

Special issue article

Coordinate My Care: A clinical approach underpinned by an electronic solution

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Coordinate My Care (CMC) is a clinical approach underpinned by an electronic solution. It puts the patient at the centre. All clinical care plans, advance care plans and patients wishes are central to a CMC record. The record can be accessed 24/7 by all legitimate health and social professionals caring for an individual patient, including the out of hours general practitioner (GP) services, 111 and the London Ambulance Service. Two-thirds of each week is out of hours; CMC provides an up-to-date record for patients at all times. The key to CMC is planning. Planning care avoids crises; avoiding crises results in fewer unnecessary hospital admissions. CMC enables more patients (82.4%) to die in their preferred place (home, care home, hospice) and fewer patients to die in hospital. CMC improves access of care to patients care homes and to patients with non-malignant diseases (55%).

Keywords: Coordination of care, End-of-life care, Electronic Palliative Care Coordination Systems, Patient centric care, Technology in health care transformation, Reduced hospital admissions, Communications

Coordinate My Care (CMC) was designed by NHS clinicians for NHS patients in their last year of life. Over a period of 2 years, clinicians in the South West London Palliative Care Network designed a template to be used as a handover form for the London Ambulance palliative care patients. This form replaced all previous (13 forms) that were in use. In 2008, the End of Life Care Strategy recommended that all localities implemented End of Life Care registers. These registers were to identify all patients who would fit the surprise question: *'would you be surprised if this patient was to die in the next year?'* If the clinician would not be surprised, the patient should be added to the register. To this end the Department of Health put out a call for pilots for End of life Care Registers. The Department of Health awarded two pilots in London: the Royal Marsden South of the Thames (Sutton & Merton) and Camden and Islington Community NHS Trust (Camden and Islington) North of the Thames. At the same time three unofficial pilots came into being. During the course of the pilot the two official pilots decided to join together. The London Ambulance Service (LAS) was a key player in all pilots. The LAS was determined that multiple registers was not an option. It would not be possible to interrogate several registers each time a call was made. Which register would be

used if a patient moved around London? Which register would be used if the patient and their GP were in different localities? A pan-London solution was required. In 2010, the three unofficial pilots joined the two unofficial pilots to become one CMC. Patients, GPs, consultants, and nurses were consulted. No one wanted the name to have anything to do with a 'register' or 'death/dying'. It was thus agreed that it would be called by a name that said exactly what it did... patient centric coordination of care with the patient's consent at every stage. The CMC approach is to engage multiple service providers around the patient and coordinate the care. CMC is one of the Electronic Palliative Care Coordination Systems.

The CMC approach

The key to CMC is what matters to patients. This seems obvious but historically the NHS care revolves around buildings and services, not around patients. CMC involves no hard infrastructure: it starts with the patient's medical, nursing, social, psychological, and personal needs. With the patient's consent, it then documents this 'care plan' and coordinates it. It is a pathway. Patients can enter the pathway from any of the old NHS world buildings – the hospital (acute), social services, the Hospice, GP surgery or home (community). The service is virtual. The approach is patient centric. This means there is a significant reduction in gaps in care and there is no repetition of sensitive and difficult conversations.

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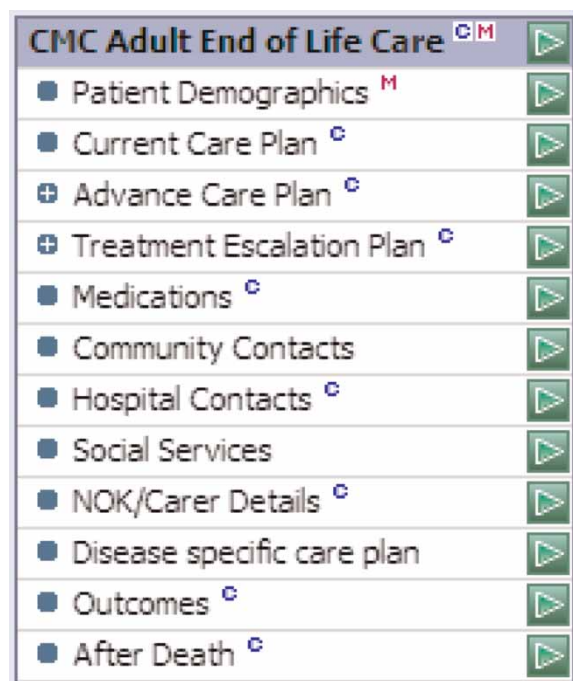
Information is shared ensuring that everyone has the right information at the right time. At all times the patient is involved in the decisions about their care. The clinician creates the care plan with the patient. The patient can request to have a printed hard copy of their CMC record. An app is being developed to enable patients to review, but not edit their own records. Indeed nothing can be changed or created in the care plan without the consent of the patient, hence the maxim, nothing about me, without me.

The CMC approach starts with the patient at the centre, the creating of bespoke care plans and the coordination of the care in a 'wrap around' model. The CMC approach to care represents a challenge to integrate care and overcome local and individual barriers. Starting with the patient at the centre the approach is about training.

Training includes:

- Identifying patients
- Consenting patient
- Having the difficult conversations
- Care planning
- Advance care planning
- Do not attempt to resuscitate (DNAR)
- Documentation of the CMC individual plans on the electronic system

CMC is being rolled out in line with 111. 111 is the non-emergency telephone number that operates 24/7 to improve access to urgent NHS services. In order for a locality to 'go-live' with 111 a tipping point has to be reached, i.e. a certain number of clinicians have to be trained. The CMC team is contracted to train 4500 clinicians by April 2013. This is no easy feat, but the team is on course to meet this target. Organizing training schedules to accommodate busy GP schedules is not easy, especially when the



preference of all GPs is to be trained during the lunch break and out of hours (OOH) GPs wish to be trained in the evenings and at weekends. Enormous flexibility is required of the CMC trainers.

The CMC solution

CMC is underpinned by an electronic *solution*. The solution is web based and can be accessed by any legitimate provider of care such as GPs, community nurses, hospital and hospice staff, as well as social services through N3, the secure NHS broadband. All patients prospectively consent to having a CMC record. A record can be created in *best interest* for patients who lack capacity.

The *solution* has frustrated and raised many barriers. Each has been looked at and addressed. Examples include:

- Double data entry – CMC will be interoperable with GP systems.
- Lack of information in the cars of the OOH GPs – mobile devices have been tested and CMC is now available in the cars in iPads and tablets.
- Over two-thirds of the week is covered by the OOH GP services. CMC is now available in the cars on iPads and tablets.
- London's 374 care homes do not have access to N3 – a secure non-N3 connection is under development.
- Patient access – a CMC app is being developed that can be downloaded by patients onto smart phones who will be able to access their own records.

Combined health and social care in looking after a patient in a nursing home is becoming vitally important. The over 80s age group is the largest growing

part of the population and they need care. Of those there, a third are expected to die in any one year – their average stay is about 18 months. Sixty percent of people in care homes have some degree of dementia, which, as a condition that can only worsen, means a patient's wishes for care and treatment in the future are best recorded as soon as possible. In care homes where CMC is already live, e.g. in Croydon, patients in nursing homes are automatically asked whether they would like to be put on CMC plans.

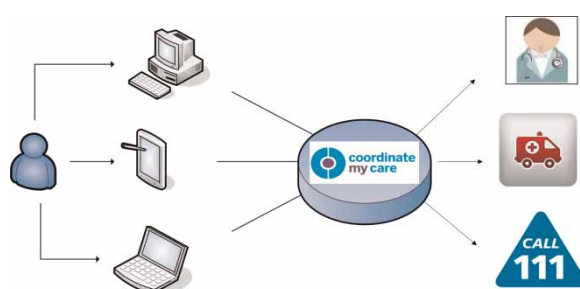
Thus far only 2 patients have refused to consent to having a CMC record. Having a CMC plan decreases uncertainty and worry about how a patient will be treated, and palliative care staff say patients are often more willing and readier than the professionals to talk about it. It is reassuring for the patient and their family to know that the patient's wishes are recorded and acted upon. It reinforces the objective that the patient's choices for living are being met. Professionals in care homes are keen to know and respond to a patient's wishes for end-of-life care and this system is ideal for them. Feedback from training sessions shows strong interest and enthusiasm for CMC from community nursing staff. Care workers will have the facility to sign patients up to CMC – the record will then be approved by a clinician. In fact, according to latest figures, 41% of CMC records have been created by professionals working in the community, as opposed to GPs or Hospitals. The care home workers could well prove to be fundamental to the success of CMC.

Interestingly, all this goes to show a huge turn round in the function of care homes from just 10 years ago. Then, around the Millennium, staff in care homes would routinely send their patients to hospital to die on a ward when their medical condition had deteriorated. Now care homes are better prepared and more willing to care for a patient right up to their death. CMC allows a patient to choose the care home as his preferred place of death and already data show that their wishes are being fulfilled.

Some of this turn round in end-of-life care in care homes came from the good work being done on the ground by palliative care specialists in the area. In St Christopher's Hospice in Sydenham, for example, more than 70 care homes have been approached by end-of-life care facilitators. With the introduction of CMC came monthly reports that highlighted good practice, this exposure enabled other localities to learn and thus it has given other areas a chance to share good practice and hence improve patient care in the very important last stages of life.

A CMC record should thus be offered to each individual as a matter of routine but nursing homes do not have N3. CMC is thus developing a best practice internet portal security, similar to that which banks and

other government department utilize, based on a three-layer model of security, i.e. non-N3 access. GPs do not wish to enter data into their own GP systems (EMIS, Vision, and TPP). This is labour intensive and can create inaccuracies. CMC is investigating all possibilities of interoperability. The jury is still out as the GPs are polarized: some want complete interoperability, other want nothing to do with pushing or pulling of data from their systems. CMC has heard the debate. A compromise will probably be phase one of interoperability, i.e. populating the demographics from the PDA/spine will be automated and CMC will be accessed via a portal. This will mean that GPs can access the CMC portal directly via a hyperlink on their computer.



The *solution* has required clinical and information governance arrangements to be in place to allow the flow of patient information, joint decision making and to hold clinicians accountable for the care provided. CMC has addressed the governance issues at local and Pan London levels.

Who benefits?

Patients

- Involved in their own decision making and care plan
- Fewer unnecessary admissions to hospital
- Fewer crises
- Updated information about wishes and management plan available to all care providers
- No need to repeat conversations and wishes constantly
- Direct access to clinician at 111, 24/7
- LAS and OOH GPs fully aware of care plan and patient wishes

Clinicians

- Sharing care of terminally ill patients
- 24/7 access to up-to-date information
- Sharing information with care providers including GPs, OOH GPs, community and palliative care nurses, hospice and hospital staff
- Prompts for more structured end-of-life care pathway
- No faxing; ability to quickly update or change record

Commissioners

- Monthly reports of outcomes including Preferred Place of Care and Death and reason for variance
- Ability to plan service
- Costs and quality of care outcomes (currently in pilot phase of development)

Monitoring the CMC approach

Quality of the care plans and CMC records is prospectively audited on a weekly basis. A real case in point was one CMC record that had ‘hypertension’ documented in the care plan. This is not helpful. It might in fact cause more of a dilemma to the LAS than no CMC record at all. In such cases the CMC clinician calls the professional who entered the care plan and discusses the patient. A more comprehensive care plan is agreed. This serves two functions: firstly, the patient has a useful care plan and secondly the training continues through constructive feedback. Weekly teleconferences are held for all localities that have gone live with CMC. A lead clinician (e.g. GP end-of-life care facilitator, community matron) dials in. Clinical problems and solutions are discussed. Clinical inci-

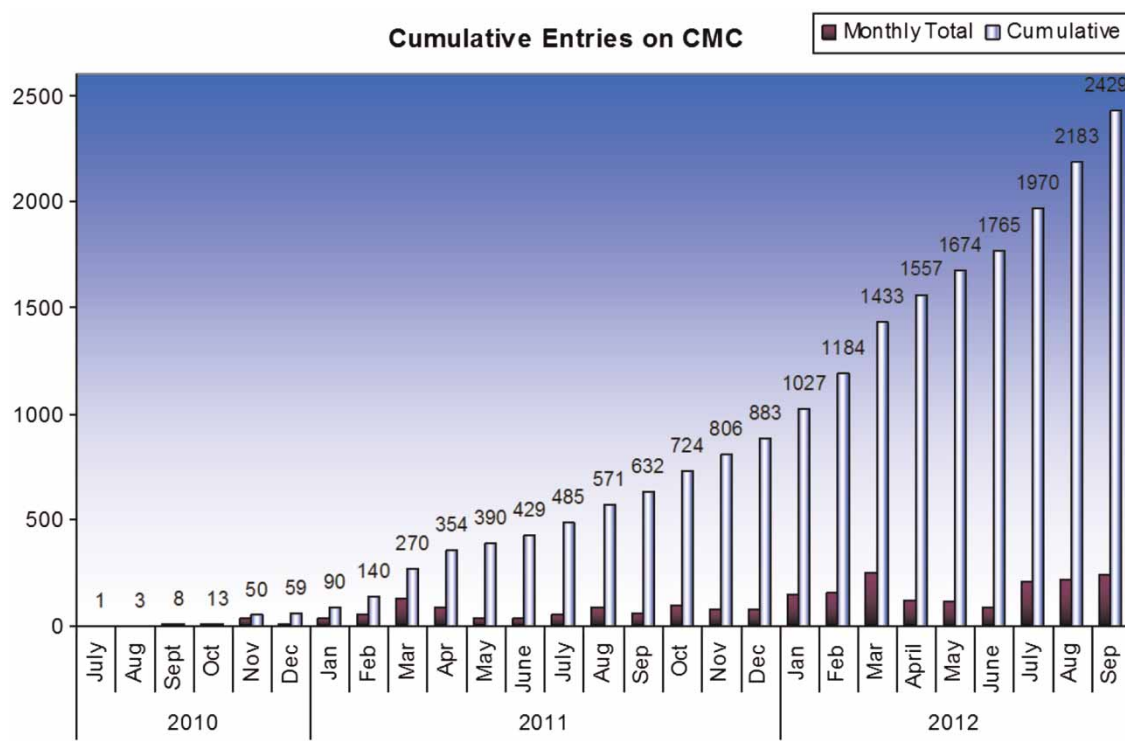
report is sent to the lead clinicians and the commissioners. Initially, CMC thought it best to send out only the data that pertained to the particular locality. Through consultation this has changes and all data are sent to all localities. Comparisons are thus easily made and good practice can be identified and shared. For example, in Hillingdon the outcomes of patients in nursing homes with a CMC record is good, reflecting an initiative that was started whereby many of the nursing homes have one or two palliative care beds and the palliative care teams provide guidance and training for the staff. Other areas are now looking to implement a similar model of care.

What is the evidence to support the CMC approach?

We know that the majority of patients wish to die at home yet in 2010, in London, 65% patients died in hospital.

There are currently 5444 patients with CMC records. Data censored 6 October 2012 there were 2272 CMC records

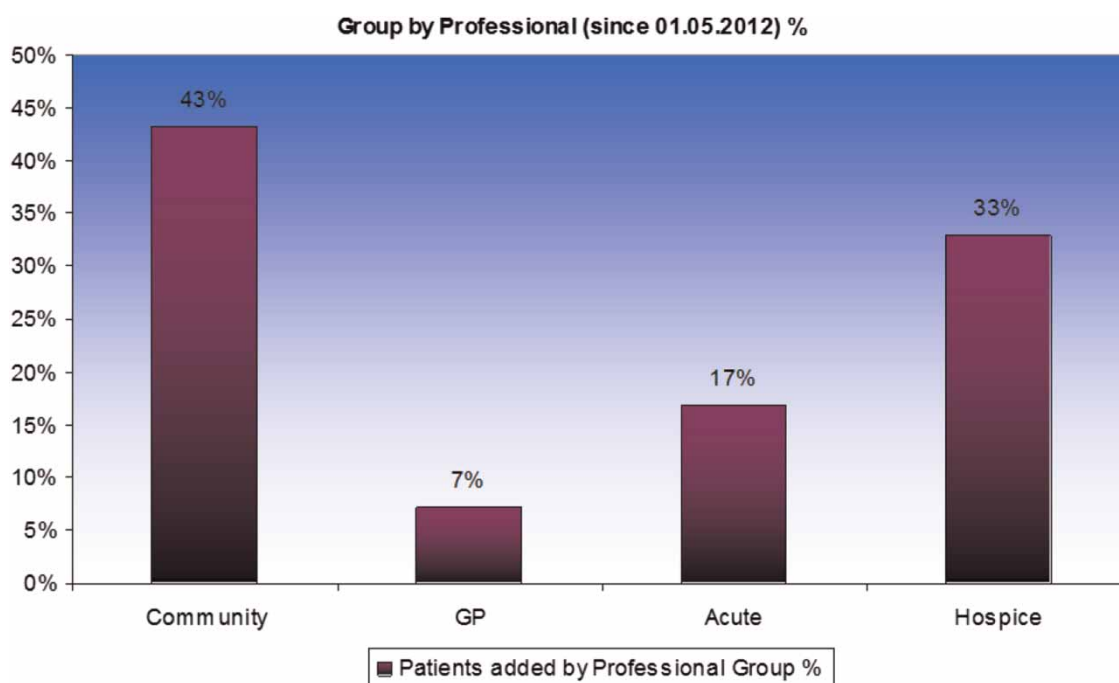
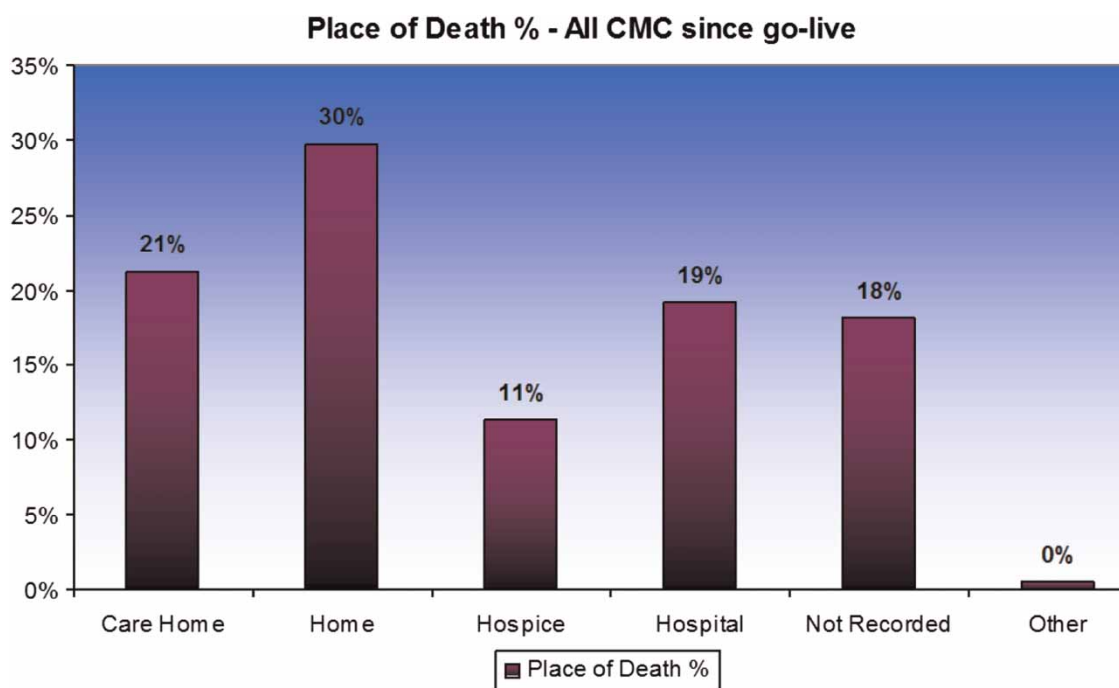
- 627 deaths
- 82.4% achieved PPD1 or PPD2
- 45% cancer 55% non-malignant (14% dementia)



dents are reported and processed. Where possible, to mitigate against the recurrence of an incident, CMC is reprogrammed and updated. All recommendations about service improvements are documented and then changes are made to the software as often as required. On the first Wednesday of the month a

Case study

An elderly gentleman in a nursing home created his CMC record with the nursing home manager. He clearly stated that he wanted to die in a hospice. Early one evening he fell out of bed. He was too heavy to left back into bed. The staff called 999. The



LAS CMC flagged up to alert them that the patient had a CMC record. En route to the home, the clinical service desk phoned the hospice to check the availability of beds. A bed was available. The message was relayed to the paramedics. On arrival, the paramedics found that the patient had a large laceration to his forehead that was bleeding profusely. With full knowledge of his CMC record, they took him to accident and emergency (A&E) where his laceration was sutured, they then transferred him to the hospice

where he died. The patient's wishes were granted and an unnecessary hospital admission was avoided.

It is clear that the CMC approach to patient care is what the patients are asking for. To quote Nigel Crips, former NHS Chief Executive, House of Lords 'Patient power needs to be built on strong intellectual foundations; The balance of power in health systems needs to be shifted so that people are enabled to live the life that they want rather than having to fit in with professionals and commercial

views'. The CMC approach is built on intellectual foundations of hundreds of NHS clinicians caring for palliative care patients. *So why is it that the CMC approach to patient care has been so difficult to sell to General Practitioners? It is clear that CMC benefits patients. The real question should be why did we not do this years ago? Using the CMC approach puts patients at the centre of their care. Patients entre CMC at all different times along their journey. CMC thus represents a 'pathway approach' to patient care. Care is not delivered in silos. Care is joined up. Delivery of care using CMC service thus represents a culture change. Changing a culture requires understanding of the benefits and training.* The CMC

approach is team working and trusting the care plans made by other professionals within the multidisciplinary team. The CMC approach enables patients to stay at home and in the community. In the community patients are the responsibility of their GPs and this inevitably requires a great work commitment. Adequate remuneration and training are the way forward. This will take time, only then will the CMC approach deliver the goals of Hannah Farrar, Director of Commissioning at London, that patients will be able to say 'I was as involved in discussions and decisions about my care as I wanted to be'.... 'I was always kept informed' and 'professionals involved with me talked to each other'.