

# Evaluation of the End of Life Care Train the Trainer (TTT) Education Model



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### **DISCLAIMER:**

This report presents findings of an independent evaluation commissioned by Health Education East of England. The views expressed in this report are those of the authors and not necessarily those of the Health Education East of England or of any of the care homes involved.

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## Glossary

ABC	End of Life Care Education Programme
ACP	Advance Care Planning
ADL	Activities of Daily Living
A&E	Accident and Emergency
CH	Care Home
CQC	Care Quality Commission
DN	District Nurse
DNACPR	Do not attempt cardio pulmonary resuscitation
EFE	End of Life Care Educator & Facilitator
EoE	East of England
EoL Care	End of Life Care
GP	General Practitioner
GSF	Gold Standard Framework (EoL Care Education Programme)
ICP	Integrated Care Pathway
OOH	GP Out-of-Hours visits
PPC	Preferred Priorities for Care
TTT	Train the Trainer EoL Care Education Programme
NVIVO	Qualitative Data Analysis Computer Software, QSR V10
SPSS	IBM Software package for statistical analysis V20

## Executive Summary

Care home residents have multiple health needs that are often complicated by the presence of dementia. This means that they rely on a range of health and social care staff as well as family members to provide care and make decisions on their behalf. Older people do not enter a care home to die, although they are in the last years of life. For this population it is often unclear, to those providing care, whether a resident is actively dying or experiencing an episode of ill health that they will recover from. End of life care training and support for care home staff can enable staff to incorporate knowledge and skills about anticipating and providing care for residents who are dying into their day to day practice. It aims to ensure that older people can receive care that is appropriate within the care home, is informed by residents' wishes about where and how they die, and avoids hospital based interventions that neither prolong life nor provide comfort.

### Chapter 1: Introduction

In October 2012 the Train the Trainer End of Life Care Education Programme (TTT) was commissioned by NHS Health Education East of England (formerly East of England Multi-professional Deanery). The programme built on the success of the ABC End of Life Education Programme that had trained approximately 4000 care home staff across the East of England in End of Life Care (EoL Care). The goal of the TTT pilot project was to consolidate the success of the programme, increase the capacity of the care home workforce to provide end of life care and develop a programme that could sustain training in and provision of End of Life Care in care homes. It used a mix of online resources, skills workshops on teaching and learning, and on-going facilitation from End-of-Life Educators / Facilitators (EFEs) with a professional background as specialist palliative care nurses, community nurses, and acute experience nurses with a passion for EoL Care. Two trainers per care home who had completed the ABC training were invited to join the TTT programme to train six of their peers (Learners) in EoL Care. The pilot ran for nine months (Oct 2012 – June 2013), and initially recruited 36 trainers from 18 care homes across the East of England. The evaluation tracked the four stages of the programme and continued data collection up to 4 months after its completion. The organising framework for the evaluation of the pilot was informed by a recognition that uncertainty is a defining characteristic of end of life care for this population and that it is often manifest in three ways, that is, uncertainty about whether the person is dying (pathway uncertainty), uncertainty about how to make decisions about treatments that are in the person's best interests and who should lead that



decision making process (relational uncertainty) and finally uncertainty about the ability of the workforce and the visiting services to have the capacity to provide end of life care in the care home (service uncertainty). The evaluation focused on the ability of the TTT programme to address these uncertainties and either resolve them or provide support mechanisms that meant staff were able to “hold” and manage times of uncertainty. The research questions focused on what supported or hindered the uptake of the programme and specifically on the introduction of Advance Care Planning (ACP), the impact of the programme on staff confidence, knowledge of and skills in end of life care, involvement with the wider systems of care and the perceived costs of the programme.

## **Chapter 2: Methods**

A mixed method design drawing on qualitative and quantitative methods of data collection was used. This included observation of the 6 workshops in the three sites, baseline assessment of the characteristics and resource use of a randomly selected sample of 274 care home residents who were tracked for 12 weeks, interviews with participating staff, focus groups, review of programme documentation, analysis of trainers’ audio diaries and a detailed review of the care notes of 150 residents who had died between October 2012 and June 2013, when the pilot programme ended.

Seventeen care homes participated, 8 of which had on-site nursing provision. Seven of these had completed or were in the process of completing End of Life Care training additional to the ABC and TTT programme. Thirty Trainers were involved in the pilot and by the end of data collection 114 learners had completed the TTT programme. Two care homes were unable to train any learners during the study period, one needed extensive support to be ready to implement the programme and one had organisational changes that meant they could no longer continue with the programme. Staff who had protected time to undertake the learning and were able to complete the modules as part of their work were in the minority. For those with limited online access and/or those who completed the modules in their own time the involvement of the EFE and opportunities to discuss End of Life Care as part of their work helped to augment their learning and maintain interest in the programme.

## **Chapter 3: Findings - Characteristics of care homes and residents**

There was a statistically significant difference between care homes with and without on-site nursing, with the latter having fewer hospital admissions.

- ❖ Seventy nine per cent of the residents who died had died in the care home, a finding that is consistent with the earlier evaluation of the ABC programme.
- ❖ Just over half of the randomly selected 274 residents had an advance care plan (ACP) in place and the majority (95%) did not have an unplanned admission during the time of data collection.
- ❖ The review of decedents' notes found evidence of discussions relating to ACP for 111 residents (74%) and detailed discussions of symptom assessment and management.
- ❖ Most activity related to ACP and EoL Care was concentrated in the last week and days of life. Over a quarter of those who died had a DNACPR in place the week before death.
- ❖ Of 92 residents, 80 (87%) died in their preferred place of death, which included one person dying in hospital as specified, and one person where care was appropriate for their needs.
- ❖ Of the 118 residents whose death was expected 63% has anticipatory medication in place.
- ❖ An unexpected finding was that of the 129 residents who had a recorded reason for admission, 23 (18%) had been admitted from hospital specifically with a diagnosis of dying and for end of life care. This would suggest that some of the care homes were being recognised for their expertise in EoL Care.
- ❖ Nearly two-thirds (65.7%) of residents had a diagnosis of dementia.

### **Benefits of the programme**

- ❖ The communication module and the ACP module were fundamental for trainers and learners.
- ❖ The flexibility and blended learning approach of the TTT programme, which combined the use of online learning and face to face and practice based teaching with expert facilitation, were seen as strengths of the programme.
- ❖ For care homes that had experience of using other EoL resources the context sensitive approach of the TTT programme was identified as preferable and more person centred. *"Previously, nine times out of ten we'd just go 'oh', if a resident*

*approached this subject. But now we talk about it...it makes one aware that one **can** talk about EoL...one can assist relatives to face what's coming" [FG0106P3].*

- ❖ The majority of care home staff believed that the TTT programme had given them confidence in providing EoL Care, encouraged the initiation of conversations about residents' priorities and preferences for EoL Care, and helped in how they worked with visiting GPs in planning care. *"...we used ACP check-lists before the training, but they have been amended since the training. In addition, we now use original DNACPR forms, whereas before we just noted it in the care plans; now we have a file of the originals" [T02111SLD].*
- ❖ There were also numerous examples given of when they would provide anticipatory care and be proactive in the assessment and management of symptoms of pain and distress.
- ❖ There was limited evidence of the programme changing how the care homes worked with wider NHS services and whether it increased their access to specialist support.
- ❖ The availability and access to an EFE was crucial, particularly in situations where there was limited online access, and when participating care homes had limited prior experience of providing EoL Care or of training learners in the work place.

### **Care home readiness**

- ❖ Care home readiness was a consistent finding that was threaded through the accounts of participants as a key influence on uptake and successful completion of the programme. For some care homes a prior history of working with end of life care resources facilitated relationships with service providers such as GPs and hospitals, either in relation to prescribing anticipatory medication, issuing signatures for DNACPR forms, or referring patients to the care home for palliative care. Better service relationships were also influenced by pro-active and clinically qualified managers. In combination, such factors enhanced the implementation of the TTT EoL Care education programme. This is to be contrasted to care homes that were in flux during the TTT pilot programme, either due to managerial change, staff turnover, or conflicting priorities at the time.

## Variation

- ❖ Variation in the professional roles and responsibilities of the trainers who taught the learners also affected uptake and implementation. Trainers who had the most opportunity to teach learners were those whose roles allowed them to spend time on the floor with learners and offer bite-size, applied teaching as and when opportunities arose. To be able to act on their learning trainers and learners also needed to have a level of authority and responsibility.
- ❖ Across the 17 care homes the evaluation found a wide variation of care home experience and prior knowledge of End of Life Care. The blended learning approach of the TTT programme meant that it was able to respond and adapt to the different levels of care home readiness. It was a programme that was valued by the care home staff, and participating care homes were able to sustain patterns of care observed from the earlier ABC evaluation (Pyper et al 2013).

## Contributions

- ❖ There are two particular contributions of the TTT programme. Firstly, to build on learning from the ABC model and extend the involvement of care home staff who otherwise would not have access to End of Life Care training. Secondly, to augment, reinforce and consolidate learning either from the use of other EoL resources or the expertise of key practitioners in the care home. The TTT programme was preferable to paper based initiatives and the care homes valued the flexibility that the programme offered.

## Perceptions

- ❖ The TTT EoL Care training was not perceived as a course that had to be passed, but as an approach that took into consideration the vulnerabilities, sensibilities and constraints that are part of the home contexts that EoL Care training is meant to strengthen. It needed the EFEs to make that happen and relied heavily on their commitment as well as on the goodwill and interest of the staff to undertake work in their own time. Where the latter were not in place there were few incentives to participate, or sanctions that could be used.

## Managerial support

- ❖ Managerial support was critical in three ways, in making sure that staff would be available, that they would have protected time, and in encouraging learners to apply their learning when working with colleagues and NHS professionals.
- ❖ Care homes without on-site nursing needed more support and facilitation, and future implementation may want to target these care homes and prioritise those care homes that have had less access to End of Life Care resources. The evaluation of the TTT programme demonstrated the importance of a long term commitment to working with care homes, and the value of a programme that can reinforce and sustain learning in organisations where staff and management often change, and where residents' dying trajectories are protracted and complicated by the presence of dementia and multiple morbidities.

## Recommendations

- The TTT programme with its blended learning approach should be continued and extended to complement the achievements of the ABC programme, in order to sustain the development of knowledge and skills and the implementation of effective End of Life Care in care homes.
- Care homes **without** on-site nursing should be targeted ahead of care homes with on-site nursing. The role of the facilitator is critical to achieving this. The EFE's role should be one that is based on a qualification in palliative care and ongoing experience in EoL care.
- A careful pre-assessment and discussion with the care home could inform a negotiated agreement about frequency and availability of EFE support with the recognition that some care homes will need more support than others. The findings suggest that, whilst EFE support can reduce as trainers and learners grow in confidence and skills, there is an ongoing need for EFE review and support, particularly at times of organisational change or turbulence in the care home.
- A review of EFE approaches to providing support should consider what a minimum level of support for a participating care home would require in EFE time, for different levels of care home readiness and whether there is an on-site clinician or not.

- The costing of EFE support should be calibrated to reflect the readiness of the care home and care home staff to participate in the programme. It also needs to take account of EFE time alongside use of other NHS services, especially in cases where there is some blurring between an EFE's role as TTT facilitator, and their presence in the care home in their role of clinical nurse specialist.
- Staff selection, both for trainers and learners, is a critical consideration for the TTT model. Aspects such as prior experience, opportunity, authority and responsibility should be discussed, assessed and monitored.
- The commitment of management, priorities and interim goals of the participating care home staff, and internet availability should be discussed prior to embarking on a TTT programme as components of care home readiness to participate.
- The development and testing of a care home readiness assessment tool to inform recruitment of care homes and levels of EFE support provided to care homes.
- Care homes should consider organising practice based teaching in units within the care home.

# 1 INTRODUCTION AND BACKGROUND

## 1.1 Introduction

This report presents the findings from the evaluation of the Train the Trainer (TTT) programme. It provides a brief introduction and background to the TTT pilot programme in the East of England and summarises how the evaluation was approached. Findings are presented in two sections. The first section discusses information about the participating care homes, resident characteristics, use of services and related End of Life Care outcomes. The second section provides a description of how the programme was implemented, of participants' views and experiences and what supported and inhibited its uptake and implementation. The report ends with a discussion of the impact of the programme and makes recommendations for future implementation and research.

## 1.2 Background to the Train the Trainer Education Model

In the UK the majority of long term care for older people is provided by independent care providers. Care home staff are experienced in caring for frail older people. However, they rely on primary health care for medical support, access to secondary care and generic specialist palliative care. Historically, health care services have an erratic relationship with care homes (Davies, Goodman et al 2011).

Structured End of Life Care initiatives such as the Gold Standard Framework for Care homes, and locally the ABC initiative have demonstrated promising results (Gandy, Roe, McClelland & Ashton 2011; Pyper, Sawyer and Pyper & Mayhew, 2013). The challenge is how to sustain these improvements so that care home staff act on the learning acquired, develop their skills and support colleagues in providing end of life care. There is a need to embed end of life care into the day to day work of care homes. *The Train the Trainer Education Model* (TTT) aims to build on earlier work and offers an approach that retains the expert input and support from specialist palliative care mediated through the targeted development of learning champions. This is the focus of this report.

The ABC End of Life Education Programme consisted of the use of online training to deliver six training modules and provide facilitated support from EFEs who held

various roles in specialist palliative care nursing, community nursing and acute experience nursing to approximately 4000 care home staff across the East of England. As a result of the success of the ABC training programme (Pyper et al, 2013 [aka PHAST Report]), the Train the Trainer End of Life Care Education Programme (TTT) was commissioned by NHS Health Education East of England (formerly East of England Multi-professional Deanery) to consolidate the learning from the ABC programme and equip more staff to provide End of Life Care.

The TTT project aimed to train two trainers per care home who had participated in the ABC programme to support six learners in their care home. Details of the ABC and the Train the Trainer End of Life Care Education Programme are listed on Appendix A.

The TTT programme, in addition to the use of the online training from the ABC EoL Care Education Programme for new learners, sought to equip trainers with the skills to disseminate their learning more widely within care homes. Trainers' responsibilities therefore included the preparation of on-line and face-to-face teaching sessions, discussions, and whenever possible offering learners bite-size micro-teach sessions in daily practice. Full teaching sessions were observed and evaluated by End of Life Care Educators / Facilitators (EFEs). The design of the TTT pilot study is described in Section 2.1.

### **1.2.1 Evaluation framework**

Older people do not enter a care home to die and for this population it is often unclear whether a resident is actively dying or experiencing an episode of ill health they will recover from (Goodman et al 2010). Because of the presence of dementia, there is often uncertainty about residents' wishes, compounded by uncertainty about who is ultimately responsible for decisions about how and where EoL Care should be provided, and how palliative care support or services will be provided to care homes if needed.

Previous research undertaken by the team identified three types of uncertainty that shape how decisions are made to provide end of life care and, importantly, inform how care is provided and care home staff's ability to support people to die in the care home. These uncertainties relate to the individual's trajectory to death, the relationships that exist between residents, staff, family and visiting health professionals, and to the ability of staff and the capacity of services to provide



support when needed. This evaluation structured its data collection and analysis based on the extent to which the TTT education model was able to ameliorate uncertainty in these three areas.

### **Pathway uncertainty**

The minority of residents in care homes die from cancer. Their pathway to death is often one of progressive deterioration and gradual functional loss. This is sometimes only apparent in retrospect (Barclay et al (in press); Handley et al 2013). The pathway to death may be characterised by incremental changes in function and health, sudden episodes of ill health from which there is a sustained recovery of over six months, a recognisable period of dying or sudden death (Goodman et al 2013). It is very difficult to differentiate between when someone is actively dying and when, for example, it is sensible to refer for a specialist opinion. There can be a fine line between ageism that says it is not worth actively treating older people and recognising when palliative care is the appropriate treatment of choice.

Equally, when an older person has dementia and/or a range of health care problems and functional limitations, assessment and treatment of symptoms such as pain, breathlessness and fatigue can be more complicated. End of life care interventions need to be able to equip practitioners with the resources, tools and skills that can address the wide range of diagnostic/assessment and treatment issues that do not reflect cancer trajectories.

### **Relational uncertainty**

In care homes effective end of life care is shaped by how NHS services work with care homes and manage the division between public and private provision. Often there are multiple professionals, family members and care home staff involved in providing and discussing a resident's care. The difficulties of maintaining communication and consistency between all those involved in a resident's care, concerns about personal and professional liability, and/or weak working relationships can influence decisions to call emergency services, persist in treatments that do not promote recovery and delay conversations about how to plan EoL Care. Interventions that improve and sustain relational working and shared decision making in EoL Care are more likely to support conversations over time and evidence informed clinical practice.

## **Service uncertainty**

Linked to the issues about bridging the divide between the NHS and long term care providers is uncertainty within the service that the workforce has the capacity to provide appropriate support and that there are resources to provide end of life care. Effective end of life care interventions should therefore be able to demonstrate how they have increased the knowledge and confidence of participants, built sustainability into the service (that addresses the known problem of workforce turnover and variable access to NHS services), and provided access to on-going specialist support and advice. They also need to address the capacity of primary care and linked specialist services to provide the resources (for example equipment) and support residents alongside their existing community dwelling caseload.

It is reasonable to assume that improved knowledge about EoL Care and use of certain end of life care tools could address **pathway uncertainty** and **service uncertainty**, or that changing patterns of working and how care is structured could help to ameliorate **relational uncertainty** and embed new practices into every day working. This evaluation framework captures the context, process and outcomes of end of life care.

### **1.2.2 Research questions**

- 1) What evidence is there that the TTT Education Model increases residents' family members', CH and NHS staff engagement with Advance Care Planning (ACP) and on-going conversations about EoL Care?
- 2) What impact does the TTT Education Model have on CH staff in relation to:
  - Confidence
  - Reported knowledge
  - Symptom assessment and management
  - Involvement with NHS services when providing EoL Care
- 3) What elements of the EoL Care Programme were the most effective?
- 4) What were the barriers and facilitators to the implementation of the programme?
- 5) What evidence is there that the programme supports an increase in quality of care for older people in care homes identified as in need of end of life care?

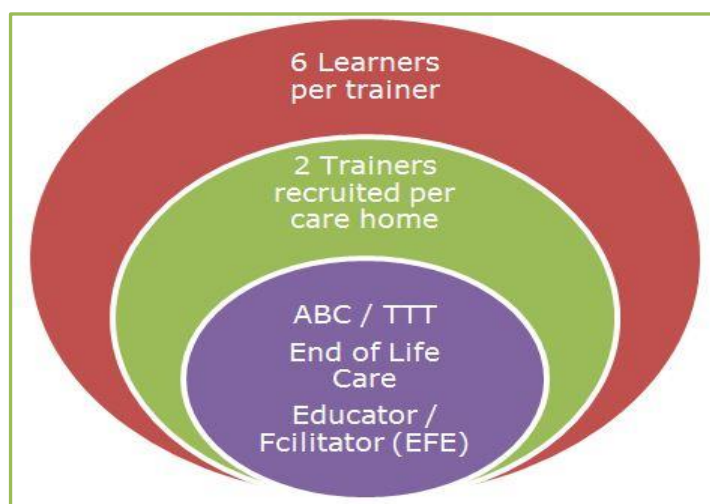
6) What impact is the programme making on wider systems of care and primary health care in particular?

These questions are debated in relation to the evaluation framework.

## 2 METHODS

### 2.1 The Train the Trainer (TTT) Pilot

The Train the Trainer (TTT) education model is a continuation of the ABC EoL Care education programme and was designed to disseminate palliative and EoL Care training throughout East of England (EoE) care homes. The TTT Pilot was planned for 18 care homes. Selected EoL Care experts in Anglia, Hertfordshire and Essex took on the role of EoL Care Facilitators/Educators (EFEs) and supported 'trainers' to deliver the ABC programme throughout the duration of the pilot. As shown in Figure 1, the EFEs are at the core, teaching trainers who in turn train learners. The diagram depicts an increasingly wider range of dissemination of knowledge and learning through the integrated relationships which underpin the design of the TTT Model.



**Figure 1: TTT Team configuration between EFEs, trainers and learners**

EFEs held various clinical and education roles and were employed by a range of organisations. Professional roles included palliative link nurse, EoL specialist, hospice nurse, EoL Care Educator, practice development nurse for care homes, palliative nursing and district nursing. Table 1 shows the mix of organisations that hosted the EFEs during the TTT pilot project.

**Table 1: EFEs' hosting organisations by Site**

Site	Hosting organisation
Site 1	NHS Trust, Cancer Network, Hospice
Site 2	Hospices
Site 3	NHS Trusts

### 2.1.1 Pilot setting

The pilot was to take place in 18 care homes across the East of England, including:

6 care homes in Anglia (12 trainers and up to 72 learners)

6 care homes in Hertfordshire (12 trainers and up to 72 learners)

6 care homes in Essex (12 trainers and up to 72 learners)

Programme terminology used in this report is highlighted below:

#### End of Life Care Educator/Facilitators (EFEs)

- End of life Care experts who supported care home staff (Trainers) to deliver EoL life care and palliative care training as part of the TTT pilot programme.

#### Trainers

- Care home staff who had completed the ABC training and had been nominated to deliver EoL Care and palliative care training to their colleagues (Learners) as part of the TTT pilot programme.

#### Learners

- Care home staff who received EoL care and palliative care training from their colleagues (Trainers) as part of the TTT pilot programme.

### 2.1.2 Pilot timeline

The pilot programme was delivered in four stages:

- **First Stage: October 2012**

Trainers attended an initial 2 day TTT workshop (Workshop 1) in October 2012 at which they were further familiarised with the EoL Care ABC programme, were given guidance around educational and facilitation skills, and had the opportunity to practice the delivery of a training session in the safety of a supportive peer group.

- **Second Stage: November 2012/December 2012**

Trainers were expected to start delivering the ABC programme within 4 weeks of attending the TTT workshop.

- **Third Stage: January 2013**

Trainers reconvened for a final workshop (Workshop 2) to provide feedback to EFEs, project leads and to each other, and discussed any outstanding issues.

- **Fourth Stage: March/April 2013**

Post evaluation to take place no later than 3 months after the TTT programme has completed within the care home.

## 2.2 Recruitment

Care homes, care home managers, EoL Care Facilitator Educators (EFEs), Trainers and Learners were recruited through Health Education East of England. Two care

home providers organisations identified care homes that could be invited to participate. Inclusion was determined by the presence of staff that had completed the ABC programme. The intervention was delivered without charge to the care homes. It was made explicit by the funders at the outset of the programme of the scheme that participation in the TTT pilot would involve an independent evaluation. Information leaflets and consent forms about the evaluation were sent out to care home managers, EFEs, trainers and learners, and all participants were offered the opportunity to refuse participation in the evaluation.

## **2.3 Data collection**

A mixed methods approach was used, using quantitative and qualitative data collection methods. The evaluation was based on the assumption that care home staff from participating care homes could commit to face to face interviews and the completion of audio diaries, and that care home managers would facilitate the evaluation and linked data collection.

### **2.3.1 Data collection instruments**

To minimise burdening participants with extra work, a 'light touch' approach was proposed, which aimed to maximise learning from routinely collected data, or from data completed as part of the TTT intervention.

**2.3.1.1** To establish the characteristics of residents and their service use in participating care homes, Resident Service Use Logs<sup>1</sup> and data extraction forms based on InterRAI Assessment instruments<sup>2</sup> were used to gather information from a randomly selected sample of 30% of residents per participating care home. Resident Service Use Logs recorded primary and secondary service use such as GP visits, out of hours (OOH) GP call outs, visits by District nurses (DN), services rendered by allied health professionals, ambulance services, visits to Accident and Emergency (A&E), and unplanned hospital admissions. The modified InterRAI Assessment Instruments were used to elicit residents' levels of frailty and dependency, cognition, and overall health condition. Service Use Logs were completed by care home staff in their role of TTT trainers. Data extraction forms were completed by a mix of TTT trainers, EFEs and members of the research team. The 30% sample was followed for 12 weeks.

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<sup>1</sup> Attached as Appendix B

<sup>2</sup> Attached as Appendix C

In addition, the research team looked through 150 residents' decedent notes, dated from October 2012 to the end of June 2013, from which information pertaining to Advance Care Planning (ACP), preferred and actual place of death, service use, and EoL pathway was extracted<sup>3</sup>. Data collected relating to Advance Care Planning in participating care homes captured information of ACP, DNACPR forms completed and signed, place of death, and Preferred Priorities for care (PPC) as recorded in care home notes. *Quantitative* data were entered into IBM SPSS (Version 20.0). Section 2.4.1 discusses data analysis in detail.

**2.3.1.2** Data collection instruments used for *qualitative* data included audio diaries, semi-structured interviews with 27 trainers, a focus group with trainers/learners per site, face to face interviews with 10 EFEs, and face to face interviews with two care home managers. Interviews were recorded, transcribed, anonymised, and entered into QSR NVivo<sup>4</sup> (Version 10). The analysis of data is discussed in detail in Section 2.4.2.

### **Audio Diaries**

It was not possible to observe care, and in attempts to involve care home staff as co-researchers in the evaluation, trainers were provided with Kindle Fire™ tablets and asked to record their reflections on aspects the TTT model. This might have included elements of module delivery, key events in the care homes, reflections on how practice might have changed or remained unaffected by the TTT training, or reflections on conversations with colleagues and/or residents concerning dying and EoL Care. The Kindle Fire™ tablets were password protected and registered with e-mail accounts linked to the University of Hertfordshire, so that sound files could be emailed from the Kindle Fire™ tablet to the researcher's desk anonymously. The use of the Kindle Fire™ tablets was demonstrated at the 2<sup>nd</sup> workshops. A protocol for their use and an Aide Memoir and were developed for trainers.

## **2.4 Data Analysis**

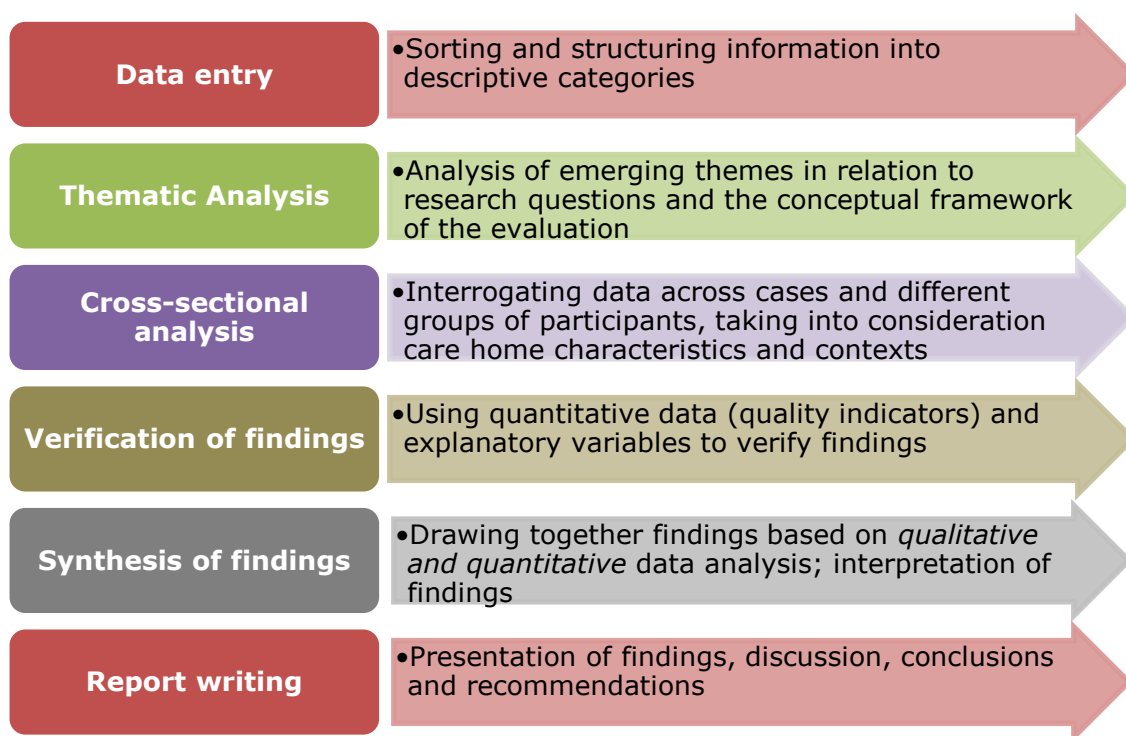
### **2.4.1 Analysis of qualitative data**

Qualitative data were collected via semi-structured interviews, focus groups and audio recordings. QRS NVivo (Version 10) was used to support data management. Processes of data analysis are depicted in Figure 2 below:

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<sup>3</sup> Attached as Appendix D

<sup>4</sup> Computer software for qualitative data management



**Figure 2: Process of data analysis for qualitative data**

#### **2.4.2 Analysis of quantitative data**

Descriptive statistics derived using SPSS (Version 20) and Stata (Version 11.2) were used to report resident and care home characteristics, estimated service use and costs, and involvement of EFEs. The chi-squared test and Fisher’s exact test (2-sided) were used to detect differences between care homes, resident characteristics, patterns of service delivery, and care homes’ uptake of the TTT programme.

### **2.5 Interpretation of data**

The organisation and analysis of data proposed to use the uncertainty framework as set out in Section 1.2.1 to evaluate the impact of the model on different aspects of end of life care. The interpretation and discussion of findings is presented in Section 3.

### **2.6 Ethical issues: Consent, anonymity and confidentiality**

Participants were given at least two weeks to decide whether or not to take part in this evaluation. At each part of the process the researcher reiterated that



participation was voluntary, and that participants could withdraw at any stage without giving a reason.

Any information that may identify participants or care homes was removed in the transcripts. The Research Ethics Committee (National Institute for Social Care and Health Research, Rec Ref 12/WA/0384), reviewed the protocol and study documents and supported the application. Governance approval was obtained from five participating local authorities.

### 3 FINDINGS

This section presents an overview of findings pertaining to participating care homes, residents, EFEs and trainers. Care home characteristics are presented in Section 3.1 in relation to care home type, ownership, additional EoL Care training and size. Section 3.2 covers residents' characteristics such as admission, funding, length of stay, diagnoses, care needs, and service use. Findings concerning TTT Module delivery, professional roles of EFEs' delivering TTT, and professional roles of trainers delivering TTT to learners are discussed in Sections 3.3 to 3.5. Specific research questions pertaining to Advance Care Planning, impact of TTT on care home staff, impact of programme elements, barriers and facilitators, and sustainability are addressed in Sections 3.6 to 3.10.

#### 3.1 Care home characteristics

The pilot project was designed to include 18 care homes across three regions. Three of these care homes withdrew at the early stages of the project. Two of them were replaced by care homes that were known to EFEs. Seventeen care homes participated in the pilot. The participating care homes were either registered as residential care homes or care homes with on-site nursing and had a mix of ownership. Some care homes had received additional EoL Care training, either prior or during the pilot project (see Table 2). The effect of TTT and additional EoL Care training is discussed in Section 3.8.3.

**Table 2: Type of CH, type of ownership, and additional training by Site**

	Site 1	Site 2	Site 3	Total
Care home residential	2	5	2	9
Care home with nursing	4	1	3	8
For profit	6	0	4	10
Not for profit	0	6	1	7
Additional EoL Care training (GSF) completed or in progress	5	1	1	7

Care home sizes ranged from under 40 beds to over 120 beds. The average size of care homes in England and Wales is 36 beds (Laing & Buisson 2009). With the exception of one care home, all care homes in our sample were larger than average (Table 3 refers). This is indicative of a trend for major providers of residential care homes and care homes with on-site nursing to operate larger homes (Laing & Buisson 2009).

**Table 3: Number of beds in each care home by Site (n=17)**

	1 – 39	40 – 59	60 – 79	80 - 99	100 – 119	120 plus	Total
Site 1	0	3	1	1	1	0	6
Site 2	0	3	1	1	0	1	6
Site 3	1	1	2	0	1	0	5
Total	1	7	4	2	2	1	17

### 3.2 Resident characteristics

A randomly selected 274 residents from across three sites (30% of the population) were followed for 12 weeks to gain an overview of their characteristics and of their use of primary and secondary care services (See Table 4).

**Table 4: Number of residents followed in each site by number of beds (n=274)**

	1 – 39	40 – 59	60 – 79	80 – 99	100 – 119	120 plus	Sample Total	Population Size	% of Population in Sample
Site 1	0	45	18	25	32	0	120	387	31
Site 2	0	38	15	5*	0	18*	76	416	18.3
Site 3	11	15	37	0	15*	0	78	310	25.2
Total	11	98	70	30	47	18	274	1113	24.6

\* Following discussions with staff who would be responsible for data collection it became apparent that, in some cases, staff would be restricted to data collection in their own units. In these instances the number of beds in these units was randomised to produce a 30% sample of the unit population.

#### Sex of Residents

Nearly three quarters (74.4%) of the randomly selected sample were female. This reflects national figures (Lievesley, Crosby & Bowman, 2011).

#### Age at Admission

The median age of residents at time of admission was 83 years old.

#### Admitted From

Information on source of admission was recorded in 241 of the 274 residents. As indicated in Table 5, residents were admitted from home, hospital, other care homes, and 'other', which included psychiatric wards or institutions for people with learning disability.

**Table 5: Admitted from by Site (n=241)**

Site	Home	Hospital	Other Care Home	Other*	Total
1	39 (35.8%)	24 (22%)	27 (24.8%)	19 (17.4%)	109
2	32 (44.4%)	15 (20.8%)	19 (26.4%)	6 (8.3%)	72
3	17 (28.3%)	25 (41.7%)	16 (26.7%)	2 (3.3%)	60
Total	88 (36.5%)	64 (26.6%)	62 (25.7%)	27 (11.2%)	241

\* Includes categories such as mental health residence, psychiatric hospital or unit, settings for persons with learning difficulties, rehabilitation hospital/unit, sheltered housing, correctional facility, and not known / not recorded

Residents admitted from hospital or from another care home were more likely to be admitted to care homes with on-site nursing ( $p=0.013$ , chi-squared test) (Table 6 refers).

**Table 6: Admitted from by Care Home Registration Type (n=241)**

Care Home Type	Home (%)	Hospital (%)	Other Care Home (%)	Other (%)	Total
Residential	48 (48.5)	23 (23.2)	20 (20.2)	8 (8.1)	99
On-site Nursing	40 (28.2)	41 (28.9)	42 (29.6)	19 (13.4)	142
Total	88 (36.5)	64 (26.6)	62 (25.7)	27 (11.2)	241

### Method of Funding

Residents who are self-funding are known to have lower dependency on admission and live longer than residents in care homes that rely on public funding. Information on the method of funding was collected for 219 of the 274 residents. As indicated in Table 7, there are more self-funding residents in care homes registered as residential homes than in those with on-site nursing (43.7% v 18.1%).

**Table 7: Funding by care home registration (n=219)**

Care Home Registration	Social Services	NHS	Self Funding	Unclear	SS & private top-up and/or NHS and private top-up	Total
Residential	44 (42.7%)	7 (6.8%)	45 (43.7%)	6 (5.8%)	1 (1%)	103
With nursing	40 (34.5%)	46 (39.7%)	21 (18.1%)	2 (1.7%)	7 (6%)	116
Total	84 (38.4%)	53 (24.2%)	66 (30.1%)	8 (3.7%)	8 (3.7%)	219

Nearly a quarter (24.2%) of residents was reported as in receipt of NHS funding for their care home placement, which appears high. One care home organisation had a statistically significantly higher proportion of residents in receipt of NHS funding than other care home organisations, which may suggest that these residents had

higher care needs. As shown in Table 8, in Site I this is considerably higher at 42%. These residents were concentrated in nursing homes (39.7% versus 6.8% in residential homes). Table 8 below breaks down funding type by care home registration and site.

**Table 8: Funding by Site (n=219)**

Site	Social Services	NHS	Self-Funding	Unclear	SS & private top-up and/or NHS and private top-up	Total
1	24 (27.3%)	37 (42%)	27 (30.7%)	0 (0%)	0 (0%)	88
2	39 (54.9%)	5 (7%)	20 (28.2%)	6 (8.5%)	1 (1.4%)	71
3	21 (35%)	11 (18.3%)	19 (31.7%)	2 (3.3%)	7 (11.7%)	60
Total	84 (38.4%)	53 (24.2%)	66 (30.1%)	8 (3.7%)	8 (3.7%)	219

However, these figures should be interpreted with caution as it was not possible to verify them.

### **Length of Stay**

At the time of data collection the median length of stay across for residents was 22.6 months (0.1-181.9).

**Table 9: Median length of stay in months by care home (n=234)**

Care Home	Median number of months (range)	N
1	27.8 (0.2 - 111.2)	12
2	10.8 (0.2 - 69.1)	11
3	32.9 (0.1 - 126.0)	17
4	23.4 (1.7 - 144.4)	29
5	23.7 (1.2 - 94.3)	23
6	21.5 (0.4 - 85.4)	17
7	24.2 (0.6 - 59.3)	17
8	20.8 (0.1 - 136.0)	16
9	15.7 (0.2 - 140.6)	12
10	27.5 (2.5 - 109.1)	15
11	10.5 (1.8 - 44.8)	5
12	5.6 (0.1 - 112.2)	8
13	38.2 (27.5 - 48.9)	2
14	24 (0.6 - 60.0)	11
15	33.4 (5.0 - 181.9)	15
16	20.4 (0.1 - 84.7)	13
17	14.5 (0.5 - 45.8)	12
Total	22.6 (0.1 - 181.9)	235

### **Mortality rates**

The average mortality rate in care homes is 26.2% (Shah et al 2013). Data were collected over a 12 week period, therefore a 6.5% mortality rate within the sample would reflect the national picture. This was broadly reflected in 15 of the 17 care homes.

### **Cognitive function**

The majority of residents had no reported change or decline in their cognitive function, which may fit with the clinical perception that people decline very slowly. For one fifth of the sample (20.4%) there was a reported decline since admission. Nearly two-thirds (65.7%) of residents had a diagnosis of dementia, which concurs with findings by Prince et al (2011). A number of care homes in the sample were dementia care registered while others had dementia specific units. Of those with a diagnosis of dementia, 42.4% were judged to have severely impaired cognition; 9.7% were judged to be independent for daily decision making.

### **Activities of Daily Living**

Activities of Daily Living (ADL) abilities ranged from requiring limited assistance and needing supervision, to extensive assistance and total dependency. A higher percentage of residents with *total dependency* in ADLs lived in care homes with *on-site nursing*. However, a higher proportion of residents in *residential care homes* were reported as needing *extensive assistance* for bathing, personal hygiene and toileting. The lower proportion of residents identified as either being totally dependent or requiring extensive assistance for eating in comparison to other ADLs is in line with other studies which have shown eating as one of the last activities to decline in end of life (Mathie et al 2012).

**Table 10: Number of residents needing extensive assistance in ADLs by Care Home Registration Type**

	Bathing (%)	Personal Hygiene	Toileting	Eating	Walking (wheelchair, scooter)
Residential	52 (50.2)	46 (44.7)	36 (35.3)	8 (7.8)	20 (19.4)
On-site Nursing	49 (32.9)	40 (27)	29 (19.9)	13 (8.8)	53 (35.6)
Total (% of sample)	101 (40.1)	86 (34.3)	65 (26.2)	21 (8.4)	29 (11.5)

\* Percentages represent the percentages of the whole sample by those who were classified as needing extensive assistance for each ADL as opposed to independent, needing minimal or moderate assistance, being totally dependent.

### Pressure Sores

Records indicated that approximately 15% (38) residents had a pressure sore at the time of data collection. However, the severity of the pressure scores was not recorded.

### Diagnoses

The care home population has multiple morbidities. Excluding dementia (see Table 11 below), mental health problems such as depression and anxiety were the highest recorded condition (42.9%), followed by cardiovascular disease (33.9). Remarkably, just over 6% of the sample had a cancer diagnosis.

**Table11: Number of residents with diagnosis**

Diagnosis	Number of Residents	% of total sample
Dementia	166	65.9
Mental Health problems	106	42.9
Cardiovascular disease	84	33.9
Stoke	48	19.3
Neurological Other	41	16.5
Diabetes	37	15
Cancer	16	6.5

With the exception of other neurological diagnoses, there was no significant difference between proportions of residents with different conditions by care home registration type.

**Table 12: Diagnosis of residents by care home registration type**

Diagnosis	Residential (%)	Nursing (%)	Total
Dementia	71 (68.9)	95 (63.8)	166
Psychiatric	43 (43.9)	63 (42.3)	106
Cardiac	34 (34.3)	50 (33.6)	84
Stroke	14 (13.9)	34 (23.0)	48
Neurological Other	9 (8.9)	32 (21.5)	41
Diabetes	13 (13.3)	24 (16.1)	37
Cancer	9 (9.2)	7 (4.7)	16

### Resident Condition Status

Based on their condition, 34 residents (13.6%) of our 30% sample were identified by care home staff as reaching end stage. Of these 34 residents four died before the end of the 12 weeks of data collection, 27 completed the 12 weeks of data collection and for 3 the daily Service Use Logs were not returned. Only eight of the 34 identified with their condition in end stage were on a palliative care register (three of these residents died during the 12 weeks of service use data collection,

three completed the 12 weeks and daily Service Use Logs were not returned for two). This suggests that recognising a resident's condition of reaching end stage was not necessarily a trigger for professionals to place residents on a palliative care treatment program.

### **Legal Guardian Status**

Care home staff indicated that most care home residents (228 from 245 (93.1%)) had a legal guardian.

### **Evidence of Advance Care Planning (modified InterRAI)**

Of the randomly collected sample 52% had some form of Advance Care Planning (ACP) in place. Those who were severely impaired were statistically more likely to have ACP in place than those who were independent or had minimal to moderate cognitive impairment ( $p=0.013$ , chi squared test). However, there is evidence in the decedents' notes that this figure has gone up to 60% in residential homes, and to 81% in homes with on-site nursing (see Table16).

**Table 13: ACP by cognitive skills for daily decision making (n=224)**

Cognitive skills for daily decision making	Advance Care Planning		Total
	No	Yes	
Independent	20	24	44
Minimum or Moderate Impairment	62	44	106
Severely Impaired	27	47	74
<b>Total</b>	109	115* <sup>5</sup>	224

### **Service Use Logs**

Data on resident service use were collected for 84 days (12 weeks). Two care homes were unable to participate in the completion of Service Use Logs, and one care home only participated for 63 days (9 weeks).

### **Primary Care Contacts**

Contacts from primary care services were recorded for 238 residents in 15 of the 17 participating care homes for up to 12 weeks. In this time, the median number of GP visits per resident across care homes was 1 (range 0-10). For District Nurse visits this was 0 (range 0-63). District nurses did not visit nursing homes. When care homes with nursing were removed from the calculation, median visits from

<sup>5</sup> ACP was recorded for 116 (of 224) residents; for one resident the level of cognitive skills was missing



District Nurses was 1 (range 0-63). This figure includes 3 residents at different care homes who received more than 20 visits by district nurses during the 12 week data collection period. Apart from the EFE visits, only 4 visits from palliative care specialists across 3 care homes were recorded during the 12 week data collection period. To put this data into context, only people with complex needs at end of life would be expected to receive assessment by a specialist palliative care nurse, otherwise they may receive care and support from community nurses or care home staff.

### **Unplanned Hospital Admissions**

The majority of residents (95%) had no admission to hospital in the 6 months covered by data collection. Eleven residents were admitted on at least one occasion during the 6 months. An emergency ambulance was used for 14 residents and 5 residents visited A&E but were not admitted (Table 14).

**Table 14: Hospital Admissions in 3 months prior to the start of the study and 12 weeks of data collection**

Hospital admissions 3 months prior to data collection (from modified InterRAI form)	Total number of hospital admissions 12 weeks of data collection (from Daily Service Use Logs)					Total
	0	1	2	3	4	
None in last 90 days	214	2	3	1	0	220
31 to 90 days ago	7	1	0	0	0	8
15 to 30 days ago	0	0	0	0	1	1
8 to 14 days ago	3	0	0	0	0	3
In last 7 days	3	3	0	0	0	6
Total	227	6	3	1	1	238

The preceding overview of care home characteristics and residents' characteristics provides a framework within which to locate findings on module delivery, the roles of EFEs as EoL Care Educators/Facilitators, and the professional roles of trainers, whose task it was to teach learners.

### **Comparisons with PHAST findings**

Data collected for the After Death Analysis (ADA) post ABC training and reported by PHAST (Pyper et al 2013) were not drawn from decedents' notes kept in care homes. In contrast, data collected for the present study were extracted from 150 decedents' notes kept in participating care homes and dated between October 2012 and June 2013. Considering the time-lag between the implementation of the TTT

programme and its recorded outcomes, data were not expected to reflect significant changes since February 2013. Small increases were recorded in anticipatory prescribing (from 47% to 49.3%), but such numbers need to be interpreted with caution as our data were collected from a subset of people 'by expectation of death', whereas PHAST data did not record such differences. Data on ADA may therefore not be comparable at all. Overall, however, the achievements of ABC appear to have been broadly maintained. One could make a case for the need to ensure the sustainability of TTT in order to give training a chance to be applied more widely and for outcomes to be recorded more consistently.

### **3.3 Module delivery: staff availability, blended learning and bite-size teaching**

Participating care homes were variously organised into units catering for residents with early dementia, advanced dementia, high physical needs, general frailty, some short-stay/respite beds, and beds for residents being admitted specifically for palliative care. Some of the learners who participated in the TTT EoL Care Education Programme were assigned to a particular unit, whereas others worked across units. This impacted on rotas and shifts, and consequently on staff availability for training.

The TTT Programme envisaged for each trainer to train six learners during the pilot study, but most trainers found it almost impossible to get six individuals together at any one time. Much of the teaching was therefore delivered as and when people were available and teaching formats were adapted accordingly.

Most care home staff did not have internet access via work-based computers. In the few instances where computers could be used, log-on problems were experienced frequently, which led to a significant drop in attendance generally, and in one care home particularly as they had initially offered on-line training only [T02091SLD]. Some learners reportedly also found it difficult to engage with the emotional aspects of watching DVDs on topics pertaining to death and dying without having access to instant debriefing through discussion and/or face to face interaction in a study group [E0205]. Consequently, there was a clear preference for learning to be mediated via discussion, and for applied teaching (bite-size micro-teach) sessions across all care homes, irrespective of the teaching module involved.

Across care homes, blended learning was therefore applied in the following ways:

- a) Learners watched a teaching module on-line (at home in their own time), followed by discussions with their trainer at work. Discussions were frequently scheduled to take place every 2<sup>nd</sup> week in order to give learners enough time to assimilate their newly acquired knowledge. In one care home, learners discussed modules in small groups, which were facilitated by their trainer, and then watched modules on-line (also mostly at home and in their own time). Subsequent discussions were held every 2<sup>nd</sup> week. Gaining an initial overview of a teaching module, prior to watching it on-line, was reported as very useful, especially if individuals found it difficult to read and assimilate information off a screen.
- b) Face-to-face only with use of reference to online modules
- c) 'Bite-size' micro teach, much of which reportedly also happened spontaneously as and when situations arose in practice. The bite-size approach was perceived by trainers and learners as more profitable than taking care home staff off already understaffed units. Getting staff released from their floor in order to attend training was reported as a major obstacle.

Two of the 17 care homes did not train any learners during the study period. For one care home it was "simply the wrong time" [E0102] to have TTT implemented, whilst the other care home was drafted into the pilot study as a replacement and needed to be prepared first, which took time and delayed TTT implementation. Of the 15 remaining care homes, seven began blended learning by watching the on-line material first, but many learners either found e-learning difficult, or had no on-line facilities at work and therefore had to watch DVDs at home. One care home attempted to use DVD teaching only which reportedly resulted in drop-outs. Six care homes used face-to-face only (due to difficulties getting staff together in groups), and 9 of 15 used the bite-size micro teach approach.

Analysis of the association between teaching approach and key outcomes (ACP in place, hospitalisation, primary care contacts) suggested that bite-size teaching was more effective. However, the numbers involved and the variation of uptake within the sample mean that this was not clinically significant.

Only four of the 17 participating care homes offered payment to learners if they came in for training on their day off. Two care homes offered time off in lieu, but as expressed by learners in one care home,

*"...we could have the time owed to us, but it was having to find the time to attend...and it is difficult once you are owed a whole shift for someone to cover, so you write it all off..." [FG0106\_AMM].*

### **3.4 Professional roles of EFE's delivering TTT to trainers**

As indicated in Table 1, EFEs were hosted by different organisations. The EFE role was interpreted in a range of ways and the frequency of contact appeared to be directly linked to the organisation of the sites, the number of care homes they had responsibility for in addition to TTT care homes, and the care home situation and its readiness to engage with the programme. This was evidenced in the differences in the reported levels of EFE support between sites (see Table 15). For example, one of the care homes in Site 1 reported low levels of participation in the TTT pilot project as there were too many conflicting demands during TTT implementation. Others were occupied with CQC inspections and/or were under pressure to meet targets for concurrently running EoL Care programmes as well.

**Table 15: EFE contact hours and contact frequency**

<b>Site</b>	<b>Contact hours</b>	<b>Contact frequency</b>
Site 1	57	70
Site 2	99	122
Site 3	27	41
Total	183	233

Site 2 included a replacement home which needed to be brought on board and required much EFE input. Seven care homes across the three sites had received other EoL Care training in addition to the TTT programme, only one of which was in Site 2. There is therefore an inverse relationship between care home readiness and the amount of training required.

Site 3 had the lowest number of EFE contact hours and contact frequency. Only five care homes in Site 3 that participated in this pilot study, one EFE did not submit any logs of contact hours or frequencies, and one of the EFEs is responsible for more than 50 care homes across her region and simply did not have the time or opportunity to engage with staff beyond conducting the basic TTT training. These findings are interesting in relation to care home readiness and the role and remit of EFEs, and will be discussed in detail in Section 3.8.

### **3.5 Professional roles of trainers delivering TTT to learners**

The professional roles of trainers delivering ABC learning modules to learners as part of the TTT EoL Care Education Programme varied across participating care homes. Roles ranged from general managers, deputy managers, clinical managers and care team/unit managers to nurses and carers with varying levels of EoL Care experience. The role of the trainer as a factor in the uptake of the TTT programme will be discussed in detail in Section 3.8 in relation to the effectiveness of several elements of the EoL Care Education Programme.

#### **Synopsis**

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- Participating care homes represented a mix of ownership
  - Resident characteristics were similar to those reported in other care home studies although a higher percentage were in receipt of NHS funding
  - Seven care homes had completed or were in the process of undertaking additional training and accreditation in EoL Care
  - At baseline 52% of residents sampled had an ACP in place
  - EFEs had a range of responsibilities in addition to their role on the TTT programme
  - EFE contact with the care homes was variable across the three sites
  - Trainers had different levels of seniority and responsibility
  - The implementation of the TTT programme in the care homes was shaped by contextual factors and staff's ability to take time away from their care work
  - Only two care homes reimbursed staff for their time on the programme
  - Bite-size teaching sessions integrated into the routine of the care home were perceived as the most effective method of training
- 

### **3.6 What evidence is there that the TTT Education Model increases residents', family members', CH and NHS staff engagement with Advance Care Planning (ACP) and on-going conversations about EoL Care?**

This section presents findings on how TTT was reported as having an impact on how staff engaged with talking about dying, their interactions with family and visiting health care professionals, their use of ACPs, and what the review of decedents' notes revealed about the use of ACPs and when they were implemented.

### **3.6.1 EoL conversations with residents and family: relational uncertainty**

Training modules in Communication Skills, Advance Care Planning, and on Comfort and Wellbeing in EoL Care aimed to equip staff to hold meaningful and informed conversations about death and dying with residents and with their families. Topics included funeral arrangements and extended to bereavement care, as families approach care home staff more often for support now [FG0106P3]. Conversations reportedly were beginning to break down stigma related to speaking about death, as staff learnt to navigate medical, social and cultural discourse of death and dying.

As expressed by trainers: *"Previously, nine times out of ten we'd just go 'oh', if a resident approached this subject. But now we talk about it...it makes one aware that one **can** talk about EoL...one can assist relatives to face what's coming"* [FG0106P3].

*"...all of the learners were saying that they were most scared of having to have those conversations with families. Every single one of them has said to me I feel so much more confident now, because I know that it's a hard conversation, but I know how to deal with it now"* [T0207SA].

The impact of the TTT EoL Education Programme on the communicative aspect of EoL Care is perhaps best summed up by the following quote: *"When I first started working [in a care home] you never heard of anyone dying in the home unless it was sudden...but now... and I wouldn't have known what to say, but if you've got an Advance Care Plan it's easy to have a conversation..."* [WS02MJH].

Increased knowledge and staff confidence was perceived as contributing to improving relationships between carers and the people they care for and their families, which in turn influenced the use of ACPs.

### **3.6.2 Advance Care Planning in participating care homes: participants' perceptions**

Trainers' perceptions of the direct influence of TTT on linkages between ACP, EoL Care, DNACPR forms and service provision were expressed in examples referring to residents, families, and GP practices. These examples show trainers' increased confidence through using ACP when engaging in EoL Care discussions, helping families to plan for EoL Care for their loved ones, and when discussing DNACPRs with GPs, all of which impacts on practice.

Trainers reported changes in their confidence: *"...we have more knowledge now ...which makes us more confident. We now know what we are asking for, whereas before we didn't know. If one doesn't know what's out there, such as ACP forms and DNACPR forms...and the statement of wishes... We can add these to our care plans now, whereas before the training we didn't have a clue..."* [FG 0212].

Trainers also reported changes in their use of documentation: *"...we used ACP check-lists before the training, but they have been amended since the training. In addition, we now use original DNACPR forms, whereas before we just noted it in the care plans; now we have a file of the originals"* [T02111SLD], and changes in how they engaged with visiting NHS professionals: *"I succeeded in having another DNACPR in place for one of my residents today....the GP was very happy with everything that I told him about the training that we had...., and the family are happy that their dad will not go to a hospital where no one knows him and probably no one will care for him like we do here..."* [TK\_0210T1\_a].

These observations were corroborated by EFEs: *"...TTT helped this process because Trainers now have the confidence to start the conversation. The communication skills module was instrumental in conveying the skills to conduct EoL Care conversations with residents, families and GP surgeries"* [E0206].

*"...via careful discussion and communication on the basis of the TTT training the family were able to plan for their loved one's EoL Care, including coming to a decision on whether to attempt resuscitation or not, just by using the ACP forms. ACP is proving to be a powerful tool to keep these poor, elderly, frail people in a place where they are known and where they are comfortable"* [E0208].

However, as the following quote illustrates, it was recognised how hard it was to achieve this level of care across the whole care home: *"....she does it all. She chases the GP to get the DNACPR forms, she has discussions with the family ahead of time, care plans are written, just in case medication is in place. The problem is that she cannot do this for the whole care home (>60 beds), so a care home needs to have more than one person being good at EoL Care; the changes have not been as wide-spread as I had hoped"* [E0207] (both trainers in each CH had the opportunity to train others). Actual numbers of learners trained per care home are discussed in Section 3.8.1 in relation to the role of the trainer as a factor in the uptake of the TTT programme.

Higher levels of confidence as a result of enhanced knowledge of Advance Care Planning impacted on staff interaction with residents and families, on symptom assessment and symptom management, on recognising the transition from living to dying, and on involving NHS services in the provision of EoL Care as and when required. Figure 2 below summarises how ACP training was reported and perceived by participants as changing practice, which in turn affects changes regarding the management of care.



**Figure 3: Impact of TTT on ACP and EoL Care in participating care homes**

As indicated in Section 3.2, 52% of randomly selected residents at baseline had an ACP in place. As all the care homes had already participated in the ABC programme and seven had received additional EoL Care training it would be expected that the care homes would achieve this level of documentation or higher. This figure increased by the end of the evaluation as was demonstrated in the review of the decedents’ notes and indicated in Table 16 below.

### **3.6.3 Review of decedents’ notes: evidence of Advance Care Planning**

The review of the 150 decedent notes demonstrated evidence of discussions around Advance Care Planning (ACP) between care home staff and residents and/or their families in 111 (74%) care notes. Of these, 105 (70%) had an advance care plan in their notes, 108 (72%) residents had a DNACPR form in place and 92 (61.3%) of residents had a PPC in place. Variations between care homes with and/or without on-site nursing are shown in Table 16.



**Table 16: Evidence of Advance Care Planning in decedents' notes (n=150)**

	<b>ACP Discussion (%)</b>	<b>ACP in Notes (%)</b>	<b>DNACPR (%)</b>	<b>PPC (%)</b>
Residential (n=65)	44 (67.7)	42 (64.6)	39 (60)	35 (53.8)
On-Site Nursing (n=85)	67 (78.8)	63 (74.1)	69 (81.2)	57 (67.1)
<b>Total (n=150)</b>	111 (74)	105 (70)	108 (72)	92 (61.3)

Residents in care homes with nursing have shorter life expectancies than residents in care homes without onsite nursing, and this may have had an impact on documentation pertaining to EoL Care. A trainer from a dementia unit in a residential home commented that families are often reluctant to discuss EoL Care (actively avoiding ACP) for relatives who suffer from Dementia as long as their physical condition does not suggest that they might be in their last year of life [T0210T1]. Evidence of discussions and records of ACP was also significantly more likely to be found in decedent notes of residents whose death was expected, irrespective of whether they died at a care home or in hospital (both  $p < 0.001$ , Fisher's exact test). This is indicated in Tables 17 and 18 below.

**Table 17: Evidence of ACP discussion by expectation of death (n=150)**

<b>ACP Discussion</b>	<b>Was Death Expected</b>			<b>Total</b>
	Yes	No	Unclear	
Yes	97	12	2	111
No	21	10	8	39
<b>Total</b>	118	22	10	150

**Table 18: Evidence of ACP recorded by expectation of death (n=150)**

<b>ACP Recorded</b>	<b>Was Death Expected</b>			<b>Total</b>
	Yes	No	Unclear	
Yes	91	12	2	105
No	27	10	8	45
<b>Total</b>	118	22	10	150

There was a statistically significant difference in whether or not a DNACPR was in place between residents whose death was expected and residents who were not expected to die any time soon, or where expectations were unclear ( $p < 0.001$ , Fisher's exact test). See Table 19.

**Table 19: Evidence of DNACPR by expectation of death (n=150)**

<b>DNACPR</b>	<b>Was Death Expected</b>			<b>Total</b>
	Yes	No	Unclear	
Yes	100	5	3	108
No	18	17	7	42
<b>Total</b>	118	22	10	150

Findings indicate a greater willingness toward discussing ACP and signing DNACPR as residents' conditions decline. Advance Care Planning (ACP) therefore appears to be a negotiated process between residents, families, care home staff and GPs, as to when to take such decisions. The date of the DNACPR was recorded for 71 residents. Over half of these residents (53.6%) had a DNACPR in place up to one month before death, with over a quarter (26.8%) being signed in the week before death. Two were signed on the day death occurred. Table 20 refers.

**Table 20: Length of time between DNACPR being signed and death (n=71)**

<b>Time period</b>	<b>N</b>	<b>%</b>
Up to one week	19	26.8
Between one and two weeks	6	8.5
Between two weeks and one month	13	18.3
Between one and three months	8	11.3
Between three and six months	10	14.1
Between 6 months and one year	9	12.7
Over 1 year	6	8.5
<b>Total</b>	<b>71</b>	<b>100</b>

### **3.6.3.1 Place of death**

Of the 150 residents whose decedent notes were surveyed, 118 (78.7%) died in a care home, and 32 (21.3%) died in hospital. As shown in Table 21, care homes with on-site nursing recorded a lower percentage of residents dying in hospital (15.3% of residents) than residential homes (29.2% of residents) during the same period of time. This was statistically significant ( $p=0.039$ , chi-squared test).

**Table 21: Place of death by type of care home (n=150)**

	<b>Care Home (%)</b>	<b>Hospital (%)</b>	<b>Total</b>
Residential	46 (70.8)	19 (29.2)	65
On-Site Nursing	72 (84.7)	13 (15.3)	85
Total	118 (78.7)	32 (21.3)	150

Although not statistically significant ( $p=0.066$ , chi-squared test), slight differences in place of death were also recorded in connection with additional EoL Care training received in some participating care homes. As shown in Table 22 below, participating care homes which had received additional EoL Care training either prior or during the study period recorded lower recorded hospital deaths than care homes that had not had the benefit of longer term additional previous and/or concurrent EoL Care training.

**Table 22: Place of death: CH with additional EoL training (n=150)**

	Care Home (%)	Hospital (%)	Total
Train the Trainer	45 (71.4)	18 (28.6)	63
Additional EoL Care Training	73 (83.9)	14 (16.1)	87
Total	118 (78.7)	32 (21.3)	150

**3.6.3.2 Preferred priorities for care (PPC)**

Residents' Preferred priorities for care (PPC) are usually recorded in ACP statements and PPC notes. This was the case for 92 (61.3%) of the 150 residents whose notes were surveyed. Of 92 residents, 80 (87%) died in their preferred place of death, which included one person dying in hospital as specified, and one person where care was appropriate for their needs. It would appear that, for many of the 12 residents who died in hospital rather than in the care home which had been stated as their preferred place of death, hospitalisation was appropriate, for example where a resident had a fall and/or fracture, where a resident requested admission to hospital, or died unexpectedly.

**Table 23: Preferred place of care by type of care home (n=92)**

	Yes (%)	No (%)	Total
Residential	26 (74.3)	9 (25.7)	35
On-Site Nursing	54 (94.7)	3 (5.3)	57
Total	80 (87)	12 (13)	92

As was the case for ACPs and DNACPR Forms, PPCs were also more likely to be recorded for residents whose death was expected than for those whose death was not expected or expectations were unclear (Table 24 refers). Of the 58 residents who did not have their PPC recorded, 38 (65.5%) died at care homes and 20 (34%) died in hospital. Findings were statistically significant ( $p < 0.001$ , Fisher's exact test).

**Table 24: Evidence of PPC by expectation of death (n=150)**

	Was Death Expected			Total
	Yes	No	Unclear	
PPC				
Yes	85	6	1	92
No	33	16	9	58
Total	118	22	10	150

## Synopsis

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- These modules increased knowledge and consequently confidence, which enabled care home staff to hold conversations about EoL with residents, their families and GPs
  - Decedents' notes evidenced that ACP, DNACPR and PPC were discussed and recorded
  - Record keeping of such discussions and notes increased since TTT began
  - There is a greater willingness toward discussing ACP and signing DNACPR forms as residents' conditions decline
  - Residents in care homes with nursing have shorter life expectancies than residents in care homes without onsite nursing and this may have had an impact on documentation pertaining to EoL Care
  - Care homes with on-site nursing recorded lower percentages of hospital deaths than residential homes
- 

### **3.7 What impact does the TTT model have on CH staff in relation to confidence, reported knowledge, symptom assessment and management, and involvement with NHS services when providing EoL Care?**

The previous section discussed care home staff's perceptions of increased confidence as a result of increased knowledge gained via the TTT model in relation as well as in relation to ACP. The following section addresses reported knowledge and increased confidence in relation to symptom assessment, symptom management, and interaction with NHS services when providing EoL Care.

#### **3.7.1 Reported knowledge on symptom assessment and management: pathway uncertainty**

The TTT programme was seen as influencing symptom management and recognition of when someone was dying by changing specific care practices, increasing anticipatory care and alerting visiting professionals improving the use of comfort measures and documentation of care.

##### **3.7.1.1 Comparing past and present care**

The interviews and focus groups enabled the care home staff to compare previous practice with how they provided care since completion of the TTT. Mouth care was

a frequently used example of where change had occurred. This was addressed in detail via a TTT teaching module dedicated to mouth-care, a practice which trainers have now recognised as a vital aspect of End of Life Care.

As one carer stated, *"I remember a lady, about two years ago, and her lips were so dry.....and I would have found some Vaseline...that was my mouth care. I honestly didn't think to clean her mouth...I didn't know – then – how much more comfortable this would have made her"* [FG0212].

One reported example of this kind of change was that *"...staff would go out and buy some juice if a particular drink was not on the care home's menu...something like pineapple juice...the training really did make staff want to participate...and it makes it so much easier on the residents in their final stages of life"* [E0101].

Trainers are also aware now that they can request medication for pain management in liquid form if a resident can no longer swallow.

Qualitative data indicated that, although experienced care home staff knew how to recognise pain and signs and symptoms pertaining to terminal agitation, TTT training re-enforced existing knowledge and took it to a different level of pro-activity. It reinforced prior learning and was seen as giving staff more authority to act.

**Comment by a nurse in her capacity as trainer,** *"Staff were giving practical EoL Care before the training, but now they are much quicker to give appropriate care; before they would have asked nurses first and waited for instructions; now it has freed up nurses' time"* [T03152SLD].

**Trainers about their learners:** *"...before the training carers and learners would come and tell me that a resident was in pain, but now they are actually telling me where that pain is" (C-T). "Yes, that's the difference; because they are more aware and know what to assess, they know what to observe, and they know the changes and they will tell you (V-T). "Overall, it has made us more aware that we can have some input and some influence over EoL Care rather than leaving it all to the nursing staff"* [FG0103P3].

### **3.7.1.2 Symptom management as reported by trainers**

Symptom assessment and management as reported by trainers focused on breathing, skin changes, mouth care, and pain management to control agitation and anxiety. Trainers talked of being able to anticipate residents' needs and being more aware of the need to ensure the resident was comfortable.

*"...as a result of the training I can anticipate the stage the resident is at and make suggestions, and once I have the go-ahead [from the nurse or the team manager], I can make the person much more comfortable. It's changed the way in which we deal with EoL Care" [FG0106].*

*"...because there is so little training in EoL Care I could only accumulate knowledge through the experiences of others, when someone says 'wait for the rattles' [breathing] for example,...but now that we have done the training we understand; or when they [residents] are getting better I always used to think 'that's it, they are getting better'...but they're not. It must be such an emotional roller-coaster for a relative to hear that their parent has gotten worse, then better, then worse....but if I know that it keeps doing this until..... so that has helped" [FG0212].*

Training was also enhanced through the professional roles of EFes. *" We have also had residents who needed to be put on syringe drivers, and working along McMillan nurses has been very helpful...people who are dying can become quite agitated, so there needs to be medication to control pain and anxiety, so that they have a peaceful passing...and working with the DN has been very helpful too" [FG0316].*

### **3.7.1.3 Symptom management: review of decedents' notes**

Of the 150 decedents' notes reviewed 140 indicated whether death was expected or not. Of these 140, 118 (84.3%) residents had been expected to die. As shown in Table 25, evidence of symptom assessment, management and control in the period leading up to their death was recorded in 47 (39.8%) cases. Whilst expectation of death did not necessarily lead to active use of symptom assessment tools such as colour charts or an Abbey Pain Score, according to discussions reflected in the care notes this meant that residents were kept as comfortable as possible, and symptoms were managed as indicated by nursing staff and/or GPs.

**Table 25: Use of symptom assessment tools by expectation of death (n=150)**

Was Death Expected	Symptom Assessment			Total
	Yes	No	Unclear (died in hospital)	
Yes	47 (39.8)	57 (48.3)	14 (11.9)	118
No	0 (0)	10 (45.5)	12 (54.5)	22
Unclear	0 (0)	4 (40.0)	6 (60.0)	10
Total	47 (31.3)	71 (47.3)	32 (21.3)	150

### 3.7.1.4 Formal protocol / Integrated Care Pathway (ICP)

As shown in Table 26 below, of the 118 residents who were expected to die (46 [39%]) had evidence in their care home notes that a protocol or Integrated Care Pathway (ICP) was used during the dying phase.

**Table 26: Evidence of protocol / ICP by expectation of death (n=150)**

Was Death Expected	Protocol / Integrated Care Pathway			Total
	Yes	No	Unclear (died in hospital)	
Yes	46 (39.0)	59 (50.0)	13 (11.0)	118
No	0 (0)	10 (45.5)	12 (54.5)	22
Unclear	1 (10.0)	3 (30.0)	6 (60.0)	10
Total	47 (31.3)	72 (48.0)	31* (20.7)	150

\*1 resident died who in hospital had evidence in their care home notes that LCP had been used during their admission.

### 3.7.1.5 Use of anticipatory medication

Of the 118 residents whose deaths were expected, 74 (62.7%) had anticipatory medication in place (Table 27).

**Table 27: Use of anticipatory drugs by expectation of death (n=150)**

Was Death Expected	Use of Anticipatory Drugs			Total
	Yes	No	Unclear (died in hospital)	
Yes	74 (62.7)	31 (26.3)	12 (10.2)	118
No	0 (0)	10 (45.5)	12 (54.5)	22
Unclear	0 (0)	4 (40.0)	6 (60.0)	10
Total	74 (49.3)	45 (30.0)	31* (20.7)	150

### **3.7.1.6 Certainty and uncertainty of dying pathways**

The use of formal protocols for residents who died in the care home was significantly more likely to be recorded in care homes with on-site nursing than in care homes without. Likewise, anticipatory medication was also more likely to be in place in care homes with on-site nursing. However, when formally recorded protocols and the use of anticipatory medication were tested with residents whose deaths were expected, differences between types of care home (residential versus with on-site nursing) disappear. This indicates that when residents were expected to die (pathway certainty), both types of care homes performed similarly (there are no statistically significant differences between them). However, when there was pathway uncertainty (not knowing whether death might be expected, or expectations were unclear) care homes with on-site nursing had more ICPs in place and evidenced higher use of anticipatory drugs than residential homes did.

### **3.7.1.7 Where are residents admitted *from* and admitted *to*?**

Care homes which benefitted from additional EoL Care training and also had nursing on-site were more likely to admit residents from hospitals. Some care notes contained hospital discharge forms requesting that a resident be discharged to GSF accredited facility. Three residents were admitted from a hospice to care homes that had nursing on site and already attained GSF accreditation, or were in the process of attaining it. In contrast, residential care homes or those without GSF accreditation were more likely to admit residents from their own homes.

Of the 150 decedent notes reviewed, 129 residents had a recorded reason for admission. Of these 129 residents, 23 (18%) were admitted for palliative or end of life care. Twenty two of these 23 residents were admitted to care homes with on-site nursing. Of these 23, five were admitted to care homes receiving TTT training only, and 18 to care homes that received / or were in the process of receiving, additional EoL Care training.

### **3.7.2 Involvement with NHS Services when providing EoL Care: service uncertainty**

As already noted, increased knowledge and confidence led to a perceived improvement of communication between care home staff and health care professionals. This was particularly evident for care homes without on-site nursing



provision. Participants reported they were more proactive in their dealings with visiting NHS professionals and more willing to express opinions or questions.

### **3.7.2.1 Improved relationships with GPs and other HC professionals**

**As expressed in a workshop discussion:** *"Learners can communicate with the GP's now, even along the lines of 'I think a resident may need this or that because s/he doesn't move, doesn't eat'... they will ask me to confirm it and then ask the GP to have a look. It helps"* (V-T). This was confirmed by one of the EFEs who said *"...yes, they [trainers] know what they are looking for now. And they aren't asking you constantly, they are just doing it, doing it themselves". "That's excellent, because that shows such a shift in their learning"* (C-PL). *"They combine what they see with their learning; it does make a difference"* (V-T).

Interaction with GPs was reported as task focused and often revolved around prescriptions for anticipatory medication and signatures for DNACPR forms. The training was seen as increasing staff confidence in asking GPs to visit and prescribe.

**As expressed by a trainer:** *"...yes, we are more confident to give them a bit more information now ....we never had any training on EoL, but TTT has highlighted certain aspects, like that one **can** ask for just-in-case medication, and that the DNACPR form might be signed more readily when wishes are recorded in the ACP [FG0106]. Similar improvements were reported from EFEs across all sites.*

**As one of the EFEs remarked,** *"...the GPs know that they [trainers and learners in the care homes] are doing the training and will help them with anything they need, for example they are getting the 'just-in-case' box immediately now.*

*The DNs also support them much better than before and the GP liaises with them [with the DNs]. They [trainers and learners] also know how to get hold of a palliative care team now which they didn't before"* [T02082SLD].

Although the most marked improvement of service relationships between care homes and service providers were reported from residential homes, such comments were also echoed by trainers in care homes with on-site nursing.

**As reported by a trainer:** *"Nurses [in their roles as learners] suggested that we might get some just-in-case medication prior to the bank holiday weekend; prior to*

*the TTT training the prompting would have come from myself or the home managers; they would not have thought ahead” [TK0105T1].*

There was also evidence of the TTT EoL Care Training having an impact on care home staff assertiveness and willingness to challenge existing practice, as this example of working with paramedics shows. *“...I did have a paramedic try to tell me that they [DNACPR forms] had to be renewed every two months and I said, we’ve got more than 50 residents...do you honestly think we can get these renewed every two months...and he said you’re going to have trouble...and I said but it says ‘indefinite’, it’s been ticked ‘indefinite’...oh but it still needs to be checked every two months. And I actually queried it and said but this can’t possibly be right and he said well I will look into it... but we had another paramedic come out the next day and I queried it with her and she said no, if it’s ticked indefinite it’s indefinite, but I don’t think the message has got through to everyone” [T02122MJH].*

### **3.7.2.2 Feedback from GPs**

Positive feedback was also received from one of the GPs. *“One of the GP practices commented on the course [TTT], particularly the GP who does a weekly round in the care home observed that there is increased staff confidence and increased triage of patients and improved symptom control” [E0206].*

Some care homes, however, did not report any significant change in how they worked with primary health care since they started TTT. The response was variable and affected by how many NHS professionals visited the care home.

As stated by one of the participating care homes *“...we work with a number of GP practices, one of which recognised that care home staff have been taught how to recognise the transition from life to death, but there is a bit of a fight with the other surgery. The third surgery is very good and will visit to do DNACPR assessments, but they use their own on-line forms, not the East of England forms, and they re-assess the residents every month” [T02101SLD].*

Pre-existing relationships between care homes and GP practices affected conversations about end of life care. As one of the care home managers stated:

*“There is a very special relationship between a care home and a GP, and since I have become manager we’ve had meetings with practice managers to see how we*

*could help each other to achieve a more joined-up approach. We are now in the process of gradually transferring residents to one particular surgery (once residents and family are happy to do so). On the whole, we have a much better working relationship now; they come here on regular visits, and they are used to our way of working, and it was the perfect opportunity to discuss the DNACPR forms. Although staff here were quite good at starting to complete these forms, it was very difficult to get GPs to commit their time to actually join in these discussions and sign them...and East of England ambulances will not accept anything but such forms”[CHM0106AMM].*

Reportedly, service providers’ awareness of staff having been trained in EoL Care has also made a difference in another care home. As one of the trainers stated, “...some of the DNs also know that this care home has received training. Prior to the training, the DNs would have to ask for everything for the residents who approach end of life, but now the care staff have taken this over. They never see the palliative care team” [T02101SLD]. In this case, it seems that TTT training has reduced the need for DNs to be called out. The level and frequency of primary care contacts was discussed in Section 3.2.

## Synopsis

- TTT enabled many care home staff to improve symptom assessment and management
- Mouth care was a frequently used example of where change had occurred
- Anticipatory medication was in place in both types of care homes (residential and with on-site nursing) when residents were expected to die (pathway certainty), but more often in care homes with nursing even where expectations might have been unclear (pathway uncertainty)
- Communications between care home staff, GPs and other HC professionals reportedly improved in most cases, although this in part reflected the quality of pre-existing relationships.
- Staff reported they were more proactive in their dealings with visiting NHS professionals and more willing to express opinions or questions
- Positive feedback on TTT was received from care home managers and GPs

### **3.8 Which elements of the programme were the most effective? Barriers and facilitators**

The uptake of the TTT model was influenced by the availability of trainers and by characteristics external to the model itself. Characteristics such as care home type (residential versus nursing), care home size (number of beds), ownership (for profit / non-profit), and additional EoL Care Education Programmes in place (or running concurrently) did not make any significant difference in relation to module delivery *per se*. However, the role and authority held by trainers in their respective care homes did appear to be important in how the programme was implemented.

#### **3.8.1 The Trainer role**

Of the 30 trainers enrolled in the programme, 14 held various managerial positions, ranging from General Managers to Deputy Managers, Clinical Manager and Care Team / Unit Managers. Findings indicate that some General Managers and Deputy Managers found it difficult if not impossible to discharge their added responsibilities as “trainers”, simply due to existing workloads, serious time constraints, and having to get groups of learners off the floor in order to attend training. As expressed by one of the Managers / Trainers: *"This is extra to my job and time consuming (T01051SA); I'm getting very frustrated that I'm not getting any time to deliver the training to staff...we have not had time to get together as a group to deliver training (TK0105T1 \_ c).*

This was somewhat different for Care Team/Unit Managers due to their hands-on role in their units and their more or less constant interaction with learners on the floor, which offered opportunities for bite-size teaching and applied learning in daily practice. Unit managers reportedly gathered their learners and discussed aspects pertaining to EoL Care, such as mouth care, pain management, or how to keep a specific resident comfortable toward their end of life [FG0106; 0211AMM; FG0212]. Both trainers and learners reported that such bite-size, applied teaching moments were not only very instructive, but also provided opportunities to discuss non-medical aspects of EoL Care. An overview of the number of learners trained in relation to professional roles held by trainers across participating care homes is presented in Table 28. The shading highlights care homes that trained nine or more learners.

**Table 28: Learners trained in relation to professional roles of trainers**

Care home	Learners trained	Role of Trainer 1	Role of Trainer 2
A	0	Care Team / Unit Manager	0
B	0	Gen Manager	Carer
C	2	Deputy Manager	Care Team/Unit Manager
D	4	Care Team / Unit Manager	Carer
E	4	Gen Manager	Deputy Manager
F	4	Trainer in CH	0
G	5	Trainer in CH	0
H	6	Care Team / Unit Manager	Night Unit Manager
I	6	Carer	Care Team/Unit Manager
J	6	Clinical Manager	Receptionist
K	9	Carer	Care Team/Unit Manager
L	10	Carer	0
M	10	Deputy Manager	Carer
N	11	Care Team / Unit Manager	Carer
O	12	Nurse	Nurse
P	12	Trainer in CH	Carer
Q	13	Nurse	Carer

Whilst some of the highest numbers of learners trained were achieved by nurses teaching learners on their floors, this pilot sample is too small to infer that such roles would be most likely to produce best outcomes. However, closer inspection revealed that the one common factor common between these trainers was the opportunity to spend much time on the floor with their learners, irrespective of what their specific roles might be. It was the opportunity to teach as and when situations arise, that allowed trainers to go through various aspects of the teaching modules with more learners than in the absence of such naturally occurring meeting places and teaching situations.

It was unclear whether a designated post of trainer in a care home would make a difference to the numbers of learners trained. As indicated in Table 28, the three trainers holding such posts trained four, five and 12 learners respectively. It was not possible to explain why there was such variability, except perhaps a trainer's personal interest in EoL Care, and the time they have available to spend with staff on the floor. As indicated in the interviews, 'dedicated trainer roles' require individuals to deliver *all* mandatory training in a care home, and EoL Care Modules might become "*just another thing to do*" [EFE 0208].

Sixteen of 17 participating care homes started with two trainers each, but four finished with only one trainer. The care home which had started with only one trainer had not trained any learners as at the end of the study period. This was a

home that joined as a replacement care home a few months into the pilot. This home has trained learners since then, and numbers of learners trained have increased in other care homes too.

### **3.8.2 Care home engagement with TTT**

Care home readiness to participate in the TTT programme was characterised by how the decision to participate had been made, availability and capacity of staff and unanticipated external events such as inspections by the regulator or staff turnover.

The explicit support of the manager was seen as key. As suggested by this EFE, *"...it's got to be individuals who are passionate, and the manager has to be committed to allowing them to do what they are supposed to be doing in the role of a trainer... much of it is therefore about organisation and leadership"* [0310].

Similar sentiments were expressed by another EFE who stated that main features of care homes where training has worked well were *"...strong managers and strong leaders, and I imagine a certain amount of stability"* [E0207].

This support had very practical implications about when staff would be available for training: *"...you need the support of the manager because she is the one who does the rota, she is the one who says when they [trainers and learners] can have time out to do the training or to meet with me, but there are lots of constraints on their time, ....sometimes I think it is very unfair when they have been on night duty, or when they have done a day's work and then they are still expected to train in the afternoon"* [E03010].

It was felt that even when staff were motivated it was not possible to deliver the programme without the manager's support. However, at the same time EFE's also recognised that *"... managers work with a limited level of staffing and don't always have the flexibility to let all of their staff off for the training at one time. They also experience a huge burden of duty and I feel it is important to recognise that the difficulties we have faced when doing the TTT training are a reality; this is how care homes work all the time"* [E0103].

Serious time constraints were reported at all levels of care home activity and staffing. There were examples of where trainers had to take on unplanned, additional managerial responsibilities, or cover for colleagues on long-term leave.

Other care homes had CQC inspections going on, which took precedence over training. As one EFE explained:

*"Both trainers in this care home were very keen, and extremely passionate about EoL Care training, but the CQC took all their time and energy" [E0102].*

At the resident level of care the hierarchical structure could mean that although care staff had been trained, they might not become 'trainers' themselves, if the care home's organisational structure does not confer the authority to work in this way. Findings indicated that, in one care home, whilst training has increased carers' general awareness of EoL Care, they were not allowed to pick up the phone and call a DN or GP, for example. As explained by one of the trainers,

*"...this is something the Care Team Managers (CTMs) do; care staff are only expected to care and then feed-back any problems. Although TTT has improved care staff confidence in speaking to families, they are not discussing EoL matters or DNACPR forms; this is done by CTMs; care staff would not be given such responsibilities" [FG0316].*

In contrast, and this has already been noted, in other care homes there was clear evidence that the trainers were pleased that learners began to take the initiative. Very often it was the level of managerial support that was perceived to be invaluable by trainers and EFEs alike.

Care home organisation, history and management, the level of management interest, how staff were organised, and who had the authority to act on a resident's behalf influenced how learning from the TTT could be implemented. Equally, the history of prior involvement in EoL Care training had a cumulative effect, as TTT was able to reinforce prior learning.

### **3.8.3 The cumulative impact of ABC/TTT/other EoL Care training**

The TTT Model follows on from ABC training modules, the completion of which was a pre-requisite for trainers to be accepted on the TTT education programme. In addition, seven care homes had either completed the GSF EoL Care Programme, or were in the process of doing so during the TTT pilot study. As one of the trainers stated, *"...the aims of TTT and GSF are very similar: to reduce hospital admissions, to ensure good EoL care for each resident, ensure that anticipatory medication is in*

*place when required, and that DNACPRs have been signed, all of which is also discussed and taught in the TTT programme” [T01042SA].*

Trainers and Learners commented on the different approach of the TTT to the GSF. The TTT programme was perceived as flexible due to its modular content, which lent itself to bite-sized delivery and is particularly useful in contexts that are characterised by time constraints. ABC/TTT was therefore seen as *much more time effective* and also better supported through EFEs and the additional resources they provided. In addition, TTT was not limited to carers only as its modules can be and have been rolled out to staff across care homes. As one CH reported, “...*as part of TTT we have encouraged all staff to take part in the training, including kitchen staff, admin staff, laundry, care assistants and nurses* [TK\_0105T1\_b]. This led to increased staff involvement with residents across departments. In contrast, trainers working in GSF accredited care homes found it difficult to engage with the amount of paperwork required by the GSF programme [T01011AMM].

However, GSF was also seen as a useful framework that supported TTT training. In one of the CHs currently going through the process of GSF accreditation, ACP checklists had already been in place [T01011AMM]. This facilitated the process of adding residents to an EoL Care Register at their GP surgery, which meant that residents were being discussed at GP’s monthly GSF meetings. This has reportedly helped to build trust between CHs and practitioners and resulted in anticipatory medication to be prescribed more readily [CH0106]. It also impacted on DNACPR forms to be signed more willingly ahead of time, rather than waiting for the crisis point.

On balance, although one might think of the GSF framework and the ABC/TTT training as competitive, these educational programmes were described as complementary where synergies between CHs and GP practices have been achieved [CHM0106].

#### **3.8.4 Contextual influences: do previous working relationships between EFE and trainer influence the uptake of TTT?**

Three of the 17 participating care homes had a working relationship over and above ABC training with their EFE prior to the TTT programme. Two of these homes were replacement homes and had to be brought on board at short notice. The third care home happened to be a home for which one of the EFEs had delivered ABC training. In both replacement homes pre-existing relationships, and the trust developed over



long periods of time, did influence working relationships, but not necessarily produce different or improved outcomes within the study period.

One care home, for example, needed a great deal of EFE input before they actually started training anyone, whereas staff the other replacement home had had the advantage of having worked with a clinician (EFE) over many years, and the care home manager had a particular interest in EoL Care. This meant that the EFE input was more as a facilitator. This care home trained 6 learners.

### **3.8.5 Level of EFE support**

As discussed in Section 3.4 and as indicated in Table 15, there was considerable variation in contact hours and contact frequency between EFEs and the care homes they worked with. High numbers of contact hours and/or contact frequencies did not necessarily translate into outcomes such as lower unplanned hospital admissions or primary care contacts in all care homes. As one EFE observed, making contact with the care home could be given as much time as working with the Trainers. Therefore, *"...it's no good just adding up teaching time, because it's at least that again, or more, trying to book sessions and to look through the off-duty [registers] trying to find the right time [for training], which is likely to be cancelled when something else goes wrong, which means having to re-book and re-assess before a teaching session is actually happening. So that can be a big barrier"* [E0102].

## **Synopsis**

- Levels of EFE support required were determined by care home readiness
- The role and responsibilities of the trainers in the care home was critical and could be a barrier or a facilitator to implementing the TTT model
- Opportunities of trainers to spend time on the floor with learners facilitated training and learning
- Organisational structure impacted on the authority of trainers & learners to implement their learning and constituted either a barrier or facilitator
- Care home engagement with TTT and managerial support are critical factors acting as barriers or facilitators to the implementation of TTT
- The cumulative impact of ABC/TTT and other EoL Care learning can build synergy between care homes and GP practices and reinforce learning

## **3.9 Sustainability of the TTT Model**

### **3.9.1 Avoiding dilution: the need for EFE's professional input**

The TTT programme had been designed to consolidate learning from the ABC programme and widen participation in the care homes. The ongoing involvement of the EFEs was seen as crucial to maintain standards of care and provide continuity when staff changed or crises were encountered. It was possible to observe that those care homes where the Trainers had more experience made fewer demands on the EFEs and they relied on their input for complex cases not to help them complete training.

The need for continued EFE support, post TTT, was summed up in the following statement: *"It is critical for mentors to go out and sit in on some of the 'training sessions' offered by newly qualified trainers to their learners...or perhaps getting a trainer to come along to a training session we [EFEs] are doing elsewhere...they need to know what's out there, and newly qualified trainers need to be kept in the loop of hearing about new developments, resources, approaches ...."* [E0104], *"...at least until a critical mass of EoL Care trained staff will have been reached over the next few years or so"* [E0102].

In this respect, the EFEs had a linking or bridging role for care homes involved in providing EoL care, especially where some care homes' roles were possibly changing from a focus on supporting the living to taking on greater responsibilities in EoL Care. As pointed out by one EFE, *"...it seems that EoL Care training is in its early stages, as nursing homes become hospices and residential homes become nursing homes..."* [E0207].

### **3.9.2 Staff selection**

The critical importance of selecting 'the right' staff for the role of trainer was highlighted repeatedly in conversation with EFEs, particularly in relation to the demands of a trainer's existing role in a care home, their interest in and passion for EoL Care, and the time available to them to train others in addition to juggling their every-day responsibilities. As discussed in the preceding section, *"...it is therefore critical to put the right person forward for training"* [E0104], and EFEs suggested that it was important to avoid selecting trainers just because they had been ABC trained.

## **4 DISCUSSION**

Seventeen care homes participated in the TTT programme. The following section summarises the key findings, considers the impact of the different elements of the TTT programme, and makes recommendations for future commissioning and implementation.

### **4.1 Care home and residents' characteristics**

Even though the residents of care homes are of a similar age the range of provision of long term care in England is highly variable (British Geriatrics Society 2011). The sample reflected that heterogeneity. It included care homes with nursing and those that offered personal care only, care homes that were part of a large for profit national chain and those that were part of a not for profit chain specialising in dementia care.

The majority of residents were over 80 and had a degree of cognitive incapacity in addition to other health needs. However, the differences in care home provision were reflected in the resident characteristics in terms of length of stay, functional ability and whether they were self-funding, in receipt of NHS continuing care or social care funding. Residents in care homes with nursing had more reported care needs, but there was overlap between the two settings. The presence or absence of a qualified nurse in the care home was an important factor in how the TTT programme was introduced, its uptake, and if other related end of life initiatives had been implemented or were being introduced in parallel to the TTT programme. Seven (41%) of the seventeen care homes had received additional training in end of life care.

### **4.2 Uptake and implementation of the TTT programme**

Care home readiness was a consistent finding that was threaded through the accounts of participants as a key influence on uptake and successful completion of the programme.

Care home contexts have varied widely throughout the three sites. Five of the six care homes in Site 1, for example, had the benefit of additional EoL Care training. Whilst some care homes might have preferred ABC/TTT training to that of other EoL Care training programmes, the cumulative and longer term effect of such training

meant that documentation of formal protocols relating to Advance Care Planning (ACP), Integrated Care Pathways (ICP), Preferred priorities for care (PPC), and DNACPR forms were already in place. This history of working with end of life care resources facilitated relationships with service providers as GPs and hospitals, either in relation to prescribing anticipatory medication, issuing signatures for DNACPR forms, or referring patients for palliative care to the care home. Better service relationships were also influenced by pro-active clinically qualified managers. In combination, such factors enhanced the implementation of the TTT EoL Care education programme. This is to be contrasted to care homes that were in flux during the TTT pilot programme, either due to managerial change, staff turnover, or conflicting priorities at the time.

This level of readiness at the organisational level of care was also evident at the practitioner level. There was also considerable variation in the professional roles of the trainers who taught the learners. Many of the trainers held managerial positions or needed to deputise or attend to conflicting priorities during the TTT pilot. Trainers who had the most opportunity to teach learners were those whose roles allowed them to spend time on the floor with learners and offer bite-size, applied teaching as and when opportunities arose. However, trainers and learners needed to have a level of authority and responsibility that allowed them to act on their learning, for example to change care plans or consult with family or NHS staff. Lack of such authority and responsibility might prevent them from acting on the knowledge gained in relation to changing a resident's pathway or in relation to influencing service provision.

The learners' participation in the programme could represent consolidation of previous learning and experience or a new area of learning. The findings would suggest that some care staff were less ready to participate in the programme than others. Discussions between the EFEs and the care home staff about who should participate and how that would be facilitated may have improved uptake and completion of the programme and the identification of staff that would be able to act on their learning.

### **4.3 TTT approach**

The blended learning approach of the TTT programme was valued by participants and compared favourably with other approaches that emphasised a more document driven approach to change. The use of online materials when used, introduced key

ideas and reinforced learning or advice from workshops and EFE input. The variability of uptake of the online modules reflected contextual factors such as no Wifi-access in the care home, the expectation that learning would be completed in the learners' own time, and individuals' confidence in using computer based technology.

Teaching modules on communication skills and Advance Care Planning were seen as most relevant to the trainer and learners' care work. Key reported outcomes included increased confidence to initiate and/or respond to sensitive EoL care conversations with residents and their families. Care home staff felt also more confident working with visiting NHS professionals, and GPs were more willing to engage in anticipatory care when they knew that care home staff had been trained in EoL care. This was borne out in the review of decedents' notes.

Modules that focused on practical topics such as 'comfort and wellbeing' and symptom management reportedly equipped care home staff to recognise signs and symptoms of dying. However, the review of decedents' notes did not provide evidence of residents having been assessed and treated for symptoms of pain and or distress. It may be that these changes had not been embedded into everyday practice at the point of the evaluation, or that these skills were being used but not documented because they were not linked to official documents or subject to external review, or because the environment is a predominantly oral culture of care.

Face to face teaching was seen as critical to ensure learning reflected everyday experiences of care and to support reflection and debriefing at the point of discussion when faced with emotionally challenging situations. The findings support findings from other practice development work in care homes that emphasise relational, non-hierarchical approaches to working, and the role of a facilitator to negotiate and support the process of change (Brown-Wilson et al 2009, Brownie et al 2013, Dewar and Nolan 2013). This was however, only possible when the trainers and the learners worked together and had sufficient time to complete and discuss their learning and apply it to particular residents.

#### **4.4 The contribution of the EFes**

The working relationship between the EFes and the trainers was central to care home staff engaging with the TTT programme. EFes had a vast amount of EoL Care

and palliative care experience through various backgrounds including hospice nursing and oncology nursing. For trainers with no background in EoL care or experience this was particularly important and valued. EFEs also provided access to additional literature on EoL Care and were available to the trainers beyond designated training sessions. EFE support complemented and reinforced the teaching elements of the TTT model. The main feature of EFE support was described as offering 'the human touch'. This was consistently identified by trainers and learners as helping to make teaching content meaningful, accessible, and applicable.

Input offered in terms of contact hours and contact frequencies varied across the three sites. There was an inverse relationship between care home readiness and programme uptake and frequency of EFE contact. Care homes that struggled to achieve their programme goals had the most contact with EFEs. It is therefore difficult to assess the minimum time allocation that would be necessary to achieve implementation of the TTT programme. It is likely that the EFEs might have under reported time spent on TTT. Hours spent on travelling to care homes, for example, were only submitted by a few EFEs and not everyone reported time taken to locate trainers and organise meetings.

#### **4.5 Does the TTT model support an increase in quality of EoL Care**

The evaluation did not have a control or comparator group apart from the PHAST data which relied mainly on HES data. Qualitative data indicated that participants valued the mix of elements such as module delivery, training content, opportunity and authority to train, and EFE support, and this was perceived to contribute to an increase in quality of EoL Care.

The review of the decedents' notes indicated two findings. Firstly, the achievements of the ABC model (as much as it is possible to compare the two studies) were broadly sustained though not dramatically improved. Most activity related to ACP and end of life care was concentrated in the last week and days of life. Resource use, both in terms of referral to secondary care, use of primary care services and OOH, did not increase. However it is impossible to know how much EFE support was a source of alternative expertise and advice in lieu of primary care support. Unsurprisingly, participating care homes had minimal contact and support from other specialist palliative care providers during the period of the evaluation. A future economic costing would need to take account of EFE time alongside use of other NHS services. It was notable that, contrary to perceived opinion, care homes

were not resource intensive users of primary care services although particular residents in care homes were.

Secondly, it was an unexpected finding that some of the care homes with on-site nursing were accepting referrals from hospitals and hospices of people diagnosed as actively dying and were admitted explicitly for end of life care. Not all of these individuals were the age of people who would normally be admitted to a care home. This would suggest that, as care homes receive training and accreditation in end of life care, it is possible that the focus of their care will shift from long term care to post-acute care where the care home assumes a "para-hospice" role. It will be interesting for future research to consider if the presence of a particular expertise begins to affect referrals, service delivery, involvement of primary and specialist care, and the case mix of the care home where a proportion of residents are admitted for a very limited time. Overall, the engagement of primary care services and evidence of closer working with GPs were evident in accounts of GPs having more confidence in care home staff's ability to provide end of life care and use of ACPs and DNACPR. However, this appeared to be limited to the last week and days of a resident's life. Despite the clear evidence that care homes' skills in end of life care were being recognised by NHS services, there is scope for more engagement by primary care with care homes and future TTT programmes may like to consider developing modules around how to work more closely with other NHS services and engage more with visiting NHS staff.

Table 29 below synthesises the findings and presents an overview of what, based on the findings, needs to be in place for uptake of the TTT programme. It shows a continuum from full implementation to factors that inhibit engagement and implementation. This would suggest that commissioners and future programmes need to consider where the focus should be, and whether it is a better use of resource to concentrate on care homes that are best placed to use the TTT programme or, in the interests of equity, to target those care homes that are only beginning to engage with end of life care issues. It needs to be recognised that achieving organisational change is a long process, and that to sustain improvement and manage organisational and staff changes a commitment to a long term programme of investment and training is needed. Those care homes that had a history of long term working in end of life care and ongoing contact with a palliative care specialist were the best placed to achieve ongoing training of their staff and, compared to care homes that were novices in end of life care, made less demands on EFE time and NHS resources.

**Table 29: Factors that support the sustained implementation of the TTT programme**

	<b>On-line</b>	<b>Training the Trainer / Learner</b>	<b>Trainer</b>	<b>Care home</b>	<b>Managerial support</b>	<b>EFEs</b>
<b>Sustained</b>	Online access at the care home Time allocated	Face-to-face  Naturally occurring encounters and opportunities for reinforcement of learning	Opportunity and authority to train  Previous experience in end of life care/ and or access to ongoing learning	Care home expertise with EoL Care, e.g. via GSF or clinically qualified manager / staff Low staff turnover	Manager enthusiastic and proactive:  Trainer role and contribution is acknowledged	Ongoing relationship (i.e. reinforce learning and be expert resources  Opportunity to review progress and identify gaps in learning with Trainer
<b>TTT feasible</b>	<ul style="list-style-type: none"> <li>• IT access</li> <li>• Protected time</li> </ul>	<ul style="list-style-type: none"> <li>• Bite size teaching sessions as part of daily routine</li> <li>• Face to face</li> <li>• Unit level focus rather than CH wide</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity and authority to train</li> <li>• Agree on criteria for staff selection</li> </ul>	Low staff turnover Stability	Manager proactive	Emotional support plus access to expert advice
<b>TTT partially effective</b>	No online access	<ul style="list-style-type: none"> <li>• Bite size teaching sessions as part of daily routine</li> <li>• Face to face</li> <li>• Unit level rather than CH</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity and authority to train</li> <li>• Agree on criteria for staff selection</li> </ul>	Some organisational turbulence but Trainers constant	Mixed support With little formal acknowledgment of trainer and learner needs	Limited access
<b>TTT minimal impact</b>	No online access	<ul style="list-style-type: none"> <li>• Training away from residents [not on the floor; delivered as just another training module]</li> </ul>	<ul style="list-style-type: none"> <li>• CH staff little or no previous EoL Care experience</li> <li>• No opportunity or authority to train</li> </ul>	Managerial leadership sometime in flux or absent	Not present	Time not made available for EFE to visit: Too many competing priorities



#### 4.6 The ability of the TTT programme to address uncertainty

A starting point of the evaluation was that different EoL Care interventions are likely to address different aspects of end of life care. Most interventions (rightly) emphasise the skills and resources required to provide EoL Care to the individual and assume that it is possible to recognise when someone is actively dying. In long term care settings the trajectory to death is often protracted, decision making is complicated by the presence of dementia and is shared across organisations and individuals. Table 30 summarises the impact of the TTT programme on relational uncertainty (staff, residents, relatives and visiting professionals), pathway uncertainty (symptom control and treatments, and service uncertainty [the capacity of the services and practitioners to support the person to die in the care home]). Overall, and further analysis is needed, it would appear that this blended learning approach combined with continuity of support via the EFEs was particularly effective at addressing issues specific to the individual's care and how staff worked together and with family and visiting professionals. It was less able to engage with wider systems of care and did not seek to engage visiting professionals or referring hospitals in training.

**Table 30: How did the elements of TTT address relational, pathway and service uncertainties?**

<b>TTT</b>	<b>RELATIONAL Uncertainty</b>	<b>DYING PATHWAY Uncertainty</b>	<b>SERVICE Uncertainty</b>
<b>Online modules</b>	✓✓	✓	x
<b>Face-to-face / bite size teaching</b>	✓	✓✓	✓
<b>EFE support</b>	✓✓	✓✓	✓
<b>Other EoL Care training</b>	✓✓	✓✓	✓✓

## 5 CONCLUSIONS

The findings of the evaluation demonstrated that the TTT programme was valued by the care home staff and that participating care homes were able to sustain patterns of care observed from the earlier ABC evaluation (Pyper et al 2013). It was

effective as a programme that supported effective working in end of life care between health care and independent long term care.

There are two particular contributions of the TTT programme. Firstly, to build on learning from the ABC model and extend the involvement of care home staff who otherwise would not have access to EoL Care training. Secondly, to augment, reinforce and consolidate learning either from the use of other EoL resources or the expertise of key practitioners in the care home.

The intrinsic heterogeneity of care home provision in England necessitates a programme that is context sensitive and that can adapt to organisational and staff changes. The findings suggest that a blended learning approach that characterises the TTT programme is preferable to paper based initiatives, and that the care homes valued the flexibility that the programme offers. Managerial support was critical in three ways, in making sure that staff would be available, that they would have protected time, and in encouraging learners to apply their learning when working with colleagues and NHS professionals. This was difficult to achieve for care homes that were without a manager or were dealing with competing events, for example CQC inspections. The organisation of the TTT programme was able to accommodate some but not all of these challenges. TTT EoL Care training was not perceived as a course that had to be passed, but as an approach that took into consideration the vulnerabilities, sensibilities and constraints that are part of the home contexts that EoL Care training is meant to strengthen. Other approaches rely on a process of accreditation that provides a useful audit of best practice but may be less able to address how to enable staff to continue to learn together and address the inevitable challenges of staff shortages and changes in leadership.

The EFE role appeared to offer valuable continuity especially at points of crisis. This input diminished as care home staff grew in confidence.

The TT programme relied heavily on their commitment and on the goodwill and interest of the staff to undertake work in their own time. Where the latter were not in place there were fewer incentives to participate or sanctions that could be used. This was compounded if staff could not access online resources in the care home.

## **6 LIMITATIONS OF THE STUDY**

- This evaluation was a snap shot of practice with a relatively short period of follow up after the completion of the workshops. It is likely that many of the benefits and results observed are an underestimate as it takes time for initiatives of this kind to embed and to change every day practice. Nevertheless, the results are promising, not least the ability of the programme to sustain the changes observed in the earlier evaluation.
- Without a comparison group it is not possible to know to what extent the findings are directly attributable to the TTT programme. The evaluation demonstrated that national commitments to improving end of life care, and the organisational uptake of other End of Life frameworks, all feed into how staff engaged with the TTT programme. The findings did demonstrate however that the TTT programme complemented these initiatives and the qualitative data would suggest that when the TTT programme was compared with other approaches, it was preferred and perceived to be more sensitive to how care homes were organised and managed.
- It was not possible to secure a complete data set. The findings about the resident characteristics and patterns of service use would suggest that the data is comparable to other similar studies. Nevertheless, the findings should be interpreted with caution and even though we were able to review 274 residents' use of resources and 150 decedents' notes, our statistical analysis was constrained by the small sample size.
- Data obtained from the Kindle was limited. Only six trainers used it to provide information of the impact of the variables on residents' outcomes.
- Whilst we quantified EFE time and involvement in the project, we did not do so for the project leads who had overall responsibility for the project involving EFEs, trainers and learners.

## **7 RECOMMENDATIONS**

- The TTT programme with its blended learning approach should be continued and extended to complement the achievements of the ABC programme, and to sustain knowledge and skills development and implementation of effective end

of life care in care homes. The role of the facilitator is key. Care homes **without** on-site nursing should be targeted ahead of care homes with on-site nursing.

- When costing EFE support this should be calibrated to reflect the readiness of the care home and the staff to participate in the programme. A careful pre-assessment and discussion with the care home could inform a negotiated agreement about frequency and availability of EFE support with the recognition that some care homes will need more support than others. The findings suggest that whilst EFE support can reduce as trainers and learners grow in confidence and skills, there is an ongoing need for EFE review and support particularly at times of organisational change or turbulence in the care home.
- Staff selection, both for trainers and learners, is a critical consideration for the TTT model. Aspects such as prior experience, opportunity, authority and responsibility should be discussed, assessed and monitored.
- The commitment of management, internet availability, and the priorities and interim goals of the participating care home staff should be discussed prior to embarking on a TTT programme as components of care home readiness to participate.
- The EFE's role should be one that is based on a qualification in palliative care and ongoing experience in EoL care.
- A review of EFE approaches to providing support should consider what a minimum level of support for a participating care home would require in EFE time, for different levels of care home readiness and whether there is an on-site clinician or not.
- Care homes (depending on overall size) should consider organising practice based teaching in units within the care home as opposed to across the whole care home.
- When costing the TTT programme there is a need to take account of EFE time alongside use of other NHS services and whether the involvement of the EFE reduces the use of specialist and generalist palliative care services.

## **8 RECOMMENDATIONS FOR FUTURE RESEARCH**

- A longer term evaluation of the impact of the programme compared with care homes that had not received TTT input but had participated in the ABC programme, and with care homes and primary care teams that received TTT as well as other end of life resources and training.
- Development and testing of a care home readiness assessment tool to inform recruitment of care homes and levels of EFE support provided to care homes.

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**Appendix A:** The six modules covered in ABC/TTT EoL Care Education Programme

The ABC East of England (EoE) EoLC education programme was developed by EPIC and the (former) EoE Strategic Health Authority, now known as Health Education East of England.

The programme includes the following modules:

- Overarching principles of EoL Care
- Communication skills
- Symptom assessment
- Comfort and Wellbeing
- Advance Care Planning
- EoL Care tools

The ABC programme is a flexible blended learning package that is tailored to meet the needs of staff in nursing and residential homes in terms of how, to who and when it is delivered in the home. It also includes mentor support and on site practice support in the form of a named End of Life Facilitator Educator (EFE) for that home. The course is designed to be flexible through any combination of face to face and eLearning delivery.

<http://endoflifecarelearning.co.uk/login/index.php>



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# RESIDENT SERVICE USE

## Daily Logs

### Dates

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Dear Trainer,

Thank you for your participation in this study.

Please complete these Resident Service Use Logs for residents who are in the room numbers listed in the left hand column, but **only for residents who were seen by** a GP, DN, palliative care team, an out of hours GP, or if an emergency ambulance was called, or a resident was admitted to A & E or to hospital.

For example, if the resident in Room 123 was seen by a GP, please tick the correct box, indicating whether this was a routine visit, or whether the visit was requested by the Care Home.

Another example: if the resident in Room 456 needed an emergency ambulance, please tick the correct box, and make a note of why the ambulance was called.

Routine visit: for example a resident was seen in the weekly GP clinic

Routine visit by a DN: for example for Insulin

Visit requested by the Care Home: for example a GP was called out to see a resident for a suspected infection, deterioration of a condition, etc. Please note if a visit was a follow-up visit for the same condition (FU Visit = Follow up visit)

**List of keys:**

CH = Care Home  
GP = General Practitioner  
DN = District Nurse

**If DN**, please differentiate as follows by inserting the letter keys as applicable:

PC = Palliative care (please note what this was for, e.g. care of syringe drivers, 'just in case' medication, assessment and personal care for palliative care residents)

W = Wound and Stoma care

I = Injections, e.g. Insulin, Vitamins, Clexane, hormones such as Zoladex

B = Taking of blood samples

**If "Other"** = Write the name of the profession in the column (e.g. speech & language therapist [SALT]; dietician; physiotherapist; occupational therapist [=OT], neurological specialist; dentist; optician; mental health team [=MH]; spiritual care representative.....)

In **Palliative Care Team** Column: Please tick whether routine or requested if the visit was from: Members of hospice staff, Hospice at home, Macmillan or Marie Curie visits.

OOHs GP = Out of Hours GP see details in box below

---

Please also indicate whether a resident was transferred or has passed away (see bottom of 2<sup>nd</sup> page per day).

If residents do not receive any visits or use any services please leave the rows blank. Please sign the sheet each day to show that any blank sheets are intentionally such.

**If you have any questions at all, please don't hesitate to ask.**

Contact details: Andrea Mayrhofer, Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire, AL10 9AB  
Tel: 01707 28 5066 Email: [a.mayrhofer@herts.ac.uk](mailto:a.mayrhofer@herts.ac.uk)

Many thanks!

## Resident Service Use \_ Daily

Date		Room Nr	GP		DN		Other		Palliative Care Team		Was OOHs GP contacted?				
			Routine Visit	Request By CH	Routine Visit	Request by CH	Routine Visit	Request By CH	By Referral	On Request	If yes, please tick, and indicate whether: 01: OOH GP provided advice telephonically 02: OOH GP visited Care Home 03: OOH GP was unavailable / no response				
											Yes	01	02	03	Reason for contacting OOH GP
01															
02															
03															
04															
05															
06															
07															
08															
09															
10															
11															
12															
13															
14															

Date	Room Nr	Emergency Ambulance			Unscheduled A & E		Unscheduled Hospital Admission					
		<input checked="" type="checkbox"/>	04	05	Reason	<input checked="" type="checkbox"/>	Reason	<input checked="" type="checkbox"/>	Reason	06	07	08
	01											
	02											
	03											
	04											
	05											
	06											
	07											
	08											
	09											
	10											
	11											
	12											
	13											
	14											

**Resident left Care Home:** Has a resident left the Care Home? If yes, please indicate Room Nr (s) here: .....  
Where did they go to? .....

**Resident death:** Has a resident passed away today? If yes, please indicate Room Nr here: .....

I confirm that today's form is completed to the best of my knowledge and that the columns left blank are done so intentionally.

Signed: .....

**Appendix C** \_ Data extraction forms adapted from InterRAI assessment instruments

**SECTION A. IDENTIFICATION INFORMATION**

1. **RESIDENT IDENTIFIER**

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2. **SEX**

1. Male                                  2. Female                                 

3. **BIRTHDATE**

Day                                  Month                                  Year

4. **NUMERIC IDENTIFIERS**

a. **Participant number (pls. leave blank)**

5. **CURRENT PAYMENT SOURCES FOR INPATIENT**

0. No                                  1. Yes

a. **Social Services**  
b. **NHS**  
c. **Self or family pays for full per diem cost**  
d. **Social Services with NHS co-payment**  
e. **Private insurance**  
f. **Other per diem**

6. **ASSESSMENT REFERENCE DATE**

Day                                  Month                                  Year

7. **PERSON'S EXPRESSED GOALS OF CARE**

8. **TIME SINCE LAST HOSPITAL STAY**  
Code for most recent instance in LAST 90 DAYS

0. No hospitalization within 90 days  
1. 31 to 90 days ago  
2. 15 to 30 days ago  
3. 8 to 14 days ago  
4. In the last 7 days  
5. Now in hospital

**SECTION B. INTAKE AND INITIAL HISTORY**

1. **DATE STAY BEGAN**

Day                                  Month                                  Year

2. **ADMITTED FROM**

1. Private home/apartment/rented room  
2. Residential home  
3. Sheltered housing  
4. Mental health residence—e.g., psychiatric group home  
5. Group home for persons with physical disability  
6. Setting for persons with learning difficulty  
7. Psychiatric hospital or unit  
8. Homeless (with or without shelter)  
9. Long-term care facility (nursing home)  
10. Rehabilitation hospital/unit  
11. Hospice facility/palliative care unit  
12. Acute care hospital  
13. Correctional facility (e.g., prison)  
14. Other

**SECTION C. COGNITION**

1. **COGNITIVE SKILLS FOR DAILY DECISION-MAKING**  
*Making decisions regarding tasks of daily life—e.g., when to get up or have meals, which clothes to wear or activities to do*

0. **Independent**—Decisions consistent, reasonable, and safe  
1. **Modified independence**—Some difficulty in new situations only  
2. **Minimally impaired**—In specific recurring situations, decisions become poor or unsafe; cues/supervision necessary at those times  
3. **Moderately impaired**—Decisions consistently poor or unsafe; cues/supervision required at all times  
4. **Severely impaired**—Never or rarely makes decisions  
5. **No discernible consciousness, coma [Skip to Section E]**

2. **ACUTE CHANGE IN MENTAL STATUS FROM PERSON'S USUAL FUNCTIONING—e.g., restlessness, lethargy, difficult to arouse, altered environmental perception**

0. No                                  1. Yes

3. **CHANGE IN DECISION MAKING COMPARED TO 90 DAYS AGO**

0. Improved                                  2. Declined  
1. No change                                  8. Uncertain

**SECTION D. FUNCTIONAL STATUS**

1. **ADL SELF-PERFORMANCE**  
*Consider all episodes over 3-day period.*

0. **Independent**—No physical assistance, set-up, or supervision in any episode  
1. **Independent, set-up help only**  
2. **Supervision**—Oversight/cueing  
3. **Limited assistance**—Guided manoeuvring of limbs, physical guidance without taking weight  
4. **Extensive assistance**—Weight-bearing support (including lifting limbs) by 1 helper where person still performs 50% or more of subtasks  
5. **Maximal assistance**—Weight-bearing support (including lifting limbs) by 2+ helpers —OR— Weight-bearing support for more than 50% of subtasks  
6. **Total dependence**—Full performance by others during all episodes  
8. **Activity did not occur during entire period**

a. **Bathing**—How takes a full-body bath/shower. Includes how transfers in and out of tub or shower AND how each part of body is bathed: arms, upper and lower legs, chest, abdomen, perineal area— EXCLUDE WASHING OF BACK AND HAIR.

b. **Personal hygiene**—How manages personal hygiene, including combing hair, brushing teeth, shaving, applying make-up, washing and drying face and hands - EXCLUDE BATHS AND SHOWERS

c. **Dressing upper body**—How dresses and undresses (street clothes, underwear) above the waist, including prostheses, orthotics, fasteners, pullovers, etc.

d. **Dressing lower body**—How dresses and undresses (street clothes, underwear) from the waist down, including prostheses, orthotics, belts, pants, skirts, shoe, fasteners, etc.

e. **Walking**—How walks between locations on same floor indoors.

f. **Locomotion**—How moves between locations on same floor (walking or wheeling). If in wheelchair, self-sufficiency once in chair

g. **Transfer toilet**—How moves on and off toilet or commode

h. **Toilet use**—How uses the toilet room (or commode, bedpan, urinal), cleanses self after toilet use or incontinent episode(s), changes bed pad, manages ostomy or catheter, adjusts clothes-- EXCLUDE TRANSFER ON AND OFF TOILET

- i. **Bed mobility**—How moves to and from lying position, turns from side to side, and positions body when in bed.
- j. **Eating**—How eats and drinks (regardless of skill). Includes intake of nourishment by other means (e.g., tube feeding, total parenteral nutrition)

**2. LOCOMOTION/WALKING**

- a. **Primary mode of locomotion** 
  - 0. Walking, no assistive device
  - 1. Walking, uses assistive device—e.g., cane, walker, crutch, pushing wheelchair
  - 2. Wheelchair, scooter
  - 3. Bedbound

**3. CHANGE IN ADL STATUS AS COMPARED TO 90 DAYS AGO**

- 0. Improved
- 1. No change
- 2. Declined
- 3. Uncertain

**SECTION E. DISEASE DIAGNOSES**

**Disease Code**

- 0. Not present
- 1. Primary diagnosis/diagnoses for current stay
- 2. Diagnosis present, receiving active treatment
- 3. Diagnosis present, monitored but no active treatment

**1. DISEASE DIAGNOSES**

**MUSCULOSKELETAL**

- a. Hip fracture during LAST 30 DAYS (or since last assessment if less than 30 days)
- b. Other fracture during LAST 30 DAYS (or since last assessment if less than 30 DAYS)

**NEUROLOGICAL**

- c. Alzheimer's disease
- d. Dementia other than Alzheimer's disease
- e. Hemiplegia
- f. Multiple sclerosis
- g. Paraplegia
- h. Parkinson's disease
- i. Quadriplegia
- j. Stroke/CVA

**CARDIAC OR PULMONARY**

- k. Coronary heart disease
- l. Chronic obstructive pulmonary disease
- m. Congestive heart failure

**PSYCHIATRIC**

- n. Anxiety
- o. Bipolar disorder
- p. Depression
- q. Schizophrenia

**INFECTIONS**

- r. Pneumonia
- s. Urinary tract infection in LAST 30 DAYS

**OTHER**

- t. Cancer
- u. Diabetes mellitus

**SECTION F. HEALTH CONDITIONS**

**1. FALLS**

- 0. No fall in last 90 days
- 1. No fall in last 30 days, but fell 31 – 90 days ago
- 2. One fall in last 30 days
- 3. Two or more falls in last 30 days

**2. PROBLEM FREQUENCY**

*Code for presence in last 3 days*

- 0. Not present
- 1. Present but not exhibited in last 3 days
- 2. Exhibited on 1 of last 3 days
- 3. Exhibited on 2 of last 3 days
- 4. Exhibited daily in last 3 days

**BALANCE**

- a. Difficult or unable to move self to standing position unassisted
- b. Difficult or unable to turn self around and face the opposite direction when standing
- c. Dizziness
- d. Unsteady gait

**SLEEP PROBLEMS**

- e. Difficulty falling asleep or staying asleep; waking up too early; restlessness; non-restful sleep
- f. Too much sleep—Excessive amount of sleep that interferes with person's normal functioning

**OTHER**

- g. Aspiration
- h. Fever
- i. GI or GU bleeding
- j. Peripheral edema

**3. FATIGUE**

*Inability to complete normal daily activities—e.g., ADLs, IADLs*

- 0. None
- 1. **Minimal**—Diminished energy but completes normal day-to-day activities
- 2. **Moderate**—Due to diminished energy, unable to FINISH normal day-to-day activities
- 3. **Severe**—Due to diminished energy, UNABLE TO START SOME normal day-to-day activities
- 4. **Unable to commence any normal day-to-day activities**—Due to diminished energy

**4. INSTABILITY OF CONDITIONS**

- 0. No
- 1. Yes
- a. Conditions/ diseases cognitive, ADL, mood or behaviour patterns unstable (fluctuating, precarious, or deteriorating)
- b. Experiencing an acute episode, or a flare-up of a recurrent or chronic problem
- c. End-stage disease, 6 or fewer months to live

**SECTION G. ORAL AND NUTRITIONAL STATUS**

**1. MODE OF NUTRITIONAL INTAKE**

- 0. **Normal**—Swallows all types of foods
- 1. **Modified independent**—e.g., liquid is sipped, takes limited solid food, need for modification may be unknown
- 2. **Requires diet modification to swallow solid food**—e.g., mechanical diet (puree, minced, etc.) or only able to ingest specific foods
- 3. **Requires modification to swallow liquids**—e.g., thickened liquids
- 4. **Can swallow only pureed solids —AND— thickened liquids**
- 5. **Combined oral and parenteral or tube feeding**
- 6. **Nasogastric tube feeding only**
- 7. **Abdominal feeding tube**—e.g., PEG tube
- 8. **Parenteral feeding only**—includes all types of parenteral feedings, such as total parenteral nutrition (TPN)
- 9. **Activity did not occur**—During entire period

**SECTION H. SKIN CONDITION**

- 1. MOST SEVERE PRESSURE ULCER**
- 0. No pressure ulcer
  - 1. Any area of persistent skin redness
  - 2. Partial loss of skin layers
  - 3. Deep craters in the skin
  - 4. Breaks in skin exposing muscle or bone
  - 5. Not codeable, e.g., necrotic eschar predominant

**SECTION I. TREATMENTS AND PROCEDURES**

- 1. TREATMENTS AND PROGRAMS RECEIVED OR SCHEDULED IN THE LAST 3 DAYS**
- 0. Not ordered AND did not occur
  - 1. Ordered, not implemented
  - 2. 1-2 of last 3 days
  - 3. Daily in last 3 days

**TREATMENTS**

- |  |  |
|--|--|
| a. Chemotherapy <input type="checkbox"/>   | h. Tracheostomy care <input type="checkbox"/>                  |
| b. Dialysis <input type="checkbox"/>   | i. Transfusion <input type="checkbox"/>                        |
| c. Infection control—<br>e.g., isolation,<br>quarantine <input type="checkbox"/> | j. Ventilator or respirator <input type="checkbox"/>           |
|  | k. Wound care <input type="checkbox"/>                         |
| d. IV medication <input type="checkbox"/>  | <b>PROGRAMS</b>  |
| e. Oxygen therapy <input type="checkbox"/>                                       | l. Scheduled toileting<br>program <input type="checkbox"/>     |
| f. Radiation <input type="checkbox"/>  | m. Palliative care program <input type="checkbox"/>            |
| g. Suctioning <input type="checkbox"/>   | n. Turning / repositioning<br>program <input type="checkbox"/> |

- 2. HOSPITAL AND A&E USE**  
*Code for number of times in LAST 90 DAYS*
- a. Inpatient acute care hospital with overnight stay
  - b. A&E visit (not counting overnight stay)

**SECTION J. RESPONSIBILITY AND DIRECTIVES**

- 1. RESPONSIBILITY / LEGAL GUARDIAN**
- 0. No
  - 1. Yes
- a. Legal guardian
  - b. Other legal oversight
  - c. Lasting power of attorney / health care
  - d. Lasting power attorney / financial
  - e. Family member responsible

- 2. ADVANCE DIRECTIVES**
- 0. Not in place
  - 1. In place
- a. Advance directives for not resuscitating
  - b. Advance directives for not intubating
  - c. Advance directives for not hospitalizing
  - d. Advance directives for not tube feeding
  - e. Advance directives for medication restriction

## **Appendix D:** Data Extraction Forms used for decedents' notes

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### **GENERAL INFORMATION**

Care Home:

Identifier:

Room number:

Gender: Male / Female

Date of birth:

Date of admission to the home:

Reason for admission:

Admitted from:

Long-term conditions:

Number of medications:

Responsibility/Legal Guardian/Power of attorney/Other:

Funding:

### **DEATH**

Date of death:

Place of death:

Cause:

Expected?



## **Baseline data items (ACP)**

Number of unplanned crisis admissions in the last 6 months:

### Advanced care planning

Advanced Care Plan discussion offered to the resident/or their family: **YES/NO**

Advanced Care Plan discussion recorded in resident's notes: **YES/NO**

ACP detail (if applicable)

Did this resident have a signed DNACPR form: **YES/NO**

### Preferred Place of death

Was a preferred place of care/death recorded: **YES/NO**

Where was the preferred place of care/death: **CARE HOME / HOSPITAL**

Did the resident die at their preferred place of death: **YES /NO**

If not, reasons preferred place of care/death was not attained (if applicable):

Where did the resident die: **CARE HOME / HOSPITAL / AMBULANCE**

Was a symptom control assessment tool used: **YES /NO/N/a**

Detail of symptom control assessment tool (if applicable):

### Use of EOL tools/protocols/frameworks

Out of hours handover form sent following local arrangements: YES/NO

Specific information given to resident/family/carer/other: **YES /NO/N/a**

Bereavement support offered to the resident's family /carer/others: YES/NO

Were anticipatory drugs prescribed for the resident in the dying phase: YES/NO

Was a protocol or integrated care pathway used for the final days of life: YES/NO N/a

Pathway used (if applicable):

Did the care home staff discuss the resident's care following the death: YES/NO

Did the team discuss this resident at the GSF meeting? YES/NO

Was the resident on the GP palliative care register: YES/NO

**SERVICE USE (3 MONTHS PRECEDING DEATH)**

GP contacts:

OOH GP contact:

OOH GP action:

Other services:

Emergency Ambulance:

Unscheduled A&E:

Unscheduled hospital admission:

Number of nights:

Review letter from hospital:

**EOL PATHWAY (3 MONTHS PRECEDING DEATH)**

Give dates and event(s) from notes, use separate sheet if necessary)

**APPENDIX E: ERRATUM**, issued 1<sup>st</sup> July 2014

The following statement was incorrect and therefore removed from Version 2 of this report:

“However, numbers of signed DNACPR had increased from 18% (post ABC training) to 60% (in residential homes) and to 81% (in nursing homes) respectively post TTT training” (version 1 of this report, p34).

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