

Hospice Facilitation of Training EKHUFT Healthcare Professionals in End of Life Care Discussions and Planning.

Project Report

July 2015

Emily Mckean, Claire Butler, Charlotte Brigden

Pilgrims Hospice in East Kent

56 London Road

Canterbury

CT2 8JA

01227 812625

Emily.mckean@nhs.net



Contents

Acknowledgments

	Page
Executive Summary	1
1. Background and purpose	2
2. Project work	5
a. Workshops	
b. Link with community	
c. Link nurse re-launch	
d. Workbook	
e. Other activities	
3. Data and findings	9
4. Discussion and recommendations	14
References	18
Appendices	20
a. Workshop questionnaire example	
b. Workshop questionnaire data	
c. Workshop group work feedback summary and themes	
d. Baby steps and feedback	

Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.

Acknowledgements

We would like to thank St James's Place Foundation for funding the study via Hospice UK. We would also like to thank Pilgrims Hospices in East Kent for providing additional support and equipment, and in particular to Claire Hinde for her admin support that was invaluable and to Amy-Jo Lynch who was instrumental in writing the project proposal and funding application.

Thanks also go to Sue Cook, Consultant Nurse in Palliative Care, at EKHUFT also provided supervision and support.

Special thanks go to all who took part in the workshops and the Education Centres at all three East Kent Hospitals University Foundation Trust sites for their help and support.

Executive summary

This report provides a summary of an intervention funded by the St James' Place Foundation via Hospice UK and was called '*Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.*' The main intervention was a series of workshops at all three hospital sites at East Kent Hospitals University Foundation Trust (EKHUFT). Questionnaire data from the workshops showed an increase in confidence in end of life discussions, with the largest increase in confidence seen in the area of documentation. This report also details other activities carried out by the End of Life Care Facilitator during the yearlong project and concludes with recommendations to further facilitate end of life discussions and planning beyond the life of the project. These include:

- Further use of the 'solution focused' methodology in the provision of training and education
- A clear, consistent place to record end of life discussions and decisions in hospital notes
- A functioning electronic system that can be viewed by all services involved in a patient's care at the end of their life
- A dedicated End of Life Care Facilitator at each hospital site.

1. Background and purpose

This project report will begin with the original background and purpose of the project as stated in the proposal submitted to *Help the Hospices* (now *Hospice UK*). There will then be a summary of how the proposal was interpreted and what interventions were provided, followed by any lessons learned, outstanding issues and limitations of the project. Finally there will be a discussion and recommendations for the future.

The aims of the project were: to facilitate advance care planning discussions and documentation, enabling patients to be discharged from hospital to their preferred place of care and to make changes that will lead to improved coordination and quality of end of life care (EoLC) that is patient-centred. The plan was to achieve this by delivering training in discussions and planning about EoLC choices, primarily to hospital staff working for the East Kent Hospitals University NHS Foundation Trust (EKHUFT). The primary outcome was for staff to identify and record patient preferences on an Electronic Palliative Care Coordination System (EPaCCS) wherever possible. EPaCCS is an IT system that provides access to patient information for professionals across different settings.

The proposal broke the planned interventions down into three areas:

1. Training hospital staff to lead EoLC discussions and planning, focusing on enhancing communication skills and confidence among staff.

The Facilitator will deliver short, simple and tailored group workshops based on the SAGE & THYME model - an established approach to healthcare communication undertaken by thousands of NHS staff that centres on listening and responding to patients' concerns and incorporating advance care planning for EoLC patients (University Hospital Manchester, 2013).

2. Training hospital staff to record and review patient preferences on EPaCCS with the view to implement them wherever possible.

This is compatible with NHS Improving Quality's targets by 2015 for 70% roll-out of EPaCCS across England from a baseline of 15%, and increasing deaths in people's usual place of residence from a baseline of 39% to 47% - part of the Transform Programme to improve EoLC in acute hospitals (NHSIQ, 2013)

3. Organising joint forums to facilitate lasting relationships and information sharing between professionals from hospitals, the community, care homes and hospices.

The scope of the project was purposefully narrow yet flexible, focusing on identified unmet local needs. Hospital teams were prioritised for training because they care for the patients before discharge from hospital to their preferred place, leading to a direct impact on patient care according to their wishes. Increased use of the local EPaCCS system, Share My Care, was also identified as being of importance. Aiming for early registration on EPaCCS is consistent with the Dying Matters Coalition's 'Find Your 1%' campaign (NHSIQ, 2013a, NCPC, 2012). Moreover, accommodating individual care preferences through staff training and forums for partnership working, driven by a Facilitator, are practical and established activities to improve the current situation (NHSIQ, 2013b, Wye et al 2012, Croucher et al, 2013). In the London EPaCCS project, 78% of patients' preferred place of death has been achieved (NHSIQ, 2014a).

The proposal identified three outcomes:

- *Increase the number of practitioner-led EoLC discussions and planning, resulting in more patient preferences recorded.*
- *Increase the number of patients being cared for in their preferred place (and decrease hospital deaths) - congruence between preferred and actual place of care.*
- *Improve confidence and competency of trained hospital staff, measurable using self-report questionnaires*

In order to meet these proposed outcomes the proposal suggested the following activities for the End of Life Care Facilitator:

- *Develop interactive training workshops for hospital staff in timely and sensitive EoLC discussions and planning, and using EPaCCS to record patient preferences.*
- *Raise awareness of the project to build working relationships quickly e.g. attend key EoLC meetings and identify internal publications.*
- *Arrange forums for ongoing collaboration between healthcare professionals, service users and carers/families.*
- *Administer questionnaires to staff pre, post-training and post-intervention.*

Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.

Measures were suggested that could sustain the work beyond the life of the grant:

- *Encourage hospital teams to identify project champions to maintain enthusiasm, teach new colleagues and influence change during and after the project*
- *Create guidelines regarding care processes to direct future care*
- *Engage commissioners/CCGs and other potential investors with the project evaluation report complete with recommendations, following monthly progress reports to build interest. Use outcome data to support business cases and requests for funding*
- *Apply for further funding and bigger grants to incorporate lessons learnt and roll-out training to other professional groups across the locality including GPs and care home staff*
- *Joint forums will help foster enduring collaborative working between hospital staff and a diverse range of health and social care professionals that should continue to flourish*
- *Charging for training in the future to keep the EoLC Facilitator in post.*

How achievable these activities, outcomes and measures were, and how they were met will be discussed in the next section.

2. Project work

The project began in July 2014 with a six week scoping exercise. During the scoping exercise meetings were held with Sue Cook Consultant Nurse in Palliative Care, Palliative Specialist Nurses at all three hospital sites – to hear their concerns and aims for the role which included: culture change, education regarding ceiling of care, advance care planning and the use of the End of Life Conversations form (a local initiative in the Trust).

A meeting was also held with the Trust IT where it was reported that because one of the 4 CCGs in the area had not bought into Share My Care (the proposed EPaCCS system), there was 'read only' access for EKHUFT staff. This meant that the project's main aim of increasing the recording of preferred place of care/death on Share My Care was not possible. This also meant that it wasn't so easy to measure the success of the project through before and after data gathered from Share My Care as per the proposal. To compound this problem the use of the Liverpool Care Pathway document had been discontinued which meant staff were no longer recording the patients EoL plans and wishes on one easily auditable document, kept at the front of the notes. It also meant that there was no document to steer people towards during training to give them a concrete guide when carrying out EoL conversations and documentation.

Personal and professional development for the facilitator included Sage and Thyme training in end of life conversations, End of Life Care for All e-training (eELCA) regarding advance care planning and advanced communication skills. Public speaking training was also undertaken to enhance teaching and presentation skills.

The facilitator took into account all elements of the scoping exercise to formulate workshops as the main intervention, using questionnaires pre and post training as a measure. A summary of project work carried out to meet other aspects of the proposal is listed below.

Project work carried out:

a. Workshops

A total of 20 workshops were planned by the EoLC Facilitator across the three hospital sites to deliver the EoLC discussions and planning training. However five of these workshops were cancelled due to low booking numbers.

Delivering training on EoL conversations and documentation requires a wide range of topics to be covered which would be difficult to present through a conventional PowerPoint teaching session. As well as the areas outlined in the *Five Priorities of Care for the Dying Person* (NHSIQ, 2014b), there are also elements to include in an Advance Care Plan (ACP) such as Advance Decision to Refuse Treatment (ADRT) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). Advanced communication skills are also a key element in Advance Care Planning and this training was not part of the project brief. It was therefore decided that the most appropriate approach to use in the workshops to achieve the aim of the project was solution focus (SF), as it is based on building on existing knowledge and skills (Kennedy and Coombs 2011). The workshops utilised a framework for solution focused coaching called OSKAR which stands for Outcome, Scaling, Know-how and resources, Affirm and action, Review (Jackson et al 2007, McKean 2015). This framework was chosen as it has been tested and used to help the coach focus on conversations and helping participants find a way forward. The model was adapted to suit the workshops and also influenced by Kennedy and Coombs (2011) approach to their workshops. The EoLC Facilitator conducted a pilot session with hospice staff prior to the running the workshops in the hospital Trust in which the method and the questionnaires were tested and feedback was gained.

The workshops began with an explanation of the project and facilitator background and most importantly the question, *'What would need to happen here today for you to feel that this was a worthwhile session?'* This was written down on a flip chart and returned to at the end of the session to illustrate that individual session goals had been met. This enabled the session to meet individual needs; the content of it shifting according to those needs. This question also helped to set the scene and the expectations of both participant and facilitator and encouraged those who mostly wanted talk about problems on the ward to engage in solution focused talk.

A more in-depth analysis of the data can be found in Section 3 'Data and findings' in this report.

b. Links with the Community

Making links with the community included the delivery of two DNACPR talks as part of Protected GP Learning Time events. These were at the beginning of the project and also served to help to educate the facilitator on the principles of DNACPR, as well as the concerns of health professionals and the relevant case law. In these talks the need to include patients in conversations, to document and to share was emphasised. It was also highlighted that EPaCCS is part of a strategic goal of the Department of Health but also the South East Coast Clinical Senate.

Links were made with the newly recruited Community EoL Facilitator and the newly established Local Referral Unit (LRU). The main aim of the LRU is to reduce hospital admissions and to that end they had arranged 'view only' access to Share My Care.

Multiagency forums were not organised as there are many of these already occurring, for example, the local neighbourhood care team meeting which is attended by Mental Health, Social Services, Community and Hospice representatives from the local CCG.

c. Link nurse re-launch

To meet the goal in the proposal of promoting and embedding good practice on the wards, as well as creating a forum (albeit not multidisciplinary), a Link Nurse event was arranged with the Palliative Nurse Specialists and Cancer Nurses Specialists who had lost momentum with the recruitment and education of link nurses on the wards. This also helped to meet the goal of identifying advance care planning champions as these individuals are already enthusiastic about best end of life care practice. The Specialist Nurses have already planned their next event.

d. Workbook

The EoLC facilitator worked towards putting together a care planning 'workbook' in order to facilitate end of life conversations beyond the end of the project which could be taken forward by hospice staff. This workbook is not to be a formal document, but rather a prompt or aid for professionals who wish to help patients think about their current and future care wishes. It will be a versatile document that can be used by any profession or grade in any setting in a collaborative way with the patient. The patient will be able to fill it in on their own or with the professional, which gives the patient the option of taking their time to think about the questions/prompts within the

document. The idea for the workbook came from the workshops where people were asking for guidance and help initiating conversations. People were keen on the Dying Matters leaflets but they are not in the workbook format, and also have a cost attached. Furthermore, a workbook that is produced by a trusted and local source such as the Hospice is likely to have a greater uptake.

e. Other activities

Other activities included:

- Input on the development of the Pilgrims Hospices Advance Care Planning policy liaising with Age UK and put them in touch with the Lions Club as they were keen to provide 'message in a bottle' bottles: a very basic way of sharing information and promoting the communication of important patient information.
- Liaising with Pilgrims Hospices education department about planned Gold Standards Framework work to see if there was any role for the facilitator to play at present. There was not but this could be an area of work for a permanent/local EoLC Facilitator in the future.
- An attempt was made to be involved in the EoL documentation steering group so that staff feedback gathered at the workshops could be included. Unfortunately this was not possible.
- Advice given on how to make a joint Primary and Secondary Care meeting more "solution focused" when tackling how to improve communication regarding end of life care and wishes.

Dissemination

Dissemination activities included:

- one hour presentation and Q&A at Pilgrims Hospice Research Day 20th May 2015
- poster presentation at a research symposium at EKHUFT 19th May 2015
- summary given at the End of Life board at EKHUFT
- summary given Grand Round at all three EKHUFT sites
- article for *InterAction* journal regarding the solution focus methodology (McKean 2015)
- eHospice article: <http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/15241>
- lay summary
- Press release via Hospice website.

3. Data and findings

Questionnaire data

As discussed above it was not possible to gather pre/post intervention data from Share My Care as hospital staff were unable to enter patient preferred place of care/death as they had 'view only' access.

Fifteen workshops were conducted across the three hospital sites. In total 153 people attended the training. Staff groups included nurses, medics (F1 to consultant), occupational therapists, physiotherapists, health care assistants, therapy assistants and all grades of theatre and day surgery staff.

As part of the solution focus method a scaling approach was used to track changes in confidence in the different areas of end of life discussions and conversations in a questionnaire before and after the workshop sessions (example in Appendix a). The use of scaling gave the participants the opportunity to recognise even small increases in confidence (Jackson et al 2007).

The pre/post questions included the following rating scale and questions:

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident.

1. How confident are you in initiating conversations about preferred place of care with a patient?
2. How confident are you in continuing these conversations?
3. How confident are you initiating conversations about preferred place of care with family/carers?
4. How confident are you in continuing these conversations?
5. How confident are you in having conversations about DNACPR with patients?
6. How confident are you in having conversations about DNACPR with family/carers?
7. How confident are you that you know what to do when a question is asked that you are unable to answer?
8. How confident are you in the documenting of Advance Care Plans?

110 of the 153 workshop attendees filled in both the pre and post-workshop questionnaire as some arrived late or left early due to work commitments.

The mean results below show an increase in confidence experienced in all questions with the biggest increase (2.09) in Question 8. The mode also shows the biggest increase in the most common response. Question 8 was 'How confident are you in the documenting of Advance Care Plans?' It is

interesting that such an increase in confidence was felt in the area of documentation when the facilitator was unable to show participants either paper or electronic documentation because these are still in development. This indicates the power of solution focused training and points to an area of further research.

Table 1: Mean score and difference

Mean score															
Q1		Q2		Q3		Q4		Q5		Q6		Q7		Q8	
Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
6.4	7.6	6.3	7.6	6.3	7.6	6.3	7.6	5.5	6.8	5.7	6.9	6.5	7.6	4.5	6.6
Difference															
1.14		1.32		1.28		1.33		1.36		1.15		1.06		2.09	

Figure 1: Mean score

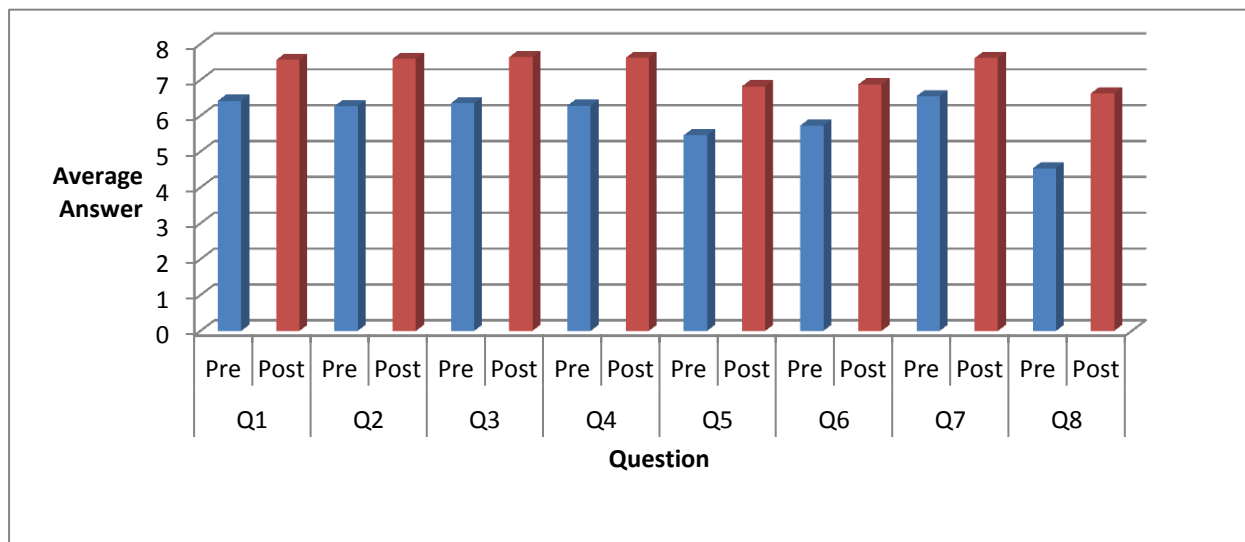


Table 2: Mode, maximum/minimum value and range.

	Q1		Q2		Q3		Q4		Q5		Q6		Q7		Q8	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Mode	6	8	6	9	7	8	5	8	9	9	8	9	8	8	3	8
Max Value	10	10	10	10	10	10	10	10	10	10	10	10	10	10	10	10
Min Value	1	3	1	3	1	3	1	2	1	1	1	1	1	1	1	1
Range	9	7	9	7	9	7	9	8	9	9	9	9	9	9	9	9

Further information on the individual data pre and post for each question is in appendix b.

Workshop feedback and themes

The workshop participants were encouraged to co-construct a ‘preferred future’ where advance care planning is working perfectly. They were split into groups of three or four and asked to put themselves in the shoes of patient and: ‘Imagine advance care planning is working really well. What would it look like?’ Themes that emerged were:

Most common	Respectful of patients wishes
	Family/carer/patient/MDT fully aware/informed
	Clear/effective communication
	Involvement and inclusion
	Healthcare professional to explain the process of dying/consequences/risks (educate)
Quite common	Clear documentation
	Pain controlled/adequate meds/comfort
	Documents shared with patients, GP, ambulance crew, family members
	Patients have been provided with choices, realistic plans
	Time allocated
	Listening & giving time for patients to express themselves
	Acknowledge things may change/acceptance
	Patients can change their mind if they so wish (if clinically appropriate)
	DNACPR conversation
	Accessible, understandable, jargon free - all parties
	Reviewed and updated regularly
	Quiet environment - Comfortable place - dignity

Next the groups were asked: ‘What is the next step to move toward the ideal advance care planning you just described? What would need to happen? What would it look like?’ Themes that emerged were:

Most common	Training and education
	Clear communication between doctors, nurses, patients and families
	Quality time - no interruptions
	Money/funding/budget
Quite common	Regular updates from IT re: new systems/simpler IT systems that talk to each other
	Availability of appropriate documentation
	Clearer documentation
	Take responsibility - talk about death
	Public awareness - information packs, GP surgery leaflets, approved persons to give advice e.g. libraries/pharmacies/clinics
	Reviewed and updated regularly
	Culture change in society regarding death – talking about it

It is interesting to note that the ‘most common’ responses are more aspirational and “vague” at a higher level. Whereas, the ‘quite common’ responses describe practical steps that could be made to achieve perfect ACP. Both sets of responses also describe the barriers staff are experiencing with end of life conversations and documentation in the acute setting. Again this indicates the power of the solution focus approach where the barriers to practice are explored without the use of ‘problem talk’ thus avoiding training becoming negative and problem focused.

A full list of all emerging themes is in appendix c.

“Baby steps” and feedback

The other benefit of the solution focus method was the use of the “baby step” which was the next part of the workshop, which encouraged participants to break the next steps down into a more personal and achievable goal.

In accordance with the solution focus methodology participants were asked to think about a small, manageable step toward the ideal advance care planning they had described in the groups. 106 ‘baby steps’ were completed. The baby steps showed that people took away a range of things from the sessions, including: taking responsibility for ensuring process/procedures are happening; initiating conversations; seeking patient thoughts.

All baby steps are included in Appendix d and an illustrative selection is given below:

'Ensuring doctors/MDT have spoken to families and patient and that they are all fully informed and have no questions.'

'Initiate 'difficult' conversations as soon as possible so opportunities are not lost.'

'Speak to patients more openly and invite them to tell me what they want and expect.'

'Discuss with patient their understanding of situation once medics have confirmed end life stage. Try and ascertain patients own discharge destination at soonest opportunity rather than await palliative input.'

'Complete an audit including patient and family feedback to improve the process overall.'

Some people wrote down a step that was personal rather than professional and some wrote a mixture of both, for example:

'1. Better communication with patients/family, 2. Share ideas with colleagues, 3. Challenge medical decision , 4. Discuss with my family about ACP, 5. Write my will.'

One response was also deeply personal and showed a profound effect that enabled the participant to deal with death in their own life.

Participants who wrote a baby step were emailed by the facilitator 1-3 months later to find out if they had been able to achieve their baby step. Only 16 out of 106 responded to these follow up emails which was disappointing but not that surprising given that the majority of workshop attendees worked in a ward setting rather than desk jobs, and so had limited access to computers in their working day. Contacting participants by phone would have been inconvenient for staff and difficult for the facilitator to achieve. Ideally the facilitator would have been able to follow up individually or in focus groups in order to gauge if the increase in confidence had continued, if baby steps were completed, or if some facilitation would help them complete their step. The 16 responses were still interesting. One reported that they were too busy to be able complete their baby step of asking patients what their plans were at discharge. This was disappointing to hear but does give an example of why end of life conversations are not happening more readily. People feel they are too busy. This is an area that needs much more research as wards are becoming busier and more stressful as efficiency measures continue and the elderly population rises. Other responses (see Appendix d) showed the baby step had been completed and the workshop had been of benefit.

4. Discussion and recommendations

It was possible to meet the major goal of 'Training hospital staff to lead EoLC discussions and planning, focusing on enhancing communication skills and confidence among staff'. As discussed above this is evidenced by the pre/post workshop questionnaire results. These results show that further training of this nature would be beneficial to staff and ultimately patients.

It was found that the benefits of this solution focus (SF) approach to end of life (EoL) conversations and documentation training were:

- Flexible and easily tailored to needs of participants and different groups of professions and bands, whilst covering all the areas involved in EoL conversations and documentation.
- Can be used with homogeneous groups but varied groups increased information sharing and improved the learning experience. It also helped professions to recognise everyone has a part to play and that many are feeling the same way about the subject or are 'all in the same boat'. This also helps to reduce the blame culture and the feelings that EoL conversations are someone else's responsibility.
- The group were empowered to take a small but manageable step towards the ideal, which provided motivation and increased confidence and self-efficacy. It will also promote personal responsibility for their small step toward the ideal but for the whole system.
- Sharing experiences both good and bad, with the facilitator always focusing on the good practice rather than the 'failed discharge', helped to share real life examples of good practice whilst acknowledging that sometimes no matter how hard we try a situation will not work out the way you or the patient want it to due to external influences that cannot be controlled.

For these reasons it is possible this form of training could contribute to a reduction in staff burnout, benefiting staff and healthcare as a whole. From the pre-post questionnaire findings it is clear that the training sessions increased staff confidence, particularly relating to documenting conversations.

The lack of access to Share My Care presented a significant hindrance regarding meeting a major objective of the project of 'Training hospital staff to record and review patient preferences on EPaCCS with the view to implement them wherever possible'. However as the project reaches its conclusion progress is being made to link different computer systems in order for the hospitals, GPs, ambulance service, community services and hospice to be able to access the information required regarding end of life wishes of patients. Furthermore, the lack of a paper document at the front of the notes, such as the Liverpool Care Pathway, meant that notes were not easily auditable regarding

the recording/reviewing of patient preferences. Again as the project reaches its end there appears to be a move to introduce another form of documentation for End of Life care in the Trust. The lack of auditable data meant the success of the workshops in terms of increased documentation could not be measured.

There were limitations inherent in this yearlong project relating to time and location which made relationship building with the hospital trust important for the success of the project. Once the workshop was devised and pilot tested, eight weeks was required for staff to have the session rostered in to their off-duty. This left an 8 month window in which four sessions at each site were arranged. However five were cancelled due to poor attendance (6-10 people were required for an optimum workshop to generate information sharing and debate). Poor attendance may have been caused by the workshops being in quick succession in a short space of time. Attendance was best where the facilitator had been able to build up a good relationship with key staff as well as the education centres. For example, there was a high turnout of therapists at one site following contact being made with the head of therapy and because the EoLC facilitator knew therapists personally at that site. On another site there was a very keen ward manager who the EoLC facilitator built up a good relationship with and she continued to send her nurses throughout the project. Getting to know these key people on all three sites was a difficult task and may have been easier to achieve if the EoLC facilitator had worked on site rather than just at the hospice. To encourage physicians to attend, Royal College of Physician CPD points were arranged, but this did not prove to be a big motivator for attendance. The workshop was then adapted to be delivered at F2 training sessions where it was successful. After these sessions a summary of the intervention was given at Grand Round on all three sites and helped to foster a better relationship with senior physicians, that could have been capitalised upon if the project were longer or the post permanent.

It is recommended that a dedicated EoL Facilitator is employed at each of the Trust's three hospital sites. A local EoLC Facilitator would:

- Roll the SF training out all year round together with advanced communications training, which would also have a SF methodology.
- Go on to the wards to support staff to achieve their baby steps and for them to share their knowledge with other staff members. Provide a sounding board to help staff to think about their practice and good or bad experiences.

Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.

- Support EoL link nurses on wards to be empowered to promote cultural change and good practice. This would then free up Palliative Clinical Nurse Specialists to do their clinical work. The EoLC Facilitator could also cover any other generic EoL work that does not require a specialist nurse.
- Provide training to every new set of F1 doctors in order to really start to influence the culture and therefore improve patient experience and outcomes. There could also be an EoL element to the staff induction.
- Represent staff at working groups or meetings, such as the EoL documentation working group, to ensure the staff voice is heard and that outcome of the meetings is fed back to interested parties.
- Foster links with community EoL Facilitators, GPs and the local hospice and feedback community developments to ward staff. Introducing an SF approach in meetings.
- Champion Share My Care/provide training on whatever EPaCCS system is put in place in the future.

This EOLC Facilitator role would help the Trust to meet the needs identified by staff in the second group activity of how to achieve perfect ACP which included:

- Improved communication (interdisciplinary and with patient/family)
- Improvements to IT to better communicate patient wishes; advanced communication and advance care planning training for all staff
- Individual professions to take ownership of their role in ACP;
- Staff to have time to reflect and give/receive feedback in order to foster a culture where staff are informed, engaged and empowered regarding EoL conversations and documentation, but have confidence that wider issues are being tackled by management and are not their personal responsibility.

Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.

Further recommendations to facilitate EoL discussion and documentation also include:

- A clear and consistent place to record EoL discussions and decisions in hospital notes.
- A functioning EPaCCs system that allows end of life discussion and decisions to be shared with all those involved in a patient's care, for example, all hospital sites, community sites, ambulance services and the hospice.

References

- Calanzani, N., Higginson, I.J., & Gomes, B. (2013). Current and Future Needs for Hospice Care: An Evidence Based Report. *Cicely Saunders International, Kings College London*.
- Caplan, G., Meller, A., Squires, B., Chan, S., & Willett, W. (2006). Advance care planning and hospital in the nursing home. *Age and ageing*, 35(6), 581-585.
- Chitnis, X., Georgiou, T., Steventon, A., & Bardsley, M. (2012). The Impact of the Marie Curie Nursing Service on Place of Death and Hospital Use at the End of Life: Research Summary. *Nuffield Trust*.
- Croucher, K., & Rhodes, D. (2013). An Evaluation of End of Life Care Facilitator Networks. *NHS National End of Life Care Programme and Centre for Housing Policy, The University of York*.
- Department of Health. (2008). End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life. *Department of Health: London*.
- Department of Health (2009). End of Life Care Strategy: Quality Markers and Measures for End of Life Care. *Department of Health: London*.
- Fisher, S., Butler, C., & Holdsworth, L. (2012). A User Group Formed to Help Guide a Research Study Evaluating a Hospice at Home Service. *Pilgrims Hospices*.
- Gao, W., Ho, Y.K., Verne, J., Glickman, M., & Higginson, I.J. (2013). Changing patterns in place of cancer death in England: A population-based study. *PLOS Medicine*, 10(3): e1001410.
- Gerrard, R., Campbell, J., Minton, O., Moback, B., Skinner, C., McGowan, C., & Stone, P.C. (2011). Achieving the preferred place of care for hospitalized patients at the end of life. *Palliative Medicine*, 25(4), 333-336.
- Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine*, 18, 460-467.
- Guy's and St Thomas' NHS Foundation Trust (2015) AMBER Care Bundle Available from: <http://www.ambercarebundle.org/homepage.aspx> [9.6.15]
- Higginson, I., & Sen-Gupta, G. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine*, 3, 287-300.
- Jackson P & McKergow M (2007) The Solution Focus: The SIMPLE way to positive change. 2nd ed. *London: Nicholas Brealey Publishing*
- Kennedy L & Coombs C (2011) Uncovering Treasure: Influencing with Solution Focus. *InterAction Vol 3(2)*
- McKean E (2015) Solution Focus: a methodology for workshops to train hospital staff in end of life conversations and documentation. *InterAction (Under review)*.

Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.

Molloy, D.W., Guyatt, G., Russo, R., Goeree, R., O'Brien, B.J., Bedard, M., Willan, A., Watson, J., Patterson, C., & Harrison, C et al. (2000). Systematic Implementation of an advance directive program in nursing homes: a randomized controlled trial. *Journal of the American Medical Association*, 283(11), 1437-1444.

National Gold Standards Framework Centre (2015) Gold Standards Framework. Available from: <http://www.goldstandardsframework.org.uk/> [9.6.15]

NCPC (2012). Find your 1 %: Helping GPs to support people to live and die well. *NHS National End of Life Care Programme*.

NHSIQ (2013a) End of Life Care Update. Available from <http://www.nhsiq.nhs.uk/news-events/news/end-of-life-update.aspx>

NHSIQ (2013b) Economic Evaluation of the Electronic Palliative Care Coordination System (EPaCCS) Early Implementer Sites. Available from <http://www.england.nhs.uk/wp-content/uploads/2013/05/economic-eval-epaccs.pdf> [9.6.15]

NHSIQ (2014a) Lessons learned. Implementing an electronic palliative care and coordination system. Available from http://www.nhsiq.nhs.uk/media/2511469/epaccs_lessons_learned.pdf [9.6.15]

NHSIQ (2014b) Priorities of Care for the Dying Person. Duties and Responsibilities of Health and Care Staff –with prompts for practice. *Leadership Alliance for the Care of Dying People*.

MNT (2013). New research reveals terminally ill willing to talk about where they want to die. *Medical News Today*. Available from <http://www.medicalnewstoday.com/releases/261449.php> 5th June [9.6.15]

Revill, S. (2011). Evaluation of the Dying Matters GP Pilot Project. *Dying Matters Coalition*.

Robinson, L., Bamford, C., Beyer, F., Clark, A., Dickinson, C., Emmet, C., Exley, C., Hughes, J., Robson, L., & Rousseau, N. (2010). Patient preferences for future care - how can advance care planning become embedded into dementia care: A study protocol. *BMC Geriatrics*, 10:2.

Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., Howel, D., & Exley, C. (2012). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, 41, 263-269.

Schucksmith, J., Carlebach, S., & Whittaker, V. (2013). British Social Attitudes 30: Dying. *NatCen Social Research*.

University Hospital of South Manchester (2013) Sage and Thyme Training. Available from <http://www.sageandthymetraining.org.uk> [9.6.15]

Wye, L., Lasseeter, G., Percival, J., Simmonds, B., Duncan, L., & Purdy, S. (2012). Independent Evaluation of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset. *Centre for Primary Health Care, Department of Social and Community Medicine, University of Bristol*.

Appendices

- a. Workshop questionnaire example
- b. Workshop questionnaire data
- c. Workshop group work feedback summary
- d. Baby steps and feedback

Appendix a – Workshop questionnaire example

Advance Care Planning workshop

Pre/post-workshop questionnaire

Band: **Medical/Surgical/Community (circle)**

1. How confident are you in initiating conversations about preferred place of care with a patient?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

2. How confident are you in continuing these conversations?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

3. How confident are you initiating conversations about preferred place of care with family/carers?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

4. How confident are you in continuing these conversations?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

5. How confident are you in having conversations about DNACPR with patients?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

6. How confident are you in having conversations about DNACPR with family/carers?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

7. How confident are you that you know what to do when a question is asked that you are unable to answer?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

8. How confident are you in the documenting of Advance Care Plans?

Not very confident 1—2—3—4—5—6—7—8—9—10 Very confident

Appendix b – Workshop questionnaire data

	Q1		Q2		Q3		Q4		Q5		Q6		Q7		Q8	
Person	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
1	9	9	8	9	8	9	8	9	8	9	8	9	8	9	6	9
2	9		9		9		9		9		9		9		9	
3	3	6	3	6	3	7	3	6	5	6	5	7	5	7	3	7
4	3	4	5	5	4	4	5	4	1	2	3	3	4	5	2	4
5	3	3	2	3	3	3	2	2	1	1	1	1	3	1		1
6	3	5	3	4	4	5	3	5	2	3	2	3	8	9	3	8
7	2	5	3	3	2	3	2	2	2	2	2	2	1	3	1	2
8	6	6	2	7	6	10	6	10	2	7	6	7	2	7	2	8
9	9	9	9	9	9	9	9	9	9	9	9	9	9	9	9	9
10	5	6	5	6	5	6	5	6					5	7	2	7
11	8	8	8	8	8	8	8	8	5	8	5	8	8	8	5	5
12	8	8	8	8	8	8	8	8	9	9	9	9	10	9		5
13	7	5	7	8	7	8	7	8	4		4		5		3	
14	3	8	6	8	7	9	1	8	2	7	3	7	7	8	3	5
15	2	5	2	5	2	6	2	5	2	2	2	2	2	8	2	2
16	8	9	8	9	8	8	7	8	1	1	1	1	4	8	2	8
17	9	9	9	9	9	9	9	9	8	9	8	9	9	8	7	8
18	8	9	8	9	8	9	8	9	9	9	9	9	8	8	6	7
19	8	9	8	10	7	9	8	9	1	1	1	1	8	10	1	5
20	9	10	9	10	9	10	9	10	9	10	9	10	8	10	7	9
21	10	10	10	10	10	10	10	10	10	10	10	10	10	10	10	10
22	7	8	6	8	7	8	7	8	7	9	7	9	6	7	6	8
23	7	8	7	8	7	8	7	8	6	7	5	7	7	8	6	8
24	7	8	7	8	7	8	7	8	7	9	8	10	8	9	3	7
25	6	9	5	9	6	9	5	8		8			6		8	9
26	8	10	9	10	7	10	7	10					9	9	8	10
27	9	9	8	9	9	8	9	8	9	8	9	9	8	9	6	9
28	7	9	7	9	7	9	7	9	7	9	8	9	7	9	7	8
29	7	7	5	7	5	6	5	7	8	9	8	9	7	7	1	6
30	7	7	5	7	5	7	6	7	7	8	7	8	8	9	2	7
31	6	7	6	8	6	7	6	8	6	8	6	8	5	8	6	7
32	8	8	8	8	8	8	8	8	9	8	9	8	9	9	4	5
33	7	7	5	6	5	5	5	5	4	4	4	4	5	5	5	5
34	7	6	6	7	6	7	6	7	5	6	5	6	5	6	6	7
35	6	7	6	7	5	7	5	7	5	6	4	6	6	8	4	6
36	7	7	7	7	5	6	5	6	3	6	3	6	7	7	5	7
37	4	7	4	7	5	6	5	7	3	3	3	3	6	7	3	5
38	8	10	8	9	8	10	8	9	9	10	8	10	6	9	8	9
39	10	10	10	10	10	10	10	10	8	9	8	9	10	10	8	10

40	8	10	8	10	10	10	10	10	10	10	10	10	10	10	10	10
41	6	7	5	6	6	6	5	6	4	6	4	6	5	8	2	7
42	6	8	6	8	6	8	6	8	3	6	3	6	7	9	2	8
43	10	10	9	10	9	10	9	10	4	10	4	9	9	10	6	8
44	6	7	6	7	7	7	7	7	3	6	3	6	9	10	6	6
45	7	8	6	7	7	8	6	7	6	7	6	7	8	9	7	7
46	3	5	4	6	3	5	3	7	3	4	3	4	2	7	7	7
47	7	8	6	8	4	6	4	6	3	4	3	4	4	7	2	4
48	8	9	9	9	9	9	9	9	9	9	9	9	9	9	9	9
49	3	5	4	7	5	6	5	7	2	6	5	7	7	6	4	6
50	3	6	3	6		6	4	6		6		6	4	6		
51	4	8	3	7	5	8	4	6	5	4	4	4	8	6	8	3
52	6	8	4	7	6	8	6	8	6	7	6	7	4	5	4	6
53	5	5	5	6	5	6	5	6	1	2	1	2	9	9	2	2
54	8	8	8	8	8	8	8	8	8	8	8	8	6	8	7	8
55	5	8	4	7	4	7	4	8	4	9	4	9	6	8	4	6
56	6	9	6	9	7	9	7	9	3	7	3	7	7	9	3	7
57	9	10	8	9	9	10	9	10	3	8	3	8	5	9	4	5
58	8	8	8	8	8	8	8	8	6	7	6	7	8	8	7	8
59	5	8	5	8	5	8	5	8	2	7	2	7	4	8	3	8
60	6	9	7	9	7	9	7	9		4		4	10	10	6	7
61	9	10	9	10	9	10	9	10	9	10	9	10	9	10	1	8
62	6	6	6	6	5	6	6	6	6	5	6	5	7	8	2	7
63	6	7	6	7	5	7	5	7	3	7	4	6	8	8	4	8
64	6	8	6	8	6	9	6	9	6	8	6	8	6	8	5	8
65	9	9	9	10	9	9	9	9	9	9	9	9	8	7	6	8
66	4	5	5	5	4	5	4	5	5	7	5	6	8	8	6	6
67	6	7	7	7	4	7	5	8	3	6	3	7	5	6	7	8
68	10	10	10	10	9	9	9	9	10	10	10	10	10	10	9	10
69	7	6	6	6	5	6	6	7	2	3	6	3	7	7	4	6
70	9	9	7	9	7	8	7	8	8	8	8	8	7	8	7	9
71	8	9	8	9	8	9	8	9	8	9	8	9	8	8	5	8
72	6	7	5	7	4	7	4	7	5	8	6	7	7	8	6	6
73	7	8	7	9	8	9	8	9	4	9	7	9	9	9	4	7
74	9	9	9	9	9	9	9	9	9	9	9	9	9	9	1	4
75	5	5	7	6	6	7	7	7	7	5	8	6	8	7	5	6
76	10	10	10	10	10	10	10	9	9	9	9	9	9	8	7	7
77	4	6	4	6	4	6	4	6	2	6	2	6	8	8	3	6
78	8		7	9	7	9	8	9	9	10	9	8	7	9	5	9
79	9	9	9	9	9	9	9	9	2	5	2	5	7	7	1	5
80	9	9	8	9	7	9	7	9	8	9	7	10	7	9	3	9
81	8	8	7	8	8	8	6	8	9	8	9	8	8	7	7	6
82	9	9	9	9	9	9	9	9	8	8	8	8	8	8	9	9

83	6	7	6	7	7	7	7	7	10	10	10	10	3	3	2	5
84	6	6	7	7	6	6	7	6	5	6	6	9	7	6	5	7
85	5	7	6	7	5	7	5	7	5	6	9	5	7	4	4	9
86	4	7	5	7	5	6	5	6	8	9	4	7	6	7	3	6
87	8	9	8	9	7	9	7	9	7	9	7	9	6	9	8	9
88	7	8	7	8	7	9	7	9	8	9	8	9	9	10	5	8
89	7	9	9	10	8	10	9	10	9	10	10	10	6	8	1	5
90	5	8	5	8	6	8	5	7	6	7	5	7	6	8	3	4
91	3	5	4	6	3	6	4	7	6	8	7	7	3	4	3	5
92	5	6	5	6	4	6	4	6	4	6	4	6	3	5	3	5
93	3	7	2	7	4	8	4	8	7	8	6	8	2	6	3	6
94	6	8	6	7	6	8	6	8	5	8	5	8	5	7	7	8
95	6	7	5	6	5	6	5	6	8	8	8	8	8	10	3	5
96	5	8	3	8	3	7	3	7	8	8	8	8	5	6	5	9
97	3	5	3	5	4	5	4	5	5	5	5	5	3	5	5	6
98	7	8	7	8	7	8	7	8	7	8	7	8	7	8	7	8
99	7	7	5	5	4	4	5	5	5	3	3	3	4	4	4	4
100	7	8	8	8	7	8	8	8	7	8	7	8	6	8	1	3
101	3	4	2	3	3	8	2	8	3	4	3	7	4	4	1	4
102	6	9	6	9	6	9	6	9	1	3	1	3	10	10	6	6
103	6	5	6	6	6	6	6	6	3	6	3	6	6	6	3	6
104	9	9	9	9	9	9	9	9	1	1	5	5	4	4	1	4
105	10	10	10	10	10	10	10	10	5	10	5	10	10	9	3	8
106	8	8	8	8	8	8	8	8	5	5	5	5	10	10	1	5
107	3	6	3	6	7	8	7	8	3	5	7	5	3	7	3	5
108	1	5	1	5	1	5	1	5	1	5	1	5	1	5	1	5
109	2	5	2	4	3	5	2	4	1	3	1	2	1	5	1	2
110	5	8	5	8	5	8	5	8	2	8	6	8	6	8	4	8

Appendix c - Workshop group work feedback summary and themes

	<u>Advance care planning is working really well, what would that look like?</u>
Most common	Respectful of patients wishes
	Family/carer/patient/MDT fully aware/informed
	Clear/effective communication
	Involvement and inclusion
	Healthcare professional to explain the process of dying/consequences/risks (educate)
Quite common	Clear documentation
	Pain controlled/adequate meds/comfort
	Documents shared with patients, GP, ambulance crew, family members
	Patients have been provided with choices, realistic plans
	Time allocated
	Listening & giving time for patients to express themselves
	Acknowledge things may change/acceptance
	Patients can change their mind if they so wish (if clinically appropriate)
	DNACPR conversation
	Accessible, understandable, jargon free - all parties
	Reviewed and updated regularly
	Quiet environment - comfortable place - dignity
	Financial/legal matters in order
Least common	Support networks in place for those left behind after death - dependants
	Post death plan
	Patients plans for end of life care and wishes have been documented
	Planned care/after care plan to avoid unnecessary readmission
	Counselling support prior and follow up
	Dying conversation - advocate to initiate, to trigger right resources & agencies
	People believe it and follow it
	Things happen speedily and efficiently
	Patient to be told first
	Confidentiality maintained
	Open/honest discussions
	Clear what treatment would be acceptable in which situations
	Documents drafted with legal advice/witnesses
	State that one family member should be named to act as a representative
	Ensure the patient's wishes are not revoked by family members
	Ensure the patient's wishes are not made under duress from family/professionals
	Discussions from professionals at each point of change of condition/situation to reiterate wishes
	Communication made easier with family
	Good integration between community and acute hospice care
	Staff confident in complex discussions
	Able to seek information freely - designated person to ask
	Information in bite-size chunks
	Audit of process
	One identified person - link to MDT

	<u>What are the steps towards ideal advance care planning?</u>
Most common	Training and education
	Clear communication between doctors, nurses, patients and families
	Quality time - no interruptions
	Money/funding/budget
Quite common	Regular updates from IT re: new systems/simpler IT systems that talk to each other
	Availability of appropriate documentation
	Clearer documentation
	Take responsibility - talk about death
	Public awareness - information packs, GP surgery leaflets, approved persons to give advice e.g. libraries/pharmacies/clinics
	Reviewed and updated regularly
	Culture change in society regarding death – talking about it
Least common	All systems linked - GP, hospice, hospital, MDT
	3 CCG's same system
	Clearer plans for each patient
	Keeping plans consistent
	Clearer policies needed
	Acknowledge that raising death will be upsetting - Fight the discomfort
	Honesty
	Noting trigger factors for initiating discussion
	Media awareness of issues & how to access services/advice
	raising awareness
	Facilities - private room
	Communication skills - taught to ask appropriate questions
	Death education alongside sex education
	e-learning module mandatory for all
	Feedback (from patient & family)
	Sharing ideas with other trusts

Appendix d - Baby steps and feedback

	Baby step
1	'I would comfort the family and patient more on an emotional level as well as a professional.'
2	'To make more attempts to open conversation, listen more.'
3	'Discuss patient fears'.
4	'Do not be afraid. Work on accepting that death is part of life. Embrace a good death!'
5	'Make a will. Bucket List. Discuss preference with GP.'
6	'Home - I will discuss my preferences with my husband. Work - Read up about ACPs.'
7	'Effective listening'
8	'Properly informed ACP. Comprehensive care. Support.'
9	'Empathy from professional staff.'
10	'To look at DNR forms to see if they have been filled in properly and if not then see what the scope is for future practice.'
11	'Meeting patient for first time. stop. count to 10. then start to speak.'
12	'Learn more re [un-readable word].'
13	'Talk to my sister who is the only member of my family left and see what we would like if something happened to us.'
14	'I have two baby girls. I will look into providing for their future if something happens to me or my wife.'
15	'Attempt to discuss with terminally ill patients their insight with regard to their illness and prognosis.'
16	'Initiating conversations with patients and finding their worries and helping them as much as possible.'
17	'Finding out a bit more about patients particular concerns.'
18	'Warning shot conversations with patients who are nearing end of life.'
19	'Take some leadership in discussing end of life plan with patients.'
20	'I can be more proactive in conversations involving EoLC in cases I feel may be appropriate.' 'Confirming patient's NOK on the ward (when they are able to communicate) for future reference.'
21	'in clinic/ward - to ensure to give warning shot to patient as well as family in terms of prognosis. - empower patients/encourage them to decide what they want to be incorporated in their ACP.'

22	'I am going to encourage very ill patients on discharge to think about making an ACP.'
23	'Communication. D/w pt ideas and expectations.'
24	'Be brave enough to take the initiative and discuss end of life with my patients and bring it up with my seniors.'
25	'Better communication with patients and relatives around death and dying and to document discussion well in notes.'
26	'Ensure good communication with patient and family in admission for elderly patients.'
27	'Ensure direct communication between patient, family and medical team.'
28	'1. Have a DNR d/w relevant patients during morning ward rounds. 2. For those with poor prognosis indicate a wider discussion -MDT -Family mtg with patient.'
29	'I will be honest with my patients in primary care who are gradually deteriorating and discuss worst case scenarios.'
30	'Try to take more time with patients to discuss advance planning before it becomes an urgent issue.'
31	'Teach about end of life symptoms.'
32	'Consider end of life care planning in outpatients rather than only in hospital.'
33	'Undertake and initiate warning shots/early conversations. Spend some time with palliative care.'
34	'Earlier discussion of care planning in out patients if end stage but stable COPD.'
35	'Introduce the Amber Care Bundle at home. Re-invest in the message in a bottle idea.'
36	'When seeing patients, especially on ward rounds and through admission to pay particular attention to if they have ACP or DNACPR etc. in place or if appropriate.'
37	'Start end of life discussions earlier with patients living at home.'
38	'Ensure the most helpful facts, wishes, i.e. future plans are documented and improved communication on the ward especially notes and verbal between staff.'
39	'Better paperwork. Communication.'
40	'Better handover of end of life care daily.'
41	'Better communication with doctors re ceiling treatment/plan of care.'
42	'Clear documentation in notes of discussions and with who.'
43	'Initiate conversations about advanced care plans more often in clinic. Document formally my own wishes.'
44	'I would like to work closer with hospice/experts in palliative care to gain more experience in advance care planning.'

45	'I will try to take staff with me when I have these discussions.'
46	'Encourage more open discussion around death/dying. Use end of life conversation form'
47	'Investigate the EPR and use. Use the end of life conversations form and encourage Drs to use it too.'
48	'Try to open up conversations with relatives. s/w ward re EPR'
49	'Speak to staff nurses and doctors about initiating end of life conversations.'
50	'Talk to my patients about their end of life wishes. Start initiating end of life conversations early with my patients and start regular use of <i>Record of end of life conversation</i> document.'
51	'Discuss with my family and husband about their end of life wishes. The form re end of life conversations to be used for all patients on our ward. Make a will.'
52	'Better communication. Be more willing and confident to discuss the end of life care and plans. Check patients/relatives understating of care and plans.'
53	'to incorporate Dying Matters into conversations to start to record patient wishes so ACP may be easier to do when appropriate.'
54	'Look at EPR to find Share My Care and EOLC info.'
55	'Make a Will. Not to be afraid to use the words death and dying when speaking to patients.'
56	'Visit local hospice or shadow palliative specialist to gain more understanding about dying over and above supplying equipment.'
57	'To not be afraid of having a conversation with a patient regarding death and their wishes and advising them as necessary.'
58	'To find out if there is a leaflet/poster and sticker for fridge. Get poster to display on unit.'
59	'To be more open with patients about 'dying' rather than facilitating their discharge.'
60	'To find out if there is a leaflet/poster and sticker for fridge. Get poster to display on unit.'
61	'communicate with family and patients their wishes end of life care planning.'
62	'Personal baby step- rewrite my will - will appoint guardians for my children. Professional baby step - to revisit ACP conversations with patients/families more often than I do at present. Incorporate relevant use of leaflets' dying matters' that I have seen today.'
63	'Remember to remind KCHT staff about the end of life conversation plan. Use awareness gained of acute trust processes to encourage us all to work together with haring of info. Use Lucy's quote 'we all die - but not all get STDs' to encourage use of Dying Matters leaflets.'

64	'Promote sharing of information across health/social care services including diagnosis, prognosis planning, discharge, support needed and discussions made by patient/family/HCPs re end of life care.'
65	'I will speak to my managers to source funding to get hold of leaflets to place on medical wards to give patients info on dying.'
66	'Ensure that the patient and relatives have understood what has been said.'
67	'Better communication. Be more willing and confident to discuss the end of life care and plans. Check patients/relatives understating of care and plans.'
68	'Try to offer more support to family and patients to make sure they know what is happening with the dying patient.'
69	'Take time to find out what the patient's wishes are and ascertain what they understand about their prognosis.'
70	'Discuss/open the conversation about plans for the future with patients/family.'
71	'Discuss death openly as part of life.'
72	'Education of relatives on what to expect in the end of life and the main aims are symptomatic control and preserve dignity.'
73	'Communicate.'
74	'Ask the patient or family if there is anything else I can do to help them.'
75	'Speak to patients more openly and invite them to tell me what they want and expect.'
76	'To spend more time talking to the person.'
77	'Increase knowledge of community options.'
78	'Ensure I tell the other staff members anything relevant to the future for the person.'
79	'Openness/honesty when communicating.'
80	'Talk to patient about wishes of end of life when someone is poorly and before EOLC in place.'
81	'Maintain good pain relief.'
82	'Feel more confident when dealing with relatives of a patient who has been newly diagnosed and is palliative.'
83	'Communicate with the patient about his/her wants and needs. Just because he/she is sick doesn't mean that they can't decide what is right and best for them as a person. if they have the capacity to do so they should have their own say.'
84	'Enquire about how to get a patient's DNACPR status identified on Patient Centre.'
85	'Listen to the patient and support them with their decisions.'
86	'Confidence to talk to patients and ask about ACP.'
87	'Incorporate into staff values and behaviours. Never miss an opportunity to support/shape and influence.'

88	'Detailed discussions with patient, family and carers.'
89	'Support staff in providing time to listen to patients to provide care.'
90	'Endeavour to understand processes. Advocate for patients and relatives.'
91	'Complete an audit including patient and family feedback to improve the process overall.'
92	'1. Understand the process 2. Ensure it is designed for patients 3. Feedback from patient.'
93	'Discuss with patient their understanding of situation once medics have confirmed end life stage. Try and ascertain patients own discharge destination at soonest opportunity rather than await palliative input.'
94	'Take the opportunity to discuss end of life care planning with the patient/relative and then actively discuss with medical team to ensure that CPR status is confirmed within the time frame of my working day.'
95	'1. Better communication with patients/family 2. Share ideas with colleagues 3. Challenge medical decision 4. Discuss with my family about ACP 5. Write my will.'
96	'1. Look at how it is documented in the trust and consider looking at getting clear documentation 2. Encourage professionals to think about ceiling of treatment when appropriate.'
97	'Communication with medical teams. Make own ACP.'
98	'Discuss with patients/relatives during their admission to raise awareness and encourage planning. Communicate with GPs. Educate my team. Look out for ACP leaflets/websites and put out on wards.'
99	'Talk to my partner re death. Read up more on the end of life care planning in UK and abroad.'
100	'Initiate 'difficult' conversations as soon as possible so opportunities are not lost.'
101	'Obtain from Health Care Professional at all levels (HCA to Consultant) the real life procedures that can be written into a valid policy for ACP.'
102	'Ensuring doctors/MDT have spoken to families and patient and that they are all fully informed and have no questions.'
103	'Clearer objectives and more personal confidence in approaching patients and discussing in advance the end of life care plan.'
104	'Ensure the end of life board clarify if nurses can complete the DNR form.'
105	'Check if fast track patients have DNR paperwork completed.'
106	'Ask families at complaint meetings what improvements can be made to EoLC and feedback to clinicians involved.'

Follow up email sent to gather feedback on the baby step

Thank you for attending the Advance Care Planning workshop in [month]. I hope you found it useful. In order to assess the impact of the sessions I would appreciate you taking a few minutes of your time to let me know whether you have been able to move forward with the baby step you hoped to achieve.

At the end of the session you set the baby step of [...].

How have you got on with this step so far?

If you were able to achieve it, what did you do?

Now this baby step has been achieved, what are your expectations for the future?

If you were not able to achieve it were you able to do anything else?

What do you need to do to help achieve the baby step?

What will be helpful?

How will other people know you need help?

Thank you for taking time to answer the applicable questions and let me know if there is any way in which I or someone else can help you to continue to increase your confidence in end of life conversations and documentation.

Many thanks

Emily McKean

End of life care facilitator

Pilgrims Hospices East Kent

	Baby step feedback via email
1	Hi the workshop helped me increase my confidence when helping the family of an end of life patient. It enabled me to understand the need for more information for the family. Thank you for the informative course.
2	I am quite happy how things are, I already was quite proactive with starting end of life discussions, and whilst I wrote down my "babystep" to start such a discussion with some patients earlier, there has since then not been a patient where I wouldn't have raised the issue anyway, so time will tell if I really have become more proactive (basically when the first patient comes along, where I'd have shied away. I don't think that I need help with this at the moment.
3	Many thanks for an interesting training workshop Thank you for attending the Advance Care Planning workshop in[x]. I hope you found it useful. In order to assess the impact of the sessions I would appreciate you taking a few minutes of your time to let me know whether you have been able to move forward with the baby step you hoped to achieve. At the end of the session you set the baby step of 'Try to take more time with patients to discuss advance planning before it becomes an urgent issue.' How have you got on with this step so far? I have managed to try this with one patient –

	<p>this is the only patient I have had who was appropriate to try this with.</p> <p>If you were able to achieve it, what did you do? I tried to raise the issue with a patient admitted to an ICT bed, however, she found it difficult to think about planning ahead due to her low mood.</p> <p>Now this baby step has been achieved, what are you expectations for the future? I will continue to raise the issue of advance planning with appropriate patients.</p> <p>If you were not able to achieve it were you able to do anything else? I will keep trying to assist this patient to make decisions regarding her care and provide appropriate support to enable her to do this.</p> <p>What do you need to do to help achieve the baby step? I will need to work closely with my colleagues to ensure we are all working towards the same goals.</p> <p>What will be helpful? Clear communication between all team members and at MDT meetings.</p> <p>How will other people know you need help? I will ask them for help or raise issues at MDT meetings.</p>
4	<p>I'm afraid i have not been able to complete my goals- work load on [ward] is so high to try and find time to teach/enable yourself time to investigate other areas of practice is so difficult. However, after the study day discussions i do feel more at ease in discussing issues with the teams involved and also have a better understanding of the fast track and continuing care check list forms.</p> <p>Thank you for your time on that day.</p>
5	<p>I have had variable success in trying to take people with me when I have difficult decisions with patients. I had one nurse asking to spend time with me during which we saw a few patients where difficult decisions were required. I guess the thing that is a barrier is staff on the wards being able to free themselves up to join me on patient visits.</p> <p>I think to improve this situation, I will now be more aware of staff feelings and try to follow up with them for a de-brief where I know these situations have arisen.</p> <p>Once again, I did like the approach you used for these sessions and do think that with the busy environment of the hospital, making big changes is a tall order whereas baby steps over time will achieve the same outcome (hopefully!)</p>
6	<p>I am aware that it is Age UK that do the yellow containers and fridge door notices but having problems getting posters to display in the unit.</p> <p>Will keep at it though.</p>
7	<p>Thank you for the email, I did find the workshop useful.</p> <p>I have attempted my baby step and faltered slightly due to the negative reaction from the MS patient. I think it did provide the patient the space to discuss future plans but she was not ready to address it. I am hoping that having the brief discussion will have facilitated the start of planning for the future for the patient and that she knows she is able to talk to therapists about her wishes.</p> <p>I am planning to discuss with my senior colleagues introducing this kind of discussion into the MS and Parkinsons group.</p>
8	<p>On all sessions with KCHT staff, I certainly ensure that I remind (or inform, as a lot are not already aware) of the KCHT resources around ACP, including the end of life conversation plan, available to them within their Staff Zone.</p>

	My expectation is to continue seeking opportunities to increase people's awareness of ACP, especially ways of improving confidence around these very important discussions. I continue to encourage use of Dying Matters resources.
9	[x] will be taking this to the end of life board again in 2015. There were already some discussions but nothing confirmed. I will ask [x] to update you in the future.
10	So far we have only had one patient in that situation. (Many of our end of life patients are too ill to travel by the time they are deemed "TLC", and needing medical care before that). She did have dementia, but I did speak with her and her daughter to clarify their plans at an earlier stage than I might have before attending your study day. She decided to go to a nursing home as her daughter was unable to support her at home. I plan to keep practising! We do occasionally get people in the situation where they could return home and in the past there have been delays when the patient was undecided, so if I sit down with them and discuss their concerns and options for support, it might help them decide and expedite discharge also. I will probably need to liaise with the Palliative Care Nurse to identify what help is out there for individual patients.
11	It has been so busy at work that I haven't even had time to think about it. My apologies. Hopefully things will become less hectic soon.
12	We are still planning to carry out the audit but as yet have been unable to start due to winter pressures and staff leave. We hope to do this in the new year.
13	Thank you for attending the Advance Care Planning workshop in [x]. I hope you found it useful. In order to access the impact of the sessions I would appreciate you taking a few minutes of your time to let me know whether you have been able to move forward with the baby step you hoped to achieve. At the end of the session you set the baby step of '1. Incorporate into staff values and behaviours - recruitment process. 2. Never miss an opportunity to support/shape and influence.' How have you got on with this step(s) so far? Tested values through band 6 interviews – need to incorporate now into generic questions for interviews If you were able to achieve it, what did you do? Now this baby step has been achieved, what are your expectations for the future? Core interview questions to test values for staff at interviews If you were not able to achieve it were you able to do anything else? What do you need to do to help achieve the baby step? What will be helpful? How will other people know you need help? This will be shared with ward managers at weekly meetings when it is ready.
14	Be Honest in communication How far have got to achieving this step? What I have learnt is that honesty pays, but also there is need to keep in mind those to whom you are being honest as not everyone wants to hear the truth, so does that mean truth comes in different formats/shades? I fundamentally believe being honest when communicating helps eliminate confusion and distrust. When I have been able to achieve it, I also have had to gauge what to say how to say it and when. This is a work in progress.

	<p>Future – Keep leaning to soften how I say it so it's less threatening to others.</p> <p>I thank you for helping me learn a bit about myself.</p>
15	<p>Life has changed for me and I have been able to take those steps though largely due to my own personal loss. I have recently cleared out all mums things, three years after her passing. Though painful I focused on the joy and gratitude that she was and still is part of my life. Rather than try to put it all out of my mind, I have reflected a lot and feel her close to me and part of me still. We never really completely lose our loved ones. Being a spiritual person I have begun to read a lot on the topic and have no doubt that death is not the end, just another chapter. Unfortunately our western culture is so shut off to these things. I wish we could talk about death more, like planning a holiday and plan for exactly what we want. It being a taboo topic is not conducive to a good death. I missed that opportunity with mum but the experience has encouraged me to do things differently if and when I am in that situation again. Life can be more scary than death, I have decided to embrace both. I have left the past behind, live for today and plan for tomorrow. I don't worry about the small stuff anymore. Wonderful things have happened to me now that I have let go and freed myself from burdens we could look back on whilst on our deathbeds and think them stupid. I am happy, mum will always be with me, I can support people facing death with compassion, love and calm. I feel strong and that I can face challenging situations.</p> <p>This probably isn't the reply you were expecting but it's truth straight from the heart.</p>

Hospice facilitation of training EKHUFT healthcare professionals in end of life care discussions and planning.