

Summary

A Greater Patient Perspective in Healthcare
– Are National Guidelines a Method of
Achieving This? (RiR 2013:4)



DATE: 05-04-2013

A Greater Patient Perspective in Healthcare – Are National Guidelines a Method of Achieving This?

The Swedish National Audit Office (NAO) has audited whether the state's governance through national guidelines is able to effectively promote a patient perspective in healthcare. The national guidelines are one of the state's primary instruments for affecting health and social care on several levels. The Swedish NAO's comprehensive conclusion is that the state can use national guidelines in order to promote patient-centered and effective healthcare.

Background to the audit

The background to the audit are the requirements for improved efficiency that the development of society places on the healthcare system. The Swedish healthcare system constitutes a significant and increasing proportion of GDP. At the same time, the opportunities to expand public finance are limited, which puts increased emphasis on improving efficiency. Research shows that patient-centered healthcare leads to improved care outcomes and reduced societal costs. Thus, by promoting care that is more patient-centered, the state also promotes more efficient healthcare.

The state has implemented a number of interventions which aim to strengthen the patient's position, for example via legislative changes, targeted reforms and the establishment of the Swedish Agency for Health and Care Services Analysis. However, several studies indicate that there are still deficiencies with regard to patient centeredness in Swedish health and social care.

The text of the Health and Medical Services Act is explicit that care has to be patient-centered. For example, the act stipulates that care has to be easily accessible, coordinated, built on respect for the patient's self-determination and confidentiality and provide the patient with the opportunity to choose treatment options. Thus, a reasonable starting point is that the state should promote patient-centered care in all governance.

The state has several instruments that have an impact on the shape of the healthcare system to bring it in line with the legislation. Of these, national guidelines can impact health and social care on several levels: not only organisation and priorities, but also the tangible situation in which patients and service users interface with the health and social care system. The guidelines aim to make the healthcare system prioritise its resources effectively and in accordance with the Health



DATE: 05-04-2013

and Medical Services Act's (HMSA) requirements for good care. Consequently, the guidelines may be an important method for promoting patient-centered care.

The audit's findings

The Swedish NAO's audit indicate that each of the national guidelines contain dimensions that take into account the patient perspective. At the same time, several guidelines lack one or more important dimensions of the patient perspective. The audit also indicates that the work to draw up guidelines can be improved through expanding the knowledge base and clarifying the role of patient advocates. The Swedish National Board of Health and Welfare (SNBHW) can also work more effectively to support the implementation of guidelines and to follow up how the national guidelines recommendations are carried out in the care system.

The Swedish NAO's comprehensive conclusion is that the state can use national guidelines to promote patient-centered and effective care. This requires that each chain in the work with guidelines is based on a patient perspective and that the guidelines reach and are used by the intended recipients.

In the following, the Swedish NAO reports its conclusions and recommendations based on the observations from the audit.

The guidelines lack important recommendations from the patient's perspective

The Swedish NAO's analysis of the content of the guidelines indicates that each of the national guidelines has recommendations with a patient perspective, but that this varies greatly between the different guidelines. These variations can partly be explained by the guidelines being concerned with activities and research areas that differ from one another. The analysis also indicates that the proportion of recommendations with a patient perspective is considerably smaller if only accounting for the recommendations that have been ranked highly by the SNBHW.

Only three guidelines have recommendations for every dimension of the patient perspective, the other guidelines lack one or more of these dimensions. Of a total of 2,700 recommendations, there are only twelve that aim to make care more accessible for patients and service users. This picture is confirmed by several patient and service user advocates, who argue that the guidelines should be able to send a clearer signal to the care system about the importance of a patient perspective.

The guidelines objectives and aims are not specified clearly

The guidelines have been developed from a tool for the professions to evaluate the effects of various treatment methods into a strategic tool for the state to have an impact on the way that care is organised and prioritised. This can be an underlying cause for the various interpretations that the stakeholders have of the objectives, aims and target groups of the guidelines. The various stakeholders view on what the guidelines can be expected to achieve is of key significance to how the guidelines are designed.



DATE: 05-04-2013

Patient and service user advocates have an unclear role and function in the work with guidelines

Patients and service users have an unclear role and limited access to the work with guidelines and thus have a low level of real influence. They are included primarily with the aim of firmly establishing the guidelines and their knowledge and experience is not made use of in a systematic way. There is a lack of a well thought out idea of what role and function the patient and service-user advocates will have in the work with guidelines and there is also a lack of a model for making use of the patient and service user advocates' knowledge and experience.

The international network G-I-N (Guidelines International Network) emphasizes that successful patient participation requires a well thought out understanding of that the advocates will bring to the work. A description of the role is needed, one which clarifies the aim, time required and expectations. International experience has also indicated methods for and good results from including representatives of patients and relatives in the work with guidelines. G-I-N advocates that patients and relatives should have a similar role to that of other experts. This means that patient representatives should be tested for conflicts of interest in the same way as other experts.

The knowledge base is limited in the work with guidelines

The Swedish NAO's audit indicates that the SNBHW's application of the model for knowledge evaluation is a barrier to achieving a broader patient perspective in the guidelines. There is lack of methods to capture and evaluate knowledge that is important to bringing a patient perspective into the guidelines.

The follow-up of national guidelines should be improved

The SNBHW have conducted five evaluations within the parts of the care system that the guidelines encompass. Three of these evaluations partly illustrate the guidelines' impact. That there are few evaluations can to some extent be explained by the methodological difficulties. The evaluations that have been conducted of the national guidelines do, however, indicate a relatively limited impact in the care system. This applies especially to primary care and health care activities where there are two responsible bodies or where the municipality has sole responsibility.

The Swedish NAO's analysis indicates that there are comparatively very few measures that specifically reflect the patients and service users' understanding of care quality. The recommendations in the guidelines (c. 2,700) are followed up with the help of around 300 indicators, of which only 20 are functioning indicators based on the experiences of patients and service users.

The state can take a clearer responsibility for supporting implementation

The Swedish NAO's audit indicates that the SNBHW can do more to support the organisations responsible for healthcare's implementation of the guidelines. The health care providers need clearer support in order to interpret how to prioritise the recommendations in the guidelines. The



DATE: 05-04-2013

SNBHW does not actively distribute the patient versions of the guidelines to patients and service users, which limits their opportunity to place demands on the health-care system.

The Swedish NAO's recommendations

If the starting point is that all state governance of the health-care system is to promote patient-centered care, this should also apply to national guidelines. The Swedish NAO's comprehensive conclusion is that the state can more effectively use national guidelines to promote patient-centered and effective care. This means that the elaboration process should be developed so that the content of the guidelines better reflects a patient perspective. This also means that interventions that aim to have the guidelines used as intended need to be developed. Producing and distributing materials that do not reach their intended recipients or come to use is not effective. The SNBHW should also conduct recurring follow-up of how the materials have been perceived and used by the recipients.

Consequently, the Swedish NAO submits the following recommendations:

To the Government:

- The Government should commission the SNBHW to develop a working method that emphasizes a patient perspective in national guidelines.
- The Government should commission the Swedish Agency for Health and Care Services Analysis to follow up the effects of national guidelines from a patient perspective.

To the SNBHW:

- The SNBHW should develop methods to broaden the knowledge base for national guidelines in order to better take into account the patient perspective. The SNBHW should also clarify the role and function of patient and service user associations in the work with guidelines. The SNBHW should make use of international experience in both of these respects.
- The SNBHW should take greater responsibility for national guidelines reaching their intended recipients. The SNBHW should also regularly follow up that the organisations responsible for healthcare and staff within the health and social care services understand and are use the guidelines as intended.



DATE: 05-04-2013

FACTS

The term *patient-centered care* aims at an approach that takes the *patient's perspective* into account.

The term *patient* refers in this report both to patients in health and medical care and to users of municipal social services. The terms *patient organisation* and *patient association* thus also cover organisations that represent users.

The SNBHW publish *national guidelines* for the more widespread diseases. The very first guidelines were published in 1996 and there are now twelve national guidelines. Each of the guidelines consists of a collection of publications that most often contains hundreds of recommendations for the health-care providers. They will indicate the benefits and risks of various measures.

