

**British Geriatrics Society**  
Improving healthcare for older people

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Corrina Grimes  
Regional Advance Care Planning Lead  
Department of Health  
Castle Buildings  
Stormont  
Belfast  
BT4 3SU

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Dear Ms Grimes,

**Advance Care Planning consultation – response from the British Geriatrics Society**

The British Geriatrics Society (BGS) welcomes the opportunity to respond to the Northern Ireland Assembly's consultation on the implementation of a national policy on Advance Care Planning (ACP). 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 4,500 members across the UK, including more than 120 in Northern Ireland. This submission has been prepared by members of both the BGS's Northern Ireland Council and the End of Life Care Special Interest Group.

**General comments**

The BGS would like to commend the Northern Ireland Assembly on the introduction of this policy. This is, we understand, the first time that a UK Government have adopted a national policy on ACP and we particularly welcome the proactive public health approach being taken to this issue. Generally speaking, we felt that the policy was well-written, imbued with common sense and a sense of sufficient ethical and legal safeguards. We welcome the messaging in the policy, particularly the focus around ACP's relevance to everyone, at all stages of life rather than limited to those who are older or otherwise nearing the end of their lives. ACP is everyone's business and we would suggest that some of the language in the document could reflect this more clearly, particularly when discussing legacies and planning for retirement.

It is not clear to us who the primary audience for this document is and whether it is aimed at members of the public who are going through the ACP process themselves or healthcare professionals who are supporting their patients through this process.

Patron HRH The Prince of Wales

We recognise that the application of the policy and the guidance documents produced may be tailored to different stakeholders and we would be happy to assist with reviewing any further documents related to older people.

### **Limitations of ACP**

While we agree that ACP is a hugely important and valuable process and is highly recommended, it must be acknowledged that it is not a perfect system and it does have limitations. One of the outcomes of ACP is that, if at all possible, the wishes of the person regarding their place and care as they die is honoured. However, this is not always possible due to system constraints and the many variables surrounding death. We feel that an ACP should be seen like a birth plan – a best case scenario for what might happen but acknowledging that the actual circumstances surrounding death may preclude the ACP from being followed. The ACP process is very important but it does not guarantee a desired outcome. The final sentence in the draft policy (page 32, lines 20-21) is a stakeholder quote which we believe is suggestive that the ACP process will result in a person's wishes being followed under all circumstances whereas more nuance may be desirable.

### **Sharing ACP decisions**

In the experience of members of the BGS End of Life Care Special Interest Group, the ACP process often fails when the decisions are not shared with loved ones and healthcare professionals. In this case, the outcomes that a person wants are not known when it comes to a time when they cannot express their own wishes and the care provided is not what the individual would have wanted. We would suggest that the section on sharing ACP conversations, recommendations and decisions (page 15) could be expanded to highlight the importance of sharing the outcomes of ACP conversations and ensuring that loved ones and healthcare professionals know what the individual's wishes are.

### **Reviewing ACP decisions**

It is important to emphasise that ACP is relevant to everyone, at all life stages. However, people's priorities and experiences change throughout their lives and the decisions they make during the ACP process may not be valid later in their lives. It is normal to expect an individual who makes an advance care plan in middle age to have different priorities when they come to retirement and different priorities again as they continue to age, especially if they become ill or develop long-term conditions. As such, we would like to see more emphasis in this document on the necessity of reviewing ACP decisions and ensuring that the wishes expressed in an ACP decision remain up-to-date.

### **ACP as a process**

We are concerned that the draft policy may imply that ACP consists of one conversation and that once this conversation has happened, the process is complete. ACP is a process that will consist of many conversations over time. We feel strongly that this must be reflected in the policy, with conversations (plural) referred to consistently to make clear that ACP will not be completed in one conversation.

## **Northern Ireland context**

While our comments are mostly about the process of ACP, our Northern Ireland Council have made some observations which are specific to the implementation of ACP in Northern Ireland.

Our members in Northern Ireland anecdotally report that family members not infrequently challenge the capacity of older relatives to make decisions around their care, particularly those with frailty. While the policy explicitly states that capacity will be assumed unless demonstrated to be absent, we have concerns that the current NHS and social care workforce will struggle to effectively assess capacity, especially when this is challenged.

Our members also commented on the rurality of much of Northern Ireland and the difficulties experienced by older people who require specialist cognitive and dementia services but cannot access these services due to lack of provision in rural areas. It will be difficult for these people to engage with the ACP process without adequate specialist support.

## **Equality Impact Assessment**

While our comments are mostly restricted to the content of the policy itself rather than the Equality Impact Assessment, we do note a lack of ethnic diversity in the volunteer partners group with 40 white participants and one from a BAME background. While we appreciate that this may reflect the ethnic makeup of Northern Ireland, we urge the Department to consider how more people from ethnic minorities could be engaged in this work to ensure that this policy meets the needs of all communities.

Thank you for the opportunity to contribute to this important consultation. If you have any questions or wish to discuss our submission with either our Northern Ireland Council or our End of Life Care Special Interest Group, please contact our Policy Manager, Sally Greenbrook ([s.greenbrook@bgs.org.uk](mailto:s.greenbrook@bgs.org.uk)), to make arrangements.

Yours sincerely,

Dr Mark Roberts  
Chair, BGS Northern Ireland Council

Professor Caroline Nicholson  
Co-Chair, BGS End of Life Care Special  
Interest Group