

# Improving end-of-life care: a critical review of the Gold Standards Framework in primary care

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## Abstract

The Gold Standards Framework aims to optimize primary palliative care for patients nearing the end of their lives. This paper critically reviews the impact of the Gold Standards Framework since its introduction in 2001 and indicates direction for further research and development. Literature was accessed using specific databases and by contacting subject area specialists. The resultant literature was appraised using an established framework to evaluate healthcare interventions. Fifteen documents were reviewed. The quality of evidence is constrained by methodological limitations, but consistently demonstrates that the Gold Standards Framework improves general practice processes, co-working and the quality of palliative care. However, implementation of the Gold Standards Framework is variable and the direct impact on patients and carers is not known. We conclude that the Gold Standards Framework has considerable potential to improve end-of-life care, but further work is needed to support uptake and consistency of implementation. Additional evidence about patient and carer outcomes will add to existing insights.

## Keywords

end-of-life, Gold Standards Framework, primary care, general practice

## Background

In most countries, end-of-life (EoL) care is provided by generalists.<sup>1,2</sup> Unfortunately, lack of infrastructure to support generalist EoL care is recognized as an international problem and evidence on which to build effective models of service provision is scarce.<sup>2</sup>

In the UK, EoL care is considered an important part of primary care, where General Practitioners (GPs) and District Nurses (DNs) deliver the bulk of care and offer important linkages to specialist services.<sup>1</sup> These practitioners face significant challenges, commonly having limited training in EoL care, few opportunities to extend skills, competing priorities and barriers to inter-professional working.<sup>2</sup> Within this environment, the Gold Standards Framework (GSF)<sup>3</sup> has been an important resource for organizing EoL care.<sup>4–7</sup> This is a comprehensive care programme that supports

practitioners to (i) identify patients in the last years of life; (ii) assess their needs, symptoms and preferences; and (iii) plan care to enable patients to live and die where they choose.<sup>3,8</sup> It does this by crystallizing what ideal care might look like and describing the general processes that are required to achieve this.<sup>8</sup>

The GSF was developed in 2000 as a grass roots initiative by Dr Keri Thomas, a GP with a special interest in palliative care, supported by a multidisciplinary reference group of specialists and generalists.<sup>8</sup> The GSF in primary care has experienced rapid expansion since this time and has been rolled out nationally with the support of the National Health Service, Macmillan and, more recently, the Department of Health End of Life Care Programme. Over half of GP practices in England are now known to have adopted the framework.<sup>9</sup> This may reflect the fact that the GSF is endorsed nationally as a model of good practice,<sup>10,11</sup> and included in the

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**Box 1.** Levels of Gold Standards Framework adoption and associated tasks (adapted from The Gold Standards Framework)<sup>3</sup>**Tasks (the '7 Cs') and evidence required****Communication (C1)**

Maintain a Supportive Care Register to record, plan and monitor patient care, Hold regular primary health care team meetings to discuss patients on register, plan care and review practice.

**Co-ordination (C2)**

Primary Health Care Team to have a nominated co-ordinator for palliative care.

**Control of symptoms (C3)**

Assess, record, discuss and address patient symptoms, problems and concerns (physical, psychological, social, practical and spiritual). Advance Care Planning tools are recommended.

**Continuity (C4)**

Systems and protocols developed to ensure continuity of care delivered by inter-professional teams and out-of-hours providers. Use of handover form and out-of-hours protocol are recommended. Information to be passed to other relevant services (e.g. hospice/oncology department).

**Continued learning (C5)**

Involvement in practice-based or external educational opportunities. Learning to cover clinical, organizational/strategic and interpersonal (e.g. communication skills) aspects of care. Significant Event Analysis and use of other tools for reflective practice (e.g. audit/appraisals) recommended.

**Carer support (C6)**

Practices to work in partnerships with carers and assess/address their needs for emotional, practical and bereavement support. Staff support to be inbuilt to promote teamwork and job satisfaction.

**Care of the Dying (C7)**

Patients in the last days of life (terminal phase) to be cared for appropriately (e.g. by using the minimum protocol or following the Liverpool Care Pathway/ Integrated Care Pathway).

Non-essential interventions and drugs to be stopped. Assessment of comfort measures, psychological and religious/spiritual support, bereavement planning, communication and care after death.

**Level of Adoption\***

**Foundation Level:** C1 and C2

**Higher Level:** C1 to C7 all working together

**Advanced Level:** Measures of consistency, effectiveness, non-cancer equity and use of some Next Stage GSF. Additional tools and developments.

\*These levels of adoption are a relatively recent development in the GSF and were revised in 2009.

Department of Health's End of Life Strategy.<sup>9</sup> The Foundation Level of the GSF (Box 1) has also been incorporated into the Quality and Outcomes Framework (QOF) part of the General Medical Services (GMS) Contract for General Practitioners.<sup>12</sup>

GP practices and community nursing teams are encouraged to implement the GSF through a stepwise approach to enhance *communication, co-ordination, control of symptoms, continuity, continued learning, carer support* and *care of the dying* (see Box 1).<sup>3,8</sup> They are supported to achieve these outcomes through the provision of training workshops, guidance documents, focused tasks and practical tools.<sup>3</sup> This is underpinned by a cascade model of support in which the national GSF team helps local GSF facilitators (appointed by Primary Care Trusts) to support practices.<sup>3</sup>

Ongoing evaluation has been a standard component of the GSF.<sup>3</sup> This has largely involved audits of practice activity using tools that were built into the GSF and undertaken in 10 distinct Phases between 2001 and 2007 (reflecting the staggered enrolment of general practices into the programme).<sup>3</sup> Given recent demands for the evidence base of EoL care to be enhanced,<sup>9</sup> this

paper reviews the findings of these audits, together with other available data, to determine what is known about the impact of the GSF on the organization and quality of care for patients nearing the end of their life. The programme was seen as appropriate when it was established in 2000, and based on the best evidence available.<sup>3</sup> The purpose of this review is therefore to contribute towards an updated evidence base for EoL primary care and to provide useful signposts for future development and research. The work was undertaken in support of a wider initiative to review the GSF in primary care by the National GSF Team (detailed in the *Next Stage GSF 'Going for Gold'*).<sup>13</sup>

**Methods**

A critical review of the literature was undertaken to determine what impact the GSF has had on EoL care within primary care. The aim was to examine the impact of the GSF on:

- (i) General Practice systems and procedures in primary care

- (ii) GSF providers (i.e. the healthcare practitioners delivering the GSF)
- (iii) GSF users (i.e. patients and carers)

The search strategy was performed by accessing relevant published articles using specific electronic databases (Medline; Cumulative Index to Nursing & Allied Health Literature; Social Sciences Citation Index). Search terms included 'Gold Standards Framework' (in the title or abstract). These were supplemented by using a snowballing approach (i.e. the references of each article were examined for earlier papers of interest). Grey literature was also sought from internet resources and contact with the National GSF Team and subject area specialists. The main inclusion criterion for document selection was provision of outcome data regarding implementation of the GSF in primary care. This was to exclude opinion pieces and essays that had no reference to evaluation. Further inclusion criteria included that the documents be written in English and provide sufficient information for assessment. All study designs were included. The titles and abstracts of identified citations were pre-screened according to the selection criteria. The resultant articles were read in full and summarized in relation to their aims, methods, participants, setting, results and conclusions.

The quality appraisal adopted here used a framework for evaluating healthcare interventions proposed by Evans.<sup>14</sup> This accepts that valid evidence can be generated by a range of different methodologies (quantitative and qualitative) and proposes a hierarchy of evidence that incorporates issues of effectiveness, appropriateness and feasibility. From this stance, the best studies not only demonstrate that an intervention works, but also show that it fulfils the needs of its recipients and determines whether it can (and should) be implemented. The framework grades different research designs in relation to each of these criteria and proposes four levels of evidence, from *excellent* which provides the strongest evidence for clinical practice, through *good*, *fair*, and finally *poor*, which is seen as being at serious risk of error or bias.<sup>14</sup> However, while this framework provides information about the relative merits of various research designs, it provides limited guidance about judging the *quality* of research. Therefore, additional references were used to appraise the calibre of quantitative and qualitative studies, respectively.<sup>15,16</sup>

The review was undertaken between November 2008 and June 2009.

## Findings

### Summary of the literature

Twenty-seven documents met the eligibility criteria. These included seven peer-reviewed published articles, eight data reports (in the public domain) summarizing

the impact of a phase of GSF implementation in primary care, and 12 conference abstracts. Key findings are presented in Table 1.<sup>17–31</sup> Conference abstracts are excluded from this table as they replicated findings from the data reports and provided no additional information or insights. Several other documents were also related. For example, the articles by King et al.<sup>19</sup> and Dale et al.<sup>21</sup> were based on earlier data reports.<sup>18,20</sup> However, these were included in the review as they were written for different target audiences and contributed a wider set of insights when taken together with the reports. The articles by Munday et al.<sup>22</sup> and Mahmood-Yousuf et al.<sup>23</sup> were also related. These presented findings from the same study, but described different datasets.

Evidence was available for all 10 Phases of GSF implementation in primary care. This included findings from the initial pilot study<sup>19</sup> (Phase 1) and self-report audit data (pre-and 12-months post-implementation) for 1356 practices participating in the GSF national roll-out (Phases 3–10).<sup>20,21,25–28</sup> Additional data<sup>31</sup> were supplied by a postal survey of EoL care sent to a random sample of general practices ( $n=2096$ ) and qualitative studies that examined the more experiential aspects of the GSF for over 70 practices using semi-structured interviews, focus groups and observational methods with a range of practice staff,<sup>18,19,22,23,29,30</sup> patients<sup>24</sup> and carers.<sup>24</sup>

### Quality of evidence

Examination of the main results from studies reviewed (Table 1) reveals a consistent pattern of themes, with few contradictory findings. These show considerable support for the GSF across all seven domains of EoL care identified in the GSF (Box 1). However, while most studies show good rigour in documentation, appraisal of the data using Evan's framework<sup>14</sup> reveals that the overall quality of evidence is *fair*. Thus, the studies generally provide valid information that allows 'identification of beneficial interventions' and assists in 'prioritizing the research agenda', but employ research methods that may have some degree of error (i.e. descriptive, uncontrolled, non-randomized, with variable response rates). Moreover, most studies have focused on *effectiveness* of the GSF (i.e. the extent to which the framework works as intended), and provide less evaluation of *feasibility* and *appropriateness*.

The main limitation is the lack of 'robust' research designs (e.g. multi-centre randomized controlled trial or controlled observational study), which makes it impossible to determine whether factors other than the GSF (e.g. skill mix, resources, policy changes) have influenced the findings. The audit data were self-reported and thus subject to intentional and unintentional bias and error. The approach used to measure change also showed some inherent difficulties in measuring 'new'

Table 1. Summary of Gold Standards Framework evaluation studies

Details of GSF	Referencels and details	Evaluation details	Outcomes/recommendations
<b>Phase 1: (2001–2)</b> Regional pilot of 12 practices in West Yorkshire.	Thomas K, Noble B. <i>Palliat Med</i> 2007; 21: 49–53. <sup>17</sup> (Peer reviewed journal article)	<b>Aim:</b> To evaluate the first Phase of the GSF in terms of its acceptability to primary care teams, effectiveness in changing practice and professionals' views on the consequences for patient care. <b>Methods/Participants:</b> 12-month prospective comparative study using focus group discussions and questionnaires. Included 12 GSF Practices, 12 non-GSF practices matched on key characteristics and 18 other practices.	Participating practices reported that the GSF was acceptable. They reported more standards successfully achieved than matched practices. Registers, team meetings and co-ordinated care were thought to have improved communication, teamwork, patient identification, assessment and care planning. <b>Key recommendations:</b> Further evaluation of national uptake and further research into clinical outcomes is required.
<b>Phase 2: (2002–3)</b> 76 practices across 18 areas of England, Scotland and Northern Ireland.	King et al. 2003; University of Huddersfield. <sup>18</sup> (Data report in public domain)  King et al. <i>Palliat Med</i> 2005; 19: 619–27. <sup>19</sup> (Peer reviewed journal article based on data given in Report above)	<b>Aim:</b> To examine practitioners' perspectives on the GSF during its first national roll-out. <b>Methods/Participants:</b> Semi-structured telephone interviews to examine practitioners' perspectives of the GSF. Participants (n = 68) included GPs, district nurses and other key stakeholders (e.g. GSF facilitators) recruited from eight GSF practices and eight non-GSF-practices that were matched on key characteristics and located in four geographical regions (in Scotland and the North of England).	Most GSF participants felt that the framework had improved their provision of community palliative care. Their ability to co-ordinate services and communicate with other members of the PHCT was better than that in the non-GSF practices. Practitioners in the GSF practices also felt that care was more consistent, with less risk that patients would 'slip through the net'. However, the GSF was also perceived to involve excessive 'paperwork' and there could be an over-reliance on one person to manage the GSF, leaving it vulnerable if that person should be unable/unwilling to fulfil the role. <b>Key recommendations:</b> GSF should be 'owned' by practice team as a whole. Co-ordinators need to be well supported. Practices should be encouraged to develop the GSF in response to local circumstances. Practices should seek to strengthen links with local specialist palliative care services. Further research should assess direct impact on patients/carers, examine role of the community nurse in palliative care and address issues of sustainability.
<b>Phases 3–6: (2003–6)</b> 1305 practices in England and Northern Ireland (NI).	Dale et al. 2007; Warwick Medical School. <sup>20</sup> (Data report in public domain)  Dale et al. <i>Qual Saf Health Care</i> 2009; 18: 174–180. <sup>21</sup> (Peer reviewed journal article based on data given in Report above)	<b>Aim:</b> To determine the impact of the GSF on primary care practices that implemented the GSF during Phases 3–6. <b>Methods/Participants:</b> Repeated measures audit, with data collected by questionnaires completed at baseline and 12 months. Total: 955 practices (73% response rate) Phase 3: 161/179 (90% response rate) Phase 4: 106/145 (73% response rate)	Few variations in results between Phases 3–6 and therefore findings presented for the entire cohort. Areas of most improvement were co-ordination and communication. At 12 months, 90% practices had a register of patients with palliative care needs, 79% discussed patients at team meetings, 71% recorded advanced care planning with the PHCT, 73% recorded patients' preferred place of death and 52% had audit review meetings. In addition 92% had a practice co-ordinator, 83% regularly sent handover forms to

(continued)

Table 1. Continued

Reference/s and details	Evaluation details	Outcomes/recommendations
	Phase 5: 249/289 (86% response rate) Phase 6: 385/626 (62% response rate) NI data: 54/66 (82% response rate)	out-of-hours providers and 85% had a procedure to use anticipatory medication in the patients' homes. Self-ratings of quality improved for practice's ability to assess, record and address patient's symptoms, support offered to carers, support offered to staff, teamwork, delivery of palliative care to cancer patients and communication with specialist palliative care workers. Total number of processes implemented (max=35) increased from 16 at baseline to 25 at follow-up. Implementation of processes was unrelated to practice size, training status, location or phase of the programme at which they entered. Instead, practices most likely to have formal processes in place to support palliative care at follow-up, were those who had greater self-confidence in the quality of palliative care they provided. <i>Key recommendations:</i> Further research is required to assess impact of GSF in terms of physical, practical and psychological outcomes for patients and their carers. More sensitive measures of quality are required.
Munday et al. <i>Fam Pract</i> 2007: 24: 486–494. <sup>22</sup> (Peer reviewed journal article)	<i>Aim:</i> To explore the effectiveness and sustainability of the implementation of GSF at practice level. <i>Methods/Participants:</i> Qualitative case study analysis 45 semi-structured interviews and observation with GPs (n = 17). District/Macmillan/practice-based nurses (n = 19) and practice managers (n = 9) recruited from 15 purposively sampled practices in three Primary Care Trusts.	Considerable variation between practices in relation to extent of palliative care processes and effectiveness of inter-professional communication. Better performance associated with practices that had clear shared purpose for palliative care with effective communication and efficient formal processes. Poor performance associated with conflicting organizational priorities, strained relationships and lack of formal processes. <i>Key recommendations:</i> More research is required to identify the levers and barriers to achieving consistently high-quality primary palliative care. More sensitive measures of quality required.
Mahmood-Yousuf et al. <i>Br J Gen Pract</i> 2008: 28: 256–263. <sup>23</sup> (Peer reviewed journal article. Presents further findings from above study)	<i>Aim:</i> To investigate the extent to which the framework influences inter-professional relationships and communication, and to compare GPs' and nurses' experiences. <i>Methods/Participants:</i> Qualitative case study analysis using 38 semi-structured interviews with GPs (n = 17), district nurses (n = 16), Macmillan nurses (n = 3) and framework facilitators (n = 2) recruited from 15 purposively sampled practices in three Primary Care Trusts.	Adoption of framework associated with earlier referral of palliative care patients to district nurses. Multidisciplinary meetings were beneficial (for sharing information, discussing management problems etc.), but difficult to arrange and maintain. Nurses preferred formal meetings, whereas GPs preferred ad hoc dialogue. GPs largely maintained control of the mode of multidisciplinary working. Best-functioning teams used range of meeting styles, with relatively non-hierarchical working style. <i>Key recommendations:</i> Further attention should be paid to inter-professional relationship, practice context and levers and barriers to the delivery of successful palliative care.

(continued)

Table 1. Continued

Details of GSF	Reference/s and details	Evaluation details	Outcomes/recommendations
	Kelt et al. <i>End Life Care</i> 2008; 2: 47–53. <sup>24</sup> (Peer reviewed journal article)	<b>Aim:</b> To explore the experiences and views of terminally ill patients and their carers regarding the care they received from practices that had adopted the GSF. <b>Methods/Participants:</b> Qualitative interpretive approach using semi-structured with terminally ill patients ( $n = 7$ ) and carers ( $n = 3$ ) recruited from five GSF practices (that had participated in the case study undertaken by Munday et al.). <sup>22</sup>	Patient priorities generally reflected the aims of the GSF, in that they placed great importance on care that was well organized, and easy and quick to access. Most patients felt that they had received good care. However, care did vary between patients and some had experienced problems accessing health care, (particularly out of hours) and lack of co-ordination (within primary care and across the primary/secondary care interface). <b>Key recommendations:</b> Results are limited by small and non-representative sample (i.e. all patients have malignant conditions, are not in terminal phase, and selected by GPs who are mostly in high-performing GSF practices). Further research is therefore required to look at the experience of a broader range of terminally ill patients and their carers.
<b>Phases 7–10: (2006–7)</b> 1355 practices in England and Northern Ireland (NI).	Shaw et al. Feb 2006; University of Birmingham. <sup>25</sup> (Data report in public domain)  Shaw et al. Nov 2006; University of Birmingham. <sup>26</sup> (Data report in public domain)  Shaw et al. Mar 2007; University of Birmingham. <sup>27</sup> (Data report in public domain)  Shaw et al. Sep 2007; University of Birmingham. <sup>28</sup> (Data report in public domain)	<b>Aim:</b> To determine the impact of the GSF on primary care practices that implemented the GSF during Phase 7–10. <b>Methods/Participants:</b> Repeated measures audit, with data collected by questionnaires completed at baseline and 9 months. Total: 401 practices (30% response rate) Phase 7: 94/262 (36% response rate) Phase 8: 104/332 (32% response rate) Phase 9: 108/405 (27% response rate) Phase 10: 95/356 (26% response rate)	<b>Communication:</b> Significant improvements in proportion of practices that had a supportive care register; monthly meetings, discussed patients. Also increased ratings of co-working with palliative care specialists. <b>Coordination:</b> Significant improvement in proportion that had a nominated co-ordinator; recorded advanced planning/patient's preferred place of care. Slight reductions in proportions of patients who died in hospital, with slight increases in home deaths. However, these changes were statistically significant in Phase 7 only. <b>Control of symptoms:</b> Significant improvement in confidence to assess/manage symptoms and, (in most phases), in the proportion of practices that assessed/recorded/addressed symptoms. Outcome best for physical and psychosocial symptoms, but less optimal for spiritual symptoms. <b>Continuity:</b> Significant improvements in proportion that routinely sent handover forms to out-of-hours providers; had procedure for anticipatory medication; recorded crisis events (with exception of phase 10). <b>Continued learning:</b> Significant increases in proportion of practices that had practice-based education and review meetings and ratings of teamwork generally improved. <b>Carer support:</b> Significant improvements in practices' ratings of the support offered to carers.

(continued)

**Table 1.** Continued

Details of GSF	Reference/s and details	Evaluation details	Outcomes/recommendations
<p><b>Phases Unspecified,</b> but period of data collection relates to Phases 1–6.</p>	<p>Walshe et al. <i>Palliat Med</i> 2008; 22: 736–743.<sup>29</sup> (Peer reviewed journal article)</p>	<p><b>Aim:</b> To explore the anticipation and adoption of the GSF in community palliative care and its impact on referral practices. <b>Methods/Participants:</b> Qualitative case study involving 47 interviews with district nurses (<math>n = 14</math>), GPs (<math>n = 13</math>), allied health professionals (<math>n = 1</math>), managers/commissioners (<math>n = 4</math>), specialist palliative care nurses (<math>n = 10</math>), specialist palliative care doctors (<math>n = 2</math>), specialist allied health professionals (<math>n = 3</math>) recruited from three Primary Care Trusts in the North West England. Trusts varied in extent to which GSF was in use; one had used it for 3 years, one was piloting the GSF in selected practices, one was preparing to pilot the GSF, but had no practices currently using it.</p>	<p><b>Care in the dying phase:</b> Significant increase in proportion of practices using an agreed protocol in the terminal phase. The patient register, communication and out-of-hours protocols were identified as the most important aspects of the GSF. Positive benefits included improved communication between professionals and appropriate anticipatory prescribing. Negative aspects included increasing nursing workload and fewer/late visits for patients. Many respondents highlighted a need for local GSF champions to support sustainability. Slow and incomplete adoption was reported. Respondents reported positive changes to working, but few mentioned patient benefits.</p>
<p><b>Phases Unspecified</b> Study ran between May 2006–Nov 2007</p>	<p>King et al. 2008; University of Huddersfield.<sup>30</sup> (Data report in public domain)</p>	<p><b>Aim:</b> To examine the relationship between community nursing roles and the delivery of primary palliative care, from the perspective of best practice described in the GSF. <b>Methods/Participants:</b> Qualitative interpretivist approach using semi-structured interviews with district nurses (<math>n = 24</math>) community matrons (<math>n = 15</math>) and key stakeholders from other professional/managerial groups (<math>n = 7</math>) recruited from three purposively selected geographical areas.</p>	<p>There were variations in the utilization of the GSF between, and within, the three geographical areas. GP support was considered a crucial factor in uptake of the GSF. GPs were felt to vary widely in their attitudes towards the GSF and resistance to implement it was attributed to perceptions of increased workload. Nurses, however, were very enthusiastic about GSF, although experience of using it varied. Nurses sought to use aspects of the GSF, even without support from the GP, although this limited what could be achieved. The GSF was felt to improve communication and co-ordination, systemize care, and raise awareness of palliative care amongst health and social care professionals. Extension of GSF to non-cancer patients varied, despite a general awareness of need to do so. Authors concluded that quality community palliative care was threatened by poor integration of nursing teams and community matrons and that community matrons require more training in palliative care, including use of the GSF.</p>
<p><b>Phases Unspecified</b> Study ran in 2007</p>	<p>Hughes et al. 2008; University of Sheffield.<sup>31</sup> (Data Report)</p>	<p><b>Aim:</b> To establish the extent to which UK Primary Care has adopted recommended practices in relation to supportive and palliative care of adults</p>	<p>Involvement with the GSF was reported by 61% of practices; 86% used reflective practice or significant event analysis. 82% had procedures for anticipatory medication, 81% had</p>

(continued)

Table 1. Continued

Details of GSF	Reference/s and details	Evaluation details	Outcomes/recommendations
		with cancer and to relate this to participation in previous initiatives, including the GSF. <i>Methods/Participants:</i> Postal questionnaire to assess practice organization, clinical practice and quality was sent to a random sample of one-third of UK general practices. A total of 2096 (60%) of practices responded.	systems for co-ordination of palliative care, 68% had regular meetings on palliative care, 65% had fully operational cancer or palliative care registers, 39% had formal protocols for care of the dying and 24.9% recorded preferred place of care. <i>Key recommendations:</i> Further research is necessary to examine the effect of EoL care on other important clinical outcomes as well as patient and carer experience.

EoL, End of Life; GP, general practitioner; GSF, Gold Standards Framework; PHCT, primary health care team.

ways of working. It was apparent that some of the key audit data requested at baseline when the GSF was introduced was not routinely recorded by practices (e.g. patient's preferred place of care).<sup>20</sup> Thus, while it was easy to show improvements in process (i.e. number of practices 'recording' preferred place of care), it was difficult to quantify change in patient-orientated outcomes (i.e. number of patients actually 'attaining' preferred place of care). The quality of data is also limited by the non-random selection of practices. Practices in the audit studies<sup>20,21,25-28</sup> are self-selecting and most qualitative studies have purposefully sampled participants who are already implementing the GSF.<sup>18,19,22-24,30</sup> The data may therefore disproportionately reflect the views of participants who have particular enthusiasm for the GSF, and non-participation may be associated with practices that were unable to implement the GSF, or reluctant to admit slow progress. Unfortunately, explanations for non-participation were not systematically collected in any studies and it is difficult to determine the extent to which the sampling strategies have biased the findings. Many of the limitations have been acknowledged by the authors and are reflected in their recommendations for future work (Table 1).

Despite these limitations, the data reviewed have a number of strengths. The consistency of results between Phases, the use of multiple research sites, and the positive triangulation of findings between studies using different research designs suggest that, taken as whole, the evidence of the impact of the GSF is likely to have a good level of validity and trustworthiness. Further strength derives from the fact that the evidence is combined from different sources with varying aims. For example, some studies were not primarily aimed at evaluating the GSF and the self-selection of practices in these studies is less likely to have been biased by their experience of the GSF.<sup>29,31</sup> The findings of these studies show considerable concordance with other studies explicitly evaluating the GSF, and thus suggest that the findings are transferable to many primary care practices. Moreover, the range of methodological approaches provides 'breadth' and 'depth'; the audit data give insight into the palliative care activity of practices, and the qualitative studies identify potential levers and barriers to adoption of the GSF. Thus, while there are limits to the inferences that can be made, within this there are a number of statements can be confidently made about the impact of the GSF, which are discussed below.

### *Impact of the GSF on general practice systems and procedures*

*There is considerable engagement with the GSF within primary care:* There has been impressive uptake of the GSF throughout the 10 Phases of



implementation. Evidence of this is further provided by Hughes et al.<sup>31</sup> who sampled a third of UK GPs in 2007 and found that 61.1% were involved with the GSF. Not all practices using the GSF will have contributed to its evaluation. However, those that have are generally optimistic about its introduction into practice<sup>29</sup> and report positive experiences of using the GSF.<sup>17–19,22,23,29,30</sup>

**The GSF represents an effective programme to facilitate the introduction, improvement and consistency of practice-based processes and organizational structures:** Most evidence regarding the GSF is concerned with its impact on practice-based systems and procedures. The greatest benefits appear to be conferred on *co-ordination* and *communication* (Box 1),<sup>17–22,25–31</sup> and nearly all practices participating in the audit studies report having a register of palliative care patients and a nominated co-ordinator after implementing the GSF.<sup>20,22,25–28,31</sup> Most practices also implement multidisciplinary review meetings to discuss their patients and improve their communication with out-of-hours providers.<sup>20,22,25–28,31</sup> As such, the review indicates that most practices are able to achieve the Foundation Level of the GSF (Box 1). Positive changes are also reported for Higher Levels including *control of symptoms, continuity, continued learning, carer support and care in the dying phase*, although the extent of improvement appears more modest.<sup>20,22,25–28,31</sup>

It could be argued that the better improvements of Foundation Level activities (Box 1) may reflect adoption of the GMS contract, which allocates QOF points for the provision of these activities.<sup>12</sup> However, review of the evidence shows that participation in the GSF was good before financial incentives were introduced. Indeed, 1393 practices enrolled in Phases 1–6 of the GSF (Table 1), which were rolled out before QOF points for palliative care were introduced (in 2006).<sup>12</sup> Moreover, Walshe et al.<sup>29</sup> note that participants ‘discussed [the GSF] as a driver for such changes, rather than the contractual changes’ (p. 738). Instead, the evidence suggests that these activities are most improved because they facilitate practice changes in previously problematic areas.<sup>22,23,29,30</sup> Respondents especially value those protocols and tools that facilitate inter-professional communication where there are different levels of expertise to be negotiated, such as out of hours and discussing appropriate anticipatory prescribing.<sup>18,19,29,30</sup>

**The GSF is accessible to most practices, but level of adoption is variable:** The review shows that many practices are able to implement the Foundation Level of the GSF,<sup>17–21,25–31</sup> and are thus entitled to claim their QOF points.<sup>12</sup> However, adoption of the Higher

Levels of care is more variable.<sup>20–22,25–29</sup> Insight into differential adoption is provided by several studies.<sup>18,19,21–23</sup> These suggest that implementation of EoL care processes is influenced more by motivational factors than by practice demographics. Analyses of audit data find no relation between practices’ adoption of the GSF and their size, training status, location, or phase of programme entered.<sup>20,21</sup> Instead, adoption appears to be related to the diverse ways the GSF is perceived, operationalized and sustained. For some, the GSF represents an extremely welcome framework that offers practical guidance to improve care.<sup>18,19,22</sup> For others it is seen as nothing more than an administrative task to enhance record-keeping.<sup>18,19,29,30</sup> In part, these differential views appear to be influenced by practices’ existing engagement with EoL care and the implications for workload. For some practices, the GSF formalizes existing high standards of care, but for others it involves new ways of working. However, variations in adoption may also stem from the flexibility of the GSF, which allows users to adapt it to their own circumstances. The inherent strengths and weakness of this approach have been highlighted in several of the reviewed documents.<sup>18,19,22,29</sup> On a positive note, flexibility serves to increase ‘ownership’ of the GSF by letting practices set their own pace of adoption (in accordance with their own needs and resources) and allowing them to introduce locally based initiatives to meet the desired outcomes. On a more negative note, ‘flexibility makes it easier to “drift” into disengagement from the framework’<sup>19</sup> and may engender a ‘cherry-picking’ approach, with practices avoiding the more challenging aspects of the GSF. Differential adoption of the GSF also has serious implications for evaluating the GSF, as the intervention being measured is not necessarily the same between practices, nor static over time. However, while the successes of the GSF may be difficult to pin down precisely, what can be said is that the GSF is associated with improved practice procedures and those using the GSF credit these improvements to their adoption of the framework.

**Implementation of the GSF requires effective change management processes and sufficient resourcing:** Several studies provide evidence that the GSF can be maintained past its initial phase of adoption.<sup>22,23,29</sup> However, not all practices are able to consolidate their initial gains.<sup>22,29</sup> Attempts to delineate the factors that influence sustainability indicate that practices who perform best at their 12-month evaluations generally continue to perform well.<sup>22</sup> According to Munday et al.<sup>22</sup> high-performing practices are characterized by efficient formal processes and supportive relationships across the Primary Health Care Team (PHCT). This includes having a

shared vision, mutual respect, commitment, consistency, inclusive decision-making and effective organization. In contrast, low performance is associated with conflicting organizational priorities, strained relationships, an absence of leadership and fluctuating involvement of specialist team.<sup>22</sup>

The role of GSF Champions is particularly highlighted. Several studies suggest that successful implementation requires an influential champion to provide initial impetus and drive forward the spread of the GSF.<sup>18,19,23,29,30</sup> The professional background of the champion seems less important than their motivational and leadership skills.<sup>18</sup> This said, Walshe et al.<sup>29</sup> note that while the GSF is aimed at supporting generalists in EoL care, it may be led by specialists and sustainability is likely to depend upon local involvement and ownership.<sup>22,29</sup>

### *Impact of the GSF on providers*

**Practitioners are more aware of EoL issues and more confident in meeting patients' needs:** Practitioners clearly value using the GSF and feel that it has improved the quality of the EoL care they provide.<sup>17-19,22,23,29,30</sup> They report greater awareness of EoL issues (e.g. the need to establish preferred place of care/death),<sup>18,19</sup> and report improved quality in their practice's ability to manage patients' symptoms, support carers, support staff, work as an effective team, and communicate with specialist palliative care workers.<sup>18-21,25-28</sup>

**The GSF facilitates multi-disciplinary working and communication, but can be undermined by lack of shared commitment:** Practitioners are most emphatic about the positive impact of the GSF on multi-disciplinary working and communication,<sup>17-19,22,23,29,30</sup> and highlight these aspects of the GSF more than others (e.g. symptom control, education, audit of direct impact on patient care or the guidance/documents) associated with GSF.<sup>29</sup> EoL care depends on inter-disciplinary working, but such working has inherent difficulties.<sup>2</sup> Walshe et al.<sup>29</sup> therefore suggest that the GSF may provide 'a way of addressing such issues in a more positive way, framed by the "authority" of the GSF' (p. 742). This appears particularly true for nurses, who perceived the GSF as improving their previously difficult communication with GPs, facilitating their ability to arrange both formal and informal meetings.<sup>29</sup> The review certainly indicates variations in how different professionals view the GSF and the influence they have upon it. The role of the GP appears particularly powerful.<sup>18,19,23,29,30</sup> On the whole, GPs report a positive experience of the GSF, and their active championing

is associated with greater enthusiasm for the GSF within the practice and a greater likelihood that it is embedded into routine practice.<sup>18,19,23,29,30</sup> However their support can be lacking and some DNs and Specialist Nurses report difficulties accessing GPs for advice and achieving co-operation.<sup>23</sup> The reasons for their resistance are not well understood, although some respondents attribute it to a perception that the GSF will involve an increased workload.<sup>30</sup> It is also possible that GPs have a wider range of competing priorities.<sup>30</sup> There is also evidence of differing communication styles, with GPs preferring informal communication and DNs preferring more formal meetings.<sup>23</sup> Where GP involvement was difficult or absent, it seems that some district nursing teams still attempted to implement the GSF, but its impact was limited by lack of GP engagement. In these cases the DNs are more likely to rely on input from Macmillan nurses, although opportunities for joint working not always possible (due to reduced staffing levels).<sup>18,19</sup> King et al.<sup>30</sup> also highlight the potentially valuable role of community matrons, who are likely to have good case management skills, expertise in long-term conditions, and a wide network of health and social agencies. However, their ability to work within the GSF framework is currently threatened by their lack of integration with district nursing teams and lack of palliative care training.<sup>30</sup>

**The GSF requires adequate resources:** Several studies highlight workload issues. These are generally associated with co-ordination of the GSF,<sup>18,19,23,29</sup> and it is notable that few complaints are evident regarding the increased demands on care (i.e. increased patient contact, attendance of multi-disciplinary review meetings, etc.), which are commonly described as welcome developments. Co-ordination of the GSF is usually undertaken by a Nurse.<sup>18,19,30</sup> However, it seems that at least some of these are 'volunteered' for the role due to their experience or interest in palliative care.<sup>18,19</sup> The Co-ordinators are responsible for most of the administrative tasks of the GSF and often assume a wider role in disseminating information amongst the PHCT.<sup>18</sup> While many find the role interesting and fulfilling, it is also associated with excessive workload.<sup>18,19,23,29</sup> In part, this is attributed to the amount of paperwork involved, but is also blamed on having to meet competing clinical commitments, and having to complete audit questionnaires.<sup>18,19</sup> The personal consequences of this are role dissatisfaction, and reduced time for education events.<sup>19</sup> In earlier studies it was noted, 'Excessive reliance on one person to keep GSF on track – especially a District Nurse managing this work alongside their normal caseload – leaves the framework vulnerable if that person should become unable or unwilling to fulfil this role' (p. 625).<sup>19</sup>

Indeed, there is some evidence that changes in District Nursing staff can lead to failure of previously effective practices and relationships.<sup>22</sup>

### *Impact of the GSF on patients and carers*

Only one study provided direct evidence of the impact of the GSF on patients and carers,<sup>24</sup> and while this showed good concordance between user priorities and the aims of the GSF, the quality of data is poor within Evan's framework.<sup>14</sup> However, those using the GSF certainly believe that it improves EoL care for patients (and carers to a lesser degree). These include increased equity in care (because provision is more consistent between practices), greater access to specialist support (through earlier identification and referral of patients) and more responsive care (through individualized needs assessment and anticipatory care planning).<sup>18,19,23</sup> The audit data also indicate potential improvements in patient choice, in that practices were more likely to record patients' preferred places of care and death following implementation of the GSF.<sup>20,21,25–28</sup> While this in itself is not sufficient to make choice a reality, it is an important pre-requisite that signals to both staff and patients that choice is an important aspect of patient rights and puts this explicitly within their care plan.

However, all inferences regarding patient and carer outcomes must be made with caution. The extent to which the perceptions of practitioners reflect those of patients is not known. It is also important to acknowledge that improved processes are not synonymous with improved patient outcomes. For example, early identification and referral of patients does not necessarily mean they are followed-up,<sup>29</sup> and the data provide no indication of whether patients' preferences are met. Moreover, the audits include little demographic or clinical data about patients, and the extent to which the GSF has supported all groups equally is therefore hard to ascertain. King et al.<sup>30</sup> also note limited extension of the GSF to non-cancer patients, despite increased awareness that the GSF applies to non-cancer diagnoses.<sup>18,19</sup>

## **Discussion**

Evaluation of the use of the GSF in primary care has provided recurrent evidence that it represents an effective programme to *facilitate* the introduction, improvement and consistency of practice-based processes and organizational structures to support EoL care. Participating practices also report improvements in the quality of the care delivered to patients and their carers.

Recent data shows that most practices in England fulfil enough of the GSF criteria to claim their QOF points for palliative care.<sup>32</sup> Indeed, achievement figures for 2008/09 show that practices claimed an average of

93% points available to them.<sup>32</sup> However, this review shows considerable variation in the ways these processes are utilized, leading some to question the validity of this current approach.<sup>22</sup> As Munday et al.<sup>22</sup> state, 'Processes, such as palliative care registers, may be sophisticated or superficial; however, it is the way that they are utilized that affects the quality of care.' (p. 493). Recognition of such debates by the National GSF Team has informed the Next Stage Review ('Going for Gold')<sup>13</sup> referred to at the outset of this paper. This sets out ongoing enhancement of the models of support for primary care, including a new training programme for PCHTs, 'Going for Gold', leading to possible quality recognition and accreditation. This augments existing resources which include support for Primary Care Trust GSF facilitators/EoL care leads, a dedicated section of the GSF website for practices and a national helpdesk.

Evaluation will continue to be a key aspect of the GSF. This will include ongoing evaluation as an integral part of the uptake of the GSF programme. It is hoped that this will be enhanced by the introduction of online evaluation systems such as the After Death Analysis (ADA) tool.<sup>33</sup> This is a much shorter instrument than previous evaluation tools that focuses on key outcome measures and therefore reduces the response burden highlighted as an area of dissatisfaction in earlier Phases of the GSF programme.<sup>18</sup> The ADA tool should contribute towards an understanding of the link between using the GSF programme and patient outcomes (e.g. whether patients died in their preferred place of death, and the number of hospital bed days), and a national spot check for all patient deaths in the primary care sector is currently underway. It has to be noted, however, that the ADA tool still evaluates the GSF from the perspectives of the service 'providers'. It will be important to include the views of patients and carers if we are to ensure that the GSF reflects their priorities for care and meets their expectations.

### *Next steps*

Developing and evaluating complex interventions such as the GSF presents methodological and practical challenges, but the steady accrual of evidence since 2001 suggests that the GSF is beneficial in supporting EoL care. While these challenges are not uncommon in service development work, they do mean that we cannot quantify the full extent of the GSF's impact or pinpoint the factors that make it effective in everyday practice. Given the increasing interest in developing appropriate guidance for evaluating complex interventions and the increased demand for outcome measures that can inform future commissioning of EoL care, further evaluation may benefit from following evaluation

frameworks such as that developed by the Medical Research Council.<sup>34</sup> These suggest a non-linear approach to evaluation and identify a number of appropriate research designs to assess effectiveness, measure outcomes and understand processes. Within this, there is particular need to include greater focus on patient outcome, economic evaluation, equity and sustainability.

Economic evaluation will certainly be an increasingly important aspect of healthcare evaluation, and will be central to decision making in the context of limited health resources.<sup>35,36</sup> The approach chosen is likely to depend upon whether the viewpoint is that of planners, budgeters, monitors, clinicians or patients. However, while service commissioners may be most interested in costs savings related to the GSF (e.g. reducing hospital admissions and deaths) compared with alternative approaches, the commitment to patient rights and the drive towards patient consumerism will mean that it is also important to assess indirect and intangible costs (e.g. greater carer burden). Key areas of care requested by patients towards the end of their lives include being listened to, dying in preferred place and support for carers,<sup>9</sup> and while these form the building blocks on which the GSF is based, there is a need to assess the extent to which the GSF increases alignment with advanced care planning.

Finally, data are required to understand how to best achieve sustainability and equity. Evaluation of the GSF has been largely limited to the 12 months post implementation. As such, little is known about the extent to which practices adopt the framework longitudinally, and what factors promote or hinder long-term success. It will be important to further delineate which factors influence variation between the practices. These are likely to be multi-factorial and include (i) system characteristics (e.g. how the GSF is initially introduced, how it is supported in the short and long term, incentives etc), (ii) practice characteristics (e.g. size, resources, patient population, organizational structures) and (iii) individual characteristics (motivation, expectations, skills of practice staff and facilitators). Determining how best to address variation in these will be critical if all practices are to have the same opportunity to implement the GSF, and is key to ensuring equity for patients. The plan to introduce a GSF national accreditation programme<sup>13</sup> will go some way towards providing the context in which such longitudinal work can be undertaken.

## Conclusion

The evidence presented here suggests the GSF has made a significant contribution to EoL care and has helped to shape the current national approach to best practice in primary care. The GSF has also received

international interest, and work is ongoing to determine the applicability of the GSF outside the UK and to facilitate appropriate uptake.

Within the UK, the GSF has certainly raised the profile of patients' and carers' needs and given clinicians tools to meet these. Practices have displayed a willingness to implement the GSF and have shown considerable ability to achieve this. The roll out of the Next Stage of the GSF in Primary Care (2009)<sup>13</sup> is drawing upon the evidence presented here and lessons learned by practitioners in the implementation of GSF since 2000. The National GSF Team is focusing on consistency and effectiveness of use of the GSF, and the introduction of a new quality improvement training programme ('Going for Gold')<sup>13</sup> and new audit tools (ADA)<sup>18</sup> are to be welcomed as a means of standardizing and monitoring both. However, the long-term success of the GSF will need more than good will. Sufficient investment will be needed,<sup>7</sup> and this will be increasingly true as populations become disproportionately elderly. Whilst the multi-million funding allocated to the EoL Care Programme<sup>9</sup> is a positive start, it will require further commitment if all individuals are to live well to the end of their lives and die in a place of their choosing. Given the chance to do so, the evidence is that the GSF programme can make a positive contribution to achieving optimal EoL care.

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