DR JULIA RILEY ON DISRUPTIVE TECHNOLOGY

The sad stories of people who want to die at home but in fact die in hospital are now well known. In London we now have some different stories to tell about how clinicians have been able to share records and work together to help patients die in their preferred place of death.

The service is called Coordinate My Care (CMC). It is not a "death register" as referred to by the *Daily Mail*. On the contrary, it is about the way a patient chooses to live. It puts the patient in control and creates an environment where clinicians can truly work together.

CMC can streamline the provision of health and social care services that require complex interventions from multiple professionals across multiple settings. We are proving that CMC can transform the way we do things and, at the same time, make the process of delivering end of life care less expensive.

By April 2013, the CMC team will have trained over 4,500 clinicians across London on how to work with patients to create an individualised care plan that includes their end of life care, records their wishes, ensures regular review of the plans and encourages healthcare professionals to act on them when they are needed.

'Now CMC is changing the end of life pathway; tomorrow it could change care for long term conditions'

Getting here has been a long and complex process. It has involved working with partners as diverse as NHS 111, the London Ambulance Service, out of hours GPs, clinical commissioning groups and PCTs, with specialist acute care services, primary care, community care and the third sector.

Although CMC is underpinned by an IT solution, it is not an IT led project. The technology has always followed the clinical and patient need.

Implementing the system across London will require a lot more work. Currently we have a few thousand people on CMC. Of those recorded, 77 per cent have died outside of hospital. Potentially, there are 57,000 people in London who could benefit from an end of life plan.

CMC is a disruptive technology. It changes the way we do things. Now it is changing the end of life pathway; tomorrow, it could change the way we deliver care for people with long term conditions. My vision is that CMC will be the single most successful innovation in end of life care.

Dr Julia Riley is clinical lead for CMC at The Royal Marsden
www.royalmarsden.nhs.uk/cmc

SERVICE REDESIGN

A KINDER SYSTEM

How technology is helping many more patients die where they want to – at home. By Clare Read

Margaret did not expect to live long. She had lung cancer and had made her plans about where she wanted to die and what treatment she wanted to receive when the time came.

But, as is the way with these things, the time came and her son – her main carer – panicked as Margaret's oral pain control failed. He called an ambulance.

Now, you might expect a sorry end to this story, one that involves Margaret being admitted to hospital and dying there against her wishes.

But you'd be wrong. Margaret was registered with Coordinate My Care and her electronic end of life care plan was available to the ambulance service, primary care team, secondary care team and the community nurses.

When the call came to the ambulance service, an automatic flag popped up and the clinical service desk was able to read the care plan.

This detailed Margaret's diagnosis, prognosis, current and anticipated problems, advance care plan, resuscitation status and her wish to die at home. It indicated that intravenous morphine was already in the house and gave the number of the 24-hour district nursing service who could administer it subcutaneously.

An ambulance was dispatched to provide immediate pain relief and to wait for the district nurse who put up the syringe driver. Twenty four hours later Margaret died peacefully at home just as she had wanted.

"Coordinate My Care can make a vast difference to patients," says Dr Julia Riley, clinical lead and palliative care consultant at The Royal Marsden foundation trust. "For the first time, everybody involved in a patient's care will be able to know what has been requested and can avoid inappropriate treatments."

Typically, two thirds of people in the UK die in hospital compared with just 19 per cent of CMC patients (see box, right).

It is about to make an enormous difference to many more patients too, as over the next 12 months it is to be rolled out across London where, in theory, 57,000 people could eligible for a CMC record at any one time. It could also be extended for use in long term conditions; the era of integrated care might just have arrived.

While the outcome for patients of CMC may feel simple – they get to say where they want to die, the information is shared among care providers and then acted on – getting to this position is not.

"It is a culture shift," says Dr Riley. "It is pathway driven and to get it to work requires engagement from everyone involved in the patient's care as well as training for the clinicians."

So while it would be tempting at first sight to see CMC as an electronic solution, there is far more to it than that.

Essentially it works like this. Clinicians (usually GPs or community nurses) identify patients who have a year or less to live and have unmet palliative care needs and use the Edinburgh Supportive Palliative Care Indicator tool to find out if they could benefit from CMC.

'Typically, two thirds of people in the UK die in hospital compared with just 19 per cent of CMC patients'

With the patient's consent, or "in best interests" if they lack capacity, the clinician and patient plan the future care and record the patient's wishes on a template that is uploaded to the CMC site. Essential information includes the demographic details, diagnosis, preferred place of death, resuscitation discussions and resuscitation status.

When a new patient record is uploaded onto CMC the out-of-hours teams (including

What you want: technology can help carers share and deliver on patients' care preferences

GPs and 111), London Ambulance Service and the patient's named GP all receive an automated, encrypted email alert so they can immediately view the details via a secure login to the CMC web portal. The patient is also offered a paper copy of the CMC entry – with plans to make secure electronic viewing by patients possible in the future.

When NHS 111 or the LAS receive a call from a patient with a CMC care record the system flags this up. Clinicians who have a legitimate relationship with the patient, whether they are in NHS 111, the ambulance service, community care, primary care or acute care, can also view the record.

The record can be updated and refined over time to include changes in the patient's wishes. At any rate it should be reviewed at least every three months, usually in the GP practices in their end of life care meetings.

CMC also generates reports – for example at the level of nursing home, GP practice, palliative care team, district nursing area or CCG. These can be used to support multidisciplinary discussions and case management and to benchmark between different areas and service providers or to support service redesign.

Quality markers are embedded into CMC. A project is underway to track the costs of each patient on CMC and the quality of care delivered. Reports written for commissioners in the future will include costs and quality of services delivered by providers in the locality.

Under CMC, "the patient is king," says Dr Riley. There are three key principles underpinning CMC. "The patient makes the decisions. The patient consents to a CMC record and the patient decides what he or she wants."

Not only must health professionals be prepared to have the difficult discussions with patients about their end of life care and record their wishes, they must also be prepared to share the information with appropriate consent and keep the record up to date.

The work carried out by CMC with nursing and care homes is a good example of just how complex doing this can be.

Jo Hockley is a nurse consultant who runs the Care Home Project team at St Christopher's Hospice in south east London. The team was set up in 2008 to support local nursing homes in providing high quality end of life care to their residents and, since July 2012, has been working to help nursing homes implement CMC.

"I think what a lot of people do not realise is that nursing homes have changed," says Ms Hockley. "They are less the places of companionship that they were ten years ago

KEY FACTS

Audit date: October 2012
Number of CMC records created: 2,827
Diagnoses: 45 per cent cancer, 55 per cent non-malignant diseases
Number of deaths: 673

Care Home	150	22%
Home	192	29%
Hospice	78	12%
Hospital	128	19%
Not Recorded	122	18%
Other	3	0%
Total	673	

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and increasingly they are places where frail elderly people are nursed for six months to two years maximum. Yes, nurses will rise to the challenge but they are very isolated from medical and geriatric input."

Ms Hockley's team helps care homes to implement the Gold Standard Framework for end of life care – a systematic approach to optimising end of life care delivered by generalist providers.

In 2008, 55 per cent of deaths among nursing home residents in Croydon's 25 nursing homes took place in the home. By July 2012 they had already driven this up to 79 per cent.

"When we were asked to get involved in CMC our nursing homes in Croydon were already working to a very high standard," she Ms Hockley. "They were already doing advanced care planning and do-not-resuscitate plans. But we were still getting unnecessary ambulance call outs and resuscitation issues."

These issues seemed to be cropping up out of hours, says Ms Hockley. "We had difficulty engaging with the night staff and weekend staff. When the out-of-hours GP said call an ambulance, they would do it."

She hoped CMC would help solve this problem by making patients' end of life care plans visible to out-of-hours GPs, NHS 111 and LAS. "I also hoped it would end the isolation of nursing home staff from medical input," she adds.

That seems to be what is happening. Care home nurses fill in the CMC templates, which are then checked by clinicians before being sent over to CMC for uploading onto the system. So when care home nurses call 111 or 999 in the night, the CMC flag pops up and the urgent care services can respond appropriately. "Our care home nurses say it is wonderful," reports Ms Hockley. "When they call NHS 111 they are put straight through to a clinician – someone who is committed to the resident staying in the nursing home rather than admitting them to hospital. They are now getting access to clinical advice in an acute situation."

Eileen Sutton, who leads NHS 111 for NHS London, adds: "We thought it was really important that patients who are terminally ill can get through to a clinician as quickly as possible."

'Practices that have not developed their end of life care will find it more difficult because it requires a complete change in processes'

She does not mean just nursing home residents but anyone with a CMC care plan. "Now when someone with a CMC plan calls us in the middle of the night or on a bank holiday, they know their care plan is accessible by our clinicians."

Ms Hockley's team has been subcontracted by CMC to carry out training in all of London's 374 nursing homes. Not all may be as straightforward as Croydon or other areas that have already implemented the Gold Standard Framework, she admits, and training will need to be tailored to local needs.

Ms Sutton echoes this point. CMC will be rolled out across London as part of the NHS 111 service but already the experience is that some health professionals have been easier to engage than others.

"Everybody gets the idea," she says. "But some have more difficulties with the changes needed. The palliative care nurses and Macmillan nurses in areas where NHS 111 is live have taken to it really well and the GP practices using the Gold Standard Framework have found it easy – for them it's what they have been waiting for.

"But those GP practices that have not developed their end of life care processes so well find it more difficult because it does require a complete change in their processes."

CMC is also just what the LAS had been waiting for, says Dave Whitmore, senior clinical adviser to the medical director and the LAS lead on end of life care.

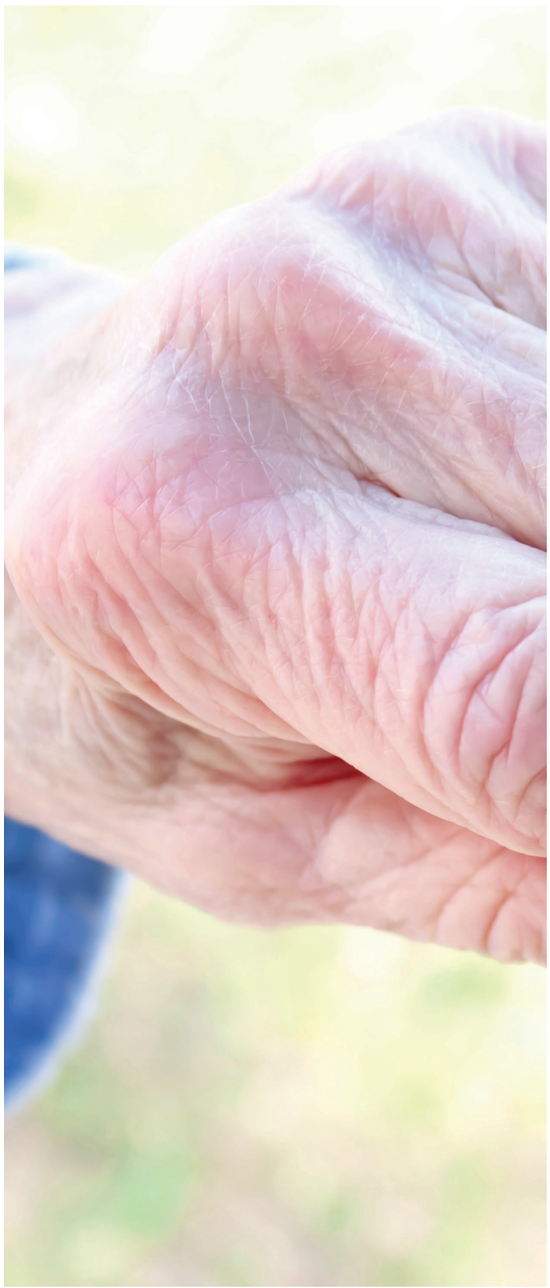
He had been working on how to share end of life records for several years and had come to the conclusion that the only way to do it was through an electronic, 24/7, single, web-based system for London.

"We get called in a crisis," he says. "The end of life plan may be in place but when it is an emergency people forget to call the palliative care team and call us instead. The only number they remember is 999."

The more the ambulance service knows about the patient, the better able they are to respond appropriately. "With CMC, ambulance control staff can see care plans, medications, the GP or nursing notes. The most important issues are flagged up at the top of the care plan and there are contact numbers for the healthcare professionals caring for the patient," he says.

He recalls the case of a man with end stage renal failure who had been discharged from hospital to die. His relatives had called an ambulance when he fell following a seizure.

LAS dispatched an ambulance but were



HIGH IMPACT TECHNOLOGY

The technology behind CMC was developed by Liquid Logic and while the technology itself is not startling, its impact is.

Tom Frusher of Liquid Logic says: "The power comes from the fact that it supports a service in a completely new way by getting the right information to the right person at the right time. It is compelling for clinicians who use it. Their basic proposition becomes not so much 'why should I use it?' as 'why haven't we been doing this for a long time?'"

Dr Riley is careful to point out that CMC was never conceived as an IT project; the IT was always led by the clinical need. "We tried to develop our solution with Connecting for Health using the summary care record, but that was a technology-led project which restricted it severely. With CMC it is the other way round and as a result the solution is very intuitive and easy to use and fits in nicely with the way clinicians work everyday."

Holding your data: the CMC care plan is accessible to clinicians 24 hours a day

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also able to call the palliative care team who sent a clinician immediately. When the ambulance arrived, they treated the now barely conscious man with diazepam before handing him on to the palliative care team.

"He died peacefully in a hospice two days later," says Mr Whitmore.

Currently crews cannot access CMC – that's done securely in the control room – and while using mobile devices to review a care plan en route to a call sounds attractive, Mr Whitmore is cautious. "We have to be sure that we are keeping people's information secure," he says. "So anything like this would need to be done very carefully."

Ambulance crews are not the only professionals who would like mobile access. As CMC is web-based, no data are held on the device and already one hospice is using iPads to enable community nurses to access CMC. Meanwhile, a pilot is underway to test mobile access by out of hours GP services.

At the moment, CMC has a few thousand records – about 3,000 by the end of October 2012 – but that could expand to a theoretical 57,000 if it is taken up right across London by all care providers, says Mr Whitmore.

"It is going to grow exponentially," says Mr Whitmore. "As a paramedic and as a manager I know having a service like CMC makes a real difference to the quality and cost of care. I also feel that if we develop it carefully it could become a much more powerful tool that we could use not just for end of life care but long term conditions."

So does Dr Riley. "We'd like to start a pilot project," says Dr Riley. "We do need a shared care record for people with long term conditions but there are a lot of issues to address."

She speaks from experience with CMC, which has involved significant pieces of work around information and clinical governance as well as systems integration to get the IT system to work and engaging with different clinical groups. "Getting robust structures around implementation for both information and clinical governance has been critical to its success and acceptance," adds project manager Kate Mansell.

CMC will be a London-wide service, and over the next year the team will be training over 4,500 clinicians to use the system. However, commissioners need to buy into it.

"Essentially we are a pathway redesign service," says Ms Mansell. "We change the way people practice. We provide the training, support for the system, ongoing clinical quality checking and reporting."

CMC has really only just begun. Dr Riley describes it as "disruptive technology". She says: "We have shown that it can change the culture to deliver full integrated, personalised end of life care. It has the potential to change the way we do things and, at the same time, make the process less expensive. My vision is that CMC will revolutionise end of life care."

CASE STUDY: DELIVERING SPECIALIST END OF LIFE CARE

Only half of the patients currently registered on CMC have cancer. One sub group of patients is those with renal failure who do not want dialysis and who therefore need to plan their end of life care.

Breeda McManus, renal consultant nurse at Barts Health Trust, explains what goes wrong. "We have had lots of patients who have made this choice but have then been admitted to hospital in an emergency and end up being treated with dialysis."

She has worked closely with CMC to develop specialist templates for these patients that improve communication between primary and secondary care to avoid this scenario. "With CMC our patients will create a care plan with their clinicians and all their decisions will be recorded. Clinicians can be kept up to date about their management, their wishes and their ongoing problems," she says.

She hopes that patients' wishes will be respected better in future and that the record will be a shared resource for community clinicians and specialists in hospital to improve care overall.

Similar work has been done around motor neurone disease and Dr Riley hopes to develop other packages around diagnoses including dementia, chronic obstructive pulmonary disease and heart failure. ●