Written evidence from the British Institute of Human Rights (COV0236)

Evidence gathered from: Our work with people working in health and care during Covid-19

Executive summary:

BIHR welcomes this opportunity to provide evidence to the JCHR as part of its inquiry into the human rights implications of the Government's response to Covid-19. Our policy responses are directly informed by people's real-life experiences of the issues, drawn from our work to support people to benefit from their human rights in their daily experiences. Our key findings are summarised below:

- Over 82% of people working in health and care who responded to our call for evidence told us it has been harder to uphold human rights during Covid-19.

- Over 76% of people working in health and care who responded to our call for told us that during Covid-19 they were not provided with legal training or clear information about upholding human rights law

- Over 79% of people working in health and care who responded to our call for evidence told us that during Covid-19 they were not provided with legal training or clear information about the use of Emergency Powers under the Coronavirus Act (CVA).

Background:

The initial Coronavirus Act was passed very quickly, and UK government has issued both law (Regulations) and guidance at speed, often with conflicting or confusing public messaging. There are some welcome references in the Coronavirus Act which make it clear that decisions to change care and support should not be incompatible with human rights. However, this was not accompanied by measures to enable people to understand what these human rights are and ensuring that frontline workers know how to make rights respecting decisions. Thus there are two elements to accountability for the responses to Covid-19: a) central Government's response through law, policy, guidance and resourcing; and b) the implementation of these responses at local level, and therefore people's everyday experiences of risks to their human rights.

BIHR's work:

The British Institute of Human Rights is a charity working in communities across the UK to enable positive change through human rights.

We work with three main groups across the UK.

1. People accessing (or trying to) access services, their family members and people that care about them.
2. Formal advocates (e.g. IMCA, IMHA, etc.), self-advocates, and other community, campaigning, and advocacy groups.

People with legal duties to respect and protect rights. Including those working in public services and those working in private, charitable, or voluntary bodies delivering public services.

BIHR's evidence submission:

Since March 2020 our work has specifically focused on the impact of Coronavirus law and policy on people and its implementation through local decision-making. Across the UK, we have worked with over 400 people accessing public services including their families and those who care about them and over 950 people working in health and care services including advocates and campaigners.

The evidence gathered through our work informs our main concerns and suggestions for the steps that need to be taken to ensure that measures taken by the Government to address the Covid-19 pandemic are human rights compliant.

We have prepared an evidence submission for each of the groups we work with, so that the Committee members have access to the direct experiences of all three groups when considering the Government's response. This submission focuses on the experiences of people working in health and care. For the purposes of this JCHR report, the data will be shown as UK wide. We will be submitting nation specific data to devolved inquiries where appropriate.

Important demographics to note when considering the evidence contained in this report:

- 90% of those who responded to our call for evidence work in England, 7.5% in Scotland, 2.5% in Wales. There were no responses from those who work in Northern Ireland. [1]
- Over 50% work in community settings, over 30% in residential settings, 17% in hospital settings, 4.88% in primary care. Other respondents included those who work in the charity/voluntary sector, hospice, safeguarding and in the therapeutic community.

- Respondents support a range of people and their families. Over 68% support older people with physical disabilities and/or health care needs, 58% support adults with learning disabilities and/or Autism, 56% support older people with mental health needs, over 14% support children with physical disabilities and/or health care needs.

BIHR's methodology:

As a human rights organisation, we ourselves use a human rights approach. We have used the PANEL human rights framework endorsed by the United Nations in our evidence gathering and as the structure of our submission. We take each principle in turn, sharing people's experiences and in doing so answer the questions the Committee is seeking views on through the lens of human rights.

[1] BIHR has not conducted specific partnership sessions in NI yet, as our emergency response focused on responding to demand from our community partners. We will be discussing future NI collaborations in due course.

Click on the headings below to read the evidence for each human rights principle.

Participation

Accountability

Non-Discrimination

Empowerment

Legality

Participation:

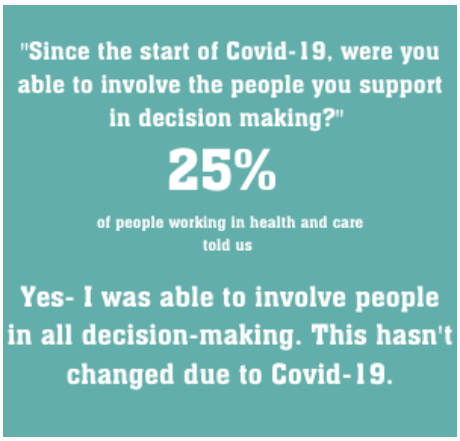
In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **People must be involved in decisions that affect their rights.**

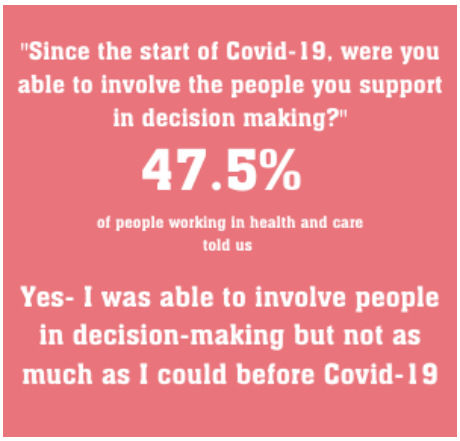
Autonomy is covered under Article 8 of the European Convention, brought into UK law in the Human Rights Act (1998), which also includes the legal duty on public authorities to respect and protect this right in their everyday functions.

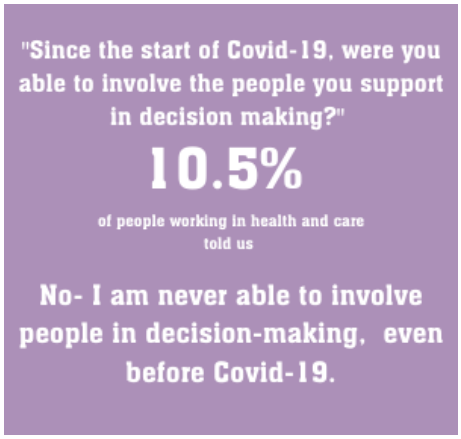
In people's daily lives, this means that changes to care and support should be discussed with the individual, their family or other chosen person. Where the person has been assessed as lacking capacity to make specific decisions about care (or changes), the safeguards under the relevant capacity legislation must be met. These safeguards include, encouraging and enabling participation, considering past wishes and feeling, consulting anyone named by the person and much more.

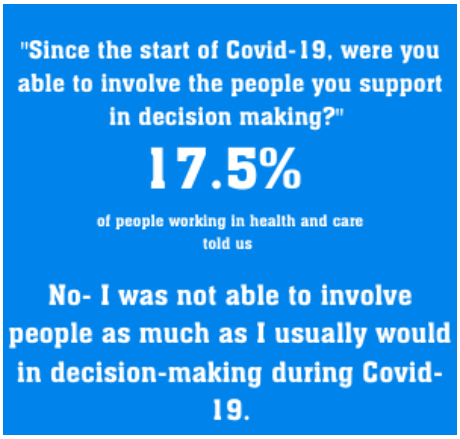
What did people working in health and care tell us about participation during Covid-19?

1. We asked: “Since the start of Covid-19 have you been able to involve the people you support in decision making which affects them?”

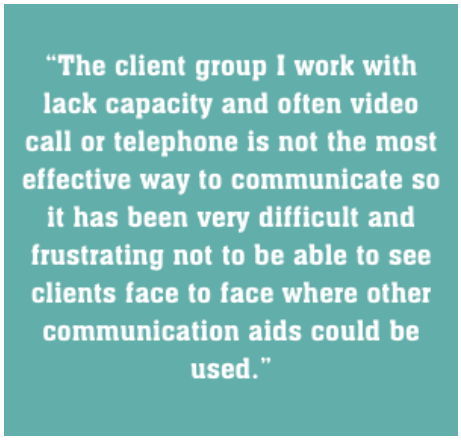




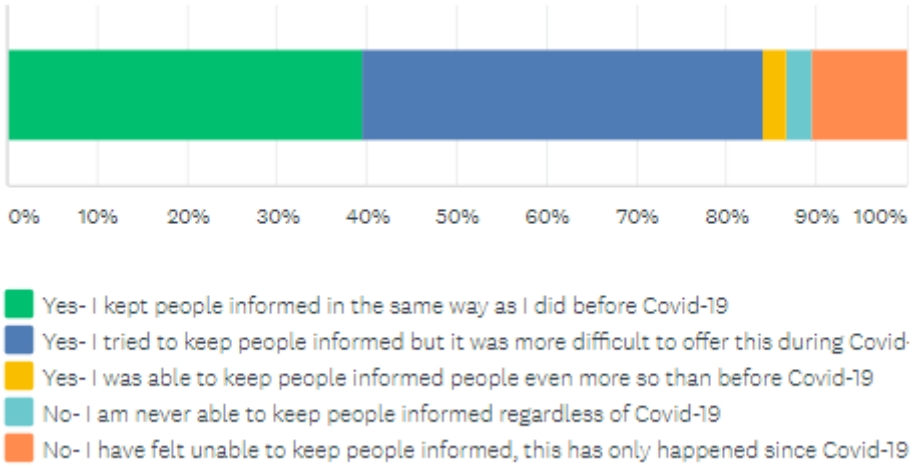




1.1 We asked, “Would you like to tell us more?”



1.2 We asked, “Since the start of Covid-19, when decisions have been made about someone’s care and support did you feel able to explain why this decision was made and for how long it would last?



BIHR recommendations for ensuring participation:

- The Government, both centrally and locally must make it entirely clear that all legal duties under the Human Rights Act remain in place regardless of Emergency Coronavirus legislation. This includes the right to autonomy (having a say over your care) under Article 8 (HRA).

- It must be made clear that where a person's participation in decisions about their care and support is restricted, this restriction must follow the 3-stage test of lawful, legitimate, and crucially proportionate (the least restrictive option possible).

- Clarity must be provided around the use of Emergency Powers, it must be made clear that where any changes are made to a person's care and support, the person and their chosen family/friends (those who will be impacted) must be supported to be involved in decision making. Easements must be applied compatibly with human rights law.

- All public officials must be supported to recognise and respond to a situation in which a person's legally protected human rights are at risk. This is necessary during Covid-19 and beyond.

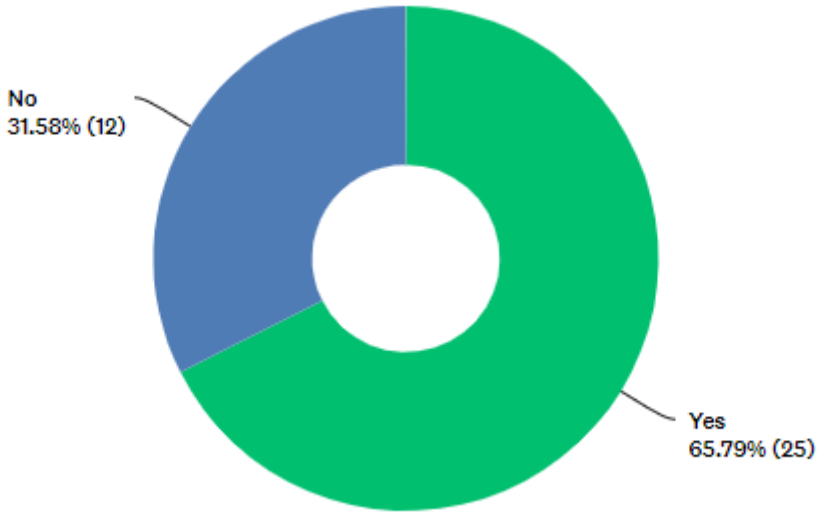
Accountability

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant*:* **There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.**

The section 6 HRA duty places a legal duty on public officials (and those delivering a function of a public nature) to respect, protect and fulfil human rights. This duty is about every decision frontline staff make, the policies and protocols put in place by managers, and the strategic decisions of leadership. This does not change under Coronavirus law and policy.

What did people working in health and care tell us about accountability during Covid-19?

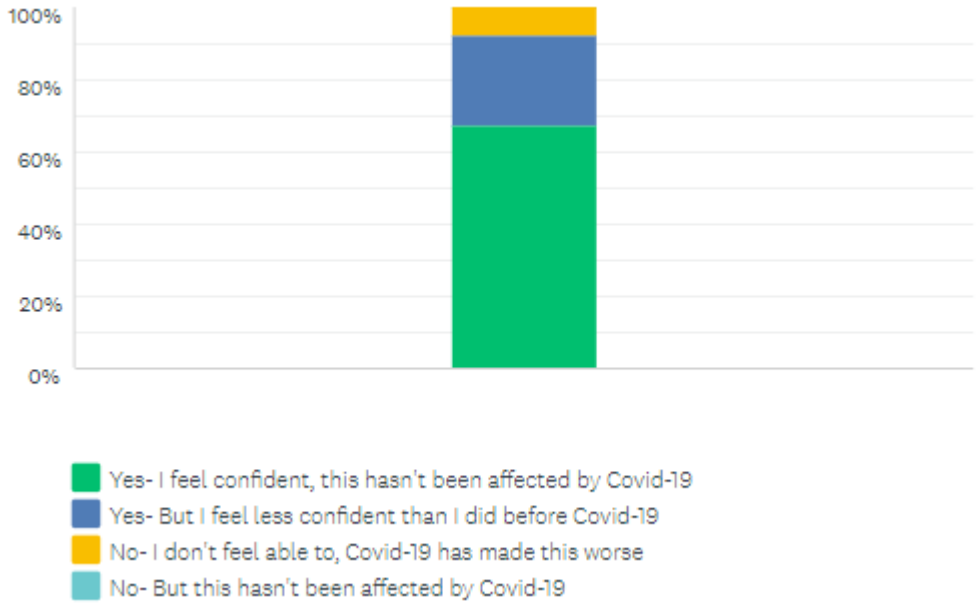
2. We asked, “When a decision was made about someone's care or support during Covid-19 were you able to tell people how they could challenge that decision or raise a complaint?”



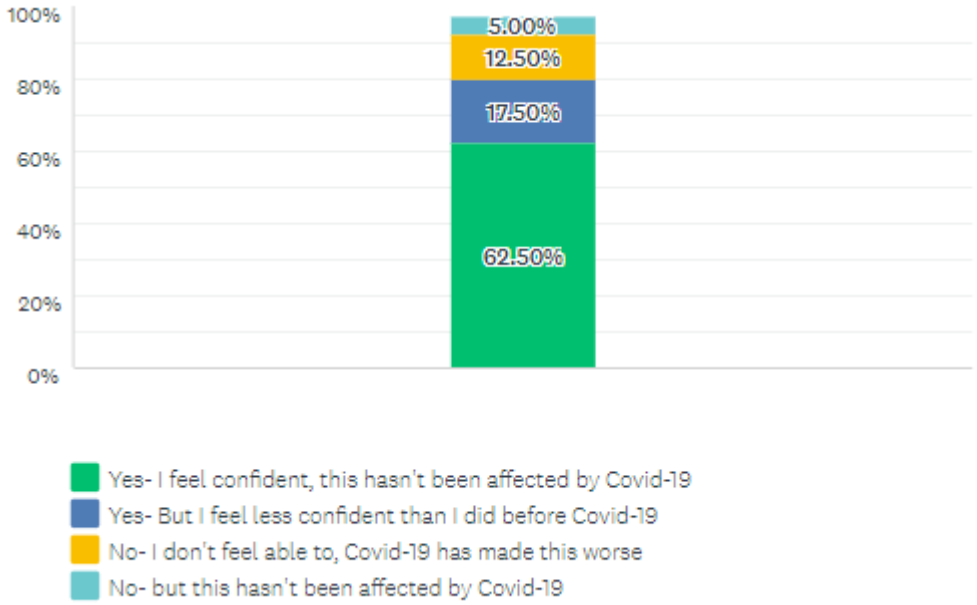
2.1 We asked, “Would you like to tell us more?”

"We do this with all decisions and all residents have external representatives and advocates who are also consulted."	"Difficulty with social workers working from home."	"Slower processes at times r.e. safeguarding."

2.2 We asked, “Do you feel able to raise a concern or challenge the body you work for about a decision/issue/policy etc that risks the human rights of people accessing care and support?



2.3 We asked, “Do you feel able to raise a concern or challenge the body you work for about your own human rights as a staff member?”



BIHR recommendations for ensuring accountability:

- There must be open and accessible processes for people, their families and those who care about them to raise issues with care and support during Covid-19.

- Where there have been changes to complaints processes as a result of Covid-19 these must be the least restrictive option available to the public service (i.e. there cannot be a blanket suspension of complaints procedures,

this is not a proportionate response). Staff should be made aware of these processes and be able to inform the people they support of how to raise an issue during Covid-19.

- There must be clear avenues for staff to raise issues they are facing when trying to uphold human rights during Covid-19. Where staff are experiencing issues with equipment, resources, technology or anything else which puts their rights or the rights of people they support at stake, this must be taken seriously as a breach of human rights law and addressed immediately.

- People working in health and care must be provided with accurate and up to date information about which Emergency Powers are in use and which are not.

- Information about the Emergency Powers being used at local level should be monitored locally and centrally via a robust procedure. People working in health and social care must be consulted about their experiences. This enables informed decisions to be made about the continued availability of the Powers. In doing this, the Government can identify trends and concerns, including human rights flash points during the pandemic, as well as positive practice which others can learn from. Please see our briefing on transparency issues in Scotland, here.

Non-discrimination

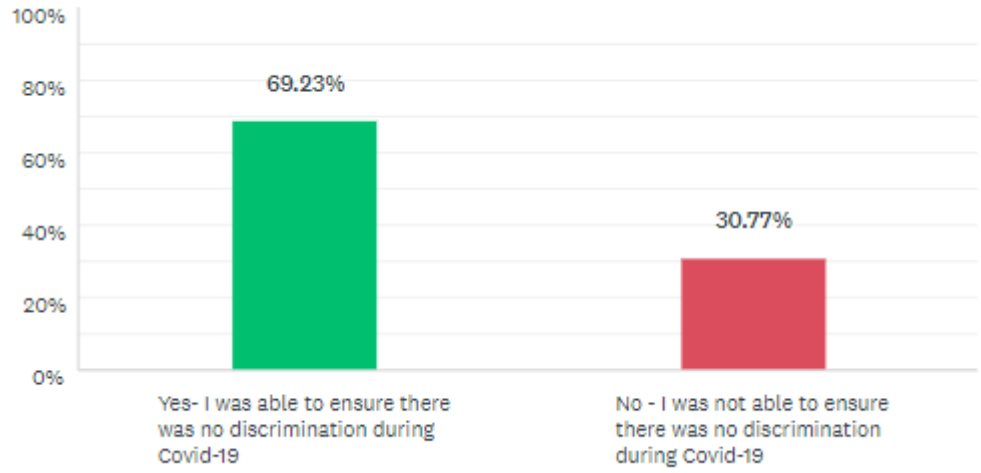
In order for the measures taken by the Government to address the COVID-19 pandemic to be human rights compliant*:* **Both direct and indirect discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.**

Article 14 in the Human Rights Act sets out that the enjoyment of rights and freedoms must be secured without discrimination on any grounds, including but not limited to sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. Importantly, and differently to the Equality Act, this encompasses discrimination beyond the nine protected characteristics, and recognises discrimination based on combined or multiple factors, such as having Autism and living in a residential unit, or being an older person and living in a care home.

What did people working in health and care tell us about discrimination during Covid-19?

3.We asked, “Were you able to continue to meet your duties under the Equality Act during Covid-19? Meaning you were able to consider specific characteristics or needs when making decisions. This could include (but is not limited to) considering

any disabilities, mental health or capacity issues, race or ethnicity, age, gender or other characteristics or needs."



3.1 We asked, "Can you tell us more about which groups were affected and how."

The data gathered through this evidence call highlighted concerns of direct and indirect discrimination impacting the following people (from our wider work we know that this list is not exhaustive and will be publishing more expansive data.)

- People with disabilities
- People with mental health issues
- People with dementia
- People with learning disabilities and/or autism
- Older people
- Young people without access to technology or phones
- Lower income families

"Severe dementia sent alone for invasive scan causing distress."

"Using online platforms for communication already alienates a population that is digitally impoverished."

"I was made aware of discrimination against older people."

"People with disabilities were severely affected with use of telephone and internet only contact."

"Those with special education needs & disabilities (SEND) and below the age of 11 were not able to receive the same support in my organisation."

"'Community Mental Health Teams stopped visiting care homes. This has meant people with mental health issues and/or dementia have remained in placement for significantly longer than needed.'"

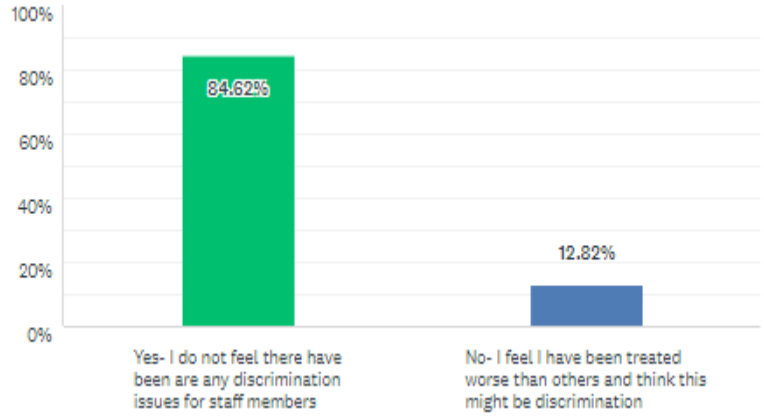
"People living with dementia in care homes not valued by this government response."

"Needs of those on the Autistic spectrum being overlooked."

"Age related.....truly feel all over 65s were written off, had do not resuscitate orders (DNRs) forced upon them and blanket Patient Specific Direction (PSD)/Covid specific Kardex's without individual assessment."

"I felt like younger children, those with learning difficulties, and lower income families who have no internet connection or devices to access support have been left behind."

3.2 We asked, “Do you feel that during Covid-19 you as a staff member have been treated without discrimination by your employer?



BIHR recommendations for ensuring non-discrimination:

- The Government must ensure that all public officials are fully trained, resourced and supported to practically implement their legal duties under both the Human Rights Act (1998) and the Equality Act (2010).

- The Government must make it entirely clear that these non-discrimination legal duties have not changed as a result of Coronavirus, and to ensure that their actions responding to Covid-19 are not discriminatory in themselves.

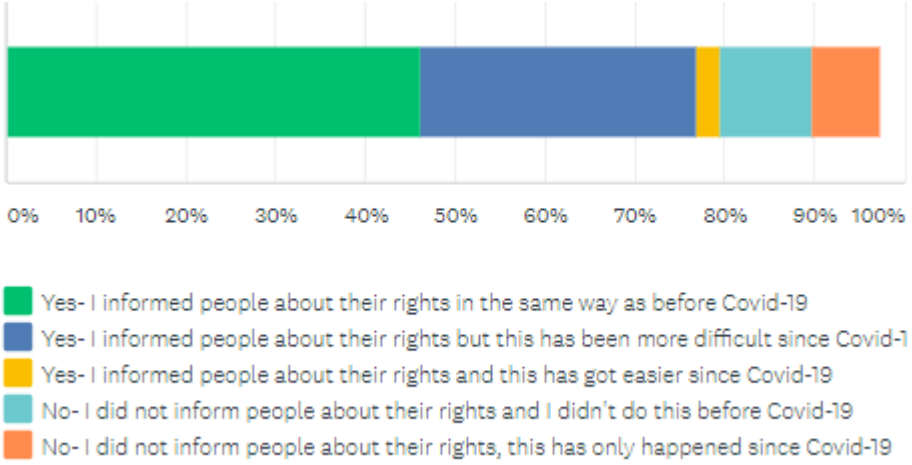
- Where the Government has knowledge that discrimination has occurred (i.e. through this evidence call) this should be independently investigated, using human rights as the central framework and remedies put in place.

Empowerment

In order for the measures taken by the Government to address the COVID-19 pandemic to be human rights compliant*:* **Everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives.**

What did people working in health and care tell us about empowerment during Covid-19?

4. We asked, “Since the start of Covid-19 have you been able to inform people about their human rights?”



BIHR recommendations for ensuring empowerment:

- The Government communications about Covid-19 (and beyond) should be centred in human rights. Thus far there has been very little evidence of this, even though the main responses to the pandemic focused on rights-restricting measures.

- All public officials must be trained, resourced and supported to embed human rights law in every interaction and to involve people in those discussions and decisions.

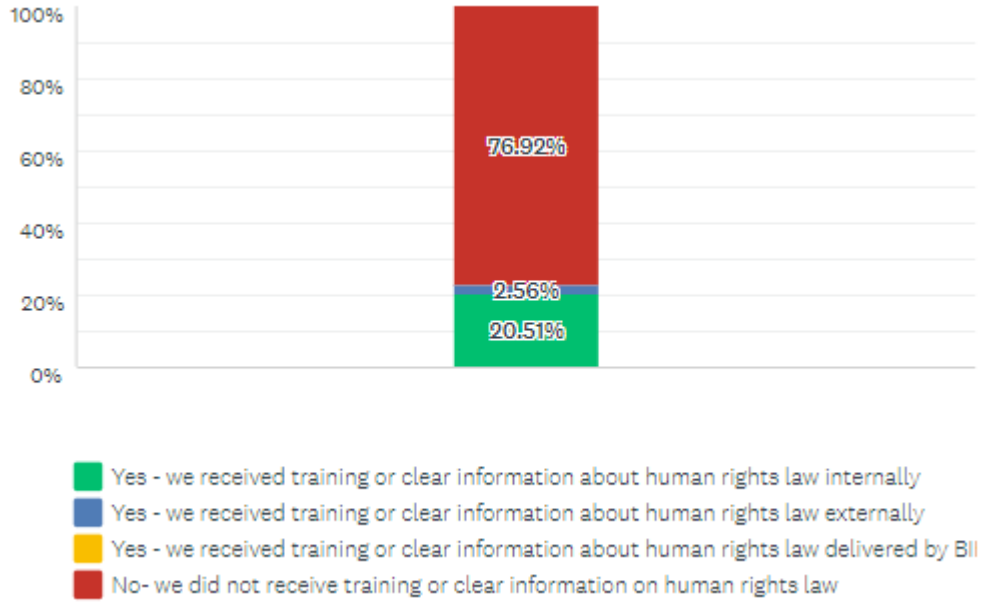
- People must be provided with easy to access, accessible information that enables them to understand their rights during Covid-19.

- The Government must make it clear that everyone in the UK has human rights protected in law, that these are relevant to their everyday interactions with public authorities, with clarity on which rights can be restricted (the process for doing this lawfully, legitimately and proportionately) and which can never be restricted even during a pandemic for example, the right not to be tortured or treated in an inhumane of degrading way (Article 3, HRA).

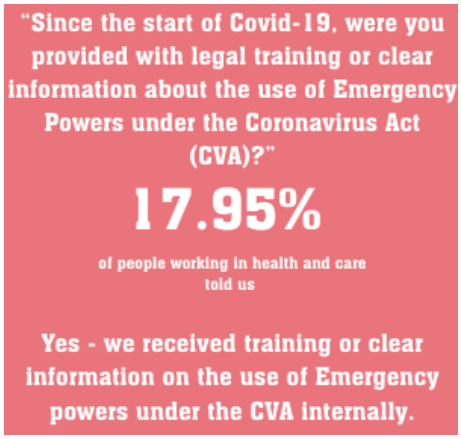
Legality

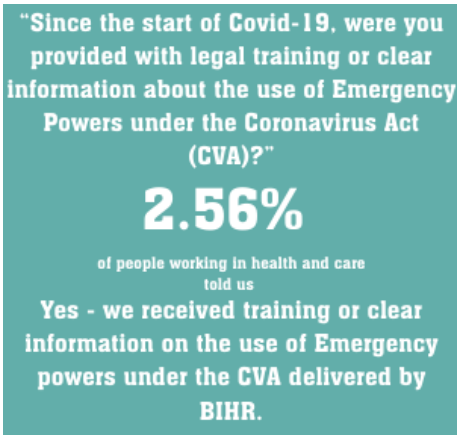
In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant**: Approaches should be grounded in the legal rights that are set out in domestic and international laws.**

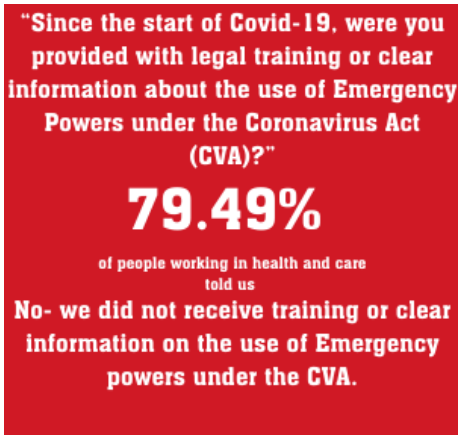
Domestically we have 16 rights under the HRA. Some of these rights can be restricted in certain very specific circumstances for example, to protect the individual or the wider public from harm). Where this has been the case during Covid-19, any restrictions have to be applied lawfully, for a legitimate aim and in a way that is proportionate to the risk. Other rights within the HRA, such as the Right to Life can never be lawfully interfered with by the state, that remains the case during Covid-19.
5. We asked, “Since the start of Covid-19 were you provided with legal training or clear information about upholding human rights law?



5.1 We asked, “Since the start of Covid-19, were you provided with legal training or clear information about the use of Emergency Powers under the Coronavirus Act (CVA)?”



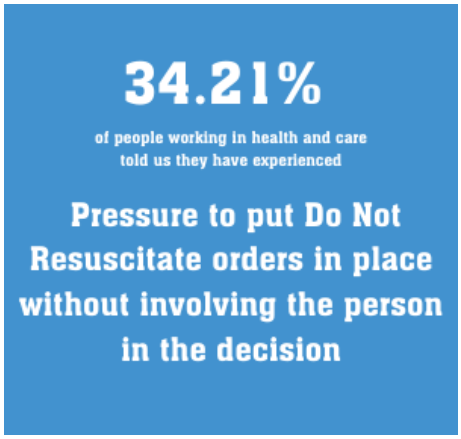


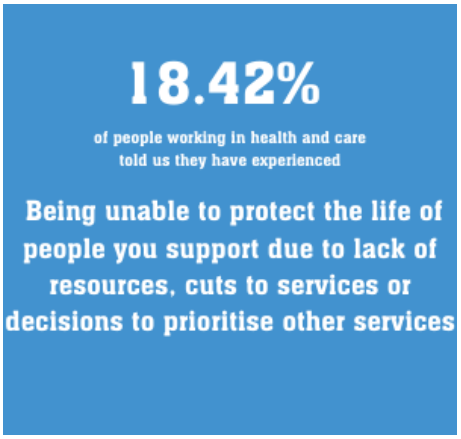


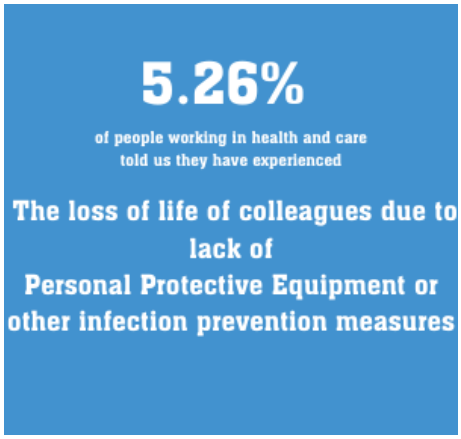
5.2 Key human rights issues identified by people working in health and care during Covid-19:

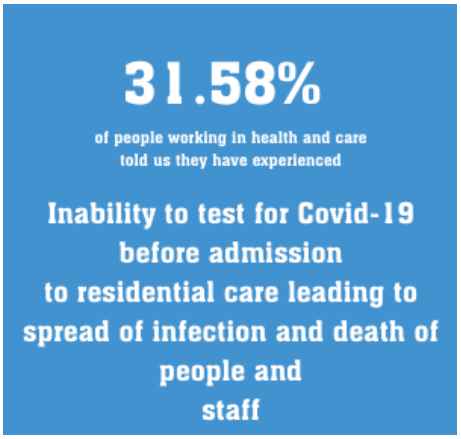
People working in health and care who responded to our evidence call identified experiencing or being aware of the following rights issues during Covid-19.

The right to life (Article 2, HRA)





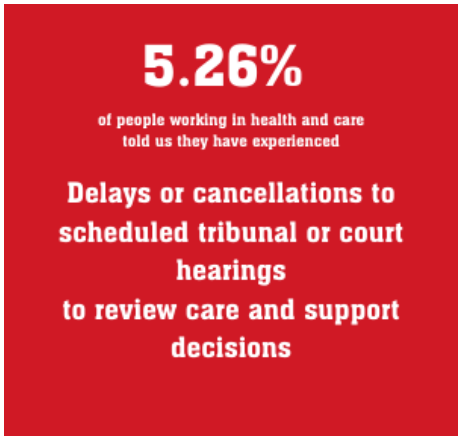




The right not to be tortured or treated in an inhuman or degrading way **(Article 3, HRA)**

The right to liberty (Article 5, HRA)

The right to a fair trial (Article 6, HRA)



The right to respect for private and family life and home and correspondence **(Article 8, HRA)**

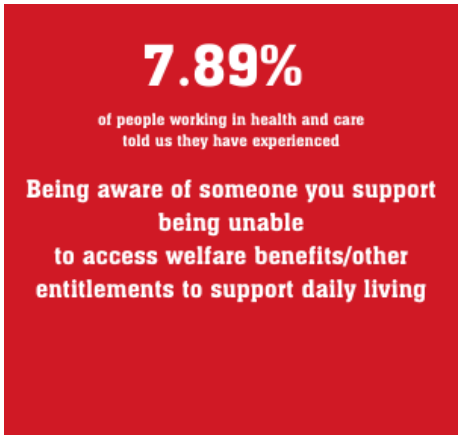
Freedom of thought, conscience and religion (Article 9, HRA)

Freedom of assembly and association (Article 11, HRA)

The right to non-discrimination (Article 14, HRA)

*This is covered in more detail under Non-discrimination above

Peaceful enjoyment of possessions (Article 1, protocol 1, HRA)



The right to education (Article 2, protocol 2, HRA)

BIHR recommendations on ensuring legality:

- Frontline staff must be trained, resourced and supported to recognise and respond to a situation in which a person's legally protected human rights are at risk. In particular, risks to rights which can never be lawfully justified, such as being left in an inhuman or degrading situation. This is necessary during Covid-19 and beyond.

- Local leadership should have oversight of these human rights risks and use this to support non-discriminatory and proportionate service-level and strategic decisions in responding to the pandemic.

- Where the use of Emergency Powers has resulted in an unlawful restriction of rights, this should be independently investigated, using human rights as the central framework and remedies put in place.

- The Government must make it clear that as a Foundation Law, any other pieces of new legislation or guidance must be applied compatibly with human rights law. Furthermore, the Government must ensure public officials across the UK are fully trained, resourced and supported to meet these legal duties.

BIHR's Call to Action

At BIHR, we welcome the JCHR's call to evidence into the human rights implications of Covid-19. The duty to investigate where human rights may have been risked, to remedy this and to put measures in place to prevent this from happening again is crucial. However, an inquiry which exists in isolation of immediate measures to ensure rights are respected and protected is not adequate. It cannot be the case that the UK operates on the assumption that there's an acceptable level of breaching human rights as long as this is reviewed afterwards.

People working in health and care (and in other public services) do not want to make human rights breaching decisions, they want to be given the tools, resources and support to uphold human rights in every single interaction with a person or their family. This is the case all the time but is even more crucial during Covid-19 when difficult decisions need to be made.

At BIHR, we know that the above information showing that, "76.92% of people working in health and care were not provided with legal training or clear information about upholding human rights law" correlates directly with the figures showing the human rights issues during Covid-19.

The UK's approach to making human rights real for people in the UK needs to be grounded not in inquiries or reviews but in immediate actions now to ensure that rights are upheld in every interaction a person has with a public service (or those delivering a public function).

Finally, we asked people working in health and care, "Is there anything else you would like to tell us about your human rights or the human rights of people you support during Covid-19?"

"There was a lack of thought in how unpaid Carers would manage during the pandemic. They have and continue to put their own health and the cared for's health at risk so they can continue caring. Some unpaid carers provide care for their loved ones 24/7 and don't get a break. Before Covid, they had access to community support groups, day centres and respite. This has all been put on hold."

"I feel human rights have been diluted under the premise of the greater good."

"I feel let down by the Government and my management."

"The infringements we are all having to live with in order to keep vulnerable people safe must not become business as usual."

"At this stage we need to be clear about the way forward and the way "out" of some situations that the people we support have found themselves in. Is there a view that services are now stretched and under resourced? If so, when discussing options, we

need to understand what options are actually available. In Cornwall, there is a severe shortage of packages of care as well as care home placements. People I support have been left in hospital for 6 weeks waiting to go home."

"…There was a general lack of support from the government for social care which should be addressed by the committee as the lack of support made it difficult for some providers to offer the standard of care expected under the human rights act, while my employer managed to maintain a high standard of care I think the events of recent months laid bare some providers and managers who were already inept but still allowed to continue providing care by the Care Quality Commission who failed to monitor poor providers effectively even before the pandemic."

"People with Learning Disabilities are the most affected due to the nature of society and the way we view disability. This isn't just during COVID-19. People with LD have been in lockdown all their lives, be it restricted staffing rotas (being unable to go out after 9/10pm), being detained in ATU's (going against Humans Rights Laws, MCA and UN-CRPD) or having their daily lives affected by societies ableist attitudes."

"... All residents have severe learning disabilities and we keep people informed and as safe as possible. Whilst recognizing the importance of wearing masks throughout long hot shifts this has really been a struggle. Though physically quite uncomfortable it has been the difference made to social interactions that has been the saddest for us. I agreed to live in at my work for the duration of lock down to minimize the risk of spreading the virus - it is already set up for full-time live-in staff at our communities. The structure is quite informal and everyone in the house at dinner time to eat and share together. Mask wearing has made this impossible as we can't sit with residents without a mask. Also, when off duty we might pop down for a cup of tea in the garden with residents but again we can't do this. After wearing a mask for 8 hours at a time, trying to remember to take a break to drink enough, the idea of putting one on again to join the community is off putting. So sadly, staff are much more confined to their rooms and miss the joy of community which is the reason most people join this particular organization. I do emphasize that I entirely respect the value of infection control but just wanted to talk about some of the more unseen effects. The organization I work for is very mindful of these worries and I think is doing all they can to support residents and staff. All residents usually attend day centres, workshops, gardening groups and meetings with family and friends. As these have been restricted, we have been provided with a variety of zoom activities but also need to provide many more activities and occupation than we would normally at a time when we are short staffed. Despite all the support we are on our knees with exhaustion."

22/07/2020