

The Royal College of Physicians and Surgeons of Glasgow

Response to Consultation by the Professional Records Standards Body, End of life Review

The Royal College of Physicians and Surgeons of Glasgow was founded in 1599 to improve quality and practice of Medicine. Based in Glasgow, we have 14,000 Fellows and Members who work as senior clinicians throughout the United Kingdom and across the world. Unlike our sister Royal Colleges, we have a multidisciplinary membership, which we believe gives us a unique viewpoint of the health environment and the needs of patients and medical professionals.

The Royal College of Physicians and Surgeons of Glasgow welcomes review of records relating to End of Life decisions. It has circulated the presentation to Office Bearers, Members of Council, the Lay Advisory Board and the Ethics Committee.

The College agrees that everyone, given the opportunity, would wish for a death, which preserves dignity and minimises suffering. The dying person's needs are the central focus for any care that is given to him or her. How those needs are to be met ought to be set out in concrete terms.

However, the Health and Care System has become fragmented with differing organisations and departments with their own (often archaic and expensive) structures and systems. There is a reluctance to adopt alternatives where better solutions may exist. There appears no overarching organisation which can administer a single effective system. Patients and their families find themselves in the middle having to navigate (with difficulty) between the different systems at a time when care, treatment and communication should be integrated and seamless.

The presentation shows fundamental barriers to those needs being met:

Siloing. The first issue is that there are so many different and (in practice) incompatible systems in use throughout the UK. The second is that there are so many people (patients and those who care for them) who potentially have a role in devising and keeping the end of life plan. The result is either an ineffective plan or needless repetition of the expression of need by patients or of effort by those who treat them (for example in data entry). We would recommend a similar UK system so that there is uniformity for the individual their family and professional staff.

Jargon. Patients find the jargon off-putting. The jargon (particularly acronyms) is a barrier to use.

Validity/Trust. The basic premise of an end of life plan appears to be popular among patients and those treating them. Clinicians like a methodical plan that deals with each of the problems the patient has.

However, there are problems firstly with whether the plan accurately reflects the patient's wishes. It may not do so because it is not clearly expressed (for example, it may have been written by the patient without adequate support), because what was written down did not reflect the patient's needs, or because it is out of date. Secondly, accessibility problems undermine trust in the process. Finally, the plan may not cover likely or unforeseen developments, such as a deterioration in the patient's conditions, leaving the plan a "dead" letter.

Accessibility. The plan needs to be accessible to all. It needs to be stored where those who need it can find the plan. The necessary information must be available within the plan.

One of our reviewers concluded that the barriers can be narrowed down: **vested interests**, an **overly complicated system**, and a **lack of leadership**.

- The **vested interests**- an organisation or individual doing things either in a preferred way or the way things have always been done- may be at the level of the “solutions” provided, there are three described at p9. They may be at the local level, as described at p11, p14 and p16 to the end of the document. The overall impression is that healthcare organisations have become focused on how things are done rather than what they ought to achieve ie meeting the patient’s needs.
- The **overly complicated system** should speak for itself. While localisation will be necessary to an extent, the system as a whole should be coherent, compatible and simple, and thus meet the patient’s needs.
- The **lack of leadership** is not meant to criticise anyone in particular. There does not seem to be an organisation or core set of individuals with an overview of the system, or the means to make the changes necessary to make the system coherent, compatible and simple, and thus meet the patient’s needs.

The College takes a different view of the recommendations described at slide 6. Extending a complicated system has the potential to produce a more dysfunctional and expensive system. This will not be helped by guidance, education, etc. We would suggest

- a **single system** for end of life care applicable to all four countries of the UK, which is compatible with existing (or preferably improved) patient record keeping systems. It needs to cross the health and care sectors. This will require collaboration.
- A **single leadership structure** to run the system.
- The **elimination of jargon**.
- A **single standard** for where end of life plans can be found in a patient’s records, how information is prioritised within them, and guidance (and training) about how patient’s needs should be understood and recorded.

The Covid 19 Pandemic has allowed the UK to change, almost overnight, how it delivers Health Care. There is an opportunity to produce a single UK system with standards shared by all four countries of the UK which would allow everyone to die as they would wish

Dr Richard Hull FRCP Glasgow

Honorary Secretary

Royal College of Physicians and Surgeons of Glasgow

9 June 20202