

# Introducing an integrated care pathway for the last days of life

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Integrated care pathways (ICPs) are multiprofessional documents designed to enable the implementation of evidence-based care and support the practical delivery of clinical governance. However, the implementation of care pathways is resource intensive and few evaluations have been conducted with respect to these areas or to the efficacy of care pathways to change practice and improve outcomes in care. This project sought to address these issues and the report outlines the approach taken by a palliative care team in South Wales, UK, to implement a care pathway for the dying throughout a district general hospital and six community hospitals. Dying can be a complex area of care and changing practice can be challenging, therefore a PRINCE Project management approach was taken and a full-time project nurse employed for the life of the project. This paper describes the strategies used to approach implementing a care pathway and provides a template for other teams who may embark on similar projects. At the end of the project, the care pathway was successfully implemented and provided demonstrable outcomes of care for those dying from cancer and nonmalignant diseases. Strikingly, a large number of patients dying from nonmalignant disease were cared for via the pathway, which was not expected. *Palliative Medicine* 2005; **19**: 33–39

**Key words:** dying; ICP; last days of life; nonmalignant disease; oncology; palliative care; project management; quality

## Introduction

Care of the dying is an area of healthcare where one would hope to achieve excellence. Professionals are expected to provide the best evidence-based care possible at this time ensuring the person has a dignified and peaceful death. However, this area of treatment and care can vary in quality.<sup>1–3</sup> It is reported that half of all deaths in the UK are anticipated, however the diagnosis of dying may be difficult to make.<sup>4–6</sup> The palliative care team in a national health service (NHS) district general hospital in South Wales, UK designed a project to improve treatment and care for those dying in the hospital setting through the introduction of an integrated care pathway (ICP).<sup>7–10</sup>

## Background

The treatment and care of the dying may vary, being affected by the person's wishes, the carers' wishes, resources, beliefs, training and experience of staff. There

is evidence that psychological distress and morbidity in the bereaved can be reduced if quality of life in dying is maximized and carers prepared.<sup>11</sup> One of the most frequent problems is recognition that the person has entered the stage of dying.<sup>6,12–15</sup> While nursing staff may recognize the patient is dying, if the team as a whole do not agree, the care delivered may be compromised or inappropriate. For the patient, time for preparation for death may be reduced or not allowed for at all, and symptoms can remain inadequately controlled.<sup>1,2</sup> Evidence demonstrates that patients in the acute hospital setting may receive inappropriate and invasive treatments right up to the point of death.<sup>1–3</sup> Also, end-of-life care and the process of withdrawing or withholding medical treatment are fraught with ethical problems and risks for staff. Discussion with patients and families about withdrawal of treatments requires sensitivity, skill and time, and requires training which is ideally a task for the experienced.<sup>16–18</sup> In reality, the junior medical staff may have more day-to-day contact with patients and families and inexperience may lead them to carry on with current treatment regimens rather than approach this delicate area. Illich was one of the first to highlight the medicalization of dying.<sup>19</sup> Alongside the rise of palliative care as a medical speciality, ICPs have been one response to improve care and dignity at the end of life.<sup>9,20</sup>

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ICPs have been described as standardizing the process of dying to such a level that reality is simplified to an algorithm.<sup>21</sup> However, both research<sup>1–3</sup> and preimplementation audit evidence regarding variance in the care of the dying provided a strong impetus for introducing a care pathway.

The project was initiated and led by a palliative care team as part of the Welsh Collaborative Care Pathways Project. This project commenced in 2000 and the care pathway is modelled on the work of John Ellershaw and the Liverpool Hospital Palliative Care Team.<sup>8–10</sup> The Liverpool Care Pathway for the Dying Patient gained ‘NHS Beacon status’ in 2000 and has been incorporated in phase three of the ‘Cancer Services Collaborative’ to support wide dissemination across the NHS.<sup>23</sup> More recently, the pathway has been recommended in the National Institute of Clinical Excellence (NICE) guidance ‘Improving Supportive and Palliative Care for Adults with Cancer’ as a framework that enables the hospice approach to care of the dying to be implemented in all care settings.<sup>24</sup>

## Project objectives

The aim of the project was to introduce the care pathway to 12 clinical areas in a district general hospital in South Wales and six community hospitals over one year. This acted as a pilot prior to introduction Trust wide. A local research fund provided support for the project, which afforded sufficient resources to appoint a project nurse to conduct training, implementation and support to the 18 clinical areas.

The project had three specific objectives:

- 1) To train all members of each participating team in how to use and implement the ICP.
- 2) To implement the ICP with the support of the project nurse.
- 3) To evaluate and report the strengths and weaknesses of introducing the ICP.

## Project design

PRINCE (PProjects IN a Controlled Environment) was adopted to introduce the ICP in order to monitor the project within a set time frame with efficient use of the project team, resources and ensure desired outcomes.<sup>25</sup> As it was intended to introduce the ICP to a significant number of areas over a relatively short period of time, a project manager commenced the preparatory work for the project prior to its implementation. This was a lone nurse specialist in palliative care (first author) that, as part of her normal day-to-day role, raised awareness of

the pathway during the nine-month period prior to commencement of the project. This important preparation time was given to gain support, increase understanding, answer concerns, and to identify and manage any potential resistance to change. The pathway document was adapted for local use by a small multidisciplinary steering group. Locally the project required approval from the Drugs and Therapeutics Committee and Clinical Policy Board. The Local Research Ethics Committee (LREC) was approached at the request of a small number of consultant staff in order to secure their support as there appeared to be concern that the pathway would prompt withdrawal of treatment at the time of dying. The LREC stated that ethical approval was not required as it was implementation of evidence-based care. This preparation time proved a worthwhile exercise to gain consensus across the hospital and raise the profile of care of the dying.

As implementing evidence into practice is a complex process, a decision was made to initially implement the pathway in those areas where there was good leadership and enthusiasm for care pathways. The idea was to produce some immediate success and a core group of champions. Training and education of staff in the 18 clinical areas was a significant component of the project. The project was staged in four parts, three months per stage; see Figure 1 for an outline of the project plan.

### Month one

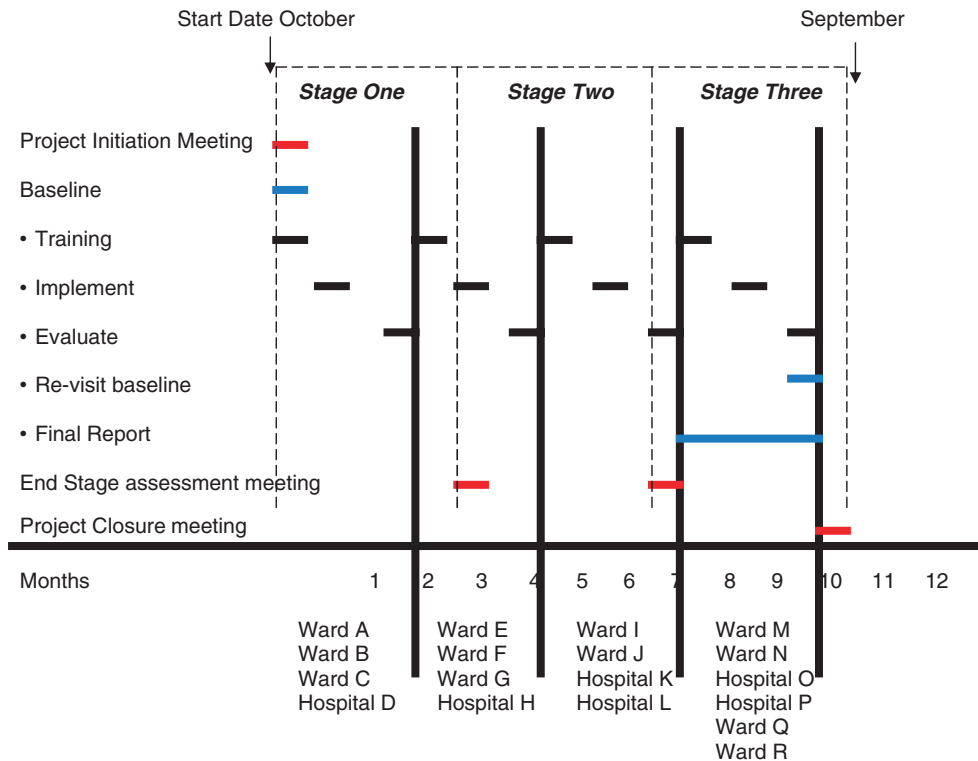
A typical project stage involved at least four clinical areas. At the commencement of each stage one month was allocated to the education and training of staff.

The objectives of the training were:

- To raise awareness of appropriate care and management of the dying.
- To highlight the needs of the family.
- To demonstrate how the theory of caring for the dying is brought into practice by the pathway.
- Details of how to complete the pathway document.
- To highlight the benefits and disadvantages of delivery of care via an ICP.

Training sessions were multidisciplinary, based around clinical teams and their pressures within the clinical environment. They had an open and flexible format to facilitate participation. They also allowed for discussion to enable participants to share and reflect on their experiences of death and dying and how this may affect their professional caring role.

The project nurse organized sessions for trained and untrained nurses, doctors, housekeeping staff, porters and administrative and clerical staff. Ancillary staff are less clinically involved in palliative care but also required



**Figure 1** The project plan.

education: it was important that all staff who may come into contact with the dying, and their carers, were able to act with sensitivity and care to those who are so vulnerable.

### Month two

The second month of a project stage involved the implementation of the pathway and monitoring of variances. A degree of flexibility and pragmatism proved necessary within the project plan to meet the individual needs of the wards and community hospitals. For example, within the limits of staff sickness and annual leave, optimum implementation times were chosen, particularly the presence of senior staff for moral support, leadership and to sanction the innovative approach. Following the month of training the project nurse supported the ward/hospital for one month of active implementation.

### Month three

On the third month an evaluation of implementation completed the three-month cycle. The project nurse recorded the number of deaths in each of the trained areas and reviewed the available notes of those who had died. If it was evident that a patient had met the criteria for the pathway and staff had not used the ICP, the nurse would arrange a case review. The aim was to gain an

understanding of why the pathway had not been initiated and challenge practice if necessary.

It was planned that the project nurse would move on from the implementation areas after the evaluation period, however it was evident that staff needed both reminders about using the pathway and continued support in completing the documentation to build their confidence. Consequently, the project nurse actively supported all areas, while training in the next stage of the project. This highlights the on-going intensive support required in such a project and the level of staff time and resources invested to achieve the desired outcome, which is only present in more recent published evaluations of care pathway implementation.<sup>10</sup>

## Main measures of implementation

The four main measures utilized to assess the implementation of the ICP: medical record audit, monitoring variances, evaluation of training and field notes, form the basis of this paper. Prior to the commencement of the project a baseline audit was conducted of the care of patients who had been expected or anticipated to die. The audit tool used was the nationally agreed tool from the All Wales Project (Figure 2). This audit was repeated at the end of the project.

1.	Patient identity number	-----		
2.	Age of patient	----- years		
3.	Gender of patient			
4.	Department	-----		
5.	Consultant	-----		
6.	Diagnosis	-----		
7.	G.P. Informed that the patient is dying		yes	no
8.	Decision not to resuscitate documented in the notes		yes	no
9a	Evidence in the case notes that the patient has been assessed		yes	no
9b	If "yes" has action been taken to alleviate symptoms		yes	no
9c	Is there evidence that the action has been reviewed		yes	no
10a	Non essential oral drugs have been stopped		yes	no
	If "no" why not	-----		
11.	Prescription of PRN for:			
	a) analgesic		yes	no
	b) anti-emetic		yes	no
	c) sedative		yes	no
	d) anticholinergic		yes	no
12	Were intravenous fluids in progress at time of death		yes	no
13.	Recording of vital signs was discontinued		yes	no
14.	Religion clearly recorded		yes	no
15.	Next of kin:			
	a) Name recorded		yes	no
	b) Contact number		yes	no
16.	Records clearly state whether family want contacting overnight		yes	no
	a) Name of contact clear		yes	no
	b) Contact number clear		yes	no

**Figure 2** Baseline audit tool.

## Results of medical record audit

Within the project period there were 451 deaths in the areas where the pathway had been implemented. These were expected and unexpected deaths. Unfortunately, the number of potential ICP deaths cannot be extrapolated from these data. However, it is estimated that half of all deaths in the UK are anticipated.<sup>4</sup> This would suggest that 50% or 225 of the 451 deaths may have required palliative care. Of the 451 deaths in total, 156 patients commenced the pathway of which 146 patients completed care via the ICP. This indicates that 65% of deaths that may have required palliative care received care via the pathway.

A considerable number of patients with a noncancer diagnosis were cared for via the pathway (60% of all patients who completed care via the pathway) and this was unexpected. Between 1996 and 2000, 16–20% of the hospital palliative care team's caseload had been patients with nonmalignant disease. This demonstrates that patients dying of nonmalignant disease are benefiting from the ICP implementation. This is welcomed, as the hospital palliative care team would not have the resources to care for all dying patients.

There is a plethora of research evidence to suggest that care at the end of life for those dying from nonmalignant disease can be poor.<sup>1–3,5,26</sup> The pathway appears to be able to address this issue in part. Also, 63% of patients did not require the palliative care team, suggesting that staff were coping with caring for their dying patients via

the pathway. This is one of the main advantages of the pathway; that other multidisciplinary teams are enabled to care for their dying patients. Table 1 demonstrates these results.

## Pre- and postimplementation audit

A pre- and postimplementation audit of medical records was conducted to evaluate the implementation of the ICP utilizing the agreed audit tool (Figure 2). A random sample of 50 people who were 'expected to die' was selected for each audit. The post audit was easier to conduct as medical practitioners had clearly indicated in the notes patients who were to be placed on the care pathway. Nine months into the project, there was considerable improvement (increase of greater than 20% conformance) in the following areas:

**Table 1** Patients cared for via the pathway

Total number of deaths	(n=451)
Total number of patients cared for via pathway	146 (32%)
Diagnosis (n=146)	
Cancer	58 (40%)
Non-malignant disease	88 (60%)
Support of hospital palliative care team (n=146)	
With support	54 (37%)
Without support	92 (63%)

- informing the general practitioner that the patient is dying;
- decision 'not to resuscitate' documented;
- prescribing as required antiemetic, sedatives and anticholinergic medication;
- the recording of vital sign observations being discontinued;
- the discontinuation of nonessential oral drugs;
- recording whether the family want contacting overnight.

## Variations of ICP

*Analysis of variances.* The Care Pathway identified areas where there was variance from the guidelines. The project nurse analysed variances throughout the project and followed up action where appropriate. At the end of the project 401 variances were identified from the pathway. Seventy per cent of reported variances were reported six times or less. The most frequently reported variances reported more than six times were:

- General Practitioner has been informed of the situation
- discontinue antibiotics
- discontinue intravenous or subcutaneous infusion
- other symptoms
- assessment of agitation
- mouth care assessment
- pain assessment
- respiratory tract secretion assessment.

The project nurse analysed variances from the ICP throughout the project and followed up where appropriate. On analysis of the variances it is evident that symptom control could have been improved in some areas. While a vast improvement in care to the dying has occurred through the use of the pathway, continued education on care of the dying and appropriate medication for symptom control would be of benefit (see Table 2). In particular, the assessment and treatment of respiratory tract secretions, pain, mouth care and agitation. Pain assessment, pain control and the management of restlessness and agitation at the end of life were of particular concern and indicate significant education is required.

## Evaluation of training

Following each training session a short questionnaire was distributed to attendees. The results indicated that the sessions were well received and staff identified a number of common issues that required addressing through additional training. Nurses reported feeling more confident to prompt a review of the clinical situation and overall the evaluations showed that clinical teams felt enthusiastic and positive about the ICP. In particular it provided clear guidance on prescribing, reducing paperwork and guiding junior staff in best practice in a sensitive and often difficult area of care.

## Sustaining the change

Difficulties in sustaining change in practice have been highlighted in the literature<sup>27</sup> and it was not known if, when the project manager and project nurse withdrew

**Table 2** Baseline and postimplementation audit results

	Baseline audit		Postimplementation audit	
	Yes	No	Yes	No
GP informed that patient is dying	3	47	22	28
Decision not to resuscitate documented	30	20	44	6
Evidence that patient has been assessed	44	6	49	1
If yes, has action been taken to alleviate the symptoms	37	7	44	5
Is there evidence that the action has been reviewed	32	18	39	11
Nonessential drugs have been stopped	17	33	37	13
Prescription for PRN analgesia	44	6	43	7
Prescription for PRN antiemetic	19	31	35	15
Prescription for PRN sedative	20	30	34	16
Prescription for PRN anticholinergic	10	40	31	19
Were I.V. fluids in progress at the time of death	20	30	23	27
Recording of vital signs discontinued	4	46	26	24
Religion clearly recorded	35	15	42	8
Next of kin name recorded	49	1	49	1
Next of kin contact number recorded	46	4	48	2
Records state whether family want contacting overnight	1	49	27	23

Increases in conformance by >20%.

Areas where further improvement needed.

their support at the end of the project, whether clinical teams would continue to use the pathway. Recommendations were made to the clinical governance committee and in particular the audit department to ensure analysis of pathway usage and variance continued. The results of three post project audits are shown in Table 3.

These results show an initial reduction in pathway usage three to five months after the project ended followed by an improvement in usage. What is interesting to note is the sustained usage for those patients dying from nonmalignant disease, which supports our earlier observation that this project has made a remarkable advance into the care of those dying from nonmalignant diseases.

## Discussion

The main aim of this project was to improve care of the dying through the structured implementation of a pre-developed care pathway. There was considerable improvement in the care of those patients entered on the ICP as demonstrated in comparing the results of the postimplementation audit to the baseline audit. However variances highlighted further improvements in treatment and care were still required. It was identified that these further improvements included ensuring 100% of dying patients are prescribed analgesic, antiemetic, sedative and anticholinergic medication. The use of intravenous and subcutaneous fluids, informing General Practitioners, and reviewing care also required improvement, in particular, assessment and treatment of respiratory tract secretions, pain, mouth care and agitation.

There is substantial evidence to suggest that successful implementation of the ICP was achieved through systematic project management, a project manager and a dedicated full time project nurse. Our findings draw a striking similarity to a report from the Kings Fund, which stressed that for implementing evidence into practice, an effective project worker is required.<sup>27</sup> Characteristics of this person include having drive, personality, motivation, enthusiasm and a nonthreatening style.

Other similarities also include:

- resources of time, money and skill;
- the change needs to benefit frontline staff;
- support early on from senior clinical leaders
- interactive project managed approach;
- expect to take years not months to change behaviour;
- a preplanned approach is needed with pragmatism and flexibility;
- target enthusiasts and start small;
- regular communication and feedback to staff.

This project has not been resource neutral and it is our belief that successful implementation of ICPs will require sufficient resources and skilled support. Change will not happen without these arrangements, particularly as 'dying' can be a challenging area of care.<sup>6,9</sup> This project highlights the level of staff time and resources required to achieve the desired outcome, which are not always apparent in published evaluations of care pathway implementation.<sup>7</sup>

Successful change in practice appeared to occur at different stages in the different clinical areas. While some wards and community hospitals embraced the change at the outset of the project, others showed some resistance and complacency. It was evident though that with sustained support from the project nurse over time the planned change in practice did take place, with many using the pathway without prompting or support by the end of the project. It was particularly noted that where there was evidence of strong leadership from the ward manager, implementation and change was smoother, with very good use of the pathway. While use of the pathway appeared to decrease shortly after the project manager and nurse withdrew intense support, within one year of completion of the project the pathway appears to be becoming part of normal practice.

Traditionally, palliative care has been largely available to cancer patients, however, 60% of the patients cared for via this pathway had a nonmalignant disease. This suggests that the ICP made a remarkable advance into a neglected area of care. One of the main objectives of the pathway was to empower other members of the multi-disciplinary team to care for dying patients with non-

**Table 3** Use of the pathway postimplementation audit results

Date	Deaths sample (n = 50)	Cared for via pathway	Cancer	Noncancer	With support of HPCT	Without support of HPCT
Dec 2001–Feb 2002	50	10 20%	4 40%	6 60%	4 40%	6 60%
July–Sept 2002	50	30 60%	14 47%	16 53%	17 57%	13 43%

HPCT: hospital palliative care team.

complex needs without the support of the hospital palliative care team. Sixty-three per cent of patients on the ICP were not referred to the palliative team. This suggests implementation of the ICP has empowered other members of the multidisciplinary teams to undertake evidence-based care.

Informal feedback from many consultant and nursing staff revealed that this project made a significant and positive difference to the care of the dying and their families. Senior clinicians highlighted that the pathway provided them and their staff with a coherent plan of care and treatment and improved communication, co-ordination and teamwork at a very difficult time.

Finally, the key message emerging from this project is that to guarantee the success of implementing an ICP one has to invest in skilled manpower, time and resources. The benefits for the organization will be an assurance of evidence-based care and sustaining practice and organizational change. For patients and carers this investment will result in tangible improvements in the delivery of treatment and care at a very sensitive and vulnerable time of their lives.

### Acknowledgements

The authors would like to acknowledge that this project would not have been possible without a generous grant from the Nevill Hall Hospital Thrombosis and General Research Fund and for the successful work of the project nurse – Linda Haywood, Gwent Healthcare NHS Trust.

### References

- Mills M, Davies TO, Macrae WA. Care of dying patients in hospital. *Br Med J* 1994; **309**: 583–86.
- Rogers A, Karlsen S, Addington-Hall J. Dying for care: the experiences of terminally ill cancer patients in hospital in an inner city health district. *Palliat Med* 2000; **14**: 53–54.
- Support Project Principal Investigators. A controlled trial to improve care to seriously ill hospitalised patients: The Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment. (SUPPORT). *JAMA* 1995; **174**: 1591–98.
- National Council for Hospice and Specialist Palliative Care Services. *Specialist palliative care: a statement of definitions*. Occasional Paper No 8 London, National Council for Hospice and Specialist Palliative Care Services, 1995.
- Addington-Hall J. *Reaching out: specialist palliative care for adults with non-malignant disease*. London: National Council For Hospice and Specialist Palliative Care Services, 1998.
- Higgs R. The diagnosis of dying. *J R Coll Physicians Lond* 2000; **33**: 110–12.
- Campbell H, Hotchkiss R, Bradford N, Porteous M. Integrated care pathways. *Br Med J* 1998; **316**: 133–37.
- Ellershaw JE, Foster A, Murphy D, Shea T, Overill S. Developing an integrated care pathway for the dying patient. *Eur J Palliat Care* 1997; **4**: 203–207.
- Ellershaw JE, Ward C. Care of the dying patient: the last hours or days of life. *Br Med J* 2003; **326**: 30–34.
- Ellershaw JE, Wilkinson S. *Care of the dying: a pathway to excellence*. Oxford: Oxford University Press, 2003.
- Parkes CM. Risk factors in bereavement: implications for the prevention and treatment of pathologic grief. *Psychiatr Ann* 1990; **20**: 308–13.
- Knight M, Field D. A silent conspiracy: coping with dying cancer patients on an acute surgical ward. *J Adv Nurs* 1982; **6**: 221–29.
- James V, Field D. Who has the power? Some problems and issues affecting the nursing care of dying patients. *Eur J Cancer Care* 1996; **5**: 73–80.
- May C. Disclosure of terminal prognoses in a general hospital: the nurse's view. *J Adv Nurs* 1993; **18**: 1362–68.
- Oberle K, Hughes D. Doctors' and nurses' perceptions of the ethical problems in end-of-life decisions. *J Adv Nurs* 2001; **33**: 707–15.
- Saunders J. Perspectives on CPR: resuscitation or resurrection? *J R Coll Physicians Lond* 2001; **1**: 457–60.
- Stewart K. Discussing cardiopulmonary resuscitation with patients and relatives. *Postgrad Med J* 1995; **71**: 585–89.
- Von Gunten CF, Ferris FD, Emanuel LL. Ensuring competency in end-of-life care: communication and relational skills. *JAMA* 2000; **284**: 3051–57.
- Illich I. *Limits to medicine: medical nemesis: the expropriation of health*. London: Marion Boyars, 1976.
- Clark D. Between hope and acceptance: the medicalisation of dying. *Br Med J* 2002; **324**: 905–907.
- Kelly D. A commentary on 'An integrated care pathway for the last two days of life'. *Int J Palliat Nurs* 2003; **9**: 39.
- Fowell A, Finlay I, Johnstone R, Minto L. An integrated care pathway for the last two days of life: Wales-wide benchmarking in palliative care. *Int J Palliat Nurs* 2002; **8**: 556–73.
- NHS Beacon Programme 2001. *NHS Beacons learning handbook: spreading good practice across the NHS*. Volume 4:2001/2002. Petersfield: NHS Beacon Programme.
- National Institute for Clinical Excellence (NICE). Improving supportive and palliative care for adults with cancer – guidance on cancer services. NICE, 2004.
- Office of Government Commerce. *Managing successful projects with PRINCE2*, revised edition. London: OGC, 2002. Retrieved from: [www.ogc.gov.uk/prince](http://www.ogc.gov.uk/prince)
- Addington-Hall JM, McCarthy M. Dying from cancer: results of a national population-based investigation. *Palliat Med* 1995; **9**: 295–305.
- Wye L, McClenahan J. *Getting better with evidence*. London: King's Fund NHS Executive, 2000.