

# Hospice UK England Strategy Consultation Meeting Notes

## Introduction and Review of Survey Findings

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

- A total of 292 responses were received.
  - 96 responses were submitted from hospice CEOs, representing 32% of all submissions.
  - The high response means we are confident that the responses are reflective of the views in the sector.
- Responses were received from members in all regions in England, Scotland, and Wales.
  - The highest number of responses was received from the South East region, which reflects historically elevated levels of engagement and dialogue.
- Highest number was from Hospice CEOs at 32%, though we received decent engagement from trustees, clinical leads, and fundraising leads.
- Members were asked to rate their satisfaction with Hospice UK on scale of 0 to 100, and the average response was 59%.
  - This is a good first measure and the aim will be to build and increase that level of satisfaction moving forward.
  - There were quite a few people who noted a score of 100 and a few very low scores.
- Overall, the members have recognised and value the renewed focus on the membership, and they feel more engaged.
  - The COVID-19 Grant is still very prominent in appreciation.
  - Practical guidance and support for funding and commissioning emerged as a clear and dominant priority.
  - The knowledge and learning events offered by Hospice UK was valued, such as our newsletters, conferences, and resources.
- The bespoke support offered by Hospice UK is not always seen, as usually hospices only reach out to us when they are actively struggling.
- Comments from Children's hospices noted that the specific Hospice UK offer to children's hospices is unclear.
  - The virtual children's meeting served to develop more in-depth consultation on what they would like to see from us.
- The national policy work, programme of learning events and data collection and benchmarking were noted as aspects of the Hospice UK offer that were particularly valued.

Some of the challenges facing the hospice sector in the future include:

- The need for palliative care will likely increase substantially due to the aging population, as individuals will live longer but in poorer health.
  - Many children who are born with poor prognosis are surviving who may have died previously.
  - There is unquestionable growing need for palliative services and the hospice sector is well-placed to help.

- The pandemic and cost of living crisis necessitate that the sector adapt and change to fit the circumstances.
- The salary uplift in the 2024/25 financial year will likely be a massive financial burden.
- There are worries that the Labour Party is not as supportive of hospices as the Conservative party, though based on anecdotal experience this may not be the case.
  - The uplifts will likely be 6% or 7%, which is difficult when many hospices are in deficit at the moment.

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

- Hospice UK must make an impact that is relevant to members or members will drift away. Progress should be clearly evidence and tangible. Advocating for hospice care in the current political climate is one of the most important things Hospice UK should be doing.
- The considerable number of different ICBs makes collaboration difficult, as hospices are all talking to different entities. Hospices do not always have sight on the issues that are common to all of us.
- Many hospices are considering rebranding, as there is a perception that hospices are religious organisations. However, this is a complex matter as the perceptions of donors and audiences both matter.
- As a national charity, Hospice UK is not well-equipped to build relationships with individual ICBs. Local hospices understand their community's landscape better than anyone, so the organisation's work should focus on the national landscape.
  - There are worries that Hospice UK will speak on behalf of all 208 hospices without listening to our individual concerns.
- Many people are taken to hospital that may benefit from palliative care. Promoting palliative care would also ease some burden on hospital services.
- Members want Hospice UK to become a stronger voice nationally on end-of-life care and build alliances with other national charities like Sue Ryder and Marie Curie.

## Groupwork – Hospice UK's Offer

### What can Hospice UK most usefully do to support the sustainability of the sector?

The children's hospices group then went three breakout groups to discuss several areas, alternating topics after 20 minutes. The following topics were discussed:

- Statutory funding, ICS relationships and system integration
- Income generation
- Any other areas, including workforce

Based on the discussion, the following major themes were highlighted by the groups.

### Statutory Funding

- There was a diversity of experience and opinions on what Hospice UK should do regarding statutory funding.
- It is crucial to have consistent data and use it to convey a compelling narrative to commissioners.
  - Hospices should be aware of what exactly ICBs need to know, which can be difficult as oftentimes the requests from ICBs are inconsistent.

- Most money from the government goes into acute care, and hospices could provide value for money if some of those resources were directed to community services.
- It could also support hospices to understand where the ICB funding inconsistencies lie.
- Spending effort to build working relationships ensures that hospices will have a seat at the table at discussion on the local system level.
  - On this point, collaboration, and communication across hospices within their regions is vital.
  - Hospice UK should focus on creating a national story, so all parts of the system understand the benefits of partnering with a hospice.
  - Offering learning to hospices by sharing examples of successful ICB collaborations would be a useful role for Hospice UK.
- Hospices must ensure their relationships with ICBs are amicable, so Hospice UK should be the one to take a firm stance.
  - Some suggested that Hospice UK should consider taking ICBs to court, which is something local hospices do not have the capacity to do.

### **Income Generation**

- The primary role of Hospice UK is to share best practice and innovations on ways to pull in additional income.
  - Many different hospices have tried to launch new products. Guidance on which were successful and unsuccessful, as well as why, would facilitate hospices to make the best decisions for their circumstances.
  - Some individual hospices have expanded commercialisation efforts which would be useful for other hospices to understand.
  - A vital role for Hospice UK is as a facilitator of data to give hospices a national voice and bring potential funding streams, as well as providing weight behind the narrative presented to national organizations.
- Building corporate partnerships on behalf of hospices would also be especially useful.
  - Hospices are small charities, and they may struggle to develop national corporate sponsorships. Hospice UK could advocate for these collaborations on behalf of the sector.
  - Putting all members together creates an opportunity for a large income stream.
- Hospice UK could also execute national campaigns in several different avenues.
  - Create understanding in the public on what hospices do and that they are funded primarily through fundraising and not government grants.
  - Some examples of potential national campaigns would be a more specific national communications campaign that brings the national voice of hospices on specific areas of income generation. It would provide arguments for hospices to bring to other organisations or corporate partners as to why funding is so necessary.
- Social responsibility is a hugely relevant topic and Hospice UK could leverage hospices as viable options for putting corporate social responsibility.
- Schools are a place where Hospice UK could facilitate a relationship.
  - Feeding into the curriculum and fundraising for that could promote the work of hospices.

- While the hospice sector benefits from being independent and having close community roots, areas of the UK with significant deprivation may not be able to support expensive hospice operations and need to rely more on government funding to achieve equity.

### Workforce

- The workforce problem is high-level, and it's part of the capacity problem overall to build a workforce alongside other considerations, like technology.
  - Defining roles and career paths is a major challenge when the roles are fragmented.
  - Staffing models exist, but the application of them is inconsistent.
  - Resourcing for roles like nursing requires a national voice.
- The problem could be mitigated by being more creative with admin roles and encouraging people to take on more responsibility.
  - Having individuals work across multiple sites, though this comes with challenges on terms and conditions.
- How Hospice UK could help is by promoting and selling the career path of the hospice sector.
- Charityworks has been highly successful for many charities, and we could institute something similar but tailored to the hospice sector.
- Workforce is a systemwide challenging affecting most hospices, and this makes it prime work for Hospice UK to be doing.
- Regarding the ED&I agenda, Hospice UK could support the coordination of best practices across the sector.
- Artificial Intelligence could support administrative tasks and relieve the burden on healthcare providers, but many do not know how it could be implemented within palliative.
- Practical help and guidance on emerging trends, such as developing generic job description templates for new roles like those in data, would help hospices innovate current roles.
- Hospice UK should ensure palliative care is on the curriculum for student doctors, nurses and AHPs to improve clinical practice and showcase hospices as a real career opportunity.
  - Palliative and end-of-life care is not really taught to students and getting it on the curriculum would help put hospices on the radar.
  - Hospice UK could support this on the national level to advocate for policy change.

### Groupwork – Membership Engagement

Nikki Vasco, Head of Innovation Resources, led a discussion on the current level of engagement of members with Hospice UK and how this could be increased in the future. The discussion mentioned:

- ECHOs and other zoom meetings were extremely helpful, and many would appreciate more being offered in topics relevant to members.
- Regional meetings are a large draw for many, especially when Hospice UK representatives are present.
- Reciprocity between Hospice UK and members is key. Hospices have a responsibility to engage their own workforces with the work of Hospice UK.

- Many hospices do not go to the Hospice UK annual conference because it can be a huge expense for small charities, especially at a time where income generation is already a major focus.
  - Many individuals perceive the conference to be overly clinical and not focused on income generation or fundraising.
  - Sessions on new businesses and innovative ways to fundraise would be relevant and attract members.
  - There could be an opportunity in future conferences to separate people into groups according to types of roles to ensure there is content relevant for everyone.
- Hospice UK should focus on the priorities of hospices, otherwise members will not engage. Setting up networks for a variety of roles, such as retail, would help connect aligned individuals across the sector.
  - Networks and forums enable the exchange of practice.
  - Forums, where individuals can ask and answer questions, would be useful for problem solving and troubleshooting, as well as build relationships between people of the same role in different hospices.
- Individuals do not always know who to contact within Hospice UK or the wider sector.
- Hospice UK would benefit from being bold in areas where it is risky for local hospices to do so.
- ECHO session could use some additional marketing to members to re-engage them after COVID-19.
- Weekly emails, like the Hospice Leaders briefing, are immensely helpful to inform members on what work is being done and any new developments.
- IT infrastructure may benefit from hospices working more closely to ensure greater efficiency.
- With the abundance of communications, it is easy for hospices to miss important updates. Communication may benefit from a traffic light system highlighting the most vital information.
  - By analysing the click-through rate for resources such as the innovation hub, Hospice UK could let hospices know what the most viewed innovations are as well as those that most hospices have not seen.
- Hospice UK's engagement at the CEO level is particularly good, but different roles may benefit from more or distinct kinds of engagement.
  - A staff-focused, twice a year summary of the membership offer may help CEOs engage their workforces.
- Mass CEO meetings are not always helpful. Meetings are more focused and relevant when they engage with thematic groupings of CEOs with common interests.
- A tiered membership offer could create more tailored memberships to different hospices who may want bespoke support.
- Other joint conferences, such as a clinical conference between hospice UK and NHS providers would help build those connections between organisations with common interests.
- Creating a reduced offer for younger people in junior positions may encourage those individuals to attend the conference. Excessive costs can be a barrier for younger people to come.

## Groupwork - Unmet Needs

Charlie King, Head of Communications and Campaigns, led a group discussion on the efforts Hospice UK could do to help address unmet needs and quality of access, noting:

- Unmet needs can present in three distinct categories
  - Geographic, areas within the UK that are being underserved.
  - Diverse populations, whether we are reaching and serving individuals with diverse backgrounds and needs.
  - Unmet needs through a critical lens.

The attendees noted the above and a summary of the discussion highlighted:

- National messaging and press on behalf of hospices to break down barriers would be useful, not just for increasing patient diversity but also staff diversity.
- Areas of high deprivation have a large mix of individuals with diverse backgrounds. This makes communication complicated and difficult.
  - Many people have a perception of hospices as religious or Christian which may prevent them from seeking help.
- A major challenge is getting the demographic data that outlines the needs and demands for services.
  - Understanding the unmet needs in each region can support business propositions for commissioners by creating a narrative for social care which would benefit from funding.
  - Deep dive research is not always as helpful as data, as data can be used to call for more funding.
- Services can only be accessed by people who know they are there. Broad marketing on the variety of hospice services available may help reach those underserved communities and demographics.
- Sharing learning is the best way to support the sector. Knowing what initiatives hospices have conducted and which have been the most successful would help others follow suit.
  - A toolkit which provides hospices guidance on what data needs to be collected, what areas of work they should be looking at, and defining what unmet need is and how some hospices have mitigated it.
- As many hospices are in deficit, it is likely that initiative on expanding demand will be cut. The funding used for breaking down barriers would go to supporting current patients.
  - Hospice UK needs to help hospices work on unmet needs as effectively and cheaply as possible because these are the services that will likely be cut during demanding times.
- Hospice UK should set expectations to collect demographic data which would benefit the national voice on unmet needs.

## Next Steps for the New Hospice UK Strategy

Regarding the next steps of the Hospice UK strategy development process, Toby noted that a full draft of the strategy will be completed by the end of this year, based on consultation from this meeting and other groups.