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Year 1 evaluation report
The first year evaluation report can be found at: http://www2.warwick.ac.uk/fac/med/newsfront/

A summary of the report can also be found at: http://www.biglotteryfund.org.uk/assets/Palliative_care.pdf

Year 2 evaluation report
The second year evaluation report can be found at: http://www.biglotteryfund.org.uk/assets/palliative_care_2ndreport.pdf

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Executive Summary

This report presents interim findings from the third year of the four and a half year evaluation of the Big Lottery Fund Palliative Care initiative.

The third year of the evaluation has confirmed the diversification of palliative care services that Lottery funding has helped to stimulate. Schemes are showing clear signs of making a difference to the quality of life of those who are taking up their services. In addition to new services, we have identified new ways of delivering existing services, the extension of existing services to new client groups and new partnerships developed to deliver services. In addition to responding to rapidly evolving national policy contexts, we have also found increased emphasis on tailoring services to local conditions, and meeting hitherto unmet and under-served categories of need.

Schemes providing hospice at home services have developed entirely new services that have mostly been designed to complement existing services. Children's palliative care services are very different to adult services, where care is provided mainly for the last few hours, days or weeks of life. Children's palliative care services work with children and their families, providing much needed support, respite and care. They also provide opportunities for children and young people to have enriching experiences, which their conditions would otherwise restrict them from participating in. Different approaches are being taken to address the issue of transition from children's to adult services. Some staff have expressed frustration at the lack of services to transfer young people to, but a considerable effort is being put into working with young people to empower them to make choices about their treatment and care. In a minority of cases, transition may be possible between an adjoining children's and adult hospice, but adult hospice staff may be ill equipped to deal with the needs of young people.

Services are being provided in new ways. A number of schemes, particularly children's schemes are examining how volunteers and 'befrienders' can be more involved in the provision of services to families. Flexibility is key to the delivery of palliative care services. By definition, the client group does not remain constant. Cancer patients continue to form the largest client group in adult hospices, however, with advancing treatments and technologies, even cancer patients are living longer and adult hospices are examining their services to provide more respite for patients and caregivers.

Some schemes in Scotland and Northern Ireland are focussed specifically on client groups with conditions other than cancer. In England, schemes have been encouraged to increase the numbers of patients with conditions other than cancer. Efforts are being made to raise awareness amongst health and social care professionals, but different illness trajectories make it harder to define end of life care needs. Proactive initiatives are underway to raise awareness of palliative care and associated services amongst health and social care professionals.
Extending culturally sensitive and appropriate palliative care services to people from BME communities, in common with extending services to people with conditions other than cancer, is taking time to develop and the number of referrals to adult services remain very small. Many of the schemes have developed services that either: enable the family to stay at home together, or provide services, in or outside of the home, to enable both the caregivers and the patients to ‘have a break.’ A considerable amount of work is being undertaken by most children’s schemes, with siblings of children who have palliative care needs, and in some cases, the siblings or children or even grandchildren of adult patients.

Many of the BIG schemes have enhanced existing or developed new partnership arrangements in order to deliver a ‘holistic’ service, tailored to local needs. Within the children’s case study schemes, there is evidence of hospice and hospice at home staff working alongside both mainstream and special schools to raise awareness of the issues around life-limiting conditions, and to provide support for those who will experience the death of a child. There is evidence to suggest that children’s schemes, whether they are providing hospice or hospice at home services, have been working together to ensure the best possible and most appropriate services for the referred children that they are working with. Although there are differences between children’s, young people and adult palliative care needs, some similarities have been highlighted where children’s and adults’ hospices are working together. Bringing together nurses from both children’s and adult nursing teams can be beneficial. The initiative has led to the development of a number of cross-sector partnership arrangements. Many of these partnerships are working effectively to achieve their objectives.

Staffing these new services has posed challenges, although many of the tensions that we identified previously, between groups of nurses, have now been overcome. Staff who are providing services demonstrate a high level of commitment and sincerity. Palliative care services appear to be responding to revised thinking on disease trajectories with a multi-agency approach to care pathways.

The evaluation research design is phased, multi-method, multi-level and flexible. A range of data collection methods is being utilised (such as: interviews; focus groups; observation of service delivery within schemes and at steering group meetings; documentary analysis; analysis of routine data and a survey of all grant schemes, which is being carried out on a rolling basis as funding comes to an end). A sample of case study schemes is being investigated at different levels of detail over their grant lifetime.

The evaluation is proceeding according to the schedule agreed with the Fund. All six level 1 case study sites have been visited twice and final visits are underway. All (12) level 2 sites have been visited and follow up telephone interviews are being conducted towards the end of the grant life.

To date, a total of 174 people have been interviewed, either individually or in focus groups. This includes national stakeholders, service providers and
those who have benefited from services. Observation of service delivery in a variety of settings, including the homes of service users and carers has generated further valuable insights and additional data.

Intensive networking within and between umbrella organisations such as: the local Strategic Health Authority (SHA); Association of Children’s Hospices (ACH); Association for Children with Life-threatening or Terminal Conditions and Their Families (ACT) and to a lesser extent, the National Forum for Hospice at Home, has enabled the research team to extend the effective range of the evaluation. This has been further extended by systematic literature reviews of key areas of palliative care, funded by the University of Warwick Research Development Fund. These areas are: children's and young people’s palliative care; effective interagency and inter-professional working in palliative care and the role of informal carers in palliative care. This work is ongoing and will generate peer-reviewed journal articles.

Issues and concerns about sustainability and continuation funding have been raised by a majority of case study schemes as their grants reach their conclusion.

The evaluation has been extended by a further six months to take account of the delays in set-up that some schemes experienced at the outset. The final report is now due in September 2007.
Section 1

1 Big Lottery Fund palliative care initiative

Big Lottery Fund (previously known as the New Opportunities Fund), as part of its Palliative Care initiative, has allocated £84 million to a range of schemes focusing upon the provision of palliative care for adults, children and individuals with cancer and other life threatening conditions. This funding is intended to facilitate the support and development of local hospices, increase the number of community teams and bereavement support services, improve response to patient preference and enhance the provision of support and information services. The programme in Wales has been excluded from this evaluation as the funding has been mainly directed towards investment in capital equipment. The focus for the schemes in relation to the other three countries, together with their allocated budgets are outlined below. (Table 1) An overview of all grant schemes included within the evaluation is provided as Appendix 1.

Table 1 Allocated Budget and Programme Focus by Country

<table>
<thead>
<tr>
<th>Country</th>
<th>Programme Focus</th>
<th>Allocated Budget</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Ireland</td>
<td>Children and Adults</td>
<td>£4,100,000</td>
</tr>
<tr>
<td>Scotland</td>
<td>Children and Adults</td>
<td>£5,400,000</td>
</tr>
<tr>
<td>England</td>
<td>Adults</td>
<td>£22,470,000</td>
</tr>
<tr>
<td>England</td>
<td>Children</td>
<td>£48,000,000</td>
</tr>
</tbody>
</table>

Source: [www.nof.org.uk](http://www.nof.org.uk)

1.1 Palliative care programmes in Scotland & Northern Ireland

BIG has funded schemes providing palliative care, support and information services for children and adults with cancer and other life threatening conditions. In Scotland, local NHS Boards are coordinating grant schemes within their areas. Four national schemes have been funded, which mainly focus on non-cancer palliative care needs of the population. Health and Social Services Boards are working with cross-sectoral organisations in Northern Ireland to develop grant schemes that address local needs. Both of these programmes are managed within their own countries.

Northern Ireland has recently undergone a review of public administration (Review of Public Administration, Northern Ireland, 2006) that is “the most fundamental change to the health and social service system for decades.” The review will lead to the demise of the existing four Health and Social Services Boards in favour of one health and social services authority, charged with promoting the health and well-being of the community, implementing the government’s policies for health and social services and managing the overall performance of the system. How this radical reconfiguration will impact on the
grant schemes in Northern Ireland will be investigated over the remainder of the evaluation.

1.2 Palliative care programme for adults in England

The aim of this programme is to improve the quality of life of adults with a life limiting or a life threatening condition. It has been targeted at areas of the country identified as having the highest palliative care need. Awards have been made to 56 multi-professional teams to enable them to care for people in their homes. These teams offer therapeutic, nursing and emotional support and a number will also make use of complementary therapies. Many of these will also be extending the availability of care for longer periods of the day.

1.3 Palliative care programmes for children in England

The aim of this programme is to improve the quality of life for children with life threatening or life limiting conditions and their families. Seventy-one awards have been made to home-based care teams to enable them to provide a range of services to allow children to be cared for at home. Thirty-nine bereavement teams are helping families who have experienced or will go through the death of a child. Twenty-five children’s hospices have benefited from a grant that will enable them to sustain or develop their provision.

BIG have commissioned an additional piece of work to provide a more complete picture of the children’s programme. This entails a review of all (135) schemes’ monitoring data and a second visit to the Level 2 grant schemes that would only have been visited once and followed up by telephone in the original evaluation schedule. The results of this work will contribute to the final report.

There has been considerable activity in the field of children's palliative care, with regional 'kick-off' workshops taking place across the country in order to re-inforce the importance of strategic planning through locally managed networks.

1.4. Evaluation scope

The main aims of the evaluation comprise an assessment of the:

<table>
<thead>
<tr>
<th>Success of the initiative in extending and increasing the provision of services, and in increasing the amount and quality of provision in areas (notably rural areas) where such provision has generally been weak.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Success of the initiative in widening access to services, including its success in reaching new target groups.</td>
</tr>
<tr>
<td>Impact on quality of life for those using services (including people with life-threatening illnesses, their families and carers).</td>
</tr>
</tbody>
</table>
Sustainability of projects and of gains made.

Extent to which the initiative has supported the Fund's mission and values, and in particular its' aims of social inclusion and partnership working.

The Fund is also interested in finding out:

- How far staff skills have been shared and developed, both for new staff and staff groups in existing services and in the context of extending provision to conditions other than cancer.
- How far services for children have been successfully co-ordinated.
- How holistic the range of services provided is perceived to be by beneficiaries, families and carers.
- How far funded projects have given beneficiaries, families and carers more choice and control.

Additional notes

- Much of the evaluation is being undertaken by working closely with a sample of (18) funded projects, but there will also be analysis across all projects to gain an overview of the initiative and to assess issues of coverage, access and availability of services. BIG and the evaluators ensured that sampling took due account both of differences between countries and of the relative weighting of the children's and adults' programmes in England.
- The evaluation commenced in April 2003. It will last for four years.
- The evaluators will produce annual reports, from which the Fund will publish evaluation summaries. A final report is due in September 2007.

1.4.1 The evaluation team

A partnership, comprising Warwick Medical School, The University of Warwick; the Department of Health Management and Food Policy, City University and a selection of appropriate colleagues from a range of additional locations, including Queen Mary, University of London, has been appointed to evaluate this programme. Contributors to this third annual report are listed on page ii.

1.5 Methods

The evaluation research design is phased, multi-method, multi-level and flexible. A range of data collection methods is being utilised (such as: interviews; focus groups; observation of service delivery within schemes; at steering group meetings and in people’s homes; documentary analysis,
analysis of routine data and a survey of all grant schemes, which will be carried out towards the end of each programme).

1.5.1 Case studies

In the second phase of this project we are carrying out more detailed evaluation of a sample of sites by means of case studies. A carefully selected purposive sample of 18 case study schemes are being investigated at different levels of detail over their grant lifetime. (NB. 6 schemes represent combined services, there are therefore 15 ‘projects’ in total under investigation, 5 at Level 1 and 10 at Level 2.)

We have proposed two levels of case study:

**Level 1** consists of in-depth, longitudinal case studies of sites over the entire duration of the evaluation. An initial visit of up to one week is being followed up by means of annual follow-ups consisting of site visits of up to three days duration and / or telephone interviews. The purpose of these case studies is to investigate in depth the origins and subsequent development of schemes, including their evolving role in the local economy of health and the dynamics of their relationships with other local stakeholder organisations. They are also being used to generate hypotheses / tentative conclusions for further investigation. Six Level 1 case study sites have each been visited twice, with final visits currently being scheduled, as part of the annual follow up.

**Level 2** consists of in-depth but briefer case studies. These consist of a single visit of up to three days, with annual telephone interview follow up. The emphasis is on understanding the operation and development of the project itself, (i.e. the ‘internal context’, (Pettigrew, 1992)) but a limited number of external key informants have also been interviewed. The purpose of Level 2 case studies is to cross-check the generalisability of findings from Level 1 cases studies and to expand the breadth of case study coverage. All twelve level 2 case study sites have been visited, with follow up telephone and email contact maintained.

A table setting out details of the selected case study sites is attached as Appendix 2.

Detailed analysis of case study data is supported by ongoing interviews with key national stakeholders; ongoing review of policy directions; analysis of documentation and review of routine monitoring data supplied by the Fund and by the case studies themselves.

A list of national stakeholders interviewed to date is attached as Appendix 3.
1.5.1.1 Methodological reflections on case study site visits

Gaining the agreement of schemes to participate in the evaluation required considerable sensitive negotiation. Services that had been in existence for many years (e.g. children’s hospices) needed to understand the difference between the standard monitoring process required by the funding body, the statutory inspection process, and the national evaluation.

Visits to all case study schemes required careful planning and negotiation, in order to access key stakeholders and beneficiaries. Second and subsequent visits have allowed greater possibilities of meeting with adult patients and sick children and their families. In the main, access has been arranged via a project worker and the evaluation team is extremely grateful for their help and support in setting up the various interviews and focus groups, and frequently accompanying the researcher to people’s homes (sometimes in remote locations).

Working within an environment where people (including children) are dying, can be difficult, stressful and emotionally draining. It has been an essential part of the planning of this evaluation, that the field researcher has adequate time for preparation and reflection on site visits. Debriefing with team members takes place after every site visit. There is also the provision of regular access to an independent professional supervisor, who, as a qualified psychotherapist is trained to listen to the concerns of the researcher and assist in minimising any emotional disturbances. Regular team meetings ensure mutual support and opportunities to feedback and update on the evaluation progress.

All interviews have been recorded, transcribed, checked and coded within a computer package (NUD*IST), which is designed for the management, storage and analysis of qualitative data. Observation of service delivery, particularly within hospices (both children’s and adult's) and within people’s own homes has provided a unique insight into service delivery and has been a genuine privilege. The commitment and sincerity of all the staff involved in these schemes has been evident throughout.

In some cases, it has been possible to meet with service users, including children and their carers, in order to discuss their views on the appropriateness of and satisfaction with new services. The evaluation team is extremely grateful to the project co-ordinators who have arranged for these interviews to take place, including one that required a translator.

Case by case site visit notes are prepared following an initial content analysis of interviews and a review of all routine data collected during the course of site visits. These notes are used to develop emerging themes and are circulated to the principal investigators (YC and RPP) for comment and validation, before being sent back to the schemes for further validation. This process ensures reliability and provides the basis of follow up site visits and
telephone interviews. Further in depth analysis of interview data across the initiative, as opposed to case by case, is carried out for the interim and final reporting process.

1.5.2 Networking

Access to and information about a number of grant schemes outside the case study sample has been possible due to extensive networking, which has taken place across this initiative. The evaluation team had previously recommended the value of networking across Living with Cancer schemes. Many of the BIG children’s schemes are linked to the umbrella organisations: Association of Children’s Hospices (ACH) and Association for Children with Life-threatening or Terminal Conditions and their Families (ACT). Events and conferences have been organized by these organisations and a course specifically for the BIG funded children’s schemes has been designed and run by the University of the West of England.

There are also regional network meetings specifically for the lottery-funded children’s schemes, facilitated by SHAs. The lead researcher (JW) has also had access to quarterly meetings at the Trent Regional SHA. Participants at these events have confirmed their value as a support mechanism, in terms of regularly meeting with their peers; exchanging information and discussing issues; successes and challenges and how they may have been overcome.

More recently, regional workshops, ‘kick-off’ meetings, instigated by the then Care Minister, Liam Byrne, to emphasise the importance of strategic regional and local planning through managed local networks.

The lead researcher has attended local and national conferences and other appropriate events. Information from these has enhanced the evaluation, provided contact with schemes outside the case study sample and opportunities to validate emerging findings.

A number of grant schemes have identified and linked into additional networks such as the National Forum for Hospice at Home and single condition organisations appear to have made contact across country boundaries e.g. the Huntington’s Disease Association and lottery funded scheme in Northern Ireland have developed strong links with the Scottish Huntington’s Disease Association. These links provide a valuable mechanism for support.

1.5.3. End of grant life survey to all schemes

A survey has been developed, adapted from a questionnaire that was used in the Living with Cancer evaluation and will be sent to all palliative care schemes as they approach the end of their grant life.

The survey analysis will be provided within the final report and will offer a more complete picture of the evaluation overall, providing information on:
1.5.4 Systematic literature reviews

As a complementary exercise to the evaluation, the University of Warwick Research Development Fund awarded a small grant to support the preparation of a number of systematic literature reviews on themes related to the BIG Lottery Fund palliative care initiative objectives. An article reviewing the literature on the knowledge and information needs of informal carers working in end of life settings has recently been submitted to an academic journal; two systematic reviews of literature relating to children’s palliative care: the roles and needs of informal carers and the provision of bereavement services, are in preparation; and a further review of the literature on interagency and multidisciplinary working in palliative care is planned. These studies help to inform our evaluation and will enable us to understand the wider significance of its outcomes.

1.5.5 Geographical analysis

Initial results produced for all the BIG Lottery Fund Palliative Care schemes showed how the highest concentration of adult grant schemes and a large proportion of children’s grant schemes were in areas where deprivation and deaths from cancer were highest.

For the next part of the analysis, a geographical analysis has been designed to explore the socio-economic conditions in the areas covered by the case study sample schemes. This will be achieved by carrying out an ecological study using data aggregated to electoral wards and employing geo-demographic profiling techniques supported by Geographic Information Systems (GIS).

Country-wide maps have been designed to show the location of the case study schemes, using major roads and urban areas. Maps are also produced to show how the schemes relate to the socio-economic deprivation, standardised mortality rates for all deaths and cancer deaths, and ethnic breakdown for the country as a whole. Each of the schemes are then explored individually, to show a more detailed breakdown of the local area. This includes population density, deprivation, standardised mortality rates for both cancer and all deaths, deaths per 1000 population, and the ethnic breakdown of each area. In each case the data will be shown aggregated to electoral wards, and the data compared to the country as a whole and the UK.
2 Recent policy developments

Earlier evaluation reports (see www.biglotteryfund.org.uk) have provided an overview of policy developments leading up to the announcement of the initiative and during the set up period. Here we update this work by incorporating a number of recent significant policy developments that are likely to have an impact on palliative care services for both adults and children.

End of life care

The NHS Confederation published a briefing paper in November 2005, (NHS Confederation, 2005) suggesting improvements for end of life care. These included a re-think of services in light of increasing demands from an ageing population, where, by 2020, the over 50s will comprise half the population. The paper suggested that palliative care services must be fit for purpose, and while most people would like to die at home, due to lack of service availability, terminally ill patients may need to be admitted to hospices in greater numbers than is currently possible. The report suggests therefore, that hospice services may need to be expanded. In order to accommodate an increasing demand, the report also states that the capacity of home and community care needs to be increased, with additional support for carers, who should be made to feel part of the care team.

A more recent report published by the NHS Confederation in May 2006 (NHS Confederation, 2006) sets out the rationale for reducing the number of hospital beds in favour of promoting more community care and opportunities for end of life care at home.

A recent progress report on the Government’s End of Life Care initiative (DH, March 2006) highlighted the need for local champions to take forward service improvement for end of life care. The report also stated that although there is evidence to suggest improvements are happening, there is still a long way to go, with many health and social care staff feeling that they have still not had the appropriate training to help care for people at the end of their lives. The Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham has been commissioned to carry out an evaluation of the whole of the End of Life Care programme, in terms of its intended and achieved outcomes relating to quality of end of life care, and to make recommendations for its further development.

The progress report re-inforced the Government manifesto pledge to double investment in palliative care services, with the intention of giving “more people the choice to be treated at home when they are dying.” The report also acknowledges, however, “that in providing more choice for people to be treated at home, it is vital that the wishes and needs of the families who are caring for the dying relative are also taken into account.” (DH, 2006)
To achieve these aims, end of life care networks are to be set up (by 2008) to improve service coordination and identify all patients in need. The networks are designed to form a collaboration between primary care services, social services, hospices and the voluntary sector as well as the acute sector. The networks are to build on pilots that are being undertaken by Marie Curie through their Delivering Choice Programme of flagship projects (www.deliveringchoiceprogramme.org.uk)

As part of an updated strategy for carers, local authorities and primary care trusts are to nominate a lead person for carers’ services to promote the health and well-being of carers. A dedicated help-line service will also be established to offer information to cover a wide range of carers needs, including benefits and training.

Cancer policy developments

The House of Commons Public Accounts Committee published a progress report on the NHS Cancer Plan in January 2006. (House of Commons Committee of Public Accounts, 2006). The report acknowledged encouraging progress against targets and commitments as set out in the Cancer Plan, five years after its publication. (DH, 2000) The report also commended cancer networks on the introduction of new approaches to the delivery of cancer services involving partnership working between strategic health authorities, acute and primary care trusts, the voluntary sector and local authorities.

This progress report highlighted the role of cancer networks in developing plans and determining where the need is greatest at local level for the distribution of the additional £50million previously allocated by Government specifically for palliative care services in England. The report also draws attention to a palliative care partnership group, chaired by the National Clinical Director, Professor Mike Richards and involving both statutory and non-statutory providers.

However, the report stated that 30% of the cancer networks still did not have comprehensive plans for providing cancer services in their locality. Performance monitoring against the Cancer Plan targets was inconsistent across the networks and relationships with primary care trusts were at best “adequate” in a third of cancer networks. The report also highlighted cancer mortality as remaining highest in areas of greatest deprivation.

National Health Service developments

A Government White Paper also published in January 2006, Our Health, Our Care, Our Say, (Secretary of State for Health, 2006) sets out plans for the delivery of health services closer to the patient. This paper, which is based on a lengthy public consultation, reinforces recent published literature on preferred place of death (Higginson, 2003) where more than 50% of people said that they would like to be cared for and die at home.
The White Paper states that a Quality and Outcomes Framework (QOF) will be used to drive health improvement, with palliative care becoming a target QOF area in 2006-7. The paper reinforces the additional investment required to improve end of life care and pledges to increase choices for patients by doubling investment in palliative care.

The White Paper also states that multi-disciplinary networks and teams at PCT and local authority level (recognising the health and social care overlap in palliative care services) should use a common assessment framework and work closely with existing palliative care teams.

The White Paper also advocates the roll out of key initiatives and tools to improve end of life care across England.

### The Liverpool Care Pathway

The Liverpool Care Pathway (Ellershaw, 2003) was developed to: “take the best of hospice care into hospitals and other settings. It is used to care for patients in the last days or hours of life once it is known that they are dying. The LCP involves prompting good communication with the patient and family, anticipatory planning including psychosocial and spiritual needs, symptom control (pain, agitation and respiratory tract secretions) and care after death. The LCP has accompanying symptom control guidelines and information leaflets for relatives.” (DH, 2006)

www.lcp-mariecurie.org

### The Gold Standards Framework

The Gold Standards Framework (Thomas, 2003) provides guidance for primary health care professionals in order for them: “to provide the best possible care when people are likely to be in the last six to nine months of life. It was started to help GPs plan care for these patients and to make sure that information about their likely needs was shared with others involved in their care. This helps with managing symptoms and by giving the patient and their family confidence in their care, especially by planning ahead for what might happen”. (DH, 2006)

www.goldstandardsframework.nhs.uk

### The Preferred Place of Care tool (PPC)

The Preferred Place of Care tool (PPC) is an example of an advance care plan (ACP) and is “a document that the patients hold for themselves and take with them if they receive care in different places. It has space for the patients’ thoughts about their care and the choices they would like to make, including saying where they would want to be when they die. Information about the family can also be recorded so that any new care staff can read about who’s who and what matters to them. If anything changes, this can be written in the plan so it stays up to date”. (DH, 2006)

www.cancerlancashire.org.uk/ppc

Carers are identified within the White Paper as providing a valuable and often unrecognised service, and as such, a New Deal for Carers is to be initiated.

Commissioners are already beginning to consider the introduction of payment by results (PBR) for specialist palliative care services, which will be effective
from April 2008. Health resource groups, made up of experts are working on how efficiency, effectiveness and value for money might be measured in palliative care.

Scotland policy developments

There have been no significant policy developments likely to impact on this initiative during this reporting period.

Northern Ireland policy developments

As reported previously, the King’s Fund was commissioned to undertake a review in order to advise on the optimal use of financial resources to deliver and sustain whole system health and social care services for the people of Northern Ireland over the next ten years. Professor Appleby’s final report was published in August 2005, (Appleby, 2005) and the key findings are detailed in the box below.

In common with the rest of the UK, significant additional resources have been devoted to the provision of health & social care in Northern Ireland in recent years. However, the short-term and uncertain basis on which funds have often been allocated has hampered the strategic planning of services. Around three-fifths of the additional funding has been absorbed by increases in staff costs, reflecting the labour intensive nature of the sector, although most of this has been in higher wages and salaries rather than more frontline staff. Whilst it is estimated that around a quarter of the additional funds have been spent on service delivery improvements, looking forward, cost pressures (such funding required to implement Agenda for Change and the new GP and consultants’ contracts) mean that a much smaller share of future funds will be available for service improvements.

Use of resources

Overall, health status in Northern Ireland as measured by the EQ-5D survey was found to be slightly worse than in the rest of the UK - linked to poorer diets, heavy smoking, lack of exercise and other lifestyle and environmental causes. As a result, hospital activity tends to be higher than in England. However, there appeared to be a number of areas where health care utilisation was substantially higher than health status would suggest, such as accident and emergency attendances, which are almost a third higher than in England.

Performance management

The impression I have gained over the course of this Review is of a system lacking urgency, of general drift, and a consequent frustration
A series of recommendations were made as a result of this review.

Although the Northern Ireland Assembly remains in suspension, a review of public administration has been undertaken and its final decisions, (taking account of the findings of the Appleby review) were published in March 2006. (Review of Public Administration, 2006) The box below highlights the key transformation to health and social services in Northern Ireland.

The reorganisation of the Health and Social Services (HSS) management structures is the most fundamental change to the health and social services system for decades. It is intended to support the Government’s commitment to improving the health and well-being of the community and to promote better services to patients and clients. When completed, this reform agenda will have transformed the health and social services in Northern Ireland into a system which is genuinely patient-centred, well governed and continually improving. The number of HSS bodies will be significantly reduced and the new management structures will be more compact and streamlined. While exact savings cannot be calculated until the final shape and staffing of the new structures is finally determined, they will be released and made available. (RPA, 2006)

Implementation of the revised structures and systems is due to be completed by Spring 2009.

Children and young people policy developments

A considerable number of policy documents and strategies have been published recently, many following up on the earlier publication of Every Child Matters, Change for Children (DfES / DH, 2004).

By 2025, the strategy for improving life chances for disabled people (Prime Minister’s Strategy Unit, 2005) aims to improve the support for independent living; improve support for families: “so that services are centred on children and their families and not on processes and funding streams” and ensure effective transition, removing “cliff edges” in service provision.

In line with the children’s National Service Framework (NSF) a series of guidance documents have been published. These include: A Guide to Promote a Shared Understanding of the Benefits of Local Managed Networks (DfES/DH, 2005) and Commissioning Children’s and Young People’s Palliative Care Services. (DfES/DH 2005a) These documents have been widely disseminated and used as the basis for driving forward local managed networks through the regional events held across the country in Spring 2006.
In his 2006 Budget, the Chancellor of the Exchequer announced the launch of a policy review of children and young people, to secure further improvements in outcomes. Under the umbrella of this review, sub-reviews will focus on support for families with disabled children (and others). (HM Treasury, 2006) A comprehensive spending review, taking in children and young people’s services, is also expected to report in 2007.

The directions set out in the recent Government White Paper (Our Health, Our Care, Our Say, DH, 2006) are likely to have implications for children’s palliative care services, with its all encompassing recognition that “additional investment is needed to improve end of life care.” The move towards joint commissioning of services and individual budgets will also impact on children’s services. The White Paper also includes a pledge for action for continuing care issues for children. (ACH bulletin 77, 2006)

The needs of children were addressed within the White Paper, with reference to the Children’s National Service Framework:

“Standard 8 of the children’s NSF requires high quality palliative care to be available to all children and young people who need it. It is to be co-ordinated by a network of agencies…to ensure provision takes account of the child or young person’s and their family’s physical, emotional, cultural and practical needs in a way that promotes choice, independence, creativity and quality of life…Community-led palliative care, available locally should be at the heart of all the provision to children and young people.” (DH, 2006)

The White Paper (DH, 2006, Para 4.107) specifically addresses the needs of disabled children, children with complex health needs and those in need of palliative care, stating that:

“Primary Care Trusts (PCTs) should ensure that the right model of service is developed by undertaking a review to audit capacity (including children’s community nursing) and delivery of integrated care pathways against NSF standards, agreeing service models, funding and commissioning arrangements with their SHAs.” (DH,2006)

This statement, whilst providing direction does not take account of the inevitable period of uncertainty likely to occur during the transition of PCT and SHA mergers and re-configuration.

A further Government report was published in March 2006 (DFES/DH, 2006), taking forward the recommendations of the children’s NSF standard 8 and Every Child Matters, Change For Children (DFES/DH,2004), addressing the issue of transition from children’s to adult services. This good practice service guide supports safe and effective transition, recognising that many children and young people now survive into adult life with complex conditions. The guide states that transition is a “process and not a single event”. The report stated that there are a number of models, with different approaches, the key being flexibility. The guide also makes it clear that: “there is no one right time
or age for transition” and “no justification for using chronological age” as the criterion for transition.

In April 2006, the Department of Health published Palliative Care Statistics for Children and Young Adults (DH, 2006), providing information on the recent trends in the number of deaths likely to have required palliative care at SHA level. The statistics provided by each SHA are broken down into 0-19; 20-30 and aggregated 0-30 years. Between 2002-2004, there were 5200 deaths in England of children and young people aged up to 30 years from causes likely to have required palliative care.

The Social Care Minister, Liam Byrne recently instigated a series of ‘kick-off’ events, held throughout April and May 2006, organised on a regional basis by SHAs and supported by BIG lottery fund. The purpose of these events was specifically to examine how BIG schemes should engage in locally managed networks (LMNs). All Lottery funded schemes were invited to attend, and some schemes were given the opportunity to present features of their work. A Department of Health representative attended and spoke at each of these events and the SHAs have been charged with providing feedback to the Minister. In a recent re-shuffle of the Cabinet (May 2006), Liam Byrne was promoted to the Home Office and replaced as Social Care Minister by Ivan Lewis.

ACH has also been active in keeping children’s palliative care services on the policy agenda. A meeting took place between ACH and the Prime Minister in May 2006. Celebrity names have brought the focus of public attention to children’s palliative care services and an awareness raising television programme was screened on May 15th, presented by Sir Trevor MacDonald, and highlighting financial uncertainty and insecurity for some hospices at the cessation of BIG grants.

On Monday 29th May 2006, the Health Secretary, Patricia Hewitt announced an additional £27 million funding package, to be spread over 3 years, to allow children’s hospices in England to offer a range of services for children who need it most - from help at home, to end of life care in hospices, and both planned and emergency respite care. The Secretary of State stated that she wants families to be able to access world-class specialist care, and give the children, their parents and carers choice about where they are cared for and may ultimately die.

These (considerable) developments over the last few months illustrate that palliative care, for adults, children and young people is high on the Government agenda with much having been written and pledged about the future development of palliative care services.
Section 2 Emerging themes

Introduction

In our second interim report (2005), we reported on the diversity of services that were being developed to meet local needs and previously unmet need. We have also demonstrated elsewhere that the challenges of turning an “abstract” unmet need into an identified case-load of service users requires considerable effort and ingenuity on the part of schemes. (Living with Cancer, Final report, 2006) Here we present emerging findings from the qualitative case study work and early analysis of monitoring data. 174 people have been interviewed to date, including national stakeholders; service providers (including volunteers), and service beneficiaries (including adults and children and their families).

A conceptual framework has been developed from our analysis, which identifies the following themes:

- new services;
- new ways of delivering services;
- new clients and client groups benefiting from services
- new partnerships through which services are delivered

Each of these themes has been broken down into sub themes, which are covered in more detail below. Vignettes drawn from site visit notes, including activities observed or described, are used to provide a ‘supportive illustration of the key issues’. (Scott, 2005) Case study visits and analysis will continue throughout the evaluation, therefore not all case studies are represented within this report. Ten complete case study vignettes are attached as Appendix 4. The vignettes relate to case study sites where analysis of interview data has been completed and are therefore not necessarily current.

There is considerable overlap between themes, as some schemes are new, and have found new ways of delivering services to new client groups, through new partnership arrangements. The thematic analysis incorporates all schemes throughout the UK, including those that focus on specific conditions other than cancer and schemes providing services to both adults and children.

We have not attempted to quantify numbers of beneficiaries in this report, as monitoring data is provided at different points throughout the year and would therefore not represent the current situation. However, our survey to all schemes towards the end of their grant life is designed to measure the level of success in reaching target groups and will be compared with the original objectives of the schemes. Analysis of the survey will be published in the final report.
Reflections on case study visits

To date 174 people have been interviewed, either individually, or within a focus group setting. They include: 19 national stakeholders from across the United Kingdom, (including experts and appropriate BIG Lottery Fund staff); service users, including a number of children with life limiting and life-threatening conditions; project and hospice managers; community palliative care nurses; district nurses; social workers; children’s specialist nursing staff and play therapists; carers; acute sector nursing staff; volunteers; consultant paediatricians; counsellors and therapists. The majority of interviews have been face to face, however, some stakeholders have been interviewed by telephone.

During the course of the site visits, respondents have welcomed the opportunity to reflect on the process of scheme development to date and have provided the research team with a wealth of data. There have also been instances, where discussion during the course of site visits (either formal or informal) has highlighted issues, which have perhaps, up to this point, not been considered in depth, by the scheme as a whole or by individuals within the scheme. These include:

- the provision of support structures and mechanisms;
- the use of terminology such as ‘palliative care’;
- issues around transition;
- issues around patients with conditions other than cancer

There has also been some debate around exactly who the beneficiaries of schemes might be. Early findings demonstrate that it is not just the patient or sick child receiving palliative care who benefit from palliative care services.

Beneficiaries of the palliative care initiative include:

- caregivers (spouses; family and friends)
- families (parents; brothers and sisters)
- extended families (grandparents; step-parents)
- siblings
- health care professionals (generalists and specialists)
- social care professionals (generalists and specialists)
- education professionals (teachers, school nurses, psychologists)
- volunteers.
1 New services

Many new services have been developed as a result of this initiative. Services have taken time to become established, but site visits and monitoring data demonstrate that services are now being delivered effectively and are valued by beneficiaries and staff.

1.1 Domesticating palliative care: hospice at home service development

Schemes providing hospice at home services have developed entirely new services that have mostly been designed to complement existing services. In some parts of the country, for example, district and community nursing services are not provided over night, services have therefore been designed to provide night services to support patients and their caregivers.

A number of different models are in evidence across the case study schemes. Some schemes are linked to an existing hospice service that provides expertise and support for the nurses or healthcare assistants who are providing support in the home. (See box below and Vignette 1)

This home-based (adult) scheme represents a partnership between a PCT and an established hospice, located within a rural area of South West England with pockets of deprivation and a higher than average level of elderly population.

The scheme aimed to facilitate an increase in overall provision of specialist, multi-professional, community palliative nursing care to enable patients (with cancer and other conditions) to be cared for at home during the final days of their lives. The service offers 24-hour therapeutic nursing, emotional and respite care.

Recruitment of health care assistants in particular proved difficult, mainly due to the unsocial hours and flexibility required within the post. The recruitment period also coincided with other agencies increasing staff levels. Staffing levels were achieved by seconding some staff from the hospice to the scheme.

Another scheme (see box below and Vignette 2) has linked the (adult) overnight palliative care service to a GP out of hours service, which provides a two-way support mechanism. The palliative care nursing staff can provide support to GPs who are called out to palliative care patients, and the GPs can provide support where and when necessary to the palliative care nursing staff. Much of the success of this scheme is credited to a telephone call to each patient or carer currently receiving palliative care services from the day time district nursing service, at 11pm, when the new palliative care staff come on duty. This call establishes whether or not services or support is required through the night. Patients and carers are reminded that they can telephone at any time during the night if their situation changes.
This (adult) service is linked to the GP out of hours service, which is based in the walk in centre at a district general hospital. This scheme also has links to a statutory sector hospice, on the same site, where the project co-ordinator is located. This model provides access to all the professionals involved with the patient e.g. GPs; district nurses; specialist palliative care team. Services are co-ordinated and flexible, meeting the needs of the client group i.e. patients and carers.

A third scheme (see box below and Vignette 3) represents a partnership between various statutory and non-statutory partners, with a shared vision for service improvement.

This scheme provides a variety of services in the home for patients requiring palliative care and their caregivers. Most of the services are provided by health and social care professionals, but a feature of this scheme is the befriending and volunteer support that is also available. Patients and caregivers may benefit from a ‘befriender’ visiting on a regular basis, to take the patient out shopping for example, or to provide other services that improve the quality of life for both patients and caregivers.

This 36 month adult palliative care scheme, builds on the strong links, learning and experience gained from an earlier Living with Cancer lottery funded scheme. This scheme is designed to serve the whole of Sunderland and will extend and improve current palliative care provision.

Services include:
- an increase in service provision to improve the out of hours palliative nursing service;
- the appointment of a practice development nurse to support and equip community nurses with skills and knowledge to provide high quality palliative care including for those with non malignant disease;
- nursing therapy including home chemotherapy and blood transfusion;
- extended social care provided by a social worker;
- complementary therapies at home;
- a volunteer befriending and sitting service and practical support including a gardening and handyman scheme;
- counselling;
- financial and welfare advice and a programme of further learning opportunities.

Case study visits in addition to the work carried out for a systematic review on the role of informal caregivers have identified the crucial role that caregivers (especially close family relatives) play in the provision of palliative care. Extended family support is an important factor in determining whether a terminally ill patient dies at home. (Gomes, 2006) Understanding caregivers’ needs, their varied experiences and the complex interactions between caregivers and patients is important if effective end of life care is to be provided. A number of health and social care providers within the case study schemes have confirmed that the needs of caregivers are of equal importance to those of the dying patient.

"It can be as much to do with the family situation, their emotional situation, their financial situation, a range of things that you might want..."
**to involve someone who’s got expertise in working with people with life threatening illness, to assist families to cope.**” (Social Services manager)

### 1.1.1 Hospice at home developments for children

Seventy-one children’s hospice at home schemes have been developed, with thirty nine bereavement schemes and 25 hospice schemes. These services are very different to the adult schemes, described above, where care is provided mainly for the last few hours, days or weeks of life. Children’s palliative care services work with children and their families, providing much needed support, respite and care.

For many children receiving these services, their lives will be affected by a life-limiting or life-threatening condition over many years, often from birth into adult-hood, with their needs fluctuating, often quite dramatically over those years.

Three very different examples of these new services are described below.

The first example, (see also vignette 6) is located within an urban area of outer London and represents a partnership between two PCTs and two local acute trusts. The palliative care team works closely with colleagues in both the hospital and community, which provides access to children and their families in both settings.

The community palliative care nurse works within the paediatric units of two acute hospitals and alongside two community children’s nursing teams. Multi-agency working includes social care agencies. Children are referred for home based palliative care from all sources, although the working arrangements mean that the nurse is usually familiar with the child and their family already.

The scheme is designed to provide tailored care including: practical support in the home; advice on illness and diagnosis; co-ordination of services; end of life support in the home; bereavement care and sibling support.

The next scheme described below (see also Vignette 9) illustrates a different model of working in the community. This scheme does not employ nursing staff, but works closely with existing services, in order to provide additional services that had previously not been available.

A social worker has responsibility for recruiting, training and supporting volunteers, who provides services within the home including sitting, taking a sibling out to music lessons etc. to allow respite for carers. An education project worker is working with schools and in the community to provide support and guidance to enable children to remain in or return to school.
An ethnic minority worker is working with the black and minority ethnic (BME) communities, identifying those who require the services and those who would be prepared to volunteer.

The final example (see also Vignette 10), illustrates a partnership between various statutory and non-statutory providers, providing a range of services for children and their families.

This scheme has established a new multi-disciplinary team to provide a round-the-clock co-ordinated care programme for children with life-limiting conditions and their families in Stockport. Services include: nursing, care co-ordination, training for carers, home help, play therapy, nutritional advice, day and night respite care, psychological support and family support.

1.2 Enriching the lives of sick children

Parents and sick children themselves, understanding the nature of their limitations, often want for them to experience the sorts of things that other healthy children do, as part of normal growing up. These ‘fulfilling’ experiences are often denied to this group of children, either because of the restrictions imposed on them by their condition and/or their reduced life expectancy, for example, being a bridesmaid; going climbing; having midnight feasts and make up parties.

“When a parent dies, you mourn the past, but when a child dies, you grieve for the future that child has been denied. Milestones in your child’s life, like starting school and college, turning 18 and getting married, never end.” (Bereavement support worker)

Often simple pleasures, which so many healthy children are able to take for granted, require extensive planning and assistance if they are to be achieved for children and young people with life-limiting conditions. The boxes below illustrate a few of the achievements that have been made possible through children’s hospice and hospice at home teams.

A seven year old girl with Duchenne Muscular Dystrophy achieved her dream of riding a horse. A hospice at home team arranged for the little girl, who is wheelchair bound, to go horse-riding. Considerable assistance was required from 6 supporters and a risk assessment had to be carried out as part of the planning process, but the little girl’s dream came true.

Children’s hospice at home scheme

A young man of almost eighteen, suffering from Duchenne Muscular Dystrophy (DMD), attends a weekly occupational therapy session
organised by a children’s hospice at home team at the nearby adult hospice day centre. He has made his mother a stained glass artefact, as a keepsake.

Children's hospice at home scheme

A group of seven teenage boys and young men (aged 13-22) attended a children’s hospice for a weekend of fun activities. The group all have Muscular Dystrophy, which means that they are all confined to wheelchairs, but have various levels of physical disabilities, for example, several still have the ability to feed themselves, whilst others do not. Their cognitive ability, on the other hand, is comparable with their chronological age.

The group acknowledged that the benefits are largely for their parents / caregivers, who can do ‘normal’ things while they are ‘out of the way,’ such as clean the house, or go out for dinner together. However, the group quickly settled into playing computer games together and levels of excitement rose. Conversations ranged from the latest computer games and pop CDs to the latest upgrades of electric wheelchairs.

Children’s hospice weekend.

The fun weekend not only provided much needed respite for the caregivers but it allowed the young men time to share experiences with others in the group and to be cared for by trusted members of staff (and volunteers), most of whom who are well known to them.

A male counsellor employed in one hospice at home bereavement team develops a bond with the children and young people he is working with through activities of their choice, such as fishing, or as below, reading books.

“I take X [name of child] to book shops, because she likes books, we’ve bought some books and we do book reviews and so we learn what they’re like and stuff through reading books, things like that. It’s all about, for me it’s about building a relationship, because they don’t, they’re not interested in how much I know, they’re interested in how much I care.” (Male counsellor, hospice at home team)

1.3 Transition from children’s to adult services

In our 2005 interim report, we identified the challenges of providing ‘age appropriate’ services and settings for adolescents and young people. This issue has continued to be highlighted within many of the children’s schemes. The Government has recently produced guidance on this issue (see above, Policy developments), which suggests that transition is ‘a process’ rather than an event and that chronological age should not necessarily be used as the criterion for transition.
Staff working with adolescents and young people as they approach the stage where it might be more appropriate for them to receive adult services, have expressed their frustrations:

"Because we push medical science forward, we don’t know what to do with these children [young people].”  (Service provider)

“We’ve got to the point, especially with children with cystic fibrosis, that I have actually got nobody to hand over the care of doing home cannulation and I don’t see why at this point, where these young people are actually waiting for heart-lung transplants and things, that they should suddenly have to start attending hospital to have something as simple as a port flush, when before it’s always been done within their own home.”  (Lead nurse, hospice at home scheme)

“I wouldn’t actually be able to make the judgements comfortably about when some of these children are ready to start their transition.  I may have quite an adult conversation with some of these children and think that they are ready, but then I will sit down with the counsellor and they will give me a different insight.”  (Lead nurse, hospice at home team)

A minority of children’s hospices are linked to an adult hospice, and here, transition may be possible between the two, if it is felt appropriate for the patient and they (or their family) have made that choice.  An oncology patient aged 19 years, with no cognitive impairment, may present very different challenges to a 22 year old with a severe neurological life-limiting condition.  The former, although unlikely to relish the prospect of being in an environment mostly inhabited by people aged over 70, would most likely not choose to be with babies and young children.  On the other hand, a young person with a neurological disability may prefer to be in an environment that is familiar and provides an appropriate level of stimulation (e.g. Postman Pat videos; sensory room and jaccuzzi).

The box below illustrates an actual case provided as an example during the course of a site visit.

A shy young man of 23, with Duchenne Muscular Dystrophy, has recently been transferred from a children’s hospice to an adult hospice where he has had to develop new relationships and become accustomed to a whole new set of people providing very intimate and personal care.  This change can lead to additional stress about relationships and body image.  In addition, the adult hospice may struggle to provide the level of care and stimulation required as the nurse / patient ratio is different between children’s and adult hospices.  

(Case described during site visit)

Another case was described below:
“I’ve got one young lady at the moment, that is going to be transitioning over to the district nursing service next year, when she leaves full time education and she’s needle phobic and she’s very worried about it, because we’ve got a good working relationship now and she knows if I don’t get her blood first go, then I’ll go for finger prick and get her blood that way. And I need to get the district nurses in visiting with me, watching how I’m obtaining her blood and following on really.” (Lead nurse, hospice at home team)

Staff working with adolescents and young people are generally skilled at identifying the individual needs of both the young person and members of their family.

“You can’t leave the siblings out and quite often I might have a teenager and have a younger sibling with exactly the same condition and it then becomes difficult to separate, because it would be stupid for two nurses to go in to see two separate children. So it’s involving the whole family then. But I do anyway, especially with the younger siblings, I talk to them while I’m treating their brother or sister and explain exactly what I’m doing and how and why.” (Nurse, hospice at home team)

One children’s case study scheme is focusing their work on adolescents and young people, in their own homes, to help them to make their own choices and decisions, about future treatment for example. They also help and encourage the young people to take responsibility for their own well-being by being compliant with medication, attending school and eating a balanced diet. Additional work with a qualified (male) counsellor allows the young people to express their fears and concerns to a person who is caring and non-judgemental, which allows their self-esteem and confidence to grow.
2 New ways of delivering services

The palliative care initiative has provided opportunities for new models of service delivery to be developed and for new providers to deliver services. Here we describe how services have been provided in new ways.

2.1 The role of the volunteer

A number of schemes, particularly children’s schemes are examining how volunteers and ‘befrienders’ can be more involved in the provision of services to their families. There is evidence to suggest that volunteers, particularly young people, perhaps looking to go into medicine or nursing, or wanting to enhance their lives by giving some of their time, are coming forward and want to be actively involved with families where a child has a life-limiting or life-threatening condition.

Although the majority of volunteers are women, there are some male volunteers in both adult and children’s services. Adding a male perspective is often very important for patients, having someone that they can identify with, and importantly, for boys and young men, having a male role model. Children with life-limiting conditions often find themselves surrounded by women who ‘nurse’ them; ‘mother’ them and ‘protect’ them. A male perspective can often add a welcome contrast.

The recruitment and management of volunteers has presented challenges to many hospice services. There is a requirement to ‘vet’ volunteers through police checks to ensure that they are ‘appropriate’ to work in people’s homes. Secondly, it is essential that volunteers are emotionally stable and can ‘cope with’ the experience of working with a family that has or will be experiencing the death of a family member. Many people volunteer following a personal bereavement or loss and they may not have overcome their own sense of grief.

“It is very important to look at loss and grief, because there’s an awful lot of volunteers come this way. “My mum died and I want to give something back.” And I make it very clear to any volunteer coordinator that my role as a trainer is to make sure that they know what they’re going into. And you get these comments “Oh well I know what it’s like because my mum died.” I say “Mm, you know what you felt like,””

(Trainer, hospice at home scheme)

Having successfully recruited, volunteers and ‘befrienders’ need ‘managing’ in terms of a) matching them appropriately with a family and b) ensuring that they receive adequate emotional support and do not feel isolated. Recruitment and management of volunteers can be resource intensive, but can also provide a free but valuable and effective workforce.
Volunteers have not been embraced within the children’s hospice movement as widely as they have in adult services. There is still anxiety in certain areas about the appropriateness of volunteer involvement and the roles which volunteers can and should undertake. (ACH conference abstract, presented by a representative from one of the case study schemes.)

The example below illustrates how volunteers can be involved in the provision of respite:

Volunteers are carefully trained and matched to families to provide support in the home in ways that make a difference. Playing with the sick child or their siblings can relieve parents / caregivers from some of the stresses and tensions that caring for a very sick child entail. Mums can put their feet up and read a magazine, take a relaxing bath or have a nap, ordinary things that really make a difference. (Children’s hospice at home scheme)

The next example illustrates how volunteers can be involved in providing support:

“Some of them [volunteers] are doing it as part of their Duke of Edinburgh, other people are doing it because they want to go into medicine, and this is giving them good experience to put on their CV, and it’s working really well. You know, they’d [children and young adult patients] rather sit with one of them [volunteers] on the Play Station than one of us [nurses]. (Nurse manager children’s hospice.)

The survey that will be sent to all grant schemes at the end of their grant life explores the role of volunteers and their contribution to palliative care services. The results of this survey will be published in the final report.

2.2 A flexible approach

Flexibility is key to the delivery of palliative care services. By definition, the client group does not remain constant.

Observation and interviews at a number of children’s hospice and hospice at home schemes has highlighted that their client groups tend to fluctuate. For example, children’s schemes may experience a spate of infant deaths, followed by a cluster of (adolescent) muscular dystrophy deaths. Some young people may discontinue attendance at a hospice when their friends have died. In other cases, a new referral may attract other people with a similar condition known to that child or family.

“We used to have five Muscular Dystrophy boys, and so we used to plan those kind of [activity] weekends, unfortunately, three of them died
Cancer patients continue to form the largest client group in adult hospices. Just as children with life limiting and life threatening conditions are living longer and often into adulthood, so with treatment advances, many cancer patients are living longer than previously. Adult hospice services are therefore examining ways of providing additional palliative care services that are not just for terminal care. This is where the experience of children’s hospice services may be of value to those providing adult services, in terms of the provision of respite, including creative and complementary therapies for example.

2.3 Key-worker roles in children’s palliative care

The introduction of key-worker roles (usually someone from health services) appears to have reduced the amount of professional contact required for each family and allows the key-worker to take the lead on service provision, liaising between different professionals and organisations. This means that the key-worker can make an assessment of need and plan services accordingly. It is inevitable that the key-worker becomes closely associated with the family. There may be ‘flashpoints’ (e.g. around a period of hospital admission or during transition) or crises (e.g. a severe life-threatening infection), or there may be periods of time when the child and family do not require any input from palliative care services. The key-worker is able to manage total, holistic service provision and maintain contact with the family and all other professionals involved in the case.

The example provided below illustrates how the key-worker role allows one professional to co-ordinate services for the entire family.

“We involved the Community Team to look at oxygen and suction and to do things like that within the home. I visited the family every week, was able to answer questions, talk to mum and dad. We looked at support for the siblings, the child was admitted to hospital only two or three times and I was able to be there when mum came into hospital, to support them then. I was able to liaise with the consultant here on the second floor, we were able to speak to the coroner, because this mum was really afraid that this baby would have to have a post mortem when she died and she didn’t want that”. (Children’s Nurse / key-worker)

The result of this holistic approach towards ‘the family’ takes a lot of pressure away from them:

“The parents aren’t having to communicate with so many professionals.” (Nurse, key-worker)
3 The extension of existing services to new client groups

3.1 Extending palliative care services for people with conditions other than cancer

In our 2005 interim report, (see pg iii for details of how to access previous reports) we drew attention to the challenges presented by extending palliative care provision to people with conditions other than cancer, which was a key objective of this initiative. It is recognised that cancer related priorities have largely driven the development of palliative care services, yet only around one quarter of all deaths in the United Kingdom are caused by cancer. However, it is widely accepted that there is a significant unmet palliative care need for patients with non-cancer terminal and long-term life-threatening conditions, such as heart failure, neurological and pulmonary conditions.

Adult grant schemes in England were encouraged to identify at least 10% of their client groups from amongst people with conditions other than cancer. In Scotland and Northern Ireland, a distinctive feature of the programmes was the inclusion of schemes that focussed specifically on client groups with conditions other than cancer. Adult case study schemes in Scotland and Northern Ireland were selected on the basis of having this focus. (See also Vignettes 1 and 2)

Huntington’s Disease scheme

This 3 year grant scheme was designed to improve the quality of life of people affected by Huntington’s Disease, through effective palliative and social care in one of four Health and Social Services Board (HSSB) areas of Northern Ireland.

Lottery funding has created a specialist service, which provides both outreach to those affected by Huntington’s disease and training and support to health and social care professionals who come into contact with their families.

The scheme represents a partnership between the statutory sector and the voluntary sector Huntington’s Disease Association.

This scheme provides an example of where an unmet need was translated into an actual case-load much more quickly and to a greater extent than had originally been anticipated, because so many families, who were already members of the Huntington’s Disease Association, were just waiting for services to be put into place.

“For example my first report of what work I’d done in that quarter, in the first one I had 18 clients, the second I had 43 clients and the third one I had 72 clients and that’s the sort of growth, even although in the first 6
People were referred to the scheme by the hospital genetics department, GPs and social workers, as well as the Huntington’s association, which had been calling for specialist services and was involved in the original proposal. Specialist training for health and social care professionals provided through the scheme, has raised awareness of the needs of this client group and ways in which they might be addressed. This has also led to an increase in the case-load and demands made of the one specialist nurse working in this area.

Scottish Motor Neurone Disease Association

This charitable sector grant scheme is providing a new service, which fills a previously unmet need across Scotland. Motor neurone disease (MND) is a rare condition, which requires palliative care almost from the point of diagnosis. Patients with MND and their carers argued that specialised counselling should be available. The Big Lottery Fund grant has enabled the organisation to expand and deliver this new service.

This scheme has been successful in recruiting trained counsellors, who are then provided additional training on the specifics of motor neurone disease and bereavement. Counsellors are located around the country (on an ad hoc basis at present, dependent on recruitment), and have the use of local health centres or CRUSE offices where they are able to offer emotional support, either face to face or by telephone to people with or affected by Motor Neurone disease. Practical support is offered by signposting to other agencies as appropriate. Internal evaluation of the services provided by this scheme has demonstrated high levels of satisfaction amongst service users (patients and (often bereaved) carers).

These two schemes illustrate a successful extension of services to conditions other than cancer. However, the picture is rather different in those schemes where services have been extended from traditional palliative care services for people with cancer to those with conditions other than cancer.

Efforts are being made to raise awareness amongst health and social care professionals, but different illness trajectories make it harder to define end of life care needs. Murray (2005) defined three distinct illness trajectories. The first represents a trajectory with steady progression and usually a clear terminal phase, (mostly cancer); the second, defined by a gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden, seemingly unexpected death (for example, respiratory conditions and heart failure); and the third, a prolonged gradual decline (typical of frail elderly people or people with dementia).

In many conditions, for example, heart failure, active care continues up to death. Different patterns of provision may be required to address the needs of these new client groups, as well as new partnerships with acute medical...
specialties and community services which may have had little, if any experience of collaborating with a hospice.

One scheme (see below and Vignette 3) has been successful in starting work to develop a better understanding of the palliative care needs of people with heart failure.

This 36 month adult palliative care scheme, builds on the strong links, learning and experience gained from an earlier Living with Cancer lottery funded scheme. This scheme is designed to serve the whole of Sunderland and will extend and improve current palliative care provision.

The scheme has benefited from a strong partnership involving a variety of statutory and non-statutory partners with a shared vision developed during the course of the Living with Cancer initiative and extended into palliative care. The experience gained over this duration has provided a level of security and confidence that has allowed this scheme to extend into practical developments with colleagues in specialities other than cancer.

"I'm involved with this project because of heart failure patients having great palliative care needs and traditionally they didn't have access to palliative care services... so I've been working closely ... to build relationships, form links and open access to those services for the heart failure patients....now we do have access to those services, the heart failure patients are getting seen by the complementary therapists...the counselling service ...the respite services and also, we've had patients coming to the hospice as well, so things are improving greatly... we've also managed to have a palliative care nurse seconded to the heart failure team, so that we can learn from each other, because....heart failure patients can be desperately ill one minute and then ...they jump between four classes.. a patient can be at stage 4, and be treated.. and then jump back to Stage 2, so the difficulty for heart failure is, when do we refer patients to palliative care services? ...

Heart failure is a more malignant disease than most cancers, however....patients aren't always informed of their prognosis at diagnosis...people don't understand the implications of it....there's an ethical issue about saying to somebody, “oh, we're going to refer you for palliative care” if they haven't been told that they've got a terminal condition." (Specialist CHD nurse)

Amongst the case study schemes, at this time, this particular scheme stands out from most of the others in its efforts to extend services to people with conditions other than cancer. The experience of the majority of schemes appears to be that they rely on referrals from professionals who have developed sufficient confidence in the services that they will refer someone with a condition other than cancer. Despite awareness raising exercises, this remains patchy.
3.2 Raising awareness amongst professionals

In order to attract new clients and client groups, many children’s and adult schemes have undertaken proactive initiatives to raise awareness, through publicity; by opening up their doors to groups of professionals (e.g. GPs and nurses) and offering palliative care training sessions. Some innovative methods have been employed to attract professionals to training events, such as personalising invitations and offering free complementary therapies. Many of these events have been successful, evaluated well and been appreciated by those who have attended, many of whom (including GPs) have never experienced the inside of a hospice.

“\textit{The response that we got to the events was fantastic, it was really a positive response that we got.}” (Nurse manager, children’s scheme)

We have discussed referrals in our earlier reports, and we return to this issue in the discussion section on page 37. The point that we would re-inforce here is that palliative care schemes have had to work hard in approaching their acute and community sector colleagues in order to raise the profile of their services.

“We’re outside the NHS, the NHS see themselves as a strong partner, they are the ones in control, and they can be gatekeepers to us. If we don’t go and network, we won’t get referrals… working in the charitable independent sector, you have to remember where you are in the hierarchy.” (CEO, hospice)

Despite some schemes having established partnership arrangements between the acute sector and hospice and community services, links with hospital consultants remain largely limited, particularly it would seem in children’s palliative care. Many children receive specialist hospital services a long way from home (e.g. Great Ormond Street Hospital and regional specialised centres). It is unlikely that the child’s consultant would have direct communication with a local hospice or hospice at home services. In addition, many consultants are reluctant to ‘hand over’ their patients to local services and prefer to continue to ‘treat’ (active / cure) rather than (passive) ‘care.’

“And the trouble is that when the child does die, the GP doesn’t know the family, doesn’t know the needs and is kind of thrown in at the deep end.” (CEO, hospice.)
3.3 Culturally sensitive and appropriate palliative care services for adults and children from BME communities.

Extending culturally sensitive and appropriate palliative care services to people from BME communities, in common with extending services to people with conditions other than cancer, is taking time to develop and the number of referrals to adult services remain very small. However, the palliative care providers have all argued that each patient, each family, each situation is individual and requires respect and understanding of the individual needs.

“We have had minimal ethnic minorities using the service.” (Service manager, Hospice at home scheme in area of high density BME communities.)

“They’re all so different anyway, everyone is so individual,” (Service provider, Hospice at home scheme in area of high density BME communities.)

Two of the children’s case studies have specifically identified working with BME families as an objective.

The aim of this home-based scheme (See Vignette 6) is to develop and improve existing services in the locality for children with life-limiting or life-threatening conditions needing home-based palliative care. The scheme represents a partnership between two Primary Care Trusts and an acute hospital trust. The scheme is located within an urban area of high levels of deprivation and almost 50% minority ethnic population.

The caseload remains relatively small, with 18 families across the two districts. However, many of the families are immigrants and translators are required to assist communication. Visits therefore require careful planning and longer than they would with English speaking families. Translators are quite widely available within the GP practices and PCTs across London, covering many of the major languages of the BME groups living there. However, some communication difficulties have been reported in relation to certain dialects.

Brent and Harrow children’s palliative care scheme.

Preparatory work for the design of a home-based scheme in Nottingham (see Vignette 9) had identified few BME families taking up palliative care services. Recruitment of a BME project worker proved difficult, but eventually, the current post-holder was recruited. This worker has considerable experience, having a background in social services and good knowledge of the communities and local health and social care providers. Her first task was to undertake a mapping exercise and to introduce her role to health care professionals. One link provided six referrals immediately, but contact with consultants in the acute sector has not proved very productive to date.
Cultural issues identified here specifically include: direct payments, so that families can access a worker who can a) speak their own language, b) provide appropriate hours at convenient times. Concerns also include knowledge of how to dress children in their ethnic attire and respecting the household by removing shoes on entry to the family home.

Nottingham children’s home based scheme

The University of Exeter is conducting a piece of research, supported by BIG, looking at the Lottery funded children’s schemes and access by people from black and minority ethnic (BME) communities to hospice services. This project will report in June 2006, and we will draw on its findings in our final report, along with our review of children’s monitoring data and case study work.

3.4 Shifting the focus of care from the individual to the extended family

Many of the schemes have developed services that either: enable the family to stay at home together; or provide services, in or outside of the home, to enable the caregivers and the patients to ‘have a break.’ Before the development of these services, children and adults could well have been admitted to hospital, as the carers were often exhausted by caring twenty-four hours a day over long periods of time.

“…evidence coming particularly from the acute services, the hospital and the Paediatric Homecare Team, that there were children that probably didn’t need to be admitted to hospital that were still being admitted to hospital, but that we couldn’t really reverse that without investing in sort of social care and have the whole package of paediatric nursing and respite care. A lot of the children in this category were being admitted into hospital to give the parents a rest, because there was no alternative.” (PCT children’s scheme manager)

A considerable amount of work is being undertaken by most children’s schemes, with siblings of children who have palliative care needs, and in some cases, the siblings or children or even grandchildren of adult patients. Schemes providing support groups or support facilities for siblings, allow the siblings to have some ‘quality time’ away from home, where the focus is entirely on them and they can identify with others in a similar situation.

Skilled family support workers and play therapists are employed to work with these children. Close relationships appear to be developed, with a trusted but non-authoritarian adult. The children are empowered to explore and examine their feelings in a safe environment. This work can promote not only better self-understanding and self-confidence, but has been shown to lead to improved behaviour and school results. A group of siblings of children with life-limiting conditions attend regular fortnightly after school sessions staffed by qualified support workers. Activities include swimming, bowling, football,
arts and craft. The siblings group recently contributed to the production of a ‘rap’, reproduced below. The words in bold are theirs:

**Siblings rap**

I’ve got a life to live I've got friends to make
Yes the siblings group helps me take a break
Whoever thought this up must be clever
Because the siblings group is the best thing ever.

It's **exciting and relaxing**
**Enjoying activities** that are **interesting**
Picnic, Run Riot or bowling
**Going to the park, cooking or swimming.**

Anything goes I'm **learning**
To take time out when my heart is burning
**Chill, put my feet up, relax**
Because my sibling is ill yeah, these are the facts.

The siblings have the opportunity to be in an environment where they are the focus of attention, rather than their sick brother or sister and they can ‘relax’ and do ‘fun things’ with trusted adults who are not in a position of authority.

This extension to focus on the extended family means that staff often have to mediate competing or conflicting wishes of relatives in multi-generational households, or where there has been family break-up.
4 New partnerships developed to deliver services

A report published by the NHS Confederation (22nd May 2006) states that:

"Palliative care services are an excellent example of how health and voluntary sector partnerships can be used to deliver home-based packages".

Many of the BIG schemes have enhanced existing or developed new partnership arrangements in order to deliver a ‘holistic’ service, tailored to local needs. We have provided a list of examples below, some of which are illustrated in more detail in this section or throughout this report and in the vignettes (Appendix 4). Although some of the partnerships are highly effective, the level of participation and risk and reward remains highly variable. Indeed, some (adult and children’s) independent hospices do not consider themselves to be working in ‘partnership’ and have to work very hard to be included in local service delivery planning.

Examples of partnerships identified through the initiative:

- health and education
- health and social care
- traditional medicine and complementary therapies
- palliative care services and non-cancer acute specialities
- children’s hospice and adult hospice
- children's hospice and children's hospice at home schemes
- adult hospice and adult hospice at home schemes
- voluntary sector and statutory sector

The survey to all schemes towards the end of their grant life will examine how well schemes have integrated with their partners and others. The results of the survey will be published in the final report.

The example below from a children’s hospice scheme illustrates the benefits of different agencies working together with a shared vision:

“We have a regular meeting with the ward staff, the community nurses, the social workers from the hospital, school nurse from the local special school… we’ve certainly had some good occasions in the past, where we’ve delivered care in the community jointly with the community nurses.” (Nurse manager, children’s independent hospice)

One (children’s) scheme provided an example of working in an environment ‘uncluttered’ by different organisational boundaries, however, this is the exception rather than the rule.
“We have it sort of fairly easy I suppose, if you think about it, we’re a unitary authority, we’ve got one local authority dealing with one acute trust dealing with one primary care trust, we live in a simple world”

(PCT manager)

Not all the partnership arrangements work well all of the time, the voluntary sector partner quoted below, whilst acknowledging the radical approach adopted in this arrangement, also illustrates one of the more common challenges in maintaining effective communication across different agencies.

“In essence I think it’s the way the bid was put together, I think it was sort of quite radical thinking in terms of looking at agencies working together and using the expertise from different agencies. I think the problem is, is kind of keeping that communication level going, which I think has been very good at times, but I think sometimes we overlapped a bit in terms of, you get involved with your own project and you’ve got to bear in mind that this, you know, keep up that communication, because you’re on the outside, you’re not working with your colleagues then and there, you know, colleagues are sort of dotted all over really.”

(Voluntary sector partner, children’s hospice at home scheme)

In some cases, different organisational cultures and ‘languages’ create a challenge to partnership working as the example below illustrates:

“There were a lot of problems, …we speak’ health speak’ and they speak ‘Social Service speak’ and I’m sorry, I really do try and learn Social Services speak but I’m born and bred health and it is a different language.”

(Lead nurse, children’s hospice at home scheme)

4.1 Health and education

Within the children’s case study schemes, there is evidence of hospice and hospice at home staff working alongside both mainstream and special schools to raise awareness of the issues around life-limiting conditions, and to provide support for those who will experience the death of a child. Specialist staff from palliative care services, have helped to overcome examples of where a life-limited child has been bullied in school and helped to develop an understanding of the limiting nature of the conditions that these children are subject to.

Many of the children, especially those who are able to attend mainstream local schools, want to be treated the same as their peers, but for example, may need to visit the toilet more frequently, may need time out to administer medication and may not be able to participate in sporting activities to the same extent as healthy children.

Providing teaching staff with a better understanding of issues around life-limiting conditions has an impact on the quality of life of the children affected
and impacts on their peer groups, providing them with a deeper understanding of life and death issues and encouraging them to be more tolerant.

One scheme is working alongside multi-agency colleagues to develop good practice guidelines:

”...good practice guidelines for schools when they’re working with children and young people with life limiting conditions. ... we have [had] a few massive multi-agency group meetings, where we looked at what the issues for schools were, what the issues for families were and then a smaller group of people went way and wrote some guidelines which have gone out for consultation” (Education worker, children’s home-based scheme)

4.2 Children’s hospice schemes and children’s hospice at home schemes

There is evidence to suggest that children’s schemes, whether they are providing hospice or hospice at home services, have been working together to ensure the best possible and most appropriate services for the referred children that they are working with. This has been achieved through the networking of schemes via local informal networks, largely facilitated by the SHAs and will continue through the more formal locally managed networks.

”Jointly we’re [children’s hospice scheme and children’s hospice at home scheme] looking at setting up a children’s strategy for palliative care and the clinical teams are working closely together, so they're kind of useful. They're using us as their in patient beds and we're using them as community support, which is really good.” (Nurse manager, children’s hospice scheme)

4.3 Children’s hospices and adult hospices working together

Although there are differences between children’s, young people and adult palliative care needs, caring for these patients and their families can highlight similarities. Symptom control is one example, where adult hospices have a lot of experience to offer children’s services. Learning to recognise behavioural response rather than verbal response is an area where children’s hospices have expertise to share with adult services. Bringing together nurses from the children’s and adult hospices can be beneficial to all:

“There was a lot of sharing, and they all [adult and children’s hospice nurses] actually felt that it was very beneficial to have that time to be able to share things with each other, we actually do learn a lot from each other and by sharing experiences.” (Nurse manager, children’s hospice. Visit 2)
Other tangible benefits of this working arrangement are the possibilities of extending support services to children who are experiencing the death of an adult relative.

“The family support worker’s role, we really have established the support for children in both the adult and children’s services now. We have dedicated days where the siblings of the children from the children’s unit and the children of adult patients come in and we focus specialist activities on them, giving them a chance to be able to talk about how they’re feeling, giving them an opportunity really to get to meet the nursing staff and then also to be able to build up relationships with them, because they’re the ones that they can obviously receive support from.” (Nurse manager, children’s hospice. Visit 1)

4.4 Voluntary and statutory sector partnerships

The initiative has led to the development of a number of cross-sector partnership arrangements. Many of these partnerships are working effectively to achieve their objectives.

For example, the voluntary sector Huntington’s Disease Association in Northern Ireland has been strengthened considerably by working in partnership with the statutory sector palliative care scheme. (See Vignette 4)

For the first time, the organisation has a link to a specialist nurse who can provide services and training. This has provided an impetus for the association and empowered its members to link more closely with the acute trust providers and the Health Board. It has also assisted the scheme by identifying a pre-existing client group with unmet needs.

“We’ve had X (specialist nurse) in post now about nine months and the difference that she’s made, just as someone that understands, can empathise with us and yet do such a professional job for us. She’s opened doors that you know, we wouldn’t even have been allowed to bang on.” (Chair of voluntary sector organisation)

However, cross sector working has identified one issue that is insurmountable, in that voluntary sector organisations such as the hospice movement, have a single focus, whereas statutory sector organisations almost always have multiple priorities and targets.

“One of the biggest issues ..has been the very different nature of the organisation, the fact that the hospice that’s all they focus on, you know they’re focussed on hospice care and palliative care and community service and we’ve [PCT] got a huge remit and palliative care is just one of them.” (PCT Manager Adult hospice at home scheme)
Staffing these new services has posed challenges. We have reported previously on the difficulties that many schemes experienced when recruiting staff at the outset. Many of these were overcome, over time. However, many nursing staff and other professionals (e.g. social workers, play therapists) were recruited to palliative care services from the acute or service sector, and took some time to adjust to the pace and requirements of a palliative care service, which they found very different from the active treatment / service provision these professionals were used to providing. Some nurses feared that they would lose their skills if they were ‘simply’ talking to patients and their families for long periods of time, they may have failed to recognise the additional skills that they were learning (e.g. listening and caring).

“"You go from a fast pace to a very slow, and I think, some nurses, it just doesn’t suit them, …and I think as well,… people come, and they care for people that have died, but they can’t care for all these people that are dying…. On a surgical ward some [patients] get better…. on the paediatric side, some of them haven’t even seen a dead child…. The adult…. [hospice nurses] most of them have nursed people who are dying, but don’t like a mix of living and dying .” (CEO, child and adult hospice)

Staffing adult and children’s palliative care services is highly dependent on getting the right skill mix in the right environment.

“"I’m an adult nurse, and I’m not child friendly, I don’t know how to get on the floor and play with children” (Adult palliative care provider)

The majority of staff recruited to the schemes are female and include: nurses, social workers and others. One scheme has recruited a male counsellor, who brings his own male perspective and adds an additional dimension to the service.

“"I’ve appreciated X [name of male counsellor] , because you know, he is a man, he’s coming from a different angle altogether. These children are often just totally surrounded by women, because the majority of nurses are women, so when they’re admitted into hospital and everything it’s just very female orientated. And it’s so nice for them to have a man brought into their life in this way.” (Lead nurse, hospice at home team)

Some staff have left schemes, due to fears and concerns that their new service would not be sustained. However, staff working within schemes have demonstrated a high level of commitment and often their contribution exceeds the expectation within their job description.
In our 2005 interim report, we also identified some tensions between different groups of nursing staff, particularly community nursing and specialist palliative care nursing. Many of these have been overcome, often through the efforts of staff working within the voluntary sector.

Also in our 2005 interim report, we concluded that a ‘re-definition of palliative care’, is taking place by virtue of new services being developed in new ways, through new partnerships, to address new client groups. Throughout this interim report, we have drawn attention to the ways that this (r)evolution is taking place. An important component of this redefinition has involved the questioning and re-thinking of a series of traditional and taken-for-granted assumptions about the nature of referral in palliative care, in the light of the chronic illness trajectories (Murray, 2005) that we referred to above.

In the past, a referral was conceptualised as a one-way, irreversible, transfer of responsibility for total clinical management between autonomous agencies (e.g. primary care to hospital or oncology to hospice). This model (see Arrow 1, slide below) represented the pattern of referrals that used to characterise the management of much chronic illness up until the 1990s, and still probably predominates in palliative care today.

The second model (Arrow 2, slide below) illustrates a referral for a specified purpose between autonomous agencies (for the purpose of investigation, diagnosis, specialist treatment), for a limited period of time, and with the expectation of referral back. (For example a GP would refer someone with asthma or diabetes, to a specialist for treatment of a complication or perturbation, with the expectation that the patient would be referred back at the end of the acute episode to receive ongoing care within primary care.)

The third model (Arrow 3, slide below) represents referral in the context of an ongoing therapeutic alliance, between agencies (e.g. hospice at home; social services; bereavement services; complimentary therapies; volunteer services) involving generalists and specialists, possibly in the form of a care pathway. It is this model, we believe that is most appropriate to palliative care in the future.
The key concern for many working in or alongside schemes at this point in time, is around sustainability and continuation, with re-configuration of many statutory health agencies (PCTs and SHAs) underway; reported financial difficulties within many NHS organisations and the difficulties of fund-raising in the current climate (with other calls on charitable funding such as the Tsunami and African appeals).

“We’re dealing with a lot of competing priorities of children schemes funded non-recurrently, the PCT and the local authority both in …deficit and financial recovery and it’s going to be hard.” (Children’s home based scheme manager)

A number of senior hospice personnel have been meeting with local and national political leaders to try to secure statutory long-term funding arrangements for children’s and adult hospice services.
Future plans

The evaluation is proceeding according to schedule. Site visits and follow up telephone interviews will continue accordingly and it is intended that all visits and interviews will be completed by the end of January 2007. National stakeholders will be re-interviewed as appropriate towards the end of the evaluation. We plan to meet with colleagues from ACH; ACT and the Department of Health in Autumn 2006, to explore the themes emerging from the provision of palliative care services for children.

The survey to all schemes is being mailed out on a rolling basis as the Lottery funding comes to an end. Reminders will be posted to non-responders and a full analysis of the survey will be undertaken. A review of the monitoring data for all English children’s schemes will continue to the conclusion of their grants.

The final evaluation report is now due in September 2007 and will further develop the richness of individual experience through:

- development of the four main themes we have identified within the current report:
  - new services
  - new ways of delivering services
  - new clients and client groups benefiting from services
  - new partnerships through which services are delivered
- an overview of work being carried out by the University of Exeter on how BIG lottery funded schemes have met the needs of people from BME communities
- results of an ecological study of case study site locations
- analysis of postal survey covering all schemes
- review of children’s monitoring data
- discussion on the success of the initiative as a whole.
References

ACH bulletin 77, April 2006.


Appendix 1 National overview of grant schemes

Overview of grant schemes across England

<table>
<thead>
<tr>
<th>Strand</th>
<th>Schemes led by statutory organisation</th>
<th>Schemes led by non-statutory organisation</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult</td>
<td>44 (78%)</td>
<td>12 (22%)</td>
<td>56</td>
</tr>
<tr>
<td>Children’s Hospice</td>
<td></td>
<td>25 (100%)</td>
<td>25</td>
</tr>
<tr>
<td>Children’s Home Based</td>
<td>66 (93%)</td>
<td>5 (7%)</td>
<td>71</td>
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<tr>
<td>Children’s bereavement</td>
<td>21 (54%)</td>
<td>18 (46%)</td>
<td>39</td>
</tr>
</tbody>
</table>

Sample selection:

Level 1: 1 Adult - statutory
1 Children’s Hospice - non Statutory
1 Children’s Home- based / bereavement - statutory

Level 2: 4 Adult – 3 statutory / 1 non-statutory
2 Children’s home-based – 1 statutory / 1 non-statutory
2 Children’s bereavement –1 statutory / 1 non-statutory
1 children’s hospice – non-statutory.

Overview of grant schemes across Northern Ireland

<table>
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<tr>
<th>Health Board</th>
<th>Total No. of schemes</th>
<th>Schemes led by statutory organisation</th>
<th>Schemes led by non-statutory organisation</th>
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<td>4</td>
</tr>
<tr>
<td>Western</td>
<td>4</td>
<td>3</td>
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<td>Northern</td>
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<tr>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Totals</td>
<td>25</td>
<td>15</td>
<td>10</td>
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</table>

Sample selection

Level 1: 1 statutory

Level 2: 1 non-statutory
Overview of grant schemes across Scotland

<table>
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<tr>
<th>Health Board</th>
<th>Total no of schemes</th>
<th>Schemes led by statutory organisations</th>
<th>Schemes led by non-statutory organisations</th>
</tr>
</thead>
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<tr>
<td>Argyll and Clyde</td>
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<td>3</td>
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<td>Ayrshire and Arran</td>
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<td>Borders</td>
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<td>Greater Glasgow</td>
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<td>Highlands</td>
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<td>1</td>
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<tr>
<td>Lanarkshire</td>
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<td>Lothian</td>
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<tr>
<td>Orkney</td>
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<td></td>
<td>1</td>
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<td>Shetland</td>
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<td></td>
<td>1</td>
</tr>
<tr>
<td>Tayside</td>
<td>5</td>
<td>4</td>
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<tr>
<td>Western Isles</td>
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<td></td>
<td>3</td>
</tr>
<tr>
<td>Direct grants</td>
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<td></td>
<td>4</td>
</tr>
<tr>
<td>Totals</td>
<td>59</td>
<td>21</td>
<td>38</td>
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Sample selection:
Level 1: 1 National project non-statutory.

Level 2: 1 grant scheme, non-statutory.
### Funded Schemes Selected for Level One Case Study (in depth)

#### England

<table>
<thead>
<tr>
<th>Lead organisation</th>
<th>Status</th>
<th>Strand</th>
<th>Amount funded</th>
<th>Base Region</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Adults</td>
<td>£399,878.00</td>
<td>North East</td>
<td>Development of current services through out of hours nursing support, home based therapies, complementary therapies, counselling, practical support and respite care; developing existing service partnerships.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Non-statutory</td>
<td>Children's Hospice</td>
<td>£561,861.00</td>
<td>South East</td>
<td>Expansion of services offered by children's hospice.</td>
</tr>
<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Children's Bereavement</td>
<td>£74,989.00</td>
<td>East Midlands</td>
<td>Development of home based bereavement service at a medical centre; targets siblings, parents and grandparents of hard to reach groups.</td>
</tr>
<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Children's Home-based</td>
<td>£399,987.00</td>
<td>East Midlands</td>
<td>Enhancement of existing services through play/art/music therapy; and lead community paediatric consultant; targeting minority ethnic and socially excluded children.</td>
</tr>
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</table>
# Funded Schemes Selected for Level Two Case Study (briefer)

England

<table>
<thead>
<tr>
<th>Lead organisation</th>
<th>Sector</th>
<th>Strand</th>
<th>Amount funded</th>
<th>Base Region</th>
<th>Short description</th>
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<tbody>
<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Children's Home-based</td>
<td>£399,865.00</td>
<td>London</td>
<td>Partnership scheme to improve home-based services aims to be flexible and responsive to local needs.</td>
</tr>
<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Adults</td>
<td>£399,960.00</td>
<td>South West</td>
<td>Improvement of services, including 24 hour therapeutic, nursing, emotional and respite care; 3 nurses and administrator to be employed at hospice.</td>
</tr>
<tr>
<td>Family Service Unit</td>
<td>Non- statutory</td>
<td>Children's Bereavement</td>
<td>£72,425.00</td>
<td>Yorkshire and the Humber</td>
<td>Families to be offered counselling and group work with Asian Social Worker and student on university diploma course.</td>
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<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Children's Home-based</td>
<td>£399,878.00</td>
<td>North West</td>
<td>24 service including nursing, care co-ordination, training for carers, home help, play therapy, nutritional advice, day and night respite, psychological and family support.</td>
</tr>
<tr>
<td>Primary Care Trust</td>
<td>Statutory</td>
<td>Children's Bereavement</td>
<td>£64,704.00</td>
<td>South East</td>
<td>Employment of bereavement practitioner to support adolescents in their transition to adult services; develop out of hours provision with volunteer support.</td>
</tr>
<tr>
<td>Primary Care Trust</td>
<td>Non- statutory</td>
<td>Adults</td>
<td>£399,476.00</td>
<td>London</td>
<td>Development of hospice at home scheme including new overnight nursing service, extended Marie Curie service; access to occupational therapy, physiotherapy, language therapy and dietician.</td>
</tr>
<tr>
<td>Primary Care Trust</td>
<td>Non- statutory</td>
<td>Adults</td>
<td>£399,476.00</td>
<td>London</td>
<td>Development of hospice at home scheme including new overnight nursing service, extended Marie Curie service; access to occupational therapy, physiotherapy, language therapy and dietician.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Non- statutory</td>
<td>Adults</td>
<td>£268,738.00</td>
<td>West Midlands</td>
<td>Day hospice and home based multi-disciplinary palliative care including physiotherapy, family therapy, social worker and Citizens Advice Bureau support.</td>
</tr>
<tr>
<td>Hospice</td>
<td></td>
<td></td>
<td>£337,909.00</td>
<td>Yorkshire and York</td>
<td>Improve sibling and carer support and develop bereavement counselling.</td>
</tr>
</tbody>
</table>
by appointing 2 new staff, installing videophone links between children in the hospice and their families at home; provision of other new therapies.

### Funded Schemes Selected for Level One Case Study (in depth)

Scotland and Northern Ireland

<table>
<thead>
<tr>
<th>Lead organisation</th>
<th>Sector</th>
<th>Amount Funded</th>
<th>Base Region</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>National disease association</td>
<td>Non-statutory</td>
<td>£100,170.00</td>
<td>Glasgow (Scotland)</td>
<td>The scheme aims to improve the mental well being of all those affected by a specific life-limiting disease by providing a new telephone counselling service and by training volunteers to provide face to face counselling for people with the disease and their carers.</td>
</tr>
<tr>
<td>Hospital trust</td>
<td>Statutory</td>
<td>£126,236.00 + £68,000</td>
<td>Eastern Health and Social Services Board (Northern Ireland)</td>
<td>The project will - i) assess the palliative care needs from a holistic perspective of people living with a specific life-limiting disease ii) Provide an innovative user and needs-led community based palliative care service.</td>
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</table>
Funded Schemes Selected for Level Two Case Study (briefer)

Scotland and Northern Ireland

<table>
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<tr>
<th>Lead organisation</th>
<th>Sector</th>
<th>Amount Funded</th>
<th>Base Region</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice</td>
<td>Non-statutory</td>
<td>£124,991.00</td>
<td>Southern Health and Social Services Board (Northern Ireland)</td>
<td>The provision of a ‘seamless continuity of care’ for discharged patients. The hospice nurse would co-ordinate the transfer of the patients palliative home care needs, catering specifically for the individual needs of the patient.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Non-statutory</td>
<td>£130,244.00</td>
<td>Highland NHS Board (Scotland)</td>
<td>To provide support in the family home to families with children with palliative care needs, train staff in other organisations who work with children with life threatening/limiting disease. Carry out a needs assessment with young people with palliative care requirements</td>
</tr>
</tbody>
</table>
Appendix 3 National stakeholders interviewed to date.

Big Lottery Fund:


Eric Samuel: Acting head of policy & development, Scotland

Julia Holmes: Palliative care initiative case manager, Scotland.

Joanne McDowell: Head of policy development & public affairs, Northern Ireland.

Gavin Adams: Operations manager, Northern Ireland.

Jill Wiltshire: Senior policy officer, Health programmes, London.

Department of Health:

Katrina McNamara-Goodger: Policy lead for children's palliative care nursing and adviser on children's services, England only. Involvement in programme from February 2002 and observer status on grant selection committee. (Now moved to free-lance consultancy post.)

Sue Hawkett: Nursing Officer, Cancer and Palliative care services, Department of Health. Involved in policy direction for programme; observer status on grant selection committee.

England:

Children’s strand

Barbara Gelb: Chief Executive Association of Children’s Hospices (ACH) Consultation and advice during programme development; committee member.

Ann Goldman: Paediatric Palliative Care Consultant, Great Ormond Street; Vice Chair of ACT

Simon Lenton: Consultant Paediatrician; Chair of Bristol care pathway group; co-author of paediatric palliative care course for lottery funded schemes; previously advisor to the Department of Health on paediatric palliative care.

Adult strand

Ms Valerie Greenhill: Lead nurse Mid Trent Palliative care strategy.
Mr Peter Tebbet: Palliative Care Development Adviser, National Council for Hospice and Specialist Palliative Care Services, commissioned by Big Lottery Fund to establish PCT target areas.

Lucy Sutton: National Council for Palliative Care.

Mary Casey: National Care Homes Commission and CSCI.

Scotland:

Dr Anna Gregor: Lead Cancer clinician for Scotland (Cancer Csar); Director of the SE Regional Cancer Advisory group.

Liz Porterfield: Head of the clinical strategy of cancer. Scottish Executive Health Department.

Patricia Wallace: Director, Scottish Partnership for Palliative Care.
Appendix 4 Case study vignettes

Vignette 1 Somerset coast adult hospice at home service.

This home-based scheme represents a partnership between a PCT and an established hospice, located within a rural area of South West England with pockets of deprivation and a higher than average level of elderly population. Somerset Palliative Care Strategy (April 2002) demonstrated that only 30% of cancer deaths were occurring in the home, with 59% occurring either in hospitals or hospices. This scheme aimed to facilitate an increase in overall provision of specialist, multi-professional, community palliative nursing care to enable patients (with cancer and other conditions) to be cared for at home during the final days of their lives. The service offers 24-hour therapeutic nursing, emotional and respite care.

The service (in common with many other schemes) took longer than expected to become established due to: recruitment difficulties; establishment of the statutory / voluntary sector partnership; awareness raising of the scheme amongst those likely to refer patients and establishing confidence in the service.

Recruitment of health care assistants in particular proved difficult, mainly due to the unsocial hours and flexibility required within the post. The recruitment period also coincided with other agencies increasing staff levels. Staffing levels were achieved by seconding some staff from the hospice to the scheme.

Strong links to the hospice have proved beneficial in terms of training community staff and extending the availability of complementary therapies to those in the community (either directly or by training hospice at home staff or caregivers.)

Referral to a service designed for the last five days of life proved problematic, despite the experience of the local district nursing team. Referrals were therefore initially less than anticipated. A decision was taken to relax the operational policy, to expand the service to provide additional respite, outside of the last few days of life. This enhancement provided the means to create more regular working patterns for the home care nurses.

To date, less than 7% of referrals relate to a non-cancer diagnosis, largely reflecting a lack of awareness amongst those likely to make a referral. Almost half of referrals reflected a ‘crisis’ rather than a planned intervention. Almost a quarter of patients lived alone. More than a third of referrals related to caregiver psychological and support needs.

Satisfaction levels amongst those who have benefited from the service (including patients and caregivers) have been high, however, it has been
demonstrated that early introduction to the nurses and the scheme prior to a crisis situation is beneficial in establishing a relationship of trust.

"It was brilliant." (Daughter / carer of deceased patient who was cared for and died at home.)

"There's something quite special about a death at home, if it goes well...you can see the family get a great sense of achievement." (Community specialist palliative care nurse.)

"We used [hospice at home nurses] very successfully, for a young man who wanted to die at home.....everybody was able to say their goodbyes… I think that made the death a lot more peaceful, it made it more dignified" (District nurse.)

Local nurse teams with palliative care skills (district nurses, community nurses, community palliative care specialist nurses and hospice at home nurses), some employed by the PCT and some by the hospice, co-operate with each other in the community to gain the best advantage from this service for their patients.

An effective steering group of highly committed individuals from various agencies, including primary care, meets regularly to monitor this service and provide guidance on advancement. The scheme had always been assured of sustainability, but the benefits were recognised early on and it acted as a lever for the development of a county-wide hospice at home service which is now mainstreamed.

Contact details: Lynda Chatfield
Deputy Director Community Services
St Margaret's Somerset Hospice
Heron Drive, Bishop's Hull
Taunton, Somerset, TA1 5HA
Tel: 01823 345905
This adult hospice at home scheme is located in an ethnically diverse and deprived area with some areas of dense elderly population in outer London, spanning two PCTs.

The scheme was designed to fill gaps in the district nursing service, which did not provide overnight cover. A scooping exercise had identified approximately sixty people within each PCT in the last 2 weeks of life and requiring palliative care services.

The service is co-ordinated from an NHS funded 12-bedded dedicated palliative care short stay unit based within the grounds of a district general hospital. The unit had been experiencing a number of night-time calls for palliative care advice, which detracted from staff focus on the in-patients. Since this service has been set up, the level of calls has reduced dramatically.

Referrals to the service are accepted from GPs, the hospital, Macmillan nurses and others, the only criteria being that the patient is receiving day-time assistance from the district nursing services. Service take-up has increased and additional staff have been recruited. Hospital admissions for patients who are at ‘end stage’ has reduced for those who wish to stay in their own homes.

The care staff are based in a GP out of hours centre, located within a walk in centre based at the hospital. Close liaison with the out of hours GPs provide a two-way back-up system, with the nurses assisting on GP palliative care call-outs and the GPs assisting with prescribing and advice to the palliative care nurse sitters. All patients on the current list for service provision get a nightly call to see if they require services through the night. If not, caregivers are advised that they can call if they feel that they need to, or in an emergency and they will receive a visit. This protocol has proved to be an unexpected benefit of the service development as it was not included within the original proposal but evolved during the set-up period.

Although the majority of service users have been cancer patients, a limited number of people with conditions other than cancer have received services. The majority of patients are female and over 40, but the service has been provided for some younger people. A limited number of people from ethnic minorities have taken up the service to date.

Nursing staff recognise that each situation is likely to be different:
"They're all so different...every one is individual, you rarely get routine calls."

(community nurse)

In addition, the service providers require quite special skills:
"It is one job that, you've got to be a certain type of person, you need to be a good nurse and you need a sense of humour, otherwise you'd always be in tear. And you need to know when you need a rest...One of the biggest responsibilities when someone is dying.. the family will remember that time for"
a long while in the future and you want to get it right... what is right for that family... you want things to be as natural as possible." (community nurse)

This scheme is valued by patients and professionals. Although continuation funding has yet to be secured, the model of service delivery has proved innovative and successful.

Contact details:
Janet Hendrickson,
C/o Margaret Centre,
Whipps Cross University NHS Hospital Trust,
Whipps Cross Road,
Leytonstone, E11 1NR.
This 36 month adult palliative care scheme, builds on the strong links, learning and experience gained from an earlier Living with Cancer lottery funded scheme. This scheme is designed to serve the whole of Sunderland and will extend and improve current palliative care provision. Although the PCT is the lead organisation, services are delivered in partnership with various voluntary (e.g. carers centre and counselling service) and statutory sector (e.g. primary care, social services and acute trust) organisations across Sunderland. The scheme also has strong links with an NHS hospice, attached to the local district general hospital.

Services include:
an increase in service provision to improve the out of hours palliative nursing service; the appointment of a practice development nurse to support and equip community nurses with skills and knowledge to provide high quality palliative care including for those with non malignant disease; nursing therapy including home chemotherapy and blood transfusion; extended social care provided by a social worker; complementary therapies at home; a volunteer befriending and sitting service and practical support including a gardening and handyman scheme; counselling; financial and welfare advice and a programme of further learning opportunities.

The scheme targets people who have cancer; coronary heart disease; lung disease; neurological and other life-threatening illness, and their carers.

Much of this scheme is likely to be sustainable, as the statutory bodies involved have already undertaken to pick up the costs of continuing health and social care initiatives. Other aspects will require further consideration.

Despite the goodwill of the partners, during the early stages, this scheme faced some difficulties in terms of low levels of referral; late referral and fewer then anticipated referrals involving people with conditions other than cancer.

Efforts to raise the number of referrals for people with conditions other than cancer include a half time funded social work care manager to help to develop non-cancer palliative care; collaborative working with a specialist heart failure nurse and the availability for training in communication skills specifically on how to break bad news.

Timing of referral was raised as an issue in terms of when to introduce services; when to withdraw services and how long services can be provided (e.g. complementary therapies and counselling). The use of terms such as: hospice, bereavement and palliative care, which are often perceived to be emotive and carry stigma have been raised within the scheme and are subject to ongoing debate amongst the professionals involved.

Users of the counselling and complementary therapies have commented: “In my opinion it doesn’t need improving as it helped me immensely”.
and:

"With the help of my counsellor I was able to address my feelings and I have now returned to work. Many thanks ..I truly found this service helpful."

Contact details:

Katherine Henderson          Michael Walls
Modern Matron                Cancer Modernisation Officer
St. Benedict's Hospice       Sunderland Teaching PCT
Monkwearmouth Hospital       Pemberton House
Newcastle Road               Colima Avenue
Sunderland                   Sunderland Enterprise Park
SR5 1NB                      Sunderland SR5 3XB
Tel: 0191 5699195            Tel: 0191 5297206
This 3 year grant scheme was designed to improve quality of life for people with Huntington’s Disease, through effective palliative and social care in one of four Health and Social Services Board (HSSB) areas of Northern Ireland. The scheme was developed in close association with the Scottish Huntington’s Disease Association, which has previously demonstrated that a specialist service can have a significant impact on the quality of life of those affected by Huntington’s disease. Lottery funding has created a specialist service, which provides both outreach to those affected by Huntington’s disease and training and support to health and social care professionals who come into contact with their families.

The project, which is one of six grant schemes within the HSSB ‘umbrella’ grant scheme, is located within a statutory sector organisation, working in partnership with the Northern Ireland Huntington’s Disease Association, a small voluntary sector organisation.

Huntington’s Disease (HD) is a high risk, familial and hereditary, progressive, degenerative, neurological condition, affecting both physical and mental states. The patient may be identified as palliative almost from the point of diagnosis, but death can often take up to 25 years. Evidence suggests that many health and social care professionals lack understanding of the condition and are therefore ill equipped to meet and manage the needs of this complex client group. As the condition has many aspects to it, in terms of services:

“it doesn’t quite just sit nicely anywhere” (Consultant in clinical genetics)

People living with HD and their families describe themselves as “the forgotten people”. Families affected by Huntington’s frequently live with multiple loss, as husbands are often succeeded by sons and grandsons with the condition. Until the development of this project, there had been no specialist Huntington’s nurse or specialist service for Huntington’s in Northern Ireland. There is no dedicated respite facility and hospices are not generally appropriate for this client group.

A Senior Health Board respondent said of the scheme:

“I think the improvements in quality of life are immense…we haven’t had [a nurse specialist focus on] Huntington’s disease until X came into post…this [Huntington’s disease] is one of the most complex and horrendous diseases that we have.”

The scheme has added credibility to and strengthened the Huntington’s Association in Northern Ireland, which had been struggling to survive, as it is constituted mainly of those with or caring for people with the condition.
Health and social care professionals now involved with the scheme have suggested that they were previously unaware of the extent of [largely emotional and social] problems related to Huntington’s disease, until this project began to raise awareness of them and provide training resources.

“And it was a very interesting situation that caused us to look differently at how we provide care and begin to look at the whole concept of exceptional packages for people as they become more dependent and more needy. So that has been a very interesting outcome” (Senior social services manager)

The scheme has received additional funding due to the failure of another scheme to get off the ground, but has been unsuccessful in recruiting a second nurse. The stress and isolation of the nurse specialist post has taken its toll.

The scheme has to date been limited to operating within the boundaries of one HSSB and could therefore be regarded as inequitable to those who live in other parts of the province. Reconfiguration of health services may impact on the future development of this service. A needs assessment being undertaken across the province will provide evidence of need and [lack of] current service availability.

The scheme takes account of Section 75 of the Northern Ireland Act, 1998, regarding the need to promote equality of opportunity, with the specialist nurse having a caseload of families from across the locality.

Two Local Health and Social Care Groups (LHSCGs) have expressed an interest in the scheme, in relation to their chronic disease management programmes. The Health Board has identified the need for this service to be incorporated within future strategic planning and is championing its continuation and development.

**Contact details:**
Marie Murphy
Belfast City Hospital,
Lisburn Road,
Belfast
BT9 7AB.
Tel: 028 9026 3982
Email: marie.murphy@bch.n-i.nhs.uk.
Vignette 5 Scottish Motor Neurone Disease

This charitable sector grant scheme is providing a new service, which fills a previously unmet need across Scotland. Motor neurone disease (MND) is a rare condition, which requires palliative care almost from the point of diagnosis. Patients with MND and their carers argued that specialised counselling should be available. The Big Lottery Fund grant has enabled the organisation to expand and deliver this new service.

MND affects 1:12,000 of the population, with an incidence of 1:50,000 cases per annum. In Scotland, there are an average of 120 new cases of MND diagnosed each year. At any one time, therefore, there are on average 240 people living with MND in Scotland.

Age of onset is usually between 40-70. Survival from first symptom is on average 2-5 years (14-16 months from diagnosis). The UK Motor Neurone Disease Association has developed a pathway for the management of the condition. Counselling (for both patients and carers) forms one small, but key element of the pathway.

The Scottish Motor Neurone Disease Association has recruited volunteers with counselling qualifications and experience. Additional training and support has been provided on bereavement issues through a collaboration with the specialist bereavement organisation – CRUSE. In addition, detailed training on the nature of motor neurone disease has been provided by specialist MND nurses. Once trained, volunteer counsellors are in a position to offer counselling across the whole of Scotland, to those people affected by motor neurone disease, either by telephone or at a mutually convenient location e.g. GP practice.

The service also offers telephone counselling from a trained counsellor employed with the BIG Lottery funding and based at the organisation headquarters, as well as face to face counselling from volunteers.

Although there were initial problems in recruitment, the scheme is now delivering a counselling service to those in need and training additional volunteer counsellors.

Contact details:
Scottish Motor Neurone Disease Association
76, Firhill Road, Glasgow G20 7BA

Website: www.scotmnd.org.uk
Email: Craig.Stockton@scotmnd.co.uk Telephone: 0141 945 1077
Vignette 6 Community Children's Palliative Care service.

The aim of this home-based scheme is to develop and improve existing services in the locality for children with life-limiting or life-threatening conditions needing home-based palliative care. The scheme represents a partnership between two Primary Care Trusts and an acute hospital trust. The scheme is located within an urban area of high levels of deprivation and almost 50% minority ethnic population.

Recruitment difficulties and a period of acclimatisation led to a long delay before service delivery commenced. The appointment of an H grade community palliative care nurse post-holder required creativity in recruiting a nurse with experience of community working, but not in palliative care. The nursing service, adopting key-worker roles, provides respite care, advice and support at the end of life for children with life-limiting and life-threatening conditions and their families.

Additional staff recruitment has been ongoing and required negotiation with the funding body to address availability and skills shortages. Additional posts advertised were for play leaders and nursery nurses rather than qualified nursing staff.

The community palliative care nurses work within the paediatric units of two acute hospitals and alongside two community children’s nursing teams. Multi-agency working includes social care agencies. Children are referred for home based palliative care from all sources, although the working arrangements mean that the nurse is usually familiar with the child and their family already.

The scheme is designed to provide tailored care including: practical support in the home; advice on illness and diagnosis; co-ordination of services; end of life support in the home; bereavement care and sibling support.

The impact of the new palliative care role and model of working has led to closer working relationships between different groups of nurses (acute and community) and community nurses from two different locations.

Various ‘tools’ have been developed to support multi-agency working including: referral criteria; evaluation tool; dependency rating tool; nursing risk assessment. A leaflet describing the service has been developed and disseminated. Data collection systems have been put in place for the monitoring and audit of services.

The caseload remains relatively small, with 18 families across the two districts. However, many of the families are immigrants and translators are required to assist communication. Visits therefore require careful planning and longer than they would with English speaking families. Translators are quite widely available within the GP practices and PCTs across London, covering many of the major languages of the BME groups living there. However, some communication difficulties have been reported in relation to certain dialects.
There are currently discussions underway to develop plans to expand respite care within the scheme. Sibling work has been identified as a key area requiring additional focus (hence the need for nursery nurse and play leaders to assist in this work).

An effective and supportive steering group is working towards the strategic development of the scheme in the longer term. The involvement of a service user to this group has proved impossible to date.

The original nurse resigned her post in Spring 2006, mainly due to uncertainties about the future of the scheme. She has not yet been replaced, due to continuing financial uncertainty, although services are being maintained. A second visit to the scheme, planned in summer 2006, will ascertain future plans and developments.

Contact details: ingrid.marriott@brentpct.nhs.uk
Vignette 7 Children’s hospice scheme

This children’s hospice scheme is situated near the north east coast and serves the population of a large rural county. The children’s hospice is a relatively new unit, attached to an existing adult hospice. The proximity and shared resources appear to provide a number of benefits to both adult and children’s units, in terms of staff training and transition between the two units where appropriate.

A high proportion of children using the services of this hospice suffer from severe neurological disabilities such as epilepsy and cerebral palsy with associated complications.

The lottery grant enabled this scheme to recruit additional nursing staff; train staff and carers to provide physiotherapy and complementary therapies (such as massage) at home.

A novel initiative here is the provision of portable videophones that can be used when parents and children are at a distance from each other. The videophones are used both for children of adult patients and where the child is the patient and the parents are not able to stay with them in the hospice. The videophones enable children and their families to maintain visual and audio contact, which can be very reassuring for both parties. They can also be used as a tool for nurses or carers in the child’s home environment to obtain advice from hospice staff. The videophone is a compact and portable unit, which connects to a standard telephone socket and electric plug.

St Andrew’s has worked hard to raise awareness of its children’s services both within the community (through its shops) and amongst health professional colleagues. Training events for health professionals have been evaluated very positively.

The hospice scheme has also been very successful at delivering support services to (more than 100) siblings.

“We have dedicated days where the siblings of the children from the children’s unit and the children of adult patients come in and we focus specialist activities on them, giving them a chance to be able to talk about how they’re feeling, giving them an opportunity really to get to meet the nursing staff and then also to be able to build up relationships with them”. (Nurse manager)

The children’s hospice unit is exploring future developments in transition for adolescents and young adults.

Bereaved parents appear to have benefited from working alongside the fund-raising team and being involved in publicity.

This scheme has established good links with other (home based and bereavement) schemes and forms part of the joint palliative care strategy for
the region. Sustainability was written into the original proposal, with nursing posts funded on a sliding scale and gradual up take by the hospice own fund-raising. The videophones were purchased at the outset and have no further revenue implications.

Contact Details:
Michelle Rollinson
Clinical Nurse Manager
Saint Andrews Hospice
Peaks Lane, Grimsby
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Vignette 8 Naomi House

The Wessex Children's Hospice Trust was established in 1991. By 1997, Naomi House was the first children's hospice in central southern England. The catchment area covers 7 counties: Hampshire; Dorset; Wiltshire; parts of Berkshire, Isle of Wight; Surrey and West Sussex.

Naomi House (known as “The House”) is a ‘centre of excellence’, which provides respite and palliative care for children with life-limiting conditions and their families. (Approx 10% of these children have a diagnosis of cancer, the remainder suffer from a range of complex conditions such as neuro-degenerative and genetic conditions. Many of the children have multiple complex conditions and the majority are wheel-chair bound). Naomi House is dedicated to providing holistic, family centred care.

This 3 year lottery grant has mainly supported the employment of additional staff to fill new roles, designed to enhance existing services, including: a play-team; sibling support; family support team and education and training co-ordinator. These new staff and services are specifically focussing on the adolescent group of referred children, who have made it clear that they would like to have services more appropriate for their age group and separate from the younger children, whose needs are very different.

Although the play team may have developed, it is unlikely that other developments would have happened without the lottery funding.

‘Referred children’ come mainly on planned visits to the House for respite, having an annual allocation following initial assessment. There are approximately 40 adolescent children currently attending, aged up to age 24. As children with complex conditions live longer due to medical advances, transition to adult services is often deemed inappropriate. In addition, the 2002 Care Standards Act requires care to be provided for ‘young people’ at separate times to younger children (although this has clearly been expressed as a requirement by the young people themselves.)

"The difficulty does come when they're [young people] living longer and longer". (Care team member)

"With medical technology keeping people alive longer, the demands that puts on society and their families are huge and so that urgently needs to be addressed." (Care team member)

Development of services is ongoing.

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Vignette 9 Nottingham Butterfly and bereavement schemes

Two separately funded schemes in Nottingham provide an example of a home-based scheme working in parallel with a bereavement scheme, both commissioned through a Primary Care Trust (PCT). A number of agencies (both statutory and voluntary) are involved in delivery of services and participate in the steering group. The schemes are designed to enhance the quality of 'referred' children’s lives, along with those of their siblings and families, by assessing their individual needs and arranging for appropriate (mainly social care) services to be put in place, provided largely by a group of volunteers who have been recruited and supported by a (limited) budget to provide ‘therapeutic’ enhancements to their quality of life. The scheme will also ensure that professionals (e.g. teachers, GPs etc) involved with the child and family have the appropriate levels of support and guidance.

The schemes faced considerable challenges in setting up completely new services. Since the proposals were submitted, there have been three changes of ‘lead’ personnel at the PCT. The schemes experienced some difficulties in recruiting to the new posts, particularly the ethnic minority worker post. There has also been a need for extensive ‘run in’ periods, during which time new recruits familiarised themselves with each other, with existing services in the locality and more widely. Selection of a sensitive and appropriate name for the home-based scheme also took longer than expected and created some delays in the distribution of information materials. In establishing an effective partnership, there have been substantial debates and negotiations, reflecting the diversity in managerial structures, accountability boundaries and organisational behaviours of the multiple participant agencies. Referrals to all aspects of the scheme were limited initially but have developed over time. Although the scheme experienced a slow start, many of the key stakeholders claimed that the value of building a strong foundation would be demonstrated in the longer term sustainability.

Home based scheme – the Butterfly project

A service level agreement has been drawn up between the PCT and the leading voluntary sector organisation, which has employed three new staff. A social worker has responsibility for recruiting, training and supporting volunteers, who will provide services within the home including sitting, taking a sibling out to music lessons etc. to allow respite for carers.

After a considerable delay, the scheme was successful in recruiting a BME project worker, with considerable experience in both social services and the community, who has been working with families to ensure that appropriate services are in place, respecting cultural needs and addressing communication requirements.

Guidelines are being developed for bereavement and educational services.
An education project worker is working with schools and in the community to provide support and guidance to enable children to remain in or return to school.

A consultant community paediatrician was also recruited to the scheme on a part time basis. The community paediatrician provides support and guidance to various health professionals in particular, as a child enters the end stages of care. In addition, a database is being developed, which will provide information on all those children with complex (palliative care) needs in the locality.

**Bereavement scheme**

A bereavement support worker has been employed within one of the partner (statutory) organisations, to work alongside an existing post-holder as well as the home-based team, to enhance bereavement capacity in the community. Information provided by this service emphasises the family’s right to choice in the matter of where the child can or might die.

The bereavement support worker is also providing education and training to other (health and social care) professionals, in order to support and empower them to assist children with palliative care needs and their families during bereavement.

Referrals come directly from families, ward staff or via the home-based Butterfly scheme and can be made either before or after the child has died, as appropriate. As identified within many of the other services, both adult and children’s, benefits are recognised where a relationship has been established before a crisis situation is reached.

This service is being delivered and evaluated through a rigorous audit process, which demonstrates that to date around half of the ‘referred’ children have been affected by cancer and a number have subsequently died. Support structures and mechanisms are in place to support the bereavement worker in this very sensitive and difficult area of work.

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This 33-month home-based scheme represents a partnership of two statutory health bodies (PCT and acute trust) and two voluntary sector organisations (Share Care and Signpost for young carers). The scheme has established a new multi-disciplinary team to provide a round-the-clock, co-ordinated care programme for children with life-limiting conditions and their families in Stockport. Services include: nursing, care co-ordination, training for carers, home help, play therapy, nutritional advice, day and night respite care, psychological support and family support.

The original proposal was based on gaps in service in the locality, identified by the paediatric home nursing service. Due to limited capacity and resources, the existing service was unable to deliver desirable levels of care. This meant that some children were being admitted to hospital inappropriately in order to give their caregivers a break.

The PCT holds a database, listing all children with a disability, including children with a life limiting condition. Data is incorporated on a voluntary basis as a result of parents being asked what their needs are and what services they are currently receiving. The Stockport database has won awards and the PCT is visited by other organisations wanting to develop a similar system. The database provides an important evidence base for the scheme.

The scheme is located in an urban area. A nurse co-ordinator was recruited in September 2003 and the scheme had an official launch with wide publicity in April 2004. The grant is due to run until summer 2006.

The team (nurses, support workers and dietician) are employed within their various parent organisations and come together regularly to discuss and review their case-load. Internal evaluation of the scheme has illustrated that the flexible model created has been successful in meeting the needs of children, families and other health professionals. The scheme is also working very closely with a separately funded local bereavement scheme.

The scheme has an open referral system, but as the nurses are based in the children’s unit of the district general hospital, many of the referrals come from hospital consultants at the point of diagnosis. The nurses therefore take on the mantel of key-worker for the family and are able to liaise with other agencies as appropriate, managing and often reducing the level of contact from different professional groups. The majority of referrals are for children with neurological conditions, with a small number of oncology cases. The scheme has exceeded its original estimates.

Flexibility is key to meeting the needs of families, many of which are for social support rather than specific health needs. Services can be provided at short notice, in the home, or within the hospital (nurses from the scheme have stayed overnight on the ward with a dying child, supporting the family and nursing staff.) However, when dealing with a crisis situation in one family,
other services have sometimes had to be pulled back, due to capacity, which has caused some annoyance to families. The provision of training for practitioners and parents to provide home-based therapies is a particular benefit for families.

"I think what makes this project work is the partnership, and the fact that it is the holistic service....you can put in nursing and you can put in family support as well. [It needs to continue] in its entirety, else it would lose its coherence." (Project manager)

The scheme was about to move into a new arrangement under the Health Act Partnership, which brings together all services for children with a disability including health, education and social services. Dragonfly was to be part of the first phase of this new partnership development. The Partnership does not involve any additional funding, each of the partners would bring their own budget. The idea is to deliver co-ordinated and effective service for children with a disability and their families.

Sustainability plans and means of securing long-term funding have been under discussion for some time.

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