1. About the British Geriatrics Society

1.1 The British Geriatrics Society (BGS) welcomes the opportunity to provide evidence to the Expert Panel's evaluation of the state of palliative care in England.

1.2 The BGS is the membership organisation for all healthcare professionals engaged in the treatment and care of older people across the UK. Since 1947 our members have been at the forefront of transforming the quality of care available to older people. Our vision is for a society where all older people receive high-quality patient-centred care when and where they need it. We currently have over 5,300 members working across the multidisciplinary team, including geriatricians, nurses, GPs, allied health professionals and pharmacists and across acute, primary and community care settings.

1.3 In this response we have set out some general comments about death and dying in older age as well as commenting on the specific themes set out by the expert panel.

2. General comments

2.1 Older people account for the largest proportion of deaths in the UK and it is vital that the palliative and end of life care systems are able to meet the needs of the growing numbers of people dying in older age with frailty, cognitive impairment and other long-term conditions.

2.2 There are approximately 670,000 deaths every year in the UK,[i] of whom around 65% occur in people aged over 75.[ii] [iii] [iv] The majority of those who die each year have multiple long-term conditions and/or frailty, rather than a single condition such as cancer or motor neurone disease. Over 60% of people over the age of 85 have more than one long-term condition[v] which is associated with a higher risk of hospital admission and death.[vi] Up to half of people over the age of 85 years live with frailty[vii] and people with severe frailty are five times more likely to die within a year than older people without frailty.[viii]

2.3 Those with frailty and multimorbidity have an uncertain non-linear dying trajectory, making it hard to predict when someone will die, but expert understanding of these conditions can help to identify people who may be in the last year of their lives. This group of people are likely to require significant health and social support over a considerably longer period than those dying of a single condition. Their care is mainly provided by the three million generalist health and social care workforce, rather than the 20,000 specialist workforce. In fact, half of all people who die, largely older adults, have no contact with specialist palliative care.[ix] Investment is needed to support this

workforce to provide palliative and end of life care to the majority of those dying each year.

3. Commissioning of palliative and end of life care in England

Commissioning should focus on the needs on the ageing population

3.1 A strategic shift is needed in the commissioning and funding of palliative and end of life care (PEoLC) to focus on the needs of an ageing population. This shift needs to be away from predominantly focusing on specialist palliative care to improving provision of palliative and end of life care across the whole health and social care system. Research by Marie Curie suggests that only 35% of Integrated Care Boards (ICBs) report that they significantly or fully understand PEoLC population health needs.[x] It is vital that this is addressed to ensure that the PEoLC needs of the majority are prioritised in commissioning and funding.

3.2 Research suggests that one in four ICBs have not incorporated PEoLC in their Integrated Care Strategy.[x] Recently, NHS England have provided grants to hospices, but this is the setting for just 5% of deaths in those over the age of 65, with hospitals (40%) being the most common place of death followed by the person's home (30%) and care homes (20%).[xi] Investment is needed on a national level focusing on a whole system approach, prioritising the needs of those dying in older age. ICBs should be required to develop a strategic plan illustrating how they will meet the PEoLC needs of their ageing population. National funding should be made available to ICBs who can show they will invest in a whole system approach to PEoLC, recognising the importance of the generalist workforce. This should be complemented by a national information campaign, aimed at the general public, highlighting key facts and statistics about who is dying.

A joined-up approach to commissioning is needed

3.3 The whole health and care system is under-resourced, placing a huge amount of pressure on healthcare professionals across services. As a result, services are under-staffed, fragmented, and not joined up. This includes palliative and end of life care services, resulting in many not receiving the care they need. Social care, which is vital in allowing many at the end of life to remain at home, is also underfunded. This results in delayed discharges from hospital, meaning many older people die in hospital waiting for social care support packages to be put in place.

4. Delivery of palliative and end of life care in England

Delivery of PEoLC needs to address inequity in access for older people

4.1 The current palliative and end of life care model in the UK does not serve an ageing population, particularly older people with dementia, multimorbidity and frailty. Older people face a great degree of diagnostic and prognostic uncertainty, unpredictability and escalating care needs which do not fit into traditional models of palliative care. Individuals with frailty are less likely to appear on end of life care registers, and therefore less likely to receive the care they need. Considering the majority of deaths each year occur in older age; this inequity needs to be urgently addressed.

4.2 A new model of end of life care is needed, incorporating the principles of geriatric medicine. This should focus on a whole system and life course approach to the delivery of palliative and end of life care, incorporating services across the health and social care system, and focussed on person-centred care. This will require the upskilling of the generalist workforce and other specialties, such as geriatricians, GPs, and nurses and AHPs, on palliative and end of life care issues. As outlined in the Chief Medical Officer's annual report 2023, generalist skills are essential in caring for an ageing population with increasing multimorbidity.[xii]

PEoLC for older people should incorporate principles of geriatric medicine

4.3 Healthcare professionals specialising in older people's healthcare, such as geriatricians, have expert understanding of conditions appearing in later life, such as multimorbidity and frailty, and are able to identify when someone is in the last months of their life. Therefore, BGS members recommend that good palliative and end of life care for older people should stem from what is working well in geriatric medicine; based on the principles of living and dying well with frailty. Comprehensive Geriatric Assessment (CGA) is a multidisciplinary holistic assessment that considers the health and well-being of the whole individual, leading to the development of a plan to address issues of concern to the older person. Through assessment, healthcare professionals can identify when a person may be reaching the end of their life, and interventions can be put in place to support a good death. CGA facilitates person-centred care focussed on meticulous assessment of problems, open communication with patients, families, and other stakeholders, setting realistic goals and expectations, discussions of the benefit versus burden of active treatment, anticipating and planning for the future, and attention to social, emotional, psychological, and spiritual aspects of care. For those nearing the end of life, CGA, alongside holistic care and honest

conversations about treatment options, enables people to prepare for death and be supported to spend their remaining time as they would wish. Holistic assessments, such as CGA, should be offered to all older people reaching the end of life to ensure end of life care needs are met.

Delivery should focus on what matters to individuals

4.4 What matters to people at the end of their lives should drive planning of end of life are services and support. Awareness that the end of life may be close should inform all clinical care for people with multiple long-term conditions and frailty. This enables proactive and compassionate communication with people and their families about how to spend their remaining time and where they wish to die. This can be documented and respected through Advance Care Planning (ACP). Most (78%) of the public are unaware of the term 'advance care planning' [xiii] and one study revealed that less than a third of respondents discussed end of life wishes in the last year of their life or formally documented their wishes.[xiii] Uptake is particularly low among older people living with frailty,[xiv] as well as minority ethnic groups, with cultural differences and language barriers often cited as a barrier to engagement with ACP services and resulting in inequitable access to quality end of life care.[xv] Honest conversations about the approaching end of life can facilitate consideration of realistic treatment options and shared decision-making to avoid over-medicalisation. Instead, people can be supported to live their remaining days in the right place for them with appropriate health and social care support focussed on their individual needs. A public information campaign is needed focused on the importance of ACP, and targeted at groups where uptake is low, such as older people with frailty and people from minority ethnic groups.

PEoLC delivery needs to be better co-ordinated

4.5 End of life for older people rarely takes a pathway approach requiring care and support from just one service. Depending on needs and services available in different areas, older people will receive care and support from a range of services. This will include primary, community, and acute healthcare; social care; care homes; voluntary organisations; and hospices. Services need to be aligned to optimise seamless transfers of care, share information across services, minimise avoidable delays and deliver appropriate, timely palliative and end of life care 24/7. To achieve this, effective health communication systems are needed to share information, including advance

care plans, between healthcare professionals and informal carers who are involved at the end of life. There is technological fragmentation within the NHS, with different parts of the system using different software and hardware to capture information about patients. Therefore, there are limitations in the ability for staff across services to work together and share care records, including advance care plans. One solution would be the introduction of a national standardised approach to data and information-sharing across services supporting palliative and end of life care.

5. Shifting to community

Proactively identifying older people in the community with palliative care needs

5.1 A life course approach to ageing well will facilitate better provision of palliative and end of life care in older age and encourage people to prepare for death at an earlier stage. The Ageing Well programme, as set out in the NHS Long Term Plan, had the potential to be transformative for older people's healthcare but has faced significant budget cuts. An important strand in this work is proactive care, now largely unfunded, which is an approach that proactively identifies older individuals living in the community who may have frailty and are therefore vulnerable to a decline in health. Through identification of such people at risk, end of life care preparation, such as advance care plans, and care support can start at an earlier stage before someone reaches a crisis point and presents at hospital. End of life care should be driven by what matters to the older person receiving the care and identifying needs as early as possible. BGS members tell us that in many cases, individuals with strong support networks, such as families that can advocate for the person, are more likely to secure good care. Proactive identification of individuals needing end of life care would help to address this inequity.

Continuity of care through primary care

5.2 Evidence suggests that older people prefer to use local services and value continuity of care.[xvi] Historically, GPs took on this role and were best placed to understand the care needs of their patients. Investment and support is vital to ensure that primary care teams are able to provide continuity of care to patients in the community, acting as their key point of contact right until the end of their life. In addition to being

preferred by patients, providing end of life care through primary care is often more cost effective and results in fewer emergency admissions.

Care homes as hospices of the future

5.3 Hospices provide a gold standard level of palliative and end of life care, but there are not enough of them to support everyone at the end of life. This is especially the case for older people with multiple conditions and frailty, who are less likely to be admitted to a hospice compared to those with single terminal conditions. As a result, only a small minority of older people (5%) die in a hospice.

5.4 Currently, around 20% of deaths of those over the age of 65 take place in a care home. The number of deaths occurring in care homes is set to double over the next 25 years, and care homes are set to become the most common place of death. This is due to an increase of more people dying in their normal place of care, and an expected increase in the number of older people being cared for in care homes, especially as dementia rates are increasing. Therefore, investment is needed to ensure that care home staff are well-equipped to provide excellent palliative and end of life care and to avoid unnecessary hospital admissions. There are many examples of care homes providing good end of life care to older people reaching the end of their life. The BGS recommends that care homes with excellent end of life care facilities should become the hospices of the future, enabling many to die in a setting attuned to their care needs and wishes of how they would like to die.

People should be supported to die in their preferred place of death, which is often home.

5.5 Over half (56%) of people dying over the age of 65 indicate that they would prefer to die at home with their loved ones around them.[xiii] However, at present 75% of people do not die where they would prefer. For those over the age of 65, around 40% die in hospital, 30% die at home, 20% die in a care home, and 5% die in a hospice.[xi] People express different reasons for their preferred place of death, but it appears that many end up in hospital as an emergency, dying there, when better recognition and provision of end of life care might have enabled them to remain at home, avoiding interventions that do not deliver better patient reported outcomes. One in eight people spends more than 30 days of their last three months in hospital and more than half are conveyed to hospital by ambulance as an emergency at least once in the last

three months of life.[ix]

6. Workforce, education and training

6.1 It is vital that the three million generalist health and social care workforce is upskilled in how to support those reaching the end of their life. This is imperative as the 20,000 specialist workforce does not have the capacity to care for everyone at the end of their life. Geriatricians and healthcare professionals specialising in older people's healthcare have the expertise to identify when an older person with multiple health conditions and/or frailty may be reaching the end of their life. However, the consultant geriatrician workforce is also under resourced, and there are not enough people with expert understanding of frailty and multimorbidity to provide end of life care for an ageing population. Education and training on end of life care should be available for all generalist health and social care professionals supporting people at the end of life, including training on managing uncertainty and parallel planning for different scenarios.

6.2 The BGS endorses The Gold Standards Framework, the UK's leading training provider for generalist frontline staff in caring for people at the end of life, offering accreditation to health and social care teams supporting PEoLC.

7. Concluding comments

7.1 The BGS urges the expert panel to focus on improving end of life care for everyone, rather than improving the specialty of palliative care. This requires the recognition of the importance of the generalist workforce in providing end of life care for older people, and the skills needed to identify when someone with multiple conditions and frailty may be reaching the end of life. The palliative care specialist workforce will never be large enough to cope with the end of life care needs of the whole population.

7.2 The BGS is happy to assist further with contributing towards the expert panel's recommendations. Please do get in touch with our Policy Co-ordinator, Lucy Aldridge (l.aldridge@bgs.org.uk) if you have any questions or would like to invite one of our expert members to give oral evidence to the expert panel.

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