

Written evidence submitted by Hospice UK (EPW0053)

Hospice UK is the national charity for hospice and end of life care. We work to ensure everyone affected by death, dying and bereavement gets the care and support they need, when they need it. Hospice UK is informed and guided by its membership of over 200 hospices across the UK. For this reason, we have unique insight into the experiences of, and workforce challenges facing, independent and charitable health and social care providers.

The key themes within this submission to the Health and Social Care Committee Expert Panel are:

- **The significant projected increase in the number of deaths that require palliative and end of life care.** In the UK, around 600,000 people die every year on average but by 2040 this number is expected to reach nearly 800,000.¹ More and more people are also set to die with complex palliative care needs in the coming years due to the UK's ageing population and the increasing number of people living with more than one chronic condition.
- **The surge in deaths in people's own homes since the beginning of the pandemic.** There have been over 100,000 additional deaths at home since the beginning of the pandemic, compared to long term rates, marking an acceleration in the long-term trend towards more people dying at home. Over 80% of hospice care is delivered in the community but this is not enough to meet the scale of care required.
- **The diversity of providers that support people at end of life.** Palliative and end of life care is delivered by a patchwork of different providers, including those in the independent, charitable and private sectors. In addition to clinical staff in hospices and other settings, there were an estimated 1.54 million people working in adult social care in 2020/2021² and 13.6 million unpaid carers at the height of the pandemic, many of whom will be supporting people with life limiting illnesses.³
- **The trauma and grief experienced by both the generalist and specialist palliative care workforce during the pandemic,** which have witnessed more death than ever before. Many generalist health and care staff have also had to support people at end of life with very little palliative care training.
- **The impact of the recent Government Health and Care Act⁴ and Integration White Paper⁵,** which both rightly emphasise the importance of the integration of services. The Health and Care Act also contains a requirement for Integrated Care Boards to commission palliative care services to meet local population need, for which the workforce will need to be sufficiently resourced and skilled to deliver.
- **Specific national policies that impact the hospice sector and its workforce,** such as the lack of a sustainable funding solution for the hospice sector, the sector's struggle to match NHS pay scales and terms and conditions and its exclusion from NHS training and education opportunities.

Key recommendations we have made within this submission include that:

¹ Institute for Public Policy Research, [The state of end of life care: building back better after COVID-19](#), 2021

² Skills for Care, [The state of the adult social care sector and workforce in England](#), 2021

³ Carers UK, [Unpaid carers pushed to breaking point and may be forced to quit work, warns Carers UK as new figures reveal devastating impact of COVID-19](#) (Accessed May 2022), October 2021

⁴ [Health and Care Act 2022](#) (Accessed May 2022)

⁵ Department of Health and Social Care, [Health and social care integration: joining up care for people, places and populations](#) (Accessed May 2022), February 2022

- **Workforce commitments and policy apply across the health and care system**, rather than focus solely on staff within the NHS or social care.
- National and ICS level **strategic and long-term workforce planning takes place and that this accounts for, and responds to, the rapidly increasing need for palliative and end of life care.**
- The **entire health and social care workforce receive essential training in supporting people in their last years.**
- Government meet the **critical need for mental health and bereavement support** among the health and care workforce.
- Opportunities for **flexible career pathways and movement of health and care staff across the system are made available to the hospice sector.**
- Government support **hospices to access workforce development funding and opportunities to share their expertise** with system colleagues as well as ensure **parity of access to NHS training opportunities** for hospice staff and volunteers.

Hospice UK's responses to the questions in the Expert Panel's planning grid can be found below. For further information, or if you have any questions, please contact policy@hospiceuk.org.

Planning for the Workforce

Commitment: Ensure that the NHS and social care system have the nurses, midwives, doctors, carers and other health professionals that it needs.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

- *Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?*

The UK's rising and ageing population is expected to result in an increase in the number of deaths that will require palliative and end of life care and exacerbate existing workforce shortages. More people are dying year-on-year, with mortality expected to rise to nearly 800,000 by 2040.⁶ The number of people aged 85 and older is also expected increase from 1.6 million in 2016 (2% of the population) to 3.2 million in 2041 (4% of the population).⁷ As a result of this factor, many more deaths will require complex palliative and end of life care in the coming years.

With 160,000 more people each year expected to require palliative care by 2040, adequate staff and volunteer resourcing across both specialist and generalist palliative care is essential.⁸ However, without sufficient strategic

⁶ Institute for Public Policy Research, [The state of end of life care: building back better after COVID-19](#), April 2021

⁷ Office of National Statistics, [Living longer: how our population is changing and why it matters](#) (Accessed May 2022), August 2018

⁸ BMC Medicine, [At least 42 percent more people will need palliative care in England and Wales by 2040](#) (Accessed May 2020), May 2017

workforce planning to respond to this projected need, the commitment to ensure the health and care system has the health professionals it needs will not be met. Strategic and long-term workforce planning at both a national and ICS level, informed by population need assessments and a specific consideration of the unique factors impacting the palliative and end of life care workforce, is required to ensure people who are dying receive the support they need in the future.

Another factor specific to the palliative and end of life care sector, which is unaccounted for in these national targets, is the sector's ageing workforce. Data released in 2014 found that approximately 44% of specialist palliative care nurses are over the age of 50⁹ and Hospice UK's 2021 workforce survey found that 33% of the clinical workforce in hospices across the UK are aged 55 and over.¹⁰ In comparison, data from 2017 shows 17% of the NHS nursing workforce is aged over 55.¹¹ The retirement of this cohort will lead to further reductions in the palliative and end of life care workforce over the next decade, at a faster rate than other specialisms. Strategic planning that accounts for the much older palliative and end of life care workforce is required to ensure the sector has the health and care professionals it needs.

The 2022 Health and Care Act contains a landmark requirement for Integrated Care Boards to commission such services or facilities for palliative care (including specialist palliative care) as they consider appropriate for meeting the reasonable requirements of the people for whom they have responsibility.¹² This is a welcome recognition of the fundamental importance of palliative care, however, this decision comes with a responsibility to resource such care across the patchwork system of providers in the sector. Existing staffing targets are insufficient to meet this new requirement as well as the increased need for palliative and end of life care driven by our increasing and ageing population. This requirement for Integrated Care Systems to commission palliative care has only just been created in law but Hospice UK hopes to see planning at both a national and ICS-level to staff its implementation.

The 2022 Health and Care Act¹³ and the Government's recent Integration White Paper are both designed to drive collaboration between local services and encourage the sharing of skills and staff across the system to meet population need.¹⁴ However, national strategic policy that excludes hospices and other independent and charitable health and social care providers runs counter to these aims. For example, whilst NHS trusts report on their number of vacancies against the agreed staffing establishment, hospices are unable to report on the number of staff they need in the same way or access the Electronic Staff Record. As a result, Government and national institutions carry insufficient data on hospices and other charitable providers, which prevents effective workforce planning across the health and care system. Hospices are major providers of palliative and end of life care and therefore, without effective data on the services they provide and the characteristics of their patients, it is impossible to plan for the long-term delivery of palliative and end of life care at a national level.

- *To what extent has the Covid-19 response affected progress on targets?*

The COVID-19 pandemic response affected efforts to initiate the necessary long-term strategic planning outlined above. A long-term NHS People Plan and local system people plans were supposed to assess what future service provision should look like and, as a result, what the workforce requirements of services will be five to ten years

⁹ National Council for Palliative Care, [Specialist Palliative Care \(SPC\) Workforce Survey 2013](#) (Accessed May 2022), September 2014

¹⁰ Hospice UK, *Unpublished 2021 survey of clinical staff working in UK hospices, 2021*

¹¹ National Audit Office, [The NHS nursing workforce](#) (Accessed May 2022), March 2020

¹² [Health and Care Act 2022](#) (Accessed May 2022)

¹³ Ibid

¹⁴ Department of Health and Social Care, [Health and social care integration: joining up care for people, places and populations](#) (Accessed May 2022), February 2022

from now. However, pandemic-related pressures, in addition to the re-organisation of the health and care system at both a national and local level, resulted in a dearth of the long-term strategic planning necessary to ensure the health and care system has the professionals it needs. Long-term workforce plans at both a national and local level are yet to be developed.

COVID-19 has also placed significant demands on the time, workload and expertise of the specialist palliative care workforce. Disruption to cancer screenings and routine appointments, and a reluctance from the public to attend medical appointments due to the pandemic, have resulted in missed diagnoses and late referrals to specialist palliative care. Consequently, the number of patients referred to specialist services at a later stage in their condition, with more complex care needs, has increased. As a result, staff are often managing periods of crisis, where patients have more intense palliative care needs, placing further demands on their time, expertise and energy. COVID-19 has also exacerbated existing symptoms of those with life limiting illnesses, increasing their reliance on health and care staff.

The palliative and end of life care sector, including hospices, has also relied heavily on the generosity of volunteers in the past. However, during the pandemic, the sector lost a significant number of volunteers due to fear of infection and respect for the national directive to stay at home. Hospices tell us that much of this workforce has not returned.

The entirety of the health and care workforce has also witnessed a huge volume of death over the last two years. Hospice UK is concerned that, without sufficient bereavement and mental health support, the trauma of working in health and care during the pandemic will lead to many individuals retiring early or changing sector, decreasing the likelihood that staffing targets will be met.

- *Does data show achievement against the target (if applicable)?*

Workforce shortages within the palliative and end of life care sector, including hospices, have increased, rather than improved, since these commitments were made. In Spring 2021, Hospice UK ran a survey of clinical staff working in UK hospices and found a:

- 11% vacancy rate in community-based and 7% vacancy rate in hospice-based nursing roles in adult hospices (with 16% vacancy rates for hospice-based nursing associate and community-based healthcare assistant roles).
- 11% vacancy rate in community-based and 9% vacancy rate in hospice-based nursing roles in children's hospices.
- 7% vacancy rate for allied health professionals and other roles in adult hospices.
- 4% vacancy rate for allied health professionals and other roles in children's hospices.¹⁵

However, the above statistics are representative only of what hospices can afford within current funding rather than the level of staffing actually required to meet population need. Even with all vacancies filled hospices would not have enough staff to meet the growing population need. Furthermore, we expect that, were Hospice UK to re-run this survey today, only a year later, vacancy figures would be much higher, given anecdotal evidence of hospices closing beds and cutting services due to a shortage of clinical staff.

¹⁵ Hospice UK, *Unpublished 2021 survey of clinical staff working in UK hospices, 2021*

New research released in May 2022 and carried out by Together for Short Lives with children's hospices in England found that the average vacancy rate for nurses and other non-medical care and support professionals at the equivalent of NHS Agenda for Change bands 5-9 inclusive is now 18.6%.¹⁶

Evidence from the NHS and other system partners that deliver palliative and end of life care paints a similar picture. Recent analysis by the Kings Fund confirms that, whilst the Government is on track to increase the full-time equivalent number of nurses working in the NHS by 50,000 by March 2024, this supply is not meeting demand and is having no impact on the number of vacancies in the NHS.¹⁷ Skills for Care's data suggests that vacancy rates in the social care sector have been steadily climbing since April 2021 and, as of February 2022, the vacancy rate sits at 9.8%.¹⁸ A significant number of people supported by social care will have a life limiting illness or be within their last year of life.

Was the commitment effectively funded (or resourced)?

- *Were specific funding arrangements made to support the implementation of the commitment? If not, why? If so, what were these, when and where were they made?*

Over the course of the pandemic, NHS England and Improvement committed £338 million of funding to purchasing extra capacity from hospices in England. Hospice UK were tasked with rapidly distributing payments to hospices to ensure necessary funds could swiftly reach the frontline. This funding enabled hospices to provide support to their communities and system colleagues during the pandemic and prevent acute services from being overwhelmed. Many hospices would have also struggled to survive the pandemic and retain their workforce without this funding.

In April 2020, the Chancellor announced an initial commitment of up to £200 million for the hospice sector. This arrangement meant hospices in England would immediately make up to 80% of their pre-existing bed capacity (totalling 6,800 beds per day) and 60% of their community capacity (totalling 82,000 community contacts per day) available to provide care for people with complex needs. A further commitment of up to £125 million of funding until March 2021 was made in response to the second COVID-19 wave. In total, these commitments resulted in £255 million being paid to hospices in England until the third tranche of funding in December.

In December 2021 a further up to £100 million was announced for hospices in England for four more months (until the end of the financial year) to enable them to provide additional support to their communities over the winter and ensure acute services are not overwhelmed by the Omicron COVID-19 variant.

- *What factors were considered when funding arrangements were being determined?*

When arrangements were made to fund the hospice sector to deliver extra capacity for the NHS during the pandemic, the most significant factor was the urgent need for extra capacity to facilitate discharges and prevent unnecessary admissions to, and additional pressures on, acute and community hospitals.

The lack of sustainable funding for the hospice sector, which on average receives one third of its income from statutory sources, was also considered. Without sustainable funding, hospices would not be in a position to provide extra capacity. The swift 40% reduction in hospice fundraising at the beginning of the pandemic also indicated that there was a risk that services would collapse.

¹⁶ Together for Short Lives, [Children's palliative care nursing workforce in crisis](#), May 2022

¹⁷ The King's Fund, [Is the NHS on track to recruit 50,000 more nurses? Hitting the target but missing the point...](#) (Accessed May 2022), April 2022

¹⁸ Skills for Care workforce intelligence, [Vacancy information – monthly tracking](#) (Accessed May 2022)

NHSEI, DHSC and Hospice UK also considered how to measure the impact of the funding, which resulted in capacity being recorded via a national tracker and hospices being required to submit a monthly monitoring report to Hospice UK. In addition to analysis of bed use and community outreach, monitoring under the scheme covered additional capacity provided under local agreements with Clinical Commissioning Groups as well as turnover and reserve levels per hospice.

- *Do healthcare and social care stakeholders view the funding as sufficient?*

The emergency COVID-19 funding for the hospice sector provided by NHSEI was sufficient to enable the sector to support the NHS in its response to the pandemic. In July, 2020, the Government calculated that the NHS received £323 million in capacity in return for its initial grant of £155 million to hospices in England. Of this grant, 70% was used to support more than 40,000 patients, ensuring the NHS did not need to manage the care of these patients during the pandemic.¹⁹ However, this emergency Government funding was a short term measure that has now come to an end. Prior to this funding, an average of 34% of adult's hospice funding and 18% of children's hospice funding came from the Government and hospices across the UK had to raise £3.1 million of charitable income every single day to fund their services.

The lack of sustainable funding model for the sector can prevent hospice leaders from engaging in meaningful strategic workforce planning within their system as they are focused on the survival of their services. It is also a significant barrier staff retention and recruitment. Hospices are not funded to match NHS Agenda for Change pay scales, terms and conditions. This makes it very difficult for them to attract the skill mix and staff they need but 66% of hospices do mirror NHS pay grades because they need to do so to recruit staff.²⁰ Welcome pay increases for the NHS workforce drive significant cost increases among hospices and other non-NHS providers during a time of increased costs in delivering services, acquiring equipment and boosting salaries.

Stakeholders across the sector that represent staff that provide palliative and end of life care have expressed that current funding for staffing is insufficient. In July 2021, the NHS workforce received a 3% pay rise in recognition of their contribution during the pandemic. The majority of Royal College of Nursing (RCN) members said this pay rise was unacceptable and in response, given the significant pressures on health and care staff created by the COVID-19 pandemic and the nursing shortage, the RCN is calling for the 2022-23 NHS pay award to be a 5% pay rise.²¹ Data from Skills for Care also suggests that 71% of independent sector care workers are paid below the Real Living Wage, with 38% paid under the next National Living Wage.²² The King's Fund has called for an environment where social care employers can offer competitive terms and conditions that reflect the value of the work of their employees.²³

- *Was any financial commitment a 'new' resource stream? If not, did reallocation of funds result in any unforeseen consequences/undesirable 'work arounds' at local level?*

¹⁹NatCen, [Evaluation of the Voluntary, Community, and Social Enterprise Funding Package Scoping Report](#) (Accessed May 2022), January 2022

²⁰ Hospice UK, *Unpublished 2021 survey of clinical staff working in UK hospices*, 2021

²¹ Royal College of Nursing, [What next for NHS pay](#) (Accessed in May 2022)

²² Skills for Care workforce intelligence, [Pay Rates](#) (Accessed May 2022)

²³ The King's Fund, [Average pay for care workers: is it a supermarket sweep?](#) (Accessed May 2022), August 2019

In February 2021 the UK Government said, of the £280 million made available to hospices in England at that time, £31 million was funded by existing Department for Health and Social Care budgets and £249 million was new funding confirmed at Supplementary Estimates 2020-21.

Was it an appropriate commitment?

- *Was (or is) the commitment likely to achieve meaningful improvement for health and social care staff and/or the health and care system as a whole?*

The commitment on workforce planning and the staffing commitments in the 2017 and 2019 Conservative Manifestos cited by the Expert Panel focus entirely on the needs of the NHS, rather than the system as a whole. This runs contrary to Government steps in the 2022 Health and Care Act and Integration White Paper to improve the quality of care that people receive through increasing the integration of services across the health and care system. For this reason, they are unlikely to achieve meaningful improvement for the system and its beneficiaries.

Integration of services and partnership working is particularly important for those with palliative and end of life care needs, who are likely to be supported by numerous different providers at any one time and for whom poor coordination of care can result in significant pain and distress. Palliative and end of life care is delivered by a patchwork of different providers including charitable hospices, domiciliary care providers, care homes and hospitals. To sustainably resource the delivery of high-quality palliative and end of life care, measures to increase the number of health and care professionals must drive staffing increases across the system, including in the independent and charitable sector, rather than focus solely on NHS institutions.

- *Is the target contained in the commitment an effective measure of policy success (if applicable)?*

As set out above, national staffing targets must strengthen the workforce across the entirety of the health and care system, including non-acute and non-NHS organisations, rather than be limited to the NHS or social care. High quality and personalised palliative and end of life care can only be delivered if system partners work together and the right number of health and care professionals with the right skills are shared efficiently within a local system. Increasing the number of medical professionals in training or practicing within the NHS is not an effective indicator of success if staffing shortages within other health and care organisations that the system relies on (such as hospices) are ignored.

The focus of these targets on the number of health and care professionals also disregards specialisms where professionals are less likely to work full time. The palliative and end of life care workforce is largely part time, meaning that many more people need to be trained than are in full-time posts. Furthermore, the new Shape of Training dual accreditation for consultants, mandatory from 2022, contains rotations in both general medicine and palliative care. This will result in less people working in palliative care at any one time, two trainees being required per post and trainees taking longer to qualify.

Building a Skilled Workforce

Commitment: Help the million and more NHS clinicians and support staff develop the skills they need and the NHS requires in the decades ahead.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

- *Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?*

The hospice sector is a key provider of training in palliative and end of life care as well as a training hub for many health and care workers that move into roles within the NHS and other institutions. However, current policy prevents the NHS health and care workforce from taking full advantage of the training opportunities that hospices have to offer as well as restricts hospice staff and volunteers from benefitting from NHS training and opportunities. For example, leading training hospices, such as LOROS Hospice and Greenwich & Bexley Community Hospice, often miss out on workforce development funding and opportunities to share their expertise and improve the skillset of system colleagues in palliative and end of life care. Hospice staff and volunteers also do not have equal access to CPD training or other training opportunities available to the NHS workforce. This lack of integration of training across the system is a significant barrier to the health and care workforce being sufficiently trained to manage the current and future palliative and end of life care need.

The Integration White Paper includes policy proposals for more flexible movement and deployment of health and care staff, joint roles across health and social care and placements for health workers in social care.²⁴ Flexible career pathways that support health and care workers to move between providers across the system enrich the training of staff and strengthen the training support they can offer to their colleagues. Flexible pathways also make health and care a more attractive sector for young people looking for a wide range of experiences across different settings, rather than a place of work for life.

However, the Integration White Paper does not mention placements in independent and charitable providers within such pathways. It is vital that opportunities for flexible career pathways are available across the system and extend to the hospice sector. Hospice UK's 2021 workforce survey found that a lack of opportunities for career progression within hospices result in an average length of service of just 7 years.²⁵ To recruit and retain more staff to palliative and end of life care and to support further integration of services, there needs to be a clear and flexible palliative care career framework, with roles drawn from the full spectrum of providers across the entire health and social care system.

- *To what extent has the Covid-19 response affected progress on targets?*

The pandemic has transformed the delivery of palliative and end of life care and the skillset required to provide high-quality care to patients. As set out above, specialist palliative care services, such as hospices, are coming into contact with patients at a much later stage in their diagnosis, having to respond to periods of crisis and support patients with much less time to identify their wishes and plan for their end of life. This has changed the nature of the care they need to deliver and created a demand for more training in personal resilience, as well as staff support.

The pandemic has also accelerated the rise in deaths in people's own homes, increasing the need for end of life care skills in the community. Since the beginning of the pandemic, there have been an additional 100,000 deaths at home, compared to long-term rates. The existing curricula and delivery of generalist training programmes often do not prioritise training in palliative and end of life care. As a result, as the death rate in private homes surged, many generalist health and care workers, such as GPs, district and community nurses or domiciliary care

²⁴ Department of Health and Social Care, [Health and social care integration: joining up care for people, places and populations](#) (Accessed May 2022), February 2022

²⁵ Hospice UK, *Unpublished 2021 survey of clinical staff working in UK hospices, 2021*

staff, have sometimes found themselves without the capacity and the knowledge they need to support people at end of life.

The increased need in the community and use of digital solutions to reduce infection and maximise resources during the pandemic has also led to the rapid introduction of virtual wards and services. These services require staff to have more advanced technological capability and better skills in communicating with patients online. A multi-disciplinary team is needed to lead on using a virtual ward model to monitor patients with complex palliative care needs in the community. New ways of working and technological solutions developed during the pandemic need to be built into existing training programmes for the generalist and specialist palliative and end of life care workforce.

As set out above, the pressures of the pandemic and the urgent need for extra capacity for the health and care system led the UK Government to commit £338 million towards buying extra capacity for the NHS in England. The hospice sector stepped up to support its colleagues across health and care and in the process became integral to the system and meeting the population's core health and care needs in the long-term. It has become clear that the hospice sector is essential to the delivery of palliative and end of life care. The sector is no longer focused on unmet need but now also responds to the core need visible to the NHS. This shift in the role of hospices that has taken place during the pandemic must be reflected in any policies to support the health and care workforce to develop the skills they need and the system requires in the decades ahead.

Was it an appropriate commitment?

- *Was (or is) the commitment likely to achieve meaningful improvement for health and social care staff and/or the health and care system as a whole?*

This commitment, like the majority of the commitments identified by the Expert Panel, is focused on the needs of the NHS workforce rather than the wider system. As set out above, the pandemic has led to increased collaboration across the system for the needs of its beneficiaries. The Health and Care Act and the Integration White Paper are both aimed at encouraging better partnership working and integration of services at all levels. Skill sharing across providers and systems is also essential to tackling widespread workforce shortages in health and care. It is therefore now inappropriate to work towards a commitment focused only on the training needs of NHS staff, rather than the staff and volunteers across the entire health and care system.

Commitment: Supporting moves towards prevention and support, we will go faster for community-based staff. Over the next three years we want all staff working in the community to have access to mobile digital services, including the patient's care record and plan that will help them to perform their role. This will allow them to increase both the amount of time they can spend with patients and the number of patients they can see. Ambulance services will also have access to the digital tools that they need to reduce avoidable conveyance to A&E.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

- *Does the commitment have a deadline for implementation?*

In 2016, the UK Government set out the intention that shared digital palliative and end of life care records, such as Electronic Palliative Care Coordination Systems (EPaCCS), would be in use across the entirety of England by 2020 (and in the majority of areas by 2018).²⁶ This commitment has not been met. The implementation of

²⁶Department of Health, [Our Commitment to you for end of life care](#) (Accessed in May 2022), July 2016

EPaCCS across the country is patchy and, even in areas where they are used, they are often not attached to digital records or are barely shared outside of their GP practice, let alone across the wider health and care system.

The ambition to roll out EPaCCS has since been joined by additional commitments to electronic patient records that can be shared across the health and care system. The NHS Long Term Plan committed to accelerating the roll out of electronic patient record systems and working to ensure Local Health and Care Records can be used across all settings.²⁷ The Health and Social Care Secretary recently confirmed that he is aiming for 90% of trusts to have electronic patient records in place or be processing them by December 2023.²⁸ The Government's draft Data Saves Lives report committed to ensuring at least 80% of social care providers have a digitised care record that can connect to a shared care record²⁹ and the Integration White Paper set out the aim to have a single, functional health and care record for every citizen, which citizens, caregivers and care teams can all safely access, both by 2024.³⁰

- *Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?*

NHS England and Improvement is undergoing a review and refresh of the standards for core content held in EPaCCS. This refresh was expected to be completed in March 2022. However, there is a pressing need to upskill the generalist workforce, including primary care, to ensure they can recognise when an individual is at end of life, conduct sensitive conversations with patients about their needs and wishes, update these records and share them with the relevant professionals. Training for health and care professionals to enable them to accurately update digital patient records in a timely way is essential to their successful roll-out.

- *How has this commitment been interpreted in practice at local authority/care provider/trust level?*

The implementation of commitments to roll out digital patient records at a local level, as well as EPaCCS that can maximise the benefit of these records for people at end of life, has been piecemeal. However, there are some examples of good practice, such as Cheshire's work to better implement EPaCCS across its system, using its 2019-2023 EPaCCS digital roadmap.³¹ The roadmap contains actions to improve direct patient access to EPaCCS, data exchange, data collection, and uptake of EPaCCS across the system.

- *Does data show achievement against the target (if applicable)?*

1% of patients of any GP surgery are likely to be in their last year of life, however, evidence shows that the use of EPaCCS across England varies significantly according to area.³² For example, a 2017 survey of 209 Clinical Commissioning Groups found the proportion with "fully operative" EPaCCS varied from 34% in the Midlands and East of England to 84% in London.³³ In comparison, the Scottish equivalent of EPaCCS, Key Information

²⁷ [The NHS Long Term Plan](#) (Accessed in May 2022), January 2019

²⁸ Department for Health and Social Care, [Health Secretary sets out ambitious tech agenda](#) (Accessed in May 2022), February 2022

²⁹ Department for Health and Social Care, [Data saves lives: reshaping health and social care with data \(draft\)](#) (Accessed May 2022), February 2022

³⁰ Department of Health and Social Care, [Health and social care integration: joining up care for people, places and populations](#) (Accessed May 2022), February 2022

³¹ [Cheshire EPaCCS Digital Roadmap, 2019-2023](#) (Accessed May 2022)

³² Marie Curie & Royal College of General Practitioners, [EPaCCS: electronic systems that help improve patient care](#) (Accessed May 2022)

Summaries (or KIS), have been more successfully adopted. In 2017, 69% of people with an advanced progressive illness in Scotland had a Key Information Summary in place before they died and as of March 2021, 1.9 million people in Scotland had a KIS.³⁴

Was the commitment effectively funded (or resourced)?

- *Were specific funding arrangements made to support the implementation of the commitment? If not, why? If so, what were these, when and where were they made?*

In 2019-2020, one of the Quality Outcome Framework measures for GP surgeries, to which one year of funding was attached, was to show quality improvement in end of life care for their patients. Some GP surgeries chose to spend this funding on introducing EPaCCS or enhancing the sharing of these records. Separate to this funding, local commissioners have used Locally Commissioned Services to incentivise the use of EPaCCS.

- *Do healthcare and social care stakeholders view the funding as sufficient?*

Introducing EPaCCS, linking them to a digital patient record and facilitating their sharing across the health and care system takes a significant amount of resource and, whilst benefitting the care people receive across the system, this reduces the resource available for the direct patient care for which GP surgeries are contracted. Therefore, it is essential that GP surgeries are sufficiently incentivised to use and share EPaCCS by sustainable funding. The Quality Outcome Framework measure funding was only available for one year and therefore could not be used to fund a long-term sustainable programme of work. Local commissioner funding for EPaCCS via Locally Commissioned Services is also only available where it has been prioritised by local commissioners. There is a clear need for nationally driven sustainable funding for the roll-out of EPaCCS in order for these systems to be successfully used and records shared by GP surgeries.

Was it an appropriate commitment?

- *Was (or is) the commitment likely to achieve meaningful improvement for health and social care staff and/or the health and care system as a whole?*

As set out above, people that require palliative and end of life care are likely to be supported by a variety of different service providers across the state, private and charitable sectors, particularly when their care is delivered in the community. The patchwork nature of end of life care delivery makes sharing accurate, consistent and timely patient data across providers and between health and care professionals hugely important. Digital patient records that all health and care workers can access and update, regardless of the setting they work in, would promote better integration between services and a more person-centred approach. This would result in significant improvements in patient care, particularly for people dying in the community.

More consistent and widespread use of Electronic Palliative Care Coordination Systems (EPaCCS) would ensure that all patients are confident that all the professionals involved in their care are aware of their end of life care wishes. Recording whether a patient is at end of life, as well as their care needs and wishes, also means patients and their loved ones do not need to share plans for their death or sensitive details about their condition time and time again with different health and care professionals.

³³ Pablo Millares Martin, [Electronic palliative care coordination system \(EPaCCS\): Interoperability is a problem cited in](#) [Javiera Leniz, Anna Weil, Irene J Higginson, Katherine E Sleeman, *Electronic palliative care coordination systems \(EPaCCS\): a systematic review*, March 2019](#)

³⁴ Scottish Partnership for Palliative Care, Every Story's Ending, [Proposals to improve people's experiences of living with serious illness, dying and bereavement in Scotland](#), September 2021

Individuals with palliative and end of life care needs often require urgent out of hours support and rolling out EPaCCS linked to digital patient records across England would ensure that emergency services and professionals working out of hours or in the community would be better informed as to how to care for individuals at the end of their life. For example, were paramedics called in response to a medical emergency concerning a patient who they knew wanted to die at home, they could work to prevent that patient from being admitted to an in-patient unit. Anonymised and coded data from EPaCCS can also be a useful population need mapping tool for commissioners.

However, for the roll-out of these digital records to achieve meaningful improvement for people with palliative and end of life care needs, all health and care workers across the system need to be confident in recognising when someone is dying, approaching a conversation with the patient about their death and updating digital patient care records and EPaCCS. Systems and the workforce also need to buy into the value of digital records and sharing information with other providers.

Wellbeing at Work

Commitment: Introduce new services for NHS employees to give them the support they need, including quicker access to mental health and musculoskeletal services.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

- *To what extent has the Covid-19 response affected progress on targets?*

Since the beginning of the pandemic, health and care systems have been under tremendous strain, exacerbating existing concerns around the mental health of their workforce and staff burnout. The 2021 NHS Staff Survey found 47% of NHS staff had felt unwell due to work-related stress during the last 12 months.³⁵ Increased workload and working hours, the intensity of working in a COVID-safe environment and anxiety about their own health and the health of their loved ones during the pandemic have all been cited as factors that have impacted the mental wellbeing of the workforce during the last two years.³⁶ These impacts have increased the need for quicker access to mental health services for health and social care staff.

Another key driver of poor mental health among the health and care workforce is the sheer amount of traumatic death they have witnessed during the pandemic. This includes staff members who were not equipped to respond to such a high volume of death, such as care home staff who had to support numerous dying residents during COVID-19 outbreaks.

Palliative and end of life care specialist staff have seen the volume of deaths they support increase dramatically and continue to be under intense pressure. As set out above, missed medical appointments and delayed diagnoses during COVID-19 lockdowns have led to many more people being referred to specialist palliative care, often at a much later stage in their illness. Patients presenting to specialist palliative care services at such a late stage limits the connection that staff can make with the patient and the personalised support they can offer. This can increase distress for the dying person, their loved ones and the frontline workers caring for them. At a meeting of the All-Party Parliamentary Group on Hospice and End of Life Care in November 2021, a healthcare assistant from St Luke's Hospice Plymouth described how, since the pandemic, it is normal for two to three

³⁵ Survey Coordination Centre, [NHS Staff Survey 2021 National results briefing](#), March 2022

³⁶ House of Commons Health and Social Care Select Committee, [Second Report – Workforce burnout and resilience in the NHS and social care](#), June 2021

patients to die a day and for patients who would normally be under the care of the hospice for twenty days to be supported for only five.³⁷

The high level of excess deaths associated with the pandemic, and the resulting trauma and grief felt by frontline staff, has increased the need for accessible bereavement and mental wellbeing support aimed at frontline workers. Over 5 million people are estimated to have been bereaved during the pandemic, with many health and care staff impacted by the deaths of loved ones as well as patients. Staffing pressures and the intensity of their work will also have resulted in many being unable to take much needed time off to grieve or use the support services that were available. Between July 2020 and November 2021, 35% of frontline workers who called the Just B bereavement and emotional wellbeing phone line were suffering from bereavement and 20% called about stress.³⁸

- How has the commitment been interpreted in practice at local authority/care provider/trust level?

During the pandemic, numerous health and care providers introduced new ways to support their workforce with their mental wellbeing and burnout. For example, many organisations introduced ‘wobble rooms’, quiet spaces where staff could go if they were feeling overwhelmed and needed a peaceful environment.

Was the commitment effectively funded (or resourced)?

- *Were specific funding arrangements made to support the implementation of the commitment? If not, why? If so, what were these, when and where were they made?*

In response to the rapid increase in need for bereavement and mental health support among the health and care workforce brought about by the pandemic, Hospice UK came together with Shout, Samaritans and Mind and the support of The Royal Foundation of the Duke and Duchess of Cambridge to run Our Frontline from April 2020 to November 2021.³⁹ The Our Frontline campaign created a single point of access (the Mental Health at Work website) for mental health services and information for frontline workers provided by numerous charities and enabled tens of thousands of key workers across the UK to access 24/7 emotional support during the pandemic. Just B, a free emotional wellbeing and bereavement support helpline for frontline workers delivered by North Yorkshire Hospice Care was one of the services offered through the Our Frontline campaign. Just B also received funding from NHS England and Improvement.

NHS England and Improvement and the Department for Health and Social Care, alongside Hospice UK, funded the Take a Deep Breath cross-media advertising campaign, a subset of Our Frontline, to connect frontline workers with the mental health services they needed.

- *Do healthcare and social care stakeholders view the funding as sufficient?*

Whilst Government and NHSEI support for Our Frontline was hugely welcome, there is still significant unmet need for bereavement and mental wellbeing support for health and care workers, including those working in palliative and end of life care. Many health and care staff are still living with trauma, grief and burnout created or accelerated by the pandemic and require additional support. Furthermore, a significant number of health and care professionals did not have the time to use the mental health services funded during periods of high COVID

³⁷ All-Party Parliamentary Group on Hospice and End of Life Care, [Oral evidence session on people's experiences of providing end of life care during the pandemic: Minutes](#), November 2021

³⁸ Ibid

³⁹ Mind, [Our Frontline Campaign Impact Report](#), February 2022

infection. There is a critical need for additional Government support for the mental health and bereavement needs of the workforce now that the funding for Our Frontline has finished.

- *Has (or will) there been (or be) a meaningful improvement in measurable outcomes, reasonably attributable to the commitment?*

Data indicates that Our Frontline and its associated Take a Deep Breath campaign supported health and care workers to access mental health support more quickly. The campaigns expanded the reach of the Shout textline, Samaritans helplines and Just B counselling and emotional support helpline during the pandemic. Between April 2020 and November 2021, 24,275 Shout text conversations were had with frontline workers and 89% of these beneficiaries said the service was helpful to them. During this same period, the Samaritans received 26,000 calls from health and care workers. From July 2020 to November 2021, Just B received approximately 20 calls a week, two fifths of these calls were for support with bereavement and a third were to request information. The NHSEI and Government supported Take a Deep Breath campaign specifically was responsible for a doubling of visits to the Mental Health at Work website.⁴⁰

Was it an appropriate commitment?

- *Was (or is) the commitment likely to achieve meaningful improvement for health and social care staff and/or the health and care system as a whole?*

This commitment erroneously focuses entirely on introducing new support services for NHS employees, including mental health support, rather than staff and volunteers across the entire health and care system. It is vital to achieving meaningful improvement for staff that accessible mental health support is made available to the entire health and care workforce and that line managers across the system are trained to identify when a staff member or volunteer requires support and signpost them to support services.

Furthermore, there has been a lack of initiative and meaningful work to assess the mental health needs of the health and care workforce. Whilst the Government can meet this commitment by introducing new, or faster access to, mental health services, an assessment of the level of need for such services and the funding and provision required to meet this need is essential to achieving meaningful improvement for staff.

Commitment: Listen to the views of social care staff to learn how we can better support them – individually and collectively.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

- *Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?*

Whilst the NHS has an annual Staff Survey to provide an indication of staff satisfaction levels and listen to the voices of its employees, there is no comparable survey for the social care or wider system workforce. This policy decision makes it exceptionally challenging to listen to the voices of social care staff and understand how they can be better supported.

⁴⁰ Ibid

The fragmented and independent nature of the social care landscape also makes it difficult to collect consistent data and create ways to hear the voices of the entire workforce. Existing channels designed to increase the voice of the workforce, such as the Freedom to Speak Up Guardian scheme, are not mandated in all settings and can be difficult to implement in smaller independent providers, including hospices. Some hospices are too small and understaffed to use a Freedom to Speak Up Guardian effectively and ensure they receive the training they need. A more integrated approach, where one Freedom to Speak Up Guardian can work with a group of smaller independent organisations, would increase the effectiveness of this policy.

Furthermore, as set out above, national policy has set a clear intention to increase integration across health and social care. Therefore, it would make sense to ensure efforts to listen to the workforce and identify how they can be better supported are made across the entire system. Specific initiatives to engage with the social care or the NHS workforce separately run contrary to aims to introduce more flexible movement and deployment of health and care staff across the system.

Was it an appropriate commitment?

- *Was (or is) the commitment likely to achieve meaningful improvement for health and social care staff and/or the health and care system as a whole?*

Hospice UK is not aware of any formal or structured approach to listening to the voices of social care workers by national Government. Furthermore, for there to be meaningful improvement for care workers and their beneficiaries there needed to be pre-planned resource available for responding to any concerns raised by the workforce. Listening to the views of staff is important but it cannot be translated into meaningful improvements for the workforce if there is no commitment to using this data to drive change.

May 2022