

# Defining Quality in Hospice Care

## Foreword

Quality is a slippery concept! I remember being told by a well-known Hospice Chief Executive that it was “more than a drawer full of thank you letters”! Indeed it is!

Quality is certainly best judged by those who receive care – but their grateful thanks can never be the only marker. A synthesis of narrative and more measurable aspects of quality are vital to understand the impact of care. However what is also crucial to understand are the individual constituents of quality that lead to those outcomes.

Just as we are getting closer to understanding the concept of dignity and what it truly means for our patients, the analysis, research and thinking behind this Report, gives us a challenge and opportunity to think deeply about our services and all settings in which dying people receive care.

This Report is very timely. At the time of writing some hospices face significant changes related to regulatory compliance, which now focus on key questions around how organisations such as hospices ensure they safe, effective, responsive, caring and well led. Many of us are also required to adopt a framework describing new priorities to guide care for people in the final chapters of their lives, recently published by the Leadership Alliance for the care of Dying People and supported by the Department of Health.

We can never be complacent about the quality of care – this report will ensure that ‘quality’ is a usable and relevant concept for us all.

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# Defining Quality in Hospice Care

## Background

The term “hospice care” is often synonymous with the concept of high quality care for people approaching the end of their life and their families. Evidence exists that the experience of hospice care is positive for those who receive it <sup>(1,2)</sup> and staff and volunteers working in hospices pride themselves on meeting the needs and preferences of those in their care to a high degree. There are strong assumptions about what constitutes good quality care, drawn largely from definitions of palliative care, as described by Help the Hospices in its definition:

**Hospice care seeks to improve** *“the lives of people who have a life-limiting or terminal illness. It helps them to live as actively as they can to the end of their lives, however long that may be. It not only takes care of people’s physical needs, but looks after their emotional, spiritual and social needs as well. Hospice care also supports carers, family members and close friends, both during a person’s illness and during bereavement”* <sup>(3, p3)</sup>.

Yet there has been little work to date reviewing the literature or consulting with experts in hospice care in a more systematic way to establish what contributes to the quality of hospice care. This is important to do for a number of reasons. It is vital in defining relevant outcomes for hospice care, in shaping the skill base of the future hospice workforce and in confirming how hospice care can contribute to the wellbeing of individuals and communities, and to the effectiveness of health and social care systems. These are important considerations for hospices as they plan to position themselves in the future, as described by the Commission into the Future of Hospice Care<sup>(4)</sup>.

During 2013 Help the Hospices conducted a workshop, a literature review and a national consultation exercise to help answer the question ‘what is quality in hospice care?’ and to seek to define the domains of quality. This paper outlines the methods used, our findings and next steps. It begins by confirming the emerging thinking about the domains of key importance.

# Proposed domains of quality

Five domains of quality are proposed with some statements about what this might mean in practice:

## 1. The quality of care experienced by patients, family members, carers and members of the general public.

- The plan for care is personal. It is focused on the 'whole person', person-centred and values-based in nature.
- Care is compassionate, coordinated and consistent.
- Users are informed and involved in decision-making.
- Wishes and preferences on the part of those seeking help or support are respected.
- Open and honest communication is at the heart of care.
- Support is available for family and carers pre and post bereavement.

## 2. The safety of the person receiving care.

## 3. The effectiveness of care.

- Care is evidence-based where available or at least reflects best practice.
- Care is outcome focused, attending to physical, psychological, social, spiritual, cultural or other specific needs.
- Care is delivered by confident and competent staff and volunteers.

## 4. Access and availability of care.

- Access to care is equitable - based on need, reflecting choice where possible, and 24/7.
- Services are appropriately resourced.
- Service delivery is integrated and collaborative.
- Support is available for staff and volunteers.

## 5. Environment.

- Care is delivered where possible in familiar surroundings, within a calm/peaceful context.

Please note: These statements have been created using the revised domains from the consultation responses (see Appendix A).

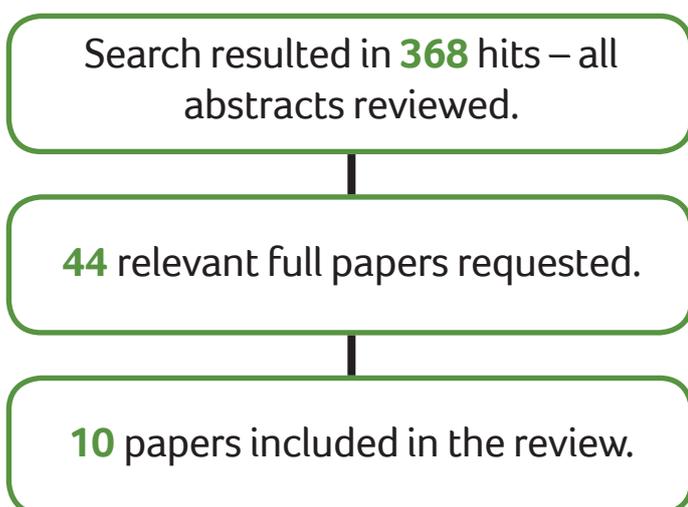
# Review of the literature and policy

Prior to the national consultation a review of the literature was undertaken - to explore how quality and its domains or characteristics are defined in relation to hospice care within published research, and relevant national policies and guidelines.

## Search strategy

The databases used were: CINAHL, CareSearch, Embase, HMIC, PubMed, Halley Stewart Library, Christopher's Hospice and Google Scholar. The following key words were used: hospices or hospice care or terminal care or palliative care, and quality assurance, health care or quality indicators, health care or quality control or quality improvement or quality of health care. We limited the search to papers written in the English language and to publications within the last 10 years. Papers were included if they reported on a definition of quality or domains of quality in hospice or palliative care. Figure one below summarises the search strategy.

Figure one:



## Findings

Of the 10 papers included in the literature review four originated from the USA<sup>(5,6,7,8)</sup>, two from the Netherlands<sup>(9,10)</sup>, one from Europe<sup>(11)</sup>, one from Canada<sup>(12)</sup>, one from Germany<sup>(13)</sup>, and one joint study from USA, Spain and Sweden<sup>(14)</sup>. Three papers reported quantitative surveys<sup>(5,7,8)</sup>, one used a mixed methods approach to developing quality indicators<sup>(9)</sup>, two were systematic reviews<sup>(10,12)</sup> and four were discussion papers or guidelines<sup>(6,11,13,14)</sup>.

There were no studies originating from the UK although the European guidelines were co-authored by UK based researchers.

Most papers provided expert clinicians' or policy-makers' views on quality, with one paper<sup>(7)</sup> providing bereaved carer views on quality, and another study<sup>(8)</sup> reported on patient, family and nurses views. Claessen et al<sup>(9)</sup> in a study that developed quality indicators, consulted with patients and carers to further refine these prior to testing.

Only one paper specifically looked at quality of hospice care and this was a USA based study<sup>(7)</sup>. Hospice care is defined differently in the USA to the UK and is often provided in a variety of settings funded through health insurance programmes when people are in the last six months of life. All other papers referred to palliative care or end of life care settings, some including hospices. This makes it difficult to generalise the findings to UK based hospices.

## Definition of quality in hospice/palliative care services

Only two of the papers offered a definition of quality<sup>(7,14)</sup> and one paper defined a ‘good death’<sup>(12)</sup>. Rhodes et al<sup>(7)</sup> defined the best possible care as:

*‘care that is consistent with the goals established by the patients and their families’* (p.366).

Ferris et al<sup>(14)</sup> defined quality as:

*“a consistent approach to their care, that includes assessment, provides them with information they need to make their own decisions based on best possible therapeutic options, and involves them in care planning and delivery”* (p.533).

## Domains of quality

Eight papers discussed domains or characteristics of ‘quality care’; one focused specifically on the development of quality indicators<sup>(8)</sup> and another paper looked at guiding principles or values associated with quality in palliative care<sup>(14)</sup>. The key domains identified within these papers are:

- structure and process of care - access & resources
- physical aspects of care
- psychological aspects
- social aspects
- spiritual/religious care
- cultural aspects of care
- care of those imminently dying
- ethical/legal/advocacy
- wishes and preferences for care/ information needs for decision making

- continuity, consistency and coordination of care
- overall patient satisfaction of care
- quality of life
- life closure and preparation for death with family
- prevention of abandonment – support for bereaved family
- communication – open/honest
- treated as a whole person including their family & respecting personal beliefs.

The tables in appendices B and C report the above domains for each paper included in this review.

## National Policy and quality

‘Quality’ in Lord Darzi’s review of the National Health Service in 2008 was deemed to centre around three broad domains: **patient safety, clinical effectiveness** and **patient experience** and applied to all patient groups<sup>(15)</sup>. These domains have since been used as a framework for NHS organisations in their quality accounts. The National Quality Board<sup>(16)</sup> has defined quality as:

*“care that is effective, safe and provides as positive an experience as possible”* (p4).

The first national end of life care strategy<sup>(17)</sup> did not define quality of care within end of life care services or hospice care, but offered a definition for a ‘good death’ which included: *“being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends”* (p.9).

The national end of life strategy quality markers for different health care organisations included some for hospices<sup>(18)</sup>. These include the following topics:

- action plan for end of life care within the organisation
- patients wishes/preferences
- patient needs assessment
- nominated key worker
- use of a care pathway for the dying
- family involvement in decision-making
- facility to admit patients 24/7
- audit of quality of care
- identification and provision of training for the hospice workforce.

The NICE quality standard for people at the end of life, QS13<sup>(19)</sup>, identified the following as quality statements:

- identification of patients at the end of life
- communication and information
- assessment care planning and review
- holistic support (physical, psychological, emotional, social, practical spiritual, religious, families and carers)
- coordinated care
- urgent care
- specialist palliative care
- care in the last days of life and after death (including bereavement support)
- workforce - training.

## Regulatory compliance and quality

All adult and children's hospices whether independent or NHS organisations are required through statutory regulation to assure themselves and their regulators of the quality of care provided in accordance with the essential standards<sup>(20)</sup>. Assurances

of the quality of care to NHS commissioners are also required where hospices provide services to NHS patients, whether by a service level agreement or NHS contract.

The NHS use the NHS Commissioning Outcomes Framework, NICE guidance, National Service Frameworks and national strategies and policies to guide their requests for information from providers, assuring themselves and the public of the quality of care commissioned.

The NHS National Quality Board (NQB) patient experience framework<sup>(21)</sup> suggests the following elements of quality, informed by patient experience:

- respect of patient-centred values, preferences, and expressed needs
- coordination and integration of care
- information, communication, and education
- physical comfort
- emotional support
- welcoming the involvement of family and friends
- transition and continuity
- access to care.

# Development of quality domains within the hospice sector

## Hospice clinical leaders' views

Through an executive clinical leaders conference organised by Help the Hospices in October 2012, over 78 delegates from 66 hospices attended, and 35 took part in a workshop to discuss 'what is quality in hospice care?'

'Quality' in hospice care was viewed by delegates as care that is:

- **driven by patient and carer experience**
- **person-centred**
- **values-based**
- **open and honest**
- **pro-active**
- **inclusive**
- **offering choice within resources available.**

Quality care in hospices was seen to include the following domains:

- **patient safety**
- **informed by evidence and standards**
- **clinically effective**
- **delivered by competent staff and volunteers.**

## Consultation with hospices, hospice users and related associations

### Method:

The clinical leaders' workshop and the findings from the literature and policy review informed the development of a set of potential draft domains of quality in hospice care.

A consultation paper with the proposed domains for quality in hospice care was distributed to 211 Hospices across the UK, and all associations affiliated with Help the Hospices. A link to the paper was also posted on Help the Hospices website, the executive online news bulletin and Facebook. The consultation was open from 19 June to 31 August. In this consultation responses were welcomed from hospices, hospice staff, and hospice users.

### Analysis:

The nominal statistics from the consultation responses are tabulated in table one. The narrative comments were compared for similarities and differences. The responses to the first four questions were synthesised into summary statements, retaining original descriptors where possible. We also asked a question about gaps in knowledge about quality in hospice care that research could potentially address, this attracted narrative responses and research questions.

**Table one: Nominal statistics**

	Yes		No		Total Number of Responses
	Number of Responses	% of Responses	Number of Responses	% of Responses	
<b>Q1: Do you agree with the proposed domains?</b>	53	91.38	5	8.62	58 <sup>(2)</sup>
<b>Q2: Is there anything included that shouldn't be?</b>	8	13.79	50	86.21	58
<b>Q3: Is there anything missing that should be there?</b>	32	61.54	20	38.46	52
<b>Q4: Do you support these domains for developing a hospice quality framework?</b>	56	96.55	2	3.45	58

**Findings:**

A total of 62 responses were received, which included 42 hospices. Not all respondents answered all questions, with some sending narrative comments only. There were 24 group responses, 22 of these were hospice service responses and two were responses from national associations affiliated with Help the Hospices. There were 25 individual responses and 13 other responses did not specify whether it was a group or individual response.

Hospice service users were asked for their views by three hospices and their responses were reported as either informing the organisations overall response (n=1) or sent as a separate group response (n=2). We also received a response on behalf of two major charities that support the care of people with life-threatening illnesses.

**Quantitative responses to survey questions about the proposed domains for care:**

The first four survey questions of the consultation feedback required a yes/no answer. 91% respondents agreed with the proposed domains and 96.5% supported these domains being used to develop a hospice quality framework.

13% responded negatively to the question: 'Is anything included that shouldn't be?' 61.5% responded yes to 'Is there anything missing that should be there?'

**Qualitative responses:**

The feedback sheet provided spaces for comments against all questions. Most respondents included comments. Some of the comments provided views on where domains best fitted or suggestions for rephrasing such as 'sensitive' communication instead of 'open and honest'.

The responses have been summarised under the question headings in appendix D.

The majority of respondents supported the domains as a basis for developing a quality framework for hospices. The domains were viewed as a 'starting point' that aligned to other national guidance. There were a few polarised views about the domains being 'enough' to be manageable with others requiring more detail.

In addition, 'integration' and 'collaboration' were viewed as important elements of quality in hospice care. 'Environment' was suggested as another domain of quality which included a 'familiar surroundings' and 'calm' and 'peaceful' or 'healing' space. In addition, although 'evidence based' was viewed as a 'gold standard' in quality care several respondents suggested this is not always available within hospice treatment/ care modalities, and that 'best practice' was important to include. 'Equity' of access to care, based on patient 'need' and available '24/7' were other suggestions that were deemed as missing from the details within the core domains.

The feedback from hospices and organisations users supported the revision of the proposed domains on page two.

There were 43 responses to the question inviting people to comment on gaps in knowledge related to quality in hospice care that research could address (appendix E).

## **Limitations of the national consultation:**

The main limitation of this consultation was the response rate of 29.38%, which is below average for a directed emailed survey. However it was encouraging to receive three responses from groups of hospice service users, in addition to user views submitted by two national end-of-life care charities.

# Using the domains to inform practice, policy and research

We encourage hospices to consider the proposed domains of quality with their staff, users, their clinical governance groups and boards of trustees. These aspirational domains of quality in hospice care could be used in a whole variety of ways on the part of hospices, for example:

- **To inform the developing patient and family experience feedback surveys.**
- **To invite feedback from others.**
- **To guide clinical and service audits.**
- **To aid discussions with NHS Clinical Commissioning Groups and other funding bodies in negotiating quality schedules, targets, service improvements alongside existing guidance for commissioners for specialist palliative care <sup>(22)</sup>.**
- **To help guide the development of frameworks for staff performance appraisals, staff competencies and revalidation.**
- **To support the development of resources for end of life care following the national review of the Liverpool Care Pathway and subsequent publication by the Leadership Alliance for the Care of Dying people on new priorities for care <sup>(23)</sup>.**

We believe they may be useful at national level too. Some work has begun to define outcome measures for use in palliative care. The proposed domains of quality could inform the development of a related framework that is specific to patients being treated and cared for by hospices.

As the Care Quality Commission, NHS Quality Board and local NHS clinical commissioning groups continue to develop robust mechanisms for assessing and assuring themselves of the quality of services provided to patients and their families, we hope these proposed domains of quality for hospice care will provide a platform for the future. We believe they could inform the development of quality standards for regulatory assessments of hospices.

Gaps in evidence about quality of care in hospices have been identified through the consultation we conducted. We hope the findings from this initial consultation on quality in hospice care, and questions posed by respondents will inform researchers in the field of palliative and supportive care about possible research questions of interest to the hospice sector.

## Next steps

**We have recommended that the proposed domains of quality in hospice care are used by hospices and others with a stake in hospice care to inform plans and work that relate to its quality. We welcome feedback from them to help further refine the domains and develop their detail. Please email [clinical@helpthehospices.org.uk](mailto:clinical@helpthehospices.org.uk) for this purpose.**

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# Appendix A: Proposed domains of quality following analysis of the responses to the consultation

## **1. Patient, family/carers and public experience**

- a. 'Whole person' /person-centred and values-based
- b. Compassionate, coordinated and consistent care
- c. Informed and involved in decision-making
- d. Wishes and preferences respected
- e. Open and honest communication
- f. Support for family & carers pre and post bereavement

## **2. Patient safety**

## **3. Effectiveness**

- a. Evidence-based where available or best practice
- b. Demonstrated by measurable outcomes for patients based on: physical, psychological, social, spiritual, cultural needs
- c. Delivered by competent staff and volunteers

## **4. Access and availability of care**

- a. Equity of access to care - based on need, in place of choice where possible, and 24/7
- b. Appropriately resourced
- c. Integrated and collaborative
- d. Support for staff and volunteers

## **5. Environment**

- a. Familiar
- b. Calm/peaceful

# Appendix B: Domains of quality

Domains:	Structure and process of care - access & resourced	Physical	Psychological	Social aspects	Spiritual, religious	Cultural	Care of imminently dying	Ethical and Legal/ Advocacy
Clasen et al		1	1	1	1			
Pasman et al	1	1	1	1	1	1	1	1
Ostgathe & Voltze	1	1	1	1	1	1	1	1
Hanson et al		1	1	1	1	1	1	
Ferrell et al	1	1	1	1	1	1	1	1
Hales et al*	1	1	1	1	1			
Engelberg et al		1	1					
Ferris et al	1	1	1	1	1	1	1	1
Rhodes et al		1	1					
Bausewein et al								

\*only looked at quality of dying/death

# Appendix C: Domains of quality

Domains:	Wishes & preferences for care, information needs, decision-making	Continuity Consistent & Coordination of care	Patient overall satisfaction of care	Quality of life	Life closure & death prep patients family	Circumstances of death, prevent abandonment family support	Communication open & honest self/family	Treated as Whole person incl. family & respect personal beliefs
Claasen et al	1							
Pasman et al								
Ostgathe & Voltze								
Hanson et al		1	1	1				
Ferrell et al								
Hales et al*					1	1		
Engelberg et al	1					1	1	1
Ferris et al	1	1			1	1		
Rhodes et al	1	1	1			1		
Bausewein et al	1	1	1				1	

# Appendix D: Summary of narrative responses from consultation

Comments on question	Summary of responses	
	General	Specific
1. Do you agree with proposed domains?	Excellent, good, agree, broad, needs more work/ fleshing out, greater definitions, very useful, important, welcome approach of placing person receiving care at heart.	'Training staff' under domain 2. <b>Change title of domain 1 to 'patient, family/carer and public'</b> . Add 'specialist MDT' & symptom management 'Sensitive' communication not 'open & honest. <b>Include bereavement in domain 1 rather than in domain 4.</b> Define 'appropriately resourced'. 'Consistent' doesn't fit with individualised care.
2. Is there anything included that shouldn't be?	Appropriate. Careful not to have too many domains, too generalist.	Lay person understanding of person-centred?' <b>Is 'appropriately resourced' a measure of quality?</b> Evidenced based where evidence is available <b>Remove 'community' from experience.</b> Remove 'Support to family'.
3. Is there anything missing that should be there?	Would benefit from more detail. There is enough – anymore would become unmanageable.	Support for staff and volunteers under domain 4. <b>Organisational effectiveness.</b> Specialist skills. <b>Facilitate choice – place of death.</b> Under effectiveness of care: pain free/symptom management. <b>Environment: familiar/healing/peaceful/calm.</b> Personal & practical. <b>Quality of life.</b> Advance care planning. <b>Feedback on experience/satisfaction.</b> Access – all ages, all settings, 24/7, equitable, based on needs. <b>Governance/accountability.</b> Responsive – timely. <b>Patient &amp; public involvement.</b> Patient safety: infection/incidents/learning/complaints. <b>Support for carers.</b> Multi-professional team/specialist. <b>Coordinated, collaborative and integrated care.</b> Audit and outcomes of care. <b>Informed and involved in decision-making.</b> Improvement culture – education and training valued. <b>Strong leadership.</b> Under 2. – clinical risk assessments/ Never events/PU's. <b>4c better under domain 1.</b> Individualised. <b>'Best practice' where no evidence.</b> Time – staff to patient ratio. <b>Value for money.</b> Add compassionate to 1.
4. Do you support these domains for developing a hospice quality framework?	Good idea Useful & sensible starting point/structure, Good basis for developing framework, will increase consistency.	Concern re measuring and who will monitor? <b>Welcome national framework.</b> Standards also useful. <b>Measurable outcomes difficult to produce.</b> Importance of specialist skills. <b>Concern not to become too complicated – ensure useable.</b>

# Appendix E: ‘What gaps in knowledge about quality in hospice care do you think can be addressed through further research?’

The development of robust outcome measures ‘across the board’ for all palliative care interventions were the most common gap identified by respondents. The other identified gaps were reported as:

- outcomes measures - psychosocial
- management of psycho-spiritual distress
- difference in care in hospices compared to care homes and hospitals
- added value of volunteers within hospice environment
- bereavement
- widening access to hospice care
- attitudes of hospice staff compared to attitudes of hospital and community based staff
- benefits for hospices in a competitive market
- why service users don’t raise issues with hospices as they would in other settings
- role of respite
- role of specialist palliative care staff as experts/educators for generalists
- hospice care as a ‘complex intervention’
- UK service user views on quality of hospice care
- longer term impact of hospice care on the morbidity and mortality of informal carers.

There were also some suggested research questions:

- How do volunteers increase the quality of care/support experienced by patients and their families?
- How are hospices perceived?
- How does quality manifest in hospices’ corporate and clinical governance structures?
- Is quality evident from the boardroom to the bedside in hospices?
- What are the unique characteristics of leadership in hospice care that enables a compassionate culture for staff and patients to thrive?
- Can hospices use business excellence models to help improve quality of services or do business excellence models provide a framework for continuous quality improvement in hospices?
- How to support and develop patients and families resilience and coping strategies?
- What makes a good hospice practitioner (qualities)?