the gold standards framework in primary care

GSF Primary Care Briefing Paper



‘Going for Gold’

A framework to enable a gold standard of care for all people nearing the end of life

The Gold Standards Framework in Primary Care - Going for Gold
Enabling Generalists in end of life care

The Gold Standards Framework enables 'generalists' to deliver high quality end of life care. It is now extensively used across the UK, embedded as mainstream within primary care and endorsed by all major policy groups, including The National Institute of Clinical Excellence, the Royal College of General Practitioners and Royal College of Nursing. The Department of Health's End of Life Care Strategy recommends GSF as the key tool to improve coordination within primary care. We have come a long way since GSF started from within general practice in England in 2000 - most practices use at least the basics of GSF and international use of GSF has grown, with adaptations in many countries. Many thousands of patients and their carers have benefited from receiving more coordinated care enabling them to die at home if preferred. But even greater challenges await us as we move on to the GSF Next Stage and the Olympian challenge.

Moving on to the Next Stage

The GSF Primary care Review 2008-9, affirmed the success and value of GSF but also the challenges ahead. Independent surveys show:

- over 90% of GP practices have a palliative care register and a planning meeting (Foundation Level GSF)
- over 60% have adopted deeper levels of GSF
- 10-15% have fully integrated GSF into standard practice

Four main challenges were highlighted:

1. **consistency** of use
2. **effectiveness** for all relevant patients
3. inequity for patients with **non-cancer** conditions
4. and a need for integrated **quality** improvement

End of Life Care in Numbers

- 1% of the population dies each year
- 17% increase in deaths from 2012
- 40% of deaths in hospital could have occurred elsewhere (NAO report example)
- 60% people do not die where they choose
- 75% deaths are from non-cancer conditions
- 85% of deaths occur in people over 65
- £19,000 non cancer, £14,000 cancer - average cost/patient in final year of life
- 2.5 million generalist workforce -5,500 palliative care specialists.

"GSF in Primary Care has become part of the fabric of improving end of life care in this country, and has already made a real difference for thousands of patients and their families. But there is still a way to go, and I welcome this new drive towards greater and deeper use of GSF, and renewed efforts towards excellence in the Going for Gold programme"

Prof Mike Richards National Director for Cancer and End of Life Care, Department of Health, England

This Briefing Paper is for all those involved in improving end of life care in their area - primary care teams, facilitators, specialists, commissioners, and other providers. For more information, we invite you to contact us at the National GSF Centre on 01922 604666 or see the GSF website: www.goldstandardsframework.nhs.uk

Going for Gold



2012 is an important milestone in the UK as we become host nation for the next Olympics Games, that symbol of life-affirming health. 2012 also marks a demographic milestone as the number of deaths in the UK is predicted to soar by over 17% for then next 20 years, until deaths outnumber births in about 2032.

Can you meet the 2012 end of life care challenge? The next three years are a crucial window of opportunity for primary care if we are to ensure that we can deliver a gold standard of end of life care for all that need it by 2012, the start of the upturn in deaths and looming avalanche of need awaiting us.

We invite you to join in this challenge - one of the greatest challenges we face in healthcare and as a society - to provide high quality care for all people nearing the end of life, with any condition, in any setting, at any time. Building on a strong foundation, with increasing emphasis on quality, it is time for fresh, new and updated ideas, tools, training and resources. The GSF Next Stage Programme - Going for Gold, launched in June 09, brings together many recent GSF developments and integrates the latest thinking from local and national experience.

The aim is to help all practices improve care at the end of life by supporting them to move on to the Next Stage of use of GSF, from Foundation to Intermediate to Advanced levels. We strongly encourage teams towards greater integration of all the composite parts of GSF for maximal patient benefit. Through quality improvement training, quality assessment tools, and means of quality recognition, we hope to increase consistency and effectiveness of GSF use, optimising care for all people nearing the end of life, regardless of diagnosis.

We now have adaptations of GSF for many settings including care homes, hospitals and others, to add to cross boundary continuity of care.

Thank you for sharing our commitment to this important work and we invite you to join us as we together 'Go for Gold'.

We look forward to hearing from you



Prof Keri Thomas
& team at the National GSF Centre.

What is the Gold Standards Framework in Primary Care?

1 Aim – GSF is a framework to deliver a 'gold standard of care' for all people nearing the end of life

'GSF is the bedrock of generalist palliative care' DN Norfolk
'It's about living well until you die'

GSF is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last year of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together.

GSF can help coordinate better care provided by generalists across different settings

3 Simple Steps

❶ Identify
Patients who may be in the last year of life and identify their stage
Use of the surprise question + prognostic guidance + needs based coding

❷ Assess
Current and future clinical needs and personal needs
Use of assessment tools, Advance Care Planning, etc

❸ Plan
Develop an action plan of care
Use 7 C's key tasks, Needs Support Matrix, passport information etc

Key Messages

- **End of Life Care is important. It affects us all**
- **In 3 years the death rate will rise and demand soar.**
- **Most die of non-cancer/co-morbidity in old age,**
- **Too few die at home or in their place of choice**
- **Hospital admissions and deaths are expensive and may be preventable -care must be brought closer to home**
- **Everyone is involved in end of life care - most care is from the usual generalist provider**
- **GFS helps improve the quality and co-ordination of care provided by generalists across different settings**

5 Goals of GSF
To provide for patients with any final illness:

1. **Consistent high quality care**
2. **Alignment with patients' preferences**
3. **Pre-planning and anticipation of needs**
4. **Improved staff confidence and teamwork**
5. **More home based, less hospital based care**

7 Key Tasks - the 7 Cs



Needs based coding - using the 'surprise question' to predict main areas of need and support required

A - Blue 'All'	B - Green 'Benefits' - DS1500	C - Yellow 'Continuing Care'	D - Red 'Days'	Navy
from diagnosis Stable	Unstable / Advanced disease	Deteriorating	Final days / Terminal care	'After Care'
Year plus prognosis	Months prognosis	Weeks prognosis	Days prognosis	

"Every organisation involved in providing end of life care will be expected to adopt a co-ordination process, such as the GSF" Department of Health End of Life Care Strategy 2008

GSF Next Stage - Why do this?

GSF in practice - what this means for patients

'Better outcomes for patient and family; most cost effective use of NHS funds.'

Care of Mr Barker age 78 with COPD: **Reactive** care before using GSF - 2000



Practice responding to occasional requests. Symptoms worsening prompts action.

Less patient choice or control

End of life never discussed, Mr Barker just worried about it but couldn't ask the questions he need to. No one asked what was important to him or discussed likely course of illness and what to expect.

Care felt haphazard

Ad hoc visits and duplication eg Nurse and GP visit same day. No future plan discussed
Advice only given if they asked- his wife felt too frightened and didn't always know what to ask for.

Wife struggling to cope unsupported

When Mr Barker became unwell at a weekend, everyone was upset and panicked. A 999 call led to A&E - 8 hour wait on trolley, no notes available. He died on the ward. His wife didn't realised he was this poorly and was not there.

Care of Mrs Smith, 81 with Heart Failure: **Proactive** care with GSF - 2009



Earlier identification by the practice as needing priority care and added to GSF Supportive care register. Early Assessment of stage of illness and likely needs.

More patient choice and control

Mrs Williams felt in control with an Advance Care Plan. End of life discussions offered sensitively so she was able to ask the awkward questions and felt reassured. Knew what might happen and what to do if it did. Holistic needs assessed

Planning -regular review and support

All the practice team including receptionists knew that she needs priority care. All aspects of care considered at team meetings. Possible future needs anticipated including out of hours care (handover form) personalised guidance (Home Pack), hospital informed (Passport information), carers support (information, training & respite) & drugs at home.

Family and Carers are supported with fewer crises.

Admission was avoided. Mrs Williams died at home as she had wanted, with her family around her.

GSF in Practice - what this means to you

Benefits to you... as Commissioners

Improving End of Life Care is important for humanitarian, personal and economic reasons. Evidence affirms that GSF enables primary care teams to provide better quality care.

Using GSF helps:

- reduce hospital admissions and length of stay (local audits - GSF has halved admissions)
- double home deaths in local audits
- achieve the DH EOLC Quality Markers (currently about 24 draft markers) with After Death Analysis ADA audit
- support appraisals and revalidation
- lead to a Quality Recognition process
- establish levels of GSF adoption in practice, encourages audit and improvements, monitors progress
- increase effectiveness of a LES and local facilitators

Benefits to you... as a Primary Health Care Teams

GSF works, is simple and easy to do. A tried and tested framework used by thousands to make a real difference to patient care.

GSF gives:

- confidence that you are doing a good job
- more satisfied patients and their carers
- more dying where they choose
- fewer crisis calls and admissions
- affirms the important role of nurses
- helps teamwork - everyone's involved
- maximum effectiveness
- transferable skills and tools
- a structure to anticipate needs earlier
- Integrates care for patients with long term conditions

GSF in Practice - evidence of 3 areas of improvement from research and audits

GSF is about systematic organisational change – its less about what you know and more about what you do & how you do it. (See summary of GSF University evaluations, research evidence and audits on GSF website.)

Attitude awareness and approach

- Greater awareness of patient needs
- Better quality of care perceived
- Greater confidence and job satisfaction
- More focused and proactive approach,
- Hard to measure benefits- teamwork communication, respecting roles etc.

Patterns of working, structure & processes

- Better organisation + consistency
- Fewer 'slipping through the net'- raising the baseline
- Better communication
- Better recording, & coordinating of care
- Better collaboration with specialists

Outcomes for Patients & their carers

- Reduced hospitalisation ie fewer crises, hospital admissions, length of stay e.g. crisis admissions reduced by 33%
- More home deaths, fewer hospital deaths e.g. hospital deaths reduced by 50%
- More Advance Care Planning discussions
- More achieve dying in preferred place of care

Summary of the Principles of GSF and Levels of Adoption

the gold standards framework

3 Simple Steps of GSF

❶ Identify

Patients who may be in the last year of life and identify their stage.
(surprise question + needs based coding)

❷ Assess

Current and future clinical needs and personal needs
(assessment tools, advanced care planning etc)

❸ Plan

Develop an action plan of care.
(use of 7 Cs + Needs support matrix, passport etc)

7 Key Tasks- the 7 Cs

C1 **Communication**
Supportive Care Register, team planning meetings, advance care plans

C2 **Coordination**
Identified GSF coordinator practice coordination, keyworker, co-ordination in other settings

C3 **Control of Symptoms**
Holistic Needs Assessment Tools
Symptom control

C4 **Continuity Out of Hours**
Handover form + out of hours protocol

C5 **Continued Learning**
Learn as you go, reflective practice
Continuous quality improvement

C6 **Carer Support**
Practical, emotional, bereavement

C7 **Care in dying phase**
Minimum Protocol for dying
Liverpool Care Pathway / ICP

Next Stage Additional Tools and Resources

Identification – Prognostic Guidance and Needs-based coding and use of Needs Support Matrices

Advance Care Planning discussions
Cross boundary care & communication - GSF care homes and hospitals - Home Packs, 'passport information' key worker for patient

Anticipatory prescribing and Just in Case Boxes

Audit using ADA audit tool. Significant Event Analysis with action planning

Carer enablement, information and support

Admission Avoidance in the Final Stage

Levels of Adoption

GSF Foundation Level

GSF Higher Level

GSF Advanced Level

GSF Quality Recognition

Foundation Level	Higher Level	Advanced Level	Quality Assured
Basic GSF C1, C2 QOF	Deeper Use GSF C1-7 all working together	Measures of consistency, effectiveness, non-cancer equity, and use of some Next Stage GSF Additional tools + developments	Quality recognition process

What's New with Next Stage GSF - Going for Gold

NEW quality development pack for local areas / PCTs

NEW resources – fact sheets, toolkits, guidance, papers.

NEW training and learning resources for practice teams

NEW accredited courses for co-ordinators and facilitators

NEW local carers groups (Caring with Confidence & Omega)

NEW quality recognition process to accredit staff and teams

NEW public awareness and increase patient and carer focus

Next stage GSF is about everyone moving to a higher level.

Some practices have implemented GSF only at the basic QOF / Foundation Level, but many are doing much more.

GSF Next Stage - the Going for Gold Programme offers you the chance to move on to the Next Stage of GSF use in your practice or local area, towards Higher or Advanced level. Working at your own pace, through self assessment and reflection, with new updated tools and resources, we hope this will support you to meet the 2012 challenge of end of life care in your area.

Going for Gold - How we can help you improve end of life care in your area

Next Stage GSF Going for Gold

1. Quality Development Package

A pack for local areas to improve the quality of end of life care

- **Quality Improvement** Learning Resource
- **Quality assessment** - using ADA online audit
- **Quality recognition** - showcasing and accrediting excellent practices.
- **Support** and coaching from GSF Team
- **New Resources** and Good Practice Guide

2. New Resources, Training and Tools

- **Updated interactive website**
- **GSF Factsheets** for other professionals e.g. ambulance, hospitals etc
- **Toolkits** Nurses Pack, Briefing Papers and guidance for commissioners
- **New tools** - Needs Based Coding, GSF Needs Support Matrices, Guidance on Advance Care Planning and more
- Links with **GSF in other settings** eg care homes, hospitals etc
- **Training** - co-ordinator accredited course, training packs etc

3. Greater Patient, Carer and Public focus

- New GSF Patient and Carer group
- More patient centred tools and measures
- Supporting carers in partnership with Omega - Caring with Confidence
- Public awareness of end of life care issues in partnership with the National Council for Palliative Care Coalition

"The fact that there is now a Gold Standard for palliative care means not only that everyone now knows what can be achieved, but that patients and families are beginning to know what they should be asking for - and expecting!" Baroness Julia Neuberger, DBE House of Lords

RCGP Royal College of General Practitioners

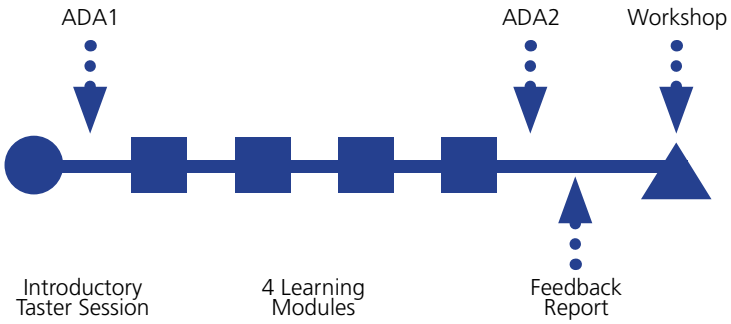
"The College is pleased to support GSF, as a major component of the new RCGP End of Life Care Strategy. It is clear that end of life care should be part of the core business of general practice, and GSF provides a standard against which we can measure our practice and a means to further improve it." Prof Nigel Mathers, Chair CIRC, RCGP

Practice Teams Going for Gold

The Quality Development Package for PCT's, areas and practice teams enables us to improve end of life care and move on to the next stage of GSF, and includes:

- Planning, support and training for the package from the GSF Central team
- Free introductory session (DVD and workbook) for team learning, supported by a local facilitator/practice lead
- Full Quality Improvement Learning Programme with DVDs and Workbook - 4 one hour sessions over 4-6 months,
- Comprehensive Good Practice Guide with details and guidance on GSF Next Stage tools
- ADA After Death Analysis audit using the on-line ADA tool before and after the training programme
- Feedback report affirming good practice and suggesting areas for further improvement
- Chance to progress to recognition with Quality Hallmark Award, further courses and showcasing best practice

Going for Gold Quality Improvement Learning Resource



What is quality GSF? Meeting the 4 challenges

Consistency	At least 20% of all patient deaths are on the practice register Audit e.g. ADA, SEA, action plans Alignment with advance care plans
Effectiveness	Dying in preferred place of choice Decreased hospitalisation Bereaved carers views
Equity of diagnosis	At least 20% of those on the register have non-cancer diagnoses
Quality Assurance	Quality recognition process-self assessment checklist, audit, folder of evidence, visit

Commissioners Going for Gold

We invite you to join us in our GSF Next Stage plan 'Going for Gold' and meet the 2012 challenge with a concerted push to improve end of life care in the community. To do this we have developed a GSF Commissioners Pack and Tool Kit to help support improvements in end of life care in your area. These will enable you to be sure GSF is well implemented in your area, that your End of Life care funds are attributed to specific developments and that your DH Quality Markers and local targets are attained. Contact us for more details.

Going for Gold Quality

- Quality assessment
- Quality improvement
- Quality recognition

"Quality is the organising principle of everything we do"
Lord Darzi, July 2008

"GSF has transformed End of Life Care here in Greater Manchester and Cheshire and I urge all primary care clinicians to adopt this framework and improve the quality of care for dying patients in their area. There is only one opportunity to get it right" Hilary Compston Associate Clinical Director Greater Manchester Cancer Network

Nurses Going for Gold



CALLING ALL NURSES! Nurses have a very important role in this work. The GSF Next Stage Programme has a special focus on the role of nurses, as key people to bring about real improvements in end of life care. To help you we have developed…

- A new GSF Nurses Guidance Pack and GSF Factsheets for nurses in various roles
- Practice coordinator accreditation through University courses - coming soon
- New DVD training for community nurses
- Quality recognition process for primary care teams and sharing good practice
- Working with the Royal College of Nursing and other nurses groups to support you

"The RCN fully supports this renewed effort and determination to ensure that the GSF is implemented across the country. Nurses play a significant part in the care of people who are at the end of their life – regardless of the setting in which care is being provided – and we welcome the opportunity to contribute towards achieving a universal gold standard for all."
Lynn Young, Primary Health Care Adviser, Royal College of Nursing

Omega, the National Association for End of Life Care

The National GSF Centre works in close partnership with the registered charity Omega. Our collaborative activities include the After Death Analysis (ADA) Audits, the Quality Unit Accreditation of excellence, the Omega Academy Training courses and working with Caring with Confidence to run local supportive information sessions for carers. Please contact Omega for more details at info@omega.uk.net or see www.omega.uk.net or phone 0845 259 3163.

What to do next...

If you would like to move forward with the Next Stage of GSF Primary Care, do contact us. We would like to hear from you if you are interested in registering with the GSF Programme Going for Gold, commissioning the Quality Development Package, the GSF Care Homes Training Programme or any other options. More details in the Commissioners Pack or email/ phone for further discussion.

We look forward to hearing from you.

"The GSF is one of the most significant developments in the improvement in end of life care since Dame Cicely Saunders founded the hospice movement."
Penny Hansford Director of Nursing, St Christopher Hospice London

"The Gold Standards Framework is an excellent template for systematic care for all patients nearing the end of life. As a GP, I found it ensured our patients received the quality of end of life care they deserved, making my life as a GP so much more fulfilling." David Colin-Thomé, National Director for Primary Care, Department of Health

"The Gold Standards Framework has lifted everyone's sights on what should be achievable in palliative care. GSF provides a bench mark for practitioners to strive for, and the building blocks towards achieving this goal."
Rt Hon Caroline Spelman MP Meriden

"I welcome the launch of the next stage Gold Standards Framework. I believe the Gold Standards Framework is essential to achieving success and is a key step in implementing the End of Life Care Strategy."
Professor Mayur Lakhani CBE, Chairman of the National Council for Palliative Care and a practising GP.

the gold standards framework

The National GSF Centre

NHS Walsall Community Health

For more details or any queries please contact the GSF Helpdesk on 01922 604666 / 667/ 524

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