GSF Phase 4 ADA

FINAL report

23 June 2015

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A report submitted by ICF Consulting Services

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Contents

Executive summary

The aim of the Gold Standards Framework (GSF) is to improve quality in end of life (EoL) care by formalising best practice using a systematic, patient-centred approach. More specifically, 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 4 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.

GSF commissioned ICF to undertake an evaluation of the programme. ICF 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).

Hospitals (and wards within them) taking part in the programme have been anonymised. The type of data available varied between hospitals. Seven hospitals, Hospitals 1, 2, 4, 5, 6, 8 and 9 implemented the GSF in more than one ward. For the staff survey, Hospitals 1 and 5 only provided baseline data and Hospitals 2 and 4 only provided baseline and follow up data for some of their wards.

For the ADA audit, only three hospitals, Hospitals 1, 2 and 4 provided baseline and follow up data. Hospital 1 also provided a breakdown by ward, while Hospital 5 provided baseline and follow up data for one ward but not for the hospital as a whole. Five hospitals responded to the Foundation survey (Hospitals 1, 2, 4, 6 and 7). Analysis is only undertaken where baseline and follow up data is available.

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, across all areas of EoL care. Hospital 2 staff reported increases in their confidence in recognising and caring for people nearing the end of life and Hospital 4 staff also reported increases in their confidence in recognising patients but reported a small decrease in their confidence caring for patients nearing the end of life.

On questions related to staff confidence in having open communication and discussions with patients and relatives, Hospital 2 staff showed improved confidence across all questions, while Hospital 4 staff showed more mixed results. Both Hospitals 2 and 4 saw an increase in the proportion of staff having routine discussions of patients nearing the end of life and both hospitals also saw increases in the proportion of discharge information sent out to GPs and District Nurses, although the proportion sent out to 'other' decreased for both hospitals.

The programme had a positive impact on the assessment of patients nearing the end of life, and a mixed impact on identification of patients and care planning

The ADA and the foundation survey showed mixed results regarding EoL practice at both the patient, and ward/ hospital level. However, improvements in care were seen in the following areas:

- The percentage of patients whose passport information was recorded on admission.
- The percentage of patients for whom DNAR/NCR/AND was recorded.
- The percentage of patients dying in hospital who had their preferred place of care recorded.
- The percentage of patients with an ACP or PPC

There was also a small decline in the mean length of hospital stay for all hospitals (Hospitals 1, 2, 4 and 5a), although none of the declines were significant. Greater impact on length of stay may be observed in the future as hospitals continue to embed changed practice.

Evidence suggests several areas for additional focus

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

- **The variation in the number of baseline and follow up responses received.** This was a problem for the ADA returns, Staff Survey returns and Foundation Questionnaire returns and should be kept in mind for future phases:
  - Hospitals 1 and 5 did not provide any follow up data for the Staff Survey. Hospitals which did provide follow up data, provided far fewer responses than at baseline and often only for some wards, making comparisons difficult and unreliable.
  - Only three hospitals submitted ADA baseline and follow up data, and for one hospital, follow up data was only provided for one ward.
  - There was a large drop in the number of hospitals responding to the Foundation Survey between the January and November follow ups which greatly affected the ability to compare results across time.
- **Difficulty interpreting the raw data submitted in the Staff Survey.** This was a particular problem for Hospital 5 which submitted data for around 30 wards across three separate sites. Wards were poorly labelled and only provided baseline data, making them impossible to analyse.
- **Changes to the foundation survey questions.** The questions in the Foundation questionnaire changed in both June and November making it very difficult to display the results and compare across time. This should be considered in future, and ideally changes to the questionnaire should only be made at the end of a Phase, rather than mid-way through.

1 Introduction

As a result of demographic changes and medical advances, the UK has an ageing population, with increasing numbers of people living with long-term conditions, often with multiple co-morbidities. Consequently, 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.

There are a number of challenges currently facing provision of end of life (EoL) care. Hospital admissions are common in the last year of life (78% of people will be admitted at least once), and after admission, a significant proportion of people go on to die in hospital, despite this often being against their wishes. The use of tools, such as Advance Care Planning (ACP) can significantly improve the chances of patients dying in their preferred place[1].

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 4 of this programme, with Phases 1, 2 and 3 now completed (reports available on request).

During Phase 4, training and support has been provided to nine hospitals[2], 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 4

GSF commissioned ICF to analyse evaluation data for Phase 4 of the programme in acute Hospitals (following previous analysis of Phases 1, 2 and 3). Nine hospitals participated in Phase 4, though one hospital (Hospital 3) and one ward (1c) dropped out part way through so have been excluded from this analysis (Table 1.1). Hospitals 6, 8 and 9 also dropped out of the analysis part way through but Hospital 6 did still submit some Foundation Survey returns, which have been analysed in the report.

This report draws on five sources of information[3]:

- 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 2014). 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;
- Semi-structured interviews with three hospitals. These covered implementation, including barriers and facilitators to implementation, and future plans.

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

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

[3] All tools are reproduced in the annexes

Table 1.1 Summary of the data reported by hospitals

		Hosp. 1	Hosp. 2	Hosp. 3[4]	Hosp. 4	Hosp. 5	Hosp. 6	Hosp. 7	Hosp. 8	Hosp. 9
Staff Survey	Baseline	🟩	🟩	▨	🟩	🟩	▨	▨	▨	▨
	Follow up	▨	🟩 Some wards	▨	🟩 Some wards	▨	▨	▨	▨	▨
ADA data	Baseline	🟩	🟩	▨	🟩	🟩 Some wards[5]	▨	▨	▨	▨
	Follow up	🟩	🟩	▨	🟩	🟩 Some wards[6]	▨	▨	▨	▨
Foundation survey	Jan.	🟩	🟩	▨	🟩	▨	🟩	🟩	▨	🟩
	June	🟩	🟩	▨	🟩 Some wards	▨	▨	🟩	▨	▨
	Nov.	🟩	🟩 Some wards	▨	▨	▨	▨	🟩	▨	▨

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; and
- Section 5: Findings from the qualitative research
- Section 6: Conclusions and recommendations.

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[4] Their staff survey data was disregarded because they are no longer submitting ADA etc. as part of phase 4.

[5] Only one ward provided baseline and follow up data so all other wards have been excluded from the analysis.

[6] Only one ward provided baseline and follow up data so all other wards have been excluded from the analysis.

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

Summary

Staff from five hospitals submitted survey returns at baseline. Data from Hospital 3 was excluded as they have withdrawn from the evaluation. Only two hospitals (Hospitals 2 and 4) submitted follow-up data, although they did not provide it for all their wards. Analysis of improvements between baseline and follow up is therefore only undertaken for these two Hospitals. There was significant drop-off in returns between baseline and follow up, limiting the comparability of responses. The survey was completed by a different sample of staff at baseline and follow up. Overall:

- Both hospitals (Hospitals 2 and 4) providing follow up data showed large improvements in staff knowledge and use of EoL tools;
- Staff confidence in recognising patients increased in Hospitals 2 and 4, but staff confidence in caring for patients nearing EoL decreased slightly in Hospital 4.

On questions related to staff confidence in having open communication with patients and relatives; discussions with patients about their personal wishes; and discussions with relatives or carers about their concerns, Hospital 2 staff showed improved confidence across all three, while Hospital 4 staff only showed increased confidence about the first question. 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).

Both Hospitals 2 and 4 saw an increase in the proportion of staff having routine discussion of patients nearing the end of life and both hospitals also saw increases in the proportion of discharge information sent out to GPs and District Nurses, although the proportion sent out to 'other' decreased for both hospitals.

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

394 responses to the staff survey were used in the analysis: 348 at baseline, and 46 at follow up.

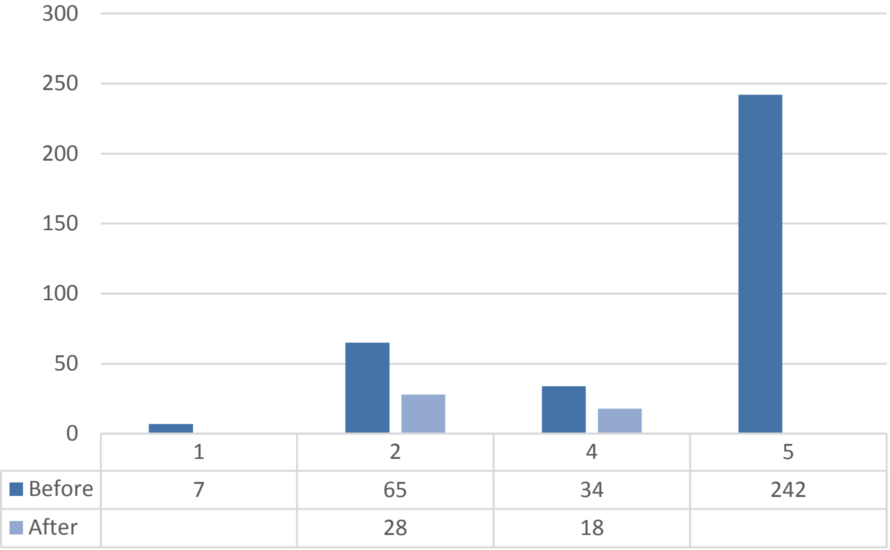
- Hospital 3 was excluded from the analysis because they dropped out of Phase 4 part way through;
- Hospital 1 originally submitted data for four wards but later clarified that only data for two wards should have been submitted so the additional two wards were removed from the analysis.

In some of the analyses, hospitals have been further broken down into wards. However, while ward-level data was provided for Hospital 5, it was very unclear so in the ward-level analyses, Hospital 5 has been broken down by hospital site instead of ward (sites a, b and c) to make the best use of the data available (Figure 2.2).

Hospital 5 submitted over twice as many baseline responses than any other hospital. Only two hospitals - Hospitals 2 and 4 - responded at baseline and follow up. Both of these hospitals had significant drop out, submitting half or fewer than half the number of responses at follow up, compared to baseline. This limits the comparability of results and 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, although all staff attended the same training.

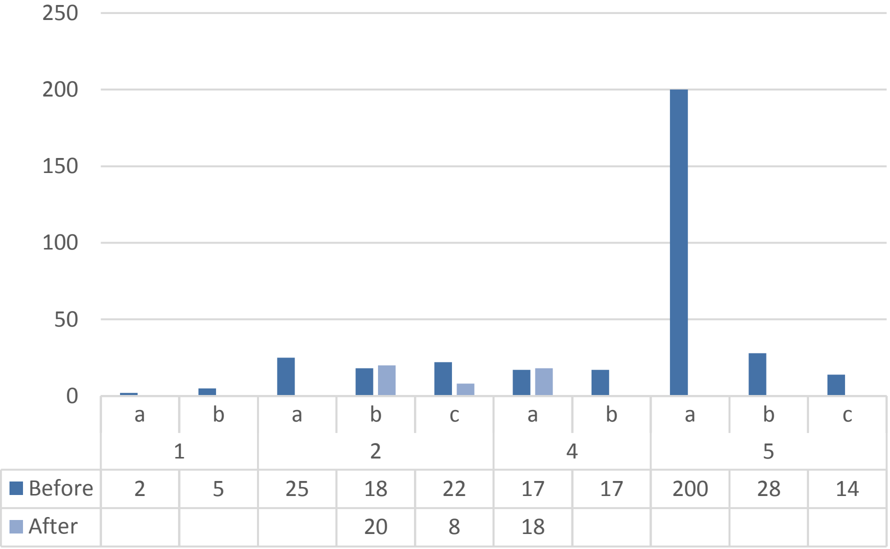
When means are quoted throughout this section, they refer to all four hospitals at baseline, and two hospitals at follow up. Again, this means that the comparability of figures is limited – the impact in the hospitals not reporting is unknown.

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



	1	2	4	5
■ Before	7	65	34	242
■ After		28	18	

Figure 2.2 **Number of responses at baseline and follow up, by hospital ward/Hospital 5 site**



	1		2			4		5		
	a	b	a	b	c	a	b	a	b	c
■ Before	2	5	25	18	22	17	17	200	28	14
■ After				20	8	18				

2.2 There was an improvement in staff knowledge of EoL tools in the two hospitals providing baseline and follow up data

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:

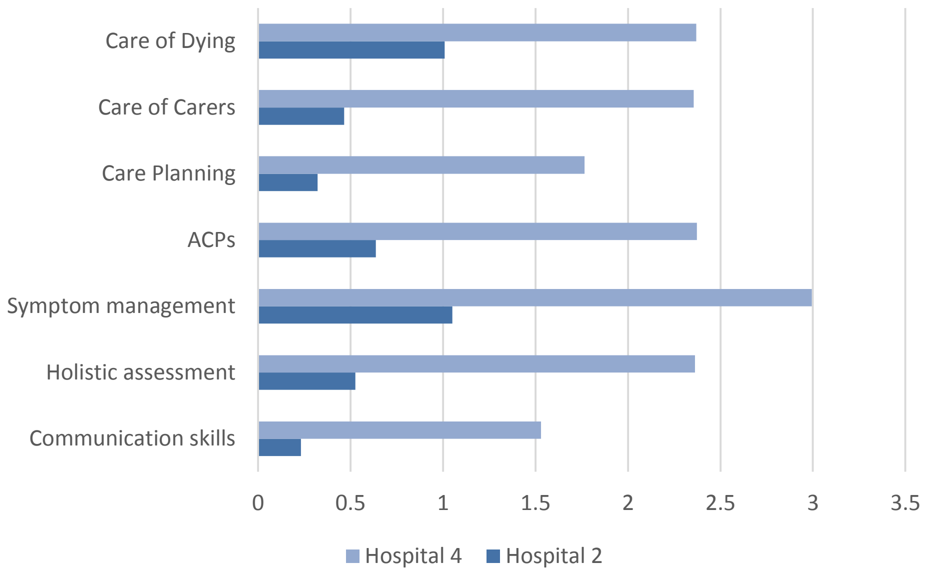
- Communication skills;
- Holistic assessment;
- Symptom management;
- Advance care planning;
- Care planning;
- Care of carers;
- Care of the dying.

Both hospitals showed improvements in all categories. Hospital 4 showed the greatest improvements, with mean improvements scores ranging from 1.5 (on communication skills) to 3.0 (on symptom management), while Hospital 2 showed improvements ranging from 0.25 (on communication skills) and 1.1 (on symptom management) (Figure 2.3, Figure 2.4, Figure 2.5). However, at ward level (Figure 2.6), there was slightly more variation in results with staff at ward 2b highlighting that more knowledge was required around holistic assessment, and at ward 2c, more knowledge was required on care planning and communication skills.

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;
- 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 2.3 Summary of change in mean score by hospital - responses to 'I feel I need to know more about the following areas of EoL care'[7]



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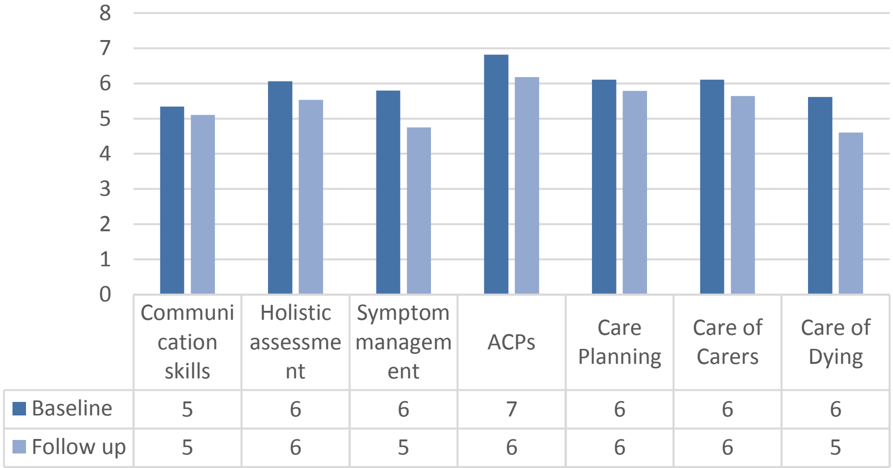
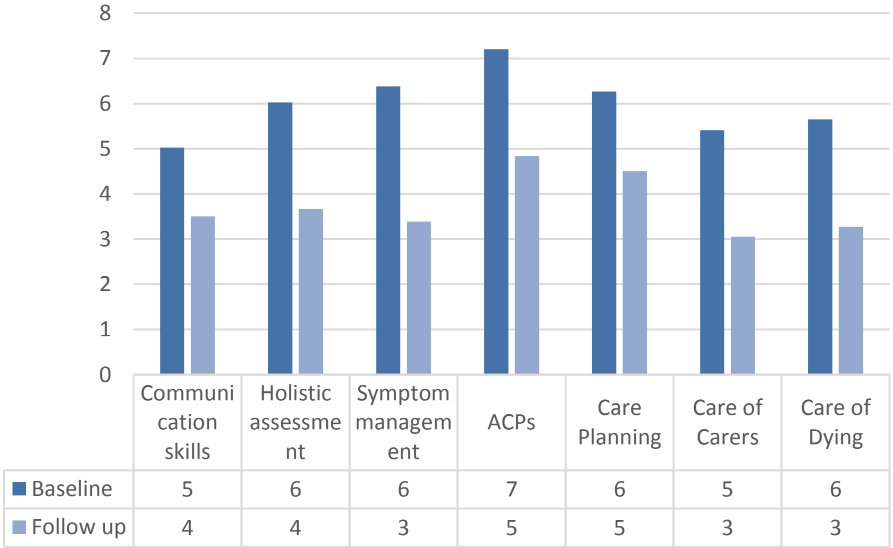
[7] Mean change in score is baseline – follow up; negative scores therefore indicate a need for more knowledge, positive scores an improvement (less need for knowledge)

Figure 2.4 **Mean responses to ‘I feel I need to know more about the following areas in EoL care’ (Hospital 2)** ***(staff rated scores rated on a scale of 1-10)***



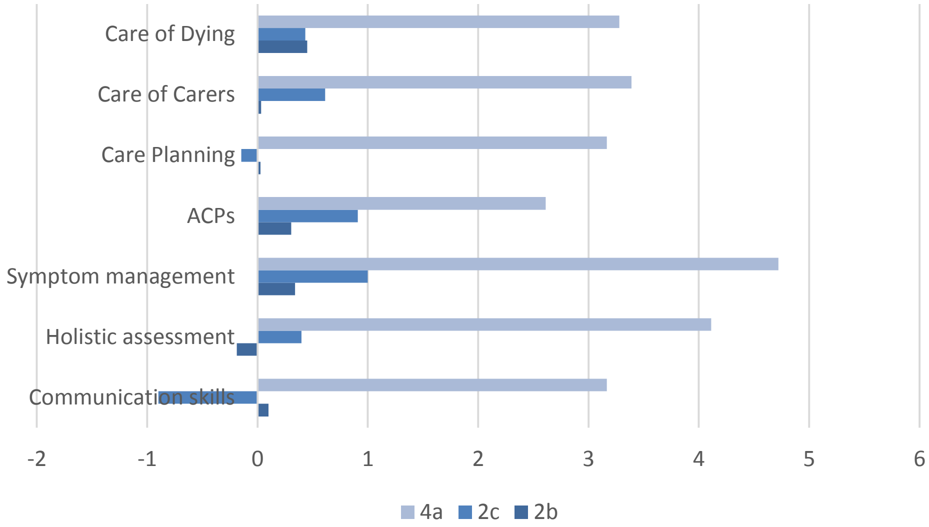
	Communication skills	Holistic assessment	Symptom management	ACPs	Care Planning	Care of Carers	Care of Dying
■ Baseline	5	6	6	7	6	6	6
■ Follow up	5	6	5	6	6	6	5

Figure 2.5 **Mean responses to ‘I feel I need to know more about the following areas in EoL care’ (Hospital 4)** ***(staff rated scores rated on a scale of 1-10)***



	Communication skills	Holistic assessment	Symptom management	ACPs	Care Planning	Care of Carers	Care of Dying
■ Baseline	5	6	6	7	6	5	6
■ Follow up	4	4	3	5	5	3	3

Figure 2.6 **Summary of change in mean score by ward - responses to 'I feel I need to know more about the following areas of EoL care'[8]**



2.3 Staff experience and use of EoL tools improved

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 24% overall; with awareness also showing large improvements (from 48% to 67%). Hospital 4 saw a decline in awareness from 68% to 56%, however, this is because more people from this category moved to responding with "yes, have used" at follow up, rather than reflecting an increase in the number of "no" responses) (Figure 2.7). Ward level results (Figure 2.8) show a similar trend with improvements in use and awareness for both wards at Hospital 2 and improvements in use at ward 4a (again awareness appears to have dropped but this is due to an increase in the number of "yes have used" responses).
- The *use* of both PPFC and ACPs remained low, increasing only very slightly between baseline and follow up (from 11% to 13% for PPFC and from 7% to 13% for ACP) (Figure 2.9 and Figure 2.11). Hospital 2 showed a small decrease in PPFC use from 3% at baseline to 0% at follow up (at ward level, this corresponds to a decrease from 6% to 0% in ward 2b and 5% to 0% at 2c). Hospital 4 showed a large increase from 3% to 33%. For ACP use, Hospital 2 showed a small overall increase from 11% to 14% (ward 2b showed a 1 percentage point decrease while 2c increased (Figure 2.12)) while Hospital 4 saw a slightly larger increase from 0% to 11%.
- All hospitals and hospital wards had large increases in *awareness* of both PPFC and ACP. The largest increase was seen in PPFC awareness at Hospital 2, where awareness quadrupled between baseline and follow up (Figure 2.9), with ward 2c showing a follow up percentage 5 times greater than the baseline figure of 9% (Figure 2.10).

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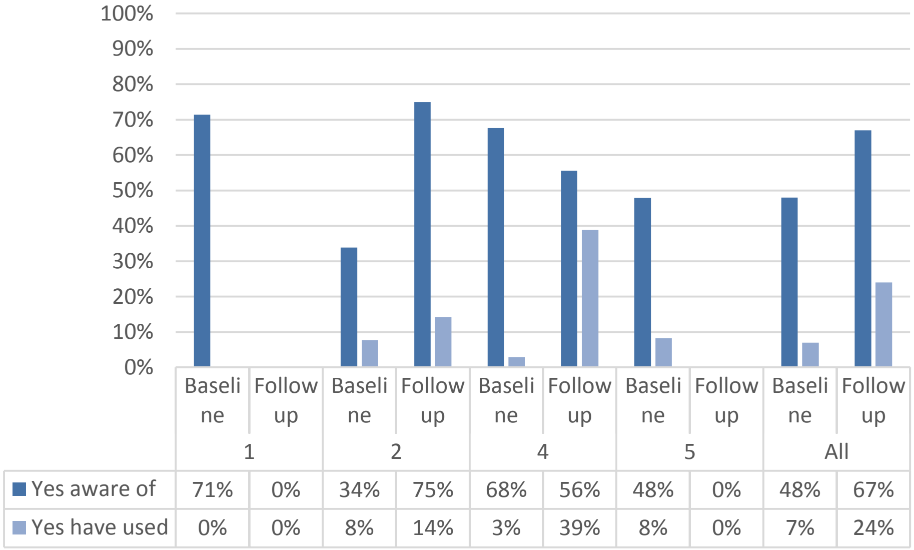
[8] Mean change in score is baseline – follow up; negative scores therefore indicate a need for more knowledge, positive scores an improvement (less need for knowledge)

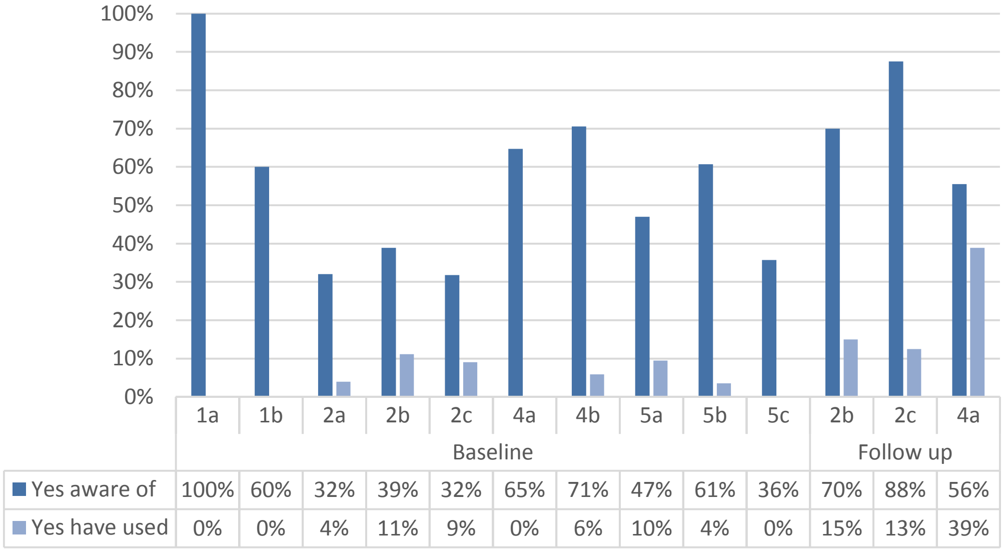
Staff were also asked whether they used any specific tools as a trigger to identify patients in the last year of life. The proportion using tools increased from 10% at baseline to 39% at follow up, with all individual hospitals improving. Hospital 4 showed the largest improvement, with almost ten times as many staff reporting using EoL tools at follow up compared to baseline (Figure 2.13).

Figure 2.7 Staff experience of GSF[9] *(staff could respond 'yes have used', 'yes aware', or 'no')*



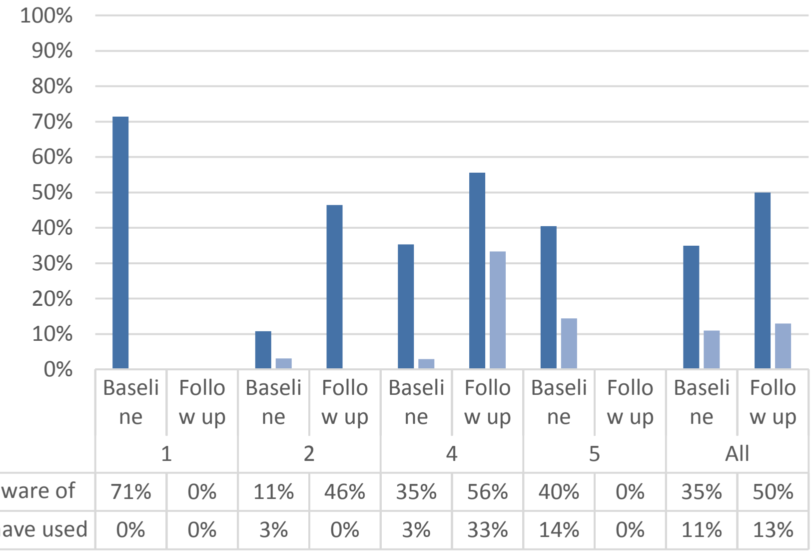
	1		2		4		5		All	
	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up
■ Yes aware of	71%	0%	34%	75%	68%	56%	48%	0%	48%	67%
■ Yes have used	0%	0%	8%	14%	3%	39%	8%	0%	7%	24%

Figure 2.8 Staff experience of GSF[10] (staff could respond 'yes have used', 'yes aware', or 'no'), by ward (or site for Hospital 5)



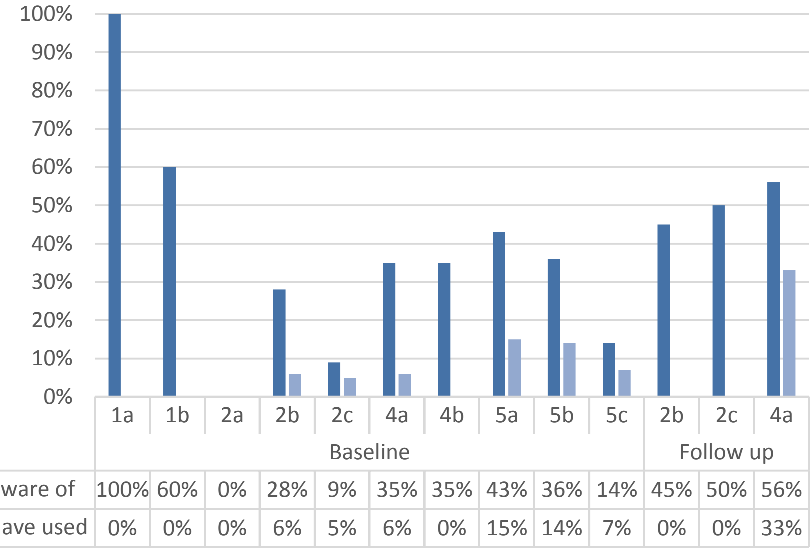
	Baseline										Follow up		
	1a	1b	2a	2b	2c	4a	4b	5a	5b	5c	2b	2c	4a
■ Yes aware of	100%	60%	32%	39%	32%	65%	71%	47%	61%	36%	70%	88%	56%
■ Yes have used	0%	0%	4%	11%	9%	0%	6%	10%	4%	0%	15%	13%	39%

Figure 2.9 **Staff experience of PPFC *(staff could respond 'yes have used', 'yes aware', or 'no')***



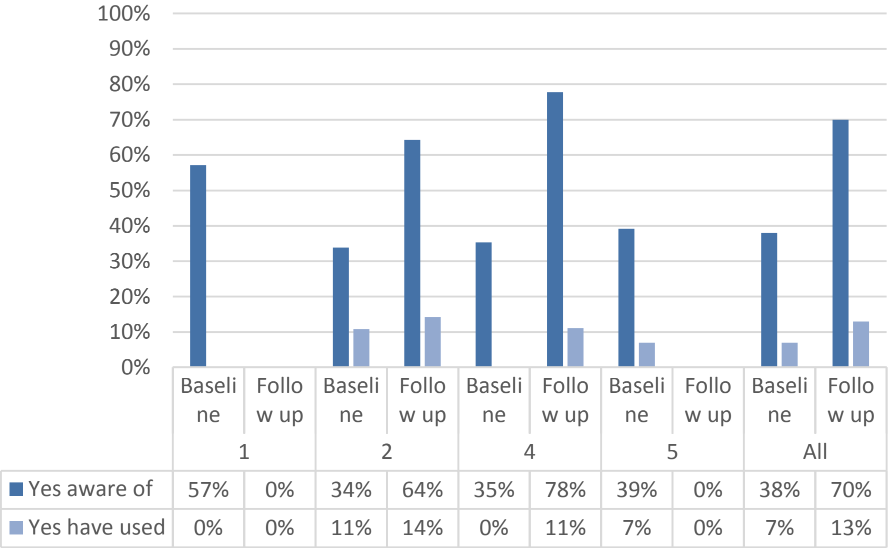
	1		2		4		5		All	
	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up
■ Yes aware of	71%	0%	11%	46%	35%	56%	40%	0%	35%	50%
■ Yes have used	0%	0%	3%	0%	3%	33%	14%	0%	11%	13%

Figure 2.10 **Staff experience of PPFC (staff could respond 'yes have used', 'yes aware', or 'no'), by ward (or site for Hospital 5)**



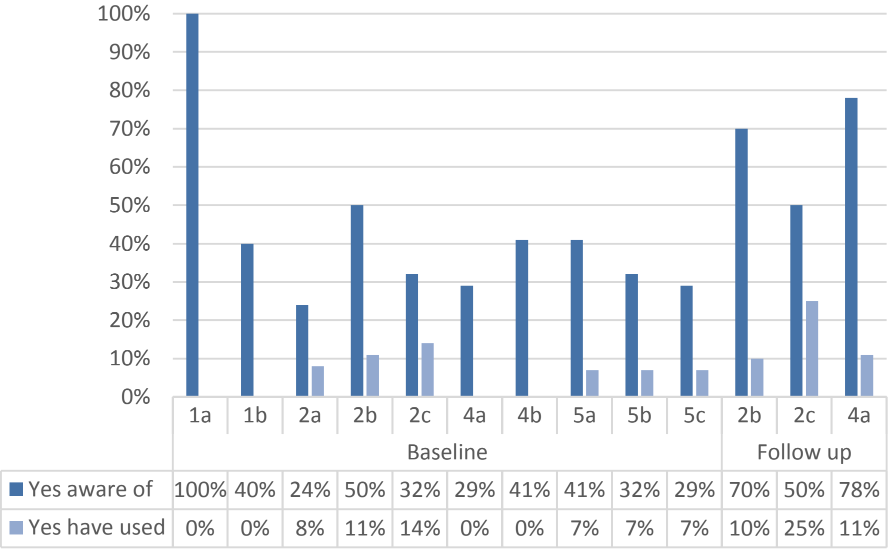
	Baseline										Follow up		
	1a	1b	2a	2b	2c	4a	4b	5a	5b	5c	2b	2c	4a
■ Yes aware of	100%	60%	0%	28%	9%	35%	35%	43%	36%	14%	45%	50%	56%
■ Yes have used	0%	0%	0%	6%	5%	6%	0%	15%	14%	7%	0%	0%	33%

Figure 2.11 **Staff experience of ACP *(staff could respond ‘yes have used’, ‘yes aware’, or ‘no’)***



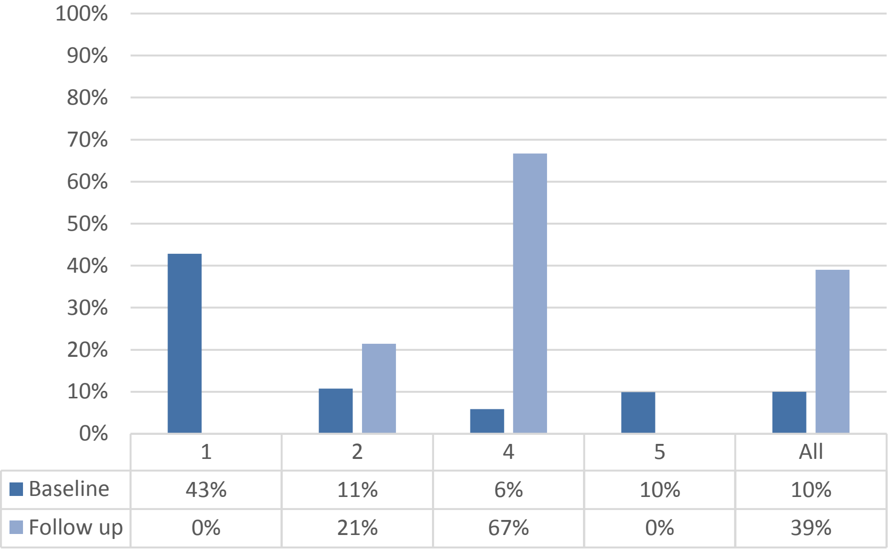
	1		2		4		5		All	
	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up	Baseline	Follow up
■ Yes aware of	57%	0%	34%	64%	35%	78%	39%	0%	38%	70%
■ Yes have used	0%	0%	11%	14%	0%	11%	7%	0%	7%	13%

Figure 2.12 Staff experience of ACP (staff could respond ‘yes have used’, ‘yes aware’, or ‘no’), by ward (or site for Hospital 5)



	Baseline										Follow up		
	1a	1b	2a	2b	2c	4a	4b	5a	5b	5c	2b	2c	4a
■ Yes aware of	100%	40%	24%	50%	32%	29%	41%	41%	32%	29%	70%	50%	78%
■ Yes have used	0%	0%	8%	11%	14%	0%	0%	7%	7%	7%	10%	25%	11%

Figure 2.13 **Proportion of staff reporting using specific tools as a trigger to identify patients in the last year of life *(staff could respond ‘yes’ or ‘no’)***



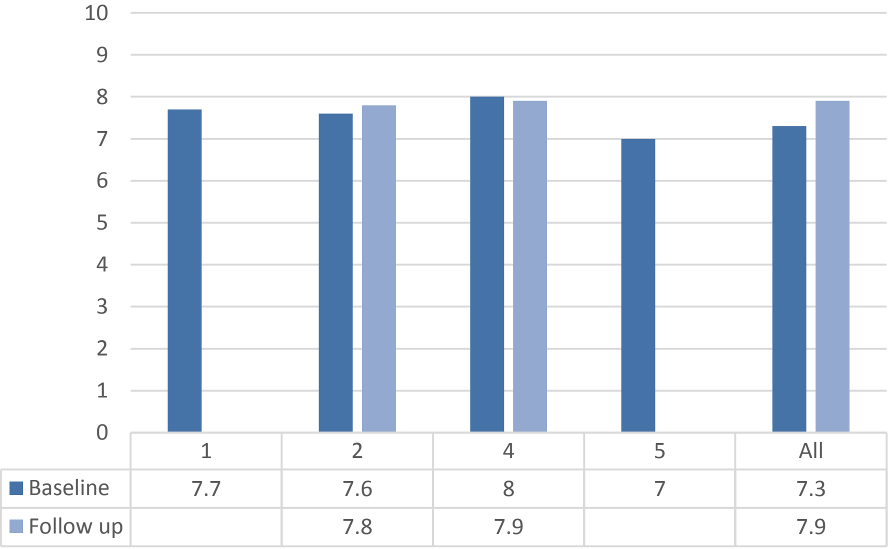
	1	2	4	5	All
■ Baseline	43%	11%	6%	10%	10%
■ Follow up	0%	21%	67%	0%	39%

2.4 Staff confidence in recognising patients nearing the end of life improved slightly; there was a mixed picture for staff confidence in caring for patients

Staff confidence in recognising patients who were nearing the end of life improved slightly for both Hospital 2 and Hospital 4 (the mean score increased by 0.6 and 0.4 respectively) (Figure 2.15).

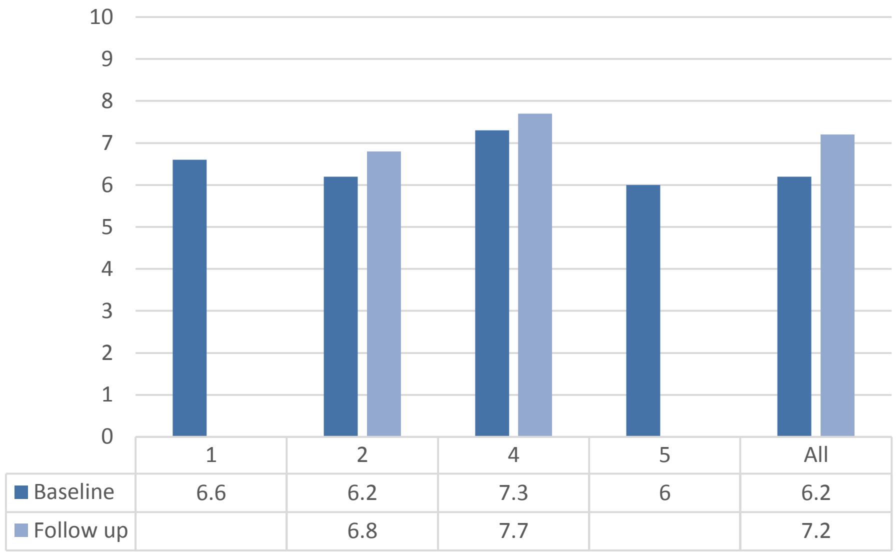
Hospital 2 showed an improvement in staff confidence in caring for patients nearing the end of life (of 0.2), however Hospital 4 showed a very slight decline (of 0.1) between baseline and follow up (Figure 2.14).

Figure 2.14 **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	5	All
■ Baseline	7.7	7.6	8	7	7.3
■ Follow up		7.8	7.9		7.9

Figure 2.15 **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)***



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:

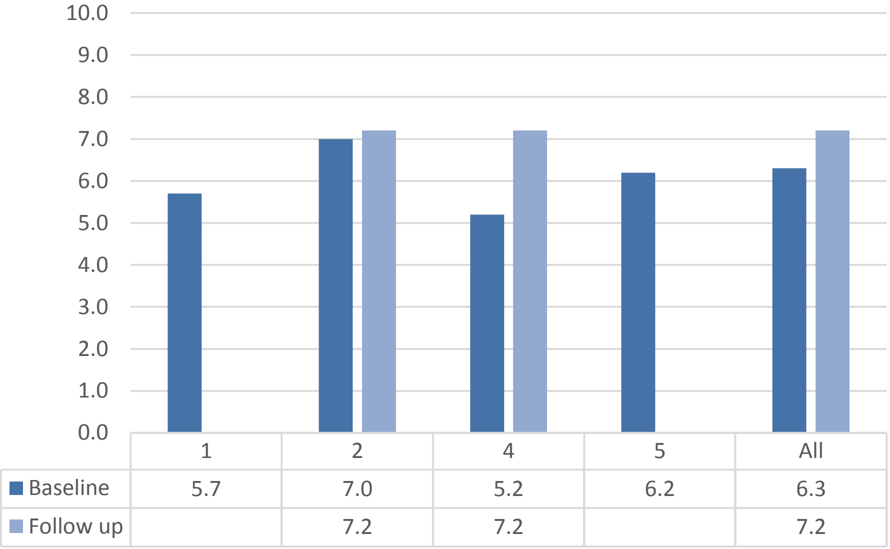
- *I feel confident in having open communication with patients and relatives about a patient’s deteriorating condition;*
- *I feel confident in having discussions with patients about their personal wishes, preferences and concerns (ACPs); and,*
- *I feel confident in having discussions with relatives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

Overall, improvements were seen in all three questions, although results varied by hospital. 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 2 showed a small improvement in all three questions (Figure 2.16, Figure 2.17, Figure 2.18) while Hospital 4 showed a large improvement of 2.0 in question one but a small decline in questions two and three.

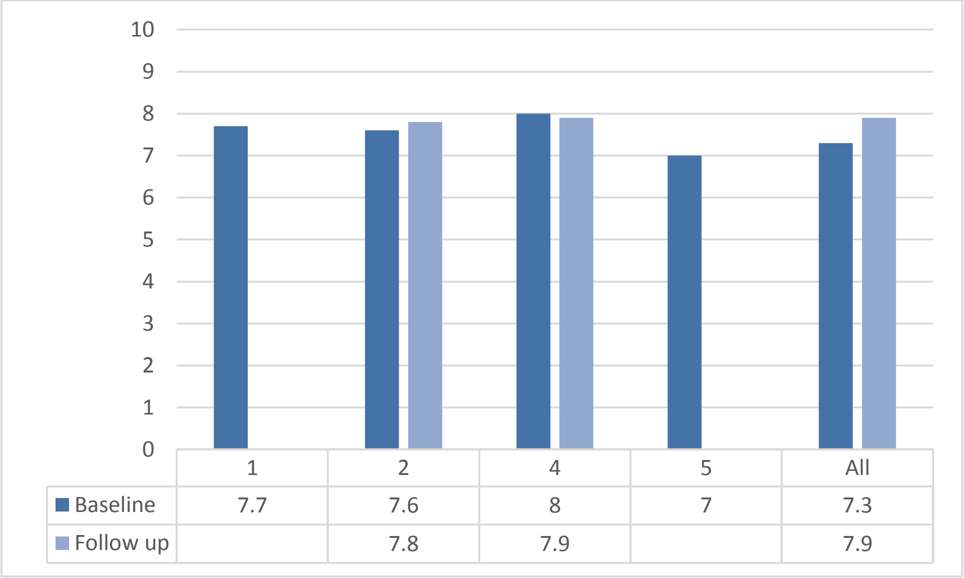
Staff were also asked whether, following such discussions, they developed a plan for future care. Both hospitals showed an increase, with Hospital 4 showing the largest increase (from 26% to 78%) (Figure 2.19).

Figure 2.16 Mean of 'I feel confident in having open communication with patients and relatives about a patient's deteriorating condition' (staff rated scores on a scale of 1-10)



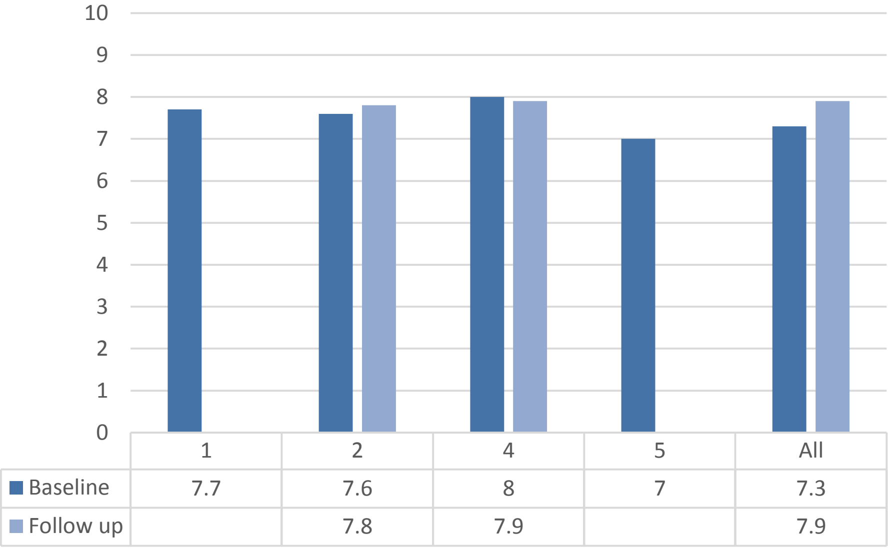
	1	2	4	5	All
■ Baseline	5.7	7.0	5.2	6.2	6.3
■ Follow up		7.2	7.2		7.2

Figure 2.17 **Mean of '*I feel confident in having discussions with patients about their personal wishes, preferences and concerns (ACPs)' (staff rated scores on a scale of 1-10)***



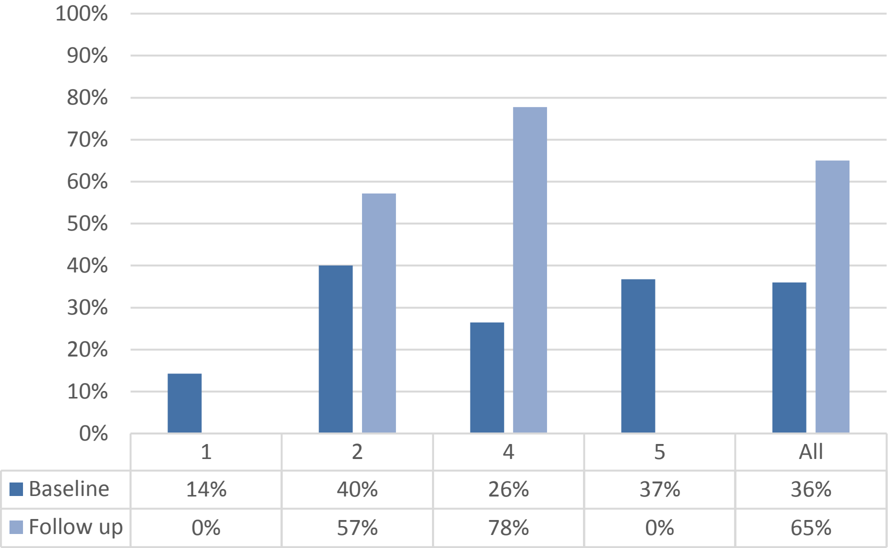
	1	2	4	5	All
■ Baseline	7.7	7.6	8	7	7.3
■ Follow up		7.8	7.9		7.9

Figure 2.18 Mean of 'I feel confident in having discussions with relatives or carers of patients about their concerns, needs and preferences (ACPs)' (staff rated scores on a scale of 1-10)



	1	2	4	5	All
■ Baseline	7.7	7.6	8	7	7.3
■ Follow up		7.8	7.9		7.9

Figure 2.19 **Following discussions with patients and carers, was a plan for future care developed? *(staff could answer 'yes' or 'no')***



	1	2	4	5	All
■ Baseline	14%	40%	26%	37%	36%
■ Follow up	0%	57%	78%	0%	65%

2.6 Both hospitals saw routine discussion of EoL care increase between baseline and follow up

Staff were asked how routinely they discussed patients nearing the end of life at multi-disciplinary team (MDT) meetings. Both Hospitals 2 and 4 showed an increase in the proportion of staff reporting they routinely discuss patients nearing EoL, with Hospital 4 showing the largest increase, from 47% to 72% (Figure 2.20). Hospital 5 had the lowest proportion of staff reporting routine discussions, with only 15% at baseline (compared to 47% at baseline for Hospital 4).

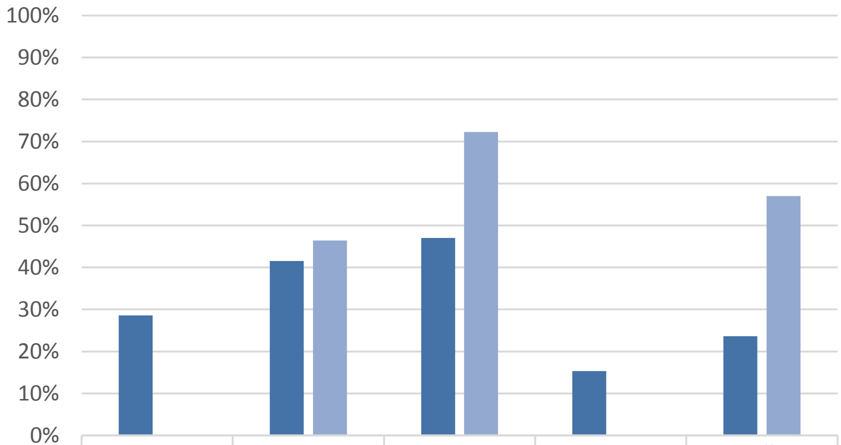
Staff were also asked whether they routinely transferred discharge information regarding EoL care and patient's wishes, and who to. There was diversity between hospitals. For information sent to GPs, Hospital 2 showed a small improvement while Hospital 4 showed a large one (from 38% to 78%) (Figure 2.21). For information sent to district nurses, again Hospital 2 showed a small increase while Hospital 4 showed a large one (from 35% to 78%)

(Figure 2.22). For both questions, Hospital 5 showed the lowest proportion of staff at baseline.

Hospitals 2 and 4 both showed a decline in the percentage of staff reporting information discharged to ‘other’ (Figure 2.23Figure 2.23). Similarly to the other responses on the Staff Survey, Hospital 2 showed a small decrease while Hospital 4 showed a large one (from 24% to 0%). Hospital 1 did not send out any discharge information to ‘other’ individuals/organisations at baseline. Overall, the proportion of staff sending out discharge information to ‘other’ was much lower than the proportions who sent information to GPs or District nurses. ‘Other’ individuals/organisations that were sent discharge information included:

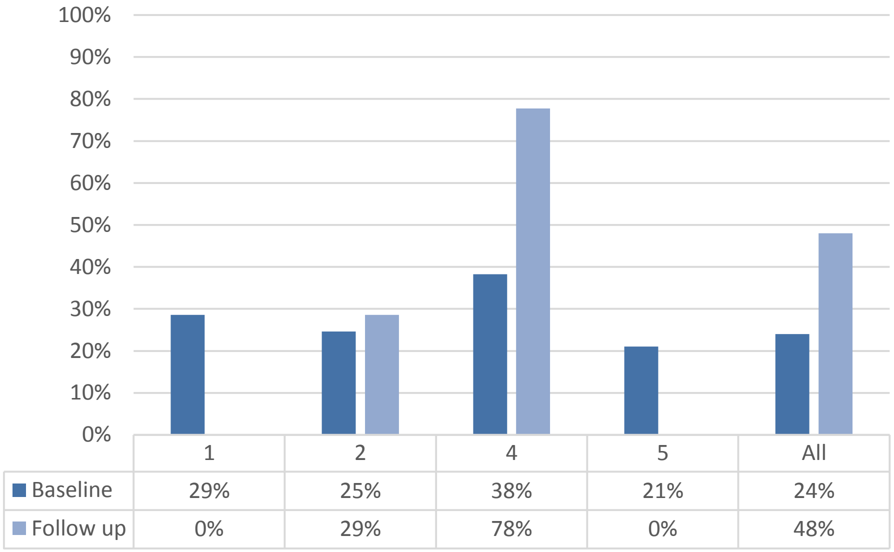
- Palliative care teams/Hospices/Chaplains
- Dieticians
- Occupational Therapists.
- Social workers
- Residential/nursing homes
- Carers or families
- Integrated Discharge Advice Teams
- Macmillan Nurses
- GSF
- Fast-track support agencies

Figure 2.20 **Proportion of staff reporting that they routinely discuss patients nearing the end of life *(Staff could answer ‘yes’ or ‘no’)***



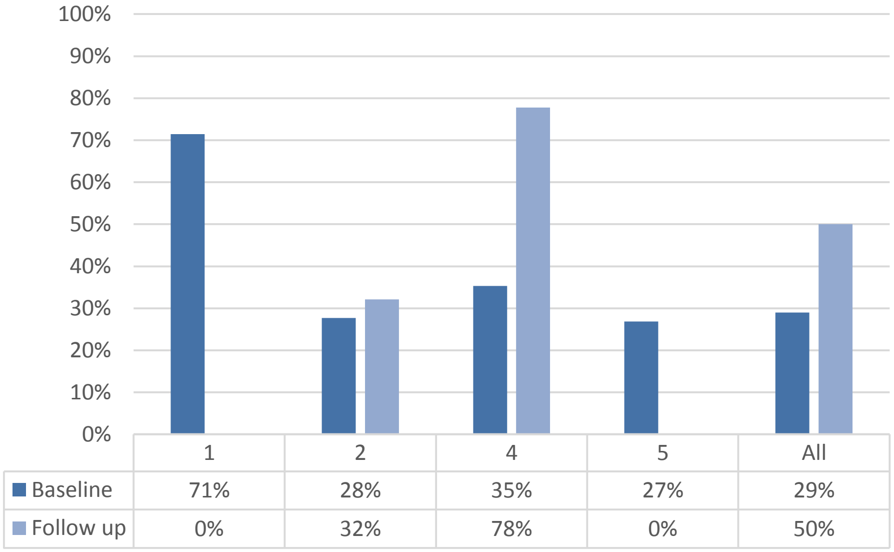
	1	2	4	5	All
■ Baseline	29%	42%	47%	15%	24%
■ Follow up	0%	46%	72%	0%	57%

Figure 2.21 **Proportion of staff who routinely send out discharge information to GPs** ***(Staff could answer 'yes' or 'no')***



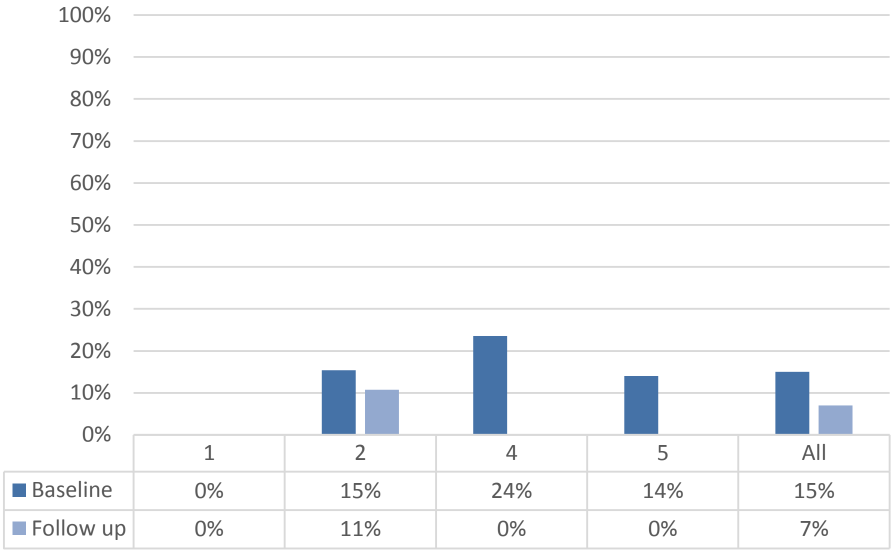
	1	2	4	5	All
■ Baseline	29%	25%	38%	21%	24%
■ Follow up	0%	29%	78%	0%	48%

Figure 2.22 **Proportion of staff who routinely send out discharge information to district nurses** ***(Staff could answer 'yes' or 'no')***



	1	2	4	5	All
■ Baseline	71%	28%	35%	27%	29%
■ Follow up	0%	32%	78%	0%	50%

Figure 2.23 Proportion of staff who routinely send out discharge information to ‘other’ individuals/organisations *(Staff could answer ‘yes’ or ‘no’)*



	1	2	4	5	All
■ Baseline	0%	15%	24%	14%	15%
■ Follow up	0%	11%	0%	0%	7%

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 4 hospitals);
- The foundation questionnaire in January, June and November 2013 (ward-level answers from 5 hospitals);

ADA data:

- In total, data were collected on 451 patients: 208 at baseline and 243 at follow up.
- Baseline and follow up data have broadly similar characteristics, although primary diagnoses and causes of death varied slightly between 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 were slightly more follow up responses than baseline which makes baseline and follow up less comparable
  - Hospital ward 5a provided a lot more follow up responses than baseline meaning Hospital ward 5a is likely to be over-represented in follow up data but under-represented in baseline. The opposite is true for Hospital 4 which provided less follow up responses than baseline
  - There was an overall decline in length of hospital stay between baseline and follow up, though this was not statistically significant.

Foundation questionnaire data:

- Five hospitals (1, 2, 4, 6 and 7) or ten wards (1a, 1b, 2a, 2b, 2c, 4a, 4b, 6a, 6b,and 7) responded to the questionnaire in January; four hospitals (1, 2, 4 and 7) or 7 wards (1a, 1b, 2a, 2b, 2c, 4a, and 7) responded in June and three in November (1, 2 and 7) or 5 wards (1a, 1b, 2b, 2c and 7).

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 'all patients' (green), 'no patients' (red), or 'some patients' (amber). Questions were asked at three time points: January (6 months after the programme start), June, and November 2014. However, the questions on the questionnaire were changed in June and again in November. While effort has been made to compare results as far as possible, this is a key problem and has limited the analysis.

Five hospitals (1, 2, 4, 6 and 7), and a total of 10 wards (1a, 1b, 2a, 2b, 2c, 4a, 4b, 6a, 6b, and 7) responded to the Foundation Questionnaire in January. However, four hospitals (1, 2, 4 and 7) or 7 wards (1a, 1b, 2a, 2b, 2c, 4a, and 7) responded in June and only three in November (1, 2 and 7) or 5 wards (1a, 1b, 2b, 2c and 7).

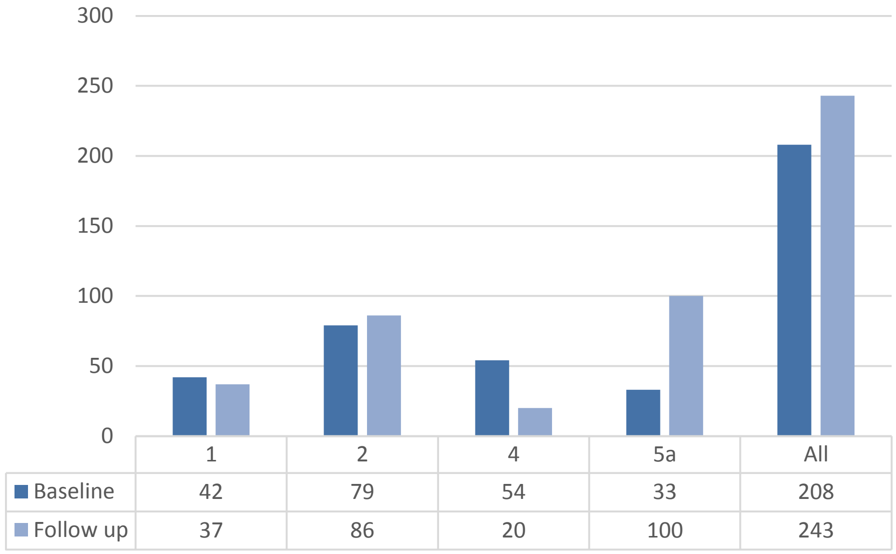
Hospitals 6 and 7 did not submit any ADA data or Staff Survey findings so comparisons are not possible. Similarly, while Hospital 5 provided both ADA data and Staff Survey data, they did not provide any Foundation questionnaire data.

3.2 Three hospitals submitted ADA baseline and follow up data

Three hospitals provided baseline and follow up data. One (Hospital 5) only provided baseline and follow up data for one ward so had been included in the analysis but labelled as 5a, to reflect the fact that data is not representative of the hospital as a whole. One hospital (Hospital three) did not provide any data.

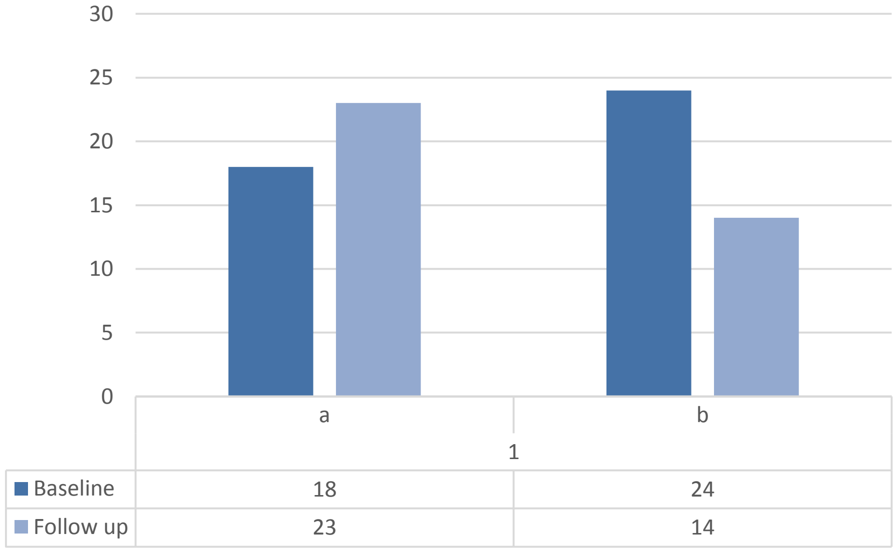
Hospital ward 5a accounts for 41% of follow up responses (100) responses (Hospital 2 accounts for 35% (86 responses); Hospital 1 accounts for 15%; and Hospital 4 accounts for 8% (Figure 3.1). However, despite providing the largest number of follow up responses, Hospital ward 5a provided the lowest number of baseline responses, at only 33 (16%). This means that follow up findings are likely to over-represent Hospital ward 5a while baseline findings will under-represent it. The opposite is likely to be true for Hospital 4, which provided much fewer follow up responses than baseline. Hospitals 1 and 2 both provided similar numbers of baseline and follow up responses. Hospital 1 also submitted data from more than one ward so for this hospital, the analysis has also been carried out at ward level (Figure 3.2).

Figure 3.1 Number of responses at baseline and follow up, by hospital



	1	2	4	5a	All
■ Baseline	42	79	54	33	208
■ Follow up	37	86	20	100	243

Figure 3.2 Number of responses at baseline and follow up, by hospital ward (Hospital 1)



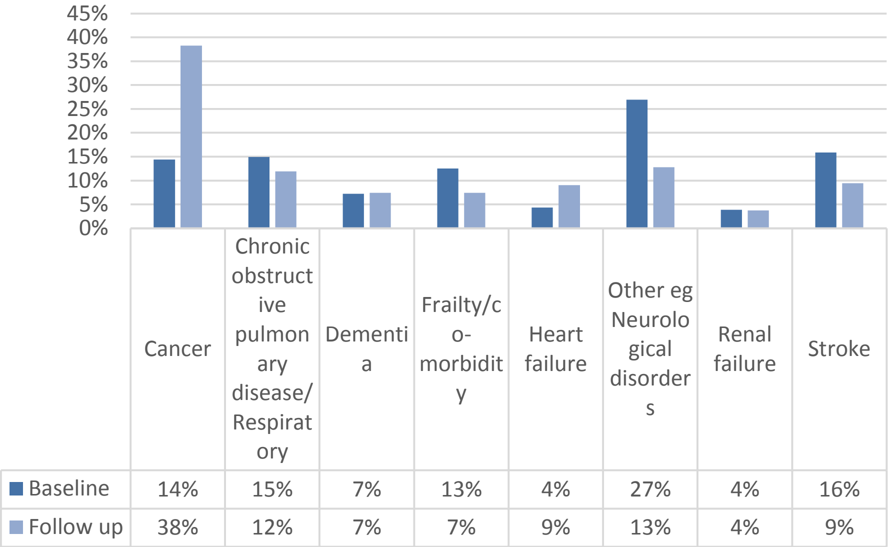
	a	b
■ Baseline	18	24
■ Follow up	23	14

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.

3.2.2 Primary diagnoses and causes of death differed slightly between baseline and follow up

‘Other’ diseases were the most common primary diagnosis at baseline (Figure 3.3). However, excluding ‘other’, stroke was the most common primary diagnosis (16%), followed by COPD/respiratory (15%). At follow up, cancer was by far the most common diagnosis (38%), followed by ‘other’ (13%) and COPD/respiratory (12%). Cancer moved from being the fourth most common primary diagnosis at baseline to the first at follow up, and Stroke moved from being the first primary diagnosis (after ‘other’) to the joint fourth primary diagnosis at follow up.

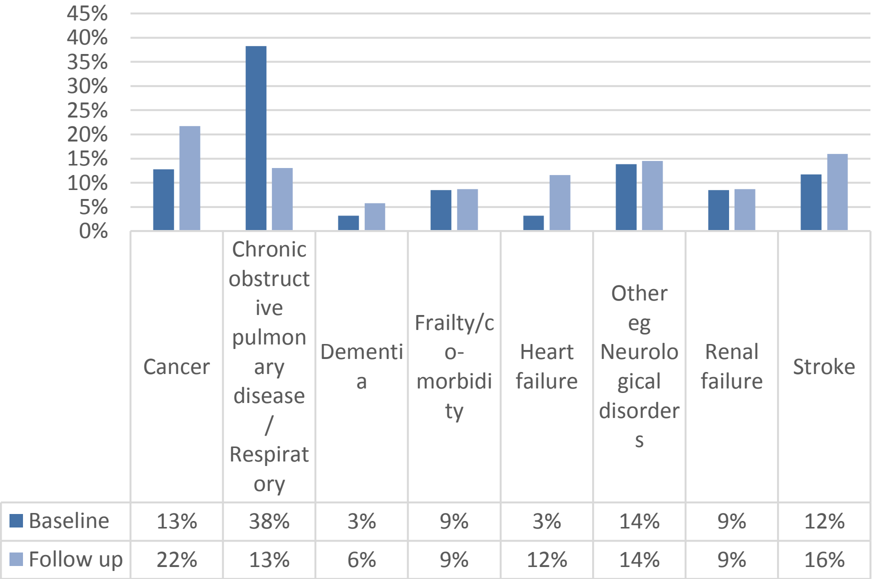
Figure 3.3 Primary diagnosis at baseline and follow up (all hospitals)



	Cancer	Chronic obstructive pulmonary disease/ Respiratory	Dementia	Frailty/co-morbidity	Heart failure	Other eg Neurological disorders	Renal failure	Stroke
■ Baseline	14%	15%	7%	13%	4%	27%	4%	16%
■ Follow up	38%	12%	7%	7%	9%	13%	4%	9%

163 responses (67%) provided information on cause of death (Figure 3.4). At baseline, the most common cause of death was COPD/respiratory, then cancer; at follow up it was cancer, then stroke.

Figure 3.4 Causes of death at baseline and follow up (all hospitals)



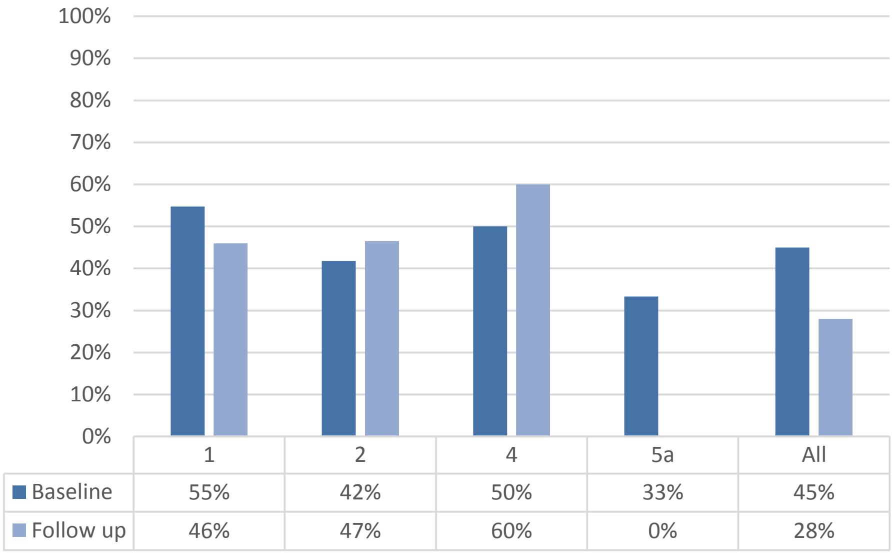
	Cancer	Chronic obstructive pulmonary disease / Respiratory	Dementia	Frailty/co-morbidity	Heart failure	Other eg Neurological disorders	Renal failure	Stroke
■ Baseline	13%	38%	3%	9%	3%	14%	9%	12%
■ Follow up	22%	13%	6%	9%	12%	14%	9%	16%

3.2.3 The proportion of patients who died varied slightly 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 only exception to this was Hospital 5a where no patients died at follow up. There was some variation by ward in the proportion of patients dying at follow up (Figure 3.6).

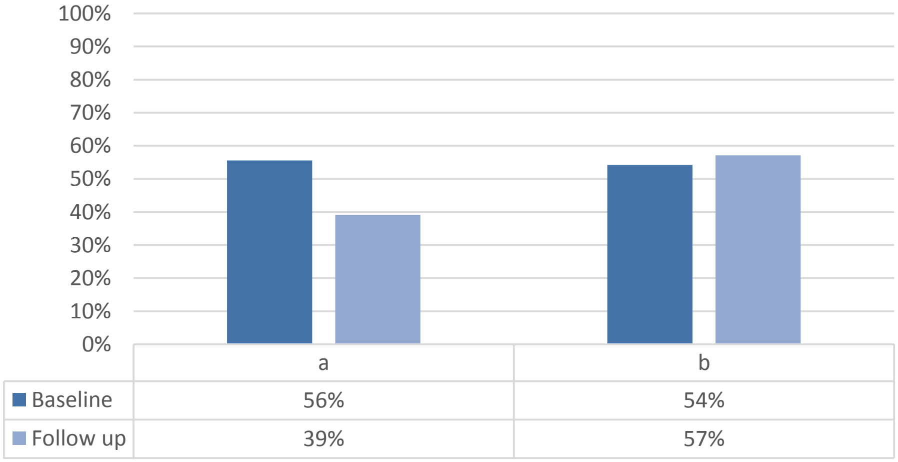
A number of questions on the ADA are relevant only to those patients who died in hospital; those who were discharged are therefore excluded from the analysis. Because no patients died at follow up in Hospital ward 5a, Figure 4.4 and Section 4.3 onwards still show Hospital ward 5a in each figure but exclude it from the calculation of 'all hospitals', in order to prevent any inaccurate skewing of results.

Figure 3.5 Percentage of patients who died in hospital at baseline and follow up, by hospital



	1	2	4	5a	All
■ Baseline	55%	42%	50%	33%	45%
■ Follow up	46%	47%	60%	0%	28%

Figure 3.6 Percentage of patients who died in hospital at baseline and follow up, by ward



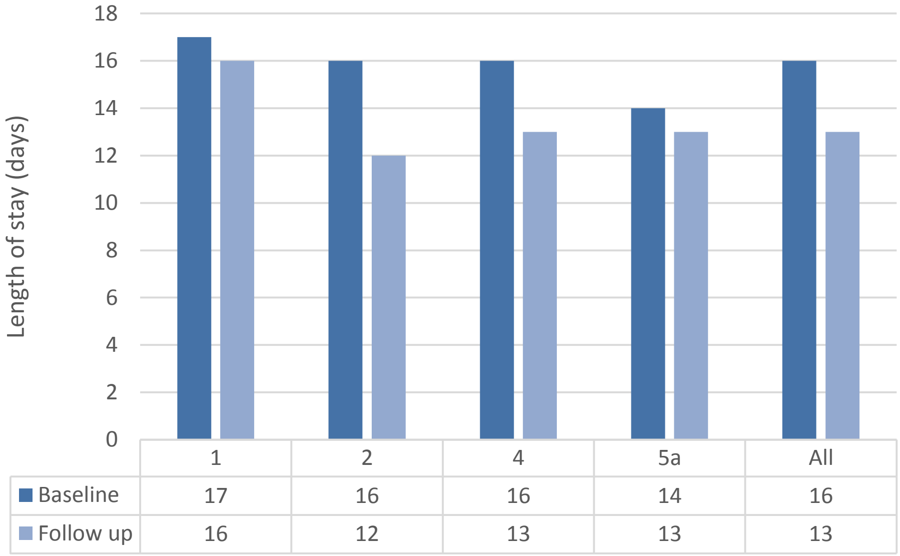
	a	b
■ Baseline	56%	54%
■ Follow up	39%	57%

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. 95 responses were excluded from the analysis because no discharge date was provided. In addition, nine returns were excluded due to a data entry error (length of stay was negative), and three were treated as outliers and also excluded (due to having unusually large values of 97 days, 115 days and 310 days).

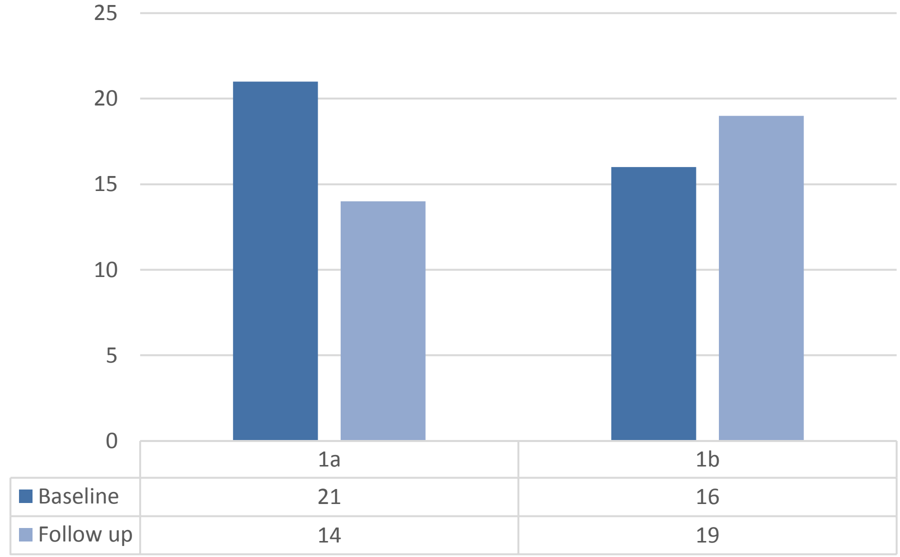
All hospitals showed a decline in mean length of stay (Figure 3.7), however the decline was not significant for any of the individual hospitals, or for all hospitals combined (Table 3.1). There was some variation in mean length of stay, and change in mean length of stay between different wards of the same hospital. Ward 1a had a particularly high value for baseline length of stay and showed a large decrease between baseline and follow up. In contrast, ward 1b showed a small increase in mean length of stay. However, care should be taken in interpreting these results as the sample sizes are small, particularly for ward 2a baseline responses, where only seven staff responded (Figure 3.8).

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



	1	2	4	5a	All
■ Baseline	17	16	16	14	16
■ Follow up	16	12	13	13	13

Figure 3.8 Length of stay at baseline and follow up, by ward



	1a	1b
■ Baseline	21	16
■ Follow up	14	19

Table 3.1 Significance of changes in length of stay

Hospital	Baseline (mean days)	Follow up (mean days)	t-value	p-value (two-tailed)	p-value (one-tailed)	Sig. change in mean?
1	17	16	0.2157	0.8299	0.4150	No
2	16	12	1.6257	0.1064	0.0532	No
4	16	13	0.8255	0.4152	0.2076	No
5a	14	13	0.1101	0.9125	0.4563	No
All	**16**	**13**	**1.4467**	**0.1489**	**0.0745**	**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 care. Answers are grouped following the structure used in the Foundation survey, using 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 end 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.

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 mixed results, with performance often very low at baseline and follow up. Findings include:

- The proportion of staff on wards who were trained in GSF varied between hospitals;
- Overall, the foundation survey suggested mixed results in identifying patients who were nearing the end of life. This is likely to be the result of poor data;
- ADA data showed a small improvement in the proportion of patients who had passport information collected on admission, but proportions remained low;
- There was a decrease in the proportion of patients who had passport information sent out on discharge; and
- Data on DS1500 forms was poor with only two hospitals responding, although a very small increase in their use was identified between baseline and follow up.

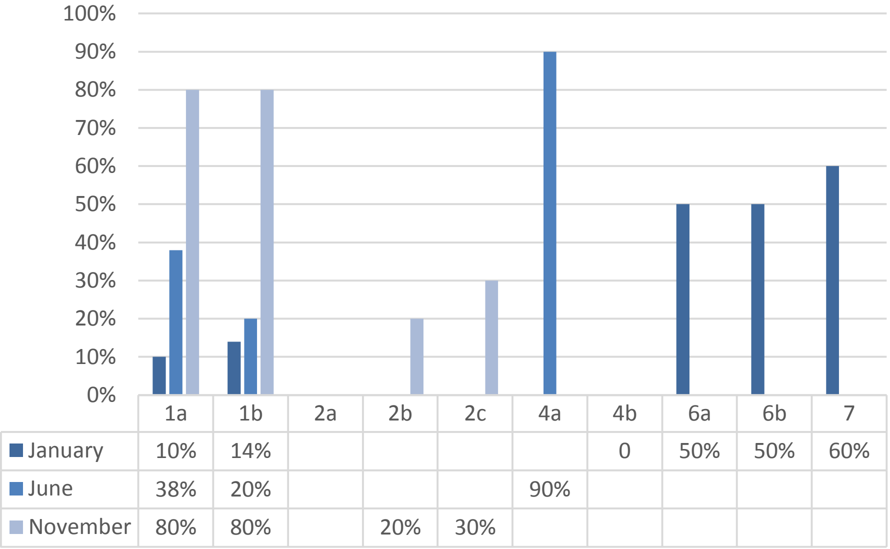
4.2.1 Information from the foundation survey suggested that the proportion of staff trained varied considerably between hospitals

In the January, June and November rounds of the Foundation survey, sites were asked to comment on the percentage of staff covered by training. The number of hospitals and wards responding to this question varied by round and was generally poor. In January, Hospitals 1, 2, 4, 6 and 7 responded, although Hospital 2 provided only qualitative information. In June, Hospitals 1, 2, 4 and 7 responded but only for some wards, and only three wards provided a percentage. In November, only three hospitals, 1, 2 and 7 responded and some ward information was not provided.

- Both wards at Hospital 1 showed a large increase in the percentage of staff covered by training (Figure 4.1). Staff were registered on a one hour session introducing GSF.

- Hospital 2 did not provide percentages in January or June but reported that all three wards were provided with an informal ward folder, wards 2a and 2c posted information on ward notice boards, provided information about patient identification at the Multi-Disciplinary Team (MDT) meeting and held a GSF launch day. In November, percentages were reported but showed relatively low proportions of staff trained compared to other hospitals.
- Hospital ward 4a only provided data for June but showed that nearly all staff on the ward were covered by training.
- Hospitals 6 and 7 only provided data for January showing that around half of their staff were covered by training.

Figure 4.1 The proportion of staff covered by training, January, June and November follow ups



	1a	1b	2a	2b	2c	4a	4b	6a	6b	7
■ January	10%	14%					0	50%	50%	60%
■ June	38%	20%				90%				
■ November	80%	80%		20%	30%					

4.2.2 Findings from the Foundation survey do not provide any clear evidence that progress was made in identifying patients who were nearing the end of life

In the baseline, January and June questionnaires, 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

These questions were altered in the November 2014 survey to:

- Every patient identified on the ward is highlighted on the supportive care register as nearing end of life (final years, months, weeks, days) has a Needs Based Coding (RAG);
- Those identified on the register use a plan of care related to Needs Support Matrices eg GSF Core Care Plan to ensure the right care at the right time;
- A proactive plan of care is discussed and agreed at regular team/MDT meetings ie at minimum weekly for most and daily for appropriate patients.

Question three about discussions around a plan of care remained the same in November 2014 so results from this question are directly comparable to earlier returns. However the first two questions around patient identification, planning and assessment are not comparable so will be considered separately. The change in questions, combined with a large decrease in the number of hospitals responding between January and November makes it very difficult to identify any clear trends over time, meaning it was not possible to fully assess the progress made in identifying patients who were nearing the end of life.

Hospitals performed best in response to '*a plan of care is discussed at ward round/MDT meeting',* although results got worse in June but improved again in November. In January, all 10 wards (from five hospitals) reported that a plan of care discussion was either routine practice or was carried out with some of their patients, but in June, Hospitals 1, 2 and 4 had moved from having discussions with 'all' patients to 'some'. An improvement was seen in November though, with four of the five wards (except 1b) from three hospitals reporting a discussion was either routine practice or was carried out with some of their patients, and Hospital 2 reporting an improvement from having discussions with 'some' patients to 'all' patients.

Responses to *'they are included on the appropriate hospital register/tagged'* were the lowest: in January, only two wards out of ten reported that they 'sometimes' did this (6a and 6b), although there was a slight improvement in June, where four out of seven wards reported they 'sometimes' did this (7, 2b, 2c and 4a). This partly reflects findings from the ADA on passport information (see sections 4.2.3, 4.2.4).

Responses to the question '*every patient nearing end of life (final months, weeks, days) is identified'* were mixed, and due to the change to the question in November (see below), are not comparable over time. In January, all ten wards from five hospitals, reported that some, but not every, patient nearing end of life was identified and all wards reported similar results in June, with the exception of ward 2b which moved from 'some' to 'no' patients, and 4a which improved from 'some' to 'all'. The results for Hospital 4 correlate with the results from the Staff Survey, where Hospital 4 saw improvements in staff confidence at recognising patients nearing the end of life, however results for Hospital 2 seem to contradict the Staff Survey results (see Figure 2.14, Figure 2.15).

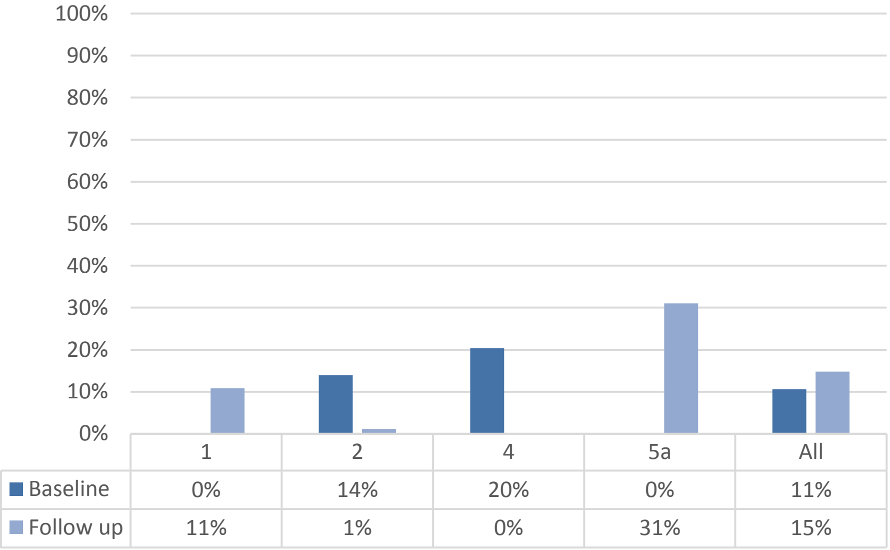
In November, using the new questionnaire categories, all five wards, across three hospitals responded with 'some patients' to *'every patient identified on the ward is highlighted on the supportive care register as nearing end of life (final years, months, weeks, days) has a Needs Based Coding (RAG)'.* Only three out of five wards responded to *'those identified on the register use a plan of care related to Needs Support Matrices eg GSF Core Care Plan to ensure the right care at the right time'* (1a, 1b and 7) with 'sometimes' with wards 2a and 2b answering with 'no'.

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 (11%) but improved slightly at follow up (15%) (22 individuals had their passport information collected at baseline and 36 individuals at follow-up) (Figure 4.2). The greatest increase was seen by Hospital 5a, from 0% at baseline to over 30% at follow up. Due to the small sample size, the data were not further split by ward or by those who died versus patients who were discharged.

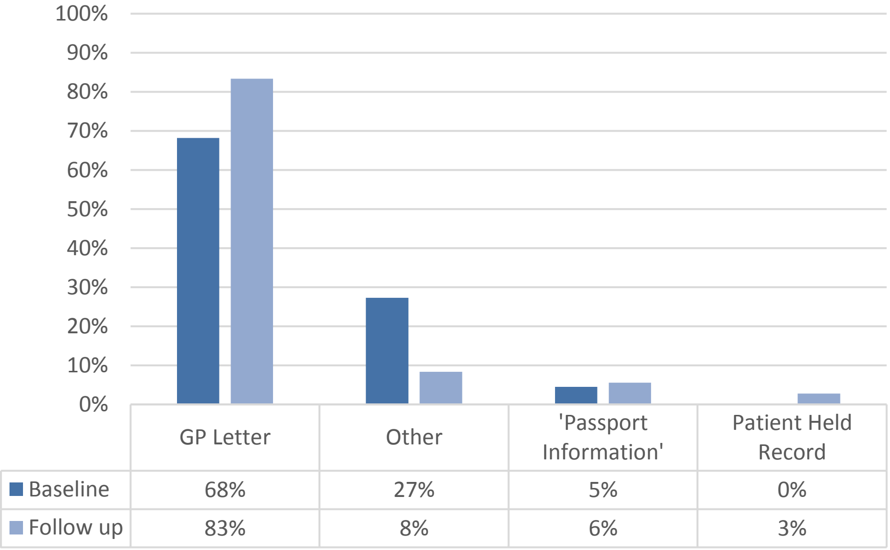
Where information was provided, it was most commonly in the form of a GP letter at baseline and follow up (Figure 4.3Figure 4.3).

Figure 4.2 Percentage of patients whose passport information was recorded on admission (all patients) *('yes' responses (other options NA, no, not recorded))*



	1	2	4	5a	All
■ Baseline	0%	14%	20%	0%	11%
■ Follow up	11%	1%	0%	31%	15%

Figure 4.3 Type of passport information collected at baseline and follow up (all patients)



	GP Letter	Other	'Passport Information'	Patient Held Record
■ Baseline	68%	27%	5%	0%
■ Follow up	83%	8%	6%	3%

4.2.4 Passport information was rarely sent out on discharge at baseline, this decreased further at follow up

A total of 45 patients (49%) who were discharged had passport information sent out at baseline, which decreased to 18% (or 13 of the follow up patients) at follow up (Figure 4.4)[11]. There was significant variation between hospitals in whether passport information was sent out. Hospital 4 reported 100% of patients having passport information sent out at both baseline and follow up; Hospitals 1 and 5a both showed an increase from 0% at baseline to 20% and 45% at follow up, respectively; while Hospital 2 saw a decrease from around 40% at baseline to only 2% at discharge.

Where information was sent out it was most commonly in the form of a GP letter (at both baseline and follow up). Gold Card and 'Other' were used more at follow up than baseline,

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[11] Although Hospital ward 5a has been included in Figure 4.4, the calculation of all hospitals has been done excluding Hospital ward 5a. This is because 5a reported no deaths at follow up but did report them at baseline, meaning the follow up data will over-represent discharged patients.

while Patient Held Records and Preferred Place of Care Documents were more used at baseline (Figure 4.5Figure 4.5). This reflects a similar trend to the information collected on admission.

Figure 4.4 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))*

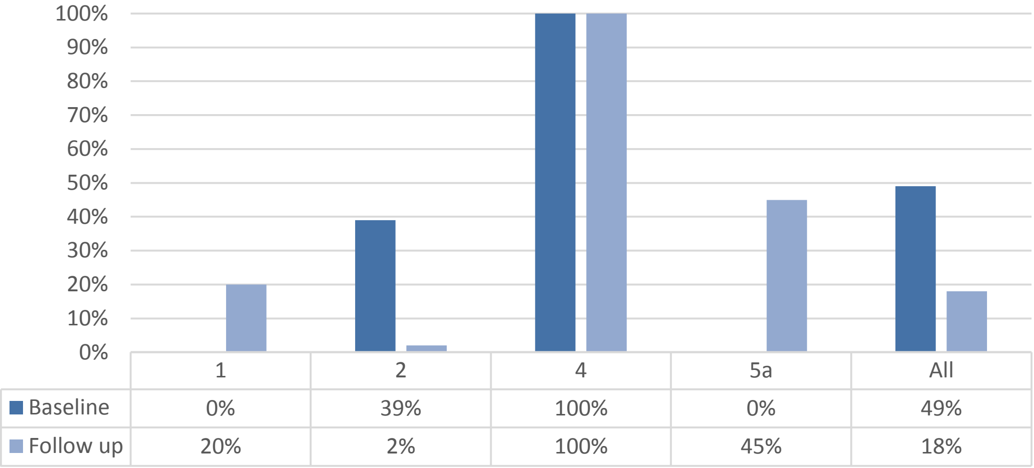
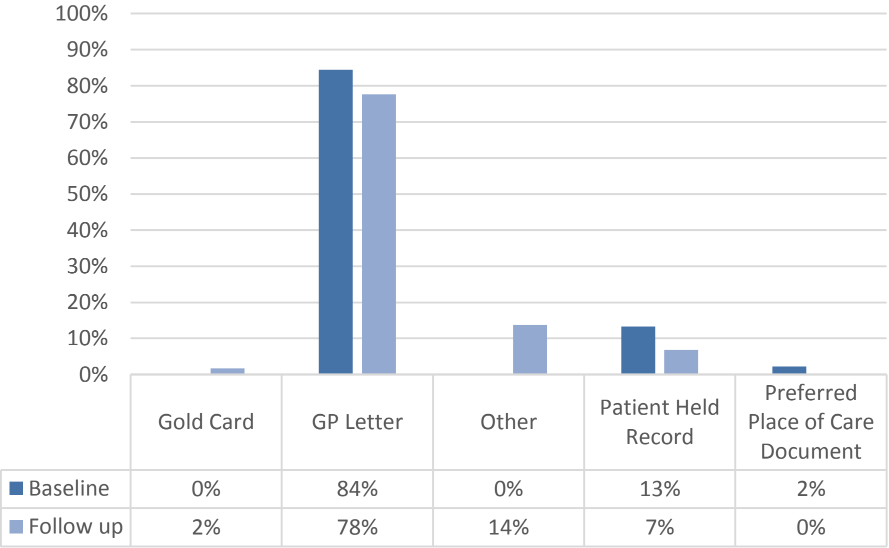


Figure 4.5 Type of passport information sent out at baseline and follow up (discharged patients only) *('yes' responses (other options NA, no, not recorded))*



4.2.5 Few DS1500 forms were completed, though this did increase between baseline and follow up

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'. Only Hospitals 4 and 5 filled in DS1500 forms: Hospital 4 filled in one at baseline and one at follow up (4% and 11% of responses, respectively) and Hospital 5 filled in none at baseline but six at follow up (0% and 6% of responses, respectively).

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, although results improved over time. Data from ADA was more positive, showing that the use of tools was either very high, or showed large improvements between baseline and follow up (with the exception of patients who used SCAs and patients dying in their preferred place of care):

- The Foundation survey found that in January no hospitals answered with ‘yes, all patients’ to the questions around clinical needs assessments, initial discussions with patients and providing information about beginning an advance care planning discussion, although results improved in June and November. 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 at baseline; although,
  - There was a large increase between baseline and follow up for patients who were discharged, meaning at follow up, discussions were held more frequently for those who were discharged.
- The recording of DNAR/NCR/AND was higher at baseline and follow up for patients who died than for patients who were discharged.
  - Results remained high at baseline and follow up for patients who died, although patients who were discharged showed a large improvement (from 24%-64%) between baseline and follow up.
- The use of symptom control assessments decreased between baseline and follow up, although variation was seen between hospitals. It was higher for patients who died, than for those who were discharged.
- The number of patients who died in their preferred place of care was generally high at baseline but decreased in all hospitals between baseline and follow up, with Hospitals 1 and 4 showing particularly large declines.

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

In January and June, 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.

In November, although the wording of the questions was changed slightly, the content of the questions remained the same. The only exception was the first question on clinical needs assessments which was split into two sections as follows:

- Clinical needs assessed using appropriate clinical assessment tools to identify their needs appropriate to their symptoms or condition including the options for escalation of care and clarification of the ceilings of care;
- Following assessment appropriate referral to specialist services according to patients’ needs.

For the question *‘clinical needs assessed using appropriate clinical assessment tool/measures’*, in January, no wards answered ‘yes, all patients’ and six wards (60%) answered with ‘no patients’. Results improved in June, with two wards out of seven (29%) answering with ‘all patients’ and no wards reporting ‘no patients’. In November, this question was split into two sub-sections with two out of five wards (40%) reporting ‘all patients’ and one out of five wards (20%) reporting ‘no patients’ for both sections, showing an improvement in positive responses but also an increase in negative responses.

Responses to the question *‘there is an initial discussion with the patient and carers and information given’,* also improved in June but got worse again in November. In January no wards answered with ‘all patients’ and six (60%) answered with ‘no patients’ while in June, two wards (29%) responded with ‘all patients’ and only one (14%) reported ‘no patients’.

However, in November, like January, no wards answered with ‘all patients’ and three (60%) answered with ‘no patients’.

The question ‘*this includes beginning an advance care planning discussion, proxy nominated person noted (or LPoA)*’ had no positive responses and 8 (80%) wards answered with ‘no patients’. In June, there was an improvement, with two wards out of 7 responding with ‘all patients’ (29%) and two wards (29%) reporting ‘no patients’. However, results got worse in November, with no positive responses and 60% of wards responding with ‘no patients’.

The questions about providing information about DNA CPR status and preferred place of care had the most positive responses, with six out of ten wards (covering four out of five hospitals) answering ‘all patients’ to the first question in January. In June all hospitals responding to the questionnaire answered positively to the first question and only Hospital 7 and ward 1b responded with ‘some patients’ to the second question, the rest responding positively. In November, only Hospital 1 responded with ‘some patients’, with the other two hospitals responding positively to both questions.

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 for patients who died; although it decreased slightly between baseline and follow up (Figure 4.6). Hospitals 1 and 4 both saw slight increases between baseline and follow up, but Hospital 2 saw a large decrease from 94% to 55%.

There was greater variation between hospitals and between baseline and follow up for patients who were discharged from hospital, than those who died. For patients who were discharged, Hospital 1 saw a 60 percentage point increase between baseline and follow up and Hospital 4 also saw an increase from 44% to 88%. However, Hospital 2 saw a large decrease from 83% to 37% (Figure 4.7).

However, overall, all hospitals reported holding discussions with carers in at least a third of cases. This contrasts with the Foundation Survey where almost all hospitals in January reported they had conducted no discussions with patients and carers, with some discussions being held in June and November.

This mixed pattern was also seen in the staff survey. Although Hospital 2 showed increases in staff confidence at having discussions with patients, relatives and carers, Hospital 4 saw small decreases in four out of the six questions about discussions with patients or carers (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))***

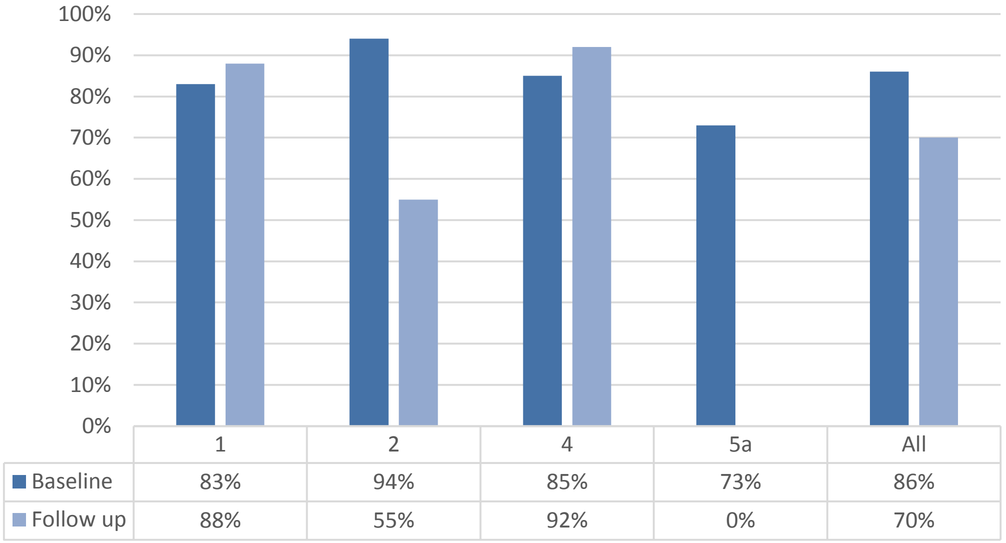
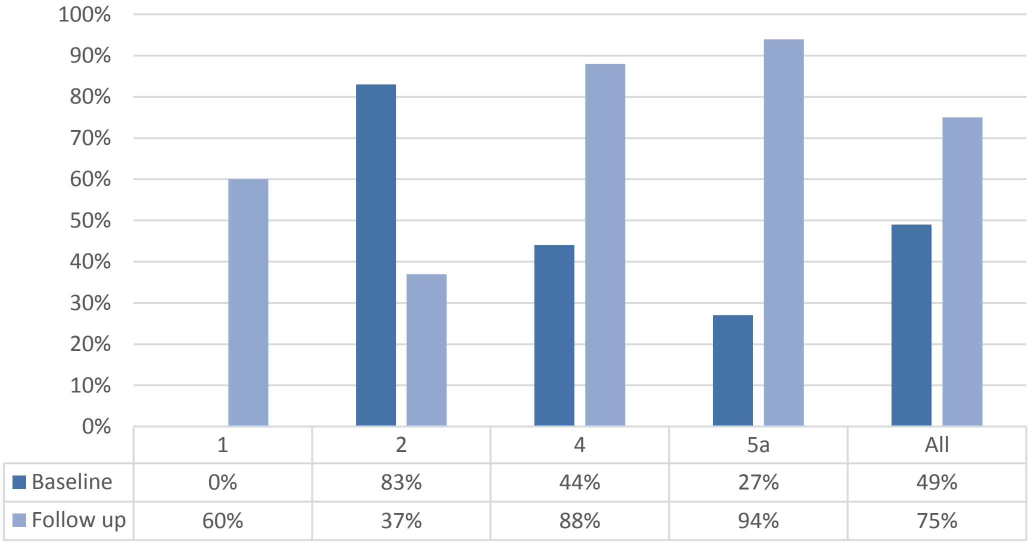


Figure 4.7 **Percentage of patients for whom a discussion with carers were held, by hospital (patients who were discharged)** ***('yes' responses (other options NA, no, not recorded))***

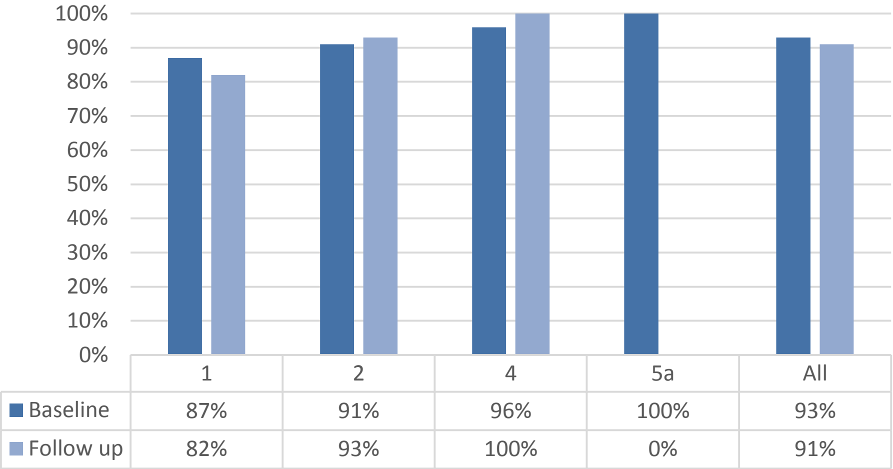


4.3.3 Recording of DNAR/NCR/AND was generally high, and increased at follow up

DNAR/NCR/AND was recorded more frequently for patients who died in hospital, than those who were discharged (Figure 4.8 and Figure 4.9). Among those who died, nearly all patients had this recorded at both baseline and follow up. Hospital 5a had the highest recorded rate of 100% at baseline, although no hospital fell below 87%. Both Hospitals 2 and 4 saw small increases between baseline and follow up, although Hospital 1 saw a five percentage point decline.

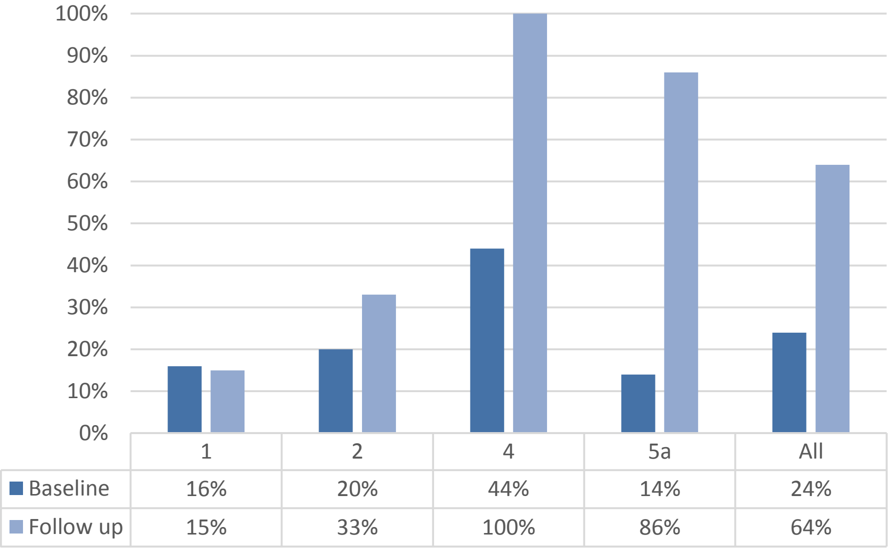
In contrast, there was substantial variation between hospitals for patients discharged. Prevalence of DNAR/NCR/AND ranged from 14%-44% at baseline and 15%-100% at follow up. Hospitals 1 and 2 both showed low proportions of patients for whom DNAR/NCR/AND was recorded at both baseline and follow up, although Hospital 2 did see a small increase. In contrast Hospital 4 had a relatively high baseline rate of 44%, which increased considerably to 100% at follow up.

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))*



	1	2	4	5a	All
■ Baseline	87%	91%	96%	100%	93%
■ Follow up	82%	93%	100%	0%	91%

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))*



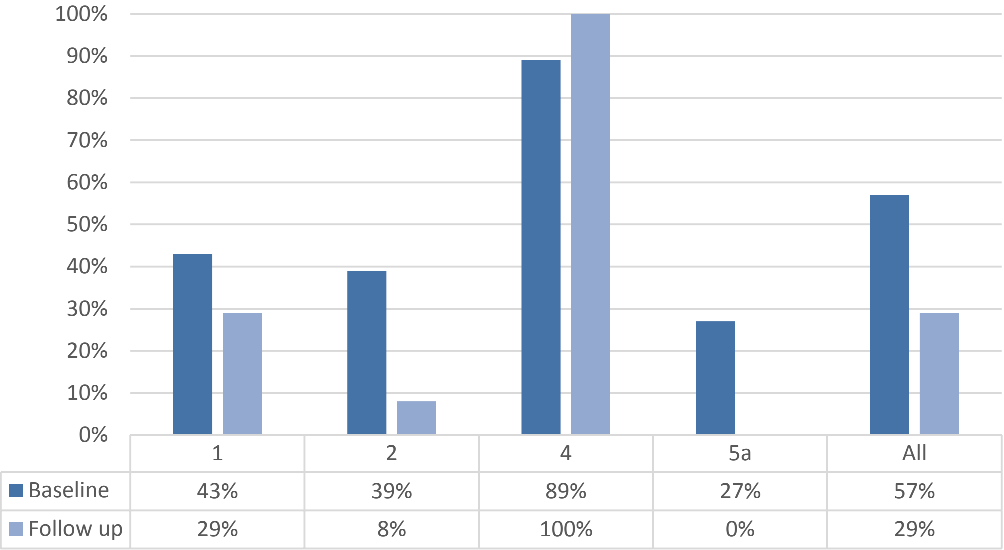
	1	2	4	5a	All
■ Baseline	16%	20%	44%	14%	24%
■ Follow up	15%	33%	100%	86%	64%

4.3.4 The use of Symptom Control Assessments decreased between baseline and follow up, although variation was seen between hospitals

The use of symptom control assessments (SCAs) decreased between baseline and follow up. However, results varied by hospital. For patients who died, at baseline, Hospitals 1, 2 and 5a had low percentages of patients with SCAs. Hospitals 1 and 2 then further declined between baseline and follow up. Hospital 2 showed a particularly large decrease from 39% to 8%. In contrast, Hospital 4 had a high baseline rate of 89% which increased to 100% at follow up (Figure 4.10).

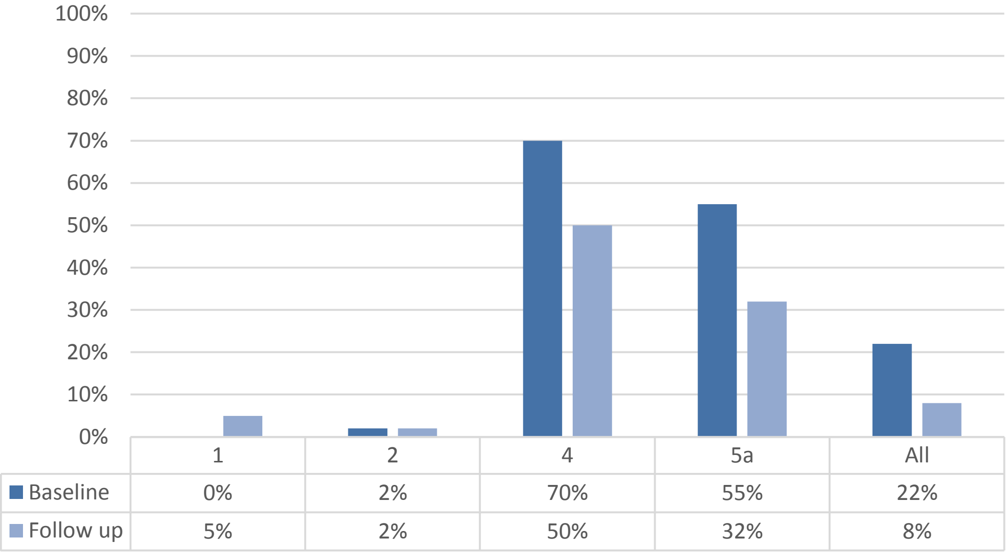
For patients who were discharged, Hospitals 1 and 2 showed even lower proportions than for patients who died, and these proportions remained very low at follow up. In contrast, Hospitals 4 and 5 both showed much higher baseline rates of over 50%, although Hospital 4 reported a decline at follow up from 70% to 50% (Figure 4.11).

Figure 4.10 Percentage of patients who use Symptom Control Assessments, by hospital (patients who died) (‘yes’ responses (other options NA, no, not recorded))



	1	2	4	5a	All
■ Baseline	43%	39%	89%	27%	57%
■ Follow up	29%	8%	100%	0%	29%

Figure 4.11 Percentage of patients who use Symptom Control Assessments, by hospital (patients who were discharged) (‘yes’ responses (other options NA, no, not recorded))



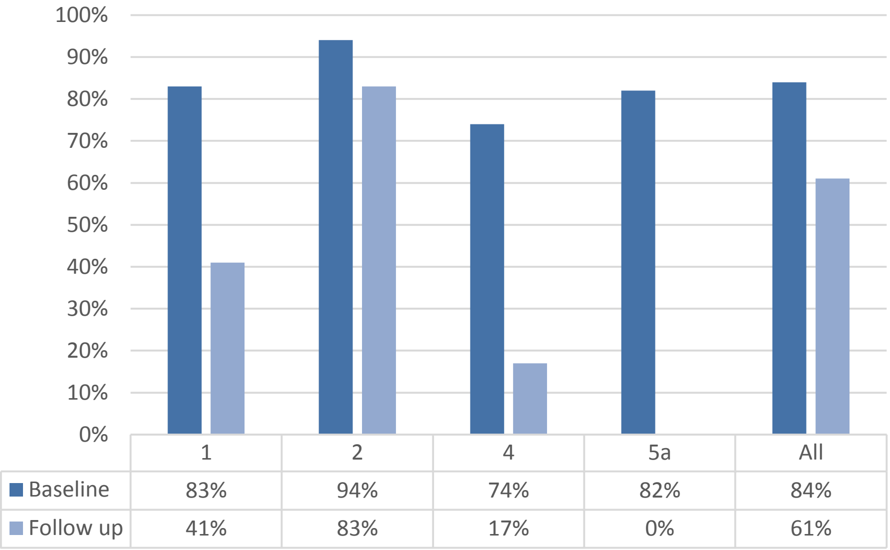
	1	2	4	5a	All
■ Baseline	0%	2%	70%	55%	22%
■ Follow up	5%	2%	50%	32%	8%

4.3.5 There was an improvement in the number of patients who died in hospital who had their preferred place of care recorded

All hospitals showed large improvements in the recording of patients’ preferred place of care, with the proportion for whom this was not recorded falling by between 11 and 59 percentage points (excluding Hospital 5a which did not report any deaths at follow up) (Figure 4.12).

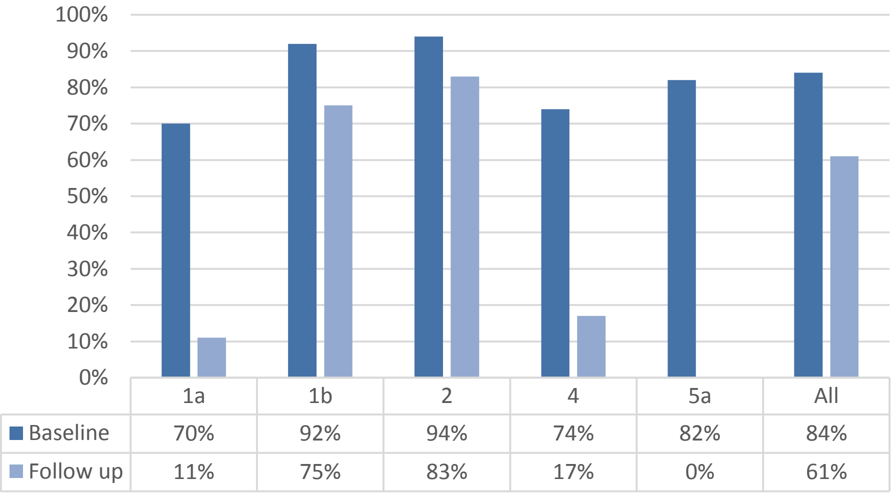
Individual ward data shows that both wards at Hospital 1 saw improvements, with ward 1a reporting a particularly large improvement from 70% of patients not having their preferred place of care recorded, to only 11% at follow up. Data are not analysed on the proportion of patients who did die in their 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 4.13).

Figure 4.12 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))*



	1	2	4	5a	All
■ Baseline	83%	94%	74%	82%	84%
■ Follow up	41%	83%	17%	0%	61%

Figure 4.13 **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))***



	1a	1b	2	4	5a	All
■ Baseline	70%	92%	94%	74%	82%	84%
■ Follow up	11%	75%	83%	17%	0%	61%

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 'all patients' to whether patients had access to the rapid discharge process, although hospitals performed worse in June and November than in January. ADA findings were more mixed:

- The proportion of patients with an ACP or PPC recorded improved between baseline and follow up for both patients who died and patients who were discharged, although a slightly larger improvement was seen in the latter patient group. There was great variation between hospitals, with Hospital 4 showing by far the largest improvement for both patients who died and patients who were discharged;
- The proportion of patients on the rapid discharge pathway was low in all hospitals and remained low at follow up. Overall, there was a small decrease from 5% to 3% between baseline and follow up.

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[12];

Overall, this was a high scoring area, although hospitals performed worse in June and November than in January. In January, eight out of ten wards answered 'all patients' to whether patients were offered the Rapid Discharge Process (the remaining two answered with 'some patients), although this decreased to only three wards (covering three hospitals) out of seven in June, and none in November, with Hospital 7 reporting 'no patients'.

Hospitals performed slightly less well on 'communication with GP', although due to changes to the questions around communications with GPs in both the June and November questionnaire, comparisons across time are difficult. In January, three out of ten wards reported communication with GP for all patients, with only two reporting 'no patients'. In June, this question was split into two sections ('Communication with GP - discharge letters including ACP' and 'follow up suggesting inclusion on GP's palliative care / GSF register for regular discussion at GSF meeting and proactive care') with three out of seven wards reporting 'all patients' for both sub-sections and only one ward and two wards reporting 'no patients' for each sub-section, respectively.

In November, the question returned to the same wording as in January, but two additional questions ('including needs based coding' and 'including progress of ACP discussion') were added. Responses to the original question were positive, with two wards out of five reporting 'all patients' and the remaining three reporting 'two patients'. However, the two new questions received more negative responses: none of the five wards responded positively and two wards responded with 'no patients' to question 2, while three wards responded with 'no patients' for question three.

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

Overall, there was an improvement in the proportion of patients with an Advance Care Plan or Preferred Place of Care, but results varied by hospital. For patients who died, improvements were seen at Hospital 1 and particularly Hospital 4 which saw an increase from 22% at baseline to 67% at follow up (Figure 4.14). However a small decrease was seen at Hospital 2. Similar results were seen for discharged patients, with Hospital 4 showing an even greater increase between baseline and follow up (from 11% to 88%) for discharged patients than for patients who died (Figure 4.15). Hospital ward 5a reported no patients with an ACP or PPC at baseline for either patients who died or patients who were discharged.

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

Figure 4.14 Percentage of patients with an ACP or PPC (patients who died in hospital) *('yes' responses (other options NA, no, not recorded))*

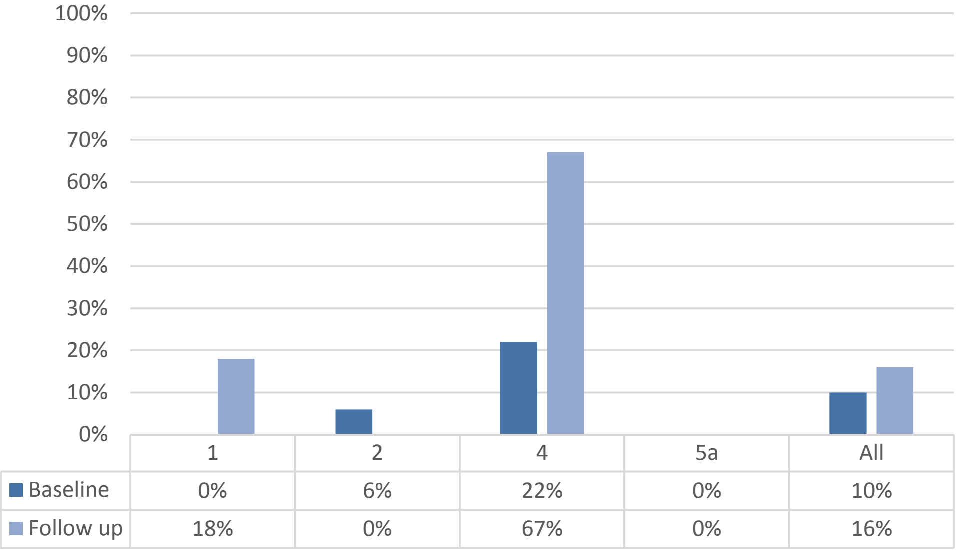
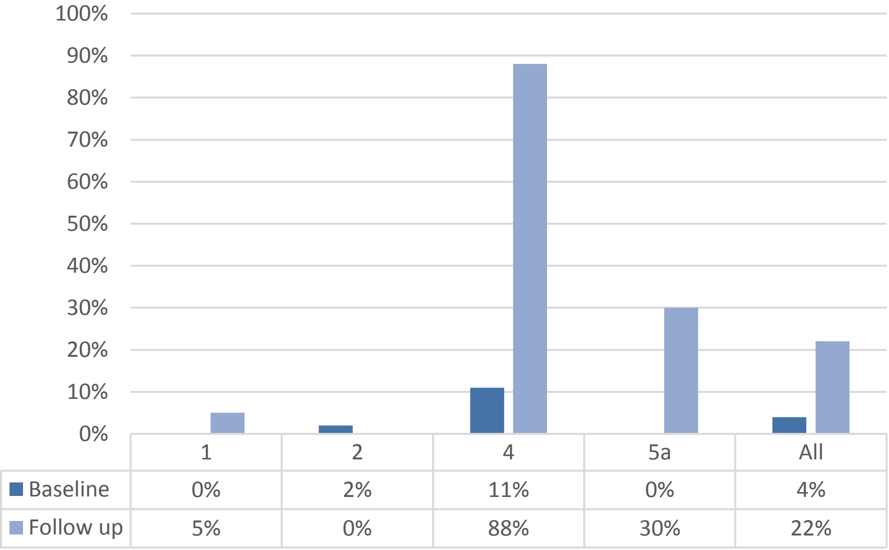


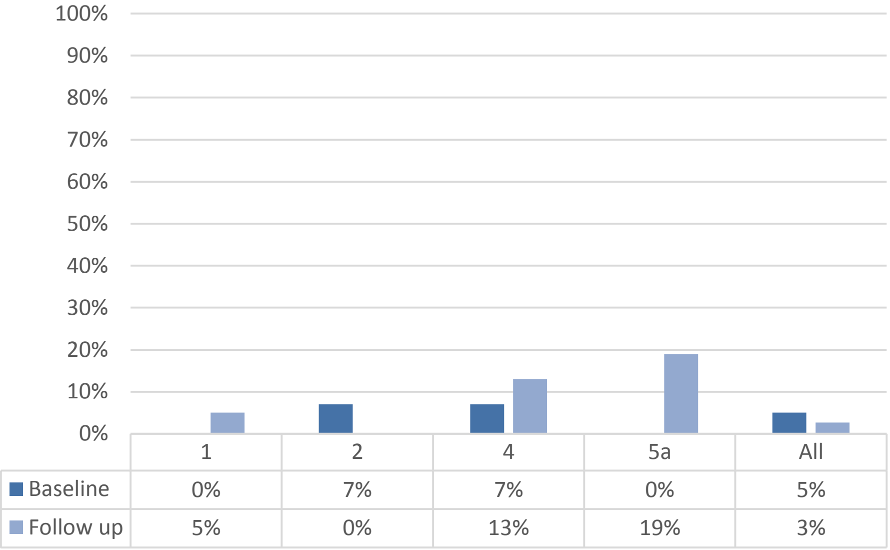
Figure 4.15 Percentage of patients with an ACP or PPC (patients who were discharged) *('yes' responses (other options NA, no, not recorded))*



4.4.3 The proportion of discharged patients on the rapid discharge pathway (RDP) was very low, and decreased slightly between baseline and follow up

No hospital reported more than 20% of patients on the RDP at baseline or follow up. Excluding Hospital ward 5a which has an over-representation of follow up patients, Hospitals 1 and 4 both showed an increase of five percentage points between baseline and follow up, while Hospital 2 showed a decrease from 7% to 0% at follow up.

Figure 4.16 **Percentage of patients on the rapid discharge pathway at baseline and follow up (patients discharged only)** ***('yes' responses (other options NA, no, not recorded))***



	1	2	4	5a	All
■ Baseline	0%	7%	7%	0%	5%
■ Follow up	5%	0%	13%	19%	3%

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. Hospital ward 5a had the highest response rate at 67%, followed by Hospital 4 at 55%. Hospital 1 and 2 both had low response rates of 7% and 16% respectively. Due to this large variation, hospital-level analysis is not be undertaken; instead, key themes are picked out.

Staff noted that positive elements of patient care included:

- Good, clear communication with family/friends/the patient, with staff listening to the families' wishes and making sure they were always involved.
- Discussions with the family were well documented and the information provided by other healthcare professionals was good:
  - For example, one respondent noted: "Excellent information sent in by GP, medical history, summary of events".
- Short hospital admissions, quick discharge and good use of the fast track pathway:
  - For example, one respondent noted "[the] patient received treatment and was discharged within a reasonable time frame".
  - Another staff member noted the patient was, "discharged in timely manner when medically fit".
  - Staff also facilitated patients dying at home, ensuring that everything was in place for them to do so.
- Identification of EoL was good and staff "recognised dying in a timely manner".
- Staff always considered the families, with staff at Hospital ward 5a staff offering the families of deceased patient's end of life mementoes and ensuring that the families or carers were supported emotionally.

More negative elements of care included:

- Problems and delays leading to untimely care:
  - For example, diagnosing dying too late; having no EoL plan in place; indecision about treating or not; fast tracking of patients taking too long; and lengthy decisions regarding the appropriate discharge destination/no discharge plans in place meaning patients often spent longer than needed in hospital.
- Poor to no documentation, or inadequate collection of patient information:

  - For example, no record of EoL wishes; no documentation of family conversations; no LCP completed; GSF was not communicated to the GP; or no transfer letter was sent with the patient.
  - One hospital reported that a patient was being cared for by two separate Trusts which led to difficulties ascertaining information regarding their Preferred Place of Care.
- Not discussing the patient’s care with their families or carers.

5 Qualitative findings

Three hospitals, 1, 2 and 5a, participated in a structured qualitative interview. The interview covered the implementation of GSF (including what worked, and what did not), what benefits it had had, and future plans. Below we draw out themes in hospitals' responses.

5.1 Implementation

Hospitals were asked about the extent to which they had implemented the GSF, what facilitators and barriers they had faced, and what their future plans were.

All sites highlighted that different wards varied in the extent to which (and speed) that they adopted the GSF. For example, Hospital 1 highlighted how one ward initially progressed quickly, but is now struggling, whilst the other ward was slower to get going but is now working well.

Hospitals were also asked about their future plans. Hospitals 1 and 2 were both planning on rolling out GSF to more wards, Hospital 1 had firm plans to roll it out as part of Phase 6, with Hospital 2 yet to confirm plans. Both of these hospitals would like to progress to accreditation, but had not yet made any concrete decisions. Hospital 5a already had one ward achieving accreditation, with another aiming to do so by the end of the year.

5.1.1 Facilitators

Hospitals highlighted a number of factors which improved the implementation of the GSF:

- Several hospitals discussed **the value of securing additional funding** to either look at other aspects of EoL care (for example, frailty, and working with front of house), or to further support the embedding of the GSF;
- Several also mentioned the **need to keep reminding staff to implement the GSF** – for example through having alerts on IT systems.
- **Senior/ clinician support was crucial to ensuring engagement**. In particular, one hospital mentioned the value of using doctor-to-doctor conversations to persuade more reluctant clinicians to engage.
- Two hospitals highlighted **the value of facilitators who were separate to the ward.** Ward-based staff were too busy to take the time out to focus and plan: *'facilitators who are not part of the ward-based team are able to promote [GSF] and demonstrate how to do [it].'*

5.1.2 Barriers

Hospitals mentioned a number of key barriers to implementation. Again, there were strong similarities between hospitals. Challenges related to:

- **Changing culture and practice is hard.** All hospitals noted that implementing the GSF is about more than just using new tools – it's about changing a whole way of working, and this is very challenging. As one hospital said: *'we didn't realise the enormity of implementing GSF, not as a one-off project but as a change in systems, culture and ongoing long-term practice'.*
- Hospitals reported that **changing the attitudes of clinicians can be challenging**. In particular, one hospital discussed how acute care was very focussed on *'making people better'*, and it can be hard to focus on improving care for life-limiting conditions.
- **Staff turnover made maintaining continuity difficult**. Two hospitals reported high levels of staff turnover within their wards. This was challenging as new members had to be bought up to speed: *'the majority of GSF coordinators have also had changes in their roles… maintaining continuity has been difficult'*

5.2 Outcomes of GSF

Hospitals had similar views on what the outcomes and benefits of the GSF had been:

- **All suggested that it raised the profile of EoL care amongst staff, and increased awareness of/ thinking in terms of the 'last year of life'.** In particular, one hospital highlighted how it had demonstrated to generalist staff what they could do to help EoL patients – that EoL care was not just the responsibility of specialist palliative care. One hospital suggested that it had started to break down taboos around talking about the end of life.
- All highlighted that the GSF had **increased the use of best-practice EoL care and tools**, for example increased use of Rapid Discharge Home to Die pathway, an increased number of ACP conversations, and use of the PEACE document (which improves communication with care homes and GPs).

5.3 Recommendations for the programme

Hospitals made three main recommendations for the programme team:

- Two hospitals suggested that their facilitators should receive their own ward folder: *'two of the coordinators at the start of the programme were not ward-based and it would have been beneficial for them to have their own 'ward folder' as they have been actively involved in supporting, leading and training'.*
- There was mixed feedback on the conference calls and workshops. One hospital felt that the calls were not that helpful, and that the workshops could have been better organised and timed, with more focus on action planning. However, other hospitals thought that the calls and workshops were really good.
- Two hospitals requested that the workshops be held in different locations – either closer to London or at the Trust site.

6 Conclusion

This final section presents a set of concluding points outlining the main findings from the report, as well as highlighting some of the data collection issues encountered.

The main concluding points are that:

- **There was an improvement in staff knowledge and confidence in all areas of end of life care.** However, there was variation between hospitals in the magnitude of the changes. Hospital 4 showed greater improvements compared to Hospital 2 in: needing to know more about the seven areas of EoL care; the proportion of staff reporting using specific tools as a trigger to identify patients in the last year of life; developing a plan for future care; and the proportion of staff reporting they routinely discuss patients nearing the end of life; and the proportion of staff who routinely send out discharge information to GPs and District Nurses. However, Hospital 4 showed small decreases in staff confidence in having discussions with patients, relatives and carers, although this may be due to a smaller sample size at follow up, rather than reflecting a change in confidence. See Table 6.2 for a summary broken down by hospital.
- **Most areas of end of life care practice have improved since implementing the GSF, although results were mixed.** Notable areas of improvement include: use and awareness of GSFs, ACPs and PPFCs; the use of specific tools as a trigger to identify patients in the last year of life; developing a plan for care; and recording of DNAR/NCR/AND. Other aspects of EoL care, including: whether or not passport information was recorded on admission; completion of DS1500 forms; and the percentage of patients with an ACP or PPC improved slightly at follow up (see Table 6.1 for a summary of these results, broken down by hospital).
- **There was an improvement in the number of patients who died in hospital, who had their preferred place of death recorded.** However, it was not possible to determine whether this then resulted in an improvement in the proportion of patients who died in their preferred place of care.
- **There was a small, statistically non-significant decline in the length of hospital stay for patients who were discharged**. This decline was seen in all hospitals reporting data (1, 2, 4 and 5a). The overall decline seen in Phase 4 was slightly smaller than that seen for the Phase 3 projects (3.0 days compared to 3.8).
- **Qualitative research shows that facilitators and barriers to implementation are similar between hospitals**. There was a low response rate to qualitative research, but the findings gave a richness of feedback on implementing the GSF. In particular, the facilitators (having facilitators, clinical buy-in and reminders, and securing additional funding) and barriers (changing culture is hard, clinicians can be reluctant, staff turnover) were common between hospitals. There would be value in expanding the qualitative research in future.
- **Overall the data available for analysis was poor, making comparisons and conclusions less robust; data collection should be improved in future**. Key issues include the differences in the numbers of responses between baseline and follow up, and the over-representation of some hospitals. As a result of these data limitations, comparisons and conclusions should be interpreted with care.

Table 6.1 Summary results of ADA by hospital

		Hosp. 1	Hosp. 2	Hosp. 4	Hosp. 5a	All[13]
Length of stay		🟩	🟩	🟩	🟩	🟩
Passport info - admission		🟩	🟥	🟥	🟩	🟩
Passport info – discharge		🟩	🟥	▨	🟩	🟥
Use of DS1500				▨	🟩	🟩
Discussion with carers	Died	🟩	🟥	🟩	🟥	🟥
	Discharge	🟩	🟥	🟩	🟩	🟩
Recording of DNAR/NCR /AND	Died	🟥	🟩	🟩	🟥	🟥
	Discharge	🟥	🟩	🟩	🟩	🟩
Use of SCAs	Died	🟥	🟥	🟩	🟥	🟥
	Discharge	🟩	▨	🟥	🟥	🟥
Patients dying in PPC		🟩	🟩	🟩	🟩	🟩
Patients with ACP or PPC	Died	🟩	🟥	🟩	▨	🟩
	Discharge	🟩	🟥	🟩	🟩	🟩
Patients on RDP		🟩	🟥	🟩	🟩	🟥
Patients on LCP/ other ICP		🟩	🟩	🟩	🟥	🟥

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

Staff…	Hosp. 2	Hosp. 4	All
Use tools to identify patients at EoL	🟩	🟩	🟩
Confidence in caring for people at EoL	🟩	🟥	🟩
Develop a future care plan	🟩	🟩	🟩
Routinely discuss patients near EoL	🟩	🟩	🟩
Routinely send out info to GPs	🟩	🟩	🟩
Routinely send out info to district nurses	🟩	🟩	🟩
Routinely send out info to 'other' organisations	🟥	🟥	🟥

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[13] Results recorded here are excluding Hospital 5a

Table 6.3 Key to Table 6.1 and Table 6.2

Improvement	🟩
Worsening	🟥
No change	▨
No data	

ANNEXES

Annex 1 Responses to the foundation survey

Table A1.1 Identification of patients

Hospital		1		2			4		6		7
Question	**Time**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	
Every patient nearing the end of life (final months, weeks, days) is identified	Jan.	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧
	Jun.	🟧	🟧	🟧	🟥	🟧	🟩				🟧
Every patient identified on the ward ins highlighted on the supportive care register as nearing end of life (final years, months, weeks, days) has a Needs Based Coding (RAG)	Nov.	🟧	🟧		🟧	🟧					🟧
They are included on the appropriate hospital register/tagged	Jan.	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟧	🟧	🟥
	Jun.	🟥	🟥	🟥	🟧	🟧	🟧				🟧
Those identified on the register use a plan of care related to Needs Support Matrices eg GSF Core Care Plan to ensure the right care at the right time	Nov.	🟥	🟥		🟥	🟥					🟧

Hospital		1		2			4		6		7
Question	**Time**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	
A plan of care is discussed at ward round/MDT meeting	Jan.	🟩	🟩	🟩	🟧	🟩	🟩	🟩	🟧	🟧	🟧
	Jun.	🟧	🟧	🟧	🟧	🟧	🟧				🟧
	Nov.	🟧	🟥		🟩	🟩					🟧

Table A1.2 Assessment of patients

Hospital		1		2			4		6		7
Question	**Time**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	
Clinical needs assessed using appropriate clinical assessment tool/measures	Jan.	🟧	🟧	🟧	🟧	🟧	🟥	🟥	🟥	🟥	🟧
	Jun.	🟩	🟧	🟧		🟧	🟧				🟩
	Nov.	🟧	🟧		🟩	🟩					🟥
Following assessment appropriate referral to specialist services according to patients needs		🟧	🟧		🟩	🟩					🟧
There is an initial discussion with the patient and carers and information given e.g. GSF card/leaflet	Jan.	🟥	🟥	🟥	🟥	🟥	🟥	🟧	🟥	🟥	🟥
	Jun.	🟩	🟧	🟧	🟧	🟥	🟩				🟧
	Nov.	🟧	🟥		🟧	🟥					🟥
a) This includes beginning an advance care planning discussion, proxy nominated person noted (or LPoA) b) DNACPR status	Jan.	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧
	Jun.	🟩	🟧	🟩	🟩	🟧	🟩				🟧

Hospital		1		2			4		6		7
Question	**Time**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	
c) preferred place of care and information leaflet given	Nov.	🟧	🟧		🟩	🟧					🟧

Table A1.3 Planning for patients

Hospital		1		2			4		6		7
Question	**Time**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	
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.	🟥	🟧	🟩	🟩	🟥	🟩	🟧	🟧	🟧	🟧
	Jun.	🟩	🟩	🟧	🟧	🟥	🟧				🟧
	Nov.	🟧	🟧		🟩	🟩					🟧
Including needs based coding and including progress of ACP discussion	Nov.	🟧	🟧		🟥	🟥					🟥
Rapid discharge process for those who wish to go home	Jan.	🟩	🟩	🟧	🟧	🟩	🟩	🟩	🟩	🟩	🟩
	Jun.	🟧	🟧	🟧	🟥	🟩	🟩				🟩
	Nov.	🟧	🟧		🟧	🟧					🟥
Progress to LCP/other pathway or tool for final days	Jan.	🟧	🟧	🟩	🟧	🟩	🟧	🟧	🟩	🟩	🟩
	Jun.	🟧	🟧	🟧	🟧	🟩	🟩				🟧

Hospital		1		2			4		6		7
Question	**Time**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	
	Nov.	🟧	🟧		🟩	🟩					🟥
Assessment of care needs and bereavement care and support	Jan.										
	Jun.	🟧	🟧	🟧	🟧	🟩	🟩				🟧
	Nov.	🟧	🟧		🟧	🟩					🟥

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
☐ 4. Renal failure	☐ 8. Other egg 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 ☐

Q18. If patient died, was it in Preferred Place of Care?

YES ☐ NO ☐ NA ☐ NR ☐

Q20. Cause of death if died :

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

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 ☐	☐ 6. Stroke ☐ 7. Dementia ☐ 8. Other egg Neurological disorders

OTHER COMMENTS

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

Annex 3 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 4 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

Annex 5 References

Insert references here using bullet styles

Annex 6 Example Annex styles

A6.1 AnnexH2

Body Text style

A6.1.1 AnnexH3

Body Text style

A6.1.1.1 AnnexH4

Body Text style