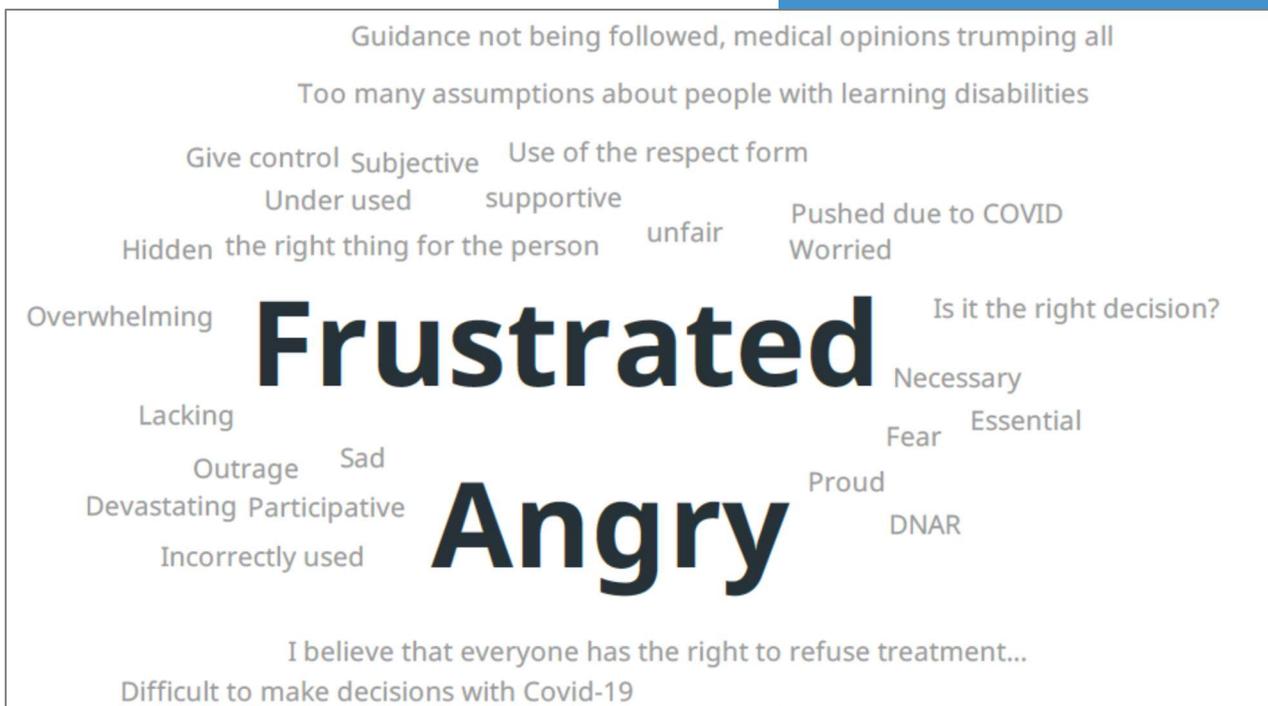


# Frustrated, Angry and Unfair:

## Staff Experiences of 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.

## 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. In addition to our December session for people with care and support needs, we held a research workshop on 11 January 2021 for staff in health, care and social work (and others involved in DNAR decisions).

## Summary

**"A person living at our care home went into hospital with pneumonia, contracted Covid-19 and was in hospital for some weeks. Staff at the hospital decided that a DNAR would be placed on his files without talking to his next of kin or informing myself as the manager of the care home. The hospital failed to inform us of the decision for ten days. The man's next of kin were obviously very distressed on hearing this and had to fight for the DNAR order to be removed, which took some time. We have raised a safeguarding alert against the hospital."**

H, Workshop Attendee

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 during 2020, 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 this 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 Covid-19 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 DNAR orders were used during the Covid-19 pandemic. [This Review takes place between October 2020 – January 2021.](#)

We have worked directly with people with care and support needs, their families, carers, advocates and supporters, and with staff members in health, care and social work to capture people's lived experiences of DNAR decisions. Our research with people with care and support needs, their families, carers, advocates and supporters took place in December 2020. [We published our findings and recommendations here](#), shared widely with people themselves and the CQC. The summary of that report can be found in the [Annex](#) to this report.

This report provides findings and recommendations from our research with staff members working across health, care and social work, who have shared their experiences of DNAR decisions. These recommendations focus on both the current Covid-19 context and the wider use of DNAR orders in "ordinary" times, and the need for them to be framed exactly as they are, as human rights issues. We hope these recommendations will be considered by the CQC in their review.

## **Our key findings**

Our evidence gathered in January 2021 is outlined in this report. It shows a worrying picture around the people's rights to involvement in care and treatment decisions, including DNARs, and in staff confidence and ability to ensure human rights considerations are part of everyday decision-making. Our evidence depicts serious issues of discrimination related to disability and age, and the intersection between the two, as well as other factors. Covid-19 has shone a spotlight on these, 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 staff in health, care and social work, primarily from a frontline perspective.

### **BIHR's Key Findings**

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

- 97% said there needs to be more easily accessible information about human rights.
- Whilst 78% felt supported to meet the legal duty to uphold human rights in their day-to-day work; only 46% said they felt supported to uphold human rights in their day-to-day work during Covid-19.
- Only 8% said people's right to involvement in care and treatment decisions is explicitly discussed with them, an only 25% felt supported to involve people in DNAR decisions.
- Over 40% of participants said it is assumed that people who have had a DNAR order placed on their file do not have mental capacity (only 26% said capacity assessments (a legal requirement) had been conducted).
- Almost 30% of participants felt DNAR decisions during Covid-19 are worse (14% said they had not changed but were usually poor). 20% had made more challenges to DNAR decisions during Covid-19; only 16% felt fully listened to.
- More than 50% of participants felt that discrimination at least sometimes happening in DNAR decisions.

## 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 all staff have legal duties to uphold these rights in decision-making.
- Recognise the role of public services and bodies, including regulators, in supporting a culture of respect for human rights, by integrating human rights across decision making, policies and processes. This should be made clear, and explicitly incorporated into qualification and ongoing training and support, learning, development and supervision, as well as the development of guidance and policy that informs practice.
- 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.
- Recognise that concerns around DNAR decision-making risking people's rights are not new; whilst Covid-19 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 Covid-19 issues.
- Public services/bodies which have a duty to uphold human rights must actively 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 Covid-19. 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 make DNAR decisions 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.
- 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.
- There should be a clear national statement on DNAR decision-making to be human rights-based.
- There must be oversight and quality assurance on the use of DNAR orders and DNAR decision-making. There is a key regulatory role for the CQC and for a consistent approach from national, regional and local commissioners.

## **With thanks**

We would 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 one of the most fundamental of human rights – our right to life (Article 2, Human Rights Act and European Convention Human Rights). Your involvement enables us to call for the development of national law and policy which truly understands people's experiences of their human rights and the reality of staff experiences in upholding human rights in everyday practice.

## **Contents**

The contents of this report are below, click on a heading to take you to that section.

1. [Human rights and DNARs](#)
2. [Covid-19 and DNARs](#)
3. [Research & methodology](#)
4. [BIHR's findings](#)
5. [Analysis and Recommendations](#)
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# **I. 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

## **I.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.

## **I.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).

## **I.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 Covid-19 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 Covid-19, 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.**

In summer 2020 we conducted research to explore the human rights implications of the UK Government's response to Covid-19, drawing on people's real-world 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 Covid-19 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, but that 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, their loved ones 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 for 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 group 3 and should be read in conjunction with our findings from research workshops with people with care and support needs, families, supporters and advocacy groups ([available here](#)).

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.

Our 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 for people was 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**

Over 70 people took part in the research workshop and completed the online survey (the questions used in both are identical to draw the data together).

#### **ii) Who took part?**

Most people taking part in the research were frontline workers, notably nurses and social workers (56%), with high representation of managers in health, care and social work (33%). Most participants worked in social work, community services and care homes (without nursing).

How would you describe your role?	
Nurse	21%
Doctor	2%
Carer or Assistant	5%
Social worker	23%
Support worker	2%
Manager (health/care/social work)	33%
Policy (health/care/social work)	12%
An independent advocate	2%
Person with care/support needs	2%
Family, friend or unpaid carer	7%
Other	12%

What kind of service do you work in?	
Hospital, emergency	7%
Hospital, inpatient (physical health)	7%
Hospital, inpatient (mental health)	7%
Long term conditions/rehabilitation	5%
Care home with nursing	5%
Care home without nursing	14%
Supported living	19%
Other residential	5%
Home care	5%
Community services	24%
GP services	2%
Social work or similar	33%
Other	19%

Most of the participants supported adults with care and support needs ranging from physical disability, mental health, learning disabilities, autism, older people and/or people from BME backgrounds.

Which best describes the people you support?	
Physical health (not disabled)	40%
Disabled (physical disabilities)	53%
Disabled (mental health issues)	51%
Learning disabilities	72%
Autistic	63%
Other mental capacity issues (e.g., dementia, brain injury)	56%
Older (aged over 65 years old)	44%
Children (aged under 18-year-old)	12%
Black and/or Minority Ethnic communities	28%
Other	19%

### i) People's location

Most participants were from the West Midlands and the South East (excluding London):

Which part of England do you work in?			
East England	5%	South West	2%
East Midlands	5%	West Midlands	26%
London	14%	Yorkshire & Humberside	14%
North East	5%		
North West	12%		
South East	19%		

## 4. BIHR FINDINGS

This section sets out our findings in the following areas:

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

### 4.A: Staff general experiences and understanding of legally protected human rights that should be upheld

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



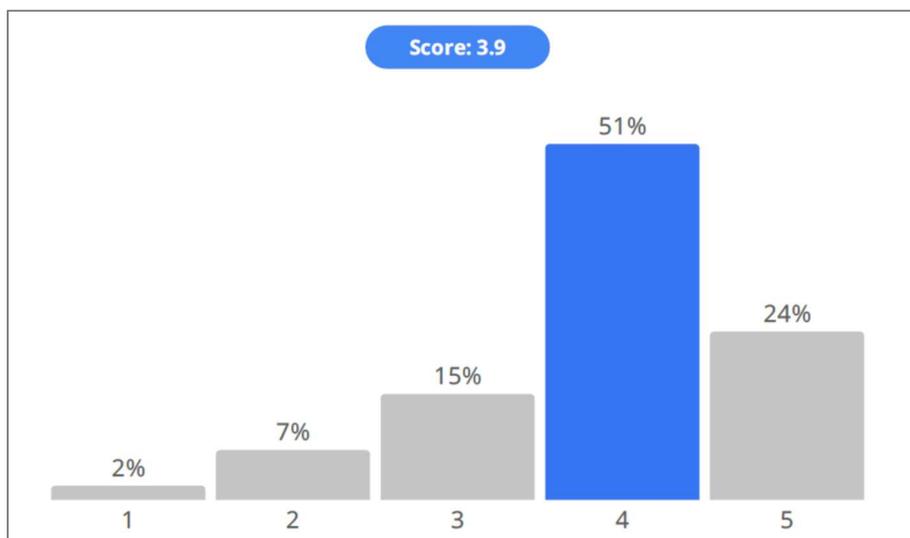
Do you feel supported to uphold human rights in your day-to-day work during Covid-19?	
Yes	46%
Sometimes	36%
No	8%
Not sure	10%

“A human rights culture is one that fosters basic respect for human rights and creates a climate in which such respect becomes an integral part of our way of life and a reference point for our dealing with public authorities ... in which all our institutional policies and practices are influenced by these ideas ... The building of a human rights culture ...[depends] not just on courts awarding remedies for violations of individuals' rights, but on **decision-makers in all public services internalising the requirements of human rights law, integrating those standards into their policy and decision-making processes, and ensuring that the delivery of public services in all fields is fully informed by human rights considerations.**”

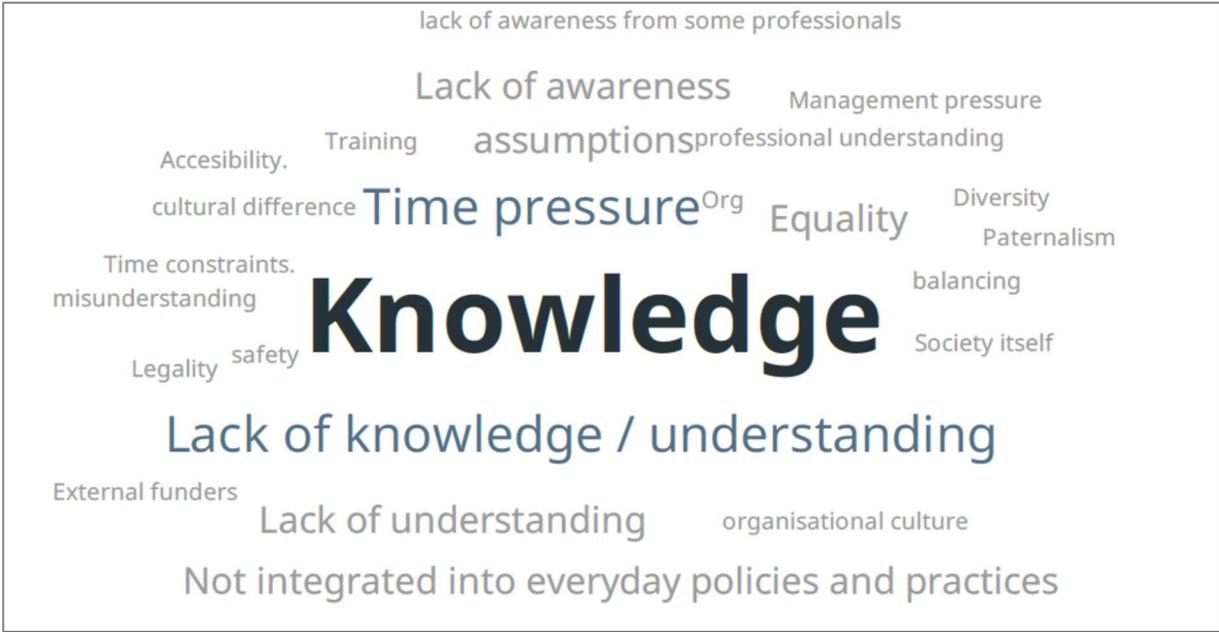


**Parliament's Joint Committee of Human Rights**

Following a discussion about what a culture of respect for human rights looks like in practice, we asked participants to tell us on a scale of 1 to 5 whether they see this in the service(s) they work in (with 1 being not at all and 5 being yes, completely):



The average score was 3.9, with just under a quarter of participants answering yes there is a culture of respect for human rights in the service they work within. We asked participants to tell us about the challenges they faced in ensuring a human rights culture in their day to day work (if any):



Finally we asked about information; **97%** of participants said there needs to be more easily accessible information about human rights.

### 4.B: Staff experiences of upholding people’s right to life

We asked participants about specific experiences upholding the right to life during Covid-19.

In general, in your experience are people's rights to life discussed with them in DNAR decisions?	
yes	13%
sometimes	<b>66%</b>
no	16%
not sure or other	8%

During Covid-19 do you feel supported to uphold people's right to life in your decision-making and practice, including around DNARs?	
yes	45%
sometimes	<b>42%</b>
no	9%
not sure	3%

**“So much changes on a daily basis”**  
**“Assessing and supporting from a distance is difficult”**  
**“It’s worrying to put trust in care homes that have had safeguarding issues”**

## 4.C: Staff experiences of people 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.

In general, in your experience as a staff member, is people's human right to involvement in care and treatment decisions explicitly discussed with them?	
Yes	8%
Sometimes	<b>66%</b>
No	21%
Not sure or other	8%

In your experience as a staff member, do people who have been subject to DNAR decisions have mental capacity to be involved in these decisions?	
Yes people have mental capacity	21%
No people do not have mental capacity, there <b>has</b> been a capacity assessment	26%
No people are <b>assumed</b> to not have mental capacity	<b>41%</b>
Not sure or other	12%

**“Not the people I have supported, but box ticked to say they have when those who know them know that would be an assumption and not because the capacity assessment was discussed or undertaken.”**

**“It is hard to check now, but often MCA decisions aren't recorded in care homes in relation to DNAR's.”**

During Covid-19, as a staff member, do you feel supported to involve people in decision making around DNARs?	
Yes	25%
Sometimes	<b>31%</b>
No	19%
Not sure or other	25%

**“I have seen reference to DNACPR in GP notes but no MCA documentation supporting the decision or who was involved in the decision.”**

## 4.D: Staff experiences of non-discrimination in DNAR decision-making

In DNAR decisions that you have experienced, or are aware of, as staff member, do you think discrimination has taken place?	
Yes	29%

Sometimes	35%
No	21%
Not sure	15%
<b>If you believe there has been some discrimination, do you think is because the person involved is:</b>	
Disabled (physically disabled)	20%
Disabled (mental health issues)	26%
Has learning disabilities	60%
Autistic	20%
Has other potential mental capacity issues (e.g., dementia, brain injury)	46%
Aged over 65 years old	31%
From a Black and/or Minority Ethnic community	3%
A child aged under 18	0%
Other reason(s)	9%

#### **4.E: Staff experiences of the use of DNARs and decision-making, including real life stories**

<b>Have you been involved in DNAR decisions during Covid-19, and have you seen an increase in DNARs in this time?</b>	
Yes I have been involved in DNAR decisions and seen them increase	27%
Yes I have been involved in DNAR decisions and these have not increased	11%
No, I have not been involved in DNAR decisions in this time	57%
No, I have not been involved in DNAR decisions in this time, but I have seen them decrease in my workplace	0%
Not sure or other (you can tell us more in the zoom chat box)	11%

Of those involved in DNAR decisions, 71% of participants have seen an increase in DNAR decisions (versus 29% of participants saying there was no increase in DNAR decisions).

<b>Is your experience that DNAR decisions during Covid-19 are being made mainly as:</b>	
Part of advanced care planning	25%
Part of emergency treatment	25%
Part of end-of-life care planning	19%
As part of an approach to blanket decisions:	
In relation to mental capacity issues/neurodiversity (e.g., learning disabilities or Autism)	13%
Older people	9%

<b>Has your experience of DNAR decisions changed during Covid-19?</b>	
Decisions are <b>better</b>	9%
Decisions are <b>worse</b>	29%
Decisions have <b>not changed</b> but were <b>usually good</b>	9%
Decisions have <b>not changed</b> but were <b>usually poor</b>	14%

I have <b>had to challenge more</b> decisions	20%
Not sure or other	20%
<b>Do you have experience of challenging DNAR decisions during Covid-19 and how do you feel about this?</b>	
Yes, I've <b>challenged</b> , and I felt <b>listened to fully</b>	16%
Yes, I've <b>challenged</b> , and I felt <b>listened to a bit</b>	16%
Yes, I've <b>challenged</b> , and I felt I was <b>not listened to</b>	13%
No, I have <b>not challenged</b> because it has been <b>not needed</b>	35%
No, I have <b>not challenged</b> because I have <b>not felt able to</b>	3%
Not sure or other	16%

## Positive Practice

During the workshop staff shared the importance of where DNARs are used as part of advanced care planning which enables people to set out how they would like a range of issues in their care and treatment to be dealt with, including decisions around end of life and death. Often ReSPECT forms, when used correctly, were identified as good examples of this; and

**A:** I have experienced people make the decision when they know they are at the end of their life, they also make advanced decisions which include their wish to remain in the care setting and not be admitted to hospital, their funeral arrangements, music they want to be played etc. there is usually a sense of peace that settles over the person knowing that everything is in order at the end of their life and that their families will not have to make decisions on their behalf.

There was also sharing of positive communication practice:

**W:** We have an older lady we support, and we discussed a DNACPR using an easy read document, she did not want this in place and this decision was respected.

- problematic DNAR decisions which include a lack of consultation and involvement, discriminatory (and blanket approaches) usage for non-medical issues, being used to deny other non-CPR resuscitation, and a lack of challenge or the clarity of capacity to challenge and change.

In many ways the findings from our staff workshop and research reflect our findings from the work directly with people, families, supporters, and advocates:

## Worrying decision-making and assumptions about DNARs in relation to disabled people and older people (and other 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. There was discussion about the use of non-medical reasons listed on DNAR orders:

M (previously worked at an accommodation service provider, now working in NHS acute hospitals): working in both sectors, you can see where the issues around DNAR decision-making come from with a lack of training on these issues for doctors, from junior through to senior clinicians who are counter signing. The Mental Capacity Act, and rights around involvement in decision-making, feature in very few medical degree courses, but we really need to get people to understand capacity and human rights and how to look at the decision properly and not a subjective decision about someone's quality of life. Hopefully when the NHS Learning Disability training is made mandatory, that will help to some extent, but there are still issues with doctors on rotation and the challenge of ensuring consistency across the trusts and hospitals. Now I'm within the NHS system, when I see "social circumstances" or "co-morbidities" as reasons for a DNAR I can challenge these and say the reasons need to be medical about the resuscitation (or at the end-of-life stage), these reasons are not appropriate."

Participants identified a range of non-medical reasons in DNAR decision-making, most commonly learning disabilities, but also physical disability, mental health issues, other capacity issues (e.g., brain injury or age) and age. It was also noted that with age, there can be difficulty in articulating the reasoning behind decisions, as a DNAR may be put in place due to age-related frailty, and the importance of being clear about what is and is not discrimination.

Issues around assumptions related to capacity were certainly a theme, and assuming that people cannot or should not be involved in decisions about their care and treatment, including DNARs.

T: I did once question a doctor about why he was discussing placing a DNAR on one of the people we care for. The doctor could not give me a diagnosis which would lead to this decision, so I suggested that the person, their family, the doctor, and I should all meet to discuss what the doctor wanted to put in place. This never happened, but the person we cared for moved on to nursing care and lived a full life for a further 5 years, receiving love and care to the end.

Alongside this, people shared the experience of medical staff discussing DNARs with a person's family, but not with the person directly, and this leading to an order being placed on a file without involving the person at all.

L: I had a DNAR removed as I assessed a man as having the capacity to consent and he wanted to be kept alive. The Dr had discussed this with his wife who wanted a different outcome.

## Challenge and accountability

Participants did also share examples of challenging these assumptions and wider issues around DNAR decision-making. The challenges shared included social care workers raising concerns with medical staff, and some challenging between medical staff as well.

B: If it is the person's decision and they have full understanding of what this means then I fully support their decision, if it is someone else suggesting it, then I would be questioning why, what the diagnosis is and would want as many people as possible who care for them to be involved in the decision-making.

However, staff did share the difficulty of challenging DNARs, and especially getting the decision remade and removing orders from people's medical files.

H: a person living at our care home went into hospital with pneumonia, contracted Covid-19 and was in hospital for some weeks. Staff at the hospital decided that a DNAR would be placed on his files without talking to his next of kin or informing myself as the manager of the care home. The hospital failed to inform us of the decision for ten days. The man's next of kin were obviously very distressed on hearing this and had to fight for the DNAR order to be removed, which took some time. We have raised a safeguarding alert against the hospital.

O: DNAR's often follow people from hospital into care homes and it can be difficult to determine how the decision was made and to challenge it when the decision-maker was a doctor who is no longer involved with the person.

L: We have heard from support providers that it has often been hard and time consuming to help people get wrongly applied DNAR notices removed when applied in hospital.

When challenges have secured change, this was around correcting information on DNARs amended, rather than the DNAR itself:

S: Whilst I have challenged DNARs, where I've been listened to is more in relation to incorrect or insufficient information recorded.

## Issues around the timing of DNAR decisions

Many practitioners shared the positive benefits of including discussion about DNARs with care planning in general and the use of ReSPECT forms was highlighted. However, there were still issues around the timing of these forms, and their correct usage:

A: GP's could be doing more to ensure ReSPECT forms are done at the right time with the right people. It's extremely difficult making these decisions in an emergency when you have just a snapshot of a person's life. Adding on to that community staff need to support GP's by having these conversations early.

L: I like the move to ReSPECT forms, but in acute settings these tend to be used just for DNAR decisions and not for recording the more holistic beliefs, wishes of individuals. Added to this they are being completed when the person is acutely unwell rather than them being completed prior to admission in the community.

## Concerns about treatment avoidance.

The issue of DNAR decisions being used or interpreted as covering a reduction of non-resuscitation treatment was also raised:

R: I'm concerned that where DNARs have been completed appropriately there is still a lack of understanding amongst staff in what this means and taking a DNAR to mean no further treatment required so only given very conservative treatment.

## 5. ANALYSIS AND RECOMMENDATIONS

As can be seen, most staff felt that human rights are about key ideas of **protection, equality, freedom and empowerment**; issues that are clearly relevant to the lives of people they support in broad health and care situations, including around DNAR making. However, when we looked at whether a culture of respect is present in their services – one in which human rights are central to every day decision making and policies – less than 25% felt this was how their services work. The key challenges staff identified in trying to secure a culture of respect for human rights in their services focused on **a lack of knowledge and understanding, misunderstandings amongst professionals and time.**

Additionally, when asked if people felt supported to uphold human rights in their day-to-day work during Covid-19, whilst 46% said yes, a similar percentage, 36% said they only feel supported to do this sometimes and 8% said no. 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 and changes to processes for securing care.<sup>2</sup> Importantly, the vast majority of people (97%) said more accessible information on human rights is needed (the remaining 3% were not sure).

It is very concerning that less than 10% of participants said the right to life was generally discussed with people during DNAR decisions. Over 70% said this happened only sometimes. People shared particular difficulties around assumptions being made around discussing these issues with older people and people who are non-verbal. A range of barriers to discussing the right to life as a routine part of DNAR decision-making:

We asked staff about the challenges they face to discussing the right to life routinely with people they are supporting:



<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.bihar.org.uk/hub-changeslawandpolicy>

**“Discussing the right to life with adults with learning disabilities does not always happen or happen in a way that allows them to make informed decisions.”**

We also asked what would support staff to do better and make the right to life part of their routine discussions:



Key issues included:

- Clear, consistent guidance and policies on roles and responsibilities
- Leadership, peer supervision, additional training
- Quality assurance and cross discipline learning
- Better understanding of advocacy
- Open and honest communication

The worrying trend in upholding rights as part of DNAR decision-making continued when exploring people’s involvement in the process and their ability to take part in decisions about their care and treatment.

As noted in section 1, a DNAR made as part of advanced care planning can be an important part of respecting people’s rights to autonomy (Article 8). However, only 8% of participants said that they experienced people’s human right to involvement in care and treatment decisions being explicitly discussed with them; with 21% stating that the right is not discussed, and 66% saying it is sometimes discussed. There is further cause for concern when that is combined with the finding that 41% of participants felt that people subject to DNAR decisions are assumed to not have mental capacity, without an assessment, as required in law (26% said there had been a capacity assessment showing a lack of capacity to make this decision, and 21% that the person in question did have capacity). Given that the MCA requires a decision-specific capacity assessment for each issue that needs to be addressed, such a high reporting of assumptions about a lack of

capacity on a question as vital as the right to life is extremely worrying. Several participants raised additional concerns that when capacity assessments are made in DNAR, they are sometimes used to make broad assessments about a range of issues rather than being limited to being decision-specific. There is clearly a significant amount of substituted decision-making taking 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 involvement in decision-making shows, it is highly unlikely that this is what is happening in practice. Again, we asked staff about the barriers they face in ensuring people's involvement in DNAR decisions:



And identifying what would support staff to better uphold people's right to be involved in decisions:



Up-to-date information and training was a consistent theme, but so too was support on how to challenge DNAR decisions, and a willingness to act on improved information and support.

The findings on challenging DNARs continue in the same worrying vein. Whilst it was encouraging that just over half of participants had not been involved in these decisions during Covid-19 (57%), over a quarter (27%) had been involved in DNAR decisions and seen them increase during the pandemic. Fairly even numbers were seeing DNARs being made as part of advanced care planning and emergency treatment. As noted by several participants, there is real difficulty in making these decisions in emergencies, without knowing a person or their situation in detail. Worryingly, almost 30% said that DNAR decisions have been worse during the pandemic, which is particularly concerning given that the starting point is one of real concern about the ability to discuss the right to life and involve people in decisions in general. 20% of our participants shared that they had made more challenges to DNAR decisions during Covid-19; the need to challenge is a concern, but the act of challenging such decisions is positive human rights practice where there are such concerns. Whilst 16% of people who have challenged felt fully listened, a further 16% felt listened to a bit, and taken with the 13% who did not feel listened to points to a need for a better response in services to challenge.

The quantitative evidence shows considerable belief that discrimination has been taking place, reflected also in the qualitative experiences shared by staff. These manifested themselves as overt reasons listed for DNAR, to inhibiting proper processes and safeguarding being followed, including capacity assessments, exclusion of the person and/or significant people in their lives in the decision-making.

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. Covid-19 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.

## **Recommendations:**

- Recognition of the role of public services and bodies, including regulators, national bodies and the government, in supporting a culture of respect for human rights, by integrating human rights across decision-making, policies and processes. This should be made clear, and explicitly incorporated into qualification and ongoing training and support, learning, development and supervision, as well as the development of guidance and policy that informs practice. This should be across functions and issues, including DNARs.
- Public services/bodies that have a legal duty to uphold human rights must actively 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 Covid-19. 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.

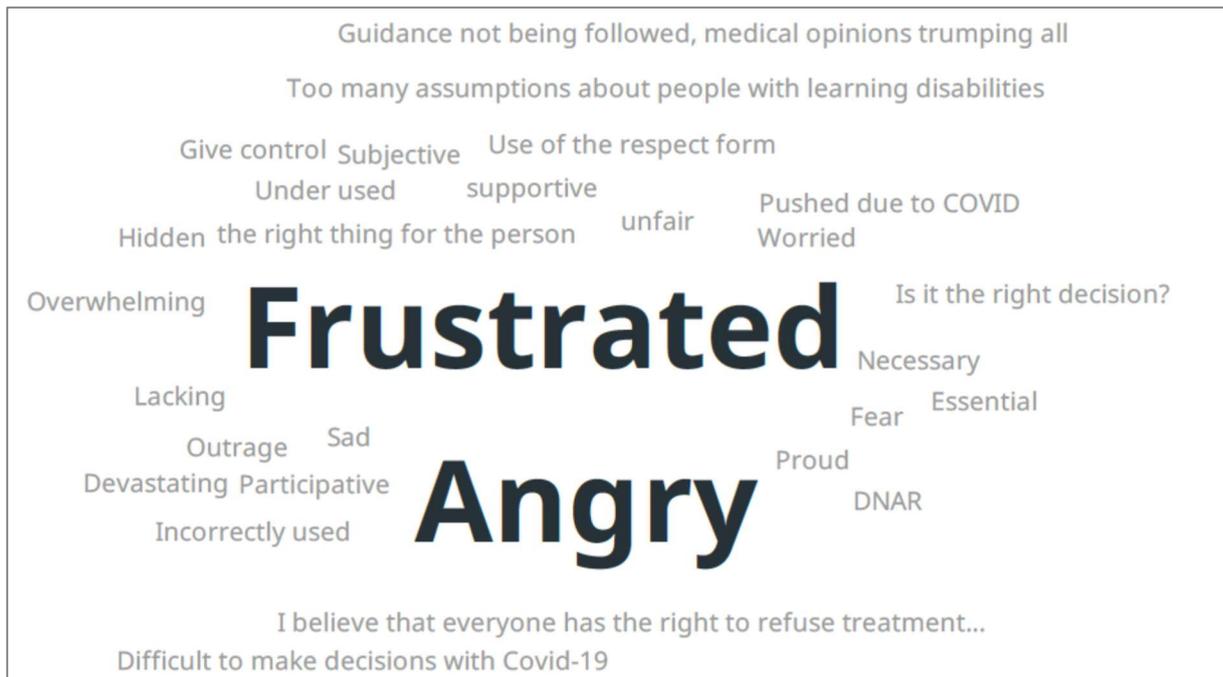
- A clear national statement on DNAR decision-making to be human rights-based, including:
  - The need for staff to have open and transparent conversations about DNARs with people themselves, using communication methods that meet that person's needs.
  - DNARs should only be used in relation to CPR rather 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 clarity that people can seek a second opinion and challenge decisions, with clarity about the processes for changing or reversing DNARs; and in particular clarity that medical decisions around DNARs must be lawful and decisions can be queried by health and care staff and people themselves, their families and supporters.
  - 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.
- There must be oversight and quality assurance on the use of DNAR orders and DNAR decision-making; we must tackle the variations in upholding people's human rights, it not acceptable that any decisions about people's lives are being made outside of the law. There is a key regulatory role for the CQC on this (see below), but it also requires a consistent approach from national, regional and local commissioners.

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 Covid-19 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 Covid-19 issues, which continue today and are not limited to the start of the pandemic, and beyond.

Finally, we asked staff to share their feelings about the DNAR decisions they had experience of:



It is important that some people noted that when DNAR decisions are made with the involvement of the person at the right time, in advance of emergency situations, that they can be positive and rights-respecting. However, as the report shows, this did not speak for most staff experiences of DNAR decision-making, with is problematic and in need of addressing. As with people, families, advocates and supporters, the main shared feelings among staff on DNARs focus on frustration and anger. Ultimately this is about life and death decisions; there is no room for these to be decisions which do not uphold people’s legally protected human rights.

# Annex: OUR RESEARCH WITH PEOPLE WITH CARE AND SUPPORT NEEDS, THEIR FAMILIES, CARERS, ADVOCATES AND SUPPORTERS

Below is the summary of our earlier report, [Scared, Angry, Discriminatory, Out of My Control: DNAR Decision-making in 2020](#) (December 2020)

## 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.

As part of BIHR’s work to assess the human rights implications of Covid19, 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 this evidence, we decided it was crucial to gather more information from people who have experienced DNAR decision making, both since and prior to the Covid-19 pandemic.

## BIHR’s 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. Covid-19 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 other related fields.

## BIHR's 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 Covid-19.
- 65% of people involved said that they (or a person they care for/about) had a DNAR order put on your 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.

## BIHR's Recommendations

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 DNAR orders were used during the Covid-19 pandemic. [This Review takes place between October 2020 – January 2021.](#)

We have therefore set out our recommendations which we hope will be considered by the CQC in their review but which also exist as standalone 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 Covid-19 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 Covid-19 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 Covid-19. 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.