The Evaluation of the Implementation of the Advance / Anticipatory Care Process (ACP) in the Demonstration Site in North Ayrshire.

FINAL REPORT

31st March 2013

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The Evaluation of the Implementation of the Advance/Anticipatory Care Process (ACP) in the Demonstration Site in North Ayrshire

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1. Executive summary

Advance and anticipatory care planning (referred to here as "ACP") promote an inclusive, collaborative and proactive approach to planning for future care needs. There is evidence that when implemented effectively, ACP can deliver significant benefits for patients, families and professionals including increases in hope and satisfaction with care and reductions in avoidable hospital admissions.

A demonstration site, focusing on patients with palliative care needs, was established in North Ayrshire in November 2010 to engage with local staff and promote the use of the ACP process. This was to be achieved principally through the provision of education and the development of documentation. The overall aim of the demonstration site (referred to in this report as "the project") was to reduce avoidable admissions to hospital by April 2013.

The evaluation reported here set out to assess the impact of ACP training on knowledge and practice of participants, and the impact of the ACP demonstration site on attitudes and behaviours of staff (including GPs), rates of completion and enactment of ACP documents and outcomes for patients.

Three main methodologies were utilised: an Electronic Questionnaire, Semi-structured Interviews and a Documentation Audit. The study population was "All Health Care Professionals (HCPs) who have participated in the implementation project in the North Ayrshire Demonstration Site".

ACP training was attended by health and social care staff, and staff from the independent sector, from across NHS Ayrshire & Arran. Respondents acknowledged that the training had helped them in their practice and reported being more able to engage in the ACP process and more able to complete the ACP documentation.

The participants in the semi-structured interviews had no difficulty recalling examples of cases where the presence of an ACP led to the achievement of patients' preferred outcomes. ACP is already delivering preferred outcomes for patients across the different clinical settings in the demonstration site. There is evidence that the use of ACP is leading to the prevention of some unnecessary hospital admissions and is facilitating the discharge of appropriate patients from hospital back to the community.

The review of the documentation has indicated an overall understanding of the process of ACP by staff in the different practice areas examined. Nevertheless there was a lack of consistency in the use of the documentation within the demonstration site with different versions of the ACP document in use and variation in the extent to which ACP is used and forms completed.

A list of recommendations is provided to support the future quality and effectiveness of ACP practice in the North Ayrshire demonstration site.

2. Context and Remit

2.1. The policy background to ACP implementation

In 2008 Audit Scotland highlighted significant inequities in the provision of palliative and end of life care across Scotland. Other research has shown that while most people with a life-limiting illness state a preference to die at home, the majority die in hospital (O'Brien and Jack 2010). In order to improve the quality of palliative and end of life care provision, the Scottish Government (2008) developed Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland (LADW), the aim of which was to ensure the delivery of high quality palliative care based on need rather than diagnosis or place of care.

LADW detailed a number of actions for NHS Boards to implement to meet the palliative care needs of people nearing the end of life. Co-ordinated care planning and effective communication between professional groups and across agencies were identified as integral to this process (The Scottish Government 2008). To give further support to NHS Boards around the integrated care of people with palliative care needs, Living and Dying Well - Building on Progress (LADWBP) recognised advance/anticipatory care planning (ACP) as a robust method of effective and efficient planning, co-ordination and delivery of appropriate care based on the needs of the individual dying person (The Scottish Government 2011). In addition LADWBP recognised that ascertaining the dying person's preferred place of end of life care may, as part of the ACP process, lead to fewer admissions to hospital near the end of life when this has not been the chosen place of care/death (The Scottish Government 2011).

According to the Scottish Government Health Delivery Directorate Improvement and Support Team (2010), advance and anticipatory care planning both promote an inclusive, collaborative and proactive approach to planning for future care needs. Advance Care Planning is commonly used to refer to end of life care while Anticipatory Care Planning is usually applied to people living with long-term conditions. However in practice, the two terms are frequently used interchangeably. Importantly, there is evidence that when implemented effectively, ACP can deliver significant benefits for patients, families and professionals including increases in hope and satisfaction with care, and reductions in avoidable hospital admissions (Davison and Simpson 2006; Baker, Leak, Ritchie et al 2012).

2.2. Evaluating quality in health services – A Framework

In its landmark document "Better Health, Better Care", the Scottish Government (2007) committed itself to improving the quality of health care provision as the principal means of improving health for the people of Scotland. The Healthcare Quality Strategy clarified this commitment by proposing a vision for healthcare in Scotland which consists of "*millions of individual care encounters that are consistently person-centred, clinically effective and safe,* *for every person, all the time*" (NHS Scotland (2010). This statement points towards a clear definition of what we mean by quality health care. Quality health care is Person-centred, Safe, Effective, Efficient, Equitable and Timely.

It is essential that the evaluation of any healthcare project consider the extent to which it demonstrates these criteria. It should particularly focus on three questions:

1. The extent to which service users and their views are placed at the centre of service provision;
2. The extent to which staff members are enabled to provide the right care in the right way; and
3. The extent to which measurable improvements in care outcomes are being achieved.

The report presented here will provide some broad answers to these questions. In particular it will comment on those aspects of service provision recognised by The Health Foundation (2012) as challenges to quality improvement, namely:

1. Design and planning;
2. Organisational and institutional contexts, professions and leaderships; and
3. Sustainability, spread and unintended consequences.

This report is specific to the project being evaluated but contextualised within the wider sphere of the Healthcare Quality Strategy examined through the theoretical lens of the Health Foundation's quality improvement standards. This means that it will not only comment on the progress made by the project in terms of reducing avoidable admissions and enabling people to die in their preferred place, but also make recommendations for how sustainable improvements in quality can be achieved.

2.3. Background to the implementation of the Advance/Anticipatory Care Planning process in the demonstration site in North Ayrshire

In 2008, the Hospital Standardised Mortality Ratio (HSMR) Case Note Review for NHS Ayrshire and Arran found that a high proportion (30%) of acute hospital deaths were of end of life patients. As a result, Palliative and End of Life Care was identified as a key area for improvement work (NHS Ayrshire and Arran 2012). A further case note review of patients who attended Crosshouse Hospital and died between February and May 2010 confirmed that of 51 admissions to hospital, at least 29 (57%) were avoidable. Those 29 patients spent a total of 420 (potentially avoidable) days in hospital. Furthermore, only 5 of the 51 patients admitted were discharged elsewhere and 46 (90%) went on to die in the hospital. Significantly, there was no evidence of advance or anticipatory care planning in the case notes of 45 (88%) of admissions (Goodwin and Connolly 2010).

In response to these findings, a demonstration site was established in North Ayrshire in November 2010 to engage with local staff and promote the use of the ACP process. This was to be achieved principally through the provision of education and the development of documentation (Appendix 1). The overall aim of the demonstration site (referred to in this report as “the project”) was to reduce avoidable admissions to hospital by April 2013.

In 2010 NHS Education Scotland (NES) launched a national training programme for ACP. This consisted of 7 hours of training divided into two distinct themes. The first theme was ‘The principles of ACP’ and the second ‘ACP in practice’. The themes and the individual session titles can be seen in Figure 2.1 below:

Theme 1: The Principles of ACP	Theme 2: ACP in Practice
What is advance care planning? Timing and triggers Ethical decision making	Communication skills : Theory Communication skills : Practice

Figure 2.1: Components of NES national training programme for ACP

As part of the implementation of Advance Care Planning as an approach to enabling more people to remain at home to die, the North Ayrshire demonstration site began by inviting all health and social care professionals to attend the ACP training (ACPT) described above. Two half-day training sessions were provided (Part A and Part B), corresponding to Themes 1 and 2 of the NES model. Part A of the ACPT was aimed at all professional carers who support people with advanced, life-limiting illness while Part B was only for professional carers who had a responsibility for discussing ACP with dying people and completing their ACP documentation.

The ACPT took place at a number of venues across the demonstration site. Each session was facilitated by two healthcare professionals who had received training, as part of the NES ACP project, on how to utilise the national training materials in education sessions. The facilitators distributed questionnaires by which they gathered demographic details of those attending ACPT as well as evaluations of the training received.

In addition to ACP training, a Clinical Improvement Practitioner post was also created (with funding for 7.5 hours from the Change Fund (ROPC)) to facilitate the implementation of ACP and associated initiatives in the demonstration site. The effectiveness of this post was to be demonstrated by:

- Increased evidence of changes and improvements in practice
- Reduction in avoidable hospital admissions
- Recommendations for further developments
- Clear exit strategy for continued sustainability

2.4. The original aims of the evaluation

The original aims of this evaluation, as set out in the project brief, were to evaluate the following:

- Reduction in avoidable admissions and visits to hospital
- Achievement of the patient's preferred place of care

During the preparation of the bid, it became apparent that it would not be possible to specify exactly how many hospital admissions might have been prevented by the implementation of ACP in the demonstration site. This was mainly because of the numerous other factors, which might also be influencing hospital admission, as well as the anticipated difficulty identifying a large enough number of cases to draw statistically significant conclusions (NHS Ayrshire and Arran 2012). Instead, the focus of the proposed evaluation was on the use of qualitative measures of changes in behaviour and practice, together with case vignettes, to demonstrate changes in practice.

2.5. The evaluation approach adopted

The proposal submitted on 24th August 2012 set out to evaluate the implementation of ACP in the demonstration site by an investigation consisting of four elements:

1. Examining data already gathered by the implementation team
2. Repeating baseline audits, which were deemed appropriate by the evaluation team
3. Collecting new data, both quantitative and qualitative, by capturing the experiences of ACP in a range of professionals working within the implementation site as well as those who had undertaken the training provided as part of the project
4. Combining and critically evaluating all the data to provide a detailed final report as well as recommendations for future developments.

This approach was subsequently expanded and refined to consider the following six aspects:

1. Impact of ACP training on knowledge and practice of participants
2. Impact of the project on attitudes and behaviours of staff
3. Impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation
4. Impact of the project on outcomes for individual patients
5. Attitudes of GPs towards ACP, attitudes of GPs towards the project as a whole and experiences of GPs of completing/using ACP
6. Impact of the project on rates of completion and enactment of ACP

A detailed proposal was approved by the Research, Development and Evaluation Office at NHS Ayrshire and Arran on 6th December 2012. Data collection took place in January and February 2013.

3. Methods

The six elements of the approved proposal were to be achieved using three main methodologies: Electronic Questionnaire, Semi-structured Interviews and a Documentation Audit. The study population was "All Health Care Professionals (HCPs) who have participated in the implementation project in the North Ayrshire Demonstration Site".

3.1. General approach

Electronic questionnaires (or paper substitutes where necessary) were distributed to all participants in the ACP training (ACPT), which was delivered as part of the implementation project. A convenience sampling approach was used to identify suitable subjects for the semi-structured interviews and the documentation audit. Efforts were made to achieve a diverse sample, representing a range of professional groups, care settings and degrees of involvement in the implementation project.

3.2. Questionnaires

This methodology was used to evaluate the Advance Care Planning training (ACPT) that took place within the demonstration site. Some data were collected by the implementation team providing the ACPT and this is presented later in the report. However more contemporary data were generated by questionnaires sent by the evaluation team to all those who had attended ACPT in 2011 and 2012.

The main aim of the questionnaires was to determine the impact of the ACPT on the confidence and competence of attendees to engage with the ACP process and to complete ACP documentation. Secondary aims were to explore the need for further ACPT as well as determining the numbers of ACP documents that had been completed by professionals since they attended the ACPT.

On consultation with the implementation team it was believed that sending an electronic questionnaire to all ACPT attendees would generate the information required to meet the aims of this part of the evaluation project. The questionnaire was developed in conjunction with the implementation team and was piloted with members of the implementation and evaluation teams to ensure that it generated the required data (Appendix 2).

A list of all ACPT attendees was made available to the implementation team. There were 250 professionals who took either Part A and/or Part B of the ACPT in the period 2011-2012. Email addresses of 174 attendees were included in the attendee list. To protect anonymity the evaluation team sent the electronic link to the survey to the implementation team who then sent it out to all ACPT attendees. There were 74 ACPT attendees where no email address was available. A paper copy of the questionnaire was sent to the workplace of each attendee. Included with this was a stamp addressed envelope requesting that the completed questionnaire be returned to the evaluation team at UWS.

3.3. Interviews

The original intention was to conduct ten semi-structured interviews, consisting of four with Care Home nurses, four with Community nurses and two with General Practitioners. In the course of the evaluation, one of the GPs selected was consistently unavailable, so only nine interviews actually took place (see Table 3.1).

Interviews were based on a pre-determined topic guide which covered three main domains:

1. Impact of the project on attitudes and behaviours of staff
2. Impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation
3. Impact of the project on outcomes for individual patients

Each interview lasted 30 to 45 minutes. Participants provided informed consent before taking part. Interviews were taped, then transcribed and analysed using simple thematic analysis. Participant confidentiality was assured by identifying the recordings and transcripts only by an anonymous study number.

Participant number	Professional group	Care setting
N001	Registered nurse	Care Home A
N002	Registered nurse	Care Home A
N003	Registered nurse	DN Team A
N004	Registered nurse	DN Team A
N005	Registered nurse	Care Home B
N006	Registered nurse	Care Home B
N007	Registered nurse	DN Team B
N008	Senior carer	DN Team B
D001	General Practitioner	GP Practice A

Table 3.1: Details of interviews conducted as part of the evaluation

3.4. Review of documentation

It was originally intended to review 24 completed ACP documents. These were to consist of six from each of two care homes and six from each of two District Nursing teams. In practice, only twelve ACPs were made available for examination (see Table 3.2).

Care Setting	Target number of completed ACPs	Actual number of completed ACPs	Reason for shortfall
Care Home A	6	6	N/A
Care Home B	6	3	These were the only completed ACPs available at the time of the visit to this site
DN Team A	6	1	The practice in this team is for ACPs to be patient-held. Therefore no completed ACPs were retained by the team (except for one which had been copied to a different format for a vision-impaired client)
DN Team B	6	2	These were the only completed ACPs available at the time of the visit to this site
All	24	12	N/A

Table 3.2: Details of ACP documents reviewed as part of the evaluation

A pre-determined checklist (Appendix 3) was used for all the audits. This highlighted the parts of the document, which were or were not completed, any evidence of periodic review and any evidence that the decisions documented were acted upon. Reviewers were also asked to estimate the overall percentage of the form that was completed.

4. Findings

The findings of this evaluation are presented in Sections 4.2, 4.3 and 4.4. Discussions of the findings and presentation of the conclusions and the report's recommendations can be found in Sections 5, 6 and 7 respectively.

4.1. Overview

The findings from the questionnaires are divided into two main sections:

- Data collected by the North Ayrshire Demonstration Site Implementation team and
- The current evaluation of the ACP training

The findings of the semi-structured interviews are presented in three blocks:

- The opinions, attitudes, practices and experiences of Care Home staff
- The opinions, attitudes, practices and experiences of District Nurses
- The opinions, attitudes, practices and experiences of General Practitioners

The findings of the documentation audit are presented in a single section.

4.2. Findings from questionnaires

Data collected by the North Ayrshire demonstration site implementation team

The evaluation team was provided with the following data which had been collected in the course of the rollout of ACP training in 2011 and 2012:

- The overall numbers and demographics of people who attended Parts A and B of the training
- The number of people who accessed part A of the training via LearnPro
- Course evaluations from 25 Part A attendees from 2011
- Course evaluations from 96 Part A attendees from 2012
- Course evaluations from 39 Part B attendees from 2011
- Course evaluations from 87 Part B attendees from 2011
- Course evaluations from 10 attendees who attended a condensed version of Part A & B course in September 2012
- A report relating to the content and delivery of the ACPT training in 2011 and 2012.

Data provided by the implementation team - findings

Numbers of Attendees and Demographic Data.

The number of people attending parts A and B of the ACPT can be seen in tables 4.1 and 4.2 below:

2011 – PART A	**2012 – PART A –**
Care Home Staff – 65	Care Home Staff – 13
NHS Staff- 34	NHS Staff – 110 (including 100 on LearnPro module)
Social Services Staff – 06	Social Services Staff – 15
Total 105	**Total 138**

Table 4.1: Number of people attending Part A of the ACPT

2011 – PART B	**2012 – PART B**
Care Home Staff – 44	Care Home Staff – 15
NHS Staff- 14	NHS Staff – 21
Social Services Staff – 04	Social Services Staff – 16
Total 62	**Total 52**

Table 4.2: Number of people attending Part B of the ACPT

The data collected also captured the work designation of attendees from care homes and the NHS. These can be seen in Figures 4.1 and 4.2 below. There were no designations identified for the Social Services attendees.

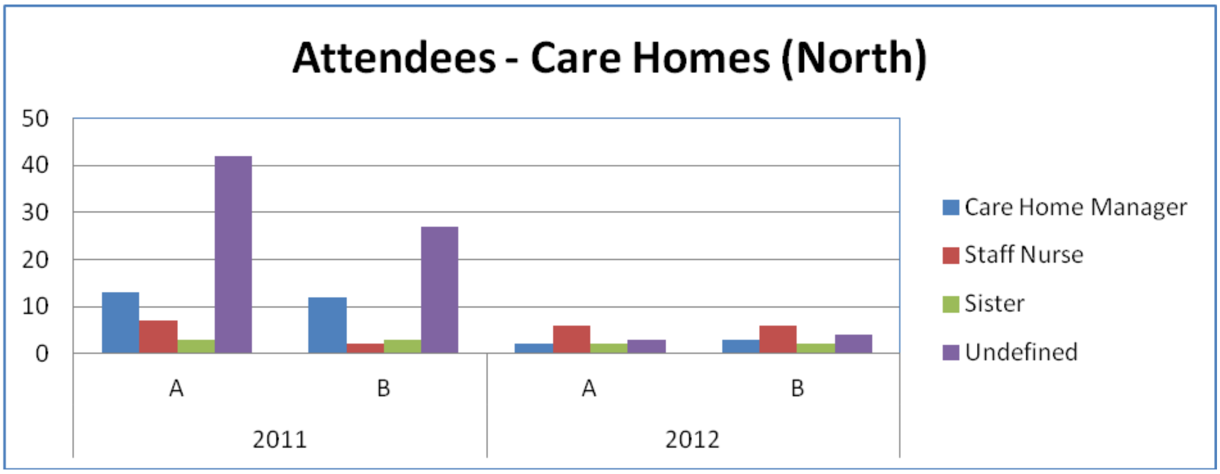

Figure 4.1: Work designations of ACPT attendees from care homes

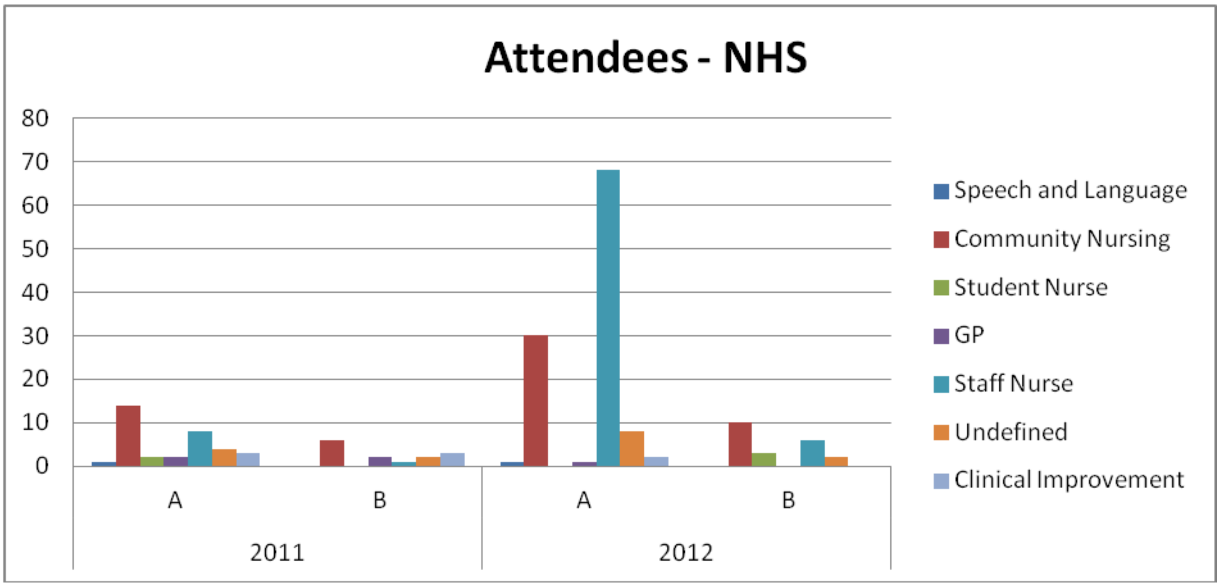

Figure 4.2: Work designations of ACPT attendees from NHS settings

In addition to the designations of attendees who came to the taught sessions there was also data provided on the designations of those who took the LearnPro module. This can be viewed in Table 4.3.

Designation	2011	2012			
		Quarter			
		1	**2**	**3**	**4**
Bank					
- ***Nursing***	2	0	0	1	0
- ***Nursing Assistant***		0	0	2	0
Clinical Improvement					
- ***Nursing***		0	0	0	1
- ***Practice Education Facilitator***		1	1	0	1
CW&SH Services					
- ***Nursing***		0	0	1	0
Domestic Services					
- ***Domestic Assistant***		0	0	2	1
GP					
-GP		0	0	0	1
Care of the Elderly					
- ***Nursing***	2	2	0	5	3
- ***Nursing Assistant***		1	0	0	0
Remote & Rural					
- ***Nursing***		2	2	1	1
Community Nursing					
- ***Nurse Assistant***		0	1	0	0
- ***Nurse***	3	10	8	3	2
- ***Management***		3	4	1	0
Theatres					
- ***Nursing***		0	0	1	0
Mental Health					
- ***Nursing***		0	2	1	1
- ***Physiotherapist***		0	1	0	0
Emergency/Urgent Care					
- ***Nursing***		0	0	1	0
Medical Specialties					
- ***Nursing***	1	0	10	12	2
Total no. of LearnPro sessions completed	**100**				

Table 4.3: Work designations of those who undertook the LearnPro module

Attendees' evaluations of ACPT Part A

Overview

The evaluation form for Part A of the ACPT training was divided into four sections:

1. Purpose of the training
2. Baseline knowledge
3. Experience of ACP
4. Training Evaluation

The aim of the first three sections was to find out why people had attended the course and what they already knew about the advance care planning process and documentation. The fourth section was completed after the course and aimed to find out what attendees had learned and whether they felt the course was of good quality and met their learning needs.

It is noted that over the two-year period the content of the evaluation forms for Part A of the ACPT underwent some changes with new questions being added and others being re-worded. For example, in some forms attendees were asked to "list three things that you have learned today" while in others this was "Useful Aspects – please rank the three most important areas for you in today's training". In both versions attendees were asked to rank their three things from 1-3 (most to least in importance). This inevitably means that the data collected is not consistent throughout the implementation period. Indeed this led to some attendees ranking course materials and teaching approaches rather than documenting what they had actually learned.

Some of the evaluations for Part A had been collated by the implementation team and were presented as raw data. The evaluation team replicated this method of data recording to collate forms that had not been done. However five batches of evaluation forms (one from 2011 and four from 2012) merely provided the collator's summary of the original evaluations rather than the raw data and due to time and resource constraints the evaluation team did not re-collate these. This inevitably means that the data from the collated APCT Part A sessions is presented in two different styles (Appendix 4).

The Evaluation Results

Only 20 evaluations from two Part A courses were provided from 2011. This means that there was no evaluation data available for 81% of the reported 105 attendees. In 2012 there was evaluation data from 96 attendees, although the attendance data reported shows only 38 attendances at Part A taught courses during this period. The reason for this anomaly is unclear.

The overall number of completed evaluations for Part A of the ACPT was 116. The data showed that the main reason given by attendees for attending the training was to facilitate ACP and to complete ACP documents (although 55 people declined to answer the question). Twenty-seven attendees were interested in becoming future ACP trainers.

In relation to baseline knowledge, 75 of the attendees (65%) had some knowledge of the anticipatory care plan. Although the qualitative comments provided along with their response are limited, there is an overall impression that their knowledge was not complete and in some instances was inaccurate. In relation to the attendees' knowledge of the ACP process, only 40% reported they knew about this. There was again the impression that this knowledge was not complete. For example, there were some comments made about ACP and capacity, which were not wholly accurate. In section two the ninety-six 2012 attendees were asked if they knew about the GP Palliative Care Register (PCR) and whether they had discussed with a GP the possibility of putting a patient on the PCR. Sixty-five people (68%) did know about the PCR although only 27 (28%) had discussed putting a patient on the PCR with a GP. Finally both 2011 and 2012 attendees were asked if they had previously used an ACP document, if they had previously done advance care planning and whether they thought they would be involved in ACP in the future. The results of these questions can be viewed in Table 4.4.

EXPERIENCE OF ACP			
	Yes	No	No Comment
Previously used an Anticipatory Care Plan (document)	10	103	03
Previously used Advance/Anticipatory Care Planning	24	86	06
Experience in last 6 months	25	43	48
Expect to use either in future	87	09	20

Table 4.4: Previous and anticipated experience of ACP

The training was well evaluated by all attendees; they either strongly agreed that it was well presented or said the course was well presented depending on the version of questionnaire they completed. In addition almost all attendees felt the course fully met their learning needs.

In 2012 an extra question was added to section 4 which asked “why is it important for patients to be on a Palliative Care Register?”. In some questionnaires the overall themes from an unknown numbers of attendees were reported while in others the raw data is available so more can be told about the numbers of attendees who gave actual responses. The themes that emerged from this data were that the PCR is important for:

- Discussing and promoting choices at the end of life
- Planning and providing the best possible end of life care
- Ensuring that people’s wishes and choices are known by the full multi-disciplinary team and by all the different agencies involved in care and support
- The prevention of suffering
- Ensuring unrequired treatments are not given and correct ones are
- The availability of medicines that would be required
- Enhancing the continuity of holistic care
- The prevention of inappropriate admissions to hospital

In the final section attendees were either asked to list three things they had learned in the course or what were the three most useful aspects of the training for them. These three items were ranked 1 (= most important), 2 (=medium importance) or 3 (= lowest importance). Again this data was collated in different ways. In addition, not all attendees listed three things and/or ranked their answers. However there were wide ranging answers provided which overall showed an increased knowledge and understanding of both advance care planning processes as well as the documentation. Towards the end of 2012 more comments were made about DNACPR, which from the report provided by the implementation team, appears to reflect a change in the content of the training. This means that the evaluation team cannot make specific comparisons between cohorts about what was learned.

There were no evaluations provided from those who had undertaken the online LearnPro module. It would have been beneficial to have compared the experiences of the taught and online participants in order to determine any similarities or differences in the relative merits of these approaches.

Attendees' evaluations of ACPT Part B

Overview

The evaluation of part B of the ACPT training was divided into 2 sections:

1. General Information
2. About Today's Training

The aim of the first section was to determine whether attendees had attended part A of the ACPT and whether they had attended previous training on communication skills. The second section aimed to determine the quality of the training as well as asking about the three most important things that had been learned/that were most useful.

In the Part B ACPT course evaluations, some collation was completed by the implementation team and some by the evaluation team. However all of the collated results for the Part B training report is the raw data. In four of the 2011 forms, only the most important topic learned in the session has been recorded rather than all the ranked data. This inevitably means that there is missing data for the majority of those who took Part B of the ACPT in 2011 to determine what had been learned. In addition it is again noted that the questions within the forms have changed over the implementation period, especially in regard to what had been learned. This again led to attendees commenting on the teaching and learning approaches they experienced rather than identifying what they learned.

Evaluation Results.

In 2011 there were 39 completed evaluations, all from March sessions. This means that there are responses from 63% of 2011 attendees. In 2012 there are responses from 87 attendees. However the attendance data report that only 52 people attended the Part B ACPT in that year. There is no explanation for this anomaly.

In Section 1, 94 (75%) of those completing the evaluation had attended Part A of the ACPT while 93 (74%) had previously attended communication skills training.

In Section 2, the data were presented in two different ways. 39 of the 2011 attendees reported the training was well presented while in 2012, 16 thought it was well presented, 21 strongly agreed it was well presented and 39 agreed it was well presented. In both years the majority of attendees believed that the training met their learning needs.

Five attendees made suggestions about the course content, although there was no overall theme from this data that would warrant a change in content.

In Section 2 of the evaluations, attendees were asked to rank from 1-3 the three things that they had learned from the session or the three most useful aspects of the training. As previously noted, this sometimes led to comments on teaching and learning resources rather than learning that had taken place. In relation to the learning that had taken place, much as seen in the Part A evaluations, a wide range of topics were identified. The main themes that emerged from the data were:

- Communication skills
- How to approach and initiate the ACP conversation
- The involvement of the patient and family
- Active listening and picking up cues
- Body language
- Using right/open questions
- The importance of DNACPR and how to approach this
- Ensuring the environment is correct
- How to deal with emotions/sensitive situations

Finally the 2012 attendees were asked if they would be interested in attending further training. The results can be seen in Table 4.5.

FURTHER TRAINING	ePCS	DNACPR	LCP
Please indicate if you would be interested in receiving further training on the following:	20	27	23

Table 4.5: Stated preferences for other training by topic (n=87).

Attendees' evaluations of the pilot of combined ACPT (Parts A and B)

Overview

At one point in the delivery of the ACPT training, the implementation team took the decision to condense Parts A and B of the training into one half day. The rationale for this was the evaluations of course attendees on the length of the original Parts A and B. However no data has been shared with the evaluation team that supports this course of action. There was no mention in the report provided of the content or duration of this condensed course. The implementation team used the PART A course evaluations to evaluate this pilot.

Evaluation Results.

Ten people; four from Care Homes and six from Social Work attended this pilot course. Of these, seven people came to the course to gain knowledge to allow them to facilitate ACP planning and complete the document. One person was also interested in becoming an ACP trainer.

In the baseline knowledge section, nine attendees knew what an anticipatory care plan was although the qualitative answers were quite short and did not give much indication of the depth or accuracy of knowledge. Seven people reported that they knew what advance/anticipatory care planning was, however only four people expanded on this in free text. Again the answers were short but they did give some insight into the attendees' knowledge base. In relation to the Palliative Care Register, nine attendees knew of its existence although only four had discussed putting a patient on it with a GP.

Attendees' previous experiences of ACP can be seen in Table 4.6.

SECTION 3 – EXPERIENCE OF ACP		
Have you previously used an Anticipatory Care Plan (the document)?	**Yes** **1**	**No** **9**
Have you Previously used Advance/Anticipatory Care Planning?	**Yes** **2**	**No** **8**
Was this experience in the last six months?	**Yes** **2**	**No** **8**
Do you expect to use either in the future? (1 no answer)	**Yes** **8**	**No** **1**

Table 4.6: Previous experience and anticipated use of ACP among attendees at the half-day combined training.

In the section on the evaluation of the quality of the training, all but one person agreed or strongly agreed that it was well presented and just right in length (one attendee did not answer the question). In relation to the identification of the "three most important areas in today's training" all ten people gave their first, second and third choices. Some people highlighted the resources and the teaching methods while others focused more on the content of the course. The themes generated were similar to those reported in the original Part B ACP training. This would appear to indicate that there was less theory covered in this pilot course and more focus on having the ACP conversations.

The current evaluation of the ACP training

As discussed earlier, a contemporary evaluation of the ACP training was carried out using a self-completing questionnaire sent to every professional who had attended either Part A or Part B of the ACPT. This included those who had taken Part A via LearnPro. It was decided by the implementation team to include all the data generated by the questionnaire and not just that from within the demonstration site.

Overall there were 39 returned questionnaires giving a response rate of 16%. This was despite the implementation team sending out reminders to attendees on three occasions.

The designation of those completing the questionnaire are shown in table 4.7.

Job Title	**Number**
CIP	01
Community Staff Nurse	03
Deputy team leader	03
District Sister	02
General Practitioner	01
Senior Charge Nurse	01
Social Work Assistant	02
Staff Nurse	17
Care Manager	01
Community Nurse	01
Deputy Charge Nurse	01
Enrolled Nurse	01
Fasdsad	01
Nurse	02
Nursing Sister	01
Social Worker	01

Table 4.7: Work designation of respondents to the current evaluation of (previous) ACP training

Attendees were then asked to identify their place of work. Results of the 39 responses can be seen below in Figure 4.1.

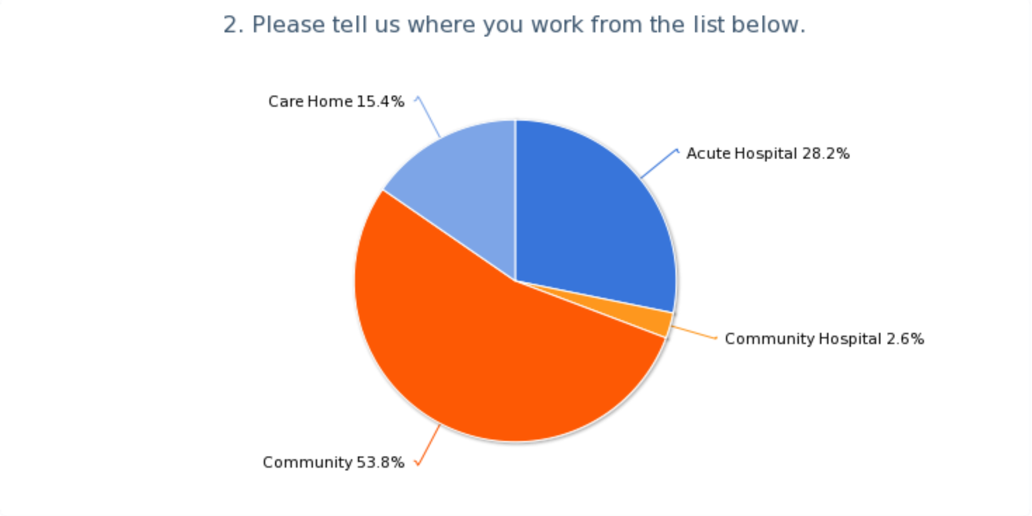

Figure 4.1: Places of work of respondents to the current evaluation of (previous) ACP training

In Question 3, course attendees were asked to identify the town in which they worked, so that the demonstration site could be identified. The results can be viewed in table 8.

Town of Work	Number
3 Towns/Kilwinning	1
Ailsa	1
Arran	2
Ayr	3
Crosshouse	1
Garnock Valley/Kilwinning	1
Kilmarnock	3
Muirkirk/Mauchline/Auchinleck	2
North Ayrshire	1
North West Coast Team	1
North and East Ayrshire	1
Stevenston, Saltcoats & Ardrossan	2
Afasdas	1
Ardrossan	3

Crosshouse and Kilmarnock	1
Dalmellington/Patna/Dalrymple/Drongan/Rankinston	1
Doon Valley	1
Galston/Newmilns/Darvel/Hurlford and surrounding countryside	1
Irvine	1
Kilwinning	1
Mossblown/Tarbolton/Coylton/Annbank/Stair/Auchincruive	1
Saltcoats	2
South west coast team	1
Team 5	1

Table 4.8: Geographical bases of respondents to the current evaluation of (previous) ACP training

Question 4 asked course attendees if they were responsible for completing ACP documents. 24 people (63%) reported that this was part of their job.

Attendees were then asked which parts of the ACPT they had attended. Responses from 25 attendees can be viewed in Figure 4.2.

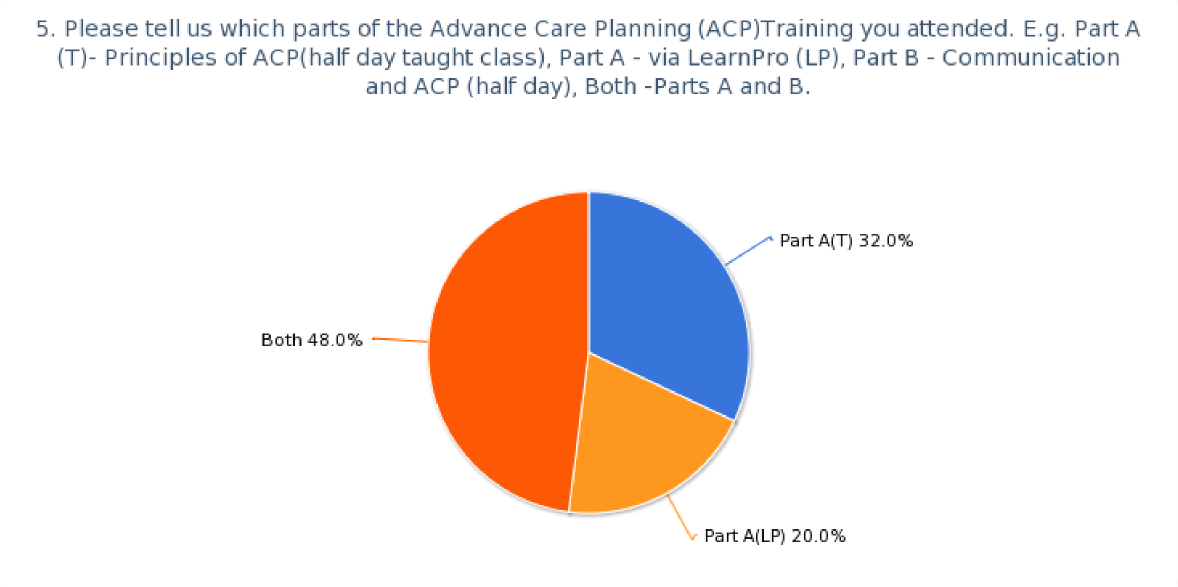

Figure 4.2: Parts of ACP Training attended by respondents to the current evaluation of (previous) ACP training

Following this attendees were asked when they had attended their ACPT. For the majority (17) this was 2012, with a few taking the training in 2011 and early 2013. There were a number of missing answers to this question.

In Question 7, attendees were asked to rank the usefulness of the three sessions in Part A of the ACPT. Results are shown in Table 4.9.

Item	**Total Score[1]**	**Overall Rank**
ACP Ethical issues	47	1
ACP - timings and triggers	45	2
What is Advance Care Planning?	35	3
Total Respondents: 25		
[1] **Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is the sum of all weighted rank counts.**		

Table 4.9: Usefulness of three sessions in Part A of ACP Training as reported by respondents to the current evaluation of (previous) ACP training

In Question 8, attendees were asked to rank the usefulness of the two sessions in Part B of the ACPT. Results are shown in Table 4.10.

Item	**Total Score[1]**	**Overall Rank**
Communication skills practice	32	1
Communication skills theory	30	2
Did not attend part B	10	3
Total Respondents: 19		
[1] **Score is a weighted calculation. Items ranked first are valued higher than the following ranks, the score is the sum of all weighted rank counts.**		

Table 4.10: Usefulness of two sessions in Part B of ACP Training as reported by respondents to the current evaluation of (previous) ACP training

The questionnaire then went on to ask about the influence of Part A of the ACPT on the attendees' understanding of the ACP process. Results from 25 attendees are seen below in Figure 4.3.

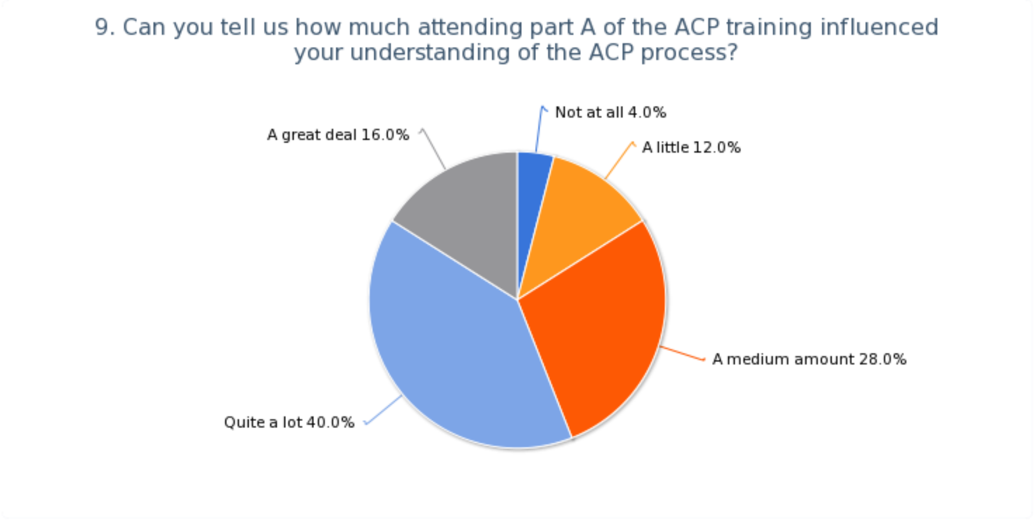

Figure 4.3: Influence that attending Part A of ACP Training had on understanding of the ACP process as reported by respondents to the current evaluation of (previous) ACP training

Following this attendees were asked to indicate how much attending Part A of the ACPT had aided their confidence in completing ACP documents. Results from 18 attendees who responded are shown in Figure 4.4.

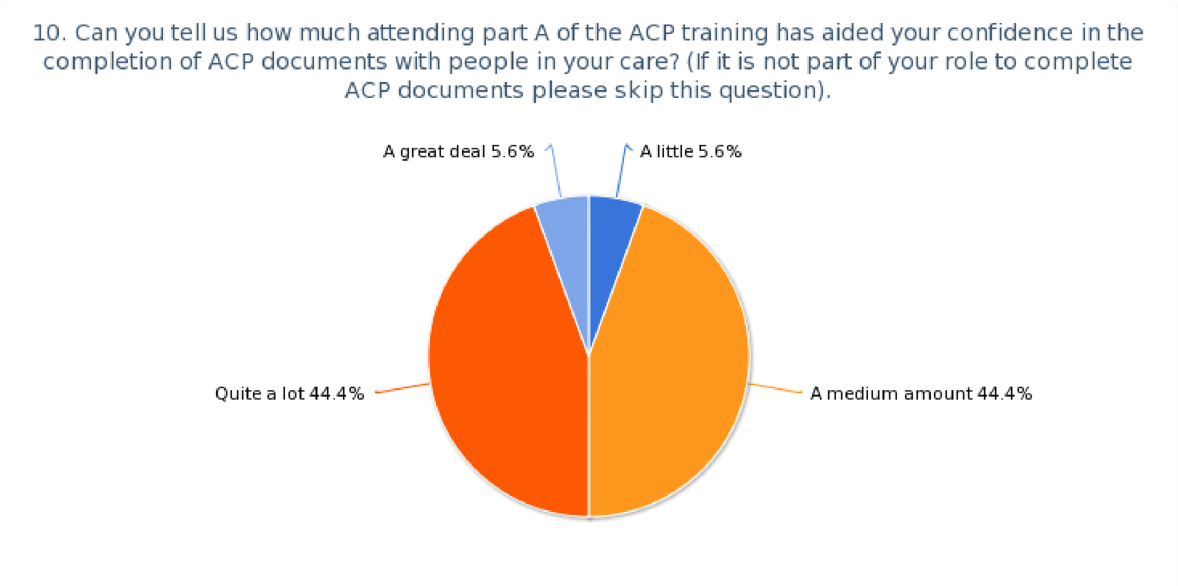

Figure 4.4: Influence that attending Part A of ACP Training had on confidence in completing ACP documents as reported by respondents to the current evaluation of (previous) ACP training

Question 11 then asked attendees about how much attending Part B of the ACPT had aided their confidence in discussing future plans with people in their care. The results from 18 attendees can be seen in Figure 4.5.

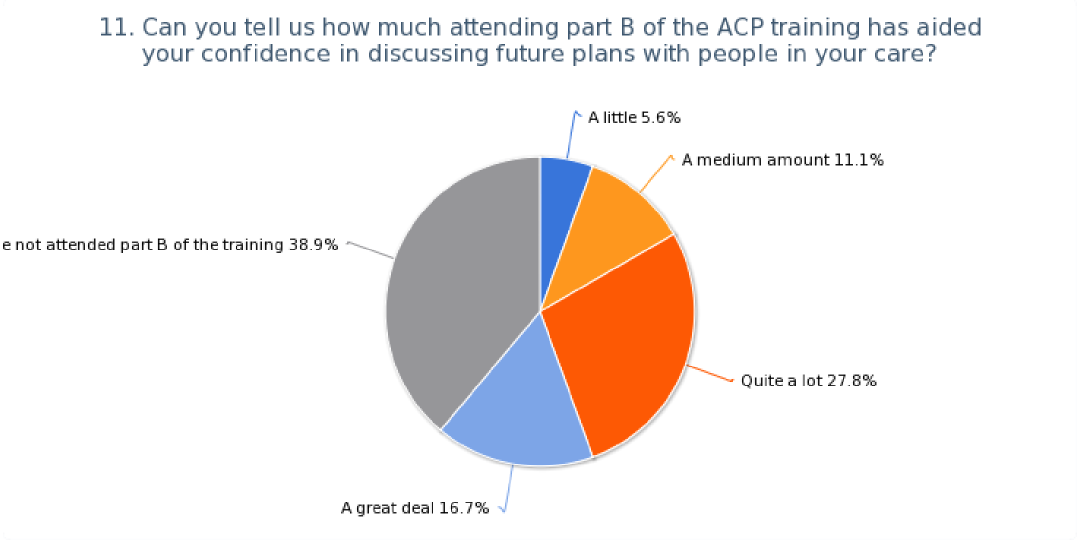

Figure 4.5: Influence that attending Part B of ACP Training had on confidence in discussing future plans with patients and families as reported by respondents to the current evaluation of (previous) ACP training

The next question asked attendees to say how much attending Part B of the ACPT aided their ability to complete ACP documents with the people in their care. The responses from 18 attendees are shown in Figure 4.6.

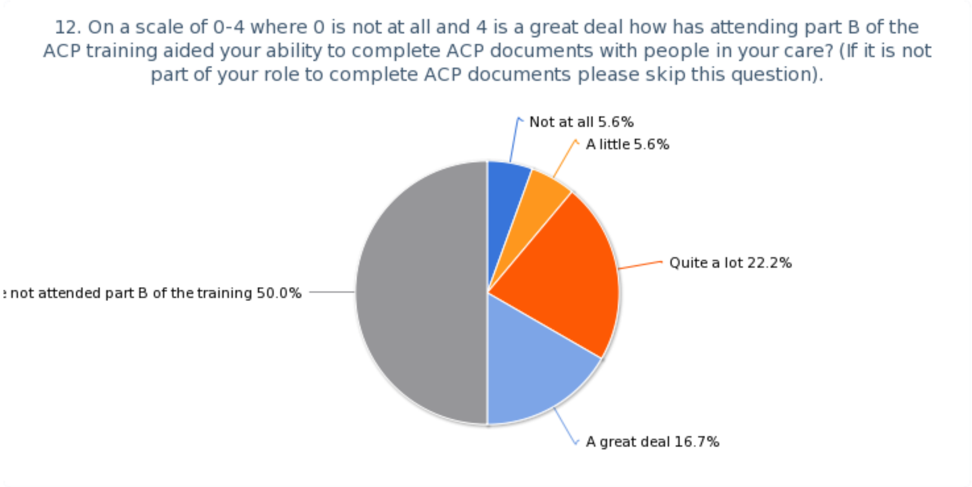

Figure 4.6: Extent to which attending Part B of ACP Training aided ability to complete ACP documents as reported by respondents to the current evaluation of (previous) ACP training

Question 13 asked attendees for any other comments they had about the ACPT. These can be viewed in Table 4.11.

Comment	Number
It was extremely enlightening	1
We need to revisit this to be updated and have other colleagues involved	1
The module was helpful but I feel a more comprehensive module and assessment would be beneficial	1
Anticipatory care planning has different meanings to different care groups. In COPD patients this means having medications in place and a written plan of what to do in response to symptoms. In the case of palliative care this could be taken to have a similar meaning. I think it is a misnomer to use the term ACP for this area of care. However I do feel the process and procedure are very valuable for this group of patients, it just requires another name for clarity!	1
As yet we do not complete ACP planning in our area. However hopefully this is something that will change in the near future.	1
Attending ACP training has enabled me to feel more confident in approaching such a sensitive and difficult topic.	1
None	1

Table 4.11: Other comments about the ACPT from respondents to the current evaluation of (previous) ACP training

Attendees were then asked if they would be interested in attending an update session on ACP. 24 people responded with 17 saying yes and seven saying no.

Finally attendees were asked to identify the number of ACPs they had completed since attending the training. The responses of 25 people can be seen in Figure 4.7.

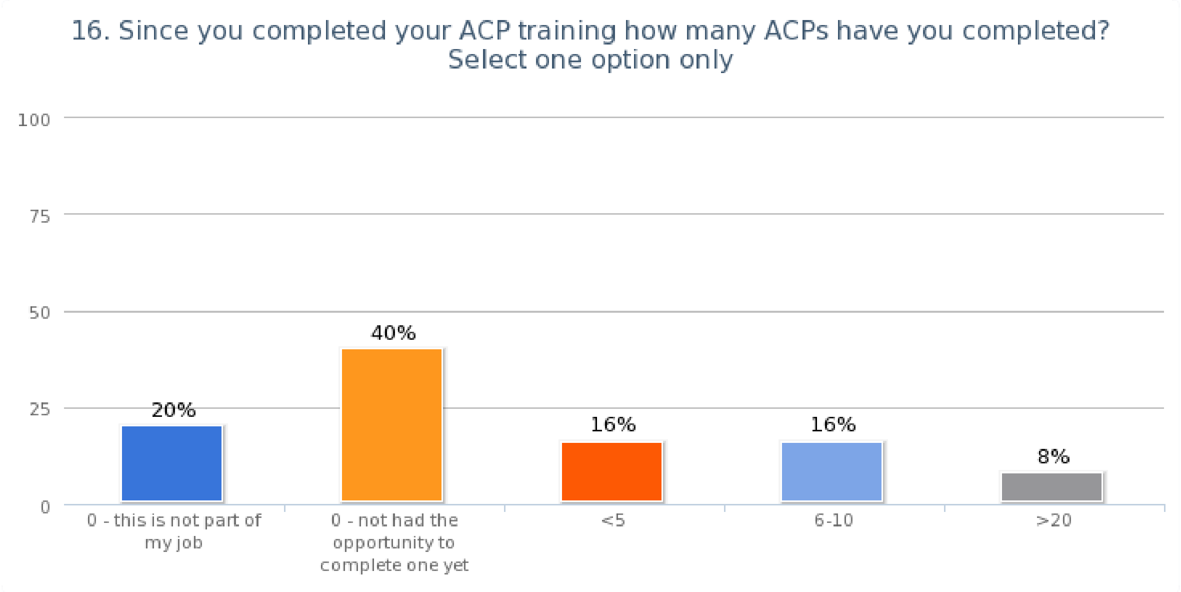

Figure 4.7: Number of ACP documents completed since attending ACP training as reported by respondents to the current evaluation of (previous) ACP training

4.3. Findings from interviews

The responses of the different groups (Care Home staff, Community Nursing staff and General Practitioners) are presented separately as follows:

Responses of care home staff

PART 1: Impact of the project on attitudes and behaviours of staff:

The first part of each interview looked at the attitudes and practices of staff who had been part of the demonstration site project (having either attended training, or worked at a site where the project was implemented, or both). Questions focused on how worthwhile the ACP process was, how much difference it made, the impact it had on attitudes and practices and the extent to which it made a difference to whether a resident's choice of place of death was respected.

To what extent do you think advance care planning is a WORTHWHILE process? / How much DIFFERENCE do you think the introduction of ACP in your practice area has made to patients/residents?

The general consensus among the care home staff interviewed was that ACP was a worthwhile process. Staff in Care Home A felt particularly strongly about this. They considered ACP to be beneficial to both the care home residents (especially those with dementia) and staff members. Some of the benefits they identified included:

- Promotes holistic care
- More person-centred
- Makes residents feel in control
- Provides reassurance that wishes are documented ("People with a terminal disease can know that they will be cared for in their place of choice")
- Makes residents feel that staff are interested in them
- Improves rapport, trust and relationships between residents and staff
- Encourages discussion of things that might otherwise not be mentioned
- Makes families feel more involved
- Cuts down on unnecessary conversations with families (particularly after the resident has died)
- Has "formalised things"
- Has led to nurses thinking "a little more ahead"
- Means that information is readily to hand

ACP was regarded as particularly beneficial in the event of admission to hospital when the document improved communication between the care home and the hospital ward and increased the likelihood that the resident would return to the care home. One respondent suggested that ACP had led to slightly fewer hospital admissions than before.

Staff in Care Home B generally felt less positive about the whole ACP process. They identified a number of practical challenges including:

- Problems with the documentation
    - "not user-friendly"
    - "first-person questions not appropriate for family members"
    - Hospital and GP staff do not understand the purpose of SBARs
- Reluctance of residents or family members to engage in the process
    - "Just don't want to complete it"
    - "Uncomfortable with it"
- Inability of some residents to engage in the process
- Problems where next of kin is a distant relative or neighbour
- Problems when discussing the ACP with staff outside the demonstration site
- Some resistance from doctors (GPs and out-of-hours)

The issue of inter-disciplinary disagreement was raised here and elsewhere. Some GPs were described as “not co-operating” although it was acknowledged that some attitudes had changed. An example of this was that one GP practice had started asking staff to complete ACPs for their patients.

Staff reported that doctors generally were more keen to over-rule the ACP (for instance to admit a resident to hospital) than the staff in the care homes. This was perceived to be a particular issue with Out of Hours doctors. The one thing considered likely to influence the doctor’s decision in favour of the ACP was the clearly expressed wishes of the family. However it was also suggested that the ACP process was more likely to be “successful” if advocated by an assertive or more experienced nurse.

When asked how much of a difference the introduction of ACP had made to residents, the staff in Care Home A responded positively (“Great difference” and “a lot”). However staff in Care Home B gave more negative responses (“None” and “No, not really”). The principal reasons given for this latter viewpoint were:

1. The way ACP decisions are communicated between individuals and agencies is inconsistent, meaning that decisions are over-ruled or not acted upon as they should

2. The information contained in ACP documentation is already available elsewhere

In what ways (if any) has your ATTITUDE towards ACP changed as a result of this project?

There was a large amount of evidence to indicate that the care home nurses interviewed had undergone changes in their attitudes towards ACP since the project began. Things that care home nurses felt positive about were:

- Feeling more comfortable about approaching people to have these conversations

- Becoming more confident and comfortable about the process

- Being much more focused on keeping the resident in the home rather than transferring them to hospital

- Feeling that the document supports nurses

Things that care home nurses felt negative about were:

- Having to ask people to participate when they don’t want to
- Having to complete ACPs routinely for everyone (“a tick-box exercise”)
- Having to duplicate information that was always collected, or a process that was already being followed

In what ways (if any) has your PRACTICE (around ACP) changed as a result of this project?

Two respondents made the point that the principles of ACP were not new to them:

"I think the conversations always took place. We are constantly managing families' expectations"

"I have always helped residents to plan for their future care in practical ways but not with documentation"

However all acknowledged that the formal introduction of ACP (as part of the demonstration site) had led to changes in their practice. The specific ways in which this had happened were as follows:

- They now take a more proactive approach:
    - "I actively think about it now. I think 'What other information could I get out of the resident in terms of what they want?' "
    - "We also raise the issue of ACP when a resident is recovering from an acute episode, saying 'If this happened again, what would you like to happen?' "
    - Before, we would have had to wait until the person became unwell.
- They begin the process earlier:
    - "My conversations are earlier"
    - "We start the process on admission, after the personal care plan is complete"
- They use the documentation as an aide-memoire
    - "The document comes in handy reminding you, if the patient's condition is changing, to have more of these conversations"
- They carry out the process in a way that involves and empowers residents and families
    - **"**We give them (families) time. Nine times out of ten they come back to us"
    - "ACP is also discussed at the residents meeting"
    - "I have become a better advocate for residents in their later life"

Nevertheless, several respondents made the point that they still exercised great caution when addressing these challenging situations:

- "You've got to bring it in slowly"
- "We can leave it with the person and go back another day to discuss it"

- “You sometimes have to be a wee bit sensitive”
- “Timing is very important. We ease it in gently. We keep it relaxed”

Some additional insights into the practice of ACP were gained from this question. For instance:

“It is quite good to start the ball rolling with DNACPR. This can then lead onto an ACP conversation”

“The staff that have been to the training are quite comfortable with filling it in”

“If there is a bit that we are not quite sure about – then we would discuss it between us”

To what extent do you think having completed an ACP affects the LIKELIHOOD that a resident will get to die in their place of choice?

This question sought to gauge the confidence that the respondents had in the ACP process to deliver positive outcomes for residents. The respondents varied in how likely they thought having a completed ACP would lead to a positive outcome. One said “Rarely’ in my experience”, and another (from the same care home) replied “Not now”. The main reason for these negative viewpoints was the feeling that clinical necessity usually overrides other considerations. For instance, even if the family and care home staff wish a resident to stay in the care home, his or her clinical condition may make transfer to hospital unavoidable.

The staff from the other care home were more positive about the extent to which having an ACP influenced place of death. They pointed out that a resident’s documented decision could be used to convince both medical staff and family members of the resident’s wishes. They also highlighted the benefit of having all of this information in one document. However these respondents acknowledged that even then, the doctor might over-rule the decision if it was considered to be in the resident’s best interests.

PART 2: Impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation:

The second part of each interview looked at the practicalities of using ACP in the care homes concerned. What factors affected whether they were completed or not? What parts tended to get missed (and what would respondents change about the documentation)? What factors determined whether the ACP was acted upon or not?

How does the situation arise where some residents have completed ACPs and SOME DO NOT?

It was evident that one of the care homes visited prioritised ACP more than the other. When asked the above question, staff in Care Home A had some difficulty answering as (it appeared that) the assumption was that everyone would have an ACP (“We tend to bring the subject up early, because we feel it is beneficial for our residents and their families”). However the reasons given for why an ACP might not be completed were as follows:

- “A resident may have dementia and no family member to answer for them”
- “Sometimes we have just not got around to it”
- “The discussion may have been initiated but the resident was not yet ready to have the conversation”
- “Occasional residents (or families) don’t want to discuss these matters”

The majority of the reasons given here were dependent on individual circumstances and seemed to relate to relatively isolated cases. The comments from the staff in Care Home B hinted at more institutional barriers including:

- “The majority of residents are unable to express their wishes”
- “Readiness of relatives to discuss is often very low”
- “Families are not comfortable answering the questions, or they just don’t know”
- “Very few families actually ask to have these conversations in advance”
- “Some of them take it away, but when they bring it back it is not really filled in”
- “The resident may have a different view from the relative who has power of attorney”
- “If it is not current or acute, it may not be regarded as very important”
- “The ACP is not classed as a mandatory plan so it is not included in the admission documentation”
- “Some people (staff) think it is not appropriate”

Which parts of the ACP documentation tend to be missed out and why?

Again it was evident from the individual responses that the practice in Care Home A was to ensure that the entire document was completed. Only two possible omissions were identified by members of this team:

“The DNACPR question is sometimes missed out”

“I feel we are repeating ourselves sometimes, and that leads to (certain) questions getting missed”

The staff from Care Home B were readily able to identify parts of the document which either were or were not regularly completed. Those that were rarely omitted included:

- Sections referring to “the very invasive things like surgery and PEG feeding – that is something the relative can cope with quite well, but others (such as IV fluids, where it may or may not work) - that is when reluctance kicks in”
- “Usually place of death is filled in. They invariably say ‘here’ ”
- “The DNACPR is never missed. It is done by the GPs. We are addressing it quite vigorously. The impact of not having a DNACPR is greater than the impact of not having an ACP”
- “The last page, the summary, is what people read”

Sections more likely to be omitted included:

- “The section entitled ‘Who is involved?’ (the names of the MDT) – usually because it is already documented somewhere else”
- “The ‘likely prognosis’ box often gets left. I don’t think nurses feel that is their responsibility. They think that is for the doctor to say”
- The section that says ‘I like to do…’ It’s not relevant to today. What they liked to do and what they like to do today are different. It is a relevant document so it should be kept relevant”

Respondents offered a number of suggestions for ways in which the document could be improved:

- Reduce duplication (e.g. ‘Who is involved’)
- Make the questions less limiting (for instance “the ‘place of death’ question limits people to the options WE think are acceptable”)
- Make the document more user-friendly (for instance “the column for initials and dates is too narrow”)
- “The ‘My wishes / what I would like’ section is not getting used as it was originally meant. It is tending to be used to document choices at the very end of life of life (priest present, burial or cremation etc) when there should also be information about the time leading up to that event”
- “The ‘I’ questions. They ask for “my wishes”, but the ACPs aren’t completed by the resident. They are completed by the staff (or rarely the family), reflecting THEIR wishes. The questions need to be changed accordingly”
- “The last page, the summary, is what people read”. [The respondent said this was the only part that she considered relevant].

How does the situation arise where some ACPs are acted upon and some are not?

Most of the respondents found it relatively easy to recall a situation where an ACP was not acted upon. The examples they cited tended to involve an admission to hospital (or some other medical intervention) near the end of life. The reasons given for such cases were as follows:

1. Duty of care

For example: "If a DNACPR is not filled out, we still have a duty of care to follow. In the event of a cardiac arrest we would have to call 999. The ACP may say the resident doesn't wish to be admitted, but it will be disregarded in such instances"

2. Unmet care needs of the individual

For example: "Their most relevant needs are what determine where they die. They will be where their needs can be met. They may be moved if the client's needs become more than we can provide"

3. Medical decision

For instance: "The GP may still feel a hospital admission would be of benefit. I can understand that. They think they have to try everything they can. They need to know they have tried everything"

4. Family uncertainty

For instance: "ACPs get acted upon when there is very clear agreement from the family. When there is less clarity, ACPs are not likely to be acted upon. For instance, if the relative is very anxious about the deterioration in the person's condition, you would have to choose hospital"

It was very interesting to note that these cases were generally regarded by the respondents as "last resorts". All recognised the seriousness of disregarding an individual's documented decision. Typical statements included:

- "Occasionally … the extreme step of admitting against the person's wishes may be taken"
- "None of these decisions are taken lightly"

There was also evidence of "damage limitation" going on. For instance, one respondent stated that in the event of admission of a resident to hospital against the wishes expressed in the ACP,

- “We would then write ‘For acute treatment only. For return to care home when treatment complete’ “

Another respondent explained that when a resident goes into hospital,

- We send a photocopy of the ACP – and we let the hospital know at the handover that we are sending it. And it is getting better.

One respondent gave an example of the measures she would take to try to prevent ACP decisions being overruled:

- “On two occasions I have used the ACP almost as a “weapon” to the GP. I did that because the relatives were very strong advocates (of the person staying in the home). Because I had that pressure from the relatives, I felt enabled to argue with the GP. It wasn’t my request, it was their request”

The same respondent highlighted the impact that overruling an ACP decision could have on the staff involved:

- “That is why we are having difficulty with ACPs not happening. Because we are accommodating the relatives feelings and wishes and not our nursing judgement. That can affect nurses’ confidence with ACPs, if they think the document will be ignored or over-ruled”

However there was also evidence of an acceptance that such actions were sometimes necessary:

- “Sometimes hospital admission is the right thing – if you can restore health. You don’t know how a situation might turn out”

- “The care needs of the resident will determine where they go”

PART 3: Impact of the project on outcomes for individual patients

The final part of each interview asked about examples of cases where ACP was either successful (in terms of honouring a resident’s end of life wishes) or unsuccessful.

Can you tell me about a case where the use of an ACP resulted in a patient’s or resident’s end of life wishes being met?

- A very timid lady (who would not advocate on her own behalf but had stated in an ACP that her preferred place of death was the care home) went into hospital for an operation which was subsequently cancelled. She came back to the care home, had a syringe driver set up and died very peacefully where she knew everyone.

- An elderly lady, a long-term resident, with no dementia, completed the ACP herself. She was admitted to hospital with a broken hip. She was not for surgery, so came back to the care home. The home continued to liaise with hospital. “That wee lady’s wishes were met – every one. Didn’t have any family, but her neighbour could not praise us highly enough for what we did – letting her die peacefully and in her ain bed” It definitely did benefit her. If she hadn’t had that plan she would have been in hospital, on a syringe driver, distressed all the time, crying and shouting out – it definitely made a difference to her”.

- A lady who was quite unwell (heart failure and chest infection), had been seen by the doctor the day before so there was no need for a visit. The care home staff telephoned the surgery to update the GP on her condition (deteriorating). Informed him that she had an ACP saying she did not want hospital admission. Response from surgery was that “as long as she is comfortable and pain free, there is no need to do anything else”. The lady died in the care home.

- A lady with end-stage COPD had completed an ACP some time before but then had a rapid deterioration. The care home staff called family, explained the change in her condition and also reminded them that they had completed an ACP with her. The staff also informed the GP. The decision was made that hospital admission would not be helpful. The ACP certainly influenced this.

- A gentleman who had been admitted to the home relatively recently was frail and elderly but reasonably well. He developed recurrent infections and stopped eating. He was commenced on oral antibiotics. However he subsequently became bed-bound and confused and continued to deteriorate. A conversation took place with family. The family initially wanted to over-rule the ACP and access more treatment. However after discussing it amongst themselves they eventually returned to their original point of view and asked for him to stay in the home. The nurses liaised between the family and the doctor. The gentleman died peacefully in the home

- An active lady with a large family (who did not all agree about what should happen in the event of a deterioration in her health) developed recurrent infections. The care home staff and GP over-ruled the ACP (at the request of some members of the family) and admitted her to hospital. When she came back, the staff met with the family and after some challenging conversations, all came to a mutual agreement. They felt they had done what was best for her, but that if she became unwell again, the decision in the ACP would be respected.

A final example was given (by a respondent who had expressed several negative views about ACP) of how end of life wishes were met without recourse to ACP:

- “Two residents died in the residential unit recently. They lived here and they died here. Neither of them had an ACP. One just refused to do it and the other wasn’t comfortable doing it. We still knew what they wanted because we were discussing that throughout the process of end of life. We were not documenting it here, there and everywhere. This [the ACP guidance] was what we did in terms of keeping them comfortable. Neither lady had expressed a desire to die in the unit. It was just an understanding that that would happen”

Now can you tell me about a case where this didn’t happen?

- We have a lady in hospital right now. She has chronic kidney failure and clotting problems. Maybe with an ACP she possibly could have come back to us (on her medication and with blood tests). She doesn’t have an ACP because she has a letter that is to be opened after her death. Her son didn’t want to make anything else.

- Another lady, her niece is her next of kin – would die at the thought of going into hospital – but the niece won’t make the decision (to say ‘no’ to hospital admission). She can’t understand that it is for her aunt’s benefit. Every time there is a review we bring it up with her. I think it is unfair. If she did fall, we would be obliged to send her into hospital and they might end up keeping her. It is no good. The relative thing can be a problem – if you have got a relative that is not willing to listen to the explanation.

- We have an elderly lady, her husband is very devoted. He can’t do enough for her, nothing is enough. So we have held off with the ACP. And yet she really needs one. If she was to go into hospital he would have a rift with the hospital. If she ended up in hospital, she is very difficult to feed and they wouldn’t have the time. She would end up with a PEG feed. We are planning, at the three month or six month review, to discuss it with him. She doesn’t even have a DNACPR. If you approached him, he would say “What’s wrong?” You have to wait for the right time. If we were to mention funeral arrangements it would kill him. The only possibility is, if she became unwell, we could tell him about it then.

- We had a resident with end stage disease who was admitted to hospital for urgent symptom control. It would not have been possible to get his symptom control in place quickly enough in the care home. The nursing staff wanted to keep him in the home and care for him there. However the doctor decided to admit. Unfortunately he died within 24 hours.

- People come here in advanced old age, and they stop eating/drinking. On five or six occasions I have seen the person be admitted to hospital and come back with a PEG tube. As a nurse, you question “why?” Even when families are advocating on their loved one’s behalf [to have minimal intervention], when the doctors in the hospital say that the artificial nutrition will make the person better, they accept it. Then once the PEG tube is started, it can't be stopped. The choice is taken away from the resident. They don't even have the choice to die. They may want to give up but the feeding will keep them alive indefinitely. However sometimes people get admitted with infection and dehydration, they get rehydrated and have another six months of good quality of life.

Can you tell me about the factors which proved DECISIVE in terms of the eventual outcomes of the cases you have described?

Only one respondent answered this question with any enthusiasm. She perhaps failed to identify really "decisive" factors, but made numerous suggestions as to how the process might be improved to increase the likelihood of successful outcomes. These suggestions included:

- Having a good rapport with residents, families and GPs.
- Having GPs who trust our care and our judgement.
- Providing GPs with updates, and advising them what we think would be the most beneficial course of action.
- Informing the GP in advance that the ACP is in place (we tell them in writing when we send the DNACPR for signing).
- Introducing ACP at a well-chosen time (not just on admission but following recovery from exacerbation).
- Giving people time to really understand the document.
- Discussing the ACP with residents, giving them time to read it and being available to answer questions.
- Explaining that we will do what we can to ensure the document is adhered to.
- Making ACP an extension of the resident's personal care plan.
- Trying to integrate the DNACPR so that the two documents support each other.
- Reviewing the document regularly.
- Putting a flag in the diary if the document is incomplete.

Two of the respondents used this question to highlight the shortcomings of ACP, implying that there were no decisive factors because the process itself was incapable of delivering the positive outcomes attributed to it. The following is a summary of these comments:

- The ACP document is secondary to the on-going dialogue with the family. Discussions happen on a daily basis. Having a document which states, at the beginning of a care home stay, what should happen at the end of a care home stay, doesn't make sense.

- It is one thing to say the resident is to die with dignity in the care home, but there is no way of knowing if this infection is going to be their last – As a nurse or GP, you will keep trying because you don't know. When the LCP starts, those decisions become clearer, but an ACP over two years does not give the clarity that an LCP does.
- The best use of the ACP is where a resident has competence, fills out the document, and then loses competence. The ACP then becomes a useful permanent record of the person's wishes.
- A decision not to admit someone to hospital does not happen on the basis of the ACP. It happens on the basis of the discussion that staff have with the GP at the time (although the staff are discussing the choices documented within the ACP).
- I have never seen a doctor take an ACP, read it and say "Oh, that is what we do".
- The actual document doesn't alter clinical judgement.
- I have never seen it happen. The ACPs aren't as precise as that. The general consensus of the ACP is taken into account (Do they want to stay here?) but also how pushy are the family and how unwell the resident is.
- Based on that assessment, we are advocating for the resident, regardless of whether the document is there or not.
- The only document the doctor takes account of is the DNACPR because that is seen as an official document and ACP is not.
- I think the ACP should have been tackled with families and relatives to begin with – not with nurses. It has never been an issue that nurses don't recognise.
- It is about care for the relatives when someone is reaching advanced old age or is first diagnosed with dementia and they are talking to the GP – start then, start educating the family. So that when they come to be admitted to the care home, they are focused on that. Not focused on whether their relative falls or not (although that is important too). But they are also focused on what to do "if anything happens". That is why we are having difficulty with ACPs not happening. Because we are accommodating the relatives' feelings and wishes and not our nursing judgement.
- ACP is a good idea, but we need education of families. Nurses already advocate out of experience and clinical judgement.

- Are mistakes being made? Absolutely. Will the ACP prevent them? I don't know.

- I don't know how you would get people to respond to the questions in the document. People put off decisions. I don't know how you will get people to address these. How would you get someone to actually do this?

- It is not needed.

- It needs to be shorter, more relevant, more focused on the end of life. The [existing care] plans that we do already have all the "I" questions in them. You don't need that in here (the ACP). Our existing care plans already cover this. And the Liverpool Pathway is the place to put this information.

- There needs to be wider knowledge about it (among staff) so that they see that it is not just another bit of paper with words on it.

- There are quite a number of residents that come in with the Golden Charter. Their wishes are known. Other people know them.

A final (positive) thought from the care home staff:

"The elderly have to be protected. This is one way of doing that. This is one way of ensuring that a person has the right to die where they choose. I think it's great for the elderly. We just try to encourage the relatives. It's their wishes. That is what is important. The paperwork doesn't matter. It doesn't make it easier for us – but it makes it easier for them as a family".

Responses of community nursing staff

A total of four community nurses were interviewed. These consisted of a team leader and a district nursing sister from each of two District Nursing teams. It should be noted that only one of the teams interviewed (DN Team A) were part of the demonstration site. The other team (DN Team B), although enthusiastic advocates of ACP, were not a part of the project. They were asked to provide volunteers for interviews because another team (who WERE part of the demonstration site) had not been to the ACP training and did not have any ACPs to show.

There were some differences in the attitudes of the different teams (and indeed the different team members) towards ACP, and these will be highlighted in the following analysis. Interestingly, these attitudes were echoed in the samples of documentation examined as part of the third element of this investigation.

PART 1: Impact of the project on attitudes and behaviours of staff:

As before, the first question asked respondents **to what extent they regarded ACP as a WORTHWHILE process and/or tool.** Most responses to this question were positive including:

> "It's definitely worthwhile. It makes it easier for those difficult questions which as a nurses you find difficult to ask"
>
> "I think having the discussion and communication with the families and the patients is a very, very worthwhile process"
>
> "I think it IS worthwhile. I think it was something district nurses always did, but there was never anything officially documented or communicated to other agencies".

Some observations about the process of ACP included:

> "It is a *way in* to ask questions that everybody finds very difficult to ask.
>
> For some long term condition patients (where there is doubt about their prognosis), it is very difficult to work out when you should ask those questions. If you have a form, it is a good way of broaching that subject".
>
> "Honesty and listening are important. We know that patients are scared"

and

> "It was always kept at the discretion of the nurse and in the nursing notes. Now it is being more openly discussed within the multi-disciplinary team and across agencies".

The community nursing group made some comments about the documentation, although these were fewer and less critical than those of the care home group. Typical comments included:

> "It needs to be reviewed as the person's condition progresses"
>
> "The document is OK. It gets left in the house. Families read it, which is probably a good thing"
>
> "I'm not a fan of the document. How useful is it to know what kind of music they like?"
>
> "The actual document doesn't look much, but the conversations needed to answer those questions can take visit after visit. It's quite a lengthy process".

How much DIFFERENCE do you think the introduction of ACP in your practice area has made to patients/residents?

These nurses were generally positive about the impact that ACP was having on the patients in their care. Comments included:

> "It is definitely part of the reason why a lot of people stay at home"
>
> "I think people did think about these things before, but there is more scope now for patients wishes to be met (particularly the non-cancer patients)"
>
> "I think even involving patients and their families more has been an improvement"
>
> "In the past, choices were limited because of resources. The greater focus on ACP, especially for non-cancer patients has helped with that".
>
> "And it is informing the patient, to make sure they have all the information they need to make their decisions"
>
> "I think it is part of trying to keep people at home"
>
> "It is a way of opening up people's mind that it is actually better to stay at home".

However there was also a viewpoint that nurses had always carried out advance care planning, even if they did not use a specific form to do so:

> "We have always taken the lead from the patient. If they have stated they wanted something, we have tried to facilitate it as much as possible"
>
> "I wouldn't say it was definitely this form...there are other factors"
>
> The answer to that is 'no'. I wouldn't give any different care if someone had an ACP or didn't.
>
> "I would say 'not really'. If people wanted to be looked after and die at home we have tried to make that happen. Sometimes something goes wrong and that's not possible"
>
> "But people are more voiced, saying 'I want to die at home'. But I don't think it has made much of a change"
>
> "I am not sure that patients are aware of a specific document".

In what ways (if any) has your ATTITUDE towards ACP changed as a result of this project?

As with the other group, the community nurses varied in their attitude to ACP. However the response to this question was mostly positive as illustrated in the following quotes:

> "It has made the discussion a lot easier. It has made our job slightly easier"
>
> "I think it makes the process more valuable for us"
>
> "It gives you a big boost because you know you have done the job right"
>
> "It has made staff more aware and more confident in having those discussions"

> “It gives you that added impetus to try and improve it for other people”
>
> “It is embraced, it is an area they want to improve – advocate for patients and their care”
>
> “Yes. I think, until this came out, it was just a matter of ‘you went in and did this’. Now we try to make sure we are representing what the patients are wanting”
>
> “I feel a bit more confident about having that conversation with them. It is talked about more now”
>
> “These subjects are maybe not as difficult to raise with patients as before”
>
> “There has definitely been an improvement there”
>
> “It has been beneficial for us. It gives us a prompt to remind us to do these things”
>
> It has made things a lot easier.

Some less favourable comments were also received, namely:

> “You have still got staff who will stand back and let others take the lead”
>
> “If people haven’t had that experience it is a scary area”
>
> “We have an over-protective attitude to some patients [which means we don’t go there]”
>
> “It’s easier with some people than others. It is difficult sometimes”
>
> “We had a patient dying recently and the GP’s first priority was to get the DNACPR form filled out. We can be too focused on the documentation. It can become a tick box exercise. It can be OUR agenda rather than theirs”
>
> “Sometimes I am not comfortable mentioning that I am going to go through the anticipatory or advance care planning with them. I don’t know how appropriate it is at times to have that discussion with them when they are not dying”
>
> “I find it difficult to go through a form like that. We have limited time. Some of the issues covered are none of my business”.

In what ways (if any) has your PRACTICE (around ACP) changed as a result of this project?

The community nurses gave numerous examples of ways in which the project had changed their practice. These are summarised as follows:

- Starting conversations earlier
- Not waiting until it is too late
- Having conversations with people with long term / non-malignant conditions
- Really asking, rather than making assumptions about wishes

- Using the document to build up trust over a period of time
- Getting various viewpoints “so that we are getting all the information and we are getting it right for them”
- Working more cohesively with care homes
- Working more with other agencies (“all singing from the same song sheet”)
- Advocating more for the patient
- Taking on the other professional groups that may not be so attuned to the process.
- Taking a little more on at a local level, rather than leaving it all to someone else like the hospice nurse.

In what ways (if any) do you think having completed an ACP BENEFITS individual patients or residents?

The following benefits were listed by respondents:

- More conversations are taking place and with more honesty
- Having the right information means that the right decisions are taken
- People get to die in their place of choice
- If someone is admitted to hospital when they want to stay at home, they can be “turned around” very quickly.
- Having the contact numbers help families to feel less stressed
- Patients feel they have been consulted (e.g. about preferred place of death)
- Patients’ families get to know their loved ones’ wishes.

To what extent do you think having completed an ACP affects the likelihood that a particular patient or resident will die in their PLACE OF CHOICE?

The respondents had mixed feelings about the answer to this question. Most comments were in general support of the suggestion that an ACP would have a positive effect. However several implied either the opposite or a neutral stance.

> “It must make a difference”
>
> “It does make a difference, especially if the patient has discussed it with their family”
>
> “As the health care professional, you are going to try your best to grant their wishes”
>
> “Yes, it has worked. They say ‘Do you not think he should be going into hospital’ and we say ‘No, do you remember they said that they wanted to stay at home’. And if the patient is well enough we can bring them into the conversation too”

> “We say to them ‘We are doing all we can to keep you at home’. It does make a difference from that point of view”
>
> “There are still wee situations where the family panic, but the majority of the time, things do go smoothly”
>
> “It is not always possible for instance if they deteriorate very quickly, or if there is no bed available in their place of choosing. The form can’t help in these cases”
>
> “Relatives can intervene, phone 999 for example. They panic, and the person is admitted to hospital, even though they didn’t want to”.
>
> “No. I think having the documentation is not enough. You also need to have conversations with colleagues (hospital staff, accident and emergency staff)”
>
> “What makes a difference is that everyone is informed of what the patient wants. The document in itself doesn’t make the difference”
>
> “You have the conversations anyway, whether they have an ACP or not”.

Part 2: Impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation

How does the situation arise where some patients/residents have completed ACPs and some do not?

Numerous reasons were given, and these are summarised in the following list:

- Some people might not want to have those discussions
- For some people the right time has not arrived
- Some people refuse to or resist completing the document
- The person may not have been told his or her diagnosis/prognosis yet
- The conversations may have taken place but have not yet been documented
- Some nurses are more proactive about having these conversations than others
- One member of the team may not have completed his or her “bit” yet.

Which parts of the ACP documentation tend to be missed out and why?

The part most often referred to in respondents’ answers was the DNACPR form. Reasons given included staff reticence, family reticence and the fact that this is the one part of the form which is often completed by someone outside the nursing team (the GP).

Some respondents made the point that the form might only be partially filled in at first, but would be completed eventually.

One respondent mentioned that the SBAR is sometimes not used, but that a telephone or face to face conversation would happen instead.

How does the situation arise where some ACPs are acted upon and some are not?

The following explanations were given:

- The patient might change his or her mind when the situation arises
- The GP might make a decision to overrule the ACP in the best interests of the patient
- The Out of Hours service may not have access to all the ACP information
- The family may be unable to cope any longer
- The patient may have “lingered longer than expected, and hospital admission is arranged to help the family”
- The family may intervene (for example to demand – or indeed to refuse resuscitation or admission to hospital)

What are the key factors here?

- The viewpoint of the family
- The viewpoint of the doctor (GP or Out of Hours doctor)
- The quality of communication (between members of the MDT, other agencies, ADOC, the Out of Hours service and the hospitals)
- Having had an honest, open and detailed discussion with the patient / family.

Part 3: Impact of the project on outcomes for individual patients

Can you tell me about a case where the use of an ACP resulted in a patient’s or resident’s end of life wishes being met?

One respondent said “The majority of the patients DO get their wishes”. The following examples were given:

- “One lady, with end stage COPD, who years ago wouldn’t have stayed at home. She would have probably ended up dying in hospital. But the lady wanted to stay at home, with her family, in her own house. And that is how things happened. She got a syringe driver, stayed at home, and slept away peacefully in her own bed”.

- “Nowadays the non-malignant patients are given palliative drugs (oramorph, lorazepam). The progression onto slightly stronger medicines and onto a syringe driver is an easier process because you are having these discussions with them. You know they want to stay at home, so you are looking at palliative drugs and syringe drivers".

- "There have been quite a few actually, end stage long term conditions have stayed at home because we have had these conversation. We have done anticipatory care planning AND advance care planning. One lady recently had end stage dementia but then she developed cancer. And we went down the road of the ACP for her cancer diagnosis".
- "A gentleman with nuclear palsy who kept getting admitted to hospital, usually because he had dislodged his PEG tube. Early on, before he lost function, we sat down and did his ACP. And his wish was to stay at home. And he died at home. The problem with that case was that we "couldn't get to him in time". He ended up bring admitted to casualty, and it took us a day or two to get him back home. But his wife was a good advocate for the ACP process and he got his wish".
- "A younger woman was dying. The ACP process helped staff to be honest with her. This involved supporting her to deal with the anger she felt around leaving two young kids and allowing her to do the things she needed to do (like get married)".
- "Our best results have come from managing to maintain people at home. One man had a bleed and was admitted to hospital, but he got home (based on what we knew from his ACP about his wishes)".
- "We were all prepared for a woman to die at home. Her husband and daughter were on board. There was no way she wanted to go into hospital. But on the Friday night she became breathless and was admitted to hospital. Fair do's to everyone though that she was turned round at A&E and sent home with a syringe pump and a nebuliser. She had said in her ACP that she wanted to die at home. At the end of the day, what she wanted was adhered to. It was noted in the notes that she wanted to die at home, and the staff at A&E turned her round".
- "An older chap who was terminal, on a syringe driver, living at home with his wife wanted to remain at home. His wishes were fulfilled. Everything went smoothly. His wife was unable to check the driver so although we were going in daily, we also asked the out of hours nurses to go in. Social work provided carers. Equipment was in the house. Palliative care was provided by the hospice. GPs were doing home visits. And the gentleman passed away in the house with his wishes met. Pain control had been an issue. Also he had a fungating tumour with a high risk of bleeding. His wife was well aware of who to contact in the event of bleeding, which she did (and which avoided involving emergency services). And it went really well. The documentation was all in place and we had discussed openly what might happen".

- “We currently have an advanced COPD patient who had become a ‘revolving door’ patient. She was also high risk on the SPARRA scale. She did not want to see herself as a ‘palliative’ patient, but the DN team have helped her identify her wishes (including to stay out of hospital) through the ACP plus education and support. This seems to have been successful as she has managed to stay out of hospital for a year”.

- “A lady with COPD had been through all the self management programme, anticipatory planning etc. But we couldn’t keep her out of hospital She had multiple admissions. And it turned out she wanted to die in hospital – it was eventually documented in her ACP. And every time she had an exacerbation she requested admission. She wanted to protect her husband who didn’t keep well. And eventually she did die in hospital. That lady had everything. All the support. All the information. But when we had the conversation, she said that she wanted to die in hospital”.

Now can you tell me about a case where this didn’t happen?

- “A recent lady who wanted to die at home was back in hospital within 24 hours because the husband believed he was getting 24 hour care. They had been given a false expectation of what was going to happen. He couldn’t cope. The right equipment wasn’t in the house. He didn’t keep well. It wasn’t possible to get home care in as quickly as it was needed (although that is a lot better these days). Perhaps things weren’t explained very well, possibly in the hospital”.

- “The last lady that we had to get put into emergency respite was because the family couldn’t cope. She had said in her ACP that she wanted to remain at home. However that lady died in the nursing home. She was quite happy to be in respite. That may well have been her choice (although officially, it was documented as “home”)”.

- “Sometimes we have everything in place, everyone knows what the patient wants, but then the family panic and dial “999”. Sometimes the person dies at home, but because they can’t find the DNACPR, the ambulance men have to start resuscitation. And everyone is left with really bad memories. Or sometimes people are taken into hospital because they can’t find the ACP. Especially dementia patients with cancer. They might have thrown the ACP out. Some of the houses we visit are very chaotic. Things get lost or forgotten about”.

- “We had a patient who had been on a syringe driver at home, an end of life patient. He had completed an ACP and it was on EMIs and was sent to the out of hours agencies. One night the gentleman stopped breathing and the wife dialled ‘999’ in a panic. She was told by the operator to start performing CPR. She expressed that he was not for resuscitation and explained the circumstances. She was then told by the operator ‘Are you refusing to perform CPR?’ She was panicking. She replied ‘No I am

> not refusing, but he is on a syringe driver. He is not for resuscitation'. 'So you are refusing to perform CPR'. They sent a blue light ambulance out to the house. The wife was sensible enough not to attempt CPR. When the paramedics arrived they said they did not have notification of his DNACPR status. They hadn't got it and proceeded to perform CPR. There was no DNACPR form in the house. All the stuff had been done. All the processes had been followed. But apparently at that point they didn't have access to ePCS. That was where the system let them down. It has been rectified now but communication between out of hours and paramedics remains a big issue. If an ACP/DNACPR had been in the house, some of the most distressing parts of this story might have been avoided".

Can you tell me about the factors which proved decisive in terms of the eventual outcomes of the cases you have described?

Factors identified as producing the unsatisfactory outcomes described above were:

- Something happening that wasn't expected
- Families being given or having unrealistic expectations
- Families who refuse the input of services and support
- Documentation not being available or not being known about

Factors identified as making a positive difference were:

- Being decisive / early intervention
- Acting immediately when someone is admitted to hospital to get them home again quickly
- Having early involvement of DN services in these cases.
- Being aware of what patients are out there (in the community) and what is happening to them
- Having a good relationship with patient and family
- Discussing potential crisis scenarios with the family
- Remembering that palliative care is just not for cancer, and that ACP should be done with people with a variety of diagnoses
- Moving quickly when a patient with a long term condition enters the end stages (as there may be little time left)
- Making all the paperwork readily available.
- Having good inter-agency communication

- Having agreement between agencies about how these situations should be managed.
- Thinking outside the box

The following suggestions for change were offered in response to this line of questioning:

> "There should be a better way of capturing the information. The documentation takes a long time to complete correctly. There needs to be something more manageable. It might be the shortened form of the ACP being used by some GPs as part of the LES"
>
> "The electronic palliative care summary (ePCS) should be updated regularly to ensure Out of Hours staff have the latest information. People still get admitted out of hours, because the doctors don't know them. However the out of hours service is becoming more likely to leave people at home. Not just because of the ACP but because of other developments such as out of hours nurses etc".

Responses of General Practitioner

It was originally intended to interview two General Practitioners for this evaluation. One GP responded positively to the initial request and was subsequently interviewed at length. The second GP who was approached was consistently unavailable and no meeting could be arranged before the evaluation came to an end. This is regrettable as an alternative viewpoint may have shed more light on the attitudes and practices of this key group of professionals. However the first GP provided very detailed and insightful responses which, taken with relevant comments from the other professionals interviewed, provide a fair summary of the situation for GPs as a whole.

The GP interviewed was generally positive about the ACP process, saying:

> "It IS necessary. The process is encouraging more GPs to think proactively [about the care needs of patients with life-limiting diseases]. However more forward-thinking practices have probably benefitted less because they were already doing it".

In terms of how much difference the project was making to patients, the GP made the following points:

- It is a useful aid to communication within the family
- It allows patients to communicate their wishes earlier than in the past. This means that when a crisis hits, we know what their wishes are

- The document makes it easier to raise a difficult topic, then to leave it until the patient feels ready to discuss it
- It encourages conversations in more depth than might have happened before

The GP reported a number of ways in which their attitude to the process of ACP had changed:

> "I always thought about anticipating care needs [but the project] has probably made me more confident talking about preferred place of care and death earlier"
>
> "I am more confident bringing up the topic of ACP"
>
> "I am more comfortable talking about DNACPR"

The following are the ways in which the GP considered their practice (around ACP) had changed as a result of the project:

- Thinking about the patient's care needs earlier in the disease trajectory
- Doing more advance planning for people with chronic diseases
- Doing ACP with people with dementia before they lose capacity
- Being more pro-active in bringing up DNACPR
- Tending to have more discussions around practical issues such as wills, carer support, the needs of the family etc
- No great change in documentation. Would have always documented these conversations, say, in the ePCS
- Still getting to grips with the relationship between ePCS, ACP and the LES component of the ACP.

The GP's responses to the questions about the benefits to individual patients of having completed an ACP included the following points:

- Care is more anticipatory than before, especially for non-malignant and dementia patients
- The patient has a little more autonomy (especially as they retain the document themselves)
- The patient can identify his or her own priorities. They can discuss what is important to them, not just what is important to us
- When professionals know what is important to the patient, they can be alert to these things (and how they might change) in the future.

When asked their opinion on the extent to which having completed an ACP affects the likelihood that a particular patient will die in their place of choice, the GP replied quite positively:

> “I would think it would make it much more likely. For me it is a really important issue and I would be trying to make sure everything was in place to enable that to happen. Especially supporting carers. And when the family knows, they can do all they can to make it happen as well. And I hope that if they don’t manage to die in their chosen place, then they would know that everything had been done to enable that and it has not been possible. And hopefully they will have been able to be cared for in their second choice. I would say in nursing homes especially, the ACP enables the person to die “at home”.

When asked to give an opinion on how the situation might arise whereby some patients in the practice have completed ACPs and some do not, the GP gave the following reasons:

Some cancer patients may not have an ACP because:

- it is easier to bring up conversations about future care with them
- we are seeing them more often so we tend to elicit a lot of the ACP information informally
- they tend to come into the surgery to see us, where time can be very limited
- they are seeing other people such as the palliative care nurse who may be better than we are at having these conversations.

Some people with non-malignant diseases, for instance those with motor neurone disease, tend to have an ACP because:

- it would otherwise be very difficult to bring up those subjects with them
- they tend to be seen at home where time is less limited
- there is a risk that they may have future communication difficulties, so it makes sense to do the ACP whilst they can write and speak clearly.

Some of the key factors here are time, opportunity and the readiness of the patient to have the conversation.

In response to the question about which parts of the ACP documentation tend to be missed out and why, the GP identified the DNACPR:

> “That is the hardest question to know when to discuss. It can get put off for various reasons. It is sometimes left until the professional perceives that the patient is “ready” to contemplate not having resuscitation”.

In response to the question about reasons why some ACPs are acted upon and some are not, the GP identified the following possibilities:

> The Out of Hours team may be unaware that an ACP exists for that patient, or communication may break down in some other way
>
> The patient may get admitted to hospital and forget to take the ACP in with them, or the family may forget, or the document may go A.W.O.L.

The key factors identified here were:

- Whether there is an ACP or not
- Whether it is lost
- Whether the family remember to take it
- Whether the hospital staff read it
- Whether we mention the patient has an ACP in the admission letter to the hospital

The GP offered two examples of cases where the use of an ACP resulted in a patient's or resident's end of life wishes being met and one where this did not happen:

- I was aware of a case where the LES element of the ACP had been completed. The [community] nurses had identified home as the patient's preferred place for care at the end of life. The patient developed a chest infection which was not responding to treatment at home. It was decided that hospital admission wouldn't help, and that the family wanted to care for him at home. ADOC had been out to treat him for the pneumonia but he did not respond to antibiotics. The decision was made to keep him at home.

- An elderly man had lung cancer and a good understanding of what his prognosis was. He had several chest infections. After one of the earlier ones he specified that he didn't want to be admitted to hospital in the event that a future chest infection did not respond well to antibiotics. His family were able to gather and spend his last few days with him. He ultimately died at home as was his wish.

- A terminally ill patient progressed very quickly after diagnosis. He had expressed a wish to die at home. He then collapsed at home. The doctor called to find the patient very anxious and distressed. His family were very anxious too and it was decided to admit him to hospital. Not much more was done in hospital than would have been done at home, and he died within 48 hours. With more experience the doctor might have anticipated that this was a potentially terminal event and advised the patient

> and family that he had the option to be cared for at home. No ACP was in place in this case. If it had been, it might well have made a difference to the decision made.

The factors thought by the GP to be decisive in these situations were identified as:

- The relevant conversations having taken place and involving the relevant people
- Those conversations being documented
- The information being communicated to the Out of Hours service and the hospitals
- The ACP document being visible to the attending doctor
- The ACP document accompanying the patient in the event of him or her being admitted to hospital. Then, if they are not responding to treatment or are not suitable for ventilation, the ACP could be taken into account and the patient discharged back home again.

Two problems identified by this GP were that:

> "Even if we complete an ACP, say for a dementia patient or someone approaching end stage COPD prior to them being on the palliative care register, there is no electronic way of communicating the contents of the ACP. (Once the person goes on the register, communication to Out of Hours/ADOC is automatic). This may change when the Key Information Summary is introduced".
>
> "Any patient that is palliative (according to the GSF) would have an ePCS completed within 4 weeks of being placed on the Palliative Care Register. Any time during that time (or after), the ACP might be completed. The ePCS is relatively easy to complete at it mostly involves ticking boxes. When the ACP is addressed depends on the GP and the patient – when they are ready to discuss it. Some people on the ePCS may never get their ACP completed. (There is an incentive under the DES/LES to do the first but not the last)".

4.4. Findings from audit of documentation

Care Home A

The six completed forms from Care Home A demonstrated definitive conversations had taken place with the residents regarding their future care. Completed DNACPR forms were documented in all six ACPs in conjunction with evidence that all of the residents were registered on the Palliative Care Register. All six residents had clearly stated their preferred place of care and two had recorded a specific request not to be admitted to hospital. Each of the ACPs had a review date entered however five out of the six residents had died prior to the date of the planned review.

Missing information included two instances where there was no evidence of any discussion of funeral arrangements/plans and four ACPs had no information entered in the section detailing carers' needs. There were also some instances where dates and/or initials were not entered. Overall level of completion was however very good, ranging from 90 to 100%.

Care Home B

Only three completed ACP documents were made available for scrutiny at Care Home B. The reason for this was not clear, but a general impression was gained that the use of the document at this site is not universal. The practice at this care home appears to be to encourage residents' family members to complete the document. It may be that this approach leads to inconsistent use of the document.

The three completed forms from Care Home B also gave evidence of a less definitive approach to conversations regarding residents' future care. Only two of the forms showed documented DNACPR decisions and there was no evidence to suggest any of the residents were recorded on a Palliative Care Register. Each of the three residents had indicated their preferred place of care. However in one instance this was picked up within the text of the plan and not in the appropriate section of the document. Only two of the documents had review dates (although both residents had died before the review day was reached).

There were numerous instances of questions being left blank in all three plans and there was a consistent lack of recordings of dates and initials. One plan had been partially completed by a resident's daughter. Overall level of completion was correspondingly low (75%, 75% and 90% respectively).

District Nursing Teams

Altogether only three completed ACP documents were provided for review by the two district nursing teams approached. One team had a policy of keeping the forms in the patients' own homes and these forms were unavailable because they were not routinely recovered after the patient's death. In actual fact, this DN team were able to provide one form for scrutiny because the patient concerned was partially sighted and the original form (which the DNs retained) had been copied into a more accessible format for keeping in the home. This form proved to be well completed, being estimated by the reviewer to be 99% complete. The only omissions from the document were initials and dates.

The second DN team were only able to provide two forms for the documentation review. These may have been the only forms that could be readily found among the notes of deceased patients. Overall level of completion of the two forms was estimated at 95% for one and 80% for the other. Missing details included information about various patients' and carers' needs and awareness as well as dates and initials. Both forms did however have first and second choices of place of care at the end of life specified.

4.5. Summary of findings

It will be evident to the reader that this evaluation produced a large amount of raw data, the analysis of which has been both interesting and challenging. The analysis of the questionnaire data was complicated by the presence of two separate sources of evidence (the initial, on-site evaluations and the current e mail/postal ones). The fact that different participants accessed different amounts and formats of training, and the fact that the wording of the original evaluation forms changed between earlier and later cohorts also meant that some specific comparisons were difficult to make.

The semi-structured interviews generated a tremendous volume of rich and detailed data, and the individuals who agreed to take part are to be commended for their generosity and honesty.

The review of documentation was a little restricted by the shortfall in the number of completed forms made available to the evaluation team. While much could be inferred from the forms which were eventually examined, nevertheless the exercise highlighted a need for ongoing monitoring of the rate of completion of ACPs in the different clinical areas.

5. Discussion

This section of the report explores and develops the main findings which emerged from the data presented in Section 4.

5.1. The extent and impact of ACP training

Attendance at ACPT

Although the data collected for care homes staff specifies whether the person completing the evaluation was based in North Ayrshire or not, the data from the NHS and Social Services lacks this information. Therefore it is not known how many of those included in the attendance data came from the demonstration site, and the conclusions drawn cannot specifically be applied to North Ayrshire alone.

It would appear that care home staff engaged more readily with the taught ACPT, while NHS staff made more use of the LearnPro online module. Compared to care homes and NHS settings, Social Services sent the fewest staff to the ACPT. By far the majority of NHS staff accessing both the LearnPro and taught sessions were nurses.

Reviewing the attendance data overall, it is disappointing that there has not been greater engagement with the ACPT given the total number of professionals working within the demonstration site. In particular there seems to have been very poor uptake of training by doctors (who play a vital role in ACP across all care settings). It may be that some professional groups (including doctors) are receiving ACPT from elsewhere and this possibility warrants further investigation.

It is noted that there were a substantial number of undesignated attendees from care homes in 2011, which means it is unclear which staff members attended from these organisations. However there does not seem to be a “support workers” category in the care home data stream and it seems likely that some of the unidentified people are support workers as this is the biggest group of employees within this sector.

Delivery of the ACPT

The report provided by the implementation team notes that the delivery of the ACPT changed in both content and length of sessions. This inevitably means that the data collected is not measuring a constant and thus information from different cohorts cannot be compared as the evaluation team did not know who had attended which version of the courses.

Evaluations of the ACPT.

Again the data collected was not consistent due to a number of versions of evaluation forms being used. However the evaluations did show that as time went on more attendees had some baseline knowledge of ACP processes and documentation and that both parts A and B of the ACPT had added to this. In addition the training allowed attendees to gain more insight into the actual process of having ACP conversations with patients and their families. It was also identified that further training in ePCS, DNACPR and LCP would be useful.

The current evaluation of the ACP training

From the data presented it can be seen that ACPT was attended by professionals from across NHS Ayrshire & Arran. Although the number of responses is very small and cannot be regarded as representative of all 250 ACPT attendees, nevertheless those who did respond acknowledged that the training had helped them in their practice. In particular they reported that they were more able to engage in the ACP process and more able to complete the ACP documentation. As in the evaluations for the ACPT training itself, the questionnaire data highlighted a need for further training. In relation to the numbers of ACPs actually being completed some professionals have not yet had the opportunity to do this while others are fully engaged in this practice. Indeed in a final comment one attendee remarked that they had initiated 75 ACPs since undertaking the training.

5.2. The attitudes and practices of users of ACP

This discussion of the main findings of the interview component of the evaluation will concentrate on three key areas:

1) The impact of the project on attitudes and behaviours of staff
2) The impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation
3) The impact of the project on outcomes for individual patients

1) The impact of the project on attitudes and behaviours of staff

Most respondents across all the clinical areas surveyed regarded the demonstration site as a worthwhile project and could identify positive differences that the introduction of formal ACP was making. Some of the regularly emerging themes included:

- It promotes holistic, person-centred care; patient autonomy

- It improves relationships between staff, patients and families
- It promotes openness, advance planning, choice
- It provides reassurance
- It improves communication
- It may reduce hospital admissions or prevent prolonged hospital stays
- it may make the patient’s preferred outcomes more likely
- It is particularly beneficial for people with long term conditions, non-malignant diseases and dementia

A significant proportion of the comments received, particularly from one of the sites visited, were critical of the implementation project and ACP generally. These focused around:

- Problems with the documentation (duplication; irrelevance; time consuming; need for review; sometimes over-ruled)
- Reluctance / Inability of residents or family members to engage in the process
- Some resistance from / communication difficulties with other professionals and other agencies

There was a discernible difference in attitude towards ACP as a result of engaging in the demonstration site and/or attending ACP training. This effect was noticeable across all the professional groups interviewed, although some variation between individuals was apparent. Attitudes were generally more positive and included:

- Feelings about self (more confident, aware, comfortable, focused, motivated; greater sense of satisfaction)
- Feelings about the process (beneficial; makes discussions easier; more valuable for all; advocates for patients; creates more openness)
- Feelings about the document (it supports staff)

There were, however, a number of negative attitudes including:

- Own feelings (uncomfortable; limited time)
- Feelings of patients (not appropriate; not wanted)
- Feelings about the document and process (a tick-box exercise; duplication; our agenda; difficult)
- Feelings about staff engagement (not universally accepted)

When asked about how the implementation project had affected their practice, a number of those interviewed made the point that the principles of ACP were not new to them (although the process and documentation may have been). However most reported that they were practicing in a different way with the main themes being:

- Being more proactive/forward-thinking
- Being more sensitive and patient; stepped approach
- Being more patient/family led
- Having conversations which are more structured (by the document)
- Advocating more
- Having a more inclusive approach (not just cancer)
- Taking more responsibility (not leaving to palliative care services)
- Working more collaboratively

One of the principal aims of ACP is to increase the likelihood that patients will receive their end of life care in their place of choice. When asked how having an ACP might affect this outcome, respondents were generally quite positive. Certainly most agreed that having a completed ACP *should* make dying in the place of choice more likely. The ways in which this might be achieved were given as follows:

- Having the patient’s wishes clearly documented
- Using the documented wishes in negotiations about place of care
- Empowering families to advocate on the patient’s behalf
- Communicating clearly with other professionals and other agencies

However the following circumstances were identified where the desired outcome might not be achieved:

- There is a rapid deterioration in condition
- A suitable bed may be unavailable
- The family forget, panic or are unable to cope
- The clinical condition makes transfer to another area necessary
- There is a lack of communication between professionals and between agencies

2) The impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation

This area of questioning was intended to highlight elements of practice in the clinical areas which were either enhancing or limiting the effectiveness of advance care planning for patients and residents. In particular, attention was given to the reasons why some patients do not have ACPs, or do not have their ACPs acted upon.

It was evident that some of the factors which might most commonly lead to a resident or patient not having an ACP were:

- Organisational culture/priorities
- Lack of time or lack of the “right” time
- Individual staff attitudes/behaviours
- Individual patient/family factors (for example cognitive impairment; patients/families who are unable/unwilling to participate; multiple agencies being involved in support and care planning etc)

The above factors might also be expected to influence the level of completion of any ACP documents which *are* initiated. The specific question about what parts tend to be omitted identified the following:

- The DNACPR form (for some clinical sites but not all)
- Repetitive questions
- Sections referring to treatments which have an uncertain outcome
- The sections entitled “Who is involved?”, “Likely prognosis”, “My wishes” and “What I like to do…”
- The SBAR

The section *least* likely to be omitted was identified as the Summary page

Respondents made a number of comments regarding how the documentation might be improved. These can be summarised as follows:

- Reduce duplication
- Make the questions less limiting
- Make the document more user-friendly
- Reword the ‘My wishes / what I would like’ section to capture more information about choices applying to the time *leading up to* the end of life

Assuming that an ACP document is in place and is completed satisfactorily, the situation can still arise where the ACP is not acted upon or is over-ruled. Taking all the responses together, the key factors influencing this critical outcome were identified as:

- Duty of care
- Unmet care needs of the individual
- Medical decision
- A change of mind on the part of the patient
- Unanticipated events
- Family intervention
- Failure of communication with Out of Hours or other services/agencies
- The ACP not being available or not being read

3) The impact of the project on outcomes for individual patients

The participants in the semi-structured interviews had no difficulty recalling examples of cases where the presence of an ACP led to the achievement of patients' preferred outcomes. Indeed the evaluation team were struck by the richness, diversity and large number of the vignettes offered. Sometimes there was uncertainty over whether the full process of ACP was carried out or whether it was simply the case that an "ACP approach" was taken. It must also be remembered that some of the cases described were outwith the demonstration site (although presumably were indirectly influenced by the increase in awareness of ACP which the demonstration site has generated). However the conclusion to be reached is that ACP is already delivering preferred outcomes for patients across the different clinical settings in the demonstration site. Specifically, there is evidence that the use of ACP is leading to unnecessary hospital admissions being avoided and is facilitating the discharge of appropriate patients from hospital back to the community.

Unfortunately the participants were also able to call to mind several cases where patients were unable to have their end of life care choices met. However by juxtaposing these two questions, and by positioning them at the end of the interview, participants were able to draw conclusions about the critical factors which they believe decide outcomes for patients. These can be summarised as follows:

- Relevant, detailed and timely conversations must take place and must involve the relevant people (and may involve an element of education about what choices are and are not possible and desirable)

- Those conversations should ideally take place within the context of an established relationship between professional, patient and family
- Those conversations must be documented in a format and in a place where they are accessible to present and future participants in the patient’s care
- Those documents should be kept up to date by a process of timely review and regular dialogue between professional, patient and family
- The information captured in ACP conversations and ACP documentation must be communicated (as appropriate) to GPs, to the Out of Hours service, to hospitals and to other agencies
- Systems must be in place (including local policies and agreed, cross-agency procedures) to ensure adherence to these standards
- Education must be in place to inform and remind staff of the importance of the ACP process

Other general factors considered to be supportive of a successful ACP process include:

- Decisiveness
- Early intervention
- Crisis planning
- Widening access (to include all relevant diagnoses)

Three specific, organisational issues which could potentially be barriers to effective delivery of ACP outcomes were identified as:

- The decision of some GP practices to adopt an abbreviated form of the ACP to satisfy the requirements of the Local Enhanced Service agreement (LES)
- The fact that some teams do not routinely update the electronic palliative care summary (ePCS) with information contained within the ACP
- The fact that some patients may have an ACP but may not yet have been added to a Palliative Care Register, and so may not be included on the ADOC/Out of Hours list of palliative patients.

5.3. The use of the ACP documentation

The findings of the documentation review suggest quite a lot of variation in practice between different care settings, teams and individuals. Some settings obviously took a rigorous and comprehensive approach to ACP and were able to provide all the documentation required to demonstrate this. The attitude taken towards ACP documentation in these settings demonstrated a commitment to a ‘thinking ahead’ philosophy. Clear recording of essential information and the use of the patient’s or resident’s own words within the ACP document were indicative of good practice. There was also evidence that a proactive approach from senior staff and a commitment to ongoing education and support were associated with greater rigour in ACP documentation.

Some settings and teams did less well in terms of the standard of their ACP documentation. The small number of plans available for review and the amount of missing information suggests that a consistent approach to completing the ACP documentation was absent. External influences such as organisational culture and senior staff retention and rotation may have affected practice in some areas.

The ACP documentation provided by the district nursing teams indicated that conversations regarding future care needs of patients were consistently taking place and a good amount of this information was documented within the ACPs. There was evidence of a consistent level of awareness of the process of ACP among the district nurses, even though one of the teams was from outwith the demonstration site. However the small number of completed documents available for review could suggest a lack of scope for internal monitoring of practice.

Some lack of information relating to carer needs and some inconsistency in the recording of dates and initials was evident in all care settings. This may indicate specific problems with the layout of the document but may also suggest inconsistent practice around the completion of the ACP forms.

6. Conclusions

This evaluation described here set out to explore the following six aspects of the effects of the project to implement the ACP process in the North Ayrshire demonstration site:

1. Impact of ACP training on knowledge and practice of participants
2. Impact of the project on attitudes and behaviours of staff
3. Impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation
4. Impact of the project on outcomes for individual patients
5. Attitudes of GPs towards ACP, attitudes of GPs towards the project as a whole and experiences of GPs of completing/using ACP
6. Impact of the project on rates of completion and enactment of ACP

The conclusions presented here correspond to each of these aspects:

6.1. Conclusions pertaining to ACP training

Impact of ACP training on knowledge and practice of participants

The data supplied by the implementation team were not collected in a systematic fashion and as such it is difficult to analyse them to provide fully meaningful results. In addition the changes made to the ACPT over time meant that the evaluation team were unable to compare the results of different cohorts. For instance it was noticeable towards the end of the training period that more attendees were commenting on DNACPR issues which is only a small part of the original NES (2010) training package. Overall, the data collected has shown that the ACPT has enhanced the knowledge and skills of professionals within the demonstration site (and possibly beyond). However a more rigorous approach to the collection of data, and more consistency in the content of the courses, would have enabled deeper analysis of the data.

The actual number of responses to the questionnaire for the current evaluation of ACP training was disappointing, and as such the results are neither representative of all ACPT attendees nor generalisable to other groups. However they give a snapshot of the opinions of a small number of ACPT attendees, which provides some evidence of the usefulness of the training and its impact on practice. It may be of use to follow up this small cohort of respondents in another year to see if they have started to complete ACP documentation and if they have any other comments about the ACP process.

6.2. Conclusions pertaining to the attitudes and practices of those using ACP

Impact of the project on attitudes and behaviours of staff

Most participants across all the clinical areas which were surveyed expressed positive views about ACP and the project to promote it in the demonstration site. Benefits for patients, families, staff and organisations were all identified. However there were also a significant number of negative comments received. This finding confirms that there is quite a lot of variation in attitude towards ACP. Some of these attitudes were certainly limiting the extent to which the formal ACP process was being carried out in the clinical areas concerned.

A number of changes in practice were identified and attributed to the effects of ACP training and/or the establishment of the demonstration site. One of the most recurrent themes was that advance care planning was being increasingly offered to groups of patients who would not necessarily have received it in the past (namely people with long term conditions, people with non-malignant diseases and people with a dementia).

Impact of the project on self-reported behaviours of individual staff with specific regard to completion of ACP documentation

The practice of the health care professionals interviewed with regard to ACP was influenced by a number of factors including organisational culture, local priorities, lack of time, own attitude and individual patient and family factors. While it might not be possible to influence patient or family circumstances to any great extent, the other factors in this list could potentially be addressed. Targeting support to influence organisational culture would seem to be a sensible starting point.

The interview data echoed the findings of the documentation review which suggested that there was quite a lot of variation in the extent to which individual ACP documents were completed. Certain sections seem to be consistently omitted, and better completion of forms may be achieved by understanding why these omissions occur and if necessary, altering the document accordingly.

Impact of the project on outcomes for individual patients

The evaluation uncovered numerous examples of good practice with regard to ACP in a variety of patients in the demonstration site (and beyond). Where it is applied appropriately and communicated effectively, ACP is already delivering patient choices including preferred place of care at the end of life. Numerous barriers to this process were identified, but so too were lessons which have been learned about what works well. Some specific organisational anomalies have been identified which could lead to failure to adequately communicate and deliver ACP decisions for some patients.

Attitudes of GPs towards ACP, attitudes of GPs towards the project as a whole and experiences of GPs of completing/using ACP

Only one GP was interviewed as part of the evaluation. Furthermore, the GP who took part had additional training in palliative care and therefore could not be regarded as representative of GPs in the demonstration site as a whole. Nevertheless the additional insight provided by this GP helped to complete the overall picture of ACP practice in the demonstration site and the aspects of practice which are or are not working well.

The responses of that particular GP demonstrated a thorough knowledge of and commitment to the principles and process of ACP. However the GP conceded that their involvement in the actual process of producing the ACP document was limited, having only been involved in compiling two documents since the demonstration site was set up. This finding suggests that GPs play a small role in compiling ACPs, the bulk of that task being carried out by community nurses and care home staff in conjunction with patients/residents and their families. Whether there might be an advantage to GPs playing a greater role in compiling ACP documents was not clear from the data collected (they already complete the DNACPR form in many practice areas). However it is probably accurate to conclude that it is more important that GPs are aware of and able to take into consideration the information contained within these documents.

Additional information about the role of GPs was gleaned from the responses of the other participants in the semi-structured interviews. All identified GPs (including Out of Hours / ADOC doctors) are crucial to the effectiveness of the ACP process. Some criticism was levelled at GPs, with the suggestion that they sometimes appeared to dismiss the preferences documented within a patient’s ACP. Certainly GPs can find themselves in conflict with the stated wishes of patients when a sudden change in condition might suggest that acute medical intervention is required. However there were other reported instances of GPs working well with the other members of the MDT to successfully deliver preferred outcomes for patients.

6.3. Conclusions pertaining to the ACP documentation

Impact of the project on rates of completion and enactment of ACP

The review of the documentation has indicated an overall understanding of the process of ACP by staff in the different practice areas examined. Nevertheless there was a lack of consistency in the use of the documentation within the demonstration site with different versions of the ACP document in use and variation in the extent to which ACP is used and forms completed. A change to the layout of the document to address the consistent omission of initials and dates may need to be agreed by users and the assessment of carers’ needs could be addressed with further training sessions. The overall ethos and approach of

Care Home A towards ACP documentation could be held up as an example of good practice and further education and support made available to areas which have not yet embedded ACP practice to the same extent.

A significant problem exists in that there appears to be no consistent auditing of ACP use in the different clinical areas. It would be extremely useful to have access to data such as how many ACPs are being completed in each area and how many patients meet the criteria for ACP but do not yet have a document in place. Such data would allow longitudinal monitoring of ACP use and would enable support and education to be targeted at the clinical settings which most need it.

6.4. Conclusions pertaining to the original aims of the evaluation

The original aims of this evaluation were to measure the extent to which the Demonstration Site contributed to:

- Reduction in avoidable admissions and visits to hospital
- Achievement of the patient's preferred place of care

As already stated, quantitative measurement of these outcomes was impossible, principally because of the large number of other factors which might have contributed to any effect. However it *is* possible to draw some pertinent conclusions from the qualitative data obtained.

The individuals interviewed were able to identify several examples of cases where admission to hospital was prevented (or stay in hospital shortened) by the presence of a completed ACP. It can be safely concluded that the advent of the Demonstration Site has resulted in greater awareness of the importance of ascertaining patients' choices with regard to hospital admission, greater use of ACP documentation to record such choices and more proactive efforts on the part of professionals to avoid hospital admissions where these are seen as contrary to patients' wishes. However whether these changes have resulted in a reduction in avoidable hospital admissions cannot be ascertained from these data.

Similarly, interviewees reported several examples where having a completed ACP led to patients achieving their preferred place of death. This process was not always smooth, and often involved additional input from professionals to ensure that choices specified in the ACP were actually met. Where the process of completing an ACP led to greater awareness amongst professional and family carers of an individual's choice of place of death, this definitely seemed to lead to more appropriate decisions being made at the end of life. It should be noted that when given the choice, at least some patients stated a preference to die in hospital (as opposed to home), and in at least one case this was achieved. Once again however, without definitive lists of preferred and actual places of death of all palliative care patients in north Ayrshire, it is impossible to conclude if the Demonstration Site led to a measurable change.

6.5. Conclusions from a quality improvement perspective

The first consideration when assessing the quality of a particular service is the extent to which service users and their views are placed at the centre of service provision. The fundamental basis of ACP is about gathering the views of service users and designing services around them. Several participants in this evaluation spoke about how ACP was empowering clients and placing them at the centre of what we do. A note of caution was introduced by the participant who questioned whether ACP was really “our” agenda and not the patient’s. Similarly, it is useful to reflect on the suggestion that the choices discussed with patients are not simply just the ones that the health care professionals regard as legitimate. Care must always be taken to ensure that ACP is not allowed to become a “tick box” activity.

The second consideration in assessing quality is the extent to which staff members are enabled to provide the right care in the right way. Once again, the participants in this evaluation gave numerous examples of how ACP enabled them to provide satisfactory outcomes for patients. One notable description of the process was “It gives you a big boost because you know you have done the job right”. Nevertheless there was some disagreement, and some frustration expressed by nurses who felt the line of questioning advocated by the ACP process was sometimes inappropriate or unwelcome. Carrying out a satisfaction survey with patients and relatives who had participated in an ACP process would be one way of checking if this standard was being reached.

The third indicator of health care quality asks about the extent to which measurable improvements in care outcomes are being achieved. In the present evaluation, the staff interviews (and to a lesser extent the documentation review) provided qualitative evidence that improvements in care are being achieved. There was consistent evidence of ACP being carried out and patients achieving the outcomes they had identified in terms of their end of life care. As already mentioned, a quantitative estimate of the impact of ACP on achievement of preferred place of death is impossible to achieve. This is partly because so many other factors can influence place of death, the population of end of life patients is so difficult to define and it is impossible to state with certainty if the final place of care was indeed the one chosen (many people deliberately choose “hospital” at the end of life even though “home” was their stated choice). Nevertheless it is interesting to speculate that the 27% reduction in HMSR at Crosshouse Hospital between the end of 2007 and the end of 2011 may have been further enhanced by the setting up of the demonstration site.

In March 2013, Health Improvement Scotland (HIS) published its quality indicators for palliative and end of life care in Scotland (HIS 2013). These indicators will have a major bearing on the practice of advance care planning. The four indicators are listed below with some preliminary observations:

Indicator	Observations
Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified	HIS states that if patients are identified as having palliative care needs then it becomes possible to assess and plan to meet those needs. Addition to the palliative care register is therefore seen as an essential early step.
Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan	HIS acknowledges that a number of different types of ACP documents are in use. However it states that “For the purpose of this indicator, the electronic palliative care summary will be used to measure the existence of a care plan”. This means it is essential that information is exchanged effectively between the different documents (see Recommendation 11).
Indicator 3: Increase in the number of electronic palliative care summaries accessed	This indicator highlights the importance of ensuring that ePCS is accessible to (and accessed by) acute services and other appropriate agencies.
4: Place of death	HIS has re-stated its commitment to see an increase in the proportion of deaths taking place at home. They acknowledge that simply ensuring that more people die in their place of normal residence does not necessarily mean that people are being enabled to die in their place of choice. However they will assume that “an increase in percentage dying in usual place of residence and a decrease in percentage dying in hospital would suggest people’s preferences are being met more often”.

A number of challenges to quality improvement in the facilitation of ACP within the North Ayrshire demonstration site were identified in the course of the evaluation. These included

- Aspects of design and planning such as:
    - The layout of the document

    - The system for obtaining patient consent for information to be shared

- Aspects of organisational / institutional contexts, professions and leadership such as:
    - The cultures of specific organisations which may not consider the ACP process a priority
    - The practices of certain professional groups which may not give adequate attention to the information contained within the patient's ACP
- Aspects of sustainability, spread and unintended consequences such as:
    - The need for refresher training for staff who have already attended ACP training
    - The need for robust systems to ensure effective sharing of the decisions contained within ACP documents (The Health Foundation 2012).

These challenges are addressed by the recommendations set out in Section 7.

7. Recommendations

On the basis of the evaluation conducted and the data presented here, the following actions are recommended to ensure the future quality and effectiveness of ACP practice in the North Ayrshire demonstration site:

1. Increase uptake of ACP training among under-represented groups including Social Services staff and NHS professionals other than nurses (especially doctors)

2. Investigate other sources of ACP training which staff may be accessing and take these into account when planning and targeting future training

3. Ensure that the attendance of care home support workers at ACP training is specifically measured

4. Standardise the evaluation of future ACP training so that accurate comparisons can be carried out

5. Make further training in ePCS, DNACPR and LCP available to personnel who have attended ACP training (or signpost to the NES website for national training materials)

6. Ensure follow up support for attendees at ACP training to ensure that they are making the transition to successfully initiating ACPs

7. Investigate (and if appropriate, challenge with support and education) negative attitudes towards ACP which prevail in certain clinical areas

8. Highlight clinical areas where ACP is being most effectively implemented and integrate the knowledge gained into future training

9. Continue to broaden access to ACP to include a wider range of patients including those with long term conditions, those with non-malignant diseases and those with a dementia

10. Utilise Protected Learning Time (PLT) and other opportunities to ensure that all GPs practicing in the demonstration site (both in and Out of Hours) have a working knowledge of ACP

11. Clarify and streamline how information about key patient choices such as preferred place of care is exchanged between the patient-held ACP, the abbreviated (LES) version of the ACP, the ePCS and the data passed to the ADOC/Out of Hours service

12. Ensure that a system is in place to confirm patient consent has been provided before ACP information is shared, and that rigorous processes are in place to protect patient confidentiality

13. Promote the universal adoption of a rigorous and comprehensive approach to ACP completion. This may involve promoting a ‘thinking ahead’ philosophy, sharing good practice, motivating senior staff and providing adequate training

14. Provide additional support to clinical settings where factors such as organisational culture and senior staff retention and rotation may be affecting ACP practice

15. Encourage internal monitoring of practice around ACP completion by case note review and audit

16. Gather robust statistics to demonstrate how many ACPs are being completed in each clinical area

17. Review the layout of the document based on knowledge of which sections are frequently omitted (for instance provide more space for initials/dates)

18. Assess the impact of having more than one version of the ACP document in use, and take action to standardise practice if necessary

Additional, strategic recommendations:

(1) An over-arching policy on ACP use (covering which patients should have an ACP completed, who should complete the ACP, the standard of completion that should be achieved, the need to obtain consent to share the contents with others and how those contents should be communicated to other agencies) should be agreed and implemented across all care settings.

(2) Additional ACP training should be offered until all relevant staff members have attended. All attendees at ACP training should be followed up after a certain period of time and provided with support to implement ACP in practice

(3) All participating care settings in the demonstration site should be audited on a regular basis to monitor the use of ACP documentation. This should include an assessment of the standard of completion of the document and an agreed course of action to be taken in the event of number of documents or standard of completion fall below an agreed level.

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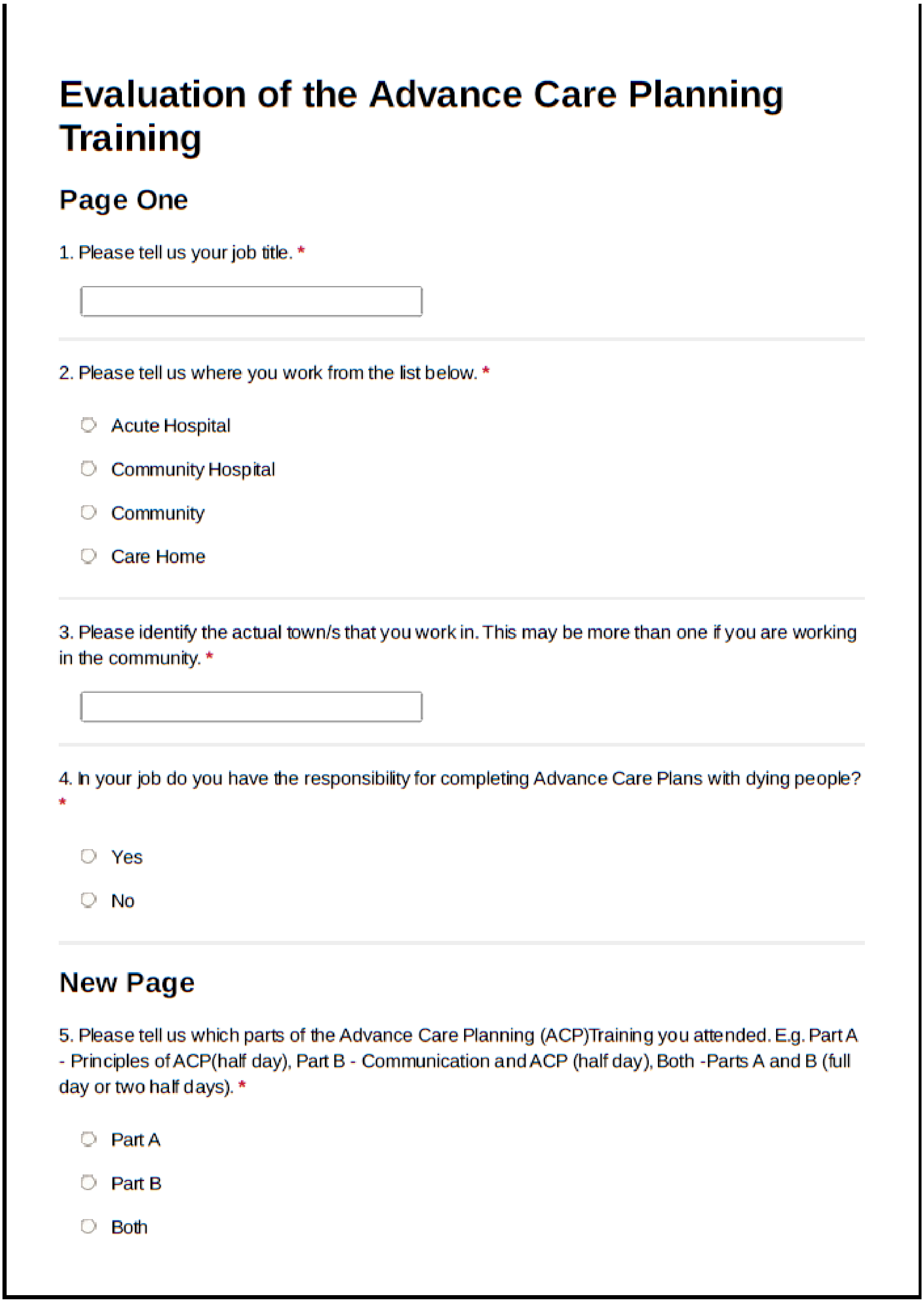
9. Appendices

APPENDIX 1

Electronic Questionnaire used in the current evaluation of the ACP Training



Evaluation of the Advance Care Planning Training

Page One

1. Please tell us your job title. *

2. Please tell us where you work from the list below. *

○ Acute Hospital

○ Community Hospital

○ Community

○ Care Home

3. Please identify the actual town/s that you work in. This may be more than one if you are working in the community. *

4. In your job do you have the responsibility for completing Advance Care Plans with dying people? *

○ Yes

○ No

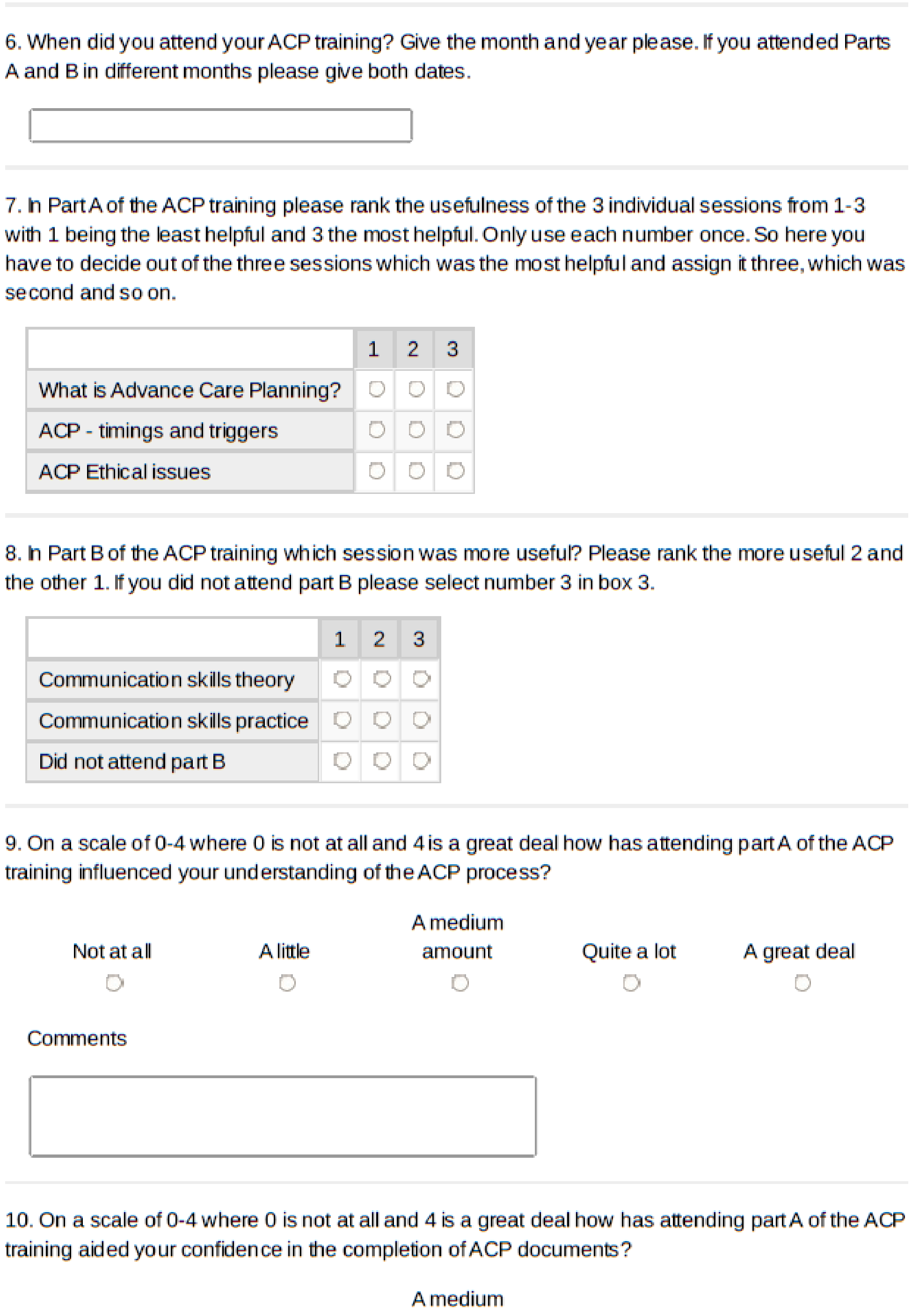
New Page

5. Please tell us which parts of the Advance Care Planning (ACP)Training you attended. E.g. Part A - Principles of ACP(half day), Part B - Communication and ACP (half day), Both -Parts A and B (full day or two half days). *

○ Part A

○ Part B

○ Both



6. When did you attend your ACP training? Give the month and year please. If you attended Parts A and B in different months please give both dates.

7. In Part A of the ACP training please rank the usefulness of the 3 individual sessions from 1-3 with 1 being the least helpful and 3 the most helpful. Only use each number once. So here you have to decide out of the three sessions which was the most helpful and assign it three, which was second and so on.

	1	2	3
What is Advance Care Planning?	○	○	○
ACP - timings and triggers	○	○	○
ACP Ethical issues	○	○	○

8. In Part B of the ACP training which session was more useful? Please rank the more useful 2 and the other 1. If you did not attend part B please select number 3 in box 3.

	1	2	3
Communication skills theory	○	○	○
Communication skills practice	○	○	○
Did not attend part B	○	○	○

9. On a scale of 0-4 where 0 is not at all and 4 is a great deal how has attending part A of the ACP training influenced your understanding of the ACP process?

Not at all	A little	A medium amount	Quite a lot	A great deal
○	○	○	○	○

Comments

10. On a scale of 0-4 where 0 is not at all and 4 is a great deal how has attending part A of the ACP training aided your confidence in the completion of ACP documents?

A medium

Not at all	A little	amount	Quite a lot	A great deal
○	○	○	○	○

Comments

11. On a scale of 0-4 where 0 is not at all and 4 is a great deal how has attending part B of the ACP training aided your confidence in discussing ACP with dying people?

Not at all	A little	A medium amount	Quite a lot	A great deal	I have not attended part B of the training
○	○	○	○	○	○

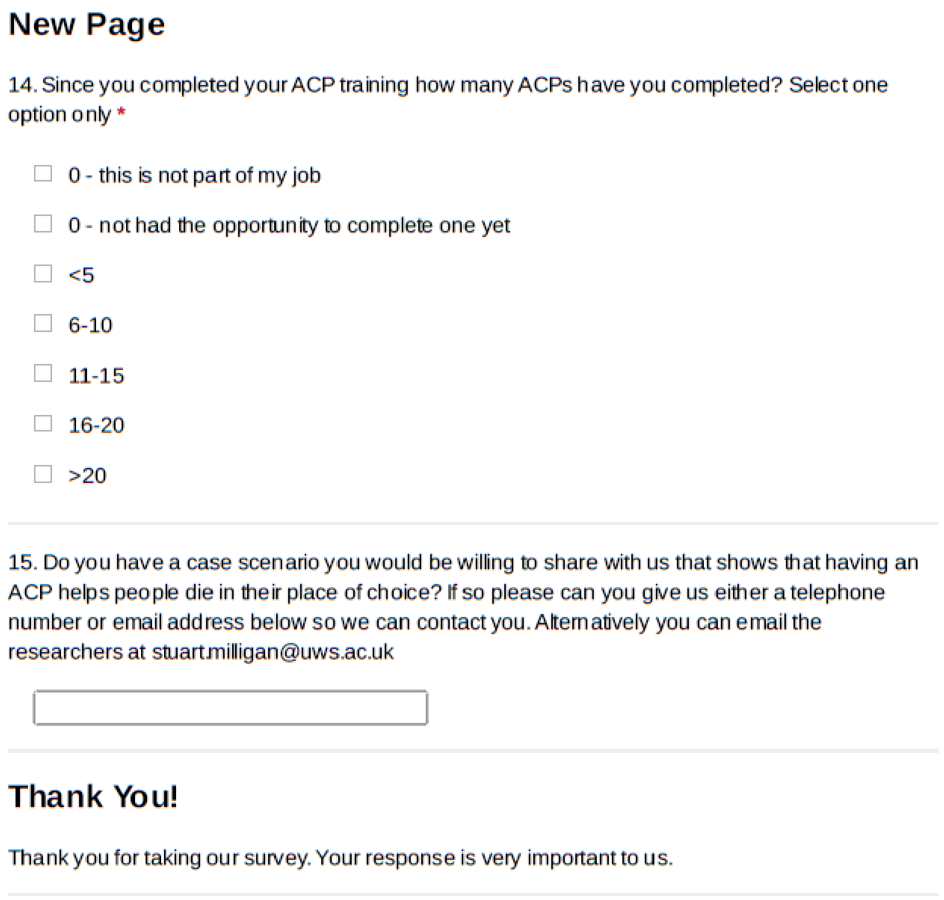
Comments

12. On a scale of 0-4 where 0 is not at all and 4 is a great deal how has attending part B of the ACP training aided your ability to complete ACPs with dying people?

Not at all	A little	A medium amount	Quite a lot	A great deal	I have not attended part B of the training
○	○	○	○	○	○

Comments

13. Please also give us any other comments you have about the ACP training that you attended.



New Page

14. Since you completed your ACP training how many ACPs have you completed? Select one option only *

- ☐ 0 - this is not part of my job
- ☐ 0 - not had the opportunity to complete one yet
- ☐ <5
- ☐ 6-10
- ☐ 11-15
- ☐ 16-20
- ☐ >20

15. Do you have a case scenario you would be willing to share with us that shows that having an ACP helps people die in their place of choice? If so please can you give us either a telephone number or email address below so we can contact you. Alternatively you can email the researchers at stuart.milligan@uws.ac.uk

Thank You!

Thank you for taking our survey. Your response is very important to us.

APPENDIX 2

ACP documentation used in the North Ayrshire demonstration site

NORTH AYRSHIRE COUNCIL

My Anticipatory Care Plan

NHS
Ayrshire
& Arran

This plan is for:

....

I prefer to be called:

....

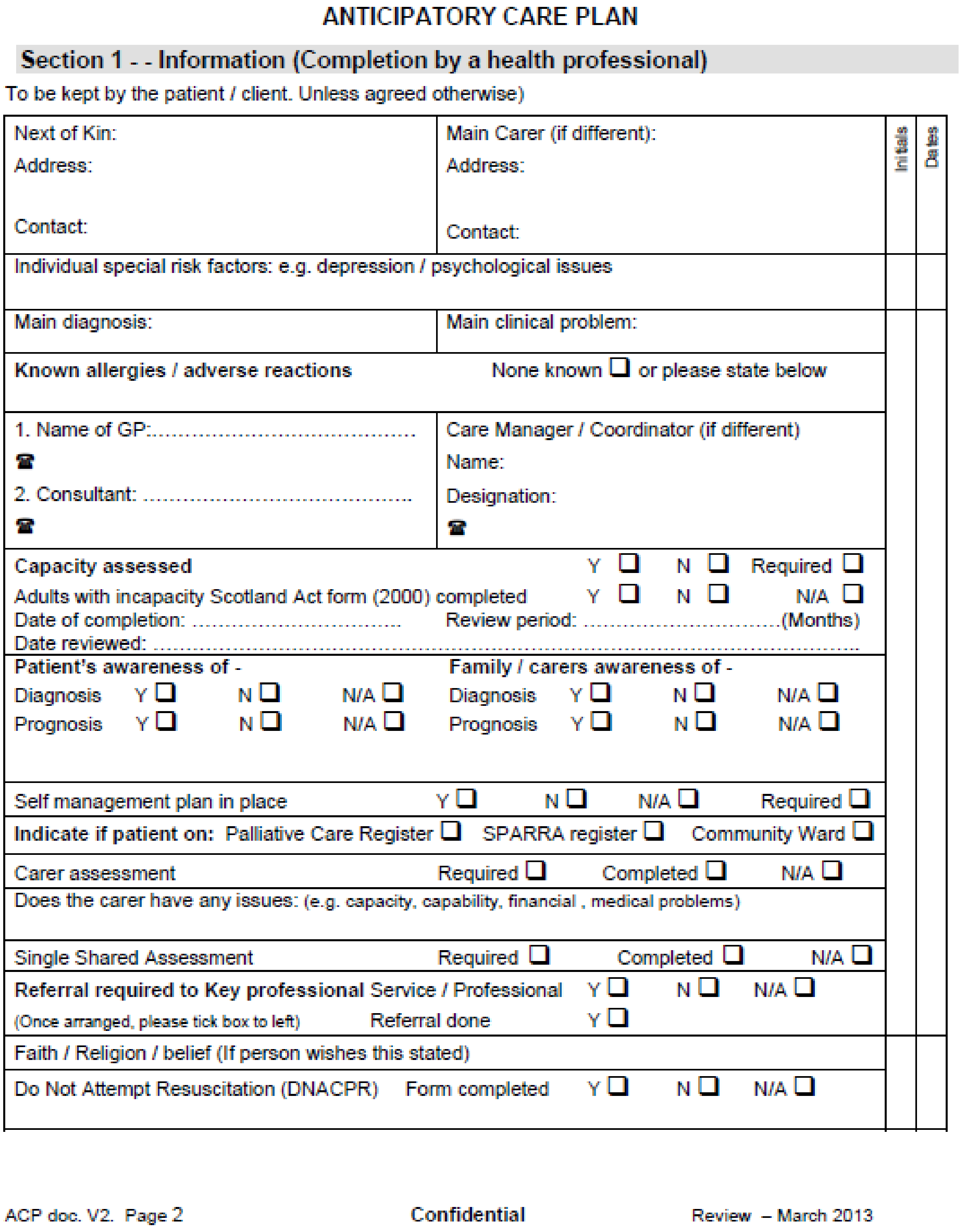
Community Health Index Number (CHI)
The CHI is the date of birth (6 digits) followed by 4 numbers ☐☐☐☐☐☐ ☐☐☐☐

Current Residence / Address

....
....
....
....
....
....

Patient's review should be a minimum 6 monthly / 12 months (delete as appropriate)

Review Date	Reviewed by	Date reviewed	Designation



ANTICIPATORY CARE PLAN

Section 1 - - Information (Completion by a health professional)

To be kept by the patient / client. Unless agreed otherwise)

Initials Dates

Next of Kin:
Address:
Contact:

Main Carer (if different):
Address:
Contact:

Individual special risk factors: e.g. depression / psychological issues

Main diagnosis:

Main clinical problem:

Known allergies / adverse reactions None known ☐ or please state below

1. Name of GP:...
☎
2. Consultant: ....
☎

Care Manager / Coordinator (if different)
Name:
Designation:
☎

Capacity assessed Y ☐ N ☐ Required ☐
Adults with incapacity Scotland Act form (2000) completed Y ☐ N ☐ N/A ☐
Date of completion: .... Review period: ....(Months)
Date reviewed: ....

Patient's awareness of -
Diagnosis Y ☐ N ☐ N/A ☐
Prognosis Y ☐ N ☐ N/A ☐

Family / carers awareness of -
Diagnosis Y ☐ N ☐ N/A ☐
Prognosis Y ☐ N ☐ N/A ☐

Self management plan in place Y ☐ N ☐ N/A ☐ Required ☐

Indicate if patient on: Palliative Care Register ☐ SPARRA register ☐ Community Ward ☐

Carer assessment Required ☐ Completed ☐ N/A ☐

Does the carer have any issues: (e.g. capacity, capability, financial , medical problems)

Single Shared Assessment Required ☐ Completed ☐ N/A ☐

Referral required to Key professional Service / Professional Y ☐ N ☐ N/A ☐
(Once arranged, please tick box to left) Referral done Y ☐

Faith / Religion / belief (If person wishes this stated)

Do Not Attempt Resuscitation (DNACPR) Form completed Y ☐ N ☐ N/A ☐

ACP doc. V2. Page 2 **Confidential** Review – March 2013

Section 1 - - Information (Completion by a health professional)

Initials | Date

In the patient's experience, is their condition likely to flare up (an exacerbation)? Y ☐ N ☐

What preventative measures or options have been agreed?

What treatment options agreed:

Date medication reviewed:

What would your patient like to happen if they themselves or their carer becomes acutely unwell?

In a Crisis or a change in the patient's condition what is their preferred place of care?
(Please specify clearly **what and in what** circumstances)

Does the patient want the relative / carer informed of this decision Y ☐ N ☐ N/A ☐

What are the patient's / family wishes re hospital care?

Is there a pre-existing Advance statement / Advance directive? Y ☐ N ☐ N/A ☐
If, yes who should we contact for this?

Does the patient have control of their financial affairs? Y ☐ N ☐ N/A ☐
If not, who does have control over their finances?

1. **Power of Attorney or** (re - financial or property) Y ☐ N ☐ N/A ☐
2. **Welfare Power of Attorney** (only effective after loss of capacity) Y ☐ N ☐ N/A ☐

Name 1 .... Contact number ....
Name 2 .... Contact number ....

Preferred place of care at end of life	**Preferred place of care at end of life**
....	....
....	....
☎	☎ ....

Please note details of those involved in this patient's care -

Name	**Relationship to you**	**Contact number**
....	....	....
....	....	....
....	....	....
....	....	....
....	....	....
....	....	....
....	....	....
....	....	....

ACP doc. V2. Page 3 **Confidential** Review – March 2013

Section 2 – My personal plan of my wishes

This section is for patient's to note their wishes

Patient's Name: ……………………………………………

Can the patient provide his / her own information for this section? Y ☐ N ☐

If you are completing this because the patient cannot provide their own information

Please record their wishes to the best of your knowledge of the patient.

Please note who completed this section ……………………………………………………………………

Relationship to patient ……………………………………………………………………………………

	Initials	Date
About your health, what changes have you noticed? **How have the changes been affecting you (the patient)?** **Have you thought about where you would like to be cared for in the future?** **For various reasons it may not always be possible to be cared for where you choose – have you considered any other options? Would you like to note this down?**		

Section 2 Continued My personal plan of my wishes

	initials	date
Things you need / want with you at all times e.g. teeth, hearing aid, glasses, photos, watch, handbag		
Things you would like to continue to do e.g. listen to music, go out for fresh air, have company and from whom?		
Special things you would like to do -		
Things that particularly distress you -		
If you are distressed, what helps?		

Section 2 Continued My Personal Plan of my wishes

Any additional information

Feel free to note questions you might want to ask anyone. Or to note anything else you think would be helpful to provide the right care or place of care.

I have a Will - Y ☐ N ☐ or Do not wish to discuss this ☐

I have a Funeral Plan / arrangement made – Y ☐ N ☐ Do not wish to discuss this ☐

You may Contact:………………………………………… about my will ☐ Funeral plans ☐

I have agreed to donate .. ……………………………………………………… organ (s) Y ☐ N ☐

Consent to share this care plan

Many health professionals may be involved in making decisions about your care. It will help you to receive the care where you wish if the information from this care plan can be shared with people such as your GP, Social Worker, Home Care Provider, Ambulance Service etc when needed.

Only information relevant to your care will be shared if and when it is required e.g. if you are admitted to hospital.

If you wish to know more about how your information will be shared, you may wish to talk to the Health Professional.

If you are happy appropriate information is shared with other services as required, please tick below.

If there is anyone or any organisation you do not wish information to be shared with, please state who / what below.

I understand how information about me may be shared, and have had the opportunity to ask questions. I am happy to share the appropriate / relevant information in this care plan.

Consent given Yes ☐ No ☐ N/A ☐

Given by (please insert name) ……………………………………………………………………

Relationship to patient ……………………………………………………………………………

Signed - Date -

Please do not share information with ……………………………………………………………………

Key Professional's log for patient (name) - ……………………………….

CHI number -

Or add a patient label with name and CHI

All entries to the ACP must be logged here and any admissions to hospital.

For ANY change to this plan, an SBAR form should be completed and sent to the patient's GP

Name	Signature	Designation	SBAR		Date
			Y	N	
			Y	N	
			Y	N	
			Y	N	
			Y	N	
			Y	N	
			Y	N	
			Y	N	
			Y	N	
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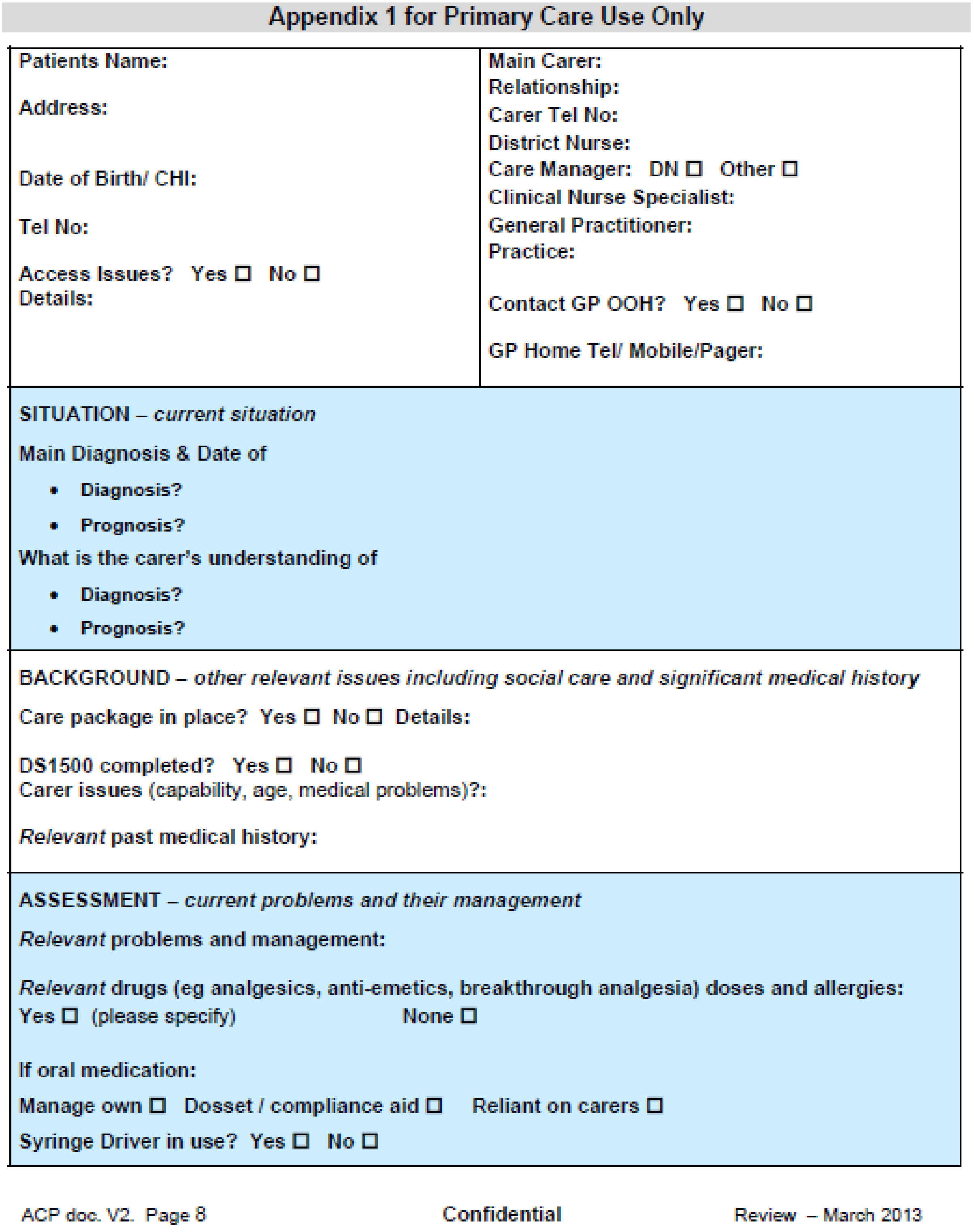
			Y	N	
			Y	N	
			Y	N	
			Y	N	
			Y	N	

NHS Ayrshire and Arran would like to acknowledge all the people who helped in the development of this document with particular thanks to: Mrs Irene Stevens, Macmillan Regional Coordinator for End of Life Care. NHS Lanarkshire, NHS Forth Valley, and The Preferred Priorities of Care Document, Lancashire and South Cumbria network June 2004.



Appendix 1 for Primary Care Use Only

Patients Name:

Address:

Date of Birth/ CHI:

Tel No:

Access Issues? Yes ☐ No ☐
Details:

Main Carer:
Relationship:
Carer Tel No:
District Nurse:
Care Manager: DN ☐ Other ☐
Clinical Nurse Specialist:
General Practitioner:
Practice:

Contact GP OOH? Yes ☐ No ☐

GP Home Tel/ Mobile/Pager:

SITUATION – *current situation*

Main Diagnosis & Date of

- **Diagnosis?**
- **Prognosis?**

What is the carer's understanding of

- **Diagnosis?**
- **Prognosis?**

BACKGROUND – *other relevant issues including social care and significant medical history*

Care package in place? Yes ☐ No ☐ Details:

DS1500 completed? Yes ☐ No ☐
Carer issues (capability, age, medical problems)?:

Relevant past medical history:

ASSESSMENT – *current problems and their management*

Relevant problems and management:

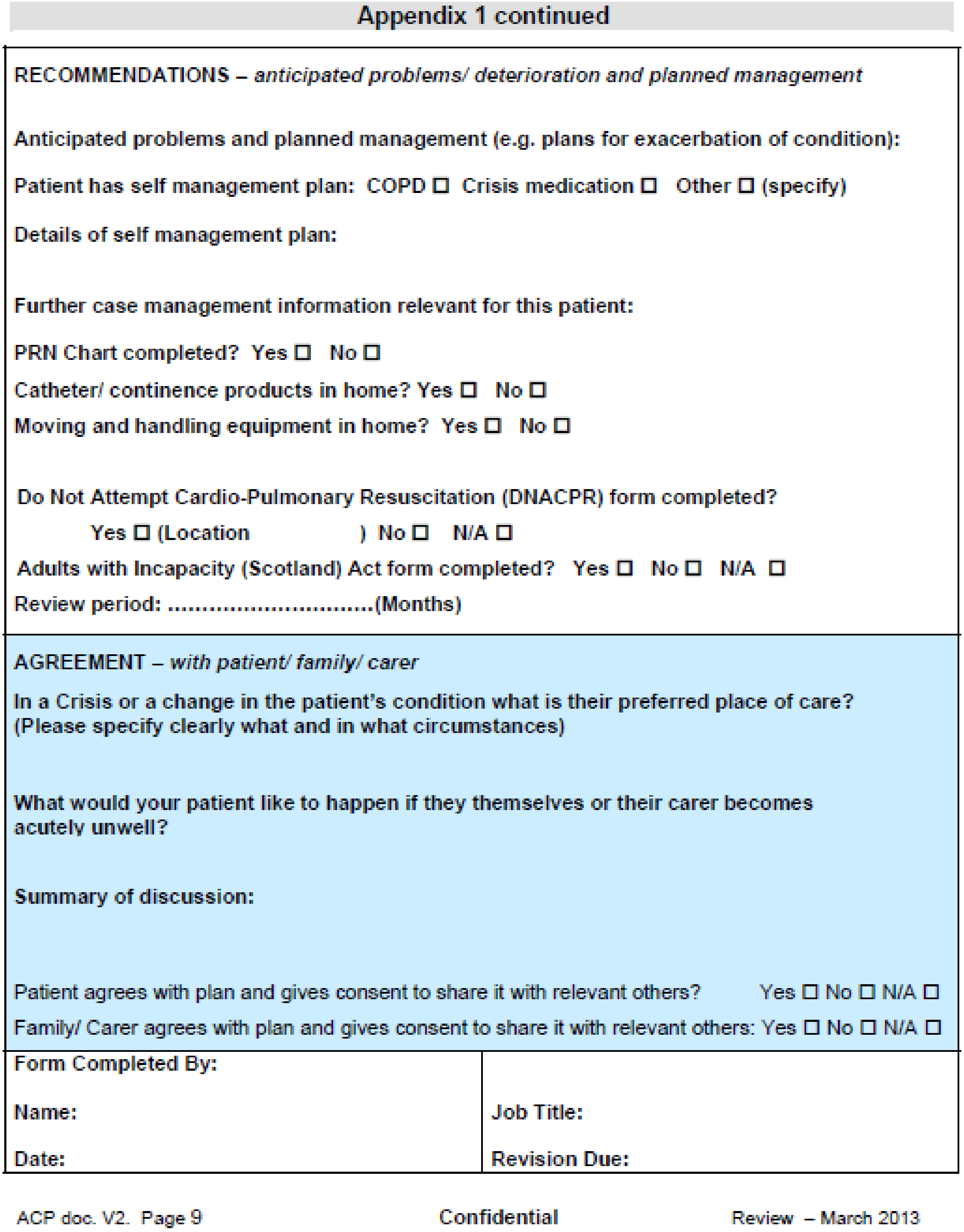
Relevant drugs (eg analgesics, anti-emetics, breakthrough analgesia) doses and allergies:
Yes ☐ (please specify) None ☐

If oral medication:

Manage own ☐ Dosset / compliance aid ☐ Reliant on carers ☐

Syringe Driver in use? Yes ☐ No ☐

ACP doc. V2. Page 8 Confidential Review – March 2013



Appendix 1 continued

RECOMMENDATIONS – *anticipated problems/ deterioration and planned management*

Anticipated problems and planned management (e.g. plans for exacerbation of condition):

Patient has self management plan: COPD ☐ Crisis medication ☐ Other ☐ (specify)

Details of self management plan:

Further case management information relevant for this patient:

PRN Chart completed? Yes ☐ No ☐

Catheter/ continence products in home? Yes ☐ No ☐

Moving and handling equipment in home? Yes ☐ No ☐

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) form completed?

Yes ☐ (Location) No ☐ N/A ☐

Adults with Incapacity (Scotland) Act form completed? Yes ☐ No ☐ N/A ☐

Review period: ....(Months)

AGREEMENT – *with patient/ family/ carer*

In a Crisis or a change in the patient's condition what is their preferred place of care? (Please specify clearly what and in what circumstances)

What would your patient like to happen if they themselves or their carer becomes acutely unwell?

Summary of discussion:

Patient agrees with plan and gives consent to share it with relevant others? Yes ☐ No ☐ N/A ☐

Family/ Carer agrees with plan and gives consent to share it with relevant others: Yes ☐ No ☐ N/A ☐

Form Completed By:	
Name:	**Job Title:**
Date:	**Revision Due:**

APPENDIX 3

Checklist for documentation review

The Evaluation of the Implementation of the Advance/Anticipatory Care Process (ACP) in the Demonstration Site in North Ayrshire.

Review Checklist for completed ACP documents

Date of review of ACP document ☐

Name of care setting ☐

Review number (at this setting) (e.g. 1, 2, 3...) ☐

Date of death of patient / resident concerned (please obtain this from the senior nurse present)

☐

Place of death of patient / resident concerned (please obtain this from the senior nurse present)

☐

Tick here to confirm that all individual identifying information has been deleted from this copy of the ACP (Name, Date of birth, Name of main carer, Name of next of kin). ☐

Now begin reviewing the ACP document....

************************************ FRONT PAGE ***

How much of this page has been completed (circle one)?

All Most Some None

Has the “Review” section been updated (circle one)?

Yes No Not appropriate

***************************** Section 1 Information (Page 2) *****************************

How much of this page has been completed (circle one)?

All Most Some None

Was a DNACPR Form completed (circle one)?

Yes No Not applicable

************************** Section 2 LES/DES Page 1 (Page 3) *************************

How much of this page has been completed (circle one)?

All Most Some None

************************* Section 2 LES/DES Page 2 (Page 4) **************************

How much of this page has been completed (circle one)?

All Most Some None

Was a DNACPR Form completed (circle one)?

Yes No Not applicable

What was the Preferred place of care?

************************** Section 3 My personal plan (Page 5) **************************

How much of this page has been completed (circle one)?

All Most Some None

First stated choice of place of future care?

Second stated choice of place of future care?

****************************** Section 3 Continued (Page 6) ******************************

How much of this page has been completed (circle one)?

All Most Some None

****************************** Section 3 Continued (Page 7) ******************************

How much of this page has been completed (circle one)?

All Most Some None

****************************** Key Professionals (Page 8) *********************************

How much of this page has been completed (circle one)?

All Most Some None

****

What is your overall estimate of how completely the ACP has been filled in? %

Any other comments:

APPENDIX 4

Raw data from the original evaluation of the ACP Training

NHS
Ayrshire
& Arran

Clinical Improvement Department

Eglinton House

Ailsa Hospital

Dalmellington Road

Ayr

KA6 6AB

Evaluation Results

Name of Course	ANTICIPATORY CARE PLANNING PART A - 2011
Date of Course	COLLATED RESULTS FOR PART A (from 2 sessions)
Venue	UNKNOWN
Trainers	UNKNOWN
No of Attendees	25
NHS	16
Care Home	04
Social Work/Local Authority	05
Other	
No of Evaluations Returned	20

SECTION 1 – PURPOSE OF TRAINING

	Yes	No	No Response
Intending to complete Part B	14		6
Facilitating Planning and Completion of Document	1	2	17
Interested in Providing Training	3	2	15

SECTION 2 – BASELINE KNOWLEDGE

Knowledge of Anticipatory Care Plan	Yes	No	Knowledge of Advance/Anticipatory Care Planning	Yes	No
	8	12		8	12

Anticipate what care need will be required for future health needs Anticipating the needs of the patient, having their views/values discussed and included Having a plan of care, planning ahead and having care plan in place in case the patient may require this to avoid unnecessary stress or wait for symptom relief Management plan in place in order to deal with a patient quickly and effectively at home Anticipate what care needs will be required for future health needs	Advance care plan to give required care Advanced to have all documentation so other services are aware Only in relation to Mental Health issues – re advanced statements preferred treatment etc. Advance care plan to give required care

NOT ON QUESTIONNAIRES	Yes	No	No Comment
Knowledge of Palliative Care Register (PCR) in GP Practices			
Previously Discussed with GP putting a patient on the PCR			
SECTION 3 – EXPERIENCE OF ACP			
	Yes	No	No Comment
Previously used an Anticipatory Care Plan (document)		18	2
Previously used Advanced/Anticipatory Care Planning	3	14	3
Experience in last 6 months	2	9	9
Expect to use either in future	17	1	2

SECTION 4 – TRAINING EVALUATION -						
	WELL	*OKAY*	*POORLY*	*Disagree*	*Disagree Strongly*	*No Response*
Well Presented	19	0				1
Suitable for Needs	23 YES	0 NO				
Length of session?	*Too Short*		*Just Right*		*Too Long*	
			11 (ONLY ON ONE BATCH)			

Why is it Important for patients to be on a Palliative Care Register? NOT ON THIS Q/AIRE
Please list 3 things that you have learned today
On one form like this:
1. What is ACP When to use it Who should be included and how to approach it – most significant
2. Go with what suits service user Confidentiality still important re family Can change
3. The actual acp and the morning session was in particular very interesting & relevant. I have had a few days training in palliative care at the hospice & could relate some of this – although not well The pm role play extremely beneficial – to be able to share/problem solve The DVD – discussion around DNACPR interesting
On one form like this:
Delegates were asked to outline 3 areas where they felt more informed as a consequence of the training and to highlight what they felt to be the most important area. The following table shows the areas in which delegates felt they had improved their knowledge and the areas they deemed to be of most importance. It should be noted that some delegates indicated one or more areas of equal importance.

Area of improved knowledge	Most important
Information on ACP and tools available to implement	5
Website contacts	1
Ethical decision making	1
Changes must be made in the way we look at palliative care	1
The gaps in communication between different disciplines	1
Knowledge of ACP paperwork	1
Involve the person to make informed choices about care	1
Identifying patients for palliative care framework	1
Palliative care indicator tools	
Other areas of improved knowledge: identifying patient for palliative care tool, structure, reinforced mdt patient review, support for staff, who participates, benefits, gp's to be more involved in patient care, Future of ACP, information re DNACPR, importance of communication between hospital, meeting other staff groups, when to commence ACP, promotion of ACP may shape delivery of services in future to work in partnership with NHS, Palliative care register – push GPs, capacity or non-capacity.	

OTHER COMMENTS
More attendance
Very interesting
Very informative and enjoyed all of this
The facilitators were very approachable & experienced in their own field – sharing knowledge & experiences. Also extremely passionate & caring – very good day!

Clinical Improvement Department
Eglinton House Ailsa Hospital
Dalmellington Road
Ayr
KA6 6AB

Evaluation Results

Name of Course	ANTICIPATORY CARE PLANNING PART A - 2012
Date of Course	COLLATED RESULTS FOR PART A (from 8 sessions)
Venue	
Trainers	
No of Attendees	101
NHS	14
Care Home	72
Social Work/Local Authority	14
Other	01
No of Evaluations Returned	96

SECTION 1 – PURPOSE OF TRAINING

	Yes	**No**	**No Response**
Intending to complete Part B	66	13	17
Facilitating Planning and Completion of Document	53	05	38
Interested in Providing Training	24	26	46

SECTION 2 – BASELINE KNOWLEDGE

Knowledge of Anticipatory Care Plan **10 = no answer**	**Yes**	**No**	**Knowledge of Advance/Anticipatory Care Planning**	**Yes**	**No**
	67	**19**		**38**	**40**

<table>
<tr><td></td><td></td><td></td><td>**18 = no answer**</td><td></td><td></td></tr>
<tr><td colspan="3">In general comments indicated a minimal understanding of relevance to future plans of care</td><td colspan="3">Comments re-iterated their understanding of the anticipatory care plan</td></tr>
<tr><td colspan="3">• Care plan that allows individual to plan what they would like/not like in future.
• Particularly for those who have palliative/chronic needs.</td><td colspan="3">• Your chance to discuss your future care & wishes to let people know what you want.
• More to do with likes and wises, generally about refusal of treatment.</td></tr>
<tr><td colspan="3">• End of life care plan. Planning for future and instructions to be followed.
• Knowledge of patient and family’s wishes.
• Planned care is formulated in anticipation of the problems that will have to be treated.
• Seeing the person holistically.</td><td colspan="3">• Where the disease process has progressed and the person has expressed their wishes for end of life care. This is formulated into a care plan.</td></tr>
<tr><td colspan="3">• Plan for end of life care: where/when/how.
• Care plan to identify interventions for terminally ill.
• Plan to improve care and obtain good death.
• Complete assessments via SPICT tool and reduce unnecessary admissions and pre-plan and document individual’s needs/wishes to provide dignified patient centred care.</td><td colspan="3">• To assess is plan is needed or how to implement to suit patients’ needs/choices.
• Plan of wishes.
• Process of discussion to find out wishes and communicate to others.
• Finding solutions to symptom management, wishes of service user.</td></tr>
<tr><td colspan="3">• Documentation – putting care plan in place so that patient/family wishes are met.
• Details of end of life care input from patient GP and family</td><td colspan="3">•</td></tr>
<tr><td colspan="3">• My understanding of ACP is to create a care plan which details the wishes of a person who requires care & support in the event that they become unwell due to exacerbation of present illness or other wishes to express how & where they wish to be cared for i.e. to remain at home within care home etc
• Documents completed by the MDT. Giving wishes</td><td colspan="3">• Ensure documents I completed as per anticipatory care plan
• Implement all aspects of care plan, including physical, social and psychological
• Person has capacity</td></tr>
</table>

to the resident making sure their wishes are met if possible • Document completed by service user, carers, family & GP. Detailing wishes of service user when condition deteriorates • Care plan discussed with person about wishes/choices for future care. The person does not have capacity • Deciding what you want to happen • Individual has an incurable disease the care plan should be initiated of what their wishes are if their condition will deteriorate • A care plan which documents and plans an individual's wishes and choices once it is appropriate to put this in place • If an individual has a chronic condition and/or is diagnosed with an incurable disease a care plan should be initiated of what their wishes are if their condition deteriorates • I believe that an ACP is a forward planning care plan which details an individual's wishes in the event that they become terminally ill. I believe that it encompasses the individual's wishes regarding DNACPR and their spiritual and religious beliefs & wishes, including their wishes of what should happen after their death • A care plan which documents the individual's wishes	• With non-capacity • Individual wishes and needs should be met • Advance is more for people with capacity • Anticipatory may be used for people who may have dementia and cannot express their wishes. So you have to anticipate wishes • I would consider it the same • When an individual with capacity anticipates what care they may require and their input
• An agree plan of action for patients for patients progression an treatment • Planning ahead to prepare for event/problem • Heard of it • Look up at planning future care for patients • Planning ahead; planning in advance; drugs in place	• An agreed plan for end of life • Discussion with patient future plans • Planned care plan that anticipates what's going to happen • Anticipating potential problems before they arrive

• Planning ahead; putting drugs/dressings in place in case of deterioration • Planning ahead in advance • Never heard of it • A care plan that anticipates care • Anticipating potential problems & putting equipment & getting prescribing completed by GP before problems arise	
• A care plan that has been put in place prior to palliative & end of life care • A plan for end of life care • To give advance instructions of what your wishes are • People state what their wishes are in advance of end of life care • A plan that is implemented for a person which discusses end of life care, cultural wishes etc • A care plan for end of life care • A method for people to express their wishes and preferences as and when they approach death • Outlining individuals wishes in the event of serious/terminal illness/end of life care ↑ • Plan of future care re end of life care/ of chronic condition • An individual person centred plan which includes the wishes of a service user	• A care plan that can be discussed with all concerned explained what would be best practice • Planning what individual's preferences of interventions where, when, how in end of life care • Identifying patients who are palliative and having discussions with pt/families/GP around future care needs • Planning ahead with a service user ensuring that their wishes are in place for the end of their life

	Yes	**No**	**No Comment**
Knowledge of Palliative Care Register (PCR) in GP Practices	65	26	05
Previously Discussed with GP putting a patient on the PCR	27	60	09

SECTION 3 – EXPERIENCE OF ACP			
	Yes	**No**	**No Comment**
Previously used an Anticipatory Care Plan (document)	10	85	01
Previously used Advanced/Anticipatory Care Planning	21	72	03
Experience in last 6 months	23	34	39
Expect to use either in future	70	08	18

SECTION 4 – TRAINING EVALUATION (Differences in questions)						
	Agree Strongly	***Agree***	***Neither Agree nor disagree***	***Disagree***	***Disagree Strongly***	***No Response***
Well Presented	41	39	01			01
	WELL	***OKAY***	**POORLY**			
Well Presented	12	1	0			
Suitable for Needs	41	39	02			
Suitable for Needs	12=YES	1=no answer				
Length of session? (Section missing in 4 forms)	***Too Short***		***Just Right***		***Too Long***	
			41			

Why is it Important for patients to be on a Palliative Care Register?

Delegates comments focussed on adhering to patient’s wishes, a high quality of care with a well communicated MD approach.

Responses included:

- For them to be open to holistic care and for health services to be aware of ACP.
- To die as they wish and prevent unnecessary suffering.
- So patients’ choices can be shared by services involved in care.
- Ensure appropriate support is provided.

- Quality of life.

Responses included:

- To ensure the best possible care that suits needs and that all members of the MDT know of wishes and care planned in advance.
- Administer best care.
- Enhance continuity of care and ensure patient and family wishes are met.
- Ensure everyone is aware of the plan.

Responses included:

- So all MDT is aware of the plan of care which is lacking in communication at the moment.
- To enable services to deliver interventions which allow people to pass away with dignity and respect.
- Introduces regular reviews from GP/SN etc.
- In order that other agencies are aware of their wishes for end of life.
- To improve communication between all health care professionals and to highlight patients most in need.
- To plan for changing or on-going changes in medical conditions as well as end of life wishes.
- To allow all professionals to be aware of condition thus allowing for appropriate care.

- So that patients wishes are met and to avoid inappropriate admission to hospital.
- To ensure needs and wishes are respected by all professionals and adhered to.
- Wishes known in MDT know planned care.

- To ensure all the MDT know and have access to the patient’s wishes
- To ensure the MDT know and have access to the patient’s wishes
- To ensure that their wishes are met through effective communication and documentation. So that unnecessary treatment i.e. CPR is not carried out – positive experience
- Holistic care for patients
- To ensure they receive all the care they require
- To ensure they have access to appropriate support & info

- In order to provide anticipatory care in their activities of daily living
- To avoid scenarios such as case study 1
- To ensure all needs and wishes are met
- That their needs and wishes are met by the MDT
- To ensure effective communication exists in order to provide most effective care

- It makes everyone aware of the service user and families wishes which wil assist the patient to live well and die well
- To enable GPs, A&E etc to be aware of the individuals wishes and needs
- Patients?? Then be known to our of hours services
- Patients cases get reviewed regularly
- To enable accurate and relevant information regards patients' health and needs to be passed and used between MDT
- In order to receive the correct care, in the correct place, at the correct time
- So they can be seen individually instead of waiting a certain time to be seen
- Patients can be known to out of hours services
- So that they are cared for where they wish to be cared for to prevent avoidable admission to hospital, let the GP know that it would be more probable to be symptom control
- So that the care needs are met as?? when they are needed
- To be given the correct treatment, meeting their needs and wishes
- To provide the correct care for those in the last year of their life
- To inform GPs, hospital doctors, district nurses etc that the patient is for palliative care
- So that all medical teams are aware of which patients are on the register which would allow patients to remain in own home to receive end of life care.

USEFUL ASPECTS/ 3 things I have learned	**1**	**2**	**3**
Definition of ACP	3		
Understanding ACP process	22	2	7
Cautions		2	2

Responsibility for implementation	1	1	1
Timescales	1		
Multi-disciplinary		1	1
Group Discussion	3	2	1
Identifying the need for ACP	1		
More about palliative care	5	3	
ACP documentation	2	2	1
DNACPR DVD		2	1
Triggers		4	1
Clinical indicators of advanced conditions/tools		2	2
Ethical and legal aspects	1	1	4
There is support from hospice/nhs and help to implement ACP			3
Issues of incapacity	1		
Palliative Care Register	3	5	2
Timings		3	1
Implementation/commencing of ACP/Anticipatory Care	3	2	1
Importance of anticipatory planning	2		
Linking ACP with palliative care and general process			1
When Palliative Care approach is required	1	2	2
Ensure wishes are met	1	2	
Importance of early intervention and collation of ACP	2		
SPICT	5	5	2
Who is involved			1
DNACPR	5	11	8
Benefits of ACP for all involved	3	4	
Opportunity to find out more/clarification about ACP	3	3	1

Review			1
Approach and sensitivity	1		
This is me		1	
Improved understanding of rationale		1	
Communication	1	1	4
Scenarios/case studies		5	
The clear presentation of the subject			1
Presentation slides	1		1
Handouts		1	
Difference between advance and anticipatory	2	1	
Useful contacts and websites for further knowledge			1
Advice on ACP		1	
Involvement of the service user/family	1		
Respect and understanding of the individual’s choices and their right to autonomy & their right to change their mind	1		1
Highlighting cautions			1
E-pcs		1	
Knowledge of DNACPR forms	1		
Importance of all relevant providers being aware of ACP			1
ACPs where appropriate		1	1
How good a death and good a life people can therefore have		1	
Potential wrong times to complete and ACP			1
Get the best results I can			1
Advance care planning when someone has capacity	1		
its ok to use the dying word			1
It’s not about the document but the discussion		1	
The timescale that ACP is developed and who is involved			2

Most delegates indicated that knowledge of ACP, timings, triggers and associated benefits was the most important aspect of the training with DNACPR highly noted. One delegate indicated a confusion between the Anticipatory Care Plan and Advance/anticipatory care planning.

OTHER COMMENTS

- Particularly enjoyed DNACPR video.
- Excellent information.
- Thoroughly enjoyed the course and the information to support me in my role.
- Very informative and have a great understanding of ACP.
- Helpful in reiterating goals and aims of ACP.
- Have been familiar with much of it through pilots but if not familiar would be an effective way of doing the groundwork etc.
- Training was helpful and will enable me to improve the quality of care I provide.
- Course very interesting for the future care needs of an increasing population.
- The whole experience was relaxed and beneficial.
- We booked and received confirmation for the full day but our names were not on the list.
- Very informative, has helped me think of how we can improve ACP and who can help us
- Nothing. I found it interesting & informative. After experiencing personal loos this is just the first palliative care course for 2 years. I found it just right for me at the moment. It has made me realise that palliative care is one of the most important aspects of my residents care and I hope to take this forward in my workplace
- Confusion in booking and not confirmation of booking
- Stated staff could not attend full day. However due to staff cover its easier to cover full day
- Having booked places by email were not on the delegate list for either morning or afternoon session.

Additional Training Needs (not a question on the forms (possibly comments by collator))

Information on power of attorney/guardianship
DNACPR
Possible DNACPR training need.

PART B TRAINING - COLLATED RESULTS 2011

Number of Courses	5 (all in March 2011)
Care Home	28
NHS	09
Social Services	01
Other/unidentified	01
total	39

SECTION 1 – GENERAL INFORMATION

	Yes	**No**
Completed Part A	36	3
Undertaken Communication Skills training	29	10

SECTION 2 – ABOUT TODAY'S TRAINING

	WELL	***OK***	***POORLY***	***Disagree***	***Disagree Strongly***	***No Response***
Was the training well presented?	39					
Was the training suitable for your needs?	Yes = 39					

	Too short	***Just right***	***Too long***
Length of session **Was it?** ***NOT ON THESE QUESTIONNAIRES***			

CHANGES	**OTHER COMMENTS**
Please suggest any changes you would make to today’s event:	

USEFULL ASPECTS-

Please rank the three most important areas for you in today’s training (1= most important)

What you benefitted most from - please rank in order of importance to you

Please list three things that you have learned from today

Topic	**1**	**2**	**3**
How to initiate the ACP conversation	7		
Taking the conversation at the patients pace and using silence comfortably	1		
Tube in fridge for meds etc	1		
Involve MDT	2		
Involve family	2		
How to approach ACP discussions	4		
What/right questions to ask	1	1	1
Effective communication skills	7	2	1
Environment		1	
Improved skills in discussing ACP/DNACPR		2	
Listening skills		3	
How to approach DNACPR	1	1	
Documentation	1	1	3
How to deal with issues that arise			1

Identify wishes/choices	1		1
Deal with difficult situations			**1**
Discussed real life situations & how to present ACP	1		
More familiar with the process, appropriate personal space etc	1		
One to one discussions	1		
DNACPR is a wider issue	1		
Importance of DNACPR	2		
How to deal with sensitive situations	2		
Importance of being timely	1		
Palliative scenarios	1		
FURTHER TRAINING – not on these questionnaires	**ePCS**	**DNACPR**	**LCP**
Please indicate if you would be interested in receiving further training on the following;			
Any other training? Please outline need			

Thank you for taking the time to complete the questionnaire.

PART B TRAINING - COLLATED RESULTS 2012

Number of Courses	7 (spread across 2012)
Care Home	52
NHS	25
Social Services	10
Other/unidentified	
Total evaluations	87

SECTION 1 – GENERAL INFORMATION

	Yes	No	**N/C**
Completed Part A	58	09	20
Undertaken Communication Skills training	64	07	16

SECTION 2 – ABOUT TODAY'S TRAINING

	WELL	***OK***	***POORLY***	***Disagree***	***Disagree Strongly***	***No Response***
Was the training well presented?	16	01				
	Agree strongly	**Agree**	**Neither agree nor disagree**	***Disagree***	***Disagree Strongly***	***No Response***
Was the training well presented?	21	39				
Was the training suitable for	19	40	01			

your needs?						
Was the training suitable for your needs?	Yes = 17					
Length of session **Was it? *NOT ON 4 QUESTIONNAIRES***	***Too short***		***Just right***		***Too long***	
			29		1	

CHANGES	**OTHER COMMENTS**
Please suggest any changes you would make to today's event: A bit of repetition but overall good Advantageous to have both parts in one day Suggested practical use of ACP documentation More case studies Handouts would be useful	

USEFULL ASPECTS-

Please rank the three most important areas for you in today's training (1= most important)

What you benefitted most from - please rank in order of importance to you

Please list three things that you have learned from today

Topic	**1**	**2**	**3**
ACP	1		1
silence		1	
When to discuss ACP	1	1	
Breaking bad news	1		
Triggers		1	1
documentation			1
Complexity of ACPs	1		

Completing the conversation			1
How to approach/start ACP discussions	3	2	
Open questions	1	2	2
Communication barriers		1	1
Communication skills	28	6	1
Communication with patient and family	1		
Benefits of early intervention	1	1	
Watching how others handle the situation		1	
Thinking of what you say and how	1	2	
Listening skills	2	2	
Seeing resident behind the disease	1		
Talking over difficult areas		2	
Case study	2		
Opportunity to improve care through ACP			1
Increased knowledge		1	
Up to date on happenings with GP/Professionals		1	
Aggressive discussions	1		
Power of attorney			1
Incapacity information		1	
DNACPR	1	1	2
How to deal with sensitive situations			
Body language		3	1
scenarios	1	1	
Sharing experiences	1		2
Role play/goldfish bowl	2	1	6
Group discussion	2		2

DVD	1	1	
Need to record all the facts		1	
Cues	1	1	2
Building relationship with patient			1
Importance of not shying away from difficult situations		1	
Relaxed atmosphere		1	
Future developments	1		
empathy	1		
Benefits to patients	1		1
Confidence in own ability		1	
Tackling emotional wellbeing	2	2	1
Discussing issues around death & dying		1	
ACPs not out in all areas	1		
How to speak to someone in palliative care	1	1	
Appreciate NHS staff difficulties		1	
timescale		1	
DNA CPR is still a grey area – will talk to resus			1
GPs need trained in this			1
resources			1
I think I have learned enough to help/assist/advise other staff on how to approach this			1

FURTHER TRAINING	**ePCS**	**DNACPR**	**LCP**
Please indicate if you would be interested in receiving further training on the following;	**20**	**27**	**23**

Any other training? Please outline need	

Thank you for taking the time to complete the questionnaire