

## **What is a good death?: A Critical discourse policy analysis**

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## **Abstract**

Objective: The concept of a good death is a motivating factor for end of life care policy; this paper examines what English end-of-life care policy defines as a good death.

Methods: Critical discourse analysis of policy documents and policy-promoting materials published between 2008 and 2016.

Results: Policy explicitly defines a good death as having the following attributes: being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends.

Critical discourse analysis of 54 documents found that rather than just being an outcome or event, descriptions of what makes a death good also includes many processes. A more extended definition includes: the person receives holistic end-of-life care; the dying person is treated with dignity and respect; the death is not sudden and unexpected; people are prepared and have ideally done some advance care planning; people are aware that someone is dying and openly discuss this; upon knowing the dying person's preferences, all involved are to work towards achieving these; the place of death is important; the person's family are involved; and the needs of the bereaved are considered.

Conclusion: This analysis indicates the complex nature of the current discourses around good death in EOLC policy, which often focuses on care rather than death. Policy should focus on outlining what quality end of life care looks like, rather than assume 'good death' is a suitable outcome statement.

Keywords: cultural issues, end-of-life care, terminal care

## **Introduction**

The concept of 'good death' is at the forefront of end-of-life care (EOLC) policy and is used as a motivator for change and care.[1,2] Policies about EOLC respond to public and professional concerns that: people are dying without dignity, death is too medicalised, and decisions are made about patients rather than with them.[3] Analysing policy is important because the documents, and their promotion, influence healthcare, and as such, policy is an example of discourse – the linguistic practices that provide a perspective on the world.[4] By examining EOLC policy discourse, this paper describes what English EOLC policy defines as a 'good death' and reflects on what this mean for how EOLC is delivered.

The concept of a 'good death' is debated within academic and professional literatures,[5] although there are attempts to develop sets of criteria.[6,7] Discussions about 'good death' describe the proprieties of the dying process, the event of death, or the status of being dead.[8] Good deaths can be viewed as a complex set of preparations and relations,[2] including a series of events which may be highly ritualised and individually evaluated as 'good'. Popular definitions within Anglo-American literature often relate to concepts of dignity and peace, and being without pain or suffering.[5] This society-level understanding of good death provides a dying script that people feel they should conform to and/or against which their death will be compared to;[9,10] policy contributes to shaping dying scripts.[11] Others argue that definitions should be individualised and studies demonstrate how different groups of people, such as patients, nurses or doctors, define good death.[12, 13] People may value elements of the dying process differently, therefore describing the same death in dissimilar terms.[14] There is also a growing body of literature on cross-cultural studies of good death,[15] highlighting the importance of context and how death is evaluated differently.

Policy discourse represents a way of standardising such diversity to create a normative view. This normative view is then used to influence healthcare delivery,[16] for example through promoting certain ways of doing care as ‘best practice’.[1] Through written text, policy exemplifies how discourse regulates and reinforces action by using recurrent contents, symbols or strategies.[17] There are currently no published studies examining how policy defines a good death. Since the concept is central to how policy frames its ambitions about EOLC, it is important to understand the ways in which ‘good death’ is described within policy and how policy suggests that good deaths be achieved. Since English EOLC is considered world-leading and globally influential,[18] this article focuses on English policy. This analysis contributes to discussions about the usefulness of the concept of good death as it is currently mobilised within policy and subsequently in healthcare practice.

## **Methods**

Critical discourse analysis addresses both the explicit and implicit understandings within a discourse.[19] The analytical approach utilised here involves perceiving language as not transparently reflecting reality but rather constructing and organising that reality;[20] it examines how words are used to invoke different practices and shape the care provided.[21] This equates to understanding both what is being said in policy documents and considering the consequences this has for practice.

EOLC policy in England is officially produced by the Department of Health, setting the frameworks and ambitions for care. Other organisations that have an interest in the provision of EOLC care and/or social policy also produce reports to influence the direction of policy and practice. This article is based on a critical discourse analysis of policy documents and

policy-promoting materials produced in England between 2008 and 2016. Initial analysis of policy documents was part of a larger ethnographic study about choice in English end-of-life care,[22] which identified that policy approached dying as a problem that could be managed through EOLC.[1]<sup>i</sup>

The dataset includes 54 documents from two kinds of textual data: policy reports released by agencies that provide direction on EOLC practices and newsletters that promote EOLC policy principles (see Table 1). The first captures policy documents that were: released during the timeframe of the research; produced from central agencies related to the production of healthcare policy and/or delivery of EOLC; readily publicly available; and cited during fieldwork as being relevant to current EOLC policy (i.e. in observations of policy events and/or during interviews with policy makers, and/or in other policy documents) (see Table 2 for inclusion and exclusion criteria). The second set of data is drawn from the National End of Life Care Programme newsletters published between 2010- 2013. This time period corresponds with the ethnographic fieldwork period of the larger project; a total of 26 randomly-selected issues were examined out of 48 published during this period. These newsletters were widely circulated but not necessarily publicly available.<sup>ii</sup> For the purposes of consistency within the analysis, this article only refers to EOLC policy in England (although similar values have been adopted elsewhere)[23] and to the care of dying adults since the first national EOLC Strategy (referred to here as the Strategy) did not include guidance for persons under the age of 18 years.

### ***Data Analysis***

Analysis focused on interrogating how a social problem is identified within the discourse (in this case: how can deaths be good),[24,25] how problems and solutions are described,

including the use of silences,[26] and the discursive strategies utilised.[27] The analysis was three fold: examining explicit definitions and references to good death; noting references to what makes deaths good or inappropriate<sup>iii</sup> (characteristics of a good death); and thematic analysis of the discourses within documents about how a good death could be achieved (processes of a good death). See Table 3 for a list of characteristics and processes.

The first stage involved searching documents for an explicit definition of ‘good death’, identifying where these two words were used in conjunction and an explanation about their meaning was provided. The second stage involved searching for descriptions of death that provided evaluative statements about the death. It also included searching for elaboration on elements featured in the explicit definition. Early on it was noted that descriptions of what makes a death good were intertwined with descriptions of quality in EOLC, although these are not entirely overlapping concepts. The third stage looked at for text that described how a good death (or good EOLC noting the overlap in the previous stage) could be achieved. This sought to identify the processes and organisational issues.

Characteristics and process themes were listed within Evernote (a software programme used for data management). Analytical notes were made about each, including information about how the themes were potentially linked between themselves and to higher-level abstract or theoretical constructs. Documents of a similar type were read until thematic saturation occurred; recent, centrally produced policy documents were nevertheless examined to confirm consistency of policy discourses over time. Quotes from documents included in this article represent the clarity of the themes identified, demonstrating the language used within the policy discourse.

## **Findings**

### ***Defining a Good Death***

The importance of the good death concept is emphasised by its mention on the first page of the condensed Executive Summary of the Strategy.[28] It is the only explicit definition provided in all the data (see Box 1). Although the Strategy acknowledges there may be individual variation, this definition is considered normative and serves as its working definition.

The term ‘good death’ is relatively absent in the rest of the documents; instead they outline in more detail problems and solutions for the care of the dying. Nevertheless, it is a concept that propels the government’s response to how EOLC should be - ‘providing the opportunity for a good death lies at the heart of this document’.[29, p.5] Since this concept is central to how policy frames its ambitions, and yet the explicit definition provided is rather simplified, it is important to understand the more nuanced ways in which ‘good death’ is described within policy.

### ***Who should be involved in a good death?***

Within the policy discourse, it was assumed that a good death is one in which healthcare professionals are inevitably involved; the necessity of this role is not questioned. The role of others is elaborated in the discussions of teamwork and family involvement in patient care. For example, the explicit definition requires the presence of ‘close family and/or friends’; similarly, it is claimed that they have a ‘significant role in ensuring that the patient receives high-quality care as they near the end of life’.[30, p.20] Through this, it is implied that family and friends, who may or may not be informal carers, have a responsibility to support the dying individual.

### ***What kinds of care should be involved in a good death?***

The policy discourse concerns itself with different kinds of care and how they contribute towards a death being good. Care itself is not defined; however, holistic care is considered a key component to EOLC, referred to as attending to the physical, psychological, spiritual and social needs of the dying person and their family.[31] Other specific elements of care mentioned include: good symptom and pain management; care of the body after death (discussed primarily in the Strategy); and bereavement support. Descriptions of care suggest that it should be ‘respectful’, ‘compassionate’, and ‘provide dignity’, although these terms are often not well-defined. The repeated calls for improvements in the quality, consistency, and accessibility to palliative and EOLC exemplify how, within this discourse, a ‘good death’ is considered to be within the remits of palliative and EOLC.

### ***The timeliness of a good death***

The timing of death is not explicitly mentioned in the policy documents; however, the discourse implies that when someone dies in relation to their illness trajectory is important. For example, for a person to have a good death, multiple policy documents require ‘timely identification’ that they are nearing the end of life. Moreover, the logic that dying may be a crucial time and require timely action is illustrated rhetorically here: ‘If a person is likely to live for only a matter of weeks, days matter. If the prognosis is measured in days, hours matter’.[31, p.13] Part of what makes a death good is getting this timing right. Accordingly, this implies that certain causes of death are more amenable to being part of a good death, such as those that create an indefinable dying trajectory.<sup>iv</sup>

However, there are notable absences in relation to timing of death in the policy discourse. One is sudden death; although a sudden death may not be part of the policy definition of a good death, certain elements of care (such as care of the body and bereavement support) are still expected to occur, and can help make an unexpected death still have elements of a good death.[31] Secondly, the precise timing of death through either withdrawal of treatment or assisted dying is not mentioned in most documents, or is explicitly excluded for being beyond the scope of EOLC policy. Consequently, whilst timing is important in relation to identification of ‘the end of life phase’, a sudden death or controlling the timing of death is not part of the policy definition of a good death.

### ***The location of a good death***

Place of death is a key issue within English EOLC policy, with its own dedicated section within the Strategy and frequently mentioned in the other documents examined. The places of death referred to in EOLC policy include: hospital, home, care home, and hospice. In policy discourse, home is mentioned as a ‘preferred place’; hospitals were described as requiring additional guidance,[32–34] or not enabling other qualities of a good death: for example, ‘privacy and dignity are difficult to achieve in the midst of a busy ward’.[30, p.4]

The official definition of good death indicates that people may wish to die in ‘familiar surroundings’. Evidence used to support policy claims highlight that people are not dying where they wish to. Place of death is used as a metric for the quality of EOLC, with a political emphasis on increasing the rate of home deaths. As one of the few quality measures for EOLC,[35] the desirability of home deaths reshapes location as a symbol of the quality of care and factor of a good death. This is illustrated in the repeated reference in texts that report the increase in numbers of people dying at home as a ‘key sign’ of improvement in care provision.[29]

### *Planning for death*

A logic present across EOLC policy is that death can be planned for, especially as a large premise is that once someone is identified as being near the end of life, planning and coordinating care can occur.[3,28,36] There are four themes within this: awareness of dying, acceptance of death, preferences, and communication and coordination. This vividly represents the shift in the discourse from what a good death is – as an object or outcome with factors about the event of death – to how it is to be achieved (the processes that it involves).

In the policy discourse, awareness of dying refers both to identifying that someone is likely to die within the next year, and wider public awareness about death. Part of the initiatives supported by EOLC policy, including Dying Matters<sup>v</sup> and call for a ‘proper national conversation about dying’,[37] is to promote the public and individual awareness of death to facilitate more discussions about dying. Raising awareness in both contexts is linked with being able to facilitate communication and planning for death, which is assumed to make a good death more likely.

Related, there is a presumption that acceptance of death follows awareness. This includes clinicians, as the Strategy states ‘clinicians and managers need to accept that death does not always represent a failure...[and] enabling people to die as well as possible is one of the core functions of the NHS (National Health Service)’. [31, p. 50] Similarly, to fulfil the explicit definition of good death, presumably to be present, people must be both aware and to some degree (although not necessarily psychologically) accept that death is near.

There are policy documents dedicated to the issue of patient choice or preference around EOLC.[38] Advance care planning is a core element of this and is featured in the Strategy as

a way of delivering a good death. The most striking example of how patient choice is rhetorically positioned to fulfil a good death is in the naming of the Marie Curie programme ‘Delivering Choice’<sup>vi</sup> for EOLC. Similarly, in a special edition on advance care planning, the National EOLC Programme newsletter claimed that ‘...enabling an individual to plan their care in advance gives them a greater sense of control over their future care and is likely to...improve end of life care’.[39, p.4] By encouraging patients to have a say about how they are cared for at the end of life, and adapting services to meet these preferences, it is expected that their deaths will be viewed as good because it is more likely to have met their expectations. Moreover, advance care planning is considered to be useful in the likelihood that a person may lose capacity before they die as this still enables an element of choice and agency to their death.[40, 41]

Underpinning all of the above is an assumption that for preferences to be met they must be communicated to all of those involved in a person’s care and that such communication enables the coordination of care.[42,31,43] This element of interwoven care as being part of a good death is exemplified in one of the newsletters promoting EOLC that described ‘enablers’ for achieving good end of life care, including advance care planning, systems for communicating and coordinating care, and quotes about how particular frameworks provide mutual understandings about plans and how this is important to getting care right.[44] Through these descriptions it is evident that planning that is communicated, built on shared understandings, and coordinated care is considered to help enable to a good death.

## **Discussion**

### ***Elaborated definition of a good death***

By examining the ways in which policy discourse projects the dying process and death, it is apparent that a good death from this perspective involves levels of awareness of dying,

preparation for dying, and dying within the presence of others. The policy discourse around good death is more elaborate than the explicit definition (see Box 2).

It does not include elements that other definitions of good death may include, particularly around sudden or assisted dying and social practices after death.[45,46]

This definition contains points that contradict one another depending on the scenario, such as individual choice and wishes to prepare for death.[47] This complexity of determining if a death is ‘good’ or not is not new.[48] Rather than state that the complexity and potential variability are down to individual choice, I contend that this complexity arises from the attempts to make policy discourse tangible to healthcare practice and the shift that occurs within discourse from defining a good death as an event or outcome to describing what makes a death good and the processes this involves. However, some of the terms used to do this – such as treating a person with dignity – may not be very helpful in describing what this looks like in practice,[11] making the definition of good death – both as a process and an outcome – difficult to operationalise. The lack of clear definition around key terms – including good death – indicates that policy-makers assume there is some shared meaning within the communities using and affected by policy.[49] Similarly, the way the policy is written (both by and for healthcare), assumes that dying is inherently medicalised<sup>vii</sup>; there are no challenges within policy about these assumptions about what end-of-life care should consist of and who should be involved.

In 2013, one of the policy documents questioned if the NHS had not grasped the concept of good death.[50] The complex nature of the implicit definition of a good death found with EOLC policy discourse suggests that it may be a difficult standard to achieve. Since policy sets a standard of what can be considered a good death, there is concern that deaths that may

not fit this model are implicitly 'bad'. [14,51–54] Whilst work is being done to improve access to EOLC and patient choice, [39,55] it is also prudent to question if such assumptions should be held as universal features of a good death. [56–58]

Similarly, is the standard being set through this discourse realistic given the tensions within how it defines good death? For example, patient choice may contradict the expectation to plan for and talk about death. [47] Due to the power of policy discourse, there is a pressure for not only for healthcare professionals, but also patients, families, and society more generally to embrace dying. Healthcare professionals may feel that they are only able to provide a 'good enough' death, focusing primarily on the physical management of dying, [59] yet previous research suggests that people can only ever talk about good enough deaths due to the gap between the ideal and reality. [60] Realising the importance of discourse, and how a focus solely on a 'good death' without a process-based definition is unhelpful as outlined in this paper, enables practitioners and policy-makers in all countries to think about how EOLC can be affected through the intentional use of language in policy. So whilst the concept of a good death can be a motivator for care, it should not necessarily be the evaluating standard.

This research examined policy documents up until 2016, including the Ambitions for Palliative and End-of-Life Care Framework set to cover 2015-2020, there has continued to be subsequent releases of guidance and data, mainly focusing on different locations of care and guidance for public health approaches.<sup>viii</sup> Whilst this study examined English EOLC policy over eight years and is therefore not representative of all EOLC policy, the Strategy, which was the first of its kind, and subsequent documents have been used to influence international thinking about EOLC. [18] A more historical or comparative view may show how the elements and importance of good death within policy have changed over time. Alternatively,

other kinds of linguistic discourse analysis could be done to demonstrate the relative weight provided to different components.

## **Conclusion**

EOLC policy in England has shifted recently from providing prescriptive standards to setting a framework of values and ambitions to work towards. As the Ambitions for Palliative and End of Life Care Framework was set to only cover 2015-2020, there is the opportunity now to rethink how policy engages with the concept of good death. From this analysis, which indicates the complex nature of the current discourses around good death in EOLC policy, it is recommended that due to the discursive power of policy there should be a shift away from using the term good death (and related ways of evaluating deaths as good, better, or more appropriate) to outlining what quality end of life care should look like. This discursive shift is in effect in some documents, yet recent publications still focus on good death as a driver for policy.[61] If this shift would be more consistently adopted it would enable a clearer emphasis on the processes that could change outcomes whilst not prescribing that all deaths are similarly good. Attempting to achieve a good death, as currently defined, is not a useful evaluating standard for meeting the ambitions of EOLC policy.

### Box 1: Explicit Definition of a Good Death

‘being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends’. [EOLC Strategy, page 9]

### Box 2: Wider definition of Good Death

- the person receives end-of-life care: provided pain and symptom management in the context of holistic care;
- the dying person is treated with dignity and respect, both before and after death;
- dying is a process: death is not sudden and unexpected;
- people are prepared for dying and death, and have ideally done some advance care planning;
- people are aware that someone is dying and openly discuss this. Part of these discussions involves ascertaining the person’s preferences;
- upon knowing preferences, all involved are to work towards achieving these;
- the place of care is deemed to be suitable in terms of treatment and care provision and may have been chosen by the person. Deaths in the home are particularly favoured;
- the person’s family are involved and the needs of the bereaved are considered.

Table 1: Documents Reviewed

<b>Policy and Guidance Documents</b>	<b>Newsletters to promote policy</b>
Department of Health. End of Life Care Strategy. London: Crown; 2008	National End of Life Care Programme Newsletter March 2010.
Department of Health. End of Life Care Strategy: Impact Assessment. London; 2008	National End of Life Care Programme Newsletter July 2010.
Department of Health. End of Life Care Strategy: what the End of Life Care Strategy means for patients and carers. London; 2008	National End of Life Care Programme Newsletter August 2010.
Richards M. The End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life [Internet]. End of Life Care Strategy . London: Department of Health; 2008	National End of Life Care Programme Newsletter September 2010.
Department of Health. End of Life Care Strategy: First Annual Report. London; 2009	National End of Life Care Programme Newsletter December 2010.
Department of Health. End of Life Care Strategy: Second Annual Report. London; 2010	National End of Life Care Programme Newsletter January 2011.
General Medical Council. Treatment and care towards the end of life: good practice in decision making. London; 2010	National End of Life Care Programme Newsletter February 2011.
Addicott R. Challenges for progress on the End of Life Care Strategy: the agenda for 2010. In: Addicott R, Ashton R, editors. Devilvering Better Care at the End of Life: the Next Steps. London: The King's Fund; 2010.	National End of Life Care Programme Newsletter March 2011.
Department of Health. End of Life Care Strategy: Third Annual Report. London; 2011	National End of Life Care Programme Newsletter April 2011.
National Institute for Clinical Evidence. Quality Standard for End of Life Care. London; 2011	National End of Life Care Programme Newsletter May 2011
Hughes-Hallett T, Craft A, Davies C. Palliative Care Funding Review: Funding the Right Care and Support for Everyone. 2011.	National End of Life Care Programme Newsletter August 2011.
Ombudsman. Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people. London; 2011.	National End of Life Care Programme Newsletter September 2011.
Department of Health. End of Life Care Strategy: Fourth Annual Report. London; 2012	National End of Life Care Programme Newsletter October 2011.
National EOLC Intelligence Network. What do we know now that we didn't know a year ago? New intelligence on end of life care in	National End of Life Care Programme Newsletter January 2012.

England. London; 2012.	
Neuberger J, Aaronovitch D, Bonser T, Charlesworth-Smith D, Cox D, Guthrie C, et al. More Care, Less Pathway: A Review of the Liverpool Care Pathway. London: Independent Review of the Liverpool Care Pathway; Crown; 2013.	National End of Life Care Programme Newsletter February 2012.
NHS Improving Quality. Snapshot Review of Complaints in End of Life Care: Key Findings. London; 2013.	National End of Life Care Programme Newsletter March 2012.
National End of Life Care Intelligence Network, Public Health England. What we know now 2013: new information collated by the National End of Life Care Intelligence Network. London; 2013.	National End of Life Care Programme Newsletter April 2012.
National Council for Palliative Care. The end of life care strategy: new ambitions. London; 2013.	National End of Life Care Programme Newsletter May 2012.
Leadership Alliance for the Care of Dying People. One Chance to Get It Right: Improving People's Experience of Care in the Last Few Days and Hours of Life. 2014	National End of Life Care Programme Newsletter June 2012.
National Palliative and End of Life Care Partnership. Ambitions for Palliative and End of Life Care. London; 2015	National End of Life Care Programme Newsletter July 2012.
NICE. Care of the dying adult. London; 2015	National End of Life Care Programme Newsletter September 2012.
The Choice in End of Life Care Programme Board. What's Important to Me: A review of choice in end of life care. London; 2015	National End of Life Care Programme Newsletter October 2012.
Care Quality Commission. Inequalities and variations in End of Life Care. 2015.	National End of Life Care Programme Newsletter November 2012.
Parliamentary and Health Service Ombudsman. Dying without dignity. London; 2015.	National End of Life Care Programme Newsletter February 2013.
NHS Finance and Operations. Our Commitment to you for end of life care: the government response to the Review of Choice in End of Life Care. London; 2016	
British Medical Association. End-of-life care and physician-assisted dying. Volume 3: Reflections and Recommendations. London; 2016.	

Table 2: Inclusion and Exclusion Criteria For Policy Documents and Guidance

Inclusion	Exclusion
<ul style="list-style-type: none"> <li>• Released during 2008-2016 inclusive</li> <li>• Policy or guidance focuses on England</li> <li>• Document produced by central agency related to healthcare policy and/or end-of-life care</li> <li>• Publicly available (i.e. online)</li> <li>• Cited by research participants as being relevant policy/guidance</li> <li>• About end-of-life care of adults</li> </ul>	<ul style="list-style-type: none"> <li>• Released before 2008 or after 2016</li> <li>• England not an explicit focus within the policy or guidance; policy or guidance written for another country</li> <li>• Document not in English</li> <li>• Not healthcare policy or guidance, or not influencing practice from a policy-perspective</li> <li>• Not publicly available for download or distribution (i.e. internal policies)</li> <li>• About end-of-life care of children (under 18 years old)</li> <li>• Not about end-of-life care explicitly</li> <li>• Not written by a relevant authority</li> <li>• No clear authorship (person or organisation)</li> </ul>

Table 3: Characteristics and process themes

Characteristics of a Good Death	Process of achieving a Good Death
<p>Being treated as an individual</p> <p>Dignity</p> <p>Respect</p> <p>Without pain</p> <p>Without other symptoms</p> <p>Death in familiar surroundings (e.g. home)</p> <p>Close family/friends are present at time of death</p> <p>Healthcare professionals are involved in end-of-life care prior to/at time of death</p>	<p>System recognition that a good death is a result of providing quality end-of-life care</p> <p>Healthcare professionals involved in delivering care prior to/at time of death, including timely identifying the end of life</p> <p>Care is holistic and involves different disciplines/professionals</p> <p>Informal care is involved (families/friends)</p> <p>Care requires teamwork</p> <p>Care requires coordination</p> <p>Pain and symptom management</p> <p>Bereavement support</p> <p>Care of the body after death</p> <p>Care provided with compassion, dignity, and respect</p> <p>Care is accessible to people when they need it during the period of their dying trajectory (hours, days, months, year)</p> <p>End-of-life care is suitably resources in order to be accessible</p> <p>Preferred place of death is ascertained and care organised around this</p> <p>Services provide support for home deaths</p> <p>Dying and death is planned for, including using advance care planning</p> <p>Patient choice is sought and is used as a driver for care delivery</p> <p>Healthcare professionals promote awareness and acceptance of dying</p> <p>Open communication in all areas of care, including between family and dying person</p>

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<sup>i</sup> The ethnographic study also included an element of discourse analysis as well as observing what happens in practice and as people live towards the end of their lives. The researcher is an anthropologist trained in these methods, with an interest in how policy, practice, and everyday experiences of living and dying interrelate with one another.

<sup>ii</sup> There is no current online archive of the newsletters; the maintenance for this website has been decommissioned by the Department of Health.

<sup>iii</sup> Findings from the ethnographic study that preceded this research article suggested that interviewees and speakers at policy-related events often contrasted different kinds of experiences and deaths as a way to argue for a particular version of ‘good death’.[22]

<sup>iv</sup> It is well acknowledged in the palliative care literature that dying may be difficult to identify for all persons. [62,63]

<sup>v</sup> Dying Matters was established by the National Council for Palliative Care in 2009 to promote public awareness of death, dying and bereavement. More information can be found at <http://www.dyingmatters.org/overview/about-us>.

<sup>vi vi</sup> More information can be found at <https://www.mariecurie.org.uk/professionals/commissioning-our-services/partnerships-innovations/past/delivering-choice-programme>. The programme pre-dated the Strategy and is referred to within policy documents as an example of best practice.

<sup>vii</sup> For a discussion about the medicalisation of death, see Clark.[64]

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viii For up-to-date guidance and resources from Public Health England, see <https://www.gov.uk/government/collections/palliative-and-end-of-life-care>.