the gold standards framework® in acute hospitals

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GSF Acute Hospital Training Programme
Report from Phase 1 Pilot 2009-10

The GSF Centre in End of Life Care
GSFAH Evaluation Lead- Bryan Archer November 2011

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

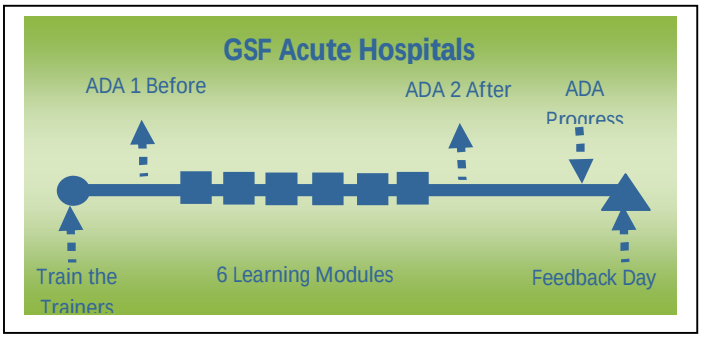
FOR PHASE 1 PARTICIPATING HOSPITALS ONLY

The GSFAH Phase 1 Pilot Evaluation Report is in 2 parts- Parts 1 and 2 are available for participating hospitals and includes specific information related to each hospital in the Appendix.
The GSFAH Report for general dissemination includes Part 1 only and excludes this appendix to retain evaluation anonymity for the respective hospitals. Further details are available in request.

The GSF AH Phase 1 Pilot Programme
Part 1. 1 Executive Summary

Introduction

The Gold Standards Framework (GSF) training programmes aim to enable generalist frontline staff to provide a gold standard of care for all people nearing the end of life. GSF is widely used in the community, in primary care and care homes, to improve the quality and organisation of care for patients thought to be in the final year of life. When patients were admitted to hospital as part of their care, the benefits of GSF in enabling high quality end of life care were usually lost, leading to suboptimal patient care, poor communication with those in the community and fewer patients able to live and die where they would choose. Hospitals are complex, high turnover organisations and were often seen as 'the missing link' and a barrier to well integrated cross boundary care.



The Phase 1 GSFAH pilot 2009-10 was run by the National GSF Centre with 15 volunteer hospitals, to assess the suitability of introducing an adapted form of GSF to the acute hospitals, to examine the effects of these changes, and to make recommendations for further improvements and developments on the programme.
This was a repeat of the pilot process undertaken in the early stages of development of the other GSF programmes i.e. GSF in Primary Care programme (2000 and updated 2009), GSF in care homes (2004), and GSF in Domiciliary care and Community Hospitals (currently underway). In these Phase 1 pilots the GSF Central team work with local, motivated and innovating leaders or facilitators to test out the transferability of the well used GSF framework principles, and to adapt this for the appropriate setting. These were then tested out at grass roots level, evaluated and further developed, leading to improvements and generic modifications. In this way the principles of GSF that lend themselves to each setting are grown up from grass roots , tested and refined for best use in the setting, with an eye always on improving well integrated cross boundary care, centred on the patient's preferences and needs . Therefore this initial pilot programme tested the feasibility of using GSF in hospitals as well as the effectiveness, with several significant recommendations for further improvement and development.

Aims. The GSF AH Programme Phase 1 pilot had 2 main purposes:

A. Testing the pilot areas for acceptability and effective implementation with a view to further roll out of the GSFAH training programme and recommendations for further improvement.
B. General Evaluation- Highlighting the three areas assessed in all GSF programmes:
    1. Improving the **quality of care** for patients in the final year/ months/ weeks of life.
    2. Improving the processes to support better **coordination & collaboration**
    3. Improving **outcomes** particularly related to improving cost effectiveness

Context

Increasing Awareness of end of life care. The development of the pilot Phase 1 GSF Acute Hospital training programme was in the context of the increasing awareness of the importance of end of life care within the NHS, the development of the first national NHS End of Life Care (EOLC) Strategy (2008) and Quality Markers (2009), EOLC Programme and local implementation of the end of life care best practice 'tools' or models in differing settings. This included the testing of GSF in an acute hospitals setting, building on the good experience in primary care and care homes, and as recommended by the DH Strategy. ***"Every organisation involved in providing end of life care will be expected to adopt a***

coordination process, such as the GSF" (Department of Health End of Life Care Strategy 2008). It also included Advance care planning and use of Liverpool Care Pathway or its equivalent in hospitals

Since the pilot began there have been a large number of other policy developments confirming the importance of this area, such as the National Audit Office Report on End of Life Care (Nov 08 www.nao.org.uk), the RCGP End of life care Strategy (2009 www.rcgp.org.uk), GMC Guidance 'Treatment and Care towards the End of Life- good practice in decision making' (2010 www.gmc-uk.org), and NICE Guidance on end of life care (final report of Quality Indicators due Nov 11). There is therefore an increasing national and local awareness of the importance of this issue.

Increasing focus on the poor quality of hospital care for the elderly. In addition, over the year since the pilot, there has been an increasing focus on the need to improve the quality of care within hospitals, especially for the elderly frail patients and those nearing the end of life. This includes three recent reports in 2011 – the Ombudsman report (Feb 11), CQC Dignity and Nutrition Inspections Report (Oct 11) and the Patients' Association Report (Nov 11), where repeated reports of seriously inadequate levels of care has raised considerable public and media concern. The Department of Health QIPP team on end of life care focussed on the need to reduce avoidable hospital admissions for better cost effectiveness within the NHS and several local quality targets (or CQuINS) and initiatives were developed to help to address this area. This in itself can add to the pressure of an already pressurised and high turnover hospital workforce, causing diminishing standards of patient-staff interaction, and deficiencies in areas such as communication, courtesy and dignity.

Therefore the context of improving end of life care for hospital patients is extremely topical. One possible solution is related to improving earlier recognition, organisation and coordination of care within and outside hospitals, and this is what the GSF AH Programme attempts to begin to address. But there are additional gaps related to dignity care, empathy discussions and motivation of staff to improve the acceptable standards of care from all members of staff, which still need to be examined in future. This is where future partnering with other organisations might be of added value in further GSFAH phases and proposals to integrate such additional training and support is underway. Exploration of these factors is part of the Phase 2 GSFAH Programme currently underway.

Methods

Of the 15 hospitals in the Phase 1 GSFAH Training Programme pilot, 11 introduced GSF into selected acute hospital wards, 1 into the whole hospital and 3 into outpatient settings only. Following several exploratory workshops and adaptation of GSF resources and evaluation methodology, the programme commenced formally in September 2009 for one year, with follow up evaluation completed November 2011. It followed the usual GSF pattern of a preparatory period with baseline evaluations, a period of training over 6-8 months and a period of embedding, follow up evaluation and next steps sustainability planning.

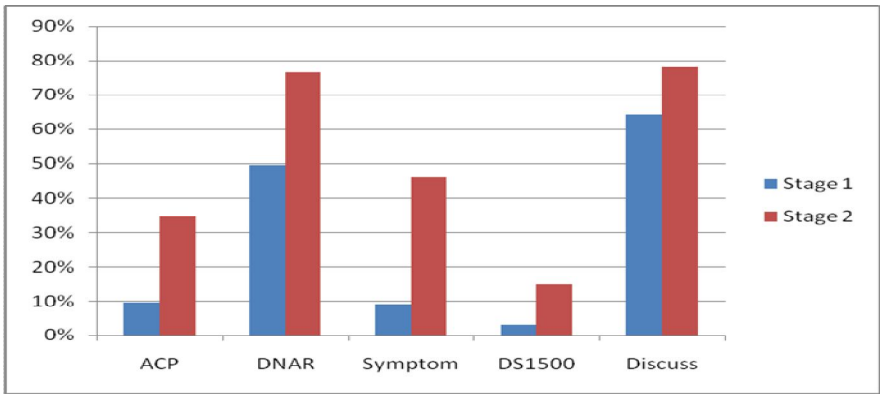
Findings

Although hospitals varied considerably in level of engagement and responses, there were specific gains in all hospitals, and significant changes in a number of key areas:

- **The 'culture'** of the ward was perceived to have changed with the growing confidence of staff – leading to a more **proactive and competent** workforce. This sets the scene for further progress, beyond the scope of this pilot
- Improvement in the levels of **confidence** of staff in identifying patients nearing the end of life, having discussions with them and knowing what to do next –although in some cases confidence was reported to have decreased possibly because of greater awareness of the issues
- Increased levels of **awareness** of end of life care best practice models, the importance of improving end of life care and the links with GSF in the community

- There was increased **identification** of people thought to be in the final months/ weeks/ days of life, but some areas struggled with what actions should follow this recognition
- There was significantly greater awareness of **advance care planning** (by 150%) and recognition of preference of place of care. It appeared that more were enabled to die in their preferred place of care, though this varied with hospital
- There was significant increase in other **best practice end of life care activities** (over 20% increased), such as completion of Do Not Attempt Resuscitation discussions (DNAR) discussions, attendance allowance DS1500 applications, symptom control assessments and discussion with families and carers.
- In every hospital there was significant increase in use of a **care pathway for the dying such as the Liverpool Care Pathway,** as patients were identified earlier and more were commenced appropriately on the pathway
- End of life care **training**, increasing significantly from 59%-72%, as did collaboration with the community for example in using passport information
- Discussions with and **support for carers** improved in 12 out of 13 hospitals, although it was felt this was an area requiring further improvement
- The number of hospitals introducing **rapid discharge policies** increased , leading to more being discharged quickly
- No decrease in length of stay was detected in the sample chosen over the short period of time of the training using the current measurement tools, but longer term it would be hoped that this would show a decrease, as would readmissions which were not evaluated. However one outpatient pilot demonstrated decreased admissions, though more information is needed to understand this better.
- Although use of GSF in outpatients was of benefit, this seemed to be easier to introduce GSF to inpatient wards, and the evaluation tools for outpatients would need to be further modified and developed in future
- Introduction into the whole hospital pilot was particularly successful, and had a real impact on integrated cross boundary care. For some this might be the best way forward, despite the considerable effort involved, and eventually whole hospital use would be the goal in all areas.
- **Most benefits were sustained-** Follow up one year later revealed that considerable improvements had been sustained in most areas, though staff turnover and ongoing support is a key issue in many hospitals. Most were continuing and consolidating the work (7/9) and several had spread it use to other wards as part of phase 2 GSFAH Programme

Increase in end of life care recommended activities before and after



Conclusion

"This work in hospitals is the missing link in GSF, completing the circle of improved co-ordination of care in primary care and care homes"

Dr Karen Groves, Consultant Palliative Care, Southport Hospital

Overall the GSFAH Phase 1 pilot training programme was found to be successfully introduced in all hospitals in varying degrees with tangible and some less tangible benefits that together contribute to improved care for patients nearing the end of life. With further work and longer term investment, introduction of GSF does have the potential to secure considerable improvements in care for patients in the final stage of life. All hospitals made some progress, with several demonstrating considerable benefit, and this has been largely sustained in the one year follow up, with several further developments. For those who struggled, most gave changes in staff/ facilitator as the main reason.

There were difficulties in changing the culture or patterns of the work of ward staff to integrate GSF in some hospitals, in particular a difficulty accessing ward staff (especially nurses) for training. However all reported qualitative differences and improvements in care, which are harder to encapsulate in qualitative evaluations. Some areas of concern were revealed such as the lack of true multidisciplinary meetings, communication gaps with community care and the mounting pressures on staff in this challenging environment. However, once this became apparent, progress was made in several of these areas since the introduction of GSF

These improvements have been translated into significant patient benefits in many areas, which is a positive step towards addressing the considerable challenges raised in this area. The context of busy hospital wards still remain a considerable challenge to the introduction of any new initiatives, but invaluable lessons have been learnt and improvements made for the future phases of the GSFAH training programme . This progress is especially important in the context of increasing pressure on hospitals, financial squeezes and redundancies, and the recent raised awareness of care of the elderly frail patients nearing the end of life in hospitals (as in recent national reports mentioned). But more is required to support the development of improvements in these areas in addition.

In conclusion, it was felt that the pilot GSF AH Programme was successfully adopted in a hospital setting, and with further refinement and development, does have the potential to support improved care for patients nearing the end of life, thereby improving the quality of care, cost effectiveness and enabling better care in line with patient preferences.

Recommendations and Next Steps for future programmes:

- **Specific recommendations** were made for further improvement in the planning and resourcing of the training programme, including evaluation tools, resources, training methods, Train the Trainers support and other developments and these have been integrated into Phase 2 of the programme.

- **There is a need for sustained support** in many hospitals if this is to become really embedded as standard practice, so recommendations were be suggested from participating pilot hospitals, based on their local experience and findings. Including this as part of a wider Strategy in end of life care is important and cross boundary pilots are being established in certain areas where tis programme has been introduced

- **Further areas to develop**. As well as the need to improve the organisation of care with better standardising of best practice in end of life care, there is a need to add value to this programme by aligning it with support in the area of compassionate care, empathy discussions, increasing awareness of dignity conserving care and other qualitative areas that have a real impact on patients. This has been brought to light recently by the three recent

reports mentioned, which raise considerable concern. This needs further work and developments are currently being discussed. A further step is to pilot better cross boundary care building on the GSFAH work locally- due 2012

- **Further funding and research.** Some additional source of funding are required to make maximal use of this initiative, and to bring added value to the ground breaking work. This would include in the development of the programme, supporting of local facilitators and in improving the evaluation and research in this area.

Next Steps

- Implementation of all recommendations for Phase 2- completed
- Phase 2 GSFAH Programme began April 2011 – planned to conclude March 2012 – 9 hospitals involved
- Development of filmed training programme for GSFAH Phase 2 in 6 modules
- Phase 3 planned for Spring 2012
- Discussions underway for development of work in empathy/ dignity conserving care with various partners to bring added value to this area of work
- Development of cross boundary care pilots and call for expression of interest pilots for 2012
- Seeking further partnership support and funding for further development and evaluation of this pilot programme, and to expand its remit to include more on quality of patient care in the light of recent reports.

Acknowledgements

With thanks to all those who took part in the GSFAH pilot programme, those on the steering group and taking part in the evaluation and project management. These include

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Particular thanks to Karen Groves, Carmel Wiseman, Helen Corner, Elaine deeming, Megan Thomas and Emma Farquhar for their support on the steering group and a Clinical Associates .

Special thanks to Bryan Archer for his support of this pilot and evaluation report.

Prof Keri Thomas,
National Clinical Lead GSF Centre, Hon Professor End of Life Care University of Birmingham

The GSF AH Phase 1 Pilot Programme – 1.2 Main Report

Background -End of Life Care

- About 1% of the population dies each year
- 56% deaths occur in hospital
- 60-70% people would choose to die at home
- Avoidable admissions - 40% of all hospital patient deaths could have occurred elsewhere e.g. at home, increasing to 50% of deaths of care homes residents (National Audit Office 09)
- Considerable savings could be made by reducing hospitalisation (QIPP)
- Each hospital admission costs about £3200/ patient with an average of 3 admissions in the final year of life
- Average cost per patient in the final year of life to the NHS is £14k for cancer patients and £19k for non-cancer patients (NAO)
- 85% of deaths occur in people over 65
- About 30% of all hospital patients are estimated to be in the final year of life
- Care of the dying pathways e.g. The Liverpool Care Pathway are well used in hospitals for the final days and hours, and in some areas is attached to a local quality assessment or CQuINs
- With the changing commissioning context and focus on cost effectiveness there is much pressure on areas to reduce avoidable hospitalisation, and care for more people in the community – hence the need for better cross boundary care.
- Numbers of hospital patients likely to be in the final year of life have been estimated to be about 25-40% at any one time, higher for oncology, stroke, elderly care wards i.e. a significant number on of the pilot wards.

The Gold Standard Framework (GSF) Training Programmes

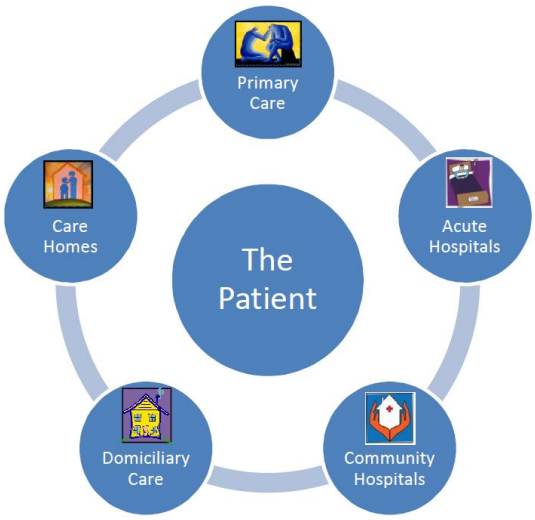
GSF is a recommended best practice model, endorsed by the DH End of Life Care Programme and National Strategy that improves quality, coordination and organisation of care for people in the final year of life. It is the most commonly practiced end of life care framework used by generalist frontline staff in the community, with Foundation Level GSF used by most GP practices since its introduction 11 years ago (then mainstreamed through the Quality Outcome Framework QOF), many practices using Next Stage GSF 'Going for Gold' at a deeper level. Over 2000 care homes (nursing, residential and disability homes) have received GSF Care Homes training over the past 7 years with up to 200/year accredited. GSF now is developing into the most widely used and credible vehicle for improved cross boundary care for patients nearing the end of life.

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 Primary Care
- From 2000
- Foundation GSF mainstreamed 90% GP practices have palliative care register and meeting (QOF)
- June 2009 Next Stage GSF

GSF Care Homes
- From 2004
- Over 2000 care homes trained
- Up to 200/year accredited

GSF Acute Hospitals
- From 2008
- Phase 1 pilot 15 hospitals
- Phase 2 February 2011



Successes using GSF in primary care and care homes – what difference does it make?

1. **Quality of care - Attitude, awareness and approach**
   - Better quality of care perceived
   - Greater confidence and job satisfaction
   - Immeasurable benefits- communication, teamwork, roles respected esp. DNs
   - Focus + proactive approach

2. **Patterns of working, structure, processes v and coordination**
   - Better organisation + consistency of standards, even under stress
   - Fewer slipping through the net- raising the baseline
   - Better communication within and between teams, co-working with specialists
   - Better recording, tracking of pts and organisation of care

3. **Patient Outcomes**
   - Reduced crises/ hospital admissions/ length of stay
   - Some doubled home death rate- more pts dying in preferred place
   - More recorded advance care planning discussions

New GSF Acute Hospital Phase 1 pilot programme.

In 2008 there was a growing interest in developing an adaptation of GSF for acute hospitals, to support patients whilst in hospital, but also to improve cross boundary communication with the community services. Acute hospitals were seen as 'the missing link', which was crucial to close if progress was to be made in integrated patient-centred care for people in the final year or so of life.

The Phase 1 GSFAH pilot was run by the National GSF Centre with 15 volunteer hospitals, to pilot the acceptability and effectiveness of introducing GSF to the acute hospital wards, to examine the effects of these changes, and to make recommendations for further improvement and resourcing of the programme.

The participating members were innovative enthusiasts, making considerable contributions to the work and its development, and their commitment is acknowledged and is greatly appreciated. Some of the funding for facilitator posts came from the North West Cancer Network, but otherwise all local hospital facilitators or leads were self-funding, and all resources, training and evaluation was funded from The National GSF Centre, then based in Walsall PCT. The GSF Centre has since moved to become a not-for-profit Social Enterprise (Community Interest Company) and continues to run this and other

training programmes across the UK and internationally. The GSF Acute Hospital Programme is now seen as a central plank in the development of integrated cross boundary end of life care.

Of the 15 hospitals in the Phase 1 GSFAH Training Programme pilot, 11 introduced GSF into acute hospital wards, 1 into the whole hospital and 3 into outpatient settings only. Following several exploratory workshops and development of resources and evaluation methodology, the programme commenced formally in Sept 2009 for one year, with follow up evaluation. It followed the usual GSF pattern of a Preparatory period, training over 6-8 months and a period of embedding, follow up evaluation and next steps sustainability planning.

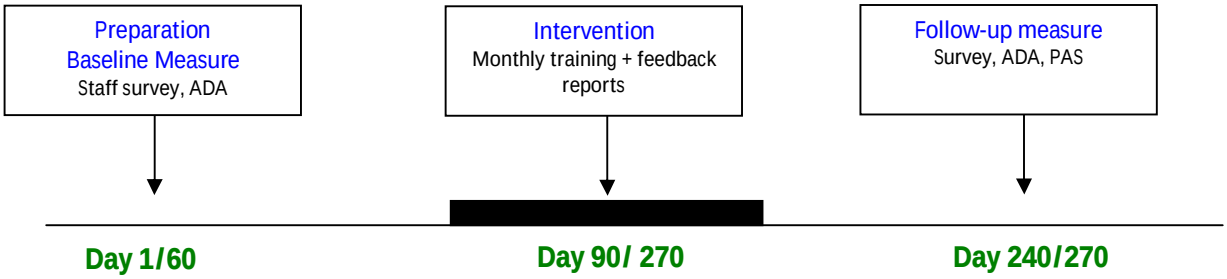
Method

The facilitators from each area helped to adapt and develop modifications of GSF materials used in other settings for the acute hospital setting, such as the 3 step process (identify assess plan), needs based coding, Needs support Matrices , and other modified resources. A steering group and evaluation team were developed, resources and PowerPoint training materials with video clips were provided, and regular monthly support via conference calls plus 4 workshops were initiated. Evaluation measures were adapted and overseen and qualitative feedback captured on film or in feedback questionnaires and analysed by an independent analyst (Bryan Archer). Some areas held mini workshops and meetings and there was a sense of shared learning across the areas. The GSF Centre is grateful to all participants for their enthusiasm and commitment and particular thanks go to Karen Groves and Elaine Deeming from Southport & Ormskirk Hospital.

The 15 participating hospitals of the GSFAH Pilot programme were involved and supported over a period of about 15 months, with 3-6 months preparation. The training commenced in February 2010, with a feedback workshop September 2010 and follow up evaluation until April 2011. Three hospitals concentrated on outpatient settings, eleven undertook the pilot on one or more wards at each hospital (breast cancer, respiratory, frail elderly etc.) with Southport & Ormskirk being the only site to include the whole hospital.

The pilot ran across multiple sites in England and required participant trusts to identify a local facilitator, a pilot area, (defined as a ward, a patient group or a specific diagnosis). Within this pilot area they were requested to collect two snapshots of information; a baseline measure, then a follow up 6 months later.

During the intervening period training plus feedback sessions were undertaken as outlined below;



Evaluation

The pilot had 2 main purposes –

A. Testing the pilot areas for acceptability and effective implementation with a view to further roll out of the programme and recommendations for further improvement

B. Highlighting the three areas assessed in all GSF programmes –
   1. Improving the perceived quality of patient care in line with preferences
   2. Improving the processes to support better coordination, collaboration, staff confidence and workforce development
   3. Improving outcomes particularly related to improving cost effectiveness

To do this a number of evaluation tools were used before and after, including the on-line ADA Audit tool (After Death Analysis and after discharge Analysis), staff surveys, PAS and HES data, monthly feedback, verbal and written reflections following implementation and 9-12 months after completion.

At the beginning and end of the pilot period trusts were asked to undertake a staff survey and collect patient information.

For the pilot the following information was requested as a minimum for the designated pilot area within the trust.

- **Baseline**
  - Staff survey questionnaire – minimum 25
  - ADA - 30 discharges and deaths before introduction of this project
- **During Intervention**
  - Monthly Feedback reports – staff and project lead following on brief training session
- **Follow up**
  - Follow up staff survey questionnaire – minimum 25
  - ADA – 30 discharges and deaths after introduction of this project

Submission Summary

Trusts submitted the following number of entries for each survey;

	Baseline	**Follow Up**	**Total**
Staff Survey	525	487	1012
Patient ADA	198	182	380

Thirteen trusts submitted information for both the baseline and follow up stages of the staff survey, eleven from an inpatient and two for an outpatients setting.

Seven trusts submitted data for the inpatient ADA and one trust submitted outpatient data for both stages. For participating trusts data tables are provided as appendices to this report.

Summary of key findings

Overall the GSFAH Phase 1 Pilot training programme was found to be successfully introduced in all hospitals but in varying degrees, with tangible and some less tangible benefits that together contribute to improved care for patients nearing the end of life. All hospitals made some progress, and some showed considerable benefit that has been sustained and built upon, especially in the area of improved cross boundary care.

These improvements have been translated into patient benefits, notably with the recording of preferred place of death and the rise of collaboration with agencies either side of the acute episode. The GSF Programme has delivered significant improvement in staff confidence, staff awareness and the use of related tools, building upon the successful delivery of the innovative training programme.

A- Piloting the GSFAH Training programme

a. Successful implementation in all hospitals but with changing staff personnel, varying degrees of sustained usage.
b. Use of at least 7 varying modes of training and implementation
c. Recommendations for improvement were made and implemented in Phase 2
d. Particular difficulty was demonstrated in accessing protected training time for nurses, or supporting introduction of GSF to nurses on the wards , which may need to be addressed at a senior nursing level
e. It was felt that 3 months was possibly too brief a time for preparation , but also that benefits would not be so apparent after 6 months of training , and that a longer implementation period and follow up evaluation might be required

B- GSF Measures

a. The quality of patient care in line with preferences
    a. Quality was perceived to have improved overall, with greater awareness of the importance of end of life care, identification of patients nearing the end of life, enquiry and discussion about their needs and preferences, use and recording of advance care planning discussions and care delivered in alignment with theses preferences.
    b. Training has significantly improved the confidence of staff in dealing with those nearing the end of life (final months/ weeks/ days).

b. Improving the processes to support better coordination, collaboration, staff confidence and workforce development.
    - Recorded improvements in the coordination of care were significant where trusts completed both data collections
    - Better collaboration with GP practices was notable in many areas , especially in the whole hospital pilot in Southport , where a GSF Registration process and GSF care Planning was successfully introduced
    - Trust could identify numerous benefits that had accrued form the pilot programme; these are fully detailed in appendix 3.
    - The use of the Liverpool Care Pathway rose for every participating trust.
    - The perceived need for training reduced significantly between the two surveys.

c. Improving outcomes particularly related to improving cost effectiveness
    - Length of stay was unchanged in the sample inpatient population, as a single cohort or as sub groups of discharged and death. For outpatients there was a significant reduction but this was based upon data from a single trust. It was thought that the

sample group was too small to show significant differences and the evaluation tools used were unable to detect any real changes.

- More hospitals introduced or built upon their rapid discharge processes
- The use of Advance Care Planning and other tools significantly increased during the pilot period.
- Recording of preferred place of care did increase in some areas

Conclusion

The Pilot Phase 1 GSFAH programme was felt to be successful as an initial pilot, in the introduction of GSF processes onto acute hospital settings in varying forms for the benefit of patients nearing the end of life. The ward areas were felt to be easier than outpatients, and the whole hospital pilot was ambitious and demanded considerable team effort and strong leadership but was an extremely successful beginning, particularly in relation to improved cross boundary communication. Common difficulties arose due to rapid staff turnover and lack of time for training especially with nurses, the need for repeated training sessions with small numbers of staff, and lack of acknowledgement of the importance of this area. A wide variety of modes of teaching was required. There were also perceived pressures of understaffing, with other regulations, targets and demands in hospitals and by patient clinical demands being the priority, leading to reactive rather than proactive care .Recommendations, suggestions and example of good practice were shared and integrated into the Phase 2 pilot programme.

In relation to key GSF elements, the pilot demonstrated significantly improved staff confidence and awareness, with better processes, and patterns of working (eg GSF flagging or registration) , improved cross boundary communication (eg fax back system to GPs to alert them to include patients on their register , MDT letters to GPs etc) and supported improved perceived quality of care. Other qualitative benefits were noted for each area at the end of the study and at follow up, and several interviews were filmed and are available demonstrating the perceived benefits of the pilot.

The key findings of the pilot can be related to the 4 original aims as follows;

A To **develop a GSF Acute Hospital Training Programme** building on GSF community principles as a simple and useful GSF adaptation for in patient use in hospitals, with a training pack of defined intervention, means of assessment, materials and other resources.

B related to GSF Aims and Measures

1. Improved perceived quality of patient care in line with preferences
2. Improved elements of the **coordination of cross boundary care** for patients in the last year of life, especially in confidence and team working of staff
3. No significant improvement in cost effectiveness was perceived for this cohort using the measures available, though perception was of improved outcomes in line with preferences for discharge.

This pilot laid the foundations for future work in this area , and further Phases of GSFAH programme (Phase commenced in April 2011 and Phase 3 is due Feb 2012) , but further support is required within hospitals if there is to be long term sustainable change in culture and activity in acute hospitals for patients approaching the end of their life .

Recommendations

The pilot programme has shown that for staff there can be a significant change in both practice and confidence within a 6 month period. For patients the data is less than conclusive, on a total and site by site basis.

Therefore the following recommendations are presented to guide future phases:

1. **Specific recommendations** were made for further improvement in the planning and resourcing of the training programme, including evaluation tools, resources, training methods, Train the Trainers support and other developments and these have been integrated into Phase 2 of the programme. (see later)

2. **There is a need for sustained support** in many hospitals if this is to become really embedded as standard practice, so recommendations were be suggested from participating pilot hospitals, based on their local experience and findings. Including this as part of a wider Strategy in end of life care is important and cross boundary pilots are being established in certain areas where this programme has been introduced. Greater senior support required, especially in nurse training e.g. Board level, quality dashboards, Lead Nurse, Medical Director, consultants, AHPs

3. **Further areas to develop**. As well as the need to improve the organisation of care with better standardising of best practice in end of life care, there is a need to add value to this programme by aligning it with support in the area of compassionate care, empathy discussions, increasing awareness of dignity conserving care and other qualitative areas that have a real impact on patients. This has been brought to light recently by the three recent reports mentioned, which raise considerable concern. This needs further work and developments are currently being discussed. A further step is to pilot better cross boundary care building on the GSFAH work locally- due 2012.

4. **Further funding and research.** Some additional source of funding are required to make maximal use of this initiative, and to bring added value to the ground breaking work. This would include in the development of the programme, supporting of local facilitators and in improving the evaluation and research in this area.

Specific recommendations to improve the programme

- Improve GSFAH programme in several ways and build on positive experiences in phase 1 e.g. better access to teaching with training DVD giving examples of peer support , posters, PowerPoint and seven different ways of teaching
- Better resources developed e.g. Good Practice guide and resource folders
- Improved filmed DVD training programme with examples from hospitals' practical experience
- Longer 3-6 month preparation stage -
    - To raise awareness amongst staff of the importance of improving end of life care e.g. with a surprise day snapshot audit demonstrating usually that 23-40% patients in hospital may be in the final year of life and helping them to understand that there is much that can be done
    - To undertake baseline evaluations that in themselves will emphasise the current gaps in care
    - To plan teaching – protected time, backfilled training sessions, opportunistic etc
- Improved evaluation tools – PAS and HES data less valuable, qualitative work helpful, ADA might need modifying – using social movement of change thinking to gradually change culture. New and more quantitative measures are required for the impact upon patients of introducing the GSF, in particular to assess changes in admission rate and length of stay.

The ADA questionnaire should be reviewed to assess the utility of the individual questions. A 6 month trial period is insufficient to gather enough cases at a ward level to measure impact upon length of stay, admission rates, or other areas and longer evaluation is advised. More complete evaluation should be sought as 5 areas did not complete baseline and follow up data, but did complete the equivalent staff surveys. The reasons and any remedies should be identified to minimise the effect in Phase 2.

- Build on cross boundary care with community at early stage and connect with GPs. Though there is an increase in cross boundary information exchange it would warrant further investigation, quantitative and qualitative, as well as being related to the adoption by other bodies within the hospital catchment area. For example use of GSF in Primary care and care homes as well as hospitals. This pilot is planned for 2012.
- Mobilise patient voice- 'gold cards' – enable them to access better care as VIPS e.g. out of hours call back within prescribed time, Access to better A and E care etc Develop virtual or real GSF Register or linked with Locality Register-

1.3 The GSF AH Phase 1 Pilot Programme – Detailed results and analysis

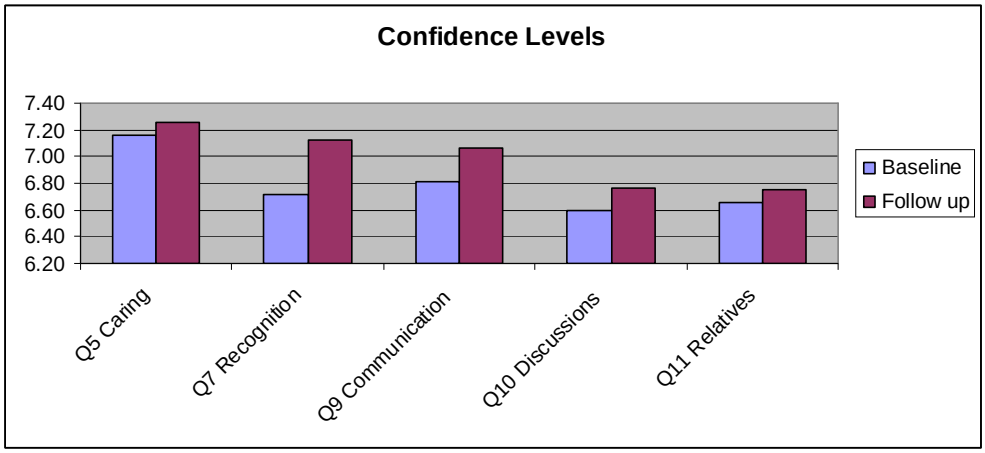
ADA and Staff Survey Highlights- (Inpatients)

The staff survey included 1,012 submissions. 525 during the baseline and then a further 487 in the follow up.

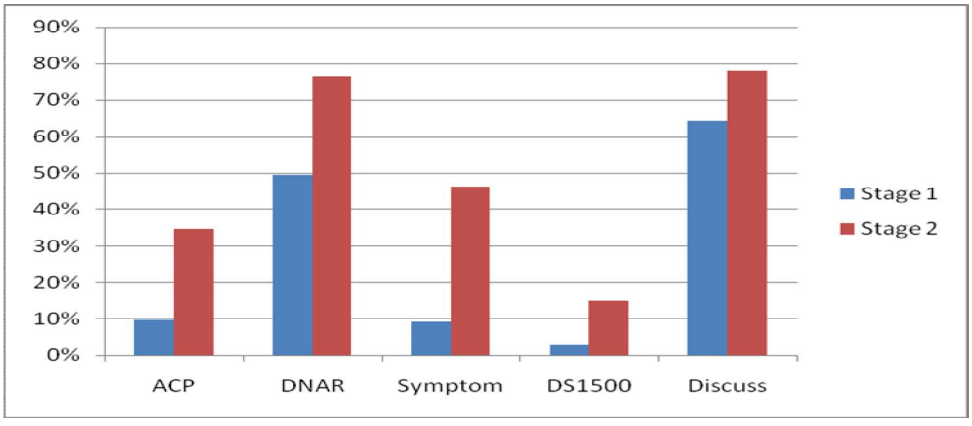
Training on end of life care rose significantly from 59% to 72% during the pilot receiving training in the following areas;

Holistic Assessment	71%
Symptom Management	80%
Advance care planning	60%
Care planning	76%
Care of carers	49%
Care of the dying	85%

This training is reflected in growing confidence levels across all areas.

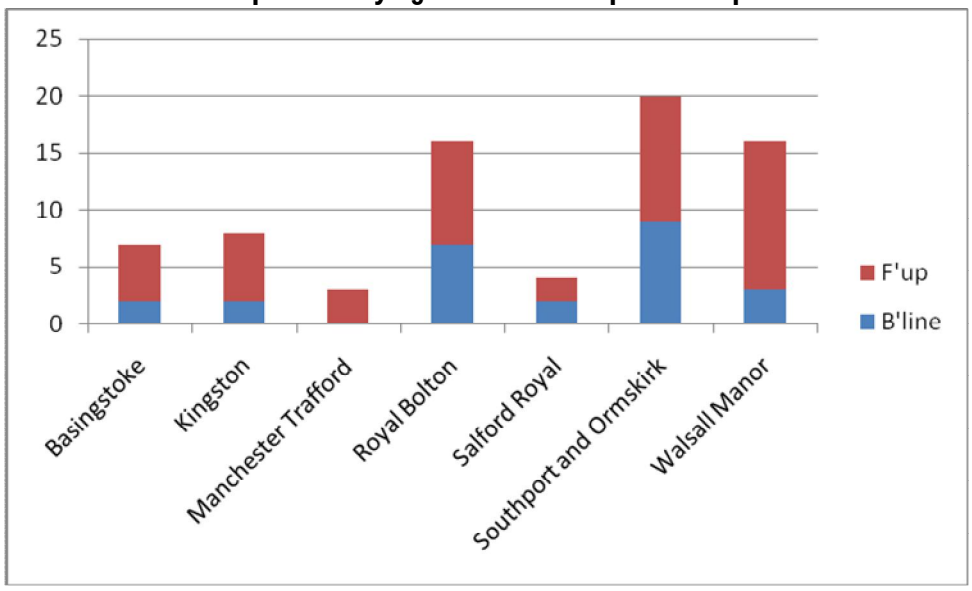


In practical terms this is evidenced in the greater use of interventions/tools over the pilot period with gains of over 20% for the majority in use.



This in particular, is applied to the Liverpool Care Pathway which increased for every participating trust.

The number of patients dying in their stated preferred place of death



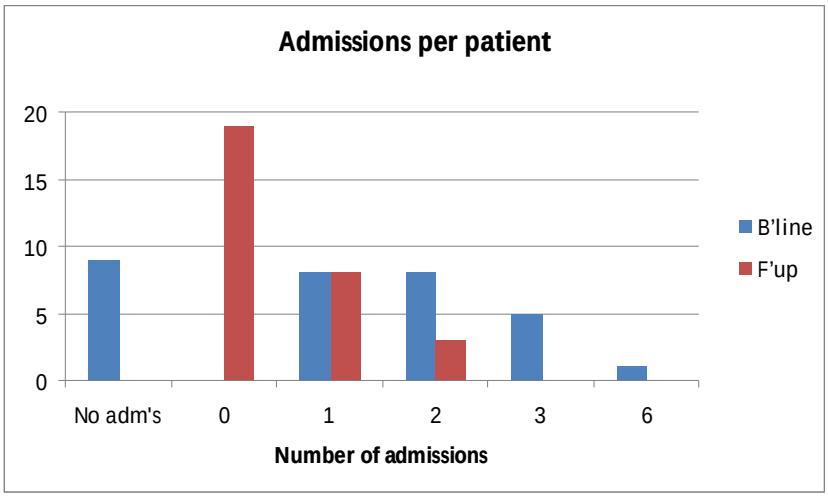
The number of patients dying in their stated preferred place of death which rose from 3 (5% of deaths recorded) in the baseline to 25 (38%) in the follow up.

Collaboration also increased significantly through the pilot period with the use of passport information increasing across the pilot group.

Outpatients

Three trusts elected to pilot the GSF in outpatients of which one completed both the baseline and follow up data collections. For that specific Trust, the most striking change was the reduction in admissions during the 6 months period between baseline and follow-up data collection from 1.5 to 0.5 admissions per patient, indicating an effective reduction in admissions for that Trust.

In all other measures there was no discernable change between the baseline and follow up data collections for the outpatients areas, suggesting that the other measurement tools used for ward training did not pick up a discernible difference during that period for outpatients. However, on a qualitative basis, the feedback was that there was a noticeable effect following introduction of the training. Therefore, despite an apparent reduction in admissions in one Trust, more work is required to develop better means of evaluating the intervention in an Outpatients setting.



Qualitative Evaluation – 1

Additional benefits of implementation survey

Written feedback quotations from Facilitator Feedback Pilot Phase 1 (as reported following end of Training programme October 2010)

"It has reinforced to nursing staff and team assistants the importance of reporting possible prognostic indicators such as reduced mobility / appetite / mood as well as cues given out by patients that may signify preferences for future care. It has also empowered them to recognise that their roles are hugely valuable in care of the dying."

"There are clearer decisions regarding patients going on and coming off the Liverpool Care Pathway (LCP) and an increased proportion of patients dying on the LCP."

"Improved communication with carers/relatives regarding disease management, progression and support as part of the Advance Care Planning Process"

"Improvement in MDT working practices with improved internal collaboration of services and defined roles and responsibilities."

"Increased staff awareness and progression in use of LCP as best practice for end of life care."

"GSF supporting the development of ICPs and cross boundary care planning Improved cross boundary communication with GPs, District Nurses, Discharge Planning. Greater likelihood of achieving preferred place of care, expediting hospital discharge."

"Mechanism put in place to inform GP's about GSF patients identified by the respiratory team."

"Greater confidence by junior doctors to assess terminal patients and feedback findings to consultants, allowing the junior doctors not only to assess and identify but to formulate a plan of care."

"A greater use of communication with patient and family, resulting in clear documentation to not only support the patient and family but the ward staff as well."

"More Consultants have started to assess patient for end of life, rather than just the problem they are admitted to hospital with."

Qualitative Findings -2

Quotes from Phase 1 Hospital Sites: (from Preparation DVD)

"GSF has helped us think through in a different way how we might assess the patients who are likely to be in the last year of life – quite a revolution in hospital care. GSF is well thought through, patient focused and joined up"
Michael Connolly
Wythenshawe Hospital

"This work has been fantastic at raising the profile of End of Life Care generally for patients. Patient care has improved enormously"
Claire Littlewood / Bernie Thomas
St. Helen's & Knowsley

"I'd recommend it to others because I think it provides a real way of making sure people towards the end of life get quality standardised care"
Shane O'Reilly, Central Manchester

"The momentum is there, everybody in the hospital has known what it's all about. It's helped across all disciplines in the hospital"
Karen Groves, Southport & ORMSKIRK

"It's stimulated GP's to send the hospital their list of GSF patients from their practice"
Elaine Deeming Southport & ORMSKIRK

"Interesting and challenging but really positive"
Lulu Kreeger, Kingston

Qualitative Findings -3

Follow up Information from Phase 1 Pilot Sites 9-12 months Post Pilot

A follow up questionnaire was sent to all 12 pilot sites to find out where they were 9-12 months post pilot.
The aim of the questionnaire was to receive an update from each of the sites to ascertain whether GSFAH had been sustained on the pilot ward / hospital / team and to be updated with any developments or service improvements directly related to the GSFAH programme.
To date there have been replies from eight of the sites.

The challenges have been around reconfiguration of trusts, redeployment of ward staff and changes of personnel from the original facilitator posts making it difficult to get a clear sense of where the pilots are now.
The table below outlines the responses from the sites. 9 replies, others awaiting.

1. Are you still implementing GSF on your allocated ward / hospital	7 Yes 2 No
2. If not, why not?	Staff change redeployment or loss of key facilitator
3. If so, has this extended to any other areas/wards?	2 Yes, part of phase 2 1 continued whole hospital 1 continued OPD 3 – no – still on same ward 2 stopped
4. What further developments or improvements have you made?	Several cited e.g. • Consolidation and continuation • Improved EoLC Strategy Steering Group & Facilitators • Improved GSF use in other areas • Prognostication improved • Rapid discharge / LCP / ACP increased
5. Have you made specific developments, progress or improved cross boundary care with GPs and others?	Several e.g. electronic passport, review of policies
6. Have you had any changes of personnel – if so who has taken on this role or facilitator if anyone?	Facilitator changed 4 out of 9
7. Do you have senior Board/Executive level support or endorsement for further spread or use of GSF AH programme?	5 Yes 2 Not answered 2 uncertain