Monitoring Standardized Cancer Patient Pathways

- Variations across Denmark, Norway, and Sweden

Report:
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- Variations across Denmark, Norway, and Sweden

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Preface

This report springs from the network *Nordic Collaboration Cancer Care Pathway*, which is a Nordic network established in 2016 with yearly meetings and working groups regarding various aspects related to cancer patient pathways (CPP). The meetings have pointed to many similarities but also certain differences in the way that Denmark, Norway, and Sweden monitor their CPPs and in the challenges that they are working to resolve. This report is the result of a cross-national project intending to describe and compare monitoring practices across the three countries. The project was funded by grants from the Nordic Collaboration Cancer Care Pathway distributed in 2019.

Summary

In Denmark, Norway, and Sweden, central health data authorities monitor various aspects of performance related to cancer patient pathways (CPP). The intension is to provide feedback to hospitals on their performance relative to others, provide performance information available to the public, provide leverage for health authorities in their efforts to push for better outcomes, and obtain information useful for improving the existing CPPs.

This report describes the monitoring practices in all three countries and discusses selected elements as well as challenges to and usages of the monitoring. The intension is to provide an overview that facilitates mutual learning and provides a tool for dialogue regarding potential improvements with regard to data and analyses.

While monitoring of CPP processing time and related indicators across the three countries generally is very similar, it differs in certain aspects. For instance regarding the specification of targets, the definition of population, and the measures that are monitored. As the only country, Sweden also regularly monitors CPP patient experiences.

The monitoring in Denmark, Norway, and Sweden covers central parts of the CPPs, and appears to be a useful tool for the employees, who seem aware of where the limitations and weaknesses exist. Though registration guidelines are thorough, and the data quality is generally high, data validity nevertheless constitutes the greatest challenge for health data authorities across the three countries. Improvements in data quality can make the inventories and comparisons across diagnoses and regions even more valid and reliable. This could improve the usefulness of the monitoring with regard to identification of best practice as well as areas that require special attention and improvements.

Potential expansions, such as assessments of processing time that consider patient preferences and comorbidities as well as inventories regarding patient experiences (which are already available in Sweden), could be valuable additions to the existing monitoring practices. Such additions could strengthen the ability to identify best practice actors and areas that need improvement, and more generally would qualify the monitoring as a tool for quality assessment of CPP performance. Moreover, similarity in the indicators across the three countries facilitates cross-border comparisons. As such, it would be valuable if the health data authorities could regularly consult each other and, to the extent possible, facilitate benchmarking of key indicators of CPP performance across the three countries.

Introduction

Background

In 2008, Denmark introduced the first cancer patient pathways (CPP), and the concept has later been copied in Sweden and Norway. The CPPs consist of guidelines regarding alarm symptoms that could indicate cancer and should result in a referral to the relevant CPP. The CPPs describe the process from cancer suspicion to treatment and follow-up. The descriptions include recommendations regarding the maximum processing time from referral until the diagnostic process has ended and until start of treatment.

Figure 1 illustrates a generic example of an organ specific CPP, provided by the Danish Health Authority (1).

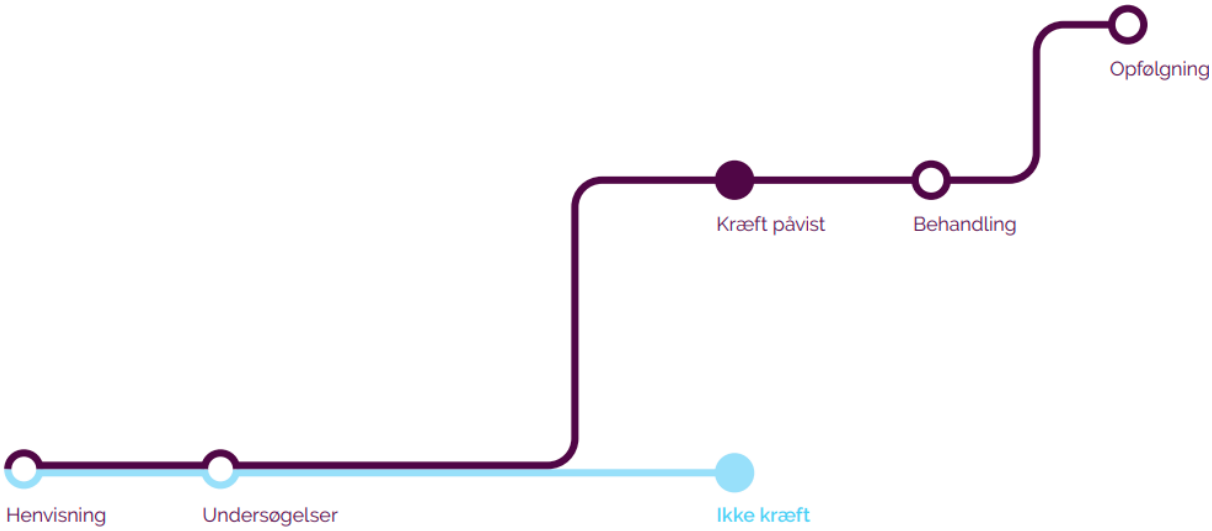

Figure 1: Example of organ specific CPP (source: Danish Health Authority).

Denmark has 32 organ specific CPPs that relate to the most common cancers such as breast cancer, lung cancer and cancer in the urinary tract. Among the organ specific CPPs, there is also one that specifically concerns cancer among children. Additionally, Denmark has one CPP for patients with metastasis from an unknown cancer and one CPP for patients who have unspecific symptoms of serious illness that could be cancer.

Sweden has 29 organ specific CPPs as well as one for patients with metastasis from an unknown cancer and one for patients with unspecific symptoms of serious illness that could be cancer.

Norway has 26 organ specific CPPs (including one for cancer among children) as well as one for patients with metastasis from an unknown cancer and one for patients with unspecific symptoms of serious illness that could be cancer.

Monitoring cancer patient pathways

Each of the three countries introduced monitoring programs in order to obtain knowledge regarding compliance to the CPP objectives. The aim of the monitoring efforts was to provide consecutive feedback to clinical and political stakeholders as a means to ensure adherence to the pathways and obtain knowledge that could facilitate continued improvement.

However, no comparison of monitoring efforts across the three countries exists. This is regrettable since a systematic comparative review of the monitoring procedures may facilitate mutual learning and function as a tool for dialogue regarding potential improvements of data and analyses. Therefore, the present project assesses the existing monitoring practices of cancer patient pathways across the three countries; for instance regarding who performs the monitoring, how often, which aspects are included, and what the primary challenges are.

Actors involved in the project

The comparison of monitoring efforts has been carried out in cooperation between on the one hand analysists and researchers from Denmark, Sweden, and Norway and on the other hand national and regional health data authorities. The Danish Cancer Society has been lead investigator and has throughout the project consulted employees at the Department of Registrations at the Cancer Registry of Norway (Kreftregisteret). Researchers from Regional Cancer Centrum South (Regionala cancercentrum syd) in Sweden also took part in formulating the project. Moreover, employees from national and regional health data authorities took part in the process of outlining and comparing the monitoring efforts. These health data authorities included The Health Data Authorities from Denmark, Norwegian Directorate of Health and the regional cancer centers from Sweden.

Methods

The process of collecting information for this report has involved continued cooperation with employees at the national and regional health data authorities. Initially, a template regarding the relevant information was drafted by the Danish Cancer Society with valuable comments from the Norwegian Cancer Registry and the Danish Health Data Authority (the template is available in appendix 1). The template was distributed to health data authorities in Norway, Sweden, and Denmark, who answered the questions in the template. Within the following weeks, follow-up telephone interviews and email correspondences answered remaining questions. A preliminary overview and comparison of the monitoring efforts across the three countries was presented at the 2019 annual meeting of the Nordic Collaboration Cancer Care Pathway, and at a workshop related to the annual meeting, researchers and practitioners (including employees at the national and regional health data authorities) discussed various aspects related to monitoring practices. Based on the inputs from this workshop, the Danish Cancer Society wrote a draft for this report. This report was distributed to health data authority employees in order for them to provide clarifications and final inputs wherever relevant.

Monitoring practices in Denmark, Norway, and Sweden

Who performs the monitoring?

In Denmark and Norway, national health authorities perform the monitoring. In Norway, it is the Health Registries Department of The Norwegian Directorate of Health (Helsedirektoratet). In Denmark, the Ministry of Health is the responsible authority, and the Danish Health Data Authority (Sundhedsdatastyrelsen) performs the monitoring.

In Sweden, the Swedish Association of Local Authorities and Regions (SKR) hosts the national database whereas the Cooperation of Regional Cancer Centers (Regionala cancercentrum i samverkan) performs the visualization of the national monitoring.

Purpose of monitoring

In all three countries, the monitoring is considered a tool to:

- Provide feedback to hospitals regarding their own performance in comparison to others.
- Provide information available to the public.
- Provide leverage for the health authorities to push for better services/outcomes.
- Obtain information useful for improving the existing cancer patient pathways.

Data sources

In Denmark, the monitoring relies on specific CPP codes embedded in the Danish National Patient Registry (Landspatientregisteret). The data are recorded by the hospitals in local IT-programs and transferred to the national registry.

In Norway, the data used for the monitoring come from a national register with CPP codes. The CPP data are part of a larger amount of data reported from the hospitals to the Health Registries Department.

In Sweden, CPP data are recorded using specific CPP codes by the county regions in local IT-programs and transferred to the national registry for waiting times that are hosted by the Swedish Association of Local Authorities and Regions (SKR). Every month, the county regions send CPP data to the Swedish Association of Local Authorities and Regions. In addition to the CPP codes reported nationally, the regions choose a number of extra CPP indicators that they want to monitor. These data are not distributed to the national data authorities, and are not the focus of this report.

In addition to data registered by hospitals, Sweden also performs a survey regarding patient experiences. Every month since 2016, a patient questionnaire has been sent to patients who completed a CPP the month before. Annual reports are compiled at the national level, and each region uses its own data for improvement work (2).

Monitoring elements

The monitoring consists of various elements that vary somewhat across the three countries. Table 1 provides an overview of the monitoring elements that are routinely monitored in at least one of the three countries. In the following paragraphs each element is described.

Table 1: Monitoring elements

Monitoring elements	**Description**
Processing time	Time from well-founded suspicion/CPP referral received at hospitals to (A) first hospital contact, (B) diagnosis, and (C) start of treatment.
The share of cancer patients referred to cancer patient pathways	The number of patients with a specific cancer who were referred to the relevant CPP relative to the total number of patients diagnosed with that specific cancer.
Patient volume	Share of CPP patients having the diagnosis disconfirmed/ share of CPP patients starting treatment.
Patient experiences	Patients' evaluation regarding aspects of the CPP.

Processing time

The primary target of cancer patient pathway monitoring is processing time for CPP patients (processing time refers to "forløbstid" (DK), "forløpstid" (NO), "ledtid" (SE)). The assessment of processing time involves a number of choices; for instance regarding which time periods to monitor, which patients to include in the monitoring, and which geographical units that are relevant for the monitoring.

Monitoring objects

In all three countries, processing time is monitored for the organ specific CPPs, the diagnostic CPP, and the metastasis CPP.

For the organ specific CPPs, the Danish and Norwegian monitoring concern the following time periods:

A. Referral period: Time from referral (i.e. reception of referral at the hospitals) to the patient's first hospital contact.
B. Investigation period: Time from first hospital contact to diagnosis/decision regarding referral to treatment.

C. Preparation to treatment period: Time from decision regarding referral to treatment to first treatment.
D. The total amount of time from referral to start of treatment.

The periods are illustrated in Figure 2.

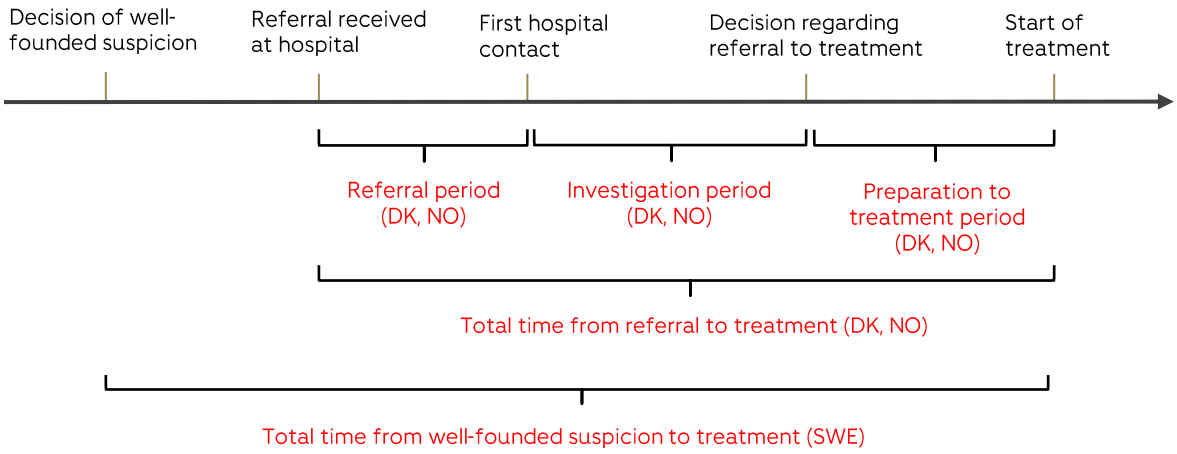

Figure 2: Illustration of CPP time periods.

In Denmark, the investigation period is monitored separately for patients who have the diagnosis confirmed and patients who have the diagnosis disconfirmed.

Unlike in Norway and Denmark, where the CPP starts when the referral is registered at the hospitals, the Swedish CPPs start at the decision of well-founded suspicion of cancer, which can be raised either in primary care or at the hospital. Previously, it was often difficult for the regions to monitor suspicion raised in primary care because of complications related to registration options in some of the IT-systems. However, now the regions have created IT-systems to overcome the problem. In Sweden, it is not mandatory to register any of the intermediate time points (period A-C in the listing above). Most regions do register the intermediate points in the CPP, but only in their own local system, and the data are not transferred to the national database.

For many cancers, multiple treatment options are possible – for instance, cancer patients may start their treatment with either surgery, medical treatment, or radiotherapy. All three countries monitor processing time for each of these possible treatments separately. Additionally, Sweden monitors processing time from well-founded suspicion to several alternative endpoints, namely palliative care, other treatment, watchful waiting, and the decision not to treat. Norway also monitors processing time until the decision of watchful waiting.

The similarities and differences regarding the monitoring objects are summarized in Table 2.

Table 2: Monitoring objects in Denmark, Sweden, and Norway.

	Denmark	**Norway**	**Sweden**
CPPs monitored	Organ specific CPPs Diagnostic CPP Metastasis CPP	Organ specific CPPs[1] Diagnostic CPP Metastasis CPP	Organ specific CPPs Diagnostic CPP Metastasis CPP
Start of CPP	Referral received at hospital	Referral received at hospital	Decision of well-founded suspicion of cancer
Time periods for organ specific CPPs	Referral period Investigation period - for patients having the diagnosis confirmed - for patients having the diagnosis disconfirmed Preparation to treatment period - surgical treatment - medical treatment - radiotherapy Total processing time to - surgical treatment - medical treatment - radiotherapy	Referral period Investigation period Preparation to treatment period - surgical treatment - medical treatment - radiotherapy - decision of watchful waiting Total processing time to - surgical treatment - medical treatment - radiotherapy - decision of watchful waiting	Total processing time from well-founded suspicion to - surgical treatment - medical treatment - radiotherapy - palliative care - other treatment - decision of watchful waiting - decision not to treat
Time periods for diagnostic CPP	Referral period Investigation period Total processing time	Referral period Investigation period Total processing time	Total processing time
Time periods for metastasis CPP	Primary referral period - with referral to secondary investigation - with clinical decision about end of CPP Primary investigation period - for all patients - for patients referred to additional investigation - for patients not referred any further Secondary referral period	Referral period Investigation period Preparation to treatment period - surgical treatment - medical treatment - radiotherapy Total processing time to - surgical treatment - medical treatment - radiotherapy	Total processing time to - surgical treatment - medical treatment - radiotherapy - palliative care - organ cancer diagnosis confirmed

Measures

The primary measure in both the Danish, Norwegian, and Swedish monitoring concerns the proportion of CPP patients for whom the standard processing time is met.

Additionally, Sweden and Denmark publish more detailed measures regarding processing time:

- Denmark monitors processing time for the 1st, 2nd and 3rd quartile of the patients (i.e. maximum processing time for the 25 %, 50 % and 75 % of the CPP patients with shortest processing time). More detailed analyses regarding the distribution of processing time

[1] From May 1 2021, the monitoring of chronic lymphocytic leukaemia and acute leukaemia was suspended.,

(e.g. the maximum processing time and processing time for the 10 % with shortest/longest waiting time) are not made routinely though a publication from 2018 (with data from 2013-2016) investigated CPPs for which processing time exceeded the CPP standard (3).

- Sweden monitors excess processing time for patients for whom the CPP standard processing time was exceeded: The share of patients for whom the processing time is (A) 1-25 % longer (B) 26-75 % longer and (C) more than 75 % longer than CPP standard processing time.

Figure 3 shows an example of processing time monitoring in Denmark.

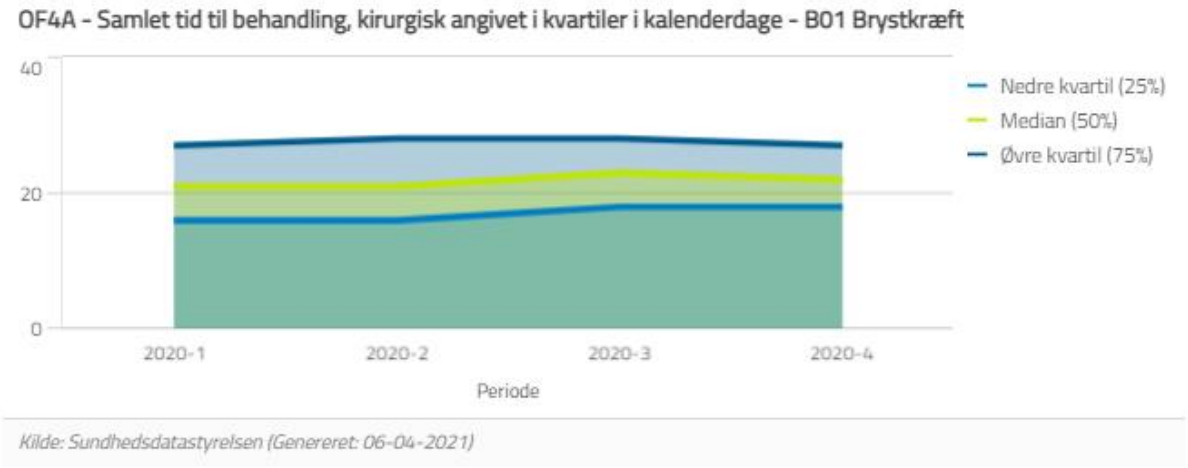

Figure 3: Processing time compliance for breast cancer patients' total time from referral to surgical treatment. Denmark, 1st-4th quarter 2020.

An illustration of the Swedish monitoring is displayed in Figure 4.

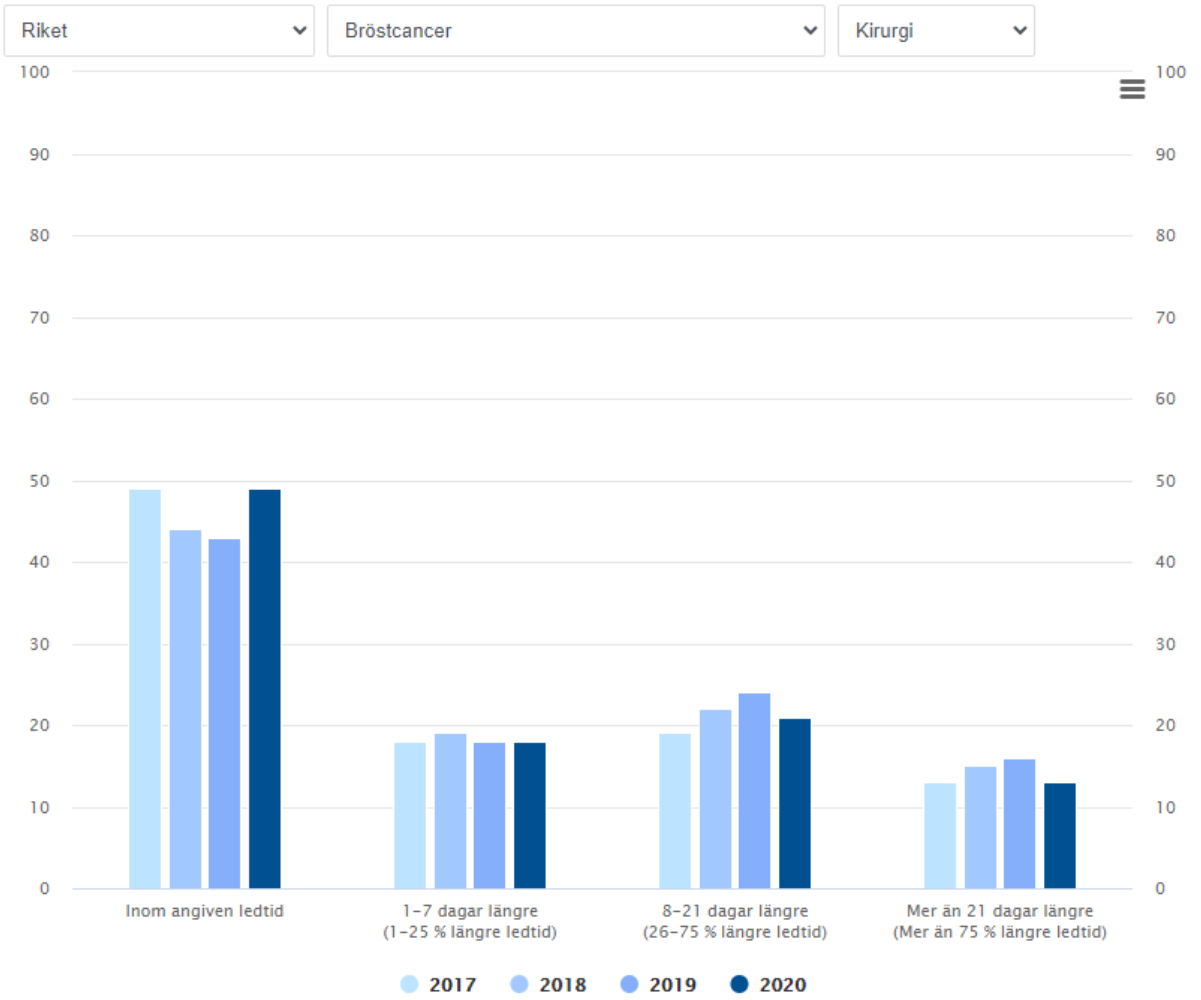

Figure 4: Illustration of processing time compliance and exceedance for the time period from referral to surgical treatment for breast cancer patients in Sweden in 2017-2020.

In Denmark, analyses are available at the national level as well as at the regional level (i.e. five regions). At the regional level, a patient is categorized based on where he/she started the diagnostic pathway; that is, the region from where the CPP referral originates. Analyses at the hospital level are not made by national authorities; rather, the regions are responsible for monitoring CPPs at the hospital level. This is done internally, and these analyses are not publicly available. There are certain regional differences with regard to how the diagnostic CPP is organized including which diagnostic procedures that should be performed prior to CPP referral. This complicates regional comparison though not comparison over time.

In Norway, the analyses are made at the national level, at the regional level (four regions) as well as at the local level (23 Helsefortak). An example of the inventory is shown in Figure 5. Patients are categorized based on the hospital trust that received the CPP referral. The Helsefortak may include multiple hospitals that are not monitored individually. The Helsefortak are relatively small units that oftentimes have only few patients with a specific cancer diagnosis within a particular month. This gives rise to certain issues regarding patient anonymity and GDPR-legislation, but the Health Registries Department is working on a solution where monitoring tables with low patient numbers in table cells are available to the hospitals, while the publicly available tables comply with the GDPR.

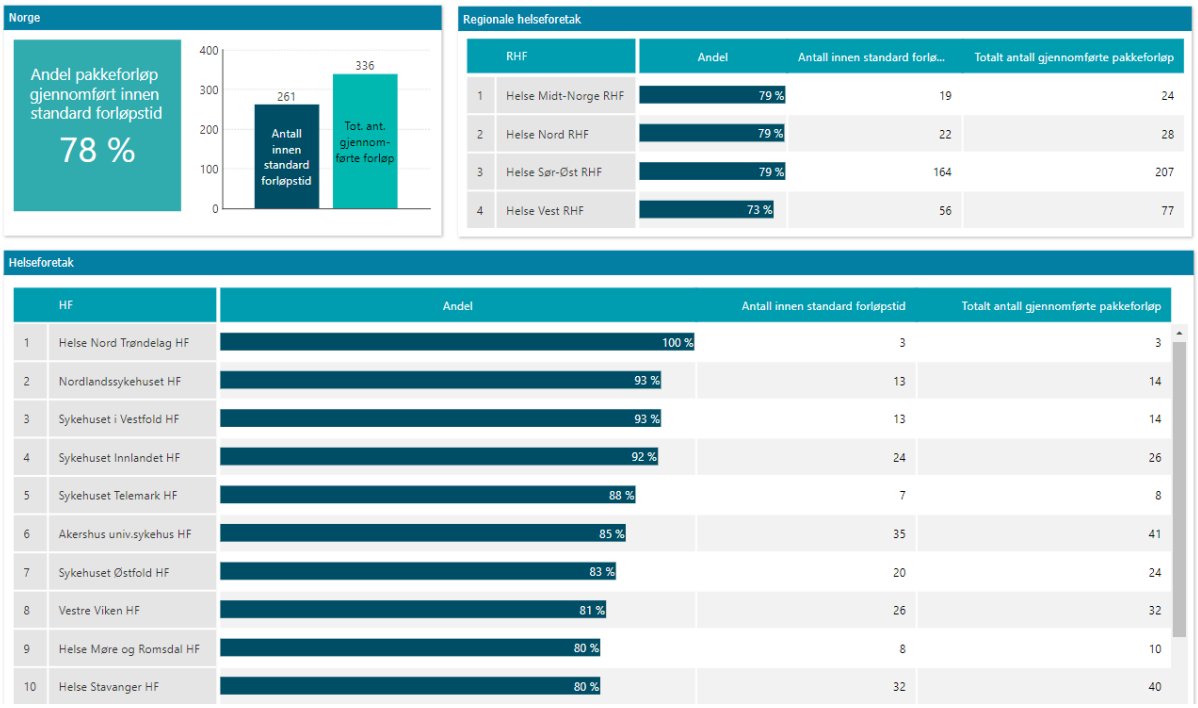

Figure 5: Illustration of processing time compliance for breast cancer patients in Norway at the national, regional and local level. The inventory covers December 2020.

In Sweden, the inventories are available at the national level, at the level of the six regional cancer centers as well as at the local level (21 county regions). The ambition is for the patients to be categorized based on where the CPP referral originates and hospitals are required to record whether patients are transferred from one region to another, although some regions have had difficulty registering it correctly. A new and more secure registration system has been introduced from 2021.

The Swedish Ministry of Health has specified the target that 80 % of CPP patients start treatment within the standard processing time specified for the individual CPPs. In Norway the target is that the standard processing time is met for at least 70 % of the CPP patients who start treatment. In Denmark, the Ministry of Health has not specified a specific target with regard to the share of CPP patients for whom the standard processing time is met, because it was considered to be inappropriate. However, Danish Regions have defined a target that the standard processing time is met for 90 % of CPP patients starting treatment. This target was not set on the basis of the monitoring data, and it has not been specified when this target should be reached.

The similarities and differences regarding the measures are summarized in Table 3.

Table 3: Monitoring measures in Denmark, Sweden and Norway.

	Denmark	**Norway**	**Sweden**
Statistical measures	Share of CPP patients for whom the standard processing time is met	Share of CPP patients for whom the standard processing time is met	Share of CPP patients for whom the standard processing time is met
	Processing time for 1st, 2nd and 3rd quartile		Share of patients for whom the standard processing time is (A) 1-25 % longer (B) 26-75 % longer and (C) more than 75 % longer than CPP standard processing time
Geographical units	Nationally 5 regions	Nationally 4 regions 23 helsefortak	Nationally 6 regions 21 county regions
Categorization of patients into geographical units	Patients categorized based on where the CPP referral originates	Patients are categorized based on the hospital trust that receives the CPP referral	Patients are categorized based on the county region where the CPP originates
Target	Standard processing time is met for 90 % of CPP patients starting treatment (target defined by the regions)	Standard processing time is met for 70 % of CPP patients starting treatment	Standard processing time is met for 80 % of CPP patients starting treatment

Population

In all three countries, patients are included only when they are registered with a CPP start and end date. This implies that some patients are excluded because they do not have a recorded start or end date.

The number of patients excluded because of missing information on dates in the registries is unknown across all countries. In Sweden, patients are required to have a registered start and end date in order to be included in the national database. As such, the Swedish national monitoring actors are unable to identify the number of patients excluded from the monitoring due to lacking date registrations; rather, the regions are responsible for their own reporting. In Norway and Denmark, patients are included in the registration files even though CPP start or end date are missing, but they are excluded from the inventories. It would be possible to follow the number of CPP patients, who are excluded, but this is currently not done. The Danish Health Data Authority reports that they would like to investigate it further in order to assess and minimize the problem.

In Denmark and Norway, the monitoring of processing times includes also patients for whom the cancer diagnosis is disconfirmed, whereas the Swedish monitoring only includes patients who have the cancer diagnosis confirmed.

In both Denmark, Norway and Sweden, all patients are included in the national monitoring irrespective of whether they are comorbid. All patients are also included irrespective of whether the CPP standard processing time is exceeded because of patient-related factors. For instance, a patient may not show up for appointments or may want treatment to start slightly later than proposed by the hospital. None of the three countries currently monitors the extent to which processing time is exceeded because of patient preferences; however, Norway has planned regular inventories regarding this point.

In Denmark, some of the regions supplement the central monitoring made by the Danish Health Data Authority with analyses that take into consideration e.g. comorbidity. However, the exclusion criteria differ across the regions, and therefore these inventories are only meaningful for comparing each region over time and not for comparison between the regions.

While the Danish monitoring includes relapse patients, relapse patients have been excluded from the monitoring in Norway since 2019. The reasons for excluding them were that the diagnostic process for relapse patients is different from that of other CPP patients, and in addition, data recording of relapse patients was generally poorer. Currently, the Norwegian hospitals are not supposed to register relapse patients with CPP registration codes, and consequently, no inventories address the processing time of relapse patients. In Sweden, relapse patients are excluded if they occur during a follow-up program whereas they are registered as a new CPP if they occur after a completed follow-up program.

The similarities and differences regarding the monitoring population are summarized in Table 4.

Table 4: Monitoring population in Denmark, Sweden and Norway.

	Denmark	**Norway**	**Sweden**
Necessary data for inclusion	CPP start date and end date	CPP start date and end date	CPP start date and end date
Monitoring of number of excluded patients due to lacking start or end date	No	No	No
Handling of patients for whom the cancer diagnosis is disconfirmed	Patients included	Patients included	Patients excluded
Handling of comorbid patients	Comorbid patients included.	Comorbid patients included.	Comorbid patients included.
	No regular monitoring of how comorbidities impact the inventories. However, the National Health Data Authority specifically asks the regions to comment on this aspect when assessing the monitoring	No regular monitoring of how comorbidities impact the inventories	No regular monitoring of how comorbidities impact the inventories.
Handling of patient-related factors causing delays	Patients included irrespective of whether CPP standard processing time is exceeded because of patient-related factors	Patients included irrespective of whether CPP standard processing time is exceeded because of patient-related factors	Patients included irrespective of whether CPP standard processing time is exceeded because of patient-related factors
	No regular monitoring of how this impact the inventories; it is currently not possible	Regular monitoring of delays due to patient-preferences are planned	No regular monitoring of how this impact the inventories
Handling of relapse patients	Relapse patients included	Relapse patients excluded	Relapse patients excluded if relapse occurs during follow-up program, and included as new CPP if relapse occurs after completed follow-up program
	Number of relapse patients monitored	Number of relapse patients *not* monitored	Number of relapse patients *not* monitored

The share of cancer patients referred to cancer patient pathways

All three countries investigate the number of CPP patients relative to the total number of cancer patients for relevant diagnosis groups. This aspect of the monitoring is imperative for evaluating the performance with regard to compliance with the CPP standard processing time objectives. Specifically, if only a relatively small share of cancer patients went through CPPs and if these patients were less comorbid than the average cancer patient, compliance with the recommended processing time would likely be unreasonably high. In Sweden, for instance, the processing time has generally increased as a larger share of the cancer patients were referred to CPPs (note, however, that this pattern changed in response to covid-19 pandemic: During the Spring of 2020, the number of patients dropped markedly, and though it increased slightly again

from August onwards, the 2020 numbers were still smaller than before, while compliance to recommended CPP processing time increased).

While in Sweden and Norway, there is an official objective of 70 % of cancer patients being diagnosed through CPPs, there is no specified threshold in Denmark, but the Danish Health Data Authority finds the inventory useful for identifying regional variation.

In Denmark, the inventory is generated by comparing the registrations of CPP patients in the National Patient Registry to the registrations in the Cancer Registry using the (pseudomized) personal identification numbers. There is a time lag of only three months, because 80-90 % of the registrations in the Cancer Registry are automatically entered from the National Patient Registry. However, data for the ongoing year is considered preliminary, since corrections to registrations in the Cancer Registry are made subsequently.

In Sweden, the database for CPP patients does not have personal identification numbers, which makes it impossible to match data to the national cancer registry. Therefore the share of cancer patients referred to a CPP is calculated by a using a proxy variable: "number of patients who start (all types of) treatment in a CPP" as numerator divided by "the calculated mean number of patients from the previous three years in the Swedish cancer registry". The inventory is available both nationally and county regionally, and the publicly available inventory is updated twice a year.

In Norway, monitoring the share of cancer patients referred to CPPs is complicated by certain factors related to registration practices, which require a substantial amount of data processing. Specifically, CPPs are registered at the person-level though a person can experience several cancer diagnostic and treatment processes. Moreover, registrations of tentative diagnoses erroneously make the total number of cancer diagnoses too large when compared to the number of CPPs.

An example of the monitoring is shown in Figure 6.

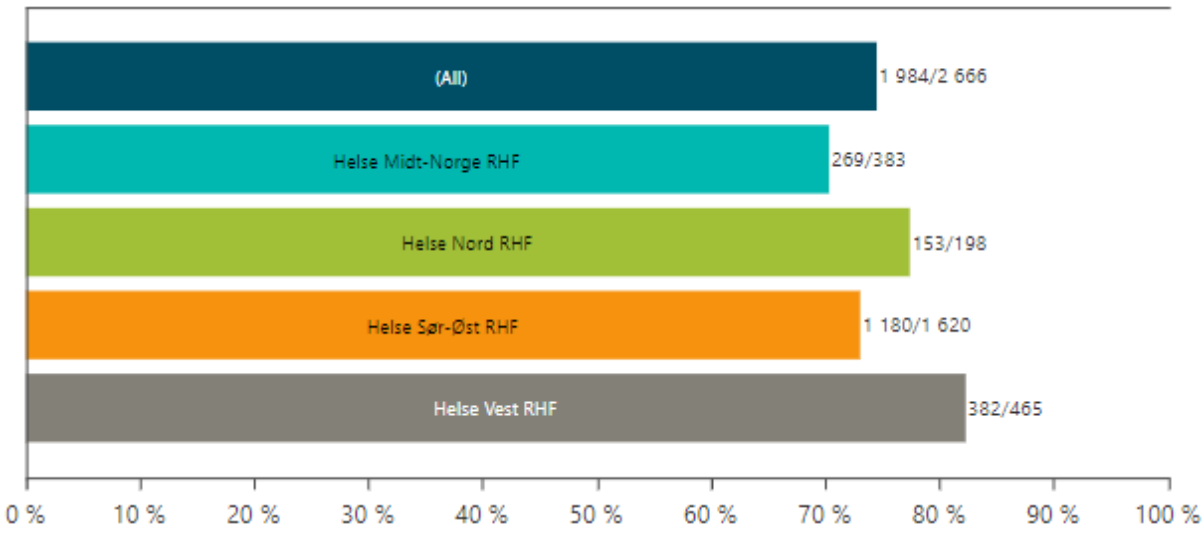

Figure 6: The share of new cancer patients in Norway who were diagnosed through organ specific CPPs – nationally and regionally. December 2020.

Patient volume

In Denmark, the monitoring of organ specific CPPs also includes inventories regarding the share of CPP patients who end up having their diagnosis disconfirmed (i.e. patients not having the organ specific CPP diagnosis). The purpose of this inventory is to display and monitor the differences in the patient volume across the CPPs. This statistic can also facilitate regional comparisons though the diagnostic process prior to the CPP may differ across the regions. Figure 7 shows an example of monitoring the share of cancer patients having the cancer diagnosis disconfirmed in Denmark. For the CPP for metastasis from an unknown cancer, the share of patients who complete primary investigation is used as a measure of the patient volume.

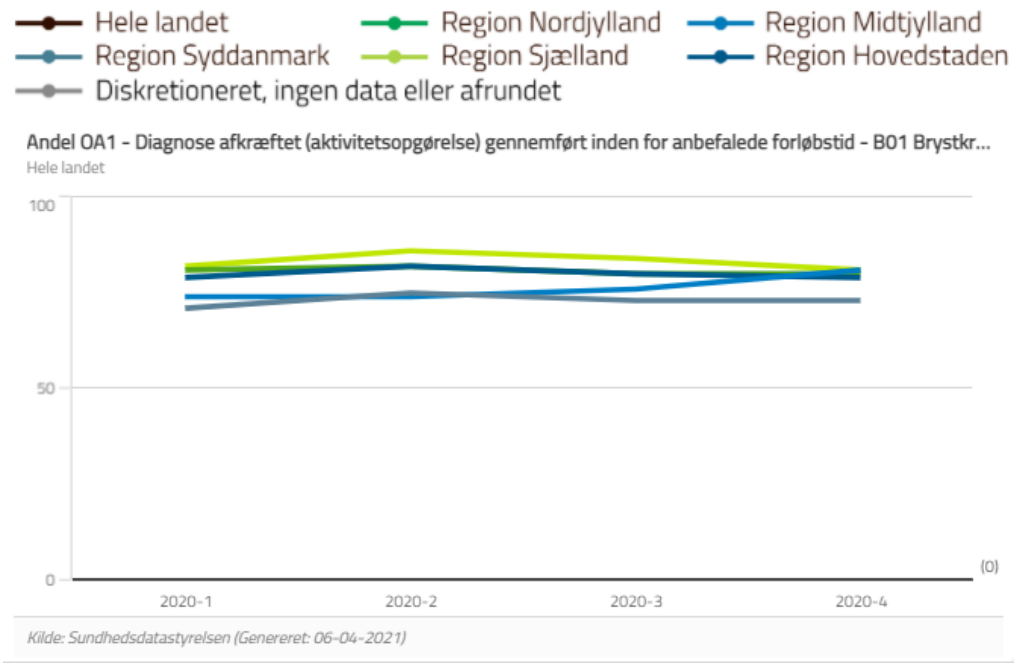

Figure 7: Share of patients referred to breast cancer CPP in Denmark who had the cancer diagnosis disconfirmed – regionally. 1st-4th quarter 2020.

Parallel to Denmark, Norway also monitors the share of CPP patients in an organ specific CPP who has the diagnosis disconfirmed. These patients may be diagnosed with a different type of cancer, with a different disease, or they may not be diagnosed at all.

In Sweden, the share of CPP patients in an organ specific CPP who has the diagnosis disconfirmed are the ones that do not start treatment in the CPP. This measure is available both nationally and on county region level monthly.

The Swedish Cooperation of Regional Cancer Centers reports that the measure can be useful for evaluating whether the criteria for cancer suspicion are appropriate or whether they are interpreted differently across regions. Specifically, regional variation is investigated carefully, and large deviations can reveal misinterpretations of the registration instructions. For instance, when the CPPs and the monitoring had just recently been introduced, one region had an extremely high rate of CPP patients starting treatment. When investigating this further, it turned out, that only patients receiving treatment were given an end date. For all CPP patients who did not receive a cancer diagnosis, the CPP was never ended, and as a consequence, they were never included in the national database.

Patient experiences

In Sweden the monitoring includes inventories concerning patient experiences based on patient surveys. Until 2019, patient experiences were monitored each year, and all CPP patients were invited to participate (with a response rate close to 60 %). Because of little variation in the responses from one year to another, the regions could decide for themselves whether to carry out the survey in 2020, and the intention for the years to come is to perform the survey nationally every other year. The survey questions come from the PREM-protocol (Patient Reported Experience Measures) and cover the areas of perceived participation/involvement, emotional support, information/knowledge, continuity/coordination, respect/care and availability. See Figure 8 for an example of the output. The inventory is made for both patients who had the diagnosis confirmed as well as for patients who had the diagnosis disconfirmed. The statistics are available at the national and regional level as well as at the local level if there is a sufficient number of patients. The survey is primarily used at the local level to identify areas or efforts that need to be improved.

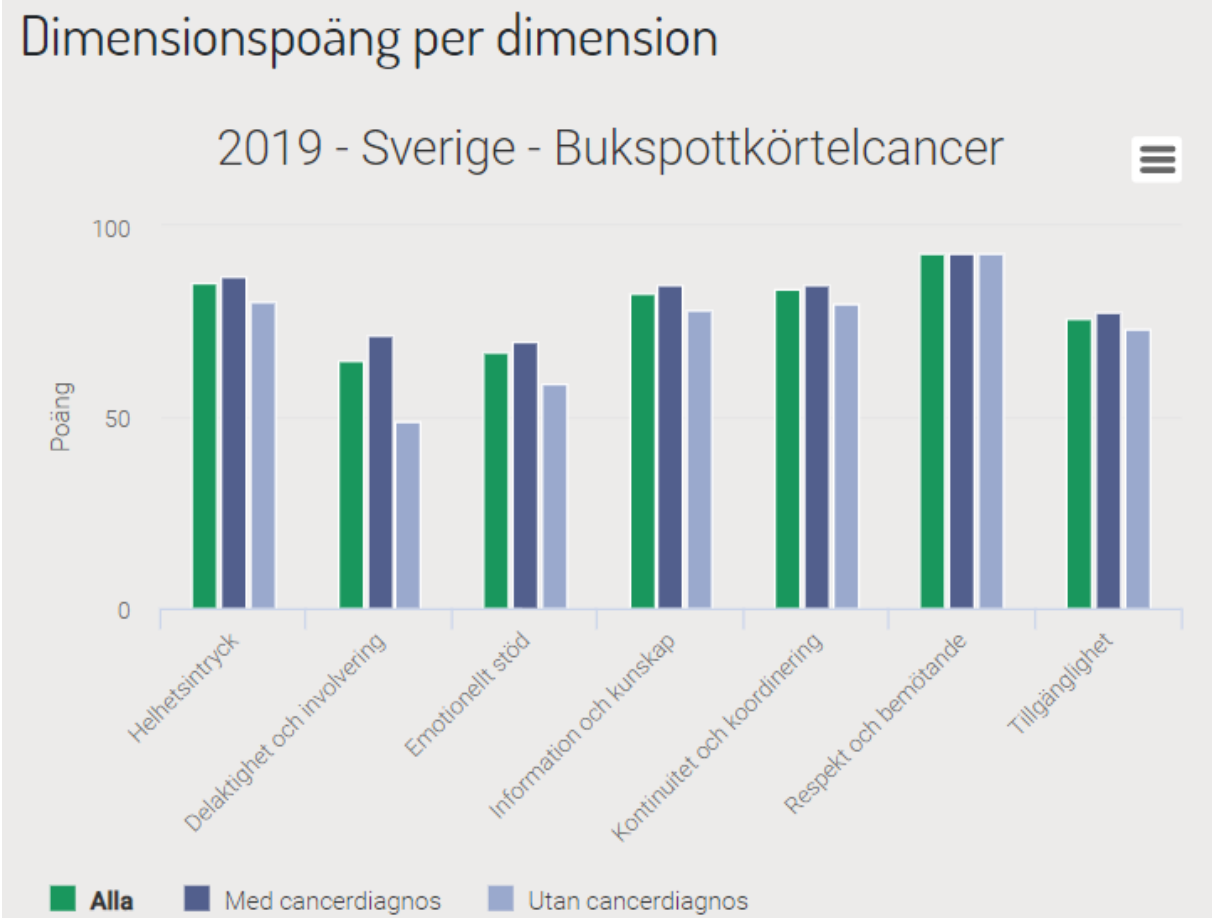

Figure 8: Output from the Swedish monitoring of patient satisfaction. The example concern pancreas cancer CPP.

In Norway, CPP patient satisfaction has been investigated as part of a research project, which ended in 2020 (4), but there is no regular monitoring taking place.

Availability

In Denmark, new inventories regarding CPP processing time, number of patients, and CPP patients diagnosed with cancer are available online four times a year (5). It is possible to choose the parameters of interest and generate tables and figures. The Danish Health Data Authority also publishes a quarterly report when new data are released. A yearly report is published as well. In addition to the measures reported in the quarterly reports, the yearly report also assesses the number of relapse patients as well as details about the inventories concerning patients not registered in CPPs. Because of the introduction of a new patient registry (LPR3), no inventories are available for data from 2019.

In Norway, inventories regarding processing time, number of patients, and CPP patients not diagnosed with cancer are also released online, and they are available at the monthly level. Similar to the Danish, it is possible to choose the parameters of interest (6).

In Sweden, the CPP performance inventories are continuously updated and publicly available online where it is possible to choose the parameters of interest (7). Additionally, regional reports and a national report are published annually. The Cooperation of Regional Cancer Centers is currently working on improvements to the national report.

Challenges

In both Denmark, Norway, and Sweden data availability and validity is mentioned as the primary challenge related to the monitoring, though the character of the specific challenges vary across the three countries.

In Denmark, the primary challenge relates to the validity of data registrations, and the problems are two-fold: First, the hospital staff may make errors when reporting, and second, the IT-systems cause frustrations, because the regions use different systems that do not comply well with each other. Among other things, the problems concern the registration of referral and date of referral for specific cancer sites. For instance, the Danish Rigsrevision documented that for some cancer sites, the registered referral data was identical to the date of first hospital appearance, which apparently was a result of two incompatible IT-systems (8). The situation with coinciding referral date and date of first hospital contact can also arise if patients are investigated in relation to other morbidities and are referred to further investigation or treatment as part of a CPP. Moreover, some patients have missing end date registration.

The challenges relate to the fact that there are many actors involved in the operation and processing of cancer diagnostics and treatment, and even though the Danish Health Data Authority provides registration guidelines, a certain level of discretion persists. This is especially the case with regard to registrations of when the diagnosis is given and when treatment has been decided on. Moreover, while the thorough registration guidelines are intended to facilitate uniform registration practices, hospitals report that employees find the guidelines complex to navigate (8).

In Norway, one challenge relates to the fact, that private practitioners working on contracts with the specialized health services do not register their patients with the relevant CPP codes. Thus,

these patients are not included in the monitoring until they enter the hospitals, and as a consequence, their processing time will erroneously appear shorter. However, from 2020 it has been possible to generate inventories that take this issue into consideration. Another challenge relates to the timeliness of reporting. While ideally the registrations are made in real time, sometimes the coding is not made until one or two months later, which makes the registrations less reliable. Finally, relapse patients have been registered differently across regions, hospitals and cancer sites, and as a consequence, the relapse patients have been excluded from the processing time inventories from 2019 onwards and from the registration practice altogether.

In Sweden, the monitoring efforts are complicated because the county regions do not use the same IT-systems, and sometimes, missing registrations or errors occur when registrations for several county regions are to be combined. Moreover, the description regarding which code to use for different end points (e.g. no cancer diagnosis, start of treatment, or that the patient is informed that no treatment will be given) is occasionally interpreted differently. Finally, the recording regarding whether patients are transferred from one region to another is oftentimes missing even though this information is required as part of the patient registration.

Across the three countries, the challenges related to missing or invalid data have direct implications for both the quality of the monitoring inventories as well as for the analytical choices in relation to the monitoring practices. For instance, since all countries require patients to have start and end dates in order to be included, the fact that an unknown number of patients have missing values on either of these variables, imply that the statistics are by definition inaccurate. As long as the issues are relatively constant, they do not obstruct looking at the developments over time. However, systematic regional variations in coding guideline interpretation and registration practices necessarily make regional comparisons less valid. While the problems are reduced by the fact that the employees performing the monitoring continuously pay attention to indications of irregularities, the data related issues nevertheless complicate the process of identifying the CPPs that perform poorly or need to be revised.

Improvements and new initiatives in the pipeline

Across all three countries, an expansion of the current monitoring scheme is being developed in order to also monitor aspects related to rehabilitation of cancer patients. However, it is complicated to define relevant indicators with regard to when the rehabilitation process begins; this is particularly complicated because the indicator ideally should be the same across cancer sites.

In Denmark, though not actually on the table yet, the Danish Health Data Authority would like to systematically follow-up on patients, who have the cancer diagnosis disconfirmed.

In Norway, the Health Registries Department is developing an inventory concerning how often exceedances of CPP standard processing time is due to patient preferences or are medically justified (e.g. because of certain comorbidities). These inventories are in demand from the hospitals. Moreover, patient satisfaction is also to become part of the regular monitoring in Norway, just like transfers of patients from one region to another are to be monitored regularly. Along the same lines, the hospitals are requesting inventories that follow the hospitals and their performance rather than the patient (i.e. patient trajectories are broken down at the hospital level for patients who are transferred across hospitals).

Use of CPP monitoring

Not complying with the objectives related to the CPPs has no direct consequences as such (i.e. no tangible penalties) for the hospitals or the regions operating the hospitals, but it may start investigation processes and have political consequences. In Denmark, the regions are required to account for exceedances of CPP standard processing times if the compliance with CPP standard processing time for a specific cancer site is generally low or low compared to the other regions. Specifically, the Danish Health Authority asks the regions to account for selected cancer sites that are among the 25 % with the lowest CPP standard processing time compliance within a given period. Similar requirements to account for exceedances are considered in Norway, and across all three countries, the monitoring of processing time for CPP patients is a salient quality indicator that receives a lot of attention politically and among the hospital management.

The national health data authorities report that the monitoring has a number of other implications. For one thing, the monitoring provides a clear incentive to improve organizational processes and workflows. This, in turn, has had immediate positive implications for timely diagnostics and treatment in general and increased focus on individual patients not being forgotten or unnecessarily delayed. Moreover, the national health data authorities mention, that the monitoring has brought about an increased understanding among hospital staff of each other's work processes. For instance, some oncologists and surgeons have become more aware of the processes related to diagnostics including pathology, because of the focus on meeting the CPP objectives regarding all phases of the CPP. The monitoring has also initiated organizational changes in many places with advance booking of appointments becoming more common, and it has increased focus on timely and valid registrations. Finally, the monitoring can be a tool for identifying CPPs that need to be reorganized; for instance, the CPP for bladder cancer in Denmark was revised because the specified standard times were unreasonably short considering that a large share of the patients had severe comorbidities.

However, the national health data authorities also notice some negative incentives related to the monitoring. Hospital staff may misreport dates or may not take comorbidities sufficiently into account in order to meet the standard processing time. In general, the health data authorities across the three countries emphasize a concern that new monitoring initiatives may create additional negative incentives, and thus need to be considered carefully before being implemented.

Discussion and recommendations

While in many regards the monitoring practices are very similar in the three countries, there are notable differences.

Population: For one thing, the three countries have different opinions and practices regarding whether or not to include relapse patients in the monitoring. While the Danish monitoring includes all patients with a start and end date, the Swedish and Norwegian monitoring also exclude patients with relapse. The Norwegian monitoring authorities explain that (a) relapse patients often have short CPP processes, (b) the condition of former cancer patients is followed by specific programs, and (c) registration practices of relapse patients vary across hospitals. Altogether, these factors imply that including relapse patients is likely to skew the monitoring inventories.

However, the Danish Health Data Authority includes relapse patients based on the argument that CPP standard processing times also apply to these patients who have the same right to a timely treatment. Moreover, based on patient files, the hospitals may not be able to see whether a patient has relapse or first occurrence of cancer if the patient was previously treated in another region. Rather than excluding the relapse patients, the Danish Health Data Authority annually provides an overview regarding the share of CPP cancer patients with relapse (9).

All three countries include patients irrespective of comorbidities or whether potential delays in the CPP are caused by the patient (e.g. absenting from appointments or patients preferring to postpone treatment), which may question that the monitoring can be seen solely as an evaluation of hospital performance. Indeed in their review from 2018 of the Danish CPP monitoring, the Danish Rigsrevision argued that the inclusion of all patients irrespective of comorbidities complicated valid comparisons of the regions (8). Moreover, they argued, by taking comorbidities and patients' preferences for prolonged processing time into consideration, the monitoring would be more useful with regard to identifying the CPPs with the greatest potential for improvements. However, monitoring actors across the three countries claim that excluding e.g. comorbid patients is complicated: It is unclear which comorbidities should qualify for exclusions, and this would likely vary by cancer diagnosis. Consequently, specifying the relevant comorbidities would require a substantial workload. Moreover, the health data authorities worry that excluding comorbid patients would give hospitals an inappropriate incentive to prioritize non-comorbid patients over comorbid patients in order to obtain a better performance score. Along the same lines, the health data authorities from the three countries are reluctant to include variables denoting whether the CPP process is prolonged because of patient preferences; they worry that patients may feel pressured to prolong the CPP process unnecessarily.

Considering these concerns, it seems appropriate that the monitoring generally includes all patients irrespective of comorbidities or whether potential delays in the CPP result from patient preferences. However, to facilitate regional comparisons and qualify discussions on the performance of the hospitals more generally, it would be relevant to see either the regular monitoring without comorbid patients as a supplement to the existing monitoring (even though this involves certain data considerations) or inventories regarding the burden of comorbidity across diagnoses and geographical regions. Such an inventory is available from Denmark in a report from 2015 covering data from 2013-2014 (10), and similar initiatives are underway in Norway. The monitoring authorities in Norway are also considering making inventories concerning delays due to patient preferences – potentially as part of the ordinary monitoring. Such inventories are in demand from the hospitals, because they would like to understand the factors affecting processing time. If these inventories were available at a regular basis, they could be valuable additions to the monitoring, though of course, that requires resources and a focus on the validity of coding practices regarding comorbidities and patient preferences.

Time periods: Denmark and Norway monitor total processing time from referral to treatment as well as the individual intermediate phases (i.e. referral period, investigation period and preparation to treatment period). This is currently done regionally, but not nationally in Sweden. Sweden includes the processing steps in primary care if the well-founded suspicion is decided at that level while Denmark and Norway start the monitoring when the CPP referral is received at the hospital.

Monitoring objects: While all countries show statistics regarding share of CPPs that are completed within the CPP standard processing time, Denmark also shows the median processing time as well as the processing time for the 1st and 3rd quartile of patients. The recent Swedish inventory

showing processing time for patients for whom the CPP standard processing time is exceeded provides an informative addition, which could serve as inspiration for the Danish and Norwegian monitoring. It would be valuable, however, to have even more fine-grained information regarding the distribution, e.g. processing time for the 10 % of patients waiting the longest – at least for the CPPs with enough patients. Similarly, it would be useful to see more information regarding the distribution of the CPP patients with short processing time, in order to, for instance, identify regions who perform particularly well with regard to specific CPPs and may serve as an inspiration for others.

Target specifications: In Norway and Sweden, the ministries have specified target values regarding the share of cancer patients who are included in CPPs and regarding the share of CPP patients for whom the standard processing time is met. In Denmark, the regions have an objective of 90 percent of CPP patients for whom the standard processing time is met, though it is not specified when this goal should be reached. When evaluating performance, such targets are useful, as they provide reference points for the hospitals and the individual departments as well as for the health authorities and the public (including patient organizations). As such, it would be valuable if the Danish central authorities clarified specific targets as well as a time horizon for when the target should be reached, just like the targets in Norway and Sweden should be reevaluated regularly.

Patient experiences: The Swedish monitoring of patient experiences provides valuable knowledge regarding how patients experience the CPP process. While definitely also very costly, such inventories constitute a distinct dimension of quality monitoring, that is likely to be useful in identifying both good examples and areas that need to be improved. Parallel initiatives in Denmark and Norway could benefit from the Swedish experience and only perform the survey every other year. In order to cut costs, it might also be feasible to randomly select part of the population, though such decisions would require thorough considerations regarding e.g. statistical power.

Concluding remarks

In many regards the monitoring practices in Denmark, Norway, and Sweden are very similar, but notable differences exist. Many of these differences (e.g. regarding whether to include relapse patients) reflect data availability and deficiencies, some of which relate to IT-issues. As such, though registration guidelines are thorough, a continued focus on data validity and streamlining is paramount. Improvements in data quality can make the inventories and comparisons across diagnoses and regions even more valid and reliable and thus improve the usefulness of the monitoring with regard to identification of best practice as well as areas that require special attention and improvements.

Each country already has considerations regarding extensions to the existing monitoring practices – for instance regarding extensions related to rehabilitation and additional analyses related to processing time assessments that take into considerations comorbidity or patient preferences. Here too, differences across regions and cancer sites with regard to registration practice and data quality constitute challenges. This again points to the importance of maintaining a focus on data validity. Moreover, the concerns expressed by the health data authorities related to the monitoring potentially generating inappropriate incentives are relevant and should be kept

in mind. That said, inventories regarding rehabilitation, regarding patient experiences (such as those already available in Sweden) as well as regarding patient preferences and comorbidities could be valuable additions to the existing monitoring practices. Such additions would strengthen the ability to identify best practice actors and areas that need improvement, and more generally would qualify the monitoring as a tool for quality assessment of CPP performance.

While overall, the monitoring across the three countries is largely parallel, the differences with regard to e.g. inclusion criteria complicate comparisons of performance and trends across the borders. Additionally, differences in IT-systems and reporting practice also cause direct comparisons to be inappropriate. That said, to the extent possible it would be valuable if the health data authorities could regularly consult each in order to develop a few indicators in a manner that is as similar as possible so that benchmarking would be meaningful. The health data authorities have previously cooperated extensively, when the Swedish and Norwegian monitoring models were established. In a similar manner, the health data authorities could continuously profit from consulting each other in order to develop the best possible monitoring schemes, for instance when developing the monitoring of rehabilitation of CPP patients. Along the same lines, if Denmark and Norway were to introduce monitoring practices with regard to patient experiences based on survey data, they could benefit greatly from the experiences learned in Sweden. The Nordic Collaboration Cancer Care Pathway could constitute a forum where the health data authorities could regularly discuss challenges and opportunities for further developments among themselves as well as present monitoring developments to a larger audience.

Appendix 1: Template

Template regarding monitoring of Cancer Patient Pathways in Denmark, Norway and Sweden.

In the questions below, 'monitoring' is understood as analysis or surveillance performed in order to follow performance and quality related to cancer patient pathways (CPP). Thus, monitoring is not data collection in itself, but factors related to data (e.g. quality, restrictions etc.) can be relevant for the monitoring, and can in that case be described with regards to the column concerning challenges.

		Description of practices	Challenges (e.g. data (in-)availability, data quality, delays in data availability or other)
Basic questions regarding the monitoring model			
1	How often is the monitoring performed?		
2	Who is performing the monitoring?		
3	Which data sources are used for the monitoring?		
4	Within which geographic units is the monitoring performed?		
5	Which cancer patient pathways (CPP) are monitored (e.g. organ specific CPPs, diagnostic CPP, CPP for metastasis)?		
Elements within the monitoring model			
6	At which point in the patient trajectory does the monitoring start?		
7	At which point in the patient trajectory does the monitoring end?		
8	Which points/phases within the patient trajectory are monitored (e.g. time from reference to (A) investigation, (B) diagnosis, (C) treatment)?		
9	Does the monitoring concern to what extent the standard CPP time is kept, and how is the monitoring performed?		
10	Does the monitoring concern patients' actual waiting time (for instance in days), and how is the monitoring performed?		
11	Does the monitoring concern maximum CPP time duration, and how is the monitoring performed?		
12	Does the monitoring concern CPP time duration for patients for whom standard CPP time is exceeded, and how is the monitoring performed?		
13	Which population does the monitoring concern?		

14	Does the monitoring concern the number of CPP patients relative to the total number of newly diagnosed cancer patients or patients with suspicion of relapse – and how is the monitoring performed?		
15	Does the monitoring concern the number of unfinished/unconcluded CPPs relative to the total number of CPPs, and how is the monitoring performed?		
Challenges and adjustments			
16	How does the monitoring handle patients with CPPs stretching across the monitoring period?		
17	How does the monitoring handle patients who are transferred between regions and/or hospitals during the monitoring period? I.e. are patients included in the monitoring irrespective of whether they are transferred between regions and/or hospitals or will they be excluded because of the transfer?		
18	Does the monitoring concern whether patients are transferred between regions and/or hospitals during the CPP? I.e. does the monitoring follow the number of patients that are being transferred between regions and/or hospitals?		
19	Are the quality indicators adjusted to account for e.g. age and gender differences within units of observation (e.g. regions)?		
20	Is the monitoring split on gender, age groups or other factors?		
Specifically concerning diagnostic CPP			
21	For patients in diagnostic CPP, does the monitoring concern how many patients are (A) diagnosed with cancer, (B) diagnosed with other diseases or (C) not getting a diagnosis – and how is the monitoring performed?		
22	For patients within a diagnostic CPP, does the monitoring concern whether they have had the required prior tests performed (e.g. blood sample and imaging) – and how is the monitoring performed?		
Specifically concerning organ specific CPP			
23	For patients in organ specific CPP, does the monitoring concern how many patients are diagnosed with the organ specific cancer – and how is the monitoring performed?		
Communication and follow up			
24	How is the monitoring communicated/made available to the public?		
25	How is the monitoring used/what consequences does the monitoring have (e.g. changes in CPPs, allocation of assignments?		

References

1. Sundhedsstyrelsen. Kræftpakkeforløb: Sundhedsstyrelsen; [cited 2021 05.05]. Available from: https://www.sst.dk/da/Viden/Kraeft/Kraeftpakkeforloeb.

2. Agdler C. Patienternas upplevelser av standardiserade vårdförlopp: Regionala Cancercentrum i Samverkan; [cited 2021 05.05]. Available from: https://cancercentrum.se/samverkan/vara-uppdrag/statistik/svf-statistik/patienternas-upplevelser/.

3. Sundhedsdatastyrelsen. Pakkeforløb med længere forløbstid end anbefalet 2013-2016 - *For pakkeforløb medtaget i monitorering af kræftområdet. Opgørelse OF4 samlet tid til initial behandling*. København; 2018.

4. SINTEF. Evaluering av pakkeforløp for kreft: SINTEF; [cited 2021 05.05]. Available from: https://www.sintef.no/prosjekter/2017/evaluering-av-pakkeforlop-for-kreft/.

5. Sundhedsdatastyrelsen. Pakkeforløb for kræft: Sundhedsdatastyrelsen; [cited 2021 05.05]. Available from: https://www.esundhed.dk/Emner/Kraeft/Pakkeforloeb.

6. Helsedirektoratet. PAKKEFORLØP FOR KREFT - SENTRALE INDIKATORER: Helsedirektoratet; [cited 2021 05.05]. Available from: https://statistikk.helsedirektoratet.no/bi/Dashboard/71613538-62de-4ab2-8409-8638fc6c25db?e=false&vo=viewonly.

7. Regionala Cancercentrum i Samverkan. Väntetider i standardiserede vårdförlopp (SVF): Regionala Cancercentrum i Samverkan; [cited 2021 05.05]. Available from: https://cancercentrum.se/samverkan/vara-uppdrag/statistik/svf-statistik/vantetider-i-svf/.

8. Statsrevisorerne & Rigsrevisionen. Rigsrevisionens beretning afgivet til Folketinget med Statsrevisorernes bemærkninger - Rettigheden i indsatsen over for kræftpatienter. København; 2018.

9. Sundhedsstyrelsen. "Monitorering af forløbstider på kræftområdet" Sundhedsstyrelsens kommentarer - *Årsopgørelse for 2018*. Københvan; 2019.

10. Statens Serum Institut. Sammenhæng mellem komorbidtet og behandling inden for standardforløbstiderne i pakkeforløb for kræft. København; 2015.