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# End-of-life care quality measures: beyond place of death

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## ABSTRACT

**Background** How quality in healthcare is measured shapes care provision, including how and what care is delivered. In end-of-life care, appropriate measurement can facilitate effective care and research, and when used in policy, highlight deficits and developments in provision and endorse the discipline necessity. The most prevalent end-of-life quality metric, place of death, is not a quality measure: it gives no indication of the quality of care or patient experience in the place of death.

**Aim** To evaluate alternative measures to place of death for assessing quality of care in end-of-life provision in all settings.

**Method** We examine current end-of-life care quality measures for use as metrics for quality in end-of-life care. We categorise approaches to measurement as either: clinical instruments, mortality follow-back surveys or organisational data. We review each category using four criteria: care setting, patient population, measure feasibility, care quality.

**Results** While many of the measure types were highly developed for their specific use, each had limitations for measuring quality of care for a population. Measures were deficient because they lacked potential for reporting end-of-life care for patients not in receipt of specialist palliative care, were reliant on patient-proxy accounts, or were not feasible across all care settings.

**Conclusion** None of the current end-of-life care metric categories can currently be feasibly used to compare the quality of end-of-life care provision for all patients in all care settings. We recommend the development of a bespoke measure or judicious selection and combination of existing measures for reviewing end-of-life care quality.

## INTRODUCTION

How quality in end-of-life care is measured helps shape how and what care is delivered. Effective end-of-life care measurement may improve provision by

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Place of death is widely used as a 'quality metric' but does not assess quality. The relevance of alternative metrics is unknown.

### WHAT THIS STUDY ADDS

⇒ Alternative metrics offer advantages over place of death, but each has significant disadvantages.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Collating existing metrics may overcome individual deficiencies.  
⇒ Propose criteria for evaluating and developing metrics.

identifying problems, tracking successes, facilitating coordination between services and supporting research.<sup>1 2</sup> Measurement can also raise the profile of end-of-life care with tangible consequences to commissioning and provision. The inclusion of end-of-life care indicators in the National Health Service (NHS) Mandate in England for example, facilitated government bodies to hold to account those responsible for care provision, thereby enhancing the clinical prominence of end-of-life care.<sup>3</sup> Importantly, quality measures inevitably define what 'good' end-of-life care is by directing resource allocation and practices of care.<sup>4 5</sup> Given this context, it is imperative that there are robust and legitimate measures of quality of palliative and end-of-life care.

'Place of death' is extensively used in quality assessment in end-of-life care policies in the UK and internationally,<sup>6 7</sup> and in end-of-life care research.<sup>8-10</sup> The metric organises where patients die into residential and institutional categories (typically acute hospital, care home, own home, hospice and other places), with 'better' quality commonly associated with death in non-hospital settings. However, it is recognised to be at best a proxy for



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assessing quality in end-of-life care. Its continued use reflects both a historic emphasis on place of death as a quality metric in policy documents<sup>7 11 12</sup> and the absence of any robust alternative end-of-life care quality measures.<sup>13</sup>

There is an urgent need to improve how end-of-life care quality is measured in policy and practice.<sup>13</sup> There are extensive potential alternative metrics to place of death,<sup>14–24</sup> but their relevance in replacing place of death to evaluate the quality of care across the spectrum of palliative and end-of-life care provision is unknown. In this paper, we review place of death and then consider other measures for use at population and national levels. Based on this, we identify priorities for future end-of-life care measures.

## PLACE OF DEATH

Place of death is widely used as a quality metric in end-of-life care policy in high-income countries.<sup>7–10</sup> In policy it has been deployed in a range of ways: as a ‘vital sign’ focusing on the ‘proportion of all deaths that occur at home’<sup>25</sup>; as a focus on deaths in ‘usual place of residence’ (in residential, care and nursing homes); and more recently to assess success by measuring reduced numbers of deaths in hospital.<sup>3</sup> As a metric it is feasible to deliver,<sup>9</sup> using death-registration data, information that is typically routinely recorded, broadly robust and often available across all care settings and for whole populations, facilitating population-level evaluations of care provision.<sup>8 26</sup> Globally, death registration including cause and place of death is often a legal requirement in countries which adhere to United Nations and World Health Organisation standards.<sup>26</sup>

Importantly, however, place of death cannot assess care quality. Its use invokes flawed assumptions about an association between where a patient dies and the quality of care they receive in that setting. Using place of death assumes that ‘good’ deaths occur in the community (particularly at home, but also hospice and care homes) and ‘poor’ deaths occur in hospital.<sup>27</sup> Dying at home does not indicate optimal care provision nor meeting patient preferences for place of death.<sup>28</sup> Poor care is reported in similar proportions across home, hospital and residential home settings.<sup>29</sup> For some patients, hospital has also been shown to be an important and entirely appropriate place for end-of-life care provision.<sup>11 30 31</sup> Not all patients wish to die at home.<sup>32</sup> Place of death is not a high priority to all patients close to the end of life, particularly compared with issues such as receiving good symptom management.<sup>32–34</sup> Preference for death at home changes over time, decreasing as illness progresses.<sup>35</sup>

The congruence between preferred and actual place of death is also widely used, particularly in research. This modification is not an effective solution as this metric fails to address the problems associated with prioritising place above other aspects of quality, and is not feasible as a population-level metric because of

limitations in recording and retrieving patient preference data.<sup>9</sup>

More sophisticated derivatives of place of death have been developed, including a recent measure of ‘Percentage of deaths with three or more emergency admissions in last 3 months of life’.<sup>36</sup> This still views place as a pertinent metric of quality at the end of life. This is significant because the association between hospital admissions and poor care is increasingly contested.<sup>7 11 37</sup>

## EXPLORING ALTERNATIVE METRICS

Out of the many alternative metrics for assessing quality in end-of-life care our focus is on ‘care at the end of life’. By this we mean the processes and provision of care, including nursing and medical care and the clinical environment, practitioner communication and related factors,<sup>20 38</sup> particularly on care in the last 3 months of life. Alternative foci, despite being important for understanding end-of-life care quality, are less feasible for population measurement because of their subjectivity. For example, both ‘experience of care’ and ‘quality of death and dying’ can be expected to vary according to patients’ or proxy respondents’ preferences and prior assumptions, hindering direct comparison necessary for population assessments.<sup>18</sup>

Recognising that each metric can be expected to differently define quality according to their measurement priority, we do not define quality. Instead, we are guided by the broad aspiration that quality end of life care involves ‘early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual’.<sup>39</sup>

Our focus in this paper is on metrics and tools that have either been designed as quality measures of end-of-life care or have been used in this way. We classified metrics according to the way in which they collect quality assessment data and assessed their relevance as population metrics by these categories. We categorised measures as either clinical instruments (typically real-time metrics designed to facilitate end-of-life care provision), mortality follow-back surveys (retrospective surveys designed to assess care provision), or organisational data (administrative information collected by organisations about care delivery). Where measures had been used in multiple ways, we categorised them according to how they are often most prevalently described. We similarly used the most prominent category in instances where metrics are composite of a variety of categories. We illustrated each category with a prominent example (tables 1–3). These illustrated examples were used to structure the relevance of the category measure for population-level comparison.

The strengths and challenges of place of death directed us to four criteria to consider the suitability of alternative metrics. First, relevance across care settings (including specialist palliative and generalist care settings), acknowledging the diversity of places

**Table 1** Clinical instrument example: OACC

Instrument	OOACC suite of measures <sup>1</sup>
Description	A collection of measures which individually assess a key aspect of palliative care, including questions relating to a patient's stage of illness, functioning, symptoms, quality of life and those of their informal care givers. <sup>1</sup> OACC data provide a perspective on a patient's care, and when collated over a period of time, can be used to monitor and evaluate patients' condition <sup>(41)</sup> . OACC is a UK example of combining measures with similar examples found internationally (eg, Australian Palliative Care Outcomes Collaboration. <sup>47</sup>
Care setting	OACC has been widely adopted in specialist palliative care settings <sup>81</sup> but there is little evidence of uptake in non-specialist palliative care health and care settings. There are recognised barriers to using OACC in non-palliative care specialist settings, including those with high caseloads, as is typical in general practice and acute hospitals. <sup>82</sup>
Patient population	Limited to patients recognised to be 'end of life' or in receipt of palliative or end-of-life care, as it is a specific clinical tool focused on end-of-life care provision.
Measure feasibility	Limited without significant resourcing. While OACC is recommended to be included in routine clinical practice, it is not clear how data collected from healthcare organisations could be pooled for population-level analysis.
Care quality	High. OACC fulfils the European Association of Palliative Care Taskforce on Outcome Measurement <sup>83</sup> recommendations <sup>1</sup> , and by combining a variety of measures addressed a wide spectrum of aspects related to quality care. The measure prioritises patients' perspectives where possible, and provides contemporaneous data.

OACC, Outcome Assessment and Complexity Collaborative.

a patient may receive end-of-life care. Second, relevance across patient populations, addressing the historic bias in end-of-life care towards cancer provision and the contemporary focus on meeting the needs of all patients with a terminal diagnosis, irrespective of condition. Third, feasibility, recognising that in the context of constrained health and care systems, metrics should not cause significant additional workload burden nor costs. Fourth, relevance for providing meaningful insight into end-of-life care quality and their potential influence on the delivery of care.

We assessed these criteria as follows:

- ▶ **Care setting:** How applicable each measure category is for assessing care across all settings in which end-of-life care is provided. We considered the feasibility of using metrics in prevalent places of care delivery, focusing on hospital, home, hospice and residential care facility.
- ▶ **Patient population:** How applicable each measure category is to assessing end-of-life care for all patients, irrespective of diagnosis. We considered specifically how well the metric assesses care quality for patients with cancer and non-cancer diagnoses, addressing particularly organ failure.
- ▶ **Measure feasibility:** How feasible and easy is administering the measurement, including collecting and

processing the data. We considered clinician and other stakeholder burden and how well metric outcomes could be collated for population-level use.

- ▶ **Care quality:** How meaningful the measure data are on quality of care at the end-of-life. We addressed the pertinence of metric outcomes for understanding end-of-life care quality, the timeliness of the data for providing contemporaneous assessments of care, and the role of the information provider, prioritising patient-reported data.

We did not seek to assess the quality of the metric for its original purpose beyond the above criteria. Similarly, while we recognise the importance of ensuring that outcome metrics are psychometrically robust,<sup>40</sup> it was outside of the scope of this paper to assess the psychometric properties of the measures for population use.

## ALTERNATIVE QUALITY OF CARE METRICS TO PLACE OF DEATH

### Clinical instruments

Clinical instruments of end-of-life care quality typically provide contemporaneous perspectives on a patient's care, and when collated over a period of time, can be

**Table 2** Mortality follow-back survey example: voices

Instrument	VOICES—views of informal carers—evaluation of services <sup>84</sup>
Description	Survey of experience of care in the last 3 months of life, as reported by the individual who registered the person's death. In England, VOICES has been used as a population-level metric, with national postal surveys undertaken annually from 2011 to 2016. Modified versions of VOICES have been used to assess end-of-life care quality (eg, in Ontario, Canada). <sup>53</sup> The survey was derived from the 1990 Regional Study of care for the Dying, <sup>85</sup> itself based on earlier work by Cartwright <i>et al.</i> <sup>86 87</sup>
Care setting	Applicable across all settings.
Patient population	Broadly comprehensive. Applicable to all patient groups. In England, use with representative sample stratified by cause and place of death in survey period. <sup>60</sup> Good coverage dependent on high response rate and equal response uptake across demographic groups. In last England survey, black and minority ethnic participants thought to be under-represented. <sup>84</sup>
Measure feasibility	Postal self-report questionnaire. Resource intensive to administer and analyse. Survey is lengthy (short-form version is 59 questions in a 15 page booklet). England version was administered by the Office of National Statistics on behalf of NHS England.
Care quality	Limited. Extensive development (including pre-testing with bereaved relatives) ensured questions asked are meaningful and relevant. <sup>21</sup> However, retrospective patient proxy views of end-of-life care by questionnaire recipient. Limited information on caregivers' views of support they received in providing end-of-life care, or of religious or spiritual needs. <sup>21</sup>

**Table 3** Organisation measure example: Quality and Outcomes Framework

Criteria	Measure suitability
Instrument	NHS England 2019/20 General Medical Services contract Quality and Outcomes Framework, End-of-life care <sup>88</sup>
Description	Metric designed to facilitate improved care, explicitly linked to funding. Current metric focuses on the identification of patients on an end-of-life care register, and the recording of advance care planning conversations.
Care setting	General practice only, although criteria assessed may have relevance for care provision in other settings (eg, advance care planning may facilitate improved awareness of end-of-life patients in hospital through better identification of needs).
Patient population	All patients recognised to be close to the end of life known to general practitioners. Excludes patients not formally recognised as end of life, likely to be those with uncertain or non-cancer terminal diagnoses.
Measure feasibility	As part of a nationally recognised payment incentive scheme, completion across English general practices is high. Collated with other QOF metrics, findings are processed and available via NHS England.
Care quality	Metrics assessed are only proxies of end-of-life care quality. While both timely identification of end-of-life patients and advance care planning are associated with good care provision, neither guarantee good care nor demonstrate that appropriate care has been enacted.

useful to monitor and evaluate a patient's condition and care provision.<sup>41</sup> Such metrics are often extensive, addressing a range of topics including physical and psychological symptoms, functional status, spiritual needs, continuity of care, advance care planning and the needs of carers.<sup>15</sup> Patients are typically the subject of these measures, addressing questions on their own symptoms and needs, but measures may also survey clinicians and lay carers. Metrics which combine multiple perspectives, as in [table 1](#), may usefully augment patient reported metrics (recognised to be a 'gold standard' in outcome metrics<sup>42</sup>) with surrogate focused metrics, facilitating continued reporting even when it is either not appropriate or feasible to seek patients' perspectives.<sup>41 43 44</sup>

Clinical end-of-life care outcome metrics can assess care quality well, especially those which combine several metrics to provide holistic overall assessment; they are increasingly robustly developed and tested. Use of clinical metrics is feasible in settings which deliver specialist palliative care: while training is often necessary<sup>45</sup> and staff can experience difficulties using them,<sup>46</sup> clinical instruments can be well accepted with evidence of widespread use, including at the population-level (eg, UK,<sup>2</sup> Australia<sup>47</sup>). However, combining data across organisations to facilitate population-level comparison is not straightforward: a pilot project in England identified significant challenges with data sharing and consent for patients without capacity, in addition to resourcing and infrastructure-related issues.<sup>2</sup>

The utility of clinical outcome metrics outside specialist palliative care settings is unclear. The burden of measurement, including clinician time, cost and training needs,<sup>44 45</sup> results in limited use in generalist or non-specialist palliative care settings, particularly those with competing measurement priorities and high clinician workloads.<sup>44 48</sup> Importantly, the clinical focus also means that populations with whom these metrics are used is limited to those recognised to be 'end of life' for a significant period of time prior to death, which constitutes a small proportion of all deaths.<sup>43</sup>

### Mortality follow-back surveys

Mortality follow-back surveys assess the quality of end-of-life care provision by seeking the views of those involved in the patient's care after their death. Respondents are typically relatives or other lay carers of the patient,<sup>16</sup> who are asked to recall the quality of care in the patient's last few days, weeks or months of life, or the end of life period generically, via surveys returned by post or online, or told to interviewers in-person or via telephone.<sup>16 20</sup> Surveys typically focus on respondents' views of the quantity and scope of provision, symptom control, communication and emotional support.<sup>20 49</sup> Survey populations and settings are diverse, drawn from national populations (eg, [table 2](#)) to hospice patients (Consumer Assessment of Healthcare Providers and Systems hospice survey<sup>50</sup>).

Surveys have been demonstrated to be practical for population-level comparisons of end-of-life care quality, for example, CODE<sup>49</sup> has been used nationally to assess hospital care for dying patients,<sup>51</sup> VOICES<sup>29</sup> collected information on bereaved people's views of the quality of care in England, and CES surveyed hospice provision in Japan.<sup>52</sup> These surveys require infrastructure to deliver measurement.<sup>53</sup> Their use of lay carer accounts removes the burden of measurement from patients and healthcare professionals. Importantly, they have the capacity to be inclusive of all deaths in a survey period, irrespective of where patients received care<sup>53</sup> and whether a patients' condition or prognosis was identified prior to death. To date, the psychometric testing of mortality follow-back surveys has been limited.<sup>19 20</sup> It remains unclear to what extent close family and friends are able to respond as patient proxies; they have themselves been recipients of care, with their responses influenced by recall biases and the effects of bereavement.<sup>54</sup>

The retrospective design of these surveys excludes opportunity for direct patient reporting, contravening the patient-centred approach of end-of-life care.<sup>1</sup> They are limited in assessing important subjective assessments such as symptom control, functional status, or psychological or spiritual well-being.<sup>55</sup>

Satisfaction surveys (eg, CANHELP,<sup>56</sup> FAMCARE<sup>57</sup>) help to ameliorate this but satisfaction does not always equate with quality care provision and are susceptible to the 'ceiling effect' with top ratings frequently used, limiting their utility.<sup>21</sup> All are at risk of response bias associated with low response rate,<sup>58</sup> and depend on the accuracy of record-keeping about the deceased to identify proxies.<sup>59</sup> Respondents may be those who are most motivated to respond because they hold strong feelings about the care experienced,<sup>58</sup> with a tendency for minority groups to be underrepresented.<sup>49 60</sup> Follow-back surveys may also affect respondents, both provoking distress and providing therapeutic benefit to bereaved participants.<sup>49</sup>

### Organisational measures

Metrics may be derived from administrative data. These vary in scope and scale, from routine data collection of clinical care provision (eg, the previous minimum dataset for specialist palliative care in England<sup>61</sup>), to satisfaction surveys administered by individual organisations about their care provision, to national hospital activity level data and funding-linked national metrics (eg, table 3). The appropriateness of repurposing such data for assessing quality in end-of-life care depends on the robustness of the data collected and its applicability for collating at the population level. Small-scale, local surveys are unlikely to be feasible to collate for national use, but data collected nationwide on end-of-life care provision (eg, table 3) identifies the potential of organisational metrics.

Data collected for population-level reporting may be expected to provide robust data which can feasibly be collated by using existing administrative processes to facilitate comparison on care provision. However, successfully repurposing metrics relies on a close match between the original purpose of data-collection and end-of-life care quality measurement. Using data not specifically designed for evaluation to assess patient quality, such as reviewing medical notes or patient surveys, are limited because the quality of the data is likely to be variable, to include superfluous clinical details and insufficient relevant information.<sup>62</sup> The organisational focus of metrics moreover means that they rarely provide comprehensive coverage, either across care providers or among patient groups, nor the impact of care provided.<sup>8</sup> While data can be combined to facilitate meaningful measurement,<sup>63</sup> linking data across settings is not straightforward and can lead to significant data loss.<sup>64</sup> Addressing this, dedicated cross-setting surveys may offer the potential to facilitate quality measurement across inpatient settings (eg, the National Audit of Care at the End of Life<sup>65</sup>), but are limited in not providing comprehensive coverage across primary and secondary care.

## DISCUSSION

In this paper, we assessed the viability of alternative metrics to place of death for assessing quality in

end-of-life care at the population-level. We found each category of metric had merit for population use, but none fulfilled all our criteria. Measures were deficient in either their potential for reporting care quality for non-specialist palliative care or because of their reliance on patient-proxy accounts of care (either before or after death). The continued use of place of death, despite the inappropriateness of the metric, reflects the known challenge of measuring quality in end-of-life care. End of life care is delivered to diverse populations in many settings. High quality end-of-life care involves addressing a patient's psychosocial, spiritual and clinical needs and considering the needs of those close to them.<sup>14 66</sup> Care provision needs to truly be patient-centred, reflecting the patient's preferences, the heterogeneity of the conditions cared for and the variation in demographic factors, inhibiting simple comparisons. There are methodological and ethical challenges in involving patients in assessing the quality of their care when they are approaching the very end of life and proxy voices, while providing perspectives on the patients' care, cannot be considered a substitute for patient reports.<sup>67</sup> Place of death is feasible, reliable and easy to measure, but does not measure care quality.

Many of the problems with the alternative metrics are associated with the timing of measurement in relation to a patient's death, reflecting the challenges of both prospective and retrospective measurement. Prospective metrics, such as clinical metrics, despite their utility in specialist palliative care settings, are of limited value in other settings where there is not a strong focus on end-of-life care provision. In these non-specialist settings, measuring end-of-life care quality can be challenging. Here, the legitimacy of end-of-life care may not always be accepted,<sup>68</sup> end-of-life care quality measurement may not be prioritised,<sup>69</sup> there may be insufficient time or incentive or the benefit of monitoring is unclear, and measurement may not be deemed acceptable.<sup>44</sup> Retrospective metrics are similarly imperfect. While they are inclusive of all patients irrespective of condition or receipt of service,<sup>62</sup> thereby addressing known problems in inaccurate prognostication and barriers to palliative care provision,<sup>70</sup> they do not discriminate between care that was appropriately not end-of-life related, such as active treatment, and problems in deficient end-of-life care which they seek to highlight.<sup>71</sup> Significantly, they necessarily exclude the voice of the deceased patient.

The use of organisational metrics invokes similar problems depending on how patients are identified: specialist palliative care data are limited to patients who received specialist care, data on generalist end-of-life care provision are often 'severely lacking',<sup>72</sup> while data available for all deceased patients, such as place of death, risk providing information of severely limited utility.<sup>26</sup>

Population measurement also requires overcoming logistical issues. While measuring the place of death is

relatively easy to collect, and available for all patients, the alternative metric categories described above all face challenges associated with data collection and ownership and sharing of results across settings.<sup>53</sup> Attempts in England to develop a national measurement tool for specialist palliative care demonstrate the need for sufficient resourcing, financial and IT support, support from clinical leaders, as well as time to establish new metrics.<sup>2</sup> Similar challenges have been reported in Canada.<sup>73</sup> While it is apparent that more accurate population-level measurement of end-of-life care than place of death is necessary, identifying, specifying, and collecting data to achieve this is challenging.<sup>72</sup>

## RECOMMENDATIONS AND SUMMARY

The need for robust measures for quality in end-of-life care is recognised by policy-makers and researchers internationally.<sup>2 74 75</sup> Currently, no country has a set of end-of-life care indicators relevant to all patients in all settings to enable population-level comparisons.<sup>13</sup> Existing alternative metrics to place of death offer promise for some patient groups or situations, but do not fulfil all our criteria of all patients in all settings. There is a need to focus not on what is easily measurable, but on what is important to those receiving and delivering end-of-life care.

End-of-life care metrics for assessing quality must be feasible, meaningful, and applicable to all end-of-life care patients in all settings. Whether prospective or retrospective, use of any alternative metric to place of death should include acknowledgement of the limitations of the approach.<sup>62</sup> Measurement should also be appropriately funded to ensure that otherwise debilitating operational issues are overcome.<sup>74</sup>

Building on the advantages of existing metrics, new metrics need to be developed. The components of 'good' end-of-life care and the domains of what should be measured is reaching consensus,<sup>45 76</sup> certainly for patient-level outcome measures. The focus should now be on enacting these recommendations into metrics which are feasible for all patient groups, robust and measure quality accurately for national and population use. The criteria presented in this paper may usefully stimulate discussion on what these new metrics could look like.

Alternatively, judiciously combining metrics from across categories, or extending and augmenting existing metrics so that they are pertinent to other settings may be a pragmatic approach to use the advantages and mitigate the disadvantages of each. Organisational examples such as the National Audit of Care at the End of Life<sup>65</sup> usefully combine a variety of metrics (mortality follow-back survey, staff reported measures and organisation audit) to overcome the disadvantages of each approach and is endorsed by the NHS. If extended to encompass community provision it offers potential as a population-level metric. Similarly extending to non-specialist community settings could make the Australian Palliative Care Outcomes Collaboration,<sup>77</sup> a clinical instrument which has a national programme with a central data repository,

able to provide comprehensive data to assess quality of care at the population level.

Another consideration is to look beyond existing metrics for alternatives that could be reformulated for measurement use. For example, the current development across the UK of Medical Examiners (distinct to the American coroner role of the same name) offers promise, encompassing case-note review, discussion with the attending doctor and separately with the deceased's next of kin for all deaths (apart from those requiring compulsory referral to a Coroner such as suicide, trauma and sudden death).<sup>78</sup> Reviews of the UK ME initiative have already demonstrated the usefulness of incorporating next-of-kin views for identifying challenges in community end-of-life care provision<sup>79</sup> and in quality care at the end-of-life during the COVID-19 pandemic.<sup>80</sup>

Moving beyond the flawed metric of place of death will not be straightforward, particularly in countries such as the UK where there is no national palliative care data collection system and a decentralised health-care system.<sup>13</sup> However, we cannot continue to use the measure: improved measurement is a high priority in end-of-life care research, practice and policy.

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