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 challenges facing, independent and charitable health and social care providers.

As a result of campaigning by Hospice UK and partner national charities, Baroness Finlay of Llandaff’s amendment to the Bill became part of the Health and Care Act 2022. This places, for the first time, a statutory responsibility on Integrated Care Boards (ICB) to recognise and commission palliative care for their populations, and reads:

“An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility:

h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service”

Whilst this is a very positive and welcome step, its implementation by Integrated Care Systems (ICS) will require both national support and local prioritisation and delivery solutions. Palliative and end of life care (PfLoLC) is a particular policy area where the balance of both national guidance and, not just local, but personalised care delivery is most pertinent and where both good practice and system tensions can be seen.

Summary of key points

- There must be more streamlined national guidance so that whole systems are clear on national priorities and assurance mechanisms both via ICBs and ICPs.
- There needs to be clear oversight of and between ICPs and ICBs that assures true integration and partnership working.
- Monitoring and assurance mechanisms need to be recognisant of national expectations versus local variations.
- The next iteration of the NHS People Plan, and a people plan for the social care sector, need to take a whole system approach to workforce planning.
- National workforce planning and a national investment in a wide framework of initiatives are needed system wide. ICSs should be held to account for widening their own reach.
in terms of workforce mapping and planning, including the voluntary sector and community organisations

- The hospice funding solution at ICS level must come from one clear source, contracted in the way other NHS healthcare providers receive their income, to avoid additional layers of bureaucracy.
- The reporting of activity from hospices should be brought in line with local mechanisms so that data of all varieties is inclusive across the system.
- Systems who recognise the value of neighbourhood and place-based partnerships and devolve prioritisation and delivery to local clinicians, services, communities and populations depict good practice.
- It is vital there is scope for variation between ICSs, so that they can adapt to the needs of their specific population, however, it is the evidence and rationale behind any variety as well as the monitoring of consistency that will be key to assuring that the variety is planned and appropriate.

1. How best can a balance be struck between allowing ICSs the flexibility and autonomy they need to achieve their statutory duties, and holding them to account for doing so?

National Frameworks; Local Delivery

The inclusion, for the first time, of palliative care as a statutory responsibility for the NHS as part of the Health and Care Act 2022, sets a welcome national agenda. The resulting suite of statutory and technical guidance establishes a consistent framework and the expectation to deliver for all regional, system-level and more local organisations and bodies across health, social care and beyond.

From a national perspective, there remains the need for more joined up working across Government departments if health, social care and the wider determinants of health, such as poverty, education and housing, are to be fully recognised and tackled in a coherent policy agenda. Hospices are providing more of their care outside hospice inpatient units and in people’s places of usual residence. These specialist end of life care providers are increasingly having to plug the gaps in ‘social care’ provision and fulfil more generalist care tasks for patients. The cost of living crisis and families living in poverty are more of a barrier to receiving good end of life care, particularly at home, than they have ever been¹. These all require joined up national government policies and investment.

However, the guidance, statutory and otherwise, being released from the central NHS and government departments aimed at ICBs and Integrated Care Partnerships (ICP) is disparate, vast and complicated at a time when structures and governance are still forming and individual people are still finding their feet in new roles and organisations. It is proving difficult for many smaller provider and non-statutory organisations, including hospices, to track all the changes and understand where and how to link effectively into their systems.

¹ Marie Curie, Dying in poverty: Exploring poverty at the end of life in the UK, May 2022
There must be more streamlined national guidance particularly between health and social care: the Department of Health and Social Care (DHSE) and NHS England (NHSE), so that whole systems are clear on national priorities and assurance mechanisms both via ICBs and ICPs.

There is a danger that NHS Trusts have statutory membership of boards and will dominate the committees and decisions that flow from them. ICSs must be both monitored but also supported in their ability to resource and deliver true wider and inclusive partnership working that encompasses non-NHS Trust organisations both within and particularly outside the NHS and statutory sector.

Hospice UK welcomes the guidance to ICBs to engage with both people and communities and with the wider voluntary sector, but the reality will need to be meaningful and not tokenistic. In the case of hospices, systems will need to recognise that they bring to the arena not just a voice from the voluntary sector, but also a substantial provider role. Whilst it is incumbent on providers to form the necessary alliances and collaborations that will facilitate representation and voice in the wider system, it falls to the ICS bodies to ensure that these are resourced, engaged and recognised as partners of equal parity in planning and decision making as well as in service delivery. It should also be understood that many in the voluntary sector, as with other non-NHS Trust partners, do not have high capacity to engage at multiple levels, and that even forming alliances to do so will require significant investment.

There needs to be clear oversight of and between ICPs and ICBs that assures that true integration and partnership working have been established. This includes allocating nationally and locally the resources to enable this to happen, particularly across the voluntary and community sector.

End of life care does provide a good example of where national guidance both sets the framework, describes the aims of good commissioning and good care provision, but also recognises that systems are in varying positions along that journey. NHSE’s Palliative and end of life care funding & contracting approaches: Achieving sustainability in partnership, includes a stepped approach for systems to self-assess and benchmark their local positions. This approach to national frameworks versus local delivery rightly leaves local systems to work from their own baselines, within their own priorities to map, model and design care for their own populations in the context of their current situations.

Population health approaches feature significantly in the rhetoric and frameworks, however, Hospice UK is mindful of the varying success of Health and Wellbeing Boards across the country to put public health at the heart of local decision making. ICSs will need to work more closely with populations and analyse data across the whole system to truly understand and take into account their population needs. This then needs to inform the ‘functions’ required by the system before plans can be put in place for services and workforce to deliver them. Accountability is to the populations and local expertise that inform this approach.

The evaluation should likewise focus on ensuring consistent approaches are embedded in systems and broad outcome targets and impacts are met, where expectations and benchmarking take into account starting points and local demographics, funding allocations and competing priorities. The increased involvement of ICPs and Local Authority mechanisms
of overview and scrutiny should both set and hold to account the local delivery of plans including those for end of life care. These should not be duplicated by national bodies as well.

Hospice UK supports the NHSE PEOlC teams who have ensured co-production of national guidance that set consistent frameworks but for local delivery. The monitoring and assurance mechanisms need to be equally as recognisant of national expectations versus local variations.

Workforce Challenge

A key challenge across the health and care service, including palliative and hospice care, is the lack of sufficient workforce. The balance of responsibilities between national and local is apparent in this complex policy and implementation agenda.

A March 2021 survey by Hospice UK found an average 11% vacancy rate in community nursing roles for adult hospices and average 7% vacancy rate in adult hospice based nursing roles. It is important to note that these vacancies are representative of what is affordable within current hospice funding rather than the level of staffing required to meet population need. Recruitment is further complicated for hospices as they struggle to match the NHS Agenda for Change pay scales and terms and conditions.

Since the start of the COVID-19 pandemic, there have been over 100,000 excess deaths at home across the UK. The increase in deaths at home is driving a demand for more staff with the ability to manage end of life and palliative care needs in this setting. Hospice UK is concerned that there is insufficient care in the community to support this many deaths.

Recent analysis 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. 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%.

The commitment on workforce planning in the 2017 and 2019 Conservative Manifestos focuses 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.

The next iteration of the NHS People Plan, and a people plan for the social care sector, need to take a whole system approach to workforce planning and encourage partnership working and integration across services, particularly in palliative and end of life care where there is such a broad spectrum of provision. Since ICSs model their

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2 The King’s Fund, Is the NHS on track to recruit 50,000 more nurses? Hitting the target but missing the point…, April 2022

3 Skills for Care workforce intelligence, Vacancy information – monthly tracking (Accessed May 2022)
People Plans on the national framework, emphasising partnership working at a national level will also lead to increased collaboration at an ICS level.

National workforce planning and a national investment in a wide framework of initiatives are needed to recruit, train and value health and care staff across the system, not just within the NHS. The setting of international recruitment regulations, the apprenticeship frameworks, the numbers of medical training places, the curricula and much of the statutory sector terms and conditions including pension rules, are all national responsibilities that help or hinder local systems in the attainment of a local workforce that is fit for purpose. Government cannot devolve nor hold ICSs to account for issues for which it holds many of the national levers.

ICSs however can, and should, be held to account for widening their own reach in terms of workforce mapping and planning, including the voluntary sector and the vast raft of community organisations and volunteers whose work is vital to the outcomes they are trying to achieve. For opening up local partnerships and education and training opportunities and for enabling people to truly engage, learn and work across and between organisational boundaries.

2. What does a permissive framework for ICSs look like in practice?
N/A

3. Are central targets consistent with local autonomy in this context?

Hospice UK’s position on central targets is in line with our comments on national guidance, frameworks and assurance versus local autonomy to prioritise and deliver, as set out in our answer above.

Metrics should take into account local diversity and priorities as well as historical baselines and resource allocations. However, ICSs should be held to account for working in true partnerships and delivering effective and integrated improvements for their populations and environment. Consistent language and mutual understanding of what good looks like, and sharing of best practice, will all help ICSs and system providers, as well as national bodies, in this aim.

4. To what extent is there a risk that ICBs become an additional layer of bureaucracy if central targets are not reduced as ICBs are set up?

There are two areas that risk being additional bureaucracy layers, one between ICBs and national bodies such as NHSE; and the other between ICSs more generally and the place-based and Local Authority structures still within them. Who sets and monitors priorities and targets, and at how many levels, will be key to not adding to the requirements of committees and reporting, especially for neighbourhood providers such as hospices.

Hospice Funding Responsibility

For hospices, whilst workforce capacity is now the greatest challenge to sustaining service delivery, a sustainable funding solution remains central to their ability to continue to deliver
high quality, individualised patient care. Prior to the pandemic, an average of 34% of adult’s hospice funding and 18% of children’s hospice funding came from NHS commissioners, with hospices across the UK having to raise £3.1m of charitable income every single day. With palliative care now a statutory ICB responsibility, there needs to be a sustainable funding solution for the hospice sector if it is to use its capacity and expertise to support the system in responding to the current and expected increase in need.

The hospice funding solution at ICS level must come from one clear source, contracted in the way that other NHS healthcare providers receive their income. If funding continues to come piecemeal in grants, sometimes locally and sometimes nationally, then the risk is that hospices will be beholden to both short-term and multi-layered taskmasters, outputs will be short-lived and reporting requirements will not be streamlined.

Reporting Requirements

Additional layers of bureaucracy were already evident when hospices were required to complete the DHSC national Capacity Tracker as a condition of the national COVID-19 emergency funding. Locally, many hospices were also part of hospital discharge / capacity monitoring groups using local dashboards and Apps for local system monitoring, for example the Phew! App in Bedfordshire. This duality of reporting should be streamlined. Moreover, the reporting of activity from hospices should be brought in line with local mechanisms so that data of all varieties – demographics, activity, impact, workforce – is inclusive across the system. Again, system investment will be required to enact this vision.

Where national systems are used for data collection, the information should be one and the same as that used by systems for their planning and monitoring and not repeated with local tools. For example, if the national workforce data collection systems both from hospitals and primary care were fit for purpose for workforce mapping and planning, then local tools (such as that being developed by regional NHS PEO LC teams) should not also be required and vice versa. These data collection systems need to be expanded, made simpler for hospices and other non-NHS organisations and more relevant for local system use.

Systems need to take into account their whole provider make-up if they are to understand both the needs and the delivery on their patch. In order for smaller, non-NHS Trust, and VSCE providers to participate in data collection and reporting, they need to be appropriately included and supported. Additional layers of bureaucracy disproportionately affect those who work at multiple levels and across various geographies and those who do not have large organisational structures and departments to carry out the requisite work. System leaders will need to work differently and more inclusively to ensure all participants have parity of access and input at all the appropriate levels.

5. What can be learned from examples of existing good practice in established ICSs?

With hospices in every ICS across the country, Hospice UK can gauge the wide variety of ICS engagement with place-based and neighbourhood partnerships, the VCSE (voluntary, community and social enterprise) sector, and the principles of subsidiary and co-production. Models and principles that Hospice UK feels strongly should be supported and embraced across all ICSs, learning from those that are seeing the best result for their populations.
Neighbourhood and Place

It is positive that the principle of subsidiarity runs strongly through all the national guidance. Hospices are at the heart of the communities they serve with the majority of their fundraising coming from their neighbourhood population. They have a knowledge of, connection to and reach into the community in a way that other organisations do not and they are locally accountable to their Trustees and neighbours such that true person, family and community based care is at the very core of what they provide.

The relationships and joint working between such community and neighbourhood based organisations are the building blocks of true integrated working and cannot be replaced or replicated at wider system level. Good examples are where hospices and GP practices are resourced to work closely together: identifying and care planning for those on palliative care registers; supporting care homes; and providing ‘living well’ services to their local patients. Systems who recognise the value of neighbourhood and place-based partnerships and devolve prioritisation and delivery to local clinicians, services, communities and populations depict good practice. Systems who enable those at neighbourhood and place level to have a true voice and say in system level planning and strategy will find their co-produced ideas more easily owned, supported and implemented.

Resourcing joint working does, however, require systems to invest fairly across their geographies and providers and recognise the current variations in support. Systems should also be mindful of the enablers of joint working, allowing time for relationships to form, clinical and social models of care to emerge and investment in the digital technology to allow sharing and collating of whole system information. Interoperable digital systems not only allow for shared care records across patient journeys, but also for the whole system data analysis for service planning. Good examples are where Electronic Palliative Care Coordination Systems (EPaCCS), such as the new Urgent Care Record in London, or shared care records, such as that in Greater Manchester, are accessible across all providers within and outside the NHS. National implementation falls well short of the Government’s 2016 commitment for nationwide coverage by 2020.

Co-production

The national NHSE PEoLC team co-produced the Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 with an array of service commissioners and providers across the statutory and voluntary sectors including Hospice UK and other national end of life care charities. As such, its transition into national guidance, and strong link to the requirements of the new statutory PEoLC guidance for ICBs, place it in a valued position. The guidance for ICPs working with VCSE alliances is also under consultation with the national Health and Wellbeing Alliance, of which Hospice UK is a member, another example of good practice and co-production. ICSs will need to ensure this level of co-production across their strategies and plans, including the Integrated Care Strategy to be produced by ICPs by the end of 2022.
VCSE alliances

VCSE alliances are forming around the country but, as with ICSs themselves, those that were pump-primed earlier in their journey as part of accelerator or exemplar programmes (Staffordshire, Lincolnshire, Norfolk and Waveney, Suffolk and NE Essex, for example) are in a more mature state and better able to engage with the system as its governance emerges. As ever, national and system funders would do well to ensure that all areas receive the same level of support and resource to establish themselves to engage, and that monitoring frameworks again recognise the different maturities of system partners in their ability to deliver.

6. What scope is there for variation between ICSs, to enable them to improve the overall health of the populations they serve and tackle inequalities?

End of life care needs are changing across the UK. The UK has an aging population which is resulting in increasing death rates. The number of people aged 85 and older is also expected to increase from 1.6 million in 2016 (2% of the population) to 3.2 million in 2041 (4% of the population). More people are dying year-on-year, with mortality expected to rise to nearly 800,000 by 2040. There has also been an increase in complexity of end of life care needs for many patients. Together, this is putting growing demand on end of life care providers.

All ICSs will have to contend with these developments, but the effect of these changes will be different depending on the population make up in different areas across the country. For example, we know that rural areas tend to have an older population, which will mean these areas will feel a stronger impact of the rise in deaths. Rural areas also often have to contend with different access needs such as managing access to online services and providing transport to inpatient or treatment facilities. As such, Hospice UK recognises that it is vital there is scope for variation between ICSs, so that they can adapt to the end of life care needs of their specific population and ensure these are met.

ICSs must also be supported to understand the end of life care needs of their population. A population health management approach to assessing need as the basis for any service or workforce redesign. As in the rationale for subsidiarity to place and neighbourhood level, personalised care can only be designed and delivered by those in close proximity to the person and their family. Whilst service mapping and understanding the gaps and inequities in provision can be done across an ICS, the nuances and needs of populations, not just across ICSs but within them, will mean that appropriate and tailored care solutions will vary. Variety should be seen as flexibility to meet need rather than necessarily inequality.

However, it is the evidence and rationale behind any variety as well as the monitoring of consistency of access and outcomes that will be key to assuring that the variety is planned and appropriate.

Hospice UK’s population needs assessment tool (PopNAT) uses nationally published data to map the demographics and outcomes specific to palliative and end of life care. This level of intelligence and detail is required as a starting point for any gap analysis or service planning for PEOlC provision. The variation across the country is clear both in terms of deprivation and age
of population, both with a direct impact on level and type of PEoLC service provision that would be required.

For example, the ICSs with the highest levels of people aged 65+ as a percentage of total population are: Dorset with 25.6%, Cornwall and the Isles of Scilly with 25.3% and Somerset with 25.2%. Whereas North West London by comparison has 13.5%.

Likewise, 49.4% of the local areas (LSOAs) of Birmingham and Solihull fall within the 20% most deprived in the country. Compared to Surrey Heartlands where only 0.7% of a similar population area is most deprived.

This population data relates directly to disease outcomes, such as deaths from circulatory disease and deaths from respiratory diseases, as can be seen in PopNAT. Therefore you would expect a variation in service type, level and spread across these ICS areas. More pertinently, there need to be clear national funding allocations and monitoring frameworks that take into account the different needs of seemingly similar sized populations. These need to hold ICSs to account for what is most pressing for their populations.

Hospice UK has been working to uncover and address inequalities in access to, and experiences of, end of life care for different communities across the UK. Our *Equality in hospice and end of life care: challenges and change* report, published in 2021, highlighted several communities that face barriers in access to end of life care, including people in prison, racialised communities and LGBT+ communities. We know, for example, that many trans people face barriers when accessing health and care services, including end of life care, and that many feel that health and care staff lack knowledge about their specific care needs.

It is vital that all ICSs work to tackle these inequalities and meet shared standards of care to avoid a postcode lottery for these communities. All regions in the UK will include a mix of communities with varying needs and access to care, and it cannot be left solely to individual ICSs to determine how to address these inequalities. Having said that, it is also important that ICSs have the ability to identify needs within their population, and listen to local VCSE and community voices in their area, and address these specifically.

7. **How can it be ensured that quality and safety of care are at the heart of ICB priorities?**

There are many ways in which ICBs in particular can ensure quality and safety of care, most importantly, by understanding the wide framework of heath and care services and providers that serve individual patients in their care journeys. These services and providers, including those from the NHS, social care, and voluntary and community sectors, need to understand common language and best practice; participate with parity in the information gathering and planning required; and deliver against integrated outcomes.

Hospices are experts in palliative care, but patients receive end of life care in a wide variety of settings and from a vast specialist, generalist, volunteer and unpaid workforce. Sharing skills and learning events, working across organisational boundaries, and having joined up teams and pathways better provides for personalised and safe care. Some of barriers to this way of working are within the gift of ICBs to address: how PEoLC services are commissioned, how hospices are funded, how knowledge and skills are utilised from across system provider. Some
remain within national control: only NHS nurses receive national Continuing Professional Development (CPD) funding; social worker pensions are not transferable into a joint hospice employment setting.

Patients and families need a real voice in designing care pathways from personal experiences, not just in reporting back on how they are functioning after the fact. ICB boards and committees need to be informed all the way through by the reality of patient, family and health and care professional experience. Listening to what is important to people, as with PEOlC’s ‘what matters to you’ ethos, as well as to professionals working at the frontline, as with PEOlC’s Strategic Clinical Networks.

8. **How best can this be done in a way that is consistent with how providers are inspected for safety and quality of care?**

The guidance emerging regarding oversight and inspection risks the most duplication and bureaucracy despite purporting to simplify things. As with strategy and decision making, oversight and monitoring risks being at multiple levels and requiring people and organisations to be linked in to an array of mechanism and meetings. This takes time and capacity which smaller organisations like hospices do not have. Already only a third of hospices are linked into local Health and Wellbeing Boards, and these are to inform and be informed by the strategies of ICPs. How ICBs translate these into plans and then implement them down through the alliances, place-based partnerships and neighbourhoods is variously a national oversight responsibility (as in the NHSE guidance) and a place-based Local Authority responsibility (via Overview and Scrutiny Committees).

On top of these various NHSE, DHSC and Local Authority responsibilities, the Care Quality Commission (CQC) retains their quality inspection role. CQC’s new approach towards developing a single assessment framework and associated quality statements is broadly welcomed. These put patient expectations and experiences of good quality care at the centre, in line with how hospices provide and evaluate care with their patients. Hospice UK hopes that this will ensure CQC inspections are more consistent and proportionate across all providers, and that inspection teams consider the nuances of hospice care as the framework is implemented in practice.

Similarly, Hospice UK welcomes the expansion of the Medical Examiner role out of the acute sector to improve the quality and consistency of death certification. The hope is that this will engender shared learning and improvement as well as ease a difficult process for bereaved families. However, given the scope of the new Medical Examiner offices, we must be mindful that the service must be adequately resourced and will not impinge on timely certification particularly for families and communities where the immediacy of funeral rituals is imperative.

9. **How can a focus on prevention within ICSs be ensured and maintained alongside wider pressures, such as workforce challenges and the electives backlog?**

In the context of end of life care, prevention is synonymous with planning. Talking about death and dying more openly and understanding people’s preferences at the end of life earlier. As well as early identification of disease and end of life phase.
Hospice UK’s *Dying Matters* campaign promotes and supports conversations about death and dying as well as giving a voice to bereaved families to share their personal stories. Hospices themselves provide a range of excellent bereavement support services to around 72,000 people annually and have expanded their services in response to the increasing need. However, it is disappointing that bereavement services do not fall within the core or specialist remit of NHSE’s PEOLC framework for services ICB’s should commission. Hospice UK advocates for *Dying Matters* to be a nationally funded campaign to break down barriers and prepare for death and dying more effectively. As with all prevention programmes, investing earlier in any pathway both smooths patient journeys and also assists the system in providing the right and necessary care ultimately better utilising resource and capacity.

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, has resulted in missed diagnoses and late referrals. As a result, end of life care services are finding that the number of patients being referred at a later stage in their condition, requiring more complex care, has increased. Improvement in screening uptake and earlier identification of cancers and potential end of life will again help both patients, professionals and systems provide the right care at the right time and place.

However, there is little point increasing referrals into a secondary care service that has no capacity to deliver more care. Hospices were part of the solution during the COVID-19 pandemic and, if resourced, can continue to reduce pressure on hospitals both with appropriate discharge to hospice care but also with admission avoidance in the first place. Getting basic care right, including at the end of life, and increasing the capacity to support people’s social care needs remain critical.

Whilst there are always acute and urgent pressures on the health and care system, none more so than currently, it also remains imperative that we break the cycle and invest in working and planning with people earlier in their wellbeing, prospective care and eventually end of life journeys. Ultimately, it is what is best for people, as well as being more rewarding for staff and better value for the health and care service.

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