

## **Written evidence submitted by Healthcare Professionals for Assisted Dying (HPAD) (ADY0410)**

Healthcare Professionals for Assisted Dying is a group of healthcare professionals who support greater patient choice at the end of life. We were established and are supported by the campaign group Dignity in Dying.

Our supporters encompass a broad range of professions and specialities, ranging from GPs, specialist consultants, nurses, mental health specialists and allied health professionals. We welcome student, practising and retired supporters and have supporters based across the British Isles.

HPAD's aims are to encourage and facilitate honest and constructive engagement in the assisted dying debate, by individual healthcare professionals and the organisations that represent them.

### **Summary**

In this response we give an overview of the views healthcare professionals have towards assisted dying, before exploring the limits of palliative care and how assisted dying can be a catalyst for improvements to palliative care. We also stress the need for safeguarded assisted dying legislation to be embedded within the healthcare system and explain how legalising assisted dying would resolve a range of ethical difficulties that healthcare professionals experience under the current law. Finally, we recommend that the Government acts pro-actively in regard to assisted dying to ensure healthcare professionals are consulted with appropriately and fully prepared for the implementation of assisted dying.

### **The views of healthcare professionals**

The views of healthcare professionals have historically often been cited as a reason not to change the law on assisted dying. In 2015, during the Second Reading debate of Rob Marris's Assisted Dying Bill, numerous MPs said the opposition of the medical profession was a factor in their decision to vote against the bill. One said: 'The vast majority of UK doctors are opposed to legalising assisted suicide or assisted dying, as are the British Medical Association'.<sup>1</sup> In 2018, in its judgment dismissing the claim of Noel Conway, who was seeking a declaration that the current law was incompatible with his human rights, the Court of Appeal made nine separate references to the British Medical Association's opposition to assisted dying.<sup>2</sup>

It has always been HPAD's view that this perception of medical opposition to assisted dying was not backed up by quantitative data and that the position of medical bodies that were active in campaigning against assisted dying was unrepresentative.

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<sup>1</sup> <https://publications.parliament.uk/pa/cm201516/cmhansrd/cm150911/debtext/150911-0001.htm#15091126000003>

<sup>2</sup> <https://www.judiciary.uk/wp-content/uploads/2018/06/conway-judgment-27062018.pdf>

This view has been validated in recent years. In 2019 the Royal College of Physicians (RCP) surveyed its members on assisted dying.<sup>3</sup> Less than half of respondents (43.4%) wanted the RCP to continue to oppose law change. 31.6% of respondents wanted the RCP to be in favour of law change and 25% thought the RCP should be neutral. The RCP Council decided that the survey results highlighted that there was no appetite within the RCP membership to campaign either for or against assisted dying and the college adopted a neutral policy.

In 2019, the British Medical Association (BMA) agreed to survey its membership on assisted dying for the first time in its history. The survey was carried out in 2020 and with nearly 30,000 responses represents the largest ever survey of medical opinion the issue.<sup>4</sup> Following publication of the survey results, members of the BMA's 2021 Annual Representative Meeting (ARM) narrowly voted for the BMA to drop its opposition to assisted dying in favour of a neutral policy. This policy was strongly reaffirmed at the 2022 ARM. A summary of the key results from the BMA's survey is included below:

- The majority (61%) of doctors voted for the BMA to change its policy of opposition to assisted dying.
- More doctors personally supported law change (50%) than opposed it (39%).
- In every branch of practice a majority of doctors voted for the BMA to drop its opposition to assisted dying. Medical students, retired doctors and, crucially, practising doctors were all more likely to support assisted dying than oppose it.
- Just 22% of respondents said doctors should have no formal role in the law should it change.
- 34% of respondents with a license to practise in the UK said they would be prepared to actively participate in the assisted dying process should the law change. According to the General Medical Council there are 243,360 licensed doctors in England and Wales.<sup>5</sup> This means we can estimate over 80,000 doctors would be prepared to participate in the assisted dying process, with a further 46,000 possible doctors, based on the 19% who said they were currently undecided about whether they would participate or not.
- In 35 of the 36 specialities surveyed there was a majority vote for a change in the BMA's policy.
- Levels of personal support varied between specialities but there was no correlation between personal opinion and vicinity to frontline practice. For example, 62% of anaesthetists supported law change compared to 46% amongst those working in medical academia.
- 70% of palliative medicine doctors – who made up just 2% of total respondents to the survey – voted for the BMA to continue to oppose law change, making this group a significant outlier. But this result highlighted a significant softening of views amongst palliative medicine doctors; in the RCP's 2019 survey 81% of palliative medicine doctors voted for a policy of opposition.

The Royal College of Nursing (RCN) has been neutral on assisted dying since 2009, following a consultation with its members which revealed a range of opinions.<sup>6</sup> The RCN's neutrality was

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<sup>3</sup> <https://www.rcplondon.ac.uk/news/no-majority-view-assisted-dying-moves-rcp-position-neutral>

<sup>4</sup> <https://www.bma.org.uk/media/3367/bma-physician-assisted-dying-survey-report-oct-2020.pdf>

<sup>5</sup> [https://www.gmc-uk.org/-/media/documents/workforce-report-2022---full-report\\_pdf-94540077.pdf?la=en&hash=9267A7B904842B44133BC982EEB3F5E8ED1A85F4](https://www.gmc-uk.org/-/media/documents/workforce-report-2022---full-report_pdf-94540077.pdf?la=en&hash=9267A7B904842B44133BC982EEB3F5E8ED1A85F4)

<sup>6</sup> <https://www.rcn.org.uk/About-us/Our-Influencing-work/Policy-briefings/pol-2314>

reaffirmed at the RCN Congress 2022, where it was also agreed that the RCN would explore how to inform its members about proposed changes to the law.<sup>7</sup>

2019 polling by YouGov found that only 13% of healthcare professionals believe that without an assisted dying law there are sufficient options available to give dying people meaningful control over their deaths.<sup>8</sup>

**Q. To what extent do people in England and Wales have access to good palliative care? How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?**

Even the very best palliative care has its limits, a fact which is accepted by those on all sides of the assisted dying debate. Therefore while HPAD backs all efforts to improve access to good palliative care in this country, that will not resolve the question of what we do to support those whose suffering cannot be relieved by even the best care.

While there is extensive literature on the prevalence of pain in terminal conditions,<sup>9101112</sup> we would like to draw the committee's attention to the fact that suffering is often multi-faceted and other forms of suffering besides pain can also sit beyond the reach of the most skilled professionals. We recognise that sometimes it is the lack of choice itself currently available to dying people that is the source of a person's suffering and it is paradoxical to ask what measures besides assisted dying might help that person. The availability of assisted dying as an end-of-life option would enable a relatively small group of people to exercise greater control over their deaths, but a significant benefit is that its presence as an option would have a therapeutic benefit for a wider group, who would be reassured they will not be forced to suffer against their wishes at the end of life.

Crucially, excluding the option of assisted dying from end-of-life care provision is inconsistent with how the healthcare system has developed in this country, where it now rightly places increasing emphasis on an individualised approach to care. How can healthcare professionals be expected to justify a system that offers choice to people throughout their lives, but then limits that choice as people's lives are coming to an end, a period of time in which choice would often have the most value? Again, while the practical benefits of a change in the law are clear, reform in this area would also have symbolic value and convey to individuals that the healthcare system recognises and respects the fact that people have their own beliefs, attitudes and values. It is imperative that palliative care and broader end-of-life care keeps pace with the rest of healthcare and wider society.

Finally, we recognise that there is a culture within palliative medicine around end-of-life choice that is detrimental to honest and open discussion of the issue. This is an area where the speciality of palliative medicine as a whole must improve. In 2019, five palliative care consultants wrote anonymously in the British Medical Journal to say that they would risk their careers if they discussed assisted dying.<sup>13</sup> This prompted a former President of the Association for Palliative Medicine (APM)

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<sup>7</sup> <https://www.rcn.org.uk/congress/congress-events/assisted-dying>

<sup>8</sup> YouGov (2019)

<sup>9</sup> <https://pubmed.ncbi.nlm.nih.gov/18023377/>

<sup>10</sup> <https://pubmed.ncbi.nlm.nih.gov/6218464/>

<sup>11</sup> <https://pubmed.ncbi.nlm.nih.gov/26516550/>

<sup>12</sup> <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england#>

<sup>13</sup> <https://www.bmj.com/content/365/bmj.l1494>

to validate the concerns of the authors and reveal that he had been ‘personally ostracised over [his] support for a neutral position on assisted dying’.<sup>14</sup> More recently, a retired palliative care consultant has documented how the APM’s leadership dismissed his request for a factual correction of an inaccurate briefing on assisted dying the APM had distributed to Parliament.<sup>15</sup> It is critical that diverse views and perspectives on assisted dying within palliative medicine are respected and heard.

### **What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?**

Embedding assisted dying within the healthcare system, as the overwhelming majority of jurisdictions that have legislation in place have done, is key to maximising the positive impact of law change.

We urge the committee to consult the Victorian Department of Health’s material on assisted dying as it shows how implement assisted dying through existing healthcare structures leads to the provision of clear information for individuals and healthcare professionals as well as centralised training and oversight.<sup>16</sup> Australian States have also demonstrated how providing assisted dying as a healthcare option and increasing funding to palliative care services can go hand in hand.<sup>1718</sup>

A study of assisted dying requests in Oregon found that conversations about assisted dying triggered palliative care interventions such as pain relief and referral to hospice services which, in some but not all cases, led to the individual changing their mind;<sup>19</sup> if people’s conversations about assisted dying did not take place within a healthcare context than there would be a reduced chance of these interventions being explored. Research shows that following the passage of assisted dying legislation healthcare professionals often report making greater efforts to improve the level of care they provide to all their patients, not just those who seek the option of an assisted death.<sup>20</sup> There are also examples of doctors who were once opposed to law change making an informed choice to support their patients once a request was made to them personally, illustrating how attitudes and indeed wider medical culture can change over time.<sup>21</sup>

While there is much to learn about what jurisdictions in the USA and Australia have done right, we can also learn about what this country can do better. For example, Victoria’s assisted dying legislation includes a ‘gag clause’ which restricts healthcare professionals’ ability to discuss the option of assisted dying with their patients. When the legislation was passed some critics highlighted how there was no evidence that such a clause was justified.<sup>22</sup> Research has found that restricting conversations about end-of-life options may lead to less optimal patient outcomes.<sup>23</sup> We believe it would be irrational to limit the conversations that healthcare professionals can have about some end-of-life options but not others.

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<sup>14</sup> <https://www.bmj.com/content/365/bmj.l1494/rr-3>

<sup>15</sup> <https://www.dignityindying.org.uk/blog-post/palliative-medicine-must-engage-honestly-in-the-assisted-dying-debate/>

<sup>16</sup> <https://www.health.vic.gov.au/patient-care/voluntary-assisted-dying>

<sup>17</sup> <https://www.nsw.gov.au/media-releases/budget-2022-palliative-care>

<sup>18</sup> <https://mforum.com.au/palliative-care-a-human-right-vad-voluntary-assisted-dying/>

<sup>19</sup> <https://www.nejm.org/doi/full/10.1056/nejm200002243420806>

<sup>20</sup> <https://pubmed.ncbi.nlm.nih.gov/11343484/>

<sup>21</sup> <https://www.acpjournals.org/doi/10.7326/0003-4819-132-6-200003210-00014>

<sup>22</sup> <https://lens.monash.edu/@politics-society/2020/02/13/1379677/voluntary-assisted-dying-the-gag-clause>

<sup>23</sup> <https://spcare.bmj.com/content/10/1/105.abstract>

The example above ties into a broader concern we have regarding how overseas practice of assisted dying informs the debate in this country. We have observed how individual cases from other countries for which we do not have the full facts have been presented as justification for keeping the law as it is. In no other area of medicine would it be acceptable to formulate best practice based on speculative, unsubstantiated claims and in our view healthcare professionals who campaign in this manner are blurring the lines between their personal and professional perspectives, which risks undermining the integrity of our professions. We urge the committee to approach the debate in an evidence-based manner, which includes full examination of relevant data and peer-reviewed research.

Finally, evidence from other countries indicates that even decades after implementation, assisted deaths remain relatively small in number. In Oregon, for example, they have never exceeded 1% of total deaths.<sup>24</sup>As we have outlined above, changing the law would result in benefits for a far greater number of people, but in terms of practical implications it is clear that assisted dying would not represent a significant demand on the healthcare system and figures from the BMA on doctors' willingness to participate in law change indicate there would be more than enough professionals prepared to support their patients through a request to make a law workable.

### **What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?**

HPAD recognises and respects the fact that some professionals have strong personal beliefs on the issue of assisted dying and may wish to conscientiously object from direct involvement in an assisted dying law. As such we support robust conscientious objection clauses in legislation to ensure that individuals can practice in line with their ethical principles. However, in line with current practice around conscientious objection, it is critical that professionals who wish to exercise a conscientious objection do so in an explicit and transparent way which does not cause distress to their patient or deny them access to services.<sup>25</sup>

We also recognise that many professionals feel ethically compromised by the current legal framework. Just as it would be wrong to force healthcare professionals to be directly involved in assisted dying, it would be equally wrong to seek to prevent healthcare professionals from conscientiously participating in assisted dying should the law change.

Examples of where professionals may feel ethically compromised include how the current law has given rise to restrictions in the support doctors can provide to someone who is seeking access to assisted dying in Switzerland. The General Medical Council (GMC) and BMA are clear that doctors are able to give someone access to their medical records even if they know they will be used to make an application for an assisted death in Switzerland, however they are not permitted to write a specific medical report for that purpose.<sup>26</sup><sup>27</sup> HPAD has seen written advice from the Medical Defence

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<sup>24</sup><https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf>

<sup>25</sup> <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice>

<sup>26</sup> <https://www.bma.org.uk/media/1424/bma-guidance-on-responding-to-patient-requests-for-assisted-dying-for-doctors.pdf>

<sup>27</sup> <https://bjgp.org/content/67/664/515>

Union which is far more restrictive than the guidance provided by the GMC and BMA. We believe this lack of clarity and the resulting ethical inconsistency is causing harm to doctors, as well as unnecessary anguish for individuals who are trying to have an assisted death overseas.

We also know that people with terminal and severe health conditions are at a greater risk of suicide.<sup>28</sup> Qualitative research shows a key motivator for these suicides can sometimes be the lack of choice within the current law, as highlighted in Dignity in Dying's report, *Last Resort: The hidden truth about how dying people take their own lives in the UK*.<sup>29</sup> In that report, one GP describes how a patient asked him for help to control the manner and timing of his death and, after the GP explained that he was unable to provide this support under the current law, that patient later ended his own life by self-inflicted gunshot wound to the head. The GP said: 'Because of my inability, my cowardliness, whatever, to help him. He decided to have the most obscene, cruel, violent death imaginable'. A law that allows professionals to explore a greater range of end-of-life options would reduce cases such as this, where doctors and other professionals take on a burden of ethical responsibility for what is in fact a failure of the law.

Free text responses to the BMA's survey on assisted dying revealed that many doctors believe it is ethically wrong for people to endure unnecessary suffering at the end of their lives,<sup>30</sup> especially when the option to have an assisted death is something that many doctors would want for themselves. Being forced to witness acute suffering at the end of life, when that person would prefer the option of an assisted death, is something that we know has a negative impact on professionals and the ethics of sustaining this must be considered.<sup>31</sup>

We would also like to comment on the idea of institutional conscientious objection, where the owners or managers of healthcare facilities could unilaterally decide to prohibit assisted dying. This would be inconsistent with the way conscientious objection currently works in this country as it would undoubtedly restrict people's access to services, particularly in a local geographic area. We also believe it would be ethically unacceptable to prevent a healthcare professional from being able to support their patient to explore an option that is legal.

Finally, for the avoidance of doubt, the medical profession does not rely on the Hippocratic Oath and assisted dying is compatible with the ethics of modern medicine; doctors now follow the World Medical Association's Declaration of Geneva which asks doctors to 'respect the autonomy and dignity of [their] patient'.<sup>32</sup>

**Q. What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying/assisted suicide services?**

**Q. What protections could be put in place to protect people from coercion and how effective would these be?**

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<sup>28</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionengland/2017to2020>

<sup>29</sup><https://www.dignityindying.org.uk/wp-content/uploads/Last-Resort-Dignity-in-Dying-Oct-2021.pdf>

<sup>30</sup><https://www.bma.org.uk/media/3367/bma-physician-assisted-dying-survey-report-oct-2020.pdf>

<sup>31</sup>[https://www.dignityindying.org.uk/wp-content/uploads/DiD\\_Inescapable\\_Truth\\_WEB.pdf](https://www.dignityindying.org.uk/wp-content/uploads/DiD_Inescapable_Truth_WEB.pdf)

<sup>32</sup><https://www.wma.net/policies-post/wma-declaration-of-geneva/>

**Q. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/assisted suicide services?**

We will answer these questions collectively. HPAD's position is that assisted dying should be an option for mentally competent, terminally ill adults. We recognise that there is an ethical distinction between empowering people who are dying to control the manner and timing of an imminent death and giving people who are not dying the ability to shorten their lives. This principle is already recognised informally in existing end-of-life practices. For example, in its framework on palliative sedation the European Association for Palliative Care recommends that continuous deep sedation, where sedatives are administered with the intention of keeping a person unconscious until they die, should only be considered when someone is in a terminal phase of their life.<sup>33</sup> It is worth noting that the practice of continuous deep sedation in this country is recognised as inconsistent and there is no formal data collection or oversight.<sup>34</sup> This is another example of how assisted dying legislation would add clarity and external scrutiny to an area of healthcare practice that is often self-policing, and where the ethics and parameters of practices have never been subjected to societal debate in the way assisted dying has.

In regard to the detection of coercion and ensuring people are making informed decisions about their treatment and care, these are already things that healthcare professionals are well-skilled in and professional guidance often explicitly states where the detection of coercion is necessary.<sup>35</sup> There are a range of end-of-life decisions that people can make which have the same outcome as an assisted death, for example the refusal of life-sustaining treatment. Doctors' ability to safeguard these decisions without unduly restricting the freedom of people to make them provides reassurances that a process for approving assisted dying requests that involves doctors would work safely and effectively.

It is also for this reason that HPAD finds suggestions that assisted dying, if legalised, should sit outside the medical profession extremely concerning.<sup>36</sup> Legislation would be safer if doctors and other healthcare professionals are involved. These professionals have the knowledge and skills to be able to talk someone through their alternative care options, assess the person's capacity to make a request and ensure the person has a voluntary, settled wish to have an assisted death. Furthermore, many professionals would find it abhorrent to be forced to refer a dying patient to an unfamiliar third party service rather than be able to support that person through an assisted dying request themselves. As outlined above, a doctor who did not want to discuss assisted dying with their patients, and/or was not prepared to support that person through an assisted dying request, should be able to exercise their conscientious objection rights and refer their patient to another doctor who would be prepared to do so. With robust conscientious objection rights in place, there is no need to take the process outside of the medical profession.

While doctor involvement in the assisted dying process is essential we would encourage the committee to explore how additional processes could be incorporated into any future legislation to

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<sup>33</sup>[https://www.researchgate.net/publication/38037679\\_European\\_Association\\_for\\_Palliative\\_Care\\_EAPC\\_recommended\\_framework\\_for\\_the\\_use\\_of\\_sedation\\_in\\_palliative\\_care](https://www.researchgate.net/publication/38037679_European_Association_for_Palliative_Care_EAPC_recommended_framework_for_the_use_of_sedation_in_palliative_care)

<sup>34</sup><https://www.sciencedirect.com/science/article/pii/S0885392412000632>

<sup>35</sup><https://apmonline.org/wp-content/uploads/2016/03/Guidance-with-logos-updated-210316.pdf>

<sup>36</sup><https://www.bmj.com/content/371/bmj.m2919>

ensure assessments work for individuals and healthcare professionals. For example in Victoria, Australia, if a person is deemed ineligible for assisted dying on the grounds that they lack capacity, the person can apply to the Victorian Civil and Administrative Tribunal for a review of their assessment.<sup>37</sup> Having this option is likely to provide added reassurances for all involved.

We also urge the committee to read the report of the Medical Advisory Group that was formed to explore the healthcare-related issues of the proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill.<sup>38</sup> This report explores some of the key questions that have arisen in regards to how assisted dying might work in practice, drawing on the knowledge of clinical experts in the UK and those involved in assisted dying provision in other countries. We will not repeat the findings of the report here but there is significant overlap with the terms of reference of this inquiry and the terms of reference of the Medical Advisory Group.

### **What capabilities would a person need to be able to consent to assisted dying /assisted suicide?**

HPAD believes mental capacity must be the cornerstone of the eligibility criteria of any assisted dying legislation. Again, doctors and other professionals routinely assess capacity, often around decisions that may result in a person's death. Therefore there is no reason to doubt that the requirement to have capacity in order to have an assisted death would not work in practice. Recent proposals for a change in the law on assisted dying would have required two doctors to agree the person making a request had capacity and they would have to refer the person to an appropriate specialist if either of them had any doubts about the person's capacity. We agree this would be a suitably rigorous process to protect the individual who is making a request.

We find any suggestion that current practice in regards to capacity assessments when people are making life and death decisions could not equally apply to assisted dying requests deeply flawed. For example the campaign group Living and Dying Well claims it would be 'perverse' to apply current standards to assisted dying requests,<sup>39</sup> yet their alternative suggestion – that doctors (or whoever they believe should assess the person) must assume the person lacks capacity until there is proof to the contrary – betrays a fundamental misunderstanding of this important area of healthcare. In a recent case in the Court of Protection, the Honourable Mr Justice Hayden observed that 'the Mental Capacity Act erects a presumption of capacity as a vital safeguard to protect adult autonomy.'<sup>40</sup>

### **What should the Government's role be in relation to the debate?**

The Government should undertake more research on the impact of the current blanket ban on assisted dying, both on dying people and healthcare professionals. This should include ensuring there is a full understanding and constancy in practice when it comes to the level of support professionals can provide to people seeking an assisted death overseas. It should also include quantifying the incidence of terminally ill people choosing to end their lives in this country, drawing on existing data and liaising with coroners and public health teams. We also recommend the

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<sup>37</sup> <https://www.health.vic.gov.au/sites/default/files/migrated/files/collections/policies-and-guidelines/v/vad-information-for-people-considering-voluntary-assisted-dying.docx>

<sup>38</sup> <https://www.assisteddying.scot/wp-content/uploads/2022/12/Medical-Advisory-Group-Report.pdf>

<sup>39</sup> <https://livinganddyingwell.org.uk/wp-content/uploads/2021/05/Truths-and-Half-Truths-about-Assisted-Dying-A5-Final.pdf>

<sup>40</sup> <https://www.bailii.org/ew/cases/EWCOP/2023/2.html>



Government regularly collects and publishes data that illustrates the limits of palliative care in order to inform this debate.

However, we also recommend the committee makes the most of the opportunity to begin the process of future-proofing this country for a time when assisted dying is legal, taking into account the fact that Scotland, Jersey and the Isle of Man are currently considering assisted dying proposals. The Government should establish meaningful channels of communication with relevant professional bodies in regards to assisted dying. We also recommend the Government convenes a meeting of the General Medical Council, the Nursing and Midwifery Council, General Pharmaceutical Council and the Professional Standards Authority to identify and resolve any relevant regulatory matters that might stem from a change in the law.

First and foremost, to ensure a person-centred approach to this issue, we recommend the committee, Government and Parliament as a whole places the wishes of dying people at the centre of the assisted dying debate.

***Jan 2023***