Written evidence on the Health and Care Bill
Submitted by Sue Ryder

About Sue Ryder

Sue Ryder supports people through the most difficult times of their lives. Whether that’s a terminal illness, the loss of a loved one or a neurological condition. For over 65 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can. We take the time to understand what’s important to people and give them choice and control over their care. For some this may mean specialist care in one of our centres, whilst others might need support in their own home. With the number of people receiving palliative care services set to increase by 55% over the next ten years\(^1\) action is needed now to support the sector to meet this demand. Estimates suggest that while as many as 90% of people who die may have hospice and palliative care needs, only around 50% of people who die receive palliative care\(^2\), this must change.

To illustrate the scale of the support Sue Ryder provides across the UK, during 2019-2020 our services:

- Cared for 6,682 people in our hospices, or by our hospice at home teams
- 280 people were supported by our neurological services
- 111,622 people visited the Online Bereavement Community\(^3\)

Executive Summary

Sue Ryder believes that the policy intentions behind the Health and Care Bill are largely positive. However, our submission raises areas of the Bill that we believe need attention to better support people accessing palliative and end of life care. These include:

- The introduction of national standards to ensure all health, social care and voluntary groups are engaged with early and are represented within Integrated Care Systems (ICSs);
- A duty to commission sufficient palliative care services in all ICSs to meet population needs;
- The urgent need for reform for adult social care in England;
- A strategic plan for the health and care workforce that encompasses all providers, including the charitable sector;
- The adoption of consistent national frameworks across all ICSs to improve patient outcomes;
- A responsibility for commissioners to ensure individuals nearing the end of their life are offered conversations about their holistic needs, wishes and preferences.

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\(^1\) London Economics commissioned by Sue Ryder, Modelling demand and costs for palliative care services in England, 2021
\(^2\) Ibid. Report Executive Summary ii.
\(^3\) There when it matters - how we made an impact 2019-20, May 2020 www.sueryder.org/sites/default/files/2020-10/07202%20-%20Sue%20Ryder%20Impact%20Report%201920%2032pp%20FINAL.pdf
To reinforce these areas that need strengthening within the Bill, Sue Ryder is supporting the introduction of two amendments:

1) Commissioning of palliative and end of life care services **Clause 15** of the Bill provides Integrated Care Boards with duties to commission hospital and other health services for those persons for whom they are responsible. **We strongly believe that a duty for Integrated Care Boards to commission palliative and end of life care services should be included in this section.**

2) Patient choice **Clauses 67 and Schedule 11** relate to patients’ rights to make choices about their care and have the potential to help realise personalised care and support for everyone at the end of life, regardless of background or social characteristics. Putting people’s individual preferences at the heart of the care and support they receive is critical to improving end of life experience for all. **Achieving this would require a responsibility for health and social care commissioners to make provision for any individual nearing the end of their life to be offered conversations about their holistic needs, wishes and preferences.**

**Response**

1. **Integration**

The overall move towards integration and horizontal collaboration is welcomed by Sue Ryder. For this to be achieved, it is vital that the new statutory ICS bodies are fully accountable and there is genuine partnership between the ICS Board and the ICS Partnership. This is a significant opportunity for organisations involved in the ICS partnership to shape service provision and delivery, so time and energy must be spent on ensuring the governance and structures allow this to happen.

ICS partnerships must be truly representative, with the patient voice embedded in all levels of decision-making. Patient groups and voluntary sector providers like Sue Ryder have high levels of expertise relating to specialised services, and should be treated as equal partners to the NHS.

Whilst the NHS and its partners should have some flexibility to deliver joined-up care informed by local priorities, there should be a national standard to ensure that all areas of health, social care and voluntary groups are represented, reflecting the needs of the local population they serve. The removal of some procurement rules means there is a risk that high-quality voluntary sector providers like ourselves that are well-placed to meet local needs, are excluded as they are not aware of opportunities to collaborate in areas they do not already operate in for that locality. **We want to see a national standard that ensures all areas of health, social care and voluntary groups are represented within ICSs and that early and ongoing meaningful engagement with local providers and communities takes place.**

ICS partnerships are expected to embed provider collaborative leadership arrangements amongst specialist service providers. Yet it is still very unclear whether specialist service providers such as ourselves should engage at a place, regional or national level. Without more detail on how collaborative commissioning will work in practice, there is a risk that ICSs will simply become enlarged CCGs, and the expertise and voice of organisations such as ours is further lost.
Greater flexibility at a local level is helpful in terms of population health, but does risk geographical variation in care. This can be positive so long as health outcomes are achieved and people do not feel they are subject to a postcode lottery of services. Yet this risk is heightened for rare diseases, such as many neurological conditions, since their patient populations are too small for a ‘needs-based’ formula of commissioning of care. Therefore, further accountability and safeguarding are needed to ensure minimum national standards are met across the country.

The proposals may help provide more joined-up care across specialised and local services, and the expansion of patient choice rights is welcome. Having said that, with patients sometimes sent across the country for a specialised procedure, the proposals risk budget and accountability disputes between places and trusts. What’s more, considerable expertise is needed to commission care for rare diseases, again requiring a national approach with clear oversight.

It is important to remember that regulation and restructuring alone is not enough to engender integration and collaboration – cultural change is also needed. Whilst the proposals would remove barriers to better integration, ultimately the level of change on the ground will depend on the quality of local relationships – risking further regional variation. There is also a risk of dominance within the ICS partnership by larger providers, which would result in a loss of community and/or population responsiveness currently met by smaller providers and providers from the voluntary sector.

Additionally, the proposals come at a time when the NHS is severely overstretched and there is a danger that more reforms pose disruption, distract from the backlog of treatment, and fail to address the health inequalities laid bare by the pandemic. Whilst legislative changes are an opportunity to progress the integration agenda and bed in new ways of working adopted during the pandemic, in implementing these proposals the health and care system must not be overburdened.

2. Funding and commissioning

Funding for the sector remains a significant challenge, with a Sue Ryder-commissioned research projecting a significant funding shortfall if no additional statutory funding is forthcoming – a scenario which could see many palliative care services withdrawn in the coming years. Therefore the Bill presents an opportunity to review how services are commissioned.

It is clear that our services are valued and absolutely critical to good quality care, yet for historical reasons the sector relies on the goodwill of the public to fund most of the specialist palliative care we provide. As a result, funding agreements with commissioners merely assist in keeping us afloat rather than strategically plan to meet the current and future needs of local populations. Covid-19 has shone a light on the inequitable basis of the funding model for specialist palliative care. A long-term funding uplift is needed to place the sector on a sustainable footing so we can continue to provide its much-needed services, as part of the wider health and care system. However, to help meet the future needs of all local populations we are supporting an amendment for all Integrated Care Boards to commission palliative and end of life care services across England.

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4 London Economics commissioned by Sue Ryder, Modelling demand and costs for palliative care services in England, 2021
www.sueryder.org/hospicefunding
Defined mechanisms need to be established for the delegation of specialised commissioning budgets to ICS bodies. In particular, safeguards need to be in place to guarantee existing levels of spending on specialised services. Questions remain on how funding for existing services will be allocated to meet population needs. Charitable providers such as ours need urgent clarity on funding allocation or our services will be at risk, impacting people’s care and lives.

In the NHS Long Term Plan, hospices are cited as an example of best-practice personalised care. With the demand for palliative care projected to increase from 245,000 patients in the coming year to 379,000 by the end of the decade, hospice funding needs to be addressed now. Without a government commitment to significantly increase levels of statutory funding to cover clinical costs for palliative care services, there is a genuine and serious risk of services being withdrawn and patients and their families losing out on the specialist, holistic support that hospices offer.

Although we are clear that funding matters aren’t a concern of the bill, we believe it is crucial to highlight the pressures the hospice sector is facing for the context of this submission. A commitment to fund 70% of total palliative care costs is the minimum required to ensure the sustainability of the hospice sector and these vital services in the medium term. This would cost the government an additional £313m per year (a total cost of £663m per year). The alternative is likely to be hospice closures, resulting in the overstretched NHS having to provide end-of-life care services at a total cost of £834m per year for the government.

Without a concrete commitment to commission palliative care services in every ICS area, local governments will face further increased demand from those who need end of life care. Too many people already miss out on the care and support they need at the end of life – particularly those from disadvantaged groups. Estimates suggest that while as many as 90% of people who die may have hospice and palliative care needs, only around 50% of people who die receive palliative care.

**We believe that there should be a fundamental right to access palliative care services for everyone who needs it.** However, this right can only be met if relevant authorities have a duty to commission sufficient palliative care services to meet people’s needs. **A duty for ICSs to provide palliative care would recognise that care for people at the end of their lives is a core part of the health and care system.** This was recognised by the Government at the start of the pandemic with some one-off funding for the sector - we need to see sustainable funding and an ongoing commitment of access for everyone who needs it.

### 3. Workforce

Regrettably, the Bill does not address current chronic workforce shortages. In addition, the proposed duty on the Secretary of State to publish a report on workforce planning once every Parliament is too infrequent. Plans should include firm targets and the Secretary of State should be held accountable for meeting these.

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6 Ibid. page 11.

7 Ibid. Report Executive Summary ii.
Ultimately, there is an overall lack of strategic, integrated, long-term workforce planning. The pandemic demonstrated the need for a strong workforce across the NHS, hospice and social care sectors. There needs to be an overarching approach encompassing all of the health and care system; planning for one part of the system in isolation can actually create more problems for the NHS in the future, especially if social care services and other providers collapse. Furthermore, huge shortages across palliative and neurological care demonstrate the need more than ever for more comprehensive and urgent workforce planning.

The increases to National Minimum Wage, National Living Wage and public sector pay add further difficulties to our already underfunded sector. They impact on our ability to remain in line with the NHS as we are challenged to stretch our statutory funding in order to retain and recruit staff. We know how important receiving high-quality end-of-life care is, and our workforce continues to provide that, but without it patients would be putting significant extra demand on the NHS and social care services.

4. Implications on social care

The Bill fails to address the urgent need for reforms to adult social care in England. Despite the Government’s pledge of an investment of £36 billion (through the Health and Social Care Levy) to be invested in the health and care system, the majority will go to the NHS over the next three years, with social care receiving only £5.4 billion, including £500 million for the workforce. An additional £4.8 billion has been allocated to local authorities for social care and other services, although this hasn’t been ring-fenced solely for social care. This still doesn’t go far enough; once again social care is being left behind. No part of the system should be looked at in isolation.

We welcome the stronger central oversight and data collection of adult social care, but the pressing need for action on social care reform still remains and, until that happens, true integration will not be reached.

5. Additional powers for the Secretary of State

We welcome the attempt to improve the political accountability of the Secretary of State for the performance of the health service. However, along with many others, we believe more detail is needed on the scope, circumstances and oversight of the proposed additional powers for the Secretary of State, and how the government is held to account by Parliament.

6. Additional powers should be used to ensure consistency in the development of national frameworks

At present, policies such as NHS RightCare Pathways are not statutory so local systems are not compelled to develop them. This significantly impacts patient populations, especially people with neurological conditions, so further thought must be given to how people who are often left behind by the commissioning process are now brought back into the system so that their needs are met.

For any further information on anything in this submission please contact: Leanne Creighton, Policy and Public Affairs Manager, leanne.creighton@sueryder.org