The Gold Standards Framework Summary of Evaluations

Reduced Summary September 09 vs 16

Prof Keri Thomas, Karen Shaw, Prof Collette Clifford and the National GSF Centre

Use of the Gold Standards Framework (GSF) in community palliative care for Primary care teams is supported by a strong and growing evidence base, by UK national policy developments and by Parliamentary support and recommendation.

The aim of this paper is to provide a summary of GSF evaluations, audit reports and research studies that we are currently aware of, to inform ongoing spread, development and further research of the Gold Standards Framework, as part of the NHS End of Life Care Programme. In the light of the current changes within the NHS, further issues are arising related to end of life care, community palliative care, GSF and its potential further usage, which we as the GSF Central Team need to be able to respond to, and to adapt and develop as needed. We need to constantly improve and develop GSF and other End of Life tools further, supported by the large number of GSF Facilitators and GP practices across the UK, in response to further challenges and suggestions.

Many current policy documents affirm the need to continue to spread GSF across the country and to develop this further with Care homes, in other community settings and as part of End of Life care strategic developments. However, there needs to be a clarity of the benefits, outcomes and areas for further improvement of the GSF, as determined by both larger University based studies and local audit studies (not for publication but for local usage). Some commissioners may rightly question what the benefits are of supporting the funding of GSF facilitators in their areas and further development of GSF in such areas as Care Homes e.g. to ask the question 'what do we as a larger healthcare community gain by funding the local GSF programme or other primary palliative care developments? We need to present evidence from a variety of sources to be able to answer this. Also we, as a GSF National team, are receiving many questions relevant to the current situation with the NHS e.g. related to commissioning, cost effectiveness, link with other areas of End of life care Planning etc, which we need to be able to address and answer and in some areas respond by developing further research studies. (See some of these listed as Frequently Asked Questions).

GSF is seen as a major player in the development of current NHS End of life care strategic developments across PCTs and SHAs, and now in the new proposed End of Life Networks. However, we need to be alert to ways of improving it further and adapting it to a changing world, whilst not losing anything of proven value.

Current policy, parliamentary and national support for GSF in England includes:-the revised Quality and Outcome Framework of the GMS GP Contract (to include palliative care points based on and linked to Level 1 of GSF), the new White Paper 'Our health, our care, our say' Jan 06 , the House of Commons Health Select Committee Palliative care Report July 04, the NHS Confederation report on End of Life Care Dec 05 , the NICE Supportive and Palliative Care Guidance March 04, Cancer Services Collaborative Improvement Partnership reports 02-06 , Royal College of General Practitioners, Macmillan Cancer relief (2003-4) the National Council for Palliative Care, Help the Hospice and NHS End of life care Programme (from Nov 04). Other support comes from the National service Frameworks for Heart disease, Renal disease, Old People etc and from the Commission for Social Care Inspection for care Homes.

Research evidence and evaluations so far.
There has been evaluation and measurement of the effects of using GSF at every stage, both nationally and in many local areas. It is hard to describe exactly what the benefits of GSF have been for those who have used it, both those who have adopted it with great enthusiasm, or those who have taken it up only minimally. Some benefits appear to be less tangible, more attitudinal and may have an impact on the team's approach to all patients with serious illness in a very significant way. Clear benefits in terms of patient outcomes are famously difficult to measure and to compare, but there are some tangible measurables which are possible to quantify.

The indications are that the GSF offers an overall sense of improved care provision, better 'patterns' of care management, with 'fewer patients slipping through the net' (ref King Pall med). Trends indicate that use of the tool can help improve communication, assessment of quality of care provision, noting of patient preferences, advanced care planning, out of hours support, and collaboration within and between teams (ref Warwick)

In summary

a) **Uptake of GSF-** between 28% and 32% of the GP practice teams in England have adopted GSF in some form at least at Level 1. This is without any extra funding for the majority of practices and minimal funding for a few.
b) **Effect and impact of GSF** - it appears that GSF can have an impact in three main ways in most practices that use it effectively:-
    1. **Awareness of and attitudes** of staff towards dying patients**.** Affirming the importance of good delivery of home based palliative care for all patients nearing the end of their lives.
    2. **Patterns of working**- structures, processes and patterns- systems , means of team-working etc The main particular benefits appear to be :-
        a. Improving communication within and between teams and with patients and their carers.
        b. Improving the consistency and reliability of care – so fewer patients 'slip through the net'
        c. Improving anticipatory care and proactive planning
        d. Some specific benefits such as anticipatory prescribing of drugs left in the home, handover forms, greater team involvement in care of dying patients eg with a white board
    3. **Tangible Patient outcomes –**eg more home deaths, more asking and recording of patients' preferences, better provision of information, better discussion and recording of advance care planning, etc

c) Effect of GSF on Strategic planning. GSF has been adopted by ? 20 PCT Locally Enhanced Services, featured as part of all known Network Palliative care Strategic plans, ? all/majority of SHA End of Life Care plans, and as part of the PEC Clinical Governance discussions of many PCTs.

This paper includes references to further information, audits and published articles. Further information will be added as it becomes available.

It is divided into:
1. University based GSF Evaluations
2. Local audits of GSF usage- PCT, Network and practice based audits- unpublished
3. Further research questions to address
4. Frequently Asked Questions

1 University based Formal Evaluations of GSF

Phase	Investigators	Methodology of study	Key lessons	Publications
Phase 1 2001	K Thomas Cardiff University MSc. dissertation	Before and after questionnaires, focus groups etc for pilot 12 practices	Pilot study – acceptability to practices, effect of changes, transferability to other practices	Thomas K, Noble B, *"Improving the delivery of palliative care in general practice: an evaluation pf the first phase of the Gold Standards Framework."* Palliative Medicine 2007;21:49-53
Phase 2 2002	Huddersfield University King et al.	Qualitative comparison of 8 GSF and non GSF practices	Increases consistency of practice Guidance for facilitation	King N, Thomas K, Martin N, Bell D, Farrell S, & *"Now nobody falls through the net Practitioners perspectives on the Gold Standards Framework for community palliative care*" Palliative Medicine 2005: 19:619-627 King N, Bell D, Martin N, Farrell S. *Gold Standards Framework, phase 2: qualitative case study evaluation /final report.* Primary Care Research Group, School of Human and Health Sciences, University of Huddersfield, 2003.
Phases 3,4,5,6 2003-4	Warwick University Dale, Munday etc.	Before and after questionnaires for 955 (73%) practices As above As above	GSF improves structure and processes or patterns especially in certain areas e.g. register, handover form, meetings, etc.	Practice audit reports sent Report written Dale J, Koistinen J, Mahmood K, Munday D, Petrova M, Thomas K. *Evaluation of the Gold Standards Framework for Palliative Care, Macmillan Phases 3-6 (2003-2005).* Report to Macmillan Cancer Support. Warwick Medical School, 2007. Kelt S, Munday D, Dale J. *Patients' experience of receiving GSF-led primary palliative care.* End of life Care 2008:2;47-53. Dale J, Petrova M, Munday D et al. *A national facilitation project to improve primary palliative care: the impact of the Gold Standards Framework on process and self-ratings*

				of quality. Quality and Safety in Health Care 2009;18;174-80.
		Qualitative study using semi-structured interviews with staff of 15 practices in 3 Primary Care Trusts.	Better performance associated with practices that have clear-shared purpose, with effective communication and efficient formal processes.	Munday D, Mahmood K, Dale J, King N. *Facilitating good processes in primary palliative care: does the Gold Standards Framework enable quality performance?* Fam Pract 2007:1-9.
		As above	Adoption of framework associated with earlier referral of palliative care patients to district nurses. Best functioning teams used range of meeting styles, with relatively non-hierarchical working style.	Mahmood-Yousuf K, Munday D, King N, Dale J. *Interprofessional relationships and communication in primary care: impact of the Gold Standards Framework.* Br J Gen Pract 2008;58:256-63.
Phases 7,8,9,10 2005-7	Birmingham University – Clifford, Shaw etc	Before and after questionnaires for 401 (30%) practices.	GSF effective in improving care-improves quality, choice, reduces inequity and improves cost effectiveness. BUT variability in usage by practices	Practice audit reports sent Summary reports for each phase available Shaw KL, Clifford CC. *Gold Standards framework. Evaluation of Phase 7 in Primary Care*. School of Health Sciences, University of Birmingham. June 2006. Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 8 in Primary Care. School of Health Sciences, University of Birmingham. November 2006. Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 9 in Primary Care. School of Health Sciences, University of Birmingham. March 2007. Shaw KL, Clifford CC. Gold Standards framework. *Evaluation of Phase 10 in Primary*

				Care. School of Health Sciences, University of Birmingham. Sept 2007. Publication pending
Independent	1.Warwick University Munday etc 2. Manchester Todd etc Walshe et al. Hughes et al. 2008. University of Sheffield	In depth qualitative study Qualitative study involving 47 interviews of multidisciplinary staff from 3 Primary Care Trusts in the North West England. Trusts varied in extent to which GSF was in use. Postal questionnaire to 2096 (60%) general practices.	GSF improves practice but variability GSF helps processes GSF improves processes and valued by staff. Identified workload issues and variations in adoption. 61% of practices reported involvement with the GSF and reported activity consistent with framework.	Publications pending Walshe C, Caress A, Chew-Graham C, Todd C. *Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts.* Palliat Med 2008;22:736-43. Hughes P, Bath P, Ahmed N, Noble B. *Improving supportive and palliative care for adults with cancer in primary care: A national survey of general practices.* University of Sheffield. April 2008.
Phase unspecified	Huddersfield University King et al.	Qualitative study using semi-structured interviews with district nurses (n=24) community matrons (n=15) and key stakeholders from other professional/managerial groups (n=7) recruited from 3 purposively selected geographical areas.	GSF improves felt to systemize care, and raise awareness, but variations in the utilisation reported. GP support considered a crucial factor in uptake of the GSF.	King N, Melvin J, Ashby J. *Community Nursing Roles and The Gold Standards Framework For Community Palliative Care: Final Report.* Centre for Applied Psychological Research, School of Human and Health Sciences, University of Huddersfield, 2008.
Phase 11 and Walsall pilot in progress	Birmingham And Walsall PCT	On line after death analysis	More focus on patient outcomes GSF improves nos. dying in preferred place, reduces hospital deaths, ?cost effectiveness	In progress

To Add references

- **Full literature search** on community palliative care- as described in Chapter 5 of the GSF text book.
- **Phase 1 2001-2** - **Cardiff University** MSC dissertation and forthcoming paper by Keri Thomas and Bill Noble (of Sheffield University) on the original 12 pilot practice, looking at whether GSF was acceptable to practices, whether it changed practice and what were the effects of the change.
- **Phase 2 2002-3 Huddersfield University** - Qualitative research study led by Dr Nigel King. Paper pending and recommendations made for best implementation. Matching GSF practices with non- GSF practices in 4 areas, with semi structured interviews and themed analysis

- **Phase 2 2002-** Cancer Services Collaborative Information Analysis Team- presentations at BMJ Quality/ IHI congresses 2004,5
- **Phases 3 - 6 2003-4 Warwick University.** Led by Dr Dan Munday and Prof Jeremy Dale- 4 Phases of before during and after questionnaires with over 1000 practices beginning GSF, as part of the Macmillan Warwick GSF Evaluation Team
- **Phases 7 -12 2005-7 Birmingham University.** Led by Prof Collette Clifford, using the same before and after questionnaires, with audit feedback for practices and PCT areas to demonstrate changes and identify areas for future development.
- **Other measurement of uptake-** by SHA End of Life care Leads
- **Other independent research studies** - several currently underway.
- Walshe C Caress A et al Priorities and protocols achieving adopting and anticipating the GSF in three English PCTs Palliative Care Congress and Palliative medicine April 06 *Conclusion The GSF was principally described as beneficial in terms of process aspects eg the way professionals particularly district nurses, could control previously difficult aspects of their work with others, particularly GPs. Further research is required to identify whether such process issues impact on patient outcomes.*
- **CGSF Care Homes- Birmingham University** -full action research study of about 100 Care Homes across England , as part of Phase 2 GSFCH 2005- currently underway

References *to add and complete*

Thomas K Caring for the dying at home: Companions on the journey *Radcliffe Medical Press* 2003

Thomas K *British Medical Journal* ABC in palliative care chapter on 'Community Palliative Care' Ed Fallion et al London (accepted 2005- in press)

Ed Watson.M Lucas C, Hoy .A *Adult Palliative Care Guidance* _Thomas K (2003,revised 06) *Community Palliative Care chapter* SWSH

Ed Watson M, Hoy A, Beck A et al Oxford Handbook of Palliative Medicine Thomas K (2003) Chapter 12 on *Community palliative* care OUP2005

King N, Thomas K, Martin N, Bell D, Farrell S, & "Now nobody falls through the net Practitioners perspectives on the Gold Standards Framework for community palliative care *Palliative Medicine2005:19:619-627*

Murray S, Boyd K, Sheikh A, Thomas K_, Higginson I Developing primary palliative care Editorial *BMJ* 2004:329:1056-1057

Murray .**S Thomas K et al How d**o people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers *Family Medicine* December 05

Thomas K Ellershaw J Improving Palliative care services; *British Journal SurgicalOncology M*arch05

Thomas K (2003) The Gold Standards Framework in Community Palliative Care, *European Journal Palliative Care* 03:10(3) 113-115

King N, Bell D & Thomas K (2004) Family carers' experiences of out of hours community palliative care: a qualitative study. International Journal of Palliative Nursing 10 (2), 76-83

King N, Thomas K, Bell D (2003) An out of hours protocol for community palliative care: practitioners' perspectives, international Journal of Palliative Nursing, 9 (7), 277-282

Thomas K, (2003) The Gold Standards Framework in Community Palliative Care, *European Journal Pall* Care 03:10(3) 113-115

Thomas K (2001) The Gold Standards Framework Project *Journal of Primary Care* Dec 03

Thomas K, Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework. Palliat Med 2007;21:49-53

King N, Bell D, Martin N, Farrell S. Gold Standards Framework, phase 2: qualitative case study evaluation /final report. Primary Care Research Group, School of Human and Health Sciences, University of Huddersfield, 2003.

Dale J, Koistinen J, Mahmood K, Munday D, Petrova M, Thomas K. Evaluation of the Gold Standards Framework for Palliative Care, Macmillan Phases 3-6 (2003-2005). Report to Macmillan Cancer Support. Warwick Medical School, 2007.

Kelt S, Munday D, Dale J. Patients' experience of receiving GSF-led primary palliative care. End of life Care 2008:2;47-53.

Dale J, Petrova M, Munday D et al. A national facilitation project to improve primary palliative care: the impact of the Gold Standards Framework on process and self-ratings of quality. Quality and Safety in Health Care 2009;18;174-180.

Munday D, Mahmood K, Dale J, King N. Facilitating good processes in primary palliative care: does the Gold Standards Framework enable quality performance? Fam Pract 2007:1-9.

Mahmood-Yousuf K, Munday D, King N, Dale J. Interprofessional relationships and communication in primary care: impact of the Gold Standards Framework. Br J Gen Pract 2008;58:256-63.

Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 7 in Primary Care. School of Health Sciences, June 2006. http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/

Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 8 in Primary Care. School of Health Sciences, University of Birmingham. November 2006.
http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/
Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 9 in Primary Care. School of Health Sciences, University of Birmingham. March 2007.
http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/ [
Shaw KL, Clifford CC. Gold Standards framework. Evaluation of Phase 10 in Primary Care. School of Health Sciences, University of Birmingham. Sept 2007.
http://www.goldstandardsframework.nhs.uk/content/evaluation_and_research/
Walshe C, Caress A, Chew-Graham C, Todd C. Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts. Palliat Med 2008;22:736-43.
King N, Melvin J, Ashby J. Community Nursing Roles and The Gold Standards Framework For Community Palliative Care: Final Report. Centre for Applied Psychological Research, School of Human and Health Sciences, University of Huddersfield, 2008.

Warwick University GSF Evaluation

Keri - This bit below is what the new information sent from Janice - Emma

Summary of GSF national audit data, phases 3-6 (2003-2005) – Centre for Primary Health Care Studies, University of Warwick

In phases 3-6 (2003-2005) of the GSF rollout, sponsored by Macmillan Cancer Support, practices completed an audit questionnaire before and after they participated in the GSF programme. The audit questionnaire has 62 questions covering the 7 C's, as well as the use of GSF with non-cancer patients and from point of diagnosis.

For phases 3-6, 955 of 1305 practices (73%) completed both a baseline and a final questionnaire, generally 12 months after starting the GSF programme. In the final questionnaire, 89% of practices report using a register of palliative care patients, 91% have a practice co-ordinator for palliative care, 80% meet regularly to discuss and plan care for palliative patients, and 82% regularly inform out-of-hours providers of patients. Confidence in delivery, quality, and co-ordination of palliative care and communication with specialist palliative care all increase from baseline. Conversely, increased administrative burden was cited as problematic (perhaps the converse of better co-ordination of care). The number of practices reporting that they routinely record patients' preferred place of death rose, but there is not sufficient data to determine whether more patients died in their preferred place. Full analysis of the cumulative audit data for phases 3-6 is continuing, and the report on this work will be available later in the summer. Those interested in the report should contact Janice Koistinen at Warwick (j.koistinen@warwick.ac.uk).

To investigate the range and depth of GSF adoption in practices, and the variety of different approaches practices might take, the GSF evaluation team at Warwick has undertaken a series of ten case studies of purposively selected practices. This has involved practice visits as well as interviews which enabled observational data to be collected from attendance at meetings, and inspection of the palliative care register as well as interviewing key informants such as the practice manager. In addition, the Warwick team has conducted a study with facilitators to gain insights into organisational issues which enhance or restrict GSF uptake. Results from these studies will be available later this year.

Keri - This bit below is what we had originally in the document - Emma

Feedback from 1600 ? practices in phases 3-6 2003,4

Methodology- before and after questionnaire including xx questions

Findings:-

- Qualitative
- Quantitative
- Unproven- causes missing baseline data , response rate, etc
- What we can say from data-
- What we cannot say from data-
- Areas for improvement in GSF-
- Areas for improvement in evaluation of GSF