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Using the Gold Standards Framework in Care Homes: An Evaluation of the Phase 2 programme

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Report prepared for Macmillan

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Acknowledgements

Executive Summary

This report summarises the findings from a research study that:

1. Evaluated the impact of introducing a modified version of the Gold Standards Framework (GSF) (Thomas 2003) into the care home setting.
2. Aimed to identify those features which supported or prevented the implementation of GSF into care homes for older people in England.

This broad programme of work had three elements:

1. The Gold Standards Framework in care homes (GSFCH) to enable improvement in end of life care of residents in care homes, based on the GSF in primary care. The GSFCH involved a development programme designed to support care homes. The programme, delivered by the GSF team, involved a series of four workshops held over a nine month period and the support of a local facilitator.
2. The research evaluation which addressed aims 1 and 2 above was managed by a team located at the University of Birmingham. The evaluation commenced in June 2005 and was completed in June 2006.
3. The GSF team and the research team developed a symbiotic working relationship in which evidence produced at each stage of data collection was relayed from the research team to the GSF team to inform consideration of issues and ongoing development of the GSFCH programme.

The Study
The overall aim of the evaluation was to examine the impact of introducing a modified version of the GSF (Thomas 2003) into the care home setting. A second aim was to examine those features which supported or prevented the implementation of the GSFCH programme.

Methods
Quantitative data were collected by surveys completed by care home managers pre, mid point and post GSFCH programme implementation. The pre and post GSFCH data were used for the analysis, and comparison between these indicated how patterns of care giving changed over the course of the GSFCH programme. Qualitative data were collected by open questions in the survey tool and by a series of case studies involving interviews with staff, residents and family carers[1] in the care home sites. A series of telephone interviews was completed with managers in a small number of homes. Facilitators were given the opportunity to comment on programme expectations in a semi-structured survey and their role was evaluated as part of the overall study.

Sample
All homes participating in the GSFCH Phase 2 were asked to take part in the evaluation. Of the 95 homes that started the programme 79 returned baseline surveys before the programme implemented. By the end of the programme 49 homes had completed both pre and post GSFCH surveys, an overall response rate of 55%. Interviews were largely located in the 10 homes that were the focus of the case studies. Interviews were conducted with care home managers, staff and a small number of residents and relatives.

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[1] In this report carers refers to family carers.

Findings

The indications are that care homes made progress in implementing improved end of life care following participation in the GSFCH programme. These are presented from the perspective of the overall project aim to evaluate factors supporting or hindering implementation of the GSFCH in the participating homes. Data from the surveys, case studies and follow up telephone interviews to staff in the homes that did not complete the GSFCH evaluation are presented under the following headings that emerged as part of the iterative commissioning process.

The care homes organisational context:

Characterisation of the client population

GSFCH was regarded as relevant to the range of illnesses and the context of care in which people in nursing homes die. Homes that did not complete the audit surveys were largely similar in a range of organisational characteristics, such as size and care delivery to those that did.

Structure, culture, and organisation of the care home

Organisational factors had the potential to influence the extent to which care homes might be able to adopt the GSF, including the relationship with other health care practitioners, access to training, management support and teamwork.

Staff and skill mix issues

Case study data indicated a link between a stable workforce, good teamwork and capacity to adopt GSFCH. Reasons why homes were unable to complete the evaluation included staffing and workload issues and GSFCH workshop location. Staff resources and training budgets impacted upon access to the four national workshops and local GSF related training.

Processes:

Relationships with the primary health care team

Improvements in relationships with primary care practices were reported as one of the positive outcomes of involvement in GSFCH by some homes. In particular communication with GPs was seen to be more productive. Staff reported greater confidence when discussing residents with GPs, resulting in a more productive dialogue. In some cases though difficult relationships endured. Some of the improvement in relationships was attributed to the programme's acknowledgement that care homes are providing skilled nursing care to people at the end of life. Staff found this acknowledgement and the programme empowering.

Impact on residents and carers

Significant differences pre and post GSF were found in relation to: increased use of end of life care register, having a coordinator for end of life care, routine use of advanced care planning and having discussions about end of life care with residents. Residents expressed a preference for staying in the care home to receive all their care. GSFCH enabled residents', wishes around end of life care to be discussed and clearly documented. Fewer residents experienced crisis hospital admissions, and more died in the care home setting following GSFCH.

Categorising care needs using a "banding" approach

The A-D banding system incorporated in the GSFCH enabled staff to identify which patients were more critically ill. This approach was not used in any homes at the outset but, upon completion, 88% had used this. Of these the majority found the banding useful.

Education and resource material

The GSFCH programme produced an increased use of the Macmillan 'Foundations in Palliative Care' training programme for staff. The programme also guided care homes through key tasks which aimed to equip staff with the skills to ensure that residents at the end

of life had a dignified, pain free death, in the place of their choice. One of the key advantages in taking part in the GSFCH was that it bought a training opportunity to the homes.

The role of the facilitator
At the outset facilitators expressed concerns about a range of issues that they felt may impact on implementation of GSF. Availability of a facilitator was a key feature in the support of care home staff yet the provision of facilitator support was beyond the remit of the GSF team.

Limitations of the Evaluation

The evaluation did not include a control group of homes. This would have presented both practical difficulties and resource implications. Consequently on the basis of this analysis it is not possible to say conclusively that the changes in end of life care are a direct result of introducing the GSFCH. Overall though the findings indicate that GSFCH has the potential to contribute towards improved end of life care.

Conclusions

- GSFCH was successfully adopted by many care homes.

- This study has shown the GSFCH produced demonstrable improvements in the quality of care at the end of life in homes that were able to adopt this approach to care.

- Introduction of the GSFCH reduced the crisis admission rate to hospital at the end of life by circa 12% in the study population.

- This pattern is also reflected in a reduction of residents' deaths in hospital, from 18% to 11%.

- Review of the data collected in the time frame of this study suggests that it is possible to identify features in care homes that may contribute to the successful implementation of the GSFCH.

- There is a relationship between the quality of end of life care offered by primary care health teams and the ability of care homes to successfully implement the GSFCH.

Recommendations

Recommendations are made in three areas: improving implementation of GSF, future care homes research and finally recommendations for policy makers. Recommendations were relayed to the GSF team as the project progressed, facilitating speedy response to the issues raised.

Summary and conclusion

Taking note of the potential limitations in methods, the indications are that implementation of the GSFCH programme has had a positive effect on participating care homes. Data from a wide range of sources demonstrated measurable differences in approaches to care pre and post the implementation of the GSFCH programme. A number of features that may help homes determine readiness to take up the GSFCH programme can be discerned. This includes key issues such as established level of team work in the home environment, existing patterns of care, motivation to develop better care at the end of life and working relationships with primary health care teams.

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Glossary of terms

ACP	Advanced care Plan
A-D categories	Categories, based upon life expectancy, which help indicate when advanced care planning should be considered, A-years prognosis, B-months, C-weeks, and D-days
Care home (nursing)/ Nursing home	A care home registered to provide nursing care. Homes may have 100% nursing beds or a combination of nursing and personal care beds. Residents may be self funding or receive full or partial funding from the NHS or local authority.
Care home (personal care) /Personal care home	A care home registered to provide personal care only.
CSCI	Commission for Social Care Inspection. Inspects all social care services in England, including all care homes whatever the status of the provider.
DoH	Department of Health
Facilitator	Responsible for acting as a link between the GSF team and care home staff.
GSF	Gold Standards Framework
GSF team	Gold Standards Framework team. The central team responsible for GSF implementation in primary care and care homes.
GSFCH	The Gold Standards Framework in care homes.
	The framework consists of 4 gears, 7 key tasks and several tools.
GSFCH Programme	The managed programme to support implementation of the GSF in care homes. Run by the GSF team it consisted of 4 national workshops, resources, teaching and local facilitation support. This study evaluated Phase 2 of the GSFCH programme, June 2005 to Feb 2006.
ICP	Integrated Care Pathway. A multidisciplinary care plan for use by all health carers in involved in a person's care.
LCP	Liverpool Care Pathway. An integrated care pathway for the last days of life.
NHS	National Health Service
Out-of-hours service	Service providing GP cover outside normal working hours.
Resident	People who live in a care home. Alternatives used include client, patient and service user.
SCR	Supportive care register. One of the GSF template forms.

SECTION 1: INTRODUCTION

The over arching aim of the study reported here was to evaluate the introduction of a managed programme for end of life care, the Gold Standards Framework, into care homes for older people in England. This development is important in the context of the NHS End of Life Care Programme (NHS 2006), which aims to improve generalist palliative care provided by all health care staff, including those in care homes, and to extend the benefits of palliative care experienced by cancer patients to all patients with end stage illness. It builds on the successful implementation of the Gold Standards Framework (GSF) into primary care teams since 2001 (King *et al* 2003, 2005, Thomas & Noble, 2007).

Use of the GSF in primary palliative care is recommended in the NICE Guidance on Supportive and Palliative Care (NICE, 2004) the House of Commons Health Select Committee on Palliative Care (House of Commons 2004), the Cancer Services Collaborative (2007), and the NHS End of Life Care Programme (NHS 2006). These recommendations are in line with national policy developments from the Department of Health NHS End of Life Care Programme and specifically the End of Life subgroup on improving care in care homes.

Implementation of the GSF in England is supported for three years, 2004-2007 by the NHS End of Life Care Programme, with funding to Strategic Health Authorities for local implementation.

Implementation and impact of the use of the GSF in primary care teams has been evaluated at each phase of the development plan devised by Dr Thomas and colleagues. This work was originally supported as part of an MSc study (Thomas 2002) and the NHS Cancer Service Collaborative. Subsequently Macmillan funded the GSF evaluation of Phases 3-6 of GSF in primary care at the Centre for Primary Health Care Studies at the University of Warwick. Other aspects have been informed by work undertaken in other collaborating institutions, supported by Macmillan's Research and Evaluation group. Use of the GSF in the community by primary health care teams was reported to be beneficial for patients, carers and staff across the UK (King *et al*., 2003; 2005, Thomas & Noble, 2007).

Macmillan Cancer Relief supported the promotion and spread of GSF in primary care in a two year GSF Support Programme 2003-4, supported by local Macmillan GP facilitators and Macmillan nurses. Macmillan published an education programme for care home staff, 'Foundations in Palliative Care', developed by researchers at the Open University. They also sponsored the evaluation reported here. The GSF in primary care and GSF in care homes' programmes are both currently supported by the Department of Health's NHS End of Life Care Programme.

Origins of the GSF

The GSF was devised seven years ago (Thomas 2002, 2003) and has since been successfully implemented in primary care. It is estimated that a third of primary care practices in England are using some aspects of GSF (King *et al*, 2005). An introduction to the GSF describes it in the following terms:

> *The Gold Standards Framework programme offers teams... a widely used, tried and tested, common sense framework of enabling tools and resources to help optimise their palliative care so that they can fulfil the wishes of both patients and carers. It aims to improve management of symptoms, reduce the elements of fear and uncertainty and enable more to attain their preference for place of care. It also improves support for carers, staff satisfaction, morale and team working with specialists and has an impact on reducing un-needed hospital admissions.* (GSF, 2005)

The basic structure of the GSF encourages practitioners to identify individuals in need of supportive care towards the end of life, to assess their needs, symptoms, preferences and any issues important to them. Planning care around people's needs and preferences can enable them to be fulfilled and in particular to allow people to live and die where they choose, often referred to as 'preferred place of care' (PPC).[2] The rationale for using the GSF in care homes is that it will assist care home staff, supported as appropriate by primary health care and specialist colleagues, in achieving the five GSF goals which are:

1. People's symptoms will be as well controlled as possible.
2. People will be enabled to live well and die well where they choose.

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2 Some documentation refers to preferred place of death, implying that the two are synonymous.

3. Security and support - patients experience less fear/anxiety, there is better information, fewer crises and fewer admissions to hospital.

4. (Family) carers will feel supported, informed, and involved.

5. Staff confidence, team working, satisfaction and communication will be better. (Thomas *et al* 2005, p10)

The Gold Standards Framework in care homes – GSFCH

Using the Gold Standard Framework in care homes
The use of frameworks such as GSF for organising care for care home residents in the last year of life has developed directly from work in primary care. Primary care teams wanted to be able to extend the improved level of care they identified through use of the GSF in primary care, for their patients who were resident in care homes.

The Gold Standards Framework in care homes evolved from the Gold Standards Framework in primary care programme. The complexity of care provision in care homes, shown in Figure 1, demonstrates the need for careful consideration of end of life care needs for people living in this sector.

The GSF has been modified for use in care homes by the GSF team. GSF for care homes (GSFCH) is seen as an extension of the care provided by the GP and primary care team in the community, underpinned with the same basic principles and criteria. However, there are particular challenges in end of life care in care homes, such as the private/NHS care partnerships, multiple co-morbidities, concomitant mental incapacity, staff turnover and cultural differences. However, as 20% of the population die in care homes, optimising care in this area is a vital part of improving end of life care (GSF 2005).

Figure 1: Characteristics of care homes for older people

- 20% of the population will die in a care home.

- Approximately 350,000 older people live in care homes in England (CSCI 2005), and 410,000 in the UK as a whole (OFT 2005).

- Care homes employ 800,000 people (CSCI 2005).

- Two thirds of care homes are independent small businesses and one third are in corporate ownership. Larger groups have in the order of 20,000 beds (Laing & Buisson 2004).

- There are three times as many care home beds as NHS beds.

- Average life expectancy of self funding residents in nursing homes is 20 months (Netten *et al* 2002).

- A census of 11,000 nursing home residents revealed high levels of dependency (Bowman *et al* 2004). Only 18% were ambulant without assistance, 19% had a normal mental state and 20% were continent.

- Multiple pathology and co-morbidity are common.

- Most common reasons for admission to care homes (nursing) were dementia (38%) stroke (25%) and frailty (22%) (Bowman *et al* 2004).

- Assessment and regulatory systems are poorly matched to residents' needs and care planning has been identified as one of the most important needs in the future (Bowman *et al* 2004).

To launch this programme in care homes the GSF team undertook a pilot project. In this phase of development, described as Phase 1 of the Gold Standards Framework in care homes project, 10 care homes in six areas of the UK participated. This phase was evaluated in a 'scoping study' (Maryon, Thomas and Meehan 2005). Phase 1 involved regular feedback, monthly conference calls, three workshops, questionnaires before and after use of GSFCH and visits from an independent analyst (KM) with clinical governance expertise to clarify developments, issues and problems and learning points. This work provided the insights required both to refine the implementation plan for the introduction of the GSFCH into a larger number of homes and to plan the larger programme evaluated here, Phase 2 GSFCH.

The GSFCH programme consists of:
- The introduction of the modified version of the organisational tool, the Gold Standards Framework to care homes (GSFCH).
- Local support to care homes from a GSFCH facilitator in the area.

- Central support of a GSF team, lead nurse, helpline, conference calls and mentoring.
- Training - provided by four national workshops in the course of the programme and specific training tailored to individual homes' needs, arranged by local GSFCH facilitators.

In addition to the five GSF goals (p 3), the aims of the Phase 2 GSFCH programme are to:

1. Improve the quality of care for patients nearing the end of their lives.
2. Improve the coordination and collaboration between care homes and GPs and primary health care teams.
3. To reduce the numbers admitted from care homes to hospital in the last stages of life (one of the main goals of the NHS End of Life care programme).
4. To make key suggestions for others interested in improving end of life care in care homes in a 'Good Practice Guide' (Thomas *et al* 2005, p5).

A longer term aim of promoting the development of a new collaborative model through which care homes and primary health care teams can work together has been suggested (Maryon *et al* 2005).

The GSFCH Development programme

Care homes were invited to apply to take part in the Phase 2 GSFCH programme. Criteria for homes' inclusion in Phase 2, which included the evaluation reported here, were:

- Awareness of GSFCH plans
- GSFCH implementation supported by a local GSF facilitator
- Support from the local SHA
- Satisfactory CSCI assessment
- Geographical location to reflect the population of England
- Willingness to participate in the research evaluation (Clifford 2005).

Homes signing up to use the GSFCH framework were offered support in progressing through the GSFCH programme. This included four whole day workshops which

were attended by a small number of staff from each home. The GSFCH programme was described and introduced in the 'Starter Pack' (Thomas *et al* 2005) and the four workshop programmes included presentations, which were relevant to the stages of the GSFCH, and specific details of how to approach the key GSF tasks. In this way homes were gradually guided through GSFCH. Participants were encouraged to access the GSF website, which had a wide range of detailed information about GSF, and other relevant sites. Care home staff are guided through the GSFCH programme and seven key tasks are identified which if addressed should result in the five goals being achieved.

These key tasks known as the 7 Cs are:

- o communication,
- o co-ordination,
- o control of symptoms,
- o continuity,
- o continued learning,
- o carer support (staff and family carers)
- o care of the dying.

(http://www.goldstandardsframework.nhs.uk/)

Homes were allocated a local facilitator who was knowledgeable about the GSFCH. They were available to explain and support GSF implementation and direct homes to local sources of support, training and contacts. Resources and supportive care templates were provided at the workshops and advice provided about additional resources. Facilitators were supported by the national lead nurse for GSFCH. The lead nurse started in post the week before the first Workshop, working part of the GSF team 15 hours a week. Care home teams participating in GSFCH were asked to identify a co-ordinator who had an interest in end of life care and could act as a link between the facilitator and the rest of the staff; in most cases this was the manager or a registered nurse.

Implementing GSFCH

Implementation of GSFCH is based upon the facilitation model, which was adopted in GSF in primary care and piloted in Phase 1 GSFCH. The pilot indicated that ideally facilitators should have a thorough knowledge of the GSF and to support this the GSF

team offers facilitators two GSF training sessions per year. A few GSFCH facilitators were GPs who had carried out the same role in primary care and most others were clinical nurse specialists in palliative care who had some awareness of GSF.

Homes participating in Phase 2 were informed about the evaluation and asked to sign up to both GSFCH and the evaluation. Members of the evaluation team were present at all four workshops. At the initial workshop they introduced the evaluation and at subsequent workshops presented ongoing findings. The GSF team, (NHS funded) and the Evaluation team from the University of Birmingham were both based in Birmingham. The four GSFCH national workshops attended by care home staff were held in the West Midlands.

Background to the Evaluation

Research Context

The project reported here focuses on 'Phase 2[3]', the GSFCH development programme that ran for nine months from June 2005. This evaluation of Phase 2 of the GSFCH commenced at the same time and followed the introduction of the programme into 95 volunteer care homes in England (Appendix 1). All but two of the homes had at least some nursing beds and were classed as nursing homes[4].

In planning this project the research team drew upon the sparse literature available to inform care giving at the end of life in care homes. The preliminary literature review using the broad headings of care homes and end of life care revealed a dearth of U.K. literature in relation to end of life care in the care home setting with the exception of work by a small number of UK based academics, (see for example Froggatt 2001, 2005, Froggatt and Payne 2006, Hockley & Clark 2002, Hockley *et al* 2005, Katz & Peace 2003).

This contrasts with a vast body of literature relating to end of life care for those with cancer (Gysels & Higginson 2004) that has relevance to the work proposed here. Similarly, there is a dearth of literature related to multi-professional team working in

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[3] The use of the phases to identify the programme gives an identifiable a time frame to the introduction and support programme by the GSF team leading this work. It also offers a time frame for evaluation purposes.

[4] The former terminology of dual registered home was used by some to describe homes which had both nursing and personal care beds.

care homes and the factors that impact on working relationships across the primary and secondary care sectors. This will be addressed as part of the project outlined below.

Questions arising from the preliminary literature review were:

1. To what extent are volunteer care homes ready to adopt new ways of working to support end of life care? Is such a framework acceptable to them and what are the current barriers?
2. Will the use of a framework such as GSFCH change practice in relation to end of life care in the care home sector?
3. What are the effects of such changes on residents' care, family views and staff practices?
4. What characteristics in team working contribute to the success or otherwise of implementing GSFCH guidelines? What other issues contribute to success or otherwise of implementing GSFCH and other frameworks including:
   - Organisational philosophy (i.e. scope of practice - nursing or general care only)
   - Skill mix (ratio of qualified health care professionals to support staff)
   - External factors including access to necessary multi-professional care support across health and social care.

5. How might GSFCH impact on relationships with the primary health care team?
6. What outcome measures best illustrate the effects of implementing GSFCH?
7. What are the best ways of evaluating the extent to which the seven key tasks of GSFCH have been achieved?
8. To what extent do disease patterns impact on the way in which end of life care is delivered; e.g. is there is difference between the care given to those people suffering with cancer compared with other conditions such as cardio-vascular or respiratory disease?

Arising out of this a research plan was submitted to the Macmillan Research and Evaluation (R&E) group. The study was designed to evaluate the implementation of GSF into care homes in England. Data from the study were to be encapsulated into a Good Practice Guide, with recommendations for practice improvement derived from the evaluation.

The aims of this one year evaluation of the introduction of phase 2 GSF into care homes in England were therefore:

1. To evaluate the impact of the GSFCH on end of life care in care homes for older people.
2. To identify the contextual and organisational features of care homes which supported or hindered GSFCH implementation.
3. To explore the extent to which care homes were able to adopt optimal standards of practice in end of life care.
4. To identify a range of indicators to inform future development of GSFCH (as defined by Macmillan R&E group).

The related research objectives set at the beginning of the evaluation were:

1. To undertake a **baseline survey** of care provision in participating care homes to determine:
   a. the nature of the client group
   b. patterns of end of life care
   c. existing systems used to organise end of life care.
2. To assess the perceived impact of using GSFCH on the **quality** of end of life care from the perspective of care home staff at operational and managerial levels.
3. To assess residents' perspectives on the impact of using GSFCH on the **quality** of end of life care planning in care homes.
4. To explore the **educational needs** of staff participating in end of life care to facilitate the intervention of GSFCH and to assess the potential for use of the Macmillan educational pack for care homes.
5. To explore the extent to which implementation of GSFCH influences **relations with local primary health care teams**, including GPs, district nurses (DN) and clinical nurse specialists (CNS) as relevant.

6. In relation to the last stage of life, to examine **hospital admissions** from care homes, especially for residents in the last week of life.

7. Within the context of the 'microsystem' (i.e. the teams in individual care homes) and through a series of case studies, investigate the **organisational factors for care homes** that impact upon optimal end of life care in care homes. [5]

Iterative processes

The interface between development and the research were seen as crucial to this project. As a new initiative it was important that findings from the research could be used to inform GSFCH development as the work progressed. From this perspective we built upon the notion of iterative working which was introduced to the project team early in the process. This was used at two levels: the commissioning level and the developmental level. These are outlined below and discussed in depth in Section 10 'Approaches to researching developmental programmes'.

Iterative commissioning

At a commissioning level the funders (Macmillan) developed an iterative approach to commissioning the research examining the implementation of the GSF which reflected the ideas discussed by Lilford *et al* (1999). It was from this background that funding for research was made available.

The iterative process in commissioning the research provided a challenge to the research team. This project formed one of several funded under the Macmillan GSF R&E programme so colleagues in that group had begun to formulate ideas of which features they felt were important to evaluate. The GSF team was keen to ensure that data collected built upon existing modes of evaluation in primary care and the pilot Phase 1 GSFCH study. Thus templates for baseline data and ongoing audit were, to some extent, prescribed.

In addition there was a need to consider how the planned mode of data collection addressed the indicators cited by Macmillan as potential outcomes of the work (Appendix 1). These requirements were cross checked against the initial project plan

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[5] This may include for example: skill mix, team work, satisfaction (staff & residents) workload.

to ensure the indicators were addressed.   The outcomes of this process can be seen in Section 2 Study methods.

Iterative working

One of the considerations in developing this research was to inform the GSFCH Central team of issues that may impact upon the implementation of the GSF programme into care homes. This resulted in an 'iterative research framework' in which emergent indicative research findings were communicated to the GSFCH development group at regular intervals, and enabled the group to use emerging data to facilitate developments in participating care homes. Homes in Phase 2 had a Starter Pack and as the project progressed emerging data contributed towards the development of 'Good practice guidelines' to support use of GSFCH within the care homes in Phase 3 (June 2006-February 2007).

A key part of review of this project is an examination of the approach adopted which will help us refine our methods of real word research in care home settings. The extent to which this approach was successful is described throughout the results and the implications for future research discussed in Section 10.

Summary

This section has given an overview of the context in which this evaluation was developed and identified the key drivers and constraints upon the evaluation. The anticipated project outcomes are wide ranging and will be addressed at different levels of detail in the report.

The following section describes how the study methodology was identified and developed in partnership with the GSF team.

SECTION 2: STUDY METHODS

This section summarizes the methods used to collect and analyse data in this study.

Methodological framework

This project reflects an action research approach in which the GSFCH research team worked in collaboration with the GSFCH team. As noted in Section 1, this facilitated an iterative process between the research team and the team responsible for implementing GSF in the care home sector.

A range of quantitative and qualitative approaches to data collection was used. To identify and evaluate the factors perceived as impacting upon the organisational capacity of care homes to adopt the GSFCH, data were gathered by survey and by a number of case studies involving interviews with staff and, to a lesser extent, residents and carers in the participating care homes. Presentation of data emerging through the research enabled the GSFCH team to make modification to the GSFCH programme as implementation progressed.

The survey tools were developed from those used in earlier evaluations of the implementation of GSF in primary care. This offered the potential for some cross sector comparison as it was anticipated that a number of aspects affecting use of GSFCH would be similar to those identified in earlier studies in primary care.

A sample of homes was accessed in the form of case studies to facilitate more in-depth review of factors impacting upon the use of the GSF in care home settings. Where possible, resident and family carers were invited to participate.

Data collection tools
Several approaches to data collection were adopted as described below.

- **Surveys**
  - **Audit Survey Tools** (baseline, intermediate and final) were developed initially from earlier evaluations of the GSF in Primary Care and refined as the project progressed. These tools, focused on the key

dimensions of the GSF, was modified to collect relevant data at 3 points in time noted below to enable the research team to track changes in practice associated with the use of GSFCH. (Appendix 2)

- o An **After Death Analysis** form (Appendix 3) was devised to record details of the five most recent deaths in care homes to provide a profile of deaths in care home residents. This was administered with the Baseline and Final Audit.

- o **Team working questionnaire** (Borrill & West 2001): This was used in case study sites to inform the context in which GSFCH was being developed.

- o **Facilitators' baseline survey** was used to identify facilitators' expectations and concerns at the start of the programme. (Appendix 4)

- **Interviews in the Case Study Phase**

Semi-structured interviews (Appendix 5) were undertaken as follows:

- o **Telephone interviews** were conducted with care home GSF coordinators to establish organisational philosophy and initial experience of implementing GSFCH prior to site visits to inform the areas of enquiry.
- o **Face to face interviews with care home staff** explored the factors they felt impacted on their ability to deliver optimal end of life care and their views on the use and impact of GSFCH.
- o **Face to face interviews with Residents and Family Carers.** A small number were accessed and able to discuss issues related to GSFCH (see Section 8).

- **Additional data collection**
  - o **Data were obtained from Facilitators** and the **GSF team** during one to one phone conversations, telephone conferences, steering group meetings, emails and face-to-face conversations.
  - o **Observation** of the work of the GSFCH team and facilitators in the four GSFCH workshops helped identify wider strategic issues that may impact on the success, or otherwise, of the implementation of GSFCH.
  - o Information about the culture of care homes, staff concerns and by proxy, an indication of the concerns of residents and relatives, were gained through the many exchanges during workshops, telephone and face to face conversations.
  - o Care home staff contacted the research team with queries about the evaluation and often provided information about their perspectives of end of life care and GSFCH.

Data Collection mapped against Macmillan Commissioning Brief

As noted in Section 1, the iterative research process demanded consideration of a range of project outcomes. These have been mapped on Figure 2, indicating the data collection methods. Indicators are presented in full in Appendix 1.

Figure 2: Commissioning brief - Project outcomes and data sources

(See also Appendix 1)

No	Indicators	Source of data
1	**Patients and carers: An understanding of those outcomes patients & carers consider desirable and the impact of the GSF on these**.	Case study interviews
2	**Structure, culture, and organisation of the care home: Candidate items relating to structure, culture, processes and behaviours associated with direct or surrogate measures which can be linked to the uptake of the GSF & candidate processes and behaviours (again associated with measures) which change in ways that may be associated with benefits for patients and carers.**	Audit Survey Teamwork survey Case study interviews
3	**Characterisation of the client population: The important characteristics of the client population in relation to key outcomes (e.g. crises) and the influence of the GSF.**	Audit surveys After Death Analysis
4	**Testing (an A to D) "banding" approach: An understanding of whether this form of banding was valid (i.e. to what extent was it possible to predict nearness to death) and how (if at all) did the use of "banding" facilitate the introduction of the GSF.**	Audit surveys Case study interviews
5	**Measures related to differences in staff and skills mix**: A**spects of staff and skill mix which need to be considered when evaluating the impact of the GSF and direct or surrogate measures of these for future studies.**	Audit surveys Case study interviews
6	**Relationships with the primary health care team: The relationships between care homes and primary health care teams (in particular GPs) and the GSF uptake.**	Audit Survey Case study interviews
7	**The added value of resource material: e.g. starter pack and/or Macmillan educational resource in relation to the success of changing behaviours or processes linked to the outcomes of interest (in addition to the role of facilitator behaviour and the use of an audit tool).**	Audit surveys Case study interviews
8	**The role of the facilitator: An understanding of the key elements of facilitator characteristics, context and behaviour, which influence the introduction of the GSF, in particular the role (if any) of primary care based facilitators.**	Facilitator surveys Audit surveys Case study interviews Observation at workshops

Sampling

Care homes' agreement to participate in GSFCH Phase 2 included agreement to contribute to the evaluation. Consequently the sampling framework assumed that all the care homes in the GSFCH Phase 2 programme (predicted at circa 80-100) would participate. The audit process involved undertaking surveys at baseline, mid point and upon completion of the development programme. Baseline Audits were circulated to all 95 homes that signed up.

Selection of case study homes was informed by the Baseline Audit Survey. Purposive sampling was used and aimed to ensure a geographical spread of homes, a range of sizes of home and to include homes which had, and had not, returned Baseline Audit data.

Data Collection and Response rates

The GSF team was keen to establish and embed the relationship between GSF facilitators and care home staff, regarding this as central to the success of GSFCH, an approach which had been adopted in primary care. Consequently facilitators were asked to be responsible for ensuring care home coordinators (usually the manager or a senior nurse) completed and returned Baseline Audits. Contacts between participants in the Phase 2 evaluation are shown in Figure 3.

Audit survey data

The *Baseline Audit Questionnaire,* was adapted from the audit used in the GSF primary care programme and had been piloted in Phase 1 GSFCH (Maryon *et al.*, 2005). The audit collected details of the care homes and the current systems in place to care for residents at the end of life. Components were expanded or added to explore organisational and educational needs specific to the care home context.

This audit was administered to care home coordinators prior to attending the first GSFCH workshop in Birmingham in June 2005. Some coordinators had very little time between agreeing to participate in GSFCH Phase 2 and attending the first workshop, consequently 59% of Baseline Audits were returned before the first workshop and the remainder were returned before Workshop 2. Managers were also asked to provide details of the care of the last five residents who had died, using a short *After death analysis (ADA) tool* (Appendix 3).

Follow up audit questionnaires were completed by coordinators six months after the initial workshop (Audit 2) and a final audit questionnaire and ADA was administered 12 months after the initial workshop (Final Audit). Feedback from coordinators revealed the Baseline Audit had been time consuming and onerous to complete and subsequent audits were much shorter with a clearer layout.

The overall response rate at each stage of the evaluation is summarised in Figure 4. At all stages homes which had notified the GSF team that they had discontinued the GSFCH programme were excluded.

Figure 3: Participants in GSFCH Phase 2 Evaluation

Contact as needed
Audit 2
Invitation to participate in
case study phase

Contact during workshops
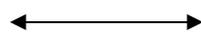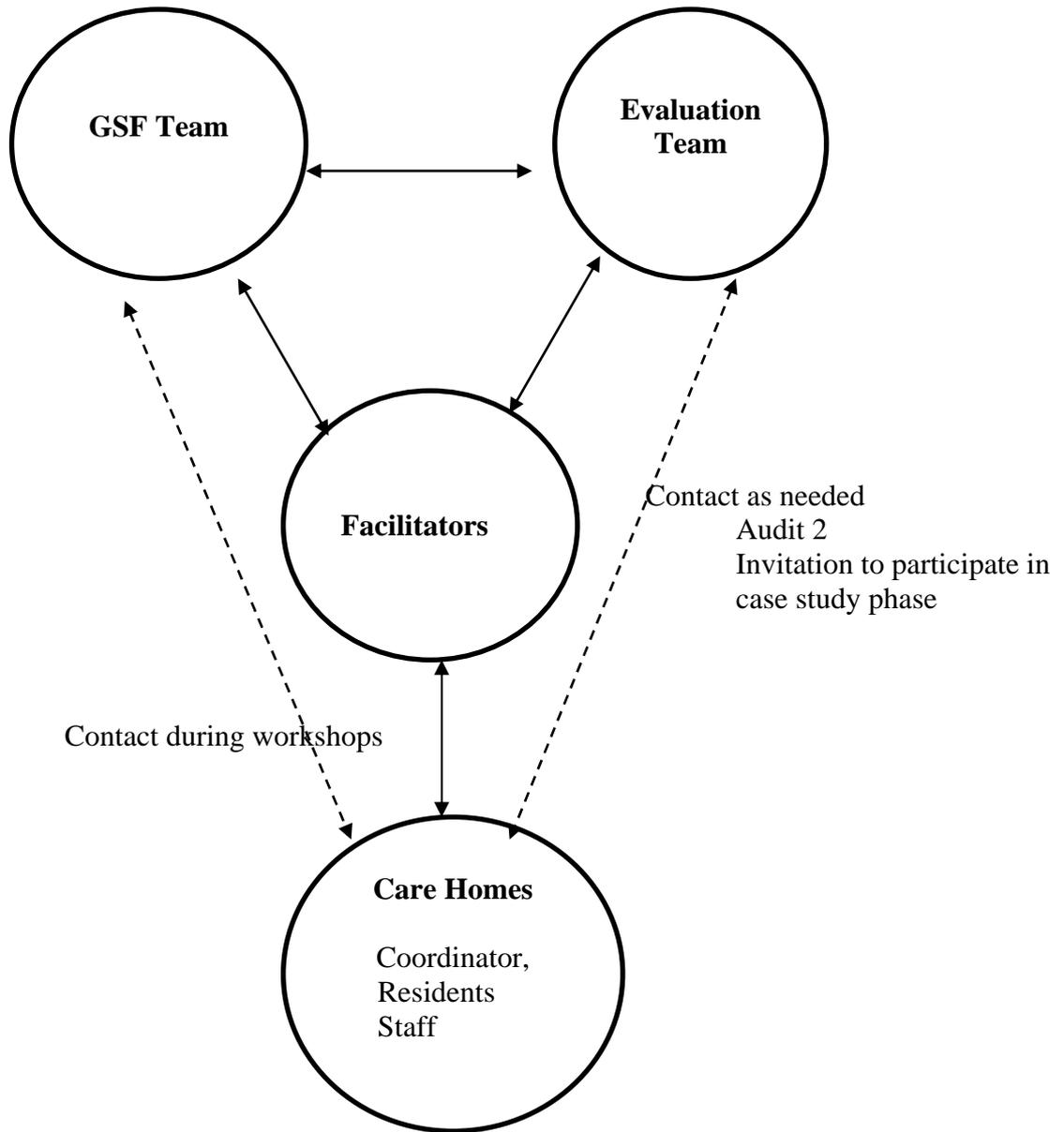
Formal lines of communication

Lines of communication as required

This model resulted in a response rate of 79 (83%) care homes returning the Baseline Audit (Figure 4).

Figure 4: Audit response rates

June 2005	95 homes - Base Audit and ADA

79 homes returned Base Audits (83%).

16 homes did not return Base Audit **

11 homes withdrew before Audit 2

November 2005 84 homes sent Audit 2 (89% of original sample of 95)

54 homes returned Audit 2 (64.2% of those sent; 56.8% of original sample)

5 homes withdrew between Audit 2 & Final Audit

May 2006 79 homes sent Final Audit (83% of original sample)

52 homes returned Final Audit (65.8% of those sent; 54.7% of original sample of 95)

** Of the 16 'non-returners, 8 homes returned a previous version of the Baseline Audit completed much earlier. These were not included in the evaluation.

A challenge to the methodological approach adopted became apparent when, in the early stages of the programme, it was noted that a few facilitators and some care home staff regarded the GSF team and the university based evaluation team as the same team. This had arisen because all documentation for the programme and audit were sent to facilitators, and subsequently via them to the care homes, from the GSF team. This was thought to be easier for GSFCH facilitators than receiving information from two teams. Efforts were made to clarify the distinction between the two teams at the GSFCH workshops. Additionally, Audit 2 was sent directly from the evaluation team

to care homes with a pre paid return envelope for each home. Facilitators were notified by email that the audits had been sent and they were simply asked to remind care home staff to complete and return them. A second reminder to facilitators was sent four weeks later. Fifty-four homes returned Audit 2 (64.2% return rate, 56.8% of original sample of 95).

The GSF team and facilitators felt the response rate for Audit 2 might have been higher had audits been given to GSF coordinators by facilitators and this approach was adopted for the Final Audit. Eight homes which no longer had facilitators were sent final audits directly by the evaluation team. Fifty-two Final Audits were returned (65.8% return rate, 54.7% of original sample of 95). Attempts were made to contact homes that did not return data to identify reasons for non-return. Where possible facilitators were also contacted.

Overall this should be seen as a good response rate given the time demands involved in completing the surveys. The response exceeded predictions which commonly cite 40% as being a good response to survey questionnaires (May 2001).

Case studies

Forty-one homes were invited to take part in the case study phase in early 2006, six months after the first workshop. Fifteen replies were received (36.5%); of these 14 homes agreed to participate and one refused. Thirteen managers consented to a site visit and one to a telephone interview only, because GSFCH had not yet been introduced to staff, reflecting the differing time scales of introducing GSFCH into homes. The remaining 13 manager interviews revealed that three homes had not introduced GSFCH to staff, resulting in 10 case study site visits to meet staff and in some cases residents and family carers (Figure 5).

Figure 5: Case study response

```
                    ┌─────────────────────────────┐
                    │         41 homes            │
                    └─────────────────────────────┘
                              │          ╲
                              ▼           ╲
        ┌─────────────────────────┐  ┌──────────────────────┐
        │  15 responses (36.5%)   │  │ 2 dropped out of GSF │
        └─────────────────────────┘  │      programme       │
                │          ╲          └──────────────────────┘
                ▼           ╲
        ┌─────────────────┐  ┌──────────────────────┐
        │  14 consents    │  │      1 refusal       │
        └─────────────────┘  └──────────────────────┘
                │
                ▼
        ┌─────────────────────────┐
        │ 14 manager /coordinator │
        │      interviews         │
        └─────────────────────────┘
                │          ╲
                ▼           ╲
        ┌─────────────────────────┐  ┌──────────────────────┐
        │ 13 consents to site     │  │ 1 no consent for     │
        │        visit            │  │ visit-GSFCH not yet  │
        │                         │  │ introduced to staff  │
        └─────────────────────────┘  └──────────────────────┘
                │          ╲
                ▼           ╲
        ┌─────────────────┐  ┌──────────────────────┐
        │ 10 site visits  │  │ 3 GSFCH not yet      │
        │                 │  │ introduced to staff  │
        └─────────────────┘  └──────────────────────┘
                 ╲       ╲
                  ╲       ╲   ┌──────────────────────┐
                   ╲       ╲  │ 7 access to residents│
                    ╲         │     and staff        │
                     ╲        ├──────────────────────┤
                      ╲──────▶│ 3 access to staff    │
                              └──────────────────────┘
```
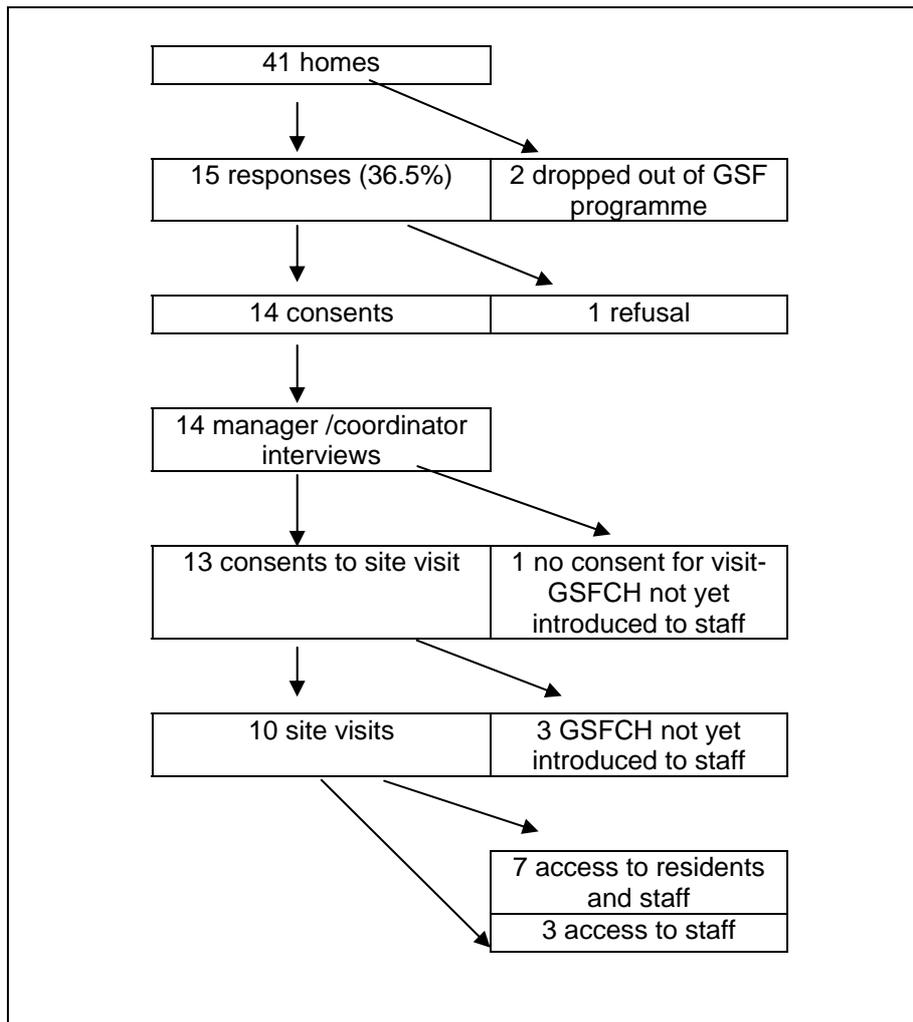
A range of staff participated in face to face interviews depending upon managers' definitions of who was in the team, their judgement of who was knowledgeable about GSFCH and who was on duty. Managers were asked to distribute participant information packs[6] to staff and residents, to notify participants of the researcher's visit and schedule interviews. In some homes staff participants were all either registered nurses and/or carers while in other homes housekeeping and domestic staff participated.

Nine staff participated in individual semi-structured interviews and 52 in small group interviews. Team-working questionnaires were administered at the end of the interview. Many managers rearranged rotas so a selection of staff could be

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[6] Packs contained a cover letter, information sheet, consent form and pre-paid return envelope.

interviewed but three managers indicated that staff whom they had hoped would be on duty had changed shifts at the last minute. At one home staff were exceptionally busy and the staff interview lasted just a few minutes rather than the allocated 30 minutes.

Seven managers distributed information packs to residents and residents were interviewed at four homes. Two managers stated that residents with whom they had adopted GSFCH were critically ill or had died and one home had not yet used GSFCH. One manager stated that a resident wanted to be interviewed but a family member refused permission and the resident was not interviewed.

Overall 85 participants were interviewed for the case study phase:

> **Telephone interviews:**   14 managers/coordinators, 10 of whom provided additional information and clarification during site visits.
>
> **Face to face interviews:**   10 homes:
>
>> 61 care home staff (in 9 individual interviews and 13 group interviews)
>> 7 residents
>>
>> 3 relatives

Ethical approval

When managers signed up for the GSFCH programme they were advised that the process would involve an evaluative component and the importance of this to future development was noted. This was seen as an important means of self evaluation as care homes would be able to use this data to monitor their own progress, a model successfully adopted in primary care evaluations of the implementation of GSF (Thomas & Noble 2007). Consequently managers were asked to indicate that, when they agreed to participate in the GSFCH development programme they would also be willing to take part in the evaluation process.

The audit data were classed as a service evaluation and, in line with NHS ethical approval guidance (www.corec.org), formal COREC approval was not necessary. Multi centre ethical approval (MREC) was, however, gained for the case study phase of the evaluation as the research team would be approaching staff and residents, some of whom might be defined as vulnerable. Ethics approval was granted in August 2005 (MREC No. 05/MREO7/68).

At all stages data collection was conducted in accordance with good Research Governance which met university and NHS standards and the study was registered with the local NHS R & D consortium. Participants gave written consent and were free to withdraw at any time.

In line with regulations for the protection of vulnerable adults the main researcher (FB) had a Criminal Records Bureau (CRB) check. Gaining ethical approval revealed that care homes, as mainly private organisations providing care to (often) self funding customers, do not readily fit either with the health services, nor the recently established health and social care structures for ethical approval of research studies. This raises challenges for future research work in this area.

Data Analysis

Quantitative data from the audit surveys and ADA tool were stored and analysed using SPSS (Version 11) and Baseline Audit data was loaded manually. Audit 2 and the Final Audit tools were developed to facilitate electronic scanning of data, however technical difficulties in these relatively new systems meant this was not always possible and all data was double checked for accuracy.

Descriptive statistics were used to summarise the key contextual data (e.g. number of beds, GP practices) using percentages to show the proportions and median and range as the measures of central tendency and distribution, respectively. Inferential statistical tests were used to examine group differences. Non-parametric tests were used due to evidence of skewness in some of the variables. Differences between those who completed the audit and those who did not were examined using the Mann-Whitney test for ordinal variables and the Chi-square test or Fishers Exact test for categorical variables, as appropriate. Comparisons of study variables between baseline and follow-up were made using the Sign test for ordinal data and McNemar Test for categorical data. The level of significance was set at $p < 0.05$.

Qualitative data, interviews and field notes, were subject to content analysis in which key themes and sub themes were identified and grouped for ease of analysis. The NVivo program (Version 2) was used for the initial coding of data, and the coding process was largely driven by the thematic areas related to GSFCH which were

explored in the semi-structured telephone and face to face interviews, in line with the template approach (Crabtree & Miller, 1992). Two members of the evaluation team conducted independent content analysis of five transcripts before jointly forming an initial coding template. Modifications were made to the coding template as the whole body of data was analysed and codes were expanded or subsumed as necessary.

SECTION 3: FINDINGS (1) BASELINE DATA

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This section reports the findings from the baseline survey undertaken in participating care homes prior to the introduction of the GSFCH programme. To put this data into context a brief overview of the care home sector is provided.

Overview of care home sector

The overall profile of care homes for older people is changing rapidly. Despite the ageing population, fewer people are living in care homes and the adult care sector has contracted substantially over recent years, capacity in 2004 was 16% lower than in 1996 (Laing & Buisson 2004). Simultaneously the number of single ownership homes has decreased and the sector is increasingly dominated by homes belonging to larger groups (Laing and Buisson, 2004). Table 1 indicates some of the changes in adult long stay care populations over recent years, though there are acknowledged difficulties in obtaining accurate data (Help the Aged 2006).

Table 1: Adults in long stay care

Population type	Area	Numbers	Source	Date
All adults [7]	UK	525,900	Laing & Buisson	2001
All adults	UK	486,000	Laing & Buisson	2004
Older people in care homes	UK	410,000	OFT based on regulators' 2004 data	2005
Older people in care homes	England	381,083[8]	CSCI	2006a October

Data on care homes for older people in England reveals that just over two thirds of homes are personal care with one third classed as nursing care (Table 2). These proportions have recently been confirmed in a local survey (Rodriguez *et al.*, 2007). Although one third of care homes in England are registered for nursing, 42% of older people in care homes are in nursing homes, the difference being due to the larger average size of nursing homes compared to personal care homes (Table 2).

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[7] Includes elderly and younger physically disabled in all sectors of long stay care; private, public and voluntary, including NHS.

[8] Higher numbers are sometimes reported possibly because homes can register the same place more than once if places can accommodate more than one client group. Numbers in Tables 1 & 2 differ reflecting difficulty in obtaining precise data.

Table 2: Care homes for older people in England 2006 (CSCI, 2006b)

Type of home	No. of homes	% of total homes	No. of licensed beds.	% of total beds	Average beds per home
Personal care	7201	70.4	191,303	58.0	26
Nursing care	3010	29.4	137,908	41.8	45
Non-medical	11	0.1	250	0.06	23
Totals	10222		329,461		

The care homes in GSFCH Phase 2- Baseline Data

Care home coordinators completed Baseline Audits which provided an overview of the homes in the programme and facilitated comparison with existing profiles of care homes for older people. Of the 95 care homes that signed up to take part in Phase 2, 79 homes completed Baseline Audits (see Table 3). Most of the homes that did not return an audit subsequently withdrew from the programme.

Table 3: Characteristics of study homes and residents

Characteristics of study homes and residents N=79 Homes which returned Base Audit	
Ownership	N= (%)
Part of a group	52 (66.7)
Single ownership	26 (33.3)
Missing	1
Type of home	
Nursing home	40 (50.6)
Dual registered	37 (46.8)
Personal care	2 (2.5)
Number of places	
Median	45
Min-Max	20-150
Residents' average age	
90 & over	4 (5.7)
85-89	25 (36.2)
80-84	27 (39.1)
75-79	7 (10.1)
Under 75	6 (8.6)
Missing	10
Average length of stay	
2 years or more	34 (47.2)
13-23 months	24 (33.3)
7-12 months	11 (15.3)
1-6 months	3 (4.2)
Missing	7

Two thirds of homes were part of a care home group with the remainder in single ownership. On this indicator the study homes differ from all care homes where single

ownership homes predominate, though nursing homes are more likely than personal care homes to be part of a group (Laing & Buisson 2004). Half described themselves as nursing homes and just under half were dual registered. Just two homes were care homes (personal care). The category 'dual registered' (i.e. homes offering nursing and personal care) no longer exists, and homes with nursing beds are classified as care homes (nursing) but the term 'dual registered' is still used by staff. Almost half of the homes were registered for terminal care (36/77=46.8%), though part way through the evaluation this registration category was discontinued by CSCI.

Total bed numbers in participating homes ranged from 20 to 150, with a median of 45. Recent survey data (Laing & Buisson 2004) revealed an average number of 44 beds in nursing homes but noted that the size of homes was increasing, therefore on this measure the homes in GSFCH are representative. Only one quarter of homes had more than 56 beds. Numbers of designated nursing beds were slightly lower with a mean of 37. Three quarters of residents were women and the average age of residents across the homes was 81 years. In almost one third of homes residents' average age was 85 or more. Almost all residents spoke English as a first language. Just less than half of homes stated the average length of resident stay was over two years, but one in five homes stated the average stay was one year or less.

Together these data indicate that the homes in the programme reflect the profile of care homes for older people in England (Sidell *et al* 1997).

Contact with primary care services varied. On average, homes worked with four GP practices but one third of homes (35%) liaised with just one or two practices. Almost one in five homes (17%) liaised with 10 or more practices and in one home residents were registered with 12 different practices.

A third of homes (37%) offered transition experience to nurses who qualified overseas and eighty percent of such homes had transition nurses currently in post. This is an important point in terms of staff skill mix as this group of staff will be learning UK working practices.

Location of dying

Almost all homes provided data on the number of deaths in the six months prior to starting GSFCH. This revealed that, on average, 11 residents had died (range 0-30). Of the 817 residents who had died in the 79 homes, 78.8% had died in the care home, 21% in hospital and one (0.1%) in a hospice.

These figures reflect data on the place of death of care home residents in earlier studies (Sidell *et al.*, 1997). Recent data on residents' place of death in one English county revealed that 70% of deaths occurred in the care home, 29% in hospital and 1% in a hospice (Froggatt and Payne, 2006). Differences between Sidell *et al's* (1997) and Froggatt and Payne's (2006) figures are probably due to the inclusion of personal care homes in the latter survey, which are likely to have a higher proportion of hospital deaths.

Preferred place of care

At baseline almost one third of respondents stated that residents did not always die in their preferred place and contributory factors were family carer issues, the need for improved symptom control and 'other' factors. In this latter category respondents indicated that admission was sometimes due to practitioners' decision to send the resident to hospital. One respondent stated that sometimes practitioners did not know residents and 'overruled' staff, family and sometimes residents' wishes.

After Death Analysis (ADA) -Baseline

Seventy five pre GSFCH ADAs were returned which provided details of the circumstances of the deaths of 366 residents, comprising the five most recent deaths among care home residents between January and June 2005.

Table 4: Place of death of care home residents [ADA data]

Place of death of care home residents				
	Type of home:			
Place of death	Nursing home N= (%)	Dual registered N= (%)	Personal care N=	Total N= (%)
Care home	158 (84.0)	132 (79.0)	4	294 (80.5)
Hospital	29 (15.4)	34 (20.3)	6	69 (18.9)
Hospice	1 (0.5)	0	0	1 (0.3)
Other	0	1 (0.5)	0	1 (0.3)
Total	188	167	10	365

Missing =1

Overall 18.9% of deaths occurred in hospital (Table 4), 80.5% in care homes and 0.3% each in hospices or resident's own home (one death each). Percentages differ slightly from the data produced by the Baseline Audit above because of different methods of data collection (i.e. focusing on actual deaths) but the figures are almost identical. Nursing homes had the highest percentage of residents who died in the care home (84%), in 'dual' registered homes the figure was 79% and in the two personal care homes six of the 10 deaths occured in hospital.

Residents' diagnoses and cause of death were recorded using a classification adopted by Seymour *et al.*, (2005) and based on National Statistics categories, but with the addition of two additional categories, dementia and 'old age/frail'. Seymour *et al* (2005) noted that although dementia is an important and increasing cause of death among older people, it is rarely recorded as a primary cause of death. 'Old age/frail' was included as a category because respondents used these terms as descriptors when completing the ADA, often for residents who had no other diagnosis.

Dying residents main diagnoses were:

- Cancer (24.7%),
- Cerebro-vascular accident (22.8%)
- Dementia (15.9%) and
- Circulatory problems, excluding CVA (11.9%).

Dementia was the most frequent secondary diagnosis (20.9%) followed by circulatory problems (12.2%), cancer (9.4%) and respiratory problems (9.1%).

Diseases of the respiratory system, typically chest infections, were the most common cause of death (24.9%), followed by cancer (21.5%). Deaths due to CVA and circulatory system occurred in 13% of residents with each diagnosis.

Dementia was only recorded as a cause of death in 3.3% of residents while 'Old age/frail' was the cause of death for 8.3% of residents. Some respondents noted that diagnosis and cause of death were assumed because residents did not always have a definite diagnosis and staff may not know the cause of death, especially when residents died in hospital.

Over one in five (22%) residents had been in the care home for four weeks or less when they died, 41% had been in three months or less. In total 60% of residents had been living in the care home for one year or less when they died but 28% had been there for over two years.

Table 5: Crisis events and crisis admissions [ADA data]

Crisis events and crisis admissions in the last six months' of life		
	Crisis events N= (%)	Crisis admissions N= (%)
None	153 (53.5)	183 (62.9)
1	81 (28.3)	84 (28.9)
2	38 (13.3)	17 (5.8)
3 or more	14 (4.8)	7 (2.4)
Total	286	291
Missing	80	75

Just over half of residents (53.5%) had no crisis events in the six months before they died; (Table 5) 28.3% had one crisis event, 13% had two and 5% had three or more. Of the 291 deaths for which data was provided, 63% had no crisis admissions to hospital but 29% had one and 8% had two or more.

Care

Data on four key areas regarded as important by the GSF team for optimal end of life care were collected using the After Death Analysis tool. These were advanced care planning, arranging for anticipatory medication, the use of a care pathway for the last days of life and whether written information had been given to families. These four areas are all structural issues, process issues are also relevant to end of life care but at this stage the focus was on structural issues. Data from homes which returned baseline ADAs reveal that PRN (i.e. as required) medication had been prescribed in 50% of deaths that occurred in the care home and an advanced care plan was in place for over one third of residents. A last days of life pathway was used in 12% of deaths and written information was given to fewer than one in five families (Table 6).

Figure 6: Care items at end of life - residents dying in the care home

Care item		N= (%)* (n=294)
Advanced care plan	Yes	102 (36)
	No	184 (64)
'As required' medication prescribed	Yes	141 (51)
	No	136 (49)
Last days of life pathway in place	Yes	34 (12)
	No	255 (88)
Written information given to family	Yes	44 (15)
	No	237 (85)

*Numbers may not total 294 due to missing data.

Motivations for participating in GSFCH

Motivations for participating in GSFCH and anticipated outcomes from the programme were captured by five open-ended questions at the end of the Baseline Audit. Content analysis was used to identify the issues and these are presented below. Baseline Audit questionnaires were completed either by nurse managers and /or the designated GSFCH coordinator who was usually a senior registered nurse and respondents' views may not be representative of other staff.

All 79 respondents answered this question, revealing that the predominant reason for participation in GSFCH was to improve the quality of care for residents at the end of life; almost every response included the words 'quality' or 'improve.'

> *To improve the quality of end of life care within the nursing home.* [Home 83]

> *You have to get palliative care right, you do not have a second chance.* [Home 56]

Aspects of care which were seen as integral to quality were residents' having a choice of place of care, giving attention to people's dignity and respecting their wishes regarding end of life care. While most responses focused on residents' needs, a number mentioned family or staff:

> *To enhance the care offered to the clients and their families – as well as staff within the nursing home.* [Home 96]

31

> *To take advantage of the education available to all staff to improve palliative care within our home.* [Home 35]

Educational opportunities within the GSFCH programme were valued both for the increased knowledge and the extra confidence that it was hoped staff would gain. A number of respondents believed their homes currently provided good quality care and expressed a commitment to keep up to date with changes in palliative care because there was always scope for improvement. Some homes were currently implementing an integrated care pathway (e.g. Liverpool Care Pathway (LCP)) for care in the final days of life and felt that the GSFCH complemented this. Smaller numbers of respondents referred to the increasing dependency of residents when admitted, alongside greater numbers admitted in the last stage of their lives and these factors had driven their interest in GSF:

> *We are now caring for more residents with complex end of life needs due to a lack of local resources.* [Home 61]

> *We are having more terminally ill patients referred to us. We have good standards of care but I feel there is room for improvement and would like to see better communications within the homes and with other related disciplines that could help us.* [Home 94]

A number of respondents felt that the GSFCH offered a useful framework for assessing the needs of dying people irrespective of underlying pathology. GSFCH was seen as providing the support and necessary frameworks to support care home residents, the majority of whom do not have cancer and often die from multiple causes:

> *Having reflected on care given to residents and relatives I feel it is necessary to improve knowledge and confidence of myself and nurses and carers. Nursing homes have been overlooked and I feel with a shortage of palliative care beds the resources are available in the home, which is promoted as part of the community needs.* [Home 76]

> *Palliative care has been largely focused on advanced malignant disease, however, there is a much wider relevance... for clients with different diagnoses.* [Home 81]

> *As a specialist nurse practitioner in gerontology, I have always believed in the 'hospice' style philosophy being utilised within nursing homes, for residents who do not necessarily have a diagnosis of cancer but are at the end of their disease process and /or aging process.* [Home 29]

Finally two respondents expressed the wish that GSFCH would help raise the profile of nursing homes and result in greater acknowledgement of their role in providing the full range of nursing care for older people.

Anticipated benefits from participating in GSFCH

Over half of the 75 respondents to this question anticipated improvements in care for dying residents as a result of participating in GSFCH. Improvements in care were anticipated from the training incorporated in the GSFCH programme and links with facilitators and other care homes. It was hoped that the educational elements of GSFCH would improve staff awareness, their confidence and team working both within the home and with primary care teams and specialist palliative care practitioners. Around a quarter of respondents cited the protocols and structured frameworks offered by GSFCH, anticipating that these would enable them to provide a better, consistent quality of end of life care. Consequently residents, their families and staff would be better supported and their dignity and choice respected. Examples of comments include:

> *A greater awareness of and a more structured approach to the quality of care we are giving to our residents in the last stages of their lives.* [Home 19]

> *Greater awareness amongst staff of the dying process and how to aid a 'good' death, reduced hospital admission in end of life care, improved relations and contact with community support teams.* [Home 50]

Four respondents expressed the wish that adopting the GSFCH would help them reduce hospital admissions and a similar number hoped it would help them provide enhanced emotional support to families, residents or staff. For one manager the GSFCH was seen as a means of empowering dying residents to express their wishes with regard to their place of care, their place of death and who should be with them in the final stages of life. The hope was:

> *That both patient and their families find death a little easier, they have dignity and choice of how and where they die. And that staff receive more information and training to enable them to deal with care of the dying and how they deal with death e.g. their feelings.* [Home 49]

Responses to this question elicited fairly general responses and homes were invited to identify one change that would improve the care of end of life residents and one that would improve the environment for staff.

Improvements for residents and staff

A quarter of respondents suggested residents' care could be improved by addressing factors related to staffing (n=19). Over half of these respondents identified the need for more care staff so that time could be devoted to being with dying residents, in particular for those without family visitors. Remaining respondents felt that care could be improved if staff accessed training on palliative care and/or bereavement. This latter area was seen as particularly important as it would improve staff's capacity to support families with whom they had built up meaningful relationships over a period of time. Bereavement courses were also valued for their potential in helping staff explore and understand their own reactions to death.

Twelve respondents hoped for changes to medical support, for example all residents registered with the same GP. Improved communications or changes to the out-of-hours services were suggested by a number of respondents:

> *Sort out 'out-of-hours' service – good care given by own GP and home's own staff breaks down when out-of-hours.* [Home 6]

Though one home identified current progress in this area:

> *GP practice acting in concert with us, particularly in relation to prescribing. This is much improved with new GP who is lead for GSF in her practice.* [Home 17]

A need for proactive, well-planned care was cited by 10 respondents, some of whom suggested the use of a care pathway to aid symptom relief and ensure inappropriate treatments were discontinued. Eight respondents identified the need to have readily accessible controlled drugs as this would facilitate timely and effective pain control, with many suggesting homes should be able to hold a stock of commonly used controlled drugs[9]:

> *Better provision of drugs available out-of-hours without having to plan ahead.* [Home 15]

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9 Homes can hold stock controlled drugs only with a Home Office licence. One home had a licence.

34

Improvements to accommodation were identified, with two homes indicating that dying residents were sometimes cared for in shared rooms which was not acceptable and five respondents wanted a dedicated 'Relatives room.'

Preventing 'unnecessary hospital admissions' was cited by six respondents as the improvement they felt would have the most impact on enhancing residents' care. Improvements suggested by small numbers of respondents were realistic funding for people receiving end of life care, better access to specialist equipment, to help residents understand that the 'end of life' is not necessarily traumatic and the need to improve communication generally or with specific groups of practitioners.

Motivations for participation - data from the baseline ADA

Additional motivations for participating in GSFCH were revealed in the ADA analysis and case study interviews during which a small number of residents' stories were provided by staff in some homes. For example:

> *'Sudden deterioration/collapse 999 transfer to hospital. No clear preferences stated by resident on admission.'* [Home 78, case 2]

> *''This lady became acutely ill. Out-of-hours service did not attend. Unable to help her symptoms. Emergency admission to hospital. Died within ½ hour* [Home 94, case 1]

Typically these situations arose because the absence of a written record of residents' or families' wishes resulted in staff adopting the default position and alerting emergency services. A desire to prevent such occurrences appeared to be the motivation for some homes participating in GSFCH. It should not be forgotten though that distressing deaths were in a minority and peaceful deaths in care homes were also recorded:

> *Both daughters present at her death, quiet dignified death.* [Home 37, case 3]

> *Excellent rapport with family. Resident had difficulty in communication. Family chose for resident to stay and die at care home.* [Home 56, case 3]

Nevertheless, Baseline Audit, ADA and workshop information revealed that staff felt that all residents were entitled to a peaceful death and no one should die in distressing

circumstances. So although crisis admissions to hospital and distressing deaths were not common, the fact that they occurred at all provided motivation to participate in GSFCH.

During workshop discussions many care home staff described the increasing dependency of residents on admission; confirmed in recent care home audit data (Bowman at al 2004). Related to this, a proportion of residents are admitted specifically to receive end of life care in NHS funded continuing care beds. In these circumstances it is even more important that end of life care is discussed and advanced care plans are made. Conversely though, as length of stay decreases there is less time in which staff and residents can build up relationships to enable the necessary conversations to take place. These factors contributed to managers' decisions to participate in the GSFCH programme.

Facilitators' views of GSFCH at Baseline

The majority of GSFCH facilitators had been facilitating the introduction of GSF in primary care practices. Most facilitators had adopted, either by choice or allocation, the GSF/GSFCH facilitator role in addition to their main employment as nurses or GPs but there were a small number of full-time GSF facilitators employed by PCTs. Consequently the amount of time facilitators could allocate to the GSF varied from full time to four hours per week. Some full time facilitators were part of care home support teams located in a PCT or Local Authority social care and health departments. Part time facilitators were in the main specialist palliative care nurses with a small number of GPs.

Most part time facilitators in Phase 2 GSFCH elected to adopt the role but two were nominated and expressed concern about their ability to meet the demands of the role. Some had little previous contact with or knowledge of the care home sector. Twenty-eight of the 37 facilitators provided data on their expectations of GSFCH and their responses are summarised below.

Facilitators' expectations

A major theme to emerge was the hope that GSFCH would improve communications in particular between care homes and NHS services, including primary care trusts, primary health care teams, out-of-hours services, and palliative care services. Five facilitators anticipated improved communication between all those involved in the care homes sector, while four anticipated improved communication with residents and their families and within and between care home teams.

Facilitators felt that care home staff had limited access to palliative care training, highlighting two staff related issues. The hope that GSFCH would increase education and training to care home staff was expressed and secondly, that GSFCH would raise the profile of palliative care in care homes, thereby improving staff morale and confidence, thereby empowering staff. One facilitator suggested that the programme would help promote proactive rather than reactive end of life care and another thought GSFCH could improve job satisfaction among care staff.

Almost all facilitators expected that GSFCH would improve the quality of palliative care for older people in care homes. Some facilitators suggested that older people in care homes were at risk of receiving poorly coordinated end of life care. A few facilitators identified existing barriers in residents' access to services:

> *Hope that GSF. …will demonstrate that residents in care homes are effectively in their 'home' and should not be treated differently to patients living independently in the community, in terms of accessing all community services* [Facilitator 3]

Almost half the facilitators anticipated that GSFCH would enable residents to end their life in their preferred place of care, resulting in fewer emergency hospital admissions for residents at the end of their lives. This was summarised succinctly by a facilitator:

> *'A reduction in death-bed hospital admissions.'* [Facilitator 28]

Changes cited by smaller numbers of facilitators included improvements in coordination of services, increased awareness of the range of services available for palliative care support and the hope that GSFCH would reduce the isolation of care homes from the rest of the health service.

Facilitators' Concerns

Twenty four facilitators reported concerns relating to the introduction of GSFCH. Three major themes emerged:

- The level of support homes would receive from GPs; (n=11)
- Concerns about the levels of staff turnover in care homes, which may hinder the introduction of GSFCH (n=10)
- Facilitators' abilities to devote the necessary time to support homes introducing GSFCH (n=10).

Concerns about the extent of GP support for GSFCH ranged from fears that GPs would show 'little interest' in the programme to concerns that GPs may actively resist any involvement in supporting homes. Some facilitators identified potential difficulties in encouraging GPs to prescribe anticipatory medication and two identified difficulties with out-of-hours services. Finally two facilitators suggested that homes which liaise with several GP practices might be overwhelmed by the task.

High levels of staff turnover in care homes was cited as a potential problem by almost half of facilitators (10/24), in most cases staff grade, i.e. care staff or qualified nurses, was not specified, but problems were anticipated if managers or the GSFCH coordinator, usually a senior registered nurse, changed.

Ten facilitators expressed concerns about the amount of their time required to provide *adequate and effective* support to care homes involved in GSFCH, some indicating that they had limited previous involvement with the care home sector and with one acknowledging that she was on a *steep learning curve* herself. Additional concerns expressed by smaller numbers of facilitators included fears that care home staff would be unable to implement GSFCH because of time and other resource constraints (n=5) while others questioned whether effective management structures existed within homes; seen as essential to ensure that GSFCH was not just a 'paper exercise' but sustained and embedded within the home beyond the final GSFCH workshop, seven months after the first workshop. Three facilitators expressed concerns about optimal means of addressing the varied levels of educational needs within care homes and lack of health service resources generally to support good palliative care.

One facilitator's view that there was:

'Poor understanding of the principles of palliative care in many care homes and what constitutes a 'good death' [Facilitator 31]

was confirmed by two other respondents. At the same time one facilitator suggested that the homes which would benefit most from GSFCH would be unlikely to join the programme. Adequacy of resources to support both GSFCH implementation and the potential increased demand for services was questioned, as was the tendency of government departments to demand rapid implementation of initiatives such as GSFCH and the LCP, without the necessary longer term strategic view, financial resources or acknowledgment that changes of the type and magnitude of the GSFCH are not instantaneous.

Facilitators' roles

One facilitator explained how important it was to ensure that managers understood that involvement in GSFCH encompasses far more than attending the four workshops and includes access to a range of support, training and materials. In addition local meetings with other care home managers and neighbouring facilitators, can potentially provide supportive contacts and information.

This facilitator developed a GSFCH computer folder, which each home received. The folder was divided into subfolders structured around the GSF '7 Cs' and covered all the information a home was likely to need to implement GSFCH. Files included all GSF materials, links to local and national policies and programmes, protocol examples, template letters, leaflets, details of self help groups and a template for an advanced care plan. However, reliance upon information and support via computer is not always appropriate for care homes; one survey reported that 38% of nurses in the independent sector had no access to a computer. Nurses who had computer access reported this was often shared with others (RCN, 2005).

She also offered each home a standard package of information and support through four facilitator-led meetings at the care home to introduce the GSFCH. In addition to the GSFCH materials, homes were provided with the Macmillan 'Foundations in Palliative Care' pack, a basic training pack in end of life care for all care home staff.

Homes were helped to identify their training needs and if these could not be met by existing training, specific training could be arranged. Staff were also notified of any training and associated funding to cover staff costs to reimburse homes who released staff to attend. The facilitator was also planning to invite staff from Phase 2 homes to the forthcoming local GSFCH Phase 3 meetings, hoping that this would help to sustain the link with facilitators and provide additional support and networking for staff. Maintaining links with homes to help sustain GSFCH was seen as particularly important partly because this facilitator's Phase 2 homes had all experienced a change in coordinator. The self-selecting nature of the homes in Phase 2 GSFCH is illustrated by the take up rate reported by this facilitator; of the 136 homes that were invited to participate in Phase 2, only seven signed up and two of these withdrew after the first workshop, giving a response rate of 3.6%.

Summary

This section has summarised the contextual data collected at Baseline from the 79 participating homes. This included factual information about the care homes and the residents.

1. Through the ADA survey, the data on the last five deaths in the care home give an indication of the nature of the deaths and models of care giving in the homes.

2. Care home managers, coordinators and facilitators' motivations and expectations of participating in the GSFCH programme have been documented.

3. Facilitators views and expectations of the GSFCH at the outset indicate a desire to improve end of life care.

4. Facilitators express concerns about a range of issues that may impact on implementation of GSFCH including the potential support from GPs, staff turnover in homes and facilitators' capacity to give the time required for optimal support.

SECTION 4: FINDINGS (2) AUDIT SURVEY DATA

This section reports on the outcomes from the audit survey data collected over the one year of the project. As noted in section 2 the project plan was to gather audit data at three points in the programme to monitor progression through the GSFCH development programme and associated introduction of the GSF into participating care homes. This was to enable comparison of pre and post test data to indicate the extent to which homes had progressed.

Of the 95 homes signed up to take part in the GSFCH , 83 returned some audit data at different points in time as illustrated in Table 7.

Table 6: Homes returning audit data (Baseline, Audit 2, Final Audit)

Audits returned	n	%
Baseline, Audit 2 & Final Audit *	40	42
Baseline, Final Audit *	9	9
Baseline, Audit 2 **	10	11
Baseline only **	20	21
Audit 2 and/or Final Audit	4	4
Total returning any Audits	**83**	**87**
No Audits returned	12	13
Total	**95**	**100**

* Evaluation complete n=49, ** Evaluation not complete n=30

Analysis was carried out to identify whether homes that completed the evaluation differed in any of the baseline indicators from homes that did not complete the evaluation. Homes that did not complete Audit 2 and Final Audit were more likely to have not followed through the GSFCH programme or to have dropped out of the scheme.

It is important to note that experience of GSF implementation in primary care revealed that some practices which joined the programme hoping to complete during a specific time period did not achieve this. Some of these practices chose to opt into the GSF programme again at a later date. As indicated in Figure 4 (page 29) a similar pattern emerged in this Phase of GSFCH. The return of Baseline Audit forms from Phase 1 (Pilot), some completed many months prior to the start of Phase 2, indicated

that some homes were not GSFCH naïve. This is not a problem; in reality it is inevitable that some homes will drop out and continue implementation of GSFCH at a later date. However, it does pose challenges for research in that definitive 'beginning' and 'end' points are not so easily identified.

An important issue here is whether there were significant differences between those who completed each phase of the GSFCH programme and the associated audit of progress, described as 'completers', and those who were classed as 'non-completers' for the purposes of the evaluation. These definitions are derived for research purposes. This will help identify factors that may inform further development work.

For this analysis, the 49 homes that completed both Baseline and Final Audits (*) are compared with the 30 homes that did not complete the evaluation (**). For this comparison it was necessary to have Baseline Audit data, so homes that did not return any audit data (n=12) or only returned subsequent audits (n=4) have been excluded. The results of this analysis are shown in Table 7.

Table 7: Comparison of care homes which did and did not complete the Evaluation of GSFCH Phase 2

	Response	Evaluation Not Completed % (n=30)	Evaluation Completed % (n=49)	Test result
Ownership of Home	Group Single ownership	71 29	63 37	.407 C
Type of Home	Nursing Dual registered	41 59	58 42	.149 C
Total number of beds	Median Range SD	49 (31-74) 10.2	43 (20-150) 20.8	.243 MW
Number of nursing beds	Median Range SD	37 (0-63) 14.6	35 (0-150) 22.3	.578 MW
Have a coordinator for end of life care?	Yes No	31 69	41 59	.388 C
Have an up to date care register for End of life care?	Yes No	3 97	21 79	.043* F
Advanced care planning undertaken?	Yes No	53 47	51 49	.842 C
Routinely discuss ACP with patients?	Yes No	60 40	63 37	.772 C
Home's ability to address residents': - physical needs (grouped data, statistical test carried out on ungrouped data).	Very good-/Good Average/Poor/Very poor	90 10	96 4	.493 MW
- emotional needs	Very good/Good Average/Poor/Very poor	57 43	73 27	.112 MW
- social needs	Very good/Good Average/Poor/Very poor	47 53	76 24	.005* MW
- spiritual needs	Very good/Good Average/Poor/Very poor	38 62	48 52	.285 MW
Do you send a routine handover form to out-of-hours provider?	Yes No	0 100	17 83	.022* F
Do you have problems accessing daytime GP services?	Yes No	29 70	9 91	.047* F
Do you have problems accessing out-of-hours GP services?	Yes No	71 29	56 44	.189 C
Are you using Macmillan 'Foundations in Palliative care.' Training?	Yes No	14 86	18 82	.757 F
In relation to end of life care rate: Quality of support offered to family?	Very good/Good Average/Poor/Very poor	63 27	63 27	.591 MW
Quality of support offered to staff?	Very good/Good Average/Poor/Very poor	47 33	55 45	.540 MW
Quality of team work in the care home?	Very good/Good Average/Poor/Very poor	70 10	79 21	.059 MW

	Response	Evaluation Not Completed % (n=30)	Evaluation Completed % (n=49)	Test result
Use an agreed protocol for the last days of life	Yes No	33 67	51 49	.140 C
Using LCP?	Yes No	7 93	19 81	.188 C
Authorise anticipatory medication?	Yes No	23 77	39 61	.156 C
Discontinue inappropriate medication in last days of life?	Yes No	76 24	90 10	.116 C
Inform family that entering the last days of life?	Yes No	100	100	
Current quality of end of life care for residents?	Very good/Good Average/Poor/Very poor	66 33	71 29	.174 MW
Confidence in caring for residents with end of life needs?	Very good/Good Average/Poor/Very poor	43 57	67 33	.076 MW
Level of co working with end of life care specialists?	Very good/Good Average/Poor/Very poor	47 53	61 29	.077 MW

Statistical tests: C= Chi squared, F= Fishers, MW=Mann-Whitney
Significance set at $p < 0.05$ significant result = *.

Comparison of home ownership, type of home, total bed numbers and number of nursing beds does not reveal any significant differences between completers and non-completers, indicating that on these measures, homes in both groups are similar.

Comparing the results of homes that completed the GSFCH evaluation with those which did not reveals that for a number of variables, homes which completed the evaluation were more likely to have in place at the baseline, elements of end of life care which are identified in GSFCH. This included having a care register for residents in need of end of life care and using a routine handover form to notify out-of-hours providers of residents near the end of life. The differences between the two groups on these measures were statistically significant. Non-completers were significantly more likely to report problems accessing daytime GP services; they also had more difficulty accessing out-of-hours GP services but the level was not significant. The assessment of the home's ability to address residents' social needs also showed a significant difference between the two groups, with homes which completed the evaluation rating themselves higher at baseline.

A higher percentage of homes that completed the evaluation reported good or very good quality of team work in the homes, confidence in caring for residents at the end

of life, and good or very good levels of working with end of life specialists. One in five of the homes that completed the evaluation were already using the LCP but differences between the two groups did not reach significance.

It is of interest that a proportion of homes which participated in GSFCH, regardless of whether or not they completed the evaluation, had already adopted a number of features that are recognised as components of good end of life care. This may indicate that these homes were already delivering elements of their end of life care in accordance with the principles of the GSFCH. This indicates that managers and senior staff had existing skills or experience of end of life care and/or that homes already had effective links with either GPs with an interest in end-of-life care, or with palliative care practitioners.

Pre and post comparison of homes which completed the evaluation.

Comparison of quantitative data from the Baseline and Final Audit reveal the extent to which homes that completed the evaluation and returned data (n=49) felt they had been able to adopt and implement elements of the GSFCH. Some questions were asked at both the Baseline and Final Audit, but others, for example the question on use of prognostic A-D categories was not asked at the baseline. This is indicated by an 'X' in Baseline Audit column in Table 8.

Table 8: Comparison of homes pre and post GSFCH

Question	Response	Baseline Audit % (n=49)	Final Audit % (n=49)	Test result
Do you have a care register for end of life needs?	Yes No	21 79	88 12	.001* M
Have you used the A-D categories?	Yes No	X[10]	88 12	
Are the A-D categories useful?	Very Of some use No	X	61 33 7	
Do you have a coordinator for end of life care?	Yes No	41 59	83 17	.001* M
Routinely undertake advanced care planning?	Yes No	51 49	77 23	.008* M
Discuss possible transfer to hospital/preferred place of care?[11]				
With resident?	Yes No	81 19	87 13	.508 M
With GP?	Yes No	89 11	84 16	.774 M
With family?	Yes No	90 10	98 2	.219 M
With staff?	Yes No	87 13	87 13	
Discuss plans for cardiopulmonary resuscitation in the event of cardiac arrest?				
With resident?	Yes No	23 77	65 35	.001* M
With GP?	Yes No	42 58	71 29	.004* M
With family?	Yes No	38 62	81 19	.001* M
With staff?	Yes No	29 71	74 26	.001* M
Use of any form or tool for physical assessment?	Yes No	65 35	80 20	.146 M

Question	Response	Baseline Audit % (n=49)	Final Audit % (n=49)	Test result
Rate your home's ability to address residents:				
Physical needs	Very good/ good Average/Poor/very poor	96 4	98 2	.007* S
Psychological needs	Very good/ good Average/Poor/very poor	73 27	78 22	.170 S
Social needs	Very good/ good Average/Poor/very poor	76 24	78 22	.078 S
Spiritual needs	Very good/ good Average/Poor/very poor	48 52	74 26	.006* S
Do you send a handover form to out-of-hours provider?	Yes No	17 83	52 48	.001* M
Staff attended 3rd GSFCH workshop	Yes No	X	70 30	
Staff attended 4th GSFCH workshop	Yes No	X	75 25	
Staff attended other end of life training?	Yes No	X	85 15	
Are you using 'Foundations in Palliative care'?	Yes No	18 82	52 48	.004* M
Do you offer information leaflets to family carers?	Yes No	27 34	36 64	.344 M
Do you routinely give families information on what to do after a death?	Yes No	92 8	97 4	.625 M
Do you have a protocol for the bereaved?	Yes No	54 46	53 47	1.0 M
If yes, do you use it?	Yes No	83 17	89 11	
In relation to end of life care rate: Quality of support to family carers	Very good/ good Average/Poor/very poor	63 37	94 6	.001* S
Quality of support to staff?	Very good/ good Average/Poor/very poor	55 45	76 24	.004* S
Quality of teamwork in the care home?	Very good/ good Average/Poor/very poor	80 20	92 8	.089 S
Use of a protocol for residents in the last days of life?	Yes No	51 49	78 22	.007* M
Use of an integrated care pathway?	Yes No	19 81	59 41	.000* M

Question	Response	Baseline Audit % (n=49)	Final Audit % (n=49)	Test result
Use of a procedure to use anticipatory medication?[12]	Yes No	39 61	70 30	.002* M
Do you conduct a medication review for symptom control?	Yes No	90 10	96 4	.453 M
Use of GSFCH advanced care plan?	Yes No	X	79 21	
Use of supportive care templates?	Yes No	X	74 26	
If yes, where are templates kept: With existing resident record?	Yes No	X	N=30 N= 2	
As a separate record?	Yes No	X	N= 9 N=13	

Statistical tests M=McNemar test, S= Sign test.
Significance set at p<0.05   Significant result= *

The levels of engagement with the GSFCH programme among the 49 homes which completed the evaluation are indicated by the finding that 70% of homes were represented at the third GSFCH workshop and 75% at the final workshop (Table 9). Eighty five percent of respondents stated that staff had accessed additional end of life educational events, apart from GSFCH, in the previous few months.

Table 9 indicates the extent to which homes adopted elements of the GSFCH. The results show that almost ninety percent of homes had used the A-D categories. These categories offer a way of identifying residents' prognostic stage (i.e. years (A) months (B), weeks (C), or days (D) before death). Estimation of residents' prognostic stage helps to enable the initiation of timely care planning. Of those who had used the A-D categories, 61% said they were very useful while a third said they were of some use. Statistically significant changes (i.e. changes the magnitude of which indicate it was unlikely to have occurred by chance) are shown in the number of homes that post GSF had a care register for end of life care, had a coordinator for end of life care and routinely undertook advanced care planning.

No significant differences pre and post GSFCH were found in the numbers of homes which discuss preferred place of care with residents, GPs, families or staff, possibly

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[12] Anticipatory medication is medication specific to symptoms in the last few days of life.

because these levels were already high at baseline, but significant changes are shown in the proportion of homes that report they are discussing resuscitation plans with residents, families, GPs and staff. At Baseline Audit 23% of homes were discussing such plans with residents but at the Final Audit 65% were having these discussions. At Baseline the majority of homes felt their abilities to address residents' physical, emotional and social needs were either good or very good, but less than half (48%) felt confident they were addressing residents' spiritual needs. This measure demonstrated a significant change ($p=0.01$), with three quarters of homes reporting post the GSFCH programme that their abilities in this area were good or very good. A significant difference was also demonstrated in respondents' assessments of their home's ability to address residents' physical needs, with a number of homes which rated themselves 'good' at baseline now rating themselves as 'very good'.

Improved communications with out-of-hours providers was indicated by the percentage of homes that sent a handover form to the out-of-hours provider, a rise from 17% to 52% ($p<.001$) during the programme. Increased educational input is indicated by the increase in homes that are using the 'Foundations in Palliative Care' pack for staff training, again a significant increase.

The quality of support to family carers, and the quality of support to staff in the context of end of life care showed significant improvements. There was judged to be an improvement in the quality of teamwork in the home, although not statistically significant, possibly because this measure was judged to be high at baseline.

Three other care items showing significant improvements between Baseline and Final Audit were the number of homes using a protocol for residents in the last days of life, the number using an integrated care pathway, and the number having a procedure to arrange prescribing of anticipatory medication. There was no significant increase in the number of homes conducting a medication review, but levels at baseline were high, indicating this is already normal practice in many homes. Areas showing minimal change following GSFCH included providing families with written information and having a protocol for the bereaved.

Implications

The evaluation did not include a control group of homes, this would have presented considerable practical difficulties in matching homes and maintaining response rates. Consequently on the basis of the quantitative data analysis it is not possible to say with certainty that the changes in end of life related care and quality ratings are the result of introducing GSFCH. Many homes were changing and reviewing practice continually as part of the normal cycle of quality improvement and GSFCH was one programme of many which may have been progressing at the same time. In particular, some homes were implementing an ICP for end of life care at the same time as GSFCH. As a group these homes were already performing well on some indicators of quality of end of life care, e.g. giving families information on what to do after a death, indicating that they were possibly already in the process of reviewing care.

Comparison of pre and post After Death Analysis (ADA) data

As with the Baseline and Final Audit data, meaningful comparison of the ADA data could only be made by matching returns from the same home. Both pre and post ADA data were returned by 44 homes (220 cases). It should be noted though that although homes were matched in the analysis, different respondents could have completed the ADA.

In order to carry out statistical tests, a score was produced for each care item in the ADA, based upon the grouped item data for each home, pre and post GSF. For example, if all five residents had an advanced care plan the score was 100%, if three out of five had a care plan the score was 60% and pro rata. Scores were also weighted according to the number of cases returned. Scores from homes that returned five cases carried more weight than homes that returned fewer cases. Overall scores were then compared using the Wilcoxon signed rank test.

In Table 9, care items identified in the ADA are listed 1-7. The analysis shows that between the two time points there was a significant change in the place of death of care home residents, with a greater percentage dying at the care home post GSFCH (80.9% pre GSF; 88.5% post GSF). To ensure accuracy, analysis of care items Nos. 2-5 was conducted on data relating to residents who died in the care home. In all four care items it appears that there has been implementation by some homes of key

features of the GSFCH, with all four variables showing a statistically significant improvement between baseline and follow up. Numbers of crisis events and crisis admissions to hospital (Nos 6 & 7) also demonstrate that at follow up smaller proportions of residents had either crisis events or a crisis admission. The change in both measures was statistically significant.

Table 9: Pre and post test ADA analysis

No.	Care item	Response		Test result
		Pre ADA n= (%)	**Post ADA** n= (%)	
1	Place of death 　　Care home 　　Hospital 　　Other 　　Total 　　Missing	 178 (80.9) 40 (18.2) 2 (1) 220 	 192 (88.5) 23 (10.6) 2 (1) 217 2	Z -4.358 P .000*
	Residents who died in the care home	**n=178**	**n=192**	
2	Advanced care plan in place 　　Yes 　　No 　　Missing	 67 (37.6) 106 (61.3) 5	 121(63.0) 71(37.0) 	Z –5.30 P .001*
3	PRN drugs listed 　　Yes 　　No 　　Missing	 94 (53.7) 81 (46.3) 3	 116 (60.4) 76 (39.6) 	Z –2.543 P .011*
4	Last days of life care pathway 　　Yes 　　No 　　Missing	 28 (15.9) 148 (84.1) 	 87 (45.8) 103(54.2) 2	Z –7.119 P .001*
5	Written information to family 　　Yes 　　No 　　Missing	 35 (20.2) 138 (79.8) 	 101 (52.9) 90 (47.1) 1	Z –10.355 P .001*
	All resident deaths	**n=220**	**n=219**	
6	Number of crisis events 　　None 　　One or more 　　Missing	 94 (51.9) 87 (48.0) 39	 126 (61.2) 80 (38.8) 13	Z –2.137 P .033*
7	Number of crisis admissions 　　None 　　One or more 　　Missing	 110 (62.1) 67 (37.8) 43	 151 (73.7) 54 (26.3) 14	Z –3.354 P .001*

Statistical test – Wilcoxon
Significance set at p<0.05   Significant result = *
N.B. The statistical tests for items 2-5 were conducted on data grouped by home. Appendix 8 offers an alternative representation of these results.

The implications of these findings are that staff are using the tools and skills introduced during the GSFCH programme. Use of these tools should result in residents receiving planned, better quality end of life care which is in line with their expressed wishes. An increase in the proportion of families who are given information indicates that awareness and delivery of care for residents' families has improved.

As with the audit data, caution must be used in interpreting these results because it is not possible to attribute these findings wholly to the implementation of the GSFCH. For example, the higher proportion of residents dying in care homes when compared to hospital may be due to the impact of using the GSFCH, or to other factors. For example, during the workshops, interviews and case study visits, staff reported that residents were being admitted at a far more advanced stage in their end of life journey, consequently they had little time to get to know them to establish their preferences about care. Similarly, one nurse reported that a PCT noticed an increase in death rates in some care homes and asked for these to be audited. It was concluded that the increase in rates was because the homes had been acknowledged as specialist homes for end of life care. Consequently they were admitting a greater proportion of residents who were in last stages of their lives.

Summary

This section has reported the quantitative data collected in the audit surveys and ADAs undertaken during the GSFCH development programme. These quantitative results need to be viewed with caution given the 'real world' approach in which it was not possible to control for variables that may have impacted on perceived improvements in care giving. However the indications are that the care homes did show progress in implementing improved end of life care.

1. Response rates are discussed to set the scene for the pre and post test comparison that is drawn between Baseline and Final Audit from the 49 homes which returned these complete data sets.

2. A comparison of homes that completed the Baseline and Final Audit with those which did not indicated differences in systems in place on a range of variables that may influence uptake of GSFCH at baseline (Table 8).

3. Of the homes that completed both Baseline and Final Audit there is evidence that homes had adopted a range of practices linked to use of the GSFCH (Table 9).

4. The ADA tool demonstrates useful potential as a means of auditing end of life care provision and indicating change over time.

5. ADA data indicated that, pre and post implementation of GSFCH, homes demonstrated improved care planning and avoidance of crises that may result in admission to hospital.

6. There was a seven percent increase in the numbers of residents dying in the care home and a reduction in the numbers dying in hospital.

The following sections in which the qualitative data are analysed and presented will help to indicate the extent to which the changes in care arose out of homes' involvement in the GSFCH programme.

SECTION 5: ORGANISATIONAL ISSUES (1) THE CONTEXT

The context in which care homes are delivering care is of particular interest as issues related to this will inform care homes in the future who wish to sign up to the GSFCH programme.

The first part of this section uses data from manager/coordinator telephone interviews and case study site visits and explores four key areas: staffing levels, team working, training issues and working with local GP and nursing services. The second part is more wide ranging and additionally draws on audit data.

Qualitative data: Manager/coordinator interviews and case study visits

As discussed in Section 2, the case study stage of this project enabled the research team to conduct a more in-depth examination of the contextual issues informing this work. Fourteen managers consented to a telephone interview (Figure 6, page 33) and these were conducted between December 2005 and February 2006. Table 10 summarises the features of the 14 homes.

Table 10: Features of homes in qualitative phase

Feature	N=14
Type of home	13 nursing care 1 personal care
Ownership	5 single ownership 9 part of a group
Premises	6 purpose built 8 modified with some purpose built
Location	Within 13 primary care trusts and 8 strategic health authorities (as June 2005)
Urban or rural area	10 urban 4 rural
Number of residents	20 to 70 (mean 46)
Type of provision	1 Personal care 6 Nursing care 7 Nursing and personal care
Registered for terminal care (nursing homes only)	7 homes
Number of GP practices with residents in the home	6 homes - 1 practice 3 homes - 2 to 5 practices 4 homes - 8 to 10 practices 1 home - data missing
Is primary care practice GSF?	10 homes - only or main GP practice is GSF 3 homes - GSF status of practice not known/uncertain 1 home - data missing

GSF coordinator	11 nurse manager
	  2 senior nurse
	  1 carer (personal care home)

GSF Facilitator in post	12 yes 2 no

By the time of the telephone interview two homes no longer had a GSFCH facilitator because facilitators had changed post and the role had not been re-allocated. One home identified a facilitator, but the individual was not known to the GSFCH team.

Some of the challenges to implementing GSFCH are indicated by the large numbers of practices with which some of the homes liaised, and the GSF status of primary care practices.

Staffing levels

Coordinators generally reported their staffing levels were at or higher than required levels (Department of Health, 2003). Some homes, which had continuing care beds funded by PCTs, noted that they were required to have 'good staffing levels'. This was not defined in staffing ratios although it was noted that the data collected at interview did not always match the audit data. There were differences in stated and

actual staff available, for example due to sick leave amongst staff. A few homes offered placements to student nurses from local universities. This meant homes had been subject to a local audit of capacity to support students and is thus an additional indicator of level of staffing and provision. Variations in staffing were reported, but generally levels were thought to be good:

> *We go through cycles where it is sometimes difficult to recruit care assistants, but at the moment we're not having any difficulties, and we rarely have difficulties with qualified nurses, we tend to have a lot of staff who stay for more than 5 years, and then you get the ones who come and go, more the care assistants.* [Manager 59]

> *We are far in excess of what staff it is said we need* [Manager 8]

One manager acknowledged that the staffing levels at her home were not necessarily typical across the care home sector:

> *Yes, we are fully established. We are probably one of the only homes in the area that are.* [Manager 3]

While managers generally reported good or very good staffing levels, on some site visits it was apparent that in practice shortages sometimes occurred. Homes tried to avoid using agency staff:

> *…we try very hard not to have agency nurses, we do have a few agency nurses, but we have requested from the agency that we always have the same ones, so they know the nursing home well. We try not to have too many staff who have difficulty with the English language, because then we have problems* [Manager 54]

Several homes stated they did not use agency staff at all and one manager commented that some staff worked one shift a week while their main employment was elsewhere. Homes felt they benefited from the skills and information these staff bought from other health care settings:

> *…we also have bank staff, and staff who might do one shift a week, and their main employment is either district nurses or health visitors, so we have a fascinating pool of knowledge, for example our district nurse uses syringe drivers all the time.* [Manager 54]

Administrative support in the homes was generally reported to be good. Nursing and care staff at one home [32] were *'struggling a little bit'* due to staff sickness and a

planned cut in staff hours, but they still felt they had a good team. Residents and relatives were not asked about staffing but some made observations about this area:

> *They seem short staffed here, they don't always have enough, they have two on when they should have four on* [Resident A]

While a relative commented:

> *They're very good here, all the staff, but the carers seem to change quite a lot.*
> [Relative A]

Implications

Generally, the homes reported good staffing levels. It is possible that only homes with good staffing levels agreed to participate in the GSFCH, or at least in the qualitative phase. However, staffing is only one factor in implementing GSFCH and other factors, such as a motivated facilitator and coordinator emerge as important.

Team working in care homes

Levels of team working in any organisation potentially influence the adoption, success and sustainability of programmes such as GSFCH. To measure staff perceptions of levels of team working in the homes which were visited a brief staff questionnaire which incorporated a validated team working questionnaire (TWQ) was used (Borrill & West 2001). The TWQ consists of a Likert scale with 16 items scaled 1 to 5. Four areas of team working are identified: Clarity and commitment to team objectives (3 items), focus on quality (4 items), decision making (5 items) and support for innovation (4 items). Scores for each area are added together and then divided by the number of respondents to provide a team score for each area. Table 11 gives details of the four areas.

The difficulties in securing good response rates from postal questionnaires (May 2001), resulted in a decision to administer the staff questionnaire during fieldwork visits to homes, when questionnaires were administered after the staff interviews. The majority of questionnaires were collected at the time but a small proportion were returned by post.

Table 11: Descriptors of objectives in Team Working Questionnaire

Area of team working	Description
Clarity and commitment to team objectives	Assesses the extent to which teams are clear about their work-related objectives, the extent to which they perceive objectives to be worthwhile and whether team members share these objectives.
Focus on quality	The extent to which team members engage in debate and review processes to achieve excellence in decisions and actions that they take to provide services. It is a measure of the degree to which team members feel that discussion and debate within the team is constructive, and that team members feel able to engage in the process of debate without being concerned that their contribution might be ridiculed or ignored.
Decision making	The extent to which members of the team feel they have influence over decisions made in the team, the degree to which team members interact with each other on a regular basis and the adequacy of information sharing amongst members of the team.
Support for innovation	The degree to which there is verbal and practical support for the development of new ideas. Questions on this measure refer to sharing resources, giving time and co-operating in implementing new and improved ways of doing things.

Results from the Team Working Questionnaire

Sixty-eight staff from nine homes[13] completed the TWQ but the numbers of respondents from some homes was small. Grades of staff completing the TWQ varied from home to home, depending upon managers' definitions of who was in the team. Consequently domestic and housekeeping staff and the PCT liaison nurse were included at two homes, indicating broad definitions of the team.

Table 12 shows the results of the team working questionnaires. TWQs were completed after the interviews and although they were anonymous with staff allocated a code number, responses may have been influenced by the close proximity of colleagues.

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[13] In one home the TWQ was not administered because only three senior staff were interviewed.

Table 12: Results of Team Working Questionnaire by home

Home	No. of staff	Clarity		Quality		Decision making		Support	
1	4	4.3	H	3.9	H	4.0	M	3.9	M
2	8	4.0	H	3.9	H	3.8	M	3.8	M
3	10	4.5	H	4.5	H	4.4	M	4.4	M
4	7	4.0	H	3.9	H	4.0	M	3.8	M
5	5	3.7	H	3.4	M	3.0	M	3.6	M
6	4	4.8*	H	4.6	H	4.4	M	4.5	H
7	12	4.6*	H	4.4	H	4.5	H	4.6	H
8	6	4.2*	H	4.3	H	4.2	M	4.3	M
9	12	3.9	H	3.9*	H	3.7	M	3.8	M

* item average based on n less one.
Letters denote High (H), Medium (M), or Low (L) scores.

Results show that staff in the nine case study homes that completed the TWQ believed there was a high degree of clarity about work related objectives (score above 3.4) indicating that teams had clear, shared, attainable objectives, which were valued by all team members. Eight homes scored highly on the quality dimension (score above 3.8) indicating commitment to achieving the highest possible performance. Scores for decision-making and support were slightly lower with all but one home returning a medium score (between 3.0 and 4.3) for decision-making and communication. Two homes scored highly on the final dimension, support for innovation, while the remainder scored in the mid range (between 3.2 and 4.4). One home scored highly in all four areas and six homes shared a pattern of high scores for clarity and quality and medium scores for decision-making and support.

As a group therefore, staff in the case study homes indicated a high level of team commitment and clarity of vision, combined with a focus on achieving a good team performance. Overall performance in the scores on decision-making and support for innovation were lower, though still within the medium range, indicating that staff felt less involved in these areas.

Care home staff may be part time and carers (NVQ or unqualified staff) in particular are poorly paid, circumstances that may result in staff not feeling as valued and possibly not wishing to play a part in innovation. Borrill and West (2001) suggest that a low score in support for innovation indicates '*little articulated or enacted support*

for innovation is given. Stability is favoured above change. The team commits few resources to innovation'. Overall the TWQ indicates that the staff in our sample were clear about team objectives and committed to meeting them.

Results from the TWQ may suggest that homes with existing effective teams, who held common goals, and had a focus on quality, are the type of homes that are predisposed to participating in GSFCH and staying in the programme.

An alternative view may be that, as the visits were conducted at a minimum of seven months after the introduction of GSFCH, the high scores could be attributed to the GSFCH having a positive impact on these teams. Evidence to support both these positions has emerged from the analysis outlined later in this report (see Section 7).

The good levels of team working revealed in the TWQs were evident in some staff and manager interviews as illustrated by the following quotes:

> *I have got a good team of loyal staff who are quite motivated, that is the first thing.* [Manager 54]

> *I think we have got quite committed staff to improving things.* [Manager 89]

Staff in this latter home described themselves as '*a very strong team'*, adding that most of them have worked in the home for several years. A registered nurse said of her manager '*She's keen, excellent, young, we're a very stable workforce'*. A carer who had worked for 21 years in a home joked '*I'm almost a resident myself'* and two other staff had worked in the same home for 12 and 5 years respectively.

Two homes had two generations from the same family on the staff. Staffing problems have been reported in the care home sector (Eyers, 2000) and the relatively low rates of turnover reported by the case study homes may indicate they experience fewer difficulties in this area. Smaller homes operated with very flat management structures:

> *'There's no hierarchy in this place, everyone's included in everything. She takes us out for meals and drinks, and makes hospital visits if we are ill.* [Nurse 1, 100]

Other staff spoke of managers who supported them if they were *stressed or upset*.

From one perspective, low levels of staff turnover may be seen as undesirable, with the risk that innovation or change may prove difficult, but it indicates that staff are happy and settled, are likely to work well as a team and have time to build relationships with residents. In addition to staff within the care team, managers often referred to the support from owners of small homes, senior managers of group homes and boards of trustees. One stated *I've got good back up from my trustees.* [Manager 59] while another described the support she received:

> *When it came to setting it (GSFCH) up, I do think that if you have this, my directors were brilliant, they are very forward-thinking people and they saw that there was a need for this. Neither of them are trained in care at all, they have no medical training, but they could see the value of it. You have to have an enthusiastic, motivated management to set this up.* [Manager 8]

One of the case study homes was run by an owner/manager, in another the owner lived next door and in another home the owner visited several times a week. Two homes were from small groups, one of which had five homes within a small geographical area and the managers felt this created a supportive environment in which to work. In turn managers supported their staff and in smaller homes staff could contact managers at any time.

Managers reported working unsocial hours if necessary, for example if a relative was making an initial visit they asked to be notified so they could meet them, arguing that this was not intended to undermine the staff on duty but that provision of holistic care may involve *rearranging your life or your work plan* [Manager 72]. Acknowledging the work of the whole team was also important; managers kept letters of thanks to show staff, ensuring individual staff were thanked if they had been singled out for praise. Feedback of families' expressions of gratitude and thanks was important because *it can be bloody hard work at times* [Manager 72].

Staff perceptions of whether they were a good team were related to their assessments of the quality of care the home provided, which in turn appeared to be related to the communication between managers and staff. When asked whether there were existing features of the home that were likely to enhance the possibility of successful implementation of GSFCH one carer responded;

Yes I do, I've been caring for 18 years or so and this is one of the best homes that I have worked in and yeah, they do (keep us informed), on the staff meetings and so forth. [Carer 1, 89]

Staff in the case study homes largely portrayed themselves as members of cohesive, motivated teams and this was borne out by the TWQ results. These characteristics, combined with low staff turnover may mean that the possibility of successful implementation of GSFCH increases. It is possible that attention to aspects of team building may be needed in some care home settings before GSFCH is initiated and a range of resources are available to assist organisations in addressing these areas (West & Markiewicz 2004)

Training

Training for care home staff may be seen as falling into two areas; mandatory training such as fire lectures or health and safety, and education and training for staff development to increase staff knowledge and skills. Training in care homes was delivered in a variety of ways: in-house training by managers, homes in larger groups had access to training departments, local palliative care services, hospices, social services and a range of other providers offered courses. Training might be free or charged for. A wealth of training is available; and the range of courses available to, and accessed by care homes was diverse, varying in depth, scope and content.

The training needs of care homes are influenced by the range of staff; the training needs of housekeeping staff or untrained carers are different to those of registered nurses who may already have experience of palliative care. There are few nationally recognised courses for care home staff, other than general NVQ training, and palliative care training needs were met by accessing a range of courses or inviting members of the palliative care teams to deliver in house training. Adequate budgets are therefore needed.

Access to training among staff in case study homes was hugely variable. Some managers had training budgets which they could use at their discretion, one manager said her training budget was fantastic (3) and another felt she was able to meet the training needs from the budget (89). Three managers did not have a set budget and

made applications for training funds on a case-by-case basis. One manager was always well supported:

> *If people need to go on a training session my directors are superb, If I need to send six people they go, they are very supportive, they realise the importance of training and we send people on anything we feel they need* [Manager 8]

Another manager had limited funds:

> *We do a lot of training…I have to make a case for each one so the fewer the better to be honest* [Manager 22]

And one manager described how mandatory training has to be prioritised:

> *The PCT funded the GSF, but otherwise I have to make a case by case basis, the mandatory element of training is rising, e.g. fire lectures, so other non mandatory courses are squeezed, the night staff have to have four fire lectures a year.* [Manager 32]

This manager set up a GSFCH session for staff but it was *very, very poorly attended.* The training was arranged for a time when staff changed shifts in the hope that staff on the later shift would come in three quarters of an hour earlier and staff finishing would stay after their shift. The manager felt the low turnout was due to the non-statutory nature of the GSFCH training which staff were not paid to attend. Difficulties in funding staff time to attend local GSFCH training was a factor for some homes that dropped out of the programme.

An RGN from a different home described how staff who were going through the 'Foundations in Palliative Care' programme were very enthusiastic about it and discussed it with colleagues who were due to go on the next course*:*

> *…the feedback we're getting back on that is wonderful and everybody is enjoying it and they're learning an awful lot more…* [Nurse 3, 89]

Motivating staff to attend courses was mentioned by a few managers, some explained they supported staff training by meeting some costs, for example if courses were free the home paid staff time, but if fees were charged the home paid these but staff had to attend in their own time. Among the case study homes there is evidence of wide variations in the arrangements for funding training and education and consequently in access to training. One nurse who had worked in several care homes and was in a position to make comparisons commented:

It's the best place I've ever worked for training [Nurse 2, 54]

The fee for joining the GSFCH programme covered attendance at the four workshops, GSFCH information and materials and support from a facilitator. Facilitators held a number of local meetings with homes, either individually or with groups of homes, during which staff were helped to identify their training needs with the aim of equipping them to deliver improved end of life care in line with the GSF framework. Training needs might be met by facilitators themselves or by arrangement with other providers, e.g. local hospices or palliative care teams. Courses ranged from those specially tailored to the care home setting or GSFCH, to existing courses, for example syringe driver training.

As a result, GSFCH related training varied from home to home and while some providers charged for training, other courses were free.

Location was also a factor in access to training. For example, a Palliative care team in one area might charge for a course (a figure of £30 per delegate was quoted by one facilitator), whilst this was provided free in another area. In one care home a number of staff reported that a forthcoming free training session was cancelled by the NHS provider when two other homes who were due to attend dropped out of GSFCH, on the grounds that it was no longer worthwhile. Staff felt they were being denied valued training through no fault of their own.

Impact of local GP and specialist palliative services on end of life care pre GSFCH

This section explores the nature of services and facilities available to individual care homes and how the staff within them saw organisational factors related to, or driven by external pressures, impact on the end of life care they offered. The first part of this section considers Baseline Audit data relating to GP services while the second part considers the more detailed findings from the 14 coordinator interviews and 10 case-study homes.

Baseline Audit data

Forty-three (54.4%) of the 79 respondents who completed the Baseline Audit made observations on GP services. Ten responses were favourable while 22 identified problems. Nine commented favourably but identified some problems and two made other comments.

Supportive GP services

Almost one quarter of respondents who made comments expressed a favourable opinion of GP services to their home. Three described the service as excellent while six said practices were supportive or very supportive.

> *Regular hours, our GP surgeries are excellent and give us continuous support* [Home 54]

In common with the above home, others specified that they were referring to daytime GP services:

> *Excellent daytime services* [Home 79]

> *Excellent during day* [Home 20]

Neither of these respondents made further comments.

Problems with GP services

Twenty-two homes identified problems with GP support, most commonly the out-of-hours GP service, including homes that had no direct access to the service. Three main sources of dissatisfaction were identified; access to the service, the decisions sometimes made by out-of-hours GPs, and issues related to prescribing medication for residents who were thought to be entering last stages of life.

A specific problem identified were GPs who were unfamiliar with patients, while one home reported that GPs were unfamiliar even with the type of people who live in care homes. Reluctance by some GPs or the out-of-hours service to visit was also identified:

> *Doctors visit who are unfamiliar with patients* [Home 68]

> *Our out-of hours GPs are reluctant to visit* [Home 95]

Consequently decisions were sometimes made which homes felt were not in line with residents' needs or wishes:

> *As we are rural we use* [name] *and they will sometimes transfer the resident to hospital rather than visit even when the needs of the resident are known* [Home 30]

> *Poor out-of hours service, GPs reluctant to make a decision and keen to send patients to hospital* [Home 80]

Reluctance to make prescribing decisions was also identified as a problem. Seven homes cited prescribing difficulties, including the lack of anticipatory prescribing and the subsequent difficulties in obtaining medication:

> *Select GPs are slow to issue prescriptions often leaving us without medication out-of-hours.* [Home 52]

Problems may be compounded if local pharmacies do not stock required items:

> *Have had to send member of staff or family to fill prescription. At weekend chemist not always had full supply of medication* [Home 29]

One home stated that GP services were *disjointed and variable* and paid a retainer to a GP to help overcome potential difficulties.

Varied responses

Nine respondents reported mixed experiences. Working relations with the majority of practices were very good, but working with some GPs who were less familiar with the care home environment, for example those working for out-of-hours services, was not as satisfactory. Responses indicated that even GPs from the same practice may differ in the perceived level of service they give to homes' residents. Finally two homes indicated that they were aware that problems could arise in accessing GP services, but anticipatory planning helped to avoid these situations.

Case study data

The services and facilities discussed in more detail during case study visits focused on local health care provision via GPs, hospices, and district and palliative care nurses. Different homes had different experiences in relation to working with each of these services and reported how these impacted on the care they offered.

Relationships with GPs

Six of the 14 homes in the qualitative phase worked with only one GP (or at least the GPs from one practice) and the remainder with several practices (in one case as many ten). Homes working with one GP or practice saw this as advantageous because *they know all our residents.* Some homes working with several practices felt that this could be a problem, but there was also a comment that contact with a range of GPs allowed homes to work with some GPs they described as *fantastic.* Several homes were working towards using fewer GPs; suggesting that this was seen as ideal although this was for practical reasons, such as GP rounds becoming time effective, as well as for optimum resident care. Homes in both groups saw their system as providing for the needs of their residents.

Some homes had regular GP visits (from weekly to five times a week) whilst others called GPs when they were needed. One home invited the GP to a weekly meeting with senior nursing staff and doctors from the neighbouring hospice. A number of homes had contracts with GP surgeries, and stated that paying retainers meant they could ask for what they wanted. A manager/owner from a home that did not pay a retainer to a GP however described how she was:

> *Shocked … when I heard of homes paying their GPs' retainers. I won't pay a GP, why? I'm not paying a GP unless he's doing more than he should.* [Manager 99]

GPs' knowledge of end of life care was seen to be an important factor in providing optimum care at this stage of life and this varied enormously. Several homes felt GPs' knowledge of this area was sometimes lacking:

> *The knowledge wasn't there for the palliative care side, for the drugs side of things* [Nurse 1, 3]

> *We've had a few problems with GPs not recognising end stage of life...*[Manager 1]

> *Two of our doctors have been out and we have asked them about palliative care and they weren't up to speed…*[Manager 92]

There were some comments relating particularly to trainee or newly qualified GPs and one manager had been told that the practice saw care homes as a good environment for trainee GPs to work and learn in. However this was not without problems, for

example, a trainee GP suggested to relatives that a family member should be admitted to hospital, when a prior agreement had been reached between staff and the family that the home would care for the resident to the end, and the staff had done a lot of work with the family about easing guilt *Things like that make the link with the GP practice difficult.* [Manager 1]

In other homes GP knowledge was seen to impact positively on care:

> *And care of the dying very very good, the GPs in the area they're brilliant*. [Nurse 2, 54]

> *GPs are becoming more aware of anticipatory prescribing and it's empowering my staff.* [Manager 8]

In some homes staff were aware that GPs improved their knowledge by consulting hospice doctors and Palliative care nurses.

The relationship between homes and practices/ GPs was also seen to impact on the delivery of end of life care. This included factors such as GP availability and willingness and expectations and trust towards homes and nurses.

Staff from several homes described different relationships depending on the GPs and practice. Many GPs were described as *helpful* but they could also be patronising. Staff recognised that GPs were often short of time but some felt that care home residents were sometimes seen as less of a priority than other patients living in their own homes. One manager stated *we really struggle with their attitude towards care homes here* [Manager 35], explaining that they are not allowed the out-of-hours service priority telephone number and could only contact GPs through the normal channels.

There were suggestions that good relationships resulted from working with practices over time so that GPs and care home managers and staff built up trust in each other. When this had been achieved it had *helped immensely.*   There were particular problems with locum and out-of-hours GPs who did not know the homes or residents. Whilst staff in one home appreciated the fact that GPs would take responsibility for putting residents on out-of-hours lists or talking to them about their wishes regarding resuscitation, most appreciated GPs 'trusting' them, by for example leaving anticipatory drugs or agreeing with their treatment plans verbally (over the telephone).

There were complaints that although GPs were *becoming more aware of anticipatory prescribing* there were still some GPs who would not leave drugs, sometimes because they did not agree with nurses' assessments of potential symptoms. Even when residents' stated wishes to remain at the care home were recorded in their care plans, there had been occasions when GPs had insisted on admitting them to hospital as they approached end of life. Examples were given to illustrate the negative impact of such practices on care. In the case of one gentleman, '*who had an advanced care plan, with no admissions to hospital*' the GP refused to visit during the night and told the home to admit him to hospital where he was given oxygen and discharged back to the home:

> *…we have oxygen in the home. If the GP had come we could have given him oxygen here. He could have stayed in his own bed all night*. [Manager 35]

The manager of one home described working proactively with GPs, introducing a system where (with resident's permission) the doctor provided the home with information about health history to supplement that given by the resident and family.

Relationship with out-of-hours GP services

Relationships with out-of-hours GP services impacted negatively on a number of homes. One manager commented that prior to introducing the GSFCH they had not been allowed to take part in the local out-of-hours scheme and just had to call a GP like anyone else. Another said they tended not to call the out-of-hours service for advice as the only advice they were likely to get was to send residents to hospital even when this was contrary to their care plan. Out-of-hours services sometimes sent nurse practitioners to see residents, as one manager observed, these nurses generally had similar or less knowledge of palliative care than the nurses working in the home and nurse practitioners would have to liaise with GPs to get prescriptions written. If possible staff in this home would wait until morning to call a residents' own GP. Staff in some other homes did not feel totally confident that plans, even when written and faxed to the out-of-hours service, would be carried through. One commented on the anomaly of sending plans on Friday nights but not on other weekday evenings. Some felt that services were improving as a result of better management. In one area a doctor had recently taken over management of out-of-hours services and staff expected that this would be an improvement, as he would have a better understanding of relevant issues.

There were also differences in facilities available to rural and more urban homes. One home for example, was next door to the GP practice, whilst staff at other homes talked about the particular problems of rurality. Nurses in one rural home explained that out-of-hours doctors may have to drive for one and a half hours to reach their home. The doctor may not to be a palliative care specialist and staff felt that if the doctor had to make decisions about which patients to visit first, care home residents at the end of their lives might not be a priority.

Relationships with palliative care services
Staff in about two thirds of the case study homes talked about their relationships with palliative care[14], Macmillan or (less often) Marie Curie nurses, and half of these also talked about relationships with local hospices. Such relationships were always seen as helpful in the task of providing optimum end of life care. Homes varied in the amount they used, and indeed felt they needed, support from such services. One or two homes talked about isolated contacts or in terms of *we have even had some liaison with hospice staff,* [Nurse 2, 54] but most talked about established relationships that provided support, advice and training generally, and in relation to specific residents. A few homes had regular meetings set up to obtain advice from Palliative care nurses and one said of the relationship *we work as a partnership really* [Manager 3].

Homes had generally been proactive in forging these relationships and some commented that before the GSFCH they had *never ever been refused help or advice but it's not been offered and pushed towards me* [Manager 32]. One manager spoke of being on the Palliative Care Steering Group in the local town. Only one home found that Palliative care nurses did not follow up residents admitted from hospital; others said they did and referred other residents to them.

Specialist palliative care nurses were praised for their quick response and described more than once as *fantastic.*

> *…we have a referral form and if I say we need them that day, they are on the phone within five minutes of getting the fax* [Manager 22]

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[14] Some palliative care nursing posts are initially funded for a specific period by Macmillan. Once funding ceases posts may be supported by the NHS. So all Macmillan nurses are palliative care nurses, but not all palliative care nurses are Macmillan nurses. Some respondents used the terms interchangeably.

Specialist nurses had provided equipment at short notice and were valued for the (free) training they had provided. Staff in one home explained how the training had helped them to better understand the needs of people in the last days of life. They had realised that they had been moving or *tidying up* residents when the resident really did not want this and it had been more a case of improving residents' appearance for the sake of relatives and staff.

Homes that had links with hospices particularly valued the 24-hour support and advice this provided.

> *…the hospices are a lifeline really…for expert advice and guidance*
>
> [Manager 8]

Hospices also provided training and emergency equipment. One manager described how in the last stages of life they would rather call hospice doctors than GPs, as their views on medication were more in line with those the home saw as most beneficial to residents.

Anticipatory medication

An issue that clearly concerned a number of case study homes was that of prescription and storage of anticipatory drugs. This issue was seen as having the potential to impact upon homes' ability to fully implement the GSFCH. Only one home had a Home Office Licence for holding stock controlled drugs that could be used for any resident who is dying, rather than a named resident. The extent to which other homes felt they could organise anticipatory drugs for named patients varied considerably. Some found GPs reluctant to prescribe anticipatory drugs while others had no problems. In some homes this varied between individual GPs.

Even in cases where there were no problems there were concerns about the availability of prescribed drugs out-of-hours, especially in rural areas, and about the costs of disposing of unused drugs. Staff in two homes expressed surprise and frustration that GPs had not allowed them to use sliding scales for calculating pain relief drug dosages when these were used by district nurses in the area.

Whilst nurses in care homes recognised that GPs were worried, especially since the Shipman case (Shipman Inquiry 2005), about prescribing anticipatory drugs or homes

keeping stock drugs, they felt that this was necessary and more trust of care home nurses was needed to provide the best care for residents.

> *I think the GPs now, they're worried since the Shipman case, we are a more litigious country now,* [Manager 59]

The manager from the home which had a Home Office licence to hold stock controlled drugs stated:

> *I can understand things from their point of view, they have the Shipman case hanging round their necks, and it so often gets repeated "I don't want to be seen to be doing a Shipman" however palliative care **needs** stocks, you need to have the syringe driver up within the hour and you can't do that if relying on an outside source of diamorphine. Local chemists don't always hold stocks and this is a rural area.* [Manager 8]

A nurse from the same home observed:

> *We are allowed to use the stock cupboard…that's there if we need it, we can do it, without any hesitation and leaving the resident or patient in agony for three or four hours before anybody can get medication to them* [Nurse 2, 8]

Summary

Qualitative data from audits, coordinator interviews and case studies reveals a number of organisational factors which had the potential to influence the extent to which the care homes might be able to adopt the GSFCH as follows.

1. There are indications that a high to medium level of teamwork was a common factor in the case study care homes. This may be an indication of their willingness to participate in the more in-depth enquiry but it also suggests that this may be a key consideration in advising homes wishing to take up the GSFCH. Even homes which demonstrated features of good teamwork struggled with various aspects of the GSFCH programme.

2. Training was an issue with access to training opportunities being variable from 'the best' to those who struggled to find funds. One of the key advantages in taking part in the GSFCH was that it bought a training opportunity to the homes.

3. In the homes visited, local services from GPs were variable. Generally, GPs known to the homes were seen as supportive. There was some debate about the value of accessing one or several GPs from a practice, with the benefits of both single GPs and team input being cited. Generally, longer term working relationships were seen as beneficial as this allowed GPs and care home staff to develop best ways of working together.

4. GPs knowledge of end of life care was seen as important in supporting GSFCH but some concerns were expressed about GPs lacking knowledge in this area of care.

5. Problems were encountered with access to services out-of-hours. This linked to the fact that in such cases GPs were reluctant to visit, not known to the patients, and were either reluctant to prescribe medication or resorted to referral to hospital.

6. Attempts to overcome this included homes paying a retainer to a GP to provide this service. This also gave the homes some control of the service they could expect. However, other homes saw this as 'shocking'.

7. The first point of call for care homes seeking out-of-hours support can be a triage nurse practitioner. This was not always seen as appropriate; firstly because the resident may not be known to the nurse and secondly, because the triage nurse may have less expertise in end of life care than the referring care home nurse.

8. Palliative care services were seen as good and responsive when required. This included both staff support, training and equipment when needed.

9. Getting access to anticipatory medication was an issue of concern to a number of homes although the extent to which this was a problem was variable. Some nurses found GPs reluctant to prescribe, others noted storage problems. This was a particular issue for rural areas.

SECTION 6: ORGANISATIONAL ISSUES (2) GSF AND THE IMPLICATIONS FOR WORKING WITH PRIMARY CARE

Introduction

This section considers the extent to which implementation of the GSFCH has influenced relations between care homes and primary health care teams. It includes views expressed in response to open questions in Audit 2 [n=53] and the Final Audit [n=52], and more in-depth opinions from interviews with coordinators [n=14] and staff in the case study homes [n=10] (see Figure 6).

Impact of GSFCH on care homes' relationships with health care providers

At Audit 2, seven homes, including two case study homes, listed improvements in communication with GPs or in the provision of out-of-hours services as the 'most useful' aspects of becoming part of the GSFCH programme. Comments about difficulties or challenges were not specifically invited at this stage, but within 'any other comments or concerns' a number of issues about GPs were raised. Eight homes described GPs as either lacking awareness of GSF or slow to accept it or insufficiently interested, cooperative or supportive. These comments all came from audit data from homes other than case study homes.

By the time of the Final Audit, comments about difficulties in relationships with primary health care teams, especially GPs, and how these had restricted implementation of GSFCH far outweighed comments about positive changes in relationships brought about by the GSFCH. Nine homes listed improved relationships with primary health care teams under 'improvements that have resulted from implementing the GSFCH'. These included better communication and relationships with GPs (or some GPs) and with out-of-hours services, and GPs becoming more involved and recognising the skills of care home staff. In the Final Audit 'challenges or difficulties in implementing GSFCH' were specifically noted and 22 homes cited

difficulties with GPs or out-of-hours services. By far the most frequently stated concerns were difficulty in involving GPs and lack or support from GPs.

One home that previously commented on a *lack of awareness* now described a *lack of support* [Coordinator 61]. Other concerns included GPs who respondents felt did not sufficiently understand GSFCH or indeed palliative care; GPs being slow to appreciate the benefits of GSF, not being proactive, not trusting nurses and being reluctant to prescribe medication including analgesia. Three homes reported ongoing difficulties with out-of-hours services and one found implementing GSFCH difficult, attributing this to the fact that no local GPs had signed up to GSF.

As discussed in Section 5, at baseline there were wide differences in relationships between homes and primary care teams. Within case study homes the general picture was that those with existing good relationships with local practices and practitioners described further advantages in implementing GSFCH: *'we have always had a good working relationship with our GP, so that's helped immensely,'* [Manager 8], whilst homes with poorer relationships reported continued difficulties or did not discuss these relationships.

For some homes, case study interviews took place at an early stage in their implementation of GSFCH (though after the third workshop) so there was still potential for such improvements to take place. However Final Audit data, (one year after the initial workshop and four months after the fourth (and final) workshop), reveals that case study homes were heavily represented in the homes that cited difficulties in relationships with GPs as one of their 'three challenges or difficulties in implementing GSF'. Whilst it is possible that taking part in interviews may have raised the issue for them, this still suggests that there were continuing significant difficulties at this stage.

Where the introduction of GSFCH was seen to have influenced relationships with primary health teams, the extent to which this had happened was influenced by the GSF status of primary care practices, and by specific factors relating to individual GPs, practices or areas.

There was a strong feeling within case study care homes that *for this* (GSFCH) *to work the GP has to be on board* [Manager 8]. This view was also supported by a facilitator who told a story of a 90-year-old man who had been admitted to hospital out-of-hours, against the wishes of his family and the care home nurses. They concluded by saying:

> *…so if you've not got the GPs on board to send the out-of-hours forms to the out-of-hours service what is the point of the GSF?* [Facilitator 9]

Positive experiences and improved relationships

Six case study homes (out of 10) reported positive experiences with primary health care practices when implementing the GSFCH, all of which also reported good existing relationships at the outset. This was evidenced by the fact that for some homes it was the local practice or Macmillan nurses who suggested to the manager that the home participated in Phase 2 GSFCH.

Managers of these homes felt that implementing the GSFCH led them to be more proactive, both in approaching GPs and in determining the content of meetings with them, and that the GSFCH opened up and progressed dialogue with GPs:

> *I think it has improved our communication with some of the GP surgeries …and the district nurses and the Macmillan staff. It's given us a much better communication link and advice link.* [Manager 32]

This improved dialogue could lead in turn to improved communication within the whole system:

> *…what we tend to do now when Dr R has reviewed on Friday, anyone who is in category D she is informing the out-of-hours service about.* [Manager 100]
>
> *…we had an initial meeting, well I did, with each surgery just to say what I was expected to do and what I hoped to do, and then one of the surgeries invited me to their monthly review palliative care meeting, and I presented three residents that I wished to go on the list…* [Manager 54]
>
> *We have also just in the last few weeks got one GP surgery that covers the home, which is taking the positive moves to invite us to their GSF meetings, end of life meetings, they have added those people* [nursing home residents] *to their list* [Manager 32]

> *She* [facilitator] *gave me a huge big document of medication which might be required at short notice for terminally ill patients…she gave me permission to give those lists to the GPs, and the GPs have took it one step further and talked to the local chemists to see how much they can incorporate locally, so we don't have far to go.* [Manager 54]

Managers felt that the recommendation of the GSFCH programme (to hold a meeting with GPs) gave them some sort of authority they hadn't previously felt in approaching GPs and put them on a more equal basis:

> *…and the fact that you asked me to have a meeting with the GPs, it was a good excuse to have that meeting, because I had my information here, I didn't feel an idiot, and was able to present myself to the GPs saying' I am involved with this' …it was very formal…and I had to stand up and say my bit as well, and I would never have done that, because I don't really like standing up in front of people, but I had your forms* [the GSF forms] *so I was able to present it so it guided me in my presentation and having the tools to do it with, really.* [Manager 54]

Managers and staff in these same six case study homes also commented on how helpful GPs had been in implementing GSFCH:

> *…the majority of GPs we work with, even if they are not GSF they are very open to listening to what we are doing… the GP practises have been very supportive of what we want to do* [Manager 8]

> *We work very closely with the GP practice, they are excellent, very supportive*
> [Manager 72]

> *Our GPs are fantastic for support. They just work with us… They are all aware we are doing it, so when we call them out they just back us up…*
> [Manager 100]

In some homes GPs had got involved directly in talking to residents about their wishes regarding end of life and in talking to relatives:

> *It is very difficult when you have someone living in your nursing home for 10 years to say 'Well hang on, if you pop your clogs what would you like to do?' so the GPs are addressing it* [Manager 54]

> *Our GP is on board and has started the conversations already about resuscitation…* [Manager 89]

> *Our GP is actually very keen to implement it herself and have conversations with the relatives as well* [Nurse 2, 89]

Four of these six homes worked with multiple GP practices and this did not seem to present any problems to them. The GSF status of the practices however was more relevant and all but one home worked with practices that were all or predominantly GSF practices.

Less positive experiences and continuing difficulties

One case study home worked with just one practice, which was not GSF. The difficulties this home had in trying to implement the GSFCH clearly illustrate the importance of GSFCH homes working together with GSF primary care practices. The manager felt that whilst they had made efforts to introduce the GSFCH this could not be fully achieved until the GP became involved:

> *…we have done the register and the advanced care plan but it's not all in place because we need to liaise with the GP…We are implementing it as far as possible* but *we can't implement it fully until the GP is on board* [Manager 1]

In contrast to the general picture that GSFCH was more successfully implemented when working with GSF primary care practices, one of the facilitators [26] described some feeling from the GPs that GSFCH did not need to be implemented in care homes when they were 'covered' by a GSF practice.

Some other homes reported initial difficulties in working with primary care practices. The manager of one home had been:

> *Trying to talk to our GP and at the moment he is saying 'Our practice isn't GSF', although it is GSF because we have seen it written down… and so we've had a few difficulties implementing it* [Manager 59]

This manager was also having difficulties liaising with the practice about appropriate forms and the details of procedures both because the practice took a long time (8-10 weeks) to respond and then they had sent an alternate form rather than commenting on the suitability of the one the home had devised and sent. At another home with a history of difficulties with some local primary care services the manager explained that whilst the GPs and district nurses in the local town had been introduced to the GSF, this was not obvious. The manager described attempting to arrange anticipatory medication:

I'm not sure how much they were interested in it, or followed it up because whenever they come and we say to them 'Well actually we are taking part in the GSF' it would be 'Oh yes' before you even get the words out of our mouth to say 'Could we go down the line of having a patch?' it would be 'I think we'll keep that up our sleeve for another day dear' [Manager 35].

This manager also said of the advanced care plan *Get it signed by a GP? No chance!* Although one GP had signed a form she felt they generally did not have time. In terms of wider primary care services she said

Meetings with GPs are difficult, never mind an interdisciplinary team
[Manager 35]

She was disappointed that despite the GSFCH the home was still not allowed the priority telephone number for the practice and had to go through the normal channels.

I think there is a massive fear within the [out-of-hours name] *system that we would inundate them with priority line calls, but we really struggle with the attitude to care homes here.* [Manager 35]

A particular issue for most case study homes, which GSFCH had made little impact on, was the availability of drugs out-of-hours. The problems for homes have been discussed in section 5 and whilst managers and staff understand the concern created for GPs by the Shipman case and the fact that GPs can be reluctant to trust nurses, there is a clear view that *'to get it* [GSF] *really up and running'* [Nurse 1, 3] homes need to be allowed to keep some anticipatory and stock drugs. This is recognised as an issue for CSCI as well as for the relationships between homes and primary health care trusts, who may be concerned about the resource implications.

Individual differences and specific issues
As well as the issues of existing relationships and the GSF status of practices, homes found some differences between individual GPs and within practices and areas. Some homes where relationships were good and further improved by the implementation of GSFCH still commented, regarding GPs:

I think we're training most of them; we've only got the odd one, maybe two, that aren't quite so flexible [Deputy Manager 8]

The manager of another home felt that:

> *Our assistants on the district nursing side have been excellent, they have been working with it, they are on top of it, and working very well, but we still don't seem to have a brilliant communication with the actual GP that works with us* [Manager 84]

This manager said the GP was new in post and overwhelmed by current changes and initiatives such as GSF and the LCP. She described how *lots of people on the GSF are people who have had crisis over the weekend* and felt that despite introducing the GSFCH the home would still struggle with continuity out-of-hours:

> *Even though we fax through to the on-call GP... on a Friday, who is on the LCP or on the GSF, what their symptom control is going to be, their preferred place of care, I don't feel 100% confident that if anything happened over that weekend that we'd all get what we wanted...I still feel that's going to be an area that could cause a problem* [Manager 84]

The manager of another home felt that such disputes about care could be minimised if GPs were asked to sign care homes' records when decisions about future care are first recorded and signed by the resident. But as we have seen above this has proved problematic for some homes and serves to illustrate the differences in experiences and expectations between individual homes.

A nurse in one home saw the fact that GPs at least had information about residents faxed to them to be an advantage. She gave an example of an incident out-of-hours, where the GP was slow in visiting and the desired outcome for the resident was not achieved, *but at least he had the information there* [Nurse 3, 84]. In another home staff talked of problems with inappropriate hospital admissions out-of-hours and how they had amended care plans to make them very specific regarding residents' wishes:

> *...the GP was very cooperative with that... and wrote in the GP notes... but we **still had** occasionally attending doctors who felt that even despite all of that, we'd phoned up for symptom relief but the patient was going to hospital.* [Manager 72]

This manager explained that a new and *extremely committed* doctor had been appointed to manage the out-of-hours service and despite her current concerns felt that:

Although it is still work in progress I think a lot of progress has been made and with the out-of-hours manager in post now I'm hopeful that, and as GSF becomes more the norm, I think it will be, hopefully it will be like ripples in a pond and eventually we will all be singing songs from the same song sheet…[Manager 72]

Problems for this home were exacerbated by local policies and practices. Only residents given a 'D' categorisation were notified to the out-of-hours service, and only GPs (not district nurses or the home) could submit this information:

So we basically we rely on the fact that when the GP has been here for his weekly visit he will pass on…these patients are in the D section. But even with that, it is not straightforward because there might be somebody in the 'A' section who needs some symptom relief, something that you don't want to hospitalise them for. [Manager 72]

In most homes concerns raised related specifically to GPs and there were few comments regarding other aspects of primary care. One coordinator felt that district nurses perceived GSF as only for younger people and not for elderly people. Another described a resident who had been resuscitated by an ambulance crew on the way to hospital, despite her recorded wishes, because

According to them they can only accept the ACP when they have four weekly reviews [Coordinator 71 Final Audit].

Some homes pointed out that the successful implementation of GSFCH required a certain level of assertiveness from staff and mentioned potential difficulties with this.

We had to be more diplomatic about how we communicated with our GPs, GPs have never wanted to give control to nurses I feel…sometimes it's the confidence within the trained nurse herself to actually speak to the doctor about it and to have that little bit of diplomatic assertiveness I call it, to say 'doctor, what do you think about this?' [Manager 8]

What I think would be interesting, also very difficult from that point of view is putting GSF into residential homes, because where you have care assistants, who, I mean its bad enough if you're a nurse and you have to have a bit of a man to man with a GP, at least you are starting from a knowledge background, but if you've got carers who've asked the doctor and the doctor has just said no, well then 'no's' the answer, I think that would be quite a challenge [Manager 72]

However, in the Final Audit two homes felt that as a result of improved confidence of staff and communication, there had been an increase in confidence of GPs and

palliative care nurses in the homes' abilities to provide good end of life care which had led to increases in referrals of residents to the home:

> *Referrals from GPs, social workers and discharge teams from hospitals have increased by 100%* [Coordinator 52].

Relationships with specialist palliative care nurses

As discussed in Section 5, homes that had working relationships with specialist palliative care nurses and hospices reported in interviews and in the Baseline Audit that these were very helpful and supportive. 'Macmillan' nurses were particularly mentioned as being helpful in the implementation of GSFCH because they:

> *Have been doing Gold Standard in the community so they have a lot of information invaluable to us and were present at some of the meetings to help answer questions* [Manager 8]

Case study homes that reported initial and continuing good relationships with primary health care teams also reported positive changes in relationships with specialist palliative care nurses:

> *…it was a tremendous thought for matron to be pushing to be trained by the Macmillan nurses and actually for them to come in and check how this has worked, therefore I would say the GSF has really has actually, has been an eye opener to us* [Nurse 1, 8]

> *We've had one in-house meeting with* [manager] *and the link Macmillan nurse, yes to discuss how things are going, have we any issues, anything we're not sure of, what's worked well, what we'd like to change, so yes, and another booked…* [Manager 100]

In some cases the relationship was seen as more formal, as in the case of the meetings described above. Another manager explained that help had always been available when requested but since the implementation of GSFCH:

> *What we've had since we came onto the scheme is an official offer of help and advice, with a specific person available to call* [Manager 32]

The Final Audit data from case study homes mentioned increased contact with specialist palliative care nurses as one of three 'improvements which have resulted from implementing the GSFCH'.

Summary

1. Improvements in relationships with primary care practices were reported as one of the positive outcomes of involvement in GSFCH by some homes, in particular communication with GPs were seen to be more productive. Homes that had existing good relationships with practices indicated that these had improved further.

2. Co-ordinators and managers were of the opinion that implementation of GSFCH was facilitated if primary care practices were either using GSF or were in tune with the ethos of GSF.

3. Where improved collaboration and communication between homes and practices was reported this had resulted in practitioners having greater awareness of each others' skills and knowledge in end of life care.

4. In the Final Audit a substantial proportion of respondents reported lack of support or lack of involvement from some GPs and/or out-of hours services.

5. Clarification is needed regarding the need to re-validate the advanced care plan at specific intervals to ensure that it is treated as a live document by all health practitioners and residents' wishes are respected.

SECTION 7: ORGANISATIONAL ISSUES (3) IMPLICATIONS OF GSFCH FOR CARE GIVING.

Care homes were at different stages in implementing GSFCH but it was early for all to identify what had improved in terms of quality of care. There were many comments in interviews that it was *'still early days'*. There was a limited view, especially by the time of the Final Audit, that quality of care had improved, but there were far more comments, both within audits and case studies, about changes in practice, and how staff and managers saw that these had or would improve the quality of care they offered.

Impact of GSFCH on quality of end of life care.

Findings in this section incorporate data from the coordinator and case study interviews, Baseline Audit [n=75], Audit 2 [n=53] and Final Audit [n=52]. This section looks firstly at perceptions relating directly to improved quality of care and then identifies the various ways in which practice was seen to have improved.

Improved quality of care

In several homes managers reported improvements in care linked to the GSFCH:

> *It has improved the quality of care for our residents* [Coordinator 89 Audit 2]

> *…the ethos of the Gold Standard is proving itself…the feedback from the staff has been very positive, and the results have been very positive for the residents and for the relatives as well.* [Manager 8]

> *I feel that the care given to dying patients in our care has greatly improved since joining and implementing the GSFCH* [Coordinator 49 Final Audit]

Negative perceptions were fewer, however, a number of staff did not identify any benefits:

> *…my clients come in and I put them on* [GSF] *with the manager, really liaise with her and decide, yes that person should be put on it, but I don't think that's making us give better care* [Nurse 4, 84]

> *We didn't really do anything new but it confirms our practice* [Coordinator 72 Final audit]

Staff in three case study homes described how implementing GSFCH had or would enable them to control symptoms, especially pain, more quickly:

> *... if somebody's in a lot of pain, acute pain, even for an hour, which it's often much longer than that, they should never ever have to be in that pain and if we've got it all set up then we can just move it into place...somebody starts vomiting or somebody gets into a real agitated state, at least we can cope with it straight away, so I think that's just going to be so much easier for all concerned* [Nurse 2, 89]

Better pain and symptom control was also identified in the Final Audit as an improvement resulting from implementing GSFCH. Some managers also saw improvements in medication management:

> *Treatments are more focussed on what they actually need; we are not giving inappropriate treatment* [Manager 8]

> *There's been a massive improvement in the nursing home with medication at the end of life* [Manager 100]

One case study manager commented that she had not had any unplanned hospital admissions since implementing GSFCH and in the Final Audit several homes listed *less hospital admissions* as an improvement identified as resulting from implementing GSFCH. Section 4 analysed the results from the pre and post ADA to determine whether this perception is supported by the quantitative data. One manager said:

> *The impact...has resulted in residents being able to remain in their rooms to die with staff they know* [Manager 76, Final Audit]

Staff in one case study home explained how they were now aware of residents' wishes relating to cremation or burial, when they would not have been previously. This was also listed as an improvement for some homes in the Final Audit.

Improved knowledge and skills

GSFCH also had an impact on knowledge around end of life care. In Audit 2, 13 homes of the 53 that responded described gaining more knowledge, information or education as one of the most useful aspects of being part of the GSFCH programme. In the Final Audit, improved knowledge continued to be identified as important with six additional homes listing this as one of the most useful aspects of involvement in GSFCH:

Up to date and relevant knowledge. Increases knowledge base for all levels of staff [Coordinator 5, Final Audit]

Staff updating their knowledge and skills, which enables us to provide a better standard of care for our dying residents and their families [Coordinator 29, Final Audit]

At the time of the Final Audit (12 months after the start of the programme) a few coordinators and managers were still concerned about finding time to cascade the GSFCH and associated training to all staff.

Improved practices relating to improvements in quality of care

Formalising and structuring work practices

Formalising and structuring work practices was one of the most frequently mentioned benefits both in the audits and case studies. In some cases it was mentioned purely as an advantage while other homes explained that practice had been good anyway, and whilst using the GSFCH had not improved this per se, it improved the organisation and recording of care and sometimes led to greater consistency.

I did exactly what I normally do but recorded it differently [Nurse 4, 84]

The home was mainly already implementing principles of GSF. However formalising practice into guidelines has ensured consistency. [Coordinator 47, Final Audit]

It was felt that the GSFCH made care more systematic, which led homes to be more organised and efficient. Several comments were made about previous 'ad hoc' practices, which created scope for certain elements of end of life care to be forgotten. When talking about implementing care for dying residents one manager explained:

…we have always done it on an ad hoc basis, but with the documentation and all the policies it is a much better format…all our staff are much happier using the GSF than before, we obviously had our own in house [system]*, but it wasn't as concrete and concise as the GSF…* [Manager 100]

In particular the GSFCH was praised for clearly setting out stages in care, enabling staff to *know where they stand* and being helpful for new staff, because:

…straight away they can see what's needed [Manager 47]

Staff in most homes had previously talked to at least some residents about their wishes regarding end of life care and resuscitation, but in an opportunistic rather than a systematic way, and rarely making any written record. Written records made it very clear what residents wanted and could be used to remind relatives if necessary:

> *…the fact that the resuscitation or no is clarified and the hospitalisation or no is clarified are two very important points for us just to help them at the end of their lives, just to make it as dignified and peaceful as we can, which we do anyway, but now we've got some real guidelines there isn't any 'Should we send them to hospital or not? Its 'We're sending them to hospital' or 'We're not sending them to hospital' cos it's written down here.* [Nurse 4, 89]

By the time of the Final Audit, structure was still identified as one of the most useful aspects of GSFCH:

> *We now have a structured directive on how to deliver a plan of care individually suited to our residents, which specifies all their needs when coming to the end of their life* [Coordinator 49, Final Audit]

Different care homes had incorporated GSFCH paperwork to differing degrees and there were mixed views as to how far this had, or would, help to structure work and contribute to improved care. Some managers and staff members were concerned that the GSFCH required more paperwork, which would increase their workload. Most of those who were using the GSFCH paperwork had found that in general it was not more time consuming. There were however some complaints about inefficiency, with forms requiring repeated information and some comments about lack of sensitivity:

> *[It] asks for the name of the resident on each page – do you really need that?*
> [Manger 35]

> *I don't like this 'Date of Death' on the front because this is the sheet you start off showing family* [Nurse 1, 84]

Some staff acknowledged that they or their colleagues found the forms 'too much' and did not always fill them in. One manager commented in the Final Audit that GSFCH had resulted in:

> *Clearer and efficient paperwork (if used properly*) [Manager 84]

Empowering staff and increasing confidence

In some homes improvements in confidence were attributed to the clear and systematic nature of the GSF. Nurses had something 'official' and 'written down', in essence giving them permission to try to ascertain residents' wishes so these could be recorded to assist care planning and demonstrated if necessary to other health professionals and/or relatives:

> *...we feel it gives us more right to ask* [about place of care and resuscitation wishes] *because its [GSF] in place...Before I felt it was sort of an intrusion into their life really, but this is in place, it makes you feel you have a right to know what to do, rather than waiting until its too late* [Nurse 2, 54]

> *The girls have more confidence talking to GPs and taking the initiative.....*
> [Manager 99]

> *It has helped them in their confidence...it has helped them to feel they are valued as nurses* [Manager 22]

> *We're making more of the decisions; it makes us more confident and assertive* [Nurse 1, 100]

> *...a lot of empowering of US and even able to talk to the relatives freely now because we have the documentation in front of us to show them 'We are moving from this stage to this stage'* [Nurse 1, 8]

Many participants talked about increases in confidence for nurses and for managers. Some care staff also reported they were now more likely to ask questions and to bring concerns about residents to the notice of nurses:

> [Previously] *you'd feel quite bad for having to question something, but now you can question it and be quite happy and they're [qualified nurses] happy to answer you, where before if you questioned them it was 'I'm the nurse and you're the carer'.* [Care staff 1, 22]

GSFCH was also seen to add value to staff roles:

> *It's obviously giving some quality initiatives to the staff...so it becomes an ownership and they become empowered, rather than 'I work at an older peoples' nursing home and I do the same thing every day' and I think that's important.* [Manager 3]

> *The staff in the home have developed a raised confidence and awareness of their invaluable role in providing care, beyond physical needs, and feel able to express an opinion or concern.* [Coordinator 52, Final Audit]

Improved communication

In the Final Audit, communication was the most frequently identified improvement that resulted from implementing GSFCH. This encompassed communication within teams, with residents and relatives, and with GPs and other health professionals. Improved confidence was linked, both as cause and effect, with improved communication within the staff group and with residents and relatives. Improved communication with local primary health care teams was also identified and has been discussed in Section 6.

It was felt that GSFCH had promoted discussions within care home teams about difficult and sensitive areas of caring. In addition to creating potential for improved care, this provided support for staff and enhanced their learning. In several homes staff felt they had begun to work better as teams and now included a wider range of staff in discussions and decision making. Care staff, as well as nurses, were sometimes included in meetings where residents' A-D status was discussed. A small group of care staff in one home described how they had been able to bring their concerns up within a meeting about introducing GSFCH to the home. They felt that although they were with residents 24 hours a day, changes in care or medication had often not been passed on to them by nurses:

> *Its brought out our concerns, we were able to say that we weren't happy about it so obviously then they knew how we felt, so it's made it that little bit better* [Care staff 1, 22]

In many homes communication with relatives was also felt to have improved. Managers and staff felt it was not only easier to approach families with the backing of the GSFCH, but:

> *….perhaps it makes us tell them more* [Nurse 4, 84]

In one home, introducing the GSFCH and associated staff discussions highlighted cultural differences in bereavement practices and consequently opened up discussions about bereavement care.

Communication with residents was also felt to have improved

> *…for the residents we are more open, we are more able to listen properly, and look for the hidden meanings of what they are actually saying, and so it is making our communication with them so much better.* [Manager 8]

> *…we are collecting more essential information, on resuscitation and funeral directors, information we used to ask about much later in residents' stays* [Nurse 1, 100]

However limitations to this were recognised especially where a high number of residents had dementia. There were also comments that communication directly relating to the GSFCH was sometimes difficult due to the language used. One manager commented with reference to one information leaflet (GSF 2005):

> *Who invented these silly words?… our residents are very elderly and they have elderly relatives, words like 'partnership' and 'systems and protocols' do not mean anything to them, or to some staff, these are NHS jargon.* [Manager 35]

It was pointed out by some nurses that abbreviations like PACA, PHCT, and CNS or terms such as 'care pathway' are not familiar to staff working outside the NHS:

> *.…we are not used to them because we do not use them on a regular basis* [Nurse 1, 100]

During an interview another manager commented;

> *I still don't know what a Liverpool Path Careway (sic) is, because I haven't worked in a hospital for some years, a Liverpool Care Pathway could be a train you got to Liverpool, I don't know, I haven't got a clue, there was too much presumption we knew that at the meeting in January[15]* [Manager 32]

A few managers felt that some of the terms used reflected the NHS origins of the GSF and exposed the different cultures of the health service and care homes.

Some managers felt they had benefited from new links with other care homes either at the four main GSFCH workshops or at locally facilitated meetings and training. Several came back from such meetings with suggestions for *what we could do better* [Manager 32] and feeling that they had *swapped ideas* [Manager 54]. However others had not attended all the Workshops or local meetings due to financial or time constraints, or felt isolated because they were the only home in their area which was implementing GSFCH.

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[15] Workshop 3

Improved focus on residents' individual needs

Using GSFCH made staff focus more on individual residents, becoming more proactive in gaining information about them, and looking at their wider needs.

> *…its really, really, patient centred, holistic…* [Manager 72]

> *We are changing our care planning processes within the home towards being more proactive as a consequence of the GSFCH.* [Coordinator 16, Audit 2]

> *It makes you think of the patient and try and find their need, so you spend more quality time talking to residents and family.* [Coordinator 7, Audit 2]

Several members of staff felt that using the GSFCH had encouraged empathy towards residents:

> *It does make you have more insight into them and their feelings and thoughts and their family's and everything…* [Deputy Manager 8]

> *It puts you in that position of 'How you would feel now if it was you?'…and you can realise what they are going through more, like when they have to take their belongings, if only a few, when they go into a home and it really sort of makes you feel that…aware….* [Care staff 2, 89]

This individual focus and improved empathy meant that staff were able to deliver *more appropriate care* [Coordinator 30], meet individual needs and *fulfil wishes* [Coordinator 79]. In some homes staff also felt that continuity of care had been improved, usually as a result of better recording, but also because monitoring of residents' needs had improved.

Identifying residents' wishes regarding End of Life care

A key part of the focus on individuals was addressing with residents their wishes regarding resuscitation and preferred place of care at the end of their life. For some homes this was entirely new, most raised such issues occasionally with residents but not with any consistency. Some appreciated the way GSFCH focussed on end of life issues for all residents, regardless of their underlying pathology:

> *Dementia care has been the poor relation to cancer and it's nice to have something which is specialist to end of life care, without having to have cancer*
> [Manager 72]

Some reservations were expressed about addressing end of life issues at all. A small number of staff felt 'preferred place of care' questions were unnecessary, as they

'knew' care home residents would prefer not to go to hospital because the care home was their home. One manager felt raising such issues was appropriate with cancer patients but not all residents:

> *It didn't work with our long-term patients, it's not easy, they come into the home to LIVE not to die, they would collapse if you asked them. The cancer patients, yes it's easier with them...* [Manager 99]

Another manager felt that resuscitation was not always an option therefore addressing this could be raising false hope. She also wanted the wording to change from 'do not resuscitate' to 'allow a natural death' seeing this as more sensitive to residents and relatives who may read the forms.

Most homes felt that addressing these issues was helpful and positive but a number of difficulties were identified. The main issue was when to hold such discussions. In a number of homes some existing residents had become very upset. Staff felt that 'suddenly' raising such issues was akin to suggesting that death was imminent. But addressing such issues on admission was also thought by many to be insensitive, because staff had not yet developed a relationship with residents or families. Many staff at all levels pointed out that increasingly, recently admitted residents may already be too ill to engage in discussions or to make such decisions. This was especially true for residents who were admitted to 'Continuing care' beds i.e. beds fully funded by NHS primary care trusts, because residents are judged to be in the last weeks of life. A coordinator stated:

> *We admit the residents at the very end of their life and do not have the chance to get to know them or their relatives.* [Coordinator 3, Final Audit]

Several managers suggested an appropriate plan would be to introduce the idea of discussing end of life care in pre-admission information about the home. In this way the discussion becomes a natural part of the admission process, perhaps in the context of 'What care would you like if you become very poorly?' With existing residents, decisions about how, when, and who to talk to should be made on an individual basis. However several homes were still raising concerns and uncertainties in the Final Audit about how and when such discussions should take place.

Other practical difficulties in identifying wishes at the end of life were also identified. One home admitted residents from the whole of the UK so relatives may live *many miles from the home,* which *limits opportunities to have long discussions* [Coordinator 59 Final Audit].

The fallibility of the A-D coding system was also pointed out by staff in several homes, because change and deterioration can happen so quickly that *the end of life framework* is not always *in place at time of death* [Coordinator 17 Final Audit]. Most trained staff were familiar with the A-D prognostic coding, although some thought this lacked clarity, as it was not clear which category, A or D, should be considered 'worst'. Several homes had introduced colour codes instead; one manager explaining that it was clear that red was the most severe category. Others were unhappy about this, suggesting a nationally recognised coding was better.

The 7 'Cs' were generally regarded, by staff who were aware of them, as a comprehensive format to help ensure that all aspect of end of life care for residents and families were considered. In some homes staff were not aware of, or familiar with, the 7C's, but explained how difficult it had been to find time to study them.

Some felt that GSFCH forms should include a space to record relative's wishes, but others pointed out that these might not always be the same as those of the resident. Sometimes it was felt that relatives were likely to *over rule* residents and *insist on admission to hospital* [Coordinator 57]. It was generally felt that in such cases residents' wishes should be respected. However, there was some concern about how best to decide, when residents were very ill or suffering dementia, when and to what extent, relatives' wishes should take priority. There was also concern for residents with dementia who had no relatives and thus no one to decide for them. In a few homes GPs were involved in discussing end of life issues with residents and in some others staff wanted GPs to sign the records of such discussions to remove responsibility from nursing staff.

Increased awareness of spiritual and emotional issues
A small number of case study homes had reached a stage at the time of the evaluation where they could comment on improved practices relating to spiritual and wider emotional care of their residents. However spirituality was generally interpreted as

religion. Only in one home did the manager suggest that thought had been given to a wider interpretation:

> *When we first looked at the gold standard I think spirituality was the most difficult thing for us, because nobody can train you to recognize that I don't think, a lot of it is from your own thoughts and your own ideas about what is spirituality, it took a lot for the staff to get past that it is purely religious* [Manager 8].

Even within this home other staff talked of spirituality in terms of religion. In all homes where spirituality was discussed, religion was in turn interpreted as Christianity, but this involved a very small number of homes so may reflect their particular populations. One home held a communion or 'hymns and praise' service each week, called a vicar or priest when people were ill and when appropriate placed bibles in coffins. One had introduced regular memorial/thanksgiving services to remember residents who had died during the last quarter and provided a minibus so that residents could attend funerals, and a third had introduced a memory book and was considering introducing memorial services. Staff were positive about the benefits for residents of such innovations:

> *…I think they found it quite valuable to think that the resident hadn't been airbrushed out of the way* [Care staff 4, home 89]

Staff in one home described how introducing GSFCH had generally opened up communication about death and dying and subsequently changed their whole attitude to dealing with death in the home. They no longer hid death, for example by closing doors when coffins were taken out, and openly discussed residents who had died. They found that residents had responded positively to this, and thought they were more able to grieve for their friends.

Better care of relatives

The 14 managers who participated in telephone interviews indicated they were at very different stages in providing end of life care for relatives before they had started the GSFCH programme. Some homes cited existing good practices, for example, providing rooms for relatives to stay in, welcoming them at meals and organising a counsellor to give a talk, and being available for relatives to contact if required. At several homes it was felt important that staff were represented at funerals and one manager explained how:

> *…..we do try not to be too jargonistic with families, because a lot of relatives are very old themselves* [Manager 3]

There was a small group of homes for whom introducing GSFCH had led to an acknowledgement that support for relatives could be improved. Focussing more on relatives was achieved in two ways. Firstly some care home respondents reported that many family members had been relieved to talk about the future plans for their relative and advanced planning was seen to remove the pressure of them having to make decisions in times of crisis. A nurse also pointed out that the A-D coding system allows relatives to have an idea when death is expected to be close and:

> *….maybe they need to settle some discord…just to make sure that the end goes well, so if anybody has been coded to have few weeks to live so that at the end of the life there will be a sweet memory by those people that are left behind* [Nurse 1, 89]

Secondly some homes introduced more direct ways of caring for relatives. The homes that introduced memorial services and a memory book saw these as being for relatives as well as residents;

> *…this memorial service may help the relatives to come to terms with the fact that they've gone but they're never going to be forgotten* [Care staff 4, 89]

Two homes began providing brief, clear information sheets to advise relatives of the requirements with regard to collecting death certificates and registering deaths in their locality, recognising that official booklets are lengthy and difficult to assimilate at a stressful time.

There was a third group of homes where it was acknowledged that care of relatives needed improving, but this had not been achieved. Some homes had not yet fully implemented GSFCH (for a variety of reasons outlined later) and others had had difficulty with this particular aspect saying, for example, that there was not enough time within shifts to see relatives.

In the Final Audit few homes mentioned improvements in the care of relatives as one of the most useful aspects of being part of the GSFCH programme, or as an improvement resulting from implementing GSFCH.

Focus on evaluation and innovation

There was a view expressed both in the audits, interviews and the case studies that the GSFCH had provided a focus on areas of end of life care that could be improved and helped generate the motivation to address these. It *allowed us to monitor our practice* [Coordinator 42] and provided *the enthusiasm to improve care* [Coordinator 72 Audit 2]. Other reflections included:

> *It's made us much more aware of what we can do and do better...sometimes you are going from day to day and thinking you are doing well but you are not really, sometimes just something being prompted, you think 'we could do that, it would be better'* [Manager 32]

> *It has made the team within* [home] *much more innovative, pro-active and person centred with the care they provide* [Coordinator 29 Final Audit]

Specifically managers talked about looking at recent deaths to see if these could have been better managed and being prompted into updating or writing policies.

GSFCH was described as a *very motivating project* [Coordinator 56 Audit 2] and one of the managers felt that *the nicest thing is the wanting to improve patient work, people wanting to be pro-active* [Manager 99].

At the time of the Final Audit the coordinator for a small group of homes (n=5) felt that although they had only recently started to work on the formal aspects of the GSFCH, participation had heightened their awareness of the range and breadth of end of life care. Consequently they identified some care practices and training needs which needed addressing before they could commence GSFCH implementation. The coordinator described the perceived improvements in the quality of care offered, and changes in policy and procedure across this group of homes which had been stimulated by their involvement in the programme (Figure 7).

Figure 7: Perceived improvements and changes resulting from GSFCH

- The homes now have a resuscitation policy and all trained staff have been given basic life support training.
- Residents and their families can now make a choice for resuscitation or not and discuss their wishes regarding last days of life.
- Trained staff have received training in verification of death and a policy is now in place.
- Each resident has a new advance care plan, whereby residents and families can choose their preferred place of care at the end of life. This means that advance wishes can be stated at a time that is not so emotive and difficult.
- Staff are building improved communications with GPs and have an out-of-hours information form that allows for better continuity of care.
- Homes are using the needs assessment form, using colour categories for the A-D groups according to their end of life status and needs. There are guidelines and a checklist that staff follow to ensure nothing is missed.
- The GSFCH link nurse and manager are holding a two-weekly meeting using the PEPSI COLA form to monitor each resident and document any changes.
- There is now an education resource file at each home that includes symptom assessment tools.
- Homes have greater links with the palliative care team in our area and we can access any of their education.
- There is an end of life register in each home and also critical incident forms.
- In addition to the Link Nurse system for registered nurses who coordinate the GSF framework in each home, we are to develop a Link Health Care Assistant programme that will up-skill health care assistants to assist in the care of residents.
- Although we are at the beginning of the project we can already see improved standards of care for residents and families and this can only go forward in a positive way for the future.
- It has been an interesting, enjoyable and worthwhile project. It is good to know we can influence the quality of end of life care for all residents.

(From a coordinator of a group of five homes)

Residents' and relatives' views

Information from residents is limited because the researcher was only able to talk to seven residents from four homes. Managers of the three other case study homes who had given permission for residents to be approached felt that residents were not well enough to be interviewed or explained that potential interviewees had recently died. In one of the latter groups the manager had arranged interviews with three family carers. Comments may also not be representative as they were all made by residents who were generally positive about their care home and/or staff and the care they received.

At the time of the case study interviews GSFCH had not been fully implemented in the care homes and managers revealed marked differences in how far GSF had been introduced to residents and relatives. Some had not yet introduced it all, some had introduced it to relatives but not residents yet, some had provided written material and some had discussed it with residents individually or in a meeting.

In three of the homes where we talked to residents there was evidence that GSFCH had been introduced to them. Two had GSF literature[16] in their rooms and some talked about being asked for their wishes regarding their future care. In the fourth home we talked to one resident who clearly wanted to remain at the home for as long as possible and although she had no recollection of being asked about future plans was certain she had told staff anyway. The manager of this home confirmed that they had mostly discussed GSFCH with relatives and had had only limited discussions with residents.

Four residents (from two homes) described conversations with staff about future care and all felt such conversations were appropriate:

> *I think it's a good idea...it doesn't do any harm to ask people* [Resident B]

Another resident stated:

> *I thought it was quite good really' cos they asked me questions say, if I died would I be buried or cremated? Where would I like to be buried? If I had a heart attack would I like to be resuscitated?* [Resident E]

> *Had those things not been discussed with you before then?*

> *No, no* [Resident E]

One resident said she was *shocked!* When she read the GSFCH information sheet because:

> *I'm not ready to pop my clogs yet…obviously preparations have to be made but I was a bit shocked* [Resident G]

This resident went on to talk about a subsequent discussion with the home manager, which she thought had taken place because she was 80 in a few weeks, and after getting over her initial shock felt it was appropriate for such questions to be asked.

In the third home residents had read about GSFCH and one remembered a conversation with the manager, but thought they had only talked about what would happen after death (i.e. cremation or burial).

Several residents had thought about their future wishes prior to any GSFCH led conversations and some had already told staff what they would like to happen. Those

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[16] GSF (2005). This was given to participants at Workshop 1.

who expressed wishes all wanted to remain in the care home for as long as possible. Some clearly did not want life prolonging treatments:

> *Well, when they gave me that* [GSFCH information] *my answer was immediate, I don't want resuscitation, If I have a heart attack or anything I just want to go* [Resident C]

However, wishes about not going to hospital were also influenced by views and previous experiences of time in hospital:

> *I just hope that nothing happens that would force me into hospital...if I thought I had to go into a national health hospital that would be the death knell for me* [Resident F]

> *I don't want to go to hospital again, they only experiment, I was a guinea pig...I was in five different wards in three days, and there wasn't a bed when I went in so I spent the first night on the men's ward* [Woman resident B]

One of the homes where we were able to talk to residents was the home that had introduced memorial services in the home as a result of GSFCH. One resident talked positively about attending such a service:

> *It was quite nice, cos* [name]*, one of the people who had died was on my floor, I used to get on very well with him and his family...* [Resident E]

The relatives we spoke to were also positive about the home and the care their relatives were receiving, and at this home care plans were being updated as part of GSFCH implementation. All three relatives had had recent conversations with the manager about future plans, and universally did not want life-prolonging treatments administered, and wanted their relatives to stay at the home if possible:

> *I really don't want her life to be prolonged; her quality of life is very very poor* [Relative B]

> *We want her here as long as possible in the care home, she can have palliative care here 'cos she's familiar with it...we want her to be kept comfortable and pain free and to let nature take its course.* [Relative A]

Similarly staff gave positive accounts of relatives' reactions to discussions about care when their relative's condition deteriorated, indicating that relatives want to discuss these issues, but are reluctant to raise them for fear of appearing uncaring:

I found [resident's nephew] *was really good when I sat down with him and his wife and discussed all of it and you know when* [name] *does get really,…. what they would want? and they were absolutely wonderful, what they just suggested was they don't want her moved at all, they want her left at home here and they were over the moon about it, they wanted that conversation but they didn't know how to bring it up.* [Nurse 3, 89]

Relatives also echoed concerns about hospitals, one lady explaining that she and her brother in law (the resident) were determined he should not return to hospital due to unhappiness at care during a previous hospital admission. She stated that:

He has been getting better since he came here [Relative C]

One relative commented that communication in the home had improved recently but it was not clear how far this was attributable to GSFCH.

One resident displayed a limited understanding of the purpose of the GSFCH. He had been given the GSF leaflet by staff and stated that anything to improve care was *a good thing*. When asked whether staff had asked him what he would like to happen in the event of him becoming very poorly, he responded:

I assume the Doctor would send you to hospital [Resident D]

In the early part of Phase 2 the GSF team had produced a template letter that staff could give to residents and their families. Some respondents felt the letter was too formal and the language not appropriate or understood. Some homes had developed their own letter and following feedback to the GSF team a single page coloured leaflet explaining GSFCH was developed for residents and families.

Due to the small number of residents and relatives interviewed and the fact that they do not represent a broad spectrum of care homes it is not possible to draw firm conclusions. However, from the perspectives of those interviewed, the biggest impact of GSFCH visible to residents and relatives so far seems to be discussions about future care and these were seen as positive. This suggests that with time for further implementation of GSFCH, the opportunity to talk to more residents and relatives would be likely to reveal further positive impacts on care resulting from GSFCH implementation.

Summary

1. Staff indicated that the implementation of the GSFCH impacted positively upon end of life care, including pain management and symptom control.

2. There was a view that the GSFCH had helped improve organisation and documentation of care which, in turn, had improved the quality of care offered.

3. A counter view of this was that some nurses found the record keeping onerous, potentially impacting upon willingness to complete paperwork.

4. The structured approach to care offered via the GSFCH framework helped increase staff confidence in care giving.

5. The GSFCH model had promoted discussion between care home staff and, in turn, between care home staff and the primary health care team, particularly GPs. This improved communication helped staff identify care deficits and, they felt, improved communication with residents.

6. Care home staff felt that GSFCH had the potential to improve end of life care for all residents and their families by providing clear structures for identifying, assessing and planning end of life care. Care planning was more systematic with GSFCH and residents' and if appropriate families' wishes about future care could be clearly documented.

7. Improvements were reported even by staff in homes that stated they already provided good quality end of life care. Other homes felt care planning for the end of life phase was already sound and GSFCH confirmed their approach.

8. GSFCH was regarded as relevant to the range of illnesses with which people in nursing homes die.

9. Team training and introduction of GSFCH can facilitate discussions about the respective roles of different staff grades, increasing insight into the unique nature of each role and increasing knowledge of the key roles each play in the care of dying residents. Care grade staff felt their input was more valued and reported better communication with nurses.

10. Managers and co-ordinators valued the opportunities provided by GSFCH for networking with other care home staff in their locality. This provided an informal support network and opportunities to ask questions within a safe

environment. Some homes, where such opportunities were less available, felt isolated in this respect.

11. There is evidence that residents want to die in their home, the care home. GSFCH can help staff anticipate needs and support residents to achieve their preferred place of care.

12. Involvement in GSFCH can help staff develop their listening skills and become more attuned to indications that residents want to discuss their future care.

13. Residents and families welcomed opportunities to discuss care in the event of serious illness, but families were reluctant to raise these issues with staff for fear of appearing insensitive or uncaring. Responsibility for opening this dialogue therefore lies with care home staff and GSFCH offers a framework for structuring these discussions.

SECTION 8: FACTORS WHICH SUPPORT OR HINDER GSFCH IMPLEMENTATION

Data about the factors which support or hinder GSFCH implementation comes from a range of sources: brief telephone interviews with homes which notified the GSF team of discontinuation, or disengaged from the programme, and analysis of the quantitative and qualitative data. All sources have provided a wealth of information about factors which have the potential to influence the ability of a care home to successfully implement the GSFCH.

This section starts by presenting data from homes which did not complete the programme and/or the evaluation. Following on, analysis of the quantitative and qualitative data from homes which stayed in the evaluation reveal features which emerge as supportive to GSFCH and those which appear to hinder implementation (Figure 8, p 111).

Homes which did not complete the evaluation

Homes which formally withdrew from the GSF programme
In the first six months of the programme 13 homes notified the GSF team of their withdrawal. Brief telephone surveys were conducted to identify the reasons, one home could not be contacted despite repeated attempts and data relates to 12 homes. Most homes identified multiple reasons for drop out.

Staffing and workload
A combination of staffing and workload issues were the most common reasons given (eight homes). One manager stated;

> *We were too busy and lots of changes of staff including one sudden 'on the spot' dismissal, consequently I have no support.'* [Manager 23]

Another manager described a similar situation:

> *The staffing situation changed from when we initially registered interest, drop out was purely on staffing issues, I didn't feel I could commit the time, I'm the manager but I was having to work as a staff nurse.'* [Manager 2]

Workshop location

The four GSFCH workshops, spread over nine months were integral to the programme and all were held in the West Midlands. Four managers stated that the time and finance to attend the workshops were either not available or could not be justified:

> *I wasn't prepared to go to Birmingham to sit and not fully connect, I wasn't aware of the workshops when* [facilitator] *first called to tell me about it.* [Manager 57]

A manager who attended the first workshop stated;

> *'It wasn't necessary for me to go again, it's a huge part of the weekly workload, I felt pressured into going, it was put to me that it was essential, but it's a long day, 6 am to 7 pm, and wasn't necessary for the information given.* [Manager 45]

Resources

A majority of homes received funding from the NHS End of Life programme via PCTs for workshop fees and travel. Other homes had to meet their own travel costs and sometimes workshop fees (£60 per workshop). Staff attendance at local GSF related training was sometimes during employers' time. At other homes budgets were more stretched and staff motivation to attend educational sessions in their own time was variable, especially for lower paid care staff:

> *'They're on the minimum wage and in their own time sometimes, I tried to pay them, I tried creative budgeting, but what are we going to get at the end of it? Morale dropped a bit, at £5 its hard enough getting people motivated, but if they are getting nothing out of it, the money is an important part of it.'* [Manager 45]

One manager felt the local weekly educational sessions arranged by the facilitator were too demanding of staff time. Another reason for drop out was identified by a recently appointed manager who had other priorities:

> *'I'm concentrating on dragging this home into the 21st century.'* [Manager 64]

Administration and other reasons

One home had recently changed ownership and 'every single scrap of paper' had to be changed to show the new logo. Two managers cited concerns about introducing more paperwork into a system which was already seen as suffering from regulatory and administrative overload, while staff at one home believed '*we had to write essays and things'*. Some managers expressed interest in the next phase of GSFCH though one manager indicated that while they had participated in the 'Investors in people' programme they were wary of connecting with the NHS, of which GSFCH was seen as a part, because '*We speak a different language.'* Finally one manager stated she wasn't aware she had agreed to participate in GSFCH until she was contacted about attending the first workshop. Finally one small specialist home only had one death a year, the manager felt they already provided good quality of end of life care and GSFCH would not enhance their care.

Managers' explanations for their withdrawal from the GSF programme correspond with issues already identified in the care home sector, such as the capacity to fund staff education and development, keeping within budgets, and difficulties recruiting and motivating staff (Bartlett and Burnip, 1998). Although staff are very committed to their work, increasing physical dependency and decreasing cognitive abilities among residents also contribute to job dissatisfaction and stress (Redfern *et al.*, 2002).

Homes lost to follow up evaluation

Other homes appeared to disengage from the GSF programme but did not notify the GSF team of withdrawal. These were included in the 30 homes who did not return Final Audits (Table 8, page 48). Attempts were made to contact managers to identify the reasons, of those contacted:

- One home had dropped out at an early stage, but had not notified the team, and six were lost to follow up despite several attempts at contact by the evaluation team, including three homes from the same area. The facilitator had notified the GSF team that they were implementing the GSFCH framework independently of the programme and the team. Neither the care home staff nor the facilitator had attended any of the four workshops.

- Seven homes said they were implementing GSFCH and a further five stated they had made some progress in implementing it. Five had not implemented GSFCH but did not describe themselves as having 'dropped out'.

- Finally for three homes there were differing accounts of their progress with GSFCH, with facilitators indicating that homes repeatedly cancelled GSFCH meetings so they had little knowledge of the extent of GSFCH implementation. The managers reported they were 'doing their own thing' with regard to GSFCH.

The circumstances of two homes which disengaged from the programme were described by the facilitator, 16 months after the start of GSFCH Phase 2:

> ...[the home]...*didn't get started at all with GSF but did work through the Macmillan 'Foundations in Palliative Care' Programme in preparation for implementing GSF. They are now aiming to implement GSF over the next few months and I am meeting with them on Friday to begin the process of setting up the supportive care register and "coding" of residents so all is not lost..* [Facilitator 26]

> …[the home] *did begin implementing GSF by setting up register/ coding/ regular meetings with GP involvement and development of advanced care plans BUT the manager has recently left and other staff not confident to lead on it, therefore its all on hold. I'm meeting with the new manager at the end of Sept with the aim of re starting ASAP as it did appear to be working well.* [Facilitator 26]

These examples illustrate that homes which 'disengaged' and did not complete the evaluation did not necessarily withdraw from GSFCH and facilitators aimed to maintain contact. Progress of these homes appears to be slower and may present difficulties to facilitators trying to support homes at different stages of implementation of the programme.

Facilitator influence

Consideration was given to whether drop out was linked with facilitator support. Four facilitators left during the course of the Phase 2 programme and were not replaced, leaving eight homes without a facilitator. Four of these homes returned Final Audits,

but two indicated they had not implemented GSFCH. These proportions indicate that active facilitator support is an ingredient of successful implementation.

There was evidence that some homes that did not return audits were clustered around certain facilitators or coordinators, possibly indicating that they had insufficient resources to devote to the role. One facilitator was found to be on long-term leave, and Final Audit forms had not reached care homes. In another area a coordinator of three homes had left and the facilitator found establishing new links with staff difficult.

Although the GSFCH programme included access to a GSFCH facilitator, this was not a given and, as noted in Section 3, facilitators' hours varied. Facilitators were not paid from the GSFCH budget, but from the NHS End of Life programme money, via Strategic Health Authorities. Consequently, while the GSF team asked facilitators to recruit care homes to the programme and offered homes facilitator support, it had no control over the longer term provision of facilitators throughout the programme.

Follow up observations

From the perspective of the evaluation, it is only possible to report on the progress of homes that participated in the final phase of the evaluation. Assumptions can not be made about the progress of homes that provided scant information. It appears that some of the non-responding homes may have adopted aspects of the GSFCH and have been prompted to re-consider their approaches to end of life care but there is no way of verifying this through the research data reported here.

The reasons care homes dropped out of the programme and/or evaluation were conveyed to the GSF team. This enabled the team to address these issues in the next phase of development. For example the need for lengthy and expensive journeys to the workshop location has been addressed and regional workshops have been organised for Phase 3 GSFCH.

Recommendations from care home staff

During telephone interviews and case study visits managers and coordinators were specifically asked to identify any aspect of implementation which they felt had been supportive, or which they would recommend. These are listed in Figure 8 (p 111). Influencing factors have been grouped into three categories:

- Internal factors i.e. those specific to the care home;

- External factors such as other services, and finally

- Factors relating to the GSFCH programme itself.

These categories are not watertight and some factors could potentially be placed in more than one category, but Figure 8 offers a framework for considering the features which enhance the likelihood of successful implementation of GSFCH and those which appear to hinder implementation.

As noted in Section 2, findings emerging in the course of the evaluation were discussed with the GSF team and some have already been incorporated into the GSFCH Phase 3 'Good Practice Guide' (Thomas *et al* 2006) and other developmental processes.

Figure 8: Factors supporting and hindering GSFCH implementation

Factors related to the care home context	
Factors supportive of GSFCH implementation	**Factors that may hinder GSFCH implementation**

Internal factors
 	
• A consistent, loyal and motivated staff team with agreed common goals
• A sound understanding of palliative care within the home which may come from staff attending training and/or the home having good links with hospices and/or specialist palliative care nurses
• Good staff to resident ratios allowing sufficient time to talk to residents and relatives and time to absorb and assimilate new initiatives
• Good communication within the home, especially relating to management keeping staff informed about developments
• Managers and staff who are able to be assertive with GPs and other health workers
• Support from owners of small homes, senior managers or boards of trustees for group homes who can see the benefits of initiatives such as GSFCH
• Good budget for training
	Internal factors
	
	• Staffing difficulties including:
	  - Minimum staffing levels and other pressures (e.g. building work, inspections, take-over of home leading to new policies) creating insufficient time to absorb and assimilate new initiatives
	  - Change of management or frequent changes of staff; use of bank staff ; long term sickness
	  - Resistance to change by some staff
	  - Staff who are new in post who may not have palliative care backgrounds
	
	• Limited budget for training – sometimes meaning that staff have to attend in their own time and thus making training difficult to enforce

External factors
 	
• Working with GPs from GSF practices, or if not from GSF practices at least interested and supportive towards homes implementing GSF
• Working with GPs who are knowledgeable about palliative care and/or have working relationships with and take advice from hospice doctors and palliative care nurses
• Long standing and mutually trusting relationships with GPs
• Working with GPs who are willing to prescribe anticipatory drugs
• Having access to a well-organised local out-of–hours services, where information is received, trusted and acted upon.
• Having existing and supportive working relationships with palliative care nurses and/or local hospices
• Having a Home Office License to keep stock controlled drugs
	External factors
	
	• Local GPs not being signed up to GSF, or only paying lip service to GSF
	• Difficulties in relationships with GPs
	  - Lacking interest and knowledge regarding GSF
	  - Not sufficiently cooperative or supportive
	  - Not sufficiently understanding palliative care
	  - Not trusting care home nurses
	  - Unwilling to prescribe anticipatory medication
	• Homes not being allowed to keep anticipatory or stock drugs
	• Care home nurses seeing themselves as having 'less autonomy' than district nurses, e.g. not being trusted to administer medication on a sliding scale
	• Difficulties with Out-of-hours services
	  - Not being allowed to have priority numbers
	  - Lacking confidence in out-of –hours services carrying through residents' plans
	Particular problems of homes in rural areas.

Factors related to the GSFCH programme	
Factors supportive of implementation	**Factors that may hinder implementation**
Organisational factors • Implementing GFSCH needs to be a 'team' responsibility – so it doesn't 'get lost' if a key member of staff is unavailable or moves on. • Homes that are part of larger groups may receive additional support to implement GSFCH, as senior managers regard GSFCH as a quality mark that can be used to promote their homes. • Having other GSFCH homes in the area so it's easy to meet and share ideas. *Facilitation* • Having a supportive facilitator, especially in the early stages of implementation, who has a clear understanding of GSF, is proactive about contact and providing information and accessible when needed to answer queries. • Having a facilitator who works directly with all levels of staff rather than leaving the manager/ coordinator to cascade information. *Staff training* • Implementing GSFCH alongside the LCP (or similar) creates a comprehensive package of care. (Although this has sometimes been problematic as staff have felt overloaded with too much new information at once).	*Organisational factors* • Being the only GSFCH home in an area can lead to feelings of isolation. This is even more the case when homes are in areas where there are no GSF primary care teams. Such homes miss out on networking and joint problem solving. • Low staff levels and other pressures on managers' time can create difficulties in completing paperwork and attending training or meetings. • Homes that are part of larger groups have to have new policies or documents ratified centrally which may delay implementation. • Larger homes (approximately 90 or more beds) found cascading information particularly difficult. • Small homes found it difficult to release staff to attend seminars/training and may be restricted e.g. in not having computer facilities in the home. • Some staff felt recording resident information was insufficiently valued, and staff could not rely on each other to complete all records. • Care planning is more difficult in homes where a high proportion of admissions are made in an emergency. *Facilitation* • Changes in facilitator or absence of a facilitator left homes with little support and not knowing who to contact with queries. Homes without facilitators felt 'let down' as one of the promised supportive elements of GSFCH was missing. • Some managers felt staff would have understood GSFCH better if it was explained directly to them by the facilitator rather than the information passed on by the manager/coordinator. *Resident related* • Having a high proportion of residents with dementia in a home can make conversations about future care difficult. • Homes that admit residents from a wide geographical area (e.g. because of a particular religion) may have limited opportunities to meet with relatives. *Culture* Some felt that assumptions were made about pre-existing knowledge e.g. not all coordinators were familiar with the Liverpool care pathway, or certain abbreviations and 'jargon'. *Regulation* Homes were required to have a green CSCI rating to join GSFCH. Some respondents noted that homes may be amber or red due to building quality or having a temporary manager. Such homes may see GSFCH as a way of helping to improve their quality of care, yet were excluded from participation.

Figure 9: Top Tips for future GSFCH implementation

General

- Homes participating in GSFCH should receive information about the programme as early as possible so that by the time of the first Workshop staff have had time to gain some understanding of GSFCH.
- Provide more written information about GSFCH, presented at differing levels for different audiences e.g. a short booklet written in 'lay terms' (this could be given to potential residents and their families)
- Use fewer acronyms and eliminate health service jargon.
- Be clear to homes that they don't need to implement GSFCH for all residents immediately but can prioritise.
- Provide more education about GSFCH for GPs and CSCI.
- Improve public awareness generally so that staff can talk to health professionals and potential residents about GSFCH and expect this to mean something.
- Provide some recognition for homes which have participated in GSFCH.
- Provide complete clarity for nurses in terms of what to write regarding resuscitation wishes – otherwise they may fear 'getting it wrong' and the possibility of facing litigation from families in the future.

- **Suggested improvements to forms**
  - More space to write on the 'PEPSI COLA' form.
  - Space for the nurse and manager to sign the Advanced Care Plan.
  - SCR2 to be more nursing home specific – would lead to homes adopting it without adaptations, leading to consistency between homes and for staff when they change jobs.
  - Some nurses are responding to the PACA form by providing a snapshot of residents' conditions at two specific time points during the day, rather than providing an overview of the intervening hours, which may reveal a different and more accurate picture.
  - Remove 'date of death' from the front of the SCR2 form, can be insensitive as this is shown to residents and relatives.

- **Suggested improvements to workshops/programme**
  - Hold workshops in easily accessible locations – some delegates found Walsall significantly more difficult for travel than Birmingham.
  - Use case studies to aid understanding.
  - In group-work the group facilitators need to manage time well so that everyone has a say and no one monopolises.
  - Arrange for participants to meet again, perhaps in a years time to provide further opportunity to learn from one another.
  - GSF Team should maintain links with the current Phase 2 homes – they may still be struggling in a couple of years when GSFCH is more established, while homes which have introduced it later may have benefited from their involvement and in turn be able to advise them.

At home level

- Introduce GSF through the staff team gradually – e.g. make sure all at management level understand fully before introducing to nurses.
- Liaise with other GSFGH homes, share experiences and ideas. This can reduce workload and provides reassurance.
- Go through all paperwork with the facilitator in person.
- Work on the relationship with GPs – they need to be 'on board' and to support the homes' introduction of GSFCH.
- Don't be afraid to ask questions at workshops and of facilitators.
- If possible get the facilitator to explain GSFCH to all staff.
- Don't assume informing and training staff about GSFCH is sufficient, check they have understood and are using it. Repeat or follow up sessions may be needed.
- *'Go for it – grab it with both hands'* [Deputy manager 22].

Summary

1. Survey and qualitative data has revealed a number of factors influencing implementation of GSFCH which relate directly to organisational factors within the care home. These include staff resources, team-working, workload issues and availability of training budgets.

2. Factors which were supportive to, or barriers to GSFCH implementation have been identified. These included factors related to the organisational context of the care home, homes' relationships with primary care and palliative care teams, and factors related to the GSFCH programme.

3. Based on their experience of joining and implementing the GSFCH, managers and staff made a number of recommendations which had the potential to improve the relevance of GSF to the care homes' setting.

4. Supportive factors, barriers to implementation and staff recommendations were conveyed to the GSF team during the evaluation. Features to which the team were able to respond have been addressed and incorporated into GSF Phase 3.

SECTION 9: FINAL CONSIDERATIONS AND RECOMMENDATIONS

The aims of this one year evaluation of the introduction of phase 2 GSF into care homes in England were:

1. To evaluate the impact of the GSFCH on end of life care in care homes for older people.

2. To identify the contextual and organisational features of care homes which supported or hindered GSFCH implementation.

3. To explore the extent to which care homes were able to adopt optimal standards of practice in end of life care.

4. To identify a range of indicators to inform future development of GSFCH (as defined by Macmillan R&E group).

Before addressing these issues for homes which completed the evaluation, consideration is given to homes that did not complete the GSFCH evaluation. This is important as the nature of the home may influence uptake of GSFCH.

Response issues

The overall evaluation response rate was 55% (52/95), representing good retention over the 12 months of the evaluation. Of the 79 homes that returned a Baseline Audit, 49 (62%) returned a Final Audit, giving confidence in the results. It was noted at the outset that a number of homes did not continue to provide data for the evaluation. It is not known if this is a failure to provide evaluation data or an indication that these homes had deferred or stopped the GSF programme. To inform this further consideration was given to the homes that dropped out of the evaluation.

One key question was whether the care homes which participated in GSFCH were representative of care homes (nursing) in England with regard to size of the home, resident profile and place of death of residents. The homes did appear to be representative and consequently the outcomes of the evaluation have implications for care homes nationally.

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GSFCH was successfully implemented by many homes as evidenced by the evaluation and staff felt it addressed one of the main areas of nursing home care. Although providing quality end of life care is important to residents and staff, many staff felt it was an area which had been largely neglected and some homes had received little support in developing practice. Other homes in the evaluation experienced difficulty staying in the programme and completing the evaluation.

Analysis of data on withdrawal indicates that a proportion of homes dropped out early in the programme for reasons relating to staffing, funding, time pressure and perceptions of the amount or type of work that the GSFCH programme would involve. Some but not all of these factors were outwith the control of the GSF Team. For example, some managers appeared to have insufficient information about GSFCH before agreeing to participate, or insufficient time to consider the implications of joining the programme. This research evaluation was needed to help offer insights into what factors related to, for example, staffing, funding and team work which may impact on implementation. This has also been built into the Good Practice Guide (Thomas *et al* 2006) that can be used to advise homes signing up to future GSFCH Phases.

It is important to note that failure to complete the evaluation was not necessarily synonymous with failure to complete the implementation of the GSFCH. A proportion of homes which did not complete the full evaluation (i.e. failed to return the Final Audit) indicated that they had started aspects of GSFCH. Some homes had not sent representatives to the later workshops and were aware they had 'lost ground'. The extent to which these staff will be motivated or able to continue the GSFCH programme is unknown. The GSF team are alert to the fact that some homes may be working at a different pace to suit local circumstances, for example, some homes were initially working to improve collaboration with primary care practices because this was regarded as essential to implementing the programme.

Outcomes of the GSFCH evaluation

This section now reports on the four evaluation aims.

Context

Baseline data reveals that some homes had an existing interest and involvement in end of life care. For example, 18% of homes which completed the evaluation were using the 'Foundation in Palliative Care' education pack and 17% were sending handover forms giving details of their residents who may require medical input out-of-hours, before they commenced GSFCH. This indicates interest in end of life care at the outset which may have been a factor in signing up for the programme. However, on other measures the participating homes appear fairly typical of care homes nationally.

The impact of GSFCH on end of life care

The evaluation indicates that the phase 2 GSFCH programme did result in homes making progress towards achieving the identified aims of the programme (page 5). There was evidence of changes in practice during the GSFCH programme as indicated on the pre-post measures on the audits and after death analysis (Section 4). This included changes in practice related to use of the advanced care plan, last days of life pathway and prescription of anticipatory medication.

Statistical significance ascribed to these items suggests that the increase in use of these aspects of care was unlikely to have arisen by chance. Quantitative measures by themselves do not indicate the reasons why such changes occurred, only that they took place. However, when results from the survey data are combined with findings from the open ended audit questions and from the qualitative data, there is some confidence that the changes seen in the increase in adoption of various care items were the result of the GSFCH programme. Increased use of advanced care plans, listing of PRN medication or giving written information to families cannot guarantee that end of life care given to residents and their families is of a better quality. Data from the interviews, case study visits and audits though reveals that many respondents believed there was a direct link between the GSFCH and recent improvements in end of life care.

Statistically significant reductions in the rate of crisis admissions to hospital indicate

that aim 3 of the GSFCH was achieved. Overall the Evaluation indicates that the GSFCH provides a framework which has the potential to ensure delivery of high quality, holistic end of life care. It does this by providing information, training, support and structured care plans for end of life care. Critical to the success of GSFCH is the identification of residents thought to be in the last year of life so that care planning can be initiated and residents' wishes with regard to preferred place of care and type of care established. Staff respondents from homes which felt they had progressed with GSFCH reported that the programme provided them with a systematic approach to delivering end of life care, addressed their educational needs and acknowledged the important role of care homes in end of life care. By addressing these three key areas the GSF programme had increased their confidence in their practice and working relationships with other health practitioners, and improved end of life care.

Contextual and organisational features of care homes which supported or hindered GSFCH implementation

Features of homes that progressed well with GSFCH

Staff from homes which felt they had progressed well with GSFCH had a number of supportive factors including: senior staff with an existing interest or experience in end of life care who were pro active in ensuring that the programme was given priority in their home. Good staffing levels, a stable workforce and support from senior management and/or home owners also featured and a commitment to on-going training and staff development was also evident. Good levels of team working were reported and evident in the case study homes. These homes often had good primary care links and support from GP practices and some had regular meetings with palliative care specialists. GSFCH may be a spur to other initiatives and some teams identified issues that needed addressing before starting GSFCH. Consequently respondents from these homes were just starting GSFCH at the time of the Final Audit. In the interim they had addressed and clarified other areas related to end of life care and felt they had made good progress.

Features of homes that experienced difficulties with GSFCH

Identified difficulties in starting or progressing with GSFCH included senior staff changes, other staffing problems, perceived or actual time pressures, difficulties

attending the four main workshops due to lack of funding, perceived or actual lack of GP support and lack of a facilitator. Homes which reported progress with GSFCH also experienced some of these features, indicating that the presence of one of these features may not impede progress but the combined effects may.

The extent to which homes were able to adopt optimal standards of practice in end of life care

Some homes in the evaluation had already demonstrated an interest in improving end of life care before they started the GSFCH programme. For example they were sending handover forms to out of hours providers and following end of life care education programmes. Such homes were adopting the principles of GSF type end of life care due to commitment by individual managers, staff and NHS colleagues, and support and encouragement from care home owners. The GSFCH programme offered a programme with the potential to improve end of life care on the required scale i.e. to a large number of homes at the same time.

Informing future development of the GSFCH

A range of recommendations for future development of the GSFCH have been made. These are discussed in 'Recommendations for practice' (pages 120-123).

Other issues raised by the evaluation

Research access and ethics

This evaluation largely reflects staff perspectives and while these are important, effective means of including residents and families views need further exploration. Difficulties were encountered in trying to interview residents and the role of managers in facilitating access to residents needs to be clarified. The fixed format approach to recruiting with multiple pieces of information which NHS ethics committees require for potential participants (introductory letter, information sheet, consent form) may not be the best way of approaching all care home residents. Interviews with relatives were not planned as part of the evaluation but three were conducted because a manager had arranged them. Further work needs to explore appropriate means of working with residents and their families so they are better represented in research that has the potential to influence the quality of their lives.

Multiple perspectives

Dissonance between telephone interview data and site visit data was found at one home. This may have resulted because the manager was not the co-ordinator and implementation issues may not have been fully communicated. This highlights the need for evaluation data that incorporates multiple views because of the potential for differing perspectives. Differing perspectives may have been found elsewhere if more homes had been visited. Finally, the findings in this evaluation largely represent the views of care homes staff, to some degree the result of access issues discussed above.

GSFCH and the Liverpool Care Pathway?

Some homes introduced both GSFCH and the LCP, or a similar ICP, within a short time scale. Consequently some staff appeared to regard the two programmes as one entity, and some of the improvements attributed to GSFCH may be due to both and it is not possible to tease out their relative contributions. GSFCH endorses use of a pathway for final days of life care e.g. the LCP, or the minimum protocol for the dying, as C7 of the GSF Framework, so simultaneous introduction of GSF and the LCP does not invalidate the outcomes reported for the former.

Timing of the evaluation

A longer period of follow up of the GSFCH may have demonstrated more progress. Some respondents stated that although the programme had been introduced to staff, experience of the use of GSFCH in practice was still growing. Conversely, longitudinal studies suffer from greater sample attrition as time progresses.

Quality homes?

A number of indicators show that the homes which participated in GSFCH appeared to be representative of care homes nationally and the homes which completed the evaluation did not differ to any significant degree from the homes which did not complete. However the possibility remains that homes which participated in GSFCH represent better quality care homes. For example some managers reported that a GSF GP encouraged their participation in GSFCH because they were 'good' homes.

Recommendations

GSFCH was successfully adopted by many care homes. It produced demonstrable improvements in key areas and addressed the concerns of residents, relatives and care home staff. In order for sustained growth and continuation of the programme recommendations are made in the following areas:

1. Recommendations for practice

2. Recommendations for future care homes research, and

3. Recommendations for policy

Recommendations for practice

The Recommendations that emerged from the research were relayed to the GSFCH development team as the project progressed, facilitating a rapid response to issues raised in the evaluation.

NB Many of the points noted below have been taken on board in the Good Practice Guide for Phase 3 of the GSFCH programme.

Improved preparation for GSFCH

1. Managers and senior staff in care homes need more information about the GSFCH programme to enable them to make informed decisions before committing to the programme. A few facilitators appeared to try to recruit large numbers of care homes at the start of the GSFCH (Phase 2) programme evaluated here and some managers had insufficient time and information to consider the implications.

Management support for improved implementation of GSFCH

2. Success in implementing, supporting and sustaining GSFCH was highly dependent upon the support and steer from management and or home owners. Homes which experience recent senior staff changes may lack the commitment to provide GSFCH the priority it requires. In some homes implementation stalled because the coordinator left and GSFCH had not been embedded. For Phase 3 GSFCH homes have been asked to identify two coordinator posts to help to address this problem.

Designated preparation period before starting the GSFCH programme

3. The development of improved preparation before starting the full GSFCH programme, a 'mini' GSF should be considered. This might include for example the prognostic coding, the advanced care plan and a requirement that homes deliver the 'Foundations in Palliative Care' training to all staff. Such a programme could act as an introduction to GSFCH and a first stage for homes that wanted to progress to the full programme. If homes are not able to complete these elements they are unlikely to manage the full GSFCH. A mini programme would also indicate the organisational and time commitment required for the full GSFCH programme and may subsequently reduce the proportion of homes withdrawing from the main programme.

Guidance on advanced care planning

4. Clarification is needed regarding the need to re-validate the advanced care plan at specific, realistic, intervals to ensure that it is treated as a live document by all health practitioners and residents' wishes respected. National and local liaison with relevant NHS bodies is needed.

Tracking and auditing participating homes

5. An audit system needs to be developed in order to monitor the progress of homes through the GSFCH programme. Lack of monitoring made it difficult to track homes and some difficulties were only revealed when homes or facilitators were contacted by the evaluation team because of non response to the post GSFCH survey. The absence of active monitoring made it difficult to gain an overall profile of homes' progress with GSFCH. Monitoring homes' progress is vital because the team needs to know the scale of the impact of GSFCH, especially for subsequent phases which may not be evaluated in the same depth as was Phase 2. Additionally, homes interested in subsequent phases of GSFCH were advised to contact Phase 2 homes. It is possible (even likely) that many homes that did not complete the survey forms are carrying on developing use of GSFCH at 'their own pace'.

Monitoring facilitator support

6. Local facilitators were critical to the success of GSFCH and were a vital link and support between the GSF team and the care homes. Facilitators were one of the strengths of GSFCH, but also the weakest area if they were not available or able to support homes. Homes in isolated areas were particularly vulnerable if facilitators left because they had neither formal facilitator support nor access to informal support networks with neighbouring homes.

7. The system for maintaining contact with facilitators and identifying replacement facilitators requires review.

Assessment of team working in care homes

8. The team working questionnaire (TWQ) was used to profile staff in case study homes. Staff were willing to complete the TWQ, it was quick to complete and provided useful profiles of attitudes towards aspects of team working. Initial use of the TWQ by staff may help indicate areas that should be addressed before commencing GSFCH and has the potential to be a useful tool for care homes wishing to evaluate and where necessary enhance team working.

Sustainability – Future monitoring and accreditation of GSFCH

9. The GSF team should consider whether homes participating in GSFCH should be accredited and subsequently monitored in any way. Managers indicated they would be citing GSFCH participation in their publicity in order to demonstrate to potential residents and their families that they offer quality care throughout a resident's stay. The team need to consider which elements of GSFCH they would expect to be in place in order for homes to claim they have adopted GSFCH.

Location of GSF Workshops

10. Centrally located workshops were a means of helping develop a peer support network for those accessing this programme, a positive feature identified by some in this evaluation. However, it was challenging to others. In particular the homes that did not complete the evaluation noted that the location of

workshops at a distance was a problem as it impacted upon staff and resources.

11. Locally based workshops should be considered. (NB Adopted by the GSFCH team in phase 3)

Funding issues

12. If GSFCH is not adequately supported and embedded in care homes the full benefit may not be realised and there is the risk that GSFCH may lose credibility. The need for a more secure and increased level of funding should be investigated if the programme is to be delivered to more care homes and be sustained.

    Staff access to local end of life training was variable, depending on locality and managers' training budgets. Some equity in this area is required.

Recommendations for future care homes research

13. Overall, the *survey tools* used to audit care provision were useful in collecting data. Future studies will be able to take a more concise approach to data collection focusing, for example, on the key issues identified here that can, to some extent, measure progression in care giving based upon implementation of the GSFCH. Use of refined audit tools will enable care home staff to audit their own progression in due course.

14. Using these tools to capture more wide ranging data, for example specific details related to characteristics of the resident population and staffing levels, were not successful and warrant further consideration as to how knowledge of these factors can inform future development of end of life care in care homes. Use of existing data sets e.g. CSCI data should be explored.

15. The *After Death Analysis (ADA) tool* was shown to be a useful means of auditing end of life care provision. Short, concise questions around issues related to the last 5 deaths in homes were helpful in measuring care homes progression in managing care at the end of life. Demonstrating positive trends through this tool shows that care could be improved giving those people near

the end of life consistency in care in the familiar home environment. This was supported by better care management demonstrated in the surveys.

16. *Access to residents proved challenging*. Full ethical approval to do so was obtained from the MREC. However, access was sometimes blocked by the 'gatekeeper role' of the home managers. This is an area the research team will be following up as it raises a number of questions about the care home managers' roles and the rights of residents in care settings that are, after all their home. We need to review other ways of accessing this group to explore their feelings about this sensitive issue.

17. *Structure, culture and organisation of the care home:* Consideration should be given to undertaking a number of more in-depth case studies of care homes. This would enable detailed and fine grained work to uncover the specific elements that influence the abilities of individual care homes to change practice.

18. *Education Resource and materials*; Consideration should be given to undertaking a detailed study of the role of the facilitator as innovator. There is also scope for wider evaluation of the value of resource materials.

19. Similar detailed study could be made regarding the work of care home managers. To what extent does their approach and style facilitate or hinder innovation?

20. Further research is needed to investigate the benefits of *Advanced Care Planning* to inform future programme development.

Recommendations for Policy Makers

21. Allow realistic timescales for change.

22. Work on fundamental capacity building, particularly in respect to the interface between the care home sector and primary care.

23. Provide clear guidance for those working in the care home sector in terms of policy priorities. This will help avoid 'policy overload' as care homes strive to address the wide ranging policy agenda.

24. Coordinate the range of monitoring and governance procedures to reduce the likelihood of duplication of effort in responding to numerous requests for performance related data.

25. Most care homes' fees for GSFCH were met by strategic health authorities from NHS 'End of Life' programme money. A minority of care homes appeared to be unable to access these funds. The system needs clarification, either all care homes (nursing) should have access to the same fund or the resources are given directly to the GSF team to deliver the programme.

26. Staff access to local end of life training was variable, depending on locality and managers' training budgets. Some equity in this area is required.

Comment on Research Methods

It is important to note that, within the time constraints of the project it was not possible to set up a number of homes that could be 'controls' by allowing us to measure care giving without the influence of GSFCH programme at 2 points in time. Hence it is recognised that other factors may have impacted upon the changes observed in the homes where care was evaluated.

SECTION 10: APPROACHES TO RESEARCHING DEVELOPMENTAL PROGRAMMES

Introduction

As noted in Section One, a key part of review of this project is an examination of the approach adopted which will help refine our methods of real word research in care home settings. The extent to which this approach was successful is discussed in the results section and the considerations of the implications for future research below serves as a reflection on the research process adopted. This draws on the experience of the research team in developing a project in care homes that:

a) was on a larger scale than much of the work in this sector to date and

b) raised methodological challenges in developing work in the 'real world' that incorporated rapid feedback from researchers to inform the next stage of development of a planned programme.

To set this in context, the status of research into end of life care in care homes in the UK to date will be considered briefly. This will be followed by a reflection on the challenges of undertaking research alongside a development project in health care. Next the issues around partnership working in this project will be considered to inform future projects involving similar collaborations. Finally the limitations acknowledged in the research will be considered.

Research in the Care Home Sector

International and national policy has highlighted the challenges of developing quality end of life care provision to support the 75% of people who die from diseases other than cancer, a group that has not historically benefited from 'good' palliative care (Davies & Higginson, 2004; Department of Health, 2007). This group includes the large number of older people who die in care homes. This consideration was key to the decision taken by the GSF team to roll out the GSF programme into the care home sector.

At the outset of the project a preliminary literature review using the broad headings of care homes and end of life care revealed a dearth of previous research in end of life care in care home settings in the UK with the exception of some notable work produced by Froggatt (2001 & 2005; Froggatt *et al.*, 2003) and Hockley *et al.*, (2005). This can be contrasted with a vast body of literature relating to end of life care for those with cancer in receipt of palliative care, indicated for example in the work reported by Payne *et al.*, (2004).

Given the focus of the GSF programme was on care teams working together to develop practice, the literature was also examined for work undertaken in relation to a range of other relevant issues in care homes including team working, working across the primary and secondary health care interface and the educational needs of staff. Again this revealed a dearth of literature at the outset, though notable exceptions referred to earlier in this report include Eyers (2000) and Redfern *et al.*, (2002).

It is interesting to note that the period in which this project was being developed and implemented has coincided with an increased interest in research and development in the care home sector. This is evident in the establishment of a National Care Homes Research & Development Forum that has bought together researchers with shared interest in this sector. This has proved to be a lively forum in which researchers collaborate to implement the much needed research and development work in the sector.

In addition to this a strong push by key agencies, such as Help the Aged, have led to the publication of a strategy document 'My Home Life' (Help the Aged, 2006), that has highlighted the need to focus on developing this sector. Consideration of end of life care is a key issue in this publication. In addition there has been a steady trickle of reports sharing experiences about various aspects of research in the sector, indicating an increased awareness of the importance of care homes' roles in providing end of life care (Froggatt *et al.*, 2006; Murphy, 2007).

This emerging literature is adding to the body of knowledge of how to use research to help evaluate care development in care homes. The dominance of action research approaches was reflected in the project reported here with one key difference to other reports of work in care homes, such as the recent commentary by Froggatt *et al.*, (2006), namely the scale of the project. Once the GSF team moved beyond Phase 1

of GSFCH, the pilot project of **12 homes** (Maryon *et al.*, 2005) the plan to roll this work out at a national level in Phase 2 reported here, led to the participation of **95 care** homes initially. Research that spans such a large number of homes is unprecedented, consequently there was little to guide the research team as to the 'best way' of conducting this study.

The vision of the GSFCH programme was to enhance end of life care in the care home sector and the purpose of the evaluation was to evaluate whether this goal was met, identifying the factors which facilitated or prevented implementation of the programme. A key requirement was to keep the GSF team informed of the research outcomes as they emerged, to help inform the next phase of GSFCH development. A commitment was also made to keep care home staff informed of research outcomes and feedback presentations were made at the four GSFCH workshops. The workshops also provided a forum where the emerging findings could be considered further with feedback from care home staff contributing to the GSF team's overall evaluation, thus providing the research team with additional insights that could be followed up in the later stages of the study. An action research approach was described. However debates within the steering group led to the need for further consideration with a general question to whether the nature and the scale of the GSFCH project, running in tandem with an integrated evaluation programme, could appropriately be described as using action research. This issue is explored further below.

Research design issues

The research reported here was characterised as being in the action research tradition. Analysis of the research model adopted highlighted three features that commonly emerge in definitions of action research. This included close <u>collaboration</u> between the research team and the GSF team in devising an <u>evaluation</u> that could be developed in tandem with the implementation of the GSFCH programme and identifying mechanisms for <u>rapid feedback</u> so that insights gained through the evaluation could be used by the GSF team to help inform ongoing development of GSFCH.

The fundamental aim of the GSFCH programme to improve the quality of end of life care meant that ongoing discussion between the research and development teams were undertaken to ensure results were available as soon as possible to help achieve

this aim. Such an approach can be seen to reflect Lewin's definition of action research as '*a way of generating knowledge about a social system whilst, at the same time, attempting to change it*' (Hart & Bond, 1995, cited p13). Although this definition is seen as seminal in the action research literature some authors are critical of Lewin's perspective, seeing it as a form of 'social engineering, perhaps a process of 'doing to' rather than 'doing with''. For example Carr & Kemmis, (1986, cited in Hart and Bond, 1995 p21) state the hall marks of action research are awareness raising, empowerment, collaboration and enabling practitioners' to develop as researchers. This perspective presents a challenge in the context of this study. At what level are practitioners defined in an action research process; are they the managers of care home groups, care home managers or the care staff working directly with residents? Here, the GSF team was implementing a programme designed to improve end of life care. It is acknowledged that they could not do this without the input and commitment of the care home sector and a number of key people in developing care home services were actively involved in the process. This included leaders from the sector actively participating in the change strategy making presentations at workshops and supporting the involvement of their own care homes. There is little doubt that on the basis of the commitment of the GSF team and the way in which the development programme was delivered, that what they sought to do was to help practitioners develop better end of life care in their sector. In so doing they would argue that opportunity for empowerment by practitioners came from the impact of knowledge about practices and procedures that would inform end of life care. What practitioners were not involved in was the research process.

To explore this further the research framework developed out of an in depth study of action research completed by Waterman *et al.*, (2001) was considered. This work concluded with a working definition of action research today as:

> ' a period of enquiry that describes, interprets, and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem focused, context specific and future oriented. Action research is a group activity with an explicit critical value basis and is founded on a partnership between action research and participants, all of whom are involved in the change process. The participatory process is educative and empowering involving a dynamic approach in which problem identification , planning action and evaluation are interlinked knowledge may be advanced through reflection and research and qualitative and quantitative' research methods may be employed to collect data. Different types of knowledge, including practical and propositional, may be produced by action

The key principles arising from this definition were considered in the context of this work (Figure 10). This analysis suggests this evaluation could be defined as an action research approach. However, there is scope for challenge in several aspects. For example, the '**social situation'** in which the GSFCH programme was located reflected diversity in nature and culture of care homes. Although they all fall into one care sector, the case study work (Sections 5-7) illustrated the diversity of context and could be said to reflect multiple social situations.   Whether it is acceptable to describe multiple homes as a 'social situation' is unclear as definitions of action research generally do not delineate the limits of the 'case'. What is clear in relation to action research previously conducted in the care home sector is that it tends to focus on single organisations or small groups (e.g. Froggatt *et al.*, 2006; Hockley *et al.*, 2005). Similar observations can be made of exemplars of action research reported in standard texts (Hart & Bond 1995). The application of the method across the sector is an appropriate application of the methodology to a multiple-case approach. This increased the richness and depth of the data and facilitated a more comprehensive analysis of the GSF implementation in care homes.

Another key consideration (Figure 10) is that the **'change intervention was aimed at improvement and involvement'**. However, when consideration is given to the nature of the '**group activity'** some questions arise that are not dissimilar to the issue raised about the context. For example, does group activity in an action research framework require equal input from all groups at all stages or is an evolutionally model such as developed here seen as acceptable?

In this case it is possible to discern 4 groups involved in the development   and research activity (Figure 11) . The stimulus for the GSFCH programme arose with the

Figure 10: Definition of action research (Waterman et al, 2001) applied to GSFCH Evaluation

Principles	GSFCH Programme
Period of enquiry	1 year
Social situation: described, interpreted, and explained	GSF Care Homes programme. National programme to inform/impact local agendas.
Change intervention aimed at improvement and involvement	GSF designed to impact on the way care is delivered
Problem focused	Challenge: can the GSF intervention improve care at the end of life
Context specific	Care homes
Future oriented	Phase 2 (reported here) to inform phase 3 in roll out programme…
Group activity	4 groups: GSF development team Research commissioning team (Macmillan) Research team Care home staff
Partnership between action researcher and participants, all of whom are involved in the change process.	Partnership clear at strategic and operational level
The participatory process is educative and empowering	GSF based on educational model designed to improve professionalism and empower through knowledge
Dynamic approach in which problem identification, planning action and evaluation are interlinked	Knowledge used at each stage used to inform next… (process evaluation)
Knowledge may be advanced through reflection and research	Regular meetings, reviews, shared learning between participants
Qualitative and quantitative' research methods may be employed to collect data.	Audit, surveys, interviews.
Different types of knowledge, including practical and propositional, may be produced by action research.	Practical focus
Theory may be generated and refined and its general application explored through the cycles of the action research process	Next steps

Figure 11: Action research involvement and funding in GSFCH Evaluation

Care Homes
Staff and Managers

NHS Strategic Health
Authorities and Primary
Care Trusts in England.

Research team

GSF team

Macmillan Research
& Evaluation

NHS End of Life
programme
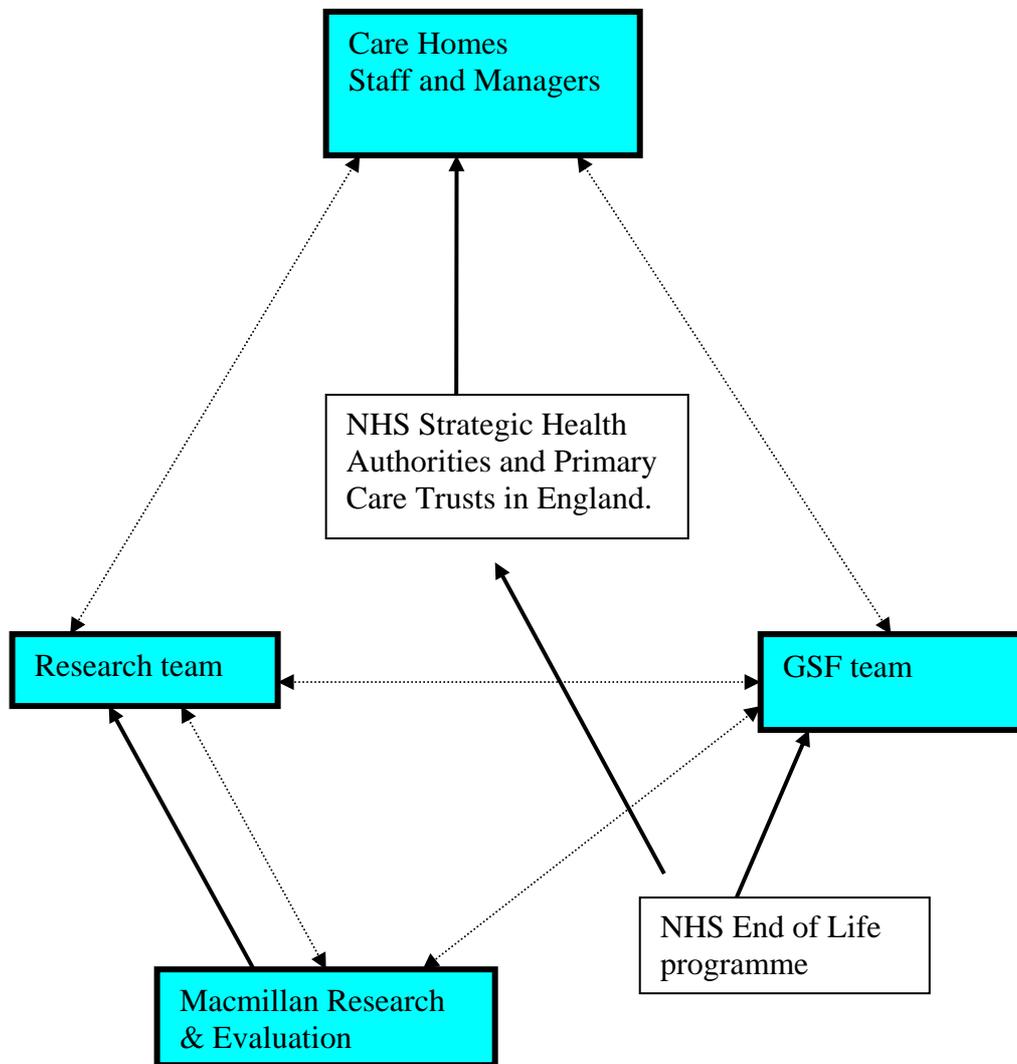
Group involved in Action Research

Funding Stream

Links during GSFCH evaluation

GSF team members who as leaders worked with other recognised leaders in the health and care home sector to plan the implementation of the programme. The work was supported by the Macmillan Research and Evaluation programme and this group was involved in the iterative commissioning process of the evaluation. The GSF team's target was to help care homes instigate a change process in their own organisations and following the initial workshop they began to adopt this role. However, unlike the GSF team and the commissioning group, the care home staff were not party to developing the evaluation process although in due course they did contribute to the data collected as a means of examining their own progress. Pre and post survey data for example allowed local evaluation of impact (Section 3). In this sense there was extensive involvement from a diverse stakeholder group, a key component of action research (Hart & Bond 1995).

In relation to other criteria, referring back to Figure 10 and Waterman et al's (2001) description of action research all groups involved need to develop a model of 'partnership' working that supported GSFCH programme delivery and evaluation. Within this framework there was recognition of the need for a flexible approach to research, to develop a plan that met the criteria for a 'dynamic' approach in which action planning and evaluation were interlinked, knowledge could be advanced through 'research and reflection' and a 'range of methods' were used.

In sum, it can be seen that using Waterman et al's (2001) definition of action research a number of features of this approach can be clearly identified in this study.

The framework offered by Hart & Bond (1995, p40) offers a means of exploring this issue further. The authors identify four core categories reflecting the main drivers or purpose behind action research projects, which are experimentation, organisational, professionalising or empowerment reasons. Within each of these four drivers, Hart & Bond (1995) identify seven dimensions including educative base, participation at individual or group level, the focus of the problem, the nature of the change, improvement or involvement, the cyclical process and the research perspective. (Figure 12).

Figure 12: Synopsis of Hart & Bond (1995). Typology of action research (p40-43).

	Experimental	Organisational	Professionalising	Empowering
Educative base	Re education	Training Managerial bias Overcoming resistance to change Client focus	Empowering professional control; advocacy on behalf of patients /clients Practitioner focuses	Consciousness raising *Empowering oppressed groups User practitioner focus*
Individuals in groups	Closed group selected by researchers for purpose of measurement Fixed membership	Work groups Selected membership Selected membership	Professional and or interdisciplinary Shifting membership	Fluid, self selecting or natural boundaries Fluid membership
Problem focus	Problem relevant to social science/management interests	Problem defined by powerful groups Relevant to managerial interests	Problem defined by professional group Some negotiation with users Problems emerge from professional practice	Emerges from members Completing definitions of success
Change intervention.	Experimental to test social science theory/generate theory	Top down- directed change by predetermined aims	Professionally led, predefined Process- led Problem to be resolved	Bottom up
Improvement or involvement	Towards controlled outcome	Towards tangible outcomes	Toward improvement in practice	Negotiated outcomes
Cyclical processes	Research component dominate Casual process noted	Action and research components in tension; action dominated	Research and action component in tension Identifies causal processes that are specific or can be generalised Spiral of cycles	Open ended process driven
Research relationship and degree of consideration	Experimenter/ respondents Outside researchers	Differentiated roles between consultant/researcher/ participants	Practitioner or research collaborators Outside resources and or internally generated Merged roles	Practitioner research /co-researchers/co change agenda Shared roles

Reference to Hart and Bond's model helps refine the framework used here. Our work did not fall into the *experimental* category so that context is easily dismissed. The GSFCH programme can however, be seen to have an underpinning philosophy designed to help *organisational development* in end of life care within the care home sector. Key to the *educational focus*, the core intervention was a training programme that had a 'managerial' focus in that it was directed via the home managers/coordinators. The GSFCH programme can be seen as offering a professionalising strategy. Although this was not a stated purpose, inherent within the change programme is improvement and empowerment of staff. The extent to which this could add to a professional agenda was perhaps limited, the care home workforce is diverse ranging from registered nurse managers to care staff with limited qualifications. However, it was anticipated that successful implementation of the GSFCH programme would *empower* staff to give better end of life care to residents in care homes, a fact borne out by this research (See Section 7).

Thus, consideration of each aspect offered by Hart and Bond (1995), demonstrates that the research strategy adopted here builds on and extends an action research approach. The major drivers were to support and evaluate the impact of an organisational change development arising from implementation of the GSFCH plan and this was achieved. The key beneficiaries in this could be the people in receipt of care at the end stage of life, which is the aim of the programme. However, professionalising strategies can be seen to help the individual staff involved, whilst supporting group development. Enhancement of staff skill will help care home managers and owners feel confident that they can deliver better quality care which in turn has the potential to empower staff, within a planned organisational delivery programme. The dimensions of this are illustrated in Figure 13, below.

Figure 13: Application of Hart & Bond typology to GSFCH programme

	Action Research agenda	GSFCH Programme:
Educative base	*Training to empower*	*User practitioner focus GSFCH workshops, facilitator support and learning materials*
Individuals in groups	*Professional and or interdisciplinary*	*Care home mangers (professional and lay; care home staff*
Problem focus	*Problems defined: improve end of life care*	*Negotiated speed of implementation to reflect local developments*
Change intervention.	*Top down- directed change by predetermined aims led, predefined Process- led Problem to be resolved*	*Pre-determined Professionally Led by GSFCH team*
Improvement or involvement,.	*Towards tangible outcomes Toward improvement in practice*	*Tangible outcomes*
Cyclical processes	*Action and research components in tension; action dominated*	*GSFCH programme set at the outset*
Research relationship and degree of consideration	*Differentiated roles between consultant/researcher/ participants*	*4 groups defined*

To set the data collection into context consideration needs to be given to the evaluative model used to collect and report on data in this study.

Evaluation

The purpose of an evaluation is "to assess the effects and effectiveness of some thing, typically some innovation, intervention, policy, practice, or service" (Robson 2002, p 202). Evaluation studies may be undertaken to determine if a programme of activity meets the needs identified; to improve the programme; to assess outcomes; to find out how it is operating; to determine efficiency and to understand why a programme does or does not work.

Robson (2002) also noted a range of different methodologies will be used and that evaluation research cannot be distinguished from any other form of research in terms of design, data   collection, techniques and methods of analysis (p204). Within descriptors of evaluation research, aspects that need to be considered in relation to this work are the distinction between formative and summative evaluation; the former considering the development of the programme, the latter considering the effects and

effectiveness. Robson notes this perspective may be seen as similar to a model process and outcome, process being concerned with the how a particular outcome was achieved (Robson 2002 p208).

The influences of evaluation research used in this study are evident in that the research was designed to explore the impact of a programme. This reflects the model of improvement orientated evaluation described by Patton (1997 p68) in that both initial and final analysis have been used to inform progression.

Whatever the focus, evaluation research is geared towards an end point and makes no claim for any interaction with others participating in the activity observed. Robson (2002 p 208) distinguishes this from action research where improvement and involvement are central to the process. From this perspective it is concluded the research adopted here reflected an action research approach in which knowledge was generated using an evaluative process (research design) to examine the impact of the GSFCH programme (the change agenda) in care homes (the social system). Close working relationships between the GSF team and the research team enabled the research to be used to inform the change agenda over the course of the project.

This analysis will serve as a basis for the GSF team and the research team to develop a framework in which a longer term collaboration can be managed. Longer term evaluation of the programme requires further consideration and as such moves the overall GSFCH project away from a single study format and refining a diverse approach. Thus it is proposed that the next stage of development will reflect the model of developmental evaluation described by Patton (1997 p104). Here the evaluators are seen as '*part of a team whose members collaborate, conceptualise design and test new approaches in a long term and ongoing process'* We can see in the work developed here and in the shared approach to disseminating outcomes by the GSF and the research teams, that we have started this approach and look forward to further development. To help inform this, further consideration is needed of the modes of partnership working that have informed this project and will underpin future work.

Partnership working

This project was based on a model of partnership working that involved the research team working with several groups. This involved close collaboration between three parties; the research team, the GSF development team and the funders (Macmillan). who were developing a model of iterative commissioning (see Appendix 1). The second partnership lay in a shared commitment of the GSF team to work with the research team to develop the evaluation in such a way that it would enable research findings to inform development of the GSF Care Home programme. This has been described as a process of iterative working. Finally, the partnership with the care homes at the two key levels of data collection, the survey work and the case study work reported in the project report were key to its success (See Figures 3 & 11). Further consideration is given below to the iterative processes involved in developing these working arrangements.

Iterative processes

A key feature of this action research was an iterative process identified at the funding stage (see page 10). As a new initiative it was important that findings from the research could be used to inform the GSF development as the work progressed. Arising from this premise we built upon the notion of iterative working which was introduced to the project team early in the process. This was applied in two main areas: commissioning and development.

The word 'iterative', is simply described as being 'repetitious or frequent' and was used in this work as a means of implementing a model of research commissioning described by Lilford *et al.* (1999). These authors identified the benefits of keeping a focus on a given topic when planning a programme of research work and keeping the option to develop new approaches to research as new insights and development emerged from earlier work.

Iterative commissioning

The iterative process in commissioning the research provided a challenge to the research team. This project was one of a number funded by the Macmillan GSF R&E programme, so group members had begun to identify which features were important

to evaluate. The GSF team was keen to ensure that data collected built upon existing modes of evaluation in primary care (King N *et al.*, 2005; Munday and Dale, 2007; Thomas and Noble, 2007) and the pilot Phase 1 GSFCH study (Maryon *et al.*, 2005). Thus templates for baseline data and ongoing audit were, to some extent, prescribed.

This meant there was little time to prepare the study within a 'real-world' time frame because of the need to obtain baseline data from homes and facilitators before the GSF team launched the Phase 2 programme. The research objectives (Page 9) drawn from the initial proposal, set the scene for the approach to the study. Colleagues at Macmillan then reflected, as part of the iterative process, on the proposal and drew up a series of indicators of outcome measures they would like to see.

Because data collection had to begin whilst the iterative commissioning was still in process, there was a need to consider how the planned data collection addressed the outcome indicators identified by Macmillan (see Appendix 1). These requirements were cross checked against the initial project plan to ensure the indicators were addressed. The outcomes of this process can be seen in Section 2 (Study methods).

Iterative working

One of the considerations in developing this research within an action research framework was to inform the GSF team of issues that may impact upon the implementation of the GSF programme in care homes. This resulted in an 'iterative research framework' in which emergent indicative research findings were communicated to the GSF team at regular intervals. This process was key to bridging what is often seen as a 'gap' between research and practice where, in many approaches to research those evaluating a process remain distant from those they are evaluating. Both the GSF team and the Research team were keen to approach this work in a way which could inform the next stage of development. This reflected the action research approach which helped us achieve our plan, although as noted organisational action research (Figure 12) is not without tensions.

Working in this manner was an important issue as it enabled the GSF Development group to use emerging data to facilitate developments in participating care homes. Homes in Phase 2 had a Starter Pack and as the project progressed emerging data

contributed towards the development of 'Good practice guidelines' to support use of GSFCH in the care homes in Phase 3. **These guidelines have been further developed in the light of data from the completed evaluation presented in earlier sections.**

Timing

One of the key challenges in establishing the research was the timing of the process in which plans were being developed to roll out the GSF programme in care homes following the initial pilot (Maryon *et al.*, 2005), at the same time as the research team were developing the evaluation plan.   The evaluative model adopted required collection of baseline data before the GSF programme was introduced to care homes to enable the impact of the programme on care to be measured against this data. This condensed the iterative process and led to some challenges as the commissioning team had derived one set of questions and the research team another.   Throughout the project this remained a crucial issue as the GSF team sought feedback from the early stages of the evaluation at regular intervals to ensure this could be shared with all participants. This was managed well, largely as a result of good working relationships between the GSF team and the research team. This is an issue worthy of further consideration as it could be key to any other teams undertaking similar projects.

Working relationships

The rapidity with which NHS and health care structures have been required to change (Glasby J *et al.*, 2007) have had an impact on practice at all levels. Consequently clinicians have little time to await the outcome of the careful, step by step processes required to ensure methodological rigour in research; rather they need to implement change quickly. Given this, in rapidly changing health care structures, researchers can be challenged on several fronts:

- Speed in designing and implementing research is required.
- Researchers need to be prepared to deliver findings in shorter time frames than in the past.
- Practitioners moved to a next stage of development whilst research reports are being prepared for wider dissemination.

Space does not allow an in-depth analysis of the implications of this but a couple of points are worthy of note:

- First clinicians and researchers recognise that time is needed for new initiatives to 'bed down'. However research funding streams are much more likely to be available when the initiative is new. This raises questions of sustainability that are often not addressed in much of health care organisational research.
- Secondly, the real costs of research are increasing. This can mean there is insufficient resource to respond to the urgent demands from clinicians for 'immediate' and detailed feedback as funding sources are limited.

This leaves little time for developing the kind of working relationships with clinicians necessary to support 'real world' research, that is research that is timely and relevant to practitioners.

In the project reported here the effective working relationships between the GSF team and the research team enabled the project to be developed in a timely and relevant manner. Both groups were committed to identifying the impact of the GSFCH programme in a fair and reasonable way that met the needs of the research commissioners and more importantly, the care home staff, particularly the mangers who needed to know if the time invested in staff development was worthwhile.

This was done following the standards set out in good research governance procedures (Clifford, 2003). Within this the requirements of flexibility, good communication and negotiation skills needed to be set alongside the need for methodological rigour. The challenge to maintaining this came in the rigour that was paid to the final analysis by the research team when the GSF team were ready to promote the next phase of development. Linked with this was the need to present the findings from the research in a clear and coherent way that was useful to all parties. This was done by an active programme of dissemination in which both parties were able to address relevant audiences. (See Appendix 9 Dissemination activity).

As a result of the learning from this wide ranging action research project, the following recommendations may assist project management in future evaluations.

Recommendations

1. Commissioners should consult with research partners before starting the formal commissioning process to identify any potentially problematic methodological issues.

2. In terms of overlap of responsibilities, the roles of the development team and the research team should be clarified as part of the commissioning process to ensure the integrity of research whilst maintaining partnership working.

3. A formal process for management and monitoring should be agreed to facilitate sharing of information to inform study design and to increase the speed of sharing emergent findings.

Limitations

Finally, consideration is given to the overall limitations of the study.

Data collection method

Research in care homes often encounters low response rates. Surveys of continence care in care homes achieved response rates ranging from 9% (Wagg *et al*., 2005) to 35% (Rodriguez *et al.*, 2007). It was hoped that the return rate in this evaluation would be higher because of the agreement between care homes and the GSF team and the interactive nature of the programme. The initial response rate was 83% dropped to 54.7% (Figure 4) at the final audit, reflecting greater sample attrition in longitudinal studies. Retention of over half the survey sample at one year follow up represents a good response rate compared to most longitudinal studies (May, 2001).

Froggatt (2006) reported that the culture and environments of care homes for older people do not lend themselves to formal research interviews and collected data with residents over a period of several months. This was not an option in this one-year evaluation. Care homes' participation in research requiring access to staff and residents can incur extra costs for homes and needs addressing if research in this sector is to be facilitated (Rooney *et al.*, 2005).

Fieldwork always raises the possibility of encountering the unexpected and this study was no exception. Difficulties encountered in interviewing staff and residents

highlight the nature and variability of the work and the client group and the relatively recent involvement of care homes in fieldwork-based research.

Staff interviews were sometimes curtailed due to pressure of work and resident interviews did not take place because residents were too ill or had died. Some staff interviews took place in cramped offices with the telephone ringing and with residents or families calling in. The case of the resident who wanted to participate, but whose relative refused, raises fundamental issues in relation to consent and autonomy. The manager commented it was *'such a shame, because this lady is so interested in it.'* Should the researcher have asserted that consent was sought from the resident not the relative and asked to see the resident? Attempting an interview may have damaged relationships between the resident, relative and the home and the researcher decided not to press for the interview. These situations raise issues that need to be addressed, firstly because care homes are increasingly research locations and secondly if the framework for ongoing research relationships is to be meaningful.

Homes which participated in GSFCH were a self-selected sample and one manager reported that at a local GSFCH meeting a PCT representative asked the care home managers *'Why are you all here? You are the best nursing homes.'* This is a consideration in the overall evaluation but has specific relevance for the case study homes. Although efforts were made to secure a representative sample of care homes in the case study it is not possible to know if this has been achieved (see Section 8) and therefore the extent to which the findings might relate to other settings needs to be considered. It should also be noted that, although the case study homes might be assumed to represent homes at the 'better' end of the care spectrum, they encountered problems as well as successes. Their experiences in implementing GSFCH were varied and can be used as learning points for subsequent phases of GSFCH.

Efforts to identify why homes had not responded to the ongoing evaluation was one way in which the research team sought to address the risk of bias in home selection. In one case study home there was a discrepancy between the manager's account and the situation revealed during the visit. The manager stated the home had implemented GSFCH but during the visit staff stated that they had been overtaken by another project, which had priority and had not been able to progress with GSFCH as

anticipated. Staff reported they were starting to implement GSFCH and by the time of the Final Audit reported slow progress.

Programme evaluation in real life situations is not straightforward because the normal processes of change and development cannot be postponed while the programme is implemented and the evaluation conducted. It cannot be stated that changes in practice identified at the completion of the GSFCH programme are solely due to the GSFCH or the result of changes that would have occurred anyway. During case study visits it was apparent that some homes had adopted a pathway for end of life care, at the same time as GSFCH. Some staff regarded the care pathway and the GSFCH as part of the same process and changes were sometimes attributed to the combination of both and it was not possible for them to identify which outcomes resulted from which programme.

Conclusion

This chapter has offered a reflection upon the approach to the research work reported. It is concluded that it is possible for those involved in developing research to work closely with a team implementing change to produce work that is timely and relevant to those commissioning research arising out of clinical development activity. To enable data to be used it must be presented as partial data at agreed intervals in the process. To be able to do this with confidence it is important that clinicians and researchers work together with the confidence arising from a shared commitment to do the best for those receiving care. The sound working relationships between the GSFCH development team and the research team supported the positive outcomes arising from the project reported here.

Undoubtedly more work is needed both to challenge the findings reported here, to monitor sustainability and to firmly establish the development evaluation models that are emerging from the ongoing collaboration between the research team and the GSF team.

Summary

1. The evaluation of Phase 2 of the GSFCH programme represented one of the first large scale action research programmes in this sector.

2. Action research was an appropriate model to adopt, supporting the collaboration of multiple players and rapid feedback and integration of research findings into the developmental cycle.

3. Commissioners, researchers and development teams need to be clear that although they each have defined roles in the innovation, their roles are also interdependent and delivery is dependent upon effective partnership working.

4. A number of recommendations have been made to assist commissioning of similar projects in the future.

5. Finally, the limitations of the approach have been discussed.

REFERENCES

Bartlett H & Burnip S (1998) Quality of care in nursing homes for older people: providers' perspectives and priorities. *NT Research* Jul-Aug; **3:** 257-268

Borrill C & West M (2001) *How good is your team? A guide for team managers.* Birmingham, University of Aston

Bowman C, Whistler J & Ellerby M (2004) A national census of care home residents. *Age and Ageing* **33,** 561-566.

Cancer services collaborative (2007) http://www.cancerimprovement.nhs.uk/View.aspx?page=/default.html Accessed 30/05/2007

Carr W & Kemmis S (1986) *Becoming critical: Education, knowledge and action research.* Falmer Press, London.

Clifford C (2005) *Improving End of Life care in care homes: An Evaluation.* Research proposal submitted to Macmillan. Birmingham, School of Health Sciences, University of Birmingham

Clifford C (2003) Research Governance - the challenge. *Nursing Times Research* **8,** 7-16.

Crabtree BF & Miller WL (1992) *Primary care research: a multi-method typology and qualitative road map.* In: Crabtree BF & Miller WL (eds) Doing qualitative research. Sage, London

CSCI (2006a) *Data on care homes and care home populations.* Data requested for the Evaluation of GSF in care homes for older people. Jan 2006 Strategy directorate, CSCI.

CSCI (2006b) *Data on care homes and care home populations.* Data requested for the Evaluation of GSF in care homes for older people. April 2006 Strategy directorate, CSCI.

CSCI (2005) *The state of social care in England 2004-5.* www.csci.org.uk

Davies E & Higginson I (2004) *Better Palliative Care for Older People.* Denmark, World Health Organisation,

Department of Health (2007) E*nd of Life care strategy.* Department of Health, pp 1-2.

Department of Health (2003) *Care homes for Older People. National Minimum Standards*. C*are homes Regulations.* 3rd Edn. The Stationary Office, London

Ellershaw JE & Murphy D (2005) The Liverpool Care Pathway (LCP) influencing the UK national agenda on care of the dying *International Journal of Palliative Nursing* 11(3): 132-134

Eyers I (2000) Care assistants overlooked? A cross-national study of care home staff in England and Germany. *Quality in Ageing* **1,** 15-26.

Froggatt K (2006) *Transitions in care. End of life issues for older people in care homes.* Presentation at School of Health Sciences, University of Birmingham 5th July

Froggatt K (2005) Focus. 'Choice over care at the end of life': implications of the End of Life Care Initiative for older people in care homes. *Journal of Research in Nursing* 10:189-202

Froggatt K. (2005) A death foretold: End of Life care for people with dementia. *Presentation at the Leveson Centre, 7th September 2005*.

Froggatt KA (2001a) Life and Death in English nursing homes: sequestration or transition? *Ageing and Society* **21,** 319-332.

Froggatt K. (2001b) Palliative care and nursing homes: where next? *Palliative Medicine* **15,** 42-48

Froggatt K & Payne S (2006) A survey of end-of-life care in care homes: issues of definition and practice. *Health and Social Care in the Community* **14,** 341-348.

Froggatt KA, Davies S, Atkinson L, Aveyard B, Binney S, Kent Y, McCaffrey S & Townend C. (2006) The joys and tribulations of partnership working in care homes for older people. *Quality in Ageing* **7,** 26-32.

Froggatt K, Payne S, Nolan M & Warnes T (2003) Developing the Provision of End-of-Life Care with Older People in Care Homes.

Glasby J, Peck E, Ham C & Dickenson H. (2007) *Things can only get better.* Birmingham, Health Services Management Centre & School of Public Policy, University of Birmingham

GSF (2005) *A programme for community palliative care.* Birmingham: Gold Standards Framework – www.goldstandardsframework.nhs.uk

Gysels M & Higginson I. (2004) *Improving supportive and palliative care for adults with cancer. Research evidence.* www.nice.org.uk

Hart E & Bond M (1995) *Action research for health and social care. A guide to practice.* Buckingham, Open University Press

Help the Aged (2006) *'My home life.' Quality of life in care homes. A review of the literature.* Prepared for Help the Aged by the National Care Homes Research and Development Forum (NCHR&DF)

Hockley J, Dewar B & Watson J. (2005) Focus. Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'. *Journal of Research in Nursing* **10,** 135-152.

Hockley J & Clark D (eds) (2002) *Palliative care for older people in care homes.* Buckingham, Open University Press

House of Commons (2004) House of Commons Health Committee Palliative Care New Inquiry Draft 21/2/04
http://www.publications.parliament.uk/pa/cm200304/cmselect/cmhealth/454/454.pdf

Katz JS & Peace S (eds) (2003) *End of life care in care homes. A palliative approach.* Oxford, Oxford University Press

King N, Thomas K, Martin N, Bell D & Farrell S (2005) 'Now nobody falls through the net.' Practitioners' perspectives on the Gold Standards Framework for community palliative care. *Palliative Medicine.* **19,** 619-627.

King N, Thomas K & Bell D. (2003) An out-of-hours protocol for community palliative care: practitioners' perspectives. *International Journal of Palliative Nursing* 9(7): 277-82.

Laing & Buisson (2001) *Care of elderly people. UK market survey.* 14th Edition. London, Laing & Buisson

Laing & Buisson (2004) *Care of elderly people. UK market survey.* 17th Edition. London, Laing & Buisson

Lilford R, Jecock R, Shaw H, Chard J & Morrison B (1999) Commissioning health services research: an iterative method. *Journal of health services and research policy* 4(3): 164-169

Maryon K, Thomas K & Meehan H (2005) *Use of the Gold Standards framework in Care Homes. Report on the introduction of GSF in 12 care homes in the pilot phase.* GSF Team, No place.

May T (2001) *Social research. Issues, methods and process*, 3 edn. Buckingham, Open University Press

Munday D & Dale J. (2007) Palliative care in the community. *BMJ.334(7598):809-10.*

Murphy K. (2007) Nurses perceptions of quality and the factors that affect quality care for older people living in long-term care settings in Ireland. *Journal of Clinical Nursing* **16,** 873-884.

Netten A, Danton R & Curtis L (2002) *Self funded admissions to care homes.* London, Department of Work and Pensions

NHS (2006) NHS End of Life care programme. Progress report March 2006 www.endoflifecare.nhs.uk

NICE (2004) General palliative care services, including care of dying patients. In *Improving supportive and palliative care for adults with cancer* London, NICE pp 105-125.

Office of Fair Trading (2005) *Care homes of older people in the UK. A market survey.* OFT780, London, Office of Fair Trading

Patton M Q (1997) *Utilisation Focused Evaluation*, 3rd edn. London, Sage Publications,

Payne S, Seymour J & Ingleton C (2004) *Palliative Care Nursing*. Maidenhead, Open University Press

Redfern S., Hannan S., Norman I. & Martin F. (2002) Work satisfaction, stress, quality of care and morale of older people in a nursing home. *Health and Social Care in the Community* **10,** 512-517.

Robson C (1993) *Real world research. A resource for social scientists and practitioner-researchers.* Blackwell, Oxford.

Robson C (2002) *Real world research.*, 2nd edn. Blackwell, Oxford.

Rodriguez N.A., Sackley C.M. & Badger F.J. (2007) Exploring the facets of continence care: a continence survey of care homes for older people in Birmingham. *Journal of Clinical Nursing* **16,** 954-962.

Rooney P, Loughrey A, O'Leary M, Smyth B & Donaghy P (2005) Addressing disincentives to care home participation in research. *BMJ.* //bmj.bmjjournals.com/cgi/eletters/331/7527/1271-c

RCN (2005) The information needs of nurses. London: RCN

Seymour J, Witherspoon R, Gott M, Ross H, Payne S. & Owen T (2005) End-of-life. *Promoting comfort, choice and well-being for older people.* Bristol: Help the Aged & Policy Press.

Shipman Inquiry (2005) www.the-shipman-inquiry.org.uk/reports.asp last accessed 21-11-06

Sidell M, Katz JT & Komaromy C (1997) *Death and dying in residential and nursing homes for older people: Examining the case for palliative care.* Milton Keynes, Report for the Department of Health by the Open University

Thomas K (2003) *Caring for the dying at home.* Oxford, Radcliffe Medical Press

Thomas K (2002) *An evaluation of the introduction to primary health care teams of a managed framework of care for palliative care patients. The Gold Standards Framework.* MSc dissertation. Cardiff, University of Wales College of Medicine

Thomas K, Sawkins N & Meehan H (2006) *The Gold Standards Framework Phase 3 Good Practice Guide. A practical guide to improving end of life care in care homes*

using the Gold Standards Framework in care homes programme. Birmingham, GSF team.

Thomas K, Sawkins N, Meehan H, Griffin T & Newell C (2005) *The Gold Standards Framework Starter Pack for the Gold Standards Framework in care homes Phase 2.* Birmingham, GSF team.

Thomas K & Noble B (2007) *Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework. Palliative Medicine* 21:49-53

Waterman H, Marshall M, Noble J, Davies H, Walshe K, Sheaff R & Elwyn G (2007) The role of action research in the investigation and diffusion of innovations in health care: The PRIDE Project. *Qualitative health research* **17,** 373-381

Wagg A, Main S, Lowe D & Potter J (2005) *Report of the National Audit of Continence Care for Older People in England, Wales & Northern Ireland.* London: Clinical effectiveness & evaluation unit, Royal College of Physicians

West M.A & Markiewicz L. (2004) *Building Team-Based Working: A Practical Guide to Organizational Transformation.* Oxford, Blackwell Publishing Inc.

Appendix 1: Iterative commissioning - anticipated project outcomes identified by Macmillan

No	Indicators
1	**Measurable outcomes from the point of view of patients and carers.** The views of patients and carers as to desirable outcomes and the impact of the GSF should be sought. It is intuitively obvious that patients and carers would prioritise the avoidance of crises (the commissioner's priority) but it would be helpful to confirm this. **At the end of the project the commissioning group expects an understanding of those outcomes patients & carers consider desirable and the impact of the GSF on these**.
2	**Measures related to structure, culture, and organisation of the care home.** The literature reminds us of the variation across care homes e.g. whether or not the care home is personal care or personal plus nursing care (noting that a criterion for entry is 24 hour access to a nurse), attitude to learning and support, attitude of owner and manager, management culture (owner/manager, religious orientation or "franchised" chain) and there are a number of measurement tools available. **At the end of the project the commissioning group expects to have candidate items relating to structure, culture, processes and behaviours associated with direct or surrogate measures which can be linked to the uptake of the GSF & candidate processes and behaviours (again associated with measures) which change in ways that may be associated with benefits for patients and carers.**
3	**Characterisation of the client population**: It would be helpful for future studies to have an estimation of the number of events (e.g. crises and deaths) per unit of time (e.g. week/month/quarter) and descriptors of age & co-morbidities associated with the outcome measures chosen (e.g. crises) Brief literature review suggests an older and more disabled population than in the community, a third with cancer and at least a half with some dementia with around a half dying after general deterioration, a third after an unpredicted acute episode and less than 10% of one defined "terminal illness". **At the end of this phase of the research, the commissioning group expects to have a clear idea of the important characteristics of the client population in relation to key outcomes (e.g. crises) and the influence of the GSF.**
4	**Testing an A to D "banding" approach**. The pre-pilot proposed a "banding system" to characterise the client population with a phased introduction of the GSF, initially focussing on those nearest to death. In addition the surprise question: *"would you be surprised if this person died in days, weeks, months etc."* is used. **At the end of the pilot the commissioning group expects to understand if this form of banding was valid (i.e. to what extent was it possible to predict nearness to death) and how (if at all) did the use of "banding" facilitate the introduction of the GSF.**
5	**Measures related to differences in staff and skills mix**: The pilot supports the literature in identifying significant issues relating to staff and skill mix. Staff is heterogeneous in relation to training, with most hands on care by care assistants, up to 50% turnover, ranging from very experienced older workers to young women with less life experience and complicated family responsibilities. There appears to be a trend towards short-term posts for health professionals from abroad. There may be difficulties in finding time and/or funding for training with very light staffing levels and staff may not be able to access training pots from the NHS confederations as they are in the private sector. **At the end of the research the commissioning group expects to understand those aspects of staff and skill mix which need to be considered when evaluating the impact of the GSF and direct or surrogate measures of these for future studies.**

6	**Relationships with the primary health care team:** the pilot confirmed that care home managers have differing relationships with outside agents e.g. GPs, district nurses and community based specialist nurses. Responsibility can be poorly defined as care in care homes is not considered a core activity or an enhanced service. The PCT's attitude to commissioning care also varies. Similarly primary health care team (and thus the GSF facilitator) may know very little about the culture, financing and organisation of care homes, whereas the GP Facilitators and previous GSF Facilitators were familiar with practice culture. **At the end of the research the commissioning group expects to understand more about the relationship between care homes and primary health care teams (in particular GPs) and the GSF uptake.**
7	**The added value of resource material:** a number of educational resources have been tested in the care home setting. The pilot has used a modified starter pack but has not specifically looked at the added value of written or other educational resources. **At the end of the research the commissioning group expects to know more about the added value of the resources e.g. starter pack and/or Macmillan educational resource in relation to the success of changing behaviours or processes linked to the outcomes of interest (in addition to the role of facilitator behaviour and the use of an audit tool).**
8	**The role of the facilitator:** in the primary care setting the role of the facilitator and the changes in role in relation to others has been a key factor. There have been a number of experiments around facilitation for education related to palliative care – e.g. link nurses, Macmillan CNS and formal training schemes but none reported in relation to generalist primary care. **At the end of the project the commissioning group expects to understand more about the key elements of facilitator characteristics, context and behaviour, which influence the introduction of the GSF, in particular the role (if any) of primary care based facilitators.**

Gold Standards Framework Care Home Evaluation

Baseline Audit Questionnaire

<u>Instructions:</u>

Thank you for completing this baseline questionnaire which forms the basis of the evaluation described in the Information Sheet accompanying this form.

We estimate it will take about 20-25 minutes of your time

The questionnaire consists of a series of questions related to care in your Care Home and the Gold Standards Framework (GSF).The first section asks for specific detail about your Care home. We will be asking you to identify key contacts at the beginning of the project only. Thereafter your home will be allocated a code number, which will be used in any future audit.

In the remaining sections, most questions require a tick box response. Many require a simple 'yes' or 'no' answer. There is opportunity to indicate if the aspect of care is 'unrecorded'. A few questions require very short written answers only. There is opportunity for additional comment at the end.

Please note - there are no 'trick' questions. The purpose of asking these questions is to provide baseline data by which you and the GSF Team can audit the impact of the introduction of the GSF programme.

For further information, please refer to the information sheet accompanying this document.

Any enquires about this document can be directed to your local GSF facilitator.

Facilitator code [   ] Care Home code [   ]

Please complete the following sections:

The Organisational Structure

Name   of   Home:
……………………….………………………………………………..

Is the home:	Part of a group	[ ] Please tick as appropriate
	Single ownership	[ ]
	A Nursing Home	[ ]
	Dual registered	[ ]

Name of local Primary Care Trust:	
Name of Owner /Manager:	
Contact Tel No:	
Contact email.	
Name of Matron/Nurse manager	
Contact Tel No.	
Contact email.	
Name of Nominated Local Co-ordinator for GSF (this is commonly the Nurse Manager/Matron)	

Agreement between Care Home and Gold Standards Framework Development team

Owner/ Manager:

I have had the Gold Standards Framework explained to me by the facilitator and agree to introducing this service improvement and taking part in the Evaluation.

Name   (in   capitals)_____   Signed: _____

Position: _____Date: _____

Nurse Manager/Matron:

I have had the Gold Standards Framework explained to me by the facilitator and agree to introducing this service improvement and taking part in the Evaluation

Name   (in   capitals)_____   Signed: _____

Position: _____ Date: _____

Baseline Questionnaire completed by:

Name: …………………………………………………………………………………………………

Title : ………………………………………………………………………………………………

Date: …………………………………………………………

Glossary of Terms used	
Advanced Care planning	Plans are developed for End of Life care
Client	Person receiving care in care home (we recognise that you may use other terms such as patient, resident or user)
Crisis/unplanned event	Urgent request for help including out-of-hours e.g. supply of drugs.
Crisis/unplanned admission	Acute admission to hospital/hospice in an emergency
DS1500	Application form for attendance allowance for those with a life expectancy of 6 months or less.
End of Life Care	Care given to patients with chronic, progressive, eventually fatal illness. Embraces the concept of palliative care (see below) but includes all conditions that may lead to death
Family Carer	Main family carer / next of kin
GP	General Practitioner
Liverpool Care Pathway (LCP)	A tool used to help plan care at the very End of Life (the terminal phase)
Out -of -Hours provider	GP out of hours services
Palliative care	The active, total care of patients whose disease is not responsive to treatment, commonly associated with Cancer
Patient	Person receiving care in care home (we recognise that you may use other terms such as client, resident or user).
PHCT	Primary Health Care Team (includes GP, district nurses, practice nurse, reception staff, practice manager etc)
Preferred Place of Care	Place identified by people at the End of Life as being the place they would prefer to be cared for before they die
Preferred Place of Death	Place identified by people at the End of Life as being the place they would prefer to die
Resident	Person in care home (we recognise that you may use other terms such as client, user or patient)
Routinely	This implies that the aspect of care referred to forms part of standard or 'everyday' or 'normal' practice for this group of patients
Service user/ User	Person receiving care in care home (we recognise that you may use other terms such as client, patient or resident)
Staff Carer	Care Home staff
Specialist Palliative Care Services	May include a range of staff with identified experience in End of Life (palliative care) (e.g. Macmillan, Hospice at Home nurses/doctors, Community Palliative care nurses)
Unrecorded	No record kept of the exact number
'You'	Your Care Home team

What percentage of your patients have known problems with:

Known disease	% of cases
Multiple disease processes	
Multi-organ Failure	
Cardiac disease	
Respiratory disease	
Renal disease	
Stroke	

Dementia	
Cancer	
Other – please describe:	

The Care Home Context

The Staff

	Please give the number in Whole time Equivalents (WTE)
Number of Registered Nurses (including manager/nurse manager)	
Number of Enrolled Nurses	
Number of Qualified Care Assistants at: NVQ level 4	
NVQ level 3	
NVQ level 2	
Unqualified care assistants	
Does your home offer transition experience for nurses from overseas: (Sometimes called Adaptation nurses)	Yes [　]　　　　No [　　]
If yes, how many are currently in post?	
What is the average length of employment of these types of nurses in your home?	
Other care staff (please describe):	

Primary Care input

Please name the GP practices that have patients in your Care Home.	Number of GPs per practice (if known)	Is this practice using the GSF?
1.		Yes [　] No [　] Not known [　]
2		Yes [　] No [　] Not known [　]
3		Yes [　] No [　] Not known [　]
4		Yes [　] No [　] Not known [　]
5		Yes [　] No [　] Not known [　]
6		Yes [　] No [　] Not known [　]
7		Yes [　] No [　] Not known [　]
8		Yes [　] No [　] Not known [　]
9		Yes [　] No [　] Not known [　]
10		Yes [　] No [　] Not known [　]

(NB if more than 10 please append further details)

The patients

	Number
How many beds does your home have?	[　]
How many places are designated 'nursing' beds?	[　]
Number of female patients, over the age of 65 in nursing beds.	[　]
Number of male patients, over the age of 65 in nursing beds.	[　]

Average age of patients:	[ ]
What is the average length of stay?: Please tick.	
Less than 1 month	[ ]
1-6 months	[ ]
7-12 months	[ ]
13 months to 23 months	[ ]
2 years or more	[ ]

Does your home register patients who are identified for Terminal Care?	Yes [ ] No [ ]
If yes, for how many beds?	[ ]
What percentage of your patients do not speak English as their first language?	[%]

If known please note:

	Number	Unrecorded
How many patients have died in the last 6 months (i.e. between November 2004 and April 2005?)		

How many of these patients died:

	Number	Unrecorded
at your care home?		
in hospital?		
in a hospice?		
in another location?		

C1   COMMUNICATION

1.1 Do you have an up-to-date care register in which patients in   Yes [ ]   No [ ]
      need of
      End of Life care have been identified?

1.2   Do you have staff meetings   Yes [ ]   No [ ]
          if you do not have staff meetings please go to question 1.5

1.3   If yes, how often do you have staff meetings?

Daily	
Weekly	
Monthly	
Quarterly	
As required	

1.4 Do you discuss your patients' at this meeting?

Yes	No

If <u>yes</u> do you specifically discuss patients' End of Life needs at this meeting?

Yes	No

1.5 How do staff communicate and record patient care? Please indicate what they use:	**Yes**	**No**
White board		
Patient record		
Drugs Cards		

Other Tools (please describe: ………………………………………

Use of other support/specialist services:

1.6 How many patients have you referred to any specialist End of Life/ palliative care services <u>over the last six months</u>?

Unrecorded

1.7 Please indicate <u>Type of contact</u> with specialist services

Type of Specialist	Regular meetings	If yes, please specify frequency.
Macmillan nurse (may be also known as Hospice at Home, or Community Palliative Care Nurses)	Yes [ ] No [ ]	
Specialist Doctor from Hospice Palliative Care team	Yes [ ] No [ ]	
Any other palliative specialist (please specify)	Yes [ ] No [ ]	
District nurses	Yes [ ] No [ ]	
If other type of contact, please give details (e.g. visit on request, contact by phone)		

1.8: Any other comment on other services to support End of Life care:

C2   CO-ORDINATION

2.1 Do you have a Nominated Co-ordinator/Link person in the home who co-ordinates all the care for End of Life patients?

Yes	**No**

2.2   Who is s/he? (*please tick one*)

Manager (if different from nurse manager/matron)	
Matron/Nurse manager	
Qualified nurse	
Senior care assistant	

	Care assistant	
Other (Please specify)………………………………		

2.3 Do you routinely undertake **advanced care planning**[17] for patients needs at the end of life?

	Yes	**No**

If yes at what stage (eg at admission or later): ………………………..…………………………….

2.4 Do you routinely <u>discuss</u> advanced care planning with: patients and family carers?

	Yes	**No**

2.5 Do you routinely <u>record</u> advanced care planning with patients and family carers ?

	Yes	**No**

2.6 Do you routinely record the **preferred place of <u>care</u>** for patients?

	Yes	**No**

2.7 Do you routinely record the **preferred place of <u>death</u>** for patients?

	Yes	**No**

2.8 Do you routinely discuss possible transfer of patients to hospital in the event of deterioration of condition?

	Yes	**No**
With patient		
With GP		
With family carers		
With care home staff		

2.9 Where do you record the outcome of the discussion?

………………………………………………………………………………………………..

2.10 Do you routinely discuss plans for resuscitation in the event of cardiac arrest?

	Yes	**No**
With patient		
With GP		
With family carers		
With care home staff		

2.11 Where do you record the outcome of the discussion?

………………………………………………………………………………………………….

2.12 In the last 6 months: Please indicate for how many patients have you recorded their preferred place of death?

Recorded	
Unrecorded	

2.13 In the last 6 months how many patients have died at their preferred place?

Died at Preferred place of death	
Not Died at Preferred place of death	
Unrecorded	

2.14 In the last 6 months, of those who have NOT died at their preferred place was this because of: (Please tick as many as apply)

---

[17] See Glossary

	Yes	No
Family carer issues		
Staff Carer issues		
Symptom control issues		
Poor communication		
Lack of community services		
Other Crisis / emergency causing admission		

Other issues – please state:

C3   CONTROL OF SYMPTOMS

For your End of Life care patients:

	Yes	No
3.1 Do you use any form or tool for **physical assessment** e.g. pain chart/visual analogue scale/PACA		

3.2   If so, which one/s   ..……………………………………………………………..

……………………………………………………………………….

3.3 Do you routinely assess patients' p**hysical** needs?   Yes [   ]   No [   ]

3.4   Do you routinely assess patients' **psychological (emotional)** needs?   Yes [   ]   No [   ]

3.5 Do you routinely assess patients' **social** needs?   Yes [   ]   No [   ]

3.6   Do you routinely assess patients' **spiritual** needs?   Yes [   ]   No [   ]

3.7 Do you routinely assess any other needs/problems concern –
      If yes please note which: Yes [   ]   No [   ]

3.8   Where do you record the patients' needs assessed:

……

3.9   Do you have access to equipment, such as syringe drivers, to
       support care of dying people ?   Yes [   ]   No [   ]

3.10   Do you use this equipment on a regular basis?   Yes [   ]   No[   ]

3.11 Do you have a system to evaluate the impact of care given in
       response to identified needs?   Yes [   ]   No[   ]

    If yes please explain how:

3.12 Please indicate how you would rate your care home's ability to address patient needs in relation to each
     of the following categories:

	1 Very Poor	2 Poor	3 Average	4 Good	5 Very Good
Physical needs					
Psychological (emotional) needs					
Social needs					
Spiritual needs					
Other needs/problems concern – Please note which:					

C4   CONTINUITY

4.1   Do you routinely send a handover form to your out-of-hours provider for your dying patients?

Yes	No

    If yes, how many handover forms have been used for dying patients in the last 6 months?

	Unrecorded

4.2   Have you had any problems accessing any of the services below to support end of life care in the last 6 months?

	Yes	No
Daytime GP services		
Out of hours GP services		
Specialist (palliative care) nursing services		
Equipment		
District nursing service		
Other – please describe…………………………….		

4.3   Have you had any problems accessing specialist advice for dying patients out of
    hours in the last six months?

Yes	No

4.4   Have you had any problems accessing drugs to support for patients out of hours in the last six months?

Yes	No

Please   add   any   comment   you   have   on   GP   services:
………………………………………………………………………………………………
……….

………………………………………………………………………………………………
………

4.5   How **many crisis/unplanned events**[18] or interventions in the

	Unrecorded

---

[18] See Glossary

home
have you encountered in the last six months with your dying patients?

4.6 How many **crisis/unplanned admissions**[19] to hospital/hospice have
there been with dying patients?

	Unrecorded

C5   CONTINUING EDUCATION

5.1 Have staff in your care home had any opportunities to attend educational events in
    the home about End of Life care?

Yes	**No**

If yes please note the number of sessions in the last six months: …………………..

5.2 Are you using the Macmillan foundations in palliative care tool

Yes	**No**

5.3 Have staff in your care home had any opportunity to attend educational events on End of Life care in other organisations ? (e.g. NVQ; modules at university, conferences)

Yes	**No**

If yes, please list the programmes and numbers of staff accessing these in the last 6 months:
 …………….………………………………………………………………… (attended by   ---------
staff)

…………….…………………………………………………………………… .(attended by   ---------
staff)

…………….…………………………………………………………………… (attended by   ---------
staff)

5.4   Do you audit care as a means of enhancing staff learning about End of Life care patients?

Yes	**No**

5.5 Do you reflect on critical incidents to help staff learn about End of Life care?

Yes	**No**

If   yes,   how   do   you   do   this?
…………………………………………………………………………………
………
……..

5.6   Do you have access to information (books/other resources) for End
    of Life care in your care home?

Yes	**No**

If yes please indicate what:
………………………………………………………………………………..
………
………..

---

[19] See Glossary

C6   FAMILY/ CARER SUPPORT

6.1 Do you maintain a separate list of Family carers' contact details or a family carers' database in your home?   Yes [   ]   No[   ]

6.2 Do you offer specific leaflets/information to Family carers ? (e.g. Home pack/   Yes [   ]   No[   ]
Carer's pack, local details, Cancerlink/Cancerbackup/Macmillan leaflets etc)

 If yes please state which you use:

6.3   Do you routinely give Family carers information on what to do after a death?   Yes [   ]   No[   ]

6.4   Main Family carer's <u>practical</u> needs e.g. transport/communication, do you routinely:

	Yes	No
Assess		
Record and address these		

6.5 Main Family carer's psychosocial (social, emotional, spiritual/religious) needs, do you routinely:

	Yes	No
Assess		
Record and Address these		

6.6 Do you routinely give carers information of what is available from the statutory services/Social Services e.g. relating to the National Carer's Strategy in England?

Yes	No

6.7   Do you have protocol for the bereaved in your care home?
   If yes - Do you use it?

Yes	No

6.8: Please tick your response to the following questions

	1 Very Poor	2 Poor	3 Average	4 Good	5 Very Good
a) In relation to End of Life care: How would you rate the current quality of support offered to Family carers in your care home?					
b) In relation to End of Life care: How would you rate the current quality of the support offered to your staff in your care home?					
c) In relation to End of Life care: How would you rate the current quality of teamwork in your care home?					

C7　CARE OF DYING PATIENTS

		Yes	No
7.1	Do you use an agreed protocol for care of patients at the last days of life?		
7.2	Do you follow a Care Pathway? (e.g. such as the Liverpool integrated Care Pathway?)		
7.3	Do you have a procedure to make available and authorise the use of anticipatory medication in the home for the dying patient?		
7.4	Do you routinely assess and discontinue inappropriate medication in the last days of illness?		
7.5	Do you usually inform carers/family when the patient is entering the dying phase, when appropriate?		

8.　OTHER ISSUES

Please tick your response to the following questions:	1 Very Poor	2 Poor	3 Average	4 Good	5 Very Good
8.1 How would you rate the current quality of End of Life (palliative) care for your patients in your care home?					
8.2 How would you rate the level of confidence, within your care home, in dealing with patients with End of Life (palliative) care needs?					
8.3 How would you rate the level of co-working with End of Life (palliative) care specialists currently in your care home?					

8.4 Why have you decided to take part in the GSF in Care Homes Pilot?

8.5 In what ways do you hope your Care Home will benefit from taking part in the GSF?

8.6 If there was one thing you could do in your care home to improve the care for End of Life patients – what would it be?

8.7 If there was one thing you could do in your home to make things better for staff caring for End of Life
      patients what would it be?

8.8 Any particular ideas/suggestions that have worked well for you as a care home team in relation
      to End of Life care?

8.9 Do you have any further comments or suggestions about the implementation of the GSF?

8.10   To help inform future work please indicate how you usually describe the older people
        whom you care for in your home

        Client   [   ]
        Resident   [   ]
        Patient   [   ]
        Service user   [   ]
        User   [   ]
        Other (please specify) ………………………………………………………..

Thank you very much for your help.

If you have any questions about the GSF please contact your Facilitator.

Please return this form to your facilitator.

Appendix 3: After Death Analysis (ADA) Form

Please complete for last 5 residents from your Care Home who have died. Please note the following;
For Place of death use: CH = Care Home, H =Hospital, Ho =Hospice, O =Other
* On a scale of 1 to 5 where 1 = Very poor care, 2 = Poor care, 3 = Average, 4 = Good care, 5 = Excellent care
Date= date of death.

	Main Diagnosis	Secondary diagnosis	Cause of Death	Place of Death	Length of Stay in Care Home	Hospital stay in last 6 months of life.If none use 'O'	No. Crisis **Events** in last 6 months of life If none use 'O'	No. crisis **admissions** to hospital (if any) in last 6 months of life	Advanced Care Plan in place	PRN drugs listed	Last days of Life Pathway used	Written Information given to family	Quality of Care provided *	Comments-Summary of main or significant aspects.
Example	CVA	Dementia	CVA	CH	3 months	10 days	2	1	Y (Yes)	Y	N (No)	N	3	Distressing crisis admission. Family upset. Good relationship with staff.
Patient 1 Date:														
Patient 2 Date:														
Patient 3 Date:														
Patient 4 Date:														
Patient 5 Date:														

Appendix 4: Facilitator baseline survey

Facilitator baseline survey

Please list the expectations you have about the introduction of the GSF into Care /Homes (up to 6 key points):

-
-
-
-
-
-

Please list any potential concerns you have about the introduction of the GSF into Care /Homes (up to 6 key points):

-
-
-
-
-
-

We would like to know how you got involved in the GSFCH project. Please can you indicate whether you:

Personally chose to participate: Yes [ ] No [   ]
Were nominated: Yes [ ] No [   ]
(If nominated please indicated the role/title of the person who nominated you)

……………………………………………………………………………………………
……..

Other: Please explain:
……………………………………………………………………………………………
………

Any other comments in relation to GSFCH (Continue overleaf if you wish):

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Gold Standards Framework in Care Homes (GSFCH) Evaluation

Interview Guide for managers/coordinators

1. Introductory Context

    ▪ Nature of the home
        • Purpose built or modified

    ▪ Staffing issues – skill mix etc
        • How was GSF was introduced to staff?

    ▪ Client issues – number and nature
        • How was GSF was introduced to residents and family?

    • Is the manager the GSF coordinator?

    • Has the GSF lead any specialist interest/training in EoL/ Palliative care.

    • Type of support from Palliative care locally?

2. Extent of use of GSFCH

    ▪ Staged introduction -
    ▪ Overall model of facilitation
    ▪ Mode of input by facilitator (face to face, email)
    ▪ Type of input (group or individual training, responding to queries…..)
    ▪ Context: other factors that may impact
    ▪ Evaluation within the home

3. Positive factors in use of GSF in Care Home

4. Negative experiences in use of GSF in Care Home

5. Views on the 7 'C's – focus on each aspect:

    1. Communication
    2. Co-ordination
    3. Control of symptoms
    4. Continuity

5. Continuing education
6. Carer (family) support
7. Care of the dying

6. Would you suggest any improvements to any aspect of the GSFCH which may aid its implementation in the future?

Interviewee profile:

Role /grade:………

Qualifications:

Length of experience in care home sector:…………..

Any additional reflections?

Any questions?

Consent

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Gold Standards Framework in Care Homes (GSFCH) Evaluation

Interview Guide for care home staff

1. Context to include perceptions of:
   - Nature of the home – management style
   - Staffing issues
   - Client type

2. Use of GSFCH in the home
   - Frequency of use
   - Preparation for using the tool -
   - Model of facilitation
   - Context: factors that may impact:

3. Positive factors of using GSF

4. Negative experiences of using GSF

5. Any suggestions of 'best ways' to use GSF

6. Views on the 7 'C' of the GSF – focus on impact of using tool in each aspect as follows:

   a. Communication
   b. Co-ordination
   c. Control of symptoms
   d. Continuity
   e. Continuing education
   f. Carer (family) support
   g. Care of the dying

7. Additional personal commentary – any other thoughts

Interviewee profile:

Role /grade:………
Qualifications:
Length of experience in care home:…………..

Any additional reflections?

Appendix 7: Interview guide for residents

Gold Standards Framework in Care Homes (GSFCH) Evaluation

Interview Guide for residents

Introduction
Clarify purpose of interview and consent, any questions?

Context
Length of time in this or previous care home

Care assessed
Has anyone asked what sort of care you would like if you
became poorly/more poorly?

If No, and no clear recollection, talk generally and draw interview to close

If Yes
- What did you think about what you were asked?
- What did you think about how you were asked?
- Do you understand the options open to you?
- Was there anything else you would have liked to have been asked?
  - If yes, what was this?

- Closing comments- is there anything you would like to ask me or to mention which you feel has not been covered?

Resident profile
Gender
Age range
Known conditions – if disclosed

Any additional reflections?
Any questions?
Consent

Post interview- letter of thanks

Appendix 8: Table 9 - Pre and post test ADA analysis. Alternative format

No.	Care item	Response		Test result
		Pre ADA n= (%)	**Post ADA n= (%)**	

1	Place of death
	    Care home
	    Hospital
	    Other
	    Total
	    Missing
		
		178 (80.9)
		40 (18.2)
		2 (1)
		220
		
			192 (88.5)
			23 (10.6)
			2 (1)
			217
			2
				Z -4.358
				P .000*

	Residents who died in the care home:	**Median (min, max)**	**Median (min, max)**	
2	**Advanced care plan in place:** Median % score for homes Min-max SD	 20 (0-100) 42.92	 67 (0-100) 34.32	Z –5.30 P .001*
3	**PRN drugs listed:** Median % score for homes Min-max SD	 60 (0-100) 38.11	 60 (0-100) 36.57	Z –2.543 P .011*
4	**Last days of life care pathway:** Median % score for homes Min-max SD	 0 (0-100) 32	 50 (0-100) 40.03	Z –7.119 P .001*
5	**Written information to family:** Median % score for homes Min-max SD	 0 (0-100) 36.86	 60 (0-100) 43.45	Z –10.355 P .001*
	All resident deaths:	**n=220**	**n=219**	

6	Number of crisis events
	    None
	    One or more
	    Missing
		
		94 (51.9)
		87 (48.0)
		39
			
			126 (61.2)
			80 (38.8)
			13
				Z –2.137
				P .033*

7	Number of crisis admissions
	    None
	    One or more
	    Missing
		
		110 (62.1)
		67 (37.8)
		43
			
			151 (73.7)
			54 (26.3)
			14
				Z –3.354
				P .001*

Appendix 9: Dissemination of findings from the Evaluation of the GSFCH Phase 2 programme

In addition to dissemination listed below, a programme of papers is in progress.

Thomas K, Meehan H, Shaw K, Clifford C, Parry M & Badger F (2007) *Web based After Death Analysis (ADA) tool for supporting end of life care in primary care.* 10th Congress of the European Association for Palliative Care 7-9th June, Budapest. Poster presentation

Shaw K, Thomas K, Clifford C & Badger F (2007) *The Gold Standards Framework. Improving the quality of end of life care in UK primary health care teams.* 10th Congress of the European Association for Palliative Care 7-9th June, Budapest. Poster presentation

Thomas K, Clifford C, Badger F, Hewison A & Shaw K (2007) *Analysing End of Life Care in care homes: After Death Analysis Tool.* European Association for Palliative Care. 6-9th June, Budapest Oral presentation

Badger F, Clifford C, Thomas K, Plumridge G, Hewison A & Shaw K (2007) *Improving End of Life Care in Care Homes. An evaluation.* 10th Congress of the European Association for Palliative Care. 6-9th June, Budapest. Oral presentation

Clifford C & Badger F (2007) *Analysing end of life care in Care Homes: After Death Analysis tool.* RCN International Nursing Research Conference. Dundee, 1-4th May Oral presentation

Clifford C, Badger F, Plumridge G, Hewison A & Thomas K (2006) *Using the Gold Standards framework in care Homes. An evaluation of Phase 2 June 2005-June 2006.* Overview report for Macmillan. Birmingham, School of Health Sciences, University of Birmingham

Clifford C & Badger F (2006) *Gold Standards Framework – an overview of the research in care homes.* CSCI seminar 'Research into practice-using research to improve care for service users in care homes. Taunton, 18 October, Oral presentation

Thomas K, Sawkins N, Clifford C, & Badger F (2006) *Improving end of life care in nursing homes in England using the Gold Standards framework in Care Homes programme.* 16th International Congress on care of the terminally ill. Montreal, Canada. September 2006 Poster presentation

Clifford C, Badger F, Hewison A & Thomas K (2006) *Improving End of Life Care: An Evaluation in Care Homes.* The 6th Palliative Care Congress, University of Sheffield, UK. April 5-7. Poster presentation.

Clifford C, Badger F, Hewison A & Thomas K (2006) *Analysing End of Life care in care homes. A new tool for after death analysis.* The 6t[h] Palliative Care Congress, University of Sheffield, UK. April 5-7. Poster presentation.