

# Care Quality Commission: 2016 to 2021 strategy consultation



## A submission from Together for Short Lives

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### About Together for Short Lives

1. Together for Short Lives is the UK charity for all babies, children and young people with life-shortening conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

### What is children's palliative care?

2. Children and young people with life-shortening conditions need palliative care from the point at which their condition is diagnosed or recognised - often at birth - until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including after they have died.
3. Children's palliative care is different to palliative care for adults. Whereas the majority of adults only need palliative care at the end of their lives, children with life-shortening conditions require palliative care over a much longer period, often from birth as they live with the instability of their condition. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-shortening conditions often have complex disabilities, while the range of health conditions which results in children requiring children's palliative care is more diverse. Children's palliative care is an approach to care in conjunction with curative treatments.

### Our response:

4. Our response was informed by our members who work across a number of services in support of children and young people with life shortening conditions.
5. As a general introduction to our response to the specific questions raised in the consultation we would like to work closely with the CQC to help improve understanding and engagement with those who are and should be providing services for children and young people with life shortening conditions and their families. We would also like to work with the CQC to help improve transparency and accountability by sharing information on data on the commissioning of services across the country.
6. We believe that this population, small in number, but critical in terms of the complexity of their care needs, is often overlooked or misunderstood by commissioners and policy makers. A key theme of this response therefore is the recognition of the difference between adult and children services. Understanding of care and services to meet those needs is undermined by a 'one size fits all' approach across adult and children service. We strongly recommend that CQC recognise this in their approach.
7. We also call for regulation that is proportionate and helpful, recognising that many service providers are charities, keen to maximise the focus of resource on providing care and support.

**Question 1: Do you agree with these 4 things that people should expect from health and social care in the future?**

8. We and our members welcome a consistent and fair approach to regulation. We and our members are concerned that the current system for regulating children's hospice services, (which are independent children's healthcare services) appears geared towards adult hospices. An example from our members relates to the PIR form; in the section on safety the only things referred to are the number of DOLS applications and there is no request for information about safeguarding children incidents/referrals. On the PIR form in the section on 'Death', there is a question about the number of service users who died whilst a DOLS application was in place, but no question about whether the Child Death Review certification had been completed and whether the organisation participated in the Child Death Reviews. The only clinical safety question is about medicine errors, nothing about other adverse clinical incidents or infection control. This raises concerns about the effectiveness of a single, shared view of quality, when there is important difference about service delivery.
9. We recognise and welcome the work that CQC has done with Together for Short Lives to make sure that the PIR fairly reflects children's palliative care. We ask that the CQC goes further to make sure that children and young people's needs are assessed accurately and in a way that ensures funding will follow need, rather than needs having to fit available funding. This is key to ensuring that a person centred rather than system centred approach is delivered.
10. We therefore look forward to the development of more child appropriate tools and literature. We would welcome the opportunity to assist in this. Linked to this we would like to see more inspectors of children's palliative care services who have prior experience of services working with children. We recommend that there is a monitoring framework that is specific for children's hospices - the current use of the joint framework for both adult and children's hospices does not sufficiently recognise the difference between adult and children.

**Question 2: Do you agree that we should use information, including what people tell us, even more?**

11. We recognise that the CQC has already addressed one main part of this, by the new inspection method being much more focused on clients' (patients and families) own feedback of the quality of the service they experience. The CQC could build on this by asking clients 'What would make for better joined up care? Who isn't talking to who, and what effect does that have on you?'
12. Some members have concerns about information governance issues. Concerns are that the CQC is able to over-ride information governance boundaries that everyone else has to comply with, (in seeking person identifiable information from providers with no formal information agreement establishing the parameters of this). We would like clearer information and guidance regarding this.
13. Members are concerned that quantitative information does not portray a full picture of service quality and believes it is important that information gathered includes qualitative information.

14. Similarly, CQC must be mindful that information shared on social media is not always accurate, often reflects just one perspective, and can be unreasonably expressed.
15. It is important that staff can share their views about a service and that the CQC can also access the views of users who are experts by experience.
16. Some members reported that their staff found the CQC framework is useful for talking through what is needed with staff. They also value advice from inspectors, the phone line and the website, and the star ratings and ratings map are considered helpful. As a result, some felt the existence of the CQC does contribute to ensuring that children and their families receive high quality care.
17. This broader issue of transparency does tie to a broader challenge for the sector and commissioners. A lack of coherent and published data on the number of children and young people with life shortening conditions and detail of their condition means it is difficult for commissioners to understand the needs of this group and then to budget accordingly. We would welcome any opportunity to consider how this might be addressed through the CQC work.

**Question 3: Do you agree that we should change the way we check services, even if this means doing some inspections less often?**

18. If we are collectively committed to raising standards, then we believe it makes sense to focus attention on those that need helps in meeting that standard the most.
19. In the same way that, where there are schools with a record of achievement at good or outstanding, Ofsted will reduce the frequency of visits – this is a good idea because it is unlikely that the standards of a service will rapidly deteriorate and it will reduce the cost of regulation.
20. However, more needs to be done to tailor inspection activity for children's health services, including hospices, under the adult social care umbrella to be more age appropriate/child focussed – for example less emphasis on DOLS and mental capacity and more on safeguarding children, meeting children's needs for play and learning etc.
21. Members express frustration that at the moment the different requirements of different bodies, (for example the quality standards of the standard NHS contract; the content of the NHS Quality Account, and the CQC requirements) are broadly similar, but all different. This means having to complete a number of returns for different organisation, instead of having a shared one. This is particularly onerous for small organisations and adds to a compliance burden which is disproportionate. This is also an issue which leads to charitable organisations spending more and more money on staff and resources which are not perceived by the general public as involved in the direct care giving work of the charity they have voluntarily funded – this makes for difficult PR questions. It is encouraging to think that the CQC will be working with partner organisations to help bring all these different systems/processes into one coordinated requirement.
22. Members have expressed a view that they would not want the focus for independent health care to be on increasing engagement with providers at the corporate level to test their oversight of quality of care at individual locations, (as stated in the consultation) to be at the expense of visiting individual locations. The current CQC approach of visiting

services and spending the majority of the time with the users of the service and with staff is welcomed.

23. In the vision for quality regulation in 2021, the CQC says: 'People trust and use expert, independent judgements about the quality of care.' Some members believe there is a challenge to achieving expert and independent judgements in the children's hospice sector as it is such a small and specialist field.
24. In the CQC 'implementing our vision over 5 years' the CQC says: 'We will support our staff and develop the right processes, capabilities and behaviours to deliver our purpose'. This is absolutely critical because children's hospices do not yet have inspectors with the 'capabilities' to deliver their purpose. We welcome that the CQC have approached TFSL for training for their inspectors – but this process has only just started.
25. We would therefore highlight that in terms of a focus on assessing quality for populations (theme 6), the CQC could benefit from more tools and resources related specifically to child-focussed services
26. Feedback from some of our members suggests that the new inspection methods are already much more responsive and accurate in their reflection of true service quality. Many of the proposals would continue some positive trends, such as the use of Experts by Experience as a way to improve the use of data and information, if they are genuinely appropriate to the services being inspected (theme 1), implementing a single shared view of quality (theme 2) and the targeting and tailoring inspection activity (theme 3) - as long as this is done in a consistent way across England and with improved communication around the inspection process. Improved consistency in the approach of CQC inspectors is a main concern for our members. A streamlined approach to the administration around registration (theme 4) would also be welcome for reducing the burden on service providers.
27. Some members expressed a view that all services applying for new registration should be treated in the same way, the scrutiny and process should be the same regardless of who is registering the new service.

**Question 4: Do you agree that we should check how well services work together?**

28. There is long identified gap between health, which in the NHS focuses mainly on children with a Continuing Health Care need (only one third to one half of children with a life-limiting or life-threatening diagnosis), and social care, which focuses on children at risk or families in crisis – in other words, on very late interventions. Nowhere in that gap is there a preventative strategy for managing stress and breakdown in families grappling with the round-the-clock care needs of their child. But there may also be gaps between statutory and voluntary services that a more client-focused inspection would shed light on.
29. High quality care is dependent on a joined up approach with comprehensive planning and commissioning of services in both statutory and charitable sectors to provide appropriate care. Yet it is important that regulation is proportionate budgets of charities are significantly less than those of a large NHS Trust, and tailoring contracts and monitoring accordingly.
30. Safe effective and cost effective children's palliative care requires effective partnership between specialist children's palliative care, other providers especially community

children's nurses, children's hospices and other providers such as primary care and hospital paediatrics. We therefore encourage the inspection to include an element of assessment of partnership working and networking but to be mindful of where responsibility for this partnership forming should rest. We also call for a consistent approach across CQC inspectorates to regulating children's palliative care services regardless of the setting in which they are delivered.

31. The CQC should continue to develop the approach of looking at patient journeys across services as well as within a service. There is wide variation here, particularly with the level of involvement of primary care services. The efficiencies could be examined for different provision of services to similar conditions.

**Question 5: Please tell us below if there is anything else you would like to say about our plans.**

32. Some member have expressed strong concerns that there has been a move to raise the rating bar and expectations for hospices. Standards ratings should be the same whatever the service.
33. In terms of consistency, teams, geographically dispersed, have had very different experiences of CQC inspections. For example, some have been inspected more frequently than others, some but not all know the name of their lead inspector, some have had a pre inspection checklist which distinguishes between adult and child services, and some have not.
34. In terms of communication, members report many of staff have completed repeated pre inspection questionnaires but have had no subsequent communication to inform them of the process following this and whether or not they will be inspected. Improving communication so that the process is clearer would be welcome.
35. Some members report concerns over service clarification. One member, for example, offers a unique service which is hard to fit into the existing CQC categories of service providers. They are registered under 'personal care' but would like to see a wider definition of 'personal and social care' which would be a better fit for their services, in the same way the category of 'Accommodation for people who require nursing or personal care' brought together both residential homes and nursing homes under one category.