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

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

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 making 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:[2]

- *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.[3]

- *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.

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

- *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.[4]

- *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.[5]

- S*olidarity*. 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.

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[4] The health service has an ethical platform, with parliamentary approval from the Riksdag, for decisions on priorities within the health service.
[5] One way to create trust in the short and long term is to stick to the facts.

Fairness in decision-making processes

Smer considers the following values or conditions to be important for good decision-making processes:[6]

- *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.

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.

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[6] 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.

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,[7] 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.

– 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.

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[7] Swedish Government 2015.

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 closeness 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.[8]

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 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

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[8] Smer 2016.

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.[9] 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.

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

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[9] 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.

providing guidance in the face of ethical choices that may have to be made in the future. This applies both nationally and internationally.