Observations by the Irish Human Rights and Equality Commission on National Guidance on Prioritisation in Access to Critical Care in a Pandemic *May 2020*



Coimisiún na hÉireann um Chearta an Duine agus Comhionannas Irish Human Rights and Equality Commission

Observations by the Irish Human Rights and Equality Commission on National Guidance on Prioritisation in Access to Critical Care in a Pandemic

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1. Introduction

The Irish Human Rights and Equality Commission ('IHREC' or the 'Commission') was established by the Irish Human Rights and Equality Commission Act 2014.

The Commission has a statutory remit to protect and promote human rights and equality in the State, to promote a culture of respect for human rights, equality and intercultural understanding, to promote understanding and awareness of the importance of human rights and equality, to encourage good practice in intercultural relations and to work towards the elimination of human rights abuses and discrimination.

The Commission's functions include keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights and equality; and to make such recommendations to the Government as it deems appropriate in relation to the measures which the Commission considers should be taken to strengthen, protect and uphold human rights and equality in the State.

2. Context

This document sets out the Irish Human Rights and Equality Commission's observations on the guidance on prioritisation in access to critical care as set out in the Department of Health's recently published documents.

These documents are:

- The 'Ethical Framework for Decision Making in a Pandemic' published on 27 March¹ (the Framework);
- *'Ethical considerations relating to critical care in the context of COVID-19'* published on 3 April (the *Considerations*)²; and
- The 'Ethical considerations relating to critical care in the context of COVID-19 Supplementary Information' published on 1 May (the Supplementary Information).³

This guidance anticipates that in the Covid 19 pandemic a situation could arise where the numbers of people who under normal circumstances might be considered for admission to an ICU is significantly greater than the number of ICU places available. Such a situation was tragically evident in Italy earlier this year.

https://www.gov.ie/en/publication/13ead5-ethical-considerations-relating-to-critical-care-in-the-context-of-c/

¹ Department of Health (27 March 2020) *Ethical Framework for Decision-Making in a Pandemic.* <u>https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/</u>

² Department of Health (3 April 2020) *Ethical Considerations Relating to Critical Care in the Context of COVID-19.*

³ Department of Health (1 May 2020) Ethical Considerations Relating to Critical Care in the Context of COVID-19-Supplementary Information'

https://www.gov.ie/en/publication/13ead5-ethical-considerations-relating-to-critical-care-in-the-context-of-c/

Even in non-pandemic situations doctors, with patients and their families, have to make decisions about whether intensive care is the right option for each individual patient. However in a crisis situation as envisaged, the issue for decision is not simply the right treatment for each individual but how scarce resources are to be allocated between individuals.

It is important at the outset to acknowledge that prioritisation engages profound and often contested issues of values and rights and that there is no general consensus on proposals for critical care triage or prioritisation. For some people the utilitarian calculation of benefit violates the principle of the equal value of each person.

Even among those who accept – however reluctantly - the need for prioritisation, there can be profoundly different views on how the outcome or benefit is to be maximised and therefore on the criteria to be applied.

3. The Framework and Considerations as currently set out

It is generally agreed that categorical factors such as sex or ethnicity should not be directly incorporated as prioritisation criteria. It is important and welcome that the *Framework* specifies that *"It is not appropriate to prioritise based on social status or other social value considerations e.g. income, ethnicity, gender"* (p. 17). It also states that *"Categorical exclusion e.g. on the basis of age should be avoided as this can imply that some groups are worth saving more than others and creates a perception of unfairness"* (p. 17).

However the *Considerations* document appears less clear about this principle when it states that "*No* single factor (e.g. a person's age) should be taken, in isolation, as a determining factor and decisions should not be made arbitrarily or in such a ways as to result in unfair discrimination" (p.3). It is important of course that it is explicitly recognised that decisions should not result in unfair discrimination. However criteria for distinguishing unfair from fair discrimination (if there is such a thing) are not explained and at face value the statement does not in fact exclude the use of age as a factor in prioritisation but only excludes reliance on using age in isolation as a determining factor.

Following the publication of the *Framework* and the *Considerations*, a wide range of disabled activists and representatives, including the Commission's Disability Advisory Committee, expressed concern at the silence of these documents on disability. It is largely these concerns, it appears, that have led to the publication of the *Supplementary Information*. This recognises that:

"Covid 19 has caused anxiety about whether people with disabilities will be equitably cared for in the event that they contract the virus and become critically ill, due to the potential for value judgements being made regarding quality of life or social worth. People with physical and intellectual disability have equal rights to the highest attainable standards of health and to a high standard of healthcare." (p.1) In addition, and importantly, it clarifies that:

".. caution re should be exercised when interpreting frailty scoring systems in the case of people with a disability. The terms disability, frailty and comorbidity are often conflated and, while they may be inter-related, they are distinct." (p. 2)

The Commission welcomes the publication of the *Supplementary Information*. However while the new document begins a necessary process of clarification and development of this difficult and complex area, much further development and clarification is required.

It is notable for example that the *Supplementary Information* explicitly reiterates the key messages of the *Considerations* including its unclear language on *"unfair"* discrimination and it arguably deepens its ambiguity about the use of categorical factors in prioritisation:

"No single factor should be taken, in isolation, as a determining factor. Age is given as one example: however the statement equally extends to other factors including disability" (p. 1)

More generally, throughout the published guidance there are important ambiguities and unanswered questions about the underlying purpose of the triage and prioritisation process. The guidance is unambiguous that:

"During a pandemic, however, healthcare resources, particularly critical care resources, are likely to become limited over time..... Decisions will therefore have to be made regarding who should be prioritised to receive intervention. These decisions should be based on the underlying rationale of maximising the benefit that can be gained from the limited amount of resources available and giving due attention to the fair distribution of benefits and burdens." (Framework p. 15)

But what exactly is this 'benefit' that is to be maximised? We are told that:

"A multi-principled approach takes into account estimates or projections of: the total number of lives saved; **the total number of life years saved; and long term functional status** should a person survive" (Framework p. 17, emphasis added).

"Access to intensive care should generally be reserved for those patients in whom a good outcome may be expected (those who will most likely survive their acute illness **with reasonable long-term status**)" (Considerations p.2, emphasis added)

"While the specific factors utilised within a prioritisation protocol may vary [...] there are certain common and interconnected features, which should be considered as part of the decision-making process including: [...] **long-term functional status should they survive**" (Considerations p.3, emphasis added)

"Factors such as frailty or the existence of co-morbidities should only be considered relevant in triage decisions insofar as they will have an impact on the patient's potential to benefit from ICU admission **and remaining survival time after discharge"** (Considerations p. 3, emphasis added)

".. as pressure increases on intensive care capacity, it may be necessary for a higher threshold to be applied in relation to which patients can access intensive care treatment" (Considerations, p.4) It is important to recognise that, as noted above, even among those who accept the need for prioritisation in certain circumstances, there can be profoundly different views on how the outcome or benefit is to be maximised and therefore on the criteria to be applied. Should benefit be defined in terms of maximising the number of lives saved or should it include wider objectives? In the former the criteria applied are intended to be strictly clinical and aim to rank critically ill patients in terms of their likelihood of survival through access to the rationed treatment. In the latter other criteria such as 'overall health' gain are introduced which take account of other factors such as years of life gained or assumptions or value judgements about quality of life .

Even strictly clinical factors may disproportionately impact on certain groups such as older people, some groups of disabled people and possibly other vulnerable groups. Crucially any disproportionate impact on these groups will most likely be greater where factors such as quality of life or duration of survival are factored into the prioritisation. It is therefore worrying that the current guidance appears to have adopted views on what and thereby who is to be prioritised in a critical care triage process, without explicitly addressing the potentially profound implications for these vulnerable groups.

In raising these issues we are very conscious that the guidance was initially developed under severe time and practical constraints in the early stages of the pandemic in February and March and against the backdrop of the very urgent fear of critical care services facing potentially overwhelming demand.

We also recognise that the State has directed enormous effort to building the surge capacity of our healthcare system in order to avoid that potential threat becoming a reality and that recent trends give rise to cautious optimism that our ICU capacity will not be overwhelmed at this time. We are conscious too though of the uncertainty that lies ahead and the possibility of further waves of the pandemic bringing about a reversal of those positive trends.

In our view the publication of the ethical guidance should be seen as opening an important values debate with potentially profound implications for rights and equality in our society. However these implications need much fuller and wider consideration. The publication of the *Supplementary Information* has started a necessary process of clarification and development of this difficult and complex area that now needs to go much further.

We welcome the fact that the *Framework* document recognises that "*The dilemma facing public health officials is how to implement public health measures in response to a pandemic in a manner that is equitable, reasonable, and proportionate, in compliance with national and international legislation and which does not discriminate against particular groups or individuals.*" (p.3). However we note that none of the guidance published to date specifically considers relevant domestic or international equality and human rights law and standards and there is no discussion of the legal and human rights requirements which clinicians need to follow in making decisions about patients. This now needs to be addressed.

4. Conclusion

Finally, it is our strong view that the *Ethical Framework* itself points the way towards what now needs to happen. It argues that the procedural value of 'inclusiveness' requires that *"stakeholders are consulted (to the greatest extent possible in the circumstances), views are taken into account, and any disproportionate impact on particular groups is considered."* (p.9)

Consultation in the preparation of these guidance documents was very limited at best and did not engage with those rights holders particularly affected nor with the general public. This crucial omission now needs to be rectified.

Irish Human Rights and Equality Commission 15 May 2020



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