

**Implementation and impact of the Gold Standards Framework in  
community palliative care: a qualitative study of three Primary Care Trusts**

**Running title: Gold Standards Framework and community palliative care**

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## **Abstract**

The Gold Standards Framework (GSF) has been widely adopted within UK general practices, yet there is little understanding of its impact on the provision of community palliative care services. This study presents data on the anticipation and adoption of the GSF within three Primary Care Trusts in North West England. Forty seven interviews were conducted with generalist and specialist palliative and primary care professionals. Important aspects of the GSF identified were the patient register, communication and out of hours protocols. Positive benefits to professionals included improved communication between professionals, and appropriate anticipatory prescribing. Negative aspects included increased nursing workload and the possibility of fewer or later visits for patients. Many respondents believed the GSF needed local champions to be sustainable. Slow or incomplete adoption was reported. The GSF was recognised as important because it facilitated changes to previously difficult aspects of work between professionals, but few respondents reported direct benefits to patient care.

## Introduction

Community palliative care services such as general practitioners (GPs), district nurses and specialist palliative care professionals are important to patients, carers, and the professionals who provide care<sup>1:2</sup>. Much of the care in the UK that patients receive in their last year of life is provided by such professionals within general practice and community nursing teams<sup>3</sup>. The Gold Standards Framework (GSF) in primary care is a locally based system which aims to optimise the organisation and quality of care for patients and carers in the last year of life<sup>4</sup>. It is a framework of tools, tasks and resources used within general practices and community nursing teams, and as such it requires these teams to work together and agree to its local implementation. The GSF can be implemented at different levels, and the expectations for general practices within each level are described in box 1.

< Insert box 1 around here >

Piloted in 2001, a third of general practices and their associated community teams in England are now using the framework<sup>5</sup>. This rapid expansion may be because it is endorsed by national palliative and supportive care guidance<sup>6</sup>, Department of Health policy<sup>7</sup>, included as a core element of the NHS end of life care programme<sup>5</sup>, and because some elements of the GSF have been reflected

in the new General Medical Service general practice contracts (such as a register of cancer patients required from 2003, and the palliative care patients register as part of the 2006 Quality and Outcomes Framework)<sup>8</sup>. Despite this rapid expansion of the GSF programme, there is little formal evaluation of its impact on professional practice or patient outcomes. Whilst the GSF programme has commissioned ongoing evaluations, to date only the results of the phase one and two evaluations have been fully published<sup>9;10</sup>, with limited results reported from phases 3 – 6<sup>11</sup>. These studies report the introduction of palliative care registers, more coordination and consistency in care and more information given to carers<sup>9;11</sup>. Practices performing best at their 12 month evaluations generally continue to perform well<sup>12</sup>. However, some GSF administration was felt to be onerous<sup>10;13</sup>, and considerable variation exists in how and to what extent palliative care registers and meetings are achieved<sup>12</sup>. Variation in the experiences and perceptions of practices about the impact of the GSF on inter-professional communication have also been reported<sup>13</sup>.

The evidence base supporting the widespread adoption of the GSF is therefore considerably less widespread and robust than might be expected for such a well supported initiative. Completed studies are affected by some methodological issues such as non-random selection of practices<sup>9;10</sup>, and purposeful sampling of those who are already involved in GSF implementation, who may therefore have particular enthusiasm for the GSF<sup>10;12</sup>. Further research into the adoption, use

and outcomes of the GSF is required to understand its use and impact in practice.

## **Methods**

### **A Research approach**

The data reported within this paper are drawn from a larger study of referrals within community palliative care services. The methods and overall findings of this study are reported elsewhere<sup>14;15</sup>. In brief, this study used a qualitative case study strategy to describe the reasons given for and influences on the referral decisions made by healthcare professionals providing community general and specialist palliative care services. The case was defined as 'those services providing community general and specialist palliative care to patients registered or residing within a specified Primary Care Trust', and three Primary Care Trusts in North West England participated. Trusts were chosen against a range of criteria such as size, demography, and palliative care provision, but in addition each Primary Care Trust differed in the extent to which the GSF was in use. One Trust (A) was an early adopter of the GSF, and had been using it within most general practices for about 3 years at the time of data collection. The second Trust (B) was piloting the GSF in selected practices, and the third (C) was preparing to pilot the GSF, but no practices were currently using the GSF. Whilst a range of data sources (interviews with patients and professionals, documentary

analysis, observation) were chosen within the Trusts to capture the complex, context dependent process of referrals <sup>16;17</sup>, this paper only reports the data from interviews with health professionals relating to their contextual discussions of their anticipation and adoption of the GSF and its impact on referral practices. It does not report patient data, nor non-interview data as these did not contribute to the findings in this area.

## **A Participants**

Both general and specialist palliative care professionals were invited to participate. Potential participants were either purposefully invited because they were identified as knowledgeable informants (about any aspects of palliative care, not specifically the GSF) during early visits to sites, but most were arbitrarily selected from staff lists of relevant professionals working in the area. Participants were asked to suggest other potential informants. Letters of invitation were sent to selected professionals, with non-responders followed up by letter and telephone by the first author (CW).

## **A Data collection**

A topic guide was prepared for each interview, which was open-ended and conversational in style (Box 2). The GSF was mentioned spontaneously by respondents as an influence on referral practices. Interviews lasted between 50

and 90 minutes. Interviews were tape-recorded and fully transcribed, supported by detailed field notes about settings, reflections on the interviews, non-verbal cues etc. Data were collected over 20 months, in 2003 – 2005.

< Insert Box 2 around here >

Research ethics approval was obtained from three local research ethics committees and the University of Manchester ethics committee. Research governance approval was also obtained from the Primary Care Trusts, and other organisations, such as hospices, employing participants. Participants gave written consent to their participation.

## **A Data analysis**

Framework analysis techniques were used firstly to analyse the data within the cases, and then to facilitate cross case pattern matching<sup>18</sup>. Following familiarisation with the data an initial thematic framework was developed, which developed iteratively during analysis. Data for each case study were then arrayed in thematic charts, and similarities and differences between and across cases examined.

Multiple techniques were used to enhance the rigour of the study, including the use of multiple sources of evidence, supervision including independent analysis



of data, peer debriefing using a research advisory group (consisting of the authors, a GP, district nurse, specialist palliative care nurse, and academics with subject expertise), and the use of ample data extracts to support developing themes<sup>17</sup>.

## **Results**

Forty seven interviews with health care professionals were conducted. Every respondent in the 'early adopter' case discussed the use of the GSF. Many other respondents discussed the use, or anticipated use of the GSF, particularly those who were piloting its use, or involved in its implementation (Table 1). The GSF also formed the context for many of the issues raised within the interviews.

< Insert table 1 around here >

Some of this discussion related to actual or potential influences on referral practices, others used the respondent led opportunities within the interviews to discuss the GSF and its impact in more general terms. It is these data that are reported here. Case study identifiers have been removed from data extracts to maintain the anonymity of those who participated.

### **A Description of the GSF**

Three elements appeared core to respondents understanding and use of the GSF: (i) a palliative care patient register, (ii) structures to enhance communication; (iii) protocols for out of hours communication, including anticipatory prescribing:

*'It's a supportive register of cancer patients.'* (DN2)

*'To sort of get the register, and you know, keep track of things, and just provide a better service.'* (GP1)

*'It's a way of improving communication within the primary care team, so we know what's going on with the patient, so we anticipate problems ... so one of the main things we do in the team is talk and put anticipatory drugs in their house.'* (DN3)

A focus on these elements may be unsurprising as this study was conducted during the adoption of the 2004 GMS contract, which allocated points for the provision of a cancer register. However, the GSF was discussed as the driver for such changes, rather than the contractual changes. These descriptions appear to fulfil elements of level 1 and 2 adoption of the GSF (box 1), with respondents rarely referring to other elements of the GSF. Its impact on communication and protocol use appeared to be consistently and particularly valued by respondents, and are now discussed further.

## **A Communication**

Communication between healthcare professionals in provision of palliative care is known to be difficult<sup>19</sup>. For practices anticipating introduction of GSF, inter-professional communication was a key area in which they anticipated improvements:

*'We're going to have monthly meetings where we're all going to talk about it [GSF]... and looking at plans for patients, and being proactive about plans, and communicating them throughout.'* (GP5)

For those practices where the GSF had been in use for some time, respondents described improvements in inter-professional communication, with nurses using positive language to emphasise the importance of such changes to them:

*'We have got the Gold Standards Framework, which has just revolutionised care. It's made a difference for patients, it's made a difference for communication between the health care professionals.'* (SN3)

Nurses highlighted the positive impact the GSF had on their previously difficult communication with general practitioners:

*'I think that's [GSF] made a lot of difference [to talking to GPs], only because it's made us communicate better, because we do talk about cancer patients now.'* (DN4)

*'It's made them [district nurses] certainly engage in significant conversations with the GPs about patients obviously to facilitate care. One of the other things that it has thrown up is the significant event analysis, that if things have gone wrong they have actually now got to go and sit back with their GPs and with their colleagues and say we need to talk this over, now this certainly never happened before.'* (SN3)

For nurses, the GSF appeared to provide structure, authority and permission to arrange both formal meetings with general practitioners and informal communication opportunities that facilitated the achievement of professional and patient care objectives.

## **A Protocols**

For respondents not yet using the GSF, many anticipated benefits which would address current difficulties they had with out of hours and anticipatory prescribing protocols:

*'Its got handover forms for out of hours, its about linking in with drugs and the appropriate, so that the doctors know the appropriate drugs as well, and so its education for GPs.'* (SN9)

Whilst the GSF was seen as the driver for these changes, such protocols were also developed and maintained to address the many concurrent changes to out of hours medical provision:

*'And then we have the huge impact of the new GP contract, so at 6pm that is it, you will not get a patient to any GP, people are understandably loathe to make modifications to either heavy duty medications that we use, and that has had a huge impact.'*  
(GP2)

The adoption of such policies and protocols, anticipated to improve care, were often the first issues to be tackled in the pilot sites, perhaps to address contract issues, but also identified as an 'easy win' to encourage enthusiasm for other elements of the framework:

*'We have looked back through our questionnaire to see what the easy things are that we can change now. For example, we didn't have a palliative care handover form.'* (DN8)

These issues continued to be important to those who had been using the GSF for some time:

*'I: So, comparing what is happening now with the GSF to what happened before you started working with the GSF, what sort of differences are there?*

*DN5: Huge differences.*

*I: In what way?*

*DN5: 'Anticipatory drugs get put in the house, GPs instigate those and that didn't happen before so I mean that is really good.'* (DN5)

The GSF appears to provide the structure and impetus to implement changes in systems and ways of working that were known to be sub-optimal, but about which respondents appeared to have struggled to make changes prior to GSF adoption.

### **A Workload and timing of referrals and care**

Negative aspects of the GSF were described, particularly adverse effects on workloads and the care pathways that patients followed. These effects were particularly noted by the nurses:

*'It's [GSF] increased district nurses workload, because everything is thrown at us as district nurses. Its imperative district nurses are on board as they are key to palliative care, but the coordination work is extra.'* (DN2)

Systems were described to discuss patients within the primary health care team, to ensure that people were aware of patients, and that they were referred at an 'appropriate' time. The impact of the framework depended on the views of the individual professionals to the referral and their role with that patient. Either such referrals were responded to:

*'But now under the Gold Standards Framework we get involved much earlier on, so when a patient is confirmed as having a palliative care diagnosis we get informed ... so we make contact with the patient and then we go out to do an assessment.'* (DN5)

Or were left pending:

*'So we get to know about patients, um, at diagnosis really, and we haven't got the staff at the moment to be able to follow them all up.'* (DN4)

It seems that protocols which meant that staff were always aware of patients, could mean that patients were visited less often. In the non-GSF Trust, nursing staff worked hard to facilitate referrals, maintaining patient contact to ensure awareness of patient progress. In the GSF Trust, because they were party to regular discussions about patients, some staff did not feel that they had to visit, but could wait until the patients had explicit 'nursing needs':

*'The ones who are on the active list, we look at how things may well progress, we tell the patients what we're doing, they know we talk about them, get their permission, and then I will have contact with them ideally. I don't always, but they know who I am, they're given my contact number, and as soon as they start to deteriorate I ask them to let me know.'* (DN3)

This finding differs from one evaluation of the GSF, which suggested that such protocols would prevent patients from 'falling through the net'<sup>10</sup>. Whilst patients may not 'fall through the net' because professionals were unaware of their existence, it may not necessarily be the case that they are receiving more or earlier care from some practitioners. It is not possible to comment on whether



different visiting patterns were appropriate to needs, or impacted positively or negatively on patient outcomes, if at all. GPs in the study did not comment on the GSF affecting their workload, perhaps indicating that the main 'work' involved in the GSF is done by nursing staff.

### **A Coordinating and leading the GSF**

Whilst the GSF is conceived as a framework to facilitate practice based generalist palliative care, the impetus to commence using the GSF appeared led by specialist palliative care practitioners:

*'[palliative care consultant] sort of recruited them [pilot GSF GP practice] and their district nurses'. (DN7)*

*'I think its [specialist nurse] and the Macmillan nurses really. I think they are going to have to be heavily involved [in setting up the GSF].' (KI3)*

If its use is initiated by specialists, then there may be future issues with ownership and sustainability. Respondents recognized that for the initiative to be sustainable it needed both a champion who could provide the initial impetus for implementation in an area, and also local involvement and ownership of the project:

*'I don't know if anybody has come forward, you see, to engage with it ... I think one of the downsides of those sorts of things is they often depend on somebody as the driver.'*(GP9)

## **A Flexibility**

A number of respondents commented on incomplete or slow adoption of the GSF:

*'If they're not having the meetings they're not really doing GSF, they're signed up to it but the system is stalled really, because this, if this surgery is signed up to the GSF, but I think that is probably one of the first meetings that we've had. Um, and they, they've not even got the, the list of patients drawn up, but they're down as one of those [practices using the GSF]. I think in some of them it's running absolutely fabulously, but I do wonder if that's the minority rather than the majority really.'*  
(SN4)

Respondents reported picking certain elements of the GSF to follow to meet their particular circumstances, or adapting how the GSF is used over time. In this quote the GPs were seen as being increasingly 'busy' with the new contract, such that other protocols, like the GSF were amended to suit that circumstance:

*'you just adapt it to suit yourself, and here they don't want the meetings, we have twice weekly meetings in-house educational, clinical sessions, and we didn't want another meeting to talk about palliative care, so we developed instead, and obviously we talk, but we developed a mechanism of a memo going round every two weeks that highlights the key issues for the principal patients, and that goes to everybody, nurses and doctors and everybody.'* (SN1)

These comments raise issues about what is meant by adoption of the GSF by teams, and how its success is measured. It was clear that even where GSF use had been reported for several years, some practices were either stalled in its adoption, or at a very early stage of its use. In addition, those who reported positively on its use commented on its flexible adoption, raising questions of how far the framework can be adopted and still be identified as 'gold standards'.

## **Discussion and conclusions**

The limitations of this study are that it was not originally conceived as a study of the GSF. It was set up to investigate the influences on referrals within community palliative care services, and hence may not have fully explored all aspects of the framework that were important to participants. However, this can be perceived as

a strength, as most participants were therefore not deliberately selected because of their interest in the GSF, and made comments about the GSF spontaneously because aspects of the GSF were important to or affected their practice. It is probable that these data are typical of many GSF users, rather than those who have initiated or championed its use.

Respondents in this study repeatedly singled out particular features of the GSF for comment. Aspects considered important included protocols for out of hours working and anticipatory prescribing and the facilitation of communication between professionals. Other aspects of the GSF were rarely mentioned, such as a focus on symptom control, education, audit or indeed direct impact on patient care. Whilst this may be an artefact of the fact that studying the GSF was not the primary focus of this research, this appears unlikely as the aspects discussed appear no more or less relevant to the focus of the research than those not discussed, and are also highlighted in the work of others<sup>10;12</sup>. It may be that these were valued aspects of the GSF for nurses in particular because they facilitated practice changes in previously problematic areas and to GPs because they matched changes to their contract.

Most research indicates that care protocols and guidelines are difficult to implement in practice<sup>20;21</sup>, and yet in this situation health care professionals appeared to welcome particular protocols associated with the GSF. It is notable that some guidelines and documentation associated with the GSF (for example

patient assessment documentation) were not mentioned by respondents, and no evidence of their use in practice was noted during the comprehensive collection of assessment documentation which accompanied this study. The valued protocols and guidelines appeared to be those which facilitated inter-professional communication in areas previously found to be difficult, or where there may be different levels of expertise to be negotiated such as communication out of hours<sup>22;23</sup>, and discussing appropriate anticipatory prescribing, particularly related to syringe driver medication<sup>24</sup>. Changes to the GP contract with the initial introduction of a cancer register, and the subsequent introduction of the quality and outcomes framework with a target of keeping a palliative care register, and regular communication meetings<sup>8</sup>, is likely to have ensured that attention has been focused on their inception and maintenance.

It was clear from the wider study from which this report is drawn that communication between members of the primary healthcare team could be problematic, and this is supported by the research of others<sup>14;15;25</sup>. Nurses in particular frequently reported overcoming such communication and practice issues by bypassing difficult professionals, and it may be that the GSF provided a way of addressing such issues in a more positive way, framed by the 'authority' of achieving the GSF. The enthusiasm of district nurses for the GSF has also been found by others, with improved communication with GPs highlighted as a possible reason for this enthusiasm<sup>10</sup>.

It has been noted that there is limited evidence for the clinical or cost effectiveness of the gold standards framework<sup>26</sup>. However, in this study, when the GSF was discussed, it was not in relation to outcomes of palliative care, such as clinical or cost effectiveness, but in relation to the valued inter-professional processes of care such as knowing and communicating about patients regularly and effectively, and improving relationships between professionals<sup>15</sup>. There were important caveats about sustainability and workload, but the GSF appears to be broadly positively anticipated and achieved because of the valued difference it appears to make to such processes of care. It is important to note that process benefits were not generally discussed in relation to interactions with patients, and the impact on direct patient care, but related to the impact on the way professionals work with each other. Palliative care has long prided itself on being a multi or interdisciplinary speciality<sup>25</sup>, despite the difficulties inherent in working in such a way. It appears that professionals value the GSF because of its positive effect on such multi-disciplinary working and communications.

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Data source	Case study site						Totals	
	A		B		C		Numbers recruited	Numbers discussing GSF explicitly
	Numbers recruited (approached)	Numbers discussing GSF explicitly	Numbers recruited (approached)	Numbers discussing GSF explicitly	Numbers recruited (approached)	Numbers discussing GSF explicitly		
District nursing staff (DN)	5 (12)	5	4 (8)	3	5 (12)	1	14	9
General practitioners (GP)	3 (21)	3	4 (34)	1	6 (28)	2	13	6
Allied health professionals (AHP)	0 (0)	0	1 (1)	0	0 (0)	0	1	0
Key informants (managers, commissioners) (KI)	1 (1)	1	1 (1)	0	2 (3)	2	4	3
Specialist palliative care nurses (SN)	4 (5)	4	3 (4)	2	3 (3)	1	10	7
Specialist palliative care doctors (SD)	0 (1)	0	1 (1)	1	1 (1)	1	2	2
Specialist Allied health professionals	0 (0)	0	2 (2)	1	1 (1)	0	3	1
Total number of interviews	13	13	16	8	18	7	47	28
(Numbers in brackets are numbers of those invited to participate)								

Table 1 Research participants, participants explicitly discussing the GSF, and their professional backgrounds, for each case study site.

<p><b>Level 1</b></p> <p><b>Communication</b> Maintaining a Supportive Care Register to record, plan and monitor patient care.</p> <p><b>Co-ordination</b> Having a nominated co-ordinator for palliative care.</p>
<p><b>Level 2</b></p> <p><b>Control of symptoms</b> Each patient has their symptoms, problems and concerns assessed, recorded, discussed and acted upon. Advance Care Planning tools are recommended.</p> <p><b>Continuity</b> Use of systems and protocols to ensure continuity of care delivered by inter-professional teams and Out of Hours providers. Anticipatory care in place to reduce crises and inappropriate admissions.</p> <p><b>Continued learning</b> Interprofessional learning focused on clinical problems, with a commitment to continued learning. The use of Significant Event Analysis. The development of a learning and reference resources.</p>
<p><b>Level 3</b></p> <p><b>Carer support</b>  To work in partnership with carers and consider their needs for emotional, practical and bereavement support.</p> <p><b>Care of the Dying</b>  Appropriate care for those in the last days of life, for example by using the Liverpool Care Pathway.</p>
<p><b>Level 4</b></p> <p><b>Sustain, embed and extend improvements in end of life care</b>  The use of audit findings to inform practice improvements and local commissioning. Developing a practice protocol for end of life care. Ensure GSF extended to non-cancer patients</p>

Box 1 The four levels of the GSF. Adapted from The Gold Standards Framework, [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

Box 2. Topic guide for interviews

Mapping palliative care within the PCT  
Public processes of palliative care (policies, procedures, referral criteria etc.)  
Sources of referral  
Processes of referral  
Referring onwards  
Influences on referral and relationships with other professionals  
Background and experience