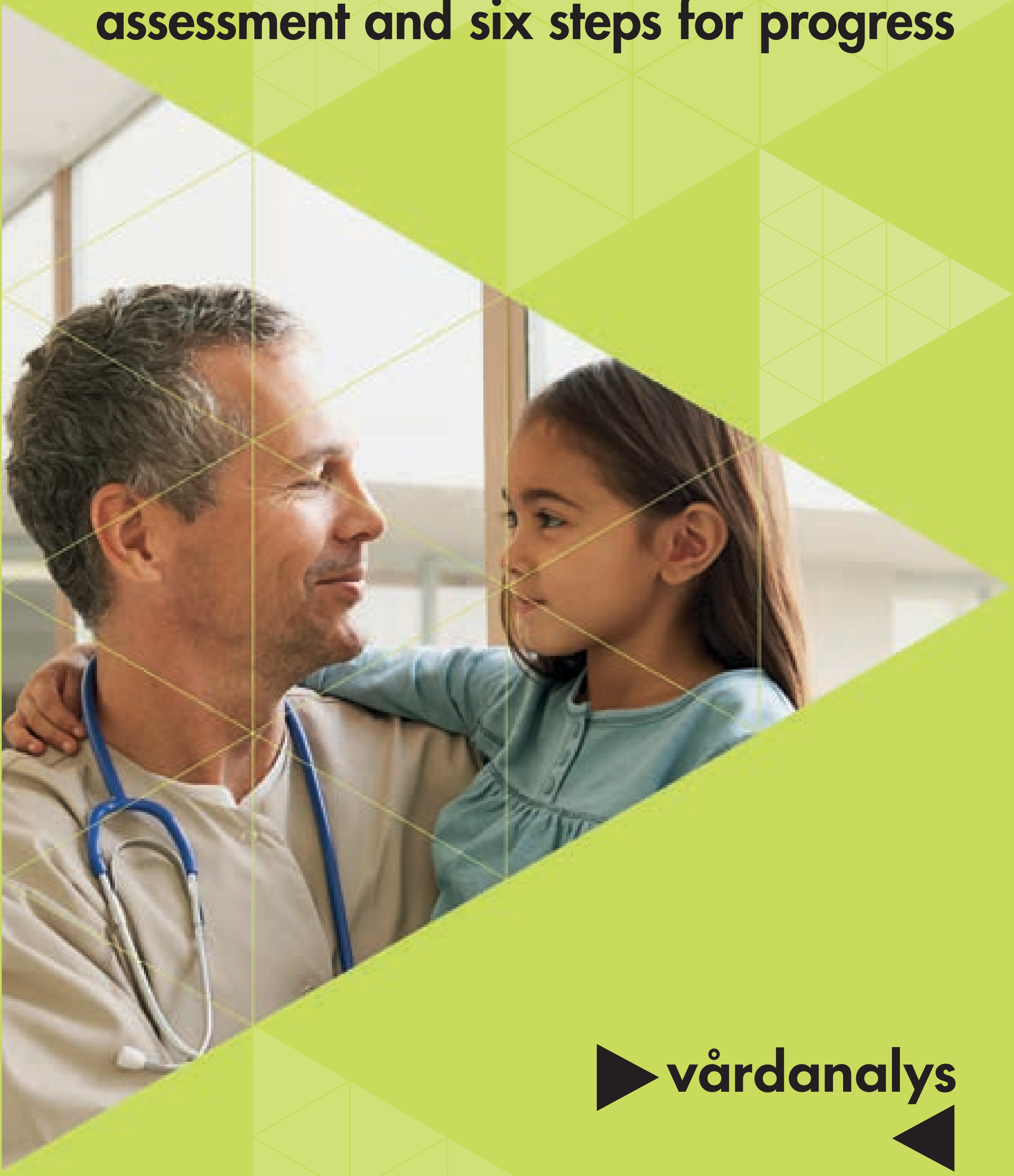
Report 2012:3 (highlight report)

Patient-centeredness in Sweden's health system – an external assessment and six steps for progress



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Patient-centeredness in Sweden's health system – an external assessment and six steps for progress

Elizabeth Docteur, Angela Coulter

HIGHLIGHT REPORT

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The Swedish Agency for Health and Care Services (Vårdanalys) is presenting the following ‘highlight report’, which has specifically been adapted for Vårdanalys seminar in Almedalen 2012. This highlight report presents the main results and conclusions from a study about patient-centered health care. The full report of this study will be published by Vårdanalys in September 2012. Since the highlight report is an excerpt from the full report, references are left out from the text, but a complete list of references can be found at the end of the report.

Foreword and acknowledgments

Today, patient-centered care is recognized as an important aspect of health care quality, but remains the least defined, conceptualized and explored. Strengthening the position of patients has been a stated policy aim in Swedish health care for more than three decades, yet we lack sufficient knowledge of the position of patients, and how we are making progress towards that goal. Against this background, the Swedish Agency for Health and Care Services (Vårdanalys) commissioned an external evaluation of patient-centeredness in the Swedish health care system.

The external study was charged to answer three questions:

1. What type of analytical framework can be used to assess the extent to which Sweden's health care system is patient-centered?
2. To what extent is Sweden's health care system patient-centered?
3. What changes in policy could help to strengthen the degree of patient-centeredness in Sweden's health care system?

Vårdanalys is honored that Elizabeth Docteur and Angela Coulter agreed to carry out the commissioned study.

Elizabeth Docteur is an independent health policy consultant with 20 years' experience of working to improve health care systems and programs through positions in the U.S. federal government, the international arena, the private sector and civil society. Previous roles include Deputy Head of the Health Division at the Organization for Economic Cooperation and Development (OECD), where she directed studies of health system performance and an assessment of the nature and impact of health policy reforms in OECD countries over 30 years, and Vice President and Director of Policy Analysis at the Center for Studying Health Systems Change.

Professor Angela Coulter is currently Director of Global Initiatives at the Foundation for Informed Medical Decision Making, Boston, and Senior Research Scientist at the Department of Public Health, University of Oxford. Previous roles include Chief Executive of Picker Institute Europe and Director of Policy and Development at the King's Fund. Professor Coulter has published more than 250 research papers and reports and several books including Engaging Patients in Healthcare (2011) and The Autonomous Patient (2002). In January the Donabedian Foundation at Barcelona University awarded her the 2012 Donabedian International Award in health care quality for her work on patient-centered care.

Vårdanalys is also grateful for comments on drafts of this report furnished by the study's expert advisors, all of whom are internationally recognized contributors to the field of patient-centered health care:

- Mats Brommels, Professor, Head of Department, and Director of the Medical Management Center, Karolinska Institute;
- Carol Cronin, Executive Director, Informed Patient Institute;
- Niek Klazinga, Professor, University of Amsterdam; and
- Ulrika Winblad, Associate Professor, Department of Public Health and Caring Sciences, Uppsala University.

Vårdanalys also wants to acknowledge the experts interviewed for this study, who gave generously of their time and knowledge to inform the evaluation and the development of recommendations for strengthening the system.

The two international experts have collaborated with Caroline Andersson and Therese Östh at Vårdanalys in carrying out the study. Vårdanalys has also engaged a reference group of Swedish experts and patient representatives who have contributed greatly to the work.

The study has been carried out by two experienced and leading health policy analysts and has followed a rigorous methodology specifically adapted for this rapid external evaluation (see Annex I: What we did). This type of study has distinct merits but also limitations. It provides an analytical framework, is data-driven to the extent possible, and benefits from the perspective of experienced external experts. Still, time limitations and lack of data dictate that the authors paint with broad strokes and ultimately have to rely on their experience and expertise to assess information and to form an opinion. Quite naturally, policy recommendations that emerge from this work should not been viewed as conclusive but rather as observations for further debate and exploration.

The results of this external evaluation will be presented in a full report to be published in September 2012. The present "highlight report" has specifically been adapted for Vårdanalys seminar in Almedalen 2012 and presents the main results and conclusions from the study.

Vårdanalys is very pleased to receive this highlight report and to share it with the interested public, stakeholders, as well as policy-makers.

We hope that this report can be of value in many ways, for instance by:

- providing an analytical framework through which the concept of patient-centeredness can be better understood and assessed;
- providing the viewpoints of external experts on the status of patient-centeredness in Sweden today; and
- offering worthwhile policy recommendations to stimulate debate and advance the policy agenda.

For Vårdanalys, the study is not an end-point but rather an important starting-point. The study will inform and direct our future work in this area. It will form the basis for consultative meetings on the topic of patient-centeredness and lead to several in-depths studies to bridge knowledge gaps, evaluate initiatives, and to further explore and refine policy options. Our intention is also to continue to develop the framework and carry out assessments and measurements at regular intervals – guided by the question "are we improving?"

Our overall and long-term aim is, of course, to contribute towards making Swedish health care truly patient-centered!

I would like to thank our two external evaluators for their excellent work, for an insightful and thought-provoking highlight report and am proud to hereby share it with all interested in making Swedish health care more patient-centered.

Stockholm, June 2012

Fredrik Lennartsson
Executive Director
Swedish Agency for Health and Care Services Analysis
(Vårdanalys)

A Framework for Assessment

In this study we present an analytical framework for assessment of patient-centered care, which consists of the following five dimensions:

- Empowering patients through information and education
- Respecting patients' needs, preferences and values as individuals
- Coordinating care across service providers and ensuring continuity of care
- Taking a holistic approach to patients as people with medical and nonmedical (i.e., social, emotional, and spiritual) needs
- Involving family and close friends in the health care experience, to the extent desired by the patient.

Assessment of Patient-Centeredness

The key findings of the assessment are:

- Sweden has made good recent progress in strengthening and improving legislation pertaining to patient information and education. Nevertheless, important gaps in information and education are evident, in terms of how well those efforts have paid off in patients' understanding and satisfaction with the information and education obtained.
- Sweden's health care system often fails to anticipate and respond to patients as individuals with particular needs, values and preferences. Failure to meet patient expectations can have demonstrable costs to patients, the health system and the public purse.
- Inadequate coordination of care across health-care providers is an important weakness in Sweden's health system. Such problems are likely to have a negative impact on health outcomes and costs, in addition to having a

negative impact on patient experienced quality of service.

- Some problems in taking a sufficiently holistic approach to patient care are evident, with relatively little variation in performance across counties.
- While evidence regarding the patients' experiences in involving family and close friends in their health care is relatively limited in depth and scope, available data suggests that there is room for improvement in this area. Several types of potential problems benefiting from further exploration were identified in the course of the present study.

Six steps for progress

Our policy recommendations for improving patient-centeredness in Sweden's health care are:

- Ensure compliance with existing legal obligations to strengthen patients' position
- Establish patients as full partners with their providers with a role in health and care decisions
- Engage and involve patients and their representatives in health policy and administrative decisions
- Sustain efforts to facilitate coordination and continuity of care
- Define a framework for assessment that reflects the priorities of Swedish patients
- Strengthen efforts to assess and track patient centeredness

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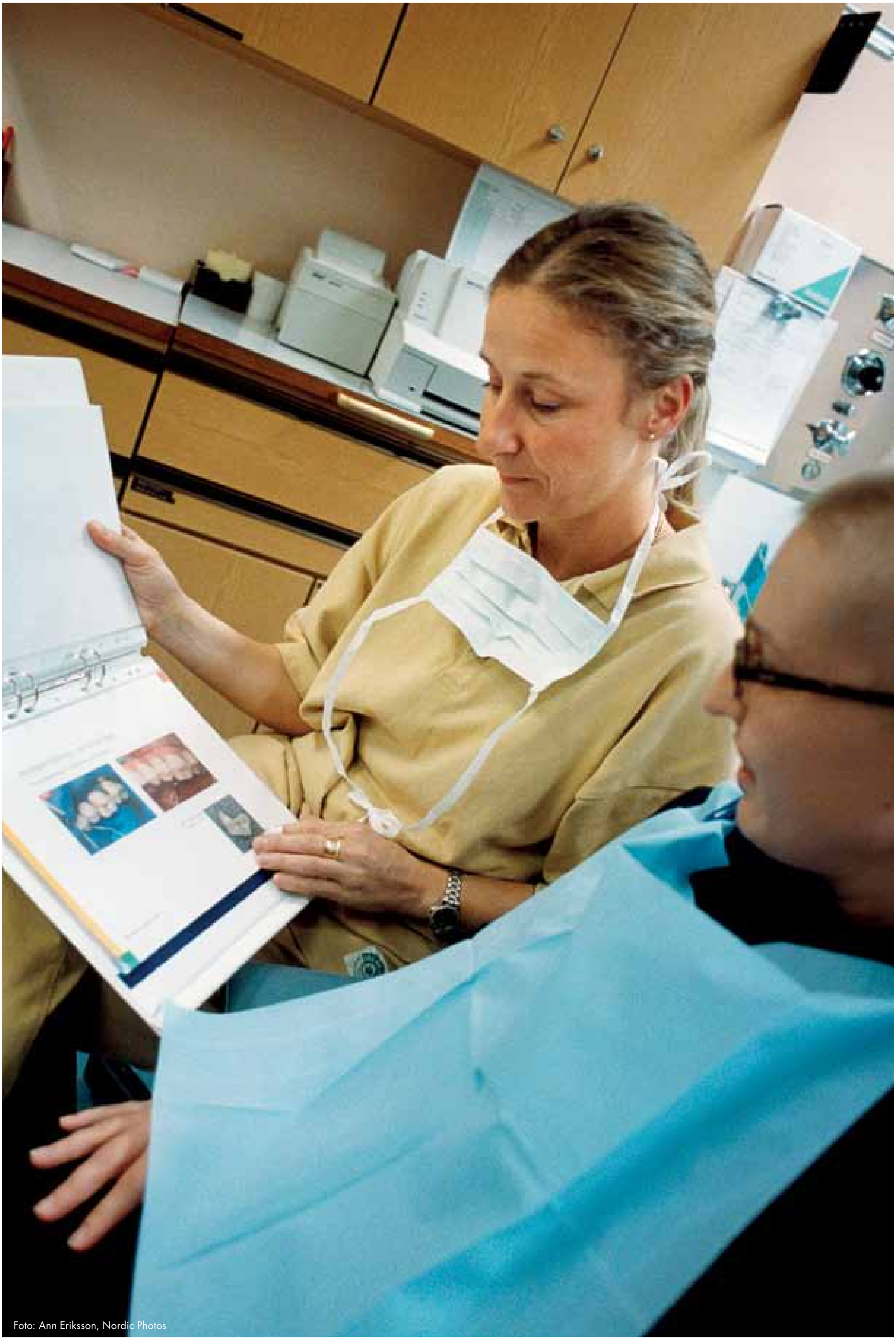


Foto: Ann Eriksson, Nordic Photos

1

Patient-centered care as a health system performance goal

Having health care and health systems meet the needs, values, and preferences of the users of health care services is increasingly recognized as a critical performance aim. A patient-centered health care system is one that is designed for, and operates on behalf of, the patients whom it serves. A number of different terms have been used to describe this aim, including “patient-centered,” “responsive,” and “person-centered”, each of these terms has been conceptualized in different ways by different users. For the purpose of the present study, we have adopted the term “patient-centered,” in deference to its emergence as preferred terminology in widespread use today, both within Sweden and internationally.

A growing body of evidence demonstrates that patient-centered health care produces better health outcomes and greater patient satisfaction. Although valuable in its own right, it can also produce savings to health systems and to society as a whole, through better patient compliance with prescribed treatments, quicker returns to work, and other avenues.

Policy makers are increasingly focused on patient-centeredness, with a number of countries, including Australia, Canada, the United Kingdom, and the United States having articulated policy goals pertaining to making their systems more patient-centered, monitoring performance and/or instituting reforms geared toward increasing the patient-centeredness of health care delivered in the country. International organizations interested in health-system performance, notably the World Health Organization and the Organization for Economic Cooperation and Development (OECD), have also adopted patient-centeredness as an aim for high-performing health systems and are working to measure and benchmark health systems according to the extent to which they meet this aim, as well as defining policies that can help countries improve their health systems in this respect.

Studies have documented shortfalls of health care and health systems in terms of patient-centeredness, some of which have garnered public attention and spurred actions by health policy makers and health care administrators geared toward making improvements. For example, findings from international surveys showing that about one-third of Swedish patients with significant health care needs reported problems due to inadequate coordination of their care, and that Swedish patients are among the least engaged by their primary care physicians and involved in their own health care decision-making, across 11 countries studied, have drawn both media coverage and popular attention in Sweden.

It is with these developments in view that the Swedish Agency for Health and Care Services Analysis (Vårdanalys), launched the present work geared towards assessing the degree to which Sweden's health system can be considered to be patient-centered.

Aim of the study

The aim of the study is to strengthen the position of patients by identifying how Sweden can obtain a more patient-centered health care. Its task was to answer several questions, namely:

1. What type of analytical framework can be used to assess the extent to which Sweden's health care system is patient-centered?
2. To what extent is Sweden's health care system patient-centered?
3. What changes in policy could help to strengthen the degree of patient-centeredness in Sweden's health care system?

To answer these questions, we examined the state of the art in conceptualizing and operationalizing models of patient-centeredness and selected a framework for assessment comprising five core dimensions used in leading international frameworks. We then applied the framework to assess how well Swedish health care presently can be characterized as fulfilling those dimensions, and explored what characteristics of the health system either facilitate or impede Sweden's progress in achieving a more patient-centered health system. Our main sources of input for this assessment included data from surveys on patients' experiences with the health system, original interviews with representatives of Swedish patients and other experts on Swedish health care, and a review of the academic and policy research literature. Finally, we developed a number of recommendations for possible avenues for accelerating and supporting progress toward a more patient-centered health care system.

Foto: Johan Hedenström, Nordic Photos

2

Our framework for this assessment: Five dimensions of patient-centered care

After undertaking a review of national and international efforts to conceptualize and operationalize a definition of patient-centered care, we concluded that there is, as yet, no standardized, internationally agreed model in place. Rather, there are a number of models in use, each specifying different conceptual dimensions.

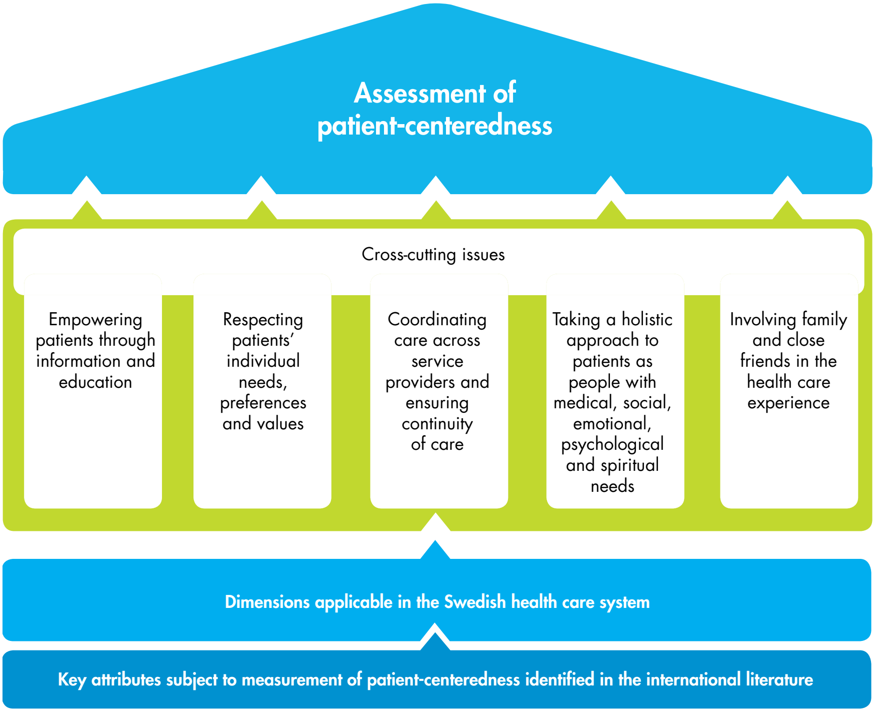
In the absence of a model developed according to the preferences and priorities of Swedish patients, and rather than make an arbitrary selection from among leading models, this study used a framework representing an amalgam of the common core elements present in nine prominent models identified and analyzed by Carol Cronin (2004).

Our study adopted the following five dimensions as a framework for assessment:

1. Empowering patients through information and education.
2. Respecting patients' needs, preferences and values as individuals.
3. Coordinating care across service providers and ensuring continuity of care.
4. Taking a holistic approach to patients as people with medical and nonmedical (i.e., social, emotional, and spiritual) needs.
5. Involving family and close friends in the health care experience, to the extent desired by the patient.

In addition to assessing these specific dimensions, we also sought to identify and describe issues that cut across these dimensions, with a particular emphasis on those facilitators or barriers to achieving a more patient-centered health care system in Sweden that are not unique to individual dimensions.

Our framework for this assessment: Five dimensions of patient-centered care



Five dimensions of patient-centered care. In addition to assessing these specific dimensions, we also sought to identify and describe issues that cut across these dimensions, with a particular emphasis on those facilitators or barriers to achieving a more patient-centered health care system in Sweden that are not unique to individual dimensions.

Foto: Lars Dahlström, Nordic Photos

3

Our assessment: How patient-centered is Sweden's health care?

Overall, our assessment revealed a number of shortfalls in terms of achieving patient-centered care in Sweden's health system. At the same time, we found evidence of progress in a number of areas. Also, the system benefits from a number of strengths that provide a good foundation on which to build when making necessary efforts to accelerate progress. Yet there are barriers that have impeded progress; tackling these can help to accelerate change.

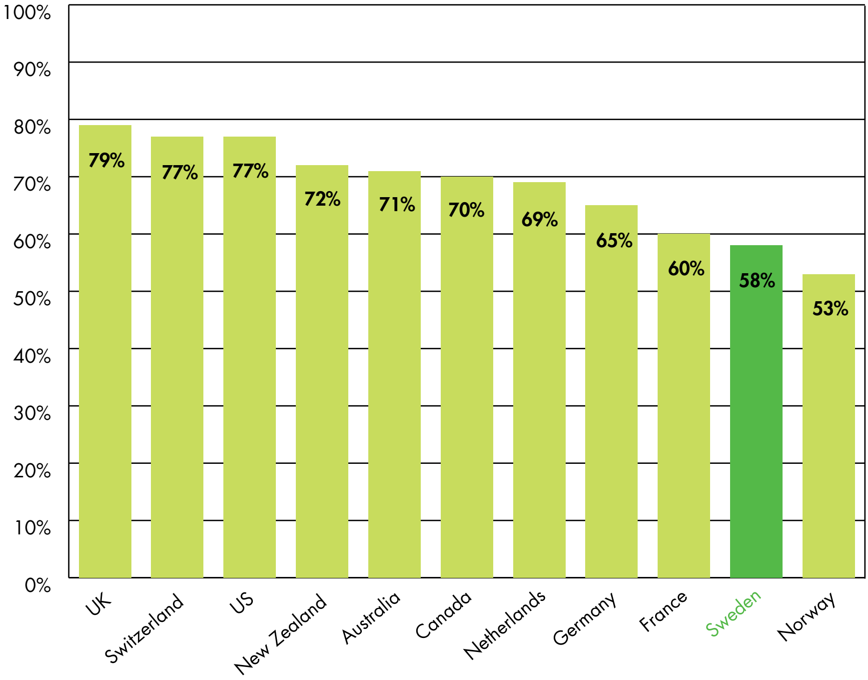
3.1. DIMENSION 1:
Empowering patients through information and education

▶ *Sweden has made good recent progress in strengthening and improving legislation pertaining to patient information and education. Nevertheless, important gaps in information and education are evident, in terms of how well those efforts have paid off in patients' understanding and satisfaction with the information and education obtained.*

Definition

A patient-centered health care system is one in which patients have access to the information needed to make good decisions about their health and health care, and which undertakes to educate patients about their conditions and their

Figure 1. Percentage of patients answering the most preferable answer on each question concerning information and education (unweighted index). *Source: IHP International Survey of Sicker Adults (2011). (For a description of the elements of the index, see Annex III.)*

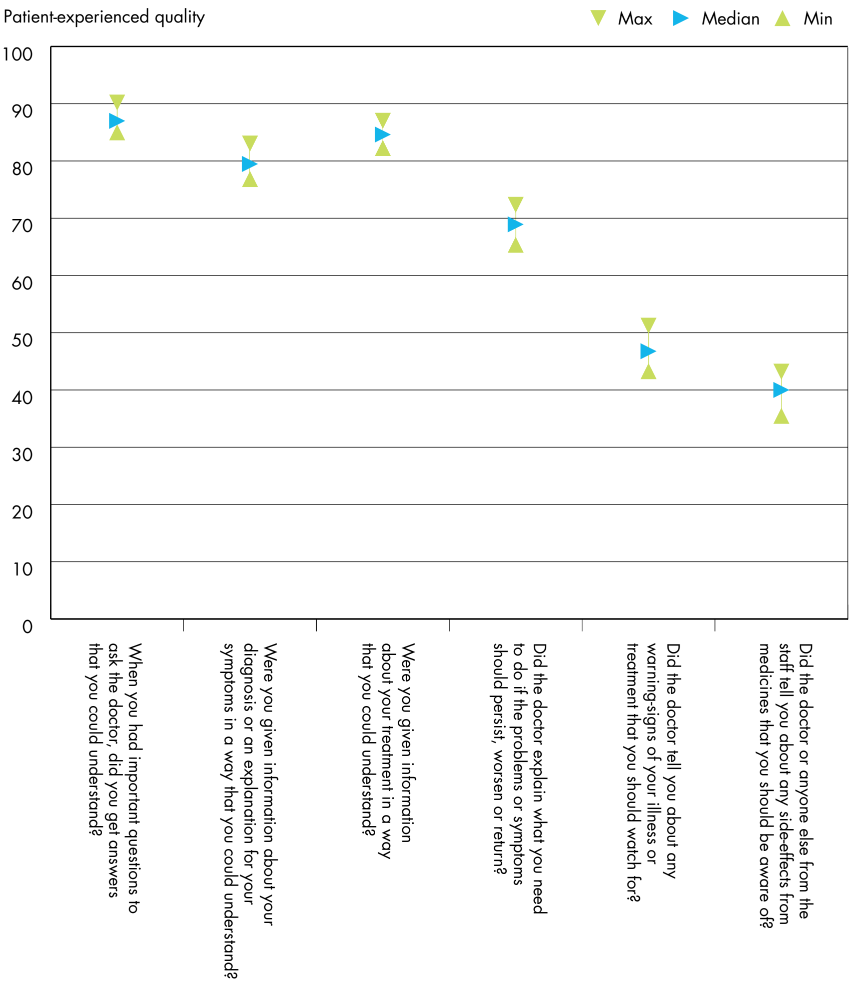


options for obtaining care. Better informed and educated patients are better equipped to actively engage with physicians as partners in their own health care.

Assessment

A number of national initiatives have been launched to improve information and education efforts pertaining to patients. For instance, Sweden's legal framework (Health and Medical Service Act 1982:763, Patient Safety Act 2010:659) establishes clear obligations for health care providers to provide patients with individually tailored information about their health condition and alternative treatments, about choice of provider and about the guarantee to obtain treatment within a specified timeframe. Also, a range of Internet-based information platforms geared toward patients have been developed. Notably, the 1177 health information portal, accessible via Internet and phone, is an increasingly used and appreciated resource among patients and the interested population at large. Furthermore, there are initiatives aimed at strengthening the patient in encounters with health care. "My Guide to Safe Care", produced

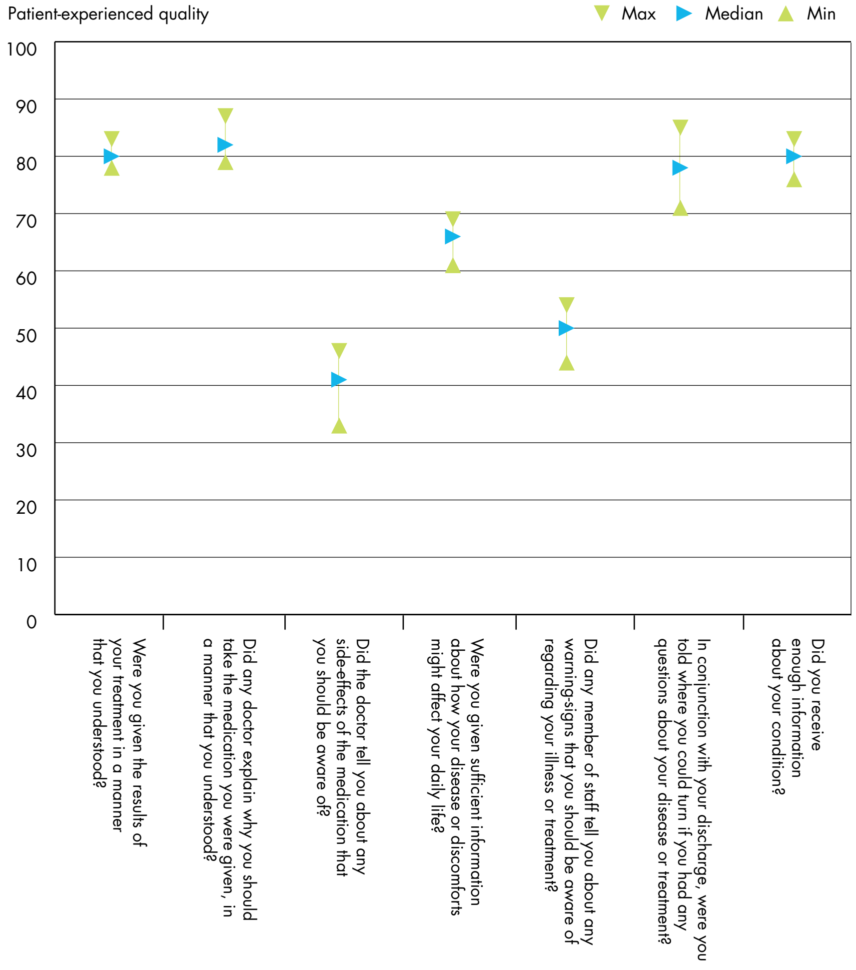
Figure 2. Patient-experienced quality results among Sweden's county councils relating to information and education. *Source: National Patient Survey, Primary Care (2011)*



by the National Board of Health and Welfare, is disseminated to patients through a variety of channels and contains a range of suggestions as to what patients can do to ensure positive encounters with the health care system. Moreover, the National Board of Health and Welfare has initiated the creation of patient versions of disease-specific information based on the national guidelines. With that knowledge, patients could point to possible inadequacies in their care process.

However, available evidence makes clear that the patient experience of-

Figure 3. Patient-experienced quality results among Sweden's county councils relating to information and education. *Source: National Patient Survey, Inpatient Specialized Care (2010).*



ten falls short of the legislative standard. In the recently conducted Commonwealth Fund International Health Policy Survey of Sicker Adults in 11 countries (IHP 2011), Swedish patients are less likely than their international counterparts to say that their providers inform them about who to contact about questions concerning condition and treatment, present options for treatment, and give them opportunities to ask questions. Only Norway lags behind Sweden in qustions relating to information and education (see figure 1).

The Swedish National Patient Survey (Nationell patientenkät) also shows that there is room for improvement in terms of meeting patients' needs for information and education. For instance, in both primary care and inpatient specialized care, doctors often fail to tell patients about the side-effects of their medicines and about warning-signs to watch out for. On the more positive side, some questions pertaining to whether information provided was understood, received higher measures of patient experienced quality (see figures 2 and 3).

The results of the assessment show that despite strengthened legal provisions and substantial information efforts, there are important gaps in the information provided to patients. The surveys clearly demonstrate that the dialogue between health care staff and patients must be developed. Some government reports also conclude that information about patients' "legal protections", such as claiming the health care guarantee and choosing care providers, was insufficient. Patients do not seem to be well-informed about the legal protections afforded to them and information to support the choice of provider is limited and used to only a limited degree.

Furthermore, findings from the expert interviews point to the fact that relatively little information, education, and support for decision-making is as yet available to support Swedish patients who want to take a more active part in their health care process, and that information that is available is not provided in the most useful ways to foster and support informed patient decision-making. This is true, for example, when assessing risks and choosing between different treatment options, information to facilitate self-care, and the option to exchange important information about health and symptoms together with the care provider. Although there are examples of innovative approaches to patient information and education, ranging from interactive websites in which information is highly tailored to patient circumstances, to videos showing procedures and explaining them to patients, progress in this area is slow, small-scale, and far from meeting patients' real needs for decision support.

This substandard performance concerning information and education to support patients to be partners in their care may in part reflect a paternalistic tradition in the provider-patient relationship that is changing only slowly. Furthermore, cost pressures, payment incentives and administrative requirements may contribute to shortened consultation visits that can leave patients feeling short-changed. The model of organizing care around a clinic can impair the patient-physician relationship, but a well-run clinic can provide timely access to information and to meet patient needs for education and support. Furthermore, the bifurcated responsibilities of national government and county councils may contribute to a disconnect between legal standards and actual practice.

3.2. DIMENSION 2:
Respecting patients' individual needs, preferences and values

▶ *Sweden's health care system often fails to anticipate and respond to patients as individuals with particular needs, values and preferences. Failure to meet patient expectations can have demonstrable costs to patients, the health system and the public purse.*

Definition

A patient-centered health care system is one in which patients are treated as individuals who bring a unique set of needs, preferences and values to each encounter with the health care system. A patient-centered health care system and the processes associated with the delivery of health care services are designed so as to anticipate and respond to patients' particular concerns, and to solicit meaningful patient input into all decisions about how health care is furnished.

Assessment

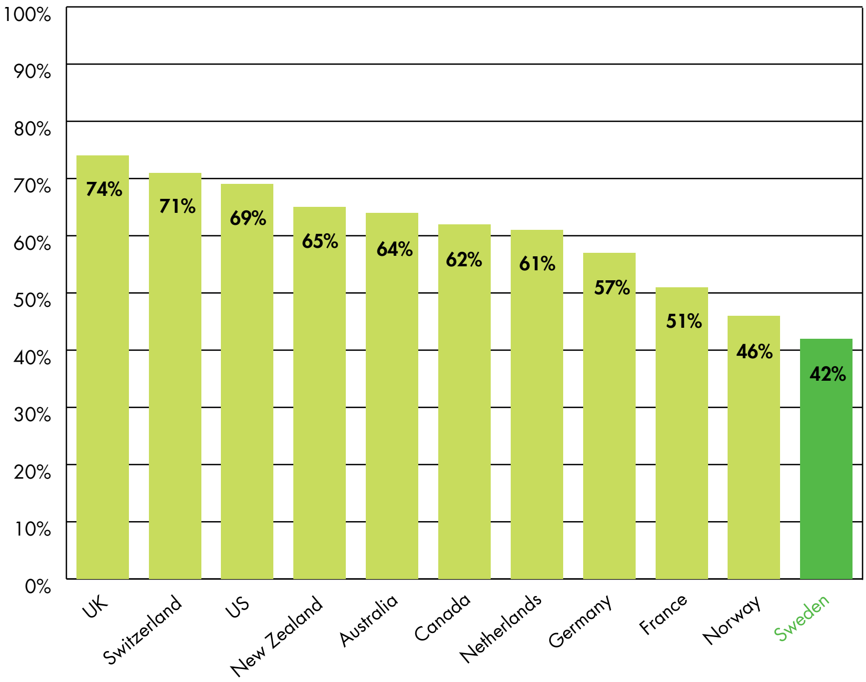
The Swedish Health and Medical Service Act (1982:763) and Patient Safety Act (2010:659) both include provisions that specify health care providers' obligations to respect patients' needs, preferences, and values. As is true in other areas, this legal framework provides a clear statement of intent, but is not always reflective of the actual state of play.

Swedish patients experience relatively poor care, in terms of how well it meets their individual needs, preferences and values. The 2011 IHP survey of sicker patients in 11 countries found that Swedish patients reported the lowest scores of any country on four relevant measures included in the survey (see figure 4). Swedish patients are the least likely to be engaged by their health care providers as partners in their care and treatment decisions. Notably, low patient engagement is associated with a range of poor outcomes, including medical errors.

The National Patient Surveys is consistent with these findings of low patient engagement, and shows that psychiatric patients are particularly dissatisfied with their experiences (see figure 5). Another notable finding is a strong dissatisfaction with health care services in terms of their convenience and orientation towards meeting patient preferences.

According to the views of some experts, Swedish health care is organized for administrative convenience rather than patient or even provider conve-

Figure 4. Percentage of patients answering the most preferable answer on each question concerning preferences and needs (unweighted index). *Source: IHP International Survey of Sicker Adults, 2011. (For a description of the elements of the index, see Annex III.)*



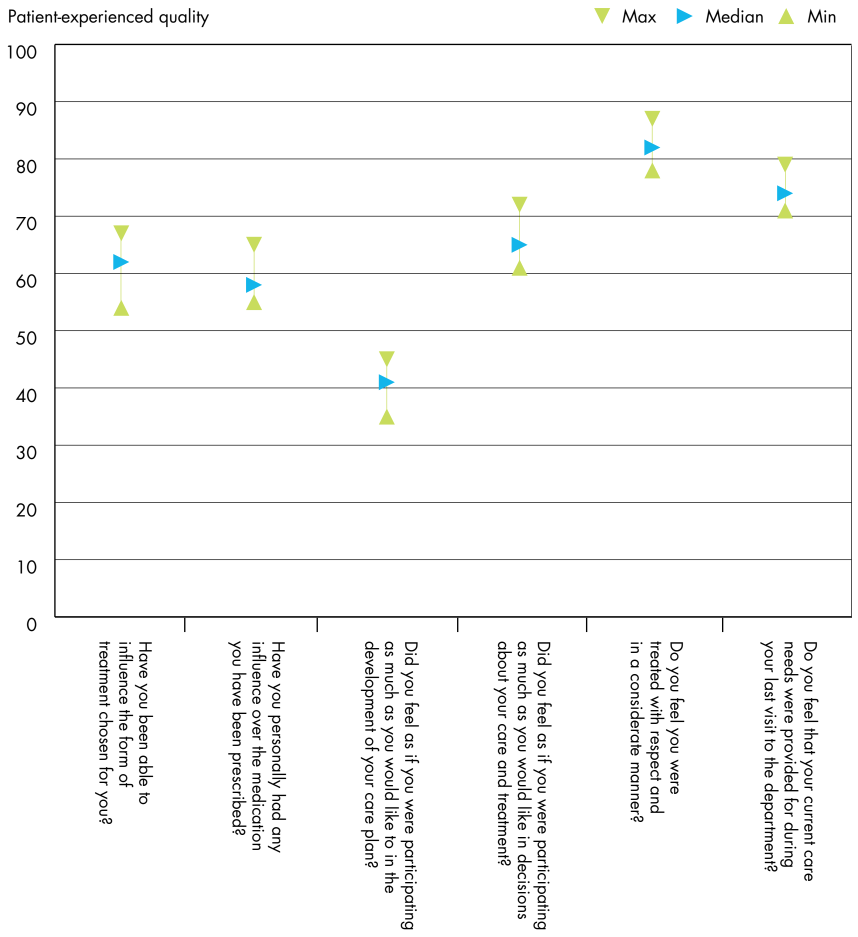
nience. This is manifest in such ways as: Difficulty of patients in obtaining appointments at convenient dates and times; long waits for appointments due to poor scheduling; and obstacles to consistently meeting the same practitioner on repeated visits. Patients with complex, chronic conditions often need to travel to several locations on multiple dates in order to see the different types of providers who care for them.

In this vein, government reforms geared toward establishing and expanding patient choice of health care provider are, in part, intended to spur competition to meet patients' needs and preferences, and to give patients an out when service is unsatisfactory. However, the reforms are relatively new and the knowledge of their actual effects is limited.

As with information and education shortfalls, time constraints, reflecting increased use of activity-based reimbursement methods, and attitudinal issues could be examples of factors in explaining why patients' needs to be treated as individuals with unique needs, values and preferences are not well met in Sweden today.

This is not to say there are no positive findings to build upon in the future.

Figure 5. Patient-experienced quality results among Sweden's county councils relating to needs, preferences and values. *Source: National Patient Survey, Outpatient Psychiatric Care (2010).*



Swedish patients generally report that their health care providers treat them with respect and listen to what they say. However, providers do not tend to treat patients as though they are genuine experts on their own health and a font of unique expertise upon which to draw in deciding on the optimal treatment. The concept of shared decision-making between patient and provider has yet to take root in Sweden.

3.3. DIMENSION 3:
Coordinating care across service providers and ensuring continuity of care

▶ *Inadequate coordination of care across health-care providers is an important weakness in Sweden's health system. Such problems are likely to have a negative impact on health outcomes and costs, in addition to having a negative impact on patient experienced quality of service.*

Definition

Coordination of care, so as to obtain optimal service in a particular episode of treatment and so as to ensure good continuity of care over the long term, is a core conceptual dimension of patient-centered care. It relates directly to the notion that the patient, rather than the disease, condition or service, is the appropriate focus of health care. Without good collaboration across providers, the patient may be subjected to quality problems associated with duplicative or contra-indicated care. Problems in continuity may also result in inferior health outcomes and patient satisfaction.

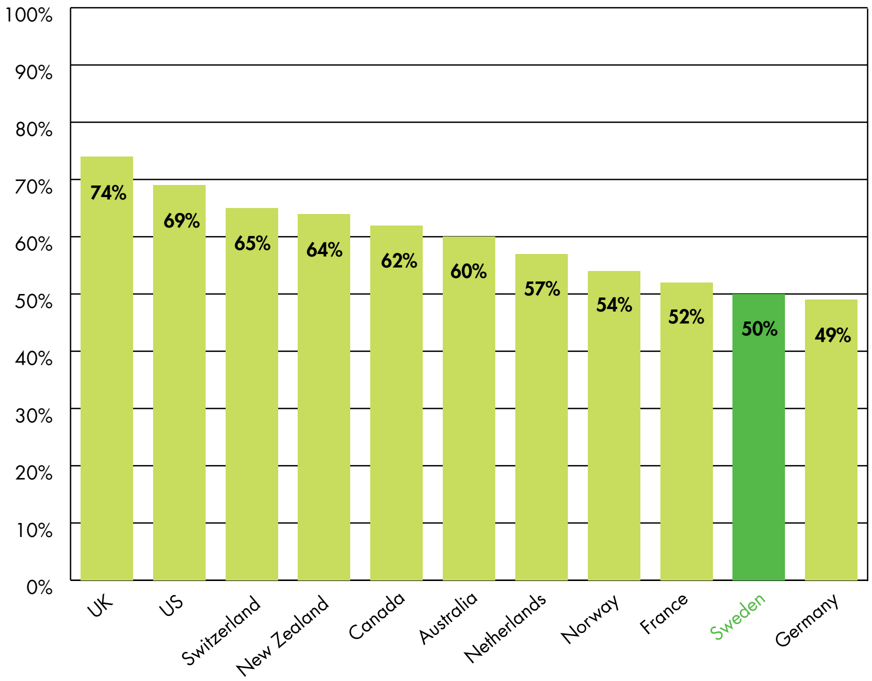
Assessment

Findings from the 2011 IHP survey reveal evidence of shortfalls in processes used to coordinate treatments and ensure good continuity in care. Only Germany lags behind Sweden in questions relating to coordination and continuity (see figure 6).

The results from the National Patient Survey show room for improvement regarding patients' experiences of coordination and continuity in care. For instance, in specialized inpatient and outpatient somatic care, far from all patients know who their responsible doctor is, or whether a plan has been conducted for their continuing care. The results from the specialized outpatient psychiatric care show more problems. Great variations between county councils are found on questions pertaining to cooperation between health care staff and with support in referrals to other psychiatric care (see figures 7 and 8).

This assessment points to several key problems, some of which may have contributed to the fact that Swedish patients are dissatisfied with coordination and continuity in care. A clear barrier to coordinated care is that the organization of health care in Sweden is structured by function in a vertical manner. Although this structure allows the resources within each unit to be

Figure 6. Percentage of patients answering the most preferable answer on each separate question concerning coordination and continuity (unweighted index). *SOURCE: IHP International Survey of Sicker Adults (2011). (For a description of the elements of the index, see Annex III.)*

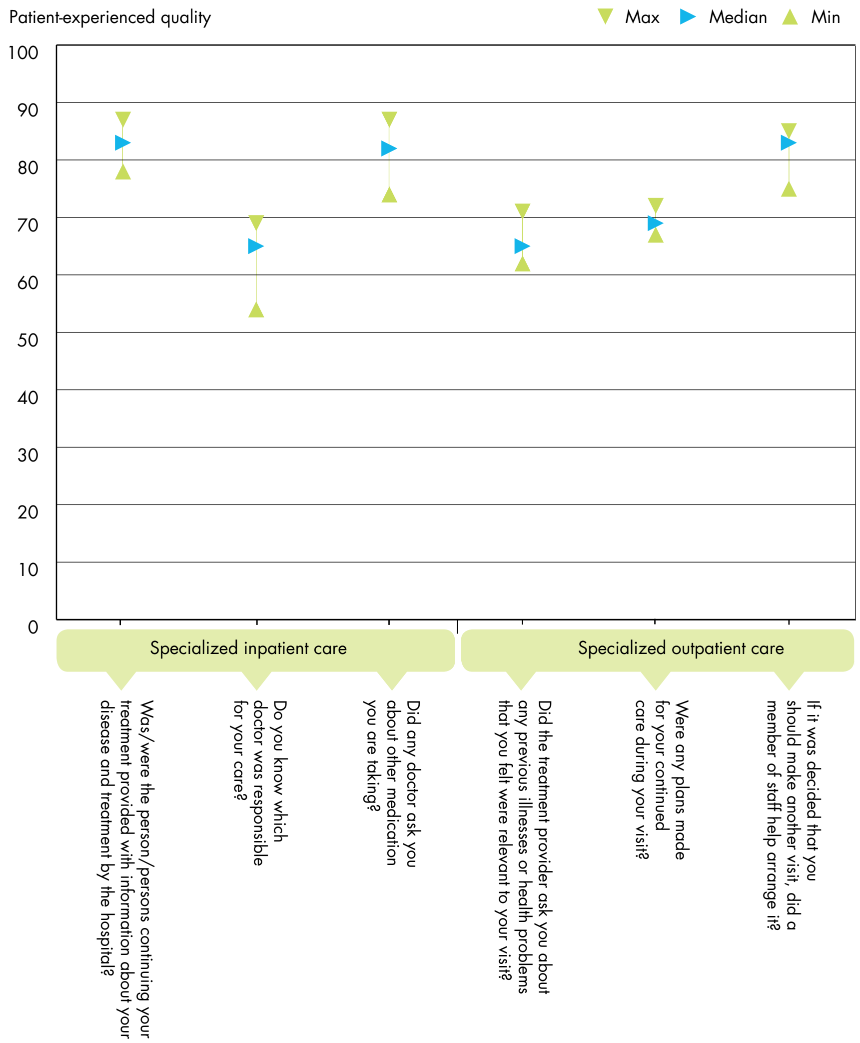


used effectively, the negative consequence is that cooperation within health care and between health and social care suffer, making it hard to create coordinated health care processes horizontally. Several reports from the National Board of Health and Welfare (Socialstyrelsen) show that this is a pertinent and ongoing structural problem in Sweden's health care system.

The deficiencies with the vertical organization are further accentuated by the reimbursement system that traditionally focuses on every unit's specific goal instead of coordination. However, local examples of efforts to improve reimbursement factors inhibiting coordination are evident. For instance, Stockholm county council reimburses the whole care episode for knee and hip surgery. In the Skåne region, the reimbursement for stroke is based on how well the patient functions in daily activities three months after the incident. However, the use of such reimbursement systems is not widespread in Sweden's health care and there is a need for a continuous evaluation of how reimbursement actually affects outcomes.

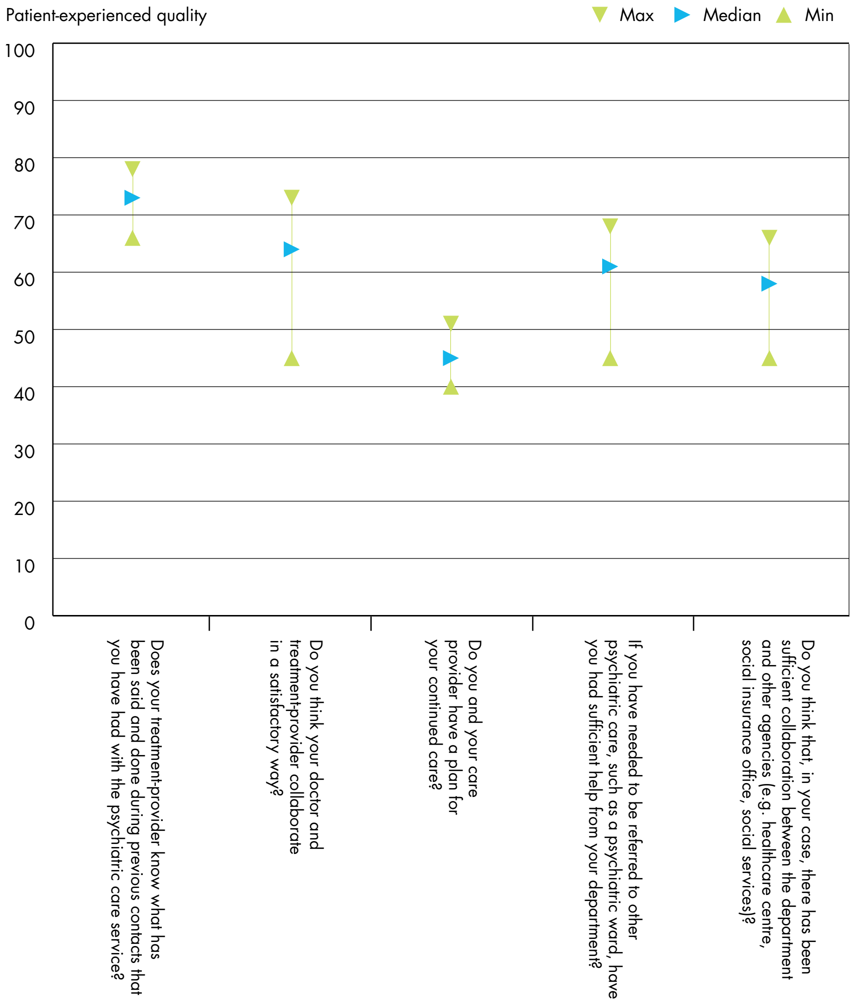
A problem commonly cited by patient representatives interviewed for this

Figure 7. Patient-experienced quality results among Sweden's county council relating to coordination and continuity. *Source: National Patient Survey, Outpatient Specialized Psychiatric Care (2010).*



study is the lack of assistance available to patients in negotiating their way through a health care episode that may involve multiple providers, as in care for patients with complex conditions or post-hospital rehabilitation care. A recently enacted 2010 provision of the Health and Medical Services Act obliges the head of the care facility to offer a permanent point of contact, if deemed necessary or if requested by the patient. However, most experts interviewed were either unfamiliar with the law or stated that it had not yet had an impact

Figure 8. Patient-experienced quality results among Sweden's county councils relating to coordination and continuity. *Source: National Patient Survey, Outpatient Specialized Psychiatric Care (2010).*



on practice. Some observed that providers lacked financial or other incentives to act as point of contact.

Local initiatives to facilitate coordination of care have also been identified in the assessment. For instance, a certain appointed case manager with the overarching responsibility for the whole care chain is sometimes employed for patients with severe mental disabilities. Another example is the use of health care attendants to support and assist patients with multi-diagnoses who often visit health care. Nevertheless, the effects of these initiatives needs to be further evaluated.

Clear barriers for coordination are the gaps in the Swedish health care information systems. A report from the Karolinska institute finds that existing information systems do not sufficiently support cooperation by providers within and between health care and social service. Moreover, the legal framework does not enable sharing of patient information between social services and health care, to the extent that is needed.

In conclusion, key problems that were identified include:

- Poor performance in terms of international comparisons on structural and procedural instruments for care coordination and continuity;
- Mediocre performance in terms of international comparisons of negative outcomes associated with poor coordination and continuity;
- Considerable room for improvement in achieving optimal performance on coordination measures included in domestic survey modules, particularly with respect to psychiatric patients;
- Problems in continuity and coordination for particular populations, such as the sickest elderly;
- Minimal impact to date of the “point of contact” reform in establishing a patient resource for health system navigation and ensuring care coordination and continuity;
- Inadequate cooperation between health and social services pertaining to problems such as confidentiality issues in the exchange of information;
- Technical problems in the functioning of electronic medical records that impede their full use to better coordinate and ensure continuity of care; and
- The reimbursement systems do not support coordination and continuity of care.

Coordination is a complex area and in order to improve outcomes it is important that decision-makers broaden the perspective and pay attention to the whole spectrum of reimbursement systems, information systems, organization and regulations – factors that together are important prerequisites for collaboration and coordination in health care.

3.4. DIMENSION 4:

Taking a holistic approach to patients as people with medical and non-medical (i.e., social, emotional and spiritual) needs.

- *Some problems in taking a sufficiently holistic approach to patient care are evident, with relatively little variation in performance across counties.*

Definition

This core element of patient-centered health care recognizes that health care is a profoundly important and personal experience for patients, which often engenders fear and anxiety, as well as a range of emotional, psychological and spiritual concerns. A patient-centered health care system anticipates and responds to those concerns, rather than focusing exclusively on the medical competencies. A patient-centered health system also takes a holistic approach to patient needs, rather than a disease-centered approach.

Assessment

In terms of taking a sufficiently holistic view of patients' situations, a relatively low variation in performance across counties suggests that this may be an area where the administration of health care by the county councils has not had any particular impact (see figure 9). Therefore, in order to find models for improvement, so as to close the gap between what is ideal and what has been accomplished to date, it may instead be useful to look at the particular hospitals that scored the highest in terms of providing holistic care for examples of best practices.

Our findings reveal some shortfalls in the ability to meet patients' needs of holistic care in some areas, for instance, a lack of guidance and support during the transition from the acute hospitalization phase to the follow-up care, which prevents patients from being sufficiently prepared for the lifestyle changes that may be required in the aftermath.

Our findings also suggest a need to further explore what the concept of holistic care means to Swedish patients. In particular, it would be useful to examine what is expected in terms of acknowledgement of patients' spiritual needs, taking into account the country's growing multiculturalism. Professional and public discussion of what is desirable and appropriate, in terms of how best to direct or guide patients seeking spiritual care in the Swedish context may be of value.

Ultimately, treating patients more holistically may require more coordinat-

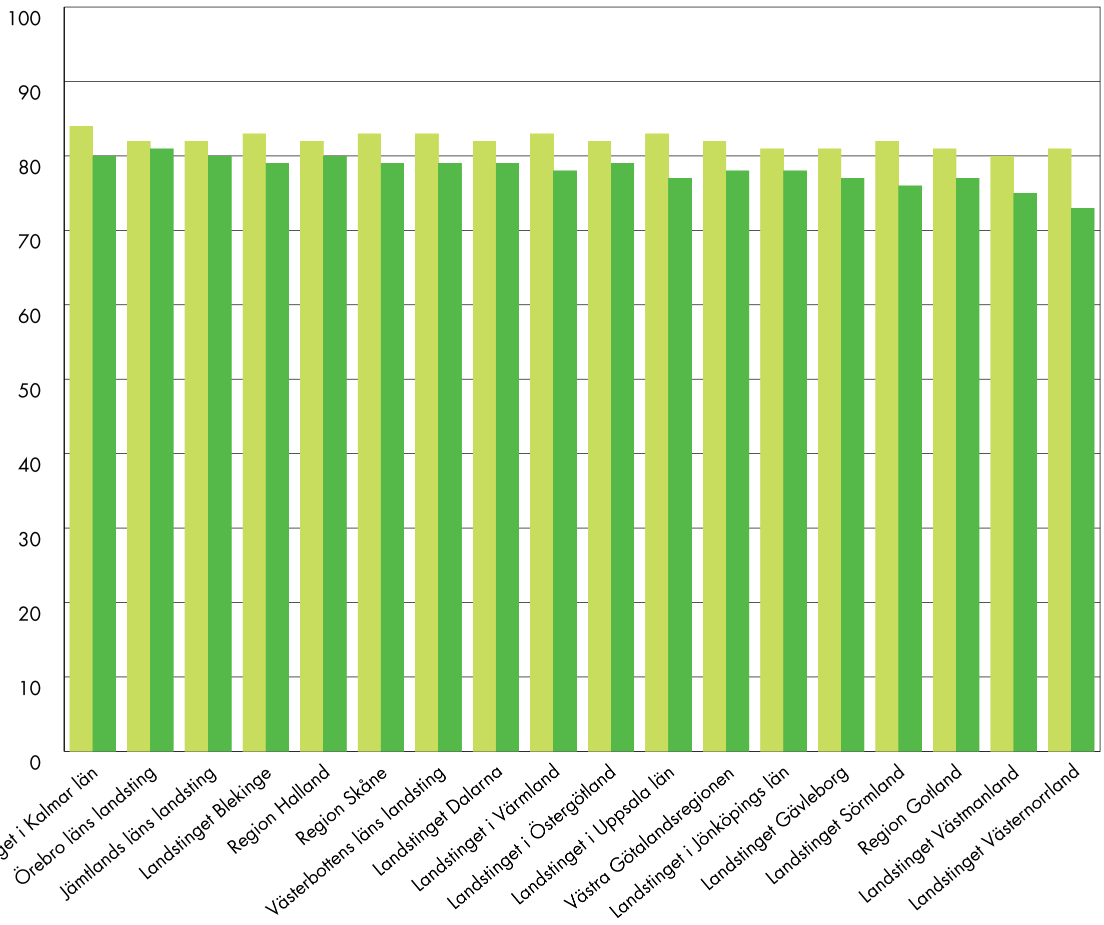


Figure 9.
Patient-experienced quality results among Sweden´s county councils relating to holistic care. *Source: National Patient Survey, Inpatient and Outpatient Specialized Care (2011).*

🟩 Outpatient specialized care: Did the treatment provider have a holistic view of your situation as regards your treatment?

🟩 Inpatient specialized care: In your opinion, did the doctors have a holistic view of your care?

ed efforts by care providers within and outside of the health sector, more consultation to determine patient needs, and possibly an expansion of roles for certain health care providers, such as nurses and nurse managers who might be well-positioned to contribute to leadership and innovation in this area.

3.5. DIMENSION 5: *Involving family and close friends in the health care experience, to the extent desired by the patient*

▶ *While evidence regarding the patients' experiences in involving family and close friends in their health care is relatively limited in depth and scope, available data suggests that there is room for improvement in this area. Several types of potential problems benefiting from further exploration were identified in the course of the present study.*

Definition

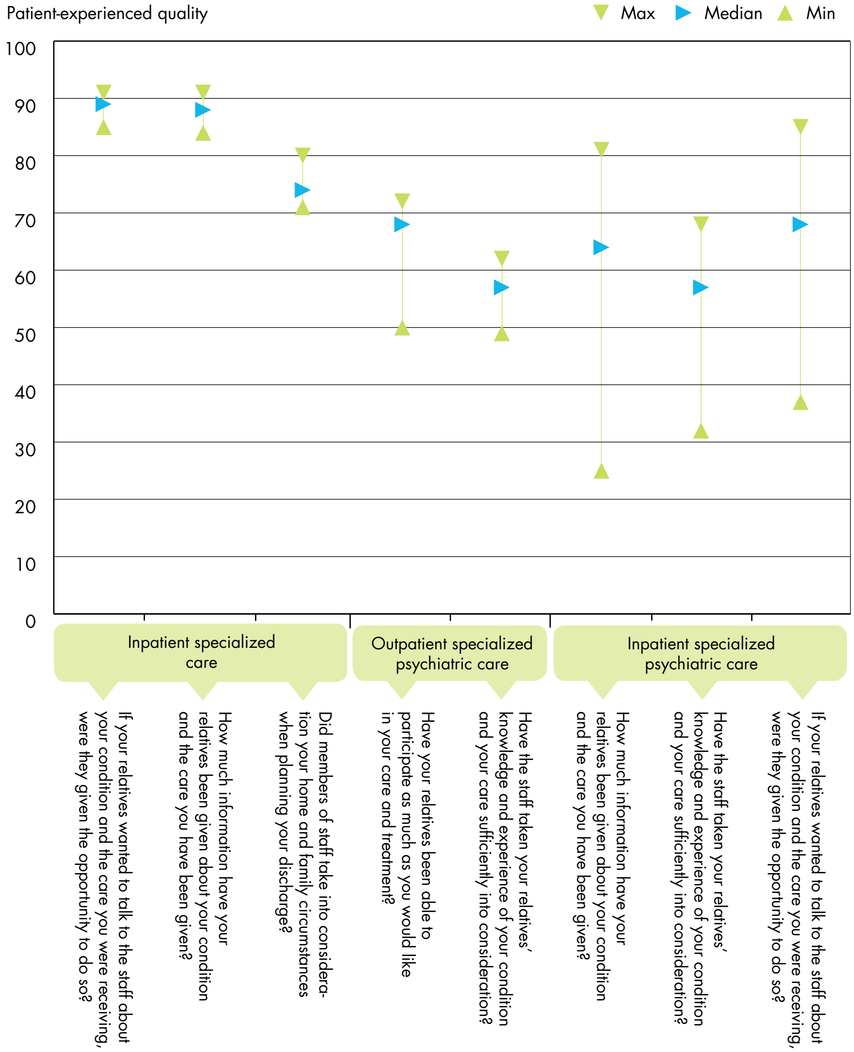
An important determinant of patient experience and outcomes of patient-centered care relates to the involvement of family and friends in a patient's health care experience. The patient focus groups conducted as part of development of the Picker Institute model of patient-centered care revealed that patients considered that their family members and close friends played a central role in a patient's experience of illness. Health care that accommodated that role, involving loved ones in decision-making, supported the caregiving role, and recognized the needs of family and close friends, was considered to be very important to patients.

Assessment

Patient experience measures from inpatient and outpatient specialized psychiatric care and inpatient specialized somatic care of the Swedish National Patient Survey show a mixed performance in terms of involving family and friends in a patient's health care experience. While results from somatic care across the counties are quite consistent, the variation in performance across counties in outpatient and (especially) inpatient psychiatric care is considerably larger (see figure 10).

Evidence as to the extent to which Swedish patients' needs to facilitate involvement of friends and family in their health care are being met is somewhat limited. Nevertheless, the involvement of family and friends is likely to be im-

Figure 10. Patient-experienced quality results among Sweden's county councils relating to involvement of family and friends. *Source: National Patient Survey, Inpatient Specialized Care (2010), Outpatient Specialized Psychiatric Care (2010), Inpatient Specialized Psychiatric Care (2010).*



portant to at least a proportion of the Swedish patient population, given the prominent role of family caregivers in aiding individuals with dementia and other conditions. Available data suggests that there is room for improvement in this area. Potential problems that would benefit from further investigation include:

- Involvement of family and close friends in the care of psychiatric patients;
- Improvements in hospital protocols relating to treatment of the partners of maternity patients;
- Unidentified needs of different patient groups to involve friends and family;
- Potential problems in the ability to designate proxies to act on a patient's behalf, when a patient desires to name a proxy in case of incapacity associated with a condition or medical treatment (something that the government just recently assigned a national commission to review); and
- Provision of support to family members caring for seriously ill patients.

As with other dimensions, a prominent barrier to improvement in this area appears to be a lack of knowledge of the protections and the support afforded to patients by law. For example, only six out of eighteen patient organizations consulted by the National Board of Health and Welfare in 2011 were familiar with the obligations stipulated in the social services to offer support to patient families. As with other dimensions, there appears to be a disconnect or lag between the enactment of protections and the implementation of those protections in actual practice. Finally, this appears to be an area where improved cooperation between national government authorities and local health care administrators has the potential to yield important benefits.

A potential facilitator to improve performance in fostering involvement of close family and friends in health care lies in the activities of the many patient organizations that are active in Sweden and that operate with public financial support. Many of the patient organizations are already active in providing education about diseases and support to patients' relatives.

3.6. CROSS-CUTTING ISSUES:

Facilitators and barriers to achieve a more patient-centered health care in Sweden

A number of characteristics of the Swedish health system that serve as either barriers to or facilitators of progress in achieving a more patient-centered health care system in Sweden have been identified. Some of these were discussed above as they pertain to findings relating to specific dimensions of patient-centered care. Others are of a more general or cross-cutting concern and are discussed below.

Achievements of Sweden's health care system support a focus on patients

One of the most important factors that should facilitate rapid improvement in Sweden, in terms of pursuing a more patient-centered health care system, is the strengths and achievement of the health care system as a whole. System-wide, there is overall high quality of care, including good outcomes and demonstrable improvement over time, and this is widely recognized among patient representatives interviewed for this study. Sweden has also made considerable recent progress in addressing issues related to timely access to health care services and survey respondents acknowledged that this is improving, albeit that it is still less than satisfactory for many patients. This creates an environment in which improving patient-centeredness of health care can be seen as a priority for attention, particularly in that attention to patient-centeredness can have a positive impact on both quality and costs.

Furthermore, while budget pressures are increasing – creating pressures for improvements in efficiency – Sweden has a relatively good position in terms of the overall economy of health care, devoting 10 percent of its gross domestic product to health care in 2009, comparable to many of the country's European neighbors and significantly less than the highest-spending systems. Nevertheless, reliance on local financing as a main source of funding stands to contribute to inequitable progress in meeting national goals. Inequities created by regional differences in resources and priorities result in very different patient experiences and options across geographic areas. Addressing such inequities, to the extent that Swedes find them unjust or unjustified, could require the national government taking on a larger role with respect to financing or delivery of care for some patients, or for taking steps to define minimum floor standards relating to certain dimensions of patient-centeredness.

The potential to exploit patient data

A second important facilitator of progress in Sweden lies in its extensive system of information collection. The quality registers of Sweden serve as an international example of best practice in terms of tracking patient care and outcomes over time. The relatively new National Patient Survey, which includes modules focused on many populations and categories of provider services, and with comprehensive instruments based on Picker Institute surveys designed to assess the patient experience of care in ways that matter most to patients, provides an invaluable source of data that have yet to be fully exploited in terms of use by providers for quality improvement purposes. The survey administration could be refined and improved with further investment, such as innovations geared to improving response rates and ensuring that sample sizes are adequate to power comparisons at levels relevant to patient choice decisions. Furthermore, a number of problems are evident: Not all county councils participate in all surveys, rendering comparisons more difficult. Also, each county council owns its own data, making it very difficult to use the data for analysis at the national level. Furthermore, the public presentation of the data is spread across the different county councils and administrative bodies, which results in an inconsistent view of overall findings.

In addition to strengthening patient surveys, there is an evident need to develop additional sources of information, such as focus groups and opportunities to provide input and feedback online. Progress in terms of electronic medical records, albeit still burdened by technical and policy issues that are not yet resolved, puts Sweden at the forefront of developed countries and stands to be a critically important facilitator of future improvements in patient-centered care. Such data infrastructure presents myriad opportunities for Sweden to make important leaps forward in patient-centeredness. Such data should also inspire provider initiatives geared toward improving performance where indicators reveal shortfalls, although experts interviewed for this study report that to date there has been less such activity than one would hope.

Patient-centeredness as a public priority

A further facilitator of progress lies in the growing attention by political and other leaders to the issue of patient-centeredness in health care. This is manifest in terms of legal and regulatory steps to strengthen patient-centeredness, such as recent provisions allowing patients to demand a point of contact in the system, as well as investment in reporting that can serve to track and incentivize improvement. However, patient-centeredness is but one priority among many that have been established for health care. Experts interviewed for this study noted that hospital administrators and other actors are sometimes unable to focus adequately on accomplishing any particular goal, given the large array of goals that have been established by actors at various levels. Efforts to establish priorities among priority areas, and to ensure consistency across goals, could help to reduce the discordance between stated aspirations and current practice.

Tracking performance and improvements in achieving patient-centeredness

Efforts to assess and track patient-centeredness in Swedish health care are evident, albeit at an early stage of development. Both the National Board of Health and Welfare and the new Swedish Agency for Health and Care Services Analysis are investing resources to develop an infrastructure that can be built upon in future work. Challenges for the future are evident; notably, there is, as yet, no universally agreed definition of patient-centered care and associated conceptual framework with validated indicators for assessment. An ideal framework for assessing patient-centeredness in Sweden's health care system would be generally consistent with frameworks used internationally, to aid in making international comparisons where possible, but would reflect the specific values and priorities of Swedish patients. Nevertheless, the extensive data available from National Patient Surveys is adequate to support focused reports on how patient-centered care is for particular populations and services; the survey data could indicate areas for follow-up via patient focus groups aimed at identifying needed changes in policy and practice. And Sweden's participation in international benchmarking efforts, such as international surveys fielded annually by the Commonwealth Fund and work by the OECD, is valuable in terms of giving insight into possible goals for improvement and better understanding of areas in which Sweden is doing relatively well.

Enhanced choice may spur a more patient-centered care, but will not suffice for all patients

The national government priority of promoting patient choice and increasing competition among providers also serves as a mechanism for facilitating advances in patient-centeredness. To the extent that patients are increasingly free to choose and make changes in their health care providers, have more options of service providers, and obtain information needed to make appropriate choices, such steps can serve to inspire competition across providers in terms of how well patients' needs are met, ultimately yielding improvements. Nevertheless, competition alone will not serve to ensure patient-centered care for all patients. The most vulnerable may have difficulties in making informed choices and others may not be able to act on choice; say, for those whose rare conditions render them with few local options for care. Providers are unlikely to compete to provide care for patients with rare and costly conditions. For this reason, choice and competition approaches require complementary steps, such as establishment of standards to ensure a baseline minimum floor quality for service, in terms of qualities valued by patients.

Existing patient protections and guarantees are valuable, but need to be strengthened

Another facilitator of patient-centered care lies in the existence of mechanisms for patient protection. These include the Patient Advisory Committes' responsibility to provide support and advice to patients, and the National Board of Health and Welfare's responsibility to supervise and receive and investigate complaints. However, improvements are needed in terms of informing patients of protections, guarantees and other opportunities afforded to them in the law. A study by the Swedish National Audit Office (2007) found that patients who were injured during care or treatment rarely had knowledge about where to file a complaint. Only six percent of patients knew where to complain, for example concerning bad encounters. Another study found that patient complaints are filed by only a very small proportion of patients who have experienced problems in their experiences with health care services. The main reasons for not making complaints are that patients do not feel adequately equipped to make them, do not know where to turn, or do not find it worthwhile, as they believe it will make no difference.

Further evaluations are also needed to find out how better compliance with legal obligations can be accomplished. Furthermore, while patient organizations in Sweden are active and empowered via public funding, they could be more effective to the extent that they operate collectively on issues of common concern. Also, it is unclear if these organizations are being utilized by actors in national and local government and in health care organizations to provide patient perspective and input on decision-making. It appears that patient consultations remain pro forma and involve using the groups to disseminate and publicize work relevant to patients more often than in work to identify and solve problems that matter to patients. Making the patient's voice heard more strongly in health care decision making may well require moving beyond the "representative" approach as well, in using, for example technology to get real-time feedback and input from patients online.

Local administration of health services has both benefits and disadvantages for patient-centeredness

One of the reasons why there appears to be a significant lag between passage of laws and changes in practice is the local administration and financing of health care in Sweden. This provides the national government with relatively few levers to accelerate change; although the process of creating agreements with County Councils that include special financing for meeting defined goals can be effective. Although the system has presumed advantages in terms of system responsiveness to preferences of local communities, drawbacks such as inequities across the country are evident. This means that both financing and capacity for implementing improvements in patient-centered care will vary across counties according to local choices and resources.

Challenges from cost-containment pressure

Cost-containment pressure, reflecting factors such as simultaneous stress on both costs and financing associated with population aging, presents challenges in terms of finding resources to devote to improvements in patient-centeredness. A possible short-term strategy for providers who want to improve in the light of cost pressures will be to identify investments in patient-centered care that have the potential impact to reduce costs, by minimizing increasing compliance and reducing complications, for example. Such savings could, over the longer term, finance investments that enhance outcomes, in terms of better patient experience with care, while not necessarily resulting in direct cost savings.

Need for attitudinal changes

Progressing towards patient-centered care will require changes in the attitudes and expectations of health care professionals and administrators, who will be asked to place patients squarely at the center of health-care decision-making, and of patients themselves, who will be asked to take on a more active role in their health care, to the extent that they are willing and able to do so. Attitudes of all parties are reportedly changing, but slowly. More leadership and greater attention to the current problems and potential to achieve better and less costly health care in the future should be beneficial in accelerating changes in attitudes, although such efforts may benefit from the support of leaders positioned to influence others, and steps such as changes in education and training programs. Health care professionals may require both support and incentives to take on new roles and responsibilities; for example, nurses may prove to be an as yet largely untapped resource in terms of filling patient needs for coaching, guidance in negotiating care and transitions, and even direction or support in meeting nonmedical needs associated with illness or injury.

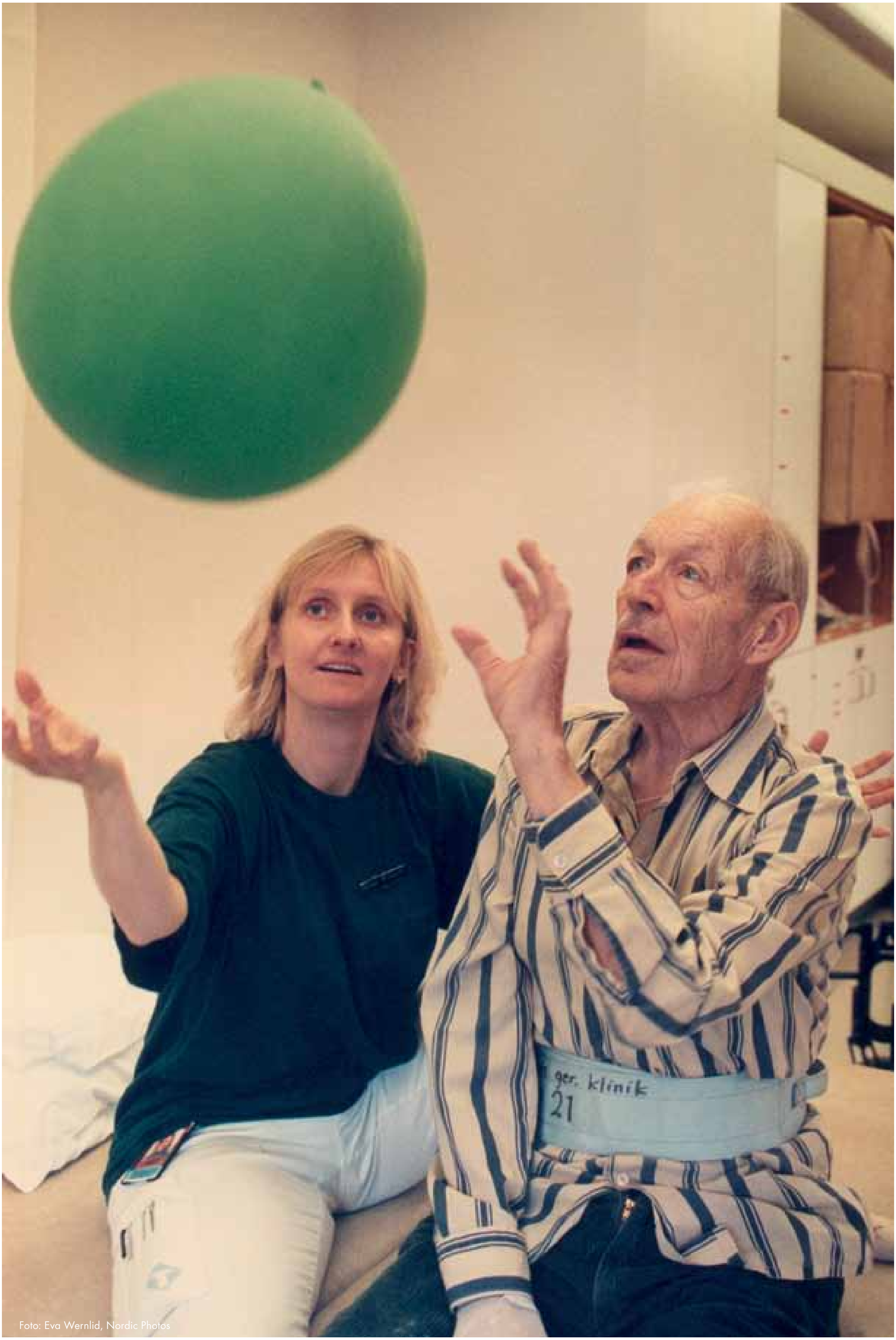


Foto: Eva Wernlid, Nordic Photos

4

Six steps toward a more patient-centered care

The present study has identified a number of shortfalls in Sweden's health care in terms of how well it meets five dimensions of patient-centered health care and has described a number of barriers to strengthening performance, as well as facilitators that build a foundation for improvement.

The authors hope that this study will serve a number of valuable objectives. The findings represent a preliminary assessment of health care in Sweden that could serve as an initial benchmark and point of comparison for future studies. Furthermore, the study's findings can be valuable both in informing the ongoing policy debate in Sweden, and in helping to develop future demand for both focused and comprehensive studies of patient centeredness, including one-off research projects and ongoing monitoring.

Limitations of the present study include the need for further work to validate the internationally derived framework for assessment used in this study, in terms of its consistency with Swedish patients' expectations and priorities; the need for additional work linking specific dimensions of patient-centeredness with satisfaction, health and cost outcomes; the presence of some gaps and shortfalls in the available indicators and data by which to assess how well the health system actually comports with certain dimensions of patient-centeredness selected for assessment; and limited availability, as yet, of standards or established benchmarks for comparison. Some of these limitations reflect the relatively early stage of work on patient-centeredness and will naturally resolve over time. For example, the availability of time trend data will provide benchmarks by which to assess improvements in performance. Other limitations will require some investment of resources to address.

Policy recommendations

Below we describe priority areas for further analysis and policy recommendations for improving Sweden's patient-centeredness.

1. Ensure compliance with existing legal obligations to strengthen patients' position

The position of patients in Swedish law has been strengthened over the last decade. Obligations for health care providers to protect and empower patients are established in various pieces of health care legislation. However, our assessment shows a widespread and disturbing discrepancy between obligations as laid down in law and the reality that patients actually meet. The existing laws and regulations are too often not complied with and the system for accountability is in practice ineffective - in particular with respect to the patient perspective. Our assessment also shows that patients do not know where to file a complaint or where to turn when in need of help and support. Findings also point to the fact that many patients do not even find it meaningful to file a complaint. The ongoing effort to collect legal obligations towards patients in a unified law might help to make them better known to patients and their representatives, thereby strengthening their position. However, experience show that merely collecting existing provisions in a unified piece of legislation will not be enough. It is therefore important that the underlying causes to the lack of compliance are better understood and that appropriate measures to address these are developed. Such avenues for improvement might for instance include a change of perspective on legislation and its implementation; a strengthened or modified supervision; a different way to make use of available sanctions; or developing other measures aimed at enforcing compliance. One measure could be to strengthen the powers of bodies that are responsible for handling patient complaints and to make improvements in terms of informing patients of where to file a complaint. Measurement and public reporting are also potentially useful directions, as provider choice and competition take hold in Sweden. One option along these lines would be to make "Compliance with legal obligations" a metric made available to patients to facilitate decision-making.

2. Establish patients as full partners with their providers with a role in health and care decisions

Swedish health care lags notably behind international leaders in supporting patients in their role as partners with their providers in care and co-producers of health. There is little information, education and especially support available for patients who want to take a more active part in their health care process. While there are some good examples of quality registers that open up for patients to exchange information with providers on health status and symptoms, these possibilities need to be further developed and spread to new areas of care, as appropriate. Decision aids to support patients with choice of providers and medical treatment exist, but could be promoted further to facilitate active partnership. This also holds for patients who wish to have more information and tools for self-care management. However, the introduction of new decisions-aids in health care is not driven by itself. Rather, it will be driven by a real demand for these supports among health care professionals, administrators and patients themselves. If this is to happen attitudes must change. The national government and the county councils must take on an active role of leadership geared toward promoting the value of establishing working partnerships between health care practitioners and patients in health care, and the value of putting patients squarely in the center of health-care decision-making. Underscoring findings of the very real impact that patient engagement has on health outcomes and costs of care will be instrumental in bringing providers and administrators to the table.

3. Engage and involve patients and their representatives in health policy and administrative decisions

Patients and patient representatives are an untapped resource in Sweden's health care in the progress towards a more patient-centered health care. Working in tandem with patient organizations, the national government the county councils, and providers should seek to more clearly define the role of patients in designing, implementing and evaluating policies and administrative decisions. Too often, the unique expertise and perspective of patients are ignored. When patients are involved, they are often afforded only token participation with little or no actual effect on decisions. Besides using traditional channels with round-table meetings, it may be possible to develop new, innovative and meaningful practices to involve patients. Also, while patient organizations in Sweden are active and empowered via public funding, they need to work to be more effective to the extent that they operate collectively on issues of common concern. Furthermore, patient organizations need to prioritize the enhancement of their capability to have a substantial impact on the policy process.

4. Sustain efforts to facilitate coordination and continuity of care

Integration and coordination of services is a critical challenge in the Swedish health care system and central to attaining patient-centered care. In order to obtain more coordinated care and improved continuity, the government should continue to support innovations aimed at increasing the development of improved organizational structures and processes geared toward supporting teamwork and integration of health care delivery in ways that is meaningful to patients in terms of meeting their needs. Other promising initiatives are approaches that reimburse the whole care chain and that reward efficient and effective health care delivery when viewed from the perspective of an episode of treatment or other broadly defined unit. There is also a need to develop methods that can be used to assess the degree of coordination in terms of both process and structural levels. The paucity of such tools makes it more difficult to identify problems pertaining to coordination between care providers, develop solutions and evaluate their effect.

5. Define a framework for assessment that reflects the priorities of Swedish patients

Reflecting its commitment to establishing more patient-centered health care in Sweden, the government should invest in work to define what constitutes patient-centered care in ways that reflect the current priorities of Swedish patients. The present study documents a good foundation of work in an international context upon which to build. But ultimately, it is important to understand what dimensions of patient-centered care are prioritized by Swedes and how those dimensions are specifically defined in terms of what constitutes success and failure in meeting the standards implied by each dimension. Such a framework could serve in efforts to establish appropriate monitoring and tracking systems, define areas for attention in government and administrative activity, and provide a common language and understanding for academic research and work by innovators to meet identified needs.

6. Strengthen efforts to assess and track patient centeredness

The government should invest in strengthening the efforts to assess and track patient-centeredness in Sweden's health care. This includes investing in improved and validated indicators and innovative data collection methods. Surveys investigating patient experiences of care are critical prerequisites to the assessment of the degree of patient-centeredness. The Swedish National Patient Survey provides an invaluable source of data that has yet to be fully exploited by patients and patient representatives, as well as for quality-improvement purposes. However, there is need for a comprehensive review of the ownership of the survey data. In order to take full advantage of, and make use of, the patient survey data for such an assessment on a national level, complete transparency and availability of the results is needed. Nonetheless, this is impeded by the fact that each county council is the sole proprietor of the data pertaining to that county council and thereby may block access for outside actors' review and analysis. To address this concern, the government should consider assuming responsibility for the National Patient Survey.

References

Agency for Healthcare Research and Quality, National CAHPS Benchmarking Database, 2006 CAHPS Health Plan Survey Chartbook, Publication No. 06-0081-EF (Rockville, Md.: AHRQ, Sept. 2006).

Agency for Healthcare Research and Quality, 2010 2010 National Healthcare Quality Report, Publication 11-004 (Rockville, Md.: AHRQ, 2011).

Andreasson, S., Essler, U., Fors, U., Johansson, L., Strindhall, M., Winge, M., “Den värdeskapande vårdprocessen– slutrapport från VVP – projektet”, 2009, Available online: http://ki.se/content/1/c6/07/65/44/Slutrapport_VVP_defFullFinal.pdf

Anell, A., Glenngård A.H., Merkur, S., ”Sweden—Health system review”, Health Systems in Transition, Vol. 14 No. 5, 2012.

Arneill, B., Frasca-Beaulieu K., “Healing Environments: Architecture and Design Conducive to Health,” Putting Patients First, S. B. Frampton, et al., San Francisco: Jossey-Bass, 2003, 163–90.

Audet, A-M., Davis J. K., Schoenbaum, S. C., “Adoption of Patient-Centered Care Practices by Physicians,” Archives of Internal Medicine, vol. 166, no. 7, April 10, 2006.

Bardes, C. L., “Defining ‘Patient-Centered Medicine,’” New England Journal of Medicine, 366:782-783, March 1, 2012.

Beach, M. C., Saha, S., Cooper, L. A., The Role and Relationship of Cultural Competence and Patient-Centeredness in Health Care Quality, October 2006.

Berwick, D. M., “What ‘Patient Centered’ Should Mean: Confessions of An Extremist,” Health Affairs, July/August 2009, vol. 28, no. 4:W55-W65.

Berwick, D. M., Wasson, J. H., Johnson, D. J. et al. “Technology for Patient-Centered, Collaborative Care,” Journal of Ambulatory Care Management Special Issue, vol. 29, no. 3, July-September 2006.

The Commonwealth Fund Commission on a High Performance Health System, Why Not the Best? Results from a National Scorecard on U.S. Health System Performance, New York: The Commonwealth Fund, Sept. 2006.

The Commonwealth Fund, "The 2011 Commonwealth Fund International Health Policy Survey", 2011. Available online: www.commonwealthfund.org

Conway, J., Johnson, B., Edgman-Levitan, S. et al., "Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System," background paper for invitational meeting of patient-centered care leaders, June 2006.

Coulter, A., Engaging Patients in Healthcare, Berkshire, England: Open University Press, 2011.

Coulter, A., Cleary, P. D., "Patients' Experiences with Hospital Care in Five Countries," Health Affairs 2001, 20 (3), 244-252.

Coulter, A., Ellins, J., Patient-Focused Interventions: A Review of the Evidence, London: Picker Institute Europe, May 2006.

Cronin, C., "Patient-Centered Care: An Overview of Definitions and Concepts," prepared for the National Health Council, February 10, 2004.

Davies, E., Cleary, P. D., "Hearing the Patient's Voice? Factors Affecting the Use of Patient Survey Data in Quality Improvement," Quality & Safety in Health Care, vol. 14, no. 6, December 2005.

Davis, K., Schoenbaum, S. C, Audet, A-M. J., "A 2020 Vision of Patient-Centered Primary Care," Journal of General Internal Medicine, vol. 20, no 10, October 2005.

De Brantes, F., Camillus, J. A., Evidence-Informed Case Rates: A New Health Care Payment Model (April 2007).

Department of Health (England), National Health Service Patient Experience Framework, October 2011. Available online: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132786.

Edgman-Levitan, S., "Healing Partnerships: The Importance of Including Family and Friends," Putting Patients First, S. B. Frampton et al. San Francisco: Jossey-Bass, 2003, 51–69.

Edgman-Levitan, S., Shaller, D., McInnes K., et al. (eds.), The CAHPS Improvement Guide: Practical Strategies for Improving the Patient Care Experience, Boston: Department of Health Care Policy, Harvard Medical School, 2003.

Ekdahl, A.W., Andersson, L., Friedrichsen, M., "They do what they think is the best for me. Frail elderly patients' preferences for participation in their care during hospitalization", Patient Education and Counseling. 2010 Aug 80(2):233-40.

Ekman, I. et al. "Person-centered care—ready for prime time", European Journal of Cardiovascular Nursing, 2011 Dec 10(4):248-51.

Ekman I., Wolf, A., Olsson, L.E., Taft, C., Dudas, K., Schaufelberger, M., Swedberg, K., "Effects of person-centred care in patients with chronic heart failure: the PCC-HF study", European Heart Journal, 2012 May 33(9):1112-9.

Ekman, I., Kjörk, E., Andersson, B., "Self-assessed symptoms in chronic heart failure--important information for clinical management", European Journal of Heart Failure, 2007 Apr 9(4):424-8.

Ellberg, L, Högberg, U, Lindh, V., "We feel like one, they see us as two: new parents' discontent with postnatal care", Midwifery, 2010 Aug 26(4):463-8.

Entwistle, V., Firnigi, D., Ryan, M., Francis, J., Kinghorn, P., "Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map", Journal of Health Services Research and Policy February 14, 2012.

Forensic Psychiatric Act [Lagen om rättspsykiatrisk vård] SFS 1991:1129.

Garratt, A., Solheim, E., Danielsen, K., National and Cross-National Surveys of Patient Experiences: A Structured Review, A report by the Nasjonalt kunnskapssenter for helsetjenesten (Norwegian Knowledge Centre for the Health Services) to the Organization for Economic Cooperation and Development, 2008.

Gelb Safran, D., Karp, M., Coltin, K., et al. "Measuring Patients' Experiences with Individual Primary Care Physicians: Results of a Statewide Demonstration Project," Journal of General Internal Medicine, vol. 21, no. 1, January 2006.

Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T. L. (eds.), Through the Patient's Eyes San Francisco: Jossey-Bass, 1993.

Groene, O., "Patient Centeredness and Quality Improvement Efforts in Hospitals: Rationale, Measurement, Implementation," International Journal for Quality in Health Care, vol. 23, no. 5, 22 August 2011.

Hasnain-Wynia, R., Baker, D. W., "Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions," Health Services Research, vol. 41, no. 4, pt. 1, August 2006.

Health and Medical Service Act [Hälso- och sjukvårdslagen] SFS 1982:763.

Hibbard, J.H., Stockard, J., Tusler, M., "Hospital Performance Reports: Impact on Quality, Market Share, and Reputation," Health Affairs, July/Aug. 2005 24(4):1150–60.

Hildingsson, I., Rådestad, I., "Swedish women's satisfaction with medical and emotional aspects of antenatal care", Journal of Advanced Nursing, 2005, 52:239-249.

Hildingsson, I., "New parents' experiences of postnatal care in Sweden", Women Birth, 2007 Sep 20(3):105-13.

Institute of Medicine (U.S.), Crossing the Quality Chasm: A New Health System for the 21st Century, Washington, D.C.: National Academies Press, 2001a.

Institute of Medicine (U.S.), Envisioning the National Health Care Quality Report, Washington, D.C.: National Academies Press, 2001b.

International Alliance of Patient Organizations, What is Patient-Centered Health Care? A Review of Definitions and Principles, 2nd edition, 2007.

International Alliance of Patient Organizations, Patient Centered Healthcare Indicators Review (for consultation), prepublication report released for consultation, March 2012.

KEFU: The Council for Local Government Research and Education, "Processorienterad ekonomistyrning i sjukvården", Institute of Economic Research and the School of Management and Economics, Lund University, 2012. Available online: http://www.kefu.se/forskning/stratforsk/processjukvard

Kelley, E., Hurst, J., "Health Care Quality Indicators Project: Conceptual Framework Paper", OECD Health Working Papers, No. 23, OECD Publishing (Paris, 2006).

Klazinga, N., Head of OECD Health Care Quality Indicators Project, Paris, France, personal communication, 2012.

Koslander, T., Arvidsson, B., "Patients' conceptions of how the spiritual dimension is addressed in mental health care: a qualitative study", Journal of Advanced Nursing, 2007 Mar;57(6):597-604.

Lewin, S.A., Skea, Z.C., Entwistle, V.A., Zwarenstein, M., Dick, J., "Interventions for Providers to Promote a Patient-Centered Approach in Clinical Consultations," Cochrane Database System Review 2001; 4, Article No. CD003267.

Lewis, S., Nocon, R. S., Tang, H., et al., "Patient-Centered Medical Home

Characteristics and Staff Morale in Safety Net Clinics," Archives of Internal Medicine, Jan. 9, 2012 172(1):23–31.

Luxford, K., Gelb Safran, D., Delbanco, T., "Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience," International Journal Quality Health Care, first published online May 16, 2011.

Lynöe N., Wessel, M., Olsson, D., Alexanderson, K., Helgesson, G., "Respectful encounters and return to work: empirical study of long-term sicklisted patients' experiences of Swedish healthcare", BMJ Open, 2011.

Mead, N., Bower, P., “Patient-centered Consultations and Outcomes in Primary Care: A Review of the Literature,” Patient Education and Counseling, vol. 48, 51-61, 2001.

Michie, S., Miles, J., Weinman, J., “Patient-centeredness in Chronic Illness: What Is It and Does It Matter?” Patient Education and Counseling, vol. 51, 197-206, 2003.

Miller, H. D., Creating Payment Systems to Accelerate Value-Driven Health Care: Issues and Options for Policy Reform, September 2007.

Mockford, C., Stainszewska, S., Griffiths, F., Herron-Marx, S., “The Impact of Patient and Public Involvement on UK NHS Health Care: A Systematic Review,” International Journal for Quality in Health Care, Vol. 24, No. 1, 28-38.

Modig, N., Åhlström, P., Vad är Lean? En guide till kundfokus och flödeseffektivitet, Stockholm, 2011.

National Audit Office, ”Statens insatser vid anmälningar av vårdskador, kommer patientet till tals?”, Riksrevisionen RiR 2007:23.

National Board of Health and Welfare, ”God Vård – om ledningssystem för kvalitet och patientsäkerhet i hälso- och sjukvården”, Socialstyrelsen, 2006.

National Board of Health and Welfare, ”Health Care Report 2009”, (in English), Socialstyrelsen, 2009.

National Board of Health and Welfare, Hälso- och sjukvårdsrapport 2009, Socialstyrelsen, 2009.

National Board of Health and Welfare, ”Lägesrapport 2010, Folkhälsa, Hälso- och sjukvård, Individ och familjeomsorg, Stöd och service till personer med funktionsnedsättning, Vård och omsorg om äldre”, Socialstyrelsen, 2010.

National Board of Health and Welfare,”National Indicators for Good Care -- A Basis for Discussion”, Socialstyrelsen, 2008.

National Board of Health and Welfare, ”Nationella indikatorer för God vård – Hälso- och sjukvårdsövergripande indikatorer, - Indikatorer I Socialstyrelsens nationella riktlinjer”, Socialstyrelsen, 2009.

National Board of Health and Welfare, ”Stöd till personer som vårdar eller stödjer närstående, Lägesbeskrivning 2011”, Socialstyrelsen 2011.

National Board of Health and Welfare, ”Tillståndet och utvecklingen inom hälso- och sjukvård och socialtjänst, Lägesrapport 2012”, Socialstyrelsen, 2012.

National Board of Health and Welfare, ”Vårdkö och kömiljard – uppföljning 2009-2011”, Socialstyrelsen, 2012.

National Board of Health and Welfare and Swedish Association of Local Authorities and Regions, Quality and Efficiency in Swedish Health Care, Regional Comparisons 2008 (in English), Socialstyrelsen, 2008.

National Commission on Patient Empowerment [Patientmaktsutredningen] Statens offentliga utredningar, Socialdepartementet, S 2011:03.

National Institute for Health and Clinical Excellence, Patient Experience in Adult NHS Services Quality Standard, updated 1 March 2012. Available online: http://www.nice.org.uk/guidance/qualitystandards/patientexperience/home.jsp.

National Patient Survey, Institutet för kvalitetsindikatorer, 2010, 2011. Available online: http://www.indikator.org/publik/

Nordberg, G., von Strauss, E., Kåreholt, I., Johansson, L., Wimo, A, ”The amount of informal and formal care among non-demented and demented elderly persons – results from a Swedish population-based study”, International Journal of Geriatric psychiatry, 20(9):862-71, 2005.

O’Connor, A.M., Stacey, D., Entwistle, V., et al., “Decision Aids for People Facing Health Treatment or Screening Decisions (Cochrane Review),” The Cochrane Library, Issue 1, Chichester, U.K.: John Wiley & Sons, Ltd., 2004.

Olsson, L-E., Karlsson, J., Ekman, I., “The integrated care pathway reduced the number of hospital days by half: a prospective comparative study of patients with acute hip fracture”, Journal of Orthopaetic Surgery Research, 2006 Sep 25; 1:3.

Olsson, L-E., Hansson, E., Ekman, I., Karlsson, J., “A cost-effectiveness study of a patient-centred integrated care pathway”, Journal of Advanced Nursing, 2009 Aug 65(8):1626-35

O’Malley, A., Carrier, E. R., Docteur, E., Shmerling, A. C., Rich, E. C., “Policy Options to Encourage Patient-Physician Shared Decision-Making,” National Institute for Health Care Reform Policy Analysis, 2011, available online at: http://www.nihcr.org/Shared-Decision-Making.html

Open Comparisons – National strategy for quality development through open comparisons within health care and social services, 2009, Available online: http://www.regeringen.se/content/1/c6/13/63/49/a3dfa6f7.pdf

Osborn, R., Squires, D., “International Perspectives on Patient Engagement: Results from the 2011 Commonwealth Fund Survey,” Journal of Ambulatory Care Management, April/June 2012 35(2):118–28.

Patient Data Act [Patientdatalagen] SFS 2008:355.

Patient Safety Act [Patientsäkerhetslag] SFS 2010:659.

Peyrot, M, Rubin, R.R., Lauritsen, T., et al., “Patient and provider perceptions of care for diabetes: results of the cross-national DAWN Study”, Diabetologia, 2006 49:279-288.

Psychiatric Compulsory Act [Lagen om psykiatrisk tvångsvård] SFS 1991:1128.

Quality Matters: Patient-Centered Care (March/April 2007). Newsletter.

Rave, N., Geyer, M., Reeder, B., et al., "Radical Systems Change: Innovative Strategies to Improve Patient Satisfaction," Journal of Ambulatory Care Management, April/June 2003 26(2):159–74.

Rosén, M., "Översyn av de nationella kvalitetsregistren – Guldgruvan i hälso- och sjukvården – förslag till gemensam satsning 2011-2015", report by LIF the research-based pharmaceutical industry in Sweden.

Schoen, C., Osborn, R., Huynh, P. T., Doty, M. M., Davis, K., Zapert, K., Peugh, J., "Primary Care and Health System Performance: Adults' Experiences in Five Countries," October 28, 2004, Health Affairs Web Exclusive.

Schoen, C., Osborn, R., Squires, D., Doty, M. M., Pierson, R., Applebaum, S., "New 2011 Survey of Patients with Complex Care Needs in 11 Countries Finds That Care Is Often Poorly Coordinated," Health Affairs Web First, Nov. 9, 2011.

Shaller, D., "Patient-Centered Care: What Does it Take?" Report produced for the Picker Institute and published by the Commonwealth Fund, October 2007.

Shortell, S.M., Schmittdiel, J., Wang, M. C., et al., "An Empirical Assessment of High-

Performing Medical Groups: Results from a National Study," Medical Care Research and Review, Aug. 2005 62(4):407–34.

Social Services Act [Socialtjänstlagen] SFS 1980:620, new Act adopted 2002-01-01: SFS 2001:453.

Stewart, M. "Towards a Global Definition of Patient-Centred Care: The Patient Should Be the Judge of Patient-Centred Care," British Medical Journal 322: 444-445, 2001.

United States Agency for International Development, 1999.

Üstün, TB., Chatterji, S., Villanueva, M., et al. WHO Multi-country Survey Study on Health and Responsiveness 2000-2001. World Health Organization, 2001.

Weinberg, D. B., Hoffer Gittell, J., Lusenhop, R. W., et al., "Beyond Our Walls: Impact of Patient and Provider Coordination Across the Continuum on Outcomes for Surgical Patients," Health Services Research, vol. 42, no. 1, pt. 1, February 2007.

Wensing, M., Baker, R., Szecsenyi, J., et al, on behalf of the EUROPEP Group, "Impact of national health care systems on patient evaluations of general practice in Europe", Health Policy 2004;68:353-357.

Wessel, M., Lynöe, N., Juth, N., Helgesson G., "The Tip of An Iceberg? A Cross-Sectional Study of the General Public's Experiences of Reporting Health Care Complaints in Stockholm, Sweden," BMJ, 2012.

Winblad, U., Från beslut till verklighet – Läkarnas roll vid implementeringen av valfrihetsreformer I hälso- och sjukvården, Disertation Thesis, Department of Public Health and Caring Sciences, Uppsala University 2003.

Winblad, U., Andersson, C., “Kåren och köerna – En ESO-rapport om den medicinska professionens roll i styrningen av svensk hälso- och sjukvård”, Expertgruppen för studier i offentlig ekonomi 2010:9, Ministry of Finance.

Winblad, U., Andersson, C., ”Vilken information behöver patienter och medborgare för att välja vårdgivare och behandling? Patienters och medborgares behov av kvalitetssäkrad och tillgänglig information”, Department of Health and Caring Sciences, Uppsala Universitet, 2011.

Wolf, D. M., Lehman, L., Quinlin, R., Zullo, T., Hoffman, L., FAAN, “Effect of Patient-Centered Care on Patient Satisfaction and Quality of Care,” Journal of Nursing Care Quality, October/December 2008, Vol. 23(4):316-321.

Wynia, M., Jennifer M., Promising Practices for Patient-Centered Communication with Vulnerable Populations: Examples from Eight Hospitals, August 2006.

Annex I
What we did

Reflecting a growing policy interest in ensuring that health systems meet the needs and expectations of the patients they serve, the Swedish Agency for Health and Care Services Analysis initiated a study to assess the degree to which Sweden's health system can be considered to be "patient-centered," or responsive to the specific and particular needs, values and preferences of the actual and potential users of health care services. The study's objective is to strengthen the position of patients by identifying how Sweden can obtain a more patient-centered health care. The study's charge was to answer several questions, namely:

1. What type of analytical framework can be used to assess the extent to which Sweden's health care system is patient-centered?
2. To what extent is Sweden's health care system patient-centered?
3. What changes in policy could help to strengthen the degree of patient-centeredness in Sweden's health care system?

In the first phase of this two-phase project, we produced a framework for assessment of a health system's patient-centeredness that could serve as a basis for assessment in the present study, as well as for occasional or regular system monitoring in the future. The assessment framework could also be modified to incorporate any newly developed information, such as information on Swedish patients' priorities and concerns.

Selection and elaboration of the framework for assessment proposed in this report was informed by a review of publications in the health policy, health services administration, and health services research spheres, as well as activities undertaken by international organizations and government actors in selected countries.

The draft framework for assessment presented in this report was subjected to peer review by a selected group of expert advisors with practical, policy and academic expertise. After making revisions to reflect comments and suggestions made by the reviewers, a second draft was submitted for review by officials from Vårdanalys and a team of independent reviewers selected by the agency.

The second phase of the study involved application of the framework to assess the patient-centeredness of Sweden's health system. Work to assess the patient-centeredness of Sweden's health system began with a stocktaking of existing data sources. The objective of this exercise was to determine where good information exists that can be used for assessment, where good information can be readily developed, and where a longer-term investment in data development would be needed.

The following served as main sources of data for the present study:

- Review of published findings from patient experience surveys, including surveys fielded in Sweden and international surveys including Swedish patients;
- Original expert and stakeholder interviews; and
- Review of academic and policy research findings on patient-centeredness in Sweden, based on an original literature review.

Patient experience data, drawn from patient surveys, constituted a very important source of information for assessing patient-centeredness. In this study two main surveys were used, the National Patient Survey (2010, 2011) and the international Commonwealth Fund survey (2011) on sicker adults.

The Commonwealth Fund International Health Policy Survey (IHP) from 2011 is a cross country survey comparing sicker adults' experiences of health care. Eleven countries participated in the study, including Sweden.

The National Patient Survey (Nationell Patientenkät) is authorized by the Swedish Association of Local Authorities (Sveriges Kommuner och Landsting) and includes a large number of questions about the patient experience with health care delivery. Response rates have been between 55 and 65 percent, with the exception of the psychiatric care surveys, which had response rate of only 35 percent (inpatient) and 43 percent (outpatient). For the purpose of the present study, this is a concern to the extent that the views of non-respondents may not fully correspond with those of the patients who do participate in the survey.

Another source of data generated for the study, was information from expert interviews. A number of experts from organizations established to represent and advocate on behalf of the interests of patients with particular types of health conditions were consulted to identify strengths and weaknesses of the health system from the perspective of patients with particular health care needs. Experts from government were consulted to identify developments in policy relating to patient-centered care. Academic experts were consulted to understand the state of the art in research pertaining to patient-centeredness in Swedish health care.

Undertaking the assessment involved a synthesis of information obtained from interviews with 34 Swedish experts (see list of experts and their affiliations in Annex II) representing patients, providers, government and other stakeholders, supplemented with illustrative examples drawn from a review of findings from academic research studies, government reports, and analysis of data from patient surveys and reports from patient organizations regarding type and amount of complaints. The findings were further informed by review of relevant legislation, regulations and recent public inquiries undertaken in Sweden.

On the basis of conclusions drawn from assessment of the evidence and crafted with input from experts familiar with Sweden's current health policy environment, we developed policy recommendations that can serve to generate and inform debate regarding possible future reforms. We also identified actionable, technical recommendations for ways in which to strengthen the ability to assess and monitor patient-centeredness in Sweden's health system in the future.

Annex II
List of experts interviewed

Marianne Aggestam, Program Officer, National Board of Health and Welfare
Kjell Asplund, Professor of Medicine, Chair of the Swedish National Council on Medical Ethics
Ingrid Burman, Chair of the Swedish Disability Federation
Daniela Bjarne, Special Advisor, Stroke Association
Agneta Calleberg, Stockholm Patient Advisory Committee
Johan Calltorp, Professor, Health Policy and Management, Jönköping Academy for Health Improvement
Inger Ekman, Director, University of Gothenberg Centre for Person-Centred Care
Birgitta Eriksson, National Board of Health and Welfare (retired)
Lars Fallberg, Director, Indikator Institute
Maria Gardsäter, Project Leader, Rare Diseases Association
Maria Hägglund, Post-doctorate researcher, Health Informatics Centre, Karolinska Institute
Åke Hedin, Association Secretary, Heart and Lung Association
Kerstin Holmberg, Gothenburg Patient Advisory Committee
Inger Holmström, Associate Professor, Department of Public Health and Caring Sciences, Uppsala University
Maria Jacobsson, Legal Specialist, National Board of Health and Welfare
Eva Jangland, Department of Surgical Sciences, Uppsala University
Ingrid Kössler, former Chair, Swedish Breast Cancer Association
Stig Lindahl, Member of the board, Prostate Cancer Association
Birgitta Lindelius, Program Officer, National Board of Health and Welfare
Annelie Liljegren, Chief Physician, Clinic for Oncology, Karolinska University Hospital

Anders Lönnberg, Chair, Stockholm Diabetes Association
Niels Lynöe, Professor, Specialist in General Medicine, Department of Learning, Informatics, Management and Ethics, Karolinska Institute
Henrik Moberg, Special Advisor, Ministry of Health and Social Affairs
Roger Molin, National Coordinator for Patients' Choice of Care, Ministry of Health and Social Affairs
Tommy Nordqvist, Gothenburg Patient Advisory Committee
Jesper Olsson, Special Advisor, Ministry of Health and Social Affairs
Olle Olsson, Program Officer, Swedish Association of Local Authorities and Regions
Lennart Persson, Chief Executive Officer, Uppsala University Hospital
Heidi Stensmyren, Specialist in Anaestesiology and Intensive Care, Second Vice President, The Swedish Medical Association
Kristina Söderlund, Communication Officer, Swedish Rheumatism Association
Karl Swedberg, Senior Professor, University of Gothenburg
Sofia Tullberg, Project Leader, Swedish Association of Local Authorities and Regions
Jimmie Travett, Chair, Social and Mental Health Association
Sven Wåhlin, Specialist in General Medicine, Stockholm

Annex III
Survey questions included in unweighted index (IHP 2011)

Dimension 1:

- When you receive care or treatment, how often does your regular doctor or someone in your doctor's practice encourage you to ask questions? Percentage answering always.
- When you receive care or treatment, how often does your regular doctor or someone in your doctor's practice explains things in a way that is easy to understand? Percentage answering always.
- During the past year, when you received care, has any health care professional you see for your condition(s) given you clear instructions about symptoms to watch for and when to seek further care or treatment? Percentage answering yes.
- Before you had surgery, were you well-informed and prepared for what the recovery would be like? Percentage answering yes, definitely.
- When you have received care or treatment from specialists, how often did they give you an opportunity to ask questions about recommended treatment? Percentage answering always.
- When you have received care or treatment from specialists, how often did they tell you about treatment choices? Percentage answering always.
- When you left the hospital did you receive clear instructions about symptoms to watch for and when to seek further care? Percentage answering yes.
- When you left the hospital were you given very clear instructions about

what medicines you should be taking? Percentage answering yes.

- When you left the hospital, did you know who to contact if you had a question about your condition or treatment? Percentage answering yes.

Dimension 2: *Respecting patients' individual needs, preferences and values*

- When you receive care or treatment, how often does your regular doctor or someone in your doctor's practice spend enough time with you? Percentage answering always.
- When you have received care or treatment from specialists, how often did they involve you as much as you want to be in decisions about your treatment or care? Percentage answering always.
- During the past year, when you received care, has any health care professional you see for your condition(s) discussed with you your main goals or priorities in caring for your condition(s)? Percentage answering yes.
- During the past year, when you received care, has any health care professional you see for your condition(s) helped you make a treatment plan that you could carry out in your daily life? Percentage answering yes.

Dimension 3: *Coordinating care across service providers and ensuring continuity of care*

- In the past 2 years, was there ever a time when doctors or other health care professionals failed to share important information about your medical history or treatment with each other? Percentage answering no.
- When you saw the specialist did he or she have information about your medical history? Percentage answering yes.
- After you saw the specialist or consultant, did your regular GP seem informed about the care you got from the specialist or consultant? Percentage answering yes.
- How often does your regular doctor / GP or someone in your doctor's / GP's practice help coordinate or arrange the care you receive from other doctors and places, such as make appointments? Percentage answering always.
- When you left the hospital, did the hospital staff provide you with a written plan for your care after discharge/Did the staff provide you with a written plan for your care after discharge from surgery? Percentage answering yes.

The task of the Swedish Agency for Health and Care Services Analysis (Vårdanalys) is to follow up and analyze health care, dental care, and the interface between health and social services from the perspective of patients and citizens. Vårdanalys takes the needs of the patients and the users as the starting-point in the investigations. The mission of Vårdanalys is to contribute to quality and efficiency improvements that benefit patients and citizens.

vårdanalys