

## Care Quality Commission (CQC): Our next phase of regulation

### A consultation response from Together for Short Lives

February 2017

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#### Summary of our response

1. Together for Short Lives agrees with the CQC's proposal to streamline the assessment frameworks, and to place children's hospices within the hospital framework.
2. We offer our help to make sure that individuals responsible for inspecting children's palliative care services understand what children's palliative care is, who provides it and what the important differences are between the settings in which it is delivered. In particular, we are keen to make sure that inspectors understand that children's palliative care is a holistic approach which includes medical and non-medical elements.
3. We ask that CQC uses the opportunity of a new approach to regulation to make sure that a consistent system is developed for inspecting children's palliative care services, regardless of the setting in which it is provided. Some of our members have reported a number of incidences under the currency system whereby inspections have been inconsistent and disproportionately focussed on issues relating to the professional backgrounds of the inspection teams.
4. We ask that CQC takes a fair and proportionate approach to regulating children's palliative care services which reflects the sectors, settings and age range of the people to whom the sector offers care and support.
5. We offer to work with CQC to make sure that it can assess the way in which networks of providers offer joined up care to children and young people with life-limiting conditions. We also offer to help develop descriptors of different types of hospice service for both children and adults.

#### About us

6. Together for Short Lives is the UK charity that, together with our members, speaks out for children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.
7. We are a membership organisation and represent professionals and organisations spanning the statutory, voluntary and private sector who provide palliative care to babies, children and young people. Our members also include families of children and young people with life-limiting and life-threatening conditions. We have asked our members for their views on CQC's proposals; this response is informed by their feedback.
8. We would welcome the opportunity to continue to work closely and in partnership with CQC to engage the children's palliative care sector and help implement the proposed reforms.

## **Our response**

### **2. Do you agree with our proposal that we should have only two assessment frameworks: one for health care and one for adult social care (with sector-specific material where necessary)?**

9. We agree with this proposal.
10. Children's palliative care is often confused with adult's palliative care. Many people think that only children at the end of their life can benefit from children's palliative care. This is not the case. Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancing quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.
11. We ask that CQC inspectors take this into account. In placing children's hospice services within the healthcare inspection framework, we ask CQC to fairly and proportionately inspect the important non-medical care which children's hospice services provide, in addition to the medical elements.
12. Together for Short Lives is keen for CQC to bring about a consistent approach to regulating children's palliative care regardless of the setting in which it is provided. These settings include hospitals, children's hospices, the community and in children and young people's homes. A number of children's hospice charities, for example, provide palliative care to children and young people in the community through hospice at home services, in addition to inpatient services.
13. Children's palliative care is also provided by a range of sectors, including the voluntary sector (which provides all children's hospice services in England) and the statutory and private sectors. NHS community children's nursing teams, for example, play a crucial role in supporting families to provide palliative care to children and young people with life-limiting or life-threatening conditions at home.
14. The current system means that children's hospice services (including both the inpatient and community services they provide) are regulated by the CQC's adult social care inspectorate. All other types of children's palliative care services are regulated by the hospitals inspectorate. This increases the risk of inspectors taking inconsistent approaches to regulating children's palliative care. By placing children's hospices within the healthcare framework, therefore, CQC has an important opportunity to align its regulatory approach for all types of children's palliative care service. It could also help to bring about approaches which fairly reflect the differences in palliative care needed by children and adults.

### **3. What do you think about our proposed changes to the key lines of enquiry, prompts and ratings characteristics? What impact do you think they will have?**

15. Overall, we believe that most of the new key lines of enquiry are reasonable and can be applied to different types of children's palliative care provider.
16. The new key line of enquiry W7.4 requires providers to have 'positive and collaborative relationships with external partners to build a shared understanding of challenges within the system and the needs of the relevant population, and to deliver services to meet those needs'. While we welcome this, we ask that CQC assesses the extent to which

providers seek to collaborate and demonstrate collaborative behaviours, rather than how well two or more providers actually collaborate. One provider can only control how it seeks to collaborate; we do not think it would be fair for a provider's rating to be adversely affected if another provider with which it was seeking to collaborate refuses to do so. For example, if a children's hospice service seeks to work with its local NHS trust, but the latter is unresponsive and unwilling to collaborate, how will this be measured by the CQC?

17. We ask that CQC develops a set of indicators to measure how well an individual provider is seeking to collaborate. One such indicator could be the extent to which a service setting is prepared to allow a professional employed by another service to work within that setting. For example, this could be an NHS trust allowing a member of a children's hospice service's care team to provide care within a hospital setting, or vice versa. We also ask CQC to clarify how a service can achieve an 'outstanding' rating for the way it collaborates.
18. E5.5, which is listed as a 'core' new key line of enquiry, states that providers must be seen to support national priorities to improve the population's health, for example in encouraging people to stop smoking. We ask that this is applied proportionately by inspectors. We do not feel that it would be fair to rate children's hospice services, for example, on the extent to which they encourage those using their services to stop smoking, given that the majority of those using these services are children, including babies and young children. We ask that a note be added to the key lines of enquiry to explain that they must be relevant and proportional to the type of provider that is being inspected.
19. We do not understand why GP practices are exempt from several of the key lines of enquiry. GPs should form part of the network of providers which care for and support children and young people with life-limiting conditions - and should be inspected in a way which is consistent with other types of provider. It is common for GPs to provide some healthcare as part of children's hospice services, and some children's hospices services have service level agreements in place with local GP practices. They therefore expect practices to uphold the same standards of care as they adhere to. For example, it is unclear why GP practices are exempt from S2.5 'Are comprehensive risk assessments carried out for people who use services and risk management plans developed in line with national guidance? Are risks managed positively?'.
  20. We also ask that CQC takes steps to make sure that its inspectors understand the differences between different types of services provided by different sectors, in different settings and to different age groups. For example, we ask that inspectors understand the important factors which differentiate the care offered by children's hospice services and hospitals:
    - Children's hospice services offer a holistic model of care which spans health and social care, and different children's hospice services provide varying degrees of clinical care.
    - Some children's hospices provide medical care 24 hours a day, seven days a week, while others do not.
    - Children's hospice charities are often small organisations in both scale and resources. While prioritising infection control, children's hospices have different approaches to this compared to NHS trusts.

21. The extent to which a children's hospice adopts a medical model of care should not be regarded as an indicator of the quality of care it is providing. Instead, inspectors must take steps to understand the characteristics of the service they are regulating - and rate them fairly and proportionately on the basis of the care and support it offers. Together for Short Lives offers to continue to work with CQC to train and educate individuals who inspect children's palliative care services to make sure that they understand these differences.
22. We ask that CQC brings about a more consistent approach to inspecting children's palliative care services. For example, children's hospice services have also reported to us that their inspectors tend focus on issues which relate to their own area of expertise during visits. For example, inspectors who are pharmacists by background tend to focus on asking services about the way in which medicines are supplied and stored. We ask that CQC makes sure that its inspection teams are balanced and take a more consistent approach to regulating services regardless of their professional backgrounds.
23. We also ask that CQC takes a more consistent approach to regulating the way in which providers apply deprivation of liberty safeguards (DOLS). Some children's hospice services have told us that they have been given conflicting advice about what can be interpreted as depriving a young person of their liberty. We ask CQC to clearly advise health and social care providers how DOLS should be applied in the context of the setting(s) in which they provide care, particularly with regards to young people.
24. As the National Council for Palliative Care (NCPC) has done, we ask that CQC works with the palliative care sector to develop 'whole person' and 'whole system' integrated inspections. We agree that, as health and care services become more integrated, CQC should assess the way in which they work together to achieve better outcomes for the people they care for. Palliative care for children and adults is delivered by networks of providers; we believe that CQC has an opportunity to pilot ways of regulating joint working by taking our sector as an example.
25. Together for Short Lives also offers to work with CQC to develop descriptors about different types of hospice services. We will write to CQC about this jointly with Hospice UK and NCPC.

**For more information**, please contact:

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