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Strategic Clinical Networks

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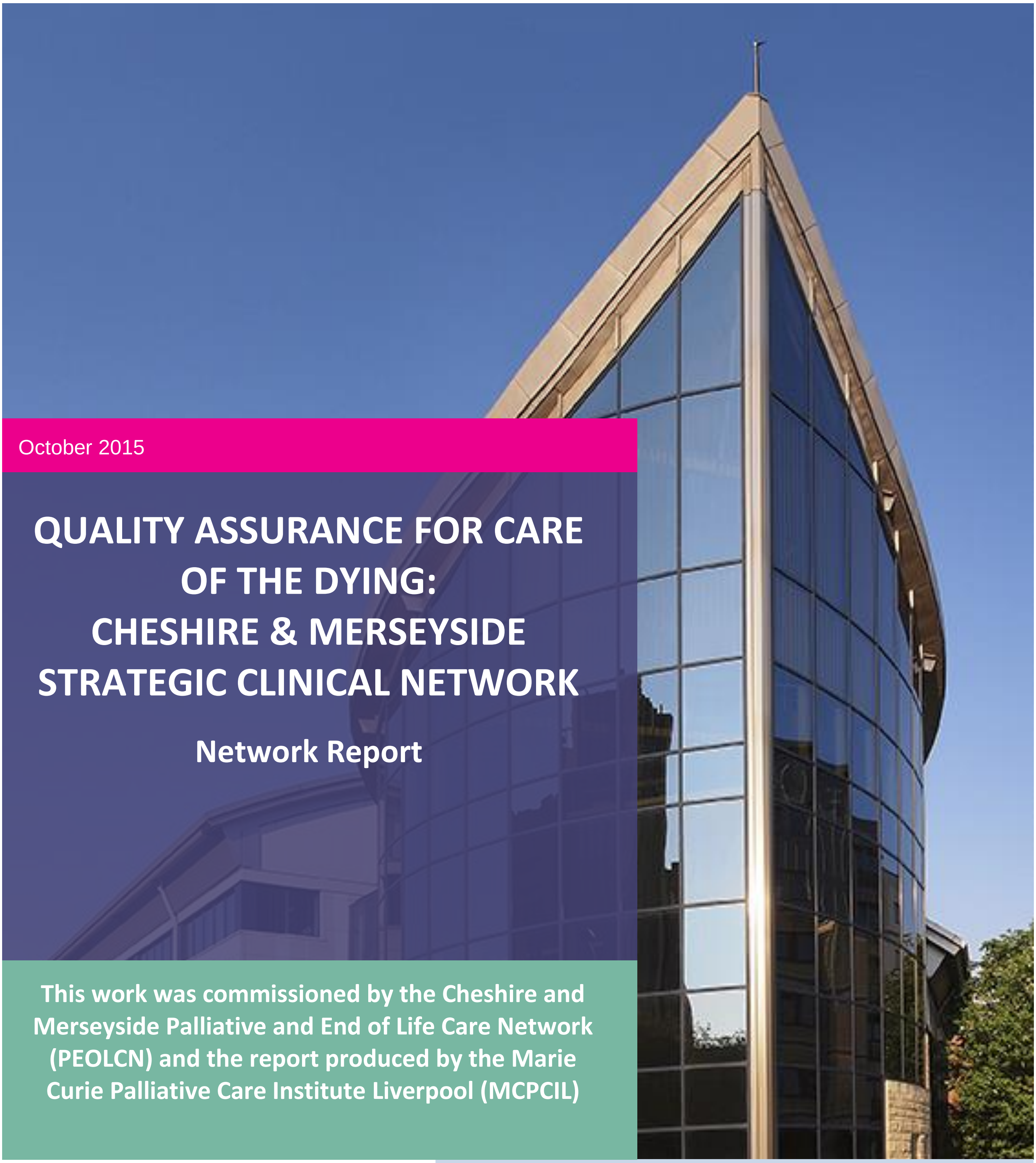
Excellence in Care for the Dying



October 2015

QUALITY ASSURANCE FOR CARE OF THE DYING: CHESHIRE & MERSEYSIDE STRATEGIC CLINICAL NETWORK

Network Report

This work was commissioned by the Cheshire and Merseyside Palliative and End of Life Care Network (PEOLCN) and the report produced by the Marie Curie Palliative Care Institute Liverpool (MCPCIL)

The Royal Liverpool and NHS
Broadgreen University Hospitals
NHS Trust

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Foreword

"Listening to what patients and their families say about the care they receive helps to improve the services we deliver. Undertaking this survey is testimony to the commitment within Cheshire & Merseyside to continue to improve the care and experience for patients at the end of life and those who care for them."

Dr Kieran Murphy
Medical Director
NHS England North (Cheshire & Merseyside)

"There is only one chance to get the care of a dying person right. The findings of this survey are welcomed and will support local plans to improve care of the dying in all care settings."

Tina Long
Director of Nursing
NHS England North (Cheshire & Merseyside)

"Improving the experience of care for people at the end of their lives is one of the key objectives within the NHS England Outcomes Framework 2015/16 and The NHS Five Year Forward View describes an ambition to empower patients and their families who are often 'experts by experience'. The Care of the Dying Evaluation (CODE™) questionnaire seeks the views of bereaved relatives on the quality of care received by their loved ones and gives us all as commissioners and providers the opportunity to evaluate the care given in whatever setting and take steps to ensure that our patients and their families receive the best possible care."

Paula Powell
Clinical Lead
Cheshire & Merseyside Palliative & End of Life Care Network

C&M SCN Peoples Voice

""How people die remains in the memory of those who live on". Health care professionals have one chance to get care of the dying person right. As a patient/care representative within the Cheshire & Merseyside Network, I welcome and support seeking the views of relatives to get an insight into what is good and what can be improved for patients and those they care for at the end of their lives. This report will help plans to improve local services."

Sharon Bird
Patient & Carer Representative
C&M PEOLCN

Acknowledgments

This work was commissioned by the Cheshire and Merseyside Palliative and End of Life Care Network (PEOLCN) and the report produced by the Marie Curie Palliative Care Institute Liverpool (MCPCIL).

We would like to express our sincere thanks to the individual relatives and friends who participated in this project for taking the time to complete the Care of the Dying Evaluation (CODE™) questionnaire and sharing their views on the care provided. This valuable information will help to improve the way in which care is delivered to dying patients across the PEOLCN. We would also like to thank all the hospitals, hospices and community trusts that participated in this service evaluation project, with particular thanks to members of staff who submitted their data.

We gratefully acknowledge the valuable support and advice of the Steering Group (see Appendix 1) throughout the project, and thank the Cheshire and Merseyside Palliative and End of Life Care (PEOLCN) Network for funding this work.

Useful Links

Cheshire & Merseyside Strategic Clinical Network	http://www.cmscnsenate.nhs.uk/strategic-clinical-network/
Cheshire and Merseyside Palliative and End of Life Care (PEOLCN) Network	http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/
Marie Curie Palliative Care Institute Liverpool	www.mcpcil.org.uk

EXECUTIVE SUMMARY

Aim of Project

The primary aim of this project was to seek from bereaved relatives their perspective of the quality of care and support provided to people and their families in the last days of life within the Palliative and End of Life Care Clinical Network for Cheshire and Merseyside (PEOLCN). Secondary aims included exploring organisational systems and processes for the management of complaints regarding end of life care and for gaining feedback from bereaved relatives; and gaining insight into the facilitators and barriers to participation in the project.

Project Overview

The PEOLCN covers a wide geographical area from Southport in the North through to Wirral in the South and extends across to include Cheshire; it has a population of over 3 million people. Within its boundary sits 30 organisations: 9 adult acute hospital trusts, 4 adult specialist hospital trusts, 10 hospices, 7 community trusts (and within Cheshire sits an End of Life Partnership organisation which works with a number of different organisations). The project sought opinion from the bereaved relatives of those people who died within the organisations who participated in the project.

19/30 organisations participated in this project, comprising 7 acute hospitals, 7 hospices and 5 community trusts. All 19 organisations completed the 'Organisational element', which sought contextual data and information regarding existing complaint management processes. 18 of the organisations completed the 'Regional Survey' element, which captured bereaved relatives' views regarding the care delivered to dying patients and themselves in the last days of life. The organisation which did not take part in the regional survey was a community trust who cited the reason for not taking part as staffing challenges and time constraints.

The organisations who took part in the project identified a lead within the organisation. In order to understand what helped facilitate and what proved difficult in the process of undertaking a bereaved relatives' survey, and to gain more in-depth information about current feedback and complaints processes within these organisations, individual interviews were undertaken with a purposive sample of named organisational representatives. A sample of participants was recruited from both organisations that participated in the Regional Survey element of the project, and those that did not. Participants were representative of organisations from all three care settings (hospital, hospice and community trusts).

Key Findings

- **Organisations take complaints seriously.** Formal systems for the receipt of general complaints were reported to be in place in all participating organisations. Separate coding systems for complaints about care in the last days of life were most likely to be present in the hospital settings, though the system for dissemination was not necessarily a formal one. In most organisations, issues and outcomes of complaints were feedback formally through Executive Boards, Trustees and clinical teams, but around one-third of organisations (mostly hospices) reported that they did not currently report in this way. It is important to note that only a very small proportion of all complaints were about care in the last hours or days of life.

- **Seeking feedback, rather than relying on complaints to find out what could be improved, is recognised as important to be able to make service improvement.** Feedback from the qualitative interviews reinforced the importance of involvement in the project as a mechanism for improvement through better understanding of bereaved relatives views and the opportunity to benchmark against other relevant, local services.

- **CODE^{TM} Surveys couldn't be sent out because next of kin information was not recorded.** Just over one quarter (n=491) of bereaved relatives of patients eligible for inclusion in the survey - (primarily for patients from the hospital and community settings) could not be sent a questionnaire; in the vast majority of these cases (n=460) this was due to missing or unverified next of kin details.

- **Overall feedback from relatives on the care received was positive.** The vast majority of bereaved relatives who returned a completed CODE^{TM} questionnaire fed back positive views on many of the aspects of care evaluated, including doing enough to control symptoms, attention to personal care needs, comfort and cleanliness of the environment, confidence in and the level of care received from doctors and nurses. However, across the board, these positive views were more likely to be reported about the care of patients in the hospice and community settings and least likely for those patients cared for in the hospital setting.

- **Staff explained care in a way which was easy to understand.** Explanations regarding the patient's condition and treatment were overwhelmingly reported to be easy to understand in all settings, although such explanations were less likely to happen in the hospital setting.

- **Relatives didn't know what to expect when the patient was dying and felt this would have been helpful.** Overall, around half of all relatives reported having had no communication with the healthcare team about what to expect when the patient was dying. Three quarters of those who reported not having had this discussion, thought that it would have been helpful, particularly for those in the community setting.

- **Relatives didn't always feel they were involved in decision making.** Only around half of all respondents perceived they had been very involved in decisions about the patients care and treatment with just under one-fifth (the majority of whom were relatives of patients in the hospital setting) reporting that they were not involved at all. Such involvement was highest in the hospice setting. Specifically, more than half of respondents reported that they had not had any discussion with the healthcare team about the appropriateness of giving fluids through a drip. This was most likely to be the case for those in the community setting, though just over two thirds in this setting also reported that it would not have been helpful.

- **Relatives reported that doctors and nurses were proactive in attempting to control symptoms but perceived more could have been done, especially to relieve retained respiratory tract secretions.** Overall, restlessness was reported to be present most frequently (and in particular within the hospital and community settings), ahead of pain and retained respiratory tract secretions. Retained respiratory tract secretions, however, were perceived to be the most challenging to control with 28 (14.8%) bereaved relatives (20 of whom were commenting on the care of patients in the hospital setting) reporting that doctors and nurses did not do enough to relieve this symptom.

- **There is room to improve emotional and spiritual support, particularly in the hospital setting.** It is interesting to note however that around half of all respondents answered 'neither agree nor disagree' to whether religious and spiritual needs were met, the reasons for which it would be interesting to unpack further.

- **Most relatives thought that hospital wasn't the right place for the patient to die.** Most respondents thought that the patient had died in the 'right' place**,** but relatives of patients who died in the hospital setting were more likely than those in the other two settings to disagree.

- **Relatives of those who died in hospital felt the support to them could have been better.** Respondents from the hospital setting were also more likely than in either of the other settings to report a lack of appropriate support for themselves at the time of the patient's death and immediately following it; to report that the patient was 'never' treated with respect and dignity by doctors and nurses in the last two days of life; and to be unlikely to recommend the organisation to friends and family.

Background

Enabling more people to die in their preferred place of care remains a national priority[1]. Of equal importance is ensuring that high quality patient care and support is given in all care settings where patients die. The United Kingdom (UK) Quality Standards for the End of Life states that people in the last days of life should be 'identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication'[2]. Recent UK guidance 'One chance to get it right' and the '6 Ambitions'[3, 4], have highlighted that individual care planning, service co-ordination (including symptom control), and clear, sensitive and timely communication are fundamental in ensuring high quality care is provided to dying patients and their families.

In order to ensure the highest quality of care provision, we need to be able to robustly evaluate the current quality of care[5]. One method, as recommended by the End of Life Care Strategy[1] is to assess this from the user-perspective by conducting bereaved relatives' surveys. Such feedback is recognised as a valuable method to improve services and remains a core component within the NHS Constitution[6]. The most recent National Care of the Dying Audit for Hospitals (NCDAH), England 2013/2014[7] included a survey of bereaved relatives which highlighted that although generally the provision of care was perceived to be very good, a small but significant minority of relatives reported extremely poor experiences.

The importance of reviewing and assessing systems and processes regarding complaints about aspects of end of life care has been recognised[7]. A previous report looking at hospital complaints found some of the main themes to be: (lack of) awareness of approaching end of life; communication; symptom management and clinical care[8]. It would be beneficial to understand more about how well complaints processes are configured to enable the identification of end of life care complaints in a variety of health care settings. Equally, an understanding of how well these systems are managed, in terms of the timeliness and appropriateness of responses to individuals and their integration with relevant governance processes to facilitate organisational continuous quality improvement is pertinent.

Aim of project

The primary aim of this project was to seek the perspectives of bereaved relatives to establish the current quality of care and support provided to people in the last days of life and their families, within participating hospitals, hospices and community trusts within the Cheshire and Merseyside Strategic Clinical Network (CMSCN). Secondary aims included exploring organisational systems and processes for the management of complaints regarding end of life care and for gaining feedback from bereaved relatives; and gaining insight into the facilitators and barriers to participation in the project.

Objectives

In order to facilitate the above aim, the primary objectives were to:

- Conduct a regional survey of bereaved people using the 'Care Of the Dying Evaluation' (CODE™) questionnaire
- Conduct an Organisational Complaints Audit of participating organisations to explore current processes for complaints
- Use anonymised data from the CODE™ questionnaire to provide feedback about the quality of care and level of family support at a network level, for the following:
  - Individual Organisation
  - Locality
  - Health care setting (Hospital, Hospice and Community Trusts)

Two secondary objectives were to:

- Undertake a regional scoping exercise focused on existing patient and family feedback processes, and complaints procedures regarding the care provided to imminently dying patients and their families
- Explore facilitators and barriers to undertaking this survey of bereaved people within the Cheshire and Merseyside Strategic Clinical Network

Methods

Full methodology in relation to this project is described within the project protocol which is available via the following web link: https://codart.liv.ac.uk/

Organisational Complaints Audit: A retrospective audit design was employed to gather data regarding current complaint management processes within each participating hospital, hospice and community trust.

Regional Survey: A self-completion postal questionnaire (CODE^{TM}) was used for this element of the project. This questionnaire was sent to bereaved family or friends, who met specific inclusion criteria (see Box 1) by participating organisations. The questionnaire could either be completed and submitted online via a data entry website, or filled in by hand and returned to the relevant participating organisation in a pre-paid envelope.

Analysis: All data were analysed descriptively, using frequencies, medians and minimum and maximum ranges where appropriate.

Qualitative Interviews: One to one interviews were conducted with the named organisational lead for the project from each participating organisation, and nominated leads from non participating organisations, to explore facilitators and barriers to the process of undertaking a bereaved relatives' survey. This was the first time a regional quality assurance project, specifically to assess the quality of care for imminently dying patients from the perspective of bereaved relatives', was undertaken within the CMSCN. We therefore anticipated that challenges may arise regarding the conduct of this type of project, and capturing these challenges may contribute to the development of recommendations and improvements for this type of project into the future. In addition, these interviews also explored in more detail the current process for the management of complaints on end of life care in each organisation, and current processes for gaining feedback from bereaved relatives on the quality of care.

Analysis: Data from interview transcripts were analysed using thematic analysis.

Box 1: Bereaved Relative Inclusion/Exclusion Criteria – Extracted from the project protocol

Inclusion criteria

Next-of-kin to:

- Adult deaths (>/= 18years of age)
- Patients whose death occurred between 1st September and 30th November 2014 inclusive. (For specific organisations, where the number of deaths is likely to be less than 20 per month, this period can be extended to include all deaths occurring between 1st May and 30th November 2014. For surveys of this nature that do not use reminder letters, response rates of between 20-25% have been reported[10]. Hence, if 60 CODE questionnaires are disseminated, we would expect that between 12 and 15 completed questionnaires will be returned. Although there is no suggested minimum number of participants, an extended inclusion period may help to provide more meaningful data for an individual organisation).
- Within the **community setting**, only patient deaths that occurred in the person's usual place of residence (own home, residential or care home) should be included.

Exclusion criteria

- In order to minimise the potential to cause additional distress to bereaved relatives, all potential participants currently involved in a formal complaint process should be excluded from this element of the project, and will therefore not be sent a CODE™ questionnaire.
- In line with an approach used by the National End of Life Intelligence Network[11] and in order to focus the survey on the families of those whose death was 'expected', the following exclusion criteria will also apply:
    - Death as a result of an accident/ untoward incident
    - Suicide is suspected
    - Overdose (including accidental) is suspected
    - Cause of death is unknown

The following further exclusion criteria will also apply within the **Hospital setting**:

- Deaths </= 24 hours of admission
- Deaths in the A&E department (appropriate Hospital setting only)
- Case of death is one of the following ICD-10 codes:
    - acute myocardial infarction (I21, I22); pulmonary embolism (I26); pulmonary aneurysm (I281); sudden cardiac death (I461); aortic aneurysm (I71); injury, poisoning or external causes (S00-T98).

Reporting

Regional Survey Organisation Report: an automated report containing individual CODE^{TM} questionnaire data for their own organisation was made available to download directly from the data entry tool, immediately following closure of the data entry period.

Generic Network Report: the overall results from the Organisational Complaints, Regional Survey and qualitative interview elements for the Network and for each individual sector.

Individual Organisation Report: as for the Generic Network Report but also illustrating the performance of the individual organisation for the Organisational Complaints and Regional Survey elements.

Clinical Commissioning Group (CCG) Report: as for the Generic Network Report but also illustrating the performance of each of the participating organisations under their directive.

How to read this report

The results are presented in three parts:

Part 1:
Participation: Organisational Complaints, Regional Survey and Qualitative Interviews
Organisational Complaints: This element is divided into two sections:

- Section 1: Information regarding complaints processes regarding care delivered to people in the last hours or days of life as reported in the audit proforma and through the qualitative interviews.

- Section 2: Information describing the patient sample

Each section begins with a series of tables presenting the audit questions and results and any additional relevant information gained from the qualitative interviews. A commentary on the findings is then provided at the end of each section.

Part 2: Regional Survey of Bereaved Relatives' Views: This element is divided in to two sections:

- Section 1: Demographic information for both the patient and the bereaved relative

- Section 2: CODE^{TM} questionnaire Results, split into the 6 sections of the questionnaire (A – F)

Each section is presented as a series of tables, with a commentary at the end of the section (for the CODE^{TM} questionnaire there is a commentary at the end of each section A – F).

The CODE^{TM} also included the NHS 'friends and family test': An explanation and the result of the NHS friends and family test score are presented.

Part 3: Findings from the Qualitative Interview element regarding current feedback processes for bereaved relatives and perspectives on participation in the Project:

- A thematic analysis is presented to illustrate the range of perspectives across organisations and within each sector

Part 4: Summary

Notes:

- Organisational Complaints Audit: Some questions were conditional on answers given to previous questions therefore the associated denominator reflects the subpopulation relevant to the question.

- Regional Survey: As the CODE^{TM} questionnaires were completed by bereaved relatives', some questions may have been left blank therefore the sample size may vary across questions. The reduced denominator has been shown for each question.
- Regional Survey: for questions in tables 25, 27, 29, 33, 38 and 41, the 'N/A' responses have been removed from the 'valid' responses, and displayed as separate proportions.

PART 1

PARTICIPATION

Organisational Complaints Audit and Regional Survey elements: 19/30 potentially eligible organisations participated in this project, comprising 7 acute hospitals, 7 hospices and 5 community trusts, from within the Cheshire & Merseyside Strategic Clinical Network. The 11 that declined participation did so for the following reasons: 8 were already undertaking bereaved relative surveys, 2 had too few deaths in the data collection period, and 1 simply reported that they were 'unable to participate' on this occasion. All 19 participating organisations completed the 'Organisational Complaints' proforma, which sought organisational contextual data and information regarding existing complaint management processes. 18 organisations (1 community trust did not take part) completed the 'Regional Survey' audit element, which captured bereaved relatives' views regarding the care delivered to dying patients and themselves.

Qualitative Interviews: A purposive sample of 9* named organisation leads participated in the qualitative interview element of the project representing 11 services. These included 4/7 hospices, 4/7 hospitals and 2/5 community settings (one of each of which formed part of an integrated service). In addition, one participant represented an End of Life Partnership organisation that had responsibility for research and evaluation across a geographical area containing several hospice, hospital and community services. Two of the interviews were undertaken face to face and the remainder by telephone. Three of the participants represented organisations that did not submit bereaved relative surveys into the project (the partnership organisation, 1 community service and 1 hospital).

**NB: 1 participant represented the Cheshire End of Life Partnership, and gave feedback on the systems and process currently in operation for organisations within the Partnership. As this information was more overarching and strategic for the partnership as a whole, the specific details have not been included in this current report. Information from this interview however will be used in subsequent publications.*

ORGANISATIONAL COMPLAINTS AUDIT

SECTION 1: Information regarding complaints about care delivered to people in the last hours or days of life.

Table 1: Complaints procedures relating to care delivered to people in the last hours or days of life

	Separate coding within formal complaints system		Named person with responsibility for dealing with complaints received		Role of named person with responsibility for dealing with complaints received	Specialist Palliative Care Team routinely notified of any complaints received	
	Yes		Yes			Yes	
	n	%	n	%		n	%
All organisations n=19	**10**	**52.6**	**15**	**78.9**		**15**	**78.9**
All hospitals n=7	**6**	**85.7**	**5**	**74.4**		**4**	**57.1**
All hospices n=7	**1**	**14.3**	**7**	**100.0**		**3**	**42.9**
All Community Trusts n=5	**3**	**60.0**	**3**	**60.0**		**4**	**80.0**

Table 2: Number of complaints, including complaints regarding care in the last hours or days of life within last financial year (1st April 2014 – 31st March 2015)

		Number of complaints in total that were received during the last financial year	Number of complaints re care delivered to people in the last hours or days of life received during the last financial year (n=17)	% complaints re care delivered to people in the last hours or days of life	
				n	%
All organisations n=19	**Total**	**2570**	**82**	**82/2343***	**3.5**
	Median	**37**	**2**		
	Range (min-max)	**1 - 483**	**0 – 23**		
All hospitals n=7	**Total**	**2169**	**61**	**61/2169**	**2.8**
	Median	**290**	**7**		
	Range (min-max)	**15 – 483**	**0 – 23**		
All hospices n=7	**Total**	**56**	**15**	**15/56**	**26.8**
	Median	**4**	**2**		
	Range (min-max)	**1 – 24**	**0 – 9**		
All Community Trusts n=5	**Total**	**345**	**6 (n=3)**	**6/227**	**2.6**
	Median	**79**	**2**		
	Range (min-max)	**2 – 139**	**1 – 3**		

**NB: denominator reduced from 2570 to 2343 because 2 organisations (from the community) could not identify complaints specifically re care delivered to people in the last hours or days of life*

Table 3: Complaint themes[1]: number pertaining to care delivered to people in the last hours or days of life that were received into participating organisations during the last financial year (1st April 2014 - 31st March 2015) *(NB: a complaint could have multiple 'themes')*

	Awareness of approaching end of life		Communication and being caring		Symptom management (including pain)		The environment		Concerns around clinical care, including withdrawal of treatment		Fundamental medical and nursing care		Other	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
All organisations n=13*/17	**8**	**6.9**	**45**	**38.8**	**9**	**7.8**	**7**	**6.0**	**11**	**9.4**	**31**	**26.7**	**5**	**4.3**
All hospitals n=6/7	**8**	**8.7**	**33**	**35.9**	**7**	**7.6**	**5**	**5.4**	**10**	**10.9**	**27**	**29.3**	**2**	**2.2**
All hospices n=4/7	**0**	**0.0**	**7**	**38.9**	**1**	**5.6**	**2**	**11.1**	**1**	**5.6**	**4**	**22.2**	**3**	**16.7**
All Community Trusts n=3/3	**0**	**0.0**	**5**	**83.3**	**1**	**16.7**	**0**	**0.0**	**0**	**0.0**	**0**	**0.0**	**0**	**0.0**

**4/17 organisations that could identify complaints relating to care in the last hours or days of life did not report receiving any such complaints during the last financial year (1st April 2014 - 31st March 2015)*
NB: 'Other' included: failure to contact priest, loss of belongings, security of belongings, discharge planning

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[1] Complaint themes taken from: Snapshot Review of Complaints in End of Life Care (NHS Improving Quality, 2013) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212480/Review_of_complaints_end_of_life_care.pdf (last accessed September 2015)

Table 4: Process for feedback of information from complaints (relating to care in the last hours or days of life) and subsequent action planning.

	Clinical teams		Executive team		Board of Trustees		Other		Issues/outcomes formed part of a formal action plan to improve care of the dying (1 April 2014 – 31 March 2015)? (% Yes)	
	n	%	n	%	n	%	n	%	n	%
All organisations n=13	**10**	**76.9**	**12**	**92.3**	**6**	**46.2**	**6**	**46.2**	**8**	**61.5**
All hospitals n=6/7	**4**	**66.7**	**5**	**83.3**	**1**	**16.7**	**5**	**83.3**	**3**	**50.0**
All hospices n=4/7	**3**	**75.0**	**4**	**100.0**	**4**	**100.0**	**0**	**0.0**	**3**	**75.0**
All Community Trusts n=3/5	**3**	**100.0**	**3**	**100.0**	**1**	**33.3**	**1**	**33.3**	**2**	**66.7**

NB: 6 organisations (31.6%) answered that they did not communicate this information

Section 1 Commentary

Just over a half (52.6% n=10) (Table 1) of all organisations had a separate coding for complaints received relating to care in the last hours or days of life, however this went up to just over four fifths (85.7% n=6), for organisations from the hospital setting, with, perhaps understandably, the hospice setting being least likely to report coding these complaints separately (14.3% n=1). Despite not having a separate coding, the majority (78.9% n=15) of all organisations had a named person responsible for receiving complaints, with 100% (n=7) of all hospices having a named person. The majority of organisations, particularly those in the community and the hospital, notified the palliative care team when such a complaint was received (78.9%, n=15). It is perhaps not surprising that this was less likely to be the case in the hospice setting as direct involvement with a specialist palliative care team from another care setting in the care of specific patients would not necessarily be universal.

Organisations in the hospital setting received the highest number of complaints about care of any sort on average per year (median 290) compared to the overall average (median 37) (Table 2). Compared to other care settings, the hospice setting received the fewest (median 4), though it is important to remember that these organisations are smaller in patient numbers and the scope of their services. Of the total number of complaints received overall, only a minority were related to care in the last hours or days of life (3.5% n=82). Proportionally the hospice setting had the highest level of complaints relating to care in the last hours or days of life (26.8% n=15), although this would be expected due to the palliative care patient cohort in the hospice setting. In line with findings from the Ombudsman report[8], 'communication and being caring' (38.8% n=35) was the most common theme of complaints received regarding care in the last hours or days of life (Table 3). The second most common theme was 'fundamental medical and nursing care' (26.7 n=31). Notably, one complaint (5.6%) in the hospice setting was regarding 'Symptom management (including pain)', and 1 complaint (16.7%) received in the community setting related to 'concerns regarding clinical care, including withdrawal of treatment'.

It is important to note that 6 of the 19 (31.6%) organisations did not communicate information about complaints received cross their organisation (Table 4). Of those organisations that did, the majority chose to communicate this information to the Executive team (92.3% n=12), and clinical teams (76.9% n=10). In the hospital setting, this information was also reported to be communicated via 'other' routes (83.3% n=5), and the qualitative interviews (see below) revealed that these were likely to include Quality, Governance and Risk teams, and end of life care groups.

Additional information on complaints procedures from qualitative interviews

Additional information about the systems and process for formal complaint was sought from the eight named organisational leads who participated in the qualitative interview element of this project. Respondents confirmed the findings from the survey element of the project, that complaints about care in the last hours or days of life are relatively rare in all settings.

A formal system for the receipt of complaints was reported to be present by all respondents interviewed. In line with the survey results, these respondents confirmed that complaints go through the relevant governance process in each organisation and are shared with both clinical teams and the executive board. Action plans are also usually developed with the support of this wider 'team' to address the issues raised, and progress on the agreed outcomes are then also generally monitored by the executive board.

Specifically, the four the hospitals that participated in this element of the project appeared to have adopted very similar formal systems for the management of complaints they receive about all aspects of care delivery. The complaint moves through the relevant quality and governance structures within each organisation and although these may be configured differently, it is usually dealt with by a specific team or division of complaints who then provide an official report to the Trust Board and action plans are developed. In one of the represented hospitals, the complaints process is currently being restructured.

In the four hospices represented in this element of the project, though formal complaints are rare, similar specific systems and processes, which appear to follow national guidance, were reported to be in place for dealing with them. Each hospice has a system whereby the complaint is formally recorded and acknowledged within two days. This is generally followed by formal investigation period lasting two or three weeks which gives an opportunity for the complainant to come in and discuss the complaint and action plan. Each complaint is formally reported to and discussed at the Executive Board. Again, similar formal complaints processes also exist in the two community organisations represented in this element of the project.

Although the survey results reveal that complaints about end of life care are unlikely to be coded separately in all settings except the hospital, in most organisations represented in the interview sample, respondents reported that it was possible to identify these complaints in a more informal fashion. For example, although in three of the four hospitals, details of end of life complaints are now identified and fed back through relevant end of life care groups (in addition to the other governance structures), this process seems to rely more on an individual recognising them as such and bringing them to the meeting, or on end of life care colleagues' relationship with the complaints team or division. Due to the size and scope of hospice care provision, the separate categorisation of end of life care complaints was less relevant.

SECTION 2: Information describing the patient sample

Table 5: Number of deaths within last financial year (1st April 2014 – 31st March 2015), and within the project aggregate data collection period (1st September – 30th November 2014)

		Number of all adult deaths during the last financial year	Number of all adult deaths during the project aggregate period	Number of all adult deaths that met the initial sample criteria* (n=18)	% deaths in the project aggregate period that met initial sample criteria (n=18)	
					n	%
All organisations n=19	**Total**	**22985**	**4376**	**1774**	**1774/3402****	**52.1**
	Median	**873**	**196**	**81**		
	Range (min-max)	**48 – 10,699**	**13 – 974**	**12 – 266**		
All hospitals n=7	**Total**	**8109**	**1703**	**1077**	**1077/1703**	**63.2**
	Median	**1380**	**277**	**169**		
	Range (min-max)	**48 – 1640**	**13 – 379**	**12 – 266**		
All hospices n=7	**Total**	**952**	**245**	**237**	**237/245**	**96.7**
	Median	**120**	**32**	**30**		
	Range (min-max)	**89 – 232**	**20 – 61**	**20 – 58**		
All Community Trusts n=5	**Total**	**13924**	**2428**	**460 (n=4)**	**460/1454***	**31.6**
	Median	**974**	**271**	**92**		
	Range (min-max)	**390 – 10699**	**100 – 974**	**74 – 202**		

** Initial sample criteria included all adult deaths, excluding 'sudden' and 'unexpected' deaths*

***NB: denominator reduced from 4376 to 3402 because 1 organisation was unable to complete regional survey element of the project*

Table 6: Patient cases which met the initial inclusion criteria but did not form part of the final sample

	% Total exclusions		**No next of kin information available**		**A complaint has been returned and awaits successful closure (as at 1 March 2015)**		**The CODE™ Questionnaire was 'Returned to Sender' by Royal Mail**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
All organisations n=18/19	**491/1774**	**27.7**	**460/491**	**93.7**	**16/491**	**3.2**	**15/491**	**3.1**
All hospitals n=7	**228/1077**	**21.2**	**200/228**	**87.7**	**16/228**	**7.0**	**12/228**	**5.3**
All hospices n=7	**12/237**	**2.6**	**10**	**83.3**	**0**	**0.0**	**2**	**16.7**
All Community Trusts n=4/5	**251/460**	**54.6**	**250/251**	**99.6**	**0/251**	**0.0**	**1/251**	**0.4**

Section 2 Commentary

Table 5 illustrates that the median number of deaths was higher in the hospital (median 1380) sector compared with the overall average (median 873), which would be in keeping with the fact that currently 49%[8] of all UK deaths occur in the hospital setting. Overall just over a half (52.1% n=1774) of all adult deaths in the national aggregate period met the initial inclusion criteria, although it was highest in the hospice setting, with 96.7% (n=460) of fulfilling the criteria for inclusion, with the community setting having the lowest proportion with just under a third of all deaths meeting the initial criteria. Of those deaths that met the initial criteria overall, just over one fifth (27.7% n=491) were not subsequently included (Table 6). In all but 31 cases in total (n=460/491), the contact details for the Next of Kin were not available in the organisation, which was a similar picture across all care settings. The community setting saw the highest proportion of subsequent exclusions with just over half (54.6% n=251) of bereaved relatives not being sent a CODE™ questionnaire. The hospital setting was more likely than the other care settings, to have an open complaint precluding inclusion.

Part 2: REGIONAL SURVEY OF BEREAVED RELATIVES' VIEWS

Section 1: Demographic Information

The following tables provide a demographic breakdown of the relative and patient cohort. This provides important information to support the interpretation of the responses to individual questions, and aids comparison across organisations and between care settings.

Demographic information for the patient

Table 7: Patient Age

	18-39		40-59		60-69		70-79		80+	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=336/354)	**2**	**0.6**	**36**	**10.7**	**39**	**11.6**	**105**	**31.3**	**154**	**45.8**
All hospitals (n=207/218)	**2**	**1.0**	**13**	**6.2**	**19**	**9.2**	**54**	**26.1**	**119**	**57.5**
All hospices (n=79/82)	**0**	**0.0**	**18**	**22.8**	**19**	**24.1**	**24**	**30.4**	**18**	**22.8**
All Community Trusts (n=50/54)	**0**	**0.0**	**5**	**10.0**	**1**	**2.0**	**27**	**54.0**	**17**	**34.0**

Table 8: Patient Ethnicity and Gender

	Ethnicity		Gender		
	White British		Female		
	n	%		n	%
All organisations (n=332/354)	**321**	**96.7**	**n=327/354**	**157**	**48.0**
All hospitals (n=204/218)	**195**	**95.6**	**n=204/218**	**101**	**49.5**
All hospices (n=79/82)	**77**	**97.5**	**n=76/82**	**37**	**48.7**
All Community Trusts (n=49/54)	**49**	**100.0**	**n=50/54**	**19**	**40.4**

Table 9: Patient Religious Affiliation

	Christian		Other		None	
	n	%	n	%	n	%
All organisations (n=334/354)	**282**	**84.4**	**7**	**2.1**	**45**	**13.5**
All hospitals (n=205/218)	**176**	**85.9**	**5**	**2.5**	**24**	**11.7**
All hospices (n=79/82)	**64**	**81.0**	**1**	**1.3**	**14**	**17.7**
All Community Trusts (n=50/54)	**42**	**84.0**	**1**	**2.0**	**7**	**14.0**

Table 10: Patient Diagnosis – Cancer/Non Cancer

	% Cancer	
	n	%
All organisations (n=354)	**188**	**53.1**
All hospitals (n=218)	**70**	**32.1**
All hospices (n=82)	**74**	**90.2**
All Community Trusts (n=54)	**44**	**81.5**

Demographic information for the bereaved relative

Table 11: Bereaved Relative Relationship to Patient

	Husband/ Wife/ Partner		Son/ Daughter		Other named category		Other	
	n	%	n	%	n	%	n	%
All organisations (n=333/354)	**160**	**48.0**	**118**	**35.4**	**44**	**13.2**	**11**	**3.3**
All hospitals (n=205/218)	**79**	**38.5**	**87**	**42.4**	**32**	**15.6**	**7**	**3.4**
All hospices (n=78/82)	**45**	**57.7**	**19**	**24.4**	**10**	**12.9**	**4**	**5.1**
All Community Trusts (n=50/54)	**36**	**72.0**	**12**	**24.0**	**2**	**4.0**	**0**	**0.0**

Table 12: Bereaved Relative Age

	18-39		40-59		60-69		70-79		80+	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=333/354)	11	3.3	101	30.3	95	28.5	78	23.4	48	14.4
All hospitals (n=205/218)	6	2.9	61	29.8	59	28.8	46	22.4	33	16.1
All hospices (n=79/82)	5	6.4	28	35.4	22	27.8	17	21.5	7	8.9
All Community Trusts (n=49/54)	0	0.0	12	24.5	14	28.6	15	30.6	8	16.3

Table 13: Bereaved Relative Ethnicity and Gender

	Ethnicity		Gender		
	White British		Female		
	n	%		n	%
All organisations (n=333/354)	**325**	**97.6**	**n=333/354**	225	67.2
All hospitals (n=205/218)	**201**	**98.0**	**n=206/218**	140	68.0
All hospices (n=79/82)	**77**	**97.5**	**n=79/82**	48	60.8
All Community Trusts (n=49/54)	**47**	**95.9**	**n=50/54**	37	74.0

Table 14: Bereaved Relative Religious Affiliation

	Christian		Other		None	
	n	%	n	%	n	%
All organisations (n=334/354)	**280**	**83.8**	**13**	**3.9**	**41**	**12.3**
All hospitals (n=205/218)	**171**	**83.4**	**11**	**5.4**	**23**	**11.2**
Hospital A						
Hospital B						
Hospital C						
All hospices (n=79/82)	**62**	**78.5**	**1**	**1.3**	**16**	**20.3**
Hospice A						
Hospice B						
Hospice C						
All Community Trusts (n=50/54)	**47**	**94.0**	**1**	**2.0**	**2**	**4.0**
Community Trust A						

DEMOGRAPHIC DETAILS: COMMENTARY

Overall, bereaved relatives, who returned questionnaires, were more likely to be female (67.2%, n=225) (Table 13), between the ages of 40 – 69 (58.8%, n=196) (Table 12), and the husband, wife or partner of the patient (48.0%, n=160) (Table 11). The patients in this sample tended to be older (77.1% between 70 and 80+, n=259) (Table 7) and more evenly split in terms of gender (male = 52.0%, n=170) (Table 8). The vast majority of relatives, and patients in this sample were White British (relatives: 97.6% n=325, patient: 96.7% n=321) (Tables 13 and 8 respectively) and of a Christian religious denomination (83.8%, n=280 and 84.4%, n=282 respectively) (Tables 14 and 9 respectively).

Patients in the Hospital sample were more likely to be older than those in the hospice and community settings, with 57.5% (n=119) over the age of 80 (Table 7). The hospice setting had a greater proportion of younger patients (i.e. patients in the 40 to 69 age range) (Table 7). Ethnicity and religious affiliation was similar across all settings, with the vast majority of patients and relatives being of White British background (Table 8), and of a Christian religious denomination (Table 9). The overwhelming majority of patients in the hospice setting (90.2% n=74) and in the community setting (81.5% n=44) had a diagnosis of cancer, which compares 32.1% (n=70) for the hospital setting (Table 10).

Section 2: CODE^{TM} Questionnaire Results

Section A: Care received from the nurses and doctors

Table 15: There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=344/354)	**132**	**38.4**	**157**	**45.6**	**21**	**6.1**	**24**	**7.0**	**10**	**2.9**
% Range (min – max)	**20.0 – 80.0**		**20.0 – 68.6**		**0.0 – 14.3**		**0.0 – 19.4**		**00.0 – 7.0**	
All hospitals (n=213/218)	**59**	**27.7**	**107**	**50.2**	**16**	**7.5**	**21**	**9.9**	**10**	**4.7**
% Range (min – max)	**20.0 – 66.7**		**33.3 – 68.6**		**0.0 – 14.0**		**0.0 – 19.4**		**0.0 – 7.0**	
All hospices (n=82/82)	**52**	**63.4**	**27**	**32.9**	**2**	**2.4**	**1**	**1.2**	**0**	**0.0**
% Range (min – max)	**50.0 – 80.0**		**20.0 – 45.5**		**0.0 – 14.3**		**-**		**-**	
All Community Trusts (n=49/54)	**21**	**42.9**	**23**	**46.9**	**3**	**6.1**	**2**	**4.1**	**0**	**0.0**
% Range (min – max)	**33.3 – 44.4**		**33.3 – 51.9**		**0.0 – 10.0**		**0.0 – 33.3**		**-**	

Table 16: There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=349/354)	**152**	**43.6**	**143**	**41.0**	**16**	**4.6**	**25**	**7.2**	**13**	**3.7**
% Range (min – max)	**20.0 – 88.9**		**11.1 – 54.8**		**0.0 – 20.0**		**0.0 – 26.7**		**0.0 - 11.8**	
All hospitals (n=215/218)	**68**	**31.6**	**99**	**46.0**	**13**	**6.0**	**22**	**10.2**	**13**	**6.0**
% Range (min – max)	**20.0 – 88.9**		**11.1 – 54.8**		**0.0 – 11.6**		**0.0 – 26.7**		**0.0 – 11.8**	
All hospices (n=82/82)	**58**	**70.7**	**22**	**26.8**	**0**	**0.0**	**2**	**2.4**	**0**	**0.0**
% Range (min – max)	**57.1 – 80.0**		**20.0 – 36.4**		**0.0 – 4.5**		**0.0 – 7.1**		**-**	
All Community Trusts (n=52/54)	**26**	**50.0**	**22**	**42.3**	**3**	**5.8**	**1**	**1.9**	**0**	**0.0**
% Range (min – max)	**45.0 – 60.0**		**20.0 – 46.4**		**3.6 – 20.0**		**-**		**-**	

Table 17: The bed area and surrounding environment was comfortable for him/her.

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=296/354)	**120**	**40.5**	**120**	**40.5**	**22**	**7.4**	**23**	**7.7**	**11**	**3.7**
% Range (min – max)	**19.4 – 100.0**		**0.0 – 54.8**		**0.0 – 14.6**		**0.0 – 19.4**		**0.0 – 13.3**	
All hospitals (n=212/218)	**64**	**30.2**	**94**	**44.3**	**22**	**10.4**	**21**	**9.9**	**11**	**5.2**
% Range (min – max)	**19.4 – 87.5**		**12.5 – 54.8**		**0.0 – 14.6**		**0.0 – 19.4**		**0.0 – 13.3**	
All hospices (n=78/82)	**54**	**69.2**	**22**	**28.2**	**0**	**0.0**	**2**	**2.6**	**0**	**0.0**
% Range (min – max)	**38.5 – 100.0**		**0.0 – 53.8**		**-**		**0.0 – 7.7**		**-**	
All Community Trusts	**N/A for this setting**									

Table 18: The bed area and surrounding environment had adequate privacy for him/her.

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=298/354)	**128**	**42.9**	**109**	**36.6**	**19**	**6.4**	**20**	**6.7**	**22**	**7.4**
% Range (min – max)	**21.9 – 90.9**		**9.1 – 60.0**		**0.0 – 16.7**		**0.0 – 15.6**		**0.0 – 18.6**	
All hospitals (n=212/218)	**72**	**34.0**	**81**	**38.2**	**18**	**8.5**	**20**	**9.4**	**21**	**9.9**
% Range (min – max)	**21.9 – 87.5**		**12.5 – 60.0**		**0.0 – 16.7**		**0.0 – 15.6**		**0.0 – 18.6**	
All hospices (n=80/82)	**55**	**68.7**	**23**	**28.7**	**1**	**1.3**	**0**	**0.0**	**1**	**1.3**
% Range (min – max)	**54.4 – 90.9**		**9.1 – 42.9**		**-**		**-**		**-**	
All Community Trusts	**N/A for this setting**									

Table 19: In your opinion, how clean was the ward area that s/he was in?

	Very Clean		Fairly Clean		Not at all clean	
	n	%	n	%	n	%
All organisations (n=300/354)	**231**	**77.0**	**62**	**20.7**	**7**	**2.3**
% Range (min – max)	**62.0 – 100.0**		**11.1 – 32.4**		**00.0 – 8.0**	
All hospitals (n=216/218)	**150**	**69.4**	**59**	**27.3**	**7**	**3.2**
% Range (min – max)	**62.0 – 88.9**		**11.1 – 32.4**		**0.0 – 8.0**	
All hospices (n=81/82)	**79**	**97.5**	**2**	**2.5**	**0**	**0.0**
% Range (min – max)	**92.9 – 100.0**		**0.0 – 7.1**		**-**	
All Community Trusts	**N/A for this setting**					

Table 20: Did you have confidence and trust in the nurses who were caring for him/her?

	Yes in all of them		Yes in some of them		No, not in any of the nurses	
	n	%	n	%	n	%
All organisations (n=347/354)	**242**	**69.7**	**87**	**25.1**	**18**	**5.2**
% Range (min – max)	**44.1 – 100.0**		**0.0 – 44.1**		**0.0 – 20.0**	
All hospitals (n=212/218)	**131**	**61.8**	**64**	**30.2**	**17**	**8.0**
% Range (min – max)	**44.1 – 100.0**		**0.0 – 44.1**		**0.0 – 20.0**	
All hospices (n=82/82)	**68**	**82.9**	**14**	**17.1**	**0**	**0.0**
% Range (min – max)	**68.8 – 100.0**		**0.0 – 31.3**		**-**	
All Community Trusts (n=53/54)	**43**	**81.1**	**9**	**17.0**	**1**	**1.9**
% Range (min – max)	**60.0 – 89.3**		**10.7 – 23.8**		**-**	

Table 21: Did you have confidence and trust in the doctors who were caring for him/her?

	Yes in all of them		Yes in some of them		No, not in any of the doctors	
	n	%	n	%	n	%
All organisations (n=345/354)	254	73.6	70	20.3	21	6.1
% Range (min – max)	50.0 – 100.0		0.0 – 41.2		0.0 – 16.3	
All hospitals (n=214/218)	137	64.0	57	26.6	20	9.3
% Range (min – max)	50.0 – 100.0		0.0 – 41.2		0.0 – 16.3	
All hospices (n=80/82)	72	90.0	8	10.0	0	0.0
% Range (min – max)	70.0 – 100.0		0.0 – 30.0		-	
All Community Trusts (n=51/54)	45	88.2	5	9.8	1	2.0
% Range (min – max)	80.0 – 100.0		0.0 – 15.0		-	

Table 22: The nurses had time to listen and discuss his/her condition with me

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=343/354)	148	43.1	120	35.0	28	8.2	31	9.0	16	4.7
% Range (min – max)	20.0 – 80.0		20.0 – 66.7		00.0 – 26.7		0.0 – 20.0		0.0 – 13.3	
All hospitals (n=216/218)	68	31.9	78	36.6	24	11.3	27	12.7	16	7.5
% Range (min – max)	20.0 – 50.0		26.5 – 54.3		0.0 – 26.7		0.0 – 17.6		0.0 – 13.3	
All hospices (n=79/82)	50	63.3	26	32.9	1	1.3	2	2.5	0	0.0
% Range (min – max)	33.3 – 80.0		20.0 – 66.7		-		0.0 – 13.3		-	
All Community Trusts (n=51/54)	30	58.8	16	31.4	3	5.9	2	3.9	0	0.0
% Range (min – max)	55.0 – 63.0		20.0 – 33.3		0.0 – 10.0		0.0 – 20.0		-	

Table 23: The doctors had time to listen and discuss his/her condition with me

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=339/354)	149	44.0	125	36.9	26	7.7	22	6.5	17	5.0
% Range (min – max)	13.3 – 87.5		12.5 – 55.6		0.0 – 26.7		0.0 – 20.0		0.0 – 12.9	
All hospitals (n=210/218)	63	30.0	87	41.4	23	11.0	21	10.0	16	7.6
% Range (min – max)	13.3 – 87.5		12.5 – 55.1		0.0 – 26.7		0.0 – 20.0		0.0 – 12.9	
All hospices (n=79/82)	55	69.6	24	30.4	0	0.0	0	0.0	0	0.0
% Range (min – max)	44.4 – 86.7		13.3 – 55.6		-		-		-	
All Community Trusts (n=50/54)	31	62.0	14	28.0	3	6.0	1	2.0	1	2.0
% Range (min – max)	60.0 – 65.0		20.0 – 30.8		3.8 – 20.0		-		-	

SECTION A COMMENTARY: the care received from doctors and nurses

The majority of relatives across all settings answered ‘agree’ or ‘strongly agree’ to the statement that there was enough help available to meet the patient’s personal care needs (84.1%, n=94) (Table 15) and enough help with nursing care (84.0%, n=289) (Table 16), although the proportion was highest in the hospice setting (96.3%, n=79 and 97.5%, n=80 respectively), and lowest in the hospital setting (77.9, n=166 and 77.6%, n=167 respectively). Importantly, 14.6% (n=31) and 16.2% (n=35) (respectively) of relatives of patients in the hospital setting disagreed or strongly disagreed that there was enough help to meet the patient’s personal care needs and nursing care needs (Table 15).

In the majority of cases in the whole sample, the bed area and surrounding environment was reported to be comfortable for the patients (81.0%, n=240) (Table 17) with adequate privacy (79.5%, n=237) (Table 18). In the hospice setting 97.4% (n=76) and 97.6% (n=78) of relatives strongly agreed or agreed with that the environment was comfortable (Table 17) and had adequate privacy (respectively) (Table 18). Of importance are the 11.7% and 14.3% of cases overall who (respectively) either disagreed or strongly disagreed, who were primarily from the hospital setting (Tables 17 and 18). Overall, relatives reported that the ward area was ‘very clean’ in 77.0% (n=231) of cases, with 97.7% (n=79) of relatives in the hospice setting reporting this level of cleanliness. Although ‘not at all clean’ was answered in only 2.3% of cases overall (n=7), all of these cases were in the hospital setting (Table 19).

Over two thirds of relatives reported confidence and trust in all the nurses caring for the patient (69.7%, n=242) (Table 20), and just under three quarters for all the doctors (73.6%, n=254) (Table 21). Again however a notable minority of patients in the hospital setting reported that they did not have any confidence or trust in either the nurses (Table 20) or doctors (Table 21) caring for the patient (nurses: 8.0% of the hospital sample (n=17); doctors: 9.3% of the hospital sample (n=20)).

For the sample as a whole, the vast majority of relatives also responded positively to statements that the nurses (78.1%, n=268) (Table 22) and doctors (80.9%, n=274) (Table 23) had time to listen and discuss the patient’s condition with them. However, whilst 86.2% (n=76) and 90.2% (n=46) in the hospice and community settings respectively either strongly agreed or agreed that nurses had time to listen and discuss, in the hospital setting this dropped to 68.5% (n=136), with around one-fifth of respondents either disagreeing or strongly disagreeing with the statement (20.2% of the hospital sample, n=43) (Table 22). For doctors (Table 23), the picture was somewhat similar, with 100% (n=79) and 90% (n=45) of respondents either strongly agreeing or agreeing that doctors had time to listen and discuss in the hospice and community settings respectively, compared with 71.4% (n=150) of respondents from the hospital setting. Again, a sizeable minority of respondents from the hospital setting either disagreed or strongly disagreed with the statement (17.6% of the hospital sample, n=37). Interestingly however, one relative also reported ‘strongly disagree’ to both statements in the community setting.

SECTION B: The control of pain and other symptoms

Table 24: In your opinion, during the last two days, did s/he appear to be in pain?

	Yes all of the time		Yes, some of the time		No, s/he did not appear to be in pain	
	n	%	n	%	n	%
All organisations (n=346/354)	**37**	**10.7**	**143**	**41.3**	**166**	**48.0**
% Range (min – max)	**0.0 – 26.7**		**20.0 – 60.0**		**33.3 – 80.0**	
All hospitals (n=214/218)	**26**	**12.1**	**81**	**37.9**	**107**	**50.0**
% Range (min – max)	**0.0 – 20.0**		**20.0 – 55.6**		**44.1 – 60.0**	
All hospices (n=79/82)	**6**	**7.6**	**37**	**46.8**	**36**	**45.6**
% Range (min – max)	**0.0 – 26.7**		**20.0 – 54.5**		**26.7 – 80.0**	
All Community Trusts (n=53/54)	**5**	**9.4**	**25**	**47.2**	**23**	**43.4**
% Range (min – max)	**0.0 – 10.7**		**35.7 – 60.0**		**33.3 – 53.6**	

Table 25: In your view, did the doctors and nurses do enough to help relieve the pain?

	Yes all of the time		Yes, some of the time		No, not at all		N/A s/he was not in pain		
	n	%	n	%	n	%		n	%
All organisations (n=303*/354)	**214**	**70.6**	**72**	**23.7**	**17**	**5.6**	**n=347/354**	**44**	**12.7**
% Range (min – max)	**54.5 – 100.0**		**0.0 – 37.8**		**0.0 – 13.8**			**0.0 – 27.9**	
All hospitals (n=181/218)**	**116**	**64.1**	**50**	**27.6**	**15**	**8.2**	**n=215/218**	**34**	**15.8**
% Range (min – max)	**54.5 – 87.5**		**12.5 – 37.8**		**0.0 – 13.8**			**2.9 – 27.9**	
All hospices (n=76*/82)**	**64**	**84.2**	**11**	**14.5**	**1**	**1.3**	**n=79/82**	**3**	**3.8**
% Range (min – max)	**66.7 – 100.0**		**0.0 – 33.3**		**-**			**0.0 – 14.3**	
All Community Trusts (n=46**/54)**	**34**	**73.9**	**11**	**23.9**	**1**	**2.2**	**n=53/54**	**7**	**13.2**
% Range (min – max)	**60.0 – 78.3**		**20.0 – 26.3**		**-**			**0.0 – 17.9**	

*NB: In addition to the 7 participants who did not provide an answer to this question, the response option 'N/A, was not in pain' was also removed from sample: *n=44; ** n=34; *** n=3; **** n=7. Where a 'N/A' response was used in an individual site, this figure will differ from that within the individual report made available for download within the electronic tool.*

Table 26: In your opinion, during the last two days, did s/he appear to be restless?

	Yes all of the time		Yes, some of the time		No, s/he did not appear to be restless	
	n	%	n	%	n	%
All organisations (n=346/354)	**51**	**14.7**	**174**	**50.3**	**121**	**35.0**
% Range (min – max)	**0.0 – 26.7**		**33.3 – 66.7**		**20.0 – 60.0**	
All hospitals (n=214/218)	**38**	**17.8**	**103**	**48.1**	**73**	**34.1**
% Range (min – max)	**0.0 – 26.7**		**33.3 – 66.7**		**23.3 – 48.4**	
All hospices (n=80/82)	**6**	**7.5**	**41**	**51.2**	**33**	**41.3**
% Range (min – max)	**0.0 – 26.7**		**40.0 – 57.1**		**20.0 – 60.0**	
All Community Trusts (n=52/54)	**7**	**13.5**	**30**	**57.7**	**15**	**28.8**
% Range (min – max)	**0.0 – 14.8**		**51.9 – 61.9**		**23.8 – 40.0**	

Table 27: In your view, did the doctors and nurses do enough to help relieve the restlessness?

	Yes all of the time		Yes, some of the time		No, not at all		N/A, s/he was not restless		
	n	%	n	%	n	%		n	%
All organisations (n=261*/354)	**139**	**53.3**	**96**	**36.8**	**26**	**10.0**	**n=345/354**	**84**	**24.3**
% Range (min – max)	**25.0 – 90.0**		**10.0 – 55.0**		**0.0 – 23.1**			**11.1 – 41.2**	
All hospitals (n=164/218)**	**73**	**44.5**	**66**	**40.2**	**25**	**15.2**	**n=213/218**	**49**	**23.0**
% Range (min – max)	**25.0 – 87.5**		**12.5 – 55.0**		**0.0 – 23.1**			**11.1 – 41.2**	
All hospices (n=55*/82)**	**39**	**71.0**	**16**	**29.0**	**0**	**0.0**	**n=79/82**	**24**	**30.4**
% Range (min – max)	**50.0 – 90.0**		**10.0 – 50.0**		**-**			**20.0 – 36.4**	
All Community Trusts (n=42**/54)**	**27**	**64.2**	**14**	**33.3**	**1**	**2.4**	**n=53/54**	**11**	**20.8**
% Range (min – max)	**43.8 – 77.3**		**22.7 – 50.0**		**-**			**20.0 – 23.8**	

*NB: In addition to the 9 participants who did not provide an answer to this question, the response option 'N/A, was not restless' was removed from sample: *n=84; ** n=49; *** n=24; **** n=11. Where a 'N/A' response was used in an individual site, this figure will differ from that within the individual report made available for download within the electronic tool.*

Table 28: In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing?

	Yes all of the time		Yes, some of the time		No, s/he did not have a 'noisy rattle' to the breathing	
	n	%	n	%	n	%
All organisations (n=339/354)	**57**	**16.8**	**128**	**37.8**	**154**	**45.4**
% Range (min – max)	**0.0 – 42.9**		**10.0 – 90.0**		**10.0 – 66.7**	
All hospitals (n=211/218)	**37**	**17.5**	**66**	**31.3**	**108**	**51.2**
% Range (min – max)	**5.7 – 26.7**		**11.1 – 42.9**		**36.4 – 66.7**	
All hospices (n=75/82)	**14**	**18.7**	**36**	**48.0**	**25**	**33.3**
% Range (min – max)	**0.0 – 42.9**		**10.0 – 90.0**		**10.0 – 66.7**	
All Community Trusts (n=53/54)	**6**	**11.1**	**26**	**49.1**	**21**	**39.6**
% Range (min – max)	**7.1 – 20.0**		**40.0 – 52.4**		**33.3 – 46.4**	

Table 29: In your view, did the doctors and nurses do enough to help relieve the 'noisy rattle' to his/her breathing?

	Yes all of the time		Yes, some of the time		No, not at all		N/A, there was no 'noisy rattle' to his/her breathing		
	n	%	n	%	n	%		n	%
All organisations (n=189*/354)	**90**	**47.6**	**71**	**37.6**	**28**	**14.8**	**n=332/354**	**143**	**43.1**
% Range (min – max)	**19.0 – 100.0**		**0.0 – 66.7**		**0.0 – 33.3**			**10.0 – 69.2**	
All hospitals (n=109/218)**	**42**	**38.5**	**47**	**43.1**	**20**	**18.3**	**n=208/218**	**99**	**47.6**
% Range (min – max)	**19.0 – 100.0**		**0.0 – 62.5**		**0.0 – 27.8**			**36.4 – 57.1**	
All hospices (n=50*/82)**	**32**	**64.0**	**15**	**30.0**	**3**	**6.0**	**n=74/82**	**24**	**32.4**
% Range (min – max)	**33.3 – 88.9**		**11.1 – 66.7**		**0.0 – 20.0**			**10.0 – 69.2**	
All Community Trusts (n=30**/54)**	**16**	**53.3**	**9**	**30.0**	**5**	**16.7**	**n=50/54**	**20**	**40.0**
% Range (min – max)	**46.2 – 66.7**		**0.0 – 42.9**		**0.0 – 33.3**			**31.6 – 48.1**	

*NB: In addition to the 22 participants who did not provide an answer to this question, the response option 'N/A, there was no noisy rattle' was removed from sample: * n=143; ** n=99; *** n=24; **** n=20. Where a 'N/A' response was used in an individual site, this figure will differ from that within the individual report made available for download within the electronic tool.*

SECTION B COMMENTARY: The control of pain and other symptoms

Just under half of the sample overall were reported not to have had pain (48.0%, n=166) (Table 24) or a ‘noisy rattle’ to their breathing (45.4%, n=154) (Table 28) at all in the last 2 days of life; however in contrast, for ‘restlessness’ this was the case for only just over a third (35.0%, n=121) (Table 26). However, for a small but notable minority of relatives the patient was perceived to have had symptoms all of the time in the last 2 days of life (‘pain’ 10.7% n=37 (Table 24), ‘restless’ 14.7% n=51 (Table 26), ‘noisy rattle’ 16.8% n=57). (Table 28)

Interestingly, the proportion of patients reported to have not been in pain and not to have had ‘noisy rattle’ was highest in the hospital setting (50.0% n=107; 51.2% n=108) (Tables 24 and 28 respectively). However, relatives of patients in this setting were also more likely to report that the patient experienced ‘pain’ (12.1%, n=26) (Table 24) or ‘restlessness’ (17.8, n=38) (Table 26) ‘all of the time’ in the last 2 days, than in the other two settings (hospice - pain: 7.6% n=6; restless: 7.5% n=6; community – pain: 9.5% n=5; restless: 13.5 n=7). ‘Noisy rattle’ on the other hand was more likely to be reported to be present ‘all of the time’ in the hospital and hospice settings (17.5%, n=37 and 18.7%, n=14 respectively) compared to the community setting (11.1%, n=6) (Table 28).

For the sample as a whole and for those for whom the question was applicable, relatives reported that enough had been done by the healthcare team to control symptoms of pain in the last hours or days of life in almost three quarters of patients (70.6%, n=214) (Table 25), however this proportion reduced to around half for restlessness (Table 27) and noisy rattle (53.3% n=139 and 47.6% n=90 respectively) (Table 29). Relatives answered that enough had ‘not at all’ been done to help to relieve symptoms in a notable minority of patients (‘pain’ 5.6% n=17 (Table 25), ‘restless’ 10.0% n=26 (Table 27) ‘noisy rattle’ 14.8% n=28 (Table 29)). For pain, only around two thirds (64.1%, n=116) of relatives of patients from the hospital setting reported that healthcare professionals had done enough ‘all of the time’ to control the symptom (Table 25), however this increased to just under three quarters (73.9%, n=34) in the community setting, with the hospice setting scoring most highly with over four fifths answering ‘yes, all the time’ (84.2%, n=64). For restlessness (Table 27), 25 of the 26 responses overall that healthcare professionals had ‘not at all’ done enough to control this symptom were reported for patients cared for in the hospital setting (15.2% of the hospital sample). For noisy rattle (Table 29), the hospital setting again had the highest proportion of relatives (18.3%, n=20) who reported that healthcare professionals did ‘not at all’ do enough to control this symptom, with the hospice setting having the lowest proportion (6.0%, n=3).

SECTION C: Communication with the healthcare team

Table 30: During the last two days, how involved were you with the decisions about his/her care and treatment?

	Very involved		Fairly involved		Not involved	
	n	%	n	%	n	%
All organisations (n=346/354)	**194**	**56.1**	**93**	**26.9**	**59**	**17.1**
% Range (min – max)	**28.0 – 100.0**		**0.0 – 48.0**		**0.0 – 27.9**	
All hospitals (n=214/218)	**97**	**45.3**	**68**	**31.8**	**49**	**22.9**
% Range (min – max)	**28.0 – 62.5**		**22.9 – 48.0**		**12.5 – 27.9**	
All hospices (n=80/82)	**54**	**67.5**	**18**	**22.5**	**8**	**10.0**
% Range (min – max)	**40.0 – 92.9**		**6.7 – 42.9**		**0.0 – 30.0**	
All Community Trusts (n=52/54)	**43**	**82.7**	**7**	**13.5**	**2**	**3.8**
% Range (min – max)	**61.9 – 100.0**		**0.0 – 28.6**		**0.0 – 9.5**	

Table 31: Did any of the healthcare team discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life?

	Yes		No		Don't know	
	n	%	n	%	n	%
All organisations (n=342/354)	**110**	**32.2**	**186**	**54.4**	**46**	**13.5**
% Range (min – max)	**12.5 – 57.1**		**35.7 – 80.0**		**0.0 – 37.5**	
All hospitals (n=210/218)	**77**	**36.7**	**107**	**50.0**	**26**	**12.4**
% Range (min – max)	**25.0 – 46.7**		**37.5 – 59.4**		**0.0 – 37.5**	
All hospices (n=79/82)	**23**	**29.1**	**41**	**51.9**	**15**	**19.0**
% Range (min – max)	**12.5 – 57.1**		**35.7 – 70.0**		**0.0 – 25.0**	
All Community Trusts (n=53/54)	**10**	**18.9**	**38**	**71.7**	**5**	**9.4**
% Range (min – max)	**17.9 – 20.0**		**67.9 – 80.0**		**0.0 – 4.3**	

Table 32: Would a discussion about the appropriateness of giving fluids through a 'drip' in the last two days of life have been helpful?

	Yes		No		N/A, we had these types of discussions		
	n	%	n	%		n	%
All organisations (n=245*/354)	**124**	**50.6**	**121**	**49.4**	**n=328/354**	**83**	**25.3**
% Range (min – max)	**17.6 – 87.5**		**12.5 – 82.4**			**0.0 – 42.9**	
All hospitals (n=145/218)**	**83**	**57.2**	**62**	**42.8**	**n=199/218**	**54**	**27.1**
% Range (min – max)	**50.0 – 63.6**		**36.4 – 50.0**			**22.6 – 38.5**	
All hospices (n=57*/82)**	**27**	**47.4**	**30**	**52.6**	**n=76/82**	**19**	**25.0**
% Range (min – max)	**23.1 – 87.5**		**12.5 – 76.9**			**9.1 – 42.9**	
All Community Trusts (n=43**/54)**	**14**	**32.6**	**29**	**67.4**	**n=53/54**	**10**	**18.9**
% Range (min – max)	**17.6 – 45.5**		**54.5 – 82.4**			**0.0 – 21.4**	

*NB: In addition to the 26 patients overall who did not provide an answer for this question, the response option 'N/A, we had these types of discussions' was removed from sample: * n=83; ** n=54; *** n=19; **** n=10. Where a 'N/A' response was used in an individual site, this figure will differ from that within the individual report made available for download within the electronic tool.*

Table 33: Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand?

	Very easy		Fairly easy		Fairly difficult		Very difficult		They did not explain condition/treatment	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=342/354)	**183**	**53.5**	**112**	**32.7**	**8**	**2.3**	**7**	**2.0**	**32**	**9.4**
% Range (min – max)	**28.6 – 92.9**		**7.1 – 64.3**		**0.0 – 7.1**		**0.0 – 9.5**		**0.0 – 21.4**	
All hospitals (n=209/218)	**96**	**46.9**	**70**	**33.5**	**8**	**3.8**	**7**	**3.3**	**28**	**13.4**
% Range (min – max)	**28.6 – 60.0**		**22.9 – 57.1**		**0.0 – 7.1**		**0.0 – 9.5**		**0.0 – 21.4**	
All hospices (n=81/82)	**54**	**66.7**	**25**	**30.9**	**0**	**0.0**	**0**	**0.0**	**2**	**2.5**
% Range (min – max)	**35.7 – 92.9**		**7.1 – 64.3**		**-**		**-**		**0.0 – 20.0**	
All Community Trusts (n=52/54)	**33**	**63.5**	**17**	**32.7**	**0**	**0.0**	**0**	**0.0**	**2**	**3.8**
% Range (min – max)	**57.1 – 75.0**		**19.0 – 42.9**		**-**		**-**		**0.0 – 9.5**	

SECTION C COMMENTARY: Communication with the healthcare team

For the sample as a whole, relatives considered themselves to be ‘very involved’ in the decisions about the patient’s care and treatment in just over half of cases (56.1%, n=194), though relatives in the community setting reported feeling ‘very involved’ in fourth-fifths of cases (82.7%, n=43). Again however, a notable minority of relatives overall reported that they were ‘not involved’ in such discussions (17.1%, n=59), with the hospital setting reporting the highest proportion (22.9%, n=49) (Table 30).

Across the whole sample, it would appear that discussions about the appropriateness of giving fluids through a drip (Table 31) were not routinely undertaken, with only around a third of relatives (32.2%, n=110) reporting that they had such discussions. These discussions occurred less often in the community setting, where almost three-quarters of relatives (71.7%, n=38) reported that they did not have such a discussion compared with around a half of patients in both the hospital and hospice setting (51.0%, n=107; 51.9%, n=41). Overall however, around a half of relatives (50.6%, n=124) reported that such a discussion would have been helpful (Table 32), with just over two thirds in the community (67.4%, n=29), just over one fifth in the hospital (42.8%, n=62) and just over a half in the hospice (52.6%, n=30) settings suggesting that it would not have been helpful. It is important to understand that making ‘blanket’ assumptions about the appropriateness of engaging in such discussions cannot be supported, and sensitive communication, using open screening questions is likely to be required to promote the provision of individualised and responsive care.

Over four fifths (86.2%, n=292) of all respondents reported that explanations given of the patient’s condition or treatment were either very easy or fairly easy to understand (Table 33). Out of those relatives who reported having had this type of discussion, the hospice and community settings show greater satisfaction with the way this was communicated to them than the hospital setting (‘very easy’ to understand: 66.7% n=54, 63.5% n=33, 53.0% n=96, respectively). However, in just under 10% of all cases (n=32) the relative reported receiving no explanation at all. 28 of these 32 responses were for patients cared for in the hospital setting (13.4% of the hospital sample).

SECTION D: The emotional & spiritual support provided by the healthcare team

Table 34: How would you assess the overall level of emotional support given to you by the healthcare team?

	Excellent		Good		Fair		Poor	
	n	%	n	%	n	%	n	%
All organisations (n=348/354)	**133**	**38.2**	**122**	**35.1**	**57**	**16.4**	**36**	**10.3**
% Range (min – max)	**13.3 – 85.7**		**14.3 – 60.0**		**0.0 – 26.9**		**0.0 – 26.7**	
All hospitals (n=216/218)	**62**	**28.7**	**73**	**33.8**	**47**	**21.8**	**34**	**15.7**
% Range (min – max)	**13.3 – 55.6**		**28.6 – 44.4**		**0.0 – 26.9**		**0.0 – 26.7**	
All hospices (n=80/82)	**47**	**58.8**	**30**	**37.5**	**3**	**3.8**	**0**	**0.0**
% Range (min – max)	**30.0 – 85.7**		**14.3 – 60.0**		**0.0 – 10.0**		**-**	
All Community Trusts (n=52/54)	**24**	**46.2**	**19**	**36.5**	**7**	**13.5**	**2**	**3.8**
% Range (min – max)	**42.9 – 60.0**		**20.0 – 42.9**		**0.0 – 15.0**		**0.0 – 20.0**	

Table 35: Overall, his/her religious or spiritual needs were met by the healthcare team.

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=332/354)	**56**	**16.9**	**99**	**29.8**	**138**	**41.6**	**20**	**6.0**	**19**	**5.7**
% Range (min – max)	**6.9 – 46.7**		**13.3 – 57.1**		**0.0 – 69.2**		**0.0 – 11.1**		**0.0 – 25.0**	
All hospitals (n=205/218)	**30**	**14.6**	**49**	**23.9**	**94**	**45.9**	**16**	**7.8**	**16**	**7.8**
% Range (min – max)	**6.9 – 22.5**		**13.3 – 55.6**		**23.5 – 66.7**		**0.0 – 7.6**		**0.0 – 10.4**	
All hospices (n=78/82)	**22**	**28.2**	**39**	**50.0**	**14**	**17.1**	**2**	**2.6**	**1**	**1.3**
% Range (min – max)	**9.1 – 46.7**		**33.3 – 57.1**		**0.0 – 36.4**		**0.0 – 11.1**		**-**	
All Community Trusts (n=49/54)	**4**	**8.2**	**11**	**22.4**	**30**	**61.2**	**2**	**4.1**	**2**	**4.1**
% Range (min – max)	**7.7 – 25.0**		**20.0 – 25.0**		**25.0 – 69.2**		**0.0 – 10.0**		**0.0 – 25.0**	

Table 36: Overall, my religious or spiritual needs were met by the healthcare team

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=333/354)	**44**	**13.2**	**92**	**27.6**	**150**	**45.0**	**26**	**7.8**	**21**	**6.3**
% Range (min – max)	**0.0 – 40.0**		**11.1 – 64.3**		**7.1 – 56.3**		**0.0 – 20.0**		**0.0 – 14.7**	
All hospitals (n=205/218)	**20**	**9.8**	**43**	**21.0**	**100**	**48.8**	**23**	**11.2**	**19**	**9.3**
% Range (min – max)	**0.0 – 22.2**		**14.6 – 44.4**		**33.3 – 56.3**		**0.0 – 20.0**		**0.0 – 14.7**	
All hospices (n=78/82)	**20**	**25.6**	**35**	**44.9**	**22**	**28.2**	**0**	**0.0**	**1**	**1.3**
% Range (min – max)	**7.1 – 40.0**		**11.1 – 64.3**		**7.1 – 55.6**		**-**		**-**	
All Community Trusts (n=50/54)	**4**	**8.0**	**14**	**28.0**	**28**	**56.0**	**3**	**6.0**	**1**	**2.0**
% Range (min – max)	**0.0 – 11.1**		**20.0 – 50.0**		**50.0 – 55.6**		**0.0 – 10.0**		**-**	

SECTION D COMMENTARY: The emotional & spiritual support provided by the healthcare team

Over all, nearly three quarters (73.3% n=255) of relatives answered ‘excellent’ (38.2% n=133) or ‘good’ (35.1% n=122) to the level of emotional support provided to them by the healthcare team (Table 34). Again however a notable minority (10.3%, n=36) reported emotional support to be ‘poor’, with the hospital setting accounting for most of these responses (n=34/36 responses, 15.7% of the hospital sample).

The most common response option to the question regarding whether the spiritual or religious needs of the patient (41.6%, n=138) (Table 35) or relative (45%, n=150) (Table 36) were met, was ‘neither agree nor disagree’. Interestingly, the highest proportion of ‘neither agree nor disagree’ for patients (61.2% n=30) (Table 35) and for themselves (56%, n=28) (Table 36) was reported by relatives in the community setting, perhaps reflecting the importance of the role of family and friends in this aspect of care in this setting. The proportion of neutral responses was also relatively high in the hospital setting (45.9% n=94 for patients and 48.8% n=100 for relatives). Around three-quarters of relatives in the hospice setting however responded either ‘agree’ or ‘strongly agree’ to these statements for patients (78.2%, n=61) and for themselves (70.5%, n=55) in contrast with the hospital (for patients 38.5%, n=79; for relatives 30.8%, n=63) and community setting (for patients 30.6%, n=15; for relatives 36.0%, n=18) where this was closer to a third. A notable minority of relatives reported ‘strongly disagree’ when asked either whether the patient’s (5.7%, n=19) (Table 35) or their own (6.3%, n=21) (Table 36) religious or spiritual needs were met by the healthcare team. The hospital setting accounted for the vast majority of those responses (patient: 16/19, 7.8% of the hospital sample; relatives: 19/21, 9.3% of the hospital sample).

SECTION E: The circumstances surrounding his/her death

Table 37: Communication that the patient was imminently dying

	Before s/he died, were you told s/he was likely to die soon?		Did a member of the healthcare team talk to you about what to expect when s/he was dying (e.g. symptoms that may arise)?		
	Yes			**Yes**	
	n	**%**		**n**	**%**
All organisations (n=350/354)	**260**	**74.3**	**n=344/354**	**176**	**51.2**
% Range (min – max)	**59.5 – 100.0**			**20.0 – 81.8**	
All hospitals (n=215/218)	**151**	**69.9**	**n=212/218**	**100**	**47.2**
% Range (min – max)	**59.5 – 77.8**			**20.0 – 61.8**	
All hospices (n=82/82)	**69**	**84.1**	**n=80/82**	**47**	**58.8**
% Range (min – max)	**62.5 – 100.0**			**40.0 – 81.8**	
All Community Trusts (n=52/54)	**40**	**76.9**	**n=52/54**	**29**	**55.8**
% Range (min – max)	**75.0 – 80.0**			**55.0 – 60.0**	

Table 38: Would a discussion about what to expect when s/he was dying have been helpful?

	Yes		**No**		**N/A, we had these types of discussions**		
	n	**%**	**n**	**%**		**n**	**%**
All organisations (n=187*/354)	**144**	**77.0**	**43**	**23.0**	**n=328/354**	**141**	**43.0**
% Range (min – max)	**33.3 – 100.0**		**0.0 – 66.7**			**21.4 – 70.0**	
All hospitals (n=119/218)**	**92**	**77.3**	**27**	**22.7**	**n=201/218**	**82**	**40.8**
% Range (min – max)	**50.0 – 93.8**		**6.3 – 50.0**			**23.1 – 50.0**	
All hospices (n=40*/82)**	**29**	**72.5**	**11**	**27.5**	**n=74/82**	**34**	**45.9**
% Range (min – max)	**33.3 – 100.0**		**0.0 – 66.7**			**21.4 – 70.0**	
All Community Trusts (n=28**/54)**	**23**	**82.1**	**5**	**17.9**	**n=53/54**	**25**	**47.2**
% Range (min – max)	**33.3 – 92.9**		**7.1 – 66.7**			**40.0 – 50.0**	

*NB: In addition to the 26 patients who did not provide an answer to this questions, the response option 'N/A, we had these types of discussions' was removed from sample: * n=141; ** n=82; *** n=34; **** n=25. Where a 'N/A' response was used in an individual site, this figure will differ from that within the individual report made available for download within the electronic tool.*

Table 39: In your opinion did s/he die in the right place?

	Yes, it was the right place		No, it was not the right place		Not sure		Don't know	
	n	%	n	%	n	%	n	%
All organisations (n=347/354)	**271**	**78.1**	**46**	**13.3**	**24**	**6.9**	**6**	**1.7**
% Range (min – max)	**58.8 – 100.0**		**0.0 – 26.9**		**0.0 – 14.7**		**0.0 – 6.7**	
All hospitals (n=214/218)	**146**	**68.2**	**43**	**20.1**	**19**	**8.9**	**6**	**2.8**
% Range (min – max)	**58.8 – 100.0**		**0.0 – 26.9**		**0.0 – 14.7**		**0.0 – 6.7**	
All hospices (n=80/82)	**74**	**92.5**	**3**	**3.8**	**3**	**3.7**	**0**	**0.0**
% Range (min – max)	**84.6 – 100.0**		**0.0 – 7.7**		**0.0 – 7.7**		**-**	
All Community Trusts (n=53/54)	**51**	**96.2**	**0**	**0.0**	**2**	**3.8.**	**0**	**0.0**
% Range (min – max)	**92.9 – 100.0**		**-**		**0.0 – 7.1**		**-**	

Table 40: I was given enough help and support by the healthcare team at the actual time of his/her death?

	Strongly Agree		Agree		Neither Agree nor disagree		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=344/354)	**158**	**45.9**	**117**	**34.0**	**35**	**10.2**	**14**	**4.1**	**20**	**5.8**
% Range (min – max)	**25.5 – 81.8**		**12.5 – 47.1**		**0.0 – 23.8**		**0.0 – 9.1**		**0.0 – 33.3**	
All hospitals (n=212/218)	**82**	**38.7**	**75**	**35.4**	**26**	**12.3**	**12**	**5.7**	**17**	**8.0**
% Range (min – max)	**25.5 – 75.0**		**12.5 – 47.1**		**3.1 – 17.6**		**0.0 – 9.4**		**0.0 – 13.3**	
All hospices (n=82/82)	**52**	**63.4**	**24**	**29.3**	**3**	**3.7**	**2**	**2.4**	**1**	**1.2**
% Range (min – max)	**42.9 – 81.8**		**13.3 – 42.9**		**0.0 – 9.1**		**0.0 – 9.1**		**-**	
All Community Trusts (n=50/54)	**24**	**48.8**	**18**	**36.0**	**6**	**12.0**	**0**	**0.0**	**2**	**4.0**
% Range (min – max)	**33.3 – 59.3**		**33.3 – 37.0**		**0.0 – 23.8**		**-**		**0.0 – 33.3**	

Table 41: After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner?

	Yes		No		N/A, I didn't have any contact with the healthcare team		
	n	%	n	%		n	%
All organisations (n=321*/354)	**302**	**94.1**	**19**	**5.9**	**n=343/354**	**22**	**6.4**
% Range (min – max)	**75.0 – 100.0**		**0.0 – 15.4**			**0.0 – 16.3**	
All hospitals (n=193/218)**	**176**	**91.1**	**17**	**8.8**	**n=211/218**	**18**	**8.5**
% Range (min – max)	**84.6 – 100.0**		**0.0 – 15.4**			**0.0 – 16.3**	
All hospices (n=80*/82)**	**79**	**98.8**	**1**	**1.2**	**n=81/82**	**1**	**1.2**
% Range (min – max)	**94.7 – 100.0**		**-**			**-**	
All Community Trusts (n=48**/54)**	**47**	**97.9**	**1**	**2.1**	**n=51/54**	**3**	**5.9**
% Range (min – max)	**75.0 – 100.0**		**-**			**0.0 – 9.5**	

SECTION E COMMENTARY: The circumstances surrounding his/her death

For the sample as a whole, around three-quarters (74.3%, n=260) of relatives reported being told that the patient was likely to die soon (Table 37). This was most likely to occur in the hospice setting (84.1%, n=69) and least likely in the hospital setting (69.9%, n=151). Only around half of all relatives (51.2%, n=176) were told what to expect when the patient was dying (Table 37), with the proportion in the hospice setting only marginally greater than in the community and hospital settings (58.8% n=47, 55.8% n=29 and 47.2% n=100 respectively). After removing the 'not applicable' responses (i.e. those who reported having been told what to expect, n=141), interestingly just over three quarters (77.0%, n=144) of the remaining relatives felt that this conversation would have been helpful. Of interest, whilst this proportion was similar across all settings it rose to just over four fifths in the community setting who would have found this conversation helpful (Hospital 77.3%, n=92; Hospice 72.5%, n=29; Community 82%, n=23 respectively) (Table 38).

A relatively high proportion of relatives felt that the patient died in the right place (78.1%, n=271) (Table 39), however of the 46 relatives who reported that the patient did not die in the right place, 43 were relatives of patients in the hospital setting (20.1% of the hospital sample), and 3 were from the hospice setting (3.8% of the hospice sample). Overall, four fifths (79.9%, n=275) of relatives 'agreed' or 'strongly agreed' that they were given enough help and support by the healthcare team (Table 40), and 88.0% (n=302) reported that they were treated in a sensitive manner at the time of the patients death (Table 41). Notably, of the 22 relatives overall who stated that they did not have any contact with the healthcare team at the time of the patients death (Table 41), 18 were from the hospital setting (8.5% of the hospital sample). This may in part reflect differences between sectors regarding policy and procedure at this time, however 17 of the 20 relatives overall who strongly disagreed that they had enough help and support from the healthcare team after the patient died were from the hospital setting (8.8% of the hospital sample) (Table 40).

SECTION F: Overall Impressions

Table 42.a How much of the time was s/he treated with respect and dignity in the last two days of life? – by doctors?

	Always		Most of the time		Some of the time		Never		Don't know	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=340/354)	**245**	**72.1**	**40**	**11.8**	**17**	**5.0**	**13**	**3.8**	**25**	**7.4**
% Range (min – max)	**40.0 – 100.0**		**0.0 – 23.5**		**0.0 – 20.0**		**0.0 – 9.4**		**0.0 – 20.0**	
All hospitals (n=213/218)	**130**	**61.0**	**34**	**16.0**	**16**	**7.5**	**12**	**5.6**	**21**	**9.9**
% Range (min – max)	**40.0 – 100.0**		**0.0 – 23.5**		**0.0 – 20.0**		**0.0 – 9.4**		**0.0 – 20.0**	
All hospices (n=75/82)	**69**	**92.0**	**4**	**5.3**	**0**	**0.0**	**0**	**0.0**	**2**	**2.7**
% Range (min – max)	**80.0 – 100.0**		**0.0 – 20.0**		**-**		**-**		**0.0 – 9.1**	
All Community Trusts (n=52/54)	**46**	**88.5**	**2**	**3.8**	**1**	**1.9**	**1**	**1.9**	**2**	**3.8**
% Range (min – max)	**85.7 – 100.0**		**0.0 – 4.8**		**-**		**-**		**0.0 – 7.1**	

Table 42.b How much of the time was s/he treated with respect and dignity in the last two days of life? – by nurses?

	Always		Most of the time		Some of the time		Never		Don't know	
	n	%	n	%	n	%	n	%	n	%
All organisations (n=341/354)	**257**	**75.4**	**45**	**13.2**	**23**	**6.7**	**10**	**2.9**	**6**	**1.8**
% Range (min – max)	**55.8 – 100.0**		**0.0 – 28.8**		**0.0 – 21.2**		**0.0 – 9.4**		**0.0 – 4.7**	
All hospitals (n-214/218)	**139**	**65.0**	**39**	**18.2**	**21**	**9.8**	**9**	**4.2**	**6**	**2.8**
% Range (min – max)	**55.8 – 100.0**		**0.0 – 28.8**		**0.0 – 21.2**		**0.0 – 9.4**		**0.0 – 4.7**	
All hospices (n=75/82)	**70**	**93.3**	**4**	**5.3**	**1**	**1.3**	**0**	**0.0**	**0**	**0.0**
% Range (min – max)	**81.0 – 100.0**		**0.0 – 19.0**		**0.0 – 10.0**		**-**		**-**	
All Community Trusts (n=52/54)	**48**	**92.3**	**2**	**3.8**	**1**	**1.9**	**1**	**1.9**	**0**	**0.0**
% Range (min – max)	**85.7 – 100.0**		**0.0 – 4.8**		**0.0 – 4.8**		**-**		**-**	

Table 43. Overall, in your opinion, were you adequately supported during his/her last two days of life?

	Yes		No	
	n	%	n	%
All organisations (n=339/354)	**278**	**82.0**	**61**	**18.0**
% Range (min – max)	**60.0 – 100.0**		**0.0 – 40.0**	
All hospitals	**151**	**73.7**	**54**	**26.3**
% Range (min – max)	**60.0 – 100.0**		**0.0 – 40.0**	
All hospices (n=82/82)	**79**	**96.3**	**3**	**3.7**
% Range (min – max)	**87.5 – 100.0**		**0.0 – 12.5**	
All Community Trusts (n=54/52)	**48**	**92.3**	**4**	**7.7**
% Range (min – max)	**80.0 – 100.0**		**0.0 – 20.0**	

Table 44. How likely are you to recommend our Organisation to friends and family?

	Extremely likely		Likely		Neither likely nor unlikely		Unlikely		Extremely unlikely		Don't know	
	n	%	n	%	n	%	n	%	n	%	n	%
All organisations (n=340/354)	183	53.8	77	22.6	35	10.3	11	3.2	18	5.3	16	4.7
% Range (min – max)	20.0 – 100.0		0.0 – 46.7		0.0 – 23.5		0.0 – 10.0		0.0 – 20.0		0.0 – 9.5	
All hospitals (n=208/218)	**78**	**37.5**	**54**	**26.0**	**34**	**16.3**	**10**	**4.8**	**18**	**8.7**	**14**	**6.7**
% Range (min – max)	**20.0 – 77.8**		**11.8 – 46.7**		**0.0 – 23.5**		**0.0 – 10.3**		**0.0 – 20.0**		**0.0 – 9.5**	
All hospices (n=82/82)	71	87.7	9	11.1	0	0.0	1	1.2	0	0.0	0	0.0
% Range (min – max)	64.3 – 100.0		0.0 – 35.7		-		-		-		-	
All Community Trusts (50/54)	34	68.0	14	28.0	1	2.0	0	0.0	0	0.0	1	1.9
% Range (min – max)	50.0 – 81.5		18.5 – 40.0		-		-		-		-	

SECTION F COMMENTARY: Overall Impressions

Encouragingly, for the sample as a whole around three-quarters of respondents reported that the patient was always treated with dignity and respect by both doctors (Table 42a) and nurses (Table 42b) in the last two days of their lives (doctors: 72.1%, n=245; nurses: 75.4%, n=257). Unfortunately, in contrast, a notable minority of relatives reported that the patient was 'never' treated with dignity and respect by doctors (3.8%, n=13) and nurses (2.9%, n=10). Again, the majority of the latter responses were from the hospital setting (5.6%, n=12 of the hospital sample and 4.2%, n=9 of the hospital sample respectively).

Around four fifths of respondents (82.0%, n=278) reported that they had been adequately supported in the last two days of the patient's life (Table 43). However, whilst over 90% reported this in the hospice and community settings, only just under three quarters of relatives reported being adequately supported in the hospital setting (73.7%, n=151). When asked if they would recommend the organisation to their family and friends (Table 44), overall just over two thirds (76.4% n=260) of relatives answered either 'likely' or 'extremely likely'. However, whilst 98.8% of respondents from the hospice setting and 96.0% in the community setting reported that they were 'likely' or 'extremely likely' to recommend the organisation, this proportion was only 63.5% (n=132) for relatives in the hospital setting. Eighteen relatives (5.3% overall) answered that they would be 'very unlikely' to recommend the organisation, all of whom were relatives of patients in the hospital setting (8.7% of the hospital sample).

PART 3: Findings from the Qualitative Interviews: current feedback processes for bereaved relatives and perspectives on participation in the Regional CODETM project

Qualitative interviews were undertaken with a purposive sample of 9 respondents, who were named as the 'organisational lead' for this project. The interviews sought first of all to capture their views on the process for end of life care complaints within their organisation, which has been summarised in Section 1 of this report. Secondly, the interviews also invited the participants to describe any existing processes they have in place for capturing 'user' feedback from bereaved relatives about care in the last days of life, as well as their perceptions and experiences of participating in this Quality Assurance for Care of the Dying project. The main findings from this second element of the qualitative interviews are summarised below.

Existing 'user' feedback processes about care in the last days of life

The interviews revealed evidence to suggest that participants in this project recognised the importance of gaining the views and perceptions of patients (if and when possible) and bereaved relatives about the quality of care that was delivered in the last days of life in order to promote quality improvement. Several respondents acknowledged the role of recent National guidance and policy relating to the care of dying patients and their families, which has reinforced the need to gain 'user' feedback in order to improve the services that are provided. In the hospital setting in particular, it was recognised that these National and sometimes regional imperatives have contributed to a growing interest, and appreciation of how 'user' feedback can be used to help inform and improve the services provided to dying patients and their families. The interviews revealed a growing appetite for finding ways to obtain this kind of feedback.

Several participants, particularly those in the hospice setting, confirmed the use of 'user surveys,' amongst other methods, for gaining feedback on services more generally. In the main, these methods were likely to include comment cards, suggestion boxes and short feedback surveys designed to gain more immediate feedback at the time of care delivery. They were rarely focused on care in the last days of life and perhaps due to the more 'ad hoc' nature of this type of feedback, were not always well completed. Though participants from some organisations reported some participation in National surveys (e.g. VOICES ONS survey and the APM FAMCARE study) and one organisation reported recently undertaking telephone interviews with bereaved relatives as part of a locality project, there was little evidence across the board of organisations routinely and systematically utilising 'user surveys' (or indeed any other method for collecting feedback) that was specifically focused on the views of bereaved relatives about care delivered in the last days of a patient's life.

Participation in the Quality Assurance for Care of the Dying Project

Reasons for Participation

As highlighted above, the majority of participants identified a lack of current 'formal' mechanisms for systematically gaining the views of bereaved relatives, which was recognised as a 'gap' that required attention. Recent National and regional imperatives further reinforced the need to bridge that gap, with several respondents identifying these as key in the attainment of organisational 'buy in' to the project. Respondents felt that participation in this project would provide valuable local information which would enable a better understanding of the experience of care in the last hours or days of life within their organisation, and hence provide a direction on which to base the improvement of future services and care delivery. Some reported that involvement in the project would provide information that would complement their existing local systems of feedback and for others, the requirement for official sign up to the project by senior members of the management team, would promote the dissemination of key 'outcomes' more widely within the organisation than merely to relevant clinical teams.

It was felt that outcomes collected as part of this project mapped well against current UK guidance, providing participating organisations with 'evidence' on the quality of care provided to dying patients and their families in their organisations. The survey as an instrument itself was valued by the majority of respondents, as the CODE questionnaire enables the views of a large number of people to be sought relatively quickly. The benchmarking element was also highlighted as important, as it enables comparison with other relevant services locally and learning through the identification and sharing of good practice. Benchmarking also offered the potential for ongoing monitoring and evaluation into the future. Respondents also identified that participating in a project that had been commissioned by the Network and the project team's experience of running previous regional and National benchmarking projects, gave them confidence that the governance and 'ethical foundations' for the project were sound. These factors also contributed to the 'buy in' from some organisations for involvement.

Setting up the Project Team

The majority of organisations had adhered to the guidance, provided as part of the project, and had set up a project team with responsibility for undertaking the project within their own organisation. Participants highlighted that the guidance provided as part of the project around the construction of these project teams was helpful, particularly for identifying the specific 'roles' required within the project team. Teams were usually kept quite small which was viewed as a positive, although if the onus fell primarily only on one individual, this could have negative implications for full participation. One respondent reported that ensuring that tasks relating to the project were incorporated into everyday working practice, as part of their 'normal business', was key in the success of the project in that organisation.

Web tool and Guidance

Respondents overall reported that the data entry website was easy to use and to navigate and the associated guidance and help notes were clear and helpful. However, initial apprehension was reported by some about using these tools, with several respondents citing a lack of 'IT skills' as a source of concern. Fortunately, any initial apprehension was generally alleviated through use of the written guidance provided, or direct contact with the regional project team using the email and telephone helpline support.

Whilst the guidance was generally well received, one respondent found it too wordy and suggested the inclusion of a flow diagram to provide an overview of the process as a whole, and to replace the need for some of the wording. Also, interestingly, although information about the ability to access to an organisation's individual results from within the web tool immediately at the end of the data collection period had been provided, few respondents in the interviews reported having realised that this was the case. This latter finding, and the feedback on the utility of the inclusion of a flow diagram will inform future iterations of the work.

The process of undertaking the project: Barriers and Facilitators

Where information was routinely available through comprehensive electronic information systems within the organisation, this helped with the identification of potential cases for inclusion, including obtaining Next of Kin details for sending out the postal questionnaire. Organisations for whom this system was less comprehensive, or where information was not routinely available electronically, found this process less straightforward. On occasion, this caused some delays in the initial stages of the project. Collecting information on current complaints for this project was also aided if the electronic information systems within the organisation had end of life care complaints coded as a separate category. Similarly, those organisations that had built in the tasks of the project into the current 'administrative' systems and day to day working, appeared to find undertaking the project less 'onerous'.

The length of the CODE questionnaire in particular was raised as an initial concern by several of the respondents, who felt that some bereaved relatives would be unlikely to complete such a lengthy questionnaire. Some respondents identified initial apprehension about sending out a questionnaire around such a sensitive topic to bereaved relatives, and highlighted their concerns about how the questionnaire might be received and perceived by them. Despite this initial apprehension, respondents reported very few negative comments from relatives following receipt of the questionnaire. In total, only 4 complaints were reported from bereaved relatives in 3 organisations. Whilst some respondents, particularly those in the hospice setting, reported being pleasantly surprised by and grateful for the relatively high return rate they received in their own organisation (sometimes around 50%), it is worth remembering that the return rate overall was only around 28%. It is impossible to say from the results of this study why the vast majority of bereaved relatives chose not to complete and return a questionnaire. Whilst this response rate is broadly in line with other surveys of this type, more work is required to ensure that the process for undertaking such surveys can be refined in a way that encourages greater participation.

PART 4: Summary

Systems for Complaint and Feedback of Bereaved Relatives Views

Encouragingly, it was reported that formal systems for the receipt of general complaints were in place in all participating organisations, although having a separate coding system specifically for complaints about care in the last days of life was most likely to be present in the hospital setting. It was also interesting to note that only a small minority of all complaints received by participating organisations, in all settings, were specifically about care in the last days of life. Of the small number of complaints received, the most common themes reflected findings from the Ombudsman Report[8], with issues such as 'communication and being caring' and 'fundamental medical and nursing care'. In most organisations, there were formal systems for feedback of the issues and outcomes of complaints through Executive Boards, Trustees and clinical teams. However around one-third of organisations (mostly hospices) reported that they did not currently report in this way and respondents in the qualitative interviews revealed that the sharing of information across the organisation about complaints sometimes relied on less formal processes.

The majority of respondents in the qualitative interviews highlighted that care in the last days of life was viewed as an important element of care within their organisation. Monitoring and assessing the quality of care that is provided at this time, particularly by gaining the views of bereaved relatives, was also seen as essential for continuous quality improvement. These findings reflect national imperatives for care of the dying, which also promote the use of 'user' surveys, and a focus on bereaved relatives' views[12, 13]. Despite these national imperatives, and organisational recognition of the need for formal systems of assessment, few participating organisations had yet implemented robust systems for the feedback of bereaved relatives' views on care at this time, and indeed, this was often cited by those questioned as a major reason for participation in this project. Of note however, is that the most common reason for the non-participation of the remaining 10 eligible organisations in this project (n=7) was that systems for the assessment of bereaved relative views were already established.

Regional Survey

Participating Organisations
19/30 potentially eligible organisations (7 Hospitals, 7 Hospices and 5 Community Trusts) participated in at least one element of the Regional CODE Project. Of the remaining 11 organisations, 8 reported already being engaged in gaining feedback from bereaved relatives; two reported insufficient deaths and one that they were 'unable to participate'. Eighteen of the 19 participating organisations sent out CODE™ questionnaires; one community organisation did not participate in this element and cited staffing challenges and time constraints as the major reason for being unable to participate.

Feedback from the qualitative interviews reinforced the importance of involvement in the project as a mechanism for improvement through better understanding of bereaved relatives' views and the opportunity to benchmark against other relevant, local services. These respondents highlighted the value of the findings from this project to inform future improvements to the services that they provide to dying patients and their families.

Sample
Of the 1,774 bereaved relatives who met the initial inclusion criteria, a CODE™ questionnaire was sent out to just under three quarters (1,283 relatives). In the vast majority of the 491 cases where a questionnaire was not sent out, primarily for relatives of patients from the hospital and community settings, due to missing or unverified next of kin details within the organisation (93.7%, n=460/491). A small minority of questionnaires sent out were 'returned to sender' (3%, n=15/491). Three hundred and fifty four questionnaires were returned in total giving a

response rate of 27%. Although lower than anticipated, this remains in keeping with response rates for these types of surveys. The sample of patients and participating bereaved relatives was made up primarily of White British and Christian respondents, which has implications for the generalisability of these findings to those of other ethnicities and religious affiliations.

Complaints about the receipt of a questionnaire were rare, with only 4 reported to the project team; 1 related to the wrong next of kin details, 3 to the unexpected arrival of the questionnaire and the sensitivity of the language used within it and the accompanying letter. This feedback will be taken into account in future projects utilising the CODE^{TM} questionnaire. As this was the first time that this survey had been undertaken on a regional basis and due to the sensitivity of the questionnaire, the decision was made not to use reminder letters, which is recognised as one method of potentially increasing such response rates.

It is important to note that the relatively small sample size precludes firm conclusions regarding the quality of care provided overall and in particular for individual organisations that submitted fewer than 10 completed questionnaires for analysis.

Regional Survey Results: CODE^{TM} Questionnaire

Overall, the vast majority of bereaved relatives who returned a completed CODE^{TM} questionnaire fed back positive views on many of the aspects of care evaluated, which included doing enough to control symptoms in the last hours or days of life, attention to personal care needs, comfort and cleanliness of the environment, confidence in and the level of care received from both doctors and nurses. However, across the board, these positive views were more likely to be reported about the care of patients in the hospice and community settings and least likely for those patients cared for in the hospital setting. Importantly, a notable minority of respondents (most likely bereaved relatives of patients cared for in the hospital setting) reported negative perceptions of care across the board.

There was evidence that communication between relatives and the healthcare team could have been improved, but importantly there were nuances in the extent to which engagement in some elements of communication would have been deemed helpful by bereaved relatives. Encouragingly, relatives from all care settings found explanations regarding the patient's condition and treatment easy to understand, although it is noteworthy that such explanations were less likely to take place in the hospital setting. In contrast, only around half of all respondents perceived that they had been 'very involved' in decisions about the patient's care and treatment, with just under one-fifth reporting that they were 'not at all involved'. Again the majority of relatives who responded negatively to this element were reporting on care in the hospital setting, whereas the highest proportion of positive responses were received from relatives of patients in the hospice setting.

More than half of respondents reported that they had not had any discussion with the healthcare team about the appropriateness of giving fluids through a drip, with this most likely to be the case for those in the community setting. Interestingly however, of those relatives who reported not having had these discussions, only around half responded that such discussions would have been helpful, with just over two thirds in the community reporting it would not have been helpful. Around half of all relatives reported having had no communication with the healthcare team about what to expect when the patient was dying. Importantly three quarters, particularly those in the community setting, thought that such communication would have been helpful. These last two findings reinforce the inappropriateness of making blanket assumptions about the importance of engaging in such discussions. Person centred care is likely to require sensitive communication, using screening questions to identify the level of desired engagement.

Elements of care pertaining to emotional and spiritual support were more likely to be reported to be poor and the religious and spiritual needs of both patients and the bereaved relative less likely to be met in the hospital setting. However, most respondents (particularly those in the community and the hospital setting) replied 'neither agree nor disagree' to whether their own, or the patient's religious or spiritual needs were met. Understanding the reasons for the high proportion of 'neutral' responses would be interesting to unpack in future research. In terms of symptom control, overall restlessness was reported to be present most frequently (and in particular within the hospital and community settings), ahead of pain and retained respiratory tract secretions. Retained respiratory tract secretions, however, were perceived to be the most challenging to control with 28 (14.8%) bereaved relatives (20 of whom were commenting on the care of patients in the hospital setting) reporting that doctors and nurses did not do enough to relieve this symptom.

Most respondents thought that the patient had died in the 'right' place. In comparison with those in other settings however, a greater (though still relatively small) proportion of relatives of patients who died in the hospital setting disagreed with this statement. Respondents from the hospital setting were also more likely than in either of the other settings to report a lack of appropriate support for themselves at the time of the patient's death and immediately following it, and to report that the patient was 'never' treated with respect and dignity by doctors and nurses in the last two days of life. Whilst more than three quarters of relatives of patients across all care settings would recommend the organisation to family and friends those commenting on the hospital setting were more likely than in either of the other settings to report such a recommendation as 'unlikely'.

In conclusion, participants in this project highlighted the importance of gaining feedback from bereaved relatives about the care delivered to imminently dying patients as a means to monitor and improve services. This was also highlighted as a gap in current feedback mechanisms, and participants valued this project as a way to 'bridge' this gap. A major finding illustrated the impact of the paucity of available and accurate next of kin information which precluded the distribution of CODE^{TM} questionnaires to over a quarter of potential bereaved relatives in this study. All organisations should ensure that they have robust systems for recording and retrieving such information in order to maximize potential participation in future studies. This is also important for any other involvement the organisation may have with relatives after the death of a patient such as bereavement support. Findings from the CODE^{TM} questionnaire element identified generally positive feedback from bereaved relatives about much of the care delivered. However there were some notable exceptions, particularly for patients cared for in the hospital setting, that require organisations to develop specific and timely solutions. It is recommended that organisations review their own results, particularly in light of the 'benchmark' for their setting to inform individual action plans to highlight and address areas for improvement. These could be shared with and progress monitored through the PEOLCN. A repeat of the Network CODE^{TM} project could then be undertaken to identify any subsequent improvements, as well as to promote the importance of ongoing assessment, monitoring and action planning to continually improve the care provided to dying patients and their families.

REFERENCES

1. Department of Health (2008) End of life care strategy. Promoting high quality care for all adults at the end of life. Department of Health: London.
2. National Institute for Health and Clinical Excellence. End of life care for adults. Quality Standards QS13, http://guidance.nice.org.uk/QS13 (2011) (last accessed September 2015)
3. Leadership Alliance for the care of dying people (2014) One chance to get it right. Improving people's experience of care in the last few days and hours of life. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf (last accessed September 2015)
4. National Palliative and End of Life Care Partnership (2015) Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, via http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf (last accessed September 2015)

5. Curtis JR, Patrick DL, Engelberg RA, et al (2002) A measure of the quality of dying and death: initial validation using after-death interviews with family members. J Pain Symptom Manage; 24(1):17-31.

6. Department of Health (2013) The NHS Constitution. The NHS belongs to us all. Department of Health: London, via http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf (last accessed September 2015)

7. Royal College of Physicians (2014) National Care of the Dying Audit Hospitals. https://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals (last accessed September 2015)

8. NHS Improving Quality (2013) Snapshot review of Complaints in End of Life Care Key. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212480/Review_of_complaints_end_of_life_care.pdf (last accessed September 2015)

9. The office of National Statistics (2015) Excel table 'Deaths by place of occurrence', via http://www.ons.gov.uk/ons/search/index.html?newquery=number+of+deaths+in+hospital (last accessed September 2015)

10. Mayland CR, Williams EMI, & Ellershaw JE (2011) Assessing quality of care for the dying: the development and initial validation of a postal self completion questionnaire for bereaved relatives. Palliative Medicine 26(7): 897–907

11. National end of life care intelligence network (2011) Predicting death. Estimating the proportion of deaths that are 'unexpected'. National end of life care intelligence network.

12. Neuberger et al (2013) More Care Less Pathway: A Review of the Liverpool Care Pathway, via https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf (accessed October 2015)

13. Leadership Alliance for the Care of Dying People (2015) One Chance to Get it Right. Department of Health, via https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations (accessed October 2015)

14. NHS Friends and Family Test, via http://www.england.nhs.uk/ourwork/pe/fft/calculations/ (last accessed September 2015)

Appendix 1: Project Steering Group Membership

Name	Title	Organisation
Professor John Ellershaw	Clinical Lead	C&M Strategic Clinical Network
Kathy Collins	Quality Improvement Lead	C&M Strategic Clinical Network
Caroline Flynn	Quality Improvement Lead	C&M Strategic Clinical Network
Bernadette Hurst	Network Manager	C&M Strategic Clinical Network
Pam Bailey	Quality Improvement Lead	C&M Strategic Clinical Network
Kath Davies	Network Assistant	C&M Strategic Clinical Network
Annemarie Challinor	Macmillan EOL Lead	Central & Eastern Cheshire
Maria Earl	Macmillan GP	Wirral CCG
Jackie Reddington	North Sefton EOL GP	North Sefton CCG
Moira McGuinness	EoL Lead	S&F/SS CCG
Sharon Bird	Patient/Carer Rep	Clinical Network/Aintree
Jan Lawton	SPC Team Leader	StH&K Trust
Karen Groves	Consultant PM	WL, S&F/Queenscourt
Paula Powell	Consultant PM	Bridgewater CHCT
Lesley Metcalfe	Deputy Director of Nursing	Wirral University Hospital
Helen Murphy	Project Manager	Liverpool CCG
Patricia Crofton	Lead Nurse	The Walton Centre
Alison Coackley	Consultant PM	CCC/StH&K/ Audit SG Chair
Anna Crofton	Lead Cancer Nurse	The Walton Centre
Chris Webster	Lead Cancer Nurse	Liverpool Women’s
Helen Thomas	Lead Cancer Nurse	Countess of Chester
Berni Hardman	Divisional General Manager	Marie Curie Liverpool
John Hampson	Public Health Specialist	CHAMPS via Cheshire West and Chester
Tom Fairclough	Procurement Manager	Knowsley CCG
Julie Gorry	CEO	Wirral St Johns Hospice
Sonia Holdsworth	Macmillan Development Manager	Macmillan
Sinead Clarke	GP Lead	South Cheshire CCG
Tracey Wright	Service Delivery Manager	Vale Royal/E. Cheshire CCG
Debbie Harvey	Macmillan GP	South Sefton CCG
Paul Barry	End of Life Care Clinical Advisor	Knowsley CCG
Paul Rose	GP Lead	St Helens CCG
Leslie Allsopp	Consultant PM	Liverpool Women’s
Kate Roberts	Commissioning Manager	Halton CCG
Sue Redfern	Director of Nursing, Midwifery and Governance	StH&K Trust
Clare Pratt	Deputy Director of Nursing	Liverpool Heart and Chest
Alison Kelly	Director of Nursing	Countess of Chester
Kerry Best	Commissioning Manager	Warrington CCG
Sam Clements	Senior Project Manager	Liverpool CCG
Salli Jeynes	Chief Executive Designate	Cheshire EoL Partnership
Stephen Burrows	EPaCCs Project Lead	C&M SCN
Paul McGovern	Senior Redesign Manager	Wirral CCG
Tracey Lewis	Organisational & Development Management	Wirral University Teaching Hospital
Vicky Oxford	Macmillan Clinical Commissioning Manager	West Cheshire CCG
Janet Cummins	Advance Care Facilitator	5BP
Audrey Meacock	Patient/Carer Rep	Healthwatch Wirral
Julie Raj	Consultant PM	Aintree

Andrea Thompson	Patient/Carer Rep	
Marion Rogers	Patient/Carer Rep	
Catriona Mayland	Consultant in Palliative Medicine and Honorary Senior Lecturer	Marie Curie Palliative Care Institute Liverpool
Jane Dowson	Business Development Lead	Marie Curie Palliative Care Institute Liverpool
Maureen Gambles	Senior Research Fellow	Marie Curie Palliative Care Institute Liverpool
Tamsin McGlinchey	Research Assistant	Marie Curie Palliative Care Institute Liverpool
Helen Mulholland	Research Assistant	Marie Curie Palliative Care Institute Liverpool

Appendix 2: Potentially Eligible Organisations: Participation and Non Participation

Organisation Name	Organisational Complaints Audit	Regional Survey (CODE^{TM} questionnaire)	Reasons for Non-Participation	Qualitative Interviews
Hospital				
Aintree University Hospital NHS Trust	✓	✓		X
Clatterbridge Cancer Centre NHS Foundation Trust	✓	✓		X
**Countess of Chester Hospital*	✓	✓		✓
Liverpool Heart and Chest Hospital	X	X	Already undertaking bereaved relatives work	✓
Liverpool Women's Hospital	X	X	Too few deaths	X
** East Cheshire Hospitals NHS Trust (Macclesfield Hospital)*	X	X	Already undertaking bereaved relatives work. Member of End of Life Partnership	X
** Mid Cheshire Hospitals NHS Trust (Leighton Hospital)*	X	X	Already undertaking bereaved relatives work. Member of End of Life Partnership	X
Royal Liverpool & Broadgreen University Hospitals NHS Trust	✓	✓		X
Southport & Ormskirk NHS Trust (Acute Hospital)	✓	✓		✓
St Helens and Knowsley NHS Trust	✓	✓		X
The Walton Centre NHS Foundation Trust	X	X	Too few deaths	X
Warrington and Halton Hospitals NHS Trust	X	X	Already undertaking bereaved relatives work	X
Wirral University Teaching Hospital NHS Trust	✓	✓		✓
Hospice				
**East Cheshire Hospice*	X	X	Already undertaking bereaved relatives work. Member of End of Life Partnership	X
Halton Haven Hospice	X	X	Already undertaking bereaved relatives work	X
**Hospice of the Good Shepherd*	✓	✓		✓
Marie Curie Hospice Liverpool	✓	✓		✓
Queenscourt Hospice	✓	✓		✓
**St Luke's Hospice*	X	X	Already undertaking bereaved relatives work. Member of End of Life Partnership	X
Willowbrook Hospice	✓	✓		✓
Wirral Hospice St Johns	✓	✓		X
Woodlands Hospice	✓	✓		X
Community				
5 Boroughs Community Trust	✓	✓		X

Bridgewater Community Trust	✓	X	Resource Issues	✓
*****_East Cheshire NHS Trust (Community Service)_	X	X	Already undertaking bereaved relatives work. Member of End of Life Partnership	X
Liverpool Community Health	✓	✓		X
Southport & Ormskirk NHS Trust (Community Service)	✓	✓		✓
St Rocco's Hospice	✓	✓		X
*_West Cheshire Community Trust_	X	X	Stated they were unable to participate	X
Wirral Community Trust	✓	✓		X

**Member of the Cheshire End of Life Partnership*