

Ethical choices in a pandemic

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Preface

The ongoing COVID-19 pandemic is one of the greatest global crises in modern times. In mid-March the SARS-CoV-2 virus was judged to be a worldwide threat and the current epidemic was classified as a pandemic.¹ In a short space of time borders were closed, travel bans were issued and a large number of countries introduced various forms of restrictions to stop the spread of the virus, all aimed at saving lives.

In this report, the Swedish National Council on Medical Ethics (Smer) wishes to provide an overview of the core ethical values, problems and challenges that are actualised in a pandemic, based on the ongoing COVID-19 pandemic. The report also contains general recommendations and proposals. The document has been drawn up during the ongoing pandemic and marks the first step in the council's analysis of ethical issues relating to the pandemic.

The council hopes that this report will contribute to a deeper understanding of the ethical dimensions of the COVID-19 crisis and how ethical analysis can be used in decision-making during a pandemic. The target group for the text is decision-makers at various levels and the interested general public.

The report was written, within a short timeframe, by a working party consisting of Göran Collste, Professor Emeritus in Applied Ethics at Linköping University and Smer expert, Göran Hermerén, Professor Emeritus in Medical Ethics at Lund University and former Smer expert, Nils-Eric Sahlin, Professor of Medical Ethics at Lund University and Smer expert, Mikael Sandlund, Professor of Psychiatry at Umeå University, Smer expert and chairman of the Swedish Society of Medicine's Delegation for Medical Ethics, and Lotta Eriksson, Head of Secretariat at Smer.

¹ The World Health Organisation (WHO) declared the spread of COVID-19 to be a pandemic on 11 March (WHO 2020a).

The final editing of the report also involved Helena Teréus, Research Officer, Michael Lövtrup, Research Officer and Maria Zetterström, Deputy Research Officer at Smer's secretariat.

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Stockholm, May 2020

Kenneth Johansson
Chairman of the Swedish National Council on Medical Ethics

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Summary

In this report, the Swedish National Council on Medical Ethics (Smer) presents an overview of the core ethical issues that arise during a pandemic. Ethical choices permeate in both the preparedness of a pandemic and in the fight against the virus.

We have a moral responsibility, during and after an ongoing pandemic, to gather knowledge, support research and learn lessons for the future. Based on such knowledge, Sweden should develop a more robust contingency plan and a national ethical framework for decision-making in the face of future pandemics. In the report, Smer outlines the values and principles that might form the foundation for such a framework. This foundation may need to be revised moving forward, based on experiences from the ongoing pandemic.

Society's goal in a pandemic is to minimise mortality and illness in the population and other negative consequences for the individual and society at large. Restrictions and other measures introduced to combat a pandemic can have both positive and negative impacts on public health. The measures may counter the spread of the virus, but they may also lead to the restrictions on fundamental democratic freedoms and rights, such as freedom of movement and personal privacy.

What decisions should politicians and authorities take? And when? The answers to these questions are governed by the development of the pandemic at different stages and have ethical dimensions. There is the issue, for example, of how measures to combat the pandemic might affect differing interests and values in society and how conflicts of interest and of values can and should be handled. What values are to be safeguarded and what principles should guide decision-making?

Ethical analysis is therefore important in both the preparation and response phase, providing an invaluable tool when it comes to mak-

ing decisions at different levels as a result of a pandemic. Ethical analysis is a way to discern value conflicts and conflicts of interest, possible options for action and their potential consequences for various values. The analysis can also clarify which principles should inform decisions before and during a pandemic, and why.

The remit for Smer is to explore bioethical issues from a general societal perspective. The council's tasks also include collecting and evaluating facts and being an agency for the exchange of information and opinion, stimulating societal debate on questions of medical ethics and having the role as an intermediary between science, general society and policy makers.

The council has drawn up this report on its own initiative. It was produced during the ongoing COVID-19 pandemic, within a short timeframe.

Purpose and objective

In this report, Smer provides an overview of the core ethical values, problems and challenges that arise in a pandemic, based on the ongoing COVID-19 pandemic. The report also contains general recommendations and proposals. However, it makes no claims to be comprehensive, instead presenting a selection of pressing issues and possible considerations. This work marks the first step in the council's analysis of ethical issues relating to the pandemic.

The council hopes that this report will contribute to a deeper understanding of the ethical dimensions of the COVID-19 crisis and how ethical analysis can be used in decision-making during a pandemic. The target group for the text is decision-makers at various levels and the interested general public.

Smer's considerations and recommendations

Ethical framework at national level

Decision-making during a pandemic is not based solely on facts and scientific evidence. Choosing between different courses of action requires the decision-maker to weigh up a range of values and value-

related conflicts. Ethical analysis is crucial in both the preparation and response phase of a pandemic.

Smer considers observation of the following ethical values and principles to be particularly important when making decisions in preparation for and during a pandemic:¹

- *Minimise harm and save lives.* Harm is unavoidable during a pandemic. The overarching objective in a pandemic should be to minimise harm and save lives – whether lives threatened by the disease or those at risk from countermeasures that lead to isolation, unemployment and weakened social support and protections.
- *Human dignity.* People are of equal worth, with the same entitlement to have their rights upheld. Human dignity is not bound up with the circumstances of the individual, but is afforded to every person, irrespective of their performance, characteristics, or their social or economic status in society. It follows from the principle of human dignity that everyone must be treated with respect and on equal terms.²
- *Personal privacy and individual liberty.* Every individual has a right to personal privacy and liberty. During a pandemic, it may be necessary to curtail these values to protect the population from serious harm. Measures that restrict people's privacy and liberty should be proportional, necessary and relevant, and they should be kept to a minimum in relation to what one wishes to achieve.
- *Fairness and equity.* Healthcare and other social interventions must be offered in a fair and ethically acceptable manner. It is important to combat inequality both nationally and internationally. During a pandemic, one may be forced to make difficult decisions about priorities when resources are in short supply.³
- *Scientific basis.* Decisions on measures must, as far as possible, be based on science and proven experience.
- *Proportionality.* The measures taken must be proportional in relation to what one wishes to achieve.

¹ These general principles highlighted by Smer are based on existing principles that feature in the Public Health Agency of Sweden's pandemic contingency plan and other ethical frameworks. The list of values and principles presented is not exhaustive.

² This does not, however, mean that everyone will be treated the same way.

³ The health service has an ethical platform, with parliamentary approval from the Riksdag, for decisions on priorities within the health service.

- *Trust*. Trust is a key component in all types of relationships, including between citizens and society, not to mention its institutions. It is essential that decision-makers retain the trust of the population during a pandemic, when difficult action must be taken, and decisions made.⁴
- *Solidarity*. The principle of solidarity applies both nationally and internationally. A pandemic can challenge conventional ideas of national sovereignty, security or territoriality. It is important to support those individuals who risk being hit particularly hard by infection or countermeasures, while also emphasising individual responsibility for the choices they make in their daily life.

Fairness in decision-making processes

Smer considers the following values or conditions to be important for good decision-making processes:⁵

- *Relevant reasons*. Decisions must be sensible and reasonable. They should be justified and based on evidence, values and principles that citizens share/can agree are relevant to meeting health needs in a pandemic crisis.
- *Openness and transparency*. The decision-making process must be open to scrutiny, and the factual underpinnings, strategy and decisions should be publicly accessible.
- *Inclusivity*. The stakeholders should be involved in the decision-making process as far as possible.
- *Mechanisms for revising decisions*. There should be opportunities to revisit and revise decisions as new information and new evidence emerges. Mechanisms should be in place to address disputes and complaints.
- *Accountability*. There should be mechanisms in place to ensure that decision-makers are answerable for their actions.

⁴ One way to create trust in the short and long term is to stick to the facts.

⁵ The various contingency plans highlight the following values/general conditions for decision-making procedures. These values are inspired by a model developed by Daniels N. & Sabin J. (2000), called the *accountability for reasonableness framework*. The model is useful in identifying key issues in ethical decision-making processes.

Smer considers observation of the ethical values and principles presented above to be important when making decisions in preparation for and during a pandemic.

It is essential to draw lessons from the crisis, both while the pandemic is ongoing and afterwards. Based on this knowledge, a national ethical framework for decision-making should be developed in readiness for future pandemics and should be decided on at the national level. The values and principles presented above could lay the foundation for such a framework.

Global ethics and international solidarity

Globalisation has made it easier for countries to support each other, but at the same time has led them to become more dependent on each other. Questions of globalisation and international cooperation have an important ethical dimension. The coronavirus pandemic transcends borders and is affecting every country in the world. Global inequality becomes particularly evident in times of crisis. The world's poor countries do not have the capacity to build up reserves to meet rising demand for intensive care and advanced medical equipment. International cooperation and working in solidarity with the most vulnerable countries and groups is vital in a pandemic.

Building on global ethics and the goals set out in Sweden's policy for global development,⁶ Smer proposes the following:

- Sweden should provide greater support to developing countries that lack the healthcare resources to combat the coronavirus pandemic.
- Sweden should work in particular to support developing countries with any future vaccination programme. For countries with major deficiencies in their health service, a vaccine may be the best and perhaps only chance to protect vulnerable people.
- Refugees and migrants are being hit particularly hard by the coronavirus pandemic. Sweden should contribute to aid for migrants on the EU's borders, for example by supporting the work of UNHCR.

⁶ Swedish Government 2015.

- Sweden should support the World Health Organisation (WHO) in its work on coordinating the international fight against COVID-19 and research aimed at finding vaccines and therapies.

Public health and pandemic mitigation

The starting points of public health work are a conception of health and assumptions about which factors affect the health of the population and how these factors can be influenced. Public health work is about both extending life and improving quality of life amongst the population.

A whole host of measures that may or will become necessary during a pandemic entail trade-offs and lines that have to be drawn. In addition, decisions must often be taken under time pressure and based on uncertain data. How do measures aimed at combating the pandemic affect different values in society, will certain values be realised at the cost of others, and how can these conflicts of values be resolved?

To stop the spread of infection in a pandemic, it may be necessary to implement measures aimed at reducing physical contact between people, including lockdown and other forms of social distancing, isolation and quarantine. Digital tools for sharing location and/or health data may also be introduced to track infections and to warn people who have come into contact with an infected person.

It is Smer's view that:

- When choosing a strategy for pandemic mitigation, an ethical analysis model can help to identify relevant factors and conflicting values and interests.
- The ethical and societal aspects must be considered before every decision on measures that risk curtailing individuals' self-determination, personal privacy or other fundamental rights and freedoms.
- The measures should be based on an interest in protecting life and health, building up evidence and being proportional. If there are less invasive options that can be considered equally effective, these should be chosen.

- Mandatory measures aimed at reducing physical contact between people must be legally defensible, subject to a time limit and no more far-reaching than is absolutely necessary.
- Society must provide for those individuals who in various ways are affected negatively by recommendations and prohibitions through financial and other means of support.
- If digital tools are introduced as part of the drive to prevent the spread of infection, these should be subject to a time limit and the data gathered should be anonymised. Questions of security, quality and data protection are key, as are oversight and accountability. The use of any national apps for virus tracking and contact tracing should be voluntary.
- Digital tools for tracking and tracing that could entail serious intrusion of an individual’s private life should not be introduced.
- The science, the values and the balancing of interests that form the basis for measures involving restrictions of people’s rights and freedoms must be openly communicated to the public.

Challenges in healthcare

Healthcare is one of the sectors of society that is put under the most strain during a pandemic. A pandemic poses a numerous ethical challenge for the health service. The report considers a limited selection of ethical issues and challenges for the health service and its personnel during a pandemic.

Roles and responsibilities of healthcare professionals

It is Smer’s view that:

- Ensuring that health professionals are protected is of the utmost importance. Personal protective equipment and initiatives to prevent the spread of infection among healthcare professionals must be prioritised.

- 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.

Priority setting in healthcare

In a pandemic, there is a risk that many people will become ill at the same time, which will put greater pressure on the resources of the health service. Even if the health service is given additional resources, there is a substantial risk that this will not be enough to meet the increased demand and shortages of various kinds will occur. The health service's resources may be limited when it comes to personnel, ventilators, beds, medication, personal protective equipment, vaccines, and so on. If the demand for healthcare exceeds the resources, priorities will have to be made. During a pandemic, the health service faces prioritisation challenges at both group and individual level.

It is Smer's view that:

- Guidelines for setting priorities in extraordinary situations should, as far as possible, be drawn up when a crisis is not in progress. This allows time for a broad and open discussion with various stakeholders, and for the health service and society to agree on what considerations should be made and what values should be adhered to in the event that tough priorities need to be set. It is also likely that different guidelines may need to be drawn up, depending on how serious the crisis is. If guidelines do need to be created during an ongoing crisis, the aim, as far as possible, should be to canvass the views of different stakeholders in open and transparent processes.
- The guidelines drawn up during the current COVID-19 pandemic must be clearly rooted in applicable regulations. It is also important that the health service is open about exactly what is being prioritised and on what basis.

- It is essential to be clear about when different guidelines for extraordinary situations should be applied, when they should no longer be applied, and how this should be communicated to those who have to decide on the priorities. Clinicians must ensure that the guidelines on this are applied at the right time, and not too early, when demand has not yet outstripped the resources. Communication to those responsible within the health service, and the healthcare professionals who will be choosing the priorities, must thus be concise and clear.
- During a crisis, it is important that there is an opportunity to review the guidelines. New evidence may mean that priorities need to be reassessed. Various stakeholders should also be included in this process to ensure social acceptance. In addition, it is important that there are forums and opportunities for a continuing open dialogue on priorities and relevant principles, and their application in concrete cases.
- When it comes to the deferral of routine healthcare, the health service should periodically consider whether certain interventions/treatments should be resumed to avoid serious risks to patients.
- Local ethics committees should be consulted on difficult issues of prioritisation.
- Finally, Smer sees a need to develop a plan setting out how to return to normal service and priorities once the extraordinary circumstances no longer apply.

Ethics and personal contact at end of life

The clinician's approach at the point when relatives and terminal patients are saying their final goodbyes before death must be guided by the principle of minimising infection risks while also finding ways to enable human contact and closeness. Situation and context must, however, determine how this is resolved in practice. Digital contact may work well for some people. They might already be used to communicating digitally and able to express emotions and intimacy in this way. For others, it can feel strange and alienating, and be no replacement for physical, personal contact.

One might reflect on where to draw the line concerning a relative's own choices, responsibilities and decision-making in relation to the wider social responsibility. Based on their own well-informed choice, should a relative who is not in the risk group for serious COVID-19 infection be permitted to be physically present at the bedside of their dying relative, if they promise to go into quarantine for 14 days after the visit? This conscious risk-taking may, from the individual's perspective, seem reasonable. From a social perspective, there is a certain risk that the relative may, despite everything, become ill enough to require hospitalisation. However, activities that – perhaps to a similar degree – increase the risk of hospitalisation are generally not advised against.

Smer believes that contact at the end of life should be seen and dealt with in terms of a trade-off rather than from the perspective of social principles. The presence of relatives at the bedside should be assessed on a case-by-case basis, with reference to the individual circumstances in question.

Experimental treatment

The SARS-CoV-2 virus was entirely unknown just a few months ago and there is no established treatment for the resulting disease, COVID-19. Any treatment given is thus to some extent experimental.

The use of experimental treatments or novel methods creates a conflict between, on the one hand, the interest in giving patients a chance of health or survival and, on the other hand, ensuring that patients receive safe, tried and tested care, the risks of which can be judged in advance.

Smer's view in 2016 was that experimental treatments should only ever be used in organised and ethically acceptable forms and should as a general rule take place within the framework of research studies.⁷

Research ethics in the time of a pandemic

According to Smer, it is important to be able to fast-track the processing of applications for ethical review of research studies aimed at increasing knowledge of or developing treatment for an ongoing

⁷ Smer 2016.

pandemic. For the purpose of ensuring the intended priorities, the criteria concerning which research is eligible for fast-tracking must be clear and relatively strict. It may be necessary to remain vigilant against attempts to “relabel” other research. The risk of other important research being crowded out also needs to be taken into account.

Fast-tracking must not mean lower quality standards. It is particularly important to maintain requirements for a science-based hypothesis and an adequate methodology in times of crisis, when poor research can do a great deal of damage to both individuals and society. Principles of research best practice must be maintained.

In the time of a pandemic, it is crucial to particularly safeguard respect for human dignity. Measures to speed up the development of vaccines or medication to combat the pandemic must not cause research subjects to be exposed to unacceptable risks. Prevailing requirements to weigh the risk of harming the research subjects against the expected social benefit should be maintained.

Smer wishes to stress the importance of research subjects receiving adequate information, not least on the considerable uncertainty that often surrounds risks and expected benefits when working on an entirely new disease. This might mean that the bar should be set higher than usual when it comes to deciding who can be included as research subjects.

Another research-related issue concerns the redeployment of existing research resources without preceding quality assurance, as is being seen at the moment.⁸ There may be a risk of allocated funding being used in this way for COVID-19 research. Is the “urgently planned” research up to standard? What was jettisoned and what did we get instead? The outcome of this is something that should be followed up after the crisis, in order to learn lessons for next time.

⁸ The Swedish Research Council has announced that a third of allocated research funding may be used for COVID-19 research for a limited period of time. <https://www.vr.se/aktuellt/nyheter/nyhetsarkiv/2020-03-27-nu-mojligt-att-anvanda-del-av-ditt-bidrag-till-forskning-om-covid-19.html>.

Communication

It is Smer's view that:

- During a pandemic, it is essential that decision-makers at different levels communicate well with the general public. Good decision-making processes and factual information engender trust, and that confidence in the decision-makers can then be maintained even when difficult measures have to be introduced.
- It is important to clearly communicate not only the evidence on which decisions are based, but also how different values have been weighed against each other and which values and principles have underpinned decisions on a particular intervention.

The future

It is Smer's view that we have a moral responsibility to learn from the crisis currently playing out. 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.

1 Introduction

Outbreaks and the spread of infectious diseases, such as the current coronavirus pandemic, lead to difficult ethical, legal, economic and practical challenges for both individuals and society. The way in which these challenges are dealt with has significance for the social contract – the trust between the individual and the democratic system, confidence in society, and solidarity between citizens – and for solidarity between countries, the protection of vulnerable groups, and public health as a whole.

The central aim of measures taken during a pandemic is to protect the population against disease and death. The spread of infection must be countered, and those who are infected must be assured of the care they need, while at the same time ensuring that people with other serious diseases are not neglected. Restrictions and other measures introduced to fight a pandemic can also have a negative impact on the health of the population, and can involve curtailing fundamental democratic freedoms and rights, self-determination and personal privacy. Both the pandemic itself and the actions taken to combat it can have socioeconomic consequences and other secondary effects that threaten life and health in the long term. The consequences of a pandemic can thus be extensive and can affect the whole of society.

What decisions should politicians and authorities take? And when? The answers to these questions are governed by the development of the pandemic at different stages and have ethical dimensions. There is the issue, for example, of how measures to combat the pandemic might affect different interests and values in society – both positively and negatively – and how different conflicts of interest and of values can and should be handled. What values must be safeguarded and what principles should guide decision-making?

Ethical analysis is a valuable tool when making decisions at different levels as a result of a pandemic, both in decision-making regarding disaster medicine and in emergency preparedness. Ethical analysis is a way to discern value conflicts and conflicts of interest, possible options for action and their potential consequences for various values. This analysis can also clarify which principles should inform decisions during a pandemic, and why.

Most national ethics councils have issued statements in line with the spread of the COVID-19 pandemic. Some ethics councils have been tasked by their respective governments with drawing up recommendations, while others have issued statements on their own initiative.¹ In recent weeks, several international ethics councils have commented on which ethical principles and values should be defended amid this crisis. UNESCO's International Bioethics Committee (IBC) and the World Commission on the Ethics of Scientific Knowledge and Technology (COMEST) have made a joint statement on ethical principles and considerations from a global perspective. The European Group on Ethics in Science and New Technologies (EGE) has published a statement emphasising the importance of protecting fundamental freedoms and rights, the importance of solidarity in Europe. The Council of Europe's Committee has highlighted the importance of human dignity and human rights being respected at times like these.²

Aim and target group

The remit of the Swedish National Council on Medical Ethics (Smer) is to illuminate issues of medical ethics from a general societal perspective. Smer's task is to disseminate knowledge concerning medical ethical issues and to promote exchanges of information and opinions and shall serve as an intermediary between decision-makers, researchers and the general public. According to its assignment, the council shall in particular highlight issues that may affect human dignity and personal privacy. The current COVID-19 crisis raises

¹ For example: CCNE 2020, the German Ethics Council 2020, the Spanish Bioethics Committee 2020, the National Council of Ethics for the Life Sciences, Portugal 2020 and the National Bioethics Commission of Mexico 2020. For more statements from national ethics councils, see the links at www.smer.se.

² DH-BIO 2020.

these ethical issues to the highest degree, at different levels and in different dimensions. One central issue relates to how to communicate in a crisis, both from society's side and in the actual care situation.

This report aims to provide an overview of the central ethical values, problems and challenges that we face during a pandemic. The report concludes with general recommendations and proposals for the future. This report has been drawn up during the ongoing pandemic and marks the first step in the council's analysis of ethical issues relating to the pandemic.

Smer hopes that the report will contribute to a deeper understanding of the ethical dimensions of the COVID-19 crisis and how ethical analysis can be used in decision-making during a pandemic. It is also hoped that the report will contribute towards debate within society.

The target group is decision-makers at various levels – national, regional and local – and the interested general public.

The report begins with a description of the objectives, values and principles that come to the fore during a pandemic, taking as its starting point the Public Health Agency of Sweden's pandemic preparedness plan and the national ethical frameworks for decision-making during a pandemic that have been drawn up in several countries. This chapter also presents the ethical values and principles that should be considered when making decisions in preparation for and during a pandemic (chapter 2). This is followed by an overview of ethical questions and choices from a global perspective (chapter 3). Chapter 4 takes the public health perspective, analysing various strategies and measures to combat a pandemic from an ethical point of view. Chapter 5 focuses on the ethical questions that may arise within healthcare in connection with a pandemic, while chapter 6 addresses research ethics aspects. Chapter 7 discusses the significance of good communication between citizens and decision-makers during a pandemic. The report concludes with a few reflections for the future (chapter 8).

2 Objectives, values and principles before and during a pandemic

2.1 Objectives, values and principles

Ethical frameworks and recommendations have been drawn up by WHO and several countries regarding contingency plans for pandemics, based on experience from previous epidemics and pandemics. No specific national ethical framework has been decided on in Sweden. The Public Health Agency of Sweden refers to WHO's ethical framework in its 2015 pandemic preparedness plan.

Society's goal in a pandemic is to minimise mortality and illness in the population and other negative consequences for the individual and society as a whole.¹ The Government's work and decision-making aim to limit the spread of infection within the country, to safeguard resources for the health service, to limit the impact on operations that are essential to society, to mitigate the consequences for citizens and businesses, to alleviate concerns, including through information, and to put the right measures in place at the right time.²

2.2 Objectives, values and principles in the Public Health Agency of Sweden's documents

The Public Health Agency of Sweden's strategy for combatting pandemics refers to the following three objectives:³

- There should be as little impact as possible on public health,
- The negative impacts on society should be as little as possible,

¹ The Public Health Agency of Sweden 2015, p. 6.

² The Swedish Government 2020.

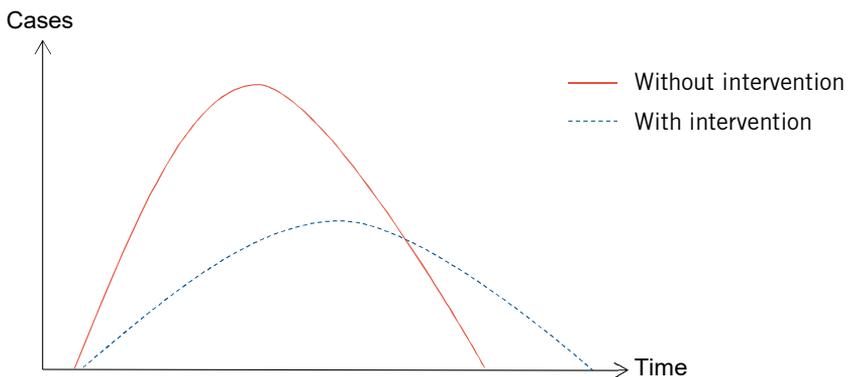
³ The Public Health Agency of Sweden 2015, p. 13.

- Confidence in the authorities, the health service and social care should be maintained.

These objectives involve values. They may also come into conflict with each other. For example, the efforts we make for public health involve significant demands on other sections of society, which in turn may have an impact on public health in the longer term.

Different strategies for achieving these objectives are medical and non-medical measures, as well as communication initiatives. The first overall strategy for achieving the objectives is to delay the progress of the pandemic so that the peak of the curve can be delayed and the curve can be flattened.⁴ This strategy involves reducing the burden on the health service and society by reducing the proportion of sick people at any given time (the peak of the curve) and by increasing the time available for making preparations. For an infection where an effective vaccine or treatment is within reach, this also provides time to develop these (shifting the curve to the right). If the number of people affected can be limited, more people can benefit from a vaccine or antiviral medication, and early vaccination offers an opportunity to reduce the total number who become sick (reducing the area beneath the curve).

Figure 2.1 The course of a pandemic with or without intervention



Source: Adapted figure from the Public Health Agency of Sweden 2015.

⁴ According to various sources, this illustrative graph was first reported in CDC 2007.

The second overall strategy is to reduce the negative consequences for those individuals who are affected by the pandemic in various ways, either directly or indirectly.⁵

The Public Health Agency of Sweden highlights the following principles which should characterise measures taken during a pandemic:⁶

- *Prepare for a serious situation when planning.* National and regional plans need to be drawn up which can deal with an influenza pandemic in which a large number of individuals die or become seriously ill, and/or the pandemic causes significant social disruption. During an initial stage with limited and uncertain information, measures must be based on this.
- *Flexible management.* Contingency planning must include scope for continual adaptation of plans and measures with regard to the development of knowledge and the course of the pandemic, both in Sweden and internationally.
- *Efficient and proportional use of resources.* The need for society's resources will be greater than usual during a pandemic, not least when it comes to the health service and social care. It is therefore essential that the use of resources is prioritised and dimensioned so that the pandemic management objectives can be achieved without the negative consequences outweighing the anticipated positive effects.

Sweden's crisis management system is based on three fundamental principles which apply for all emergency preparedness work:

- *The principle of responsibility:* The party responsible for operations under normal conditions has a corresponding responsibility during a crisis. This also includes initiating and carrying out cross-sectoral cooperation.
- *The principle of equality:* As far as possible, operations during a crisis should be similar to normality.
- *The principle of proximity:* A crisis should be managed when it occurs and by those who are most closely affected and responsible.⁷

⁵ The Public Health Agency of Sweden 2015.

⁶ Ibid.

⁷ Ibid, p. 15.

2.2.1 Prioritisations and ethical aspects

The Public Health Agency of Sweden highlights prioritisations as an area with difficult positions to be taken and where ethical aspects need to be included in planning for a pandemic. Despite good planning, resources may not be sufficient, and prioritisations may need to be made between different solutions and between groups with the same or different needs. The agency emphasises that the following areas in particular may require prioritisations: vaccines, antiviral medications and the allocation of resources within different operations, such as the health service.⁸

The prioritisations within the health service are based on the ethical platform for prioritisation decisions.⁹ This platform takes as its starting point the principle of human dignity and the principle of need and solidarity, which take precedence over the principle of cost-effectiveness. Care on equal terms following an assessment of the individual's needs is central to this platform.

Within infection control, it is not only the needs of the individual that are of interest – protecting other individuals and society as a whole is also taken into consideration.

According to the Communicable Diseases Act (2004:168), medical officers for infectious diseases and other relevant authorities can allow infection control considerations to take priority over considerations that would normally apply within the health service in certain situations, if this leads to people being protected against infection. The Public Health Agency of Sweden emphasises that infection control in a pandemic situation can involve deviating from the ethical principles that are normally applied. This is also the starting point for WHO's guidelines for ethical considerations in pandemic planning. The agency's plan also states that it is not appropriate to decide whether certain prioritisations should always be more important than others ('level grouping') in pandemic planning. Instead, this must be continuously reviewed in view of the development of the pandemic.¹⁰

Both the Communicable Diseases Act and WHO stress that measures which contravene ethical principles and the order of priority that would otherwise be applied must be used with care and be

⁸ The Public Health Agency of Sweden 2015, Appendix 4.

⁹ Govt Bill 1996/97:60 p. 20.

¹⁰ Ibid.

in proportion to their intended benefit. These measures must thus be weighed up against the long-term negative consequences of taking less powerful infection control measures.

WHO also emphasises the importance of the forms of prioritisation being adequate and fair. The authorities need to be open about the prioritisations made, the reasons why and the knowledge on which they are based. They should also be reviewable.

2.3 Values and principles that should guide decision-making during a pandemic

The various ethical frameworks for decision-making during a pandemic report similar values and principles. One of them is presented in Appendix 1 as an example. The ethical values and principles presented below are based on most documents.¹¹

Smer considers observing the following ethical values and principles to be particularly important when making decisions in preparation for and during a pandemic:¹²

- *Minimise harm and save lives.* Harm is unavoidable during a pandemic. The overarching objective in a pandemic should be to minimise harm and save lives – whether lives threatened by the disease or those at risk from countermeasures that lead to isolation, unemployment and weakened social support and protections.
- *Human dignity.* People are of equal worth, with the same entitlement to have their rights upheld. Human dignity is not bound up with the circumstances of the individual, but is afforded to every person, irrespective of their performance, their characteristics, or their social or economic status in society. It follows from the principle of human dignity that everyone must be treated with respect and on equal terms.¹³

¹¹ e.g. the Joint Center for Bioethics Pandemic Influenza Working Group 2005, Thompson et al. 2007, NEAC 2007, Kass 2005, CDC 2007, WHO 2007, WHO 2016, the Public Health Agency of Canada 2011, GOV.UK 2017, the Department of Health Ireland 2018, the British Columbia Ministry of Health 2012, the United Kingdom Department of Health 2007, Smith and Upshur 2019.

¹² These principles are based on existing principles that feature in the Public Health Agency of Sweden's pandemic contingency plan and other ethical frameworks. The list of values and principles presented is not exhaustive.

¹³ This does not, however, mean that everyone will be treated the same way.

- *Personal privacy and individual liberty.* Every individual has a right to personal privacy and liberty. During a pandemic, it may be necessary to curtail these values to protect the population from serious harm. Measures that restrict people's privacy and liberty should be proportional, necessary and relevant, and they should be kept to a minimum in relation to what one wishes to achieve.
- *Fairness and equity.* Healthcare and other social interventions must be offered in a fair and ethically acceptable manner. It is important to combat inequality both nationally and internationally. During a pandemic, one may be forced to make difficult decisions about priorities when resources are in short supply.¹⁴
- *Scientific basis.* Decisions on measures must, as far as possible, be based on science and proven experience.
- *Proportionality.* The measures taken must be proportional in relation to what one wishes to achieve.
- *Trust.* Trust is a key component in all types of relationships, including between citizens and society, not to mention its institutions. It is essential that decision-makers retain the trust of the population during a pandemic, when difficult action must be taken, and decisions made.
- *Solidarity.* The principle of solidarity applies both nationally and internationally. A pandemic can challenge conventional ideas of national sovereignty, security or territoriality. It is important to support those individuals who risk being hit particularly hard by infection or countermeasures, while also emphasising individual responsibility for the choices they make in their daily life.

¹⁴ The health service has an ethical platform, with parliamentary approval from the Riksdag, for decisions on priorities within the health service.

Fairness in decision-making processes

Impartial procedures are important for the legitimacy of decisions.¹⁵

The following values or conditions are important for good decision-making processes:¹⁶

- *Relevant reasons.* Decisions must be sensible and reasonable. They should be justified and based on evidence, values and principles that citizens share/can agree are relevant to meeting health needs in a pandemic crisis.
- *Openness and transparency.* The decision-making process must be open to scrutiny, and the factual underpinnings, strategy and decisions should be publicly accessible.
- *Inclusivity.* The stakeholders should be involved in the decision-making process as far as possible.
- *Mechanisms for revising decisions.* There should be opportunities to revisit and revise decisions as new information and new evidence emerges. Mechanisms should be in place to address disputes and complaints.
- *Accountability.* There should be mechanisms in place to ensure that decision-makers are answerable for their actions.

2.4 Recommendations

Decision-making during a pandemic is not based solely on facts and scientific evidence. Choosing between different courses of action requires the decision-maker to weigh up a range of values and value-related conflicts. Ethical analysis is crucial in both the preparation and response phase of a pandemic.

Smer considers observing the ethical values and principles presented above to be important when making decisions in preparation for and during a pandemic.

¹⁵ Tyler 2006.

¹⁶ The various contingency plans highlight these values/general conditions for decision-making procedures. They are inspired by a model developed by Norman Daniels and James Sabin, called the *accountability for reasonableness framework*. The model is useful for identifying key issues in ethical decision-making processes. See Daniels and Sabin 2008, p. 258, and Daniels 2000.

It is essential to draw lessons from the crisis, both while the pandemic is ongoing and afterwards. Based on this knowledge, a national ethical framework for decision-making should be developed in readiness for future pandemics and should be decided on at national level. The values and principles presented above could lay the foundation for such a framework.

3 Global ethics and international solidarity during the pandemic

3.1 Introduction

Globalisation has been a defining characteristic of recent decades. This had been driven by both economic and political forces, and now extends to all sectors of society. The economic driving forces usually include the development of a borderless financial market, the growing number and size of multinational companies, and increased world trade. Political globalisation has been a response to the economic driving forces to some extent, but also involves international conventions for dealing with global problems such as climate change and pandemics in a global way. The World Health Organization (WHO) is the international body tasked with coordinating efforts to fight the global coronavirus pandemic.¹

Globalisation has led to countries becoming more dependent on each other. This has become obvious during the coronavirus crisis, with medical equipment needing to be imported from other countries and continents. Through countries closing their borders to prevent the spread of COVID-19 and also not exporting medical equipment that they have needed themselves; certain countries have found themselves without essential medical equipment. These events illustrate the limitations of globalisation. National interests are still of great importance, and – as we will see below – national self-interest is playing a major role during the coronavirus pandemic.

Issues relating to globalisation and international cooperation have an important ethical aspect, and a number of ethical concepts are initially reported. Reference is then made to certain international organisations' statements and positions on the coronavirus pan-

¹ Collste 2004.

demic. Global practical ethical issues are addressed in the following section, and the chapter concludes with a few reflections on the significance of the coronavirus pandemic for global ethics.

3.2 Concepts

The global coronavirus pandemic has brought questions about global ethics, global justice and international solidarity to the fore, but what do these concepts mean?

The concept of global ethics can be assigned different meanings. Global descriptive ethics involves a description of ethical norms and values in different parts of the world, and within different cultures and religions. Global normative ethics refers to perceptions of what is desirable and good, and which norms and values should be applied globally. This includes ideas about human rights, meaning that all humans should be given the right to life, freedom and wellbeing, regardless of where they live.

The concept of justice refers to the ethical principles that should govern social institutions and societal and political decisions. Global justice refers to ethical principles that should govern decisions within global institutions and relationships between states. There are different perceptions about what justice involves, but a current widespread perception is based on the philosopher John Rawls' idea that just means equal political rights, and that the distribution of value should be to the greatest benefit of the least advantaged.²

According to the Swedish National Encyclopaedia, the concept of solidarity means unity between people within a group, a class, a nation or the entire world, with a readiness to provide mutual assistance.³ According to this definition, international solidarity means unity between people and nations worldwide, with a readiness to provide mutual assistance.

Most people would certainly agree that it is important to defend human rights, global justice and international solidarity during a global pandemic. It is during tough times that values such as fairness and solidarity are put to the test. However, during the coronavirus

² Rawls 1971.

³ Swedish National Encyclopaedia (2020).

pandemic we have seen flagrant breaches of these values, and short-term national self-interest guiding the actions of many countries.

3.3 International organisations

During the coronavirus crisis, several international organisations have issued statements emphasising the importance of values such as international solidarity and global justice. Here are a few examples.

On 3 April 2020, the UN General Assembly unanimously adopted a resolution emphasising the importance of global solidarity and international cooperation during the coronavirus crisis. In particular, it emphasised the importance of supporting the poorest and hardest-hit countries, and the importance of respecting human rights in the fight against the epidemic.⁴

The World Health Organization (WHO) has acted as an international coordinator and a global source of information during the coronavirus pandemic.⁵ As early as 2005, 196 countries came together within the framework of the International Health Regulations (IHR) to cooperate in the event of a global pandemic. They agreed to build up their capacity to detect, assess and report on risks to public health, and in the event of a global pandemic to provide WHO with tools to limit the spread of infection by closing ports, airports and national borders and to limit non-essential trade.⁶ During the current coronavirus pandemic, WHO has particularly emphasised support for refugees and migrants, stressing that these groups are especially vulnerable. It is therefore important that national health authorities include migrants in their protective measures without any discrimination.⁷

UNESCO, the UN's body for research and education, emphasised the importance of international cooperation in connection with COVID-19 research in a statement on 6 April 2020. Society's measures to combat the pandemic should be based on science and proven experience. When carrying out research, the precautionary principle should be observed, and the informed consent of research subjects should be respected. UNESCO encourages international coopera-

⁴ UN 2020.

⁵ WHO 2020d.

⁶ WHO 2020e.

⁷ WHO Regional Office for Europe 2020.

tion and international solidarity and warns against national special interests taking priority. It also stresses that wealthy nations have a particular responsibility to support poor nations in the battle against the pandemic.⁸

In a statement, the European Group on Ethics in Science and New Technologies (EGE) emphasises the importance of solidarity with those who are most vulnerable during the coronavirus pandemic. The group also stresses that there is a risk that decisions to restrict freedoms and rights to stop the spread of infection will be ‘normalised’, so that measures remain in place after the end of the pandemic. EGE also emphasises the importance of research findings being openly reported and shared.⁹

3.4 Global ethics in practice

How are international solidarity and principles of global justice working during the coronavirus pandemic? As we will see, there have been certain positive initiatives at global level, but several countries have acted primarily on the basis of their national self-interest and in contravention of international agreements and international law.

On 23 March 2020, UN Secretary General António Guterres issued a global call for peace during the coronavirus pandemic. He urged those involved in armed conflicts to agree to a ceasefire in order to fight coronavirus.¹⁰ The Secretary General’s initiative has been supported by a petition which gathered several million signatures.¹¹ Guterres’ appeal has proven to be successful, and *The Guardian* reports that arms have been laid down in several conflicts, including in Yemen, Libya, Cameroon, Colombia, Syria and Ukraine.¹²

Global inequality becomes particularly evident in times of crisis. The world’s wealthy nations have an opportunity to build up preparedness for the growing need for intensive care beds and advanced medical equipment, for which poor countries do not have the necessary conditions. Doctors Without Borders emphasises that the coronavirus pandemic does not respect national borders, and that the same

⁸ UNESCO, International Bioethics Committee & World Commission on the Ethics of Scientific Knowledge and Technology 2020.

⁹ EGE 2020.

¹⁰ Guterres 2020.

¹¹ AVAAZ 2020.

¹² Wintour 2020. See also Davidson 2020.

must be true of efforts to fight the pandemic. The organisation stresses that it is the poor, those who live in war-torn countries and refugees who are the worst hit, asking: “How are you supposed to wash your hands regularly if you have no running water or soap? How can you implement ‘social distancing’ if you live in a slum or a refugee camp? How are you supposed to stop crossing borders if you are fleeing from war?”¹³

The international aid agency Oxfam warns that the coronavirus pandemic may have devastating consequences for the world’s poor. In its report ‘Dignity Not Destitution’, it estimates that up to 8 per cent (over half a billion people) more of the world’s population may be forced into poverty as countries’ economies close down to prevent the spread of COVID-19. More than half the world’s population may therefore be living in poverty after the pandemic.¹⁴

The coronavirus pandemic transcends borders and is affecting every country in the world. There is thus a real need in all countries for medical equipment for intensive care treatment, including everything from protective masks to ventilators. At the same time, many countries are thought to be poorly prepared and lack access to essential medical equipment. On several occasions, the US has used various methods, such as offering a higher price, to try to obtain personal protective equipment and intensive care materials that were intended for other countries. For example, according to *The Guardian*, 200 000 protective masks that had been manufactured by 3M in China and purchased by a German regional government were rerouted to the US at a Thai airport.¹⁵ The US has also prevented exports of protective masks from American companies to Latin America and Canada. Making reference to the national emergency situation, President Trump ordered the export of three million protective masks purchased by Canada to be halted.¹⁶ The Trump administration has also offered large sums of money to the German producer Curevac for exclusive rights to their coronavirus vaccine. However, the German Minister of Health has explained that there will be no question of American exclusive rights.¹⁷

¹³ Doctors Without Borders 2020. See also Alfvén et al. 2020.

¹⁴ Oxfam 2020. See also Khorsandi 2020.

¹⁵ Borger, Holmes and Willsher 2020.

¹⁶ Borger and Leyland 2020.

¹⁷ *The Guardian* 2020.

France has also stopped the export of personal protective equipment destined for other countries, involving several million face masks made at Mölnlycke's French factory. Following strong pressure, however, France reversed its decision.¹⁸

In an opinion piece in the newspaper *Dagens Nyheter*, a group of researchers and care staff urged the Swedish Government to increase its humanitarian aid to poor countries that had been hit hardest by the coronavirus pandemic. They wrote: "At a time when more and more countries are closing their borders and looking after their own interests, Sweden must continue to stand up for important values and combine national and global action. Strong and effective international development cooperation and generously coordinated humanitarian aid are a key part of this".¹⁹

3.5 Recommendations

It is obvious that, in many cases, the global response to the coronavirus pandemic has been characterised more by national self-interest than by values such as international solidarity and global justice.

Building on global ethics and the goals set out in Sweden's global development policy,²⁰ Smer proposes the following:

- Sweden should provide support to developing countries that lack the healthcare resources to combat the coronavirus pandemic.
- Sweden should work in particular to support developing countries with any future vaccination programme. For countries with major deficiencies in their health service, a vaccine may be the best and perhaps only chance to protect vulnerable people.
- Refugees and migrants are being hit particularly hard by the coronavirus pandemic. Sweden should contribute to aid for migrants on the EU's borders, for example by supporting the work of UNHCR.
- Sweden should support the World Health Organization (WHO) in its work to coordinate the international fight against COVID-19 and research aimed at finding vaccines and therapies.

¹⁸ Ekblom and Hellekant 2020.

¹⁹ Alfvén et al. 2020.

²⁰ Swedish Government 2015.

4 Public health and pandemic mitigation

4.1 Current questions

The starting points for public health work are a conception of health, a concept defined in many different ways, and assumptions about which factors in a particular society affect the health of the population, as well as conceptions about how these factors can be influenced. It is not only a matter of prolonging life, but also of improving the population's quality of life.¹

A whole host of different measures may or will become necessary during a pandemic. This could involve recommendations about measures with varying degrees of severity that involve restrictions on people's freedoms and rights. Checking compliance with recommendations and regulations may require monitoring, for example monitoring mobile data. These measures may be voluntary or combined with various forms of obligation and sanctions.

When fighting pandemics and carrying out preventive work, it is important to know something about the anticipated effects. What is the likelihood that the intended effects will be achieved? What is the risk of unintended negative effects?

The answers to these questions may vary in different contexts.

Solidarity with those who are affected, and other members of the population is a central principle. This involves not exposing oneself to the risk of becoming infected and not unwillingly contributing to the spread of infection by, for example, failing to heed the Public Health Agency of Sweden's recommendations on hand hygiene and keeping a safe distance.

¹ In connection with public health work and public health ethics, see e.g. Dawson and Jennings B 2012, Dawson 2011, and Wilhelmson and Tengland 2016.

In the liberal, individualistic traditions that have dominated in Anglo-Saxon countries and the medical ethics that have developed there, the focus has been on the freedoms and rights of individuals. However, public health ethics focuses primarily on issues relating to the health of the population. A pandemic brings ethical issues to the fore within a number of ethical areas.

Free and informed individual consent has been a cornerstone of both traditional clinical ethics and research ethics. Concepts such as solidarity (within and between countries), cooperation, dependence, trust and confidence are central starting points for public health work, not least when a society is threatened by a pandemic. Alleviating and preventing other people's suffering is an important ethical challenge. By their very nature, people are social beings who live together and are dependent on each other.²

There are laws, regulations and recommendations governing public health work. The Communicable Diseases Act is one of them. When an infection is classed as a threat to public health and a threat to society, decisions can be made on actions such as quarantine, isolation and health checks on entry, and closing off areas. Depending on the actions that apply, it is the medical officer for infectious diseases, the Public Health Agency of Sweden or the Administrative Court who makes decisions on this in Sweden.

Many trade-offs and difficult questions about where to draw the line arise in this context. Some of these relate to vague regulatory concepts, while others relate to knowledge gaps and uncertainties, or the time pressure under which authorities have to work during a pandemic. For example, when should patients be isolated in an individual room? What personal protective equipment should healthcare and care home professionals use? It is reasonable to assume that this will vary with the nature of their work and the risks they are exposed to – and expose others to.

Many other questions arise in an epidemic. Is there a risk of discrimination against certain groups, such as the elderly and the socially disadvantaged? Are the restrictions in reasonable proportion to the risks? Should the health service offer preventive and curative treatments to certain risk groups or to healthcare professionals, to reduce the risk of spreading infection and to ensure that healthcare for those affected in the event of a pandemic does not collapse due to a

² Dawson 2011.

shortage of staff? Is this compatible with the principle of the equal value of all people? The requirement for care to be given on equal terms is set out in the preamble to the Health and Medical Services Act.

Should the entire population be tested to provide reliable data for prognoses of when herd immunity has been achieved? When individual choice comes up against what the good of the collective, this leads to thresholds and the problem of where to draw the line. We might assume that it is ethically defensible to introduce certain restrictions if thousands are saved and one person is affected, but that it is not defensible if one person is saved and thousands are affected. But what if 750 are saved and 350 affected? Or if 500 are saved and just as many are affected? On what grounds are these distinctions drawn? And by whom? As not everyone can be first to receive a vaccine or a diagnosis, who should be prioritised?

The more fundamental ethical questions that arise in this context include principles for weighing up different interests and values. Is the protection of individual freedoms and rights more important than what is good for society as a whole? If not, which restrictions of these freedoms and rights are ethically defensible? Should we strive to maximise the good, or is it also important to consider the effects of initiatives with regard to respect for human rights being threatened and/or different perspectives of fairness? And if so, how should these be defined?

Healthcare professionals have a greater risk of being affected by infections, and of passing them on to others. This same is true of those working in care homes for the elderly, as is clear from the COVID-19 pandemic. It is therefore important that they have knowledge about hygiene routines and how infection is spread, and that they have personal protective equipment. When a vaccine is available, these workers should be vaccinated. Against this background, there have been discussions about who should be given priority for vaccination, and whether any such future vaccination should be voluntary or mandatory and free.

Relevant arguments for and against mandatory vaccination include the effectiveness of the vaccine when it comes to protecting against infection, how necessary mandatory vaccination is to achieve the desired protection against the spread of infection, the risk that individuals and society will be lulled into a false sense of security and thus fail to take other necessary preventive measures, the costs and

administration involved in carrying out vaccination, any negative side-effects of vaccination, and considerations regarding what is best for the population as a whole versus the right of individuals to make decisions about their own lives. Which of these arguments carries the most weight?

4.2 Choosing a strategy

How should the coronavirus pandemic be combated? Which decisions should politicians and public health authorities take? And when? Naturally, the answers to these questions are determined by the development of the pandemic at different stages. The answers to these questions also have aspects relating to social ethics. The question involves how measures aimed at combating the pandemic may affect different values in society, how certain values may be actualised at the cost of others, and how can these conflicts of values be resolved.

4.2.1 Discussion on the choice of strategy

There have been intense discussions on which strategy Sweden should choose for dealing with the coronavirus pandemic. Several commentators have been critical of the Public Health Agency of Sweden's 'soft' strategy, which – in contrast to some other countries – has involved more recommendations and fewer prohibitions, less legislation, etc. Opinions are divided among epidemiologists, infectious disease researchers, etc. This section begins by providing an overview of certain opinions. It then describes how an ethical decision model can be used to clarify the discussion.

In mid-March, a research team at Imperial College London published various scenarios from mathematical models of the spread of the COVID-19 virus.³ Based on these scenarios, social distancing is recommended in order to reduce the spread of the virus as far as possible. The study led to the UK changing its strategy for combating the coronavirus pandemic and introducing a lockdown of society. In a follow-up study a few weeks later based on statistics on

³ van Elsland and O'Hare 2020.

the development of the coronavirus pandemic in eleven European countries, the results of different strategies were compared.⁴ The mathematical models produced by Imperial College's research team have been strongly questioned.⁵

Imperial College's calculations have been used as the basis for harsh criticism of the Public Health Agency of Sweden's softer strategy. Critics have argued that Sweden, too, should introduce stricter restrictions and close down society. They believe that the recommendations to isolate risk groups such as those aged over 70 are insufficient, and that general social distancing by means of a politically mandated curfew, for example, is necessary in order to reduce the spread of infection and thus avoid overloading the health service. They also say that the agency's incorrect strategy may lead to thousands of deaths.⁶

In response to this criticism of the Swedish strategy, it has been argued that mathematical simulations are not sufficient grounds for political decisions. These require more than mathematical models, for example knowledge about different sustainable interventions and the effects of measures regarding infection epidemiology, infection control, health, and social functions (including economic consequences and subsequent effects on health), which must be constantly adapted in line with the prevailing infection epidemiology situation, according to those who have defended the agency's strategy.⁷

These mathematical simulations need to be seen in a wider context: it should be clarified what these models include and exclude, and the models' unavoidable uncertainties need to be highlighted and discussed. People's actions are controlled by many factors – psychological, social, and so on – and by ideals and norms. Assumptions about these factors are crucial to the assertions resulting from these models and are also subject to particular uncertainty. How will people react to political decisions? What happens to society in the short and long terms if a curfew is imposed? Interventional measures in the form of social distancing, isolation, etc. may have negative consequences for social values such as trust, confidence and caring.⁸

⁴ Flaxman et al. 2020.

⁵ See e.g. Harfor 2020, Cookson 2020, Begley 2020, Hamzelou 2020.

⁶ Rocklöv and Rootzén 2020; Brusselaers et al. 2020; Carlsson et al. 2020.

⁷ Björkman 2020. Ludvigsson 2020.

⁸ Collste and Timpka 2020.

It is possible to include these factors in models, but this requires particular consideration when it comes to interpreting and drawing general conclusions from the results.

There is therefore intense ongoing debate about the best strategy for dealing with the coronavirus pandemic. This debate is interesting for a number of reasons. It shows the public that researchers within fields such as epidemiology and infection control may be deeply divided in their opinions and interpret empirical evidence in different ways. In other words, a critical discussion is taking place, just like in research and academia in general, but now in a much more public forum. On the basis of their interpretations, they make policy recommendations which are also based on normative premises which are often not reported.

In order to clarify the discussion, we can apply an ethical decision-making model⁹ which may help to identify relevant factors when making decisions. The first part of the ethical decision-making model involves identifying possible alternative courses of action – everything from lockdown and strict social distancing, via recommendations and voluntary measures, to not doing anything at all. The debate referred to above features two main alternatives: either a lockdown or the softer strategy chosen by the Public Health Agency of Sweden. From this point, we will focus on these two alternatives.

The next step in the decision-making model involves identifying the consequences of the different strategies. In order to address this question, we must focus on possible and particularly relevant consequences. The consequences brought up in the discussion relate to the number of deaths and the number of people who become ill if one strategy or the other is chosen, as well as the social and psychological consequences for people and the short- and long-term economic consequences – and the subsequent effects on health.

What is the likelihood of the various possible consequences occurring? The likelihood of the outcome is incredibly important for making a well-founded decision, but when it comes to the choice of strategy to combat the coronavirus pandemic, the outcome is extremely hard to assess. There was no experience of COVID-19 prior to the outbreak of the epidemic, and the grounds for assessing the likelihood of one outcome or the other are therefore extremely uncertain.

⁹ See e.g. Smer 2018 and Collste 2019.

Naturally, the question of evaluating different consequences is central to an ethically well-founded decision. The main value highlighted in the discussion is the value of human life – how many deaths from COVID-19 and other causes such as suicide, abuse, exposure to violence and cardiovascular problems will one strategy or the other lead to? However, other values have also been mentioned in the discussion, such as physical and mental well-being, freedom, experiences of alienation and economic values.

The decision-making model clarifies what a decision-maker has to take into account when choosing a strategy, but it should be emphasised that assessing the possible consequences and their likelihood is difficult for a disease that we have no previous experience of. The decision is also hard because of the extreme complexity of weighing up values against each other. Assume, hypothetically, that a certain strategy will probably involve fewer deaths, but also results in serious mental consequences for a large number of people. In such a hypothetical scenario, how is the value of human life weighed up against the value of mental health problems? How many people's mental ill-health corresponds to one death?

Smer's conclusion regarding the choice of strategy to combat the coronavirus pandemic is that an ethical analysis can help us to identify relevant factors but can hardly provide complete data for a recommendation. Based on an overview of different possible scenarios, decision-makers take a position on which decision can be assumed in an overall assessment to have the best consequences, based on the values and principles that should provide guidance and to which they have chosen to attach particular importance. Decision-making during a pandemic cannot therefore be based solely on facts and scientific evidence. When weighing up different alternative courses of action, a position is also taken on values and value conflicts, with the ethical analysis being of great importance both during the pandemic preparedness phase (in other words, identifying important principles and values that should apply) and in the decision-making process during ongoing pandemic management. The outcomes of different strategies can be reviewed and evaluated afterwards.

4.3 Interventional measures during a pandemic

4.3.1 Introduction

To stop the spread of infection in a pandemic, it may be necessary to implement measures aimed at reducing physical contact between people, including lockdown and other measures for social distancing, isolation and quarantine. These measures may be supplemented with measures to check compliance with prohibitions and recommendations, including monitoring by sharing mobile data that shows people's movements. Sharing location and/or health data via mobile phones may also be introduced to track infections or to warn people who have come into contact with an infected person. One thing that these measures have in common is that they may infringe in various ways on self-determination and personal privacy and may seriously encroach on fundamental civic freedoms and rights.

These measures may be mandatory to a greater or lesser extent. At one end of the spectrum is recommendations, which are voluntary by definition and which the individual can – in principle – choose not to follow (even if social pressure to follow them can be strong). At the other end is legislation, with stiff punishments for those who break it. This spectrum should be taken into consideration when discussing restrictions on freedoms and rights.

4.3.2 Social distancing

During the current pandemic, Sweden has chosen to rely mainly on non-binding recommendations to reduce physical contact between people. This is known as social distancing.¹⁰ Certain formal prohibitions have been introduced, such as a ban on public gatherings of more than 50 people and a ban on visiting the country's homes for the elderly. A temporary paragraph has been added to the Communicable Diseases Act, allowing the Government to temporarily ban gatherings above a certain size, to decide on closing down commercial, social or cultural operations, to introduce travel restrictions and to implement other similar measures. In many other countries,

¹⁰ WHO has announced that it has started talking about 'physical distancing', since the organisation strongly encourages social contact via digital platforms – see WHO 2020 f.

governments and authorities have introduced more invasive measures during the current crisis, such as lockdowns and curfews.¹¹

The aim of various social distancing measures is to protect public health by reducing the spread of infection. Since the risk of serious illness varies between different groups, it also involves protecting risk groups and showing solidarity with those at the greatest risk of coming to harm. Experience from the current pandemic shows that many people are prepared to submit to strict restrictions in order to prevent infection – they may even wish for stricter restrictions than those that apply. At the same time, social distancing measures may involve significant restrictions on self-determination and may seriously encroach on fundamental democratic freedoms and rights.¹² Checks and other measures for enforcing prohibitions may infringe on personal privacy.

The difficult value conflicts that arise in connection with social distancing mean governments have a real responsibility not to introduce unnecessarily invasive measures. This applies in relation to both how extensive the measures taken are, and whether they are voluntary or binding. Recommendations do not involve as much of an intervention in terms of self-determination as binding rules, which is one argument for relying on voluntariness as far as possible.

Another strong argument for voluntariness is the potential risk that binding measures will not be lifted when the crisis is over, instead becoming permanent to some extent.

Recommendations also have the advantage of allowing a degree of flexibility that may alleviate psychosocial, economic and other negative effects of the measures, such as not prohibiting all journeys and instead allowing citizens to decide whether or not a particular journey is essential. Binding rules must be clear for reasons of legal security and may therefore need to be more ‘conventional’ than is necessary from a purely infection control perspective.

¹¹ Many countries have decided to close schools, shops, restaurant, etc. Several countries have introduced restrictions on how many others outside one’s own household people can socialise with. Curfews have been introduced in Italy, Spain, the UK, France and Austria, for example, where people have been prohibited from leaving their homes. Only the most essential activities are exempted from this prohibition, including buying food and going to work if remote working is impossible.

¹² Rights in the Constitution of Sweden that may be affected include the freedom of assembly (Chapter 2, section 1, point 3 of the Instrument of Government), the freedom to demonstrate (Chapter 2, section 1, point 4 of the Instrument of Government), the right to personal privacy (Chapter 2, section 6 of the Instrument of Government), the freedom of movement within the Realm (Chapter 2, section 8 of the Instrument of Government) and the freedom of trade (Chapter 2, section 17 of the Instrument of Government).

The main argument against voluntariness is that it can be hard for voluntary social distancing measures to be sufficiently effective. Far-reaching, long-lasting measures to reduce physical contact between people are demanding and can create incentives for generous interpretation of the recommendations. Individuals may also be tempted to grant themselves exemptions, arguing that their actions are of little significance in the grand scheme of things.

Another argument could be that it is hard to achieve sufficient sustainability via voluntary measures, not least if they prove successful and a sense of ‘the danger being over’ begins to spread. However, there is no evidence regarding whether voluntary or mandatory measures provide the most sustainability. Voluntariness can also lead to a greater sense of joint responsibility for combatting the pandemic and can mean that the measures are tolerated for longer.

When deciding between voluntary and mandatory measures in the case of social distancing, fairness may be a factor to take into consideration. It is considerably harder or more burdensome for some people to follow restrictions than others. Examples may include those who live in cramped conditions and homeless people. Recommendations allow exceptions for those who have strong reasons and may lead to the burden of restrictions being allocated more fairly than if everyone has to follow the same rules without exceptions. On the other hand, voluntariness means that some individuals may choose to disregard the recommendations while others make significant sacrifices to take responsibility and show solidarity, which could be perceived as unfair and create social tension. Binding rules that everyone must follow may be seen as fairer.

Another important aspect to take into account is trust. Choosing to rely on voluntariness can be a way of signalling trust in citizens’ sense of responsibility.¹³ This in turn can strengthen trust in society and thus the desire to submit to restrictions in everyone’s best interests.¹⁴ In a democratic society, mandatory measures – particularly if they are highly invasive – require citizens to trust the government and authorities to act in the best interests of the public. If decision-makers fail to treat this trust responsibly, this can have serious negative societal consequences.

¹³ According to the Public Health Agency of Sweden, experience shows that a well-informed, motivated person understands and follows given recommendations, and that taking individual responsibility is better than forced measures – see the Public Health Agency of Sweden 2020a.

¹⁴ However, voluntary rules can also be perceived as decision-makers relinquishing their responsibility by passing it on to citizens.

4.3.3 Isolation/quarantine

Isolation/quarantine has the same underlying aim as social distancing – to prevent the spread of infection – but is aimed at individuals. However, the purpose of these measures is not to protect the individual themselves, who is already carrying or suspected of carrying the infection, but to protect others. Isolation/quarantine can therefore be particularly sensitive from the viewpoint of human value.

Just like social distancing, isolation/quarantine can be either mandatory or voluntary. Provisions on this are included in the Communicable Diseases Act (2004:168).

The ethical conflicts in the case of isolation/quarantine are largely the same as those for social distancing: voluntariness is less of an intervention in terms of self-determination, but risks being less effective in certain situations. In some cases, it might be absolutely essential to separate an individual from others to prevent the spread of diseases that pose a threat to society. According to the Communicable Diseases Act, medical officers for infectious diseases can decide whether an individual who has – or can be assumed to have been exposed to – a disease that poses a threat to society should be held in quarantine. The Administrative Court can also rule that a person carrying a disease that poses a threat to society should be isolated if voluntary measures are insufficient.

4.3.4 Digital tools

Ever since the outbreak of the COVID-19 pandemic, the possibility of using technology – particularly mobile phones and wearable tech – to combat the pandemic has been discussed. Different applications have been introduced or considered in many parts of the world (see box below). The aim may be to warn people who have been in contact with infected people, or to monitor compliance with prohibitions and recommendations on social distancing or quarantine. When implementing such measures, several countries have decided on temporary legislation granting exemption from regulations that would hamper efforts to monitor the population.

Examples of digital technology in the work against COVID-19

When travellers arrive in *Hong Kong*, they must download an app that shows if they move outside the area where they have permission to be. *South Korea* also requires a state app to be downloaded and used to monitor people's movements. In *China*, citizens must report their health status daily via an app, which also logs who they have been in contact with. *Singapore* uses a voluntary app which saves data locally on users' phones. It is only when people are diagnosed that they are asked whether they use the app and are willing to share the data held on their phone.¹⁵

In both *China* and *South Korea*, apps are used which map outbreaks and then warn citizens to avoid these locations.

Israel has introduced temporary legislation to monitor the population digitally.¹⁶ The authorities track the individual's movements and inform those who have been in contact with infected people.

In *Lichtenstein*, a research programme has begun whereby the entire population will be offered a bracelet that continuously measures details such as the wearer's temperature, breathing and pulse, and reports this data in real time. The idea is to be able to identify COVID-19 before symptoms even appear, and thereby be able to isolate infected individuals in the event that a suspected second wave of infections occurs.¹⁷

In *Norway*, a voluntary app allows users to report if they have been infected. Mobile positioning and Bluetooth technology will be used to send warnings to others who have also downloaded the app and have been in close proximity to the infected person.¹⁸

In *Sweden*, the Public Health Agency of Sweden uses anonymised and aggregated data from Telia's mobile phone network to study how movements within the population contribute towards the spread of COVID-19 within the country, and to see how different recommendations are complied with.¹⁹ The use of tracking apps has not yet been deemed to be appropriate in Sweden.²⁰

¹⁵ Norén 2020a.

¹⁶ Livni 2020.

¹⁷ Jones 2020.

¹⁸ Norén 2020b.

¹⁹ Public Health Agency of Sweden 2020b.

²⁰ Carlsson 2020.

Just like with other measures in a pandemic, the primary objective of using digital technologies is to protect lives and health. However, this objective can come into conflict with other ethical values. If location data from mobile phone operators begins to be gathered to monitor compliance with physical distancing measures or quarantine, or to track those who have been or risk being infected, this presents a threat to personal privacy linked to (automatic) monitoring of individual citizens. Such data can be used to answer questions other than pandemic-related issues about where the individual has been and who they have met. If health data – which is classed as sensitive personal data – is collected, there will be additional threats to privacy. A mandatory requirement to use a particular app is, in itself, a restriction on self-determination.

The fact that these technologies risk infringing democratic freedoms and rights and contravening fundamental ethical values means that any implementation requires careful consideration. One basic requirement for digital tools to be ethically defensible is that there must be support for them having an effect. The UK's Ada Lovelace Institute has evaluated different forms of digital technology in the work to combat COVID-19. Their report deals with health apps for contact tracing, symptom tracing and immunity certification (see below). They point out that there is currently no evidence that existing infection tracing and symptom apps work, and that their introduction – aside from the ethical issues – raises a number of difficult questions regarding functionality, quality and security.²¹

How different digital tools are designed and implemented determines the scale of the ethical conflicts. One important question to ask is, therefore, whether the measures are proportional in relation to the objectives that they intend to meet and whether there might be other more effective measures that are less invasive. This could involve models where data is not gathered centrally, for instance, or where only anonymised data is collected.

One important aspect relates to whether it is voluntary or mandatory to use the digital tools. For example, the effectiveness of digital tools is often related to how many people use a tool. Individuals may be interested in using digital tools to protect themselves and others. The key question is whether enough people will begin

²¹ The Ada Lovelace Institute 2020.

using the tool voluntarily for it to be effective in the work to fight the spread of infection.

In this context, it may need to be considered that methods for limiting infection based on digital technologies may offer alternatives to other measures to limit the spread of infection which may be more invasive and/or have a greater negative impact on the national economy. If a large proportion of the population uses apps that warn those who have been close to infected people that they need to be tested or to isolate themselves, society – particularly during a later stage of the pandemic – would be able to ease general measures for social distancing.

Trust is also a central value in relation to digital tools. If citizens are to use these tool voluntarily, they need to be able to trust that shared data will not be misused. The more sensitive the shared data, the greater the trust that may be required. Just as with social distancing, making it voluntary to use an app can be a way to demonstrate trust in citizens, which in turn may increase voluntary use. In contrast, making this mandatory may be interpreted as distrusting citizens. Transparency when it comes to which data will be processed and for what purposes is essential for trust. If it emerges that collected personal data is misused or falls into the wrong hands and individuals' personal privacy has been violated, confidence in society's institutions may suffer great harm.

Another ethical aspect that needs to be considered is equity. Those who have lower levels of digital competence, or who do not have the latest mobile phone models with the necessary capabilities, may not be able to use these apps. This may relate to groups to a certain extent, such as the elderly, for whom the need for protection is particularly great.

One particular area of concern relates to whether states' encroachment into citizens' personal sphere may be normalised, and that personal privacy and human rights may also be threatened in the long term.²² In a joint statement, more than 100 organisations that work for human rights emphasised that human rights must be defended if states use digital technology to combat COVID-19. They point out that authorities cannot disregard the right to privacy, and that they must ensure that their actions take human rights into

²² See Harari 2020.

consideration.²³ Several international and national ethics councils have also emphasised the importance of personal privacy and human rights being defended.²⁴

The European Data Protection Board has stated that the EU's General Data Protection Regulation does not prevent measures being taken to prevent the spread of infection during the current pandemic, but that it is also important for the individual's right to a private life and the protection of personal data to be defended under the unique prevailing circumstances.²⁵

The Ada Lovelace Institute has proposed that the UK Government should set up two independent bodies: one to evaluate the evidence for apps and provide advice on their design and implementation, and another with responsibility for ongoing monitoring of implementation and policy. It also points out the need for specific regulation regarding the digital monitoring mechanisms and any immunity certificate brought into use during the crisis, which should include a time limit on their use.²⁶

4.3.5 Immunity certificates

The possibility of using 'immunity certificates' in the work to combat the pandemic is currently being discussed in several countries.²⁷ Such a certificate could be issued to those who can demonstrate that they have had COVID-19, for example via a test showing current infection or an antibody test showing that they have been infected. Certificates could also be issued in future when someone is vaccinated against the disease. The aim of a certificate is to indicate that the person has a lower risk of being infected by the virus.

Immunity certificates could be used in countries that have closed down society and are considering various options for re-opening society without the spread of infection gathering pace. Individuals who can demonstrate that they have been infected could avoid certain restrictions. In addition to the benefits that this brings for the individual, such certification could also have positive effects for re-

²³ Amnesty International et al. 2020.

²⁴ See e.g. DH-BIO 2020, EGE 2020, German Ethics Council 2020.

²⁵ The European Data Protection Board 2020a.

²⁶ Ada Lovelace Institute, 2020.

²⁷ Edlin and Nesbitt 2020; Bienkov 2020; Smout, Bruce and Howcroft 2020.

starting the economy and various societal functions without risking increased spread of infection. Those who can produce a certificate confirming that they have been infected could also avoid quarantine requirements when travelling between different countries.

However, issuing immunity certificates raises a number of practical, medical, legal and ethical questions.²⁸

One fundamental issue relates to how strong immunological protection against re-infection is, and how long it lasts. To date, there is no evidence for achieving short- or long-term immunity by having had the virus.²⁹ It will be some time before we can know for certain whether this protection lasts for even six months or longer.

A requirement to produce an immunity certificate to avoid certain restrictions also involves the individual having to provide information about their own health, which may be particularly sensitive from a privacy point of view.

An immunity certificate could also lead to discrimination within society, where immunity offers greater opportunities to work and to move freely. This could lead to social tensions, and to the stigmatisation of those without immunity.³⁰ Even if a vaccine becomes available in the future, it will probably not be possible to vaccinate everyone for medical reasons.

Another risk with immunity certificates is that individuals may be tempted to become infected on purpose, particularly in countries where tough restrictions apply. Individuals may feel compelled to become infected in the hope of achieving immunity, for example in order to return to work or get a job.³¹

If an immunity certificate offers major advantages for the individual, it is also conceivable that a market for fake certificates or using other people's certificates could arise.³²

²⁸ One requirement for an effective strategy based on immunity certificates is, of course, reliable testing that does not give false positives. Many of the antibody tests launched so far have proven to have poor reliability, even if these tests are constantly improving.

²⁹ Graham 2020; Edwards 2020; the Ada Lovelace Institute 2020, p. 43.

³⁰ The Ada Lovelace Institute 2020, p. 51.

³¹ Baker and Larsen 2020.

³² This is hardly likely to be a problem in Sweden, but could pose a risk in other countries.

4.3.6 Recommendations

The council believes that, when choosing a strategy for pandemic mitigation, an ethical analysis model can help to identify relevant factors and conflicting values and interests.

The council is also of the opinion that:

The ethical and societal aspects must be considered before every decision on measures that risk curtailing individuals' self-determination, personal privacy or other fundamental rights and freedoms.

The measures should be based on an interest in protecting life and health, building up evidence and being proportional. If there are less invasive options with acceptable effectiveness, these should be chosen.

Mandatory measures aimed at reducing physical contact between people must be legally defensible, subject to a time limit and no more far-reaching than is absolutely necessary.

Society must support those individuals who are affected negatively by recommendations and prohibitions in various ways.

If digital tools are introduced as part of efforts to prevent the spread of infection, these should be subject to a time limit and the data gathered should be anonymised. Questions of security, quality and data protection are key, as are oversight and accountability. The use of any national health apps for virus tracking should be voluntary.

Digital tools for tracking and tracing that could entail serious infringements of an individual's private life should not be introduced.

The science, the values and the balancing of interests that form the basis for measures involving infringements of people's rights and freedoms must be openly communicated to the public.

5 Challenges in healthcare

5.1 Introduction

Healthcare is one of the sectors of society that is put under the most strain during a pandemic. A pandemic poses ethical challenges for the entire health service. This chapter considers a limited selection of ethical issues and challenges for the health service during a pandemic.¹

5.2 Roles and responsibilities of healthcare professionals

The coronavirus pandemic involves difficult practical and ethical challenges for the health service and its employees. In a crisis situation, such as an epidemic, doctors and other healthcare professionals must quickly adapt and respond to an enormous increase in seriously ill patients who need urgent assistance.

Healthcare professionals are a particularly vulnerable group who are exposed to significant health risks in direct contact with infected patients. They will also need to deal with situations where difficult prioritisations have to be made between patients in situations where there are insufficient resources for everyone.

They will probably face situations where they are unable to meet the objectives of professional ethical guidelines and the principles which normally apply within healthcare. In such a situation, they will be exposed to considerable pressure and will risk both exhaustion and being affected by what is known as ethical stress.²

¹ A large number of ethical challenges arise within care, such as at care homes for those with functional impairments and care homes for the elderly. Healthcare professionals and care professionals encounter the same and similar challenges. Due to time limitations, we have restricted the number of issues addressed in this report.

² See e.g. Vårdförbundet 2020, Dagens Medicin 2020.

Table 5.1 Simplified presentation of the differences in perspectives, objectives and duties between clinical ethics and a public health perspective

Clinical ethics*	Public health perspective
<p><i>Obligation to provide care:</i></p> <ul style="list-style-type: none"> – Healthcare professionals shall always have the patient’s health as the primary goal, and shall if possible cure, often alleviate and always comfort. – Respect the patient’s wishes and privacy. <p>Focus on the individual patient.</p>	<p><i>Observe people’s equal rights and value:</i></p> <ul style="list-style-type: none"> – Promote fairness in the allocation of risks and advantages. – Promote the health and safety of the population. – Protect health among the population. – Allocate limited resources according to need. <p>Focus on the population.</p>

* Image inspired by Berlinger et al. 2020.

One important issue relates to the roles and responsibilities of healthcare professionals during a pandemic. Generally speaking, there is great deal of willingness to do one’s part. Amid the current crisis, people from healthcare backgrounds who have worked in administrative backgrounds for decades are helping with patient care, retirees are returning to work, and specialists are changing fields. Those studying to work in caring professions are signing up to help where needed. At the same time, healthcare professionals are a particularly vulnerable group during epidemics of infectious diseases, as they have direct contact with sick patients.

It can be hard to weigh up the risks of being infected oneself, unwittingly infecting others, and carrying out one’s work in the best possible way for the patient. Weighing up these risks can involve a number of different people. If healthcare professionals have relatives in a risk group, this also involves their interests. The risk of professionals unintentionally passing the infection on to others within and outside the health service is a major problem. From the carer’s perspective, it is important that staff do not fall ill as care will then generally be threatened. At the same time, the care provider may find it hard to comply with the safety requirements if there is a shortage of personal protective equipment or if the care provider has insufficient knowledge about what constitutes an adequate level of protection.

When the need for care increases quickly in the form of a large flow of patients with serious conditions, the workload of the health

service increases. When viewed as an organisation, the health service is flexible. There is preparedness for crises and catastrophes, and those working within operations are used to adapting and improvising according to the situation.

The Swedish health service has been under pressure for a number of years, for example with long waiting times for planned procedures, under-dimensioned primary care, and over-full accident and emergency departments. A number of government inquiries³ have been appointed to propose solutions to what the media sometimes refers to as ‘the healthcare crisis’.

There has been a focus on the health service in connection with the COVID-19 crisis. Questions which have seemed unanswerable are suddenly resolved, and the Government promises that funding will be made available to solve the crisis.

In itself, this extraordinary situation creates ethical conflicts. Many care interventions are postponed, and various recommendations to cut down on personal contact in care involve medical risk-taking, the size of which can be hard to estimate. This includes responsibility for ongoing contact and check-ups with patients with long-term illnesses, who may be suffering from multiple comorbidities. Patient groups who are not inclined to seek care despite needing it risk falling by the wayside. Hence, there is a risk that patient safety will suffer.

Healthcare professionals are confronted with the dilemma of providing the best care to the individual patient while also taking responsibility for public health and the wider group of patients (see figure above).

In an extraordinary healthcare situation, such as a pandemic with a higher number of patients with particularly serious life-threatening conditions, the assessment of the need for care will be more acute.

It can be expected that there will be widespread public understanding of the importance of not seeking care for minor complaints. However, it also seems that patients with serious conditions will refrain from seeking care. For example, considerably fewer patients have come to hospital with acute stroke since the outbreak of the coronavirus pandemic. However, the incidence of stroke is relatively constant, and science and proven experience are clear about the significant benefits of rapid diagnosis and treatment in the case of stroke. Could it be that people are refraining from seeking

³ SOU 2017:53, SOU 2018:39 and SOU 2019:29.

care out of consideration for the severely overburdened health service, or due to a fear of becoming infected or being turned away?

If the bar for which care needs can be dealt with has to be raised dramatically, and for a longer period of time, there is a risk of professional indifference. Being able to say “Just a few years ago we couldn’t offer a cure for your condition, but effective treatment is now available, and I would like to offer you it” is an important source of professional pride. If a doctor faces situations on a daily basis whereby medical conditions that would normally have been dealt with immediately must instead be turned away or added to a waiting list to be dealt with at some unspecified point in time, key aspects of professional motivation may be affected. This can be particularly true when combined with the feeling that one does not have any particularly effective help to offer seriously ill COVID-19 patients.

5.2.1 Recommendations

In this context, Smer would like to emphasise that it is of the utmost importance to ensure that healthcare professionals and care professionals are protected. Personal protective equipment and initiatives to prevent the spread of infection among healthcare professionals and care professionals must be prioritised.

It is also important that 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.

5.3 Priority setting

In a pandemic, there is a risk that many people will become ill at the same time, which will put greater pressure on the resources of the health service. Even if the health service is given additional resources, there is a substantial risk that this will not be enough to meet the increased demand and shortages of various kinds will occur. The health service’s resources may be limited when it comes to personnel, ventilators, beds, medication, personal protective equipment, vaccines, and so on. If the demand for healthcare exceeds the resources, priori-

tisations will have to be made.⁴ During a pandemic, the health service faces prioritisation challenges at both group and individual levels:

- *Prioritisation at group level.* Many of the patients who are affected by the pandemic are seriously ill and may need intensive care or other life-sustaining treatment in order to survive. According to the principle that care should be prioritised by need, resources may need to be redistributed from other operations to intensive care in particular, and other less urgent care may need to be postponed or not provided at all.
- *Prioritisation at individual level.* Even if intensive care is assigned more resources, it may be hard to meet the need during a pandemic. Prioritisations between different patients with very great and sometimes equal care needs may therefore have to be made.

The ethical platform for priority setting

Since healthcare resources are not unlimited, prioritisations always need to be made. Prioritisations are made at group level, for example when regions set the budgets for various operations, and at individual level when resources are insufficient for all care needs and healthcare professionals have to decide which patient should receive care or should receive care first. In 1997, the Riksdag adopted an ethical platform for priority setting within the health service, which has been included in the Health and Medical Services Act (2017:30). The platform includes three principles that express basic values which should guide prioritisations at both individual and group levels.

- *The principle of human dignity.* All people have equal value and the same rights, regardless of their personal qualities and their functions in society.
- *The principle of need and solidarity.* Resources should be directed to the person or operation with the greatest need.
- *The principle of cost-effectiveness.* When choosing between different operational areas or measures, a reasonable relationship between cost and effect should be striven for, measured in terms of improved health and quality of life.⁵

⁴ A growing body of literature discusses the challenges of prioritisation ethics. A selection of articles is presented at www.smer.se. See also e.g. Emanuel et al. 2020 and Truog et al. 2020.

⁵ SOU 1995:5 p. 115.

Since these principles have different aims, the order in which they are ranked is important when dealing with conflicts. The principle of human dignity should be applied first, followed by the principle of need and solidarity, and finally the principle of cost-effectiveness.

Applying the principle of human dignity when making prioritisations means that people cannot be differentiated between based on their personal qualities or their functions in society, such as talent, social position, income, health conditions, age, etc.⁶ According to the principle of need and solidarity, the most seriously ill and those with the poorest quality of life should be prioritised. The more serious the illness or injury, or the poorer the quality of life as a consequence, the greater the need. At the same time, there is no need for interventions that do not improve health or quality of life. The degree of seriousness of the illness can be assessed based on various factors: the suffering experienced, the medical prognosis, the disability and the existential need that the illness results in.⁷ The benefit aspect is built into the concept of need. This means that one is only deemed to need a *specific measure* if one will benefit from it, or – conversely – that one does not need an intervention that one will not benefit from.⁸ The medical decisions that are taken must always be based on science and documented good results.⁹ According to preparatory work, the benefit of care can be graded in principle. In relation to health-related needs, it can be seen in the form of cure or improvement in health. In relation to needs relating to quality of life, it can be seen in the form of reduced suffering, improved social function and other measures that are deemed to give an improved quality of life by the patient in question.¹⁰

The prioritisation platform has led to a discussion on certain difficulties in connection with interpretation and application.¹¹ Several commentators have also defended the platform in its current form.¹² However, it can be noted that it applies, and that it forms a starting point for the work of all health service players, whatever their role or responsibility.

⁶ SOU 1995:5 p. 117 and Govt Bill 1996/97:60 p. 20.

⁷ SOU 1995:5 p. 110 ff. and Govt Bill 1996/97:60 p. 17.

⁸ SOU 1995:5 pp. 112 & 136 and Govt Bill 1996/97:60 p. 18.

⁹ Govt Bill 1996/97:60 p. 18.

¹⁰ SOU 1995:5 p. 111.

¹¹ See also SOU 2020:23 p. 46.

¹² Smer 2009; Sahlin 2008; Sahlin 2010; Höglund, Hermerén and Sahlin 2016; Hermerén and Sahlin 2018; Hermerén and Sahlin 2019.

5.3.1 Prioritising routine healthcare

Based on the principle that care should be provided according to need, it may be necessary in connection with a pandemic to deprioritise some routine healthcare on the grounds that resources need to be reallocated. Surgery, care visits and other interventions may need to be cancelled. However, care may be required at an early stage for certain diseases in order to prevent a more serious condition developing and the need for more extensive treatment arising. Even less serious conditions may lead to more serious diseases or injuries and suffering if left untreated for a longer period of time.

In connection with the ongoing pandemic, the National Board of Health and Welfare has drawn up principles for prioritising routine healthcare during the COVID-19 pandemic.¹³ The document presents a model for deprioritising certain care (other than intensive care) during the pandemic. One aim is that high-priority routine healthcare should not risk being deprioritised as a result of the pandemic. Another aim is to reduce ethical stress for healthcare professionals. The model involves care being ranked in different prioritisation groups, and deprioritising care in accordance with this ranking, as far as required by the shortage of resources. Care interventions that only have a minor medical effect and where a delay has a minor impact on the patient's health or quality of life are deprioritised in the first instance.

In connection with a pandemic, such as the COVID-19 pandemic, there is a risk that urgent routine healthcare will also be deprioritised due to resources being reallocated.

This must be taken into consideration when rationing and deprioritising care, and the National Board of Health and Welfare's model is an instrument for use in this process. It is also important not to overlook resuming treatment for patients who risk deteriorating if the pandemic continues for a long time.

The inquiry into the preparedness of the health service has stated that an objective for the civilian health service during crises in times of peace and war should be to have the capacity to carry out care that cannot wait. This also includes care provided at an early stage to prevent more serious medical conditions developing. The inquiry notes that the prioritisation platform drawn up by the Riksdag applies when prioritising the need for care. It also states that "although the

¹³ The National Board of Health and Welfare 2020a.

general standard of care cannot be the same, the medical treatment results for the vast majority of patients should correspond as far as possible to a normal peacetime situation”.¹⁴

5.3.2 Prioritising intensive care resources

One important factor in the state’s and the authorities’ assessment of which measures need to be taken in connection with a pandemic is the population’s need for intensive care in relation to the number of intensive care beds available. By recommending social distancing and the isolation of risk groups, the aim is to avoid the virus spreading too quickly among the population as a whole. In order to increase the number of intensive care beds, resources such as staff and ventilators can be reallocated, and temporary care facilities may need to be established. If a situation arises where the need for intensive care beds is greater than the number of available beds, the health service will however be forced to make difficult decisions.

The prioritisation of intensive care resources is currently being discussed in most countries. When these resources are no longer sufficient to meet the need for intensive care, patients who would otherwise have received care must be deprioritised, which can have critical consequences for individual patients. This creates ethical stress for healthcare professionals who have to make these decisions and leads to the question of who should be given priority for care. Should a young patient be prioritised over an elderly one? Should a patient who plays an important role in society be given preference over an ordinary citizen? If so, who should make the assessment? When should ventilator treatment be ended to make way for someone else?

According to the Swedish prioritisation platform, the patient with the greatest need should be prioritised. As mentioned above, the principle of human dignity does not allow for prioritisation based on chronological age and social function. A patient’s need is determined by the degree of seriousness of the disease or injury, or how impaired the quality of life is as a result. The need is also assessed based on the patient’s benefit from a treatment. When it comes to COVID-19 patients who need intensive care, the severity of the condition is deemed to be equal in many situations. Healthcare pro-

¹⁴ SOU 2020:23.

professionals must then assess the benefit to the patient. This benefit is determined by the level of cure or improvement in health. In terms of needs relating to quality of life, it can be determined in the form of reduced suffering, improved social function and other measures that are deemed to give an improved quality of life by the patient in question. If there is a high likelihood that a patient will die shortly after intensive care treatment ends, the benefit of the treatment is deemed to be low. Because intensive care treatment using ventilators places great demands on the body, those with certain underlying conditions risk coping less well with the treatment than previously healthy individuals. The guidelines for how intensive care should be allocated in the event of a shortage of resources is different in different countries, but many seem to agree that the chance of survival should carry significant weight when it is not possible to provide intensive care for everyone.

In Sweden, the National Board of Health and Welfare has drawn up principles for prioritisation within intensive care under extraordinary circumstances.¹⁵ The aim is to support the health service when making decisions on prioritisations, and the principles are intended to be applied in those cases where infections as a result of the COVID-19 pandemic lead to the need for intensive care exceeding available resources.

The board writes that, under extraordinary circumstances and with limited resources, the indication for intensive care needs to be made stricter and intensive care resources need to be reserved for patients where care has a significant likelihood of contributing to continued survival. This means greater restrictiveness in terms of beginning or continuing intensive care than would normally be the case. The principles also state that prioritisation may not be based on the patient's chronological age in view of the principle of human dignity, but that consideration may be given to the degree of patient benefit that can be achieved.

The National Board of Health and Welfare's principles have been discussed and questioned, including because they include wording that can allow for interpretations whereby chronological age is, in reality, assigned decisive significance when making prioritisations on the grounds of patient benefit being interpreted based on anticipated remaining length of life. This could lead to younger patients taking

¹⁵ The National Board of Health and Welfare 2020b.

priority over older patients with the same needs, which goes against the prioritisation platform's principle of human dignity.¹⁶

Can deviations be made from the prioritisation platform in a crisis?

As described above, the ethical platform for prioritisations in the health service is enshrined in law. If prioritisations are to be based on values other than those established by the Riksdag, decisions must be made at national level and the legislation must be amended. In a crisis situation, it might feel less appropriate to change the underlying requirements for prioritisations. There is a risk that this will create even more uncertainty within care regarding which principles apply, and ethical stress for healthcare professionals who have to make prioritisations. However, a crisis like the COVID-19 pandemic brings the question of prioritisation to the fore.

Clear guidelines and recommendations are important for professionals when making prioritisations. Nevertheless, it is important that national guidelines are clearly based on the values and principles that have the support of society and that apply according to the law – not least in order to contribute in a crisis situation towards shared resources being allocated democratically and to avoid arbitrary prioritisation decisions. Smer wishes to underline the importance of an open discussion being held on prioritisations based on different ethical starting points. The discussion on whether deviations from the prioritisation platform should be permitted in certain cases, or whether an amended platform should be applied, should however be held at national level and have the broad support of society.

5.3.3 Recommendations

Smer is of the opinion that guidelines for setting priorities in extraordinary situations should, as far as possible, be drawn up when a crisis is not in progress. This allows time for a broad and open discussion, and for the health service and society to agree on which considerations should be made and which values should be adhered to in the event that tough priorities need to be set. It is also likely that different guidelines may need to be drawn up, depending on how serious the crisis is. If guidelines do need to be created during

¹⁶ Engström et al. 2020, Engström and Sandlund 2020.

an ongoing crisis, the aim should be to canvass the views of different stakeholders in open and transparent processes.

The guidelines drawn up during the current COVID-19 pandemic must be clearly rooted in applicable regulations. It is also important that the health service is open about exactly what is being prioritised and on what basis.

It is essential to be clear about when different guidelines for extraordinary situations should be applied, when they should no longer be applied, and how this should be communicated to those who have to decide on the priorities. Clinicians must ensure that the guidelines on this are applied at the right time, and not too early, when demand has not yet outstripped the resources. Communication to those responsible within the health service, and to the healthcare professionals who will be choosing the priorities, must thus be concise and clear.

In a crisis, there should be opportunities for reconsidering previous guidelines and those drawn up during the crisis. New evidence may mean that priorities need to be reassessed. Various stakeholders should also be included in this process to ensure social acceptance. In addition, it is important that there is continuing open dialogue on priorities and relevant principles, and their application in concrete cases.

When it comes to deprioritising routine healthcare, the health service should consider whether certain interventions or treatments should be resumed to avoid serious risks to patients.

Local ethics committees should be consulted on difficult issues of prioritisation.

Finally, Smer sees a need to develop a plan setting out how to return to normal service once the extraordinary circumstances no longer apply. In such a plan, it is important to specify what is meant by ‘extraordinary circumstances’, so that it is possible to assess when returning to normal is appropriate.

5.4 Ethics and personal contact at end of life

The COVID-19 pandemic has raised the question of how relatives should say their goodbyes to family members when there is a risk of infection.¹⁷ The question has also been addressed in the media. For

¹⁷ Regional and local guidelines have been drawn up for relatives visiting dying patients during the COVID-19 pandemic. See e.g. Starlander 2020.

example, the newspaper Aftonbladet¹⁸ describes how only two of a dying mother's children were allowed to visit her at a home for the elderly, in accordance with the National Board of Health and Welfare's guidelines, while all four of her children were allowed to enter her room after she had died to empty it of her possessions. This example illustrates the problem with applying rules in this serious and existentially important situation.

The death of a close relative can be one of the hardest and at the same time one of the most important events in one's life. Most people want to be close, to share the difficulty and the anguish, and to provide comfort and support. Not being able to do so can lead to regret and feelings of guilt, which can remain with people throughout their lives.

At the same time, the physical presence of a dying relative with COVID-19 can involve a serious risk of infection. The risk of infection also affects encounters between healthcare professionals and dying patients, and between healthcare professionals and relatives. One possibility is for meetings with relatives to take place digitally and remotely instead.

How should these conflicts during the final stage of life be resolved? How can a son or daughter say goodbye to their dying parent without taking excessive risks with regard to infection? How can healthcare professionals meet patients and relatives in a dignified manner?

Within the health service, there is normally a highly positive attitude towards relatives being present at the end of life. They bring the patient security and provide healthcare professionals with valuable information. They can be consulted during the care period and on those occasions when the duty doctor has to make decisions on issues such as limiting treatment. One objective within care is that no one should ever have to die alone. Relatives who are willing and able should be able to visit a critically ill patient and/or be there when the patient dies. Within palliative care, the presence of relatives during the final stage of the disease process is even part of the definition for the form of care.¹⁹

¹⁸ Karlsson 2020.

¹⁹ Starlander 2020.

5.4.1 Recommendations

The clinician's approach at the point when relatives and terminal patients are saying their goodbyes before death must be guided by the principle of minimising infection risks while also finding ways to allow for human contact and closeness. Situation and context must, however, determine how this is resolved in practice. Digital contact may work well for some people. They might already be used to communicating digitally and be able to express emotions and intimacy in this way. For others, it can feel strange and alienating, and offer no replacement for physical, personal contact.

One might reflect on where to draw the line concerning a relative's own choices, responsibilities and decision-making in relation to the wider social responsibility. Based on their own well-informed choice, should a relative who is not in the risk group for serious COVID-19 infection be permitted to be physically present at the bedside of their dying relative, if they promise to go into quarantine for 14 days after the visit? This conscious risk-taking may, from the individual's perspective, seem reasonable. From a social perspective, there is a certain risk that the relative may, despite everything, become ill enough to require hospitalisation. However, activities that – perhaps to a similar degree – increase the risk of hospitalisation are generally not advised against.

Smer believes that contact at the end of life should be seen and dealt with in terms of a trade-off rather than from the perspective of social principles. The presence of relatives at the bedside should be assessed on a case-by-case basis, with reference to the individual circumstances.

5.5 Experimental treatment

COVID-19 was entirely unknown just a few months ago, and there is no established treatment for the disease. Any treatment given is thus to some extent experimental. The use of experimental treatments or novel methods creates a conflict between, on the one hand, the interest in giving patients a (last) chance of health or survival and, on the other hand, ensuring that patients receive safe, tried and tested care, the risks of which can be judged in advance.

The question of using experimental treatment methods comes to the fore in situations where a patient's life is at stake and there are no proven treatment methods. During the 2014 Ebola outbreak in West Africa, an advisory group of experts quickly investigated for WHO whether and under which conditions it was ethically acceptable to offer those affected experimental medications or vaccines. Ebola is a highly contagious disease. Its mortality rate has been estimated at between 25 and 90 per cent during outbreaks in the affected West African countries.²⁰ In its analysis, the expert group decided that, in connection with the outbreak in West Africa, it was ethically acceptable to offer methods that had shown promising results in research and in animal models, but that had not yet been evaluated in terms of the safety and effectiveness of human treatment.²¹ They stressed that one requirement for experimental treatment and compassionate use²² is that treating physicians should gather and share the data generated, and that clinical studies should be established according to the prevailing conditions.

Around the world, various forms of COVID-19 treatment are currently being used in the hope that it will save lives. Many clinical studies are in progress. Experience from treatment strategies is being shared regionally, nationally and internationally. WHO is coordinating this work.

Smer previously dealt with issues relating to innovative methods and experimental treatments in 2016 but did not address the specific issue of experimental treatment in connection with a pandemic at that point.²³ The council noted in its report that current legislation offers very limited scope for experimental treatments outside clinical trials.

Smer's view was that experimental treatments should only ever be used in organised and ethically acceptable forms and should as a general rule take place within the framework of research studies.²⁴

²⁰ WHO 2020b.

²¹ WHO 2014.

²² Compassionate use is when a non-approved medication is permitted to be used for special humanitarian reasons.

²³ Smer 2016.

²⁴ Ibid.

6 Research ethics in the time of a pandemic

Research during a pandemic is important in order to gain knowledge and understand the effects of various measures, such as lockdown, social distancing and quarantine. Research is also essential in order to quickly obtain effective treatment and a vaccine. WHO points out that there is a moral obligation to carry out research during a pandemic.¹

The Swedish Ethical Review Authority has established a system for giving priority treatment to applications for ethical reviews of research linked to COVID-19. Its starting position is that priority should only be given to projects that can be expected to provide benefits during the current pandemic, or to projects where sampling or other data collection for research purposes (other than clinical routines) must necessarily take place in the near future involving infected patients who are currently receiving care.²

Research on humans is regulated by both Swedish and European legislation. For example, Sweden has the Ethical Review Act (2003:460), the Medicinal Products Act (2015:315) and the Act on responsibility for good research practice (2019:504). There are also a number of current EU regulations and directives within this field, including the regulation on clinical trials on medicinal products for human use, the regulation on advanced therapy medicinal products, the General Data Protection Regulation (GDPR) and the directive on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells. Alongside these, there are a number of ethical guidelines that are not legally binding but that still play an important role in practice, such as the Declaration of Helsinki³ and

¹ WHO 2016 and WHO 2020c.

² The Swedish Ethical Review Authority 2020.

³ The World Medical Association 2018.

the Council for International Organizations of Medical Sciences' (CIOMS) guidelines for epidemiological research. All European Academies (ALLEA) has drawn up the European Code of Conduct for Research Integrity.⁴ WHO has produced an ethical guide based on available ethical guidelines, providing guidance for research relating to COVID-19.⁵ The European Network of Research Ethics Committees (EUREC) has issued a statement on research ethics committees' responsibilities during a pandemic.⁶ The European Data Protection Board has published guidelines for data processing in research relating to the COVID-19 pandemic.⁷

The fundamental ethical problem in the case of research on humans is striking a balance between two requirements that are both legitimate, but that sometimes come into conflict with each other. One is the research requirement, which is justified by research being able to provide new knowledge which contributes towards individuals' choices and the development of society. The other is the protection requirement, which means that research subjects must be protected against different forms of harm related to the research. The regulations for research on humans set out the starting points for striking such a balance so that the scientific value is sufficiently high in view of the risks, and that the knowledge cannot be obtained in a less risky manner. The welfare of the individual must also take priority over the needs of society. To further protect the individual, there is a requirement that research subjects must be given information about aspects such as the risks that the research can involve, and must give their voluntary, explicit consent.

In times of pandemic, finding vaccines, therapeutic medications and diagnostic tests is often urgent. The question is whether this urgency can justify changes to current research ethics practice and legislation. One uncontroversial adaptation to the current conditions would be if the ethical review boards' meeting times could be more flexible, so that they could take a position at short notice on research applications that are relevant to fighting an ongoing pandemic, or other administrative relaxations that do not affect safety. Changes regarding the assessment of which risks are acceptable to

⁴ ALLEA 2017.

⁵ WHO 2020c. Another source relating to research ethics in the event of health risks is the Nuffield Council on Bioethics 2020.

⁶ EUREC 2020.

⁷ The European Data Protection Board 2020b.

expose research subjects to would be more controversial. One example could be to skip certain stages of the research chain when developing medications and vaccines against COVID-19. Developing vaccines and medications is a rigorous, time-consuming process which generally involves laboratory research, animal testing (often on both large and small animals) and several phases of clinical studies, first with small study populations and then with increasingly large populations. Removing any of these stages could lead to faster results but could also expose research subjects further down the line to greater risks.

In this context, it is also important to be aware that research subjects may be tempted to take risks that they would not be prepared to take otherwise, due to erroneous ideas about the benefits to them of taking part. For example, they may believe that participation will make them immune to the virus when the aim of an early test is only to verify safety and to see whether any sort of immune reaction is achieved, which does not necessarily mean that research subjects will gain immunity. Here, providing information to the research subject is crucial.

Respect for human value is a fundamental ethical principle that comes to the forefront in research on humans. Even if research subjects sometimes benefit from the research they participate in, research on humans generally involves certain individuals being exposed to risks in order for others to receive help and protection in the future. This could be seen as an instrumentalisation of the individual and as something that contravenes respect for human value, according to which a person should not be treated merely as a means to an end. It is, among other reasons, in order to defend human value that research on humans requires voluntariness, informed consent and a reasonable balance between risk and benefit.

Fairness and equity are also key ethical aspects in research on humans. The fact that certain individuals are exposed to risk in order for others to reap the benefits of the knowledge gained can be seen as a deviation from the principle of a fair division of burdens and benefits. From an equality perspective, the choice of individuals who participate in this research is therefore crucial. This is particularly true if society were to lower the safety requirements in order to combat a pandemic. Fairness also involves a wide range of different groups taking part in research, so that the medications and vaccines

developed can be used by as many members of society as possible: young or old, male or female, different ethnic groups, and so on.

One important question, if it is to be permitted in a crisis situation for research subjects to be exposed to higher risks than normal in order to promote everyone's best interests, is how to withdraw from this situation so that the lower safety requirements do not become permanent. This could involve limiting the time for which these lower requirements apply, or reviewing them regularly.

6.1 Recommendations

According to Smer, it is important to be able to fast-track the processing of applications for ethical review of research studies aimed at increasing knowledge of or developing treatment for an ongoing pandemic. For the purpose of ensuring the intended priorities, the criteria concerning which research is eligible for fast-tracking must be clear and relatively strict. It may be necessary to remain vigilant against attempts to 'relabel' other research. The risk of other important research being crowded out also needs to be taken into account. Fast-tracking must not mean lower quality standards. It is particularly important to maintain requirements for a science-based hypothesis and an adequate methodology in times of crisis, when poor research can do a great deal of damage to both individuals and society. Principles of research best practice must be maintained.

In the time of a pandemic, it is crucial to particularly safeguard respect for human dignity. Measures to speed up the development of vaccines or medication to combat COVID-19 must not cause research subjects to be exposed to unacceptable risks. Prevailing requirements to weigh up the risk of harming the research subjects against the expected social benefit should be maintained.

Smer wishes to stress the importance of research subjects receiving adequate information, not least on the considerable uncertainty that often surrounds risks and expected benefits when working on an entirely new disease. This might mean that the bar is set higher than usual when it comes to deciding who can be included as research subjects.

Another research-related issue concerns the redeployment of existing research resources without preceding quality assurance, as is being seen at the moment.⁸ There may be a risk of allocated funding being used in this way for COVID research. Is the ‘urgently planned’ research up to standard? What was jettisoned and what did we get instead? The outcome of this is something that should be followed up after the crisis, in order to learn lessons for next time.

⁸ The Swedish Research Council has announced that a third of allocated research funding may be used for COVID-19 research for a limited period of time. <https://www.vr.se/aktuellt/nyheter/nyhetsarkiv/2020-03-27-nu-mojligt-att-anvanda-del-av-ditt-bidrag-till-forskning-om-covid-19.html>.

7 Communication

Communication is of central importance in a pandemic. How the Government, authorities and other decision-makers communicate plays a decisive role in terms of how the public will follow the advice and instructions given, and whether trust and confidence in society are maintained.

Science Advice for Policy by European Academies (SAPEA) published a report titled *Making sense of science for policy under conditions of complexity and uncertainty* in 2019, explaining that scientific knowledge can be precise, complex and uncertain, all at the same time.¹ How is this complexity captured? How are the knowledge and the uncertainty communicated? There are countless examples showing that if this is not done wisely, this can negatively affect our confidence in both research and experts.

Many people do not trust experts² or their risk assessments. According to researchers, there are three circumstances that are particularly damaging in terms of trust. Firstly, negative events are more visible than positive events. Things that have ‘gone wrong’ during the coronavirus crisis have received considerable media attention, while the successful everyday work to manage the crisis is not always given coverage in debate programmes. Failures and errors are noticed more than successes. Secondly, negative events are given greater importance than positive events. And thirdly, there is an asymmetry between confidence-eroding and confidence-building factors: it appears to be easier to intentionally or unintentionally create distrust than to create trust. Ultimately, it is hard to win someone’s trust but

¹ SAPEA 2019.

² Slovic 1997. In Sweden, however, we have a higher degree of interpersonal trust (Holmberg and Rothstein) and trust in experts. According to a Sifo survey conducted in March 2020, confidence in the Public Health Agency of Sweden, for example, is high. A full 65 per cent responded that they have very high or fairly high confidence in the agency, with only 15 per cent saying that they have very low or fairly low confidence. Falkirk 2020.

easy to lose it. Once individuals or organisations have done something ‘negative’, thereby misappropriating their trust capital, they often end up in a trust-breaking spiral. They then risk rapidly losing their entire confidence capital. The reason for this seems to be that negative actions result in attention being drawn to the individual or organisation that has committed this action. It is our actions that create the expectations of those around us, and the expectation will be that someone who has done something negative, something trust-breaking, will continue in the same track.³

In *Making Sense of Science*, the American researcher Baruch Fischhoff writes: “The goal of science communication is not agreement, but fewer, better disagreements”. Even during a pandemic, it is crucial that the information given to the public, to decision-makers at different levels and to politicians is of such a nature that it has the objective not of absolute agreement, but of well reflected disagreement.⁴

Research into research communication has shown that sensitivity is essential in order to succeed in disseminating knowledge and information. Those who inform must know what the recipient of the information wants to know. It is important to know which decisions will be made, and why. If the informer succeeds in identifying which decisions the recipient of the information faces, it is easier to convey the scientific knowledge that can facilitate this decision-making. However, this naturally involves a number of difficulties that must be taken into account. There may be many recipients, who may face a wide range of decisions. Some may wonder when they can return to work after having had COVID-19, while others may need to make decisions about how to stop the spread of the virus in a home for the elderly.

One important thing that the research shows is that the informer must ensure in all contexts that the chosen information strategy actually works for the purpose. There are no ready-made strategies for informing people about knowledge and uncertainty – these strategies must be tailored according to the purpose.⁵ A particularly difficult problem is how to communicate uncertainty and risks. Extensive

³ Slovic 1997; Slovic 2000.

⁴ Fischhoff 2013.

⁵ Fischhoff 2013; Fischhoff and Davis 2014.

research has been carried out into this particular problem, and here too we have clearly seen that there is no communication panacea.⁶

But what information does the public want? How does the man in the street want authorities and politicians to provide information about a pandemic? In March 2014, an outbreak of Ebola in West Africa hit several countries hard. The outbreak continued for two years, and it has been estimated that more than 11 000 people died. In 2015, a group of American researchers mapped what the US population thought about the disease.⁷ A questionnaire survey asked 3 447 randomly selected Americans about their attitudes, behaviours and risk assessments. The survey showed that the respondents' assessments did not contradict scientific knowledge. They had therefore understood the relevant parts of the scientific information they had received. Their assessments also turned out to be contradictory and hard to quantify. In addition, the survey showed that what the respondents wanted most of all in a situation of this kind was facts. To quote Fischhoff, they wanted "facts, not spin". What was important for them was that the knowledge situation was presented correctly, and not in an incorrect, embellished or skewed manner. And they wanted facts, even if the information they received worried them.⁸

Only time will tell whether the Public Health Agency of Sweden and other authorities have followed the advice and recommendations provided by knowledge about communicating knowledge and risk. What can, however, be seen is that our authorities have had the following ambitions during this pandemic:

- to provide information about what they know and to present facts,
- to say when there is insufficient scientific evidence for a measure,
- to clarify when knowledge exists but is not entirely robust due to the evidence being weak,
- to be clear about when there is a lack of knowledge,
- to provide evidence for their risk assessments, for example the risk of a general spread of infection, and to provide different kinds of evidence that supports different hypotheses: risk reduction, unchanged risk and an increase in risk,

⁶ Fischhoff and Davis 2014.

⁷ Fischhoff et al. 2018.

⁸ Fischhoff et al. 2018; Hamill 2020.

- to emphasise that the scientific basis will change, and that this will require regular reviews of advice and recommendations,
- to emphasise the need to share knowledge, not only within and between authorities, but also globally, and
- to be clear that decisions cannot be made on individual facts and must instead consider the full scientific basis, all available facts and all available information.

All these points have an ethical dimension. The reason for this is that we can neither make decisions nor give advice and recommendations without taking values into account. The question is which values, and whose. And do these values come into conflict with the values of others?

The decision to focus on communicating facts is already based on values. Scientific knowledge and facts are valued more highly than political statements. Statements of fact can be contradicted, and people may like or dislike spin.

Honesty about the knowledge situation requires us to report truthfully what we know, what we do not know, and how robust our knowledge is. This is something that is discussed in *Making Sense of Science*. This virtue also includes not biasedly seeking information and facts that support what we ourselves believe, and not avoiding being receptive to contradictory information. It also involves weighing up the available information and knowledge in an evidence-based manner.

Spin is problematic, and political spin is particularly problematic in times of crisis. However, there are also serious forms of scientific spin. This could include marketing hypotheses that have been confirmed to varying degrees. This is morally problematic, as it can lead to the public choosing not to follow the advice of the authorities. Another example is powerful ‘one-fact statements’. These types of statement can affect our behaviour but should not do so because they are not relevant in the context. The decisions that must be made, and the advice and recommendations that must be given, neither support nor are supported by these facts, despite them falling within the relevant scientific field in a broad sense.

7.1 Recommendations

During a pandemic, it is essential that decision-makers at different levels communicate well with the general public. Good decision-making processes and factual information engender trust, and that confidence in the decision-makers can then be maintained even when difficult measures have to be introduced.

Smer believes that it is important to clearly communicate not only the evidence on which decisions are based, but also how different values have been weighed up against each other and which values and principles have underpinned decisions on a particular intervention.

8 The future

Spring 2020 has changed Sweden and the world in many ways. We have already learnt new things, and we have lost much of what we have taken for granted. It is only afterwards that we will be able to know how the pandemic has changed our society and our habits. Right now, it is hard to get an overview of what changes such as social distancing, new communication habits and less travelling will mean in the long term. Will everything gradually go back to how it was before the COVID-19 pandemic, or will new behaviours and habits remain?

Here, we conclude with a few reflections on what we can learn from the coronavirus pandemic and the possible consequences for bioethics in Sweden and the world.

- It quite soon became clear that Sweden, in contrast to our neighbour Finland, was not sufficiently prepared for a crisis of this type. Stores of vital medical equipment were empty, as the health service had applied a just-in-time system for delivering equipment and medication. As the need grew and borders closed, the risks that this system involved became clear. This problem has a medical-ethical link, as the lack of access to equipment combined with a shortage of staff may have contributed to the fact that there was deemed to be a need to draw up a specification based on applicable regulations, in the form of national guidelines for prioritising application under extraordinary conditions. The principles for the health service's prioritisations that have been applied so far were not deemed to be sufficiently specific for the anticipated shortage. Even though it may not have been possible to be constantly prepared for a pandemic, it is an important lesson for the future that the health service needs to be much better prepared to deal with crises.

- The coronavirus pandemic has particularly affected those living in homes for the elderly. This is where the COVID-19 mortality figures are the highest. The older population is at a greater risk of dying from the virus. The extensive spread of infection among the elderly probably reflects shortcomings in care for the elderly, such as low staffing levels and untrained staff. These shortcomings can be seen as an expression of a restriction in the application of the principle of human dignity, which involves everyone having the same right to medical and social care, whatever their age. One lesson to learn from the consequences of the coronavirus pandemic on the older population is that care for the elderly must be given the right conditions for the principle of equal human value to be realised in practice.
- In the US, it has been reported that vulnerable groups within society are being hit the hardest by the crisis, both economically and in terms of mortality. In Sweden, too, an increased spread of infection and mortality in socially vulnerable areas and groups has been reported in the Stockholm area.
- Pandemics do not respect national borders. The coronavirus pandemic has reminded us that we live in a globalised world, where we are dependent on each other. International cooperation and international solidarity are therefore also important. It is a common interest for all the world's inhabitants for nations to be open and transparent when it comes to information about pandemics and their development, and for cooperation to be strengthened in order to restrict pandemics and in connection with researching vaccines and medications.
- We have a great moral responsibility for future generations. The current crisis will affect our children, our grandchildren and future generations. The costs of the crisis will largely be paid by them.
- Different countries have chosen different strategies for combating the coronavirus pandemic. However, one thing that these all have in common is that the freedoms and rights of individual have been restricted in various ways to achieve the common goal of limiting the spread of infection. In order to develop new vaccines and medications quickly, the pace and intensity of research has been stepped up. In certain cases, this has involved loosening the

rules and principles of research ethics regarding informed consent and the protection of research subjects. It is incredibly important that these limitations on the freedoms and rights of individuals, as well as the loosening of research ethics regulations, do not become permanent following coronavirus.

The crisis has revealed that we do not currently have robust preparedness system. We have a great moral responsibility to learn from the crisis situation currently playing out. 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.

9 Conclusion

Ethical choices feature in both the preparations ahead of a pandemic and the battle against the virus. Ethical analysis is therefore important in both the preparation and response phases.

We all have a moral responsibility, during and after an ongoing pandemic, to gather knowledge, support research and learn lessons for the future. Based on such knowledge, Sweden should develop a more robust contingency plan and a national ethical framework for decision-making in the face of future pandemics. Decisions on these strategies should have broad backing and be decided on at national level.

In this report, Smer has presented values and principles that it believes should provide guidance for decision-making in the event of a pandemic. These can form the basis for such a framework. This foundation may need to be revised moving forward, based on experiences from the ongoing pandemic.

This report has been drawn up during the ongoing pandemic and marks the first step in the council's analysis of ethical issues relating to the pandemic.

In it, Smer has provided an overview of current ethical challenges, with the aim of giving the reader a deeper understanding of the various ethical values, problems and challenges that arise in connection with a pandemic.

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Example of an ethical framework from The University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group, 2005

Table 1 Substantive Values to Guide Ethical Decision-Making for a Pandemic Influenza Outbreak

Substantive value	Description
Individual liberty	In a public health crisis, restrictions to individual liberty may be necessary to protect the public from serious harm. Restrictions to individual liberty should: <ul style="list-style-type: none"> • be proportional, necessary, and relevant; • employ the least restrictive means; and • be applied equitably.
Protection of the public from harm	To protect the public from harm, health care organizations and public health authorities may be required to take actions that impinge on individual liberty. Decision makers should: <ul style="list-style-type: none"> • weigh the imperative for compliance; • provide reasons for public health measures to encourage compliance; and • establish mechanisms to review decisions.
Proportionality	Proportionality requires that restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual level of risk to or critical needs of the community.
Privacy	Individuals have a right to privacy in health care. In a public health crisis, it may be necessary to override this right to protect the public from serious harm.

Substantive value	Description
Duty to provide care	Inherent to all codes of ethics for health care professionals is the duty to provide care and to respond to suffering. Health care providers will have to weigh demands of their professional roles against other competing obligations to their own health, and to family and friends. Moreover, health care workers will face significant challenges related to resource allocation, scope of practice, professional liability, and workplace conditions.
Reciprocity	Reciprocity requires that society support those who face a disproportionate burden in protecting the public good, and take steps to minimize burdens as much as possible. Measures to protect the public good are likely to impose a disproportionate burden on health care workers, patients, and their families.
Equity	All patients have an equal claim to receive the health care they need under normal conditions. During a pandemic, difficult decisions will need to be made about which health services to maintain and which to defer. Depending on the severity of the health crisis, this could curtail not only elective surgeries, but could also limit the provision of emergency or necessary services.
Trust	Trust is an essential component of the relationships among clinicians and patients, staff and their organizations, the public and health care providers or organizations, and among organizations within a health system. Decision makers will be confronted with the challenge of maintaining stakeholder trust while simultaneously implementing various control measures during an evolving health crisis. Trust is enhanced by upholding such process values as transparency.
Solidarity	As the world learned from SARS, a pandemic influenza outbreak will require a new vision of global solidarity and a vision of solidarity among nations. A pandemic can challenge conventional ideas of national sovereignty, security or territoriality. It also requires solidarity within and among health care institutions. It calls for collaborative approaches that set aside traditional values of self-interest or territoriality among health care professionals, services, or institutions.
Stewardship	Those entrusted with governance roles should be guided by the notion of stewardship. Inherent in stewardship are the notions of trust, ethical behavior, and good decision-making. This implies that decisions regarding resources are intended to achieve the best patient health and public health outcomes given the unique circumstances of the influenza crisis.

Source: University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group, 2005, p. 6–8.

Table 2 Procedural Values to Guide Ethical Decision-Making for a Pandemic Influenza Outbreak

Procedural values	Description
Reasonable	Decisions should be based on reasons (i.e., evidence, principles, and values) that stakeholders can agree are relevant to meeting health needs in a pandemic influenza crisis. The decisions should be made by people who are credible and accountable.
Open and transparent	The process by which decisions are made must be open to scrutiny, and the basis upon which decisions are made should be publicly accessible.
Inclusive	Decisions should be made explicitly with stakeholder views in mind, and there should be opportunities to engage stakeholders in the decision-making process.
Responsive	There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis. There should be mechanisms to address disputes and complaints.
Accountable	There should be mechanisms in place to ensure that decision makers are answerable for their actions and inactions. Defense of actions and inactions should be grounded in the 14 other ethical values proposed above.

Source: University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group, 2005, p. 6–8.