Less Survivable Cancers Taskforce

Public Consultation on a Right to Palliative Care Bill

1. Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?

- **Strongly agree**
- Partially agree
- Neutral (neither support nor oppose)
- Partially disagree
- Fully disagree
- Unsure

The Less Survivable Cancers Taskforce is a coalition of charities representing the six common cancers with the lowest survival rates in the UK: brain, liver, lung, stomach, oesophageal, and pancreatic cancers.

In 2023, the Taskforce launched a survey to better understand the experience of palliative care among people with these cancers. This work covered all four nations from the UK, and while the majority of the respondents were from England, similar themes were found across the four nations. The proportion of survey respondents closely mirrored the population spread of the nations.

The results of this survey have consistently shown that there are notable gaps in palliative care specifically for these six cancers. Some of the key results indicating a lack of universal access to palliative care are the fact that:

- over a fifth of respondents (22.4%) said that no palliative care was received at all
- 44.6% of respondents said they were not quickly connected to a named contact in a palliative care team
- 32.5% reported not being offered any sort of holistic needs assessment or similar exercise; and
- 20.6% of respondents selected the option 'Not been advised on palliative end-of-life care options'.

Our findings suggest that there are gaps in palliative care for this patient cohort both regarding general palliative care, and also access to specialist palliative care services, for instance less than a third (31.1%) said they did not have any access to a specialist dietitian, despite the fact that digestive issues and nutritional problems were often cited as the symptoms that people struggle with the most.

Palliative and end-of-life care is a vital part of the pathway to get right for the less survivable cancers. While there is guidance such as the Scottish Palliative Care Guidelines that do reflect lots of the priorities and 'best practice' that we have found in our survey, the bottom line is that the basics are not being universally delivered and many people simply fall through the cracks, having to self-advocate for care at a very challenging moment on an often short timeline.

We therefore strongly support the proposal for introducing a right to palliative care to drive improvements in delivering palliative care to everyone who needs it, and believe this will be a vital vehicle for people requiring this care for a less survivable cancer.

2. What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?

This definition covers many of the key points that people living with a less survivable cancers and their carers raised in our survey.

The definition correctly identifies that there are several overlapping 'pillars' to best-practice palliative care for less survivable cancers, and in the context of an often-siloed healthcare system it is vital that they are better coordinated. When we asked about how well coordinated a patient's care was: 17.5% said it was very well coordinated; 35.5% said it was reasonably well coordinated; 25.7% said it was not particularly well coordinated; and 21.5% said it was not at all very well coordinated. In other words, there was an almost exactly even split between respondents saying their care was on the whole well coordinated, and those saying their care was on the whole poorly coordinated. Notably, 'very well coordinated' was the least commonly chosen option. We would therefore welcome a definition that explicitly includes a recognition of the wide scope of subjects and challenges that palliative care encompasses, in order to ensure the coordination of these areas of care is at the heart of efforts to improve it.

This definition also includes a reference to the people surrounding a patient, which is vital. The survey ran by the Taskforce sought input from people currently living with a less survivable cancer, as well as people answering on behalf of a person, who is either living with or has died from one of these six cancers. A very large proportion (85%) of our responses came from people who were carers rather than answering on behalf of themselves, and a strong theme emerged of the huge caring responsibilities that fall to family, friends, and other support networks. However, very few of them are included in the conversations and planning of the palliative care for the patient - 19.9% of patients reported that they were informed about how family or loved ones could care for them. The definition should therefore also keep a recognition of the fact that palliative care should encompass people around the person receiving palliative care.

3. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).

What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?

- **Strongly agree**
- Partially agree
- Neutral (neither support nor oppose)
- Partially disagree
- Fully disagree
- Unsure

The LSCT survey on palliative care asked for non-identifiable information about the person receiving palliative care, including age, rough location, ethnic background, and access to private healthcare.

As part of the survey we invited respondents to rate their (or their loved one's) experiences of care on a scale of 1-10, inquiring how positively they felt about different parts of their palliative care experiences. The responses for Scotland were:

- 6.68 / 10 for whether the patient's overall palliative care needs were met
- 4.42 / 10 for whether the patient's psychological and emotional needs were met
- 5.43 / 10 for the quality of care for loved ones surrounding the patient
- 5.95 / 10 for the quality of specifically end-of-life care (defined as last six months)

While there was variation between each of these categories, our limited sample does indicate that when these questions are filtered by ethnicity, people from non-white backgrounds were overall less satisfied with the palliative care received. There was also some indication that people with access to private healthcare were overall more satisfied with the palliative care that was received.

Our limited results certainly require further investigation, but this does indicate that there is a deep-rooted issue with inequalities in palliative care, and therefore that a universal right to palliative care could be a vital part of addressing health inequalities.

One of the key cross-cutting themes from the research conducted by the Taskforce is the need for patients and carers to consistently self-advocate for their care - this requirement can act as a filter for people with more time, resources, and understanding of healthcare systems and structures. Many of the people with positive experiences expressed gratitude that they were able to advocate or have an advocate on side, for instance one respondent in Scotland stating:

"*He felt safe once he was in the Hospice and thanks to the staff there he had a good death with all of his family present. We were looked after too. But these places are like hens' teeth and we were very fortunate to get a bed for his last eight days and I could stay there with him*"

And another told us:

“They did meet mum’s needs but we had to really push for her to get this care”

The Taskforce is already aware of deep social inequalities in outcomes for the less survivable cancers, evidence shows that “people with a less survivable cancer from the most deprived backgrounds face significant health inequalities compared to their counterparts from the least deprived backgrounds”. It is therefore unfortunately unsurprising that there could be a strong health inequalities problem in palliative care access for this patient cohort. Taskforce members are aware that health inequalities influence late presentation and limited symptom awareness amongst those with less survivable cancers. Later presentation, combined with co-morbidities, limit or remove treatment options and lead to presentation with later stage or untreatable disease. A right to palliative care could contribute to rebalancing some of the disadvantages experienced.

4. What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented.

The existing guidelines for palliative care are a strong basis for what ‘good’ likes like and do reflect many of the key concerns for best practice palliative care that were highlighted by respondents to the Taskforce’s survey. The evidence provided to us by people with experience of palliative care for a less survivable cancer indicates that the reality of the situation is less positive.

Whether the delivery of palliative care remains the responsibility of Integration Authorities, or is transferred to another responsible body, clear and tangible targets should be developed to track that any improvements in palliative care as a result of the introduction of this right apply to all areas of healthcare. In practical terms, the Taskforce would welcome targets that track and disaggregate cancer types, for instance, as often targets and measurements that do not break down tumour types mask a heterogenous picture underneath the surface.

Furthermore, any body that is tasked with partial or whole responsibility of a right to palliative care should also seek to meaningfully engage with patient charities to ensure the patient voice is at the heart of reinvigorated efforts to improve universal palliative care.

One vital aspect of the practical implementation of a right to palliative care is the need to recognise that palliative and end-of-life care intersects with other structural issues facing the health and social care system. For instance, a recurrent theme in the Taskforce's survey findings is that patients and their carers often had a high degree of satisfaction with their palliative care team or specialist once they had access to them, but were also very conscious that they had little capacity and were stretched:

"There were many moments where his care could have been better. The individuals we met (on a whole) were all good at their jobs, just stretched"

The right to Palliative Care should be integrated across all relevant health strategies, including the current Cancer Strategy and its future Action Plans.

Similarly, the number of people who have access to palliative care for a less survivable cancer may be massively impacted by improvements in early and fast diagnosis, as the these cancers are consistently diagnosed at a later stage - around 1 in 3 patients with a less survivable cancer will only be diagnosed after an emergency admission to hospital. In other words, galvanising other areas of care for these cancers are likely to be as large a part of improving palliative care access. A body or bodies who are responsible for implementing this right may need to engage with a wider part of the pathway to address some of the systematic challenges to palliative care access.