

Evaluation of end of life care initiatives in care homes on the Fylde Coast

Project report for
North Lancashire Primary Care Trust

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Contents

	Page
Executive Summary	3
1. Introduction	4
2. Background	4
3. Aims of the evaluation	6
4. Methods	6
5. Findings	8
6. Discussion	18
7. Conclusion	19
8. References	21
Appendices:	23 - 26
Appendix A: Study flow chart	23
Appendix B: Questionnaire	24
List of tables:	
Table 1: Use of end of life care tools	9
Table 2: Summary of length of time tools in use	10
Table 3: Types of available training	11
Table 4: Place of death	11
Table 5: Benefits and challenges of using the tools	12
Table 6: Characteristics of focus group participants	16

Executive summary

This report details a study that was commissioned by North Lancashire Primary Care Trust to evaluate end of life care in care homes on the Fylde Coast. The evaluation was undertaken by the International Observatory on End of Life Care at Lancaster University, and focused on recent end of life care initiatives, in particular the three end of life care tools – the Gold Standards Framework (GSF), the Liverpool Care Pathway (LCP) and the Preferred Priorities for Care (PPC) – and their implementation and use in care homes.

Methods

The evaluation used mixed methods and consisted of three strands: a postal questionnaire completed by seventeen care home managers; individual telephone interviews with four care home managers; and two focus groups with a variety of care home staff (one in a care home using all three tools and one in a care home using none of the tools).

Key findings

Key findings from the evaluation can be summarised as follows:

- There is strong commitment within the care home sector to improving end of life care for residents, and increasing choice and participation in decision making.
- The experience of using the end of life care tools has been predominantly positive, with both process and outcome benefits identified.
- The support and training provided by the PCT End of Life Care Facilitator is highly valued by care home staff.
- There remain some challenges, particularly in relation to communication, cross-boundary working and relationships between care homes and primary care professionals.
- Where strong working relationships exist between care home staff and primary care staff, end of life care can be successfully provided even without the use of the end of life care tools.

Recommendations

The report makes the following recommendations:

- Relationships between care homes and primary care are critical to the success or failure of end of life care in care homes, and therefore need to be developed and sustained.
- The end of life care tools can help to enhance communication between care homes and primary care.
- Initiatives that address end of life care provision in care homes need to encompass wider health and social care systems.
- Further research is needed to increase understanding of how end of life care is provided in care homes not using the tools, and to develop objective measures of the quality of end of life care provision in care homes.

Evaluation of end of life care initiatives in care homes on the Fylde Coast

1. Introduction

In November 2008 the International Observatory on End of Life Care at Lancaster University was commissioned by North Lancashire Primary Care Trust (PCT) to undertake a short evaluation of end of life care initiatives that have been undertaken in care homes on the Fylde Coast. This report details the background, methods and findings of this evaluation, and concludes with some recommendations for both practice and research in this area.

2. Background

Recent government initiatives have used a range of health and social care interventions to promote older people's ability to stay in their own homes, even with increased frailty and disability [1]. However, for some older people a move into a communal supported setting does occur. Two different settings of care exist for older people no longer able to remain in their own homes: nursing homes, which provide on-site nursing care (medical care is provided by primary care services); and residential homes, which provide on-site personal care (both nursing and medical care are provided by primary care services).

In the UK there are an estimated 15,700 care homes providing nursing care and/or personal care to more than 400,000 older people with a range of different needs [2]. Residential homes greatly outnumber nursing homes. For example, in England in 2001 there were 21,800 residential homes, 2,940 nursing homes and a further 2,940 care homes that had dual registration (personal care and nursing) [3]. Across the whole of Lancashire there are 308 care homes for older people (213 residential homes and 95 nursing homes), of which over a hundred lie within the area covered by North Lancashire PCT (76 residential homes and 36 nursing homes), and a further 49 within Blackpool PCT (40 residential and 9 nursing homes) [4].

The context within which older people reside in care homes is complex. Care home organisations operate with different models of care and support, are located in a mixed care economy and engage with diverse populations [5]. The services they provide encompass health and/or personal care, and are shaped by structural elements such as size of the home and the nature of, and access to, internal and external health and social care staff. In order to provide high quality care and support to individuals residing in care homes, such organisations need to be able to draw upon a wide range of resources. The most important resource available to a care home is its staff. Historically, there have been ongoing difficulties in recruitment and retention of staff [6] and much care is provided by untrained care workers. In the UK, a high proportion of the workforce are non-nationals, which raises challenges with respect to communication skills and mutual cultural awareness [7]. There are also known difficulties in care home staff accessing education in a range of areas [8].

Care homes also have varied relationships with wider health care providers. The differentiation between care homes (nursing) and care homes (personal care) can create confusion (especially as some are dual registered). Whilst nursing homes can provide general nursing care with their on-site nurses, access to specialist nursing services is not always straightforward. This may be because specialist nurses (such as specialist palliative care nurses [9]) are not always clear about their remit in such settings. This may reflect workload pressures or contractual issues relating to the location of care homes predominantly within the independent sector.

All care homes rely on external services for medical advice and support. Currently, in the UK, all residents of care homes are entitled to receive free individual direct patient services from a General Practitioner (GP). However, medical services beyond this to the care home, such as proactive screening or medications management can be charged for. In such situations, GPs may receive a retainer payment from the care home, or may establish what are termed Personal Medical Services through a private contract. Concerns have been raised that older people residing in care homes receive an inequitable service [10].

Approximately 4% of people aged 65 and over in England reside in a care home [11]. The majority of residents live with progressive chronic illnesses that have resulted in disability and a loss of function [12]. As life expectancy is generally limited once people move into a care home [13], care homes for older adults are therefore an increasingly important site of end of life care delivery; in England and Wales approximately 21% of people over the age of 65 die in care homes [14]. A number of end of life care challenges common to both nursing and residential care homes have been identified. These include staff preparedness, relationships with wider health and social care services, commissioning and funding processes [10, 15, 16].

The recent End of Life Care Strategy for England [14] aims to promote the delivery of high quality services in all locations and pays specific attention to care homes. A range of developments has been undertaken in the United Kingdom (UK) to support the provision of high quality end of life care in care homes. These include outreach work from Clinical Nurse Specialists, the use of 'hospice beds' in nursing homes, end of life care education for care home staff and the development of link nurse schemes [17, 18].

A number of national initiatives have been endorsed to support the provision of end of life care across all care settings, and within the End of Life Care Strategy [14] three end of life care tools are being promoted. These are: the Gold Standards Framework (GSF), a tool which was developed for use in primary care and has now been adapted for care homes; the Liverpool Care Pathway (LCP) for the dying, which is used in the last few days of life; and Preferred Priorities for Care (PPC), a person-centred advance care plan. In January 2008 it was estimated that 7.6% of English care homes had implemented one or more of these tools [14]. Evidence for the impact of these three specific end of life tools in care homes, however, is limited and on a small scale [19 – 23]. There is therefore a need to undertake further evaluation work regarding the use of tools in this setting.

3. Aims of the evaluation

The evaluation had three aims:

- To evaluate the initial work undertaken to introduce at least one of the three end of life care tools into care homes in the Fylde Coast area.
- To scope the evidence base on the process of undertaking this implementation work and the impact it has had on care in care homes as reported by care home staff and managers and other stakeholders.
- To summarise this initial activity to include models of service delivery, opportunities, challenges and barriers to different models of end of life care (and use of end of life care tools) and a scoping of the published research evidence, with recommendations to inform the design of a subsequent detailed research proposal to evaluate the extension of these initiatives into the wider North Lancashire area.

The care homes that took part in the evaluation were mainly nursing homes, although a small number of residential care homes also participated. All of the care homes are located on the Fylde Coast of North Lancashire, and lie within either North Lancashire PCT or Blackpool PCT.

4. Methods

The study design consisted of three strands which used different methods; this was done to maximise the amount and variety of data that could be collected in a relatively short period of time. The design of the study is captured in the flow chart (Appendix A).

Ethical approval

A full proposal for the study was developed and submitted to the Ethics Committee in the Division of Health Research at Lancaster University. A researcher attended the meeting of the Ethics Committee and answered questions about the study. Minor amendments were required by the Committee; these were made and ethical approval was granted.

Data collection

Different methods of data collection were employed in each of the three strands of the study; a questionnaire was used in Strand 1, individual interviews in Strand 2, and focus group interviews in Strand 3.

Strand 1: Questionnaire

The questionnaire was developed by the research team with input from both the End of Life Care Commissioning Manager and the End of Life Care Facilitator from North Lancashire PCT. A meeting was held with these two key stakeholders to ascertain what questions they would like answered through the evaluation. A draft questionnaire was then approved by all parties and piloted.

Piloting the questionnaire

The questionnaire was piloted in order to determine how long it took to complete, whether all the questions were understandable, and whether the questions were considered to be

appropriate. In order to pilot the questionnaire in care homes that would not be involved in the evaluation, a researcher approached the Lead for End of Life Care in Care Homes in Greater Manchester at NHS North West. She was asked to identify three care homes within Greater Manchester where one or more of the end of life care tools were known to be in use. These three care homes were then contacted and sent the draft questionnaire, together with a feedback form and a return envelope. In the event, only one feedback form was returned to the research team; however, this provided very positive feedback about the questionnaire so no amendments were made.

The questionnaire

The final questionnaire consisted of 10 items, including questions about which tools were in use, whether any of the tools had been used but discontinued, the benefits and challenges of using the tools, the numbers of staff employed in the care home, staff training around end of life care, resident deaths, the number of GPs working with the care home, and demographic information about the manager completing the form (see Appendix B). The questionnaire also provided space for additional comments.

The questionnaire was sent to 30 care home managers on the Fylde Coast in late December 2008. Contact details of the managers were provided by the End of Life Care Facilitator for North Lancashire PCT. Each care home manager was sent a pack which contained an invitation letter which explained the study, the questionnaire and a contact form. Two prepaid returned envelopes were also included in the pack, so that the questionnaire and contact form could be returned separately; this was done in order to ensure anonymity of the respondents.

Further efforts were made to ensure that as many people as possible took part in the study. In early January, a researcher attended a meeting of Fylde Coast Care Home Managers to present the study and encourage people to complete and return the questionnaire. Three people present at that meeting had not received the questionnaire so were provided with a pack. In late January the original 30 care home managers were contacted by telephone to remind them again about the questionnaire, and encourage them to return it if they had not already done so. A further 11 questionnaires were re-sent by post or email to those who said they had either not received it or had lost it.

Strand 2: Interviews

A contact form was included in the questionnaire packs and respondents were asked to complete and return it if they were willing to take part in an interview. Seven care home managers returned the contact form; six of these were sent packs inviting them to take part in an interview. The interview packs consisted of an invitation letter, an information sheet explaining the study in detail, a consent form and a prepaid return envelope. Managers were asked to read the information sheet and then complete and return the consent form if they were still willing to take part in an interview. Participants were given the choice of whether to be interviewed by telephone or face-to-face.

Three of the six managers returned consent forms in the first instance, and another one after a reminder was sent. They were all contacted by the researcher to arrange a convenient date and time for the interview to take place. All opted for telephone interviews,

and these took place in January and February. The other two managers, who had returned forms expressing an interest in taking part in an interview but had not yet returned consent forms, were contacted by phone and reminded about the study. One expressed uncertainty about taking part, and the other indicated a willingness to take part but still did not return a consent form, so no further contact was made. The final interview sample therefore consisted of four care home managers.

Semi-structured interviews were conducted with the managers. Areas for discussion included how the respondents first heard about the tools; which tools they chose to use and why; their experience of implementing the tools; barriers or challenges to using the tools; staff training needs; sustainability of the tools; cross-boundary working and the impact of the tools on staff confidence.

Strand 3: Focus group interviews

Two focus group interviews were conducted, one in a care home where all three end of life tools were in use, and the other in a care home that was not using any of the tools. The first home was approached after the manager returned a contact form volunteering to take part in an interview. Contact with the second home was made after the researcher was introduced to the manager at the Fylde Coast Care Home Managers meeting she attended.

The focus group discussions followed a similar schedule to that used in the individual manager interviews. In both cases, the discussion began with the participants being asked to reflect on the last death that had occurred in the care home and describe some of the circumstances around it. A range of issues relating to end of life care in the care home were then considered.

Data analysis

Numerical data from the returned questionnaires were entered into the Statistical Package for Social Sciences (SPSS 15.0 for Windows) and a descriptive statistical analysis was undertaken. Data from the open questions about the benefits and challenges of using the tools were analysed qualitatively using open coding. Interview data from both the individual interviews and the focus group interviews were transcribed and analysed thematically using Atlas.ti computer software to manage the data.

5. Findings

The findings from each of the three strands of the evaluation will be presented in turn in this section; a discussion about the findings as a whole is presented in the following section.

Strand 1: Questionnaire

A total of 33 questionnaires were distributed, and 17 were completed and returned, giving a response rate of 52%. Of these, 14 were from nursing homes and 2 from residential care homes (one was not specified).

Profile of sample

Fourteen (82%) of the care home managers who completed the questionnaire were female and two (12%) were male (one respondent did not complete this question). The ethnic origin of 16 of the respondents was White British (again one did not complete this question), and the average age (from 15 respondents) was 51.5 years (range 36 – 64). The average length of time in post was 5.4 years (range 2 months – 16 years).

Use of tools

The following table shows how long each of the end of life care tools had been used in the care homes. Respondents were also asked whether they had started using any of the tools and then discontinued their use; all 17 replied ‘no’ to this question, indicating that all the tools that had been initiated were still in use.

Table 1: Use of end of life care tools

Care Home	GSF	Number completed	PPC	Number completed	LCP	Number completed
1	Just started	0	18 months	6	18 months	5
2			8 months	Not stated	Not yet used	0
3			3 months	1	2 months	1
4	9 months	all	9 months	all	4 years	4
5	3 months	50	1 year	50	1 year	6
6			6 months	10	6 months	2
7			6 months	4		
8			6 months	All		
9	3 months	2	3 months	all	3 months	1
10			6 months	1		
11	2 years	60	2 years	60	2 years	13
12	Just started	0	4 months	Not stated	7 months	Not stated
13			1 year	14		
14	Just started	0	Just started	0		
15			Not yet started	0		
16			Not stated	7	Not stated	2
17			Not yet started	0		

It is important to clarify how the term “in use” is defined in relation to the end of life care tools in this study. Each of the tools requires a degree of training before it can actually be initiated for a specific care home resident. For this reason, in five instances in this study training had been provided so the tool in question was available for use; however, at the

time of data collection it had not actually been used. Table 2 provides a summary of how long each of the tools had been in use, and demonstrates that in most cases the tools are relatively new to the care homes; only one of the homes had been using any of the tools for more than two years.

Table 2: Summary of length of time tools in use (N = 17)

Length of time used	GSF	PPC	LCP
Training provided but tool not yet used	3	1	1
Less than 3 months			1
3 – 6 months	2	7	2
7 – 12 months	1	4	2
13 months – 2 years	1	2	2
More than 2 years			1
Tool in use but time not stated		1	1
Total number of homes introducing or using tools	7	15	10

Analysis of the data also revealed how many of the three tools were in use in the care homes in this study. Only a third of the care homes (six) were using all three end of life care tools. Reasons for the selection of tools were explored in the interviews with care home managers and will be discussed below.

Staff

Managers were asked how many staff they employed (both qualified nurses and care workers). One did not complete this question; the remaining 16 employed a total of 313 care workers (an average of over 19 per home). The fourteen nursing homes in the sample also employed a total of 120 qualified nurses (average 9 per home). Although managers were also asked about the number of whole time equivalent staff they employed, only just over half of them (9) provided this information, so its value is limited. The number of residents per home was not sought in the questionnaire, so it was not possible to calculate staff: resident ratios.

Training

Data were collected about the availability in the care home of different types of training related to end of life. The focus of training concerned the end of life care tools, communication skills, syringe drivers, symptom control and spirituality. Table 3 shows the numbers and percentages of care homes where each type of training was available.

Table 3: Types of available training

Type of training	Number of care homes where training available (N=16)	% of care homes where training available
End of life care tools	15	94
Communication skills	11	69
Symptom control	11	69
Syringe drivers	14	88
Spirituality	8	50

Respondents were also asked to specify any other training that was available to staff. Only two responses were received to this question; in one home a Level 3 National Vocational Qualification (NVQ) in palliative care was available, and in the other training about bereavement.

As well as the availability of training, the questionnaire also sought to discover how many care home staff had accessed training and how many still required training. The data provided in response to these questions, however, were difficult to interpret. Some respondents for example simply stated that “all” staff had received training, or that “50%” of staff still required training, but how many members of staff this actually referred to, and whether it meant qualified nurses or care workers, was unclear.

Place of death

Respondents reported a total of 133 deaths of care home residents during the year 2008 (N=16). The annual average number of deaths per care home was 8, and ranged from 0 to 22. Table 4 shows the place of death of these 133 care home residents, and demonstrates that over half of them died in a care home setting.

Table 4: Place of death

	Number of deaths	Percentage
Care home	77	58
Hospital	56	42
Hospice	0	0
Other	0	0
Total	133	100

GP practices and GPs

Respondents were asked how many GP practices they worked with, and how many individual GPs. The number of GP practices per care home ranged from 1 to 13, and across all 17 care homes totalled 81 (an average of almost 5 practices per care home). The number of individual GPs working with each care home ranged from 1 to 22, and totalled 185 (an average of almost 11 GPs per home).

Benefits and challenges of using end of life care tools

Respondents were asked to list the three most significant benefits and the three most significant challenges or difficulties they had experienced in using the end of life care tools.

A total of 35 benefits and 29 challenges were stated. Open coding of these data revealed two broad types of benefits (process benefits and outcomes benefits), and five categories of challenges. Table 5 summarises these findings and provides examples from the data to illustrate the codes.

Table 5: Benefits and challenges of using the tools

	Categories	Codes	Examples
BENEFITS	Process Benefits	Knowing what to do	"All staff aware of resident and family's wishes"
		Planning what to do	"Planning and preparation for dignity and peaceful death"
		Implementing tools	"We have found the PPC useful"
	Outcome benefits	Continuity of care	"Clients with those they know at the end of life"
		Place of care/death	"Prevent unnecessary hospital admissions"
		Changes in service provision	"All required drugs prescribed in advance"
		Staff achievement	"Giving staff confidence and authority to provide continuing care"
CHALLENGES	Use of tools	Paperwork/ documentation	"Having to evidence in a portfolio things that we automatically do"
		Time consuming	"Being able to sit and spend time to complete the tools"
	Changing practice	Need for further training	"Unable to have Verification of Death practical skills certified"
		Bringing about change in practice	"Getting all staff to adopt!"
	Communication	Difficulty of topic	"Talking about end of life care and death"
		Residents with confusion/dementia	"Communication to confused elderly residents"
	Working with Primary Care	GPs and District Nurses	"Encouraging GPs to come on board initially and gaining their respect and trust"
	Managing change	Sudden changes	"Sudden deterioration means not always able to use LCP"
		Prognostication	"When to recognise when to use the Liverpool Care Pathway"

Respondents were also invited to make open comments at the end of the questionnaire, although only seven comments were received.

Strand 2: individual interviews

Four care home managers took part in individual telephone interviews in the second strand of the evaluation. Three of the interviewees were female and one was male, and all described their ethnic origin as White British. Their ages ranged from 36 to 58 (average age 46), and the length of time they had been in their current post ranged from 1 to 15 years (average 6.5 years). Three were from nursing homes and one from a residential care home. Eighty-six codes were created through the analysis, which through an iterative process were eventually grouped into three major themes: using the tools, making choices and cross-boundary working.

Using the tools

The largest theme that emerged from the analysis concerned the use of the end of life care tools. The respondents were asked which tools they had chosen to use and why, and then their experiences of implementing their chosen tools were discussed. For one manager the decisions had been very deliberate:

Preferred Priorities of Care we chose to use because we wanted to identify what the wishes of our clients were, and know what they would like to prioritise in the care, where they would like to be and what their thoughts were on acute treatments and resuscitation [...] We use the Liverpool Pathway because we like the idea of assessing the residents every four to six hours, and we like the prompts – so you're not just looking at the patient with no prompts, it helps the nurses identify the things that could be coming and help to think it through.

[Manager 1]

For other managers the choice was more opportunistic and was based on what was available and practical at the time; one manager for example wanted to implement the GSF but had been unable to do so because of funding issues. All four homes had adopted PPC; this was seen as the easiest tool to implement in terms of time and training, because unlike the other tools it did not require an audit or any other special preparation.

However, the issue of difficult communications was highlighted, particularly in relation to PPC, when respondents discussed their experiences of implementing the tools. One manager felt that the challenge of PPC lay in “approaching the subject of death and dying with residents and relatives”, whilst another felt that it had to be introduced very carefully to avoid misunderstandings about it. The timing of introducing the tools, particularly the PPC and LCP, was also thought to require careful consideration.

Care home staff clearly have a crucial role in relation to end of life care, and the success or otherwise of the tools depends heavily on their willingness to undertake training and engage with the processes of implementation. The data also revealed a need for all staff, including ancillary staff, to be involved in using the tools, as exemplified in the following extract:

I haven't got a huge staff turnover here, but there's new staff coming on board all the time and therefore they've all got to be a part of it. The trained nurses tend to be pretty steady here, we haven't had anybody new for a couple of years,

but the care staff you've always got one or two that sort of move round and it's really important that everybody is part of it. I would include the ancillary staff in that because so often a resident will talk to a cleaner while she's cleaning his room, so everybody's got to be on board really. [Manager 2]

Not only do all staff need to be included in implementing the end of life care tools, but they also have training needs, and this was another very important issue that emerged from the interviews. Whilst the managers were all very committed to providing training for their staff, there appeared to be varied levels of need for training across the different care homes. For example, one manager felt that all her staff had needed communication skills training in order to implement PPC, whereas another reported that this was not required because the members of staff undertaking this role were all qualified nurses and had received communication skills training in their basic training.

All the care homes had been offered training by the PCT End of Life Care Facilitator, which they very much valued, and some had sought additional training resources. One reported having problems finding training for her staff, whilst another had developed her own training programme and was in the process of helping all staff to undertake it.

Closely related to the issue of training was that of support for staff, and again the support provided by the PCT End of Life Care Facilitator was highly valued by the managers. One viewed her as a "trouble-shooter" who could be called upon at any time to help with difficult issues. There was also evidence that staff supported each other within the homes, and worked very much as a team.

Making choices

This second theme concerns the ways in which residents and families are engaged in the process of making choices about care. The managers reported wide differences in the extent to which residents wanted to be part of the decision making process about their care and whether or not they wanted to use the different tools. The tool that most heavily relies on the direct participation of the residents is PPC, unlike the other two tools which can be used even without a resident's knowledge. Residents (and to a lesser extent families) therefore have a choice about whether or not they want to complete it. One care home manager reported that only half of the residents had completed a PPC, whereas in another home there were only three who had not. However, the managers appeared to value the fact that residents were given the option, and respected the decisions that were made.

Although some residents might want to be involved in the decision making process about their care, the data revealed particular challenges in relation to residents with dementia or impaired mental capacity, as one manager explained:

I think the PPC has been the most difficult to implement because you need so much cooperation from relatives and residents to do that, and that's been especially difficult with the people with dementia. [Manager 2]

Although the managers gave a few examples of occasions when family members did not agree with the processes of end of life care planning promoted by the care home, the data

showed that staff valued the involvement of family members, as exemplified in the following extract:

What we usually do is let them settle in; with somebody long-term I always say let them settle in, we'll get to know them and involve the family and say in a month's time we'll tackle it, with the family included. And that seems to work.
[Manager 3]

Cross-boundary working

The third theme that emerged from the analysis concerns the ways in which care homes work with other health care organisations and professionals. Introducing end of life care tools to the care home had necessitated changes to the ways in which the homes worked with primary care, and as a result some of the managers had experienced difficulties in working with GPs and District Nurses; one manager reported such severe problems working with District Nurses that at one point she wanted to stop using the tools altogether. However, there was evidence in the data that, once established, the tools have helped care homes and primary care to work together more effectively:

We had a couple of GPs that would just, not fob us off, but were a bit, what can I say, they wouldn't listen to our opinion. Now since we wrote the letter to say we are doing the GSF, when they have come in to see various residents, they have listened to what we have said. And ok, they have not always taken it on board but at least we feel we have been listened to. The staff feel that has been a general improvement overall.
[Manager 1]

It was also clear from the data that if at all possible the care homes wanted to keep residents in the home at the end of life and avoid unnecessary hospital admissions. The managers' perceptions of hospital care were extremely negative; for example, one manager felt that hospital nurses knew nothing about the end of life care tools, and another said:

I don't think there's anything worse than somebody bumping along to [hospital] in an ambulance [...] to then die in a medical assessment ward. [Manager 2]

The managers also believed that people outside the care home had negative perceptions about care homes and the staff who work in them. The manager who had experienced great difficulties working with District Nurses felt that the problems stemmed from the nurses' attitudes to the care home and beliefs that "anybody can work in a care home". Another manager, who worked in a residential home, felt that she and her colleagues were "looked down upon" even more than staff in nursing homes:

But at times you get, definitely in care homes, there's a great differential; I mean of course we look after the dying, that's the same as nursing homes. But you're just sort of looked down upon as care assistants I find. You know, when professionals, nurses and people come in, they just look; but you have to be quite highly trained nowadays.
[Manager 4]

Strand 3: focus group interviews

A total of 12 care home staff took part in two focus group interviews, and the characteristics of the participants are shown in Table 6. Care Home A is a nursing home (where all three end of life care tools are in use), and Care Home B is a residential care home (using none of the tools).

Table 6: Characteristics of focus group participants

Participant number	Gender	Age	Ethnic origin	Job title	Time in post
A1	Female	55	White British	Acting Matron	4 months
A2	Female	34	Filipino	Staff Nurse	6 years
A3	Female	54	White British	Staff Nurse	2 years
A4	Female	39	White British	Housekeeper	6 years
A5	Female	34	White British	Assistant Housekeeper	1 year
A6	Female	46	White British	Senior Auxiliary	6 years
B1	Female	45	White British	Care Manager	7 months
B2	Female	NR	White British	Senior Carer	6 years
B3	Female	58	Chinese	Care Assistant	1.5 years
B4	Female	23	White British	Care Assistant	1.5 years
B5	Female	22	White British	Senior Carer	1.5 years
B6	Female	53	White British	Clinical Manager	4.5 years

NR = no response

Analysis of data collected from the two focus group interviews echoes many of the themes that emerged from the individual interviews with care home managers; however, some additional issues are highlighted here.

Team working within the home

In both focus groups the ways in which different groups of staff worked together was discussed. The contribution made by the housekeeping staff, for example, was emphasised in the first care home. They were described as “the eyes and ears” of the nursing and care staff, and one of the housekeepers explained the role they played in end of life care:

Everyone is so busy and under a lot of pressure, they haven't always got time. Even us nipping in and out with the clean towels or nipping back in to empty the bin, things like that, just being visually aware of the what the resident's state is and if they look alright. And if they don't look alright then we will alert somebody straight away, because you can tell [when someone is dying] even though we are not trained.
[FG1]

There appeared to be a high degree of awareness amongst all members of the care home staff when someone was approaching the end of life, as well as awareness of colleagues' needs for support when caring for dying people; in the second care home, for example, some of the ways in which the staff provided informal support for each other were identified. In both homes there was a clear sense of team working, as well as pride in the way they worked together to provide high quality end of life care.

End of life care without using tools

Of particular interest are some of the issues raised in the second focus group, the one that took place in a care home where none of the end of life care tools had been initiated. As all the other data in the study were collected from care homes using one or more of the tools, this focus group offered an opportunity to understand an alternative approach to providing end of life care. There was a high degree of confidence amongst the participants in their ability to care for residents at the end of life, and a great willingness to keep the residents in the home if at all possible:

We were constantly with her, giving her more care than she would have got in a hospital, because we sat with her, holding her hand, until the minute she died.

[FG2]

Because many of the residents live in the care home for many years, there was evidence of very strong bonds between the staff and the residents, as exemplified in the following extract:

Especially if you have known them, I mean there was [resident's name], I was her key worker for four years, and because I was her key worker I used to do little bits extra for her, and that was really bad for me to see her go, but I knew she was looked after.

[FG2]

The need to employ staff who genuinely care about the residents was highlighted as of great importance by one participant, who felt that the word “care” was the key to end of life care, and that “you can’t train somebody to care”.

Staff in this care home also discussed the ways in which they worked with GPs and District Nurses. They were unable to recall any occasions where end of life care had not been as good as they would have liked. Their usual practice was that when it became apparent that a resident was approaching the end of life, the care home staff would ask the GP to visit the resident every few days to reassess and agree care. The GP would then notify and update the out-of-hours service as appropriate. In contrast to some of the other care homes in this evaluation, despite not using any of the end of life care tools, this residential home had not experienced the distressing situation of having a resident admitted to hospital inappropriately only to die there shortly after admission.

Relationships

Findings from this second focus group interview indicate that it is not solely the use of the tools that enables the provision of high quality end of life care, but that an extremely important factor is the establishment of good working relationships between the care home and primary care staff. Of particular importance are the relationships with GPs and District Nurses, although it was apparent from the second focus group that the care home had good working relationships with other members of the primary care team, such as the receptionist at the GP practice, which enabled calls about a resident to be dealt with quickly and effectively. One participant described the care home’s relationship with the District Nurses:

I think we have a good relationship with them; you have to have a good relationship with them because you all have to be working for the same purpose.
[Focus Group 2]

The other participants agreed, adding that they feel they have “good back-up” from the primary care team. This care home therefore appears to be using a team approach not just internally but also externally with health care providers from outside the home.

6. Discussion

The findings from all three strands of this evaluation raise some very interesting issues about the provision of end of life care in care homes on the Fylde Coast, and this section of the report will attempt to clarify and crystallise these issues. It will conclude with some recommendations both for practice and for further research.

Experience of using tools

All of the care homes that took part in this evaluation (with the exception of the home that participated in the second focus group) were either using or about to start using one or more of the three end of life care tools. The study findings demonstrate strong commitment within the care home sector to improving end of life care for residents and increasing choice and participation in decision-making about care. Despite some initial difficulties, the experience of using the tools was reported as a predominantly positive one, improving not only end of life care at the point of delivery but also helping care home staff to develop relationships with primary care. Communication between care home staff, residents, families and primary care staff had been facilitated through the use of the tools. The tools had also provided many opportunities for learning and development, and the role of PCT End of Life Facilitator had been fundamentally important in introducing the tools to the care homes in the first place.

Cross-boundary working

However, findings from the second focus group indicate that use of the end of life care tools is only one piece of the jigsaw. Another crucial piece is the willingness and ability of the care homes and local primary care services to work together and develop trusting and supportive relationships. Where strong relationships exist, this study provides some evidence that end of life care can be successfully delivered even without the use of the tools. Therefore cross-boundary working is of extreme importance, as a care home cannot work in isolation. These findings echo those of other recent research studies, which show that end of life care provision requires a whole systems approach [5, 24, 25].

In the Fylde Coast, the facilitation, training and support provided by the End of Life Care Facilitator is highly valued by the care homes. This finding is also supported in other research [24]; however, facilitation has resource implications and raises questions about the long-term sustainability of such posts.

Place of death

This evaluation also revealed some interesting findings in relation to the place of death of care homes residents. Despite the emphasis in the End of Life Care Strategy [14] on reducing the number of inappropriate hospital deaths, over two fifths of deaths reported in this evaluation took place in hospital, which is somewhat higher than in another recent study [26], although these results should be interpreted with caution because of the relatively small sample size. None of the reported deaths occurred in a hospice, and the reasons for this are unclear; it may be because none of the residents who died had specialist palliative care needs, or alternatively it may be that specialist palliative care was provided in the care home by, for example, a Macmillan Nurse. Another factor that needs to be taken into account is that several of the care homes in this evaluation had only very recently started using any of the end of life care tools, so they may not have been well enough established to make a difference to the numbers of hospital deaths. It is also important to remember that for some of the care home residents a hospital death may have been entirely appropriate.

This evaluation took place over a short time scale, and the number of questionnaires and interview respondents was therefore limited. In addition, no data were collected from residents or family care workers, so it is not possible to comment on their perspectives. However, it has nevertheless yielded valuable findings that have implications for those endeavouring to improve end of life care in care homes.

7. Conclusion

We have found the GSF programme has definitely improved end of life care. We are far more aware of our residents' wishes, and we are now more confident in discussing end of life care. We are more aware of spirituality, now understanding that it is not just organised religion. We are more confident in speaking to GPs, especially if the resident does not wish to be admitted to hospital. We are actually planning care and anticipating need, therefore our crisis admissions have reduced. I am so interested in it that I am assisting my manager to plan an end of life strategy across our group of care homes.

[Comment from Questionnaire 11]

This report has provided an account of a small scale study that was undertaken to evaluate the use of the end of life care tools in care homes on the Fylde Coast. It has demonstrated that care homes are beginning to use the tools, and are discovering their benefits (as illustrated in the comment above), although because many of the care homes in this study have introduced the tools relatively recently their longer-term impact is more difficult to evaluate.

However, findings from this evaluation clearly indicate that models of working that best support the use of the tools need to be underpinned by cross-boundary working and, significantly, that good cross-boundary working may be even more important than the tools themselves. The evaluation therefore concludes with the following recommendations:

Recommendations for practice

- Relationships with primary care professionals (particularly GPs) are critical to the success or failure of end of life care in care homes and need to be developed and maintained.
- The end of life care tools can help to enhance communication between staff in care homes and primary care.
- Initiatives that address end of life care provision in care homes need to encompass wider health and social care systems.

Recommendations for further research

- Objective measures of the quality of end of life care provision should be developed through further research.
- Further evaluation is necessary to develop greater understanding of how end of life care is provided in care homes not using the tools.

Acknowledgements

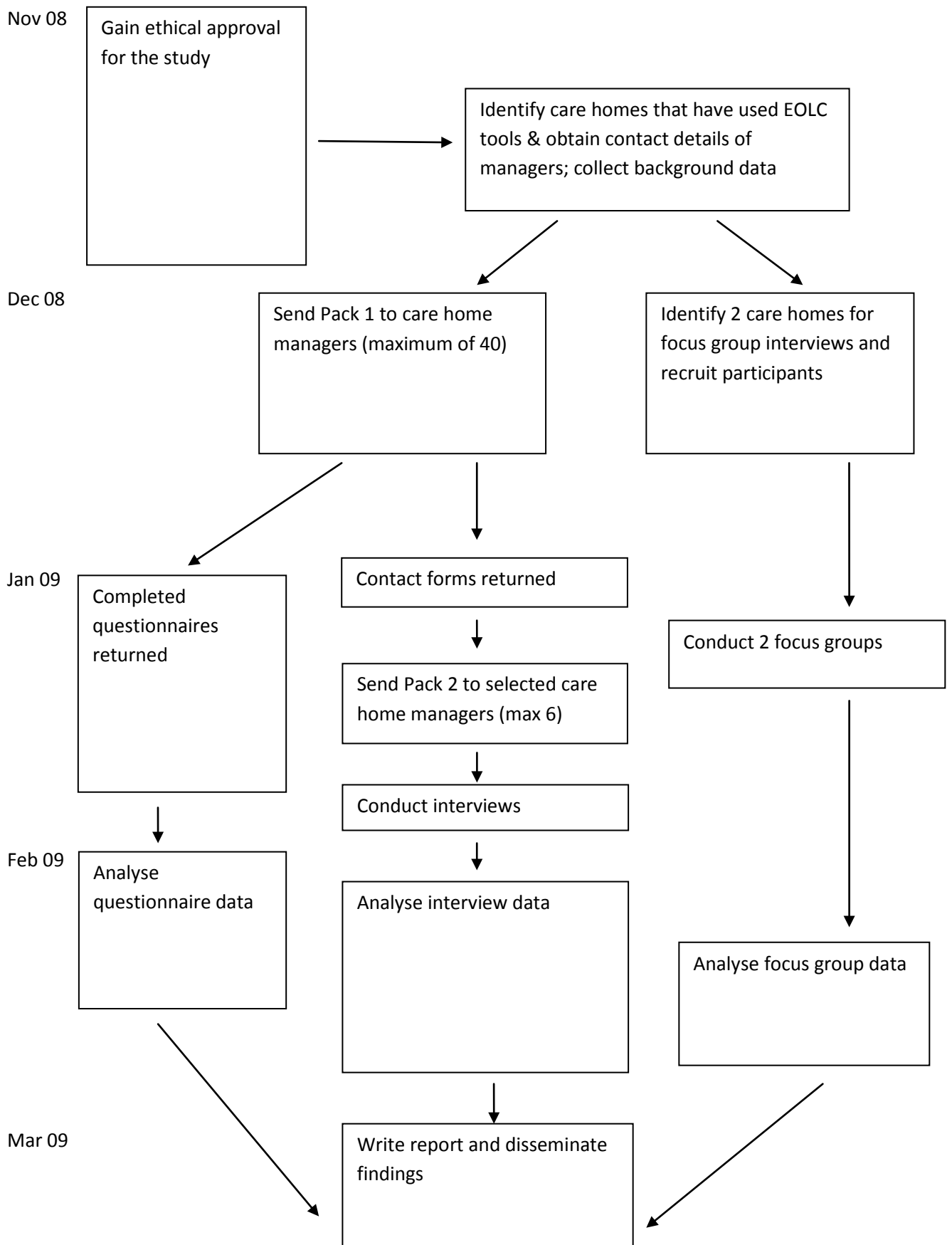
We would like to thank all the care home managers and staff who gave so generously of their time to take part in the study.

8. References

1. Personal and Social Services Research Unit (2008) *National Evaluation of Partnerships for Older People Projects: Interim Report of Progress*. Canterbury: PSSRU, University of Kent.
2. Office of Fair Trading (2005) *Care Homes for Older People: A market study*. London: Office of Fair Trading.
3. Department of Health (2001) *Community Care Statistics 2001: Bulletin 2001/29*. London: Department of Health.
4. Commission for Social Care Inspection. <http://www.csci.org.uk/registered-services-directory> (accessed 20 March 2009).
5. Froggatt K, Vaughan S, Bernard C. (2009) Advance care planning in care homes for older people: an English perspective. *Palliative Medicine* (accepted for publication).
6. 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**(6), 512-517.
7. Burton-Jones J. and Mosley P. (2004) *"One World" Working with Racism: A Report of a Partnership Project between Anchor Trust and the Relatives and Residents Association*. London: Anchor Trust.
8. Dalley G. and Denniss M. (2001) *Trained to care? Investigating the skills and competencies of care assistants in Homes for older people*. London: Centre for Policy on Ageing.
9. Froggatt KA, Poole K, Hoult L. (2002) The provision of palliative care in nursing homes and residential care homes: A survey of clinical nurse specialist work. *Palliative Medicine*. **16**, 481-487.
10. Glendinning C, Jacobs S, Alborz A, Hann M. (2002) A survey of access to medical services in nursing and residential homes in England. *British Journal of General Practice* **52**(48), 545-548.
11. Bajekal M. (2002) *The 2000 Health Survey for England: The Health of Older People*. London: Department of Health.
12. Bowman CE, Whistler J, Ellerby M. (2004) A national census of care home residents. *Age and Ageing* **33**, 561-566.
13. Netten A, Darton R, Curtis L. (2001) *Self-funded admissions to care homes*, in *DWP Research Report No. 159*. Leeds: CDS.
14. Department of Health (2008) *End of Life Care Strategy - promoting high quality care for all adults at the end of life*. London: Department of Health.
15. Easterbrook L, Vallely S. (2008) *"Is it that time already?" Extra Care Housing at the End of Life, A policy-into-practice evaluation*. London: Housing 21/NHS End of Life Care Programme.

16. Froggatt K, Davies S, Meyer J. (2009) Research and Development in Care Homes: Setting the Scene. In Froggatt K, Davies S, Meyer J (eds) *Understanding Care Homes: A Research and Development Perspective*. London: JKP, 9-22.
17. Froggatt K. (2004) *Palliative Care in Care Homes for Older People*. London: The National Council for Palliative Care.
18. National Council for Palliative Care and NHS End of Life Care Programme. (2007) *Building on Firm Foundations: Improving End of Life Care in Care Homes*. London: The National Council for Palliative Care.
19. Froggatt K, Wilson D, Justice C, MacAdam M, Leibovici K, Kinch J, Thomas R, Choi J. (2006) End-of-life care for older people in long-term care settings: A literature review. *International Journal of Older People Nursing*, **1**, 45-50.
20. Jones A, Johnstone R. (2004) Reflection on implementing a care pathway for the last days of life in nursing homes in North Wales. *International Journal of Palliative Nursing* **10**(10), 507-9.
21. Clifford C, Badger F, Plumridge G, Hewison A, Thomas K. (2007) *Using the Gold Standards Framework in Care Homes: An Evaluation of the Phase 2 Programme*. School of Health Sciences, Birmingham: University of Birmingham.
22. Partington L. (2006) The challenges of adopting care pathways for the dying for use in care homes. *International Journal of Older People Nursing* **1**, 51-55.
23. National Audit Office. (2008) *End of Life Care*. In *Report by the Comptroller and Auditor General HC1043 Session 2007-2008*. London: The Stationery Office.
24. Seymour J, Froggatt K, Kumar A. (2008) *End of life care in care homes: understanding and mapping innovative solutions*. London: Department of Health (report submitted for publication).
25. Payne S, Froggatt K, O'Shea E, Murphy K, Larkin P, Casey D. (2009) Improving palliative and end of life care for older people in Ireland: a new model and framework for institutional care. *Journal of Palliative Care* (accepted for publication).
26. 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**(4), 341-348.

Appendix A: Study Flow Chart



Appendix B: Questionnaire



Evaluation of end of life care initiatives in care homes on the Fylde Coast

Questionnaire for care home managers

Thank you for taking the time to complete this questionnaire. By completing and returning the questionnaire, you are giving your consent for the information you provide to be used in the study. Please answer the questions as directed and return the completed questionnaire in envelope "A".

1. Which end of life care tools were used in your care home in the period January to December 2008?

Tool	Please tick if used
Gold Standards Framework	
Preferred Priorities for Care	
Liverpool Care Pathway	

2. Please complete the following table about the tools that you are currently using:

Tool	How long have you been using it?	How many residents did you use it with in 2008?
Gold Standards Framework		
Preferred Priorities for Care		
Liverpool Care Pathway		

3. Have any of the three tools been used previously in the care home but are now discontinued?

Yes		No	
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If you ticked "Yes" above please provide details about which tools have been discontinued and why:

4. Please list what in your experience have been the three most significant benefits of using the end of life care tools:

1.
2.
3.

5. Please list what in your experience have been the three most significant challenges or difficulties you have faced in using the end of life care tools:

1.
2.
3.

6. How many care staff work in your care home?

	Number of staff	Whole Time Equivalents
Qualified nurses		
Care workers		

7. Please complete the following table about different types of training available to your staff:

Type of training	Is this training available for staff?	How many staff have received this training?	How many more staff require this training?
End of life care tools			
Communication skills			
Syringe drivers			
Symptom control			
Spirituality			
Other (please specify)			

8. Please complete the following table about resident deaths from January - December 2008:

Place of death	Number of deaths in this location
Care home	
Hospital	
Hospice	
Other (please specify)	

9. a. How many GP practices does your care home liaise with?
 b. How many GPs does your care home liaise with?

10. Please provide the following information about yourself:

Your job title	
How long you have been in this post	
Your gender	
Your age	
Your ethnic origin	

We would welcome any further comments you would like to make (please continue on a separate sheet if necessary):

Thank you very much for your help in completing this questionnaire.

Please return the completed questionnaire in envelope "A" to:

Dr Mary Turner

Research Fellow

International Observatory on End of Life Care,

Division of Health Research,

Bowland Tower East

Lancaster University

Lancaster LA1 4YT