NICE Guideline on Critical Care in Adults: An Ethical Analysis

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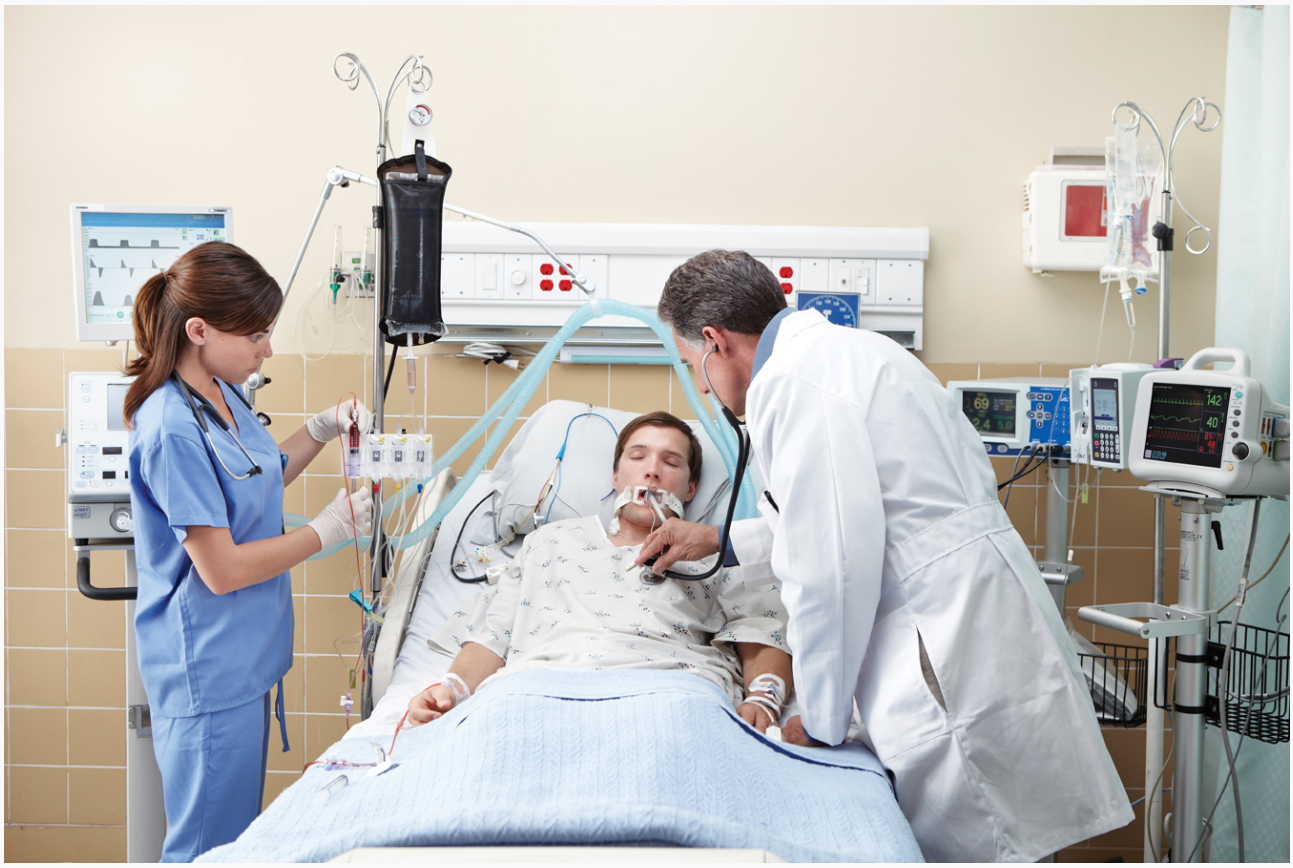

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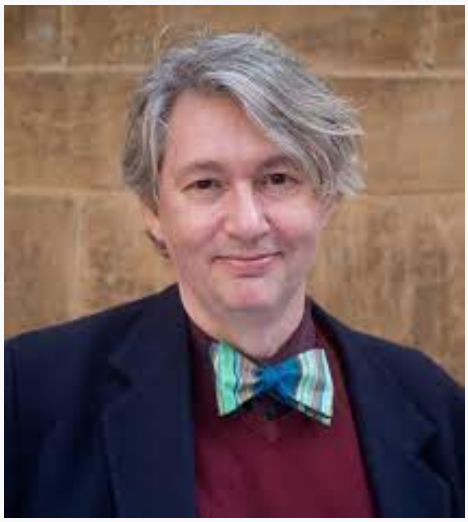

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Introduction

This paper takes as its focus a guideline produced by the National Institute for Health and Care Excellence (NICE), the national advisory body for rationing health and social care in England. It should be read together with the first COVID-19 Briefing Paper of the Anscombe Bioethics Centre, Resource allocation and ventilators: A statement of Catholic principles. **[1]** Ethical analysis of the NICE guideline is relevant even after the United Kingdom has passed the first peak in cases of COVID-19 both because the danger of a second peak is real and because the model for rationing exemplified in the guideline may be used for other healthcare emergencies.

It is well known that COVID-19 can cause breathing problems so severe that patients may need to be given oxygen using a ventilator. There is no cure for COVID-19 and many of those on ventilation will not survive. **[2]** Nevertheless, ventilation undoubtedly saves lives, helping some people through the worst until the body successfully fights off the infection. A key target for health services has therefore been to ensure that there are enough ventilators to go around during the pandemic. The ethical question is how these should be allocated in the fairest and most effective way.

It is the role of NICE to produce evidence-based guidelines to help providers and commissioners decide what treatments or forms of care to offer and to whom. In the context of the current pandemic, NICE has produced several documents, of which the first and to date most controversial is COVID-19 rapid guideline: critical care in adults (NG159). **[3]** The purpose of the guideline is 'to maximise the safety of patients who need critical care during the COVID19 pandemic… [and to] enable services to make the best use of NHS resources'. **[4]** What does this guideline say and how far does it accord with a Catholic understanding of the requirements of justice?

The Content of the Guideline

The document begins by recommending that on admission to hospital all patients, not only suspected COVID- 19 patients, be assessed for 'frailty'. **[5]** Frailty is not the same as disability or illness. Frailty, as the term is used by doctors, refers to a person's mental and physical resilience. As people age, they gradually lose their ability to 'bounce back and recover from events like illness and injury'. **[6]** However, someone's frailty cannot be inferred just from that person's age. An individual who is 70 years old and who has suffered from a serious injury may well be frailer than someone else who is 80 years old but in good health. NICE recommends the Clinical Frailty Scale (CFS) as a tool to measure frailty. This gives a score from 1 (very fit) through 5-6 (mildly and moderately frail) to 9 (terminally ill). **[7]**

The NICE guideline recommends that decisions about referral to critical care should be informed by a CFS assessment because it is relatively easy to administer and there is evidence that higher CFS scores are associated with poorer patient outcomes. **[8]** The score helps estimate whether critical care would

help this patient. However, the first edition of the NICE guideline was criticised strongly by healthcare professionals and by disability groups **[9]** for recommending the routine use of the CFS with all patients. Subsequently NICE has revised the guideline several times to make clear that CFS scores should not be used in any patient aged under 65 or in any patient with a stable long-term disability. These patients require an 'individualised assessment of frailty'. **[10]** Even for those over 65 without stable long-term disabilities, where a CFS score can be used, this should be done 'as part of a holistic assessment' **[11]** and not in isolation. Furthermore, doctors should also 'involve relevant specialists if needed, such as for people with dementia'. **[12]**

NICE does not provide an overall scoring system but states that the 'risks, benefits and possible likely outcomes' **[13]** of the different treatment options should be discussed with patients, families and carers, using 'decision support tools' where available. Decisions about admission to critical care should involve the critical care team. **[14]** The guideline also mandates that healthcare professionals 'sensitively discuss a possible "do not attempt cardiopulmonary resuscitation" decision with all adults with capacity and an assessment suggestive of increased frailty'. **[15]** Those who would not benefit from admission to critical care should 'receive optimal care within the ward'. **[16]** In the case of COVID-19 patients this ward-based care may well involve use of oxygen and, for some, non-invasive forms of ventilation. **[17]**

Areas of Agreement and Causes of Concern

The key strength of this document, from a Catholic perspective, is that it is framed in relation to the risks, benefits and likely outcomes of the different treatment options. It is an evaluation of treatments not an evaluation of persons. The primary reason not to refer a patient to critical care is that this patient is unlikely to benefit but would have to endure the burdens of invasive treatment such as intubation and the risks of harm including the harm of dying in a highly medicalised environment. It is clear that increasing frailty decreases the likelihood of benefit from critical care and, as stated in Briefing Paper 1, likelihood of benefit is ethically relevant to allocation decisions. **[18]** The NICE guideline is also to be commended for making clear that, if a patient is in hospital and would not benefit from critical care, the patient should be offered 'optimal care within the ward'. **[19]** The decision should never be thought of as a choice between critical care or no care.

It is also reasonable for the guideline to recommend that healthcare professionals raise, in a sensitive way, the issue of cardiopulmonary resuscitation (CPR). When CPR is needed it is always in response to an emergency and there is no time for reflection and discussion. However, in a patient who is frail and has other underlying health conditions, CPR is unlikely to be beneficial (despite the impression many people have from the media or from television hospital dramas) and, even if successful in the short term, CPR may cause pain or injury. To protect such patients from overzealous and harmful actions they need a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decision recorded in their notes. Hence, it is right to discuss the issue in advance, but sensitively and in a way that is clearly related to the risks, benefits and likely outcomes of this treatment (CPR) for this patient. Such an approach is in accord with Catholic principles.

There are, however, aspects of the NICE guideline that are causes for concern:

- The first edition of the guideline was clearly defective in recommending that CFS scores be used with patients where the scale has not been validated (those under 65 or with stable long-term disabilities).
- The revised versions are better in recommending use of the CFS only for a subsection of patients and only as part of a 'holistic' assessment of frailty, informed by relevant specialists. However, the guideline continues to illustrate what it means to be frail by reference to a threshold number 'for example, a CFS score of 5 or more'. **[20]**
- The guideline also includes a one-page 'critical care referral algorithm' **[21]** to help clinicians decide whether to refer a COVID-19 patient to critical care. Again, the current version is better than the one given in the first edition, but it still includes the 'over 65' and 'CFS score of over 5' criteria to illustrate assessments and it does not highlight the need to involve specialists in assessment of frailty and in the decision whether to refer the patient to critical care. It is likely that this one page summary will remain the most influential part of the guideline and there is a danger that the assessment will become a 'tick box exercise' if doctors are not adequately supported and rely on the algorithm. **[22]**
- The guideline commendably states that those who would not benefit from critical care should receive 'optimal care within the ward'. **[23]** However, in the algorithm this recommendation is reduced to 'ward-level care safe currently: continue to review'. **[24]** This phrase does not make clear that ward-level care should be 'optimal' for the individual patient, will not be the same for all patients and, for some, will involve active treatment options and not only symptom control.
- NICE does not describe in any detail how frailty and co-morbidity can be combined into a holistic assessment. Without such detail, some units have produced tick-box 'decision support tools' in which age, frailty, and co-morbidities are each scored with a number. Such combined numerical scores are simplistic, un-evidenced and misleading in that they typically treat age, frailty and co-morbidity as independent variables. This leads to 'double counting' and to unfair discrimination against older patients and against those with pre-existing disabilities. One such 'decision support tool' has been highlighted in the media. **[25]** It was not produced or approved by NHS England or by NICE and was repudiated by both bodies. However, this repudiation received much less publicity than the original article **[26]** and similar decision support tools may be in use elsewhere. **[27]** There is no explicit warning in the NICE guideline of the dangers of adopting combined numerical scoring tools for deciding admission to critical care.

Likely Outcomes and Refusals of Treatment

Ethical decisions about offering or accepting treatment should consider the 'risks, benefits and possible likely outcomes'. **[28]** A likely outcome that is less than full recovery is to this extent less beneficial and the patient should weigh up the benefits before accepting the risks and burdens of treatment. However, there is a problem with the way NICE expresses the aim of treatment as being to 'recover from their critical care admission to an outcome that is acceptable to them'. **[29]** This goes beyond stating that partial recovery is less desirable inasmuch as it is partial. It invites the question as to whether life with disability is 'acceptable' to the patient.

The problem is not only that people are very poor at predicting how they would feel if they became disabled. **[30]** The deeper problem is that asking what 'quality of life' is 'acceptable' **[31]** invites the thought that some states are worse than death, some lives unworthy of life. Even to ask the question is to place on disabled people the burden of having to justify their future survival. **[32]** To invite people to refuse treatment because life with disability would be unacceptable to them is to encourage suicide by omission. **[33]**

In this regard it is extremely worrying that in supporting documents for the NICE guideline the link for further advice on advance refusals of treatment directs the unwary reader to the website of Compassion in Dying. This is a sister organisation to Dignity in Dying, formerly known as the Voluntary Euthanasia Legalisation Society. Compassion and Dying promotes the use of advance refusals as a means to hasten death. This is evident from the wording provided by the organisation for an advance refusal of treatment in the context of COVID-19:

> If I develop symptoms of coronavirus (COVID-19), whether it is suspected or confirmed, I refuse the following:
> - to be admitted to a critical care department (i.e. intensive care or a high dependency unit)
> - mechanical ventilation, both invasive and non-invasive
> - all other life-sustaining treatment, including but not limited to clinically assisted nutrition and hydration, antibiotics and cardio-pulmonary resuscitation (CPR)
> - My priority is to be made comfortable and I accept all forms of palliative medications to ensure this.

Note that this refusal is recommended to all patients without any knowledge of the benefits or burdens of the different interventions to this or that patient. It is a blanket recommendation of a blanket refusal of all life-sustaining treatment. Interventions which may well be burdensome with little prospect of benefit, such as CPR, are listed alongside non-invasive ventilation and clinically assisted hydration which are less burdensome and may well be beneficial at least in some situations for some patients. All interventions are refused which fall under the description 'life-sustaining' and thus the clear aim of this statement is to encourage the thought that one could or should avoid sustaining a life that falls below what is acceptable, a life unworthy of living. **[34]**

Because this advance refusal omits any consideration of the burdens or benefits of specific treatments in relation to the individual patient, and because it includes the blanket refusal of clinically assisted nutrition and hydration whatever the patient's particular circumstances, it is contrary to a Catholic understanding of respect for human life. Compassion in Dying have argued **[35]** that part of the benefit they provide is that the use of their refusal forms will bring 'cost savings' for the NHS. It is deeply regrettable that NICE should be associated, even indirectly, with the unethical promotion of blanket refusal of treatment as a means of rationing resources. **[36]**

Unacknowledged Triage and the Discouragement of Treatment

The NICE guideline was updated on 9 April 2020 to include links to 'ethical guidance from the British Medical Association, the Royal College of Physicians and the General Medical Council'. **[37]** The guidance of the BMA addresses a situation where 'demand outstrips the ability to deliver to existing standards'. **[38]** It envisages that this may require 'withdrawing [life sustaining] treatment from an individual who is stable or even improving but whose objective assessment indicates a worse prognosis than another patient'. **[39]** It is useful to contrast this approach with the NICE guideline, which is based on the premise that, through great efforts of social distancing by the general public and through the provision of increased capacity within the NHS, there will always be enough resources to offer urgent life-saving treatment to all those who could reasonably hope to benefit.

Had the NHS been overwhelmed, as some health systems in other countries were, then the NICE guideline would have had to be revised to include some overt triage criteria related to an estimate of the resources available, but this did not happen even during the peak of demand. The NICE guideline advocated provision of critical care based on an individualised assessment of risk and benefit. Nevertheless, in practice it seems likely that at least some healthcare professionals have discouraged admission to hospital and / or admission to critical care for people who might have benefited out of a fear that otherwise the system would be overwhelmed. This may be called unacknowledged triage.

Unacknowledged triage, whether by omitting to refer patients or by discouraging patients from requesting treatments or by encouraging advance refusals of potentially beneficial treatment or by blanket policies for advance care planning **[40]** is not transparent and hence it carries the risk of causing avoidable harms. There are some indications that this has occurred during the pandemic, perhaps on a large scale. This is suggested, for example, by the decrease of 29% in people presenting at accident and emergency during the pandemic **[41]** and in the marked increase in overall deaths during the pandemic, not all of which are directly attributable to the virus. **[42]**

It would be a cruel irony if the fear of scarcity has done greater harm than the scarcity itself, or if people who could have benefited have been refused admission while critical care beds were standing empty. NICE is clear that its guideline 'does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian'. **[43]** The pre-pandemic guidance on best practice for decision making in critical care remains valid, and the first question to consider is 'How will critical care treatments help the person in the short and long term?'. **[44]** This in turn is an expression of the first duty of any doctor which is to 'make the care of your patient your first concern'. **[45]**

Endnotes

[1] D.A. Jones, *Resource allocation and ventilators: A statement of Catholic principles*, Anscombe Bioethics Centre, COVID-19 Briefing Paper 1 (8 April 2020), hereafter 'Briefing Paper 1': https://bioethics.org.uk/research/covid-19-briefing-papers/resource-allocation-and-ventilators-a-statement-of-catholic-principles-prof-david-albert-jones/

[2] According to the Intensive Care National Audit and Research Centre, of those patients who received ventilation within 24 hours of admission to critical care only 40% were still be alive 30 days later (*ICNARC report on COVID-19 in critical care*, 24 April 2020, p. 20).

[3] COVID-19 rapid guideline: critical care in adults (NG159) © NICE 2020 Originally published on 20 March 2020, updated 25 March, 31 March, 9 April, 24 April and 29 April 2020. https://www.nice.org.uk/guidance/ng159 Hereafter, 'NG159'.

[4] *Ibid*., p. 4, Overview.

[5] *Ibid*., p.6, 1.1.

[6] Age UK 'Understanding frailty' https://www.ageuk.org.uk/our-impact/policy-research/frailty-in-olderpeople/understanding-frailty/ (Page last updated 3 May 2019).

[7] Specialised Clinical Frailty Network https://www.scfn.org.uk/

[8] FFor example, C. Fisher, *et al*. 'Predicting intensive care and hospital outcome with the Dalhousie Clinical Frailty Scale: a pilot assessment', *Anaesthesia and intensive care* 43.3 (2015): 361-368; D. Basic and C. Shanley 'Frailty in an older inpatient population: using the clinical frailty scale to predict patient outcomes', *Journal of Aging and Health* 2015;27:670-85; S. Juma, M. Taabazuing and M. Montero-Odasso, 'Clinical frailty scale in an acute medicine unit: a simple tool that predicts length of stay', *Canadian Geriatrics Journal*, 2016. 19(2), 34.

[9] For example, I. Tuffrey-Wijne 'COVID-19: "The Clinical Frailty Scale is not suitable for use with people with learning disabilities' *Nursing Times* 26 March 2020; J. Pring 'Coronavirus: Anger over "terrifying and discriminating" intensive care guidance', Disability News Service, 26 March 2020. https://www.disabilitynewsservice.com/coronavirus-anger-over-terrifying-and-discriminating-intensive-careguidance/

[10] *Op. cit.*, NG159, p. 6, 1.1, as amended 25 March 2020.

[11] *Ibid*., p. 6, 1.1, as amended 25 March 2020.

[12] *Ibid*., p. 6, 1.1 as amended 24 April 2020 (role of specialists) and 29 April 2020 (example of dementia).

[13] *Ibid*., p. 7, 2.1.

[14] *Ibid*., p. 7, 2.2 as amended 25 March 2020, p. 8, 2.4 as amended 25 March 2020.

[15] *Ibid*., p. 7, 2.4.

[16] *Ibid*., p. 8, 2.6.

[17] British Thoracic Society Guidance: *Respiratory support of patients on medical ward*, V1.0, 16 April 2020.

[18] *Op. cit*., Briefing Paper 1, p. 3.

[19] *Op. cit.*, p. 8, 2.6.

[20] *Ibid.*, p. 7, 2.2.

[21] *Ibid.*, p. 7, 2, link to 'critical care referral algorithm' as amended 31 March 2020.

[22] On the danger of clinical tools becoming 'tick box' exercises see J Neuberger, C Guthrie, D Aaronovitch *et al*. *More care, less pathway. A review of the Liverpool Care Pathway*. London: Department of Health; 2013, especially 1.90, 3.13.

[23] *Op. cit.*, p. 8, 2.6.

[24] *Ibid.*, p. 7, 2, link to 'critical care referral algorithm'.

[25] P. Foster, B. Staton and N. Rovnick, 'NHS "score" tool to decide which patients receive critical care', *Financial Times*, 12 April 2020.

[26] The original *Financial Times* story which did not report the views of NICE or NHS England was picked up by *The Times*, *iNews*, *Daily Mail*, *The Sun* as well as news services such as *Disability News Service*, *FR24 News*. The *Financial Times* amended the story in the online version the following day to include the views of NHS England and NICE but this was not picked up by any newspaper, but only by some blogs and more specialist publications such as *GM Journal*.

[27] *The Irish Sun* investigated and found some Irish hospitals that were using a similar numerical decision tool. N. Cotter, A. Higgins 'Points Of No Return: Coronavirus in Ireland – Patients ranked by points system weighted against elderly to decide who goes into ICU', *The Irish Sun*, 15 Apr 2020.

[28] *Op. cit.*, NG159, p. 7, 2.2.

[29] *Ibid.*, p. 10, 4.2.

[30] See, for example, I. Basnett, 2001, 'Health care professionals and their attitudes toward decisions affecting disabled people', in G.L. Albrecht, K. Seelman and M. Bury (eds.), *Handbook of Disability Studies*, Thousand Oaks, CA: Sage Publications, 450–467.

[31] Regrettably, this way of framing the desired outcome of critical care is not special to NICE but is common among intensivists, see for example 'Care At The End Of Life: A guide to best practice, discussion and decision-making in and around critical care'. Faculty of Intensive Care Medicine, September 2019, p. 10, 'Qualitative/holistic aspects of care involve asking the questions "Do proposed treatments offer a minimum quality of life acceptable to the patient?"'.

[32] K. Fitzpatrick and D.A. Jones, 'A Life Worth Living? Disabled People and Euthanasia in Belgium', in D.A. Jones, C. MacKellar and C Gastmans, *Assisted Suicide and Euthanasia: Lessons from Belgium*, Cambridge: Cambridge University Press, 2017, pp. 133-149; D.A. Jones 'Assisted dying and suicide prevention', *Journal of Disability & Religion*, 22.3 (2018): 298-316. X. Symons and R. Chua '"Alive by default": An exploration of Velleman's unfair burdens argument against state sanctioned euthanasia'. *Bioethics* 34.3 (2020): 288-294.

[33] *Op. cit.*, Briefing Paper 1, p. 3.

[34] I. Brown, 'When is life unworthy of living? Lessons from the systematic killing of children with disabilities in Nazi Germany.' in R. Hanes, I. Brown, and N. E. Hansen (eds.), *The Routledge history of disability*. London: Routledge, 2018, pp. 421–433.

[35] Compassion in Dying, *My Life, My Decision: Planning for the end of life Summary Report 2017*, London: Compassion in Dying, 2017, p. 17, 'Cost Savings'.

[36] See also Michael Wee 'Coronavirus and the misuse of "do not resuscitate" orders', *The Spectator*, 6 May 2020.

[37] *Op. cit.*, NG159, p. 10, 4.2, as amended 9 April 2020.

[38] BMA. *COVID-19 – ethical issues. A guidance note*. London: British Medical Association, 2020, p. 3.

[39] *Ibid.*, emphasis added.

[40] Instances of which were reported in the media and were condemned in a joint statement by the RCGP, BMA, CPA and CQC in 1 April 2020: 'It is unacceptable for advance care plans, with or without DNAR form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need'. https://www.rcgp.org.uk/about-us/news/2020/april/joint-statement-on-advance-careplanning.aspx

[41] *Statistical Commentary: A&E Attendances and Emergency Admissions* (March 2020): https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2020/04/Statistical-commentary-March-2020-jf8hj.pdf

[42] J. Appleby, 'What is happening to non-COVID deaths?', *BMJ* 2020; 369: m1607.

[43] *Op. cit.*, p. 2.

[44] *Ibid.*, p. 7, 2.1, link to 'Information to support decision making'.

[45] GMC, *Good medical practice*: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medicalpractice

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