family** ☐ **CHAS staff** ☐ **CHAS volunteer** ☐ **Professional**

2. Section A

This section contains the 15 research questions that were identified from analysis of the first questionnaire as being the highest priority areas for future research. Participants rated these questions as either (4) *very important* or (5) *extremely important*. The average rating given to each of these 15 questions by the 274 people who completed the first questionnaire was 4 (‘very important’). The aim of this second questionnaire is to further reduce the number of questions to identify those that are **most important** to all who work with or use the CHAS service. To help us do this we would appreciate it if you would rate each of the 15 questions again. The ratings you gave in the first questionnaire are also provided as a reminder. You may wish to rate the question the same or change your rating to reflect which of these research questions are of the highest importance or priority in your opinion. If you would like to say more about changes you have made to a question’s rating, please tell us in the comments section at the end.

Please return the completed questionnaire in the pre-paid envelope by Monday 23rd July 2007.

If you have any questions or queries about the questionnaire or project, please contact Dr. Cari Malcolm, from the Research Team, on 01786 849260 or email cari.malcolm@stir.ac.uk

SECTION A

For EACH of the 15 questions below, please circle ONE number on the scale to indicate how important you think each question is as a future research priority for CHAS.

	your previous rating	*not at all important*	*least important*	*important*	*very important*	*extremely important*
1. Identify ways to promote awareness of CHAS and the wide range of services it offers to children and families?	***3***	1	2	3	4	5
2. Find out the number of children in Scotland with palliative care needs and the number of children who meet CHAS' current referral criteria?	***4***	1	2	3	4	5
3. Find out the reasons why professionals refer or do not refer children and families to CHAS?	***4***	1	2	3	4	5
4. Find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by CHAS (such as the Home from Home service)?	***5***	1	2	3	4	5
5. Work together with local services to review and develop outreach respite teams across Scotland which would allow more families to access CHAS services within their own homes and/or communities?	***5***	1	2	3	4	5
6. Find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals?	***5***	1	2	3	4	5
7. Find out the specific care needs of young people (16+) with limited cognitive abilities (learning, understanding, communicating)? e.g. how will their care needs change during the transition to adult services?	***5***	1	2	3	4	5
8. Explore ways CHAS could work together with other services (health, social care, voluntary etc.) to meet young people's needs for the transition to adult services?	***5***	1	2	3	4	5
9. Review the psychological support CHAS provides to young people (16+) who know they have a life-limiting condition and make recommendations for staff training and development?	***4***	1	2	3	4	5

	your previous rating	*not at all important*	*least important*	*important*	*very important*	*extremely important*
10. Find out what families want from the CHAS service with regard to end-of-life and bereavement care?	***5***	1	2	3	4	5
11. Explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues?	***5***	1	2	3	4	5
12. Identify the symptoms experienced by children with **very rare life-limiting conditions** to develop management and control strategies?	***4***	1	2	3	4	5
13. Identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are?	***3***	1	2	3	4	5
14. Find out what the needs of siblings (brothers and sisters) are throughout each stage of a child's illness including bereavement support?	***5***	1	2	3	4	5
15. Explore ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital?	***3***	1	2	3	4	5

If you would like to provide comments or explanations for your rating of any of the above research questions please tell us here.

Appendix G - Round 2 results for total sample and individual participant categories: numbers, means and standard deviations (SD)

Two tables are presented for each of the 14 themes below, one with results for the total sample and one with results for the different participant categories. The number of respondents, mean and standard deviation (SD) for each research question is presented. The mean, as a measure of central tendency, represents the group opinion of the sample or participant category. For example, a mean which is close to 3 indicates that the group opinion was at the 'important' level. The rating scale on the questionnaire for each research question was (1) 'not at all important', (2) 'least important', (3) 'important', (4) 'very important' and 5 'extremely important' and should be used in interpretation of the tables. The means highlighted in bold font indicate the highest rating for each item by the total sample or each participant category.

Theme 1: Awareness of children's hospice care

Table 1. Theme 1 (total sample)

Research questions Thinking about children's hospice care how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q1.1	find out what the public and professionals understand about CHAS and the service it provides to children and families?	274	3.91	.94
Q1.2	explore the meanings the public and professionals associate with the term 'children's hospice'?	274	3.54	1.11
Q1.3	identify ways to promote awareness of CHAS and the wide range of services it offers to children and families?	274	**4.13**	.95

Table 2. Theme 1 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q1.1	92	3.91	.90	123	4.10	.91	55	3.47	.96
Q1.2	92	3.62	1.04	123	3.59	1.10	55	3.33	1.00
Q1.3	92	**4.12**	1.00	123	**4.29**	.91	55	**3.80**	1.01

The highest mean rating for this theme by the total sample was Q1.3 relating to identifying ways to promote awareness of CHAS. There was some minor variation in the ratings for each item between the participant categories. CHAS staff and volunteers rated Q1.1 at the 'very important' level while families and professionals rated it at the 'important' level. Families and CHAS staff rated Q1.3 at the 'very important' level while professionals rated it at the 'important' level. As reflected in the total sample table above, all participant categories gave the highest rating to Q1.3 within this theme.

Theme 2: Improving access to children's hospice care

Table 3. Theme 2 (total sample)

Research questions Thinking about improving access to hospice care how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q2.4	find out the number of children in Scotland with palliative care needs and the number of children who meet CHAS' current referral criteria?	274	**4.06**	1.11
Q2.5	find out the reasons why professionals refer or do not refer children and families to CHAS?	274	4.01	0.91
Q2.6	find out what professionals know and understand about CHAS' referral criteria?	274	3.99	1.01
Q2.7	explore the reasons why a family chooses to use or chooses not to use hospice services?	274	3.75	1.02
Q2.8	explore the reasons why children with cancer and their families are not being referred to or are choosing not to use CHAS?	274	3.79	1.10

Table 4. Theme 1 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q2.4	92	**4.10**	.93	123	**4.02**	.95	55	**4.04**	1.22
Q2.5	92	3.98	.84	123	4.02	.90	55	4.02	1.00
Q2.6	92	4.07	.91	123	3.98	.95	55	3.95	.93
Q2.7	92	3.68	1.02	123	3.73	1.03	55	3.84	1.00
Q2.8	92	3.76	1.13	123	3.72	1.11	55	3.96	1.00

The highest mean rating for this theme by the total sample was Q2.4 relating to identifying the number of children in Scotland with palliative care needs who meet the CHAS referral criteria. There was some minor variation in the ratings for each item between the participant categories but typically the mean for each question across the participant categories was within the same rating level with the exception of Q2.5. Families rated Q2.5 at the 'important' level whereas CHAS staff and professionals rated is at the 'very important' level, with a very small mean difference is only 0.04. As reflected in the total sample table above, all participant categories gave the highest rating to Q2.4 within this theme.

Theme 3: Supporting families who are new or potential users of the service

Table 5. Theme 3 (total sample)

Research questions Thinking about CHAS supporting families who are new to the service, or are potential users of the service, how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q3.9	explore the 'fixed ideas' families hold about using a children's hospice before they visit Rachel/Robin house, and how this compares to their future visits?	274	**3.62**	1.01
Q3.10	pilot a 'buddy system' where a new family is paired with an existing family?	274	2.77	1.06
Q3.11	explore the role of volunteers in increasing awareness amongst families who are potential users of CHAS?	274	3.02	.97

Table 6. Theme 3 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q3.9	92	**3.82**	1.02	123	**3.60**	1.00	55	**3.40**	.96
Q3.10	92	2.78	1.14	123	2.66	1.05	55	2.98	.93
Q3.11	92	3.18	.93	123	2.98	.99	55	2.91	.95

The highest mean rating for this theme by the total sample was Q3.9 relating to exploring the ideas families hold about using a children's hospice before they visit. There was some minor variation in the ratings for each item between the participant categories but typically the mean for each question across the participant categories was within the same rating level with the exception of Q3.11. Families rated Q3.11 at the 'important' level whereas CHAS staff and professionals rated is at the 'least important' level, with a mean difference of 0.27. As reflected in the total sample table above, all participant categories gave the highest rating to Q3.9 within this theme.

Theme 4: Community care (outreach) provided by CHAS

Table 7. Theme 4 (total sample)

Research questions Thinking about community care (outreach) provided by CHAS how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q4.12	find out what families across Scotland, including rural and remote areas, want with regard to home care services provided by CHAS (such as the home from home service)?	274	4.03	.89
Q4.13	identify how the '*home from home'* service CHAS provides differs or compares to the care currently provided by other community services?	274	3.66	1.07
Q4.14	work together with local services to review and develop outreach respite teams across Scotland which would allow more families to access CHAS services within their own homes and/or communities?	274	**4.06**	.92

Table 8. Theme 4 (Participant categories)

Research questions	Families			CHAS			Professionals		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Q4.12	92	**3.95**	0.99	123	3.99	.85	55	4.24	.79
Q4.13	92	3.61	1.11	123	3.58	.99	55	3.93	1.15
Q4.14	92	3.93	1.00	123	**4.06**	.78	55	**4.29**	1.03

The highest mean rating for this theme by the total sample was Q4.14 relating to CHAS working with local services to review and develop outreach respite teams across Scotland. There was some minor variation in the ratings for each item between the participant categories for two research questions. Professionals rated Q4.12 at the 'very important' level whereas families and CHAS staff rated it at the 'important' level, with a mean difference of 0.29. Unlike previous themes the participant categories gave the highest rating to different research questions in this theme with families rating Q4.12 highest, and CHAS staff and professionals rating Q4.14 highest.

Theme 5: Hospice and respite care needs of young people (age 16+)

Table 9. Theme 5 (total sample)

Research questions Thinking about hospice and respite care needs of young people (aged 16+) how important do you think it is for CHAS to:		N	Mean	SD
Q5.15	find out the needs of young people (16+) with life-limiting conditions from the viewpoint of young people themselves, their parents and professionals?	274	**4.34**	.95
Q5.16	find out the specific care needs of young people (16+) with limited cognitive abilities (learning, understanding, communicating)? e.g. how will their care needs change during the transition to adult services?	274	4.17	1.04
Q5.17	explore ways CHAS could work together with other services (health, social care, voluntary etc.) to meet young people's needs for the transition to adult services?	274	4.08	1.02
Q5.18	review the psychological support CHAS provides to young people (16+) who know they have a life-limiting condition and make recommendations for staff training and development?	274	4.25	.96

Table 10. Theme 5 (Participant categories)

Research questions	Families			CHAS			Professionals		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Q5.15	92	**4.38**	.82	123	**4.31**	1.03	55	**4.44**	.81
Q5.16	92	4.35	.88	123	4.11	1.02	55	4.09	1.14
Q5.17	92	4.14	.93	123	4.07	1.03	55	4.13	1.0
Q5.18	92	4.35	.83	123	4.24	.98	55	4.24	.96

The highest mean rating for this theme by the total sample was Q5.15 relating to find out the needs of young people (16+) with life-limiting conditions. There was little variation in the ratings for each item between the participant categories with all research questions being rated at the level of 'very important' by all categories. As reflected in the total sample table above, all participant categories gave the highest rating to Q5.15 within this theme.

Theme 6: Spiritual and emotional care

Table 11. Theme 6 (total sample)

Research questions Thinking about the spiritual and emotional care CHAS provides to children and families how <u>important</u> do you think it is for CHAS to:		N	Mean	SD
Q6.19	evaluate whether the spiritual/emotional care provided by CHAS staff is adequate, consistent and effective?	274	**3.65**	1.05
Q6.20	develop and test standards of care specific to children and families that chaplains can use as none currently exist?	274	3.27	1.13

Table 12. Theme 6 (Participant categories)

Research questions	Families			CHAS			Professionals		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Q6.19	92	**3.70**	1.01	123	**3.67**	.99	55	**3.56**	1.15
Q6.20	92	3.32	1.18	123	3.31	1.04	55	3.15	1.14

The highest mean rating for this theme by the total sample was Q6.19 relating to evaluating the spiritual care provided by CHAS staff. There was little variation in the ratings for each item between the participant categories with all research questions being rated at the level of 'important' by all categories. As reflected in the total sample table above, all participant categories gave the highest rating to Q6.19 within this theme.

Theme 7: Bereavement and end-of-life care

Table 13. Theme 7 (total sample)

Research questions Thinking about bereavement and end-of-life care and support CHAS provides to children and families how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q7.21	find out what families want from the CHAS service with regard to end-of-life and bereavement care?	274	4.23	1.03
Q7.22	explore how families make decisions when planning end-of-life care?	274	3.78	1.16
Q7.23	explore the reasons why families may choose to use CHAS for end-of-life care rather than use other services or remain at home?	274	3.72	1.14
Q7.24	explore the impact of cultural differences on the bereavement process of the family and their support needs?	274	3.74	1.11
Q7.25	explore how families feel about the experience of using the Rainbow Room (bereavement suite)?	274	3.73	1.10
Q7.26	test the possibility of offering services of the Rainbow Room to families after having a stillborn child?	274	3.16	1.26
Q7.27	explore the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues?	274	**4.24**	.99
Q7.28	identify ways to ensure the continued role of community professionals (e.g. social workers, community nurses) when a child and family come to the hospice at the end-of-life stage?	274	3.88	1.12

Table 14. Theme 7 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q7.21	92	4.35	.89	123	4.15	1.11	55	**4.31**	.94
Q7.22	92	3.96	1.11	123	3.61	1.16	55	3.95	1.11
Q7.23	92	3.84	1.04	123	3.60	1.18	55	3.89	1.08
Q7.24	92	3.82	1.04	123	3.62	1.14	55	3.96	1.04
Q7.25	92	3.82	1.13	123	3.69	1.07	55	3.76	1.05
Q7.26	92	3.37	1.23	123	3.06	1.27	55	3.07	1.25
Q7.27	92	**4.39**	.89	123	**4.21**	.96	55	4.09	1.04
Q7.28	92	4.07	1.09	123	3.74	1.09	55	3.98	1.08

The highest mean rating for this theme by the total sample was Q7.27 relating to exploring the needs of CHAS staff regarding bereavement and how to communicate with children and their families on end-of-life issues. There was variation in the ratings for one research questions between the participant categories. Families rated Q7.28 at the ‘very important’ level whereas CHAS staff and professionals rated it as the ‘important’ level, with a mean difference of 0.33. Unlike previous themes the participant categories gave the highest rating to different research questions in this theme with families and CHAS staff rating Q7.28 highest, and professionals rating Q7.21 highest.

Theme 8: Pain and symptom management

Table 15. Theme 8 (total sample)

Research questions Thinking about pain and symptom management in children and young people how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q8.29	identify the symptoms experienced by children with **very rare life-limiting conditions** to develop management and control strategies?	274	4.22	1.03
Q8.30	identify services, techniques and provisions available to relieve pain and other symptoms in children with life-limiting conditions and assess how effective they are?	274	**4.35**	.97

Table 16. Theme 8 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q8.29	92	4.37	.77	123	4.20	1.10	55	4.05	1.19
Q8.30	92	**4.49**	.70	123	**4.35**	1.05	55	**4.15**	1.16

The highest mean rating for this theme by the total sample was Q8.30 relating to identifying services and methods available to relieve pain and symptoms. There was little variation in the ratings for each item between the participant categories with all research questions being rated at the level of ‘very important’ by all categories. As reflected in the total sample table above, all participant categories gave the highest rating Q8.30 within this theme.

Theme 9: Education of children and siblings

Table 17. Theme 9 (total sample)

Research questions Thinking about children and young people's education how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q9.31	find out whether the educational needs of children and siblings using the CHAS service are being met, and if not how this can be improved?	274	3.28	1.15

Table 18. Theme 9 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q9.31	92	3.23	1.14	123	3.28	1.23	55	3.42	.98

There was only one research question for this theme. There was little variation in the ratings for this theme between the participant categories with all categories rating the research question at the 'important' level.

Theme 10: Supporting the wider family

Table 19. Theme 10 (total sample)

Research questions Thinking about CHAS supporting the wider family how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q10.32	Find out what the needs of siblings (brothers and sisters) are throughout each stage of a child's illness including bereavement support?	274	**4.05**	.91
Q10.33	explore the process for CHAS to make referrals to community services when they identify a support need of siblings?	274	3.73	1.01
Q10.34	Find out what the support needs of men (e.g. fathers, grandfathers, uncles) are during a child's illness and through bereavement?	274	3.91	1.03
Q10.35	Find out what the support needs of the extended family (e.g. grandparents) and close friends are, and explore how these needs are being met?	274	3.27	1.04
Q10.36	explore how CHAS staff can support and empower parents in their contact with other services e.g. help with accessing equipment?	274	3.73	1.09

Table 20. Theme 10 (Participant categories)

Research questions	Families			CHAS			Professionals		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Q10.32	92	**4.13**	.84	123	**4.00**	.96	55	**4.04**	.88
Q10.33	92	3.75	1.06	123	3.72	.98	55	3.75	.99
Q10.34	92	3.99	1.12	123	3.85	1.00	55	3.91	.95
Q10.35	92	3.30	1.09	123	3.25	.96	55	3.31	1.09
Q10.36	92	4.01	.98	123	3.64	1.15	55	3.55	1.07

The highest mean rating for this theme by the total sample was Q10.32 relating to identifying the needs of siblings. There was little variation in the ratings for each question between the participant categories with research questions being rated at the level of ‘important’ or ‘very important’ by all categories with one exception. Families rated Q10.36 as ‘very important’ while CHAS staff and professionals rated it at the ‘important’ level. As reflected in the total sample table above, all participant categories gave the highest rating to Q10.32 within this theme.

Theme 11: Diversity

Table 21. Theme 11 (total sample)

Research questions Thinking about the issue of diversity how important do you think it is for CHAS to:		N	Mean	SD
Q11.37	identify ways for CHAS to encourage/promote diversity amongst staff and volunteers (e.g. ethnicity, gender) including recruitment to the organisation?	274	3.22	1.10
Q11.38	explore how people from a range of cultures and ethnic groups perceive CHAS and identify their support needs?	274	**3.35**	1.05

Table 22. Theme 11 (Participant categories)

Research questions	Families			CHAS			Professionals		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Q11.37	92	3.27	1.08	123	3.20	1.07	55	3.20	1.19
Q11.38	92	**3.35**	1.03	123	**3.38**	.99	55	**3.36**	1.18

The highest mean rating for this theme by the total sample was Q11.38 relating to exploring how people from different cultures and ethnic groups perceive CHAS and identifying their support needs. There was little variation in the ratings for each question between the participant categories with all research questions being rated at the level of ‘important’ by all categories. As reflected in the total sample table above, all participant categories gave the highest rating to Q11.38 within this theme.

Theme 12: CHAS staff and volunteers

Table 23. Theme 12 (total sample)

Research questions Thinking about issues specifically related to CHAS staff and volunteers how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q12.39	investigate the impact of stress and the effectiveness of current coping strategies among CHAS staff and volunteers?	274	**3.94**	.94
Q12.40	evaluate whether current induction/orientation programmes meet staff needs and how it impacts on their sense of belonging within a growing organisation?	274	3.75	.98

Table 24. Theme 12 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q12.39	92	**3.98**	.85	123	**4.03**	.93	55	**3.71**	1.05
Q12.40	92	3.82	.86	123	3.82	1.02	55	3.47	1.05

The highest mean rating for this theme by the total sample was Q12.39 relating to investigating the impact of stress among CHAS staff and volunteers. There was a slight variation in the ratings for one research question with CHAS staff rating Q12.39 at the ‘very important’ level whereas families and professionals rated it at the ‘important’ level. As reflected in the total sample table above, all participant categories gave the highest rating to Q12.39 within this theme.

Theme 13: Service Development

Table 25. Theme 13 (total sample)

Research questions Thinking about CHAS and service development issues how <u>important</u> do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q13.41	identify ways to promote and encourage a greater emphasis on active planning of end-of-life care and palliative care for children amongst other service providers (e.g. children's hospital wards and community services)?	273	3.85	1.03
Q13.42	conduct a study to measure the quality of life and experiences of a child/young person and their family attending a children's hospice compared to one who doesn't have that opportunity?	274	3.51	1.12
Q13.43	evaluate the policies and procedures in place to address infection control issues within the hospice?	274	3.64	1.15
Q13.44	find out what day-to-day medical cover is required in a children's hospice?	274	3.66	1.09
Q13.45	explore ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital?	274	**4.10**	1.02
Q13.46	Find out how knowledgeable GPs and paediatricians are with children's palliative care issues?	274	3.99	1.07
Q13.47	identify ways to support families who want to express concerns about the CHAS service?	274	3.77	.99
Q13.48	identify ways CHAS staff can share their expertise in children's palliative care with professionals?	274	3.97	.92
Q13.49	explore the possibility of CHAS supporting professionals in the community/health service who are caring for children with palliative care needs in isolation and would benefit from peer support or clinical supervision?	274	3.89	1.03
Q13.50	identify the support needs of families of neonates (newborn babies) with palliative care needs and the possibility of CHAS providing this support?	274	3.80	1.06
Q13.51	evaluate how families value the hydrotherapy service and the benefits received by the child/young person?	274	3.18	1.10

Table 26. Theme 13 (Participant categories)

Research questions	Families			CHAS			Professionals		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Q13.41	92	4.00	.91	123	3.68	1.10	54	4.02	.98
Q13.42	92	3.61	1.10	123	3.49	1.16	55	3.42	1.07
Q13.43	92	3.89	1.02	123	3.59	1.22	55	3.36	1.16
Q13.44	92	3.78	1.02	123	3.69	1.12	55	3.44	1.12
Q13.45	92	**4.36**	.79	123	**3.98**	1.08	55	3.93	1.15
Q13.46	92	4.21	.91	123	3.91	1.12	55	3.89	1.15
Q13.47	92	3.68	.98	123	3.83	.96	55	3.76	1.07
Q13.48	92	4.12	.80	123	3.92	.99	55	3.89	.94
Q13.49	92	4.03	.88	123	3.71	1.11	55	**4.09**	.99
Q13.50	92	3.88	.96	123	3.85	1.04	55	3.58	1.18
Q13.51	92	3.42	1.10	123	3.15	1.12	55	2.89	1.01

The highest mean rating for this theme by the total sample was Q13.45 relating to exploring ways to provide additional medical cover so children whose condition is fragile or medically unstable can be cared for in the hospice instead of a hospital. There was some variation in the ratings for each question between the participant categories with six questions given different ratings. Families and professionals rated Q13.41 at the ‘very important’ level, CHAS staff at the ‘important’ level, with a mean difference of 0.34. Families rated Q13.45 at the ‘very important’ level, CHAS staff and professionals at the ‘important’ level, with a mean difference of 0.43. Families rated Q13.46 at the ‘very important’ level, CHAS staff and professionals at the ‘important’ level, with a mean difference of 0.32. Families rated question 13.48 at the ‘very important’ level, CHAS staff and professionals at the ‘important’ level, with a mean difference of 0.23. Families and professionals rated Q13.49 at the ‘very important’ level, CHAS staff at the ‘important’ level, with a mean difference of 0.38. Families and CHAS staff rated Q13.51 at the ‘important’ level, professionals rated at the ‘least important’ level, with a mean difference of 0.47. Unlike previous themes the participant categories gave the highest rating to different research questions in this theme with families and CHAS staff rating Q13.45 highest, and professionals rating Q13.49 highest.

Theme 14: Strategic Planning

Table 27. Theme 14 (total sample)

Research questions Thinking about CHAS and strategic planning issues how important do you think it is for CHAS to:		**N**	**Mean**	**SD**
Q14.52	review different models of children’s hospice care and the benefits of each in terms of quality of care and cost?	274	3.47	1.02
Q14.53	conduct an action research project aimed at the integration of CHAS within the wider children’s palliative care network exploring barriers to integration and how the regional area is proactive in terms of its children’s palliative care provision?	273	3.27	1.18
Q14.54	identify where the hospice movement in Scotland fits into services of palliative care for children with cancer?	274	**3.58**	1.04
Q14.55	explore the lessons learned from the implementation of the Gold Standards Framework (GSF) for adult palliative care in the community to initiate the development of a GSF for children’s palliative care services?	274	3.44	1.13
Q14.56	CHAS to establish a collaborative system for conducting research in the field of children's palliative care involving statutory and voluntary services, and academic institutions?	274	3.33	1.12

Table 28. Theme 14 (Participant categories)

Research questions	**Families**			**CHAS**			**Professionals**		
	N	**Mean**	**SD**	**N**	**Mean**	**SD**	**N**	**Mean**	**SD**
Q14.52	92	3.38	.89	123	3.47	1.13	55	3.56	.98
Q14.53	92	3.29	1.17	122	3.11	1.17	55	3.56	1.17
Q14.54	92	**3.53**	1.02	123	**3.56**	1.10	55	**3.71**	1.12
Q14.55	92	3.33	1.13	123	3.42	1.12	55	3.71	1.15
Q14.56	92	3.27	1.12	123	3.29	1.19	55	3.53	.92

The highest mean rating for this theme by the total sample was Q14.54 relating to identifying where the hospice movement in Scotland fits into services of palliative care for children with cancer. There was little variation in the ratings for each item between the participant categories with all research questions being rated at the level of ‘important’ by all categories. As reflected in the total sample table above, all participant categories gave the highest rating to Q14.54 within this theme.

Appendix H – Potential barriers and facilitators to research as suggested by professionals during the telephone interviews

Professionals were requested to share what in their opinions may be some of the key challenges or barriers and the key facilitators that CHAS should be aware of when developing their research programme. The ideas put forward by the professionals during their interview are listed, in no particular order, below. It is important to be clear that the barriers should not be thought of as insurmountable issues and all are challenges that can be managed.

Barriers

- Financial issue of securing funding and resources to carry out research. Potential concerns about moving money away from direct care to research would need to be addressed.
- There is the potential for conflict with other services and/or organisations who are undertaking similar research in terms of duplication of work. There is therefore a need to develop an awareness of the research currently being conducted locally and nationally within the hospice movement and wider arena of children's palliative care. This could be done through conducting a scoping exercise.
- CHAS will need to establish a culture of research and in doing this will present the challenge of facilitating change within an organisation and encouraging staff and volunteers to recognise the value and importance of independent research and evidence-based practice.
- Ethical issues such as obtaining consent and ethical approval when working with vulnerable populations such as children with life-limiting conditions and their families will need to be addressed. When conducting qualitative research it will be vital to ensure a sensitive, safe and ethical approach is taken regarding children's and families' attitudes and perceptions of their condition.
- It may be necessary to link with other hospice organisations nationally to have access to a larger pool of potential participants and thus produce results with sufficient statistical power to yield meaningful results.
- When conducting research in the area of symptom control it will be important for CHAS to liaise closely with paediatric consultants in the NHS as they are often primarily responsible for controlling the child's medication.

- It may prove more difficult to locate and include children with a life-limiting condition who are not currently using the hospice, so assessing unmet need or those accessing other services could be challenging.
- There may be interface issues, ownership of data issues and confidentiality issues due to the shared responsibility of care for the children and their families between the hospice, NHS and social care organisations. This could pose challenges in how CHAS handles the information or data flow between the services and in maintaining patient confidentiality.

Facilitators

- Being research active offers CHAS the opportunity to work in a collaborative partnership with other services responsible for the care of the children with life-limiting conditions and their families.
- CHAS are experts in a very specialised field and they are in an ideal position to contribute to the development of an evidence-base in children's hospice and palliative care.
- CHAS' Clinical Governance Committee recognises the importance of developing a future programme of research.
- CHAS' very strong fundraising profile may be a facilitator in terms of securing the funding required to undertake research.
- CHAS offer excellent study days and open the invitation to attend to professionals in the community and acute care settings. This affords the opportunity for professionals to network with others who are research-active in the field.
- Involving health and social care professionals in research through inclusion in project steering groups will facilitate and encourage research developing an organisational research culture.
- Undertaking research will give CHAS the opportunity to develop links and partnerships with academic institutions and centres of clinical excellence.
- CHAS have a strong reputation and are held in high regard by the families who use the service thus they are potentially a supportive and enthusiastic participant population.
- Professionals in the community who have responsibility for the care of children with life-limiting conditions hold CHAS in a high regard and recognise the potential benefits of increasing the evidence-base of hospice care. They are

therefore likely to encourage and support families in participating in research conducted by CHAS.

- Policy drivers and national recognition of the need to continue to improve the evidence-base for children's palliative and hospice care for children will support valid and important research in this field

Appendix I: Current UK Centres and teams active in children's palliative care research

This list was shared with the project research team by ACH representative following participation in the telephone interview.

The table below outlines key groups and UK Centres active in children's palliative care research. The aim is not to list anyone who has published a paper in this area but to identify key groups and key members of those groups together with any specific interests. Hopefully this list will help in identifying suitable collaborative projects and research partnerships.

Centre	***Research active professionals ****	***Key research interests***
University of Wales at Cardiff Ty Hafan Hospice	Dr. Richard Hain (Senior Lecturer) Ruth Davies J Fenton-May J Dulson	Opioid pharmacology Pain assessment Palliative care education Palliative chemotherapy Transition to adult services Analgesic prescribing
Leeds Jimmy's and Martin House	Dr. Mike Miller Martin House K Murphy V Thom S Gardiner	Palliative care in Battens disease Palliative gastrostomy Epidemiology
Birmingham/West Midlands	Dr. Lisa Cuddeford MA Leung Acorns Children Hospice	Models of home nursing
Nottingham/East Midlands Rainbows Hospice	Dr. William Whitehouse Sat Jasaal Zoe Wilkes A Wolff	DNAR orders and personal resuscitation plans Children's palliative care networks Audit methodology Epilepsy Neurology
Great Ormond Street Hospital	(Dr. A Goldman) Dr. Finella Craig Dr. Gillian Watterson	Palliative care in PICU, cardiology and cystic fibrosis Topical analgesia
University of West Lancashire	Dr. Ann Hunt (Lecturer) Bernie Carter	Pain including assessment in neurodisability
UKCCSG palliative care working group	Dr. Richard Hain I Hewitt A Goldman J Imeson M Childs	Palliative steroids in CNS tumours Symptoms in cancer palliative care Use of opioids in cancer palliative care Place of end-of-life care for cancer patients Palliative chemotherapy Nausea and vomiting
ACT and ACH Research Group		Mapping children's palliative care services Palliative care minimum dataset
Bath	A Baverstock	Debrief

	F Finlay Dr. Simon Lenton Dr. Mary Lewis	Models of care including home nursing Epidemiology End-of-life plans Pain in neurodisability
Oxford/Helen House	Justin Amery Suzie Lapwood Sister Francis Dominica	Palliative care education and training
Sheffield	Prof Chris Eiser	Quality of life in chronic disease including paediatric malignancy
Liverpool Alder Hey	Lynda Brook	Pathway for the dying child
Claire House	Jan Vickers (A Hodgson)	Home platelet transfusion Rapid discharge for end-of-life care Palliative care drug boxes
Marsden London		Strong opioids at the end of life Palliation of CNS tumours
Warwickshire	A Thompson	Palliative care literature Models of care/networks

*Professionals who have published at least twice in the last 5 years on paediatric palliative care related fields.