

Children's Hospice Services Strategy Consultation Meeting Notes

Summary of Strategy Consultation Exercise

Toby Porter updated the group on the results of the members' survey, noting:

- The regional spread was good, with the highest number of responses from the South East and London regions. Scotland exhibited great engagement proportional to the number of hospices in the region.
- Most respondents (30%) were chief executives, through Hospice UK received many responses from hospice Trustees, chairs, clinicians, and other professions as well. The pattern was broadly similar across Children's hospices.
- Data was highlighted as a priority for the sector, which is a refreshing surprise given that it has only become a priority within Hospice UK in the last year.
- Many comments from Children's hospices noted that they want to see greater differentiation between Together for Short Lives (TfSL) and Hospice UK.
- Workforce was also highlighted as an area that Hospice UK could support local hospices with, though work is more recent than commissioning.
- Equitable access and reducing barriers to equal and inclusive access was also raised as a critical area of work.

Toby Porter then opened the door to questions from the group, who raised:

- Transition is a crucial area which requires more national focus. A lot of transition work is ad hoc and not fully incorporated into services.
 - The geographical patch is quite large along with the number of adult hospices children's hospices must work with.
 - It is difficult to implement new transition services when funding is limited.
- It is important to consider how Hospice UK can use language that is inclusive of children's hospices while recognising that the work is slightly different.
- As stated, differentiation between TfSL and Hospice UK would make the relationships and strengths of the two clear and make work more efficient.
 - Some campaigns are more or less relevant to children's hospices, and Hospice UK and TfSL may be suited to different campaigns.
 - While work may not necessarily be exclusive to one or the other, it would be efficient for the two to have more identifiable roles and specialisations.
 - The nature of relationships with ICBs share commonalities between adult and children's services but the types of funding are different.
 - It is vitally important for TfSL to work closely with Hospice UK. It doesn't make sense for both to do the exact same thing but amplifying each other would be beneficial to both.
- It is sometimes difficult to explain the differences between children's hospices and adult hospices to external stakeholders. Guidance on messaging would be useful to go over some of the complexities.

Groupwork – Children's Hospice Offer

Part I: What are the 5 biggest challenges and ii) the 5 biggest opportunities facing charities providing children's hospice services over the next 3-5 years

Part II: Where/how do you think Hospice UK could add most value to your organisations and sector over this timeframe?

The children's hospices group then went into five breakout groups to discuss the above questions. Key themes of the discussion noted:

- Transition is a major issue, and work should place more emphasis on respite.
 - Adult carers are looking for respite, which is work that could be suited to Hospice UK and TfSL.
- The distinct roles for Hospice UK and TFSL –who leads, who supports, who amplifies –should be clarified.
 - Hospice UK has a bigger presence with politicians, and TFSL working together on Advocacy could be highly effective.
 - ICB support is a major issue and could be worked on together.
- Workforce recruitment and retention is something that children's hospices, and the sector as a whole, has struggled with.
 - The skills mix of clinical staff is vitally important and determines quality of care.
 - It is a particularly salient challenge in children's hospices, as services are small and have a smaller talent pool.
- Funding continues to be a major challenges, especially commercial income and statutory funding are inconsistent and make it difficult to create a sustainable income stream.
 - The costs of events are increasing while the profits are decreasing.
 - Hospices are focused on surviving the short term which makes long-term planning difficult.
- The needs of families are changing, and patients often need more time and effort on safeguarding which means employing more social workers.
- Data is important but a lot of hospices are not set up to provide all the data the system needs.
 - Funds and trusts require more data, and the data required by different ICBs is inconsistent.
 - Local benchmarking would be useful in identifying inequitable services, as different hospices offer different services.
- Collaboration is a top opportunity, and Hospice UK is uniquely suited to facilitating conversation and ensure hospices have safe spaces to discuss.
- The national voice element of Hospice UK is highly valued.
- The children's hospice grant is only available in England, not Wales, Scotland, or Northern Ireland. Children's hospices would benefit from all nations work.

Next Steps for the New Hospice UK Strategy

The group then discussed the Children's Hospice Grant, noting:

- NHS England will be requesting a half year report on how the grant has been spent and ask us for further reporting on what changes have occurred since the grant has been doubled.
- The latest proposition from NHS England is that the grant will be distributed by ICBs.
- Minister Helen Wately will send a letter setting out the proposal to ICBs, and once Hospice UK has eyes on the contents of the letter, we will pull together a briefing for Chief Executives and distribute.

Regarding the next steps of the Hospice UK strategy development process, Toby noted:

- A full draft of the strategy will be completed by the end of this year, based on consultation from this meeting and other groups.
- We have gotten more engagement from the South East region and London in particular, so one of the focuses will be pushing for a four nations' approach.
- Levels of engagement are inconsistent with Children's Hospices. It may be beneficial to ask for a reaction based on what we have decided so far.
- A clear aim is to develop a more structured process for how we work with TfSL and creating more avenues for collaborations between our senior leadership teams.
- We are looking to see Children's Hospices as a specific subsection and communicate with them more than we do now.
- Our three-year transition programme has recently completed, and we are in the process of mapping out our next phase. Communication with children's hospices on the focus of the next phase would be useful.
- Making the language of Hospice UK more inclusive to children's hospices would be beneficial. Even minor changes like adding "children's hospices" or "paediatric care" would ensure Children's hospices are not overshadowed.
- Hospice UK has a clear role of advocating for Children's hospices within the overall hospice movement.