

NHS Hospice Charities 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:

- NHS charities are not supported as much as other groups.
- Conference is valuable, but it feels as if it's mainly for independent hospices and not for NHS charities.
 - We work closely with the clinical teams of hospices, but we are not responsible for clinical decisions so that aspect is not relevant to us.
 - NHS charities make plans and support the funding of hospices, but we are not involved in the strategy process.
- The group is not NHS hospices, but charitable trusts that support hospices. There may be a bit of a name issue if it is not clear, but we are run differently than independent hospices.
 - We are always referred to as NHS hospices, so we need a stronger identity.
- The most relevant work is engaging with the NHS more so than engaging with the government as a whole.
- As a charity, we feel that our role is to be commissioning services and encourage new and best practices. We should be pushing boundaries and ask about gaps in provision to advocate for communities that are not cared for.
 - The work of NHS charities is not just to fundraise for local hospices but to influence developments in service and structure and we are in a fortunate position to be able to do that
 - Along with hospices, we should educate the public on end-of-life care.

Groupwork – Hospice UK's Offer for Charities Supporting NHS Hospices

Part II: What are i) the 5 biggest challenges and ii) the 5 biggest opportunities facing charities supporting NHS 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 NHS hospice charities group then went into five breakout groups to discuss the above questions. Key themes of the discussion noted:

- As charity run hospices, NHS hospice charities have a unique relationship with NHS trust.
 - The challenge is to perfect that relationship to benefit the hospices and create strong links with commissioners.
- The frequent changes with ICBS have made it difficult to settle and create beneficial relationships.
- Collaboration across charities is vital. If our group were a single entity, we would be the biggest charity in the country and working together can help support delivery.
 - Hospice UK needs to work similarly by helping hospices band together to advocate support on the funding issues.
- A fundraising campaign, such as the one planned on legacies would be extremely helpful.
 - Finding local fundraisers is difficult. Our fundraising models are new, and we plan for two or five years.
- The demand on service will increase as the population ages. In the last 18 months, demand has gone up 50% and requires an awful lot of service to continue funding which may not be sustainable.
- The possible election in the future may be an opportunity to highlight the issues of the hospice sector and advocate for support.
 - The Labour Party will likely invest in the NHS, but we do not know what that means for charities supporting NHS hospices.
- Meeting with MPs to put the hospice sector into perspective may serve to garner support. If all community midwives were cut there would be a huge decrease in quality of birth services. We could make the same argument for palliative care.
 - Many patients are admitted to hospitals when they could be better cared for at home.
- Working with local communities and hospices to tell that local picture and help convey the national impact is a role for Hospice UK.
- Financial and other benchmarking is incredibly valuable but requires a lot of infrastructure.
 - Gathering data is difficult, but also analysing the data accurately.
 - If NHS charities contribute to the data, it is possible that it would be skewed.
- It would be great to have a designated NHS hospices group like regional groups.
- The group is more coherent than ever and now meet more regularly. It's good that Hospice UK is now aware and NHS charities are reassured by it.
 - Traditionally Hospice UK is very invested in NHS England and that relationship delivered the COVID-19 grant.
 - Over the last year, power has moved away from NHS England to the Department of Health and Social Services.
 - The restructures in NHS England involves significant reduction of headcount and capacity, meaning we need to reevaluate our relationship with the NHS.
 - End of Life is soon going to move into Major Conditions.

- Government officials and the NHS are all supportive of the palliative care sector, but they have not given us commensurate financial support.
- The ICB system means that hospices have more local significance than Hospice UK.
- Palliative care is low on the agenda for ICBs.
 - The sector is very resilient, as we are positive and unified.
 - The strategic narrative should be on the necessity to meet the demands of an aging population and on what the impacts will be if the hospice sector loses significant capacity.
 - Demand for outpatient services, IPUs and complex services has never been higher.
 - Bereavement and therapeutic style services also need to expand due to the raising awareness in the public.
- One issue is that we don't have standard rates for good practice, such as what the bed occupancy should be.
 - It is important to use evidence-based data to be accurate and convincing.
 - The financial benchmarking of Hospice UK is beneficial, but there is not much performance benchmarking.
- Over the next year or two we will have better data; however, it is still a question whether it is the role of Hospice UK to measure the performance of hospices.
 - Proxy indicators like CQC rate, patient safety, serious incidents would be useful, but it would be unwise to set out who is high performing and who is not.

Next Steps for the New Hospice UK Strategy

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.
- Hospice UK does not currently have any dedicated resource to work with the NHS hospice supporting charities.
- As with children's hospices, Hospice UK could certainly do more to listen to the specific voices of the group and how they differ to local hospices.
- Hospice UK has a clear commitment to do better in our next strategy.