

Hospice UK responds to Health Education England's Strategic Framework Call for Evidence 2021

On 6 September 2021, Hospice UK responded to Health Education England's call for evidence to support the development of a long-term strategic framework for health and social care workforce planning, which will replace [Framework 15](#).

Stakeholders were asked to identify factors that would drive workforce demand and supply over the long-term within six overarching drivers of change categories. These categories are:

- Demographics and Disease
- Public, People who need care and support, Patient and Carer Expectations
- Socio-economic and Environmental Factors
- Staff and Student/Trainee Expectations
- Science, Digital, Data and Technology (including Genomics)
- Service Models and Pandemic Recovery

Outlined below are 17 factors within these drivers of change categories identified by Hospice UK and set out in the organisation's consultation response.

Demographics and Disease

Increasing population

An increasing population in England, and across the UK is driving increased demand for palliative and end of life care that will need to be met by a larger and more skilled workforce. The ONS has projected that the UK population will increase by 3 million between 2018 and 2028 to 69.4 million. More people are also dying year on year, with mortality expected to rise to nearly 800,000 by 2040. The IPPR has identified that, on current projections, more people will die in 2031 than in the 2020, despite the rise in deaths related to the COVID-19 pandemic.

This trend is extremely concerning given the existing workforce shortages within palliative and end of life care and the challenges in recruitment, retention and retirement. In the hospice sector alone, there is an anecdotal and increasing average 11% vacancy rate. With 160,000 expected to require palliative care by 2040, sufficient staff and volunteer resourcing within the specialist palliative care field, including the hospice sector, is essential. However, this increase in demand cannot be met by specialists alone. All health and care workers across the system need to be confident in, and capable of, delivering end of life and palliative care. More integrated ways of planning and delivering palliative and end of life care across the workforce are necessary to achieve this and maximise the scarce specialist resource available.

Ageing population with more complex needs

By 2035, over 65s will represent a quarter of the population and almost half of all deaths will take place among those over the age of 85. England's ageing and increasing population will demand a larger workforce but, crucially, it will also increase the complexity of palliative care required. This increased complexity in care will create a demand for new skills in both the specialist and generalised workforce.

People with life-limiting and chronic conditions, including children, are living longer. As a result, hospices and other palliative care professionals will need to be equipped to manage more complex care over a longer period of time. It will also be essential to facilitate partnership working across the health and social care sector, where hospices and other palliative care specialists can share their expertise with generalists working in hospitals, care homes, General practice, private homes and other settings.

The non-specialist workforce will require the right skillset to provide palliative and end of life care for patients with less complex needs, increasing the time specialists have to manage more complex cases. To achieve this, HEE needs to support the specialist palliative care workforce to train and support the wider workforce in delivering high quality, personalised and coordinated end of life and palliative care. There are existing sources of education that can be nurtured, such as training hospices provide for their own staff and staff in other settings, as well as the Gold Standards Framework, which offers quality training in end of life care for generalist frontline staff.

Ageing workforce

An increasing challenge for the delivery of palliative and end of life care is its ageing workforce. Data released in 2014 found that approximately 44% of specialist palliative care nurses are over the age of 50. Hospice UK has also recently collected data on the workforce within hospices and found that over 50% are over the age of 50. Unfortunately, this data has not yet been processed but, once it is finalised, Hospice UK would be delighted to share this with Health Education England and discuss what the findings reveal about workforce planning priorities for palliative and end of life care.

Hospice UK expects to see a reduction in the palliative and end of life care workforce over the next decade due to the retirement of this aging workforce. The hospice sector specifically is traditionally slow to respond to more flexible working and therefore loses younger and more ambitious talent. Therefore, there is a clear need to attract staff to hospices earlier in their careers and retain them within the specialism.

Key to this is a more dynamic approach to workforce planning that allows for flexible patterns of work across the entire health and social care system. Staff need to be offered a clear career framework that includes palliative care roles drawn from the full spectrum of providers. Flexible ways of working would also help retain older members of the workforce, and their expertise, within palliative and end of life care by providing them with options for less demanding roles within the sector. The diversity of roles within palliative and end of life care makes it well placed to offer alternative roles for older members of staff or volunteers.

Hospices also need to be supported to access the opportunities available to host placements and train staff. Many hospices do not have the infrastructure to arrange for student placements or make the most of CPD funding or the apprenticeship levy. Support from HEE will be required to enable hospices, either individually or in partnership, to apply for these opportunities.

Impact of the pandemic on health

Research by Age UK found that the pandemic has made it harder for older people to look after their physical health due to reduced opportunities for physical activity and delays in accessing healthcare and treatment. For some, COVID-19 has also exacerbated existing symptoms and problems related to long-term conditions. An increase in the frailty of people with life limiting conditions and their difficulty managing their condition, will increase the workload for those managing their palliative and end of life care. The pandemic has also led to a significant shift towards care being delivered in the community, placing new demands on district nurses, care home staff and hospice at home services.

The disruption to cancer screenings and routine appointments, as well as a reluctance from the public to attend appointments with their GP, due to the pandemic have resulted in an estimated 50,000 missed cancer diagnoses. Hospices are now finding that the number of patients with late stage cancer, requiring more complex care, has increased. This is placing further demands on the specialist workforce and their time and expertise. New ways of working to personalise care will also be required to address this increased complexity.

Hospices are informing us that, since the pandemic, people in need of palliative and end of life care are being referred to specialist services at a much later stage. As a result, the benefits hospices can offer for patients are limited because their workforce is immediately thrust into managing periods of crisis, where patients have more intense palliative care needs, and loses the time to plan personalised care pathways.

Public, People who need care and support, Patient and Carer Expectations

Expectation that palliative care will be provided across all settings

The National Palliative and End of Life Care Partnership, of which both Hospice UK and Health Education England are members, set out six ambitions for Palliative and End of Life Care in 2021. One of these six ambitions is that each person gets fair access to care regardless of who they are, where they are or the circumstances of their life. However, good end of life care is not available across all settings. As set out above, more and more people are dying at home or in care homes, placing pressure on community services and driving a demand for more workers with the ability to manage end of life and palliative care needs in these settings.

Non-specialist workforce based in non-medical settings, such as prisons or homeless hostels, often lack the skills to provide high-quality palliative care. External specialists can also lack expertise in how to care for groups who are typically excluded from quality end of life and palliative care. For example, inequality of access for people in prison is particularly acute. A recent report by Hospice UK identified many challenges in prison settings, including care that did not make use of the skills and specialisms available from the health and social care sector.

Future workforce planning needs to support and encourage knowledge sharing between palliative care specialists, such as hospices, and the workforce in other settings expected to provide palliative and end life care as well as encourage partnership working between multiple multi-disciplinary agencies to combat inequalities in access. Partnership working will require palliative and end of life care specialists to develop new skills in cross-sector collaboration. However, this will improve access to care and, in the long run, reduce staffing pressures as improved knowledge sharing will enable workers in non-medical settings to respond to straightforward needs without specialist resource. London Ambulance Service's work with St Christopher's Community Nursing Team to ensure they provide dignified, compassionate and respectful end of life care is a great example of successful knowledge sharing.

Expectation that patients will be involved in their care

Increasingly, there is an expectation among specialist palliative care professionals and patients that people should be actively involved in their own care. It is essential that, across the palliative and end of life care sector, efforts are made to engage people receiving care in conversations about their own care and make sure that their voices are heard. Involving patients in their own care will help them to make informed decisions and ensure that their personal needs and wishes are met. One of the key outcomes of HEE's health and social care workforce planning should be that those receiving care are empowered to advocate for what kind of care they would like to receive.

Socio-economic and Environmental Factors

Inequalities in access to palliative and end of life care

It is vital that every person has equal access to palliative and end of life care regardless of who they are, where they live or the circumstances of their life. However, as many as 1 in 4 people, who could benefit from palliative and end of life care, do not receive it. This is not unacceptable and Hospice UK is actively working to tackle inequalities in access to care.

An extensive literature search by Hospice UK has found persistent inequalities in hospice care provision, which are particularly prevalent for people without cancer, the oldest old, racialised communities and those living in rural or deprived areas. In order to tackle persistent inequalities, access to specialist palliative care must be improved and the generalist workforce (across all settings) be equipped with the skills to manage straightforward palliative and end

of life care needs. Everyone across the health and social care workforce must be confident in delivering care.

Education programmes must equip staff with the ability to provide care and support to all irrespective of age, gender, ethnicity and condition, including patients with learning disabilities and autism. Key to this is tackling the barriers of identification and communication. Currently, the generalist workforce is not equipped to identify when someone might be approaching end of life, particularly if they are from a group often excluded from care. This non-specialist workforce also lacks the confidence and skillset to speak about death with their patients and adapt their terminology to better communicate with people from different backgrounds to them.

Local and place-based planning must prioritise equality of access and include all relevant stakeholders, including voluntary sector providers. New ways of working and new roles will also be needed to improve equality of access to palliative and end of life care. For example, The Prince and Princess of Wales Hospice in Glasgow has increased its volunteers and referrals from ethnic minority communities through the introduction of a dedicated Cultural Liaison Officer. St Luke's Hospice in South Yorkshire has also employed an Engagement and Quality Officer who, through actively engaging with the South Asian population of Sheffield, has doubled the number of patients the hospice has from this group. Digital solutions fostered in response to the COVID-19 pandemic, such as the UK's first virtual children's hospice established by Children's Hospices Across Scotland, can also be used to increase access to care, particularly for those in remote and rural areas. However, they do risk exacerbating existing inequalities when people lack the equipment, resources or IT skills to engage with them. To combat its lack of access to specialist palliative care consultants, one hospice in rural Scotland is accessing consultant support remotely.

The fragile nature of funding for end of life care

The COVID-19 pandemic has exposed the fragile nature of funding for end of life care, which is currently delivered by a patchwork of providers and funded by a mixture of public, private and charitable sources. High quality end of life care must be available for all but currently there is significant unmet need, especially for marginalised groups.

On average, hospices rely on donations for two thirds of their income. In 2020, the COVID-19 pandemic prompted a funding crisis in the hospice sector due to a lack of donations, threatening the sustainability of essential end of life and palliative care. Without support from the UK Government, English hospices would have struggled to survive.

This funding crisis has created uncertainty in the sector and harmed hospices' ability to plan for the longer-term. In order to provide specialist support to other organisations across the health and social care landscape, and work collaboratively to support the system's recovery from COVID-19, hospices will need financial support to grow to better support generalists across the sector.

Shifts in end of life care settings

Both Government and Hospice UK share an ambition to facilitate a shift towards community-led, integrated and person-centred care where more people are able to die where they want. Surveys indicate that around 80% of people would prefer to die at home or at their place of residence. It is expected that deaths in hospices, care homes and private homes will increase substantially, accounting for 76% of all deaths. This shift towards dying at home will place new demands on the health and social care workforce in the community.

In 2020/2021, pressure on hospitals to free up beds for COVID patients led to a rapid increase in people dying in private homes and in care homes. However, we have very little information regarding the quality of these deaths and whether people who died in care homes and private homes received good end of life care. Qualitative research by the Institute for Public Policy Research found that ‘the lack of preparation for a shift of end of life care to social, community and home settings made it hard for care quality to be maintained, and to significant stress amongst workers and carers’. The think-tank argues that the strain on the health and care system caused by the pandemic cannot become ‘business as usual’.

In order to provide the infrastructure for shifts in people’s place of death, HEE needs to plan for and support integrated care provided in the community and coordinated by multiple agencies. Hospice at home services will need many more carers and planning will need to ensure there is an effective mix of skills within palliative and end of life care, consisting of both unregistered and registered workforce. Furthermore, Hospices, and their varied workforce, need to be seen and valued as equal partners within this system with a unique offering and expertise. As previously mentioned, specialist palliative care staff, including those based in hospices, can train and support the wider workforce. For example, there is a clear role for specialists to train and support the workforce within care homes to manage palliative and end of life care needs.

Staff and Student/Trainee Expectations

Career development and flexible working expectations

There is a current shift in the expectations of those entering the palliative and end of life care workforce, who are now looking for a wide range of experience across different settings, rather than a place of work for life. Typically, hospices have been slow to respond to more flexible working as they are used to staff and volunteers staying in their roles for longer periods. As a result, the hospice sector is missing out on new talent as the workforce within palliative and end of life care ages and the number of deaths per year increase. A lack of opportunities for career progression within hospices mean that the average length of service is just under six years.

Future workforce planning needs to create a more flexible pattern of work across the health and social care system, which allows people to move across providers, including hospices. This should include increased opportunities and support for hospices to expand their placement capacity and make better use of apprenticeships, for example by supporting smaller hospices to collaborate on an application for the apprenticeship levy.

A 2020 review by the King's Fund investigated how to transform the workplaces of nurses and midwives to ensure they thrive and flourish and are better able to provide compassionate and high-quality care. Included within the King's Fund framework for nurses' and midwives' core needs was 'flexible, high-quality development opportunities that promote continuing growth and development'. Mentorship is key to retaining workers within palliative and end of life care, as well as support for the wellbeing of staff.

A key concern for the hospice sector is a lack of access to the mechanisms and resources available to NHS staff. Equity in access to CPD training and other opportunities is vital for hospices to retain and attract staff. Volunteers also contribute approximately £200 million to hospices per annum and need good access to training and educational resources and support, equal to NHS staff. This training must be available to volunteers but also accessible with regards to timing, location and cost. Volunteer roles in the hospice sector include both clinical and broader roles and the skilled work undertaken by much of the volunteer workforce should be recognised.

Hospice UK would like to emphasise how important it is that HEE consider the entire health and care workforce within its strategic framework, recognising the contribution of both volunteers and family carers.

Changes in palliative care training

From 2022, the implementation of the Shape of Training dual accreditation (internal medicine and palliative medicine) will be mandatory. This dual accreditation with rotations in both general medical and palliative care means that less people will be working in palliative care at any one time, two trainees will be required per post and trainees will take longer to qualify. This is likely to exacerbate existing staff shortages within hospices and palliative and end of life care more broadly.

Equality, diversity and inclusion in the workforce

There is a need to ensure that the palliative and end of life care workforce is inclusive and represents societal diversity. Diversity in the workforce will increase access to care for typically excluded groups. Hospice UK's recent report 'Equality in hospice and end of life care: challenges and change' highlights the importance of a diverse workforce supported by an

inclusive workplace to support the care of increasing diverse populations and enable people to reach their full potential.

Examples of work to increase the diversity of staff within the hospice sector include Hospice of St Francis' radical review of its approach to recruitment, which included changing the job profile requirements for all posts. Efforts to improve diversity should apply as much to leadership positions as frontline roles and support from HEE will be necessary to encourage hospices and other settings to increase the diversity of their entire workforce. Education programmes for end of life and palliative care must also take into account different cultural and linguistically diverse needs to improve the diversity of the sector.

Disparity in terms and conditions across voluntary sector and NHS

Current disparity in terms and conditions of employment between the palliative and end of life care providers in the voluntary sector and the NHS mean that hospices and other charities in this space are struggling to attract and retain high quality staff. For example, non-NHS providers, including hospices, are unable to match the recently announced 3% pay rise for NHS staff, placing them at a disadvantage.

Without a commitment to support the voluntary sector to match NHS terms and conditions, there will be a shortage of staff within voluntary organisations that support and provide expertise to the NHS. An integrated health and care system will require a skilled workforce across both NHS and non-NHS settings.

Service Models and Pandemic Recovery

Post-pandemic workforce recovery

A multinational study of palliative and hospice services and the challenges they faced during the COVID-19 pandemic found that 40% of services experienced staff shortages. Our hospice members also tell us that they have lost much of their volunteer workforce as a result of COVID-19. Hospice UK is also concerned about burn out among health and care workers, due to the COVID-19 pandemic, and a resulting lack of long-term resilience amongst the workforce. The pressure of the last 18 months is likely to lead to many health and social care workers retiring early due to exhaustion, exacerbating existing staffing shortages.

The high level of excess deaths associated with the pandemic also means frontline staff are in need of more bereavement support than ever before. Line managers will need to be trained to identify when a staff member or volunteer requires mental health support and signpost them to support services such as Hospice UK's 24/7 Just 'B' helpline, which offers emotional wellbeing, bereavement and trauma support nationally to NHS, care sector staff and emergency service workers.

Hospice UK would like to encourage HEE to consider the broad spectrum of the workforce across the health and care sector in its future planning, for example, it should consider the decline in the physical and mental health of carers who have been supporting their family members during the course of the pandemic and the impact this decline will have on the sector's workforce as a whole.

Increase in integrated working

Providers across the health and care system are developing and promoting integrated systems that can deliver personalised care focused on the individual. In order to achieve this, the entire health and care workforce needs to be skilled in managing basic palliative and end of life care and specialists must be available to support and train generalists as well as provide care to patients with more complex needs.

Primary and secondary care must be able to access specialist palliative care, whether this is provided in a hospice or hospital, in order to work in an integrated way. An integrated approach could be as simple as ensuring generalist care home staff are able to call a palliative care consultant or nurse for advice and support. An advanced integrated system might employ methods like arranging for nurses and other allied health professionals to complete a training rotation in palliative care services.

Increase in digital delivery due to the pandemic

Many hospices moved a number of services online to ensure their service-users could access support remotely. For example, Children's Hospices across Scotland launched the UK's first virtual children's hospice. Online services allow hospices and other palliative and end of life care providers to reach many more patients based in remote or rural areas and can make efficient use of limited workforce resource. However, as outlined earlier, there is a risk of exacerbating existing inequalities by assuming patients have both the equipment and the skills to participate in online services. Importantly, there has been no assessment of the success of online programmes rolled out during the pandemic compared to in-person services. It is important that the health and care sector evaluate these programmes and listen and respond to what patients want from future services.

Technological innovation can also maximise the impact of the scarce specialist palliative care workforce. For example, the EnComPaSS (Enhanced Community Palliative Support Services) project in Sheffield, allowed one senior nurse or doctor to monitor multiple patients in their own homes from a remote setting and provide direction to St Luke's Community Nurses working in the patient's home.

Hospice UK's Project ECHO is a good example of how technology can improve knowledge sharing. Project ECHO uses videoconferencing technology to create virtual knowledge sharing networks across the health and social care system. Project ECHO has been a real

asset to hospices, allowing them to share solutions to both financial and clinical challenges brought on by the COVID-19 pandemic. In order to facilitate further knowledge sharing and training in palliative and end of life care, digital capability needs to be built into palliative and end of life education programmes. The digital framework for the NHS also needs to be extended to the voluntary sector and include the entire workforce across the health and care system, including volunteers.

Demand for bereavement support due to the pandemic

The significant increase in deaths related to COVID-19 has led to, and will continue to lead to, larger numbers of people becoming bereaved. As outlined above, there will also be a greater need for bereavement support for the health and care workforce who have worked through the COVID-19 crisis and supported many COVID patients at end of life. As a result, a whole new workforce and infrastructure for bereavement support will be required.

Hospices have significant expertise in supporting the bereaved but they alone cannot meet the demand that has emerged as a result of the pandemic. Bereavement support needs to be considered at a commissioning level as otherwise it is simply viewed as auxiliary to existing roles and deprioritised.

Hospices' significant experience of providing holistic care to people with life limiting conditions and their families, including bereavement support, makes them well placed to offer specialist support and training on bereavement to others across the health and care workforce. Capacity and resilience also needs to be built within local communities.