NORTHERN IRELAND HUMAN RIGHTS COMMISSION

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Sent via email to: committee.health@niassembly.gov.uk

23 June 2020

Dear Éilis,

Re: COVID-19 testing in care homes

Thank you for your letter dated 26 May 2020 regarding COVID-19 testing in care homes.

Protecting life

This issue engages the right to life (Article 2 of the European Convention on Human Rights). This right includes a requirement on the State to take reasonable steps to prevent intentional and unintentional deprivation of life within its jurisdiction.[1] It also must take reasonable steps to counteract a known real and immediate risk to life.[2] The European Court of Human Rights is clear in *Osman v United Kingdom* (1998) that a violation occurs when:

> having regard to the nature of the right protected by Article 2, a right fundamental in the scheme of the Convention, it is sufficient for an applicant to show that the authorities did not do all that

[1] *Öneryildiz v Turkey* (2004) ECHR 657; *LCB v UK* (1999) 27 EHRR 212, at para 36.
[2] *Osman v UK* (1998) ECHR 101, at para 116; *Burke v UK*, Application No 19807/06, 11 July 2006, at para 1.

> could be reasonably expected of them to avoid a real and immediate risk to life of which they have or ought to have knowledge. This is a question which can only be answered in the light of all the circumstances of any particular case.[3]

A significant number of COVID-19 related deaths in Northern Ireland have occurred in residential and nursing care homes, with NISRA figures indicating 340 of 802 deaths (42.4 percent) as of 12 June 2020. When the figures for those from care homes who died in hospital is factored in, then a majority of deaths have been care home residents. The Commission is deeply critical of the slow introduction of testing within care homes. Residents discharged from hospital to care homes should have been tested automatically from the outset of the pandemic. The Commission has been clear, in its joint work with the Commissioner for Older Persons, that priority testing should have occurred within care homes from the beginning. In effect, a ring of steel to protect Northern Ireland care homes from the coronavirus should have been created. It is evident that arrangements for care homes was not given the same priority as hospital care and this appears to have contributed to the death toll of residential care residents.

In addition, the late arrival of Personal Protective Equipment, the delay in including care home deaths in COVID-19 statistics to enable an understanding of the issue, and the relative underfunding and general neglect of the care home sector have also played a role.

Invasive procedure

In your letter, it was rightly pointed out that the test for COVID-19 is an invasive procedure and quite unpleasant. Also that persons living in care homes are particularly vulnerable. Thus, the procedure itself may engage human rights.

If carried out by a trained healthcare professional who is taking reasonable care, it is unlikely that the test itself would reach the threshold to engage Article 3 ECHR (freedom from torture, inhuman and degrading treatment), which is an absolute right and not to be violated under any circumstances. It may also engage the right to physical and psychological integrity element of Article 8 ECHR (right to respect for private life). This right is a qualified right, which means that it can be limited under certain circumstances, where it is necessary and proportionate in pursuit of a legitimate aim. Article 8(2) ECHR clarifies that "public safety" and "for the protection of health" are legitimate aims. Equally, not

[3] *Osman v UK* (1998) ECHR 101, at para 116.

testing potentially resulting in COVID-19 spreading undetected or residents receiving delayed treatment, engages the physical and psychological integrity element of Article 8 ECHR. In such cases where rights have to be balanced, it falls to looking at the particular circumstances.

In this scenario, it is balancing considerable discomfort versus potentially curtailing the spread of COVID-19 and enabling earlier intervention in treating a resident. As we have seen, if left unaddressed the results can be brutal, prolonged and life-threatening, particularly in care homes. Thus, not testing has the potential to engage Articles 2 and 3 ECHR and unlike Article 8 ECHR, these rights are not qualified. Concerning Articles 2 and 3 ECHR, potential violations arise if it can be shown that the public authorities were aware of a real and immediate risk and did not take reasonable and proactive steps to address this. The statistics speak for themselves and we already know that once in a care home, particularly if it is undetected, it is very difficult to contain COVID-19 and its devastating impact.

Any interference with Article 8 rights should be proportionate and no more than is required to meet the legitimate aim. As a result, consideration should be given to ensuring the testing is no more obtrusive than necessary and that where possible individuals fully understand what is going to happen and why. The UN CRPD is also clear that reasonable accommodation should be made to ensure equal enjoyment of these rights (Article 5(3)). This requires consideration of what measures can be taken to ensure that the effect of the test is alleviated, particularly for those with a pre-condition that will only add to the stress of an already unpleasant procedure.

The question of obtaining consent must also be considered. In considering forced medical treatment and compulsory medical procedures, the former European Commission on Human Rights has found that on some occasions relatively minor medical tests, which are compulsory or authorised by a court order may constitute a proportionate interference with Article 8 ECHR, even without the consent of the patient. To ascertain whether a violation has occurred in such circumstances, consideration is given to whether the compulsory test is "in accordance with the law", is "for a purpose or purposes authorised by Article 8(2) ECHR" and is "necessary to those purposes in a democratic society".[4] The former European Commission on Human Rights has found that a requirement to undergo medical treatment or a vaccination can be justified if "the interference is based on the need to protect the health of the public and of the persons

[4] *Acmanne and Others v Belgium*, Application No 10435/83, Judgment of 10 December 1984, at 256.

concerned".[5] The ECtHR has indicated that adequate information on the health risks[6] and providing adequate means for ensuring compensation for injuries caused by State medical errors are required.[7]

In summary, arrangements for involving individuals and, where appropriate family members, should be taken to ensure assent wherever possible.

Data protection

As the testing procedure involves obtaining individuals' personal data, the Data Protection Act 2018 and General Data Protection Regulations must be followed.

Article 1 of the General Data Protection Regulations sets out the guiding principles for processing personal data. Articles 1(b) and 6(1)(e) of the General Data Protection Regulations allow for data to be gathered in the public interest, but consideration must be given to the lawful processing of this data, which is further confirmed by section 8 of the Data Protection Act. For example, how and for how long this data will be stored, what it will be used for, who will have access to it and for what purpose, and how and when it will be destroyed.

Section 35(2)(a) of the Data Protection Act and Article 6(1)(a) of the General Data Protection Regulations indicate that consent of the data subject is one way, but not the only way, to ensure that processing of personal data is lawful. In the absence of consent, Article 35(2)(b) of the Data Protection Act states that processing personal data can also be lawful if "the processing is necessary for the performance of a task carried out for… [a law enforcement] purpose by a competent authority". Article 6(1)(e) of the General Protection Regulations supports that such a task can be driven by what is in the public interest.

Articles 12-15 of the General Data Protection Regulations require transparency and Articles 16-20 of the Regulations concern the right to rectification, erasure of personal data or restriction of processing. Therefore, information about the test and its outcomes and any unpleasantness of the COVID-19 test should not be disregarded. The right to request information on or destruction of this data must also be made clear to the individual being tested and/or their next of kin, as appropriate. However, Article 17(3)(c) of the General Data Protection Regulations includes a limitation on the right of erasure when it is "in the public interest in the area of public health". Section 15 of the Data Protection Act also includes an exemption where it "is necessary to protect the rights of others, as

[5] *Boffa and 13 Others v San Marino*, Application No 26536/95, Judgment of 15 January 1998, at 34.
[6] *Vilnes and Others v Norway* (2013) ECHR 240, at para 244.
[7] *Codarcea v Romania* (2012) ECHR 217.

allowed for by Article 23(1) of the General Data Protection Regulations".

Article 89(1) of the General Data Protection Regulations requires that "processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes, shall be subject to appropriate safeguards, in accordance with this Regulation, for the rights and freedoms of the data subject". However, section 19 and Schedule 1 of the Data Protection Act provide that cases of approved medical research (such as conducted by the National Health Service) or medical diagnosis for purposes in the public interest are exempt from the requirements set out in Article 89(1) of the General Data Protection Regulations, even if it is likely to cause substantial damage or substantial distress to a data subject.

In addition to the Data Protection Act and General Data Protection Regulations Article 8 ECHR must be considered in this context. The ECtHR has stated that:

> the protection of data, not least medical data, is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by Article ECHR. Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the ECHR. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.
>
> Without such protection, those in need of medical assistance may be deterred from revealing such information of a personal and intimate nature as may be necessary in order to receive appropriate treatment and, even, from seeking such assistance, thereby endangering their own health and, in the case of transmissible diseases, that of the community.
>
> The domestic law must therefore afford appropriate safeguards to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 ECHR.[8]

The ECtHR has further found that the collection and storage of a person's health-related data for a very long period, together with the disclosure and use of such data for purposes unrelated to the original reasons for their collection can be

[8] *Z v Finland* (1997) ECHR 10, at para 95.

viewed as a disproportionate interference with an individual's Article 8 ECHR rights.[9]

Article 8 of the European Charter of Fundamental Freedoms of the European Union, (which applies only when EU law is involved and it is potentially so here) also provides further clarity providing that:

1) Everyone has the right to protection of personal data concerning him or her.

2) Such data must be processed fairly for specific purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.

3) Compliance with these rules shall be subject to control by an independent authority.

In summary, the arrangements for retaining the biometric material collected should be transparent and used only for the purposes obtained and kept no longer than required.

I hope that you find this information useful. The Commission is ready and willing to provide any further assistance as required, including providing further written or oral evidence.

Yours sincerely,

Les Allamby
Chief Commissioner

[9] *Surikov v Ukraine* (2017) ECHR 100, at paras 70 and 89.

Committee for Health

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26 May 2020

Dear Les,

At its meeting on 21 May, the Health Committee discussed COVID-19 testing of residents in care homes and has asked me to write seeking your view of the consent issues arising and how they should be handled. The Committee is also writing to RQIA on the matter.

Members noted that residents are often frail, elderly and sometimes living with conditions like dementia; and that testing has been described by officials as an invasive procedure and quite unpleasant. The Committee is also conscious that COVID-19 is a notifiable disease under the Public Health Act 1967 which imposes certain requirements.

The Committee would be grateful for your view to inform its ongoing scrutiny of the handling of the pandemic and, in particular, the treatment of a vulnerable section of society.

With kind regards,

Éilis Haughey
Clerk
Committee for Health