Foreword

The coronavirus pandemic has placed unprecedented pressure on health and care services, clinicians, professionals and workers. Together, they have worked to respond to the challenges that the pandemic has created, and to provide people with the care, treatment and support they need.

This support has included talking about whether people would want to receive cardiopulmonary resuscitation (CPR) if they stopped breathing or their heart stopped. At the beginning of the pandemic we heard concerns that decisions were being made without involving people or their families, and were being applied to groups of people, rather than taking into account each person's individual circumstances. We acted quickly to remind providers that such actions were unacceptable, and we welcomed the Secretary of State's request to look more widely at this issue.

Our review has set out to establish a picture of how 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were being made in the earlier stages of the pandemic – shining a light on what contributed to important conversations around end of life care being done well, and what may have led to them falling short. While it is not in our gift or the scope of our review to make judgements about what may or may not have contributed to specific deaths, it is important to understand the impact of not discussing DNCAPR decisions at an appropriate time as part of a holistic conversation about advance care planning.

What we have found through our review is a worrying picture of poor involvement, poor record keeping, and a lack of oversight and scrutiny of the decisions being made. Without these, we cannot be assured that decisions were, and are, being made on an individual basis, and in line with the person's wishes and human rights.

Our report highlights that more work is needed to support health and care clinicians, professionals and workers in holding conversations about DNACPR decisions as part of a holistic approach to advance care planning. More widely, it shows the need for a cultural shift to ensure that everyone feels supported to hold open and honest conversations about what they would like to happen at the end of their lives.

When done in the right way these conversations can be a positive experience for all involved. The outbreak of the pandemic has provided an opportunity for change. We need to capitalise on this momentum to ensure that conversations about advance care planning and DNACPR decisions are high on everyone's agenda.

Rosie Benneyworth

Chief Inspector of Primary Medical Services and Integrated Care

Summary

From the beginning of the COVID-19 pandemic, there were concerns that 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were being made without involving people, or their families and/or carers if so wished, and were being applied to groups of people, rather than taking into account each person's individual circumstances.

In October 2020, the Department for Health and Social Care commissioned CQC to conduct a special review into these concerns. Our review, which took place between November 2020 and January 2021, looked at how DNACPR decisions were made in the context of advance care planning, across all types of health and care sectors, including care homes, primary care and hospitals.

During our review, we heard about the experiences of over 750 people and about the distress that people face when they do not feel involved in decisions about their care. When done well, DNACPR decisions are an important aspect of advance care planning, and people should be fully involved in discussions about their care.

Our findings show that there needs to be a focus on three key areas:

1. Information, training and support

The quality of people's experiences is greatly impacted by having the time and information they need to talk about what care and support they want.

People's experiences of DNACPR decisions varied. We heard that some people felt they had been involved in the decision-making process, as part of a holistic conversation about their care. However, others felt that conversations around whether they would want to receive cardiopulmonary resuscitation (CPR) came out of the blue and that they were not given the time or information to fully understand what was happening or even what a DNACPR was. In some cases, people were not always aware that a DNACPR decision was in place. This could be hugely distressing for people and their families and/or carers.

It is concerning that some people across a range of equality groups, including older people, people with dementia and people with a learning disability, told us that they were not supported to the extent they needed to be in advance care planning conversations, or given the information they needed in an accessible way.

Every DNACPR decision must take account of each person's individual circumstances or wishes. While most providers we spoke with were unaware of DNACPR decisions being applied to groups of people, we heard evidence from people, their families and carers that there had been 'blanket' DNACPR decisions in place.

The training and support that staff received to hold these conversations was a key factor in whether they were held in a person-centred way, that met people's needs and protected their human rights.

If people and health and care staff are not fully informed about advance care planning, or given the opportunity and enabled to discuss DNACPR decisions in a person-centred way, there is a clear risk of inappropriate decision making and a risk

Recommendations

- **DNACPR decisions need to be recognised as part of wider conversations about advance care planning and end of life care, and these decisions need to be made in a safe way that protects people's human rights.** To do this, a new Ministerial Oversight Group must be set up to look in depth at the issues raised in our report. The group, which should include partners in health, social care, local government and voluntary and community services, should be responsible for overseeing the delivery and required changes of the recommendations of this report.

  Lead responsible body: Department of Health and Social Care

Information, training and support

- **People must always be at the centre of their care, including advance care planning and DNACPR decisions.** To do this, providers must ensure that people and/or their representatives are included in compassionate, caring conversations about DNACPR decisions as part of advance planning conversations. This includes making reasonable adjustments for disabled people to remove any information or communication barriers. Providers must also ensure that clinicians, professionals and workers have the necessary time to engage with people well.

  Lead responsible body: Providers

- **Everyone needs to have access to equal and non-discriminatory personalised support around DNACPR decisions, that supports their human rights.** To do this, health and social care systems must consider diversity, inequality and mental capacity factors when planning care for the local population, in partnership with local communities, including voluntary and community services.

  Lead responsible body: Integrated care systems

- **Clinicians, professionals and workers must have the knowledge, skills and confidence to speak with people about, and support them in, making DNACPR decisions.** To do this, there needs to be clear and consistent training, standards, guidance and tools for the current and future workforce. This needs to be in line with a national, unified approach to DNACPR decision making. Providers also need to ensure that there is training and development available for all health and care professionals.

  Lead responsible body: Health Education England, Skills for Care and providers

A consistent national approach to advance care planning

- **People, their families and representatives need to be supported, as partners in personalised care, to understand what good practice looks like for DNACPR decisions.** This should include what their rights are and how to challenge and navigate experiences well. In addition, there needs to be positive promotion of advance care planning and DNACPR decisions, as well as a more general focus on living and dying well. To do this, there needs to be more widely

publicised and accessible information available via a national campaign and in partnership with the voluntary sector and advocacy services.

Lead responsible body: Department of Health and Social Care and NHS England and NHS Improvement

- **People, their families and/or representatives, clinicians, professionals and workers need to be supported so that they all share the same understanding and expectations for DNACPR decisions.** To do this, system partners across health and care need to work with voluntary sector organisations, advocacy services and people to establish and assure a national unified approach to policy, guidance and tools that supports a positive experience of DNACPR decisions for people.

  Lead responsible body: Department of Health and Social Care

- **People need to have more positive and seamless experiences of care, including DNACPR decisions, when moving around the health and care system.** This requires the system to ensure digital compatibility between providers, enabling them to share real-time updates and information between professionals, services and sectors.

  Lead responsible body: NHSX and integrated care systems

Improved oversight and assurance:

- **There must be comprehensive records of conversations with, and decisions agreed with, people, their families and representatives that support them to move around the system well.** This requires providers to ensure standards of documentation and record keeping and sharing of information around the system.

  Lead responsible body: Providers

- **Integrated care systems need to be able to monitor and assure themselves of the quality and safety of DNACPR decisions.** To do this, there needs to be a consistent dataset and insight metrics across local areas.

  Lead responsible body: Integrated care systems

- **Health and social care providers must ensure that all workers understand how to speak up, feel confident to speak up and are supported and listened to when they speak up.** To do this, providers must follow national guidance to foster positive learning cultures and ensure consistency and clarity of speaking up arrangements across the patient pathway.

  Lead responsible body: National Guardian's Office

- **CQC must continue to seek assurance that people are at the centre of personalised, high-quality and safe experiences of DNACPR decisions, in a way that protects their human rights.** To do this, we will ensure a continued focus on DNACPR decisions through our monitoring, assessment and inspection of all health and adult social care providers.

  Lead responsible body: CQC