Enhancing confidence and competence in end of life care.

An evaluation of an educational pathway for community care staff

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Acknowledgement

Glossary

Mentors – within the remit of this study these were palliative care specialist nurses (PCSN) and senior hospice nurses who were given the following definition of mentoring:

> '[Mentoring is] the process whereby an experienced, highly regarded, empathic person (the mentor), guides another individual (the mentee) in the development and re-examination of their own ideas, learning and personal and professional development. (SCOPME 1998).

> "giving support, assistance and guidance in learning new skills, adopting new behaviours and acquiring new attitudes" (Jordan, 2005)

Palliative care specialist nurse – this refers to Band 7 nurses who specialise in palliative care and may be referred to as Macmillan nurses

Participants –within this report the term 'participants' will be predominantly used to signify the community nurses (Band 5 community staff nurses) and district nurses (Band 6 district nursing sisters) who took part in the 'pathway' project.

Pathway –the term pathway will be used to signify the period over which the project ran. Principally from when participants and mentors were paired up and during which participants took part in their selected educational options (approx. 6-7 months).

The project team

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1. Introduction

In 2008 the Department of Health produced The End of Life Care Strategy (DH 2008) which highlighted the importance of developing workforce knowledge, skills and attitudes in the health and social care workforce in order to improve the quality of end of life care.

In recognition of the importance of this area, and in order to support the strategy, common core competences and principles for health and social care workers working with adults at the end of life were developed by the Department of Health, working with the NHS End of Life Care Programme (2009). The seventh principle, relating to workforce development, states that;

> 'Workers are supported to develop knowledge, skills and attitudes. Workers take responsibility for, and recognise the importance of, their continuing professional development'

This principle acknowledges the need for on-going training education and development as key to the provision of best quality care, based on best evidence available in end of life care. While much may have been done to develop specialist services it is key that non specialist community staff also have the confidence and competence to work with service users, their carers and families, as well as other staff and colleagues involved in providing care at this key point in someone's life.

The North East was the first region in the UK to adopt a broad-based public health approach to end of life issues. In 2010 the North East of England Strategic Health Authority produced a charter for 'A Good Death' which was developed by a multi-agency advisory group. This charter sets out key principles for individuals and organisations in relation to good practice when dealing with people who are dying, their carers and families, and the bereaved. The charter's top priorities include a focus on identifying training needs, education and workforce development.

All individuals approaching the end of their life are entitled to high quality care, which is respectful and sensitive, with competent and compassionate care being critical to facilitating dignified care at the end of life (National End of Life Care Programme 2011). District nurses (DN) and community-nursing teams are responsible for providing generalist palliative nursing care, including end-of-life care (last 6 – 12 months of life), to people living in community settings. District nursing teams comprise of qualified nursing staff and healthcare assistants, generally led by a senior nurse with a specialist qualification in District Nursing (Shipman et al 2008). District nursing teams can play a vital role in end of life care (Hughes 2004); with some district nurses seeing themselves as having a central role in end of life care, although studies have highlighted concerns that they may not have the necessary skills for this work (Wright 2002).

Caring for the dying is stressful work particularly for nursing staff, who can develop more of a personal relationship with patients due to the frequency of contact and the intimacy of their care giving (Peterson et al 2010). Research has shown that when dealing with patient's end-of-life issues, nurses face feelings of apprehension, anxiety and discomfort (Allchin 2006). Although this work was undertaken with student nurses, the way that less experienced nurses' progress from being potentially, 'stressed' or 'anxious' when caring for people at the end-of-life; too confident, competent nurses needs demystifying.

Smith and Porock (2009) in a study exploring the needs of community nurses, identified that experience alone was not sufficient to improve nurses attitudes to caring for the dying patient, although training was significantly related to nurse attitude, no particular training was found to have a significant impact on attitude. Hurtig and Stewin (1990) cite Stoller's (1980) work, which recognized that anxiety can increase with nursing experience. Their findings propose that cumulative nursing experience was not a factor in nurses dealing with fear of their own death, rather the opposite was indicated. Although this work is now thirty years old, death continues to produce complex feelings and responses that add to the challenge faced when caring for those at the end of their life (Leishman 2008).

Research has identified that the role of the DN is central to the provision and co-ordination of palliative care, with this work being highly valued by the nurse (McIlfatrick & Curran 1999). Although some DN's do not feel confident or competent discussing end of life issues (Dunne et al 2005), the competence and confidence of the nurse is essential for effective, high quality patient care. Concerns have been raised in the United Kingdom about the inadequate education opportunities which might limit the confidence of district nurses providing support to palliative cancer patients (Department of Health 2001).

The Department of Health invested six million pound in a three year national education and support programme in the principles and practice of palliative care, which was launched in 2001 as part of the NHS Cancer Plan (Department of Health 2001). By March 2004 1,700 DN's were reported to have participated in the palliative care education programmes across England; with other members of community nursing teams said to have benefited, as participants shared their knowledge with colleagues, however this is speculative.

A study to evaluate these educational programmes (Shipman et al 2008) used a mixed method approach to assess the views of the programme and identify any measurable effect on knowledge, confidence and perceived competence. A sample of 1280 (random selection of nurses from eight Cancer Networks) was contacted prior to the intervention and again one year later. There was reliance upon the nurses' to report any changes in their confidence, and identify competence and knowledge about how the programme had impacted upon their practice. Almost three quarter of respondents considered that the palliative care provided had improved, implying an increase in competence and confidence; however the researchers recognized that some respondents thought they were not as

knowledgeable or skilled as they had previously assumed and that their confidence in their practice had been dented. However, the final results of this study reported the findings based upon a 32% (374) response rate (participants who responded to both arms of the study); although a significant number, due to the varied intervention (different methods of delivery, learning tools and the extent of topics covered) this study could not be replicated and there is no data to identify which interventions were beneficial to the respondents.

Hughes et al (2006) also evaluated an educational programme; this classroom based programme was generally well received by the participants. With some participants stating one of the most useful aspects of the course was the opportunity to discuss aspects of patient care with other practitioners. Hughes et al found that following the programme confidence in practice showed an increasing trend over time, with the desire for education being lower on course completion than at its start, but a substantial proportion of the respondents still expressed a wish for more education. The study identified that communication skills were given lower priority compared to other 'clinical skills' such as the management of symptoms. The findings were unable to quantify the rationale for this; suggesting it may reflect greater confidence of nurses in those skills, rather than them being considered less important.

The support needs of staff working in palliative care although well recognised are generally directed at hospice and specialist palliative care staff and not at generalist staff delivering palliative care. The generalist and specialist levels of palliative care delivery, and the expectation that generalist staff deliver 'generalist palliative care' may have evolved without consideration being given to the impact upon the services and the individuals involved in delivering this care. Nurses need to be offered education and development which enables them as an individual to identify and understand how they can continually improve their competence and confidence in this complex, sensitive work.

With this in mind in 2011 South Tyneside NHS Foundation Trust commissioned the development, piloting and evaluation of an educational pathway for district nursing staff with the broad aim of increasing competence and confidence. After development of the pathway it was implemented and ran between ran between February 2012 and November 2012 with a selection of community nursing staff from across the area involved.

This report describes the pathway, its implementation and findings from the evaluation undertaken by the project team.

2. The Pathway

Educational philosophy

The aim of the pathway was to increase both the *confidence* (through links to specialist nurses and mentoring) and *competence* (through access to a range of education /training opportunities) of participants in providing care for palliative care and end of life patients in the community.

The philosophy underpinning the pathway development was based upon the belief that education and learning are complex social processes which take place in complex settings. Parlett and Hamilton (1977, p13) describe the learning environment as an interrelated whole including, social, cultural, institutional, psychological and historical variables which interact to produce,

> 'a unique pattern of circumstances, pressures, customs, opinions, and work styles which suffuse the teaching and learning that occur'.

Such complexity means that experiential learning (Kolb 1984) based within, or closely linked to the work environment and involving participation in a 'community of practice' (Lave and Wenger 1991) may be especially relevant and powerful (Eraut 2000,2004,2007, Eraut et al 2005, Steven 2009, Steven et al 2007).
Indeed Lave and Wenger (1991) propose that understanding and experience are inextricably linked, in constant interaction, 'mutually constitutive'. Thus 'situated learning' may be particularly relevant in areas such as end of life care where; each case is highly individual; care is delivered across a multitude of diverse situations and environments; and 'community of practice' include a broad range of practitioners.

Therefore the pathway took a learner centred approach underpinned by principles of adult education (Knowles 1980, 1984) and built on the 4 competency areas for end of life identified by the Department of Health (DoH 2008/9):

- Advance care planning
- Communication skills,
- Assessment and care planning,
- Symptom management, maintaining comfort and well being

The pathway process

The pathway process (see Figure 1) involved participants being linked with a mentor; undertaking a learning needs assessment; then planning a course of action by choosing from a menu of educational activities. The menu of educational activities was developed to include both formal and informal activities and individual and whole team options. In order to build upon established good practice the pathway incorporated existing initiatives such as the 6 day Palliative care foundation course run by South Tyneside FT specialist palliative care team.
 Other options included;
- The mentoring scheme ,

- Facilitation of the formation of semi- formal links with specialist services (i.e. palliative care specialist nurses/Macmillan nurses etc)

- Access to additional training sessions and university modules covering pertinent topics such as communication skills, aspects of grief and loss, principles of palliative care (see Table 1).

Figure 1: Diagrammatic overview of the pathway

Self-assessment

Learning needs assessment / framework / tool

Leading to

Development of action plan

Supported by a mentor

Menu of options

Work based | University based

Mentor preparation course / sessions

Northumbria University

Formal

Mentoring scheme

Mentoring meetings to support the learning process

Individual approach

Observational work

Formal non accredited

Existing Work Based Learning

Palliative care foundation course

Individual approach

6 day course

Informal

Links with PC specialist nurses

Program of visits by PCSN to DN teams

- rapport building
- PCSN nurses doing sessions / talks for DN teams

Whole team approach

Formal University Accredited

Menu of Standalone modules that participants could choose from

Individual approach

9

Preparing those involved

District nursing team staff

The community staff who volunteered to participate in the project each met with one of the research team member (GW) and were briefed regarding the purpose, aims and process of the initiative. Participants were given opportunities to ask questions or seek clarification on the process and the evaluation.

Mentors

Experienced practitioners (i.e. PCSN and senior hospice nurses) from across the geographic area covered by the participating NHS Trust were also recruited to act as mentors to the community nursing staff. In order to limit role conflicts or conflicts of interest where ever possible the mentors were assigned to community nursing staff participants from a different locality and for whom they had no managerial responsibility.

In preparation these volunteers attended two half day sessions organised and facilitated by the team (GW,AS,JA). The sessions drew on existing mentor training provided by Northumbria University and the work of Connor and Pakora (2007) and Egan (2007), and covered:

- the pathway process and how it would work

- the principles of mentoring and mentoring skills

- the tools and frameworks that they could utilise

- details of the evaluation study.

The mentors remit was explained as being that of;

1. Assisting staff in developing their action plan
2. Acting as a mentor (as outlined by Connor and Pakora 2007) which entailed meeting with the staff member at regular intervals (as agreed by mentor and mentee) to discuss issues perceived to be of importance to the mentee. Such issues would potentially relate to the mentees learning, their feelings and perceptions regarding EoL care provision, their thoughts and feelings regarding confidence and competence in specific areas, specific cases they may be dealing with and so on.
3. If mentor and mentee felt it would be beneficial, mentors were also encouraged to shadow the mentee during their normal practice. This was however only to take place where all involved agreed and was only to be a purely developmental exercise.

It was emphasised that the mentor relationship was to be a developmental and supportive one and *in no way* constituted a monitoring or quality control exercise.

Tools and documents

Training needs analysis questionnaire

A rapid review of existing UK relevant self-assessment tools was undertaken by the information scientist (DG) which identified the 'NHS National End of Life Care Programme Training Needs Analysis (TNA) Questionnaire' (NHS National End of Life Care Programme 2011) as appropriate for the study.

Developed through the National Communication Skills Pilot and based upon the Department of Health's End of Life Care (EoLC) common core competences and principles (DoH 2009), the TNA questionnaire covers overarching values and knowledge and 4 EoLC competence areas:

1. Communication Skills
2. Assessment and Care Planning
3. Symptom management, maintaining comfort and wellbeing
4. Advance care planning

The TNA questionnaire is described by the authors as a

'systematic gathering of information to find out employees' capabilities and to identify any gaps in the existing skills, knowledge and attitudes' (DoH 2011 page 2).

Therefore at the heart of the TNA is a 'gap analysis' which in essence helps identify any differences the participant has between; 'the standard that exists',(i.e. where they are at that point in time in relation to each competency area) and 'the desirable standard' for the competencies (Grant 2002, Furze & Pearcey 1999). Thus the TNA assists participants in identifying areas for further educational development and/ or support.

The TNA questionnaire was tailored to meet the needs of participants in this study principally by removing sections of limited relevance—i.e. those requiring demographic, personal and employment information (see appendix 1).

Action planning

Two documents were developed to assist mentors and mentees in the action planning stage:

- Guidance on process and opportunities
- Guidance on developing an action plan

The guidance on process and opportunities (see appendix 2) covered how the project works and what learning opportunities were available as part of the project. This document was distributed to both mentors and mentees early in the study in order to provide information and offer opportunities for questions and clarification.

The booklet offering guidance on developing an action plan (see appendix 3) was developed for use by mentors and mentees in conjunction with the Training Needs Analysis Questionnaire. This booklet covered; self-assessment, action planning, choosing from the opportunities available and engaging in the educational opportunities.

The menu of options available included a range of possibilities as outlined in table 1

Table 1: The Education Menu

Work Based – Informal Non Accredited	Work Based – Formal Non Accredited (Formal Individual approach)	University Accredited (Formal Individual approach)
Individual approach • Shadowing Palliative Care Specialist nurse / Macmillan nurse • Visits to hospices • Joint client/patient visits – District Nurse and PCSN *Whole team approach* • Sessions delivered by PCSN in health centres to DN teams (as identified and negotiated in joint discussions)	• Mentoring scheme • Palliative Care short course (6 study days) • Liverpool Care Pathway and Advanced Care Planning (1 study day) • Effective Communication Skills (1 study day)	• AC0342 Principles of Palliative Care (20 credits Level 6) • AC6613 Managing Pain and Symptoms (20 credits Level 6) • AC0733 Managing Pain and Symptoms (20 credits Level 7) • AC0343 Aspects of Grief and Loss (20 credits Level 6) • AC0008 Foundations of Cancer (20 credits Level 6) • AC0313 Communicating Effectively in Difficult Situations (20 credits Level 6) • AC0665 Common Cancers in the UK (20 credits Level 6)

3. Recruitment and sample

The local context

South Tyneside Foundation Trust community services which commissioned the study covers a large geographical area including Sunderland, Gateshead and South Tyneside. This area has a mixed socio-economic profile and includes both urban and rural areas. There are 14 District nursing teams across this area: 3 in South Tyneside, 4 in Gateshead, 7 in Sunderland.

Recruitment

All district nursing team staff, palliative care nurse specialists and senior hospice nurses were sent an invitation to participate which included information about the project and links to the project team. Initially the evaluation hoped to recruit members of staff (up to 3)from the same teams to form 'clusters' thus allowing for exploration and analysis of both individual and team learning that may take place. However as with any pilot study the sample was dependent upon the group of volunteers who came forward and recruitment was such that only one team 'cluster' volunteered to take part. Thus data collection and analysis at a team level was not possible.

Palliative care nurse specialists and senior nurses working in specialist palliative care were invited to volunteer to act as mentors to the participants. All mentors were paired with participants who worked in a different locality, with one pairing being based in the same office but covering a different geographical area therefore having no current or previous 'clinical work' connections.

Table 2 Profile of Participants

The following tables offer a profile of the roles and backgrounds of those initially recruited.

Location	Area 1	Area 2	Area 3
Number of participants	4	4	3

Role at time of interview	District Nursing Sister	Community Staff Nurse
Number of participants	6	5

Mentors	Roles
Mentors were not area specific as some cover the entire patch	6 Palliative care specialist nurses 5 Senior Hospice nurses

Length of time in present post /role
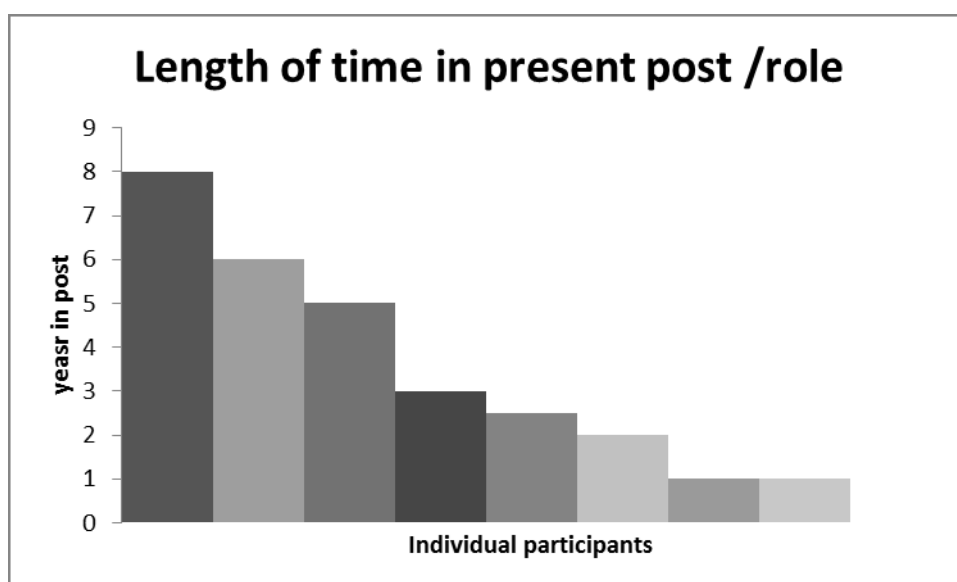
The participants came from a wide range of backgrounds with diverse employment and education experience. For example some had taken up post directly after qualifying while others had considerable nursing experience (approx. 22 years in one case). Some had also worked in similar or lower grade roles in other locations. Thus participants brought a rich variety of experience both to their role, and to the educational pathway project.

Attrition
Of the original 11 participants recruited 3 dropped out leaving 8 to complete their time on the pathway. Those who withdrew did so because of leaving the organisation, one to take up a new role in another organisation and one to undertake full time education. Another was unable to continue with the project due to work commitments.

Data protection and Ethics

The project study proposal and all associated documentation were reviewed and granted approval by the Faculty of health and life sciences (former School of Health, Community and Education studies) Ethics committee at Northumbria University. With regard to NHS ETHICS the NRES algorithm (requirements for REC review version dated August 2011) states that 'REC review is not normally required for research involving NHS or social care staff recruited as research participants by virtue of their professional role' therefore NHS ethics approval was not required. However the proposal was reviewed and agreed by the appropriate R&D manager for South Tyneside Foundation Trust and governance procedures were adhered to throughout.

Participants were informed that they could withdraw at any point without this having any impact on their employment or future continuing education. Interviews were audio-recorded and transcribed verbatim, with all identifying information removed. Participants were allocated a unique identifier and the key for the ID codes was available only to the research team, along with the data files which have been kept on a password-protected University server. Sound files will be destroyed approximately three months after production of the final report and transcripts will be kept for three years in line with University policy. Participation was voluntary and all participants gave their written informed consent to take part in the study and for the (anonymised) information to be used for analysis and dissemination purposes.

Anonymity

Great care has been taken throughout the writing of this report to maintain the anonymity of those involved. To this end identifying codes for participants have been changed from chapter to chapter.

4. The Evaluation

Methodology

The evaluation is based on the belief that education and learning are complex social processes which take place in complex settings. Parlett and Hamilton (1977, p13) describe the learning environment as an interrelated whole including, social, cultural, institutional, psychological and historical variables which interact to produce a unique pattern of circumstances, pressures, customs, opinions, and work styles which suffuse the teaching and learning that occur.

Given the complex, very individual and context- bound nature of providing and delivering end of life care, it was felt difficult (if not impossible) to simply measure practitioners skills, knowledge, confidence and competence pre and post initiative and assert that any changes are directly a result of that initiative. In addition such an approach may miss valuable learning to be gained from a more rounded evaluative approach. It was felt important, for the development of confidence and competence in end of life care, to capture and explore *what works best ,for whom, and under what circumstances* so that the developmental, educational and individual needs of the care staff can be better met in the future.

A multi facet realistic evaluation (Pawson and Tilley 1997) methodology was employed allowing exploration of the context, mechanisms and outcomes for the pathway. This approach offers the opportunity of getting inside the 'black box' of what actually happens when an initiative is translated into practice, and to unpick what works for whom and in what circumstances.

The developers of realistic evaluation suggest that 'outcomes are explained by the action of particular mechanisms in particular contexts' (Pawson and Tilley 1997 p59). Pawson and Tilley (1997) argue that causal powers reside not in objects or individuals but in the social relations and organisational structures that they form. Realistic evaluation therefore attempts to explore context (C), mechanism (M), outcome (O) relationships i.e. *what works, for whom, and in which circumstances* (Pawson and Tilley 1997). Therefore the relationship between causal *mechanisms* (courses undertaken, mentoring, hospice visits, education and training provision etc.) and their effects/*outcome*s (workforce feelings of confidence, knowledge, skills, competence, learning experiences intended and unintended) is not fixed but contingent on the *context* (practice setting and culture, nature of the work, access to education and training, group make up, facilitation, education delivery methods, incentives etc.)

Design and methods

Data collection

A mixed methods design was utilised and data were collected via:

- Interview with the nurse participants at three points during the running of the 'pathway',

- One off interviews with the mentors at the end of the 'pathway'

- Completion of the training needs analysis tool by participants at the beginning and end of the 'pathway' project,

- Collection of a copy of the participant's individual action plans.

Participants were also asked to consider keeping reflective notes on their educational experiences and to make these available to the researchers, however very few of those involved were able to do this and the data collected in this way was limited.

Figure 2 Data collection points
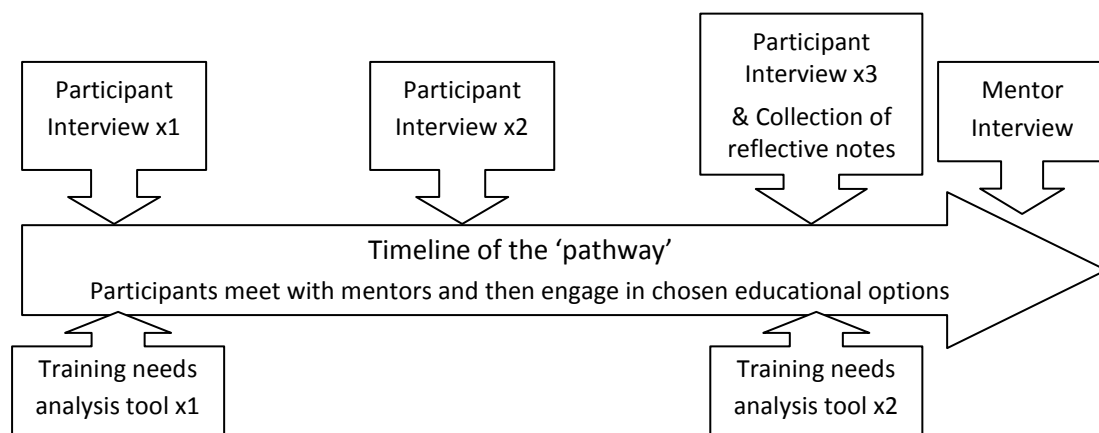
Table 3 Data collected

When collected / Data collection method	Start Feb 2012	Middle	End Dec 2012	Total
1:1 Interview:				
Nurse participants	11	8	8	27
Mentors			7	7
Documents: Training needs analysis questionnaire	9		7	16
Action plans	6	2		8
Reflective notes			2	2
Learning Logs		2		2

Methods

   1. Interviews

Semi-structured interviews lasting approximately 30-45 minutes were undertaken with participating staff at three points during the project allowing for detailed exploration of:

- Participants perceived needs and feelings of confidence

- Their experiences of the pathway

- Reflections on the experience

The first interview acted as a baseline with subsequent interviews allowing for any changes or developments to be identified, explored and tracked.

Where appropriate, issues raised by respondents were followed up during the interview and incorporated into subsequent interviews. Such an approach is common in qualitative research and allows the exploration of previously unidentified areas of importance (Silverman 2000, Kvale 1996) and the tracking of issues. The use of interviews facilitates respondents in sharing their private views and perceptions, while allowing them some control over their level of participation and disclosure (Kvale 1996). In order to obtain diverse perspectives on the programme one-off interviews were also held with the mentors.

Data collection took place predominantly on NHS premises –i.e. in private rooms in community health centres or at the hospice.

   2. Training Needs Analyses questionnaires

Completed copies of the TNA questionnaire were collected for each participant at the start and end of the project. Although the questionnaire is not designed to be a sensitive 'measure' of learning needs, and self-assessment of skills and competence is a highly complex issue (Yeo, Steven& Pearson 2009) collecting the TNAs before and after was felt to offer additional insights into the potential changes and developments brought about throughout the life of the project.

3. **Action plans**

Copies of action plans were collected where possible (n=8). In addition participants were asked to provide copies of any assignments or documentation from formal educational courses or workshops attended, were possible keep records and reflections on learning opportunities engaged in. However few such documents were provided.

This may indicate a lack of available time and energy to engage in the completion of such documentation (which is substantiated by the interview data) and, or in some cases a lack of self-confidence or experience in preparing such documents, or a lack of engagement in the process of the project.

Analysis

Interviews were transcribed verbatim, anonymised and analysed using an iterative approach drawing on grounded theory principles of constant comparative analysis (Strauss and Corbin 1990).

Each participant was given a code and each set of interviews was assigned an indicator A=first interview, B= second, and C = third interview. However participant codes have been changed and randomly reassigned within the report in order to maintain the anonymity of participants.

The NVIVO software package was utilised for coding by the researchers using thematic analysis (Silverman 2000, Strauss and Corbin 1990). Initial descriptive coding sought both similarities and differences reducing the data into 'chunks' and was followed by further reduction into smaller categories. Grouping and regrouping of the categories was then undertaken to form larger themes and descriptions of the experiences and processes of the pathway. The researchers then returned to the transcripts in order to further populate and refine the categories. Comparisons were also made between respondent types and across data collection points in order to identify cross cutting themes or issues.

Analysis was structured around the Context, Mechanism, Outcome framework of realistic evaluation. For the purposes of this study the following broad definitions were used:

Context was defined as the culture, routines, work structures within which the participants operated as community nurses. For example these could be related to their working conditions or the population with whom they worked.

Mechanisms were defined as the interactions or activities influenced or impacted on the participants 'learning' and feelings of confidence or competence. For example any educational activities they engaged in either of their own volition, as part of their job or through their involvement in the pathway project.

Outcomes were defined as any changes in the confidence, competence, knowledge or skills of the participants. Such changes may be observed, perceived or measured in some way

Disaggregation of data for analysis often results in the fragmentation of peoples experiences and the loss of a story or sense of wholeness therefore in addition to the analysis described above a small number of **case study vignettes** were also developed. These are composites allowing data to be recompiled so that the sense of a whole personal experience could be captured (see appendix 4) however it must be stressed that these do not represent individuals involved in the project.

Timescale

2011			2012											
October	N	D	J	F	M	A	M	J	J	A	S	Oct	Nov	Dec
			Individual meetings with participants Consent gained	Participants paired with mentors	First meetings between mentees and mentors									
Development of the tools and pathway options				Individual interview					Individual interview			Individual interview	Mentor interviews	
				Development of action plans								end of educational initiatives		
		Mentor Introduction to project	Running Mentor preparation sessions	Briefing staff on use of self-assessment tool										

5. Findings

In order to develop and implement effective measures to enhance confidence and competence in end of life care it is important to understand the work context of those involved. In this project the 'work context' also functions as the 'learning environment' for the community and district nurses. Therefore the first round of interviews included questions regarding; end of life care delivery in the community, experiences and feelings of confidence, perceived needs, and aspirations for involvement in the project.

5.1 Community nursing :Context issues

Diverse patient group & remit

The context within which community nurses engage with palliative and end of life care is complex. Nurses involved in this study described coming into contact with a **diverse range of conditions, illnesses and patient ages** (18 years and over). Patients could receive care and support at any stage during the trajectory of their medical condition, and care could be delivered either in the home or other settings such as a health centre.

> *"My job is to do with various, very general nature of the work – from wound dressings to bloods... It's all clinical procedures, which are normally performed in a patient's home...".(A2)*

Common categories of patients included; those requiring wound care, or managed care as a consequence of long term conditions (e.g. diabetics), alongside palliative and end of life care patients. In addition **staff worked alone much of the time** and the potential to become isolated in their practice was noted.

> *"It's always good to get updates on what's changing. ... To say, well, yes – that is what I do or this is the way we do it. Because you can get quite isolated and insular, working on your own." (A6)*

However part of the context of community nursing is **working closely with GPs** and as with any inter-professional relationship the success of the relationships vary,

> *"it's quite... Quite frustrating sometimes, to try and pin... Pin the GP down. So... But that's... I would say that's probably fifty percent. The other fifty percent are really good..." (A9)*

> *"Some GPs will just not respond to your request of a visit. Even though you're explaining that this patient is end of life, you know, and you feel it is the last – going to be the last few days –... And that can be quite frustrating". (A11)*

Thus the community and district nurses **roles were varied, were enacted in diverse settings, and often alone, and encompassed a wide range of treatment and care activities**. Commenting upon the diversity of their role and responsibilities one nurse summed it up by saying:

> *"A wide diversity, really... We do get a lot of palliative care patients, at various points through their disease progress. And a lot of wound care, post-op patients, patients with long-term conditions....Cancer patients, towards the end of death as well. Anybody between 18 and 100 really. Anybody that has any health need and can't attend a surgery, really". (A1)*

Defining palliative and end of life care

Differentiating between what constitutes **palliative care as opposed to end of life care** was discussed by some of the participants,

> *"palliation is just about prolonging life. I mean, that could go on for a long, long period. But towards the end of life, when you're seeing a... a change in the patient quite, rapidly... I think palliation, or the palliative side of it, is really more the psychological support". (A3)*

> *"Obviously end of life… The prognosis is very, very, very short. You know, 24, 48 hours". (A7)*

One participant questioned the blanket use of the term palliative care while another expressed a wish for clarity regarding the terms

> *"Palliative care is normally when they're entering the last six months of their life - Now, that's not my perception of it. I don't know if I'm right or wrong. I would like some clarity on it. Because to me palliative care is nursing a patient with a terminal condition and there may be times within that palliative care where they are well and they're going out and they're getting on with their life, but ultimately... It's not reversible, what they've got." (A4)*

Palliative care refers to people with advanced progressive illness, and can be applicable early in the course of the illness (National Institute for Clinical Excellence [NICE] 2004). Both palliative care and end of life care identify patient centred holistic care as fundamental alongside the support for the family (DH 2008, NICE 2004). End of Life care is ultimately the final part (last 6 – 12 months) of a palliative care journey, although, the transition from palliative care to end of life care can be complex for staff (National Council for Palliative Care 2006).

The role of community and district nursing staff

For some of the participants palliative care and end of life care tended to feature more prominently in their caseloads. **Involvement in such care appeared to be linked to the individual level of experience and role of the nurse**.

> *"We have a lot of palliative patients in this area. Traditionally we're very heavy on palliative care". (A6)*

> *"A lot of my role involves facilitating patients in end of life care in the home environment" (A11)*

For others, generally staff nurses it appeared less prominent and **some did not see palliative or end of life care as an integral part of their role** and responsibilities

> *"I think it [*palliative or end of life care*] seems to be a small part of it so far". (A5)*

"It was bit of a shock at first because you found that some of them [staff nurses] were saying, "Well, you know, I don't get paid to do palliatives. It's not my role". (A4)

Numbers of those **patients requiring palliative care at any one time was variable** but for more experienced staff it was likely that they would be caring for a minimum of one patient requiring some degree of palliative care.

" you could have three palliative care patients all at... going at the same time. And then you might have a lull. But... you're always seeing some palliative care patients within your day. Certainly as a sister" (A1)

Having received a referral for palliative/end of life care for a particular patient (via the hospital or, alternatively, by way of a specialist nurse etc) the degree **of involvement appeared to be related to the wishes of the individual patients** especially in the early days post diagnosis and/or referral. Involvement might be offered in the form of a supportive telephone call or home visits on an "as needed" basis, whilst for some patients no actual involvement would be identified.

"Sometimes it's very early, where people have literally just been told in clinic. And other times, as today, I've got a lady who is end stage dementia." (A6)

"We might have them when they are initially been diagnosed. A lot of specialist nurses let us know. And sometimes they would like us to visit. Often we just ring them – quite a lot [of patients] don't want us at that point. Or we'll visit and just negotiate that..." (A1)

When asked what types of patients required palliative/end of life care, **participants suggested most tended to have a cancer diagnosis**. However participants also reported caring for patients with other diagnoses such as chronic pulmonary obstructive disease (COPD), heart failure, motor neurone disease and dementia.

"More often than not it's cancer. But we do have some sort of end of life patients who are in like heart failure… Motor neurone disease is another one" (A8)

"… previously it was more your cancer-related patients, but now that's extended to your dementia, your...Your cardiac failures, COPD. So quite a variety, really" (A11)

With regards to cancer patients, their needs and those of their carers tended to vary throughout their cancer journey. 'Support needs' following diagnosis were less "hands-on" as opposed to the care and support needs required at end of life, where the care became very intense. Towards the very end of life the patient (and carers) required support so that the patient was allowed to have as comfortable, pain-free and dignified a death as possible.

Type of care provision

Participants often talked about **care provision** in terms of it being either **'hands on'** (clinical or task based) **or 'supportive'** (psychological, spiritual and emotional) and a dualistic view of care provision was sometimes evident.

"Sometimes they're having treatment, of course, so... You're going to support them through... And we're not maybe doing anything hands on, it's just a support thing, I think". (A1)

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"I've done palliative support visits for them…and that's providing psychological support, so it's not necessarily doing any hands on nursing intervention". (A11)

"When they become end of life, then we'll be doing hands-on care". (A9)

The **type of care provided was often related to the stage of the disease** or condition, with earlier stages of the disease trajectory often being equated with the provision of psycho-social support and later stages 'end of life' being seen as more hands on intensive.

"Obviously people's symptoms and problems change as the disease progresses. And sometimes it is really just an informal chat…Just monitoring symptoms". (A8)

"I think palliation, or the palliative side of it, is really more the psychological support because patients know they're not..going to die imminently". (A3)

Although this dualistic, chronological view of care provision was not so clear cut.

"We need to go in daily to do the [syringe] driver. And obviously support for the patient themselves, as well as the family" (A10)

However one participant felt there could sometimes be an **over emphasis on technical**, hands on care provision

"Because I think a lot of the managing of the end of life, for some people they get too transfixed with the medication side and they forget about the rest of it" (A11)

Workload issues and pressures

Interviewees spoke of the pressures they experienced when attempting to support terminally ill patients at home, particularly those who were not, as yet, at end of life stage. Support visits were perceived as being challenging, for example, in terms of the lack of available time needed to undertake such visits successfully. **Staff spoke of the pressures of heavy workloads.**

"And just because we are so busy as District nurses, we don't have that amount of time, really…" (A1)

"…well we come every fortnight – and sometimes I go and I think, "there's really no need. They've got telephone numbers. They've got…they know who we are." (A1)

Some interviewees felt that, for some patients visits should be reduced or, in some situations, patients should have the opportunity to make contact with the district nursing service by telephone if they required support. Although others found that some patient's didn't want to be 'a bother' so declined a visit

*"It *was not that she didn't want us to come, she did. It was just that she thought that it was a bother and we had other people to care for, because she was well, but she was taking up our time" (A4)*

For some a challenge appeared to be attending to patients with whom they were not familiar and who were **not on 'their' caseload**,

"going to patients who aren't mine, on my case load. And that quite often happens if it's a weekend" (A11)

Thus district and community nurses dealt with a wide range of patient needs which fluctuated depending upon the seniority of the nurse, the illness trajectory and the wishes of the patient and family.

Supporting and nurturing other staff

Interviewees spoke about the perceived **responsibility of more senior [and more experienced] staff to develop the skills and knowledge of palliative care amongst more junior colleagues** within their teams, but this was seen to differ from place to place.

"So I think that it's down to individual managers as to how much ownership they take and how much they go out and support the staff..." (A4)

Others described how they involved more junior members of staff, touching on the ways in which they 'eased' them into dealing with end of life care,

"Like we have a few new staff nurses here and once they've sort of found their feet within the community, then they would maybe do a couple of visits with someone else, just to get the gist of what we do really" (A8)

"Some of the junior members of staff – we do try and get them involved. And especially if it's... It's a more simple case, we do try and get them involved. Especially at the end of life, so that they've got experience of syringe drivers and how to deal with, you know, death and dying and... They can learn from more experienced staff about" (A1)

"And I'm...And supporting my staff. Who in...Are sort of new into this type of nature of work" (A11)

One interviewee spoke about the **guidance and support** that they had received when they first came into post and how this, in turn, had helped them to support less experienced staff at a similar grade (Grade5)

"Because that was done to me when I came here, I've sort of actively taken band 5s in with me" (A4).

Helping nursing colleagues make the transition from hospital based care to working within a community setting was also seen as important.

"I've worked in the community now for…. quite long time. So I'm sort of – I feel quite confident to do that myself [palliative or end of life care]. But a lot of the girls have been hospital-based and obviously visiting people at home is just completely different really" (A8)

Therefore **participants acknowledged the need and/or responsibility to help staff develop skills and confidence** in relation to end of life care. However the support offered and the willingness or ability of staff (be they more senior or more experienced) to nurture and 'educate' other staff seemed to vary from team to team.

5.2 What they did: Mechanisms

Identification of educational needs

The training needs assessment (TNA) questionnaire offered participants a structured way of considering their personal strengths and weaknesses and educational/training needs in relation to their role in end of life care. Some participants completed this tool prior to meeting their mentor whilst others completed it during the meeting. **The TNA was perceived as useful both for the mentor and the mentee and appears to have been easy to use**.

> *"It was very easy to understand, really straightforward...it was a good document. It was very helpful. Very insightful. " (B2)*

> *"...I'd done that. So I showed it to x, which was obviously useful for her...because then she could see...what my needs sort of where..." (B8)*

> *"Yeah, I think that it's quite straightforward, isn't it?" (B5)*

The breadth of topics covered within the TNA had the potential to overwhelm and for one participant resulted in the identification of numerous areas for development. The impact had been to leave him/her feeling somewhat incompetent and lacking in confidence.

> *"...it just made me look really incompetent because I was saying I wasn't confident in anything...oh dear...I really should have been confident in more things...when you start to question yourself "am I confident? Actually, no I'm not"* (interviewee)

Non-completion of the documentation was less common, however one participant came to the project with a clear idea regarding their desire to develop in palliative care as part of their future career. This participant used the initial meeting with their mentor to explore this idea and discussed the steps necessary to achieve their goal.

> *"...I realised that this palliative care was the thing for me, really...and I was really at a crossroads deciding what path to take next really...and the [other] thing was looking at what sort of education might be helpful to, like, further my career the way I want to go, really. So that the sort of thing that we talked about*." (B9)

It could be argued that this was action planning, albeit in a less formal manner than would have been achieved through completion of the documentation. Indeed this mentor kept in contact by email and highlighted a number of opportunities for the participant to consider. However it was suggested by the mentor that completion of the action plan might have helped in the achieving of milestones along the way.

> *"I think, probably, for me, on reflection, using the action plan - having something written down – might have just reinforced the need to…you know, be able to revisit that and say "Well we're not actually meeting the milestones that we agreed in the action plan." So I think on reflection that might have made a difference. And I would certainly consider that in the future." (M9)*

In general, the use of the learning needs assessment and action planning documentation was seen as being both of use and of value.

Educational activities

Mentoring formed a core element of the pathway with participants having the opportunity to choose from a wide range of formal and informal educational activities listed in the pathway 'menu' (see table 1 page 12).The range of activities that participants engaged in varied from shadowing specialist staff to signing up for relevant university modules as illustrated in table 4 and figure 3.

Table 4 Educational activities by participant

Activity / Participant	Meetings with mentors	Episodes Shadowing staff	Hospice visits	University module /6 day PC course	Other formal e.g. lectures, seminars	Other informal e.g. self-study
A	2		3			
B	3	1		x		
C	5	1				1
D	2	1		x		1
E	3	2	2			
F	2				2	
G	3	1			1	
H	2	7		x		

*please note for reasons of anonymity the codes used for participants have been varied throughout the report.

Figure 3 Educational activities

The following graph illustrates the numbers of participants engaging in each activity.
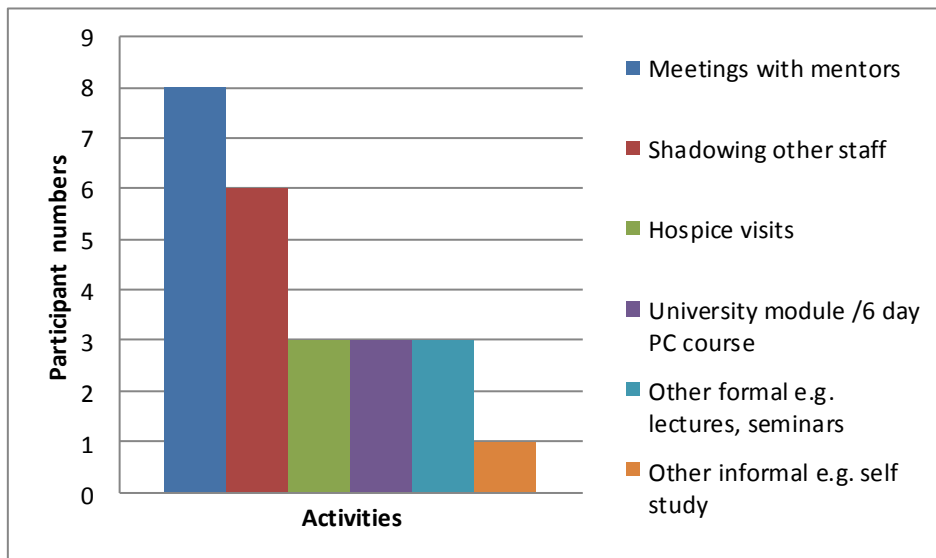
Mentor meetings

The mentoring scheme formed a core part of the pathway but was not prescriptive with the organisation and frequency of the meetings being at the discretion of the participant and mentor. However all of the participants met with their mentor at least twice as illustrated in figure 4.

While all participants engaged in mentoring meetings as part of the pathway project, some meetings included a short teaching session

> *"we did a couple of little sessions on that as well. Yeah. Just, like, the... Just, sort of, you know, the general, sort of, pain and nausea and what have you. And again it just, sort of, refreshes your memory". (C8)*

Figure 4 Number of meetings with mentors during the study period
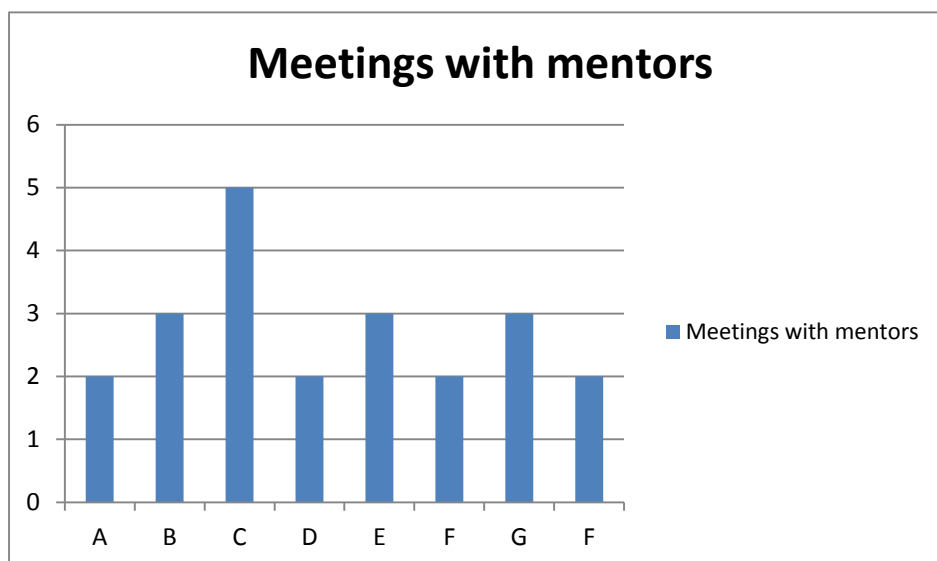
One participant who met their mentor formally twice also reported having several informal meetings facilitated by the close proximity of their 'bases' within the same building, although they had no clinical overlap.

Another participant reported 5 meetings with their mentor. However two of these meetings were facilitated discussions on specific areas of low confidence or identified need, while a third involved the participant observing the mentor in practice.

Thus the **frequency** and **duration of mentor meetings varied between participants** with some spending a full day together while others met for a shorter period of time

> *"I'd emailed …….. and then we had telephone contact and back and forwards, so I went through and spent a full day with (mentor)" (B4)*

> *"Well, about... Half an hour to an hour" (B10)*

> *"Probably about an hour or a bit more actually – it might have been an hour and a half. It was quite long anyway" (B5)*

The **initial meeting** took many varied formats, with some taking place in the mentors workplace which had the additional benefit of allowing participants to meet some of their learning needs.

> *"The first meeting, we just had a bit of a talk about where I'm at, my experiences in palliative care, strengths and weaknesses, things I would like to be working on..." (B2)*

> *"And I went to X Hospice, which was good in itself because one of the things I needed to do, I think, was to go to the hospice. That was quite good" (B5)*

> *"that's where her (mentor) work-base is... And it was an opportunity to also have an insight into her role. Because, yes, you might know what they (palliative care specialist nurse) do, but really watching somebody work and experience somebody who is very experienced doing it" (B6)*

Practicalities
Making time to actually be able to meet could be problematic for both mentees and mentors due to various reasons generally related to **workload pressures**. Getting time out of practice to meet or undertake learning activities proved difficult for some

> *"...we've both had quite busy schedules, so that's been difficult...getting as many regular meetings as we would like"…There was a couple of things I had to move back to the start of August due to work commitments – that has been a bit of a problem late" (B2)*

> *"However, there's been a few negative sides of it, from the point of view of being released from work. I think that's been the biggest problem. You arrange with your mentor to go and do something or to attend a course, and you just physically can't get there" (B6)*

> *"Initially it was... It was difficult to get time with [mentor]...it was too stressful because we couldn't seem to like get together..." (B8)*

Being released from work to attend modules delivered in a higher education setting appeared to be given greater credence than being given time to meet with a mentor. Whilst it was recognised

that having set meeting times might not always work, it was suggested that having some regular protected time (e.g. an afternoon or a day every fortnight) may be beneficial and allow optimal use of the time available.

> "…I think it could have been so much more…We could have achieved more in the time, if she'd been released when she should have been…And you know that that would not always be possible. But I think to have really made something of the project, to have been really able to change her practice and her level of confidence that's what we probably would have needed. And it felt like we hardly got any of that…" (M6)

Where mentees had been provided with protected time this was seen as being of benefit

> "…So she seemed really positive and excited that she was going to have some protected, definite time to be able to go and engage with stuff…she had, kind of, embraced that with both hands…" (M10)

Lack of available time to meet was problematic and could become more critical if a mentor then found themselves having to address developmental needs in a short but intense period of time.

One senior nurse spoke of her frustration of not being able to participate fully in the project nor attend the meetings etc. set up by her mentor. Such situations were perceived to be out with the mentees control , for example the impact of staff going off sick, the total absence of band 6 bank staff cover and limited availability of band 5 cover.

> "there's been a few negative sides to it, from the point of view of being released from work…You arrange with your mentor to…and you just physically can't get there. I think that it's worse being a band 6…although we can sometimes release the band 5's, it's usually us who can't….I think that's been the most frustrating bit" (code removed to maintain anonymity)

Issue related to **location** also impinged upon ease of **access to the mentor**. Interviewees might, in some cases, be in very close proximity to their mentor, for example in the same building (which, theoretically, facilitated relationship development),

> "…that's definitely been a great help. She's always there…we've got more of a relationship since we started speaking to each other "(B2)

For some, geographical distances impacted upon their ability to meet up more regularly. Making initial contact sometimes proved problematic but was overcome through telephone contact followed up by a meeting at a workplace such as a hospice. Another issue was the impact of part-time working which could have significant implications for mentor and mentee being able to meet,

> "And it's more difficult because I am part-time, you see." (code removed to maintain anonymity)

Whilst it was acknowledged that **the needs of patients were of prime importance** to both the mentor and the nurse being mentored; **having to cancel planned meetings was frustrating and time consuming.**

> "I think that it's really difficult…This is my own interpretation. I think it's really difficult for people to assign time for meetings and study, that's not actually formalised – where you're

not attending a classroom. And I think if someone is carrying a busy caseload, it tends to be the case load comes first. So the study is, sort of, second. Where if you have to attend a classroom at a certain time…" (M2)

This particular mentor went on to explain that three planned meetings had needed to be cancelled due to pressures of workload, either that of the mentee or because of that of the mentor.

"…initially I think we had about three meetings which were cancelled…I think the first two I actually switched my workload to accommodate. And I think the third one; in all honesty, I think I had to cancel. For my own workload pressures. And like I say, I was a wee bit disappointed…But I understand that when somebody, like I say, is very, very busy, patients come first" (M2).

For most mentors there had been problems arranging meetings with their mentees, whether this was in terms of establishing initial meetings which might then be further compounded if subsequent meetings also had to be cancelled or re-scheduled due to work-related constraints.

Most participants did however find ways to get together even if meetings were not regular or required persistence on both sides to successfully organise. In addition some felt it was **important to overcome difficulties** stick to identified meeting dates once they had been arranged rather than allow work commitments to continually impact on them. One interviewee commented on how a colleague had urged her to continue with her meeting despite work commitments potentially impinging on this proposed meeting

"No, no, you've got to do it...because it is important" (work colleague)

"But it's difficult, you know, you just get sucked into the world..." (B8)

While another described how the **perceived benefit of being involved, both for the individual and their colleagues,** was seen as outweighing workload pressures

"we are low on staffing levels but, you know, you just explain why you're doing it, how it's going to benefit where I'm working – not just for me, but for me as a Band 6 supporting Band 5s and developing them. The more knowledge I've got, the more I can support them and it's developing a future work force, so it's not a problem at all" (B4)

Thus participants and mentors faced a series of challenges in arranging and undertaking meetings but managed to overcome these where possible.

Mentors role: experiences and issues

On occasions there appeared to be some degree of **incongruity between what the mentors perceived their role and responsibilities to be and what an individual mentee might want** from such a relationship. For the mentors issues emerged regarding their role and these included feelings of responsibility for participants learning experiences and concerns regarding whose responsibility it should be to make contact.

"…I felt it was up to them to…Instead of…I didn't feel that it was my role to be chasing…" (M2)

"Yeah. I've felt like a lot of the time I was pushing to meet…And this time I felt, given that I'd made a lot of the moves and pushed when we would meet and how we would meet and how that would be…I thought, I think I need to give her the opportunity to come back to me and see what happens…And I haven't heard anything" (M6)

"Although I felt the onus was on me to contact her on occasions…I had to, sort of, sometime steps back and think she should really be making the initiative to contact me sometimes" (M4)

"…I've kind of thought it through in terms of could I have been more available in myself? But I did think that there had to be a lot more commitment from the nurse who was participating in the project. And I feel that that has been a challenge and that has been a struggle. So that's probably where a lot of the difficulties have been" (M9)

Thus some mentors seemed to find it difficult to know how to straddle this dividing line of **not appearing "too pushy" whilst wanting to provide or offer development opportunities.** This situation was further compounded if the participant was denied the time to engage fully with any learning opportunities offered.

In general the mentor would plan, in collaboration with the mentee, a programme of educational activities aimed at addressing the identified training needs of the individual mentee. However **some mentees were more proactive in the approaches adopted to meet their identified needs**; for example by arranging and undertaking formal academic study. Such pro-activity influenced the dynamics of the mentoring relationship and as the following quote illustrates could relieve feelings of responsibility, whilst also stimulating doubt for the mentor regarding their ability to effectively meet the participants needs.

"I'm relieved that she didn't need me as much as maybe I thought she needed me, because I haven't been able to provide her with that" (M3)

The feelings highlighted by the previous quote highlights issues regarding the interpretation of the nature of the mentoring relationship. There was suggestion by the mentors themselves that, **possibly, [some] mentors were too supportive and too directing of the individuals** that they mentored and that this approach might need to be re-considered.

"…one thing it's made me think as well – I think maybe I help the other staff too much. Tell them what they need to be doing and what they don't [spoke about having mentees with own objectives etc.] …I think that I should expect a bit more of that…"other people can do it" You know, get yourself as motivated and…You know be a bit tougher on the others because of that." (M3)

The expectations of those being mentored also varied. **Perceptions regarding the amount and depth of knowledge and skills they needed in terms of palliative and/or end of life care were sometimes at odds with the mentors views**. Some mentees appeared to find it difficult to comprehend that they did not need to have the degree of experience, knowledge and experience that specialist nurses possessed. Having a more generalised knowledge was a benefit, rather than a failing as community nurses themselves worked differently to those of their more specialist colleagues.

Doing it differently in the future: recommendations

The mentors were asked what they thought would need to be done differently or what would work better in the future if such an opportunity was to arise again.

Whilst opinions about how best relationships might be developed were mixed, it was clear that **a more formalised and structured approach was the preferred option for the future**. Being able to meet together on a regular basis [pre-planned meeting dates] was seen as being useful or necessary, particularly in view of the impact of workloads and working patterns, for example where staff worked part-time.

> *"I personally think…It needs more continuity. I think maybe meet every month or every, sort of, two weeks, to see where we're at and shadow each other. ..We made those arrangements, but we never got the opportunity to do it because of workloads…What I would personally say is that it may well be stipulated that you meet monthly. I think, even if it was just a half an hour face to face contact. Because I think in the busyness of things it's easy to say that things are going okay –and they may not be…" (*M4)

> *"Right, So monthly contact you feel, would be realistic for two busy workloads, I guess?"* (Interviewer) *"Yeah"* (Respondent) (M5)

> *"I think probably to establish and just firm up how often you're going to meet up – and probably have that planned, that you actually diary beyond the next meeting. So you actually have, perhaps, 4 or 5 diaried opportunities built into the work plan for the next foreseeable months…"* (M9)

Being able to observe the mentee in their work-related setting was also suggested by several of the mentors.
> *"I think at the start – when we first met with who we're going to mentor - that it would have maybe been nice to do that in the person's working area…Just for me to have more of an understanding about what her role was and what it entailed. And I think maybe, in hindsight, spending a day with her or some time with her would have been really useful…"* (M10)

Having **a midpoint review of the action plan was also seen as being useful** as was having the mentee achieve certain things by certain dates within a more formalised structure.

> *"I think that it's very difficult for everybody to be extremely structured and stick to plans, because things change…and time slips away with you. I think I would have said it would have been good to have had a full review of the action plan halfway through. "*(M6)

> *"…because of the climate we work in and things being so busy, I think, sometimes you need some structure in it for it to say "Right" you know …"this is what we expect and we expect you…to have contact at least once a month…And feedback…whether it be telephone or…and have it structured."* (M5)

Several **mentors also suggested having a final meeting** with their mentee to establish what learning had taken place and whether their mentee needed any further support would have been useful to 'round things off'.

"…she emailed me back saying that she'd enjoyed them all, got lots from them all, but she didn't feel that there was any need to meet up. For me, I would have liked to have had that final communication and just draw everything together."(M10)

Hospice visits

Three participants made visits to Hospices. The duration of the visits varied between spending a full day or a half day in the hospice or visiting solely to observe a ward round.

One of the participants spoke of how useful they had found a visit to a local hospice, particularly the opportunity to observe practice within the adult in-patient unit.

"…[I]also went on the inpatient unit. The adult...It was a really, really good insight there. Just to find out more about the service which you're offering. And you are talking to patients on a daily basis with...but not fully knowing, understanding yourself. So that has made a big difference." (B2)

Being able to ask about and begin to understand the actual roles of the members of the multi-disciplinary team MDT rather than simply knowing that x was a named consultant, a named social worker etc. was seen as being useful.

"But you want to see exactly what their role was in that area. Because they can be in very general terms." (B2)

The opportunity to visit for a fixed time period was perceived as providing a useful, if somewhat frustrating opportunity as it offered snapshot of what happened at the hospice but, in some respects, didn't allow for a more in-depth learning experience.

"...I would have liked to have spent more time there and to see a day in the life of what it would be like on that kind of ward[adult hospice in-patient unit]" (B2).

Having a suitable opportunity to spend a longer period of time [observing] in a specific health-related setting such as a hospice was seen as a useful learning opportunity. Yet venues such as hospices, by the very nature, are working environments serving the needs of patients and their families, individuals who, in general, have very complex needs which call for compassion and sensitivity when being addressed. At the same time a vast range of different groups, both professionals and lay people wish to visit these types of establishments in order to learn about the work that they do. It is how best to balance these needs so that ,first and foremost, the patients being cared in the hospice aren't disadvantaged by all by the visits of all who wish to learn but which then can offer the healthcare professionals the educational development that they require in order to provide effective and empathetic patient care.

Shadowing

While there are obvious overlaps between the activities of 'visiting the hospices' and 'shadowing other staff' **six participants specifically reported shadowing specialist palliative care staff** . One participant commented on the visit undertaken accompanying a Macmillan PCSN being perceived as too short,

> *"...I went out with a Macmillan nurse for one day, which I don't think is long enough, one day." (B3)*

This perception also appeared to be endorsed by the mentors themselves in that one agreed with her mentee that a visit of one day was possibly not of much value suggesting that a week might be of more use. This situation then became problematic for the nurse manager of the mentee who envisaged that if she allowed one member of staff that length of time away from work then the same "rule" would need to be applied to all staff.

However after spending several days with a specialist palliative care team, the mentee reported having learned much in this time

> *"...not just from the communication, but a little bit about pain management and symptom control ...more complex things. I did learn an awful lot. And spending, like, the full day with her (Palliative Care Specialist Nurse) and being with her all the time, it was really quite a relaxed atmosphere" (C3)*

The previous quote touches on the **benefits of *'being with'* the specialist nurse *'all the time'.*** This aspect was also highlighted by other participants who described the benefits of having time to debrief, with one specifically identifying how traveling together was felt to be an efficient way to enable debriefs and discussions

> *"one thing about doing the shadowing was that if you go out in the same car as the nurse you're shadowing, then in between patients you can talk about the patient. Usually beforehand they can tell you about them and what's happened. And then afterwards you can talk about it and... I think that really helps and that's like having a concentrated, personal, one on one, palliative care foundation course". (C5)*

> *"she gave me an update of the patient that she was going to see before we went. And then after we had a big discussion of what happened while we were there and anything that I wasn't sure, she discussed with me". (C10)*

Thus shadowing specialist staff offered participants the opportunity to both observe the practice of experienced colleagues and engage in discussions about the care provision and planning.

Being able to observe and assimilate the working of the hospital specialist palliative care team with that of the community nursing team was also of positive value.

> *"...we've got this very experienced group of people who are doing a fantastic job and it was lovely to see the differences between what happens in the community and my role...and actually their role, and how it flows together...so it just gives you the full picture of what's going on." (B6)*

Depending on the relationship which developed between the participant and the person being shadowed the experience also offered a **safe comfortable forum in which to ask questions**

> *"it was really quite a relaxed atmosphere. And she was quite open and she asked me to ask any silly questions I felt I had. And I felt quite comfortable. But that was with her. Whether anybody else would be the same, I don't know". (C3)*

The use of 'silly' in this context alludes to a perception of lacking competence (i.e. I should know this therefore the question is silly), while the use of 'comfortable' and 'relaxed' in relation to the atmosphere seems to indicate a forum where the participant felt confident enough to 'expose' his/her uncertainties. **Creating this sort of open, safe learning environment is highly valuable** but may, as the participant notes, depend on the individuals involved.

The value of such 'safe' learning environments and the issue of 'exposing' ones uncertainties or areas of weakness was also raised in relation to in-house education and training. This type of learning situation was viewed as 'unsafe' given nurses may feel unable to ask questions for fear of appearing incompetent and risk feeling foolish

> *" if you have too big a group no one's going to sort of ask any stupid questions, nobody's going really to say "Oh actually, something's actually upset me" or "I'm worried about this/I don't feel that I'm doing well on that" you wouldn't would you. Not in front of your colleagues" (code removed to maintain anonymity)*

Thus shadowing presented many opportunities for learning and also in some cases offered a safe environment to ask questions and 'expose' areas of perceived weakness.

Formal activities

Three of the participants reported undertaking or arranging formal educational activities. From the training needs analysis and mentor discussions one participant identified a specific area for further academic study. **Links to the university via the pathway project enabled the participant to arrange admission to a postgrad certificate programme**

> *"I felt I need something more theoretical to back up what I was doing, to get the underpinning knowledge to go... So I spoke to x [lecturer]at the university in a telephone conversation and we discussed the type of courses that we thought would meet my needs, you know. And we've come up with a plan where I'm going to do a post-grad cert in palliative care". (B4)*

Although booked just prior to the pathway starting, another participant undertook a university module whilst participating in the pathway and was able to link this to activities engaged in as part of the project

> *"I did a level 6 at [university], which I think is very important – to have the academic side. .... And where I found a great benefit was I went out with a MacMillan Nurse for one day, which I don't think is enough, one day. And that was absolutely brilliant. And I learned so much more in that one day, linking it with the academic side from the university". (B3)*

As part of the pathway project a third participant attended the 6 day foundations of palliative care course run by the specialist palliative care team within the employing trust. This participant was initially concerned about being released to attend because of workload issues and staffing levels, but **did manage to complete the course and was very positive about the learning and benefits gained**

> *"the palliative care course that I did…The foundation course. Yeah, I think for 6 days, I felt I got so much out of it. It was brilliant. It made a big difference".*

> *Interviewer: "Given that you're talking about that are you able to tell me what you got out of it and maybe how?"*

> *"Right. Well, it was just things that I just never would have known before. Like one of my patients had a high calcium level. And I recognised the symptoms of it – and before I wouldn't have done".*

> *"… things like that – knowing what to look out for, what kind of emergencies... I'm sort of looking out for more different things. I think I'm aware of more different questions to ask and... And then even just this morning I had what would have been a really difficult conversation for me 6 months ago" (C5)*

> *"because I've got so many things that I need to learn that I'm not sure anybody else in there needs to learn- that's why I'm thinking it would be good for me to go on the foundation course [in palliative care]that covers so many different areas..."(B5)*

For approximately half of the participants **taking part in formal education** initiatives was also seen as an important and useful way of learning, keeping up to date and stimulating them to reflect on their practice.

> *"I did the foundation course in palliative care. That sort of gave me a bit more confidence to go out and actually meet people for the first time …I think it filled in the gaps of knowledge that I had, maybe, from the academic side. Sometimes you go in and you don't understand that piece fits to that... now I'm a bit more holistic in that. .. It is spiritual and the other elements... The emotional side as well" (A11).*

> *"after doing the course and applying it back into practice .…doing the Foundations of Palliative Care helped me because at that point, I thought I was doing things right and you go in and you think "I was so patronising, the things I was saying." …I felt, a lot of the things I've said I was getting wrong. So it did help to do that".(A4)*

One participant contrasted academic, classroom based education with hands on practice based learning and appeared to find both useful

> *"I did a foundation course here …. Which was really good, but it wasn't hands on. It was just... You know, you come to the classroom – which I think is completely different to being out in... With a patient. And then I've just gone back to university to do this diploma, which I'm finding really good" (A3)*

Thus engaging in formal educational activities was perceived as valuable by those involved who were able to translate the learning into their daily practice and use it to enhance patient care.

Informal activities

Informal activities were undertaken for some in a planned way; with one mentee being directed to use Current Learning in Palliative care (CLIP)(Help the Hospice) worksheets by her mentor, which were said to be helpful

> *"Yeah, I think they're quite useful. I think it just, sort of... Gets everything together. It just helps you to reflect a little bit better, I think. On what you've been talking about and what you're, like, hoping to learn. Just, sort of, condenses it all" (C8).*

For others being able to learn about particular topics as a team within their workplace at convenient times such as lunchtime is beneficial

> *"The palliative nurses here for training sessions... On a lunch-time. ... If there's anything that anybody wanted to know a bit more about, then they were quite happy to cover that in one of the sessions" (A10)*

Whilst visiting their mentor one mentee reported the value of being able to attend an impromptu presentation being delivered by a palliative care consultant on Parkinson's disease and end of life care. Being able to retain a copy of the presentation notes was seen as useful asset to the nurse as she would be able to refer back to the notes if she needed to.

What works: Perceptions regarding 'effective' learning mechanisms

The power of learning through observation/observed practice

When talking about what helped increase confidence (and therefore potentially competence) participants mentioned a number of mechanisms for learning about end of life and palliative care. **Watching, observing or shadowing colleagues or specialist nurses was one of the most frequently mentioned ways of learning and was rated very highly by those interviewed.** Such episodes offered opportunities whereby mentees could observe interactions; listen to conversations and, at appropriate times, engage in suitable opportunities and a number of interviewees indicated that they had learnt a great deal from being able to access this type of opportunity.

> *"I would go out with them… I would always be going out with a senior colleague…, Just seeing it [LCP], ..seeing it in practice, I think, was the most beneficial … trying to pick parts from their practice which I would put into mine, just to practice better…." (A2)*

> *"I get more from watching somebody – observing somebody – actually doing something… I've been out with, (Macmillan nurse)... watching how they approach some things… "(A3)*

"I was trying to develop my palliative care skills, and I was doing some regular support visits with the support of the Sister and one of the MacMillan nurses. So that was really good – I felt like I was starting to develop my skills" (A5)

"I think, …. I think, maybe if I saw what the MacMillan nurse did or… Could understand what their role was, it would give me more confidence that actually what I'm doing isn't wrong, what you're doing is right" (A7)

"It's observation...if you see someone that you think does it well, then you've sort of got a foundation to base it on...that's just the sort of learner that I am. I like the theory. Then I like to see and then I like to do." (B4)

"...watching somebody work and experience somebody who is very experienced doing it. And I picked up a lot of ideas of how to broach things with people as well. And even just phrases to use...which was very useful. "(B6)

[re shadowing and visits], "that's where I learn a lot of it from, you know, like watching other people and how they work… you watch your Band 6s and your Band 7s and your link nurses and you kind of learn from them as you watch them" (C2)

"And going out with the specialist nurse was really good, because we went to visit the patients at home." (B10)

While much of the learning reported in these shadowing episodes related to roles and communication one nurse described how she had arranged to go out with the overnight nurses in order to learn more about the management of syringe drivers.

Another participant, having had the opportunity to observe and discuss issues with her mentor, spoke of how she had been able to learn that silence during conversations was actually a good thing rather than being, as she had previously thought, something bad; she had come to appreciate that it was a period of time in which a patient or carer could think, rather than time which she, as the nurse, had previously wanted to fill with words in attempt to overcome silence. **The power of being able to listen and watch experienced communicators was regarded as valuable.**

"...I think that it was just listening talking to him...because it can be difficult when people say...it's difficult to know what to say back when someone says "well, what's the point, I'm going to die..." (B8).

Watching their interactions with... You know, the patients, with regards... You know, the way they do their assessments – sometimes a little bit deeper. Just watching the way they talk about death and dying... Which I did find a little bit awkward...(C4)

Another nurse had visited a setting with her mentor and had encountered a patient known to her. Thus she had become an "active participant" in that hospital based staff had involved her in discussions asking her information about patients that she was involved with the community setting.

"...I could possibly give a bit of information across that they might not have known..."(B6)

However once more **workload issues were felt to impact on the potential to observe others**.

"I'd like to do more observed practise, but... You know. Workloads don't permit that we can do lots of it. But, when we have the opportunity, we do... I do go out and double up with my staff and see how they're getting on" (A11).

Those who took part in shadowing or hospice visits all reported multiple benefits and talked highly of the experience in terms of their learning and increasing their confidence.

Support and reassurance

Gaining **reassurance from other colleagues, having someone to ask, and being offered support** were seen as valuable in building and maintaining confidence in practice and this was in part one of the benefits of having a mentor .

"The benefit of a second opinion. But, like, I can always call a colleague just to come along and just to help assess the patient and see what they think. ...in the team we've got some very experienced, highly trained nurses, and I don't know if sometimes whether... I keep looking to them" (A2)

" I was always needing to, sort of, ring the MacMillan nurse and find out advice about how to adjust her medication and things like that. So it was... A good learning experience".(A5)

" It's something at the level of a staff nurse. I was always keen on going to meet new palliatives– and I was supported by my manager as well, that brought my confidence on". (A11)

A desire for more support was also expressed.

" a bit more confidence and support would be helpful… Some things you might be able to do but maybe just don't feel as confident to do it, in case you're not doing it right". (A10).

Several participants commented on the **value of having a mentor,** even if they did not meet regularly just **having a named person to contact was positive** for them.

"And … was just giving me pointers as to areas which she thought may helpful" (B2)

"And she can put you in the right direction. So I think it's good. I haven't used her greatly – but I think it's good to have a named person". (B3)

"I think she's very supportive. In fact, what I was saying to her was that it's really great having a mentor but, you know, how could you have time for all the nurses? "(B5)

One participant felt it would not have been possible to achieve the learning gained without a mentor. This **may highlight the 'blind spots' all individuals have** during self reflection or consideration of learning needs, **and the value of having a mentor to assist in guiding the mentee to consider some of those areas.**

"I couldn't have done it without one. I couldn't. I'm good at self-directed study but, again, she sort of like – it's getting back to how do you know what you don't know?"(B4)

Although the value of having access to a mentor was appreciated, as one respondent indicated palliative care was only one part of her role. Although the interviewee appreciated having access to a mentor and appreciated that she would help her in whatever she could in relation to palliative/end

of life care, the value of having such access was questionable when there were so many other aspects to her role as a district nurse.

> "So I have no doubt that she's there. Do you know what I mean? But it's how much I can use her in the midst of everything else. Do you know what I mean? "(B9)

In addition one participant who highlighted a feeling of needing to be reassured in her practice linked this to the **isolating nature of community nurse work**.

> *" It's always good to get updates on what's changing....Because you can get quite isolated and insular, working on your own. And it is reassuring to actually think, "Well, yes, I do do that. So I'm doing it right" (A6)*

Opportunities to come together with other practitioners, for example in organised or formal education initiatives, also seemed to offer opportunities for experience sharing which was valued.

> *[re six-day palliative care course]…. "there was quite a big group of us and it's nice to listen to other people and their experiences- That was very valuable". (A8)*

As with other 'learning' **repeated experience of seeing or dealing with a situation was recognised as increasing confidence**

> *"At first it was very daunting, but I think the more knowledge you get and the more experience you get and the confidence, you feel as though as you can do... You know, you can take them through that journey". (A3)*

Some of the comments seem to indicate participants desired further development of a **'community of practice'** which supports observation or shadowing of others, fosters a culture in which they can ask for reassurance or support, and opportunities for sharing experiences. While these learning activities are available, albeit perhaps to different degrees, and such 'communities of practice' undoubtedly exist to varying extents across community nursing, the 'lone working' and insolating nature of community nursing may make opportunities for spontaneous learning interactions less likely therefore indicating the need for legitimised spaces and opportunities.

5.3 What changed, what was gained: Outcomes
In this section the outcomes from the pathway are reported which include

- Areas of low confidence and/or competence and or learning needs identified both through the interviews and the TNA questionnaire.

- Changes in confidence or competence reported during interview or via the post pathway TNA

- Any experiences reported which highlight or evidence changes in perceived or competence and any other benefits, gains or issues reported as resulting from participation in the pathway project

The context within which the community nurses work and the varying degrees of support, education or experience available seems to result in mixed levels of confidence (and potentially also competence) in dealing with end of life or palliative care.

During the interviews participants often described areas of care they felt confident in and comfortable dealing with, and many also mentioned the range of expertise and experience which existed across their community team. Some referred to examples of excellent practice and colleagues who were highly experienced and felt to be very competent in delivering EoL care.

Participants reported feeling uncomfortable or unconfident in dealing with a range of areas of care provision many of which mapped into the competency areas in the TNA document. However a few participants also identified other areas such as a perceived lack of knowledge about the range of different types of cancers encountered

> *"...we were coming up with a lot of cancers and I'd never heard [sic] some of them – didn't know the trajectory or anything."* (B4).

> "*Just general information about cancer care, really...I think that I'm honing in on the lung cancer module, really. Because I think that's basically the bulk of it..the disease that we see*" (B9)

Some also felt that they lacked adequate knowledge about non-related cancer conditions such as Parkinson's disease, COPD (chronic obstructive pulmonary disease) and their management at the end of life.

The following sections report the TNA results in tandem with findings from the interviews.

Areas of low confidence or training need

The training needs analysis (TNA) questionnaire was developed through the National Communication Skills Pilot and based upon the Department of Health's End of Life Care (EoLC) common core competences and principles (DoH 2009). The TNA questionnaire covers 4 EoLC competence areas, plus overarching values and knowledge:

1. Communication Skills

2. Assessment and Care Planning

3. Symptom management, maintaining comfort and wellbeing

4. Advance care planning

Participants are asked '*What EoLC training do you feel you need to increase your confidence and competence?* And instructed to read and respond to statements related to each competency area.

Participants were asked to respond to the statements by ticking one of the following options,

- Strongly agree
- Agree
- Do not agree or disagree
- Disagree
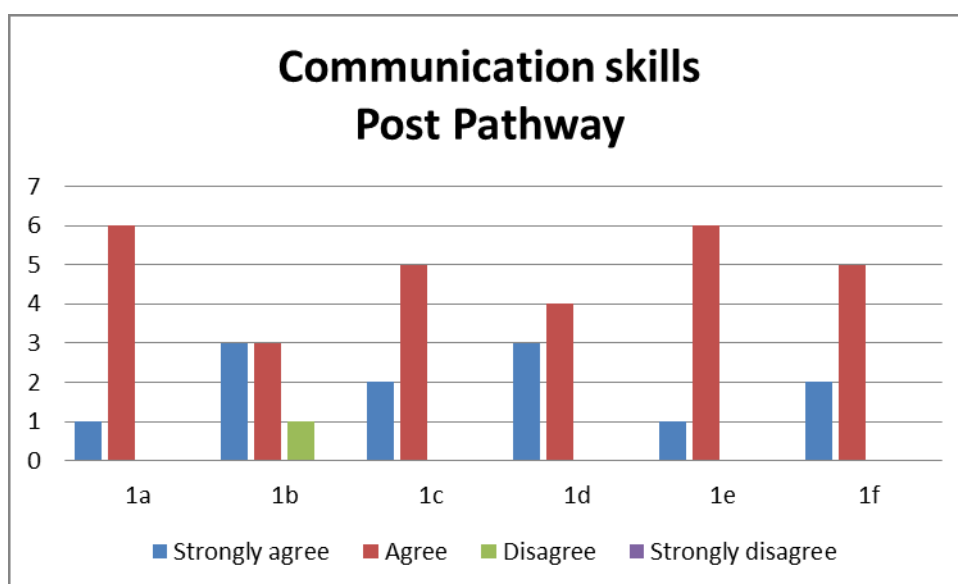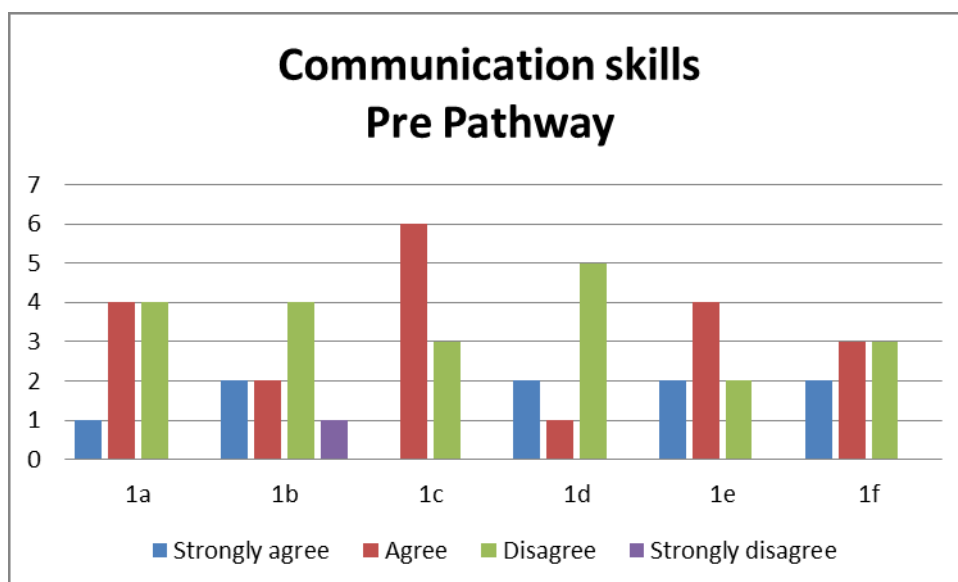- Strongly disagree
- Not applicable for my role

The questionnaire was used pre and post pathway as a proxy measure of outcomes in the form of changes in self-perceptions of confidence and competence. These were cross referenced with data from the interviews to compare and contrast and in effect triangulate findings. The following sections cover these results.

1. Communication Skills

The following statements were included in the TNA section on communication.

1a	I feel confident to develop and maintain communication with people at the end of life, their families & others involved in their care about matters or situations related to end of life care
1b	I feel confident to listen to and talk with a dying person about issues surrounding their care and their death
1c	I feel confident to listen to and talk with friends and relatives of a dying person about their issues and concerns surrounding care at the end of life and death
1d	I feel confident to provide information and support about end of life in a range of formats, including written and verbal, as appropriate to the circumstances and the situation
1e	I feel confident to work with individuals, their families and friends in a flexible and sensitive way that demonstrates awareness of the impact of death, dying and bereavement.
1f	I feel confident to recognise and respond to any variation over time, in individuals', their families' and friends' priorities.

Several participants expressed concern regarding their levels of confidence and competence in relation to communication. The following graphs show the responses collected at the start and end of the pathway.

**Communication skills
Pre Pathway**

**Communication skills
Post Pathway**

It is noticeable pre pathway that 5 participants out of 9 who filled in the questionnaire reported disagreeing (1 strongly) with statement 1b and 1d, and for every statement there was some level of disagreement indicating that some aspect of communication was an area of low confidence for someone in the group participating in the pathway . However the post pathway 'scores' show a marked movement towards agreement indicating enhanced levels of confidence, with only one 'disagreement' recorded in 1b.

Areas of concern and lack of confidence/competence at the start of the pathway

A lack of confidence in dealing with communication was also reported in the interviews. Many participants identified a lack of confidence both in themselves and others in relation to communication and support.

> *"A lot of the Staff Nurses don't feel they want to take the full responsibility of that. They haven't got the confidence. They're happy to go with somebody as a second person, but*

they don't always feel that they have the confidence to do... Do more of the talking and the support side when it's so... You know, the last couple of weeks and everything is really tense and ..." (A1)

Some felt uncomfortable or unconfident in dealing with particular areas of care provision. Some expressed a **lack of confidence in communication skills** or dealing with specific situations including spiritual or psychological support

*"I like the communications side of it, but I've got my limits, I think, …. I think, maybe if I saw what the MacMillan nurse did or... Could understand what their role was, **it would give me more confidence** that actually what I'm doing isn't wrong, what you're doing is right and... One of the things that **I struggle with is patients who are in denial**... Won't mention the "c" word, you know. They just pretend there's nothing wrong. So, **I get a bit stumped at that point"**. (A7)*

*"And I'm not sure if patients who last longer on the pathway than we would expect them to... **That's what I find quite difficult**…**To find the right thing to say**, when they're asking those sorts of questions – what's the right answer? It's the difficult questions … just sometimes addressing the really, really difficult questions. The moral questions. More than the medical".(A2)*

*"I've never... I don't feel like I've done proper, like, **psychological care** with them, because they seem to have accepted that they've lived with this disease [COPD] for so long. And it's just become part of their life that they don't seem to rise to the opportunity. **I feel I do it really badly, to be honest. I do"**. (A4)*

This lack of confidence was still present in the second interviews where c**ommunication skills** were again identified as the area of greatest need. In reflecting upon their perceived inability to communicate effectively participants tended to use terms such "*clumsy*", "*not streamlined*" or "*making a right mess of this*". In the final interviews participants often reconfirmed communication as having been an area of need or *'an issue'*.

Post pathway – what changed what was learned

After participating in the educational activities (shadowing, mentoring etc) the **TNA results indicated significant changes in perceptions of confidence and competence**. Only one participant still disagreed with statement 1b, and this is the only negative response across the whole of the section.

Being able to communicate effectively was seen as very important and having the chance to discuss communication issues with a more experienced colleague was seen as positive.

"Like, collusion – was a big one, as well. So, problems that I have had recently in practice, which is what I've been talking about with [my mentor]" (B2)

While discussions were useful, **observing a more experienced nurse** [e.g. the mentor or another nurse] **communicating was seen as a powerful and valuable learning opportunity**, as illustrated below.
"...they were firing questions at her and I think that I might have got flummoxed. You know. But they were just firing questions at her and it was all of this anger that was coming out

because the lady was dying. But she talked...at the end...the situation changed. They were so calm, so relaxed...and I thought...it's a skill. That's a learnt skill to be able to do that...It was good, her communication." (B4)

"*it was a good learning curve – to watch them interact with some of the younger people*".(C4)

In this particular instance having the skills to defuse potentially difficult situations was seen as an asset. Furthermore the need for counselling skills was also touched upon by some participants. The following participant felt they gained significantly from the experiences afforded to them through the pathway project.

"*But also I thought my communication wasn't great… What I did bring out of it [pathway experience]was I talk far too fast and I don't like silence. But the palliative MacMillan Nurse talked me through all that and said silence was good. So it was just things like that, I had on my mind, which were identified from this managing pain and symptom control[area of the TNA]And spending a day with MacMillan Nurse X. And mentioning my communication skills. So…*"

Interviewer : "And did you find that reassuring then"?

"*Yes. Because I think having… That time quite close with her and going in… And listening to how she spoke to patients – I don't think I was doing anything wrong, but I wanted the reassurance, yeah*".(B3)

In the final interview the following participant reinforced this feeling of having gained in confidence and once more **observing experienced staff emerged as a key experience**.

"*I had, an issue…with communication…But I think watching [mentor] and listening to the way she speaks to people… I feel a little bit more clued up …I think I've sorted the things out*" (C8)

"*My biggest problem was my communication…but I feel so…I am much better with the communication now from doing this one at…The module at university and working with x….I think that it's really important to know why you're doing [something]…You know, you're having breaks in your conversation. So I understand that a lot more now. But I also found it beneficial just to see that put into process…into action…*" (C3)

In addition other **respondents spoke of how involvement with the project, together with the opportunity to access university education had created a balance in terms of being able to amalgamate theoretical knowledge with the development of their practice**. For one participant this coming together had enabled the nurse to improve her communication skills, and obtain reinforcement that her communication skills were improving.

Thus participants felt they had learnt a significant amount about communications skills in end of life care through the pathway project and this was reflected in the post pathway TNA scores.

2. Assessment and Care Planning

The following statements were included in this TNA section.

2a	I feel confident to carry out effective holistic assessment (Includes background information, information regarding prognosis, physical, social /occupational, psychological, emotional, religious and/or spiritual well-being, risk, goals and priorities and the needs of families and friends, including carer's assessments).
2b	I feel confident to carry out regular review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly communicated.
2c	I feel able to recognise when a person is dying
2d	I understand and can use end of life care assessment tools and documentation to support my practice - e.g. Gold Standards Framework (GSF), the Liverpool End of Life Care/Care of the dying pathway (LCP/ICP).
2e	I feel confident to contribute to multi-disciplinary assessment and information sharing.
2f	I feel confident that I know who to contact to help provide the best possible care for patients with advancing disease.

Most participants agreed or strongly agreed that they felt confident with regard to the statements contained in this section on assessment and Care Planning and only 5 'disagrees were recorded, 2 in relation to the use of assessment tools.

The following graphs shows the responses collected.

Assessment and care planning Post pathway
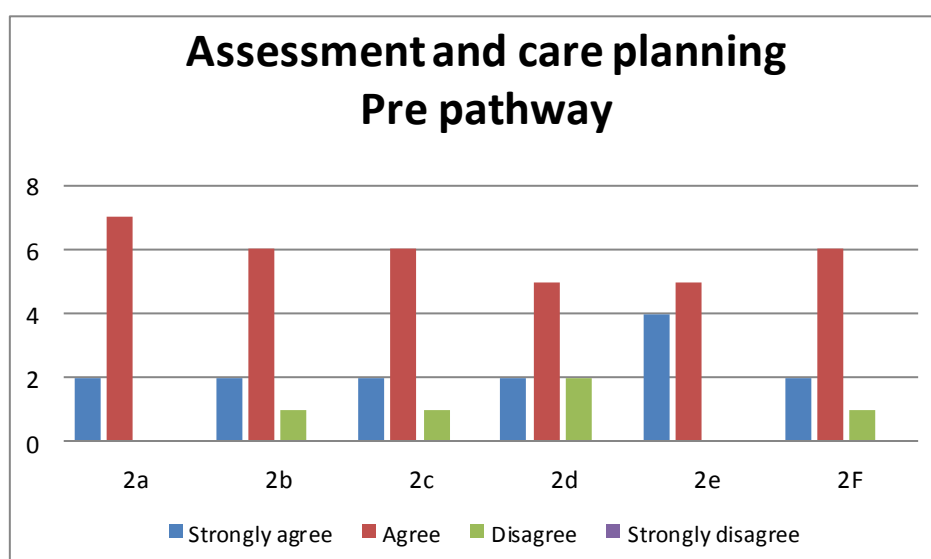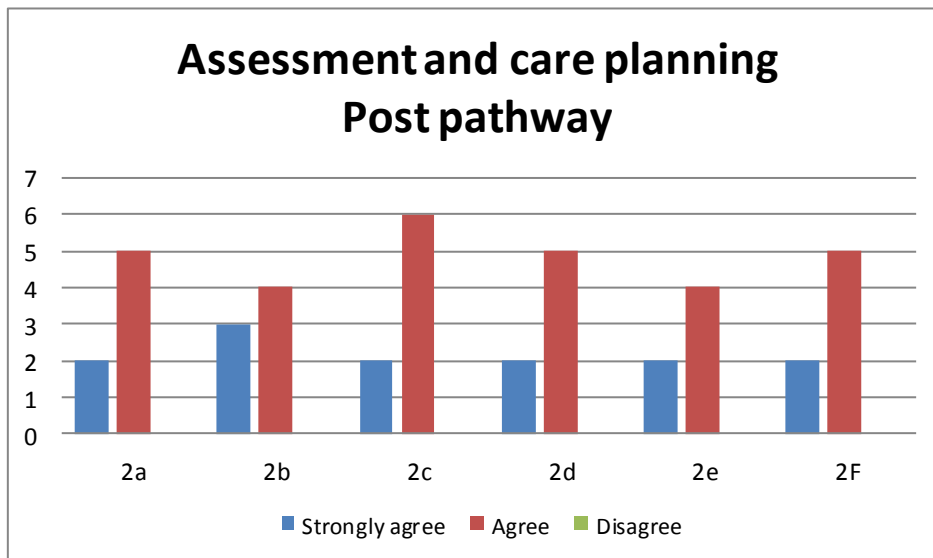
The post pathway TNAs recorded no 'disagree' statements.

Areas of concern and lack of confidence/competence at the start of the pathway

Although most participants agreed or strongly agreed that they felt confident with regard to the statements in this section, the complex needs of some of the patients and knowing when to carry out reviews was discussed as well as specific areas in need of further development

"When I first went out to him, he was newly diagnosed with lung cancer and he just came up from hospital and he wasn't in such a good way where you needed lots of equipment. You need a social package all set up. A lot of things going on, and he was the first visit because he hadn't been known to us – and there was so much going on there. I just felt, "Have I done it… Am I doing the right thing? When should I next come back to see him?" (A2)

"Possibly going over signs and symptoms would be useful. Things like signs and symptoms of, sort of... Spinal cord compression". (A6)

"But I just need to make sure I know exactly what everyone's roles are, so I know what to offer people." (A5)

Post pathway – what changed what was learned

While specific areas of concern or low confidence linked to this part of the TNA were not so evident in the initial interviews in talking about their experiences on the pathway and what they felt they had gained several references were made both directly to assessment and to other issues related to the statements in this section of the TNA.

"Watching their interactions with... You know, the patients, with regards... You know, the way they do their assessments – sometimes a little bit deeper. Just watching the way they talk about death and dying... Which I did find a little bit awkward..." (C4)

The same participant reports changing their approach from caring for patients using a clinical, or medical approach to considering the patient and their needs more holistically.

> *"…looking at that person more as to who they were, what was important to them…To me, I might have thought, "Oh well, you know…they're coming to the end of their life…… And it's much more than that, it was moving away from, like a clinical, medical model to a more personal approach and…Because I do that now I find it much more comfortable. Much more comfortable. And it seems to come a lot easier."(C4)*

A greater awareness of a patients changing needs also seemed to emerge for another participant.

> *"But it's just things like that – knowing what to look out for, what kind of emergencies... Like when a patient now says to me – who's got prostate cancer – "Oh, I've got pain in my lower back" I'm looking out for spinal cord compression and things like that as well. I'm not just thinking about their pain control. So I'm sort of looking out for more different things. I think I'm aware of more different questions to ask" (C5)*

In addition another perceived benefit of such visits/observed practices was that the nurses felt more knowledgeable and confident about talking about the role of the hospice and the types of support that might be provided, for example respite care.

> *"I think that I've been able to tell them a lot more specifically about what these environments can offer…Just a much better [idea] of how things actually work; how the system actually works…Because there have been some times when they've asked about it and I haven't really known a great deal…" (C2)*
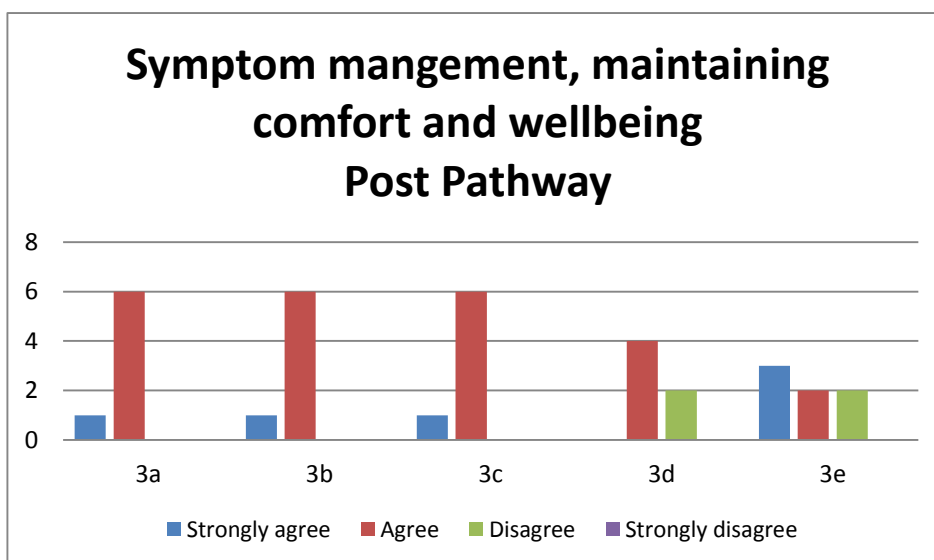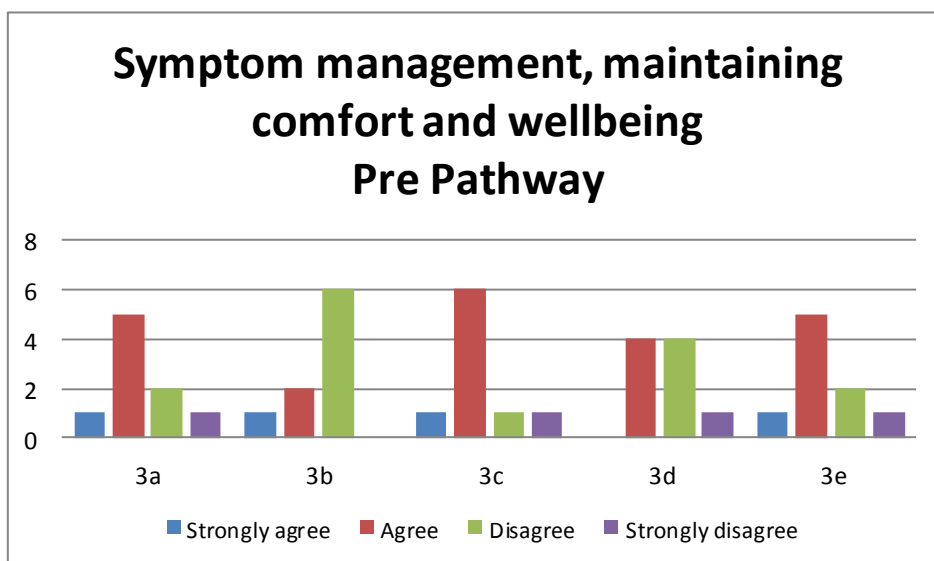
3. Symptom management, maintaining comfort and wellbeing

The following statements were included in this TNA section.

3a	I am confident about helping an individual with their pain and other symptoms.
3b	I understand and can advise on coping strategies and therapies other than drugs to help people cope.
3c	I am confident to support a person in distress
3d	I am comfortable discussing a person's anxiety about the dying process and what will happen, be that the individual who is dying, their friends or family.
3e	I am confident that I am able, in partnership with the individual, their family and friends, to develop, implement and monitor an EoLC plan which will meet the needs of the individual.

As illustrated in the following graphs participants felt least confident and comfortable dealing with areas b and d. Statement d relates to communication skills and further reflects the concerns

expressed earlier in relation to the area covering communication. However some participants also raised symptom control and medications as an issue.

Symptom management, maintaining comfort and wellbeing Pre Pathway

A bar chart titled "Symptom management, maintaining comfort and wellbeing Pre Pathway" showing responses for statements 3a–3e with categories Strongly agree, Agree, Disagree, Strongly disagree.

Symptom mangement, maintaining comfort and wellbeing Post Pathway

A bar chart titled "Symptom mangement, maintaining comfort and wellbeing Post Pathway" showing responses for statements 3a–3e with categories Strongly agree, Agree, Disagree, Strongly disagree.

It is noticeable pre pathway that several disagree (15 across all statements) and strongly disagrees (4) were recorded, with the largest numbers relating to statements b and d. However in the post pathway TNAs a strong movement can be seen in the reported levels of confidence. This is especially noticeable in relation to statement b where post pathway no disagrees are recorded.

Areas of concern and lack of confidence/competence at the beginning

In the first interviews concerns were expressed regarding symptom management and medication administration.

*"Sometimes **I find difficult is if it's like quite a complex diagnosis and there are lots of symptoms to manage** and sometimes you have maybe a couple of syringe drivers going. I find that sometimes a little bit stressful, just with all of the different drugs"* (A8)

"And sometimes I'll feel, oh, should we put this [medication]in now? Should we not put this in? What kind of strengths should we put in?" (A2)

"Well, I feel quite competent…Unless it's something that's out of the ordinary, you know. Someone who's quite…Got quite complex pain, or whatever, that's when I get a bit stuck and that's when we would probably use MacMillan and then maybe the palliative... Doctors" (A9)

One participant also alludes to the **complexity of care situations** and feelings of uncertainty regarding whether they were doing the right thing at the right time. This feeling seems to straddle assessment and management as is illustrated further,

*"I'm thinking to myself, "Should I be thinking like this? Should I...? **Should I be feeling so lost**, ..What exactly am I looking for? I've looked over the basics – like his physical health needs. What... What else can I provide? You know, is there any other...? Is there something I'm missing?... Is there, you know, things that I'm not doing for this patient, which I should?" (A2)*

Post pathway – what changed what was learned

Post pathway the TNA results were very positive and again participants reported having learned much from the nurses shadowed and their mentors.

*"I learnt so much from [Specialist Nurse] – not just from the communication, but a little bit about pain management and **symptom control**... more complex things, it was great to have that…it was more the **symptom management**, you know, …But no, I am a lot more confident and more comfortable with that. …This has all developed from talking to the MacMillan nurse and through university. So, I've gained lots on that side as well."(C3)*

"with like symptom control sort of things. ..Drugs, like... Before I did the study [pathway] and things. It was... Where, in the past, I've just accepted that, you know, when we're working with the specialist nurses and they're saying "Right. They'll need amitriptyline instead of the morphine" I've sort of just gone along with it and knew that that's the drug that they wanted but never sort of questioned why and how that sort of works. …….But sort of like now, I keep thinking "Right. Why are they taking that? How does that work? How does that affect the body?" So it... I feel that where I've skimmed the surface it's made me go deeper" (C4)

"We did a couple of little sessions on [symptom control]... Just, sort of, you know, the general, sort of, pain and nausea and what have you. And again it just, sort of, refreshes your memory." (C8)

One participant planned to do further formal study on the subject of symptom control and had organised this.

Coming to appreciate that patients had **emotional needs** as well as the more physical needs; both of which could legitimately and equally be addressed was another issue that was identified (and which also relates to the previous section on assessment). It was appropriate just to be able to take the time in order to sit and talk to patients.

> *"…Pain, I can give you drugs for that pain" You know. "I can give you something to stop you feeling sick" it's all medical. But, if I sit with someone for a half an hour and talk to them – about nothing. About random things. I feel that I've done as much there as what I've done about controlling other symptoms. Where I think that the psychological used to get – not pushed to one side…I was aware but I probably didn't spend much time on that…Now, before I really did the course, I didn't put as much value on, like, the emotional side of things. "(C4)*

4. Advance care planning

The following statements were included in this TNA section.

4a	I understand how 'Advance Care Planning' enhances end of life care and how these plans impact on delivery of care.
4b	I feel confident to communicate effectively and sensitively to support the individual as they decide upon preferences and wishes for their future care.
4c	I feel confident to work sensitively to support an individual's family and friends through the Advance Care Planning process.
4d	I understand the legal status and implications of the Advance Care Planning process in relation to the Mental Capacity Act 2005. (I recognise it is part of my role to find out what is known about an individual's wishes should they lose mental or physical capacity to express their wishes.)
4e	If an individual shares with me views about their future care, with permission, I would feel confident, to discuss this with the rest of the care team.

As illustrated in the graphs below pre pathway several 'disagrees' were recorded highlighting participants concern regarding their levels of confidence and understanding of the areas included. The largest number of disagrees related to statement 4b which again relates to communication and support. However, although lower in number, disagrees were also recorded for other statements with the exception of 4e with refers to sharing information with the rest of the care team.

Advance care planning Pre Pathway

Advance care planning Post pathway
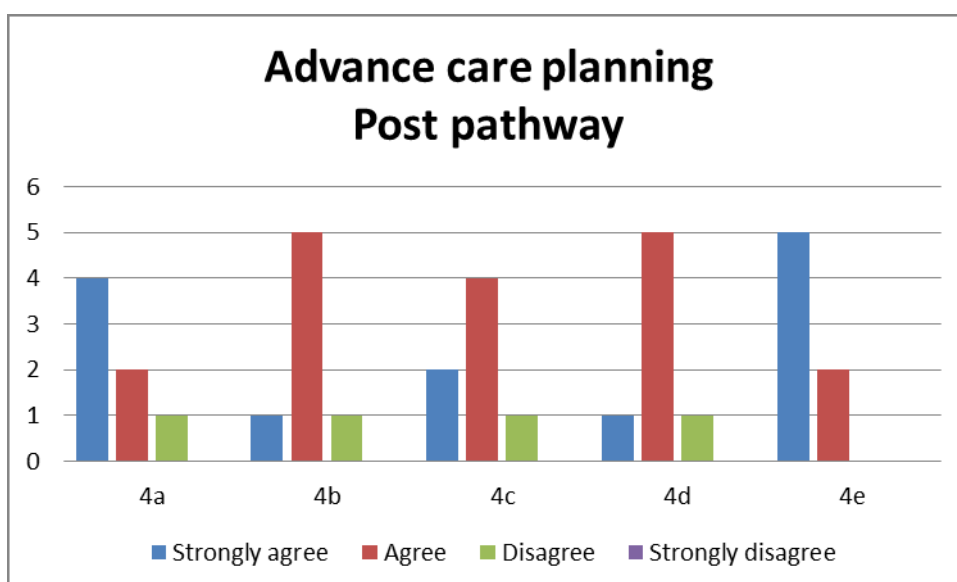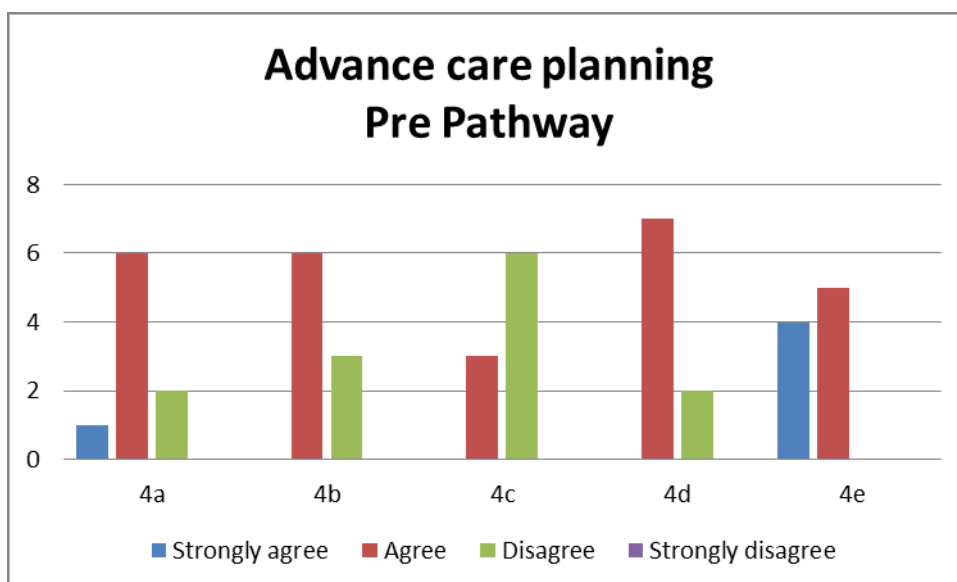
Post pathway the number of disagrees is noticeably reduced and the number of agrees and strongly agrees substantially increased suggesting a heightening of perceived confidence.

Areas of concern and lack of confidence/competence at the beginning

Confidence in dealing with the documentation and processes involved in Advance care planning was reported in the first and second interviews as an issue for some

> *"**I don't always feel comfortable, …I think it's because it was a new document...** There's not a lot of training surrounding that. .. It's probably my own lack of confidence that I'm looking for someone else's reassurance that I've filled this in, I've completed this, correctly. And I think, until I get that reassurance, I won't feel 'comfortable' with it "(A11).*

"I'd said I'd felt really uncomfortable with doing the advance care plans – how to initiate that." (B4)

"I know people say it's whatever the patient wants, but sometimes they look at you for guidance of what they should put down." (B6)

Thus several areas of perceived weakness or low confidence emerged across the group and several participants expressed feelings of uncertainty regarding areas of their work and a general desire for reassurance.

" You know, your advance care planning – when to do it in that area. You know, that is a biggee over here. We have a lot of COPDs as well". (A4)

"I don't always feel comfortable, if that's the word, discussing things like an advance care plan, for instance" (A11)

"When you're introducing patients to the advance care planning – I found that difficult." (B3)

Post pathway – what changed what was learned

Some participant highlighted that their knowledge of advance care planning had been improved as a result of participating in the project.

"…Well, I've learned, certainly, more about the advance care plans…" (C8)

"I thought like an advance care plan – it's just about where you want to be to die and stuff like that. And it's so much more than that, isn't it?(B4)

Another spoke of how being able to discuss the more theoretical aspects surrounding patient care and support had been of particular use, for example, in being able to discuss the benefits and disadvantages of advance care plans, a resource that was not routinely used within the practice where they were employed.

"…and just sharing things like that you know. The advance care plan …Because we always that it was someone else's job and really it's not, it's ours…" (C4)

This nurse went on to explain that as a result of the knowledge that they had gained and been able to share with colleagues the team was now going to *"bring someone in"* to provide training to all staff to develop their practice around this subject.

However in the third set of interviews some participants continued to express reservations regarding the advance care plans and this seemed to relate to limited experience, or a lack of use of these documents in their day to day activities.

"The advance care plans... We don't do them as routine here… Because we always thought it was somebody else's job" (C4)

"I think it's just low because it's the new documentation, and I think it's the style of the new documentation. And unless you're using them all the time it's difficult to get your head round it "(C6)

"And things like advance care statements and things like that – I just didn't know anything about them before. And now I would definitely do that. I think... I'm getting there" (C5)

Although for one nurse who had been unable to access the training relating to this topic their knowledge and experience remained low.

"I haven't got any experience with the end of life. The advance care plan that they do at home, where they would like to be at the end. So I didn't have any experience with that "(C10)

5. Overarching values and knowledge

The following global statements were included in this section.

5a	I have thought about what is important to me in the meaning of my life.
5b	I recognise that my role is vital in delivering good end of life care and understand my own professional/role boundaries
5c	I feel my contribution to developing end of life care in my team is valued.
5d	I understand how society and culture influences attitudes to dying and death.
5e	I feel confident to be able to support a bereaved relative.

Ovberarching values and knowledge Post Pathway
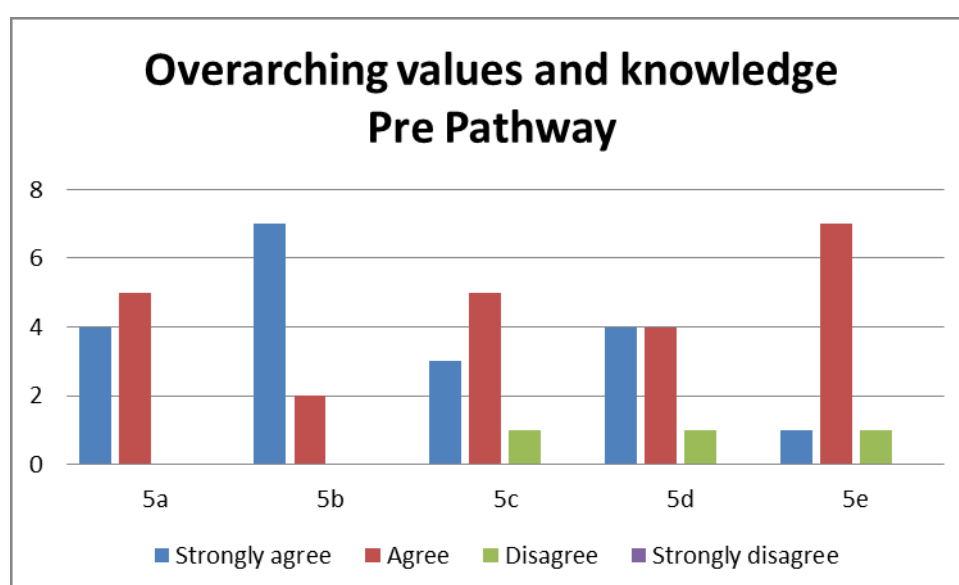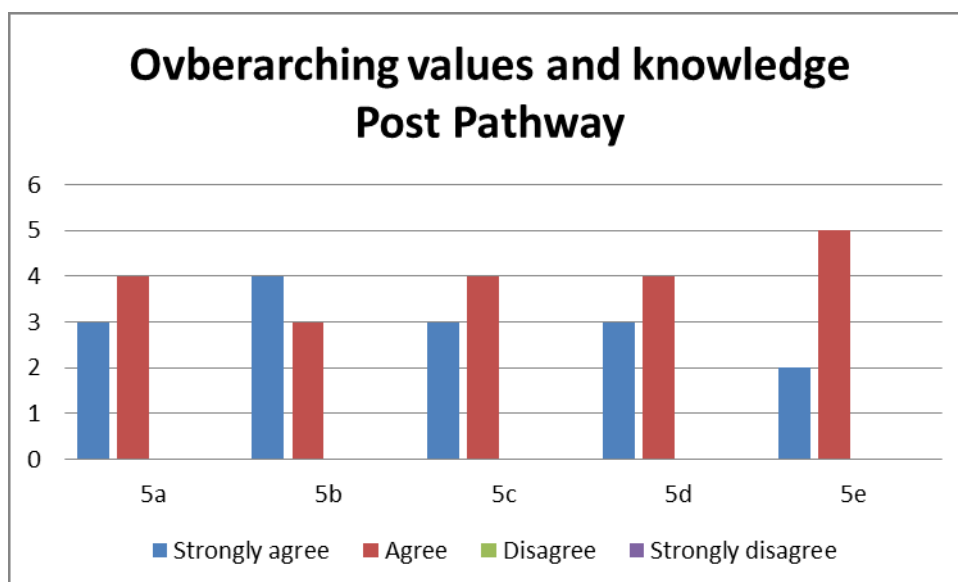
As can be seen in the graphs above, participants generally agreed with the statements in this section of the questionnaire. In the pre pathway TNAs only one disagreement was recorded in each of the last three statements which related to; feeling their contribution was valued, understanding how society and culture influences attitudes to dying and death, and feeling confident to be able to support a bereaved relative.

Feeling confident to support relatives may also be linked to feelings of confidence in offering support in general which is also touched upon in previous sections of the TNA and in various parts of the interviews.

5.4 What they thought: Participants views of being involved in the pathway project

Anecdotal evidence suggested that nursing staff could be in post for significant periods of time without any formal training on the care of palliative care patients. Such staff did receive training associated with the more practical aspects of such care, for example the management of syringe drivers, but sometimes failed to develop a more holistic picture of such care. Those putting themselves forward for the project were likely to already have an interest in palliative care, and this is a limitation of this type of pilot study. Some had volunteered whilst others had been nominated by their managers. Interviewees were asked about what their involvement with the end of life project had meant for them personally. Those participating in the project appeared to find engagement with the project a valuable experience.

> *"…it's given me a lot more focus on palliative care. Because we are so generalist …where palliative care just seems to be part of the job which you do. Instead of a specific focus. ..So I've spoken to the palliative link nurse. You know, just a bit more about the study as well…taking more of an actual, specific role in palliative care…I think that I've paid a lot more attention to the recent events in palliative care and made an extra effort, I think, to get involved as much as I can with palliative care." (C2)*

"…It's been absolutely wonderful because I would do things automatic [sic] or not do things, where by doing the study it's sort of, like, helped me look at where I was. And reflect and evaluate where I want to be and how I can get there. And I think the fact that I took part in the study prompted me…it made me…do it for, like, a conscious effort to…To do something about it and look where I can get the knowledge and skills from. So I think that it's been a really, really good experience. A really good chance to take part in it." (C4)

"It's been brilliant because…It's given me the courage and…Well, sort of the reason to be able to go to the sister or a palliative care nurse or whoever, and just say "Oh can I do this because I'm on this palliative care research project" And I could have done all of these things before, but I probably wouldn't have put myself forward because I wouldn't have had that, kind of, extra reason to be able to say, "I'm in this scheme"…I think that it just gave me a, sort of,…a bit more of a reason to be able to feel that I could ask for things." (C5)

"I wanted to do the project because, obviously, it's a good developmental –and it's also a chance to consolidate, as well, And, sort of, give yourself a boost and a bit of encouragement – like, yes, you're doing the right thing. So I have found it very useful in that respect…" (C6)

"After the initial problems, just sort of getting started…It's been quite useful. I've, sort of, found a good friend in…my mentor. And like now it's sort of finished and that , I know she's always there if I need her…just as point of reference or for help with anything –which is nice to know. She's really helpful…Well, I've learned, certainly more about the advanced care plans and what have you. And really just a little more about what is going on in the {sic} palliative care. So it's been useful, I think. Yeah,…I've enjoyed it" (C8)

"It's been good, but we didn't have the time to do it very well…Because at the time we were really short-staffed in the summer, and before…" (C9)

A minority, however, perceived that access to the study had not necessarily been of overall benefit to them. This was possibly because they were already focussed on such a patient group and their care needs and were already accessing educational developmental opportunities prior to the implementation of the study

" I personally haven't found it very different…Nothing has really changed in as much as I've actually accessed doing a level 7 in communication. Because that's where it was identified within this pilot scheme that you're doing – that my communication…I felt very lacking in confidence with it around end of life care. But I have to say, prior to being approached with this, I'd already accessed these modules. So I think that most of the things…I'd identified myself prior to being approached. And I'm just busy doing effective communication with end of life, and it's been brilliant."

Although the same participant when discussing her shadowing experience said

Because I learnt so much from (PCSN) – not just from the communication, but a little bit about pain management and symptom control, just to sort of... A bit more complex things. And it was great to have that (time). And I did learn an awful lot.

Overall participants found having access to a mentor to be worthwhile. Whilst some participants, for whatever reason, made more use of their mentor and the opportunities afforded, it was recognised that mentors were a valuable resource, being both more experienced and also more knowledgeable. It was suggested that the mentor needed to be appropriate to the needs of the

mentee. Whilst this relationship might be regarded as being the "gold standard" in practice such a relationship might be more difficult to facilitate.

> *"absolutely brilliant…but an appropriate mentor, I think, for me, it would have been a Macmillan nurse"* (C3)

One participant, in describing what a good mentor meant to them said:

> *"it's almost like a cosy blanket…You know, somebody who knows what you're doing, and you're stepping into their world to learn and you know that. Not protected – but it's that kind of security that you've got what they're actually telling you is up to date, and it's, you know, relevant and…it works.* "(C6)

Thus having access to a mentor provided reassurance and a point of reference for those involved. Therefore the overall feeling from participants was that being involved had been beneficial and had afforded them experiences and learning opportunities they would not have otherwise had.

6. Final remarks and suggestions

The context

This project took place against a backdrop of major structural re-organisation of all health services in the UK and during a period of economic crisis across much of the EU. Although it is unclear what influence these wider contextual factors may have had on the community nurses in this project, what did emerge strongly from participants was a sense of substantial workload pressures often coupled with staff shortages.

Participants spoke of the difficulties they faced generally in finding time to engage in educational activities. They often felt a conflict between the need to 'get the work done' and a desire to engage in educational activities or CPD, and this was compounded by staffing issues and workload pressures. While care delivery was nearly always prioritised over education or CPD, during the project some participants reported sticking to pre-arranged meetings and being encouraged by colleagues to attend educational activities which were perceived as 'important'. It appears that the project 'legitimised' involvement in educational activities and 'not attending' may also have been viewed as letting the organisers down. However while care provision must be maintained, the quality of care must also be considered. For best quality care provision practitioners need to be up to date with current evidence and thinking and feel confident and competent in the care they deliver (DH 2008)

The community nursing context is further complicated by the diverse patient population and wide remit covered. In addition community nurses may spend much of their working hours alone visiting patients and this potentially leaves them isolated in their practice and reduces shared time where they can learn with and from each other. Indeed educational theorists Lave and Wenger (1991) describe how those working and learning together build relationships and engage in shared learning often within the workplace. In essence these 'communities of practice' develop 'a shared repertoire of resources: experiences, stories, tools, ways of addressing recurring problems—in short a shared

practice'. This shared learning requires time and interaction, and it may be that these are limited in community nursing by the very nature of the job.

Furthermore defining palliative or end of life care was an issue, and knowing what part community nurses could, or should, play in end of life care was debated. Differing practices were reported across the areas and teams represented in the sample, in some EoL care was viewed as the remit of senior staff, while in others a mixture of nursing staff were involved and often worked together. While participants acknowledged the need and/or responsibility to help staff develop skills and confidence in relation to end of life care the support offered and the willingness or ability of staff (be they more senior or more experienced) to nurture and 'educate' other staff seemed to vary from team to team. In some places it appeared that junior grades were encouraged to accompany those more senior as a form of staff development (akin to a community of practice approach), while in other areas this did not appear to happen or be possible.

The process

The Training needs assessment tool, coupled with the action planning document offered an opportunity for participants to explore their educational/training needs and possible ways forward. Some participants completed the TNA prior to meeting with their mentor whilst others completed it during the meeting. One participant did not use the action planning document but did develop a learning strategy akin to action planning, albeit in a less formal manner. The TNA afforded participants an opportunity to reflect upon their practice and think through ways of enhancing their confidence and competence in relation to identified issues. However as individuals we all have 'blind spots' and this is where the mentor was undoubtedly valuable in assisting participants to reflect on their confidence and competence, and to explore areas and opportunities.

Mentoring emerged as a key mechanism regarded as very valuable by participants and although the mentoring scheme formed a core part of the pathway it was not prescriptive. The organisation and frequency of the meetings was at the discretion of those involved and participants met with mentors between two and five times during the course of the project. However making time to actually meet could be problematic for both mentors and participants, mainly due to workload pressures including staffing issues. In addition although mentors had undergone preparation and were given guidance documents some mentors and participants were unsure regarding the role of the mentor and how prescriptive or directing it should be. This highlights a certain amount of crossover between notions of mentoring and clinical supervision, and perhaps indicates the need for more formalised negotiation of roles and expectations at the beginning of a mentoring relationship.

Participants reported finding the pathway process reasonably easy to navigate although more opportunity to discuss the process, the documents and ways of accessing opportunities may have been useful. In addition providing further support for mentors may have been beneficial e.g. in the form of a forum for mentor peer support or further visits from organisers. Mentors also suggested the following adjustments would be useful in future programmes: a slightly more structured format for mentoring, protected time, setting targets for completing actions and (if mentoring was not to continue), having a final meeting to round things off or bring closure.

Alongside engagement with mentoring, shadowing nurse specialists and visiting hospices were the main activities undertaken. Watching, observing or shadowing colleagues or specialist nurses was one of the most frequently mentioned ways of learning and was rated very highly. Such episodes offered opportunities for elements of 'experiential learning' (Kolb 1984)whereby mentees could observe interactions; listen to conversations and, at appropriate times, engage in suitable opportunities. A number of interviewees indicated that they had learnt a great deal from being able to access this type of opportunity. Gaining reassurance from a range of colleagues including specialist nurses, mentors or senior colleagues was also seen as crucial to enhancing and maintaining confidence. This may also highlight the isolating nature of community nursing which renders difficult or infrequent the opportunities available for nurses to receive such confirmation of their practice.

Some participants undertook, or arranged to attend, more formal educational activities such as the 6 day Palliative care course or University modules. Being able to mix academic, theoretical elements with practice based experiential learning opportunities was viewed as beneficial in terms of keeping up to date and being able to relate theory to every day practice. One or two participants also engaged in informal self-directed study as part of their learning activities.

Legitimisation of education

Throughout the project it emerged that being involved in the pathway project had in effect legitimised participation in educational activities- be they formal (e.g. university modules) or informal (e.g. shadowing or hospice visits).There was a strong feeling that education or CPD activities came bottom of the list of priorities for community nurses, to be engaged in only when time permitted or out of working hours. Patient care was, as it should be, seen as taking precedence over other activities and this view coupled with workload pressures and staffing issues, seemed to militate against engagement with CPD or other educational activities. However the project gave participants the opportunity to focus more on palliative care and for some gave permission to ask to do more palliative care within their working day.

> *It's given me the courage and the... Well, sort of the reason to be able to go to the sister or a palliative care nurse of whoever, and just say, "Oh, can I do this? Because I'm on this palliative care research project."(C5) (staff nurse)*

> *And I think the fact that I took part in the study prompted me, where... You know, I think if I hadn't I might have just plodded along and picked up little bits here and there. But it made me, sort of like, do it for, like, a conscious effort to... To do something about it and look where I can get the knowledge and the skills from. (C4)*

Furthermore, during the project some participants reported feeling it was important not to change arranged meetings or activities and being encouraged by colleagues to attend opportunities as they were 'important'. Thus the formal status of the project and its backing from the managers and the NHS Trust appears to have legitimised or sanctioned engagement in the activities offered. This perhaps indicates a need for greater visibility of managerial backing for such educational activities.

Feelings of confidence and competence: outcomes

Dealing with 'hands on' care such as medication administration or other 'nursing tasks' was often viewed as easier or more 'comfortable' than providing the more 'supportive' aspects of end of life care. This was borne out both in the interviews and in the strong lack of confidence reported in the first TNA questionnaires completed at the start of the project. The main areas of low confidence related to communication skills in general, but were also noticeable in areas concerning the provision of 'support', advising on coping strategies, or discussing anxiety (see pages 44 - 46). However post pathway the TNA scores indicated substantial increases in confidence in these areas. This increase also emerged in the interviews with participants enthusiastically describing how they felt they had learnt a considerable amount about dealing with these issues, particularly through shadowing and observing specialist nurses.

Whilst assessment and care planning were not issues of concern highlighted in the initial interviews or significantly noticeable from the first TNA scores, some learning was reported by individual participants including: the development of an understanding of the roles of other staff and of the hospice; a move to a more holistic approach and a greater awareness of changing needs. Once more observing experienced staff undertaking assessments and planning care was cited as a main source of heightened confidence and learning.

In the initial interviews participants described several areas of low confidence or uncertainty regarding symptom management, medication administration and dealing with complex care situations. Furthermore in the first TNA scores more than half of the participants reported not feeling confident in advising on coping strategies and therapies other than drugs and five did not feel comfortable discussing a person's anxiety about the dying process. Levels of confidence in dealing with both of these areas increased post pathway and this was recorded both in the interviews and in the TNA scores, with participants describing gaining insight into emotional needs and developing a greater knowledge ad understanding of medications and symptom control.

In relation to advance care planning initial TNAs indicated that more than half of the participants lacked in confidence in relation to supporting 'an individual's family and friends through the Advance Care Planning process' or in communicating effectively and sensitively to support the individual. These areas again relate in part to communication and the provision of support and post pathway scores show a growth in confidence in these areas. Furthermore the interview data confirmed this and highlighted perceived learning or development in areas such as dealing with complex situations and dealing with advanced care planning documents which were mentioned by a number of participants.

Thus participants felt they had gained a great deal from their involvement in the pathway project, and this was borne out in the increase in confidence recorded in the TNA scores. The main area of concern, and indeed of increased confidence or comfort, related to communication and providing support, this was followed by symptom management and care planning. It could be argued that communication is key to any aspect of care provision at any point on the life course. However given the sensitive, often difficult nature of end of life care, confident, competent care provision is crucial.

As one participant noted after the project

"I feel much more confident. I filled it in…You know, the questionnaire…I did it at the beginning and I looked at it and I thought, "Ee I should be sacked" I shouldn't be…you know at this level. And then when I filled it in at the end of [the course]…It was just when I'd finished the course here…And it was amazing, the difference. All of the ticks were sort of on the confident end, and I felt…And just reading through and thinking about it, I thought Yeah, actually, I can do that now" That's good" (*code removed to maintain anonymity*)

6.1 Key points

Mentors

There were examples of where the mentor and mentee had managed to work together, in spite of everything, in order to achieve the desired outcomes that had been identified.

> *"…it was a shame that I couldn't attend all of the things that I wanted to [but] the things that I did miss. We got together and it was covered. So I didn't miss out on that…And we worked very much together to arrange…and it was difficult at times [down to workload] But we always got together and achieved what we wanted to achieve…"* (C6)

The mentors were central to the pathway experience and therefore need to be selected, prepared and supported carefully.

Linchpin- the coordinator

The project was co-ordinated by (Lecturer Practitioner Palliative care) and having this key person in place to drive the initiative undoubtedly facilitated the running of the pathway on a number of levels including; distribution of tools and documents, arranging workshops and organising places for participants on formal courses, assisting participants in arranging meetings and generally being there as a point of reference for those involved. This role is crucial in such a project.

Being able to spend a greater period of time in a specific setting
Having a suitable opportunity to spend a longer period of time [observing] in a specific health-related setting such as a hospice was seen as a useful learning opportunity. Yet venues such as hospices, by the very nature, are working environments serving the needs of patients and their families, individuals who, in general, have very complex needs which call for compassion and sensitivity when being addressed. At the same time a vast range of different groups, both professionals and lay people wish to visit these types of establishments in order to learn about the work that they do. It is how best to balance these needs so that ,first and foremost, the patients being cared in the hospice aren't disadvantaged by all by the visits of all who wish to learn but which then can offer the healthcare professionals the educational development that they require in order to provide effective and empathetic patient care.

Does feeling more confident actually have an impact on practice?

While this project aimed to increase both the confidence and competence of community nurses in relation to end of life care, and appears from the data to have succeeded in greatly enhancing confidence in several areas, it is unclear exactly what impact this may have on practice. Indeed the assumption is that the effect will be positive however the actual impact is unknown and given the complexity of end of life care provision such impact is arguably un-measurable.

In addition the following question is raised- Does feeling more confident have an impact on competence? These are indeed different concepts and this study has actually only evaluated confidence but can make the suggestion that shadowing and mentoring would also offer a system for monitoring and enhancing competence.

Cascade effect to teams- wider learning

It is unclear if, or to what extent, this sort of project may lead to the cascade of knowledge, skills and enhanced confidence in other staff and this is an area which requires further investigation. In addition the sustainability both of such projects and of the levels of confidence gained is unknown. It may be that staff require 'updating' or regular opportunities for shadowing specialist or experienced colleagues.

6.2 Study Limitations
 There are several limitations to this study which need to be acknowledged.

The majority of the participants volunteered to take part and the numbers involved are small, therefore the sample is not representative of community nurses on the whole and care must be taken when extrapolating from the findings as they are not 'generalizable' in a statistical sense . As with any voluntary sample the participants may actually represent   those with a particular interest in end of life care and may therefore be 'skewed'. However enhancing the confidence and potentially the competence of this group may have the advantage of encouraging enthusiastic 'champions' who could potentially educate others in their practices acting as cascade or dissemination mechanisms.

Furthermore the project ran for a limited length of time and therefore exploring longer term outcomes and impacts, and the sustainability of initiative and of levels of 'confidence' was not possible and would require further research.

An economic evaluation of the cost of the mentor and participants time on the pathway was not undertaken and this would also be a valuable area for consideration in any future work.

7. Suggestions

- Whilst care provision is paramount and takes precedence over other activities (as illustrated by the participants in this study) there needs to be a balance between care provision and evidence based, confident and competent care provision.

- Continuing professional development for End of life care needs to be 'legitimised' within the role of community nursing. For this to happen backing from various levels of management is needed and this backing needs to be clearly communicated down to all levels of staff.

- Although this study has begun to scrape the surface of EoL care provision in the community we do not really know what it is like for community staff to care for end of life patients and there is a need for further investigation of the 'emotional labour' involved for them.

- Mentoring has emerged as a powerful tool in enhancing the confidence and competence of community staff in caring for EoL patients and therefore service commissioners and care provider teams could be encouraged and facilitated to set up mentoring schemes with time for mentoring written in to both community staff and nurse specialist roles (as in medicine /psychiatry etc). However this would require careful preparation, planning and managing in order that specialist nurses do not become overburdened.

With the expectation that greater care provision be delivered in the community (CfWI) there is a need to ensure community staff are appropriately trained, and supported while receiving this training. The Vision for District nursing (DH 2013) clearly identifies the DN role as key in supporting and caring for patients at the end of life. District nursing teams are delivering generalist palliative care and end of life care on a daily basis and how they have been supported and educated to deliver this care has varied. All organisations are required to have assurance that their staff have the necessary knowledge and skill to deliver high quality end of life care (DoH 2009), meeting the required competencies. With competence being one of the 6 C's underpinning compassionate person centred care (DoH 2012).

We conclude that district and community nurses should receive on-going opportunities for CPD in palliative and end of life care, that mechanisms for enhancing their confidence and competence is paramount to ensure the quality of palliative and end of life care is consistently of the highest quality.

Appendix 1: Training Needs Analysis document

NHS

**National End of Life
Care Programme**

Improving end of life care

Training Needs Analysis Questionnaire

(Based upon the NHS National End of Life Care Programme documentation)

To be completed by community staff undertaking the End of Life educational pathway for community care staff.

What is End of Life Care?

End of Life Care (EoLC) incorporates all elements of care and interactions in the daily lives of those people nearing the end of their lives - whether from disease progression or old age. A wide group of both health and social care workers are involved in this provision.

The care and support provided does not necessarily include medical or nursing care but will include the holistic assessment, care planning and management of all symptoms including pain, and provision of psychological, social, spiritual and practical support.

How long have you been in your present job role?

Please choose one answer only

☐ Less than 1 month

☐ More than 1 month but less than 1 year

☐ 1 year or more please state how many years?

End of Life Care and Communication skills training

a. Have you attended any EoLC or communication skills training in the last 3 years?

Please choose one answer only

☐ Yes

☐ No

b. if 'Yes' please provided details of the EoLC or communication skills training have you attended within the last three years in the table below; please circle the appropriate statements.

	Course Title	Was EoLC the main focus of study?	How long was the course?	Who provided the training?
1		Yes	≤1 day	
			2-5 days	
		No	>5 days	
2		Yes	≤1 day	
			2-5 days	
		No	>5 days	
3		Yes	≤1 day	
			2-5 days	
		No	>5 days	
4		Yes	≤1 day	
			2-5 days	
		No	>5 days	

5		Yes	≤1 day	
			2-5 days	
		No	>5 days	
6		Yes	≤1 day	
			2-5 days	
		No	>5 days	
7		Yes	≤1 day	
			2-5 days	
		No	>5 days	
8		Yes	≤1 day	
			2-5 days	
		No	>5 days	
9		Yes	≤1 day	
			2-5 days	
		No	>5 days	

About Your Skills in EoLC

This question asks you to consider your role in providing end of life care and your confidence and skills. It can be used to inform your appraisal/personal development review (PDR)

What EoLC training do you feel you need to increase your confidence and competence? Please read and respond to the statements below:

1. Communication - Please choose one answer only for each statement

Statement	Strongly agree	Agree	Disagree	Strongly disagree
I feel confident to develop and maintain communication with people at the end of life, their families & others involved in their care about matters or situations related to end of life care				
I feel confident to listen to and talk with a dying person about issues surrounding their care and their death				
I feel confident to listen to and talk with friends and relatives of a dying person about **their** issues and concerns surrounding care at the end of life and death				
I feel confident to provide information and support about end of life in a range of formats, including written and verbal, as appropriate to the circumstances and the situation				
I feel confident to work with individuals, their families and friends in a flexible and sensitive way that				

demonstrates awareness of the impact of death, dying and bereavement.				
I feel confident to recognise and respond to any variation over time, in individuals', their families' and friends' priorities.				

2. Assessment and care planning

Please choose one answer only for each statement

Statement	Strongly	Agree	Disagree	Strongly ly
I feel confident to carry out effective holistic assessment (Includes background information, information regarding prognosis, physical, social /occupational, psychological, emotional, religious and/or spiritual well-being, risk, goals and priorities and the needs of families and friends, including carer's assessments).				
I feel confident to carry out regular review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly communicated.				
I feel able to recognise when a person is dying				
I understand and can use end of life care assessment tools and documentation to support my practice - e.g. Gold Standards Framework (GSF), the Liverpool End of Life Care/Care of the dying pathway (LCP/ICP).				
I feel confident to contribute to multi-disciplinary assessment and information sharing.				
I feel confident that I know who to contact to help provide the best possible care for patients with advancing disease.				

3. Symptom management, maintaining comfort and wellbeing

Please choose one answer only for each statement

Statement	Strongly agree	Agree	Disagree	Strongly disagree
I am confident about helping an individual with their pain and other symptoms.				
I understand and can advise on coping strategies and therapies other than drugs to help people cope.				
I am confident to support a person in distress				
I am comfortable discussing a person's anxiety about the dying process and what will happen, be that the individual who is dying, their friends or family.				
I am confident that I am able, in partnership with the individual, their family and friends, to develop, implement and monitor an EoLC plan which will meet the needs of the individual.				

4. Advance Care Planning

Please choose one answer only for each statement

Statement	Strongly agree	Agree	Disagree	Strongly disagree
I understand how 'Advance Care Planning' enhances end of life care and how these plans impact on delivery of care.				
I feel confident to communicate effectively and sensitively to support the individual as they decide upon preferences and wishes for their future care.				
I feel confident to work sensitively to support an individual's family and friends through the Advance Care Planning process.				
I understand the legal status and implications of the Advance Care Planning process in relation to the Mental Capacity Act 2005. (I recognise it is part of my role to find out what is known about an individual's wishes should they lose mental or physical capacity to express their wishes.)				
If an individual shares with me views about their future care, with permission, I would feel confident, to discuss this with the rest of the care team.				

Overarching values and knowledge

Please choose one answer only for each statement

Statement	Strongly agree	Agree	Disagree	Strongly disagree
I have thought about what is important to me in the meaning of my life.				
I recognise that my role is vital in delivering good end of life care and understand my own professional/role boundaries				
I feel my contribution to developing end of life care in my team is valued.				
I understand how society and culture influences attitudes to dying and death.				
I feel confident to be able to support a bereaved relative.				

Enhancing confidence and competence in end of life care:

Piloting and evaluating an educational pathway for community care staff

Guidance on process and opportunities:

- **How the project works**

- **What learning opportunities are available**

northumbria
UNIVERSITY

Choose
South Tyneside NHS
NHS Foundation Trust
Providing a range of NHS services across Gateshead, South Tyneside and Sunderland

The idea behind this project is to offer access to a range of learning opportunities related to End of Life care to community nursing staff in order to enhancing confidence and competence.

This booklet describes:

- The project process -what does it mean, how will it work

- The options available - what learning opportunities there are on offer to choose from
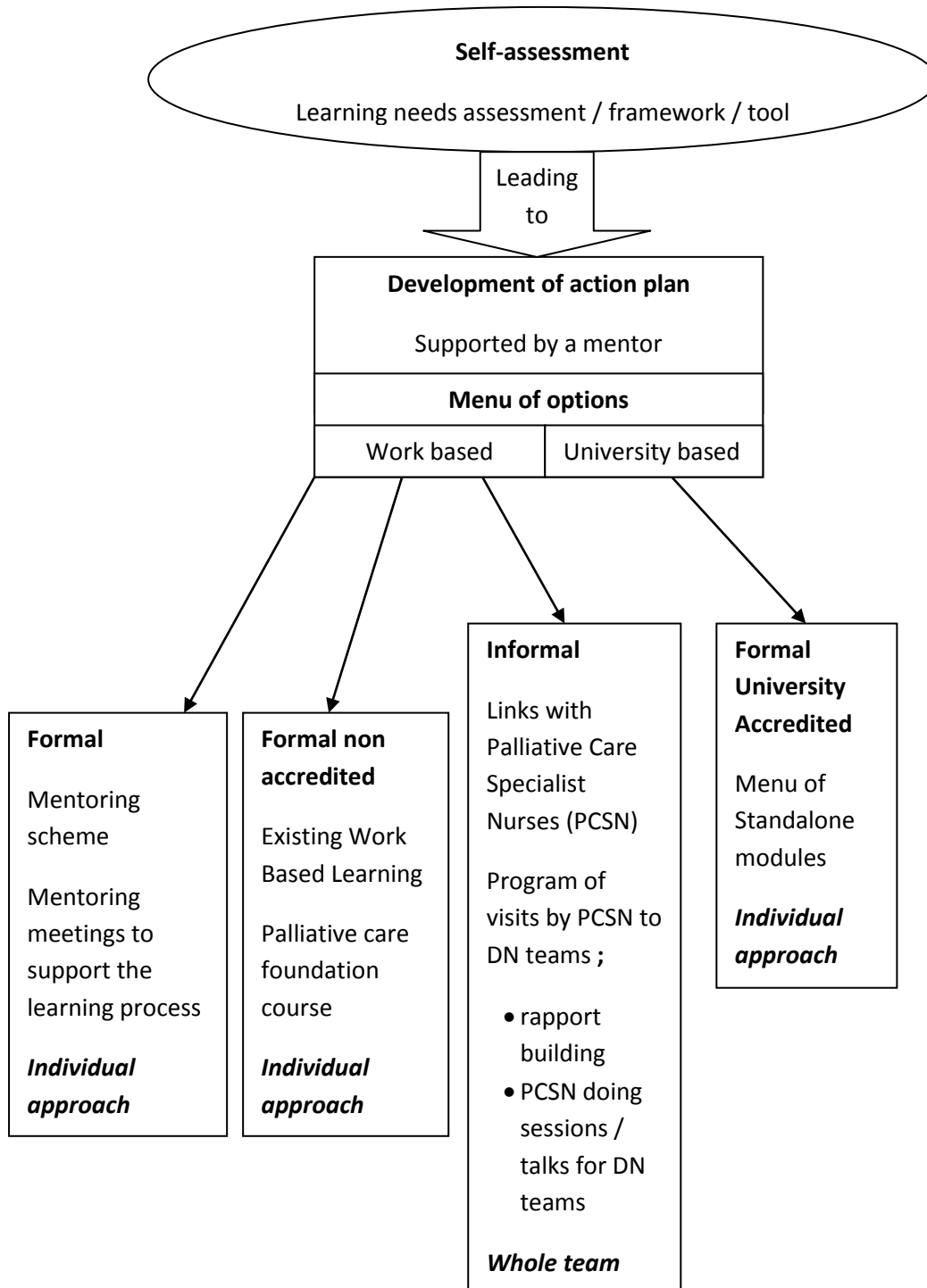
Educational philosophy

The planned pathway will take a learner centred developmental approach underpinned by principles of adult education and will build on the 4 competency areas for end of life (DoH 2008/9):

- communication skills,
- assessment and care planning,
- Symptom management, maintaining comfort and well being
- Advance care planning

The pathway aims to increase both the confidence (through links to specialist nurses and mentoring) and competence (through access to a range of education /training opportunities) of the individuals (and potentially teams) in providing care for palliative care and end of life patients in the community. The pathway will incorporate both individual and whole team approach options.

The process- how it works


```
                    ╭─────────────────────────────────────╮
                    │           Self-assessment           │
                    │                                     │
                    │  Learning needs assessment /        │
                    │         framework / tool            │
                    ╰─────────────────────────────────────╯
                               Leading
                                  to
                    ┌─────────────────────────────────────┐
                    │    Development of action plan       │
                    │                                     │
                    │        Supported by a mentor        │
                    ├─────────────────────────────────────┤
                    │           Menu of options           │
                    ├──────────────────┬──────────────────┤
                    │   Work based     │  University based │
                    └──────────────────┴──────────────────┘
```

Formal

Mentoring scheme

Mentoring meetings to support the learning process

Individual approach

Formal non accredited

Existing Work Based Learning

Palliative care foundation course

Individual approach

Informal

Links with Palliative Care Specialist Nurses (PCSN)

Program of visits by PCSN to DN teams **;**

- rapport building
- PCSN doing sessions / talks for DN teams

Whole team

Formal University Accredited

Menu of Standalone modules

Individual approach

Work Based – Informal (Non Accredited)

Whole team approach
Sessions delivered by Palliative care Specialist Nurses (PCSN) in health centres to DN teams (as identified and negotiated in joint discussions)

If the mentor and mentee/learner feel that it may be useful to have a PCSN visit the whole community team within which the mentee works (perhaps over a lunch time) for example to;
- give a short talk /share expertise ,
- introduce themselves, offer advice,
- for a question and answer session,

If the mentees 'home' team are in agreement this can be negotiated/ organised with the PCSN.

Individual approach

There are several things that the mentee/learner can opt to do as part of on an individual approach e.g.

- Shadowing PCSN
- Joint Visits – District Nurse and PCSN
- 1 day visit to Hospice in-patient unit or day care

The list we have given below are only suggestions and the mentor and mentee may think of other activities that would suit the particular needs of the mentee/learner.

Work Based – Formal (Non Accredited)

(Formal Individual approach)

Mentoring scheme

The mentor and mentee/learner can negotiate the frequency and duration of their meetings as they feel appropriate for the learning needs of the mentee.

While we would recommend that they meet at least 3 times (start, middle, end) during the course of the project (February to September 2012) beyond this recommendation the relationship is completely negotiable.

Indeed some mentor and mentee pairs may wish to meet more frequently and/or;

- have the mentor use the meeting time to share their expertise on a specific topic (almost like a teaching session), or

- have the mentee spend time with the mentor in their practice (i.e. the mentee/learner could shadow the mentor), or

- have the mentor 'shadow' the mentee in practice (i.e. spend time with them in practice so that the mentor can offer case specific advice, information and expertise)

Palliative Care short course (6 study days)

This programme aims to enable practitioners to increase their knowledge and skill for providing services to adults with palliative and end of life care needs. A range of topics is covered over the 6 days, which include, pain and symptom management, spiritual care, bereavement care, communication, dealing with ethical dilemmas, care in the last days of life and advance care planning.

Liverpool Care Pathway and Advanced Care planning (1 study day)

This study day provides a series of topics presented by specialists in palliative care to allow the practitioner to consider Advance care planning and the Liverpool care of the dying pathway in more depth. An overview of the End of Life strategy and the key initiatives from this is presented, followed by short workshops exploring common symptom management for people at the end of life, spiritual care, bereavement care and the challenges of communication.

Effective Communication Skills (1 study day)

Communicating with people at the end of life can be challenging, this study day allows practitioners to reflect upon the challenges and difficulties they face, reflect on this and discuss and identify potential strategies to be used in practice. This is an interactive day facilitated by specialists in palliative care.

Northumbria University Modules (Accredited)

There are a number of relevant Northumbria university modules listed below that you (the mentee /learner) can choose to attend.

While there is no charge for attendance you may have to negotiate time out with your line manager.

All modules are 1 day a week over 10 weeks.

AC6613 / AC0733 – Managing Pain and Symptoms (Level 6 and Level 7)

This module is focussed on patients who have palliative care needs, students will be encouraged to consider the many components that contribute to the delivery of quality palliative care. A flexible learning approach is adopted to assist in the development of specific knowledge relating to the management of symptoms in advanced disease. This module will enable the practitioner to critically examine their practice when caring for this vulnerable group of patient's and will consider the

holistic needs of the patient and their carers. Participants will be encouraged to reflect and explore personal experiences arising from their own clinical practice in order to consider enhancing their professional practice.

Aim:

The philosophy underpinning this module is that accurate assessment is the key to managing pain and symptoms in advanced disease and that effective relief is the essence of quality of life. This module will enable the student to develop advanced skill and knowledge related to complex pain and symptom management, and identify best practice based on the evidence.

AC0008 – Foundations of Cancer (Level 6)

This module focuses upon the multidisciplinary concepts of care and adopts a flexible learning approach to assist you to develop specific knowledge related to the care of people with cancer. The module philosophy has the cancer patient and their family as the central focus and you will be encouraged to reflect and explore personal experiences arising from your previous practice. Patient narratives will be used to enhance this process. The module incorporates a reflexive approach throughout so enabling you to consider and appraise professional interventions. Lectures, discussions and seminars will assist you to draw upon and develop your existing theoretical and practice knowledge in order to apply the module content to your professional practice.

Aims

- Assist practitioners to explore the nature of cancer from a variety of perspectives with particular focus upon the psychosocial and pathophysiological elements.
- To examine the potential impact of a cancer diagnosis upon the individual and their family.
- To explore how professional intervention may assist the individual and his/her family

AC0342 – Principles of Palliative Care (Level 6)

This module is taught using a combination of taught elements and enquiry based learning. It will enable the participant to develop an in-depth understanding of palliative care principles and practices. Students will be expected to explore local, national developments in palliative care. The experience of the palliative care patient will be explored through a variety of methods including patient biographies. The needs of cancer and non-cancer patients will be compared and contrasted. The emotional and informational needs of the cancer patient and their family will be explored considering the contribution of the multidisciplinary team. The summative assessment requires you to demonstrate the interface between theory and practice.

Aim

The philosophy of this module is to consider palliative care in so far as is possible, from the patient and family perspective, through the use of a variety of teaching and learning strategies. The student will also develop a deeper understanding of palliative care principles and practices, and apply these to a variety of contexts of care.

AC0664 – End of Life Care For All (Level 6)

This module is aimed at practitioners who care for all patients at the end of life. The module focus is on the patient pathway, patient choice, e.g. preferred place of choice, the importance of multi-disciplinary care delivery will be a key component of the module. A flexible learning approach is adopted to assist in the development of specific knowledge relating to end of life care in both the cancer patient and patients suffering diseases other than cancer.

This module will enable the practitioner to critically examine their practice when caring for this vulnerable group of patient's and will consider the holistic needs of the patient and their carers. Participants will be encouraged to reflect and explore personal experiences arising from their own clinical practice in order to consider enhancing their professional practice. Lectures discussions and seminars will assist the participant to draw upon and develop existing theoretical and practical knowledge in order to apply the module content to professional practice. This will be supported by the utilisation of Blackboard and e-Learning methodologies.

Aims

- Enable the student to evaluate and consider care delivery at the end of life
- Provide the opportunity for the student to explore the challenges of care delivery at the end of life.
- Explore the holistic multi-disciplinary care necessary to facilitate quality end of life care.

AC0343 – Aspects of Grief and Loss ()

This module aims to assist the practitioner to gain confidence in working with and caring for, dying people and bereaved relatives. This is achieved by a critical analysis of the psychological and sociological perspectives of loss and grief. Due consideration is given to the experience and situation of death and dying within contemporary society which will enable the student to develop an enhanced awareness of the social, physical, emotional, and spiritual manifestations of loss and grief. Cultural and developmental differences are given prime consideration and in particular how this may influence the appropriateness and effectiveness of intervention strategies. A flexible learning approach is adopted throughout the module to assist in the development of specific knowledge relating to this vulnerable client and patient group. Lectures, discussions and seminars will assist the participant to draw upon and develop existing theoretical and practical knowledge in order to apply the module content to professional practice. This will be supported by the utilisation of Blackboard and e-Learning methodologies.

Aims

- To encourage the student to critically analyse current theories of loss and grief.
- To enable the student to reflect and evaluate personal contributions to care
- To consider the multidimensional perspectives of spirituality

AC0313 Communicating Effectively in Difficult Situations (Level 6 and 7)

In addition to the physical aspects of their disease, many people with cancer face major psychological issues. By listening and talking, health professionals play an important role in helping

them make the many adjustments required along the way. Primarily, this module invites practitioners to reflect and subsequently develop, their personal communication skills with this client group, their family and colleagues. The module incorporates a reflexive approach throughout so enabling you to consider and appraise appropriate communication strategies with this client group.   Lectures, discussions and role plays will assist you to draw upon and develop your existing skills in order to apply the module content to your professional practice.

In order to achieve the summative learning outcomes of the module, students must be prepared to participate within individual and small group scenarios as and when requested. This involves working with experienced actors particularly during 3 days which must be attended. Some of this work includes the use of AV recordings.

Aims

- To enable the practitioner to reflect upon their interpersonal skills and identify personal needs and achievements
- To develop confidence and skill by exploring ways of enhancing their practice when engaged in communicating with patients, their family/significant others and colleagues. (Formal Individual approach)

Enhancing confidence and competence in end of life care:

Piloting and evaluating an educational pathway for community care staff

Guidance on action planning

This booklet offers guidance on developing an action plan (see the diagram below) that will help you meet your learning needs through involvement in appropriate learning experiences.

Use this guidance together with your completed TNA Questionnaire and the Guidance on process and opportunities booklet.

Process

Step 1: Self-assessment

Learning needs assessment using TNA questionnaire
This can be done either:
- Individually and then taken to a meeting with the mentor or,
- Undertaken during a meeting with the mentor

Step 2: Action Planning

Action planning: choosing from the learning opportunities

Action planning is best undertaken during a meeting with the mentor who can use their experience to advise and guide. It could be done in the same meeting as the self-assessment discussion or at a following meeting.

Step 3: Engaging in the learning opportunities

Action: attending modules, having mentor meetings, etc as felt to be appropriate for the learning needs that have been identified.

Helping to consolidate learning
Reflect on the learning experiences and potentially:
- keep reflective log/diary
- discuss with mentor or colleagues
- use new knowledge and skills in practice

Step 1: Self-assessment

When you are reviewing your learning needs using the TNA questionnaire, you may find it helpful think about the following categories:

• Am I a Beginner with no or very little experience in the area of activity?

  For example, you may never or hardly ever have been involved with the care of someone at the end of their life. In these situations it will probably be clear that learning needs will be related to 'getting started' or gaining a sound foundation for approaching such situations.

 • Do I have some experience in the area of activity?

For areas where you already have some experience the focus of learning needs/ development will be on improving your practice in areas that are important to your role, for example, you may want to become more effective in communicating with the patient or their family or in managing and maintaining comfort and wellbeing. You may also identify that you need to extend your existing abilities into new contexts, for example providing support and care for patients with diverse diagnoses / prognosis or spiritual needs.

• Do I have considerable experience in the area of activity?

Considerable experience means that you have engaged in this area of activity in different contexts, used different approaches, been innovative, have some evidence of success and a strong under-pinning understanding giving a rationale for your work.   You may feel that you do not need further development in these areas but on the other hand, if an area of strength such as pain management or communication is core to your practice you may feel it is important to develop your expertise further or refresh your knowledge of the area.

Step 2: Action Planning

Action planning is best undertaken during a meeting with the mentor who can use their experience to advise and guide. It could be done in the same meeting as the self-assessment discussion or at a following meeting.

Once the TNA self-assessment questionnaire is completed discuss it with your mentor. These discussions may include:

- levels of confidence
- experiences of end of life care to date,
- particular areas of unease
- perceived areas for further development

At the end of the discussions areas for development/ learning needs should be clearly identified (e.g. need to learn more about pain control, or communication in certain circumstances etc).

Choosing from the learning opportunities

Use the learning needs identified as a starting point and consider the range of formal and informal opportunities available (i.e. the modules, courses, mentoring, links with Palliative Care Specialist Nurses etc outlined in the Guidance on process and opportunities booklet).

Choose the options which seem to best fit your learning needs – for the Formal University Accredited modules mapping the needs to the learning outcomes may be useful (see appendix A for further information).

Record the choices on the form provided in appendix B.- Record of learning needs and learning opportunity choices

Step 3: Engaging in the learning opportunities

Send a copy of your form (Appendix B) to Gail White

Lecturer Practitioner - Palliative care
South Tyneside NHS Foundation Trust incorporating Community Health Services
Based at
St Benedict's Hospice
Newcastle Road,
Sunderland, SR5 1NB
Telephone No: 0191 5656256 Ext 48302
Mobile 07768618299
email: gail.white@sotw.nhs.uk

Gail will assist in registering you on the chosen courses or modules, or help in setting up the informal learning mechanisms and opportunities.

We also recommend in order to consolidate the learning that takes place, the nurses participating reflect on the learning experiences and potentially:

•   keep reflective log/diary (see example in Appendix C: Learning Log Template)

•   discuss with mentor or colleagues

•   use new knowledge and skills in practice.

Appendix A: Aims and outcomes for formal university modules

Module title	Module Aims	Learning outcomes
Managing Pain and Symptoms (level 6)	This module will enable the student to develop advanced skill and knowledge related to complex pain and symptom management, and identify best practice based on the evidence.	- Demonstrate an in-depth understanding of a variety of symptoms and pain that cause distress in advanced disease. - Critically evaluate the need for assessment skills and the usefulness of tools for effective symptom management. - Appraise the contribution of the multi-disciplinary team in the effective management of pain and symptoms in advanced disease - Explore the legal and ethical consequences of clinical practice in palliative care. - Consider the quality of life dimension in relation to effective pain and symptom control in advanced disease.
Managing Pain and Symptoms (level 7)	The aim of this module is to enable the student to extend their repertoire of skills and knowledge when managing pain and symptoms in advanced disease and conceptualise the notion of quality of life	- Demonstrate reflexivity and innovation in relation to managing symptoms and pain that cause distress in advanced disease. - Critically evaluate the need for assessment skills and the usefulness of tools for effective symptom management. - Critically appraise the contribution of the multi-disciplinary team in the effective management of pain and symptoms in advanced disease - Critically analyse the legal and ethical consequences of clinical practice in palliative care. - Reflect on the quality of life dimension in relation to effective pain and symptom control in advanced disease.

Module title	Module Aims	Learning outcomes
Foundations of Cancer (Level 6)	• Assist practitioners to explore the nature of cancer from a variety of perspectives with particular focus upon the psychosocial and pathophysiological elements. • To examine the potential impact of a cancer diagnosis upon the individual and their family/significant others. • To explore how professional intervention may assist the individual and his/her family/significant others	• Evaluate the impact of cancer upon the individual and their family • Critically evaluate the current provision for the prevention and early detection of cancer • Examine the practitioners role in the holistic care of a patient at all stages of the disease trajectory • Demonstrate the use of effective communication skills and reflects upon personal performance during patient/family interactions • Appraise current cancer provision within the context of contemporary practice
End of Life Care For All (Level 6)	• Enable the student to evaluate and consider care delivery at the end of life • Provide the opportunity for the student to explore the challenges of care delivery at the end of life. • Explore the holistic multi-disciplinary care necessary to facilitate quality end of life care.	• Critically analyse ethical and legal dilemma's encountered in everyday practice when providing end of life care • Appraise and explore the prevailing physical symptoms and problems that cause distress in advanced disease • Critically explore social, psychological and spiritual needs of patients requiring end of life care • Critically reflect upon and discuss current policy drivers and their impact on practice • Critically examine the practitioners own contribution to effective care delivery and multi-disciplinary teamwork.
Principles of Palliative Care (Level 6)	The philosophy of this module is to consider palliative care in so far as is possible, from the patient and family perspective, through the use of a variety of teaching and learning strategies. The student will also develop a deeper understanding of palliative care principles and practices, and apply these to a variety of contexts of care.	• Explore how the principles of palliative care can be applied in a variety of settings, throughout the patient journey. • Appraise the social and political trends that influence the delivery of palliative care. • Critically evaluate how palliative care principles may be relevant to patients with non-malignant disease. • Critically reflect on the holistic needs of the palliative care patient and their family considering the challenges in professional practice

Module title	Module Aims	Learning outcomes
Aspects of Grief and Loss (level 6)	• This module will encourage the student to critically analyse current theories of loss and grief. • Enable the student to reflect and evaluate personal contributions to care and • Enable the student to consider the multidimensional perspectives of spirituality	• Appraise cultural and developmental factors which contribute to perceptions death, dying and bereavement • Critically analyse theories of grief with reference to the stage/linear model and contemporary phenomenological and existential approaches • Demonstrate understanding of spiritual concerns that contribute to the quality of life and the quality of death • Critically reflect and evaluate upon personal contribution to care for this client group.
Communicating in Difficult Situations (Level 6)	•To enable the practitioner to reflect upon their interpersonal skills and identify personal needs and achievements •To develop confidence and explore ways of enhancing their practice when engaged in communicating with patients, their family/significant others and colleagues within the cancer care arena.	On completion of the unit the practitioner will be able to: • Reflect upon personal strengths and weaknesses with regard to communication within the context of cancer care • Reflect critically upon the application of effective communication skills and strategies with patients and their relatives/significant other throughout their cancer journey • Critically evaluate an aspect of interpersonal care and identify opportunities for practice development
Communicating Effectively in Difficult Situations (Level 7)	The aim of this module is to enable the student to extend their repertoire of skills and knowledge to assist them to communicate effectively in difficult situations. The practitioner will critically reflect on their own interpersonal abilities and identify personal needs and achievements whilst identifying challenges for advanced communication in practice.	On completion of the unit the practitioner will be able to: • Critically appraise personal strengths and weaknesses with regard to communication. • Demonstrate reflexivity in the application of effective communication skills and strategies with patients and their relatives/significant other throughout their disease trajectory • Critically evaluate an aspect of interpersonal care and identify opportunities for advanced practice development

Appendix B: Record of learning needs and learning opportunity choices

Learning needs identified (by area)	1st Choice of learning opportunity	2nd Choice of learning opportunity
Communication		
Assessment and care planning		
Symptom management , maintaining comfort and wellbeing		

(Feel free to add or delete rows as necessary)

Appendix C: Learning Log Template

Date of event	What was the development activity? What did I do?	What was I expecting to learn?	What have I learned?	How will I apply this learning?

Learning Log: Guidance Notes

A learning log is a tool that enables you to record and reflect upon each development activity that you undertake to achieve the development objectives you have identified in your Personal Development Plan (PDP).

Learning logs should be completed as soon as possible after undertaking each learning activity so that you can capture all the key learning points from the activity whilst they are still fresh in your mind. Completing a learning log after each learning activity can really help you reflect on what you actually learned and assess that against what you had hoped to learn from the activity. In undertaking this process you can identify if there are any further gaps in your learning that you need to address. During the process you can also think about what how your learning can be applied to your working practices.

When we undertake any kind of learning activity, unless we record it somewhere, we can forget about it. Keeping a detailed learning log can be a really useful mechanism for keeping track of your learning and reminding you of aspects of your learning that you may have forgotten about but which could be useful to you in the future.

How do I 'do' my Learning Log?

Try to write something down in your learning log after every new learning experience.

- What you did
- Your thoughts
- Your feelings
- How well (or badly) it went
- What you learnt
- What you will do differently next time.

On a regular basis review what you have written and reflected upon this. Be honest with yourself.

Ask yourself questions such as:

- Have I achieved anything? If so, what?
- What progress have I made
- Have I put any theory into practice?
- How does what I have been doing lead to me becoming better at a skill?
- How can I use this to plan for the future?
- How can I use this to plan new learning?
- Experiences?

Appendix 4 – A case study

Participant X has worked as a community nurse for several years. She works within a team of District nursing sisters, community staff nurses and health care assistants. They visit people in their own home for *various things* which include visiting people with palliative and end of life care needs. The needs of palliative care patients include symptom control, skin care and monitoring their appetite. Sometime these visits were said to be, *just an informal chat.* For patients at the very end of life visits include giving personal care, symptom management and ensuring people have a peaceful death at home. Describing herself as more of 'a hands on' person who learns from watching others, she is also currently involved in formal study and has an interest in palliative care.This nurse has been in her post for many years, she feels reasonably confident visiting patients once she knows them but visiting new patients is an area where she feels less confident. She finds visiting patients at home different to working in a hospital.

> *"I mean, I've worked in the community now for – it's about xx years…I feel quite confident to do that myself (visit patients). But a lot of the girls have been hospital-based and obviously visiting people at home is just completely different really. So, just learning to work, you know, with someone in their own home rather than in hospital."*

Caring for people at the very end of life (last days) is more of a challenge for this nurse and an increase in confidence is essential for both the nurse and the community team to which she belongs.

> *"'I think once my confidence is built again, I'll be able to help [others in the team]"*

This nurse values the importance of the nurse patient relationship and how getting to know someone means you can identify any changes in their condition. The most challenging areas of palliative care and end of life care for her are; dealing with collusion, communication and complex symptom management. She identified the services that would support these complex situations, alongside the need to personally keep up to date. Completing the Training Needs Analysis (TNA) tool also enabled her to identify other learning needs which had not previously been recognised.

> *" And this is where I really identified some of the questions – where I identified that my communication skills weren't brilliant…And that's where I think I initially found out where I felt comfortable doing the end of life, rather than managing it. So this really started to make me think – this tool".*

The assurance of being up to date was the key aspiration for this nurse. A detailed action plan linked to the End of life common core competencies was produced in partnership between her and her mentor. The action plan identified shadowing and observing her mentor and discussion with her mentor as the main choices for the learning.The initial meetings for this nurse and her mentor (palliative care specialist nurse) proved problematic due to them working in different areas and both having busy clinical case loads. Once meetings were planned in advance they met several times. The meetings between this nurse and her mentor included, shadowing the mentor when doing her clinical work and one to one teaching sessions. Being able to shadow her mentor and observe the practice of a knowledgeable practitioner gave this nurse assurance of her own ability

> *"Well, I thought I had, like, an issue, sort of, with communication…When I've visited people in my own job and you come away and you think, Oh… You feel, oh, maybe I could have done this better or that better…But I think watching (mentor) and listening to the way she, sort of, speaks to people and things that she said, it kind of, at the end of it, I've thought, Well, actually, I'm not as bad as I thought I was."*

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