Does national policy in England help deliver better and more consistent care for those at the end of life?

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Abstract

Objectives: To explore the extent to which national policy in end of life care in England influences and guides local practice, to ensure that care for patients over the age 75 years is of a consistently good quality.

Method: This paper reports on phase one of a larger study and focuses its discussion on the high level (macro) determinants emerging from the analysis. Fifteen in-depth interviews were conducted with professionals involved in the development of English policy in end of life care.

Results: Factors influencing the quality of end of life care were stratified into three system levels: meso, macro and micro. English national policy was reported to be an important macro-level determinant of effective outcomes and examples were provided to demonstrate how policy was influencing practice. Yet the complexity of the area and the range of interacting contributory factors mean the value of policy alone is hard to assess. At the macro-level concern was voiced around: whether policy was effective in tackling rising inequity; lack of mandatory leverage to exert change relating to end of life outcomes; the impact of ongoing infrastructural change on statutory services; workforce pressures; over-reliance on acute services; and continued abdication of responsibility for end of life care to medical professionals supported by the continued dominance of the medical model of care.

Conclusions: The links between the existence of policy at the macro-level of the system, and the effective enactment of good practice remain unclear although strategies are suggested to help achieve greater national consistency in end of life care outcomes. Policymakers must pay attention to the following: controlling the rise in localism and its contribution to

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regional inequalities; the impact of continuous infrastructural change together with increasing workforce pressures; encouraging broader professional and public responsibility for recognition; and care of those at the end of life.

Keywords: End of Life Care; national policy; equity in outcome

Introduction

The changing demographic in England with its rapidly aging population, increases the urgency to find new innovative ways to give people end of life care (EOLC). There is growing evidence to suggest that, for many, EOLC in England continues to be delivered reactively rather than proactively, particularly in the acute hospital setting.[1] A comparative study of palliative care policy in both European Union and other countries[2] suggests that while things are improving, there is still scope to further align policy with system building blocks: in particular, policy must be linked to practical steps enabling service provision.

The impact of poor experiences of EOLC is profound, not just for the dying person, but on the families, carers and professionals around them. Whilst strategy reports over the last decade[1,3] have laid out aspirations for EOLC responsive to individual needs and preferences, Care Quality Commission (CQC) data[4] reveal huge variability in provision. There is little research done to elucidate how national policy helps guide local practice in the care of older people facing the end of life (EOL) or to compare how local priorities, determining service delivery are made.

This paper reports on phase 1 of a larger study which sought to explore the rhetoric and reality of EOLC policy from the perspective of those involved in developing regional and local EOLC policy. The study asks to what extent EOLC policy helps ensure that finite resources are distributed equitably and fits with the needs and preferences of patients. This initial phase of the work was used to map the key concepts, clarify definitions and develop a theoretical framework to inform the second phase currently underway, comprising of case studies in three English clinical commissioning groups (CCGs).

The focus of this paper is on macro-level determinants, pertaining to the impact of national EOLC policy, offering insights both from interviews carried out with key stakeholders involved in developing English policy.

Context

The Economist Intelligence Unit[5] notes that only a handful of countries internationally recognize EOLC in their healthcare and medical education policies, and, to be effective, policies must be backed by service delivery. A study looking at palliative care in Ireland found that where robust policies were in place they can provide a roadmap, helping set markers to monitor progress[6].

Commentators also warn of the need for policy alignment. That is, policies in one sector (for example, social care) should not impact deleteriously on another sector (for example, health) – as has been seen to be the case in the UK following dramatic cuts in social care.[7]

In England, the way healthcare is delivered has undergone significant change since the passing of the 2012 Health and Social Care Act.[8] The creation of over 200 CCGs, responsible for local commissioning of healthcare, followed by the introduction of 44 larger Sustainability and Transformation Plans (STPs) in 2016, grouping CCGs into larger operational units, and subsequently the move to Integrated Care Systems, has created a situation of ongoing flux in service delivery.[9] Alongside these changes, the decentralization of powers from the Department of Health to local governance mechanisms has removed some of the levers that were previously used to drive through national policy.[10] Incentives for implementing good EOLC practice exist through a number of mechanisms. Notably, since 2016 CQC have placed more emphasis on inspecting EOLC provision, with a thematic review examining variation across acute, community and independent hospices.[4] One incentive to achieve good practice locally is the Commissioning for Quality and Innovation (CQUINs) system, introduced in 2009, which makes a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of care, including EOL.[11]

Delivery of EOLC in England continues to evolve and develop. Guidance provided to STPs made specific mention of how EOLC services could be used to extend choice for patients and deliver efficiencies within the system. However, an audit by the End of Life Coalition[12] investigated the inclusion of EOLC within emerging STP planning. It showed that of the 44 existing STPs, 18 either made no mention of EOLC or articulated no specific actions.

Policy needs to provide a vision of what it wants to achieve along with a roadmap of how to get there. Contextual factors pertaining to the structure of health services are integral to the successful delivery of policy, and policy therefore should not be considered without reference to structural mechanisms. Since 1999, rules determining service provision have taken on unique characteristics across the four devolved nations. The current study is focussed on EOLC in England.

Method

In-depth qualitative interviews[13] were conducted between 1 June 2018 and 1 October 2018, with ethics permission from the University of Kent. A list of key experts was drawn from those involved in the national consultation around the 'Ambitions for Palliative and End of Life Care',[1] a document produced by a collaboration of 27 different organizations. Additional respondents were contacted on the recommendation of those being interviewed (snowball sampling). Informed written consent was sought from all participants.

Semi-structured interview guides and a series of verbal prompts were developed. Flexibility around wording was deemed important to explore different areas depending on the context and experience of each interviewee.[13] The interview method drew on an approach influenced by Critical Realism,[14] demanding a level of active engagement and discussion between respondent and interviewer. Relevant literature and recent EOLC relevant policy were used in the subsequent analysis to review interview data against social contexts, constraints and resources.

Interviews were audio-recorded and transcribed verbatim. All data was imported into the software programme NVivo which allows for full text reviewing both of interview data and field notes. Once the data was coded into themes and concepts by the primary author, these were discussed and reviewed by the co-authors. Visual maps and tools, such as logic models, were used to help visualize links between the various factors and processes involved (context, mechanism, agency, inputs, outputs, outcomes).

Results

Thirty prospective interviewees were approached, and ultimately 15 interviewed (Table 1). Those interviewed included professionals working for statutory organizations, charitable and voluntary organizations, and clinicians. Many of the interviewees had a clinical background but were now working in a policy role. In this scoping study we describe the role of each of the interviewees quoted below, but to protect their privacy the first interviewee is referred to as “SS1”, the second “SS2”, etc.

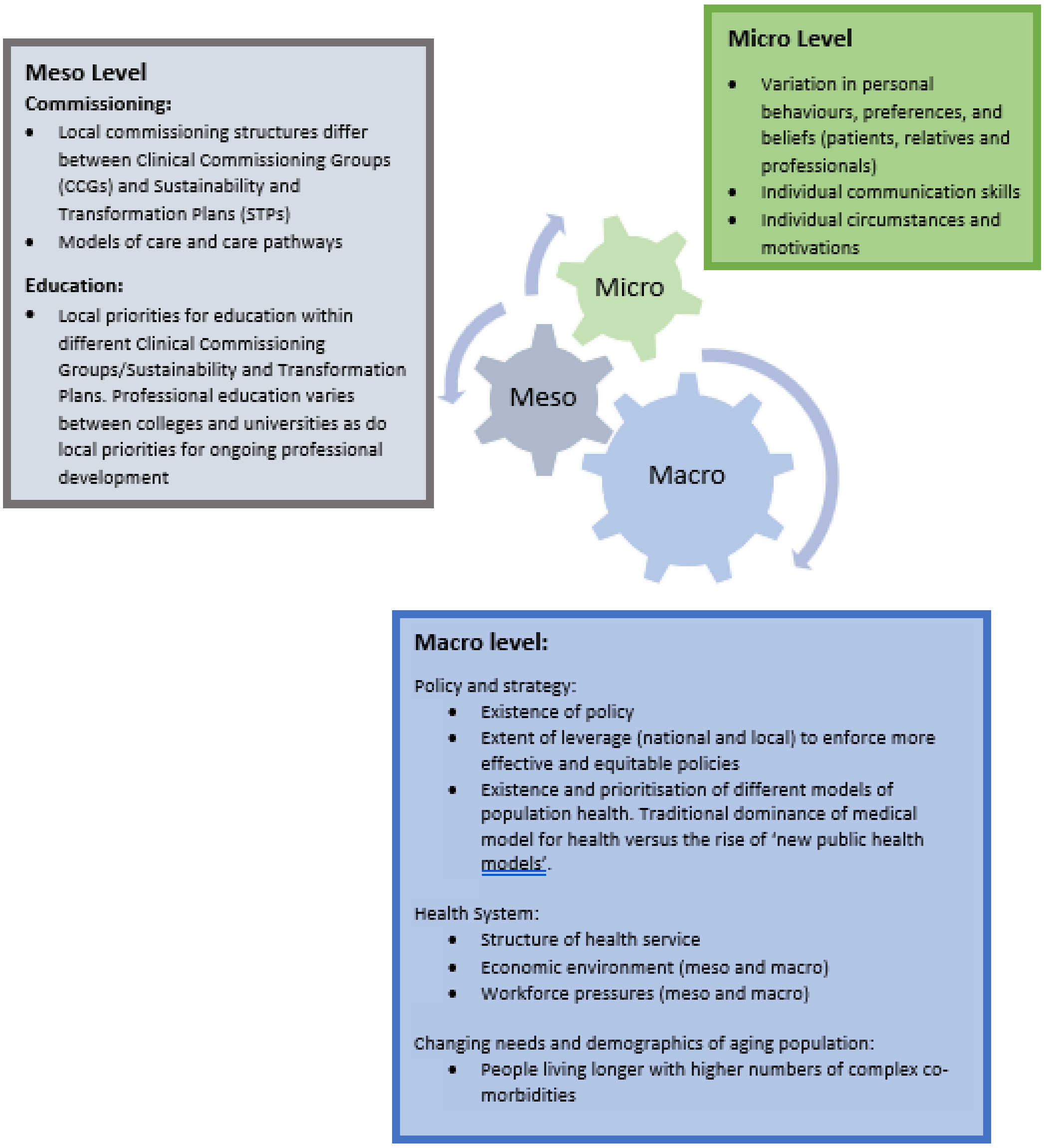
Table 1 : Scoping Study Interview contact sheet

Total numbers contacted with request to interview	30
Non- response after 2 follow up emails	8
Responded to say they were not the most appropriate person or had moved to different roles	7
Final number of interviews conducted	15

Key themes arising

For the purposes of this contextual overview, determinants and challenges relating to achieving more consistent outcomes in EOLC are stratified by the level of the system where the determinant is located. Figure 1 represents a summary of the various interacting factors which emerge from the scoping interviews. The items listed do not exist in isolation but interact with each other both within and between system levels. This paper will consider only macro-level determinants.

Figure 1: System level factors affecting the delivery of End of Life Care



Meso Level

Commissioning:

- Local commissioning structures differ between Clinical Commissioning Groups (CCGs) and Sustainability and Transformation Plans (STPs)
- Models of care and care pathways

Education:

- Local priorities for education within different Clinical Commissioning Groups/Sustainability and Transformation Plans. Professional education varies between colleges and universities as do local priorities for ongoing professional development

Micro Level

- Variation in personal behaviours, preferences, and beliefs (patients, relatives and professionals)
- Individual communication skills
- Individual circumstances and motivations

Macro level:

Policy and strategy:

- Existence of policy
- Extent of leverage (national and local) to enforce more effective and equitable policies
- Existence and prioritisation of different models of population health. Traditional dominance of medical model for health versus the rise of 'new public health models'.

Health System:

- Structure of health service
- Economic environment (meso and macro)
- Workforce pressures (meso and macro)

Changing needs and demographics of aging population:

- People living longer with higher numbers of complex co-morbidities

Is English EOLC policy effective in tackling inequities?

The term 'policy' was interpreted by interviewees in different ways. Whilst there was an expectation that policy was generally accompanied by a national mandate, the extent to which this was the case in England was questioned. In the main it appeared that English EOLC policy, following decentralization of budgets in the Health and Social Care Act, was seen more as an attempt to offer guidance, through the sharing of good practice, rather than something enforced through mandatory powers.

Interviews suggested that the latest guidance, 'Ambitions for Palliative and End of Life Care',[1] was broadly welcomed as a successful attempt to bring a number of policy reports together and unite stakeholders in a common direction. The 27 organizations involved in the development of the Ambitions report were seen to play an active part in shaping content. Policy and strategy documents were seen as providing a best-practice template against which gaps in provision could be identified. Whilst respondents acknowledged the huge variability in the way commissioning was undertaken, most were confident that national EOL policy, in the form of the 'Ambitions Framework',[1] was used as a reference tool to help identify gaps and future service plans. Examples were cited of how the document had been used to address inequalities in provision in a range of different settings, including for example custodial settings which had culminated in the launch of a 'dying well in custody' charter. In addition, several respondents had been directly involved in drawing up local plans which were inspired and guided by national policy:

> Our local hospital strategy is written with national policy and guidance very much in mind. For instance, in a number of policy documents there is reference to a '7-day palliative care service' being available – we have successfully persuaded our trust to partner with Macmillan to extend our palliative care service and offer it 24/7. I don't think we'd have been able to achieve this without being able to refer to national guidance. (SS3, clinician)

> I've seen it [national policy] used at CCG level - the whole local economy comes together to look at the framework and use self-assessment tools to identify gaps and then they challenge each other to see what can be done to become more 'compliant' with policy and ensure that they aren't just putting on a sticking plaster - but really building best practice. (SSI, policy/strategy role and clinician)

The intention, in proposing a set of ambitions, is that an aspirational benchmark is set against which inequalities in provision can be monitored and tackled. This was felt to be particularly important in working to increase equity for the treatment of different conditions – for example, whilst cancer has traditionally had a disease trajectory which makes it easier to recognize and plan for, there was recognition that one result of this was that a range of other conditions had not received commensurate funding and resource. Moreover, national strategy was seen to be influential in the way that CQC set the standards against which inspections are carried out: 'CQC look to national policy and guidance to inform the way they inspect and what they're inspecting.' (SS3, clinician).

However, whilst examples of good practice were identified, some respondents worried that despite efforts to consolidate policy, the number of documents in circulation continue to confuse and, although rhetoric is strong, there remains a chasm between policy and practice:

> The big issue is how to translate the policy into practice across CCGs where there is so much inequity.…Many policies are directed at people already working in EOLC and not enough at the need for cultural change and shifts in medical practice – we need to involve other professional and non-professional groups. EOLC must become everyone's business. *(*SS11*,* policy/strategy role*)*

Respondents also regarded a number of structural considerations as obstructing policy. These are now presented.

Statutory leverage to influence good practice

Respondents said that the fact there is currently little mandatory leverage to improve areas of poor practice contributed to the rise of localism characterized by patchy provision across the country. Respondents said this been accentuated since the 2012 Health and Social Care Act[8] took away central control for EOLC and devolved more powers and budgets to CCGs:

> Palliative and end of life care is a local statutory responsibility of CCGs. It's locally determined. This is challenging…because what we see is huge local variation. You can use levers such as CQUINs and Improvement and Assessment Frameworks – we try to encourage these to give end of life the clout it needs (SS2, policy/strategy role)

Whilst respondents acknowledged that the 'Five Year Forward View'[15] flagged the importance of EOLC, it was not seen to be given equal status to other conditions for which there was a much clearer mandate:

> If you look at diabetes or atrial fibrillation or mental health – all these conditions are really clearly mandated for in the NHS – but not EOL…I believe there needs to be stronger mandate for EOLC…it's utterly essential. (SS6, clinician and commissioner)

The impact of ongoing structural change on statutory services

The number of significant changes to the internal organization and workings of the NHS was mentioned in some capacity by most respondents and was seen to add delays to the pace of change:

> I think ultimately from an EOLC perspective STPs will be a positive influence. But at the moment, whilst CCGs are still battling to get their palliative care services in order and to improve quality, the extent of the workforce pressure means there is little time to look towards the forward STP vision. (SS1, policy/strategy role and clinician)

Significant power and control are vested in commissioners, who hold the budgets for service delivery, yet levels of education, time and support provided to services was reported as widely divergent between different CCGs. There was concern that given the piecemeal way services have built up over the years there is a lack of unitary oversight:

> Nothing is joined up and nothing is properly compared. If enormous amounts of money are invested, what are the outcomes? And how does it impact on tariffs?…We just keep on adding little bits here and there but there's not a significant strategic overview apart from at a very high finance level...The CCG commissioners, who often don't know very much about EOLC, are left to decipher how to implement complex multi morbidity services in EOL. There's no guidance as to how this will impact on front line staff or workforce capacity or effect outcomes. (SS6, clinician and commissioner)

Over-reliance on acute settings

There is growing evidence that EOLC could be more effectively managed in the community rather than acute sector (both from perspective of patient experience and cost).[16] This has heralded a move towards more integrated care plans, reflected in the 'Five Year Forward View',[15] and now being implemented through a combination of new models and care pathways, vanguards, and Accountable Care Organisations. As one respondent said:

> We've shifted too far towards acute...Waiting times and people stuck on ambulance trolleys outside A&E are a nice sexy topic in the media. It gets a lot of attention and funding – but nobody is really telling the story that those ambulances are there because there isn't enough nursing support in the community to be able to keep people from dialling 999 when things get bad. For people whose preference it is to use a hospital, that's fine, but what we understand from most people is that's not the case. (SS10 policy/strategy role, clinician and commissioner)

The way services have built up over the years has been influenced by a set of pervasive cultural/societal values, leading to the prioritization of one aspect of care over another and a tendency to value clinical interventions and acute services over community support. Amongst the respondents there was a clear narrative emerging that the acute sector must lose its predominant hold on EOLC and that a re-adjustment of resources is necessary.

Another perceived difference between care in acute and community centred on the notion of 'risk'. It was suggested that organizational capability to tolerate risk and uncertainty may impact on the ability of individual professionals to make informed choices in different settings.

> Improved discharge into the community needs to be tackled at a number of levels, not only in relation to boosting community skills and resource but also challenging some risk averse cultures which create an over-reliance on medical practitioners. (SS9, Clinician)

Workforce pressures

Workforce pressures, compounded by rising demand and tightening budgets, were highlighted as a significant challenge, particularly in the community:

> There is a massive crisis ahead which everyone is closing their eyes to. Recruiting in the South East, for example, post Brexit, is a nightmare. It will become close to impossible to recruit nurses and HCAs [healthcare assistants] - but people haven't yet woken up to the problem. I'd like to do a big piece of work looking at workforce needs. (SS8, policy/strategy role)

Respondents regarded the lack of integrated planning across different sections of the work force as a further obstacle to good practice. Notably, the fact that carers were employed by social care, rather than health, meant that although health and social care professionals need to work together to provide integrated care for patients at the EOL, this was not reflected in workforce management and planning.

Models of population health - medical model versus 'new public health models'

Respondents were committed to a re-education both of professionals and the public, to spread awareness that a broader responsibility needed to be taken for EOLC. The numbers dying annually are too large to be dealt with effectively by a relatively small, specialized workforce:

> Everyone, across different professions, must take responsibility for EOLC and share responsibility for identifying those at the EOL...It needs to be everyone's responsibility. (SS5, policy/strategy role)

Indeed, one respondent said EOL commissioners need to pay attention to more than just palliative services:

> Good EOLC requires not only palliative care. It requires, drugs, district nursing, social care, equipment etc. So, commissioners are wrong to think that palliative care is the only thing they have to worry about - it requires a myriad of things. And those things that contribute to a better experience at EOL are the responsibility of a number of different commissioners. (SS10, policy/strategy role, clinician and commissioner)

Two clinicians referred to the impact they felt traditional models of medicine and treatment had on the way others perceived their work. One said that their role in improving the experience of EOL is relatively undervalued: 'I see what I do in palliative medicine to be as important as what an oncologist does in cancer or what a surgeon might do.' (SS3, Clinician)

Discussion

Respondents in the scoping study were unanimous in their view that EOLC in the UK, when it is working at its best, is second to none. The model of palliative care practised in hospices across the UK is recognized by the Economist Intelligence Unit[5] as ranking higher than 80 other nations. Yet significant challenges remain, particularly in relation to consistency of provision. Hospice care is highly acclaimed and creative models for accessing more patients in the community are being embedded – demonstrated by Hospice UK, which suggests that more than 200,000 people with terminal and life-limiting conditions in the UK are treated by hospices each year.[17] Nonetheless, respondents in this study questioned the sustainability of current provision.

It is estimated that 92,000 people per year in England, Wales and Northern Ireland have unmet palliative care needs and national data shows that less than 6 percent of the population die in a hospice in England.[18,19] The sense of fragmentation and the way services have built up piecemeal over the years has meant that comparing the cost effectiveness of services across different sectors has not been undertaken. Instead, there has been a tendency to accept and replicate historical patterns of commissioning. This is compounded by the unusual situation in healthcare whereby a significant contribution to service provision is made by third sector (mostly charitable) organizations, each with their own governance and agendas.

Respondents remarked upon the rise of localism, especially since the Health and Social Care Act of 2012, along with the need for more support and standardization for commissioning. Moreover, the impact of different value systems and norms of behaviour within different professional groups and settings was evident in the interviews. EOL policy, whilst viewed as important, was just one of several determinants that must be considered as part of a complex and interconnected whole.

Another factor at play is that the NHS, due to protocols built up over the years to protect patients and professionals, may be more risk-averse than other settings and lacks flexibility to make choices which may be in the best interests of patients. Managing uncertainty at the EOL was also cited as problematic, and professionals need more support to manage this, particularly with the move to enable more care in community settings.

Although policy cannot be considered as an isolated factor, there are aspects which can be unpicked and scrutinized. Policy, we suggest, must not only be aspirational but should also provide guidance and support in achieving the goals laid out. The policy document 'Ambitions for Palliative cCare'[1] attempts to do this by not only defining six ambitions but by supporting these with a series of building blocks that it recommends need to be in place if the ambitions are to be achieved. These include: the know-how in terms of models of care; workforce skills and capacity; measuring systems; and appropriate systems infrastructure. In line with this, there was strong support for the move towards more integrated care and, in particular, a shift in resources away from hospital to community, edging perhaps towards greater sharing of responsibility between professionals and civilians.

A major challenge for national policy is the rising local inequities in the way care is provided. This was highlighted by many respondents and backed starkly by recent national data presented in the 'Atlas of Variations in End of Life Care'.[20] One solution, given a finite budget and ever-growing demand, may be to harness the lay community. That is, a policy of building 'compassionate communities' and developing skills and engagement amongst non-professional groups. The new public health movement has embraced a growing partnership between citizens and professionals, acknowledging that better social networks and an individual's greater connectedness to the community confers better health.[21]

Responsibility for EOL may have shifted too far into the medical domain and respondents suggested that there should now be a rebalancing towards a broader, shared responsibility between a range of professionals and civilians.[22] Recent evaluations of programmes based around such principles remind us of both opportunities and challenges. While it has been demonstrated that social networks can play an important role in promoting wellbeing at the EOL,[23] policies designed to 'empower citizens' such as the Expert Patient Programme have been shown to increase inequalities, as they tend to cater for a predominantly white, middle-class population.[24]

Limitation of the study

The method by which we recruited study respondents, primarily involving individuals who played a pivotal role in formulating national strategy, will have created bias favouring those more likely to advocate the intrinsic value of policy in relation to improving practice. That said, the interview data was reinforced by many of the key themes emerging from the literature. The data reiterates the complexity involved in exploring the value of national policy and its influence in helping develop local systems, which may lead to the more consistent and effective provision of local EOLC services.

Conclusion

Ivan Illich, a Catholic priest and social commentator, laid down a challenge to the rise of medical technology in the 1970s.[25] His hypothesis, as controversial then as it is now, was that modern medicine has gone too far, staging an omniscient battle to eradicate death, pain and sickness, and in doing so turning people into consumers or objects of its treatment and care, rather than active purveyors of their own health. Whilst it is hard to imagine a scenario where acute care environments will not continue to be a valid and welcome setting for many at the EOL, strategy and policy is increasingly shifting to embrace a new understanding that, as we live longer - often with a number of different health conditions, we have to take more responsibility for our own care and the care of others in our community.

The findings presented here suggest that not only will policy continue to play an important role in shaping the direction of future EOL services, but it may be increasingly influenced by the voices of commentators advocating new models for a more compassionate and community focussed public health system.[26,27] The challenge will be to ensure that this ameliorates EOLC inequities.

Conflict of interest

The authors declare no conflict of interest.

Funding

Funding for this work was provided by The Centre for Health Service Studies, University of Kent, in the form of a PhD scholarship.

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