Ethics in a pandemic response

An Anthology

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the Swedish National Council on Medical Ethics (Smer)

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An Anthology

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Foreword

This anthology published by the Swedish National Council on Medical Ethics (Smer) is part of the Council's work to examine and reflect on the ethical dimensions of the COVID-19 pandemic. During the pandemic, Smer organised a series of seminars and dialogues in which experts, practitioners, and commentators from Sweden and abroad contributed their insights. Several of the authors represented in this anthology took part in these discussions.

The chapters demonstrate the importance of integrating ethical analysis into decision-making during crises. The pandemic revealed not only the difficult trade-offs between competing values and interests, but also the absence of sufficiently robust structures for ethical deliberations. Ethical preparedness before a pandemic or a crisis occurs is a significant investment in lives, time and resources. Our aim is to contribute to the strengthening of ethical preparedness – in Sweden as well as internationally – so that future crises may be addressed with greater openness, fairness, and respect for human rights.

This volume was edited by Göran Collste and Mikael Sandlund, expert members of Smer, together with Lotta Eriksson, Secretary General of Smer. Each author is solely responsible for the content of their respective contributions.

Stockholm, October 2025

Sven-Eric Söder
Chair of The Swedish National Council on Medical Ethics

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1 Introduction: Ethics in a pandemic response

Lotta Eriksson *Secretary General, Swedish National Council on Medical Ethics, led and coordinated the Council's pandemic-related work from 2020–2022.*

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Background

The COVID-19 pandemic confronted societies with profound ethical dilemmas: how to balance individual freedoms against collective health, protect the vulnerable while maintaining essential services, and make life-and-death decisions under conditions of uncertainty. The pandemic revealed that managing a health crisis involves far more than medical expertise and scientific evidence. Decision-making also requires systematic ethical reflection on difficult value conflicts and trade-offs, as well as on fundamental questions about how societies should protect their citizens. For decision-makers at all levels – from individual healthcare workers facing seemingly impossible choices to governments balancing competing values under conditions of uncertainty – it became clear that ethical reflection and guidance are essential components of a crisis response.

Every major decision during a health crisis involves value judgements that go far beyond scientific evidence: whom to protect first, what freedoms to restrict, how to allocate scarce resources, and how to balance individual rights against collective needs. Yet in practice, such decisions are often justified primarily on technical or medical grounds, are made using processes that lack systematic ethical reflection, and communicated with limited transparency about the underlying moral choices. In some countries, including Sweden[1], criticism focused on excessive deference to medical and scientific expertise[2], while in others the concern was that politicians failed to sufficiently heed expert advice or micromanaged decisions that should have been left up to relevant professional authorities.[3] The UK COVID-19 Inquiry highlighted another dimension of the relationship between experts and policy, finding that decision-makers 'did not receive a broad enough range of scientific advice and often failed to challenge the advice they did get,' with expert committees suffering from 'groupthink' and providing advice that was 'biased towards biomedical advice' while lacking socio-economic perspectives – issues that may have compounded the structural problems observed in other countries.[4] All these findings highlight that effective pandemic governance requires not just transparent relationships between experts and policy, but systematic ethical frameworks that can make explicit the value judgements that inevitably shape how societies choose to protect lives, preserve freedoms, and allocate resources under conditions of uncertainty.

The ambition with this collection of essays has been to gather experiences and analyses of the ethical dimensions of the pandemic from the perspectives of different roles – decision-makers, philosophers, clinicians, journalists, and international policymakers. The authors

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[1] To understand Sweden's public policymaking during the pandemic, read for example: S. Andersson, N. Aylott and J. Eriksson, 'Democracy and Technocracy in Sweden's Experience of the COVID-19 Pandemic', *Frontiers in Political Science*, 4 (2022), 832518, doi.org/10.3389/fpos.2022.832518.

[2] The Swedish Corona Commission criticised the Government for placing 'too much responsibility on the Public Health Agency' and thereby in practice delegating political responsibility. Coronakommissionen, *Sverige under pandemin. Slutbetänkande* (Stockholm: SOU 2022:10, 2022), available with Summary in English here https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2022/02/sou-202210.

[3] For example, Norway's Corona Commission criticised the Norwegian Government for exercising 'strong central control' and engaging in 'micromanagement' (*detaljstyring*), noting that 'several of the weaknesses in the response could have been limited or avoided if only important and central decisions for further response had been brought to the government's table.' Koronakommisjonen, *Myndighetenes håndtering av koronapandemien* (NOU 2022:5, 2022), p. 12. https://www.koronakommisjonen.no/kommisjonens-rapport-og-presentasjoner.

[4] UK COVID-19 Inquiry, "Module 1 Report 'In Brief' summary – The resilience and preparedness of the United Kingdom," 18 July 2024.

are drawn from the many experts, practitioners, and commentators who participated in seminars and dialogues organised by the Swedish National Council on Medical Ethics during the pandemic, creating a multifaceted understanding of how ethical considerations shaped, and should shape, pandemic responses. By giving examples of both successes and failures, the anthology aims to contribute to a foundation for ethical preparedness in future health emergencies.

Sweden's strategy in an international perspective

The COVID-19 pandemic forced all societies to confront difficult trade-offs under conditions of uncertainty. Sweden chose a markedly different path from most European countries, which imposed strict lockdowns and stay-at-home orders in early 2020. This divergence attracted considerable international attention and positioned Sweden's strategy at the centre of both criticism and praise. Sweden never introduced a national lockdown, nor the strict stay-at-home orders and curfews that characterised many other European countries, and initially lacked the legal instruments to enforce such measures. Instead, the authorities largely adhered to Sweden's pre-pandemic preparedness plan, which aimed to minimise overall mortality and morbidity, protect at-risk groups, and reduce other negative societal consequences in a manner that would be sustainable over time. This approach reflected the Swedish model of public administration, where government agencies enjoy a high degree of autonomy and ministerrial rule is prohibited, as well as a long-standing culture of mutual trust between the authorities and citizens.[5]

The strategy relied primarily on recommendations and behavioural guidance issued by independent government agencies, most prominently the Public Health Agency of Sweden. Citizens were encouraged to work from home where possible and limit domestic travel, and individuals over 70 were asked to reduce social contacts. Public gatherings were restricted stepwise (a maximum of 50 people in March 2020 reducing to 8 people in November 2020), visits to elderly care facilities were prohibited, and upper secondary schools were closed for periods of time and replaced with remote learning, while primary schools remained open throughout the whole pandemic. Crucially,

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[5] *Coronakommissionen*, *Sverige under pandemin*, SOU 2022:10.

Swedish citizens largely complied with these recommendations, voluntarily staying home and following the guidance without legally mandated restrictions. Surveys conducted during the first wave indicated that more than 80 per cent of Swedes had voluntarily adjusted their behaviour, and mobility data showed dramatic reductions in movement.[6]

The economic implications of Sweden's approach were notable: the country's GDP declined less severely in 2020 than that of most European nations, partly attributable to the less restrictive measures on business operations.[7] The strategy also reflected Sweden's evidence-based approach to public health measures: face masks were not initially recommended due to limited scientific evidence of their effectiveness and concerns that they might undermine more scientifically established interventions such as physical distancing and hand hygiene. Sweden only introduced face mask recommendations for public transport in January 2021, a decision that became a source of international criticism and domestic debate.[8]

Sweden's strategy was controversial internationally and often referred to as "the Swedish experiment." It was also frequently portrayed using misleading narratives – most notably the unfounded claim that Sweden deliberately pursued "herd immunity" by allowing the infection to spread widely in the community.[9]

The outcomes of the strategy proved more complex than early narratives suggested. During the initial phase of the pandemic, mortality was high among older persons in nursing homes and in home care. The Swedish independent commission that evaluated the Government's response to the COVID-19 pandemic and subsequent analyses identified several factors behind this outcome: the virus was already more widely spread than initially assumed, testing capacity and protective equipment were insufficient, and recommendations to protect older people came late and were unevenly implemented in the care sector.[10] Over the longer term, however, available data on excess

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[6] S. Holmberg och B. Rothstein, *Social Trust – The Nordic Gold?*, QoG Working Paper Series 2020:1.

[7] F. N. G. Andersson och L. Jonung, 'The COVID-19 lesson from Sweden: Don't lock down', *Economic Affairs*, 44(1) (2024), 3–16, doi:10.1111/ecaf.12611.

[8] A. Björkman, M. Gisslén, M. Gullberg och J. Ludvigsson, 'The Swedish COVID-19 approach: a scientific dialogue on mitigation policies', *Frontiers in Public Health*, 11 (2023), doi:10.3389/fpubh.2023.1206732.

[9] Read for example: R.E. Misinformation and de-contextualization: international media reporting on Sweden and COVID-19. *Global Health 16*, 62 (2020). doi.org/10.1186/s12992-020-00588-x.

[10] *Coronakommissionen*, *Sverige under pandemin*, SOU 2022:10.

all-cause mortality rates indicate that Sweden experienced fewer deaths per population unit during the pandemic (2020–2022) than most high-income countries.[11] The decision to keep primary schools open has also been highlighted as beneficial, as Swedish children did not experience the severe learning losses reported elsewhere. Thus, the overall picture is more complex than the misleading narratives suggest.

Sweden's strategy raised several prominent ethical questions in Sweden's public debate during the pandemic. The high mortality in nursing homes raised questions about the dignity and protection of vulnerable groups. The reliance on voluntary compliance and personal responsibility prompted discussions about individual freedoms and collective responsibility in public health. The decision to keep primary schools open generated debate over the balance between the child's right to education and the protection of teachers and other staff. Later, the vaccination rollout gave rise to discussions about how to prioritise limited doses – whether based strictly on medical risk, as in Sweden, or by also giving precedence to healthcare workers and other professional groups. These issues illustrate how ethical considerations became apparent throughout the pandemic response.

Smer's contributions

These ethical challenges required systematic analysis and guidance, a task that the Swedish National Council on Medical Ethics (Smer) stepped forward to fulfil. The Council assumed an advisory role during the pandemic, providing ethical analysis and guidance to the Riksdag (the Swedish parliament), the Swedish Government, central government agencies, and the healthcare sector. With its unique composition – including representatives from all political parties in the Riksdag alongside experts in medicine, medical ethics, law, and representatives from healthcare professional organisations, patient organisations, and government agencies – Smer was uniquely positioned to bridge the gaps between different perspectives and lend legitimacy across political and professional boundaries.

From the pandemic's earliest phase, the Council engaged systematically with key institutions. In March–April 2020, Smer consulted with the National Board of Health and Welfare on new guidelines

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[11] Björkman et al., "The Swedish COVID-19 approach."

for priority setting and rationing of healthcare resources under extraordinary conditions[12], emphasising that Sweden's legally enshrined ethical platform for priority setting in healthcare and its three guiding principles – human dignity, need and solidarity, and cost-effectiveness – should guide all decisions. The Council stressed the importance of open and transparent processes, appropriate timing, and clear communication in implementing these guidelines.

In May 2020, Smer published the report *Ethical choices in a pandemic*[13], which addressed core ethical dilemmas including global ethics and international solidarity, public health strategies, priority setting, ethical aspects of end-of-life care, experimental treatments, research ethics, and the importance of communication. The report provided both analysis and practical recommendations for decision-makers and the broader public.

The Council also provided consultation to the Public Health Agency on vaccination policy. This was initiated by the Agency seeking Smer's guidance rather than through ongoing advisory arrangements. Beginning with discussions with state epidemiologist Anders Tegnell and colleagues in December 2020–January 2021 concerning the overall prioritisation strategy for COVID-19 vaccination, the Agency subsequently requested the Council's ethical analyses on childhood vaccination across different age groups: assessments for 16–18-year-olds (June 2021)[14], 12–15-year-olds (September 2021),[15] and 5–11-year-olds (January 2022)[16]. Since the trade-off of risks versus benefits differed significantly across age groups, these ethical analyses supported the Agency's evidence-based approach to sensitive vaccina-

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[12] Comments on a draft of the publication 'National principles for priority setting in healthcare during the COVID-19 pandemic' from the National Board of Health and Welfare. 11 April 2020.

[13] The Swedish National Council on Medical Ethics (Smer), Ethical choices in a pandemic, (2020:3).

[14] The Swedish National Council on Medical Ethics (Smer), *Summary of the Council's discussion and positions in June 2021 regarding the offer of COVID-19 vaccination to children and adolescents*, 2 September 2021, https://smer.se/2021/09/02/sammanfattning-av-radets-diskussion-och-stallningstaganden-i-juni-2021-gallande-vaccination-mot-covid-19-av-barn-och-ungdomar.

[15] The Swedish National Council on Medical Ethics (Smer), *Statement on the ethical aspects of offering COVID-19 vaccination to children aged 12–15 years in Sweden*, 16 September 2021, https://smer.se/wp-content/uploads/2021/09/smer-yttrande-till-fohm-vaccination-barn-och-unga-12-15-ar-inkl-bilagor.pdf.

[16] The Swedish National Council on Medical Ethics (Smer), *Statement on COVID-19 vaccination of children aged 5–11 years*, 29 December 2021, https://smer.se/wp-content/uploads/2022/03/smers-yttrande-vaccination-barn-och-unga-5-11-ar-webb-sign.pdf.

tion decisions. Additionally, Smer invited Public Health Agency representatives to participate in the Council's webinars addressing broader ethical questions during the pandemic.

Beyond these advisory functions, Smer served as a platform for broader dialogue, organising webinars and seminars on topics such as uncertainty in decision-making and vaccine justice. The Council signed the WHO Declaration for Vaccine Equity in February 2021[17], demonstrating its commitment to global solidarity. It also initiated collaboration with the Swedish disability rights movement, resulting in a co-authored op-ed[18] on pandemic impacts and future preparedness planning, while engaging in regional ethics dialogues to strengthen ethics capacity at the local level.

The Council contributed to wider public debate through opinion pieces and statements, including ethical concerns about vaccination certificates. Its most widely noted public intervention came in September 2021, when Smer declared that healthcare workers have a "moral obligation" to be vaccinated against COVID-19.[19] While unusual in its normative tone, this statement attracted significant media attention and was widely disseminated at the regional level, contrasting with the Council's longer analytical reports.

Recent evaluations indicate that the pandemic made ethical issues more apparent across Sweden's healthcare regions and increased recognition of the need for robust ethical frameworks. Smer's work during this period demonstrates how ethics councils can contribute to crisis management through systematic analysis, stakeholder consultation, and public dialogue. However, a comprehensive assessment of Smer's actual impact during the pandemic, particularly in comparison with the roles played by ethics councils in other countries, remains an important area for future research and analysis.

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[17] The Swedish National Council on Medical Ethics (Smer), Uttalande: Smer ställer sig bakom WHOs deklaration för en rättvis fördelning av vaccin, 2021-02-23. https://smer.se/wp-content/uploads/2021/02/uttalande-ang-smer-skriver-under-whos-deklaration-for-rattvis-fordelning-av-vaccin-slutgiltig.pdf.

[18] E. Wallenius and K. Johansson, "Krisberedskapen behöver bli mer inkluderande" (Crisis preparedness needs to become more inclusive), e*Dagens Samhälle Debatt*, 22/23 March 2021, https://www.dagenssamhalle.se/opinion/debatt/krisberedskapen-behover-bli-mer-inkluderande.

[19] The Swedish National Council on Medical Ethics (Smer), *Statement on COVID-19 vaccination of healthcare and care staff*, 7 September 2021, https://smer.se/2021/09/07/uttalande-om-vaccination-mot-covid-19-av-vard-och-omsorgspersonal.

Chapters in the anthology

The contributions in this anthology reflect a wide spectrum of perspectives on the ethical challenges of the COVID-19 pandemic. They move from the viewpoint of decision-makers at the heart of crisis management, through international and global justice frameworks, to analyses of governance, precaution, and clinical and organisational ethics, and finally to the role of journalism in shaping public understanding and trust.

Read together, the chapters illustrate how ethics was present at every level of the pandemic: in the choices of individual clinicians and vulnerable patients, in the structures of the healthcare system and public administration, in national strategies and global vaccine distribution, and in the democratic arena where citizens sought reliable information. Each contribution thus provides a different angle, but all converge on a central lesson: that ethical preparedness, openness about value conflicts, and resilient structures for reflection and dialogue are all essential if we are to be better equipped for future crises.

Anders Tegnell's chapter *Ethics in a pandemic – some personal reflections* offers a personal and reflective account from Sweden's former state epidemiologist, providing rare insight from a key decision-maker at the centre of the COVID-19 response. Rather than a systematic academic analysis, the text presents Tegnell's own experiences, dilemmas, and assessments, showing how decisions were shaped by the "best available knowledge," proportionality, and Swedish traditions of voluntary compliance. He reflects on the ethical complexities of measures such as protecting older people, keeping schools open, regulating gatherings and restaurants, and prioritising vaccination. The chapter illustrates the constant balancing act between individual rights and freedoms, the needs of society, and uncertain and emerging evidence, while underlining the importance of building ethical preparedness into future pandemic planning.

Dave Archard's chapter *Ethical Preparedness in Public Health Emergencies: Lessons from the UK's COVID-19 Response* analyses how the UK's initial pandemic strategy emphasised "following the science," while ethical considerations were largely sidelined. The Nuffield Council on Bioethics stressed early on that science can provide input but cannot resolve the difficult value conflicts, which is required in a crisis. Transparency, fairness, and solidarity were identified as key principles for building trust, and the Council underlined the need for a clearer system for providing ethical advice during emergencies. The chapter concludes with a forward-looking discussion of "ethical preparedness" as a vital component of crisis readiness, emphasising the need for clear principles, institutional structures, and open public dialogue to better meet the next health emergency.

Laura Palazzani's chapter *The Pandemic and the Ethical Dilemma of Limited Resources: Who to Treat?* examines how COVID-19, which spread rapidly in northern Italy, forced hospitals into acute triage situations. Against this backdrop, the chapter provides a philosophical and critical analysis of different theories of justice and explores how these approaches influenced early national and international guidelines for the allocation of scarce intensive care resources. Particularly controversial were the initial Italian (SIAARTI) and other European recommendations that introduced age limits and "years saved" as criteria when ICUs were overwhelmed. In contrast, egalitarian and personalist positions, together with opinions from national and international ethics committees, emphasised non-discrimination, human dignity, and case-by-case clinical assessment. The chapter thus situates the Italian experience within a broader European and global debate on justice and fairness in times of scarcity.

In their chapter, *Tesi Aschan and Laurence Lwoff* analyse how the Council of Europe worked to uphold democracy, the rule of law and human rights during the COVID-19 pandemic. Based on experiences from Member States and the organisation's own initiatives, the chapter discusses issues such as derogations from the European Convention on Human Rights, the protection of vulnerable groups, the crisis of trust and misinformation, and the impact of the pandemic on healthcare systems. It also highlights the bioethical statements adopted by the Council of Europe's Committee on Bioethics (DH-BIO) and the tools and recommendations developed, including on vaccination, access to medicines and medical equipment, and health literacy – all aimed at strengthening solidarity, trust and equitable access to healthcare.

Göran Collste's chapter *'Where you live should not determine whether you live': Global justice and the distribution of COVID-19 vaccines* addresses one of the starkest ethical failures of the pandemic: the unequal global distribution of vaccines. Despite early calls for solidarity and equal access, wealthy countries secured the vast majority of doses, leaving low-income countries with minimal protection. Collste situates this within debates on global justice, international solidarity, and human rights, contrasting “vaccine cosmopolitanism” with “vaccine nationalism.” He argues for a middle path – “global vaccine sufficientarianism” – where states may prioritise their own citizens only after a basic global vaccination threshold has been met. The analysis highlights the role of institutions such as the WHO, WTO, and COVAX, while showing how patent protections and national self-interest hindered equity.

Erica Falkenström’s chapter *Why organisational ethics in health care matter* argues that without understanding the organisational conditions shaping pandemic responses, future policy and ethical guidance will rest on shaky ground. Based on an analysis of 12 Swedish policy documents, the chapter demonstrates that during COVID-19, a number of the guidelines drifted away from Sweden’s established ethical platform (human dignity, need-based care), creating contradictions and risking unjust outcomes, particularly when tools like frailty scales were applied outside specialist contexts. The core message is that organizational ethics in healthcare represents a critically neglected area that policy-makers and moral philosophers must better understand to improve both healthcare delivery and ethical guidance.

Lena Wahlberg & Nils-Eric Sahlin’s chapter *The Corona Commission and the Precautionary Principle* takes as its starting point the Commission’s critique that Sweden’s pandemic strategy relied too heavily on the legal standard of “science and proven experience” in the face of great uncertainty. The authors show that the precautionary principle has no single meaning and that the Commission’s version – framed as a general duty to act under conditions of uncertainty – risks arbitrariness. Instead, they argue for retaining the standard of science and proven experience, emphasizing that evidence-based measures are more effective, have fewer negative consequences, and promote greater public compliance than arbitrary interventions. They contend that when knowledge is uncertain and we are able to wait, it is more reasonable and prudent to wait for better evidence rather than act without adequate scientific support.

Ingemar Engström & Mikael Sandlund’s chapter *Doing good in the eye of a storm* offers a clinical ethics perspective, drawing on their experience as physicians and former chairs of the Swedish Society of Medicine’s Ethics Delegation. They describe how frontline professionals suddenly faced an array of ethical dilemmas: decisions that needed to be made despite considerable knowledge gaps, redeployments outside of regular competencies, and prioritisation under the threat of scarcity of intensive-care resources. The authors emphasise the importance of Sweden's priority-setting platform but note how new concepts such as "patient benefit" and "biological age" entered guidelines during the crisis, raising ethical and legal concerns.

Last in the volume, *Ulrika Björkstén's* chapter *The role of science journalism during the COVID-19 pandemic* offers a distinct perspective, written from the vantage point of a leading science journalist. Drawing on her role as head of Sveriges Radio's Science Desk and as science commentator during the first year of the pandemic, she reflects on how journalism had to navigate an unprecedented flow of uncertain data, conflicting expert voices, and daily press briefings followed closely by a mass audience. Björkstén's contribution concludes the anthology by reflecting on how science journalism navigated the pandemic's challenges – from dealing with uncertainty regarding the critical question of which experts should be given a platform, to revealing journalism's own responsibility in determining whose voices would shape public understanding.

The contributions in this anthology provide complementary perspectives on the ethical dimensions of the COVID-19 pandemic – from policymaking and global justice to clinical practice, organisational structures, precautionary reasoning, and the media's role in shaping public trust. By weaving together personal reflections, theoretical analysis, and professional experience, the anthology underscores the importance of ethical considerations at all stages of social crisis situations such as the COVID-19 pandemic. It is our hope that the insights gathered here will not only contribute to a deeper understanding of the Swedish and international experiences of COVID-19, but also contribute to discussions on ethical preparedness for the challenges of future health crises.

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2 Ethics in a pandemic – some personal reflections

Anders Tegnell *is a Swedish MD, public health specialist and former state epidemiologist at the Public Health Agency of Sweden (PHA) in 2013–2022. He played a key role in Sweden's response to the COVID-19 pandemic. Previously, he worked at the Swedish Institute for Infectious Disease Control, led the Department of Knowledge-Based Policy and Guidance at the National Board of Health and Welfare, and has served as an expert on bioterrorism and pandemic preparedness in the European Commission.*

Background

Pandemics have followed humans ever since the basic circumstances needed for their spread came into being. These were essentially that people lived together in substantial numbers and that there were contacts between these aggregations of humans. Pandemics have been accompanied by fear and many attempts, with limited success, to stop or at least limit their impact. Specific groups in society have often been blamed for the spread of diseases, and discrimination and even violence against these groups are not uncommon.

Measures to try to stop pandemics have been many, even though they have seldom had any substantial long-term effect. They have often had major negative effects on societies and the lives of individuals, and of course also have a substantial ethical dimension. Even if there have been many misconceptions over the centuries about exactly how a disease is spread during a pandemic, there has been an understanding that human-to-human contact (especially if they are sick) is involved. Many of these measures therefore have involved avoidance of contact, for example quarantining of ships, but also that the rich and powerful fled a crowded city for the countryside.

Ethics in the management of a pandemic have a number of challenges. When planning for combating a pandemic, it is crucial to balance the consequences for individuals against the consequences for the population. It is also often difficult and sometimes impossible to know in advance what the negative and positive consequences of the measures to manage the pandemic will be when it involves an unknown pathogen. In addition, the effects of the measures themselves might be unknown and untried.

During the course of a pandemic, these challenges persist. But in addition, a need arises to analyse these challenges very quickly based on very limited facts. Furthermore, knowledge about the pandemic and the pathogen changes with time, and an analysis done early in a pandemic might not be valid a few months later. There are also substantial effects of the measures beyond the health area, as well as political and legal factors that need to be taken into account.

Decision-making during a crisis is always a challenge, and even more so when there is a desire and expectation that the decisions should be based on science or at least established experience, as well as the principle of proportionality. Even if the situation involves a novel pathogen, experience from similar pathogens can be utilised. Data from other countries are not always published but are often available through the international networks that Sweden and other countries are members of. Refraining from making a decision is very often not an option, and in the end the ‘best available knowledge’ is often used. In reality, the best available knowledge is quite often used in public health crises, since hard evidence is rarely available from other areas of medicine nor from the health care system.

My experience

Planning for a pandemic

My first substantial contact with pandemic planning was when I worked at the European Commission in the early 2000s. The work was in its early stages and focused on evaluating the threat of different pathogens and the possibilities of vaccination with a focus on bioterrorism. However, extensive social measures were not discussed. Neither were the ethical aspects of these measures. On returning to Sweden and the National Board of Health and Welfare, I was tasked with updating Sweden's plan for pandemics. Initially, this was mainly about how to apply Sweden's Communicable Diseases Act to a pandemic. It has an ethical dimension, but that was not evaluated further at that time.

It was when it came to using medical countermeasures such as vaccines and antiviral medications that we became aware of the ethical dimensions of how to prioritise limited amounts of medicines and vaccines. We followed the ethical platform for prioritisation from the Swedish health care system, i.e. that those with the greatest risks and needs should have priority. We were in contact with a specialist in ethics, who wrote a background paper for us, and mainly agreed with this strategy. But not everybody agreed, and there were even voices saying that random allocation would be more ethical.

Non-medical measures have always been a part of pandemic planning, even if the evidence for their efficacy has often been lacking. There are of course many non-medical measures in public health such as therapies to stop smoking, etc. In Sweden, along with medical preventive measures, they have been put forward on a voluntary basis and the experience is in general very positive. One example is the voluntary childhood vaccination programme, which reaches at least 98 per cent of all children. From an ethical as well as a sustainability standpoint, it is very positive to be able to operate in a voluntary manner.

During the swine flu pandemic, the use of medical countermeasures was discussed extensively, in particular, whether we should give priority to at-risk groups or whether we should prioritise maintaining essential services in the society. It was very difficult to actually define who these groups were, and how medical measures could be used to protect them. That pandemic never ended up having a major impact on society, so the question never became critical and the available resources were only directed towards at-risk groups.

Work to identify what is actually essential for society to continue functioning continued after that pandemic, mainly through the Swedish Civil Contingencies Agency, but as far as I know, the ethical dimension of prioritising essential services function instead of the health of individuals has rarely been addressed.

When the present pandemic started, we followed the pandemic plan that was in place. Its main objectives were to minimise mortality and morbidity in the entire population, and to protect at-risk groups. This work has also been apparent in the public health context in Sweden. One example is equity, which is very important and needs to be taken into account even in a pandemic. Another is the requirement that all measures should be based on science or established experience, and that proportionality always needs to be considered.

In the early stages, we tried to keep the disease from establishing itself in Sweden. This was done by asking people to do what the Communicable Diseases Act asks them to do, i.e. seek care if they had signs or symptoms of the disease. This worked for a short while, but cases began coming into Sweden from many more countries, and many cases entered Sweden undetected. As a consequence, the pandemic was very quickly established in Sweden.

We then moved into the next phase and a discussion started on what could be done to flatten the epidemic curve. Reports from China indicated that a very extensive lockdown of society was being used and seemed to be effective, and many countries began to use similar strategies.

In Sweden, we questioned if such measures would not have more negative effects on public health than would be acceptable in the pandemic that was developing. We believed that more focused interventions such as stopping big events and asking people to work from home had the possibility to reach similar effects. The legal tools that would have permitted such an extensive lockdown were not available but could probably have been developed if they had been urgently needed. That a lockdown would have had an encroachment on the individual's freedom is another factor but the main concern was the likely effects on public health. As stated above, we also have a strong tradition of voluntary measures in public health in Sweden, with a high level of compliance and trust among the population. Another important factor was that we did not believe that the world would get rid of COVID-19 and we needed sustainable measures that could be used over a long period of time. To have most of the measures based on trust and voluntary action is a good basis for sustainability. Even if we did not explicitly consider ethics, of course ethics played a role in all of these reasonings.

With trust and voluntary action as overarching concepts and taking into account the Swedish context, we went further to look at measures in specific areas and for specific groups in the population. The data from China clearly showed that the elderly were at high risk, and data from other countries soon supported this conclusion, and that people with some medical conditions had an increased risk. Based on this information, special recommendations were developed for the elderly and people belonging to at-risk groups on medical grounds. The recommendations were designed to minimise the risk for individuals in these groups, and in practice were asking them to isolate themselves as much as possible. This of course had negative consequences, but their heightened risk was also substantial. We tried to ameliorate the advice for example by saying that meeting outside made the risk very small, and eventually these groups were offered vaccines as a priority. Still, many isolated themselves extensively and many suffered therefore, and this is one area where an ethical discussion would have been helpful.

In Sweden, early information from health care providers indicated that there was an over-representation of people with a background in other countries among the severely ill.

This was soon confirmed by an analysis of the available data and by reports from neighbouring countries. The reasons behind this are still not clear, but was likely a combination of socio-economic factors, occupational hazards, living in close quarters, and with the older generation living with the younger. All of these factors were known to increase the risk of infection, and here was a group that were affected by several of them at the same time. We still lack an understanding of how these risks could have been mitigated, but most of them most likely need to be dealt with before a crisis. The lack of health equity in health care in Swedish society is therefore another area for ethical discussion.

We then had to make decisions on which parts of society needed to be regulated. This had to be based on the risk of the spread of infection in that specific type of location. This then had to be balanced against the potential negative effects of lockdowns, whether long or short.

Unfortunately, early on in the pandemic not much was known about the relative risks of different environments and was mainly based on case reports. Examples were from South Korea, were a big gathering started the spread in the country, while another was the restaurants in Ischgl, Austria, where many ski tourists were infected. Neither was there much experience from locking down parts of society and the effects that this might have. Often, they could be guessed at, and would entail the loss of employment and the effects of being jobless. Schools were slightly different, since we know that being absent from school leads to a risk of not completing one's education. Lower education level is clearly linked to an increased risk of poor health outcomes.

With this as a background and based on the legal possibilities, we looked at different options. For all of these, it was clear that a lot of data were missing regarding their potential effects and their effects on the spread of the infection, but even more so on the possible negative effects. Still, decisions had to be made based on the available knowledge, which is not an uncommon situation in public health and communicable disease control.

Schools were closed early on in many countries, mainly based on a tradition of closing schools during severe flu seasons in some Asian countries. In our analysis, we looked at the epidemiology, which clearly showed early on that the disease burden among children was small. Their role in spreading the disease was less clear, but there were no indications that children were driving the transmission, which they sometimes do during the flu season. On the other hand, there was clear evidence of the negative effects on children who do not attend school. For some children, remote learning could be an alternative, according to the school authorities, but that would not work for the youngest children. In other words, our analysis led to the view that the positive effects of closing schools were small if any, but the negative consequences, especially long-term, could be extensive. Here, we had a clear case that it did not make sense, either ethically or epidemiologically, to close schools. This is an opinion that is now shared by most experts.

Restaurants was another area of concern in the early stages, and again they were closed in many countries. In discussions with their national organisation Visita, we designed a set of rules that were made legally enforceable. We focused on making it possible to keep a distance also in restaurants, since it was quite clear that close proximity was the reason behind the outbreaks originating in restaurants seen so far. Compliance, as measured by the inspection authorities, was high, and as far as it could be measured, it worked. Very few outbreaks were recorded as originating in restaurants, and the results from contact tracing did not show that restaurants were an important site of infection.

In many ways, big gatherings were seen as easier to shut down, but that involved very difficult factors. To shut down a big concert had economic consequences of course, but those could be handled in a rich country. The effects of stopping demonstrations and other manifestations of democracy, as well as religious services, are very different, not least from an ethical dimension. Here, dialogue with politicians and religious leaders was very important to ensure compliance with the measures that were seen as needed.

So far, I have mainly discussed non-pharmaceutical measures but of course, much was also happening in health care. Neither the PHA nor I were involved in this, but it is my understanding that the health care system followed procedures that were in place before the pandemic when prioritisation was needed. Reports indicated that there were enough resources to treat everybody who needed treatment, but the pressure on hospitals was great. Vaccines were different, as this is within the remit of the PHA to handle, and we were tasked by the Swedish Government with developing a vaccination programme. In this process, and to get input on the ethics of the prioritisations, we suggested holding a meeting with The Swedish council on medical ethics, Smer, and got a favourable response. This was in line with previous work on vaccine programmes the PHA has conducted together with Smer.

More than five years since the start of the pandemic we can now have a clearer view of the effects of the pandemic and the measures that were taken. Even if many studies and evaluations have been made and are still in development it is clear that to get a good picture is going to be difficult. Results so far show that lockdowns have extensive effects on a country and society but their ability to stop or alter the spread of a pandemic is limited.

In summary, there were many ethical considerations that needed to be made during a pandemic. Over the course of the first two years of the pandemic, most of these issues were handled without any formal ethical review, and we can now analyse them in hindsight and in very close collaboration with Smer.

The protection of vulnerable groups is an example where ethics is complicated, and the equal value of all people is a concern. It is one area where we need to improve before the next pandemic. There have been serious violations of privacy and many of the measures had, or at least potentially had, a great impact beyond communicable disease control. Effects such as isolation, loss of employment, loss of social support and protection have been evident. They have been discussed, but it is obvious that a deeper ethical discussion would have led to a deeper understanding of the possible effects on our society of the pandemic we were living in.

Regarding ethical issues prior to the next pandemic, there are a number that are better to discuss during the planning phase so as to have at least a basis for discussion during the actual event. During the pandemic, it would be valuable to have a group of individuals to discuss measures with; a group who are well-prepared to tackle the issues that it might evolve. In this group, it is essential to have people who are experienced in considering the ethical dimensions related to policies affecting the population.

3 Ethical Preparedness in Public Health Emergencies: Lessons from the UK's COVID-19 Response

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Introduction

In the United Kingdom the onset of the global pandemic in early 2020 ushered in a period of extraordinary confusion and uncertainty. The British Government struggled to agree upon and put in place measures to cope with what can be readily acknowledged was the most significant health emergency of the last couple of hundred years. From the outset the Government declared that it would 'follow the science' and did so in the form of requesting advice from SAGE – the Scientific Advisory Group for Emergencies – whose official function is to provide scientific and technical advice to support government decision makers during emergencies. The Government communicated the policies it deemed necessary by regular three person press conferences in which the Prime Minister, or other senior Minister, was most often flanked by the Chief Medical Officer and the Chief Scientific Officer. However, it was clear to the Nuffield Council that the public deserved to hear more, both about what justified the relevant measures and policies, and what role ethics had in this justification.

Following the Science Is Not Enough

The Council throughout the pandemic worked assiduously to make it clear that following the science was not enough. This is both because there need not be any single agreed scientific view and because science should inform rather than entirely determine policy. It is an 'input' not an 'output'. Most importantly ethics needed to be embedded in anything the Government did or failed to do.

Our frustration with the lack of transparency in Government decision-making prompted us to issue a major statement, 'COVID-19 and the basics of democratic governance' in April 2020 signed by myself, the Director of the Nuffield Council, and all Members of the Council.[1] In the statement we lamented the lack of openness in Government decision making and insisted that it was not enough simply to follow the science, inasmuch as science is never entirely neutral. Ethics had, we said, to be a critical part of all decision-making. Our key demands were that the public be shown what the Government was doing and thinking across the range of issues of concern, that the Government set out the ethical considerations that informed its judgements, explain how it had arrived at decisions, invite a broad range of perspectives into the room, including wider public representation, and think ahead by consulting and engaging other civic interests.

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[1] Nuffield Council on Bioethics, COVID-19 and the Basics of Democratic Governance (London: Nuffield Council on Bioethics, April 2020), https://www.nuffieldbioethics.org/news/statement-covid-19-and-the-basics-of-democratic-governance.

The Nuffield Council's role during the pandemic

The Council is not and never has been a government body and it retains its independence through its particular mode of funding. But neither is it a politically partisan organization, and it is committed in advance to no particular view on bioethics or on individual topics of importance. The pandemic put the Council under significant pressure in that it was committed to a programme of work decided in advance of the emergency and yet was obligated to respond to the various issues the pandemic threw up. At the same time, it had to work under the lockdown conditions which were introduced. This meant, as it did for everyone, virtual meetings, working from home and for many coping with extra childcare issues when schools were closed.

Nevertheless, the Council did produce a very impressive range of outputs. Some were pandemic related, others not. For example, we published key background documents on the treatment of young persons with gender dysphoria and on the negotiation of disagreements between parents and medical staff about the treatment of seriously ill children. Remarkably we published at the beginning of 2020 a major Report, Research in global health emergencies: ethical issues,[2] which was the product of two years' work by an interdisciplinary group of experts. Nevertheless, it could not but appear extraordinarily timely with its outline of an 'ethical compass' to assist Governments, research funders, researchers and other stakeholders in their negotiation of public health emergencies. This Report has subsequently been widely cited, remains hugely influential and has led to the creation of a worldwide network of groups seeking to implement its recommendations.

The Council also published several briefing documents and blogs, written by the Chair or a Member of Council or Executive, addressing COVID issues. Throughout the pandemic we briefed the press and media on COVID matters, as well as giving radio and television interviews. The Chair briefed those assisting the Government to prepare recommendations on the question of whether mandatory vaccination should be introduced.

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[2] Nuffield Council on Bioethics, Research in Global Health Emergencies: Ethical Issues (London: Nuffield Council on Bioethics, January 2020).

Core ethical principles in a crisis

The principal issues that the Council commented on that arose as a result of the pandemic were: the lockdown; the rules for prioritizing those in receipt of life saving and life continuing care and treatment; the rules for prioritizing those to receive COVID vaccines; whether the COVID vaccine should be mandatory; the possible issuing of vaccine 'passports' or certificates; and what should be regarded as an acceptable level of otherwise preventable deaths. These issues were ones addressed by other national ethics committee, and it was extremely useful for the Nuffield Council to be able to consult these and compare views.

In addressing these issues, the Council firstly was insistent, as argued in their 2020 statement, that any policy or regulation should be explained and justified in a transparent and robust manner. The key ethical principles the Council used to evaluate any policy were those of a presumption of individual freedom, fairness, and a balancing of harms and benefits.

One value that is not often invoked in the United Kingdom bioethical literature is solidarity. Yet this is an important concept in Europe. Moreover, the concept is as our commissioned report on it in 2011 noted, an 'emerging' one.[3] Solidarity is an ideal feature of a society whose members are bound together by shared interests, goals and values, recognizing their interdependence and being prepared to accept the burdens, as well as benefits, of that common identity. Solidarity captures the sense that we are all in it together, and no phrase could be more apt for the collective experience of the pandemic. At the same time the concept enjoins us to share what befalls us in a way that leaves no one behind and all play our part. No concept perhaps is better suited to the challenges of a public health emergency.

The Council was able to use its major published 2007 Report, Public Health: Ethical Issues[4] to inform its analysis. This Report rested its recommendations on the idea that the State has a duty of 'stewardship' to look after the individual and collective needs of the population, that there is a 'ladder of intervention' whereby public

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[3] Nuffield Council on Bioethics, Solidarity: Reflections on an Emerging Concept in Bioethics (London: Nuffield Council on Bioethics, 2011), https://www.nuffieldbioethics.org/publications/solidarity.

[4] Nuffield Council on Bioethics, Public Health: Ethical Issues (London: Nuffield Council on Bioethics, 2007).

health measures of varying intrusiveness may be acceptable, and that any intervention must be proportionate, that is of a degree and extent that it is necessary to secure the desired outcome.

Unequal impacts and global justice

In making its evaluations of measures the Council consistently emphasized that COVID and the measures taken to combat it impacted differently on different groups. Some communities – ethnic minorities, for instance – suffered disproportionately in the pandemic, having worse health outcomes from contracting COVID, for example. This was because, in the first instance, members of these communities had poorer initial health profiles. But some communities were employed in jobs and social roles that exposed them to greater risks of infection. At the same time lockdown, and its restrictions, impacted unequally on some already socially disadvantaged groups.

The Council followed some other ethics committees in suggesting that individuals at greater risk because of their critical role in the pandemic (for instance, health workers) should have a high priority for receiving the vaccine. The Council also stressed that the pandemic was a global health emergency, and that measures to combat it should acknowledge the different needs and resources of countries. For instance, it was important to stress that a fair distribution of the vaccine needed to take account of the fact that richer Northern countries often had a significant surplus of vaccines, whereas poorer Southern nations had a shortfall of necessary vaccines.

Ethical Preparedness – three key elements

What then are the lessons to be learned from the pandemic? The Government has now instituted a major COVID-19 public Inquiry[5] whose terms of reference are to 'examine, consider and report on preparations for and the response to the pandemic' in the United Kingdom. In meeting its aims the Inquiry will 'consider any disparities evident in the impact of the pandemic on different categories of people,' and will conduct a major Listening Exercise ('Every Story Matters')

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[5] https://covid19.public-inquiry.uk.

to hear and consider the experiences of bereaved families and those who suffered hardship or loss as a result of the pandemic. It will highlight lessons identified from preparedness and the response to the pandemic.

The Inquiry is unlikely to issue its Report for a number of years. For its part the Council has already commented on the United Kingdom's degree of preparedness for the pandemic. It was noted by us, as it was by many commentators and other organizations, that a decade of austerity and cuts to public funding had had a significant deleterious impact on our public services. That those in the National Health Service managed to cope as well as they did is tribute to their commitment and dedication to the service. It was also made public by some that a series of official exercises had been conducted before 2019 that imagined various pandemic scenarios.[6]

Jeremy Farrar's and Anjana Ahuja's insider account of the progress of the pandemic in the UK, *Spike: The Virus Vs. The People – the Inside Story*[7], offers a remarkable and chastening narrative of missed opportunities, catastrophic delays, and executive failures, alongside the exemplary courage and extraordinary hard work of the scientists who did their very best to work out research-based solutions to the impossible task facing frontline health workers. Its final chapter is a superb summary of the various preparations we might make to do better in the next pandemic. And we know there will be one.

At one point the authors say that they 'wish that ethical considerations had been built into the UK's coronavirus response right from the beginning'.[8] As indicated above the Nuffield Council did seek from the outset to identify and foreground the ethical considerations that we thought should be relevant in formulating and implementing various policies. If these important issues are to be taken seriously next time around, we need what we, building on valuable work by others[9], are calling 'ethical preparedness'.[10] This means being ready as a society not just to deal practically and efficiently with a

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[6] R. Coombes and Q. Moosa, 'My Battle with the Government over Transparency and COVID-19 Pandemic Preparedness', BMJ, 375 (2021), n2992, doi.org/10.1136/bmj.n2992.

[7] J. Farrar and A. Ahuja, Spike: *The Virus vs. The People – the Inside Story* (London: Profile Books, 2021).

[8] Ibid., p. 229.

[9] University of Southampton, Clinical Ethics, Law and Society (CELS), https://www.southampton.ac.uk/cels.

[10] K. Wright, 'COVID-19 and the Ethical Imperative of Preparedness', Nuffield Council on Bioethics Blog, 24 February 2020. https://www.nuffieldbioethics.org/news-blog/covid-19-and-the-ethical-imperative-of-preparedness.

pandemic, but to do so in a way that is ethically appropriate and fully justified.

What then do we understand by ethical preparedness? Drawing on the lessons from COVID, we suggest the following three elements are likely to play an important role:

First, there needs to be clarity regarding the moral principles and values that are to underpin policy responses. It is sometimes thought that in a public health emergency the normal moral rules, for example relating to fairness or human rights, do not apply, and that 'anything goes' in order to preserve lives at all costs. In our own Research in global health emergencies report, however, we argued that the 'moral compass' remains consistent; what may need to change is the practical ways in which its values are realized. So, for example, what seem to be draconian restrictions on free movement and personal liberty may be temporarily justifiable by the need to control an untreatable and highly contagious disease, but such measures bring with them duties to ensure that everyone has access to essential goods (for example through ensuring adequate compensation for those prevented from working), and that the impacts of the restrictions are not unfairly borne by those who are already most disadvantaged.

Throughout the pandemic, the Government appeared to subscribe to one moral rule, namely that the right thing to do was whatever produced the greatest overall benefit in terms of lives saved. This was captured in one of the principal slogans the Government employed, that of 'protect the NHS' and 'save lives'. Yet, there is broad agreement that, even in a crisis, doing the right thing (which in the exigencies of any particular situation may be simply the least bad thing) must take account of fairness. The Council and many others consistently highlighted[11] the disproportionate impact the pandemic, and the policy response to it, had on certain social groups. Taking account of this fact will be, as noted, a key aim of the Public Inquiry. The fact that health has social determinants and that those from certain disadvantaged backgrounds already have poorer health prospects is also relevant to public health policy beyond health emergencies. The moral point is also worth stressing: if we as a society are genuinely concerned about the health of everyone within the population, then

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[11] D. Archard, 'Putting Ethics into the 'Stuff Like This'', Nuffield Council on Bioethics Blog, 2 March 2021, https://www.nuffieldbioethics.org/news-blog/putting-ethics-into-the-stuff-like-this.

our national response should aim not just for an overall reduction of harm but also for inequalities to be mitigated and reduced.

Doing the right thing also means taking proper account of individual rights – to liberty, to privacy, and to living by one's own beliefs, while recognizing that, at times, and to the least degree possible, those rights may need to be limited for the safety and wellbeing of others. This difficult balancing act of reducing harm, tackling unfair health inequalities and minimizing measures that are coercive or implemented without people's consent, is further described in the Council's Public Health report. We should also once again note the importance of solidarity in capturing what is rightly and fairly demanded of everyone when we undergo a major collective emergency such as the pandemic.

A second element of ethical preparedness is ensuring that procedures, institutions, and regulations are in place so that ethical guidance can be provided in a clear, determinate, authoritative, and unambiguous fashion.

In the early months of the pandemic, there was much justified criticism of the confusing plurality of guidance being offered to frontline staff on such matters as deciding which patients should be prioritized for treatment. Such guidance came from official bodies, professional organizations, learned societies, and academics, but not from the Government. The confusion led those making the critical decisions to worry as to what they should do, and, crucially, to be concerned that they might be subsequently liable to censure, discipline or worse, for those decisions they had to make under great pressure.

Two issues arise. The first is whether there should be a single authoritative national ethics body recognized as such and able to provide the Government with ethical advice on critical matters. This is, for instance, the role of the French Comite Consultatif National d'Ethique and the German Deutsche Ethikrat. The Nuffield Council is often characterized as the United Kingdom's de facto national ethics committee. But it is, as noted, independent of government.

The second issue concerns what should be done to harness the many different sources of ethical expertise and advice available nationally. The Nuffield Council works within a complex UK bioethics landscape comprising many different bodies, organizations and individuals with bioethical experience and expertise, and has consistently sought to explore how this diverse expertise can best be convened and made available to feed into policy considerations.

A third element of ethical preparedness is making sure that the Government understands and articulates that ethical considerations need to be an integral part of policymaking and actively engages the public in exploring the competing values and interests at stake. The Government must be seen to make ethically robust policy, and the public must be involved and see that this is what is being done. Transparency of policy making, including explicit recognition of the values that are informing policy decisions, is the essential key to trust between Government and public. Yet an insistence that policy should be led only by science is not enough to provide an answer to policy questions that concern competing interests and values.

The public are highly capable of grasping moral matters. Indeed, they have been quick to criticize a Government for prioritizing self-interest over the public good. What is fair or unfair in particular contexts, and what it means to recognize and protect competing rights, are more difficult matters. Yet that is why it is so important to create the conditions under which there can be public discussion of ethical issues. The Nuffield Council consistently stressed[12] the importance of public engagement with, and public discussion of, key bioethical subjects – including highlighting how this is of even greater, not lesser, importance in times of emergency.

Building trust for the next crisis

A final thought on preparedness is appropriate. Being ethically prepared and being practically prepared for a pandemic are interconnected. Having to make the best possible, even if not ideal decisions in difficult circumstances should not be taken to imply that those circumstances – scarce resources, existing disadvantage, poorer health outcomes for some – are simply facts of nature. They are the result of longstanding policies and official inaction that are open to moral scrutiny. If we make choices in what philosophers and economists

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[12] S. Burall, 'Why the Government Must Engage the Public on Its COVID-19 Response', Nuffield Council on Bioethics Blog, 21 April 2020, https://www.nuffieldbioethics.org/news-blog/why-the-government-must-engage-the-public-on-its-covid-19-response.

call non-ideal conditions, we need to recognize why they are not the best and what can be done now to ensure they are better next time.

Being ethically ready for the next pandemic, or any other public health crisis, is a real priority. Key issues include addressing the inequalities that COVID has exposed and exacerbated; building trust and transparency into government policies and actions; and involving the public in policymaking.

The Nuffield Council on Bioethics will be taking up these themes, among others, in work with national ethics bodies around the world in the coming years.

No-one welcomes the prospect of another pandemic, or indeed of another public health emergency of any kind. But we know that the question is when, not if, the next one will arise. At the least, we should ensure we are prepared to meet its ethical challenges.

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4 The pandemic and the ethical dilemma of limited resources: who should be treated?

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Introduction

The issue of the distribution of health resources is certainly not a new topic in bioethics. For some time, medical ethics has raised the problem at different levels and in different areas. The problem lies in the 'macro-distribution' of resources, that is, the decisions taken in the context of health policies in the broad sense (how much to invest in health and in which sectors as a priority). It is also a problem of 'micro-distribution', that is, of decisions of selection of patients by priority of access to cure/care.

The COVID-19 pandemic makes the existence of the problem evident in a dramatic way. On the one hand, the rapid and exponential growth of the infection (the high percentage of patients requiring hospitalizations, access and even prolonged stay in intensive care units with the use of assisted ventilation), and on the other the limit of the resources (not available for all), expose the dramatic possibility of such choices. All possible efforts have being made to expand distributable resources to avoid being faced with the tragic decision of who to treat and who not to treat (increasing the number of beds in intensive care, transferring patients to other facilities, buying necessary technologies, etc.

However, if and when one is faced with the choice of who to include and who to exclude from access to intensive care or ventilation, on what basis does one choose? There is agreement on the fact that distribution should be "fair", according to the shared meaning of justice as "not to harm others" and to "give each his/her own". Nevertheless, within the pluralist discussion there are different ways of conceiving justice on a theoretical level and applying it on a concrete level.

Competing theories of justice and different approaches

Libertarian theory

The theory of libertarianism, starting from an individualistic Anthropology interprets justice as the protection of self-determination: "not to harm" others assumes the meaning of not hindering or restricting the freedom of others; "giving each his own" takes on the meaning of attributing resources to each individual according to his/her will, merits, abilities, the contribution he/she provides to society, free initiative.

The argument that is at the basis of the libertarian theory is the consideration according to which nobody is responsible for natural and social inequalities. The results of the "natural lottery" (or the unforeseeable changes in fate of an individual due to natural forces, illnesses or natural damage) and the "social lottery" (or the unforeseen changes due to social actions) are "unlucky", not unjust. It follows that society is not forced to compensate the differences or to make up for damage due to natural causes or social circumstances. At a macro-level, there is no "direct obligation" to help the weak. At the most one can "sympathise" or have a philanthropic attitude towards those who are more emarginated. But the need of others must not limit individual freedom: the rights of autonomy of individuals prevail over social obligations of beneficence. At a micro level, in the choice regarding patient's selection the rich are prioritized over the poor, individuals who hold important social positions over the indigent or marginalized, those who are more autonomous over those who are less or no longer so. It is an approach, according to which the selection of patients for treatment is based on individual free choice and the ability to pay ('the riches first'), as a requirement for participating in the free market.

Still present on the level of theoretical debate, this theory is rarely mentioned in the context of discussion on the COVID-19 pandemic[1], and even the health systems of the countries inspired by this model (minimum State, maximum market) have sought and are still seeking solutions to protect public health, due to the inevitable inequalities that it entails on the medical and socio-economic level.

The libertarian model is therefore the object of criticism for the human and social implications that it brings, in particular towards the weakest, the poor and the marginalized, exposed to risks and excluded from access to care. This model does not adequately take into account the social effects of individual actions, in the false hope that an "invisible hand" will solve problems, accentuating subjective egoism, the cold logic of calculation and indifference to needs, denying the constitutive dimension of social responsibility towards others.

Utilitarian theory

Utilitarian theory, in the search for the maximisation of benefits and minimisation of costs for the greatest number of individuals, proposes a distribution of the resources so as to reach the best pragmatic result possible in relation to social productivity, with the same expenditure.[2] Justice takes on, in this perspective, the meaning of not harming another person, where, 'harming' means causing suffering or decreasing quality of life of individuals having interests. Collective utilitarianism identifies distributive justice with the necessary to give the greatest possible number of individuals the satisfaction of their preferences.

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[1] A critical discussion of the position in A. Lavazza, M. D. Garasic, *What if some patients are more "important" than others? A possible framework for COVID-19 and other emergency care situations,* ABMC Medical Ethics (2022) 23.

[2] J. Savulescu, D. Persson, D. Wilkinson, *Utilitarianism and the Pandemic*, Bioethics, 20 May 2020. J. Savulescu, J. Cameron, D. Wilkinson, *Equality or Utility? Ethics and Law of Rationing Ventilators*, *British Journal of Anaesthesia*, 2020, 125(1), 10–15. J. Cameron, J. Savulescu, D. Wilkinson, 'Is Withdrawing Treatment Really more Problematic than Withholding Treatment?', *Journal of Medical Ethics*, 25 May 2020. J. Harris, *'Why Kill the Cabin Boy?'*, *Cambridge Quarterly of Healthcare Ethics*, 16 April 2020, pp. 1–6.

At the macro-allocation level, the financing of sectors that permit the increase of social wellbeing is privileged and the areas of healthcare that make it possible to recuperate the patient's activity in terms of efficiency and convenience are given priority. Such objectives are pursued also at the cost of sacrificing those who are not yet able to or who are no longer able to produce for society, with the consequent marginalisation of the weaker subjects. At a micro-allocation level, this theory justifies the priority the "*quality adjusted life years*" (QALY), i.e. the number of years of life taking into account the quality and costs. The allocation of limited resources in terms of access to care is deemed to be correct when it achieves, at the same expense, the best possible pragmatic result in relation to convenience and efficiency, therefore combining the number of patients who survive, the years of life left to live, with quality.

In this perspective, the right to access treatment and health care is recognised only to those who have a life "worthy" of being lived in relation to the achievement or likelihood of achieving an expected number of years of life left to live and a certain standard of quality of life. The utilitarian approach correlates the maximum benefit obtainable with the prioritisation of younger people over older people, who have less life expectancy (in terms of the number of years left to live as well as the presumed level of quality of life) and they have already lived years of life. For the same reason also people with disability may be excluded ('disability adjusted life years', DALY) and poor people as disability and poverty are correlated to lower conditions of health and quality of life expectancy.

Along this line, some scientific societies of medicine, above all in the area of intensive care medicine, expressed their views. The Sociedad Española de Medicina Intensiva Crítica y Unidades Coronarias and the Sociedad Española de Enfermería Intensiva y Unidades Coronarias in the document *Plan de Contingencia para los Servicios de Medicina Intensiva frente a la pandemic COVID-19*[3] there is an explicit reference to limit of treatments for elderly people (including age) and people with cognitive disabilities. In this direction, also the document *Ethical Principles concerning Proportionality of Critical Care during the 2020 COVID-19 Pandemic in Belgium*, advice by the Belgian Society of

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[3] Plan de Contingencia para los Servicios de Medicina Intensiva frente a la pandemia COVID-19, Sociedad Española de Medicina Intensiva, Crítica y Unidades Coronarias (SEMICYUC), marzo 2020, www.semicyuc.org.

Intensive Care Medicine[4], where it is underlined that "elderly patients, cognitive impairment should be assessed and taken into account". The Schweizerische Gesellschaft fur Intensivmediz published the document *Kovid-19 Pandemic: Triage von intensivmedizinischen Behandlungen bei Ressourcen Knappheit* (24 March, revised 4 November 2020)[5] where age is considered as a 'stringent criterion' for admission and discontinuation of treatment in triage, justifying also in certain cases the withdrawal of proportionate treatment (i.e. ventilator). This discussion emerged in Italy with reference to the document to the Italian Society of Anesthesia Analgesia Resuscitation and Intensive Therapy (SIAARTI), *Recommendations of Clinical Ethics for Admission to Intensive Treatments and for their Suspension, in Exceptional Conditions of Imbalance* (2020).[6] The document justifies the possibility of "placing an age limit on entry into intensive care", firstly in order to allow access "to those who have the most chance of survival and secondly to those who can have more years of life saved, with a view to maximizing the benefits for the greatest number of people". It should be acknowledged that the principle of the "probability of survival" remains primary, however the anagraphic data is also introduced (number of years of life saved) on equal terms. The reason that justifies this choice in the document is explained with reference to the fact that the same resources could be used for a shorter time for a patient in less serious conditions, saving money compared to their being used for elderly and frail patients.

The criteria of the utilitarian vision are susceptible to a fundamental objection: these are criteria that deny the authentic meaning of justice, which recognises the dignity of every human being recognised as person without making extrinsic distinctions between lives with dignity or without dignity, lives with greater dignity or lesser dignity, based on conditions regarding quality of life, number of years left to live, or productivity. Moreover, the QALY criterion is susceptible to further scientific and philosophical objections: the uncertainty and difficulty in calculating the probabilistic prediction

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[4] Belgian Society of Intensive care medicine, *Ethical Principles concerning Proportionality of Critical Care during the 2020 COVID-19 Pandemic in Belgium*, 2020.

[5] The Schweizerische Gesellschaft fur Intensivmediz published the document *Kovid-19 Pandemic: Triage von intensivmedizinischen Behandlungen bei Ressourcen Knappheit* (24 March, revised 4 November 2020) https://www.sgi-ssmi.ch/de/covid-19.html.

[6] Società Italiana di Anestesia, Analgesia, Rianimazione e Terapia Intensiva (SIAARTI), *Recommendations of Clinical Ethics for Admission to Intensive Treatments and for their Suspension, in Exceptional Conditions of Imbalance*, 2020.

of the number of years of life left to live; the subjectivity of the way of understanding and living the quality of life (not projectable on others); the individual variability compared to the generalized 'average' referring to groups of individuals (for example, using age as a selection criterion, does not consider the individual physiological variability of individual persons, regardless of age).

The theory of justice as equality

There has been in bioethics a reaction against the libertarian and utilitarian vision applied to distribution of scarce healthcare resources, as it is incompatible with the shared fundamental value of equality among all human beings.

The theory of justice as equality, where "giving each one his/her own" takes on the egalitarian value of giving "to each individual equally" and the social value of "giving according to need", is the theory of the "minimum market" and the "maximum state". The state and society must intervene to guarantee minimum standards of healthcare and assistance as fundamental rights. This theory maintains that society must take on the responsibility for the inequalities arising from the "natural lottery" and the "social lottery". The natural and social inequalities, in a cooperative society, must be "corrected", searching for compensation of the differences. In this context healthcare and medical assistance are considered basic needs which should be guaranteed to each individual, "maximising the minimum", or increasing the possibility and the opportunity of access to healthcare and medical assistance for the most vulnerable. At a micro-allocation level, an effort is made to guarantee equal access to treatment and an equal opportunity for everyone.[7]

The theorisation of equal access is also supported by T.L. Beauchamp and J.F. Childress, based on the theorisation of "principlism" (the application of the principles of autonomy, beneficence, non-maleficence and justice). They believe that there is a right to a "decent minimum of care" and that health care is an aspect of social protec-

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[7] N. Daniels, *Just Health Care: Studies in Philosophy and Health Policy* (Cambridge University Press, New York 1985). N. Daniels, *Health Care Needs and Distributive Justice*, Philosophy and Public Affairs, 1981, 10(2), 146–179. E.J. Emanuel, *Justice and Managed Care. Four Principles for the Just Allocation of Health Care Resources*, Hastings Center Report, 2000, 30(3), 8–16.

tion against external threats from which the individual alone cannot protect himself, as in the case of the pandemic.[8]

This position is also shared by the personalist theory that recognises the ontological primacy of the dignity of the human person.[9] This theory puts at the centre the common good, considering the intrinsic dignity of every human being, outlining justice as protection of the life of every human being. "To give everyone their own" means to recognise what is ontologically "due" to each human being at a personal and at a social level, on the basis of human nature itself. In this sense, "to give" means to recognise through reasoning, not to allocate with an act of subjective will or individual decision. This recognition means considering justice as solidarity and subsidiarity, based on the duty/right to act in view of the common good, and therefore in the obligation to cooperate for the good of society, helping the weakest, defenceless and needy. The criterion of justice is outlined in the inseparable consideration of the individual good of every human being and the common good of society.

At the macro-allocation level, this theory proposes sufficient investment in healthcare, in an inclusive way, leaving no one behind. At the micro-allocation level, this perspective considers that the main criterion of justice can be translated in the primary consideration of the dignity recognised in every human being. The selection of patients for access to care applies the objective medical assessment, case by case, of the clinical condition, as urgency, the severity of the illness, and the presumed prognostic efficacy of the treatment in terms of probable recovery, according to the criteria of proportionality and appropriateness.[10] In this perspective, any deviation from this logic introduces arbitrary elements of discrimination (as social position, age, possession of certain abilities etc.).

If 'in fact' circumstances (such as scarcity of resources) inevitably force one not to be able to cure everyone, but to cure some and not others, the criterion cannot be defined on subjective or social (non-

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[8] T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics* (Oxford University Press, Oxford 2012). J.F. Childress, *Priorities in Biomedical Ethics* (Westminster Press, Philadelphia 1981).

[9] E.D. Pellegrino and D.C. Thomasma, *A Philosophical Basis of Medical Practice* (Oxford University Press, New York 1987). E.D. Pellegrino, *Rationing Health Care: Inherent Conflicts within the Concept of Justice*, in W.D. Bondeson and J.W. Jones (eds.), *The Ethics of Managed Care: Professional Integrity and Patient Rights* (Kluwer Academic Publishers, Dordrecht 2002), 1–18.

[10] As in general in clinical practice, disproportion or unreasonable obstinacy in treatment (to be considered ineffective, futile and burdensome) is not ethically justifiable.

medical) grounds but should be defined only on objective (medical) grounds, i.e. on the basis of the patient's clinical condition. It is clear that scarce resources cannot be misused and wasted, but must be effective, that is, used to save lives. But we must not forget that the needs of every sick person must be placed at the center in equal terms. In the case of the pandemic, it should also be remembered that this criterion must be applied to all patients. Those who are most vulnerable, such as elderly people or people with disabilities, poor people, must not be marginalized by selective logic inspired by individualism or social convenience. However, this does not mean treating 'at any cost' or implementing practices of clinical obstinacy, which must always be duly suspended when disproportionate, ineffective and burdensome, as well as the patient's autonomy of refusal or renunciation of treatments, with the verification of the awareness and full information of the consequences.

This is the position expressed by the Comité Consultative National d'Etique (France) in the document *Enjeux éthiques face à une pandémie* (2020).[11] The Nuffield Council on Bioethics (UK) in the document *Ethical Considerations in Responding to the Covid-19 Pandemic* (2020)[12], while focusing mainly on social policy issues, reiterates the need for an 'impartial' criterion for micro-distribution that recognizes an equal moral worth to everyone. The Deutscherethikrat in Germany in the document *Solidarity and Responsibility during the Coronavirus Crisis, Ad Hoc Recommendation* (27 March 2020)[13], considers the criterion of human dignity to be the only guarantor of equality against all forms of discrimination (of gender, ethnic origin, age, social role, disability), stating that any differentiation, direct or indirect, with reference to the protection of life is unacceptable. In particular, a distinction is made between 'ex ante triage', which can also 'let some patients die' given the scarcity of resources and the factual impossibility of saving them (admitting that no one can be forced to do the impossible) and 'ex post triage' stating that

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[11] Comité Consultatif National d'Éthique (CCNE), *Enjeux éthiques face à une pandémie* (2020), https://www.ccne-ethique.fr/sites/default/files/2021-07/R%C3%A9ponse%20CCNE%20-%20Covid-19%20%20Def.pdf.

[12] Nuffield Council on Bioethics, *Ethical Considerations in Responding to the COVID-19 Pandemic* (2020), https://cdn.nuffieldbioethics.org/wp-content/uploads/Ethical-considerations-in-responding-to-the-COVID-19-pandemic.pdf.

[13] Deutscher Ethikrat, *Solidarity and Responsibility during the Coronavirus Crisis, Ad Hoc Recommendation* (27 March 2020), https://www.ethikrat.org/fileadmin/Publikationen/Ad-hoc-Empfehlungen/englisch/recommendation-coronavirus-crisis.pdf.

discontinuity of treatment, i.e. the suspension of a proportionate treatment, to save another patient by re-assigning resources is never legitimate. The San Marino Bioethics Committee reiterated for COVID-19 a principle expressed in the document *Bioethics of disasters*[14] (2017) of the "priority of treatments calculated on the basis of a correct application of triage, respecting all human life, regardless of age, gender, social or ethnic affiliation, ability"; in the document *Response to the request for an urgent opinion on ethical aspects related to the use of assisted ventilation in patients of all ages with severe disabilities in relation to the COVID-19 pandemic* (March 16, 2020), the committee reiterates that disability can never be an exclusion criterion, based on the principle of equality between every human being regardless of differences.

On a similar position the Bioethics Commission of Austria, in the *opinion Zum Umgang mit knappen Ressourcen in der Gesundheits Versorgung im Kontext der COVID-19-Pandemie* (March 2020)[15] defines the triage criterion with reference to the clinical and prognostic criterion. The Conselho Nacional de Etica para as Ciencias da Vida in Protogallo in the document *The Public Health Emergency caused by the COVID-19 Pandemics, Relevant Ethical Issues* (April 2020)[16] stresses necessity, effectiveness and proportionality as the criteria for the selection of care priorities. In the document of the National Committee of Luxembourg *Repères éthiques essentiels lors de l'orientation des patients dans un contexte de limitation des ressources thérapeutiques disponibles due à la crise pandémique du COVID-19* (31 March 2020)[17] the principle of intangible human dignity is affirmed, to deduce the principles of fairness and justice.

The Italian Committee for Bioethics in the COVID-19 opinion *The clinical decision in conditions of lack of resources and the criterion of triage in pandemic emergency* (8 April 2020)[18]starting from the

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[14] San Marino Bioethics Committee, *Bioethics of Disasters* (2017), Comitato Sammarinese di Bioetica | Documents and Opinions.

[15] Astrian Bioethics Commission. *Opinion Zum Umgang mit knappen Ressourcen in der Gesundheits Versorgung im Kontext der COVID-19-Pandemie* (March 2020).

[16] National Council of Ethics for the Life Sciences (CNECV, Portugal), *Public health emergency situation due to the COVID-19 pandemic: Relevant ethical aspects* (Lisbon: CNECV, 2020) position-statement-covid-19.

[17] Commission Nationale d'Éthique (C.N.E.), *Repères éthiques essentiels lors de l'orientation des patients dans un contexte de limitation des ressources thérapeutiques disponibles due à la crise pandémique du COVID-19* (Luxembourg: C.N.E., 31 March 2020) https://cne.public.lu/dam-assets/fr/publications/avis/Prise-de-position-COVID-19.pdf.

[18] Italian Committee for Bioethics (CNB), *The clinical decision in conditions of lack of resources and the criterion of triage in pandemic emergency* (Rome: CNB, 8 April 2020)

Constitutional principles (in particular art. 32 on protection of health, art. 2 on duties of solidarity and art. 3 on equality) and by Law 833 (1978), establishing the National Health Service, reaffirms that "it is always necessary to do everything possible to guarantee all, without exception", respecting "the principles of justice, equity and solidarity, to offer all people equal opportunities to reach the maximum health potential allowed". The clinical criterion is considered the most appropriate reference point for the allocation of resources, underlining that "any other selection criteria defined a priori, such as age, sex, social status and role, belonging ethnicity, disability, responsibility for behaviors that induced the disease, costs, is considered by the Committee to be ethically unacceptable". With reference to triage in pandemic emergency, the document specifies the criteria of 'clinical appropriateness', understood as a medical evaluation of the efficacy of the treatment with respect to the clinical need of each individual patient, with reference to the urgency and severity of the onset of the disease and to the prognostic possibility of recovery.

The issue was also addressed by international bioethics committees, as the topic is closely connected to fundamental human rights, including the right to the protection of health, expressed in international constitutions and regulations. The Committee on Bioethics of the Council of Europe (DH-BIO, now CD-BIO) in the *Statement in the Context of the COVID-19 Crisis* (April 2020)[19] affirms, recalling the basis of the Convention on Human Rights and Biomedicine (1997)[20], the principle of equity access to care, without discrimination. The European Group on Ethics in Science and New Technologies of the European Commission, in *the Statement on European Solidarity and the Protection of Fundamental Rights in the COVID-19 Pandemic* (2020),[21] although it does not address the specific problem of resource distribution, outlines the principles of dignity, justice and solidarity. The International Bioethics Committee and the World

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https://bioetica.governo.it/media/4008/p136_2020_covid-19-clinical-decision-making-in-conditions-of-resource-shortage-and-the-pandemic-emergency-triage-criterion_en.pdf.

[19] Committee on Bioethics, Council of Europe (DH-BIO), *Statement in the context of the Covid-19 crisis* (April 2020), https://rm.coe.int/inf-2020-2-statement-covid19-e/16809e2785.

[20] Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicin*e (Oviedo, 1997), https://rm.coe.int/168007cf98.

[21] European Group on Ethics in Science and New Technologies (EGE), *Statement on European solidarity and the protection of fundamental rights in the Covid-19 pandemic* (2020). https://research-and-innovation.ec.europa.eu/system/files/2020-04/ec_rtd_ege-statement-covid-19.pdf.

Ethics Committee of Scientific Knowledge and New Technologies of UNESCO in the *Statement on COVID-19: Ethical Considerations from a Global Perspective (…),* stresses that the ethical foundation of macro and micro-allocation must be based on principles of justice, charity, equity: "In the case of patient selection in the context of scarcity of resources, the clinical need and the effectiveness of the treatment should be of primary consideration." The reference is to human rights and health protection, art. 14 of the UNESCO Universal Declaration on Bioethics and Human Rights (2005) which states "the highest attainable standard of health" as a fundamental human right. Vulnerable people "become even more vulnerable in the period of the pandemic", in particular due to poverty, discrimination, gender, disease, loss of autonomy, age, disability, ethnicity, prison, migration and therefore must be adequately protected in their health needs.

We all know that inequalities already exist, but the challenges raised by COVID-19 tend to worsen them. We need to reduce injustice and try, as far as possible, to promote justice, in the intrinsic meaning of equality (non-discrimination) and equity, in the sense of inclusivity and 'inclusive health', considering that no one should be left behind-excluded and that we need every effort to guarantee affordable access for everyone, according to needs. In this sense, preparedness, cooperation (beyond private competition/interests) and benefits of sharing of knowledge needs to be central starting points for public health in a society threatened by a pandemic, recognizing 'health as common good' beyond pluralism and territorial borders, in a universal moral language between 'moral friends'.

It is essential to draw lessons from the crisis, both while the pandemic is ongoing and afterwards. We have achieved awareness about the relatedness and interconnectedness of all individuals: the need for common values in bioethics in the framework of human rights.

We have a great moral responsibility to learn from the crisis situation. This will help us to be better prepared for the next pandemic and to develop frameworks for providing guidance in the face of ethical choices that may have to be made in the future. This applies both nationally and internationally. Ethical analysis is therefore important in both the preparation and response phases. We all have a moral responsibility, to gather knowledge, discuss and learn lessons for the future.

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5 Human rights challenges and human rights as a resource during the COVID-19 pandemic – Council of Europe perspectives

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> While the virus is resulting in the tragic loss of lives, we must nonetheless prevent it from destroying our way of life – our understanding of who we are, what we value, and the rights to which Europeans are entitled. There is an urgent need to co-ordinate states' responses, to exchange good practices and to help each other in the quest for a quicker recovery.
>
> Marija Pejčinović Burić,
> Secretary General of the Council of Europe

Introduction

On March 11th, 2020, when the spread of the SARS-CoV-2 virus was declared a pandemic by World Health Organisation (WHO), few governments were prepared for such a crisis. The pandemic has had a devastating effect on individuals, families and communities worldwide. Governments have had to make fast, difficult and controversial policy choices which had an impact on some of the individual rights and freedoms that are an integral part of our democratic societies governed by the rule of law.

The COVID-19 pandemic has revealed and exacerbated existing weaknesses, discrepancies and challenges in protecting human rights in a health crisis. There have been reports of increased inequalities, such as more restrictive measures and restricted accessibility to health care for the elderly, and higher rates of mortality in certain socio-economically weaker neighbourhoods. Also, in the wake of the pandemic a polarization within communities has emerged, followed by declining levels of trust in policies and programmes issued by the authorities, especially concerning the attitude to mass-vaccination.

Although the acute phase of the pandemic is now over, COVID-19 continues to circulate and cause new infections across Europe. While the high death tolls that one saw in the beginning of the crisis can now be avoided with proper health care measures, another concern is the increasing numbers of patients seeking health care for post-infectious symptoms, also known as "long COVID" or PACS (Post-Acute COVID Syndrome). Health authorities will need to allocate adequate resources to address this emerging situation and optimize health outcomes, having in mind human rights perspectives.

Challenges to Europe's founding values of democracy, rule of law and human rights

The major challenge facing states was to respond to the crisis effectively, whilst ensuring that the measures they took did not undermine their genuine long-term interest in safeguarding Europe's founding values of democracy, rule of law and human rights.

Very early in the pandemic, the Council of Europe (CoE) took action to support its member states in finding ways to respond to the crisis, while respecting those values.

On April 7th 2020, the Secretary General of the CoE, Marija Pejčinović Burić, issued a toolkit for governments across Europe on respecting human rights, democracy and the rule of law during the COVID-19 crisis.[1] The toolkit covered four key areas:

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[1] Council of Europe, *Respecting Democracy, Rule of Law and Human Rights in the Framework of the COVID-19 Sanitary Crisis*: A Toolkit for Member States, SG/Inf(2020)11, 7 April 2020.

- Derogation from the European Convention on Human Rights (ECHR) in times of emergency.
- Respect for the rule of law and democratic principles in times of emergency, including limits on the scope and duration of emergency measures.
- Fundamental human rights standards including freedom of expression, privacy and data protection, protection of vulnerable groups from discrimination and the right to education.
- Protection from crime and the protection of victims of crime, in particular regarding gender-based violence.

Derogation from obligations under the ECHR

During the pandemic, all member states undertook emergency measures in the fight against the spread of the virus. Ten member states[2] derogated from their obligations under the ECHR which is possible 'in times of war or other public emergency threatening the life of the nation'.[3]

The Venice Commission of the CoE prepared a detailed opinion on the protection of national security and public safety which may justify restrictions to the full enjoyment of certain human rights, and even derogations from certain human rights obligations. Restrictions to human rights and freedoms, and derogations from them must regulated by law and, preferably, have a basis in the constitution. Any restrictions on human rights should be necessary in a democratic society and proportionate to the aim.[4] Such measures should not last longer than is strictly required during a state of emergency.

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[2] Council of Europe, *Derogations under Article 15 of the European Convention on Human Rights in the Context of the COVID-19 Pandemic*
https://www.coe.int/en/web/conventions/derogations-covid-19.

[3] Article 15, European Convention on Human Rights (ECHR).

[4] *Venice Commission, Compilation of Venice Commission Opinions and Reports on State of Emergency*, CDL-PI(2020)003, 2020, p. 12.

Vulnerable persons and groups

The SARS-CoV-2 virus proved to be more harmful for some individuals' health than others. In addition to some of the typically vulnerable groups, such as the elderly and the socio-economically weaker populations, persons with underlying health conditions, e.g. diabetes and obesity, seemed to be affected more severely. Other factors may yet make some more prone to long-term health problems. A better understanding of how to protect the more vulnerable is necessary.

In the Secretary General's tool kit[5], member states were reminded of the specific needs of persons belonging to disadvantaged groups, and the need to prevent discrimination towards them. This includes positive measures to promote equality. Decisions and policy making should also reflect the need to protect the most vulnerable individuals and groups based on the principle of solidarity.

A "new" trust crisis

A challenge for many governments during the pandemic was the communication and management of false rumours and misinformation, in particular around the virus and vaccines. This revealed an erosion of trust in information and decisions from health authorities and the government. Mistrust towards competent authorities is not new, but the COVID-19 pandemic took this towards other circles, including scientists and clinicians in some countries.

The implementation of measures to fight the pandemic, including the use of masks, restriction of movements and gatherings, as well as the uptake of vaccines, has suffered as a result.

The COVID-19 pandemic therefore highlights the importance of trust in managing crises and the role of transparency, accountability and more generally public dialogue to help build trust.

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[5] Council of Europe, *Respecting Democracy, Rule of Law and Human Rights in the Framework of the COVID-19 Sanitary Crisis*. SG/Inf(2020)11.

Challenges to heath care systems

The COVID-19 pandemic greatly affected healthcare systems and revealed their fragility. This raised major ethical challenges for healthcare professionals and competent authorities, faced with difficult decisions to take at a collective and individual level in a context of uncertainties and scarce resources.

During the COVID-19 pandemic, ethical analysis based on human rights proved to be instrumental to address those challenges and to take decisions concerning individuals, as well as societies.

Anticipating these challenges and assessing the capacities needed to deal with them requires efficient management in line with ethical principles and respect for human dignity and human rights.[6]

Council of Europe's role in protecting human rights in biomedicine and health

As an intergovernmental organisation aiming at protecting human rights, rule of law and democracy, the CoE provided member states with tools and expertise to ensure the crisis does not undermine common values and principles[7] calling for greater solidarity and better coordination in responding to the crisis. It offered a reference framework and a privileged platform to help states addressing common challenges.

Setting priorities in the light of the pandemic

On the occasion of the 20th anniversary of the Convention on Human Rights and Biomedicine, in 2017, the CoE Bioethics Committee (DH-BIO)[8] analysed challenges raised by the evolution of practices and scientific and technological development in biomedicine.

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[6] Council of Europe, *A Council of Europe Contribution to Support Member States in Addressing Healthcare Issues in the Context of the Present Public Health Crisis and Beyond*, Information Document SG/Inf(2020)24, 7 May 2020.

[7] Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms* (European Convention on Human Rights, as amended), Arts 2–3; Council of Europe, *European Social Charter* (revised, 1996), Art. 11; Council of Europe, *Convention on Human Rights and Biomedicine* (Oviedo Convention, 1997), Art. 3.

[8] As of 1 January 2022, the DH-BIO was replaced by the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO), which took over and extended its responsibilities.

The analysis resulted in the Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020–2025) (SAP) adopted in 2019, and articulated around three main pillars, Governance of Technologies, Equity in Health Care, and Physical and Mental Integrity.

The relevance of the challenges identified were reinforced by the COVID-19 pandemic, especially in regard to two main *human rights issues,* namely: equity in access to healthcare and empowerment.

Statement on human rights considerations relevant to COVID-19 pandemic

In a statement on human rights considerations relevant to the COVID-19 pandemic[9], adopted on 14 April 2020, the DH-BIO referred to the Convention on Human Rights and Biomedicine (Oviedo Convention) to guide decisions and practices, both in clinical and research fields in a context of emergency and health crisis management.

The first principle that the DH-BIO highlighted in its statement is the principle of equitable access to health care laid down in Article 3 of the Oviedo Convention which "requires particular vigilance in their application on the current pandemic".

On this occasion, the DH-BIO also underlined "the fundamental and indissociable link between human rights, solidarity and responsibility which [were] essential in addressing the current crisis caused by the COVID-19 pandemic".

Statement on COVID-19 and vaccine: Ensuring equitable access to vaccination during current and future pandemics

The DH-BIO statement[10], adopted on 22 January 2021, focused on access to vaccine. Faced with a scarcity of vaccines, prioritisation was considered essential to uphold the right to life and the right to the protection of health. Concerned not to increase existing disparities, attention was drawn to persons who are systematically disadvantaged in accessing healthcare and call was made for the development of strategies to ensure appropriate support and removal of barriers to

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[9] Council of Europe, *DH-BIO Statement on Human Rights Considerations Relevant to the COVID-19 Pandemic*, SG/Inf(2020)2, April 2020.

[10] Council of Europe, *COVID-19 and Vaccines: Ensuring Equitable Access to Vaccination during the Current and Future Pandemics* (DH-BIO Statement), 22 January 2021.

vaccination. Furthermore, access to vaccination should be tailored to the needs of persons in vulnerable situations having difficulties in accessing health service, including migrants and refugees. Finally, particular emphasis was placed on transparency, information and communication to contribute to building trust and the promotion of public dialogue to help understand citizen's concerns.

These works paved the way for the development of a legal instrument and a guide foreseen under the SAP but the scopes of which were refined to better respond to the human rights challenges raised by the pandemic: a recommendation on equitable access to medicinal products and medical equipment in a situation of shortage and a guide to health literacy.

Recommendation of the Committee of Ministers on equitable access to medicinal products and medical equipment in a situation of shortage

Shortage of medicinal products and medical equipment is not unusual. The causes of shortage are multifactorial, including lack of raw materials, or problems in manufacturing and logistics. But unpredictable events such as epidemiological outbreaks may significantly increase demand and reduce the capacity to guarantee availability. When such products or equipment are necessary for severe or life-threatening health conditions, the potential resulting harm to the health of individuals requires that measures be taken to safeguard the fundamental rights of the individuals concerned and to recognise and strengthen the value of solidarity between individuals.

The CoE *Recommendation on equitable access to medicinal products and medical equipment in situations of shortage*[11] lays down a set of principles that should guide national priority setting regarding access to medicinal products and medical equipment with a view to guarantee equitable access to them in situation of shortage. This includes reference to non-discrimination in the access to such products and equipment, prioritisation based on medical criteria, appropriate support and removal of barriers and respect for the dignity of persons who do not access to the products or equipment. Specific attention

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[11] Council of Europe, *Recommendation CM/Rec(2023)1 on Equitable Access to Medicinal Products and Medical Equipment in a Situation of Shortage*, adopted by the Committee of Ministers, 1 February 2023.

is also to be paid to individuals who are systematically disadvantaged in relation to health including as a result of socioeconomical conditions, legal status, disability or age.

Accountability, reasonableness and relevance, inclusiveness and consistency in the implementation of policies were considered key procedural principles.

It is important to point out that, in accordance with the remit of the work of the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO), the recommendation only addresses equitable access to medicinal products and medical equipment within a country. However, faced with a complex and globalised production and distribution chain, international cooperation and coordinated action is encouraged to guarantee timely measures to appropriately address situations of shortage. An exchange of lesson learnt and good practices between countries could also be very useful in the prevention and mitigation of shortage situations.

Guide to health literacy – Contributing to trust building and equitable access to healthcare

The efficiency of health systems relies to a large extent on the way they are perceived, understood, and trusted, as well as on the accessibility of the services they offer, whilst ensuring respect for human rights. Those elements are greatly affected by people's health literacy. Health literacy is an important determinant of health and a constituent of avoidable and unfair health inequalities.

The concern that existing healthcare resources were less accessible to certain patients' groups due to their particular social circumstances and the need to combat such health disparities had prompted the CDBIO to address the issue of health literacy. The COVID-19 pandemic has increased the relevance of this topic and clearly shown that health literacy was a matter of public concern and leads to health disparities.

The guide[12], including through practical examples, aimed at supporting the development of more accessible and inclusive health systems in which health literacy serves as a profound pillar in relation to good

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[12] Council of Europe, *Guide to Health Literacy – Contributing to Trust Building and Equitable Access to Healthcare*, launched 18 January 2023.

governance. It also aimed at improving health literacy policy, research and practice as part of a human rights agenda, identifying needs and developing targeted health literacy solutions, namely for people in vulnerable situations.

To ensure equitable access to healthcare, five main actionable objectives are highlighted in the guide: (1) access to valid health information, (2) access to appropriate care, (3) communication between individuals, health professionals and health authorities, (4) shared decision-making regarding treatments and care, and (5) access to digital spaces to understand and use health services. Health literacy thereby contributes to equity and trust in health systems which are critical when addressing health threats such as those raised by the COVID-19 pandemic.

Re-building trust –public dialogue

The Oviedo Convention requires, in its Article 28, that fundamental questions raised by developments of biology and medicine are subject of appropriate public discussion, in the light, in particular of relevant medical, social, economic, ethical and legal implications.

The major components of public dialogue – namely information awareness raising, exchange and feedback loops between policy makers, scientists and the public – can help to build trust in the management of a crisis. Open, inclusive and transparent dialogue can foster better understanding of issues at stake and developments including pandemics.

In learning lessons and in being more prepared for crises like the COVID-19 pandemic, public dialogue helps in transparently communicating and promoting public health measures in tiles of uncertainty.

Fostering such dialogue contributes to promoting democratic governance and transparency. This is the objective of the CoE Guide to public debate on human rights and biomedicine, which underlines the importance of dialogues between actors, groups and individuals, including those in vulnerable or disadvantaged situation, to reach informed decisions.

Conclusions

The challenges faced in European states during the pandemic illustrated the importance of democracy, the rule of law and human rights in times of crisis. They reinforced the need for intergovernmental organisations to promote solidarity and international cooperation between states. Having a common goal brought societies together to find a solution to the problem, which was exhibited by governments, companies and individuals cooperating. Across borders there was a valuable exchange of research, medical knowledge and treatment methods. A good example is the speed at which vaccines were developed as a result of collaboration between pharmaceutical companies, research institutes and governments.

For governments, reviewing their actions during the pandemic would help them learn how to better prevent, prepare for and manage future crises, whilst safeguarding the protection of human rights, including social rights.

The pandemic demonstrated the importance of a value-based approach for decisions both at an individual and collective level. One solution does not fit all and sharing lesson learnt and exchanging on success and failures within and between countries would be essential in upholding this approach. Public dialogue on the basis of the results of the analysis and with a view to identify priority values would help rebuild trust in governments and scientific institutions.

The intergovernmental cooperation has proven to be of significance, not only in combatting the pandemic, but also in building more robust systems and common regulations for a future management of a crisis safeguarding Europe's founding values of democracy, rule of law and human rights. This is promising as there is still a lot of common groundwork to be laid.

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Venice Commission, *Compilation of Venice Commission Opinions and Reports on State of Emergency*, CDL-PI(2020)003, 2020.

6 ‘Where you live should not determine *whether* you live.’ Global justice and the distribution of COVID-19 vaccines

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When the world was suddenly struck by the COVID-19 pandemic in 2020, the search for vaccines began almost immediately. The world’s leading pharmaceutical scientists and pharmaceutical companies were enlisted for the task, and the USA, the EU, the UK, Russia and China spent considerable sums on developing vaccines against this new infectious disease. After less than a year, a vaccine was available – a process that normally takes 10 to 15 years.[1]

How then should the new vaccines be distributed? In the summer of 2020, a number of world leaders published an article in *The Washington Post* titled: “The international community must guarantee equal global access to a COVID-19 vaccine”. These world leaders asserted that “… we must urgently ensure that vaccines will be distributed according to a set of transparent, equitable and scientifically sound principles. Where you live should not determine *whether* you live, and global solidarity is central to saving lives and protecting the

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[1] This article is an updated version of my article ‘Where you live should not determine whether you live’. Global justice and the distribution of COVID-19 vaccines, *Ethics & Global Politics*, Volume 15, Issue 2.

economy"[2]. It was clear that the efforts involved to achieve this radical goal would be huge.

When you look at access to healthcare resources the gaps between rich and poor countries become very apparent. Low-income countries in Africa and Asia can only provide USD 20–50 per person per year, while healthcare costs in high-income countries amount to USD 6 000–15 000 per person per year.[3] These figures clearly show that where you happen to live is indeed crucial to your chances of surviving.

Soon after the pandemic hit the world in 2020, the COVID-19 Vaccines Global Access Facility (COVAX) – a collaboration between the World Health Organization (WHO), Gavi (a global vaccine alliance), and the Coalition for Epidemic Preparedness Innovation (CEPI) – was established to assist in global access to vaccines. With donations from rich countries and private sponsors, its goal was to distribute two billion doses in 2021 and to achieve the vaccination of 20 per cent of the population of every country globally.

However, it soon became apparent that the world's rich countries would commandeer most of the vaccines available.[4] Even before the vaccines were available on the market, they had reserved vaccine doses for their own populations. For example, 80 per cent of Pfizer's vaccine doses had already been procured by the end of 2020.[5] In January 2021, WHO Director-General Tedros Adhanom Ghebreyesus warned that the world was "... on the brink of a catastrophic moral failure ... The price of this failure will be paid with lives and livelihoods in the world's poorest countries".[6]

But could it be that the world's low-income countries did not have the same need for vaccination against COVID-19? At the beginning of the pandemic, it was claimed that the need for vaccination was greatest in the rich countries because they had a higher proportion of elderly people and because the elderly were at particular risk from COVID-19. However, this claim proved to be incorrect. Low-income countries were affected in multiple ways by the pandemic. In the absence of vaccines, these countries introduced strict lock-

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[2] Trudeau et al. (2020).

[3] World Bank (2022).

[4] Oxfam, 'Small group of rich nations have bought up more than half the future supply of leading COVID-19 vaccine contenders', Oxfam Press Release, 2020.

[5] A. G. Kartal, 'Richest countries already bought 80 % of Pfizer vaccine', Anadolu Agency, 2021.

[6] United Nations, 'Vaccine nationalism, hoarding putting us all at risk', 2021.

downs, which led to increased unemployment and reduced access to necessities such as food and healthcare. This led to acute suffering and famine for many people already living on the poverty line.[7] In addition, children and young people in these countries were affected by the closure of schools and universities, which has had serious social consequences.

The number of people infected with SARS-CoV-2 (the coronavirus that causes COVID-19) in low-income countries has also been underestimated. The WHO has shown that the number of cases was seven times as high as initially assumed, and that the death rate was two to three times higher than officially reported.[8] A study published in *The Lancet* shows that the global excess mortality rate due to COVID-19 has been 18 million to date, and that it was highest in South Asia, North Africa, the Middle East, and Eastern Europe. The conclusion is that low- and middle-income countries were hit much harder by the COVID-19 pandemic than high-income countries.[9] These countries' needs for vaccines were thus not less than those of the high-income countries.

The catastrophic moral failure that Tedros warned of had become a reality. While 70–80 per cent of the population in middle- and high-income countries had received at least two doses of a vaccine by spring 2022, only 14 per cent of the populations of low-income countries had received at least one dose.[10] The low level of vaccination coverage in low-income countries was due to numerous factors, including poor infrastructure, poor organisation of healthcare, difficulties in storing mRNA vaccines, and vaccine scepticism, but primarily it was due to poor access to vaccines.[11] COVAX was only able to achieve about 25 per cent of its target of distributing two billion doses during 2021.[12]

Since 1994, drug and vaccine production has been protected by global patent rights. This means that a company that has produced a

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[7] A. Josephson, T. Kilic and J. D. Michler, 'Socioeconomic impacts of COVID-19 in low-income countries', *Nature Human Behavior,* vol. 5, no. 5 (2021), pp. 557–565.

[8] P. Beaumont, 'Africa transitioning out of pandemic phase of Covid, WHO says', *The Guardian*, 10 February 2022.

[9] H. Wang et al., 'Estimating excess mortality due to the COVID-19 pandemic: A systematic analysis of COVID-19-related mortality, 2020–21', *The Lancet*, vol. 399, no. 10334 (2022), pp. 1513–1536; P. Beaumont, ibid.

[10] Our World in Data. (2022).

[11] N. Aizenman, 'Why low-income countries are so short on COVID vaccines', *NPR*, 10 November 2021.

[12] O. Irfan, 'Why are rich countries still monopolizing COVID-19 vaccines?', *Vox*, 9 November 2021.

vaccine has the right to income from the vaccine for a period of 20 years, and no other company is permitted to produce the same vaccine during that period. To increase access to the COVID-19 vaccines, in October 2020 India and South Africa approached the World Trade Organization (WTO), proposing that patent rights for vaccines should be temporarily waived. Their proposal cited the TRIPS agreement that regulates patent rights globally. Under this agreement, patent rights may be waived temporarily in the case of a national emergency or other circumstances of extreme urgency. The proposal from India and South Africa was supported by over 100 WTO member states as well as organisations such as the WHO, UNAIDS, Oxfam and *Médecins Sans Frontières*, but met with strong opposition from the vaccine-producing companies and the European Union, including the Swedish Government. Ultimately, the proposal was also supported by the USA and France, but it was not until June 2022 – when the pandemic was almost over – that the WTO member states reached a compromise that made it possible for companies other than those that owned patent rights to produce the vaccines.

The global distribution of COVID-19 vaccines has therefore been largely determined by the national interests of high-income countries. So, what does an equitable distribution of vaccines actually look like? What ethical principles should guide their global distribution? In its report *Ethical choices in a pandemic*, the Swedish National Council on Medical Ethics (Smer) described the principle of global justice and the principle of international solidarity in relation to the pandemic.[13] Similar principles have also been described by ethics councils in other countries.[14] These principles appear to have broad support, and I will clarify them below. The principle of global justice can guide global institutions, and the principle of international solidarity can guide the decision-making of individual nations, for example when rich nations are attempting to strike a balance between their own country's vaccination needs and those of poorer countries. In this chapter, I will discuss these principles and their application to the global distribution of vaccines, followed by a discussion of what are the grounds for an individual's right to access vaccines. In the ethical debate on the global distribution of vaccines, two main stances can be identi-

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[13] The Swedish National Council on Medical Ethics, Ethical Choices in a Pandemic (2020:3).

[14] Nuffield Council on Bioethics, Ten Questions on the Next Phase of the UK's COVID-19 Response (2020); Deutscher Ethikrat, International Perspectives on Pandemic Preparedness and Response (2021).

fied: 'vaccine cosmopolitanism' and 'vaccine nationalism'. I will conclude this article by arguing in favour of a middle course between these two, which I term 'global vaccine sufficientarianism'.

Global justice and international solidarity

There has been a lively debate on the meaning of 'justice' in the fields of ethics and political philosophy, especially since philosopher John Rawls published his work *A Theory of Justice* in 1973. In this book, Rawls elaborates a theory of justice where he proposes that, hypothetically, it is under a 'veil of ignorance' of their own position in society that people can reach an agreement on principles of justice. Rawls's theory is institutional. In a just society, social institutions, or in Rawls's words 'the basic structure,' are organized so that they are the subject of justice.[15]

According to the "difference principle," primary goods, i.e. those that are crucial for a dignified life, such as access to healthcare and education, should be distributed equally unless an unequal distribution would be to the advantage of the least favored.[16] The starting point is therefore an equal distribution. An unequal distribution of vaccines against serious viral diseases such as COVID-19 is justified only if it would be to the advantage of the least favoured. According to the difference principle, during the COVID-19 pandemic, when most of the available vaccine doses have been accessible only in high- and middle-income countries, priority should have been given to the need for vaccine doses in low-income countries.

Although there is no global state that can regulate the distribution of vaccine doses, there are global institutions, such as the WHO and the WTO, that potentially could have an influence on this distribution. The WHO, in that it has been coordinating international cooperation to fight the pandemic, including through COVAX. However, the WHO lacks the resources to enforce a just and fair distribution and can only appeal to rich countries to donate to the vaccination programmes of poor countries, which its Director-General did

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[15] Although Rawls himself argued against applying the difference principle on a global scale (Rawls 1999, p. 116), a number of political philosophers have also applied this theory to global institutions (Beitz 1979, Pogge 1989, Tan 2005, Collste 2005). With a Rawlsian lens, these philosophers argue that Rawls' principles of justice could also guide decision-making within global institutions.

[16] J. Rawls, A Theory of Justice (Oxford University Press, Oxford, 1971).

repeatedly during the pandemic. COVAX was an important international initiative to increase access to vaccination in poor countries. However, the targets it set were not achieved.

As we have seen, the proposal to waive patent rights for COVID-19 vaccines was blocked in the WTO. Public health scientists Erondo and Singh write that for the principle of global justice to be applied to distribution of vaccines, institutional changes are needed: "… ultimately vaccine donations are a temporary response. They cannot replace long-term solutions to vaccine inequity. A real solution is to democratise vaccine production. There must be a particular emphasis on production capacity and increased access to technologies and knowledge transfer".[17]

And what about the principle of international solidarity? What does it mean when applied to the global distribution of vaccines? The Cambridge English dictionary defines solidarity as 'agreement between and support for the members of a group'.[18] Given this definition, international solidarity means that vaccines against COVID-19 should be distributed so that countries with resources to purchase vaccines, distribute them in support of low-income countries that lack these resources.

The principles of global justice and international solidarity have been posited in the international debate on the global distribution of vaccines during the COVID-19 pandemic. They arguable form a basis for a global ethics. However, as we have seen, they were not the guiding principles for the global distribution of vaccines against COVID-19. Instead, rich countries hoarded large quantities of vaccine doses for their own populations.

Who has the right to vaccines?

Who has the right to vaccines and on what grounds? In the international debate on the global distribution of vaccines, two responses to this question have emerged: vaccine cosmopolitanism and vaccine nationalism. So, what are the reasons for advocating a vaccine cosmopolitanism, meaning that every person, irrespective of their nationality, has the same right to vaccines; and how can vaccine nationalism,

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[17] N. Erondo and R. Singh, 'New donation pledges won't fill global COVID-19 vaccine shortfalls', *The Conversation*, 5 October 2021.

[18] *Cambridge Dictionary.*

which claims that citizenship is a relevant factor in the distribution of the vaccines, be justified? Is there perhaps a well-founded middle course? These are questions that I will now discuss.

Vaccine cosmopolitanism

'Where you live should not determine *whether* you live'. This moral assessment is intuitively convincing and can be supported by a number of moral arguments. According to the principle of human dignity, all human beings are of equal value. If the principle of human dignity is to go beyond mere rhetoric, it must be assumed that every person has certain fundamental rights, such as the rights to life, well-being and freedom. It thus implies that every human being also has the same right to the resources needed to meet their basic human needs. During the COVID-19 pandemic, vaccination against SARS-CoV-2 was a necessary resource to meet the need for health.

Another argument is based on one of the fundamental conditions of human life. We cannot influence where and into what circumstances we are born. Our starting point in life, biological as well as social, is thus a lottery of nature and social circumstances. However, this starting point is crucial to the way our lives subsequently develop, what chances we have in life, and what opportunities and difficulties we may face throughout the course of our lives. Yet from a moral standpoint, these arbitrary beginnings should not be allowed to determine the value of the lives we live. The role of justice is to compensate those people who have been unlucky in the lottery of nature and social circumstances "... no one should be worse off because of her poor luck", writes philosopher Kok-Chor Tan.[19]

The country in which you are born is part of nature's lottery. Philosopher Simon Caney asks the rhetorical question: "Given that it is an injustice that some face worse opportunities because of their class or their ethnicity, is it not an injustice that some face worse opportunities because of their nationality?"[20]

Since every human being was at risk of being infected by COVID-19 during the pandemic, according to vaccine cosmopolitanism, every human being had the same right to be protected by vaccina-

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[19] K. C. Tan, Justice, Institutions & Luck (Oxford University Press, Oxford, 2012), p. 88.

[20] S. Caney, Justice Beyond Borders (Oxford University Press, Oxford, 2005), p. 123.

tion, regardless of where they lived. This view is expressed by philosopher Nicole Hassoun in the following way: "A truly ethical proposal would treat all people equally and help countries get vaccines to people when they lack capacity to do so on their own."[21]

During the COVID-19 pandemic, the global distribution of vaccines was guided by vaccine nationalism rather than by vaccine cosmopolitanism. How can this be explained? Can vaccine nationalism be justified? These are the questions discussed in the next section.

Vaccine nationalism

We have seen that the rich countries purchased large quantities of vaccine doses to cover their vaccination needs, while many low-income countries were virtually without vaccines during the first year of the pandemic. In practice, the global distribution of these vaccines was not guided by the principles of global justice and international solidarity. An obvious explanation for this is that the behaviour of countries in a situation of great uncertainty and the risk of the pandemic spreading was not guided by ethical principles but by national self-interest. The UN Secretary-General Guterres called this behaviour 'vaccine nationalism' and its results are apparent in the unequal global distribution of the vaccines. Does this mean that principles such as global justice and international solidarity, as expressed in the article that the world leaders wrote in *The Washington Post* in 2020 for example, are mere rhetoric and hypocrisy?

A different interpretation is that these global leaders were expressing principles and ideals which, although being in conflict with their national self-interest, nevertheless are able to set limits on self-interest. They expressed a desire for an ideal course of action, which they were not, however, capable of following in practice – global ethics as a corrective in global politics. And if public opinion, NGOs and others, can remind these politicians of their declarations and promises, their decisions may nevertheless be nudged closer to this ideal course of action. Perhaps their support of COVAX and the stand taken by some world leaders in favour of temporarily waiving the patent rights on vaccines can be interpreted in this way?

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[21] N. Hassoun, 'How to distribute a COVID-19 vaccine ethically', *Scientific American*, 25 September 2020.

But could vaccine nationalism ever be justifiable? A possible argument for vaccine nationalism is based on a Hobbesian view of the legitimacy of states. For example, philosopher Bernard Williams claims that a state must fulfil certain legitimation demands for its citizens to have reason to submit to the state and to comply with its laws. The state is constituted on the basis of the consent of its citizens, which presupposes that their fundamental interests are served.[22] This view of the state's legitimation also implies that a state's citizens can expect their political decision-makers to satisfy their needs for vaccines during a pandemic by adhering to a sustainable vaccine strategy that provides full or close to full vaccination coverage.

According to another argument for vaccine nationalism, there are moral reasons for states to act in their own interests. A state is a polity, and political leaders have primary obligations to their own citizens. These obligations are based on important ethical values such as public confidence, solidarity, trust and keeping promises,[23] "A just distribution of the vaccine's initial supply can reflect these associative ties and moral commitments to one's community and its members" wrote medical ethicists Ferguson and Kaplan.[24] In light of this, a state's citizens could expect their elected leaders to safeguard their interests as far as possible, for example by meeting their citizens' needs for vaccination against COVID-19.

We have thus seen that vaccine nationalism is not only motivated by national self-interest, but that this position is also justifiable by reference to the legitimation of the state and to moral arguments such as public confidence, solidarity and keeping promises.

A middle course

So far, I have discussed arguments for vaccine cosmopolitanism and vaccine nationalism. We have seen that there are strong moral arguments for vaccine cosmopolitanism, but there are also moral reasons for political leaders to prioritise their own citizens. Could it be that rich states have both global obligations *and* primary obligations to

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[22] B. Williams, *In the Beginning Was the Deed: Realism and Moralism in Political Theory* (Princeton University Press, Princeton, 2005).

[23] D. Miller, *Citizenship and National Identity* (Polity Press, Cambridge, 1999).

[24] K. Ferguson and A. Kaplan, 'Love thy neighbour? Allocating vaccines in a world of competing obligations', *Journal of Medical Ethics* (2020).

their own citizens? This could imply that their global obligations are less pressing and limited to humanitarian aid. This stance is in line with how states acted during the COVID-19 pandemic. As we have seen, rich countries commandeered large quantities of vaccine doses for their own populations but provided also support to COVAX.[25]

However, even if states do have obligations to their citizens, this does not rule out having moral reasons for contributing to global justice. Firstly, states operate within global institutions such as the WHO and the WTO, and within them they ought to be promoting global justice. As philosopher Simon Caney writes, “They can … pursue their ends within the context of a fair overall framework.”[26] Secondly, the principle of ‘where you live should not determine whether you live’, and the principle of the equal value of all people, are more fundamental than the obligations that political leaders have to their own citizens. States therefore do have the right to prioritise their own citizens, but only on the condition that the pandemic does not have disastrous consequences and a very high mortality rate in countries without access to vaccines. This view, we can call it global vaccine sufficientarianism, implies that when the global population has achieved a certain level, a threshold of vaccine distribution, political leaders in high-income countries could prioritize their own population.

The view that states have obligations to their citizens appears reasonable on the face of it. However, the question of how these obligations should be balanced against obligations arising from the principles of a global ethic remains unanswered. Perhaps vaccine cosmopolitanism is too demanding if it means that vaccines against COVID-19 should be distributed equally among all the people in the world. A more realistic stance, which also takes into account the obligations of states to their own citizens during a pandemic, is that while states can certainly provide their own citizens with vaccines, they do so on the condition that the global population has the necessary resources, including vaccines, to avoid catastrophic consequences from the pandemic. This non-ideal view takes into account both the fundamental principle of the equal value of all people, and allows that political leaders have primary obligations to their own citizens.

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[25] Global leaders, ‘Global leaders commit further support for global equitable access to COVID-19 vaccines and COVAX’, UNICEF, 23 September 2021.

[26] S. Caney, *Justice Beyond Borders* (Oxford University Press, Oxford, 2005), p. 140.

What would be the implications of this stance in terms of the global distribution of vaccines against COVID-19? During the first year of the pandemic, a bigger portion of the available vaccine doses should have been allocated to low-income countries. Instead, the 'immunisation gap' continued to widen between rich and poor countries through the hoarding of vaccines by rich countries.[27] A study published in *The Lancet* estimates that about 600 000 deaths could have been avoided globally if all countries had reached 40 per cent vaccination coverage by the end of 2021. There was sufficient vaccine to achieve this goal if the vaccine doses had been distributed fairly.[28]

The practical implications of the middle course that I am proposing here, which entails a fair global distribution of COVID-19 vaccines, and which I have argued for above (global vaccine sufficientarianism) come close to the stance posited by a number of international ethicists in an article published in 2021. The article argues for a middle course between vaccine cosmopolitanism and vaccine nationalism, which is termed 'fair priority for residents." How many vaccine doses is a government entitled to allocate to its own population, the authors ask. Their reply is "… governments can retain COVID-19 vaccine doses for their residents only to the extent that they are needed to maintain a noncrisis level of mortality".[29] This level corresponds to "… the level of mortality that is experienced during a worse-than-average, but not terrible, year of influenza".[30] In order to serve the interests of its own citizens, governments are therefore entitled to use as many vaccine doses as are normally required to keep an outbreak of a serious influenza under control. Once this threshold has been reached, vaccine doses should be shared with low-income countries that are experiencing high mortality rates due to their lack of resources to vaccinate their populations. It has been shown that repeated vaccination is necessary for protection against infection by SARS-CoV-2. As a result, low-income countries should continue to be given priority for as long as their basic needs for vaccine doses remain unmet.

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[27] Global Times, 'GT investigates: Rich countries hoarding vaccines in disregard of poorer regions breathes life into new variants, worsens economic disparity', *Global Times*, January 2022.
[28] O. J. Watson et al., 'Global impact of the first year of COVID-19 vaccination: A mathematical modelling study', *The Lancet Infectious Diseases*, vol. 22, no. 9 (2022), pp. 1293–1302.
[29] E. J. Emanuel et al., 'On the ethics of vaccine nationalism: The case for the Fair Priority for Residual Framework', *Ethics & International Affairs*, vol. 35, no. 1 (2021), pp. 1–20.
[30] Ibid.

The view that a greater proportion of available vaccine doses should go to low-income countries can also be justified by the long-term interests of the rich countries themselves. 'Nobody is safe until everyone is safe' means that as long as SARS-CoV-2 remains in any corner of the world, the risk of its global spread remains. It has also been shown that new mutations occur in countries with low vaccination coverage.[31]

Conclusion

I have discussed above the issue of how vaccines against COVID-19 should have been distributed based on a global ethics. I took as my starting point the principles of global justice and international solidarity.

The WHO, through its work with COVAX, contributed to a global distribution of vaccines based on the principle of international solidarity. But despite appeals to the world's rich countries, COVAX failed to achieve its goals. The WTO is an important stakeholder and is able to influence the global distribution of COVID-19 vaccine doses. The WTO manages the global rules governing proprietary rights and patent rights, and many of its member states pushed for the temporary waiving of patent rights to vaccines so that vaccines can be produced in more countries. Such a decision is in line with the principle of global justice. The proposal was submitted in October 2020, but only in June 2022, when the pandemic was almost over, could the WTO reach a compromise that partially waives these patent rights.

Weighing up national self-interest against global vaccine need, which I have argued for above, and which Emanuel et al. have epitomised in *fair priority for residents*, offers a general principle for a fair non-ideal global distribution of vaccines. Specific factors such as the high risk of future outbreaks of pandemics, and corrupt regimes that constitute an obstacle for vaccine distribution in poorer countries, may, of course, affect the actual distribution of vaccine doses.

In conclusion, a fair global distribution of vaccines should:

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[31] L. Elliott, 'The Omicron variant reveals the true global danger of vaccine apartheid', *The Guardian*, 28 November 2021.

- Balance global justice and international solidarity with leaders’ obligations to their Citizens.
- Chart a middle course between extreme vaccine cosmopolitanism and narrow nationalism.
- Honour the international solidarity commitments made by political leaders during the pandemic.
- Materialize through collaborative efforts between the WTO, WHO, COVAX, and other international and national stakeholders.

This approach recognizes both our shared global humanity and the practical realities of a world organized into nation-states with differential capacities and responsibilities[32]

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[32] Thanks to Lotta Eriksson for helpful comments.

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7 Why organizational ethics in health care matter

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Without a decent understanding of the organizational circumstances that brought about certain shortcomings in pandemic response, the basis for future decisions on policy and ethical guidelines will be insufficient and may have further undesired consequences. Yet surprisingly little attention has been given to ethical aspects of the healthcare system and the organizational context in which ethical decisions concerning health care are made. Based on an analysis of 12 key policy documents on Swedish pandemic preparedness, this chapter highlights the importance of organizational ethics in health care.

Introduction

Over decades, Swedish health care has suffered from structural and organizational problems. The symptoms include a lack of care places, long care queues, unequal access to care, impaired work environments, increasing health problems and decreasing motivation among employees in the sector.[1] Concerning pandemic preparedness, the situation was far from satisfactory when COVID-19 emerged. For instance, there was a lack of competent staff. And health care for the elderly has long been neglected. In other words, the Swedish healthcare system was already under considerable pressure.

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[1] A. Anell, *Vården är värd en bättre styrning* (SNS, 2020), E. Anskär, M. Lindberg, M. Falk and A. Andersson, 'Legitimacy of work tasks, psychosocial work environment, and time utilization among primary care staff in Sweden', *Scandinavian Journal of Primary Health Care*, vol. 37, no. 4 (2019), pp. 476–483.

During the ongoing pandemic, several organizational shortcomings were also reported. In particular, the care for elderly people was criticized. Apart from the general spread of infection, the Corona Commission found that the long-known structural deficiencies had the greatest negative impact on elderly care during COVID-19.[2] In Sweden, responsibility for care of the elderly is divided between 21 regions and 290 municipalities. In turn, the national government have a responsibility in these areas. There are in addition many private contractors, contributing to a fragmented organizational structure of the system. It is far from clear who is responsible for what.

According to the Swedish constitution, public authority must be exercised with respect for the equal value of all people and for the freedom and dignity of the individual. Discrimination is prohibited. The same ethical and democratic value system is found in the Health Care Act, which states that care must be provided with respect for the equal value of all people and for the dignity of the individual person.[3] Those who have the greatest need for health care must also be given priority, which reflects a principle of solidarity. The Health Care Act also emphasizes that there must be the staff, the premises and the equipment needed for the provision of good care. Consequently, there is no doubt about what (according to the law) constitutes the goal of taking responsibility, and what is required to do so. However, there are good reasons to examine whether the existing organizational structures and key policy documents are based on and consistent with the same value system.

Organizational ethics in health care

Organizational ethics in health care deals with ethical aspects of the structure, organization and control models of one or more organizations or a system. Responsibilities and ethical aspects of working methods, policy documents and guidelines are examined, as well as how conflicting goals, values and interests are and should be handled. Issues concerning how organizations or a whole system affects society

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[2] SOU 2020:80.

[3] SFS 2017:30.

by the actions and decision-making of its actors are also of interest.[4] A point of departure in this chapter is that it is reasonable to raise ethical demands on the structure of the healthcare system, i.e. how its organization, systems and institutions are designed. One motive for choosing this starting point is that the structural design (albeit piece by piece, layer upon layer) has been intentionally planned to achieve certain effects. The design also brings functions, positions and power relations. Financial and personnel resources are also distributed to maintain the functions. The design thus regulates the relationships and interactions between different actors and activities in the healthcare system.[5] The fact that superior levels affect subordinate levels through their decision-making also makes it reasonable to raise ethical demands on the political and administrative governance of health care. Decisions concerning policy, control models, regulations and budgets may, for instance, enable or limit the interests and actions of various stakeholders. These circumstances strongly affect the local caregivers' organizational action conditions (OAC) and thus the profession's opportunities to carry out their work. In the long run, the structural design of a healthcare system affects the culture and norms within the sector,[6] not least concerning which goals and values are given the highest priority in different practical settings. As pointed out by Lascoumes and Le Gales, policy instruments embody a particular view of the world and help create versions of the world.[7] Far from being neutral technological devices, such political instruments embody ideas and values.

Policy documents (PDs) are instruments of control produced to guide decisions and activities within a subject area in a certain direction. They are normative in nature and constitute one of several tools for governance. How a certain PD is received and understood in local healthcare settings depends on the approaches, routines and

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[4] J. Gibson, R. Sibbald, E. Connolly and S. Singer, 'Organizational ethics', in P. Singer and A. Viens (eds), The Cambridge Textbook of Bioethics (Cambridge University Press, 2014), pp. 243–250, The Swedish National Council on Medical Ethics, Report: *Governance models in healthcare – draft of a model for ethical analysis* (2019), https://smer.se/wp-content/uploads/2020/06/governance-models_report-2019_2-web.pdf.

[5] L. Emanuel, 'Ethics and the Structures of Healthcare', *Cambridge Quarterly of Healthcare Ethics*, vol. 9, no. 2 (2000), pp. 151–168.

[6] Ibid.

[7] P. Lascoumes and P. Le Galès, 'Introduction: Understanding public policy through its instruments – From the nature of instruments to the sociology of public policy instrumentation', Governance, vol. 20, no. 1 (2007), pp. 1–21.; E. Falkenström and S. Svallfors, 'The knowledge-management complex: From quality registries to national knowledge-driven management in Swedish health care governance', *Politics & Policy*, vol. 50, no. X (2022), pp. 1–14.

culture gradually developed over the years and established through various forms of governance, organization and educational programmes in the area. For instance, the many New Public Management (NPM) reforms have contributed to a cultural transformation.[8] Concerning ethics, the NPM-inspired reform of patient choice, for instance, carried new goal conflicts between demand-driven and needs-driven care, and the applied compensation systems can make it difficult to focus on the patient's need for care.[9]

Previous studies on healthcare governance in Sweden have also shown that the structure of health care, designed by policymakers, determines OAC, which can either support or obstruct intended actions in the healthcare system. The possibilities for healthcare staff to act responsibly based on professional knowledge and codes of conduct were highly affected.[10]

Questions of concern

Based on an analysis of 12 key PD's (six of which were produced by the authorities before COVID-19 and six after its outbreak) and their recommendations, I will discuss some important aspects of organizational ethics in health care in relation to pandemic preparedness. The original study and complete analysis are presented elsewhere.[11] A list of the analysed documents can be found at the end of this chapter.

To manage COVID-19, a new and stricter order of medical priority-setting was hurriedly produced and introduced by the National Board of Health and Welfare in the spring of 2020.[12] From the perspective of organizational ethics in health care, not only questions concerning the values or principles themselves, or how they should be applied, by whom and when are of interest. It is also essential to delve into questions concerning the social and organizational context: Why did the need for a stricter order arise at that time? How can the sudden need for new principles be understood? What was

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[8] K. Sahlin, *Debatt pågår! Offentlighetens organisering* (Sveriges Kommuner och Landsting, 2017).

[9] Riksrevisionen, *Primary Health Care Governance – Based on Need or Demand?* (RiR 2014:22, 2014).

[10] E. Falkenström, *Verksamhetschefens etiska kompetens: Om identifiering och hantering av intressekonflikter i hälso- och sjukvården* (2012). E. Falkenström and A. T. Höglund, *På spaning efter etik: Etisk kompetens och ansvarstagande för ledning och styrning av hälso- och sjukvården* (2018).

[11] E. Falkenström, *Svensk pandemiberedskap i organisationsetisk belysning: Empirisk analys och åtgärdsförslag* (Forskningsrapport 2020:1, Institutet för framtidsstudier, 2021).

[12] See PD 8 (and PD 9) in the list of analysed documents at the end of this chapter.

the main purpose of the new order? Who would gain from it, and who would lose? What possible risks could such new regulations and recommendations entail?

Ethical deviations and risks in the PDs

As pointed out by the authorities before COVID-19, the purpose of Swedish crisis preparedness, pandemics included, is to protect the life and health of the population, the functionality of society and the ability to maintain our fundamental values such as democracy, the rule of law and human freedoms and rights. In event of a pandemic, society's overall goal is to minimize mortality and morbidity in the population, as well as to minimize other negative consequences for the individual and society.[13] These sentences refer to and confirm the well-established ethical and democratic value system in Sweden. They also point to a clear target of orientation for all actors within the healthcare system.

Yet, in significant respects, some of the PDs produced during COVID-19 deviated from the well-established ethical goals and values in the Swedish society. For instance, although one purpose of these PDs was to be able to provide good care and care based on individual need, the emphasis was on older people's ability to cope with a certain treatment (intensive care) rather than assessing individual's need for care.[14] In this regard, the PDs contained ethical values and principles which deviated not only from professional ethics and the established ethical values and goals in society but also from the ethical underpinnings emphasized in the PDs produced by the authorities before COVID-19.[15] This appears to be particularly problematic since the recommendations were also aimed at municipal health care, which does not have the same knowledge of and experience in applying the prioritization platform compared to regional health care.

The PDs produced during COVID-19 also contained internal contradictions. On the one hand, the frail, multimorbid elderly were pointed out as the patient group that was hardest hit by COVID-19, and on the other hand, they were presented in the PDs as a group of patients who as far as possible should be kept away from the hospi-

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[13] See PD 1 in the list below.

[14] See PD 8; PD 11; PD 12.

[15] See for example PD 1.

tals, where the most advanced medical care is provided. Although they share in common the fact that they are older, these are persons with individual needs and conditions, hence singling them out as a patient group makes the issue even more ethically problematic. In an uncertain, emotionally stressful and chaotic situation during a serious pandemic, such contradictory guidelines may have ethically undesirable consequences. For example, sufficient individual considerations may not be taken.

Despite the explicit purpose and good intentions to support decision-makers during COVID-19, other problematic aspects of ethical importance were also found in the PDs produced after its outbreak. For instance, the National Board of Health and Welfare argued that their new principles for prioritization in intensive care under extraordinary conditions were based on the ethical platform decided by the Parliament, which put the principle of human dignity first. But the new principles deviated from the ethical platform. On the one hand, the PD stressed that the principle of human dignity does not allow prioritization based on the patient's chronological age, social situation, or functional impairment, nor based on whether the patient had contributed to their own condition. On the other hand, the reasoning in the PD appeared to go against the principle of human dignity. Well-established ethical goals and values tended to be relativized and reduced. This deviation was justified in a footnote:

Normally, the measure's patient benefit is assessed based on the parameter's life span and quality of life. In this situation, it is impossible to assess the patient's future quality of life, therefore the principles only focus on life span. (PD 8, p. 8.)

In the same PD, the National Board of Health and Welfare also pointed out that an assessment of biological age requires that various factors be weighed together, which according to the authority could be done using established estimation scales. The National Board of Health and Welfare then presented its new and stricter order of medical priority-setting, where expected remaining life span was placed at the centre. It is important to be reminded that this PD was also directed to municipal health care, where many are temporarily employed and lack medical training. Also, the municipalities are not allowed to employ medical doctors. The emotionally stressful circumstances during the pandemic may have increased the uncertainty regarding the care of elderly people. For example, was it ethically justifiable or not to refrain from sending elderly people with COVID-19 to emergency hospitals, where doctors make the final prioritization decisions? Yet another risk was that, even though individual medical assessments were advocated in several PDs aimed at municipal care, it was repeatedly emphasized that it would be an advantage if these assessments could take place remotely. The authorities also recommended that doctors use the Clinical Frailty Scale (CFS) as a guide to assess medical needs and benefits of care (if the doctor had sufficient knowledge and experience with the tool). Possible risks of the use of CFS during COVID-19 were not highlighted in the PDs, however. For instance, what effect might the prevailing work situation have had on the individual medical assessment guided by the new and stricter principles? It may further be risky if the doctor does not know the actual patient and in such a stressful situation must rely on information from others, such as a nurse in a local nursing home with whom the doctor may never have spoken before. In the National Board of Health and Welfare's PD *Working methods in municipal health care in case of COVID-19*, reference was also made to CFS and the National Board of Health and Welfare's PDs with national principles for prioritization.[16] At the same time, there was a lack of reference to the statutory prioritization platform, definitions of its ethical principles and clarifications of which values, according to this prioritization order, should be superior to other values. Consequently, there is a risk that these circumstances have propelled unethical actions in the caregiver organizations. This result is also supported by the many reported experiences of deficient care of elderly people in Sweden, which was obviously not based on the principle of human dignity nor on the principle of care based on need.[17]

Vulnerabilities were not sufficiently reduced

Considering the long-term organizational deficiencies in Swedish health care, the new and stricter national principles for priority setting – which were hurriedly produced in the spring of 2020 – can be understood as a well-founded concern that the actual resources in the healthcare system would not be sufficient for the medical needs

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[16] PD 8, PD 9.

[17] For instance, experiences reported by media, authorities, and the Corona Commission.

related to COVID-19. Hence, the new principles seemed to be motivated by the current resource shortage situation, combined with the extensive spread of infection. A certain context-sensitivity is thus apparent. Nonetheless, the fact that the long-term problems related to the organization and structures of health care have not been rectified implies that risks and vulnerabilities were not sufficiently reduced by regions and municipalities in line with previous policy and directives on crisis preparedness in the time between pandemics.[18] Instead of taking necessary and sufficient measures in time at the organizationally superior levels, increased pressure was put on the already overloaded healthcare staff when the severity of COVID-19 became evident. This is where the new principles enter the picture. Of course, this also had negative consequences for patients such as the multimorbid elderly group, who were kept away from the hospitals. This indicates that the authorities' regulations and recommendations regarding crisis/pandemic preparedness were not complied with.

Were the new principles used for the wrong purposes?

The regions are responsible for meeting their citizens' need for care, and they have independent taxation powers.[19] It is thus in their interest that resources and care places be adequate, and that they can justify their decisions on resource allocation. Technically, the PDs containing new and stricter principles for prioritizing care needs during COVID-19 could have been used with the unspoken purpose of showing that the care places were sufficient rather than preventing a shortage of competent staff. If this was the case, it means that the interests of a region outweighed those of the citizens or certain groups of patients in terms of receiving care based on need. *Yet, the purpose of the Swedish platform for priority-setting is not to compensate for a potentially inadequate distribution of resources in the regions or society.* It is to distribute resources based on need and to organize care queues in accordance with the purpose of health care. However, based on the original analysis,[20] there is an obvious risk that the principles of stricter priorities, together with the instructions to municipal

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[18] PD 1, PD 5, PD 6, PD 7.

[19] Blomqvist, P., & Winblad, U. (2021).

[20] Falkenström, E. (2021).

health care on care flows[21] and recommendations concerning medical assessment of the elderly's need for care, primarily served this interest of the region. That is to say, they may have been used to prevent a shortage of care places (which is not necessarily the same as having sufficient number of care places relative to the actual need for care) and thereby to hide an earlier failure to take responsibility. Also, this may have contributed to the group identified as the most vulnerable and hardest hit by COVID-19 being sacrificed in the actual pandemic response.

Conclusion

Overall, the analysis of PDs implied that Swedish healthcare providers may have had insufficient organizational action conditions (OAC), political guidance and administrative support to act ethically in relation to the expressed purpose and goals of the Swedish preparedness for crises and pandemics. In some cases, the guidance even appeared counterproductive. The whole idea of pandemic preparedness is to be prepared when the next unknown health crisis occurs. But rather than reducing well-documented structural risks and vulnerabilities in advance, ensuring that necessary and sufficient resources were in place – and ensuring that established ethical principles (such as the prioritization platform) were well known and legitimate at all decision-making levels – new and higher demands were put on healthcare providers during COVID-19. This is why organizational ethics in health care matter. Ethical values and principles should shape the ideal practice. They should form the basis of how organizational functions and policy are designed and how resources are allocated. They should not be devalued or adjusted relative to a shortage situation caused by insufficient actions and failure to take responsibility at superior levels in the healthcare system. Policymakers also need to understand the social and organizational context in which the recipients of their PDs operate. If such an understanding is lacking, there is a risk that the PDs may be misunderstood, having unintended or counterproductive effects, or they may simply be impossible to comply with. It is not primarily new ethical principles that are needed but rather a willingness among policymakers to let the existing and

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[21] PD 12.

well-established ones guide the design of the healthcare system. Finally, moral philosophers should not always accept the premises. Instead, they should be more interested in the contextual conditions that produce the insufficiency that their ethical principles are supposed to remedy.[22]

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8 The Corona Commission and the Precautionary Principle[1]

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Introduction

The Corona Commission was appointed by the Swedish Government in 2020, tasked with evaluating Swedish authorities' handling of the pandemic.[2] In its report, the Corona Commission criticises the Government's predominantly evidence-based strategy during the pandemic.[3] One of the Commission's main conclusions is that the requirement in the Communicable Diseases Act (2004:168) that disease prevention and control measures must be based on 'science and proven experience' is inappropriate when scientific knowledge is limited.[4]

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[1] We would like to express our sincere gratitude to Marianne Thormählen for her proficient and generous proofreading of this chapter.

[2] Regeringskansliet, Dir. 2020:74, Utvärdering av åtgärderna för att hantera utbrottet av det virus som orsakar sjukdomen covid-19 (2020).

[3] SOU 2022:10, *Sverige under pandemin* (Statens offentliga utredningar, 2022), pp. 620–22.

[4] SOU 2022:10 p. 669.

According to the Commission, the current principles of crisis management should be supplemented by a precautionary principle[5], which, in the Commission's version, is a 'principle of action', 'an obligation to act even in the face of great uncertainty about a threat or risk'.[6]

In Swedish law, the notion of 'science and proven experience' defines the standard of evidence for decision-making, policy and practice in areas as diverse as medicine, education, environmental risk assessment, veterinary care and social care. In this chapter, we will discuss the Corona Commission's arguments for abandoning this gold standard in favor of a precautionary principle. As we will discuss in detail below, the Commission's 'principle of action' seems to us to be a problematic version of the precautionary principle, and especially so if used to guide disease control. We are not convinced that a future application of this principle would lead to the results that the Corona Commission expects. Moreover, we believe that many of the concrete measures proposed by the Commission would have been possible to take without abandoning the requirement for science and proven experience.[7]

The precautionary principle – a principle with many (more or less problematic) faces

Before adopting a position on the Corona Commission's conclusion that a precautionary principle should guide infectious-disease control when faced with scientific uncertainty, one should first be aware that the precautionary principle lacks a single and unequivocal meaning. Swedish philosopher Per Sandin has shown that the precautionary principle comprises several variables, or 'dimensions'. The meaning of a particular version of the principle varies accordingly and depends, inter alia, on the lack of evidence (or uncertainty) that is required to trigger its application, and on how serious the feared threat has to

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[5] SOU 2022:10 pp. 662–663.

[6] SOU 2022:10 pp. 621, 670 f.

[7] This text was written and proofread in 2023. It was not possible to include any publications or developments that occurred after this date. It is worth noting, however, that SOU 2025:48 reaches similar conclusions to ours. The Corona Commission's application of the precautionary principle has also been criticised by Anders Nordgren. Unlike us, Nordgren does not focus on the value of evidence, but instead highlights the principle's lack of clarity and proposes a framework for specifying it in relation to pandemics. (A. Nordgren, 'Pandemics and the Precautionary Principle: an analysis taking the Swedish Corona Commission's report as a point of departure', *Medicine, Health Care and Philosophy* 26, 2023).

be. Moreover, different versions of the principle allow for different kinds of intervention. In some instances, the principle expresses a freedom to act, while in other contexts it is instead formulated as an obligation to act.[8]

The Corona Commission's version of the precautionary principle should be seen in this light. In the Commission's definition of the principle, it says that "in responding to a threatening situation when the information available is highly uncertain and incomplete […] decision-makers […] should not passively wait for a better understanding, but actively take steps to counter the threat".[9] The Commission also explicitly refers to the principle as a 'principle of action'.[10] The Commission's version of the precautionary principle therefore gives the decision-maker a comparably powerful mandate, amounting to an obligation, to adopt more or less far-reaching measures in situations of knowledge uncertainty, without evidence, without science and proven experience.

The precautionary principle can be more or less problematic depending on how it is interpreted and the contexts in which it is applied. One situation in which intervention appears unproblematic is when the danger is great but the risk of its actually materialising is small, at the same time as the cost of acting to effectively counteract the danger is limited. In a situation such as this it is strictly speaking not even necessary to invoke a precautionary principle, since even a mere comparison of the expected benefits of different alternative courses of action indicates that intervention is justified. Another situation where appeal to a precautionary principle appears reasonable is when it is uncertain but possible that something (such as a new but not very helpful technology) is dangerous, but the cost of counteracting the potential risk (by not using the technology, for example) is low. Again, the same course of action can be justified by comparing the expected benefits of different alternatives. In these situations, the precautionary principle is harmless and does not conflict with a traditional expected-utility analysis.

However, it is significantly more problematic to appeal to the precautionary principle to justify intervention when the intervention may constitute a risk in itself. In such a situation, a precautionary

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[8] P. Sandin, 'Dimensions of the Precautionary Principle', Human and Ecological Risk Assessment: An International Journal 5 (1999).

[9] SOU 2022:10 p. 18.

[10] SOU 2022:10, see for example p. 621 and pp. 671 et seqq.

principle can potentially be used as an argument in favour of both intervention and non-intervention. It does not say which of these two alternatives is preferable. In such situations, therefore, the precautionary principle provides no real guidance but may potentially be dangerous by seemingly justifying nearly any intervention. This is illustrated by the observation that many of the measures taken by policy makers outside Sweden during the pandemic – school closures, lockdowns, restrictions on business activities, curfews, etc. – are interventions that have had significant unfavourable effects on people's cognitive and social development, education, well-being and health etc., in addition to foreseeable negative economic effects. The possibility that these interventions could lead to unfavourable effects was foreseeable at the time when the measures were taken. In this situation, therefore, a precautionary principle could have been used as a justification not only for intervening but also for not intervening.

The Corona Commission's approach to overcoming these limitations is to understand the precautionary principle as a principle of action, "an obligation to act even in the face of great uncertainty about a threat or risk".[11] The Commission thus appears to assume that active interventions are always preferable to non-action. We have at least two objections to this approach. The first objection is that it is problematic to make a conceptual distinction between active measures and passivity: not only closing schools and shopping centres is an active measure; so is the decision to leave things as they are, keeping them open. Our second objection is that the Corona Commission's action principle raises, but leaves unanswered, the important question of why it would be better to actively adopt a certain course of action than to refrain from it, when the situation is such that we have no evidence that the relevant course of action would lead to a better outcome. Active interventions that are not based on science and proven experience can have unforeseen and far-reaching negative consequences; and in these situations, we fail to see what justifies the Commission's preference for action over deliberate inaction or thoughtful passivity.

These are not the only reasons why we are doubtful about using the Corona Commission's version of the precautionary principle as a guide for action in future pandemics. There are also specific aspects of infectious-disease control that, in our view, make the application

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[11] SOU 2022:10 pp. 621, 670.

of the precautionary principle in that context particularly problematic. One such aspect concerns the question of who bears the cost of an intervention that is based on the precautionary principle. In some applications of the precautionary principle, the costs associated with the principle will first and foremost burden those who prompt, and have something to gain from, a potentially dangerous activity. For example, the well-known Wingspread Declaration formulates the principle as follows: "Where an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically. In this context *the proponent of an activity*, rather than the public, *bears the burden of proof*."[12] In a similar vein, the version of the precautionary principle in Chapter 2 Section 3, Paragraphs 1 and 2 of the Swedish Environmental Code (1998:808) says: "[P]recautions shall be taken [by *the operator* to combat damage] as soon as there is cause to assume that an activity or measure may cause damage or detriment to human health or the environment" (italics added). Both these formulations imply that the costs associated with the principle should be borne by the person who wants to carry out the activity and who primarily has something to gain from it. It does not follow that the precautionary principle is as reasonable in situations where no such person can be identified, and where the costs of the application of the principle must instead be borne by individuals who have not prompted, nor have anything to gain from, the danger to be mitigated by the measures. There is therefore also a distribution dimension to the precautionary principle, and this dimension may be more or less unjust depending on the context. As far as we know today, no one has introduced the coronavirus to line their pockets. The Corona Commission's proposal to apply the precautionary principle in this situation appears to be more problematic than an application where the costs fall on those who are responsible and have something to gain from a potentially dangerous activity.

It is also interesting to note that the Corona Commission's version of the precautionary principle seems to attribute less value to knowledge than the Wingspread Declaration and the Environmental Code. The latter two can be read as a call to use caution and acquire knowledge before doing something you may regret in situations where knowledge is lacking. In contrast, the Corona Commission's prin-

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[12] Wingspread Statement on the Precautionary Principle (1998), italics added.

ciple of action can be read as a call to do something that is believed to be good even if there is no evidence for it. The comparison may not be entirely fair, as the Commission's principle is presumably aimed at emergency situations that need to be dealt with immediately (although this is also problematic and is not clear from their definition of the principle). Even so, the comparison does serve as an important reminder that a precautionary approach does not necessarily imply taking immediate action but may consist in waiting for more and better knowledge, when the information available is highly uncertain.

Another complicating aspect concerns the nature of the costs of applying the precautionary principle. In certain situations, an application of the principle primarily entails an economic cost. For example, to illustrate the plausibility of the principle, the Corona Commission refers to the former Swedish Disaster Commission's[13] description of the utilisation of resources in various operations: "The Swedish Disaster Commission aptly described how, at an everyday level, this principle guides fire and rescue operations. The basic rule in that context is to deploy sufficient resources for a relatively major incident and subsequently stand some of them down if it turns out that they are not needed."[14] It is easy to concur that, in the event of an accident, it makes sense to send out more resources than one is sure are actually needed. However, the plausibility of a 'better safe than sorry' approach in rescue operations is not necessarily extrapolatable to infectious-disease control. Hence, the analogy limps. In fire and rescue operations, the costs of a precautionary approach are primarily economic. In the area of infection control, on the other hand, the costs of the interventions in question are not only financial, but also consist of reduced freedom and well-being, lack of education, loneliness, etc. It is far from obvious how we should balance this type of cost against the benefit in the form of the reduced spread of infection that various interventions may provide. In this respect, too, an application of the Corona Commission's precautionary principle in the field of infection control appears to be more problematic than in some other areas.

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[13] SOU 2005:104.

[14] SOU 2022:10 p. 19.

Would an application of the precautionary principle have yielded the answers the Commission believes it would have done?

In the Corona Commission's view, Swedish authorities should have taken several concrete precautionary measures during the pandemic. To begin with, people returning from winter breaks by the end of February 2020 should have been met by more active reception arrangements and provided with clear information and instructions to home-quarantine for at least seven days. Moreover, a temporary ban on entry to Sweden and temporary closures of a number of indoor settings should have been implemented by March 2020 at the latest. According to the Commission, however, it was right to keep preschools and compulsory schools open and switch to distance teaching at upper-secondary schools and universities.[15] The Commission also says that it is not convinced that extended or recurring mandatory lockdowns, as introduced in many other European countries, would be a necessary element in the response to a *new* pandemic.[16] The Commission does *not* say, however, whether it would have been right to introduce lockdowns in Sweden to the extent that occurred elsewhere, given the state of knowledge during the *COVID-19* pandemic.

We do not dispute that the measures identified by the Corona Commission could have been taken on the basis of the Commission's version of the precautionary principle. The Corona Commission's principle of action could presumably be used to justify most measures. We find it more difficult to see how the Corona Commission could maintain its adherence to this principle and at the same time come to the conclusion that it was right to keep preschools and compulsory schools open. On the contrary, given the information that was available at the beginning of 2020, closing preschools and compulsory schools seems to us to be fully in line with the Corona Commission's version of the precautionary principle. The Commission's argument for nevertheless not doing so is that many experts at the time assumed that children rarely became seriously ill and probably did not contribute to the spread of infection. Reasoning hypothetically, the Commission says that on the basis of the knowl-

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[15] SOU 2022:10, pp. 602 et seq.
[16] SOU 2022:10, p. 643.

edge available at the time, a closure of preschools and compulsory schools would have had to be carried out with the intention of protecting elderly people from serious disease, not with the intention of protecting children. According to the Commission, such a strategy would not have been justified, "as infectious-disease-control measures targeting a particular group [in this case, the group of children] require [...] very strong reasons unless the measures are primarily intended to protect that particular group".[17] It is telling that the Commission, in order to come to the conclusion that it was correct to keep schools open, needs to supplement its version of the precautionary principle in this line of argument with a kind of 'group membership' principle that limits the extent to which infectious-disease-control measures may target a particular group. Although a group-membership principle might explain why schools should not have been closed, despite the Corona Commission's precautionary principle appearing to recommend this, the moral grounds for kindred principles have been disputed.[18] The Commission does not explain on what moral grounds a group-membership principle would be justifiable in this context.

A clear-cut test of the Commission's precautionary principle is to ask how it relates to the lockdowns imposed in many of the countries that, unlike Sweden, claim to have applied a precautionary principle, instead of a requirement that their infectious-disease-control management must be based on science and proven experience. Unfortunately, as already noted, the Commission does not say whether it would have been right or wrong to introduce extended or recurring lockdowns during the corona pandemic, given the knowledge available at the time. The Commission *does* say, however, that it is not convinced that such a lockdown will be necessary in the event of a new serious pandemic.[19] For our part, we find it difficult to see how anyone could come to the conclusion that it would have been wrong to introduce extended or recurring mandatory lockdowns if we take the Commission's version of the precautionary principle seriously. Nor can we see on what grounds the Commission concludes, on the basis of today's experiences, that extended or recurring mandatory lockdowns are not warranted in the event of a new pandemic. What

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[17] SOU 2022:10, p. 607, our translation.

[18] L. Broström and M. Johansson, 'Involving children in non-therapeutic research: on the development argument', *Medicine, Health Care and Philosophy*, vol. 17, no. 1 (2014), pp. 53–60,

[19] SOU 2022:10, p. 643.

evidence is there for such a far-reaching claim? It seems premature to take it for granted that the experiences from different countries' handling of the COVID-19 pandemic show that extended and recurring lockdowns have no favourable effect, regardless of how they are implemented or what transmission routes any new virus might have. In our view, the absence of clear answers to these questions is a reflection of the arbitrariness that seems to us to be inherent in the precautionary principle advocated by the Corona Commission.

Could any of the measures proposed by the Commission have been taken without abandoning the requirement for science and proven experience?

Thus, as far as we can see, an application of the Corona Commission's version of the precautionary principle would not have led to the results the Commission claims. Moreover, we believe that some of the concrete measures proposed by the Commission would have been possible to take without abandoning the requirement for science and proven experience. Whether the requirement for science and proven experience is appropriate in situations where scientific knowledge is uncertain depends, of course, on the precise meaning of that requirement. If interpreted as a demand for scientific certainty, the requirement seems to hinder interventions in all situations where the information available is uncertain.

Complete scientific certainty does not exist. If interpreted as a demand for scientific certainty, many of the measures taken in, for example, healthcare (an area where the requirement for science and proven experience is extremely important and a patient-safety issue) would not fulfil this requirement. We have argued elsewhere that the requirement for science and proven experience in health care should instead be interpreted as a requirement for sufficient evidence, in the form of scientific studies and clinical experience, for the safety and efficacy of medical treatments. This interpretation typically implies that the treatments' expected utility for the individual patient must outweigh the risks to which it exposes the patient.[20] If extrapolated to an infection-control context, this interpretation would be read as

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[20] L. Wahlberg and N-E. Sahlin, 'Om icke vedertagna behandlingsmetoder och kravet på vetenskap och beprövad erfarenhet', *Förvaltningsrättslig tidskrift* (2017).

a requirement for sufficient evidence for the efficacy of infection-control measures, to the effect that the expected benefit of these measures must outweigh the risk of unfavourable consequences that they may entail. With this interpretation of the requirement for science and proven experience, complete scientific certainty is thus not necessary to justify an intervention.

We acknowledge that it is not unproblematic to carry out an expected-utility analysis in a situation where the information available is uncertain. Even so, the requirement for science and proven experience does provide us with some important guidelines and limitations in such situations as well. First, unlike the Corona Commission's precautionary principle, an approach based on science and proven experience emphasises the value of knowledge and the need to sometimes acquire additional knowledge before acting. As we have seen above, this is in line with some versions of the precautionary principle in other contexts. Second, our interpretation of the requirement for science and proven experience prescribes that if we have reason to believe that an intervention has significant unfavourable consequences and comes with significant risks (such as in the case of closing schools or lockdowns), the intervention must not be undertaken unless there is sufficiently strong evidence to show that its benefits can be expected to outweigh these risks. Conversely, if we expect the negative impacts of an intervention to be moderate (as may be the case for a recommendation to wear a face mask), less support is required for the expected benefits of the intervention. But in both situations, evidence is required for the intervention to be implemented – the requirement that it be based on science and proven experience does not allow interventions for which there is no evidence at all.

We find it difficult to see that, at the beginning of 2020, there was sufficient evidence that the expected benefits of the closure of compulsory schools, or for that matter of lockdowns, would exceed the unfavourable impacts that such measures risked having. Such measures would hence not have accorded with the requirement for science and proven experience. On the other hand, it seems to us that some of the interventions that the Commission discusses, and whose expected negative effects were moderate – an orderly reception of sports-holiday travellers, online teaching for upper-secondary-school pupils and perhaps even face masks – would have been compatible with a requirement for science and proven experience according to our interpretation. Thus, we do not believe that we need to give up the requirement for science and proven experience in order to be able to act in situations like this, or that lack of scientific certainty is a reason to replace this requirement with a version of the precautionary principle that could be used to justify most courses of action without evidence.

The question of how we should act where knowledge gaps exist has no one right answer

Thus, the absence of complete scientific knowledge does not need to preclude interventions that accord with science and proven experience. As explained above, in our view some of the measures discussed by the Corona Commission could have been justified on the basis of science and proven experience, without having to invoke a precautionary principle. In some cases, however, the uncertainty of the available information is so profound that there is really no evidence at all to justify a particular action. In these cases, too, the introduction of a precautionary principle is neither self-evident nor unproblematic, especially if the principle is formulated in the way proposed by the Commission.

Is the precautionary principle a marker of policy, a normative principle that guides us in how to act (i.e. a decision-making principle) or an epistemic principle that tells us how to deal with situations where there is a great deal of uncertainty in the information available?

The precautionary principle is a vaguely formulated principle. As a marker of policy, its value and the decisions made in the principle's name will be contingent on underlying political values. In other words, there is a risk that the principle will legitimise measures that demonstrate decisiveness rather than rational decisions based on science and proven experience.

In a couple of articles[21], Martin Peterson has analysed the inherent problems of the precautionary principle. Among other things, Peterson shows that the precautionary principle and three principles of rational decision-making are logically incompatible. The precautionary principle clashes with our notions of what a rational decision is. The Corona

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[21] M. Peterson, 'The precautionary principle is incoherent', Risk Analysis 26 (2006); M. Peterson, 'The precautionary principle should not be used as a basis for decision-making', EMBO Reports 8 (2007).

Commission thus seems to advocate that we should not manage uncertainty and risks in a rational way; and it does so without giving us good reasons why prevailing scientific theories of rational, i.e. sensible, decision-making and risk-taking should no longer be applied.

Maximising utility and, if in doubt, maximising *expected utility* are two rules for decision-making that theories of rational decision-making unanimously recommend. These theories teach us that, given what a rational decision-maker knows and their values, they will choose the option that maximises the (expected) utility. But to be able to make such a choice, the knowledge and values of the decision-maker must be quantifiable. It must be possible to say in numbers how good a certain outcome is, and how likely it is that the outcomes relevant to the decision will in fact materialise.

The problem is that we may lack sufficient information to be able to calculate these figures with the desired precision. The Public Health Agency of Sweden's difficult task of issuing recommendations during the pandemic was partly an expression of this problem. The uncertainties in the available information that the Agency struggled with, the lack of robust scientific evidence and sound proven experience, must have made its decision-making complicated. Knowledge gaps, evidence that perhaps points in different directions, and values that are not clear mean that the traditional theory of rational decision-making cannot be applied without further ado. During the pandemic, our decision-makers were often in this predicament. The reason for the dilemma is that with a lack of evidence and experience, it is difficult to put precise numbers on the likelihood of something happening. The best you can do, if you want to be completely honest, is to specify some range of uncertainty. With deep uncertainty in knowledge and values, our knowledge and values only expressible in terms of probability and utility intervals, it is no longer possible to maximise the expected utility – the classic rule for decision-making is no longer useful.

Consequently, another type of theory is needed to guide the decision-maker in situations of deep uncertainty in terms of knowledge and/or values.[22] In recent decades, theories have been developed that

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[22] N-E. Sahlin, 'Unreliable probabilities, paradoxes, and epistemic risk', in S. Roeser, R. Hillerbrand, M. Peterson and P. Sandin (eds), *Handbook of Risk Theory: Epistemology, Decision Theory, Ethics, and Social Implications of Risk* (Springer, 2012); N-E. Sahlin and S. Schwaag Serger, 'Decision-making in a time of spin and unspoken values', in M. Benner, G. Marklund

should be able to deal with the types of problems mentioned above. However, it has been shown that when the uncertainties are themselves uncertain, there are many competing rules for decision-making. As already mentioned, the rule of maximising expected benefit is no longer an option. Different decision rules may, when applied to the same situation, recommend the same course of action, different courses of action, or completely fail to identify any course of action at all. If there had been a 'meta' theory with the help of which we could choose a rule for decision-making depending on the nature of the knowledge uncertainty and lack of clarity, the problem would have been solved, but such a theory does not exist and seems impossible to formulate.

The problem may appear more serious than it is. In the individual case, in practice, it is fairly easy to apply several generalised rules for decision-making to the same problem. If the recommendation is the same, it is clear: choose the proposed course of action. If different courses of action are recommended, the theories also tell us why and provide us with guidance. But in the latter cases, we need to clarify our values before choosing one of the options, why we prefer one rule for decision-making over the others.

This procedure is quite different from applying the type of precautionary principle proposed by the Corona Commission. The theories mentioned say that in situations where there is a great deal of uncertainty in the available information, and no course of action is immediately supported by science and proven experience, we should carefully analyse the state of knowledge, our tools for making decisions. We need to compare the basis and recommendations of alternative rules for decision-making and make transparent how we decide to decide. Such an approach in itself lies much closer to the requirement of a basis in science and proven experience than to the Commission's precautionary principle. In contrast to a principle which encourages arbitrary action, we should not make choices in order to demonstrate decisiveness.

The limitations of utility maximisation are illustrated by the discussion of prioritisation issues during the pandemic. At a conference in 2021, Peter Singer and Katarzyna de Lazari-Radek gave the intro-

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and S. Schwaag Serger (eds), *Smart Policies for Societies in Transition: The Innovation Challenge of Inclusion, Resilience and Sustainability* (Edward Elgar Publishing, Cheltenham, 2022).

ductory lecture on 'What ethical theories tell us'.[23] They argued against the kind of principles – human dignity, needs and solidarity – that underpins the Swedish prioritisation platform in healthcare: We should maximise benefits, not let human dignity, needs and solidarity guide priorities. And if there is uncertainty, the expected benefit should be maximised. But even in prioritisation situations, the uncertainties may be uncertain; we can have both great knowledge uncertainty and great value uncertainty. Then the utilitarian can no longer maximise (expected) utility (same problem as above). What do Singer and de Lazari-Radek do then? The only way out is to rely on other principles. But which principles? The ones mentioned have been dismissed by Singer and his peers. This is the utility-maximising utilitarian's ethical dilemma of prioritisation.

The value of science and proven experience

In our opinion, the Corona Commission has too readily abandoned the requirement for science and proven experience in favour of a problematic version of the precautionary principle. The most natural argument for maintaining a requirement for science and proven experience is, of course, that measures based on knowledge typically have better prospects of leading to the intended result and are less likely to have negative consequences than measures that do not have such support. Consistency with science and proven experience thus tends to support effectiveness.

Maintaining the requirement of science and proven experience is valuable for other reasons as well. The knowledge that an edict is based on science and proven experience is likely to promote people's willingness to follow the edict, compared to one that is plucked out of thin air. In contrast to measures based on a precautionary principle, measures based on science and proven experience also make it possible to explain the mechanisms more clearly and provide a mental model of *why* a certain behaviour is needed, which has been shown to be a relevant factor in changing people's behaviour.[24] A requirement for a basis in science and proven experience also includes a require-

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[23] Swedish National Council on Medical Ethics (Smer), What Ethical Theories Tell Us? (web film), https://www.youtube.com/watch?v=0XcRnsbPdVQ. Visited 2025-08-14.

[24] A. Wallin, 'Okunskap och riskkommunikation: Att knuffa eller ge en karta', *Statsvetenskaplig tidskrift* 123 (2021).

ment to be able to produce evidence that the measure advocated is likely to achieve the intended goal, which in itself limits the scope for arbitrariness and abuse of power.[25] Requirements for knowledge, in the form of science and proven experience, thus have a value in this way as well. In light of this, requiring interventions to be based on science and proven experience, and waiting for more knowledge when the available knowledge is uncertain and we are able to wait, are in our opinion reasonable and prudent starting points which we should be careful not to abandon. Taking action rather than not acting when knowledge is lacking is, in our view, neither reasonable nor prudent.

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[25] L. Wahlberg, 'Om värdet av vetenskap och andra belägg vid pandemiskt beslutsfattande', *Statsvetenskaplig tidskrift 123* (2021).

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9 Doing good in the eye of a storm

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Introduction

Never in modern times have the ethical challenges in healthcare been more striking than during the COVID-19 pandemic, especially during the initial phase when knowledge about the virus's characteristics and how to treat it was extremely limited, as well as how to treat the large numbers of patients who sought care.

All professions in the healthcare system were faced with difficult ethical questions in a novel way with no authoritative answers being available. The point of departure of this article is the medical profession, since both of its authors are physicians. However, we are very much aware that everyone who worked in healthcare or care of older people was faced with either similar or profession-specific ethical challenges. Therefore, the line of reasoning in this text ought to also apply to the situation of other professional groups.

It is routine for physicians to make many decisions regarding individual patients, which is why physicians are very experienced in making medical decisions at the individual level, and they gain increasing confidence in this as their professional experience grows. However, physicians are not always as well equipped to see their role in the structural ethical issues that are also routine in healthcare. This can mean having the big picture in mind when it comes to setting priorities in routine healthcare – something that has always existed and always will. Although the need for healthcare in the medical sense is a finite phenomenon, conversely the *demand* for medical care does not seem to have any upper limit. Depending on where you work in the healthcare system, constant questions about setting priorities arise. Of all the physician's patients, which have the greatest need and thus the right to draw on their time and attention?

Of course, this is not a question that can very well be answered in every new patient situation. However, for the current ethical platform for priority setting[1] to be efficiently implemented, this question must be consistently integrated into planning time allocation, and prioritising between patients and between different levels of intervention – in the emergency department, in the queue to get surgery, at the primary care health centre, or in the physician's interventions in the care of older people.

When COVID-19 became a fact in the Swedish healthcare system, the situation rapidly changed in these respects. Admittedly, the Public Health Agency of Sweden initially played down the risk of widespread infection, but it was not many days before everyone who worked in Swedish healthcare was facing a situation that was entirely new for most of them. The priority setting issue was debated early in the pandemic, but it was not the only ethical issue that came to light.

In the following analysis, we have chosen to limit our discussion to the medical ethics challenges that arose in the directly clinical setting.

Professional ethics

Basically, there are no specific ethical theories or values that are only valid for a particular profession or field of work. On the other hand, at times some ethical conflicts and ethically challenging situations do arise in a profession-specific way, which can then form the basis

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[1] The ethical platform for priority setting in Sweden consists of three key ethical principles in descending order of priority: (1) Principle of human dignity, ensuring equal human values and rights; (2) Principle of need and solidarity, ensuring distribution according to the greatest needs; (3) Principle of cost-effectiveness, ensuring reasonability between costs and effects. 1996/97:SoU14.

for formulating ethical guidelines for the profession. The duties a profession is required to perform are the starting point for professional ethics: the goals that professionals are to attain, and the values they are to embody. In order to do this, good, up-to-date medical knowledge about the body's functions and the manifestations and treatment of diseases needs to be combined with a moral awareness and the capacity to reason in an ethical way. We argue that 'professional ethics' consists of primarily the following three components:

Legal and public administration frameworks

All professionals must practise their profession based on the relevant legislation and regulatory frameworks of various kinds including acts, ordinances and regulations issued by the Riksdag (the Swedish parliament) or by the various government agencies with responsibilities for the healthcare sector. This constitutes the legal framework that everyone who works in the healthcare system must be aware of and comply with. In addition to these rules, a number of guidelines have been published in recent years at different levels within the healthcare system that aim to put into practice policy and/or professional ambitions such as greater freedom of choice, exposure to competition, evidence-based care, and efficiency in the healthcare system.

The number of rules that govern the healthcare system has undoubtedly increased in recent years and it is no easy task for the individual professional to be fully across all of these rules. Nevertheless, no one can escape these requirements.

The legislation contains several ethical principles. They are not always clearly formulated in the legislation. Examples include the introductory sections of the Health and Medical Services Act (HSL). One such is Section 1, Chapter 3, which stipulates that "Health and medical care must be provided in ways that respect the equal value of all people and the dignity of the individual. Those with the greatest need for health and medical care are to be given priority". This rule applies generally in health and medical care and must be applied without exception. This fundamental principle is also repeated verbatim in the Patient Act, which also regulates matters such as access to healthcare, information, informed consent, and patient participation in the decisions governing their care.

It is highly likely that most citizens, at least at a fundamental level, would assent to the principle of the equal value of all people and that needs should guide priorities in health care. The person with the greatest need for care and with the most serious illness should be given priority over others with less serious or non-acute health problems. However, it is not always easy to put this principle of need into practice in the presence of political decisions that conflict with this principle. These include healthcare guarantees of various kinds, freedom of establishment, or the option of separate queues for appointments for care funded privately or by private health insurance.

However, it is not entirely clear what is meant by a need for care in this context. The legislative history shows that it is the medical need that is intended to guide the setting of priorities in the healthcare system and nothing else. However, this principle has been challenged in recent years by a policy direction in which the demand for care, rather than the need for care, has become more heavily emphasised. This may seem strange, since it is common knowledge that resources in the healthcare system are finite and that prioritisations must always be made. This phenomenon can be seen as a balancing act between providing care based on need (which is a key value of professional ethics in this area) and retaining the confidence of large voter groups in publicly funded healthcare (which can be experienced as a political necessity).

Basic ethical principles

Medical ethics, which is a branch of philosophy, has roots in the writings of Hippocrates from the 4th century BCE onwards. While it is an academic discipline that rests on a theoretical foundation, it has practical implications that can be studied empirically. There are usually two overall goals for ethical action: to do good, and to do right. Generally, these are compatible goals, but in discussions on medical ethics, it is apparent that different stakeholders tend to lean one way or the other in their reasoning in this regard.

Four principles, which were formulated in 1977 by Beauchamp and Childress[2] have since become the norm as the pillars of a matrix

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[2] T. Beauchamp & J. Childress, *Principles of Biomedical Ethics* (Oxford: Oxford University Press, 1977).

for medical ethics: autonomy, beneficence, non-maleficence, and justice. Beneficence and non-maleficence are principles that can be traced back to Ancient Greece, while autonomy and justice are principles of a much more recent period, formulated primarily after the Second World War.[3]

These principles are intended to serve as a basis for thinking and practical action in health care. They are the result of what previously prevailed – an ad-hoc style of medical ethics based on individual cases – being replaced by reasoning of a theoretical and philosophical nature. In practice, however, it is not always possible to abide by these four principles simultaneously – they can often come into conflict with each other. For example, patient autonomy may conflict with upholding the principle of distributive justice in setting priorities and may even run counter to doing good when a patient declines an effective treatment that the physician proposes.

There is, assuredly, rather extensive criticism of why these four principles have become so dominant in medical ethics, as there are many other principles that could also be highlighted as alternatives or supplement these four principles. For example, increasingly over roughly the last 15 years, Smer[4] has only rarely used these four principles exclusively in its analyses. Instead, the principles and values that are most relevant to the problem being examined are identified.

Professional ethics guidelines

Many health-care employee organisations have developed ethical guidelines for their members. These are necessarily of a rather general nature. Our assessment is that these guidelines were not particularly helpful in the situation brought on by the pandemic. Nor have we been able to find pandemic-specific guidelines from any organisation for employees in the healthcare system. The message to members of these organisation was instead a call for compliance with the authorities' recommendations. The impression one is left with is that they left it up to the authorities to provide an ethical reflection on the situation, which in retrospect can be seen as inadequate. In particular, we can see a potential benefit in providing ethical guidance that

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[3] B. Varkey, 'Principles of clinical ethics and their application to practice', *Medical Principles and Practice*, 30(1), 2021, 17–28, doi.org/10.1159/000509119.

[4] The Swedish National Council on Medical Ethics.

had the support of health-care employees, and preferably had been co-produced through cross-professional partnering between occupational groups in health care. The latter in particular would reduce the risk that different occupations/professions might come up with different recommendations and guidelines.[5] Similarly, there is a need to ensure that ethical guidelines from professional organisations do not conflict with the applicable law. This is always a requirement of course, which in a pandemic situation may need to be pointed out much more, as legislation that is rarely applied may become relevant. It is best if ethical guidelines intended to provide guidance under extreme and unusual circumstances are worked out during periods of more normal situations in health care, since there is then greater scope for reflection and garnering support for the guidelines.

New ethical challenges

What then were the new ethical challenges that the pandemic brought with it, that differed from those that exist under normal circumstances?

Here, two categories of challenges can be identified: qualitative challenges concerning entirely or somewhat new questions; and quantitative challenges that primarily concern questions of the prioritisation of resource allocation.

Decisions based on limited knowledge

One of the most obvious qualitative challenges, especially at the beginning of the pandemic, was the lack of knowledge. Such situations also arise in routine healthcare, but this was a new and previously unknown pathogen with the capacity to spark a pandemic. The Public Health Agency of Sweden, WHO and the European Centre for Disease Prevention and Control (ECDC) were initially largely at a loss to know what to do, although it was obviously known that pandemics can and will occur. The fact that the virus also first appeared in China, which initially chose to play down the problem and limit international scrutiny, did not make the situation any easier. Experiences

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[5] A study of public and professional guidelines developed in the UK found 29 such guidelines. A content analysis of these guidelines revealed that they were often of a rather general nature and not always congruent or free of objections. Varkey, B. (2021).

from previous viral epidemics such as swine flu and avian flu could be used as a base, but the SARS-CoV-2 virus behaved differently.

Svenska Infektionsläkarföreningen (SILF), Swedish Society of Infectious Diseases, along with *Svenska Läkaresällskapet* (SLS), the Swedish Society of Medicine, took a clear lead early in the pandemic in developing professional knowledge, which they shared through weekly webinars that provided scientific updates to physicians working in various specialties within the healthcare system. Several other specialty associations, such as the Swedish Association of General Practice, also started equivalent fora for information and knowledge sharing. Online communities also emerged where physicians and nurses shared experiences and supported each other.

The growth in international scientific knowledge was exceptionally strong right from the early stages of the pandemic. Many of the major scientific journals ended up applying new strategies for publishing research results, which includes many journals providing platforms where pre-prints of accepted articles could be published quickly and expediently. There were also open scientific platforms where articles not yet peer-reviewed could be published rapidly. This course of action placed high demands on the reader, who had to assess themself the quality of the non-peer-reviewed articles. In this context, the professional evaluation of this published knowledge provided by Sweden's physicians' associations therefore came to be of central importance. However, producing new knowledge under great pressure of time is not without risk, and the scientific community can be tempted to compromise on quality requirements by departing from the usual evidence requirements and research ethics requirements. In this respect, too, pre-developed strategies for conducting clinical research during a health crisis would probably be of value[6]. Another disadvantage was that other research important to the healthcare sector ground to a halt. Restrictions and recommendations to avoid person-to-person contact stopped many clinical trials, and funding was redirected to COVID-19 related projects, something that the OECD among others noted.[7]

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[6] L. Valmorri, B. Vertogen & C. Zingaretti, 'Clinical research activities during COVID-19: The point of view of a promoter of academic clinical trials', *BMC Medical Research Methodology*, 21, 2021, art. 91, doi.org/10.1186/s12874-021-01291-0.

[7] C. Paunov & S. Planes-Satorra, 'What future for science, technology and innovation after COVID-19?', *OECD Science, Technology and Industry Policy Papers*, No. 107, OECD Publishing, 2021, doi.org/10.1787/de9eb127-en.

SILF also initiated a national care programme together with *Svenska Hygienläkarföreningen* (the Swedish association of hygienic physicians) and *Föreningen för Klinisk Mikrobiologi* (the clinical microbiology association), the first version of which was published at the end of June 2020. The process had the support of the National Board of Health and Welfare and the National programme groups for Infectious diseases and medical diagnostics within the National system for knowledge-driven management. The work was carried out with the utmost urgency outside the established structures for knowledge management in order to achieve the maximum growth in knowledge in the shortest possible time. The document was presented as a "National guide to integrating government agency guidelines and recommendations into healthcare in practice".[8] These guidelines focused exclusively on medical issues such as communicability, infection prevention and control, diagnostic microbiology, clinical imaging, treatment and follow-up. The care programme was updated regularly, and the current version was published in late autumn 2023. In December 2020, SLS organised a major conference titled "State of the Art COVID-19", which was then repeated in November 2022.

In our opinion, the work described here that was done within the profession is an excellent example of what is possible when specialists in a particular field step forward and take the lead, without a particular remit to do so, to coordinate the development and dissemination of knowledge in the most efficient and effective way possible. It was not one of the government agencies responsible for health and medical care that drove these processes; rather it was professionals who, on a more or less non-profit basis, put together and distributed the best possible knowledge in the shortest possible time. In our view, it is unlikely that the more cumbersome and bureaucratic system for knowledge management could have achieved this.

Despite these efforts from many physicians and researchers however, many clinics ended up in difficult situations where decisions of various kinds had to be made without much knowledge to go on. There were also instances of healthcare professionals being redeployed away from their regular workplaces and tasks to COVID-19 care, such as

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[8] 6. Infektionsläkarföreningen, Nationellt vårdprogram COVID-19 (version 5.1), november 2023, https://infektion.net/kunskap/nationellt-vardprogram-covid19.

in intensive care units[9]. This may have contributed to the stress reported by many nurses and physicians, as they could be put to work in areas that they did not feel entirely comfortable in, but where there was no alternative either. Solidarity between different specialties was put to the test, but our picture is that this did not create particularly problematic tensions in the medical profession. For many physicians, this resulted in work situations quite unlike everyday healthcare and instead more like a long drawn-out disaster, where the customary decision support and algorithms were absent. In this process, collegial learning was of central importance.

However, these guidelines from the professional associations contained nothing about the ethical aspects of the decision-making. In our view, the responsible authorities (regions and county councils) should have taken a clearer, and consistent lead overall to establish forums for ethical reflection and discussion, where people would have had the opportunity to air and discuss shared experiences. In such forums, difficult ethical dilemmas due, for example, to a lack of knowledge and experience[10], resource scarcity, healthcare professionals' fear of becoming infected themselves and infecting others, experiences of not having the right skills when transferred from their regular roles to working with COVID-19 patients, can be aired in a collegial atmosphere.

Smer pointed out in its report "It is essential that healthcare professionals are not left to make difficult decisions by themselves. Support should be available in the form of guidelines and recommendations for dealing with difficult situations, and counselling and opportunities for recovery should be prioritised".[11] In the report, Smer does not take a position on the types of guidelines and recommendations, nor on which groups or government agencies would be most appropriate to issue them. In our view, professional associations in close cooperation with the responsible authorities and Smer would be a good alternative.

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[9] E. Ahlvin Govenius & R. Dalerot, Att omplaceras till intensivvården under Covid-19 (Borås: University of Borås, 2021), https://hb.diva-portal.org/smash/get/diva2:1587960/FULLTEXT01.pdf.

[10] J. Persson & N-E. Sahlin, *Vetenskapsteori för sanningssökare* (Stockholm: Fri Tanke förlag, 2013), pp. 166 ff.

[11] The Swedish National Council on Medical Ethics, *Ethical choices in a pandemic (2020:3)*, p. 16.

A liberated profession

The picture we have of the medical profession's work situation is that they worked tirelessly and with great dedication under difficult circumstances. However, the load was very variable depending on specialty and level of care and varied significantly at different times and in different parts of the country.

Some physicians also said that being able to temporarily avoid the many meetings and administrative burdens that can be a feature of today's healthcare systems engendered a sense of relief within the medical profession, and that these aspects of the job are often perceived as onerous for the profession. They were simply not required to do some tasks that are perceived as time-consuming in an increasingly bureaucratised healthcare system where documentation requirements have laid claim to more and more time. Instead, they were able to focus on the key driving force for the vast majority of people in the medical profession; namely to treat people with a need for different kinds of care based on their medical skills. Thus, the responsibility for and management of the situation came to be professionalised, and many physicians experienced their work situation as very demanding but also meaningful in a new way, particularly a little later in the pandemic when they had learned more and more about the best possible treatment for the disease. A closely related experience was that decisions within the regions' bureaucracies were suddenly made faster. Cases that had been dealt with in an irritatingly energy-consuming way at repeated meetings involving protracted discussions for years and years were suddenly quickly resolved.

However, when the pandemic reached its first peak in spring 2020, large sections of the medical professions began experiencing great fatigue. Overtime often exceeded the upper limits and, like all other staff in the healthcare system, physicians began to wonder whether the course of the pandemic would come to dominate sentiment in healthcare. How long would the pandemic continue and when could one expect more time for recovery?

While some parts of the medical profession worked under extraordinary conditions, a great deal of the planned care was cancelled. This, too, became a stress factor in some specialties when physicians saw that operations, post-operative checks and examinations were postponed in ways that placed the patients in a predicament. This was seen by many physicians as a significant ethical problem. Some physicians wondered whether it could be right to continue with some care not associated with COVID-19, if this could be done without being a drain on the low supplies of protective equipment and anaesthetics. At the same time, they wanted to remain in solidarity with those parts of the healthcare system that were labouring under heavy workloads due to the pandemic, which was taking up more and more space in the healthcare system and meant that the queues for elective surgeries grew in ways that entailed increased risks for many patients. In addition, it was known that this would create even longer care queues. Many also felt that a change in how people were seeking care was worrying. This change was noted even before the figures showed that fewer patients than expected were diagnosed with stroke, heart attack and cancer.

Ethical challenges in prioritisations

Quite early in the pandemic, as in many other countries, a fairly broad discussion ensued about priorities in the healthcare system. As the number of cases grew rapidly, questions arose as to whether it would be necessary to impose limits on treatment if critical care resources began to run out. It became clear early on that the situation had the potential to challenge the principles for setting priorities in health care that had existed previously. Let us first recapitulate how priorities are set under the relevant legislation.

Decisions on setting priorities in the Swedish healthcare system, regardless of the form of practice, must be made in compliance with the ‘Ethical platform for priority setting in health care’, which was adopted by a unanimous Riksdag (Parliament) in 1997, and which has since been incorporated in part into the legislation. The platform comprises three principles – human dignity, needs and solidarity, and cost-effectiveness – which must be followed in that order.

The principle of human dignity does not constitute any real basis for priority setting, but is instead a prohibition on discrimination, which means a direct prohibition on setting priorities based on gender, social or economic status, ethnicity or age. Nor should anyone be given lower priority because they are afflicted with a disease that is in some sense self-inflicted. This principle is usually not questioned, except when it comes to age and the degree of responsibility/liability of the individual for the condition they have brought upon themselves. This issue of responsibility/liability was raised in some quarters in the pandemic debate when some commentators proposed that a person who failed to vaccinate themselves should perhaps be given lower priority than a person who had made sure that they got vaccinated. We will return to the complex question of age as a basis for priority setting.

The needs and solidarity principle states that those who have the greatest need for health care should be given priority over those with less need, and who, out of solidarity, should accept waiting longer for care. That the healthcare system has a special obligation to ensure that weaker groups in society get their rights to health care, and that the goal is "good health and equal treatment for the whole population", are usually added in this context. While large sections of the Swedish population would likely fundamentally support this formulation, but it is by no means easy to interpret and implement this principle in practice. How do you measure a need and how can you compare different types and degrees of need? In everyday clinical practice, physicians are usually well-schooled in evaluating the needs of the presenting patient, and in attempting to meet the patient's needs with care interventions of various kinds. At the same time, the individual physician is also expected to prioritise that patient in relation to other patients with greater needs, which is a much more difficult task. The responsibility for the individual patient rests with the individual physician, while the responsibility for the equitable distribution of the healthcare system's finite resources according to need lies with the municipal and regional politicians and officials responsible for healthcare. Without a doubt, this set of problems came to a head during the pandemic when the needs for health care threatened to overwhelm the resources available in the healthcare system.

In simple terms, the cost-effectiveness principle can be described as the treatment option that is most cost-effective should be chosen for treating otherwise comparable pathologies.

When the authorities and healthcare providers began to suspect that the pandemic would prompt new priorities, a lively debate ensued in the daily and professional press about this challenge. Potentially, the healthcare system could end up in a situation where it was forced to make life-and-death priority decisions in a new way.

In March 2020, the National Board of Health and Welfare issued new principles for priority setting in intensive care under extraordinary circumstances[12] which were then followed by guidelines for priority setting for routine healthcare during the pandemic. These guidelines were developed within the Board of Health and Welfare with the support of only a few experts in medical ethics and in anaesthesia and intensive care. These two documents were produced in a very short time without the normal referral procedure due to the situation being seen as urgent, and because there was significant uncertainty and a great need for guidance in the healthcare system. When the principles for priority setting in intensive care under extraordinary circumstances were published, they were well received by many physicians. They were somewhat reassured by have something to go by.

Around the same time, emeritus professor of philosophy Torbjörn Tännsjö initiated a national conversation in which he championed the principle that age should be a primary point of departure for setting priorities from a utilitarian philosophical standpoint or, as the headline in his op-ed in the *Dagens Nyheter* daily newspaper read: "We should save the young if the healthcare system cannot save everyone."[13] Tännsjö argued that the principle of need implies that we should prioritise based on age. Thus, an opportunity arose for philosophers advocating utilitarian principles to engage in public debate. We believe that to some extent this view also came to influence government agencies such as the National Board of Health and Welfare.

The principles stress that access to intensive care should be decided "according to need and patient benefit". Departing from the platform for priority setting, the National Board of Health and Welfare formulated three 'dimensions' as the basis for setting priorities: 1) the degree of severity of the health condition (patient need); 2) the patient benefit of the intervention; and 3) the reasonableness of the use of the resources in relation to the size of the patient benefit.

The concept of patient benefit was defined as follows: "Normally, patient benefit is assessed based on the parameters life expectancy and quality of life. In this situation, it is impossible to assess the

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[12] National Board of Health and Welfare, Nationella principer för prioritering av intensivvård under extraordinära förhållanden, March 2020.

[13] T. Tännsjö, 'Vi bör rädda de unga om vården inte kan klara alla', *Dagens Nyheter*, 25 mars 2020, https://www.dn.se/debatt/vi-bor-radda-de-unga-om-varden-inte-kan-klara-alla.

patient's future quality of life, therefore the principles focus only on life expectancy." [14]

This definition came to be the focal point of subsequent public debate. We and others argued that patient benefit is not a term that is found in the priority setting platform. Could this constitute a shift in the ethics in setting priorities, influenced by utilitarianism? Did the emphasis on remaining life expectancy entail a new interpretation of the priority setting platform that lacked support in policy, as the critics argued?

We argued that this was an "inappropriate simplification where patient benefit is defined solely as life expectancy", the consequence of which was that a younger person would always take precedence over an older person, all else being equal – i.e. an age-based priority setting that was not deemed acceptable in the Swedish healthcare system following the Riksdag (parliament's) decision to adopt the platform for priority setting.[15]

Instead, critics argued that the interpretation of the term 'need' should be based on three components: 1) the degree of severity of the illness; 2) the possibility to treat the condition effectively; and 3) the prognosis concerning whether the patient would be able to benefit from the treatment based on the idea that a person does not need care that is meaningless or ineffective.

In the subsequent exchange of words, it never became entirely clear what the National Board of Health and Welfare meant when it stated that in "this situation it is impossible to assess the patient's future quality of life". In addition, the Board wanted to play down any differences of opinion and maintained that all guidance from the Board was in accord with the platform for priority setting.

Was this then a pseudo-debate, or was there a fundamentally important difference in the ethical reasoning of the Board and the critics? Was it in fact a new interpretation of the platform for priority setting that had crept into the Swedish healthcare system? There are very probably differing opinions about this.

Our picture, however, is that this attitude came to pervade the healthcare system to a certain extent, at least in theory. For example, local guidelines for intensive care were designed in which priority

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[14] National Board of Health and Welfare. (2020, March).

[15] I. Engström & M. Sandlund, 'Viktigt att prioriteringar i vården görs öppet och transparent', *Dagens Nyheter*, 30 mars 2020, https://www.dn.se/debatt/viktigt-att-prioriteringar-i-varden-gors-oppet-och-transparent.

groups were defined in terms of "biological age" ranges, without referencing any systematic way of determining biological age. One example of new ethical principles spreading nevertheless is Karolinska Hospital's document "Decision support for responsible physicians in making decisions to initiate or discontinue intensive care"[16]. It stipulated, among other things, that intensive care should not be given if the patient had "a co-morbidity with an expected survival time shorter than 6–12 months". Furthermore, intensive care should not be given to patients with a biological age greater than 80 years, patients with a biological age of 70–80 years with "significant failure in a maximum of one organ system" or patients with a biological age of 60–70 years with "significant failure in a maximum of two organ systems". This algorithm-based decision support was exposed by the tabloid newspaper *Aftonbladet*[17] and the hospital was somewhat disinclined to discuss these group-based principles for setting priorities for access to intensive care. As we understand it, the decision support was hardly used in a concreted situation, since it was not really needed, but perhaps also because of the negative coverage it received in the media. Fortunately, beds in intensive care were mainly sufficient for those who needed such care. For example, the intensive care units that were set up in field hospitals inside trade fair halls outside Stockholm never needed to be used.

The physician's role in the care of older people

Another controversial issue of an ethical nature concerned the physician's role in the care of older people. Based on the argument of minimising cross-infection, the National Board of Health and Welfare urged physicians *not* to visit patients in residential care homes for older people as they usually would, as far as possible. It was instead suggested that most consultations should be done remotely and primarily based on information from the staff at the home.[18]

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[16] Karolinska University Hospital, Internal communication, 2020.

[17] O. Svensson, 'Dokument visar: De prioriteras bort från intensivvården', *Aftonbladet*, 9 april 2020, https://www.aftonbladet.se/nyheter/samhalle/a/lAyePy/dokument-visar-de-prioriteras-bort-fran-intensivvard.

[18] National Board of Health and Welfare, Arbetssätt i kommunal hälso- och sjukvård vid covid-19, 28 July 2020, https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/arbetssatt-i-kommunal-halso-och-sjukvard-vid-covid-19.pdf.

There were also recommendations in general health care which stated that, as far as possible, patients in residential care homes for older people should not be transported to hospitals, far less to intensive care. These group-based consultations and prescriptions are not compatible with good health care for older people.

Summary

Our view is that the ethical debate on the healthcare system's ways of working and priorities during the pandemic ended up being rather elementary. The Swedish National Council on Medical Ethics' proposal for an ethical framework for decision-making during a pandemic received lukewarm attention.

Where it did occur, public debate on the ethical issues primarily concerned questions of priority related to the issue of access to intensive care resources. This was a very important debate that shone a spotlight on the validity of the platform for priority setting moving forward, and the threats to it that thus came to light. However, the debate involved mostly professional ethicists and the voices from the people, whether in organized form or not, were lacking.

It is clearly apparent that the medical profession ended up taking a great deal of responsibility in both the clinical and the scientific work. Many physicians made contributions well above and beyond what is in their job descriptions. It can be said that the work of gradually developing new knowledge was impressive, despite the absence of direct remits from society or public policy. This was done out of necessity and curiosity – two strong driving forces in a fraught pandemic situation.

Did the medical profession get enough support from the responsible authorities and the government agencies? Our picture is that this varied greatly between different parts of the country. In general, both the responsible authorities and government agencies had clear aims to support the healthcare professions in various ways, but there was also a level of uncertainty, which can be construed as a sign of a poorly prepared organisation. It is quite clear that preparedness in the form of supplies of personnel protection equipment for the staff was unacceptably poor, which meant that many employees were forced to work under risky conditions. Preparedness to create scope for ethical reflection was also poor in many places, as was scope for staff to recover from long and intensive shifts.

There is good reason to ponder on whether society has now developed a better preparedness for good ethical awareness in the healthcare system for the next pandemic, which in all probability will come at some stage. In addition, a conscious effort is needed to build ethical competence and awareness into the system and established forums for ethical reflection. Unfortunately, we have not seen any signs that such systematic initiatives have been taken thus far.

It is indeed remarkable that the central government Corona Commission did not delve into the ethical aspects of managing a pandemic, in either the healthcare system or in public health.[19]

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[19] SOU 2022:10. Interim reports SOU 2020:80 and SOU 2021:89. In a separate statement of opinion from member Camilla Lif, she pointed out that the ethical issues were neglected during the Corona Commission's work and that the member concerned had not gained a hearing for her proposals.

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10 The role of science journalism during the COVID-19 pandemic

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Introduction

In this text, I aim to provide as good an insight as possible into how we reasoned at *Sveriges Radio* (Sweden's national public service broadcaster, hereinafter 'Swedish Radio') during various phases in our reporting during the pandemic. I want to share some of our own reflections on how we met the various demands that can legitimately be made of journalism, and especially of public service radio in such a situation. Finally, I briefly discuss what we learned from this protracted crisis, and what I hope this has meant in the long term for science journalism's standing in newsrooms and editorial offices as well as among the general public.

I lived through the first years of the pandemic as head of *Vetenskapsradion* (hereinafter 'the Science newsroom') at Swedish Radio, and as science commentator in broadcasts from the radio's news department *Ekot* (hereinafter 'the National newsroom'). I use the term 'lived through' very deliberately, because I have not been even close to such a high-pressure work situation in my entire professional life even though I have covered a number of terrorist attacks and a severe earthquake in Europe on site in the past for Swedish Radio.

The pandemic resulted in an immediate and major shift in the way we worked in the science newsroom. And I am not just referring to the fact that – like the rest of society – we overnight had to change to remote work from meeting physically. My main point here is that both the journalistic content and our methods changed radically.

In science journalism, traditionally you are able to set your own agenda. You rarely need to be in the midst of the news flow – while not placing yourself outside it either. Instead, you alternate between two positions: one being far *ahead of* the general news flow, and the other following somewhat *behind* it.

Science journalism’s two categorisation mechanisms

Prior to the pandemic, I used to define the task of science journalism with the aid of two categories.

The first category concerns monitoring scientific progress and reporting on new findings and on fields of research that might not gain real importance until some point in the future, if at all. The aim is to keep the public informed about the direction of frontier research. This means reporting on new, often uncertain, and always in some sense preliminary or tentative results. A new scientific discovery is of course always tentative pending further corroboration of the results, even when it has undergone peer review and been published in a scientific journal. It is an important task of science journalism to be clear about this when reporting.

The second category, traditionally more prominent in in-depth programs and feature articles, focuses on scientific knowledge that can deepen our understanding and help tackle a range of societal challenges. Examples include how to cure different diseases, but also educational research or brain research that can shed light on problems in schools from several different angles, or research and results that can help us solve our future energy supply, manage the climate crisis, etc. Here, science journalism involves identifying relevant scientific fields and synthesising what they have shown in order to shed light on a distinct public affairs issue. The task of science journalism then becomes to sift through research orientations and findings to provide a collected and accurate picture of the overall state of knowledge on the issue.

In simple terms, you can summarise these science journalism ‘categorisation mechanisms’ as follows:

1. Follow the sciences' own agenda – identify interesting findings in the flow of scientific journal articles. This concerns new, and in some sense always preliminary or tentative knowledge.
2. Follow society's agenda – explore what different disciplines have to say on major or important public affairs issues. This concerns scientific knowledge that has been 'solidified'.

How the conditions for science journalism changed during the pandemic

Perhaps you might see now where I am heading with this. What happened during the pandemic was that these two approaches to science journalism began to merge. Moreover, the rate of knowledge production became so rapid that the preliminary nature of new findings became even more prominent.

Suddenly, we had to deal with a rapid flow of new knowledge that was tentative in the highest degree, that was available in scientific reports that had not yet been peer-reviewed – or not available in any reports at all – and which dealt with a huge question that was currently dominating the news entirely: How dangerous was COVID-19, and how should we as a society and as individuals protect ourselves from it?

One could summarise the categorisation mechanism in science journalism during the pandemic, especially in its initial stages, as follows:

1. Report on the tentative knowledge available to help us understand and deal with the one currently dominating public affairs issue.

Another way of expressing this is that science journalism suddenly became pure news journalism. We had to invent a new way of working, where we were constantly referring to science that was hot off the press, or not yet completed studies.

Another change in the conditions for science journalism during the pandemic concerned our relationship to expertise. The challenge concerned establishing who constituted an expert, who represented a relevant expert qualified to comment on a given aspect of the pandemic, and who could be considered an independent expert. Science journalism necessarily relies upon continuous dialogue with experts to assist in determining which research carries the greatest credibility and bears the most significance.

The Science newsroom is often referred to internally at Swedish Radio as the 'expert newsroom', but that expertise is in primarily two things: 1) Being aware of the tentative nature of scientific knowledge and to ask questions that identify and clarify what knowledge can be relied on and what is not reliable. 2) Being an expert in expertise, i.e. being trained in determining which researcher has the relevant expertise to speak about a particular scientific field. The latter became a challenge during the pandemic because expertise became linked in a very tangible way to power. This was perhaps particularly true in Sweden, where the words of the Public Health Agency weighed so heavily in relation to public policy. In addition, many independent experts, or in some cases self-styled experts, also became activists and made public statements far beyond their areas of expertise. This made the work of science journalism even more complex during the pandemic.

The challenges we faced can be summarised as follows:

1. Sift through tentative knowledge. Preprints were available to all, so tentative knowledge was widely cited.
2. Just keeping up with it all! The sheer speed of the knowledge production.
   a) The distinction between independent experts, public authority experts, and experts acting as advocates.
   b) What disciplinary knowledge applies? Establishing who holds expertise in what particular areas.

The Science newsroom's reporting and new approaches

So what did this shift mean for our work? In this extreme situation, how did we handle the two classic tasks of journalism – to inform and to scrutinise?

Up until COVID-19 was declared a pandemic I would say that the Science newsroom's reporting was business as usual. We reported at our own pace on the new disease in Wuhan in China – and gathered the most reliable information that was available in order to shed light on the issue, just as we had always done. It was not until March, after the virus had become well-established in Italy, that we started reporting on it more frequently. And then it all began to snowball.

A pandemic was declared by the WHO on 11 March 2020. By Friday 13 March, we had launched a completely new format: a daily short podcast series, which we called the Science newsroom's coronavirus special.[1] Our starting point was the public's questions, and to seek out the best answers that were available at each time. The very first episode in this series dealt with a major question right then – what was the role of children in spreading the infection and was it helpful to close schools? During the pandemic, a total of 73 episodes in the coronavirus special series were recorded and broadcast on Swedish Radio's P1 channel (its news and current affairs channel). Initially, the Science newsroom was tasked with producing one 8-minute episode per day. This is the equivalent of at least one full-time position – or as it turned out, more than that in order to do it well. We fortunately very quickly received an injection of funds equivalent to two positions, a new level of staffing that Swedish Radio granted the Science newsroom during most of the pandemic. This new format enabled us to take command over the news flow. It was a question-driven type of news journalism. Instead of – as science journalism normally does – basing our reporting on which *answers* carried the most weight in the available scientific reports, we were now doing the opposite. We started every day by determining which *question* about the pandemic was most interesting to ask – and the answers simply had to be as reliable, vague or varied as each given situation allowed. Rather than limiting ourselves to asking those questions that could give us the most reliable answers we made every effort in our reporting to be as transparent as possible about the certainties and uncertainties in the current state of knowledge. This meant we also returned to the same questions multiple times, and the answers were modified according to the expanding body of knowledge during the course of the pandemic.

Another change in our way of working during the pandemic arose from the fact that the Public Health Agency, along with other relevant government agencies such as the Swedish Civil Contingencies Agency (MSB) and the National Board of Health and Welfare, started holding a press conference daily at 2 p.m. A press conference that was followed in real time by large sections of the Swedish population

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[1] Vetenskapsradions coronaspecial https://www.sverigesradio.se/grupp/33918.

who were isolated at home, and in many cases were worried and scared and without much that could compete for their attention. The media broadcasting entire press conferences live from government agencies was an entirely new situation. The skills of science journalists were suddenly needed in real time to comment on and analyse the messaging from the government agencies and their experts. In this situation, cooperation between the Science newsroom and the National newsroom became crucial. An entirely new position as science commentator was created to analyse the experts' statements in the National newsroom's live broadcasts, in a role similar to that of the well-established political commentators or economic commentators at Swedish Radio.

I often receive questions about this role in particular and would therefore like to emphasise that the commentator's role is not about knowing all the scientific answers. It is about helping listeners to make sense of the messaging they are getting from experts: What scientific questions have been asked? What potential uncertainties are there in the answers provided? What can be known and what cannot be known at a certain stage based on the state of knowledge as a whole? How should different types of expertise be understood? During the pandemic, the commentator's role involved following both developments in the pandemic itself and the progress made in the knowledge about it, and reminding the public of how the pandemic situation as well as the state of knowledge had evolved. For example, it involved explaining why the same rates of infection had completely different meanings before and after vaccinations were carried out, and that rates of infection could rarely be compared between countries, because testing was done in different ways in different countries. Furthermore, the methods of testing changed during the course of the pandemic.

Managing the government agencies' daily press conferences

One thing that surprised us at the Science newsroom, and I think equally surprised most Swedish journalists, was the importance that the daily press conference took on as a national campfire, the fact that so many people tuned into the press conferences live every single day. As a journalist, you are used to regarding press conferences as a place to acquire knowledge that you can then process, cross-check with other sources, and only after that report on. It should also be noted that in Sweden, it is traditional among journalists to save their 'best' questions for one-on-one interviews. As a reporter, you do not want to ask your smartest questions in front of all the other journalists. You want to save them for after the press conference so that you can produce your own news. But we quickly realised that the press conferences had a much larger audience than our own broadcasts. As a public service newsroom, our most important task was to communicate information and relevant questions to as large an audience as possible. We therefore chose to give up on the idea that the news must first be broadcast in our own channels, but instead saw the press conference as a journalistic arena in its own right. In that context, the focus on formulating the right kinds of questions became crucial. Therefore, discussing which questions were the most relevant to ask, well in advance of the daily press conference, became a new ingredient in our every day work. These questions were sometimes about current developments, but increasingly we also started to use the press conferences to publicly ask questions based on our own research regarding the pandemic. While this led to other media outlets sometimes getting the scoop and beating us to report on news that was based on our research – something you would normally want to avoid as a journalist – it also meant that we reached a larger audience, and we often got a mention for the Science newsroom of Swedish Radio in other media that quoted us as the source.

Our new way of working was also reflected when *Institutet för Mediestudier* (hereinafter, the 'Institute for media studies') scrutinized Swedish journalism's critical stance at the government agencies' press conferences. In this analysis, the science newsroom of Swedish Radio turned out to have asked the most critical questions of all Swedish national media during the press conferences.[2] If you analyse in detail how the Institute for media studies defined 'critical questions', it is clear that it included both direct querying of government agency decisions and questions with no direct connection to the government agencies' messaging. According to the Institute's analysis, foreign media adopted a more directly critical stance: "Why are you doing X

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[2] L. Truedsson and B. Johansson (editors), *Journalistik i coronans tid*, Institutet för Mediestudier 2021.

in Sweden and not Y like other countries?" The local journalists asked critical questions about the effect of government agencies' guidelines and the state of the health care system in their region based on good local knowledge. The Science newsroom of Swedish Radio distinguished ourselves by setting the agenda with questions based on our own research, thus contributing questions not directly linked to the government agencies' own messaging.

Why is this important? To answer this question, I would like to return to the dual tasks of journalism: to inform and to scrutinise. Maintaining the capacity to do both, even in a crisis situation, is crucial for public trust in journalism and thus in society at large. Journalism must provide accurate information, especially in a crisis, but must never be perceived as dancing to the government agencies' tune. Both tasks are equally important for the public's long-term trust in facts as well as social institutions. When government agencies and journalism are perceived to be walking in lockstep, the seeds of conspiracy theories and knowledge resistance find fertile ground. It is therefore crucial that journalism is able to maintain a distance from government agencies even in a situation where the media's task is also to ensure that crucial information efficiently reaches the public.

The study from the Institute for media studies shows that the Science newsroom of Swedish Radio succeeded quite well during the pandemic in informing the public about what was known while also scrutinising that knowledge. At an early stage, we also made a program that went behind the scenes in the Public Health Agency's analysis department and described how the Agency developed its scenarios.[3] This was a publication that received a lot of attention and was cited extensively by other media, especially in editorials. But perhaps we were not quite as good at more actively and explicitly scrutinising how the government agencies were interpreting the current state of the knowledge, and what consequences this had for how Sweden was handling the pandemic? At the end of spring 2020, Swedish Radio's investigative journalism desk, in cooperation with us in the Science newsroom, conducted an investigation into how the Public Health Agency had interpreted the state of knowledge at any given moment in relation to what the global knowledge consensus was at the time. Our role was to help evaluate retrospectively what the state

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[3] *Coronautbrottet – så görs analyserna*, Vetenskapsradion 7 April 2020. https://www.sverigesradio.se/avsnitt/1475828.

of knowledge had been at each point in time. For example, we reviewed the chronology of articles and statements from the World Health Organization (WHO) while the investigative journalism desk looked into what the Public Health Agency of Sweden had stated at the same points in time. Together, we were able to show that the Public Health Agency had systematically positioned itself more or less in opposition to the precautionary principle when it came to their views on how quickly the infection was spreading. Thus, they had systematically interpreted the situation somewhat more optimistically than the WHO and other international actors.[4] This investigation led to headlines in the world press when, in an interview with the desk's Daniel Öhman, Anders Tegnell (head of the Public Health Agency) stated that "we could have done some things differently".

As it turns out, our approach is quite typical for covering a pandemic, and according to several media researchers also typical for communicating about risk in general. Initially the coverage is focused on informing the public, and it is not until further into the crisis that the media takes a step back and becomes more critically scrutinising.

Poor coverage of vaccine development

One issue that, in retrospect, I think we should have devoted even more energy to was the development of potential cures and vaccines. Vaccine development progressed much faster than most commentators thought possible, and this affected Sweden's strategy. In retrospect, many analyses have pointed out that more restrictive lockdowns could have been justified in a different way if it had been known how quickly a vaccine would be in place to protect vulnerable groups. Perhaps this is a question that we should have focused on earlier and more thoroughly in our coverage: Within reason, how far away is a vaccine? Although we did several segments and reportages about vaccine development, in retrospect it is easy to say that it would have been justified to put even more effort into that particular question – given how crucial the vaccine turned out to be for the progression of the pandemic. The rapid development of mRNA vaccines is an example of how short the gap has become between groundbreaking,

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[4] Vetenskapspodden, Sveriges Radio 5 June 2020.
https://www.sverigesradio.se/avsnitt/1507687.

basic research and its technological application, and it can probably be seen as a failure of science journalism that we did not manage to cover this better. The lesson for science journalism is to not forget its core task even in a crisis situation – to simply follow and report on the leading edge of research. However, another aspect of the rapid development of vaccines proved even more important than the pace of scientific progress. It was the rapid approval process for the vaccines, made possible by the fact that regulatory agencies for medicinal products around the world permitted regulatory reviews to overlap clinical trials in their different phases (one, two and three). This meant that they ran in parallel instead of, as is normally the case, the reviews following after the studies are completed. This approach shortened the time to produce the vaccines by many months. A third crucial ingredient in the rapid implementation of industrial-scale vaccine production was the successful collaboration between academic researchers, innovative start-up companies, and well-established pharmaceutical industries that could quickly scale up the production. In this context, cooperation between science journalists and business journalists might have done better in shedding light on the possibility to develop a vaccine rapidly. “Innovation journalism” at the intersection of science and economics is still a neglected genre in journalism.

Which experts were given exposure in the media?

Another area where I think, as science journalists, we have some lessons to learn concerns the type of expertise that was given media exposure. Both Swedish Radio’s Science newsroom and other newsrooms focused on medical expertise. An analysis published by Public & Science Sweden in late 2021 showed that between 70 and 85 per cent of the experts who made statements in the media during various phases of the pandemic were medical practitioners, while only a few per cent were experts in any of the humanities. Social scientists got a bit more exposure the longer the pandemic progressed, but in the initial phase of the pandemic, when the question of keeping schools open or not was discussed, social scientists accounted for only a few per cent of the experts interviewed.[5] Ethicists are a category of expertise in the humanities who would have deserved more attention. The pandemic was not just about the medical aspects of infection and contagion. The choice of strategy to protect the population against the disease was based on both facts and values, and entailed handling difficult conflicts of objectives. For example, it entailed striking a balance between protecting the lives of the elderly by limiting the spread of virus in the community on the one hand, and on the other hand allowing children and young people to go to school and socialise with their peers. What were the consequences for young people's mental health of recurring school closures and remote learning in upper secondary school? It remains impossible to answer that question. Similarly, the ban on visitors to care homes that were in force during a large part of the pandemic entailed a great deal of mental suffering for many older people and their relatives. How was this suffering balanced against the risk that family members would carry a virus that shortened the lives of the residents? Ethicists could have helped to bring out the ethical choices behind these decisions. By giving ethicists more exposure in the media, the pandemic would have been seen more clearly as not just a medical crisis, but also as the moral and societal crisis that it ultimately proved to be. Besides school closures and bans on visiting residential aged care homes, Sweden's strategy was largely based on trust and voluntary action. That was also a normative choice that could have been illuminated better with the help of both philosophers and social scientists.

Another question that would need to have been addressed at an early stage is how the international response to the COVID-19 pandemic was shaped by its origins in China, a totalitarian state. I spoke about this in a later phase of the pandemic with Britta Lundgren, Professor of Ethnology at Umeå University, who had studied how the world reacted to the swine flu pandemic some years earlier. It is easy to forget now, but at first the mortality rate of the swine flu was thought to be relatively high, and young people were also affected to a much higher degree than during the COVID-19 pandemic. Despite this, the international response was completely different from

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[5] Vetenskap & Allmänhet: *Kommunikation om corona – medierapportering och förtroende i samband med covid 19-pandemin.* VA Report 2021:4.
https://vetenskapallmanhet.se/2021/11/varapport2021_4/
English Summary available: Communication about corona – media reporting and trust during the COVID-19 pandemic – English summary.

that to COVID-19; locking down entire communities was never in question. Britta Lundgren argued that the difference could be explained at least in part by the fact that COVID-19 had spread around the world from China, while swine flu, although originating in Mexico, spread around the world from California. She argued that in some sense the country of origin set the standard for how the disease should be handled. This type of reflection based on a body of knowledge in the humanities could have been very useful in public debate at an earlier stage.

The fact that academic knowledge in the humanities in particular got so little exposure in the Swedish media during the pandemic probably reflects a broader view in Swedish society regarding expertise, which is often limited to medicine, technology, and economics. Medical doctors were often asked questions that should rightly have been put to an ethicist. For science journalism, there is reason to reflect on how the term ‘science’ is defined. In Swedish, *vetenskap* is a much broader term than ‘science’ is in English, and traditionally encompasses all academic knowledge traditions, including the arts and social sciences. In spite of this, the natural sciences and medicine dominate the science journalism genre in Sweden too – especially in news reporting. Knowledge in the humanities rarely lends itself to the simple reporting of results that normally dominates in science news journalism (categorisation mechanism 1 described in the introduction above). However, in the more reflective and analysis-focused productions of science journalism (categorisation mechanism 2 in the introduction above), there is scope to integrate medicine, natural sciences, technology, social sciences and humanities far better in seeking answers to societal challenges. Such an approach would have been especially important during the pandemic.

Activism, polarisation and disinformation

Another aspect of the expert role, and how as science journalists we handled the scrutinising role of journalism during the pandemic, concerned the large number of researchers and experts who quickly turned into activists. During the pandemic, a long list of opinion pieces and posts were published, signed by researchers using their academic titles, even though the subject area only bordered on or lay totally outside their own area of expertise. This was particularly pronounced during the first months of the pandemic when there was a great polarisation of opinions on how best to deal with the situation. Helping the public to navigate this landscape and determine which expert knowledge is relevant for a particular issue is a central task of science journalism, but often difficult. This also proved to be the aspect of our reporting that was the most delicate to navigate. We sometimes received harsh criticism from some of the independent experts who were expressing opinions outside of their own areas of expertise and who felt that, by pointing this out, we had aligned ourselves too closely with the government authorities in our reporting.[6] Journalism in general has a reflex to side with the challenger of establishment, especially in a conflict with government authorities. In science journalism, however, our task is to communicate expert consensus. Consequently, when the authorities' position cannot be easily distinguished from expert consensus, there is a risk that journalism will be perceived as the authorities' megaphone. The challenge in science journalism is not only to be independent in relation to expert government agencies but also to credibly scrutinise the body of knowledge used by self-styled experts. This is a dilemma that is not easy to navigate because it is rare that an unambiguous line can be drawn around expert knowledge. This was particularly true in a situation like the pandemic, when both the state of knowledge and the expert consensus were marked by great uncertainty. For journalism, this underlines the need for a professional corps of specialised and independent science journalists capable of making independent assessments. In an atmosphere of infected and complex controversy, it may be virtually impossible for a generalist journalist to distinguish one professorial title from another. On the whole, I would say that Sweden's professional science journalists did well when scrutinising the statements of activist and largely self-styled experts. At the same time, we missed important points related to the protection of the elderly, such as the need for face masks and better hygiene routines in their care. This was especially true in the early stages of the pandemic. As the pandemic progressed, it became clearer which experts, or self-styled experts, had remained stuck

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[6] Lena Einhorn, 'Oviljan till debatt ett hot mot demokratin', *SvD* 24 March 2021 https://www.svd.se/a/oAwkXB/oviljan-till-debatt-ar-ett-hot-mot-demokratin.
Reply by Ulrika Björkstén and Alisa Bosnic, Einhorn sällar sig till ett narrativ vissa vill sprida, *SvD*, 28 March 2021 https://www.svd.se/a/rg1P08/einhorn-sallar-sig-till-ett-narrativ-vissa-vill-sprida.

in an activist stance and thus had difficulty in taking on the growing body of new evidence about the infection in order to contribute to a constructive debate. Other critics or advocates of the Public Health Agency instead updated their views as the body of knowledge grew and involved themselves in a discussion that gradually became more nuanced, about the best strategy for managing the pandemic.

We also had to deal with the fact that Sweden's COVID-19 policy attracted international attention. As a science commentator and head of a public service newsroom, I was frequently interviewed by international media. Those who drew attention to Sweden's COVID-19 policy often had an agenda. As a public service journalist, I therefore needed to remain aware of the context in which the interview would be used. Even if I only answered simple questions about what the COVID-19 situation was like in Sweden and how and where face masks were being used (or not used). I had to be careful to only allow interviews with well-established, professional media. Swedish COVID-19 policy also became weaponised in American domestic politics where, for example, the use or not of face masks became a political stand. This polarising attitude seeped into the debate in Sweden and made it more difficult to discuss in what contexts masks were effective and when they were not. No matter what was published on that particular topic, it almost inevitably caused a storm of indignant e-mails and posts on social media.

Disinformation and various types of pressuring and smear campaigns were also part of this reality. With the National newsroom of Swedish Radio, we investigated one of the smear campaigns that focused specifically on targeting various Swedish experts and government agency representatives. These campaigns had succeeded in having a major impact in both the Swedish and international media, and our investigation identified how this had been orchestrated.[7] This investigation is another example of how different areas of journalistic competence need to work together to fulfil the scrutinising role of journalism. In this case, on the one hand, a journalist from the National newsroom who is an expert in investigating various types of pressuring and smear campaigns, and on the other, a science journalist who is used to assessing the reliability of various scientific claims.

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[7] Vetenskapsradion 9 February 2021. *Dold Facebookgrupp oroar experter* https://www.sverigesradio.se/avsnitt/dold-facebookgrupp-oroar-experter-covid-19-pandemin-och-informationspaverkan-vetenskapsradion-pa-djupet.

Both sets of skills were needed to conduct the investigation. This publication eventually led to a wider debate on the role of university staff and academic expertise in the public sphere.

The pandemic meant that science journalism developed as a genre and became more news-oriented, and at Swedish Radio collaboration between different fields of journalism was strengthened. In the longer term, it also seems that the pandemic has strengthened science journalism in a way that appears to be permanent – despite the cuts that are again affecting Swedish newsrooms due to difficult times economically. Since the pandemic, several media outlets, such as the major Swedish daily newspaper Dagens Nyheter, have invested heavily in new science journalism positions. Over all, science journalism has matured as journalistic field and become more integrated with news journalism, public affairs journalism, and commentary.

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