Phase 2 GSF Acute Hospital Programme Evaluation – Final Report

The Gold Standards Framework Centre

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The Gold Standards Framework Centre

A report submitted by ICF GHK

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Document Control

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Executive summary

The Gold Standards Framework (GSF) aims to improve quality in end of life (EoL) care by formalising best practice using a systematic, patient-centred approach. The GSF aims include improving:

- The quality of care provided by generalist frontline staff;

- Coordination and communication across boundaries; and

- Patient outcomes by reducing hospitalisation, and enabling more to die in their usual place of residence.

The Phase 2 Gold Standard Framework Acute Hospital (GSF AH) programme was introduced to specific nominated wards in eight hospitals over a 12 month period between May 2011-May 2012. The GSF AH Programme provides a set of resources; a train the trainers programme; facilitator training and DVDs; on-going facilitator support; workshops; and independent evaluation.

The independent evaluation included an analysis of data yielded from the completion of staff surveys of confidence levels; organisational surveys examining the impact on ward processes; an online audit tool, the 'After Death/Discharge Analysis (ADA)'; and a focus group which elicited qualitative feedback from project leads.

Levels of local hospital support and implementation has been variable, usually due to workforce issues and competing demands on time. Implementation of the GSF AH has been of tangible benefit overall, and has begun to improve care for people nearing the EoL in hospitals, and their continuity of care in the community. In the relatively short timescale of the programme there is evidence of early impact in terms of achieving short term outcomes, namely in terms of staff knowledge, awareness, and confidence. Findings showed that some changes in practice are also beginning to emerge; longer term impacts are likely to emerge in the future, as this practice becomes embedded.

Improvements have been seen in staff confidence and some areas of practice

- There was an increase in staff knowledge and awareness about EoL care;

- There was an increase in staff confidence in caring for and recognising dying patients;

- There was an increase in early identification of patients nearing the EoL, and the introduction of electronic registers;

- There was an increase in use of the GSF, Liverpool Care Pathway, and Advance Care Planning/Preferred Place of Care tools;

- Care planning after EoL discussions increased for the majority of hospitals, and there was an increase in the proportion of staff routinely discussing EoL patients at MDT meetings;

- There was an increase in routine transfer discharge information of EoL wishes to primary care;

- There was an increase in the use of DNAR;

- Communication with carers improved for both discharged patients and those who died; and

- Length of stay decreased in some hospitals for discharged patients, and patients dying in their preferred place saw a modest increase with more hospitals reporting patients dying in preferred places at follow-up.

Some areas of practice require further improvement

- Identification of more patients on the register and offering early ACP discussions;

- Discussing care at an MDT, and having processes for recording MDTs saw a decline at follow-up;

- Communication with carers specific to patients' deteriorating condition and their concerns, wishes, and preferences remained unchanged; and

- Communication from primary care to hospitals remained poor at follow-up, with no hospitals reporting an increase in this.

1   Introduction

In developed economies, people live very different lives to those of fifty or a hundred years ago. Improvements in public health and advances in medical technologies have led to an aging population and increasing numbers of people living with serious and long-term illnesses later in life. Moreover, changes in patterns of work and family life mean that older people are also now more likely to live alone, placing an increased emphasis on the use of health and social care services.

There is a gap between where people die and where they would wish to die as demonstrated by a Demos report which stated that 60% of the half a million deaths each year in the UK occur in hospitals, compared to the 8% who would choose to die in a hospital.[1]

Nationally, estimated NHS costs for hospital admissions in the last year of life are around £1.3 billion for adults and £18.2 million for children. Demographic trends are set to increase these pressures. From 1981 to 2008, the percentage of the England's population aged 65 years or over rose from 15% to 16%, an increase of 1.1 million people[2]; and annual numbers of deaths are expected to rise by 17% from 2012 to 2030[3].

A recent collaborative report by the NHS confederation, local government, and Age UK[4] highlighted how care for older people is currently below the standard that would be expected by the NHS Constitution principles and rights. According to this report 'delivering dignity' requires person-centred care, and a change in the way services are designed, commissioned and monitored.

The Gold Standards Framework (GSF) aims to improve quality in end of life (EoL) care by formalising best practice using a systematic, patient-centred approach. As part of a broader approach to improve EoL care, the GSF Centre ran a Phase 1 pilot programme with acute hospitals in 2010 involving 12 hospitals (Phase 1 report available on request). Phase 2 of this programme was launched in May 2011. The programme delivers training and support based on three key elements:

1. Identification of patients in the last year of life;

2. Assessing EoL care on the basis of patient needs, symptoms and preferences; and

3. Planning to enable patients to live and die where they choose, cross-boundary care, and inter-professional team working.

1.1   This report presents an analysis of quantitative and qualitative data to describe the implementation and impact of the GSF in acute hospitals

ICF GHK was commissioned from October 2011-October 2012 to analyse evaluation data for Phase 2 of the GSF programme with acute hospitals. Eight hospitals[5] participated in Phase 2 of the programme, and completed the following quantitative surveys before and about a year after implementing the GSF in their hospitals:

■ **Staff Survey**: looking at knowledge and confidence in recognising deterioration and EoL, and in implementing the GSF;

■ **Organisational Survey:** looking at the effects on routine practice across the organisation (or wards participating); and

■ **After Death/Discharge Analysis (ADA)**: Looking at elements of practice and the patient experience.

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[1] Leadbeater, C and Garber, J (November 2010) *Dying for Change*. Demos.

[2] Office for National Statistics, population estimates.

[3] Gomes and Higginson (2008). *Where people die (1974- 2030): past trends, future projections and implications for care*.

[4] Commission on dignity in care for older people. (2012). *Delivering dignity*.

[5] Hospitals are numbered in this report to protect anonymity.

- In addition we collected qualitative data on implementation of the programme through holding a focus group with GSF leads from participating hospitals. The aim of this focus group was to ensure that contextual qualitative data could be captured to describe barriers and facilitators for implementing the GSF.

This document is the Final Report which presents the analyses and interpretation of the quantitative and qualitative data collected during the programme.

1.2 This report is structure in five further sections

Following this introduction to the research there are five remaining Sections supported by 4 Annexes:

Section 2 describes impact of the GSF at the level of staff;

Section 3 describes impact of the GSF at the level of patients;

Section 4 describes impact of the GSF at the level of organisational practice;

Section 5 describes the factors affecting the implementation of the GSF in acute hospitals;

Section 6 brings these findings to present a conclusion;

Annexes 1-4 present the research tools used for data collection.

2 The impact of GSF on staff knowledge and confidence to deliver end of life care in acute hospitals - results from the staff survey

> **Section Summary**
>
> - There was an improvement in staff knowledge, with a small-medium decline in the number of staff needing more knowledge at follow up.
>
> - More staff were aware of or had used EoL care tools at follow up, (over 85%). At follow up, more staff were also using specific EoL tools to identify patients – an increase from 12% to 67%.
>
> - Staff were already reasonably confident at baseline, in caring for patients nearing the EoL. This either stayed the same, or improved slightly by follow up.
>
> - There was no net change in staff confidence related to discussing EoL patients' deteriorating conditions with patients and relatives. Similarly there was no change in discussing concerns, personal wishes, and preferences with families/carers; a very modest increase was observed for these discussions with patients.

This section will present findings on how participation in the GSF programme impacted on outcomes at the level of staff. Findings come from an analysis of the Staff Survey data, comparing data at baseline and follow up to determine change.

A total of 358 completed Staff Surveys were received across both time-points. Staff outcomes described here are those relating to knowledge and confidence in:
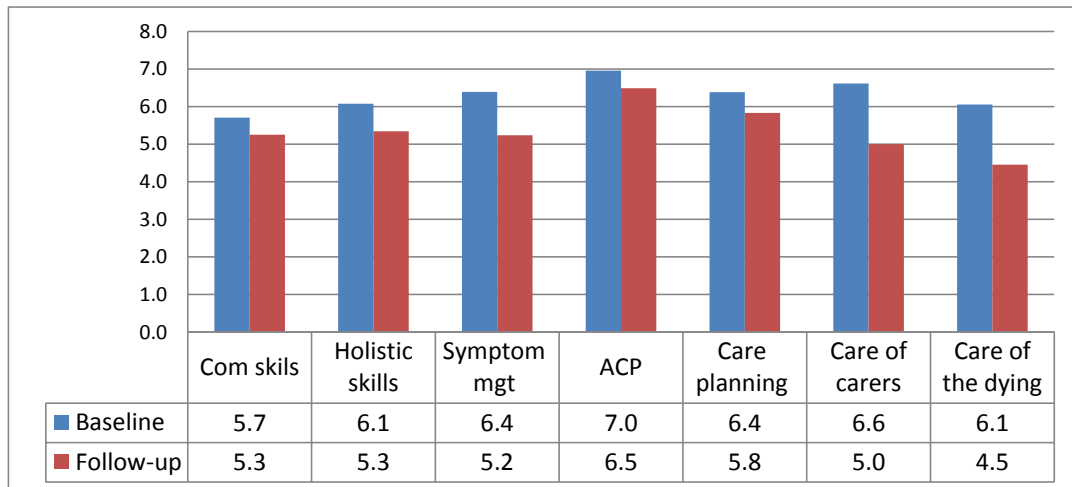
- Caring for people near the EoL; and

- Recognising those patients who are nearing the EoL.

The Section will end with a description of response rates, and the implications of these on the trends observed.

2.1 There was an improvement in staff knowledge and use of EoL care tools

Fewer staff needed more knowledge at follow up. Staff were asked to rate their responses on a scale of 1-10 (with one representing 'strongly disagree' and 10 representing 'strongly agree'), to the statement "*I feel I need to know more about the following area in EoL care*". The mean ratings at both time points are summarised in Figure 2.1 below. There were small-medium declines in all of the areas, suggesting that more staff were confident in their knowledge of EoL care as a result of implementing GSF.

Figure 2.1 **The mean responses to "I feel I need to know more about the following areas in EoL care"**

	Com skils	Holistic skills	Symptom mgt	ACP	Care planning	Care of carers	Care of the dying
Baseline	5.7	6.1	6.4	7.0	6.4	6.6	6.1
Follow-up	5.3	5.3	5.2	6.5	5.8	5.0	4.5

More staff were aware of or had used EoL care tools at follow up. Staff were also asked if they were aware of or had used the three national EoL tools, namely the Gold Standard Framework (GSF), the Liverpool Care Pathway (LCP), and the Priorities for Care (PFC), which is an example of Advance Care Planning (ACP). The proportion reporting 'yes (aware of)' or 'yes (have used)' were measured at each time point and the results are summarised in the figure below. As PFC and ACP are variations of the same tool, these data are reported as the proportion that said yes to either one or the other. There was a positive increase across all three. At follow up, over 85% had either used or were aware of each of these tools.

Figure 2.2 **Staff experience of National EoL tools**

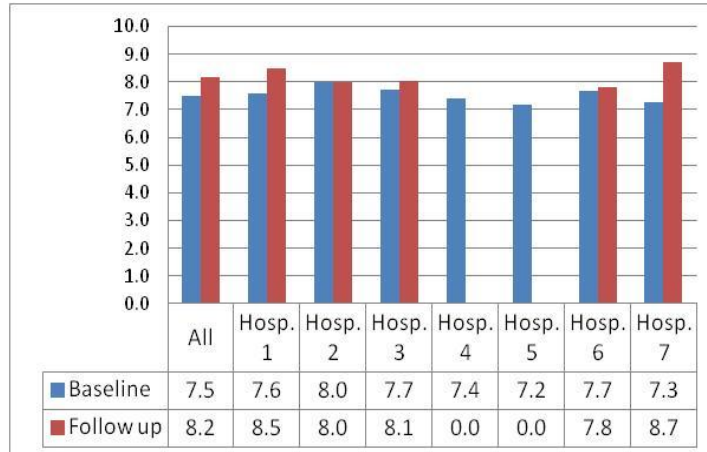|	GSF	LCP	Either PFC or ACP
Baseline aware	41%	29%	38%
Baseline used	7%	61%	14%
Follow up aware	37%	19%	64%
Follow up used	61%	80%	21%

Similarly, more people at follow-up were using specific EoL tools to identify patients. Such tools include the GSF prognostic Indicator Guidance or variations of this. In response to the question "*do you use any specific tools as a trigger to identify patients in the last year*" only 12% said yes at baseline, but this increased to 67% at follow up.

2.2 More staff felt confident in caring for and recognising EoL patients at follow-up

There was an increase in confidence in caring for EoL patients by follow-up. Staff were asked to rate their confidence in caring for people nearing the EoL, using the same 1-10 rating scale as previous questions. The results are summarised by total sample and each
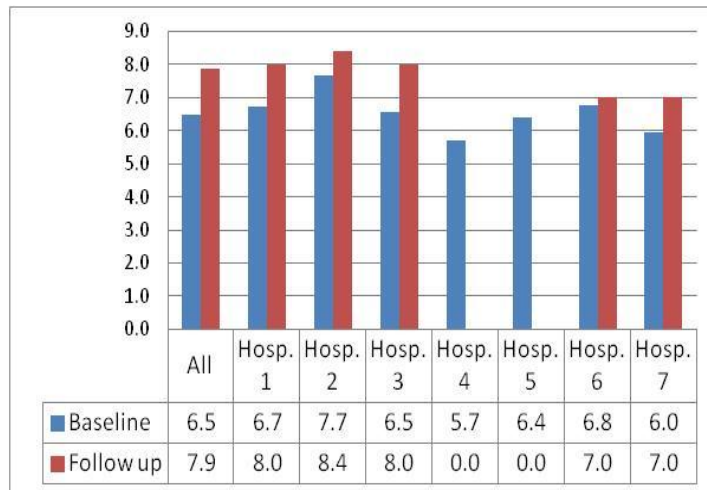
hospital in Figure 2.3 below. There was a mean increase across the total sample from 7.5 to 8.2, and individual hospital ratings also increased or remained the same at follow-up. This suggests that staff were already reasonably confident in caring for patients nearing the EoL, and that this either stayed the same or improved slightly as a result of implementing the GSF.

Figure 2.3   Staff confidence in caring for people nearing EoL improved in most hospitals

	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7
Baseline	7.5	7.6	8.0	7.7	7.4	7.2	7.7	7.3
Follow up	8.2	8.5	8.0	8.1	0.0	0.0	7.8	8.7

Staff were also more confident in recognising when EoL care should be implemented. They were asked to rate their confidence in recognising patients who may be in the last year of life. The results are summarised in Figure 2.4 below. This shows that the mean score for the total sample increased from 6.5 to 7.9 and that there was a positive increase in all hospitals where data were available.

Figure 2.4   Staff confidence in recognising patients in their last year of life increased

	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7
Baseline	6.5	6.7	7.7	6.5	5.7	6.4	6.8	6.0
Follow up	7.9	8.0	8.4	8.0	0.0	0.0	7.0	7.0

2.3   Confidence in communication on EoL care issues was variable

There was no net change in staff confidence related to discussing EoL care issues. Staff were asked to rate their response on the 1-10 scale, to the statement "*I feel confident in having open communication with patients and relatives about a patient's deteriorating condition*". The average score at baseline and follow up was 6.6, indicating no change. However trends in relation to this outcome were variable across hospitals. In hospitals 1 and 7 staff confidence improved, from a mean of 7.4 to 8.5 for hospital 1, and from 5.9 to 7.9 for hospital 7. Conversely there were moderate decreases in the mean ratings in hospitals 2, 3, and 6.

Figure 2.5   Staff confidence in discussing patients' deteriorating condition with patients and relatives

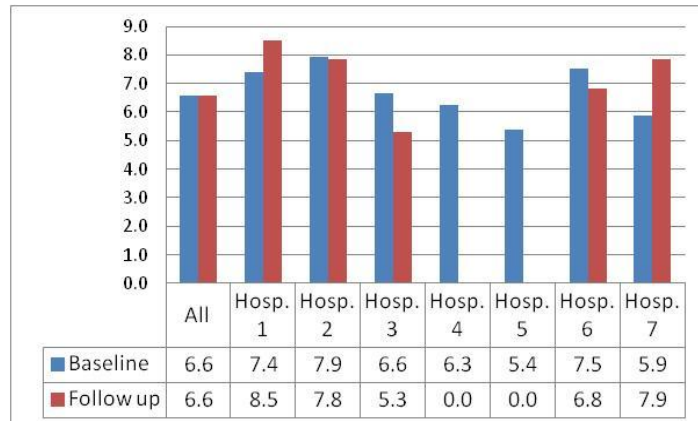|	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7
Baseline	6.6	7.4	7.9	6.6	6.3	5.4	7.5	5.9
Follow up	6.6	8.5	7.8	5.3	0.0	0.0	6.8	7.9

Figure 2.6 and Figure 2.7 below illustrate the change in staff confidence related to discussing concerns, personal wishes, and preferences. There was a very modest increase in the total sample (from 6.5 to 6.6) in confidence in discussing issues with patients, but there was no change in discussing this with family and carers (6.5 for both). Responses to both questions were variable by hospital. The mean score for both questions declined in hospital 3.

Figure 2.6   Staff confidence in discussing concerns, personal wishes and preferences with patients
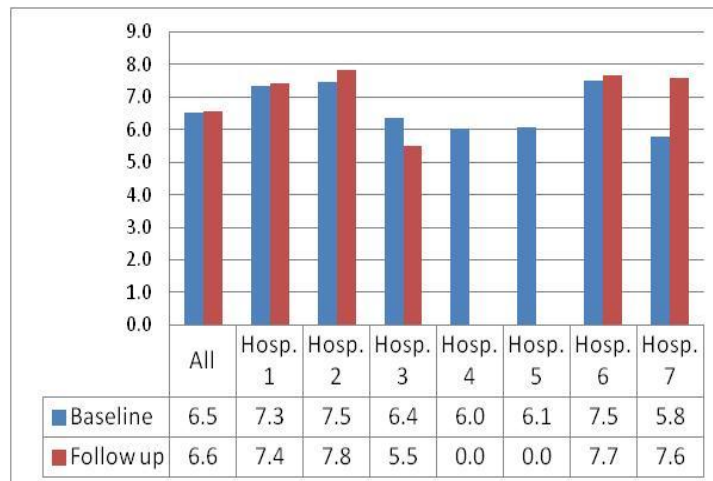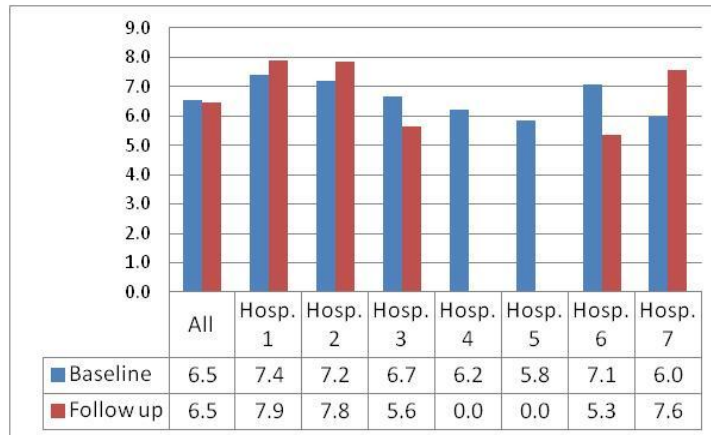
	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7
Baseline	6.5	7.3	7.5	6.4	6.0	6.1	7.5	5.8
Follow up	6.6	7.4	7.8	5.5	0.0	0.0	7.7	7.6

Figure 2.7   Staff confidence in discussing concerns, personal wishes and preferences with relatives and carers

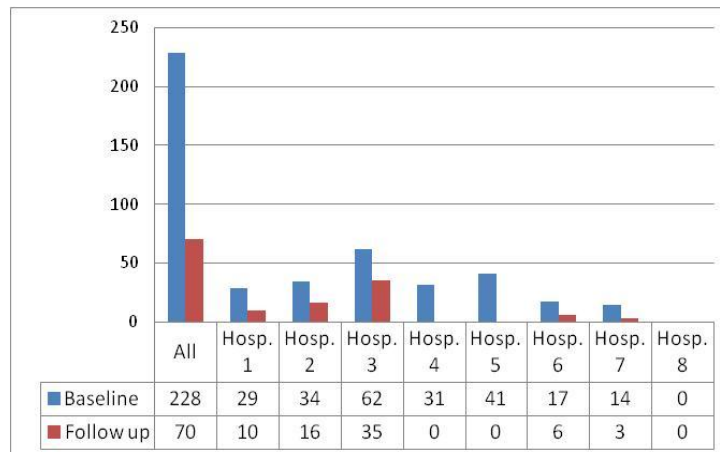|	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7
■ Baseline	6.5	7.4	7.2	6.7	6.2	5.8	7.1	6.0
■ Follow up	6.5	7.9	7.8	5.6	0.0	0.0	5.3	7.6

2.4   The response rate dropped at follow up; thus trends are biased towards certain hospitals

The response rate was almost three times higher at baseline compared to follow up and variable across hospitals. 288 responses were collected from seven hospitals at baseline, compared to only 70 across five hospitals at follow up. Hospitals 4, 5, and 8 did not submit any responses at follow-up and over half of the responses at follow up came from hospital 3.

The implications of this are that the trends identified across the total sample will be biased towards what happened in hospital 3, and may also be influenced by any pre-existing levels of knowledge, confidence, and practices in this hospital. In general results from the Staff Survey should be interpreted with caution due to the very small sample size at follow up for some hospitals.

Figure 2.8   The number of responses at baseline and follow up, by hospital

	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7	Hosp. 8
■ Baseline	228	29	34	62	31	41	17	14	0
■ Follow up	70	10	16	35	0	0	6	3	0

3   The impact of GSF on length of hospital stay and death in preferred place – results from the ADA audit

Section Summary

■ The majority of hospitals met the minimum recommendation for completing ADAs, and the patient samples at both time-points were comparable – primary diagnoses and main causes of death were similar.

■ Three out of six hospitals for which there were data available showed a decline in mean length of hospital stay, ranging from 2.5-17.3 days.

■ Figures for patients dying in their preferred place remained low, but did improve at follow up, (from 3% to 12%). Good practice also increased across hospitals, with the number of hospitals showing patients dying in preferred places, increasing from 2 to 4.

This Section will present data which shows impact at the patient level. Findings come from an analysis of the After Death/Discharge Analysis (ADA) data, comparing data at baseline and follow up to determine change. The total sample was split and analyses were performed separately for those that were discharged from hospital and those that died in hospital.

The Section begins with a description of the ADA response rates and patient sample, before describing outcomes related to length of hospital stay and patients dying in their preferred place. A total of 494 completed ADAs were received across both time-points.

3.1   All hospitals met the minimum recommendation for completing baseline ADAs; the majority also met these at follow up

Hospitals were asked to complete at least 15 ADAs for patients who had died, and 15 for patients who had been discharged. The number of ADAs completed by each hospital show that this requirement was met by all at baseline. At follow up the majority of hospitals met this requirement, with two not submitting any follow up ADAs (hospitals 7 and 8), and two others submitting inadequate numbers for each type of patient; hospital 3 completed two few ADAs for discharged patients (n=5) and hospital 5 completed too few for patients that had died (n=10). Figures 3.1-3.3 below show total response rates, and the sample splits at baseline and follow up.

Figure 3.1   The number of ADA responses at baseline and follow up, by hospital
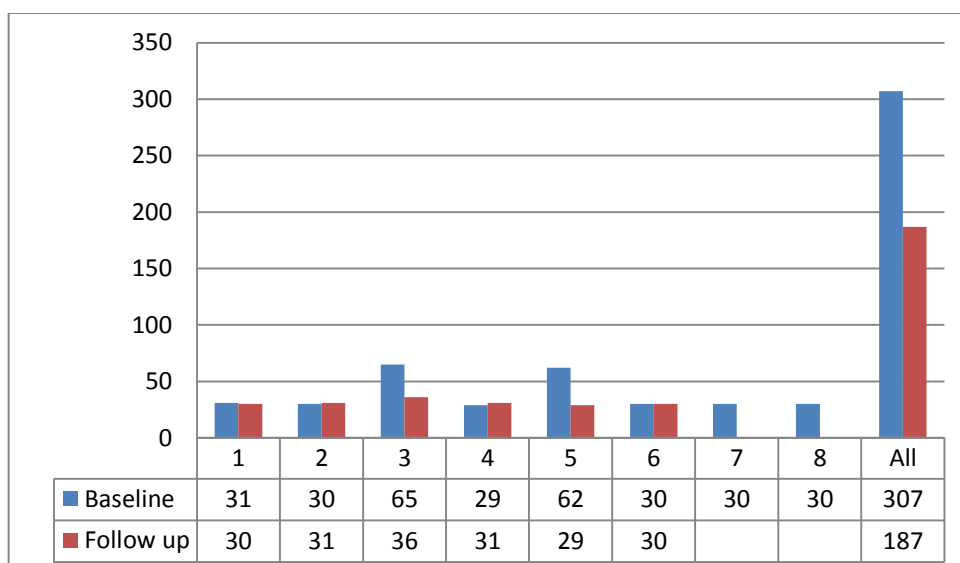

	1	2	3	4	5	6	7	8	All
Baseline	31	30	65	29	62	30	30	30	307
Follow up	30	31	36	31	29	30			187

Figure 3.2   The number of baseline ADAs for patient deaths and discharges

	1	2	3	4	5	6	7	8	All
Died	16	17	30	14	28	15	15	15	150
Discharged	15	13	35	15	31	15	15	15	154

Figure 3.3   The number of follow up ADAs for patient deaths and discharges

	1	2	3	4	5	6	7	8	All
Died	15	15	31	16	10	16			103
Discharged	15	16	5	15	18	14			83

3.2   The primary diagnoses at baseline and follow-up were similar; showing a comparable sample across both time-points

Cancer remained the primary diagnosis at baseline and at follow up, varying by only 1%. The rate of COPD/respiratory disease and heart failure also remained similar. Overall, cancer, COPD/respiratory disease, and heart failure accounted for around 64% of diagnoses at baseline, and 68% at follow up. The principal change between the two time-points was a significant reduction in the number of patients diagnosed with 'other e.g. neurological disorders', dropping from 16% to 4%.
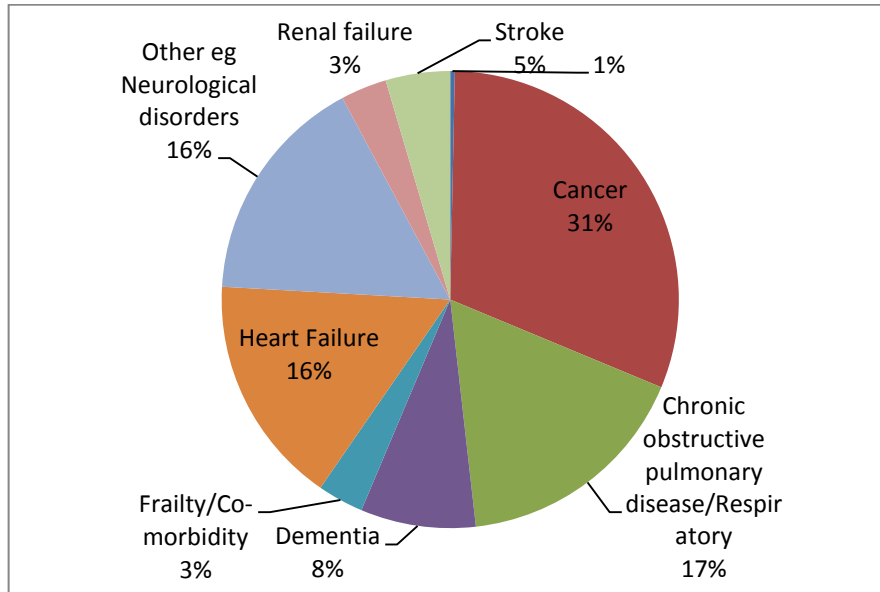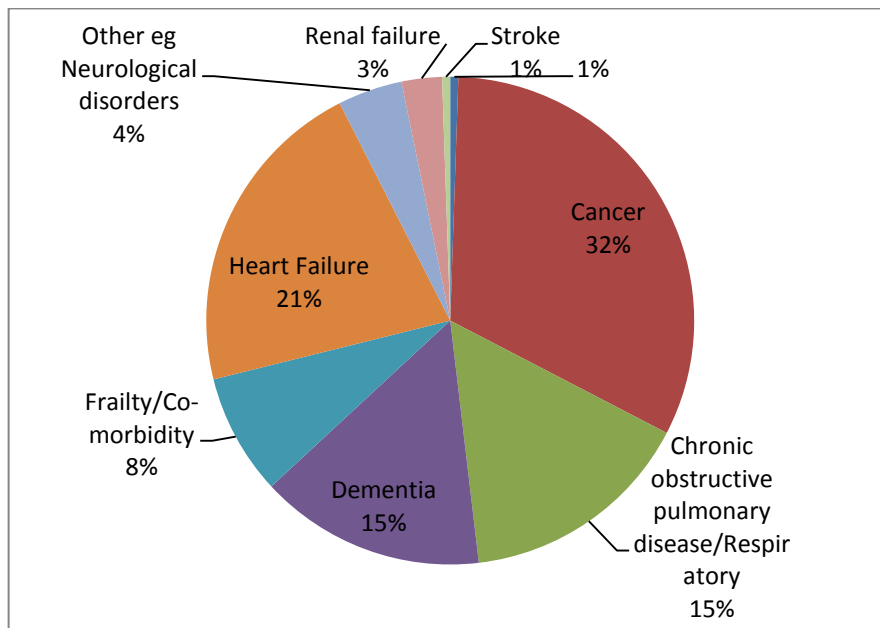
Figure 3.4   Primary Diagnosis at baseline

Pie chart — Primary Diagnosis at baseline:
Other eg Neurological disorders 16%; Renal failure 3%; Stroke 5%; 1%; Cancer 31%; Chronic obstructive pulmonary disease/Respiratory 17%; Dementia 8%; Frailty/Co-morbidity 3%; Heart Failure 16%

Figure 3.5   Primary Diagnosis at follow up

Pie chart — Primary Diagnosis at follow up:
Other eg Neurological disorders 4%; Renal failure 3%; Stroke 1%; 1%; Cancer 32%; Chronic obstructive pulmonary disease/Respiratory 15%; Dementia 15%; Frailty/Co-morbidity 8%; Heart Failure 21%

3.3   The main causes of death at baseline and follow up were similar to each other, and to the figures for primary diagnosis

The main cause of death at baseline and follow up was cancer, followed by COPD/ respiratory disease; this is in line with the primary diagnosis on admission. At baseline, 'other' was the 3rd largest cause of death, at 19%. This declined to only 2% at follow-up. Again, this reflects patterns seen in the primary diagnosis data.
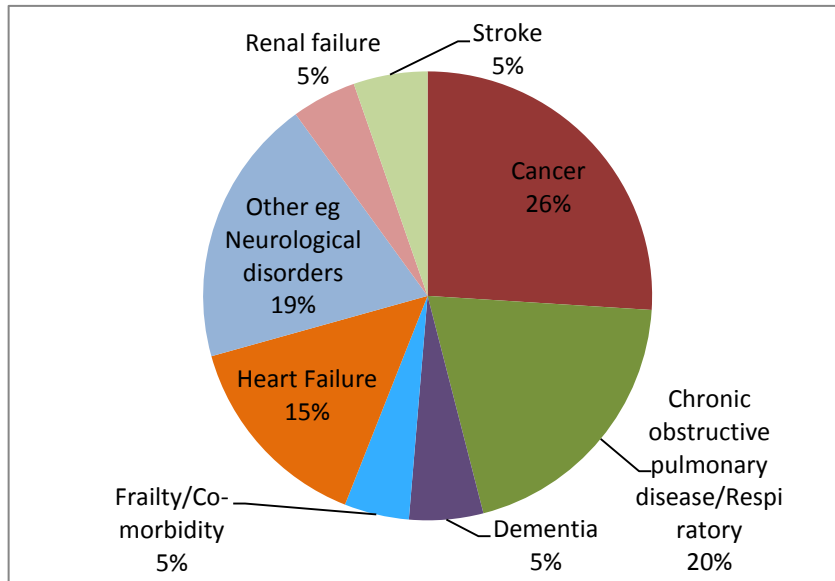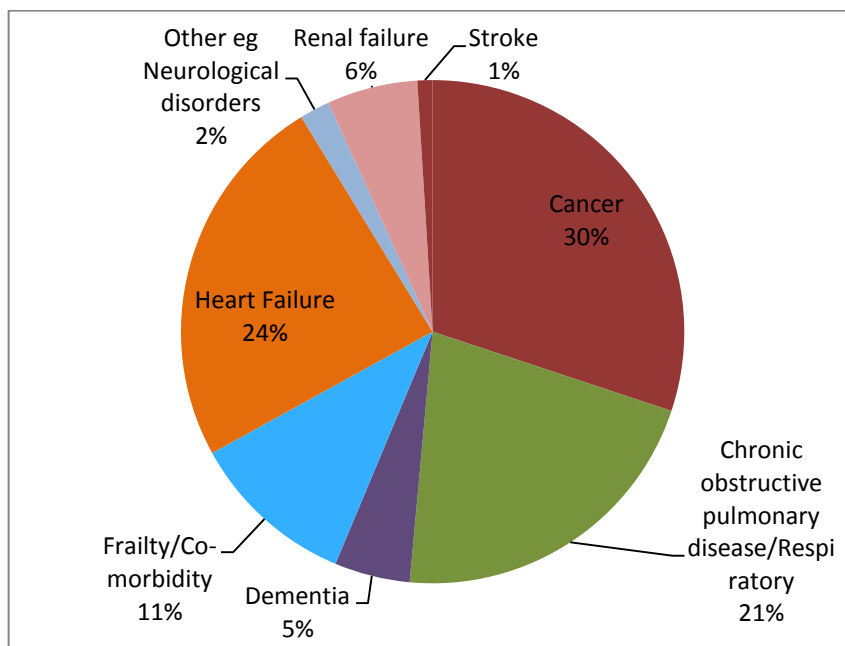
Figure 3.6   Causes of death at baseline

Pie chart showing: Cancer 26%, Chronic obstructive pulmonary disease/Respiratory 20%, Dementia 5%, Frailty/Co-morbidity 5%, Heart Failure 15%, Other eg Neurological disorders 19%, Renal failure 5%, Stroke 5%

Figure 3.7   Causes of death at follow up

Pie chart showing: Cancer 30%, Chronic obstructive pulmonary disease/Respiratory 21%, Dementia 5%, Frailty/Co-morbidity 11%, Heart Failure 24%, Other eg Neurological disorders 2%, Renal failure 6%, Stroke 1%

3.4   In some hospitals the length of stay for patients who were discharged decreased at follow up; yet there was an overall increase which may be explained by data outliers

Overall, there was an increase in hospital stay between baseline and follow-up for those who were discharged; however the mean length of stay varied considerably by hospital, at both time-points. Hospitals 1 and 2 showed a small increase in length of stay, whilst hospital 6 showed a very large increase; hospital 6 therefore heavily contributes to the overall increase observed.
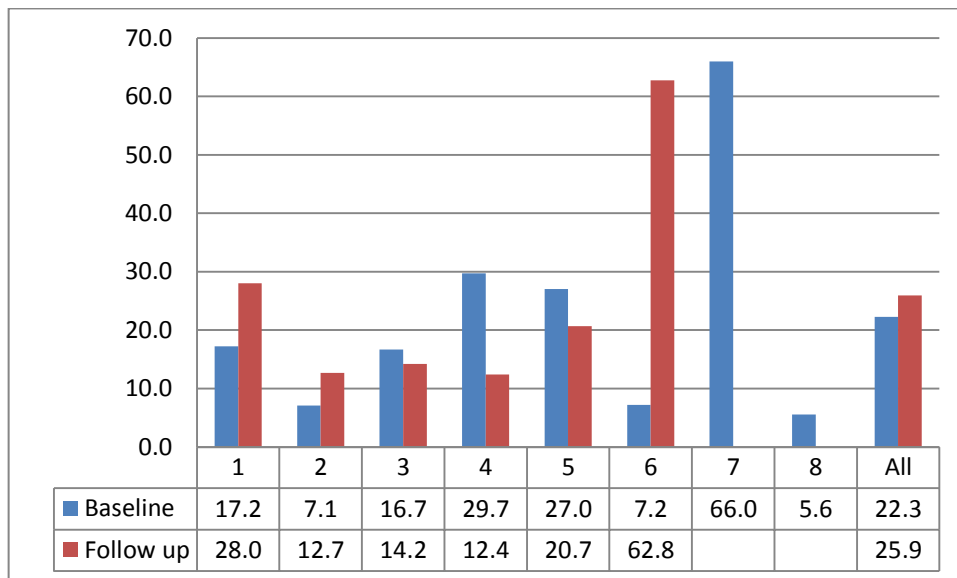
A closer consideration of the breakdown of data in hospital 6 shows that the majority of this increase is accounted for by 2 patients who stayed for 370 and 344 days. It is likely then that this large overall increase does not represent a general increase in length of hospital stay, but is affected by two outliers. If Hospital 6 is excluded from the average, then there is an overall decline in mean hospital stay of 1.9 days.

Hospitals 3, 4 and 5 all showed a decline in mean hospital stay at follow up. This decline was largest (17.3 days) for Hospital 4. Hospital 5's average length of stay declined by 6.4 days to 21 days, and Hospital 3 declined slightly by 2.5 days to around 14 days. Independent two-tailed t-tests were applied to check the significance of any changes. Overall, there was no significant change in the mean number of days between baseline and follow up.

Additionally, there was no significant difference between the means of any of the individual hospitals, apart from in hospital 4 where the length of stay was significantly lower at follow-up ($p=0.016$). The lack of a significant difference for the other hospitals could be partly a function of the very small sample size (around 15 for each round), whilst the insignificant overall change is probably a function of the large variance in mean length of stay between hospitals. It may also be possible that the full effect of implementing the GSF is yet to be seen for hospital length of stay.

Date of death was not recorded, therefore we were unable to calculate length of hospital stay for those patients who died in hospital.

Figure 3.8   Average length of hospital stay at baseline and follow up, for patients discharged from hospital

	1	2	3	4	5	6	7	8	All
■ Baseline	17.2	7.1	16.7	29.7	27.0	7.2	66.0	5.6	22.3
■ Follow up	28.0	12.7	14.2	12.4	20.7	62.8			25.9

3.5   There was an improvement in the number of patients who died in their preferred place, though figures remained low

150 patients died at baseline, and 103 at follow-up. At baseline, only 3% of patients died in their preferred place; this rose to 12% at follow up. Additionally, only patients in hospitals 1 and 2 died in their preferred place at baseline, this good practice extended to hospitals 4 and 6 at follow up. The number of missing data for this was also high, suggesting that this is only part of the picture. In around 60% of ADAs whether or not the patient died in their preferred place was not recorded; this declined only 3% between baseline and follow up, indicating that recording patient choice being met/unmet is still an area for development.

4 The impact of GSF on the quality of end of life care practice in acute hospitals - results from the ADA audit, Organisational Survey, and Staff Survey

> **Section Summary**
>
> - The use of processes to identify and asses patients improved; no hospital at baseline was using electronic registers, and by follow up this had improved to half the sites having these.
>
> - The number of patients with an Advance Care Plan/Preferred Place of Care doubled for discharged patients, and more than doubled for patients who died in hospital.
>
> - The hospitals for which there were sufficient data showed an increase in the percentage of patients on the rapid discharge pathway. The number of patients supported by integrated care pathways - such as the Liverpool Care Pathway - also increased.
>
> - There was an increase in the use of Symptom Control Assessment for both patients who died, and those who were discharged. It was more commonly used for those who died.
>
> - There was an increase in the use of DNAR/NCR/AND for both patients who died, and those who were discharged. It was more commonly used for those who died.
>
> - There were no observable improvements in the use of DS1500 forms; rates dropped at follow up for discharged patients, and for those patients who died the rate remained similar at follow up.
>
> - The ADA data show that for discussions with carers, there was a 20% increase in the overall percentage for both patients who died and those who were discharged; the rate remained at about 20% higher for those who had died. This contrasts with findings from the Staff Survey, which asks about more specific types of communication.
>
> - The ADA showed that for the majority of hospitals, care planning after EoL discussions increased, and that there was an increase in discussing EoL patients at MDT meetings. The Organisational Survey showed however, that there was a decrease in discussing care at MDT meetings, and in processes for recording MDTs and advance care planning discussions.
>
> - There were improvements in communication with primary care, with routine transfer of information to GPs and district nursing teams seeing an increase. However there were no responses indicating that organisations are receiving information from GPs, either at baseline or at follow up.

This Section will present data on outcomes at the level of organisational practice and wider systems of care. Findings come primarily from the ADA and the Organisational Survey, although some relevant findings from the Staff Survey are also included here.

Outcomes discussed include those which relate to codified practice through the use of specific EoL care pathways and tools. Outcomes related to communication practice are also described in relation to patients/carers; care teams; and across wider systems of care.

4.1 There was improvement at organisational level in the process for routinely identifying patients, and in the use of EoL care tools

The Organisational Survey measured change in routine practice, with each participating hospital being asked to complete a survey at both baseline and follow up. The survey contains 15 questions with response options for 'yes', 'no', and 'don't know'.

There were 8 completed surveys at baseline and 7 at follow-up. One participating hospital did not complete the baseline survey, and another did not complete a follow-up. One hospital completed 2 baseline surveys for 2 different wards.
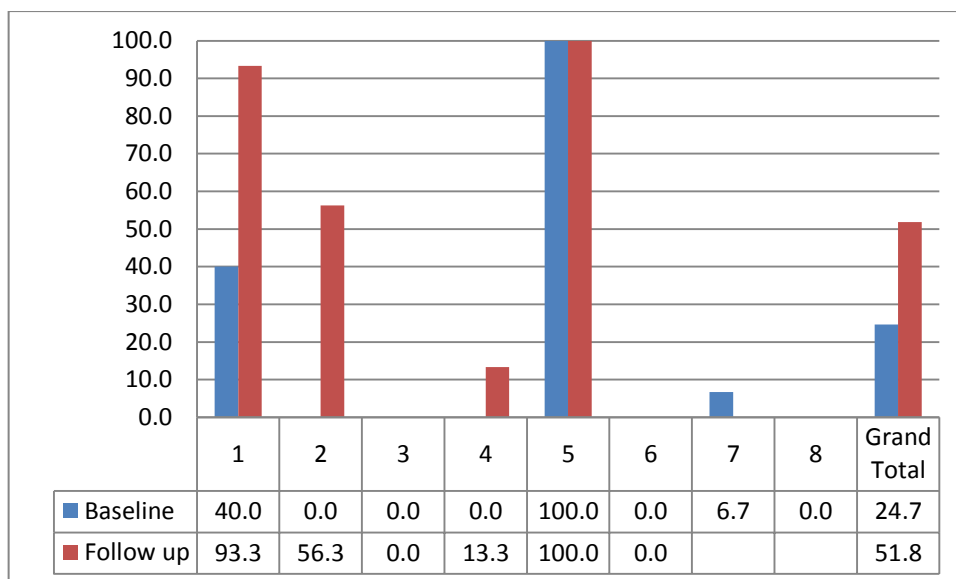
The Organisational Survey showed that the use of processes to identify and assess patients had improved at follow up. At baseline half the patients responded that they did use such processes, and by follow up all but one organisation responded that they did. The GSF also seems to have impacted on the introduction of electronic registration; no site stated that they used this at baseline, and half of the organisations were using it by follow up.

There was also a slight increase in the use of assessment tools, with 3 out of 8 organisations saying they used these in routine practice at baseline, and 4 out of 7 saying that they did this at follow up.

4.2 The number of patients with an Advance Care Plan or Preferred Place of Care improved
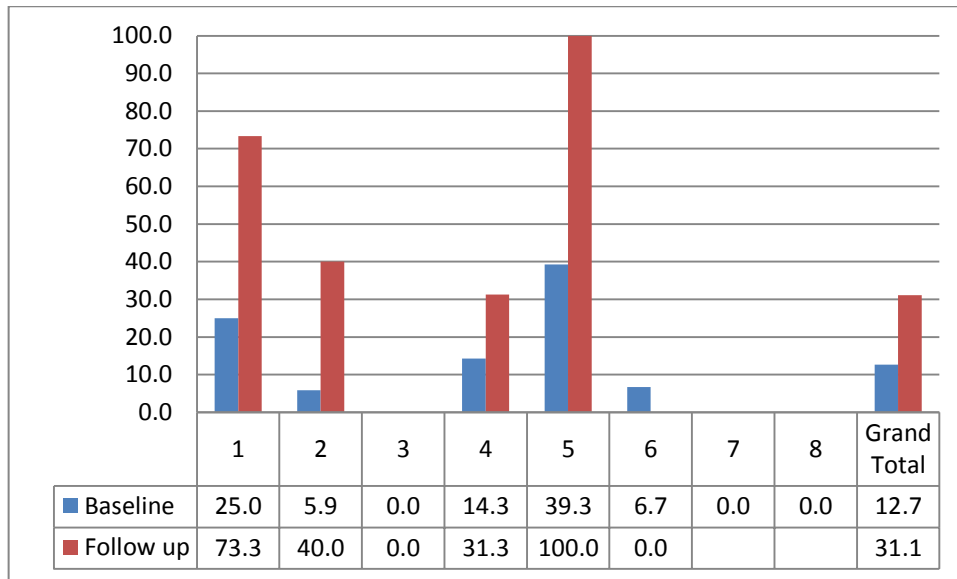
ADA data showed that overall, there was an increase in the percentage of patients who had an Advance Care Plan (ACP) or Preferred Place of Care (PPC) between baseline and follow-up. This was the case for both patients who were discharged and those who died. The percentage of those discharged who had an ACP doubled to just over 50%. Hospitals 1, 2 and 4 showed an increase (the latter two from a baseline where no ACPs/PPCs had been used), and hospital 5 maintained its 100%. Hospital 3 showed no change from baseline where ACPs/PPCs were not used for any of the patients that ADAs had been completed for.

Figure 4.1 Percentage of discharged patients who had an ACP/PPC at baseline and follow up, by hospital

	1	2	3	4	5	6	7	8	Grand Total
■ Baseline	40.0	0.0	0.0	0.0	100.0	0.0	6.7	0.0	24.7
■ Follow up	93.3	56.3	0.0	13.3	100.0	0.0			51.8

Patterns were similar for those patients who died, although figures at both time-points were lower than those for patients who had been discharged. Only 30% of those who died had an ACP or PPC at follow up, but this figure had more than doubled since baseline (13%), showing a similar level of improvement to that seen with patients who were discharged. Hospital 5 had only 40% of patients with these at baseline, increasing to 100% at follow-up to match their rate for patients who were discharged. Hospital 6 showed a decline of 7% - though in reality this amounted to a difference of one patient.
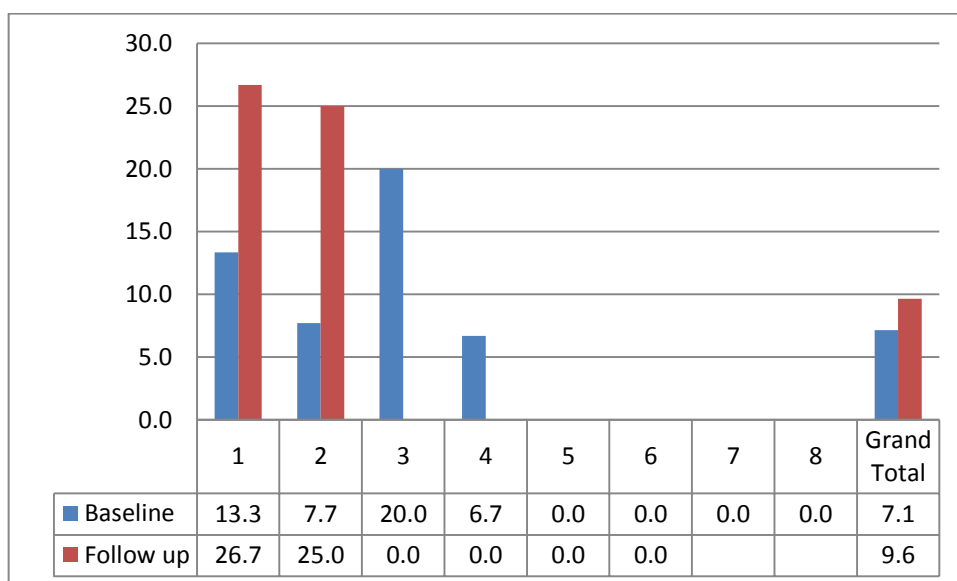
Figure 4.2 **Percentage of patients who died in hospital that had an ACP/PPC at baseline and follow up, by hospital**

	1	2	3	4	5	6	7	8	Grand Total
Baseline	25.0	5.9	0.0	14.3	39.3	6.7	0.0	0.0	12.7
Follow up	73.3	40.0	0.0	31.3	100.0	0.0			31.1

4.3 There was a slight overall improvement in the percentage of patients on the rapid discharge pathway, though only two hospitals completed follow-up data on this

ADA data show that for discharged patients there was a slight overall increase (from 7-10%) in the percentage who were on the rapid discharge pathway. This increase was entirely accounted for by hospitals 1 and 2. Hospital 1 roughly doubled the proportion of patients using this pathway to nearly 30%, whilst hospital 2 more than tripled their usage to 25%. Hospitals 3 and 4 presumably stopped using this pathway after the baseline, as indicated by no patients for whom ADAs were submitted at follow up being on the pathway. There was no reported use in the other four hospitals, at either time-point.
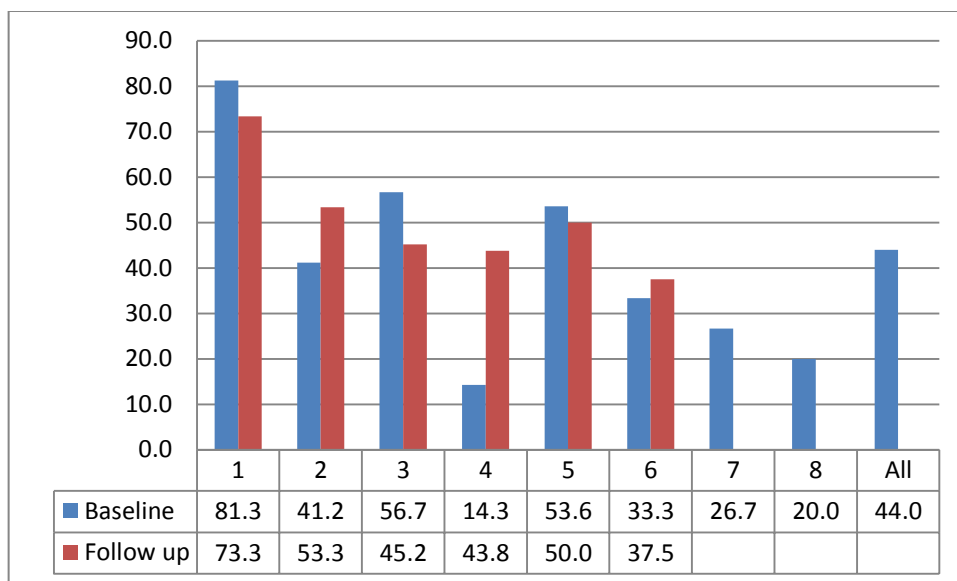
Figure 4.3 **Percentage of patients on the rapid discharge pathway at baseline and follow up, by hospital**

	1	2	3	4	5	6	7	8	Grand Total
Baseline	13.3	7.7	20.0	6.7	0.0	0.0	0.0	0.0	7.1
Follow up	26.7	25.0	0.0	0.0	0.0	0.0			9.6

4.4 Change in the use of the Liverpool, or other integrated care pathway varied significantly by hospital

ADA data also show that the overall proportion of patients supported by the Liverpool or other integrated care pathway increased from 44% at baseline to 50% at follow up. However, a breakdown by hospital shows that the majority of this improvement came from hospital 4, which more than doubled the number of patients supported with these pathways. This increase is not unexpected, since this hospital had a significantly lower percentage of patients on the pathways at baseline, compared to other hospitals. Hospital 2 also increased the number of patients on integrated care pathways by over 10%, and hospital 6 improved by 5 %. Hospitals 1, 3, and 5 had fewer patients on these pathways at follow-up than at baseline.

Figure 4.4   Change in percentage of patients who were on the Liverpool or other integrated care pathway during their last days of life

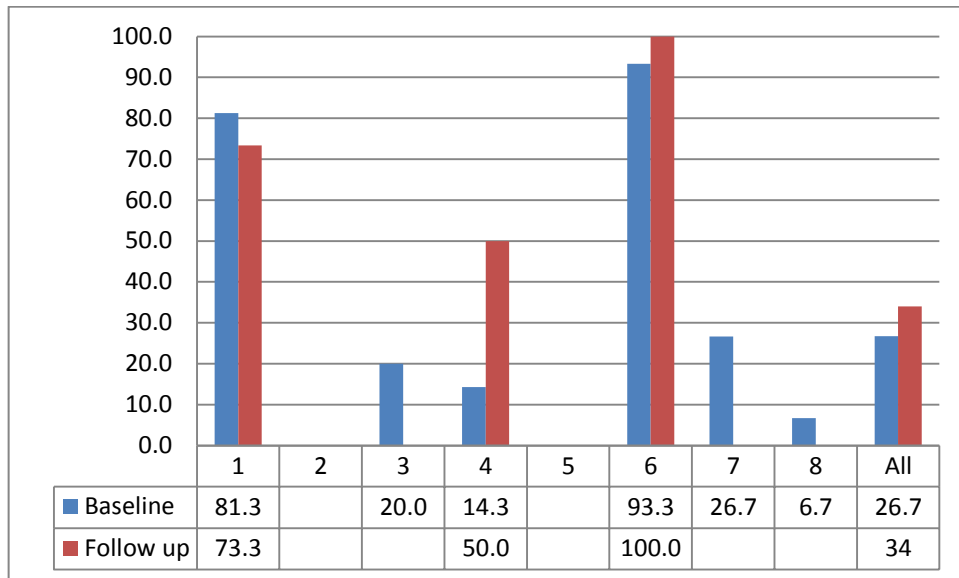|	1	2	3	4	5	6	7	8	All
Baseline	81.3	41.2	56.7	14.3	53.6	33.3	26.7	20.0	44.0
Follow up	73.3	53.3	45.2	43.8	50.0	37.5			

4.5 Symptom Control Assessment was primarily used for patients who died in hospital, and its use varied by hospital

ADA data show that the use of Symptom Control Assessment (SCA) was much more common amongst patients who died in hospital than those who did not, though there was an increase in use for both groups.

Again, there was strong variation between different hospitals; 2 and 5 had no patients for whom the SCA was being used, whilst hospital 6 reached 100% of patients who died receiving the SCA. Hospital 4 showed the greatest improvement, increasing from 14% to 50%.

Among those who were discharged, use of the SCA was much lower, and the vast majority of its use came from hospital 6. Hospital 6 accounted for all 10% of patients discharged at baseline who had an SCA, and 16% of those at follow-up, whereas hospital 1 had increased use by 3 patients, and hospital 2 by 2 patients.

Figure 4.5   Change in percentage of patients who died in hospital who had an SCA used

	1	2	3	4	5	6	7	8	All
Baseline	81.3		20.0	14.3		93.3	26.7	6.7	26.7
Follow up	73.3			50.0		100.0			34

4.6   There was generally a high, and increasing percentage of patients who had a DNAR, NCR, or AND status recorded

ADA data indicate that overall the percentage of patients with a status of Do Not Attempt to Resuscitate (DNAR), Not for Cardio Resuscitation (NCR), or Allow Natural Death (AND) recorded increased for both patients who were discharged and those who died.

The percentages with these recorded were much higher for patients who died in hospital, reaching nearly 100% at follow up. All hospitals saw increased levels, though hospital 7 still saw a lesser increase with 81% at follow up, compared to over 96% at the other hospitals where comparative data were available. It is not possible to observe changes in hospitals 7 and 8 as they did not submit any follow up data. Hospital 8 had a considerably lower rate than the others at baseline, with only 33% of patients who died having a DNAR, NCR or AND recorded.

Rates of DNAR, NCR and AND were lower for patients who were discharged, though they still showed an increase from 53% to 60%. The majority of this increase was accounted for by hospital 2, which roughly doubled its rates. Percentages at hospitals 3 and 5 declined. There was much greater variation in percentages of patients discharged who had a DNAR/NCR/AND recorded, from around 10% for hospitals 4 and 6, to 100% for Hospital 1.

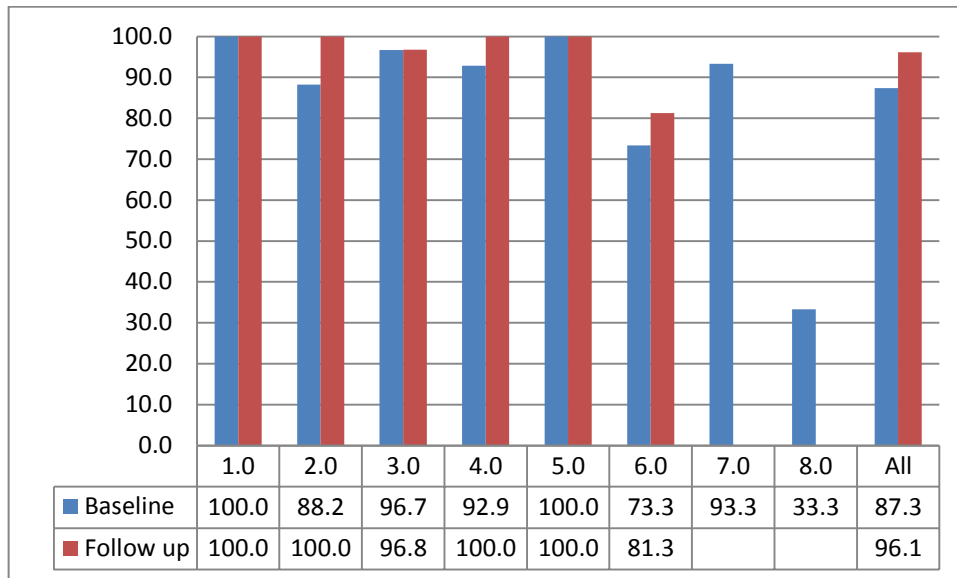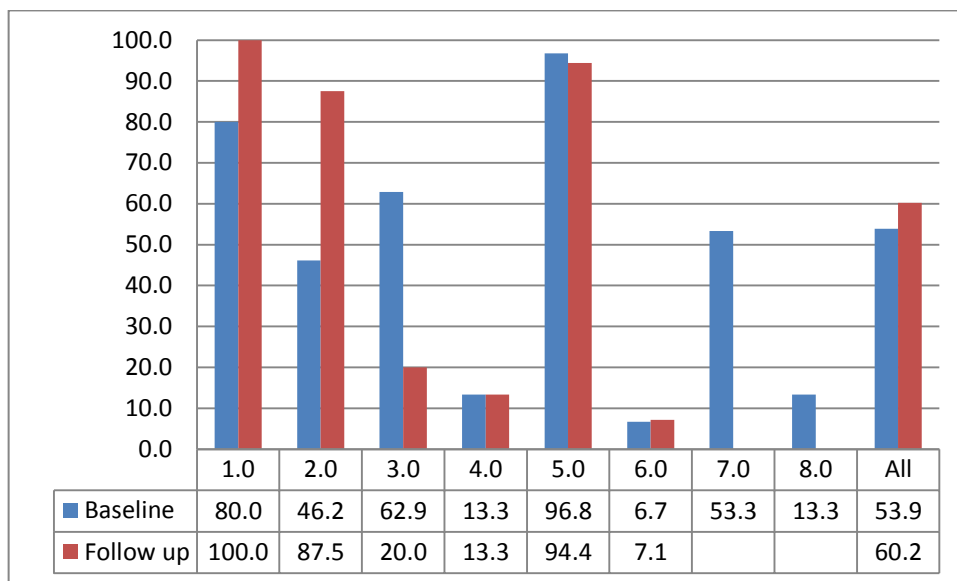**Figure 4.6   Percentage of patients who died in hospital who had a DNAR/ NCR/AND recorded**

	1.0	2.0	3.0	4.0	5.0	6.0	7.0	8.0	All
Baseline	100.0	88.2	96.7	92.9	100.0	73.3	93.3	33.3	87.3
Follow up	100.0	100.0	96.8	100.0	100.0	81.3			96.1

Figure 4.7   Percentage of patients discharged who had a DNAR/NCR/ ANDR recorded

	1.0	2.0	3.0	4.0	5.0	6.0	7.0	8.0	All
Baseline	80.0	46.2	62.9	13.3	96.8	6.7	53.3	13.3	53.9
Follow up	100.0	87.5	20.0	13.3	94.4	7.1			60.2

4.7   Very few DS1500 forms were completed for either patients who died or those who were discharged

ADA data show that for patients who died in hospital only 2 DS1500 forms were completed at both time-points. For those who were discharged there were 7 at baseline and only 2 at follow-up. For those who were discharged there was a significant decline in 'not done' from around 30% to around 10%, however the majority of this decline came from hospital 3, whose reduction in completing the forms had also caused the decline of the overall figure from 7 to 2.

For patients who died there was little change between baseline and follow up other than a 10% decline in the percentage of patients for whom a DS1500 was recorded as 'not applicable'.

4.8 The percentage of patients for whom there was a discussion with a carer increased overall for both those who died in hospital, and those who were discharged

The ADA data show that overall the percentage of patients for whom there was a discussion with a carer increased by around 20% for both those who died in hospital and those who were discharged; it remained around 20% higher for those who died in hospital, though similar levels of improvement were seen.

Among those discharged, all hospitals showed an improvement between baseline and follow up. The biggest increase was for hospital 5, which moved from a discussion in the case of just one patient, to a discussion in the case of 16 patients. Hospital 6 showed a very small improvement, and percentages there remained lower than for the other hospitals.

For those who died in hospital, discussion with a carer was more frequent, and also improved. Again, hospital 5 showed the largest improvement, whilst hospital 7 recorded all its patients at baseline as 'not applicable' for talking to a carer.

Figure 4.8   Change in percentage of discussions held with carers for discharged patients, by hospital
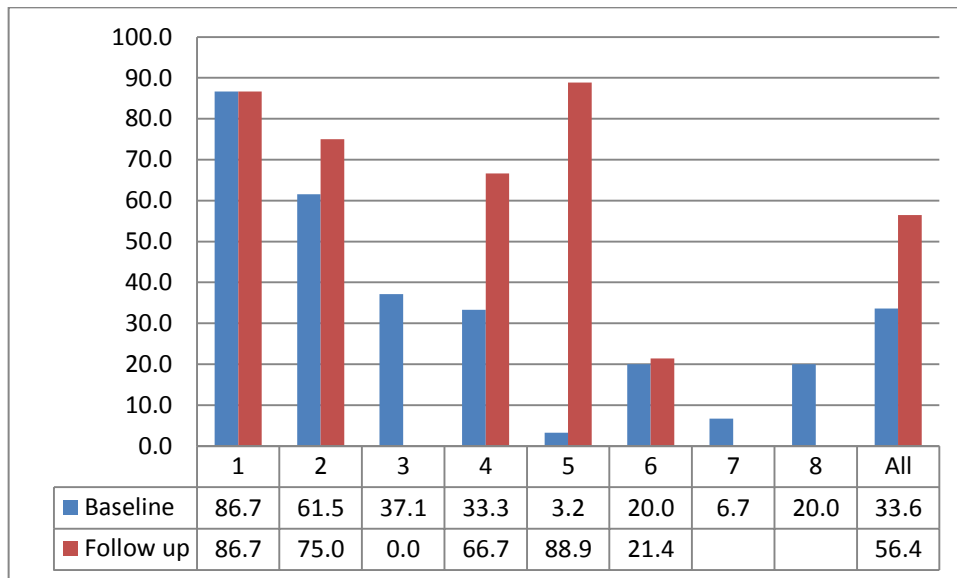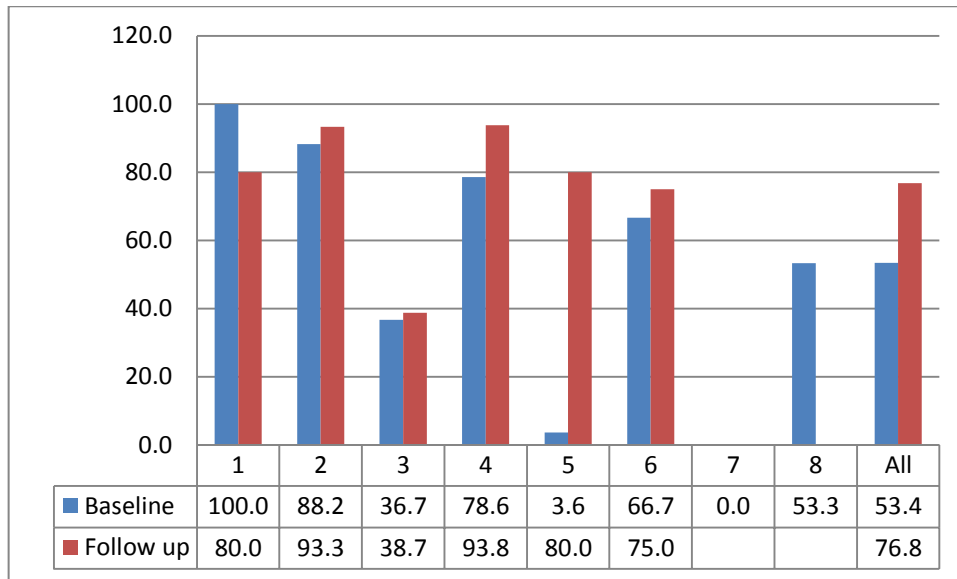

	1	2	3	4	5	6	7	8	All
Baseline	86.7	61.5	37.1	33.3	3.2	20.0	6.7	20.0	33.6
Follow up	86.7	75.0	0.0	66.7	88.9	21.4			56.4

Figure 4.9   Change in percentage of discussions held with carers for patients who died, by hospital

	1	2	3	4	5	6	7	8	All
■ Baseline	100.0	88.2	36.7	78.6	3.6	66.7	0.0	53.3	53.4
■ Follow up	80.0	93.3	38.7	93.8	80.0	75.0			76.8

The overall trend of increase in carer discussions found with the ADA data can be compared to the Staff Survey which showed more inconsistent findings for communication with carers and relatives, (see Section 3).

This may be explained by the **type** of communication that both surveys ask about: for the Staff Survey respondents are asked to specify practice on communication specific to 'deteriorating condition' and 'concerns, personal wishes, and preferences', whereas the ADA question relates more to generic discussion with carers and information provision.

This is supported by findings from the Organisational Survey which showed little positive change in discussion of personal wishes or goals of care: where 3 out of 8 organisations responded that they did discuss personal needs, wishes, and preferences at baseline, this had dropped to only 2 out of 7 organisations responding that they did this at follow-up. Similarly 5 out of 8 organisations had said they discussed goals of care at baseline, and this had dropped to 4 out of 7 at follow-up.
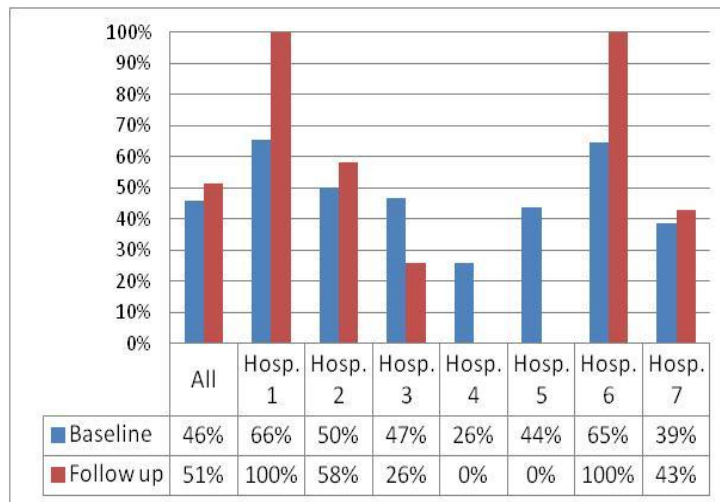
It is interesting to compare this to findings on practice related to using the ACP/PPC, where there was an improvement observed; the increase at follow-up was quite dramatic for some organisations. Discussing patient wishes is integral to an ACP/PPC. There appears therefore to be another discrepancy, where respondents reported more use of advance planning yet no such improvement was observed for responses to the specific question about discussing wishes. There may be two reasons for this: either organisations have implemented practice of using advance care tools in written form without yet fully utilising them for discussions, or they are still not yet being used routinely. The ADA data comes from a **selection** of patients, whereas the Organisational Survey asks about **routine** practice.

A final reason for these discrepancies might be the response categories; the Staff Survey asks for responses on a 1-10 scale which allows for more observable subtleties, whereas the ADA response categories are a yes-no dichotomy.

4.9   Care planning after EoL discussions with patients and carers increased for the majority

Figure 4.10 below illustrates findings from the Staff Survey, which shows the proportion of respondents that said that they developed a plan for future care after EoL discussions. This increased from 46% to 51% but the responses varied by hospital. 100% responded affirmatively at follow up in hospital 1 and 6, and in hospital 3 this declined from 46% to 26%.
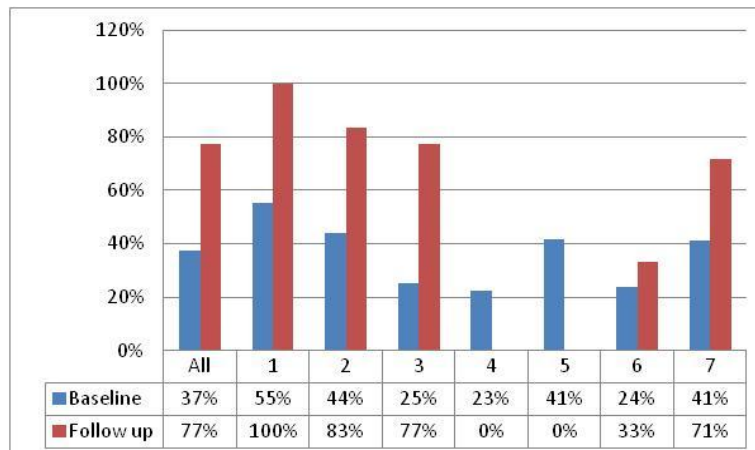
Figure 4.10   The proportion of staff developing a future care plan after EoL discussions

	All	Hosp. 1	Hosp. 2	Hosp. 3	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7
Baseline	46%	66%	50%	47%	26%	44%	65%	39%
Follow up	51%	100%	58%	26%	0%	0%	100%	43%

4.10   The Staff Survey showed improvements in coordination and communication between those delivering EoL care

The responses from the Staff Survey indicated that communication within hospitals on EoL issues improved. There was an increase in the proportion routinely discussing EoL patients at MDT meetings. This is illustrated in Figure 4.11 below. In response to the question *"Do you routinely discuss patients nearing the end of life at regular MDT meetings?"* the proportion responding 'yes' across the total sample increased from 37% to 77%. Improvement was consistent across all hospitals where data were available.

Figure 4.11   Proportion that routinely discuss patients nearing EoL at regular MDT meetings

	All	1	2	3	4	5	6	7
Baseline	37%	55%	44%	25%	23%	41%	24%	41%
Follow up	77%	100%	83%	77%	0%	0%	33%	71%

4.11   Communication with primary care improved, but this remains one-sided
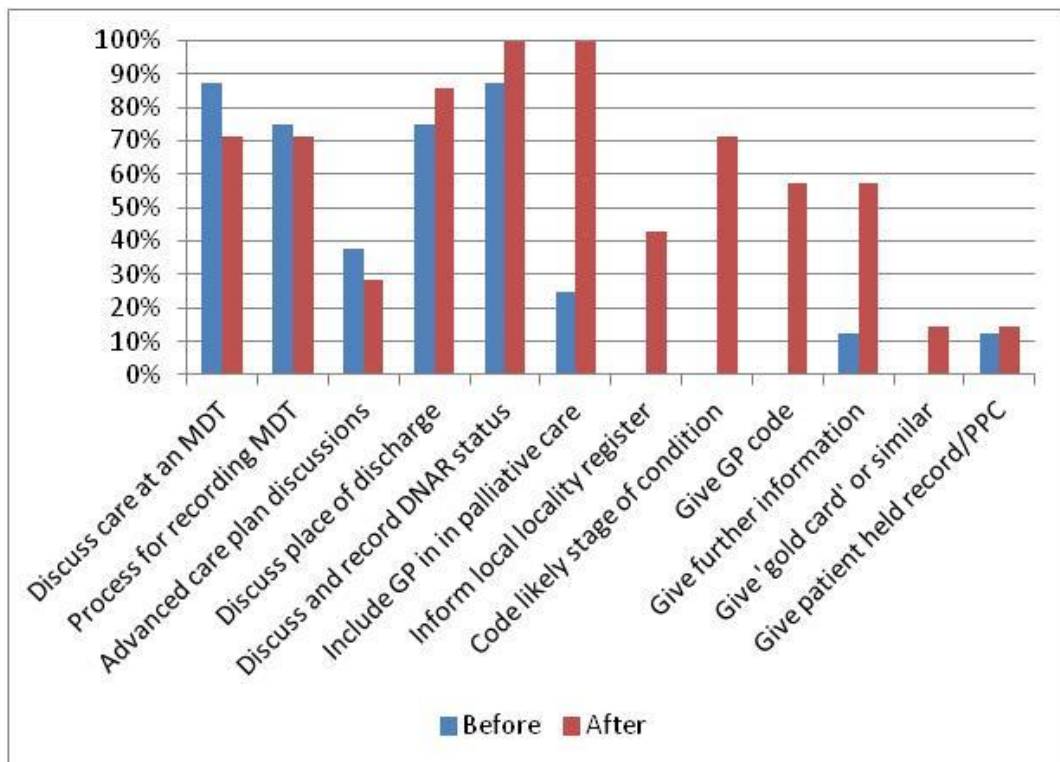
The Staff Survey showed that communication with colleagues in primary care had improved. Staff were asked if they routinely transferred information regarding EoL care and patients' wishes to district nursing teams and to GPs. There was a modest improvement in the proportion responding 'yes' in relation to district nursing teams: a rise from 38% to 49%. This improvement was greater in relation to GPs, where the proportion responding 'yes' rose from 33% to 67%.

The Organisational Survey showed that 5 out of 8 organisations sent discharge letters to GPs detailing discussions of EoL care with patients at baseline. By follow up all but one organisation reported that they did this. However no organisation reported receiving information from GPs at baseline or at follow up, highlighting that this is still an area for improvement.

4.12 More consideration is being given to planning end of life care

The Organisational Survey showed that the proportion of organisations planning further actions has increased in most cases. The figure below summarises findings on planning end of life care. The area of planning which has seen the most improvement is including the GP in palliative care – presumably this has been through the increase in information transfer to primary care. This is supported by the fact that giving further information has also seen a big increase. Areas which have seen a decrease in routine practice have been discussing care at an MDT, having a process for recording MDTs, and advance care planning discussions.

Figure 4.12   Routine planning of further actions has increased on the whole

5 Implementation of the GSF in acute hospitals has varied; a number of facilitators and barriers were reported – results from the focus group feedback

> **Section Summary**
>
> - Findings indicate that senior management and clinician support was important for successful implementation of the programme.
>
> - Implementation of the programme was more successful when there was allocated protected time for a project lead or facilitator.
>
> - Raising awareness and embedding culture shift takes time but can be effective in empowering generalist frontline staff.
>
> - Hospitals have found collecting evaluation data challenging, but see the value of this.
>
> - Early outcomes were beginning to be seen during the implementation of the programme. These outcomes related to heightened awareness, learning, and improvements in staff confidence.

Contextual factors form an important backdrop to the implementation of any healthcare programme. This section describes implementation of the GSF in Phase 2 hospitals. It draws on barriers and facilitators for implementing the programme, using themes which emerged from the focus group discussion with GSF leads. The section ends by describing some early outcomes which were reported as the programme was being implemented.

5.1 Organisations chose to implement the GSF for specific outcomes it aims to achieve

Organisations participating in the GSF programme selected coordinators to lead the work as per the conditions set by the GSF Centre. These leads included both generalists (e.g. generalist nurses), and specialists (e.g. nurses working in palliative care teams). Some of the organisations also had the support of clinical champions such as consultants, but this was not consistent across all eight organisations involved.

Focus group participants described the reasons for their organisations participating in the programme. There was recognition of GSF's national standing as a quality improvement programme for end of life care practice: one participant described the framework as a *"national lever".* Another participant stated that the goals of the GSF fitted with her organisation's priorities. All the GSF leads described these goals as reasons for their participation in the programme. The goals described related to improved quality of care, and include the following:

- Awareness raising with the general public to encourage talking more openly about death and dying;

- Educating workforces;

- Introducing end of life care strategies in acute hospitals;

- Improving communication with patients and carers;

- Decreasing the number of hospital admissions;

- Decreasing the length of hospital stays;

- Improving communication between teams and organisations – for example sharing information with GPs to avoid inappropriate admissions; and

- Enabling people to have better deaths.

5.2 Profile raising activities have been integral to implementing the GSF

Part of the challenge for EoL care quality improvement is its acceptance as 'everyone's business'. GSF leads from participating organisations reflected on the challenges to involve generalist staff: a common perception held amongst workforces is that EoL care is fundamentally the role of palliative care specialists. Awareness raising activities have therefore been a key feature of implementing the GSF in acute hospitals.

Many of the organisations had held a launch day to mark the implementation of GSF, with the aim to raise awareness of end of life care and the framework. A few organisations had also held a 'surprise day', which acts to encourage generalist staff to consider how EoL care may be relevant to their roles. The 'surprise day' asks the question: "would you be surprised if this patient died in the next year?" An answer of 'no' should elicit reflections on how quality end of life care could ensure a 'good death' for the patient(s).

The momentum of launch/surprise days was maintained by raising awareness of the GSF branding as a method to keep organisations engaged with EoL care. This included various activities which were on-going; for example branding GSF 'stalls', holding bake days, and designing a GSF screensaver for PCs.

Raising the profile of EoL care beyond specialist staff includes seeking active involvement at all levels: from senior management and consultant level, to domiciliary care workers. One example of good practice came from a hospital where implementation of the GSF included domiciliary care in the training. In this hospital it was recognised that domiciliary care workers can have an important role to play in EoL care; the GSF lead here stated that these workers often spend time talking to patients and carers, whereas each staff nurse carries a caseload of up to 15 patients at any time.

In this example, the GSF lead reported that the domiciliary care team was very interested and keen to be involved. Benefits of their involvement included their own sense of empowerment through being allowed the opportunity for development, and the inclusivity of the approach which went beyond hierarchical boundaries to make the learning more of a team approach. The impact of a team approach was that those involved were more likely to talk about the issues after training.

The Sections below will further explore how senior management and clinician involvement impacted on implementation.

5.3 One of the main challenges to implementing the GSF has been senior level buy-in

A number of barriers were identified by GSF leads from participating hospitals. These included lack of time to commit to the framework, and changing personnel which made maintaining early momentum more difficult. However, the most consistent theme for barriers to implementation was a lack of senior buy; no hospital cited the involvement of senior managers, and the general consensus amongst leads was that this would greatly support implementation of the framework across the hospitals.

Similarly involving clinicians has been challenging for hospitals. The GSF recommends that a clinical champion should support the nominated coordinators at participating sites. One lead reported that a few consultants were supportive in her organisation, but many other organisations struggled to secure this support. This was explained by cultural factors and staff attitudes, where EoL care is primarily considered to be the 'nurses' job'.

One final barrier discussed by a few leads was information governance when setting up EoL care registers, which caused in setting up the registers.

5.4 Many facilitators were identified for implementing the GSF; a key success factor was support for a dedicated champion

The most consistent theme to arise out of the focus group was that ensuring leads had allocated time to work on implementing the GSF is the most powerful facilitator for success.

Although all organisations had a nominated coordinator acting as the GSF lead, the majority were doing this as part of their day job. This meant that they had limited time to dedicate to the role. In one organisation the GSF facilitator was allocated 14.5 hours a week to implement the GSF. The group of GSF leads thought that this was a key success factor; with protected time an enthusiastic and passionate lead is able to champion for improving EoL care.

Facilitators for implementation also included achieving senior buy-in, for which profile-raising was seen to be an important mechanism, (see above). A mechanism for achieving clinical support was identified: to first seek support from a palliative care consultant, who could then help engage other consultants.

This idea of snowballing was also identified as a broader approach to achieving GSF spread across organisations; implementing the framework with one ward first would allow a pilot approach, where learning could then be built into wider roll-out across other wards in the hospital. GSF leads discussed how the choice of ward is also important; a ward should be selected where there is the right volume of EoL care patients, and some supportive processes already in place (e.g. where MDT meetings are already held).

Building relationships with key people throughout the trust was also identified as a facilitator. In particular bed managers were cited as a key role to seek involvement from; their support can be vital for making change happen so that patients have a 'good death'.

5.5 Capturing evaluation data has been challenging at times, but worthwhile

Hospitals participating in the GSF programme collected data at two time-points from three different sources: from administering the Staff Survey, the ADA audit, and the Organisational Survey. GSF leads stated that the data collection was difficult, but recognised the value of it as they want to *"know the evidence, and where (they) are."*

The most challenging data collection cited was the administration of the Staff Survey, where achieving appropriate response rates has been challenging. In particular leads felt that they struggled with asking senior doctors to complete the survey. One lead discussed how in her organisation they were able to get better responses to the Staff Survey by integrating the data collection into training sessions, where attendees were asked to complete surveys before the session.

In terms of improving the data collection tools, GSF leads thought that they generally captured the right information. Two further improvements were suggested, that:

- The ADA could capture more information on communication about Advance Care Planning and death and dying; and
- That the Staff Survey could capture information on previous and desired EoL care training.

Finally there was evidence to suggest that organisations are using data in reflective practice. Many expressed a desire to see their data against others so that they could compare relative progress. One GSF lead discussed how data can be used as a lever to engage more senior buy-in; she noted for example that in her organisation the number of deaths showed higher than expected levels, and that this could be used to draw attention to GSF.

5.6 Early outcomes were being seen whilst GSF continued to be implemented

Finally, the focus group discussion also included early outcomes that were beginning to be seen whilst the programme was being implemented. These early outcomes related on the whole to heightened awareness, learning, and improved staff confidence.

Practice level outcomes being seen were identification of EoL care patients through the implementation of registers. A greater willingness to discuss patients in teams was also reported.

6   Conclusions

Having described the findings we draw together the key messages and highlight where lessons can be learnt to inform future work with supporting GSF in acute hospitals. We conclude that:

- **In sum, the GSF has impacted on the level of staff and organisational practice. Changes in patient level outcomes are also beginning to emerge.** This progress is in line with the expected first stage of attainment of Foundation Level GSF AH. The programme goal is to deepen this and spread practice to other wards in Stage 2, which will lead to full GSF Acute Hospital Accreditation. In order to capture impact more fully, it will be important to revisit the organisations once longer term outcomes have had time to develop. Improving data quality will also ensure a greater level of confidence in making firmer conclusions on impact.

- **There was an improvement in staff knowledge and confidence in most areas of end of life care.** More staff were aware of, and had experience of using EoL care tools at follow up. Similarly, most were more confident caring for and recognising when EoL care was required. The one area where confidence was more variable was in discussing EoL care with carers and families. This was also shown in findings for the organisational practice of discussing patients' wishes. Communication skills around specific types of discussion may still be an area for development with the acute workforce.

- **There is some evidence that length of hospital stay has been reduced for patients in some hospitals.** Due to considerable gaps in these data the effect of outliers easily skew findings. The evidence for this outcome should therefore be treated tentatively, and revisited when more data become available. Similarly there is emerging evidence that patients dying in their preferred place is improving – an increase of nine percentage points was observed from baseline to follow up.

- **Most areas of end of life care practice have also seen improvements since implementation of the GSF.** Processes for identifying patients; the use of EoL care tools; advance care planning; and communication with primary care teams all saw improvements. Modest improvements were also observed for the use of rapid discharge; the Liverpool; and other integrated care pathways. Inter-professional communication is still an area for development however, since no hospitals have reported any improvement in communication from primary care teams to them.

- **Current interpretations of the data require some caution.** There were a number of limitations with the data, including a substantially lower response rate at follow up; uneven distribution of responses by hospital for the Staff Survey; and Organisational Surveys being completed at both time-points by different members of staff and for different wards. We cannot therefore rule out that some findings might be a result of internal processes rather than organisational change.

- **Contextual issues form an important backdrop to implementing the GSF in acute hospitals.** The public sector reforms undoubtedly make these challenging times to be implementing organisational change. GSF leads reported that despite profile-raising activities, senior level engagement was one of the most challenging issues faced in implementing the GSF. An important lever for engagement may be to use the public sector reform priorities to engage senior buy-in; for example by using the economic argument for supporting quality improvement in EoL care. Evaluation data will be key for achieving this, and GSF leads recognised this as such.

ANNEXES

Annex 1   Focus group topic guide

This Guide is for a focus group with lead staff involved in the project. Its purpose is to gather qualitative data, including information on the contextual factors of the project and to gain some evaluative views on design and implementation. The Guide is designed for use in a 2-hour focus group. Questions are broad and the facilitator should prompt around each issue (example prompts are provided). People are to be interviewed on the basis that they will not be indentified in any reporting; this should be made clear at the start of the interview.

Rationale for project

1   Please describe the problem or opportunity that this project was established to address.

Why did you choose to be involved?

How was it identified (policy rationale / data led)?

Who is affected by the problem?

* How robust does the evidence base seem to be? Why not 'do nothing'?*

What other options were considered?

Desired effects & data

2   Given the problem you have just described, what are the desired outcomes of this project?

Prompt to be clear about the expected changes (from what to what?) and target group / level of effect (i.e. individuals, services, organisations, systems, policy?)

3   How long should it take for these effects to be seen?

Prompt around main effects and timing – outcomes may well be sequential (e.g. change in knowledge leading to change in behaviour)

4   What indicators are you using to measure success?

What has your experience been of using the project tools (i.e. Staff questionnaire, Systematic General Questionnaire, ADA)?

How well do they record 'success' in your organisations? What other factors contribute to success that are not measured by these tools?

5   Have there been any outcomes so far, and what are these?

Prompt for patient, carer, staff, organisational, and wider effects.

Design & implementation

6   Please describe the main features of the project: how was it expected to operate in your organisations? Did things go according to plan?

7   What are the main mechanisms that were expected to lead to change?

Prompt to be as specific as possible – i.e. changes in incentives / regulations / culture / knowledge etc. Prompt around assumptions to tease out the logic of each mechanism.

8   What have been the main issues in relation to implementation to date?

This is a key question – what has gone well / less well and why?

Inputs

9   Please describe the resources required to implement the project.

Key issues here include: the degree to which resources are additional – or are a re-direction of existing investments; and, the type of resource – i.e. all cash funding or in-kind support?

Contextual factors

10   What are the main external factors that influence (either help or hinder) the implementation and effectiveness of the project?

Prompt here around changes in policy, organisational structures, broader economic / social conditions. The key thing here is the way in which these factors interact with the intervention.

Early conclusions & lessons

11   What conclusions and lessons have you drawn from the work to date?

12   Do you have any other comments, or are there any other issues you would like to raise?

Annex 2   Staff Survey

Hospital:	To be completed online http://www.goldstandardsframework.org.uk/registration_area/ then click GSFAH Staff Survey Enter Username & Password or manually and pass completed survey to your project lead
Name :	Ward:
Role :	Date completed;

1.   **Your profession**
        Doctor Grade:_____
        Nurse Grade:_____

         Other (Please specify):_____

2.   **I feel I need to know more about the following areas in end of life care?**

a) Communication skills   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree
b) Holistic assessment   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree
c) Symptom management   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree
d) Advance care planning   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree
e) Care planning   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree
f) Care of carers   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree
g) Care of the dying   Strongly disagree   **0 1 2 3 4 5 6 7 8 9 10**   Strongly agree

         h) Comments: _____

3.   **Do you have any experience of the National End of Life Care Tools?**

     Gold Standard Framework   **Yes (aware of)** ❑ **Yes (have used)** ❑ **No** ❑

     Preferred Priorities for Care   **Yes (aware of)** ❑ **Yes (have used)** ❑ **No** ❑

     Liverpool Care of The Dying Pathway **Yes (aware of)** ❑ **Yes (have used)** ❑ **No** ❑

     Advance Care Planning   **Yes (aware of)** ❑ **Yes (have used)** ❑ **No** ❑

     Comments:_____

4.   **I feel confident in caring for people nearing the End of Life?**

     Strongly disagree   1 2 3 4 5 6 7 8 9 10 Strongly agree

5.   **I feel confident in recognising patients who may be in the last year of life?**

     Strongly disagree   1 2 3 4 5 6 7 8 9 10 Strongly agree

6.   **Do you use any specific tools as a trigger to identify patients in the last year of life?**

Yes ☐ No ☐   **Please state:**_____

7.   **I feel confident in having open communication with patients and relatives about a patient's deteriorating condition?**

     Strongly disagree   **1 2 3 4 5 6 7 8 9 10 Strongly agree**

8.   **I feel confident in having discussions with patients about their personal wishes, preferences and concerns (Advance Care Planning)?**

     Strongly disagree   **1 2 3 4 5 6 7 8 9 10 Strongly agree**

9.   **I feel confident in having discussions with relatives or carers of patients about their concerns, needs and preferences (Advance Care Planning)?**

     Strongly disagree   **1 2 3 4 5 6 7 8 9 10 Strongly agree**

10. **Do you develop a plan for future care in the light of such discussions?**

Yes ☐ No ☐   **Comments:**_____

11. **Do you routinely discuss patients nearing the end of life care at regular MDT meetings?**

       Yes ☐ No ☐

Comments:_____

12. **Do you routinely transfer discharge information regarding End of Life Care and patient's wishes (including Advance Care Planning discussions of needs and preferences) to?**

GP Practice   **Yes ☐ No ☐**

District Nursing Team   **Yes ☐ No ☐**

Other, please specify   **Yes ☐ No ☐** _____

13. **I need to know more about the following areas of care? Please state:**

       _____

       _____

14. **Any other comments or suggestions?**

       _____

Thank you

Annex 3   After Discharge/Death Analysis

NA = Not Applicable   NR = Not Recorded

PILOT SITE DETAILS

Hospital :		**Q1.** Ward/Unit :
Completed by :	Job title :	Date :
Q2. What stage are you completing ADAs for (please circle one): Baseline / Follow up /Accreditation		

DIAGNOSIS DETAILS

Q3. Primary Diagnosis :

- ☐ 1. Cancer
- ☐ 2. Heart failure
- ☐ 3. Chronic obstructive pulmonary disease / Respiratory
- ☐ 4. Renal failure

- ☐ 5. Frailty/co-morbidity
- ☐ 6. Stroke
- ☐ 7. Dementia
- ☐ 8. Other eg Neurological disorders

ADMISSION / DISCHARGE DETAILS

Q5. Date of admission / contact :	**Q8.** Date of Discharge from hospital :
Q6. Was passport information received on admission? Yes ☐ No ☐ NA ☐ NR ☐	**Q9.** Was Rapid Discharge Pathway used for this patient? Yes ☐ No ☐ NA ☐ NR ☐
	Q10. Was passport information sent out on discharge? YES ☐ NO ☐ NA ☐ NR ☐
Q7. If passport information was received on admission was it?- ☐ 1. Patient Held Record ☐ 2. GP Letter ☐ 3. Gold Card ☐ 4. 'Passport Information' ☐ 5. Preferred Place of Care Document ☐ 6. Other	**Q11.** If passport information was sent on discharge? ☐ 1. Patient Held Record ☐ 2. GP Letter ☐ 3. Gold Card ☐ 4. 'Passport information' ☐ 5. Preferred Place of Care Document ☐ 6. Other

DURING ADMISSION

Q12. Did patient have Advance Care Plan / Preferred Place of Care?	YES ☐ NO ☐ NA ☐ NR ☐
Q13. Was Do Not Attempt Resuscitation / Not for Cardiopulmonary Resuscitation / Allow Natural Death recorded?	YES ☐ NO ☐ NA ☐ NR ☐
Q14. Was symptom control assessment tool used?	YES ☐ NO ☐ NA ☐ NR ☐
Q15. If DS1500 appropriate was it completed?	YES ☐ NO ☐ NA ☐ NR ☐
Q16. Discussion with carer and information provided?	YES ☐ NO ☐ NA ☐ NR ☐

DEATH DETAILS

Q17. Did patient die during admission? YES – the patient died during this admission ☐ NO – the patient was discharged ☐	**Q20.** Cause of death if died : ☐ 1. Cancer ☐ 2. Heart failure ☐ 3. Chronic obstructive pulmonary disease / Respiratory ☐ 4. Renal failure ☐ 5. Frailty/co-morbidity ☐ 6. Stroke ☐ 7. Dementia ☐ 8. Other eg Neurological disorders
Q18. If patient died, was it in Preferred Place of Care? YES ☐ NO ☐ NA ☐ NR ☐	
Q19. Was Liverpool (or other) Integrated Care Pathway for the Dying used to support care in the last days of life in the hospital? YES ☐ NO ☐ NA ☐ NR ☐	

OTHER COMMENTS

POSITIVES	NEGATIVES	IDEAS
What went well?	What did not go well?	What could be done better?

Annex 4 Organisational Survey

Completed by Facilitator before and after

Baseline before April 2011   Follow up – March 2012

Name: Date:

Hospital: Ward:

For each question please answer yes, no or don't know (DK). When answering please think back and report on your usual care provided **before** April 2011, when you commence the GSF Acute Hospital Training Programme.

On your ward, do you routinely

1. Use processes to identify which patients may be considered to be nearing the end of life- i.e. in the final months, weeks or days? YES ☐ NO ☐ DK ☐

2. Hold an electronic register or tagging system for such patients? YES ☐ NO ☐ DK ☐

3. Assess their clinical needs using the appropriate assessment tool? YES ☐ NO ☐ DK ☐

4. Discuss their personal needs, wishes and preferences through 'advance care planning' discussions? YES ☐ NO ☐ DK ☐

5. Discuss their 'goals of care'? YES ☐ NO ☐ DK ☐

6. Plan further actions (tick any appropriate) e.g.

    a. Discuss their care at an MDT meeting? YES ☐ NO ☐ DK ☐

    b. Have you a process for recording the MDT plan for these patients? YES ☐ NO ☐ DK ☐

    c. Have advance care planning discussions with these patients? YES ☐ NO ☐ DK ☐

    d. Discuss their preferred place of care or discharge? YES ☐ NO ☐ DK ☐

    e. Discuss and record their DNAR status? YES ☐ NO ☐ DK ☐

    f. Suggest to their GP that they are included on the palliative care/ GSF register either during admission or at discharge? YES ☐ NO ☐ DK ☐

    g. Add their names to a local locality register if you have one? YES ☐ NO ☐ DK ☐

    h. Code their likely stage of condition based on needs base coding system YES ☐ NO ☐ DK ☐

    i. Inform their GPs of their code

    j. Give them further information YES ☐ NO ☐ DK ☐

    k. Give them a 'gold card' or similar YES ☐ NO ☐ DK ☐

    l. Give them a patient held record/ PPC/ other? YES ☐ NO ☐ DK ☐

    YES ☐ NO ☐ DK ☐

7. Receive information from GPs about their palliative care patients YES ☐ NO ☐ DK ☐

8. Receive letters from GPs including information about what was understood by the patient, and their preferences e.g. place of care? YES ☐ NO ☐ DK ☐

9. Send discharge letters to GPs including information about what was discussed and understood by the patient, and their wishes and preferences? YES ☐ NO ☐ DK ☐

10. Have a rapid discharge system or protocol for your ward? YES ☐ NO ☐ DK ☐

11. Provide information to carers? YES ☐ NO ☐ DK ☐

12. Have staff training in end of life care? YES ☐ NO ☐ DK ☐

13. Have staff training in communication skills?   YES ☐ NO ☐ DK ☐
14. Discuss issues around empathy and the culture of caring?   YES ☐ NO ☐ DK ☐
15. Audit your care for people nearing the end of life?   YES ☐ NO ☐ DK ☐