

Scotland Strategy Consultation Meeting Notes

Hospice UK strategy consultation

Craig Duncan (Chief Operating Officer, Hospice UK) 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.

Funding and sustainability

What do hospices hope we can realistically achieve over the five or six year life of the strategy?

- National framework for statutory funding – to include a minimum percentage for funding agreed services. Plus an agreement to match and mirror clinical pay rises.
- Commissioning should become more of a partnership – what do commissioners need and what can hospices provide?

What do hospices want Hospice UK to do to help achieve that?

Statutory funding

- Continue to help hospices engage with MSPs. Briefing papers that Helen and Aileen produce are really helpful and hospices can adapt them to use in different influencing discussions.
- Make sure Hospice UK isn't going over hospices' heads to advocate with government – hospices need to be at the negotiation table but Hospice UK can facilitate discussions. Get all IJB leads in the room with Scottish Government and hospices, so that decisions can be made instead of passing back and forth.
- Continue to work cohesively with other agencies such as Marie Curie to advocate for the sector and shift the government mindset. Do we need to tie in with Scotland Hospices Together?
- Set up a Think Tank – reconsidering the concept of 'hospice'. What can hospices offer? Hospice UK can provide the space for hospice leaders to think, rather than react.

- Develop a proposed funding model, to include a clear target for statutory funding (50%? 100%?).
- Facilitate discussions with commissioners. Share information about how the health system works in reality, to help hospices navigate it.
- Support hospices to learn negotiation skills and share examples of success.
- Facilitate discussions between hospices, sharing experiences and connecting people. For example, can hospices work together to offer commissioned services?

Other sources of funding

- Share knowledge and skills to help hospices access pots of money that are not traditionally seen as being for palliative care. Share funding that is available across all nations (not just England).
- Make more approaches to corporate partners and make sure these are UK wide.
- Share ideas about commercial income generation and link like-minded leaders to discuss and develop ideas.
- Lead national fundraising campaigns such as a legacy campaign.
- Podcasts sharing innovation would be helpful – you can listen to them on the way to work, etc.
- Consider a newsletter sharing innovation ideas – short snippets linking to more information.

Engagement

There was feedback that Hospice UK's engagement with Scottish hospices has improved significantly over the last year. As well as Conference being in Glasgow, Toby has made an effort to engage with and visit Scottish hospices. There is renewed energy as Helen has returned from maternity leave and Aileen has started in post.

What do hospices hope we can realistically achieve over the five or six year life of the strategy?

- Hospices know who they need to talk to at Hospice UK about different topics, and can get in touch with people easily.
- Hospices know about and can access all Hospice UK's support (there were several examples in the discussion throughout the day where hospices were not aware of a network/resource/service we offer).
- Hospices are engaged with each other as well as Hospice UK – especially across the 4 nations.

What do hospices want Hospice UK to do to help achieve that?

- Feed back data from the strategy survey from a Scottish perspective, not just 'Hospice UK' as a whole. The stats on the presentation were for the whole UK, with some key points from Scottish hospices. Some members felt that the stats from the Scottish sector might have been quite different.
- Make sure there is a Scottish representative on the Board.
- Provide a list of key contacts at Hospice UK and what they do (and keep it up to date)

- In person induction for new CEOs – either a 121 chat over coffee with someone from HUK or a regular meeting at Hospice House. Explaining everything the organisation offers.
- Provide more opportunities for hospices to engage face to face. Conference is good but it can be overwhelming. Organise group visits to hospices who are innovating in a particular area.
- Target everyone who works in a hospice – would a nurse know what is available to them?
- Visit hospices regularly and engage with all levels of staff.
- Make sure newsletters are succinct, not bombarding people with lots of information or making them click several times to find information.

Four nations engagement

- The next strategy needs to be explicit about the four nations – acknowledging that all nations do different things and setting out the benefits of Hospice UK.
- Use social media more to target professionals – there was a sense that CEOs are more likely to engage on social media than read emails (because they have to be engaged on social media for work and don't have time to read everything in their inbox). Some people thought that LinkedIn is more important to professionals in Scotland than England.
- Link hospices up across all 4 nations, according to themes they are interested in, e.g. leadership, rural hospices. There was a sense that Scottish hospices are reasonably engaged with English hospices but not with Welsh or Northern Irish hospices.
- Some funding and bursaries are only available to hospices in England. Make this clear at the beginning, so hospices in other nations don't waste time looking at an opportunity they aren't eligible for. Seek to develop opportunities for other nations.

Assisted Dying

How can Hospice UK support hospices around Assisted Dying?

- Provide safe spaces to discuss issues surrounding Assisted Dying, facilitated by someone who provides a balanced view. For example, Ardgowan Hospice held an ethical discussion session for staff around Assisted Dying, facilitated by one of their consultants, which was really helpful.
- We need to unpick the complexity of the issues around Assisted Dying as a sector, with Hospice UK as facilitators.
- Although we have “no collective view”, we still need to engage in discussions/attend parliamentary debates. There was a feeling it is easier for Hospice UK to engage than individual hospices, as we are not engaged in direct patient care.
- Put forward what Assisted Dying means in practice – how the complexities will affect hospices and what safeguards we would want to see in place.
- Highlight where existing legislation needs to be updated to marry up with Assisted Dying legislation, and how the AD Bill will interact with existing legislation (e.g. safeguarding, power of attorney, transition, Incapacity Act).
- Advocate to ensure hospices get adequate funding if Assisted Dying legislation is passed.

- Hospice UK can provide briefings/explainers about the Bill and the process for it becoming law.
- Provide resources and support for hospice staff needing to have conversations about Assisted Dying with patients and families (people will start to ask soon!).
- Pull together information about the stances of various agencies on Assisted Dying and how this affects hospice staff, e.g. Royal College of Nursing, Association of Palliative Medicine. Stances vary and some staff will be members of these bodies.
- Provide information setting out the nuances of the issue, for leadership teams and Boards to consider.

Workforce

What do hospices hope we can realistically achieve over the five or six year life of the strategy?

- This is a complex area and is closely linked with the discussions on funding and sustainability.

What do hospices want Hospice UK to do to help achieve that?

- Education programmes to support with staff development. Can we centralise some training to reduce costs and ensure standardisation across the sector?
- Training and resources for junior fundraisers to help attract people to the sector.
- Develop more training opportunities for non-clinical staff.
- Continue to provide grant funding for bursaries.
- Share a list of training opportunities and bursaries, even those that aren't provided by Hospice UK.
- Leadership training and coaching for middle management.
- National networks and support (local networks are helpful but they can become insular).
- Wellbeing support for staff – a safe space for staff to talk with peers from all over the country (not just people in the same hospice). Would need to be well facilitated and have good governance.
- Support hospices to recruit from outside the sector – raise awareness of what it's like working in a hospice. Help make palliative care more exciting as a speciality.
- Advocacy around the Safe Staffing Act in Scotland – hospices are not currently mentioned but should be equal partners in delivery of the Act.
- Build conversations about regulation into conversations about the National Care Service, to help ensure service delivery is person-centred.
- Benchmark current staffing levels and staff benefits offered by hospices.
- Provide safe staffing tools.
- Support hospices around volunteer management – the demographics and needs of volunteers are changing. Sharing learning around how we can best utilise volunteers. A network for volunteer managers.
- Develop clear development pathways e.g. volunteer to career, CNS pathways.

Equitable access/unmet need

Issues raised

- There needs to be equity of access to palliative care for young adults across Scotland. Not every hospice needs to provide this support but there should be hubs that have the right knowledge, skills and infrastructure.
- Reduction in availability of NHS continuing/complex care beds in Scotland is increasing the pressure on hospices.
- Hospices are seeing younger patients – e.g. St Andrews recently had three women aged under 40 in the IPU, with seven children aged under 5 between them. It was a challenge to provide the right care and support for the whole family.
- Hospices have always seen it as their job to fill the gaps in provision, redesigning services to meet need. But the current funding situation doesn't necessarily allow this.
- There are challenges with 'long-stayers' – people staying in the IPU for over a year. They don't need to be in a hospice but there is nowhere else that provides the same quality of care. Some families don't want to pay for care elsewhere. Others don't want to lose benefits (if a patient is in hospital for a long period of time, Carers Allowance and other benefits stop). This stops the hospice caring for other people.

What can Hospice UK do to support hospices?

- Facilitate discussions around palliative care for young adults and advocate for national funding.
- Provide resources and opportunities for hospices to think differently about filling gaps in provision. How can hospices work collaboratively with other organisations? What are hospices really good at, and what can they train other providers to do?
- Advocate for hospices to have the same access to discharge support and social worker support as Acute beds, to help with moving patients on from the IPU.
- Map what happens to benefits when someone has been in a care home, hospital etc for >8 days. Is this just a Scotland issue or does it affect the whole UK?
- Gather data to support discussions around unmet need – e.g. St Andrews reported not being able to see 20% of referrals.
- Hospices would appreciate a briefing on the rights they have under power of attorney laws etc.

Priorities for the next strategy

We asked people to stick post it notes to a flip chart to help us prioritise.

What should Hospice UK continue doing?

- ECHO
- ECLIHP
- Helen Malo's input
- More fundraising



- More networking

What should Hospice UK stop doing?

- Being England-centric