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## **EPaCCS and the need for research**

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We agree with Sleeman and Higginson [1] who emphasised the need to gather evidence of effectiveness of EPaCCS before widespread and uncritical adoption by the NHS. An EPaCCS evaluation framework was recently developed by our team on behalf of end of life commissioners in Leeds [2]. There was, and remains, a scarcity of guidance on approaches to gathering evidence for EPaCCS but we identified factors that highlight the complexity of EPaCCS evaluation:

### **1) Most EPaCCS will differ**

The principle of EPaCCS, as pointed out by Petrova et al [3] is a robust one; its aim is to support sharing of up-to-date key information about patients believed to be in the last year of their life. This feels like an intuitive approach that could improve care for patients at end of life. However, as Petrova et al [3] report, fewer than half of England's clinical commissioning groups have a functioning EPaCCS. Implementation of EPaCCS systems have led to disparate local approaches to adapting and embedding EPaCCS templates in electronic medical record systems, across wide-ranging and diverse multidisciplinary teams. Before conducting our evaluation in Leeds, we undertook fifteen interviews with health professionals delivering community care. While intended to inform how EPaCCS is used in Leeds, it highlighted the diverse approaches to EPaCCS use; a district nurse opened an EPaCCS for any new patient entering a care home, a GP created an EPaCCS in response to any referral from a palliative care team, and a GP opted out of using EPaCCS for an alternative template that collates similar items. Such diversity in the use of EPaCCS was occurring locally in one city, despite an intensive citywide training programme. Furthermore, general practices in Leeds use one of two separate electronic medical record systems, with slightly different EPaCCS templates. The EPaCCS templates have also been iteratively developed, with subsequent changes to the form used in practice. This level of complexity highlights the need to consider carefully how individual EPaCCS might be evaluated, in particular how regional or national comparisons and evaluations are framed.

### **2) EPaCCS is not static**

Our evaluation sought to identify the number of days before death that items were added to a patient's EPaCCS record. Documented preferences for DNACPR wishes were recorded a median of 34 days before death, with EPaCCS records being created a median of 31 days before death. A range of initiatives for improving documentation of DNACPR wishes had taken place in Leeds before and during EPaCCS implementation. The crossover in clinical codes in an EPaCCS template with other items on a patient's medical record, and the occurrence of parallel service improvement initiatives limited the extent to which our evaluation could attribute improvements to EPaCCS.

### **3) Qualitative work is crucial**

Our brief engagement with health professionals prior to the evaluation highlighted that qualitative work will be essential to understanding how EPaCCS is currently being used. A recent qualitative study by Wye et al [4] found that most users of EPaCCS were community health professionals, which may account for attributions to EPaCCS of increases in patient home deaths. Qualitative approaches can offer crucial insights into what is happening on the ground, away from broad claims of EPaCCS benefits. Engaging with health professionals may also help to identify why so few eligible patients are being registered on EPaCCS. Wye et al [4] reported low numbers of patients registered on EPaCCS (9% and 13% in two separate regions), aligned with reports of systems such as Coordinate My Care achieving 16.6%[3]. In Leeds, 26.8% of all eligible deaths were recorded. This was calculated using Public Health England data on the average number of deaths with underlying cause of cancer, circulatory and respiratory over two years as a denominator. Using these data may be a useful proxy for patients eligible for EPaCCS, rather than all patient deaths. However, even with this refined calculation, in-depth exploration of health professional perspectives is going to be essential to understand why low numbers of patients are being registered.

### **4) Enacting change or reporting practice?**

A key issue that our evaluation highlighted is the difficulties of interpreting EPaCCS data. Having separated association from causality, we considered whether EPaCCS acts to improve practice or whether it documents and reflects what is already taking place in practice. Where, in our evaluation, items from an EPaCCS record are entered ahead of the creation of an EPaCCS template, could health professionals already be capturing data that is clinically meaningful? Could EPaCCS just be collecting what is already good practice?

While the principle of EPaCCS is a robust one, generating evidence around its use and evaluating its impact on information sharing is far more complex. Without understanding the health professional perspective, alongside their approaches, motivations and interaction with EPaCCS, it is difficult to evaluate the effectiveness of the approach. We look forward to seeing research develop in this area to enable untested assumptions about the role of EPaCCS to be challenged. It will also hopefully lead to a better understanding of the cause of low uptake, bringing us closer to understanding whether EPaCCS can improve the coordination of end of life care for patients and their caregivers.

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