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Title: Coordinate My Care: A clinical service that coordinates care, giving patients choice and improving quality of life.

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Abstract

If palliative care is to lead the way towards a new model for integrated care, the ability to share information across the whole of health and social care is essential. Coordinate My Care (CMC) is a service dedicated to preserving dignity and autonomy at the end of life. Its care pathways enable health professionals from primary, secondary and community care to put the patient at the centre of health care delivery at this most sensitive time. This service is underpinned by an electronic solution. The record displays the patient's diagnosis, prognosis, current and anticipated problems, advanced care plan, resuscitation status and patients wishes. The CMC record can be accessed 24/7 by all health and social care professionals who have a legitimate relationship with the patient. From August 2010 -1st March 2012 1087 CMC patient records were created. The primary diagnosis was non-cancer in 52.3%, cancer in 46.3% and unknown in 1.4%, 42% of all patients were cared for by generalist only and had no specialist palliative care involvement. At the time of analysis 207 had died. Actual place of death was home 38.6%, care/nursing home 16.4%, hospice 12.1% and 30% in hospital. This equates to 55% of patients dying in their usual place of residence and reflects that 70% died outside of hospital. The CMC service has a well defined pathway underpinned by an electronic solution. It has been shown to change culture and deliver fully integrated, personalised end of life care.

A pan-London CMC roll out will take place over the next 12 months.

Introduction

If palliative care is to make a giant leap, and lead the way towards a new model for integrated care, the ability to share information across the whole of health and social care is essential. The ability to capture and, crucially, share information across all facets of the patient pathway is a fundamental requirement that underpins any aspiration to forge a sustainable model of integrated palliative care. There has been much talk in recent months of the concept of so-called 'disruptive technologies' – the notion that something very simple can transform the way we do things and, at the same time, make the process more efficient. The consumer world is full of examples of disruptive technologies that were dismissed when they were first introduced but have gone on to become an essential way of life. ATMs are a perfect example.

The End-of-life Care Strategy highlighted the national agenda to improve care for patients, irrespective of diagnosis, during the last year and ultimately at the end of their life. We know that the majority of people would prefer to be cared for and ultimately to die at home (1,2). However, two years on from the introduction of the End-of-life Care Strategy and despite over £286 million of investment, 53% of deaths still occur in hospital (3).

The NHS needs to make unprecedented savings in the next 5 years and more care is being shifted into the community setting which is in line with the end-of-life care agenda. Current plans to merge hospitals will not automatically lead to efficiency savings, ongoing financial constraints can no longer only be met by treating more patients whilst trying to cut costs. Blank and Van Hulst (4) assessed the impact of 63 groups of health care innovations and found that only one – the adoption of information and communication technology for hospital processes – both saved costs and led to statistically significant efficiencies. In the current climate new technology holds the greatest potential for increasing productivity. We believe that the availability of cost-effective affordable technology and its integration into patient care will be crucial in facilitating coordination and delivery of high quality end-of-life care.

At the moment, palliative patients with complex needs are cared for by multiple service providers. In addition there is no consensus between geographical areas in the way key services are provided, with delivery by different professionals or organisations and effectively a postcode lottery for care. The mismatch of patients needs with individual services is enhanced by poor coordination across different settings, resulting in huge frustration for patients, service users and carers. The disproportionate access to scheduled (within working hours) and unscheduled (out-of-hours) care for these patients remains a key challenge given that their health needs are often rapidly changing. It is recognised that 'achieving integrated care would be the biggest contribution that health and social care services could make to

improving quality and safety' (5). For palliative patients, who by definition have a limited prognosis, there is some urgency to address issues and make real changes to meet individual needs.

Patients with complex needs, particularly at end-of-life, should be entitled to an agreed care plan, a named key worker responsible for co-ordinating care and access to the benefits that modern technology can provide. The end of life care QIPP (Quality, Innovation, Productivity and Prevention) work stream aims for cost savings in end of life care by concentrating on identifying people who are approaching the end of life and planning for their care in their preferred place (3).

Our priority is to provide integrated health and social care both for individual patients and at a population level, by bridging the divide between community and acute care settings, with integration of the voluntary sector who remain key providers in end-of-life care. The challenge is to improve patient outcomes by working together – different professionals in different settings - providing a seamless and patient centred cost-effective service. A recent report by the Kings Fund to the Department of Health and the NHS Future Forum suggests that integrated care can be delivered without further legislative change or structural upheaval and that the aims of integrated care are widely supported by NHS staff as well as patient groups, and key stakeholders (6)

Something fundamental needs to change to move this forward and we propose that the adoption of a disruptive technology to revolutionise care is a promising way forward. The Department of Health has supported the development of locality end of life care registers called Electronic Palliative Care Co-ordination Systems (EPCCS). We have developed the EPCCS into a multi professional service called Coordinate My Care (CMC). This review outlines the progress from inception, development and piloting of the Coordinate My Care Programme which is now being rolled out across London.

What is Coordinate My Care (CMC)

CMC is a service dedicated to preserving dignity and autonomy at the end of life. Its care pathways enable health professionals from primary, secondary and community to put the patient at the centre of health care delivery at this most sensitive time, together with their carers. The service focuses on working with patients and families to understand their wishes and preferences for place of treatment and death, and ensures that this is honoured, even when the instinct is to elevate the (unwanted) level of care. Its aim is to put the patient at the centre and provide better coordinated services by improving communications between hospital and community teams. The teams are joined together through CMC to deliver the care that is designed specifically for each individual patient (7) (Figure 1).
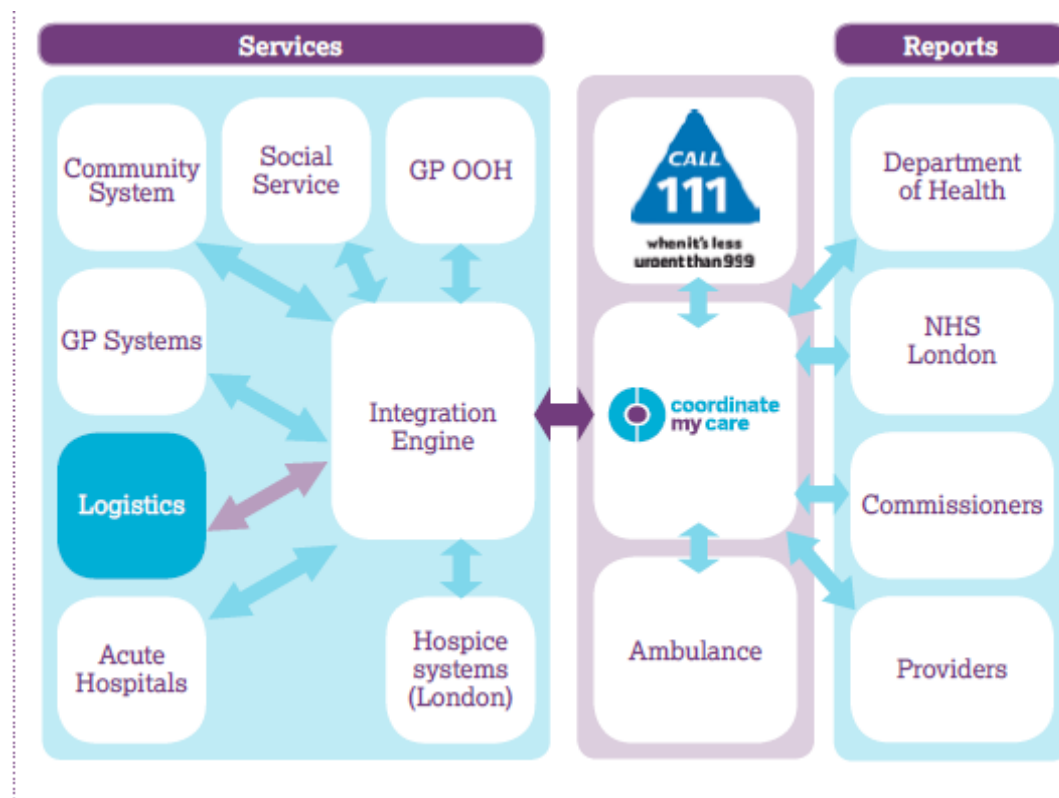
Figure 1: The CMC approach

This service is underpinned by an electronic solution (Figure 2). The Scottish SPICT tool aids the identification of patients (8). A CMC record is then created at this point when the patient is identified as being in the last year of life. The record is electronic and displays the patient's diagnosis, prognosis, current problems, anticipated problems, advanced care plan, resuscitation status and patients wishes. All patients prospectively consent to having their details added to CMC. If patients do not have capacity they may be added "in best interest". The CMC record can be accessed 24/7 by all health and social care professionals who have a legitimate relationship with the patient. It is a central password protected web-based record that has a robust security structure allowing professionals secure access to only that information which is relevant to them and their geographical areas of work (7).

CMC integrates end of life care pathways across London between health and social services both in and out-of-hours, including; GPs, community nurses, community palliative care teams, hospitals, hospices, social workers, London Ambulance Service, 111, intermediate care and nursing/care homes. The service is clinician led with clinical governance embedded into its framework. Information added by any health care professional is immediately viewable by all other legitimate professionals.

Figure 2: Diagram of CMC integration with service providers (7) (Logistics still to be added)

CMC is a progressive technology that requires a clinical culture change in terms of delivery of the service. As such CMC includes a highly defined clinical teaching and training package which encompasses; identification, consenting, medical plan (current problems and anticipated problems), Advance Care Plan, resuscitation status, patients specific wishes and guidance on how to input data onto CMC.

CMC continues to evolve in line with stakeholder feedback. Currently expert working groups are being established to develop managed care pathways and templates to assist generalist

end of life care providers in meeting the needs of patients with a variety of conditions such as; Motor Neurone Disease, Chronic Obstructive Airways Disease, Renal Failure, Heart failure, Dementia and Cancer

What is 111?

NHS 111 service is an urgent care response service that patients and carers can ring for help. It provides information and, if required, referral to a commissioned urgent care service identified from the London Directory of Services or CMC (7). The service is free and operates 24 hours a day, every day. CMC is interoperable with 111. The 111 Call Handlers have direct links to CMC. If the patient is on CMC, the 111 system flags their details and the call is handed over to a nurse within the NHS 111 service who will be able to navigate the caller through the CMC record to help them access the right care, in the right place at the right time. This ensures patients and their carers, can quickly and easily access the services they need to deliver their care plan and in doing so, fulfil their wishes. If the caller is calling about a problem that is not identified in the CMC care plan, the clinician takes the caller through the normal NHS Pathways clinical assessment system, as for any other 111 call.

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The CMC integrated pathway

Identifying patients

CMC advocates identifying patients appropriate for CMC by utilising the Supportive and Palliative Care Indicator Tool (SPICT) (8). SPICT is a clinical tool developed to identify patients with one or more advanced, progressive illness and a limited prognosis (likely less than one year) who may have unmet supportive and palliative care needs (8). GP practice and community nursing team meetings (e.g palliative care, supportive care, long term conditions) can act as a prompt to highlight or review patients who meet the criteria of SPICT and are appropriate for inclusion or updating on CMC.

Consent

All patients are prospectively consented. If the patient lacks capacity, they may be consented "in best interest" when it is encouraged, wherever possible, that the patient's relatives or next of kin are informed and involved. CMC provides a patient information sheet about the service to aid the consenting process and CMC advocates that the consenting process forms part of a wider necessary discussion about end of life care issues. This should always be patient-centric and embarked on at an appropriate time for the individual patient.

Completion of the CMC record

CMC is a contemporaneous record. Thus, it is not essential to complete all fields immediately. There are 11 mandatory fields on the CMC template that must be completed in order for a patient's details to be successfully added to CMC. These mandatory fields include patient demographic details (forename, surname, date of birth, GP and address), diagnosis, preferred place of care and death, resuscitation discussions and resuscitation status. Completion of preferred priorities of care can occur around the patient's journey and when it is appropriate to have the discussions with the patient and their family or carer. If it is not an appropriate time to have a definitive answer to the mandatory fields entered e.g. preferred place of death, CMC has drop down menu for this and the response 'not yet discussed' may be entered. This allows the clinician time to get to know the patient and fill in the field when the time is right. In addition, the St Christopher's Advance Care Plan and the Do Not Attempt Resuscitation form taken from the Resuscitation Council, BMA and Royal College of Nursing joint statement 2007 have been integrated into CMC electronically (9,10)
When a new patient record is uploaded onto CMC the out-of-hours (OOH) teams (including GPs and 111), London Ambulance Service (LAS) and the patient's named GP all receive an automated, encrypted email alert and the new patient details can be immediately viewed on CMC. The patient is also offered a paper copy of the CMC entry. In the full course of CMC development, it is planned that, in 2013, patients will be able to access MY SPACE, i.e. their own CMC record using a PIN number.

In line with recommended good practice, CMC supports GPs to review and update CMC when clinically guided. A minimum of 3 monthly review date is recommended to ensure the information is still valid and up to date to reflect the clinical situation.
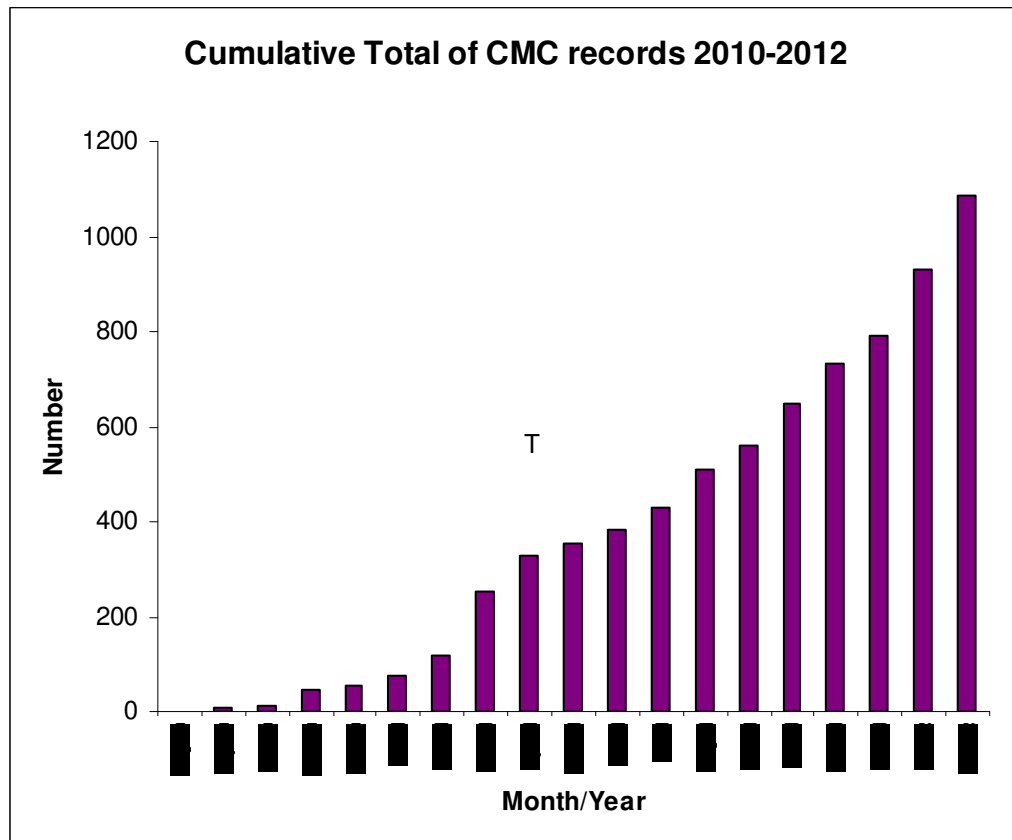
Reports

The automated reporting facility embedded in CMC provides potential for CMC to enhance current systems within the community and hospital settings for monitoring patients approaching the end of life, auditing clinical practice and can also aid case load management. Automated reports can be generated at the level of an individual nursing home, GP practice or district nursing area, for an individual specialist palliative care team or at PCT/CCG level. This includes a full list of patients on CMC to aid multidisciplinary discussions and case management. Outcome reports include; number of patients with a CMC record, number of deaths, details of preferred place of death, along with actual place of death and reason for variance between actual and preferred place of death. This allows comparisons between different geographical areas, as well as between different service providers (7).

Results

CMC records were created from August 2010 and censored on 1st March 2012. During this period there were 1087 patients entered (Figure 3). Of these 207 had died.

Figure 3: Cumulative Total of patient records added to CMC over August 2010- March 2012

Cumulative Total of CMC records 2010-2012

The demographics of patients with a CMC record are shown in table 1 . The mean age of patients was 80 years old (SD 13), 59% were female and in 4 cases the gender was not complete. The primary diagnosis was non-cancer in 569 (52.3%), cancer in 503 (46.3%) and unknown in 15 (1.4%). Fifteen percent of patients had dementia and 12% were frail elderly.

Table 1: Details of cancer and non-cancer diagnosis of patients with a CMC record

Details of Diagnosis			
Cancer Diagnosis	503	% of cancer diagnosis	% of all diagnosis
Gastrointestinal	129	25.6	11.9
Lung	103	20.5	9.5
Breast	55	10.9	5.1
Prostate	35	7.0	3.2
Pancreas	24	4.8	2.2
Haematology	26	5.2	2.4
Gynaecological	24	4.8	2.2
Neuroncology	23	4.6	2.1
Renal	21	4.2	1.9
Other	61	12.1	5.6
Non- cancer	n=569	% of non cancer diagnosis	% of all diagnosis
Dementia	165	29.0	15.2
Frail Elderly	135	23.7	12.4
Chronic Obstructive Pulmonary Disease	46	8.1	4.2
Other Respiratory disease	5	0.9	0.5
Ischaemic Heart Disease/Heart Failure	55	9.7	5.1
Renal failure	45	7.9	4.1
Cerebral Vascular Accident	43	7.6	4.0
Other Neurological disease	57	10.0	5.2
Other	18	3.2	1.7

Record entry (Table 2)

The consent field is mandatory, either through informed patient consent or best interest, and hence consent is completed for every CMC entry. Eighty four percent of CMC records were initiated in the community. The CMC team uploaded a proportion (19.7%) for professionals with no N3 link. The median length of time on CMC for all patients was 106 days (1 to 567) and for those patients who have died it was 38 days (1 to 455). Less than 5% of patients requested a copy of their CMC record.

Table 2: Professionals initiating the CMC record and number of patients requesting a copy of their record

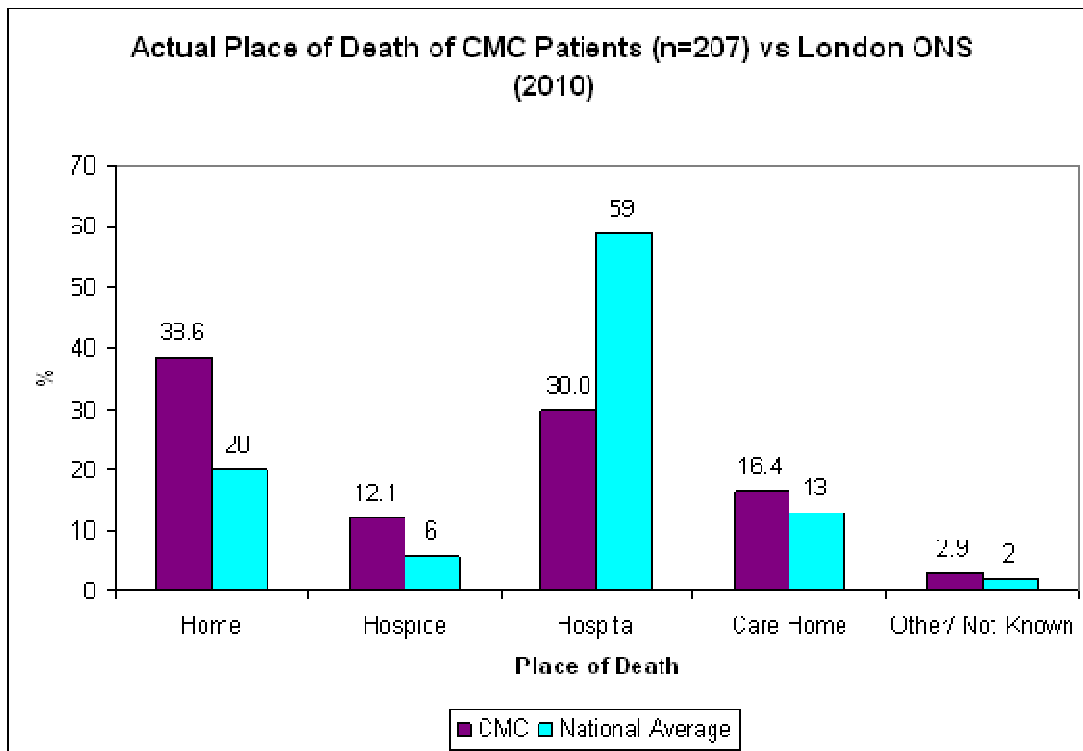| Professionals consenting and initiating a CMC record	n=1087	%
General Practitioner	416	38.3
Acute hospital team	139	12.8
Community palliative care team	178	16.4
Community nurses (District nurse, matron, disease specific specialist nurses)	314	28.9
Blank	40	3.7
Professionals uploading record onto CMC	n=1087	%
CMC team	214	19.7
Other Professionals	833	76.6
Blank/unknown	40	3.7
Patient requested a copy of CMC record	n=1087	%
Yes	50	4.6
No	954	87.8
Blank	83	7.6

Outcomes

Preferred place of death (PPD)

Sixty two percent of the 1087 patients PPD was their usual place of residence; home 33% or nursing/care,home 29%. Eleven percent requested a hospice, 2% hospital and 3% other locations. For 21% of patients this question had not yet been asked and in 1% the clinician deemed it inappropriate to ask.

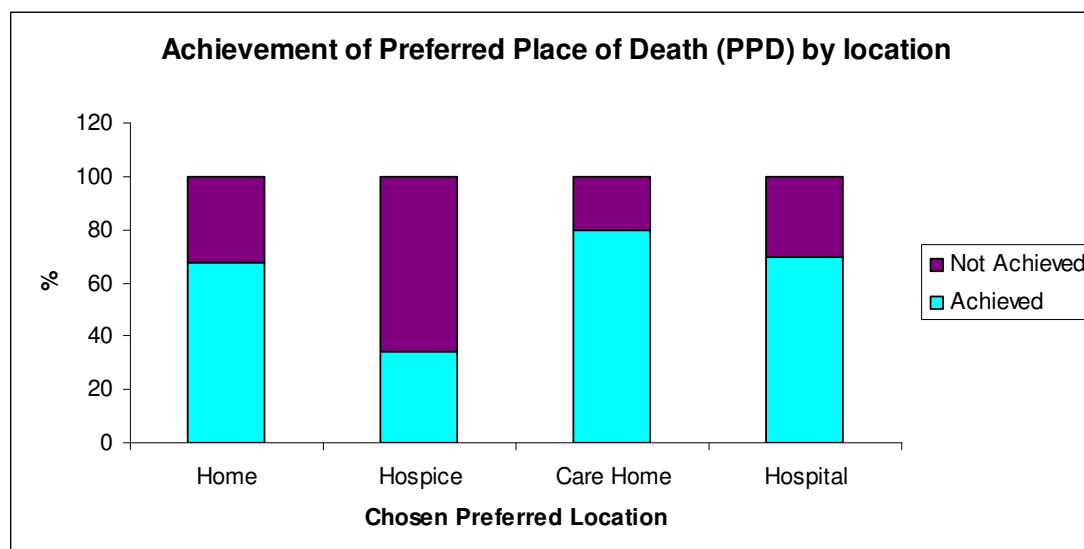*Actual place of death (Figure 4)*

Actual place of death (n=207) was home 38.6%, care/nursing home 16.4%, hospice 12.1% and 30% in hospital. This equates to 55% of patients dying in their usual place of residence and reflects that 70% died outside of hospital.

Figure 4: Actual place of death for CMC patients (n=207) vs ONS National data 2010 (3,12)

The figure below (Figure 5) shows how actual place of death equates to patient's preferred place of death. If patients did express a preference this was achieved as follows for the main locations; home 56/82 (68%), hospice 11/32 (34%), care home 20/25 (80%) and hospital 7/10 (70%). In 26% of patients who died, preferred place of death had not yet been discussed or was deemed to be inappropriate to discuss. Of those in whom preferences were not yet discussed at the time of death 49% (26/53) died in hospital.

Figure 5: Achievement of Preferred Place of Death by location of choice

In Sutton and Merton, one of the early adopters of CMC, the After Death Audit 2009 (11) showed that 32% of patients on a GP paper End of Life Care register died in their PPD, compared to 62% who had their preferences documented electronically on CMC (2012).

Discussion

Key findings
Consent
In 2010 an audit of 154 faxed hand over forms (13) sent to the London Ambulance Service showed that 112 (72.7%) forms had the consent questions answered. The answer to 'Do you have the consent of the patient for the transfer of information?' was "no" in 36 (32%). Not withstanding the lack of consent, details were shared with other providers. In CMC, consent is mandatory, a patient's details cannot be shared unless consent is given or it is in the patients' best interest.

Health Care Professional Engagement
Eighty six percent of CMC records were initiated by community professionals, with generalists (GPs, district nurses and community matrons) responsible for 67%. This shows a high level of health care professional engagement for the concept of information sharing and integrated care. Previous research into the Scottish Emergency Palliative Care Summary (ePCS) supports this showing patient, carers and HCPs all view the ePCS positively, none raising concerns about confidentiality (14). GPs highlighted that the experience of completing the ePCS also had benefits for in-hours care, and OOH staff felt better informed about palliative care patients.

Interestingly, amongst the negative concerns regarding the ePCS was the reluctance to engage in new technology requiring additional computer skills. These negative concerns are repetitive themes in evaluations of information technology across health care worldwide (15,16). However, 77% of CMC records were uploaded onto the IT system by the clinicians themselves showing that, in contrast to this previous work, it is clinician engagement in the IT system that underpins the CMC service. . GPs interviewed regarding ePCS expressed difficulty in knowing when in a patient's illness trajectory it is appropriate to complete the ePCS (14). These findings endorse the ethos of CMC and highlight that education and training around identification of end-of-life patients and communication about sensitive issues must go hand in hand with any electronic register implementation.

Social care professionals are now being trained to enter patients onto CMC. There is a specific template for social care involvement on the record.

Data Quality

Overall, the data quality of information on CMC has improved compared to the audit of 2010 faxed hand over information to London Ambulance (13). However this report highlights areas for improvement pertaining to the design and set up of the information technology used to store the CMC records. The main area of concern is blank/missing data. Diagnosis is unknown/blank for 1.4% of CMC records. Although the field in mandatory it is currently a free text box. This has resulted in some diagnoses being ambiguous. The new version of CMC has mandatory coded diagnoses on a drop down menu along with free text. This will resolve the problem. Also, the professional entering the data is unknown/blank in 3.7% of records. This is because this field currently relies on the user entering their details manually onto the record. In the new version of CMC an 'e signature' will be automatically generated whenever a user logs onto the system. This will be viewable by all other users to allow professionals to be aware of exactly who added or edited patient details.

Patient Outcomes

CMC is a useful service for all patients with multiple diagnoses entering the pathway from many settings. Over half (52%) of patients with a CMC record had a non cancer diagnosis. Fifteen percent had dementia.

It is difficult to find previous baseline data to make direct comparisons with CMC data. The Office of National Statistics (ONS) publishes yearly figures for place of death. For London these data were as follows for 2010; Hospital 59%, Home 20%, Hospice 6%, Care home 13 %.(12). This equates to 33% dying in their usual place of residence, 55% of patients with a CMC record died in their usual place of residence. However, ONS data is for all deaths, including acute deaths and patients not identified as end of life. Therefore a comparison to CMC has limitations. Nonetheless, when compared to the ONS London data for 2010, the

overall CMC data do show an emerging change in trend with more care being delivered outside of hospitals (41% vs 70%).

The closest comparator data available for a single locality is from the After Death Audit (ADA) conducted in 2009 across the UK (11). This was a snapshot retrospective audit of GP records for all deaths over February and March 2009. Sutton and Merton PCT, one of the early adopters of CMC, participated in this audit prior to implementing CMC. Within Sutton and Merton out of hospital deaths increased for patients on CMC compared to those on a GP paper register for ADA data (79% versus 65%) and the proportion of patients dying in their place of usual residence has also increased for CMC (63%) compared to ADA data (37%). Of those on a GP practice register ADA data (11) show 56% had PPC recorded compared to 80% of Sutton and Merton patients on CMC with a documented PPD. PPC and PPD were not documented separately in the ADA audit

Documentation of a PPD is not always complete. End-of-life care discussions are sensitive, and CMC reflects that such discussions and decisions, including preferred place of death, are an iterative process. For this reason, the CMC record is easily editable and also allows clinicians to share with others that these discussions have yet to be embarked upon. Whilst it may not be appropriate to discuss PPD at the time of entering a patient on CMC, more training needs to take place to encourage professionals to have these discussions and update the PPD when appropriate.

Overall, CMC rates of achieving patient preferences for place of death are lower than recently published data (17) for patients known to a community palliative care service. This is to be expected as only just over half of patients (58%) on CMC are known to a specialist palliative care team, the remainder are under the care of generalists in the community. This, along with the fact that 49% of patients who did not discuss their preferences died in hospital, highlights the need for ongoing training in communication skills and advance care planning for community professionals.

Only 34% of patients on CMC who chose hospice as their preferred place of death achieved this preference. This is an area of concern, and may indicate a lack of availability of hospice beds for end-of-life care alone (as most hospice units are now specialist units in symptom control/complex needs) and a lack of access to admit to a hospice unit out of hours or in an emergency setting. Rapid response community teams may be needed to care for these patients in their usual residence, and hospice as a choice may not always be a realistic option.

Although the numbers are small, recent implementation of CMC in care homes has showed a positive trend. Where patients in care homes express a preference to die in the care home, it

is achieved in 80% of cases. To build on this, a new CMC accredited training package is being developed to empower the staff to deliver end of life care in the homes.

Reporting

CMC has a reporting facility that can be used as a tool for governance, future planning and commissioning. CMC has the function to track individual patient journeys, recording, amongst other aspects of care, hospital admissions and community visits. It therefore enables increased awareness of patient pathways to facilitate anticipatory commissioning of services whilst also acting as a risk assessment tool generating auditable data to improve current practice.

Unanswered questions

There are some unanswered questions. Firstly, this review only gives information about the patients for which a CMC entry was completed. It is unable to tell us whether the introduction of the CMC has had an impact on the sharing of information with OOH teams for the patients on GP practice paper registers. There may be patients on GP registers who have not been entered onto CMC. Secondly, the DOH report on the 8 locality end-of-life register pilots concluded that at the time of the report none of the pilots were at the point where they had evidence that locality registers improve quality of patient care (18). This is true of the CMC data presented here. Although, compared to previous available data, patients with a CMC record have an increased home death rate, place of death is only a surrogate marker for a good quality end of life care. Surrogate markers may not necessarily give an accurate representation of the quality of care. Data collection regarding other markers of quality at the end of life is ongoing and for future publications.

The London Ambulance Service (LAS)

The LAS is the only pan-London Trust. It covers 31 Primary Care Trusts. CMC offers a standardised record that alerts the ambulance crew to the patients wishes, resuscitation status, care plan and which professional to contact for ongoing care. This empowers the crews to deliver care according to the plan and avoids them taking the patients to Accident and Emergency.

Implementation and next steps

A pan-London CMC roll out will take place over the next 12 months. All areas in London will have a CMC service by April 2013. This roll out will be synchronized with the 111, unscheduled care telephone number. The implementation of CMC is endorsed by NHS London.

Conclusion

CMC is a 'disruptive technology' – and shows potential to transform the way we do things and, at the same time, making the process more efficient and less expensive. CMC has been shown to change culture and deliver fully integrated, personalised end of life care. It can streamline the provision of health and social services that require complex interventions from multiple professionals across multiple settings. CMC service represents a change of culture. Changing a culture requires facilitation and training. The CMC service has a well defined pathway that is underpinned by an electronic solution. The vision is that CMC will be to End of Life Care what the ATM has been to banking.

Table 3: Advantages to CMC

Patient and carer

- Patient centric care plan: right care, right place, right time

- Wishes and preferences available to all care providers

- Ability to access own copy of record

- Ongoing process. No need to have to make decisions at any specific time

- Able to access clinician at 111 directly

- Brings end of life care services to patients who do not require specialist palliative care

- Delivers greater equity to patients with non-malignant diseases

- Delivers greater equity to patients cared for by generalists rather than palliative care specialist

Health and social care professionals

- A range of care providers can update record

- No need to repeat discussions – information each time they see a new health professional

- Ensures that all health and social care providers receive the same information

- Opportunity for specialists to train generalists

NHS

- Provides real time data to support commissioning

- Potentially saves costs in preventing unnecessary hospital admissions and interventions

- Provides auditable outcome measures that support a governance infrastructure

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