# Summary

Sweden represents an average European country as far as numbers of deaths during the first and second waves of the pandemic are concerned. During the third wave, mortality has been low and, up to now, Sweden has fared better than most countries in Europe.

In the spring of 2020, Sweden chose a different path to many other countries, one based on a voluntary approach and personal responsibility rather than more intrusive measures. The majority of other countries, by contrast, made greater use of lockdowns or other intrusive regulatory interventions. Whether Sweden's choice of path was reasonable, or whether it would have been better to introduce other types of measures to limit the spread of the virus, is a question the Commission will return to in its final report. To address that question, it is necessary to gain a better understanding of what information key decision-makers had as a basis for their assessments regarding disease prevention and control measures during the various phases of the pandemic. Several other aspects of Sweden's handling of the crisis, moreover, remain to be investigated and assessed. These include, in particular, the impacts of the emergency on the economy and personal finances, and what capacity the Swedish machinery of government and its institutions had to manage a crisis. Only after that will the Commission be able to assess whether the path chosen by Sweden represented a reasonable balance between effective disease prevention and control and other interests. With answers to these questions, it will also be possible to better assess questions of responsibility.

The Commission has initiated a research programme – A Research Programme on COVID-19 in Sweden: Spread, Control and Impacts on Individuals and Society – in collaboration with researchers at Stockholm University. The programme is based on very extensive gathering of data on medical and socio-economic outcomes, generally at the individual level, from a large number of sources. It currently involves some thirty external researchers at various universities and other institutions, a number of whom have written background reports to this report. We have also engaged the services of several independent experts, who have likewise provided us with background reports.

The Commission's most important overall conclusions based on the review carried out to date and presented in this report are:

- Sweden's handling of the pandemic has been marked by a slowness of response. The initial disease prevention and control measures were insufficient to stop or even substantially limit the spread of the virus in the country.
- The path chosen by Sweden has placed the emphasis on disease prevention and control measures based on a voluntary approach and personal responsibility, rather than more intrusive interventions.
- Sweden's pandemic preparedness was inadequate.
- Existing communicable diseases legislation was and is inadequate to respond to a serious epidemic or pandemic outbreak.
- Sweden's system of communicable disease prevention and control was and is decentralised and fragmented in a way that makes it unclear who has overall responsibility when the country is hit by a serious infectious disease.
- The health care system has been able, at short notice, to adapt and to scale up care for people with COVID-19. This is largely thanks to its employees. Adaptation has been achieved at the price of extreme pressure on staff and of cancelled and postponed care. We will therefore live with the consequences of the pandemic for a long time to come.
- In several areas there is a problematic lack of data, making it harder to monitor the pandemic while it is in progress and to satisfactorily evaluate its management when it is over.

# The spread of the virus in Sweden

As far as is currently known, the coronavirus began to spread in the Chinese city of Wuhan some time in late 2019. As early as January 2020 cases were reported from other countries: Thailand, Japan and South Korea. The virus then spread to Europe, probably via Italy.

Early on, the discussion came to revolve around skiing tourism in the Alps. Schools in many European countries have winter breaks in February and March, and many people took holidays in resorts in the Alpine region at that time. Studies show that regions which, like Stockholm, had their school winter sports breaks in week 9 (the last week in February) suffered appreciably higher excess mortality in weeks 14–23 than regions that had those breaks in other weeks. Travel to the Alps during the winter sports holiday, in other words, was a major factor in the early spread of the virus in Europe.

To obtain a picture of how the disease reached Sweden and spread across the country, the Commission has requested a background report based on analyses of the genetic make-up of the virus. We have also made use of other data, collected through Stockholm University's COVID-19 programme, relating to travel abroad during the critical weeks of spring 2020. Based on this information, the Commission can draw the following three conclusions:

- 1. If the virus was in circulation at all in Sweden prior to week 9 of 2020, its spread was extremely limited.
- 2. The virus probably spread to Sweden as a result of people travelling, chiefly from Italy and Austria, during week 9.
- 3. The great majority of those who contracted COVID-19 in spring 2020 became infected in Sweden rather than abroad.

Once the virus had reached Sweden, it spread rapidly in the country. With hindsight, it is likely that the rise in transmission was considerably more dramatic in March 2020 than was indicated by the data presented in real time by the authorities.

Infection has not been evenly distributed across the population. The analyses carried out as part of Stockholm University's COVID-19 programme show that, other things being equal, occupational groups exposed to particularly extensive contact with other people have run the highest risk of being infected. The risk of infection has also been greater for those employed at larger workplaces, and those living in larger families.

Data obtained from movements of mobile phones show that, when the pandemic struck in March 2020, there was a rapid decrease in individual mobility, even before the Public Health Agency of Sweden called on people to work from home and avoid unnecessary travel. People thus chose – even in the absence of advice and recommendations – to change their behaviour so as to avoid the risk of becoming infected or infecting others.

By international standards, the health of Sweden's population is good. However, appreciable differences exist between different groups. Similarly, the pandemic has affected different sections of the population to differing degrees. According to two background reports, morbidity and mortality from COVID-19 were clearly associated with level of education, income, gender and marital status. Individuals with less education, those on lower incomes, men, and single people ran a greater risk of being admitted to hospital and intensive care and of dying as a result of COVID-19 than individuals with more education or higher incomes, women, and people who were married (or cohabiting). There is much to suggest that differences in infection risk and in underlying health alone cannot explain these socio-economic and demographic differences.

Research shows that the risk of developing serious COVID-19 and of dying as a result of the disease was particularly high among people born outside Sweden, even when socio-economic, demographic and medical factors are taken into account. The risk decreased during the second and third waves, but was still remarkably high.

The risk was also high among older members of the population, and among those in long-term residential care (including sheltered housing, as well as care and nursing homes) it was high during the second wave as well, despite good access to personal protective equipment (PPE), increased testing capacity and better knowledge.

During the second wave, too, the Commission sees a clear association between community spread of the disease and infection rates in residential care facilities for older people. The variants of the virus occurring in these settings early in the pandemic were the same as those that were brought home by people returning from winter sports breaks in Italy and Austria, and that subsequently spread in the wider community. This reinforces the assessment in the Commission's first interim report that community spread of the virus was the principal source of its transmission in residential care.

The research underlying yet another background report to the Commission suggests that the infection was brought into residential care facilities by staff rather than relatives. According to the research in another background report, the risk of dying of COVID-19 was higher in facilities with higher staff turnover and in larger facilities. Whether residential care units were private or publicly owned, on the other hand, does not appear to have influenced the risk of becoming ill or dying.

There are still significant gaps in our understanding of the spread of the disease in the elderly care sector. Broadly, this reflects the lack of national data relating to residential care for older people. The Commission is of the opinion that this deficiency needs to be remedied, not least to make it possible, when an infectious disease is spreading, to monitor developments in real time and adapt interventions to what is happening.

# Sweden's handling of the pandemic

# Measures were voluntary, less intrusive and late

Based on the knowledge that the virus was brought to Sweden chiefly by people returning from winter sports holidays in Italy and Austria during week 9, and that it subsequently spread rapidly across the country, the Commission concludes that the choice of measures early in the pandemic decisively affected the way the spread of the disease unfolded in the country.

Sweden differed at that juncture from its Nordic neighbours and many other countries. The Danish and Norwegian Governments adopted a series of stringent measures on 11–12 March 2020, and a few days later the Government of Finland decided that emergency conditions existed, making it possible to introduce more intrusive interventions. The Government and authorities of Sweden took no corresponding measures. Instead, Sweden's non-pharmaceutical interventions, especially in the spring of 2020, consisted almost exclusively of general advice and recommendations from the Public Health Agency, which the population were expected to comply with on a voluntary basis. An evaluation of Sweden's choice of path is one of the questions the Commission will return to in its final report. We can already note, however, that the measures which Sweden introduced in spring 2020 seem to have come late, not only in relation to our Nordic neighbours, but also – not least based on current knowledge – in relation to the transmission of the virus occurring in the country at that time. The measures taken in the early phase of the pandemic failed to stop or even substantially limit its spread in the country.

The mandatory regulations which Sweden adopted in March 2020 included a ban on entry to the country, based on an EU agreement. Apart from that, they were limited to two areas: (1) a limit on the number of people attending public gatherings and events, first of 500 (from 12 March 2020) and then of 50 people (from 29 March 2020), and (2) a ban on visits to residential care facilities for older people (from 1 April 2020). In addition, the Public Health Agency called on upper secondary schools and municipal adult education and higher education institutions to introduce remote and distance learning (on 17 March 2020). The Government had at that point, on 13 March 2020, adopted an ordinance that made it possible to offer remote and distance learning.

Regarding the ban on visits to residential care facilities, a background report suggests that the virus had been introduced into such facilities by staff rather than relatives. It is therefore unclear whether the ban actually made any difference to the spread of the disease in these settings. However, the Commission considers that, in the spring of 2020, it was justifiable to assume that a ban on visits could help to reduce the spread of infection in residential care.

Early in the pandemic, testing capacity was very limited, both in Sweden and in most other countries. Reporting therefore revolved around key statistics such as numbers of hospital admissions, admissions to intensive care and deaths. These metrics relate to events late in the course of the disease and thus entailed a delay in monitoring the pandemic. A study of other data sources suggests that COVID-19 cases were already rising rapidly in Sweden in the early weeks of March 2020. If the key statistics just mentioned dominated domestic monitoring, it is possible that the information they provided may have been a contributory factor behind the late deployment of measures to combat the pandemic and the slowness of response that characterised Sweden's handling of it. Norway and Denmark not only opted for more rigorous interventions early in the pandemic. They were also quicker than Sweden in putting in place new legislation that created scope for more stringent measures. Finland was already prepared, with an Emergency Powers Act that could be put into effect early on. The temporary amendment to Sweden's Communicable Diseases Act, which gave the Government far-reaching powers to close down various types of activity (known as the Authorisation Act), should have been adopted much earlier. So too should the temporary Pandemic Act (the COVID-19 Act). It should already have been clear during the first wave that the tools provided by the Communicable Diseases Act were insufficient.

During the second and third waves, the Government and public authorities introduced several new and more stringent measures, measures which they had dismissed or expressly refrained from using during the first wave. These about-turns occurred largely without any justification being offered on the basis of new knowledge. As examples, mention may be made of various restrictions on restaurants, family quarantine, measures to avoid crowding in retail settings, and recommendations on wearing masks on public transport. In some cases, these were measures which many countries had already adopted in spring 2020 and which were also discussed in the public conversation in Sweden at that time. The Commission has no reason to doubt the wisdom of introducing the new measures. But expressly refraining from adopting them during the first wave and then doing so during the second without clear justification presumably caused confusion among the public that can hardly have been conducive to high levels of compliance.

As regards early measures, however, the Commission wishes to mention that the Ministry for Foreign Affairs and the Foreign Service advised against certain travel and gave assistance to stranded Swedes who had difficulty returning home. These interventions seem to have been essentially successful.

# Testing and contact tracing

Testing and contact tracing are fundamental tools in limiting and stopping outbreaks of infectious diseases, and the importance of testing was something WHO highlighted early on. Under the Communicable Diseases Act, moreover, diseases that represent a danger to public health and to society are notifiable and subject to mandatory contact tracing. This presupposes that it can be established that a given individual is a carrier of such a disease, which in turn means that it has to be possible to test them. To comply with the Act, then – as the spread of the virus gathered momentum – large-scale testing and contact tracing should have been carried out. It took far too long, however, to build up a large enough testing capacity.

How such a capacity was developed in Sweden, compared with a selection of other countries in Europe, and how the different regions of Sweden managed testing are the subject of two background reports.

Testing and contact tracing on the same scale as during the pandemic have never previously been undertaken. It is not surprising, therefore, that Sweden and most other countries encountered a number of difficulties in building up such a system of testing. Among other things, considerable resources were called for in terms of personnel, materials, personal protective equipment and funding. At the same time, the care of people who had contracted COVID-19 required resources of the same kinds.

Another factor that may have contributed to the slow scaling up of testing is that Sweden's pandemic preparedness, like that of many other countries, was geared towards a flu pandemic and did not foresee a need for testing on a scale never previously carried out.

On 30 March 2020 the Government tasked the Public Health Agency with drawing up a national testing strategy, having begun its preparatory consideration of the terms of reference for this as early as around 1 March. The Agency presented a strategy some three weeks later, on 17 April. Finally, on 11 June the Government approved an agreement with the Swedish Association of Local Authorities and Regions (SALAR) that made increased testing possible. The Government's target from April of 100 000 tests a week could not be met until the beginning of September 2020. While the Commission understands many of the challenges and difficulties involved in building up and managing large-scale testing, it nevertheless takes the view that progress was far too slow. It was significantly slower in Sweden than in comparable countries such as Norway, Denmark and Finland.

The Public Health Agency's early testing guidelines concentrated more on priorities than on a clear endeavour to rapidly expand testing capacity. According to these guidelines, from 12 March, the focus was to be on sick people in need of hospital care (priority group 1) and staff working in health care and care of older people who were known to be exposed and had symptoms (priority group 2). Suspected cases not requiring hospital care were primarily to be managed by isolation in the home and social distancing. The national testing strategy from 17 April 2020 defined two new priority groups, namely (3) key workers and (4) individuals in "other relevant parts of society". Concerning testing and laboratory analysis relating to priority group 3, the Public Health Agency wrote that they "should be handled outside the health care responsibility of the region concerned". The Agency did not clarify, though, whether it considered that such testing fell within the regions' responsibility for communicable disease prevention and control.

Under the Communicable Diseases Act, each region (that is, regional council, representing the regional tier of local government) is responsible for ensuring that necessary disease prevention and control measures are taken within its area. In addition, when a doctor suspects an infection, he or she is required to examine the patient and take the necessary tests. The regions thus have a responsibility to test everyone with symptoms of COVID-19. Given the limited testing capacity that existed in spring 2020, not all regions were able to shoulder this responsibility. The Commission can understand that, in that situation, the Public Health Agency set an order of priority, as a support to the regions. However, we consider that the Agency should have made it clearer that these priorities were only temporary, until such time as the regions were in a position to fully meet their obligation.

On 11 March 2020 the Government and its support parties announced that the state would cover "extraordinary measures and additional costs" in the health care sector linked to the coronavirus. When the Public Health Agency published the national strategy, the Riksdag (the Swedish Parliament) had in addition decided to provide an extra SEK 1 billion for testing. Even so, a dispute arose over money and responsibility for testing of priority groups 3 and 4 in particular, but also of priority group 2. Some regions took the view that these groups were not their responsibility and that, if they were to test them all the same, they needed to be given special funding for the purpose. SALAR adopted the same position and the question was the subject of negotiations in April and May 2020.

Although the Public Health Agency could have been clearer in the national testing strategy about the question of responsibility, the Commission believes there can be no doubt that the regions are responsible for testing any individual who may be suspected of being infected with a disease representing a danger to public health or society, regardless of whether that person is a nurse (priority group 2), a police officer (priority group 3) or a forklift operator (priority group 4). The Commission is of the view that it can hardly be described as anything other than a complete failure when a discussion about responsibility and funding was a factor in preventing any large-scale testing getting started until the first wave was over.

In spring 2020, the focus was on testing rather than on contact tracing. Only when an additional SEK 5.8 billion was allocated to the regions in early June did the Government task the Public Health Agency with helping them to build up a capacity for tracing. Not until 22 July 2020, however, did the Agency present initial guidance on the subject. The first wave had thus receded without any very extensive contact tracing being carried out. The Commission considers that the process took too long and that the late implementtation of tracing hampered efforts to fight the pandemic.

The Commission also finds it remarkable that it was only towards the end of February 2021 that the Public Health Agency changed its recommendation on tracing an infected individual's contacts back in time from 24 to 48 hours. International experts had been advocating 48 hours as early as the spring of 2020.

Before the next larger-scale epidemic virus outbreak, the responsible authorities must ensure that there is sufficient capacity to rapidly scale up the use of testing and contact tracing.

# Personal protective equipment and medicines

In spring 2020, Sweden and the rest of the world found themselves in an exceptional situation. The novel coronavirus meant that in some cases use of personal protective equipment (PPE) increased by several hundred per cent and existing stocks ran out in a matter of days. The situation was similar in large parts of the world, and basically the whole world was competing for the limited quantities of equipment available.

Sweden's emergency stockpiles had been dismantled over a period of several years and were virtually non-existent when the outbreak occurred. Instead, purchasing of PPE was based almost everywhere on the "just-in-time" concept, whereby organisations seek to keep stocks as small and efficient as possible. For these reasons, the shortage of PPE during the first wave of the pandemic in spring 2020 became so acute that staff – particularly those employed by municipalities – were at times forced to work without appropriate equipment. In the late spring, supply chains began to work again.

Indications that Sweden could be facing a serious crisis inadequately prepared reached the Government as early as the end of January/beginning of February. They included a request from the Public Health Agency for COVID-19 to be classed as a disease dangerous to public health and to society, and a situation analysis from the Swedish Civil Contingencies Agency. In February the National Board of Health and Welfare admittedly made limited purchases, but neither the Board nor the Government took any initiative at that time to provide themselves with information about the situation in municipal health and social care. Only on 16 March 2020 did the Government task the National Board of Health and Welfare with securing supplies of PPE. In the Commission's eyes, therefore, the six weeks in February and early March were lost time in terms of tackling the shortage of personal protective equipment.

The task of securing PPE supplies was entrusted to an agency that in no sense had either the organisational capacity for or experience of procurement on the world market on the scale that was required. The National Board of Health and Welfare was thus given a completely new job to do, and had to expand its procurement unit and establish close collaboration with the Swedish Armed Forces and the Defence Materiel Administration. The process which the Board employed in its purchasing seems both complicated and back to front, with few proactive features. It is the Commission's view that the Government should not have entrusted this task to the Board, but to an established procurement agency. Possibly an even better – or at least a complementary – option would have been to adopt an unconventional approach, such as taking steps to create a national Command Centre similar to the one established by Region Stockholm.

The National Board of Health and Welfare's remit was regarded as clear by the Government and by the Board itself, namely that it was only to supplement regional and municipal councils' own purchasing. But several other parties found it unclear. Some suppliers were uncertain whether they were allowed to supply directly to care providers, and some care providers wondered whether they were permitted to use their own equipment or had to send it in to the Board of Health and Welfare.

The Commission wishes to stress that regions and municipalities made huge efforts to secure purchases of their own and in many cases managed to do so, largely thanks to an admirable degree of drive, inventiveness and commitment. Regional and municipal councils have applied for central government grants of SEK 5.4 billion, evidence that they have purchased large quantities of PPE. The regions' central purchasing organisation, Adda, has supplied municipalities, in particular, with PPE through an online shop. The Commission finds it difficult to understand, though, why Adda was not able to offer equipment until late May 2020.

Both the business community and civil society made considerable efforts to provide PPE for the health and social care sectors. Among other things, companies repurposed their production to supply products such as hand rub and masks. However, it has emerged that several businesses that offered help had difficulty getting a response from the authorities. Several companies and trade associations demonstrated a willingness to contribute, but the public sector, chiefly the National Board of Health and Welfare, was unable to assist in bringing about larger-scale repurposing of their production.

Before the next crisis, especially if there is a risk of it affecting world trade, national preparedness must be significantly improved, in terms of both maintaining stockpiles and purchasing the necessary products at a national level. This in turn requires effective reporting channels that can help to collate the needs of individual actors in order to arrive at a national picture. The authorities must also make better use of the contribution from the business sector, despite uncertain information and a risk of costs to the public purse.

Personal protective equipment is designed to protect employees, on the one hand, and patients and residents, on the other. The interests of these two groups are safeguarded by different sets of regulations and guidelines, and are the responsibility of different authorities, primarily the Public Health Agency and the Swedish Work Environment Authority. In our first interim report we observed that

there should have been early and consistent guidelines conveyed by both the Swedish Work Environment Authority and the Public Health Agency of Sweden surrounding the use of PPE. Alternatively, it should have been stated how the objectives of protecting staff and preventing the spread of the virus were to be weighed against each other.

It is now clear that the different messages from the two agencies were due to them in fact holding different views on the use of PPE and being unable to agree. Under the extreme conditions prevailing in the spring of 2020, the Work Environment Authority and the Public Health Agency should have been transparent about there being a shortage of PPE. They should have issued guidelines or support to care providers, clearly stating what steps could be taken in the face of this shortage to reduce the infection risks to staff and service users. It is difficult to see the Work Environment Authority's actions as anything other than a betrayal of all the employees who, faced with an acute shortage, were forced to provide health and social care without appropriate PPE or other help to protect themselves by alternative means. This was particularly the case in municipal health and social care.

The demand for certain medicines also grew in spring 2020. One result of the increased demand was a shortage of certain intensive care drugs. Overall, though, the supply of medicines has been relatively good during the pandemic, and the great majority of people have had access to the medication they require. Sweden was better equipped for the pandemic when it came to medicines than in the case of personal protective equipment.

# Health care during the pandemic

# The health care system's capacity to handle the pandemic

During the pandemic, Sweden's health care system has been placed under strains that are without parallel in modern times. There were a number of shortcomings in Swedish health care even before the pandemic that may have affected the system's capacity to handle the virus outbreak. For example, the health care system shows poor results by international standards when it comes to ensuring continuity and access. Another weakness is IT systems that do not communicate with each other and a lack of data, which makes follow-up more difficult. Several of these concerns were emphasised by the Commission in its first interim report, as was the shortage of health care staff employed by both regions and municipalities prior to the pandemic.

But the Swedish health care system also has strengths which the Commission judges to have been of importance for its capacity to handle the pandemic: good medical outcomes, well-developed highly specialised care and a high degree of digitalisation.

In March and April 2020 the number of admissions to hospitals and intensive care rose very rapidly. This was especially true of Stockholm and Västra Götaland. The second wave began in October 2020, but admissions did not increase at the same rate then as in the spring of that year – although at many hospitals they did finally rise to the highest levels at any time during the pandemic. Compared with other EU countries, Sweden has had the lowest number of hospital beds per capita. The need for additional space for patients with COVID-19 was therefore considerable in every region. This necessitated an extremely rapid ability to adapt and to reallocate existing resources.

Based on our own inquiries and two background reports, on infectious disease care and intensive care respectively, the Commission can conclude that the health care system was by and large successful in making the necessary adaptations. Patients in need of hospital care for COVID-19 seem in general to have received care. This also seems to have been largely the case as regards intensive care. Adaptation was achieved despite a lack of rehearsed pandemic plans and extra capacity. The price paid for it by health care staff was high. They were frequently pushed to perform far beyond what could reasonably be asked of them. The shortage of staff before the pandemic became even more accentuated as patients' care needs and sickness absence among employees increased sharply. The health care system has had to manage the pandemic by using existing employees almost to breaking point. Staff have worked overtime and rescheduled and limited their holidays. The lack of PPE, especially during the first wave, caused considerable anxiety and stress. Health care workers have spoken of constant worry about becoming infected and infecting other patients and their own families. They have also described how the pressure of the situation, with many people seriously ill and a sense of not being able to do enough for their patients, also gave rise to ethical stress. The pandemic has made clear the lack of margins in the supply of staff in health care.

The Commission considers that staffing issues must be included in health care contingency planning. A first step towards remedying the shortage that existed even before the pandemic must be for regions and municipalities to offer health care staff working conditions that encourage them to remain and develop in their professions.

The private health care sector has contributed by seconding staff, caring for COVID-19 patients and taking over surgery. There is nonetheless cause to consider stipulating – by law or agreement – that private care providers that benefit from public funding, at least, also have an obligation to support public providers in a national crisis. This is of course particularly true of regions where private providers are common.

Collaboration between regional councils and between regional and municipal councils has been enhanced and deepened. This has partly been achieved through the health care professions' own organisations, and SALAR has played an important coordinating role. Digital ways of working have become more common, mobile teams have been created and joint training programmes have been carried out. At the same time, many development projects have had to take second place.

The Commission's conclusion is that regions and municipalities need to further strengthen their collaboration in order to ensure under normal circumstances that patients receive good, coordinated health and social care. The lack of coordination is particularly apparent when it comes to digital systems that communicate with each other, allowing information to be exchanged. Strengthened collaboration thus needs to cover everything from governance of care to integrated, patient-centred medical record systems.

The Commission is also of the opinion that a more developed system of national follow-up, allowing for both real-time data and retrospective follow-up, needs to be made a high priority. In addition, we consider it important to develop an understanding of post-COVID-19 syndrome (long COVID) and to disseminate this knowledge in primary and other care sectors that come into contact with the patients concerned.

## Cancelled and postponed care

Care of COVID-19 patients has displaced other care and services. Face-to-face appointments in primary and specialised care have decreased in number (although digital appointments have increased), and in many cases planned surgery has been cancelled. Rehabilitation of both COVID-19 patients and those with other diagnoses has also had to take lower priority. At the same time, there are clear signs that people have deliberately refrained from seeking care to avoid becoming infected, infecting others or being a burden on the health care system. The Commission has been able to make a preliminary assessment of these indirect effects on the basis of another of the background reports submitted to it.

Child health care seems to have been affected only marginally, and maternity care also shows good outcomes and small changes generally compared with previous years. The number of myocardial infarctions has decreased. For groups with chronic conditions such as rheumatoid arthritis or diabetes, numbers of appointments have fallen. In the case of diabetes care, checks on eye and foot status have therefore become less frequent, which is concerning as lasting damage may have arisen. The frequency of psychiatric appointments is unchanged, if both face-to-face and remote consultations are included.

In cancer care, a fall of over 6 per cent in the number of new reported cases has been seen. Some regions have completely suspended breast cancer screening, and there has been less followup of PSA tests for prostate cancer. There has also been a decrease in screening for cervical cancer, of almost 5 per cent, though with large regional variations. Planned surgery shows a decrease of 11 per cent, while emergency surgery shows a small rise of 3 per cent.

The reordering of priorities which the health care sector has been forced to undertake has been informed by pragmatism and a reasonable weighing of the factors involved. Lessons learned from the first wave seem to have been put to good use in later phases. It is important to point out, however, that it is too early to assess the long-term health effects of cancelled and postponed care.

# Indirect consequences of the pandemic

# The price of social isolation

The pandemic has fundamentally changed many people's livelyhoods, housing situations, working conditions, study environments and – not least – social contacts. Just as with ill health and deaths resulting from COVID-19, the indirect impacts of the pandemic on people's well-being, way of life and so on have fallen unevenly. It is clear that groups that were already vulnerable and at risk have been hit harder than others, and that socio-economic and medical factors are of great significance.

What has also become clear in a major societal crisis like this is the important part civil society plays in people's lives. For some, the support of this sector has been crucial during the pandemic. The knowledge, skills and experience of civil society therefore need to be put to better use in the next crisis.

Many older people have felt considerable anxiety about becoming seriously ill and not receiving care. The recommendation on social isolation aimed at the elderly has resulted in poorer mental health for certain groups and also posed a risk to their physical health. Civil society organisations describe how many older people have found this an extremely difficult time, and how many continue to do so.

For many people with disabilities, too, the effects of the pandemic have been very keenly felt. Reports speak of a marked deterioration in the well-being of individuals with disabilities, especially those with neuropsychiatric and learning disabilities. While social and health care provision for children and young people with disabilities has not been affected to any great degree, the impacts and strains on many families have been very significant. Civil society organisations also report a rise in mental ill health among children.

The general health of most of the population remains good, although minor mental health issues are still common. There are also studies that suggest there has been an increase in mental ill health, but to date the National Board of Health and Welfare has not seen any major changes compared with previous years in reporting of psychiatric conditions from the health care system.

Regarding individuals with dependency problems, there is no unequivocal evidence as to whether substance misuse has increased or decreased, but situation analyses and official reports convey a clear picture of social problems and vulnerability.

For many people, more widespread digitalisation has increased social contacts and facilitated access to health care, but for others it has led to greater social exclusion. This is true, not least, of some older people and people with disabilities. This may be due, for example, to unfamiliarity, a lack of ability, or inadequate access to equipment.

Regarding the pandemic's impact on domestic violence and honour-based violence and oppression, too, there is no clear-cut picture, partly owing to a lack of statistics. The various bodies and organisations in this area, however, express great concern about an increased need for support measures and about the pandemic having long-term consequences for this type of vulnerability.

It is not yet possible to see the full, overall consequences of the pandemic, and there are a number of difficulties in assessing the pent-up need for social support measures. One such difficulty is the lack of statistics and data sources that could provide a more complete picture. Despite this, the Commission has attempted to provide some insight into the "social backlog" that has arisen or could arise as a result of the pandemic.

While this social backlog does not appear to be as large as could initially be feared, the Commission's assessment is that there will probably be an increased need for support and interventions as a consequence of the pandemic. This is indicated above all by the sharp rise in non-implemented decisions on various interventions in 2020 that have been reported to the Health and Social Care Inspectorate, and by the concerns voiced by civil society organisations, among others. The social backlog will probably also prove to be unequally distributed.

The Commission considers that further follow-up and research need to be carried out in this area as well, to create a more complete picture of the negative consequences the pandemic has had for individuals.

# The effects of remote and distance learning

During the pandemic a number of forms of education switched to remote and distance learning. In upper secondary schools, this was true of all teaching in the spring of 2020 and some teaching through to spring 2021. Compulsory (primary and lower secondary) schools and preschools largely remained open, although some schools covering years 7–9 did make use of distance learning. Almost all adult education and higher education have been based on distance learning throughout the pandemic and are only now beginning to open up.

The Commission notes that access to education has been good, but that the change to distance learning has created difficulties. This is particularly true of vocationally oriented programmes, on which it has proved difficult to replace some practical elements of courses.

Even before the pandemic there were differences in teaching quality and student outcomes between schools and between different groups of young people. To some extent, these differences have become greater over the course of the pandemic. Distance learning has suited some students, but by no means all. The spring of 2020 proved especially chaotic for upper secondary students with neuropsychiatric impairments. The Swedish education system has thus become less equitable during the pandemic.

The studies and reviews carried out in Sweden indicate that stress and anxiety among school and university students have increased during the time distance learning has been used, particularly among upper secondary school students. However, as yet no clear-cut picture has emerged, in either Swedish or international studies, of whether school closures during the pandemic have been a factor behind increased mental ill health in young people. The Commission has received a background report on the effects of remote and distance learning on knowledge and mental ill health. It shows that documented student outcomes in the form of grades from lower and upper secondary schools and higher education institutions remain largely unchanged.

It is not possible at this stage to assess the full consequences of remote and distance learning in terms of student outcomes, mental ill health among young people, or possible gaps in knowledge for some students. The Commission believes that there needs to be a follow-up of learning, chiefly among students who have received parts of their upper secondary schooling in the form of distance education. It is also important to follow up mental ill health among these students.

# Shortcomings behind Sweden's handling of the pandemic

# Communicable diseases legislation is inadequate

The provisions of the Communicable Diseases Act are key to what possibilities exist to manage a pandemic. The Act is based on a voluntary approach and personal responsibility, but also includes a number of basic tools to combat the spread of infectious diseases: testing, contact tracing, rules of conduct, quarantine, isolation and lockdown of areas. Several tools which it ought to have been possible to use have not been employed. Some have been used to too limited an extent, and a few could not be used at all.

The Commission concludes that in several respects the Communicable Diseases Act has proved inadequate for handling a pandemic, as it is too focused on the individual. In a pandemic, the challenge is not just to look after individual citizens, but to protect an entire population.

Isolation can only be used if there are relatively few cases of infection and disease, as the Act provides that isolation has to take place in a health care facility. This has hardly been an option during the pandemic, given the shortage of hospital beds. Isolation also presupposes an application by the County Medical Officer to a general administrative court, which is virtually impossible when large numbers of people are ill at the same time.

Although, from a strictly legal point of view, certain measures under the Communicable Diseases Act could have been used, other practical or administrative obstacles or difficulties have arisen, for example a lack of areas to separate groups of travellers for border control or for quarantine.

Other tools – such as bans on visits and restrictions applying to restaurants – are simply not available under the Act and had to be implemented instead using more generally worded powers set out in other laws and regulations. The Government, moreover, was forced to introduce two rounds of new, more intrusive legislation.

In several regards, then, the Communicable Diseases Act lacks rigorous and usable tools for handling a serious pandemic. Having to bring in alternative measures under other legislation has not only hampered a rapid response, but also limited what interventions it was in fact possible to adopt.

# County Medical Officers should be given a stronger position

Every region is required to have a County Medical Officer, who plays a central role in communicable disease prevention and control and is responsible for leading and organising efforts in this area in the region concerned. County Medical Officers are to be independent in matters involving the exercise of authority. As the body responsible for health care, however, the region has overall responsibility for planning, organising and funding this work. This unclear relationship between region and County Medical Officer – a disease control function that is to operate with a high degree of independence, yet is dependent on the financial and organisational muscle of the region – was already discussed during the drafting of the Communicable Diseases Act. The Commission has learned that the position and influence of the County Medical Officer vary widely between regions.

The relationship between individual County Medical Officers and the Public Health Agency is not clear, either. The Commission's impression is that it has sometimes been unclear whether County Medical Officers can and should make assessments that differ from those of the Agency. This should not have been unclear: the Public Health Agency has a coordinating role, but County Medical Officers decide what disease prevention and control measures are to be introduced. The Commission is therefore of the view that the position of County Medical Officers needs to be strengthened and clarified. What arrangements should be put in place to achieve this, however, requires further investigation. A reasonable balance needs to be struck between strong disease control experts around the country, capable of making decisions, and the possibility of achieving the coordinated national action that may be needed in a pandemic. One question that should be considered is whether there is not also a need for expertise in disease prevention and control at a local level.

#### Inadequate pandemic preparedness

Hardly any government or government agency realised in February 2020 how large-scale or prolonged the pandemic would prove to be. Sweden, like most other countries, was not prepared.

The present and previous governments ought to have remedied the shortcomings in pandemic preparedness which several earlier reviews had identified and drawn attention to. The Swedish National Audit Office's review in 2008, and the evaluation by the Swedish Civil Contingencies Agency and the National Board of Health and Welfare of the handling of swine flu in 2010, had already highlighted deficiencies in terms of leadership, organisation and collaboration in managing a pandemic.

A number of county administrative boards (central government agencies operating at the regional level) and municipalities lacked pandemic plans before the pandemic broke out, and where such plans existed they were generally not updated or integrated into the activities of the bodies concerned. Nor had regional and central government bodies conducted exercises on any significant scale or involved private health and social care providers in such exercises.

Sweden's pandemic preparedness, moreover, was too narrow in that, like that of other countries, it was mainly geared to influenza pandemics. A typical flu pandemic has a relatively short duration of illness and known routes of transmission, and offers good prospects of rapidly putting a vaccine in place. During the first phase of the corona pandemic, this may have been part of the reason certain decisions were taken too late by the authorities. It may also help to explain why allowance was not made for a substantial and long-term need for personal protective equipment (PPE) or for testing and contact tracing.

As regards preparedness in terms of equipment and supplies, in spring 2020 Sweden essentially lacked emergency stockpiles of health care products and medicines, and the shortage of PPE immediately became acute. Preparedness in this respect must be strengthened, as must the health care system's preparedness regarding premises and staff.

In view of these shortcomings, the only conclusion that can be drawn is that Sweden's overall pandemic preparedness was inadequate.

At the same time, the Commission wishes to stress that contingency plans are not sufficient to handle a larger-scale crisis. There also needs to be a mental preparedness, giving those concerned the courage to act in a timely fashion and make far-reaching decisions on the basis of very uncertain information.

It is presumably not possible to be fully prepared for an outbreak of an unknown virus that results in a pandemic whose seriousness and duration are difficult to foresee. But one lesson should be that it is necessary to continuously practise the ability to think creatively and proactively. Innovative thinking may also require decisionmakers to actively seek out the knowledge and experience of outside experts, such as those working in higher education, civil society or other non-governmental bodies.

A large number of actors at different levels have responsibilities for disease prevention and control and pandemic management. It is remarkable that there is no authority tasked with following up and supporting these actors' pandemic preparedness or pandemic planning, including their supplies management and staffing. The Commission's view is that the Public Health Agency or some other central administrative authority should be given such a role on a clear, statutory basis.

#### A problematic division of responsibilities

A large number of Swedish authorities and other actors – both public and private – are linked to disease prevention and control, pandemic preparedness and pandemic management. They operate at different administrative levels. The Public Health Agency has a coordinating responsibility for communicable disease control at the national level, while regional and municipal councils have the operational responsibility. At the same time, regions and municipalities have farreaching self-government. The "principle of responsibility" gives these various bodies the same areas of responsibility in times of crisis as in normal times. All this combined creates a decentralised but also a fragmented system, and has the result that responsibility is diluted and unclear. It may also result in individual bodies disregarding national consequences in their planning prior to a pandemic.

The existing formal division of responsibilities between the various central government authorities associated with disease prevention and control does not give any one of them the task of leading other authorities in a major crisis. Consequently it was not evident in advance how crisis management would de facto be organised during the pandemic. The leading role in combating the pandemic has, however, been assumed by the Public Health Agency.

The Commission is of the opinion that there may be advantages in one authority having a broad perspective and responsibility for both communicable disease control and the whole spectrum of other public health issues under normal circumstances. But during such a major and protracted societal crisis as the pandemic there are clear risks in letting a single authority strike difficult balances between disease control and other societal interests. It may also be problematic for one and the same authority to be responsible for assessing both risks (risk evaluation) and possible measures (crisis management).

The Commission intends to return in its final report to these specific and general questions concerning the Public Health Agency's organisation, functions and handling of the pandemic, as well as to the broader issue of the division of responsibilities for crisis management.

The pandemic also raises questions about how central government steering of the regional and municipal levels should be designed so as to guarantee effective crisis management in society. Health care is the responsibility of 21 regions and 290 municipalities, which are governed by directly elected councillors. In the light of the existing health care legislation (general provisions set out in a framework act) and local self-government, regions and municipalities have far-reaching powers of self-determination in this area. This decentralised responsibility, combined with the responsibility principle, has meant for one thing that, apart from through legislation, state governance of health care has had to be exercised through agreements between the Government and the Swedish Association of Local Authorities and Regions (SALAR).

SALAR came to play a very central role in combating the pandemic and, for want of other alternatives, has performed a necessary function in terms of coordination and overcoming the problems with the decentralised system. However, it is problematic in several respects that a significant share of the responsibility for actual handling of the pandemic has rested on an employers' association and special interest organisation such as SALAR.

To sum up, the Commission considers that the way in which Sweden has chosen to organise communicable disease prevention and control has given rise to a number of problems in terms of combating the pandemic. We will return to these problems in our final report.