



ASSISTED DYING FOR TERMINALLY ILL ADULTS (SCOTLAND) BILL

Medical Advisory Group Report

November 2022

Foreword

Dr Sandesh Gulhane MSP (Chair of the Medical Advisory Group)

In submitting this report, I wish to take the opportunity to express my gratitude to several people.

My main thanks go to my colleagues of the Assisted Dying for Terminally Ill Adults (Scotland) Bill Medical Advisory Group (MAG). They are all experts in their field who gave their time, enthusiasm and expertise to help guide the group from initial thoughts to recommendations.

Likewise, I am grateful to the executive secretariat team for keeping me right and for pulling the culmination of the group's work into this report. I wish to thank the many individuals who gave their time, shared their knowledge, and acted as liaisons to wider networks of practitioners and lived experience voices to make sure that all sectors and voices were included in our considerations.

We have also been greatly assisted by discussions with international colleagues who have helped us to gauge the most appropriate recommendations for Scotland. The evidence provided by colleagues in Australia, Canada, and the US helped to shape our final recommendations. A great deal of critical analysis, research, and testing of the recommendations was undertaken with the help of those stakeholders who now operate in jurisdictions where assisted dying is legal. That we have managed to complete this report is due to the knowledge, lived experience, commitment, and enthusiasm of all these colleagues and contributors.

I am grateful to the many practitioners who responded to the [public consultation](#) on the proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill. Their responses have helped us identify improvements and current good practice.

Finally, I wish to record my sincere appreciation to those who have shared their lived experience by responding to the public consultation on Mr McArthur's proposal. I feel humbled to have read what they shared, and their testimonies have helped to inform and shape the work of this group. I join in their hope that what follows will be better for everyone.



Dr Sandesh Gulhane MSP



Glossary of Terms

Active pharmaceutical ingredient (API): also referred to as 'assisted dying substance', is the substance someone would self-administer to end their life. The active pharmaceutical ingredient is likely to be provided in a form that will be appropriate to the individual, such as a powder or liquid.

Adult: In Scotland, a person who has attained the age of at least 16 years.

Assisted dying: Following the process of repeated requests, safeguarding protocols, and eligibility assessments, a mentally competent adult who is terminally ill may lawfully be provided with assistance from a registered healthcare practitioner to self-administer medication that will end their life.

Assisting practitioner: a registered healthcare practitioner who is responsible for delivering the assisted dying substance to the patient for them to self-administer and stays with the patient until they have self-administered the substance or decided not to take the substance. The role of assisting practitioners includes registered nurse practitioners.

Attending registered medical doctor ('attending doctor'): a person who is a registered medical practitioner who accepts the person's first request and subsequently coordinates the assisted dying process.

Care navigator service: an official service to provide support, assistance, and information in relation to assisted dying to patients and their families, friends and carers, and healthcare practitioners.

Conscientious objection: when a healthcare practitioner does not wish to provide or participate in a procedure because it conflicts with their personal beliefs or values.

Independent registered medical doctor ('independent doctor'): a registered medical practitioner who accepts a referral to conduct an independent medical assessment of the person.

Mental capacity: a person has mental capacity in decision-making in relation to assisted dying if the person is capable of —

- (a) understanding information about an assisted dying decision as required to be provided to the patient,
- (b) remembering the information referred to in paragraph (a) to the extent necessary to make an assisted dying decision, and
- (c) understands the matters involved in an assisted dying decision, and
- (d) understands the effect of an assisted dying decision, and
- (e) can weigh up the factors referred to in paragraphs (a), (b), (c) and (d) for the purposes of making an assisted dying decision, and
- (f) can communicate an assisted dying decision in some way.

Registered medical practitioner: the legal term for medical doctors who are regulated by the General Medical Council.

Registered healthcare practitioner: includes doctors, nurses, pharmacists and others involved in the provision of healthcare in the UK.

Supported decision-making: when a person is supported in making informed decisions about their medical treatment and given, in a way the person understands, information about medical treatment options. This support includes: (i) using information or formats tailored to the particular needs of the person (ii) communicating or assisting a person to communicate their decision with the use of an interpreter, proxy, or speech and language therapist (iii) giving the person additional time and discussing the matter with them (iv) using technology to assist the patient where appropriate.

Terminal illness: the person has been diagnosed by a registered medical practitioner as having a progressive disease, illness, or condition from which they are unable to recover and that can reasonably be expected to cause their death.

Introduction

In September 2021, a [public consultation](#) on proposals for a Private Members Bill on Assisted Dying for Terminally Ill Adults in Scotland was launched by Liam McArthur MSP. The consultation received an unprecedented number of responses and raised issues relating to medical practice that required exploration before a final bill proposal is presented to the Scottish Parliament.

Mr McArthur invited a group of senior healthcare practitioners to form a working group to advise and inform the process ahead of the final bill being drafted. These healthcare practitioners came from a range of specialisms and ensured that a wealth of experience was represented and considered.

Since the [End of Life Assistance \(Scotland\) Bill \(2010\)](#) and [Assisted Suicide \(Scotland\) Bill \(2013\)](#), many more jurisdictions have passed assisted dying legislation. At the time of writing, some form of assisted dying is legal in at least 25 jurisdictions, including all six states in Australia, New Zealand, ten states in the USA and the District of Columbia, Canada, Spain, Switzerland, Belgium, and the Netherlands.

The passage of numerous assisted dying laws has created an abundance of medical opinion and practice, which has been vital to examine to formulate the best model for Scotland. The group's findings and recommendations align with Scotland's healthcare system, devolved parliament, culture, and person-centred needs.

Members of the Medical Advisory Group

The members of the Medical Advisory Group are:

- Dr Sandesh Gulhane MSP & GP, Chair of the Medical Advisory Group.
- Professor Corri Black, Consultant in Public Health, University of Aberdeen, Deputy Chair of the Medical Advisory Group.
- Prof. Sam Ahmedzai, Palliative care specialist and Honorary Consultant Physician in Palliative Medicine.
- Sir Graeme Catto, Former President and Chair of the General Medical Council.
- Dr Carey Lunan, Deep End GP & Chair, Past Royal College of General Practice (RCGP) Scotland Chair, member of RCGP Health Inequalities Standing Group.
- Dr Gillian MacDougall, Consultant ENT Surgeon.
- Professor Harry McQuillan, CEO, Community Pharmacy Scotland.
- Siobhan Neylon, Palliative care nurse and clinical education lead, Highland Hospice.
- Kenny Steele, CEO, Highland Hospice.
- Dr Stuart Sutton, GP and Clinical Director, Renfrew Health & Social Care Partnership.
- Alison Thomson, Executive Director of Nursing, Mental Welfare Commission.

Terms of reference

The Medical Advisory Group was formed to explore the healthcare-related issues of the proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill and to offer advice and direction to Liam McArthur MSP, and his team.

The Medical Advisory Group was asked to:

- Analyse the themes from the consultation responses regarding medical practice and the role of healthcare practitioners.
- Take evidence from a range of medical practitioners with experience in assisted dying overseas to look at best practices for Scotland.
- Consider specific implementation factors such as patient pathways, peer support/training, and pharmaceutical requirements.
- Gather research and evidence pertinent to the bill and exploration of relevant areas.

The group was asked to produce a report on the healthcare-related issues of the proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill and to offer recommendations to Liam McArthur MSP to inform the bill drafting process.

This report outlines the issues, challenges, and opportunities that the medical profession would be presented with should assisted dying be legalised in Scotland. It respects the views of individual healthcare practitioners by providing a suggested framework for those who wish to be involved in the assisted dying process whilst providing reassurance for those who do not.

The report seeks to provide information and a clear steer on the medical aspects that relate to assisted dying to help inform policymakers, professional bodies, health and social care colleagues, patients, the public and other key stakeholders.

This document is a working group report and is not intended as practice guidance. The group is assured that should assisted dying be legalised in Scotland, guidance will be published by the professional bodies and organisations responsible for doing that. This report is not definitive or overly prescriptive, as the finer details of practice and procedure

will be developed depending on the exact nature of any new legislation. Importantly, further exploration will be required to accommodate patients' needs in a variety of settings should the current proposal become law. The Medical Advisory Group encourages fellow practitioners and stakeholders to take an active participatory role in this debate.

If legislation is passed, healthcare practitioners will have a key role in developing suitable protocols and guidance. Any legislation and subsequent regulations should give careful consideration to the principles outlined in this document to ensure firstly that the considerations of patients are respected at all times, that healthcare practitioners sympathetic to any changes in the law are engaged, and that concerns amongst those who would not wish to be involved are respected.

Issues regarding personal conscience can generate debate, but the views of each individual must be respected. In respecting personal viewpoints, professional responsibility requires clinicians to accommodate these issues in ways which combine compassion with legal and medical integrity.

Meeting structure and international evidence

The group held six meetings over the period March-November 2022, chaired by Dr Sandesh Gulhane MSP. In addition to formal meetings, the group discussed various issues via email, telephone and in person with Liam McArthur MSP and his team.

The group invited healthcare practitioners from jurisdictions where assisted dying has been legalised to attend the meetings. The group heard evidence from Dr Catherine Forest from California, USA, Dr Stefanie Green from Canada, and Dr Cameron McLaren from Victoria, Australia, all of whom are considered experts in their field.

The international experts spoke to the group over three meetings about how assisted dying works in practice, including giving an in-depth look at the patient pathway in their respective jurisdictions, exploring what works well and discussing the challenges and opportunities for healthcare practitioners and patients.

The experts addressed misinformation about assisted dying and shared their first-hand clinical experience of the process in practice. Dr Catherine Forest also brought lived experience to the discussions and spoke movingly of her personal experience supporting her partner, Will Forest, through an assisted death in California.

An additional session was held to explore what assisted dying training might look like for healthcare practitioners. The Australian models of assisted dying have mandatory training for health practitioners as part of their law. Professor Ben White and Professor Lindy Willmott were responsible for developing the mandatory training in Victoria, Western Australia, and Queensland. They are both eminent academics in their respective jurisdiction and have advised the government, practitioners, and other stakeholders on the introduction of assisted dying in Australia. Professors White and Willmott, and their colleague Kat Waller, held a mock training session for the group to give a sense of the training requirements in Australia, looking at the mandatory modules and the processes that led to the development of what has been hailed as considered, robust, and informative training.

The evidence given by Dr Catherine Forest, Dr Stefanie Green and Dr Cameron McLaren, and the session held by Professor Ben White, Professor Lindy Willmott and Kat Waller were invaluable to the group. The Medical Advisory Group thanks them for their time and expertise and looks forward to continuing to learn from them as the proposal in Scotland moves forward.

Medical Themes

Several medical questions and themes arose during the public consultation phase of the proposal which the group were asked to give recommendations on. The key medical themes arising from the consultation that the group addressed included:

- Eligibility criteria for assisted dying including age, diagnosis, and the requirement for mental capacity.
- Safeguards for patients and practitioners.

- Personal and institutional conscientious objection.
- Training requirements for healthcare practitioners.
- Informed decision-making in the context of discussions with healthcare practitioners about assisted dying.
- Supported decision-making.
- Healthcare practitioner qualifications and experience.
- The role of nurse practitioners.
- Referral to specialists – when this is appropriate and the acceptance of outcomes.
- Doctor-patient relationship.
- Person-centred care.
- Self-care and peer support.
- Palliative care, including international evidence.
- Existing end-of-life choices.
- Lived experience.
- The prevention and detection of coercion into or out of assisted dying decisions.
- Residency requirements.
- Disability issues as they relate to assisted dying.
- Care navigator services.
- Witnessing requirements.
- Preliminary pharmaceutical considerations.
- Advance requests.
- Savings/rescue provisions.
- Cooling off/waiting periods.
- The patient pathway process.

The group's considerations on these themes are explored throughout this report, with key findings and recommendations included at the end of each chapter.

Key Findings & Recommendations

Chapter 1: Role of Healthcare Practitioners

- Conscientious objection to assisted dying should be accommodated in legislation and apply to registered healthcare practitioners only (i.e., those with direct and hands-on involvement) in line with the current legal precedents.
- That a duty to refer the patient to another practitioner and/or a care navigator service is stipulated.
- Consideration of how conscientious objection is approached in employment contracts and via organisational policies will need to be addressed to avoid terminally ill patients being forcibly transferred (as is happening overseas) to an institution willing to provide assisted dying.
- Mandatory training for healthcare practitioners should be part of the proposed legislation.
- The two doctors responsible for co-ordinating the assisted dying process would need to be on the GMC register and, at a minimum, have successfully completed their Foundation Year 1 (FY1) year of training. They need not be a specialist in the disease, illness, or condition that the patient has.
- Nurse practitioners should play a key role in developing the proposal and its implementation should it become law. In line with practice overseas, it is recommended that they are included in the process as assisting practitioners.
- If a patient is referred to a specialist when capacity or terminality is in doubt, the specialist's decision must be adopted in respect of the matter for which the patient was referred.
- A practitioner peer support and self-care network should be established in Scotland prior to the implementation of assisted dying, such as those in effect in Australia and Canada. If legislation is passed, there will likely be an implementation phase before patients can access the service; this would be the time for such a network to be established.

Chapter 2: Wider end-of-life care

- That a universal right to palliative care be introduced in Scotland, with a recognition that Mr McArthur’s proposal is not the appropriate place for this.
- The MAG supports efforts for sustained investment in secure, accessible, integrated, and person-centred health and social care digital systems to improve care coordination and optimise palliative care for people across care settings.
- That existing medical and legal principles which support the current end-of-life options are fitting with the principles which underpin assisted dying – namely, the relief of suffering and compassion towards those at the end of life who want choice and control over their death.
- Legislators should seek to address the issue of citizens travelling abroad to access assisted dying by taking a more safeguarded and compassionate view of those in Scotland who are terminally ill and want the choice of an assisted death at home.
- That lived experience from Scotland and overseas should permeate consideration of this issue. Personal testimony should be facilitated when drafting assisted dying legislation, including at committee evidence sessions.

Chapter 3: Eligibility Criteria

- That only self-administration should be provided for and not euthanasia, i.e., no direct administration of the API by a healthcare practitioner.
- Assisted dying should be for terminally ill adults only; in Scotland, that means those who have reached the age of at least 16 years of age.
- The group unanimously supports the definition of terminal illness as laid out in Liam McArthur’s proposal; “where a registered medical practitioner has diagnosed a person as having a progressive disease, illness, or condition from which they are unable to recover, and that can reasonably be expected to cause their death”.
- Professional bodies should provide guidance on assessing capacity in relation to assisted dying decisions post-legislation. Capacity assessments in relation to assisted dying decisions should also be part of any mandated assisted dying training.
- If the person's mental capacity in relation to an assisted dying decision is in doubt, a referral should be made to a fully registered healthcare practitioner with appropriate

skills and training (for example, a psychiatrist or psychologist) who can assess the person's mental capacity.

- If a person permanently loses decision-making capacity in relation to an assisted dying decision at any time during the process, the person ceases to be eligible for access to assisted dying.
- Supported decision-making should be utilised for mentally competent patients who require assistance to navigate the process.
- As part of the safeguarding process, multiple stage checks for coercion into or out of assisted dying decisions should be present.
- The person must have been ordinarily resident in Scotland for at least 12 months and be registered with a medical practice.
- Face-to-face appointments would always be preferable, but teleconferencing may overcome access issues for some patients, particularly in rural communities. The group agreed that this should not be included in primary legislation and instead be included in professional guidance post-legislation.
- Consideration should be given to whether a specific statutory provision disallowing assisted dying for people with disabilities only should be considered.

Chapter 4: Accessing Assisted Dying

- The group agreed that an assisted dying care navigator service should be established.
- That independent witnesses should be required throughout the assisted dying process.
- That the API should remain with the assisting practitioner at all times to prevent any medication from being in public circulation and that any unused medication should be returned to the dispensing pharmacy to be destroyed.
- Requests for assisted dying should be contemporaneous, with capacity retained right up to the point of self-ingestion; as such, advance requests for assisted dying via advance directive or any other anticipatory request should carry no actioning power.
- Ingestion of the API should be by the patient, with no direct administration allowed; technology and other assistance should be used to ensure the voluntary nature of the act.

- The healthcare practitioner should remain with the patient until they have self-ingested the API for reasons of safety, accountability, and support.
- Consideration should be given to whether a 'savings/rescue provision' is included in the legislation.
- That a 14-day (or 48 hrs if the patient is expected to die within the 14-day period) waiting period should commence at the start of the assisted dying process (after the first formal request for assisted dying is made) rather than after the full assessment process has been completed, as was initially proposed in the consultation.

Chapter 5: Patient Pathway

- The group recommends that the 14-day (or 48 hrs) waiting period starts when the patient makes the first formal request rather than starting from the second formal request and assessment as was initially proposed in the consultation.
- The minimum 48 hours waiting period only occurs if the patient is expected to die within the 14-day waiting period.
- The group also recommends that data be collected formally on the functioning of the waiting period to provide evidence for future reviews of the legislation.
- Guidance on how to carry out capacity assessments and detecting coercion for healthcare practitioners should be provided by professional medical regulators post-legislation and training should be provided to healthcare practitioners who have opted-in to facilitate the assisted dying process.
- The patient should be continually informed that they can decide not to go ahead with the assisted dying process at any stage.
- The group discussed the importance of arranging the date of the assisted death being fully person-centred and agreed that there should be no maximum time frame for when the assisted death must take place after the final declaration has been signed.
- The assisting practitioner (whether that be the attending doctor, the independent doctor, a nurse practitioner or another healthcare provider who is qualified and has undertaken the training) should be present at the assisted death.

- As outlined in the proposal, mandatory reporting and recording of information should be present at each stage of the process.
- Where the [Medical Certificates of the Cause of Death form](#) asks for the disease or condition directly leading to death, this should be stated as the underlying disease, illness or condition from which the person died.

Chapter 1: Role of healthcare practitioners

1.1 Introduction

The medical advisory group (MAG) was tasked with considering the role of healthcare practitioners in the assisted dying process. The group considered how to achieve equal and non-discriminatory entitlement to rights. Recommendations are made that give effect to the rights, the will and the preferences of the individual and of healthcare practitioners who assist individuals with the assisted dying process.

Firstly, it is important to note the shift that has occurred in the medical profession since previous attempts to reform the law were brought in Scotland. It is accurate to say that not all healthcare practitioners are supportive of assisted dying, in the same way that not all healthcare practitioners are supportive of IVF or abortion, for example. However, with assisted dying, the views of the medical profession now align more with those of the general public. Regarding the Scottish public's views on this issue, the group notes that the response to Mr McArthur's consultation was 78% in favour.

In September 2021, the British Medical Association (BMA) dropped its long-standing opposition to assisted dying, and in March 2019, the Royal College of Physicians (RCP) dropped its opposition in favour of neutrality following member surveys.¹ Additionally, the group was interested to read submissions from many hundreds of healthcare practitioners who responded to the public consultation in support of the proposal. What is notable, however, is the number of healthcare practitioners responding who were in support of a change in the law but felt that they had to maintain anonymity for fear of potential negative repercussions on their careers. The group notes the importance of healthcare practitioners being able to discuss assisted dying in a respectful environment and hopes that this report helps to foster an open and respectful dialogue on the topic.

¹ [RCP, 'The RCP clarifies its position on assisted dying'](#) (30 March 2020); G. Iacobucci, ['BMA moves to neutral position on assisted dying'](#) (2021) 374 BMJ ; The Royal College of Nursing, Royal College of Nursing Scotland, Royal College of Psychiatrists, and Royal Pharmaceutical Society all hold a neutral stance on assisted dying, with many other professional bodies not taking a formal position.

1.2 Conscientious objection

A conscientious objection is when a healthcare practitioner does not wish to provide or participate in a legal and clinically appropriate treatment or procedure because it conflicts with their personal beliefs or values. Conscientious objection is based on sincerely held beliefs and moral concerns, not self-interest or discrimination.²

The usual way of explaining why it is necessary to accommodate conscientious objection involves citing the need to protect individuals from being obliged to violate their moral integrity in the course of performing their professional roles. Given that attempts to legalise assisted dying have put the medical profession at the centre of facilitating it and that resistance to legalisation historically came primarily from medical practitioners, it is crucial that there is space for objection and non-participation. Conscientious objection is already valid in other equivalent 'life and death' decisions, such as termination of pregnancy and withdrawal of life-sustaining treatment.

Nevertheless, the prevailing narrative on assisted dying has, perhaps rightly in an environment focused on person-centred care, been from the perspective of patient autonomy - to have choice and control over their body and medical treatment. The group recognised that a patient's autonomous request for assisted dying could conflict with a healthcare practitioner's exercise of their own autonomy - whether they wish to partake in the assisted dying process. The group discussed the practicalities of conscientious objection and decided that assisted dying should be an opt-in process, with those who conscientiously object having a duty to provide the patient with enough information to seek out another practitioner willing to provide the service (the 'duty to refer')³ or to a care navigator service.⁴

The General Medical Council (GMC), in its *Personal beliefs and medical practice* guidance, states that a doctor must "make sure that the patient has enough information to arrange to see another doctor who does not hold the same objection as you."⁵ The group unanimously

² British Medical Association, '[Conscientious objection and expressing personal beliefs](#)' (2022).

³ [Christopher Cowley, 'Conscientious objection in healthcare and the duty to refer', J Med Ethics \(2017\) 43.](#)

⁴ See section 4.2 of this report.

⁵ General Medical Council, '[Personal beliefs and medical practice](#)' (2020) page 03, section 12 (c).

agreed that conscientious objection to assisted dying should apply to doctors, nurses and pharmacists, in line with the current legal precedents.⁶ The group is aware of the legislative competency issues around conscientious objection in Scotland⁷ and is assured by Mr McArthur's commitment to including provision for this in the bill if that is constitutionally possible.

1.3 Institutional objection

The group considered whether conscientious objection should extend to organisations, such as hospices, as well as individuals. The group read submissions to the public consultation where a majority thought that objection should be limited to individuals only, and not apply to organisations, primarily to ensure that patient's wishes are respected and access issues are avoided. Conscientious objection extending only to individuals and not to institutions is the approach in most jurisdictions worldwide, such as Queensland and New South Wales in Australia. Furthermore, it is the group's understanding that legal protection for conscience in the UK extends only to individuals and not to institutions.

However, the group is aware that issues have arisen in jurisdictions such as Canada, where institutions have particular policies that prohibit assisted dying resulting in equitable access issues and terminally ill patients being transferred to unfamiliar alternative locations in order to access this legal right.⁸ To counter negative repercussions for terminally ill patients wishing to access assisted dying, consideration as to how conscientious objection is approached in employment contracts and via organisational policies will need to be addressed (as well as how conscientious objection is accommodated via statutory provision, should that be possible in our devolved nation) to avoid terminally ill patients being forcibly transferred to an institution willing to provide assisted dying.

⁶ *Greater Glasgow Health Board v Doogan* [2014] UKSC 68.

⁷ Amanda Ward, 'From Criminality to Compassion. Reforming Scots Law on Assisted Dying: A Fullerian, Compassion-Based Analysis' (PhD thesis, University of Strathclyde 2022) at 6.5, p. 215.

⁸ <https://globalnews.ca/news/8664275/group-opposes-forced-health-transfers-bc/>

1.4 Training

The group agreed that healthcare practitioners are well placed to be involved in assisted dying - in assessing eligibility criteria, assessing capacity, and detecting coercion. Even though practitioners are familiar with these kinds of assessments, it was agreed that those wishing to participate in assisted dying should undertake mandatory training before they become involved in the formal assisted dying process, i.e. assessing patients as eligible for assisted dying and/or prescribing the assisted dying substance. Mandatory training provides consistency and accountability for clinicians and uniformity for the process collectively.

Training is not mandatory in all jurisdictions, with some, such as Canada, considering practitioners already competent in the skills required to participate in the assisted dying process. In others, such as in Australia, training is mandatory before practitioners can be involved in assisted dying. Research from Victoria on the first two years of mandatory training has found that 97% of practitioners who completed the training found it helpful or very helpful. 93% reported being confident or very confident in their knowledge of the assisted dying legislation, and 88% reported being confident or very confident in the application of the legislation.⁹ Likewise, whilst it is not mandatory to undertake training before involvement in the assisted dying process in Canada, Health Canada recently announced \$3.3million in funding to assist assessors and practitioners in developing and implementing a national, fully accredited assisted dying training course across Canada.

To see how assisted dying training might work in practice, a training session was held for the Medical Advisory Group, facilitated by Professor Ben White and Professor Lindy Willmott from Queensland University of Technology, who were responsible for developing the mandatory training in Victoria, Western Australia and Queensland. They were joined by Kat Waller, who manages the Voluntary Assisted Dying training programs for both Victoria and Western Australia. Victoria was the first jurisdiction internationally to require participating practitioners to undertake mandatory training, and this is now a feature of assisted dying

⁹ Willmott L, Feeney R, Yates P, Parker M, Waller K, White BP. A cross-sectional study of the first two years of mandatory training for doctors participating in voluntary assisted dying. *Palliat Support Care*. 2022 Jul 28;1-7. doi: 10.1017/S1478951522000931.

laws in all Australian states. The MAG was given an overview of the training in Queensland, which consists of 12 mandatory modules, with time for discussion and questions.

Two guiding principles underpinned the development of the training in Australia:

1. Comprehensively explain the assisted dying process and associated obligations under the legislation.
2. Provide accessible and clinically relevant training for busy medical practitioners, nurse practitioners and registered nurses.

The training development was collaborative, with input from legal writers, academics, and practitioners. In Queensland, the training was reviewed by the health department, went through a consultation phase, and received feedback from external stakeholders.

Safer Care Victoria's Credentialing and scope of practice for senior medical practitioners' policy suggests it is best practice for training renewal to be undertaken every three years and so a 'renewal module' has been developed to ensure that efficiency and accountability are key.

The nature and content of training to be provided for in Scotland should be mandated by the Health Secretary and would require input from the wider stakeholder community when being developed. International best practices from jurisdictions such as Australia and Canada provide a rich resource that should be utilised. The group recommends that mandatory training is part of the proposed legislation, that this should be developed in conjunction with a broad stakeholder group and that insight and evidence should be sought from international colleagues to ensure that practitioners are confident in applying the statutory requirements of the law.

1.5 Informed decision-making

The group discussed whether healthcare practitioners should be permitted to raise the topic of assisted dying with patients.

The General Medical Council's *Good medical practice* guide states that all doctors "must work in partnership with patients, sharing with them the information they will need to make decisions about their care, including their condition, its likely progression and the options for treatment, including associated risks and uncertainties."¹⁰ It is therefore considered good medical practice to communicate all available options for treatment and support to patients. Furthermore, it has been shown in Victoria, Australia, that the legislative prohibition on health practitioners initiating conversations about assisted dying may, in cases where patients seek information about all end-of-life care options, leads to less optimal patient outcomes.¹¹

Benefits have been reported by doctors in Canada who have been able to discuss wider end-of-life options after a patient has requested information about assisted dying. For example, one of the international experts noted that assisted dying: "...has drawn people to the attention of palliative care" and that patients have instead taken this route as opposed to an assisted death. The international experts assisting the Medical Advisory Group felt strongly that assisted dying is part of a continuum of already available end-of-life care options and that they are not mutually exclusive. This anecdotal evidence is further supported by academic evaluation.^{12 13}

In Oregon, the legalisation of assisted dying has resulted in more open conversations and careful evaluation of all end-of-life options.¹⁴ Requests for assisted dying often facilitated discussion of other important issues relevant to the patient, and many practitioners felt that this discursive process increased their confidence and assertiveness in exploring all end-of-life issues with their patients.¹⁵ International precedent clearly illustrates that an open

¹⁰ General Medical Council, '[Good medical practice](#)' (2013), p.16.

¹¹ Willmott L, White B, Ko D, et al. [Restricting conversations about voluntary assisted dying: implications for clinical practice](#) *BMJ Supportive & Palliative Care* 2020;10:105-110.

¹² S M.Gerson, et al., '[The Relationship of Palliative Care With Assisted Dying Where Assisted Dying is Lawful: A Systematic Scoping Review of the Literature](#)' (2020) 59 (6) *Journal of Pain and Symptom Management* 1287.

¹³ Colburn B. [Disability-based arguments against assisted dying laws](#). *Bioethics*. 2022 Jul;36(6):680-686. doi: 10.1111/bioe.13036; see also: T. Stainton, 'Disability, vulnerability and assisted death: commentary on Tuffrey-Wijne, Curfs, Finlay and Hollins' (2019) 20 *BMC Medical Ethics* 89.

¹⁴ Wang Shi-Yi et al, 2015, [Geographic Variation of Hospice Use: Patterns of the End of Life](#), *Journal of Palliative Medicine*. September 18(9): 771-780.

¹⁵ Dobscha, S. K. et al. (2004). [Oregon physicians' responses to requests for assisted suicide: a qualitative study](#). *J. Palliat. Med.*, Vol 7, 451–461.

dialogue about assisted dying and wider end-of-life options complement one another and the doctor-patient relationship.

Following evidence sessions with clinicians from Australia, Canada, and the USA, the group unanimously agreed that healthcare practitioners should be permitted to raise the subject with their patients as part of a wider discussion about their care options, including palliative and hospice care. This helps to reduce health inequalities by ensuring patients have access to the same information despite potentially varying levels of health literacy, awareness of rights and language barriers.

1.6 Healthcare practitioner's qualifications and experience

The consultation document set out the suggested assisted dying process for Scotland. It proposed that two independent medical assessments would need to be carried out by fully registered medical practitioners with up-to-date licences to practice. This means that the two doctors responsible for co-ordinating the assisted dying process (the 'attending' doctor and the 'independent' doctor) would need to be on the GMC register and, at a minimum, have successfully completed their Foundation Year 1 (FY1) year of training.¹⁶

The group deliberated on whether either of the two doctors should be a specialist in the disease, illness, or condition that was set to end the person's life. Such requirements are not present in any other area of healthcare where the patient is making a competent, informed decision and imposing this requirement could result in delays and further suffering for the patient.

Additionally, the workforce for an assisted dying service is likely to be small, which may render service provision inequitable, particularly for those in remote and rural areas. Assisted deaths in Oregon and California account for under 1% of total deaths.¹⁷ In Victoria, assisted deaths account for 0.58% of total deaths.¹⁸ With an average of approximately 58,000 deaths per year in Scotland over the past five years, 0.3-1% of these would be expected to be assisted deaths. This equates to 174-580 people per year, which would

¹⁶ [What is full registration? - GMC \(gmc-uk.org\)](https://www.gmc-uk.org/what-is-full-registration/)

¹⁷ [Oregon Death With Dignity Act 2021 data summary](#), page 5; [California End of Life Option Act 2021 Data Report](#).

¹⁸ Voluntary Assisted Dying Review Board, [Report of operations](#), July 2021 - June 2022 , p.1.

require a small workforce to provide the necessary support for access to an assisted dying service.

The group agreed that ideally, one of the two doctors would be a specialist in the person's disease, illness, or condition but that this should not be mandatory. If there is any doubt about the terminality of the patient's disease, illness or condition, or any other associated uncertainties, a referral to a specialist should be made.

The attending doctor should not be a relative, partner, or family member of the patient and not a beneficiary under the will of the patient or otherwise benefit financially or in any other material way from the death of the person.

The independent doctor should also not be a relative, partner, or family member of the patient and not a beneficiary under the will of the patient or otherwise benefit financially or in any other material way from the death of the person. Additionally, if possible, the independent doctor should not be a colleague in the same practice or clinical team as the attending doctor.

1.7 Role of nurse practitioners

The group recognise that nurses are vital team members in the provision of person-centred and high-quality care to individuals at the end of their lives. Nurses play an essential role in ensuring all citizens are afforded respect, autonomy, and dignity at the end of life. They have a unique and central role in care teams as they address the physical, emotional, social, and spiritual needs of people with terminal illnesses and promote continuity of care across the end-of-life trajectory. The group recognised the key role nurse practitioners would play in an assisted dying service in supporting patients and doctors.

Alongside nurse practitioners providing ongoing care and support across the healthcare spectrum, the proposal recognised their crucial role in a front-facing way by proposing their involvement as assisting practitioners.¹⁹ This would involve nurse practitioners being included in the remit of practitioners (including doctors) who have responsibility for delivering the API (prescribed by the attending doctor upon completion of the assessment

¹⁹ [Assisted Dying for Terminally Ill Adults \(Scotland\) Bill 2021 Consultation](#) at p.20, Step 3.

process) to the patient; re-confirming the patient's capacity and that the person has not revoked or wishes to revoke their decision; preparing the API for self-administration by the patient and staying with the patient until they self-administer the API or decide not to take it.²⁰

This follows international precedent. For example, in Western Australia and New South Wales, nurse practitioners are eligible to act as administering practitioners if they meet specific requirements. While forming legislation, consideration was given to the role nurses play in the delivery of palliative care in Australia. Special consideration was given to addressing the disparity in healthcare resourcing for rural and remote areas. Including nurse practitioners in the delivery of assisted dying has helped people, particularly in rural areas, access the same healthcare services as those living in more metropolitan areas.

Nurse practitioners also play a vital role in the delivery of assisted dying in Canada, where they are eligible to participate in all aspects of the assisted dying process. The role of nurse practitioners in Canada includes prescribing, compounding, dispensing, administering, and documenting the medications for assisted dying.

The group believes that nurse practitioners should be able to be involved in the assisted dying process and recommend that those who meet certain criteria and who have undertaken assisted dying training should be eligible to act as assisting practitioners. The group was reassured by the many hundreds of nurse practitioners who responded to the public consultation in support, many of whom shared personal and professional testimonies of unbearable suffering. Given the intention to facilitate conscientious objection for healthcare practitioners, this would include nurse practitioners who did not wish to take part. Including nurse practitioners in this way increases the number of healthcare practitioners eligible to provide the service post legislation, particularly in rural parts of Scotland. Nurses will also play a vital role in providing information and education about assisted dying to patients. Nurses should play a key role in developing the proposal, and its implementation should it become law.

²⁰ The assisting practitioner would then be responsible for returning the medication to the dispensing pharmacy for it to be destroyed.

1.8 Referral to a specialist

Mr McArthur's consultation document proposed that a person should be referred to a psychologist or other appropriately trained specialist if either doctor assessing the patient's eligibility had any doubt about the patient's capacity to make a decision about assisted dying. This acts as an important safeguard in protecting potentially vulnerable people.

The Medical Advisory Group believes that if there is doubt about the patient's mental capacity from either the attending or independent registered medical doctors involved in the assessment, a third independent practitioner should be asked to assess this. This must be a fully registered healthcare practitioner with appropriate skills and training, such as a psychiatrist or psychologist.

Likewise, the group agreed that if the attending or independent doctor is unable to determine whether the person's disease, illness, or condition meets the requirements of being diagnosed as a terminal illness, they must refer the person to a specialist registered healthcare practitioner who has appropriate skills and training in that disease, illness, or condition.

The registered healthcare practitioner to whom the patient is being referred will have expert knowledge in assessing complex cases of mental capacity or the patient's disease area, thus the group believes that their decision should be adopted in respect of the matter for which the patient was referred. This is standard practice in healthcare when a second or other opinion is sought.

1.9 Doctor-patient relationship

Research on the potential and actual impact of assisted dying legislation on the doctor-patient relationship is of paramount importance.

Where assisted dying is legal, trust in doctors is high. The British Medical Journal reported on a study of 11 European countries, which indicates that the Dutch have the highest regard

and trust for their doctors.²¹ In other research, Dutch doctors discussed end-of-life decisions with their patients and families more than any other country studied.²²

Polling in the UK has shown that 93% of people say an assisted dying law would either increase or have no effect on their trust in doctors.²³ The BMA undertook qualitative research in 2021, which found that overall, the public presented a balanced range of views on the doctor-patient relationship as it relates to assisted dying.²⁴

Where assisted dying is actively discussed, physicians report a range of experiences. In a study of three jurisdictions, physicians noted that the discussions were opportunities to address patient concerns, explore patients' fears of dying, clarify information about symptom control, and reassure patients that they would not be abandoned. Where assisted dying was permitted (Netherlands and Oregon), physicians had substantially more experience with end of life discussions; they felt comfortable discussing the end of life choices available and described how the legal regulations helps to facilitate their discussions.²⁵

The patient's experience of the doctor-patient relationship was examined in a qualitative study that included their family members. Those who were considering or had experience with assisted dying identified three key themes. They highlighted the importance of open discussion about assisted dying as an end-of-life choice, the physicians' expertise in dealing with the dying process, and the maintenance of a therapeutic doctor-patient relationship, even when the clinician and the patient disagreed on assisted dying.²⁶

Patient trust should serve to reinforce the functioning of the clinical relationship as a health partnership. The Medical Advisory Group discussed the doctor-patient relationship whilst considering the patient pathway. The group concluded that if the law had sufficient safeguards built in to protect both patients and doctors, they would expect relationships

²¹ Kmietowicz, Z., "[R.E.S.P.E.C.T. – why doctors are still getting enough of it](#)", *BMJ* 2002; 324 (7328): 11-14.

²² Van der Heide, Agnes; Deliens, et.al., "[End-of-life decision-making in six European countries: descriptive study](#)", *The Lancet* 2003; 362: 345-350.

²³ Populus, 2019.

²⁴ BMA '[End-of-life care and Physician- assisted dying project](#)' (2021).

²⁵ Voorhees, Jennifer, R. *et al* 2014. '[Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands](#)', *The Gerontologist*, 54 (5): 808-817.

²⁶ Back, Anthony et al. 2003. '[Clinician-Patient Interactions About Requests for Physician-Assisted Suicide: A Patient and Family View](#)'. *Archives of Internal Medicine*, 162(11): 1257-1265.

between doctors and patients to improve, particularly because Mr McArthur's proposal includes a mandatory discussion of care options, including palliative and hospice care. One of the international experts who spoke to the group, Dr Cam McLaren, stated that "Many patients have actively sought me out as I provide voluntary assisted dying; they want me to be their oncologist because my involvement has strengthened their trust in me. Equally, there are non-participating oncologists available for those who prefer".

The doctor-patient relationship is fundamentally based on trust, and patients trust their doctors when they practise competently and with integrity, are compassionate and reliable, and use open communication.²⁷ The group agreed that the passage of assisted dying legislation would allow terminally ill patients to have honest, transparent conversations with their care team, including about their fears and wishes for the end of life. This would provide a space for wider discussions on palliative and other end of life care options, both within the doctor-patient relationship and the wider public health sphere.

1.10 Person-centred care²⁸

Person-centred care aims to counterbalance the traditional medical model of paternalism that evolved in the early days of organised healthcare. The shifting context of paternalism and patient autonomy has been driven by medical and biotechnical innovation and by patients' assertion of individual identity and their desire for autonomy and control over their own bodies.

Person-centred care has been described as 'a movement that has an explicit focus on humanising health services and ensuring the patient is at the centre of care delivery'.²⁹ Delivering person-centred care is a strategic priority for NHS Scotland and the Scottish

²⁷ Pearson, Stephen D and Lisa H Raeke. 2000. '[Patients' trust in physicians: many theories, few measures and little data](#)', *Journal of General Internal Medicine*, July (15)7: 509-513.

²⁸ [NHS Education for Scotland](#) describe person centred care as: "Person centred care is about ensuring the people who use our services are at the centre of everything we do. It is delivered when health and social care practitioners work together with people, to tailor services to support what matters to them. It ensures that care is personalised, co-ordinated and enabling so that people can make choices, manage their own health and live independent lives, where possible."

²⁹ McCormack, Brendan et al. 2015. '[Patient-centredness: the 'state' of the art](#)', *International Practice Development Journal* 5 (Suppl) [1].

Government.³⁰ Scottish Government guidance focuses on finding out who and what is important to the person and working with them and their loved ones to support their care. This involves providing information to allow patients and families to make informed decisions with the aim of delivering ‘healthcare services which respect individual needs and values, and which demonstrate compassion, continuity, clear communication and shared decision making’.³¹ The group agreed that Mr McArthur’s proposal is resolutely in step with these aims.

The group discussed the entire patient pathway at length, with a particular focus on person-centred care. The group received evidence from three international practitioners, who shared their experiences of patient pathways in their jurisdictions and advised on how a patient pathway might function in Scotland. These experts agreed that safeguards were critical when considering assisted dying legislation, but they shouldn’t act as a barrier to access for patients, with one commenting that “more safeguards don’t necessarily make a safer system” in reference to overly bureaucratic processes or long cooling off periods for patients. The group felt that the safeguards proposed by Mr McArthur were sufficient to allow patients to move through the pathway safely and efficiently, therefore providing a person-centred service for those who wish to use it.

1.11 Self-Care and Peer Support

The international experts who spoke to the Medical Advisory Group were unanimously in favour of an external support structure being set up before the implementation period of any legislation is complete.

Each of the international experts referenced the value of peer support in their own practice, which exists at regional, national, and international levels in their jurisdictions. For example, in Canada, there is the [Canadian Association of MAiD Assessors and Providers](#) (CAMAP), which was set up by a group of doctors after federal legislation was passed. They set up CAMAP as they felt there was a need to establish training resources, create medical standards, and encourage the standardisation of care across the country. Not only is the

³⁰ NHS Education Scotland, [‘Patient- Centred Care’](#) (2021).

³¹ Scottish Government, [‘Person-centred care: advice for non-executive board members’](#) (2019).

organisation respected and recognised as expert on assisted dying in Canada, but it has also provided vital support and a self-care structure for practitioner assessors and providers where they can access educational resources, apply for research grants and collaborate with other practitioners about their experiences. Similarly, the Victorian Voluntary Assisted Dying Community of Practice was set up in the state of Victoria, Australia, after legislation was passed there. Dr Cameron McLaren spoke of the critical role played by this organisation in providing support and guidance for clinicians. While the organisation was set up after legislation was passed, Dr McLaren recommends that similar networks should be set up before legislation is implemented in Scotland to help practitioners feel connected and supported.

Peer support is crucial to practitioner well-being in all sectors, particularly when new services are introduced. All the international experts urged the group to set up an external support structure in Scotland before legislation is implemented to allow clinicians to receive support and guidance from the beginning.

The MAG agreed that self-care resources would need to be available to all parties, particularly those closely involved in supporting a patient through the process of assisted dying as an assessing, independent, or assisting practitioner. The benefits of self-care and peer support are clear, and efforts should be made to establish self-care and peer support networks for Scotland. If legislation is passed, there will likely be an implementation phase before patients can access the service;³² this would be the time for such a network to be established.

1.12 Chapter 1 Recommendations

- The group unanimously agreed that conscientious objection to assisted dying should be accommodated in legislation and apply to registered healthcare practitioners only (i.e., those with direct and hands-on involvement) in line with the current legal precedents.
- That a duty to refer the patient to another practitioner and/or a care navigator service is stipulated.

³² In Australia, this is on average 18 months.

- Consideration of how conscientious objection is approached in employment contracts and via organisational policies will need to be addressed to avoid terminally ill patients being forcibly transferred (as is happening overseas) to an institution willing to provide assisted dying.
- The group recommends that mandatory training is part of the proposed legislation, that this should be developed in conjunction with a wide stakeholder group, and that insight and evidence should be sought from international colleagues to ensure that practitioners are confident in applying the statutory requirements of the law.
- The two doctors responsible for co-ordinating the assisted dying process would need to be on the GMC register and, at a minimum, have successfully completed their Foundation Year 1 (FY1) year of training. They need not be a specialist in the disease, illness, or condition that the patient has.
- Nurses should play a key role in developing the proposal, and its implementation should it become law. In line with practice overseas, it is recommended that nurse practitioners are included in the process as assisting practitioners.
- If a patient is referred to a specialist when capacity or terminality is in doubt, the specialist's decision must be adopted in respect of the matter for which the patient was referred.
- A peer support and self-care network should be established in Scotland prior to the implementation of assisted dying, such as those in effect in Australia and Canada. If legislation is passed, there will likely be an implementation phase before patients can access the service; this would be the time for such a network to be established.

Chapter 2: Context of wider end-of-life care

2.1 Introduction

The Medical Advisory Group was asked to consider how assisted dying would fit alongside the wider context of end-of-life care, particularly hospice and palliative care. As part of their deliberations, the group considered international precedence, existing end-of-life choices, and lived experience.

2.2 Palliative care

Any person considering an assisted death should not be doing so because they cannot access – or believe they cannot access – high-quality end-of-life or palliative care services. The Scottish Government is currently developing a new Palliative and End of Life Care Strategy,³³ but their [2015 Strategic Framework for Action on Palliative and End of Life Care](#) committed to ensuring access to palliative and end-of-life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.

A key theme across the groups' discussions was a desire to see increased general and specialist palliative care provision across Scotland.

The group unanimously agreed that patients requesting assisted dying should be informed of all other care options, including palliative and hospice care. The group marked the differences between general and specialist palliative care and deemed that patients should be informed of both options. However, they did not support the view that patients had to accept alternative care or treatment options in order to access assisted dying. This decision was based on the legal right that patients have to choose or refuse treatment options, provided they have mental capacity.

Consent is required from adult patients with capacity any time a doctor wishes to initiate an examination, treatment, or intervention. For consent to be valid, the patient must have capacity, have been offered relevant information, be acting voluntarily and be aware that they can refuse. Competent adult patients can refuse to consent to any treatment, and such

³³ Parliamentary Question S6W-09578, see: palliativecarescotland.org.uk August update.

refusals must be respected. Patients are not required to justify their decisions, but doctors must ensure they have based their decision on accurate information and correct any misunderstandings.³⁴

The member in charge of the proposal, Liam McArthur MSP, has given and reiterated his support for a right to palliative care during meetings of the Medical Advisory Group and shared that he was in discussions with colleagues to ascertain where this would most appropriately sit within Scottish legislation. The proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill will not have a provision for a right to palliative care, it will however mandate (as part of the two separate clinical assessments) that all other care options, including palliative and hospice care, are explored prior to any assisted death.

2.2.1 International evidence

Palliative care in the UK has been ranked number one in the world, with Scotland's services amongst the best in Europe.³⁵ However, it is expected that up to 20% more people will require palliative care by 2040 and that the complexity of need will increase markedly.³⁶ Service delivery models must adapt to meet the growing demand and complexity associated with dying from multiple diseases within different disease groups. Palliative care experts in Scotland have called for sustained investment in secure, accessible, integrated, and person-centred health and social care digital systems to improve care coordination and optimise palliative care for people across care settings.³⁷ The Medical Advisory Group lends its backing to this initiative.

The group unanimously agreed that an increase in access to and funding of palliative care is paramount, alongside assisted dying legislation. The group recognised that in several jurisdictions where assisted dying is now legal, there has been a consistent trend showing increased investment in palliative care. Most recently, the government in New South Wales,

³⁴ BMA, '[Consent and refusal by adults with decision-making capacity: A toolkit for doctors](#)' (2019).

³⁵ A report for the Scottish Parliament by Professor David Clark: '[International comparisons in palliative care provision: what can the indicators tell us?](#)' Published 15th September 2015 SP Paper 784 9th Report, 2015 (Session 4) at para. 72 in ref to the Quality of Death Index.

³⁶ Finucane AM, Bone AE, Etkind S, et al. '[How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery](#)' *BMJ Open* 2021;11:e041317. doi: 10.1136/bmjopen-2020-041317.

³⁷ Ibid footnote 35.

Australia, committed to an additional \$743 million of funding over the next five years, just one month after assisted dying legislation was passed there.³⁸ Similar increases in funding of and access to palliative care services have followed the introduction of assisted dying legislation in Victoria³⁹ and Western Australia,⁴⁰ as well as Oregon⁴¹ in the USA.

Despite Scotland's excellent comparative palliative care system, many people still experience no relief from pain and suffering as they die,⁴² thus still necessitating the need for safe and legal access to assisted dying. The response to Mr McArthur's public consultation, where many citizens shared testimonies involving grave suffering despite excellent palliative care support, are a stark illustration of this. Assisted dying services can and do operate synergistically alongside palliative care services in other jurisdictions, and the group believes that this should be the case in Scotland. Improvements to palliative and other end of life care should continue to develop alongside the introduction of an assisted dying law, giving patients greater choice, control, and relief from suffering.

2.3 End-of-life choices

At present, there are a number of methods to relieve patient suffering which can have the effect of hastening death. These include, but are not limited to, voluntarily refusing food and fluids, withdrawal of treatment, continuous deep sedation (or palliative sedation), or administering medication to relieve pain and suffering, which may have the unintended consequence of hastening death (double effect of medication).⁴³ Some of these options can be chosen by the patient, i.e., voluntarily refusing food and fluids or withdrawal of treatment, and others are decided upon following discussion with loved ones and amongst the multi-disciplinary team, such as palliative sedation and double effect.

³⁸ NSW Government, [\\$743 million to enhance end-of-life care in NSW | NSW Government](#) (2022).

³⁹ Premier of Victoria, The Hon Daniel Andrews, ['Palliative Care Boost To Support Terminally Ill Victorians'](#) (2017).

⁴⁰ Government of Western Australia, ['Massive boost for palliative care services across Western Australia'](#) (2019).

⁴¹ In 2015, the Oregon Health Authority established the [Palliative Care and Quality of Life Interdisciplinary Advisory Council](#).

⁴² Dignity in Dying Scotland, ['The Inescapable Truth About Dying in Scotland'](#) (2019).

⁴³ This is a long-established legal principle utilised by practitioners in the UK to justify the use of existing end-of-life practices such as double effect, where increasing doses of drugs are given to a patient to relieve their suffering, with the consequence that it may shorten their life. The intention of both assisted dying and other end-of-life practices is the relief of suffering.

There are limitations to each of these options; patients may suffer because of the slow dying process if they choose to refuse food and fluids, for example.⁴⁴ The scientific understanding of what a person's awareness of thirst and hunger is during continuous deep sedation is also rudimentary.⁴⁵ The group was clear in their deliberations that the purpose of assisted dying legislation was not to remove any of these options for those who wish to use them but to add an additional option for exercising control at the end of life, which some may find more acceptable. In this respect, the option of assisted dying is not primarily to hasten death or shorten life but to relieve suffering from terminal illness.

Additionally, the group considered the number of UK citizens travelling to Switzerland for an assisted death. Many of their experiences have been shared via personal testimony in the media and in responses to Mr McArthur's consultation. Accessing assisted dying overseas is only an option for those who are well enough to travel and navigate the arduous process. In Scotland, people have the additional risk of their loved ones being prosecuted if they support someone to do so.⁴⁶ Research from Dignity in Dying found that one person every eight days travels to Dignitas for an assisted death.⁴⁷ The minimum cost to go abroad for an assisted death is over £9,000,⁴⁸ which adds an additional element of inequality.

The requirement to be physically able to travel to Switzerland also means that dying people end their lives sooner than they would have done if assisted dying were a legal option at home.⁴⁹ Important conversations about alternative care options that might be available to the person in Scotland may also not take place due to overseas assisted deaths having to be done in secret. The MAG believes that the current situation is unsafe, unfair, and untenable. The group proposes that legislators should seek to address this issue by taking a more safeguarded and compassionate view of those in Scotland who are terminally ill and want the choice of an assisted death at home.

⁴⁴ Klein Remane U and Fringer A., '[Voluntary Refusal of Food and Fluid in palliative care: a mapping literature review.](#)' *Pflege*. 2013 26 (6).

⁴⁵ Rady MY and Verheijde JL. '[Distress from voluntary refusal of food and fluids to hasten death: what is the role of continuous deep sedation?](#)' *Journal of Medical Ethics*. 2012.

⁴⁶ Amanda Ward, 'From Criminality to Compassion. Reforming Scots Law on Assisted Dying: A Fullerian, Compassion-Based Analysis' (PhD thesis, University of Strathclyde 2022).

⁴⁷ Dignity in Dying, '[The True Cost: How the UK outsources death to Dignitas](#)', (2017).

⁴⁸ The Switzerland Alternative, '[Fees to be paid](#)' (2022).

⁴⁹ Ibid footnote 46.

2.4 Lived experience

Several members of the Medical Advisory Group, as well as the international experts who gave evidence, had harrowing stories to share of their own personal and professional experiences of end-of-life care. They articulated how often, despite the very best of care, including specialist palliative and hospice care, their patients and loved ones still suffered. Further examples of similar experiences were shared with the group from responses to Mr McArthur's public consultation on the proposed bill, such as:

I have experienced my mother dying of cancer in dreadful pain. She was in a hospice but they were unable to alleviate her suffering. The last words I heard her say were 'I want to die'.⁵⁰

There were thousands of personal experiences shared by those supporting the proposal. The above is just an example of the personal accounts given by individuals and is broadly typical of the sorts of situations articulated. Another example of a personal account is:

I sat with my mother for weeks while she slowly died of cancer. Every day was agony and she begged to be allowed to go. In the end we watched her die of dehydration, this took 7 days from her last drink. Nobody should ever have to die like this.⁵¹

Healthcare practitioners also shared their experiences of patients they cared for whose symptoms could not be relieved, such as in the example below:

While investing in palliative care is of the utmost importance, this in itself will not improve the suffering of some terminally ill patients whose symptoms are simply not relieved by palliative care. We need to recognise and accept that palliative care has the same limitations as other medical treatments in that it cannot help everyone.⁵²

One of the Medical Advisory Group medical practitioners shared his own experience of his father's traumatic death:

He received excellent palliative care in the community from a multidisciplinary team including a palliative care clinical nurse specialist, his dedicated GP, and a team of

⁵⁰ Response ID 181258850.

⁵¹ Response ID 181196452.

⁵² Response ID 178860109.

compassionate and caring district nurses. Ultimately though he found himself in a situation he had long dreaded and had always made clear he never wanted to experience. He became increasingly frail and suffered seizures despite maximum dose treatment. He lacked for nothing in terms of his palliative care treatment - but fundamentally nothing could change the fact he felt his dignity had been stripped from him. He was being forced to live through weeks of life that had no value to him and only offered increasing distress, despair and anger at his plight.

Conversely, international practitioners who spoke to the group shared their own positive experiences of patients having an assisted death, including Dr Catherine Forest, who introduced herself to the group as a “provider (of assisted dying) and a widow” as she shared the story of her husband’s assisted death in California.

Dr Forest also shared her experience of helping a terminally ill patient through the process of requesting an assisted death:

I turned to the patient and responded, “I’m glad you’re here. I want to reassure you that I am participating in the aid-in-dying law. We can talk about how it works and if it is right for you among all the options for end-of-life care. I can stay your doctor no matter what.” I paused for a minute, then continued: “Is it okay if we talk a little more about your concerns?”

When he collected himself, he continued, “I don’t want to die — my life is great. I have amazing kids, and me and my buddies — well, we just have done it all... I just don’t want to die this way, all hooked up to machines and struggling to breathe. I don’t want everyone around to watch me peter out, not even able to walk across the room.”

My patient has chosen to focus on palliative care and hospice, for now, so that he can enjoy his kids and his buddies as long as he can. Patients requesting medical aid in dying want to live — just not in a way that they experience as suffering. He is pretty sure he will ingest the medication to hasten his death when his suffering outweighs

*his desire to live, but for now, with our help, he is simply living the life he has to the fullest he is able.*⁵³

Similarly, Dr Stanley Koshy and Dr Navin Rajan, have spoken movingly of their experience of the first year of assisted dying in New Zealand:

Even though one of our principles is to cause no harm, in this particular instance, by inaction we're causing harm, by causing a person a huge amount of suffering. I was scared, [it being] the first time doing something like this. It was quite emotional for me, and I tried to hold it together during the process of actually doing it. I felt that I had done something useful. I was doing a good thing. I remember the third or fourth person [whose death] I was involved with: the man's last words were to thank me as he was slipping off into sleep. I just feel happy now". Dr Navin Rajan⁵⁴

Dr Stanley Koshy has said that *"At the end of each instance, it has been hugs all around, and 'thank you for doing this'. People have just been so appreciative."*

The group considered all the lived experiences shared with them, which they felt added an important aspect to the argument that assisted dying should be legalised in Scotland. Lived experience from Scotland and overseas should permeate consideration of this issue, which can often be too focused on the clinical and legal aspects. There is now a wealth of evidence that can be utilised given the unprecedented response to the public consultation - this is something that has never before been accessible when considering law reform in Scotland. Personal testimony should be facilitated when drafting assisted dying legislation, including at committee and evidence sessions; incorporation of this would better support a person-centred approach.

⁵³ Dr Catherine Sonquist Forest, ['I'm a doctor. Here's what it's like helping terminally ill patients end their lives'](#) (Vox.com, 2021).

⁵⁴ Hannah Martin, ['Assisted dying: Doctors reflect on 'emotional' and 'rewarding' first year'](#) (Stuff, 2022).

2.5 Chapter 2 Recommendations

- That a universal right to palliative care be introduced in Scotland, with a recognition that Mr McArthur's proposal is not the appropriate place for this.
- The MAG supports efforts for sustained investment in secure, accessible, integrated, and person-centred health and social care digital systems to improve care coordination and optimise palliative care for people across care settings.
- That existing medical and legal principles which support the current end-of-life options are fitting with the principles which underpin assisted dying – namely, the relief of suffering and compassion towards those at the end of life who want choice and control over their death.
- Legislators should seek to address the issue of citizens travelling abroad to access assisted dying by taking a more safeguarded and compassionate view of those in Scotland who are terminally ill and want the choice of an assisted death at home.
- That lived experience from Scotland and overseas should permeate consideration of this issue. Personal testimony should be facilitated when drafting assisted dying legislation, including at committee and evidence sessions.

Chapter 3: Eligibility Criteria

3.1 Introduction

Section 1.1 of the consultation document detailed safeguards that would be part of the assisted dying process, whilst section 3 of the consultation outlined the proposed assisted dying process itself. The Medical Advisory Group considered the eligibility criteria that should be satisfied before a patient can enter into and access assisted dying, ensuring that all proposed safeguards are met in a way that complies with the proposed legislation but also supports terminally ill patients to access assisted dying in a clear, safeguarded, and supportive way.

The suggested framework outlined below demonstrates that the views expressed by those both for and against the proposal have been acknowledged and considered in developing the groups position. The framework takes account of the issues that need to be addressed before a prescription to end a person's life can be dispensed.

The group acknowledges that previous attempts to change the law initiated by the late Margo MacDonald MSP included allowing assisted dying via doctor administration (euthanasia) and for a wider patient group than in Mr McArthur's proposal. The group is aware that this did not receive support from healthcare practitioners, MSPs or wider stakeholders. Mr McArthur's proposal for a change in the law applies only to mentally competent adults suffering from a terminal disease, illness or condition. It is therefore in this context that the Medical Advisory Group specifically examined the issues around assisted dying from a medical perspective and did not specifically address the wider issue of either euthanasia or a broader patient group in this report.

The group supports the approach taken by Mr McArthur, whilst acknowledging that in some jurisdictions, direct administration following a voluntary request is the preferred method of delivery of the assisted dying substance and that a broader patient group is included. In Scotland, the use of medical and technical equipment can be utilised to ensure equal access for patients who are unable to self-administer the API by swallowing; for example, an IV drip could be set up, which the patient could open themselves when they are ready.

Eligibility criteria vary from one jurisdiction to another. Assistance in dying regimes are thus formulated as responses to a range of policy and moral objectives: alleviating pain and suffering at the end of life, upholding personal autonomy, reducing harm, clarifying the role and obligations of practitioners, and so on. Moreover, terminology, information, and stakeholders differ between contexts, which adds a layer of complexity to the debate. In line with the proposal's suggested eligibility criteria, the group considers that the following criteria must be met before a person is eligible to begin the formal process of requesting and accessing assisted dying in Scotland.

3.2 Adults

People are protected under the Equality Act 2010 from discrimination based on age. In Scotland, a person is an adult when they reach sixteen years of age. The group agreed with the approach in Mr McArthur's proposal, that only adults should be able to access assisted dying and that the age of sixteen was appropriate and in line with existing Scots law. Nonetheless, the group felt that more thought should be given to supporting patients who want to access assisted dying but are still under the care of paediatric services, potentially from ages 16-21. It is well documented that the vast majority of assisted deaths are by older people, with the median age being approximately 73.⁵⁵ Therefore, the likelihood of younger people using assisted dying is very small and certainly less than 1% of the total number of people who might access it.

3.3 Terminally ill

The group reviewed evidence from the previous two Scottish bills and criticisms that terminology and lack of decisive definitions were major issues, namely that "terminal", "life-shortening", and "unacceptable" were too flexible and would potentially allow eligibility to be cast too wide. Similar terminology has since been accepted in jurisdictions such as

⁵⁵ The most recent [governmental report](#) from Oregon states that since assisted dying was legalised, 8.1% of assisted deaths have been people under 54; 0.6% of assisted deaths over the time it's been legal were people aged 18-34 (p.10); In Victoria, Australia, the [Voluntary Assisted Dying Review Board](#) reports that only 8.2% of people were aged 18-54 (p.14).

Canada, which decided upon death being “reasonably foreseeable” in the setting of a “grievous and irremediable medical condition”.

In Scotland, the Social Security (Scotland) Act 2018, slightly amended by the Social Security Administration and Tribunal Membership Act 2020, introduced the Scottish definition of terminal illness. It gives Mr McArthur’s proposal a statutory anchor to which the definition of terminal illness can be drawn. Thus, ‘terminal illness’ is described as a progressive disease where the consequence of that illness is that death can be reasonably expected, no time limit applies. The patient typically has an illness, disease or condition that is advanced and progressive, or with a risk of sudden death and that is not amenable to curative treatment, or treatment is refused by the patient. This definition for the purpose of social security considerations is based on the clinical judgement of a registered medical practitioner. Recommending that assisted dying should only be for terminally ill patients – and relying on already established statutory definitions of this - means that interpretation issues are forgone or reduced.

Limiting assisted dying to people who are terminally ill requires that the person is not going to recover; their death is foreseeable as opposed to being a considerable number of years away, thus, it simply hastens the inevitable, since the person is not only going to die with the disease but of it.

It is worth noting here that whilst other jurisdictions adopt ‘terminal’ criteria only, many include ‘unbearable suffering’ also. The group considered this problematic as whilst suffering is usually present in terminally ill people already, there is inhumanity in laws that include necessary suffering as part of the criteria. If the basis of law reform is compassion, a person’s condition should not have to develop to such a point of intensity that they are suffering unbearably. Suffering can also cloud competency, and the objective is to make sure that any person availing themselves has full capacity.⁵⁶ Suffering is also difficult to quantify and is subjective in nature, therefore harder to assess. In the international

⁵⁶ Amanda Ward, ‘From Criminality to Compassion. Reforming Scots Law on Assisted Dying: A Fullerian, Compassion-Based Analysis’ (PhD thesis, University of Strathclyde 2022).

literature, there is no generally accepted definition of unbearable suffering in the context of a request for assisted dying.⁵⁷

Thus, the meaning of 'terminally ill' where a “person has been diagnosed by a registered medical practitioner as having a progressive disease, illness, or condition from which they are unable to recover, and that can reasonably be expected to cause their death” is recommended. Treatment which only temporarily relieves the symptoms of an inevitably progressive disease, illness or condition is not to be regarded as treatment which can reverse that disease, illness, or condition.

Whilst recognising that feedback and responses to the public consultation highlight that some would prefer the full Chief Medical Officer (CMO) definition⁵⁸ to be adopted, this would take the proposal back into the territory and difficulties of previous bills, where definitions are hard to pin down and depend upon the interpreter. Therefore, the group unanimously supports the definition of terminal illness as laid out in Mr McArthur’s proposal.

3.4 Mental Capacity

The consultation document proposed that “the person has reached a voluntary, clear, settled and informed wish to end their own life” and that “the person has decision-making

⁵⁷ The concept of “unbearable suffering” was found to contain physical, psychological, social and existential dimensions and to entail many different motivations. Based on a literature review, Dees et al. (2010) defined unbearable suffering in the context of a request for assisted dying as “a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind.” Unbearable suffering was defined by Ruijs et al. (2013) as “a subjective experience that is so serious and uncontrollable that it overwhelms ones bearing capacity; Peisah, C., Sheahan, L. and White, B.P. (2019), [‘Biggest decision of them all – death and assisted dying: capacity assessments and undue influence screening’](#) Intern Med J, 49: 792-796. <https://doi.org/10.1111/imj.14238>.

⁵⁸ The disease is advanced; progressive with decreasing reversibility; deterioration of an incurable condition; Increasing need for input of health and social care providers; not amenable to further curative treatment, or alternative treatment which is not tolerated or chosen by the patient or their legal representative; Where death will be an inevitable consequence of the condition; Any significant events that are likely to impact on function and life e.g. fall with significant harm; Rapid/erratic decline, unstable; A deteriorating condition carrying a high risk of sudden death; Worsening or anticipated worsening of symptoms despite optimal management; The decision should be made on clinical grounds and be based on suitable clinical expertise and opinion, as well as the experience of your patient and their carers or family. Scottish Government, [‘GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND \(BASRiS\) FORM FOR TERMINAL ILLNESS v1.0’](#) (2021).

capacity in relation to an assisted dying decision”. The group considered mental capacity in relation to the assisted dying decision and process, recognising that capacity can fluctuate and is decision-specific. They considered that a person has mental capacity in relation to an assisted dying decision if the person is capable of —

- (a) understanding information or advice about an assisted dying decision as required to be provided to the patient,
- (b) remembering the information or advice referred to in paragraph (a) to the extent necessary to make an assisted dying decision, and
- (c) understands the matters involved in an assisted dying decision, and
- (d) understands the effect of an assisted dying decision, and
- (e) is able to weigh up the factors referred to in paragraphs (a), (b), (c) and (d) for the purposes of making an assisted dying decision, and
- (f) can communicate an assisted dying decision in some way.

These criteria are in keeping with existing capacity law in Scotland, where a person is presumed to have decision-making capacity unless the person is shown not to have capacity. These are fundamental, internationally accepted principles based on capacity for consent, which formed the basis of the approach to capacity assessments.

The British Medical Association and the Association for Palliative Medicine provide guidance on how to assess capacity.⁵⁹ [Guidance](#) has also been provided in Scotland by the government and National Education Scotland. The group recognised that following legislation, up-to-date guidance will be provided by professional bodies on assessing capacity, specifically in relation to decisions about assisted dying. Capacity assessments in

⁵⁹ The [British Medical Association](#) and [other publications](#) provide toolkits and guidance on how to assess capacity.

relation to assisted dying decisions should also be part of any mandated assisted dying training.

If the person's mental capacity in relation to an assisted dying decision is in doubt, a referral should be made to a fully registered healthcare practitioner with appropriate skills and training (for example, a psychiatrist or psychologist) who can assess the person's mental capacity. For the avoidance of doubt, if a person permanently loses decision-making capacity in relation to an assisted dying decision at any time during the assisted dying process, the person ceases to be eligible for access to assisted dying.

The group notes that practitioners vary in their understanding of capacity assessments, with some expressing views that doctors are very familiar with this, whilst others are not as confident with them. The group are aware that Liam McArthur MSP and his team are keeping a close eye on the [review into Scottish Mental Health Law](#) and its impacts on capacity law in Scotland. Overall, the group is content that, with appropriate training and support, healthcare practitioners are well placed to make decisions on a patient's capacity in this context, as they do in other healthcare situations that require practitioners to consider a patient's capacity.

Those responsible for training, oversight and implementation of assisted dying must ensure that this education is expert-driven, outcome-focused and tailored to the clinical task at hand. Such training has proven highly useful for healthcare practitioners in permissive jurisdictions, but guidance on how to assess capacity in relation to assisted dying decisions should also be readily available.

3.4.1 Supported Decision-Making

In line with existing medical practice, the group suggests that the bill includes provisions for supported decision-making. Whilst this will need to be used infrequently, principles of supported decision-making should be recognised within the bill, i.e., that a person has capacity if they satisfy the mental capacity criteria and thus can make a decision about assisted dying with practicable and appropriate support.

This support includes: (i) using information or formats tailored to the particular needs of the person (ii) communicating or assisting a person to communicate their decision with the use of an interpreter, proxy, or speech and language therapist (iii) giving the person additional time and discussing the matter with them (iv) using technology to assist the patient where appropriate. The role of supported decision-making should be considered and included in the training provided to healthcare practitioners.

Furthermore, and in the same vein, the group wanted to ensure that access to assisted dying is equitable for all, and they considered how patient access must be non-discriminatory. In this sphere, they considered that patients who cannot sign documents should be able, as with other medical processes, to secure help by using a proxy.

A 'proxy' means a solicitor who has in force a practising certificate as defined in section 4 (c) of the Solicitors (Scotland) Act 1980 (c.46); a member of the Faculty of Advocates; a Justice of the Peace in Scotland; in relation to a document to be signed in a place outwith Scotland, a Notary Public or other person with authority under the law of that place to sign or otherwise execute documents on behalf of persons who are unable to sign.

For the purposes of this proposal, a fully qualified and registered proxy may, with instruction from and on behalf of a mentally competent person, sign documentation concerning the assisted dying process only if the patient authorises the proxy to sign documentation on the person's behalf. A document signed by the proxy must be done in the presence of the person and has the same effect as if signed by the person. A proxy may not sign a document unless satisfied that the person understands its effect. A proxy may not sign a document on behalf of a person in relation to whom the proxy is disqualified. Such disqualifying relationships are set out elsewhere and are similar to those of witnesses as laid out in section 4.3 of this report.

3.4.2 Coercion

In addition to assessing capacity, the proposal mandates that the two doctors involved in assessing the patient are satisfied that the patient is 'acting voluntarily and without coercion' and refers to the need to 'protect individuals who may be subject to abuse'. The

group agreed that testing the voluntary nature of the decision—i.e., freedom from undue influence, is necessary when undertaking a capacity assessment.

The group discussed how coercion can already influence current end-of-life decisions and that doctors have both a responsibility to identify it and guidance to help them do so. These are similar to the safeguards proposed in law reform attempts in Scotland, which already exist in assisted dying legislation around the world. For example, in preparation for the implementation of assisted dying in Victoria, Australia, the Department of Health and Human Services published information and training modules to support healthcare practitioners in detecting possible coercion around decisions relating to assisted dying.⁶⁰ This acknowledged that doctors should already be alert to coercion in a range of healthcare scenarios. The international experts advising the Medical Advisory Group confirmed between them that they had supported hundreds of patients to have an assisted death and had never been presented with a case of coercion into assisted dying.

Permissive assisted dying laws will always contain upfront safeguards and be accompanied by secondary legislation to which professional bodies/regulators, such as the GMC and others, will respond. Post-legalisation, they have an obligation to publish their own guidance and oversight (introducing even more accountability and clarity) in addition to the already available, arguably sufficient, healthcare guidance on coercion. It has been shown that much of the perceived or forecasted negative consequences of legislating to allow assisted dying has been disproved by countries who now have accumulated decades of data on the practice.

The group considered the satisfaction of capacity and coercion assessments to be one of the foremost safeguards of Mr McArthur's proposal. For this reason, both capacity assessments and coercion screening are conceived as integral elements for the effective functioning of assisted dying laws, alongside the option to refer for specialist opinion. We expect practitioners will be cautious in their approach to assessing capacity in this setting. Healthcare practitioners involved in assessments for the purposes of the proposal

⁶⁰ Department of Health, [‘Voluntary Assisted Dying Training for Medical Practitioners’](#) (2022).

need to understand the determination of both capacity and undue influence and how risks might arise in this context. This must be done in a way that enables autonomy, safety, and quality care at the end of life.

3.5 Residency requirements

The proposal stated that the person must have been ordinarily resident in Scotland for at least 12 months and be registered with a medical practice as per the usual ways of approaching this. The group acknowledged that, at present, many Scottish and UK citizens take advantage of permissive assisted dying practices overseas and consider that this would ultimately stop if residents could secure a peaceful death in their home country. The group considers this a compassionate and responsible way to give patients greater choice and control at the end of life in their home country without having to travel overseas.

Additionally, we can be sure that patients have been properly assessed for all health and social care alternatives prior to any assisted death. The group see this as a fundamental safeguard for people at the end of life and a way of providing more care and support, even if a proportion of those who initially request assisted dying will not ultimately go through with it. As evidence from other jurisdictions shows, simply having the choice of assisted dying acts as ‘emotional insurance’ to people, which gives them comfort and reassurance. Around one-third of people who go through the assisted dying process in Oregon do not end up having an assisted death, instead dying of natural causes.^{61 62}

Continuing with considerations of residency and the geography of Scotland’s communities, the group discussed how they utilise teleconferencing as part of ordinary practice and the benefits of this. The international experts detailed how during the COVID-19 pandemic, the use of teleconferencing tools like Zoom aided with eligibility assessments. The group recognised how this could be useful, particularly for undertaking eligibility assessments of patients in rural or remote areas in Scotland. They unanimously agreed that face-to-face appointments would always be preferable, but that teleconferencing may overcome access

⁶¹ [Oregon Death With Dignity Act 2021](#) data summary, p.15.

⁶² Having the choice of assisted dying allows people to maintain a quality of life with reduced anxiety and existential symptoms. L. Ganzini et al., [‘Interest in physician-assisted suicide among Oregon cancer patients’](#) (2006) *Journal of Clinical Ethics* 17:27-38.

issues for some patients. The group agreed that this should not be included in primary legislation and instead be included in professional guidance, post-legislation.

3.6 Disability

It should be explicitly acknowledged that a person is not eligible for access to assisted dying solely because the person has a disability alone within the meaning of section 1, Disability Discrimination Act 1995.

To be eligible for assisted dying, the person must meet all of the eligibility criteria set out in this section. The group suggests that a specific statutory provision prohibiting assisted dying for people with disabilities only should be considered for the sole purpose of alleviating potential concerns of people with disabilities who have reservations about assisted dying. Likewise, the group is aware that many people with disabilities responded to the consultation in support of the proposals and would welcome having the choice of assisted dying should they ever become terminally ill and thus qualify under the proposal.

It is argued that assisted dying is a human/constitutional right,⁶³ a view that has been upheld in a number of jurisdictions.⁶⁴ Currently, in Scotland, people are denied that right due to a concern that vulnerable people may feel subject to coercion into assisted dying. This argument is outdated and not supported by evidence. Likewise, it should not be assumed that certain groups of people are inherently vulnerable - a view expressed, for example, by disabled people who responded to the consultation wishing to be shown equal respect.

Protection of vulnerable people is central to the principles of the proposal, but the perception of vulnerability in this debate should be considered more broadly, and compassion towards some of the most vulnerable and overlooked people in society – the terminally ill who want the choice of assisted dying - should be shown equal respect. The Medical Advisory Group heard from a number of experts in jurisdictions which have legislated for assisted dying, who report no evidence of heightened risk to vulnerable

⁶³ Martin, S., '[Assisted Suicide and the European Convention on Human Rights: a Critical Analysis of Case Law](#)', (2018) Trinity College Law Review January, 244-275. See also, Martin, S. (2021). *Assisted Suicide and the European Convention on Human Rights* (1st ed.). Routledge.

⁶⁴ See [Carter v Canada \(Attorney General\)](#) 2015 SCC 5.

groups.⁶⁵ The research undertaken by the group concluded that where assisted dying is legal, there is no evidence that it will disproportionately impact patients in vulnerable groups. The group considered a recent publication by Professor Ben Colburn, which analysed all empirical studies examining the question of whether assisted dying laws have a disproportionate effect on people with disabilities. The group was reassured that concerns were not borne out.⁶⁶

To conclude this chapter, the itemised criteria being satisfied, the person may make a first formal request for assisted dying by voluntarily requesting access during a medical consultation and completing a patient declaration which outlines their voluntary wish to access assisted dying.⁶⁷ The above requirements being satisfied, the person may begin the assessment and safeguarding process.

Nothing in the bill should preclude a patient from informally discussing assisted dying with their healthcare practitioner prior to any formal request. As noted, in countries where assisted dying has been legalised, there is evidence that it has a positive impact on open dialogue and doctor-patient discussions around wills and preferences at the end of life.

3.8 Chapter 3 Recommendations

- That only self-administration should be provided for and not euthanasia, i.e., no direct administration of the API by a healthcare practitioner.
- Assisted dying should be for terminally ill adults only; in Scotland, that means those who have reached the age of at least 16 years of age.
- The group unanimously supports the definition of terminal illness as laid out in Liam McArthur’s proposal; “where a registered medical practitioner has diagnosed a person as having a progressive disease, illness, or condition from which they are unable to recover, and that can reasonably be expected to cause their death”.

⁶⁵ Battin, M. van der Heide, et.al., (2007) ‘[Legal physician assisted dying in Oregon and the Netherlands: evidence concerning the impact of patients in “vulnerable” groups](#)’. *Journal of Medical Ethics* 33.10:591-597.

⁶⁶ Colburn B. [Disability-based arguments against assisted dying laws](#). *Bioethics*. 2022 Jul;36(6):680-686. doi: 10.1111/bioe.13036.

⁶⁷ See Chapter 5 of this report which outlines the patient pathway and associated paperwork.

- Professional bodies should provide guidance on assessing capacity in relation to assisted dying decisions post-legislation. Capacity assessments in relation to assisted dying decisions should also be part of any mandated assisted dying training.
- If the person's mental capacity in relation to an assisted dying decision is in doubt, a referral should be made to a fully registered healthcare practitioner with appropriate skills and training (for example, a psychiatrist or psychologist) who can assess the person's mental capacity.
- If a person permanently loses decision-making capacity in relation to an assisted dying decision at any time during the process, the person ceases to be eligible for access to assisted dying.
- Supported decision-making should be utilised for mentally competent patients who require assistance to navigate the process.
- As part of the safeguarding process, multiple stage checks for coercion into or out of assisted dying decisions should be present.
- The person must have been ordinarily resident in Scotland for at least 12 months and be registered with a medical practice.
- Face-to-face appointments would always be preferable, but teleconferencing may overcome access issues for some patients, particularly in rural communities. The group agreed that this should not be included in primary legislation and instead be included in professional guidance post-legislation.
- Consideration should be given to whether a specific statutory provision disallowing assisted dying for people with disabilities only should be considered.

Chapter 4: Accessing Assisted Dying

4.1 Introduction

Stakeholders involved in providing and regulating assisted dying are numerous (e.g., healthcare practitioners, ethicists, lawyers, politicians, social workers, and volunteers, among others). Thus, the group considered that assisted dying has a higher level of scrutiny than currently exists for other end-of-life choices and that this is an inherently positive aspect. This chapter considers the medical aspects that are present as a patient seeks to access the assisted dying service.

4.2 Care Navigator Service

Firstly, the group agreed on the importance of establishing an assisted dying care navigator service. The purpose of an assisted dying care navigator service would be to provide support, assistance, and information in relation to assisted dying to patients and their families, friends and carers, and healthcare practitioners. The service would be able to give information about what the assisted dying process involves for those interested in accessing it, as well as answering questions healthcare practitioners might have about their role and responsibilities under the legislation. The care navigator service would also be able to help patients find healthcare practitioners willing to participate in assisted dying if their own healthcare team has a conscientious objection by holding a confidential register of healthcare practitioners who had completed the mandatory assisted dying training.

The Medical Advisory Group heard from Dr Cameron McLaren about how ‘voluntary assisted dying navigators’ work in Victoria. While some patients are supported through the assisted dying process by their healthcare team, some might need additional support or information. The navigators also help patients to find a doctor who can provide assisted dying if their own healthcare team has a conscientious objection. From 1 July 2021 to 30 June 2022, there were 1,062 contacts made to the Care Navigator Service seeking information or support, 30% of whom lived in regional or rural areas.⁶⁸ Family members and

⁶⁸ Voluntary Assisted Dying Review Board, [Report of Operations July 2021 - June 2022](#).

friends of those who have had an assisted death in Victoria have said about the Care Navigators:

I wish to express my thankfulness to the way in which you enabled (my dad) to begin the process for his wish to die peacefully at home surrounded by his family. From my first phone call to you, the steps were put in place by you for his end of life care to be as he wished. You were so caring and professionally skilled in the way you immediately helped us.

The Care Navigator... was amazing, she just organised everything to happen. She was always up there seeing [the applicant] and I think he felt very reassured by her presence.⁶⁹

Likewise, in Ontario, a 'care coordination service' has been established to help patients and healthcare practitioners access information and support for assisted dying and other end-of-life options. They support patients by providing information about assisted dying, hospice and palliative care and can put patients in contact with healthcare practitioners who can provide assisted dying. They support healthcare practitioners by helping them to find another practitioner to carry out the second assessment and provide information on pharmacies that have opted-in to dispense the API used.

4.3 Witnesses

The group recognised that people still have concerns about the safety of assisted dying primarily due to the required medical consultation and the death itself taking place in a private setting. As such, it is recommended that independent witnesses should be required at each stage of the assessment process to further bolster safeguarding. The group are aware that this is not standard practice for any other part of healthcare but that it would help ensure the voluntary nature of the patient requests and for any concerns to be raised with someone out with the direct clinical team.

It is recommended that the witness should not:

⁶⁹ Ibid footnote 68 at p.12.

- (i) be a relative, partner, or family member of the person; or
- (ii) believe or have knowledge of being a beneficiary under a will of the person; or
- (i) otherwise benefit financially or in any other material way from the death of the person; or
- (ii) be an owner of, or be responsible for the day-to-day management and operation of, any health facility at which the person is being treated or resides; or
- (iii) be a person who is directly involved in providing health services or professional care services to the person.

4.4 Pharmaceuticals

Pharmacists play a key role in supporting patients in their own communities and are, in many cases, the healthcare practitioner with whom patients and families have the most interaction. The Medical Advisory Group has considered all aspects of assisted dying, including the pharmaceutical requirements. This required the active ingredients to be considered, the form that those ingredients would take – most commonly referred to as the formulation, and the sourcing and manufacturing processes involved. Pharmacy stakeholders are monitoring international developments in this area and will consider all available evidence.

There has been some concern about ‘lethal medication’ being in public circulation. The group agrees with the proposal that this should not happen and that the correct approach is one where the API stays with the assisting practitioner at all times. If the person does not ingest the API due to them changing their mind, for example, it should be returned to the dispensing pharmacy because of the doses involved and the controlled status of the supplied product. This would also give a robust and auditable approach to governance in the early stages of assisted dying. The pharmacy would then destroy the API upon receipt. This ensures that the integrity of anything being supplied again from the pharmacy cannot be questioned, as a new API would be provided in the future. The group noted that the nature of pharmaceuticals and community care means that individuals, particularly at the end of

life, often already have access to potentially 'lethal medication' and that the process for managing substances under the assisted dying proposals is far more robust and safeguarded than what is in place at present.

The group are reassured by Mr McArthur and his team's meetings with pharmacy stakeholders in Scotland, who have advised that further information will be available once the APIs and formulations to be used are decided upon.

4.5 Advance Requests

The group discussed the possibility of patients being able to document their wishes for an assisted death in advance, for example, in an advance directive⁷⁰ or anticipatory care plan. Requests for assisted dying should be contemporaneous. As with other areas of healthcare, patients can state their wish for an assisted death (should they meet the criteria at a future point) via advance directives, but the group recommends that advance directives should not have any legal actioning power. That is, a patient should not be able to access assisted dying at a future point because they have requested it via advance directive or any other anticipatory care document. Assisted dying should be requested, assessed, and the process followed contemporaneously to make sure that all safeguards are followed.

Examples of the potential risks and difficulties associated with advance requests for assisted dying were noted in Phase 1 of Jersey's public engagement process on the topic.⁷¹ Concerns included the length of time between an advance directive being made and the assisted death taking place and how the assessment process would be completed if the individual did not have decision-making capacity – both in terms of moving the process forward and ensuring the request is voluntary, clear, settled, and informed. They concluded that there was no reason that a patient should be prevented from recording their wishes in such a document, but that it would have no bearing on the assisted dying process in any way and that all steps in the process would need to be followed as in any other situation. The Medical Advisory Group was clear that capacity would need to be maintained right up until

⁷⁰ "An Advance Directive allows you to record any medical treatments that you don't want to be given in the future, in case you later lack capacity and cannot make or communicate a decision for yourself." [Compassion in Dying](#) (2022).

⁷¹ Jersey Government, [Assisted Dying in Jersey Consultation](#) (2022) p.48.

the day an assisted death was scheduled and, as such, do not recommend the use of advance requests in Scotland.

4.6 Self-Administration

In respect of an API which has been prescribed for a person who has satisfied the criteria, assessment and safeguard process, the assisting practitioner may prepare the medicine for self-administration by that person. Assistance only goes so far as to provide the help needed so that the person can take the substance themselves.

The group suggests that a medical device could be prepared to enable the person to self-administer the medicine if they cannot swallow. This might be an IV (the person would press the plunger to ensure self-administration) or technological assistance if the person is unable to swallow. The decision to self-administer the medicine and the final act of doing so, which will directly cause the person's death, must be undertaken by the person for whom the medicine has been prescribed, reaffirming the voluntary nature of the act. The cause of the person's death must be that person's own direct and deliberate act by self-administration of an authorised substance and not by the actions of a healthcare practitioner.

4.7 Savings/Rescue provision

The international experts raised the issue of whether a savings or rescue provision would be made explicit in the legislation. Such a provision would allow the assisting practitioner to carry a medical IV kit to administer medication to the patient if the self-ingestion did not work for any reason. The group was reassured that the likelihood of an assisted death not going to plan was minimal but that it was good practice to help the patient die peacefully, rather than not assisting after the point of self-ingestion. The practitioner would be able to provide symptom relief for any signs of distress in line with existing end-of-life practices.

The assessment process should include conversations with the patient about the small risk of complications to ensure people are making an informed decision, as well as conversations about what the person would like to happen in those circumstances, which should be documented appropriately so the assisting practitioner is aware, e.g., a record in the patient's notes, anticipatory care plan or advance directive outlining a wish not to be

resuscitated. Dr Stefanie Green outlined how in Canada, clinicians have the option of carrying a rescue IV kit when a patient chooses to self-administer, which gives practitioners reassurance. Dr Cam McLaren added that in Victoria, the healthcare practitioner is not required to be present for self-administration but that there is no option of an IV rescue kit if something were to go wrong. He would be in favour of attendance at the death being mandatory in Scotland and of a rescue provision being present.

All of the international experts agreed and added that this would be the compassionate, safe and good quality care thing to do. A member of the Medical Advisory Group shared that doctors he has spoken to strongly favour having a rescue IV option for compassion and safety reasons and that “this isn’t euthanasia [as the patient has already self-ingested] but is supportive medicine”. The group unanimously agreed that the assisting practitioner should be present for self-administration by the patient, but no recommendation is made at this stage on whether a rescue IV kit should be facilitated in the legislation.

4.8 Assisting Practitioner

Responses to the public consultation called for more detail on the role of practitioners at each stage of the process. Whilst the role of assisting practitioners has been touched upon throughout this report, it is helpful to cover their role here explicitly.

Upon a prescription for an API being dispensed, the API stays with the healthcare practitioner at all times until the assisted death occurs. The assisting practitioner must remain with the person until the person has—

- (a) self-administered the assisted dying substance; or
- (b) decided not to self-administer the assisted dying substance;

The assisting practitioner is to be regarded as ‘remaining with’ the person if the assisting practitioner is in close proximity to the person; for patient and family privacy, the practitioner should only be required to remain in the same room until after self-ingestion is complete, thereafter once the API has been taken safely, they may leave the patient and family in privacy, providing contact details should any further assistance be required. In

Oregon, where assisted dying has been legal for over 20 years, the median time from taking the medication until death is 32 minutes. Patients themselves typically become unconscious in five to 10 minutes.⁷²

It is the Medical Advisory Group's recommendation that the healthcare practitioner stays with the patient to serve specific purposes; (i) making sure that the API is kept with a registered practitioner at all times and is not in public circulation (ii) to help prepare the API for self-administration, and (iii) to oversee that the self-administration has been done safely. The approximate time to death after self-administration can vary depending on the patient. It will be at the practitioner's discretion whether they stay present until the person has died or whether they leave the patient providing contact details should the family or another need to contact them.

An assisting practitioner must only deliver the prescribed medicines to the person for whom they have been prescribed immediately before their intended use, and if the person decides not to self-administer the medicine, the assisting practitioner must immediately remove the medicine from that person and, as soon as reasonably practicable, return it to the pharmacy from which it was dispensed for it to be destroyed.

In ordinary practice, one of the two doctors who has assessed the patient as part of the assisted dying pathway (the attending or independent practitioner) should act as the assisting practitioner. Additionally, doctors and nurse practitioners meeting the qualification and training requirements should be able to act as the assisting practitioner to help with access and workforce requirements. The importance of including nurse practitioners in this step is explored more in section 1.7 of this report.

4.9 Cooling off/Waiting periods

The proposal stated that after the medical examinations had been completed, there would be a 14-day waiting period, shortened if the person is expected to die within 30 days, but at least 48 hours must have passed since the examinations.

⁷² [Oregon Death with Dignity Act](#) Data Summary 2021.

After lengthy discussion and expert input, it was decided that the waiting period could actually contribute to greater suffering for a terminally ill person. Often, the person has already considered assisted dying for some time, whether that has been a long-held philosophical belief or a consideration from the point of diagnosis, potentially years or months earlier. The waiting period is supposed to act as a reflection period for the person, to ensure that their decision is not a flux one, and to allow the person to discuss the choice with family/friends and others. The experts explained that many patients die within this cooling-off period, and how others stop taking their pain medication to ensure that they can remain completely *compos mentis* to satisfy the capacity criteria. The experts were unanimous that 14 days was not useful at the proposed stage in the process. The group discussed, in conjunction with Mr McArthur, that the 14-day waiting period should be removed or reconsidered.

Mr McArthur felt strongly that a cooling-off period was necessary to allow time for reflection and consideration but that this could be done after the first request for assisted dying was made, rather than after the medical assessments had been completed as was initially proposed. Therefore, it is recommended that the 14-day reflection period begins after the first formal request for assisted dying is made. The medical examinations can take place during this time, allowing opportunities for discussion with healthcare practitioners and exploration of alternatives. It is recommended that data is collected on the functioning of cooling off/waiting periods to decipher whether it is a valuable safeguard or a barrier that prolongs suffering.

As with all other medical situations that a person requests and/or consents to, it should be explicitly stated that the patient can change their mind at any time and not go ahead with the process.

Chapter 4 Recommendations

- The group agreed that an assisted dying care navigator service should be established.
- That independent witnesses should be required throughout the assisted dying process.

- That the API should remain with the assisting practitioner at all times to prevent any medication from being in public circulation and that any unused medication should be returned to the dispensing pharmacy to be destroyed.
- Requests for assisted dying should be contemporaneous, with capacity retained right up to the point of self-ingestion; as such, advance requests for assisted dying via advance directive or any other anticipatory request should carry no actioning power.
- Ingestion of the API should be by the patient, with no direct administration allowed; technology and other assistance should be used to ensure the voluntary nature of the act.
- The healthcare practitioner should remain with the patient until they have self-ingested the API for reasons of safety, accountability, and support.
- Consideration should be given to whether a savings/rescue provision is included in the legislation.
- That a 14-day (or 48 hrs if the patient is expected to die within the 14-day period) waiting period should commence at the start of the assisted dying process (after the first formal request for assisted dying is made) rather than after the full assessment process has been completed, as was initially proposed in the consultation.

Chapter 5: Patient pathway

The group was asked to consider the steps a patient would go through to access an assisted death and to discuss how this would work in practice for healthcare practitioners and patients.

The purpose of this proposed patient pathway is to recommend what the group think would be feasible for healthcare practitioners and to aid Mr McArthur in the drafting of the Assisted Dying for Terminally Ill Adults (Scotland) Bill. The group notes that a full patient pathway will be developed post-legislative scrutiny and will require input from other stakeholders, such as professional bodies and regulators.

The proposed patient pathway was discussed by the group with Dr Catherine Forest, Dr Stefanie Green, and Dr Cameron McLaren. The international experts showed the group the patient pathways in Victoria, California, and Canada and gave evidence about what works well and what Scotland could learn from international experience.

The proposed patient pathway, as recommended by the group, is outlined here. More detail about each step is set out below.

1. Verbal request for assisted dying.
2. Discussion with healthcare practitioners about options.
3. First formal request (written) to attending registered medical doctor.
4. First formal assessment by the attending registered medical doctor.
5. Second formal assessment by the independent registered medical doctor.
6. Final patient declaration and data capture.
7. Arrange date of assisted death.
8. Healthcare practitioner delivers active pharmaceutical ingredient to the patient, and the patient self-administers this.
9. Mandatory reporting.

1. Verbal request for assisted dying.

A patient makes a verbal request for assisted dying to their registered healthcare practitioner. The patient and the healthcare practitioner would have a general discussion about their eligibility, disease, illness or condition, and motivations for requesting an assisted death. This is not a formal request.

2. Discussion with healthcare practitioner about options.

A patient's healthcare practitioner will inform them of all their options, including palliative care, social care, psychological support, and third-sector signposting. It should be made explicit that (as well as understanding that they have the option of hospice/palliative and other care) the person understands what this would involve and its potential benefits. If, after this discussion, the patient wants to continue with the assisted dying process, they can proceed to the next stage which is a formal request.

3. First formal request (written) to 'attending registered medical doctor'.

A patient makes the first formal written request for an assisted death, which is witnessed by the attending registered medical doctor and an independent witness. Identification is to be shown to the independent witness. At this stage, the witness is only confirming the patient's identity and witnessing their signature, so acceptable ID would include a passport or driver's licence. Full details of valid ID to be used for this stage and for the eligibility checks should be set out in the proposed bill and professional guidance.

The group discussed this step at length and agreed that the requirement for an independent witness was an important safeguard. They also recognised that the need for an independent witness might create unnecessary barriers for patients requesting assisted dying if there was not an appropriate person available to witness

the first formal request. The group agreed that to maintain the independence of the witness, they must not be a relative, partner, or directly involved in the patient's care or treatment but also agreed that to avoid unnecessary barriers, the independent witness can be another healthcare practitioner in the same practice or clinical team, for example, a nurse practitioner or a receptionist.

The group heard from Dr Stefanie Green that accessing an independent witness is sometimes challenging in Canada. Volunteer witness programmes send out volunteer witnesses when required, and telehealth witnessing is now permitted, which has helped, particularly in rural areas of Canada. This is something that could be explored post-legislation.

As noted in Section 4.9 of this report, the patient pathway initially stated that the 14-day waiting period started after the second formal request and associated process had been carried out. The group noted their concerns about the 14-day waiting period after hearing evidence from permissive jurisdictions that waiting periods can be an unnecessary barrier for dying people. The international experts detailed how some patients die during the waiting period, often having deaths they had wished to avoid because they have stopped taking their pain medication to ensure they satisfy the criteria of retaining full mental capacity.⁷³

However, the group also notes the necessity of including a waiting period as a safeguard to ensure someone has a settled and enduring wish for an assisted death. The initial proposal stated that the minimum 48 hours waiting period only occurs if the patient is expected to die within 30 days. The group recommends that the minimum 48 hour waiting period occurs only if the person is expected to die within the original 14 day waiting period.

⁷³ Commonly used opiates can sometimes effect the patients capacity and/or alter competency.

In practice, the arrangements for an assisted death, including the two independent medical assessments, ordering and receiving the API from a pharmaceutical special manufacturer etc. may take more than 14 days or 48 hours. However, it was agreed that minimum timescales (waiting periods) are a necessary safeguard, with the group recommending that data be collected on the functioning of the waiting period to provide evidence for future reviews of the legislation.

In summary, the 14-day (or 48 hours if the person is expected to die within the 14-day window) waiting period should start when the patient makes the first formal request, rather than starting from the second formal request and assessment.

4. First formal assessment by the ‘attending registered medical doctor’

The attending registered medical doctor (‘attending doctor’) would assess if the patient meets the eligibility criteria. They would also check that the person understands their diagnosis and prognosis, and understands they have other available options such as palliative and hospice care. The attending doctor would talk through the process of assisted dying and ensure the patient understands all of the information given.

The attending doctor would assess if the patient has capacity and that the patient is not being coerced into the decision. The attending doctor does not necessarily have to be a specialist in the patient’s disease, illness or condition, but should be (i) a fully-registered medical doctor (ii) have undertaken approved mandatory assisted dying training (iii) not be a relative, partner, or family member of the patient and (iv) not a beneficiary under the will of the patient or otherwise benefit financially or in any other material way from the death of the person.

The group discussed that assessing capacity and coercion is something that healthcare practitioners were well placed to carry out and is a routine part of their work already, for example, in cases of patients refusing chemotherapy or withdrawing treatment. This was seconded by the international experts who said

that assessing capacity and detecting coercion were routine parts of medical practice. Nevertheless, guidance on how to carry out capacity assessments and detect coercion should be provided by professional medical regulators post-legislation, and training should be provided to healthcare practitioners who have opted-in to facilitate assisted dying.

The patient should also be informed that they can decide not to go ahead with the assisted dying process at any stage.

The group unanimously agreed that during the assessment of the patient, there should be an option for referral for psychiatric or psychological evaluation if capacity is in doubt or referral to a specialist in the person's disease, illness, or condition if terminality is in doubt, or for any other clinical assessment if that was felt necessary.

5. Second formal assessment by the 'independent registered medical doctor'

The independent registered medical doctor would repeat the assessments made by the attending registered medical doctor, i.e., they would check if the patient meets the criteria and assess capacity and coercion. As with the attending doctor, the independent registered medical doctor does not necessarily have to be a specialist in the patient's disease, illness or condition, but should be (i) a fully-registered medical doctor (ii) have undertaken approved mandatory assisted dying training (iii) not be a relative, partner, or family member of the patient and (iv) not a beneficiary under the will of the patient or otherwise benefit financially or in any other material way from the death of the person. Additionally, if possible, the independent doctor should not be a colleague in the same practice or clinical team as the attending doctor.

As with the first medical assessment, during the second assessment of the patient, there is an option for referral for psychiatric or specialist evaluation or other clinical assessment if required.

The first and second formal assessments can be completed simultaneously as long as the two practitioners are independent of each other. The group thought this would ensure a timely process for the patient, without unnecessary waiting times between assessments.

6. Final patient declaration and data capture

After the two medical assessments have been completed, and if the patient still wishes to proceed, the patient should sign a final declaration form stating that, having been through the full assisted dying criteria, examination, and safeguarding process, they still wish to proceed with an assisted death. Data should be captured at this point on the reasons and motivations for wanting an assisted death. This could be done by the practitioner and patient discussing it and/or via a questionnaire that the patient should complete.

7. Healthcare practitioner and patient arrange the date of the assisted death

When the patient is ready, the healthcare professional and the patient will arrange the date of the assisted death.

Previous attempts at legislation required the assisted death to take place within a specified time frame (the End of Life Assistance (Scotland) Bill required the death to take place within 28 days from signing the final declaration, and the Assisted Suicide (Scotland) Bill required the death to take place within 14 days). The group discussed the importance of the assisted death being fully person-centred and agreed that there should be no maximum time frame within which the assisted death must take place after the final declaration is signed, to avoid any pressure on patients. Capacity will be assessed again prior to self-ingestion of the API on the arranged date, as will the voluntary nature of the act (i.e., checking again that there is no coercion, and that the decision is the person's own).

Given that the person is terminally ill and does not have long left to live, in most cases, a great deal of time will not pass between the final declaration being signed and the assisted death. In Oregon, over the whole period of assisted dying being legal (over 20 years) the median time from first request to death is 45 days.⁷⁴

All the above steps being satisfied, the attending doctor writes a prescription and sends it to the patient's chosen participating pharmacy. The active pharmaceutical ingredient is likely to be provided in a form that will be appropriate to the individual, such as a powder or liquid.

8. The assisting healthcare practitioner delivers the API to the patient and the patient self-administers the medication.

When the assisting healthcare practitioner delivers the assisted dying substance to the patient, the healthcare practitioner will carry out a final assessment of capacity (including voluntariness) and the patient either affirms or revokes their declaration.

If the patient affirms their declaration and is assessed as having capacity, the patient will self-administer the API. The international experts advised that self-administration should not be limited to oral administration but that it could include self-administered IV plungers for those who are unable to swallow. The group supports a definition of self-administration that is not limited to oral administration, so as not to discriminate against people who are unable to take the assisted dying substance orally.

The international experts recommended that it should be mandatory for the assisting practitioner to be present whilst the person self-ingests the API. Although some healthcare practitioners may see this as a burden on their time, the group unanimously agreed that it was vital for patient safety. With the number of assisted deaths likely to be low and the positive impact practitioner attendance at the death

⁷⁴ Oregon Government, [Oregon Death with Dignity Act Data Capture \(2020\)](#).

has on the family and the practitioner the group were assured that this was appropriate. This ensures that the patient and family are supported through the dying process, and that there are no complications when the patient self-administers the API.

As recommended at section 4.8 of this report, the assisting practitioner is to be regarded as 'remaining with' the person if the assisting practitioner is in close proximity to the person; for patient and family privacy, the practitioner should only be required to remain in the same room until after self-ingestion is complete, thereafter once the API has been taken safely, they may leave the patient and family in privacy, providing contact details should any further assistance be required. It will be at the practitioner's discretion whether they stay present until the person has died or whether they leave the patient providing contact details should the family or another need to contact them.

It is not mandatory that the attending medical doctor is the healthcare practitioner delivering the API. Other healthcare practitioners, such as registered nurse practitioners, may deliver the API and oversee the assisted death, as long as they have undertaken the mandatory assisted dying training. The international experts stated that most attending doctors prefer to be present for the assisted death, as they consider this as the final step in supporting their patient through the process.

9. Mandatory reporting

The final step in the patient pathway is that the healthcare practitioner completes the death certificate and mandatory reporting.

In permissive jurisdictions, mandatory reporting and monitoring of the assisted dying process is carried out by various bodies, including bespoke review boards. The Medical Advisory Group considered where the paperwork (patient declarations, medical assessments, questionnaires etc.) should be sent and that they should be held centrally within NHS Scotland. One approach would be for the paperwork to be

electronically sent to the Chief Medical Officer's office and/or to Public Health Scotland (PHS), which would use the information to prepare assisted dying statistics. This was the approach previously adopted by the Scottish Government in relation to abortion.⁷⁵ Likewise, other avenues could be utilised that are already present within healthcare.

Regarding death certification, Mr McArthur's proposal stated that:

Death certificates are public documents, and in the interests of privacy, the primary cause of death would be noted as the underlying illness from which the person died. It is envisaged that the paperwork and the potential creation of a reporting and oversight body would satisfy public health awareness, research and resource allocation requirements.⁷⁶

The group considered international approaches, for example, in Canada, provinces differ in what they put on their death certificates; some mandate that assisted dying is put on the death certificate whilst others have made it illegal for this to be put as the cause of death and instead put the underlying illness or condition.

In Scotland, the medical certification of cause of death form completed by healthcare practitioners asks for the 'disease or condition directly leading to death', with a section for additional information. The purpose of a death certificate is to certify *why* someone died, rather than the practicalities of *how* someone dies. Requiring the completion of mandatory reporting at each stage of the process will provide the necessary information needed for public health records and monitoring of the law - a death certificate alone will not do this. Not recording someone's underlying condition on their death certificate would hinder knowledge and research into terminal conditions. For example, figures for how many people die following a motor neurone disease diagnosis in Scotland would be obscured with potentially harmful unintended consequences.

⁷⁵ Scottish Government, [Abortion notifications and data - changing the process: consultation](#) (2022).

⁷⁶ Page 20.

The Chief Medical Officer's guidance in Scotland states that "From a public health point of view, preventing this first disease or injury will result in a greater health gain than treating subsequent direct/immediate cause of death...most routine mortality statistics are based on the underlying cause. Underlying cause statistics are widely used to determine priorities for health service and public health programmes and for resource allocation."⁷⁷

The approach proposed by Mr McArthur follows international precedent from Australia and the US. For example, guidance in Oregon states that:

The Oregon Health Authority, Center for Health Statistics recommends that physicians record the underlying terminal disease as the cause of death and mark the manner of death "natural" for patients who die under Oregon's Death with Dignity Act (DWDA)." ...The Attending Physician is then required to complete a follow-up form with information about whether the death resulted from ingesting the medications, or from the underlying disease. The recommendations for completing the death certification are intended to balance the confidentiality of patients and their families, while ensuring that we have complete information for statistical purposes.⁷⁸

In Victoria, guidance states that:

For people who access voluntary assisted dying, the Register of Births, Deaths and Marriages will record both the cause and manner of death. The cause of death will be the underlying disease (for example, cancer, motor neurone disease). The manner of death will be recorded as 'voluntary assisted dying'. The extract from the Register (commonly called the death certificate) that your family receives will not say that you accessed voluntary assisted dying. It will only record your underlying disease.

⁷⁷ Chief Medical Officer for Scotland, [Guidance for Doctors Completing Medical Certificates of the Cause of Death \(MCCD\) and Its Quality Assurance](#), (2018) at p. 14.

⁷⁸ Oregon Health Authority, [Death with Dignity Act](#).

The group agreed that Mr McArthur's approach where the underlying illness, disease or condition was recorded was the most clinically appropriate, and that data about assisted deaths should be collected via the mandatory reporting procedures, rather than being listed on someone's death certificate.

Chapter 5 Recommendations:

- The group recommends that the 14-day (or 48 hrs) waiting period starts when the patient makes the first formal request rather than starting from the second formal request and assessment as was initially proposed in the consultation.
- The minimum 48 hours waiting period only occurs if the patient is expected to die within the 14-day waiting period.
- The group also recommends that data be collected formally on the functioning of the waiting period to provide evidence for future reviews of the legislation.
- Guidance on how to carry out capacity assessments and detecting coercion for healthcare practitioners should be provided by professional medical regulators post-legislation and training should be provided to healthcare practitioners who have opted-in to facilitate the assisted dying process.
- The patient should be continually informed that they can decide not to go ahead with the assisted dying process at any stage.
- The group discussed the importance of arranging the date of the assisted death being fully person-centred and agreed that there should be no maximum time frame for when the assisted death must take place after the final declaration has been signed.
- The assisting practitioner (whether that be the attending doctor, the independent doctor, a nurse practitioner, or another healthcare provider who is qualified and has undertaken the training) should be present at the assisted death.
- As outlined in the proposal, mandatory reporting and recording of information should be present at each stage of the process.

- Where the [Medical Certificates of the Cause of Death form](#) asks for the disease or condition directly leading to death, this should be stated as the underlying disease, illness or condition from which the person died.

ENDS

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