PROPOSED RIGHT TO PALLIATIVE CARE (SCOTLAND) BILL – MILES BRIGGS MSP

SUMMARY OF CONSULTATION RESPONSES

This document summarises and analyses the responses to a consultation exercise carried out on the above proposal.

The background to the proposal is set out in section 1, while section 2 gives an overview of the results. A detailed analysis of the responses to the consultation questions is given in section 3. Section 4 includes Miles Briggs's MSP commentary on the results of the consultation.

Where respondents have requested that certain information be treated as confidential, or that the response remain anonymous, these requests have been respected in this summary.

In some places, the summary includes quantitative data about responses, including numbers and proportions of respondents who have indicated support for, or disagreement with, the proposal (or particular aspects of it). In interpreting this data, it should be borne in mind that respondents are self-selecting and it should not be assumed that their individual or collective views are representative of wider stakeholder or public opinion. The principal aim of the document is to identify the main points made by respondents, giving weight in particular to those supported by arguments and evidence and those from respondents with relevant experience and expertise. A consultation is not an opinion poll, and the best arguments may not be those that obtain majority support.

Copies of the individual responses are available on the following website:
Right to Palliative Care Bill Consultation Responses | Marie Curie

Responses have been numbered for ease of reference, and the relevant number is included in brackets after the name of the respondent.

A list of respondents is set out in the Annexe.

SECTION 1: INTRODUCTION AND BACKGROUND

Miles Briggs's draft proposal, lodged on 6 March 2024, is for a Bill to:

> give people of all ages living with terminal illness and residing in Scotland a legal right to palliative care.

The proposal was accompanied by a consultation document. This document was published on the Parliament's website, from where it remains accessible: Proposed Right to Palliative Care (Scotland) Bill | Scottish Parliament Website

The consultation period ran from 9 March 2024 to 4 June 2024.

The following organisations and individuals were sent copies of the consultation document or links to it.

Hospice UK
CHAS
Scottish Partnership for Palliative Care
Alzheimer Scotland
MND Scotland
Macmillan Cancer
British Heart Foundation
Carers Scotland
Carers Trust
Neurological Alliance Scotland
Scottish Huntington's Association
Parkinson's UK Scotland
MS Society Scotland
Muscular Dystrophy UK
Cancer Research UK
Breast Cancer Now
Cruse Bereavement Care
Age Scotland
Faith in Older People
Independent Age
Enable
Inclusion Scotland
ALLIANCE
University of Glasgow
Poverty Alliance
Care Not Killing
Dignity in Dying
Association for Palliative Medicine

Royal College of Nursing
Royal College of GPs
Shared Care Scotland
Coalition of Carers
Pancreatic Cancer UK
Marie Curie Scotland

The Scottish Partnership for Palliative Care shared the consultation with their wider membership.

The consultation was also shared widely on social media.

The consultation exercise was run by Miles Briggs MSP's parliamentary office.

The consultation process is part of the procedure that MSPs must follow in order to obtain the right to introduce a Member's Bill. Further information about the procedure can be found in the Parliament's standing orders (see Rule 9.14) and in the *Guidance on Public Bills*, both of which are available on the Parliament's website:

- Standing orders (Chapter 9): Standing Orders | Scottish Parliament Website
- Guidance (Part 3): http://www.scottish.parliament.uk/parliamentarybusiness/Bills/25690.aspx

SECTION 2: OVERVIEW OF RESPONSES

In total, 63 responses were received.

The responses can be categorised as follows:

- 26 (41.2%) from private individuals (members of the public);
- 14 (22.2%) from third sector organisations representing people with specific health conditions;
- 7 (11.1%) from religious and secular organisations;
- 5 (7.9%) from hospices;
- 5 (7.9%) from membership organisations and trade unions representing healthcare staff;
- 2 (3.2%) from pro- and anti- assisted dying campaigning organisations;
- 1 (1.6%) from an anti-poverty third sector organisation;
- 1 (1.6%) from a third sector organisation supporting veterans;
- 1 (1.6%) from a third sector intermediary;
- 1 (1.6%) from a higher education institution.

There were:

- 2 (3.2%) respondents who asked to be published anonymously, and,
- 2 (3.2%) respondents who requested complete or partial confidentiality.
- 3 (4.8%%) submissions were marked “not for publication” by the respondent.
- 4 (6.3%) late responses were accepted after the deadline.

The consultation on the proposed Right to Palliative Care (Scotland) Bill received a positive response from both individuals and organisations. A majority of respondents agreed with establishing a legal right to palliative care for people of all ages living with terminal illnesses in Scotland. This support was consistent across various types of organisations, including third-sector groups representing specific health conditions, hospices, and professional bodies, as well as among private individuals. Respondents highlighted the importance of ensuring equitable access to palliative care, upholding human dignity, and providing holistic support to improve the quality of life for people with a terminal illness and their families.

Some respondents raised concerns regarding the practical implementation of the proposed right. Key issues included resource constraints, workforce shortages, and the feasibility of delivering consistent palliative care services across all regions, particularly in rural and remote areas. Organisations representing healthcare staff, and some individuals emphasised the need for adequate funding and workforce planning to ensure that the legal right translates into actual improvements in care delivery. Additionally, there were discussions about the terminology used in the proposal, with suggestions to refine definitions to avoid excluding certain groups who could benefit from palliative care but might not identify as terminally ill.

SECTION 3: RESPONSES TO CONSULTATION QUESTIONS

This section sets out an overview of responses to each question in the consultation document.

General aim of proposed Bill

Page 6 of the consultation document outlined the aim of the proposed Bill and what it would involve. Respondents were asked:

Question 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?

53 respondents (84.1% of the total) answered this question via the provided checkbox. (Other responses may have indicated whether or not they supported the general aims of the Bill, but only checkbox responses have been included in the following quantitative analysis.)

Strongly Agree	47	74.6%
Partially Agree	3	4.8%
Neutral (Neither agree nor disagree)	2	3.2%
Partially Disagree	0	0%
Strongly Disagree	0	0%
Unsure	1	1.6%
Blank/Did not answer	10	15.9%

- A significant majority of respondents (79.4%) agreed with the proposed Bill. There were 0 responses that disagreed. 3 respondents (4.8%) reported being neutral or unsure.
- 10 (15.9%) respondents did not indicate their position via the provided checkbox.

The main reasons given for supporting the proposed Bill were:

- Ensuring equitable access and reducing inequalities
- Upholding human dignity
- Alleviating suffering and enhancing quality of life and autonomy
- Providing holistic care
- Legal assurance and minimum standards
- Aligning with human rights standards
- Supporting families and carers
- Preparing for increasing demand

The main reasons given for disagreeing with the proposed Bill were:

- Resource constraints and feasibility concerns
- Implementation challenges and system capacity in rural areas
- Slippery slope and unintended consequences
- Legal rights may not lead to actual improvements
- Terminology concerns potentially excluding some groups

Other points mentioned were:

- Condition specific needs and data

Reasons for supporting the Bill

- **Ensuring equitable access and reducing inequalities**

Many supporters emphasised the importance of guaranteeing that all terminally ill adults, children, and young people in Scotland have equal access to high-quality palliative care. This approach aims to address current disparities based on income, location, socioeconomic status, or medical diagnosis, ensuring that no one is disadvantaged in receiving the necessary care. The Salvation Army highlights:

> "The reasons why different groups do not access palliative care are varied, ranging from socio-economic deprivation and financial hardship to cultural factors which inhibit engagement and the fear of ostracism. A right to palliative care would require local authorities and health boards to make provision for people disadvantaged by socio-economic deprivation and for rural and island communities. In the case of rural and island communities, sustainable models of provision would have to be identified and implemented."

The "Inverse Care Law" is also widely acknowledged in responses from hospices and organisations representing the healthcare workforce, such as the Royal College of Physicians of Edinburgh:

> "Any new legislation would need to address existing reasons for inequity of access to palliative care in Scotland. The Inverse Care Law applies to palliative care as much, if not more, than it does for any other aspect of health and social care. In a palliative care context, the Inverse Care Law most severely affects people experiencing socio-economic deprivation and financial hardship, older people, women, minoritised ethnicities, LGBTQ+ people, people with learning disabilities and rural and island communities. The rising cost of living has worsened the impact of poverty on those living with terminal illness and these issues must be addressed within the scope of any new legislation. Any new law presents an opportunity to address the existing inequities of access to palliative care by marginalised groups and the new law must highlight the responsibility of commissioning bodies to prioritise specific actions to improve outcomes for those currently most disadvantaged."

- **Upholding human dignity**

Respondents, particularly religious and secular organisations, strongly highlighted the need to provide compassionate care that affirms the dignity and intrinsic value of individuals as they approach the end of life. Ensuring that every person is treated with respect and their inherent worth is recognised,

regardless of their health condition, was viewed as essential. This is represented in the response of the Salvation Army:

> "The Salvation Army believes that every human being is created in the image and likeness of God and is therefore endowed with an inalienable dignity and worth which we are all called to recognise and honour in our individual and collective relationships with one another."

Private individuals, such as GB, also strongly supported this sentiment:

> "Every person has a right to compassionate and loving treatment as they reach the end of their lives, and their families also need consideration and help as they face the end of life of their loved one."

- **Alleviating suffering and enhancing quality of life and autonomy**

Effective management of pain and distressing symptoms to improve the quality of life for terminally ill individuals was a common theme. Empowering patients with choice and control over their end-of-life care, including respecting personal and cultural preferences, was seen as a way to enhance autonomy and dignity. The Humanist Society Scotland responded:

> "While it is widely acknowledged that palliative care cannot alleviate all pain or suffering in every case, it is vital that anyone diagnosed with a terminal illness has access to a choice of palliative support. People should be fully informed of their options, and these must be tailored to their evolving physical, psychological, and social needs from the point of diagnosis. Humanists promote fulfilment in our life because we believe it is the only one we have. As such, we are chiefly concerned with individual well-being and the right to personal autonomy at every stage of a person's life. In our view, terminally ill adults must be empowered to make informed decisions about their care and death that are right for them."

- **Providing holistic care**

The importance of offering comprehensive support that addresses the physical, emotional, social, and spiritual needs of patients and their families was frequently mentioned by both individuals and representative organisations. This holistic approach ensures that care extends beyond symptom management to support overall well-being. One private individual, SP, responded:

> "I believe that all children and adults in Scotland should have the right to palliative care. This care should be offered as soon as a diagnosis is made that their condition is terminal and that an early death is likely. I think it's important that the right kind of palliative care is offered to ease suffering so that a patient has the ability to "live with" their condition and not "suffer from" their condition. That the needs of family carers are recognised and supported in caring for their loved ones. That a holistic

approach to care is offered to include spiritually and psychosocial needs of both the terminally ill and their carers."

- **Legal assurance and minimum standards**

Some respondents considered it necessary to provide clarity on care expectations through legal backing would make palliative care a guaranteed service, not subject to variability or discretion. Age Scotland argued that minimum service standards will help to ensure the effective implementation of the proposed bill.

> "We support the call for Minimum Service Standards for palliative care, as explored in depth in Marie Curie Scotland's response to this consultation. We believe that incorporating these minimum service standards would help to ensure that the right is implemented and upheld in practice, creating accountability on the delivering bodies to ensure that a difference is made with the introduction of a legal right."

- **Aligning with human rights standards**

Some respondents advocated for recognising palliative care as a fundamental human right and aligning Scotland's statutory guidance with international standards and frameworks. They argued that this would position palliative care within a global context of human rights and ethical obligations. Marie Curie Scotland, for example, highlighted the United Nations General Assembly's International Covenant on Economic, Social and Cultural Rights as one basis for this:

> "Under Article 12.1 of the International Covenant on Economic, Social and Cultural Rights, everyone has a right to "the highest attainable standard of physical and mental health". The legislation identifies an obligation for States to "respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons…to preventive, curative and palliative health services" and in relation to older people, an obligation to ensure "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."

- **Supporting families and carers**

Preventing the overburdening of families by ensuring they have the necessary resources, training, and emotional support was another key reason for support. Organisations representing carers stated that adequate support for carers reduces stress and improves the quality of care provided to patients. The National Carer Organisation, for example, highlighted the importance of the right encompassing and reflecting the needs of carers:

> "A right to palliative care should ensure all those affected by terminal illness get the support they need and want, while alleviating the care burden and expectations of unpaid carers. It is vital that people are able

> to focus the time they have left with the people that matter to them most, not predominantly relying on unpaid care and fighting against systems to try and receive social care support."

- **Preparing for increasing demand**

Addressing the growing need for palliative care due to an ageing population was also a significant concern, particularly among organisations representing conditions that commonly affect older people. Ensuring services are sustainable and well-funded was seen as vital for proactive planning, enabling the healthcare system to meet future demands without compromising care quality. Several organisations cite Marie Curie's research on future palliative care needs in Scotland:

> "Marie Curie research highlights that by 2040, up to 10,000 more people will need palliative and end of life care each year, a 20% increase. It is also projected that by 2040 that the largest increase in palliative care need will be for those aged over 85, which will account for almost half (47%) of people with palliative care needs."

Reasons for neutral/unsure support

- **Resource constraints and feasibility concerns**

Many respondents, including those in strong support of the proposed bill, were concerned that introducing a legal right to palliative care without guaranteed additional resources could overburden an already strained healthcare system. They feared that, due to demographic changes, current workforce shortages, and funding limitations, the government might be unable to fulfil the legal obligation to provide care which could lead to ineffective implementation, further strain on existing services, and the diversion of funds from other essential healthcare areas. This is reflected in the British Medical Association's response:

> "While BMA Scotland is fully supportive of patients accessing the palliative care they need, we do have concerns about how these needs can be met with current resourcing across the NHS and social care services. We know that for the demand being placed on the NHS, it remains substantially understaffed, under-resourced and under-funded. BMA Scotland is concerned that any additional expectation on health and social care staff at this time without adequate funding and resourcing will only lead to additional burnout and retention problems and ultimately will do nothing to encourage people to work in these sectors."

Similarly, the issues of understaffing, recruitment and retention were raised by Erskine Veteran's Charity:

> "Our members are clear that with the current understaffing, under-resourcing, and under-funding, a change in the law would have little impact to no impact on the delivery of services. While we believe it

shouldn't matter whether you are at home, in a care home or in the NHS, you should have the same access to specialist palliative care input, the reality is that health and social care services are struggling to recruit and retain staff and there is no flexibility or give in the system."

- **Implementation challenges and system capacity in rural areas**

Concerns were also raised by both representative organisations and individuals about the practical challenges of implementing such a right, especially given existing disparities in service quality and accessibility across Scotland. Respondents questioned whether the capacity of the healthcare system, particularly in rural and underserved areas, might not be sufficient to deliver the required level of care. Without addressing underlying resource and workforce issues, legislation alone could prove ineffective or even exacerbate current shortcomings. One retired children's palliative care nurse living in Orkney highlighted:

> "The issue is delivering this outside of the central belt of Scotland. Where I live here in Orkney a home death can't be assured or safe. Folk living in the isles would have to go to our local hospital in Kirkwall, travel to Inverness for hospice care or get telephone advice on symptom management from the hospice in Aberdeen."

- **Slippery slope and unintended consequences**

A small number of individual respondents expressed concerns about a potential "slippery slope" associated with the proposed bill on the right to palliative care in Scotland. They expressed concerns that, while the legislation aims to improve end-of-life care, the definition of palliative care might gradually extend to include assisted dying, and that this could result in pressure on vulnerable groups, such as people with chronic health conditions or disabilities, to end their lives.

- **Legal right may not lead to actual improvements**

There was scepticism about whether establishing a legal right would result in meaningful improvements in care delivery without sufficient resources and proper implementation mechanisms. Additionally, some respondents, such as the End of Life Studies Group at the University of Glasgow, highlighted that a wider approach was needed to address the social determinants of health, rather than one limited to the palliative care sector:

> "The social determinants of dying are, after all, a result of social determinants across the whole life course and therefore require a whole life course approach to address, as well as a 'whole-systems' approach, and a right to access one specialism will be unlikely to change substantive outcomes for people. Ultimately, the idea of a legal right to palliative care feels more symbolic than pragmatic. There is little evidence that services change significantly as a result. There is already a lot that can be achieved without opening up another long and complex

legislative process. New service development models within Health and Social Care Partnerships is one way forward, as is looking to spread good practice and level up provision across the nation."

- **Terminology concerns potentially excluding some groups**

Specific concerns about the use of the term "terminally ill" were raised by groups representing people with specific illnesses which might exclude individuals who do not identify as terminally ill but could still benefit from palliative care. It was feared that this could inadvertently limit access to necessary services for certain groups, as highlighted in the response from Parkinson's UK Scotland:

> "Many people with Parkinson's would not identify themselves as terminally ill - indeed, many have been told that their condition is not terminal, and that they will die with, rather than of, Parkinson's. There are great sensitivities around understanding of the word terminal. Some people with progressive and incurable conditions would consider the use of terminal to suggest that they are reaching the end of their life imminently. They may not consider this to be the case and still benefit from general and / or specialist palliative care. For this reason, we believe that eligibility of the legal right to palliative care should be based on the wording used in the WHO definition of palliative care - of life-threatening conditions, rather than terminal illness."

Other points raised

- **Condition-specific needs and data**

Several organisations representing people with specific conditions highlighted the importance of condition-specific data collection and addressing the unique needs of individuals with particular conditions. Groups such as MND Scotland and Parkinson's UK Scotland stressed that gathering detailed data on specific illnesses is crucial for assessing the impact of the right to palliative care and for addressing existing inequalities. Understanding the unique experiences of people with these conditions was felt to be essential for tailoring services to meet their needs effectively.

In addition, organisations like Cerebral Palsy Scotland and CHAS (Children's Hospices Across Scotland) emphasised the need for specialised knowledge and understanding when providing palliative care to individuals with complex conditions. They highlighted the importance of involving parents, carers, and family members in the decision-making process and ensuring that healthcare professionals have the necessary expertise to address the intricate needs of these individuals:

> "It is essential that condition-specific data is collected so that inequalities in access for people with certain conditions or groups of conditions can be identified and addressed."

Question 2: What is your view on the World Health Organisation's 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?

59 respondents (93.6% of the total) answered this question.

The main reasons given for supporting the WHO's definition of palliative care as the basis for the legal right to palliative care were:

- Comprehensive and holistic care
- Alignment with existing laws

The main reasons given for disagreeing with the WHO's definition of palliative care as the basis for the legal right to palliative care were:

- Potential exclusion of certain groups
- Changes in language needed to enhance inclusivity

Other points mentioned were:

- Need for supplementary guidance and national standards
- Inclusion of financial and social support
- Adaptation for younger populations
- Avoidance of potential conflicts with assisted dying legislation

Reasons for supporting the WHO definition

- **Comprehensive and holistic care**

Many representative organisations emphasised that the WHO definition ensured a holistic approach to palliative care, addressing physical symptoms but also emotional, psychological, social, and spiritual needs (covering all aspects of 'total pain'). This comprehensive framework, they argued, would guarantee that care was patient-centred and encompassed all facets of a person's well-being, leading to more effective and compassionate support. As argued by MND Scotland:

> "The World Health Organisation's definition of palliative care is a robust and widely recognised standard that could provide a strong foundation for enshrining a legal right to palliative care in Scotland. The definition appropriately frames palliative care as a holistic approach aimed at relieving suffering and improving quality of life for both the terminally ill person and their loved ones. It highlights the need to address the full range of physical, emotional, social and spiritual needs through comprehensive interdisciplinary assessment and management."

Hospice UK advocated the adoption of the WHO definition, as part of a broader public health approach to palliative care:

> "We support the benefits of taking a wider public health approach to palliative care and would want to see what is defined in statute around

palliative care, sit in a wider public health approach to palliative care. However, we accept that for the purposes of legislation, there would need to be a reasonably tight definition of palliative care and the WHO definition would be the most sensible approach."

- **Alignment with existing laws**

Adopting the WHO definition was also seen as a way to align new legislation with existing statutory guidance in other parts of the UK, such as England. Organisations believed this consistency would help avoid confusion, promote coherence in healthcare policies, and ensure that patients received comparable levels of care regardless of their location. Children Hospices Across Scotland (CHAS) responded:

> "CHAS does not object to the use of the WHO definition, which has the benefit of being used elsewhere in the UK and of being an authoritative articulation of the scope of palliative care. It has the benefit of:
> • Focusing on quality of life, not on death
> • Directly referencing children and their families
> • Alluding to the concept of 'total pain'."

Reasons for disagreeing with the WHO definition

- **Potential Exclusion of Certain Groups**

Some respondents highlighted that the term "life-threatening illness" might inadvertently exclude certain populations, such as older adults in care homes, or those who may not identify with the term "palliative." They were concerned that this could lead to unequal access to care and services for these groups. Cerebral Palsy Scotland noted:

> "We accept that the WHO definition is the one most widely used and we welcome a definition that focuses on an approach that improves the quality of life of patients and their families as they navigate life-long and life-limiting conditions. However, we note the term 'life-threatening' rather than 'life-limiting', which we are concerned would mean people with cerebral palsy who would benefit from access to palliative care due but would be denied access until a point of crisis.
> Palliative care includes, but is not exclusively about, end of life care. We agree with the Scottish Partnership for Palliative Care that "End of life care is part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care."

- **Changes in language needed to enhance inclusivity**

A third sector intermediary, The ALLIANCE, suggested amending certain terminology within the definition for greater clarity and accessibility, and avoiding words that might disempower individuals, like "suffering" or "patient." The ALLIANCE argued for the need to adopt clear and compassionate

language to improve communication and understanding among patients, families, and healthcare providers:

> "A formal definition of palliative care in Scotland should use slightly different wording to the WHO's definition, to be more easily understood and communicated. The word "psychosocial" for example may be unfamiliar to many people, and the same principle could be conveyed by a phrase such as "physical, mental, social, environmental or spiritual", which likewise emphasises there is more to the provision of palliative care than simply alleviating pain and other physical symptoms. We also recognise the point made in the consultation paper that the terminology of "suffering" can be perceived in a very negative light. It may also encourage thinking of people living with life-shortening and terminal conditions as unfortunate, disempowered victims, when the aim should be to empower people to live a good life and exercise choice and control over the circumstances of a good death."

Other points raised

- **Need for supplementary guidance and national standards**

Palliative care organisations suggested that the WHO definition should be supported by additional statutory guidance or national standards. They argued that supplementary materials would clarify eligibility criteria and practical implementation, ensuring consistent care across all regions of Scotland. This could involve developing detailed guidelines tailored to Scotland's legal and healthcare frameworks to facilitate the uniform application of palliative care services. The Scottish Partnership for Palliative Care called for:

> "the WHO definition…to be supplemented by more specific guidance. We believe the guidance should include a statement of national standards which help to illustrate what palliative care means for the purposes of this Bill. These standards should complement and not duplicate existing health and social care standards. These standards should be based around what matters to people who are seriously ill, dying or bereaved (see response to Q1). The standards would also be an opportunity to make some important aspects of palliative care more explicit, for example social care, bereavement support and support for carers. This specific guidance would have 3 purposes. Firstly to inform the work of service providers in delivering the right to palliative care. Secondly to provide the basis of monitoring and reporting of the realisation of the right to palliative care. Thirdly the guidance would form the basis of clear information for the public about their entitlement to palliative care."

- **Inclusion of financial and social support**

There was a call from Citizen's Advice Scotland to include financial support within the definition of palliative care explicitly. The organisation emphasised

that addressing financial circumstances is crucial for the overall well-being of patients and their families given the increased financial burdens that can accompany serious illness—such as higher energy bills and the need for housing adaptations—. They stated that incorporating financial and social support measures would provide a more comprehensive approach to palliative care. Citizen's Advice Scotland responded:

> "CAS supports the call from Marie Curie in *Dying in the Margins; The Cost of Dying* for equity-informed palliative and end of life support for people experiencing deprivation and financial hardship. Many people who are at the end of life will have additional needs that are likely to come with additional costs. While some of these additional needs may be provided for, such as end of life care in the home, there will be costs that aren't, such as the need to heat the home for longer or hotter, or by maintaining a more expensive, healthy, tailored diet or accessing private or complementary treatment".

- **Adaptation for younger populations**

Recommendations were made to adapt the definition to address the palliative care needs of specific populations, particularly children. By incorporating principles from the Association for Children's Palliative Care (ACT) definition, some respondents argued that the legislation could ensure that care begins at the diagnosis or recognition of a condition, not solely at end-of-life stages. Simplifying the language and tailoring the definition would make it more inclusive and effective for younger patients. A private individual, Francis Edwards, suggested:

> "Add the ACT definition: 'palliative care is defined as an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and it focuses on enhancement of the quality of life for the child and support for the family. It includes the management of distressing symptoms, provision of respite, and care through death and bereavement' (Association for Children's Palliative Care and the Royal College of Paediatrics and Child Health 2009)."

- **Avoidance of potential conflicts with assisted dying legislation**

Concerns were raised by private individuals and the Catholic Bishops Conference of Scotland about potential conflicts between the WHO definition and issues related to assisted dying. To prevent misunderstandings and maintain ethical clarity, it was suggested that the legislation should explicitly state that assisted dying is not a component of palliative care. They stated that this clarification would help delineate the scope of palliative care services and uphold the intended principles of the Bill. The Catholic Bishops Conference of Scotland noted:

> "We do, however, feel that it is important to express some caution in relation to the definition, specifically the potential for future modifications. In some countries, palliative care has, in a deeply

troubling perversion of its true meaning, been taken to include euthanasia and/or assisted suicide."

Question 3. 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)?

37 respondents (58.7% of the total) answered this question via the provided checkbox. (Other responses may have indicated whether or not they supported the general aims of the Bill, but only checkbox responses have been included in the following quantitative analysis.)

Strongly Agree	22	34.9%
Partially Agree	5	7.9%
Neutral (Neither agree nor disagree)	5	7.9%
Partially Disagree	0	0%
Strongly Disagree	0	0%
Unsure	5	7.9%
Blank/Did not answer	26	41.3%

- Where respondents did answer the question via the checkbox, 27 respondents (42.8%) strongly agreed or partially agreed. There were no responses that disagreed.
- 10 respondents (15.8%) reported being neutral or unsure.
- 26 (41.3%) of respondents did not indicate their position via the provided checkbox.

The main reasons given for support were:
- Reducing health inequalities through equitable access
- Targeted support and improved data

The main reasons given for disagreeing were:
- Implementation challenges in rural and remote areas

Other points mentioned were:
- Workforce planning and resource allocation
- Emphasising trauma-informed care in palliative services

Reasons for supporting impact on different groups

• Reducing health inequalities through equitable access

Individual respondents, hospices, and third-sector organisations representing specific conditions all highlighted that enshrining a right to palliative care would significantly reduce health inequalities by helping to ensure better access for marginalised and under-served populations. This includes individuals living in more rural, remote, and socio-economically deprived areas, as well as those from minority backgrounds, people with disabilities,

people in prison, and older adults. By addressing geographical and socio-economic barriers, many respondents thought that the legislation would help terminally ill patients receive the care they need, regardless of their location or sociodemographic background. Professor Ben Colburn at the University of Glasgow responded:

> "I think the right to palliative care would benefit all groups within society by offering individuals an important and valuable option for their end-of-life journey. If implemented properly, i.e. by focusing on upholding autonomy and alleviating suffering in its various forms, and by attending to the specific circumstances and priorities of the individual patient, I think it would go a long way towards mitigating existing inequalities people from marginalised groups face in their experiences of death and dying."

- **Targeted Support and improved data**

Hospices, including Hospice UK, supported the principle of adopting a considered, equity-informed approach to establish a right to palliative care. They emphasised that such an approach would help identify, understand, and address current inequities in palliative and end-of-life care, particularly through improved data and reporting. Hospice UK stated:

> "By taking a considered, equity-informed approach, a right to palliative care should help identify, understand and address current inequities in palliative and end of life care. At the moment we have no systematic way of measuring people's experiences of care at the end of life or know how well we are addressing people's needs or who is missing out. A right to palliative care provides an opportunity to have much better data and reporting, and more clearly identify where there are gaps or fragmentation in the current system. A right to palliative care could also require a specific focus on underserved communities, for example identifying the needs and barriers experienced by particular groups; ensuring service design is informed by their views; reporting on the experiences and outcomes of particular groups; and staff training on their needs."

Reasons for opposing impact on different groups

- **Implementation challenges in rural and remote areas**

While 27 respondents (42.8%) strongly agreed or partially agreed with the view that the proposed bill would have a positive impact on many groups in Scotland, some respondents highlighted concerns about the practical difficulties of implementing such a right in rural and remote areas. Some respondents perceived a risk that disparities between urban and rural regions could worsen due to limited service access, geographic isolation, and workforce shortages. Concerns were raised that the legislation might unintentionally widen inequalities by overstretching services in high-demand areas and straining

resources for smaller healthcare providers. Such a view was raised by Citizens Advice Service Scotland:

> "We would urge that the additional impact of living in a remote or rural area be considered in defining what a right to palliative care means. Less frequent and accessible public transport and higher fuel costs in rural areas will impact on people's ability to attend medical appointments as well as on family members, carers and health care professional's ability to support people in their homes."

Other points raised

- **Workforce planning and resource allocation**

Third-sector organisations representing people with specific conditions, hospices and professional bodies strongly highlighted the importance of robust workforce planning, professional training, and adequate resource allocation to realise the right to palliative care for all groups effectively. Respondents said that investing in training would equip healthcare professionals with the skills necessary to address the varied circumstances of terminally ill patients from different sociodemographic backgrounds. Moreover, they suggested that allocating resources to expand specialist services into community and rural settings would help mitigate geographic disparities. It was also highlighted that the social care sector is particularly under-resourced in the current climate. The Scottish Huntington's Association responded:

> "There should be more mandatory training for staff in general hospitals, care homes and community settings in the principles and delivery of good palliative care. I think that expansion of specialist palliative care services out with specialist palliative care settings would be required - e.g., in GP surgeries or community settings within council areas, as well as in hospitals."

- **Emphasising trauma-informed care in palliative services**

The End of Life Studies Group at the University of Glasgow put forward the view that to better support individuals with terminal illnesses who have experienced structural vulnerabilities or multiple disadvantages, there is a need to integrate trauma-informed care into palliative services:

> "Those with experience of structural vulnerability across the life course are at higher risk of mental health issues which can be exacerbated at end of life and are also at higher risk of multi-morbidity and greater symptom burden at end of life. Specialist palliative care which could play more of a consultative and advocacy role could be part of a future care landscape which gives more attention to those who have experience of structural vulnerability and accumulated disadvantages. It is our view that trauma-informed care should be mainstreamed across specialist palliative care and then taken up more generally via the advice and education cascaded by those specialists."

Additionally, Marie Curie highlighted that implementing a trauma-informed approach requires whole-system integration. They stressed the importance of education for professionals to recognise and appropriately respond to trauma presentations:

> "Implementing a trauma informed approach requires whole-system integration across health and social care, social security and housing, and education for professionals which empowers them to recognise and appropriately respond to trauma presentations.
> This should encompass developing training, trauma assessment techniques, and intervention strategies specific to palliative care to improve end of life experience for patients and caregivers ensuring a trauma-informed environment that supports psychological safety and minimises the risk of re-traumatisation".

Question 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 implemented?

59 respondents (93.6% of the total) answered this question.

The main recommendations for implementation were:

- Collaborative and integrated delivery across sectors
- Essential data collection for monitoring implementation
- Establishment of national standards within a legal framework
- Public awareness and positive narrative

The main challenges to implementation were:

- Resource allocation and impact on other healthcare services

Other points mentioned were:

- The National Care Service Bill as a legislative vehicle

The main recommendations for implementation were:

- **Collaborative and integrated delivery across sectors**

Respondents advocated strongly for a collaborative approach to implementing the right to palliative care, involving stakeholders such as NHS Scotland, local authorities, Integration Authorities, Health and Social Care Partnerships, third-sector organisations, hospices, social care providers, and faith-based groups. An integrated model was viewed as the best way to ensure holistic and person-centred care. The involvement of organisations like Marie Curie, the Scottish Partnership for Palliative Care (SPPC), and third-sector services was emphasised as crucial for delivering comprehensive care and filling service gaps.

Additionally, while a multi-sector approach was deemed essential, there was a strong view among respondents that palliative care should reside with Integration Authorities. Organisations like Marie Curie advocated for a duty on Integration Authorities to ethically commission at least a Minimum Service Standard of palliative care, tailored to local population health needs. Age Scotland and the Neurological Alliance of Scotland recommended that Integration Authorities continue to oversee the delivery and implementation of palliative care services. Alzheimer Scotland suggested that reformed Integrated Joint Boards could assume responsibility, operating against agreed principles and standards while consulting with palliative care providers:

> "Given that the delivery of palliative care services is the responsibility of a number of bodies and organisations, it is clear that responsibility for delivering palliative care must encompass an integrated approach that presents all providers with an opportunity to engage in strategic planning and a supportive approach to operational delivery. With the development of joined-up national and local strategic plans, it may be appropriate for reformed Integrated Joint Boards to assume responsibility for palliative care to be delivered against a set of agreed principles and standards, while seeking input from groups made up of palliative care providers who can input on specific issues. Clarity is required around the make-up and operational function of reformed Integration joint Boards to explore this opportunity further."

References were made to the Public Bodies (Joint Working) (Scotland) Act 2014, suggesting that palliative care should be integrated within existing health and social care partnerships to enhance coordination and resource allocation. Several respondents, such as St Columba's Hospice, identified existing examples of effective collaboration:

> "It needs to be clearly recognised that palliative care is everyone's business and is provided across all care settings, so any legislation would need to recognise the multiplicity of services involved and have a broad range of approaches to measuring successful delivery. Innovation in enhancing provision of palliative care services should be encouraged. Examples of responsive, rapid and well co-ordinated projects like the Highland End of Life Care project or REACT project in Bradford show how a centralised hub responding to need can help address the needs of specific areas.

•Essential data collection for monitoring implementation

There was a suggestion from palliative care providers and third sector organisations representing people with specific conditions on the importance of robust data collection in the implementation of the right to palliative care. Age Scotland and About Dementia, in a joint response, suggest integration authorities should be responsible for collecting and publishing information on the number of people accessing palliative care:

> “As the main accountable bodies, integration authorities should also be held responsible and liable for collecting and publishing information publicly on the number of people accessing palliative care, how and when this was offered and the experiences of those who have accessed it, as is suggested in the policy intent of the consultation document. We would also suggest that data is disaggregated by diagnosis, for example so that there is evidence of the number of people living with dementia receiving palliative care in Scotland each year. This would allow gaps in care to be identified and addressed to ensure that the right is being accessed equitably.”

References were made to the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care 2016-2021, which outlines the importance of data in improving palliative care services. The need for mandatory data collection was emphasised, including patient experience data linked to national standards, as well as qualitative feedback from individuals and families to measure care effectiveness beyond quantitative metrics. The adoption of tools like the National Survey of Bereaved People (VOICES) was suggested to understand end-of-life experiences better.

Organisations highlighted the importance of monitoring, measurement, and reporting on care delivery to Parliament, drawing parallels with the reporting duties in the proposed National Care Service Bill (Scotland). The Care Inspectorate's role in monitoring performance and identifying gaps and pressures was also noted. Additionally, the use of a National Digital Platform and a nationally consistent, integrated care record was advocated to streamline data sharing and improve the quality of palliative care provision.

- **Establishment of national standards within a legal framework**

Respondents consistently highlighted the necessity of establishing national standards as a cornerstone for implementing a legal right to palliative care in Scotland. Organisations such as Marie Curie advocated for Minimum Service Standards to ensure universal access and quality across both specialist and generalist services. It was proposed that these standards would define expectations for individuals and families, outline healthcare providers' responsibilities, and mandate that Integration Authorities commission services tailored to local needs. Age Scotland further supported the adoption of national standards alongside local delivery, as did Alzheimer Scotland in their response:

> “Minimum palliative care standards that should be adopted at pace across the country, including the right to early intervention and planning which are key to delivering person-centred care. This should be set out at a national level but must co-exist with local delivery plans to ensure consistency.”

Additionally, organisational respondents emphasised detailed and specific national standards to address existing inconsistencies and ensure equitable access across diverse regions and populations. Hospice UK and the British

Heart Foundation stressed the importance of clear provisions for core service requirements, enhanced data collection, and comprehensive workforce training. The Scottish Partnership for Palliative Care recommended a tiered approach to implementation, starting with baseline Minimum Service Standards followed by higher standards for continuous improvement. Children's Hospices Across Scotland (CHAS) underscored the need for measurable standards in children's palliative care to ensure meaningful impact and accountability. Collectively, these national standards were seen as essential for achieving a unified, accountable, and high-quality palliative care system that meets the diverse needs of Scotland's population.

Reference was made to the Health and Care (Staffing) (Scotland) Act 2019, highlighting the need for adequately trained staff and workforce planning to deliver high-quality palliative care. The "Framework for the Delivery of Palliative Care for Children and Young People in Scotland" (2012) was cited as an example of setting key outcomes and objectives for care provision across Health Boards.

- **Need for public awareness and a positive narrative**

Respondents from hospices and organisations supporting people at the end of life raised the importance of increasing public awareness about palliative care. It was suggested that the Scottish Government, Integration Authorities, the NHS, and Local Authorities should collaborate on campaigns to educate the public about what palliative care is, its benefits, and how to access it. A commonly held view was that such campaigns should clarify that palliative care is not only for those nearing the end of life but is available from the point of diagnosis for any terminal illness, including conditions like COPD and heart failure. It was also recommended that campaigns should aim to break societal taboos around death and dying, fostering open discussions about end-of-life preferences. Children's Hospices Across Scotland (CHAS) suggested:

> "Irrespective of the exact wording of the definition of palliative care on the face of the Bill, significant work will need to be done to raise awareness that the right exists, and also to ensure that there is widespread understanding about what this means, how the right will be realised, and what to do if an individual suspects their right is being breached. We also believe that as with rights-based legislation such as UNCRC, a wide range of supportive communications materials would need to be produced, including simplified child-friendly versions. These should be produced in collaboration with children and young people with life-shortening conditions and their families, as well as staff in the paediatric palliative care workforce."

This view that a positive public awareness campaign is necessary was also shared by a small number of individual respondents, such as GB:

> "Care should be taken that the "narrative" is positive and convincing."

The main challenges to implementation were:

- **Resource Allocation and Impact on Other Healthcare Services**

Concerns were raised about the potential impact of implementing the right to palliative care on other healthcare and social services due to resource allocation challenges. Some respondents were worried that directing resources toward expanding palliative care services might lead to cost-cutting or reduced funding in other critical areas of healthcare. There was apprehension that without additional resources, councils and health boards might struggle to implement the right effectively, potentially leading to inefficiencies or unintended consequences on other sectors. The risk of competition for limited resources could put a strain on existing services and negatively affect overall healthcare provision. These challenges highlight the importance of strategic planning and careful consideration of resource distribution to ensure that the implementation does not adversely impact other essential services. Erskine Veteran's Charity expressed concern that additional funding might not be allocated to care homes, which play a significant role in palliative care:

> "It is clear and obvious that finances are stretched across the budgets held and dispersed from the Scottish Government. This is a significant concern for us when envisioning creating a right to palliative care. Firstly, we are concerned where this new money would come from? To be clear, to introduce the right cannot be done meaningfully or successfully without accompanying funding. Even if the funding is to develop training opportunities across society (not just statutory services) this is the minimum that would be required. Should the right be taken further and specific specialist services be developed we have significant concerns that organisations, such as care homes, who deliver quality palliative care services every day, would not benefit from this additional funding".

Other points raised:

- **The National Care Service Bill as a legislative vehicle**

Respondents presented varying perspectives on whether the proposed Right to Palliative Care Bill should be enacted as a standalone act or incorporated into the broader National Care Service (NCS) Bill. While some organisations argue that a standalone bill is necessary to ensure palliative care is not marginalised and receives dedicated attention, others believe that integrating it within the NCS Bill would allow for a unified framework and clear duties for Integration Authorities to commission and improve palliative care services. However, concerns about the NCS Bill's uncertain inclusion of children's services, delayed timelines, and ongoing restructuring of health and social care services have led many to question its suitability as the primary legislative vehicle. Consequently, third sector organisations and hospices put forward the view that a dedicated Right to Palliative Care Bill may be required to achieve comprehensive and timely implementation.

Question 5. Are there any other comments you wish to make on the proposed Bill, for example on its financial implications, impact on equalities and sustainability?

59 respondents (93.6% of the total) answered this question.

Additional comments on the proposed bill were focused on:

- Financial implications
- Impact on inequalities
- Long term sustainability

Other specific recommendations:

- Engaging directly with faith and belief groups
- Mandating education and standards for palliative care across health and social care
- Ensuring the independent hospice sector is sustainably funded and valued for its contribution
- Using community pharmacies as a resource to improve care in rural areas

Additional comments on the proposed bill were:

- **Financial implications**

Both organisational and individual respondents acknowledged that the successful implementation of the proposed Bill would require a significant financial commitment from the Scottish Government. It was believed that ensuring palliative care for all terminally ill individuals would likely involve substantial investment in services and infrastructure. However, it was also suggested that the public might be willing to accept these costs, provided that the process is transparent, and the allocation of funds is clear. Some respondents pointed out that proactive palliative care could potentially lead to long-term cost savings, for instance by reducing expensive emergency hospital admissions during the final stages of life. Individual respondent, JW, said:

> "Investing in proactive palliative care is vital and could be funded by the avoidance of expensive unnecessary emergency admissions which escalate in the last year of life and reallocation of the resources to the community to educate, enable and equip the staff there, including GPs, community nurses, specialist palliative care charities, social care nurses working in care homes, and social care staff employed by local authorities and in care homes, and all the AHPs, all with a remit to support people in their own homes including care homes."

- **Impact on equalities and addressing individual needs**

Ensuring equal access to palliative care for all was a central concern for many respondents, who emphasised the need for the Bill to address inequalities across various groups, including those based on age, race, gender,

socioeconomic status, and geographic location. Many respondents highlighted the challenges faced by individuals living in remote or rural areas, people with disabilities, and other marginalised groups, stressing that these barriers must be addressed to achieve true equity. Additionally, it was noted that palliative care plans should be flexible and tailored to meet the specific needs, preferences, and beliefs of each patient and their family. ST, who cared for their mother, responded:

> "By tailoring a person's palliative care to meet their specific needs and doing this in collaboration with the person and their families, then the individual who is terminally ill, as well as their families, will have ownership of this palliative care plan and feel more secure and reassured about their future. The plan is more likely to succeed and the palliative care offered will be more effective if this process is carried out. Effective palliative care should meet the outcomes stated in the definition of Palliative Care, whatever that will be. Also key to avoiding negative impacts, especially for certain individuals who may feel marginalised within society for whatever reason, is the building of relationships between the professional person and the individuals and their families. If possible, time should be taken to get to know each other so that the professional person can have a better understanding of the concerns, history and effects the terminal diagnosis is having on the individual and their family."

- **Long-term sustainability**

Sustainability was a key theme, with organisational and individual respondents stressing the importance of long-term funding and resource allocation to ensure the ongoing delivery of palliative care services. Concerns were raised about the need to develop the healthcare workforce, with calls for increased training and support for professionals involved in providing palliative care. Additionally, respondents emphasised the need for comprehensive data collection and monitoring to track the effectiveness of the proposed right to palliative care and to identify areas for improvement, ensuring that services remain responsive to changing needs over time.

Other specific recommendations:

Other specific recommendations made in response to question 5 are presented below.

- **Engaging directly with faith and belief groups**

Religious groups, such as the Scottish Evangelical Alliance, advocated for the inclusion of faith and belief organisations in the legislative process surrounding the proposed Bill. They emphasised that many of these groups would strongly support the Bill and could offer valuable expertise in areas such as spiritual care and chaplaincy services. They argued that their involvement would be beneficial in ensuring that the legislation addresses the holistic needs of patients, particularly in terms of emotional and spiritual

support, areas where faith communities have considerable experience and ongoing involvement in end-of-life care.

- **Mandating education and standards for palliative care across health and social care**

The Royal College of Physicians of Edinburgh emphasised the importance of mandating education in palliative care across all health and social care disciplines, alongside the development of national standards to ensure consistency in care quality and access:

> "We consider that national standards for palliative care would need to be developed alongside a range of outcome measures and quality indicators which are sensitive and responsive to equity of access and to the wide variation in needs and preferences across different groups, cultures, geographical locations and care settings. Fellows considered that the Scottish Partnership for Palliative Care is already well placed to co-ordinate the collaborative effort which would be required to deliver and maintain such standards and funding for the SPPC should be secured at National level within any legislation to enable its work to continue and to expand. Standards should be independently and collaboratively developed and maintained and the SPPC is the organisation with the focus and authoritative experience to most effectively share practice and oversee this essential work."

- **Ensuring the independent hospice sector is sustainably funded and valued for its contribution**

Hospice UK's response expressed the view that the independent hospice care sector must be sustainably funded and recognised for its contribution to delivering palliative care across Scotland:

> "For independent hospice care providers to be part of the solution they need to be sustainable over the long-term and their staff need to be valued for the vital work they do on a par with NHS staff. To ensure this, the promised new national funding framework for hospice care needs to be developed and implemented properly, including that 50% of hospice care costs will come from statutory funding. In addition, Scottish Government needs to factor in the impact of the hospice sector into future NHS pay awards and ensure there is a mechanism for funding to flow to hospice care providers to allow them to match NHS pay awards for their staff."

- **Using community pharmacies as a resource to improve care in rural areas:**

The Royal Pharmaceutical Society responded regarding the role of community pharmacies in providing palliative care, emphasising their potential to address health inequalities, particularly in rural and remote areas:

“The consultation document states that the inverse care law applies in palliative care. Community pharmacies are one of the few services that has the potential to buck the inverse care law, with academic literature stating that “community pharmacies offer a key resource for tackling health inequalities”. In our view, community pharmacies are a key resource to provide palliative care services, and the Daffodil Standards for Community Pharmacy which were published last year provide a strong underpinning to this. Ensuring community pharmacies are adequately resourced to support patients, families and carers palliative care needs will be critical to the success of this initiative. Furthermore, appropriate use of community pharmacy will support everyone, particularly those living in remote and rural areas, to access palliative care services.”

SECTION 4: MEMBER'S COMMENTARY

I would like to express my gratitude to all those who responded to my consultation on a proposal for a Members Bill to give people of all ages living with terminal illness and residing in Scotland a legal right to palliative care.

The responses to this consultation will inform the drafting of the Bill or any amendments to government legislation that would take forward the intent to make the Right to Palliative Care explicit in law.

I was pleased to see that the consultation on the proposed Right to Palliative Care (Scotland) Bill received a positive response from both individuals and organisation, with a majority of respondents in agreement that establishing a legal right to palliative care for those of all ages with terminal illness in Scotland should be enshrined in law.

To best achieve the implementation of this, the main recommendations were as follows:

- Collaborative and integrated delivery across sectors
- Essential data collection for monitoring implementation
- Establishment of national standards within a legal framework

Whilst there was general agreement, there was some concern raised about the practical implementation of the proposed right with issues including resource constraints, shortages in the workforce, and the feasibility of delivering consistent palliative care services across all regions. Indeed, resource allocation and the impact on other healthcare services was marked as one of the main challenges. Rural and remote areas were highlighted as areas where equitable access may be difficult to guarantee, with recommendations including using community pharmacies as a resource to improve care in these areas.

Other specific recommendations included mandating education and standards for palliative care across health and social care and ensure that the independent hospice sector is sustainably funded and valued for its contribution.

I would once again like to thank all those – both organisations and individuals - for responding to the consultation.

During the consultation process, many people have shared their personal stories with me on how our palliative care has delivered for their loved ones and in the minority of cases how systems have not been in places to meet people's needs.

One comment which has stayed with me is that 'the end-of-life deserves as much beauty, care, and respect as the beginning.

Miles Briggs
MSP for Lothian Region

ANNEXE

Name of organisation/individual	Response number
Age Scotland and About Dementia	29
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British Heart Foundation	31
British Medical Association (Scotland)	32
Catholic Bishops Conference of Scotland	35
Cerebral Palsy Scotland	59
Chest Heart and Stroke Scotland (CHSS)	36
Children's Hospices Across Scotland	57
Christian Action, Research and Education for Scotland	33
Church of Scotland	39
Citizens Advice Scotland	34
Colburn, Ben	25
Davidson, Ian	19
DG	23
Dignity in Dying Scotland	58
DR	18
Edwards, Francis	17
Erskine Veterans Charity	38
Evangelical Alliance (Scotland)	56
Free Church of Scotland	40
GB	11
GB	26
Glasgow End of Life Studies Group	41
Health and Social Care ALLIANCE Scotland	60
Hospice UK	43
Hughes, Michèle	6
Humanist Society (Scotland)	51
Independent Age	44
JB	10
JP	9
JR	12
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Less Survivable Cancers Taskforce	45
LS	5
Macmillan Cancer Support	42
Marie Curie	27
McGuire, Maria	7
MM	8
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National Cancer Organisation	48
Neurological Alliance of Scotland	47
O'Hagan, Frank	21
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Name of organisation/individual	Response number
Our Duty of Care	50
Parish of St Mary Magdalene	22
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Private individual	2
Private individual	4
Private organisation	49
Queen's Nursing Institute Scotland	53
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Scottish Huntington’s Association	63
Scottish Partnership for Palliative Care	62
SP	14
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Tough, Alan	3