Empowering local leaders
As the system moves towards new ways of working, we are keen to explore how we can empower local leaders within ICSs.

Question
Please share examples from the health and care system, where local leaders and organisations have created transformational change to improve people’s lives. (250 word limit)
This can include the way services have been provided or how organisations work with residents and can be from a neighbourhood, place or system level.

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. The organisation is informed and guided by its membership of over 200 UK hospices.

Choice and quality of, and equity in access to, end of life care is more important than ever. Mortality is predicted to rise to 800,000 by 2040. 3.2 million people are also expected to be over the age of 85 in 2041, increasing the complexity of palliative care required.

Hospices contain considerable specialist expertise in palliative and end of life care and are constantly evolving the way they deliver services. As primarily small, community-rooted and charitably funded organisations, they have the ability to initiate innovative solutions and be flexible in response to changing need. For example, many have increased their community services in response to the high number of excess deaths at home (105,000 in the UK during 2020-2021).

Hospices are developing new partnerships to transform care. For example, Nottinghamshire Hospice and Beaumond House Hospice are equal partners in an end of life care provider alliance in Mid-Nottinghamshire, alongside NHS foundation trusts and primary care. The partnership, End of Life Care Together, has a formal contracting and governance structure that allows for finance and risk sharing between organisations and truly joined up services to patients. This is an example of a diverse place-based provider alliance centred around the patient.

Question
Do you have examples where policy frameworks, policies and support mechanisms have enabled local leaders and, in particular, ICSs to achieve their goals? (250 word limit). This can include local, regional or national examples.

Hospice UK welcomes the inclusion of palliative care as a statutory commissioning responsibility for Integrated Care Boards (ICBs) in the Health and Care Act 2022. The NHS England (NHSE) palliative and end of life care (PEoLC) team is an example of a national and regional body supporting ICS clinical, provider and commissioning leaders.
The Ambitions Partnership, consisting of national stakeholders such as Hospice UK, has co-produced the Ambitions Framework, which sets out agreed standards for good end of life care for all. The Framework underpins NHSE statutory guidance for ICB delivery.

NHSE has co-produced, with national and ICS exemplar partners, a suite of technical guidance for end of life care commissioning. This guidance aims to address long-standing issues such as the sustainability of hospice funding; how to utilise the expertise, funding and capacity of voluntary sector providers; and coordinating access to specialist services across care settings and the 24-hour time period.

However, there remains a disparity in the funding and provision of palliative and end of life care across ICSs. The issue now is whether systems prioritise end of life care in their Integrated Care Strategies and 5-year Plans. Hospice UK is calling for the regulatory framework for ICSs to include this new statutory duty for palliative care provision and to monitor its improvement against good practice standards and guidance.

Question
Do you have examples where policy frameworks, policies, and support mechanisms that made it difficult for local leaders and, in particular, ICSs to achieve their goals? (250 word limit). This can include local, regional or national examples.

The political focus on acute sector waiting times and backlogs prevents systems from prioritising out-of-hospital care. Short-term funding pots do not allow systems and providers to tackle systematic problems with long-term staff recruitment or service development. For example, national discharge funding concentrates on getting people out of hospital rather than more effective admission avoidance initiatives. National and local policymakers' focus on prevention and treatment is also a barrier to the planning and delivery of good end of life care.

Hospices support over 300,000 people a year and face specific challenges relating to workforce and funding policy. On average children’s hospices receive 18% of their funding from statutory sources and adult hospices receive 33%. Their remaining income is from charitable donations, raising £1.1 billion each year. This means hospices struggle to plan ahead or invest in their services.

National and ICS workforce planning rarely includes the full spectrum of palliative and end of life care providers and often omits the voluntary sector. Hospices’ charitable status means they sit outside the statutory system and often miss out on support. For example, nationally agreed pay increases for NHS staff are not accompanied by increased funding for non-NHS providers delivering NHS-commissioned services.

NHS engagement with, and funding of, voluntary sector organisations delivering end of life care varies across the country. Whilst new statutory duties for both palliative care and wider partnership working are important levers for change, Hospice UK would like robust assurance mechanisms for their enactment by ICBs.

Question
What do you think would be needed for ICSs and the organisations and partnerships within them to increase innovation and go further and faster in pursuing their goals? (250 word limit)

Collective local leadership, ownership and accountability across the ICS is key to meeting its goals. Integrated Care Partnerships (ICPs) need sufficient input into, and oversight of, ICB planning and delivery so that the NHS, local authorities, the voluntary and community sector, and local populations are aligned.
There needs to be coordinated and supportive national regulation and oversight, with CQC, NHSE and government bodies working together to a realistic set of national targets and quality standards. ICSs must be accountable to these targets without diminishing the focus on locally agreed outcomes frameworks. Funding allocations and performance measures should also recognise the vast disparity in population need and baseline provision across ICSs. Current and unmet need, and any resulting warranted service variation, should be factored in.

There needs to be parity of esteem between partners, with smaller and non-statutory organisations represented at all levels of ICS governance, planning and decision-making. These partners must be unencumbered by bureaucracy and able to research what works locally and innovatively build on this.

ICSs should recognise that the voluntary sector includes providers, advocates, funders and umbrella bodies across the health and social care sector and beyond. The sector cannot be engaged as if it were one group with one purpose. In order to effectively work alongside the voluntary sector, ICSs need to help establish alliances to enable cross-organisational representation; offer remuneration for the time organisations spend engaged in this work; and put in the time and effort to build relationships and understand cultures and language.

Question
What policy frameworks, regulations or support mechanisms do you think could best support the active involvement of partners in integrated care systems? (250 word limit). Examples of partners include adult social care providers, children’s social care services and voluntary, community and social enterprise (VCSE) organisations. This can include local, regional or national suggestions.

Hospice UK welcomes the development of NHSE guidance for ICBs on working with the voluntary sector and local populations. However, this does not always align with guidance from the Department of Health and Social Care (DHSC). The various entities working alongside ICPs, still include Health and Wellbeing Boards, Oversight and Scrutiny Committee and local authorities accountable to the local electorate. There is a need for national guidance to be coherent and structures to be simpler.

Working with partners is hugely complex and multi-layered, with planning taking place at system, place and neighbourhood level. Adult hospices are often embedded in neighbourhoods, whereas children’s hospices span multiple ICSs. It remains unclear where they should be engaging and how funding decisions will be made. Smaller organisations do not have the resource or capacity to build relationships and attend meetings across these complex structures. This creates a risk that only large organisations, such as ICBs and NHS trusts, will have their voices heard in all necessary arenas.

Where partnership working is better established, ICSs have pursued solutions that promote alliance building and networks of representation. For example, subsidiarity to Morecombe Bay place-based partnership, which is responsible for end of life care alongside other local population care needs. Also, North West London’s 3rd Sector Together which is funded by the ICB and supported as part of a national accelerator programme. It has a wide membership and robust governance and is a trusted partner at committees up to, and including, the ICB board.

National targets and accountability

Question
What recommendations would you give national bodies setting national targets or priorities in identifying which issues to include and which to leave to local or system level decision-making? (250 word limit)
Hospice UK is pleased that ICBs have a statutory duty to deliver palliative and end of life care as appropriate for their populations. However, given the rapidly growing need for palliative and end of life care, this must be a higher national priority. Palliative care is currently only included in the NHS Long Term Plan in the context of personalised care. Hospice UK would like to see the Long Term Plan refresh also include addressing inequity of access and provision across communities, care settings and the 24-hour period.

Government needs to set national targets, which set expectations for good end of life care, including advance care planning; shared care plans/records; and choice in care setting. These targets should be measured according to meaningful outcomes for patients and families, and realistic improvement measures for systems.

Systems should be required to ensure access to 24/7 specialist palliative care advice, but be able to decide how this is provided locally. Similarly, there should be a national expectation that ICSs invest in both specialist community services and domiciliary care to ensure people actually have the choice to die at home but the coordination and deployment of this investment should be down to local providers.

Local clinicians, providers and people with lived experience should build on existing planning and provision using place-based population needs data and though the lens of equity.

**Question**

What mechanisms outside of national targets could be used to support performance improvement? (250 word limit). Examples could include peer support, peer review, shared learning and the publication of data at a local level. Please provide any examples of existing successful or unsuccessful mechanisms.

Mechanisms to support performance improvement should include partnership organisations within ICSs and across the ICP and ICB holding each other to account. Organisations, particularly NHS trusts, will need to undergo a significant culture change to think both as individual bodies and across system partnerships. Local authorities already have established mechanisms for accountability to the local electorate and community groups, which ICBs should draw upon.

Improvement requires listening to the experience of those who have and have not used services. Providers already gather feedback, but systems need to collect and collate this in a more consistent and useful fashion. This needs to be supplemented by the gathering of wider experiences, via surveys or through community groups, at both a local and national level.

National organisations can facilitate the sharing of learning. For example, Hospice UK supports hospices across the UK to share best practice. Research bodies such as the Nuffield Trust, the Cicely Saunders Institute and Higher Educational Institutions are important partners in supporting evidence-based improvements in end of life care. NHSE’s PEOlC team’s regional leads work closely with ICS colleagues to guide and support quality improvement.

Previously used successful mechanisms include funding quality improvement through the GP quality outcomes framework, which improved end of life care registers and advance care planning. The focus was decided by GP practices and the measurement was improvement from baseline. In contrast, the national capacity tracker that recorded hospice activity during COVID-19 was cumbersome and did not impact local decision making.
Data and transparency
We recognise that key to reaching greater local control and accountability is the transparent use of data, both at a local and national level.

Question
Do you have any examples, at a neighbourhood, place or system level, of innovative uses of data or digital services? (250 word limit). Please refer to examples that improve outcomes for populations and the quality, safety, transparency or experience of services for people; or that increase the productivity and efficiency of services.

It is essential that people at the end of their lives have their care plans and choices shared with themselves and across providers. Whilst shared care plans and records have long been an aspiration, their implementation is still piecemeal across the country. However, there are examples of good practice. The Greater Manchester Care Record enables providers to see each other’s patient notes. Suffolk and North East Essex’s ROSI (Record Once Share Insight) electronic care plan enables providers and patients to share end of life wishes, advance care plans and emergency care decisions. Providers enter information into a single record and patients record what is important to them via an app.

Inclusive service planning requires systems to collate data from across the health and care system, rather than just from NHS trusts. A critical gap in the planning and provision of palliative and end of life care services is the lack of data from the hospice sector. Currently, the amount and quality of data recorded and the capability of the systems in which it is held varies considerably.

ICBs need to ensure they are utilising hospice data when planning, delivering and monitoring services. This will require ICB investment in data systems and analysts. North West London has a data dashboard called WSIC, which records both NHS and hospice activity and shares information with all contributors. Martlets Hospice in Hove developed an outcomes data dashboard built upon the Outcome Assessment and Complexity Collaborative outcome measures for palliative care.

Question
How could the collection of data from ICSs, including ICBs and partner organisations, such as trusts, be streamlined and what collections and standards should be set nationally? (250 word limit)

Automated data collections by one organisation such as NHS Digital’s GP extraction service are time and resource effective. However, other national collections such as the Community Services Data Set (CSDS) are proving complicated to utilise. Hospices are mostly unable to extract and upload necessary data to the dataset for a variety of system, coding and capability reasons.

Information gathering is currently neither streamlined nor inclusive. Local systems set up their own dashboards like WSIC in North West London or capacity trackers like the Phew! App in Bedfordshire, alongside national datasets. Even workforce numbers are reported through a variety of national and local means, few of which include the hospice sector and other voluntary sector providers.

National bodies and ICS bodies need to agree which methods are most useful and effective for local service delivery as well as national reporting requirements. Direct national reporting by providers should only be used where this is preferable for ICB/ICPs and fed back to them for their use.

Most importantly, collection needs to be widened to include the service provision, outcomes and workforce across both health and social care, including providers outside the statutory sector.
Question
What standards and support should be provided by national bodies to support effective data use and digital services? (250 word limit)

The information standards developed by the Professional Records Standard Body, such as for palliative and end of life care, are key to national definitions for, and consistency in, what data is collected, recorded and shared by the multiple agencies involved in patient care.

NHSE’s Health Systems Support Framework and NHS Digital’s Health and Social Care Network (HSCN) accredited suppliers lists are helpful in nationally assuring system standards. However, implementing new HSCN connectivity or an electronic patient record system is prohibitively expensive and time-consuming for smaller organisations, such as hospices. ICBs should support smaller organisations with implementation, as their involvement is essential to the interoperability and completeness of datasets. However, digital and data systems require not just infrastructure but also staff training and skills in how to use them and analyse the data.

National negotiations with electronic patient record system suppliers would be helpful in ensuring data definitions, fields and codes are simple, consistent and relevant. Again, this is essential for interoperability and comparing datasets. As shared patient records and care plans are rolled out differently across the country, sharing good examples and lessons learned nationally is essential. Hospice UK is doing this for hospices on our Innovation Hub.

It is important to note that the standards for Electronic Palliative Care Coordinating Systems (EPaCCS), which capture and share information from people’s discussions about their care, were set in 2012. A decade later, roll out and usage is not consistent across England.

System oversight
ICSs are continuing to develop, and DHSC, NHS England and the Care Quality Commission (CQC) are still in the process of developing their working relationships with them. We recognise that there is significant variation in maturity, capability and performance between different systems and partner organisations, including trusts. This will require an appropriate balance between autonomy, support, regulation and intervention. We are keen to explore whether there are any principles we can identify to help set that balance.

Question
What do think are the most important things for NHS England, the CQC and DHSC to monitor, to allow them to identify performance or capability issues and variation within an ICS that require support? (250 word limit)

National bodies should work through the local accountability structures of ICBs, ICPs and local authorities. CQC regulation of the quality of service provision by individual organisations should remain but its assessment needs to be within the context of integrated care provision and partnership working. The performance of individual organisations should also be monitored alongside the ICB/ICP jointly responsible for the whole system’s performance. As with funding mechanisms, regulation frameworks must support whole system working not continue to individualise the providers within it.

ICSs should be held to account for publishing transparent, robust and consistent data against national targets, local frameworks and patient experience. This includes understanding the population need for palliative and end of life care, including unmet need; the palliative and end of life care services that are being commissioned; and the experiences of those who are, and are not, accessing these services.
It is important locally and nationally to monitor outcomes and what matters for patients and families. This can only be done by involving those with lived experience throughout the process, and not in a tokenistic fashion. It is also important to understand the reasons for unwarranted variation and why services are not meeting basic quality standards or expectations. However, the varied needs of different populations and historic starting points of systems must also be considered.

Question
What type of support, regulation and intervention do you think would be most appropriate for ICSs or other organisations that are experiencing performance or capability issues? (250 word limit)

NHSE should be supportive of ICBs as they attempt significant system and cultural change. The organisation should offer guidance, share best practice and input capacity and capability where required. DHSC should ensure the role of ICPs is not side-lined by ICB’s focusing on the NHS. DHSC should also ensure that voluntary and community sector organisations are seen as equal system partners and that social care is given equal focus to health care. This includes setting an example by working across government at a national level.

CQC will continue as the service quality and outcome regulator but their assessment framework for ICSs needs to assure they are also delivering the intended integration agenda. CQC should be assessing whether partnership working is real and widespread, voices are heard throughout the governance structures and if there is collective accountability.

Where ICS leadership is strong and partnership working apparent, intervention should be supportive. Where these attributes are clearly lacking, CQC will still need to hold individual organisations to account for patient safety and service quality, and the DHSC will need to reassess the leadership of the ICS bodies. Intervention could be through partnership with successful ICSs, a capacity injection to assist turnaround or an overhaul of finance and governance depending on the reasons for poor performance.

National bodies should not underestimate the time it will take to make such a significant cultural change. They should also avoid putting so much focus on short-term targets that they risk longer term priorities never being addressed.