

Act without impact

Assessment of the Swedish Patient Act
2014–2017



Summary

BACKGROUND AND PURPOSE

The Swedish Patient Act came into force on 1 January 2015. The overarching purpose of this act is to strengthen and clarify the position of the patient and further promote the patient's integrity, self-determination and participation. Many of the obligations featuring in the Patient Act already apply under other statutes, some have been amended, but there are only a few new obligations in this act.

The Swedish Agency for Health and Care Services Analysis has been commissioned by the Government to monitor the implementation of the Patient Act. The monitoring shall shed light on whether, from a citizen and patient perspective, this legislation has the desired effect. The monitoring was carried out during the period 2014-2017. In keeping with this assignment, we have already published two earlier sub-reports. The first sub-report indicated the baseline position prior to the Patient Act coming into force and highlighted the actions that were implemented at the time. The second sub-report identified obstacles and success factors affecting the introduction and impact of the Patient Act. The following final report examines whether and how the Patient Act strengthens the position of the patient and presents an overall picture based on the previous sub-reports.

DESCRIPTION OF PROCEDURE FOR COMPILING THE FINAL REPORT

With a view to answering the question about whether the Swedish Patient Act has had an impact in terms of strengthening the position of patients, we have approached the issue in this report from two angles: one is the patient's actual position and the other is the patient's legal position.

- We use the term "actual position" to describe what patients consider that they actually benefit from the health care service in the form of participation, influence, information etc.
- We use the term "legal position" to describe what patients are entitled to expect from the health care service by law and how this can be ensured.

The division into the patient's legal position and the patient's actual position forms the basis for our analysis of the patient's position, where the legal position also affects the actual position.

The assignment has been carried out using an extensive set of methods and sources. Monitoring the patient's actual position has been based on the patients' perspective. The analysis is based on two comprehensive questionnaires completed by patients, legal guardians or children and ordinary citizens. The questionnaires have been repeated the year before and after the Patient Act was introduced. The responses provided information regarding their experience of whether the health care services were operating according to the Patient Act at the time of the questionnaire. The survey questions are based on the various chapters and provisions in the Patient Act. They reflect both the direct wording from the legal text and the legislator's intentions with the act. We have also used other sources, such as national statistics or results from other questionnaires, where this has been possible, and we have considered them relevant for the purposes of comparing and validating the results on specific questions.

The legal position is affected by a series of factors. One factor is how the provisions appear in the Patient Act and other adjoining legislation, primarily the Swedish Health care Act and Patient Safety Act, especially as the Patient Act refers to provisions in these laws. As a part of our analysis and assessment of the patient's legal position, we have evaluated provisions in the Patient Act (and the provisions to which the Patient Act refer), using a number of criteria based on legal research. In this report we answer various questions, including what type of control the provision provides (for example, whether it involves direct content management or more indirect control using overall targets for organisations) and whether responsibility for fulfilling the obligations is clear. We have also carried out a comparative analysis of patients' legal position in Sweden, Norway, Finland and Denmark, based on the Patient Acts in these countries.

RESULTS AND CONCLUSIONS

Our main conclusion is that the patient's position has not been strengthened since the introduction of the Swedish Patient Act.

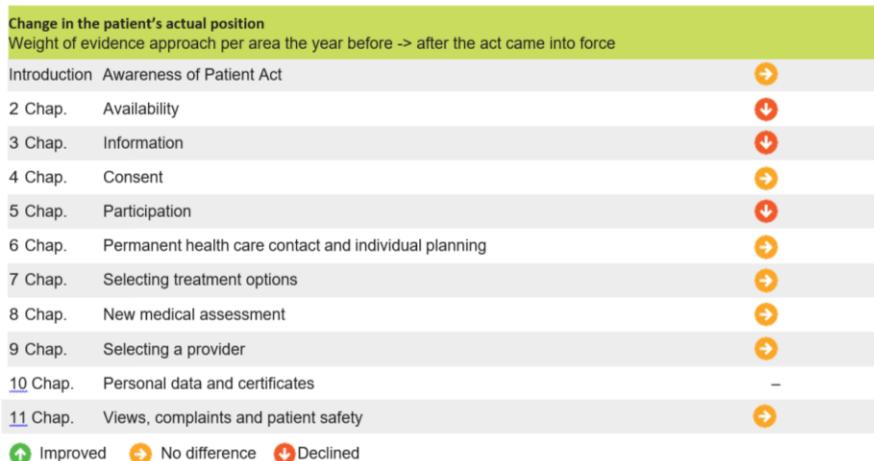
There is nothing overall to indicate that the patient's position has improved since the Swedish Patient Act was introduced. Therefore, the purpose of the act has not been achieved yet. The metrics we calculated before and after, based on the patients' experiences, indicated that the patient's *actual* position is unchanged or weakened. The analysis also shows that the patient's *legal position* is weak, especially in light of how the framing of the Patient Act.

Summary

It may seem unreasonable to expect results just two years after the act came into force. However, most of the obligations have been in place for a considerably longer time, indicating that there has previously been a lack of compliance.

We cannot detect any pooled improvement in the patient's actual position in any of the areas covered by the Patient Act

The outcome of our weight of evidence approach to the change in the patient's actual position is illustrated in the figure below. The assessments are based on an analysis of statistically significant differences in patients' experiences in 2016 compared with 2014. The provisions concerning the selection of assistance aids (part of Chapter 7 of the Patient Act) and personal data and certificates (Chapter 10) have not been dealt with in this report and are therefore not included in the assessment.



Our analysis also indicates that the patient's actual position, seen from the patients' perspective, has been weakened in a number of areas. This applies to accessibility (Chap. 2), information (Chap. 3) and participation (Chap. 5). One factor, which probably affects all the results, is that there is still a low level of awareness about the Patient Act. Regarding several of the provisions featuring in the Patient Act, which we have examined, we can also see, based on international comparisons, that Sweden is low down in the rankings. This relates, for instance, to issues about information and accessibility and is the case over time.

Remaining lack of awareness

The proportion of persons who are familiar with what obligations the health care service has towards them, according to our survey, has not increased since the introduction of the Patient Act. This is true for both patients and the public. The level of awareness of the law is also still low among health care staff.

Patients do not feel that their information needs are being met

A smaller proportion of patients feel that they have received sufficient information and/or relevant information at the right time in their dealings with the health care service. A smaller proportion also feel that their relatives have received information when they need it, in cases where the patients have not been able to receive it themselves. There is also a smaller proportion of patients than before who feel that those who have provided the information have made a point of ensuring that they as a patient/relative understand it. The provisions of the Patient Act concerning the information, which patients should receive, have not been effective. It is more the case that this type of information has decreased.

Accessibility has decreased

Patients feel that there is poorer accessibility to the health care service in different respects. Fewer patients feel that it is easy for them to get to see health care staff when required or that it has been easy to get in touch or gain access to treatment. Patients also think that efforts to achieve the targets based on the National Guaranteed Access to Health care in Sweden have eased off, mostly with regard to guaranteed visits in the primary care sector. This actual trend, seen from measurements of waiting times taken nationally according to the guaranteed access scheme, also indicates a worse performance in terms of achieving the targets for this period. Patients' access to primary care can be improved through the extended opportunities, which are now available to look for and get treatment online. Even with this possibility, we still cannot detect a positive impact on accessibility overall.

Patients do not feel that the health care services are seeking their participation

Furthermore, a smaller proportion of patients feel that the health care services are seeking and welcomes their participation. Patients' wishes to be more involved are also confirmed by other studies. Patients also think that they have been given a somewhat lower level of support by the health care service in adapting the self-care they provide to themselves to their individual needs.

The option to freely choose outpatient care in another county has not had a considerable impact

The results from our patient survey indicate that a somewhat lower proportion

of patients knew about the option to seek outpatient care in another county. Among the patients who sought treatment in another county there are significantly more than before who feel that they have received the practical help they need.

Analyses of the actual changes to inter county care in the primary care sector and in the specialist outpatient sector also indicate that no major changes occurred after the Patient Act came into force.

Inadequate conditions affect the likelihood of a patient seeking treatment in another county

Apart from the potential obstacles posed by the geographical, administrative and economic aspects, there is no national easily available information, which enables patients to compare the choice of care available and its quality. There is also a lack of clarity regarding the varying rules on referrals. There are still activities that in fact require a referral, even though the county council's official standpoint is that they do not apply referral requirements.

We have identified three main explanations to the results

1. The patient's legal position is still weak

An initial explanation as to why the patients' actual position has not been strengthened is that the patient's legal position remains weak.

The Patient Act is largely based on a framework law model and many provisions with equivalent content have been available for a long time in other laws, mainly the Health care Act and Patient Safety Act. In individual cases, mainly when it relates to the patient's options to choose a provider of publicly financed outpatient care, the Patient Act has contributed to strengthening the legal position.

The major shortcomings in the patient's legal position are the combined lack of clarity in the legislation (the obligations are not expressed precisely, nor do they have a clear target recipient) and lack of supervision, control or other type of monitoring of compliance with the legislation. There are no legal rights involved either, which means that the patient, with a few exceptions, does not have the right to appeal before a court of law. These shortcomings were present earlier and remain with the Patient Act.

Compared with Norway, Finland and Denmark, the patient's legal position is weaker in Sweden. For example, patients in Norway may invoke certain rights (e.g. right to choose a hospital, right to information and participation in decisions and treatment) before a court of law.

It should also be noted that EU law grants, in certain respects, more far-reaching rights than the Swedish Patient Act. The EU's provisions on patient mobility between states is fundamentally different from patient mobility in Sweden as stipulated in the Patient Act. The free choice of provider in Sweden is governed by the county council's referral rules and there is no equivalent way for patients to assert their "right" if a care provider or county council obstructs or hampers the free choice of provider in outpatient care.

The lack of any clear responsibility, supervision, control and monitoring of compliance with the Patient Act is, in our assessment, a factor contributing to the fact that the Patient Act has not influenced behaviour in the health care service in any noticeable way.

2. There are shortcomings in the health care service's conditions for applying the Patient Act and strengthening the patient's actual position

A second explanation as to why the patient's actual position has not been strengthened is that the health care service has not yet created adequate prerequisites for enforcing the Patient Act and, in turn, strengthening the patient's position.

Our overall analysis shows a number of factors that are particularly vital to the patient's actual position being affected positively and for the law to be complied with to a greater extent. Briefly, these factors are as follows:

- Culture which promotes the patient's position
- Awareness of the Patient Act and provision of information to patients
- Control and management which gives priority to the patient's position
- Knowledge support and specific tools for applying the act
- Monitoring of how the health care service promotes the patient's position and the effects
- Digitisation, which helps to strengthen the patient's position.

These prerequisites are not connected to the patient's legal position, but may be affected by a stronger legal position for the patient. We consider that the extent to which the health care service manages to create these prerequisites greatly affects the impact of the Patient Act. Even though there have been many provisions with the same content around for a long time in other legislation, our analysis shows that improvements are required when it comes to all of these factors.

3. The efforts at both national and local level in relation to the introduction of the Patient Act and period after this have been inadequate

A third explanation for the fact that the patients' actual position has not been strengthened since the introduction of the Patient Act is that the efforts which have been made at county council, municipal and national level have been fairly limited overall in relation to the whole Patient Act.

These efforts have also been focused, in terms of time, on the introduction of the act. The lack of improvements in the patient's actual position, viewed from the patients' perspective, confirms this situation.

The *State* has not adequately used supplementary means of control to strengthen the impact of the Act and simplify its introduction and enforcement. As we have described in detail in the second sub-report, some county councils carry out more strategic activities with regard to the patient's position and have successfully integrated efforts promoting the Patient Act with ongoing development activities. However, the overall picture is that the efforts of the *county councils*, besides information campaigns, have mainly been characterised by the "administrative management" of the inter county care, while the patient's position does not seem to have made any clear impression on the way the health care service is controlled and managed. A good one in 10 municipalities has not run any campaigns at all in connection with the introduction of the Patient Act, nor any kind of information campaigns aimed at staff.

Considerations on recommendations

Our analysis indicates that the patient's position in the health care service has not been strengthened since the introduction of the Swedish Patient Act.

The short period of time does not explain the shortcomings

Our monitoring of the Patient Act's impact was carried out for just two years after the act came into force. This period may be regarded as too short to be able to see any positive results. But many of the obligations have been in place for a considerably longer time than that. If the health care service has been dealing with these issues over the long term, the introduction of the Patient Act should have at least contributed to a slightly positive *trend*, given that the introduction drew a relatively large amount of attention to these issues.

Increased expectations are likely to result in less confidence in the health care service

There is probably a movement towards a culture in the health care services promoting a stronger position for patients. A movement, to which so-called “megatrends” in society contribute. An example of this is the increasing digitisation and accessibility to information. This helps raise the level of health literacy (increased access to, understanding and use of information), but also the expectations and demands that health care activities and services must be like those in other sectors. This may mean that, in the future, it will be taken for granted that patients will be involved in their care, resulting in the decline of a paternalistic approach. However, there is a risk with this trend that a growing gap may also arise between the health care sector and other sectors in terms of expected and actual services, based on the “customer’s” needs, which can further reduce confidence in the health care service.

There is good reason then for increasingly focusing on the relationship between expectations and confidence and for strengthening citizens’ and patients’ trust in the health care service.

A strong position for some patients is likely to increase inequalities in the health care service

Furthermore, we consider it a risk if the provisions of the Patient Act is not implemented in a systematic manner for the benefit of all patients, and if the development in this area is pushed by well-off and well-informed patients, who are the most able in terms of becoming actively involved and “demanding their rights”. Therefore, the fact that county councils are not fulfilling their obligations under the law in a systematic way is likely to put less well-off groups of patients at a disadvantage and fuel increasing inequality within the health care service.

The move towards digitisation may mean that such inequality will increase between the groups who can utilise the opportunities which digitisation brings and the other less affluent groups. In this regard, it is important for the health care service to take responsibility for all patients. Viewed from this perspective, the affluent groups who contribute more themselves to health care can create more space and resources for the less affluent groups. It is also important that there is a pressure on the health care service to meet these megatrends so that it is not merely left to the patients themselves.

Strengthening the position of the patient needs to become part of the health care service’s overall development

The introduction of the Patient Act is not considered to have had an impact on the county council’s strategies or approach to any greater extent. We think that the effort aimed at strengthening the position of the patient needs to become part

of the health care services' overall development. One way of doing this is for it to be highlighted at management level as an integrated part of increasing patient safety, quality development and efficiency. Ensuring a stronger position for patients is not a "cost" but is *part of the solution* to the challenges the health care services are facing.

**THE SWEDISH AGENCY FOR HEALTH AND CARE SERVICE ANALYSIS
RECOMMENDS A COLLECTIVE STRATEGY FOR STRENGTHENING THE PATIENT'S
POSITION**

The Swedish Agency for Health and Care Services Analysis has been commissioned by the Government to present recommendations to the Government, local authorities and health authorities on how the legislation's impact and intentions should be consolidated further. Following on from the analysis above, we believe that further action is required for the purpose of the Patient Act to be achieved.

We consider that a collective strategy is needed to strengthen the patient's position. The strategy needs to create the necessary pressure for change and remedy the shortcomings we see as explanations as to why the Patient Act has not already helped strengthen the patient's position.

The strategy should comprise two parts, implemented in parallel or in connection with each other:

- Strengthening the patient's legal position
- Stepping up the health care service's efforts to ensure the impact of the Patient Act

Furthermore, the strategy needs monitoring, and an ongoing strategic dialogue is needed on how the adaptation process in the health care service can be speeded up and the patient's position strengthened.

Strengthen the patient's legal position

- *We recommend that the Government initiate a global review in order to strengthen the patient's legal position.*

We think that some of the following basic points should be part of such a global review:

- *Make it clear what the obligations are and the responsibility for fulfilling them*

The provisions in the Patient Act and adjoining provisions in the Health care

Act (1982:763) and Patient Safety Act (2010:659; PSL) should be clarified. This means clarifying:

- *The content of the obligations*, i.e. providing assistance with interpreting the provisions and putting them into practice using examples and case descriptions.
- *Who is responsible for fulfilling the obligations*, i.e. assistance with explaining who is responsible for what and how this responsibility can and should be shared where there are several recipients involved.

- ***Ensure monitoring of the Patient Act's application***

A global review aimed at strengthening the patient's legal position should also include appropriate monitoring of compliance with the Patient Act. We argue that the provisions in the Patient Safety Act give the Social Care Inspectorate responsibility for performing regular systematic monitoring of the Patient Act's application. However, requirements for prioritising the focus of the monitoring through legal amendments or in some other way should be considered further.

- ***Increase the care providers' reporting on self-monitoring in terms of the patient's position***

A review should also examine possible initiatives for increasing the care providers' self-monitoring with regard to the Patient Act's provisions. These new requirements may be influenced by the requirements which already exist for self-monitoring in the area of patient safety, related to the patient safety reporting requirements in the Patient Safety Act.

- ***Consider new complaint handling options***

A global review should also involve examining whether it is appropriate to grant patients access to an individual examination in the event of a complaint concerning compliance with the provisions of the Patient Act. There is good reason to monitor the impact of the new complaint system, including from this perspective, and to consider whether patients, on the other hand, should be entitled to contact the Health and Social Care Inspectorate also when breaches in terms of compliance with the Patient Act's provisions are involved.

Step up the health care service's efforts to increase the impact of the Act

► ***We recommend the health authorities to step up their efforts to increase the Patient Act's impact and strengthen the patient's position.***

We consider that some of the following basic points should be part of such actions.

- *Increase awareness among patients and staff and find a new way to provide information*

The health authorities should introduce new ways of informing the public, patients and staff about the Patient Act. Increasing awareness among patients will also increase the requirements for the health care service to comply with the Patient Act. One basis for making an impact is that care staff themselves are informed and are sufficiently aware of the act.

- *Improve the information provided to patients*

Patients should be given better tools to enable them to participate more and become more involved in their care. This mostly involves providing access to information and guiding patients correctly, when they are looking for information, but also enabling patients themselves to share their information with the health care service to a greater extent.

This also raises the need to further develop sources of general information (such as information about the choice of care, referral rules and quality), whereby nowadays it is resource-intensive for patients and care staff individually to search properly for this type of information. Both work methods and specific tools are also required to support practitioners when it comes to providing patients with individual information.

- *Develop monitoring of the patient's position*

Health authorities should develop a system for monitoring compliance with the Patient Act on an ongoing basis. It is important that the monitoring process is transparent and that the results can be broken down at clinical or another equivalent level. Patients, relatives and user representatives should also be given, to a greater extent, the opportunity to participate in the design, implementation and analysis of the monitoring process.

- *Implement, develop and distribute knowledge support and specific tools*

Health authorities should make better use of the different types of knowledge support that are available and convert them to procedures or other practical tools that can be used in the health care service. The work methods deployed in the health care service also need to be changed in line with the procedures. It is also important to look for new types of knowledge support and procedures or produce them when there is none. Health authorities should also make better use of and distribute the many existing good examples of development work that includes the patient's position. The existing forums are in this area can be used for this purpose.

- *Prioritise the patient's position in the health care service's control and management procedures*

A strong position for patients should be made a priority at every level in the health care sector's control and management activities.

Development efforts to promote the patient's position should be sought and initiated and the results should be monitored. Health authorities should establish clearer control and incentives for health care organisations to prioritise activities promoting change, aimed at fulfilling the intentions of the Patient Act. This relates to everything from designing the procurement procedure to how to create incentives through contractual approaches, remuneration and monitoring.

- *We recommend that the State and health authorities develop basic and advanced training courses in areas such as the position of patients.*

- *Prioritise the patient's position in training courses*

The *State* (higher education establishments) should ensure that health care training courses include sufficient training on the legislation and knowledge for strengthening patients' position, general management and change management. *Health authorities* should offer ongoing courses, seminars and/or advanced training in equivalent areas (legislation and knowledge for strengthening patients' position, general management and change management) for different groups of staff within the health care service. This type of in-service training should not just be optional to attend, but should rather be targeted at strategically selected groups of staff.

Initiate long-term monitoring and strategic development of the patient's position

We consider that the implementation of a collective strategy will continue for a long time in the future and that it will be necessary to develop an ongoing and recurring assessment of the patient's position and the impact on patients and the health care system as a whole.

- *We recommend that the Government initiate long-term monitoring of the patient's position and an in-depth dialogue with health authorities about the health care service's development.*

- *Monitor and assess the strategy*

The Government should initiate regular monitoring of the patient's position. This includes providing feedback to health authorities and organisations with

opportunities for making comparisons and public reporting of the results and differences in terms of compliance with the Patient Act.

The Government should also consider how to generate and distribute more knowledge on the *impact* of a stronger position for patients and on working with the specific provisions of the Patient Act.

- *Initiate dialogue with the health authorities about strategic development*

The Government should initiate dialogue with the health authorities on strategic development in the health care sector. Part of this should include how a collective strategy can be implemented to strengthen the patient's position. Patients and users should participate in the dialogue about how the patient's position can be strengthened as part of the health care service's overall strategic development.

FINAL REFLECTIONS

If it transpires that the patient's situation is not being strengthened, in spite of the increased efforts to do so, for instance in the form of a collective strategy, which we are proposing, additional steps need to be considered. We have considered that it is too early to submit such more far-reaching recommendations, but, as part of our final reflections, we would still like to raise some further conceivable measures for consideration.

- *Consider introducing in the long term a “rights” concept and certain legal rights*

We argue that there is reason for the Government to consider in the long term whether it would be appropriate to modify the terminology in this area. As part of jurisprudence, the current obligations are regarded patient rights, even if they are not regarded legal rights. Using the terms as understood in jurisprudence could push for a change of perspective within the health care services to where the patient's influence and participation will be taken for granted. The pros and cons of changing the terminology like this need to be considered. It might also be considered whether it is appropriate to introduce additional legal rights in the health care sector in certain respects.

- *Consider introducing in the long term sanctions for breaching compliance with the Patient Act's provisions*

We argue that in the long run there may be reasons to consider whether it is appropriate to *expand* the current sanction system in the health care sector to include some of the provisions in the Patient Act. Such an expansion could include both actions aimed at care providers and at health care staff, but obviously needs be considered with caution.