coordinate my care
Urgent Care Plan

COORDINATE MY CARE REVIEW OF HOW DNACPR WERE USED DURING THE FIRST WAVE OF CORONAVIRUS PANDEMIC

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Introduction

In March 2020, as the Covid-19 pandemic started to rapidly grow across the UK, Care Quality Commission (CQC), British Medical Association (BMA), Care Provider Alliance (CPA), Royal College of General Practitioners (RCGP) sent a statement to adult social care providers and GP practices, with their shared position on the importance of advance care planning being based on the needs of the individual. "The importance of having a personalised care plan in place, especially for older people, people who are frail or have other serious conditions has never been more important than it is now during the Covid-19 pandemic."…"It is unacceptable for advance care plans, with or without Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need."[1]

Later, in October 2020, The Department of Health and Social Care asked the CQC to review how DNACPR decisions were used during the coronavirus pandemic, building on concerns that CQC reported earlier in the year.

Advance care planning, when administered routinely and early in patients' journeys, enables the patient to make informed decisions about how much treatment they would like to receive, as well as how, where and by whom they would like to be cared for during a crisis. DNACPR discussion can be part of this advance care planning and support patients in making an informed decision about what intervention they would like to receive in the event of cardiac or respiratory arrest, including refusing resuscitation.

Although the virus stopped a lot of 'normal activities', life went on. About 2 million people in England still had severe long-term conditions or were at the end of their lives. With the pandemic at play, they were required to 'shield' at home, in care homes or hospices. In many cases their conditions deteriorated rapidly with or without contracting Covid-19. There is no national system in place to alert urgent health care providers as to what underlying conditions those patients had, how their illness trajectory might change or how to care for patients who were already in the last stage of life due to long lasting illness (including but not limited to DNACPR).

In light of the current national reviews into the use of 'blanket' DNACPR, Coordinate My Care (CMC) conducted a review of its utilisation during this period.

About Coordinate My Care

CMC is an NHS service developed by NHS clinicians for NHS patients to support urgent and advanced care planning for frail, palliative and patients with complex and life-limiting conditions. It is currently commissioned only in London and Cornwall. The service **has been in operation for over 10 years** and it is (1) advocating the importance of routine advanced care planning, (2) gathering evidence around (a) improved patient outcomes, (b) impact of advance care planning on unnecessary hospital admissions and dying in hospital[2] (c) emotional benefits of early discussions with the patients and their loved ones[3], and (d) the wider economic benefits to the NHS[4]. The digital platform and the wraparound service has been designed to ensure

[1] https://www.cqc.org.uk/news/stories/joint-statement-advance-care-planning ;
https://www.cqc.org.uk/news/stories/cqc-review-use-dnacpr-during-pandemic
[2]https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0242914#:~:text=Compared%20to%20other%20observed%20characteristics,1.62%2C%20p%3C0.001
[3]https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf
[4] Frontier Economics, End-of-life care – CMC pilot cost analysis Final Report. June 2013
https://www.coordinatemycare.co.uk/publications_category/publications/

the best possible integrated care is available at times when it is most needed and that the clinical decisions are supported by high-quality patient-centred information available 24/7.

Patient Consent Model

CMC is the first standard, multidisciplinary digital care plan in the world that can be started (via www.mycmc.online) edited and viewed by patients and clinicians, allowing patients' wishes to be considered by everyone who will be responsible for their care. Most importantly, it embeds patient consent, vital clinical information about a patient's illness and medication, how and where the patient would like to be cared for, details of people to be contacted in an emergency and more. **CMC's consent model ensures that no decisions about a patient's treatment (including DNACPR) are made without the patient and where appropriate involving a loved one.** By its design, CMC cannot be applied on a blanket basis. The CMC service allows a full audit trail of discussions that took place and any subsequent changes in individual care plans. Full audit details can be viewed by the patient. This enables comprehensive reviews of the system wide utilisation of the service, even during the biggest health crisis.

Review

To date, over 125,000 CMC care plans have been created for London patients. All patients who have capacity, consent to having a CMC care plan. Furthermore, patients can withdraw their consent at any time. Overall, 725 care plans have been deleted from the system due to patients either changing their minds about having a CMC care plan or moving out of the CMC commissioned area.

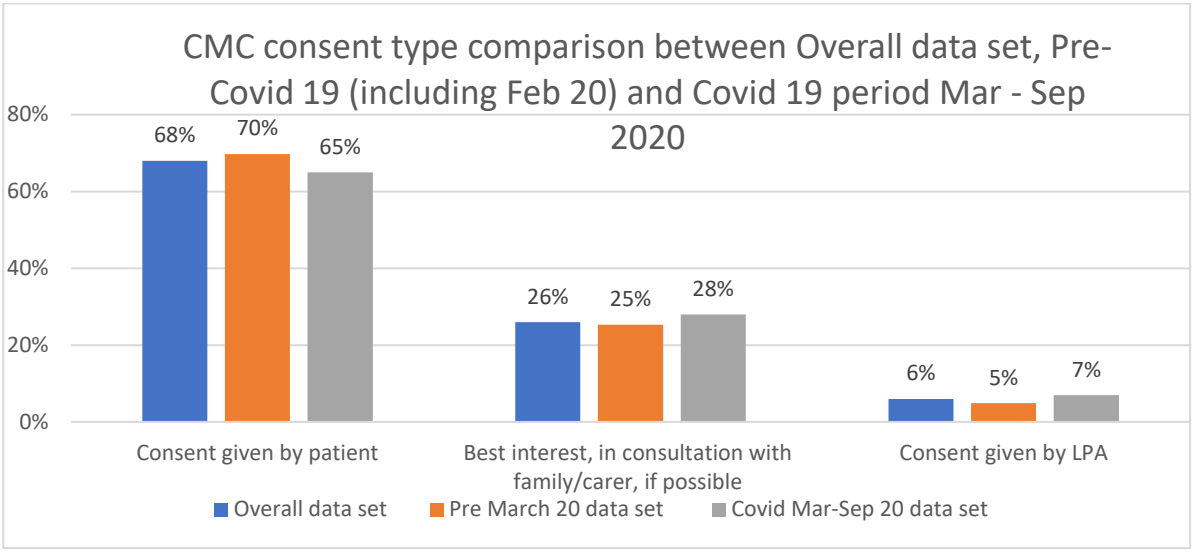
If a patient lacks the mental capacity to consent, the clinician, with the patient's loved ones or Lasting Power of Attorney (LPA) for health and wellbeing, can create a CMC plan in their best interest. If a plan is created in a patient's best interest, it is mandatory for the clinician to explain why this decision has been made. Examples of such explanations include: *'Patient has multi infarct dementia'; 'advanced dementia and severe frailty (CMC created in 2013); 'increasingly frail and has had a decline since her last hospital admission due to advancing dementia. Patient has clearly expressed her wish to have no life sustaining treatment in this situation.'; 'Details re Mental Capacity: A best interest decision has been made through consultation with Pt's siblings, residential home team, GP and Palliative Care team. Pt has indicated that she's happy to be looked after in her current RH.'; 'Details re Mental Capacity: Husband Mr XX has shared information to support a best interests decision'; 'Made in best interest of patient and in agreement with nephew Mr XX who has the POA'*.

We have reviewed 107,614 published CMC care plans to identify consent patterns, to establish the proportion of DNACPR decisions recorded between March and September 2020 and the percentage of DNACPRs where the patient had mental capacity to discuss and make an informed decision to refuse resuscitation.

Overall, 68% of CMC care plans were created with the direct consent from patients, 6% with the consent of an LPA and 26% in the best interest and provided clear justifications for such decisions, as outlined below *(Figure 1)*. Although we observed a significant increase in patients being added to CMC in the first wave of the Covid-19 pandemic, the consent pattern remained consistent with the pre-Covid and overall data sets.

In the period between March and September 2020, we observed 2 percentage point (pp) increase in consenting via LPAs and 3pp increase in best interest decision in agreement with the family.

Figure 1.



CPR decisions were added to 27,161 CMC care plans between March and September 2020. Records show that:

- 15,898 (59%) patients were recorded 'not for resuscitation' *(Figure 2)* with:
  - 8,327 (52%) of these recorded as having the mental capacity to discuss CPR decision (consistent with pre-Covid data); and
  - 5,908 (37%) as not having capacity to discuss *(Figure 3)*;
- there were 7,760 (29%) patients for resuscitation, which is more than the same decision in pre-Covid-19 data (18%); and
- 3,507 (13%) with CPR not yet discussed.
- During first wave of Covid-19, 90% of care plans show a clear yes/no CPR decision, compared to 88% Pre-Covid-19 (*Figure 4).*

Figure 2

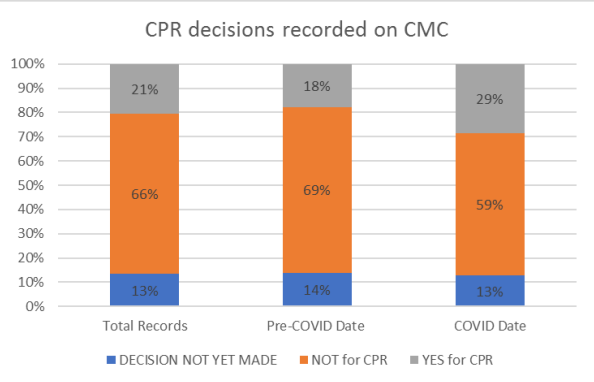
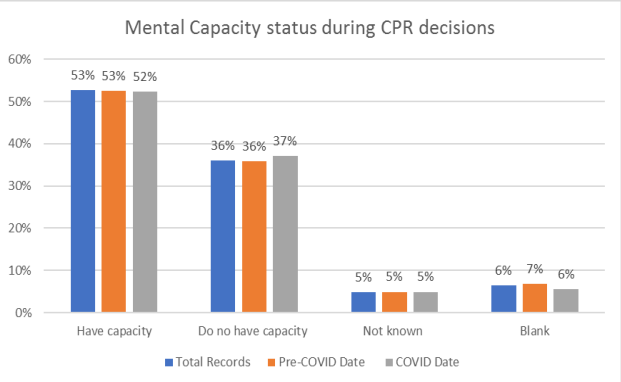


Figure 3



We also reviewed 5,908 CMC care plans which included DNACPR during the first wave of pandemic and where no mental capacity was indicated. All provide supporting information around the resuscitation discussion with Family/LPA, date and details. Examples below:

- *No Capacity to discuss CPR: CPR not successful due to frailty and comorbidities. End stage renal failure approaching end of life. Discussed with son.*
- *Discussed with daughter and wife (daughter had discussed with her brother- joint LPA)*
- *Metastatic lung cancer & co morbidities CPR unlikely to be successful. Discussed with [named] & daughters [named]*
- *Patient has expressed that she would not like CPR to be commenced, Has DNACPR in place since 2016. Review today. Best interest Discussion with LPA [named]*

- *Team unable to have discussion with patient due to patient having cognitive impairment and fluctuating alertness. Consent gained from next of kin [named], who is [named] son*
- *Abu has hep C advanced liver disease and HCC with lung metastases. Gradually deteriorating, end stage malignancy. Discussed with NOK nephew, [named]*
- *Due to significant cognitive impairment, lacks capacity to discuss this. Discussed with son [named]*

The revised data set includes three fields where Mental Capacity status was recorded. Namely: Have Capacity to Discuss (with options yes, no, don't know and blank); Mental Capacity (free text); Resus Decision Details (free text). For the purpose of this analysis we included only clear yes, no answers. Note that 'blank' and 'don't know' in the 'Have Capacity to discuss' data files accounts for the 10% of the care plans, compared to 12% pre-Covid-19, which can be a marker to suggest that CMC care creators were extra cautious. Mental capacity status can be elicited from two other data fields Mental Capacity (free text); Resus Decision Details (free text), but this would require a further manual manipulation of the raw data set and can be undertaken as a separate study.

Figure 4

		Have Capacity to Discuss					Percentages of Capacity indicated during CPR decision			
	Resus Decision		DK	N	Y	Grand Total	Yes or No	Have Capacity	No Capacity	Unknown
COVID Date		0				0				
	DECISION NOT YET MADE	3,503				3,503				
	NO	884	779	5,908	8,327	15,898	90%	52%	37%	10%
	YES	7,760				7,760				
Pre-COVID Date		14				14				
	DECISION NOT YET MADE	10,310				10,310				
	NO	3,476	2,520	18,463	27,068	51,527	88%	53%	36%	12%
	YES	13,288				13,288				
Total Record		14				14				
	DECISION NOT YET MADE	14,391				14,391				
	NO	4,558	3,443	25,623	37,511	71,135	89%	53%	36%	11%
	YES	22,074				22,074				

Conclusion

The pandemic fast-tracked the adoption of previously insurmountable changes within NHS and health care delivery, including a significant increase in CMC care plan creation for patients in London. Evidently, with the right systems in place, even during the crisis, the conversations about advance care planning (including DNACPR) took place and were recorded on CMC, by those health care providers who have fully integrated CMC.

Consent patterns pre- and during the Covid-19 pandemic and the review of CPR records showed that during March-September 2020 65% of CMCs were created with direct consent from the patient, 28% were best interest decisions and 7% of LPAs consented. 59% of patients were 'not for resuscitation', during the first wave of pandemic, compared to 69% in pre-Covid-19 data. The majority (8,327) were able to discuss and express their views (52% had capacity to discuss, 37% were not able to discuss and 10% not known). Where no capacity to discuss resuscitation was recorded, further evidence as to why such a decision was appropriate and the details of the patient's family and cares who were involved were also provided. A further analysis of the information about family discussions in the 'no capacity' cases could be undertaken. During first wave of Covid-19 90% of care plans show a clear yes/no CPR decision, compared to 88% pre-Covid-19 data set.

CMC has shown that embedding personalised advanced care planning into the standard health care practice enables bespoke patient-centred care, even during the pandemic. CMC is an NHS service tested and proven in London that can be rapidly scaled nationally. It is our duty to deliver benefits of urgent and advanced care planning to patients nationwide.