Coordinate My Care is the digitally-enabled urgent care plan that embeds consent, connectivity and clinical context into a service that better coordinates care at times of most need. Professor Julia Riley, consultant in palliative medicine and clinical lead for Coordinate My Care, shares how the service – part of the NHS Innovation Accelerator programme – is improving patient outcomes and enabling a paradigm shift in how the NHS approaches unscheduled care.

When a member of my family was dying of metastatic malignant melanoma, she wanted to remain at home with her four children, all under the age of five. Yet, time and again, when she needed help in the out-of-hours period, a well-meaning GP or paramedic would arrive, not knowing anything about her or her wishes, and she would be taken to hospital.

For myself and many others, this lack of information sharing made an already painful situation much worse.

There is also the additional impact on the NHS. Twenty per cent of those in the last year of life have five or more unplanned admissions, creating an often unwanted burden for both the patient and the NHS. For many, this is the last thing they want.

It was for these situations that Coordinate My Care (CMC) was created.

CMC offers one standard, digital urgent care plan making sure that the patient’s wishes are taken into account by everyone who will be responsible for their care. It includes important information about the patient’s illness and medication, how and where the patient would like to be cared for, and people to contact in an emergency. It shares this information with all the health professionals who might be involved in treatment: from paramedics and emergency services to hospital doctors and specialist nurses.

Though it is underpinned by an IT platform, CMC has been developed as a clinical service that changes the culture of how urgent care is conceived and delivered, from one that is reactive, to one that is proactive and patient-centred.

To enable that change has not been easy. It has meant embracing the lessons that all healthcare organisations should apply to realise the benefits of a digital strategy, as outlined by independent health charity, the Nuffield Trust in its *Delivering the benefits of digital healthcare* report.

Transformation has to come first, so technology supports new ways of working. By providing trusted information to care providers at times of urgent need, and as part of their clinical workflow, we have been able to support that transformation. That has meant ensuring that care plans are created with the patient and a trusted clinician, and that information is audited regularly and shared appropriately at the point of care. To further encourage trust in the data, and support robust information governance, over 1,000 information sharing agreements are in place with organisations across London.

Culture change is crucial, and to support this we have trained over 20,000 individuals on how the service operates. This extensive training covers how to identify vulnerable patients, how to have difficult conversations around care choices and how to operate in a ‘virtual multi-disciplinary care team’. Online learning and real-time support is also provided.

The system is user-centred, designed around the needs of both care providers and patients, and can be accessed by any type of mobile device. To aid the clinician, GPs can access the record directly from their GP system; for others, a flag on the record is present to indicate the presence of a care plan.

CMC is a rich source of data, which is used to improve the service. CMC creates monthly reports that are given to teams caring for patients. Those teams can see how they compare against others to enable the sharing of good practice. Commissioners can also benchmark providers to inform current and future service delivery.

CMC has been in existence for nine years, since the publication of the 2008 end of life care strategy. In that time, it has seen multiple iterations so that it can integrate into numerous NHS pathways, including those for out-of-hours GPs, 111 and ambulance services. Thousands of hours of professional time have informed developments, with contributions from those involved in the clinical, enterprise architecture, design, patient safety, pharmacy, communications and testing aspects of the service. Patients have provided feedback on the development of the service at every important stage.
Coordinating this approach to care also requires robust interoperability. CMC is currently a pan-London service, commissioned by the capital’s 32 clinical commissioning groups to ensure that patients can benefit from the service wherever needed. This has meant we have designed and delivered an interoperable solution, based on InterSystems’ HealthShare information platform, that can be seen by any legitimate and authorised user through multiple systems, and that draws in centrally managed data services such as the Spine.

Information governance and security, the final piece of the digital health jigsaw for the Nuffield, has been the starting point for the service. Patients, or their nominated loved ones, give their consent to create and share the care plan across secure NHS and social care networks.

The result is a system that is delivering benefits now, and can benefit the wider NHS.

The system has been designed to be scalable. Both the platform and the contractual arrangements have been positioned so that they can be adopted by other areas across the NHS, not only for urgent care, but other services such as cancer treatment.

The impact of the system, which has been awarded National Innovator Accelerator (NIA) status after rigorous peer review, is clear. Around 50% of all deaths occur in hospital nationally. Among patients who have created a CMC urgent care plan, just 18% die in hospital, with more spending their final days in their preferred place of care.

There are financial benefits. An independent health economic evaluation* of the service showed an overall cost saving of £2,100 per patient who died with a CMC care plan in place. If all patients who were predicted to die in a year had a plan, the total estimated cost savings, if they stayed out of hospital, would be £892,500,000, nearly a billion pounds.

The results for the patient are also compelling. As Mary, a patient with renal cell cancer who set up a CMC plan in 2016, said: “Now I have a plan, I feel so much happier. Because I’ve got some control over things. I will probably need urgent care in the middle of the night again – that’s how cancer goes. But, this time, everyone will know what to do with me. They’ll know exactly what I have, and how it’s being treated. I won’t have to explain it all and repeat myself to different people. I’ll get the right painkillers, at the right time. And I’ll be in my own home, instead of sitting in pain in A&E. I’ll get the care I need, the way I want it. Sitting here, feeling strong today, I can’t tell you how reassuring that is.”

Mary is one of over 35,000 patients in London who now have CMC urgent care plans. Her story is one of many that shows how we can achieve patient-centred, integrated care. CMC demonstrates that, by using technology, training and extensive engagement with multiple partners, this can happen. Something that should reassure us all.

* Electronic Palliative Care Coordination System
Coordinate My Care (CMC): a service evaluation

Professor Julia Riley
Consultant in palliative medicine and clinical lead for Coordinate My Care

Professor Julia Riley is the clinical lead for Coordinate My Care (CMC), the pioneering clinical service that creates and implements urgent care plans in London. In addition to her role as clinical lead of CMC, she is also a Palliative Care Consultant, Royal Marsden & Royal Brompton Palliative Care Service and Visiting Professor, Palliative Medicine & End of Life Care in the Institute of Global Health Innovation at Imperial College, London. Professor Riley, who is editor of the European Journal of Palliative Care, discusses how information sharing is a critical component to end-of-life care.