

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

(February 2021)



Stop Hello Eat
Words
person Day open

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



DNAR means 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.

	<p>This report is about what staff who work in health, social care, and social work have told us about DNARs and human rights. We call it "our report" or "this report".</p> <p>We have given this information to the Care Quality Commission.</p>
	<p>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.</p> <p>The CQC is reviewing DNAR decisions in 2020, and especially during Coronavirus, to see if these decisions have been wrong.</p>
	<p>We use the words "staff and officials" in our report.</p> <p>This means people who work in services like health and care. It also means officials such as social workers, police and teachers.</p>
	<p>Who are we?</p>
	<p>When we write "we", we mean the British Institute of Human Rights.</p> <p>We sometimes shorten our name to BIHR.</p> <p>We are a human rights charity that works across the UK.</p>



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.



If you want to email us about this report, please contact Carlyn on cmiller@bihr.org.uk or Sanchita on shosali@bihr.org.uk



What this report is about



We asked staff that work in health, care, and social work about their experiences of DNAR decisions in 2020.



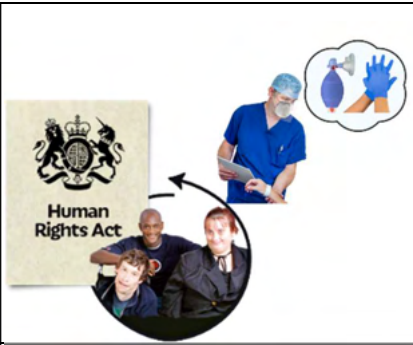
This report tells you:

- About why human rights are important for DNAR decisions.
- What staff 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. But there are rules about when and how staff can make these restrictions of rights.



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




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



Our 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:

	<ul style="list-style-type: none"> • you are the end of your life and trying to treat you would cause harm; or • 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>Our 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. 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)

Our 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, a UK law which says you should not be discriminated against for 9 reasons. The Human Rights Act covers the same 9 reasons and more.



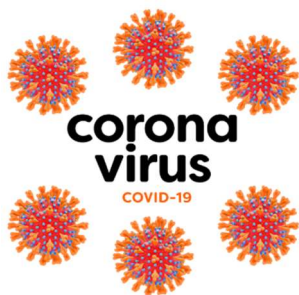
Human rights and DNAR decisions during Coronavirus



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 without a good reason.

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 big problem during Coronavirus.



The CQC is investigating DNAR decisions during Coronavirus.

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



Our research: How we worked with staff



We held an online workshop to help staff working on health, care and social work find out more about human rights and so they could tell us about DNAR decisions they had experienced.



We also had a survey staff could fill in online. These were open to anyone who wanted to share their experiences.

We also did the same thing with people, families and supporters in December 2020. You can read the report about that here: www.bihhr.org.uk/dnar-decision-making-2020-bihr



Over 70 staff took part in our research.

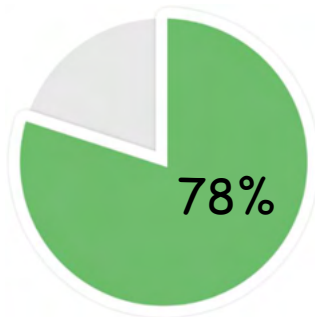
Most people who took part were nurses, social workers and health or care managers. Most of the staff supported adults with care and support needs. This includes physical disability, mental health, learning disabilities, autism, older people and/or people from Black and Minority Ethnic backgrounds.



Most people were from the West Midlands, South East England, Yorkshire & Humberside or London.

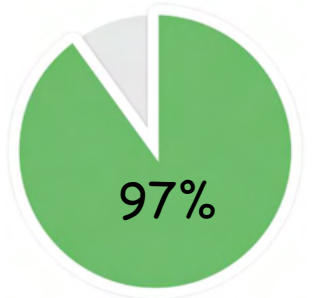


Our research: What we found out about human rights



78% of staff said that they felt supported to uphold human rights in their day-to-day work.

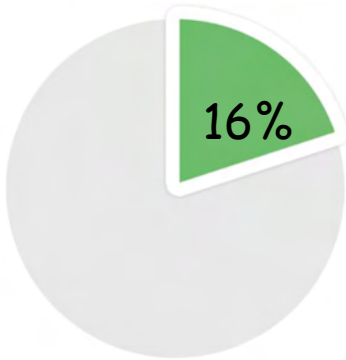
But, only 46% said they felt supported to uphold human rights in their work during Coronavirus.



97% of staff said there needs to be more accessible information about human rights.

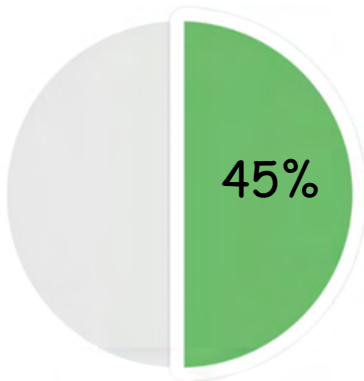


Our research: What we found out about the right to life



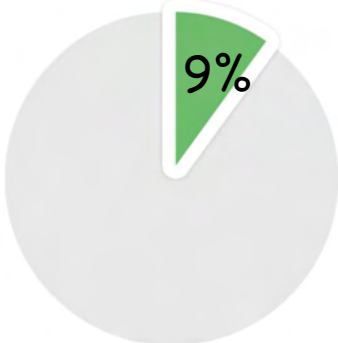
16% of staff said that, in their experience, the right to life was **not** discussed with people in DNAR decisions.

66% of staff said the right to life was **sometimes** discussed with people in DNAR decisions.



Less than half of staff felt supported to uphold people's right to life in DNAR decision making during Coronavirus.

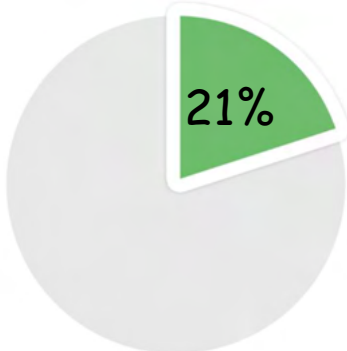
42% of staff said that they **sometimes** feel supported to uphold people's right to life in DNAR decision making during Coronavirus.



9% of staff did **not** feel supported to uphold people's right to life in DNAR decision making during Coronavirus.

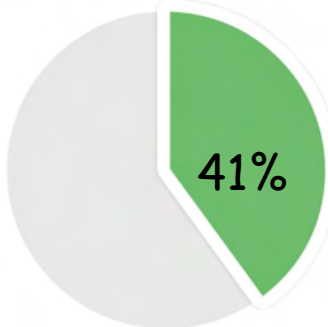


Our research: What we found out about the right to be involved in decisions and family life



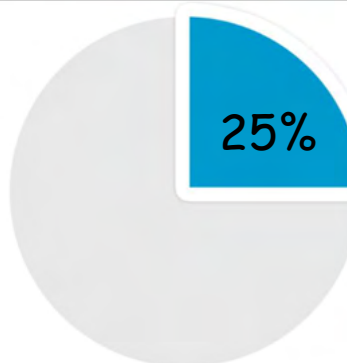
21% of staff said that, in their experience, people's right to be involved in decision making is **not** discussed with them.

66% of staff said that people's right to be involved in decision making was **sometimes** discussed with them.



41% of staff said that it was **assumed** that people who had a DNAR decision made about them did not have the capacity to be involved in this decision. This means a capacity assessment had not taken place.

The law in the Mental Capacity Act says staff should do a capacity assessment to decide if someone can make a decision about their care and treatment. Staff should not make assumptions about this.

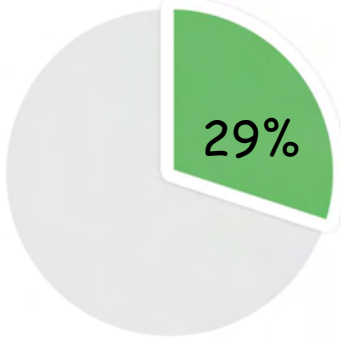


Only 25% of staff felt supported to involve people in decision making around DNARs.

31% of staff **sometimes** felt supported to involve people in decision making around DNARs.

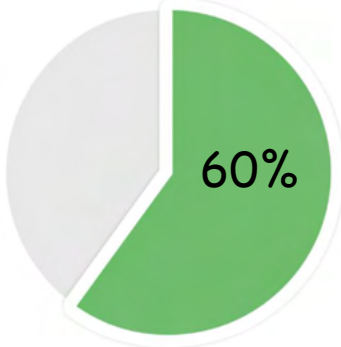


Our research: What we found out about the right to not be discriminated against



29% of staff felt that discrimination **was** an issue in the DNAR decisions they had experienced.

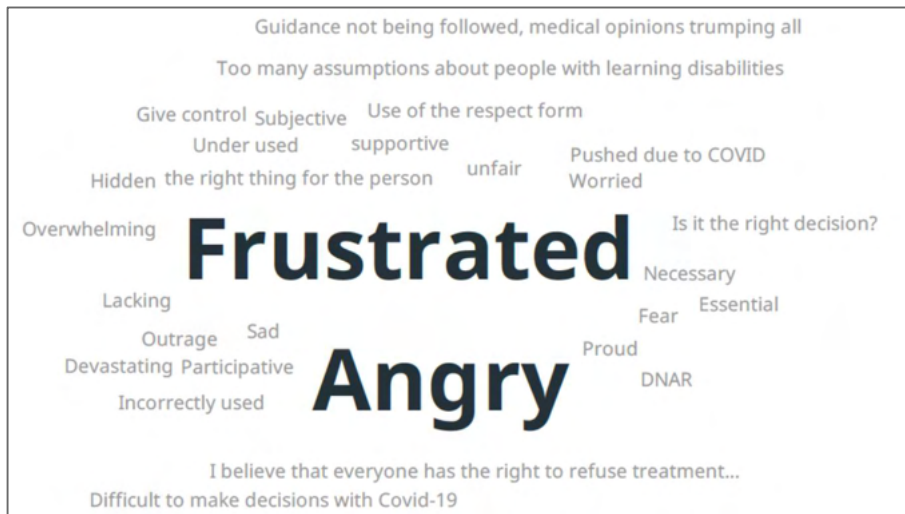
25% felt that discrimination was **sometimes** an issue.



Staff thought the most common reason for people being treated worse in a DNAR decision is because the person has learning disabilities (60%).

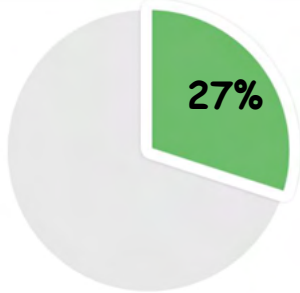
Other reasons for discrimination included because someone has other mental capacity issues such as dementia or a brain injury is or because they are over 65 years old.

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

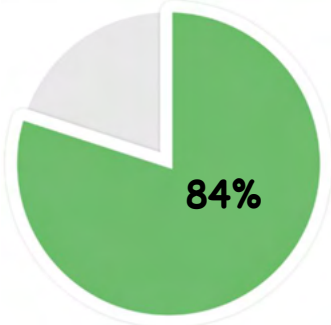


Our research: Staff's experiences and stories

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



27% of staff had been involved in DNAR decisions during Coronavirus and thought that they were being used more.



Of the staff who had who had seen a DNAR order put in place, 84% were not related to end-of-life care. This means they were used in situations where a person was not dying.

We heard some stories from staff about how people have been involved in making DNAR decisions which have been good:



One staff member talked about Susan, an older woman they support. They talked about DNAR with Susan using an easy read document. Susan said she did not want a DNAR order made and this decision was respected.



One staff member said they had experienced people make plans about what they want to happen at the end of their life. This included people's wishes to stay in the care home they lived in rather than going to hospital and saying what they wanted at their funeral such as what music they want to be played.

The staff member said this helped people feel calm because they had put everything in order at the end of their life and that their family and friends will not have to worry about make decisions for them.

But a lot of the stories staff shared about DNAR decisions were not good. Here is one of the stories:



Will works in a care home. Jim was living at the care home and went into hospital with pneumonia. Jim got Coronavirus when he was in hospital and had to stay for a few weeks.

Staff at the hospital decided to make a DNAR order for Jim without talking to Jim, his family or Will who is the manager of the care home where Jim lives.

The hospital didn't tell Jim's family or Will about decision for ten days. When Jim's family found out they were very upset. It took the long time and was difficult for the family to get the DNAR order removed.



Our recommendations: What needs to happen now



All public services such as the NHS and care services and regulators like the CQC must think about how to protect people's human rights in every decision they make about people.



All staff 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.



There needs to be a system to check that DNAR orders are made properly.

The CQC has an important job to do on this.

So do the organisations decide what health and care services are available (commissioners) in the UK government and in local communities.



The CQC must:

- Make it clear that DNAR decisions are about people's human rights, and that it is the law that medical (and other) staff have to protect these rights when making decisions.
- Be clear that discrimination in DNAR decisions is not lawful. This means saying that medical decisions in the NHS must follow 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.