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**End of Life Care Strategy: Quality Markers Consultation**  
BSRM Response

Rehabilitation Medicine specialist physicians assess, treat and manage people with progressive disabling conditions in hospitals, care homes and in the community. The BSRM, the Royal College of Physicians and the National Council for Palliative Care contributed to the publication of national evidence based guidelines for the clinical management of people with Long Term Neurological Conditions in March 2008. *Long term neurological conditions: management at the interface between neurology, rehabilitation and palliative care. Concise Guidance to Good Practice series, No 10, London: RCP 2008.* This document explores this interface and establishes key medical skills, p8, care guidelines, p9, and Appendix 3, p15, tools for implementation. Some of these could be drawn into quality markers for this end of life care strategy.

This End of Life Care Strategy attempts to apply a comprehensive range of markers across all potential health care settings and in practice is attempting to collect too much detail at this stage. The key aim of this document is to improve end of life care by using markers to encourage consistency across a range of health care settings and BSRM holds the following views on this:

- A few core indicators only need to be identified for each of the listed areas.
- The proposal for a locality wide register is not supported. Patients near end of life are not in a position to give consent for their clinical details to be shared in a register. It is easy to identify patients who have died and for their care to be audited retrospectively. The potential effects of being placed on such a register are significant and there are serious confidentiality issues.
- People with a progressive disabling condition living at home are often managed by community rehabilitation teams. There should be quality markers to record referral to palliative services in line with best practice guidelines, and to record that such teams have the relevant palliative care skills.
- Sharing information about DNAR orders and Advance Planning Decisions is one of the quality markers linked to holding a register, and is specified as a desirable content. Advanced Directives are now covered by the Mental Capacity Act and awareness and correct use of this legislation should become a quality marker for this area of health care across all settings. The Motor Neurone Disease Association and some Ambulance authorities have developed the “message, or the drugs, or the documents, in a bottle in the fridge” approach to make sure that the end of life care is provided according to the person’s wishes, and people are not carted off to hospital inappropriately near life’s end. This is an alternative and practical solution that avoids the use of registers. The fridge is often marked with a green cross.

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- Patient autonomy during the final phase of life is enhanced through the prior discussion of resuscitation guidance and the facilitation of advance directives. Discussions with relatives must take into account the Mental Capacity Act and the guidance that it offers. In care or nursing homes there should be documented evidence of training and adherence to its code of practice. This is not mentioned.
- An indicator audit of proportion of care home residents dying in hospital may provide an insight into the capacity of some homes to provide end of life care.
- Equality and Diversity training is now mandatory across health care sectors, but there is a need to monitor the training of staff in cultural and religious awareness to ensure that they are aware of the processes available for referral to chaplaincy services and to other faith groups for people who have indicated this need as they approach end of life.

This is an area of health care which is as important as the health care needs of those who are starting the journey of life. This is an important consultation to discover and identify the current perception of needs, shortfalls in care, and where we are doing well. BSRM is happy to help further with this process and thanks you for making this guidance available for consultation.

**Professor Christine Collin**

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