Written evidence from the Royal College of Nursing (COV0166)

1. Introduction

1.1. The Royal College of Nursing (RCN) is the largest trade union and professional body in the world, representing 450,000 members across the UK.

1.2. Responding to the COVID-19 pandemic has had significant impacts upon human rights and involved the UK Government enacting unprecedented measures without the usual level of scrutiny. We therefore welcome this inquiry and look forward to its recommendations informing future policy decisions on COVID-19 and other pandemics.

1.3. The Terms of Reference of this inquiry is human rights issues in the UK, however the issues in our submission involve devolved matters so we focus on some key areas of concern for our members in England. The RCN will respond separately to relevant inquiries on human rights matters in the devolved nations.

1.4. For the purposes of this response we have used the Human Rights Act (1998) and the Equality Act (2010) as a frame of reference for our inclusion of specific rights.

2. Summary

2.1. During the pandemic, there have been concerning evidence of trends where unequal treatment is related to a protected characteristic, including ethnicity, age, and disability.

2.2. The pandemic has highlighted and exacerbated existing health inequalities and broader structural discrimination. The disproportionate impact of COVID-19 on people from Black, Asian and Minority Ethnic (BAME) groups is very concerning. It is critical to understand the underlying factors driving and sustaining inequalities, including systemic discrimination against BAME groups, and commit to urgent and meaningful action to address these.

2.3. Despite being most at risk from COVID-19, the lack of regard for older people's rights and specifically the rights of care home residents in the development and implementation of guidance is concerning. Lack of access to appropriate Personal Protective Equipment (PPE), testing and guidance for care home staff has exposed key workers and those they care for, to unnecessary risk. Although we focus on the workforce angle, it is important to note that many people within these settings will be older, and as such must not be discriminated against for equal access to protection based upon their age or disability.

2.4. Insufficient guidance for mental health services on issues such as PPE has led to variation in interpretation, confusion for staff and patients, and left patients and staff vulnerable to infection. Breaches in the Mental Capacity Act and safeguarding processes have been reported. It is a breach of the Equality Act to discriminate someone based on their disability, which in some cases will include mental health conditions. Specific challenges have arisen from changes/interruptions to service provision, whilst temporary changes to the Mental Health Act (MHA) in the Coronavirus Act 2020 such as fewer health care professionals being required to

undertake certain functions and extended time limits for the detention and transfer of patients also have human rights implications.

2.5. People with learning disabilities (LD) are among the most vulnerable to human rights abuses, particularly during the pandemic, and deaths from COVID-19 amongst people with LD are disproportionately higher. There are important considerations which must be made in relation to discrimination for these groups within the Equalities Act framework. Specialist staff were diverted away from vital care services for people with LD which will have impacted upon health outcomes and may have increased the use of restrictions of liberty, such as restraint and isolation.

3. **Recommendations for Government**

Guidance

3.1. The rights of vulnerable groups, including older people, people with LD and children, must be explicitly considered within future policy development to ensure equity of access.

3.2. All guidance should be available in accessible formats, with input from relevant stakeholders, experts and people with lived experience. It should be informed by published human rights impact assessments.

3.3. Appropriate guidance on PPE for specific health and care settings must be provided, including mental health and learning disability settings.

Inequalities

3.4. Any public inquiry into COVID-19 must consider the social determinants of health and the role of institutional racism and systemic inequality within health and care. It must be informed by the lived experience of BAME communities, including health and care workers.

3.5. The Government must prioritise the reduction of health inequalities within recovery plans and deliver a national, funded cross-government strategy to tackle health inequalities and the social determinants of health with clear objectives, measurable targets and timeframes.

3.6. Robust, transparent data on the number of health and care workers who have contracted COVID-19, received treatment, and died (including role, setting, ethnicity and nationality as well as underlying health conditions) is needed to understand the impact thus far and plan effectively for future waves.

Mental health

3.7. The Government, in consultation with the Chair and members of the Independent Review of Mental Health Act, must urgently review the impact of changes to the Mental Health Act in the Coronavirus Act 2020.

4. Further information

Inequalities

4.1. The pandemic has not impacted all equally and the measures taken in response are exposing and exacerbating inequalities, structural discrimination and disadvantage[1]. Age, ethnicity, sex and geographical area are factors which increase the risk of infection, severity of symptoms and mortality[2]. Death rates from COVID-19 in England have been higher among people of Black and Asian ethnicity than any other ethnic group[3] and in deprived areas of England and Wales people are dying from COVID-19 at more than twice the rate of affluent areas[4].

4.2. Children's rights are of particular concern: for many children experiencing 'lockdown' in cramped and/or poor-quality accommodation with an inability to social distance and/or lack of access to outside space, they are risking significant long-term health impacts. School closures threaten to widen the attainment gap between children, whilst the interruption to vital health visiting and school nursing services could also impact on children's rights by reducing opportunities for early intervention, prevention and child protection. Our members have also reported an increased use of food banks and domestic violence during lockdown.

4.3. Access to health and care services has been disrupted during the pandemic, with staff and resources redeployed and many services suspended or cancelled[5]. Our members are concerned about the impact on vulnerable groups, including people with long term conditions.

4.4. Evidence of fewer people accessing medical assistance during the pandemic[6] is concerning because of the potential longer-term impacts and the backlog of demand when the workforce and resources are depleted. Evidence of a reduction in vaccination rates in England in March/April[7] is particularly worrying given the life-long risks from preventable infections.

4.5. Many issues can affect access to services, including information and guidance not being communicated in an accessible or culturally sensitive way, and/or individuals feeling they are not being taken seriously. This has been highlighted in evidence of BAME communities having systematically different experiences of health care and the service they receive[8].

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[1] Health Foundation 2020 https://www.health.org.uk/publications/long-reads/will-covid-19-be-a-watershed-moment-for-health-inequalities

[2] PHE (2020) Disparities in the risk and outcomes of COVID-19 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892085/disparities_review.pdf

[3] PHE (2020) Beyond the data: Understanding the impact of COVID-19 on BAME groups https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

[4] ONS (2020) https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsoccurringupto1may2020andregisteredupto9may2020provisional

[5] Health Foundation (2020) https://www.health.org.uk/news-and-comment/blogs/covid-19-five-dimensions-of-impact

[6] BHF (2020) https://www.bhf.org.uk/what-we-do/news-from-the-bhf/news-archive/2020/june/half-heart-patients-harder-get-medical-treatment-lockdown; GP Online (2020) https://www.gponline.com/millions-patients-avoiding-calls-gp-during-covid-19-pandemic/article/1681384

[7] McDonald et al, (2020) Early impact of the COVID-19 pandemic and social distancing measures on routine childhood vaccinations in England, January to April 2020 Eurosurveillance Vol 25, (19), 14/May/2020 https://www.eurosurveillance.org/content/10.2807/1560-7917.ES.2020.25.19.2000848

[8] PHE (2020) Beyond the data: Understanding the impact of COVID-19 on BAME groups

Race and ethnicity

4.6. We are deeply concerned about the disproportionate and high impact of COVID-19 on BAME groups, including health and care workers. For example, evidence shows that people of Bangladeshi ethnicity had around twice the risk of death than people of White British ethnicity. People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10% and 50% higher risk of death when compared to White British.[9]

4.7. A recent report indicated that the risks associated with COVID-19 transmission, morbidity and mortality can be exacerbated by factors such as housing, and that individuals from BAME groups are more likely to work in occupations with a higher risk of COVID-19 exposure; and they are more likely to use public transport to get to work. Furthermore, systemic racism and poorer experiences of healthcare and work may mean that individuals in BAME groups are less likely to seek care when needed, or as NHS staff they are less likely to speak up when they have concerns about Personal Protective Equipment (PPE) or risk.[10]

4.8. Although official data remains limited, analysis suggests that the death rate amongst this group accounts for more than half of clinical deaths[11]. There have been concerning reports of BAME staff being asked ahead of others to care for people with COVID-19[12] and many BAME staff are employed in social care where the distribution of PPE has often been slow and inconsistent. An RCN member survey highlighted that for nursing staff in high-risk environments only 43% of BAME respondents said they had enough eye and face protection equipment, compared with 66% of white British nursing staff. Furthermore, 70% of BAME respondents said that they had felt pressured to care for a patient without adequate protection, almost double the number of white British respondents who reported they had felt this pressure.

4.9. More needs to be done to understand the factors which have caused this, including the role of discrimination.

Care homes

4.10. Despite repeated concerns being raised about the lack of adequate PPE, hand sanitiser, and testing for nursing staff in the community and social care, delays put staff, patients and their families at risk. It is crucial that we understand the underlying causes of these issues and the high death rate from COVID-19 in care homes[13] to ensure that staff and patients are better protected in the future.

4.11. We are concerned that the interpretation and implementation of guidance for care homes was not sufficiently monitored and resulted in significant variation. An example was visiting access, including at end of life. 'Lockdown' in care homes was poorly guided - a care home is someone's own home and should be considered in the same way to make sure rights are respected and upheld accordingly.

[9] PHE (2020) Disparities in the risk and outcomes of COVID-19
[10] PHE (2020) Beyond the Data: Understanding the impact of Covid-19 on BAME groups
[11] Nursing Notes (2020) https://nursingnotes.co.uk/
[12] Nursing Times (2020) https://www.nursingtimes.net/news/coronavirus/exclusive-bme-nurses-feel-targeted-to-work-on-covid-19-wards-17-04-2020/
[13] ONS (2020) https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsoccurringupto1may2020andregisteredupto9may2020provisional

4.12. The downturn in challenges to Deprivation of Liberty (DoL) authorisations[14][15] is concerning because the increased vulnerability and isolation of residents during a pandemic requires scrutiny of the basis of DoLs to be scrupulous and vigilant. Members have reported that assessments for DoL authorisations have reduced and that remote assessments can disadvantage residents.

4.13. We were also concerned about the arbitrary discharge or prevention of discharge from hospital into care homes, particularly for people returning to their own homes. Furthermore, in devising clinical pathways the blanket addition of dementia in relation to frailty in the assessment of critical care access had to be clarified[16].

Mental health

4.14. We have concerns about the lack of human rights impact assessments undertaken and informing the development and implementation of policies for mental health services. This is particularly important given the protections offered by the Equalities Act for these groups from discrimination. We have concerns about patients who may have been restricted in their movements whilst being acutely unwell, held either formally under the Mental Health Act (MHA) or informally who may not have the capacity to understand the requirements around self-isolation, be unable or unwilling to agree to testing, and unable to practise social distancing.

4.15. Breaches in the Mental Capacity Act and safeguarding processes have been reported which pose serious concerns for the rights of patients including increased prescribing of antipsychotic medications and gaps in local practice determinations.

4.16. Clear guidance on PPE for mental health services has still not been provided, and differing interpretation has led to confusion for staff and patients, and increased vulnerability to infection and risk of transmission. Mental health trusts are struggling with protocols, managing the direct contacts of patients with suspected or confirmed COVID-19, sourcing appropriate PPE and the dress code for staff[17].

4.17. Temporary changes to the MHA within the Coronavirus Act 2020 include fewer health care professionals being required to undertake certain functions and extended time limits for the detention and transfer of patients[18]. Given the human rights implications of increased powers to detain individuals and deprivation of liberty, it is vital that these changes are not normalised.

Learning disabilities

4.18. Members have concerns about the impacts of COVID-19 on the rights of people with learning disabilities (LD). A significant number of people with LD have died as a result of COVID-19[19] and they are at greater risk of premature and avoidable death with complex co-morbidity of underlying health conditions.

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[14] The Deprivation of Liberty Safeguards (DoLS) are an amendment to the Mental Capacity Act 2005 to ensure people who cannot consent to their care arrangements in a care home or hospital are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and in the person's best interests. Representation and the right to challenge a deprivation are other safeguards that are part of DoLS https://www.scie.org.uk/mca/dols/at-a-glance

[15] Hayden (2020) MR JUSTICE HAYDEN VICE PRESIDENT OF THE COURT OF PROTECTION letter to Directors of Adult Social Services https://courtofprotectionhandbook.files.wordpress.com/2020/05/letter-vp-to-adass-4-may-2020.pdf

[16] NICE (2020) https://www.nice.org.uk/guidance/ng159

[17] Staff who usually wear their own clothes rather than uniform

[18] Coronavirus Act 2020 http://www.legislation.gov.uk/ukpga/2020/7/contents/enacted

[19] CQC 2020 https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability

4.19. Diagnostic overshadowing has been a concern for people with LD during the pandemic. To receive equal access to health care, people with LD require reasonable adjustments, which may include specific communication and physical adaptations.

4.20. Members are concerned that an absence of meaningful activity during the pandemic for people who have LD can lead to behaviour that causes concern and requires increased restraint. Other concerns relate to care plans not having been updated, relevant medication reviews not undertaken, and care and support centres being closed. Nursing staff are having to prioritise people who are particularly vulnerable and those who are struggling to adapt to changes in routine as a result of the pandemic. Reports of people with LD being asked to consent to Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) notices by their GP surgery are very concerning[20].

4.21. Consideration must be given to the PPE requirements in LD settings, particularly specialist and secure services, but adequate guidance on PPE in LD settings has not been provided.

17/07/2020

[20] Mencap (2020) https://www.mencap.org.uk/press-release/mencap-responds-concerning-gp-letters-about-coronavirus-medical-treatment