



Protect, respect, connect

Decisions about
living and dying well
during COVID-19



Our purpose

The Care Quality Commission is the independent regulator of health and adult social care in England.

We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

Our values

Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

Teamwork – learning from each other to be the best we can

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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.

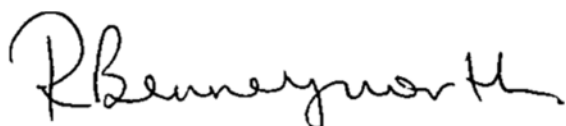
This support has included talking about whether people would want to receive cardiopulmonary resuscitation (CPR) if they stopped breathing or their heart stopped. At the beginning of the pandemic we heard concerns that decisions were being made without involving people or their families, and were being 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 DNACPR 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

of unsafe care or treatment. It also raises concerns that people's human rights and rights under the Equality Act 2010 had not been considered or were at risk of being breached.

2. A consistent national approach to advance care planning

There is a need for a consistent national approach to advance care planning and DNACPR decisions, and a consistent use of accessible language, communication and guidance to enable shared understanding and information sharing among commissioners, providers and the public.

Across all the areas that we looked at, there were many types of advance care planning in use. These included ReSPECT plans, local treatment escalation plans and DNACPR decisions.

Not only do these models use different approaches, but they also use different types of forms and documentation. This lack of consistency and the problems this causes could affect the quality of care received by the person, and result in missed opportunities to support them in the right way at the right time.

How health and care professionals talked about advance care planning and DNACPR decisions also varied. The huge number of acronyms and use of inaccessible language could be confusing and prevent people from being fully engaged in conversations around their care.

Every area we looked at had taken steps to make sure that services were aware of the importance of taking a person-centred approach to DNACPR decisions and advance care planning. However, we found that providers had to cope with a huge amount of guidance about all aspects of the pandemic that lacked clarity and changed rapidly, leading to confusion.

3. Improved oversight and assurance

There is an urgent need for regional health and care systems, including providers, clinical commissioning groups and patient representative bodies, to improve how they assure themselves that people are experiencing personalised, compassionate care in relation to DNACPR decisions.

Most providers and health and care professionals told us that people, their families, carers or advocates were involved in conversations about their care, including DNACPR decisions. But poor record keeping and lack of audits meant that we could not always be assured that people were being involved in conversations about DNACPR decisions, or that these were being made on individual assessments.

Once DNACPR decisions were in place, it varied whether providers and local systems reviewed them. We were also concerned about whether local areas had oversight of training and support for health and care professionals to ensure they were making sound clinical decisions that are person-centred and protect people's human rights.

Our 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/or 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*

Introduction

It is important for people to be able to talk about their care so that they have the chance to express their wishes about how they want to be treated if they become seriously ill or are approaching the end of their life. This should be done in full consultation with their family and/or carers, and health and care professionals so everyone is aware of how they wish to be treated and what matters most to them. This includes whether they would want to be resuscitated if their heart stops or they stop breathing.

Putting a 'do not attempt cardiopulmonary resuscitation' (DNACPR) decision in place is meant to be a positive, empowering act. When done well, it can help people to feel reassured that their wishes will be respected, and that they will be supported to experience a dignified and peaceful death.

At the beginning of the pandemic, there were concerns that DNACPR 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. There were particular concerns that this was affecting people with a learning disability and older people.

In October 2020, the Department for Health and Social Care commissioned CQC, under section 48 of the Health and Social Care Act 2008, to conduct a special review of DNACPR decisions taken during the COVID-19 pandemic.

Through our review we have looked at how DNACPR decisions were made, within the context of advance care planning, across all types of health and care sectors, including care homes, primary care and hospitals. We have also explored how DNACPR guidance was implemented.

We published an [interim report](#) in December 2020 that set out our progress up to that point and our expectations around DNACPR.

This final report sets out what we found through our review. We focus on the impact on people and their human rights, and we make recommendations for change.

Background

What is advance care planning?

Advance care planning provides people with an opportunity to think about what matters most to them and what level of care and treatment they wish to receive. These discussions can take place at any time, and may include details such as:

- where and how they would like to be cared for, for example at home or in a hospital, a nursing home, or a hospice
- how they want any religious or spiritual beliefs to be reflected in their care
- practical issues, for example who will look after their pets if they become ill
- what healthcare treatments they want, or do not want, as they near the end of their life

- who they want to be with near the end of their life.¹

As part of these conversations, there may be discussions about whether to attempt [cardiopulmonary resuscitation \(CPR\)](#) if their heart stops or they stop breathing.

Thinking and talking about dying can be a daunting prospect, and many people may find it overwhelming to think about what they want to happen at the end of their lives. But it is important for each person to talk about their thoughts and wishes with their family, loved ones, carers and professionals so they know how the person wishes to be treated. Thinking and talking about this as part of a holistic discussion about care can make this easier.

What is cardiopulmonary resuscitation?

CPR is an emergency procedure that aims to restart a person's heart if it stops beating or they stop breathing. It can involve chest compressions, delivery of high-voltage electric shocks across the chest, attempts to ventilate the lungs and injection of drugs.

CPR is an invasive and traumatic medical intervention and most CPR is unsuccessful. In most hospitals the average proportion of people who survive is about 15% to 20%; out of hospital the survival rate is lower, around 5% to 10%.² Due to the nature of the treatment, in some circumstances CPR can do more harm than good. In some cases, CPR can cause injuries such as punctured lungs, broken ribs and bruising.

In creating an advance care plan a person can tell their family, loved ones and healthcare professionals whether or not they would want to receive CPR. If they don't, they can express their wishes through a [DNACPR](#) decision.³

What are DNACPR decisions?

A DNACPR decision is an instruction to healthcare professionals involved in a person's care not to attempt CPR. DNACPR decisions are intended to be a positive intervention. They are designed to protect people from unnecessary suffering by receiving CPR that they don't want, that won't work or where the harm outweighs the benefits.

Every decision about whether or not a person should receive CPR must be made after careful assessment of each individual's situation. This should be done in consultation with the person and, if the person agrees, their family. It should never be applied to groups of people (known as 'blanket' DNACPR decisions).

DNACPR decisions are based on clinical judgement and must be signed off by the most senior clinician responsible for a person's care, as defined by local policy. However, the law is clear that these decisions should be made with the person

¹ <https://www.nhs.uk/conditions/end-of-life-care/advance-statement/>

² British Medical Association, Resuscitation Council (UK) and Royal College of Nursing, [Decisions relating to cardiopulmonary resuscitation](#), 2016

³ DNACPRs are also known as DNARs (do not attempt resuscitation) but for the purposes of this report we use DNACPR.

wherever possible.⁴ If people are able to make decisions around their care, and do not wish to receive CPR, they can make an advance decision to refuse CPR.

Decisions about CPR must be free from any discrimination, for example in respect of a disability, and not based on a professional's subjective view of a person's quality of life. Where people do not have the capacity to give their views about whether they would want CPR, then the views of their family or their chosen representatives must be taken into account, unless there are convincing reasons why this cannot happen, (for example an emergency situation where relatives cannot be contacted).⁵ Each decision is unique and is to be guided by the quality of future life that the person themselves would regard as acceptable. It should provide reassurance to the family that their loved ones' wishes will be respected.

A DNACPR decision only relates to CPR. It does not mean that other care and treatment would be stopped or not provided. A DNACPR decision must not be allowed to compromise high-quality delivery of any other aspect of care.

Advance care planning with ReSPECT

[ReSPECT](#) is a good example of an advance care planning process that, when done well, can support everyone to make decisions around their future care and treatment. A type of treatment escalation plan, ReSPECT helps to focus conversations around people's wishes and preferences. It is designed to help people make personalised recommendations for their clinical care and treatment in a future emergency, when they may not be able to make or express their choices. This can include whether or not to be taken to hospital, whether or not to be admitted to critical care or placed on a ventilator.

These recommendations are created through conversations between a person and their family, loved ones and health and care professionals, so everyone understands what matters to the person and what is realistic in terms of their care and treatment. As part of these conversations, there may be discussions about whether to attempt CPR if their heart stops or they stop breathing.

People's preferences and the recommendations of their healthcare team, including any decisions around whether or not they should receive CPR, are recorded on a non-legally binding form. People can keep this form, and review and adapt it if circumstances change.

First introduced by the Resuscitation Council in 2016, the ReSPECT process and form has been adopted by a number of health and social care organisations across England. The aim is to encourage health and care professionals to break down the barriers and to hold open and honest conversations with the people they care for about their wishes for care and treatment in an emergency.

⁴ Tracey v Cambridge University Hospital NHS Foundation Trust

⁵ Winspear v City Hospital Sunderland NHS Foundation Trust

Human rights, equality and DNACPR decisions

Putting in place blanket DNACPR decisions, not discussing with people whether or not they want CPR to be attempted, and people not understanding when a DNACPR decision is in place, are all human rights issues and need to be recognised as such.

Article 2 of the European Convention on Human Rights protects people's right to life. Under Article 2, public authorities have positive obligations to protect life, including "a duty to prevent avoidable deaths."⁶

Though clinicians can make DNACPR decisions, if these decisions are made in ways that do not protect people's rights to life, it is possible that this may be a breach of Article 2. This may happen, for example, by putting a DNACPR decision in place without the knowledge of the person and/or those close to them and then failing to provide CPR should the person's heart stop beating. Not consulting with the person or their representatives when making a DNACPR decision also risks breaching Article 8 of the of the European Convention on Human Rights, which protects their right to respect for their private and family life.

All DNACPR decisions must be made on an individual basis according to need. Applying 'blanket' DNACPR decisions to groups of people in particular equality groups, such as people with a learning disability or older people, whether or not a DNACPR form has been completed, is potentially discriminatory and unlawful.

If DNACPR decisions are made based on assumptions about people who are disabled or an older person, this could also breach Article 14 of the European Convention on Human Rights – the right not to be discriminated against in connection with other human rights.

Poor DNACPR decisions that put people's human rights at risk have long been an issue in England. This has been a particular concern in relation to people who are disabled (including people with physical disability and people with a learning disability) and/or older people.⁷

The December 2020 Women and Equalities Select Committee discussed concerns about inappropriate use of DNACPR decisions in the early part of the pandemic. It looked at the impact of these on people's ability to access life-saving treatment for COVID-19, particularly for older people and people with a learning disability in social care settings and hospitals.⁸ While action was taken to address this, the committee found that there were concerns that DNACPR decisions had potentially been used in a discriminatory way. It also found that this showed a concerning disregard for disabled people.

Also in December 2020, the British Institute of Human Rights (BIHR) published initial findings of their work looking at the human rights implications of COVID-19. Like the Women and Equalities Select Committee, the report highlighted concerns around DNACPR practices during the early stages of the pandemic, particularly in relation to older people and people with disabilities. It highlighted evidence that pressures on the health and care providers had potentially led to blanket DNACPR decisions being

⁶ www.equalityhumanrights.com/en/human-rights-act/article-2-right-life

⁷ BIHR report: [Scared, Angry, Discriminatory, Out of My Control: DNAR Decision-making in 2020](#)

⁸ Women and Equalities Select Committee report: [Unequal impact? Coronavirus, disability and access to services](#)

issued for people with a learning disability, or DNACPR notices being issued without proper consultation.⁹

Coronavirus (COVID-19) pandemic and concerns around DNACPR decisions

At the beginning of the pandemic we were concerned that a combination of unprecedented pressure on care providers, confusion around guidance, and miscommunication may have led to DNACPR decisions being incorrectly conflated with other clinical assessments around critical care. This included concerns that inappropriate or blanket DNACPR decisions were being issued.

Together with the British Medical Association, Care Provider Alliance and Royal College of General Practitioners, we wrote to adult social care providers and GP practices on 30 March 2020. This statement reminded all providers that it was unacceptable for advance care plans, with or without a completed DNACPR form, to be applied to groups of people of any description. NHS England then wrote to all NHS trusts, clinical commissioning groups, GP practices, primary care networks and community health providers on 7 April to reiterate this.

Some people we spoke with during our review highlighted that, where there were concerns that inappropriate or blanket DNACPR decisions were in place, people and their families felt unable to challenge the issue or were unaware that it was inappropriate. We also heard that people working in adult social care settings felt overwhelmed, overloaded and unsupported in raising concerns. In many cases it was not clear who to raise concerns with. Some people told us that care providers had challenged blanket DNACPR decisions, but they felt no one was listening.

Concerns around DNACPR decisions are not new. Before the outbreak of COVID-19 there had been concerns about aspects of DNACPR decisions. These concerns revolved around ensuring that:

- The senior clinician responsible has made the decision in consultation with the person and in line with the Mental Capacity Act 2005.
- The decision is based on clinical judgement, is free from any discrimination, in line with the Equality Act 2010 and Human Rights 1998, and is not based on a subjective view of a person's quality of life.
- The decision has been communicated in a way that is accessible and meets people's needs.
- Professionals have the time, support and training to be able to have the sensitive and ongoing conversations needed to take people's preferences into account.
- People's legal rights are understood by the public and by care workers.

⁹ BIHR report: [Scared, Angry, Discriminatory, Out of My Control: DNAR Decision-making in 2020](#)

How we carried out our review

An overview of how we carried out the review is set out below. The [appendix](#) has full details.

Our review focused on three areas:

- **People at the centre:** How are providers and systems putting people at the centre of their care in approaches to DNACPR decisions to protect human rights, protect people from discrimination and meet people's individual needs? What have people's experiences been since the start of the pandemic?
- **Shared vision, values, governance and leadership:** How have providers and the health and care system worked in partnership to influence and agree a shared approach for the use of DNACPR decisions that protects human rights, gives equal access to care and treatment and prevents avoidable deaths? What are the enablers and barriers for the appropriate use of DNACPR decisions?
- **Workforce capacity and capability:** How do providers and the system work together to ensure that clinicians, professionals and workers involved in the use of DNACPR decisions have the right knowledge, skills and tools to deliver personalised approaches to DNACPR decisions in line with the relevant legislation, and how are staff and people supported to raise concerns in order to improve care?

We used the following methods:

- A review of existing literature, guidance and evidence to understand what was already known about the use of DNACPR decisions before the pandemic and what impact they have had on people's experiences during the pandemic.
- Initial conversations with nearly 50 stakeholders who have a specific interest in the scope of the review. These included organisations that represent or advocate on behalf of the public and family, carers, care providers, and care professionals.
- A voluntary information request sent to around 25,000 adult social care providers. While responsibility for making DNACPR decisions does not predominantly rest with adult social care providers, we asked them a range of questions to understand their views of the experiences of people in these settings. We analysed 2,048 responses, which were received from 7 December 2020 to 21 December 2020. The relatively low response rate affects our confidence in the findings and means the results may not be generalisable. However, it is important to record and share the experiences of people working in services.
- With the support of voluntary sector partners we ran several public surveys to ask people who use services and their families and carers about their experiences of DNACPR decisions during the pandemic. We analysed 613 responses, which is not representative of all the cases of people across the country. However, it does allow us to capture the lived experiences of those who have had a DNACPR decision, or their families/carers.
- We carried out fieldwork to explore how primary, secondary, social care and system partners worked together in seven clinical commissioning group (CCG) areas. These were chosen to cover a cross-section of geographical areas and a mix of demographics. However, the findings are not necessarily representative, but instead they explore individual experiences. In the fieldwork we:

- Carried out an in-depth review of the experiences of seven people – reviewing the relevant care records and, wherever possible, speaking to the person experiencing care and their families, and a range of relevant health and care professionals.
- Reviewed the DNACPR records of 166 people who have been affected since the pandemic. These did not consider every example of DNACPR decisions since the pandemic, but allowed us to consider a larger number of decisions.
- Held 156 interviews and focus groups with clinicians, professionals and workers from different roles and organisations involved in providing care.
- Spoke to commissioners and system leaders to explore practice across the system, collaboration and how oversight arrangements ensure best practice in DNACPR decisions.
- Spoke to local advocacy organisations that have engaged with the public and providers over the use of DNACPR decisions to share our emerging findings and ask for feedback on these, and thoughts on recommendations.

Action we took

As a result of concerns found during our fieldwork, we carried out two focused inspections and made recommendations for improvement.

For concerns raised through our information request to adult social care providers we passed this information on to inspectors who contacted the providers to find out if action had been taken. If particular concerns about quality or safety were raised through these conversations, we:

- Checked if the provider raised their concerns with the relevant medical professionals involved in signing the DNACPR decision, and advised them that they needed to do this if not.
- Considered whether the provider had breached CQC's regulations.
- Will take appropriate action where breaches in CQC's regulations are found.

People at the centre

Key points

- The increased pressure on staff time and resource due to the pandemic meant that conversations about people's care were often taking place at a much faster pace in busier settings. This had an impact on DNACPR decisions, including how well families and people were involved, which could risk breaching their human rights.
- Generally, people were involved in decision making but there was evidence that they were not always supported or given the right information to have meaningful conversations to ensure they understood the outcome of any conversation. This risked breaching their human rights.
- While most providers we spoke with were unaware of inappropriate DNACPR decisions or 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.
- 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.
- There was a general lack of awareness and confidence among people, families and care workers about what a DNACPR decision meant, and how to challenge this.

When done well, DNACPR decisions are made with full involvement of the person, their family and/or carer, and take account of people's individual needs and circumstances.

It is important that any conversations around DNACPR decisions and advance care planning are carried out with kindness and compassion, in line with best practice and people's human rights. People and their families must be fully involved and listened to, and their wishes considered in any decisions made about their care.

Restrictions introduced in response to the coronavirus pandemic have created additional challenges for health and care professionals in holding these conversations.

We have seen some examples of providers and systems adapting, and continuing to ensure that people and their families or carers were at the heart of any conversations about their care. We have also found evidence where people have not been involved as they should have been, with a huge impact on them and their families and loved ones.

This is reflected in the very different experiences of Jonah and Jim and their families:

Jonah's story

Max (Jonah's brother) told us about his brother's experience of care at the end of his life. Jonah, who was in his late 50s, had been left with a disability and memory loss following a car accident when he was a teenager. This left him unable to make decisions for himself, so Max had lasting power of attorney to make health and welfare decisions on his behalf.

Jonah had been cared for in a nursing home for the last 20 years as his condition had deteriorated, and he was very well known to the service. Max described the service as being like family.

In March 2020, Jonah developed flu like symptoms with a fever. Three days later he developed a cough so the nursing team contacted an out-of-hours GP for advice. Jonah was reviewed by the GP, and as he was stable the doctor decided that he should stay at the home.

However, because of his deteriorating condition, and in light of the pandemic, it was felt that advance care planning would be appropriate. The GP contacted Max to discuss Jonah's condition, any escalation of treatment and make an advance care plan. They agreed that escalation of treatment would not be in Jonah's best interest. Max's opinions were recorded and a DNACPR decision made.

Jonah died soon after the DNACPR decision was made. Max told us that he had experienced a peaceful death and appropriate care was given whenever it was needed.

Jim's story

As part of our review, we spoke with Melanie about her father's experience of care and involvement in his DNACPR decision.

Jim, who was in his 80s, was taken to hospital at the beginning of the pandemic after becoming unwell with a chest infection. Jim, who still worked, had normally been fit, well and active and went out most weeks in his car to visit friends or go to the cinema.

About 12 hours after being admitted to hospital Jim called Melanie. He was upset and confused, and told her he had signed away his life and was going to die. He told her that a doctor had put an order in place that they wouldn't restart his heart if it stopped. He was upset that he had agreed to it because he didn't want to die.

Melanie told us that she tried to speak to the medical and nursing staff about this decision. She felt that the conversations were all one way and no one asked about her dad, about what he was like and what his life was like at home. Because Jim was able to make decisions about his care, no one had discussed the decision with her. However, she was concerned that her dad was vulnerable because he was ill, likely to be confused as he had a bad infection, and he was all alone. She felt he would have just gone with what they told him.

Jim died while in hospital. Not being allowed to visit because of the pandemic, and the way in which the DNACPR was applied, made his death even more distressing for Melanie and her family.

The challenges caused by the pandemic

Restrictions on visiting introduced because of the pandemic created challenges in holding conversations about advance care planning, including DNACPR decisions, in some health and care settings. It also hindered the ability of people's families, carers and advocates to support them or challenge a DNACPR decision if this was needed.

"My relative whilst elderly and infirm, was judged to be able to make the decision during conversations with doctors whilst in a hospital setting. As I was unable to see them due to COVID restrictions, I was concerned that they did not fully understand the ramifications."

Respondent to our public survey

DNACPR discussions should take place as part of a holistic conversation about advance care planning, and can take place in a variety of health and care settings. Among the 613 people who responded to our public survey, just under half (49%, 298) said the DNACPR was applied in a hospital setting; 31% (189) said that it was applied following a discussion with their GP over the phone; and just over a quarter (28%, 172) said it was applied while living in a care home or in supported living accommodation.

Some providers went to substantial lengths to continue to involve people, carers, family or advocates in discussions about their care. For example, at one acute hospital, during the earlier part of the pandemic, staff and medical students who were freed up from their usual roles helped to staff a contact centre for relatives of patients in critical care wards. As family and friends were not allowed to visit, this created a way to hold important conversations.

One acute hospital continued to allow one person to accompany people with a learning disability or anyone who was vulnerable into hospital. Another hospital continued to allow families to use the relatives' room if appropriate, to have conversations face-to-face.

Due to the pandemic and the increased pressure on staff time, some professionals we spoke with felt conversations were often taking place at a much faster pace in busier settings. This led to concerns about how meaningful these conversations were, and that some people had or may have been rushed into making DNACPR decisions, or decisions about advance care planning in general, since the start of the pandemic.

Through engagement with our expert advisory group and advocates we heard that relatives often felt these conversations came out of the blue, and would be much less distressing if they were not held at the time of an emergency. We also heard that the huge number of acronyms and use of inaccessible language could be confusing and prevent people from being fully engaged in conversations around their care.

Where providers or systems were using models to guide conversations with people and their families or carers, for example ReSPECT and Coordinate my Care, people tended to have better information to make these decisions. These often happened well in advance of any urgent care, and gave people the time to consider what treatment options were available to them.

Where health and care services were using the same model of care across an area, people experienced a more seamless pathway of care. For example, in one area,

there had been an increase in contact from a specialist group of district nurses set up to support adult social care providers. The community nurses were helping to ensure that ReSPECT forms and 'suitable care plans' were in place for people.

With the restrictions in place during the pandemic, health and care professionals often sought to support people to have conversations about their care using remote and digital technology. However, this was not always accessible for everyone – see section on ['Remote consultation and the use of digital technology'](#) for more on this.

It is worth noting that the National Institute for Health and Care Excellence (NICE) are developing a new guideline on how to make shared decision making part of everyday care in all settings. The guide will promote ways for health and care professionals and people using services to work together to make decisions about treatment and care.

People's involvement in DNACPR decisions

Everyone has the right to be treated as a partner in their care and to be able to express their wishes about what care and treatment they want to receive.

We found that people and those close to them had mixed experiences of how well they were involved, and supported to be involved, in conversations about their care. This included whether or not they had enough information about, and understood, the implications of what a DNACPR decision means as part of advance care planning.

Health and social care professionals we spoke with said that most of the time the person, their families, carers or advocates were treated as partners in their care and DNACPR decisions.

"The [DNACPR] was put in place at the request of my care client after a chat with the district nurse. My client felt the whole subject was conducted in a frank but compassionate manner that reassured her that her wishes would be respected. As part of her care team we all know she has this in place and it is reassuring for us too to know what we should do to give her the end of life care she wants."

Respondent to our public survey

This was supported by the findings from our public survey, which showed that 71% (49 out of 69) of individuals with a DNACPR decision in place said they felt completely or mostly supported to participate in a conversation about their DNACPR decision, and that 70% (48 out of 69) of them felt completely or mostly listened to and able to speak up. However, when the survey was completed by the relative or carer responding on behalf of the individual with a DNACPR decision, only 48% (263 out of 544) felt that the person was completely or mostly supported to participate in a conversation and 58% (315 out of 544) of the relatives or carers themselves felt completely or mostly listened to and able to speak up.

However, most areas we looked at were not monitoring DNACPR decisions. This meant that there was not enough evidence available to assure us that people were always being properly involved in conversations about their care or DNACPR decisions. In addition, the results of our public survey raised specific concerns that people from particular equality groups were not fully involved in their care. For example, while 73% (30 out of 41) of people aged 65 and over, 81% (17 out of 21) of people who lacked capacity and 78% (18 out of 23) of people with dementia felt

completely or mostly supported to participate in a conversation about DNACPR decisions, relatives and carers reported only 44% (142 out of 325), 44% (66 out of 149) and 50% (96 out of 193) on behalf of these groups respectively.

Our public survey also showed that only 65% (45 out of 69) of individuals with a DNACPR decision in place and 52% (285 out of 544) of relatives or carers felt that their loved one was given enough information about the DNACPR decision. These results are similar to the findings of our reviews of care records – only 42% (65 out of 156) of the records we looked at showed that people had been given enough information in an accessible way, where recorded.

When conversations took place, we were concerned about whether people were being given the right information in a way that they understood, and that they were given enough time to make properly informed decisions.

“The DNACPR was not provided in an accessible format and was not understood by the patient who thought it was a consent form to donate her organs if she were to die. The patient is dual sensory impaired.”

Respondent to our public survey

Some clinical commissioning groups (CCGs) had tried to focus on providing information on the DNACPR process in an accessible format, and support families, GPs and care homes to have advance planning conversations. Health and social care professionals told us that most people had enough time and information to make an informed decision, but it was difficult to be fully assured as we also heard about many examples where this was not the case.

Poor record keeping about DNACPR decisions also meant that we could not always be assured that people, their families, carers or advocates were being adequately involved. For example, in our review of people’s care records we found that 51% (85 out of 166) of DNACPR decisions had been made as a standalone decision – that is, not part of a conversation about advance care planning. Providers and health and care professionals need to ensure that conversations around DNACPR decisions are held as part of a wider conversation about advance care planning. They also need to make sure that DNACPR decisions are not being used in a potentially discriminatory way for people, such as people with a learning disability, who are not near the end of their lives.

Furthermore, we heard that some people had been discharged from hospital with a DNACPR decision that they or their families were not aware of, or that families had been pressured into agreeing to these decisions.

“I only found out about the [DNACPR] when they were discharged from hospital; no-one had mentioned it to me before nor to the person concerned. It was a tremendous shock.”

Respondent to our public survey

“The first we knew about it was a letter from the hospital after my father had been discharged. No conversation was had with us or my father.”

Respondent to our public survey

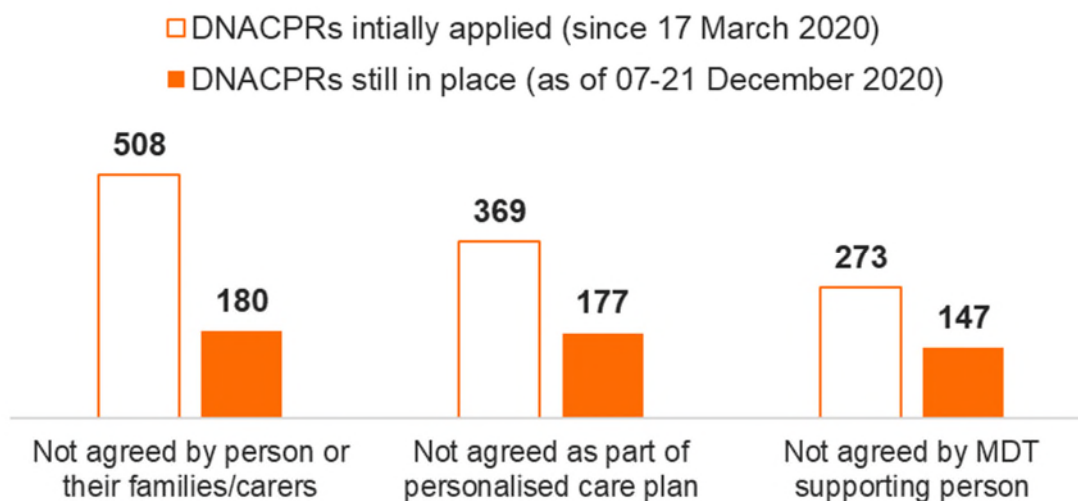
“I felt pressured to accept the decision of the doctors as they illustrated a terrible picture (i.e. immense suffering of the person) if I did not.”

Respondent to our public survey

This is supported by the results from our public survey which found that 30% (21 out of 69) of individuals with a DNACPR in place and 28% (150 out of 544) of relatives or carers said they were not aware that the DNACPR had been applied.

Indeed, the 2,048 adult social care providers who responded to our information request said that 5.2% (508 out of 9,679) of DNACPR decisions put in place since 17 March 2020 had not been agreed in discussion with the person, their relative or carer. While many of these decisions made during the COVID-19 pandemic had been reviewed in response to national messaging and support, our information request also showed that around a third (180 out of 508) were still in place at the point of our information request (7 December to 21 December 2020). Overall 3.8% (369 out of 9,679) of DNACPR decisions put in place since 17 March 2020 had not been considered as part of a personalised care plan, of which almost half were still in place (48%, 177 out of 369) (figure 1).

Figure 1: The number of inappropriate DNACPR decisions reported by adult social care locations that responded to our information request



As a result, people were potentially being denied the opportunity to discuss their DNACPR decisions, advance care plans, and end of life care needs and wishes. This presented a risk of inappropriate decision making and a risk of unsafe care or treatment.

These figures also raise serious concerns that individuals' human rights – to be involved in DNACPR decisions about themselves or their families – were potentially being breached in more than 500 cases across the adult social care services that responded to our information request. As the majority of people receiving care in adult social care locations are disabled people, including older disabled people, these figures raise concerns about whether the providers making these decisions were at risk of breaching the Equality Act 2010.

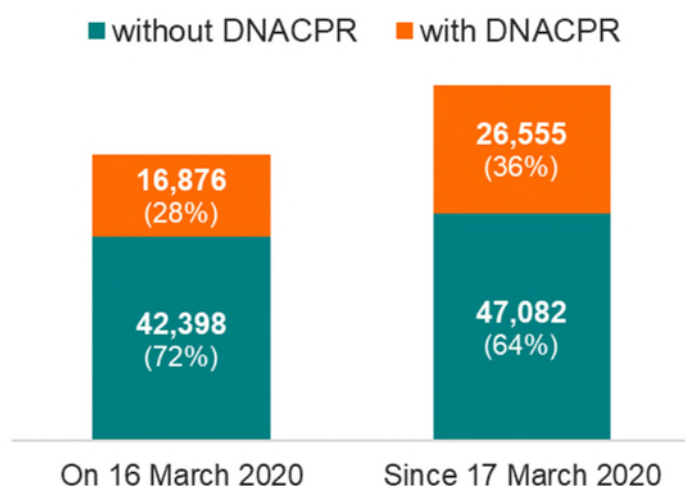
Use of blanket DNACPR decisions

Applying a DNACPR decision to groups of people of any description (known as 'blanket' DNACPR decisions), is potentially discriminatory and unlawful under the Equality Act 2010. People's rights may also be at risk where individuals are not properly informed or involved in conversations about putting a DNACPR decision in place, or where decisions are not reviewed in a timely way.

At the start of the pandemic, there were concerns that a combination of unprecedented pressure on care providers, confusion around guidance, and miscommunication may have led to blanket DNACPR decisions being made, or DNACPR decisions that were inappropriate – that is concerns they were being applied to groups of people or made for an invalid reason such as being frail.

Figures from our information request to adult social care providers appear to suggest that the total number of DNACPR decisions increased. Respondents said that, at 16 March 2020, 28% (16,876 out of 59,274) of people in their adult social care settings had a DNACPR decision in place; this increased to 36% (26,555 out of 73,637) in the period between 17 March and December 2020 (figure 2). For nursing homes, this increase was larger, with the percentage of people with a DNACPR decision increasing from 74% (7,009 out of 9,434) on 16 March to 92% (10,647 out of 11,539) from 17 March onwards.

Figure 2: People with a DNACPR decision in place, in the adult social care settings that responded to our information request (7 to 21 December 2020)



Health and social care professionals told us in our fieldwork that they had not seen any guidance issued to suggest that DNACPR numbers needed to increase or that blanket DNACPR decisions should be put in place. At an organisational level, providers (including acute hospitals, mental healthcare trusts, community services, primary medical services, and adult social care providers) largely told us that they were unaware of the blanket and/or inappropriate use of DNACPR decisions. In addition, one CCG area we looked at had introduced an area-wide policy that there should be no blanket restrictions in either community or acute settings.

However, there were concerns raised about DNACPR decisions in the very early days of the first lockdown. This led the British Medical Association, Care Provider Alliance, Royal College of General Practitioners, CQC and NHS England to jointly remind all providers and CCGs that it was unacceptable for advance care plans, with or without a completed DNACPR form, to be applied to groups of people of any description.

As part of our review, we heard evidence from a variety of people we spoke with that there had been blanket DNACPR decisions in place. This was supported by the meeting we held with advocacy groups. For example, one person told us:

“There was a letter informing of a blanket ban from the clinical commissioning group that COVID-positive people with a learning disability couldn’t be sent to hospital should be cared for at home – this was discriminatory and involved no individual care decisions. Following action, the letter was overturned.”

Advocacy focus group

While responsibility for making DNACPR decisions does not predominantly rest with adult social care providers, it is worrying that 119 (6%) of the 2,048 adult social care services that responded to our information request felt that people in their care had been subject to blanket DNACPR decisions, at any time since 17 March 2020.

During our fieldwork, we were told that there were some blanket DNACPR decisions imposed but quickly revoked, and some were considered but not initiated after discussions with the CCG. For example, in one area we looked at, a GP had sent out letters to care homes for people with a learning disability about putting blanket DNACPR decisions in place, but these letters were retracted following discussions with the CCG.

We also heard from Healthwatch that, at the beginning of the pandemic, many care homes did not have the capacity to consider whether DNACPR decisions had been made appropriately and based on individual needs, as they faced many challenges such as shortages of personal protective equipment (PPE), food and staffing. This suggests that some inappropriate DNACPR decisions could have gone unnoticed. For example, Healthwatch told us about one care home where, at the beginning of the pandemic, everyone over 80 with dementia had a DNACPR applied. Initially the care home had not recognised that was inappropriate and not person-centred, but this was raised with them and addressed.

Lack of clarity on the numbers of DNACPR decisions in place, and lack of data about DNACPR decisions for people in some equality groups, such as people with a learning disability, illustrates the need for better oversight of DNACPR decisions so that local areas can monitor any significant increase or decrease in DNACPR decisions and the reasons why, and ensure that people’s rights are protected.

Equality, the Mental Capacity Act and best interest decisions

Everyone should be involved in decisions about their care, with due regard for their equality characteristics. This is essential to making sure that they are treated equally and feel valued, that they, their family, carer or advocate do not feel coerced into making a major decision, and that their human rights are upheld.

There should be no discrimination in decision making. For example, a disabled person who is not terminally ill should not be treated as being at the end of their life.

Someone with a learning disability and other health conditions should not be assumed to have a poor quality of life. In addition, under the Equality Act 2010, providers are legally required to make reasonable adjustments for disabled people. This includes removing any information and communication barriers, so that people can take part in these important conversations.

Our public survey (613 respondents) showed a varying picture of how well people in different equality groups were involved in their care. Respondents included both people with a DNACPR decision (69), and relatives or carers answering on their behalf (544.) Of the respondents with a DNACPR decision, people who lacked capacity, autistic people and people with a physical disability were more likely to feel involved in a conversation about their medical treatment once the DNACPR had been applied. People with a hidden disability or disabling health issue felt least involved. Relatives and carers responding on behalf of individuals said that autistic people, people with a learning disability and people from a Black and minority ethnic background were most likely to feel involved, but people who lacked capacity were least likely to feel involved.

We heard examples of providers making positive changes during the pandemic to help people in particular equality groups, such as people with a learning disability, to make appropriate care decisions. At one trust, senior clinicians were 'placed at the front door' to see people on admission and identify who needed additional support in a timely way. Specialist learning disability nurses were also stationed in urgent and emergency care departments.

In another area we reviewed, support was available from specialist nursing teams in hospitals – for example every inpatient with a learning disability was referred to the specialist nurse on admission to support them in their care. The CCG's website also had information about advance care planning in accessible formats.

We saw some good examples of how clinicians took a person-centred approach to care planning for people who were unable to make advance care decisions for themselves. In one area we heard about an example of a best interests assessment that was done well. This involved the person's parents, the healthcare professionals and the care workers who cared for them. Together they discussed what the person's advance care plan should look like, including the ceiling of treatment the person should receive. (A ceiling of treatment is considered to be the highest level of intervention the medical team decides is appropriate, which is in line with the patient's and family's wishes, values and beliefs). The healthcare professionals gave their contact details to the care workers so they could be contacted if they needed support and to get advice if the ceiling of care was reached.

However, in other areas we had concerns around whether people's capacity had been fully considered by the clinician when making decisions about their care. This is supported by our review of care records. Out of the 166 care records we reviewed, 103 showed evidence of a best interests assessment being required. Of these, only 32% (33 out of 103) showed that an assessment had been carried out where appropriate. The remaining 63 care records did not record whether an assessment had been carried out or not, which may be because the person did not need a best interests decision.

In our public survey, only 70% (48 out of 69) of individuals with a DNACPR decision felt that their best interests and capacity were completely or mostly considered. Fifty

seven per cent (308 out of 544) of relatives or carers felt that the person's best interests and capacity had been completely or mostly taken into consideration. For people with a learning disability and autistic people the corresponding figures were 76% (16 out of 21) and 94% (17 out of 18) for individuals respectively; and 70% (69 out of 98) and 81% (57 out of 70) for relatives or carers answering on behalf of individuals.

Susan's story

During our review, we heard about Susan's experiences of having a DNACPR put in place while being cared for in hospital.

Susan, who was in her 60s, had a learning disability and a physical disability, and was not able to make decisions for herself. She was admitted to hospital in an emergency with suspected COVID-19 from her care home. While in hospital, staff carried out the appropriate capacity assessments under the Mental Capacity Act (MCA). These confirmed that she was not able to make decisions about her care and treatment. A DNACPR decision was also applied for a seven-day period.

The records we looked at showed that this had been discussed with Susan's next of kin. However, her relatives told us they wanted some time to have a wider discussion with their family and they would get back to the hospital the following day. When the family called back the next day they were told the DNACPR decision had been imposed by the clinician anyway. Susan's health improved and she was discharged home after seven days. The DNACPR decision expired.

A short time later, Susan became ill again and she was readmitted to hospital. Again, the hospital carried out assessments under the MCA. However, this time the records showed that the time period for the DNACPR was indefinite. It was also unclear what level of discussion had taken place with her family.

When we spoke to Susan's family they told us that they were aware a DNACPR decision had been made while Susan was in hospital, but they were not aware that this was an indefinite decision. They told us that the communication could have been better. While the nurse had asked them about the DNACPR decision, they had not been provided with any information to help them better understand the process.

This highlights the importance of communication, and people their families, carers or advocates being partners in care. It also illustrates how important it is to regularly review these decisions and the need to respond to any concerns raised.

A lack of understanding about caring for people with a learning disability and assumptions about people's quality of life were key barriers to involving them appropriately.

One professional informed us that they had found frailty assessments had not been used holistically for children with a learning disability and assumptions had been made about people's quality of life. The child and/or their family had not always been involved in the discussions.

Conversations and people's involvement were better when liaison nurses for people with a learning disability were involved and/or the community learning disability team were able to act as a link between the hospital and the care home.

However, in some cases we were concerned about the training for clinicians, professionals and workers leading these conversations. This included whether they had the right knowledge and skills around the Mental Capacity Act and making best interest decisions. As a result, we found that these were not consistently applied. This had an impact on how effectively DNACPR decisions were made. In some cases, assumptions had been made about who could make decisions when someone did not have the capacity to consent themselves, resulting in an advocate not being considered.

More broadly, we were concerned that people might be being discriminated against. One respondent to our public survey said:

“We were alerted by the care home that an attempt was being made to impose blanket DNACPR decisions on all those in care homes in the area. The form emphasised the idea that our loved ones would be more comfortable being looked after in familiar surroundings rather than go to hospital. We felt it was entirely inappropriate pandemic or not.”

Respondent to our public survey

In our public survey, when asked ‘did you experience any treatment during the DNACPR process that you would consider unfair or discriminatory?’, 48% (33 out of 69) of individuals with a DNACPR decision said yes they had; 44% (237 out of 544) of relatives or carers answering on their behalf also said yes.

Health and care professionals we spoke with were not aware of any substantial differences between DNACPR decisions for people in particular equality groups, such as people with a learning disability or older people, compared to the general population. However, they were not always able to support this with data because of a lack of systematic auditing in most areas.

Access to care when DNACPR decisions were in place

Overall, health and care professionals we spoke with told us they were confident that people with a DNACPR decision in place were not stopped from accessing care and treatment. However, around half of the 613 members of the public who responded to our survey did feel that they (54%, 37 out of 69) or someone they cared for (44%, 241 out of 544) experienced delays or had been denied treatment because of a DNACPR. One respondent to our public survey told us:

“I had to fight to remove [the DNACPR] as she was being denied any treatment.”

Respondent to our public survey

In the early days of the pandemic, we heard that ambulance staff had been reluctant, or had refused, to take people to hospital. It was not clear from these accounts if the DNACPR decision had been the sole or main reason behind this. In another area, we heard an example of someone who was kept in the community too long instead of being transferred to hospital.

However, we also found a good example where an ambulance trust we contacted was using assessment tools to tell them the best setting for the person to receive the care and treatment they needed. Following this assessment, the hospital was not always deemed to be the most suitable place and multidisciplinary care would be offered in the community.

Understanding of DNACPR decisions and the ability to challenge

An important part of being treated as a partner in your care is having a sense of control. While health and social care professionals told us people had mostly been involved in conversations about their care, we were less assured that these were done in a meaningful way. This presented a risk that people may not have enough information about what DNACPR decisions are, what the outcomes of those conversations would be, and how to challenge a decision.

Our review has highlighted that health and care professionals, like many people, find it difficult to talk to people and their loved ones about advance care planning. We heard that the way in which health and care professionals sometimes introduced conversations about advance care planning, including DNACPR decisions, could be distressing for people.

A lack of understanding about the DNACPR process, assumptions about people's quality of life, and poor communication could all affect how well people were involved in conversations about their care. These led to people feeling that they had little say in advance care planning, and DNACPR decisions being made inappropriately.

Conversations with our expert advisory and advocacy focus groups echoed these concerns. They told us there needs to be better awareness among the public about what advance care planning, and DNACPR decisions, mean in practice. We also heard that people don't know where to go for information and very often they are trying to find this information at a time of immense pressure and distress.

This suggests that clinicians need to improve how they engage with people, and that people need to be given better information at the time the conversations take place. Opening up the conversation about DNACPR decisions, and advance care planning more generally, needs to be done at a national level in the same way as we are now better equipped and more confident to talk about organ donation.

We did find a good example of more positive practice, where the registered manager of a care home told us that the GPs held advance care planning conversations, including discussions around DNACPR decisions, with new residents when they first came to live at the home so they knew people's wishes from the start.

We were concerned that when people, carers, family or advocates were not happy with the decisions made, they were not always confident in challenging decisions or clear on how to complain. This places people at risk of their complaints and concerns not being heard, acted on and/or resolved. In our public survey, only 61% of individuals with a DNACPR decision (42 out of 69) and their relatives or carers (333 out of 544) knew who to contact to raise concerns around the DNACPR order and process. This was even lower for people with dementia, where only 48% (11 out of 23) of individuals with a DNACPR decision knew who to contact if they had concerns. However, 65% (125 out of 193) of relatives or carers of someone with dementia knew who to contact if they had concerns.

Within all areas we found that individual providers had their own complaints procedures, where necessary, along with signposting mechanisms to relevant organisations if concerns and complaints could not be resolved locally. Health and care professionals we spoke with confirmed that feedback was encouraged, and that their concerns and complaints procedures had continued throughout the pandemic. In most areas, we heard that providers and CCGs had not received any concerns about DNACPR decisions. Where these had been received, we were told they had

been managed via the complaints procedure and assurances, explanations and apologies had been made where appropriate.

Some health and social care professionals told us that they were worried that other professionals lacked the confidence to challenge DNACPR decisions, or they didn't know enough about the DNACPR process to be able to challenge decisions. Barriers included GPs and care workers not wanting to overturn clinical decisions made in a hospital setting, and nursing staff feeling unable to challenge the decisions of senior doctors. In some areas, we found that clinicians, professionals and workers not feeling able or supported to speak up was part of the culture of the organisation.

Moving between services proved a complex time for reviewing decisions. We found some clinicians were reluctant to review DNACPR decisions on discharge from hospital, or to overturn decisions when someone's clinical condition had improved. We were frequently told by adult social care workers that people could sometimes be discharged from hospital with an advance care plan and DNACPR decision in place that was not relevant for someone living in the community and it needed to be reviewed.

We also heard of an example in one acute hospital where DNACPR forms were not being challenged when a person was moved between acute care settings. Instead, we heard that the conversation would happen again as part of the transition of care. In another example, we found staff had not challenged an inappropriate DNACPR decision when a patient arrived with it in place. While it was removed, this poor practice was not challenged with the other care setting.

Despite this, most CCG and provider leaders and senior professionals we spoke with told us they felt clinicians, professionals and workers would raise concerns or challenge decisions if needed. For example, leaders in one community services provider told us about the various ways they could raise concerns. They told us that their workers were competent and confident to raise concerns, and they had a strong incident reporting culture where concerns were shared.

In other areas we heard how processes, such as Freedom to Speak Up Guardians, were in place for clinicians, professionals and workers to raise concerns. We heard how responsive some organisations were to matters that were escalated through this route. Care staff and system leaders felt the culture in several trusts was very open and people had the right environment to raise complaints and concerns.

Review of DNACPR decisions

Overall, we found variation in whether there were robust systems in place to make sure that DNACPR decisions were routinely reviewed by an appropriate professional when a person moved between services, and/or when there was a change to their health condition.

Responsibility for making sure that DNACPR decisions are reviewed is shared between the clinicians completing the reviews, the senior clinicians and the provider. In some areas we found reviews might not be carried out in a timely way. This was supported by our review of care records, which showed that scheduled reviews had taken place for very few of those people. Review rates were consistently low across all areas, with only 19% (32 of the 166) of DNACPR decisions we looked at being reviewed or having a review date scheduled.

In some areas our review of case records showed that reviews had taken place, but were not always done well. In these cases, DNACPR decisions were extended without talking to the person or other appropriate individuals. This made it difficult for people to challenge the decision once they returned to their usual setting. This was felt by some to be a particular issue for older people, with or without dementia, and people with a learning disability.

A lack of resource at the weekend was also a challenge in some mental health and community hospitals with clinicians not being available outside of office hours to carry out the necessary reviews. This meant that DNACPR decisions would remain in place until a review could take place. This presented the risk that care was not person-centred or in line with the person's wishes, the agreed ceiling levels of treatment and DNACPR decision if one was in place. This could lead to people receiving inappropriate or unsafe care and treatment.

Staff training and support

Key points

- There was a wide range of training available across organisations, including training on the Mental Capacity Act, Deprivation of Liberty Safeguards and advance care planning.
- However, we were concerned that not all clinicians, professionals and workers had access to this due to a lack of funding and difficulties freeing up time to attend training sessions.
- Where staff had training, there were concerns about whether it was giving them the necessary knowledge and skills to engage with people in a meaningful way, and ensure that their needs were met and their rights protected.
- Clinicians, professionals and workers sometimes lacked the support to make difficult decisions, with some people turning to advocacy organisations for information and guidance.
- Clinical commissioning groups and local health and social care providers don't have a complete oversight of decision making around DNACPR decisions.

Good training should provide health and care professionals with the knowledge, skills and confidence to talk to people and their relatives or carers about advance care planning. This may include what level of care and treatment they want to receive at the end of their lives. It should help professionals to make sure that they are holding these conversations at the appropriate time and that they always take a personalised approach, which puts people at the centre of their care and ensures that their human rights and rights to equal treatment are protected.

Our review has highlighted concerns around how well these conversations are taking place, if at all, and whether clinicians, professionals and workers are receiving the right training to enable this. This includes access to training, the quality of the training available, and whether training gave them the confidence to challenge inappropriate DNACPR decisions.

Amelie's story

Amelie told us about her experience of losing her father, John, during the pandemic. John was a fit and healthy man in his 70s; he lived a full and active life. John became unwell and went to hospital for a series of tests. He received a call from the hospital telling him he needed to attend for an urgent appointment because they had found a blood clot and he needed blood thinning medication.

John went to this appointment expecting to receive this treatment, but instead he was told he had a tumour. He was alone at this appointment because relatives were not allowed to attend due to COVID-19. He was given a completed DNACPR form and was sent home in a taxi. Yet at this stage the tumour had not spread and was not terminal.

Amelie told us how this had made her father feel, “He was scared, it made him panic, it made him think he was going to die really soon”. He told his daughter he was a “goner.”

The DNACPR decision had not been made as part of an individualised advance care plan for Amelie’s father. No discussion had taken place about the decision, the reason for the decision or what his options for treatment were. It wasn’t done in a sensitive, compassionate way.

Amelie’s father later died from his tumour. The experiences of how frightened her father was after his diagnosis stay with her and she told us how she felt she had failed her dad because she wasn’t with him and couldn’t stand up for his rights when he needed her to.

Amelie told us, “These decisions that are made by doctors, they don’t die with the person, they live on.”

Availability, access and effectiveness of training

The majority of staff we spoke with felt that they had the training needed to make sound clinical DNACPR decisions. However, we were concerned that they did not always have the necessary knowledge and skills, or were not trained to the required standard. Our concerns were echoed at our advocacy focus group where we heard that, for example, “a lot of the staff think they know about the Mental Capacity Act, but don’t have the depth of understanding they need”.

We heard that there was a wide range of training available that related to advance care planning, though the offering varied depending on organisation or area. Courses available included training on the Mental Capacity Act (MCA), Deprivation of Liberty Safeguards (DoLS), safeguarding, advance care planning and end of life care. The latter included topics such as palliative care and having sensitive conversations about death. We also heard that there was specific training available on DNACPR decisions and the ReSPECT process.

In many organisations, some of the training programmes were required by the employer and had been since before the pandemic. In others, training had been rolled out after the start of the pandemic. We also heard about new training that had been developed in response to the pandemic. For example, in one area, the clinical education leads worked with frontline staff to train them on how best to start advance care planning conversations during a pandemic, and how best to hold them when restrictions meant they had to be done at a distance (such as over the phone).

In another clinical commissioning group (CCG) area, we found a range of opportunities available. This included round table events, buddy schemes for GPs, and palliative care education webinars. These were part of the CCG’s incentive scheme, which also included training on the Mental Capacity Act and discussions around DNACPR decisions.

While there was a wide range of training available, we heard concerns that not all clinicians, professionals and workers were able to access it. Reasons for this included a lack of funding and difficulties freeing up time to attend training sessions. This affected staff from all sectors. In one of the areas we reviewed, the CCG decided to make advance care planning training available free to frontline staff, with a good uptake as a result.

We also heard that there was less focus on training for clinicians, professionals and workers during the pandemic because of the pressures that services were facing. This is despite the fact that there was increased interest in advance care planning from staff at the beginning of the pandemic. In one area, local leaders said that doctors in acute hospitals in particular wanted training on advanced care planning and DNACPR discussions and decisions. In one area we heard:

“They are frightened of getting it [advance care planning] wrong. They have resuscitation training, but no training relating to the conversations around whether resuscitation is appropriate. That topic needs to be expanded.”

Without appropriate training, health and care workers may not be aware of when it is, and is not, appropriate and lawful to be holding discussions about DNACPR decisions. This includes whether it may potentially be discriminatory for people in some equality groups, for example people with a learning disability, who are not at the end of their lives.

Not having a good understanding of advance care planning, the Mental Capacity Act, and the DNACPR process, can lead to issues such as people being assessed as having capacity when they no longer do. It can also lead to clinicians making decisions for people in particular equality groups, such as people with a learning disability and older people, that are not appropriate or are based on assumptions about their quality of life. It also puts clinicians under pressure and creates a fear that they may be held to account if something goes wrong.

We were concerned that where health and care workers, particularly those in care homes, did not have the training they needed, they would not be able to identify concerns or issues with incorrectly completed documentation. In addition they may not see it as their responsibility to challenge an inappropriate DNACPR decision, or feel confident in raising concerns where they identified problems. This means that people may not be protected from unsafe care or treatment, and may be at risk of having their human rights breached.

Support for staff

Overall, most senior leaders we spoke with felt that there was enough support for frontline staff to follow good practice when making difficult decisions in pressurised circumstances and complex busy settings. However, there wasn't enough evidence to determine if the support that clinicians, professionals and workers received was effective or happened at the right time.

We heard that meetings and forums took place in many different forms, including clinical forums to discuss complex cases, daily and weekly staff meetings to discuss cases and issues, and safeguarding panels.

In one area we looked at, a buddy scheme with hospital matrons and care homes had been put in place before the pandemic to help connect hospitals and care homes. Since then, a 'Flying Squad' team from a hospice supported adult social care homes with emotional and educational support and advice and guidance. Another area had rapidly developed an end of life hub to provide support. We were told this had been positive in giving professionals advice when needed.

In two of the areas we looked at, we heard there was an on-call team of senior professionals that health and care workers could call for advice and guidance, and discuss complex decisions with.

However, the advocates we spoke with raised concerns about the effectiveness of training, and queried the level of support for clinicians, professionals and workers. Their organisations often received calls from health professionals seeking advice on the Mental Capacity Act, advance care planning, and DNACPR decisions. One advocate told us that they had ended up creating a guide to advance care planning, which they shared with local health professionals, because of the volume of enquiries that they were receiving. This brings into question both the effectiveness of training the health professionals had received, and the level of support they were receiving in their respective organisations.

Other advocates told us that they do a lot of awareness raising with providers, with some describing how they had been involved with delivering training on the Mental Capacity Act and advance care planning to health professionals.

Oversight of training and decision making

While we found evidence of training and development around advanced care planning and DNACPR decision making, in most cases the training had not been evaluated. This meant that they were unable to show how training had improved people's experiences.

One area used their engagement with the Learning Disabilities Mortality Review (LeDeR) Programme to make improvements. This programme looks at why people are dying, and what can be done to change services locally and nationally to improve the health of people with a learning disability and reduce health inequalities. Being part of the programme had helped the CCG to actively identify the need for additional training in DNACPR decisions, Deprivation of Liberty Safeguards, the Mental Capacity Act and mental capacity assessments. This was viewed positively: that there were systems in place to identify shortfalls and action was taken as a result.

When applying a DNACPR decision, responsibility for ensuring this is done properly should rest with the senior responsible clinician, as defined by local policy. Providers should then be responsible for auditing DNACPR decisions at a local level. There appeared to be a perception that if somebody had received training, they would be able to make decisions in line with best practice and legislation, but we heard little about oversight and monitoring of practices related to DNACPR decisions.

For example, at one acute hospital our review of case records found that some of the DNACPR decisions that had been made by junior doctors had not been countersigned by a senior clinician.

This raises questions about the level of support that some frontline staff had been given to manage the pressures brought on by the pandemic and be in a position to follow relevant guidance. This includes, for example, guidance set out by the British Medical Association, Resuscitation Council UK and Royal College of Nursing.

We found evidence of mechanisms in place to support clinicians in making complex decisions and for seeking advice. While these had been effective in part, they did

not give local leaders complete oversight of the pressures that services were under, or any additional support that clinicians, professionals and workers may need. This presented a risk of staff working without the support and capacity they needed to work fully within the required guidelines and legislation, all of which outline key ethical and legal principles that should inform any decision.

As a result of our findings, we were concerned that there aren't processes in place to monitor decision making around DNACPR decisions across local areas, and ensure that health and care workers have the relevant training. This meant they would not be able to identify any additional support that they may need. Without proper oversight, systems could not be sure that clinicians, professionals and workers were being supported to keep their professional practice and knowledge up to date in line with best practice, and to work within this. This is an area that needs rapid evaluation given the issues we have identified with staff knowledge and understanding. It is also pivotal to the development of end of life strategies at a system-wide level.

Leadership, governance and assurance

Key points

- Advance care planning, end of life care and DNACPR decisions were often not sufficiently high on the agenda at a system level, and leaders lacked oversight of DNACPR decisions.
- Providers and commissioners could not always demonstrate how they were assured of the quality of DNACPR decisions.
- While we found evidence of learning from incidents at local provider level, there was minimal evidence of learning being shared across areas. A lack of evaluation and oversight also meant that it was difficult to say how effective any learning from incidents had been in improving people's experiences.
- Leaders of providers and clinical commissioning groups told us that clinicians, professionals and workers knew how to challenge DNACPR decisions but had never been challenged themselves or had records of complaints and concerns.

During the COVID-19 pandemic, all health and social care leaders and system leaders had to make crucial operational changes in the face of pressures never experienced before. In a bid to be effective and responsive to people's needs, we found that these leaders worked together collaboratively and proactively throughout the pandemic.

We saw, for example, improved communication and support for integrated working between adult social care and primary medical services. We found examples of GP services working more closely with adult social care services to raise awareness of enhanced care models. (The Enhanced Health in Care Homes model moves away from traditional reactive models of care delivery, towards proactive care that is centred on the needs of individual residents, their families and care home workers. Such care can only be achieved through a whole-system, collaborative approach.) This led to a more personalised approach for some people, with the right multidisciplinary team involved.

While there had been less focus by clinical commissioning groups (CCGs) on advance care planning, end of life care and DNACPR decisions at the start of the pandemic, they did give more attention to preventing blanket and inappropriate DNACPR decisions latterly following concerns raised by national organisations and the media.

Commissioners had played a role in the collating and dissemination of guidance and information, but there were some concerns around the reach of this and how well it was understood. It was acknowledged that there had been lots of guidance, but much of this was conflicting or confusing and DNACPR decisions hadn't been given a high priority.

Some frontline staff we spoke with in one area, particularly those working in adult social care, felt that leaders were not visible enough, leaving them feeling isolated.

Oversight and assurance of DNACPR decisions

The majority of people we spoke with told us that they weren't doing anything differently for DNACPR decisions during the pandemic and that they were following existing processes and protocols.

While every area was keen to express the importance of person-centred care, oversight of DNACPR decisions varied between and within the different areas we looked at. Without strong auditing processes in place, they could not be sure that decisions were always appropriate and that people's rights and interests were being respected.

Lack of a consistent approach also meant that reviews were potentially being missed or not done in an appropriate manner. We found that, on occasion, inappropriately placed DNACPR decisions were only found during audits or when documentation was reviewed when patients moved to different services.

There had been some action taken to rectify some shortfalls locally and acknowledgement from some systems where developments were needed. However, work is needed to develop a long-term solution so that systems can assure themselves that poor practice is addressed and eradicated, and better outcomes for people are assured.

Sharing learning from incidents

Where learning was being shared across a local area, it showed positive leadership, engagement and collaboration to upskill clinicians, professionals and workers, learn lessons as a system to prevent inappropriate use of DNACPR decisions, and promote better outcomes for people. For example, one trust we spoke with told us that they had commissioned a review to look at all deaths during COVID-19. They shared the learning from this review with the clinical commissioning group and other health and social care providers in the local area. As a result, improvements were made to how care was commissioned and more integrated models of care were put in place across the area to promote a consistent approach.

Leaders in providers told us that clinicians, professionals and workers knew how to challenge, but these leaders had never been challenged themselves or had records of complaints and concerns from the public. They also generally believed that, if frontline staff had concerns, they would feel able to raise them via the right channels. However, as we highlight in the training section of this report, we had concerns that clinicians, professionals and workers did not feel able to raise concerns.

System response to the pandemic and DNACPR decisions

Key points

- Collaboration between clinical commissioning groups, health and social care providers and patient representative bodies increased during the pandemic. Local areas that had established infrastructures and governance processes worked together better to manage the challenges created by the pandemic.
- While increased collaboration had generally strengthened approaches to advance care planning, end of life care and DNACPR decisions, there were mixed views about how effective this was.
- The types of advance care planning in use, including ReSPECT, local treatment escalation plans and DNACPR decisions, varied between services and across geographical boundaries, creating challenges for clinicians, professionals and workers, and impacting on the quality of care for individuals.
- The pandemic accelerated the use of digital technology. While it improved access for many, it created challenges for some people in some equality groups.

The aim of our review was to look at how DNACPR decisions were made, in the context of advance care planning, across all types of health and care services including care homes, primary care and hospitals. To do this we looked at seven clinical commissioning group (CCG) areas and how the CCGs, health and social care providers and patient representative bodies in these areas worked together as a 'system'.

Usually, these organisations work together to ensure that health and social care provided in their area meets the needs of their local populations. During the pandemic, they found themselves in an unprecedented situation. It tested how well they were able to work in partnership, including how well they collaborated to make decisions and provide guidance around DNACPR decisions and advance care planning more widely.

How well systems worked together and communicated

Generally, we found that collaboration between organisations had increased during the pandemic. Areas that already had infrastructure and governance processes in place were better able to work together to manage the overall challenges created by the pandemic. However we found that, before the pandemic, systems had underdeveloped strategies for advance care planning and end of life care.

Some areas had existing groups, boards and forums in place, such as ethics committees, to support sound decision making. Other areas had created new groups or changed the purpose of other groups to focus on end of life care, including reviewing and sharing guidance. For example, in one area we were told that the end of life board was transformed into an operational group at the start of the pandemic to help advise on end of life care planning for the whole of the region. Set up by the local Health and Wellbeing Board, the board was originally part of a project called 'Live and Die Well', which brought end of life professionals from across the area together to discuss processes and best practice.

Some systems had specifically recognised that communication with the adult social care sector needed to improve, and had taken action to do this. For example, one area we looked at had set up a 'care provider cell' to support local providers, which focused on making information accessible to care providers.

There were mixed views of how successful the increased collaboration had been in strengthening approaches to advance care planning, end of life care and DNACPR decisions during the pandemic.

Time pressures, increased numbers of meetings, lack of opportunity to meet face to face, and complicated and confusing governance routes were all described as influencing factors. A Healthwatch representative in one area told us they hadn't been invited to key meetings for three months, which had an impact on their ability to raise the voice of people who use services.

How well system partners communicated with their local populations also varied. We were concerned there did not appear to be many system-wide engagement strategies to foster trust and confidence with the public. Many of the system partners we spoke with said there were no strategies for raising awareness about DNACPR decision making or were not aware of them.

Some people, including members of our expert advisory group, felt that public messages about DNACPR decisions should be provided on a national level.

Guidance around DNACPR decisions

At times of immense pressure like the pandemic, it is vital that any communication and guidance to health and care services is well considered and clear, and there are robust arrangements in place to manage how it's sent out, understood and implemented.

Every area we reviewed had taken steps to make sure that services were aware of the importance of taking a person-centred approach to DNACPR decisions and advance care planning. This included, in a number of areas, the issuing of guidance. We also heard about forums being set up to share learning and ensure consistent practice, as well as a general sense of heightened awareness around the importance of personalised approaches to DNACPR decisions.

For example, in one area we found an end of life care group that had been in place since before the pandemic and included colleagues from the local hospice, hospitals, community and CCG. During the pandemic, the group discussed the national guidance issued, including around DNACPR decisions. A particular focus was how they would support community patients and people who didn't want to go to hospitals.

However, we identified a number of challenges that had an impact on the DNACPR process. For example, we consistently heard that, at the start of the pandemic, providers had to cope with a huge amount of guidance about all aspects of the pandemic that lacked clarity and changed rapidly, leading to confusion. The number of meetings and governance routes could also cause confusion. This could have put people at risk of inappropriate or blanket DNACPR decisions being made. We also heard about some difficulties for ambulance services, where guidance on when to take people into hospital or not was rapidly changing, although this may not have related directly to DNACPR decisions.

End of life care strategies

An end of life strategy aims to promote high-quality care for people at the end of their life by providing them with more choice about where they would like to live and die, and the care and treatment they would like to receive. It is important to have a coherent, joined-up strategy and approach to ensure the equal provision of care for all people at the end of life, and their families and carers.

Local health and care systems should have a strategy to ensure that there are clear guidelines and frameworks in place to guide decision making and that outcomes for people are monitored effectively. It also helps to ensure that information and guidance is shared in a consistent way across a local area.

The areas we looked at were at different stages with their end of life care strategies. Most had underdeveloped strategies for end of life care, advanced care planning and DNACPR decisions. One had no strategy at all. This meant that frameworks weren't always well embedded or applied consistently. It was also sometimes unclear how advance care planning, end of life care and DNACPR decisions would translate into action. OBJOBJOBJ

Where we found end of life strategies had been embedded, these were often supported by a framework, such as the Gold Standards Framework (a model that enables good practice to be available to all people nearing the end of their lives, irrespective of diagnosis). Where strategies and frameworks were not embedded, we found inconsistent approaches contributed to less positive outcomes for people.

Lack of consistency and geographical barriers

Different approaches and models of advance care planning, including ReSPECT, local treatment escalation plans and DNACPR decisions, were in place in all the areas we looked at. The type of model used varied both between services and across geographical boundaries.

Not only do these models use varying approaches, but they also use different types of forms and documentation. This lack of consistent approach created challenges for clinicians, professionals and workers, such as when moving between services. We found that it was a particular issue for ambulance staff who sometimes had to be aware of multiple different models and know which was in use depending on which local health authority area they were in. Generally, we found that where there were two or more approaches in place in a local area, there were more difficulties than in areas where all providers used the same methodology, regardless of which model this was.

Where a model was working well, it was not always rolled out across the local area. For example, one area could demonstrate that the advance care planning model in use across the area was having a positive impact for people, but this had only been embedded in some services. This meant that there may have been missed opportunities to support the whole local population more effectively, which may have been achieved if an agreed strategy had been put in place.

Where different models were in use, we sometimes found that when people were moved between hospitals and care homes (or vice versa), forms had to be converted to match the model in place at the service. For example, ReSPECT forms were sometimes converted into Treatment Escalation And Limitations (TEAL) forms or

DNACPR forms. Models such as the ReSPECT form take a longer period of time to complete as they are based on a holistic conversation with the person. While these decisions may cause no harm to the person, there would be additional work created for clinicians, professionals and workers in re-doing the documentation into different formats.

These factors could all potentially impact on the quality of care received by the person, their carer, family or advocate, and result in missed opportunities for support in the right way at the right time by the right person. Furthermore, it leads to the potential for mistakes due to the lack of consistency and the barriers that have been experienced interpreting information. It created additional work for clinicians, professionals and workers, already in an extremely busy environment, giving rise to the potential for forms not to be completed accurately or comprehensively, placing the person at risk of unsafe care or treatment or neglect and harm.

Remote consultation and the use of digital technology

The pandemic has accelerated the use of digital technology and has changed the way in which CCGs, providers and representative bodies communicate with people, carers, family and advocates. Across all areas we looked at, while acknowledging the need for an increased use of technology, people we spoke with stressed the continued need for face-to-face contact if they were going to be truly inclusive and person centred.

Digital solutions and remote consultation (which includes telephone conversations) had increased across the areas we looked at, born out of necessity but embraced and appreciated by many. Digital solutions were most commonly used by GPs, community teams and care homes. For people living in care homes, we heard how doctors had carried out digital ward rounds and remote consultations.

“Digital platforms and remote consultations had been an enabler in many ways. For example, it had enabled relatives to be involved in multidisciplinary team discussions, which offered a more personalised approach, which they are not sure would have happened prior to COVID. It has supported the multidisciplinary team to adopt a person-centred approach and work together as a team to support the individual not just DNACPR and gave an indication re ceiling of treatment and preferred place of care. This made for a more efficient and system-wide approach.”

Some of the benefits of the digital technology were described as:

- being able to access appointments safely that people may not have been able to attend otherwise
- being able to easily include carers and family members
- benefits for people with physical disabilities
- not needing to wear a mask.

However, digital technology was not always accessible to everyone. For example, older people or those with a cognitive or hearing impairment may have found it more challenging to have these conversations on a screen.

This was supported by the findings of our [COVID-19 inpatient survey](#). Three-quarters of respondents said that they were able to keep in touch with friends in family, for example by phone, mobile messaging or video calls. But older patients and those with a sensory impairment, including people who were blind or deaf, as well as people with a learning disability, a mental health condition or neurological condition were less likely to feel they were able to keep in touch 'often'.¹⁰

This shows that digital technology is not accessible to all and some people may not be able to fully engage in conversations and have an equal relationship in their care. This may mean that their personal needs and choices are not met and they may face inequalities in care and treatment.

There were also logistical challenges as not everyone had access to digital technology. Some local areas had made investments to overcome these challenges. For example, we heard how one provider had proactively reviewed their processes and purchased additional mobile phones and tablet computers to help clinicians, professionals and workers to communicate with families and also help people remain in touch with loved ones during their stay. However, one Healthwatch representative told us that, "There are relatives still describing those issues, so pretty sure there are still gaps."

Some clinicians, professionals and workers did not feel equipped or confident to have conversations remotely and we heard some accounts of when DNAPCRs had been put in place remotely without consulting with the person. One member of staff told us they would attempt this conversation with a person they knew well, but they wouldn't with others. This undermines the process of personalised models of advance care planning and DNACPR decisions. Not feeling able or confident to have these conversations remotely presents the risk that they will not take place, or they will be of a lesser quality.

Increasingly, local health and care systems are using technology that is joined up across their local area. We heard about different examples in different parts of England. However, some healthcare professionals, particularly those that work in the community, told us about the challenges of different advance care planning documentation and the effect it had if it could not be put into the electronic patient record system.

¹⁰ Care Quality Commission, [Inpatient experience during the COVID-19 pandemic](#) November 2020

Conclusion and recommendations

Our review has highlighted that while many of the concerns raised are not new, it is the pressures of the pandemic that has exposed them and demonstrated the lasting impact of these on people.

Since the start of the pandemic, there have been particular concerns that 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions were being applied to groups of people rather than taking into account each person's individual circumstances. While we did not find there had been a national blanket approach to DNACPR, there was undoubtedly confusion at the outset of the pandemic and a sense that some providers felt under pressure to ensure DNACPR decisions were in place. This risks undermining public trust and confidence in the health and care system and demonstrates the need for better oversight of DNACPR decisions.

All the health and care professionals we spoke with recognised the importance of ensuring that conversations around advance care planning are carried out with kindness and compassion, in line with best practice and people's human rights. But how well people were involved in conversations about their care and whether or not they wanted to receive cardiopulmonary resuscitation varied.

Some people experienced compassionate, person-centred care where they were fully involved in conversations, and their wishes were understood and their rights upheld. The impact on people when this did not happen was hugely distressing. In these cases, conversations took place at short notice and people did not fully understand what was happening or what a DNACPR was.

Having the time and information to talk about what care and support people want and need to have a dignified and peaceful death is essential. During the pandemic, clinicians, professionals and workers have faced additional challenges in having to hold conversations under pressure and often during emergency situations. A lack of training and support for staff, and how confident they were in holding these conversations, has impacted on the quality of people's experiences.

Being faced with unexpected conversations around DNACPR decisions, and having them at a time of crisis was made worse for people and their families and/or carers due to a lack of available accessible information. To ensure people are able to be fully involved in these conversations, there needs to be a consistent approach in the language used and the way that advance care planning and DNACPR decisions are talked about. This needs to be supported by greater awareness of their rights under the Human Rights Act 1998 and the Equality Act 2010.

As the independent regulator of health and adult social care services, we are committed to reducing inequalities, eliminating discrimination, advancing equality, and protecting human rights. With an expectation for people to be at the centre of their care, we will continue to improve our monitoring and oversight of DNACPR decisions, including whether these are carried out in a safe way that protects people's human rights.

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

Appendix A: How we carried out our review

Assessment framework

All aspects of the review were guided by our assessment framework, which we developed in consultation with our stakeholders. We focused on the following areas:

- **People at the centre:** How are providers and systems putting people at the centre of their care in approaches to DNACPR decisions to protect human rights, protect people from discrimination and meet people's individual needs? What have people's experiences been since the start of the pandemic?
- **Shared vision, values, governance and leadership:** How have providers and the system worked in partnership to influence and agree a shared approach for the use of DNACPR decisions that protects human rights, gives equal access to care and treatment and prevents avoidable deaths? What are the enablers and barriers for the appropriate use of DNACPR?
- **Workforce capacity and capability:** How do providers and the system work together to ensure that clinicians, professionals and workers involved in the use of DNACPR have the right knowledge, skills and tools to deliver personalised approaches to DNACPR in line with the relevant legislation, and how are staff and people supported to raise concerns in order to improve care?

Methods

Review of literature and guidance

We carried out a review of the literature, guidance and evidence to understand what was already known about the use of DNACPR before the pandemic and what impact the use of DNACPR had on people's experiences during the pandemic. This included understanding best practice in approaches to thinking about future care and treatment if a person was to become seriously ill or approaching the end of their life.

Engagement with external stakeholders and experts

To ensure that the views of interested parties, and in particular the views of people affected by the use of DNACPR during the pandemic, have influenced and shaped the scope of the review from the outset, we held initial conversations with nearly 50 stakeholders who had a specific interest in the scope of the review. These included organisations that represent or advocate on behalf of the public, and family carers, care providers, and care professionals. Many of these organisations and individuals have continued to provide their expertise and insight through our [Expert advisory group](#), which influenced the scope and approach, and has influenced our recommendations.

Bespoke information collections

To help us to understand the scale of the issue, we sent a voluntary information request to around 25,000 adult social care providers (including care homes, nursing homes, domiciliary care agencies, supported living schemes, Shared Lives and extra care housing). While responsibility for making DNACPR decisions does not predominantly rest with adult social care providers, we asked them a range of questions to understand their view of the experiences of people in these settings. We

asked about the number of inappropriate DNACPR decisions put in place since 17 March 2020, what made them inappropriate and if they remained on people's records at the point of submission of the information request. In total, 2,171 responses were received from 7 December 2020 to 21 December 2020. However, a number of data quality issues were identified within the responses. These were likely a result of services incorrectly interpreting the questions. These issues meant the data was cleaned and analysis was only carried out on 2,048 responses. The relatively low response rate affects our confidence in the findings and means the results may not be generalisable. However, it is important to record and share the experiences of people working in services.

With the support of voluntary sector partners, we ran surveys to ask people who use services and their families and carers about their experiences of DNACPR decisions during the pandemic. We made sure that some communities who may need support in sharing their experiences through this survey were enabled to do so. We analysed 613 responses, which is not representative of all the cases of people across the country. However, it does allow us to capture the lived experiences of those who have had a DNACPR decision, and their families or carers.

Fieldwork activities

We carried out fieldwork to explore how primary, secondary, social care and system partners worked together in an area – including the impact of commissioning arrangements. This helped us to ensure best practice in DNACPR decision making was followed nationally. However, the findings are not necessarily representative, but instead they explore individual experiences

We identified seven [clinical commissioning group \(CCG\) areas](#) as case studies for our review, listed below. These covered a cross-section of geographical areas and a mix of demographics so that the lessons we learn will be of value to people in health and social care across the country, wherever they are working.

We focused activity at a CCG level, the level at which clinical services are planned and delivered and where population health management is used to target interventions to particular groups, in partnership with NHS organisations and local government.

Wherever it was possible and appropriate to do so, we carried out our fieldwork virtually. This included:

- **Retrospectively tracking people's journeys through care:** To gain an understanding of people's experiences of care and how decisions about their care and treatment were made and communicated, we carried out an in-depth review of seven people's experiences. This involved reviewing the relevant care records and, wherever possible, speaking to the person experiencing care and their families and a range of relevant health and care professionals.
- **Sampling DNACPR records:** We reviewed the DNACPR records of 166 people who have been affected during the pandemic. These did not consider every example of DNACPR decisions since the pandemic, but allowed us to consider a larger number of people's cases. We accessed care records through a range of care settings (acute, mental health hospitals, care homes and GP services).
- **Information from local advocacy groups:** We spoke with local advocacy organisations that have engaged with the public and providers over the use of

DNACPR decisions to share our emerging findings and ask for feedback on these, and thoughts on recommendations.

- **Interviews and focus groups with frontline staff:** We held 156 interviews and focus groups with clinicians, professionals and workers from different roles and organisations involved in providing care, which includes the use of DNACPR decisions, to understand practice, challenges and enablers for best practice.
- **Interviews with commissioners and members of the wider system:** We spoke with commissioners and system leaders to explore practice across the system, collaboration and how oversight arrangements ensure best practice in DNACPR decisions.

CCGs selected as part of the review:

- NHS Birmingham and Solihull CCG
- NHS Bristol, North Somerset and South Gloucestershire CCG
- NHS Cambridgeshire and Peterborough CCG
- NHS Morecambe Bay CCG
- NHS Sheffield CCG
- NHS South East London CCG, with a focus on Greenwich
- NHS Surrey Heartlands CCG, with a focus on East Surrey

Expert advisory group members

Access	Disability Rights UK
Age UK	Equality and Human Rights Commission
Alzheimer's Society	General Medical Council
Association of Directors of Adult Social Services (ADASS)	Healthwatch England
Association of Mental Health Providers	Kate Masters – Campaigner
British Geriatrics Society	Learning Disability England
British Institute of Human Rights	Learning Disabilities Mortality Review (LeDeR)
British Institute of Learning Disabilities	Local Government Association
British Lung Foundation	Marie Curie
British Medical Association	Mencap
Care England	National Autistic Society
Carers UK	National Care Forum
Challenging Behaviour Foundation	NHS England and NHS Improvement
Choice Support	Nursing and Midwifery Council
Cloverleaf Advocacy	PowHer
Compassion in Dying	

Race Equality Foundation
Royal College General Practitioners
Relatives & Residents Association
Resuscitation Council UK
Rethink Mental Illness

United Kingdom Homecare
Association (UKHCA)
University of Bristol
Voluntary Organisations Disability
Group (VODG)
Warwick Medical School
Voiceability

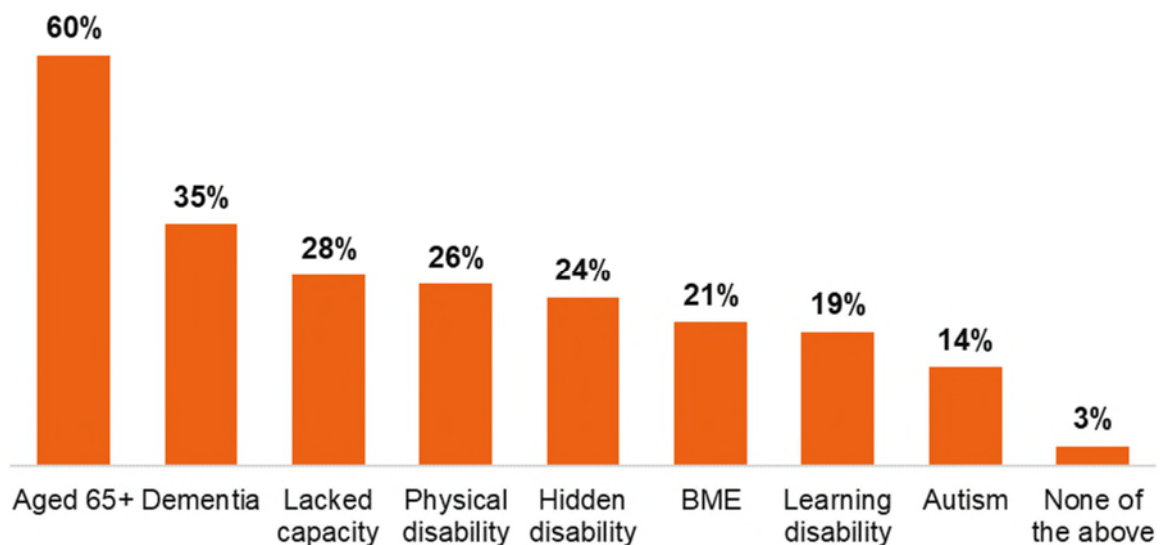
Appendix B: Data appendix

Public survey

With the support of voluntary sector partners, we ran several public surveys to ask people who use services and their relatives or carers about their experiences of DNACPR decisions during the pandemic. In total, 613 responses were collected: 69 from individuals with a DNACPR decision and 544 from relatives or carers of individuals with a DNACPR decision. Individuals with a DNACPR decision were asked about their own experiences during the process. Relatives or carers were asked to answer about their loved ones' experiences, on behalf of their relative or friend, as well as questions about their own experiences.

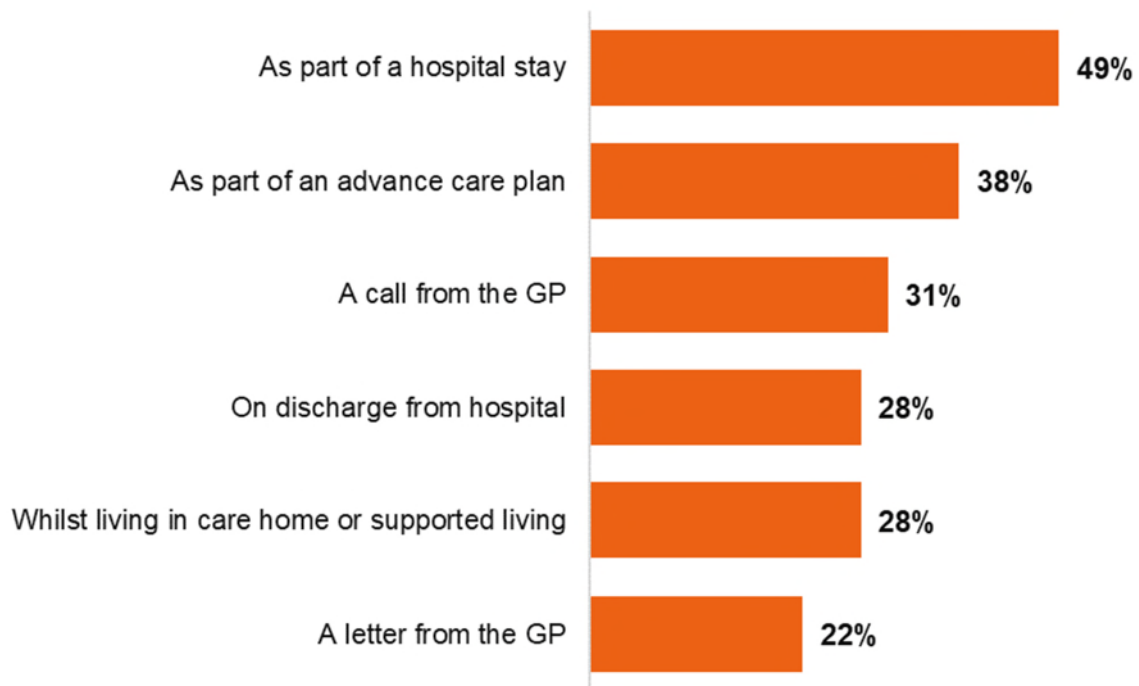
It is recognised that the data collected is not representative of all the experiences of people across the country. However, it does allow us to capture the lived experiences of those who have had a DNACPR decision, and their relatives or carers.

Figure 3: Breakdown of protected characteristics of the 613 individuals with a DNACPR decision identified from our public survey



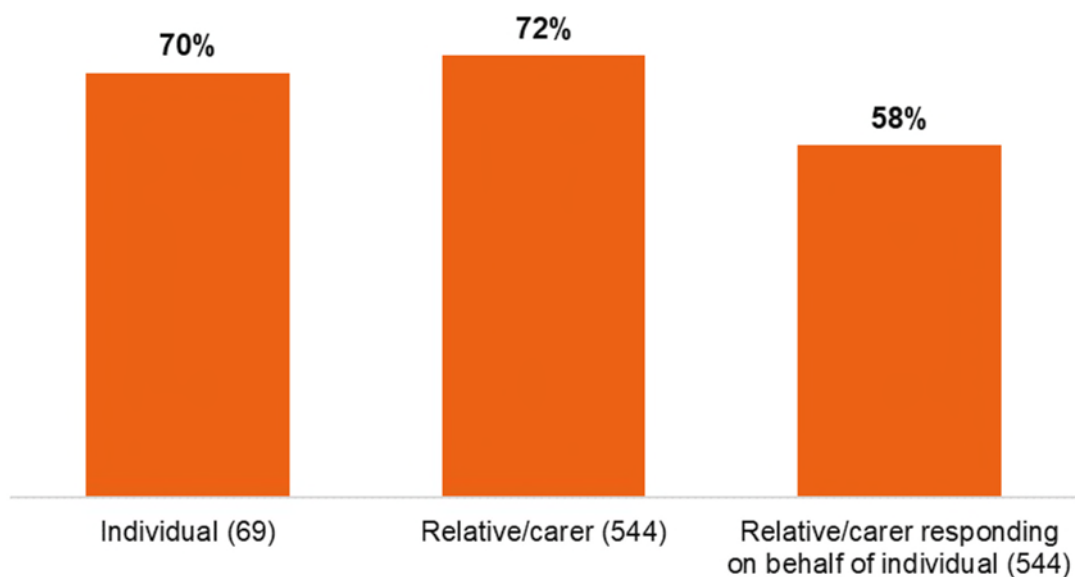
The chart above shows the breakdown of protected characteristics of the 613 individuals with a DNACPR decision that responded to our survey (either directly or via relatives or carers responding on their behalf). Figures add up to more than 100% as individuals may have reported more than one protected characteristic.

Figure 4: Breakdown of how DNACPR decisions were applied



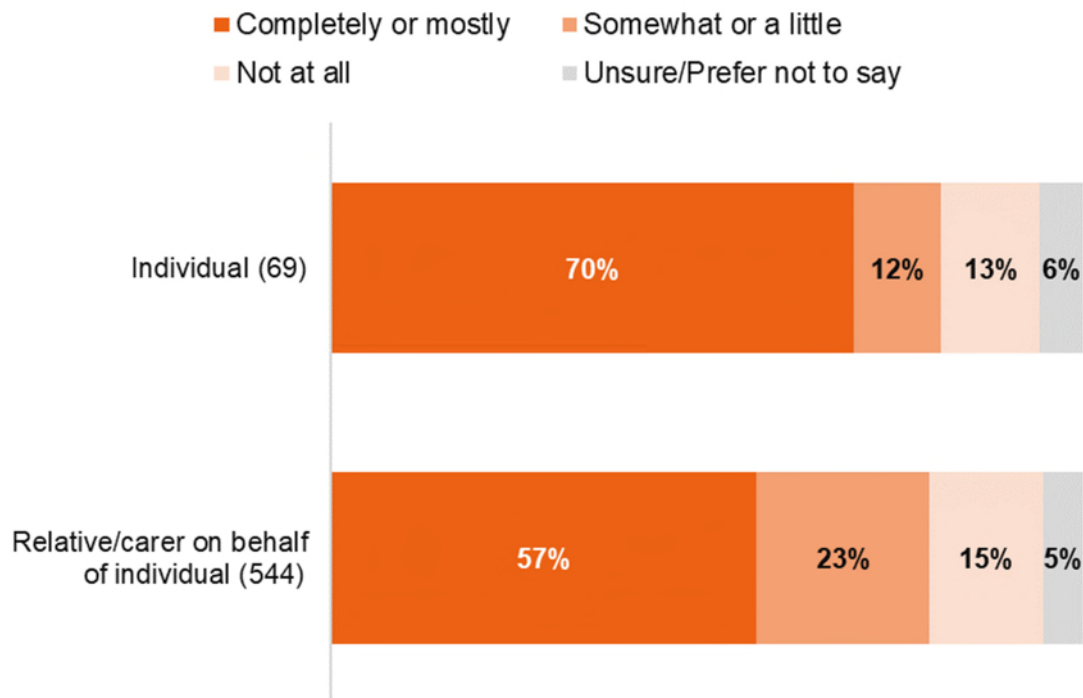
298 out of the 613 DNACPR decisions were applied as part of a hospital stay (49%) and 234 had been part of advance care planning (38%). Figures add up to more than 100% as DNACPR decisions may have been applied by more than one of the options on the chart.

Figure 5: The percentage of individuals with a DNACPR decision and relatives or carers that were aware that a DNACPR decision had been applied



70% of individuals with a DNACPR decision and 72% of relatives or carers of individuals with a DNACPR decision reported that they were aware of the decision at the time that the DNACPR had been applied. Where a relative or carer had responded to the question on behalf of an individual with a DNACPR decision, only 58% stated that the individual had been aware of the decision.

Figure 6: The percentage of individuals with a DNACPR decision who felt best interests and capacity were considered



70% of individuals with a DNACPR decision reported that their best interests and capacity to consent were completely or mostly considered. Where a relative or carer has responded for the individual this figure is lower, 57%.

Figure 7: The percentage of individuals with a DNACPR decision who felt supported to participate in a conversation about their decision

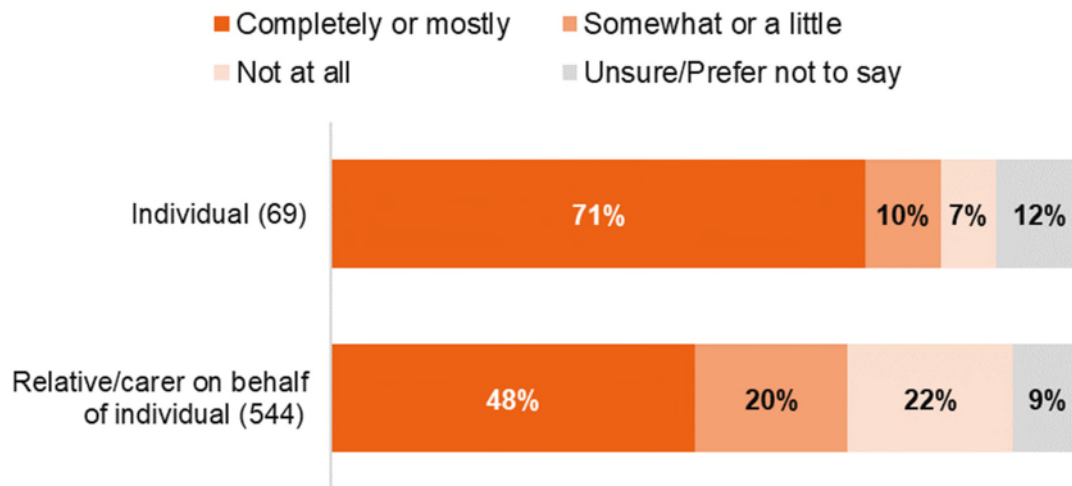
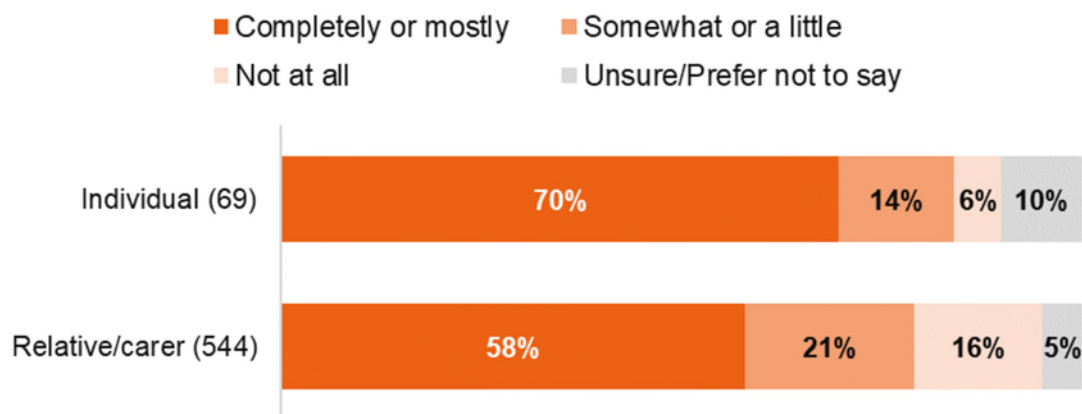
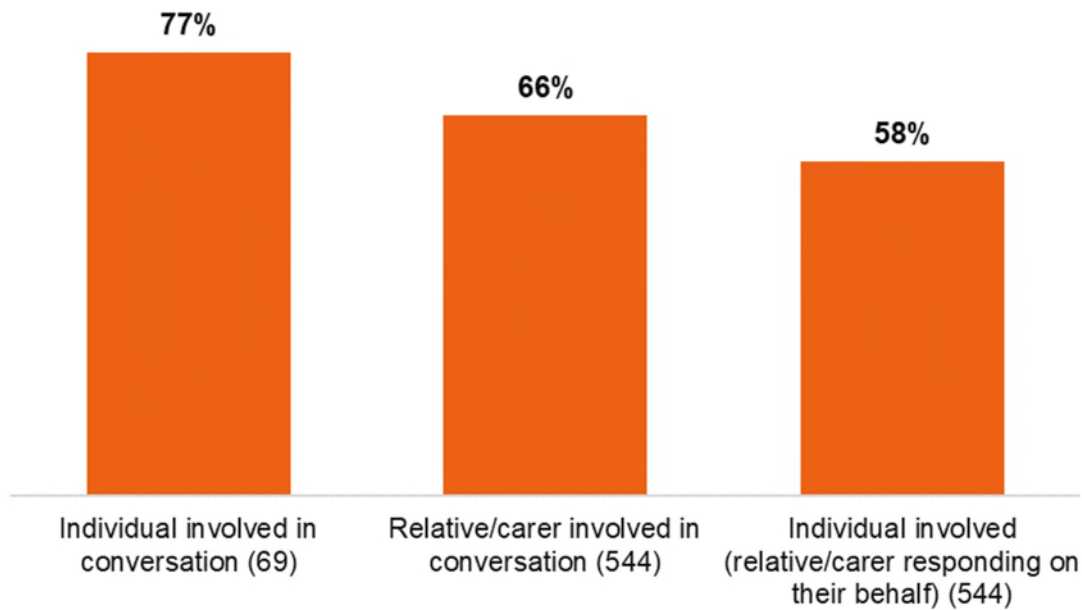


Figure 8: The percentage of individuals with a DNACPR decision and relatives or carers who felt listened to and able to speak up



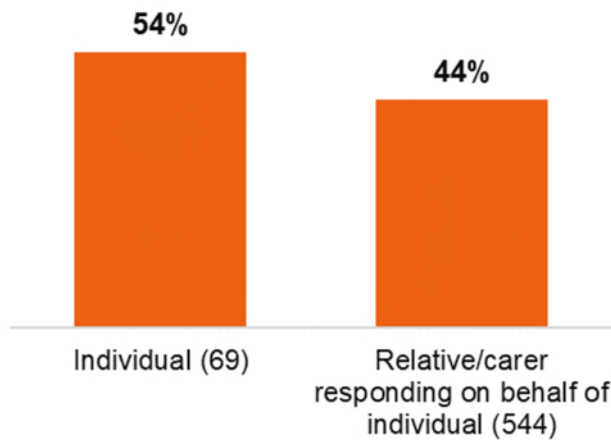
High proportions of individuals with a DNACPR stated that they were supported to participate in a conversation about the decision (71%) and felt completely or mostly listened to and able to speak up (70%). Responses were less positive from relatives or carers with just under half (48%) stating that their relative/friend with a DNACPR was completely or mostly supported to participate in a conversation about the decision and 58% stating that they felt completely or mostly listened to and able to speak up themselves.

Figure 9: The percentage of individuals with a DNACPR decision and relatives or carers who were involved in a conversation about medical treatment once their, or their loved one's, DNACPR decision had been applied



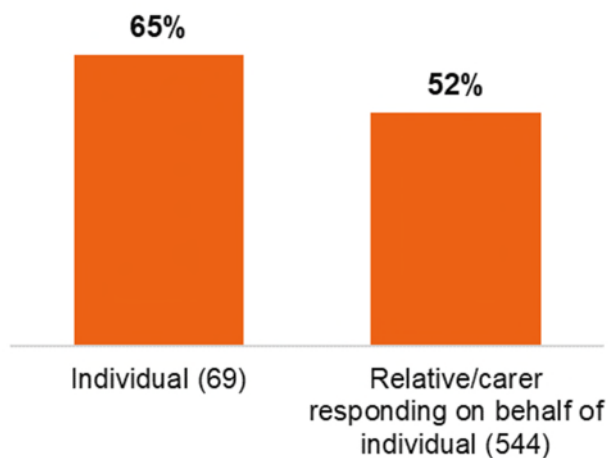
While individuals with DNACPRs responding on their own behalf reported fairly high involvement in conversations about medical treatment after the DNACPR was applied (77%), relatives or carers reported less involvement for themselves (66%) and less involvement of their loved one who they were responding on behalf of (58%).

Figure 10: The percentage of individuals with a DNACPR decision who felt that the decision caused delays or prevented other medical treatment



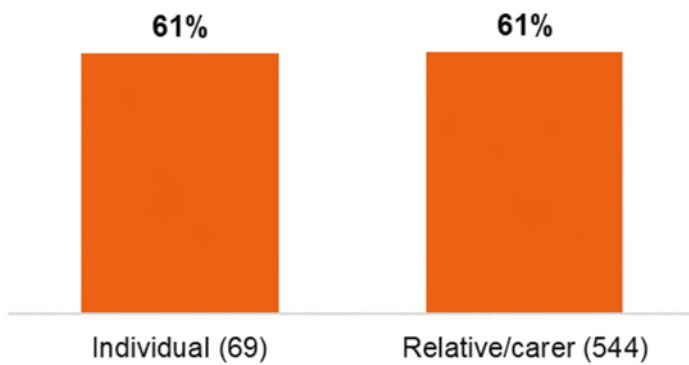
54% of individuals with a DNACPR decision and 44% of relatives or carers responding on behalf of an individual with a DNACPR stated that the decision had caused delays or prevented other medical treatment.

Figure 11: The percentage of individuals with a DNACPR decision who received enough information about the decision



Only 65% of individuals with a DNACPR decision and 52% of relatives or carers answering on behalf of individuals stated that enough information about the DNACPR decision was provided.

Figure 12: The percentage of individuals with a DNACPR decision and relatives or carers who were aware of who to contact in case they had any concerns surrounding the DNACPR decision process



61% of individuals with a DNACPR and 61% of relatives or carers knew who to contact with concerns around the DNACPR decision and process.

Figure 13: The percentage of individuals with a DNACPR decision that felt that they had experienced unfair or discriminatory treatment

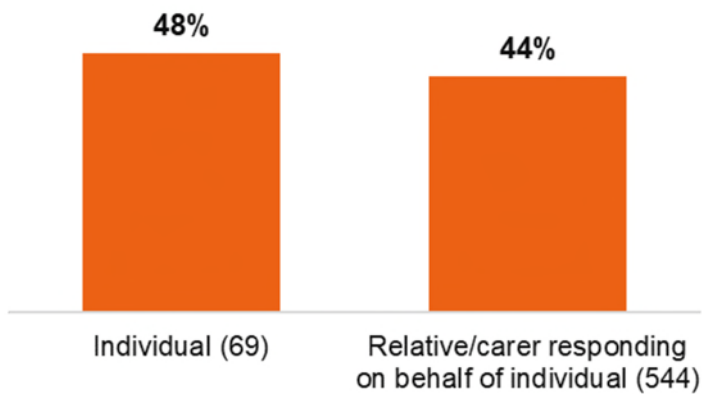
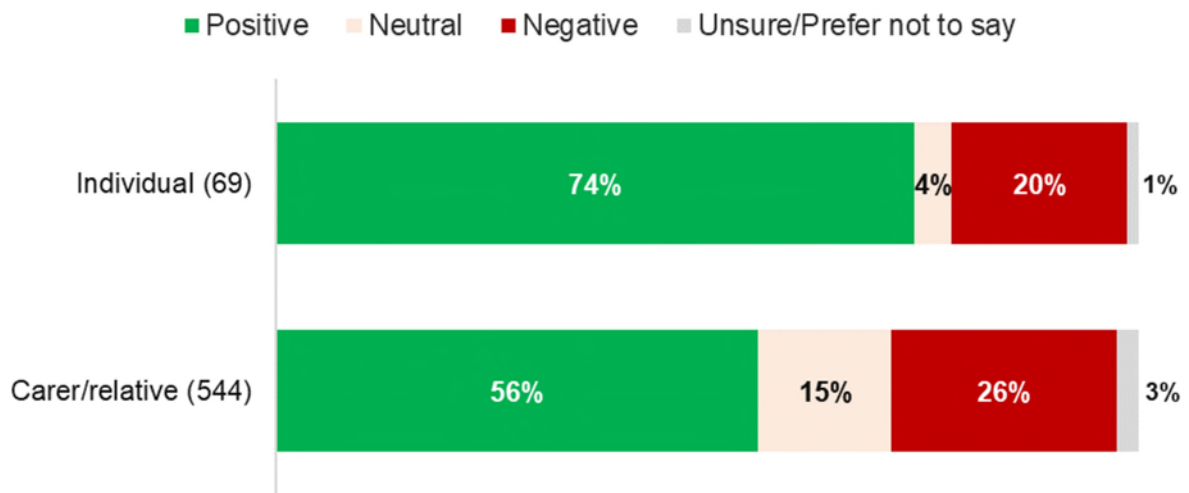


Figure 14: The impact of DNACPR decisions on trust and confidence in the health and care system for individuals with a DNACPR decision and relatives or carers



Unfair or discriminatory treatment was reported by both individuals with DNACPR decision and by relatives or carers responding on behalf of individuals. The DNACPR process appears to have had more of a negative impact on relatives or carers than the individuals with decisions in place.

Figure 15: Survey responses from individuals with a DNACPR decision – breakdown by the individual’s protected characteristics

	Protected characteristics of individual with DNACPR applied								
	Aged 65+	Dementia	Lacked capacity	Physical disability	Hidden disability or disabling health issue	Black or minority ethnic group	Learning disability	Autism	None of the above
Number of respondents	41	23	21	22	28	22	21	18	4
I was aware that the DNACPR decision had been applied	80%	61%	76%	73%	75%	55%	67%	89%	75%
My best interests and capacity to consent were completely/mostly considered	76%	78%	81%	82%	68%	86%	76%	94%	50%
I was completely/mostly supported to participate in a conversation about DNACPR	73%	78%	81%	73%	71%	91%	76%	94%	75%
I felt completely/mostly listened to	73%	78%	76%	68%	68%	82%	71%	94%	75%
I was involved in conversation about my medical treatment after DNACPR had been applied	83%	78%	100%	95%	71%	86%	86%	100%	75%
I was provided with sufficient information about my DNACPR	73%	65%	81%	82%	71%	64%	62%	94%	50%
I knew who to contact if I had any concerns about the DNACPR	66%	48%	71%	64%	61%	64%	67%	94%	50%
DNACPR decision has had a positive impact on my trust and confidence in health and care system	71%	78%	90%	73%	71%	95%	81%	94%	50%
My DNACPR has not caused delays or prevented other medical treatment	46%	30%	19%	45%	54%	18%	19%	6%	75%
I have experienced fair treatment during the DNACPR process	49%	39%	29%	50%	54%	41%	38%	11%	75%

Figure 16: Survey responses from relatives or carers responding on behalf of individuals with a DNACPR decision – breakdown by the individual’s protected characteristics

	Protected characteristics of individual with DNACPR applied								
	Aged 65+	Dementia	Lacked capacity	Physical disability	Hidden disability or disabling health issue	Black or minority ethnic group	Learning disability	Autism	None of the above
Number of respondents	325	193	149	140	122	106	98	70	14
My relative/friend was aware that DNACPR had been applied	55%	52%	51%	56%	59%	71%	76%	80%	57%
I was aware that the DNACPR had been applied	74%	77%	80%	72%	71%	81%	86%	83%	57%
My relative/friends best interests and capacity to consent were completely/mostly considered	58%	62%	63%	59%	55%	61%	70%	81%	50%
My relative/friend was completely/mostly supported to participate in a conversation about DNACPR	44%	50%	44%	53%	52%	59%	65%	77%	57%
I felt completely/mostly listened to	58%	62%	64%	58%	51%	64%	72%	76%	57%
My relative/friend was involved in conversation about their medical treatment after DNACPR had been applied	56%	53%	50%	56%	57%	72%	74%	80%	57%
I was involved in conversation about my relative/friend's medical treatment after DNACPR had been applied	64%	76%	76%	70%	60%	71%	79%	86%	57%
My relative/friend was provided with sufficient information	48%	55%	53%	53%	50%	70%	70%	79%	50%
I knew who to contact if I had any concerns about my relative/friend's DNACPR	56%	65%	65%	62%	61%	71%	79%	87%	57%
My relative/friend's DNACPR has had a positive impact on my trust and confidence in health and care system	49%	60%	57%	58%	55%	74%	79%	90%	50%
My relative/friend's DNACPR has not caused delays or prevented other medical treatment	62%	58%	45%	53%	56%	28%	30%	29%	79%
My relative/friend has experienced fair treatment during DNACPR process	60%	59%	46%	53%	52%	35%	29%	27%	64%

The tables above provide the survey results broken down by protected characteristics of the individual with a DNACPR (that is, in figure 16 it is not the protected characteristics of the relative or carer). Please note that the total number of respondents in figures 15 and 16 is more than 69 and 544 respectively, as individuals with a DNACPR decision could have more than one protected characteristic.

Adult social care provider information request

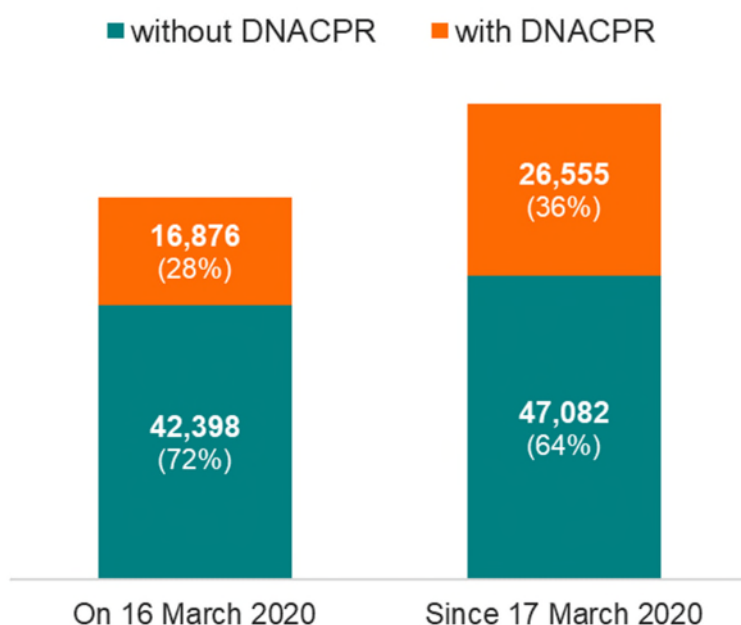
We sent a voluntary information request to around 25,000 adult social care providers (including care homes, nursing homes, domiciliary care agencies, supported living schemes, Shared Lives and extra care housing). While responsibility for making DNACPR decisions does not predominantly rest with adult social care providers, we asked them a range of questions to understand their views of the experiences of people in these settings. We asked about the number of inappropriate DNACPR decisions put in place since 17 March 2020, what made them inappropriate and if they remained on people's records at the point of submission of the information request.

In total, 2,171 responses were submitted between 7 December to 21 December 2020. However, a number of data quality issues were identified in the responses, which were likely a result of services incorrectly interpreting the questions. These issues meant the data was cleaned and analysis was only undertaken on 2,048 responses.

The relatively low response rate affects our confidence in the findings and means the results may not be generalisable. However, it is important to record and share the experiences of people working in services.

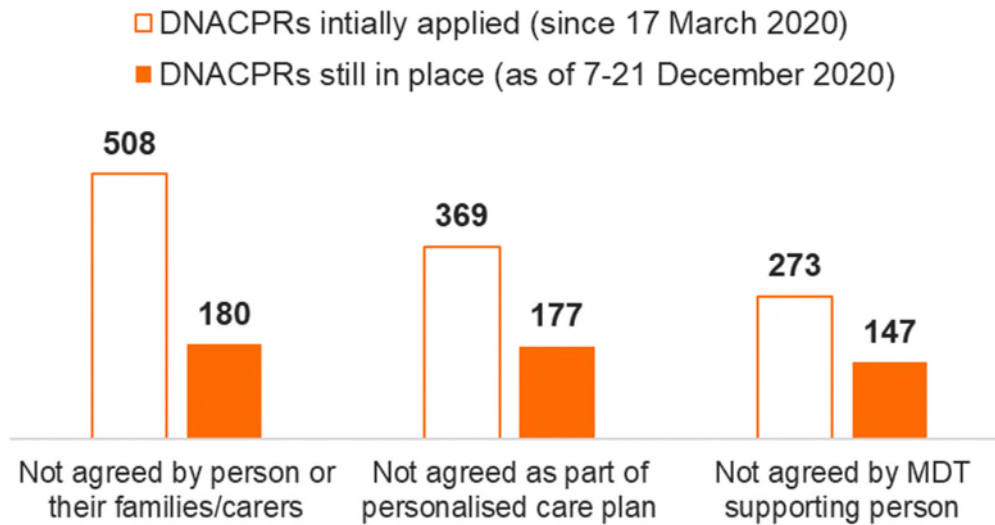
We wanted to understand how many DNACPRs were in place on 16 March 2020 compared to the number that had been applied since 17 March 2020.

Figure 17: People with a DNACPR decision in place, in the adult social care settings that responded to our information request (7 to 21 December 2020)



Of the sample that responded to our information request, the percentage of people in adult social care settings with a DNACPR decision increased from 28% on 16 March 2020 to 36% since 17 March 2020 (until the time the information request was submitted 07-21 December 2020).

Figure 18: The number of inappropriate DNACPR decisions reported by adult social care locations that responded to our information request



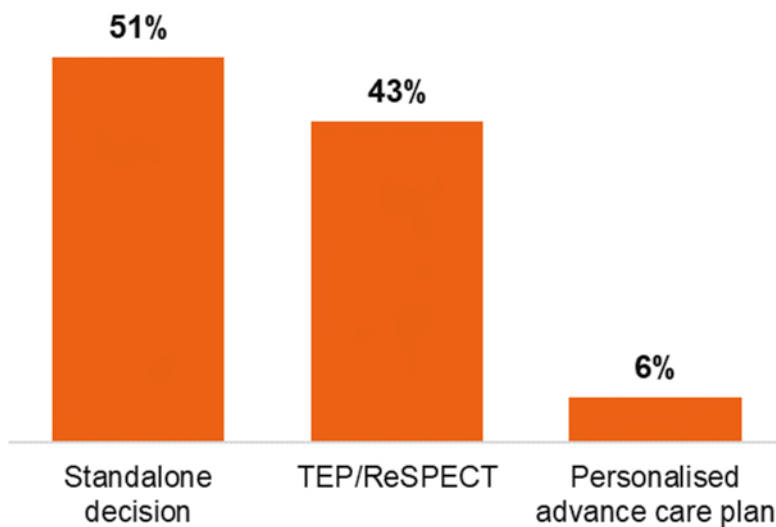
Of the people who had a DNACPR since 17 March 2020, some had not been agreed with the person or their relatives or carers (where the individual lacks capacity), as part of a personalised care plan, or with the multidisciplinary team supporting the person. A number of these still remained on people's care plans when this survey was completed in December 2020.

119 of the 2,048 (6%) adult social care services that responded to our information request felt that the people their service provided care for were subject to blanket DNACPR decisions, at any time since 17 March 2020. Please note that 624 services responded 'N/A' to this question, including 148 that stated that they had at least one person in their service with a DNACPR within the time periods included in the information request.

Review of DNACPR forms

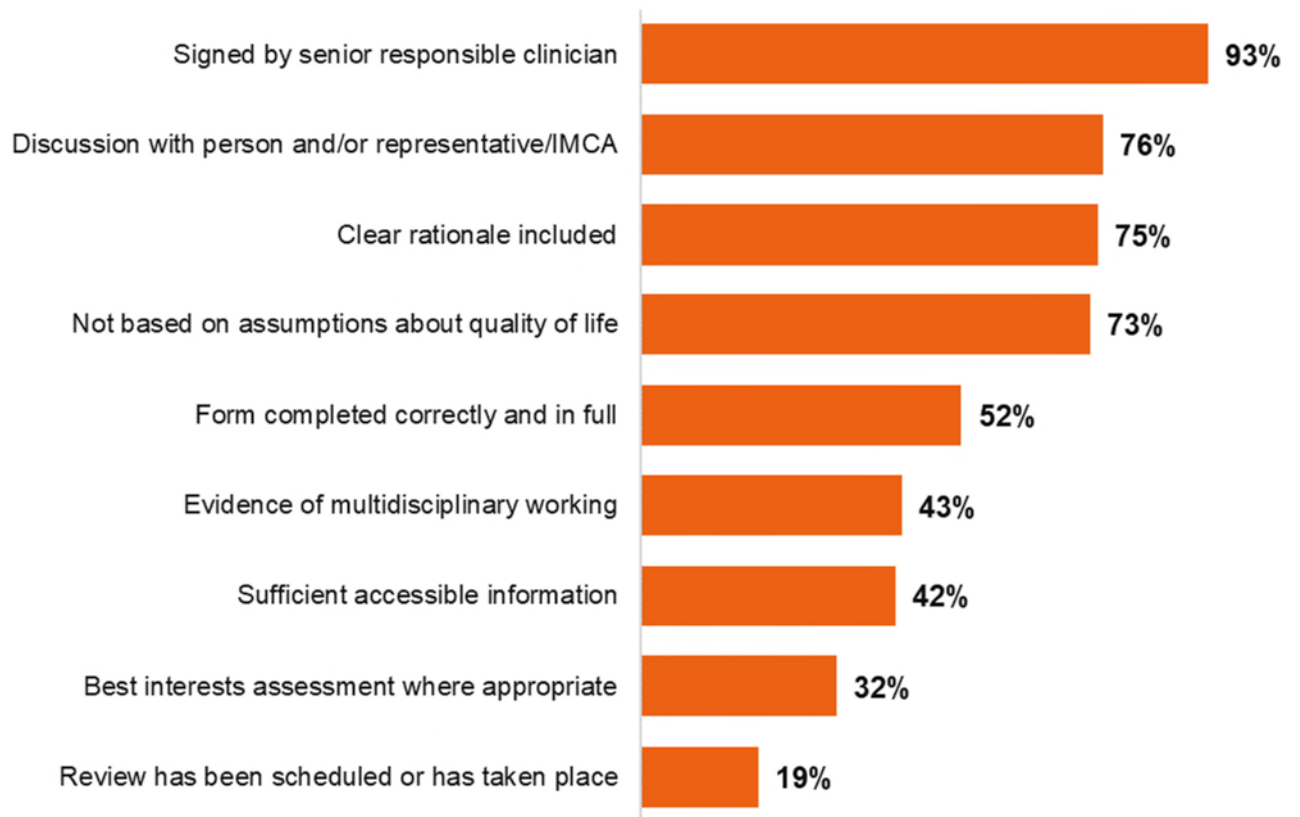
During the fieldwork we reviewed the DNACPR records of 166 people who have been affected during the pandemic. These did not consider every example of DNACPR decision since the pandemic, but allowed us to consider a larger number of decisions. We accessed care records through a range of care settings (acute, mental health hospitals, care homes and GP services).

Figure 19: Breakdown of how the DNACPR decisions that were reviewed were applied



Just over half (51%) of the reviewed DNACPRs were put in place as part of standalone decisions. DNACPRs in place as part of treatment escalation plan (TEP) or ReSPECT plans were the next most common (43%), whereas personalised advance care plan DNACPRs accounted for only 6% of reviewed forms.

Figure 20: Findings from the review of DNACPR forms across all forms and inspection settings



Findings varied considerably across the DNACPR form review questions. 93% of DNACPR forms (154 out of 166) had been signed by a senior responsible clinician, whereas only 19% (32 out of 166) included evidence of a review being scheduled or having had taken place.

Percentages based on 166 DNACPRs, except for *sufficient accessible information for decision making* (156) and *best interests assessment where appropriate* (103).

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