BMA Scotland is the trade union and professional association for doctors. We represent over 17,000 members from all branches of medicine across Scotland. The BMA is the voice of the medical profession – we look after doctors so they can look after you.

BMA Scotland lobbies and campaigns on the issues impacting the medical profession, we publish and promote research and reports on a variety of health, scientific and ethical matters.

We are member led and represent all branches of the medical profession. We support our members in their professional lives, advocate for fairness and equality, and negotiate for better terms and conditions.

Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?

Strongly Agree

Please explain the reasons for your response, including what you think a right to palliative care should deliver.

BMA Scotland agrees those facing the end of their life, who desire access to palliative care, should have their needs met. If health and social care services were adequately resourced then the they would be more able to consistently ensure that patients' needs are addressed and met. BMA members are all too aware of the impact on patients and family when end of life care doesn't meet or address their needs, causing additional distress. While this distress is most acutely felt by the patient themselves and their family, it can also be felt by medical professionals through moral distress.

Moral distress is defined as the psychological unease generated where professionals identify an ethically correct action to take, but are constrained in their ability to take that action. Even without an understanding of the morally correct action, moral distress can arise from the sense of a moral transgression. More simply, it is the feeling of unease stemming from situations where institutionally required behaviour does not align with moral principles. This can be as a result of a lack of power or agency, or structural limitations, such as insufficient staff, resources, training or time. The individual suffering from moral distress need not be the one who has acted or failed to act; moral distress can be caused by witnessing moral transgressions by others[1].

It is worth noting that palliative care is often provided beyond specialist palliative care services and teams. Many geriatricians' posses these skills as do many GPs. Too often any increase in palliative care resources focuses on the specialty itself alone and not wider general palliative care. The majority of those requiring palliative care go nowhere near a hospice. More needs to be done to help the public understand generalist palliative care and how that can address and meet their needs. Good palliative care in the community requires a fully functioning multi-disciplinary team (MDT) including palliative care and district nurses. That being said, patient and family expectations need to be managed, the reality of providing palliative care in the community, or enabling those wishing to die at home to do so, requires a lot of resource through health and social care and sometimes, for an array of reasons, it is not always possible.

While BMA Scotland is fully supportive of patients accessing the palliative care they need, we do have concerns about how these needs can be met with current resourcing across the NHS and social care services. We know that for the demand being placed on the NHS, it remains substantially understaffed, under resourced and under-funded. BMA Scotland is concerned that any additional

[1] BMA, 'Moral distress and moral injury, Recognising and tackling it for UK doctors', June 2021

expectation on health and social care staff at this time without adequate funding and resourcing will only lead to additional burnout and retention problems and ultimately will do nothing to encourage people to work in these sectors.

What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care? Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

The World Health Organisation has clearly come to an informed decision on the definition of palliative care and BMA Scotland would not argue with it. Patients however don't always want to be labelled as 'palliative' until they are ready to accept the situation, so some caution and sensitivity is and would be required on the part of the clinician.

Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings). What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?

Unsure

Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

We are clear that social determinates of health affect how people can and are able to interact with health and social care services. BMA Scotland is also aware that while there are issues around the recruitment and retention of doctors across all urban and rural Scotland, this problem is felt more acutely in remote and rural areas, as well as urban areas of deprivation.

Further work is required on workforce planning as well as consideration to what we want health and social care to provide. It is clear than neither can continue to provide satisfactory levels of care without reform, which is why BMA Scotland has called on the Scottish Government, alongside opposition parties to hold a National Conversation, looking at the future of the NHS; the public's expectation, what health care is able to provide with current resources and what needs to be done to bridge that gap. The Scottish Government have promised to carry out such an exercise and BMA Scotland look forward to engaging with it.

Only with adequate staffing and resource can we expect consistent and equal access to generalist and specialist palliative care services for those who need it, regardless of any protected characteristics, circumstances, situation or placement.

What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented. Please explain the reasons for your response.

BMA Scotland remains concerned that to legislate for a right to palliative care, as the NHS and social care is currently structured and funded, could have an adverse effect on patients and health care staff. Our members are clear that with the current understaffing, under-resourcing, and under-funding, a change in the law would have little impact to no impact on delivery of services. While we believe it shouldn't matter whether you are at home, in a care home or in the NHS, you should have the same access to specialist palliative care input, the reality is that health and social care services are struggling to recruit and retain staff and there is no flexibility or give in the system.

BMA Scotland has previously outlined its concern about how we measure success in the NHS. We believe that monitoring the performance of NHS and measuring what it does is a vital part of running the whole system; identifying pressures, gaps in resource and increased demand. If data from that is used properly, it can help to produce targeted solutions that benefit both patients and healthcare professionals. We have however seen evidence of data collection and a 'target culture' being used as a political stick to beat NHS staff with, albeit unintentional. Caution is needed and consideration about what the data is intended to show and how it will be used, focus should be on measuring and achieving good patient journeys and outcomes[2].

Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability? Please explain the reasons for your response.

BMA Scotland believes that any legislation must include consideration for additional funding and resource. Creating a right alone will not improve outcomes and could inadvertently create additional problems for staff and raise patients' expectations to levels that are impossible to deliver on.

Consideration should be given to nurturing better links across specialties and departments linking to specialist palliative care. Some patients for who treatment is no longer possible are simply discharged rather than transferred direct to palliative care, and this can cause additional distress. A seamless and direct transfer across to palliative care services from other specialties would clearly be beneficial for patients and their carers.

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[2] BMA Scotland, '*Measuring our NHS: Transforming Scotland's approach'*, 2020