

## **2. Part B GSF Literature search – GSF Citations Sept 2013**

### **Studies where GSF is cited and referenced**

#### **Tabulated account of reviewed published articles- outlining method, results, conclusion and recommendations**

| Study authors and publication details  |   | results<br>Conclusion / recommendations/ discussion  |
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| <p>ABEL, J., RICH, A., GRIFFIN, T. and PURDY, S., 2009. End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year. Palliative medicine, 23(7), pp. 616-22.</p> | <p>Focus on EOLC strategy but asks-<br/><br/>Although a strict definition of 'end of life' is difficult, the question posed to healthcare professionals within the Gold Standards Framework documentation is helpful – 'would you be surprised if the patient died within the next 6–12 months?</p> | <p>The objectives of this study are to ascertain how many patients who died in a district general hospital in England might have been able to be cared for at home, to obtain the cost of each inpatient stay, to make an estimate of the maximum resource implications of care packages for these patients, and to calculate the savings in hospital admissions that could be used for the development of community services. These objectives are dependant on full implementation of the End of Life Strategy. A descriptive study of all inpatient deaths in one year in a district general hospital in the south west of England was conducted. Data collection -- case notes of all patients who died at the hospital from the beginning of June 2006 to end of May 2007. A total of 599 case notes of 627 patients who died in the study period were reviewed. A total of 331 patients (56%) were not assessed as being in the last year of life. Of the remaining 44%, 152 (26%) were clearly in the last year of life and 110 (18%) had significant co-morbidities and could probably have been recognised as being in the last year of life. A total of 399 (67%) of patients were appropriately admitted to hospital for their final illness, 194 (33%) could have been looked after at home. At least 119 (20%) clearly and 75 (13%) probably could have stayed at home. The mean cost of admission was &amp;pound;3173 per patient. A total of 77 (13%) of patients were admitted from nursing homes and 53 (69%) of these could have</p> |

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|  |                      | <p>stayed in the nursing home to die. A total of 44% of all patients who died within the district general hospital had chronic life threatening illnesses. A maximum of one third of all hospital deaths could have been looked after at home if excellent end of life services were in place. When commissioning end of life care services, it is possible to calculate how many extra patients may need community care packages and the cost that could be redistributed from hospital to community for these services.</p> <p>[PUBLICATION ABSTRACT]</p>   |
| <p>ALBERS, G., HARDING, R., PASMEN, H.R.W., ONWUTEAKA-PHILIPSEN, B.D., HALL, S., TOSCANI, F., RIBBE, M.W. and DELIENS, L., 2012. What is the methodological rigour of palliative care research in long-term care facilities in Europe? A systematic review. <i>Palliative medicine</i>, 26(5), pp. 722-33.</p> | <p>Refers to GSF</p> | <p>The European population is rapidly ageing, resulting in increasing numbers of older people dying in long-term care facilities. There is an urgent need for palliative care in long-term care facilities. Aim: The aim of this study was to systematically review the literature on palliative care research in long-term care facilities in Europe with respect to how the palliative care populations were described, and to determine the study designs and patient outcome measures utilized. We used a systematic literature review. The search strategy included searches of PubMed, Embase and PsychINFO databases from 2000 up to May 2010, using search terms related to 'palliative care' and 'end-of-life care' combined with search terms related to 'long-term care'. We selected articles that reported studies on patient outcome data of palliative care populations residing in a long-term care facility in Europe. This review demonstrated that there are few, and mainly descriptive, European studies on palliative care research in long-term care facilities. Fourteen studies were retained in the review, of which eight were conducted in the Netherlands. None of these studies described their study population specifically as a palliative care or end-of-life care population. Retrospective and prospective designs were applied using many different measurement instruments. Most instruments were proxy ratings. Symptom (management) was the most frequently measured outcome. To improve future research on palliative care in long-term care</p> |

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|   |   | <p>facilities, agreement on what can be considered as palliative care in long-term care facilities and, the availability of well-developed and tested measurement instruments is needed to provide more evidence, and to make future research more comparable</p>  |
| <p>ALLEN, A., 2011. End of Life Care for People with Dementia: A Best Practice Guide. Nursing Older People, 23(6), pp. 8.</p>                       | <p>Book Review</p>                                  | <p>Readers are provided with a useful and clear overview of the distinctions between end of life and palliative care with this book. The principles of best nursing practice and recent developments in each area of healthcare have been captured concisely, including the Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities of Care. Promotion of the application of these best practice tools is as important in the treatment of people with dementia as it is in the care of cancer patients.</p>   |
| <p>ANDERSON, A. and CHOJNACKA, I., 2012. Benefits of using the Liverpool Care Pathway in end of life care. Nursing Standard, 26(34), pp. 42-50.</p> | <p>Refers to GSF in references<br/>Focus on LCP</p> | <p>The Liverpool Care Pathway (LCP) is an integrated care pathway used to manage terminally ill patients in their final days or hours of life. It was developed by the Marie Curie Palliative Care Institute Liverpool to incorporate 'gold standard' care associated with the hospice setting into mainstream healthcare. The LCP has been advocated by the National Institute for Health and Clinical Excellence and the Department of Health for use in the care of dying patients. A literature review was undertaken to determine whether there is sufficient evidence that the LCP represents best practice in end of life care and whether patients cared for using the LCP receive better end of life care. Eight research articles were selected for inclusion in the review. The key themes of symptom management, communication and documentation were identified, and the research surrounding these themes was analysed. The analysis showed that use of the LCP promotes better care for patients in the terminal stage of illness; however, some weaknesses in the research were identified and recommendations have been made for further research and</p> |

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| <p>ANDREWS, N, SEYMOUR J (2011) Factors influencing the referral of non-cancer patients to community specialist palliative care nurses <i>International Journal of Palliative Nursing</i>, Vol 17, No 1</p> | <p>Refers to GSF registers</p> | <p><b>Aim:</b> To understand why non-cancer patients are under-represented on the caseloads of community Macmillan specialist palliative care nurses by exploring what influences community health professionals' referral patterns of non-cancer patients in one locality of a primary care trust. <b>Design:</b> The study adopted a qualitative design, making use of semi-structured interviews with a purposive sample of community health professionals comprising three GPs, three district nurses, and three community matrons. The framework approach was used for analysis. <b>Findings:</b> The classification of patients, the perception of the palliative care service, the existence of different pathways of care for cancer and non-cancer patients, and the role of other specialist nurses all seem to influence the referral patterns of community health professionals. <b>Conclusion:</b> Although further research is required to fully understand all of the relevant viewpoints, in particular those of patients and carers, it appears that innovative new models of service delivery could be developed that address the engrained</p> |

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|  |                                       | perception of the Macmillan nursing service as being for dying cancer patients only, as well as the blurred boundaries between Macmillan nurses and other senior clinical nurses.   |
| ASHTON, S., MCCLELLAND, B., ROE, B., MAZHINDU, D. and GANDY, R., 2009. An end-of-life care initiative for people with dementia. <i>European Journal of Palliative Care</i> , <b>16</b> (5), pp. 240-243. | Full text not available               |   |
| BIRCH, D. and STOKOE, D., 2010. Caring for people with end-stage dementia. <i>Nursing Older People</i> , <b>22</b> (2), pp. 31-6.  | Refers to GSF in relation to dementia | In the UK, the DH's end of life care initiative (DH 2003) introduced the Gold Standards Framework (GSF), which aimed to improve communication, community-based continuity and co-ordination of care (Thomas 2003). The GSF provides guidance on possible prognostic indicators for identifying the last six to 12 months of life in a number of diseases including dementia (Box 3, page 34). The symptoms in Box 3, if present, can indicate that end of life care may be appropriate. The ability to identify the end stage of dementia by use of the GSF assists in anticipating treatment decisions and is paramount to the care planning of patients entering the final phase of their lives. Healthcare professionals need to be able to work with colleagues, patients and their families to ensure that symptoms are managed in the most appropriate and effective way. |
| BLACKFORD, J, STREET A. 2013<br>Facilitating advance care planning in community  | Refers to GSF                         | This paper describes the development of a tool for palliative care nurses to initiate and facilitate advance care planning (ACP) conversations in community palliative care practice. Seven   |

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| <p>palliative care: conversation starters across the client journey<br/> <i>International Journal of Palliative Nursing</i> 2013, Vol 19, No 3 p 132-139</p> |  | <p>community palliative care services located across Australia participated in a multi-site action research project. Data included participant observation, individual and focus group interviews with palliative care health professionals, and medical record audit. A directed content analysis used a pre-established palliative care practice framework of referral, admission, ongoing management, and terminal/discharge care. From this framework a Conversation Starter Tool for ACP was developed. The Tool was then used in orientation and continuing nurse education programmes. It provided palliative care nurses the opportunity to introduce and progress ACP conversations.</p> |
| <p>BLAND, P., 2012. GPs' vital role in end of life care. <i>Practitioner</i>, <b>256</b>(1752), pp. 5.</p>   | <p>Refers to GSF in literature</p>           |   |
| <p>BOWDEN, H., 2010. Going for gold in primary care. <i>Primary Health Care</i>, <b>20</b>(4), pp. 22-24.</p>  | <p>Description of GSF training / process</p> | <p>Caring for people who are approaching the end of their lives and their families is at the heart of general practice. Primary care teams may have small numbers of patients in the final year or so of life, but this is when most health care and support is needed. A new training package from the gold standards framework builds on existing programmes to enable primary care teams to achieve the best possible care for patients and their families</p>   |

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| <p>BOWER, B., RODERICK, S. and ARNOLD, S., 2010. Improving integrated team working to support people to die in the place of their choice. <i>Nursing Times</i>, <b>106</b>(32), pp. 14-6.</p> | <p>Local practical discussion of GSF</p> | <p>Dying in a place of one's choice is considered to be a quantifiable measure of the effectiveness of end of life services in primary care. Although most people say they would prefer to die in their own home, very few actually do so. This article looks at how a team of community nurses and GPs changed their practice by using recognised end of life care tools. These helped practitioners in supporting adults with terminal illnesses to die in a place of their choice. A subsequent audit of patients' actual place of death against their preferred place demonstrates how working in more integrated ways has helped. [PUBLICATION ABSTRACT]</p> <p>The Gold Standards Framework offers a practical structure for primary care practitioners to coordinate and support care pathways centred on the needs of patients and their carers (Pellett, 2009; Thomas, 2003).</p> <p>This means GPs, community nurses, Macmillan nurses and other professionals involved in end of life care meeting together. Through liaison and discussions, practitioners are prompted to look at the seven Cs of care provision. From November 2009, we increased the frequency of the practice's GSF multidisciplinary team meetings from every three months to every eight weeks. Although the number of patients on the GSF registers and hence the related workload increased, practitioners were still able to identify people with complex needs before they had a crisis in the last few weeks of life.</p> <p>Community nurses, practice nurses and GPs were empowered to add patients with any illness requiring palliative care who were likely to be in the last year of life to the register.</p> <p>Previously, the register had focused on people with a cancer diagnosis believed to be in the last six months of life. With structured meetings being held every eight weeks, clinicians are now better able to monitor individualised care pathways</p> |
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|   |  | <p>before the person dies and adjust care coordination to meet changing needs (DH, 2009; Grande et al, 1997). As practitioners experienced in coordinating end of life care, the community nurses maintain a lead role in organising the care of patients who want their involvement. However, being a busy practice covering two sites, patients would often see the allocated duty GP on the day they requested a visit. Now, through the GSF meetings, a lead GP who knows the patient well is identified, and makes any medical visits to add further continuity to care.</p> <p>The GSF meetings are jointly chaired by the GP lead for end of life care and the community charge nurse. The meetings act as a dynamic forum for identifying care issues and group problem solving (DH, 2009). The chairs identify action plans from the discussions. The most appropriate clinician is then nominated to work alongside patients and carers, supporting them in exploring and meeting their needs (Ellershaw and Ward, 2003). Recent deaths are reflected on to facilitate constructive practical learning (Thomas, 2003).</p> |
| <p>BOWERS, B., 2012. Quality indicators to measure end-of-life care. <i>Nursing Times</i>, <b>108</b>(34/35), pp. 21-2.</p> |  | <p>district nursing numbers continue to decline at a time when there is increasing demand from an ageing population for more care to be provided at home (Royal College of Nursing, 2012). In end-of-life care structure relates to care provider attributes (having access to out-of-hours services and adequate numbers of staff available to provide care during the day); process relates to care given to patients (district nurses proactively talking to patients about their needs and informing out-of-hours services about these); and outcome is what happens to patients (did they die in the place of their choice?).</p> <p>If district nurses already use established end-of-life pathways, such as the Gold Standards Framework, measuring the percentage of patients who die in their</p>   |



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|   |  | preferred place of is a relatively quick exercise.  |
| <p>BROWN, M.A., SAMPSON, E.L., JONES, L. and BARRON, A.M., 2013. Prognostic indicators of 6-month mortality in elderly people with advanced dementia: A systematic review. <i>Palliative medicine</i>, <b>27</b>(5), pp. 389-400.</p> | <p>In contrast, in the United Kingdom, the Gold Standards Framework (GSF) does not promote the development of care focused on time remaining but instead promotes planning and anticipation of worst-case scenarios in order to promote care driven by patient preferences.<sup>28</sup> The GSF prognostic guidelines (which are widely used but have not been prospectively validated) aim to identify patients in the last 6–12 months of life, with the ABCD register classifying prognosis on a scale of years, months, weeks, or days, and this status is reviewed monthly</p> <p>Review of Literature</p> | <p>Background: For end-of-life dementia patients, palliative care offers a better quality of life than continued aggressive or burdensome medical interventions. To provide the best care options to dementia sufferers, validated, reliable, sensitive, and accurate prognostic tools to identify end-of-life dementia stages are necessary. Aim: To identify accurate prognosticators of mortality in elderly advanced dementia patients consistently reported in the literature. Design: Systematic literature review. Data sources: PubMed, Embase, and PsycINFO databases were searched up to September 2012. Reference lists of included studies were also searched. Inclusion criteria were studies measuring factors specifically related to 6-month outcome in patients diagnosed with dementia in any residential or health-care setting. Results: Seven studies met the inclusion criteria, five of which were set in the United States and two in Israel. Methodology and prognostic outcomes varied greatly between the studies. All but one study found that Functional Assessment Staging phase 7c, currently widely used to assess hospice admission eligibility in the United States, was not a reliable predictor of 6-month mortality. The most common prognostic variables identified related to nutrition/nourishment, or eating habits, followed by increased risk on dementia severity scales and comorbidities. Conclusions: Although the majority of studies agreed that the Functional Assessment Staging 7c criterion was not a reliable predictor of 6-month mortality, we found a lack of prognosticator concordance across the literature. Further studies are essential to identify reliable, sensitive, and specific prognosticators, which can be applied to the clinical setting and allow increased availability of palliative</p> |

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|  |                      | care to dementia patients.  |
| BURNS, C. and HURMAN, C., 2013. Reducing hospital admissions from care homes. <i>Nursing Times</i> , <b>109</b> (1/2), pp. 23-5. | Local service review | <p>Admission to hospital can be a frightening experience for care home residents, and is often unnecessary. In east Surrey a number of care home residents were being transferred to the acute hospital inappropriately. To reduce avoidable attendance/admissions, a community matron for care homes role was developed. The matrons used an advisory, supportive and facilitative approach to assist care home staff in developing their competence and confidence in managing their residents' care. The service has significantly reduced avoidable attendance/ admissions and has improved care quality. [PUBLICATION ABSTRACT]</p> <p>In order to enable more residents to die in their care homes rather than in hospital, staff were given education, advice and support on the Gold Standards Framework in Care Homes, which is a national system-focused approach that enables care homes to provide quality care for all residents nearing the end of life (National Gold Standards Framework Centre, 2010). Advanced care planning and "thinking ahead", where a voluntary discussion about an individual's future care and wishes takes place, are key aspects of the Gold Standards Framework to enable services to provide high-quality end-of-life care. A local audit was completed to compare local and national figures to review the transfer of residents at the end of life from care homes to the acute hospital within this locality.</p> |
| BYRNE, J. and BEETY, D., 2007. Tools to improve end-of-life care for neurological patients. <i>British Journal of</i>            |                      | Discussion how tools such as the Gold Standards Framework and Preferred Priorities of Care can improve care at the end of life for people with neurological conditions  |

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| <p><i>Neuroscience Nursing</i>, <b>3</b>(5), pp. 190.</p>   |                              |   |
| <p>COLLINS, F., 2004. Using 'gold standards' to raise awareness of palliative care. <i>Nursing times</i>, <b>100</b>(48), pp. 30-31</p>   | <p>Description</p>           | <p>The gold standards framework (GSF) is a practice-based system aimed at improving the organisation and quality of palliative care services for patients who are at home in their last 12 months of life. The aim is for patients to receive a better quality service with greater control over their care and an increased likelihood they will die where they choose.</p>  |
| <p>COVINGTON, M., 2013. End-of-life care: implementing the Gold Standards Framework. <i>Nursing &amp; Residential Care</i>, <b>15</b>(3), pp. 146-149.</p>  | <p>Description of 1 home</p> | <p>The Gold Standards Framework programme for care homes aims to ensure quality end-of-life care. One home shares its experience of implementing the programme and achieving Beacon status</p>  |
| <p>DAVISON, S.N., 2011. Integrating Palliative Care for Patients with Advanced Chronic Kidney Disease: Recent advances, remaining challenges. <i>Journal of palliative care</i>, <b>27</b>(1), pp. 53-61.</p> | <p>Refers to GSF</p>         | <p>Patients with ESRD have extensive and unique end-of-life care considerations and needs. Despite substantial advancements in renal palliative care over the past decade, much research is still required. Identifying CKD patients whose illness trajectory has shifted and would likely benefit from a palliative approach to care should be a priority of all nephrology programs. Further research on symptom management, the effectiveness of ACP, the life expectancy of conservatively managed and incident dialysis patients, anticipated changes in functional status and HRQL with the initiation of dialysis (especially among the frail elderly), and the best way to deliver renal palliative care is required to maximize the integration and effectiveness of renal palliative care services.</p> |

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| <p>DESAI, A.K. and GROSSBERG, G.T., 2011. Palliative and end-of-life care in psychogeriatric patients. <i>Aging Health</i>, <b>7</b>(3), pp. 395-408.</p>              | <p>Refers to GSF</p> | <p>Rapidly growing number of elderly persons and their families are burdened by one or more terminal illnesses in the later years of their life. How best to support their quality of life is a major challenge for healthcare teams. Palliative and end-of-life (PEOL) care is well positioned to respond to this challenge. While the evidence of PEOL is just beginning, much of the suffering can be relieved by what is already known. PEOL care for the elderly needs to go beyond the focus on the patient and should rest on a broad understanding of the nature of suffering that includes family and professional caregivers in that experience of suffering. The dissemination of PEOL care principles should be a public health priority. This article aims to improve understanding of appropriate PEOL care in the elderly and discuss future perspectives</p> |
| <p>DOHERTY, L. and BERRY, L., 2009. Poor record on end of life care of older patients found in acute hospitals. <i>Nursing Older People</i>, <b>21</b>(10), pp. 7.</p> | <p>Refers to GSF</p> | <p>editorial</p>   |
| <p>DRENNAN, V., 2009. End-of-life care challenges. <i>Primary Health Care</i>, <b>19</b>(1), pp. 6.</p>  | <p>Editorial</p>     | <p>Refers to shipman et al article</p>   |
| <p>EYRE, S., 2010. Supporting informal carers of dying patients: the district nurse's role. <i>Nursing Standard</i>, <b>24</b>(22), pp. 43-</p>                        | <p>Refers to GSF</p> | <p>This article explores the role of the district nurse in supporting family and friends who act as informal carers for patients who wish to die at home. The district nurse can support carers by promoting patient comfort, assessing carer needs, using communication and counseling skills, providing timely information, planning for anticipated needs, and co-ordinating and liaising with appropriate services and</p>   |

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|  |  | <p>professionals. This requires the district nurse to develop a trusting carer-nurse relationship. The Gold Standards Framework and Liverpool Care Pathway for the Dying Patient are discussed as a means of guiding healthcare professionals to optimise palliative care for patients and carers. The author suggests that the principles discussed are equally applicable to any nurse who cares for dying patients and their families.</p>   |
| <p>FINUCANE A, STEVENSON B, MOYES R, OXENHAM D, MURRAY S. 2013 Improving end-of-life care in nursing homes: Implementation and evaluation of an intervention to sustain quality of care</p> <p>published online 23 April 2013<br/><i>Palliat Med</i></p> |  | <p><b>Abstract</b><br/> <b>Background:</b> Internationally, policy calls for care homes to provide reliably good end-of-life care. We undertook a 20-month project to sustain palliative care improvements achieved by a previous intervention.<br/> <b>Aim:</b> To sustain a high standard of palliative care in seven UK nursing care homes using a lower level of support than employed during the original project and to evaluate the effectiveness of this intervention.<br/> <b>Design:</b> Two palliative care nurse specialists each spent one day per week providing support and training to seven care homes in Scotland, United Kingdom; after death audit data were collected each month and analysed.<br/> <b>Results:</b> During the sustainability project, 132 residents died. In comparison with the initial intervention, there were increases in (a) the proportion of deceased residents with an anticipatory care plan in place (b) the proportion of those with Do Not Attempt Cardiopulmonary Resuscitation documentation in place and (c) the proportion of those who were on the Liverpool Care Pathway when they died. Furthermore, there was a reduction in inappropriate hospital deaths of frail and elderly residents with dementia. However, overall hospital deaths increased.<br/> <b>Conclusions:</b> A lower level of nursing support managed to sustain and build on the initial outcomes. However, despite increased adoption of key end-of-life care tools, hospital deaths were higher during the sustainability project. While</p> |

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|   |  | <p>good support from palliative care nurse specialists and GPs can help ensure that key processes remain in place, stable management and key champions are vital to ensure that a palliative care approach becomes embedded within the culture of the care home.</p>   |
| <p>FROGGATT, K., VAUGHAN, S., BERNARD, C. and WILD, D., 2009. Advance care planning in care homes for older people: an English perspective. <i>Palliative medicine</i>, <b>23</b>(4), pp. 332-8.</p>                                      | <p>Focus ACP – EOLC tools<br/>Refers GSF</p> | <p>Advance care planning (ACP) as a process of discussing and recording wishes for future care and treatment is increasingly being promoted and discussed in the UK, reflecting recent changes in legislation. This study describes current ACP practice in care homes for older people drawing on data from a questionnaire survey (n = 213) of, and interviews (n = 15) with, care home managers. Whilst consultation about general care is taking place in the majority of homes surveyed using both formal and informal processes, the number of residents that have completed any ACP processes varies. Managers face intrinsic and extrinsic challenges related to the ascertaining of, and the implementing of wishes as they address ACP in the care home context. Until these wider contextual factors are addressed it will be difficult for staff in care homes to effectively undertake and implement ACP in care homes.<br/>[PUBLICATION ABSTRACT</p> |
| <p>GALLAGHER, J. and FORMAN, M., LOUISE, 2012. Development of a standardised pro forma for specialist palliative care multidisciplinary team meetings. <i>International journal of palliative nursing</i>, <b>18</b>(5), pp. 248-253.</p> | <p>Service review</p>                        | <p>A pro forma of the caseload of the community palliative care clinical nurse specialists in the Central Lancashire Community Specialist Palliative Care Team was devised to provide a brief overview of each patient's plan of care for use in the multidisciplinary team meetings and as a consequence of preparing for the UK Department of Health's peer review process. The pro forma was also designed to be used in everyday clinical practice in Gold Standards Framework meetings in the community. It has been evaluated by the team and found to be helpful for highlighting key issues in clinical practice, such as symptoms, psychological and emotional needs, and Preferred Priorities of Care. Over the past 2 years, it has</p>   |

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|  |                            | also complemented the organisation's drive to become 'paperless'. This article looks at how the pro forma was developed, how it has evolved over time, and how it works today. Consideration has also been given to its benefits and limitations   |
| GREAVES, C., BAILEY, E., STOREY, L. and NICHOLSON, A., 2009. Implementing end of life care for patients with renal failure. <i>Nursing Standard</i> , <b>23</b> (52), pp. 35-41. | Focus on PPC refers to GSF | Traditional palliative care services have focused on individuals with cancer. The NHS National End of Life Care Programme, launched in December 2003, has been working to address this anomaly and to try to enhance end of life care provision for other patient groups. This article reports on work in the area of renal failure at Westmorland General Hospital, Cumbria, where the Preferred Priorities for Care tool has been introduced to support patients nearing the end of life.  |
| GRIFFIN, T., THOMAS, K. and SAWKINS, N., 2009. 'Going for Gold': GSF in Care Homes Training Programme. <i>End of Life Care Journal</i> , <b>3</b> (1), pp. 54-57.                | Full text not available    | The Gold Standards Framework in Care Homes (GSFCH) Training Programme is now the most widely used care homes' training programme in UK end-of-life care. It can assist commissioners and care homes to meet their local and national quality targets. The key aims are to improve quality of care and collaboration with GPs and reduce hospitalisation. The programme has evolved over the last 5 years and is closely linked to the GSF in Primary Care Programme, which is used by the majority of GP practices. The work is still developing and is backed by a growing evidence base and the shared experience of over 700 care homes. Attaining quality care is now firmly on the government agenda (Darzi, 2008). The GSFCH programme provides quality improvement, quality assurance and quality recognition for end-of-life care in care homes, enabling all care homes to meet the standard of excellence required. This article will provide further details of this exciting programme, its key lessons and demonstrated benefits, with ideas for future development |

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| <p>GROVES, K., 2009. Imagine: a creative challenge towards holism. <i>Palliative medicine</i>, <b>23</b>(1), pp. 5-7.</p>               | <p>Informed critical comment</p> | <p>the IT literate GP who had his Gold Standards Framework (GSF) register on the computer at the surgery, but those GSF registers would be linked electronically, and accessible by all who needed that information (hospitals, A&amp;E departments, out-of-hours services, specialist palliative care services) to ensure that appropriate care took place.5 Regular GSF meetings would occur in every practice. Do patients know they are on the GSF register? Should they? What eligibilities does this give them? Why is the hospital the missing link in the GSF chain? Why does the out-of-hours service need a separate fax? Why are specialist palliative care services still using pen and paper?</p> |
| <p>IBADETE FETAHU, 2012. Long-term conditions. A guide for nurses and healthcare professionals. <i>NursingTimes.net</i>, , pp. n/a.</p> | <p>Book review</p>               | <p>The section on end of life care is excellent and clearly describes all the tools available for staff to use including the Liverpool care pathway, the Gold Standards Framework and the preferred priorities for care.</p>   |
| <p>ILEY, K., 2012. Improving palliative care for patients with COPD. <i>Nursing Standard</i>, <b>26</b>(37), pp. 40-6.</p>              | <p>Refers to GSF</p>             | <p>COPD is not fully reversible and is a common cause of death in the UK. It is difficult to predict when a patient with COPD has end-stage disease and requires palliative care. Patients with COPD are less likely to receive palliative care than those with cancer. The need to discuss treatment options, palliative care and end of life care with these patients is important, although it is acknowledged that these discussions can be difficult for patients and healthcare professionals<br/>Advance care planning should be instigated by the patient, may include the carer, and should be documented and reviewed regularly (Gold Standards Framework 2008).</p>                                 |



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| <p>INGLETON, C., PAYNE, S., SARGEANT, A. and SEYMOUR, J., 2009. Barriers to achieving care at home at the end of life: transferring patients between care settings using patient transport services. <i>Palliative medicine</i>, <b>23</b>(8), pp. 723-30.</p> | <p>Refers to GSF but focussed on Marie Curie DCP</p> | <p>Enabling patients to be cared for in their preferred location often involves journeys between care settings. The challenge of ensuring journeys are timely and safe emerged as an important issue in an evaluation of palliative care services, which informed a service redesign programme in three areas of the United Kingdom by the Marie Curie Cancer Care "Delivering Choice Programme". This article explores perceptions of service users and key stakeholders of palliative care services about problems encountered in journeys between care settings during end-of-life care. This article draws on data from interviews with stakeholders (n = 44), patients (n = 16), carers (n = 19) and bereaved carers (n = 20); and focus groups (n = 9) with specialist nurses. Data were gathered in three areas of the United Kingdom. Data were analysed using a framework approach. Transport problems between care settings emerged as a key theme. Four particular problems were identified: (1) urgent need for transport due to patients' rapidly changing condition; (2) limited time to organise transfers; (3) the management of specialist equipment and (4) the need to clarify the resuscitation status of patients. Partnership working between Ambulance Services and secondary care is required to develop joint protocols of care to ensure timely and safe transportation between care settings of patients, who are near their end of life. Commissioning of services should be responsive to the complexities of patients' needs and those of their families. [PUBLICATION ABSTRACT]</p> |
| <p>INGLETON, C. and FROGGATT, K., 2009. 'Delivering 'gold standards' in end-of-life care in care homes: A question of teamwork? ': Commentary. <i>Journal of Clinical Nursing</i>, <b>18</b>(12), pp.</p>  | <p>Crit of GSF</p>                                   | <p>Comments on an article by Alistair Hewison et al. (see record 2009-07334-012). Hewison et al. reported findings on a study that investigated the introduction of the Gold Standard Framework (GSF) for improving end-of-life care into care home in England. A central feature of the study by Hewison et al. is that of teamwork and its importance in the successful implementation of new programs of care. The authors urge that organizations wishing to implement such</p>  |

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| 1812-1815.  |                             | programs should address the quality of teamwork before introducing them into practice. (PsycINFO Database Record (c) 2012 APA, all rights reserved)  |
| JOHNSON, M.J. and GADOUD, A., 2011. Palliative Care for People with Chronic Heart Failure: When is it time? <i>Journal of palliative care</i> , <b>27</b> (1), pp. 37-42.   | Refers GSF                  | There are several scoring systems for prognosis in CHF, including two Web-based tools (11-14). However, for the vast majority of patients, these are probably less useful when applied to an individual. Clinical acumen and conditions such as progressive renal dysfunction, cardiac cachexia, escalating diuretic doses, recurrent episodes of decompensation despite optimally tolerated therapy, or changes in biochemical markers could act as triggers for a palliative care discussion (15-19).  |
| JONES, L., HARRINGTON, J., BARLOW, C.A., TOOKMAN, A., DRAKE, R., BARNES, K. and KING, M., 2011. Advance care planning in advanced cancer: Can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. <i>Palliative &amp; Supportive Care</i> , <b>9</b> (1), pp. 3-13. | RCT about ACP<br>Refers GSF | Abstract Objective: Little is known about the effectiveness of advance care planning in the United Kingdom, although policy documents recommend that it should be available to all those with life-limiting illness. Method: An exploratory patient preference randomized controlled trial of advance care planning discussions with an independent mediator (maximum three sessions) was conducted in London outpatient oncology clinics and a nearby hospice. Seventy-seven patients (mean age 62 years, 39 male) with various forms of recurrent progressive cancer participated, and 68 (88%) completed follow-up at 8 weeks. Patients completed visual analogue scales assessing perceived ability to discuss end-of-life planning with healthcare professionals or family and friends (primary outcome), happiness with the level of communication, and satisfaction with care, as well as a standardized measure of anxiety and depression. Results: Thirty-eight patients (51%) showed preference for the intervention. Discussions with professionals or family and friends about the future increased in the intervention arms, whether randomized or preference, but happiness with communication was unchanged or worse, and satisfaction with services decreased. Trial participation did |

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|   |                   | <p>not cause significant anxiety or depression and attrition was low. Significance of results: A randomized trial of advance care planning is possible. This study provides new evidence on its acceptability and effectiveness for patients with advanced cancer.</p>   |
| <p>KELLY, C., 2011. Palliative care for patients with chronic respiratory disease. <i>Nursing Standard</i>, <b>26</b>(5), pp. 41-6.</p> | <p>Refers GSF</p> | <p>The article provides an overview of the key issues relating to palliative care for patients with chronic respiratory disease. The need for palliative care in this patient group is identified and the illness trajectory considered. Issues of communication, provision of palliative care services and symptom management are discussed and the need for improved services highlighted</p> <p>The Gold Standards Framework (GSF) (2008) outlines different disease trajectories and identifies prognostic indicators, which are clearly defined for COPD (Box 2). There is limited evidence that these indicators can predict end of life in COPD, but research in this area is continuing. In addition, the GSF advocates the use of the surprise question: 'Would I be surprised if the patient were to die in the next 12 months?' If the answer to this question is no, then end of life care should be provided and GSF principles should be adhered to. Although less clearly defined, these same indicators can be useful in identifying palliative care needs of patients with chronic respiratory disease other than COPD.</p> |
| <p>KENT, A., 2012. Motor neurone disease: an overview. <i>Nursing Standard</i>, <b>26</b>(46), pp. 48-57, quiz 58.</p>                  | <p>Refers GSF</p> | <p>Motor neurone disease (MND) is a relatively rare, progressive and incurable neurological condition affecting patients' speech, mobility and respiratory function. Care of patients with MND is complex and involves various healthcare professionals and services. There is a need to discuss symptom management and promote palliative and end of life care from the point of diagnosis to ensure appropriate holistic care is provided.</p>   |

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|  |  | <p>The Gold Standards Framework (2005) should be used to provide a model for end of life care. Given the disease trajectory and prognosis of MND, it is imperative that any interventions and management should be timely; planning ahead is crucial. Managing crises can reduce individual autonomy as choices in such circumstances are often limited.</p>   |
| <p>KILLICK, S., PHARAOH, A. and RANDALL, F., 2010. Advance care planning in care homes. <i>Palliative medicine</i>, <b>24</b>(4), pp. 445-6; author reply 447-8.</p>   | <p>We wish to raise the following points about the article 'An evaluation of the implementation of a programme to improve end-of-life care in nursing homes'. <i>Palliative Medicine</i> 2009; 23: 502–511</p> | <p>The paper states that post-Gold Standards Framework in Care Homes (GSFCH), 67% of residents had an Advance Care Plan in place (Table 4). raise concern as to whether the discussions taking place were in fact appropriate or whether they were being conducted purely as a box-ticking exercise in order to meet with the guidance of the GSFCH</p>  |
| <p>KING, M., VASANTHAN, M., PETERSEN, I., JONES, L., MARSTON, L. and NAZARETH, I., 2013. Mortality and Medical Care after Bereavement: A General Practice Cohort Study. <i>PLoS One</i>, <b>8</b>(1), pp. n/a.</p> |  | <p>Bereaved spouses or partners are thought to be at increased risk of morbidity and mortality. However, there are few large prospective studies and results are inconsistent. We estimated the relative mortality, prescription of psychotropic medication and use of primary medical care services in adults whose cohabitee died of cancer. To do this, we undertook a cohort study using The Health Improvement Network (THIN) UK primary care database. Participants were 1) people aged over 40, who were registered with general practices and had been exposed to the death of a cohabitee from cancer; and 2) a comparison cohort frequency matched on five year age bands and sex who were cohabiting with a living partner. The baseline was chosen as six months before the date of the cancer death for the exposed group and a random date for the unexposed group. Incidence rate ratios (IRR) with 95% confidence intervals (CI) were estimated using random effects Poisson regression to account for clustering within general practices and adjusting for other key variables. 92,129 patients were</p> |

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|  | Refers GSF | <p>studied for a median follow up of 4 years. Cohabitees of patients who died of cancer were less likely to die of any cause (IRR 0.71, CI 0.68-0.74) after adjustment for age, gender, number of non-psychotropic prescriptions 6 months before the cancer death/index date, use of psychotropic medication 6 months before the cancer death/index date, smoking, alcohol and area deprivation score. Exposed patients were more likely to receive a prescription for antidepressant or hypnotic medication and to attend their GP both before and after the death of the cohabitee. In conclusion, we did not confirm increased mortality in cohabitees of people dying from cancer.</p> <p>People with cancer are more likely to be placed on registers as part of the Gold Standards Framework, a structured care programme in UK general practice (<a href="http://www.goldstandardsframework.org.uk/">http://www.goldstandardsframework.org.uk/</a>), and be offered opportunities to discuss future care planning and preferred priorities for care and place of death.</p> |
| <p>KINLEY, J., FROGGATT, K. and BENNETT, M.I., 2013. The effect of policy on end-of-life care practice within nursing care homes: A systematic review. <i>Palliative medicine</i>, <b>27</b>(3), pp. 209-20.</p> |            | <p>The number of older people in the UK is increasing. A significant proportion of end of life care for this population is currently provided and will increasingly be provided within nursing care homes. To identify the impact of implementing end of life care policy with regard to the use of the Gold Standards Framework in Care Homes programme, the Liverpool Care Pathway (or an Integrated Care Pathway) and educational/training interventions to support the provision of end of life care within nursing care homes within the UK. Systematic literature review of published literature and reports. An electronic search was undertaken of five databases-Medline, CINAHL, EMBASE, Web of Science and the Cochrane library and websites of government and palliative care organisations for papers and reports published between 2000 to June 2010. The reference lists of</p>   |

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|  |                         | <p>studies that were retrieved for the detailed evaluation were hand-searched for any additional relevant citations.. Only studies that included comparative outcome data were eligible for inclusion. Eight papers/reports, incorporating information from three studies were identified. Two studies reported on the implementation of the Gold Standards Framework in Care Homes programme and one the implementation of an Integrated Care Pathway for the last days of life. Improvements occurred in resident outcomes and in relation to staff recognising, managing and meeting residents needs for end of life care. The studies provided limited evidence on improved outcomes following the implementation of these interventions. Further research is needed, both within the UK and internationally, that measures the process and impact of implementing these initiatives.</p> |
| <p>LAKASING, E., 2009. Providing good palliative care for patients at home. <i>Practitioner</i>, <b>253</b>(1717), pp. 28-31.</p>                | <p>GP opinion piece</p> | <p>Three-quarters of people wish to die at home though currently only a quarter of deaths occur in this setting. Primary care has the potential to deliver high-quality domiciliary palliative care that could potentially increase the proportion of the population realising their wish. The main tenets to successful management are close liaison between the patient, their carers and other agencies, and effective use of the therapeutic armamentarium for symptomatic relief.</p>  |
| <p>LEE, L., 2012. Giving staff confidence to discuss sexual concerns with patients. <i>Cancer Nursing Practice</i>, <b>11</b>(2), pp. 28-32.</p> |                         | <p>The PEPSI COLA aide-memoire (Box 1) is used to carry out a comprehensive holistic needs assessment of the patient. Relationships are included under the assessment of Emotion in the aide-memoire (Gold Standards Framework 2010).</p>   |

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| <p>LEYSHON, J., 2012. Managing severe breathlessness in patients with end-stage COPD. <i>Nursing Standard</i>, <b>27</b>(6), pp. 48-56; quiz 58.</p> | <p>Describes GSF</p>    | <p>The disease trajectory in chronic obstructive pulmonary disease (COPD) can be long and uncertain, making it difficult to identify when patients are at the end-stage of the disease. Patients with COPD have been found to experience similar levels of symptom burden to those with lung cancer, yet they are less likely to receive palliative care and treatment with opiates, anxiolytics or antidepressants. This article focuses on pharmacological and non-pharmacological approaches to the management of severe breathlessness in patients with end-stage COPD.</p> <p>Use of the GSF (2011) is intended to help identify all patients, regardless of diagnosis, nearing the end of life who would benefit from additional support. Specific indicators for different diseases are listed in the GSF (2011) to help clinicians identify patients who may benefit from a palliative care approach. Box 1 identifies clinical indicators for identification of patients with COPD who might benefit from palliative care (GSF 2011).</p> |
| <p>LOVERIDGE, C., 2009. A national strategy for COPD - opportunity or threat? <i>Practice Nurse</i>, <b>38</b>(1), pp. 38-39,42-45.</p>              | <p>Refers GSF</p>       | <p>COPD is a terminal, long-term condition and the care of patients with end-stage COPD has been sub-standard.( <a href="#">n5</a>) Over recent months this has improved with the recognition of the need for palliation and hospice support. The use of the Gold Standards Framework (GSF)( <a href="#">n14</a>) to identify patients at the end of life has raised the profile of patients living with end-stage disease and in turn that of patients with COPD.</p>   |
| <p>MCGINN, M., 2010. End of life care... 'Online cancer education forum'. <i>European Journal of Cancer Care</i>, <b>19</b>(2), pp. 144-144.</p>     | <p>Online education</p> | <p>This module presents background and encourages personal reflection and learning on end of life care terminology, concepts and ethics for all healthcare staff working with adult cancer patients. Consideration is given to resuscitation issues, communication skills competence and end of life care pathways such as Gold Standards Framework and Liverpool Care Pathway for the Dying</p>   |

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| MITCHELL, G.K., 2011. Primary palliative care: Facing twin challenges. <i>Australian Family Physician</i> , <b>40(7)</b> , pp. 517-8.  |  | roll out of GSF type system in Australia  |
| MORITA, T., MIYASHITA, M., YAMAGISHI, A., AKIYAMA, M., AKIZUKI, N., HIRAI, K., IMURA, C., KATO, M., KIZAWA, Y., SHIRAHIGE, Y., YAMAGUCHI, T. and EGUCHI, K., 2013. Effects of a programme of interventions on regional comprehensive palliative care for patients with cancer: a mixed-methods study. <i>Lancet Oncology</i> , <b>14(7)</b> , pp. 638. | Japan<br>In the past 10 years or so, the UK has implemented the Gold Standards Framework, which stresses communication and coordination in the community through development of a palliative care registry and regular meetings. <sup>10</sup> The results of a review <sup>10</sup> suggested that the most important perceived benefit of the Gold Standards Framework is enabling of communication between health-care professionals in the community—a finding consistent with those from studies in Australia, <sup>11</sup> Canada, <sup>12</sup> and the Netherlands. <sup>13</sup> | Improvement of palliative care is an important public health issue, but knowledge about how to deliver palliative care throughout a region remains inadequate. We used surveys and in-depth interviews to assess changes in the quality of palliative care after regional interventions and to gain insights for improvement of palliative care at a regional level. Methods In this mixed-methods study, a comprehensive programme of interventions for regional palliative care for patients with cancer was implemented from April 1, 2008, to March 31, 2011 in Tsuruoka, Kashiwa, Hamamatsu, and Nagasaki in Japan. Interventions included education, specialist support, and networking. We surveyed patients, bereaved family members, physicians, and nurses before and after the interventions were introduced. We also did qualitative interviews with health-care professionals after the interventions were introduced. Primary endpoints were numbers of home deaths, coverage of specialist services, and patient-reported and family-reported qualities of care. This trial is registered with UMIN Clinical Trial Registry, Japan (UMIN000001274). Findings 859 patients, 1110 bereaved family members, 911 physicians, and 2378 nurses provided analysable preintervention surveys; 857 patients, 1137 bereaved family members, 706 physicians, and 2236 |



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|  |   | <p>nurses provided analysable postintervention surveys. Proportions of home deaths increased significantly, from 348 of 5147 (6·76%) before the intervention programme to 581 of 5546 (10·48%) after the intervention programme (<math>p&lt;0\cdot0001</math>). Furthermore, 194 of 221 (87·78%) family members of patients who died at home answered that these patients had wanted to die at home. The ratio of patients who received palliative care services to all patients who died of cancer increased significantly (from 0·31 to 0·50; <math>p&lt;0\cdot0001</math>). The patient-reported (effect size 0·14; adjusted <math>p=0\cdot0027</math>) and family-reported (0·23; <math>p&lt;0\cdot0001</math>) qualities of care were significantly better after interventions than before interventions. Physician-reported and nurse-reported difficulties decreased significantly after the introduction of the interventions. Qualitative interviews showed improved communication and cooperation between health-care professionals because of greater opportunities for interactions at various levels. Interpretation A regional programme of interventions could improve the quality of palliative care. Improvement of communication between health-care professionals is key to improvement of services</p> |
| <p>MURRAY, S.A. and OSMAN, H., 2012. Primary palliative care: the potential of primary care physicians as providers of palliative care in the community in the Eastern Mediterranean Region/Soins palliatifs en soins de santé primaires : potentiel des médecins des soins de santé</p> | <p>Cross cultural comparison discussion<br/>Refers to GSF</p> | <p>Palliative care focuses on improving the quality of life and relieving suffering in patients with progressive chronic illnesses. Palliative care services remain very limited in the Eastern Mediterranean region although the need for them is high and increasing. The World Health Organization has identified the development of palliative care as a regional priority. This review highlights the urgent need to provide such care in the region and proposes that primary care providers in the region are well placed to provide palliative care in their communities. As palliative medicine is not established as a specialty in the region, training and support</p>   |

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| <p>primaires en tant que fournisseurs de soins palliatifs en communauté dans la Région de la Méditerranée orientale. <i>Eastern Mediterranean Health Journal</i>, <b>18</b>(2), pp. 178-83.</p>                                    |                  | <p>in palliative care are required to build capacity in end-of-life care and to allow all patients who would benefit from this approach access to it equitably and early in their illness. [PUBLICATION ABSTRACT]</p>   |
| <p>MURRAY, S. and BOYD, K., 2011. Using the 'surprise question' can identify people with advanced heart failure and COPD who would benefit from a palliative care approach. <i>Palliative medicine</i>, <b>25</b>(4), pp. 382.</p> | <p>Editorial</p> | <p>Having conducted a literature review and reviewed several prognostic tools including the Prognostic Indicator Guide in the Gold Standards Framework, we have produced a Supportive and Palliative Care Indicators Tool which uses this question with others to identify patients, and we now are evaluating it in hospitals and general practice (Edinburgh)</p>   |
| <p>NEWMAN, R. and THOMAS, K., 2011. Failing to plan is planning to fail: advance care planning for people nearing the end of life. <i>Aging Health</i>, <b>7</b>(5), pp. 677-680.</p>  |                  | <p>Following the inaugural meeting in Melbourne, Australia, in 2010, the newly formed International Society for Advance Care Planning and End of Life Care (ACPEL) held its second International 3-day conference in London in June this year, hosted by the UK team of which Keri Thomas was convenor. This article gives an overview of the conference and one delegate's perspective (R Newman). With over 400 delegates from across the world representing 22 different countries, the conference and society represent the increasing international recognition of the importance of holding and recording advance care planning discussions with people nearing the end of their lives, with a particular focus on the growing needs of the elderly in our society.</p> |

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|   |   | <p>The event coincided with the 7th Annual Conference of the Gold Standards Framework (GSF), with presentations of work in care homes, domiciliary care, primary care, acute hospitals and other areas [102]. The first day concluded with the presentation of the GSF Quality Hallmark Awards by Baroness Julia Neuberger to some of the successful GSF accredited care homes, with interviews and a celebration of their success</p>  |
| <p>ÖNAÇ, R., FRASER, N.C. and JOHNSON, M.J., 2010. State financial assistance for terminally ill patients: the discrepancy between cancer and heart failure. <i>British Journal of Cardiology</i>, <b>17</b>(2), pp. 73-75.</p> | <p>Full text unavailable<br/>Seems to show GSF benefit if GSF meetings are held</p> | <p>Until recently, supportive and palliative care for patients with heart failure has been neglected in primary and secondary care. Patients dying from cancer have benefited from a co-ordinated approach to ensure all aspects of care, including advanced planning and financial assistance, are considered. We reviewed the use of DS1500 applications for state financial benefits for patients dying from cancer (n=54) and heart failure (n=24) in one primary care practice. There was a marked inequality in favour of those with cancer, both in terms of DS1500 application form usage (cancer 33% versus heart failure 0%), but also access to palliative care service referrals (cancer 54% versus heart failure 8%) and discussion in Gold Standards Framework practice meetings (cancer 61% versus heart failure 4%). There should be equal provision of a 'gold standard' of care for patients with terminal disease irrespective of aetiology.</p> |
| <p>PADDY, M., 2011. Influence of location on a good death. <i>Nursing Standard</i>, <b>26</b>(1), pp. 33-6.</p>   | <p>Mentions GSF</p>   | <p>With the recent emphasis of the Department of Health on reducing unnecessary hospitalization at the end of life and improving community care for people dying at home, it could be assumed that dying at home is the gold standard. However, healthcare professionals should be able to give a patient choice over where they die, whether that is at home, in hospital or in a hospice. This article asks the reader to consider whether location of death has an influence on the quality of death</p>   |

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| <p>PAYNE, S., 2011. Perspectives on Cancer Care. <i>Cancer Nursing Practice</i>, <b>10</b>(5), pp. 8.</p>  | <p>Book review<br/>Mentions GSF</p>                   | <p>For example, chapter 12 focuses largely on the Liverpool Care Pathway and the Gold Standards Framework in facilitating palliative and end of life care, although interestingly there is little mention of advance care planning.</p>  |
| <p>PAYNE, S., 2009. The role of the nurse in palliative care settings in a global context. <i>Cancer Nursing Practice</i>, <b>8</b>(5), pp. 21-26.</p> | <p>Refers to using GSF in context of broader EOLC</p> | <p>This article introduces palliative care and palliative care nursing. It goes on to consider models of palliative care delivery and provide a more detailed account of the three elements of palliative care nursing – working directly with patients and families, working with other health and social care professionals to network and co-ordinate services, and working at an organisational level to plan, develop and manage service provision in local, regional and national settings. It concludes by detailing the challenges for palliative care nursing and outlines a possible way ahead</p> |
| <p>PELLETT, C., 2009. Provision of end of life care in the community. <i>Nursing Standard</i>, <b>24</b>(12), pp. 35-40.</p>                           | <p>Description of local use of GSF</p>                | <p>Many people who are terminally ill would prefer to die at home. Integrated professional working is necessary to enable patients to remain in their homes for end of life care. This article describes how an integrated district nursing team in Lincolnshire provides end of life care to patients in the community. The team uses the Gold Standards Framework and the Liverpool Care Pathway to provide optimum care to patients and their families and carers at the end of life</p>  |
| <p>PENDER, S. and PEARCE, F., 2012. End of Life Care community services. <i>Journal of Community Nursing</i>, <b>26</b>(5), pp. 4-4,6.</p>             | <p>Discussion re local implementation of EOLC</p>     | <p>Caring for people approaching the end stages of their lives can be a challenging yet immensely rewarding area in which to work. Front line staff such as nurses and therapists are the visible face of care provision; however, the organisation and co-ordination of service provision from support and administrative staff can have a tangible impact upon the quality of service provision received by the patients and their families. This article aims to give a brief outline of how one community healthcare organisation developed a system and</p>   |

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|  |  | <p>associated processes to provide a single point of referral for end of life care from a range of community nursing services</p> <p>In addition, all referrals would include the key end of life care performance indicators and best practice tools such as the Gold Standard Framework<sup>5</sup> and the Liverpool Care of the Dying Pathway<sup>6</sup>. Recording of the patients preferred priorities of care and provision of anticipatory prescribed drugs were also included. These served as both a prompt to remind of best practice provision and a method of data capture for baseline best practice on referral.</p>   |
| <p>POPPE, M., BURLEIGH, S. and BANERJEE, S., 2013. Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED). <i>PLoS One</i>, <b>8</b>(4), pp. n/a.</p> | <p>Focus on ACP<br/>Mentions GSF briefly</p> | <p>Background<br/>End-of-life-care is often poor in individuals with dementia. Advanced care planning (ACP) has the potential to improve end-of-life care in dementia. Commonly ACP is completed in the last six months of life but in dementia there may be problems with this as decision-making capacity and ability to communicate necessarily decrease as the disease progresses. Choosing the right time to discuss ACP with people with dementia may be challenging given the duration of the illness may be up to nine years.</p> <p>Aims<br/>To explore the acceptability of discussing ACP with people with memory problems and mild dementia shortly after diagnosis.</p> <p>Methods<br/>In-depth interviews were conducted with 12 patients and eight carers who had participated in ACP discussions and six staff members from a memory clinic and a community mental health team who had either conducted or attended the discussions for training purposes.</p> <p>Results<br/>Patients and carers found ACP a positive intervention that helped them think about the future, enabled people with</p> |

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|   |  | <p>dementia to make their wishes known, and resulted in their feeling relieved and less worried about the future. The importance of sharing the ACP documentation between health service providers was highlighted.</p> <p>Conclusions</p> <p>This qualitative evaluation of ACP in early dementia has encouragingly positive results which support the wider application of the intervention in memory services and community mental health teams. Strategies are suggested to support the implementation of ACP further in clinical practice.</p>   |
| <p>PORDES, P., ASHCROFT, A. and WILLIAMS, P., 2011. An electronic resource to support staff providing end of life care. <i>Nursing Standard</i>, <b>26</b>(12), pp. 41-6.</p> | <p>Refers to GSF and outlines an online tool for prognostication within the Trust's intranet</p> <p>Green stage: months rather than years<br/>Yellow stage: weeks rather than months<br/>Red stage: days rather than weeks</p> | <p>The Department of Health's End of Life Care Strategy provided the opportunity to develop effective care, regardless of the setting. However, providing end of life care is challenging for all healthcare practitioners, with each care setting experiencing unique challenges. Within one acute NHS trust, the challenges of identifying and diagnosing dying were identified. An electronic resource tool was developed to aid prognostication and provide a single point of reference to assist healthcare practitioners in improving end of life care for patients in an acute hospital setting.</p> |
| <p>REYNOLDS, J. and CROFT, S., 2010. How to implement the Gold Standards Framework to ensure continuity of care. <i>Nursing times</i>, <b>106</b>(32), pp. 10-13.</p>         | <p>Descriptive on how to use GSF as a process</p>  | <p>The Gold Standards Framework aims to ensure all patients have a "good death". This article focuses on the framework as a coordinated programme of care for those in the last 12 months of life, irrespective of diagnosis, identifying key actions to support its implementation in primary care.</p>  |
| <p>REYNOLDS, J. and CROFT, S., 2012. Cardiopulmonary resuscitation in end of life care. <i>Nursing Standard</i>,</p>  | <p>Focussed on CPR but discusses GSF</p>   | <p>The Gold Standards Framework (GSF) (2011) contains specific clinical indicators of advanced disease that may also support decision making.</p> <p>To achieve successful end of life care it is essential to</p>  |

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| <p>26(51), pp. 35-42.</p>   |  | <p>identify and assess patients proactively. This includes regular monitoring of the patient's condition to ascertain whether CPR is likely to be in the patient's interests. Following identification of those in the last year of life, it is recommended that the patient should be added to the supportive care register (GSF 2009), co-ordinated by the GP practice, in addition to an electronic palliative care co-ordination system (National End of Life Care Programme 2010), both of which aim to share information between service providers regarding end of life care preferences and plans for care as appropriate. If the patient is in a care home, hospice or hospital, an additional register specific to the organisation may be in use and therefore it is important to put in place mechanisms that ensure all registers remain up to date.</p> <p>Once added to the register, it is recommended that patients are coded according to whether they are considered to be in the last months (green), last weeks (yellow) or last days (red) of life (GSF 2011). Identification and coding of these patients enables the multidisciplinary team, in conjunction with patients and their relatives and carers, to plan ahead and review regularly their specific needs. This would include whether or not undertaking CPR would be in the patient's best interests.</p> |
| <p>REYNOLDS, J. and CROFT, S., 2011. Applying the Preferred Priorities for Care document in practice. <i>Nursing Standard</i>, 25(36), pp. 35-42.</p> | <p>Focussed on ACP but refers to GSF</p> | <p>Patient choice and control should be central to the delivery of high-quality, end of life care. Advance care planning (ACP) is a process through which a patient's choices and preferences for care can be discussed and documented. It also enables patients to express what they would want to happen to them in the event that they lose capacity to make decisions. This article focuses on the use of the patient-held Preferred Priorities for Care (PPC) document, an example of an ACP tool. This article aims to provide a greater understanding of the PPC document as an end of life care</p>  |

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|   |  | <p>tool and increase practitioners' knowledge, confidence and competence in undertaking ACP conversations with patients and their carers. Four case studies are provided to link theory to practice</p> <p>It is never too early to discuss PPC. However, in accordance with best practice, every patient ought to be provided with the opportunity to discuss PPC as soon as they are considered to have a life expectancy of less than 12 months and are therefore eligible for inclusion on the Gold Standard Framework supportive care register. This is held at the patient's general practice and lists the patients who are considered to be in the last 12 months of life. An example of a supportive care register can be found on the Gold Standards Framework (2009) website. Inclusion on the register ensures discussion of the patient takes place at each meeting where proactive care planning is considered in an effort to promote quality of life (Thomas 2003). If the patient's disease trajectory is unpredictable, it is important to broach ACP discussions when the patient is well, in anticipation of any adverse events where it would be important to be aware of his or her wishes to enable plans to be arranged for such an event. It also promotes and demonstrates that the patient is central to care delivery.</p> |
| <p>ROBERTS, D. and GASPARD, G., 2013. A palliative approach to care of residents with dementia. <i>Nursing Older People</i>, <b>25</b>(2), pp. 32-36.</p> |  | <p>Dementia is a progressive, life-limiting illness. People with the condition who move into a care home deserve palliative care. This article discusses an interprofessional pilot workshop for direct care providers held in a care home in British Columbia, Canada. The workshop aimed to incorporate a palliative approach into dementia care for residents. Workshop development, teaching strategies, evaluation and outcomes are shared. The four-hour workshop was structured to promote critical reflection and challenge participants to consider that people with dementia and their families need palliative care much earlier than</p>   |



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|   |                          | <p>during the last days of life. Commitment to change statements gathered as part of the workshop indicated that participation increased knowledge, skill and confidence to incorporate a palliative approach into care for people with advanced dementia and their families.</p> <p>A number of national and international organisations advocate that palliative care for older people should be integrated in health systems including care homes (Australian Government National Health and Medical Research Council (NHMRC) 2006, World Health Organization (WHO) Europe 2011, National Gold Standards Framework (GSF) Centre 2012).<br/>Implementation of the UK GSF in care homes (National GSF Centre 2012), a quality assurance programme for all residents near the end of life, has shown significant increases in the number of residents who remained in their care home to die and decreases in unnecessary hospital admissions (Badger et al 2009).</p> |
| <p>ROWLANDS, C. and ROWLANDS, J., 2012. Challenges in delivering effective palliative care to people with dementia. <i>Mental Health Practice</i>, <b>16</b>(4), pp. 33-36.</p> | <p>Literature review</p> | <p>This literature review surveys palliative care received by people with dementia, and identifies challenges and barriers to its delivery. These include communication problems, lack of understanding of dementia as a terminal disease, difficulty with prognostication, and lack of training of general and mental health care staff in palliative care and the specific needs of this client group.</p> <p>A gap in research mirrors the gap in practice. The literature shows that individuals with end-stage dementia have a number of symptoms for which they do not receive effective palliation and often the dying phase goes unrecognised. Further investigation resulting in evidence-based action should address these issues without delay</p> <p>The presentation, progression and prognosis of dementia also vary between dementia types.</p>   |

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|  |  | <p>The prognostic indicator guidance was developed as part of the gold standards framework to assist healthcare professionals to recognise when people are nearing the end of life, so that timely planning and better care could be undertaken (Thomas and Free 2008).</p> <p>This framework has been widely adopted in England, especially in general practice. It is also beginning to be adopted throughout the UK by GPs who are all required to formulate a palliative care register to include all their patients who have a life-limiting illness that could result in a prognosis of less than one year. There seems to be no evidence available of its use in mental health services.</p> |
| <p>SAMPSON, E.L. and BURNS, A., 2013. Planning a personalised future with dementia: 'the misleading simplicity of advance directives'. <i>Palliative medicine</i>, <b>27</b>(5), pp. 387-8.</p>                                      | <p>Discussion<br/>Relates to article below</p>                 | <p>As with many innovations intended to improve the quality of healthcare, consideration of implementation is key when trying to change practice. This has been demonstrated by programmes such as the UK Gold Standards Framework or the Australian 'Let me Decide' programme, which successfully use ACP supported by intensive training, support and education of staff to implement and sustain effective change.</p> <p>This article highlights what Hertogh<sup>9</sup> neatly describes as 'the misleading simplicity of advance directives</p>  |
| <p>SAMPSON, E.L., JONES, L., THUNÉ-BOYLE, I.C., KUKKASTENVEHMAS, R., KING, M., LEURENT, B., TOOKMAN, A. and BLANCHARD, M.R., 2011. Palliative assessment and advance care planning in severe dementia: An exploratory randomized</p> | <p>Refers to GSF as a framework but focus is on ACP at EOL</p> | <p>palliative care and advance care plan (ACP) intervention. Patients had undergone emergency hospital admission and had severe dementia. The intervention consisted of a palliative care patient assessment which informed an ACP discussion with the carer, who was offered the opportunity to write an ACP for the person with dementia. Carer--patient dyads were randomized to 'usual care' or the intervention. Carer-related outcome measures included the Kessler Distress Scale, Decision Satisfaction Inventory, Client Satisfaction Questionnaire and the Euroqol-5D, measured at baseline, six weeks, six months and three months after</p>   |

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| <p>controlled trial of a complex intervention. <i>Palliative medicine</i>, <b>25</b>(3), pp. 197-209.</p>                    |                                | <p>bereavement. The Satisfaction with End of Life Care in Dementia Scale was completed if the patient died. The 32 patient participants were physically frail and in the advanced stages of dementia: 62% had pressure damage to the skin, all needed feeding assistance and 95% were in pain. Nearly 50% died during the six-month follow-up period. Carers were difficult to recruit during acute admission; 33 patients and carers entered the study (22 intervention arm; 11 control arm). Only seven carers made ACPs. The care planning discussion was well received, but few carers wrote an ACP, despite intensive support from an experienced nurse specialist. Advance care planning is, in theory, a necessary intervention for people with severe dementia; the reluctance of carers to write plans needs to be explored further.<br/>[PUBLICATION ABSTRACT]</p>   |
| <p>SAWKINS, N. and BAWN, R., 2010. The GSF competency document. <i>End of Life Care Journal</i>, <b>4</b>(2), pp. 58-59.</p> | <p>Full text not available</p> | <p>Implementing education that results in a change in culture and improved clinical practice is challenging. In order to evaluate the effect of educational initiatives it is necessary to assess pre-course proficiency levels with post-course proficiency levels. The Gold Standards Framework (GSF) competency document, which was originally developed to assess the palliative care educational needs of district nurses, aims to assess the competency level and knowledge of health and social care staff. It is a self-assessment tool that has been adapted for use in a variety of settings. The assessment is based around the seven Cs of the GSF. There are 10 general topics and 10 related specifically to symptom control. Learners complete the document before a course and then at a later date. The results can help direct learning. They can also be used as part of an appraisal system and a personal development plan.</p> |

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| <p>SAWKINS, N., 2010. Nurses need to speak the language of compassion. <i>Nursing Times</i>, 106(37), pp. 28.</p> | <p>Short editorial type piece</p> | <p>rather than creating an extra layer of paperwork, it helps save time. Since its inception 10 years ago the National GSF Centre has always listened and learnt from professionals. With nurses being able to take a proactive, coordinating role as the main workers in end of life care, the GSF Centre has developed a new resource - the GSF nurses' pack, with all the information and practical steps to implement the framework into everyday practice.</p> <p>Nurses in care homes have been instrumental in implementing the GSF Care Homes programme. Almost 1,500 homes have been through its training programme and I have witnessed some fantastic transformations in practice</p> <p>As well as the new development of the nurses' pack, the framework is opening up what is possibly its most critical front yet - acute hospitals. By linking the work of nurses in primary care, care homes and hospitals there is, at last, an unmissable chance to offer patients well-coordinated cross-boundary care and for nurses to take the lead to deliver the very best care for people nearing the end of their lives, in the place they want it.</p> <p>The hospital programme, being piloted in 16 sites across the country, will effectively give nurses permission to spend more time with patients, ascertain what they want and help deliver it. The three simple steps of identifying those patients nearing the end of life, assessing their needs and planning their care puts nurses in charge.</p> <p>We can improve the systems that don't work, by talking the same "GSF language", so that nurses in hospitals can communicate with their colleagues in care homes and the community to join up the work in the different settings - always putting the patient at the centre and achieving better outcomes for them.</p> |
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| <p>SEYMOUR, J.E., KUMAR, A. and FROGGATT, K., 2011. Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. <i>Palliative medicine</i>, <b>25</b>(2), pp. 125-38.</p> | <p>A mixed methods design was employed, consisting of two in-depth qualitative case studies 25 of nursing homes and a postal survey of the managers of 180 nursing homes surrounding the case study sites.</p> | <p>Nursing homes are a common site of death, but older residents receive variable quality of end-of-life care. We used a mixed methods design to identify external influences on the quality of end-of-life care in nursing homes. Two qualitative case studies were conducted and a postal survey of 180 nursing homes surrounding the case study sites. In the case studies, qualitative interviews were held with seven members of nursing home staff and 10 external staff. Problems in accessing support for end-of-life care reported in the survey included variable support by general practitioners (GPs), reluctance among GPs to prescribe appropriate medication, lack of support from other agencies, lack of out of hours support, cost of syringe drivers and lack of access to training. Most care homes were implementing a care pathway. Those that were not rated their end-of-life care as in need of improvement or as average. The case studies suggest that critical factors in improving end-of-life care in nursing homes include developing clinical leadership, developing relationships with GPs, the support of 'key' external advocates and leverage of additional resources by adoption of care pathway tools. [PUBLICATION ABSTRACT]</p> <p>Seventy eight percent of the responding care homes (64) self-rated the quality of their end-of-life care. Of these, one home described it as 'needs improving', three as 'average', 33 as 'good' and 27 as 'excellent'. Ninety-eight percent (80) of the responding care homes responded to a question about use of end-of-life tools. Most (50) reported use of the LCP, with smaller numbers reporting use of the GSF (21) and/or Preferred Priorities of Care (PPC) (4). Sixteen homes were using both the LCP and the GSF. Eight care homes reported they were using their own care pathway or one that had been locally developed. Of the 60 homes rating their end-of-life care as</p> |
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|  |   | <p>'good' or excellent', the majority (46) reported use of a care pathway. The four homes rating their care as 'needs improving' or 'average' reported that they were not using a care pathway.</p>  |
| <p>SHAW, K.L., BADGER, F.J., BROOK, L., BROWN, Z., CUDDEFORD, L., THOMAS, K. and WALLIS, M., 2010. The role of general practitioners in children's end-of-life care: a survey of preferred involvement. <i>Palliative medicine</i>, <b>24</b>(2), pp. 196-7.</p> | <p>Letter to the editor re empirical work – survey of GPs</p> | <p>This is the first survey to examine children's EoL care from a GP's perspective. Whilst it is unrealistic to expect GPs to develop expertise in children's EoL care or assume lead roles, the findings endorse GP training in children's palliative care,<sup>3</sup> increased support for GPs and improved integration of children's EoL care across the primarysecondary care interface. The EoL strategy<sup>6</sup> advocates theGold Standards Framework (GSF)<sup>7</sup> for adult patients and several GPs had applied it favourably to children, including using GSF tools to help staff identify relevant children, assess needs and structure care.<sup>1</sup>While it may be possible to integrate a 'children'sGSF' within the existing GSF structure, this must recognize important differences between adult and children's EoL care.<sup>8</sup> What is clear, is that GPs will benefit from early notification of relevant children, updates at key transitions, access to care plans, information on family preferences and support fromtheir specialist colleagues to ensure that they can work effectively to support EoL care for children.</p> |
| <p>Shipman C, Gysels M, White <i>Pet al</i> (2008) Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. <i>British Medical Journal</i>. 337, a1720.</p>                           |   |  |

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| <p>SINGLETON, C., 2010. Developing Practical Adult Nursing Skills - 3rd Edition. <i>Journal of Community Nursing</i>, <b>24</b>(6), pp. 35.</p>                     | <p>Book review</p>  | <p>The final chapter describes "managing pain and promoting comfort" illustrated by thought provoking scenarios, I was pleased to see discussions on non-pharmacological strategies including a brief mention of complementary therapies but disappointed that there were no references or suitable websites to guide the reader towards further information to expand their knowledge in these important areas. I was also surprised that there was no mention of the three end of life tools, Gold Standards Framework, Liverpool Care Pathway or the Preferred Priorities for Care, which may not be initiated in hospital but if they were started in primary care, should continue in the acute setting.</p> |
| <p>SINGLETON, C., 2009. Palliative Care Nursing: Principles and Evidence for Practice - Second edition. <i>Nursing Standard</i>, <b>23</b>(28), pp. 30</p>          | <p>Book review</p>  |   |
| <p>STOBBART-ROWLAND, M., 2010. Going for gold: be recognized for excellent end of life care. <i>Nursing &amp; Residential Care</i>, <b>12</b>(10), pp. 498-500.</p> | <p>Description of GSF training process re care homes</p>                | <p>Almost 1500 homes have now completed the Gold Standards Framework Training since its inception in 2004. Across the UK managers can see the benefits of completing GSFCH training and accreditation</p>   |
| <p>STOBBART-ROWLANDS, M. and BREWSTER, H., 2010. Gold Standards Framework training for care homes. <i>Primary Health Care</i>, <b>20</b>(2), pp. 22-25.</p>         | <p>Description of GSF programme in care homes<br/>Uses case studies</p> | <p>Care homes are likely to play an increasingly important role in future provision of care to people with complex health and social care needs nearing the end of their lives. This article explores how an innovative system-based product, the Gold Standards Framework for Care Homes and training programme, offers care home staff the tools to provide that high level of end of life care.</p>  |

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|  |  | <p>Figures for a GSF accredited care home in West Yorkshire before and after training show an increase in the number of residents dying in the home from 80 per cent to 100 per cent over the nine to 12-month training period, with hospital deaths falling from 20 per cent to zero. There was a reduction in days spent in hospital and crisis admissions in the last six months of life before and after GSF accreditation – from 55 days to zero for hospital admissions and from three to zero crisis admissions. The number of unplanned hospital admissions in the last six months of life was recorded for each of the residents concerned, but the data do not provide information on the reason for admission – something that evaluations might usefully consider</p> <p>One care home lead nurse in Yorkshire said:<br/>'Doing GSF has been life-changing for me and for us as a care home. It has affected the quality of care we provide in so many ways, from the moment someone first looks round the home to the memorial book following their death. It's been fantastic.' Indeed, Badger et al (2009) said: 'More homes now achieve a consistent standard in ELC, getting the right care at the right time for the right person, with fewer residents slipping through the net. The evaluations have also shown that there is better tracking overall of patients when they are in hospital, enabling a faster discharge.'</p> <p>Case studies 1 and 2 show how GSF has had a positive impact on staff and patients at the care homes involved. Staff at another accredited care home have said they feel the home has become much more of a learning environment, with all staff contributing to the identification and planning of care. Residents are only admitted to hospital for appropriate reasons, fewer crisis admissions</p> |
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|   |  | <p>occur and out-of-hours calls have been reduced significantly. In the past year, all deaths of residents have occurred in the care home</p>   |
| <p>STONE, K., PAPADOPOULOS, I. and KELLY, D., 2012. Establishing hospice care for prison populations: An integrative review assessing the UK and USA perspective. <i>Palliative medicine</i>, <b>26</b>(8), pp. 969-78.</p> | <p>Literature review – prison population<br/>The integrative review used a narrative overview design<sup>14</sup> to synthesize the literature related to end-of-life care within the prison environment</p> | <p>models of care based on the hospice model have delivered effective support to dying people since their inception. Over the last 20 years this form of care has also been introduced into the prison system (mainly in the United States) to afford terminally ill inmates the right to die with dignity. the aim of this review is to examine the evidence from the United States and the United Kingdom on the promotion of palliative care in the prison sector, summarizing examples of good practice and identifying barriers for the provision of end-of-life care within the prison environment both in the USA and UK. an integrative review design was adopted using the Green et al. model incorporating theoretical and scientific lines of enquiry. literature was sourced from six electronic databases between the years 2000 and 2011; the search rendered both qualitative and quantitative papers, discussion papers, 'grey literature' and other review articles. the results highlight a number of issues surrounding the implementation of palliative care services within the prison setting and emphasize the disparity between the USA model of care (which emphasizes the in-prison hospice) and the UK model of care (which emphasizes palliative care in-reach) for dying prisoners. the provision of palliative care for the increasing prison population remains under-researched globally, with a notable lack of evidence from the United Kingdom.</p> <p>At present the Gold Standards Framework (GSF), an initiative set up to improve palliative care endorsed by the UK Department of Health, is currently in the process of developing a workbook for end-of-life care within the prison setting.<sup>32</sup> This appears to be an important</p> |

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|   |                              | <p>attempt to move forwards in this area. The UK Prison Reform Trust<sup>29</sup> stated in 2008 that for the prison population the lack of palliative care 'is a major concern' (p.4) and the findings compiled in this integrative review echo this point.</p>   |
| <p>SUTTON, L. and SAM, E., 2009. Investing in our future: end-of-life care and primary care. <i>Primary Health Care</i>, <b>19</b>(4), pp. 26-29.</p> |                              | <p>The <i>End of Life Care Strategy</i> and Lord Darzi's next stage review are still in the initial stages of implementation but local developments are already taking place. Primary care is in an excellent position to lead on this work, particularly through practice-based commissioning. Clinical leadership and strong commissioning at all levels will be essential to improving the quality of end-of-life care that cuts across conditions and meets the needs of individuals.</p> <p>District nurses report spending approximately 40 per cent of their time with palliative care patients.</p> <p>Discussions, assessments and care planning should be based on the needs of the person, not only their prognosis, and tools such as the Gold Standards Framework tool (GSF) can help with this.</p> <p>The impact of tools such as the GSF is reliant on training and their use within a wider organisational approach to end-of-life care</p> |
| <p>TAPSFIELD, A., 2006. Improving the care of dying patients in the community. <i>Nursing times</i>, <b>102</b>(35), pp. 28-30.</p>                   | <p>Full text unavailable</p> | <p>Palliative care services provided by the primary sector have changed considerably over recent years and patients and carers want choice over end-of-life care. In response to this need, the Macmillan Gold Standards Framework has been introduced and funded by the NHS as its chosen end-of-life programme. Clinical experience suggests the framework provides a better quality of care, improves staff morale and patient satisfaction, and reduces hospital and hospice occupancy.</p>  |

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| <p>THOMAS, K., 2009. Measuring for quality care: use of the GSF After Death Analysis. <i>End of Life Care Journal</i>, <b>3</b>(4), pp. 49-51.</p>  | <p>Full text unavailable</p> | <p>Overview: In 2008, Lord Darzi stated that: 'We can only be sure to improve what we can actually measure.' This applies to end-of-life care (EoLC) as well as many other areas. Yet, EoLC has always been a hard area to measure in any meaningful sense. After Death Analysis (ADA) is a web-based, EoLC audit tool, developed as part of the Gold Standards Framework (GSF) programmes in primary care, care homes and hospitals. It has been used as both a comparative and spot-check benchmarking tool in different care settings and has been extensively evaluated and refined. It is available as a simple, online, audit tool through the new charity Omega, the National Association for End of Life Care (<a href="http://www.omega.uk.net">http:// www.omega.uk.net</a>). ADA is a means of assessing the provision of care for patients nearing the end of life and can thereby become a key tool for improvement in care standards in the future.</p> |
| <p>THOMAS, K. and BASS, M., 2010. The work of specialist palliative care professionals in implementing the Gold Standards Framework. <i>Palliative medicine</i>, <b>24</b>(2), pp. 249-250.</p> | <p>Full text unavailable</p> |   |
| <p>THOMAS, K. and REYNOLDS, J., 2010. Update means primary care GSF covers far more... Gold Standards Framework in primary care (practice, page 10, 17 August). <i>Nursing times</i>,</p>       | <p>Full text unavailable</p> |   |

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| <p>106(42), pp. 26-26.</p>  |  |   |
| <p>THOMAS, K., 2010. Using prognostic indicator guidance to plan care for final stages of life. <i>Primary Health Care</i>, 20(6), pp. 25-28.</p> |  | <p>Primary care teams would benefit from being able to focus care where it is most needed, particularly in identifying patients nearing the end of their lives. Prognostic indicator guidance uses prompts to enable them to achieve this. It is difficult to predict which patients may be in their last year of life, yet doctors and nurses agree that if they could identify these patients earlier the task of delivering high quality end of life care would be much easier. About 1 per cent of the population dies each year (Office for National Statistics 2005), on average 15 to 20 people for every GP per year. If we could find ways to identify these patients earlier, we might be more able to provide better care for them as they approach the end of their lives.</p> <p>Primary care teams, care homes and hospitals that use this method of identification, assessment and planning find it much easier to provide top quality proactive care. They also find they are better able to adhere to patients' wishes and avert crises as well as reducing inappropriate hospital admissions and hospital deaths. Systematic and regular use of the surprise question and the PIG guidance enable primary care teams to identify more patients for whom they would like to be able to do the right thing at the right time.</p> |

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| <p>THOMAS, S., 2010. Where is the money going? <i>Primary Health Care</i>, <b>20</b>(4), pp. 3.</p>  | <p>editorial</p>                              | <p>Projects such as the gold standards framework (page 22) show just how services can be developed, but primary care nurses need resources to be able to do this. Targets have been set but they will not be delivered without cash.</p>  |
| <p>TRUEMAN, J. and TRUEMAN, I., 2011. COPD: criteria to assist in the identification of the palliative phase. <i>British Journal of Nursing</i>, <b>20</b>(10), pp. 635-639.</p> | <p>Refers to same issues as article below</p> | <p>For people with chronic obstructive pulmonary disease (COPD), hospital admission can be associated with a poor prognosis. Consequently, the end stage of the illness needs to be recognized for timely palliative care to be initiated. Tools to enhance the palliative phase such as the Gold Standards Framework and the Liverpool Care Pathway rely on the recognition of the final phase of a person's life. The illness trajectory of cancer makes this recognition far easier than for COPD, as a result many patients and their families manage at home with limited support. Lincolnshire Respiratory Network has developed criteria to help recognize the end-stage COPD, which correlate well with recent recommendations from the <i>Consultation on a Strategy for Services for COPD in England</i> (Department of Health, 2010). However, there needs to be appropriate training to assist practitioners in their confidence to refer patients with end-stage COPD to palliative care providers.</p> <p>This programme was developed to enable the principles of end-of-life care for</p> |

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|  |  | <p>cancer patients to be spread into other disease groups. This has included promoting the use of the Gold Standards Framework (GSF) and The Liverpool Care Pathway (LCP). The GSF is a systematic approach to optimizing the care delivered by primary and secondary care teams for any patient nearing the end of life (Griffin and Sawkin, 2010). The LCP integrates and follows on from the GSF and is concerned with the final 72/48 hours of life (National End of Life Care Programme, 2009). These tools are being promoted in the palliative management of non-cancer patients. Furthermore, they are an integral part of care planning for people with long-term conditions to support high-quality care of non-cancer patients, already commonplace within cancer care provision (DH, 2009). This work has been further reinforced by the consultation document <i>Our Health, Our Care, Our Say</i> (DH, 2006) which recognized the need for additional investment to improve the end-of-life care through education of practitioners to care for dying patients. Therefore, it is important to consider whether the provision of palliative care for patients with COPD is equal to that provided to patients with cancer and whether any barriers exist which may hinder its effective implementation.</p> |
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| <p>TRUEMAN, J. and TRUEMAN, I., 2011. Developing criteria to assist in the palliative phase of COPD. <i>British Journal of Nursing</i>, <b>20</b>(6), pp. 364-369.</p> |  | <p>For people with chronic obstructive pulmonary disease (COPD), hospital admission can be associated with a poor prognosis. Consequently, the end-stage of the illness needs to be recognized for timely palliative care to be initiated. Tools to enhance the palliative phase, such as the Gold Standards Framework and the Liverpool Care Pathway, rely on the recognition of the final phase of a person's life. The illness trajectory of cancer makes this recognition far easier than for COPD, and as a result, many patients and their families manage at home with limited support. The Lincolnshire Respiratory Network has developed criteria to help recognize the end stage of COPD, which correlate well with recommendations from the Consultation on a Strategy for Services for COPD in England (Department of Health, 2010). However, there needs to be appropriate training to assist practitioners in their confidence to refer patients with end-stage COPD to palliative care providers.</p> <p>This programme was developed to enable the principles of end-of-life care for cancer patients to be spread into other disease areas. This has included promoting the use of the Gold Standards Framework (GSF) and The Liverpool Care Pathway (LCP).</p> |
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|  |  | <p>The GSF provides a detailed guide on how to provide holistic and patient-centred care (National Gold Standards Framework, 2011). Where primary and secondary care teams have adopted the GSF, patients are placed on the local palliative care register and the care teams are encouraged to have regular multidisciplinary meetings to discuss and review the progress of patients.</p> <p>To ensure that clinicians working in primary and secondary care understood how to use the end-of-life criteria tool developed by the Respiratory Network, a number of presentations were delivered as part of the GSF meetings for primary and secondary care. In the longer term it is hoped that the use of the prognostic indicators will enable the development of a robust communication system to notify practices of patients who need to be placed on the GSF register. It is also recognized that there needs to be some more formal evaluation of the tool to measure the impact it has had within the locality.</p> <p>However, it is recognized by the Respiratory Network that continued educational input and regular review of the criteria is required to ensure that there remains a consensus between patients, carers, primary and secondary care teams that these indicators are appropriate. When considering the criteria in the context of the more recent recommendations found within</p> |
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|  |  | <p>the COPD consultation document (DH, 2010), the use of weightloss/ reduced muscle mass may be a useful supporting clinical indicator.</p>   |
| <p>VALEN, K., YTREHUS, S. and GROV, E.K., 2011. Tilnorminger anvendt i nettverksgrupper for kompetanseutvikling i det palliative fagfeltet. <i>Vard i Norden</i>, <b>31</b>(4), pp. 4-9.</p> | <p>Refers to GSF but text is Norwegian</p> | <p>ABSTRACT</p> <p>Background of the study: Palliative nursing requires specialized knowledge and skills to enable nurses facing complicated conditions and symptoms. Norwegian white papers recommend health services to take place close to the home, which necessitates specialized nursing competence at all levels of nursing care. In Norway, The Center for Competence in Palliative Care coordinates the regional palliative care service, while community employees coordinate the patient-oriented palliative care.</p> <p>Aim: Palliative Care Network of nurses with special competence in palliative care provides the nurses 'training. This study describes how nurses develop competence through participation in this Network.</p> <p>Method: By means of two focus groups ten self-selected nurses have been interviewed.</p> <p>Result: The Network is referred as arena for socialization</p> |

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|   |   | <p>and learning, where nurses share their experience as a source of knowledge. Case discussion from the clinical field is preferred learning approach. Integration of theory and research in practice is highlighted however it seems challenging to implement research into practice-discussions. Therefore, such focus is to be contained in lectures, web presentations, and daily communication between participants within the Network.</p> <p>Conclusion: Case-based learning has been emphasized as an important approach for nursing competence development. The Network strengthens the nurses' competence and enhances their professional confidence.</p> <p>Keywords: palliative care, focus group interviews, competence development, network, nurses</p> |
| <p>VAN MECHELEN, W., AERTGEERTS, B., DE CEULAER, K., THOONSEN, B., VERMANDERE, M., WARMENHOVEN, F., VAN RIJSWIJK, E. and DE LEPELEIRE, J., 2013. Defining the palliative care patient: A systematic review. <i>Palliative medicine</i>, <b>27</b>(3), pp.</p> | <p>Refers to GSF and references it.</p> | <p><b>Abstract</b><br/> <b>Background:</b> The lack of a clear definition of the palliative care patient hampers the comparison of results across different studies and impedes implementation of research findings in everyday practice.<br/> <b>Aim:</b> The aim of this article is to propose minimum characteristics that define a palliative care patient.<br/> <b>Design:</b> The design involved a systematic review of medical literature searching randomised controlled trials (RCTs) in palliative care for clear descriptions of their palliative care patients. We systematically describe relevant characteristics</p>  |

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| 197-208.  |                           | <p>of the study populations of 60 eligible RCTs.</p> <p><b>Data sources:</b> The data sources used were MEDLINE, EMBASE, CINAHL, and PSYCHINFO, including all non-cancer RCTs (1 January 1995–4 March 2010) and an equivalent number of the most recent cancer RCTs (1 January 2003–4 March 2010).</p> <p><b>Results:</b> Half of the non-cancer studies were excluded because they did not relate to palliative care. We conclude that published RCTs have no clear definitions of their palliative care patients and illustrate the diversity of this patient, the lack of consensus concerning the attributes of illnesses needing palliation and the ambiguous use of the adjective ‘palliative’.</p> <p><b>Conclusions:</b> We propose elements of the patients’ health status (e.g. a progressive, life-threatening disease with no possibility of obtaining remission or stabilisation, or modifying the course of the illness) and the care delivered to them (e.g. a holistic interdisciplinary approach that focuses on supporting the quality of the end of life) to be included in the definition of a palliative care patient. We also suggest considering the patients’ readiness to accept palliative care and a vision of palliative care shared by the patient and all caregivers involved as potentially important elements in this definition.</p> |
| <p>WAINWRIGHT, G., 2011. Excellence in end of life care. <i>Learning Disability Practice</i>, 14(3), pp. 24-25.</p> | Short case study as below | <p>The GSF helped us to identify Patsy’s palliative care requirements, assess her needs, symptoms and preferences, and plan her care. The prognostic indicator guide and coding register helped us to plan her care in various stages: the final years, months, weeks and days of life. Finally, an ‘after death’ analysis summarises the quality of end of life care and looks at the provision of specific services and care related to preferences (Thomas 2010). The GSF provides a framework in which to offer best practice in end of life care and provides staff with the tools</p>   |

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|   |  | and confidence to deliver that care in an effective and person-centred way. In a small home such as Heatherstones, the death of a client is a relatively rare occurrence, so it is particularly significant.   |
| WAINWRIGHT, G. and TUFFREY-WIJINE, I., 2011. Excellence in end of life care/Commentary. <i>Learning Disability Practice</i> , <b>14</b> (3), pp. 30-31.   | Short case study based in eight-bed nursing home for adults with learning disabilities. It has a staff of seven nurses and ten support assistants. | Staff at a nursing home used information from the Gold Standards Framework to develop appropriate care for a 62-year-old woman with Down syndrome who developed dementia. They were able to ensure that there was a comfortable environment for the resident and her family to be together during the last weeks of her life.  |
| WALKER, S., READ, S. and PRIEST, H., 2011. Is routinely ascertaining preferred place of death for hospice patients possible or desirable? <i>Journal of palliative medicine</i> , <b>14</b> (11),.<br><br>Walker, Susan, Research Institute for Life Course Studies, Keele University , Keele, STS, United Kingdom, ST6 4BG, <a href="mailto:s.walker@ilcs.keele.ac.uk">s.walker@ilcs.keele.ac.uk</a> |  | Initiatives such as the Gold Standards Framework suggest that good end-of-life care includes choosing a place for one's death. It is recommended that within a care pathway approach, people approaching the end of life should be identified by professionals in order that discussions about preferences for care can be initiated. However, no standardized template for ascertaining preferred place of death in use across all palliative care settings in the UK, and it is unknown to what extent this is being actualized within the clinical context. These issues are further discussed with regards to current health care services in the UK. (PsycINFO Database Record (c) 2012 APA, all rights reserved) |
| WALSHE, C., 2011. The evaluation of complex interventions in palliative care: An exploration of the potential of case study research strategies. <i>Palliative medicine</i> ,   | Refers to GSF in discussion re case study method   | Background: Complex, incrementally changing, context dependent and variable palliative care services are difficult to evaluate. Case study research strategies may have potential to contribute to evaluating such complex interventions, and to develop this field of evaluation research. Aim: This paper explores definitions of case study   |

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| <p>25(8), pp. 774-81.</p>  |  | <p>(as a unit of study, a process, and a product) and examines the features of case study research strategies which are thought to confer benefits for the evaluation of complex interventions in palliative care settings. Results: Ten features of case study that are thought to be beneficial in evaluating complex interventions in palliative care are discussed, drawing from exemplars of research in this field. Important features are related to a longitudinal approach, triangulation, purposive instance selection, comprehensive approach, multiple data sources, flexibility, concurrent data collection and analysis, search for proving-disproving evidence, pattern matching techniques and an engaging narrative. The limitations of case study approaches are discussed including the potential for subjectivity and their complex, time consuming and potentially expensive nature. Conclusions: Case study research strategies have great potential in evaluating complex interventions in palliative care settings. Three key features need to be exploited to develop this field: case selection, longitudinal designs, and the use of rival hypotheses. In particular, case study should be used in situations where there is interplay and interdependency between the intervention and its context, such that it is difficult to define or find relevant comparisons. [PUBLICATION ABSTRACT]</p> |
| <p>WALSHE, C., CARESS, A., CHEW-GRAHAM, C. and TODD, C., 2011. Equity, choice or chance? Community palliative care. <i>Journal of Community Nursing</i>, 25(1), pp. 16-18.</p> | <p>Refers to GSF in references:<br/><br/>Walshe, C, Caress, A., Chew-Graham, C, Todd, C. (2008a) "Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three Primary Care Trusts". <i>Palliative Medicine</i> 22: 736-743.</p> | <p>[...] disparities in access may be related to disparities in clinical need that were not revealed in this study. [...] the issues revealed here about patients knowing about or choosing to use services may affect the apparent equity of access.</p>  |

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| <p>WARD, L., FENTON, K. and MAHER, L., 2010. The high impact actions for nursing and midwifery 6: where to die when the time comes. <i>Nursing Times</i>, <b>106</b>(32), pp. 18-19.</p> | <p><b>Case studies</b></p> <p><b>CASE STUDY 1: A COMMUNITY MATRON FOR SUPPORTIVE AND PALLIATIVE CARE</b><br/>Impact of the initiative:<br/>Forty nine out of 51 people under the community matron's care died in the place of their choice.</p> <p>Her work has helped to reduce inappropriate hospital admissions for patients at the end of life and, during her first year, she prevented 25 admissions with a caseload of 50 patients. This saved an estimated £41,000.</p> <p><b>CASE STUDY 2: INTEGRATED END OF LIFE CARE</b><br/>Impact of the initiative<br/>More than 80% of patients are now achieving their wish to die at home. There has been a significant improvement in the prescription of anticipatory medication and in the use of the Leeds Care of the Dying pathway.</p> <p>The CAPCCS teams provide 1,500 contacts each month in support of district nursing and the sitting service provides 5,000 nights of one to one care in a year. CAPCCS has achieved a 5% reduction in admission to hospital due to improved symptom control at home.</p> <p><b>CASE STUDY 3: PATIENTS WHO WANT TO DIE AT HOME GIVEN ANTICIPATORY DRUGS</b><br/>It uncovered a range of problems, including poor documentation, poor recording of DNACPR and patients not identified as being in the end of life phase. However, there were also areas of good practice within the community nursing teams, with 31 practices developing their services in line with the Gold Standards Framework by 2007.</p> | <p>Around half of the 500,000 deaths in England each year occur in acute hospitals, while around half of all complaints made to acute trusts relate to an aspect of end of life care. However, research suggests that 40% of people who die in hospital have no medical need to be there, and that 55% of people with cancer would prefer to die at home while only around 25% do so. When people die in hospital despite having a preference to die at home and no medical reason to be in hospital, it causes unnecessary distress to patients and their families, and is costly to the NHS. This article, the seventh in our series on the high impact actions for nursing and midwifery, looks at how nurses can help to improve end of life care. [PUBLICATION ABSTRACT]</p> |
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| <p>WATERWORTH, S., RAPHAEL, D. and HORSBURGH, M., 2012. Yes, But It's Somewhat Difficult- Managing End of Life Care in Primary Health Care. <i>Ageing International</i>, <b>37</b>(4), pp. 459-469</p> |                                | <p>A qualitative study was undertaken to investigate the perceptions of General Practitioners regarding the management of older people with heart failure, particularly at the end of life. Semi-structured interviews were conducted with 30 General Practitioners in Auckland, New Zealand during 2008. Participants identified that the needs of older patients with heart failure could not be addressed in isolation from the wider issues which affect older people. This complexity influenced all components of patient need including the typical course of the disease, the provision of prognostic and end of life information, and how palliative care was provided, including referral to specialist services. Some participants also believed that older people's palliative care management should be approached differently to that of younger people stating, for example, that they were concerned about the amount of information older people could take in. A model which takes into consideration the experiences of the older person and fits them into, not a 'dying model' but a 'life model', one that supports the natural transition to end of life is needed. A 'life planning model' used early in the management of patients would be a useful way forward and one which would allow the integration of the different paradigms of cardiology, gerontology, palliative care and nursing.].</p> |
| <p>WATSON, J., HOCKLEY, J. and MURRAY, S., 2010. Evaluating effectiveness of the GSFCJ and LCP in care homes. <i>End of Life Care Journal</i>, <b>4</b>(3), pp. 42-49.</p>                             | <p>Full text not available</p> | <p>Background: The palliative care needs of older people residing in care homes are not always recognised. Approximately two-thirds of people in care homes have dementia. However, people with advanced dementia are not always recognised as having a terminal condition and, consequently, their end-of-life care needs are not well understood. The Gold Standards Framework in Care Homes (GSFCH) and the Liverpool Care Pathway for the Dying Patient (LCP) (care home version) are advocated to improve the quality of end-of-life care in care homes. However, evidence on the efficacy of such tools to improve outcomes</p>   |

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|  |   | <p>or change practice is lacking. Aim: The aim of this research was to evaluate the impact on the quality of end-of-life care of the GSFCH and LCP in care homes with nursing. Methods: Qualitative interviews were conducted with 22 bereaved relatives/friends before, and 14 bereaved relatives/friends and six care home managers after, implementation of the GSFCH and LCP into seven care homes with nursing. Content analysis guided by the 7Cs of the GSFCH was conducted. Results: Care home staff changed their attitudes about dying. This enabled more informed end-of-life decision-making involving families/friends, staff and GPs. Findings suggest that improvements in care of the dying occurred following implementation of both tools. Conclusion: The GSFCH and LCP improve end-of-life care by influencing end-of-life culture, decision-making and practice.</p> |
| <p>WHEELER, N.L. and OYEBODE, J.R., 2010. Dementia care 1: person centred approaches help to promote effective communication... first in a three-part series on dementia. <i>Nursing times</i>, <b>106</b>(24), pp. 18-21.</p> |   | <p>Background This first in a three part series on dementia care explores communication. The Gold Standards Framework includes a workstream on improving end of life care in care homes; communication is one of seven key tasks within the GSF. Aim and method This study aimed to gather care home staff views on communication issues. Focus groups were conducted with 36 members of direct care staff from nine nursing and residential care homes. Results Three types of communication were identified: staff to staff; staff to resident; and staff to family. Discussion and conclusion The implications of different approaches to communication are discussed, and recommendations made for practice.</p>  |
| <p>WHYTE, A. and WATERS, A., 2009. Dying in good hands. <i>Nursing Standard</i>, <b>23</b>(44), pp. 18-9.</p>  | <p>Refers to GSF<br/>The Gold Standards Frameworks another care model to help co-ordinate services for the dying in community settings. By the end of last year, 90 per cent of GP practices were using it. The strategy's overall aim is to help more people to die in the setting</p> | <p>The End of Life Care Strategy, published a year ago, sets out best practice. Nurses are starting to deliver the strategy but more needs to be done.</p>  |



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|   | <p>they choose, usually at home surrounded by loved ones. Its implementation is supported by the National End of Life Care Programme team, which continues to collate and share examples of good practice</p>  |   |
| <p>WILSON, F., GOTT, M. and INGLETON, C., 2013. Perceived risks around choice and decision making at end-of-life: A literature review. <i>Palliative medicine</i>, <b>27</b>(1), pp. 38-53.</p> | <p>Refers to GSF and The introduction of the white paper 'High Quality Care', as well as the Gold Standards Framework and Liverpool Care Pathway (LCP), aim to support all communities equitably and recognize lack of training and knowledge in working with different BME communities.6,61,62 Nevertheless, all emphasize the drive towards supporting dying at home yet this may be an ethnocentric goal. Service provision that is culturally insensitive may act as an additional risk factor in shaping end-of-life decisions.</p> | <p>the World Health Organization identifies meeting patient choice for care as central to effective palliative care delivery. Little is known about how choice, which implies an objective balancing of options and risks, is understood and enacted through decision making at end-of-life. to explore how perceptions of 'risk' may inform decision-making processes at end-of-life. an integrative literature review was conducted between January and February 2010. Papers were reviewed using Hawker et al.'s criteria and evaluated according to clarity of methods, analysis and evidence of ethical consideration. All literature was retained as background data, but given the significant international heterogeneity the final analysis specifically focused on the UK context. the databases Medline, PsycINFO, Assia, British Nursing Index, High Wire Press and CINAHL were explored using the search terms decision*, risk, anxiety, hospice and palliative care, end-of-life care and publication date of 1998-2010. thematic analysis of 25 papers suggests that decision making at end-of-life is multifactorial, involving a balancing of risks related to caregiver support; service provider resources; health inequalities and access; challenges to information giving; and perceptions of self-identity. Overall there is a dissonance in understandings of choice and decision making between service providers and service users. the concept of risk acknowledges the factors that shape and constrain end-of-life choices. Recognition of perceived risks as a central factor in decision making would be of value in acknowledging and supporting meaningful decision making processes for patients with palliative care</p> |

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|   |   | needs and their families.  |
| <p>YOHANNES, A.M., 2011. Palliative care and management principles in older patients with advanced chronic obstructive pulmonary disease. <i>Aging Health</i>, 7(3), pp. 409-421.</p> | <p>Refers to GSF in text<br/> “Furthermore, a recent survey of 239 acute hospital units admitting COPD patients in the UK reported that only 49% of units had a formal referral pathway for palliative care and only 13% of those units had a policy of providing information about palliative care to patients with advanced-stage COPD [10].”</p> <p>Buxton KL, Stone RA, Buckingham R, Pursey NA, Roberts CM: Current and planned palliative care service provision for chronic obstructive pulmonary disease patients in 239 UK hospital units: comparison with the gold standards framework. <i>Palliat. Med.</i> 24(5), 480-485 (2010).</p> | <p>Advanced chronic obstructive pulmonary disease (COPD) patients are likely to develop comorbidities that may contribute to a substantial burden of symptoms such as intolerable dyspnea, fatigue and poor-health status. Evidence from the available literature suggests that advanced COPD patients are less likely to receive palliative care and/or supportive care compared with cancer patients. Factors that contribute to this disparity are multifactorial, including diagnostic uncertainty of when to provide palliative care, patients' unwillingness to discuss advanced care planning with their general practitioners, lack of appropriate guidelines regarding when to refer patients to palliative care and lack of adequate resources. A few unblinded studies of palliative-care provision that included advanced COPD patients with other life-threatening diseases demonstrated some benefits in reducing healthcare utilization, improving quality of life and greater patient and caregiver satisfaction with the service. Therefore, further studies are required employing randomized controlled trials to show the benefits of a patient-centred multidisciplinary palliative care program and its cost-effectiveness for this patient group.</p> |