

Human Rights and DNARs: People's Experiences of DNAR Decision- Making in 2020



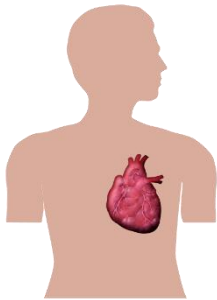
Stop Hello Eat
Words
person Day Open

We have explained some of the words that are used a lot in this report:



DNAR stands for Do Not Attempt Resuscitation.

This is when doctors decide that they will not restart your heart if you become very unwell.



DNARs are also sometimes called DNRs (which means Do Not Resuscitate) or DNACPR (which means Do Not Attempt Cardiopulmonary Resuscitation).



Human rights are protections that every person has just because they are human.

Human rights are about making sure people are listened to and treated with dignity and respect and fairness.

Human rights are protected by a UK law called the Human Rights Act.



This report is about what people have told us about DNARs and their human rights. We call it "our report" or "this report".

We have given this information to the Care Quality Commission.



The Care Quality Commission (CQC) checks services like GPs, hospitals and care homes to make sure they are giving good health and social care to people.

The CQC is reviewing DNAR decisions in 2020, and especially during Coronavirus, to see if these decisions have been wrong.



We use the words "staff and officials" in our report.

This means people who work in services like health and care. It also means officials such as social workers, police and teachers.



Who are we?



When we say "we", we mean the British Institute of Human Rights.

We sometimes shorten our name to BIHR.

We are a human rights charity that works across the UK.



We are working with 2 other organisations.
One is **Learning Disability England**.

Learning Disability England exists to make life better for and with people with Learning Disabilities and their families.



The other organisation we are working with is **Turning Point**.

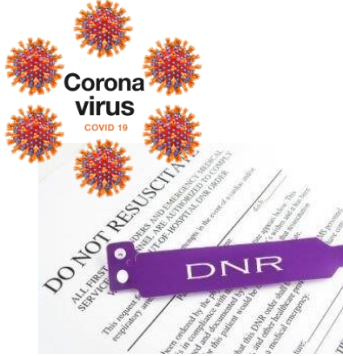
Turning Point provide lots of different health and wellbeing services.



Thank you to everyone who took part in our research.



What this report is about



We asked people about their experiences of DNAR decisions in 2020.



This report tells you:

- About why human rights are important for DNAR decisions.
- What people told us about their experiences of DNAR decisions
- What we think this means for people's human rights.



At the end of the report, we make recommendations for what needs to happen to make sure DNAR decisions uphold people's rights.

This includes recommendations for the CQC.



Human Rights and DNAR decisions



According to the law in the Human Rights Act, **everyone** has human rights. We all have human rights just because we are human.

Some rights can be restricted sometimes by staff and officials. Making a DNAR decision might restrict some of your human rights.



We all have the 16 rights in the Human Rights Act.

Below we tell you some of the rights that are important to DNAR decisions:






Right to life (Article 2)

The Right to Life (this is sometimes called Article 2)

No one should deliberately take your life away from you. This includes medical staff. This right can **never** be restricted.

Medical staff can decide to not treat you if:

- you are the end of your life and trying to treat you would cause harm; or

	<ul style="list-style-type: none"> • you are not fully conscious, and you will not recover.
 	<p>You can ask for a DNAR order if you want to plan your care in advance.</p> <p>Doctors can also decide to make a DNAR, so they will not try and restart your heart if it stops.</p> <p>This decision should be medical. It should NOT be based on discrimination (treating you worse because of who you are, for example, because you are disabled or older).</p>
 <p>Right to respect for private and family life, home and correspondence (Article 8)</p>	<p>Right to involvement in decisions and rights of people who care about you (this is called your Article 8 rights to family and private life)</p> <p>This right covers a lot of things that are important to all health and care decisions, including:</p> <ul style="list-style-type: none"> • well-being (including physical and mental health) • choice and being involved in decisions • taking part in your community • your family relationships • relationships including friends <p>This right means that you should be involved in decisions about your care and</p>



treatment. This includes being involved in decisions about DNARs.

If a mental capacity assessment says you cannot make these decisions, you should still be involved as much as possible. And staff should still try to find out your wishes and feelings about the decision they are making.



This right can be restricted by staff and officials. This might include when they make DNAR decisions.

But restrictions are only allowed if staff follow these 3 tests:



1. Does a law allow the restriction? Ask staff and officials to tell you what law they are using.



2. Is there a good reason to restrict your right? These reasons are explained in the Human Rights Act. The reasons are usually to protect you or other people.



3. Is the decision **proportionate**. This means the **least restrictive option**. Have staff thought about all the other things they could do instead?

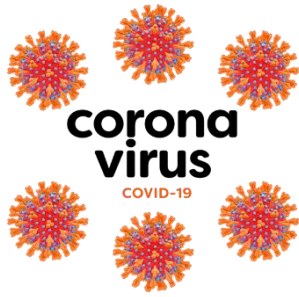


Right not to be discriminated against in relation to any of the human rights listed here (Article 14)

Right to non-discrimination (this is called Article 14)

This is your right to not be treated worse because of who you are, e.g., because you are disabled, a carer, older person, a child, from a Black or Minority Ethnic community.

This right is also in the Equality Act. The Human Rights Act covers the same 9 reasons for discrimination and more.



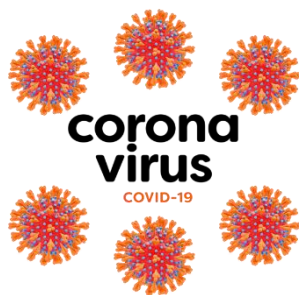
Human rights and DNAR decisions during Coronavirus



We are worried because people have told us that some DNAR decisions are being made because people are disabled, have learning disabilities, are autistic, are older, and/or have dementia.

This is discrimination because it is treating some people worse.

We are also worried that people are not being involved in decisions about DNARs that affect them or the people they care about.



We are worried this happens a lot.

Our research in the summer of 2020 said this discrimination is a problem during Coronavirus.



The CQC is investigating DNAR decisions during Coronavirus.

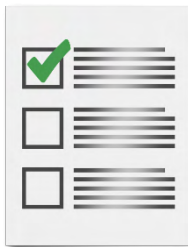
We decided to ask people to share their real-life experiences so we can tell the CQC how DNAR decisions are affecting people.



Our research: How we worked with people



We held an online workshop to help people find out more about their human rights and so they could tell us about DNAR decisions they had experienced.



We also had a survey people could fill in online.

These were open to anyone who wanted to share their experiences.



74 people took part in our research.

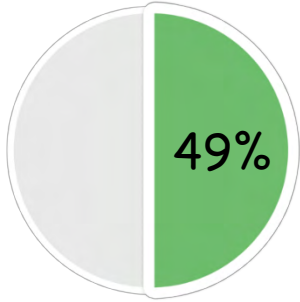
Most people who took part were advocates, supporters, friends or family of people who are disabled, have mental health issues, have learning disabilities, are autistic, or older.



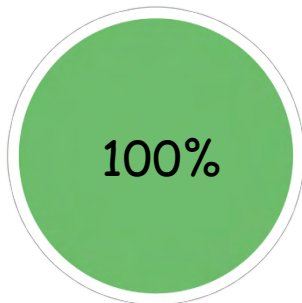
Most people were from the East of England, South East England, or North East England.



Our research: What we found out about human rights



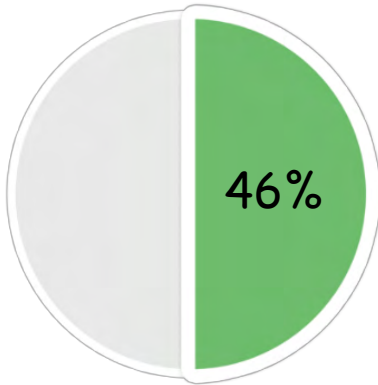
Almost half (49%) of people said they had not been given information about their human rights during Coronavirus.



100% of people said there needs to be more accessible information about human rights.

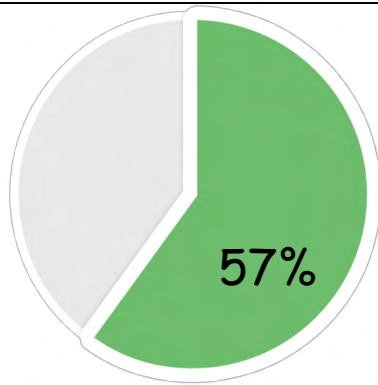


Our research: What we found out about the right to life



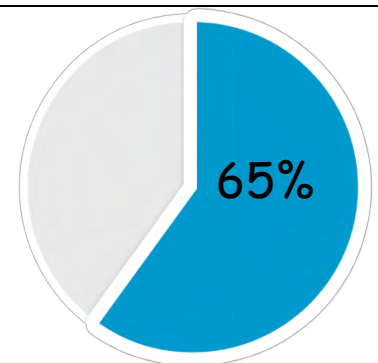
Almost half (46%) of people said they had not been given information about their right to life.

24% of people said they were not sure if they had been given information about their right to life.



31% of people said they had been told their life will have more protection during Coronavirus.

But 57% said they had not been given information about their right to life during Coronavirus.

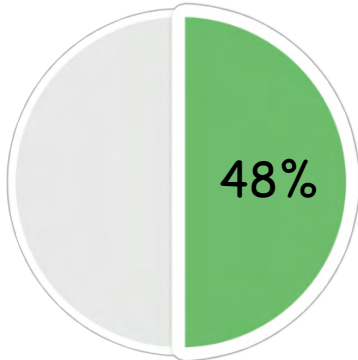


65% of people had a DNAR order on their medical records or the records of a family member or friend.

Only 26% were made because the person was at the end of their life.

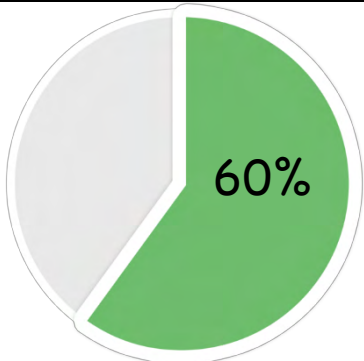


Our research: What we found out about the right to be involved in decisions and family life

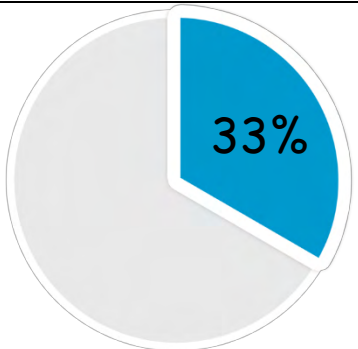


Almost half (48%) of people did not have capacity to make DNAR decisions for themselves.

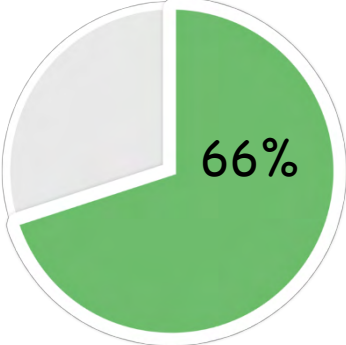
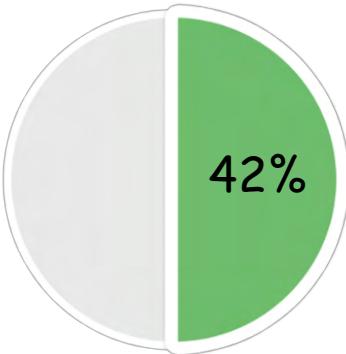
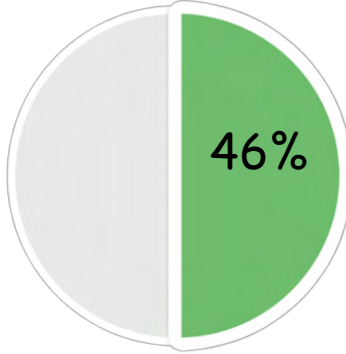
This means other people made the decision for them.



60% of people had been told by staff about the right to be involved in decisions about care and treatment, and that their wishes and feelings are very important.

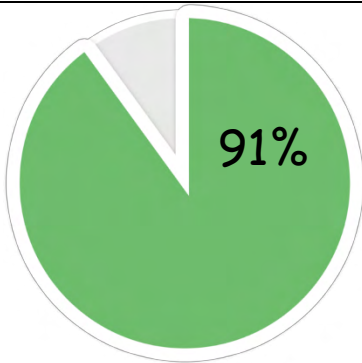


Only 33% of people were involved in DNAR decisions as part of planning their care in advance with staff.

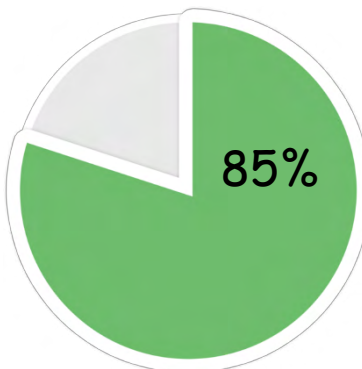
	<p>66% of people said they had not been involved in decisions about putting a DNAR on their medical file (or the file of the person they care about).</p>
	<p>Almost half of people (42%) said DNAR decisions have got worse during Coronavirus because they are not involved in making the decisions about their care and treatment.</p> <p>Also 13% decisions had not got worse but they are never involved in decisions any way.</p>
	<p>Almost half (46%) said they felt a bit listened to when staff made DNAR decisions.</p> <p>25% of people said they did not feel listened to when staff made DNAR decisions.</p>



Our research: What we found out about the right to not be discriminated against



Almost everyone (91%) said think the DNAR decisions they have experienced have been about staff treating people worse because of who they are. This is discrimination.



People thought the most common reason for staff treating people worse in a DNAR decision is because the person has learning disabilities (85%).

Other reasons for discrimination included because someone is over 65 years old or because they are disabled.

We asked people to share what DNARs made them feel, and this is what they told us:



Our research: People's stories

(We have changed people's names to protect their identity)



Emma had a good experience of DNAR decisions. Her dad was very unwell and near the end of this life. He would not survive if doctors tried to resuscitate him. But the doctor still asked Emma what she thought and involved her in the decision to make a DNAR.

But most of the stories people shared about DNAR decisions were not good. Here are 3 of the stories:



Ian supports people with care and health needs. He has seen a lot of DNAR decisions that list disabilities as reasons for not providing resuscitation, including learning disabilities and non-verbal. These are not medical reasons to withhold treatment. This is discrimination. Ian says he sees too many DNAR forms used like this. He challenges them.



Virginia works in a hospital. She is worried because she has seen doctors using the NICE frailty scale to make DNAR decisions about people with learning disabilities. This is even after it was said in April that this should not happen. She saw this happen in December.



Virginia is also worried because she sees DNARs being used to stop people coming to hospital for other treatment that could help them. A DNAR should not be used for other treatments.



Nancy is autistic. She has carers help her get washed and dressed. They do not provide medical care. When new carers came to help, they asked her if she has a DNAR.

Nancy told us, "why would I need one and why would you need to ask that question. I was quite upset about it and tried to explain why I was upset, and it made me think do I trust them. I said okay I am Autistic, and I have some medical problems but that is a personal question, and I don't think it is something you should want to know, you're only coming to help me shower. It's not like you're giving me medicine."



Our recommendations: What needs to happen now



All staff need to make DNAR decisions that respect people's human rights.

This includes people's rights to life, to be involved in decisions about care and treatment, and to not be treated in a discriminatory (or worse) way.



All staff involved in health and care should tell people about their human rights when they are getting care, support, and treatment.

This includes during DNAR decisions.

This information should be clear and accessible for people, to meet their communication needs.



The CQC must:

- Make it clear that DNAR decisions are about people's human rights, and that medical (and other) staff have legal duties to uphold these rights in their decision-making.
- Be clear that discrimination in DNAR decisions is not lawful. This means saying that medical decisions in the NHS must respect the Human Rights Act and the Equality Act.
- Make sure that the voices of people with lived experience of DNARs are really important in its Review of DNARs.
- Make sure that when they look at documents about DNARs they check if all the information is there and that it is accurate.
- Recognise that bad DNAR decisions have been around for a long time. Many older people and disabled people have been worried about bad DNAR decisions which do not involve them or treat them worse. These DNAR decisions may have got worse during Coronavirus. They have to be stopped.