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# **Gold Standards Framework Scotland (GSFS)**

***Final Report***

[www.gsfs.scot.nhs.uk](http://www.gsfs.scot.nhs.uk)

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## **INTRODUCTION**

The Gold Standards Framework Scotland (GSFS) Project is based in general practice and aims to improve cancer and palliative care in the community. It builds on the good work being done in primary care and focuses on making simple improvements in planning and communication. The GSFS benefits everybody – patients, carers, and health professionals: encouraging consistently good quality care for patients in their chosen environment; acknowledging carers and supporting them with relevant information; improving teamwork and confidence amongst staff.

The Gold Standards Framework was developed, initially in West Yorkshire, by Dr Keri Thomas, a practising GP with a special interest in palliative care. Based on over 70 practice visits, workshops and with the help of a Gold Standard Reference Group of specialists and generalist doctors and nurses, a number of key tasks were developed, aimed at improving the organisation of care for those in the last year of life. Current evidence was assessed with a full literature search. The pilot was evaluated with focus groups, questionnaires, interviews and clinical assessments and all found the project valuable.

Following this, a second pilot phase, carried out as a joint venture with the NHS Cancer Services Collaborative, successfully extended use of the framework to a further 76 practices across the UK, including practices in Lanarkshire, Grampian and Glasgow.

In Scotland, the framework was modified to address the needs of all cancer patients from the point of diagnosis onwards. This modification was in recognition of the partnership funding from the Big Lottery Fund (BLF), Macmillan Cancer Support and NHS Scotland (through the 3 Scottish Cancer Networks). The principles underpinning the Scottish development remain identical to those of the wider Gold Standards Framework project and there is continued emphasis on the provision of high quality palliative care. The most significant difference is that practices are encouraged to maintain a cancer register as well as a palliative (supportive) care register in order to ensure that all cancer patients are appropriately supported at key points in their cancer journey. The project aimed to offer the framework to every practice in Scotland and to achieve 60% take-up of the framework over 3 years – from October 2003 to October 2006.

**GSFS Project Team**

## **SECTION 1: SUMMARY OF ACTIVITIES**

### **I - EXECUTIVE SUMMARY**

- 100% of all Scottish general medical practices have been offered the framework
- More than 70% of all Scottish general medical practices have taken up the framework surpassing the project's target
- 70 GP and Nurse Facilitators have supported the three-year project
- The 3 key funding stakeholders are the Big Lottery Fund (BLF), Macmillan Cancer Support and NHS Scotland (via the 3 Scottish Cancer Networks)
- Analysis of practice questionnaire submissions reveals that most improvements in care and processes occur within the first 6 months of using the framework
- More than 45% of the practices that have taken up the framework have already completed a 6-month questionnaire
- Of the 7 key task areas of the framework Communication and Co-ordination have seen the biggest improvement in practice
- 10 face-to-face interviews have been conducted with patients and carers throughout Scotland resulting in a positive audit of the GSFS
- A comprehensive database of all Scottish general medical practices has been developed including relevant contact details
- IT integration involving the whole GSFS dataset, methods of data collection, analysis, review prompting, support for multidisciplinary team meetings, as well as the interface with OOH, is in hand with the developers of all Scottish general medical practice systems, OOH, NHS 24, ECS and other relevant organisations
- A GSFS web site ([www.gsfs.scot.nhs.uk](http://www.gsfs.scot.nhs.uk)) has been developed to facilitate ongoing take up of the framework
- There is widespread support throughout Scotland to sustain the framework beyond the end of the 3-year GSFS Project

**II - ACHIEVEMENTS AGAINST PROJECT TARGETS**

	<b>Actual Number of Practices at 31.10.06</b>	<b>% of Practices Offered the Framework</b>	<b>% of Practices Completed the Baseline Questionnaire</b>	<b>% of Practices Completed the 6-Month Questionnaire</b>	<b>% of Practices Completed the 12-Month Questionnaire</b>
<i>Targets</i>	<i>N/A</i>	<i>98%</i>	<i>60%</i>	<i>30%</i>	<i>N/A</i>
		<i>Of Actual</i>	<i>Of Actual</i>	<i>Of Baseline</i>	<i>Of Baseline</i>
<b>Scotland</b>	<b>1036</b>	<b>100%</b>	<b>72%</b>	<b>46%</b>	<b>23%</b>
<b>NOSCAN</b>	<b>264</b>	<b>100%</b>	<b>71%</b>	<b>57%</b>	<b>28%</b>
<b>Grampian</b>	84	100%	82%	77%	41%
<b>Tayside</b>	71	100%	68%	67%	44%
<b>Highland</b>	70	100%	77%	37%	7%
<b>Shetland</b>	10	100%	10%	0%	0%
<b>Orkney</b>	15	100%	27%	0%	0%
<b>Western Isles</b>	14	100%	86%	17%	0%
<b>WOSCAN</b>	<b>528</b>	<b>100%</b>	<b>76%</b>	<b>52%</b>	<b>28%</b>
<b>Greater Glasgow</b>	214	100%	68%	53%	26%
<b>Forth Valley</b>	57	100%	88%	56%	26%
<b>Lanarkshire</b>	100	100%	84%	19%	12%
<b>Ayrshire &amp; Arran</b>	61	100%	80%	84%	67%
<b>Argyll &amp; Clyde</b>	96	100%	78%	61%	24%
<b>SCAN</b>	<b>244</b>	<b>100%</b>	<b>64%</b>	<b>17%</b>	<b>4%</b>
<b>Lothian</b>	128	100%	76%	14%	4%
<b>Fife</b>	58	100%	55%	28%	9%
<b>Borders</b>	23	100%	52%	0%	0%
<b>Dumfries &amp; Galloway</b>	35	100%	46%	19%	0%

### **III - BENEFITS TO PATIENTS AND CARERS**

There are feedback forms in each GSFS home pack allowing patients and carers to comment on "good aspects", "problems", "solutions" and "improvements" relating to their care. A number of useful comments highlight what is important in the eyes of patients and carers.

#### **Good aspects:**

*"Regular contact with a variety of agencies allows me to feel confident and call on help as and when required."* Patient in Tayside

*"The nursing team from [...] have given all the help and support during the day to ensure that [...] was kept clean and comfortable in his own home as was his wish. They were also a great comfort to us both in times of stress. I cannot praise them enough for what they have done."* Carer in Glasgow

#### **Problems:**

*"Obtaining equipment necessary for home nursing. In spite of urgency being highlighted, response to the request was very slow - some items a week or more, which is far from satisfactory. Request for night nurse on Tuesday 6<sup>th</sup> Sept. It is now Fri 9<sup>th</sup> and no nurse so I have had to cope on my own all night and have come to the decision [...] will need to be admitted to the hospice as I can no longer cope on my own."* Carer in Glasgow

#### **Solutions:**

*"Bath seat has given more freedom to have a bath without having someone there. Also the new banisters on the stairs."* Patient in Grampian

*"Being in home surroundings."* Patient in Ayrshire & Arran

#### **Improvements:**

*"More overnight care would be appreciated."* Carer in Ayrshire & Arran

*"More cover would have been appreciated in evening."* Carer in Grampian

The project was fortunate to receive forms illustrating one family's journey over the last months:

**Form 1 - completed 03/05/05 by the Patient**

**Good aspects:**

*"Weekly visit from District Nurses. Help from Macmillan Nurse. Referral to [...] Centre - care there. Help with ordering medication. Palliative care nurses calling."*

**Problems:**

*"Ordered a commode 4 weeks ago and still not arrived."*

**Solutions:**

*"Excellent care from District Nurses and Macmillan Nurses."*

**Improvements:**

*"Someone to take me out shopping once a week for personal items."*

**Form 2 - completed 21/06/05 by the Patient**

**Good aspects:**

*"Regular visits from District Nurses. Night sitting service from Marie Curie Nurses to let my daughter sleep."*

**Problems:**

*"2.5 month wait for commode. Problems changing colostomy bag."*

**Solutions:**

*"[...] hospice. Visits from Macmillan Nurse. Calls from overnight palliative care team. Night-time District Nurses change bag and carer in morning changes it too."*

**Improvements:**

*"Before my daughter returned to stay with me, I would have liked someone to take me shopping for personal things."*

**Form 3 - completed 22/08/05 by the Carer**

**Good aspects:**

*"Hospital bed. Special mattress. 4 times a day nursing care. Day hospice at [...] Centre. Marie Curie Nurses. Morphine syringe driver."*

**Solutions:**

*"Everything we needed was anticipated and we received it at the right time."*

**Improvements:**

*"7 nights Marie Curie Nurses, but I know that is unrealistic and was very grateful for help received. Advance notice of when coming was not always given."*

**Comments:**

*"My mum has now passed away. I cannot let the moment pass without saying a big thank you to all who assisted me in keeping her at home where she died peacefully surrounded by family."*

## Patient and Carer Interviews

In order to evaluate the impact the framework has on patients and carers in Scotland, 10 semi-structured interviews with patients and carers associated with general medical practices following the GSFS were conducted by an independent researcher from the University of Edinburgh. The interviews were recorded (with permission), transcribed, and analysed with the aid of the software package NVivo to identify key themes based around the 7Cs of the Gold Standards Framework.

### Results:

Between May and September 2006, the team received 14 contacts for potential interviewees, from across Scotland. 10 of these people completed interviews. Nine were conducted face to face in people's homes and one took place over the phone. One person died before an interview could be arranged. One person could not find time within the duration of the evaluation. Two people withdrew because they felt too unwell.

The final sample comprised of eight women and two men. Two interviews were with patients alone, four were with patients who wished to have their carer contributing also, and four were with bereaved carers. Four people had breast cancer, two had bowel cancer, one had stomach cancer, one had a glioma, one had COPD and one had rheumatoid arthritis.

The interviews lasted from 20 minutes to an hour and a half. All were recorded. Overall, the people interviewed were very pleased with the care and support provided by their local primary care team. Many gave vivid examples of how to provide excellent palliative care in the community.

It proved difficult to separate out the 7Cs of the Gold Standards Framework as many aspects, particularly **communication, co-ordination and continuity**, appeared in people's accounts as a package greater than the sum of its parts. However, it seemed that adopting the framework could help to avoid the problems so often narrated in interviews of patients and carers. Patients and carers often feel excluded from care planning, with little idea of whether or not there is a plan and if so what it might encompass. Sometimes the patient and carer are not aware of who knows about their care plan and therefore who to contact in times of difficulty.

*“And the GP came in and so she'd met them all. All 3 nurses came in at different times, so while [main nurse] was the main nurse and liased and passed everything on and filled in the books, the other 2 came in sometimes, and everything was written down so they just needed to look at the book. And [palliative care nurse] came as well and they all liased. [Palliative care nurse] used to go come on a Tuesday and then on a Tuesday they had a meeting along in the surgery and she would go to that where you know people were discussed and their treatment and their medication if it was being increased or whatever so it didn't matter who I spoke to I knew that they knew exactly what was going on. It was a team effort.”* Bereaved carer of Patient 5

*“We would be quite happy with any of the doctors actually but certainly [doctor] is the one who um is sort of in charge, he’s my doctor and obviously knows me best, but they do have briefing meetings they do the four doctors, I don’t know who else, the four doctors do meet on a regular basis to exchange information so that they are keeping each other up to date.”* Patient 3

There were many other examples of proactive and well co-ordinated care from all members of the primary care team, and including receptionists and pharmacists. All the patients and carers interviewed felt well supported, and in possession of as much information as they felt they required. Even out-of-hours care had been thought about in advance and the arranged system had worked well.

*“New Years day we had the senior partner in because he couldn’t breathe and you were right into the hospital again and it was blood clots on his lungs and he was taken right away and you know all these stories that you read in the paper about NHS 24, I mean when I phoned in that day they were superb. But then again I feel it’s flagged up. As soon as he had (patient 12) diagnosis it gets flagged up you know so that if I do phone and he needs help it’s already flagged up and they know the circumstances. So we’ve not anything to complain about (patient 12) have we?”* Carer of Patient 12

The interviews covered **control of symptoms** and provided strong evidence of an holistic approach to care from the practices involved - not only physical symptoms such as pain, breathlessness, nausea and constipation were mentioned, but also psycho-social concerns such as anxiety, depression, feelings of isolation, home helps, aids and adaptations, financial worries and spiritual concerns.

*“And [Dr R] I mean he said all along when you want this help, whatever it is it will be there and he kept offering it.”* Patient 12

**Carer support** is a vital part of the Gold Standards Framework. The whole family is affected by the illness and family carers have many concerns. Good support from the primary care team can make them feel valued and involved, especially where there is a two way process of information and knowledge exchange.

*“I mean it’s a huge drain on his emotional wellbeing you know looking after me. Obviously that takes a lot out of him.”* Patient 8

**Continued learning** was a difficult area for patients and carers to comment on, but some were aware of their practice taking on students to train or attend training days themselves and reading up on the latest research.

**Care of the dying.** The interviews provided evidence of good care up to and beyond the death of the patient.

*“Near the end they talked everything through with us, so there were no surprises, and everyone knew what might happen, and what to do. We all sort of agreed how it should be.”* Bereaved carer of Patient 2

*“I’ve tried to explain this to my sister that now I’ve been so close to my Mum and seen her through all the stages, I don’t think I have the same fear of dying as I probably had before, because I know as Mum got to the later stages she was ready, she actually wanted to go. She said to me it’s the end of the road, hen, the end of the road and I said I think so Mum, but we’ll get there and I’m here with you all the way. So I don’t think there’s the fear. They gave us both that confidence, and I’ve got it still.”* Bereaved carer of Patient 5

**Conclusion:**

Often it was not so much what the GPs or nurses did that made the difference as that knowing they are committed to their care and on hand at any time gave patients and family carers the confidence to be, and to die, at home. Proactive care is highly valued by both patients and family carers. For example, when GPs or nurses call in on a regular basis without being asked or when they take the time to go through what might happen at the weekend, or when they are away, and what to do in the event of something untoward happening.

The general themes to emerge from the interviews were:

- People feel supported and informed
- People are enabled to care
- Proactive and ongoing contact is much appreciated
- General feeling that there is a team approach to care
- Bereavement contacts valued

*“I would be far more stressed out than I am if it wasn’t for that practice. I know that because if I go to them and say I really am struggling a bit which I have from time to time they’re very sympathetic and we’ll sit there and chat about it say right here are the options which we will try and I know that that helps me.”* Patient 7

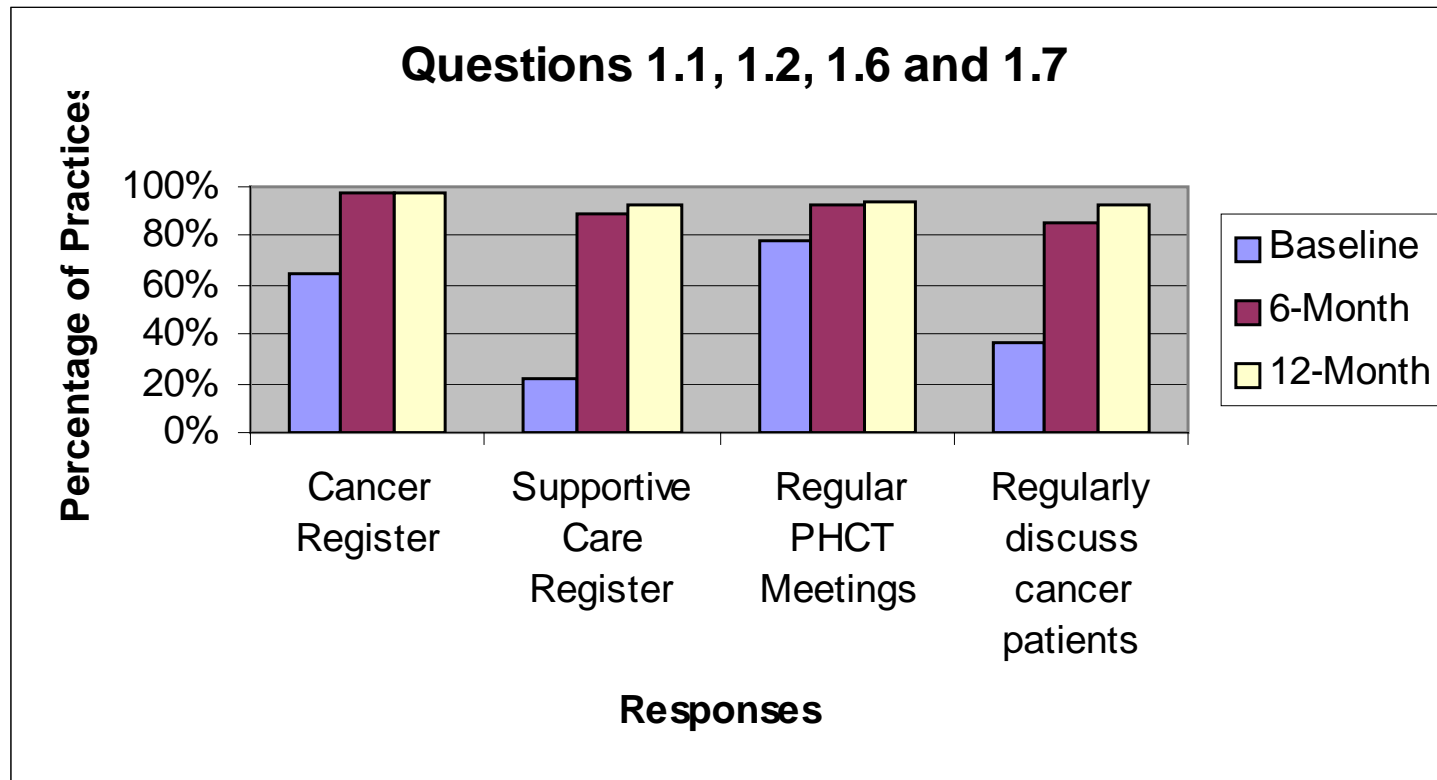
*“I had the physical work, but none of the worry. I genuinely feel that we didn’t do anything wrong.”* Bereaved carer of Patient 5

**Marilyn Kendall and Scott Murray, University of Edinburgh**

**IV - BENEFITS TO HEALTH PROFESSIONALS**

The following graphs compare data provided at baseline, 6 and 12 months by all 172 practices that managed to complete their 12-month questionnaire by October 31, 2006. A number of benefits to primary health care teams have been revealed.

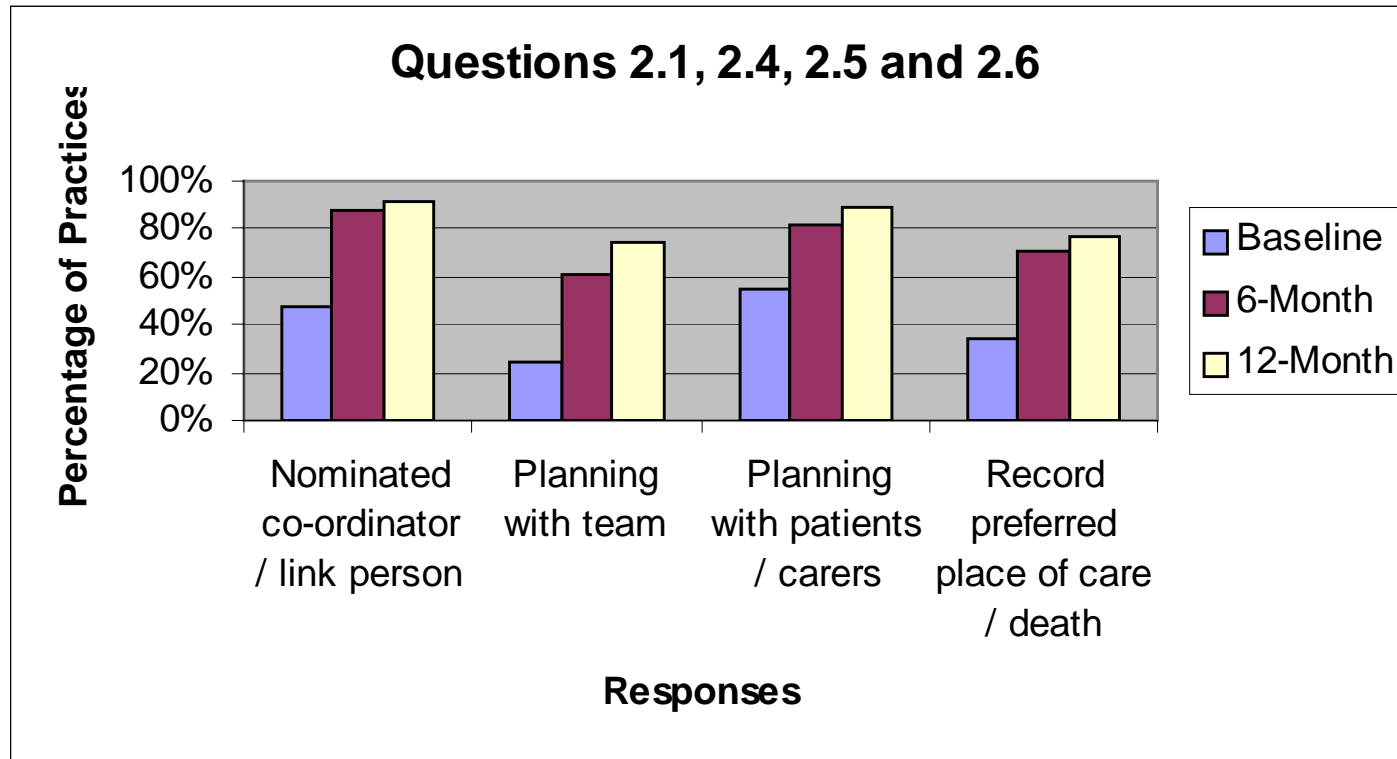
*CI - COMMUNICATION*



*"Enhanced teamwork and communication. Patient care more structured. Good feedback from both patient and carers."*  
 District Nurse in Grampian

Practices have experienced significant improvements surrounding communication, especially in terms of multidisciplinary team meetings.

C2 - CO-ORDINATION

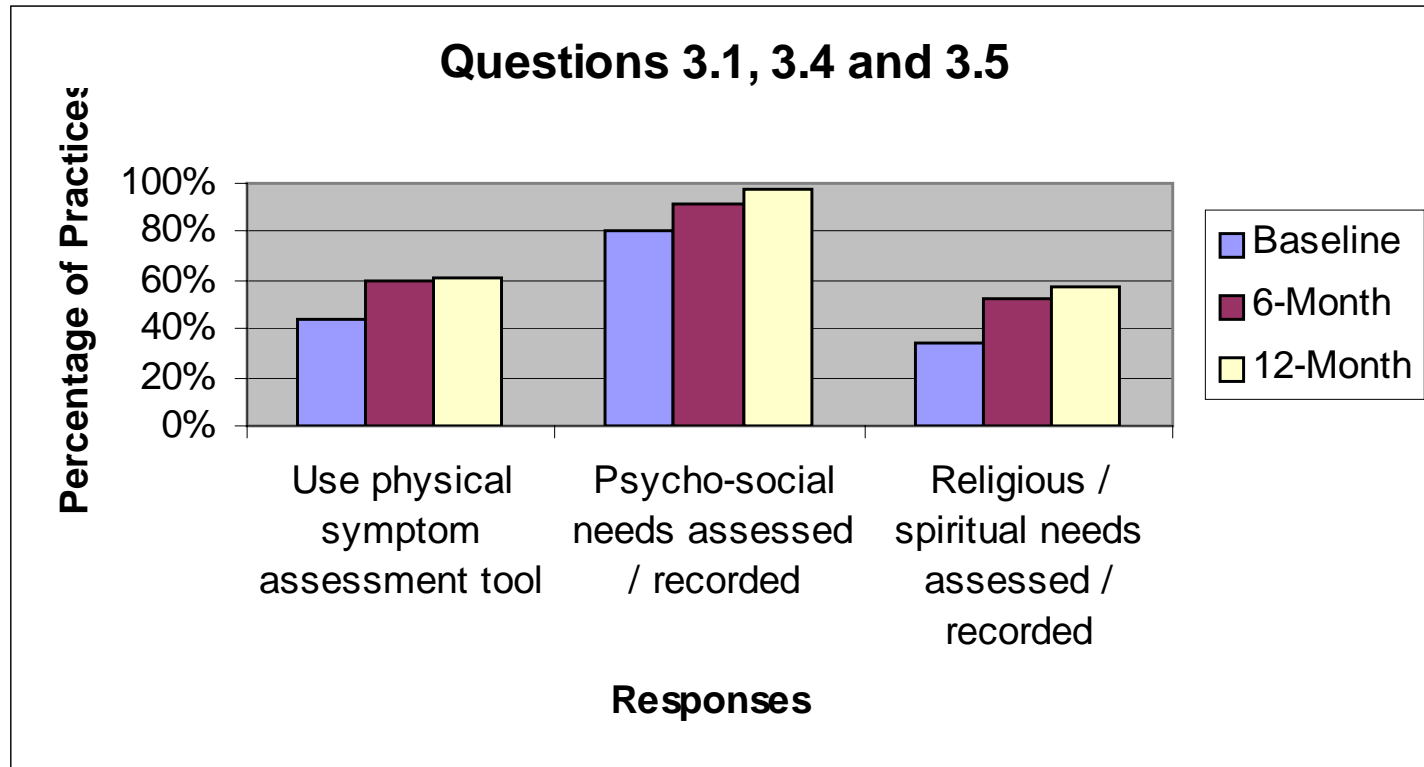


*"Closer working relationships. More knowledge of others roles. Better team work."*  
 District Nurse in Lothian

Supporting data -

'Preferred Place of Death' analysis has revealed that in fact the number of patients dying in their preferred place between completion of the baseline questionnaire and 12-month questionnaire has reduced from 69% to 52%. However, this could be down to the fact that there has been an improvement in recording and more accurate numbers are retrievable at 12 months than are noted at baseline. 34% of the practices are recording patients' preferred place of death at baseline, whereas 77% of practices are recording this at 12 months.

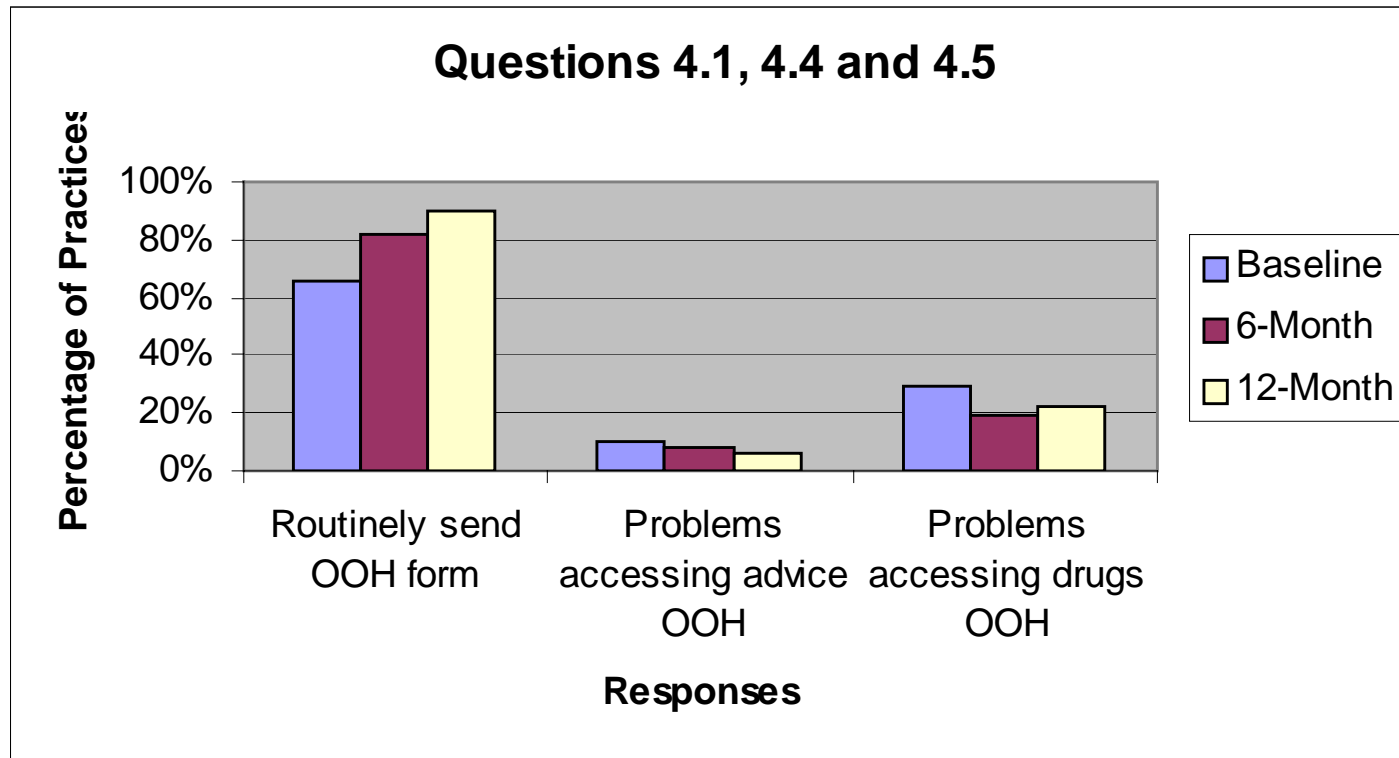
C3 - CONTROL OF SYMPTOMS



*"Improved recording of information including a palliative care register, prompts to offer DS1500, discuss prognosis and preferred place of death."*  
 GP in Forth Valley

The physical symptom assessment tools used by practices include: locally developed pain charts, integrated care pathways, regional pain audit tools, SIGN guidelines, visual analogue scales, body maps, symptom control checklists, hospice guidelines.

C4 - CONTINUITY



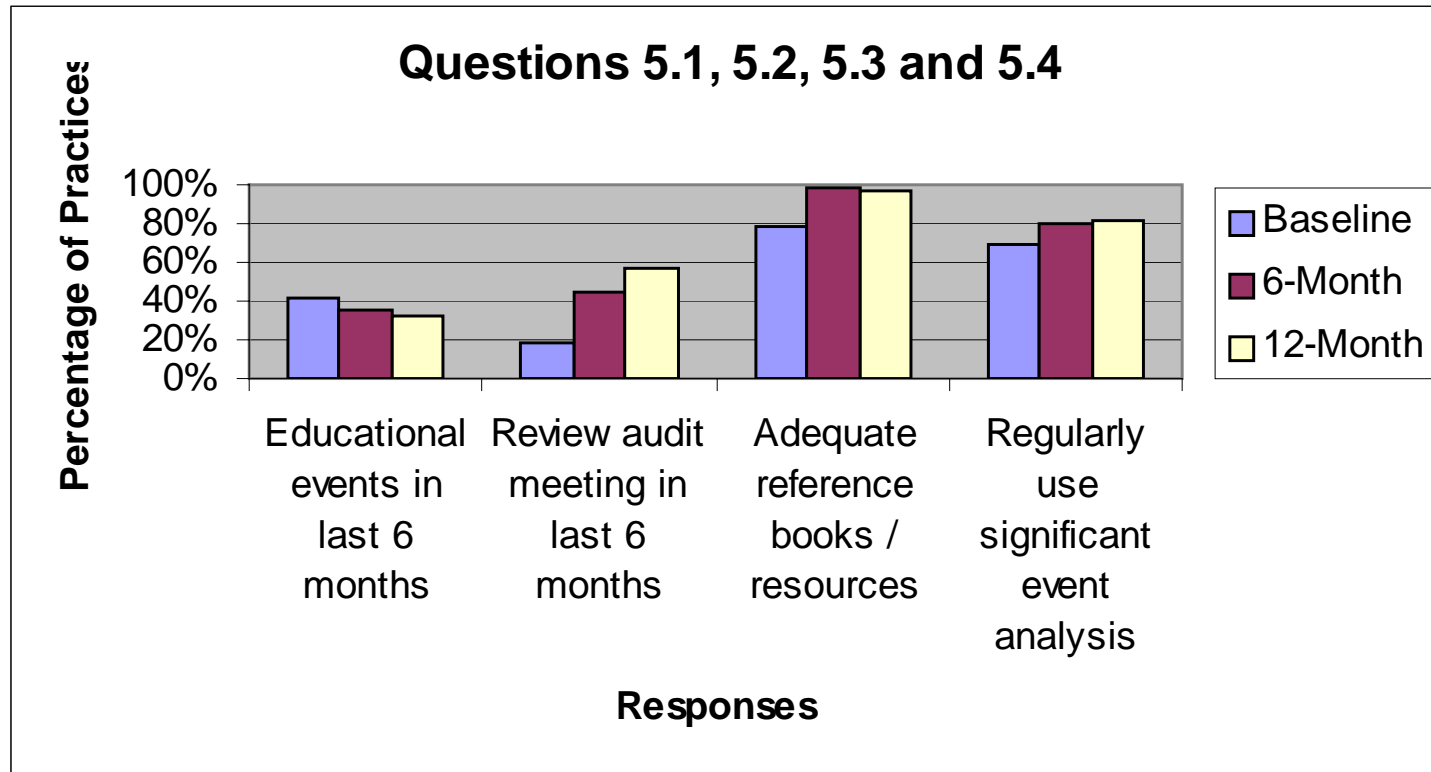
*"More thinking ahead and discussing possible needs. Liaison with consultants increased. Recording of interventions and services in a retrievable format."*

District Nurse in Argyll & Clyde

Supporting data -

The figures for crisis / unplanned events at home and admissions to hospital / hospice have reduced between baseline and 12 months. Analysing responses from the 39 practices that recorded relevant figures **both** at baseline and 12 months, crisis / unplanned events at home came down from 81 to 39 (a reduction of 59%) and crisis / unplanned admissions to hospital / hospice came down from 69 to 49 (a reduction of 29%).

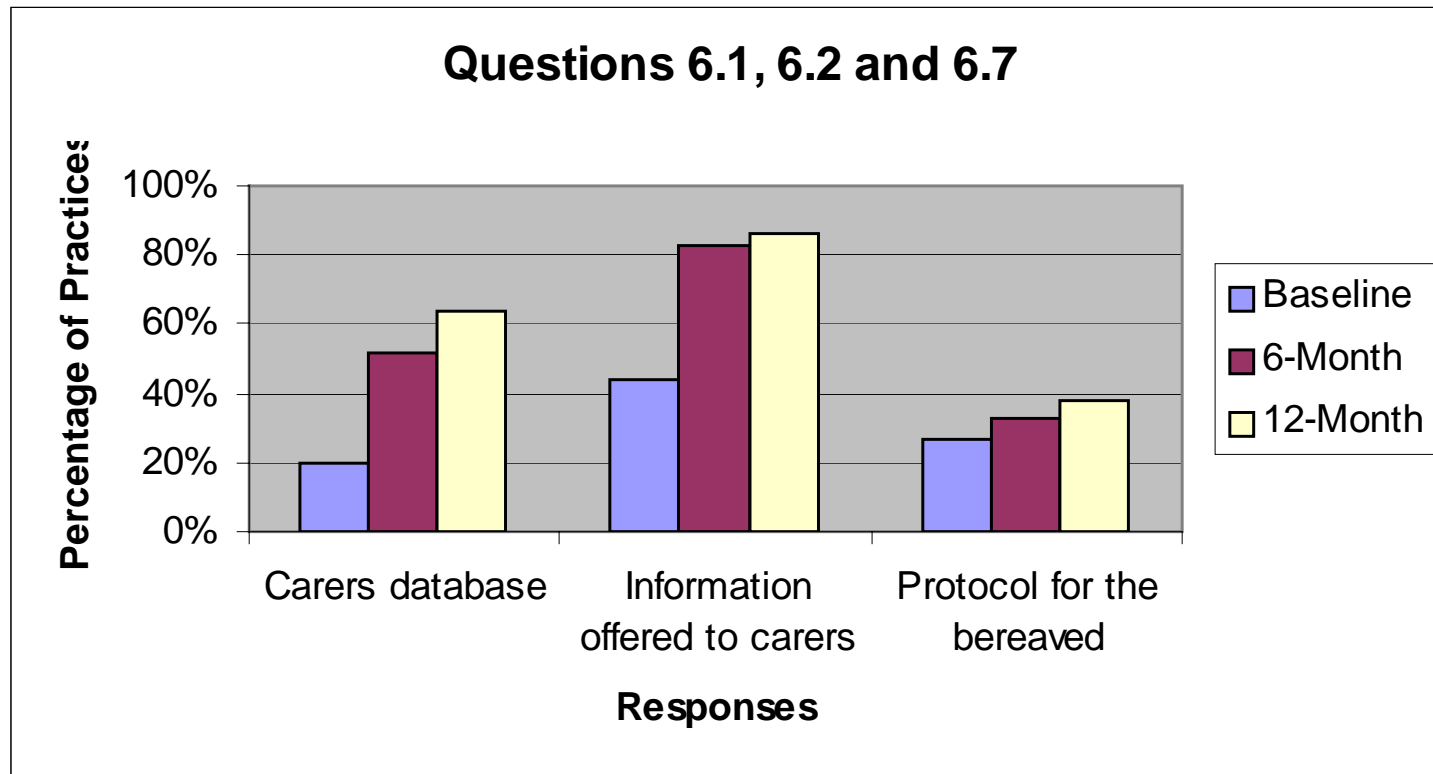
C5 - CONTINUING EDUCATION



*"Adopting the framework has facilitated improved planning of patient care during the final weeks of life. It has resulted in new enthusiasm amongst staff and a thirst for knowledge to improve individual care standards."*  
 District Nurse in Tayside

The number of educational events held in the last six months is shown to reduce from baseline to 12 months as promotion of the GSFS tends to be done in conjunction with an educational event organised by the regional GSFS facilitators at the start of the process. Once practices have taken up the framework they are relied upon to arrange their own educational events to suit their practice's needs.

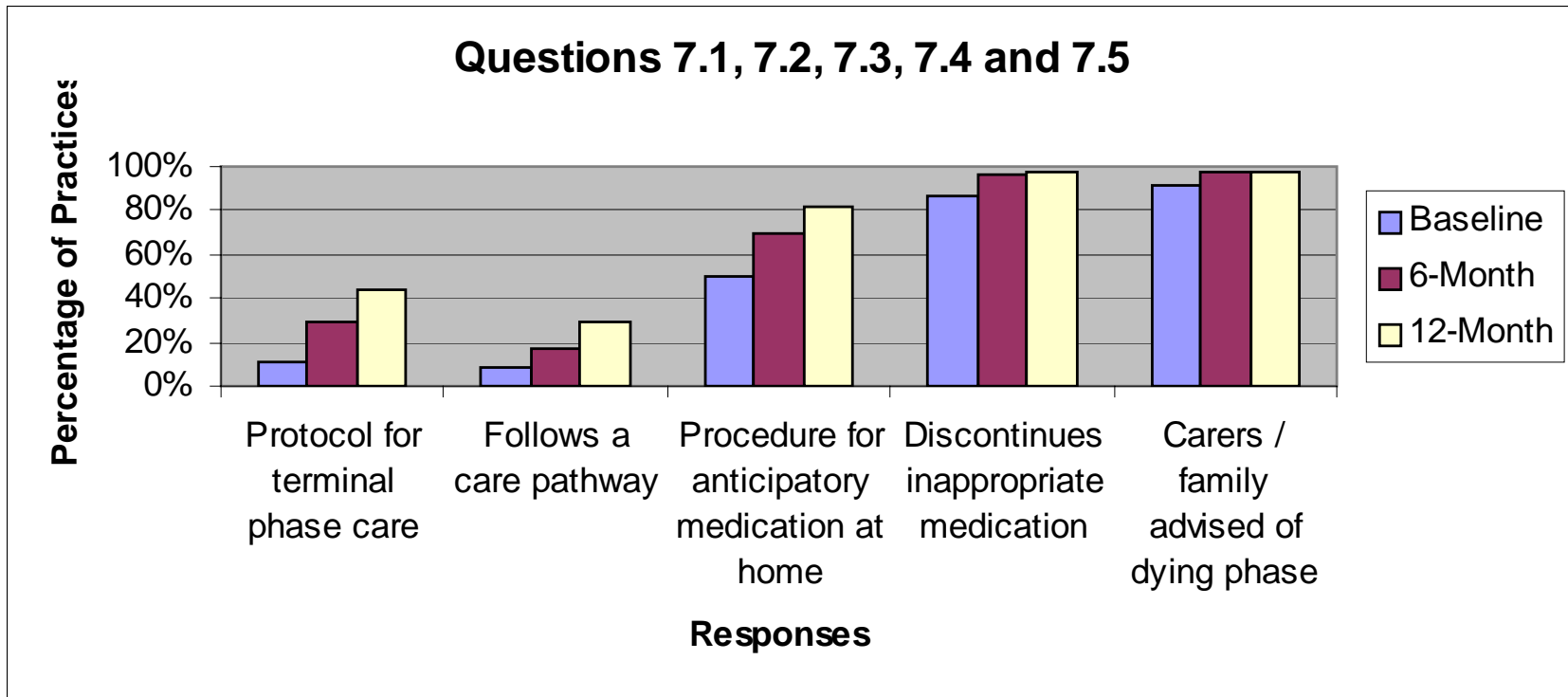
C6 - CARER SUPPORT



*"General increased awareness of the needs of palliative care patients and their carers by all members of PHCT."*  
 District Nurse in Greater Glasgow

Bereavement protocols have been developed in a number of health board areas. These bereavement guidelines have been made available to interested practices throughout the country, along with recommended reading lists.

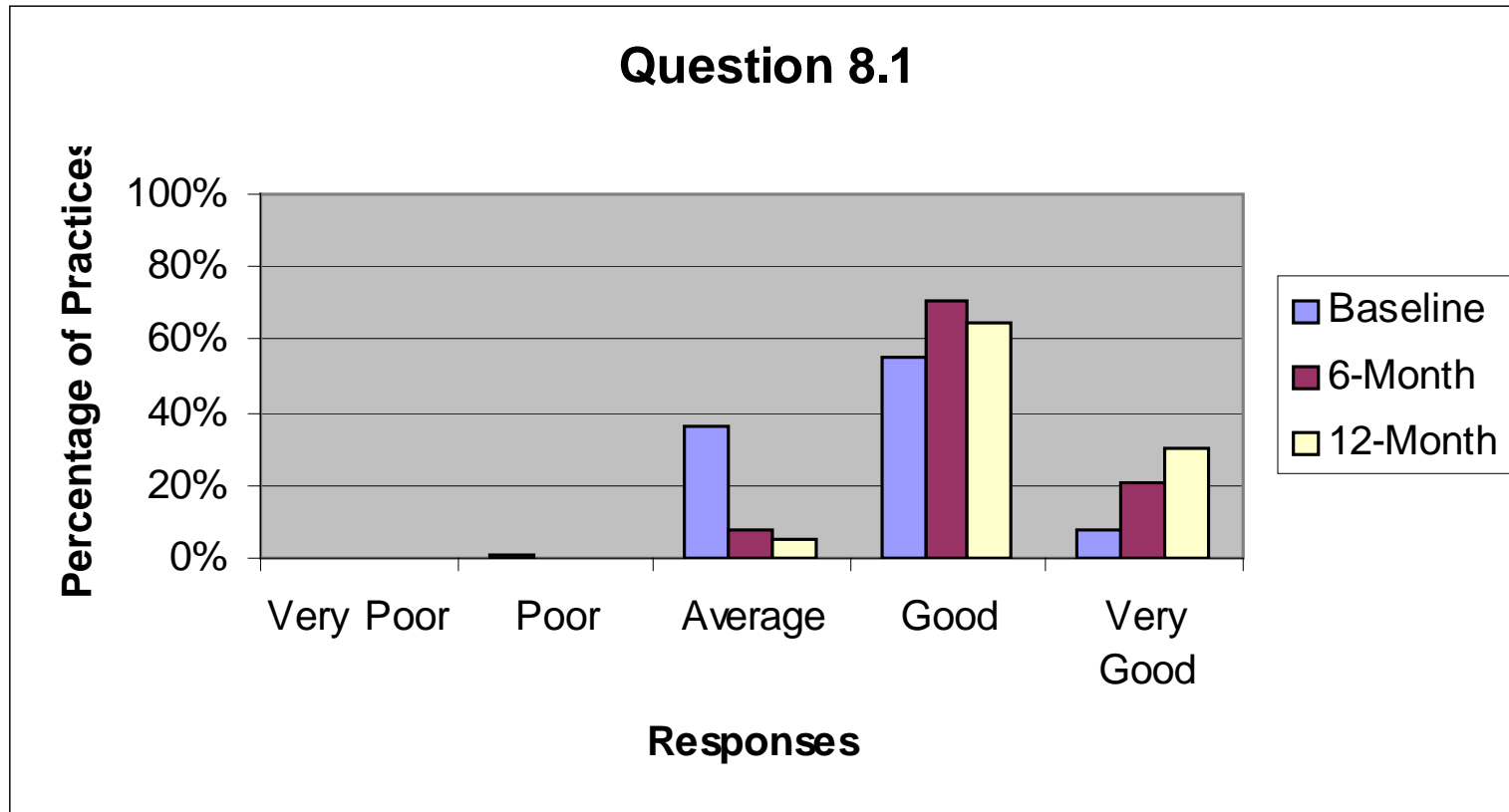
C7 - CARE OF THE DYING



*"More patients able to die in a dignified way at a place of choice. Improved quality of care for terminal patients. Better team work. Fewer crisis calls and emergency admissions."*  
 Practice Manager in Ayrshire & Arran

The 'Liverpool Care Pathway' has been adapted by a number of health board areas to suit their palliative care needs. Other health board areas have found alternative integrated care pathways that they have also adapted. Following a care pathway tends to be an element of the framework that practices leave until after the 12-month mark to explore more fully.

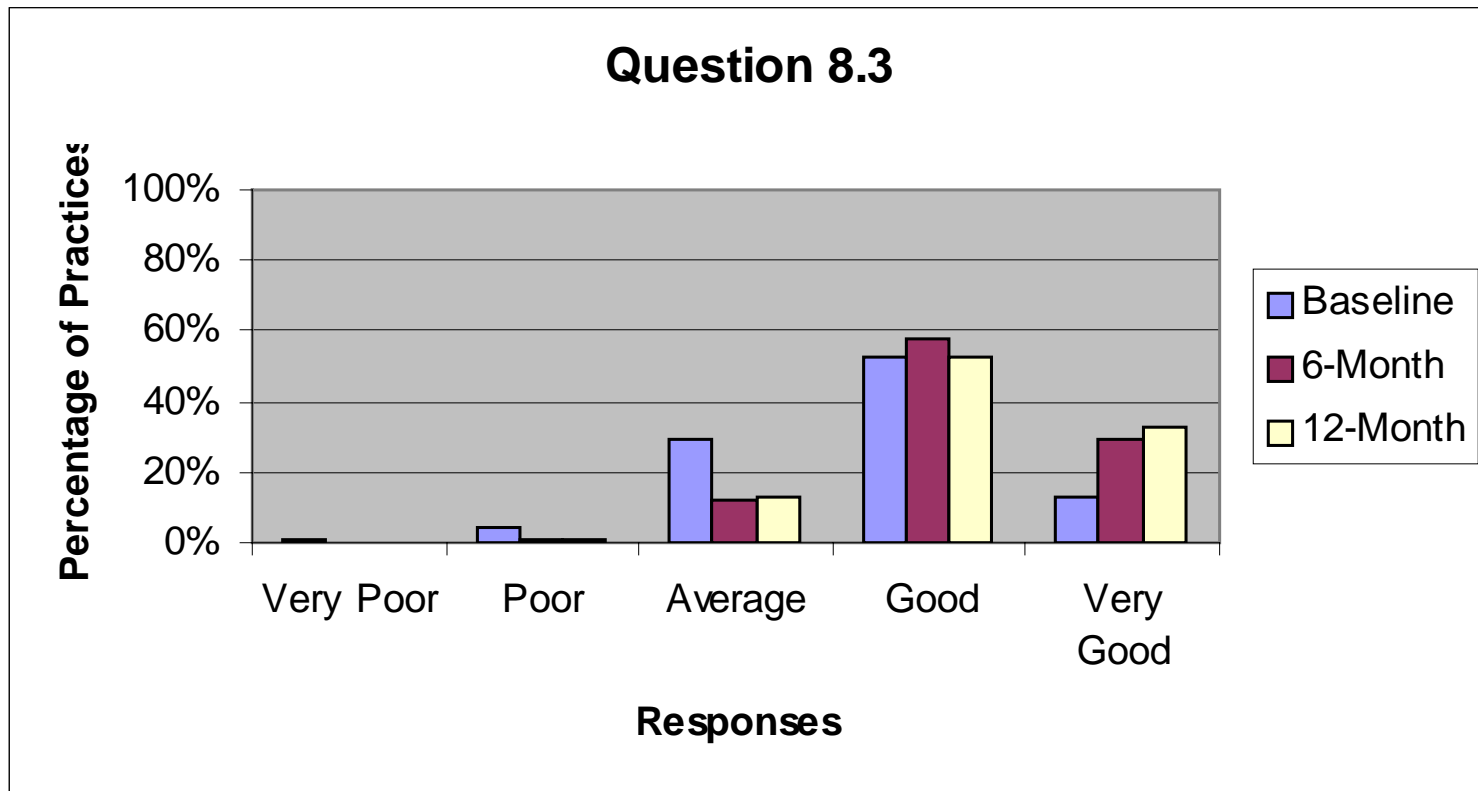
*SELF-RATED QUALITY OF PALLIATIVE CARE*



*"We are now much more confident and competent in supplying a higher standard of care to our patients and carers."*  
 District Nurse in Argyll & Clyde

Self-ratings for the quality of palliative care have improved from baseline to 12 months in that many more practices regard themselves as having 'good' or 'very good' palliative care at 12 months than did at baseline.

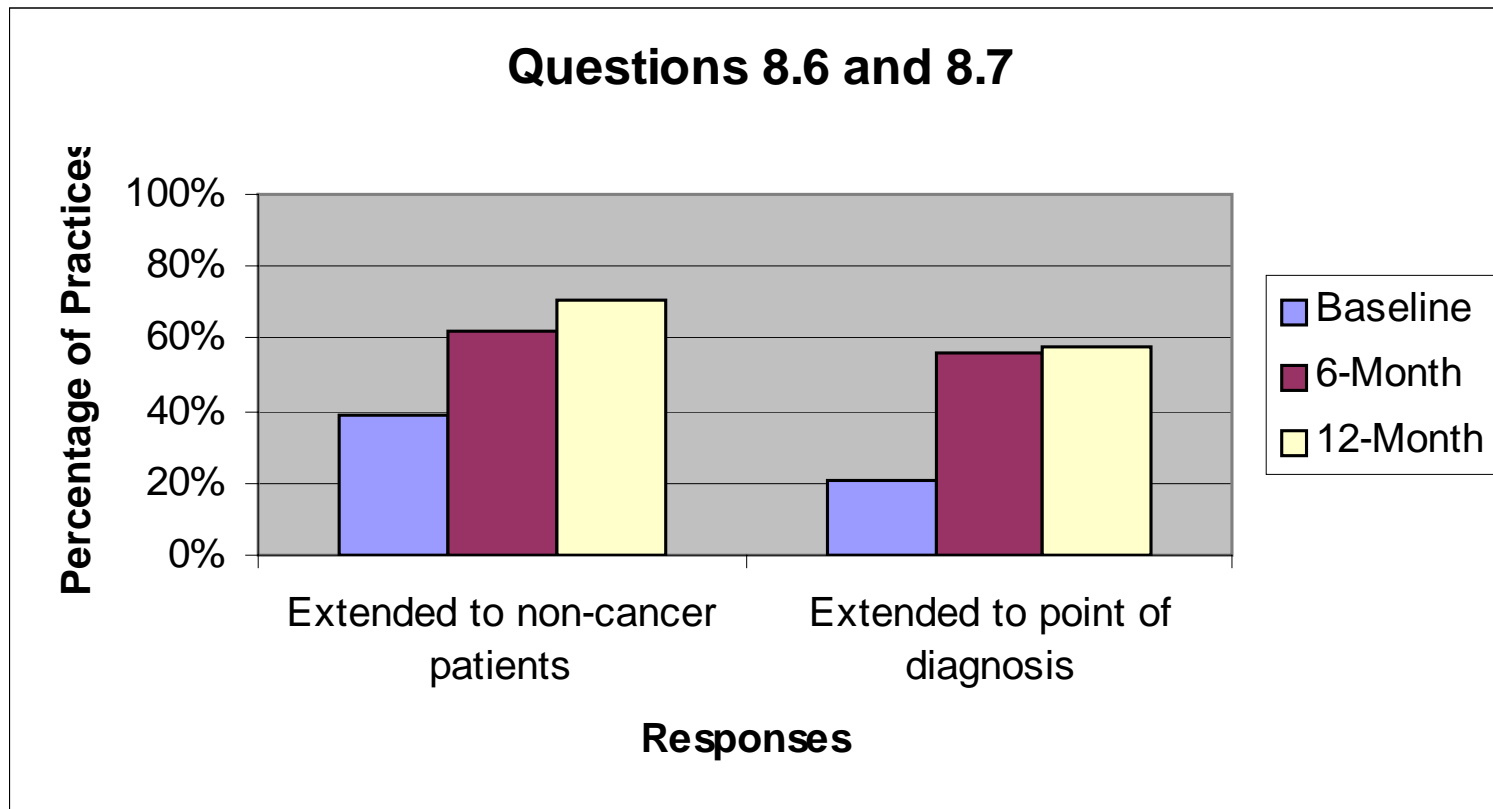
*SELF-RATED CO-WORKING WITH PALLIATIVE CARE SPECIALISTS*



*"Better access to support and advice re patients when required. Assistance in symptom control much improved as support is readily available."*  
 GP in Forth Valley

Co-working with palliative care specialists is considered by practices to be better by the time of their 12-month questionnaire. This is helped by more and more practices inviting specialists along to their regular multidisciplinary team meetings at which all palliative care patients are discussed.

*EXTENSION OF THE GOLD STANDARDS FRAMEWORK*



*"Record all cancer diagnosis. List new cancer diagnosis on register, and patients who are undergoing active treatment as well as palliative and terminal care patients. Register is discussed weekly at meetings."*  
 GP in Tayside

By the 12-month mark, the framework has been extended by 71% of practices to include all palliative care patients. After all, patients with non-malignant diseases have the same care and information needs as cancer patients. They expect equally good symptom management, a multidisciplinary approach to care, continuity of care, as well as support for informal carers.

Within 12 months, the framework has also been extended by 58% of practices to include cancer patients from diagnosis. This has been easier for some practices than others, depending largely on the practice population.

*GAINS AND BENEFITS OF ADOPTING THE GOLD STANDARDS FRAMEWORK*

The following table shows what practices believe they have gained and how they have benefited from adopting the framework:

Q.8.4 What do you hope to gain from GSF? / Q.8.5 How has your practice benefited from GSF?	Number of Responses at Baseline	Number of Responses at 6 Months	Number of Responses at 12 Months
Better care for patients / increased patient satisfaction	<b>58</b>	<b>66</b>	<b>74</b>
Improved service / support for carers and relatives	23	21	25
Improve standards / service	<b>33</b>	<b>32</b>	<b>36</b>
Standardised care / formalised care / provided protocols and guidelines	<b>42</b>	17	18
Developed bereaved protocol / guidelines / service	0	1	2
Developed more proactive / holistic approach / symptom control / anticipatory care	16	18	18
Good practice / sharing information / ideas / pooling knowledge	9	13	8
Improved recording / documentation	20	23	11
Improved / increased teamwork / extended team building	32	<b>34</b>	<b>40</b>
Improved relations with / availability of specialist palliative care team	0	3	1
More co-ordinated / structured / better organised care / integrated care pathways	<b>40</b>	<b>38</b>	<b>31</b>
Primary / secondary care liaison	0	1	0
Improved communication within practice / team / PHCT / with patients and carers	<b>48</b>	<b>69</b>	<b>68</b>
Improved staff education / knowledge / understanding / awareness / development	19	23	26
Improved job satisfaction / morale / motivation / personal development	15	6	5
Increased staff confidence	9	10	6
Able to assess / audit / demonstrate quality of care / check all patients being covered	14	12	11
Better support for those involved in palliative care	10	4	7
Identified and addressed gaps / deficiencies in service / areas for improvement	11	8	6
More patients were able to be cared for / die at home / place of choice	3	5	1
Fewer crisis events and interventions / emergencies	2	2	3
Increased availability / use of resources / information / services for staff / carers / patients	1	1	2
Better continuity of care	9	8	5
Improved OOH communication / service / planning	3	9	5
Regular meetings / protected time to discuss	5	16	15
Early identification / awareness / earlier involvement with patient and family	2	5	5
Focus on / highlighted palliative care / raised profile of palliative care	1	3	1
PHCT interest / initiative / told to take part / peer pressure	0	0	1
No benefit / largely unchanged / not yet in place	0	3	1

*SUMMARY OF MOST SIGNIFICANT CHANGES FOR PRACTICES*

- The practices concur that the Top 5 gains / benefits from the framework are:
  - Better care for patients / increased patient satisfaction
  - Improved communication within practice / team / PHCT / with patients and carers
  - Improved / increased teamwork / extended team building
  - Improve standards / service
  - More co-ordinated / structured / better organised care / integrated care pathways
- Most changes in practice continue to occur between baseline and 6 months - especially with regard to those tasks within the framework that fall under Communication and Co-ordination.
- The rise in regular meetings being held illustrates practices' commitment to the multidisciplinary process.
- The responses from practices under Co-ordination and Continuity, in particular, demonstrate improvements regarding continuous and anticipatory care in the community.
- Working in partnership with carers has become increasingly important in the eyes of practices.
- The use of evidence-based protocols and guidelines helps practices ensure that no patient 'slips through the net'.
- The significant changes, positive gains, and real benefits that practices are experiencing as a result of adopting the Gold Standards Framework are they believe making a difference in palliative care. This is reflected in the number of practices that have extended the framework to include non-cancer patients as well as cancer patients from diagnosis.

*SUMMARY OF WHERE THERE HAS BEEN LEAST CHANGE*

- There has been only a slight increase in the use of physical symptom assessment tools and in the recording of holistic needs.
- There remain a few problems with some practices accessing specialist advice and drugs out of hours.
- In comparison with other task areas within the framework Continuing Education has seen relatively little change.
- Most practices have not tackled the seventh task area Care of the Dying which includes terminal phase protocols and integrated care pathways until the 12-month mark, once other principles of the framework have been firmly embedded.

**V - APPROACH, OBSTACLES, SOLUTIONS, OVER / UNDER PERFORMANCE**

The following tables show how rollout and facilitation of the GSFS in each of the cancer networks / health board areas was approached, what obstacles were encountered, what solutions were devised, and precisely what progress was made.

**WOSCAN**

	<b>Approach</b>	<b>Obstacles</b>	<b>Solutions</b>	<b>Performance</b>
<b>Greater Glasgow</b>	Practice level approach. Two-tiered facilitation. 5 GP & 7 Nurse facilitators.	Involved in pilot. Already established approach. Limited communication. Time to agree funding.	Flexibility required with facilitation structure. Links with WOSCAN Project GP Lead proved useful.	145 out of 214 practices (68%) 'signed up' to the framework.
<b>Forth Valley</b>	Board and practice level approach. 1 GP & 1 Nurse facilitator.	A few reluctant practices to begin with. Timing - GMS contract.	Enthusiastic facilitators persevered, arranged educational events & more.	50 out of 57 practices (88%) 'signed up' to the framework.
<b>Lanarkshire</b>	Practice level approach. 1 GP & 2 Nurse facilitators.	Involved in pilot. GP struggled alone at start. Strong political climate and hospice influence.	Recruitment of the two Nurse facilitators gave a significant boost to the area latterly.	84 out of 100 practices (84%) 'signed up' to the framework.
<b>Ayrshire &amp; Arran</b>	Board and practice level approach. 1 GP & 2 Nurse facilitators.	A few stragglers amongst the practices. Chasing follow up questionnaires.	Facilitators arranged relevant evaluation, well reflected in SEA feedback.	49 out of 61 practices (80%) 'signed up' to the framework.
<b>Argyll &amp; Clyde</b>	Practice level approach. 3 GP & 7 Nurse facilitators.	Three distinct areas within the health board - all with different rollout methods.	Tried to be flexible and supportive with the variety of facilitation.	75 out of 96 practices (78%) 'signed up' to the framework.

## SCAN

	<b>Approach</b>	<b>Obstacles</b>	<b>Solutions</b>	<b>Performance</b>
<b>Lothian</b>	Board and practice level approach. 4 GP & 3 Nurse facilitators.	Timing: GMS / single system working and involvement of CHPs. HR: Agenda For Change.	Time - had to be patient and persevere. A lot of help from senior people required. Recruitment of strong facilitation team (May 2006).	97 out of 128 practices (76%) 'signed up' to the framework.
<b>Fife</b>	Board and practice level approach. 1 GP & 1 Nurse facilitator.	Recruiting facilitators - few candidates available and / or willing. East / west division often unhelpful.	Perseverance and a dedicated facilitation team. Local study days. A lot of support from national project team.	32 out of 58 practices (55%) 'signed up' to the framework.
<b>Borders</b>	Practice level approach. 1 GP & 1 Nurse facilitator.	Previous projects and local initiatives almost deemed the GSF obsolete.	Approached all practices regardless to offer them the chance of adopting the framework.	12 out of 23 practices (52%) 'signed up' to the framework.
<b>Dumfries &amp; Galloway</b>	Board and practice level approach. 1 GP & 1 Nurse facilitator.	Timing - GMS contract. OOH issues. Staff shortages. Rurality. Geography - huge area to cover.	Waited to start in 2005, underlined GSF benefits re OOH, held practice meetings & networking events. Nurse facilitator made it happen.	16 out of 35 practices (46%) 'signed up' to the framework.

## NOSCAN

	<b>Approach</b>	<b>Obstacles</b>	<b>Solutions</b>	<b>Performance</b>
<b>Grampian</b>	Board and practice level approach. 5 GP & 9 Nurse facilitators.	Involved in pilot. Own ideas about facilitation. Limited communication.	Helped having experienced project nurse in area.	69 out of 84 (82%) practices 'signed up' to the framework.
<b>Tayside</b>	Board and practice level approach. 1 GP & 3 Nurse facilitators.	Three distinct areas. 1 facilitator in post before national project team.	National team flexible and supportive with the variety of facilitation.	48 out of 71 (68%) practices 'signed up' to the framework.
<b>Highland</b>	Board and practice level approach. 1 GP & 3 Nurse facilitators.	Time - slow start as palliative care working group set up.	Strong palliative care team. Regular meetings, good communication.	54 out of 70 (77%) practices 'signed up' to the framework.
<b>Shetland</b>	Board and practice level approach. 1 GP & 1 Nurse facilitator.	Rurality. Geography. Previous local initiatives almost deemed the GSF obsolete.	Still struggled to engage practices.	1 out of 10 (10%) practices 'signed up' to the framework.
<b>Orkney</b>	Board and practice level approach. 1 GP & 1 Nurse facilitator.	Rurality. Geography. Previous local initiatives almost deemed the GSF obsolete.	Slow take up, but a few practices eventually engaged.	4 out of 15 (27%) practices 'signed up' to the framework.
<b>Western Isles</b>	Practice level approach. 1 Nurse facilitator.	Rurality. Geography. Finding available facilitator.	Excellent regional facilitation team made it happen.	12 out of 14 (86%) practices 'signed up' to the framework.

## **VI - SUMMARY OF OBSTACLES**

*With regard to agreeing the strategy of the project -*

- Contractual and copyright negotiations, resolution problems.
- Prolonged discussions around project strategy, personalities clashing, securing leadership resources given constraints.
- 'Agenda for Change', different HR processes in each health board area.
- Staff changes, losing project team members, struggle to recruit personnel to national team and facilitator posts.
- Geography, travel, central project office, being a national team without being part of a national infrastructure.

*With regard to evaluation of the project -*

- Confidentiality and informed consent.
- Questionnaires capture only a 'moment in time' and rely on self-assessment.
- Answers provided often depend on who completes the questionnaire - i.e. doctor, nurse, practice manager, PHCT together.
- There are many 'stories' behind the statistics and it can be difficult to capture the full context.
- The data collected is more qualitative than quantitative which is deemed by some to be inadequate in terms of providing 'evidence'.
- It is difficult to measure the impact of the Gold Standards Framework alone as so many other factors influence practice.

*With regard to practices adopting the framework in Scotland -*

- GMS contract, different priorities, lack of time.
- No significant financial incentive.
- Too much paperwork, lack of IT integration.
- Staff shortages, change of staff, changing strategic structures - e.g. LHCCs to CHPs.
- Many GPs will only speak to GPs - although in many cases the nurses were very keen to adopt the framework, they had to wait on agreement from the GP(s) before signing up to the GSFS.
- Some practices claiming they do it all and believing they already incorporate all the tools of the framework into their palliative care.
- Definitions - What is meant by "palliative care", "from diagnosis"? What constitutes a register? Distinction between the two registers?
- Dovetailing the GSFS Project with other initiatives - e.g. SCAN cancer register project, regional pain audit projects.

*With regard to gaining patient and carer feedback -*

- Nurses not comfortable about leaving a home pack, not knowing when best to leave a home pack with the patient (and carer).
- Certain areas using their own home packs and not those from the GSFS.
- Carers not being registered with the same practice as the patient.
- Too costly to provide postage stamp on envelopes addressed to the project office for the return of completed feedback forms.

## **VII - SUMMARY OF SOLUTIONS**

*With regard to agreeing the strategy of the project -*

- Ensured representation of all stakeholders either as full members or as observers on the GSFS Steering Group.
- Shared meeting agendas, minutes and other papers with all relevant people.
- Used an established finance department and department budget to manage the project's spend.
- Amended the GSFS packs to accommodate logos, paperwork, leaflets and other appropriate materials from the stakeholders.
- Issued reports to stakeholders on a quarterly and annual basis as required.

*With regard to evaluation of the project -*

- Self-assessment is a good way of encouraging practices to engage with the project and the questionnaire is often used as an audit and educational tool. It is important to start somewhere and a great deal can be learned from a 'moment in time', particularly when comparisons are made between baseline, 6 and 12 months. As long as it is acknowledged that the questionnaire is self-assessment and there are other influences (e.g. GMS contract, local initiatives) besides the framework on practice the results of the project remain valid.
- Qualitative data is as valid as quantitative data and actually lends itself better to this project. Evaluation of the project has tried to take account of all the stories and ensure that any statistics presented are indeed presented in context.

*With regard to practices adopting the framework in Scotland -*

- By the end of the project 60% of the GSFS Facilitators were nurses, which reflected a change from the first 18 months of the project when 75% of the total number of facilitators were nurses. This change shows how critical it was to have GPs influence GPs latterly.
- 80% of the GSFS Facilitators managed to incorporate facilitation of the framework into their existing roles. Those facilitators who did not incorporate facilitation of the GSFS into current roles were in areas where the project had to advertise for GSFS Facilitators. In these health board areas GSFS facilitation funding was used to pay for specific or separate sessions instead of backfill or extra sessions.
- Although in total 70 GSFS Facilitators were involved in the project, not all of these professionals were facilitating at the same time or throughout the entire 3 years of the project. Facilitation plans had to be wholly flexible in order to accommodate each health board area's different approach to rollout of the GSFS. This meant that some facilitators were involved for only 6 months and others were for all 3 years of the project.
- Any reporting of the data collected has ensured that individuals and practices remain anonymous.

*With regard to gaining patient and carer feedback -*

- In order to make the GSFS home packs more user friendly, facilitators have been encouraged to develop, adapt and add to the packs to ensure that they are entirely relevant to each health board area.
- Patient and carer interviews were introduced towards the end of the project in order to try and counteract the limited amount of patient and carer feedback received via the forms included in the GSFS home packs.

GSFS Final Report

The following table shows what was achieved with regard to GSFS facilitation in order to overcome many of the obstacles and challenges facing the project:

	Actual Number of Practices at 31.10.06	% of Practices Completed the Baseline Questionnaire	Number of GSFS Facilitators			Sustainability	
			Number of Nurse Facilitators	Number of GP Facilitators	Total Number of GSFS Facilitators	Number of Facilitators who link GSFS facilitation in to current post	Number of Facilitators doing only GSFS
<b>Scotland</b>	1036	72%	41	28	<b>70</b>	55	15
<b>NOSCAN</b>	264	71%	17	9	<b>27</b>	27	0
<b>Grampian</b>	84	82%	9	5	<b>14</b>	14	0
<b>Tayside</b>	71	68%	3	1	<b>4</b>	4	0
<b>Highland</b>	70	77%	3	1	<b>4</b>	4	0
<b>Shetland</b>	10	10%	1	1	<b>2</b>	2	0
<b>Orkney</b>	15	27%	1	1	<b>2</b>	2	0
<b>Western Isles</b>	14	86%	1	0	<b>1</b>	1	0
<b>WOSCAN</b>	528	76%	19	11	<b>30</b>	24	6
<b>Greater Glasgow</b>	214	68%	7	5	<b>12</b>	8	4
<b>Forth Valley</b>	57	88%	1	1	<b>2</b>	2	0
<b>Lanarkshire</b>	100	84%	2	1	<b>3</b>	1	2
<b>Ayrshire &amp; Arran</b>	61	80%	2	1	<b>3</b>	3	0
<b>Argyll &amp; Clyde</b>	96	78%	7	3	<b>10</b>	10	0
<b>SCAN</b>	244	64%	6	7	<b>13</b>	4	9
<b>Lothian</b>	128	76%	3	4	<b>7</b>	0	7
<b>Fife</b>	58	55%	1	1	<b>2</b>	0	2
<b>Borders</b>	23	52%	1	1	<b>2</b>	2	0
<b>Dumfries &amp; Galloway</b>	35	46%	1	1	<b>2</b>	2	0

## SECTION 2: THE FUTURE

The following tables indicate how the GSFS will be sustained in each cancer network / health board area going forward.

### NOSCAN

	<b>Plan to sustain GSFS</b>
<b>Grampian</b>	Informal facilitation continuing.
<b>Tayside</b>	Formal facilitation in Angus continuing until January 2008.
<b>Highland</b>	Palliative care network providing informal facilitation.
<b>Shetland</b>	To be determined.
<b>Orkney</b>	Formal facilitation until the end of 2006.
<b>Western Isles</b>	To be determined.

### WOSCAN

	<b>Plan to sustain GSFS</b>
<b>Greater Glasgow</b>	Network being set up to continue facilitation / information sharing.
<b>Forth Valley</b>	Informal facilitation continuing. LCP adaptation underway.
<b>Lanarkshire</b>	Formal facilitation continuing until January 2007.
<b>Ayrshire &amp; Arran</b>	Facilitation continuing. Extending to community hospital and care homes.
<b>Argyll &amp; Clyde</b>	With the health board dissolving, Argyll is linking with Highland and Clyde with Greater Glasgow.

### SCAN

	<b>Plan to sustain GSFS</b>
<b>Lothian</b>	Formal facilitation continuing until the end of 2006. Nurse facilitation ongoing until end of March 2007.
<b>Fife</b>	Formal facilitation until the end of 2006.
<b>Borders</b>	To be determined.
<b>Dumfries &amp; Galloway</b>	Informal facilitation continuing.

## **SECTION 3: LEARNING**

The following bullet points give an idea of lessons learned, e.g. for future national projects, primary care projects.

- The project has naturally entered a different phase for every year of the 3-year project. In the first year there was an element of 'trial and error', particularly around facilitation of the framework. The second year saw a clear process emerge and a good network of facilitators established. The third and final year of the project has really seen the framework take off, especially with practices seeing neighbours adopting and benefiting from the framework and not wishing to miss out. Despite the many frustrations early on, perseverance has paid off with so many health professionals, patients and carers now benefiting from the framework in Scotland.
- If circumstances allow, a project of this nature should be front-loaded in terms of project personnel. That is, the national project team for this project could have been full-time for at least the first year, if not 18 months, in order to establish the office, team, and resource packs; determine project strategy; recruit facilitators; raise awareness of the GSFS throughout the country.
- Ideally, a national project team should be hosted by the health board in which its office / headquarters is located. This would greatly assist the team with regard to HR, payroll, IT and housekeeping issues / queries that arise on an ongoing basis.
- Flexibility is important at all levels, especially when working with different health boards. A balance is required to maintain standards and protocols, but there is a need to be sufficiently flexible too in order to adapt to changing circumstances, scenarios, and personalities.
- It should be emphasised that the statistics from the GSFS Project are complex and therefore must always be presented in context in order to avoid misrepresentation and indeed misinterpretation.
- Service user (patient and carer) consultation and feedback should not be left to chance, but ought to be considered a priority and made an integral part of any evaluation process from the very start of a project.

**Nic Parkins, GSFS Project Manager**

## **SECTION 4: SUMMARY AND RECOMMENDATIONS**

This report has outlined the success of the Gold Standards Framework Scotland Project. The targets of offering the framework to 98% of Scottish general medical practices and a 60% uptake of the framework by those practices have not only been achieved, but to my delight have been exceeded! All those involved in its implementation, the practices themselves, the facilitators, the central project team, the steering group and the funding bodies have acknowledged this success and must be given credit for the achievement. Most importantly the feedback from the patients and carers who have benefited from the project has also been very positive, in particular around being empowered and given the confidence to manage their own care.

A number of outcomes that flow from the work of the GSFS fit well with the strategic aims of "Delivering for Health". In particular with its emphasis on advanced care planning and anticipatory care the adoption of the framework has been shown to reduce the number of crises and unplanned events at home and to reduce the number of emergency hospital admissions. Increasing the levels of satisfaction in terms of the preferred place of care and the preferred place of death allows care to be delivered "as close to home as possible" and exemplifies a patient-centred approach.

The Steering Group and the Project Team therefore agree that it is imperative that this work is sustained and expanded to ensure that all patients requiring support in all community settings in every area of the country are cared for according to the principles laid out in the framework. It is hoped that in time the framework becomes embedded into every practice as routine care. It is also felt that further research is required to guide future developments.

Discussions led by the Scottish Partnership for Palliative Care (SPPC) around end of life care will create strategic recommendations regarding future opportunities and projects for palliative care in Scotland. These discussions have already led to the SPPC taking responsibility for the national co-ordination and data collection of GSFS activity until such time as all those practices signed up to the project have been involved for a minimum of 12 months.

Specifically, further work is required as follows:

- Ongoing support for practices that have adopted the framework, particularly those that have signed up in the last 6–12 months of the project, via SPPC and local palliative care structures
- National co-ordination and data processing of this work to allow ongoing regular feedback to participating practices, Health Boards, CHPs and Cancer Networks, via SPPC
- Expansion of the framework's principles into residential and nursing homes where increasing numbers of the elderly are being cared for to the end of life, possibly via a new project

- Electronic integration of the GSFS dataset, including the OOH Palliative Care Summary into the Emergency Care Summary (ECS), via the GSFS IT sub group
- Research aimed at clarifying appropriate outcome measures and prognostication methods as well as further work to capture the patient and carer experience, via the University of Edinburgh and other research organisations

Recommendations:

- The SEHD should support the national co-ordination and data processing of GSFS activity until all practices that have signed up to the project have been involved for a minimum of 12 months
- Health Boards and CHPs should commit to supporting the ongoing facilitation and data collection required for sustainability
- The SEHD, Health Boards, Palliative Care Managed Clinical Networks and the SPPC should support extension of the framework's principles into Nursing and Care Homes
- The SEHD should support further research into prognostication and outcome measurement with GSFS data and further work around the experiences of patients and carers

**David Millar, GSFS Steering Group Chair**

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### **GSFS Steering Group**

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## GLOSSARY

<b>CHP</b>	Community Health Partnership
<b>DS1500</b>	An application form regarding Disability Living Allowance and Attendance Allowance for those with a life expectancy of 6 months (or less)
<b>ECS</b>	Emergency Care Summary
<b>GMS</b>	General Medical Services
<b>GP</b>	General Practitioner
<b>GSF(S)</b>	Gold Standards Framework (Scotland)
<b>HR</b>	Human Resources
<b>IT</b>	Information Technology
<b>LCP</b>	Liverpool Care Pathway
<b>LHCC</b>	Local Health Care Co-operative
<b>NOSCAN</b>	North of Scotland Cancer Network
<b>OOH</b>	Out of Hours
<b>PHCT</b>	Primary Health Care Team
<b>QOF</b>	Quality Outcomes Framework
<b>SCAN</b>	South East Scotland Cancer Network
<b>SEA</b>	Significant Event Analysis
<b>SEHD</b>	Scottish Executive Health Department
<b>SPPC</b>	Scottish Partnership for Palliative Care
<b>WOSCAN</b>	West of Scotland Cancer Network