

1. Literature Search Part A- Empirical work involving evaluation of GSF

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

Study authors and publication details		results Conclusion / recommendations/ discussion
ASHTON, S., MCCLELLAND, B., ROE, B., MAZHINDU, D. and GANDY, R., 2010. End of life care for people with dementia: an evaluation of implementation of the GSF and LCP... Gold Standards Framework...Liverpool care of the Dying Pathway. <i>Palliative medicine</i> , 24(2), pp. 202-202	Empirical work But links GSF and LCP	Background: End of Life care needs of older people with advanced dementia were identified by North West NHS as a priority. Implementation of advance care planning by use of Gold Standards Framework (GSF) and Liverpool care of the Dying Pathway (LCP) was studied in five long term care 'pilot' sites in Greater Manchester. Aims: To determine the effects of introducing GSF and LCP from the perspectives of staff, service users, family caregivers and practitioners involved in the care of older people with dementia. Methods: A case study design using mixed methods was used in four nursing care homes and one NHS (mental health) ward. A wide range of views and experiences were documented (n=200). A self completed survey of all care staff; General Practitioners and other Multi-disciplinary

		<p>team members; Interviews with the relatives and senior nursing care staff; focus groups with key care staff; Economic evaluation of potential costs/benefits in preventing unscheduled hospital admissions.</p> <p>Results: Qualified staff perceived that the use of the end of life care tools and staff education improved their assessment skills of the physical and cognitive decline and management of the dying resident. Anticipatory prescribing was viewed as a key element in the management of pain and other distressing symptoms. GP's were more confident that care staff could assess and manage symptoms and use medication appropriately. Staff were more confident that residents achieved their preferences for place of death at home and reduced inappropriate hospital admissions due to advance care planning undertaken with residents, relatives and GP's.</p> <p>Conclusion: General agreement by care staff and the wider MDT that the use of GSF/LCP tools promoted staff confidence to assess monitor and meet the needs of dying residents, enabled good communication with indicative economic benefits for reducing hospital admissions</p>
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<p>BADGER, F., CLIFFORD, C., HEWISON, A. and THOMAS, K., 2009. An evaluation of the implementation of a programme to improve end-of-life care in nursing homes. <i>Palliative medicine</i>, 23(6), pp. 502-511.</p>	<p>Empirical work</p>	<p>The Gold Standards Framework in Care Homes programme aims to improve the quality of end-of-life care for residents. The impact of introducing phase 2 of the programme to homes in England was evaluated. A pre-post survey design was adopted, focusing on indicators identified as markers of good end-of-life care. The 95 homes in phase 2 of the programme were invited to participate in the evaluation. Homes completed a baseline survey of care provision and an audit of the five most recent resident deaths. The survey and audit were repeated post programme completion. Forty-nine homes returned completed pre- and post-surveys, 44 returned pre- and post-data on deaths. Although some staff found completion of the programme challenging, homes that returned pre- and post-data demonstrated improvements in aspects of end-of-life care. There were statistically significant increases in the proportion of residents who died in the care homes and those who had an advanced care plan. Crisis admissions to hospital were significantly reduced. This evaluation indicates that appropriately funded structured programmes have the potential to assist nursing homes improve the provision of end-of-life care to older adults, in line with government health policy.</p>
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<p>BADGER, F.J., SHAW, K.L., HEWISON, A., CLIFFORD, C. and THOMAS, K., 2010. Gold Standards Framework in Care Homes and advance care planning. <i>Palliative medicine</i>, 24(4), pp. 447-448.</p>	<p>Focus on ACP discussion</p>	<p>The evaluation of the introduction of the Gold Standards Framework in Care Homes (GSFCH) should be considered in the context of the available guidance on end-of-life care at the time the fieldwork was conducted, and the early stage of Gold Standards Framework (GSF) development. The introduction of new legislation and guidance which impacts on end-of-life care means that the subject of advance care planning (ACP) should be introduced at an early stage and residents should not be excluded from this process on the basis of diagnosis. The programme helped raise awareness of the importance of end-of-life care and participants identified a number of positive outcomes.</p>
<p>BADGER, F., PLUMRIDGE, G., HEWISON, A., SHAW, K.L., THOMAS, K. and CLIFFORD, C., 2012. An evaluation of the impact of the Gold Standards Framework on collaboration in end-of-life care in nursing homes. A qualitative and quantitative evaluation. <i>International journal of nursing studies</i>, 49(5), pp. 586-595.</p>	<p>Empirical work</p>	<p>In the United Kingdom approaching 20% of people aged 85 years and over live in care homes and most will die there. Improving end-of-life care is a government health priority and homes may work with primary care staff and specialist palliative practitioners to provide comprehensive end-of-life care. Consequently effective collaboration between care home and health service practitioners is vital to ensure high quality end-of-life care. To evaluate the impact of a training programme to improve end-of-life care in nursing homes, on collaboration between nursing home staff and other health practitioners. Evaluation using survey methods and qualitative case studies. All 95 nursing homes in the first national 'Gold Standards Framework in Care Homes' programme in England were invited to</p>

participate in the evaluation. A survey of homes' characteristics, the approaches to end-of-life care, and liaison with other services, was completed pre and post programme implementation. Case studies were conducted in a sub-sample of 10 homes to provide important context and depth to the evaluation. Pre and post surveys were returned by 49 (52%) homes. Improved collaborations as a result of the programme were anticipated by 31% of managers. Challenges to collaboration included working with large numbers of general practitioners, out-of-hours services and access to specialist practitioners. Improved collaborations between home staff and health service practitioners were identified by 33% of managers as one of the main programme outcomes. Staff reported increased knowledge of end-of-life care, and enhanced confidence, which in turn resulted in improved communication and collaboration. Post-programme, staff felt more confident initiating contact and discussing residents' end-of-life care with general practitioners and those working in specialist palliative care services. The Gold Standards Framework in Care Homes programme can contribute towards end-of-life care by helping to improve the quality and quantity of communication and collaboration between nursing home staff and primary care and specialist practitioners. Further research is needed to determine why this was not consistent across all homes.

<p>BOYD, K.J., WORTH, A., KENDALL, M., PRATT, R., HOCKLEY, J., DENVIR, M. and MURRAY, S.A., 2009. Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals. <i>Palliative medicine</i>, 23(8), pp. 767-76.</p>	<p>Empirical work Heart Failure Cites GSF as a way of working</p>	<p>The objective of this study was to evaluate the key components of services for people with advanced heart failure from multiple perspectives and recommend how care might be delivered in line with UK policies on long-term conditions, palliative and end-of-life care. Serial interviews were conducted over 2 years with patients, case-linked family carers and professionals ($n = 162$); followed by four focus groups involving patients, carers and key professionals ($n = 32$). There were 36 patients with advanced heart failure, 30 family carers and 62 professionals included in the study from a UK health region with various heart failure care models. Participants confirmed the value of a key health professional coordinating care, holistic assessment and regular monitoring. A lack of time and resources due to competing priorities in primary care, failure to respond to the fluctuations of a heart failure illness trajectory, concerns about the balance between direct care from specialist nurses or a more advisory role and difficulty in judging when to move towards palliative care hindered consistent access to proactive care. A heart failure care framework, with key stages and service responses, was developed. We conclude that patients with long-term conditions needing palliative care should be identified and managed using pragmatic criteria that include a proactive shift in care goals. [PUBLICATION ABSTRACT]</p>
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<p>BUXTON, K.L., STONE, R.A., BUCKINGHAM, R.J., PURSEY, N.A. and ROBERTS, C.M., 2010. 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>Palliative medicine</i>, 24(5), pp. 480-485.</p>	<p>Empirical work</p>	<p>Current and planned palliative care service provision for chronic obstructive pulmonary disease patients in 239 UK hospital units: comparison with the gold standards framework</p> <p>Patients with chronic obstructive pulmonary disease report a symptom burden similar in magnitude to terminal cancer patients yet service provision and access has been reported as poor. In the absence of a specific national chronic obstructive pulmonary disease service framework the gold standards framework might support service developments.</p> <p>We surveyed 239 UK acute hospital units admitting chronic obstructive pulmonary disease patients, comprising 98% of all acute trusts, about their current and planned provision for palliative care services. Only 49% of units had a formal referral pathway for palliative care and only 13% had a policy of initiating end-of-life discussions with appropriate patients.</p> <p>Whilst 66% of units had plans to develop palliative care services, when mapped against the gold standards framework few were directly relevant and only three of the seven key standards were covered to any significant degree. We conclude that service provision remains poor and access is hindered by a lack of proactive initiation of discussion.</p> <p>Planned developments in chronic obstructive pulmonary disease palliative care services also lack a strategic framework that</p>
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		risks holistic design.
DALE, J., PETROVA, M., MUNDAY, D., KOISTINEN-HARRIS, J., LALL, R. and THOMAS, K., 2009. A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality. <i>Quality & Safety in Health Care</i> , 18(3), pp. 174-180.	Empirical work	<p>A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality</p> <p>Background: Improving quality of end-of-life care is a key driver of UK policy. The Gold Standards Framework (GSF) for Palliative Care aims to strengthen primary palliative care through facilitating implementation of systematic clinical and organisational processes.</p> <p>Objectives: To describe the general practices that participated in the GSF programme in 2003–5 and the changes in process and perception of quality that occurred in the year following entry into the programme, and to identify factors associated with the extent of change.</p> <p>Methods: Participating practices completed a questionnaire at baseline and another approximately 12 months later. Data were derived from categorical questions about the implementation of 35 organisational and clinical processes, and self-rated assessments of quality, associated with palliative care provision.</p> <p>Participants: 1305 practices (total registered population almost 10 million). Follow-up questionnaire completed by 955 (73.2%)</p>

		<p>practices (after mean (SD) 12.8 (2.8) months; median 13 months).</p> <p>Findings: Mean increase in total number of processes implemented (maximum =35) was 9.6 (95% CI 9.0 to 10.2; p<0.001; baseline: 15.7 (SD 6.4), follow-up: 25.2 (SD 5.2)). Extent of change was largest for practices with low baseline scores. Aspects of process related to coordination and communication showed the greatest change. All dimensions of quality improved following GSF implementation; change was highest for the “quality of palliative care for cancer patients” and “confidence in assessing, recording and addressing the physical and psychosocial areas of patient care”.</p> <p>Conclusion: Implementation of the GSF seems to have resulted in substantial improvements in process and quality of palliative care. Further research is required of the extent to which this has enhanced care (physical, practical and psychological outcomes) for patients and carers.</p>
FENNING, S., WOOLCOCK, R., HAGA, K., IQBAL, J., FOX, K.A., MURRAY, S.A. and DENVIR, M.A., 2012. Identifying Acute Coronary Syndrome Patients Approaching End-of-Life. <i>PLoS One</i> , 7(4), pp. n/a.	Empirical work	<p>Background Acute coronary syndrome (ACS) is common in patients approaching the end-of-life (EoL), but these patients rarely receive palliative care. We compared the utility of a palliative care prognostic tool (Gold Standards Framework (GSF)) and the Global Registry of Acute Coronary Events (GRACE) score, to help identify patients approaching EoL.</p> <p>Methods and Findings</p>

		<p>172 unselected consecutive patients with confirmed ACS admitted over an eight-week period were assessed using prognostic tools and followed up for 12 months. GSF criteria identified 40 (23%) patients suitable for EoL care while GRACE identified 32 (19%) patients with $\geq 10\%$ risk of death within 6 months. Patients meeting GSF criteria were older ($p = 0.006$), had more comorbidities (1.6 ± 0.7 vs. 1.2 ± 0.9, $p = 0.007$), more frequent hospitalisations before ($p = 0.001$) and after (0.0001) their index admission, and were more likely to die during follow-up (GSF+ 20% vs GSF- 7%, $p = 0.03$). GRACE score was predictive of 12-month mortality (C-statistic 0.75) and this was improved by the addition of previous hospital admissions and previous history of stroke (C-statistic 0.88).</p> <p>Conclusions</p> <p>This study has highlighted a potentially large number of ACS patients eligible for EoL care. GSF or GRACE could be used in the hospital setting to help identify these patients. GSF identifies ACS patients with more comorbidity and at increased risk of hospital readmission.</p>
GARDINER, C., GOTTFRIED, M., INGLETON, C., SEYMOUR, J., COBB, M., NOBLE, B., BENNETT, M. and RYAN, T., 2013. Extent of palliative care need in the acute hospital setting: A survey of two acute hospitals in the UK. <i>Palliative medicine</i> ,	Empirical work	In common with international health policy, The End of Life Care Strategy for England has highlighted the delivery of high quality palliative care in the acute hospital setting as an area of priority. The aim of this study was to explore the extent of palliative care need in the acute hospital setting, and to explore agreement between different sources in the

27(1), pp. 76-83.		<p>identification of patients with palliative care need. A cross-sectional survey of palliative care need was undertaken in two UK acute hospitals. Hospital case notes were examined for evidence of palliative care need according to Gold Standards Framework (GSF) prognostic indicator criteria. Medical and nursing staff were asked to identify patients with palliative care needs. Patients (or consultees) completed assessments of palliative care need. Of a total in-patient population of 1359, complete datasets were collected for 514 patients/consultees. 36.0% of patients were identified as having palliative care needs according to GSF criteria. Medical staff identified 15.5% of patients as having palliative care needs, and nursing staff 17.4% of patients. Patient self-report data indicated that 83.2% of patients meeting GSF criteria had palliative care needs. The results reveal that according to the GSF prognostic guide, over a third of hospital in-patients meet the criteria for palliative care need. Consensus between medical staff, nursing staff and the GSF was poor regarding the identification of patients with palliative care needs. This has significant implications for patient care, and draws into question the utility of the GSF in the hospital setting.</p>
GRIFFITHS, J., EWING, G. and ROGERS, M., 2013. Early support visits by district nurses to cancer patients at home: A multi-perspective qualitative study. <i>Palliative medicine</i> , 27(4), pp. 349-	Empirical work	Many palliative cancer patients spend much of their last year at home. In the UK, district nurses make frequent support visits to patients and carers at this time, yet surprisingly little is known about their supportive role in palliative care. Current

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studies are limited to district nurses' reports of practice, which offer limited insight into their content. Patients' and carers' views on district nurse support visits are largely unknown. To present findings of a multi-perspective study that explored how district nurse early support visits are both described and carried out. Focus groups with district nurses to explore views on the purpose of early support visits. Observation of support visits to identify how they are conducted. Patient and carer interviews to elucidate and verify district nurse data. Participants included 58 district nurses, 10 palliative care patients and nine carers from four Primary Care Trusts in contrasting urban and rural locations. District nurses had difficulty articulating early support visits. Observations however revealed a complex role comprising extensive physical and practical assessments, practical interventions, information giving, liaison, facilitation and referral. Patients and carers confirmed that they felt valued, reassured and supported by district nurses. A multi-perspective approach provided new insights into district nurse support visits. Monitoring work described appears to have additional psycho-social benefits for patients and carers. The supportive role of district nurses needs to be clearly articulated and recognised so that colleagues, patients and carers access this valuable resource for palliative care patients.

<p>HAGA, K., MURRAY, S., REID, J., NESS, A., O'DONNELL, M., YELLOWLEES, D. and DENVIR, M.A., 2012. Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model. <i>Heart</i>, 98(7), pp. 579-583.</p>	<p>Empirical work Full text not available</p>	<p>OBJECTIVE: To assess the clinical utility of the Gold Standards Framework Prognostic Indicator Guide (GSF) and the Seattle Heart Failure Model (SHF) to identify patients with chronic heart failure (CHF) in the last year of life. DESIGN, SETTING AND PATIENTS: An observational cohort study of 138 community based ambulatory patients with New York Heart Association (NYHA) class III and IV CHF managed by a specialist heart failure nursing team. MAIN OUTCOME MEASURES: 12 month mortality, and sensitivity and specificity of GSF and SHF. RESULTS: 138 CHF patients with NYHA class III and IV symptoms were identified from a population of 368 ambulatory CHF patients. 119 (86%) met GSF criteria for end of life care. The SHF model identified six (4.3%) patients with a predicted life expectancy of 1 year or less. At the 12 month follow-up, 43 (31%) patients had died. The sensitivity and specificity for GSF and SHF in predicting death were 83% and 22%, and 12% and 99%, respectively. Receiver operator characteristic analysis of SHF revealed a C index of 0.68 ± 0.05 (95% CI 0.58 to 0.77). Chronic kidney disease (serum creatinine $\geq 140 \text{ }\mu\text{mol/l}$) was a strong univariate predictor of 12 month mortality, with a sensitivity of 56% and specificity of 72%. CONCLUSIONS: Neither the GSF nor the SHF accurately predicted which patients were in the last year of life. The poor prognostic ability of these models highlights one of the barriers to providing timely palliative care in CHF</p>
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<p>HANNON, K.L., LESTER, H.E. and CAMPBELL, S.M., 2012. Recording patient preferences for end-of-life care as an incentivized quality indicator: What do general practice staff think? <i>Palliative medicine</i>, 26(4), pp. 336-41.</p>	<p>Empirical work QOF related</p>	<p>Introduction: Since April 2009, indicators for the UK Quality and Outcomes Framework pilot have been developed and piloted across a nationally representative sample of practices. In October 2009 a single palliative care indicator was piloted for 6 months that looked at, 'the percentage of patients on the palliative care register who have a preferred place to receive end-of-life care documented in the records'. Aim: The aim of this study was to gain the views and experiences of general practice staff on whether the inclusion of a single incentivized indicator to record the preferred place to receive end-of-life care would improve the quality of palliative care. Any issues arising from its implementation in a pay-for-performance scheme were also explored. Methods: Interviews took place with 57 members of staff in 24 practices: 21 GPs, 16 practice managers, 12 nurses and eight others (mostly information technology experts). Results: The indicator was not deemed appropriate for incentivization due to concerns about incentivizing an isolated, single issue within a multi-faceted, multi-disciplinary and complex topic. Palliative care was seen to be too sensitive and patient specific to be amenable to population-level quality measurement. In implementation, the indicator would pose potential harm to patients who may be asked about their end-of-life care at an inappropriate time and by a member of staff who may not be best placed to address this sensitive topic. Conclusions: The most appropriate time to ask a patient</p>
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		<p>about end-of-life care is subjective and patient specific and therefore does not lend itself to an inflexible single indicator. Focusing on one isolated question simplifies and distracts from a multi-faceted and complex issue and may lead to patient harm. [PUBLICATION ABSTRACT]</p>
HARDY, B., KING, N. and FIRTH, J., 2012. Applying the Pictor technique to research interviews with people affected by advanced disease. <i>Nurse Researcher</i> , 20(1), pp. 6-10.	<p>Empirical work Using Pictor technique Refers to GSF</p>	<p>To outline some of the challenges facing people affected by advanced disease who want to participate in research interviews, and to present Pictor, a method that can help manage some of these challenges. Patients and lay-carers may have many issues that affect their ability to participate in qualitative research interviews. These issues can include the physical effects of disease, its treatments and emotional distress. An ongoing study exploring experiences of advanced disease when multiple agencies are involved. The Pictor technique involves the creation of a chart that supports the exploration of the participant's experience of roles and relationships. The technique has previously been used with health professionals and this paper reports on its use with lay-participants. The technique accommodates some disease-related difficulties which helped people with advanced disease to reflect on their experiences of primary care service provision. Participants then communicated these experiences with the researcher. Pictor is a tool that can help manage some of the difficulties experienced by people with advanced disease who are participating in research interviews. This has benefits for</p>

		researchers and participants
KING, N., THOMAS, K., MARTIN, N., BELL, D. and FARRELL, S., 2005. 'Now nobody falls through the net': practitioners' perspectives on the Gold Standards Framework for community palliative care. <i>Palliative medicine</i> , 19(8), pp. 619-627.	Empirical work	The Gold Standards Framework (GSF) seeks to facilitate consistent and high quality community palliative care through a set of guidelines, mechanisms and assessment tools. The present study set out to examine practitioners' perspectives on the GSF during its first national roll-out. Two general practices that had adopted the GSF were recruited in each of four geographical areas, and each matched as closely as possible with a non-GSF practice. Sixty-eight semi-structured telephone interviews were carried out with general practitioners and district nurses in 16 selected practices, along with the GSF facilitator and up to four other 'stakeholders' in each area. Analysis revealed that the majority of GSF participants felt that the framework had strengthened their provision of community palliative care. In particular, communication within primary health care teams and co-ordination of services improved, aspects which were better in the GSF practices than in the matched non-GSF practices. Practitioners felt there was more consistency of care, with a reduced likelihood that individual patients would 'slip through the net'. The most common areas of concern were in relation to the workload associated with the role of the GSF co-ordinator.

		Implications for the development and effective implementation of the framework and for further research are discussed.
MACPHERSON, A., WALSHE, C., O'DONNELL, V. and VYAS, A., 2013. The views of patients with severe chronic obstructive pulmonary disease on advance care planning: A qualitative study. <i>Palliative medicine</i> , 27(3), pp. 265-272.	Empirical work	<p>there are concerns that end-of-life care for these patients is inadequate. Advance care planning is encouraged, with the hope that it will improve communication and avoid unwanted interventions, which have been particular concerns; in practice, these discussions rarely occur. We have little knowledge of the views of patients with COPD on advance care planning. Understanding this could help integrate advance care planning into the routine management of patients with COPD.</p> <p>Aim: To explore the views of people with severe COPD about advance care planning. Design: Qualitative design, with data collection incorporating audio recorded semi-structured interviews. Analysis followed a grounded theory approach.</p> <p>Setting/participants: Patients with severe COPD (n = 10, Gold Standards Framework criteria) were recruited from primary and secondary care settings. Results: Participants felt they had not been given enough information about their diagnosis and prognosis, and were keen for more discussion with healthcare professionals. They wanted more involvement in decisions about their treatment when those decisions were required. Participants were happy to discuss their general views about future care, but felt</p>

		<p>uncomfortable with the traditional model of binding 'advance directives'. Conclusions: Considering advance care planning as a repeated process of discussion of prognosis, concerns and probable preferences for care would be more useful than encouraging binding advance decisions. Further research should assess the effectiveness of this approach. Local coordination of who is responsible for information provision is needed, and greater involvement of patients with COPD in management decisions as they arise. (PsycINFO Database Record (c) 2013 APA, all rights reserved) (journal abstract)</p>
MADDEN, P., COUPLAND, V., MØLLER, H. and DAVIES, E., 2011. Using maps and funnel plots to explore variation in place of death from cancer within London, 2002-2007. <i>Palliative medicine</i> , 25(4), pp. 323-32.	<p>Empirical work relating to place of death</p> <p>Refers to GSF but useful method for place of death data</p>	<p>London has a high proportion of hospital deaths, which health policy seeks to reduce. We explore variation and trends in place of death from cancer within London between 2002 and 2007. Mortality data based on death certificates were used to define deaths from cancer at home, hospice, hospital and nursing home and examine trends over time for London. Proportions of deaths in each place were presented in maps for 31 London primary care trusts (PCTs). Funnel plots were used to identify consistent performance outside the control limits of three standard deviations. There was little overall change in place of death for London, but consistent variation between PCTs. Outer London PCTs had higher proportions of home deaths and inner London PCTs higher proportions of hospice deaths. Funnel plots identified consistent high outlying performance for home, hospice and hospital deaths. No PCT</p>

		<p>showed a change of 10% or more in home deaths, but five showed decreasing hospital deaths and three increasing hospice deaths. Maps and funnel plots appear useful for identifying areas with differing performance for home, hospital, nursing home and hospice deaths. These methods may help further investigation of how local services may successfully support deaths outside hospital.</p> <p>[PUBLICATION ABSTRACT]</p>
<p>MAHMOOD-YOUSUF, K., MUNDAY, D., KING, N. and DALE, J., 2008. Interprofessional relationships and communication in primary palliative care: impact of the Gold Standards Framework. <i>British Journal of General Practice</i>, 58(549), pp. 256-263.</p>	<p>Empirical work</p>	<p>multidisciplinary teamwork, interprofessional communication between GPs and district nurses, and early referral of patients to district nurses. These aspects of palliative care are highlighted in the Gold Standards Framework, a programme recently established in UK primary care.</p> <p>AIM: To investigate the extent to which the framework influences interprofessional relationships and communication, and to compare GPs' and nurses' experiences.</p> <p>DESIGN OF STUDY: Qualitative interview case study.</p> <p>SETTING: Fifteen participating practices from three primary care trusts in England.</p> <p>METHOD: Thirty-eight semi-structured interviews were undertaken with GPs, district nurses, Macmillan nurses, and framework facilitators.</p> <p>RESULTS: Adoption of the framework often resulted in earlier referral of palliative care patients to district nurses. Multidisciplinary team meetings enabled communication for sharing knowledge, discussing management</p>

		<p>problems, and keeping colleagues informed; however, arranging and maintaining such meetings was often problematic. Nurses particularly valued formal meetings while GPs generally preferred informal ad hoc dialogue. GPs largely maintained control of the mode of multidisciplinary working. The best functioning teams used a mixture of formal and informal meetings with a relatively non-hierarchical working style.</p> <p>CONCLUSION: Implementing the framework enabled processes of communication associated with high quality palliative care in general practice, but there was marked variation in how this worked in individual teams. In general, hierarchical doctor-nurse relationships persisted</p>
MATHIE, E., GOODMAN, C., CRANG, C., FROGGATT, K., ILIFFE, S., MANTHORPE, J. and BARCLAY, S., 2012. An uncertain future: The unchanging views of care home residents about living and dying. <i>Palliative medicine</i> , 26(5), pp. 734-43.	Empirical work 6 care homes	<p>Aim: This research aimed to explore the views, experiences and expectations of end-of-life care among care home residents to understand if key events or living in a residential environment influenced their views. The research used a prospective design. The paper draws on the qualitative interviews of 63 care home residents who were interviewed up to three times over a year. This was a sub-sample of the larger data set of 121 care home residents. The residents were recruited from six care homes (providing personal care with no on-site nursing) in the UK. Four main themes were identified; Living in the Past, Living in the Present, Thinking about the Future and Actively Engaged with planning the future. Many residents said they had not spoken to the care staff about end-of-life care;</p>

		<p>many assumed their family or General Practitioner would take responsibility. Core to the older person's ability to discuss end-of-life care is their acceptance of being in a care home, the involvement of family members in making decisions and the extent to which they believed they could influence decision making within their everyday lives. Advance care plans should document ongoing dialogue. These findings can inform how primary health and palliative care services introduce, discuss and tailor existing frameworks and programmes of end-of-life care.</p>
MCKEOWN, A., AGAR, R., GAMBLE, M., ELLERSHAW, J.E. and HUGEL, H., 2008. Renal failure and specialist palliative care: an assessment of current referral practice. <i>International journal of palliative nursing</i> , 14(9), pp. 454-458.	Empirical work	<p>Aims: This retrospective audit assessed the referral practice for patients with end-stage renal failure from the nephrology service to the specialist palliative care team in a large teaching hospital in the north-west of England.; Methods: Forty-nine referrals with 'renal' as a primary diagnosis over a two-year period were identified from referral data. General and palliative care notes were reviewed and a data collection tool was designed.; Results: Most common reasons for referral were for 'placement' (38.6%) and 'dying/distressed' patients (22.7%), although psychological support was also prevalent (15.9%). Renal teams discussed stopping dialysis in the majority of cases (89%), but documented preferred place of care less frequently (48.3%) and achieved discharge to these locations in less than half of cases (21.4%).; Conclusion: There was well-established referral practice between the</p>

		<p>renal and the specialist palliative care team at the hospital examined. The renal team appropriately referred for symptom control and support in the dying phase of patients. There are issues surrounding placement and increased implementation of end-of-life care tools, including the Liverpool Care Pathway, Gold Standards Framework and Preferred Place of Care documentation for renal patients, which needs to be an ongoing priority.</p>
MUNDAY, D., PETROVA, M. and DALE, J., 2009. Exploring preferences for place of death with terminally ill patients: Qualitative study of experiences of general practitioners and community nurses in England. <i>BMJ: British Medical Journal</i> , 339 (7714),.	Full text not available Empirical work focus on PPC	<p>Objective: To explore the experiences and perceptions of general practitioners and community nurses in discussing preferences for place of death with terminally ill patients. Design: Qualitative study using semistructured interviews and thematic analysis. Participants: 17 general practitioners and 19 nurses (16 district nurses, three clinical nurse specialists). Setting: 15 general practices participating in the Gold Standards Framework for palliative care from three areas in central England with differing socio-geography. Practices were selected on the basis of size and level of adoption of the standards framework. Results: All interviewees bar one had experience of discussing preferred place of death with terminally ill patients. They reported that preferences for place of death frequently changed over time and were often ill defined or poorly formed in patients' minds. Preferences were often described as being co-created in discussion with the patient or, conversely, inferred by the health professional</p>

		<p>without direct questioning or receiving a definitive answer from the patient. This inherent uncertainty challenged the practicability, usefulness, and value of recording a definitive preference. The extent to which the assessment of enabling such preferences can be used as a proxy for the effectiveness of palliative care delivery is also limited by this uncertainty. Generally, interviewees did not find discussing preferred place of death an easy area of practice, unless the patient broached the subject or led the discussions. Conclusions: Further research is needed to enable development of appropriate training and support for primary care professionals. Better understanding of the importance of place of death to patients and their carers is also needed. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)</p>
OLIVER, M., 2010. The relevance of psychosocial indicators in community palliative care: A pilot study. <i>Australian Journal of Advanced Nursing (Online)</i> , 27(3), pp. 20-30.	Empirical work Australia	<p>Objective The objective is to discuss a framework in psychosocial care in community palliative care and the outcomes of a pilot study. This study adds to the existing body of knowledge in palliative care especially in psychosocial aspects of community care.</p> <p>Design and Setting Prior to pilot testing the psychosocial indicators for use in community palliative care, a twelve item framework in psychosocial care was developed and validated using the Delphi technique and group consensus from ten experts in community palliative care. The study setting was the community palliative care services consisting of multidisciplinary health</p>

		<p>professionals. Subjects A purposive sample of six participants comprising of palliative care nurses and allied health professionals participated in the pilot study. Using the psychosocial framework in community palliative care participant views on what constitutes psychosocial care in community palliative care was determined. Interview transcripts were the data sources that informed the pilot study. Main outcome measure The main outcome was the pilot study results validating the psychosocial framework consisting of 12 indicators in community palliative care. The study findings demonstrate the appropriateness of psychosocial indicators discerning patient and caregiver needs in community palliative care. All participants in the pilot study independently confirmed evidence of the 12 psychosocial indicators in their practice. Conclusion The pilot study shows that by incorporating psychosocial care in community palliative care improves decision making in the terminally ill. The implication for practice is that psychosocial aspects of palliative care can indicate patient's care needs leading to better satisfaction.</p>
PERCIVAL, J. and JOHNSON, M., 2013. End-of-life care in nursing and care homes. <i>Nursing Times</i> , 109(1/2), pp. 20-2.	Empirical work	<p>More than 70,000 people die each year in nursing and residential care homes, yet comparatively little attention has been paid to end-of-life care practice and its challenges in this setting.</p> <p>We conducted interviews and group discussions in 12 homes, involving 73 residents, 97 members of staff and 16</p>

		<p>relatives. These revealed that personalised care, dignity and respect, making time, talking about death, relatives' roles, and staff support were priorities for all concerned. Training is vital in helping staff to engage sensitively, respectfully and creatively with dying residents. Staffing levels must be sufficient so staff can sit with residents and care in a way that is attuned to their personality, life history and wishes. Supportive relationships between staff and relatives help to ensure a "civilised death".</p> <p>In England, the End of Life Care Strategy (DH, 2008a) established the NHS National End of Life Care Programme. Three initiatives that subsequently emerged are the Liverpool Care Pathway (LCP), the Gold Standards Framework (GSF) and Preferred Priorities for Care (PPC)</p>
PETROVA, M., DALE, J., MUNDAY, D., KOISTINEN, J., AGARWAL, S. and LALL, R., 2010. The role and impact of facilitators in primary care: findings from the implementation of the Gold Standards Framework for palliative care. <i>Family practice</i> , 27(1), pp. 38-47.	Empirical work	<p>Background.</p> <p>Facilitation is the process of providing support to individuals or groups to achieve beneficial change. It is intrinsic to the Gold Standards Framework (GSF) for palliative care, a programme introduced widely in UK general practices.</p> <p>Objectives.</p> <p>To explore how GSF facilitators fulfil their role and the impact of the facilitators' backgrounds and approach on practices' uptake of the programme.</p> <p>Setting.</p> <p>Primary care organizations and general practices in England and Northern Ireland.</p>

		<p>Methods. Self-completed questionnaire and semi-structured interviews with facilitators. Practice audit questionnaire. Descriptive statistics. Thematic analysis. Linear and random effects models. Results. A total of 102 (59.6%) facilitators completed a questionnaire; interviews were performed with nine facilitators. A large variability was found in the facilitators' professional backgrounds, role setup and activities. The impact of several facilitation characteristics on practice change was modelled for 63 (36.8%) facilitators and 266 practices (20.4%). No evidence was found of an association between practice change and facilitators' specialist knowledge of palliative care, mean facilitation time per practice, mean number of visits, facilitator budget and incentives offered to practices. Facilitators with a GP background were associated with higher levels of GSF change than those with a clinical nurse specialist background ($P = 0.0078$ with Bonferroni correction, significance threshold for corrected $P = 0.008$). The interviews indicated that the differential implementation of the framework might have been strongly affected by internal and external practice-related factors that were not readily amenable to facilitation.</p> <p>Conclusion. This study goes some way towards untangling aspects of facilitation associated with successful implementation of</p>
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		the GSF. Further prospective research and evaluation is needed to identify ways of improving its sustainability, effect on patient outcomes and cost effectiveness.
SHAW, K.L., CLIFFORD, C., THOMAS, K. and MEEHAN, H., 2010. Review: improving end-of-life care: a critical review of the Gold Standards Framework in primary care. <i>Palliative medicine</i> , 24(3), pp. 317-329.	Empirical work – review of published articles / evidence with clear inclusion criteria Results tabultaed	The Gold Standards Framework aims to optimize primary palliative care for patients nearing the end of their lives. This paper critically reviews the impact of the Gold Standards Framework since its introduction in 2001 and indicates direction for further research and development. Literature was accessed using specific databases and by contacting subject area specialists. The resultant literature was appraised using an established framework to evaluate healthcare interventions. Fifteen documents were reviewed. The quality of evidence is constrained by methodological limitations, but consistently demonstrates that the Gold Standards Framework improves general practice processes, co-working and the quality of palliative care. However, implementation of the Gold Standards Framework is variable and the direct impact on patients and carers is not known. We conclude that the Gold Standards Framework has considerable potential to improve end-of-life care, but further work is needed to support uptake and consistency of implementation. Additional evidence about patient and carer outcomes will add to existing insights.

<p>SHAW, K., CLIFFORD, C., THOMAS, K. and MEEHAN, H., 2010. Review: Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. <i>Palliative medicine</i>, 24(3), pp. 317-29.</p>	<p>Empirical work</p>	<p>The Gold Standards Framework aims to optimize primary palliative care for patients nearing the end of their lives. This paper critically reviews the impact of the Gold Standards Framework since its introduction in 2001 and indicates direction for further research and development. Literature was accessed using specific databases and by contacting subject area specialists. The resultant literature was appraised using an established framework to evaluate healthcare interventions. Fifteen documents were reviewed. The quality of evidence is constrained by methodological limitations, but consistently demonstrates that the Gold Standards Framework improves general practice processes, co-working and the quality of palliative care. However, implementation of the Gold Standards Framework is variable and the direct impact on patients and carers is not known. We conclude that the Gold Standards Framework has considerable potential to improve end-of-life care, but further work is needed to support uptake and consistency of implementation. Additional evidence about patient and carer outcomes will add to existing insights. [PUBLICATION ABSTRACT)</p>
<p>TAUBERT, M. and NELSON, A., 2010. 'Oh God, not a Palliative': out-of-hours general practitioners within the domain of palliative care. <i>Palliative medicine</i>, 24(5),</p>	<p>Empirical work with GPs</p>	<p>To date, the experiences of out-of-hours general practitioners with regard to palliative care patients and their management are yet to be evaluated, since the new General Medical Services contract came into force. In 2007 the</p>

pp. 501-9.

National Institute for Health Research highlighted the need to identify factors that improve and hinder the delivery of optimum palliative out-of-hours care. By interviewing general practitioners who work out-of-hours shifts, this project explored factors influencing confidence in dealing with symptom control and palliative care provision outside regular working hours. Face-to-face semi-structured interviews were conducted with nine out-of-hours general practitioners employed by Serco. Interviews were conducted by a specialist doctor in palliative care who had in the past worked as an out-of-hours general practitioner. Interviews were analysed using Interpretative Phenomenological Analysis. General practitioners expressed concerns relating to constraints within the system provided by the private company-owned out-of-hours provider. Data from interviews was thematically very rich and brought out many different subject areas, some similar to previous interviews, some different. Sub-themes related to the process-driven aspects of working in out-of-hours: * Motivation * Time-pressure constraints and continuity * The out-of-hours doctor within the domain of palliative care * Isolation within system General practitioners stated that their motivation was mainly financial. There was clear concern about the lack of continuity, and inadequacy of notes and follow-up, and there was a demonstrated need for more learning on the topic of palliative care. Pressure from the out-of-hours provider to see more patients

was felt to be oppositional with the need to spend adequate time with this vulnerable patient group. General practitioners felt as unwanted strangers who were viewed with suspicion by patients and carers in palliative care situations. It was clear that most of the doctors interviewed felt a strong sense of isolation when working out-of-hours shifts, and some felt less inclined to contact specialist palliative care services.
[PUBLICATION ABSTRACT]

Access to shared electronic care records and implementation of handover via forms sent from in-hours practices to out-of-hours providers (as provided by the Gold Standards Framework) could address this isolated work pattern

Future research
Some of the comments made by GPs expressed concern about their isolated working patterns, and this is something that needs to be addressed. Figures published by the General Medical Council have shown that GPs who work on their own are six times more likely to attend a disciplinary hearing than those working in group practices,¹⁶ and the NHS is aware of the problems that can face lone workers.¹⁷ Future research should

		<p>focus on an organizational review of how out-of-hours doctors could feel less isolated and more included in decisionmaking processes for out-of-hours palliative care situations.</p> <p>Improving knowledge of how GPs can access specialist palliative care day and night and using examples of excellence could be a further area of research.</p> <p>Change management should focus on the reasons why some areas of the UK are succeeding in creating handover systems between in-hours and out-of-hours services, while others are not.</p>
<p>WALSHE, C., CARESS, A., CHEW-GRAHAM, C. and TODD, C., 2008. 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(6), pp. 736-743.</p>	<p>Empirical work</p>	<p>The Gold Standards Framework (GSF) has been widely adopted within UK general practices, yet there is little understanding of its impact on the provision of community palliative care services. This study presents data on the anticipation and adoption of the GSF within three Primary Care Trusts in North West England. Forty-seven interviews were conducted with generalist and specialist palliative and primary care professionals. Important aspects of the GSF identified were the patient register, communication and out-of-hours protocols. Positive benefits to professionals included improved communication between professionals and</p>

		<p>appropriate anticipatory prescribing. Negative aspects included increased nursing workload and the possibility of fewer or later visits for patients. Many respondents believed that the GSF needed local champions to be sustainable. Slow or incomplete adoption was reported. The GSF was recognised as important because it facilitated changes to previously difficult aspects of work between professionals, but few respondents reported direct benefits to patient care.</p>
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