# Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill – Liam McArthur 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. These three sections have been prepared by the Scottish Parliament's Non-Government Bills Unit (NGBU). Section 4 has been prepared by Liam McArthur MSP and includes his commentary on the results of the consultation.

Where respondents have requested that certain information be treated as "not for publication", or that the response remain anonymous, these requests have been respected in this summary.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 opposition to, 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. This is to inform deliberations on the policy specifics of the Bill resulting from this process. 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: https://www.assisteddying.scot/. All responses have an allocated number. Those made via Smart Survey have an additional Smart Survey identification (ID) number listed, and those not made via Smart Survey are marked accordingly. Responses made in response to the BSL or easy read versions of the summary are also clearly identified.

Due to the high number of respondents, a complete list of all who responded is not attached to this summary, however a list of the published and attributable organisations that responded can be found at the Annexe. To see all published responses, please access https://www.assisteddying.scot/.

# Section 1: Introduction and background

Liam McArthur's draft proposal, lodged on 22 September 2021, is for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life.

The proposal was accompanied by a consultation document, prepared with the assistance of NGBU. This document was published on the Parliament's website, from where it remains accessible:
Proposals for Bills – Scottish Parliament | Scottish Parliament Website

The aim of the proposal is to enable mentally competent adults who are terminally ill to be provided with assistance to end their life at their request. In Scotland, a person is terminally ill if a registered medical practitioner has diagnosed them as having a progressive disease, which can reasonably be expected to cause their death. The person must be 16 years of age or over, which is the age of majority in Scotland, and have been a resident of Scotland for at least twelve months.

Further details of the proposal can be found at pages 19-22 of the consultation document. Note that in his Foreword to the document, Liam McArthur explains why his proposed Bill refers to "assisted dying" rather (as was the case with previous proposals to legislate in Scotland) than "assisted suicide" in the first footnote of the consultation document[1].

Liam McArthur also provided two alternate summary versions of the consultation – an easy read version and a British Sign Language (BSL) version. Both of these versions had their own version of the questions set out in the full consultation document, and both were made available on the following website: https://www.assisteddying.scot/.

The consultation period ran from 23 September 2021 to 22 December 2021.

Liam McArthur notified 57 individuals (all constituents with whom he had previously engaged in correspondence related to assisted dying) that the consultation was open and asked them to contribute. Liam McArthur spoke at the Humanist Society Scotland's "The Time is Now: Assisted Dying Symposium", on 26 November 2021[2] and also made a number of media and press appearances (including frequent promotion on social media) during the

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[1] Footnote 1 of the consultation document states: "There is no universally agreed definition of assisted dying, we feel that it is appropriate to use assisted dying as the umbrella term here but note that previous attempts (Assisted Suicide (Scot) Bill) referenced assisted suicide, and that internationally it can be referred to as medical aid in dying, physician-assisted death inter alias. The use of 'suicide' in this context is not appropriate, given that the person will only be able to request an assisted death if they have a terminal illness that will end their life i.e. the choice to live has already been taken away, the choice of an assisted death allows the inevitable dying process to be less traumatic."

[2] Humanist Society Scotland, The Time is Now symposium, 26 November 2021. Available to view at: The Time is Now: Assisted Dying Symposium 2021 - YouTube.

consultation period to raise awareness about the consultation and discuss the proposal.

Liam McArthur decided that his office would not contact organisations to invite responses. Liam McArthur assessed that ongoing publicity surrounding the proposals and consultation would be sufficient in raising awareness among relevant stakeholders, and he did not wish to risk inadvertently excluding any such stakeholders by not giving some notice of the consultation but not others.

Liam McArthur's work on his proposal is supported by three organisations: Dignity in Dying Scotland; Humanist Society Scotland; and Friends at the End.

The consultation exercise was run by Liam McArthur'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.

Note that Members are advised by the Non-Government Bills Unit to include standard questions relating to the potential financial, equalities and sustainability impact of a draft proposal for a Member's Bill in consultation documents. This is to ensure an opportunity for views to be gathered on the potential impacts of a proposed new law on:

- the finances of various groups (such as different organisations and individuals);
- equalities, and people with protected characteristics; and
- sustainability, including work to protect and enhance the environment, achieve a sustainable economy, and create a strong, healthy, and just society for future generations.

These are standard questions and were not specific to this proposal.

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): Part 3: Stages of Bills – special cases | Scottish Parliament Website

# Section 2: Overview of responses

In total, 14,038 responses were received. The vast majority (13,975) of these were submitted via the online Smart Survey webpage. Sixty-three responses were received by other means, as follows:

- 46 responses to the full consultation were sent to Liam McArthur either electronically or in hard copy via the post;
- 16 responses were submitted in response to the easy read summary version of the consultation;
- 1 response was received in response to the BSL summary version of the consultation.

The responses can be categorised as follows:

- 81 (0.58% of the total number of respondents) from organisations as follows (note that the majority of organisations self-selected a categorisation):
    - 1 (1% of organisations) from a public sector organisation (Scottish Human Rights Commission);
    - 1 (1% of organisations) from an independent regulator (General Pharmaceutical Council);
    - 14 (17% of organisations) from representative organisations (trade union, professional association);
    - 57 (70% of organisations) from third sector organisations (charitable, campaigning, social enterprise, voluntary, non-profit); and
    - 8 (10% of organisations) from other organisations (note that the organisations which selected this option all appeared to be either representative or third sector organisations).

One organisation asked to remain anonymous, and one asked for its response not to be published.

- 13,957 (99.42%) from individuals as follows (note the majority of individuals self-selected a categorisation):
    - 35 (0.25% of individuals) from individual politicians;
    - 163 (1% of individuals) from academics with expertise in a relevant subject;
    - 1,609 (11.5% of individuals) from professionals with experience in a relevant field;
    - 12,150 (87% of individuals) from private individuals (members of the public).

It was clear that responses from individuals included a wide variety of current and retired health care professionals and workers (nurses, doctors, social workers, palliative care workers, policy and administrative staff), vets, charity workers, religious figures and legal professionals.

The status of submissions was as follows:

- 9,051 (64.5% of all submissions) published and attributed submissions;
- 3,665 (26% of all submissions) anonymous submissions; and
- 1,322 (9.5% of all submissions) submissions that the respondent marked "not for publication".

A campaign, fully opposed to the proposal, was organised by the Right to Life organisation. 3,352 emails[3] were received by Liam McArthur, on the same day all from the same organisational email address (but copied to different email addresses, seemingly those of individuals) as part of the campaign. Given that the responses all came from the same email address (that of the Right to Life organisation), and the identical/very similar nature of the responses, they have not been counted as individual responses and are not counted in the data presented in the summary.[4] A summary of the views expressed in the campaign can be found on page 7 and an example of the contents of the campaign can be accessed on this webpage: https://www.assisteddying.scot/.

The consultation received the highest number of responses received to date for a consultation for a proposed Member's Bill in the Scottish Parliament. Views on the proposal to introduce assisted dying for terminally ill competent adults in Scotland were broadly polarised, with strong views expressed both in support and opposition. Only 3% of respondents expressed a view other than full support or full opposition. Among those that did were some representative organisations which did not give a view as opinions amongst the relevant memberships were mixed. Views on the details of the proposal, and how assisted dying should be implemented in Scotland, were more nuanced, with a wide range of issues, questions, and concerns raised by respondents on both sides of the debate.

A clear majority of respondents (10,687 - 76%) were fully supportive of the proposal, with a further 244 - 2% partially supportive. Many respondents gave first hand experiences of living with, and caring for, family, friends and patients with a terminal illness who had experienced great pain and suffered what was often described as a "bad death". Many of these respondents believed that assisted dying should be available for people in Scotland, as it is in other parts of the world. They believed that a humane society should make provision to spare its people from unbearable pain and suffering and allow

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[3] A proportion of these respondents also made incomplete responses via a Right to Life organised webpage which linked to the Smart Survey hosting the consultation. To avoid duplication, and as most were incomplete, the Smart Survey responses were discounted. Note that although 3,352 emails were received, these were not verified so it is not known if this figure included multiple responses from the same individual.

[4] Based on the responses received it was possible to produce a percentage on levels of support for the proposal if factoring in all those submitting responses based on RTL campaign wordings. This has also been included for reference (see Q1 response analysis).

people the autonomy to legally choose to end their lives in a safe and regulated manner. Many supportive respondents believed the proposal was an improvement on previous attempts to legislate for assisted dying and were fully satisfied with the proposed safeguards set out in the consultation document. Many believed that the proposal successfully balances the provision of a right to assisted death for competent terminally ill adults with a clear and appropriate set of safeguards built in to every step of the process, together with a right for health professionals involved to conscientiously object.

A proportion of those supportive of the fundamental principle of legalising assisted dying put forward changes they wished to see to the specifics of the proposal. One of the most common changes called for related to concerns about the intended definition of “terminal illness” proposed in the consultation document[5]. Many believed a wider group of people should be able to choose an assisted death than the intended definition would allow for, such as those with potentially longer-term degenerative conditions, such as various neurological conditions and forms of dementia. A significant number of respondents also raised concerns about the proposal that the life ending substance must be self-administered, noting that some people who would wish to choose an assisted death would not be able to take the medicine themselves. Many respondents believed this to be potentially discriminatory and called for a health care professional to be able to administer the drug in certain circumstances, or that there should at least be clarity on how life would be ended in such circumstances.

A minority of the overall number of respondents (2,975 - 21%) were fully opposed to the proposal, with a further 52 - 0.4% partially opposed. One of the most common reasons given for opposing the proposal was a fundamental belief, often founded in a particular religion, that human life is sacred and must not be purposefully ended under any circumstances. A large number of those opposed also believed that no safeguards would ever be able to prevent some people from feeling pressure to end their lives, perhaps through fear of being a burden on family, friends, health care services and/or wider society, or even being coerced for various reasons into deciding to choose an assisted death. Fears were expressed that there could never be certainty that a decision was being made solely of the individuals own free will. Many of those opposed also stated their belief that legislating to give effect to the proposal would be a “slippery slope” i.e. that any legislation passed would likely be amended in the future to weaken safeguards and extend the option for assisted death beyond the competent terminally ill adults currently proposed. Such responses often cited other countries and jurisdictions where a form of assisted dying is legal, and where they believe

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[5] The consultation document states: “In Scotland, a person is terminally ill if a registered medical practitioner has diagnosed them as having a progressive disease, which can reasonably be expected to cause their death.” A link is provided in the consultation document to the following Scottish Government document (Social Security Policy, Terminal Illness): https://www.gov.scot/policies/social-security/terminal-illness/ and the document states: “Whilst this is a specific policy adopted for a specific purpose, it is generally agreed as a reasonable definition and has been adopted for the purposes of this consultation.”

such changes have occurred over time. Fears were also expressed, including by disability organisations, that the proposal would further stigmatise and threaten some of the more vulnerable people in society, such as young people, older people and people with a disability.

The Right to Life campaign was fully opposed to the proposal, citing many of the concerns mentioned in other opposed responses, including that:

- people will opt for an assisted death because they feel they are a burden, or out of a sense of duty, rather than make a purely autonomous decision;
- it would normalise suicide and create a double standard, where some suicide is legal and permitted, and some is not;
- it would start a “slippery slope” towards wider euthanasia of vulnerable people in society;
- no safeguards will ever be sufficient to ensure assisted dying is safe; and
- instead of pursuing the proposal, investment should be made in palliative care.

A majority of the organisations that responded to the consultation were fully opposed to the proposal (47 organisations - 57.5% of organisations, see footnote 10 for details), the majority of which (32 - 68% of organisations) were either specifically religious organisations, or were organisations clearly linked to a particular religion (see footnote 11 for details). Of the individual respondents that identified as members of the public (which represented 87% of individuals who responded), a clear majority (over 80%) were fully supportive.

There was a more even split amongst those individuals who identified as being professionals with experience in as relevant subject, with 50% of them fully supportive and 46.5% of them fully opposed. Those professionals, both supportive and opposed, included a range of (current, previous and retired) health care professionals (including GPs, doctors, nurses, and social workers – including mental health specialists), religious figures (including priests, ministers and rabbis), pharmacists, vets and legal professionals.

# Disclaimer and methodology

Note that the inclusion of a claim or argument made by a respondent in this summary should not be interpreted as verification of the claim or as endorsement of the argument by the Non-Government Bills Unit.

Every question which asked respondents to select a single response from a range of options summarising their view (questions one, three, four, five, seven, eight and nine) featured a proportionately small number of respondents whose selected check-box answer did not appear to match the reasons given for the response in the relevant text box. For example, there were responses which indicated support (full or partial) for the proposal in question one and then set out reasons why they were opposed, and vice versa, and people who selected “neutral” or “unsure” to a particular question who then set out very clear views of either support or opposition. Given the high number of responses, and given the proportionally small number of instances, and to avoid repetition, likely mistakes when selecting a particular option are not noted under the summary of each relevant question. Neither does the data presented adjust for this – the data accords to the selections made by respondents, regardless of whether that selection appears to be contradicted in subsequent written explanation. However, the views expressed in the text boxes have been taken into consideration and are reflected in the relevant narrative parts of the summary.

There were also a number of responses, of various viewpoints, which contained identical, near identical, or very similar text. It seems that organisations (both those supportive of and opposed to the proposal) encouraged their members to respond, and in certain cases may have provided suggested/recommended text for people to use. However, as these were not clearly identifiable campaign responses, the relevant individual responses made have been counted as separate responses to the consultation.

Please be aware that this summary includes accounts of personal experiences and expressions of opinions which some readers may find upsetting.

# Section 3: Responses to consultation questions

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

## Aim and approach of the proposed Bill

Section 1 of the consultation document outlined the aim of the proposed Bill and what it would involve. Respondents were asked:

**Question 1: Which of the following best expresses your view of the proposed Bill (Fully supportive / Partially supportive / Neutral / Partially opposed / Fully opposed / Unsure)? Please explain the reasons for your response.**

This question was compulsory and therefore all 14,038 respondents answered.

A large majority of respondents (76%) were fully supportive of the proposal (including 13 organisations – 16% of the organisations that responded) for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life. A further 2% were partially supportive (including three organisations – 4% of organisations). 21% were fully opposed (including 46 organisations – 57.5% of organisations), with a further 0.4% partially opposed. 0.3% were neutral (including 16 organisations – 20% of organisations), and 0.2% were unsure (including two organisations – 2.5% of organisations), although the last two options were selected by some organisations that explained that, rather than adopting a specifically neutral or unsure position, they were of no collective view, as their members had a range of opinions.[6]

As can be seen from these statistics, and the numbers involved, views were largely polarised, with the majority of those supportive and opposed expressing very strong views (albeit with far more respondents fully supportive than opposed). While many responses expressed detailed comment on the specifics of the proposal and made suggestions for ways it could be adapted and improved, for many respondents there was no common ground, as a clear majority strongly believed a form of assisted dying should be legalised in Scotland, whilst a smaller minority strongly believed that it should not.

Many responses to this question included detail on the specific aspects of the proposal. Rather than being summarised here, those comments are included in the summaries of the questions to which they are most relevant. The main reasons given for supporting, opposing, or being neutral/unsure/having no collective view are set out here.

### *Reasons for supporting the proposed Bill*

A majority of those supporting the proposed Bill shared the belief that introducing a legal form of assisted dying in Scotland was long overdue (making reference to the previous attempts made to legislate on this issue). Most supportive responses also demonstrated a shared belief in the main reasons assisted dying should be introduced, which included that it would be:

- **civilized, humane and compassionate** to give those experiencing extreme pain, distress and/or indignity the ability to end their suffering;
- **comforting** to know that there was a safe, legal, option of assisted dying (whether or not a terminally ill person decided to pursue the option);
- **democratic** to allow people autonomy to choose an assisted death, and therefore increase their rights;
- **fair and just** that people in Scotland should have the same rights afforded to millions of people in other countries and jurisdictions around the world;

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[6] If the 3352 responses that were part of the Right to Life campaign were included in the overall figures, they would read as follows: 17,390 responses; 61.45% fully supportive; 1.40% partially supportive; 0.28% neutral; 0.29% partially opposed; 36.38% fully opposed; 0.17% unsure.

- **based on strong scientific evidence and other experience** from all the other countries and jurisdictions that have introduced forms of assisted dying;
- **safer** than currently used end of life methods, such as the removal and/or refusal of life-sustaining treatment, the use of "double effect" palliative sedation (i.e. pain relief which may hasten death), voluntarily stopping eating or drinking or people taking, or being assisted to take, their own lives in uncontrolled and unsupervised environments;
- **legal**, as it is not acceptable that some people are currently put in the position where they either break the law and risk prosecution in Scotland (often in unsafe conditions) or seek an assisted death in another country (an option many feel discriminates in favour of those with the means and capacity to do so); and
- **prudent** in a world of growing and ageing populations to prevent resources being used for terminally ill people who would otherwise choose to not continue to live or be kept alive and enable palliative care and other resources to be used by other people.

Many responses, particularly those by individual members of the public, gave accounts of personal experience of witnessing loved ones suffering what was often referred to as a "bad death" and believed that palliative care had limits in some instances, and was not always able to spare the terminally ill person from pain, distress and indignity. Many respondents noted that it was possible to end the suffering of an animal, but not a human, which did not seem right. Other supportive respondents believed it would be comforting for terminally ill people to have an assisted dying policy in place, and that having a policy in place would not mean there would be an automatically large uptake. The organisation Christians Supporting Choice for Voluntary Assisted Dying (Australia) (ID 181215529) stated:

> "Five states in Australia have now passed a Voluntary Assisted Dying Act (VAD). VAD has now been an end of life choice, in addition to palliative care, for two years in Victoria, used by relatively few dying people but providing great comfort and peace of mind to those given approval to access this choice."

This view was echoed in many individual responses, such as by retired physician, Graeme Catto (ID 175157550), who stated:

> "Terminally ill patients inevitably are concerned at what will happen if their suffering becomes unbearable. Being currently unable to discuss any form of assisted dying with their doctor places an unnecessary barrier at a time when honesty is essential. Knowing that assisted dying is potentially available, brings a degree of comfort to all patients whether or not they decide to opt in. Experience from Oregon indicates that many mentally competent, terminally ill adults wish to discuss the issue, with a much smaller number taking the matter further and only around 0.4% opting for an assisted death."

There were thousands of personal experiences given in support of the proposal. The following is a small selection of personal accounts given by individuals, and are broadly typical of the sorts of experiences recounted across many responses that were fully supportive of the proposal:

> Polly McClure (ID 175326110): “I have always been fully supportive of assisted dying as was my dad before he got ill. This was further reinforced when my dad was in palliative care and died of pancreatic cancer. It was a living hell for him most importantly, and for family and friends. His suffering was utterly horrific and completely unnecessary. I will never forget the terror in his eyes and pleas for help to end his life. He would have gone to dignitas but was diagnosed too late. My dad was a daredevil, independent and strong. For him to be put in this position was cruel. People in Scotland should have a choice. Scotland champions itself as being a compassionate country so bring in this compassionate law, like other countries have rightly done.”
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> John F. Robins (ID 178020540): “The right to die without unnecessary suffering has been denied for far too long. I have had relatives die of cancer, including a brother with the same cancer I have who died earlier this year. Despite the best care a hospice could provide his last few weeks were no more than a living death which he wanted out of. He ended up in a coma, with no food or liquids and it took him a further five days to die. Who knows what nightmares and agony he went through during those days? I work for an animal welfare group and if someone let their dog die the way my brother did, I would have them prosecuted for cruelty.”
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> Norah Stewart (ID 181215760): “Having nursed my mother 56 and listening to her begging to die to end the pain of cancer when the drugs did not work, having nursed my father 65 and listen and watch his stomach tumor burst and watch the fear in his eyes as the black bloody foam came out of his mouth and nose while he drowned in it, having nursed my mother in law 64 fade away screaming in pain from cancer and bed sores the size of a child's hand.......these deaths were inevitable and therefore could and should have been managed better in this age of experience and understanding of the right to a quality of life, end of life care and support should be a person’s right ....pets are treated with better kindness at the end of their life....my mother and father's deaths, their fear and their pain will remain with me for the rest of my life.”
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> Anonymous individual ID 181300388: “Three years ago, my 83 year old mother was diagnosed with terminal stomach cancer. As her palliative care consultant delivered the diagnosis he commented on the remarkable dignity with which she received the news. This dignity was incredibly important to my mother but it was systematically stripped from her over the next few months as the cancer took hold and her condition deteriorated. My mother had been a supporter of assisted dying for the terminally ill for many years and would have opted for this

> herself had she had the choice. As it was her death and the time leading up to it was a truly horrific experience for her and her loved ones. Society can do better."
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> Anne Ross (ID 181575319): "Having cared for both parents and helped care for another close relative till they died, I have seen different deaths; my mother had a death you would not put a dog through and yet she & we were unable to ease her passing as we would a loved pet. She was very clear about not wishing for interventions "to keep me here" but could not choose to die in dignity and peace. That is not a death I want for myself or anyone else. I also do not want my children to have to watch me die in such a way in such circumstances i.e. where death is the only outcome, there is no possibility of getting better."
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> Shirley McEwan-James (ID 181192872): "My partner died, aged 56, from mesothelioma. Knowing I would have helped him die if necessary, though illegal, allowed him to cope with the horror of it all. No-one should be denied the right to choose."
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> Susan Alder (ID 181195806): "Both my parents died of cancer in agony. They should have been able to die before the worst of it happened."
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> Dr Jenevora Williams (ID 181196452): "I sat with my mother for weeks while she slowly died of cancer. Every day was agony and she begged to be allowed to go. In the end we watched her die of dehydration, this took 7 days from her last drink. Nobody should ever have to die like this."
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> Annie Gregory (ID 181193372): "My brother and his wife both had terminal illnesses. Palliative care was not effective. They killed themselves in a hideous fashion using a so-called suicide bag. I have not had a single night's sleep without nightmares since then. I do not want anyone else to go through this EVER. People must have the right to control their own bodies and to decide when it is time to quit calmly and supported by their families."

Many individuals also commented on the success of assisted dying being introduced in other countries and jurisdictions around the world. Examples include:

> William Blair (ID 175201079): "In other countries e.g. some states in America, this option has been running for decades now without any incidences of abuse reported. Countries like New Zealand have also recently allowed assisted dying to be introduced into law - why should Scotland be left behind in this compassionate stance?"
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> Anonymous respondent (ID 179364282): "It is of the utmost importance that the law is changed as soon as possible. Many other countries in

> the world permit assisted dying, with appropriate safeguards in place. Scotland lags behind these countries and does a disservice to its people when it does not permit assisted dying in the law."
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> Anonymous respondent (ID 179949581): "Research and statistics from other countries e.g. Netherlands and Switzerland show that such a bill can be implemented well with appropriate safeguards."
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> Retired NHS Consultant Physician, Dr Vasco Fernandes (ID 181197293): "Such a law exists in many countries and has most recently become available in Canada, Australia and New Zealand … The Assisted Dying Bill would mean fewer such people suffering - not more unnecessary deaths. Countries like the Netherlands, Belgium and Switzerland have proven that assisted dying laws are safe, fair and compassionate. Opponents have been proven wrong. Our country, known worldwide for its compassion and fairness, is being left behind."

Many of those supportive of the proposal also indicated support for the main elements of the proposal set out in the consultation document, including strong support for many of the proposed safeguards (such as the requirement for two doctors to be involved in various assessment processes, that the terminally ill person should be deemed mentally competent, and that the person must be aged 16 or over). See the summaries of responses to questions three and four later in this document.

Thirteen organisations were fully supportive of the proposal[7]. The Humanist Society Scotland (ID 181336267) outlined its support for people to have the right to choose an assisted death if they wished, and stated:

> "We believe that the model proposed in this consultation provides robust and significant safeguards that will ensure that only those who are able to make a conscious and clear decision with regard to an assisted death are ultimately able to do so. As a community that greatly values personal autonomy, we oppose any individual actions or laws that might undermine or pressure an individual into taking a decision that they do not actually want. We believe the steps proposed in this Bill to access an assisted death have introduced a 'high bar' of safeguards that will ensure assisted death could only be enacted by an individual who had a clear and settled will to access such an option."

The grassroots campaign organisation My Death, My Decision (ID 181513253) highlighted human rights and compassion aspects in its response, stating:

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[7] Scottish Pagan Federation; Thistle Humanists; PlaySpace Publications; Christians Supporting Choice for Voluntary Assisted Dying (Australia); Friends at the End; Dignity in Dying Scotland; Humanist Society Scotland; Caledonian Humanist Association; A Quiet Revolution; My Death, My Decision; DIGNITAS – To live with dignity – To die with dignity; The Scottish Youth Parliament; and the National Secular Society.

> "The right to die in a manner and timing of your own choice should be seen as a fundamental human right. As society has become increasingly adept at extending the length of someone's life, but not necessarily its quality, the case for a balanced and compassionate change in the law has become clearer and the cruelty of the current law on assisted dying has become starker. Rather than approaching the issue with compassion and care for the individual, the law in Scotland forces people to die abroad or take matters into their own hands, which in reality means the lonely and distressing option of suicide or the painful and inhumane process of starvation. Just as compassion has motivated people to support assisted dying for those who are terminally ill, compassion for others should underscore support for a change in the law for adults of sound mind who are facing constant and unbearable suffering."

The organisation Dignity in Dying Scotland (ID 181277811) highlighted the inequality it believes exists currently in the choices and decisions available to terminally ill people in Scotland. The response describes the current position as, "… unequal, uncompassionate and unsafe". The response states that some have the resources (and the support of complicit healthcare professionals) to plan trips abroad to end their lives[8] (but often doing so prematurely, when they are able to make the journey), whereas others lack such resource and support, with some deciding to end their lives at home[9]. Its response provides accounts of personal experience from people considering ending their life abroad, or family members whose loved ones have done so, and states that, "Dying on your own terms in Scotland is unattainable for many terminally ill people." Its response concludes:

> "This Bill would protect families from making the impossible choice between breaking the law or watching a loved one suffer. It would enable healthcare professionals to offer the full range of options their patients want. It would bring Scotland in line with the growing number of liberal, progressive societies around the world that pride themselves on safe, compassionate assisted dying laws. We are fully supportive of it."

### ***Reasons for partial support***

Two hundred and forty-four responses (1.74%) indicated partial support for the proposal, which included three organisations (Community Pharmacy Scotland (ID 181270061), The Company Chemists' Association (ID 181441418), and End of Life Choices Jersey, ID 181280486). Both Community Pharmacy Scotland and The Company Chemists' Association

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[8] The response by Dignity in Dying states: "Currently, one person every eight days travels from the UK to Switzerland in order to end their life" and cites the following reference: "The True Cost: How the UK outsources death to Dignitas, 2017".

[9] The response by Dignity in Dying states: "It is estimated that between 300 and 650 dying people take their own lives every year in the UK" and cites the following reference: "Last Resort, Dignity in Dying, 2021".

outlined issues and/or concerns about the potential impact on pharmacy and pharmacists.

Several themes emerged from those who were partially supportive of the proposal, rather than fully supportive, which reappear as themes in answers to many of the consultation questions:

- **eligibility:** that the proposal does not go far enough and should be extended to other people (beyond those who are terminally ill, aged 16 and over and mentally competent). Many different suggestions were made, including those suffering from forms of dementia and/or certain neurological conditions to anyone experiencing a very poor quality of life. Many respondents also believed that it should be possible to make a "living will" (usually formally known as an "advance directive") where a person stated their wish for an assisted death in the future while they were still mentally competent to do so;
- **proposed safeguards:** that some of the proposed steps/safeguarding measures are too cautious/not cautious enough – including reassurance sought on how people would be practically protected from being pressured and/or coerced into choosing an assisted death;
- **taking the life-ending substance:** that it should be possible for those not able to self-administer the end of life drug to have it administered by someone else (the proposal set out a requirement that the end of life drug must be self-administered); and
- **disability concerns:** that the concerns of people with a disability, and any representative disability organisations, must first be addressed.

Please see other parts of this document, such as the summary of responses to questions three, four and eight, for further comment on these issues.

### *Reasons for opposing the proposed Bill*

A minority of respondents (2,945 - 21%) were fully opposed to the proposal to introduce a form of assisted dying in Scotland. This included 47 organisations[10] (out of 81 organisations that responded to the consultation in total) which represented a majority (57%) of the total number of organisations that responded. The majority of those organisations (32[11]) were either entirely

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[10] The organisations fully opposed to the proposal were: Dundee City Taxi Drivers Association; The Black British Human Rights Watch; Regional Palliative Medicine Group (RPMG) - The representative consultant body of Palliative Medicine consultants across Northern Ireland; Living and Dying Well; California State branch of American Association of Medical Ethics; Association for Palliative Medicine of Great Britain and Ireland; Inclusion Scotland; Bios Centre; Better Way; Not Dead Yet; Glasgow Disability Alliance; Care not Killing and Our Duty of Care; Scottish Council on Human Bioethics; one anonymous organisation; one organisation who asked for its response not to be published, plus the 32 organisations listed at footnote 11.

[11] MAD Together Trust; St Helens LIFE Group; The Free Church of Scotland; Stornoway Free Church Kirk Session (elders); Medical Ethics Alliance; Catholic Truth (Scotland); Cross Free Church of Scotland; Kirk Session, Garrabost Free Church of Scotland; Kiltarlity, Kirkhill & Beauly Free Church of Scotland; Premier Christian Communications; Bishops' Conference of

of a religious basis or appeared allied to a particular religion or belief. Three[12] were organisations campaigning for and representing people with disabilities (note these were the only disability specific organisations that responded).

The main reasons given by many of those who were fully opposed to the proposal included:

- fundamental disagreement in principle, in the main founded in religious belief, that all **human life is sacred and that only God can give life and take it away**;
- that **prognoses are often inaccurate**, with frequent examples of people outliving predicted times left to live;
- that the proposal poses a **threat to vulnerable people** and that no safeguards could ever be enough to entirely protect people (this theme included many comments citing the Covid pandemic as having both demonstrated and increased the threat to the most vulnerable in society);
- that many **people will feel pressured and/or coerced** into choosing an assisted death;
- that vulnerable people, such as **younger and older people, and people with a disability, would face increased stigma and devaluing of their lives**;
- the belief that other countries that have introduced a form of assisted dying have seen safeguards relaxed and/or weakened, and the definition of those able to choose an assisted death widened (this was often referred to in such responses as evidence of a **"slippery slope" towards wider euthanasia** which they feared would also happen in Scotland in due course);
- that it would **contradict messages to tackle mental-health issues and instances of suicide** and instead increase instances of suicide in people who are not terminally ill;
- that the proposal would **lead to a decline in investment and standards of palliative care**;
- that, by assisting death rather than upholding life, **the role of health care professionals would be damaged**, as would the relationship and trust between doctors and patients (frequent mention was made in opposed responses of the "first do no harm" principle of the Hippocratic Oath taken by some medical professionals); and

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Scotland; Christian Concern; Urray and Strathconon Free Church of Scotland Scottish Charity, SC038130; Christian Life Issues Group of the United Free Church of Scotland; Harris Free Church of Scotland (Continuing); British Islamic Medical Association; The Christian Institute; Church of Scotland; Edinburgh Lay Dominican Fraternity; Kinloch Free Church of Scotland; The Apostolic Church UK in Scotland: Scottish Charity No. 037835; Anscombe Bioethics Centre; Evangelical Alliance; North west Pro-life; Glasgow Reformed Presbyterian Church of Scotland; Knockbain Free Church of Scotland; Salvation Army; Christian Medical Fellowship; CARE (Christian Action Research and Education) for Scotland; Society for the Protection of Unborn Children; Fellowship of Independent Evangelical Churches; and Church in Society Committee of the Scottish Episcopal Church.

[12] Inclusion Scotland; Not Dead Yet; and the Glasgow Disability Alliance.

- that the **drugs used to end life can be unsafe, painful and dangerous**.

The views of many of those opposed was reflected in the summary provided in the joint response by Care not Killing and Our Duty of Care (non-Smart Survey, response 14023), which described the proposal as "uncontrollable, unethical, unnecessary."

Many of the reasons for opposing the Bill are expanded on in more detail in summaries of the other consultation questions. A majority of opposed responses cite negative experiences from other countries and jurisdictions (including the states of Oregon and Washington in the USA, Canada, the Netherlands and Belgium). See for example the following individual respondents: Marie MacDonald (ID 176459861), "Experience in other countries should warn us that assisted suicide even with the hope for safe guards does not work"; Joe Fodey (ID 175635037), "If you really want to see the future you are risking take a look at the situation in Belgium or the State of Oregon in the USA both of which, as far as I am aware started with a small, misdescribed measure."; and anonymous response (ID 179172170), "Assisted dying may sound compassionate, offering relief to those who feel their lives are intolerable. But if you look at the countries where it has already been legalised, a bleak picture starts to emerge. Criteria for who could access assisted suicide and euthanasia were continually expanded.".

A proportion of opposed responses also stated that if the proposed Bill were to be passed it would see a decline in the moral fibre of society in Scotland, with life devalued.

Many of those opposed expressed sympathy with terminally ill people. The Scottish Council on Human Bioethics (non-Smart Survey, response 14,000) stated:

> "… those wanting to legalise assisted suicide do not have a monopoly on the concept of sympathy and kindness. Those opposed, are just as much motivated by genuine and sincere sympathy towards patients."

Many opposed responses mentioned that sanctity of life must take precedence over individual autonomy, and that improved, more effective and better accessible palliative care was what was required, and what the priority should be, for terminally ill people, not assisted death. The Christian Medical Fellowship (non-Smart Survey, response 14,016) stated that it believed the proposal was founded on an unproven assumption that there are limits to palliative care and that a number of people every week reach those limits and thus need an alternative. It stated its belief that good quality palliative care is effective in almost every case and kills the pain not the patient. It stated:

> "We do not believe that the proposals fit the problem. The problem is not that palliative care is ineffective. It is that palliative care is not accessible across Scotland. The solution is not to eradicate the patient, but to invest in training and provision of more excellent palliative care

> services. We are concerned that legalising assisted dying would inevitably strengthen the perception that people with certain types of disease or disability have lives 'not worth living', that they would be 'better off dead', and that the costs of their care would be better directed towards healthcare provision for the more socially or economically 'productive' members of society. The quotient of compassion in the caring professions and respect for human life in society in general would inevitably ebb. We suggest that this would be out of step with the deepest intuitions of the people of Scotland."

The Glasgow Disability Alliance (non-Smart Survey, response 14,024) (in a response based on consultation with 240 disabled people) was one of a number of responses that opposed the proposed Bill on the grounds of a perceived threat to the safety of people with a disability. This issue is covered in more detail in the summaries of other consultation questions (such as question four on safeguarding and question eight on equalities impacts). In its submission, the Glasgow Disability Alliance stated:

> "… we do not believe that this type of legislation is appropriate while disabled people remain unable to access their human rights on a basis equal to non-disabled citizens. We have also considered evidence and research from other countries, states and provinces where assistance to die is legally permitted and are very concerned over these findings."

The response from the Glasgow Disability Alliance was also one of a number of opposed responses that also opposed the proposal because of experiences during the Covid pandemic, stating:

> "… over the past two years many more disabled people reported feeling suicidal and at breaking point due to feelings of hopelessness, physical pain, mental distress and lack of dignity, for example, losing social care support to wash, go to the toilet or deal with effects of incontinence. Many people cited their experiences of the pandemic as the 'tipping point' that cemented their fears in relation to this legislation."

Amongst the responses fully opposed to the proposal there were also accounts of personal experiences from those who have experience of/are experiencing serious or terminal illness, and their friends and families, explaining why they did not want to see assisted dying made available in Scotland. For example, S Smith (ID 175145047), gave a personal account:

> "For the last 18 months I have undergone cancer treatment, chemo, surgery, radiotherapy and now hormone and targeted treatments. There were times when I was so low, particularly at the start of the treatment, that I would have agreed to assisted dying. But, now … during my cancer journey I have come to terms with how strong the will to live is. It really isn't my choice or anyone else's choice or right to take away life."

### *Reasons for partial opposition*

A small minority of respondents were partially opposed to the proposal (52 respondents, 0.37%, all individuals). This included people who appeared supportive of (or at least not opposed to) the basic principle of providing for a form of assisted death in Scotland, but were critical of aspects of the proposed implementation, and respondents who appeared more opposed in principle, but believed there may be narrow exceptions (such as where brain death has occurred).

Professor Jaideep J Pandit, Professor of Anaesthesia at the University of Oxford, UK (ID 175383434), believed the proposal protected vulnerable people but that the proposal that the life-ending medicine must be self-administered would restrict those able to choose an assisted death and the type of medications that could be used. Professor Pandit stated:

> "… in insisting on self-administration of medication it will (a) restrict assistance only to those who can self-administer; (b) restrict the type of medications that can be used. It is erroneously assumed or implicit in the wording of the Bill that there is some medication that can achieve assistance in dying that can be self-administered, but it is not clear what that medicine is."

Others who were partially opposed were not opposed in principle, but believed it was safer, when the potential benefits and risks were balanced, to make no change to the current position. Examples include:

> Dr Kim Nurse, (ID 181380094): "As a doctor, I accept there are situations where assisted dying is appropriate. I can think of patients who I look after whom would benefit hugely from this, to have a choice as to when their life ends when they have a terminal illness. However, as a doctor I am also greatly concerned regarding the implementation of this and the practicalities."
>
> Anonymous respondent (ID 181197208): "On balance, whilst I believe individuals should be entitled to direct for end of life care and which may include certain steps which may hasten death I am concerned that the proposed legislation will create an environment where deaths will be sanctioned when the individual involved has not clearly expressed such a wish."

Other reasons for partial opposition included fear of people making rash decisions (perhaps due to undiagnosed mental health conditions); the risk of people feeling they are a burden and/or being subjected to pressure/coercion to choose an assisted death; 16 being too young for people to make such a definitive choice; that courts should approve each case to ensure there was no coercion; uncertainties with prognoses; and a lack of confidence in the consultation document and some of the data it presented and sources it cited. These reasons are all explored further in this document.

The issue of disability was raised by some respondents, including by this anonymous individual (ID 181536938):

> "As someone with a disability I am worried about the pressure there will one day be to end my life if I become a burden on others or the state. While I know this proposal is limited to the terminally ill, I fear that is discriminatory and will one day be amended. Having had a pre-natal diagnosis of a baby with Down syndrome I know I was repeatedly asked to have a termination by doctors because of the "burden" that child would place on myself and others and this culture worries me. That said I have seen those with terminal illnesses in the family suffer greatly and understand the motivation behind the bill. I'm just not sure that in practice those with disabilities would be protected"

### ***Neutral, unsure and no collective view***

A very small number of respondents stated they were either neutral (40 respondents, 0.29%) or unsure (33 respondents, 0.24%). This included 16 organisations that selected the "neutral" option[13] and two (The Royal College of Psychiatrists in Scotland, ID 181554005, and the Royal College of Physicians of Edinburgh, non-Smart Survey, response 14,013) that selected the "unsure" option. Some of these were umbrella organisations that took a neutral position[14], neither supporting or opposing the proposal, as there was a range of views amongst members. This included four[15] organisations that selected "neutral" and both of those that selected "unsure", which clarified that they did not consider themselves neutral or unsure (the option being selected because they felt there was no better alternative available) but were actually of no collective view due to differing member views.

Some of the individuals who stated they were neutral about the proposal noted that it was not their personal view that was important, but that people in Scotland with a terminal illness should have the right to choose an assisted death as a point of principle – noting that laws need not, and often cannot, accord only to one specific viewpoint.

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[13] The following organisations selected the "neutral" option: Royal Pharmaceutical Society; Association of British Insurers; Scottish Partnership for Palliative Care; Scottish Care; Parkinson's UK Scotland; Neurological Alliance of Scotland; Hospice UK; Scottish Association for Mental Health; Scottish Council of Jewish Communities; Children's Hospices Across Scotland; Royal College of Physicians and Surgeons of Glasgow; Royal College of Nursing; General Pharmaceutical Council; British Medical Association Scotland; Marie Curie; Scottish Human Rights Commission.

[14] This included the British Medical Association which highlighted the range of views held by its members by pointing in its submission towards the results of two pieces of research aimed at exploring members' views on assisted dying, including an all-members survey in 2020 which received 28,986 responses, and a smaller scale discussion with its members in 2015. See its response for further details: https://www.assisteddying.scot.

[15] Hospice UK; Scottish Council of Jewish Communities; Children's Hospices Across Scotland; and the General Pharmaceutical Council all selected "neutral" but stated they were actually of no view.

Many of the medical and health-based organisations that responded stated they were either neutral, of no collective view, or unsure – either because they represented members with mixed views, both supportive and opposed, or because as an organisation they did not feel it appropriate to actively support or oppose the proposal, and instead noted thoughts and concerns with aspects of the proposed implementation detail. For example, the Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) which took no position, noted:

> “Doctors have a professional responsibility to protect the interests and respect the wishes of their patients; it is in this spirit that the College identifies issues requiring greater clarity and identifies expected practical difficulties regarding the current proposals as we understand them.”

The Scottish Council of Jewish Communities (non-Smart Survey, response 14,025) explained that different Jewish communities had different views: Orthodox Judaism was fully opposed (on the grounds of human life being sacrosanct and any act to hasten death being equivalent to murder), whereas most liberal Jews are supportive of assisted dying being one end of life option in certain circumstances. The response states that Reform Judaism is split on the issue.

One organisation, the Scottish Association for Mental Health (non-Smart Survey, response 14,029), noted a change in its position since the last time the issue was debated in Scotland, explaining it had moved from being opposed to being neutral:

> “This is a shift from our position on the Assisted Suicide Bill in 2010 where we were opposed to the possibility that someone with a mental health problem which caused them to find their life to be intolerable may request assistance. We believe this current bill proposal to be a positive change in language and definitions.”

Frequent reasons given by respondents explored later in this document for being neutral or unsure about the proposal included the already mentioned issue of eligibility and the definition of terminal illness, and two other issues that were mentioned frequently throughout answers to many of the consultation questions: a lack of specialist palliative care leading people to choose assisted death and the need to prioritise improving the standard and consistent access to palliative care (see the section on palliative care under the summary of responses to question two); and issues relating to capacity and mental health (see the section on capacity and mental health under the summary of responses to question four).

In relation to eligibility and the definition of terminal illness, concerns were raised by Parkinson’s UK Scotland (ID 181559748) and the Neurological Alliance of Scotland (ID 181560705) about how certain neurological conditions, currently often categorised as “terminal” or “progressive” would fit with the proposed definition.

Parkinson’s UK Scotland (ID 181559748) stated that the proposed definition would increase the likelihood, “… that people with progressive neurological conditions like Parkinson’s would identify themselves - and be identified by clinicians - as being terminally ill than if a prognosis-based definition was used.” The response goes on to say it would be essential that guidance is produced for clinicians about how determination that a person was reaching the end of their life would be arrived at, and that being diagnosed with a progressive condition such as Parkinson’s would not be the only factor considered.

The Neurological Alliance of Scotland (ID 181560705) noted that the proposed definition[16] acknowledges the difficulties in giving accurate prognostications in terms of months or years, and therefore not defining terminal illness with reference to a time period, but that additional safeguards would be needed to ensure that any condition must be sufficiently advanced for it to be considered that they were reaching the end of their life. The response added:

> “Without this safeguard, anyone with a progressive neurological condition could fall under the umbrella of this legislation at any time from diagnosis, without reference to symptoms, quality of life, or life expectancy. The Neurological Alliance of Scotland believes that there is a high risk that the definition of people who are 'unable to recover, irrespective of how much time they have left to live' could cover many people with neurological conditions who - even though they have a terminal or progressive condition - may have many years of life left.”

Several “unsure” responses also raised this issue, including Dr Naomi Richards, Director of the End of Life Studies Group, University of Glasgow (ID 181564324). Dr Richards described the proposed definition of terminal illness as “unworkable” noting, as others did, that it was a deliberately looser and less restrictive definition arrived at to enable access to social security benefits for those nearing the end of their lives. Dr Richards believes that using that definition would lead to unintended consequences if applied to this proposal and stated that the law in Oregon requires a person to have a prognosis of six months or less to live to be eligible. Dr Richards questioned whether the proposal’s intention was that Scotland should have a broad definition so that a wider group of people (those further from a natural death) would be eligible but noted that this would not deliver clarity for those involved adding:

> “There are a number of new laws on the statute books in countries around the world and most of these stipulate very clearly a prognosis in terms of months (all 5 Australian state laws, New Zealand). It would seem prudent to stick to this formula if this is a Bill designed for those who are terminally ill, to have access to assisted dying, which seems to be the case.”

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[16] See footnote 5.

Issues relating to palliative care were raised in several submissions (including by the Scottish Partnership for Palliative Care (ID 181456887), Scottish Care (ID 181554943) (the representative body for the independent care sector), and the Neurological Alliance of Scotland, (ID 181560705). Scottish Care states that a rigorous examination of the current state of palliative and end of life care is required, stating it is important that the current extent of, and access to, palliative care in Scotland is understood, adding: “We would consider such an assessment to be a primary first step in considering any legislation on assisted dying. In relation to which we simply do not recognise the Consultation’s assertion [[17]] that Scotland has one of the best palliative care systems in the world. This is without evidence and foundation.”

The Neurological Alliance of Scotland (ID 181560705) also commented on the provision of palliative care in Scotland, and states that the consultation document seemed focussed on the provision of specialist palliative care only. It stated that people with neurological conditions often lack access to such specialist care, and most die with general care in hospitals, care homes or in their own homes. Marie Curie (non-Smart Survey, response 14,035) stated that not all terminally ill people are receiving the care and support they need. Its view was that a quarter to a half of people are not getting all or some of the care they need when they die, and that this gap in care is likely to grow. The response, which supported the introduction of a statutory right to palliative care, stated there was a lack of evidence about the quality of palliative care and that research should be carried out before the proposal was taken further.

Concerns were also raised about the proposal that assisted dying would only be made available to mentally competent adults. The Neurological Alliance of Scotland (ID 181560705) highlighted a range of challenges this could provide for people with various neurological conditions (such as: problems with speech; cognition; capacity; and depression). It calls for the legislation to include, “a requirement for people with neurological conditions to have their capacity assessed by a clinician who has particular expertise in assessing people with neurological conditions.”

### Question 2: Do you think legislation is required, or are there other ways in which the Bill’s aims could be achieved more effectively? Please explain the reasons for your response.

12,364 respondents (88% of the total) answered this question, including 74 of the 81 organisations that responded to the consultation.

The vast majority of responses mirrored the views the respondent had expressed in answer to question one. A large proportion of those supportive

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[17] See page 13 of the consultation document, which states: “Palliative care in the UK has been ranked number one in the world, with Scotland’s services amongst the best in Europe.” This sentence is referenced by the following footnote: “A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us? Published 15th September 2015 SP Paper 784 9th Report, 2015 (Session 4) at para. 72 in ref to the Quality of Death Index.” The consultation document is available here: Assisted Dying Consultation 2021 - FINAL (parliament.scot).

of the proposal stated that legislation was required to deliver its aims, whilst most of those opposed to the proposal did not think legislation was required because they did not want to see assisted dying available in Scotland.
Many of those supportive of the proposed Bill, noted that it is currently not legal in Scotland to assist the death of another person in any circumstance, and therefore legislation is required to alter that position – and that there were not alternatives available to deliver the same outcome via a non-legislative route. Other reasons given included that legislation would:

- allow for a democratic, transparent, process of engagement and debate (see, as an example, the response by David Windmill, ID 175118950);
- remove legal uncertainties of the current position and ensure clarity and legal boundaries (see, as an example, the response by David McCrum, ID 181193049);
- ensure statutory safeguards were in place, improving safety (see, for example, the response by Sara Fenton, ID 181426703);
- guard against malpractice (see, as an example, the response by Lynn Levy, ID 181407387); and
- prevent healthcare practitioners (HCPs)/family members being open to prosecution (thereby removing the threat of prosecution from family and friends) (see, for example, the response by Andy Rickford, ID 181457283).

The organisation Christians Supporting Choice for Voluntary Assisted Dying (Australia) (ID 181215529), in views echoed by many respondents, summarised its views on why legislation was required as follows:

> "Legislation is needed as this provides the necessary principles behind the law, a framework for access to the choice, and penalties for any attempted abuse of the law.

The Royal Pharmaceutical Society (ID 181033648) believed that legislation would enable appropriate clarity and safeguards to be set out in law, such as conscience clauses and protection from prosecution for those involved in the process, such as pharmacists, pharmacy technicians and other health care professionals.

Many of those opposed to the proposal noted that they did not want to see the policy delivered at all, so did not suggest alternative methods for achieving the policy aims. Other frequent points made by those opposed to legislating included that:

- the current legal position was sufficiently clear and required no clarification (see as an example the anonymous response ID 178697563);
- the aim of alleviating suffering could best be delivered by other means (including by improved investment in, and improved standards and provision of, palliative care and hospices) (see as an example the response by Dr Niall Watson, ID 179030992);

- better education about death, illness, terminal illness, and palliative care should be provided instead (see as an example the response by Sharon Quick, MD, ID 181412356); and that
- better investment in mental health care should be made instead (see as an example the anonymous response ID 179598182).

Some organisations gave specific reasons relevant to their own perspective about why legislation was not required. The Glasgow Disability Alliance (non-Smart Survey, response 14,024) stated:

> "We feel the aims of this Bill could be achieved more effectively by government prioritising the Actions contained in a Fairer Scotland for Disabled People strategy. Doing this would ensure disabled and ill people would have access to their rights to financial assistance, healthcare, social care, housing, education, employment and so on, like any other citizen. Further, we call on government to prioritise Independent Living for disabled people, as outlined in the UNCRPD [United Nations Convention on the Rights of Persons with Disabilities]."

The issues of, a) how clear the current position is, and b) the role of palliative care in addressing/delivering the aims of the proposals were the most discussed across consultation responses and are therefore discussed here in more detail.

### *Clarity of the current position*

There was disagreement among respondents on whether the current legal position was sufficiently clear with, broadly speaking, those supportive of the proposal believing it wasn't clear, and those opposed believing it was. Views were expressed on the understanding of the current position, whether the law is sufficiently and appropriately clear, and whether a degree of ambiguity and/or flexibility in the law is desirable or not.

A majority of respondents, including several organisations, thought that legislation was required to bring clarity to what was referred to by the National Secular Society (non-Smart Survey, response 13,986) as "Scotland's ambiguous laws regarding assisted dying." The Humanist Society Scotland (ID 181336267) believed that legislating would provide clarity, adding:

> "… the introduction of legislation on assisted dying would include regulation and safeguards to ensure that assisted deaths in Scotland would be overseen by a qualified medical practitioner. We believe legislation would also reduce the number of people who choose death by suicide after receiving a terminal diagnosis. There have also been a number of cases in Scotland where loved ones assist a terminally ill family member to die. If people in Scotland had the legal right to access an assisted death, fear of pain and suffering after a terminal diagnosis would be mitigated by the knowledge that an assisted death is available should one choose to access it."

The Scottish Human Rights Commission (non-Smart Survey, response 14,037) gave a detailed response (referring to its submission on a previous related Bill in the Scottish Parliament, a link to which is provided in its response) in which it sets out "the framework within which determinations on whether to adopt legislation permitting assisted death may be made". The Commission stated that, "… there is a strong case for increased clarity in the law of Scotland on the criminalisation of assisted suicide in Scotland…".

Several respondents believed that the law could be better clarified by making other legislative changes, including by creating a specific offence of encouraging/assisting suicide/death and then setting out exceptions. Three academics with an interest on end-of-life matters, especially assisted dying, Professor Liz Wicks, Dr Clark Hobson and Dr Nataly Papadopoulou, in a joint response that was fully supportive of the proposal (ID 181564982), noted the position set out in the consultation document[18] that there is no statutory offence of assisted suicide in Scotland as there is in other parts of the UK and thought there was an argument that, "… the aims of the Bill could be achieved more effectively with the creation of a distinct criminal offence of encouraging suicide, alongside clear judicial guidance that assisting a suicide will not entail any criminal liability".

The Anscombe Bioethics Centre (ID 181564621) believed that legislation would not provide the desired clarity due to there still being circumstances in which assisted dying was not legal. It also thought that clarity would be better achieved by firstly establishing a clear offence of assisting death, and then carving out exceptions. One anonymous academic (ID 181547421), fully opposed to the proposal overall, stated that the room for discretion provided by the current law had merit, and allowed for "common sense" to play a part in whether a "mercy killing" should be prosecuted. The response also stated that any desired clarity could be achieved by setting out in law when an apparent "mercy killing" should be treated as culpable homicide, rather than murder, with a range of appropriate sentencing options, adding:

> "The key to such legislation would be preservation of the principle of the sanctity of life: even mercy killing is wrong, and should remain a criminal offence, but in extreme circumstances it may be excusable and should be dealt with accordingly. What the law should not do is provide for a system of state-sponsored assistance of suicide which breaches the fundamental principle of the sanctity of life."

A smaller number of respondents thought the current position was sufficiently clear and/or appropriate and required no change. Knockbain Free Church of Scotland (ID 181575057), in a view echoed by various other respondents, stated its belief that the current law strikes the right balance, declaring it wrong to assist someone to end their life but showing, "compassion and mercy to those who have done so by usually not prosecuting as it is not in the public interest", adding that this position allows, "prosecutors to fully

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[18] See pages 8-9 of the consultation document, available here: [Assisted Dying Consultation 2021 - FINAL (parliament.scot)](#).

investigate the whole circumstances of a death and thereafter prosecute a case where there is evidence and they believe it is in the public interest, for example where there was abuse - which provides the safeguards required."

### *Palliative care*

Some of those supportive of the proposal, and who thought legislation was required, supported increased investment in, and improvement in, the standard and availability of palliative care but stressed that was a distinct issue rather than an alternative to assisted dying. Many such responses argued that any improvements in palliative and end of life care would not mean assisted dying was not required, and that the two things were not mutually exclusive. Examples from individuals included Neil Anderson (ID 175152367), who stated, "Legislation is required - as is a more robust national system of palliative care...and the 2 are not mutually exclusive, quite the reverse.", and retired GP, Jack A Macfie (ID 178860109), who stated:

> "I think legislation is required. While investing in palliative care is of the utmost importance, this in itself will not improve the suffering of some terminally ill patients whose symptoms are simply not relieved by palliative care. We need to recognise and accept that palliative care has the same limitations as other medical treatments in that it cannot help everyone."

Some respondents who thought legislation was not required (or should not be a priority) thought that the focus should be on increased investment in, and improvement in, the standard and availability of, palliative care, rather on legislating for assisted dying. The Royal College of Physicians and Surgeons of Glasgow (non-Smart Survey, response 14,017) stated:

> "We would question whether this Bill is necessary if the quality of palliative care is increased and uniform across the country. The discussion paper suggests that this is an alternative to good palliative care. We do not believe this to be the case."

Many of the palliative care related organisations that responded gave detailed comment on this point. The Scottish Partnership for Palliative Care (ID 181456887) acknowledged that legislation would be required to bring about the changes proposed in the consultation, but believed, "a much greater reduction in suffering at the end of life could be achieved by improving provision of palliative and end of life care in Scotland."

Scottish Care (ID 181554943), which was neutral on the overall proposal, called for a Scottish Human Rights Act to underpin a human right to palliative and end of life care and support, and for legislation to fully incorporate the International Covenant on Economic, Social and Cultural Rights[19], including a "right to health" which should include palliative and end of life care, adding, "It

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[19] United Nations General Assembly, International Covenant on Economic, Social and Cultural Rights (1976). Available at: International Covenant on Economic, Social and Cultural Rights | OHCHR.

would be deeply regrettable that at a time when there is a potential to enshrine in law a right to assisted dying that there was not at the same time enshrined in Scottish law a right to palliative and end of life care."

**Question 3: Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering) (Fully supportive / Partially supportive / Neutral / Partially opposed / Fully opposed / Unsure)?**

**Please explain the reasons for your response, including if you think there should be any additional measures, or if any of the existing proposed measures should be removed. In particular, we are keen to hear views on Step 2 - Reflection period, and the length of time that is most appropriate.**

13,664 respondents (97% of the total) answered this question, including 74 of the 81 organisations that responded to the consultation. The breakdown of each option is broadly reflective of the answers given to question one, with 70% fully supportive (compared to 76% fully supportive overall), 6% partially supportive (compared to 2% partially supportive overall), 21% fully opposed (the same as to the overall proposal) and 0.61% partially opposed. 1% were neutral, and 1% were unsure (slightly higher numbers compared to question one). It therefore seems from this data that a relatively small number of those fully supportive of the proposal as a whole, indicated partial support for (or were neutral or unsure towards) the proposed process.

A large majority of respondents were fully supportive of the proposed three-step process, with many comments made that the safeguards were well thought out and very important, and that the proposed steps were clear, proportionate and appropriate. Examples from individual responses included:

> Maureen Unity McKendrick (ID 181543253): "I think the measures describe robust and logical steps which provide safeguards all the way through what must be an incredibly hard road. I think the steps will provide reassurance to the patient, families and friends at each stage that they are being listened to and supported in a humane and respectful way."
>
> Anonymous response (ID 181344087): "The proposals appear proportionate to the intended effect, i.e. allowing a mentally competent individual to make the decision to end their own life, but with appropriate safeguarding in place."
>
> Iona Donnelly (ID 176286248): "The proposed process is clear, comprehensive and sympathetic to the desires of the patient."

A minority of respondents were fully opposed (almost all of which were fully opposed to the overall proposal), with many either stating that as they were opposed to assisted dying, they were therefore also opposed to any proposed aspects of how it may work in practice, and/or repeating arguments made in opposition to the proposal as a whole when answering question one (such as it being morally wrong; the process being unsafe and open to abuse (people feeling a burden and feeling pressured/coerced into choosing an assisted death), and the process placing health professionals in an unfair and unethical position).

There were many suggestions made to strengthen and/or improve the three steps and a number of frequent concerns raised. These are set out here, taking each proposed step in turn. Note that the three steps include the various proposed safeguarding measures which are the subject of question four. There was therefore considerable repetition and overlap in the answers given to questions three and four. The summary of question three therefore focuses on the three steps and the most frequent comments made, and more detailed comment on the specific safeguarding measures can be found in the summary to question four.

### *Step 1 – declaration*

Step 1 of the proposed process involves a mentally competent person aged 16 or over with a terminal illness making their own clear decision to end their life. The person talks to their doctor about why they want assisted dying and the doctor explains other choices the person has. Two doctors then examine the person and consider their medical information. Each doctor decides on their own if the person is: a) terminally ill; b) has the capacity to make the decision; and c) making the decision on their own and not being pressured by anyone else. To proceed, the person must then sign a form that says they want help to end their life. Those who help people to have assisted dying must be registered HCPs. The HCP must sign a form and get all the information they need to help the person to have an assisted death.

Several themes arose in the responses about Step 1:

- that the definition of terminal illness proposed should be changed to include those with conditions which seriously affect a person’s quality of life but may not be considered to be terminal (see as examples anonymous response ID 175143463; individual response Joanne Howe, ID 178999634; and Easy Read response 3);
- that prognoses are often uncertain and inaccurate (see as an example Living and Dying Well, ID 181443000);
- the relationship between the two doctors should be clarified and/or at least one should have a historic relationship with the terminally ill person (see as examples the response from Peter Greenaway Hollings, ID 180027793 and the Royal College of Physicians and Surgeons of Glasgow, non-Smart Survey, response 14,017);
- that a declaration should be able to be made at an earlier time, when a person who is not yet considered to be near the end of their life but is mentally competent (and may not be at a later stage) – often referred to in responses as “living wills” (see as examples anonymous response ID 180122692 and Easy Read response 9);

- clarity is needed on how the mental capacity assessments will be made, with some calling for a full mental health assessment to be required for all undertaking Step 1 (see as examples the responses by the Scottish Partnership for Palliative Care (ID 181456887) and Easy Read response 9);
- clarity is required on how it can be assured that a person is not being pressured and/or coerced into choosing an assisted death (see as examples the response from an individual, P A Campbell, ID 180396003 and from the Evangelical Alliance, ID 181572890);
- arrangements should be made for people physically unable to sign a declaration to prevent discriminating against such people (see as examples individual responses by Gregory Kousourou, ID 175136012 and Norry Passway, ID 175926344 and Easy Read response 11); and
- consideration needs to be given as to how equal access to this stage of the process will be ensured for people in remote and rural communities (some concern was also expressed about the appropriateness of this part of the process being undertaken remotely). (see as examples the response from an individual, Alexander James MacInnes, ID 181468017 and from The Christian Institute, ID 181545444).

The Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) was partially opposed to the proposed steps, believing that the proposed definition of terminal illness was too wide, stating that instead: "… the proposed Bill should make reference to the CMO's [Chief Medical Officer's] more specific guidance around the BASRiS[20] eligibility guidance." It also raised concerns about doctors being required to explain available options to a terminally ill person, stating that such a role would require, "excellent communication skills and significant experience and competence in all areas of generalist and specialist palliative care and is unlikely to be fulfilled by any single doctor." The College proposed an alternative, suggesting instead that "a multidisciplinary team assessment and exploration of options and choices would be a more realistic suggestion for this stage of the process so that all physical and psychosocial needs can be assessed."

The Royal College of Physicians and Surgeons of Glasgow (non-Smart Survey, response 14,017) agreed that the proposed definition was too loose, commenting, "There appears very little understanding that there is real difficulty in the area of prognosis (life expectancy). Any proposed legislation would need a closely defined definition of Terminal Illness." It also found Step 1 to be too simplistic, with limited safeguards, stating:

> "We consider the conversation concerning forms of available treatment should occur long before the individual considers assisted dying. It can be a long conversation over a period of time and needs to come early in a terminal disease. We refer you to the General Medical Council's

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[20] The response referenced the following: Social Security Scotland - Chief Medical Officer's guidance for clinicians completing a BASRIS form) Disability-Benefits-Terminal-Illness-CMO-guidance-V1.0.pdf (socialsecurity.gov.scot).

> advice on consent. Of importance is what is considered a valid consent."

The response also suggested that the consultation document was confused in its use of some terminology, stating:

> "Registered Medical Practitioner is the legal term for Medical Doctors who are regulated by the General Medical Council. Healthcare professional or practitioner is a looser term which may include Medical Doctors but also Registered Nurses, Pharmacists, Physiotherapists, Occupational Therapists, Healthcare Support workers, and others. The majority have a statutory regulator. The paper is not specific about the particular skills and to which professional it refers."

The response also outlined concerns that the two doctors (attending and independent) are not clearly defined, with clear eligibility based on the relationship with the patient made clear, adding that:

> "… the length of personal knowledge of the individual is important as is the training in assessment skills and in the consenting of patients considering ending their lives and prescription of lethal medication to them. They will also need ongoing continuing professional development to maintain skills. Are the doctors involved in ongoing care? In which case there may be a conflict of interest. The necessary speciality background of the doctors needs to be considered."

The Royal College of Psychiatrists in Scotland (ID 181554005) thought clarity was needed around the capacity process and assessment and suggested that capacity should perhaps be reconsidered again after any reflection period. It also believed that those conducting capacity and mental health assessments should be clearly defined to ensure suitability. Similar issues were raised by the Scottish Association for Mental Health (non-Smart Survey, response 14,029) which raised the issue of what the definition of capacity would be, how it would be assessed, and what qualifications would be needed by those carrying out assessments, stating:

> "In any draft bill we would like to see the meaning of the word "capacity" defined and expanded on, with reference to the definitions set out in existing adult and child protection legislation. This legislation is currently being reviewed by the Scottish Mental Health Law Review which is expected to report in 2022. We would want to see any recommendations on capacity be a determinant of the definition in this context."

The Scottish Association for Mental Health also wanted to see detail on the extent of the psychological support required, and how that would be funded and fit alongside the current maximum 18 week waiting time. In terms of how some of the detail may work, it stated:

> “We believe that there may be a necessity to expand upon the role and responsibilities of the two doctors involved in assessing the patient, for instance the Mental Health Act contains provisions on conflict of interests and Approved Medical Practitioners. We would also be keen to see any health professionals being given responsibility under this bill to have received thorough psychological training. We would welcome more detail around the doctors, their legislative responsibilities, training etc in the draft bill.”

The organisation Children’s Hospices Across Scotland (non-Smart Survey, response 14,022) raised concerns about the impact of Step 1 on young people. It stated that some young people do not fully understand that death is permanent, adding, “… this is extremely important because it means a young person might ask for assisted suicide for reasons that have nothing to do with an actual desire to die in the sense that death is understood by older adults.”

### ***Step 2 – reflection period***

Step 2 provides for a period of reflection and the consultation document specifically asked for views on the suggested reflection periods. It is proposed that a person who has completed Step 1 is not permitted to have medicine for assisted dying until a suggested period of up to 14 days after Step 1 has been completed. This gives the person time to think about their decision and change their mind if they wish. If the attending doctor and independent doctor agree that the person’s death is reasonably expected to occur within 30 days, the reflection period can be shortened.

Many supported the proposal as set out in the consultation document, with some suggesting appropriate time frames for a shorter period for certain cases.

A significant number of responses, including respondents fully supportive of the proposal overall, thought the suggested 14-day period of reflection was too long, with others, albeit fewer respondents, indicating that it was too short. Various alternatives were proposed. Scottish Association for Mental Health (non-Smart Survey, response 14,029) felt a reflection period of 14 days may be too short for someone with a mental illness and noted that depressive episodes can last longer and inhibit decision making. It believed a longer reflection period may be needed in such cases. The Neurological Alliance of Scotland (ID 181560705) noted there was a range of views within its membership regarding the proposed length of time for reflection with some members feeling it should be longer to take into account the fluctuations in mental health in those with neurological conditions.

Many of those opposed to a reflection period were opposed to this as part of a wider opposition to all the steps and the proposal as a whole. However, some of those supportive of the proposal were also opposed to any period of reflection, believing that once a person had decided and completed the first step then an assisted death should be provided. The Caledonian Humanist Association (ID 179637632) stated, “we are not supportive of any legally imposed period of reflection if the other criteria have been met", and DIGNITAS (ID 181537153) stated that there should be no reflection period for anyone who had completed Step 1 of the process, stating that its experience is that:

> "… generally, people who contemplate end-of-life-choices make up their mind as part of their "personal life philosophy" long before they would face a health situation in which they would get in touch with DIGNITAS … Any time frame – 30, 14 days, or shorter – leads to possibly prolonging the suffering … In the Swiss legal system … there is no such mandatory waiting period and it does not appear to have posed a problem in 35 years of this being practice."

Respondents also commented on the proposed shorter reflection period for people reasonably expected to die within 30 days. Many respondents were supportive of flexibility to shorten the reflection period if death was expected quickly. However, Parkinson's UK Scotland (ID 181559748) stated it was:

> "… uncertain about how people expected to die within 30 days would be identified, given studies that show that prognostication is very difficult and doctors' estimates of life expectancy can be very inaccurate. We also note that there is no suggestion about a minimum waiting period for people whose death is expected within 30 days. We would suggest that one would be needed if the bill were to go ahead."

### *Step 3 – prescribing/delivering*

Step 3 completes the process by ensuring the prescribing and delivery of the end of life medicine. A doctor who assessed the person at Step 1 prescribes the medicine for assisted dying. An HCP prepares the medicine and stays with the person when they take the medicine. The HCP fills out a form and sends it, along with the other forms and all the information about the assisted death, to an organisation that will be in charge of assisted dying for terminally ill people in Scotland.

Most respondents were supportive of this step, including strong support for the proposed administrative elements of the proposal including that an organisation that will have administrative responsibility (this is covered in more detail in the summary of question five).

A frequent concern raised in responses was what would happen if a person was not physically able to self-administer the medicine. Many respondents were concerned that such people would not have access to assisted dying (which some thought would be discriminatory). Some respondents asked if health professionals or another person (such as a willing family member or friend) would be able to administer the medicine in such circumstances. Concerns were also raised about what would happen if the medicine did not work and/or if the patient appeared in pain and/or distress. The organisation Children's Hospices Across Scotland (non-Smart Survey, response 14,022) stated that young people[21] can differ in the way they metabolise medications and questioned what would happen if the medicine did not work as expected, adding:

> "There is currently no evidence base that could inform training, nor any competencies that could ensure young people were not inadvertently made to suffer during the process of assisted suicide. This safeguard is inherently weaker in young people than in older adults."

### *Other comments*

Many responses made suggestions for additional parts of the process or raised issues about the process as a whole. These included:

- that the whole process should be managed and decided by the courts (see as an example the anonymous individual response ID 181502683);
- an additional step after the reflection period to again formally confirm intent/consent (see as an example individual response by Adrian May, ID 175189473);
- that the role of family/friends throughout the process needs to be clarified (some called for it to be possible for family/friends to be able to have decision-making powers in certain circumstances) (see as examples the Free Church of Scotland (ID 180245159) and the Christian Medical Fellowship, (non-Smart Survey, response 14,016);
- clarification is needed about what practical and emotional support will be made available for all involved (see as examples Hospice UK, non-Smart Survey, response 14,028, and the Scottish Association for Mental Health, non-Smart Survey, response 14,029);
- clarity is required on where the process take place and whether it will be possible for the assisted death to happen at home (see as an example Hospice UK and individual respondent Alex Creel, ID 175136100);
- Hospice UK noted that special care and a specific approach was needed for young people with a terminal illness as there are often different issues and prognosis is often harder and less reliable in younger patients;
- Glasgow Disability Alliance (non-Smart Survey, response 14,024) thought the entire three-step process would not work for disabled people and that more time would be needed for disabled people to engage with the process, adding that it did not consider it would be safe or fair, stating: "until supported decision making is fully implemented, many people will be unable to fully understand and participate in the processes set out in this proposal".

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[21] Note that the proposal would apply to those aged 16 and over.

**Question 4: Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document (Fully supportive / Partially supportive / Neutral / Partially opposed / Fully opposed / Unsure)? Please explain the reasons for your response.**

13,268 respondents (94.5% of the total) answered this question, including 71 of the 81 organisations that responded to the consultation. 67% of those who answered the questions were fully supportive (10% less than were fully supportive of the proposal as a whole), with a further 8% partially supportive (compared to 2% who were partially supportive of the overall proposal). 19% were fully opposed (compared to 21% fully opposed to the overall proposal) with under 1% partially opposed. Just over 3% were neutral, and just under 3% were unsure, higher numbers than were neutral or unsure of the proposal as a whole. This data suggests that while there is strong support for the proposed safeguards, some of those fully supportive of the overall proposal, were less supportive (or had more suggestions to make) about the safeguarding measures.

The safeguards set out in section 1.1 of the consultation document are that:

- two doctors independently confirm the person is terminally ill;
- two doctors establish that the person has the mental capacity to request an assisted death;
- if either doctor is unsure about the person's capacity to request an assisted death, the person is referred to a psychologist or other appropriate specialist;
- two doctors assess that the person is making an informed decision without pressure or coercion;
- two doctors ensure the person has been fully informed of palliative, hospice, and other care options;
- the person signs a written declaration of their request, which is witnessed and signed by both doctors;
- a suggested waiting period of 14 days allows the person time to reflect on their decision. This timeframe is shorter if the person is expected to die within 30 days;
- the life-ending medication is stored at a pharmacy and is delivered to the person by a registered HCP;
- an HCP brings the medication, checks the person continues to retain their capacity, and a settled intention to die, and remains present;
- the person must administer the life-ending medication themselves;
- it would continue to be a criminal offence to end someone's life directly;
- every assisted death would be recorded and reported for safety, monitoring, and research purposes.

As mentioned previously, given that these safeguards mostly form part of the three-step process which was the subject of question three, there was considerable overlap and repetition in the views expressed between answers to this question and answers to question three. In addition, comments on the final listed safeguard (reporting) preempts much of the comment made in answer to question five (on the issue of a reporting body). This summary of question four gives a brief overview of the broad reasons people chose a particular option to indicate their view, and then summarises views on many of the specific safeguards. In doing so, there is some overlap and repetition with question four. Most comment on reporting can be found in the summary of question five.

### *Broad reasons for views expressed*

A clear majority of respondents to this question (67%) fully supported the proposed safeguards set out in the consultation document (99% of which were also fully supportive of the proposal as a whole). Of those that explained their answer, a significant number repeated support for the overall proposal and for the proposed safeguards. Many (including, for example, the Humanist Society Scotland, ID 181336267) commented that the proposed safeguards were necessary to protect all involved and were proportionate and not obstructive but also sufficiently strong to protect the vulnerable. There was a great deal of comment that adequate safeguards were essential for the success of the proposed Bill.

Many respondents believed that the proposed safeguards were consistent with those in place in other countries and jurisdictions that have legislated for assisted dying. The Association of British Insurers (ID 181478295) stated that it, “supports that there are strong safeguards in place that put transparency, protection and compassion at its core and is modelled on legislation that has passed rigorous testing in other countries around the world.”

Several academics echoed these views, such as Robert Slater (ID 181271328), who stated, “These safeguards have been formatted and put into practice over time, successfully, in several countries”, and Dr Sarah Sivers, an academic at Robert Gordon University, ID 175195360, who stated:

> “The safeguarding provisions are again broadly in line with ones which are shown to work in other jurisdictions. Clearly there is a need for such safeguards, but the measures set out in the proposal in [section] 1.1, coupled with those in [section] 3.1 strike the necessary balance, in my view, between being sufficiently permissive to allow for an assisted dying mechanism for those who wish to use it, while still retaining the necessary protections and safeguards to ensure that those who are vulnerable are protected, and to ensure that decisions made are taken on an accurate, voluntary and informed basis.”

Some who were fully supportive noted that the proposed safeguards seemed a good starting point, and that there should be flexibility to adjust them if necessary following experience of the legislation being implemented and assisted dying having taken place (i.e. to learn through experience).

A minority of those who responded to this question (19%) were fully opposed to the safeguards proposed (99% of which were also fully opposed to the overall proposal). Of those who explained the reasons for their response, many repeated and re-emphasised arguments for their general opposition to the overall proposal (i.e. that no safeguards could make the proposal acceptable, or that they hoped the proposal would be rejected, and therefore the issue of safeguards would be moot – many noted that having no legal assisted dying was the only definitive safeguard). Many opposed responses believed safeguards in other countries and jurisdictions that have introduced assisted dying have been eroded over time and thought the same was likely to happen in Scotland. Examples included individual respondents David Clarkson (ID 176055593) who stated: “Other countries have found that the number of people opting to end their lives has increased over time and I think this increase is inevitable if the Bill is passed. All safeguards are open to challenge and are often eroded by courts or Parliament - these would be no different”, and Veronica Craig (ID 177928357), who stated: “These safeguards are not and never could be watertight. They would be eroded over time as has happened in other countries who passed such a bill.” Similar views were expressed in many other opposed responses, most of which believed that whatever safeguards were initially included in Scottish legislation would be weakened and/or removed over time.

Some who were opposed noted that if the proposal did go ahead then safeguards were essential. A very small number of respondents who were fully supportive of the overall proposal (or, it seems, at least to legalising a form of assisted dying) thought there were too many safeguards and/or that they were overly restrictive.

Three-point three percent of respondents that answered the question were neutral and 2.7% were unsure, however there was a wide variety of views expressed by these respondents. Some were waiting for more information and debate before coming to a view.

### *Selection of comments on the main themes*

The following selection of comments give a broad overview of the most frequent views expressed on the main themes which emerged across the consultation responses.

#### The role of the two doctors

The Neurological Alliance of Scotland (ID 181560705) made a number of suggestions for changes to the proposed safeguarding measure of having two doctors attend/be responsible for various parts of the process including: the doctor who signs the declaration being required to have known the person for at least six months; and the independent doctor being required to have professional experience and knowledge of the condition involved. The response acknowledges that these changes may risk a number of people being unable to have an assisted death due to conscientious objection of their doctors involved and suggests exceptions could be made in such cases.

DIGNITAS (ID 181537153) stated that requiring two doctors at various parts of the process could act as an additional barrier to assisted death, prolonging both the process and thereby the suffering experienced. The response noted that in Switzerland a single doctor can consult colleagues on a case-by-case basis and states that has “proved to work well for 35 years” and goes on to recommend the proposal be changed accordingly. DIGNITAS also questioned if doctors should be the gatekeepers of the process at all, stating that rather than two doctors diagnosing terminal illness the focus should be on quality of life, with the doctor(s) establishing that the person:

- “understands the information relevant to the decision relating to access to assisted dying and the effect of the decision; and
- has reached a voluntary decision without coercion or duress; and
- is informed as to palliative, hospice and other care options – this should include information as to the potential negative effects of unguided DIY-suicides; and
- is able to communicate the decision and their views and needs as to the decision in some way, including by speech, gestures or other means, and also able to administer the life-ending medication themselves; and
- has discussed the matter with their loved ones with the aim of avoiding a “negative surprise effect and impact” for these loved ones.”

### Widening eligibility

As has previously been mentioned, many respondents felt that the proposed eligibility criterion that assisted dying would only be available for those deemed terminally ill[22] was too restrictive and would exclude many people who are suffering with a poor quality of life. One individual, Beth McRobb (ID 180284679), in a response reflective of many other individual responses, explained why she wanted the proposal to go further than the proposed definition of terminal illness and eligibility for assisted dying, stating:

> “I am supportive. However, I would go further. Having already - in good health - written my wishes for the way I would want things to be handled if I developed dementia, I feel that my advance directive negates the need for me to be able to discuss what I want to happen towards the end of my life if I have lost the mental capacity the proposal required. Having made this clear in a letter held with my GP and with my lawyer, I would want this aspect of the bill to be able to meet my desires to end my life with dignity.”

Another individual, Julie Lang (ID 180434036), gave a personal account, explaining her reasons for wanting the proposal to go further:

> “I am fully supportive of the safeguards as proposed, but I would like to see a wider definition of 'terminally ill'. My late husband's condition included the inability to swallow, requiring tube feeding, and a permanent tracheostomy which compromised his respiratory function

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[22] See footnote 5.

> and his ability to speak. He had recurrent, life-threatening episodes of aspiration pneumonia. These would have worsened over time as he became more frail. He would not have died of his incapacities, but eventually would have died because of them."

Another individual, Linda Anderson (ID 175157707), commented specifically on the issue of dementia, which was raised by a significant number of respondents:

> "Dementia sufferers are overlooked in this bill as they cannot consent when their disease is advanced and when they really need the assisted death. Can they consent early in their diagnosis when they don't really know what's ahead in 5 or 10 years time? Dementia sufferers are a really difficult group and would definitely require further consideration."

Other respondents, predominantly those opposed to the proposal as a whole, set out fears that eligibility would be extended over time to allow wider access to assisted dying with fewer safeguards. Some organisations (while taking no view on the proposal) specifically called for reassurances that this would not happen in Scotland. For example, the Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) stated:

> "The College is very concerned to note the speed with which Canada has moved from legislation similar to the proposed Assisted Dying Bill to legislation which allows euthanasia by lethal injection for individuals irrespective of capacity and irrespective of terminal illness. We would be seeking assurance and stringent safeguards against that situation occurring in Scotland."

### Feeling a burden and issues of pressure/coercion

As stated elsewhere in this summary, one of the most frequent views expressed either in opposition to the proposals, or at least in concern, is that terminally ill people may feel that they are a burden on those around them, including family, friends, organisations (employers, the NHS etc) and the wider community and society. As a result of this, or for other reasons (such as for practical/financial reasons) they may feel pressured and/or be coerced into deciding to have an assisted death. Some respondents believed it would be impossible to safeguard against this in all cases, and that it was inevitable therefore that a proportion of those who chose an assisted death would do so not of their own free will. One anonymous individual (ID 175268187), in a response echoed by many others of those opposed to the proposal, stated:

> "No safeguards can fully protect the vulnerable - there will ALWAYS be a cohort of people who feel pressurised to end their life prematurely due to a concern about being a burden on their family and loved ones. I do not believe that any safeguards can fully protect these vulnerable people against this."

The Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) (which was partially opposed to the proposed safeguards) commented on the proposed role of doctors assessing whether a person was making the decision of their own free will, stating:

> "The proposed Bill mentions that the doctor would be responsible for ensuring that no coercion was taking place, but contains no robust method of assessing this or indeed for identifying the extent to which the fear of being a burden is contributing to the request for assisted dying. The College wishes to raise concerns about the undue legal, clinical and personal responsibility this would place on its Fellows and Members."

The Scottish Council of Jewish Communities (non-Smart Survey, response 14,025), which was not supportive or opposed but rather raised issues from amongst its members (who held different views) stated:

> "The death of a burdensome relative may be welcome to some people, and we are therefore concerned at the possibility of misuse of assisted dying as a cover for murder, particularly as the proposal not to include information on the death certificate risks subverting existing legislation that was introduced to prevent another Shipman scandal … Although the proposed safeguards may limit the scope for direct abuse, a considerable potential still exists for indirect abuse, not to mention well-intentioned but dangerous legal uncertainly."

### Delivery and administration of life-ending medication

Another of the recurring concerns expressed in responses was the requirement for the end of life substance to be self-administered and the concern that this would exclude some who would otherwise been eligible and wished for an assisted death. One anonymous individual (ID 180308624) gave personal experience of the problems there may be with requiring the life-ending medication to be self-administered:

> "I agree with all points in section 1.1 with the exception of how the medication is administered. Unfortunately, from personal experience I know that the ability to self-administer medication can be a real problem/issue for some people either due to inability to grasp/hold or swallow at the end of a terminal illness (calls for someone else to administer – relative, friend etc)."

And the Neurological Alliance of Scotland (ID 181560705) stated that some people with advanced neurological conditions may have significant physical impairments which meant they would be unable to self-administer the medication and would be excluded from being able to have an assisted death, adding that, "Failing to consider these issues could mean that people may choose to die at an earlier point than they otherwise would, rather than empowering them to die at a time of their choosing."

Pharmaceutical organisations commented on the delivery of the life ending medication. This included the Company Chemists' Association (ID 181441418) which wanted more details on the role pharmacists would play in the supply of the medication, stating:

> "Currently a pharmacist carries a 50:50 share of the responsibility, and liability, for the appropriateness and safety of medicines supplied, along with the prescriber. The pharmacist will need to be made fully aware of all relevant facts surrounding each individual case if they are to sanction the supply. Data would need to be captured on whether the medicines have been taken. It is likely that both the prescriber and supplier would want/need to be satisfied that the medicines had been taken correctly or returned. It would not be sufficient simply to have a returns process for accepting unused medicines, reliant upon the patient arranging for return."

### Capacity and mental health issues

The Scottish Human Rights Commission (non-Smart Survey, response 14,037), which was neutral on the overall proposal, noted that the process includes an assessment of mental capacity by doctors, and went on to outline current consideration of relevant legislation. It stated:

> "The assessment of capacity and its use as a determining factor in incapacity legislation is currently under review by the Scottish Mental Health Law Review [23], in recognition of the fact that it may no longer offer appropriate protection for the full range of human rights. The outcome of that Review remains to be determined, however, changes to the Adults with Incapacity (Scotland) Act 2000 are likely and any proposed Bill should take steps to align with their proposals on capacity and supported decision-making."

Many of those opposed to the proposal (and therefore the requirement of safeguards) and some of those supportive, expressed concerns about, in determining a person was "competent" how the capacity of a person would be assessed and how mental health issues, such as depression, would be considered.

One individual, Archie MacArthur (ID 177559660), who was fully opposed to the safeguards set out, stated:

> "None of these safeguards appear to consider the possibility of this being a temporary perspective, say, as a symptom of depression. In addition to the increase of workload on GPs, and the requirement for another doctor to be included in the decision, the difficulty of ensuring the thinking of the applicant is not simply a result of temporary depressive symptoms is something that requires familiarity with the applicant and their circumstances beyond the purview of many GPs.

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[23] Terms-of-Reference-1.pdf (mentalhealthlawreview.scot).

> The provision of sensitive care not only for physical but psychological distress may help to clarify their sense of the value of their life."

The Bishops' Conference of Scotland (ID 181501158) thought the safeguards should include mandatory psychiatric or psychological assessment, a view supported in several other responses. Another frequently expressed view was that the legislation must set out who will make any such assessments and what experience they should have, and qualifications they should hold. The Scottish Association for Mental Health (non-Smart Survey, response 14,029) was concerned if: "… doctors involved will have training in the subtle and complex signs of domestic, elder and disability abuse, and if they do detect these signs what their next steps and actions would be." Another respondent, in a response not published, drew a link between the proposed period of reflection and psychological issues, stating that the proposed 14-day period would not allow for diagnosis and effective treatment of depression, particularly that associated with terminally illness (such as processing grief).

The Royal College of Psychiatrists in Scotland (ID 181554005) believed that additional training should be given to clinicians being asked to assess capacity and cautioned against psychiatrists becoming the arbiters on whether a person is considered mentally sound to request an assisted death. In terms of the proposed referral to a specialist if the doctors are not sure on capacity, it stated:

> "We would urge that, alongside the development of a Bill to deliver these proposals, efforts are made to clearly establish the referral criteria and professionals who would be expected to conduct these assessments. We would also urge consideration be given of what happens if a person requests the opportunity to end their life due to a terminal illness, but no longer has or has diminished capacity. Relatedly, the need to consider whether a person with fluctuating capacity will need reassessed after the period of reflection should be considered. This would apply in particular to neurodegenerative diseases such as Alzheimer's. On the professionals involved, specialist training and support must be developed ahead of the Bill's implementation that ensures the knowledge and support is in place for a multidisciplinary workforce required to deliver aspects of the bill, including capacity assessments."

Parkinson's UK Scotland (ID 181559748) made detailed comments on the capacity safeguards, highlighting the need for appropriate capacity assessments for people with Parkinson's. The response stated that the doctors involved in assessing capacity of people with Parkinson's should have specific expertise in the condition, and that people must be provided with communication support if needed (including with both written and oral communication).

DIGNITAS (ID 181537153) stated that people should be assumed to have the capacity unless there is clear evidence to the contrary, adding: "a psychiatric illness may impact a person's mental capacity, but it need not." Its submission provided details of various human rights points and constitutional court judgments it considers relevant.

### Safeguards too restrictive

Some concern was expressed by some supportive of the proposal that there were too many safeguards and/or that they were too restrictive. Some feared this would delay assisted dying from being able to take place or prevent it altogether. One individual, C. McLeod (ID 175149682) who was fully supportive of the proposal but neutral towards the safeguards, believed the eligibility criteria were too narrow, consent should be able to be given at an earlier stage, and that the requirement to self-administer was also restrictive. The response states:

> "The precautions are too restrictive to benefit many people who are suffering, or who are afraid that they will suffer in future. As a result, even if the Bill becomes Law, a few people will continue to die prematurely by suicide or travelling abroad; many more will continue to endure prolonged suffering and degradation; and almost everyone will live in fear that this is how they will spend their final years … I hope that if the proposals become Law, experience will enable the safeguards to become less restrictive at some future date."

Another individual, Alistair Easton (ID 175136045) thought that it should be possible for the safeguards to be relaxed in certain circumstances:

> "I wish that an adult could, well in advance of their death and when there can be no doubt about their mental ability, register their wish that, should they need to seek an assisted death, a less complex route, still with safeguards, should be followed."

### Other comments

A number of responses raised concerns based on experiences during the Covid pandemic of failures to protect vulnerable sick people. Parkinson's UK Scotland (ID 181559748) stated:

> "The Covid-19 pandemic exposed some very concerning practices around existing end of life decision-making, including blanket imposition of so-called "do not resuscitate" (do not attempt CPR) orders on groups of patients without consultation. This caused significant anxiety amongst people with Parkinson's in Scotland and rUK [rest of the UK] … Many disabled people and older people - including people with Parkinson's and their families - would require a very high level of scrutiny to be in place to make sure that the system was not abused."

And the Neurological Alliance of Scotland (ID 181560705) stated:

> "People with neurological conditions were amongst those who experienced the imposition of Do Not Resuscitate orders (Do Not

> Attempt CPR) without consultation or consent during the pandemic in Scotland, and this is a very recent example of why we need to ensure that the safeguards referred to in the consultation to protect vulnerable people are fit for purpose. We believe that this area would require extensive additional consultation prior to any new law being put into place."

The Scottish Human Rights Commission (non-Smart Survey, response 14,037) was one of several respondents to suggest consideration of judicial or independent assessment to ensure that the decision was being made voluntarily, rather than the proposed process governed by health care professionals, stating:

> "Such a system would offer a higher degree of scrutiny and, accordingly, stronger safeguards for the right to life. It might also allow for appropriate tests to be designed to recognise the legal capacity of disabled people in a manner respecting Article 12 CRPD [Convention on the Rights of Persons with Disabilities]. Judicial determination would, however, provide a lesser degree of autonomy for the individual. The Commission believes that a system of judicial or independent assessment ought to be more closely considered."

Some of those opposed to the proposal and the safeguards predicted problems with life insurance for people who choose an assisted death. The Association of British Insurers (ID 181478295) supported strong safeguards being in place that are based on transparency, protection and compassion and are modelled on legislation in place elsewhere that has been rigorously tested. It states that it has sought the views of member companies in parts of the world which have legalised assisted dying (including Canada and Switzerland) and that, "There was no significant impact identified on the majority of life insurance policies. If assisted dying is introduced in Scotland, we propose that insurers will still be able to rely on other checks when assessing a claim."

### ***Other suggested safeguards***

There were also various suggestions made for further safeguards, or views expressed from a particular perspective on the safeguards generally. These included:

- that, to add further protection, an additional person witnesses the declaration made by the terminally ill person (suggestions included that this witness should not be a health care professional or a family member, but someone who knows the person) (see as an example the response by Sue Henderson, ID 180519738);
- that (given the strain on NHS resources) a timescale is placed on that maximum waiting time of each part of the process, and the overall time someone should have to wait from start to finish (see as an example the response by Ann Marshall Masson, ID 181573811);

- the BSL respondent stressed the need for consent to be able to be given in other languages, including BSL;
- Hospice UK (non-Smart Survey, response 14,028) stated that if the proposal becomes law, then a legal right to palliative care would be required, and Scottish Care (ID 181554943) stated “There needs to be independent evidence that the best available palliative care provision was accessible by the individual”;
- all decision-making should be made by the courts (see as an example the response by Dr Matthew Davis, ID 179929641);
- a person requesting an assisted death should be protected from being pressured due to financial motives by provision of an independent legal and financial check (see as an example the anonymous response ID 181569186);
- clarity is needed on what would happen if a person changed their mind at the last moment and what would happen if the medication was not successful (see as an example the response by the Royal Pharmaceutical Society, ID 181033648);
- The organisation Children’s Hospices Across Scotland (non-Smart Survey, response 14,022) called for specific consultation with young people with life limiting conditions. It also questioned what would happen with young people who lacked capacity to make a decision, and asked if parents would have any powers of authority;
- Glasgow Disability Alliance (non-Smart Survey, response 14,024) repeated reasons for its opposition raised under question three, stating again that no safeguards would ever be sufficient, and that disabled people would not be safe if the proposal went ahead;
- the Neurological Alliance of Scotland (ID 181560705) and Parkinson’s UK Scotland (ID 181559748) both made extensive comments on the proposed safeguards and what would be most appropriate for people with neurological conditions. For a full account of the views expressed see the published responses online[24].

Several respondents also called for clarity on how conflicts would be resolved, for example, if the two doctors did not agree on aspects of the required assessments (see as an example anonymous response ID 181258347).

**Question 5: Which of the following best expresses your view of a body being responsible for reporting and collecting data? (Fully supportive / Partially supportive / Neutral / Partially opposed / Fully opposed / Unsure)? Please explain the reasons for your response, including whether you think this should be a new or existing body (and if so, which body) and what data you think should be collected.**

13,206 respondents (94% of the total) answered this question, including 68 of the 81 organisations that responded to the consultation. Just over 60% of those who answered this question were fully supportive of a body being responsible for reporting and collecting data, with a further 7% partially supportive. 14% were fully opposed (with just 0.8% partially opposed), while

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[24] The consultation responses are available at: https://www.assisteddying.scot/.

12% were neutral and 6% unsure. Comparing these numbers to those for the overall proposal (question one), it seems that some of those fully supportive of the proposal were either partially supportive, neutral or unsure about the need of an administrative body. It also seems that a small proportion of those opposed in principle believed that if the proposal were to go ahead (which they hoped it would not) then there should be a body responsible for reporting and collective data.

Many of those supportive believed it was essential for reasons of safeguarding and transparency that data is collected and reported, with a proportion believing that the law and/or guidance may need to be changed as a result of practical experience of assisted dying being used (see as examples individual respondent Elizabeth Morrison, ID 180489856 and anonymous individual ID 181197720). Amongst those opposed, some thought that a body would be a waste of public money and believed that experience in other countries has shown such data collecting and reporting bodies to be ineffective and self-serving and not able to prevent cases of pressure and coercion (see as examples individual respondents Julie Gilmore (ID 178697144) and Jacqueline Kane (ID 180538699) and the response by North west Pro-life, ID 181573910). Others suggested that any such body would not be independent but would be an organisation supportive of, or even encouraging, assisted dying and that it would therefore not be trustworthy (see as examples individual respondents Felix Trimbos ID 179957758, and anonymous respondents ID 181519257 and ID 181536724). Some opposed responses stated that the Covid pandemic has shown data collection and reporting to be unreliable (for example, Charles McEwan (ID 178720411), while some thought the money would be better spent on improving palliative care standards and accessibility (for example, Mrs Janet MacSween ID 180350835).

Many respondents commented on the proposed approach to death certification[25]. Many respondents were supportive of the proposal that the underlying illness would be listed as the primary cause of death. However, some, including a proportion of those otherwise supportive of the proposal, disagreed with the proposed approach and believed that the primary cause of death should be given as the assisted death procedure, rather than the underlying illness (see, for example, Professor Gareth G Morgan (ID 175850639), the Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013), and also the longer section on death certification on page 50).

Broadly, there was not a large number of responses that thought the proposal should go ahead without such a body being responsible for collecting and reporting data. Many respondents gave views on who the body should be and what its role should be. The most frequent issues raised are set out here:

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[25] The consultation document states: “Death certificates are public documents, and in the interests of privacy, the primary cause of death would be noted as the underlying illness from which the person died. It is envisaged that the paperwork and the potential creation of a reporting and oversight body would satisfy public health awareness, research and resource allocation requirements.”

### *Current body v new body*

There was a mix of views on whether a current body or a newly created body should be responsible for reporting and collecting data, although a majority thought that a new body should be established (with many explaining that the body should be seen to be completely independent and not part of any other organisation). Many respondents felt strongly that a body should be responsible but had no strong view on the origins of that body and were content for law and policy makers to make that decision. Some felt using an existing body would save on cost, compared to establishing an entirely new body.

Those who thought a new body should be established often stressed the need for it to be independent, trustworthy and free from undue influence, be that from public or private sector, or personal, political, religious, legal, and/or financial views and interests. Some respondents thought it important that the body be clearly distinct from the Scottish Government. One individual, James Duke-Evans (ID 181199418) stated that, “A new body would be unencumbered by existing organisation's workloads or budgets and could be designed for transparency and efficiency”. The Company Chemists' Association (ID 181441418) thought a new body could be constituted from all those involved in the process, including health professionals, patients and their families, along with the judiciary.

Of those who thought an existing body could/should take on the role, suggestions of the identity of that body included: various parts of the NHS (including Public Health Scotland); the Procurator Fiscals office; the Registers of Scotland; the Scottish Government; the British Medical Association Scotland; and local authorities. As an example, Gordon Drummond, (ID 175800846), an academic with experience in a relevant subject, commented, “Existing bodies (or preferably, one body) are better: Public Health Scotland are experienced and accredited, regularly audited, and well-established repository for healthcare data.”

In contrast to many who thought there should be a new body created so that it could be independent of Government, some who thought an existing body (including a Government department) would be appropriate specifically thought it important that the body be under a degree of Scottish Government control and/or supervision to ensure it was appropriately neutral and subject to appropriate scrutiny. Some thought, regardless of whether it was a new or existing body, it should report to either Scottish Ministers, or to the Scottish Parliament, to ensure transparency and allow for scrutiny.

### *Role and operation of the data collecting and reporting body*

A large number of respondents to this question gave views on what the role of the body should be, and how it should operate. A high number of suggestions were put forward, the most frequent of which are summarised here. Broadly, suggestions fell into two camps: those who accepted the role proposed in the consultation document and suggested what data should be collected and how it should be reported; and those who believed that a body should have a wider and/or different fundamental role from that proposed. Views and suggestions put forward on what data should be collected, and how it should be reported, included:

- what medicine was taken;
- whether the medicine was successfully administered or returned;
- how consultations were conducted and what information was given (Living and Dying Well, ID 181443000, suggested that consultations be recorded to protect both patient and doctor);
- the effect of the medication (time from taking the medicine to death, any complications etc);
- characteristics of patients[26] (personal information, demographics, background, socio-economic information etc.);
- details of the relevant terminal condition;
- the extent of the care, including palliative care, a person has received;
- reasons a person gave for seeking an assisted death; and
- details of all attending doctors/health professionals/others throughout the process (including their experience and expertise, and their relationships with the patient and each other).

As an example, Ben Colburn (ID 178526627), an academic with experience in a relevant subject, stated:

> "I think that, with a view to sustaining public confidence in these measures and informing future legislative decisions, it will be important to gather data on: the number of requests for assisted dying; on the number of requests approved; on the outcome for people whose requests are approved, including how many assisted deaths are carried out, and the number of people who decide not to take up the option after all; and the terminal conditions for people in each of these categories."

The Scottish Human Rights Commission (non-Smart Survey, response 14,037) stated it was essential to collect and report data to ensure every use of assisted dying was appropriate and upheld human rights. The response cites comments made by the Committee on the Rights of Persons with Disabilities:

> "Establishing regulations pursuant to the law requiring collection and reporting of detailed information about each request and intervention for medical assistance in dying; and Developing a national data standard and an effective and independent mechanism to ensure that compliance with the law and regulations is strictly enforced and that no person with disability is subjected to external pressure."

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[26] Note that Children's Hospices Across Scotland thought there would be an extra layer of sensitivity when dealing with the data of young people.

Dignity in Dying Scotland (ID 181277811) agreed that the patients end of life concerns should be recorded, but believed that lessons should be learned from elsewhere, stating that in the USA, HCPs retrospectively select reasons a person want an assisted death from a list of pre-selected general concerns which leads to the publication of misleading information, adding:

> “This has led to misleading claims that people who choose an assisted death in the USA do so because they are concerned about being a burden. However, being a burden is not in the top three concerns reported. These concerns are recorded by a doctor from a closed list of options and should not be used to make sweeping statements about the complex reasons that inform any medical decision. It’s important under a change in the law in Scotland that terminally ill people who meet the eligibility criteria and safeguarding themselves define why they want the choice of assisted dying, rather than their doctors doing so.”

Some also thought it important that instances were recorded of an assisted death being requested and refused, or of patients initially requesting and then changing their minds. Scottish Association for Mental Health (non-Smart Survey, response 14,029) stated it was important that the body has a statutory duty to report to Parliament regarding:

> “… equalities characteristics of those requesting assisted dying, terminal diagnosis, comorbidities, disability and medications as well as rejected and accepted requests, geography, socio-economic status and some way to identify doctors involved. This will enable transparency and the proper analysis of trends.”

The most common views of those who thought the body should have a fundamentally different role included that it should:

- monitor each case and assess the effectiveness and appropriateness of safeguards (protecting against potential abuse of the system) (see as an example the response by Lisa Pettigrew-Rennie, ID 181220254);
- collect and analyse information about the thoughts, feelings, motivations, and circumstances involved from the terminally ill person and their family and friends, and make recommendations for change as a result (see as an example the response by Anne Ayres, ID 181202756); and
- advise Government on any changes required to guidance and/or legislation (see as an example the response by Ronald Anthony Plummer, ID 181268269).

The Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) stated:

> “… the College would recommend that a regulatory body would require independent oversight and governance of all stages of the process

from eligibility assessment to capacity assessment to medication decisions and prescribing to death and certification."

In terms of how the body (whether existing or new) should operate, the most frequent comments included:

- privacy issues would require careful consideration – who would have access to the information and on what basis? As an example, Parkinson's UK Scotland (ID 181559748) believed there should be a presumption of access for friends and relatives where possible;
- the body should work with other organisations as required and appropriate (this included a suggestion by The Royal College of Psychiatrists in Scotland (ID 181554005) which said the Mental Welfare Commission "…would have a role in monitoring and recording capacity assessments. This would include gathering data on those who apply for but are refused assisted suicide. This would allow for a review of capacity assessments as a safeguard in such instances.")
- the body should not duplicate the work of other organisations, or over-report. Scottish Care (ID 181554943) made this point and asked several questions, including:

    - who would be required to enter all the information?
    - how would it work in relation to data collected for people that are in hospices, care homes and those who are receiving palliative care?
    - how would it work/look for people who receive care and support more generally?
    - how would it integrate with existing systems (Care Inspectorate, Turas [an online platform used by NHS Education for Scotland] etc.)?
    - how would this integrate with NHS-held data?

### *Death certification*

Many respondents commented on what cause of death should be recorded on a death certificate of a person who had had an assisted death. The consultation document stated: "Death certificates are public documents, and in the interests of privacy, the primary cause of death would be noted as the underlying illness from which the person died. It is envisaged that the paperwork and the potential creation of a reporting and oversight body would satisfy public health awareness, research and resource allocation requirements."

Many respondents supported this approach, see, for example, individual respondent Barbara Mair (ID 175276674): "I like the idea that an assisted suicide will not appear on the death certificate as this could cause trauma to friends and relatives of the deceased person", and retired medical professional Dr Gordon Paterson (ID 175143542): "As stated in the consultation document, the death certificate should record the underlying cause of death with no reference to assisted dying".

The Association of British Insurers (ID 181478295) also believed that death certificates should state the underlying illness, stating:

> “For claims of dying where assisted dying has taken place, insurers may request information on the underlying illness. So, any death certificates should state the underlying illness where assisted dying has been undertaken. As proposed in the Bill, assisted dying will not be classified as “suicide” for life insurance purposes. We agree where consultation states that “the use of ‘suicide’ in this context is not appropriate, given that the person will only be able to request an assisted death if they have a terminal illness that will end their life i.e., the choice to live has already been taken away”. In the UK, the majority of life insurance policies will have a standard 1-year suicide exclusion clause. There may be a minority of older polices which have ongoing suicide exclusions. However, if the Bill does not classify assisted dying as “suicide”, we do not foresee this to have an impact on a claim.”

Other respondents did not agree that the cause of death should be limited to the underlying illness that allowed the person to choose an assisted death, and believed that the method of assisted death, and the fact assisted death took place, should either be the only reason given on a death certificate, or also form part of the cause of death information. This included opposition and/or concerns raised by medical and palliative care organisations. The Scottish Partnership for Palliative Care (ID 181456887) stated:

> “The purpose of death certificates is to record objectively so far as can be determined the cause of death and that is the legal duty of the completing clinician. In the case of assisted dying the cause of death will be self-administration of lethal medication. Death certification also accommodates recording of underlying or contributary conditions. Not recording the actual cause of death, as the Proposal suggests, would undermine the basis of death certification in Scotland (and the public health record and research based on it). This approach seems out of line with the approach adopted in other “sensitive” circumstances of death. Not recording assisted dying on the certificate could create stigma about the person’s choice.”

And the Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) stated:

> “The College would strongly suggest that physicians should not be required to omit the true cause of death as is suggested on the proposed Bill. Cause of death should be entered as self-administration of lethal medication, to allow adequate scrutiny by the Medical certification of cause of death (MCCD).”

Other respondents thought that the proposed approach to death certification would be misleading and amount to false reporting. A number of responses cited the Harold Shipman case and believed that excluding the method of assisted death from the death certificate could open the process up to similar cases of abuse and/or murder in future. The organisation Not Dead Yet (ID 181524112) stated:

> "As in U.S. states, the Scottish proposal would require that deaths by assisted suicide be listed on death certificates as caused by the underlying illness. A system of oversight which requires dishonesty from the outset cannot serve transparency or justice."

**Question 6: Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.**

9,148 respondents (65% of the total) answered this question, including 68 out of the 81 organisation that responded to the consultation. This was an open question with no check-box options available for a respondent to indicate a view. As such, due to the high number of responses, there was a wide range of different comments made. A reasonable number of responses offered no other comments other than repeating support or opposition for the proposal as a whole, and therefore equivalent support or opposition for the inclusion of a form of conscientious objection.

There was clear majority support for a form of conscientious objection to be included in the proposal (many thought it was essential) including from some of those otherwise opposed to the proposal (taking the view that if the proposal goes ahead, which the respondent hoped it would not, that conscientious objection must be included). The most frequent themes raised by respondents can be grouped as follows:

- who should be able to conscientiously object?
- how should objection be done?
- what are the consequences of various people being able to object?
- must those who object have to refer patients to someone who doesn't object?

### *Who should be able to conscientiously object?*

A relatively small number of respondents (otherwise supportive of the proposal) were not supportive of health professionals being able to conscientiously object to taking part in assisted dying. As an example, one individual academic respondent, Ken Donaldson (ID 175145213) stated:

> "There should be education available for professionals who conscientiously object and it should be necessary for staff to fulfil their contractual obligations and allocation to other posts if necessary."

One individual academic, Michael Cholbi (ID 181485219) also commented on whether any form of objection should be included in the proposed Bill, stating:

> "The most prominent example of conscientious refusal in UK health law (the Abortion Act) disallows refusal when necessary to prevent

> "permanent injury to the physical or mental health" of a patient. Arguably, the refusal to participate in assisted dying may also amount to failing to prevent "permanent injury to the physical or mental health" of a patient. In addition, facilitating conscientious objection may result in indefensible disparities in patient access to assisted dying, if (for example) large numbers of professionals within a particular clinical setting or region opt out of participation."

Other respondents believed that any objection process should be limited to medical practitioners directedly involved in the process only. For example, the Humanist Society Scotland (ID 181336267) believed it should be limited to doctors/nurses and not include other individuals, such as administrative staff and other health care workers (such as caterers, cleaners etc.) and not organisations and health care providers (including charities). Three academics, Professor Liz Wicks, Dr Clark Hobson, Dr Nataly Papadopoulou, in a joint response (181564982) commented on the limits they believed should be placed on who could object:

> "The Supreme Court has ruled in Doogan v Greater Glasgow and Clyde Health Board (2014) that 'participation' in treatment involves only hands-on involvement in that process, and does not include administrative or managerial tasks. A similar approach should be adopted in relation to conscientious objection to assistance in dying."

Many other responses made various suggestions for inclusions beyond the attending doctors. The British Medical Association Scotland (non-Smart Survey, response 14,034) stated:

> "… we are clear that there must be robust protection for conscientious objection written into any legislative proposal on physician-assisted dying. Crucially, the right of conscientious objection should apply to all health, care, and administrative staff. In the event of a change in the law, we would expect that clinicians would share relevant clinical information and background as required by GMC Good Medical Practice. They must, however, have the right to conscientiously object to prescribing life-ending medications. Beyond this, there will need to be careful consideration of the scope and specifics of clinician involvement to ensure that doctors' rights to conscientious objection are protected."

Several responses commented on the role of pharmacists. The General Pharmaceutical Council (non-Smart Survey, response 14,033) stated it was important that any objection process covered pharmacists and pharmacy technicians. Community Pharmacy Scotland (ID 181270061) agreed that any conscientious objection must be extended to cover "the registered technicians involved in the provision of pharmaceutical care within the pharmacy team" and added:

> "The inclusion of the CO [conscientious objection] Clause clashes with the legal/contractual obligation to supply the medicines if the request

> comes via an NHS prescription. The CO Clause must give a clear legal position on the choice of the individual to opt out of the service, and must be taken into account, and supersede other legislation in place."

Community Pharmacy Scotland (ID 181270061) and the Company Chemists' Association (ID 181441418) both had concerns about how a conscientious objection would work with the legal duty for pharmacists to provide medication with "reasonable promptness" and with the General Pharmaceutical Council's standards on ethical, personal and faith beliefs. The Company Chemists' Association (ID 181441418) called for consultation with all those that would be involved in conscientious objection to ensure that "there are no unintended consequences of involvement, or abstention."

Another frequently raised issue was whether conscientious objection should extend to organisations, such as hospices, as well as individuals. A majority thought objection should be limited to individuals only, and not apply to organisations, to ensure that patient's wishes are fulfilled. An individual professional, Tanya Louise Battel (ID 181491667) gave views based on experience in Queensland, Australia. The response notes that in Queensland objection is limited to individuals and is not extended to organisations, but that the law:

> "… requires the healthcare entities to not carry out the procedure but that "entity" must allow the applicant's own VAD [voluntary assisted dying] doctor to access that applicant in any healthcare facility in which they find themselves and, if the applicant's move to another facility that provides for Assisted Dying would cause death or significant suffering to the applicant then the process must be undertaken in that facility. Evidence based material was provided to the parliamentary debate of cases where it would not have been possible for an individual to have to have been moved from, e.g. a catholic run institution, to appease the religious objection by a healthcare facility. It is imperative that the focus of this remains on the individual seeking to access end of life options."

The organisation Living and Dying Well (ID 181443000) was one of a number of respondents that believed organisations (such as a care home or hospice), as well as individuals, should be able to opt in/out on the basis of conscientious objection, but added:

> "If an establishment receives funding from the public sector, legislation must stipulate that the public sector body funding cannot be withdrawn on the grounds that an organisation has a conscientious objection."

### *How objection should be done (including opt-in v opt-out)*

There were mixed views on whether conscientious objection should be operated on an "opt-in" or "opt-out" basis. Some respondents thought that an opt-in or opt-out from being required to take part should be included as part part of employment contracts.

Several medical organisations favoured an “opt-in” approach. The Royal College of Physicians and Surgeons of Glasgow (non-Smart Survey, response 14,017) stated that taking part in assisted dying should be a matter of professional decision-making and objection rather than framed specifically as a conscientious objection and should be operated on an “opt-in” basis, adding, “The practice of medicine is to support life and maintain quality of life to the end. Views held are strongly held in the light of experience and are not a matter of conscience for the majority.” The Royal Pharmaceutical Society (ID 181033648) also believed objection should be on an “opt-in” basis as this would avoid those wishing to not participate from having to clearly signal that to colleagues. The Company Chemists’ Association (ID 181441418) also held this view, believing it may help reduce the risk of delay or refusal to supply medicine due to beliefs.

Some respondents also stressed the need for it to be possible for someone to change their mind either way (someone who previously objected no longer doing so, and vice-versa).

Dignity in Dying Scotland (ID 181277811) offered views on some of the practicalities involved in any objection process, stating that healthcare professionals should declare a conscientious objection as soon as a patient has made their intentions known so that patients do not have to repeat written declarations with another doctor. Its response set out how the process is done in other jurisdictions:

> “In Victoria an objecting healthcare professional is required to tell their patient that they are conscientiously objecting within seven days of the patient’s request. In Western Australia, this must be done within two days. In New Zealand an objecting healthcare professional must inform the patient that they have a conscientious objection, and tell them of their right to ask the statutory body for assisted dying for the name and contact details of a replacement medical practitioner. This is already the case in Scotland for conscientious objections to abortion.”

Other respondents also made references to the laws on abortion and equivalent conscientious objection provision, with references made to section 4 of the Abortion Act 1967.

The Society for the Protection of Unborn Children (non-Smart Survey, response 13,994) did not think the Scottish Parliament would be able to legislate to provide for conscientious objection as the issue was reserved to the UK Parliament. It added that, as a result, no reassurance could be given on issues such as who would be able to object (including whether organisations would be able to object)[27].

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[27] The consultation responses are available at: https://www.assisteddying.scot/.

### *Potential consequences of conscientious objection*

Many responses acknowledged the potential tension between allowing full conscientious objection for all involved and ensuring that a patient's wish for an assisted death was fulfilled and not prevented or delayed as a result. Some respondents pointed to the Human Fertilisation and Embryology Authority Code of Practice[28] (and the Human Fertilisation and Embryology Act 1990[29]) as a potential basis for a similar assisted dying process of objection, with some believing that an appropriate balance between individual conscience and patients' rights could be achieved by limiting objection to involvement in the specific process only and not in pre-or post-care. The National Secular Society (non-Smart Survey, response 13,986) summarised the thoughts of many respondents, stating: "It is vital that facilitating conscientious objection is not applied so broadly that patients seeking lawful assisted dying are inhibited from making this choice due to the personal objections of healthcare professionals."

Some highlighted that this could be a particular issue in rural and/or remote areas, where there may be a lower number of available attending doctors and other personnel. Some respondents thought if there were not enough available doctors to meet demand, then use could be made of retired doctors and that assessments could be completed online (see, for example, the response by the academic Peter van Mill, ID 175144874). Others specifically commented in opposition to any virtual/online aspect, stressing the need for face-to-face assessment for such an important process (see, as examples, The Christian Institute, ID 181545444, and the individual response by Alexander James MacInnes, ID 181468017).

An individual academic, Dr John Walley (ID 181436992) thought the potential tension between objections and service delivery should be directly addressed in the proposed Bill:

> "If this isn't considered in the Bill it is likely that there will be implicit or explicit pressure brought to bear on the local health care professionals to provide a service that they object to. I can also imagine a situation when external support may be required in organisations such as hospices, where the majority of staff may be determined to help a person under their care, but not to assist in their dying. I would therefore suggest regional services to be set up to provide the assessment and delivery of assisted dying."

One anonymous physician (ID 181265688) thought (based on a British Medical Association survey) that doctors who work with patients eligible to request an assisted death were more likely to object, whereas doctors supporting assisted death were more likely to work in other areas of medicine, and not with assisted death patients. The response raised concerns that a

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[28] Human Fertilisation and Embryology Authority Code of Practice (9th edition). Available at: [Read the Code of Practice | HFEA](). 
[29] Human Fertilisation and Embryology Act 1990 (c.37). Available at: [Human Fertilisation and Embryology Act 1990 (legislation.gov.uk)]().

patient could be too frail to move from a hospital department or hospice staffed by people who did not want to participate, resulting in either a patient’s wish not being honoured, or staff having to participate against their wishes. The respondent feared that healthcare workers or organisations could be prosecuted for not fulfilling a person’s wish for an assisted death, adding, “It must be made law that no individual and no organisation can be prosecuted for refusing to facilitate an assisted death.”

Community Pharmacy Scotland (ID 181270061) highlighted potential continuity of care issues that may result from a pharmacist previously involved with a patient’s care then not taking part in the assisted dying process as a result of a conscientious objection. It noted that handing over to another pharmacist could present availability challenges, particularly in remote and rural areas, and lead to delays.

Many respondents questioned who would have access to the information (whether opt-in or opt-out) about who would/would not take part in assisted death, with some suggesting that the information must be private and accessed only on a professional need to know basis. Frequent concern was expressed about the potential consequences for those choosing not to participate (such as lack of promotion opportunities, or even people losing their jobs). The Black British Human Rights Watch (ID 180920844) stated:

> “We have seen cases where those who "oppose" an enacted 'law', are themselves, persecuted, sacked, vilified, and run out of town, as 'non-co-operators’. I presume, this would place individuals in the unenviable position, of being laid open to legal prosecution, charges, fines and imprisonment, for something they genuinely object to for moral, ethical or religious reason.”

The Company Chemists’ Association (ID 181441418) felt there was a risk, should any information about those objecting be made public, that individuals could be targeted by campaigners and called for the process to take account of that risk. Some individual healthcare professionals also commented on this issue. Dr Joan R S McDowell (ID 181443685) believed consultation would be needed with all professional bodies and noted that there are very few situations where a nurse can conscientiously object (assisting with a termination and medical electroconvulsive therapy are given as examples) and that as nurses often work in teams, pressure is often applied by colleagues to participate if an objection is raised. The response adds, “to conscientiously object, in nursing, is actually very difficult and this bill would make things even worse. It would divide a work force and cause untold damage within nursing teams.” An individual academic, June Rose Reid (ID 175132781) called for specific support for junior doctors as the hierarchy of medical staff could make junior staff wishing to make a conscientious objection vulnerable to either having to participate against their wishes or risk career damage by objecting when senior colleagues may not.

### *Referral*

An issue amongst some respondents was whether an attending doctor who steps aside as a result of conscientious objection should be required to refer the patient on to another, willing, doctor. A majority of respondents commenting on this topic believed that a referral should be made in such circumstances (mostly those who supported the proposal as a whole) and were concerned that failure to do so may deny a person their right to an assisted death. Many were of the view that it is currently possible for doctors to opt out of carrying out abortion procedures but that any such objecting doctors must refer the patient on to another physician. Those who believed such a referral should not be made (mostly those opposed to the overall proposal) believed doing so would render any conscientious objection null and void, as the doctor would still be assisting in the process.

Those who believed a referral must be made included the Humanist Society Scotland (ID 181336267), which stressed that any objection process cannot block a person's right to an assisted death and that clear referral pathways would be needed. The response suggested that equivalent processes in abortion law, and related experience, would be useful in guiding the process for assisted dying. Dignity in Dying Scotland (ID 181277811) agreed, and stated that there was already guidance on objection provided by the General Medical Council and the British Medical Association, adding: "We believe that the objecting healthcare professional should make a referral to another healthcare professional who is willing to be involved in the process to prevent unnecessary stress and harm to the patient."

The British Medical Association Scotland (non-Smart Survey, response 14,034) stated in its submission:

> "In the event of a change in the law, we would expect that clinicians would share relevant clinical information and background as required by GMC Good Medical Practice. They must, however, have the right to conscientiously object to prescribing life-ending medications."

Many individuals also supported an objecting doctor being required to refer a patient on to a non-objecting doctor. Examples include:

> Individual respondent Samuel Wood (ID 181506693): "If healthcare professionals are unwilling to provide a service that is permissible by law, they should refer to a clinician who can provide advice, referrals and the procedure itself.".
>
> Individual respondent Barry Edward Whyte, (ID 175144283): "Patients should be allowed to have the legal right to request assistance from Healthcare Professionals, but only if the Bill has been implemented in Legislation and binding in Law, and a referral to another consenting doctor should be made if the initial doctor has declined permission".

Three academics, Professor Liz Wicks, Dr Clark Hobson, Dr Nataly Papadopoulou, in a joint response (ID 181564982) recommended that the proposed Bill includes a requirement to refer, adding:

> "While it is acknowledged that this act of referral itself may force a doctor to act against his or her conscience, it is a proportionate interference with the right to act in accordance with their conscience in order to protect the autonomous choice of the patient."

Among those arguing against a requirement to refer were the Association for Palliative Medicine of Great Britain and Ireland (ID 181553173) which stated that, "Full conscientious objection would be the ability to decline any involvement in the process including any suggestion of ongoing referral". The British Islamic Medical Association (ID 181527386) agreed, stating that requiring referral would not, "adequately respect the moral and spiritual concerns of the objecting doctor", adding, "For Muslim professionals in particular, it is impossible to reconcile a bill which enforces someone to be any way complicit with hastening of death with their fundamental religious belief of protecting life." Some individual professionals stated that objecting should also mean not referring. Dr James Haslam (ID 180927996) stated:

> "I am a doctor passionately opposed to physician-assisted suicide and euthanasia. I want nothing to do with it and would conscientiously object to any involvement whatsoever - including mentioning it to patients as an option, (effectively) referring then to a willing colleague, or participating in any related assessments, reporting, prescribing, and administering. All these actions constitute complicity and would cause me moral injury to engage in."

# Financial implications

**Question 7: Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to: a significant increase in costs / some increase in costs / no overall change in costs / some reduction in costs / a significant reduction in costs / don't know. Please indicate where you would expect the impact identified to fall (including public sector bodies, businesses and individuals etc).**

**You may also wish to suggest ways in which the aims of the Bill could be delivered more cost-effectively.**[30]

13,119 respondents (93.5% of the total) answered this question, including 67 of the 81 organisations that responded to the consultation. Roughly a third (33.5%) were unsure of the cost implications, and a further approximate third

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[30] Please note, as is explained in section 1 of this document, that this is a standard question that Members are advised to include in consultation documents by the Non-Government Bills Unit in order to ensure views on the potential financial impacts of any proposed legislation are gathered.

thought there would be a reduction in costs (17% thought there would be a slight reduction, and 16% predicted a significant reduction). The final third was split between 16% of respondents that predicted no overall change in costs, and 18% that thought there would be an increase in costs (13.5% thought there would be some increase, and 4.25% thought there would be a significant increase).

Most comments made in answer to this question were broad, rather specifically on costing elements, and tended to fall into one of two camps. Firstly, a significant number of people thought it was inappropriate for a question on costs and funding to be asked at all (mostly those supportive of the proposal as a whole), as they felt the issue of assisted dying is too important and sensitive to depend in any way on cost implications (see section 1 and footnote 30). A second broad group of respondents (mostly those opposed to the proposal as a whole) were deeply concerned (with some respondents expressing very strong views) that the proposal was being founded on financial grounds, and that either a primary or additional reason for proposing the Bill was to save money.

When answering question five about a body being responsible for reporting and collecting data, and whether that should be an existing or new body, some respondents who thought it should be an existing body cited cost saving as a reason for preferring that option, noting that establishing a new body would inevitably involve greater additional cost.

### *Increase in costs*

A minority of respondents thought the proposal would lead to an increase in costs. Some respondents thought costs would increase for public sector bodies, because the NHS would cover the costs of assisted death, or for individuals, as they thought the individual terminally ill person would or should be responsible for costs or may face increased insurance costs. Of those who thought the NHS would cover the costs, some thought that any money spent on assisted death would be better spent on other areas of the NHS, or on palliative care. Some thought costs would increase in the short term but would reduce over the medium to long term due to fewer people needing care for as long a period.

Among reasons given by those who thought costs to the NHS and other health care organisations would increase were factors such as: the cost of the end of life medication; staff training costs; potential additional staff required to meet demand as a result of conscientious objection and/or other pressures on the NHS; increase in demand and provision of mental health services; potential legal/court costs (for alleged abuses of the system); cost of producing required guidance; increased insurance costs; data collection and record keeping costs.

Examples included:

- the Royal College of Physicians and Surgeons of Glasgow (non-Smart Survey, response 14,017) stated: “Financial costs of developing a system are not discussed in the proposal. The resources to provide this service may need to be found and could be significant. No mention is made of the educational and continuing professional development needs of staff and cost of oversight of the system. They may be better spent on providing better palliative care”;
- the Royal Pharmaceutical Society (ID 181033648) believed there would be some increase in costs due to the training required for pharmacists and costs in implementing any conscientious objection process;
- Scottish Care (ID 181554943) believed the proposal would result in new expenditure which would negatively impact on the required investment in palliative and end of life care;
- Living and Dying Well (ID 181443000) believed a combination of current extreme pressure on the NHS and the likely number of healthcare professionals who would refuse to participate would lead to a substantial increase in costs. It also noted that there would need to be a substantial increase in palliative care funding if access to palliative care is to be guaranteed before an assisted death can be requested;
- some individual respondents who fully supported the proposal thought there would be a variety of increased costs. See as an example Brian Kerr (ID 181346759), who believed costs increases could include: funding a new public body; additional work and training for healthcare professionals and staff; and public information campaigns, and believed the costs could not be met by existing budgets and that savings would not be made as a result of the proposal coming into force;
- some individual respondents thought that assisted dying should be available both on the NHS and via private providers (note that the consultation document made no specific proposal on this) (see as an example the response by Sarah Conlon, ID 176014056).

### *Reduction in costs*

Roughly a third of those who answered this question thought there would be a reduction in costs, although slightly more thought there would be some reduction (16.73%) than a significant reduction (15.87%). This includes a reasonable split of those supportive and opposed to the proposal and seemed mainly based on a belief that each person who chooses an assisted death will mean less money is required for their care, therefore saving various costs for public sector organisations (including pensions), businesses and individuals. Many such respondents noted this was likely, but that financial reasons are not why they support the proposal (if they do) and/or should not be a factor in deciding to progress the proposal.

Many individuals detailed personal experience, such as anonymous individual (ID 175118889): “The cost of maintaining my husband's health in this last 6 years was enormous and we were literally just struggling to keep him alive minute by minute when he didn't have a life”. Others expressed views on the cost of maintaining life, such as anonymous individual (ID 175128972): “Keeping people alive, in ITU, in Hospice, on mechanical ventilation at home, medications, professional care interventions are expensive, there must be a massive cost savings if such intervention is sooner rather than later. This can financially benefit all sectors, NHS, voluntary, social care, social security, pharmaceutical, family finances, workforce, local authority etc”. Others noted that savings would also be made as a result of terminally ill people, and their friends/families, no longer travelling abroad to have an assisted death (see as an example the individual response by Derek Watson, ID 175145755).

Many respondents opposed to the proposal thought there would be a reduction in costs for the reasons already covered and expressed concern that saving money may be a factor driving the promotion of the proposal. Some also stated that some terminally ill people may feel and/or be pressured into opting for an assisted death for financial reasons, such as by family members who would benefit financially as a result, or by the organisations/professionals (or even wider society) providing for their treatment and care. Examples include anonymous individual (ID 177905181): “There is no doubt in my mind that ending the life of a sick person will be much cheaper than providing the necessary care to support them. From the perspective of the state, this may appear a great incentive to legalise assisted death – you should not put a cost on a human life…”
The joint response by Care not Killing and Our Duty of Care (non-Smart Survey, response 14,023) stated:

> “Legalising and facilitating assisted suicide as a treatment option makes the lethal option the cheapest one, and in so doing cheapens every life deemed eligible. Mr McArthur should acknowledge this point about the danger of cost savings becoming a motivation for people seeking assisted suicides and/or a subtle pressure which becomes applied on healthcare professionals to acquiesce to such requests.”

Many respondents opposed to the proposal and who thought costs would reduce thought there was a financial motive behind the proposal and highlighted a footnote in the consultation document (in the section on potential resource implications) which set out the results of a cost analysis conducted in Canada which showed potential savings in health care costs as a result of assisted dying[31] (see section 1 of this document, and the introduction to the summary of this question, which explain that estimating the potential financial impact in the consultation document for a proposal for a Member’s Bill in the Scottish Parliament is standard practice). Some thought money would be saved as a result of people being assisted to die, rather than taking their own lives, such as costs of police investigations, autopsies and possible prosecutions.

Other views expressed included that assisted dying may be encouraged to save money, due to the pressures brought by a growing and ageing

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[31] See footnote 124 on page 28 of the consultation document: Assisted Dying Consultation 2021 - FINAL (parliament.scot).

population and financial challenges. Anonymous individual (ID 181576353), stated:

> “This would be viewed as a cost saving measure by NHS and people would be pressured to take their lives like what happened in the pandemic and DNRs. This would be shameful if Scotland killed its people to save money rather than investing and valuing palliative care”.

### ***No change in costs***

Sixteen percent of those that responded to this question thought there would be no notable change in costs as a result of the proposal. The vast majority who answered this way were fully supportive of the overall proposal. Of those who explained their reasons for their answer, it seems that many of the fundamental views were the same as those advanced by those who thought there would be either an increase or reduction in costs, with the difference being that this group of respondents concluded that the likely increase in costs (due to the costs of introducing assisted dying such as guidance, training, supply of medicine, collecting and reporting data and establishing a body to be responsible etc.) would be balanced by a reduction in costs (due to people dying earlier than they otherwise would).

Some thought the likely number of people opting for an assisted death would be low, meaning that any costs were likely to be marginal and therefore effectively cost neutral. Friends at the End (ID 181246325) touched on many of these points in its response, explaining why it thought there would be no overall change in costs as follows:

> “We envisage this service being offered to patients for free as part of the NHS. There would, therefore, undoubtedly be a cost to the NHS in setting up the service, training up healthcare professionals to deliver the service, and either setting up a new regulatory body or putting resources into a pre-existing governing body to monitor the service. On the other hand, there might be a potential cost saving to the NHS as the patient would not require ongoing palliative or hospice care. The number of people accessing assisted dying would likely be small, perhaps 100 a year in Scotland, and so any costs are also likely to be small.”

This was echoed by the organisation My Death, My Decision (ID 181513253), which acknowledged that there would be additional spending, particularly when developing and beginning the new process (such as training, implementation of new systems, and provision of educational material) but thought that this would be balanced by some people living in a care home or hospice setting and receiving a great deal of palliative care deciding to have an assisted death. Many of the individuals who answered this way also echoed these views. As an example, one individual, Christine Shepherdson (ID 181400014), stated, “I think the additional costs of administering the scheme will be offset by the reduction in end of life care costs for those who are being forced to live when they don't want to.”

Many respondents stated their belief that experience in other jurisdictions had shown assisted dying could be operated without incurring additional costs. See as examples the individual response by Caroline Smith (ID 181281281), who stated: “I think that any potential increases in costs would be offset by decreased expense in other areas as has been the case in other countries where assisted dying has been legalised”, and the individual response by Diane Vallar (ID 175237013), who stated: “Countries where assisted dying is [in place] apparently have reported that their schemes have been 'cost neutral'. We could learn from their experiences and develop our own system accordingly.”.

### ***Those unsure and other comments***

Roughly a third of those who answered this question (33.54%) didn’t know what the cost implications would be, with most repeating views already set out. Some who answered this way made more general comments about funding issues.

The Association of British Insurers (ID 181478295) gave views on how the insurance sector may respond to the introduction of assisted dying (note that some respondents suggested that insurance costs may rise, or insurance policies become untenable, as a result of the proposal), and concluded:

> “… insurers will continue to assess claims on a case-by-case basis and if the safeguards proposed in the Bill are upheld, there should be no significant impact on the majority of life insurance policies. The ABI has not investigated or considered the cost implications for organisations beyond the life insurance industry.”

The Neurological Alliance of Scotland (ID 181560705) and Parkinson’s UK Scotland (ID 181559748) were among the organisations stating that end of life decisions should not be made on the basis of saving money, whether for individuals or organisations.

The Scottish Partnership for Palliative Care (ID 181456887) gave no tick box response but did comment, stating that access to high quality palliative care was vital and that increased funding was required and should be factored into resource implications for the provisions of assisted dying and included in the Financial Memorandum accompanying any Bill introduced. It also stated:

> “As part of any implementation of an Assisted Dying Act resources should be allocated to support a programme of research into the impacts on public attitudes and behaviours, the impacts on provision of mainstream care received towards the end of life, the experiences of people and their families, of staff involved and other relevant and emergent issues.”

# Equalities

**Question 8: What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation? (Positive / Slightly positive / Neutral (neither positive nor negative) / Slightly negative / Negative / Unsure).**

**Please explain the reasons for your response. Where any negative impacts are identified, you may also wish to suggest ways in which these could be minimised or avoided.**[32]

13,366 respondents (95% of the total) answered this question, including 70 of the 81 organisations that responded to the consultation. Roughly a third thought there would be a positive impact (29.5% thought a positive impact, and 4% thought a slightly positive impact), and roughly a third thought there would be a neutral impact (33%). The remaining third was split between those who thought there would be a negative impact (19% predicted a negative impact with 1% predicting a slightly negative impact) and those who were unsure (14%).

A significant number of comments were made about people with specific protected characteristics (particular in relation to age, disability, and religion and belief). The summary therefore first summarises broad reasons why respondents thought there may be a positive, negative, or neutral impact, and then sets out in more detail predicted impacts on specific protected characteristics.

### *Positive impact*

Roughly a third of respondents to this question thought the proposal would have a positive impact on equality. The vast majority of those were also fully supportive of the overall proposal. Many who explained the reason for their answer repeated views previously made in support of the proposal and thought that the freedom to choose an assisted death that the proposal would give to terminally ill adults would be fairer, and more equal, than the current situation of assisted death not being permitted. Many stated that every individual should have the right to decide for themselves if they wished to live or die. One individual, Morag Price (ID 181569483), stated:

> “This should have a positive impact on the basis of rights for the individual conscience. Religious beliefs should never be accepted as grounds for objection to legislation. The right to freedom of conscience, the right to not choose an assisted death will remain a protected

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[32] Please note, as is explained in section 1 of this document, that this is a standard question that Members are advised to include in consultation documents by the Non-Government Bills Unit in order to ensure views on the potential impacts on equalities, and people with protected characteristics, of any proposed legislation are gathered.

> characteristic. I am aware that some disabled people have concerns that they would be coerced into this. As a disabled person I do not share those concerns and I am more concerned that I will be coerced to continue living at the point where I know death is imminent and have no control of where and when I die."

Dignity in Dying Scotland (ID 181277811) stated:

> "The overall impact of the proposed Bill on equality will be positive. Everyone will benefit from having more choice available to them at the end of life. Everyone will benefit from being able to have open and honest conversations with their healthcare professionals about their wishes and fears for the end of their lives. This Bill will provide peace of mind for dying people and their loved ones, no matter how many people make use of the law. There will be no disproportionate impact on any of the protected characteristic groups outlined in the Equality Act 2010."

Other general views expressed about why the proposal would have a positive impact on equality included that it would:

- be available equally to all terminally ill people, regardless of protected characteristic (note however that the proposal is restricted to adults (those aged 16 and over)) (see as an example the individual response by Helen Stevenson, ID 175145116);
- improve the rights for some protected groups by allowing them access to assisted death (sparing them pain, suffering and indignity) (see as an example the individual response by S Brown, ID 175788841);
- tackle the current inequality of religious groups and individuals unfairly imposing their views on others (see as an example the individual response by Rob Wherrett, ID 176016383);
- address the economic inequality of only the wealthy being able to afford to travel abroad for an assisted death (see as an example the individual response by Bill Willard, ID 181401870); and
- positively address sex inequality as a higher proportion of carers are women (see as an example the individual response by Linda Stewart, ID 181255861).

The BSL respondent stated it was important that non-English speakers were not disadvantaged and that all relevant materials must be available in BSL and other languages and formats to ensure maximum accessibility. The response also noted that BSL interpreters would have an important and sensitive role in conveying life and death information.

Of those who thought there would be a slightly positive impact, it was often the case that some of these views were balanced with various concerns (for example, about the views of and/or impact on people within vulnerable groups, such as people with a disability or older people – see for example the individual response by Jonathan Stokes, ID 180050488).

### *Negative impact*

Twenty percent of respondents to this question thought the proposal would have a negative (19%) or slightly negative (1%) impact on equality. The vast majority who answered that way were fully opposed to the proposal as a whole. Many who explained the reasons for their response repeated arguments made under previous questions for their opposition to the wider proposal. Others noted that they believed the proposed Bill would have a negative impact on the most vulnerable people in society, particularly older people and people with a disability (including those who were not terminally ill) because they would feel their lives were not valued and, if terminally ill, be pressured and/or be coerced into choosing an assisted death. Some also felt it would have a negative impact on the protected characteristic of religion or belief, as many such people are fundamentally opposed to assisted death (see as an example the individual response by Connor Stephen, ID 176243107).

The following comment from an anonymous individual (ID 177963485), was echoed in a number of other responses: “If enacted, it would be understood by some as sending a clear signal from the Scottish Parliament into the whole of society that certain lives were of less value, and no longer worth living.” Some felt the proposal would have a negative effect on equality because not everyone would be eligible (see comment on eligibility elsewhere in this document). Comments included that it was discriminatory on the basis of age, as only terminally ill adults aged 16 or over would have access to assisted dying (see as an example the individual response by Jane Martin, ID 179934815), and that it discriminated generally on the basis of medical condition, as only people deemed to be terminally ill would be eligible. DIGNITAS (ID 181537153) thought the proposal would have a neutral impact on equality but commented on the issue of discrimination in eligibility, stating:

> “To only allow access to assisted dying for individuals who are terminally ill (as defined in the consultation document) is to discriminate against individuals who suffer from health conditions that are, by medical opinion, not “progressive” and “reasonably expected to cause death … DIGNITAS suggests that the proposed Bill adopts eligibility criteria that do not give precedence to what some doctors judge about suffering of their patient, but rather to focus on the personal experience / point of view of the individual/patient …”

Some respondents thought the proposal, if enacted, would bring equality in death without addressing equality in life. The Scottish Partnership for Palliative Care (ID 181456887), which gave no specific view on this question, stated: “The proposed legislation would create an explicit legal right to an assisted death, but as things stand there would be no corresponding explicit right to palliative care in Scotland.”

Few respondents (whether they thought there would be a positive, negative, or neutral impact) set out how any negative impacts could be mitigated (other than by not proceeding with the proposal). Some thought mitigation could be achieved by strict adherence to the safeguards together with education programmes and information and awareness raising campaigns (for example, anonymous individual respondent ID 175431739).

### *Neutral impact and those unsure*

Roughly a third of respondents (33%) thought the proposal would have a neutral impact (neither positive nor negative) on equality. Of those that explained the reasons for their response, most noted that terminal illness can happen to anyone, regardless of protected characteristics, and that the proposed policy will provide equal access to assisted death for all competent terminally ill adults that wish it. Some appeared to have selected this option as they were not sure what the impact may be, while others noted that they thought the question was irrelevant. Others noted that some with a protected characteristic, such as some with a particular religion or faith, may choose not to request an assisted death because of their belief, but noted that this demonstrated the choice that all would have.

Fourteen percent of respondents were unsure of the likely impact of the proposed Bill on equality. Of those who explained the reasons for their answer, many noted that they did not feel suitably qualified, experienced and/or knowledgeable to answer the question, while others noted that they did not understand either the relevance of the question, or what the question was asking. Others noted that, while they had answered ‘unsure’ they did not think the proposed Bill would have any negative impact on equality or any of the protected characteristics.

### *Impact on people with a disability*

Three organisations specifically representing views of people with a disability (Inclusion Scotland, ID 180598455, Not Dead Yet (ID 181524112) and the Glasgow Disability Alliance, non-Smart Survey, response 14,024) were all fully opposed to the proposal and thought it would have a negative impact on equality for those with a disability. Other organisations also expressed concerns about the potential negative impacts on people with a disability (examples include Care not Killing and Our Duty of Care, non-Smart Survey, response 14,023, Society for the Protection of Unborn Children, non-Smart Survey, response 13,994, and The Free Church of Scotland, ID 180245159). There were mixed views amongst individual respondents, including those disabled people who responded, with some thinking the proposal would have a positive impact on disabled people, and some a negative, or potentially negative, impact.

The main reasons given by those who thought there would be a negative impact on people with a disability were broadly that:

- such a change in the law would lead to some people with a disability feeling their lives were not valued and/or that they were a burden on those around them (a number of respondents cited the Covid pandemic as highlighting why vulnerable people need greater protection);

- the proposal, if enacted, would make some people with a disability fear that the law may be extended (as some believe it has been in other countries and jurisdictions) over time, and/or eligibility criteria widened, and safeguards reduced.

The Glasgow Disability Alliance (non-Smart Survey, response 14,024) stated that research it has carried out, and research by other organisations representing people with disabilities, shows that disabled people are experiencing “supercharged inequalities” as a result of the Covid pandemic. It noted that even before the pandemic, the UN declared the experiences of disabled people as a “human catastrophe”, and that facing discrimination, abuse, hostility and poverty are daily experiences for many disabled people. It added:

> “Increased pressure to opt for Assisted Suicide is a real and present fear for many disabled people…Until we address the Supercharged barriers and inequality disabled people face, bringing forward such legislation is entirely against everything the Scottish Government stands for. We do not feel the proposed Bill is compatible with A Fairer Scotland for Disabled People and the incorporation of the UNCRPD … Our view is that until disabled people have equal access to their rights, it is unjust to bring forward this proposed legislation. Scotland must learn from the negative impacts from every other country, state and province that has enacted similar legislation.”

Inclusion Scotland (ID 180598455) also made reference to “supercharged inequalities” caused by the Covid pandemic, highlighting the lack of value placed upon disabled people’s lives, and lack of access to treatment and care, concluding that “we believe that this can be viewed as the worst time in history to propose legislation to enable assisted suicide. The Bill proposed is not safe and is being introduced at a precarious uncertain and dangerous time for disabled people.”

Views were also expressed by individuals, including some personal accounts from disabled people who asked for their responses not to be published. One example of these unpublished responses stated that consultations such as these made the respondent feel they should take the easy way out rather than trying to live. Another, the carer of a child with disabilities, feared that, should the proposal become law, that such people would be viewed as contributing less to society, and a financial burden and felt the proposal was a threat to disabled people.

There were also accounts by disabled people who thought the proposal would have a positive or neutral effect on disabled people. Examples included:

> Anonymous individual (ID 175920411): “As a disabled person, I would like to see greater choice - but the key issue here is autonomy. everyone can make choices about their lives and they should be allowed to make decisions about how and when to end their life.”

> Alison Joanna Saunders, (ID 179919958): “As a physically disabled person I see no impacts on equality - if the process is applied equally across all folks there is no issue. I think the arguments I have heard that disabled people will be put under more pressure by carers to end their life is spurious as the requirement to have a terminal illness & poor quality of life is something separate & outside of the disability issue & the options would be discussed to give the carers more support if that is an issue.”
>
> Miss Charlie Boyd, (ID 175213348): “I believe this would be hugely positive for elderly and disabled people, as they are very often overlooked in society. They are frequently forced to suffer in silence as their world grows smaller and their pain and suffering increases over time.”

Other respondents thought that, due to the proposed safeguards, the proposal would not expose disabled people to any increased risk. Ben Colburn, an academic at the University of Glasgow, explained that he has carried out academic research into how assisted dying laws might affect vulnerable people, including people with disabilities[33], and stated:

> “My findings have been that there is no evidence that people with disabilities (or vulnerable people) are disproportionately affected or imperiled by assisted dying laws. It is also clear that some (but not all) people are nevertheless concerned about those vulnerabilities. I think the safeguards set out [in the consultation document] will do an excellent job of assuaging those concerns.”

Dignity in Dying Scotland (ID 181277811) stated:

> “Systematic reviews have examined the uptake of assisted dying amongst vulnerable people, including people with disabilities. One concluded that the hypothesis that people with disabilities might be disproportionately impacted ‘does not seem to be borne out’, and that ‘in no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than in the general population... data do not indicate widespread abuses of these practices.’ Disability Rights Oregon, an organisation committed to protecting Oregonians living with disabilities, has never received a complaint of abuse or attempted abuse under Oregon’s law.”

The Humanist Society Scotland (ID 181336267) agreed that there is no data to support claims that people with disabilities have been disproportionality impacted in other parts of the world that have legalised assisted dying. It also felt that the proposal would increase choice and control for disabled terminally

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[33] Ben Colburn, Disability and Assisted Dying Laws Policy Briefing (Glasgow: Policy Scotland, 2021). Available at: https://policyscotland.gla.ac.uk/wp-content/uploads/2021/09/PolicyBriefingDisabilityAndAssistedDyingLaws.pdf.

ill adults and would be equally applied to disabled and non-disabled people. It added: “An argument simply on the basis of a ‘slippery slope’ is a bad faith argument given there is no legitimate opposition to the proposals for terminally ill people.” Community Pharmacy Scotland (ID 181270061) believed that most people in Scotland with a disability were supportive of legalising assisted dying for terminally ill people and noted that having a disability would not make someone eligible for an assisted death under the terms of the proposal – only a terminally ill competent adult with a disability would be eligible.

Some other points were raised in responses, such as potential challenges and/or discrimination people with disabilities may face with some of the specific aspects of the proposal. These points have been highlighted in the summaries of responses to other questions, and broadly focused on:

- ensuring that people with additional support needs and/or learning difficulties did not face insurmountable barriers in trying to access assisted dying;
- the proposal potentially discriminating against those who are not deemed to be terminally ill, but who may have a debilitating condition and a very poor quality of life; and
- the issue of potential discrimination against people whose disability meant they were unable to self-administer the medication, as proposed.

### *Impact on younger and older people*

Many respondents thought there would be a positive impact on older people, such as the Community Pharmacy Scotland (ID 181270061) and the Humanist Society Scotland (ID 181336267), which believed that a higher proportion of terminally ill people in Scotland would be older people, who would have increased choice and control as a result of the proposal. Many individuals echoed these comments, for example, Owen Kane (ID 181196152): “It will be positive for older people who are more likely to be diagnosed with a terminal illness”, and Sarah Driver, (ID 181256162): “I believe that this will have a positive impact on equality when it comes to age in particular. Too often the views of older people are dismissed and ignored whereas now they will have a voice when facing a terminal illness.”
Other respondents thought there would be a disproportionately negative impact on older people, as more older people are likely to be diagnosed with a terminal illness. The organisation Living and Dying Well (ID 181443000) was one of several respondents that highlighted the potential for elder abuse, with what appears to be a decision taken by an older person of their own free will actually resulting from pressure and/or coercion and feeling a burden to those around them. Several respondents believed that older people were more susceptible to persuasion, and more likely to be vulnerable. The organisation Christian Concern noted:

> “Discrimination on grounds of age is an obvious risk with any legislation to bring in assisted suicide. Discrimination against older people is likely

> to increase, especially those who are retired and no longer earning an income from work. Those older people living alone are much more vulnerable to subtle pressures to succumb to assisted suicide."

Some respondents thought the proposal was discriminatory on the grounds of age, as those under 16 were excluded. Some thought that children under the age of 16 should have access to assisted dying, with some respondents suggesting that parents and carers should have a decision-making role if a child wished to have an assisted death. Eithne Greenshields (ID 180121066), stated: "I think there may be some children who wish to end their lives to ease their pain and may have the mental capacity to do so. I think they should be able to do this if they are mature enough to decide" and anonymous respondent, (ID 181226067), stated: "I don't believe there should be any age restrictions. Terminal illness can strike any age group. Parents of children under the age of 18 should have the option not to see their child suffer needlessly".

Other respondents expressed concern about potential negative impacts on young people aged between 16 and 21, as assisted dying would be available to those terminally ill competent people aged 16 and over. In relation to issues of appropriate age of consent, some noted that it did not seem right to allow people aged 16 to choose an assisted death, at the same time as consideration was being given to raising the legal age of marriage due to coercion concerns. Some thought 16 was too young for eligibility (see the response by Children's Hospices Across Scotland, non-Smart Survey, response 14,022). Concerns raised included:

- diagnosis and prognosis often being harder in young people;
- some young people not having full understanding of the consequences of choosing an assisted death;
- young people being denied the same access to assisted dying due to unconscious age bias;
- young people being more susceptible to influence from adults (including family members);
- young people can metabolise medicine and may therefore not react to medication intended to end life in the same way as older people;
- there are things that the law does not permit people to do at various young ages (16-21) for legal and practical reasons, despite that being the age of majority in Scotland, and consideration must be given to that in the context of assisted dying.

### *Impact on religion or belief*

There were strong, mixed, views expressed about the impact of the proposal on people with a particular religion or belief. Many of those supportive of the proposal thought that the proposal was based on individual choice and therefore would not discriminate against anyone's religion or belief. Many such responses also believed that some religious groups and individuals had had a disproportionate influence on the wider societal debate on assisted dying and were seeking to impose their own beliefs on people who did not share them. One individual, Cathy Otty (ID 178514152), stated:

> "Currently non-religious people's choices are being impacted by a religious belief / value that assisted dying is against god. It is not fair for those who believe otherwise to have to suffer at the end of their lives."

Those sentiments were echoed in many other responses (also see the response by the National Secular Society, quoted in the 'Sustainability' section). Some suggested that this was a form of discrimination by religious groups/people on secular people or others who do not share their view). One anonymous individual (see Easy Read response 7) was one of many respondents setting out concerns that some people with religious views are forcing their own views and opinions on those who don't share them which is not fair or equal – believing that they don't have to take advantage of assisted dying themselves but are intent on stopping others from doing so. This view was echoed by the organisation, Christians Supporting Choice for Voluntary Assisted Dying (Australia) (ID 181215529), which stated that the beliefs of someone opposed to assisted dying should not take precedence over the beliefs of someone that is supportive.

Many of those opposed to the proposal cited their own religion or belief and stated that the proposal would directly contradict that. Some were concerned that individuals with a religion or belief who were expected to be part of the process would not be able to opt-out by claiming a right to statutory conscientious objection in law. This included concern that organisations, such as a hospice or care home operated by a particular religious group, would not be able to opt-out and would therefore be forced to participate in a practice contrary to their own religion or belief. The views of the British Islamic Medical Association (ID 181527386) were echoed by other respondents in relation to their own particular religion or belief:

> "… the legislation actively discriminates against Muslim professionals and other professionals who consciously object. For Muslims in particular the bill will compel them to choose between their profession and their fundamental beliefs."

### *Impact on pregnancy and maternity*

Several responses believed that a pregnant person should not be permitted to choose an assisted death. The Apostolic Church UK in Scotland (ID 181516071) commented that, "We believe the rights of the unborn child need to be taken into account as per ECHR [European Convention on Human Rights] Article 2." An individual, Elizabeth Davis (ID 175131722), believed that pregnancy would be a complicating factor, as two lives would be taken on the consent of one person, adding, "I feel that a pregnant woman who wishes to die, can only be allowed to make that decision up until the current legal time limit for an abortion. Thereafter, unless the foetus is in danger due to the person's illness or injury, a woman must endure the pregnancy and live until the baby reaches full term." Another individual, Barbara Mair (ID 175276674), questioned if a person could be denied the right to assisted death on the basis of being pregnant, and stated:

> "… I believe that a pregnant woman should be able to make that choice for herself with the caveat that if the fetus is viable it will be delivered before the medication is administered (probably surgically) and given at least the chance to live. However, if the fetus is not viable, then the decision must be solely with the woman concerned - and viability should be based on the same as the abortion laws."

### *Impact on other protected characteristics*

Comments made in relation to other protected characteristics not previously mentioned included:

- one respondent Kevin Illingworth (ID 179235821), believed that "LGBTQI[[34]] people are more adversely affected by mental health issues and may be pushed down this disgusting route";
- a small number of respondents were of the view that assisted dying was largely supported by white people and was a disproportionate threat to other races and ethnic minority groups. One individual, Catherine Waterhouse (ID 179477499), stated: "Assisted suicide is particularly dangerous for marginalised groups. Assisted suicide proponents have been characterised as the ''white, well-off, worried, and well'', who fail to understand the disproportionate impact of an option of assisted suicide upon people who are socially marginalised and whose limited options for genuine care and support seriously limit their autonomous choices.";
- the Anscombe Bioethics Centre (ID 181564621) stated its belief that in other jurisdictions where assisted dying is legal, eligibility has been extended to include those with gender dysphoria, with a handful of cases of people citing gender reassignment as a reason for requesting, and being given, an assisted death. The responses acknowledged that the proposal would not permit such eligibility in Scotland, but, given the experience in places such as the Netherlands and Belgium, which the consultation document makes reference to, adds, "… It should be acknowledged explicitly that to encourage or assist suicide on the basis that someone has sought gender reassignment is direct and lethal discrimination against someone with a protected characteristic and the Scottish Parliament should condemn such actions unequivocally."

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[34] LGBTQI is an umbrella term used for lesbian, gay, bisexual, transgender, queer and intersex people.

## Sustainability

**Question 9: In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:**

- **living within environmental limits**
- **ensuring a strong, healthy and just society**
- **achieving a sustainable economy**
- **promoting effective, participative systems of governance**
- **ensuring policy is developed on the basis of strong scientific evidence.**

**With these principles in mind, do you consider that the Bill can be delivered sustainably? (yes / no / unsure). Please explain the reasons for your response.**[35]

13,228 respondents (94% of the total) answered this question, including 63 of the 81 organisations that responded to the consultation. A clear majority of those who answered this question (66%) thought the proposal could be delivered sustainably. 18% thought it could not be delivered sustainably, and 16% were unsure. These figures broadly mirror the overall support-opposition percentages for the proposal as a whole, with a small proportion of each being unsure.

A number of respondents, regardless of the answer provided, questioned the relevance of the question to the proposal and/or indicated that it was not clear or easily understandable (note that, as any new law can impact on work to protect and enhance the environment, achieve a sustainable economy, and create a strong, healthy, and just society for future generations, the question is a standard question used in consultations for proposed Member's Bills in the Scottish Parliament and was not specific to this proposal). A significant number of respondents who explained the reason for their answer also repeated their particular point of view on the overall proposal. The summary below focusses on views given specifically on the issue of sustainability.

### *Proposal delivered sustainably*

66% of respondents who answered this question thought the proposed Bill could be delivered sustainably. The vast majority of which (97%) were also fully supportive of the overall proposal. Of those who commented on sustainability issues, the most common themes were:

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[35] Please note, as is explained in section 1 of this document, that this is a standard question that Members are advised to include in consultation documents by the Non-Government Bills Unit in order to ensure views on the potential impacts on sustainability of any proposed legislation are gathered.

- assisted dying for terminally ill competent adults would help to make Scotland a fairer, more just and compassionate society (see, as an example, anonymous individual response, ID 181530843);
- saving resources that would otherwise have been spent on providing care would help towards a sustainable economy (see, for example, individual respondent Nicola Toneri, ID 175142050);
- assisted dying being available in Scotland would mean reduced numbers travelling abroad to seek an assisted death, which would help Scotland live within its environmental limits (see, for example, individual respondent Bridget Howell, ID 181200562);
- being able to choose an assisted death would help to ensure more participative systems of governance (see, for example, individual respondent Lynne Elizabeth Wright, ID 181235731);
- there is strong scientific evidence, including evidence from other countries and jurisdictions, that palliative care cannot spare all terminally ill people from pain, suffering and indignity, and that assisted dying can be delivered safely and appropriately (see, for example, individual respondent Sandra Heard, ID 181406944).

Some individual responses addressed the issue of Scotland's growing and ageing population, and the potential impact on resources, for example, one anonymous individual (ID 175117405), stated, "While we are living longer, many of us will develop cancer in later life which we may not wish to be treated for and depending on age and outlook may prefer to end our lives. Having the option of assisted dying may mean that there are then more facilities for those who wish to receive treatment and for other NHS requirements." And another anonymous individual (ID 175134187), commented: "We have a ticking time bomb of an ageing population. The choice to die with dignity is one that I know many people, including myself, would appreciate. It is a matter of ethics and empathy and on a practical level, it may also ease pressures on the NHS and our care sector".

Other respondents commented on issues such as a just society and basing the proposal on scientific evidence. Dignity in Dying Scotland (ID 181277811) believed the proposal was founded on strong scientific evidence and principles of justice and democracy. The Humanist Society Scotland (ID 181336267) believed that bodily autonomy, where it has no ill effects on others, is a "building block of a just society" which the Bill would ensure is enshrined in law "from birth until death". It also stated its belief in decisions being made on the basis of reason and strong scientific evidence, which it believes is the case with assisted dying due to successful implementation in other parts of the world. It rejected concerns that the proposal would be the start of a "slippery slope" towards euthanasia of older people or those with disabilities. Friends at the End (ID 181246325) agreed that there is sufficient scientific evidence from other jurisdictions to support assisted dying and show it is safe, compassionate and dignified, adding, "This proposal enhances people's rights and therefore adds to a strong and just society. The additional costs of such a service are likely to be small and so the effects on the economy would be minimal…". The National Secular Society (non-Smart Survey, response 13,986) believed that scientific evidence should inform the proposal rather than the debate being dictated by some religious groups, stating:

> "Strong opposition to assisted dying comes from religious leaders who regard life as sacred and assisted dying as intrinsically harmful. Their views are frequently rooted in religious beliefs and scriptures rather than scientific evidence. We support the democratic right of all people to contribute to this debate. However, the over-representation of religious groups and the special status granted to religious groups currently impose a disproportionate level of influence."

### ***Proposal not sustainable***

Eighteen percent of those who answered this question thought the proposed Bill would not be able to be delivered sustainably, the vast majority of whom (96.5% of those who answered this way) were also fully opposed to the proposal as a whole.

Of those who explained the reasons for their answer, many made reference to the principle of ensuring a strong, healthy and just society, and did not think that assisted dying supported that principle. Rather some respondents believed the proposal would make Scotland less just, and a more dangerous place to live, especially for vulnerable people (with frequent mention of older people and people with disabilities). Some of those respondents, in expressing strong views, went further, and suggested that the consultation referencing the sustainability principle of "ensuring a strong and healthy society" indicated a "survival of the fittest" mentality, with physically strength being prioritised and physically weaker or sick people being considered expendable. A number of such responses referenced the policies of Nazi Germany in comparison. Others drew comparisons between the response to the Covid pandemic and the efforts made to protect the most vulnerable, and the proposal, which, in the view of some, would subject vulnerable people to pressure and send a message that their lives were not valued[36].

Comments were made by individuals, such as Jamie Dickson (ID 175122410), who stated: "I don't see how valuing death will lead to a strong, healthy and just society. In fact, I think it would have the opposite effect. It would make us less caring, it would give us a distorted view of death and it would cause injustice to be done to those who felt they ought to partake in the practice (as victims or perpetrators)", and Andrew Bathgate (ID 176391392), who commented: "As a society we have a responsibility to care for our most vulnerable people. This Bill does not, in my mind, achieve this as it suggests that some lives are not worth living. We prioritised our most vulnerable in the

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[36] As previously stated, note that, as any new law can impact on work to protect and enhance the environment, achieve a sustainable economy, and create a strong, healthy, and just society for future generations, the question on sustainability is a standard question (with standard wording) used in consultations for proposed Member's Bills in the Scottish Parliament. The question, and its wording and referencing of sustainability principles, was not specific to this proposal.

recent pandemic as an expression of a just society and this Bill does not do that.”

Several organisations also believed the proposal was not sustainable, mainly religious groups, or groups affiliated to a particular religion or belief. This included North west Pro-life (ID 181573910), which stated: “In no way does assisted dying ensure a “strong, healthy and just society” with the question having connotations of Nazi Germany which killed the disabled and infirm to create an Aryan race and it is deeply shameful to even publish such a question in a public consultation”, and the Evangelical Alliance (ID 181572890): “We have spent two years as a society protecting those who are most vulnerable and to suddenly stop this approach, far from promoting a society that is strong, healthy and just, would rather lead to one where the strong are valued over the vulnerable, the healthy valued over those who are terminally ill or disabled and one where injustice and pressure could be brought upon those who are least able to resist undue influence.”

Some respondents who thought the proposal could not be delivered sustainably highlighted the principle of ensuring the policy is developed based on strong scientific evidence and suggested that the studies and evidence presented or referenced in the consultation document were selective and/or unreliable and questioned where the strong scientific evidence to support the proposal could be found (see, as examples, individual respondent George Burt (ID 180450147), anonymous individuals (ID 180996717 and ID 181265688). Many who answered this way called for further, independent, research to be carried out and published before the proposal was progressed any further. The Royal College of Physicians of Edinburgh (non-Smart Survey, response 14,013) commented specifically on the evidence base behind the prescription of medication that may be used to end life, stating:

> “The College would like to highlight that there is no robust evidence base to inform any clinical practice regarding the prescription of lethal oral medication. The proposed Bill would require a doctor to issue a prescription for a patient with no evidence-based guidelines to support the prescribing choices. Oregon uses cocktails of up to 5 drugs and is on the 4th protocol in seven years (see Oregon 2020 DWDA report). The report acknowledges that such mixtures have resulted in more prolonged deaths.”

### *Unsure*

Sixteen percent of respondents who answered this question were unsure what the proposal’s impacts on sustainability may be. Some noted that they either didn’t see the question as relevant or didn’t fully understand it, while others did not believe they were sufficiently knowledgeable and/or qualified to give a view. Another view expressed by more than one respondent was that sustainability lessons may be able to be learned from the other countries and jurisdictions around the world that have implemented assisted dying legislation. Some who selected “unsure” noted that they found this question offensive, and that sustainability should not be a part of the debate about the merits of assisted dying.[37]

# General

**Question 10: Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?**

6,445 respondents (46% of the total) answered this question, including 58 of the 81 organisations that responded to the consultation. The majority of comments made in response to this question either stated that the respondent had nothing to add, or repeated views expressed in response to earlier questions, and/or reiterated support or opposition to the proposal as a whole. Many respondents also repeated, or provided additional, personal experiences of either living with, or supporting a loved one through, a terminal illness. The issues of palliative care (with calls for increased funding and other improvements) and eligibility (that assisted dying should be available to others, not just those deemed terminally ill) were frequently raised and are covered elsewhere in this summary. A significant number of respondents also indicated that the proposed legislation was long overdue and urged progress to be made in passing the legislation as quickly as possible, whilst a smaller number urged that the proposal should not proceed.

The summary of this question presents a selection of the most frequent comments made by respondents and of any distinct comments made that have not been covered in the summary of the previous questions and may be of interest. As is the case with the other questions, given the high number of responses, for a full account of the answers given to this question please consult the published responses[38].

### *“Assisted dying” or “assisted suicide”*

The reasons for using the term “assisted dying” rather than “assisted suicide” in the proposal for a Bill are set out on page 2 of this document. A number of respondents (both individuals and organisations) felt that using the term “assisted dying” in the title of the proposal was misleading and suggested it was about palliative care rather than ending life. Some felt the term was being used deliberately to mislead people rather than, in their view, using the more understood, and previously used, term of assisted suicide, to describe voluntarily taking your own life. Some called for the proposed Bill to be renamed, to be consistent with previous Bills in the Scottish Parliament, as an “assisted suicide” Bill. Some respondents also thought perceived public support for assisted dying could be partly explained by people not understanding that assisted dying was the same broad proposal/concept as assisted suicide. Often related to this, some respondents thought that the word “medicine” should not be used to describe the substance that will be

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[37] See footnotes 35.

[38] The consultation responses are available at: https://www.assisteddying.scot/.

used to end life, as they felt medicine was something to treat and/or cure, not to end life. Many other respondents supported the use of the term "assisted dying" rather than "assisted suicide" and felt it was a better description of a situation where people were not choosing to end a life that would otherwise expect to continue, but where they wished to die slightly sooner to be spared pain, suffering and indignity.

### ***Human rights***

The Scottish Human Rights Commission (non-Smart Survey, response 14,037) as previously stated, outlined issues relating to human rights, and the European Convention on Human Rights, in its response. It stated that:

> "The European Court of Human Rights (ECtHR) has not taken the view that the ECHR requires either the prohibition or the permission of assisted dying. The approach of the ECtHR is to recognise that domestic authorities are better placed than the Court to decide on nationally sensitive issues (this is known as the "margin of appreciation") … The ECtHR has consistently found that the right to private and family life encompasses the right to decide how and when to die, and in particular the right to avoid a distressing and undignified end to life (provided that the decision is made freely). However, it continues to recognise the margin of appreciation allowed to states to determine whether assisted dying should be permitted … If a State does criminalise assisted dying, it has an obligation to ensure that related offences are clearly defined in law, and a clear policy as to when it would, and would not, be appropriate to prosecute individuals who help others to die is indispensable."

The Scottish Council on Human Bioethics (non-Smart Survey, response 14,000) took a different view and stated its understanding that international legal instruments oppose assisted suicide. It stated:

> "Mr MacArthur indicates that a prohibition on assisted suicide may be "raising basic questions about whether it is compatible with Scotland's international obligations under the European Convention on Human Rights.[39]" However, the reverse is true since the Council of Europe Parliamentary Assembly Recommendation 1418 (1999)[40] on the Protection of the human rights and dignity of the terminally ill and the dying, which is one of the last legal texts of some substance on the issue, indicates in Article 9.c. that:
>
> > The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe

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[39] Assisted Dying for Terminally Ill Adults (Scotland) Bill Consultation, Liam McArthur MSP, Para 2.1.

[40] Council of Europe Parliamentary Assembly Recommendation 1418 (1999), Protection of the human rights and dignity of the terminally ill and the dying, http://assembly.coe.int/documents/adoptedtext/ta99/erec1418.htm.

> to respect and protect the dignity of terminally ill or dying persons in all respects by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while:
>
> i. recognising that the right to life, especially with regards to a terminally ill or dying person, is guaranteed by member states, in accordance with Article 2 of the European Convention on Human Rights which states that "no one shall be deprived of his life intentionally";
>
> ii. recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person;
>
> iii. recognising that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death."

### *Practical issues/questions*

A number of respondents asked questions or made stand-alone points about practical elements of the proposal, including:

- what medicine will be used to end life and how will it be acquired? (see as an example the response by Professor Jaideep J Pandit, ID 175383434);
- how long does the medicine take to work, and what are its precise effects? (see as an example anonymous response ID 179894135);
- would organs be able to be donated after taking an assisted dying drug? (see anonymous response 175148212);
- people should be able to sign a document in advance saying they don't ever want an assisted death (see as an example easy read response 9);
- could every person in Scotland be given the right to create an end of life plan? (see as an example anonymous response ID 179301389); and
- how will the proposal fit with Scotland's approach to 'do not resuscitate' procedures? (see as an example the individual response by Fiona Barr, ID 175249552).

### *Further consultation, research and scrutiny*

Several respondents called for either further research or further consultation (or both) to be carried out before the proposal is progressed any further. This included the Glasgow Disability Alliance (non-Smart Survey, response 14,024), which stated it:

> "… calls for disabled people's voices to be amplified in this debate – without fear of backlash and negative consequences. Many people told us they are terrified of this proposal, but also terrified to speak up as they are exhausted dealing with their day to day lives, compounded by the pandemic and its ongoing impacts. We call for safe spaces and time to put forward our concerns as individuals and as organisations, along with our DPOs [Disabled People's Organisation] colleagues across Scotland."

Some organisations that were neutral or that took no view at this stage, noted their intentions to consider and consult further with members as the proposal developed. This included the Royal College of Nursing Scotland (non-Smart Survey, response 14,032), which stated:

> "Should the Bill progress, the RCN will play an active role in any discussion around assisted dying to ensure that the nursing voice is heard. The implications of the Bill if enacted would require extensive consultation with professional bodies, regulators, patient groups and all relevant stakeholders."

And the Royal College of Psychiatrists in Scotland (ID 181554005), which stated:

> "Should this legislation be passed, the College would expect to be consulted again and could provide more detail on how the Act may work in practice in mental health settings. The Code of Practice and any documents related to the implementation of the legislation would be extremely important and the College would be happy to provide further advice at that stage."

The British Medical Association Scotland (non-Smart Survey, response 14,034) noted its concern around what it perceived as the lack of operational detail of the proposal and stated its intention to analyse and investigate the proposal over the coming months, noting that it may change its position (from neutral) as a result. Its response which also referenced and linked to two pieces of research it has carried out in recent years, including an all member survey in 2020.

Scottish Partnership for Palliative Care (ID 181456887) believed that very clear guidance and legal positions would be required for key organisations involved, such as the British Medical Association Scotland, General Pharmaceutical Council, and Nursing and Midwifery Council.

One individual respondent, Alexander Paterson (non-Smart Survey, response 13,985) offered a number of practical suggestions as a result of his experience with assisted dying as an oncologist practising in Alberta, Canada (which has a sizable Scottish community). Suggestions included that the methods of delivering assisted dying could be expanded to include intravenous methods. See the full response for details. Another individual, Professor Jaideep J Pandit (ID 175383434), a Professor of Anaesthesia at the

University of Oxford, gave a detailed response to this question which covered the types of medication that could be used, the actual process and effects of administering various different drugs, and potential alternative approaches. The full response should be consulted for details.

A small number of respondents called for the resulting Bill to be subject to a free vote in the Scottish Parliament, rather than parties being whipped to vote a certain way.[41]

### *Polling*

A number of respondents commented on the issue of public opinion polls on the issue of assisted dying. There were a mix of views, from some who pointed to recent polls which suggested a majority of people in Scotland support the introduction of assisted dying and thought this should be taken into account by MSPs, and the Parliament, when deciding on the proposal (see as an example the individual response by G H Sutherland, ID 177960304), to others who questioned the wording of the question(s) asked in polling, and whether people taking part fully understood what they were being asked (see as an example the response by The Free Church of Scotland, ID 180245159).

Some respondents thought that the issue was too complex and important to rely upon any opinion polls and believed that polls could not capture the various details and nuances involved in a satisfactory way (see as an example the individual response by Professor Katherine Sleeman, ID 181539349). Others noted they were wary of polling outcomes because such polls are often being promoted by a group with a settled and fixed viewpoint and are not therefore truly independent (see as an example the individual response by Rev Dr Donald Murray MacDonald, ID 179867405).

### *Post enactment issues*

Several respondents commented on what may be required in addition to, or after, a Bill had been passed and enacted. Issues raised included that:

- training should be provided for health care professionals involved in any part of the process (see as an example the individual response by David Gray, ID 181498477);
- the legislation should be formally reviewed (suggestions include annually and every 5 years) (see as an example anonymous response ID 175203834);
- assisted dying should not be available to those in prison or to those not normally resident in Scotland (see anonymous response ID 175207771);

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[41] There have been occasions in the Scottish Parliament, as there have been in the UK Parliament, when Members are given a free vote – i.e. they are not asked to vote a certain way by their party leaders. Free votes have traditionally been allowed on ethical issues that are seen as a matter of conscience. An example in the Scottish Parliament was the vote on passing the Marriage and Civil Partnership (Scotland) Bill in 2014.

- education programmes about terminal illness, death and assisted dying should be introduced from a young age (see as an example the individual response by Nicola Strang, ID 181445810); and
- once enacted, there should be channels established for organisations and people (professional and public) to report concerns and/or recommend improvements (see as an example anonymous response ID 175195494).

Some concern was expressed about the possibility for legal cases to result from assisted deaths and questioned what protection there would be in the proposed Bill for medical professionals involved should the family and/or friends of someone who had had an assisted death question the legitimacy of the process. Others questioned how abuses of the process would be protected in law and what role the courts may have in that (see as examples, anonymous individual respondent (ID 176180782) and Helen Thomson, (ID 175152410).

The organisation Friends at the End (ID 181246325) commented on the need for support for those involved:

> “This whole procedure will be new to everyone involved, and it will not be something which is done commonly — if there are only 100 assisted deaths in Scotland every year, a GP is unlikely to be involved more than once every 30 or so years. There does therefore need to be some sort of central and expert resource that professionals can call on for advice and help, particularly in the early years after AD becomes legal.”

The Scottish Partnership for Palliative Care (ID 181456887) stated that should an assisted dying bill be passed, then the Scottish Parliament must ensure that “it also places an explicit human right to palliative care on the face of the anticipated Scottish Human Rights Act. This would be in line with a recent resolution of the United Nation Human Rights Council adopted in October 2021, which calls upon states to ensure access to palliative care. Scotland could be a world leader in taking such a step.”

# Section 4: Member's commentary

Liam McArthur MSP has provided the following commentary on the results of the consultation, as summarised in sections 1-3 above.

We now know that the consultation on my proposal for a Member's Bill on assisted dying for terminally ill adults with mental capacity received the largest ever public response for a Member's Bill since the Scottish Parliament was established in 1999. That is no small achievement and I want, therefore, to start by offering some well-deserved thanks.

First, I wish to pay tribute to the unstinting efforts of the Parliament's Non-Government Bills Unit and the team in my office – Amanda Ward, George Lewes, Jack Norquoy and Maddy Planche. Their precision and attention to detail, as well as the clarity of their advice, have been of the highest quality and ensure the public can have the upmost confidence in this vitally important process. I am grateful also to Dignity in Dying Scotland, Friends at the End and Humanist Society Scotland for their invaluable support and look forward to continuing to work with them closely as this proposal progresses. So too, members of the Medical Advisory Group, chaired by Dr Sandesh Gulhane MSP, which has been established to look at and advise on the detail of how to make such proposals work in practice.

And finally, to the more than 14,000 individuals and organisations who took the time to share their views and respond to my proposal, I offer my heartfelt gratitude. Thousands of personal stories have been shared – an aspect missing from previous attempts to reform the law in this area. These personal testimonies have been extremely moving. Those sharing them have shown real bravery. As well as my thanks, I offer an assurance that I will do all that I can to ensure these testimonies inform the debate we have and decisions we take in the interests of providing greater choice at the end of life, which is clearly so desperately needed.

Of the 14,038 responses received, 13,957 came from individuals and a large majority (78%) were in favour, with 76% fully supportive and a further 2% partially supportive. It is worth reminding ourselves that during the previous attempt to change the law in this area back in 2015, 64% of respondents to the consultation were opposed to the proposals. The overwhelming support for my proposals, however, better reflects the consistently strong public backing for a change in the law on assisted dying that we have seen in polling over recent decades. It also reinforces how much the debate has moved on since Margo MacDonald and Patrick Harvie attempted to pilot their bills through parliament.

In the years since, of course, extensive international evidence has been able to demonstrate that assisted dying can be implemented safely, reliably and responsibly. Many consultation responses considered the dozens of countries and states around the world that now have assisted dying laws, including Australia, New Zealand, Canada and many US states. While it is important that the Scottish Parliament considers what might be appropriate in relation to our own circumstances here in Scotland, we are now in the fortunate position of being able to learn from what has worked well in other jurisdictions and consider how best practice might be applied in a Scottish context. This, alongside lessons learned from previous attempts to change the law in Scotland, and recent detailed Scotland-specific academic research, will enable a robust and credible Bill to be drafted, one that hopefully will command both public confidence and parliamentary support.

It is also worth noting that recent years have seen several medical organisations revising their position on this issue and moving from a stance of opposition to one of neutrality. I was pleased to see the British Medical Association and others respond to the consultation from a position of neutrality and expressing a willingness to engage with the process over the coming months. I certainly look forward to taking up that offer.

This important shift to a neutral position by key medical organisations reflects the diversity of views held by those working in these professions. I was struck, however, by the hundreds of responses received from retired and practising healthcare practitioners (HCPs) who support my proposal. Indeed, it was interesting that quite a number of HCPs who were supportive also wished to remain anonymous. We have learned from elsewhere that once assisted dying becomes legal, it allows for a much more open and honest conversation around death and dying generally and that it benefits the doctor patient relationship. This was reflected in many of the responses from HCPs and others living in countries that have made the change, which I hope will give the public and medical professionals in Scotland some reassurance. As well as the ongoing work of the Medical Advisory Group, I look forward to working closely with the broad range of medical organisations and members of the medical community as I take my proposal forward.

As noted in the summary report, much of the opposition from both organisations and individuals appears to be based on religious or faith-based concerns. At the same time, I was pleased to see responses from many individuals who consider my proposals to be entirely compatible with their own religious or faith-based beliefs and the compassion that underpins these. Even so, I am fully committed to ensuring that the rights of those HCPs with moral objections, who would otherwise help directly in the assisted dying process will be respected. It is essential that any future Bill is drafted to enable individuals who want the choice of an assisted death, while at the same time protecting those who take a different view.

I am conscious too that concerns were raised by some advocacy organisations about the implications of my proposals for those with a disability. Amongst individual disabled people who responded, there was both support and opposition. I respect the concerns that have been expressed, though having reviewed the evidence from international best practice, I am reassured that disabled people are not adversely affected by the introduction of a choice for those with a terminal illness to seek an assisted death. A clear legal framework built around decisions taken at the end of life can provide, I believe, a protective barrier where one is currently lacking. The robust safeguards and monitoring and reporting requirements will also provide an opportunity to assess other health and social care needs and any further support that might be appropriate. Nevertheless, I remain very keen to engage directly with those in the disabled community through the drafting of my bill and beyond to see what more might be done to address any concerns.

Another key theme from the consultation responses has been the call for improvements in access to good quality palliative and end-of-life care. Some have argued that this would render the need for assisted dying redundant. However, I disagree as do many who responded to the consultation. We must continue to support both increased investment in palliative care in Scotland and give people greater choice at the end of life. We know that people choose assisted dying in their final weeks and days of life and have received palliative and hospice care in the lead up to this. Indeed, many consultation responses paid tribute to the excellent palliative and other care received but went on to relate how the suffering of loved ones got to a point where no more could be done.

This consultation has shown overwhelming support for increased investment in, and improved access to, good quality palliative and specialist palliative care, both amongst those supportive of a change in the law and those opposed. Likewise, there has been broad support expressed for a future Scottish Human Rights Act to underpin a human right to palliative and end-of-life care and support. I fully endorse both propositions and will lend my strong support to collective efforts to achieve this.

However, I remain absolutely determined to ensure that the rights of terminally ill people who want the choice of assisted dying are finally realised. The response to this consultation confirms that the current prohibition is unsustainable. Too often, despite the best efforts of those providing palliative and end of life care, this legal restriction results in prolonged, unpleasant and undignified deaths for our dying citizens and far-reaching consequences for families and friends. Many of those families have shared their experiences, describing tragic suffering, terrifying and painful deaths. These experiences must inform what happens now and it is time for the Scottish Parliament to take proportionate and long overdue action.

Such action enjoys strong public support and the results of this consultation provide a clear mandate to proceed with my proposal for an Assisted Dying for Terminally Ill Adults (Scotland) Bill. I will be seeking, therefore, to do just that and given the level of cross-party support to date from MSP colleagues, I am confident that I will be in a position formally to introduce a Bill into the Scottish Parliament in the near future. I look forward to working with all interested parties in moving the aims of my proposal forward in the months ahead.

Meantime, to the individuals who responded to my consultation who are currently living with terminal illnesses and experiencing intense suffering, you have starkly illustrated just how important this issue is and how desperately we need to do more to provide peace of mind at a frightening and uncertain time. I will keep you at the forefront of my thoughts as we move through this challenging legislative process in the hope that we can contribute to the common goal of securing a good death for all our citizens.

# Annexe

The responses of all respondents that gave permission to publish can be found at: [https://www.assisteddying.scot/](https://www.assisteddying.scot/). Due to the high number of respondents, for practical reasons a full list is not provided here. However, the 79 published and attributable organisational responses[42] made to the consultation were as follows (Smart Survey ID numbers are shown for those responses made using Smart Survey, and a response number is shown for those not made via Smart Survey):

Responses made via Smart Survey:

| | | |
|---|---|---|
| 1. | 177773082 | Dundee City Taxi Drivers Association |
| 2. | 179595204 | Scottish Pagan Federation |
| 3. | 179917350 | MAD Together Trust |
| 4. | 179985912 | St Helens LIFE Group |
| 5. | 180245159 | The Free Church of Scotland |
| 6. | 180283075 | Thistle Humanists |
| 7. | 180696915 | Stornoway Free Church Kirk Session (elders) |
| 8. | 180920844 | The Black British Human Rights Watch. |
| 9. | 180930854 | Medical Ethics Alliance |
| 10. | 180931648 | Catholic Truth (Scotland) |
| 11. | 181033648 | Royal Pharmaceutical Society |
| 12. | 181211328 | PlaySpace Publications |
| 13. | 181227852 | Cross Free Church of Scotland |
| 14. | 181215529 | Christians Supporting Choice for Voluntary Assisted Dying (Australia) |
| 15. | 181246325 | Friends at the End |
| 16. | 181270061 | Community Pharmacy Scotland |
| 17. | 181280486 | End of Life Choices Jersey |
| 18. | 181277811 | Dignity in Dying Scotland |
| 19. | 181336267 | Humanist Society Scotland |
| 20. | 181337284 | Kirk Session, Garrabost Free Church of Scotland |
| 21. | 181345192 | Regional Palliative Medicine Group |
| 22. | 181441418 | The Company Chemists' Association |
| 23. | 181443000 | Living and Dying Well |
| 24. | 181458386 | Kiltarlity, Kirkhill & Beauly Free Church of Scotland |
| 25. | 179637632 | Caledonian Humanist Association |
| 26. | 181470847 | California State branch of American Association of Medical Ethics |
| 27. | 181478295 | Association of British Insurers |
| 28. | 181482690 | Premier Christian Communications |
| 29. | 181501158 | Bishops' Conference of Scotland |
| 30. | 181509776 | Christian Concern |
| 31. | 189798262 | A Quiet Revolution |
| 32. | 181513253 | My Death, My Decision |
| 33. | 181486781 | Urray and Strathconon Free Church of Scotland |

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[42] Note that two further responses were received from organisations. One was anonymous, and one was not published at the request of the respondent.

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|---|---|---|
| 34. | 181456887 | Scottish Partnership for Palliative Care |
| 35. | 181523974 | Christian Life Issues Group of the United Free Church of Scotland. |
| 36. | 181524525 | Harris Free Church of Scotland (Continuing) |
| 37. | 181524112 | Not Dead Yet |
| 38. | 181527386 | British Islamic Medical Association |
| 39. | 181545444 | The Christian Institute |
| 40. | 181537153 | DIGNITAS – To live with dignity – To die with dignity |
| 41. | 180846882 | Church of Scotland |
| 42. | 181552011 | Edinburgh Lay Dominican Fraternity |
| 43. | 181553173 | Association for Palliative Medicine of Great Britain and Ireland |
| 44. | 181553353 | Kinloch Free Church of Scotland |
| 45. | 181554943 | Scottish Care |
| 46. | 181516071 | The Apostolic Church UK in Scotland |
| 47. | 181554005 | The Royal College of Psychiatrists in Scotland |
| 48. | 180598455 | Inclusion Scotland |
| 49. | 181559748 | Parkinson's UK Scotland |
| 50. | 180836660 | Bios Centre |
| 51. | 181560705 | Neurological Alliance of Scotland |
| 52. | 181544957 | Better Way |
| 53. | 181564621 | Anscombe Bioethics Centre |
| 54. | 181565419 | The Scottish Youth Parliament |
| 55. | 181572890 | Evangelical Alliance |
| 56. | 181573910 | North west Pro-life |
| 57. | 181575188 | Glasgow Reformed Presbyterian Church of Scotland |
| 58. | 181575057 | Knockbain Free Church of Scotland |

Responses not made via Smart Survey:

| | | |
|---|---|---|
| 59. | 13,986 | National Secular Society |
| 60. | 13,994 | The Society for the Protection of Unborn Children |
| 61. | 14,000 | Scottish Council on Human Bioethics |
| 62. | 14,013 | Royal College of Physicians of Edinburgh |
| 63. | 14,015 | Christian Action Research and Education |
| 64. | 14,016 | Christian Medical Fellowship |
| 65. | 14,017 | Royal College of Physicians and Surgeons of Glasgow |
| 66. | 14,022 | Children’s Hospices Across Scotland |
| 67. | 14,023 | Care Not Killing and Our Duty of Care |
| 68. | 14,024 | Glasgow Disability Alliance |
| 69. | 14,025 | Scottish Council of Jewish Communities |
| 70. | 14,028 | Hospice UK |
| 71. | 14,029 | Scottish Association for Mental Health |
| 72. | 14,030 | The Salvation Army |
| 73. | 14,032 | The Royal College of Nursing Scotland |
| 74. | 14,033 | British Medical Association Scotland |
| 75. | 14,034 | General Pharmaceutical Council |
| 76. | 14,035 | Marie Curie |
| 77. | 14,036 | Fellowship of Independent Evangelical Churches |
| 78. | 14,037 | Scottish Human Rights Commission |

79. 14,038 Church in Society Committee of the Scottish Episcopal Church.