Introductory Comments

1. The Royal College of Physicians of Edinburgh (RCPE) is a very “broad church” and includes within its Fellows and Members doctors from a diverse range of medical disciplines, including palliative care. The College has responded previously to related consultations and has participated in public and professional engagement activities (including “hot topic” events) to stimulate informed debate on this very complex and challenging subject. College views have also been influenced by the informed perspective of our lay advisers.

2. At this time the College takes no organisational stance on the merits of legislating for end of life assistance, recognising that Fellows and Members will have their very personal perspectives and that it will for the Scottish Parliament to determine the fate of this Bill, informed by public opinion and the views of those who will have a role in implementation.

3. Doctors have a professional responsibility to protect the interests and respect the wishes of their patients; it is in this spirit that the College identifies issues requiring greater clarity and identifies expected practical difficulties enacting the legislation as currently drafted. Comments are provided in response to the consultation questions:

Do you agree that a person should be able to request end of life assistance from a registered medical practitioner?

4. The proposed legislation provides for the “designated practitioner” being any registered medical practitioner (with no direct relationship with the patient) and it may be assumed that the majority (but not all) will be from Primary Care. The College has a number of concerns in relation to the role of the “designated practitioner”:

- whether the nature of the relationship between GPs (and their teams) and their patients (and their families) will change as a result of accepting this additional statutory responsibility;

- whether all doctors agreeing to participate (GP or hospital based) will have the necessary knowledge and experience (or access to same) to confirm that eligibility criteria are met in all cases, particularly with regard to considering all feasible alternatives;

- it appears that practitioners with no former doctor-patient relationship to the requesting person will be able to accept this role, including those in private practice.
the grade, seniority and experience of doctors is not laid out in legislation and there is no reference to specific training for this sensitive and important screening role;

how often can a request be made by a patient? Could there be a continuous repetition of the procedure to different doctors until approval is granted? How would other doctors know that a request had been turned down previously?

it is unclear whether the support of a “designated practitioner” can be withdrawn at any time if he or she disagrees with the patient, particularly with regard to the preferred manner of death and who will be directly responsible for administration;

it may be impractical for a single “designated practitioner” to deliver all components over what may be several months eg unable to attend at death through sickness or caught up in another emergency. The obligation to be available to complete the procedure may deter doctors from participation and may be a particular problem in the more remote areas of Scotland.

it could be protective of both doctors and patients to preclude the “designated practitioner” from certifying the eventual death of the person requesting assistance.

**Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?**

5. It would be important to ensure that psychiatric assessment of capacity confirmed the mental age for some patients.

6. The College notes that the eligibility criteria requiring registration with a GP for 18 months is restricted to Scotland in an attempt to limit “end of life tourism”. Is this unfair to patients at the end of their lives who move from other parts of the UK to be closer to family members as they become increasingly dependent?

**Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?**

7. The College has concerns about the definitions of “live independently” and “permanently physically incapacitated” (section 4 (2) (b)). It is unclear how dependent or incapacitated people would have to be to meet these criteria and consistent decision taking will be difficult in the face of subjective interpretation. This leaves the “designated practitioner” vulnerable to criticism and/or challenge and the College recommends further debate on these points. As they stand, the definitions would include a large number of people seen in geriatric practice and living in institutional care.
The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

8. The College agrees that the checks and balances introduced by requiring confirmation at 3 stages (2 pre-approval and again before administration) are helpful but has particular concerns about the time limits. Patients often experience periods of hopelessness and then recover; a 2 day cooling off period before administration may be inadequate and a 28 day expiry period may serve to actually encourage action by patients approaching the deadline and who may be worried about having to repeat the full procedure. The data from Oregon (where there are no such deadlines) indicate that many patients, having achieved the option, never go on to access assistance to end their lives. The College would be concerned that imposing a deadline forces the issue.

9. It is far from clear whether there is an expectation that normally the “designated practitioner” would be expected to take an active role in the act of assisted death in addition to being in attendance.

Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

10. Many doctors are concerned that the more formal safeguards are established, the more the legislators risk depersonalising and bureaucratising the last days of an individual life. The need for compassion and humane care at this difficult time may be overtaken by concerns about compliance with the law. However, the College recognises the importance of safeguards and offers the following comments and questions:

Specialist Knowledge

11. The College has concerns that individual “designated practitioners” will have the knowledge or be able to access the knowledge to support patients through the process and confirm eligibility safely and consistently. For example, specialist opinion may be required to update the prognosis, assess alternative solutions (including specialist palliative care) and ensure full and informed discussion on all options. This may require additional investigations which will take time and resources, particularly if the “designated practitioner” is neither the patient’s GP nor consultant. The College also notes that the consultation responses to the Joffe Bill in Westminster recommended that requesting persons should be required to experience palliative care rather than merely discuss it before finalising their decision.
Terminally Ill
12. The definition of “terminally ill” within Section 4 (4) and which provides for an expectation of death with 6 months implies a more exact estimation than is feasible for many patients, and/or may require expert opinion. This may delay or deter approval for all but the more certain/extreme cases resulting in patients dying before the necessary procedures have been completed and adding to their distress. Equally difficult is public scepticism of physicians’ ability to predict life expectancy and whether eligibility decisions will be taken accurately and consistently. Finally, the legislation does not clarify whether the 6 month prognosis is with or without treatment and for some neoplastic conditions this is particularly relevant.

Mental Competence
13. The detection of blatant coercion or major mental incapacity may be easily confirmed, but the College believes it may not always be straightforward to identify a more subtle combination of depression, mild cognitive impairment and the perception of being a burden. Also, the effect of inter-current medication with psychotropic drugs on the decision making process should be taken into account. Such cases will take time to confirm and may be difficult if two independent psychiatrists are involved in the assessment stages. Also, it is not clear why the psychiatrist but not the “designated practitioner” is required to ascertain the requesting patient’s motives and feelings towards the option of end of life assistance (Section 9 (2) (e)). The College also believes the decision of mental competence may not always be best left wholly to a psychiatrist and for some requests the views of a lawyer or social worker may be helpful – the legislation precludes this option.

Revocation
14. Section 3 provides for approval to be revoked at any time by the patient, informally or otherwise. The College seeks clarity on the role of other members of the health care team who may become aware of a change of patient view and their responsibility for informing the “designated practitioner”.

Conscientious Objection
15. There are important issues of conscientious objection for all members of the team caring for the patient in the last weeks of life and the Bill is silent on this question. Indeed the Bill, as worded, implies that current GMC guidance will already require a “refusing” doctor to find and refer a patient to another registered practitioner willing to take on this role. This responsibility may fall disproportionately on GPs given their more regular contact with patients. At present, it is thought that the numbers of doctors who will opt out of this new responsibility may be high and this may be a particular problem in the more remote areas of Scotland.
Witnesses
16. Section 6 (2) (b) requires the witnesses to confirm to “the best of their knowledge and belief” that the requesting person is making the request without coercion, but it is far from clear how close and knowledgeable these witnesses need to be and on what basis they will be judged to have made a “reasonable” decision. Where patients require interpretation services, care should be exercised to ensure the interpretation is fair and free from undue personal influence.

Other considerations

Palliative Care Professionals
17. RCPE shares the concerns of the Scottish Partnership for Palliative Care that an unintended effect of this legislation may be to compromise the practice and development of palliative care. All members of the multi-disciplinary palliative care team work towards supporting end of life choices for their patients and it is important that this definition included in Section 1 (2) of the proposed legislation does not inadvertently place them in an unlawful position.

Administration of Assistance
18. The “designated practitioner” is obliged to be present at the time of death but there are no provisions within the legislation to control who administers the assistance, and it is unclear whether “designated practitioner” is expected to supervise and intervene in the event of complications (eg unexpected side effects or failure to die). The competence of those empowered to administer assistance should be laid out to minimise the risks of complications or failure. It is critical that non-medical personnel are not empowered to undertake medical procedures for which they have no training. Also, the “designated practitioner” and the requesting person should meet to determine the mode, time and administrator of the required assistance and it may be helpful if this agreement was witnessed.

19. The Policy Memorandum (para 106 and 107) comments on the need for the “designated practitioner” and the psychiatrist to agree how and where assisted death is to take place, but there is no provision for this within the proposed legislation. This is justified by reference to the need for expert opinion, but it is unclear whether the final decision rests with the “designated practitioner” and, if so, what methods will be recommended and whether training will be available to support this new role.

Reporting to the Procurator Fiscal
20. The Policy Memorandum (para 116-124) implies that all such deaths will be reportable to the Procurator Fiscal (PF), who will retain the right to investigate, but there is nothing in the draft legislation to specify the level of monitoring to reassure the public and the profession that end of life assistance is proceeding appropriately. The College queries whether the option to advise the PF on approval has been considered
to create an opportunity for the PF to intervene if there is cause for concern in advance of the death rather than monitoring after the event.

**Advance Directives**
21. The College is aware that patients facing a difficult death are enthusiastic for advance directives to guide those caring for them when they are no longer able to communicate their wishes. The Bill takes no account of this option and, indeed, requires regular updating by repeating the request for assistance if set time targets are not met (see para 8 above).

**Other Drafting Issues**
22. Clause 1 (2) implies that assistance would be available to allow “another person” to die with dignity and may require a drafting amendment to be clear that the person seeking assistance to die must also be the one who requests such assistance.

23. Clause 4 (2) (a) and (b) – should be linked to ensure the intolerable life is due to the illness or permanent incapacity.

24. Clause 6 (3) (a) – the legislation should confirm who has responsibility for assessing the practicality of including a witness from a care home.

25. Clause 6 (3) (b) - the legislation should extend to cover volunteers in care homes in addition to employees.

26. Clause 5 (2) and 6 (5) – the legislation should cover the position when the “designated practitioner” may have, but is unaware of, a relationship or pecuniary interest with the requesting person.

27. Clause 6 (4) – it may be safer to preclude staff from the same medical team from acting as witnesses.

28. Clauses 7(4) and 8 (3) – the time periods within which the next steps must be taken are laid out, but the legislation does not specify the form of notification to the person requesting assistance.

29. Clause 11 (3) and (6) – it may be necessary for the designated practitioner to be present when the end of life assistance in administered AND at the end of life to allow the doctor to discharge his/her responsibilities fully in terms of providing a third check on the continuing will of the requesting person.

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