

## Shared healthcare records for multi-agency input

# Electronic palliative care co-ordination system: an electronic record that supports communication for end-of-life care – a pilot in Richmond, UK

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### Key messages

- Multiple success factors contribute to improving end-of-life care.
- Communication via electronic records provides instant access to information for key healthcare providers.
- Shared electronic records can help people to die in their preferred place of care.
- A large proportion of patients recorded on the electronic system preferred to die in their home or care home.

### Why this matters to us

We are passionate about achieving high-quality, well co-ordinated, integrated patient-centred care. Our work around electronic palliative care co-ordination systems has highlighted the benefits of timely, well-communicated, multiprofessional care in the last year of life results in terms of improved patient choice and outcomes. Delivery is enhanced when supported by multiprofessional workforce training on identification of and care planning discussions with patients with a potentially life-limiting illness.

### ABSTRACT

Most people prefer to die at home, however, the majority die in an acute hospital. Supporting a patient in their preferred place of care may be aided by exchange of information across sectors. Richmond piloted an electronic palliative care co-ordination system (EPaCCS) to enhance interprofessional communication for end-of-life care. One such EPaCCS is the Coordinate My Care (CMC) hosted by the Royal Marsden NHS Foundation Trust, now

supported across London. It focused clinicians on having advance care planning conversations with patients and their carers and then documenting the outcome onto an electronic web-based record that can be shared with key healthcare professionals.

**Keywords:** advance care discussions, communication, Coordinate My Care, end-of-life care

## Introduction

Around 461,000 people died in the UK in 2010.<sup>1</sup> An estimated 1% of patients registered at a general practitioner (GP) surgery throughout England and 0.63% in the greater London area are in their last year of life.<sup>2</sup> Nationally, the majority of patients die in an acute hospital setting (54.5% die in acute hospitals versus 20.3% at home, 17.8% in care homes and 5.2% in hospices), whereas most of the population would prefer to die at home.<sup>3,4</sup>

National statistics show that home deaths have been declining, with rates falling 13% in 30 years, a pattern that reflects a global trend.<sup>5,6</sup> Projections suggest that, if this trend continues, by 2030 fewer than 10% of patients will die at home.<sup>7</sup>

In England, 78% of individuals will have a minimum of one hospital admission in the last 12 months of life.<sup>4</sup> Such admissions may not only subject patients to unnecessary investigations, but also remove individuals from the comfort of their home surroundings, potentially contravening a patient's previous autonomous choice, acting as a source of distress to both the patient and their carers.

Hospitalisation around end-of-life care currently costs between £2800 and £3400 per admission. In England, a 10% reduction in the number of hospital admissions ending in death could potentially result in a saving of £52 million.<sup>8</sup> The national Quality, Innovation, Productivity and Prevention (QIPP) Strategy aimed for a saving of 5% in end-of-life care costs.<sup>2</sup>

The Department of Health's 2008 national *End of Life Care Strategy*, highlighted that surveys consistently show that the majority of us wish to die at home (71%) or in another community setting (ONS National Survey of Bereaved People, 2012). Despite significant investment following the Strategy, over half (54.5%) of all deaths still take place in hospital. The Strategy recommended the development of electronic locality registers as a way of improving the co-ordination of care for people at the end of life and their families and carers.<sup>9,10</sup> Eight localities piloted an electronic palliative care co-ordination system (EPaCCS) through the Department of Health.

The London Borough of Richmond's end-of-life care strategy emphasised the need to build care around the needs and choices of local patients. The EPaCCS opened up an opportunity to not only record patients' important medical conditions and preferences around end-of-life care but to also co-ordinate these with key healthcare professionals involved in their care, and to respect and support people's choices and wishes about where they die, the nature of the care and support they receive wherever possible.<sup>11</sup>

This paper outlines the effect of the EPaCCS, in Richmond, in respect of: (1) enabling patient choice over place of death, and (2) reducing hospital costs.

## Methods

Coordinate My Care (CMC) is accessible 24 hours a day 7 days a week for healthcare professionals that have a username and password and are using a NHS secure N3 computer (hospitals, GP practices and community nursing sites already have this in place). Clinicians were asked to identify patients early using their clinical skills alongside the prognostic indicator tool – the Supportive and Palliative Care Indicators Tool (SPICT<sup>TM</sup>).<sup>12</sup> After identification, if appropriate, clinicians approached their patients to discuss their illness and their wishes for care, and request their explicit consent to record the information on CMC. Historically, Richmond clinicians used their clinical judgement to identify those patients with prognoses of short months or weeks. Therefore, identifying patients in their last year of life was a shift in thinking and practise; recognising this may be difficult to do for many clinicians.<sup>13</sup>

The current trend in primary care towards shift work, reduced continuity of care and out-of-hours practitioners who do not know a patient's medical history, makes sharing individual patient's wishes between services increasingly important. CMC provides a way to do this. To encourage CMC uptake, Richmond developed four initiatives: (1) GP local enhanced service, (2) community nursing commissioning quality and innovation (CQUIN), (3) care home initiatives, and (4) multiprofessional training on end-of-life care discussions and symptom control.

## Results

Between 1 November 2010 and 9 August 2012 in Richmond, 200 CMC users were trained and 597 patients were placed on CMC. Of the patients on the system, 485 (81%) were over the age of 70. The preferred place of care (Table 1) and preferred place of death (Table 2) were recorded for 520 (87%) patients. Of the 457 patients who expressed a preferred place of death, 35% wished to die at home, 30% in a care home, 7% in a hospice and 5% in a hospital (Table 2).

Table 3 compared the preferred with actual place of death of the 138/597 (23%) patients who died during this 20-month period.

Table 4 shows 2010 ONS data for place of death of all people in London.<sup>14</sup> This reveals that 59% of patients died in hospital and 20% at home, compared with 33% (hospital) and 29% (home) in our study (Table 3). This difference needs further examination because the ONS included all deaths, not merely those considered to be in the last year of life.

**Table 1** Preferred place of care for Richmond patients on CMC

Place of care	<i>n</i>	%
Home	281	47
Care home	202	34
Hospice	11	2
Hospital	26	4
Not yet discussed	74	12
Other	3	1
Total	597	100

**Table 2** Preferred place of death for Richmond patients on CMC

Place of death	<i>n</i>	%
Home	208	35
Care home	180	30
Hospice	39	7
Hospital	30	5
Not yet discussed	135	23
Other	5	1
Total	597	100

**Table 4** Place of death – all causes in London 2010 (ONS)

Place of death	<i>n</i>	%
Home	9543	19.8
Care Home	6227	12.9
Hospice	2956	6.1
Hospital	28 528	59.1
Other	1043	2.2
Total	48 297	

### Developments during the study

During the study, lessons on good governance were learned and acted on, including:

- patients' consent to sharing their details, as well as involvement in care planning discussions was essential
- regular updating of the record was important
- family and carers should be involved in discussions where possible, in particular with do not attempt resuscitation (DNAR) decisions
- clinicians need training and support to fulfil their role in end-of-life care.<sup>15</sup> Richmond therefore developed Difficult Conversations<sup>®</sup>, an interactive multi-professional communication skills training workshop, including how to have difficult conversations and how to identify patients in the last year of life.

In Richmond, among 337 patients in the last year of life who registered on CMC over the course of the pilot year (November 2010 to November 2011), there were 125 emergency admissions. Local analysis estimates

**Table 3** Comparing preferred against actual place of death for 138 patients who died during the study

	Preferred place of death		Actual place of death	
	<i>n</i>	%	<i>n</i>	%
Home	56	40.6	40	29.0
Care home	22	15.9	19	13.8
Hospice	15	10.9	15	10.9
Hospital	7	5.1	45	32.6
Not recorded	38	27.5	19	13.8
Total	138		138	

that Richmond patients have, on average, two emergency admissions in the last year of life. Assuming that patients on CMC were in their last year of life, 354 emergency admissions were expected, and the EPaCCS was predicted to facilitate a reduction in admissions of 229. Assuming that the pilot saved 229 admissions, it is estimated that there were savings of around £687 000.<sup>11,16</sup>

## Discussion

To date, the results are promising. In Richmond, the combination of CMC, care home initiatives and clinician training, patient consent and family/carer involvement has produced higher than expected numbers of patients dying in their place of choice. Further work is needed to be done to understand what combination of approaches is most helpful to maintain and improve this even further.

Although initial work suggests that up to 229 admissions may have been saved, further cost–benefit analysis is needed, in particular, to include the cost of hospice and home care that will offset cost-savings in hospitals.

This paper highlights Richmond's primary care experience of CMC as an example of an EPaCCS to communicate information about end-of-life care patients between legitimate professionals. However, it is not integrated with systems such as the special patient notes (SPN) system (also described in this issue of *LJPC*) that can consider communication of information for other conditions. This is important to rectify in the next stage of development to avoid operating parallel systems. Richmond is presently evaluating integration of CMC with NHS 111 telephone service delivery.

The Neuberger report on Liverpool Care Pathway<sup>17</sup> suggests a 'one size fits all pathways' should be replaced with a more personalised care plan to ensure high quality end-of-life care. EPaCCS may be one tool to support and assist with this goal.

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**GOVERNANCE**

This study was overseen by NHS Richmond.

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