

# Scared, Angry, Discriminatory, Out of My Control: DNAR Decision-making in 2020



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## About BIHR

The British Institute of Human Rights (BIHR) is a charity working in communities across the UK to enable positive change through human rights. We work to support people with the information they need to benefit from their rights; with community groups to advocate for better protections in their areas or interest groups; and with staff across public services to support them to make rights-respecting decisions. This enables us to call for the development of national law and policy which truly understands people's experiences of their human rights. We work with over 2,000 people using public services, community groups and the staff members delivering them; our recommendations are directly informed by people's real-life experiences of the issues.

## Summary

"I'm only 46 years old, 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's 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 or medical help."

N, Workshop Attendee, who was asked by carers if she had a DNAR order in place

A Do Not Attempt Resuscitation decision is when medical professionals decide to not provide CPR (cardiopulmonary resuscitation) to an individual. A DNAR order is also sometimes called a DNACPR order or DNR order.

When DNAR orders are made with the full involvement of a person, as part of advanced care planning or a treatment plan, this can be an example of good human rights practice.

The use of DNARs orders without involving the person and/or their loved ones raises a number of human rights issues including: the right to life, the right to be free from inhuman and degrading treatment, the right to family and private life and the right to be free from discrimination.

## Background

As part of [BIHR's work](#), to assess the human rights implications of Covid-19, we discovered that almost [1 in 10 people](#) accessing health, care and support services had experienced a DNAR order being placed on their file without consultation or pressure to agree to an order. Over [1 in 3 staff members](#) had experienced pressure to put DNAR orders in place without involving the person in the decision.

Based on the DNAR evidence above, we decided it was crucial to gather more information from people who have experienced DNAR decision making, both since and prior to the Coronavirus pandemic.

Around the same time as our work to gather further evidence of people's experiences of DNAR orders, the Department of Health and Social Care (DHSC) asked the Care Quality Commission (CQC) to [review](#) how do not resuscitate orders were used during the Covid-19 pandemic. This Review takes place between October 2020 – January 2021.

This report therefore sets out our recommendations which we hope will be considered by the CQC in their review, but which also exist as standalone recommendations about DNAR orders and the need for them to be framed exactly as they are, as human rights issues.

## Key findings

Our evidence gathered in December 2020 is outlined in this report. It shows a worrying picture around the rights of involvement in care and treatment decisions, including DNARs. Our evidence depicts serious issues of discrimination related to disability and age, and the intersection between the two, as well as other factors. Coronavirus has shone a spotlight on this, and some reported an increase in worrying DNAR decisions; but none of this is new, these problems are ongoing.

This report focuses on the experiences of people and their loved ones. We will be conducting similar work at the start of January 2021 with frontline staff in health, care, social work and related fields.

## Key findings

Of the people who attended our research workshop and completed our survey:

- 100% of people involved said there needs to be more easily accessible information about human rights.
- Almost 60% of people involved said they'd received no information about their right to life during Coronavirus.
- 65% of people involved said that they (or a person they care for/about) had a DNAR order put on their medical file. 21% said they didn't know.
- Of those who had seen a DNAR order put in place, almost half (47%) were not related to end-of-life care.
- Less than a third of people (29%) who were involved in DNAR decision-making felt fully listened to, most felt listened to a bit (46%), and 25% felt not listened to.
- 91% of people involved felt that discrimination was an issue in the DNAR decisions they'd experienced.

## Recommendations

To achieve a culture of respect for human rights in the UK which ensures that people's legally protected rights are respected, protected and fulfilled, we must:

- Make it clear that DNAR decisions are about people’s legally protected human rights, and that medical (and other) staff have legal duties to uphold these rights in their decision-making.
- Be clear that discriminatory DNAR decisions are never lawful; and that all medical decisions within the NHS are subject to the Human Rights Act, and related legislation such as the Equality Act.
- Ensure that the voices of people with lived experience of DNARs are at the heart of any review.
- Any review of documentation must include testing the veracity and completeness of the information provided.
- Recognise that concerns around DNAR decision-making risking people’s rights are not new; whilst Coronavirus has shone a brighter spotlight on these issues, they are part of a wider pattern of the discrimination experienced by disabled and older people within health and care. Recommendations for action must include a focus on Coronavirus issues, which continue today and are not limited to the start of the pandemic, and beyond.
- Public services/bodies which have a duty to uphold human rights, should inform people receiving their services of their human rights as they apply to those services. This should include specific information about people’s human rights during Coronavirus. For the purposes of this report, this should include information about human rights in relation to DNAR decisions.
- All of the above must go together with ensuring frontline staff making decisions, including DNAR decisions, do so from the basis of human rights, fully understanding their legal duty under the Human Rights Act to uphold people’s rights and to make lawful and non-discriminatory decisions. This requires several measures including working directly with people – on an equal footing - to understand the issues and put change measures in place; learning and development; supervision and review of decision-making; clear direction from senior management and leadership; ensuring independent, securely funded advocacy with the ability to challenge decision-makers.
- There should be a clear national statement on DNAR decision-making to be human rights-based.

## **Partner organisations**

Working with Learning Disability England and Turning Point we committed to providing a platform for people to share their experiences of DNAR decisions and in doing so, build their human rights knowledge and skills.

We held an online workshop on 2 December with over 60 people affected by DNARs, including disabled people, older people, people with learning disabilities, Autistic people, family and friends, as well as advocates and medics.

This report focuses on the experiences of people and their loved ones. On 11<sup>th</sup> January we will be running a [similar workshop](#) with frontline staff in health, care, social work and other related fields. This research will be published early next year.

## **With thanks**

We'd like to take this opportunity to thank everyone who shared their experiences with us. It is not an easy thing to do but in doing so you have allowed us to shine a spotlight on issues involving our most sacred human right – the right to life (Art 2, Human Rights Act and European Convention Human Rights). Your involvement is what enables us to call for the development of national law and policy which truly understands people's experiences of their human rights.

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# 1. Human rights and DNARs

This section sets out:

1.A What is a DNAR

1.B Human rights law and what this means for DNAR decisions in practice

1.C Human rights concern about DNAR decisions in practice

## 1.A: What is a DNAR?

A Do Not Attempt Resuscitation decision is when medical professionals decide to not provide CPR (cardiopulmonary resuscitation). A DNAR order is also sometimes called a DNACPR order or DNR order.

CPR is an emergency treatment used to restart a person's heart and breathing if they stop (called a cardiopulmonary arrest). The aim is to keep the person alive whilst identifying and correcting the cause of the cardiopulmonary arrest (where it is correctable). CPR can include chest compressions (repeatedly pushing firmly on the chest); inflating the lungs by inserting a tube into the windpipe or placing a mask over the mouth and nose; and defibrillation, which uses electric shocks to correct the heart's rhythm. CPR can be a life-saving treatment, depending on the situation; but it is important to remember that CPR is an invasive treatment and is not always successful. When CPR is successful in restarting the heart, recovery will depend on many factors. Additionally, even if CPR does restart the heart and breathing, during the time the heart is not beating the brain may not get enough blood supply and brain damage may occur. The different types of CPR can also result in bruising, cracked or broken ribs and/or punctured lungs.

DNAR decisions are medical decisions. Often, these decisions will take place as part of advance care planning to allow people to decide that they do not want CPR in certain situations. It can also be discussed with people as part of their treatment plan, where medics do not think CPR would be beneficial, for example because someone is at the end of their life.

## 1.B: Human rights law and what this means for DNAR decisions in practice

A DNAR decision also needs to be a lawful decision. This includes complying with the law in the Human Rights Act. It is crucial to note that the Human Rights Act includes a legal duty on public bodies, and those exercising public functions, to act compatibly with the human rights it contains. This means:

- respecting human rights i.e., taking a step back and not breaching or restricting people's rights
- protecting human rights, i.e., taking positive reasonable steps to ensure people's rights are safeguarded

- fulfilling human rights, i.e., having the right processes in place so people can enjoy their rights, and procedures for investigating when things go wrong.

The Human Rights Act contains several human rights which are relevant to DNAR decisions, including:

- The right to life (Article 2). In a healthcare context this means not deliberately taking a person's life (the respect duty), but it does allow for withdrawal of treatment where there is no prospect of survival or improvement from a minimally conscious state. The positive duty to protect this right does not extend to taking all measures at any cost. The measures must be reasonable (judged against the body of medical opinion) and they should not cause harm that will result in inhuman or degrading treatment (see below). For example, severe physical trauma caused by a DNAR procedure that may have little chance of success.
- The right to not be treated in an inhuman or degrading way (Article 3). This is an absolute right, which means treatment that amounts to this standard is never lawful, no matter the reason for it. Treatment can include an active decision or action (e.g., providing treatment) or an omission (e.g., failing to provide treatment). As above, the positive duty to protect against inhuman and degrading treatment requires taking reasonable steps when someone's right is known to be at risk, or it ought to have been known it would be at risk.
- The right to private and family life, which upholds choice and involvement in decisions about your life (including care and treatment) and your family unit (Article 8). This right can be restricted, provided the staff in a public body (including NHS services) have followed a 3-stage test:
  - Is there a law that allows the restriction?
  - Is it for a legitimate aim (outlined in the right itself, usually the protection of the person or wider community)?
  - Is it proportionate, i.e., has the option least restrictive of the right been taken?

In terms of DNAR decisions this means that people have a right to be involved in such decisions, unless a medic can show the 3 tests above have been met. If there are queries about whether a person is able to make this decision, then a Mental Capacity Act (MCA) assessment should be conducted. The use of the MCA still needs to be human rights compliant and the Human Rights Act sets out that all other law and policy should be interpreted in a way that makes it compatible with human rights (unless there is no way this is possible). This means even if people lack capacity to make decisions about DNARs, their wishes and feelings must still be an important part of the decision-making process for medics.

This right also protects family life, and this is where consultation with family members (or other significant people in a person's life) is an important part of the human rights protections, unless medics can meet the 3-stage test above to exclude such considerations.

"... since a DNACPR decision is one which will potentially deprive the patient of life-saving treatment, there should be a presumption in favour of patient involvement. There need to be

convincing reasons not to involve the patient ... doctors should be wary of being too ready to exclude patients from the process on the grounds that their involvement is likely to distress them. Many patients may find it distressing to discuss the question whether CPR should be withheld from them in the event of a cardio-respiratory arrest ...the fact that she may find the topic distressing is unlikely to make it inappropriate to involve her ... The duty to consult which this court has described involves a discussion, where practicable, about the patient's wishes and feelings that is better undertaken at the earliest stages of the clinical relationship so that decisions can be reviewed as circumstances change. That involves an acknowledgement that the duty to consult is integral to the respect for the dignity of the patient."

Court of Appeal in *R (on the application of Tracey) v Cambridge University Hospitals NHS Foundation Trust and Secretary of State for Health* (2014)

- The right to not be discriminated against in the enjoyment of these rights (Article 14). This means none of the above rights should be restricted in a way that is discriminatory. It also enables different treatment to support people to enjoy their rights equally with others, for example making adjustments for disabled people or children. The reasons for discrimination are open-ended. This means it covers all the same areas at the Equality Act; race/ethnicity, sex, gender reassignment, disability, age, marriage/civil partnership, maternity, religion/belief, or sexual orientation. The Human Rights Act includes all of these and other issues, e.g., homelessness, and the combination of reasons, e.g., being discriminated against because you are a young woman with a learning disability (sex and disability).

## 1.C: Human rights concerns about DNAR decisions in practice

A DNAR order which considers the human rights set out above does not raise concerns. In fact, a DNAR which has been made with the full involvement of a person, as part of advanced care planning or a treatment plan, can be an example of good human rights practice.

The concern arises with DNAR decisions that are disproportionate and/or discriminatory. For example, this might include:

- Making assumptions about a person's quality of life because they are disabled or older and that they should not have CPR
- Making assumptions about what a person would want without discussing it with them
- Where a person has been assessed as lacking capacity to make a decision about a DNAR (or related to care and treatment), making that decision without finding out what they want or would have wanted
- Relying only on what the family or significant others of a person would want without finding out what that person wants or would have wanted themselves
- Using a DNAR as a justification to not provide other care and treatment, including refusal to take or admit someone to hospital for other treatment
- Performing CPR at all costs when success is futile and will result in suffering.

## 2. Covid-19 and DNARs

This section sets out:

- 2.A: The context of Covid-19 and DNARs
- 2.B: BIHR's summer 2020 research
- 2.C: The Care Quality Commission Review

### 2.A: The context of Covid-19 and DNARs

BIHR's experience is that poor DNAR decisions which risk people's human rights have long been an issue in the UK. In particular, we have seen this in relation to people who are disabled (including physical disability and learning disabilities) and/or older. In our experience the discriminatory and/or disproportionate use of DNARs are part of wider systemic issues around inequalities within public service provision. This spans a lack of access to basic services like appropriate education and housing, through to shorter life expectancy and shocking avoidable deaths when in the hands of health and care services<sup>1</sup>.

However, Covid-19 has shone a bright spotlight on this issue of potentially life-saving treatment, particularly around DNAR decisions. "[Strain](#)" on the NHS has been one of the dominant narratives during the pandemic, and many measures taken have been to avoid overloading the healthcare system. Within this context the idea of "rationing" treatment and services – as opposed to universal healthcare – becomes easier to justify. Within weeks of the first pandemic measures and lockdowns in the UK, reports began surfacing of worrying practices around DNAR decisions:

- [According](#) to a care provider, three services (in Somerset, Derbyshire and East Sussex) were contacted by GPs to say that they have deemed the people they support, who have learning disabilities, and other complex needs, should all be DNR. There was no mention of consultation with families or best interests' assessments.
- According to the [Guardian](#), people in care homes in Hove, East Sussex and south Wales are among those who have had DNAR notices applied to their care plans during the coronavirus outbreak without proper consultation with them or their families.
- Care homes in Leeds have reported that district nurses have been asking them to "revisit do not resuscitate conversations with people who said they didn't want them" and a care worker in Wales [told the Guardian](#) that after a visit from a GP, all 20 of their residents had DNAR notices attached to their plans.
- A GP surgery in Wales [sent a letter](#) asking patients with life-limiting illnesses to complete a "do not resuscitate" form.
- [The NICE Clinical Framework Guidance](#), on how doctors should decide who could get emergency care during the coronavirus crisis [was rewritten](#) after complaints that the initial guidelines suggested that disabled people could be denied treatment.

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<sup>1</sup> BIHR has written a number of blogs on these [issues](#), and the [campaigns and protests held in response](#).

## 2.B: BIHR's summer 2020 research

Since the pandemic hit the UK in March 2020 BIHR has worked with over 2000 people directly, offering human rights support to challenge and change practices and policies to ensure they are upholding human rights. This includes people using services, their families and those who care about or for them, advocacy, and community groups, and over 1200 frontline staff and leaders across health, care, education, and social work. [Our research](#) explored the human rights implications of the UK Government's response to Covid-19, drawing on people's real work experiences. The research, with over 260 people, revealed worrying findings about upholding people's rights during the pandemic, including around the use of DNAR orders:

Issue	People	Community groups	Staff in public services
Not been provided with information on training on upholding human rights during Covid-19 (that they have not changed)	N/A	N/A	76%
More worried about your human rights because of the pandemic	100%	N/A	N/A
Has been harder to uphold human rights during the pandemic	N/A	N/A	82%
Less confident to raise concerns about human rights in the pandemic?	57%	34.7%	22%
Experienced life not being protected because of reduced services or the prioritisation of other services	16.3%	29%	18.4%
DNAR orders being made without involving the person in the decision or being pressured to agree to it	9.3%	70.8%	34.2%
Consider discrimination has been a factor in the concerning issues experienced around people's care and treatment during the pandemic	50%	47.8%	30.7%

Our findings have been reflected in other research and inquiries, including [Learning Disability England's snapshot survey on the use of DNARs in 2020](#) early this year. 88 organisations responded to the survey. The findings included:

- 13 organisations reported that they had seen an increase in blanket DNARs in March and April.
- 8 organisations had seen DNARs placed in people's records without consultation in March
- Despite the publicity and clear guidance 10 reported this happening in April.
- Many organisations provided more detailed comments on the experiences of DNARs amongst people they were supported, including:

- “Blanket re-assessment from GP practice of all LD patients. Use of frailty scales to justify DNAR in a case of two people with LD but no significant underlying health issues.”
- “The tenants of 2 flats were sent a blanket letter from their GP to advise that due to Covid-19 all tenants would need to be put on a DNAR, they are all adults with learning disabilities with no need to have DNARs in place.”
- “We have seen an increase in people being admitted to hospital and DNACPR being used without consulting the person or their carers, or sometimes where the only person consulted is a relative who has minimal contact with the person and therefore does not know **them** well. This has happened before corona virus and has continued - we have seen more people come home from hospital with DNACPR in place without our knowledge or evidence of a best interest process. The respect process has been beneficial in having these conversations and supporting people to make plans for future care.”
- “We became aware of the guidance from NICE and from NHS Chiefs, specifically around not using the Clinical Frailty Scale or DNACPR on people with learning disabilities, Down's Syndrome and autism. We didn't trust that that information would reach the frontline paramedics/first responders so attached a very assertive letter to everyone's hospital passports, with an injunction to staff to ensure they drew healthcare staff's attention to it. So, we have acted preventatively. What I would say is that the issue is about blanket DNR, but it is also about adverse triage: decisions not to take people to hospital, decisions not to escalate treatment which are equally if not more worrying for the people we support.”
- “People who would usually be admitted to hospital told that they would not receive ICU support or ventilation. These were people with no underlying health conditions.”

From this, we know that there is cause for concern that people's legally protected human rights are being risked during the pandemic, including in relation to DNAR decisions.

## 2.C: The Care Quality Commission Review

In October, the Department of Health and Social Care (DHSC) asked the Care Quality Commission (CQC) to [review](#) how do not resuscitate orders were used during the COVID-19 pandemic, building on concerns that we reported earlier in the year. [This Review](#) takes place between October 2020 – January 2021. In December 2020 the CQC released their [interim report](#), which found that at the beginning of the pandemic, a combination of unprecedented pressure on care providers and other issues may have led to decisions concerning DNACPR being incorrectly conflated with other clinical assessments around critical care. The CQC states that there is no evidence to suggest that blanket approaches to DNACPR decisions are being used currently, people who use services and groups that represent them told CQC that early in the pandemic they or their loved ones received DNACPR decisions which were not based on their wishes and needs, and without their

knowledge and consent. They go on to say it is unacceptable for decisions to be applied to groups of people of any description.

When the Review was announced in October, BIHR and the organisations we work with, were clear that people with lived experience of DNAR decisions should be at the heart of this review. This includes people needing care and treatment and their families and those who care about or for them; the community and advocacy groups supporting people; and the frontline staff involved in making these decisions. In addition to providing early evidence to the CQC (in the interim report) and sitting on the Expert Reference Group for the Review, we have undertaken people-focused research to produce this human rights analysis.

## 3. Research & methodology

This section sets out:

- 3.A: Our approach to the research
- 3.B: Who has participated in the research?

### 3.A: Our approach to the research

Working with Learning Disability England and Turning Point we committed to providing a platform which will provide the following three groups to identify and share their experiences of DNAR decisions and in doing so build their human rights knowledge and skills:

1. people requiring care/treatment and their family/carers
2. advocacy and community groups
3. frontline staff

This human rights analysis focuses on the experience of groups 1 and 2. We will be conducting similar work at the start of January 2021 with frontline staff in health, care, social work, and other related fields.

In line with the CQC's review, we have a focus on DNAR decisions in relation to older people and disabled people (adults and children, covering physical and mental impairments, as set out in law). However, our methodology allows people to identify other potential discriminatory issues.

This experience-led research has taken place via 1) an online information and research workshop; and 2) an online survey, with identical questions. The workshop and the questionnaire were provided in accessible Easy Read, to enable as many people as possible to take part and reduce participation barriers, including those related to communications and/or learning disabilities.

### 3.B: Who has participated in the research?

#### i) Numbers

67 people took part in the research workshop, with an additional 7 people completed the online survey (the questions are identical for comparison purposes).

#### ii) People's identity

Most people taking part in the research were an advocate, paid supporter, or a family member, friend or carer:

Person who needs or has needed health or social care services or support	4%
Family member or friend	17%

Paid (or other) carer	17%
Advocate	35%
Community or support group member	30%
Staff member in a service or local authority	
Other	2%

Most people taking part cared for or about someone (an adult) with care and support needs ranging from physical disability, mental health, learning disabilities, autism, older people and/or people from BME backgrounds.

### iii) People's location

Most people involved in the research were from the South East (excluding London), the North East and East of England:

East of England	15%
East Midlands	6%
London	7%
North East	19%
North West	13%
South East	25%
South West	8%
West Midlands	6%
Yorkshire and Humberside	4%

## 4. BIHR findings

This section sets out our findings in the following areas:

- 4.A: People’s general experience and understanding of their legally protected human rights
- 4.B: People’s experiences of having their right to life upheld
- 4.C: People’s experiences of having their rights to involvement in decision-making upheld
- 4.D: People’s experiences of having their right to non-discrimination upheld
- 4.E: People’s overall experiences of DNARs, including real life stories

### 4.A: People’s general experience and understanding of their legally protected human rights

We asked people to share what the term “human rights” made them think or feel:



- RESEARCH QUESTION: Have you ever been told about your human rights?

Yes	87%
No	8%
Not sure	5%

- RESEARCH QUESTION: Have you been told about your human rights during Covid-19?

Yes	32%
No	49%
Not sure	19%

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

## 4.B: People's experiences of having their right to life upheld

We asked people about specific experiences around the right to life during Covid-19.

- In general, have health or care staff told you about your right to life (or the right to life of a person you care for/about)?

Yes	30%
No	46%
Not sure	24%

- During Coronavirus have you been told new or different information about your right to life (or the right to life of the person you support?)

I have been told I will have more protection for my right to life.	31%
I have been told I will have less protection for my right to life.	3%
I have not been given information about my right to life	57%
Not sure	9%

- Have you (or a person you care for/about) had a DNAR order put on your medical file?

Yes	65%
No	13%
Not sure	21%

- Was this used because the person was near the end of their life?

Yes	26%
No	47%
Not sure	26%

## 4.C: People's experiences of having their rights to involvement in decision-making upheld

Remembering that involvement in decision-making is a key human right, albeit it one that can be restricted, we asked people about their experiences of involvement around DNAR decisions, in general and during Covid-19.

- Do you (or the person you care about/for) have the mental capacity to decide about your care and treatment, including DNARs?

Yes	30%
No	48%
Not sure	21%

- Have health or care staff told you about your rights to be involved in decisions about your care and treatment, and that your wishes and feelings are very important?

Yes	60%
No	22%
Not sure	18%

- Have you (or the person you care about/for) been involved in advanced care planning, which includes deciding whether you would like a DNAR in the future?

Yes	33%
No	63%
Not sure	3%

- Have you (or a person you care for/about) been involved in discussions about putting a DNAR order put on your medical file?

Yes	20%
No	66%
Not sure	14%

- In your experience has involvement in DNAR decisions changed during Coronavirus?

Decisions are better because I am more involved.	0%
Decisions are worse because I am less involved	42%
Decisions have not changed but I have always been involved	3%
Decisions have not changed but I have never been involved	13%
Not sure or other	42%

- If you (or a person you support) was involved in DNAR decisions how do you feel about this?

Listened to fully	29%
Listened to a bit	46%
Not listened to	25%

#### 4.D: People's experiences of non-discrimination in DNAR decision-making

Given concerns about potentially discriminatory use of DNARs, we asked people about their experiences of this issue, and the grounds for any discrimination:

- Do you (or the person you care about/for) think the DNAR decisions you have experienced have been about treating you worse because of who you are?

Yes	91%
No	0%
Not sure	9%

- Do you think this worse treatment has been because you (or the person you care for or about) is?

Disabled (physical health issues)	18%
Disabled (mental health issues)	12%
Learning disabilities	85%
Autistic	9%
Aged over 65 years old	27%
From a Black and/or Minority Ethnic community	6%
A child aged under 18	6%
For another reason.	12%

(Note: people could choose more than one option for this)

#### 4.E: People’s overall experiences of DNARs, including real life stories

During the session, people shared many experiences of DNAR decisions and discussions. There was some sharing of good practice where DNAR’s had been made as part of advance care planning, using the ReSPECT forms. However, this had been led by parents with disabled children initiating discussions about future care and treatment. Another example of positive practice around making sure there is involvement included:

E’s father had become very unwell and was nearing the end of his life. It was clear that he would not survive if resuscitated. However, the doctor still asked what E thought and gave her time to process what was happening.

However, for the most part, the experiences shared indicated worrying decision-making and assumptions, a lack of challenge or accountability, related poor processes and recording, and concerns about treatment avoidance.

#### Worrying decision-making and assumptions about DNARs and disabled people and older people

Several people shared their experiences of assumptions within health and care around disability and the almost automatic assumption that a DNAR should be in place. Members of the self-led group Stop People with a Learning Disability Dying Early shared examples where the reasons for a DNAR order being made were “Down’s syndrome” and “learning disabilities”. Others also noted that “non-verbal” is a “reason” for a DNAR being issued. Clearly, these are not medical reasons for a DNAR order. There may be health issues that a person is experiencing which are relevant to a DNAR order; however, simply listing a person’s disabilities, indicating discriminatory decision-making.

I, who supports people with care needs, shared several examples of discriminatory and worrying decision-making. One example involved noting “learning disabilities and non-verbal” as the reason for a DNAR in a respect form, which goes on to say that the person should not have dialysis. He said “Sadly I see far too many of these orders. I absolutely acknowledge what clinicians are saying that an advanced decision for the right clinical reasons can save someone pain and indignity at their time of death, but I see far too many DNAR and ReSPECT forms not used in this way”

V noted that the point [Clinical Frailty Scale for Frailty Assessment](#) is still being used in a discriminatory way; she was alerted to an incident of this the day before the workshop (1 December 2020). The Scale sets out guidance for NHS clinicians about which patients should be admitted to hospital and referred to critical care. It was challenged in March, with a legal case being started, arguing that it discriminated against people with learning difficulties, and/or mental health issues, and/or Autistic people. The [NICE guidance was changed](#) in April 2020 to specifically state that the CFS assessment “should not be used in younger people, people with stable long-term disabilities (for example, cerebral palsy), learning disabilities or autism. An individualised assessment is recommended in all cases where the CFS is not appropriate.”

A consistent theme was DNAR decision-making which did not involve the person themselves or their friends and family. Sitting alongside this, several people shared experiences of challenging medical staff where DNARs had been put in place without completing a mental capacity assessment or consultation.

In M’s experience doctors can assume a lack of capacity and understanding if a person is non-verbal. In her experience it is important that doctors explore capacity using all types of communication options, e.g., signing, written, technology, or however each person communicates.

D shared that older people with no family and friends are being assessed as lacking capacity there has been no involvement of the person or a referral for an Independent Mental Health Advocate to support in decision-making.

From the group taking part in the research workshop, it was clear that assumptions about DNAR appropriateness or being almost “automatic” are pervasive. For example:

N is autistic. She has carers support her most days to assist with washing and dressing. When new carers arrived to assist N, she explained her needs. One of the first things they asked was whether she had a DNAR order in place. The carers do not provide medical care or assistance; yet it was assumed that asking about a DNAR was a perfectly appropriate question. N said in our workshop

“I’m only 46 years old, 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's 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 or medical help."

#### Lack of challenge or accountability

The people in our workshop shared issues around the ability to challenge DNAR decisions, and confusion on how to change orders. For example, some shared that they thought the doctor that made the DNAR decision was the only clinician that could reverse or withdraw a DNAR order, whereas others believed that any clinician could review and change an order.

V noted "As a clinician I've challenged DNARs and seen an alarming increase since March of this year with clear evidence that the Human Rights Act, Mental Capacity Act and Equality Act have not been adhered to; whilst this has been raised in safeguarding, the difficulty is getting that order changed." V noted that what she is seeing is whilst people are being named on orders there is in fact very little discussion and consultation in the first place. And then to get orders overturned is practically very difficult. She noted that many colleagues working within the NHS have become aware that they family members have had DNARs placed on their files with no consultation.

The experiences of advocates of DNARs were that they were often involved after orders had been made, and they became aware of them and sought further clarifications, and often had to challenge. These challenges tended to be around a lack of involvement or concerns about the veracity of recorded involvement.

M is an advocate. One of M's clients had a DNAR order put in place. The client did lack capacity to make this decision. However, on the DNAR form the doctor had recorded M's name as the advocate and having spoken with M about the decision. M had never had this conversation with the GP. This experienced was mirrored by others in the workshop, including staff who have been recorded as agreeing to orders which they have not discussed with the deciding clinician.

V noted "As a clinician I've challenged DNARs and seen an alarming increase since March of this year with clear evidence that the Human Rights Act, Mental Capacity Act and Equality Act have not been adhered to; whilst this has been raised in safeguarding, the difficulty is getting that order changed." V also noted that what she is seeing is whilst people are being named on orders there is in fact very little discussion and consultation in the first place. And then to get orders overturned is practically very difficult.

There seemed to be a particular issue around people who have no family and are "unfriended" (they have no other significant person in their lives), For people in this situation there is a significant risk that their rights to involvement in DNAR decision-makings will not

be respected. As such the role of advocates is vital, however, advocates reported several concerning experiences:

V noted that advocates often find DNAR orders have been placed on people's files and then they must go back and challenge because the processes are not always followed. This is especially for people who are unfriended.

D has been advised that a DNAR order was placed on her client's file, but she was told this was done in an emergency and therefore the client did not need advocacy support.

V noted that at the start of the pandemic a GP contacted an advocate to ask how they could put a DNAR order on the files of two people with learning disabilities living in the same care home. The advocate gave advice and sent guidance (including around involvement), but then did not hear back from the GP. No formal referral for advocacy was made. It is unknown how many DNARs may have been put in place without advocacy, when it is in fact required.

D shared that older people with no family and friends are being assessed as lacking capacity there has been no involvement of the person or a referral for an Independent Mental Health Advocate to support decision-making. This includes for DNAR.

### Poor processes

An issue that was raised several times was the lack of a single unified process and reporting form for DNARs. People noted this means there are different protocols and ways of recording DNAR decisions, which makes it difficult to know what processes should be followed, and to make comparisons about what is happening.

The lack of appropriate forms can also hinder poor recording, as it is too easy to note a person's disability or age as a reason, when there may be related health issues, but these are not included as there is a lack of prompting or space. One participant noted that this means the full recording of the reason and issues related to health responses are not always captured. Of course, the fact that disability or age is itself the "fallback" position for the reason's section on forms raises discrimination concerns.

I noted that "fundamentally, even if there are underlying health issues, we need to stop people writing "learning disabilities" or "Down syndrome" etc on the forms. We need to understand this is akin to writing someone's colour on the form. It really is quite shocking discrimination".

Indeed, we had people share ReSPECT forms (created to help bring about a more personalised approach to DNAR decision-making) that still contained quite clear discrimination about disability/age. This highlights the importance of ensuring both the forms/processes are person-centred and that the staff using them do so in a way that is non-discriminatory and focused on securing the rights of the person in question. That said, there was also consensus that much more needs to be done to ensure one single process, form and recording is used for DNAR decision-making across England.

I noted that the forms themselves are problematic. “We don’t have a national standard form, that’s an issue. None of the forms make it clear that you can get a second medical opinion.” Clarity on these would help.

### Concerns about treatment avoidance, especially during Coronavirus

Several participants raised concerns about DNAR decisions resulting in care and treatment avoidance – whether intentional or not. For example, the positive use of the ReSPECT form noted above for a DNAR order involving a parent and their profoundly learning-disabled child, came about because the mother involved was concerned that ambulances in the local area were asking for ReSPECT forms and then not taking people from care homes to hospitals if a DNAR was in place:

M, a mother, noted that the local ambulance service was using ReSPECT forms with DNARs as a “do not take to hospital” form. This was why she investigated the use of the form and worked with the GP and the learning disabilities nurse from the local hospital, to ensure her child’s form was clear because this was “a big alarm for me”. But as M said, people do not know about how to use the forms in a way that people have positive care and support.

L, who works in nursing noted that in her experience the understanding and education on use of DNARs and communicating with people is not good enough. She has been in conversations where medics are discussing DNARs but not fully exploring the issues and discussing that this is about heart failure rather than treatment for all issues. She noted that a DNAR can be a good and valid tool, but it does not prevent treating people for other issues unrelated to heart attack.

V, who works within hospitals, noted that there has been an “increase in hospital avoidance care plans, which feel like DNARs coming in the back door”. Due to her role, she can see that there have been discussions about avoiding hospital admission for some patients – she flagged people with learning disabilities and dementia – but there is very little transparency about this, even less than with DNARs. This makes it even more difficult to challenge. This means that whilst people should be able to access hospital care, they are not getting to hospital in the first place.

## 5. Analysis and Recommendations

As can be seen, most people felt that human rights are about key ideas of **protection, equality, freedom**, issues that are clearly relevant to their lives and particularly in relation to health and care, including DNARs. However, when we explored people's access to information about their human rights, both in general and during Covid-19, it is clear this needs to be improved. Whilst 87% of people having access to information about human rights in general appears high, it is important to note that many people identified sources of this information being charities and support groups, rather than the public services that have a legal duty to uphold people's human rights. Further, access to specific information about human rights during Covid-19 was poor. Less than one third of people confirmed they had received information about their human rights during Covid-19. This is worrying given the context; the pandemic and the response to it raises a significant number of human rights issues, particularly in relation to health and care. For example, restrictions on people's treatment, curtailing, stopping or postponing treatments, changes to processes for securing care, etc.<sup>2</sup> Importantly 100% of people involved were clear that more accessible information on human rights is needed.

In general information given to people accessing health and care services about their right to life was low; less than one third had been told about their right by staff. The situation was more worrying when looking at what information people had been given about their right to life during the pandemic. More than half had not been given any information about their right to life, with 3% saying they had been told there would be less protection of this right, and almost 10% not sure about what they have been told.

Encouragingly, 60% of people reported health and care staff telling them about their general rights to be involved in decisions about care and treatment, and that the person's wishes and feelings are important.

Of those involved in the research 65% has a DNAR placed on their medical file, or the file of the person they care about/for; 21% were not sure. Of those who had seen a DNAR order put in place almost half (47%) were not related to end-of-life care. This is important. DNARs which are part of end-of-life care may raise fewer human rights concerns than orders used at other points in a person's treatment journey, where there is a potential for discriminatory or disproportionate usage. However, human rights still apply to end-of-life care, and DNARs at this stage should be human rights compliant.

As noted in section 1, above, a DNAR made as part of advanced care planning can be an important part of respecting people's rights to autonomy (Article 8). Almost one third (30%) of those involved in our research stated people had mental capacity to determine issues related to care and treatment, including DNARs. However, almost half (48%) stated that they/the person the care for/about did not have mental capacity to make these decisions. This means substituted decision-making will have taken place, i.e., someone else would have made the decision to place a DNAR order on a person's medical file. This decision-making should be rights-respecting and based on what the person themselves would have wanted (Article 8, underpinning the Mental Capacity Act). However, as the data on

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<sup>2</sup> For example, for more information about the human rights implications of lockdown restrictions and changes to law and policy see BIHR's range of Explainers on our Human Rights and Coronavirus Hub here: <https://www.bih.org.uk/hub-changeslawandpolicy>

involvement in decision-making shows, it is highly unlikely that this is what is happening in practice. Rather, what people have reported is a lack of being involved in DNAR decisions (only 20% reported having been involved in discussions), and over 40% felt DNAR decision have been worse during Coronavirus because they are less involved in decision-making. It is important to note that 13% also felt that decisions had not changed, but this was because they have never been involved in decisions. Less than a third of people (29%) who were involved in DNAR decision-making felt fully listened to, most felt listened to a bit (46%), and a quarter felt not listened to. The qualitative evidence shared by people raises significant concerns about the extent to which people themselves, and their family / friends and advocates are being actively involved in decision-making about their care and treatment, particularly in relation to DNARs. We heard consistent evidence of disregard or poor practice on the safeguards for these Article 8 rights, such as appropriate communication in decision-making and inclusion of advocates.

The quantitative evidence shows considerable belief that discrimination has been taking place; over 90% of people felt this was taking place, particularly on disability grounds (including various mental capacity issues). The qualitative experiences shared by people with care and support needs, their families, carers and supporters and advocates, and the medical staff who joined us, showed significant issues of discrimination. These manifested themselves as overt reasons listed for DNAR, to inhibiting proper processes and safeguarding being followed, including capacity assessments, securing advocacy support, exclusion of the person and/or significant people in their lives. Considerable problems with the processes for recording and documenting DNAR decision-making was also shown, from problems with the actual forms, through to issues about the truthfulness of some information contained within them, and usage that results in preventing other treatments (not simply CPR).

Overall, the research shows a worrying picture around the rights of involvement in care and treatment decisions, including DNARs, as legally protected in the Human Rights Act. This is exacerbated by discrimination related to disability and age, and the intersection between the two, as well as other factors. Coronavirus has shone a spotlight on this, and some reported an increase in worrying DNAR decisions; but none of this is new, these problems are ongoing. Additionally, national measures such as the NICE clinical frailty scale which were challenged on discriminatory grounds are still be used, at least in some areas, to deny treatment to groups who, according to the updated guidance, should not be subject to the scale. This is indicative of the pervasive nature of discrimination.

## Recommendations:

- Public services/bodies which have a duty to uphold human rights, should inform people receiving their services of their human rights as they apply to those services. This should include specific information about people's human rights during Coronavirus. For the purposes of this report, this should include information about human rights in relation to DNAR decisions.
- This needs to go together with ensuring frontline staff making DNAR decisions do so from the basis of human rights, fully understanding their legal duty under the Human Rights Act to uphold people's rights and to make lawful and non-discriminatory decisions. This requires several measures including working directly with people – on an equal footing - to understand the issues and put change measures in place; learning and development; supervision and review of decision-making; clear

direction from senior management and leadership; ensuring independent, securely funded advocacy with the ability to challenge decision-makers.

- A clear national statement on DNAR decision-making to be human rights-based, including:
  - The need for medical staff to have open and transparent conversations about DNARs with people themselves, using communication methods that meet that person's needs.
  - DNARs should only be used in relation to CPR rather than explicitly or implicitly preventing other care and treatment that would benefit a person.
  - Clarity that discriminatory decision-making is not lawful and must change. This includes banning simply listing disability or age as a "reason" for a DNAR.
  - Ensuring that people can seek a second opinion and challenge decisions, with clarity about the processes for changing or reversing DNARs.
  - The use of a standardised process and form which puts the person and the centre, and requires all components of the form to be completed and reviewed to ensure the veracity of its information
  - There must be clear and consistent national oversight on DNAR decision-making on an ongoing basis, not simply as part of a one-off Review. This should involve key roles for regulators and others.

In relation to the CQC Review (and reviews more generally) it is important that they:

- Make it clear that DNAR decisions are about people's legally protected human rights, and that medical (and other) staff have legal duties to uphold these rights in their decision-making.
- Be clear that discriminatory DNAR decisions are never lawful; and that all medical decisions within the NHS are subject to the Human Rights Act, and related legislation such as the Equality Act.
- Ensure that the voices of people with lived experience of DNARs are at the heart of its review.
- Any review of documentation as part of the review process should include testing the veracity and completeness of the information provided.
- Recognise that concerns around DNAR decision-making risking people's rights are not new; whilst Coronavirus has shone a brighter spotlight on these issues, they are part of a wider pattern of the discrimination experienced by disabled and older people within health and care. Recommendations for action must include a focus on Coronavirus issues, which continue today and are not limited to the start of the pandemic, and beyond.

Finally, we asked people to share the thoughts and feelings they have around DNAR decision-making; Scared, Angry, Discriminatory and Out of My Control were consistent themes. Better than this must be possible.

