### Additional author information

<table>
<thead>
<tr>
<th>Electronic Palliative Care Coordination System-Coordinate My Care (CMC): a service evaluation</th>
<th>A retrospective service evaluation</th>
</tr>
</thead>
</table>

| St Andrews Health Centre, Hannaford Walk, London E3 3FF, Bakhai Khyati |
| GP Partner, Frontier Economics Limited, 71 High Holborn, London WC1V 6DA, Bell Matthew |
| Director, Greenwich and Bexley Community Hospice, 185 Bostal Hill, Abbey Wood, London SE2 0GB, Branford Ruth |
| Palliative Care Consultant, Frontier Economics Limited, 71 High Holborn, London WC1V 6DA, Cilauro Federico |
| Analyst, McKesson UK, Warwick Technology Park, Warwick, CV34 – 6NZ, Thick Michael, Chief Medical Officer & Chief Clinical Information Officer, Royal Marsden NHS Foundation Trust, Fulham Road, SW3 6JJ, London, Mansell Kate, Coordinate My Care General Manager, 48 Mulgrave Road, Sutton, Surrey, SM2 6LX O’Sullivan Clare, EoLC Lead, Sutton CCG, Frontier Economics Limited, 71 High Holborn, London WC1V 6DA, Woolley Nicholas |
| Consultant, Royal Marsden and Royal Brompton Palliative Care Service, Royal Marsden NHS Foundation Trust, Fulham Road, SW3 6JJ, London, Riley Julia, Clinical Lead Coordinate My Care & Palliative Care Consultant |
the lead author (the manuscript’s guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained
Electronic Palliative Care Coordination System- Coordinate My Care (CMC): a service evaluation

Bakhai Khyati, Bell Michael*, Branford Ruth, Cilauro Federico*, Thick Michael, Mansell Kate, O’Sullivan Clare, Woolley Nicolas*, Riley Julia

Abstract

Background:
The End of life care strategy (2008) supported the development of Electronic Palliative Care Coordination Systems (EPaCCS) to better coordinate patients’ care. Coordinate My Care (CMC) is the Pan London and Surrey Downs EPaCCS.

Aim:
To evaluate the cost effectiveness of Coordinate My Care (CMC).

Design and Setting
A retrospective service evaluation of patients who died in Sutton/Merton, aged 75 and above, between 1st April and 31st March 2012.

Method:
Data were collected on usage of services in: A&E, hospital in-patient care, Ambulance visits/transfers, General Practice, Out of Hours GP visits, community services and hospice care (including Hospice at Home). A cost was attached to these resources based on national and local available data. Three groups were compared:

(1) Patients with CMC record

Two “control groups” matched for age, gender and place of death.

(2) Patients not on CMC who died in 2011/12 (i.e the same time period as CMC group, but had no CMC record)

(3) Patients not on CMC who died in 2010/2011 (i.e. the year before CMC was introduced)

Results:
Patients in the CMC group had fewer hospital encounters (p<0.005), fewer A&E attendances (p<0.005) and shorter length of stay in hospital (p<0.005). The net impact is that mean treatment cost is £2,102 lower for CMC patients versus non-CMC patients.

Conclusions
CMC promotes personalised care planning and coordination of the care plan between health and social care providers 24/7. This avoids crises and decreases costs; emotional costs to patients and families, and financial costs to the NHS.
**Key Words**

Palliative Care  
Electronic Records  
Primary and Secondary Care

**How this fits in**

It is estimated that 50% of people in their last year of life experience two or less unplanned hospital admissions while 20% have five or more admissions. Each hospital admission costs an average of £3,000. Our study suggests that a patient centric model represents a transformation of care that improves outcomes and decreased overall costs but, importantly, It highlights that if more patients die in the community greater resources should be assigned to community care and clinicians. This study is an example of how services can be transfigured using clinically driven information technology and this model of care could be further extended for long term conditions that represent approximately 10% of the population.
Main text

Introduction

Surveys show that the majority of people want to die at home. Consistently across most of the UK, less than 30% of people do. As the population ages, the demand on hospitals will continue to rise and it is predicted that the number of deaths in hospital will increase. To address this issue, aspects of care that can be delivered in the community, such as End of Life Care, are being shifted to primary care. In 2008, the Department of Health published the *End of life care strategy*, which supported the development of Electronic Palliative Care Coordination Systems (EPaCCS)- end of life registers- to better coordinate patients’ care. Coordinate My Care (CMC) is the Pan London and Surrey Downs EPaCCS.

The key to the success of CMC is the personalised care plan that is an urgent care record that can be accessed by all urgent care providers such as the patient’s GP, the out of hours GP service, NHS 111 and the Ambulance services 24/7.

CMC was piloted in Sutton and Merton and was then rolled out to the rest of London. Thus far (19th February 2014) 10,507 CMC records have been created, 3,530 patients have died. Of those patients who have died and expressed a preference about place of death 79.6% achieved either first or second preferred place of death. (See figure 1). Deaths outside of hospital made up 82% of recorded deaths on CMC; Home (39.7%), Care home (26.7%), Hospice (14.9%), (0.7%) died in other places and only (18%) patients died in hospital.

CMC is innovative in its ability to share information across different health and social care organisations, providing integrated care across the acute and community sectors 24/7. This study was set up to establish whether CMC improved coordination of care and resulted in the use of fewer unnecessary acute services than non-CMC patients, and as a consequence reduced the financial costs. It was hypothesised that patients who had a personalised care plan documented electronically onto CMC, would utilise less acute and emergency services and more community services.

Acute and community resource utilisation was assessed in the last six months of life for patients with a CMC record and compared to matched (control) cohorts of non-CMC patients. The study considered only the costs of NHS services used.

Method

Three cohorts of patients over the age of 75 years were compared: Those with a CMC record were compared to a cohort of patients who died in the area before CMC was introduced and a second cohort of patients who did not receive a CMC record during the period of time when CMC was available in the area.
Retrospective data were collected on usage of services by a cohort of CMC patients and two control cohorts of non-CMC patients in seven main categories: A&E, hospital in-patient care, Ambulance visits/transfers, General Practice, Out of Hours GP visits, community services and hospice care (including Hospice at Home). Frontier Economics supplemented these data with additional information on the costs of providing different NHS services. This information was drawn primarily from locally available data and public sources including 2010/11 Unit Costs of Health and Social Care research (PSSRU) and NHS Reference costs.

**Results**

*Hospital, Accident & Emergency and unplanned care*

Patients with a CMC record had fewer A&E attendances and fewer hospital admissions than patients in the same-year control group (p<0.005). CMC patients also had shorter total length of hospital stay (p<0.005).

The mean number of A&E attendances was 1.2 for CMC patients, and 1.5-1.9 for non-CMC patients in the 6 months prior to death. The mean number of hospital inpatient attendances was 1.7 for CMC patients and 2.3-2.6 for non-CMC patients.

In addition to requiring fewer hospital admissions, CMC patients had a shorter mean length of stay in hospital when admitted (p<0.001).

In general, patients with a CMC record used more community services. This somewhat offsets the lower usage of hospital and unplanned care service by the CMC patient group.

Data were collected in relation to GP in-hours activity, Community Palliative Care Team (CPCT), and community visits from a range of professionals including district nurses, HCAs, dietitians, occupational physiotherapists and podiatrists. Data were also collected in relation to inpatient hospice care, and the Hospice at Home service.

We were able to obtain GP data from a subgroup of GP practices that provided data. In this subgroup there were more GP in-hours consultations in the CMC group compared with both Control Groups 1 and 2 (p<0.01).

There was also an increase in use of CPCT services and in other community services between the CMC group and the control groups. The mean number of CPCT encounters was 2.5 for CMC patients, compared with 1.2-1.3 for non-CMC patients. The total quantity of community services received (in hours) was 27.7 on average for CMC patients, compared with 15.9-25.2 for non-CMC patients.

CMC patients exhibited slightly longer hospice stay and greater usage of Hospice at Home services. However these were not statistically significant.

**Cost analysis**

The per-patient cost of hospital, emergency and unplanned care is £2,324-2,467 lower for CMC patients compared with non-CMC patients (See Figure 2). The cost
of community services is £365-974 higher (See Figure 3). The net impact is that the mean treatment costs of CMC patients are £1,350-2,102 lower than for non-CMC patients.

Discussion

CMC represents a paradigm shift in delivery of End of Life Care. Patients with a CMC personalized care plan made less use of hospital, emergency and unplanned care and greater use of community services in the last 6 months of life compared with patients without a CMC record.

This was a retrospective service evaluation with small numbers in each cohort. Whilst it demonstrates trends, a larger prospective study would be more powerful. The strength of the study is the detail in which resource use was captured for each individual patient.

The limitations include the incomplete nature of the data for particular categories such as GP encounters, Out of Hours and Ambulance usage. The data for all categories was computer-generated, apart from GP data. For this, a member of the GP staff looked at each of the required patients’ notes and recorded the type of encounter. Thus, across different practices, the quality of data collection may vary.

A full assessment of the impact of the CMC pilot would require consideration of all the costs and all the benefits associated with CMC. This would include non-financial benefits, such as the value to patients from experiencing greater choice and a more efficient, integrated service and the costs of the CMC system itself, for example implementation costs (e.g. purchase of IT system and training).

CMC promotes choice on the location of place of death, which has been used as a quality marker and represents a service transformation with a move away from unscheduled hospital care and towards scheduled, in hours, community care. It discourages working in silos and promotes equity of care as seen by the outcomes for patients with non-malignant life limiting illnesses. The key driver behind it is personalised care planning and coordination of the care plan between service providers, which avoids crises and costs; emotional costs to the patients and their families, and financial costs to the NHS.

This evaluation suggests that a shift in patient care towards the community will lead to an increase in the time required from GPs. To facilitate this, further resources need to be made available to GPs by commissioners, or alternative community resources need to be invested. Community services could improve by:

- making rapid response community nursing services available 24/7;
- equipping health and social care staff at all levels with the necessary skills to communicate with, and deliver care to people approaching the end of life, and their carers; and
- developing specialist palliative care outreach services by encouraging CCGs and hospices to work together to provide appropriate support to all adults in the community, regardless of their condition.

This study raises many further questions. More research needs to be supported that looks at the quality of care provided. Routine evaluation of patient and care
outcomes at the end of life will help demonstrate the quality of care received. Other factors, that are equally important, including the costs to family and carers need to be considered.

**Conclusion**

CMC represents a paradigm shift in end of life care. CMC patients make less use of hospital, emergency and unplanned care. CMC patients make greater use of community services. The average cost of treating CMC patients is up to £2,102 lower than non-CMC patients.

**Strengths and Weaknesses**

This is a retrospective service evaluation with small numbers in each cohort. Whilst it demonstrates trends, a larger prospective study would be more powerful. Another strength of the study is the detail in which resource use is captured. For example, for each patient/NHS number, information has been obtained from the community on what type and what banding of staff was utilised. Similarly, the details on the type of encounter was collected e.g. Doctor Home Visit, Nurse consultation etc.

The limitations include the incomplete nature of the data for particular categories such as GP encounters, Out of Hours and Ambulance usage. The data for all categories was computer-generated, apart from GP data. For this, a member of the GP staff looked at each of the required patients’ notes and recorded the type of encounter. Thus, across different practices, the quality of data collection may vary.

A full assessment of the impact of the CMC pilot would require consideration of all the costs and all the benefits associated with CMC such as the value to patients from experiencing greater choice and a more efficient, integrated service and the cost of CMC itself (e.g. purchase of IT systems and training staff). This study considered only the costs of NHS services and not the impact on quality of care.

The strength of this study lies in the detail at which it examined the patient journey. It examined staff cost according to band of staff were utilised, and look at primary care cost plus the cost by type of consultation. and it did not only look at average hospital stay cost but considered actual cost per patient. Thus it provides real data that have not been calculated through statistical modeling. Our study suggests that a patient centric model represents a transformation of care that improves outcomes and decreased overall costs. It did however confirm that if more patients die in the community greater resources should be assigned to community care. It contradicts the dogma that clinicians know best and shows that when patients have choice they choose more appropriate care that is less costly to deliver.

This study is an example of how services can be transfigured using clinically driven information technology. This has implications for public health that are beyond palliative care. The population of London is 7.7 million. It is expected that approximately 50,050 (0.65%) of this population will die each year. If 15% of these deaths are acute, unpredictable deaths, approximately 42,543 patients could benefit from having a CMC record and this would represent a potential cost saving of up to
£89,425,386 per annum for London for end of life care alone. This model of care could be further extended for long term conditions that represent approximately 10% of the population.

**Figure 1: Place of Death of CMC Patients in London from August 2010**

![Place of Death of CMC Patients in London from Aug 2010](image)

**Figure 2: Cost of hospital, emergency and unplanned care for patients**

![Cost of hospital, emergency and unplanned care for patients](image)

**Figure 3: Cost of community care for patients**

![Cost of community care for patients](image)
NO DECLARATIONS OF COMPETING INTEREST

The study has been approved by the Royal Marsden Research committee but was not deemed necessary to go via the ethics committee for approval. This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.
REFERENCES

References


5. For more discussion of cost structures in healthcare, see Frontier Economics for Monitor, “A study investigating the extent to which there are economies of scale and scope”, http://www.monitor-nhsft.gov.uk/economiesofscalescope
