SPPC RESPONSES – Assisted Dying for Terminally Ill Adults (Scotland) Bill

This paper contains responses to two calls for views on aspects of the Assisted Dying for Terminally Ill Adults (Scotland) Bill:

1. Health, Social Care and Sport Committee - call for views on the Bill. (P1-36)

2. Finance and Public Administration Committee - call for views on the Financial Memorandum. (P37-44)

HEALTH, SOCIAL CARE AND SPORT COMMITTEE QUESTIONS

(Where a choice of responses is given SPPC's selection is highlighted thus)

Name of Organisation

Scottish Partnership for Palliative Care

Information About your Organisation

Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. SPPC provides a voice for organisations and individuals working in this area, a means of staying informed and connected, and a vehicle for collaboration. SPPC also engages with the public and communities through our Good Life, Good Death, Good Grief alliance.

SPPC was founded over 30 years ago and has grown to be a collaboration of more than 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, all IJBs, local authorities, all the hospices, other Third Sector organisations and a range of professional associations.

SPPC works closely with Scottish Government to facilitate engagement with the sector and to inform and support implementation of policy. SPPC recently won a Public Service Award for its portfolio of work.

This response is based on engagement with our member organisations and other stakeholders. It represents the corporate view of SPPC, but may not reflect the exact position of each and every member organisation across all issues. References for the evidence cited in this paper are available on request.

The nature of the Assisted Dying for Terminally Ill Adults (Scotland) Bill means that this response covers a lot of complex and important detail. We have briefly summarised some of our key points at the end of our answer to Q8.

Question 1 – Overarching question

The purpose of the Assisted Dying for Terminally Ill Adults (Scotland) Bill is to introduce a lawful form of assisted dying for people over the age of 16 with a terminal illness.

Which of the following best reflects your views on the Bill?

- Fully support
- Partially support
- Neutral/Don’t know (but see comment below)
- Partially oppose
- Strongly oppose

Space for further comment on your answer

None of the options adequately describe SPPC’s view. “Neutral” and “Don’t know” are very different positions and should not be combined within one option. We would have liked an “Other” option in this question. We have only chosen an option because the online survey will not allow us to respond to any further questions unless we do so. We don’t wish our forced choice to be included in the statistical analysis of responses to this question.

SPPC’s POSITION AND APPROACH

Assisted dying raises issues of a moral, personal and ethical nature upon which many of SPPC's member organisations (for example our member NHS Boards) are institutionally unable to hold a position.

SPPC therefore does not adopt a position in principle either in support or in opposition to a change in the law.

Instead, SPPC's approach is:-

- To take a factual and evidential approach rather than a moral or religious one
- To educate and inform about palliative and end of life care
- To challenge misinformation about palliative and end of life care
- To acknowledge and give an account of complexities which tend to get lost in polarised debates
- To be clear about the potential and the limits of palliative care to relieve suffering
- To be clear about the current deficiencies in care towards the end of life experienced by some people, and to advocate the changes necessary for improvement
- To critically review and present a view on the specific provisions of the proposed Bill, such that if the Bill is passed potential harms (to vulnerable people and the practice and provision of palliative care) are minimised.

It is important that law making is informed by a broad perspective and relevant facts, and that issues needing consideration by MSPs are identified. This response from SPPC is written with that intent. This response provides relevant contextual information as well as directly responding to areas of focus set out in the consultation questionnaire.

Which of the following factors are most important to you when considering the issue of assisted dying? (rank your top 3)

- Impact on healthcare professionals and the doctor/patient relationship
- Personal autonomy
- Personal dignity
- Reducing suffering
- Risk of coercion of vulnerable people

- Risk of devaluing lives of vulnerable groups
- Sanctity of life
- Risk of eligibility being broadened and safeguards reduced over time
- Other, please provide further details (200 words)

SPPC is primarily concerned with two areas. Firstly, we are concerned with the interests of people who may be vulnerable - many people approaching the end of life may be vulnerable for different reasons. Secondly, we are concerned with the practice and provision of palliative care. These two areas cut across most of the factors listed in the question. Many of the factors listed have complex philosophical and practical interrelationships and we can't meaningfully rank a top 3. It is important to acknowledge openly that there may be trade offs between the different factors. For example, maximising personal autonomy may increase the risk of coercion of vulnerable people, since procedural safeguards are seldom fully effective (we say more about safeguards in Q3).

We expand on the practice and provision of palliative care in the next box.

Space for further comment on your answer

In order to understand the potential implications of the Bill for the practice and provision of palliative care in Scotland one must first have an understanding of what palliative care is and how it is provided. We therefore begin with an explanation of some key information about palliative care.

WHAT IS PALLIATIVE CARE?

Though more specific formal definitions can be helpful a good way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close.

Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making.

However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Palliative care interventions are holistic and aim to modify the impact of illness/disease by addressing symptoms and should be delivered alongside treatments aimed at controlling or modifying the underlying condition(s). Palliative care can and should be provided alongside treatment aiming to cure or remove the underlying illness/disease where such treatments exist. For example palliative care can address physical symptoms caused by side effects of chemotherapy for cancer.

Although most people die in later years some babies, children and young people will also need palliative care. Palliative care for these groups has important differences. The submission from Children's Hospices Across Scotland, a member of SPPC, provides expert and detailed comment on the implications of the Bill for babies, children and young people.

GENERALIST PALLIATIVE CARE BY ALL HEALTH AND SOCIAL CARE PROFESSIONALS

In Scotland most of the care that people receive when their health is deteriorating could be termed generalist palliative care, being provided by health and social care professionals to people living in the community, in care homes and or who are in hospitals.

It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home, in prison or in a medical ward, in ICU or a homeless shelter, or in a neonatal ward.

SPECIALIST PALLIATIVE CARE BY MULTI-PROFESSIONAL SPECIALIST TEAMS

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled 'palliative' are usually specialist palliative care. Key contributions of specialist palliative care include:

- assessment and management of complex physical, psychological and spiritual symptoms
- supporting complex clinical decision-making, seeking to apply relevant ethical and legal frameworks alongside clinical assessment and respect for personal autonomy and values
- direct provision and management of symptom management interventions
- providing care and support to those important to the person receiving care, including facilitating bereavement care
- providing specialist advice and support to the wider care team which is providing direct care to the person
- liaison with and between different settings

- providing formal and informal education and training for the wider health and social care system
- attending and providing input to multidisciplinary team meetings, including key decision-making contributions
- providing strategic expertise and leadership to support the health and care system to recognise and meet the needs of people approaching the end of their lives.

END OF LIFE CARE

Palliative care includes, but is not exclusively about, end of life care.

End of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories . There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

PROVISION OF PALLIATIVE CARE

Palliative care is provided by the NHS, the Third Sector, the Independent Sector and local authorities. There is considerable geographic variation in the models and level of provision.

Organisations involved in delivering palliative care include primary care; care homes; care at home services; hospices; NHS 24; Scottish Ambulance Service; NHS specialist palliative care units; acute hospitals; community hospitals.

Legal responsibility for the strategic commissioning of adult palliative care lies with Integration Authorities (IAs).

OPIOID MEDICINES AT THE END OF LIFE

Doses of opioids may be increased when someone is dying if needed to control symptoms of pain and/or breathlessness. Sometimes this is misunderstood as the increased dose having ended the person’s life (and sometimes even misinterpreted as the doctor having used opioids to end the person’s life).

However, appropriate doses of opioid medicines (e.g. morphine) titrated to the person’s pain or other symptoms do not shorten life. The Scottish Palliative Care Guidelines are available to all health and care staff to support best practice in this area. Where someone has pain and/or other symptoms which persist they should be referred to specialist palliative care.

SEVERE SYMPTOMS AT THE END OF LIFE

Specialist Palliative Care has very effective approaches to managing even the most severe symptoms and so most people die peacefully and comfortably. Suggestions that people frequently die in distress due to great pain which drugs cannot address are misleading.

Sometimes the drugs and doses necessary to control severe symptoms may cause side effects of decreased or absent awareness. In exceptional cases the person may become unconsciousness or sedated as a side effect.

This is a rare situation which usually only happens when someone is very clearly in their final hours or short days and only when other means of managing the symptoms have been fully explored.

Question 2 – Eligibility

The Bill proposes that assisted dying would be available only to terminally ill adults.

The Bill defines someone as terminally ill if they ‘have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death’.

An adult is defined as someone aged 16 or over. To be eligible a person would also need to have been resident in Scotland for at least 12 months and be registered with a GP practice.

Eligibility – Terminal illness

Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?

- No-one should be eligible for assisted dying
- Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness should be narrower than in the Bill
- Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness in the Bill is about right

- Assisted dying should be available only to people who are terminally ill, but the definition of terminal illness should be broader than in the Bill
- Assisted dying should be available to people who are terminally ill, and to people in some other categories.
- Other – please provide further detail

In the next section we raise some issues relating to the definition of terminal illness contained in the Bill.

If you have further comments, please provide these

DEFINITION OF TERMINAL ILLNESS

The definition of terminal illness used in the Bill is imprecise. Key terms in the definition such as “advanced” and “progressive” don’t have accepted standard definitions. There are multiple ways to define “premature” mortality.

Using the definition in the Bill to determine eligibility for “assisted dying” is therefore likely to result in a lack of clarity for the public and the medical practitioners tasked with assessing eligibility. A combination of an imprecise definition and the application of individual judgement of the assessing medical practitioner will likely lead to inconsistencies in who is deemed eligible.

We note that the Policy Memorandum (para 32 p8) states *“It is not the intention that people suffering from a progressive disease illness/condition which is not at an advanced state but may be expected to cause their death (but which they may live with for many months/years) would be able to access assisted dying.”* Whilst the expressed intent here is imprecise (“many months” and “many years” are different periods) it suggests restricted eligibility. The Financial Memorandum further reinforces this impression stating *“It is thought likely that a terminally ill adult who dies as a result of being provided with assistance to end their life would have a very short time left to live, and therefore that care would have continued for a matter of days or, at the most, weeks.”*

However, the definition in the Bill is similar to that used in the social security system to determine expedited access to welfare benefits for people who are terminally ill. This definition is broad. An imprecise and broad definition may be an advantage when not wishing to exclude people from rapid receipt of financial support. However, the definition in the Bill seems unlikely to be an effective way to identify a narrow group of people who are very near the end of their life for assisted dying. As drafted the definition would likely include some people who would otherwise live for a considerable period.

Furthermore assessing how and when a disease will progress, and when death may occur is full of uncertainty and a difficult challenge even for clinicians very experienced in this field.

In summary: the definition in the Bill is not precise enough, which will lead to variation in interpretation and could mean that people with years to live are deemed eligible, which is at odds with the stated policy intent of the Bill.

It is really important that the person seeking assisted dying clearly understands this imprecision when making their decisions. Under the Bill there can be a significant gap between being assessed as eligible and the action of taking the lethal medication. The timing of the assisted death is decided by the person.

POWER TO REVISE ELIGIBILITY THROUGH MINISTERIAL GUIDANCE

We note that the Bill section 23.2 (a) gives powers to Scottish Ministers to make guidance on assessing eligibility (and under section 23.5 (a) to revise such guidance). However, the definition of terminal illness is fundamental to the operation of the Bill. SPPC believes that a clear and adequately precise definition of "terminal illness" should be on the face of the Bill and not left to Ministerial guidance (and subsequent Ministerial revision).

TERMINAL ILLNESS AND YOUNG PEOPLE (aged 16-21)

Many children and young people live with a life shortening illness (and require palliative care) for a much longer period than older adults. It is common for their condition to fluctuate and it is even more difficult to identify when death may be imminent. The Bill needs to contain measures to be able to differentiate between a young person with a diagnosis of a life shortening condition and who may meet the Bill's definition of "terminal illness" (but who may live for many years) and a young person with a diagnosis of a terminal life shortening condition for whom death is clearly imminent. The Bill needs to specify an appropriate level of medical expertise required to undertake such an assessment.

FUTURE BROADENING OF ELIGIBILITY

Over time assisted dying will likely become less controversial and become normalised. This shifting social and cultural context will increase the likelihood of a broadening of eligibility. Over time safeguards can come to be viewed as barriers and be subject to challenge: a provision which may provide a safeguard for one person may represent an unfair barrier to a different person. What may be a welcome choice for one person, may come to seem like an inescapable duty to another person who is feeling they are a burden to the people who look after them.

Having established the right to assisted dying for some parts of the population it becomes difficult to deny that right to other parts of the population. Existing legislation is likely to be challenged on the basis of equalities and human rights. This is the experience for example in Canada where a law enabling assisted dying was passed in 2016. In 2021 the law was revised to broaden eligibility. From March 2027 assisted dying will be available to people “whose only medical condition is a mental illness”. The introduction of this change has been delayed from 2023 to allow health authorities more time to prepare.

It is possible to see where the Bill as drafted might be challenged. For example Section 3 (2) (a) seems to exclude from eligibility anyone suffering from any mental disorder. Under the terms of 3 (2) (c) this would exclude someone with any (a) mental illness; (b)personality disorder; or (c)learning disability, regardless of whether or not their condition was impacting on their capacity to make a decision to access Assisted Dying.

It seems very possible that the proposed Bill would be followed at a future point by a broadening of eligibility. This might take the form of new primary legislation. However, by offering an initially imprecise definition of terminal illness, together with granting Ministers powers to revise how this definition is interpreted in practice, the Bill provides a mechanism for changes in eligibility without need for further primary legislation.

As with the rest of this paper this likelihood is raised as something which it is important to acknowledge and consider.

Eligibility – minimum age

Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?

- No-one should be eligible for assisted dying.
- The minimum age should be lower than 16
- The minimum age should be 16
- The minimum age should be 18
- The minimum age should be higher than 18
- Other – please provide further detail

SPPC has concerns that the proposed minimum age of 16 is too low.

If you have further comments, please provide these

There are three distinct and strong reasons to suggest that 16 may be too young to be eligible for AD.

Firstly, there is considerable scientific evidence that young people's brains are not fully mature until well after the age of 16. There is evidence that adolescents are more prone to risk-taking behaviours and less able to undertake complex decision-making than older adults.

Secondly, many young people with a life limiting illness have experienced significant adversity and this may inhibit and disrupt typical cognitive and emotional maturation.

Thirdly, young people aged 16-21 will be going through a process of transitioning from children's to adult services. This is often a very difficult, stressful and isolating experience, with the loss of familiar and longstanding supports and relationships. The transition process can impact on emotional and mental wellbeing.

In Scotland, the definition of a child varies in different legal contexts. 16 year olds can vote in Holyrood elections, get married and serve in the army (but only with parental agreement). However, statutory guidance which supports the Children and Young People (Scotland) Act 2014, includes all children and young people up to the age of 18. There are many other domains in which people aged 16 are treated differently to older adults: in the judicial system a differentiated approach is taken in the sentencing of young people. In a safeguarding context 16-17 year olds are often dealt with under child protection rather than adult safeguarding rules. A person must be 18 and above to serve as a juror; buy alcohol in licensed premises; consume alcohol in licenced premises; buy cigarettes & tobacco; place a bet; and get a tattoo. To drive a large goods vehicle or be sent to adult prison a person must be 21. The United Nations Convention of the Rights of a Child (UNCRC), recently incorporated into Scots law, defines children as all "human beings below the age of eighteen years". Consideration should be given to whether there may be any conflict between the right around child protection under UNCRC, and the right to an assisted death under the Bill if enacted.

Question 3 – The Assisted Dying procedure and procedural safeguards

The Bill describes the procedure which would be in place for those wishing to have an assisted death.

It sets out various procedural safeguards, including:

- examination by two doctors
- test of capacity
- test of non-coercion
- two-stage process with period for reflection

Which of the following most closely matches your opinion on the Assisted Dying procedure and the procedural safeguards set out in the Bill?

- I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle
- The procedure should be strengthened to protect against abuse
- The procedure strikes an appropriate balance
- The procedure should be simplified to minimise delay and distress to those seeking an assisted death
- Other – please provide further detail

SPPC believes that the procedural safeguards should be strengthened to reduce the risks of harm. We also believe that it is not sufficient to consider only procedural safeguards. The level of risk is also determined by context. It is important to consider contextual factors which may increase risks. For example poor access to services may influence people's decisions. We expand on these issues below.

SPPC does not believe that all risks can be eliminated.

If you have further comments, please provide these

ACCESS TO HIGH QUALITY PALLIATIVE CARE AS AN IMPORTANT CONTEXTUAL SAFEGUARD

Imagine you are a health or social care worker, supporting someone approaching the end of life, providing palliative care. You want to maximise their wellbeing, to listen to their fears and concerns and to try to meet their needs. They feel they have a poor quality of life and voice an interest in assisted dying – at this point it isn't a settled intent but rather it is a call for help. You think they would benefit from a specialist palliative care assessment but the local hospice has limited capacity. You know they would benefit from a package of care at home, but you also know that due to tightened eligibility or workforce shortages or lengthy assessment processes you can't realistically offer them that when it is needed, or possibly at all. You believe they would benefit from specialist psychological support, but that service too is not available locally or has a huge waiting list. You know they are concerned about how tired and stressed their family carer is, especially at nights and weekends, but there is no 24/7 support line for them and the local district nurses just don't have the capacity to drop in regularly. You can understand how the person seeking help may feel, and what decision they may eventually reach – yet you believe that with the right care they could have a vastly increased quality of life, but it isn't within your power to provide that care.

The ready availability of good general and specialist palliative care towards the end of life (including social care) is a fundamental safeguard. A proportion of those seeking assisted dying in other jurisdictions are reported as not being in receipt of palliative care. Of those in receipt of palliative care and seeking assisted dying a larger percentage receive palliative care only briefly (despite the fact that some palliative care interventions may take time to have an effect). In reports from other jurisdictions about "assisted dying" it is often not clear what "being in receipt of palliative care" actually means in practice. A concern that good palliative care won't be available towards the end of life should never form part of anyone's decision to shorten their life. Experiencing deficient care or the non-availability of care towards the end of life should also never form part of anyone's decision to shorten their life.

High quality palliative and end of life care must therefore be consistently and reliably available to everyone in Scotland when they need it for as long as they need it, and evidence must also be available to provide public reassurance about the quality of that care. Consequently very significant investment in improving palliative care (in the broadest sense, including social care) should be an integral part of any move to legalise assisted dying. Whilst good palliative care does not eliminate all potential risks and harms, it seems very likely that strengthened palliative care will reduce risks to some vulnerable people. We explore resource issues in our response to the Finance and Public Administration Committee call for views on the Bill.

No one should choose to end their life because they didn't receive the care they needed, or didn't believe they would get the care they needed, or didn't understand the positive impact which specialist palliative care or other services/support could have on their quality of life.

Access to and understanding of good quality palliative and end of life care is therefore an important safeguard against people choosing assisted dying due to concerns about poor care towards the end of life.

EXPLANATION AND DISCUSSION OF PALLIATIVE CARE AS PART OF THE ASSISTED DYING PROCESS

We note that in the Bill (Section 7 Assessment under section 6: further provisions) that the assessing medical practitioner must explain and discuss (in so far as the practitioner *"*considers it appropriate") with the person being assessed *"*any palliative care or other care **available***"*. The nature of this explanation and discussion is unclear (as are the circumstances when it would be considered "*inappropriate*" – GMC guidance would suggest that not explaining and discussing could only happen in exceptional and well justified circumstances). It is not clear how the assessment be carried out where good quality palliative care and/or access to specialist palliative care is not "available". Does the assessing practitioner not explain or discuss palliative care? Would this be consistent with professional duties to inform patients about relevant care/treatments? Alternatively, do they explain palliative care (including specialist expertise in assessing and addressing suffering) but inform the person that it is not available to them? We know that the sense of dignity and of self-worth of individuals is strongly impacted (both negatively and positively) by how health and care practitioners and the health and care system relates to them. What impact could it have on the person and their decision-making to be told that care and support which might address their suffering may not be available to them? This reinforces the importance of equitable access to high quality palliative care as a key safeguard.

Given the common misunderstandings (on the part of professionals as well as the public) about what constitutes "palliative care" the scope of discussion required needs to be clearly spelled out in the Bill. It is common for doctors including GPs and secondary care doctors to be unaware of what specialist palliative care can achieve for a patient in terms of symptom management and psychosocial support to improve the quality of life.

A practical issue which arises is what reliable and up to date information source will the assessing doctor use to determine the local availability of palliative care.

DEFICIENCIES IN PALLIATIVE CARE IN SCOTLAND

The non-availability of the particular support someone needs towards the end of life is not a hypothetical scenario. Whilst there is much excellent palliative care provided in Scotland, there are also deficiencies, a lack of reliability in delivery and inequities in access. There are no systematic mechanisms in place to measure and understand the experiences and outcomes of people dying in Scotland (for example the experiences of people approaching the end of life and bereaved relatives are not identified in reports of the regular Scottish Government Health and Care Experience Survey). In our recent report Every Story's Ending SPPC engaged with a wide range of stakeholders to take stock of recent developments and current challenges in the care of people approaching the end of life in Scotland, in order to inform future development. The report identifies areas where palliative care in Scotland should be improved:-

- Inequitable access to specialist palliative care and very stretched services in some areas
- Inadequate access to responsive support in the community (including social care), particularly in the evening, overnight and at weekends
- Absence of digital systems to allow anticipatory/future care plans to be recorded, updated and shared between relevant health and social care settings
- Lack of adequate skills, knowledge and confidence on the part of many health and social care staff
- Failures to identify people with palliative care needs systematically
- Failures to have timely, open, honest and supportive conversations in the context of uncertainty and deteriorating health
- Patients and families left unaware of their health situation and available options for care
- Burdensome investigations and interventions of low benefit towards the end of life
- People undergoing treatments which do not reflect their life goals and priorities
- Missed opportunities for rapid discharge home
- Lack of anticipatory care planning and care co-ordination leading to avoidable re-admissions and poorer outcomes in the community
- Inadequate symptom management
- Other unidentified and unmet holistic care needs (e.g. psychological, spiritual and practical concerns)
- Lack of dignity/privacy for people and families in the time around death due to the physical environment in some settings
- Inequities of support for people with particular characteristics and/or life circumstances.

A MISSING ESSENTIAL SAFEGUARD: ASSESSMENT OF THE REASONING AND MOTIVATIONS OF THE APPLICANT INCLUDING THE CAUSES OF ANY SUFFERING

The Policy Memorandum states as one of the primary objectives of the Bill the avoidance of “the existential pain, suffering and symptoms associated with terminal illness”.

The views, feelings and wishes of people approaching the end of their lives change over time and may alter frequently during the course of an illness. People who have a desire for an early death or who express a wish to get assistance to shorten their life because of distressing physical or psychological symptoms often change their minds when these symptoms are explored, understood and addressed through appropriate palliative care. It is experience of such situations which give rise to some of the concerns about assisted dying expressed by many specialist palliative care practitioners. Indeed, many palliative care specialists would consider the expression of suicidal ideas to be a reason for essential referral for specialist palliative care assessment.

Addressing symptoms may involve medicines but may also involve psychological and spiritual support since the causes of pain and distress are often complex and multifactorial. Cicely Saunders, founder of the modern hospice movement developed the concept of total pain as a framework for exploring, understanding and addressing people’s distress which can have its origin in physical, psychological, social and spiritual issues. A holistic approach should be taken in exploring causes of suffering which may be reversable. For example, alongside physical symptoms issues such as damp cold housing and financial distress should also be considered and addressed.

We note that the original proposal for legislation stated:

“under this Bill proposal, 2 doctors would be required to independently assess the person making a request, including enquiring about their <u>reasoning and motivations</u>. This is an opportunity <u>to make sure all options have been explored</u> and to refer the person for psychiatric assessment if necessary”.

However, in the Bill as eventually published there is no requirement within the stipulated assisted dying process for the assessing doctors to explore/understand the applicant’s reasoning and motivation, nor to identify/assess any causes of suffering which may have led to their request to end their life, even though this suffering may be preventable in some instances.

In the process set out in the Bill assisted dying is not positioned as the final stage of a sequence which is only reached after other efforts to address suffering. Instead assisted dying is available without any legal requirement for exploration of the applicant's suffering and the potential to relieve it.

In many countries the experience of suffering is one of the eligibility criteria for AD. This is true for jurisdictions such as New Zealand and Australian states where eligibility is primarily linked to a terminal diagnosis (the person must be expected to die within a specific limited time frame), as well as for countries like Belgium, Canada and Holland where there is broader eligibility and intolerable suffering is broadly sufficient grounds even without a terminal diagnosis. In Oregon suffering is not part of the eligibility criteria. However, there is a requirement to report on the aspects of suffering which may have led the individual to access assisted dying. The Assisted Dying for Terminally Ill Adults (Scotland) Bill seems to be an international outlier (and perhaps unique?) in requiring no inquiry as to the suffering which may have led the person request AD, and also no data collection and reporting of the reasons why people chose to request AD (including suffering). We say more about this in our response to Q7 on Reporting and Review Requirements.

EXPLORING SUFFERING AND RESPECTING AUTONOMY

SPPC believes that as part of the assessment process the practitioner responsible should explore the motivations of the applicant, including exploration of any physical, psychological, social or spiritual causes of suffering or distress.

The practitioner would need to be appropriately skilled and qualified to undertake this aspect of assessment. Discussing people's wishes towards the end of life can often involve sensitive and complex conversations, which very many healthcare professionals find difficult. The option of an assisted death may be an easier, quicker and simpler conversational route (for both healthcare professionals and some terminally ill people) than a long and complex conversation which seeks to surface, explore, understand and plan to address the causes of suffering. However, this latter sort of conversation will often lead to people having an improved and positive experience of whatever time they have left until their natural death. Where the practitioner feels inadequately equipped for such exploration, or remains in doubt, they should refer the person for assessment by specialist palliative medicine practitioner (just as the Bill requires referral to other appropriate specialists for other aspects of assessment such as capacity and whether or not the person meets the definition of terminally ill).

Whilst the Bill states that the assessing doctor may *discuss and* explain palliative care, a stronger safeguard would be that the person should ***experience*** multidisciplinary specialist palliative care, if they are not already in receipt of such care. People commonly and understandably only appreciate the benefits of specialist palliative care once it is experienced rather than explained in the abstract. There is an argument that informed consent on this decision necessitates a specialist palliative care assessment and input which should be a multidisciplinary assessment including psychosocial care needs – and clear documentation of what was discussed and what the unmet needs were and why.

A very reasonable safeguard would be for a request for assisted dying to be viewed as grounds for referral to specialist palliative care.

It should be clear what the obligations of practitioners are when seeking to understand and address potentially reversible causes of suffering. On the one hand the views and preferences of adults with capacity should be respected, but there are also ethical imperatives to address reversible suffering when someone is choosing to end their own life as a consequence of that suffering. Practitioners may face criticism having tried to balance these concerns. Are they expected to do everything reasonably possible to address suffering or are they expected to take at face value the person's expressed wish to die in a way which would not be ethically acceptable in other circumstances? Should any balancing between these positions be left to the ethical preferences of individual practitioners, or should the Bill be clear about what society expects of those trying to manage these complex and challenging situations?

Some people will have an enduring wish to hasten their death, and such individuals have a need and a right to be respected, affirmed and valued, regardless of the legality or otherwise of assisted dying.

ASSESSMENT OF CAPACITY

Severe mental disorder resulting in lack of capacity may be readily detectable. However, a potentially very common combination of factors affecting a requesting person (mild depression, mild cognitive impairment, multiple morbidities and an internalised perception that they are a burden to relatives or others) may be much more difficult to identify. Patients seeking AD commonly report 'feeling a burden' as an important reason for their decision. Currently around half of those accessing AD in Oregon report "Burden on family, friends/caregivers" as a concern. The proportion of people reporting this as a concern has grown steadily and very significantly since assisted dying was introduced. A similar trend can be seen in Washington State.

The Bill doesn't specify the level of skills, knowledge, experience and standard of diligence required by assessing medical practitioners for the reliable identification and exclusion of such individuals. We also note that the process for assessing capacity is not specified. We note that in the Bill these matters are left for Scottish ministers to determine through regulation, although they are fundamental components of the intended safeguards (and also matters of concern to participating practitioners). We also note that the Finance Memorandum states: "The amount and type of training required will be for NHS Scotland to determine", rather than this being regulated by Ministers.

There is similar lack of detail on the level of skills, knowledge, experience and standard of diligence required by assessing medical practitioners in relation to coercion and the application of the definition of “terminal illness”. The Bill should be more explicit on these matters, setting out details.

CAPACITY IN YOUNG PEOPLE (aged 16-21)

Assessing capacity in this group may be particularly complex. In other jurisdictions the proportion of all patients referred for psychiatric assessment is only 1%. SPPC’s view is that there should be a mandatory multidisciplinary assessment of all young people wishing to access assisted dying.

Currently, the parents of young people under the age of 16 years deemed to be without capacity in Scotland are given de facto parental responsibility to consent on their behalf to medical interventions. At the age of 16 and above, parents need to legally obtain the right to guardianship over their child for medical decision-making, through the Adults with Incapacity Act 2000 (Scotland). SPPC would like to see clarification that parents could not request an assisted death on behalf of their child in such a situation.

THE DEFINITION AND ASSESSMENT OF COERCION

The Bill states that medical practitioners’ assessments must ascertain whether in their opinion the person wishing to access AD made the necessary declarations *“…*voluntarily and has not been coerced or pressured by any other person into making it.”

The Policy Memorandum points to existing GMC guidance on Decision Making and Consent in this context. This guidance highlights issues for practitioners to be aware of in terms of the exercise of free will (the term coercion is not used), and factors which may increase a person’s vulnerability to coercion, for example if they are:

“a. experiencing domestic or other forms of abuse

b. resident in a care home

c. cared for or supported by others because of a disability

d. detained by the police or immigration services, or in prison

e. subject to compulsory treatment or assessment orders, or at risk of becoming so”

The GMC Guidance also highlights that

“Pressure can come from others – partners, relatives or carers, employers or insurers – or from patients’ beliefs about themselves and society’s expectations.”

SPPC notes therefore that the conception of coercion in the Bill is significantly narrower than that in the GMC guidance. In Section 6 (2) (c) and elsewhere the Bill states the medical practitioner must ascertain whether the person wishing to access AD made the necessary declaration *"…voluntarily and has not been coerced or pressured by any other person into making it."* The Bill's conception of coercion is that it is pressure exerted **by one person on another**. The GMC's conception of coercion quoted above expands this to include the influence of a person's internalised beliefs and society's expectations.

SPPC's position is that the GMC's conception of coercion is more appropriate and safer in the context of AD, and that this should be on the face of the Bill.

SPPC notes that it is common for people to feel that they are a burden (emotional, physical or financial) towards the end of life. In the U.S state of Oregon, where assisted dying has been legal since 1998, a recent study published in the BMJ has shown that there has been an increase over time in patients feeling a burden and describing financial concerns as reasons for choosing an assisted death. In the Scottish context many older people face the prospect of the need to meet future long term care costs. The cost of living crisis has increased levels of financial hardship.

At a practical level the Bill should be clear about what steps are expected of the medical practitioner to enable an adequate assessment of coercion. The practitioner should be required to document the steps taken to ascertain the absence of coercion and the specific conclusions reached. This could include whether or not the individual falls into any of the categories which may increase vulnerability, highlighted by the GMC. Some of these factors may be easy to establish (e.g. resident of a care home) but others (e.g. subject to domestic to abuse) may be difficult or impossible to establish within a short consultation, and will require more detailed guidance and possibly additional training.

Assessing whether or not coercion is happening can be very complex. For example, there may be finance involved with various family members giving different versions of a truth, challenging each other and different practitioners (who may reach different conclusions on limited evidence), and/or the person seeking AD presenting differently at different times or differently to different professionals. It will not be possible to achieve certainty in every instance.

Robust detection of coercion is vital. Data from the Office for National Statistics (England and Wales 2022) shows that around 1 in 30 people aged 60 to 74 and approximately 1 in 50 people aged 75+ are subjected to domestic abuse each year – equating to 400,000 older people each year. Domestic abuse is defined as physical abuse, sexual abuse, violent or threatening behaviour, controlling or coercive behaviour, economic abuse, psychological, emotional or other abuse.

The Bill should be clear whether the inability to access appropriate care and resource to live a dignified life should be judged a coercive factor or not. For example, a patient in hospital who is unable to be discharged home as they would choose due to a level of social care and nursing care needs which cannot be provided by stretched community services, refuses to be discharged to a care home and chooses AD instead as their preferred available option. Should this be viewed as a form of coercion – because the person is choosing AD from an unacceptably limited range of alternative options?

SPPC believes that some young people living with a life-shortening illness may be at particular risk of coercion. They may be socially isolated, financially disadvantaged, and / or living a life where they are not as empowered as they might like to be. Specific guidance and training should be available for the assessment of young people.

THIRD AND FINAL ASSESSMENTS OF CAPACITY AND NON-COERCION

15 (3) (b) i and ii require that the registered medical practitioner (or the health professional they authorise) be satisfied at the point they attend and supply the approved substance that the person still has capacity to request AD and is not acting under coercion. Again there is a need to clarify what process will be used to make these assessments, remembering that a significant period of time may have elapsed since the previous assessments and declarations were made. These final assessments should be documented, and the proposed Final Declaration should be amended to include reference these assessments.

Since these final assessment may be undertaken by an authorised health professional (rather than registered medical practitioner) there is a need to be clear about the skills and competencies required. Assessing capacity and coercion are less likely to be part of the usual experience of a pharmacist or nurse.

SIGNING BY PROXY

Section 12 sets out arrangements for a proxy to sign the AD declarations where the person requesting AD is unable to do so for various reasons. Section (12) (4) (a) requires that the proxy (who must be a solicitor, advocate or justice of the peace) must be satisfied that the person understands the nature and effect of making the declaration. This is effectively a further assessment of capacity but this time undertaken and confirmed by a lawyer. There is a resultant need to specify what process should be used by this proxy, and what skills and competencies are required by the lawyer undertaking the process.

PRIOR RELATIONSHIP

The Bill does not require the initially assessing practitioner to have any prior knowledge of the requesting person or their social and family circumstances.

Several aspects of the envisaged assessment are likely to be more difficult in these circumstances, for example the assessment of coercion. The Bill requires that the second independent assessing practitioner must be a person that “has not provided treatment or care for the person being assessed in relation to that person’s terminal illness” 6 (6) b. Therefore, the whole process may be carried out without input from a professional who knows the person and their circumstances well. SPPC believes that where neither of the assessing practitioners have prior knowledge of the person and their social and family circumstances they should be required to request and consider a report from a practitioner who has that familiarity with the person. This might be the person’s GP, but given the nature of modern general practice it may be that another practitioner may know the person and their circumstances better.

PARTICULAR VULNERABILITY AND ELIGIBILITY WHEN PEOPLE HAVE DIFFICULT LIFE CIRCUMSTANCES

As previously mentioned the policy memorandum states as one of the primary objectives of the Bill the avoidance of “the existential pain, suffering and symptoms associated with terminal illness”. However, it is possible that a person meeting the eligibility requirements in the Bill might seek to end their life for other reasons – for example a person with difficult life circumstances such as being homeless or in prison. Such people may have particular vulnerability. It is also recognised in other legislatures that patients with a terminal illness choose AD because of a sense of not wanting to be a financial, physical or emotional burden on their family. It is not clear from the Bill how an application for AD will be handled in such circumstances and what the appropriate response would be. Would a prisoner be granted expedited compassionate release before assessing whether they have a continuing wish for AD? Would a homeless person be provided rapidly with housing before assessing whether they wish to continue to progress their wish for AD?

SENIORITY OF THE COORDINATING REGISTERED MEDICAL PRACTITIONER AND SECOND ASSESSING DOCTOR

We have highlighted above the need to specify the necessary knowledge, skills and competence of those involved in assessment processes. In addition SPPC believes that the coordinating registered medical practitioner and second assessing doctor (the people actually signing off the AD request) should be professionally senior (for example at consultant or general practitioner level). As drafted the Bill would permit two doctors in the most junior roles to sign off an assisted death. This is not desirable and would be out of line with other medical decisions of significant magnitude which require senior sign off.

Question 4 – Method of dying

The Bill authorises a medical practitioner or authorised health professional to provide an eligible adult who meets certain conditions with a substance with which the adult can end their own life.

Which of the following most closely matches your opinion on this aspect of the Bill?

- It should remain unlawful to supply people with a substance for the purpose of ending their own life.
- It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill
- It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill, and it should also be possible for someone else to administer the substance to the adult, where the adult is unable to self-administer.
- Other – please provide further detail

If you have further comments, please provide these below

The Bill currently fails to acknowledge or deal adequately with potential complexities involved around the person ending their life. Some examples are provided below:

WHAT IF THE MEDICATION DOESN'T HAVE THE EXPECTED EFFECT?

The Bill is silent about dealing with any medical complications arising during the assisted death. Experience from other jurisdictions suggests that complications are not unusual. Ingestion of medication is not a reliable route for some people, especially if they are already ill. People may vomit the medication or fail to absorb a lethal or rapidly lethal amount. The person may then not die, or the process of dying may be more protracted and distressing than expected.

The role of any clinical professionals called to intervene in circumstances where complications arise need to be made clear. What is the duty of care owed in such circumstances? Will they be expected to administer intravenous medication to cause the person's death if the oral route fails and/or causes distress? This would constitute euthanasia, and the Bill should be very clear and explicit about this if the legislative intention is to authorise this in certain circumstances. Is there a need to check with the person that they wish to continue with the AD? If there is then what should the clinician do if the person no longer has capacity? This need for clarity goes beyond the attending registered medical practitioner and/or authorised healthcare professional mentioned in the Bill. There is a need for clarity for others who may become involved in the event of complications (e.g. ambulance staff, GP, A&E staff etc). All will need guidance and direction so that they are clear what actions are expected – they may have a concern about criticism and sanction for doing either too much or too little. What would be the position of someone called to attend in such an "emergency" scenario who has a conscientious or other objection to involvement in AD?

Some people accessing AD may want to know what would happen in the event of there being complications in the dying process. As the Bill stands these questions can't be answered. This makes it difficult for the clinicians involved to meet normal standards of informed consent.

WHAT IF THE ILLNESS TRAJECTORY DOESN'T FOLLOW A PREDICTED PATH?

The Financial Memorandum (para 93, p18) sheds more light on the assumptions about when the assisted death will occur (in relation to their wider illness trajectory) stating:

"It is thought likely that a terminally ill adult who dies as a result of being provided with assistance to end their life would have a very short time left to live, and therefore that care would have continued for a matter of days or, at the most, weeks."

It is unclear whether this will be the case in practice and as explored earlier the definition of terminal illness is much broader than this. Assisted death at this very late stage of illness may be hard to plan and schedule as the person would have wished. They may die naturally in advance of the scheduled date. If their condition deteriorates, would it be expected that the medical practitioner bring forwards the date at short notice? People may choose to take the medication at an earlier stage, concerned about a loss of capacity as their disease progresses. A study of the experiences of palliative care practitioners involved in assisted dying in Canada reported that the requirement for the person to have capacity can impact on symptom management strategies - people were reluctant to receive adequate opioids and other medication to control pain or other symptoms in case it impacted on their eligibility for assisted dying. People commonly wanted to delay assisted dying to spend time with family, but were also concerned that by delaying they might lose capacity and become ineligible. In these circumstances people sought guidance from palliative care staff about prognosis, which was difficult to provide with the precision sought.

DEALING WITH COMPLEX SOCIAL AND EMOTIONAL SITUATIONS

Aside from clinical complications it is easy to envisage complex scenarios being precipitated by the proximity of death and loss at the scheduled time of the assisted death e.g. sudden uncertainties, conflicts between family members, suggestions of undue influence. The attending healthcare professionals would need to be equipped to cope with such circumstances, and be working within a clear framework of guidance.

PEOPLE WITH REDUCED DEXTERITY OR SWALLOWING DIFFICULTIES

The particular needs of people with reduced dexterity and/or swallowing difficulties should be considered. These are quite common symptoms (for example amongst people with some progressive neurological conditions such as advanced multiple sclerosis or motor neurone disease).   People with such conditions might chose an earlier death if self-injection or doctor/nurse injection were not available as options.

EVIDENCE BASE ON DRUGS FOR ASSISTED DYING

In other jurisdictions a wide variety of lethal drug combinations are used for people undergoing AD. The normal processes used to generate an evidence base for new drugs (or existing drugs being used for a new purpose) have not been put in place, nor is there consistent and reliable recording of drugs and doses used in individual instances. As a result, there is not an established evidence base on the best medications and routes of administration to achieve reliably a pain-free dignified assisted death. There is even less evidence relating to the use of drugs for this purpose in the case of young people aged 16-21.

It is our understanding that Scottish government does not have powers to approve drugs for use in assisted dying and that a mechanism to change this situation has not yet been agreed with the Westminster Parliament. Medication intended to cause death would be an entirely new medical intervention in a Scottish context. Normally a new drug wouldn’t be licensed without an evidence base on efficacy and safety produced through appropriately rigorous research.

PLACE OF DEATH

The Bill doesn’t say anything about where AD will take place. The Financial Memorandum states that “only around 10% of people” die in hospital which is factually incorrect - in 2023 46% of people died in a hospital. The Policy Memorandum says that the place will be chosen by the person accessing AD. Some may choose a hospice (for example if they are already an inpatient) or the care home where they are already living. The Policy Memorandum and the Finance Memorandum assume that since the staff doing the actual AD will attend the premise at the chosen time, that the impact on other staff in the institution will be minimal. This underestimates the impacts and demands on staff who work at the premises. For example, in a care home nurses and social care workers will be providing care and support to the person (and their family) for a potentially extended period in the run up to the AD. Any issues or complications (for example family conflict or concerns about coercion) or need for extra emotional/psychological support will land with frontline care home staff in the first instance. Care home staff may also then need to seek support from Care Home Liaison Nurses/Mental Health Care Home Liaison Nurses/District Nurses/Advanced Nurse Practitioners. Premises staff are also likely to provide support to attending family afterwards (and be fully involved in the "final acts of care" – washing and laying out the body of the deceased). The place of death therefore has implications for resources and levels of training required for staff. It also has implications for the scope of conscientious objection provisions – it can be seen that an AD in a care home or hospice may involve a wide group of staff.

Question 5 - Health professionals

The Bill requires the direct involvement of medical practitioners and authorised health professionals in the assisted dying process. It includes a provision allowing individuals to opt out as a matter of conscience.

Which of the following most closely matches your opinion on how the Bill may affect the medical profession? Tick all that apply.

- Medical professionals should not be involved in assisted dying, as their duty is to preserve life, not end it.
- The Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out.
- Assisting people to have a "good death" should be recognised as a legitimate role for medical professionals
- Legalising assisted dying risks undermining the doctor-patient relationship
- [✓ Other – please provide further detail]

“Assisting people to have a good death” is already recognised as a legitimate role for medical professionals. Indeed assisting people to have a good death is a major part of the health and social care system. Some respondents may however interpret this question as really asking whether participation in assisted dying should be recognised as a legitimate role for medical professionals. This lack of clarity in terminology is problematic and should have been addressed prior to publication of this consultation. Those undertaking the analysis of the survey need to be aware of this ambiguity, and the presentation of the analysis of responses to this question also needs to be carefully considered.

SPPC understands and respects the reasons why the term “assisted dying” is preferred by many advocates for a change in the law to “assisted suicide”. However the term “assisted dying” is non-specific, confusing and doesn’t reflect defining characteristics of the practise which differentiate it from palliative and end of life care (i.e. the choice to purposely shorten life and to control the timing of death).

If you have further comments, please provide these (2000 words)

WITHOUT WESTMINSTER AGREEMENT THERE WILL BE NO PROTECTIONS FOR CONSCIENTIOUS OBJECTORS

SPPC has some concerns about whether the provisions for conscientious objection in the Bill are adequate. At a macro level our understanding is that Clause 18 (which addresses conscientious objection) has no effect except on condition that the Scottish Parliament is granted powers by Westminster in respect of the regulation of health professionals (currently a reserved matter). Clause 22 states that anything in the Bill which relates to reserved matters has no effect (unless agreement is reached with Westminster). It is therefore possible that AD could become legal in Scotland without any protections for conscientious objectors.

ONLY CERTAIN STAFF MAY HAVE THE RIGHT TO CONSCIENTIOUSLY OBJECT

In terms of the detailed wording of Clause 18 we note that in this context “participation” has been given quite a specific meaning by the UK Supreme Court when interpreting a similar conscience clause (section 4 of the Abortion Act 1967, as interpreted in *Greater Glasgow Health Board v Doogan* [2014] UKSC 68), so that conscientious objection would only be protected for those ‘directly’ involved in the AD process, although a larger number of people could be expected to have indirect involvement.

IT ISN’T CLEAR HOW SOMEONE WOULD PROVE THEIR CONSCIENTIOUS OBJECTION

Clause 18 is similar to law which provides protections to health professionals who have a conscientious objection to abortion. Both the Abortion Act 1967 and the AD Bill place the burden of proof on the objector. The Abortion Act goes on to state that a sworn statement will be enough to discharge that burden. The AD Bill has no such provision about proof. It is not clear why this is omitted, and it is also quite hard to think of how else an objector might prove their conscientious objection.

LEGAL DUTIES COULD CONFLICT WITH CONSCIENTIOUS OBJECTION

Recent case law gives doctors a duty to inform patients of all reasonable treatment options (*Montgomery v Lanarkshire Health Board* [2015] UKSC 11). This means that, should AD become lawful, doctors may be under a legal duty to raise the subject of AD with all patients who meet the eligibility criteria. If the Bill does not intend to impose such a duty on doctors, it should be amended to include a clause stating that there is no duty on doctors to raise AD with eligible patients.

THERE ARE OTHER VALID REASONS FOR NON-PARTICIPATION, NOT BASED ON CONSCIENCE

SPPC is also concerned about the position of health and care practitioners who may have other valid reasons for not wishing to participate in AD, although these reasons are not on the basis of conscience. For example a practitioner might have concerns about the impact of participating in AD on their emotional wellbeing and mental health. Some staff involved in the care of patients towards the end of life will experience moral distress as a result of assisted dying. Reports from other jurisdictions suggest that many practitioners struggle with ethical dilemmas and value conflicts (professional and personal). This is true for staff involved with people seeking assisted dying but not directly involved in provision. Appropriate frameworks of guidance and support for emotional, psychological and spiritual wellbeing of staff are a necessary part of any proposal for assisted dying.

Polls suggest that far fewer medical professionals report a willingness to being involved with assisted dying than express support for it in principle. Evidence suggests that support for assisted dying is lower amongst those specialties with extensive involvement with palliative and end of life care.

A survey of palliative medicine doctors in Scotland in 2022 found that 75% of respondents would not be willing to participate in any part of the assisted dying process. 98% of respondents stated that assisted dying should not be part of mainstream healthcare.

An alternative legal model addressing the concerns raised above would be to enshrine an assumption of non-participation and adopt an “opt in” rather than an “opt out " system. Such a system would likely reduce the volume of conscience claims, but it would not eliminate such issues and so would still require to make meaningful statutory provision for conscientious objection.

The Bill seeks to protect practitioners from civil and legal liability for anything which happens during the lawful provision of AD. However practitioners may feel vulnerable to a claim (for example from a bereaved family of someone who has accessed AD) alleging that some aspect of the AD was unlawful. Current professional indemnity protection does not cover AD.

Any approach to objection should be flexible enough to allow a person to change their position. The fact that they had previously participated in AD should not preclude them from objecting to future participation on conscientious or other grounds. The experience of AD may lead some to change their position.

Question 6 - Death certification

If a person underwent an assisted death, the Bill would require their underlying terminal illness to be recorded as the cause of death on their death certificate, rather than the substance that they took to end their life.

Which of the following most closely matches your opinion on recording the cause of death?

- I do not support this approach because it is important that the cause of death information is recorded accurately
- I support this approach because this will help to avoid potential stigma associated with assisted death
- [✓ Other – please provide further detail]

SPPC does not support the approach in the Bill for 2 reasons. We believe data on the death certificate should accurately reflect the cause of death. We also believe that deliberately hiding AD as the cause of death risks reinforcing any stigma which may or may not attach to AD.

If you have further comments, please provide these (2000 words)

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 contributory conditions. Not recording the actual cause of death, as the Bill requires, would undermine the basis of death certification in Scotland (and the public health record and research based on it). This approach is 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 – such an approach plants and reinforces a view that a death through AD is in some way shameful.

Many practitioners may feel uncomfortable or unable to complete a death certificate which did not record accurately and fully the cause of death.

Question 7 – Reporting and review requirements

The Bill proposes that data on first and second declarations, and cancellations, will be recorded and form part of the person's medical record.

It also proposes that Public Health Scotland should collect data on; requests for assisted dying, how many people requesting assisted dying were eligible, how many were refused and why, how many did not proceed and why, and how many assisted deaths took place.

Public Health Scotland would have to report on this anonymised data annually and a report would be laid before the Scottish Parliament.

The Scottish Government must review the operation of the legislation within five years and lay a report before the Scottish Parliament within six months of the end of the review period.

Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?

- [✓ The reporting and review requirements should be extended to increase transparency]
- The reporting and review requirements set out in the Bill are broadly appropriate

- The reporting and review requirements seem excessive and would place an undue burden on frontline services
- Other – please provide further detail

If you have further comments, please provide these

A robust reporting regime should allow for monitoring, scrutiny, audit, regulation and research into a controversial, contested and potentially evolving area of public policy. SPPC does not believe that the arrangements proposed in the Bill are sufficient.

THE BILL REQUIRES REPORTING ON DATA WHICH WOULD NOT BE AVAILABLE

Clause 24 sets out the data which Public Health Scotland (PHS) must provide to ministers in relation to AD. 24 (2) c iii says that data should be provided on “the reasons given by persons as to why they did not go on to make a second declaration, be provided with an approved substance or, as the case may be, to use the substance,”

However, the Bill contains no requirements for these reasons to be discussed with the medical practitioner. There is no place for recording this information on any of the declaration forms published as part of the Bill. It is therefore unclear how PHS will report on this since there is no process for creating a data source.

The same is true for the provision of data in respect of 24 (2) e “the reasons given by persons wishing to be lawfully provided with assistance to end their own lives.” There is nothing in the Bill which requires the collection and recording of data on this topic so it can’t be reported on. This reinforces our concern expressed in response to Q3 of this call for views – that exploring and understanding the reasons and motivations for seeking AD are not part of the assessment process.

Understanding people’s reasoning and motivation is vital to understanding how the Bill is operating in practice, yet the Bill fails to establish a process to gather and report on this issue.

THE LIMITED DATA SET PROPOSED IN THE BILL DOES NOT SUPPORT PROPER UNDERSTANDING OF THE OPERATION OF THE BILL

The characteristics and circumstances in 24 (3) are a limited list seeking to understand more about who accesses AD. This will make it harder to quantify and understand inequalities in relation to uptake. For example the proposed data set wouldn't pick up if homeless people or prisoners were disproportionately likely or unlikely to access AD. Postcode district is only a crude measure of economic and social disadvantage, and may be unreliable in a small sample size.

Other important data to gather are the rates of referral to specialists in relation to assessment of capacity, terminality of condition, and psychiatric assessment. Unlike many jurisdictions Scotland should also record referral to specialist palliative care and the outcome of that referral. Also, given the lack of precision in the Financial Memorandum, it would be important to record the time inputs required of practitioners to operate the AD processes.

INFORMATION GOVERNANCE

Information governance relating to the data gathered through the declarations should support exploration of important research questions.

ARRANGEMENTS FOR SCRUTINY

We note that the Bill doesn't say anything about the regulation, scrutiny and inspection of organisations providing an AD service, and reporting of those processes as happens for other services. SPPC believes that the arrangements should be made explicit within the Bill. The data required to support effective inspection and scrutiny of AD services will be of a more detailed and specific nature than that needed for an annual report to Ministers or a 5-year review of the operation of the Bill (though it could also inform these). In some jurisdictions where AD has been legalised, there are poor levels of completion of the documents which are supposed to provide an audit trail for each individual death, and are the source for some of the data for higher level reporting. Robust processes and auditing of those processes and sanctions for non-completion need to be put in place.

LACK OF RECORDING AND REPORTING ON UNTOWARD INCIDENTS AND CONCERNS

We note that the Bill doesn't require any recording of untoward incidents. This should include: instances where the lethal substance was taken but death took a long time; complications requiring intervention; side effects; what the substance involved and dose was; time between administration of the lethal medication and death. There should be a requirement to collect and publish data on this. In addition to the importance of including this in annual reports to parliament, Clause 27 proposes a review of the operation of the Act after 5 years. Subsection 2 (b) says that this review must include “any concerns with the operation of the ACT which have been raised”. It is important that systems and processes are put in place from the outset of the implementation of the Act to identify and record concerns otherwise the 5 year review will have little to inform it.

DATA TO EVIDENCE THAT PRACTITIONERS INVOLVED IN AD HAVE REQUISITE COMPETENCE

The Bill allows for Scottish Ministers to specify the skills and qualification required of those practitioners assessing, signing off and delivering AD. There is a need for data to be recorded to quality assure that these requirements are being met in practice, including that practitioners have undergone relevant training, and kept their practice up to date.

SCOPE OF THE 5 YEAR REVIEW TOO NARROW

SPPC would like to see the scope of the 5 year review broadened. We would like to see the review consider issues of wider public importance. This should include for example:-

- the impacts of AD on the practice and provision of palliative care (including impacts on health and social care professionals involved to different degrees in AD)
- changes in resourcing of palliative care since the passing of the Act
- levels of public understanding and awareness of AD (measured against a baseline when the Act comes into force).
- levels of public understanding and awareness of palliative care (measured against a baseline when the Act comes into force).

UNDERSTANDING CRUCIAL CONVERSATIONS

Crucial aspects of how AD operates in practice will be difficult to measure and understand because it concerns the nature and quality of relationship and interaction between the person seeking AD and the practitioners supporting them (both in initial informal discussions and during the formal processes). One option in respect of the formal assessment processes might be to legislate to require anonymised digital recordings of the encounters, which could be used for research purposes.

Question 8 – Any other comments on the Bill

Do you have any other comments in relation to the Bill?

LACK OF DETAIL ON THE FACE OF THE BILL

SPPC is concerned that a number of key issues are either left to subsequent guidance or included in the Bill but remain unclear or are not mentioned at all. Many of these issues are not trivial, but rather are fundamental to how a system of AD may operate in Scotland. Leaving key issues to guidance makes it more difficult to comment on the potential impacts of the Bill.

These issues include:

- A consistently operable definition of “terminal illness” (not clear)
- The competencies, standards of diligence and training required of assessing medical practitioners (left to guidance)
- The process by which coercion will be reliably identified (left to guidance)
- The response expected of health and care workers in the event that a person has complications and /or doesn’t die as expected during AD (not mentioned)
- Responsibility for scrutiny of organisations with a duty to provide AD (not mentioned)
- Lack of a process whereby concerns may be raised about individual cases of AD (not mentioned)
- Lack of a process for the review and investigation of individual cases (not mentioned)

LACK OF CONSIDERATION OF THE PARTICULAR NEEDS OF YOUNG PEOPLE

As noted at different points in this response the Bill doesn’t take account of the specific needs and circumstances of young people (aged 16-21). There are very significant medical, neurological, social and psychological differences between an older adult with an advanced progressive illness and a young person with a life-shortening condition that may meet the Bill’s definition of “terminal illness”, but these are not reflected in the Bill.

THE NEEDS OF INDEPENDENT AND THIRD SECTOR ORGANSATIONS

In making any detailed guidance consideration should be given to the particular requirements of Independent and Third sector organisations who are major providers of palliative care.

Some Third sector organisations such as hospices are concerned about potential negative impacts on their fundraising and reputation if they are involved (or required to be involved) in providing AD. Sustainable funding is already a problem for hospices. Some organisations may feel caught between the expectation of statutory funders that they be involved in AD and the legal requirement to work within their registered charitable purposes which may not encompass AD. Such organisations may need an “organisational opt out or for participation to be based on an “opt-in” system.

LACK OF ANY SPECIFED ORGANISATIONAL RESPONSIBILITIES

The Bill doesn’t say anything about organisational duties to provide AD. The Policy Memorandum makes many assumptions (implicit and explicit) about the role of specific organisations but none of these are reflected in the Bill. The Bill deals entirely in terms of what actions individual practitioners may take in certain circumstances.

This makes it harder to assess the impact of the Bill on different organisations.

PALLIATIVE CARE CONSULTATIONS IN A CONTEXT WHERE AD IS LEGAL

It is a fundamental change to role of clinicians to encompass the deliberate shortening of life. Fundamental to good palliative care are open and honest conversations between clinicians and the people they care for, exploring people’s needs, hopes, wishes, plans and fears for the future. The legalisation of AD may change the feel and dynamic of some of these conversations as the role of the clinician has changed very significantly.

EMBEDDING OF AD WITHIN THE HEALTH AND SOCIAL CARE SYSTEM

In producing this response SPPC heard from some stakeholders that if AD is to be legalised it should be delivered by a process and institutions separate to the health and social care system. Arrangements such as these are in place other jurisdictions, for example in Austria and Switzerland.

PRIVILEGING OF ASSISTED DYING VS PALLIATIVE CARE

SPPC is struck that should the published Bill become law then people in Scotland will have a right to AD grounded in statute, with timescales, choice of place and other aspects of delivery backed by specific ministerial guidance. Ministers will be required to report to parliament on AD each year, and a more substantial five year review will also be mandated.

These arrangements for AD will be in stark contrast to those relating to palliative care, despite the fact that palliative care can benefit vastly more people than will ever access AD, based on the numbers projected in the Policy Memorandum.

OPPORTUNITIES TO SUPPORT PEOPLE TO LIVE AND DIE WELL BETTER WITH PALLIATIVE CARE

Despite its relevance and great benefit to tens of thousands of Scots each year there is currently no explicit statutory underpinning for the timely provision of high-quality palliative care for people who need it. There are no current national standards for palliative care. There are currently no arrangements for annual reporting to Scottish Ministers on the quality and outcomes of care for people needing palliative care. There are no national programmes of investment to improve palliative care. Many of the recommendations arising from the Health and Sport Committee's 2015 Inquiry into palliative care remain unfulfilled.

These matters should all be addressed as matters of urgency, for the betterment of the people of Scotland, regardless of what happens with this Bill. We cover resourcing of palliative care in our submission to the Finance and Public Administration Committee.

IN CONCLUSION - 5 KEY POINTS

ONE

Ensuring equitable reliable receipt of general and specialist palliative care is an essential safeguard. Regardless of the Bill this should be progressed as a genuine national priority.

TWO

The definition of "terminal illness" in the Bill is not precise enough, which will lead to variation in interpretation and could mean that people with years to live are deemed eligible, which is at odds with the stated policy intent of the Bill.

THREE

Under the process set out in the Bill assisted dying is not positioned as the final stage of a sequence which is only reached after other efforts to identify and address suffering are completed. Instead assisted dying is available without any legal requirement for exploration of the applicant's suffering and the potential to relieve it.

FOUR

The Bill makes no mention of arrangements for the inspection, scrutiny or audit of the provision of assisted dying services, nor arrangements for raising and investigating concerns about individual cases.

FIVE

The Bill lacks detail on many issues which are fundamental to how a system of AD may operate in Scotland. Many key issues are left to be determined through Ministerial guidance. This makes it more difficult to comment on the potential impacts of the Bill and reduces the potential for adequate scrutiny.

Questions asked in the Finance and Public Administration Committee Call for Views on the Finance Memorandum (FM) Published Alongside the AD Bill

1. Did you take part in any consultation exercise preceding the Bill and, if so, did you comment on the financial assumptions made?

Yes, SPPC took part in the consultation on the proposal for the Bill and commented on the financial assumptions.

2. If applicable, do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum (FM) published alongside the Assisted Dying for Terminally Ill Adults (Scotland) Bill?

No.

In our comments during the consultation exercise we made these key points relating to financial resources which are not reflected in the FM:

THE CLAIM THAT INTRODUCING AD WILL BE FOLLOWED BY AN INCREASED INVESTMENT IN PALLIATIVE CARE IS ILL-FOUNDED

Firstly, SPPC's position is that equitable access to palliative care is an important safeguard which can reduce (but not eliminate) some of the potential harms of assisted dying (AD) to vulnerable people. We argued the need for significant investment in palliative care. The consultation proposal included data and statements about how in other jurisdictions the introduction of AD has been accompanied by increased investment in palliative care. SPPC challenged the idea that this was consistently true, and also whether there was any inevitability in any such link. SPPC said:

> "Proponents and those contemplating voting to legalise assisted dying should seek firm commitments from Scottish Government about significant and

> specific investment needed to improve palliative care. SPPC would be happy to work with the proponents of the Bill to identify some of the resource requirements for improving palliative care. The Financial Memorandum accompanying the draft Bill should reflect costs relating to the improvement of palliative care in Scotland."

The consultation Proposal noted that when the Australian State of Victoria passed assisted dying legislation the government provided funding of Aus$72 million. By SPPC's calculation this would equate to £33 million in Scotland, allowing for Scotland's smaller population. The Proposal also noted that after assisted dying was legalised in Canada the government committed to providing $6 billion over ten years to improve palliative care. This would equate to £512m in Scotland again allowing for our smaller population (calculated in 2021).

The potential financial consequences of AD for palliative care in Scotland remain uncertain. The Finance and Public Administration Committee, and the Health, Social Care and Sport Committee might decide it would be helpful to invite Scottish Ministers for any views they have on future investment in palliative care.

THERE IS A LIKELIHOOD THAT PALLIATIVE CARE RESOURCES WILL BE SPREAD EVEN MORE THINLY TO RESPOND TO ASSISTED DYING REQUIREMENTS

Secondly, SPPC highlighted the differential impacts of costs and savings within the health and social care system. Although assisted dying may lead to some savings (people die earlier and so make less use of health and social care services) it is important to remember that additional costs may be incurred in one service/setting whilst savings accrue elsewhere without a mechanism to redistribute funds between siloed budgets (this is a well established flaw within Scotland's health and social care system). There is a concern that this may occur for specialist palliative care services. Whilst the Bill does not stipulate that specialist palliative care practitioners should be involved in the provision of assisted dying such practitioners can be expected to be working with people who are seeking and eventually proceeding with assisted dying. Specialist services in other jurisdictions report increased demands on time and diversion of resources from palliative care in order to support people and families around assisted dying. Assisted dying may be experienced as an unfunded additional demand locally even though there may be net savings across the system. The reality for many services will be additional pressures and difficult choices between undertaking assisted dying assessment and its enactment, and meeting the needs of other people and their families.

SPPC has heard concerns from General Practitioners about the time required to operate the Bill as envisaged, including complex and sensitive discussions, lengthy assessment processes and the requirement for them (or a health professional they nominate) to be in attendance at the AD until the person dies. The AD will take place at a venue chosen by the person and hence is not likely to be on the practice premises, requiring travel time as well as attendance. These demands may not sound significant but they are being made of a system which is already very over stretched.

We note with grave concern the risk that costs of AD will be met from existing finite and very pressured palliative care budgets. The FM makes frequent multiple references to how costs will be "*met by existing budgets*". Obviously the reality is that existing budgets are already under great pressure and the opportunity cost of money for AD is reductions in funds for other purposes. Where AD costs come from palliative care budgets the costs of AD will impact on work to provide and improve palliative care. Logically it would make sense for AD costs to be met from budgets where any savings from AD might be expected to accrue (for example from acute hospital budgets). However, SPPC believes it is very possible that a default mindset may be for AD costs to be met from palliative care budgets, as has happened in Australia, and that IJBs, NHS Boards and SG will choose to meet AD costs from palliative care budgets. This is something that the Committee might wish to explore further.

A significant proportion of specialist palliative care in Scotland is provided by voluntary hospices, funded in part by charitable fundraising and in part funded by IJBs. There are pre-existing deficiencies in funding and funding mechanisms for Scottish hospices. Many hospices have concerns about the cost (and other) impacts of AD on their operation, including potential impacts on their ability to raise charitable funds. The submission to the committee by Hospice UK goes into these issues in more detail.

RESEARCH SHOULD BE BUILT IN TO THE PROCESS FROM THE START

Thirdly, SPPC argued that 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 on mainstream care received towards the end of life, the experiences of people and their families, of staff involved and other relevant and emergent issues.

3. Did you have sufficient time to contribute to the consultation exercise?

Yes.

4. If the Bill has any financial implications for you or your organisation, do you believe that they have been accurately reflected in the FM? If not, please provide details.

The costs to SPPC have not been accurately reflected in the Financial Memorandum.

SPPC is a Third Sector organisation which provides a network / umbrella body for virtually all organisations involved in providing and improving palliative care in Scotland. We also work directly with communities and provide public information.

In terms of the Bill roles we are likely to play include: inputting to the development of guidance; supporting development and sharing of good practice; dissemination of policy; developing and providing public information.

The FM provides some estimates of costs to SG of developing guidance. However, these estimates don’t appear to take account of the fact that these guidance development processes are largely dependent on input from practitioners and other non-SG stakeholders, including many in the Third and Independent sectors. These processes can be very time consuming for participants. A very relevant example is the process to develop guidance for a new approach to the assessment of eligibility for benefits of terminally ill people. SPPC chaired a Stakeholder Reference Group. SPPC was also a member of the Clinical Advisory Group. These groups met for well over a year and consumed a significant amount of SPPC staff time, and the same was true for other Third and Independent Sector stakeholders. In our experience there is generally no reimbursement of costs by SG.

Unless additional funding not currently identified in the FM were made available to SPPC any work related to implementing the Bill would have an opportunity cost of having less resource for the improvement of palliative care.

5. Do you consider that the estimated costs and savings set out in the FM are reasonable and accurate?

We recognise the uncertainties and difficulties in estimating costs based when the numbers of people accessing assisted dying is uncertain. We say more about the number of people projected to access AD in question 7. Other key parameters are unclear (as the FM recognises savings achieved are largely dependent on counterfactuals – how long a person who ended their life might otherwise have lived and the services therefore that were not consumed). However, aside from these unavoidable uncertainties there are some fundamental problems with some of the thinking behind the cost estimates.

THERE IS NOT ENOUGH CLARITY ON PATHWAYS AND ORGANISATIONAL RESPONSIBILITIES TO MAKE POSSIBLE AN ACCURATE PREDICTION OF COSTS

The Bill is very largely silent on the organisational arrangements by which AD will be delivered. It would make AD a legal activity for registered practitioners, but places no duties on organisations to provide such a service. The assumption in the policy memorandum seems to be that the AD process will largely be led by General Practitioners. The lack of clear pathways or even basic organisational responsibilities in the Bill makes it harder to estimate costs and savings and organisational impacts. For example, the FM when considering the costs of AD to private and third sector care homes and hospices (para 81 p15), states that:

"…..as the parts of the assisted dying process that will incur more significant costs (such as the assessment process and other costs incurred by registered medical practitioners) will not directly involve such organisations, it is anticipated that any costs incurred by private and third sector care homes and hospices as a result of an assisted death taking place on their premises will be minor."

There are two issues with this. Firstly this pre-supposes the non-involvement of some categories of organisation, but the Bill itself doesn't say anything about which organisations will or won't be involved. The Bill doesn't even place a duty on NHS Boards to provide AD. Providing palliative and end of life care are core functions of all hospices and many care homes (those for older people) so it is quite plausible that some may become involved in the AD process set out in the Bill (hospices employ nurses, doctors and pharmacists and very many care homes employ nurses).

The Financial Memorandum states that "only around 10% of people" die in hospital which is factually incorrect - in 2023 46% of people died in a hospital. The Policy Memorandum says that the place will be chosen by the person accessing AD. Some may choose a hospice (for example if they are already an inpatient) or the care home where they are already living. The Policy Memorandum and the Finance Memorandum assume that since the staff doing the actual AD will attend the premise at the chosen time, that the impact on other staff in the institution will be minimal. This underestimates the impacts and demands on staff who work at the premises. For example, in a care home nurses and social care workers will be providing care and support to the person (and their family) for a potentially extended period in the run up to the AD. Any issues or complications (for example family conflict or concerns about coercion) or need for extra emotional/psychological support will land with frontline care home staff in the first instance. Care home staff may also then need to seek support from Care Home Liaison Nurses/Mental Health Care Home Liaison Nurses/District Nurses/Advanced Nurse Practitioners. Premises staff are also likely to provide support to attending family afterwards (and be fully involved in the “final acts of care” – washing and laying out the body of the deceased). The place of death therefore has implications for resources and levels of training required for staff.

MANY COSTS HAVE NOT BEEN ANTICIPATED

The FM focusses on the costs (and savings) associated with the small numbers of people projected to access AD. However, whilst the FM projects that the numbers of people proceeding through the formal processes set out in the Bill are small, there is a need for a very large number of staff across the health and social care system to receive appropriate training. Frontline staff working in primary care, in care homes, care at home, hospitals and hospices will likely be asked about AD by the people they are providing care and treatment for, and the families of those people. Staff need to be able to respond appropriately in these early “informal discussions”. The Policy Memorandum recognises this (p11), but the Bill focusses only on the formal AD process.   We know that it takes skills, knowledge and confidence to engage well in conversations about end of life issues generally, and many staff find these interactions difficult. Even those who are already well equipped will require additional training to be able to respond appropriately if AD is on the agenda. It doesn’t take much imagination to understand that engaging with a person who is considering ending their own life (alongside the challenges of living with a serious illness) may be a very complex, demanding and challenging interaction. It is vital that staff are properly prepared and supported to be able to respond at a level appropriate to their role. Aside from the costs of developing and delivering appropriate training the biggest and very significant cost is releasing staff from frontline duties to be able to attend/engage with training. Far from being organisations likely to incur “minor” costs (para 81), hospices and care homes are likely to be organisations which will incur very significant costs in this regard. Beyond hospices, care at home services and care homes other Third sector providers of palliative care likely to be impacted include nursing services provided by Macmillan Cancer Support and Marie Curie. There are many other Third sector organisations who provide information, advice and support around end of life issues and there will be cost implications for each of them. Beyond costs around initial implementation there will be substantial recurrent training costs for new staff. These are omitted in the FM. Liam McArthur MSP’s letter to the Convenor of the Finance and Public Administration Committee (17th June 2024) correcting various aspects of the FM acknowledges the will be ongoing annual training costs and says that these will be "*absorbed by existing training budgets in future years*" (footnote p2). Again, the idea of absorbing additional substantial costs within existing overstretched budgets seems intuitively unconvincing.

We note that the FM doesn't mention NHS 24, the key channel for health care public information and 24/7 telephone access, as an organisation for whom AD will have cost implications.

We note that the Bill makes no provision for the inspection and scrutiny of services providing AD, and there is consequently no cost identified in the FM. Para 78 covers regulatory and representative bodies which regulate individual practitioners. There is no provision for the regulation and scrutiny (including inspection) of organisations responsible for providing AD.

6. If applicable, are you content that your organisation can meet any financial costs that it might incur as a result of the Bill? If not, how do you think these costs should be met?

SPPC is a Third Sector organisation whose income comes from a mix of subscriptions from our members (NHS Boards, Hospices, other charities and professional association), charitable grants, SG grants and conferences. There is always uncertainty about our income from one year to the next, and often major delays in receipt of funds from statutory sources during which we are only able to continue operating by using charitable reserves. In this context it is hard to be sure that SPPC can meet the financial costs we might incur as a result of the Bill. What seems most likely to happen is that SPPC will have to move some existing resources to work on AD. This would be at the expense of work on our core purpose of improving palliative care. We might need to pay for legal advice to be sure that any work was within our legally registered charitable purposes.

7. Does the FM accurately reflect the margins of uncertainty associated with the Bill's estimated costs and with the timescales over which they would be expected to arise?

In this section we look at the numbers of people which the FM estimates will seek assisted dying. It is obviously difficult to give precise estimates. In general terms however SPPC believes that the estimates in the FM are on the low side. We explain this thinking below:

The estimates in the FM are derived from international comparisons, and exact comparators don't exist. Oregon and Victoria have different eligibility criteria to those in the Scottish Bill. Specifically both Oregon and Victoria link eligibility to a specific "6 months left to live" criterion (Victoria also allows those with 12 months left to live if they have a degenerative neurological disorder). These criteria are tighter than the definition of "terminal illness" used in the Bill before the Scottish Parliament. We've commented extensively on this definition in our submission to the Health, Social Care and Sport Committee, and due to the definition's imprecision we believe eligibility for AD is potentially quite broad.

In addition to having to use imperfect comparators, there are then choices about how to use this international data. For example in Para 14 p3 of the FM a choice has been made to suggest a baseline year 1 figure for Scotland of 5 AD deaths per million population. This is close to the Oregon baseline (4.87) but is only a quarter of the Victoria baseline (16). This paragraph goes on to project numbers as "increasing steadily". However, the numbers quoted in the FM for Victoria have more than doubled in the first 3 years (35 per million) and are already approaching those achieved in Oregon only after 20+ years (54.9 per million).

Again SPPC is not suggesting that the numbers in the FM are necessarily wrong. We are highlighting that it is easy to make a good case that the numbers in Scotland will be higher than those suggested in the FM. The Medical Advisory Group established by the MSP sponsoring the Bill calculated an upper range of 580 annual AD deaths per year (based on 1% of total deaths being AD once it has become established). The FM calculations choose to use a figure of 400 annual deaths per year (31% lower than the estimate by the Medical Advisory Group).

Beyond the challenges of quantitative comparisons and statistical interpretation are the different cultural and institutional factors at play in different jurisdictions. Furthermore, over a 20 year period eligibility criteria may well change (eligibility tends to broaden over time). Many jurisdictions end up with AD deaths accounting for very significantly more than 1% of total deaths.

Mark Hazelwood
CEO
Scottish Partnership for Palliative Care

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