

# How has COVID-19 impacted cancer research in Sweden

2021

# Summary

EY has been commissioned by The Swedish Cancer Society to investigate how Swedish cancer research has been impacted by the COVID-19 pandemic. The purpose has been to identify the effects of the pandemic on different factors that impact the outcome of cancer research. Risk analyses have been performed based on the identified effects. The risk analyses summarise several challenges that stakeholders and decisionmakers should consider in future.

The report is based on the methodological assumption that five factors can impact the research: time, competence, funding, data and infrastructure. The analysis shows that factors are impacted by two different circumstances:

1. Unique effects of the pandemic, which involve risks that are difficult to avoid.
2. Structural aspects amplified by the pandemic, that is, problems that were already identified prior to the pandemic, but which have been aggravated during a crisis.

## Unique effects of the pandemic

One effect of the pandemic, which has had consequences on several levels, is halting patient enrolment in clinical trials. The stop was introduced to different extents at all seven university hospitals in Sweden, primarily between the months of March and August. The overall picture provided by interviewees indicates that the decision was made without crisis management plans or continuity plans. The analysis shows that the halting of patient enrolment risks leading to delayed studies and reduced data collection.

Another effect of the situation of the Swedish healthcare system being under pressure is that staff are reallocated from research to other types of care. Researchers state that approximately 25-50 percent of staff from their clinical trials have been reallocated for periods. This has delayed the research even further. However, the redistribution has also resulted in increased interaction between clinics and staff, which is regarded as having positive effects on both competence and co-operation in the future.

International travel and physical conferences have stopped due to the pandemic. In addition, researchers involved in preclinical studies have largely shifted to teleworking from home and have thus had less physical presence in the workplace. The report shows that all these effects constitute substantial risks for the development of research, particularly if the pandemic continues over a longer period. The research is

said to be highly dependent on meetings among researchers. Meetings and spontaneous discussions are the main hub in the development of ideas and problem solving.

The research is dependent on international collaboration. For certain collaborations, the pandemic has resulted in a lost year, both with respect to current projects and initiating new contacts. While the majority of established researchers do consider that there are significant personal consequences, younger researchers are affected to a much greater extent. Their careers are dependent on forming international contacts, publishing and marketing within limited timeframes.

Digital initiatives have flourished during the pandemic. Although digital meetings are not a substitute for physical conferences and exchanges, increased digital presence means that international discussions and meetings can take place at a greater frequency and within areas where this was not previously relevant.

## Structural aspects that are reinforced by the pandemic

The Swedish healthcare and medical care system suffers from several structural problems. The report shows that the structural problems exacerbate the situation for Swedish cancer research during a crisis such as the COVID-19 pandemic.

The overall structural problem is the low level of national governance. This problem is exemplified by the halting of



enrolment where the basis for the regions' decision can be questioned, at the same time as national support on this issue is lacking. The pandemic highlights the fact that structures around clinical research in Sweden contribute risks for the continuity of research in times of crisis. A low level of national coordination, structure and strategy for clinical research also means that research must rely on individuals who are passionate about the profession to a much higher extent than for healthcare. In times of crisis there are risks with this informal governance. Decision makers can implement drastic measures more easily without taking into account the consequences on research. Another structural problem is the lack of statistics at a clinical level, as well as at regional and national levels. Without basic figures on how research is performing and what resources are needed, it is difficult to make properly balanced decisions in times of crisis. Several interviewees reacted strongly with regard to the lack of statistics.

Several stakeholders have consistently stated that research and care are excessively viewed as two separate parts that compete for resources. This makes it possible to prioritise care at the expense of research, as the regions' conditions and

catalysts for conducting care production are greater than for research. Prioritising care production can also be ascertained on an individual level. Several of the clinical researchers interviewed maintain they have lost the incentive to conduct research. The reduction in clinical research activity during the pandemic has created concern that the trend involving less time and attractiveness to clinical research will be intensified in future.

Finally, we note that companies and management functions within Swedish cancer research consistently have a positive image of the researchers' and clinicians' willingness to cooperate and their initiative to solve problems. Competence, strength of innovation and determination are regarded as being characteristic of Swedish research and contribute to a hopeful view of the future – despite an already well documented discussion of the downward trend of clinical research. The pandemic has resulted in relaxed structures, greater dialogue and new perspectives that can give excellent opportunities to reverse the negative trend of recent years. This report highlights the fact that initiatives are required on a national level, where the government is ultimately responsible for addressing structural weaknesses.

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# Introduction

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# 1



## 1.1. Background

The COVID-19 pandemic puts new demands on Sweden's healthcare and medical care systems. While focus remains on challenges faced by the healthcare system in respect to capacity and healthcare debt, the effects of the pandemic on research have remained a relatively unresearched area, despite research constituting the cornerstone of continued development of our Swedish healthcare and medical care.

In the spring of 2020, the Swedish Cancer Society and EY presented a report highlighting the impact of the COVID-19 pandemic on cancer care. In the report several interviewees expressed unease regarding the consequences the pandemic could potentially have on Swedish cancer research.<sup>1</sup> During the autumn of 2020, the Swedish Cancer Society tasked EY with investigating how the COVID-19 pandemic had impacted cancer research. The results of this investigation are presented in this report.

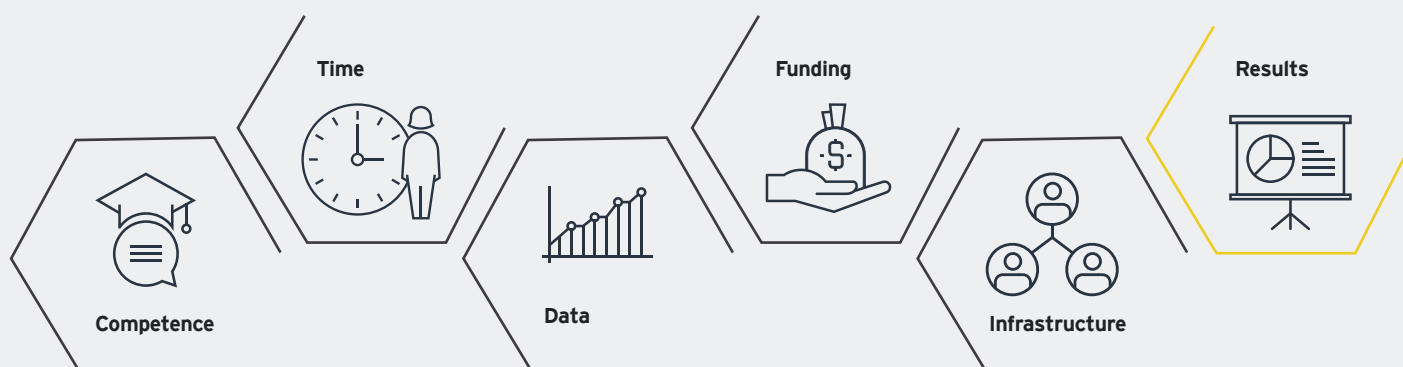
## 1.2. Purpose

The purpose of this report is to identify how the COVID-19 pandemic has impacted Swedish cancer research. Positive and negative effects are both highlighted. Risk analyses are conducted based on the identified effects, and summarise possible challenges for stakeholders and decision makers to consider in the future.

## 1.3. Method

### 1.3.1. Model for impact on research

A simple model is used to analyse how cancer research has been impacted by the pandemic. The ambition with the model is to include all factors that can impact the results of a research study, see Figure 1.



**Figure 1:** Basic model that the report is based on. Five factors that impact the research results have been identified.

<sup>1</sup> This is how cancer care is impacted, The Swedish Cancer Society <https://www.cancerfonden.se/rad-och-stod/coronavirus-och-cancer/sa-paverkas-cancervarden>

The purpose of analysing each individual factor in the model is to look at whether there is a risk that the research results are impacted by the pandemic. Figure 2 clarifies the implications of the different factors.

Competence	Time	Data	Funding	Infrastructure
Access to competence and development of it.	Time that researchers spend on their core tasks.	Access to data, and quantity and quality.	Capital available for researchers to implement their ideas.	Structural opportunities and obstacles.

Figure 2: Explanation of the factors that impact research.

From an early stage in compiling the report, we could determine two different categories of circumstances that impact the five factors:

1. One category is effects that are unique to a crisis and that involve risks that are difficult to avoid. This can, for example, be limitations on travel or that a certain type of study is stopped. We have chosen to designate these as *Unique effects of the pandemic*.

2. The second category consists of problems that were already identified prior to the pandemic, but that make the situation more difficult during a crisis. This may include administrative processes, which normally fall under a research study, but are further magnified during the pandemic and create concern about the future. We have chosen to call these *Structural aspects magnified by the pandemic*.

Figure 3 clarifies the model and the effects that impact on the five factors.

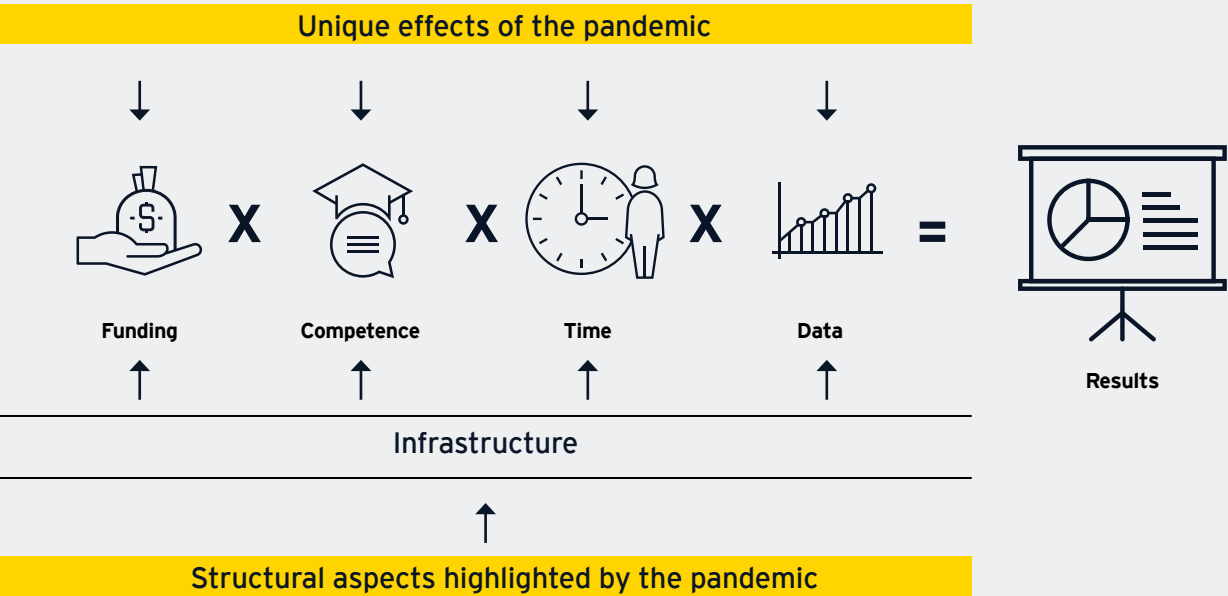


Figure 3: There are two categories of circumstances that impact the five factors: direct effects and structural aspects. The report is structured according to these.

### 1.3.2.

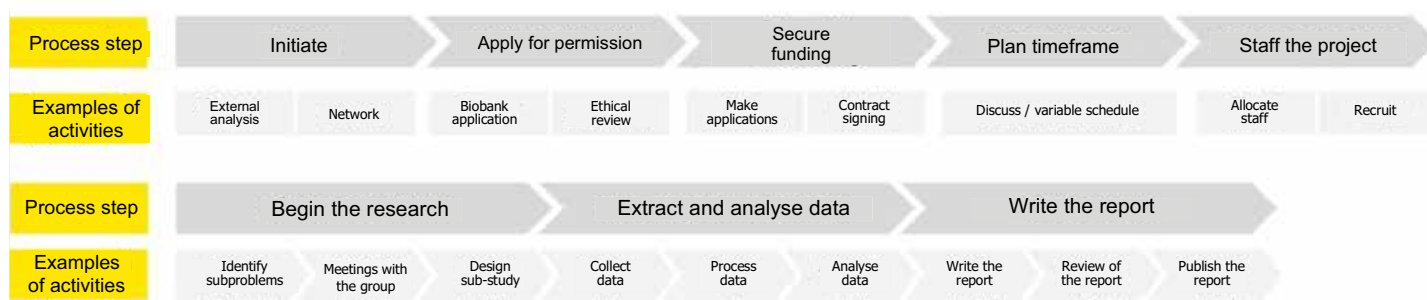
#### Application of the model to research

To better apply the model described above to the broad term of cancer research, process mapping was carried out where the steps within the research process were defined. The process mapping was implemented together with experienced cancer research representatives from the Swedish Cancer Society. Figure 4 shows a generic downscaled process with examples of activities. It indicates how both unique effects of the pandemic and structural aspects highlighted by the pandemic can impact research. By using the process mapping we were able to ensure, to a greater extent that relevant stakeholders were included and that the correct questions were asked.

### 1.3.3.

#### Division into research processes

Cancer research is often categorised into four broad categories, which are basic research, epidemiological, translational and clinical research. However, early in the analysis it was clear that the impact of the pandemic on research could be simplified by dividing it into two main categories. These are whether the research includes patient contact or not. This is due to the findings in this report being mainly dependent on whether or not the research relies on the healthcare system to produce results. The categories also largely coincide with whether or not the research groups include clinical competence, in other words, whether the researchers might need to help out with care. Therefore, the report is based on these two general process divisions.



**Figure 4:** A simplified picture of a research process with examples of process steps and activities. Examples of how the pandemic may affect research can be glimpsed here.



**Figure 5:** Division into two research tracks to facilitate the analysis. Transitional research is included in both, because certain groups work partly in clinics, while others are to a great extent independent from the healthcare system. With respect to direct patient contact, do the studies include patients or healthy volunteers. Clinical trials within research faculties are conducted using pre-existing patient data from sources such as biobanks or using datasets such as molecules, cells or animal research.

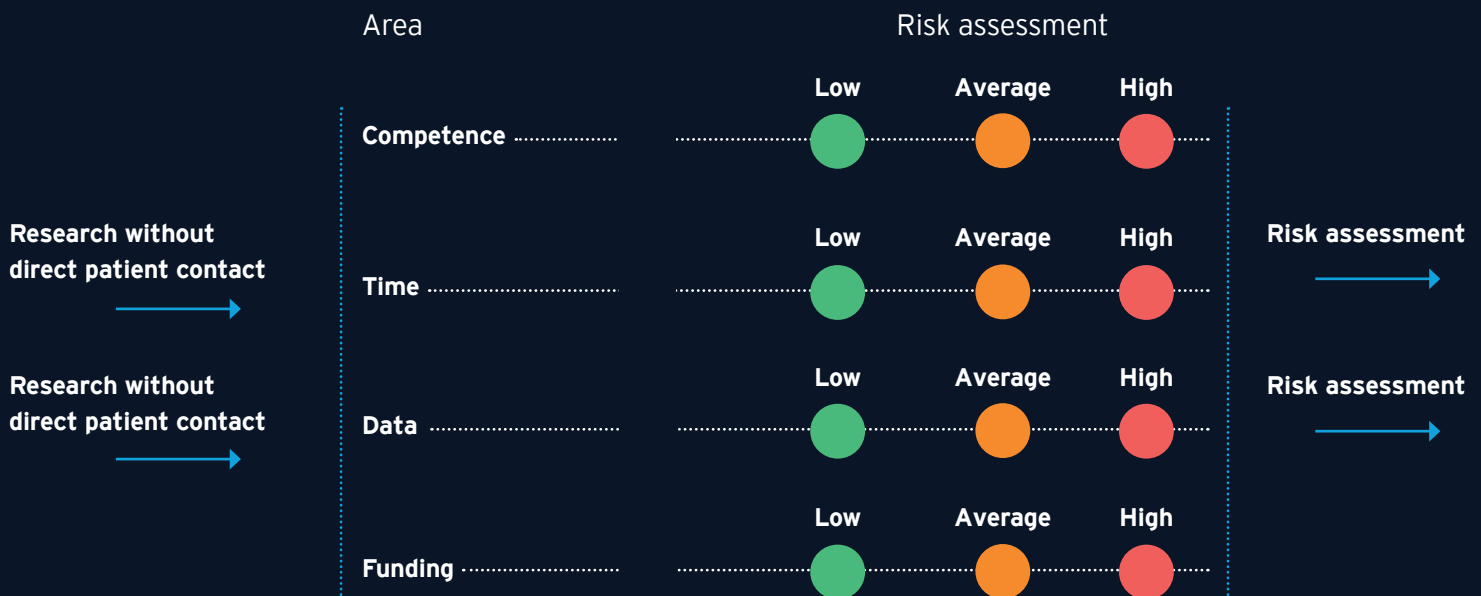
### 1.3.4.

#### Risk analysis

The report includes a risk analysis where the two processes undergo separate risk assessments, which are specified in the parameters of the basic model (Figure 1). The direct effects and the structural observations also undergo separate risk assessments. With risks, the intent is to consistently review the risk so that the results from cancer research in Sweden become fewer and of lower quality. A fundamental assumption is that we will produce more and better results.



## Risk assessment – Illustrative results



**Figure 6:** Both research categories undergo a risk assessment with respect to the four parameters of Competence, Time, Data and Funding. The risk assessment is also divided up into direct effects and structural aspects.

### 1.3.5.

#### Data collection

The discussion in this report is primarily based on results from interviews. A total of 40 persons were interviewed, of these 25 were researchers, 7 were company representatives and funders, and were 8 heads of operations and managers. The individuals were selected by experts from the Swedish Cancer Society. See the Appendix for further information. The interviews were conducted during December 2020.

During the planning phase of the report, the intent was to analyse data from a number of different sources. The data we planned to collect was the following:

- ▶ The number of patients included in clinical trials during 2020 compared with the same period in previous years at all seven university hospitals.
- ▶ The number of ongoing cancer studies during 2020 compared with the same period in previous years at the respective university hospitals.
- ▶ Withdrawals from biobanks in 2020 compared with the same period in previous years.
- ▶ Research funding from major funders.

- ▶ The number of studies delayed during 2020 and the duration and reason, according to the interviewees.
- ▶ The number of staff reallocated during 2020, according to the interviewees.

As regards the number of studies and patients included at the university hospitals, EY only received access to data from the Karolinska University Hospital. EY also investigated data on the number of clinical cancer studies via the EU Clinical Trials Register and the WHO International Clinical Trials Registry Platform. However, when comparing data that Forum Middle Sweden had compiled for 2019, the outcome indicated that the number of studies registered on the international platforms is severely underrepresented. There was also a discrepancy between countries depending on the database used, which made it difficult to compare Sweden on an international scale. As data from Forum Middle Sweden for 2020 will not be compiled before summer 2021, as stated by an interviewee, EY decided to only include data from the Karolinska University Hospital. For trends during recent years prior to the pandemic please see the Swedish Cancer Society report for 2019.

The data points collected from researchers are based on personal estimates and should only be viewed as a rough indication.

### 1.3.6.

#### Delimitation

As noted above, the purpose of this report is to identify whether the COVID-19 pandemic has impacted Swedish cancer research. Based upon possible identified effects a risk analysis is being conducted to illustrate areas where the results of cancer research risk being impacted negatively. The purpose is not to analyse how the research results have been impacted.

either red or green text indicates the effects of the pandemic and structural aspects highlighted by the pandemic. Each area has its own heading and discussion and a final risk analysis and conclusion. The areas with multiple effects have equivalent subheadings.

Risk analyses within each area are summarised in Chapter 4.

### 1.4.

#### The report structure and summary of identified risks

This table shows the structure of the analysis contained in the report. The columns are comprised of the four factors that impact the research. The rows are the different areas that have been impacted by the pandemic. Each box containing

	Time	Competence	Data	Funding
Areas	Effects of the pandemic			
Enrolment halted	Studies are delayed		Lower quantity	
Reallocation of staff	Studies are delayed	New experiences Permanent reallocation	Lower quantity	
Less presence in the workplace		Fewer exchanges between colleagues		
Stoppage of international travel		Less interaction and careers that are impacted		
Stoppage of physical conferences		Fewer contacts, less collaboration and exchange of ideas		
Financial position impacted				Increased funding Uncertain funding
Digitalisation	Less travel	Increased collaboration		
Combination effects	Less time for other things			Unease about the future
Areas	Structural aspects highlighted by the pandemic			
Low level of national governance	Fewer opportunities to study Local decisions are dependent on individuals			
Prioritising care production	Less time for research	Lower incentives for research		
Low level of co-operation between research faculties and clinics		Lower incentives for research, poorer ideas		
High proportion of administration	Less time for research	Lower incentives for research	Lower quantity	



## Unique effects of the pandemic

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# 2

## 2.1.

### Patient enrolment halted for clinical trials

According to representatives for cancer research who have been interviewed the main effect of the pandemic is patient enrolment in clinical trials being halted. In connection with the interviews, we requested statistics on the number of clinical trials stopped, how many patients are affected and comparisons with previous years. We have also requested statistics on when and what types of studies have been resumed and the number of studies started during the year compared with previous years. The Karolinska University Hospital stands out as it is the only one of the five university hospitals that we have been in contact with that keeps the statistics we request. Other university hospitals have not been able to provide the same type of data. See Section 3.1 for a discussion on the lack of statistics. Thus, the report below is based on an analysis of the respondents' answers and an identification conducted by NASTRO where the scope of the enrolment halt is shown<sup>2</sup>.

During the spring of 2020 all seven university hospitals in Sweden decided to halt enrolment of patients in clinical trials for cancer. We have interviewed representatives from five of these hospitals. The purpose behind the stop was stated to be the following:

- ▶ Free up staff from studies and move them to care production.
- ▶ Reduce the influx of patients to hospitals to lessen the spread of infection.
- ▶ Free up beds in the intensive care ward (patients included in clinical drug trials can become severely ill and require admission to an intensive care ward).

It is important to note that all hospitals have continued with treatment of patients already included in ongoing treatment studies. How it has been possible to implement follow-up studies varies among the hospitals and hospital departments. In some cases, there has been no follow-up at all. Clinical trials in both early and late phases have been stopped. Scope as regards duration and degree of stop varied among different hospitals.

The Karolinska University Hospital is the only hospital that continued enrolling patients throughout 2020. This was despite the fact that the Karolinska University Hospital was the hardest hit by the pandemic. Thanks to collected documentation on all ongoing studies it was possible to review each study and decide on the most relevant measures for each specific situation.

Interviewees at other university hospitals have described how a total enrolment halt of new patients in clinical cancer studies became a reality. At Skåne University Hospital in Lund, the total stop lasted between March and June, despite Region Skåne only experiencing a mild impact from the pandemic during that period. During early autumn enrolment in the studies was resumed, but the interviewees stated that after the total stop it took several months to regain the same capacity in the studies. At the time of the interview, the interviewees said they were worried that an enrolment halt in the studies would once again become a reality when the second wave of the pandemic hit. Uppsala University Hospital, The University Hospital of Umeå and Sahlgrenska University Hospital began halting enrolment to different extents from March to August.

In interviews with managers and research heads we noted that there was a lack of crisis management or continuity plans for the decision to halt enrolment. Interviewees state that it would have been desirable to have support from key parties with respect to guidelines for how the research activities should be handled. There is even a lack of impact analyses on what this type of decision leads to for cancer patients and cancer research.

Interviewees give a diverse picture of what the enrolment halt in clinical trials entails and what consequences it has. Some interviewees maintain that this may involve extremely serious risks, both from a patient perspective and a research perspective. Patients may not get vital treatment and data collection can be impacted negatively. Other interviewees consider that a temporary stop for a couple of months will actually not have any effects if the stop is just temporary. Another group maintains that it is impossible to know what consequences this type of measure may have. In the section below the potential consequences of the stop are discussed on the basis of the interview results.

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**47 percent fewer studies were started and 3 percent fewer patients included**

at the Karolinska University Hospital's Centre for Clinical Cancer Studies. Compared with other hospitals, the Karolinska has avoided shut downs to a relatively high degree.

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<sup>2</sup> Experiences from describing cancer studies during the pandemic, NASTRO, [https://nastro.se/wp-content/uploads/2020/10/NASTROs\\_erfarenheter\\_av\\_cancerstudier\\_under\\_pandemin.pdf](https://nastro.se/wp-content/uploads/2020/10/NASTROs_erfarenheter_av_cancerstudier_under_pandemin.pdf)

**2.1.1.****Delays impact studies to different extents**

The enrolment halt for clinical trials means that studies are delayed. As a single factor the enrolment halt does not necessarily mean a longer delay of the study than the stop itself. However, the delay becomes more extensive if the enrolment halt is combined with longer lead times than normal for making applications, rejections to requests to begin studies and reallocation of staff.

Delays in clinical cancer research have had different consequences for different researchers. In the majority of cases it has been possible to shift the focus of the work temporarily. For example, laboratory and clinical work has been reallocated to authoring reports and making applications. The delays have also given researchers the opportunity to complete work that would have been postponed in normal cases. Group leaders of research groups also relate that it has been possible to redistribute researchers and resources between projects and that only some of the ongoing studies have been impacted for longer periods of time.

The risk of significant delays occurs when larger domino effects occur because of the delays. Most researchers express unease that we are approaching a threshold when lead times for making applications, slow administrative work within certain institutions and reallocation of staff creates a scenario where researchers do not have approved projects and clinical research stops because of this.

**11 of 13 clinical researchers state that their cancer studies have been delayed.**

Delays of six months are common, but often it has been possible to use the time for other things.

**2.1.2.****Data quantity and quality are impacted negatively**

The enrolment halt means that the patient data in the studies is reduced, which leads to a reduced amount of data. Several interviewees state that the data quantity in the studies has been negatively impacted, as a significant proportion of enrolment has not been obtained. Several researchers describe the pandemic as a year with a “notch in the curve,” something that can have certain effects on the data set in future studies.

It has been possible to have some enrolment at distance, for example, where patients are included in a training programme that can be done at home. However, the researchers interviewed were worried about the risk of patients not performing procedures correctly and the quality of collected data consequently being deficient.

Additional impact on data can be attributed to monitoring not being conducted to the same extent. Monitoring is a type of quality control for clinical drug trials and is conducted at the clinical trial site. Monitoring is performed by a monitor (one person) who is hired by the study sponsor or by the investigator. In the interviews, it emerged that in several cases hospitals stopped monitoring for several months. This can lead to administrative problems and errors in the study protocol during the monitoring process. Neither researchers nor funders have expressed any risks for patient safety or faulty data collection.

In summary there have yet to be any observable risks of data being impacted negatively to a greater extent. Sweden has also, to a higher degree than other countries, had an open society – a trend that, according to researchers, is reflected in enrolment continuing to be greater in Sweden than in some other countries. However, major consequences will occur if a reduced data quantity is combined with the individual researcher having a lack of time. This is described in the next two sections.

**Time: Mean risk**

Groups of researchers have to a great extent been able to redistribute work and focus on tasks other than the collection of data from clinics. The risk increases during longer duration of stop or extended lead times due to the pandemic. With vaccinations against COVID-19 beginning and lead times that are apparently under control, the risk is not regarded as high.

**Data: Low risk**

Researchers do not describe any significant long-term effects for data collection in their projects, and the risk will increase first in individual cases where a lack of time also prevails for producing results.





## Conclusion – enrolment halt

The stop has led to delays and impact on data. Risks of significant after-effects are deemed as low to medium. The duration of the stop is decisive. Many researchers are thankful that in Sweden the stop has been relatively limited and they express much greater apprehension for a more united, long-term stop. The lack of directives and continuity plans for decision making as regards the stop is a sign of structural challenges, see Section 3.1.



## 2.2.

### Reallocation of staff

Sweden's healthcare system is under high load even when the country is not in a crisis. The majority of clinical researchers say that so much time is required to ensure production of care that the conditions necessary for outstanding clinical research are being pushed aside. This phenomenon was already known about, it was discussed in the Swedish Cancer Society Report 2019 and elsewhere.<sup>3</sup> It is stated that the pandemic will result in a situation that is much worse and provides a taste of what awaits research if the healthcare system remains under strain in future.

#### 2.2.1.

##### Studies are impacted when staff must step in to help in the healthcare system

A direct effect of the healthcare system being under pressure is that staff are reallocated from research to care production. This has different consequences for studies depending on the hospital's organisation.

The role of the clinical research nurse has been highlighted as key to clinical trial activities. Recruitment is difficult in this occupational group and there is a shortage of clinical research nurses throughout the country. The development and continuity of clinical trials is often dependent on individual clinical research nurses. Experience and expertise are often strongly linked to individual studies, which makes activities extremely vulnerable and dependent on the personnel. Thus, it is particularly unfortunate that clinical research nurses are reallocated from research and moved to care production, which has become a reality during the pandemic.

The report shows that staff have been reallocated from clinical trial units to care because of the pandemic. Among other things, clinical research nurses have reportedly been required to change tasks to work in care wards or with administering COVID-19 tests. Several interviewees have stated that the reallocation of staff has been extensive, but we have not been given official figures on this.

One example is an interviewed clinical research nurse who was reallocated to intensive care because of the pandemic. Because of this, the follow-up studies in lung cancer that this person was responsible for were at a complete standstill from March to November.

The organisation of the study units differs across the country. For example, the clinical research nurses at the clinical trial unit at Karolinska University Hospital are divided into larger units so that staff can be reallocated between studies more easily depending on current needs. This means the research activities will become less vulnerable to various types of staff loss. Based on the interviews conducted, a combined estimate is that 25-50 percent of staff involved in clinical cancer studies have been reallocated to healthcare for periods of time.

Time:  **Medium risk**

Reallocation of staff has severely affected many research groups. Several projects are delayed due to a staff shortages and group heads point out that the delays become longer than the actual time that personnel are absent, as the work is disrupted in different ways.

Delays in research due to temporary reallocation of staff to care can be greater than the actual period of time that a staff member disappears for. Interviewees have identified two causes for this observation. Some tasks must be completely redone if there is an interruption. This applies to cell cultures, for example. The other reason is greater unease among staff for the near future. Researchers report anxiety in the face of unexpected decisions that prevent groups from continuing as planned, even though in practice additional stops might not occur. It may be possible to alleviate unease about decision making through clearer governance. Clearer governance can help research groups to feel secure that management is aware of their project and that decisions are made taking into account the needs of the studies'.

**25-50 percent of staff in clinical cancer studies have been reallocated to healthcare for some period of time**

in the majority of the interviewees' studies. Some have stated a higher figure.

<sup>3</sup> The Swedish Cancer Society Report 2019, <https://www.cancerfonden.se/cancerfondsrapporten/forskning>

**2.2.2.****Risk of increased long-term skill shortages – but the pandemic is also a door opener.**

As shown in 3.2.1 the role of the clinical research nurse is central. There is widespread apprehension among interviewees of a possible negative trend of availability of clinical research nurses. In conjunction with the pandemic, clinical research nurses have been reallocated to care production to a greater extent than normal. This is not a decision questioned by the interviewees; however, we note apprehension among researchers that this will increase in the future. Several interviewees believe that Sweden risks losing personnel interested in research to care production to a greater extent as the healthcare debt increases.

Several interviewees also highlighted positive effects resulting from staff reallocation. This includes exchange of knowledge when clinical research nurses work in different departments. This may result in new ideas for clinical research.

Interviewed researchers and company representatives state that cancer is one of the most interesting fields within medical research. None of the interviewees sees any risk of the pandemic, in the long-term, eradicating the position of cancer research in favour of e.g., research within virology. Rather, it is believed that the pandemic has boosted interest in research in general.

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**Only 1 in 37 reallocated projects was cancer related.**

This applies to projects sponsored by the Swedish Research Council.

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Competence: ■ Average risk ■ Positive effects

There is a shortage of clinical research nurses and many doctors who conduct research have a severe lack of time. A drastic redistribution of these resources to care, even though temporary, risks worsening the negative trend of access to research competence. However, clinical research nurses have gained new experience, which can benefit competence development and bring new ideas to clinical research when the nurses return to it.

**2.2.3.****Reallocation of projects is low**

An initial hypothesis in this report was that there would be a risk of ongoing cancer studies shifting focus – from cancer research to projects related to COVID-19.

None of the researchers interviewed claim that this has happened. However, one of the researchers interviewed has reallocated staff within their research group to COVID-19 related projects. Interviewees are of the opinion that the reallocation of research focus has, for obvious reasons, largely taken place in other research fields other than cancer research, such as virology.



## Conclusion – reallocation of personnel

Personnel shortages in care have resulted in personnel shortages in clinical and translational research, whose researchers, research team members and clinical research nurses often have care competence. This has had a significant impact on studies. Unlike delays in individual projects depending on inclusion (see the previous section), where research group focus has temporarily been able to be shifted, a reallocation of staff is much more uncompromising towards research. The effects may persist longer than anticipated and the current priorities and decisions may also lead to more long-term consequences for the willingness of clinics to become involved in research.

## 2.3.

### Less presence in the workplace

Just as employees at many different types of workplaces in the country, many researchers, primarily preclinical researchers, have had to work from home. All interviewees state that their research groups have worked at distance to some extent. The research groups that conduct preclinical research and those whose research does not require access to laboratories or clinics have experienced the greatest transition to working from home.

The majority of researchers express, in strong terms, that the lack of spontaneous, physical encounters negatively impacts research. Spontaneous contact in the workplace is regarded as key to generating ideas, developing reasoning, problem solving and feedback.

Interviewees state that working at distance functions well during short periods, but long-term physical absence from the research group risks impacting development of reasoning and problem solving.

The interviewees in this report consist largely of experienced researchers who head research teams. They believe that the lack of spontaneous contact primarily affects younger researchers such as doctoral students and postdoctoral students as they are more dependent on having continuous contact with colleagues. As a research head it may be difficult to manage a group at distance over the longer term, not least when it comes to maintaining motivation.

#### Competence: Mean risk

Research is highly dependent on spontaneous discussions because developing ideas and problem solving are so central. The pandemic has stopped this, which entails a risk of ideas becoming lost and that research results are negatively impacted in the long term.

**Research is greatly impacted by the negative aspects involved with working at distance.**

Exchanges among colleagues in the workplace – where ideas flourish.

## 2.4.

### Stoppage of physical conferences

Researchers around the world have been hit hard by cancelled international travel and physical conferences. Conferences are

a meeting place where researchers can exchange ideas and market their research and themselves as researchers, either through presentations or by submitting abstracts.

Many conferences have been held digitally. The extent in which interviewees have elected to participate varies greatly. Some state that the digital conferences enable them to participate more frequently as travel and overnight stays are no longer required. Digital conferences are also said to provide the freedom to access more points on a programme as the flexibility to “jump in and out of presentations” is greater. Others believe that the quality of presentations and implementation become much worse and choose not to attend or give a presentation. Many also state that they have refrained from submitting abstracts to digital conferences. However, the interviewees expressed that the option to participate digitally at physical conferences is also desirable in future.

During conferences there is the opportunity to hold spontaneous meetings with international colleagues. This is regarded as essential to connect with others and generate ideas, just like the spontaneous meetings that take place within the researchers' own research groups as described in Section 2.3. Several researchers stress that spontaneous encounters at conferences have led to lifelong cooperation and that the research world loses a large part of its “soul” when this type of peer exchange is foregone.

## 2.5.

### Stop to international travel

Marketing and creating contacts in the form of travel has stopped. For example, a researcher who has published an article in the renowned periodical Nature, explains that the planned USA tour has had to be cancelled. This severely impacted the research group's marketing, which can lead to a loss of potential opportunities and future projects. Other researchers describe having held off publishing articles during 2020, because the articles risk having a lesser impact. This is a reason why projects with strict deadlines risk being affected more negatively by the pandemic (just like the studies that are affected by halted enrolment).

The cancelled travel has not only impacted conferences and marketing. Interviewees describe several cases where research group members recruited internationally have not been able to travel to Sweden for several months after the planned date. Funding of the service has then been delayed or, in certain cases, been completely absent, which is why the planned service has been postponed.

### 2.5.1.

#### **A lost year in the early stages of a career can have major consequences**

The interviewed researchers are all associate professors or professors. The interviewees are not especially worried about their own careers and missed opportunities due to the pandemic. They state that they have already established a contact network and long-term co-operation and that these will continue during the pandemic, at times even with a temporarily increased intensity.

Instead, interviewees express a much greater concern for their younger colleagues who are dependent on building up their contact network. These are often doctoral students, postdoctoral students and researchers who are currently in

the process of building up their own groups. Here, a missed year of building contacts can have far greater consequences. Researchers around the world are dependent on international exchanges and forging new contacts while they are young. But in a small country such as Sweden, the international forum plays a particularly important role. In addition, the positions available in the beginning of a career have relatively strict time limits and short spans. For example, a post doctorate position usually lasts two years. During these years it is normally expected that articles will be published, often at a university in another country. This gives merits ahead of the next step on the career path. Studies being postponed for a year lead to significant consequences for young researchers.

#### **Competence: — Mean risk**

Research is highly dependent on spontaneous discussions because developing ideas and problem solving are so central. The pandemic has stopped this, which entails a risk of ideas becoming lost and that research results are negatively impacted in the long term.

**Young preclinical researchers are the most vulnerable to shutdowns.**

## **Conclusion – less presence in the workplace and stop to international travel**

Spontaneous encounters and discussions in the workplace and at conferences are a cornerstone of research. International travel and conferences are also extremely important for marketing and for forging new collaboration.

All researchers have been impacted by cancelled conferences and fewer opportunities to present their results. Interviewees have expressed a sense of unease that younger preclinical researchers are greatly impacted by the pandemic. Interviewees call it “a lost year,” something that can have significant consequences for a young researcher’s career.



## 2.6.

### Financial position impacted

EY has interviewed major research funders within the field of cancer research, including the Swedish Cancer Society, The Knut and Alice Wallenberg Foundation (KAW) and the Swedish Research Council. According to these funders 2020 has been a positive year from a cancer research funding perspective.

How the funders' financial situation will impact funding during coming years remains to be seen.

Funding: ■ **Low risk**

The overall picture is that the major funders have continued providing the agreed support. Unease related to funding primarily involves smaller funders. Researchers describe smaller funders as having expressed uncertainty and, in certain cases, support has been paused with reference to the uncertain times.

## Funding 2021 compared with 2020

- ▶ The Swedish Cancer Society has received more donations in 2020 and can increase its funding in 2021.
- ▶ The Knut and Alice Wallenberg Foundation has not had any negative impact on their resources for cancer research.
- ▶ The Swedish Research Council is a State funder, whose funds are regulated, among other things, by the provisions of the Swedish Research Proposition. The Swedish Research Proposition proposes significant increases to State resources for research for the years 2021-2024.

In the interviews, it is noted that the unease associated with funding during 2020 primarily applies to smaller funders. In some cases, they have communicated with researchers about payments being paused until the situation is stabilised. None of the funders have communicated plans to cancel existing support in the long-term. Interviewees generally describe funders as being understanding and willing to extend the availability period for the funding.

### 2.6.1.

#### Potentially increased interest in research generates more revenue

The Swedish Cancer Society sees positive figures thanks to an increase in donations. Whether or not there is a link to the pandemic is unclear. One possible underlying reason may be an increased interest in research as there is an increased presence of research in daily life. Swedish non-profit membership organisation VAs (Public & Science) annual barometer for 2020 shows that Swedes' confidence in researchers has increased from 79 percent in 2019 to 88 percent in 2020.<sup>4</sup> It is worth noting that the situation may look different internationally. The American Cancer Society, a cancer focused philanthropic organisation, expects donations to decrease by USD 200 million and they could not implement the autumn appropriation period.<sup>5</sup> This is a noteworthy contrast to the Swedish Cancer Society's positive figures.

The Swedish Research Proposition (Forskningspropositionen (2020/21:60)) with increased appropriations to research should also be partly viewed in the increased focus on research in the shadow of the pandemic.

<sup>4</sup> VA barometer 2020/21, Public & Science <https://v-a.se/2020/12/va-barometern-2020-21/>

<sup>5</sup> Dana-Farber Cancer Institute, <https://www.dana-farber.org/newsroom/news-releases/2020/study-offers-global-review-of-impact-of-covid-19-on-cancer-treatment-and-research/>





## Conclusion – Financial situation impacted

After a shaky spring 2020 with cancelled dividends the stock market experienced an upturn. In addition, financial support from the public and state is on the increase. However, research expenses in relation to results have increased, as staff and facilities have been unused. There is also a sense of unease about a decrease in future funding for researchers who have been significantly impacted by shutdowns and delays. But funders are perceived as being understanding and researchers generally have a positive outlook on future projects.

## 2.7. Digitalisation

### 2.7.1.

#### Less travel and increased collaboration

Working at home and cancelled trips have also brought positive effects beyond the negative effects described in Sections 2.4 and 2.5. New solutions have resulted in new opportunities. Above all, researchers note that meetings that could not be conducted in past because of geographical distance can now take place thanks to the digital adaptation. Most noteworthy is that different parts of the constellation can have more frequent contact, such as contact between doctors at the clinic and researchers within the research faculty. Co-operation between research faculties and clinics is discussed in greater detail in Section 4.4.

In the northern Swedish country of Västerbotten it is described how long trips no longer need to be carried out. For the most part the region has also experienced a more positive attitude towards digital international meetings and conferences. Less travel time means more time to spend on clinical work or time for research. Here, the aspect of equality has been highlighted as being central, as regions located far away from major cities or airports can compete much easier thanks to a higher proportion of digital meetings.

#### Competence: Positive effects

Although digital meetings cannot replace physical conferences and exchanges, the increased digital presence means that international conversations and meetings can take place at greater frequencies and within areas where this was not previously possible.

### 2.7.2.

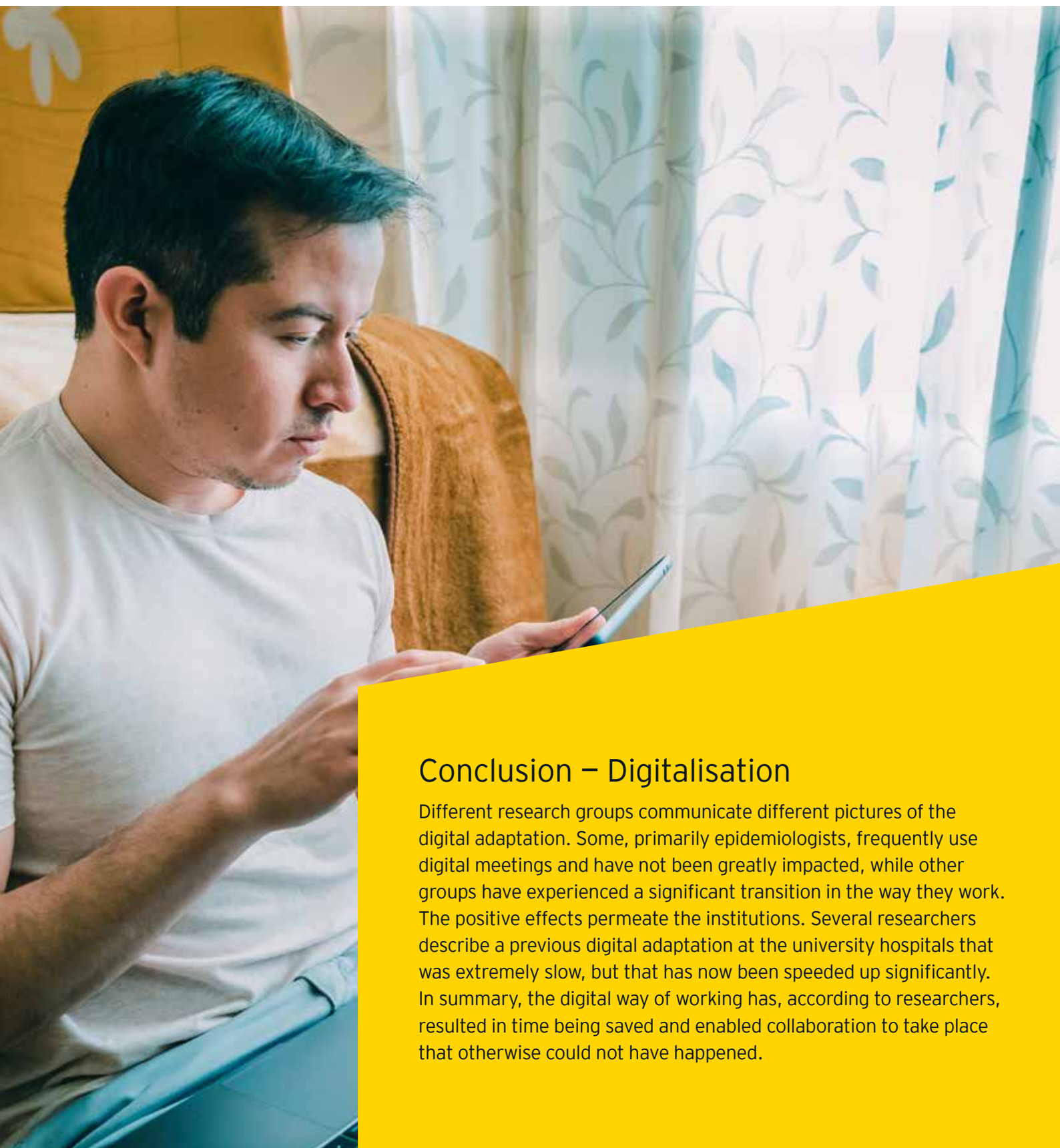
#### Increased international exchanges

Although most researchers believe that digital conferences completely lack several of the central components that a physical conference has, there are opportunities to create higher levels of participation and a more rewarding exchange within more local seminars. Thanks to video attendance becoming used more frequently it has been easier to attract international researchers to sessions where international attendance would have otherwise been lacking.

#### Time and Competence: Positive effects

Digital meetings lead to opportunities that have never been seen before for different departments to have frequent contact and fruitful collaboration. This is promising for e.g., co-operation between research faculties and clinics, which according to all stakeholders should be improved. Digital meetings streamline and enable contact, particularly in Sweden's more sparsely populated regions.

Digital meetings have enabled increased collaboration between individuals and groups.



## Conclusion – Digitalisation

Different research groups communicate different pictures of the digital adaptation. Some, primarily epidemiologists, frequently use digital meetings and have not been greatly impacted, while other groups have experienced a significant transition in the way they work. The positive effects permeate the institutions. Several researchers describe a previous digital adaptation at the university hospitals that was extremely slow, but that has now been speeded up significantly. In summary, the digital way of working has, according to researchers, resulted in time being saved and enabled collaboration to take place that otherwise could not have happened.

## 2.8. Combination effects

### 2.8.1. Reprioritisation in the healthcare and medical care system has resulted in time available for research

The decisions and prioritisations that have surrounded the healthcare and medical care system during the pandemic have led to several researchers having time freed up for research. For example, some planned medical care has been postponed, clinical trials stopped, and travel and conferences have been cancelled.

When asked what trends the interviewees have been able to identify during 2020, several state that the number of requests for article reviews has increased. Interviewees state that one explanation for this might be that time has been freed up because of cancelled activities and that this time has been able to be spent on writing articles.

Other interviewees indicate that they have seen tougher competition when it comes to making applications for research spending during the latter part of 2020. The interviewees also believe that this may be dependent on the fact that there is now more time to spend on developing applications for research than there ever was before.

### 2.8.2. Unease that poorer research results at present will lead to less spending in future – but there is positive communication with funders

Future funding of projects largely depends on the researcher's prior results. Enrolment halt, long lead times for receiving responses to applications that have been made and access to data, unexpected lack of staff due to reallocation to care, illness or international researchers who were unable to join, have led to reduced datasets and unease that ideas and insights into the research have not progressed significantly within certain projects. Several researchers also indicate that they cannot market their research as well and that publications are not distributed as widely. Researchers who need to publish

or report to funders, despite the research not having resulted in deeper insight during the year, express a sense of unease that this will impact their future funding. This may, in turn, make it more difficult to produce outstanding results in future. Thus, the pandemic risks creating a negative spiral for certain researchers and groups.

However, at the same time, researchers describe funders as being much more understanding and having accepted longer availability periods or increased support. Therefore, the hope is that the temporary decrease in results during the pandemic can be weighed into future support from funders, and the risks are generally viewed as being minor.

Funding: ■ Low risk ■ Positive effects

Individual researchers can be hit by unfortunate timing with respect to making applications, collection of data and publication. This leads to delays, potentially poorer data and less publicity, which can impact researchers' future funding. However, at the same time, researchers describe goodwill among funders and hope that this can compensate for a bumpy year for affected researchers.





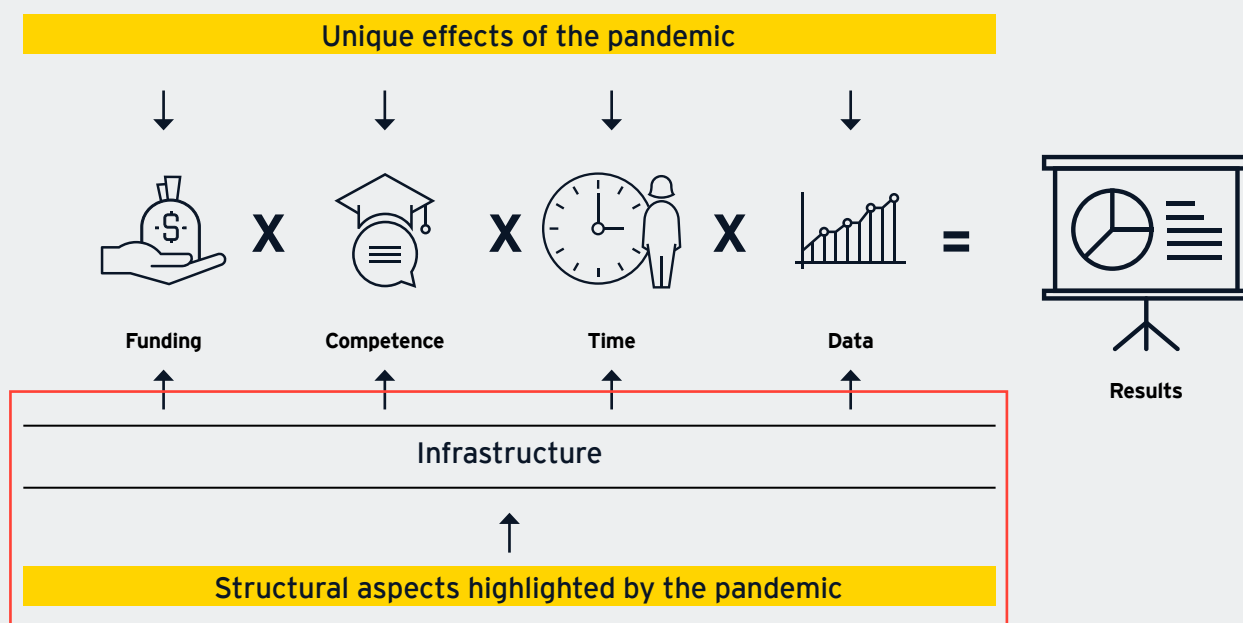
## Structural opportunities and problems

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# 3

Several of the challenges highlighted by researchers, research funding companies and managers have a different nature to the direct effects the pandemic has posed through restrictions and shut downs. For example, this is highlighted by the discussion on the enrolment halt where decision making processes in the regions are viewed from several angles as needing extra support. Interviewees conveyed several recurring challenges of this nature. Therefore, in the

coming section an attempt is made to summarise the structural problems and opportunities that prevail in Sweden and that have been amplified by the COVID-19 pandemic.



**Figure 7:** Chapter 3 focuses on the structural aspects highlighted by the pandemic. This has been a well-known problem for quite some time and is significant for long-term development in Sweden by impacting competence, time, data and funding.



### 3.1. Low level of national coordination

#### 3.1.1. **The pandemic clarifies the need for national coordination to conduct clinical trials**

In a small country such as Sweden, coordination is required to be able to conduct clinical trials. This is to be able to ensure sufficient data in clinical studies. A rare patient group in a special study often requires the entire country as a catchment area to have enough patients included in the study. As stated in the general description of a research process in the report methodology there are several process steps involved in starting a research project. To be able to maintain a fast pace with respect to start-up and executing research studies these initial process steps must be conducted relatively quickly and effectively. However, this is not the case today.

According to research funders interviewed it is internationally known that Sweden is unable to manage starting up clinical trials at the same pace as many other European countries and that schedules are often not adhered to. Both researchers and funders specifically highlight Denmark and Norway as models, as these countries coordinate clinical studies via larger national nodes. In this way both resources for implementation within the time frame and requisite data set (patients) are ensured.

From a risk perspective, the pandemic highlights Sweden's need for improvement when it comes to starting and conducting studies. The present reality is that studies are often stopped and that time plans are not followed for various reasons. Examples of reasons are temporary loss of staff and at times healthcare is under more pressure at the clinic. This is a fact during a crisis such as the COVID-19 pandemic.

To continue conducting studies according to plan, an overview of resources is required, so that interruptions can be compensated by providing support in the form of extra capacity that is identified elsewhere. The pandemic clarifies the picture that all stakeholders have already conveyed: that the clinical cancer research needs a national cohesive structure for implementing clinical trials.

As six major regional nodes have been introduced via Clinical Studies Sweden, several steps have been made towards national coordination. The cooperation is based on strengthening the prerequisites for conducting clinical trials, for example, through support in the form of study protocol, permit applications, data management and statistics. The Southern Sweden Region is responsible for coordinating the nodes and each region has a mandate over the resources allocated to the node they belong to. But it is difficult for nodes to obtain the resources required to satisfy the tasks they have.

The researchers interviewed clearly do not use the support available within the framework for the nodes in any larger extent. To be able to start a study and recruit patients the researchers use a more informal professional network instead. Although most researchers believe that this functions well, the pandemic highlights the risks of a lower level of national structure in cancer research. This is discussed in more detail in Section 3.1.2 below.

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**Cancer researchers almost exclusively use their personal networks and not the nodes.**

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## 3.1.1.1.

**Striking lack of statistics**

Within the framework of this report, EY requested a data set to be able to analyse the differences in the number of studies started during 2020 compared with previous years and the number of patients enrolled in clinical trials. Of the five university hospitals that EY has been in contact with, only the Karolinska University Hospital was able to supply figures relating to the number of ongoing and started clinical trials and the number of patients included year by year.

The Karolinska University Hospital also stands out as regards decisions on inclusion in studies during the pandemic (see Section 2.1).

All interviewed parties state that there are problems with hospitals and regions not keeping statistics relating to studies on an aggregated level. An interviewed doctor points out that receiving data relating to the clinic lead time for responding to study enquiries and data concerning the number of patients

included in the study would have been valuable from a development perspective. However, this data is not accessible.

It should be noted that work is currently being conducted to collect data on a larger scale within the framework of Forum Middle Sweden. The work encompasses seven regions and involves compiling and quality assurance of data related to clinical trials, such as the number of studies completed, and the number of studies commenced. It has been reported that data for 2020 will be available later in 2021 and therefore it cannot be used in this report.

Many regions do not have access to critical data on current ongoing studies.

#### Competence, Funding, Time, Data: ■ High risk ■ Positive initiative

We note that decisions on halting enrolment have been made without continuity plans and that national coordinated support in the decision-making process has been requested. We also note an extensive lack of aggregated data in respect of ongoing studies. Entire organisations, from clinical trial unit to regional management, lack data in respect of ongoing studies and other fundamental KPIs. According to the stakeholders, Sweden is less good at initiating and driving studies at a fast pace compared with our neighbouring countries. The stakeholders believe that the regions generally fail to prioritise clinical research to the extent required to improve these items.

According to EYs prior experience with regional and national organisations, a clear responsibility and mandate are required, as well as targets that can be followed up for changes to be made in practice. Those ordering studies have various requirements, and for Sweden, it is important to be able to offer a clear counterparty who can take on the responsibility for managing the client's enquiries and delivering as agreed. It should be possible to keep statistics on studies at a national level, deviations should be analysed, and responsibility should be taken to improve future implementation.

It is serious that there are obvious areas for improvement, such as keeping basic statistics, and that there is no responsibility or that prerequisites are lacking. It is also alarming that the research principals have not identified a significant need for these figures to ensure that they are collected. This can be seen as yet another sign that clinical research needs a higher level of national coordination, with an actor who has clear responsibility and interest to initiate and conduct studies in clinical research.

The pandemic highlights the aspects above and poses a risk that the negative trend of the number of clinical trials in Sweden will get worse. We see potential impact on all four factors in the model. Because coordinating functions, such as Clinical Trials Sweden are aware of this problem, work is currently being done to rectify the situation. There are strong indications that the regions should intensify this work. To correct the recent trend, the regions should be given sufficient incentives and prerequisites for ensuring that clinical trials have the resources that are required.

### 3.1.2.

#### **The pandemic highlights vulnerability in cancer research that is dependent on individuals.**

The researchers interviewed unanimously state that there is a strong dependence on individuals as regards initiating studies and coordinating patient inclusion across regional borders. At the same time, most interviewees believe that implementation of studies works well for them because they have good contact networks. Judging by the interviews, the dependence on individuals within cancer research primarily results in two statements:

1. Researchers are dependent on personal networks to sell in studies to clinics.
2. Passionate people are needed in clinics who can drive studies despite low incentives.

Researchers describe decisions on inclusion being based on reasons other than considerations resulting from a structural overview based on capacity and need. This lack of more formal and transparent structures for participation in studies risks producing an unmotivated unequal standard of care for cancer patients. Those patients who are not sufficiently familiar with or healthy enough to raise their own voices are particularly vulnerable. Both knowledge and tenacity are required for patients to be able to navigate through the system on their own and potentially be recruited to a study.

In the interviews, it was noted that there were weak structures in place for recruitment of patients to studies. During a pandemic recruitment risks becoming even more random. When regions are under more pressure or uncertain about the immediate future, structures that are more rigid may be needed to ensure that studies continue to be implemented. However, it can be difficult to conduct decision making on a more formal basis when a regional overview of ongoing studies and capacity is lacking, this was discussed in the previous section. Through its initiatives on keeping statistics, Forum Middle Sweden has enabled patients to see what studies are currently being conducted in the regions. This is a step in the right direction for protecting patients.

#### Competence, Data: ■ Average risk ■ Positive effects

We note that establishing studies and recruitment of patients largely rests upon structures dependent on individuals and not on a more formal national or regional overview. Unless formal criteria for participation and study start up are put in place, clinical trials risk becoming less accessible to patients who would otherwise be able to be included in them.

However, the pandemic illustrates the vulnerability in this system. In reality the processes require side structures with a greater mandate to ensure continued development in clinical research.

However, the solution-oriented attitude and goodwill that several researchers and companies express are noteworthy, also how positively they regard commitment of clinic staff. The pandemic has further highlighted just how important these individuals are and how well co-operation between clients and clinical staff can function in practice, even during a healthcare crisis.

## Research often works well because researchers almost exclusively use their personal networks.

But there are also risks associated with weak governance in times of crisis.



## Conclusion – Low level of national coordination

The discussion concerning national coordination is based on the following parts:

- The decision concerning halting enrolment has been made without continuity plans and support has been requested but is lacking.
- Sweden is slower than neighbouring countries when it comes to initiating and conducting studies.
- Fundamental statistics are still lacking for the most part.
- Research largely relies on informal processes and goodwill of individuals. This is often perceived as functioning well but involves risks in times of crisis and in the long-term.

The data that exists shows Sweden has lost a considerable amount of ground during the past decade compared to neighbouring countries. They all have much clearer national governance of clinical research. Good initiatives have already been taken in relation to certain aspects of this problem, and the Swedish government should continue with national initiatives to put all regions in a position to be able to and want to support the drive for improvement, which is currently in the starting blocks.

## 3.2. Prioritising care production

### 3.2.1. **Inadequate conditions for regions to conduct research are reflected in the pandemic**

The interviews provide a problematic picture of priorities within the Swedish healthcare and medical care system, which are not favourable to clinical research. Research representatives in cancer research state that time and staff resources must often be secondary to care production. Sweden, even in times without pandemics, has a healthcare and medical care system that is overstretched, where resources including clinical research nurses are often reallocated to ordinary care tasks. Therefore, these structural problems are particularly noticeable during a crisis.

In Section 2.1 it is shown that in March 2020 hospital managements decided to halt enrolment in studies and that clinical research nurses were reallocated from clinical trials to care production. This took place without continuity plans or consequence analyses for the clinical trials. This occurred in all regions regardless of how hard the pandemic impacted medical care. These measures are questioned by several interviewees who believe that this is one of several signs that clinical research is not resistant in times of crisis.

One reason that care can be prioritised at the expense of research is the excessively clear dividing line between care and clinical research that has already been ascertained by several actors.<sup>6</sup> In the interviews various causes are discussed for clinical studies being subordinate to care production. This is attributed, among other reasons, to the fact that the regions' task with respect to care production is more clearly defined than that focused on research. The COVID-19 pandemic exposes the vulnerability in cancer research and that there is no central research principal to ensure its continuity during a crisis. Another reason provided is poor economic conditions for regions and hospital management to conduct research in a financially strained medical care system.

#### **Competence, Time: High risk**

Research is undermined by the division between clinical research and care, and inadequate prerequisites for the regions to prioritise research together with care production. The pandemic risks exacerbating the stagnating development of clinical research, as focus on short-term solutions increases at the expense of research.

<sup>6</sup> The Swedish Research Council, Investigation of the organisation of clinical committees, The Swedish Research Council

### 3.2.2.

#### **Prioritising care production during the pandemic compounds the already low incentive for care staff to conduct research**

A researcher education is demanding and often involves a significantly lower salary than a position as a doctor. Both salaries and promotions are commonly based on the number of years in service, without taking similar regard to research merits. According to the researching doctors interviewed, this alone is enough to reduce attractiveness for care staff. Several of the researchers stated that the reality is far different from what they had hoped for in the beginning of their careers. Much of the time that was to be spent on research is spent on administrative tasks related to care.

Between 2005 and 2017 the percentage of doctors conducting research decreased from 20 percent to 17 percent.<sup>7</sup> Several researchers question how development will

go in future with respect to the ongoing generational change, where a generation with other expectations and priorities in life replaces the older one.

Several interviewees believe that incentives for research risk further deterioration during the pandemic, as focus on ensuring a specific type of care production increases at the expense of cancer research at the clinic.

#### **Competence, Time: High risk**

A lack of formal support structures for research care staff increases the risk of research being prioritised away in the short-term in times of crisis and a long-term slowdown. To ensure the attractiveness of this occupation this should be included in a national plan to a greater extent.

## **Conclusion – prioritising care production**

The regions prioritising of care production at the expense of research comes from the dividing line that exists between care and research plus the lack of state governance. There should be a clearer national plan to create conditions and incentives for the regions to conduct research and attract competence to research. The COVID-19 pandemic worsens the problems that clinical research already suffers from in this respect. This has been discussed many times over the years and there are already good ideas. What remains is allowing these ideas to become reality.

<sup>7</sup> Swedish Medical Association, <https://slf.se/pressrum/%E2%80%8Bforskartutbildade-lakare-ar-nu-kritiskt-fa/>



### 3.3.

#### High proportion of administration

All interviewed researchers state that the proportion of administration in the Swedish healthcare and medical care system has increased over a long period. Several interviewees in clinical research state that more time has to be taken from core research tasks to spend on administrative tasks. Administrative requirements are partly linked to the research process, and partly to work in the clinic. The interviewees state that IT systems with associated processes are designed so that only doctors perform the administrative tasks and there is not an option for administrative staff to take care of these tasks. The increased amount of administration is linked to several other factors that we will not go into greater detail about within the framework of this report.

A picture of the problem is painted where highly paid staff spend time attending to administration, which in turn leads to administration becoming very expensive. This impacts time and resources allocated to research, as these are only prioritised once care production has been ensured.

The pandemic has not changed this situation. However, in this strained situation the pandemic reinforces the need to make the administrative processes more effective. Several clinical researchers describe how the “administrative mountain of debt” grows and in this respect look to the future with unease. As described earlier in the report there are also cases where administration has temporarily stopped as staff responsible have been absent.

#### Competence, Time: Low risk

The pandemic involves moderate risks with the potential for some sections of clinical studies to be stopped as administrative tasks are not completed when key persons are absent. The long-term risks to clinical research are deemed as being high, because administration is one of the primary reasons why care staff have a lack of time. This in turn is a primary cause of limited research. The pandemic illustrates this as now there are even greater time constraints within certain parts of the healthcare system, which increases the need to make processes even more efficient.

#### 3.3.1.

##### Sweden's unique data collection becomes even more important during a pandemic

All stakeholders interviewed describe Sweden as having unique prerequisites for world class research because of its personal

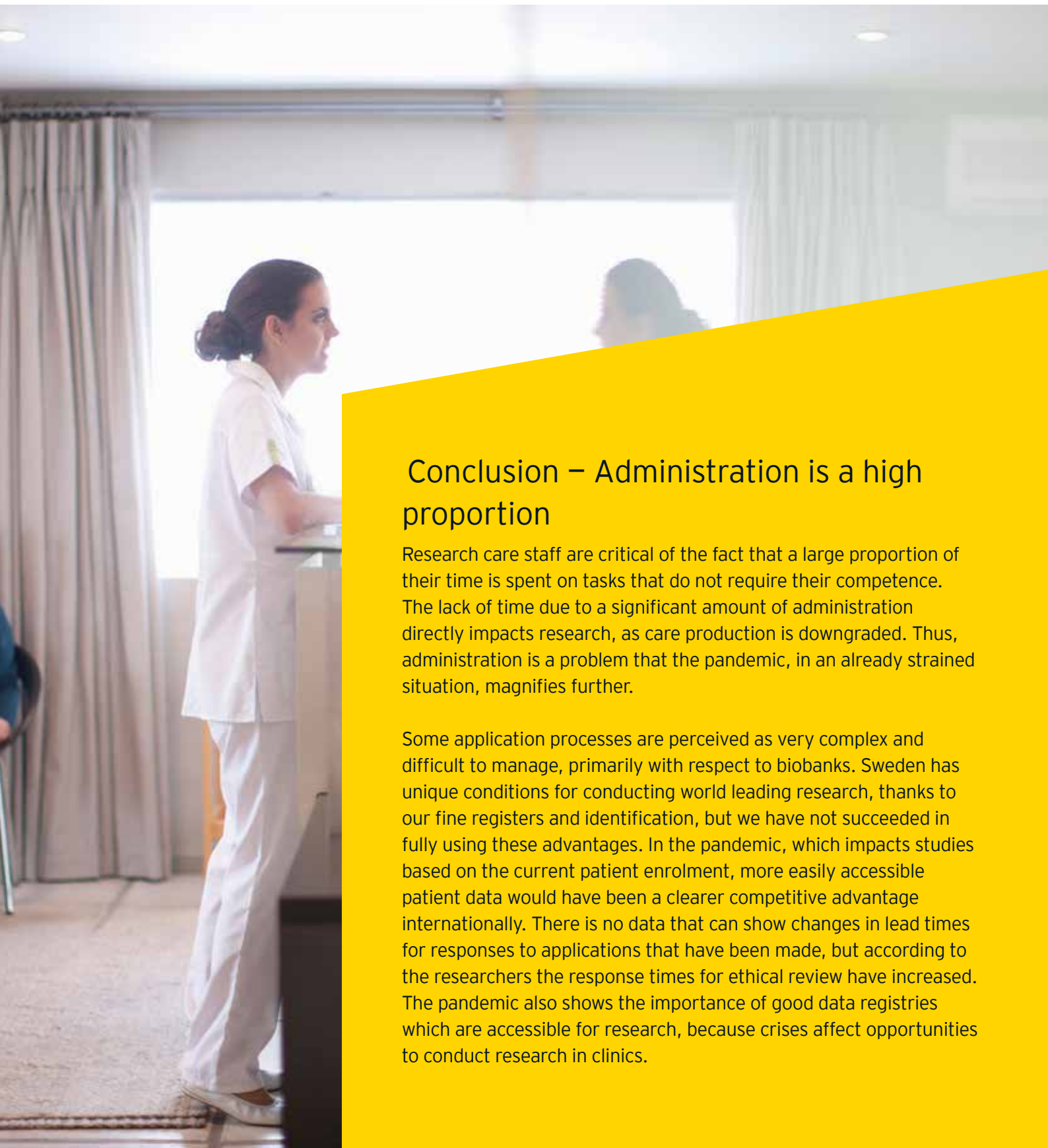
identification number system, the national quality register and biobanks. Stakeholders also convey their disappointment at this potential not being fully utilised.

According to researchers and managers this is largely dependent on problems with data that has not been used because of bureaucratic processes and lack of coordination. The regulatory framework and formalities in making applications are perceived as being extremely complex and there is a widespread unease that the trend experienced in recent years involving processes that are even more cumbersome will continue. Management associated with biobanks is consistently mentioned as the most sensitive point. For cancer researchers the situation can be extra painful. They often need access to samples from many different biobanks, which generates the need for several different applications to be made. This problem is described above all by preclinical staff. Many request more support in association with administrative processes.

In order to investigate the effects of the pandemic on the initial steps of the research process, EY had requested and sought data from biobanks concerning the number of applications made and lead times in the processes for the years 2019 and 2020. Data could not be obtained, partly because statistics for 2020 will arrive later in 2021, and partly because there is no division by diagnosis. As far as EY is aware, more in-depth statistics relating to e.g., speed are not collected. This makes the initial process steps relating to analysis of the pandemic's effects on cancer research much more difficult. Researchers themselves state that the pandemic has impacted ethical review to the extent that lead times in some cases have been extended as COVID-19 studies have been prioritized. The longest case observed in the interviews involved delays of six months. Younger researchers have been impacted by this to a greater extent as their career plans are dependent on them being able to conduct the project. Among the interviewees there is doubt concerning how prioritisation of studies relating to COVID-19 has occurred. This doubt is primarily about whether the quality requirements for COVID-19 studies have been equal to other research or whether the requirements have been lower. The boundaries for EYs report do not allow for further investigation of whether there is justification for this type of criticism. But as these doubts have been expressed in several interviews, we believe that they should be highlighted as an observation.

#### Competence, Time: Low risk

The pandemic entails moderate risks with longer administrative processes for making biobank and ethical review applications.



## Conclusion – Administration is a high proportion

Research care staff are critical of the fact that a large proportion of their time is spent on tasks that do not require their competence. The lack of time due to a significant amount of administration directly impacts research, as care production is downgraded. Thus, administration is a problem that the pandemic, in an already strained situation, magnifies further.

Some application processes are perceived as very complex and difficult to manage, primarily with respect to biobanks. Sweden has unique conditions for conducting world leading research, thanks to our fine registers and identification, but we have not succeeded in fully using these advantages. In the pandemic, which impacts studies based on the current patient enrolment, more easily accessible patient data would have been a clearer competitive advantage internationally. There is no data that can show changes in lead times for responses to applications that have been made, but according to the researchers the response times for ethical review have increased. The pandemic also shows the importance of good data registries which are accessible for research, because crises affect opportunities to conduct research in clinics.

### 3.4.

#### Low level of co-operation between research faculties and clinics

Several researchers would like to see improvements in cooperation between research faculties and clinics in Sweden. For example, several preclinics see the need for greater involvement from clinics in their research and express a desire to reach out more to clinics directly to conduct discussions. With less cooperation between research faculties and clinics basic research will become less attractive and less productive within the most relevant areas. Clinics do not get access to competence at the forefront, which in the end results in less talent for innovation and there are no opportunities for patients to potentially receive better treatment through the study.

#### 3.4.1.

##### The researching doctors cite lack of time as the primary reason for low collaboration, but also see positive effects with the pandemic

Also in this case, the lack of time within clinics and prioritisation of care production are fundamental causes of the problem. Due to the pandemic, many clinicians have even less time to spend on research, which risks leading to even less cooperation with the research faculties. At the same time, some interviewees stated that a changed workload can also result in them having more time to spend on doing other things.

According to researchers, one additional reason for the relatively low level of co-operation in Sweden is because basic research is seldom located within the same physical area as the clinic. However, co-operation could be facilitated through the consequences the pandemic has brought along with it, e.g., the creation of new spontaneous points of contact to solve problems. The increase in digitalisation is also key as it enables smoother contact between different groups. Video meetings make it easier for the surgeon to participate in the latest research faculty discussions without having to spend time travelling. But one doctor feels that some type of initiative is needed to conduct research meetings on a local level where this type of contact is initiated and maintained.

Competence: ■ Average risk ■ Positive effects

The pandemic entails a risk of the lack of time increasing further: time that will be taken away from research. Less time for doctors to be involved in research may lead to less relevant results within basic research and patients may potentially receive poorer treatments, because doctors are becoming less skilled in new treatment methods. In the long term, less cooperation between research faculties and clinics may result in basic research becoming less attractive. At the same time, the pandemic also brings new opportunities for clinics and research faculties to initiate contact with each other.



## Conclusion – low level of co-operation between research faculties and clinics

Clinical research and clinical cancer research in Sweden have experienced a decline in the number of researching doctors over a longer period. This is due to a lack of time in combination with a prioritisation of care production and a lack of incentive for doctors to research. The effects are visible both within research faculties, where there is a risk of research not being as relevant and interesting, and within clinics where competence decreases. At the end of the day this affects the patient, because clinics are not familiar with and cannot offer the treatments that are expected to provide to best results. The pandemic risks amplifying the divide between research faculties and clinics, where clinics have less and less time for research. However, many interviewees express a sense of hope and that the relaxed structures will contribute to developing new points of contact between clinics and preclinics.



## Risk analyses

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# 4



The pandemic has led to many effects and risks for cancer research. In the analysis, we quickly discovered that there were two different types of risks. There are effects that are unique for a crisis and that involve risks that are difficult to avoid. This can, for example, involve limitations on travel or that patient enrolment is stopped for a certain type of study. The second category consists of aspects where the pandemic highlights how vulnerable cancer research in Sweden is. These aspects make a crisis even more difficult, but their development was already observed even before the pandemic. One example is prioritising care production, which even in normal cases absorbs resources from research, but which the pandemic further amplifies and may possibly make more permanent.

## 4.1.

### Effects of the pandemic

#### 4.1.1.

##### Research with patient contact

### Risk assessment – Illustrative results



**Competence:** The competence of research care staff can be positively impacted when staff are reallocated from ordinary research positions to work in clinics. At the same time competence can be impacted negatively as research is neglected in decisions made during the pandemic. However, the negative aspects are deemed as being more long-term structural problems and are covered in the risk analysis in the next section.

**Time:** Reallocation of staff and enrolment stop are the primary reasons for less time being given to research during the pandemic. Several organisations are extremely vulnerable to reallocation of clinical research nurses. However, staff that are not reallocated may often spend time on other tasks related to research, which may be positive.

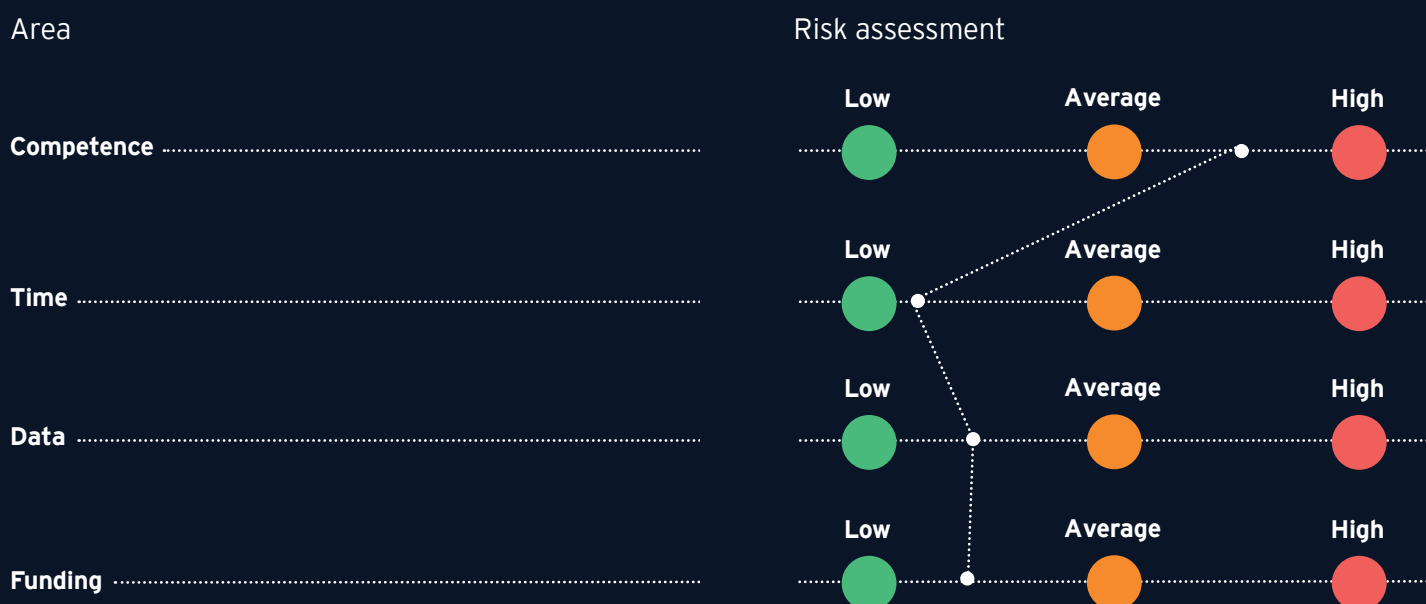
**Data:** Enrolment halted or fewer opportunities for patients to travel to clinics means less data collection. Researchers have been pragmatic and have been able to collect some data at distance, but the risk of poorer quality often makes this difficult.

**Funding:** The deteriorated financial situation and delayed projects have involved communication with funders, who have often been able to extend the availability periods of the funding. However, the ongoing costs, despite fewer results for many research groups, mean that more funding may be needed. There is also concern that researchers, because of the pandemic, have not been able to deliver as many ground-breaking research results and that this will have a negative impact on future funding.

## 4.1.2.

## Research without patient contact

## Risk assessment – Illustrative results



**Competence:** It is above all younger researchers who have planned an international exchange or who are in the process of establishing their own research group who are impacted. International exchange and delivery of results is highly important in this phase of the career. The effects are greater here than for clinicians who can often fall back on work in clinics.

**Time:** Less travel for meetings, both to colleagues locally and international meetings, results in more time to spend on research. In this way, the pandemic and digitalisation have made work more effective. However, bottlenecks have occurred where university administration lags and lead times for submitted applications increase.

**Data:** Preclinics and epidemiologists generally see a low impact on data. In some cases, material has been delayed. Biobanks receive less material during the pandemic, but so far researchers see this as a relatively short "notch in the curve." No significant risks to research have been identified based upon this.

**Funding:** There has been some unease among smaller funders and funding for the coming year can be impacted by funders who are dependent on equity dividends. There is also concern that researchers, because of the pandemic, have not been able to deliver as many ground-breaking research results and that this will have a negative impact on future funding. However, this risk is regarded as being lower for research than for patient contact as they are impacted to a lesser extent.

## 4.2. Structural aspects highlighted by the pandemic

### 4.2.1. Research with patient contact

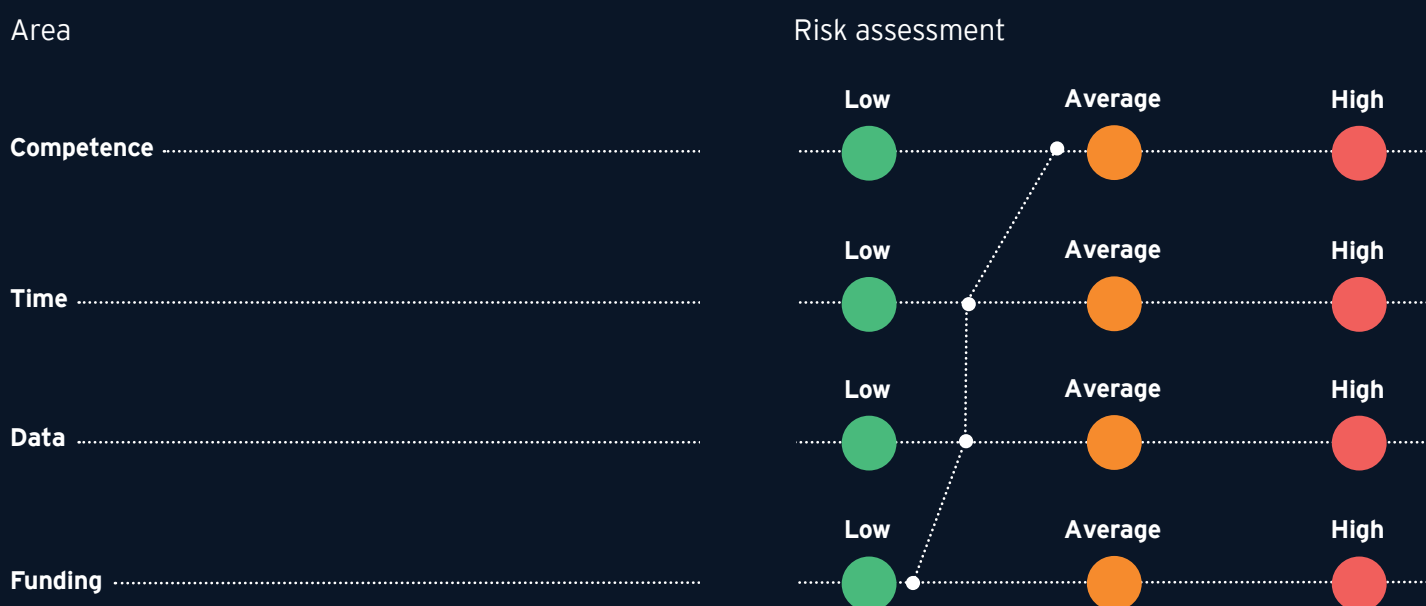


The risk level for the structural aspects within all four factors has increased due to the low level of coordination. This is because responsibility and the mandate to improve fundamental processes is spread out or is not clearly defined. The low level of coordination may, for example, mean not knowing which studies are currently in progress so that more well-founded decisions can be made concerning halting patient enrolment, or not being able to analyse key parameters to gauge performance and then act based upon this. Otherwise, the risks for the four factors are as follows:

- Competence:** There is a lack of incentive for healthcare staff to conduct research and cooperation between the research faculties and clinics is relatively low. There is also to a large extent a lack of formal support structures that ensure that research is conducted. Therefore, passionate people are needed in clinics who can drive clinical research forward despite low incentives. The pandemic clarifies how easily research can be downgraded in this environment. The influx of competence risks being stopped to an even greater extent, as clear incentives and structures for continuous research are lacking.
- Time:** A healthcare system under pressure has less time for research, as research is given less priority than care production. This is especially clear during the pandemic. Care production has an even higher priority, which makes it even more difficult for staff to spend time conducting research during normal work hours.
- Data:** Cancer researchers usually use personal contact networks or other less formal structures to recruit patients to studies. However, the pandemic illustrates that this system is vulnerable. The processes for initiating clinical trials and continuing enrolment are in reality dependent on structures with a superior mandate that currently pays less regard to research. This impacts access to data because this is based on inclusion.
- Funding:** There are no signs in the analysis that the pandemic will endanger financing from Swedish funders in the long term. However, Sweden's slow implementation of studies results in a potential risk of the number of studies financed by companies being reduced. Companies can apply to other countries instead.

## 4.2.2.

## Research without patient contact



Researchers generally present a positive image of the attitude towards basic research in Sweden. Structural risks here are not as significant as those for clinical research. But there are still aspects to highlight in conjunction with the pandemic:

**Competence:** Preclinics express a desire to be able to work closer to clinics. When clinics involve themselves in basic research to an ever decreasing extent, interest in applying for it also declines, as does the relevance of preclinical studies. To some extent, the pandemic has amplified the focus on care and lack of time, which increases this divide. But the pandemic has also served as a door opener, thanks to new points of contact and more digital meetings.

**Time:** Preclinical researchers and epidemiologists have, to some extent, experienced an increase in the administrative burden over the years, due to more and more complicated application procedures and lack of support for them. The present situation has made matters worse. The pandemic has increased administrative lead times, which has delayed research. However, our understanding is that researchers have still been able to keep themselves busy and that a longer crisis would be needed for the effects to be felt more.

**Data:** Researchers who do not have patient contact use registers and biobanks to a greater extent. However, there is widespread dissatisfaction with the difficulty involved in gaining access to data from these. The processes are bureaucratic, and the pandemic has resulted in longer lead times. In long-term crises this can generate significant chain effects, but this has not been observed yet. The pandemic also highlights the potential of data already collected when the healthcare system is under pressure. Sweden would benefit from making data more widely accessible.

**Funding:** There are no signs in the analysis that the pandemic will endanger funding from Swedish funders in the long term. The researchers interviewed did not express any greater concern either.



## Conclusions

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# 5



The pandemic has resulted in several unique effects and risks. The pandemic also amplifies pre-existing trends, both positively and negatively.

The unique effects impact research both with and without patient contact and can be summarised by the following four areas.

#### **Halted patient enrolment affects clinical research**

Clinical cancer research has been significantly impacted by enrolment halts and reallocation of staff. As statistics are largely lacking it is difficult to know just how hard they are affected. However, the figures that are available indicate that both inclusion of patients and reallocation of staff from cancer research have been considerable. This not only affects researchers who are required to conduct studies, but also patients who lose potentially lifesaving treatment.

#### **Limitations on physical meetings affect preclinical research**

Cancer research without patient contact has largely been affected by limitations on international travel and conferences, access to competence from abroad and changes in close collaboration with colleagues. The basic research is dependent on a close exchange of ideas and developing contact with colleagues, both within the group and around the world. Rigid career paths mean that a lost year of productivity and publicity can have negative consequences for young researchers.

The structural problems and opportunities highlighted by the pandemic provide us with the opportunity to present several recommendations. This primarily concerns clinical research.

#### **Higher level of national coordination for implementing studies**

A low level of national coordination and formal support structures for initiating and implementing clinical trials is particularly vulnerable during a pandemic, when the principal has other priorities. Different stakeholders have noted that projects are slow to be initiated, plans are delayed and responsibility for implementing projects and follow-up is often lacking. This is a sign that we need a higher level of national

#### **There are unexpected benefits and optimism**

As a direct consequence of the turbulence, clinics now have more time to spend on new projects and ideas. Staff that are reallocated, e.g., clinical research nurses, state that they have had positive experiences and learned new lessons to bring back to cancer research. Now when certain plans have had to be changed, preclinics also see the opportunity to address application procedures and ideas that have been overshadowed up to now. Many interviewees also believe that what is in some ways a “lost year” will not have any long-term impact on their research. They are ready to look to the future after the crisis.

#### **Digitalisation increases collaboration**

The increased digital presence means that international discussions and meetings can take place at greater frequencies and within areas where this was not previously possible. Digital meetings also create opportunities that have never been seen before for different departments to have frequent contact and fruitful collaboration. This is promising for e.g., co-operation between research faculties and clinics. Digital meetings streamline and enable better contact, particularly in Sweden's more sparsely populated regions.

coordination to maintain the clinical research and to address international competition.

#### **Better prerequisites for regions to conduct research**

During the pandemic, inadequate prerequisites and plans for the regions to conduct research have contributed to research largely being downgraded during the pandemic. To avoid care production being prioritised at the expense of research, an approach is required where research becomes part of the healthcare system to an even greater extent. This is ultimately guided through funding, which provides an incentive for regions to conduct research, even in a shorter perspective.

### **Increased and formalised career choices and incentive for clinical researchers**

To some extent, there are inadequate structures for career choices and incentives for care staff to conduct research. There is the risk the pandemic will reinforce obstacles to an influx of competence to clinical research because clinical research is largely being downgraded. Clear and attractive career paths are required to attract healthcare staff to research.

### **Closer collaboration between preclinical and clinical research**

Both clinical and preclinical research would become more attractive and productive within the most relevant areas through closer collaboration. However, it has been difficult to

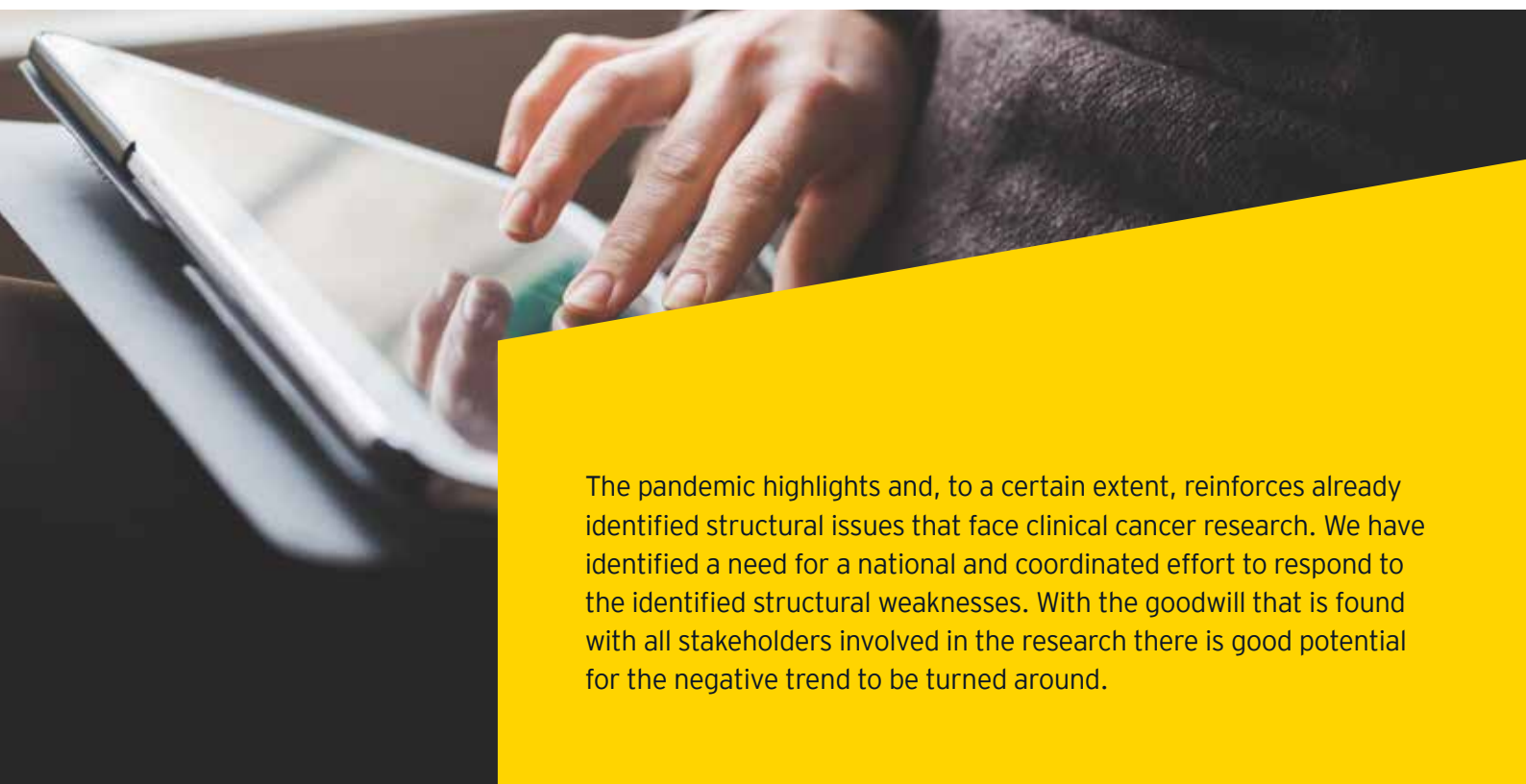
identify solutions to facilitate this because research faculties and clinics are often located at different places. In this case, digitalisation is positively impacted by the pandemic.

### **Introduction of statistics from clinic level to national level**

To be able to improve activities, from a clinic level, up to a national level, statistics are required that can be accessed.

### **Make the most of commitments and optimism**

The goodwill found among all stakeholders involved in the research is a springboard to the future, provided the national structures are favourable enough.



The pandemic highlights and, to a certain extent, reinforces already identified structural issues that face clinical cancer research. We have identified a need for a national and coordinated effort to respond to the identified structural weaknesses. With the goodwill that is found with all stakeholders involved in the research there is good potential for the negative trend to be turned around.

# Appendix

# 6

## 6.1. Interviewees

All researchers interviewed have senior posts within their respective research groups. In addition, many researchers have management positions within their respective businesses, institutions and universities. Many of the researchers have medical qualifications and are active consultants. The researchers were selected by experts from the Swedish Cancer Society.

All company representatives have senior posts related to the company's cancer research in Sweden. The companies are selected by the Swedish Cancer Society and comprise companies with and without involvement in vaccination development for COVID-19.

### Researchers

#### Preclinical

Professor of medical chemistry  
Professor of medical biochemistry  
Professor of molecular medicine  
Professor of medical chemistry  
Professor of immunology  
Professor of molecular cellular biology  
Professor of molecular cellular biology

#### Translational and epidemiological

Associate professor of pathology  
Professor of pathology  
Professor of molecular oncology  
Professor of experimental oncology  
Professor of gastrointestinal cancer  
Associate professor of epidemiology  
Professor of nutritional epidemiology.

### Clinical

Professor of urology  
Professor of urology  
Professor of experimental oncology  
Professor of surgery  
Associate professor of surgery  
Professor of surgery  
Associate professor of surgery  
Professor of general care  
Associate professor of oncology  
Associate professor of haematology  
Professor of oncology

### Companies and funders

Medical director of oncology at company A  
Senior CRA at company B  
Head of clinical operations at company C

Manager of Government Affairs in company D

Executive Secretary of the Swedish Research Council

Director of the Knut and Alice Wallenberg Foundation

The Swedish Cancer Society

### Managers and heads of operation

Department manager at the Centre for Clinical Cancer Studies.

Director of research and development

Responsible for research and development

Operations managers for the regional cancer centre

Operations managers for the regional biobank centre

Senior adviser LIF

National cancer coordinator

## 6.2.

### Report strengths and weaknesses

The results and conclusions in this report should be viewed considering the methods employed, as well as the resulting opportunities and limitations. The purpose of the report has been to gather data amidst the COVID-19 pandemic to obtain information about how researchers and other stakeholders perceive the current situation. The fact that there has been the opportunity to gain a direct overview into what the current situation looks like can be viewed as a strength, as opposed to data collection having been done at a later point in time as memories can fail. In-depth interviews contribute to a basic understanding of how the pandemic directly affects the research and what problems and opportunities are highlighted by the pandemic. The interviews have been conducted with persons across Sweden to differentiate how they have been impacted depending on the region they are affiliated with. Interviewees have often held different roles, which contributes to a broader understanding of how cancer care is impacted.

Although the study includes 40 interviews with researchers and other stakeholders, there is reason to interpret the results with a certain degree of caution. One reason is that the number of interviews does not provide an overall generalisation, but describes the correlation based on local and individual conditions. For example, some of the

results largely depend on how the conditions are in the specific clinic or region the person is affiliated with. In addition, only researchers sponsored by the Swedish Cancer Society were interviewed, which may result in the selection and the views being more one-sided than in reality.

Finally, it should be stressed that this is an investigating study primarily with open questions to identify the aspects highlighted by researchers. The focus and the precise formulations for the questions were clarified as the interview progressed. Therefore, all researchers have not answered the same questions. The questionnaire also had different formats depending on the stakeholder category. Flexibility has been regarded as necessary to product as much fruitful material as possible, but among the complex discussions the authors' interpretation of the answers also weighs in on the analysis. Risk analyses of each highlighted topic do not necessarily correspond with the picture portrayed by the interviewees but may be EYs professional opinion about what constitutes or does not constitute substantial risks. For example, EY may have an alternate opinion in the discussion concerning dependence on individuals. Researchers generally described the current system as working well for them, but EY has weighed in other stakeholders' perceptions and the risks that such as structure generally entails for organisations.





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