Phase 3 GSF Acute Hospital Programme Evaluation - Final report

The Gold Standards Framework Centre

21st February 2014

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The Gold Standards Framework Centre

A report submitted by ICF GHK

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FINAL

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Contents

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 hospital admissions, and enabling more people to die in their preferred place of care.

The Phase 3 GSF Acute Hospitals programme was introduced to nine hospitals. The programme includes access to: a set of resources; a train the trainer programme; facilitator training and DVDs; on-going facilitator support; workshops; and independent evaluation.

ICF GHK was commissioned by GSF to undertake an evaluation of the programme. They analysed data from: a staff survey; a foundation survey completed for each ward/hospital; and an online audit tool - the 'After Death/Discharge Analysis (ADA). In addition, GSF staff completed of five structured interviews with staff. These were analysed by ICF GHK.

Hospitals (and wards within them) taking part in the programme have been anonymised. The type of data available varies between hospitals. For the staff survey, two hospitals submitted data for baseline only, and four submitted baseline and follow up. For the ADA audit, six hospitals submitted baseline and follow up. Seven hospitals responded to the foundation survey. Four hospitals, Hospitals 1, 2, 6 and 8, implemented the GSF in more than one ward.

The programme improved staff knowledge, use of EoL tools, and confidence in recognising and caring for people nearing the end of life

Across all hospitals, staff knowledge and use of EoL tools improved, with staff less likely to report a need to know more about all areas of EoL care. Across all hospitals except Hospital 2, staff also reported increases in their confidence in recognising and caring for people nearing the end of life.

However, on all other questions, related to: staff confidence in having discussions with patients, relatives and carers; their routine discussion of patients nearing the end of life; and whether and what type of discharge information they send out with patients, Hospitals 8 and 9 showed an improvement, whereas Hospitals 2 and 6 showed a decline.

The programme had a positive impact on the identification, assessment and care planning for patients nearing the end of life. There was also a small (non-significant) reduction in the length of stay in some hospitals.

The ADA and the foundation survey showed that there were improvements in EoL practice at both the patient, and ward/ hospital level. Improvements in care were particularly marked in the following areas (all of which were low at baseline):

- The collection and transference of passport information on admission and discharge;
- The use of DS1500s[1];
- The use of symptom control assessments;
- The proportion of patients on rapid discharge pathways.

There were more modest improvements in the use of Advance Care Plans/ Preferred Places of Care; the recording of Do Not Attempt Resuscitation/ Not for Cardio Resuscitation/ Allow Natural Death; and whether discussions with patients and carers were held.

There was also a small decline in the mean length of hospital stay for three hospitals (Hospitals 2, 4 and 6). These declines were only significant for Hospital 4; greater impact on length of stay may be observed in the future as hospitals continue to embed changed practice.

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[1] Form issued if a patient is suffering from a potentially terminal illness, used by the DWP to determine potential benefits (including Disability Living Allowance and Incapacity Benefit)

Evidence suggests several areas for additional focus

Evidence gathered for this evaluation suggests scope for improvement/ additional focus on:

- Hospitals 2 and 6 showed declines in their staff confidence and routine behaviours. This is a surprising finding, and would merit further investigation, particularly since ADA data (and anecdotal evidence) would suggest that the reverse is true.
- There was a large reduction in responses at follow up for both ADA and the Staff Survey; for the data to be robustly comparable, this should be addressed in future Phases.

1   Introduction

Demographic changes and medical advances mean that the UK has an ageing population, with increasing numbers of people living with long-term conditions, often with multiple co-morbidities. This has led to an increased focus on end-of-life care, with reforms needed to ensure it both better fits the needs and wishes of patients and their families, and delivers high quality and cost-effective care.

Provision of end of life (EoL) care currently faces a number of challenges. Hospital admissions are common in the last year of life (78% of people will be admitted at least once), and, once admitted, a significant proportion of people go on to die in hospital, despite this being against their wishes in many cases.

The use of tools, such as Advance Care Planning (ACP) can significantly improve the chances of patients dying in their preferred place[2]. The policy context within which EoL care operates is also changing; most significantly, the Liverpool Care Pathway (LCP) has ceased to be the preferred model of care, to be replaced by more generic EoL care planning[3].

The Gold Standards Framework (GSF) aims to improve quality in EoL care by formalising best practice using a systematic, patient-centred approach. This report focuses on Phase 3 of this programme, with Phases 1 and 2 now completed (reports available on request).

Phase 3 has provided training and support to nine hospitals[4], on three key elements:

1. Identification of patients nearing the EoL;

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, to allow them access to care which is interdisciplinary - working across organisations and teams.

1.1   This report describes the implementation and impact of Phase 3

ICF GHK was commissioned by GSF to analyse evaluation data for Phase 3 of the programme in acute Hospitals; this follows previous analysis of Phases 1 and 2. Nine hospitals participated in Phase 3, though two hospitals (Hospitals 3 and 7) provided either no data, or only baseline data, so are excluded from this analysis (Table 1.1).

This report draws on four sources of information[5]:

■ Staff survey: this was completed by individual staff from hospitals, and focuses on their knowledge and confidence in recognising and caring for people at the EoL, and in implementing the GSF. It was not completed by the same staff at baseline and follow up;
■ Foundation survey: one of these was completed for each ward within a hospital, at three time points (January, June and November 2013). It focuses on the ward's ability to identify, assess, and plan care for patients nearing EoL;
■ After Death/Discharge Analysis (ADA): this includes baseline and follow up data, completed for each patient, again covering the identification, assessment and planning of care for patients nearing the end of life;
■ Structured interviews: GSF staff conducted five interviews with staff from participating hospitals; these were analysed by ICF GHK and offer more in-depth qualitative insight into the implementation of the GSF.

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2 Macmillan Cancer Support (2012b) Rich picture for people at the end of life

3 Independent review of the Liverpool Care Pathway (2013) More Care Less Pathway

4 All hospitals are made anonymous in this report, referred to by number rather than name.

5 All tools are reproduced in the annexes

Table 1.1   Summary of the data reported by hospitals

		Hospital 1	Hospital 2	Hospital 4	Hospital 5	Hospital 6	Hospital 8	Hospital 9
Staff Survey	Baseline							
	Follow up							
ADA data	Baseline							
	Follow up			No 'died'				
Foundation survey	January		Some wards			Some wards		
	June							
	November							

Table 1.2   Key

Data available	
No data available	
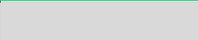
1.1.2   The remainder of this report is structured in the following way:

- Section 2: Findings from the staff survey;

- Section 3: Description and comparability of baseline and follow up data from ADA and the foundation survey;

- Section 4: The impact of the GSF on EoL care practice – findings from ADA and the organisational survey;

- Section 5: Findings from the structured interviews; and

- Section 6: Conclusions and recommendations.

2 The impact of GSF on staff knowledge and confidence: results from the staff survey

Summary

Staff from six hospitals submitted survey returns at baseline, with four of those also submitting at follow up. There was significant drop-off in returns between baseline and follow up, limiting the comparability of responses. The survey was not completed by a different sample of staff at baseline and follow up. Overall:

- Three of four hospitals showed large improvements in staff knowledge and use of EoL tools, Hospital 8 showed a slight decline in use;
- Staff confidence in recognising, and caring for patients nearing EoL improved in all hospitals except Hospital 2.

On all other questions, related to: staff confidence in having discussions with patients, relatives and carers; their routine discussion of patients nearing the end of life; and whether and what type of discharge information they send out with patients, Hospitals 8 and 9 showed an improvement, where Hospitals 2 and 6 showed a decline. Care should be taken in interpreting both these results; declines in confidence can sometimes reflect a prior lack of staff awareness of good practice (with declines in confidence occurring when they begin to undertake new and additional work).

2.1 The variable quality of some of the data limits the analysis

546 staff responded to the staff survey, 403 at baseline, and 143 at follow up. Hospital 2 submitted twice as many responses at both baseline and follow up than any other hospital. Only four hospitals - Hospitals 2, 6, 8 and 9 - responded at baseline and follow up. Three of the four hospitals reporting at follow up showed significant drop out, with all submitting fewer than half the number of responses at follow up, compared to baseline. This limits the evaluation's ability to draw strong conclusions (Figure 2.1). Alongside this, the staff surveys were filled out by different staff at baseline and follow up. Whilst all staff attended the same training (and thus positive/negative impacts should be seen throughout), small sample sizes, particularly where this reflects a drop off in responses between baseline and follow up, can mean that the samples are non-comparable.

When averages (overall means) are quoted throughout this section, they refer to all six hospitals at baseline, and four hospitals at follow up. Again, this means that the comparability of figures is limited – the impact in the two hospitals not reporting is unknown.

Figure 2.1   Number of responses at baseline and follow up, by hospital

	1	2	4	6	8	9	All
Baseline	61	146	39	37	73	47	403
Follow up		60		33	31	19	143
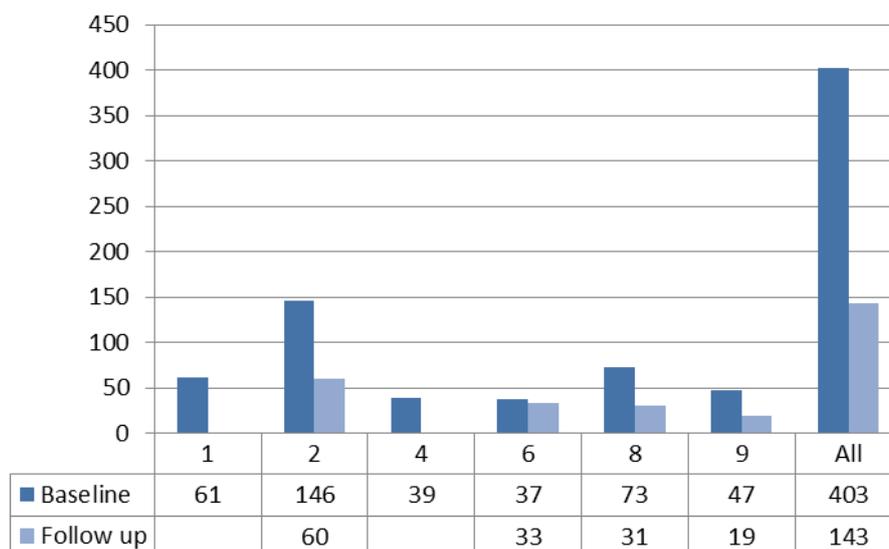
2.2 There was an improvement in staff knowledge of EoL tools in some hospitals; this question should be revised in future phases

Staff were asked to rate their responses on a scale of 1-10 (with one representing 'strongly disagree' and 10 'strongly agree') in response to the question '*I need to know more about the following areas of EoL care'*. The areas asked about were:

- Communication skills;
- Holistic assessment;
- Symptom management;
- Advance care planning;
- Care planning;
- Care of carers;
- Care of the dying.

Three Hospitals (Hospitals 2, 6 and 9) showed improvements on all or most of the categories. Hospital 8 showed a worsening (an increased need for knowledge) on all of the categories.

Hospital 9 showed the greatest improvements, with mean improvements in scores ranging from 1.7 (on care of carers) to 2.2 (on the use of ACPs). Hospital 2 showed similarly large improvements, with a range of 1.5 (care of carers) to 1.9 (ACPs and symptom management). Hospital 6 saw smaller improvements of between 0.2 and 0.5, with staff reporting a need for more knowledge at follow up, compared with baseline, on two categories – communication skills and holistic assessment. In Hospital 8 staff reported that they needed more information about EoL care at follow up across all categories.

These findings should be read with care for several reasons:

- This question is reverse scored. Respondents were asked whether they '*Feel I need to know more about the following in end of life care'*, and asked to rate their responses on a scale of 1 – 10. In this case, higher scores indicated a 'poorer' outcome (the need for more information), which is the reverse of other questions on the survey (for example those relating to confidence) where higher scores are more positive (they indicate higher confidence). It is possible that some user error may have occurred here;
- Lastly, increases in a need for knowledge could reflect that staff are now beginning to use new tools and techniques, which they were not using before – thus highlighting to them gaps in their knowledge.

Figure 2.2 **Summary of change in mean score by hospital - responses to 'I feel I need to know more about the following areas of EoL care'[6]**
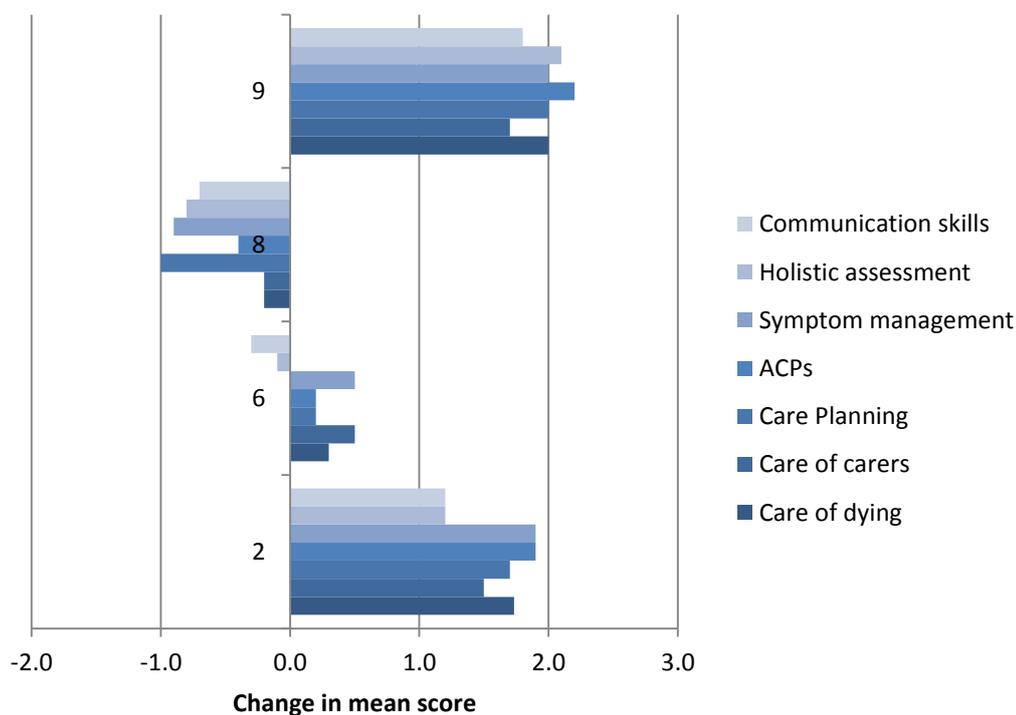
Figure 2.3 **Mean responses to 'I feel I need to know more about the following areas in EoL care' (Hospital 2)** *(staff rated scores rated on a scale of 1-10)*

	Care of dying	ACPs	Care Planning	Symptom management	Care of carers	Holistic assessment	Communication skills
Baseline	5.7	6.4	5.7	6	6.1	5.5	5.2
Follow up	4.0	4.9	4	4.1	4.2	4.3	4

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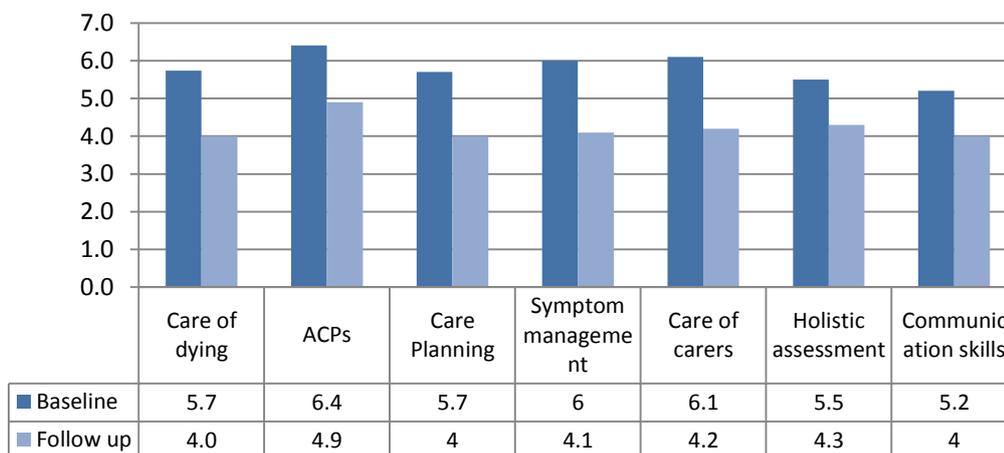
[6] Mean change in score is baseline – follow up; negative scores therefore indicate a need for more knowledge, positive scores an improvement (less need for knowledge)

Figure 2.4 **Mean responses to 'I feel I need to know more about the following areas in EoL care' (Hospital 6)** *(staff rated scores rated on a scale of 1-10)*

	Care of dying	ACPs	Care Planning	Symptom management	Care of carers	Holistic assessment	Communication skills
Baseline	4.7	6	5.1	5.3	5.6	4.7	4.4
Follow up	4.4	5.5	4.9	5.1	5.1	4.8	4.7
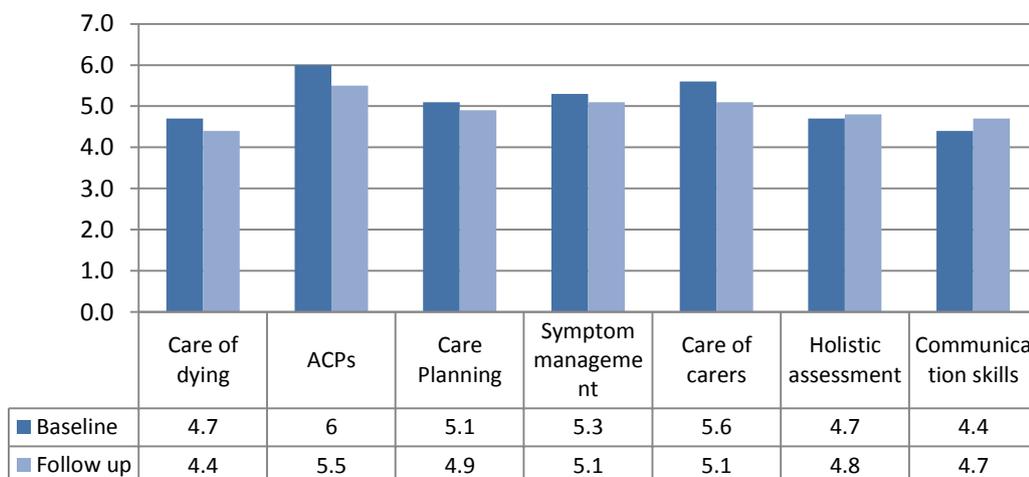
Figure 2.5 **Mean responses to 'I feel I need to know more about the following areas in EoL care' (Hospital 8)** *(staff rated scores rated on a scale of 1-10)*

	Care of dying	Care of carers	Care Planning	ACPs	Symptom management	Holistic assessment	Communication skills
Baseline	4.9	5.3	4.8	5.6	4.4	4.7	4.7
Follow up	5.1	5.5	5.8	6	5.3	5.5	5.4
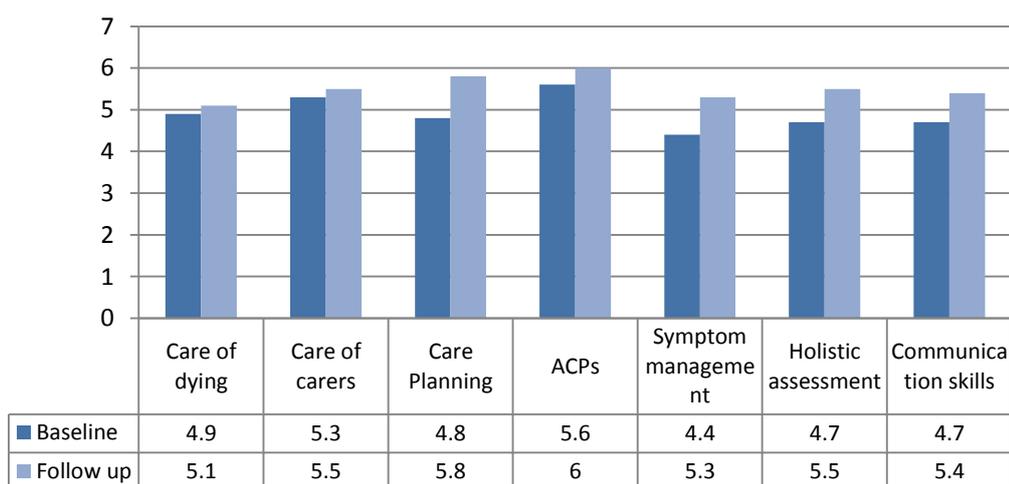
**Figure 2.6** **Mean responses to 'I feel I need to know more about the following areas in EoL care' (Hospital 9)** *(staff rated scores rated on a scale of 1-10)*

|	Care of dying	Care of carers	Care Planning	ACPs	Symptom management	Holistic assessment	Communication skills
Baseline	6.6	6.8	6.8	7.3	6.8	6.6	6.3
Follow up	4.6	5.1	4.8	5.1	4.8	4.5	4.5
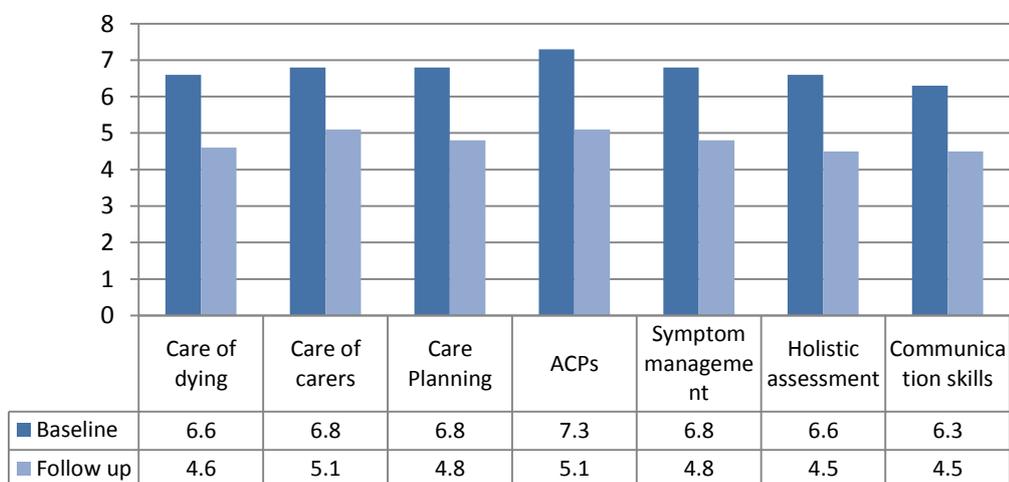
2.3   Staff experience and use of EoL tools improved

Many more staff were aware, or had used, EoL tools at follow up. Staff were asked to answer 'yes have used', 'yes am aware of' or 'no' to the question '*do you have any experience of the National End of Life Care Tools?*' Staff were asked to rate their experience on/ use of four tools; the GSF, preferred priorities for care (PPFC), the Liverpool Care Pathway (LCP) and (Advance Care plan) ACP. Due to the changes in recommended care around the LCP, this was excluded from the analysis.

The use of GSF showed the biggest improvement, (use increased from 7% to 18% overall); with awareness also showing large improvements. All individual hospitals also showed large improvements in both use and awareness (Figure 2.7).

The use of both PPFC and ACPs remained low, and increased only very slightly between baseline and follow up. Three of the four hospitals showed small increases in the use of both PPFC and ACPs, with one hospital, Hospital 8, showing a small decline in use. However, awareness of both of these almost doubled for most hospitals (Figure 2.8 and Figure 2.9).

Staff were also asked whether they used any specific tools as a trigger to identify patients in the last year of life. The proportion using tools increased from 17% at baseline to 46% at follow up, with all individual hospitals improving. Hospitals 2 and 8 showed the largest improvement, with over half of staff reporting using EoL tools at follow up (Figure 2.10).

Figure 2.7   Staff experience of GSF[7] *(staff could respond 'yes have used', 'yes aware', or 'no')*

	1	2	4	6	8	9	All
■ Used Baseline	10%	4%	0%	8%	12%	11%	7%
■ Used Follow up		75%		85%	65%	47%	71%
■ Aware Baseline	39%	53%	36%	41%	59%	45%	48%
■ Aware Follow up		12%		12%	26%	32%	18%
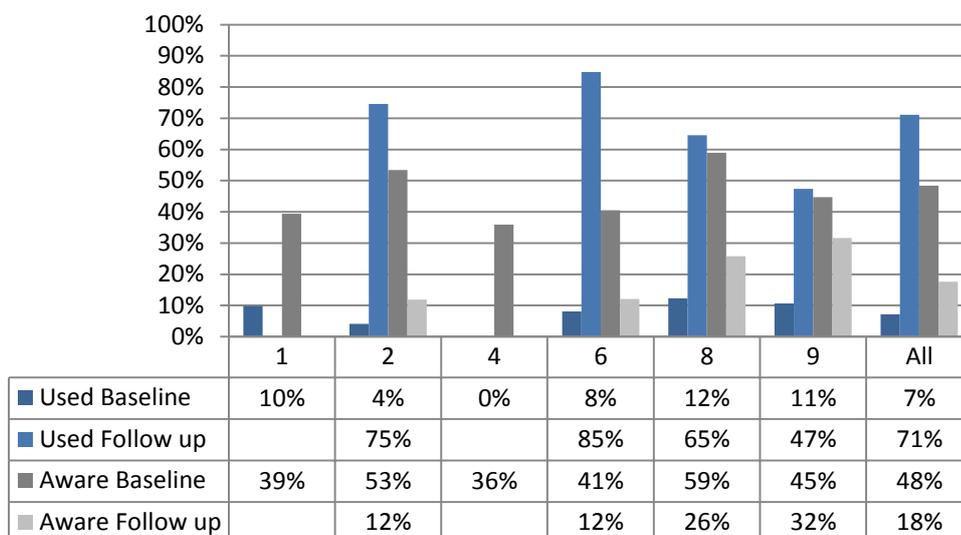
Figure 2.8   Staff experience of PPFC *(staff could respond 'yes have used', 'yes aware', or 'no')*

	1	2	4	6	8	9	All
■ Used Baseline	13%	5%	0%	8%	11%	9%	7%
■ Used Follow up		5%		12%	6%	16%	8%
■ Aware Baseline	21%	38%	15%	38%	34%	17%	30%
■ Aware Follow up		58%		70%	61%	53%	61%
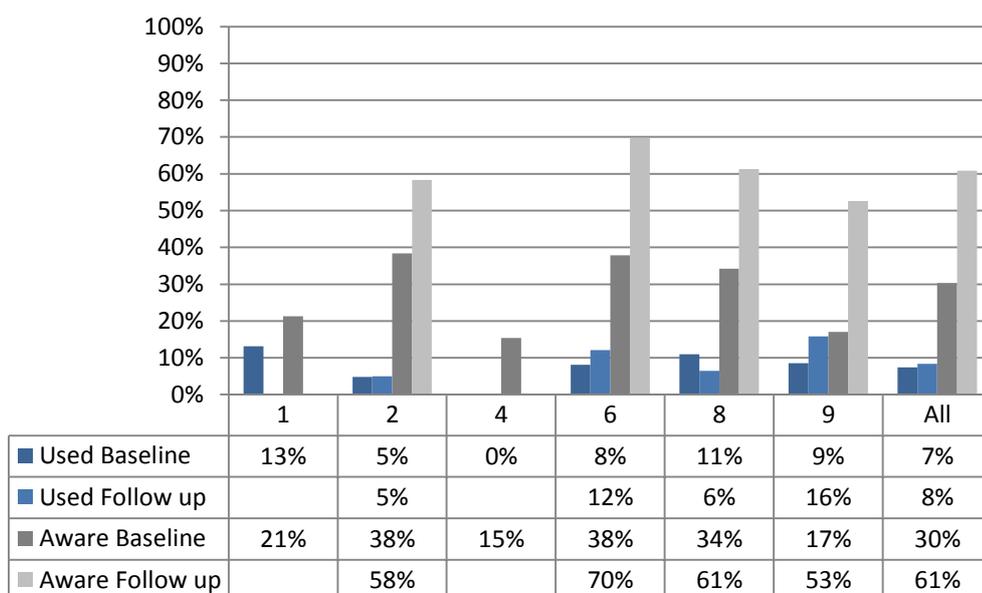
Figure 2.9 *Staff experience of ACP (staff could respond 'yes have used', 'yes aware', or 'no')*

	1	2	4	6	8	9	All
Used Baseline	11%	3%	10%	5%	16%	2%	7%
Used Follow up		10%		6%	13%	5%	9%
Aware Baseline	39%	45%	28%	41%	34%	30%	38%
Aware Follow up		65%		85%	68%	68%	71%
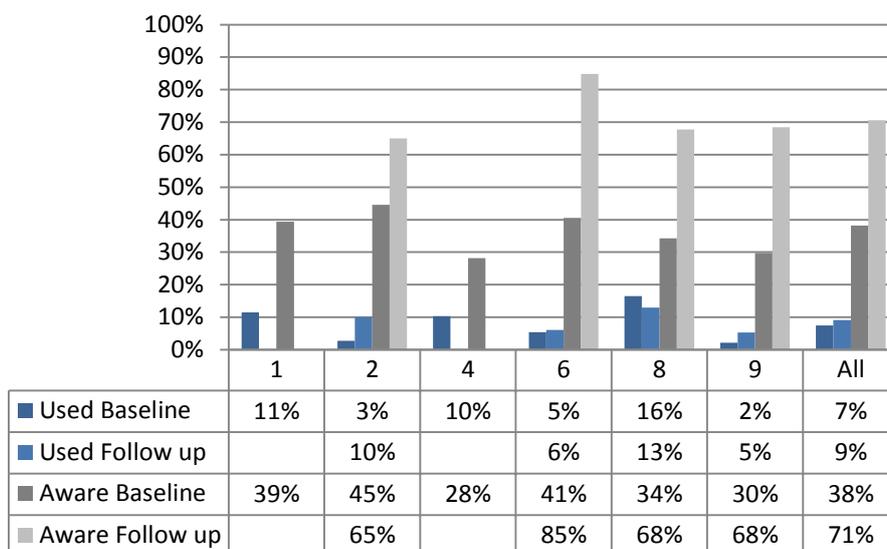
Figure 2.10 **Proportion of staff reporting using specific tools as a trigger to identify patients in the last year of life** *(staff could respond 'yes have used', 'yes aware', or 'no')*

	1	2	4	6	8	9	All
Baseline	13%	13%	23%	15%	23%	22%	17%
Follow up		52%		36%	52%	37%	46%
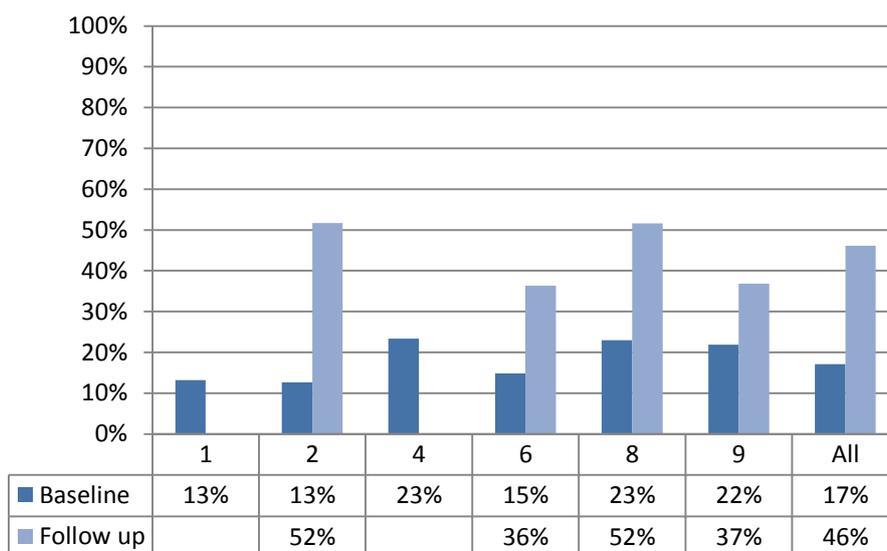
2.4 Staff confidence in caring for, and recognising, patients nearing the end of life improved

Three hospitals (Hospitals 6, 8 and 9) showed an improvement in staff confidence in caring for patients nearing the end of life (mean improvements in score ranged from 0.2 to 1.4), and one hospital (Hospital 2) showed a very slight decline. Hospital 2's staff also reported lower overall confidence at follow-up than other hospitals (Figure 2.11).

There was also variation in staff confidence in recognising patients who were nearing the end of life. Hospitals 8 and 9 both showed larger improvements in mean scores (by 0.6 and 0.9 respectively), where Hospitals 2 and 6 showed a slight decline. Again, staff in Hospital 2 reported generally lower confidence at follow up than other Hospitals, with confidence declining between baseline and follow up.

These declines in confidence are a surprising finding, and would merit further investigation, particularly since ADA data (and anecdotal evidence) would suggest that the reverse is true.

Figure 2.11 **Mean of 'do I feel confident in caring for people nearing the end of life?'** *(staff rated scores on a scale of 1-10)*

	1	2	4	6	8	9	All
Baseline	7.8	7.3	7.7	7.8	7.1	6.8	7.4
Follow up		7.2		8.0	8.3	8.2	7.7
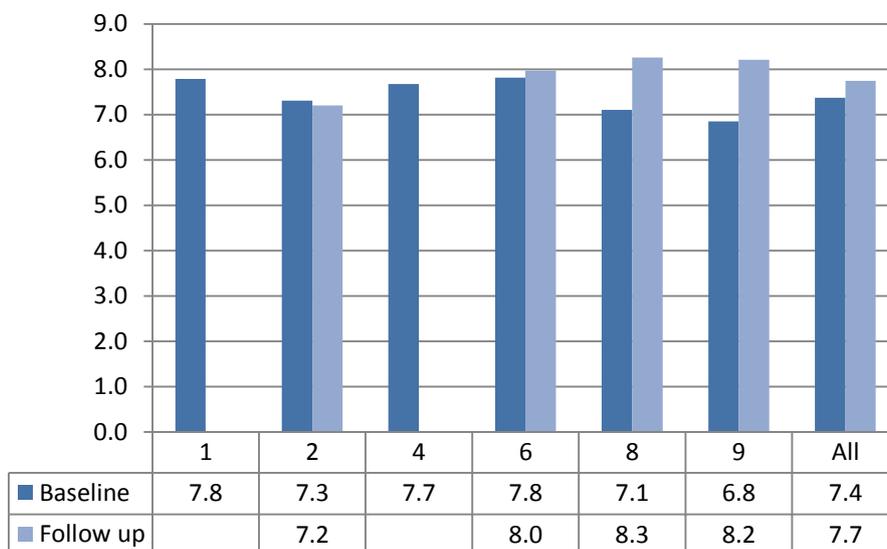
Figure 2.12 **Mean of 'do I feel confident in recognising patients who may be in the last year of life?'** *(staff rated scores on a scale of 1-10)*

	1	2	4	6	8	9	All
Baseline	6.5	6.6	6.5	7.4	6.8	6.8	6.7
Follow up		6.5		7.4	7.4	7.7	7.1
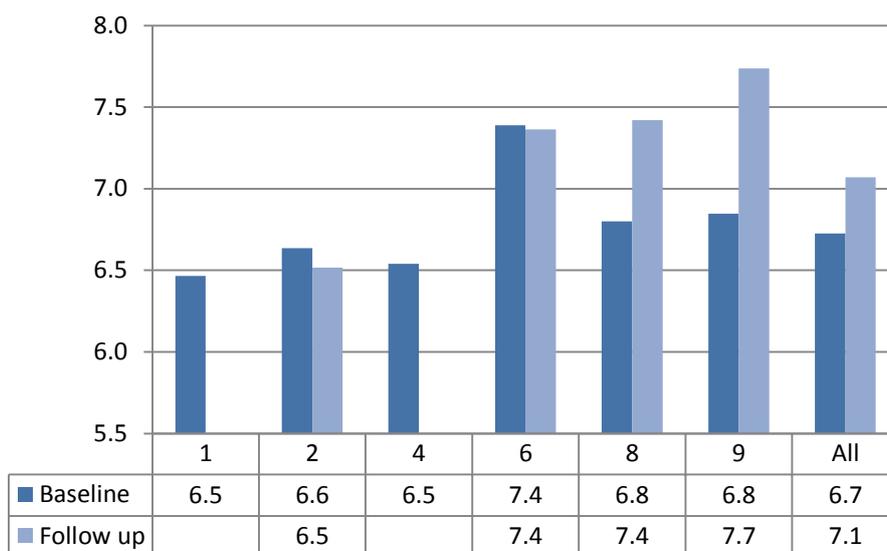
2.5 Some hospitals saw improvements in staff confidence in having discussions with patients, relatives and carers

Staff were asked to rate their confidence on three questions related to their communication with patients and their carers:

■ *I feel confident in having open communication with patients and relatives about a patient's deteriorating condition;*
■ *I feel confident in having discussions with patients about their personal wishes, preferences and concerns (ACPs); and,*
■ *I feel confident in having discussions with relatives or carers of patients about their concerns, needs and preferences (ACPs)*

Some hospitals showed improvements in these questions, and some showed declines. Care should be taken in interpreting these results as 'confidence' (either declining or rising) is not necessarily indicative of improvement; confidence can decline at the start of a programme

before increasing again, as staff are faced with new challenges, tools and protocols, as well as realisations of what they have not been doing previously.

Hospital 8 reported small improvements for all three questions, whilst Hospital 9 showed improvement for two questions, and a decline in confidence in discussing concerns, needs and preferences with relatives or carers. In Hospitals 2 and 6 staff reported falls in confidence for all three of these questions, with the falls particularly high for Hospital 6.

Staff were also asked whether, following such discussions, they developed a plan for future care. As above, Hospitals 8 and 9 showed an increase for this question, whereas Hospitals 2 and 6 saw a decline.

Figure 2.13 **Following discussions with patients and carers, was a plan for future care developed?** *(staff could answer 'yes' or 'no')*

	1	2	4	6	8	9	All
Baseline	35%	46%	53%	64%	46%	37%	46%
Follow up		42%		45%	58%	42%	46%
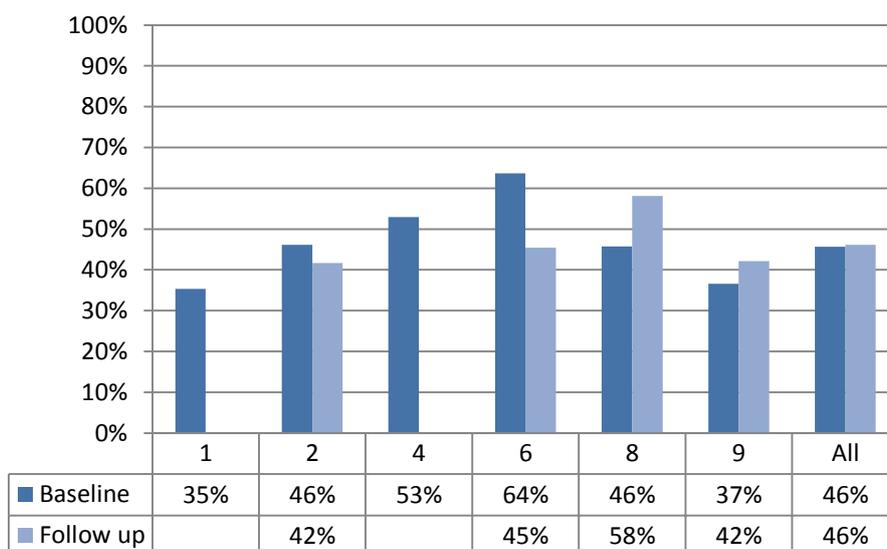
2.6 Some hospitals saw routine discussion of EoL care increase slightly between baseline and follow up

Staff were asked how routinely they discussed elements of end of life care. They were asked whether they routinely discussed patients nearing the end of life at multi-disciplinary team (MDT) meetings, and whether (and how) they routinely transferred discharge information regarding EoL care and patients' wishes. As with other questions on the staff survey, Hospitals 8 and 9 showed an improvement, and Hospitals 2 and 6 a decline (Figure 2.14).

Staff were also asked whether they routinely transferred discharge information regarding EoL care and patient's wishes, and who to. Again, there was diversity between hospitals. For information sent to GPs, Hospital 9 showed an improvement (from 44-58%), Hospital 8 showed a very slight improvement (from 42-45%) and Hospitals 2 and 6 showed declines (Figure 2.15). For information sent to district nurses, again Hospitals 8 and 9 showed improvements, and 2 and 6 declines (Figure 2.16).

All hospitals showed a decline in the percentage of staff reporting information discharged to 'other' (Figure 2.17). 'Other' individuals/organisations that were sent discharge information included:

■ Community palliative care teams (including Macmillan nurses);
■ Palliative discharge teams;
■ Hospices, and hospice staff; nursing homes and nursing home staff;
■ Social services.

Figure 2.14 Proportion of staff reporting that they routinely discuss patients nearing the end of life *(Staff could answer 'yes' or 'no')*

	1	2	4	6	8	9	All
Basline	40%	34%	16%	62%	40%	25%	35%
Follow up		32%		52%	45%	26%	38%
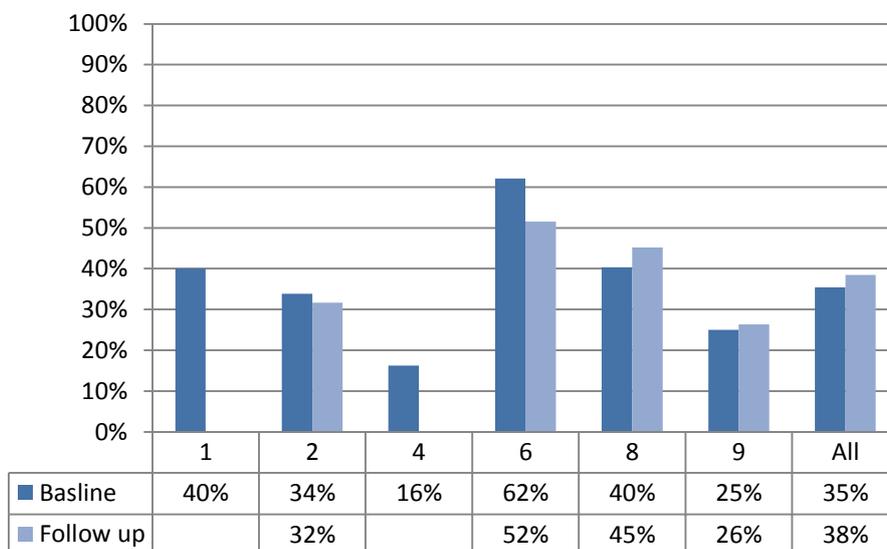
Figure 2.15 Proportion of staff who routinely send out discharge information to GPs *(Staff could answer 'yes' or 'no')*

	1	2	4	6	8	9	All
Baseline	29%	32%	26%	68%	42%	44%	37%
Follow up		18%		42%	45%	58%	35%
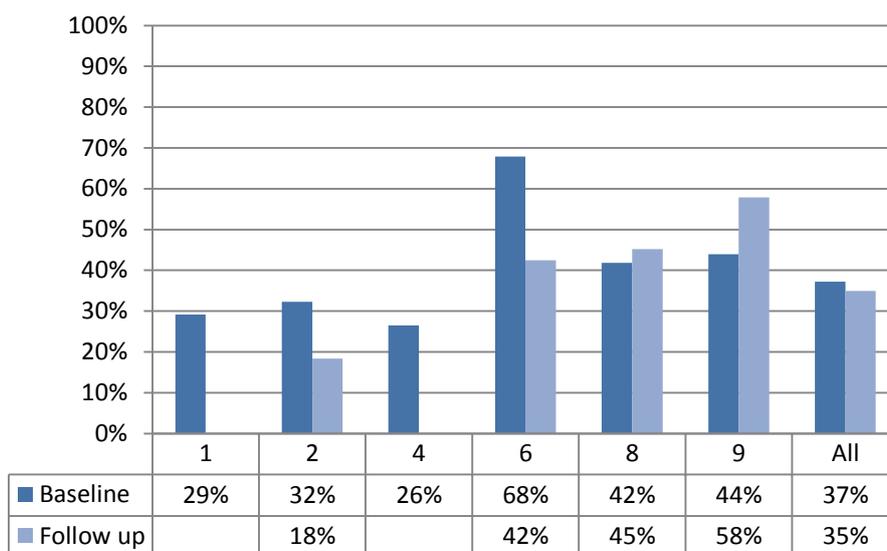
Figure 2.16 **Proportion of staff who routinely send out discharge information to district nurses** *(Staff could answer 'yes' or 'no')*

|	1	2	4	6	8	9	All
Baseline	23%	32%	17%	56%	42%	43%	34%
Follow up		27%		48%	58%	63%	43%
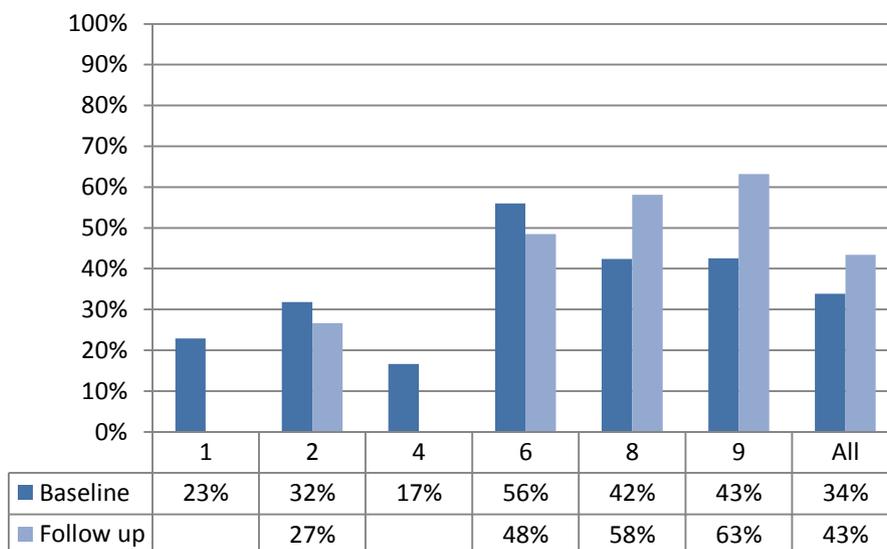
Figure 2.17 **Proportion of staff who routinely send out discharge information to 'other' individuals/organisations** *(Staff could answer 'yes' or 'no')*

	1	2	4	6	8	9	All
Baseline	15%	28%	32%	63%	33%	36%	31%
Follow up		10%		36%	16%	21%	19%
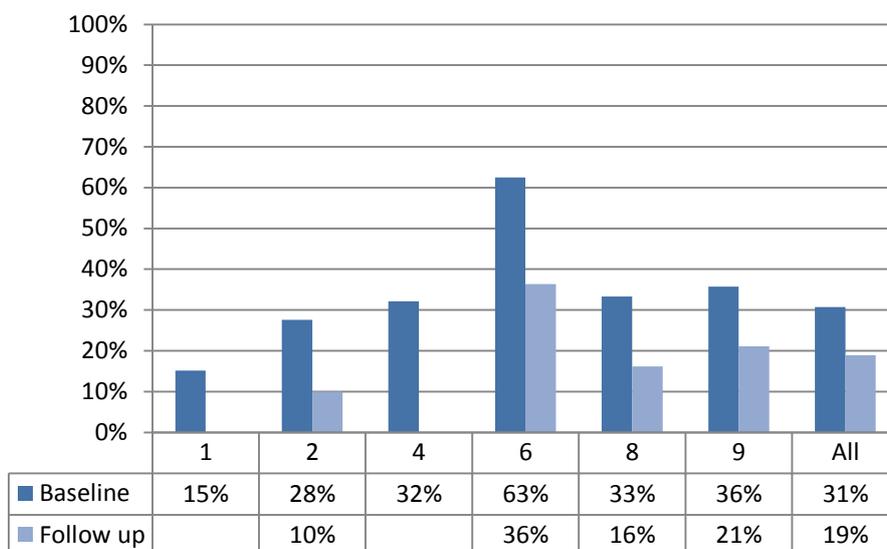
3 Descriptive information and comparability of baseline and follow up data – ADA and the Foundation survey

Summary

■ This section describes the evidence available from:
  – The baseline and follow up ADA questionnaire (patient-level data from 6 hospitals);
  – The foundation questionnaire in January, June and November 2013 (ward-level answers from 7 hospitals);
  – In total, data were collected on 556 patients: 257 at baseline and 299 at follow up.

■ Baseline and follow up data have similar characteristics:
  – Primary diagnoses and causes of death were similar at baseline and follow up;
  – Around half of patients at both baseline and follow up died in hospital.

■ However, there are a number of issues with the data, which limits confidence in results:
  – There is a significant reduction in the number of returns between baseline and follow up; This means that the two samples are not necessarily comparable;
  – This is a particular issue for Hospital 4 which had only 9 follow up patients, none of whom died in hospital;
  – Some hospitals have submitted far more responses than others, and will be over-represented in any overall conclusions.

■ There was an overall decline in length of hospital stay between baseline and follow up, though this was not statistically significant.

3.1 The Foundation level questionnaire asked for summary information about ward progress at three time points

The Foundation level questionnaire asked facilitators to report on their ward/hospital's progress on three elements of the GSF:

■ Identifying patients nearing the end of life;
■ Assessing patients near the end of life;
■ Planning end of life care.

Respondents could answer questions 'yes' (green), 'no' (red), or 'working towards' (amber). Questions were asked at three time points: January (6 months after the programme start), June, and November 2013. All Hospitals responded at least once to the questionnaire (with all responding in June); Hospital 1, which submitted no ADA follow up data, responded to this questionnaire. However:

■ Two wards in Hospital 2 (b and c), Hospital 5, and three wards in Hospital 6 (b, c and d) didn't respond in January;
■ Hospitals 1, 4 and 5 didn't respond in November.

3.2 Six hospitals submitted ADA baseline and follow up data

Six hospitals provided baseline and follow up data. Three (Hospitals 1, 3 and 7) provided only baseline data and are excluded from this analysis. Hospital 6 accounts for 40% of all follow-up responses. Hospital 4 provided only 9 follow up responses (Figure 3.3). Three hospitals (2, 6 and 7) submitted data from more than one ward. Where relevant, and where sample sizes are large enough, analysis is broken down by ward (Figure 3.4). One question on the ADA asked about the use of the Liverpool Care Pathway (LCP) or other Integrated Care Pathway (ICP). In late 2013 *More Care, Less Pathway* recommended that the LCP no longer be used; meaning that it can no longer be considered 'best practice' – these responses were therefore excluded from the analysis.

3.2.1 Primary diagnoses and causes of death were similar at baseline and follow up

Cancer remained the primary diagnosis at both baseline and follow up, though it was slightly more common (68% compared to 62%) at follow up. Frailty/ co-morbidity moved from being the 6th most common diagnosis at baseline, to the 2nd most common at follow up. All other diagnoses decreased in prevalence between baseline and follow up (Figure 3.1). Hospital 2 is a specialist cancer hospital, 99% of its primary diagnoses were cancer. When Hospital 2 is excluded from the sample cancer remains the primary diagnosis, though the difference between baseline (45% of cases) and follow up (56% of cases) increases.

The main cause of death at both time-points was cancer, reflecting the most common primary diagnosis. Frailty/co-morbidity was the second largest cause of death at baseline, and the joint second largest (together with heart failure) at follow up. 'Other' and COPD/respiratory accounted for around 8% of deaths each, at baseline and follow up.

Figure 3.1   Primary diagnosis at baseline and follow up (all hospitals)

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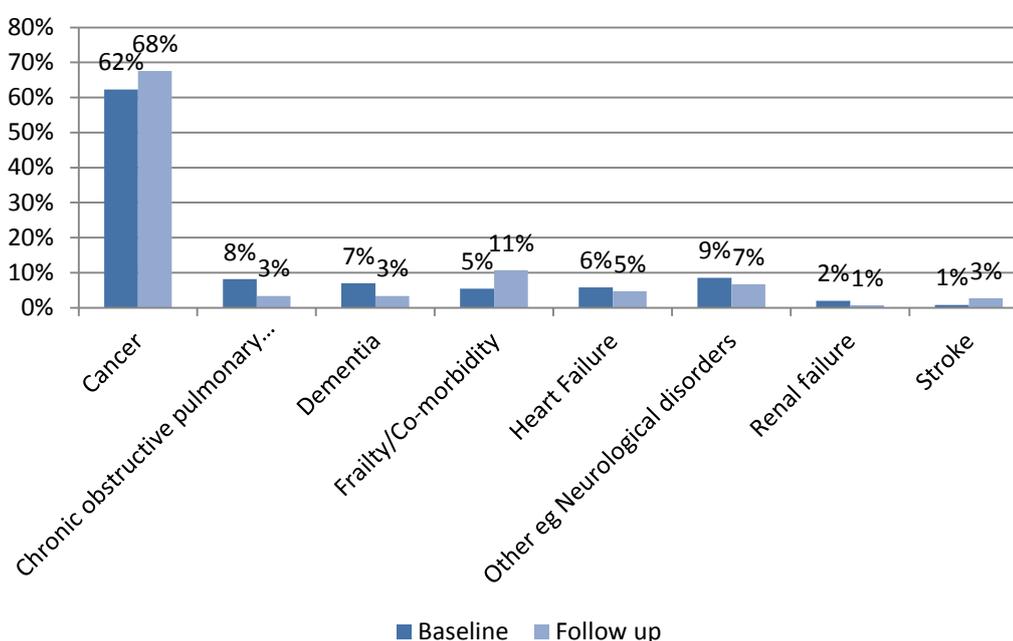
Figure 3.2   Causes of death at baseline and follow up (all hospitals)
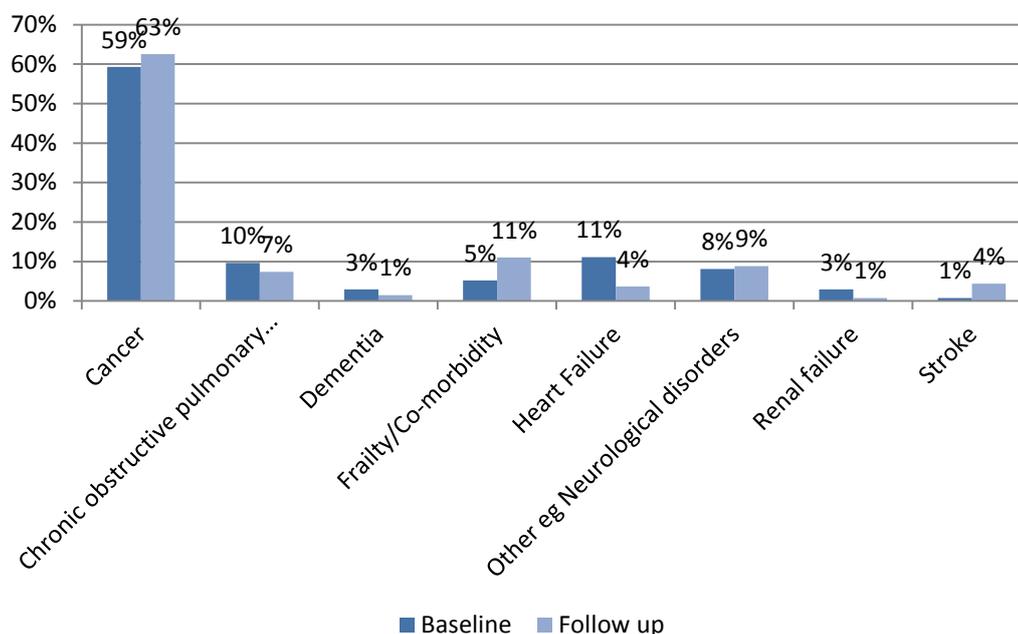
3.2.2   The proportion of patients who died varied by hospital and time-point

Figure 3.5 shows the percentage of patients who died in hospital at baseline and follow up, broken down by hospital. Most hospitals showed similar proportions of patients dying in hospital at follow up, as at baseline (within 10 percentage points). The main exceptions to this were hospital 6 (66% died at baseline and 52% at follow up) and Hospital 4, where no patients died at follow up. The lack of patients dying at follow up from Hospital 4 means it will be excluded from much of the analysis. There was some variation by ward in the proportion of patients dying; this variation was seen at both baseline and follow up (Figure 3.6).

A number of questions on the ADA are relevant only to those patients who died in hospital; those who were discharged are therefore excluded from the analysis.

Figure 3.3   Number of responses at baseline and follow up, by hospital

	2	4	5	6	8	9
Baseline	83	30	31	55	29	29
Follow up	81	9	29	119	31	30
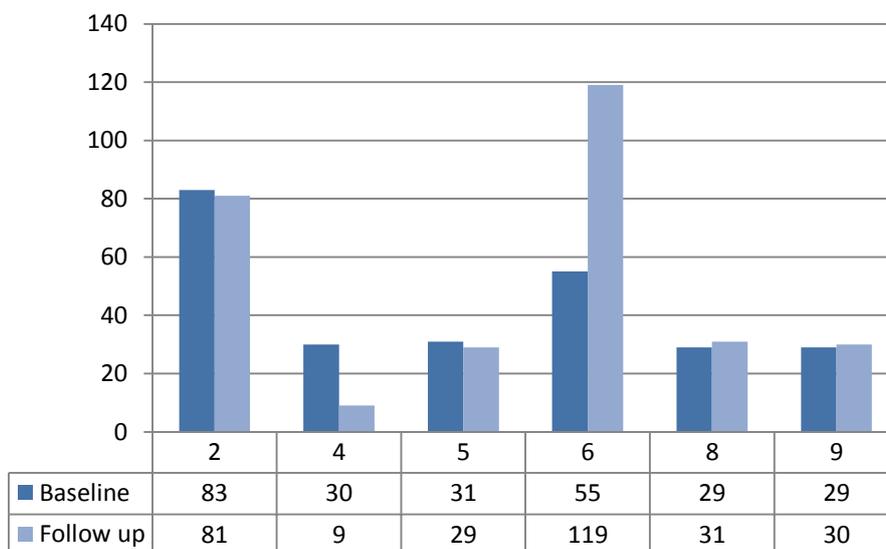
Figure 3.4   Number of responses at baseline and follow up, by hospital ward (Hospitals 2, 6 and 8)

	2a	2b	2c	6a	6b	6c	6d	8a	8b	8c	8d
		2				6				8	
Baseline	30	24	29	17	10	12	16	12	7	3	7
Follow up	34	19	28	30	30	28	31	10	7	4	10
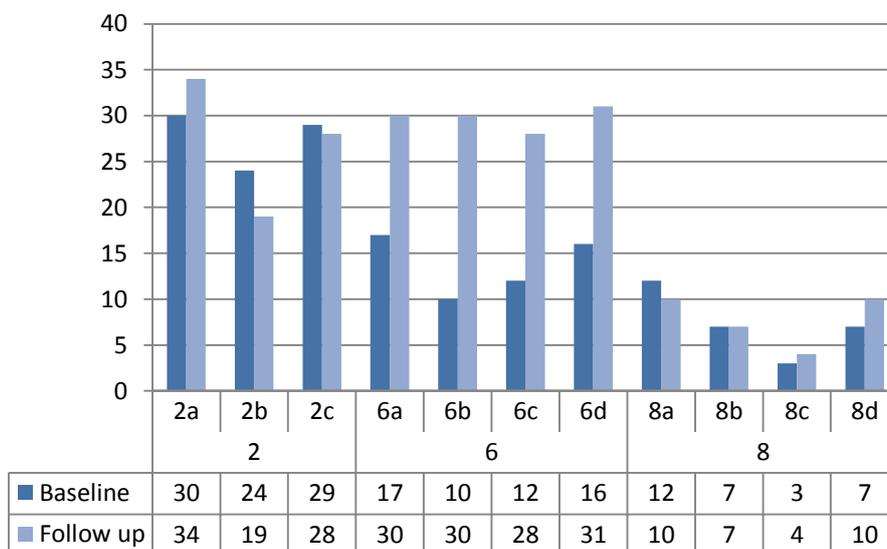
Figure 3.5   Percentage of patients who died in hospital at baseline and follow up, by hospital

	2	4	5	6	8	9	All
Baseline	52%	50%	45%	55%	66%	52%	53%
Follow up	41%	0%	52%	52%	52%	50%	47%
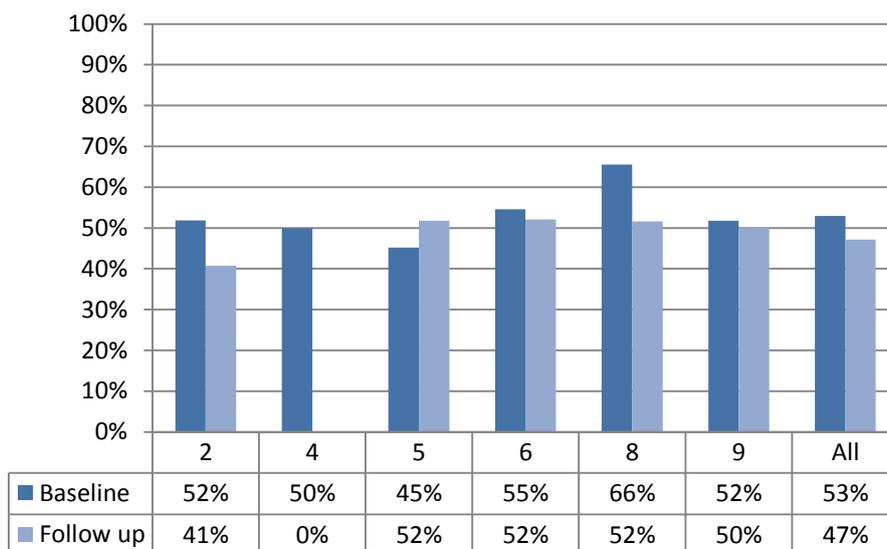
Figure 3.6   Percentage of patients who died in hospital at baseline and follow up, by ward

	2a	2b	2c	6a	6b	6c	6d	8a	8b	8c	8d
Baseline	57%	50%	48%	53%	70%	42%	56%	67%	57%	33%	86%
Follow up	41%	37%	43%	50%	53%	46%	58%	50%	71%	25%	50%
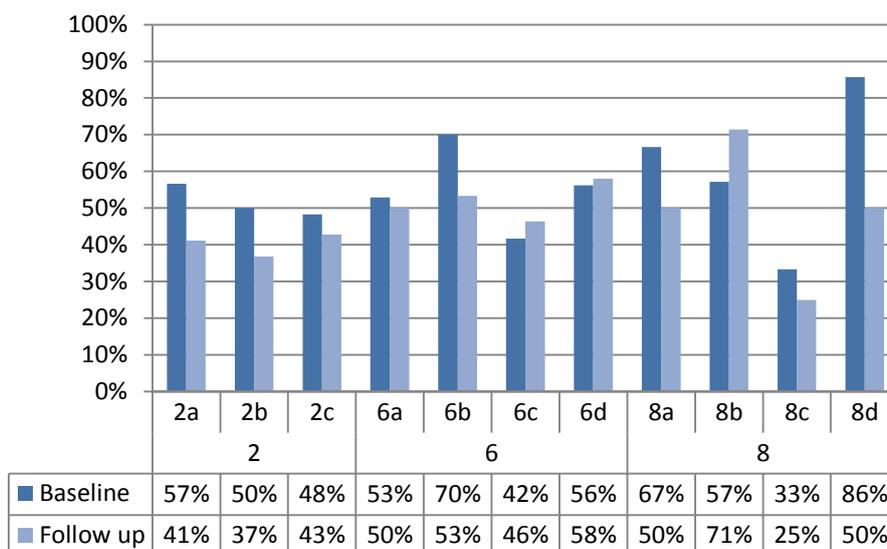
3.3   Length of stay declined between baseline and follow up; this decline was not statistically significant

Length of stay was only calculated for those individuals who were discharged from hospital, as date of death was not consistently recorded. In addition, five returns were excluded due to a data entry error (length of stay was negative). Embedding changed practice takes a considerable amount of time, and impact on length of stay may continue to improve in the future.

Three hospitals, Hospitals 2, 4 and 6, showed a decline in mean length of stay (Figure 3.7). This decline was only significant for Hospital 4 (Table 3.1). However, since Hospital 4 provided many fewer responses at follow up, compared to baseline (9 compared to 30), it is possible that their returns are quite biased, and this result should be read with care. Three hospitals, Hospitals 5, 8, and 9 saw small increases in length of stay.

There was some variation in mean length of stay, and change in mean length of stay between different wards of the same hospital. Of particular note were wards 2a, 6a and 6b, and 8b and 8d, which all saw large declines in average length of stay. The remaining two wards in Hospital 8, 8a and 8c, saw increases in length of stay. However, care should be taken in interpreting these results as the sample sizes are small, particularly for Hospital 8 (Figure 3.8).

Figure 3.7   Length of stay (in days) at baseline and follow up, by hospital

	2	4	5	6	8	9	All
■ Baseline	16.4	33.7	14.3	19.5	20.0	9.8	18.6
■ Follow up	14.5	13.0	14.9	14.2	20.8	13.2	14.8
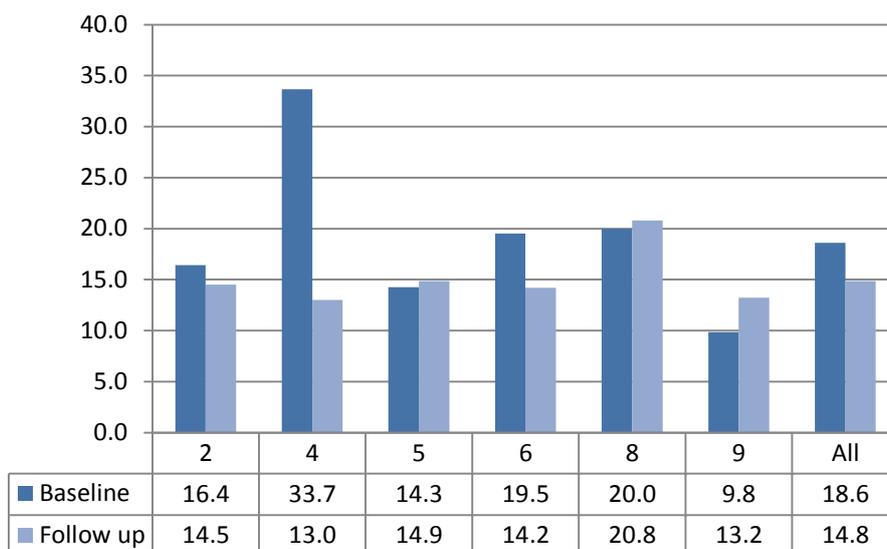
Figure 3.8   Length of stay at baseline and follow up, by ward

	2a	2b	2c	6a	6b	6c	6d	8a	8b	8c	8d
		2				6				8	
■ Baseline	33.7	14.3	20.7	31.8	32.7	7.1	12.3	7.3	35.0	26.5	28.0
■ Follow up	13.0	14.9	18.0	20.9	18.6	7.1	10.1	12.8	6.0	62.7	9.6
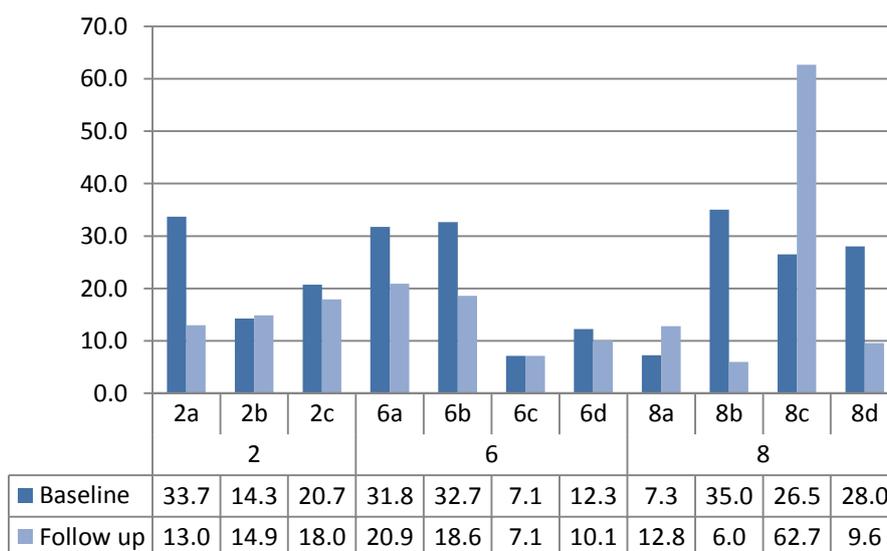
Table 3.1   Significance of changes in length of stay

Hospital	Baseline (mean days)	Follow up (mean days)	t-value	p-value (two-tailed)	Sig. change in mean?
2	16.4	14.5	0.4076	0.6843	No
4	33.7	13.0	2.9442	0.0063	Yes
5	14.3	14.9	0.0249	0.9804	No
6	19.5	14.2	0.8876	0.3767	No
8	20.0	20.8	0.2375	0.8137	No
9	9.8	13.2	-0.3406	0.7371	No
All	**18.6**	**14.8**	**1.6616**	**0.0974**	**No**

4 The impact of implementing GSF on the quality of end of life care practice

4.1 Introduction

The section below uses information from ADA and the Foundation survey to analyse the impact of the GSF on the quality of EoL. Following the structure used in the Foundation survey, answers are grouped according to the following categories:

- The identification of patients nearing the end of life, including:
  - Summary findings from the foundation survey;
  - The collecting and dissemination of passport information;
  - The use of DS1500 forms.

- The assessment of patients nearing the ned of life:
  - Summary findings from the foundation survey;
  - Conversations held with patients and carers;
  - Recording of DNAR/NCR/AND;
  - The use of symptom control assessments;
  - Proportion of patients dying in their preferred place of care.

- Care planning for patients nearing the end of life
  - Summary findings from the foundation survey;
  - Proportion of patients with an ACP or PPC recorded;
  - Proportion of patients on the rapid discharge pathway;
  - Use of the Liverpool or other ICP in the last days of life.

Where relevant, comparisons will be made with the results from the staff survey.

4.2 The identification of patients nearing the end of life improved greatly between baseline and follow up

Summary

The identification of patients nearing the end of life was an area which saw particularly large improvements between baseline and follow up – with performance often very low at baseline. Findings include:

- The proportion of staff on wards who were trained in GSF varied between hospitals;
- Overall, the foundation survey suggested that there was progress in identifying patients who were nearing the end of life;
- ADA data showed very large improvements in the proportion of patients who had passport information collected on admission;
- Large improvements were also seen in the proportion of patients who had passport information sent out on discharge;
- Similarly, there was a large increase in the proportion of patients who had a DS1500 issued, from only 6 at baseline, to 68 at follow up, although this improvement was limited to a few hospitals.

4.2.1 Information from the foundation survey suggested that between half and all of staff on the wards were trained

In the November round of the foundation survey, sites were asked to comment on the percentage of staff covered by training. Hospitals 2, 6, 8 and 9 responded to this, with only Hospitals 2 and 6 providing a proportion. Hospital 6's four wards reported that the percentage of staff trained was between 88-90%. This was much higher than Hospital 2, where all wards reported 56% of staff trained. Hospital 8's wards varied between 'significant change' (8a), 'most' (8b) and 'all' (8c and d). Hospital 9 also reported that 'most' staff were trained.

4.2.2 Findings from the foundation survey suggest that some progress was made in identifying patients who were nearing the end of life

Hospitals were asked three questions around their identification of patients nearing the end of life:

- Every patient nearing the end of life (final months, weeks, days) is identified;
- They are included on the appropriate hospital register/tagged;
- A plan of care is discussed at ward round/ MDT meeting

Hospitals performed best in response to *'a plan of care is discussed at ward round/MDT meeting',* with 9 (of 15) wards, from three hospitals (2, 6 and 8) reporting that they did this at the final time point. Responses to 'they are included on the appropriate hospital register/tagged' were the lowest, with only one ward (6d) reporting that they did this in November. This partly reflects findings from the ADA on passport information (see sections 4.2.3, 4.2.4). All other hospitals reporting were 'working towards' this, except ward 8a. The remaining wards from Hospital 8 had improved between June and November from 'no' to 'working towards' this question.

Six wards, from three hospitals, reported that every patient nearing the end of life was identified. Three-quarters of Hospital 8's wards worsened between June and November, moving from 'yes' to 'working towards'. Two hospitals (1 and 5) reported that they were not identifying patients near the end of life at all; Hospital 1 reported this in January, but had improved to 'working towards' by June (and didn't report in November); Hospital 5 reported this in June, and didn't report in January and November. These results fit with those from the staff survey, where Hospitals 6, 8 and 9 showed improvements in staff confidence at recognising patients nearing the end of life (see Figure 2.11, Figure 2.12).

4.2.3 The ADA showed that passport information was rarely collected on admission, though this did improve at follow up

Passport information was rarely collected on admission at baseline. This improved to a large degree at follow up, with Hospitals 4, 6 and 9 increasing the proportion of patients who had this collected by between 44-93 percentage points. Hospital 5, which collected far more passport information than other hospitals at baseline (on 33% of patients), saw this decline to 0% at follow up. Given the small sample size, analysis was not done separately for patients who died/were discharged, or by ward.

Where information was provided, it was most commonly in the form of 'other' at baseline and a GP letter at follow up. At baseline, information was collected in multiple forms; at follow up it was overwhelmingly collected by GP letter (Figure 4.2).

Figure 4.1   Percentage of patients whose passport information was recorded on admission (all patients) *('yes' responses (other options NA, no, not recorded))*

	2	4	5	6	8	9	All
■ baseline	0%	7%	33%	4%	0%	0%	5%
■ follow up	0%	100%	0%	48%	0%	48%	27%
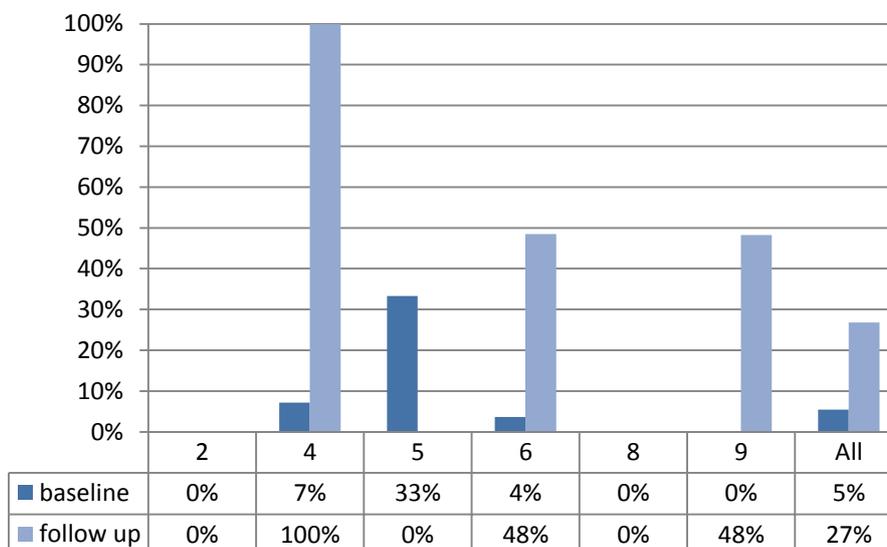
Figure 4.2   Type of passport information collected at baseline and follow up (all patients)

	GP Letter	Other	Passport	Patient Held Record
■ Baseline	33%	44%	22%	0%
■ Follow up	88%	8%	2%	2%
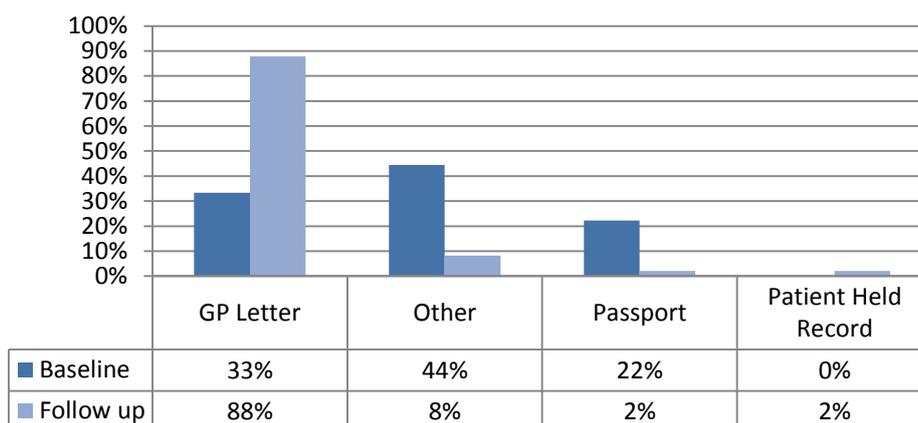
4.2.4   Passport information was rarely sent out on discharge at baseline, this improved at follow up

There was significant variation between hospitals in whether passport information was sent out on discharge. Hospitals 2 and 8 did not send out information at baseline or follow up; and Hospital 5 sent it out at baseline, but not at follow up. Hospitals 4, 6 and 9 all improved between baseline and follow up, sending out passport information with over 80% of their discharged patients. All wards in Hospital 6 sent out passport information on discharge (covering between 67% and 100% of patients). The improvements in performance here contrast with the findings from the staff survey, which showed only modest increases in the routine transference of discharge information (section 2.6).

Where information was sent out, it was most commonly in the form of a GP letter (at both baseline and follow up). Gold cards, 'other' and patient held records were all used more at follow up than baseline (Figure 4.4). This contrasts directly with the information collected on patients on admission, where GP letters were much more common at follow up.

Figure 4.3   Percentage of patients who had passport information sent out at baseline and follow up (discharged patients only) ('yes' responses (other options NA, no, not recorded))

|	2	4	5	6	8	9	All
■ Baseline	0%	7%	59%	8%	0%	0%	11%
■ Folllow up	0%	100%	0%	81%	0%	93%	44%
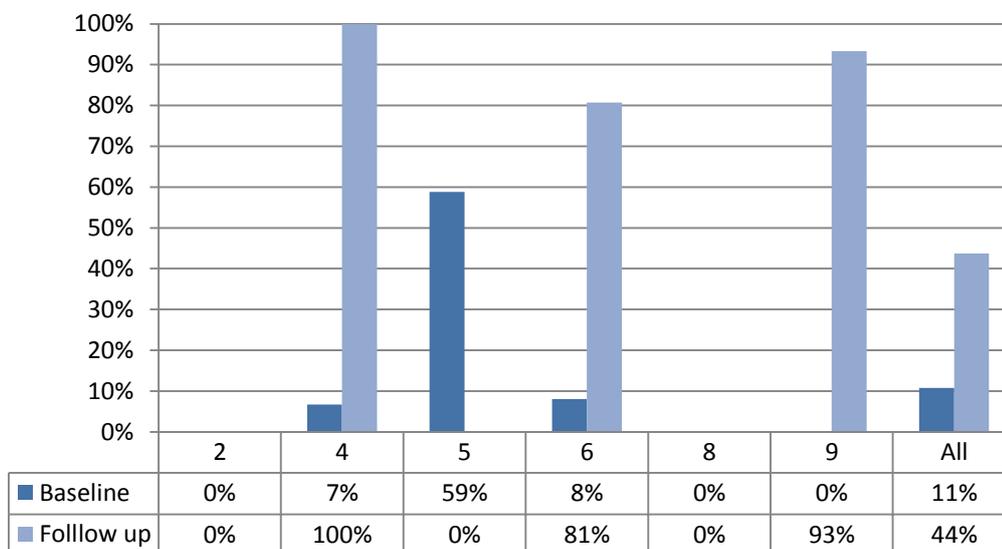
Figure 4.4   Type of passport information sent out at baseline and follow up (discharged patients only) ('yes' responses (other options NA, no, not recorded))

	Gold Card	GP Letter	Other	Passport	Patient Held Record
■ Baseline	0%	83%	8%	8%	0%
■ Follow up	13%	60%	15%	0%	12%
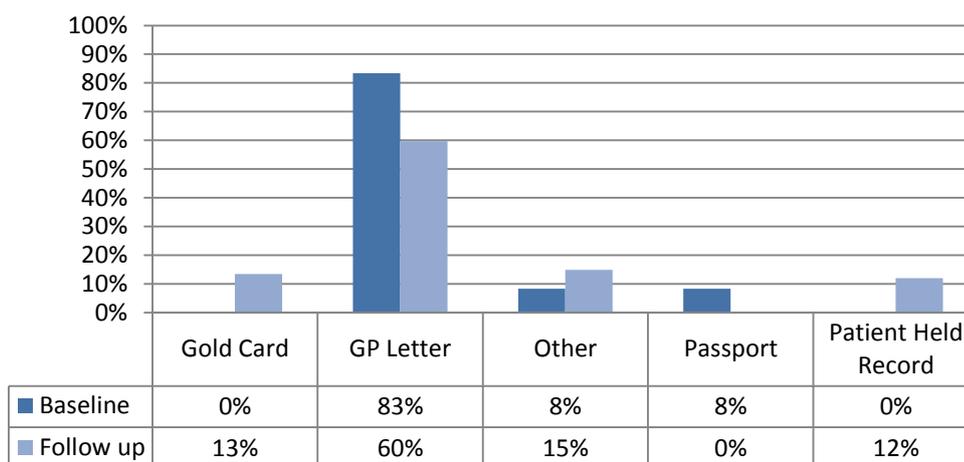
4.2.5   Few DS1500 forms were completed, though this did increase between baseline and follow up

ADA data show that the completion of DS1500 forms improved in most hospitals. Only Hospitals 4 and 8 filled in DS1500 forms at baseline, with Hospitals 2, 6 and 9 joining them at follow up; all (bar Hospital 4) showed an increase. Hospital 2 filled out DS1500 forms for a much higher proportion of its patients at follow up (79% those that died and 56% of those discharged), than any other hospital. In addition, all of its wards filled out DS1500 forms. Only two of Hospital 6's wards (6a and 6b) filled out forms, together with three of Hospital 8's.

This question in ADA was framed as 'where DS1500 was appropriate, was it completed?' analysis has therefore also been done excluding all those patients coded as 'NA, not applicable'. This made little difference to the overall proportions of patients who had a DS1500 completed; it remained at 4% at baseline and increased slightly to 25% at follow up.

Figure 4.5 **Where DS1500 was appropriate, was it completed?** *('yes' responses (other options NA, no, not recorded))*

	2	4	5	6	8	9	All
Baseline	0%	3%	0%	0%	24%	0%	3%
Follow up	65%	0%	0%	5%	26%	3%	23%
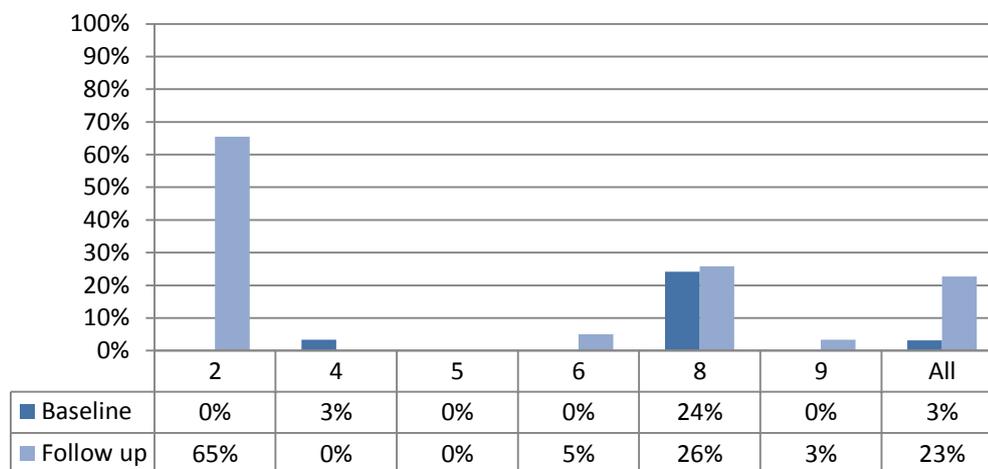
4.3 The assessment of patients nearing the end of life

Summary

The assessment of patients nearing the end of life was the lowest performing area of the foundation survey. However, data from ADA showed that the use of tools either very high, or showing large improvements between baseline and follow up:

- The foundation survey found that only two hospitals were holding full discussions with patients and carers. This contrasted with the ADA data which showed that discussions were held with carers in the majority of cases. ADA data also showed that:
  - Discussions were held more frequently for those who died, than for those who were discharged; and,
  - There was little improvement between baseline and follow up, partly because the figures were already high (84% and 89%).

- The recording of DNAR/NCR/AND was generally high, and increased slightly at follow up.
  - It was much more common for patients who died (94% at follow up), than for those who were discharged (58% at follow up).

- Symptom control assessments were rarely used at baseline, but increased at follow up to 52% of those who died, and 35% of those who were discharged.

- The number of patients who died in their preferred place of care remained low, though there was a slight improvement (to 10%) at follow up

4.3.1 Assessing patients nearing the end of life was the lowest-performing area of the Foundation survey

Hospitals were asked three questions on their assessment of patients nearing the end of life:

- Clinical needs assessed using appropriate clinical assessment tool/ measures;
- There is an initial discussion with the patient and carers and information given;
- This information given was either:
  - Beginning an advance care planning discussion, proxy nominated person noted;
  - DNA CPR status;
  - Preferred place of care and information leaflet given.

Generally, scores here were lower than for questions on identifying and planning with patients, and only Hospitals 6 and 8 reported 'yes' to any of the questions asked. The question where scores were highest was on 'clinical needs assessed using appropriate clinical assessment tool/measures'. In November, eight wards answered yes to this.

However all eight wards came from just two hospitals, Hospitals 6 and 8. Of the remaining hospitals reporting, all said that they were still 'working towards' this.

4.3.2 ADA data and the Foundation survey offer contrasting views on conversations held with patients and carers

ADA data showed that the proportion of patients for whom a discussion with a carer was held was high; it also increased slightly between baseline and follow up. Discussions with carers were held more frequently for patients who died in hospital, than for those who were discharged. For patients who died in hospital, three hospitals (Hospitals 2, 6 and 8) saw improvements, (of between 7 -17 percentage points). Two hospitals (Hospitals 5 and 9) showed declines. For Hospital 5, this decline was small (6 percentage points); for Hospital 9 it was larger (33 percentage points).

There was also variation between hospitals for patients discharged. Hospital 4 held discussions with carers in 100% of cases at both baseline and follow up. All other hospitals showed improvements, ranging from the slight (from 53% to 57% for Hospital 5), to the large (from 45% to 75% for Hospital 2). Hospital 9 was the only hospital to show a decline in the proportion of patients supported between baseline and follow up, though this declined slightly from an already high level (93%- 87%).

This contrasts with information from the foundation survey, where only two hospitals, 6 and 8, reported having discussions with patients and carers, with Hospital 9 reporting they were 'working towards' this. Hospitals 2, 4 and 5 said that they were not doing this. There was little noticeable pattern of improvement/worsening, with Hospitals 1 and 2a improving from 'no' to 'working towards' and Hospitals 8d and 9 worsening from 'yes' to 'working towards'.

This mixed pattern was also seen in the more detailed questions asked in the staff survey. Half of hospitals (2 and 6) showed falls in staff confidence at having discussions with patients, relatives and carers, and half (8 and 9) showed an improvement (section 2.5).

Figure 4.6 **Percentage of patients for whom a discussion with carers were held, by hospital (those who died in hospital)** *('yes' responses (other options NA, no, not recorded))*

|	2	4	5	6	8	9	All
■ Baseline	77%	93%	86%	87%	74%	100%	84%
■ Follow up	94%		80%	94%	88%	67%	89%
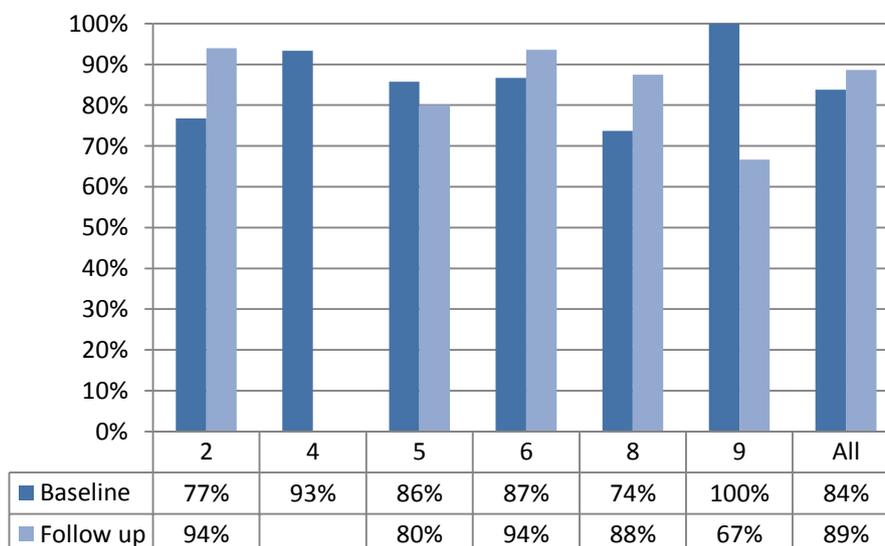
Figure 4.7   Percentage of patients for whom a discussion with carers were held, by hospital (patients who were discharged) *('yes' responses (other options NA, no, not recorded))*

	2	4	5	6	8	9	All
Baseline	45%	100%	53%	80%	20%	93%	64%
Follow up	75%	100%	57%	89%	40%	87%	78%
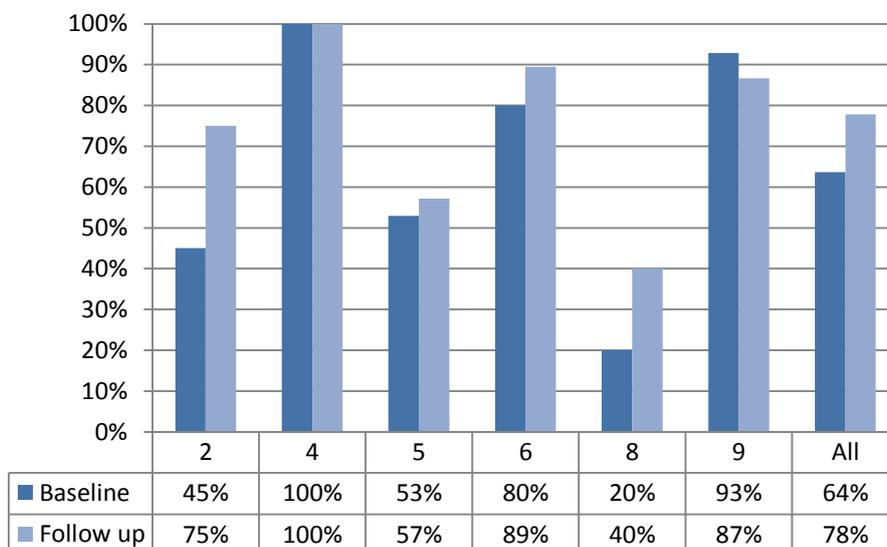
4.3.3   Recording of DNAR/NCR/AND was generally high, and increased at follow up

DNAR/NCR/AND was recorded more frequently for patients who died in hospital, than those who were discharged. Among those who died, nearly all patients had this recorded at both baseline and follow up. However, whilst Hospital 9 maintained its 100% record, and Hospital 2 increased to nearly 100% (from 84%), Hospitals 5, 6 and 8 showed a decline.

There was also substantial variation between hospitals for patients discharged. Prevalence of DNAR/NCR/AND ranged from 13%-80% at baseline and 14%-100% at follow up. The proportion of patients who had DNAR/NCR/AND recorded declined for Hospitals 5, 6 and 8 amongst both patients who died and those discharged, with the declines larger for those discharged.

Figure 4.8   Percentage of patients for whom DNAR/NCR/AND was recorded, by hospital (patients who died) *('yes' responses (other options NA, no, not recorded))*

|	2	4	5	6	8	9	All
Baseline	84%	87%	100%	100%	95%	100%	93%
Follow up	97%		80%	94%	94%	100%	94%
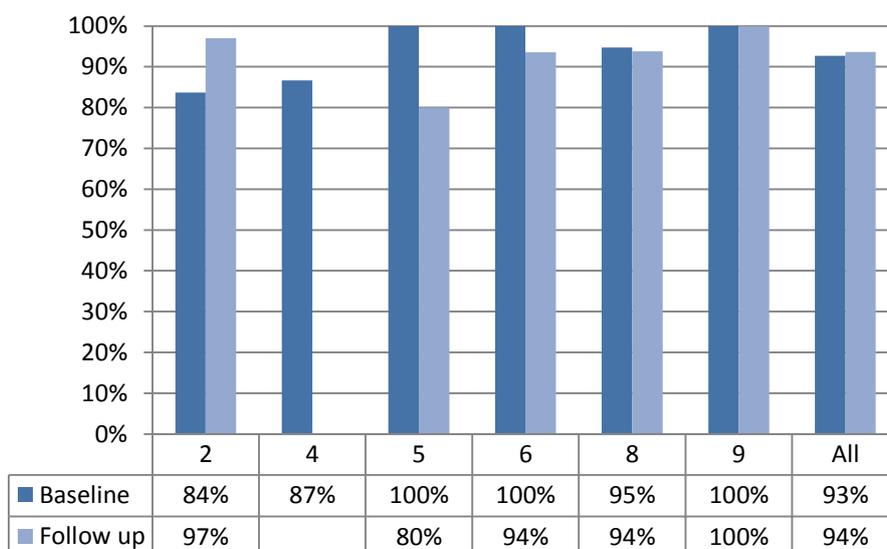
Figure 4.9   Percentage of patients for whom DNAR/NCR/AND was recorded, by hospital (patients who were discharged) ('yes' responses (other options NA, no, not recorded))

	2	4	5	6	8	9	All
Baseline	13%	87%	41%	80%	60%	43%	47%
Follow up	48%	100%	14%	70%	47%	73%	58%
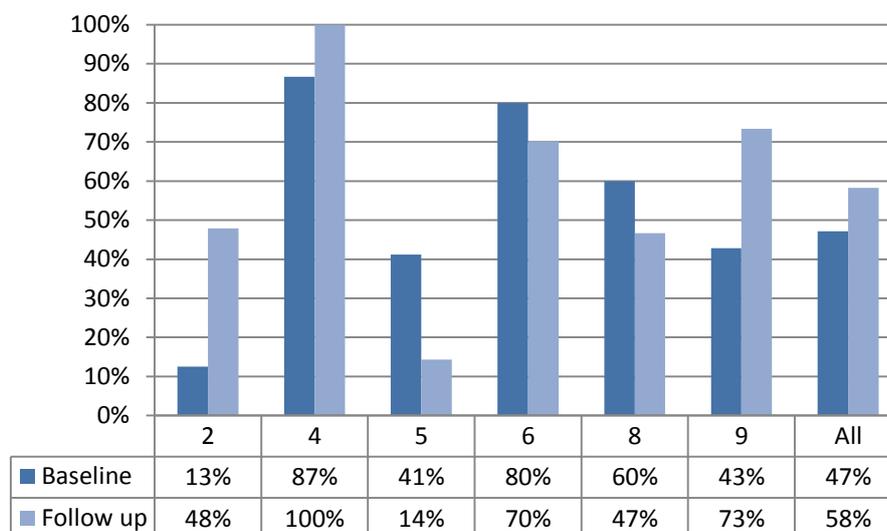
4.3.4   The use of Symptom Control Assessments increased substantially between baseline and follow up

The use of symptom control assessments (SCAs) increased significantly between baseline and follow up. At baseline, only two hospitals (8 and 9) reported any SCAs, and these were all for patients who died. At follow up all hospitals except Hospital 5 were conducting some SCAs, though the proportion ranged from 31% (Hospital 8) – 100% (Hospital 2) for patients who died, and 7% (Hospital 6) to 89% (Hospital 4) for patients discharged.

4.3.5   There was an improvement in the number of patients who died in hospital who had their preferred place of care recorded; though there was large variation between hospitals

All hospitals (except Hospital 5) showed large improvements in the recording of patients' preferred place of care, with the proportion for whom this was not recorded falling by between 29 and 40 percentage points. Hospital 5 did not record this for 93% of its patients, at both baseline and follow up.

Individual ward data shows that all wards in Hospital 2 saw improvements, and three of four wards in Hospital 6 and Hospital 8. Data are not analysed on the proportion of patients who did die in their preferred place of care, as this would only be recorded for those who died in hospital, and thus reflect only those patients who wished to die in hospital.

Figure 4.10 **Percentage of patients dying in hospital whose preferred place of care was not recorded, at baseline and follow up** *('not recorded' responses (other options NA, no, yes))*

	2	4	5	6	8	9	All
Baseline	84%	60%	93%	93%	74%	93%	84%
Follow up	55%		93%	61%	44%	53%	60%

Table 4.1 **Percentage of patients dying in hospital whose preferred place of care was not recorded, at baseline and follow up** *('not recorded' responses (other options NA, no, yes))*


	2a	2b	2c	6a	6b	6c	6d	8a	8b	8c	8d	All
		2			6				8			
Baseline	82%	92%	79%	100%	100%	80%	89%	75%	100%	100%	50%	84%
Follow up	57%	57%	50%	60%	69%	92%	33%	40%	60%	100%	20%	60%
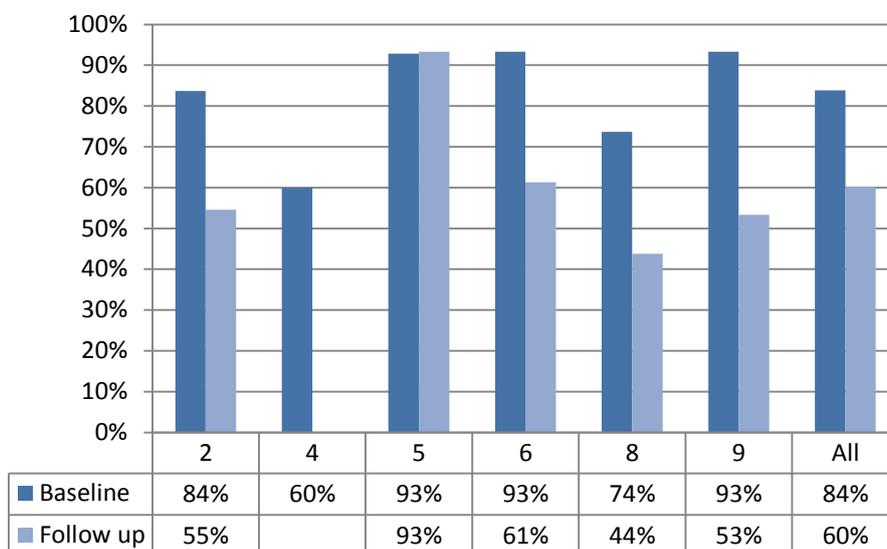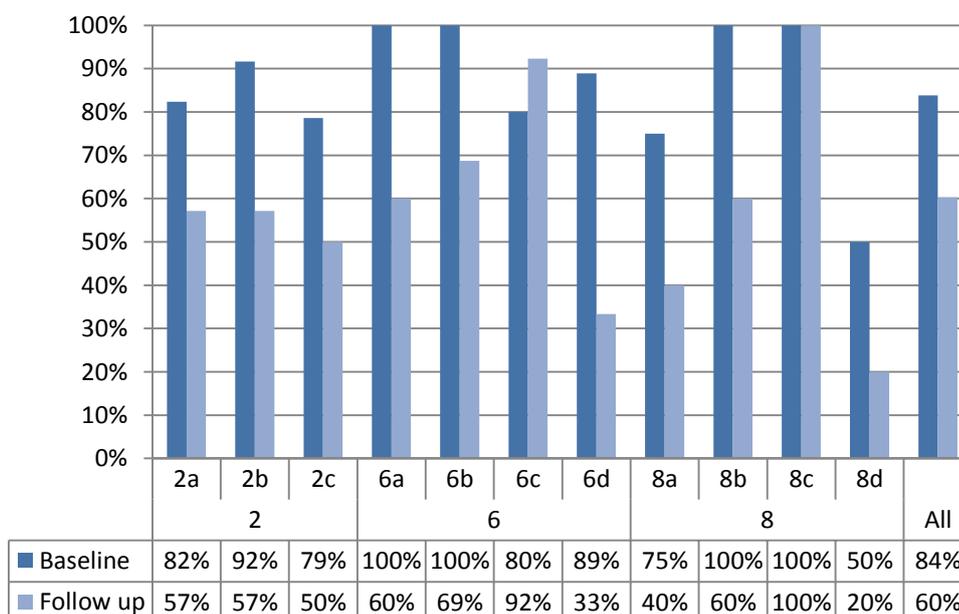
4.4 Care planning for patients nearing the end of life

Section summary

This was the highest scoring area of the foundation survey, with almost all hospitals (and wards within them) answering 'yes' to whether patients had access to the rapid discharge process and progressed to the LCP or other pathway during their final days. ADA findings were more mixed:

■ The proportion of patients with an ACP or PPC recorded improved, with larger improvements seen for Hospitals 6, 8 and 9. Patients who were discharged were more likely than those who died, to have this recorded;

■ The proportion of patients on the rapid discharge pathway improved from 5% to 22%, with each

> individual hospital also showing improvement.

4.4.1 According to the foundation survey, hospitals performed well at planning patients' end of life care

Hospitals were asked about their use of plans and systems in relation to:

- Communication with GP – discharge letters including ACP, follow up suggesting inclusion on GPs' palliative care/ GSF registers for regular discussion at GSF meeting and proactive care;
- Rapid discharge process for those who wish to go home[8];

Overall, this was a high scoring area. Almost all Hospitals (and wards within them) answered 'yes' to whether patients were offered the Rapid Discharge Process. Hospital 5, which only responded to the June questionnaire, was the only Hospital not answering 'yes'; they said they were working towards this. Across all hospitals, there was little change in the answers to these questions, with hospitals starting from a high baseline.

Hospitals performed less well on 'communication with GP', though there was improvement. In January, only Hospital 9, and one ward in Hospital 8 (8d) reported that they were doing this. By June, all of Hospital 8, 9, and half the wards in Hospital 6, were doing this. By November, all wards in Hospital 6 were communicating with GPs. Of the remaining hospitals, only Hospital 2 responded in November, and suggested that they were 'working towards' this aim.

4.4.2 The proportion of patients with an Advance Care Plan or Preferred Place of Care improved

All hospitals, except Hospital 5, showed improvement in the proportion of patients with an ACP or PPC, though the extent of this improvement varied. For patients who died, large improvements were seen for Hospitals 6, 8 and 9. For patients discharged, Hospitals 6, 8 and 9 still showed improvements, but Hospital 2 also improved from 15% to 31%, and Hospital 4 from 20% to 100% (again, the small follow up sample size here (n=9) means this finding should be treated with caution).

There was some variation within hospitals. In Hospitals 6 and 8 only two of the four wards reported patients having ACP/PCP at baseline. All of these reported patients with ACP/PPCs at follow up.

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[8] Staff were also asked about their use of LCPs, but these responses were excluded from the analysis, due to the change in guidance.

Figure 4.11   Percentage of patients with an ACP or PPC (patients who died in hospital) *('yes' responses (other options NA, no, not recorded))*


	2	4	5	6	8	9	All
Baseline	14%	7%	0%	7%	16%	7%	10%
Follow up	15%		0%	29%	38%	20%	23%
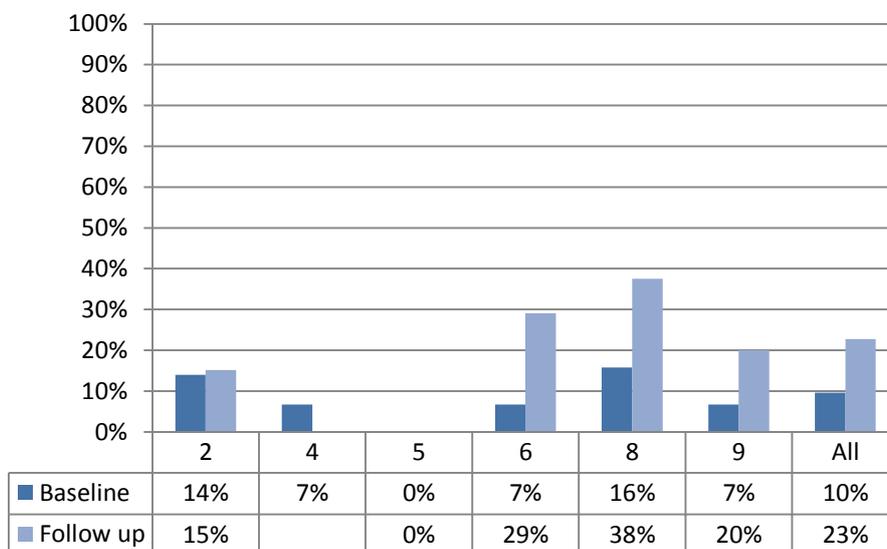
Figure 4.12   Percentage of patients with an ACP or PPC (patients who were discharged) *('yes' responses (other options NA, no, not recorded))*

	2	4	5	6	8	9	All
Baseline	15%	20%	6%	12%	0%	14%	12%
Follow up	31%	100%	0%	37%	13%	60%	35%
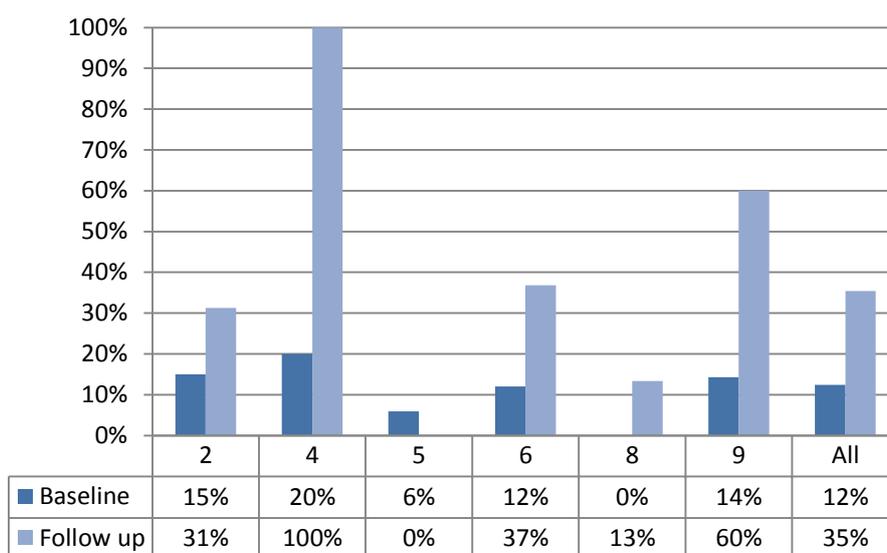
4.4.3   All hospitals except one saw an improvement in the proportion of discharged patients on the rapid discharge pathway (RDP)

The proportion of discharged patients on the RDP improved in all individual hospitals, except Hospital 5. The largest improvements were seen in Hospitals 6 (from 4% to 42%) and 8 (from 0% to 33%). Hospital 4, as well as having low proportions of patients on the RDP, and low improvement from baseline to follow up, also had a much higher proportion of 'no' responses than other hospitals (as compared to not recorded or not applicable). At follow up, patients were not on the RDP in 89% of cases (range 20-63% for other hospitals).

The breakdown by ward shows that all of Hospital 6's RDP patients came from one ward (6d) at baseline, but that at follow up all wards now had between 36%-47% patients on the pathway. At follow up in Hospital 8 all wards except 8b had patients on the pathway, and Hospital 2 only had patients on the pathway from 2c (and this was just 6%).

Figure 4.13 Percentage of patients on the rapid discharge pathway at baseline and follow up (patients discharged only) *('yes' responses (other options NA, no, not recorded))*

	2	4	5	6	8	9	All
■ Baseline	0%	13%	6%	4%	0%	14%	5%
■ Follow up	2%	11%	0%	42%	33%	20%	22%
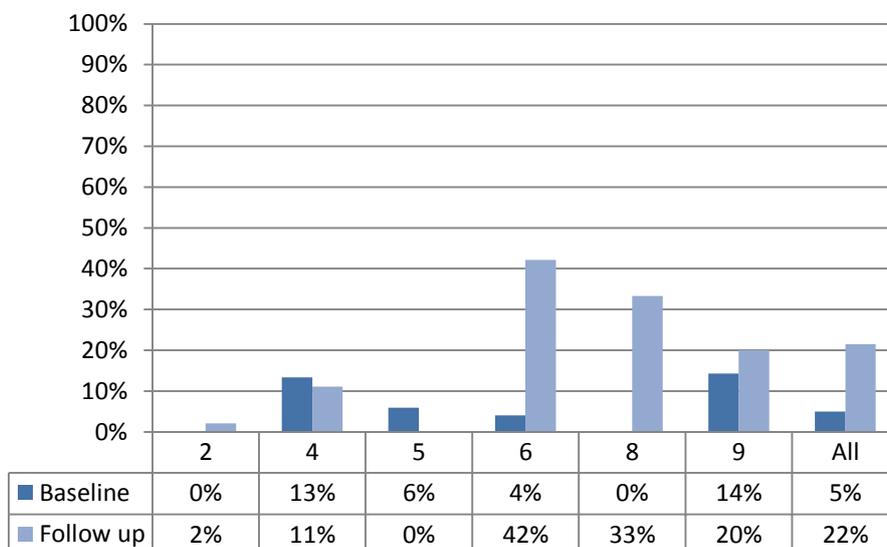
4.4.4 Staff comments related to high-quality discussions with patients

Staff were asked to note positive and negative aspects of patients' care. Responses to this question varied considerably by hospital – with some hospitals' staff much more likely to comment than others. For example, Hospitals 5 and 6 submitted positive comments for nearly 90% of their patients, Hospitals 2 and 4 for less than 10%. Due to this large variation, hospital-level analysis is not be undertaken; instead, key themes are picked out.

Positive comments at follow up overwhelmingly related to good, clear communications with family/friends/ the patient. This was often linked to clear recording of a patient and family's wishes, such as the recording of DNA CPR. Other areas of positive practice highlighted included:

- Clear, helpful communications between hospital staff and other relevant professionals involved in care. This included communications with primary and community-based care;
- Rapid discharge, and discharge to preferred place of care, generally leading to the patient achieving a peaceful death, with well controlled symptoms;

Some negative comments at follow up were also noted, these centred around the following themes:

- No, poor, or insensitive communications with the patient, or the patients family, often meaning that their wishes were not known (or met);
- Active treatment continued up to death, a lack of documentation around patient's wishes (e.g. DNA CPR, no ACP in place);
- Admission/discharge managed poorly, patient not treated in PPC, nursing home/hospice not well communicated with.

5   Findings from the staff interviews

GSF staff conducted five semi-structured interviews with members of staff from the acute hospitals, with notes from the interviews sent to ICF GHK for analysis. The interviews were conducted one year into the GSF programme, and qualitatively explored the impacts of the programme, the extent to which they had been embedded into routine practice, what challenges had occurred, and what future plans were.

Interviewees presented a mixed picture on the extent to which they were actively using GSF. Three indicated that they were now routinely using RAG coding, and discussing patients at relevant meetings. One suggested that they were now meeting their CQUIN target of 50% of GSF patients identified on their discharge summary. Discharge summaries were reported as an area that was particularly successfully implemented, with several interviewees reporting that these were improving communications between the wards and GPs, and between GPs and their patients.

However, most interviewees also noted some delays and problems with implementation. Issues included IT problems, and the engagement of consultants and nurses – particularly in finding the time to participate in training, and getting multiple stakeholders to agree.

A range of benefits were identified by sites. Several mentioned the attitudinal change it had caused in staff (both GPs and ward staff) – especially in getting them to plan ahead and think more individually about patients. One interviewee reported that a consultant had adopted the process in their out-patient clinic as well. Interviewees also noted some wider benefits to the programme, these included:

- Highlighting further areas of EoL training/educational need for staff, including around organ donation;
- One interviewee noted that the wards had seen fewer admissions from their regularly admitted patients, and no new admissions from GSF-identified patients;
- Improvements in bereavement care, including tailored care for children and those with learning disabilities.

The majority of interviewees mentioned interpersonal skills and leadership as key facilitators of success. In particular, having ward-based facilitators/champions helped increase ownership of the programme; a site which didn't have a designated facilitator highlighted this as something which would have improved their implementation. One interviewee also mentioned the benefit of monthly informal training sessions. Three interviewees mentioned that they had extended the programme to additional wards, with the remaining two indicating plans to do so. All also mentioned an interest in accreditation.

Interviewees were asked if they had any recommendations for further improvements. Recommendations were varied, and there was little commonality between interviewees. Points made included:

- The networking function was useful; however interviewees would value hearing from hospitals which had struggled with implementation, not just those that were successful;
- The amount of information provided by GSF was occasionally overwhelming, and they should consider having shorter power points;
- More locally-based (to the hospital) GSF training would be useful;
- The data collection was very time consuming, and had a large impact on the day-to-day running of the project.

6 Conclusions and considerations

This final section presents a set of concluding points. It also offers points for consideration, which relate largely to data collection. No specific recommendations are made for improvements to the programme, because the evidence base is too limited in this area.

The main concluding points are that:

- **Overall, implementation of the GSF has had an impact on patients, staff and organisational-level practice**. This progress is in line with the attainment of Foundation Level GSF AH. The programme expects that hospitals will now look to further embed this practice, and spread it to other wards in Stage 2, thus progressing to full accreditation. It is encouraging that all staff interviewed indicated that their hospitals were planning on moving towards accreditation;

- **There was an improvement in staff knowledge and confidence in most areas of end of life care**. However, there was some variation between hospitals. Hospitals 2 and 6 showed a decline in staff confidence in: having discussions with patients, relatives and carers; their routine discussion of patients nearing the end of life; and their transference of discharge information. This is a surprising finding, and would merit further investigation (see summary Table 6.2);

- **Most areas of end of life care practice have improved since implementing the GSF.** Notable areas of improvement include: the collection and transference of passport information upon admission and discharge; the use of DS1500s; the use of symptom control assessments; and the proportion of patients on rapid discharge pathways. These were also amongst the poorest performing areas at baseline, partly reflecting the scope for improvement. Other aspects of EoL care, including: the use of ACPs/PPCs; the recording of DNAR/NCR/AND; and discussions with patients and carers, improved slightly at follow up. Generally, these were already practiced quite widely, and there was less scope for improvement (see summary Table 6.1).

- **There was an improvement in the number of patients who died in hospital, who had their preferred place of death recorded;** it was not possible to ascertain whether this then resulted in an improvement in the proportion of patients who died in their preferred place of care.

- **Phase 3 of the GSF has led to a small, statistically non-significant decline in the length of hospital stay for those discharged**. This decline was seen in three hospitals (2, 4 and 6), and was statistically significant for Hospital 4. The overall decline seen in Phase 3 was slightly smaller than that seen for the Phase 2 projects (3.8 days compared to 6).

- **Current interpretations of the data require some caution; data collection should be improved**. There are a number of important limitations with the data, which mean confidence in conclusions, particularly changes between baseline and follow up, should be interpreted with care. Key issues include the drop-off in responses between baseline and follow up, and the over-representation of some hospitals. Accepting the pressures and trade-offs inherent in any service improvement programme (time spent measuring is time not spent doing), high-quality evaluation data is important in making the case for a programme to hospitals and commissioners; this is an area for future focus.

- **Explanatory evidence would improve GSF's evaluation**. The nature of the evidence base presented here is very largely quantitative. In the main, it shows whether and by how much things have changed. This is important and useful; it also prompts evaluative questions as to *why* the results are as they are. Evidence explaining why changes are / are not achieved would greatly improve the evaluation presented here. More qualitative evidence would also help to understand some of the negative findings – particularly given that they run contrary to some of the more anecdotal evidence. In addition, there would be particular merit in explaining positive deviance: factors underpinning cases where significant and positive changes have resulted.

Table 6.1   Summary results of ADA by hospital

		Hospital 2	Hospital 4	Hospital 5	Hospital 6	Hospital 8	Hospital 9	All
Length of stay		green	green	red	green	red	red	green
Passport info - admission		grey	green	red	green	grey	green	green
Passport info – discharge		grey	green	red	green	grey	green	green
Use of DS1500		green	red	light grey	green	green	green	green
Discussion with carers	Died	green	white	red	green	green	red	green
	Discharge	green	light grey	green	green	green	red	green
Recording of DNAR/NCR/ AND	Died	green	white	red	red	red	grey	green
	Discharge	green	white	red	red	red	green	green
Use of SCAs	Died	green	white	grey	green	green	green	green
	Discharge	green	green	grey	green	grey	green	green
Patients dying in PPC		green	white	grey	green	red	green	green
Patients with ACP or PPC	Died	green	white	grey	green	green	green	green
	Discharge	green	green	red	green	green	green	green
Patients on RDP		green	red	grey	green	green	green	green
Patients on LCP/ other ICP		grey	white	red	green	red	red	red

Table 6.2   Summary of results of the staff survey, by hospital

Staff…	Hospital 2	Hospital 6	Hospital 8	Hospital 9	All
Use tools to identify patients at EoL	green	green	green	green	green
Confidence in caring for people at EoL	red	green	green	green	green
Develop a future care plan	red	red	green	green	green
Routinely discuss patients near EoL	red	red	green	green	green
Routinely send out info to GPs	red	red	green	green	red
Routinely send out info to district nurses	red	red	green	green	red
Routinely send out info to 'other' organisations	red	red	red	red	red

Table 6.3   Key to Table 6.1 and Table 6.2

Improvement	
Worsening	
No change	
No data	

Annex 1 Responses to the foundation survey

Table A1.1 Identification of patients

Hospital		1	2			4	5	6				8				9
Question	Time		A	B	C			A	B	C	D	A	B	C	D	
Every patient nearing the end of life (final months, weeks, days) is identified	Jan.	Red	Amber	Grey	Grey	Amber	Grey	Green	Grey	Grey	Grey	Amber	Amber	Amber	Amber	Green
	Jun.	Amber	Amber	Amber	Amber	Amber	Red	Amber	Amber	Green	Green	Green	Green	Green	Green	Green
	Nov.	Grey	Amber	Amber	Amber	Grey	Grey	Green	Green	Green	Green	Amber	Amber	Amber	Green	Green
They are included on the appropriate hospital register/tagged	Jan.	Red	Amber	Grey	Grey	Red	Grey	Amber	Grey	Grey	Grey	Red	Red	Red	Red	Red
	Jun.	Amber	Amber	Amber	Amber	Amber	Red	Amber	Amber	Amber	Green	Red	Red	Red	Red	Amber
	Nov.	Grey	Amber	Amber	Amber	Grey	Grey	Amber	Amber	Amber	Amber	Red	Amber	Amber	Amber	Amber
A plan of care is discussed at ward round/MDT meeting	Jan.	Red	Red	Grey	Grey	Amber	Grey	Green	Grey	Grey	Grey	Amber	Amber	Amber	Amber	Green
	Jun.	Amber	Amber	Amber	Amber	Green	Amber	Amber	Green	Green	Green	Green	Green	Green	Green	Amber
	Nov.	Grey	Green	Green	Green	Grey	Grey	Green	Green	Green	Green	Amber	Green	Amber	Green	Amber

Table A1.2   Assessment of patients

Hospital		1	2				4	5	6				8				9
Question	Time		A	B	C				A	B	C	D	A	B	C	D	
Clinical needs assessed using appropriate clinical assessment tool/measures	Jan.	red	red	grey	grey	orange	grey	orange	grey	grey	grey	orange	orange	red	orange	orange
	Jun.	orange	orange	orange	orange	green	orange	green	green	green	green	green	green	green	green	orange
	Nov.	grey	orange	orange	grey	grey	grey	green	green	green	green	green	green	green	green	orange
There is an initial discussion with the patient and carers and information given e.g. GSF card/leaflet	Jan.	red	red	grey	grey	red	grey	red	grey	grey	grey	red	red	red	orange	red
	Jun.	orange	orange	orange	orange	red	red	orange	orange	orange	green	orange	orange	orange	orange	orange
	Nov.	grey	red	red	red	grey	grey	green	green	green	green	orange	orange	orange	green	orange
a) This includes beginning an advance care planning discussion, proxy nominated person noted (or LPoA) b) DNACPR status c) preferred place of care and information leaflet given	Jan.	red	red	grey	grey	orange	grey	green	grey	grey	grey	orange	orange	orange	orange	green
	Jun.	orange	orange	orange	orange	orange	red	orange	orange	orange	green	orange	orange	orange	orange	orange
	Nov.	grey	orange	grey	grey	orange	grey	orange	grey	grey	grey	orange	orange	orange	orange	orange

Table A1.3   Planning for patients

Question	Time	1	2 A	2 B	2 C	4	5	6 A	6 B	6 C	6 D	8 A	8 B	8 C	8 D	9
Communication with GP - discharge letters including ACP, follow up suggesting inclusion on GP's Palliative Care/GSF registers for regular discussion at GSF meeting and proactive care	Jan.	Red	Red	Grey	Grey	Red	Grey	Orange	Grey	Grey	Grey	Orange	Orange	Orange	Green	Green
	Jun.	Orange	Orange	Orange	Orange	Red	Red	Orange	Orange	Green	Green	Green	Green	Green	Green	Green
	Nov.	Grey	Orange	Orange	Orange	Grey	Grey	Green	Green	Green	Green	Green	Green	Green	Green	Green
Rapid discharge process for those who wish to go home	Jan.	Green	Green	Grey	Grey	Green	Grey	Green	Grey	Grey	Grey	Green	Green	Green	Green	Green
	Jun.	Green	Green	Green	Green	Green	Orange	Green	Green	Green	Green	Green	Green	Green	Green	Green
	Nov.	Grey	Green	Green	Green	Grey	Grey	Green	Green	Green	Green	Green	Green	Green	Green	Green
Progress to LCP/other pathway or tool for final days	Jan.	Green	Green	Grey	Grey	Green	Grey	Green	Grey	Grey	Grey	Green	Green	Green	Green	Green
	Jun.	Green	Green	Green	Green	Green	Orange	Green	Green	Green	Green	Green	Green	Green	Green	Green
	Nov.	Grey	Green	Green	Green	Grey	Grey	Green	Green	Green	Green	Green	Green	Green	Green	Green

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Annex 2   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	☐ 5. Frailty/co-morbidity
☐ 2. Heart failure	☐ 6. Stroke
☐ 3. Chronic obstructive pulmonary disease / Respiratory	☐ 7. Dementia
	☐ 8. Other egg Neurological disorders
☐ 4. Renal failure	

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

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Annex 3   Staff Survey

Hospital:	
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 4   Structured Questionnaire

The aim of the questionnaire is to explore more qualitative feedback and develop a thematic review of other benefits, drawbacks, unintended consequences and factors related to implementing the programme. We seek to ask each of the sites some time following the planned training programme whether GSFAH had been sustained on the ward and to be updated with any developments or service improvements directly related to the GSFAH programme

1. To what extent are you actively using GSF on your allocated ward / hospital? (more open)	
2. What benefits have you found?	
3. What difficulties have you encountered?	
4. What further developments or improvements have you made?	
5. How successful has implementation been? Have you made specific developments, progress or improved cross boundary care with GPs and others?	
6. What have been the key facilitators to this development/ progress? E.g.have you had any changes of personnel, structure, etc? Please give details	
7. Do you have senior Board/Executive level support or endorsement for further spread or use of GSF AH programme? If so, has this extended to any other areas/wards? Is this part of your CQUIN? How has this helped implementation?	
8. What are your future plans? Do you want to proceed to GSFAH accreditation?	
9. Any recommendations or suggestions for further improvements	
10. Any other comments?	

Annex 5   List of Acronyms

ADA – After Death/Discharge Analysis

ACP – Advance Care Plan

COPD – Chronic Obstructive Pulmonary Disease

CQUIN – Commissioning for quality and innovation

DNAR/NCR/AND – Do not attempt resuscitation/ not for cardio-resusciation/ allow natural death

DNA CPR – Do not attempt cardio-pulmonary resuscitation

DS1500 – Form issued if a patient is suffering from a potentially terminal illness, used by the DWP to determine potential benefits (inlcuidng Disability Living Alowance and Incapacity Benefit)

EoL – End of Life

GSF – Gold Standards Framework

GSF AH – Gold Standards Framework Acute Hospitals

ICP – Integrated Care Pathway

LCP – Liverpool Care Pathway

MDT – multi-disciplinary team

PPC – Preferred Place of Care

PPFC – Preferred priorities for care

SCAs – Symptom Control Assessment(s)

RAG – red, amber, green coding

RDP – Rapid Discharge Pathway