CQC strategy consultation response – Hospice UK

March 2021

About us

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

People and communities

1a To what extent do you support the ambitions laid out in this theme?

- Hospice UK supports the ambitions in this theme.

1b Please give details

- We welcome the decision to put people's experiences and needs rather than providers at the heart of regulation, and also to prioritise those who face the most disadvantage in society.

- Enabling the input of feedback through multiple avenues is a positive step to allow greater accessibility and also to reach more communities. It will be important however to ensure that whichever channel people choose to use to comment on their experiences their information and views are treated, recorded, and responded to in the same way. The commitment to provide responses is a positive step in achieving this.

- Hospice UK has similarly committed to improving the input of people's experiences into our work, and reducing inequalities in end of life care is at the core of our strategy. Research indicates that people are willing to share their experiences, however fear of harm or perceived vulnerabilities relating to involving dying people in research and challenges around timescales and flexible avenues for input can result in a dearth of shared experience relating to death, dying and bereavement.

- These challenges are in part due to the nature of end of life care, however we would welcome the opportunity to work alongside CQC to establish the most effective ways of understanding and representing people's experiences of palliative and end of life care. We encourage the regulator to prioritise the gathering of these views, from every corner of the community, and to gaining a better understanding of what is happening for people at a time when the level of excess deaths remains high, and the place and journey of end of life care is different to the years prior to the pandemic.

- We welcome the emphasis CQC places on centring service users' perspectives and collecting feedback; further clarification will be needed as to how inspectors will use this feedback proportionally. CQC should elaborate how they plan to balance volume and severity when it comes to feedback. If CQC received a single piece of feedback that described a severe but isolated concern, compared to many pieces of feedback that may be individually less severe but indicative of systemic issues, how would this be reflected in assessments?

- We are pleased to see emphasis from CQC on both local health and care services and commissioners understanding the diverse needs of the populations they serve, and the need to work together to meet these needs and reduce inequalities. Hospice and end of life care services are often very collaborative in nature, working across systems including other voluntary providers, social care, physiotherapy, primary care and community services in order to provide holistic palliative care which best suits the person and their specific needs. This collaboration will be of increasing importance within new ICS models and it is good to see this highlighted in the CQC strategy. We encourage CQC, alongside the rest of the sector, to make use of population level data to better understand need. Hospice UK has developed a tool, PopNAT, which is designed to help the sector map what is happening across local areas.

- During the covid-19 pandemic in particular hospices have taken a leadership role in establishing and supporting partnership working in their local area, through forming care coordination hubs, linking with community services to provide support, and supporting care home staff to deliver care during the crisis. Three quarters (76%) of hospice leaders surveyed told us their support to care home residents and staff had increased due to covid-19.

- The interfacing of services including hospice care for someone at the end of life is something we would look to support CQC to understand and assess for the benefit of those receiving care. It would also be of benefit to focus on and capture the experiences of people as they move between services, including when transitioning between children's and young persons and adult services, to better understand the views of those with the most complex needs and to ensure that services link well together.

- It is particularly welcome to see the acknowledgement that a person's health and wellbeing is significantly affected by factors outside of health and care services.

- We are pleased to see CQC's proposal to work with voluntary and community organisations to develop a shared understanding of the factors that contribute to inequalities, and would be keen to work with the CQC on this as it is an area of focus for Hospice UK.

- We encourage CQC to move towards system regulation, rather than individual provider regulation. This is particularly important in palliative and end of life care, where people will interface with a very large number of services from a wide range of different providers.

Smarter regulation

2a To what extent do you support the ambitions laid out in this theme?

- Hospice UK supports the ambitions in this theme.

2b Please give details

- CQC's proposals around smarter regulation will require understanding of the unique way in which hospices operate, from sources of funding through to models of commissioning and service delivery. Support for palliative and end of life providers with gathering and analysing the data CQC will require would be welcome as well as transparency about how it will be used. Hospices and other palliative and end of life care providers are likely to have ever growing demands for data so the more this can be streamlined with processes that avoid duplicate, the better. We also hope that the evolution of how data informs CQCs approach (including ratings) will avoid stifling innovation and willing for positive risk taking.

- Moving away from a set schedule of inspections to creating a more flexible approach where care is assessed continuously is a positive proposal. This should create a regulatory system which understands, and therefore responds better to, the needs of individuals on an ongoing basis and sees the fuller picture of a person's care. Again the regulator's ability to meet this ambition will require a planned approach to gaining the experiences of people with palliative and end of life care needs and their families.

- We strongly support the strategic aim not to rely only on scheduled all-inclusive on-site inspection visits, but to use the full range of regulatory tools available to CQC. The vast majority of hospice care is provided in the community, away from the hospice sites or buildings. Policy initiatives, integrated models of health and care and personal choice of people receiving services are all likely to lead to more palliative and end of life care being delivered this way in the future. We believe CQC's proposed approach will therefore allow for a more accurate picture of quality.

- We are pleased to see proposals that intend to share data and information held on services with voluntary organisations, where it will help with their work to improve care. This should help create a more seamless experience for people and fill some of the gaps in data and information which can make it difficult to understand the holistic needs and experiences of those at the end of life.

Safety through learning

3a: To what extent do you support the ambitions set out in this theme?

- Hospice UK mostly supports the ambitions in this theme.

3b: Please give more details to explain why you chose this answer

The importance of culture

- We agree with CQC's assertion that organisational culture plays a key role in improving safety for both staff and service users and that safety must be a top priority for all regardless of seniority or role. We welcome CQC's proposed risk-based approach to regulating services.

- CQC aims to establish a national agreement on what is meant by "safety" and "safe care" in different health and care settings; some considerations remain, and further clarification will be needed:

  - In the proposals, CQC state that they will clarify how their definitions of "safety" and "safe care" will apply in different services. Despite CQC's commitment to not "look at how one service operates in isolation", it remains unclear how the assessment of safety and safe care will apply in scenarios in which, as is typical with palliative and end of life care, people are in contact with multiple services in the health and social care space. This will be especially true for children and young people. Families can be in contact with more than 30 professionals from education, social care, health and other services and often inadequate levels of communication between these different agencies means that families can be further burdened with stress as they attempt to navigate through uncoordinated systems.

  - There is therefore a need to assess how the integration of care and the effectiveness of coordination impacts safety as opposed to focusing on individual providers.

- o CQC do not explicitly mention how these safety considerations will apply to care that is not provided within dedicated health and care settings, such as in the community, in people's homes. For example, over 80% of hospice care is provided in community-based settings. Further clarification will be needed as to how CQC's assessments of safety will apply in these settings.

- o CQC also state that their definitions of "safety" and "safe care" will reflect the priorities of service users. From a health inequalities perspective, it will be important for CQC to also reflect the views of communities with unmet need who currently face barriers to access and are not in contact with these services.

- o We welcome the emphasis CQC places on centring service users' perspectives and collecting feedback; further clarification will be needed as to how inspectors will use this feedback proportionally.

- o In palliative and end of life care settings, the perspectives and feedback of families and loved ones will also be an important consideration, particularly for those who may be receiving related services themselves (for example respite care or bereavement support). Consideration will also need to be given into how people who are experiencing loss (or impending loss) are supported to give feedback in a way that is sensitive to their situation.

- CQC proposes that safety assessments will also focus on checking for open and honest organisational cultures – so that risks are not overlooked or hidden, and staff can report openly and honestly. We agree that this is a positive direction of travel, but more clarity will be needed on what this will look like in tangible terms.
Organisational cultures vary widely, not just within sectors, but amongst services themselves, as such, a one-size-fits-all approach to what an open and honest organisational culture looks like will not be tenable.

- We agree with proposals to share insights, learning, and exemplary practices that have resulted from their regulatory action so that all services can learn from one another and improve. It is important that palliative and end of life care services are represented in this work and for these proposals to take a full life course approach, including for bereavement, in the practice examples they seek and promote.

Building expertise

- We agree that knowledge is crucial to having the right safety cultures and that shifts in safety culture won't happen without the right expertise at all levels across health and social care – including at CQC. The makeup of palliative and end of life care services is ever changing and the scale at which they are delivered continues to grow. Care is provided by both specialists and generalists, and increasingly within the community.

- We welcome CQC's encouragement of providers to demonstrate their proactivity when it comes to learning, providing training and support, and using information and data. The size and budgets of palliative and end of life care providers greatly varies, and regulation will need to recognise different approaches to learning offers. Hospice UK offers providers a range of learning and support opportunities through resources, networks (for example Project ECHO) and the Gold Standards Framework.

- We also welcome CQC's acknowledgment that accurate assessment of safety cannot happen unless they increase their own in-house expertise.

- Further clarification will be needed as to how this will be assessed and how inspectors will account for proportionality; different services will have varying resource that can be ring-fenced for investing in training and support, for example.

- CQC state that the aim of their proposals is to "minimise harm"; further explanation and clarity will be needed in how this will apply in palliative and end of life care settings where what constitutes good and poor outcomes can differ significantly from the rest of the health and care sectors. For example, for health and care settings outside of the palliative and end of life care sector, the focus is rightly on rehabilitation and recovery. There will be need for CQC to shift this lens when assessing palliative care services, where staff adjust care towards quality of life and anticipating and planning for death.

- The regulator is correct in wanting to identify gaps in support and safety expertise and state they will work with others to meet this need. We encourage CQC to use the considerable existing expertise that may exist locally and regionally.

- For example, there are existing regional palliative care networks that would be able to provide valuable insights regarding their local contexts, such as:

  o Pallaborative North West, a collaborative of health care professionals working in specialist palliative care, patients, and members of the public from across the North West of England committed to improving palliative and end of life care.

- o Children's Hospices across London (CHaL), a charity that brings together six children's hospices to improve and increase the services offered to children and young people with life-limiting or life-threatening conditions.
- o Hospice UK leads the Executive Clinical Leads in Hospice and Palliative Care (ECLiHP) network, a forum for executive clinical leaders engaged in the strategic planning and operational delivery of hospice care. With dedicated leads in 14 regions across the UK, there is considerable regional expertise that could inform CQC's work.

- We encourage CQC to examine and highlight the considerable work hospices engage in providing educational support and training to other parts of the health and care system, for example:
  - o Care homes in Wigan Borough were offered free training in end of life care from Wigan and Leigh Hospice. The charity offered training to all 22 nursing homes and 31 residential care homes in the borough to help them deal with the challenges of the Covid-19 pandemic.
  - o At the request of a local health lead working for a prison healthcare provider, St Peter's Hospice in Bristol held a virtual training session for prison nurses from five prisons in the Bristol area with no experience of delivering end of life care. Prison staff were anxious at the prospect of having to deliver end of life care within the prison, in a climate exacerbated by Covid-19. Their anxieties included managing multiple patients at the end of life within the prison and handling Covid-19-related medication shortages. The sessions that the hospice delivered were invaluable, putting worries at ease. An attendee attested, "anxieties were so high prior to it, but after, they were much more comfortable around the prospect of end of life care."
  - o In January 2018 Mountbatten Hospice was awarded a contract by the Isle of Wight Council to help maintain and raise standards across the care sector. The council commissioned the hospice to design, with the support of existing good and outstanding providers, a learning and development programme for every CQC Registered Manager on the Island – free to those managers at the point of delivery. The "Island Better Care Programme" supports Registered Managers to understand what is needed under the CQC's inspection format and how they can meet criteria for being safe and well-led. As of July 2019, Mountbatten had welcomed 71 of the Island's 105 registered care services onto the five-day programme. The work contributed to 85% of the nursing homes, care homes and domiciliary care providers who have taken part in the programme have seen their CQC ratings either improve to, or remain at, "good" on re-inspection.

- We agree with CQC that strong leadership contributes to a culture of safety, and these are just a few of the many examples demonstrating how hospices help embed this culture in other parts of the system in which they operate.

Involving everybody
- We agree that leaders, staff, and service users' perspectives must be taken into account to ensure safe, high-quality care and welcome CQC's encouragement of this collaborative approach.

- Regarding CQC's proposal to assess services on how they are involving people, as previously stated, it will be important to account for the perspectives of those with unmet need who are not currently in contact with and face barriers to access to these services in order to improve accessibility.

Regulating safety
- We welcome CQC's acknowledgement that some of the greatest safety risks occur "when people struggle to access the right care, when they're transferred between services or after they're discharged."
    o The question remains as to how CQC propose to either themselves, or assess how services, take into account the views of those with unmet need who are not in contact with them.

- We welcome CQC's recognition of the variable nature of services, the safety risks they may pose, and how these systems can make it hard for staff to take the right and safest action.

- Further detail will be needed regarding what CQC considers good and poor culture, how this impacts safety and risk, and as previously stated, organisational cultures vary widely and as such, a one-size-fits-all approach to what a "good" culture looks like will not be tenable. We wish to avoid any approach that inadvertently links good culture with maintaining and reinforcing the status quo. We know that one in four people who need palliative and end of life care miss out on the full support they need, and changing this should be at the heart of a good culture.

- We agree that learning and improvement must be the primary response to all safety concerns in all types of service and welcome this line of service assessment and push for public transparency from CQC.

- We welcome CQC's commitment to faster intervention where they identify risks to service users and instances where improvement is not timely or sustainable; again, further clarification will be needed as to how they propose to use service-user and staff feedback proportionally.

- We welcome CQC's commitment to assessing service collaboration and patients' care pathways between services. Palliative and end of life care is an exemplar of a multiagency system, involving: the NHS, social care, the voluntary sector (notably, charitably funded hospices), communities, families, and carers. We encourage CQC to identify and share this good practice.

Consistent oversight and support

- CQC recognise that to improve safety, service providers may need support and guidance; they recognise that national support and oversight does not exist in all sectors.

Accelerating improvement

4a: To what extent do you support the ambitions set out in this theme?

- Hospice UK mostly supports the ambitions in this theme.

4b: Please give more details to explain why you chose this answer

Collaborating for improvement

- CQC recognise that the support that's available to help services improve the quality of their care varies between and within health and care sectors and we welcome the aim for all sectors to have equal and consistent access to the support they need to improve.

- We also welcome CQC's aim to establish and facilitate national sector-wide improvement coalitions with a broad spectrum of partners within both health and care, including those representing people who use services.

- It will be important to take into account the perspectives of the voluntary sector; charitable organisations often sit at the heart of their communities, providing essential services that meet otherwise unmet needs. They hold valuable data and insights regarding the local populations that they serve, which will pertain to their health outcomes and the wider determinants of health. Engaging these organisations will be critical to reflecting service users' perspectives.

- Charitable organisations are not only community connectors, some are also providers of essential, specialist clinical care, such as charitable hospices. They are an integral part of the palliative and end of life care sector, delivering

palliative and bereavement care to 225,000 people and their families each year across the UK.

- We welcome the proposal to establish national sector-wide improvement coalitions and the recognition that they will need to work collaboratively to improve the availability of support, focusing on areas where there are gaps, both nationally and at a local system level.

- We encourage CQC to engage with the considerable existing expertise within regional collectives of providers, for example, hospices often seek and take a leadership role in local systems.

- The Leeds Palliative Care Network brings together charitably funded hospices, acute hospital trusts, community providers, the local authority, commissioners, and a wider range of voluntary sector organisations. Key successes of the group include ensuring palliative is a core component of the Leeds plan for health and care, supporting the development of the Leeds Care Record (a single city-wide joined-up digital care record) and driving standardisation and consistency (for example, in advance care planning and education).

Making improvement happen

- CQC states that the concept of "good" care rapidly changes, with the benchmark getting higher; as such they want to encourage continuous improvement in quality. Clarification will be needed as to how CQC propose to assess services proportionally and how they will strike a balance when encouraging improvement in a timely but sustainable manner.

- We welcome CQC's collaborative and supportive rather than didactic approach in encouraging improvement amongst services. Hospice UK has received positive feedback from hospices regarding the supportive approach the regulator has taken during the covid-19 pandemic.

- We welcome the proposal to offer benchmarking data so that services can self-assess how they are performing against similar services and areas.

Encouraging innovation

- We agree with CQC's recognition of the improvement opportunities presented by innovative practice and technological change. When "championing" innovation and technology-enabled services, it will be important for CQC to remain proportionate in their assessments as innovation can be resource-

intensive from both a funding and workforce perspective. It will be important for CQC to encourage a balance between pace and sustainability.

- We agree with CQC that consideration of how the use of technology may disadvantage people and we encourage the assessment of digital exclusion.

An approach based on evidence

- We welcome CQC's stated data- and intelligence-led approach; we encourage CQC to partner with service providers and Hospice UK in their commissioning of research to inform and build their evidence base regarding palliative and end of life care; there is a considerable existing body of research in this space that CQC would benefit from examining prior to further investment.

- Data-driven working will require understanding of the unique way in which hospices operate. We welcome the support that CQC propose in gathering this information, but further clarification and transparency will be needed as to how this data will be used.

- As with other providers facing increased demand and pressures in the wake of covid-19, hospices are likely to have ever growing demands for data (for example, from ICSs and Government). As such, we encourage CQC to adopt a streamlined approach that does not lead to duplication.

5a. To what extent do you support our ambition to assess health and care systems?

- Hospice UK strongly supports the ambition to assess health and care systems.

5b. Please give more details to explain why you chose this answer

- We encourage a move towards a more integrated, joined up approach to regulation of the health and care system that focuses on the needs and wishes of people with palliative and end of life care needs.

- We believe it is important the regulator reflects the shift towards further integration across health and care, which continues to develop through moves to establish Integrated Care Systems in all parts of the country. With current proposals to place ICSs on a statutory footing, CQC's proposed ambitions should help to ensure the regulator is proactive in ensuring system changes do not allow standards of safety and quality of care to slip. CQC will need to

be flexible to changes that occur as a result of the recent Government White Paper on health and care reform.

- Palliative and end of life care is delivered by a range of professionals, generalist and specialist, in a range of settings. Provision of that support can look very different depending on your geographical location, place, health condition or any protected characteristic. Developing assessment frameworks that deliver the information and reassurance people need, and the safety and quality of care they deserve, will be challenging. A CQC review of end of life care services in 2016 found while over 90% of hospices inspected were rated by CQC as good or outstanding, 42% of end of life care services in acute hospitals were inadequate or require improvement. Often that level of variation exists within the same local health and care system, and problems are often felt most acutely at the interface between different services

- A broader, system wide view of assessment must not mean focus is too top-level, drawing away from health and care outcomes identified by and for people. CQC should make use of its own commitments in "Integrated care: our shared commitment" which outlines what good, coordinated care is to the individual.

- CQC will need to ensure assessments of systems still translate to accessible information for the public who are likely to be faced with a myriad of individual services. People, their families and carers need to be able to recognise how their experience of palliative and end of life care fits within a system led approach.

- Hospice UK are keen to support CQC through this transitional process that recognises the policy direction towards Integrated Care Systems will take time to develop and become functioning entities. The regulator will need to recognise that different areas will see a change in practice and governance occur at different rates. A flexible response to regulation, with close communication with ICS boards and committees as well as services, will be key.

- Assessment of systems should not assume all parts of the system are able to behave and respond to assessments in the same way. Though progress towards integrated ways of working is swift, individual contracts and variable funding and support are still an important aspect in determining what individual services can do. This is particularly pertinent for those who rely on charitable fundraising, which makes up the majority of hospice funding, and the struggling social care sector. Hospice UK would welcome CQC's support in work to develop a model of funding palliative and end of life care that is equitable and better integrated within the wider health and care system.

- Through activities and services funded by charitable fundraising, charitable hospices act as commissioners themselves, seeking to meet the palliative and end of life care needs of the local population. Frequently this enables hospices to be flexible and innovative in approach, and the unique way in which this part of the system operates will need to be understood and factored into assessments of local systems.

- We believe there is currently a blind spot regarding the ability to assess local systems' approach to end of life care, with local authority commissioning processes of social care currently out of scope. We would support a move to give CQC further opportunity to assess this key part of end of life care provision. In 2020 23% of people in the UK died in care homes and many of the further 28% who died at home and others who died in hospital will have received some form of support from social services.

- Hospices often seek and take a leadership role in local systems. We believe this matches well with CQC's emphasis on strong leadership contributing to a culture of safety, and we have seen some hospices help to spread that culture to other parts of the system in which they work during covid-19, for example in care homes. Within local system assessments we encourage CQC to identify and map how local leaders offer expertise and knowledge that benefits people using services outside of their own remit.

6a. To what extent do you think the ambitions in the strategy will help to tackle inequalities?

- Hospice UK believe the ambitions in the strategy will help to tackle inequalities, providing they are followed with action.

6b. Please give more details to explain why you chose this answer.

- Tackling inequalities as a core element of the new strategy is a positive and welcome move and we support the intended focus on people who are the most disadvantaged in our society, have had distressing or traumatic experiences, and are more likely to experience poor outcomes and inequalities.

- As a complex issue that has been a part of the national health policy agenda for many years, only by applying this ambition to everything the regulator does are we likely to see progress. We believe that CQC has a role in showing leadership in this area and responsibilities to people using services, with as many as 1 in 4 not receiving appropriate palliative and end of life care

services. We are confident that this approach will result in a trickledown effect, encouraging a similar culture among services.

- In 2016 CQC carried out a review into how dying patients are treated across different settings. A [resulting report](#) on addressing inequalities in end of life care found that where commissioners and services are taking an equality-led approach that responds to people's individual needs, people receive better care. It recognised that 'achieving good quality, personalised care at the end of life for everyone is the responsibility of the health and care system and the wider community'. The report made a recommendation which we would want to see echoed through the new CQC strategy: 'Leaders of local health and care systems to work together to develop a plan for delivering good quality, equitable end of life care for everyone in their community'.

- It is essential that neither the regulator nor the systems CQC assess are allowed to lose sight of what is important, impact and outcomes for people. The success of this strategy will depend on how the ambitions are carried out, not by the ambitions themselves. The strategy out for consultation is to be commended for ambition, however it remains top level, and both the detail and the plans that sit behind it will be the main driving factor. For example the consultation states CQC will 'support local systems to understand the needs of their local populations' but at this stage gives limited additional detail on how that will happen.
The strategy also states a wish to 'reduce variation in safe and quality care', but appears neither specific nor detailed on how services ensure access to services in the first place, which is often the first significant driver of health and care inequalities.
Hospice UK would welcome the opportunity to support CQC in further developing those plans, and in working to align our own strategic objectives in this area to those of the regulator.

- We are concerned by the lack of consistent data, evidence and testimony relating to palliative and end of life care across all health and care settings. There is an even greater gap regarding care for people with protected characteristics and/or facing inequalities in access and quality of care. The new CQC strategy states 'we want to understand why there's such variation across the country' and we believe this will not be possible until the need for evidence from all corners of the community is met.

- In practice we hope this part of the strategy will lead to more lines of communication for people using services to be delivered through voluntary and grass roots organisations, both operating within the health and care sector and outside it.

- Services need to ensure they are recording data relating to protected characteristics as required by the Equality Act 2010. The regulator should be proactive in checking that this is happening across local systems.

- The strategy highlights a desire to give inspectors the tools, resources and skills to talk confidently to providers about inequalities for people with protected characteristics, and take appropriate action. This is positive but there also needs to be equal if not more energy behind reaching and talking to people in receipt of services and their families. Hospice UK encourages CQC to include specific KPIs for contractors seeking and supplying Experts by Experience to include people with protected characteristics. Current KPIs for recruiting Experts by Experience are instead focused on the timescales of providing experts by experience.

- The regulator should avoid placing too much emphasis on assessing organisational policies and procedures, which alone do not adequately reflect the required organisation and system wide emphasis on an inclusive and fair culture.

- The new strategy champions everyone having better quality of care and helping providers to reduce inequalities and share best practice. While a positive approach, CQC will also need to be tough on systems that enable inequalities relating to health and care to continue. If the regulator is able to build a better understanding of what drives these inequalities, it will need resource and a full range of regulatory tools to put measures in place to make necessary change.

- We encourage CQC to focus on improving understanding of and tackling inequalities through plans to 'invest in new research'. As outlined earlier in our response this investment should first incorporate a stock take of existing research, something Hospice UK would be keen to support with.

- It is essential the two main strategic priorities around systems and inequalities interlink and drive one another forward. For example making use of population level data from across systems and system assessments should be used by the regulator to steer how those systems (and CQC itself) tackles inequalities. This should be true of combatting challenges around inequalities both in the immediate and also in planning for the health and care provision needed for the future.

For further information please contact policy@hospiceuk.org