



Health Reform Monitor

The national program on standardized cancer care pathways in Sweden: Observations and findings half way through[☆]



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ABSTRACT

In 2015, the Swedish government initiated a national cancer reform program to standardize cancer care pathways. Primary aims included shortened waiting times among patients with suspected cancer, increased patient satisfaction and reduced regional variation. The implementation phase of the program is now more than half way through and both achievements and challenges have been identified.

The ongoing evaluation demonstrates that professional engagement and adjustments on the meso- and micro-level of the system are essential to achieving sustainable improvements. Waiting times have shortened for the pathways launched first, and patients are satisfied with a more transparent process. Physicians in primary care are satisfied to inform patients about the pathways but point out problems with comorbidity and complicated diagnostic procedures related to unspecific symptoms. Mechanisms and ethical considerations behind possible crowding-out effects need to be thoroughly highlighted and discussed with staff and management. The results so far appear promising but meso- and micro-levels of the system need to be more involved in the design processes.

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1. Purpose, content and design of the program

Access to care has long been an area of concern in the Swedish health care system, and a number of national policies have been introduced over the years to address this challenge [1]. The waiting times to specialized care have also increased somewhat in recent years [2].

Waiting times in cancer care have been viewed as particularly problematic. Starting in early 2015 Sweden embarked on a national four-year program to introduce Standardized Cancer care Pathways (SCP) [3]. The SCP reform program was initiated by the Swedish government (Ministry of Social affairs) drawing on support

from six Regional Cancer Centres (RCCs). In addition to a central agreement with the Swedish Association of Local Authorities and Regions (SALAR) [4], the 21 independent Swedish counties are incentivized to implement the reform with a national performance-based reward grant of two billion Swedish kronor (equivalent to approximately 23 € per capita). By 2018, more than 30 cancer diagnoses will be covered in the program. The SCP program, a model that originated in Denmark, focuses on the initial diagnostic phase, which demands involvement from several care providers, professions and levels of care. The SCP program is based on the clinical concept of *well-founded suspicion of a potentially malignant condition*, designed for each cancer diagnosis. The designed SCP manual describes the set of alert symptoms that warrant further investigations. It also defines which symptoms and results delineate well-founded indication of cancer and specify what the referral to a sub-specialist must contain. The SCP ends with the start of first treatment; subsequent care is conducted as usual. The total number of days from well-founded suspicion of cancer to start of first treatment is defined by the total number of days for each step and constitutes the total SCP target time for each diagnosis.

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Table 1
Number of patients referred to standardized pathways, and who started their first treatment.

Diagnosis	Number of patients referred to the pathway	Number of patients starting first treatment	Proportion of patients %	Yearly, cancer incidence ^a
Acute myeloid leukemia - AML	278	228	82	328
Head and neck cancer	2754	809	29	1525
Oesophagus and stomach cancer	746	427	57	1 328
Prostatacancer	4887	2299	47	10 985
Uretreal and bladder cancer	8681	1374	16	2 965
Total	17346	5137		

^a Source: cancercentrum.se and The national cancer register (NBHW).

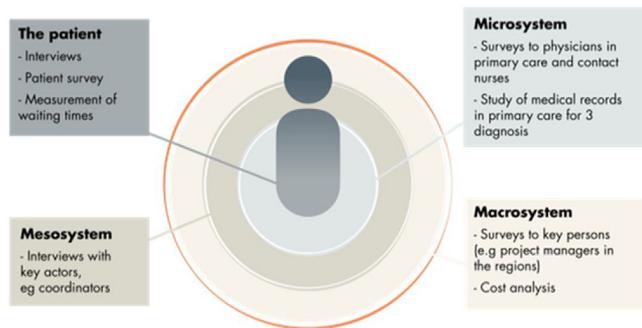


Fig. 1. Levels and sources of evaluation.

2. The evaluation covers different levels of the system

The Swedish National board of Health and Welfare (NBHW) has been assigned to monitor and evaluate the SCPs and submit annual reports to the Ministry of Health. The evaluation is grounded in the patients' perspective and the design is formed to highlight different levels of the system (Fig. 1).

The analysis and findings in this report are based on a number of different sources:

- Analysis of county council/regional action plans for implementation in 2016
- In-depth dialogues in four county councils/regions with key people involved in the implementation and process teams
- Questionnaires directed at county and regional project managers and personnel in the health sector and web-based surveys of primary care physicians first experience in remitting patients to SCPs.

In order to ensure that the evaluation contributes to mutual learning and collaboration throughout the program on a national level, the NBHW organized two dialogue meetings with the project managers in the regions responsible for implementing SCPs. These meetings covered issues such as primary care specific challenges, possible mechanisms behind crowding-out effects, as well as broader issues related to integrated and coherent care. Summaries from these dialogue meetings have been compiled and returned to participants. Furthermore, the results of different surveys have been sent back to the regions' health system leadership to promote improvement of the program.

3. Overall observations of the process of implementation

The total number of patients referred to standardized care pathways during the first 15 months of the implementation period was 17,346. During the same period, 5137 patients started their first cancer treatment within the SPC program [5]. The monitoring also demonstrates that the duration of patients' care journeys decreased for the first implemented diagnosis (acute myeloid leukemia, head-

and neck, oesophagus and stomach, prostate and ureteral bladder cancer). There were substantial differences (range 16–82%) among the different diagnosis in the proportion of patient starting their cancer treatment [5] (Table 1).

Patient reported experiences measures, (PREM) have been developed especially for the SCP-reform. The pilot study shows that the patients generally are satisfied with the waiting times and a more transparent process [5].

There is a consensus in the county regions that the focus on standardized care processes stimulates important development and improvements of cancer care. Efforts in most regions prior to the national program addressed development of care processes. These efforts have contributed to the opportunity for more sustainable solutions. The national concept of *well-founded suspicion of cancer* is valued at the meso- and micro-level even as it is stressed that the concept needs further development to be applied more adequately.

As anticipated, the regions have approached the initiative in different ways based on local conditions and needs. While some challenges are similar among the regions, as for example short-ages of general practitioners, they also vary among regions as well as among diagnoses and procedures. One common challenge in all regions has been to involve primary care, something confirmed in international research [6]. Identified challenges related to SCP in primary care ranges from administrative codes of registration, engagement and time for learning about SCP, the use of locum tenens physicians (in Swedish, "stafettläkare"), comorbidity and diffuse non-specific symptoms among patient referred to the pathways, and the frequency of specific symptoms so-called alert symptoms described in the pathways. For some of the diagnoses, the physicians in primary care only meet one patient per year or even more seldom. Another general challenge raised is the pace of implementation phase. A number of the informants in the follow-up report problems with lack of time for reflection and learning, as well as follow up studies on consequences of the implementation of SCP.

Some of the more specific challenges are related to lack of capacity and competence in some counties and regions e.g. radiologists, pathologists and urologists related to prostate cancer and specialist nurses in head-neck cancer.

Finally, the project leaders in the regions report that one substantial challenge has been the involvement of management. The understanding of SCP is rather high for functions in close and direct contact with patients, while middle management often seems to lack conceptual understanding of SCP.

4. Primary care physicians are generally satisfied but report problems with underestimated complexity in procedures

The 298 primary care physicians who responded to an electronic survey in the spring of 2016 cover all county councils and regions in Sweden but were un-evenly distributed. Nevertheless, their responses provide insights from experiences at the front-lines of primary care early in the SCP implementation [5]. Their responses reflect differences between different contexts, in part

concerning *how* the SCPs were implemented. For example, the county councils differed in how they supported the use of SCPs, e.g. in whether they provided electronic templates for referrals from primary care to diagnostic work-up at hospital and in how such templates were designed. Consequently, responses demonstrate a range of experiences among primary care physicians from interacting with patients and referring them according to SCPs. The wide range of experiences among GPs may reflect the variation in effect on sustainability at the micro level.

When asked “How easy or difficult do you think it is to explain the SCP idea to patients?”, 61% of respondents checked “very easy” (22%) or “rather easy” (39%). An even greater share, 71%, responded that the SCP helps promote patients’ sense of comfort during their diagnostic assessment to a “very” or “rather” great extent. In free text comments, respondents suggest that thanks to the SCP, patients need not wait excessively for their diagnostic evaluation, as was common before, and that they have more accurate expectations regarding the diagnostic process and its likely duration. Contentiously, the terminology connected with the SCP includes telling patients that there is a “well-founded indication of cancer” in their case, which is more explicit than was usually the case in similar situations before. This explicit mention of cancer suspicions might cause unwarranted anxiety among patients. This, in turn, is particularly unfortunate considering that the majority of patients referred according to the SCP will end up being “freed” of the cancer suspicion, illustrated in following quotations.

The word “cancer” frightens people. The oral information usually works well but the written information can become overly direct and explicit for the many unsuspecting patients.

Some [patients] are content that we take their concerns seriously, that there is quick progress and that someone takes charge of the diagnostic efforts.

The majority of respondents indicate that they think the SCP can help promote better coordination across actors and phases in the cancer diagnostic and early treatment process.

5. Does the cancer pathway program lead to crowding out effects?

When specific programs addressing one specific area or patient groups in health care are implemented, it is essential to consider risks for crowding out effects and consequences on horizontal prioritizing. Priority in Swedish health care needs to be in accordance with the so called ethical platform [7]. The platform is based on the three principles of ethics: the human dignity principle, the needs-solidarity principle, and the cost-effectiveness principle. The *human dignity principle* addresses factors that should *not* determine the priorities for care, e.g. personal characteristics and functions in society. The *needs-solidarity principle* means that more of health care’s resources should be given to those in greatest need, those with the most severe conditions, and those with the lowest quality of life. The *cost-effectiveness principle* provides that when choosing between different services or interventions, one needs to strive for a reasonable relationship between costs and effects, measured in terms of improved health and quality of life [7].

During the evaluation we have defined crowding out effects as *situations where lower priority patients are given care before patients who have a higher priority* [5].

Crowding out effects may occur due to several reasons and at different levels. A distinction between three types of crowding out effects can be made: a) crowding out of other parts within the care process for the same patient, b) crowding out within the same group of patients, and c) crowding out of other care among patients outside the cancer pathways, both vertically and horizon-

tally. Crowding out within the first group may occur because of the SCP program as it only covers one part of the care process [3].

By analysing information from implementation plans, meetings, surveys and interviews, we have found some main areas to follow regarding risk for crowding out effects [3]. Different professionals interpret the concept of crowding out effects differently; for example, staff working close to patients express greater concerns about crowding out effects than those with a distance to the patient. Furthermore, a diagnostic procedure is considered to be a risk area due to limited resources and a shortage of specialists. Some also mention organisational challenges as a risk when organisations try to fulfill the criterion of the SCP, which could lead to the crowding out of other patients. Finally, the pace of the implementation process program is reported to cause a risk for crowding out effects as, for the moment, nearly 30 SCP are implemented within a few years.

In general, we have found that a majority of respondents view the program positively. The fear of crowding out effects is mainly focused on some diagnostic procedures or due to the risk of unnecessary examinations carried out [3]. It is not yet clear whether this focus on actions, programs, and resource allocation for several years of cancer care have influenced other care areas negatively.

6. Conclusions

Preliminary findings suggest that the waiting times shortened for patients referred to SCP for the first five pathways in the program. The long-term effects are, however, uncertain at this point.

Patients seem in general positive about improved transparency and information of their care process. However, far from all patients have so far been referred to SCP due to e.g. comorbidity. Moreover, other system related factors have caused challenges, for example the role of primary care, and communication gaps between primary and specialist care. The impacts of these aspects might have been underestimated in the design of the program.

The evaluation up to this point in time also revealed that local circumstances and engagement at both the meso- and micro-level are essential to ensure sustainable improvements. Moreover, engagement and cooperation among primary care physicians and other specialists is crucial.

Despite these and other challenges, the prospect of impact looks promising due to broad stakeholder engagement and a willingness to increase learning and cooperation among different levels of the system.

Conflicts of interests

None to declare.

Authors’ contributions

First author (IS) was the project manager during the second year of the evaluation at the National Board of health and Welfare. All five authors (IS, FN, TD, JT and CC) have contributed to the evaluation design and to the content of the manuscript. The last author (CC) was participating in the start-up and the overall design of the evaluation project.

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