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# Patient-Centeredness in Sweden's Health System

An assessment and six  
steps for progress



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# **Patient-Centeredness in Sweden's Health System**

An assessment and six steps for progress

Elizabeth Docteur and Angela Coulter

## **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 progress in recent years, in enhancing and improving patient information and education efforts. Nevertheless, in light of evident shortfalls, more efforts are needed to ensure that patients are informed and are otherwise adequately equipped to partner with their providers to ensure good health outcomes.
- ▶ Sweden's health care system often fails to anticipate, and respond to, patients as individuals with particular needs, values and preferences. Failure to involve patients in their own health care can have demonstrable costs for patients, the health system and public finances.

- ▶ Inadequate coordination of care across health care providers is a major weakness of the Swedish healthcare system. Such problems are likely to have a negative impact on health outcomes and costs, in addition to how patients experience 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 that would benefit 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



## 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 concept. 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 our progress towards that goal. In light of this, the Swedish Agency for Health and Care Services Analysis (*Myndigheten för vårdanalys*) commissioned an external evaluation of patient-centeredness in the Swedish health care system.

The external study was instructed 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?

The Swedish Agency for Health and Care Services Analysis is grateful that Elizabeth Docteur and Angela Coulter agreed to carry out the commissioned study.

Elizabeth Docteur is an independent health policy consultant with twenty 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.

The Agency 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.

The Swedish Agency for Health and Care Services Analysis 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 the Agency in carrying out the study. The Swedish Agency for Health and Care Services Analysis 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 Appendix I: What we did). This type of study has distinct advantages, 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 must paint with broad strokes and ultimately 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 be viewed as conclusive but rather as observations for further debate and exploration.

The highlights of this report were published separately in July this year and presented at a policy seminar in Almedalen. The report and the seminar contributed to making “patient-centeredness” the key theme of the health care debate in Almedalen. The Agency is now very pleased to receive this full 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, such as 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 the Swedish Agency for Health and Care Services Analysis, 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, and for an insightful and thought-provoking report, and am now proud to share it with all who are interested in making Swedish health care more patient-centered.

Stockholm, November 2012  
Fredrik Lennartsson  
Executive Director  
Swedish Agency for Health and Care Services Analysis  
(*Myndigheten för Vårdanalys*)



## Summary

Because meeting the needs, values and preferences of the users of health care services is increasingly seen as a critical aspect of health-system performance, policy makers in a number of countries have articulated policy goals pertaining to making their systems more patient-centered. A patient-centered health care system is one that is designed for and operates on behalf of the patients whom it serves. A growing body of evidence demonstrates that patient-centered health care produces better health outcomes and greater patient satisfaction. In addition to its intrinsic value, this approach can also produce savings for health systems and society, through better patient compliance with prescribed treatments and a quicker return to work.

Survey findings showing that Swedish patients are more likely than patients in many other countries to experience problems due to inadequate coordination of their care, and that Swedish patients are among the least engaged by their physicians and least involved in their own health care decision-making have drawn recent attention in Sweden.

It is with these developments in view that the Swedish Agency for Health and Care Services Analysis (*Myndigheten för vårdanalys*), commissioned the present study to strengthen the position of patients by identifying how Sweden can obtain a more patient-centered health care.

In undertaking the present study, we examined models of patient-centeredness and selected a framework for assessment comprising five core dimensions used in leading international frameworks. We applied the framework to assess how well Swedish health care can be characterized as fulfilling those dimensions, and explored what characteristics of the health system either facilitate or impede Sweden's progress. Finally, we developed a number of recommendations for possible avenues for accelerating and supporting progress toward a more patient-centered health care system.



## **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 standard, 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.

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

- 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; and
- Involving family and close friends in the health care experience, to the extent desired by the patient.

In addition to assessing the system's performance along these specific dimensions, we also sought to identify and describe issues that cut across these dimensions, with a particular emphasis on those facilitators of, or barriers to, achieving a more patient-centered health care system in Sweden.

## **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. The system benefits from strengths that provide a good foundation on which to build when making needed effort to accelerate progress. Yet there are barriers that have impeded progress; tackling these can help to accelerate change.

## 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 efforts. Nevertheless, in the light of evident shortfalls, more efforts are needed to ensure that patients are informed and otherwise equipped to partner with their providers to ensure good health outcomes.*

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

Swedish law obliges caregivers to provide patients with certain information, although evidence shows this obligation is not always met. Patients are not well-informed about the legal protections afforded to them, and information to support provider choice is limited and used to only a limited degree. Swedish patients are more likely than their international counterparts to say that their providers do not spend enough time with them, do not present options for treatment, and do not give them opportunities to ask questions. Doctors often fail to tell patients about the side-effects of their medicines and the danger signals to watch out for.

Furthermore, findings show that relatively little information, education and support for decision-making is as yet available to assist Swedish patients who want to take a more active part in their health care process, and that the information 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 among different treatment options, information to facilitate self-care, and options to exchange important information about health and symptoms together with the care provider.

This substandard performance 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 contribute to shortened office visits, which may constrain the dialogue between patients and providers.

Moreover, the bifurcated responsibilities of the national government and county councils contribute to a discontinuity between legal standards and actual practice.



Swedish patients do reasonably well, however, in terms of telephone access to providers. And information portals such as the 1177 website and telephone support service are increasingly used by patients and regarded as successful, although still requiring further development.

## **DIMENSION 2: RESPECTING PATIENTS' NEEDS, PREFERENCES AND VALUES AS INDIVIDUALS**

- ▶ *Sweden's health care system very often fails to anticipate and respond to patients as individuals with particular needs, values and preferences. Failure to involve patients in their own health care has demonstrable costs to patients, the health system and public finances.*

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 service delivery are designed to anticipate and respond to patients' concerns, and to solicit meaningful patient input in all decisions about how health care is furnished.

Health care in Sweden too often fails to meet patients' needs, preferences and values. Swedish patients reported the lowest scores among patients in 11 countries surveyed in 2011. Swedish patients are least likely to be engaged by their providers as partners in their care and treatment decisions. Notably, low patient engagement is associated with a range of poor outcomes, including medical errors.

This is not to say there are no positive findings upon which to build in the future. 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 upon optimal treatment. The concept of shared decision-making between patient and provider has yet to take root in Sweden.

Time constraints and attitudinal issues help to explain why patients' needs to be treated as individuals with unique needs, values and preferences are not adequately met in Sweden today. According to the views of experts interviewed for this study, Swedish health care is organized for administrative convenience rather than patient or even provider convenience. Some promising examples of efforts to shake up this paradigm are evident, but they remain the exception rather than the rule.

### DIMENSION 3: COORDINATING CARE ACROSS SERVICE PROVIDERS AND ENSURING CONTINUITY OF CARE

- ▶ *Inadequate coordination across healthcare providers is a major, widespread and persistent 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.*

Coordination of care, to obtain optimal service in a particular episode of treatment and to ensure good continuity of care over the long term, is a core conceptual dimension of patient-centered 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.

Key problems identified in the course of the present study include:

- Poor performance in terms of international comparisons on structural and procedural instruments for care 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;
- Minimal impact to date of the “point of contact” reform in establishing a patient resource for health system navigation, care coordination and continuity;
- Inadequate cooperation between health and social services;
- Technical problems in the functioning of electronic medical records that impede their full use to better coordinate and ensure continuity of care; and
- Problems in continuity and coordination for populations like the sickest elderly.

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



#### **DIMENSION 4: TAKING A HOLISTIC APPROACH TO PATIENTS AS PEOPLE WITH MEDICAL AND NONMEDICAL (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.*

This core element of patient-centered health care recognizes that health care is a profoundly important and personal experience that 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.

Caregivers and administrators can do more to take a holistic view of patients, so as to better meet their needs. Relatively low performance variation across counties suggests that this may not be an area in the administration of health care by the county councils that has had a particular impact. To find models for improvement, it may be useful to look instead at particular hospitals that scored highest for examples of best practices.

Our findings also suggest the need for further work to explore what the concept of holistic care means to Swedish patients. In particular, it would be useful to examine what patients expect in terms of acknowledgement of their spiritual needs, taking into account the country's growing multiculturalism.

Ultimately, treating patients more holistically may require more coordinated 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.

#### **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, 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.*



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. Many patients consider that their family members and close friends play a central role in how they experience illness. Health care that involves loved ones in decision making, supports the caregiving role, and recognizes the needs of family and close friends are considered to be very important to patients.

While evidence as to the extent to which Swedish patients need to facilitate the involvement of friends and family in their health care are being met is somewhat limited, available data suggests that there is room for improvement. Issues that would benefit from further investigation include:

- Involvement of family and close friends in the care of psychiatric patients;
- Changes in hospital protocols relating to the partners of maternity patients;
- Potential problems in the ability to designate proxies to act on a patient's behalf, in case of incapacity associated with a condition or medical treatment; 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 knowledge of protections and support afforded by law. And as with other dimensions, there appears to be a discontinuity or lag between enactment of protections and implementation of those protections in actual practice. Finally, this appears to be an area in which improved cooperation between national government authorities and local health care administrators has the potential to yield important benefits.

The activities of the many patient organizations in Sweden that receive public funding can facilitate increased involvement of close family and friends in health care. Many of these patient organizations are already active in providing education about diseases and support to patients' relatives.

## **CROSS-CUTTING ISSUES: FACILITATORS AND BARRIERS TO ACHIEVING 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 were identified in the course of this study.



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

Sweden's accomplishments in achieving an effective and relatively cost-efficient health system that achieves good health care outcomes provide a strong foundation for renewed focus on enhancing patient-centeredness.

## **The potential to utilize patient data**

Sweden's relatively strong performance in terms of health data infrastructure can serve to power a drive to enhanced patient-centeredness. Existing data shows a great deal of untapped potential.

## **Patient-centeredness as a public priority**

Growing attention by political and other leaders to the issue of patient-centeredness in health care is manifest in terms of legal and regulatory steps to strengthen patient-centeredness, such as recent provisions allowing patients to name 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. Refining priorities and ensuring 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 still at an early stage of development. Challenges for the future are also evident. Notably, for example, there is not yet a universally agreed definition of patient-centered care and associated conceptual framework with validated indicators for assessment.

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

Promoting patient choice and increasing competition among providers can facilitate advances in patient-centeredness. Nevertheless, competition alone will not serve to ensure patient-centered care for all. The most vulnerable may be incapable of informed choice or unable to act on choice. These include, for example, those whose rare conditions render them with few local options for care. Providers are unlikely to compete for patients with rare and costly conditions. Choice and competition-based approaches require complementary steps, such as establishing 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**

Improvements are needed in terms of informing patients of protections, guarantees and other opportunities afforded to them in the law. Also needed are better mechanisms for enforcing legal obligations and remedies for patients who have not been treated in the manner legally prescribed, and ensuring that laws enacted promptly translate into changes in practice.

## **Local administration means both benefits and disadvantages for patient-centeredness**

Local financing and administration of health care contributes to the lag between the passage of laws and changes in practice, and provides the national government with relatively few levers to accelerate change. Drawbacks such as inequities across the country are evident, as both financing and capacity for implementing improvements in patient-centered care vary across counties according to local choices and resources.

## **Challenges from cost-containment pressure**

Cost-containment pressure presents challenges in terms of finding resources for improving patient-centeredness. There is a need to identify investments in patient-centered care that have the potential to reduce costs, by increasing compliance and reducing complications, for example.

## **Need for attitudinal changes**

Advancing 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 in the center of health-care decision-making, and of patients themselves, who will be invited to take on a more active role in their health care.

## **POLICY RECOMMENDATIONS: SIX STEPS TOWARD A MORE PATIENT-CENTERED CARE**

We offer a prescription for improving Sweden's patient-centeredness and accelerating progress:

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

A fundamental shift in the perception of obligations toward patients is need-



ed. The government must prioritize strong mechanisms to monitor and ensure compliance with the law.

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

Information and decision tools need to be promoted to facilitate active partnership between patients and their providers, for example, by affording patients a choice of providers and treatments, and self-management.

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

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.

## **4. Sustain efforts to facilitate coordination and continuity of care**

To obtain more coordinated care and improved continuity, the government should support innovations aimed at increasing the development of improved organizational structures and processes that foster teamwork and integration of health care delivery.

## **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.

## **6. Strengthen efforts to assess and track patient-centeredness**

Steps are needed to strengthen monitoring of patient-centeredness in Sweden's health care, including validated indicators and innovative data collection methods.





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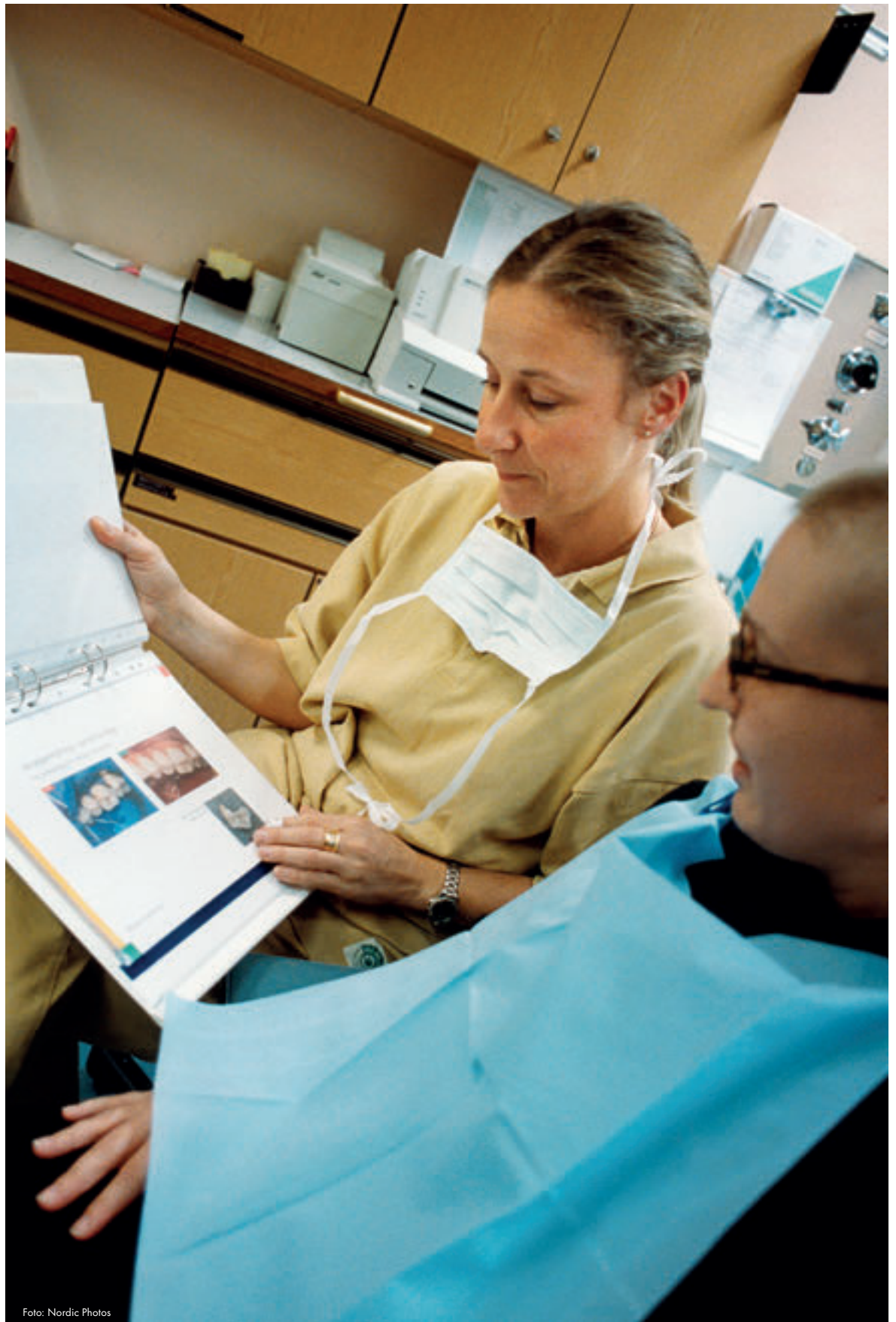


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## Introduction

The extent to which health care and health systems are responsive to the specific and particular needs, values and preferences of the actual and potential users of health care services is increasingly recognized in health policy circles 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,” and, as discussed later in this report, 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, both within Sweden and internationally.

Patient-centeredness has been squarely in the lens of health services researchers for more than a decade, resulting in a fairly rich literature on considerations such as what factors are associated with a health care delivery system’s being patient-centered, and to what extent patient-centeredness is associated with desired outcomes, such as patient and provider satisfaction, more effective and appropriate care, and more efficient delivery of health services. Policy makers also are increasingly focused on patient-centeredness as a goal, with a number of countries, including Australia, Canada, the United Kingdom, and the United States having articulated policy goals pertaining to improving patient-centeredness, 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 (WHO) 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.

Several studies have highlighted shortfalls of health care and health systems in terms of patient-centeredness, some of which have garnered public attention and even 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 (Schoen, et al., 2011), 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 (Osborn and Squires, 2012), 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 (*Myndigheten för vårdanalys*), launched the present work geared to assessing the degree to which Sweden's health system can be considered to be patient-centered. The study's objective is to strengthen the position of patients by identifying how Sweden can obtain a more patient-centered health care. Its 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?

To answer these questions, we examined the state of the art in conceptualizing and operationalizing models of patient-centeredness, and selected a framework comprising five core dimensions used in leading international frameworks for use in the assessment undertaken in this study. We then applied this 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 data for this assessment were patient survey data on Swedish patients' experiences with the health care system, original interviews with representatives of Swedish patients and other experts on Swedish health care, and academic and policy research literature. Finally, we developed a number of policy recommendations

for possible avenues for accelerating and supporting progress toward a more patient-centered health care system.

## 1.1 ROADMAP

This report begins with an overview of the concept of patient-centered care, examining how the term has been used and in what contexts, and looking at the evidence basis for endorsing patient-centered care as a goal of a high-performing health system. Subsequent sections of the report consider how to conceptualize and operationalize a definition of patient-centeredness for purposes of making an assessment of Sweden's health system, with consideration of types of data and available benchmarks. This is followed by a presentation of findings from a preliminary assessment of patient-centeredness in Sweden's health system, including a set of recommendations geared at supporting and strengthening the move to a more patient-centered health system in Sweden. The appendices to this report present more details on the methodology used in this study and provide the names of experts who were interviewed.











## Patient-centered care as a health system performance goal

In this section we review several of the most prominent and influential efforts to define and assess patient-centeredness in health care, as well as recent activities in Sweden. Our review shows that work to assess the patient-centeredness of health systems is still in relatively early stages. There is a range of terms being used to refer to the general notion of health systems being responsive to their users, although the term “patient-centeredness” is commonly used. There is no single commonly agreed definition of the term patient-centeredness in widespread use at present, nor is there a commonly agreed set of dimensions by which to operationalize the definition. Finally, although there have been efforts by authorities to report on patient-centeredness at the national level, within Sweden and countries such as the United States and the United Kingdom, these efforts are quite new and measurement and interpretation of results remain at an early stage of development.

### 2.1 PICKER INSTITUTE DEVELOPS PATIENT-CENTEREDNESS CONCEPT AND MEASURES

The Picker Institute is widely acknowledged to have played a leading role in advancing concern about “patient-centered care.” Beginning in 1987, The Picker Institute conducted focus groups and telephone interviews with U.S. patients and families in an effort to learn what aspects of the patient care experience are most important to patients. On the basis of this work, the Institute created survey instruments that measure the patient’s experience of care across the following dimensions (Gerteis et al., 1993):



- Respect for patients' values, preferences, and expressed needs, including an awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient needs and autonomy.
- Coordination and integration of care across clinical, ancillary, and support services and in the context of receiving "frontline" care.
- Information, communication, and education on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care, and health promotion.
- Physical comfort, including pain management, help with activities of daily living, and clean and comfortable surroundings.
- Emotional support and alleviation of fear and anxiety about issues such as clinical status, prognosis, and the impact of illness on patients, their families and their finances.
- Involvement of family and friends in decision-making and awareness and accommodation of their needs as caregivers.
- Transition and continuity as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions.
- Access to care, with attention to time spent waiting for admission or time between admission and placement in a room in the inpatient setting, and waiting time for an appointment or visit in the outpatient setting. [Although the principle of access was not part of the original seven-dimension framework, this dimension was added subsequently.]

These principles have influenced the efforts of governments and other institutions to define standards of care. For example, the principles were recently adapted by the Department of Health in England as the National Health Service's Patient Experience Framework (Department of Health, 2011).

The Picker Institute surveys are used by organizations for quality improvement purposes in the United Kingdom, the United States, Germany and Switzerland.

## **2.2 THE WORLD HEALTH ORGANIZATION DEFINES AND ASSESSES RESPONSIVENESS**

In the 2000 World Health Report, the World Health Organization identified "responsiveness" as one of three aims of health systems, together with producing health and being fair (WHO, 2000). The notion of responsiveness was considered to have two dimensions:

- respect for human beings as persons, which entails appreciation of human dignity, confidentiality and autonomy; and
- client orientation, including prompt and timely service, adequate amenities, access to social support and freedom to choose providers.

While this framing is consistent with approaches used elsewhere, the WHO standards are global in application and thus may not be as finely pinpointed to the specific needs and expectations of the more developed countries.

To assess the extent to which world health systems could be considered “responsive” in terms of respect for persons and client orientation, the World Health Organization commissioned a survey resulting in interviews with 1790 key informants in 35 countries (WHO, 2000). It found that the nations with the most responsive health systems were the United States, Switzerland, Luxembourg, Denmark, Germany, Japan, Canada, Norway, Netherlands and Sweden. In its report, WHO (2000) explained that the reason these are all advanced industrial nations is that a number of the elements of responsiveness depend strongly on the availability of resources, and that many of these countries were the first to begin addressing the responsiveness of their health systems to people’s needs.

While the World Health Organization also employs the term “patient-centered care” in some publications, the term has not been defined in the WHO Health Promotion Glossary. The WHO European Observatory on Health Systems and Policies adopted the definition put forward by the U.S. Agency for International Development: “An approach to care that consciously adopts a patient’s perspective. The perspective can be characterized around dimensions such as respect for patients’ values, preferences, and expressed needs in regard to coordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, involvement of family and friends, transition and continuity” (USAID, 1999).

### 2.3 THE UNITED STATES DEFINES AND ASSESSES PATIENT-CENTEREDNESS

In 2001, the U.S. Institute of Medicine (IOM) named patient-centered care as one of the six fundamental aims of the U.S. health care system. In their highly influential report, *Crossing the Quality Chasm*, the IOM defined patient-centered care as:

*Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect pa-*



*tients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.*

In its report, the Institute of Medicine (2001) did not specify a particular set of dimensions associated with the definition of patient-centeredness it put forward, although the report made reference to the original seven dimensions put forward by Gerteis, et al. (1993) in their report sponsored by the Picker Institute. In a slight adaptation, the IOM report's reference combined the concepts of care coordination and care transition, which were set forward as separate dimensions by Gerteis and colleagues. The IOM report did not include the concept of access as a dimension of patient-centeredness; instead, timeliness was treated as a separate aim for health care quality improvement.

The Agency for Healthcare Research and Quality (AHRQ) in the U.S. Department of Health and Human Services was charged with producing an annual report on the state of health care quality in the United States, using the framework developed by the IOM (IOM, 2001b). The IOM framework has been operationalized in the annual report on an ad hoc basis, reflecting large gaps in terms of existing indicators and data by which to assess patient-centeredness. With respect to assessing patient-centeredness, as of 2011 the AHRQ tracks and reports annually on a few survey-based measures of patients' experience obtaining care, including measures relating to how well patients perceive communication with their doctors and hospital staff, as well as measures relating to patient engagement, including the extent to which physicians involve patients in making decisions about their care. In addition to reporting the measures, the report also describes steps taken by the government to increase patient-centeredness through policy changes intended to reduce barriers and increase engagement (AHRQ, 2011).

With the passage of health reform legislation in 2010, a number of initiatives intended to assist in advancing the cause of patient-centered care have been launched in the United States, including establishment of a new research agency, the Patient-Centered Outcomes Research Institute, which is charged, in part, with ensuring that the information patients want and need to compare alternative health care treatments is generated through research. Additional work is under way to operationalize concepts of "person centeredness and family engagement" as part of a National Quality Strategy geared towards measurement and improvement. The legislation also includes provisions aimed at strengthening what is known as shared decision-making, a term used to describe a collaborative activity in which patients and their health care providers together determine the best course of treatment, taking into account evidence

and patient preferences. Shared decision-making may be supported by tools such as references that explain how probable outcomes vary depending on patient characteristics and what trade-offs alternative treatment approaches entail (e.g., surgery versus medication management) (O'Malley et al., 2011).

## 2.4 THE OECD SELECTS PATIENT-CENTEREDNESS AS A DIMENSION OF HEALTH CARE QUALITY

According to the OECD, patient-centeredness is “the degree to which a system actually functions by placing the patient/user at the center of its delivery of healthcare and is often assessed in terms of patients’ experiences with their health care” (Kelley and Hurst, 2006).

In 2006, the Organization for Economic Cooperation and Development (OECD) published a framework for assessing health-care quality in member countries (Kelley and Hurst, 2006). The framework was developed on the basis of a review of existing quality and performance assessment frameworks used by national authorities in OECD countries. Reflecting the finding that at least five of the national frameworks used incorporated the concept of patient-centeredness or responsiveness, the OECD framework also incorporated “responsiveness” or “patient-centeredness” as one of three (together with effectiveness and safety) dimensions of health-care quality subject to assessment.

The OECD is in the process of defining measures of patient-centeredness to include in regular benchmarking exercises. As a first step in this direction, OECD contracted with the Norwegian Knowledge Centre for the Health Services to undertake a comprehensive review of existing national and cross-national surveys of patient experiences (Garrat, Solheim and Danielsson, 2008). Based on the findings from this review, the OECD is currently working to develop its own model population-based survey of patient experiences and is working to facilitate cross-national sharing of best practices pertaining to use of such surveys.

## 2.5 DEFINING AND REPORTING ON PATIENT-CENTEREDNESS IN SWEDEN

In Sweden, as well, activities geared to promoting and assessing patient-centeredness in health care are evident. Sweden’s National Board of Health and Welfare (NBHW) (*Socialstyrelsen*) has been active in work to define patient-centeredness and to provide information about the patient-centeredness of health care in Sweden. A definition of patient-centeredness published in 2006 described patient-centered health care as “care given with respect and



consideration for the specific needs, expectations and values of the individual, and that these are taken into account in clinical decisions.” (NBHW, 2006). A more elaborate definition followed:

*Patient-centered care is based on respect for equal rights and on the dignity, self-determination and integrity of the individual. The patient is received in a social context and the care is carried out with respect and consideration for specific needs, condition, expectations and values. Care is planned and carried out in consultation with the patient. Communication shall be an integrated part of all care and treatment. The knowledge, understanding and insight of the patient are prerequisites for him or her to participate in and have influence on their health, care and treatment (NBHW, 2009).*

The National Board of Health and Welfare has also set forth several indicators of “good care” that is patient-centered:

- The patient is treated with respect as an individual;
- The patient’s own knowledge and experience are considered and taken into account;
- The patient is offered individualized information about his or her health condition, diagnosis, and methods for examination, care and treatment;
- The patient receives sufficient information and support to be able to manage his/her health;
- The patient is able to choose his or her provider to maintain desirable continuity of care;
- Treatment goals are decided together with the patient; and
- The patient participates in the planning and implementation of his or her own care.
- These indicators were selected by national experts consulted and convened by the National Board of Health and Welfare.

In a 2009 report, the National Board of Health and Welfare provided an overview of patient-centered care in Sweden, compiling information from the international and Swedish research literature, as well as in surveys such as the regional population surveys administered by nearly all county councils. The report drew upon results of the Eurobarometer surveys of the European Union and noted that Swedish health care is relatively highly rated by patients, relative to how many other European patients rate their own care. Results from surveys conducted in county councils provide information on regional varia-



tion within Sweden in terms of patient satisfaction and experiences with care. (In Sweden, the term “county council” refers not only to the actual legislative body, but also to the territory of its jurisdiction.)

Sweden has also been engaged in activities geared towards making international comparisons of patient experiences in health care. Sweden has participated in the work of the Nordic Council, which seeks to compare patient experiences across Scandinavian countries. Sweden also participates in OECD work that has resulted in efforts to test and cross-culturally validate a core set of questions on patient experiences in ambulatory care in a number of economically developed countries (Klazinga, 2012).

On a national level, the Ministry of Health and Social Affairs in collaboration with the Swedish Association of Local Authorities and Regions initiated the National Patient Survey (*Nationell Patientenkät*) in 2009. The National Patient Survey is a periodic survey on patient-perceived quality, including issues such as participation, trust, and information. The results are expected to contribute to improvement of health care from the patient perspective. It can also serve as the basis for comparison, management, research, and information to citizens and patients.









## Does a patient-centered health system deliver better care?

Many experts in patient-centered care would argue that a health system oriented around consumer needs and desires is inherently better, irrespective of whether such a system produces better health outcomes at lower costs. As an example, recognized expert in health care quality Donald Berwick (2009) stated the following:

*For better or worse, I have come to believe that we – patients, family, clinicians, and the health care system as a whole – would all be far better off if we professionals recalibrated our work such that we behaved with patients and families not as hosts in the care system, but as guests in their lives. I suggest that we should without equivocation make patient-centeredness a primary quality dimension all its own, even when it does not contribute to the technical safety and effectiveness of care.*

Beyond the experts, patients who might have had a dehumanizing or disrespectful encounter with the health care system can only agree. Nevertheless, evidence regarding the positive impact of patient-centeredness on health outcomes and costs strengthens the case for the importance of patient-centeredness as a policy goal in its own right. And as summarized in Box 1, studies do show that orienting health care around patients' preferences and needs has demonstrated its potential to improve patients' satisfaction with their care, as well as their health-related behaviors (such as inclination to seek follow-up care) and clinical outcomes (AHRQ, 2011; Groene 2011). For example, a recent study by researchers at the Karolinska Institute found that positive patient experiences with their physicians influence the patient's view of when he or



she feels ready to return to work following a period of sick leave (Wessel et al., 2012). Patient-centered care also has been shown to reduce both underuse and overuse of medical services, as well as to reduce hospital readmission rates. Despite some findings of a positive effect in terms of cost savings, certain studies have shown that patient-centeredness runs the risk of increasing some costs, as well.

**Box 1. Summary of key research findings on the importance of patient-centeredness**

The 2010 (U.S.) National Healthcare Quality Report included a review of the research literature linking patient-centeredness with health system outcomes. They found that patient-centered approaches, such as those that rely on building the provider-patient relationship, improving communication, fostering a positive atmosphere, and encouraging patients to actively participate in provider-patient interactions had the following types of effects:

**Morbidity and mortality**

- Patient-centered approaches to care have been shown to improve patients' health status and to lessen patients' symptom burden.
- Patient-centered care encourages patients to comply with treatment regimens.
- Patient-centered care can reduce the chance of misdiagnosis due to poor communication.

**Cost**

- Patient-centeredness has been shown to reduce underuse and overuse of medical care.
- Patient-centeredness can reduce the strain on system resources and save money by reducing the number of diagnostic tests and referrals.
- Although some studies have shown that being patient centered reduces medical costs and use of health service resources, others have demonstrated that patient-centeredness increases providers' costs, especially in the short run.

Source: The Agency for Healthcare Research and Quality [AHRQ], 2010

Importantly, the research undertaken to date linking desired health outcomes with patient-centeredness (or specific attributes of health care considered to be dimensions of patient-centeredness) has focused on patient-centeredness at the provider or sub-system level, rather than at the level of the national health system. The extent to which national health systems found to be more patient-centered are also more likely to have better health outcomes, increased patient satisfaction, and more efficient production of health remains an area for future study, building on existing work to assess patient-centeredness at the national or systemic level.







## Defining a framework for assessing the patient-centeredness of health care in Sweden

Despite lack of international consensus at present, a great deal of work has been done to develop frameworks for assessing patient-centeredness. Furthermore, some work has been done to compare and contrast alternative frameworks. Cronin (2004) undertook a systematic review for the National Health Council (a U.S.-based organization representing persons with chronic conditions and disabilities) of nine existing models and frameworks for defining and assessing patient-centeredness in health care and reported finding a fairly high degree of consensus with respect to the key attributes of patient-centered care. In 2007, the International Alliance of Patient Organizations published the second edition of its review of definitions and principles associated with patient-centered health care (IAPO, 2007). That work incorporated and built upon the work of Cronin and others.

In the sections that follow, we discuss the selection of a definition of patient-centeredness that is appropriate and meaningful in the Swedish context; identify and describe the dimensions of patient-centeredness that are of most important and policy relevant; investigate how those dimensions can be assessed or measured; and review what data or specific information can be used for assessment.

### 4.1 DEFINING THE CONCEPT

Some experts and stakeholders have asserted that patient-centeredness can only be meaningfully defined and measured with the input of the patients



themselves (see, for example, Stewart, 2001 and IAPO, 2007). What is it about health care or a health system that constitutes patient-centeredness to the patient? This thinking then implies that the most appropriate definition and conceptualization of patient-centeredness in the context of the Swedish health care system would be generated on the basis of input from Swedish patients. While an exercise devoted to generating such a definition through active patient engagement could be considered valuable whether conducted by a government agency, academic enterprise or non-governmental organization, developing such a definition is beyond the scope of the present study.

One way of thinking about what patient-centeredness means is underscore what it does not mean. Stewart (2001) observed that patient-centeredness is often presented in terms of what it is not – among other things, technology centered, doctor centered, hospital centered and disease centered. Similarly, patient-centeredness is often contrasted with the population health or public health perspective in that a patient-centered perspective considers individuals of paramount importance (IAPO, 2007). While these observations have utility in helping to hone in on the essence of the concept, they are of limited use in terms of identifying a definition that can be operationalized for the purpose of the present study.

Even though the debate about what patient-centeredness means is by no means resolved, there is no universal agreement that the term itself should be used in its present formulation. Some prefer to use the term person-centeredness, in an effort to avoid placing an undue focus on the medical aspects of a person's relationship with the system of health care and its related social systems. This term is used, for example, by the University of Gothenberg's Centre for Person-Centred Care.

In its work to review and define patient-centeredness for purposes of assisting the patient organizations that constitute its membership, the International Alliance of Patients' Organizations (IAPO) found that there are "numerous proposed definitions of patient-centered healthcare, which encompass many of the same core principles, but no globally accepted definition." The IAPO report further concluded that the lack of an agreed definition might not be problematic, as it might be more useful to promote the idea that the healthcare system should be organized around the patient (or the individual who is a prospective user of health services), with respect to the patient's preferences, values and/or needs, and to formulate tools and targets needed for operationalizing this, without taking the step of endeavoring to reach consensus on a global definition.

This approach has an obvious value as compared with the alternative of

making an arbitrary selection from among the range of definitions that have been put forward. The concept is understood, for the purposes of the present study, to encompass the range of desirable attributes of health care discussed in the following section. In other words, for the purpose of the present study, the Swedish health system can be said to be patient-centered to the extent that it is characterized by the attributes discussed below.

#### 4.2 SPECIFYING KEY ATTRIBUTES SUBJECT TO MEASUREMENT

There can be a temptation to include all positive or desirable qualities of health care as components of patient-centeredness. For example, it is hard to imagine describing health care that is neither safe nor effective as “patient-centered.” Nevertheless, having sufficiently safe and effective care could also be considered a prerequisite for (but not synonymous with) patient-centered care, much as having adequately functioning internal organs is essential for good health. Some attributes of health care might be considered even more directly related to patient-centeredness, yet arguably still separable. For instance, care that is not accessible to patients (meaning affordable, convenient and available on a timely basis), will clearly not be considered by patients to be patient-centered, yet the concept of accessibility seems readily separable as a distinct concern. If care is inaccessible, it is clearly not patient-centered, but accessibility does not seem to get at the essence of what it means for health care to be patient-centered. It is likely for this reason that neither accessibility nor patient safety is included among the elements of patient-centered care in any of the nine prominent models of patient-centered care reviewed by Cronin (2004). For the purposes of the present study, safety and effectiveness, together with accessibility, were considered as desirable and important characteristics of health systems in their own right, but separate and distinct from health care’s being patient-centered.

Cronin (2004) reviewed nine prominent models of patient-centered health care, to identify points of similarity across the models. The nine models studied were those produced by the U.S. Agency for Health Care Research and Quality (2001), the (U.S.) Foundation for Accountability (2001), the (U.S.) Institute of Medicine (2001), the (U.S.) National Health Council (2002), (international) Picker/Commonwealth (Gerteis, Edgman-Levitan et al., 1993), (U.S.) Planetree (Frampton, Gilpin and Charmel, 2003), Canadian clinician researchers Stewart, Brown et al., (1995), U.S. nurse researchers Johnston and Cooper (1997), and U.S. academic researcher Grin (1994).



Based upon her review, Cronin (2004) identified 45 discrete concepts or dimensions of patient-centeredness included in the nine prominent models she analyzed. The following six core elements were identified most frequently:

- Education and shared knowledge (appeared in five of the nine models),
- Involvement of family and friends (appeared in five of the nine models),
- Collaboration and team management (appeared in four of the nine models),
- Holistic care, including sensitivity to nonmedical, specifically emotional and spiritual, dimensions of care (appeared in four of the models),
- Respect for patient needs, desires and preferences (appeared in three of the models), and
- Free flow and accessibility of information (appeared in three of the models).

The fact that these six elements were common across three or more of the nine models suggests that there is some degree of agreement among stakeholders and experts on the importance of these elements. This, in turn, suggests that it is appropriate to include these elements as attributes of patient-centered care by which to assess health care provided in Sweden. A further consideration lies in the fact that, by focusing on elements that are most common across existing frameworks, findings from an assessment of Swedish health care based on those core elements stand to be consistent with ongoing international efforts and interpretable in terms of international comparisons.

So as to maximize the value of the framework to Swedish health policy, it would be useful to assign weights to the six core attributes that reflect the importance assigned to them by Swedish patients. It may also be the case that some of the dimensions common to several frameworks are less important to Swedish patients overall. It would also be useful to know which of the concepts not included in the six core or common elements are considered most important in Sweden. It may well be the case that dimensions that are not as commonly included in patient-centeredness frameworks, such as accessibility of services, are highly prioritized by Swedish patients. Such developmental work represents an interesting possible future research project.

In the absence of such information at this point, however, the present study adopted a framework for assessing patient-centeredness in Swedish health care based on the six core elements identified by Cronin, using slightly revised terminology and presentation as indicated below. The study's investigators also decided to combine the closely related dimensions relating to patient education and free flow of information into a single dimension. Thus, the study adopted the following five dimensions as a framework for assessment:

- 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; and
- Involving family and close friends in the health care experience, to the extent desired by the patient.

In addition to assessing these specific dimensions, the assessment will also identify and describe cross-cutting issues that become evident through the research, with a particular emphasis on those facilitators or barriers to achieving a more patient-centered health care system in Sweden that are not uniquely concerned to individual dimensions.

Below we describe the attributes of patient-centered care included in the present study, drawing upon the presentations used in the original frameworks from which these dimensions were drawn. We also illustrate the various issues that comprise each dimension by identifying example questions for research to assess the extent to which Sweden's health care could be considered patient-centered, using this framework. Addressing the full range of questions was not feasible in the context of the present study, due to constraints of data and resources available for research and analysis. However, a range of questions are included as a way to make clear the scope of the analysis and to lay the groundwork for future studies that might adopt this framework.

In developing the questions, an effort was made to incorporate each of the three traditional domains of health-care quality and performance measurement: structure (or the environment in which care is provided), process (or the methods by which care is provided), and outcome (or the consequences of health care). Structural characteristics could include factors such as legal restrictions or rights, or characteristics of the delivery system, such as organizational aspects of hospitals or primary care clinics, or the presence of patient organizations. Procedural characteristics could include guidelines or practice protocols that put forward standards of practice. Many of the questions focus on outcome, in that they are intended to assess whether the care obtained by patients is consistent with the desired attribute. But it is also important to understand which structural or procedural aspects of health care contribute to success in achieving the desired outcome and which, if any, present barriers to achievement.



## **Empowering patients through information and education**

Patient-centeredness is commonly understood to be characterized by the free flow and accessibility of information by patients. In explaining the inclusion of this dimension in their framework, Gerteis and colleagues (1993) noted that “patient often express fear that information is being withheld from them, or that they are not being completely or honestly informed about their illness or prognosis.” Patient-centered care is also achieved when patients are actively equipped, through education, and empowered to be stewards of their own health and partners with their health care providers in decision-making.

Assessing the extent to which this element characterizes Swedish health care entails answering questions such as the following:

- To what extent are patients’ needs for information being met?
- To what extent are patients’ health and medical records available and accessible to patients?
- To what extent do patients have access to information regarding their condition and alternative treatment paths?
- To what extent is information made available in a culturally (and linguistically) sensitive and accessible manner?
- To what extent do providers engage in efforts to educate and inform their patients about their conditions, prognosis and alternative treatment or care management options paths?
- Are patients satisfied with the outcomes of efforts to educate and inform patients about their conditions and alternative treatment paths?
- Are patients adequately supported so as to strengthen self management?
- What structural or procedural characteristics of health care in Sweden facilitate or present barriers to the free flow and accessibility of information?
- What health policies facilitate or present barriers to the free flow and accessibility of information? What health policies facilitate or present barriers to patient education and shared knowledge?

## **Respecting patients’ needs, desires and preferences as individuals**

This core element represents a fundamental appreciation of the patient as an individual with unique circumstances, needs, desires and preferences. It pertains to the critical role of patient engagement in care decision-making and addresses the individual’s role as a consumer of health care services and a client of the health care system who is to be well-served. Assessing this element entails addressing questions such as:

- To what extent are patients' needs, desires and preferences taken into account by providers in health care decision-making?
- To what extent are patients free, versus constrained, in the choices they face?
- Do providers listen carefully, take enough time to hear what the patient says, and show respect for the patient's input?
- To what extent are patients formally engaged in shared decision-making?
- To what extent are shared decision-making tools (e.g., patient decision aids or advance directives) made available for patients faced with preference-sensitive decisions (e.g., care at the end of life, cancer therapy)?
- What structural or procedural characteristics of health care in Sweden facilitate or present barriers to providers' respect for patient needs, desires and preferences?
- What health policies facilitate or present barriers to the provision of health care in a manner that is respectful of patient needs, desires and preferences?

### **Coordinating care across service providers and ensuring continuity of care**

Coordination and continuity of care is a core conceptual dimension of patient-centered care in that it relates directly to the notion that the patient, rather than the disease, condition or service, is the appropriate focus of health care. Without collaboration across providers, the patient cannot be treated holistically. In order to assess the extent to which the Swedish health system is characterized by collaboration and effective team management, the following types of questions can be examined:

- To what extent do providers actively collaborate with each other and with the patient to ensure holistic treatment of individual patients?
- To what extent is there coordination and integration of care across clinical, ancillary, and support services, and in the context of receiving "frontline" care?
- Are patients satisfied with the extent to which their providers collaborate in caring for them, both in terms of an episode of care and as a patient with chronic conditions?
- What structural or procedural characteristics of health care in Sweden facilitate or present barriers to provider collaboration and team management of care so as to provide the patient with a care experience that is coordinated and seamless, in terms of continuity?
- What health policies facilitate or present barriers to provider collaboration and team management?



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

This core element 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. Assessing the extent of sensitivity to such concerns entails answering questions such as these:

- To what extent does health care exhibit sensitivity to the nonmedical and spiritual dimensions of care? How is that sensitivity manifest?
- What structural or procedural characteristics of health care in Sweden facilitate sensitivity to the nonmedical and spiritual dimensions of care?
- What structural or procedural characteristics of health care in Sweden present barriers to provider sensitivity to nonmedical and spiritual dimensions of care?
- What health policies facilitate or present barriers to the provision of health care in a manner that is sensitive to nonmedical and spiritual dimensions of care?

### **Involving family and close friends in the health care experience, to the extent desired by the patient**

A common dimension 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 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 (Gerteis et al., 1993).

Assessing this element entails answering questions such as these:

- To what extent do patients have opportunities to involve family and friends in their health care? To what extent is such involvement encouraged and supported?
- Are patients satisfied with the extent to which family and friends are in-



involved in their health care?

- What structural or procedural characteristics of health care in Sweden facilitate or present barriers to involvement of friends and family in health care?
- What health policies facilitate or present barriers to involvement of friends and family in health care?

#### 4.3 APPROACH TO ASSESSING THE PATIENT-CENTEREDNESS OF SWEDEN'S HEALTH CARE

Applying the framework described above in an evaluation of Sweden's health care system entails assessing the extent to which health care in Sweden is characterized by the five core dimensions, as perceived by patients and experts who represent and work with patients. Identifying relevant facilitators and barriers in structural characteristics of the health system, including health policies, and in processes used in the delivery of health care is important so as to make the assessment meaningful and actionable. A key in this effort is to link what is, at its core, a personal and local experience to aspects of the health care system that are amenable to change via policy incentives or otherwise. Patient-centered health care is furnished by providers and is a local phenomenon, but characteristics of the system, which are shaped by national and regional and local factors, play an important role in determining whether patients experience patient-centered care.

#### Metrics and sources of data for measurement

A range of different types of data can be used to assess the patient-centeredness in Sweden's health care system, including data from patient experience surveys, information from health-system experts, descriptive data on health system structures and processes, and findings from studies published in the academic and/or policy research.

The following served as main sources of data for the present study (for a more detailed description of the sources of data used in the study, see Appendix 1):

- 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.

Different types of data have different strengths and weaknesses and the study aimed to take account of those strengths in using data appropriately. For example, when making an assessment of how well Swedish health care conforms to identified standards of patient-centeredness, data reflecting actual patient experience were accorded priority. With respect to identifying barriers and facilitators in the Swedish health care system, the perspectives of experts who have a broad view and understanding of the system were prioritized.

Patient experience data, drawn from patient surveys, constitutes a very important source of information for assessing patient-centeredness. In this study two main surveys were used, the Swedish 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 survey is conducted every year and Sweden has earlier participated in 2009 and 2010.

A survey of the quality of health care as experienced by Swedish patients, the National Patient Survey, was launched in 2009. Not all county councils have participated in each survey module. (For a detailed description on participating county councils, see [www.indikator.org](http://www.indikator.org)).

The surveys include a large number of questions about the patient experience with health care delivery. One issue that has proved problematic is obtaining a high response rate among those surveyed. Response rates have been between 55 and 65 percent, with the exception of the psychiatric care surveys, which had response rates 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 correspond with those of the patients who do participate in the survey. It also may influence the reliability of estimates at the county level and the extent of cross-county variation observed.

A review of academic and policy research literature was conducted as a source of information that can be used in assessing Sweden's patient-centeredness. The review included English-language publications in the academic literature, as well as Swedish-language publications in the policy or "grey" literature.

A final, important source of information for the present assessment came from a series of original interviews with 34 selected experts in the Swedish

health care system. The experts were selected by referencing Swedish sources, including publications listing recognized health care leaders. Particular effort was made to interview a range of leaders from organizations representing patients, as well as individuals who are familiar with the patient experience (e.g., individuals who help patients with complaints or grievances). Academic researchers who have studied patient-centeredness and government officials involved in various initiatives relating to patient-centered care were also interviewed. Interviews sought to obtain both objective information (e.g., on specific barriers and facilitators to provision of patient-centered care) that supports the assessment, as well as subjective opinions (e.g., on aspects of patient experience).

### **Standards and benchmarks**

In a review for the Cochrane Collaboration on the impact of interventions for providers to promote a patient-centered approach in clinical consultations, Lewin and colleagues (2001) concluded that there is a lack of a “gold standard” measure of patient-centeredness by which to assess care. Groene (2011) comments that a single standard may not be appropriate due to the different motives for assessment (e.g., quality improvement), and may not be possible due to the conceptually broad nature of patient-centeredness.

Several types of standards and benchmarks could be used to assess the degree to which Sweden’s health system is patient-centered. One approach would be to benchmark the performance of designated geographic areas (e.g., counties) against the top performers. Another approach would be to compare the performance of the Swedish system against that of other countries in its peer group (e.g., developed countries, Scandinavian countries). Yet another approach would be to assess performance against a standard defined through a political or other process (e.g., an articulated goal that 90 percent of patients will report at least adequate satisfaction with all aspects of their care experiences). As an example, the National Institute for Health and Clinical Effectiveness (NICE) in England published a set of quality standards by which to evaluate adult patient experiences (NICE, 2012). A subsequent step would be measurement to assess the extent to which those standards are met.

Relatively few benchmarks are available for use in the present study, in part due to the relatively very limited time series data available. Therefore, the study employed an ad hoc approach to make best use of those standards that do exist. Findings from the international survey of patients, produced by the Commonwealth Fund, were exploited to gain a sense of how Swedish



patients fare in comparison to patients in other countries. These surveys can shed light on how patients in different countries experience their health care. However, a common criticism is that the results might reflect differences in expectations as well as real experiences of health care. In addition to the international survey, the Swedish National Patient Survey was used to shed light on how different areas within Sweden perform, relative to one another, and to illustrate the range of performance and opportunities for improvement by emulating best practices.

Given the relative dearth of standards and benchmarks, one value-added of the present study is to establish a descriptive baseline against which future studies assessing performance can be benchmarked.





## How patient-centered is Sweden's health care today?

The findings from our research to assess patient-centeredness in Sweden's health care system are presented below. The results represent a synthesis of information obtained through analysis of data from patient surveys, interviews with 34 Swedish experts representing patients, providers, government and other stakeholders, a review of findings from academic research studies and government reports. The findings were further informed by review of relevant legislation, regulations and recent public inquiries undertaken in Sweden.

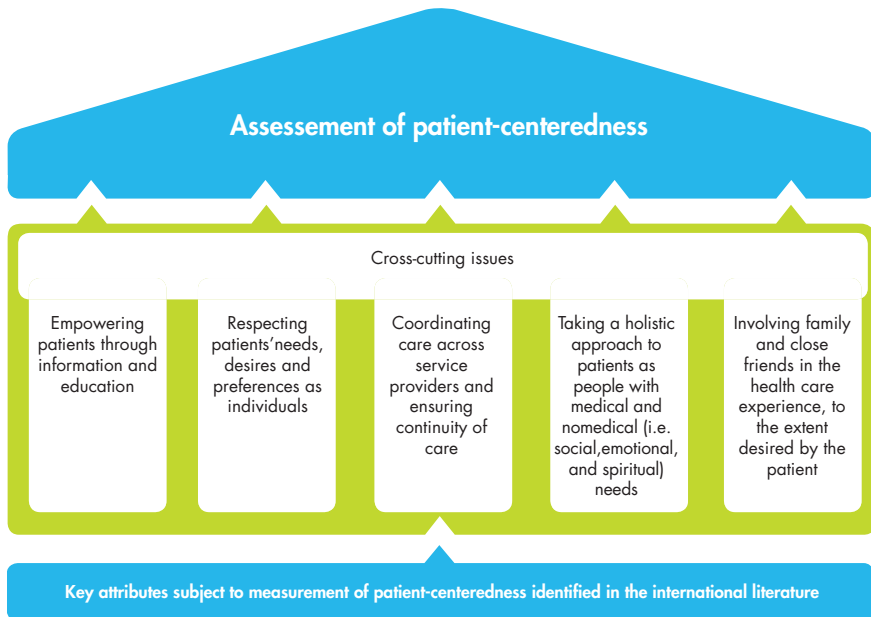
Presented first in the section below are findings pertaining to each of the five different dimensions of patient-centered care that are common to several of the most prominent, internationally recognized and used frameworks (see Figure 1):

- 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; and
- Involving family and close friends in the health care experience, to the extent desired by the patient.

This is followed by a discussion of cross-cutting issues, with an emphasis on key facilitators and barriers to achieving patient-centered care in Sweden that were identified in the study and that are not specific to any particular dimension.



**Figure 1.** Framework for assessment of patient-centeredness in Sweden's health care



## 5.1 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, in the light of evident shortfalls, more efforts are needed to ensure that patients are informed and otherwise equipped to partner with their providers to ensure good health outcomes.*

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



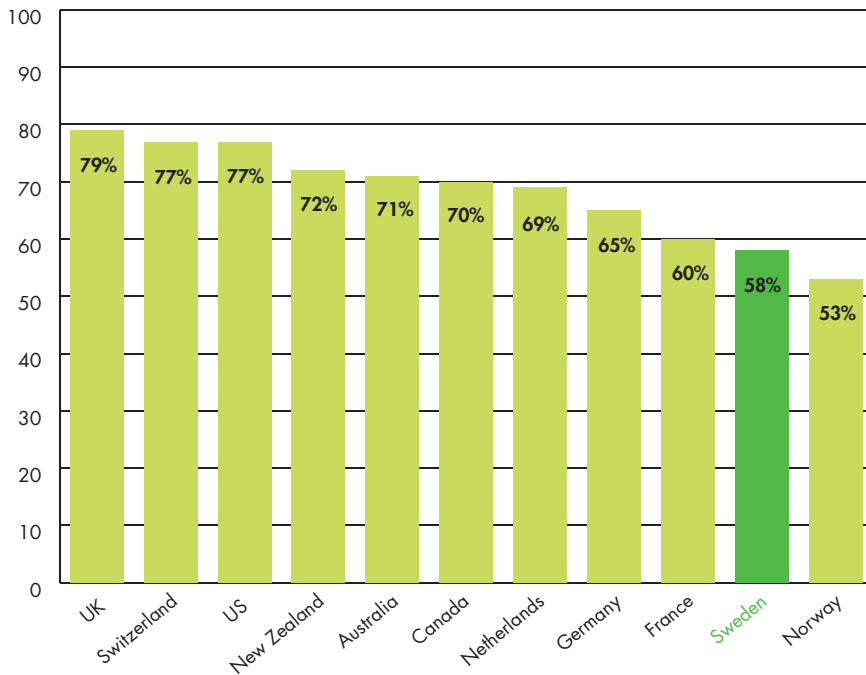
## An overarching look at patient views

Below we review recent survey findings that compare Swedish patients with patients in other countries, in terms of their satisfaction with information and education, and review findings from selected modules of the National Patient Survey.

### *International survey of sicker adults shows that Swedish patients' information needs are not well met*

In a recently conducted international survey of sicker adults in 11 countries, a number of questions concern patient experiences relating to patient information and education. The results show that sicker adults in Sweden are generally less satisfied with these aspects than are their counterparts living in other countries (IHP, 2011). In fact, only Norwegian patients were less likely to report a positive experience in terms of having their information and education-related needs met (see Figure 2).

**Figure 2.** Percentage of patients answering the most preferable answer on each question concerning information and education\*. Source: IHP International Survey of Sicker Adults (2011)



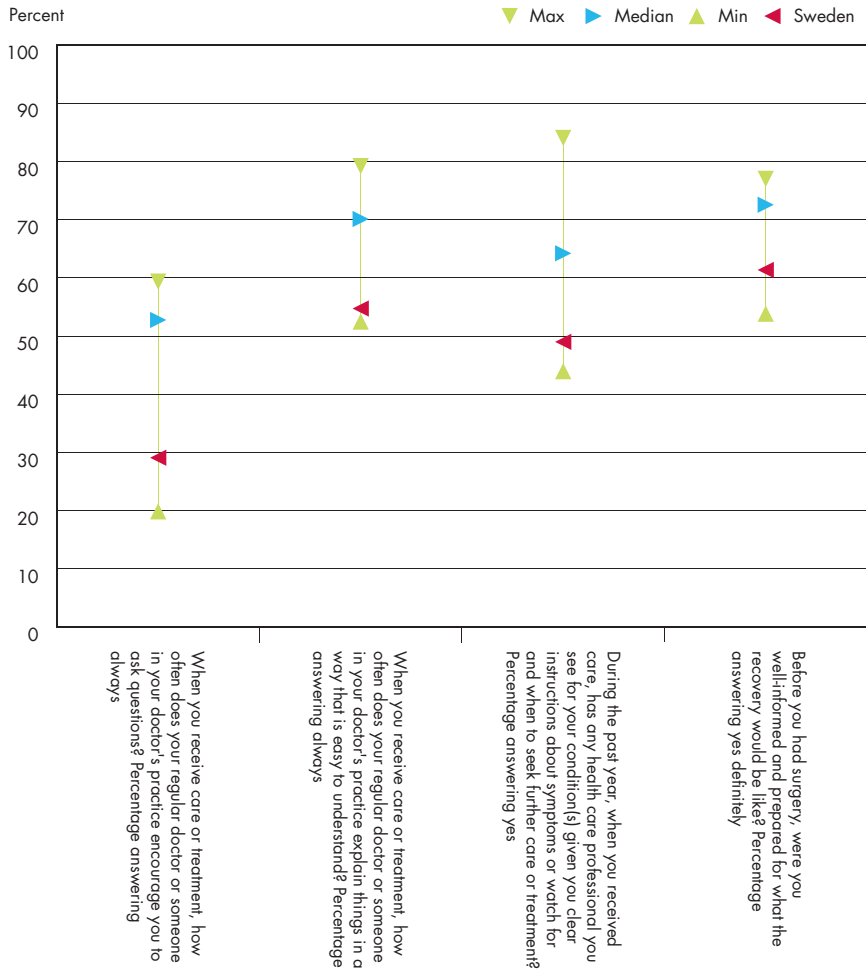
\*Unweighted index. For a description of the elements of the index, see Figure 3 and 4.

Looking more specifically at the individual questions asked, Swedish patients were below the international median in terms of reporting a very satisfactory experience on eight out of nine questions relating to information and education (see Figures 3 and 4). For example:

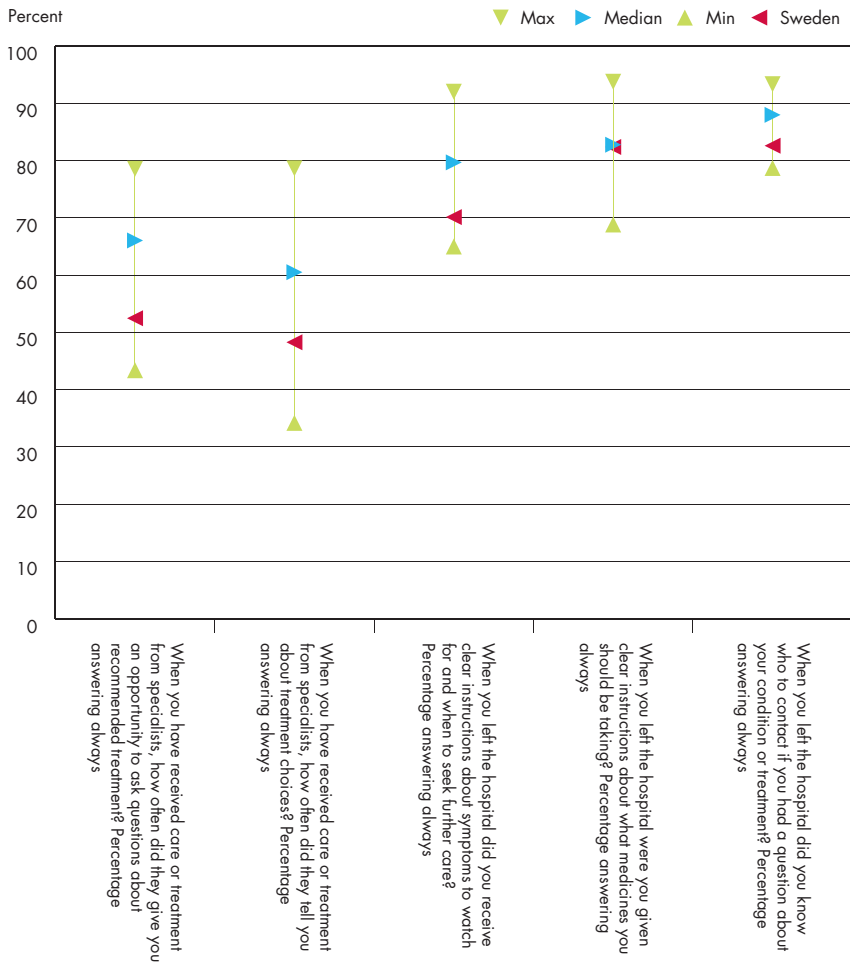
- Less than 50 percent of sicker Swedish patients said that specialists always told them about their choices of treatment, a rate below the international median and considerably below the best performing country, where more than three quarters of sicker patients said they were always told about choices (see Figure 4).
- Together with Norway, Sweden shows the lowest levels of success in terms of health care professionals explaining things in a way that is easy to understand. 78 percent of sicker Swedish patients state that the staff often or always explains things in a way that is easy to understand, compared to 93 percent and 91 percent in Switzerland and France (IHP, 2011). Focusing exclusively on the “always” responses shows Sweden at almost 15 percentage points below the median response (see Figure 3).

**Figure 3.** Sicker adults reporting positive experiences relating to patient information and education. (Percentage of patients in Sweden and 10 other countries.)

Source: IHP International survey of sicker adults, 2011



**Figure 4.** Sicker adults reporting positive experiences relating to patient information and education. (Percentage of patients in Sweden and 10 other countries.)  
 Source: IHP International Survey of Sicker Adults, 2011



In addition to being less likely to have reported very positive experiences in the area of information and education, Swedish patients were also more likely than their international peers to report relatively poor experiences. Swedish patients were, for instance, second only to those of Norway in terms of being most likely to say that their physicians “rarely or never” encouraged them to ask questions. Close to a third of sicker Swedish patients reported this problem, compared with just 6 percent of patients in the United Kingdom and Switzerland (IHP, 2011).

### *The Swedish National Patient Survey*

Each module of Sweden's National Patient Survey includes questions that examine patient experience in terms of how well information and education needs and patient expectations are met. Below, we will summarize relevant results from four of the modules (primary care, outpatient- and inpatient specialty care, and inpatient psychiatric care), and will illustrate strengths and weaknesses of information and education efforts that are common across these types of services. (See Appendix III for results on the above mentioned modules and on outpatient psychiatric care).

#### PRIMARY AND SPECIALTY CARE

There is evidence of plenty of room for improvement in terms of meeting primary and specialty care patients' needs for information and education. Areas that fell particularly short of the mark in primary care as well as in outpatient and inpatient specialty care included findings that patients were often not informed about potential side-effects of prescribed medications, and failures of their doctors to tell them about warning signs to watch out for, or potential problems associated with their conditions or treatments. In many of these cases, the median patient-experienced quality measure across Sweden's county councils was below 50 on a 100-point scale (see figures 5 and 6).

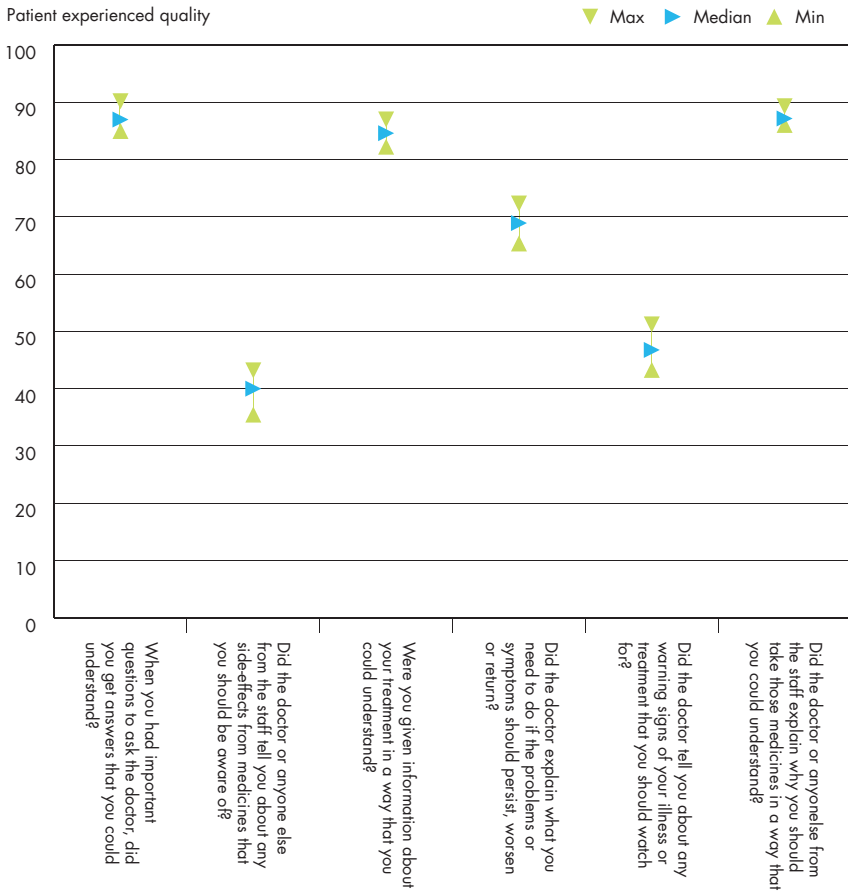
Areas in which Sweden's primary and specialty care are doing better include providing understandable test results and treatment information, giving understandable answers to questions posed to health care providers, and explaining the rationale for prescribing medicines (see figures 5 and 6).

While cross-county variation was modest for most primary and outpatient specialty care measures, variation was greater (10-15 points) for inpatient specialty care on measures assessing provision of information to patients on side-effects of medication, warning signs to be aware of concerning illness or treatment, and where patients can turn after being discharged from hospital with questions about the disease or treatment (see figure 6).



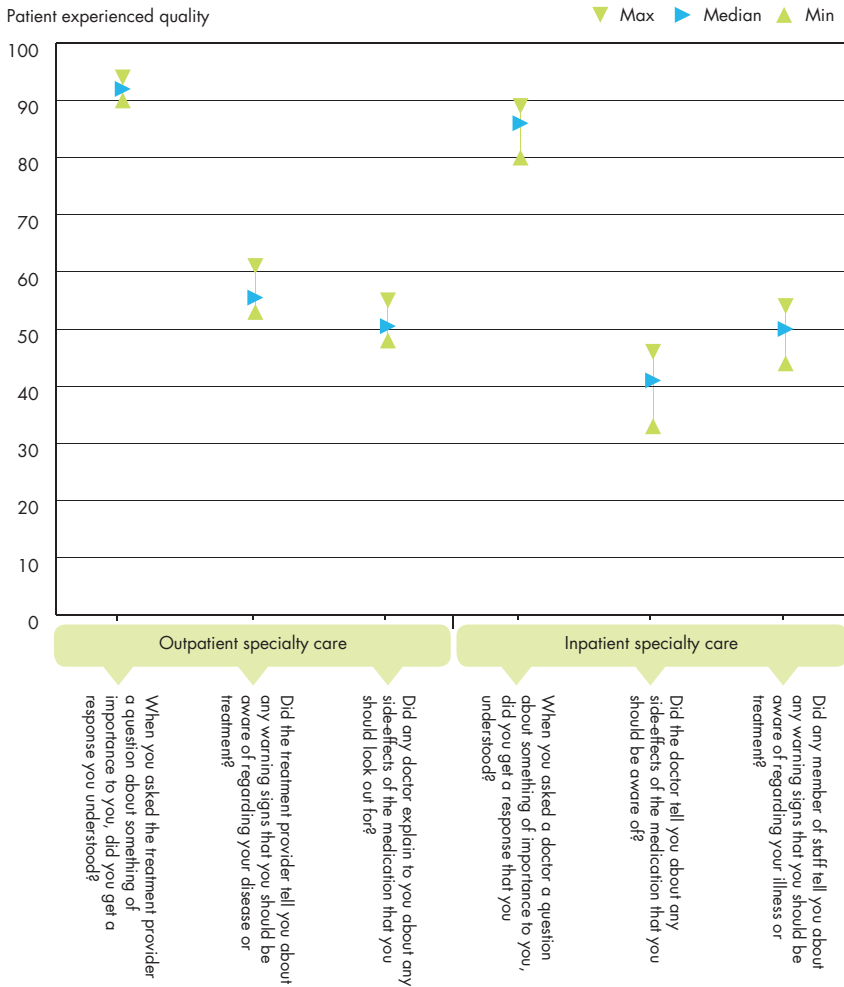
How patient-centered is Sweden's health care today?

**Figure 5.** Primary care patients' experiences relating to information and education in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*).  
 Source: National Patient Survey, primary care (2011)



\* See Appendix III for a more detailed description.

**Figur 6.** Inpatient and outpatient specialty care patients' experiences relating to information and education in Sweden's county councils. (Patient-experienced quality measures on a 0–100 scale\*.)  
 Source: National Patient Survey, outpatient and inpatient specialty care (2010)



\* See Appendix III for a more detailed description.

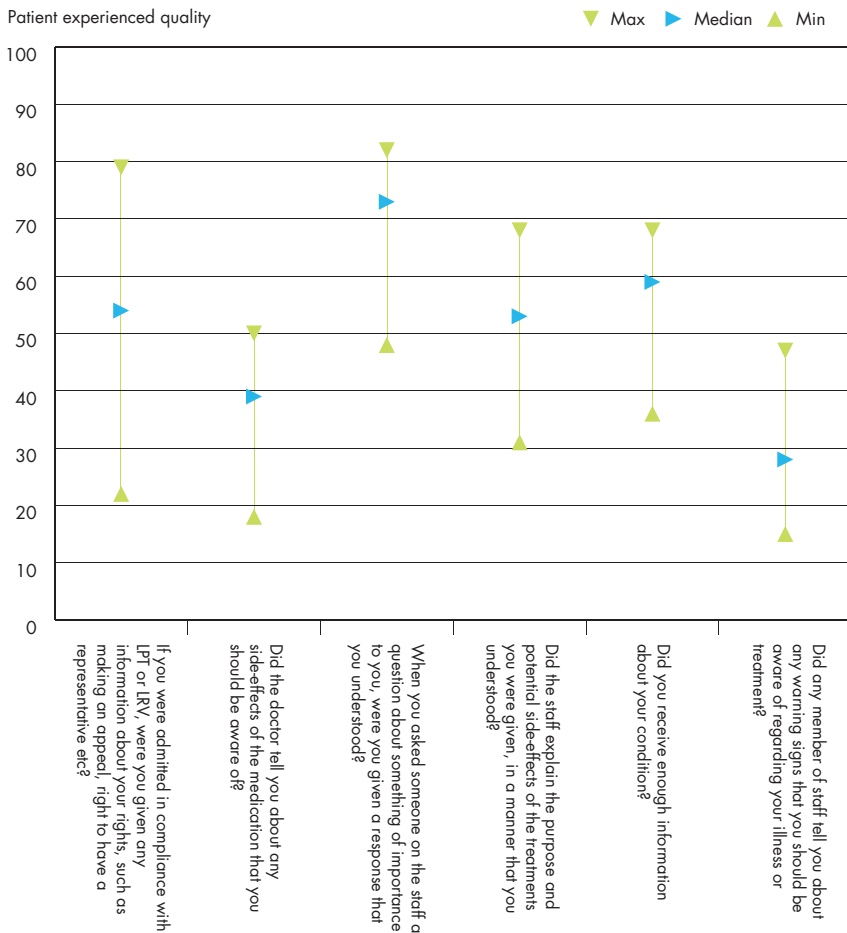
### INPATIENT PSYCHIATRIC CARE

The results from Sweden's 2010 survey on inpatient psychiatric care are very notable in terms of the degree of variation seen across county councils. Compared to inpatient specialty care and primary care, the variations between the county councils are much larger. Although some county councils show rela-

tively good results with respect to providing information about compliance with provision of information about the Swedish Psychiatric Compulsory Act (1991:1128) (Lagen om psykiatrisk tvångsvård) (LPT) and the Swedish Forensic Psychiatric Act (1991:1129) (Lagen om rättspsykiatrisk vård) (LRV), about hospital routines and visiting times, and other measures, there are county councils which scored below 50 in patient-experienced quality (see Figure 7).

As was true for primary care and inpatient specialty care, the areas in which problems are most common relate to telling patients about side effects and warning signs.

**Figur 7.** Inpatient psychiatric patients' experiences relating to information and education in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*.)  
 Source: National Patient Survey, inpatient psychiatric care (2010)



\* See Appendix III for a more detailed description.



## Legal framework, recent initiatives and reforms

To enable patients to avail themselves of various rights established in recent reforms, both the Health and Medical Service Act (1982:763) (*Hälso- och sjukvårdslagen*) and the Patient Safety Act (2010:659) (*Patientsäkerhetslagen*) contain provisions requiring the health care services or medical staff to provide the patient with individually tailored information about his or her health status; methods for examination, care and treatment that exist; his or her possibilities to choose care providers within publicly financed health care; and the health care guarantee (see Box 2).

Responsibility for implementing steps needed to comply with the legal obligation to inform patients rests with the county councils and municipalities. This has contributed to diversity across the country in terms of the impact of the reforms

### **Box 2. Recent reforms enacted to strengthen the position of patients**

In recent years, the Swedish national government has put in place reforms in an effort to strengthen the position of patients. A number of these reforms have been incorporated into the legal framework, such as the health care guarantee (sometimes referred to as the "waiting-time guarantee," which stipulates a specific timeframe within which treatment must be furnished), the permanent point of contact (a person who is responsible for securing a patient's need for security, coordination, continuity and safety in care), choice of health care provider, and the option to get a second opinion.

## *Development of public and private initiatives to furnish information on conditions, treatments, and providers*

A range of public and private initiatives have been launched in an effort to furnish patients with better information about their health conditions, treatments and providers.

The establishment of the "1177" health information portal, accessible via the Internet and phone (with a staff nurse responding to consumer and patient inquiries), was highly regarded by the interviewed experts. The portal's features cover a wide range of services, from guiding patients to the appropriate healthcare establishments to providing information on disease symptoms, and enabling users to compare healthcare facilities. Information provided on the website is tailored to the patient's location, to assist in defining local options for service. Experts reported that patients are increasingly aware and make use of this resource, although it is not clear that patients are taking full advantage of the information available to inform decisions about choice of provider. Many experts reported that available data are not yet adequate to



provide patients with information for decisions with respect to many types of care and providers, although progress is evident. According to Inera, the company in charge of implementing 1177.se, the website logs 2.5 million users every month; 95 percent of who search for specific disease-related issues or pose questions to the site's "questions service." About five percent visit the page to "search for and compare" health care providers and only one percent make use of the comparison guide (Inera, 2012).

In addition, information directed towards patients can also be found at the county councils' websites and at privately financed webpages, such as Omvard.se. At the website, vantetider.se, prospective patients can find out about the current waiting times for various appointments, planned examinations and treatments at primary and specialized care providers.

Other initiatives have been undertaken to assess what information patients want and lack, and to engage patients in decisions about how best to communicate the information desired. For example, "My Guide to Safe Care," was recently produced by the National Board of Health and Welfare and disseminated to patients through a variety of channels, including provision at site of care. The guide provides a range of suggestions as to what patients can do to ensure positive and successful encounters with the health care system.

Another development is the National Board of Health and Welfare's initiative to create patient versions of disease-specific information based on the national guidelines. One of the incentives for the initiative was to educate patients about what to expect from the health care system in regards to the specific areas, such as depression, dementia, type 2-diabetes and adult dental care. With that knowledge, patients could point out inadequacies in their care process, supported by the guidelines (NBHW, 2012).

### *Early efforts to meet needs for information to support patients' choice of provider*

In support of current government efforts geared toward enhancing and supporting patient choice, the National Commission on Patient Empowerment (S 2011:03) (*Patientmaktsutredningen*) is conducting an inquiry, to be completed in 2013, that is investigating issues such as patients' needs for support, advice and information to make informed decisions about their choice of care providers. The Commission is also charged with setting standards as to how to provide information and guidance concerning the health care system's obligations towards patients in a simple and accessible way, adapted to different groups of patients, such as children, elderly, persons with disabilities, and

non-native Swedish speakers.

A move towards more transparency of publicly reported performance data was identified as a possible enabler of more patient-centered care by experts interviewed for this study, although many experts pointed out that efforts are as yet in their infancy and not developed to the point of being adequate to support choice. Among the most prominent public initiative to support transparency of the Swedish health care's quality and efficiency is the "Open comparisons" of health care, published by the Swedish Association of Local Authorities and Regions (SALAR) (Sveriges Kommuner och Landsting, SKL) and the National Board of Health and Welfare, which provides extensive information about how different counties and regions perform in different areas of health care. The data come from the national quality registries and from the National Patient Survey findings and is compiled to make comparisons between different counties and sometimes even units. One of the purposes of the open comparisons is to give patients and citizens full insight into what publicly financed health care provides in terms of quality and efficiency. However, as noted by interviewed experts, very few patients actually use this available information, and it is not yet tailored as information for supporting choice. Questions remain as to whether the indicators are correct in terms of scope and number, and in terms of how well they reflect the areas of interest of actual patients. However, in the national strategy document for Open Comparisons, development of information to support patient choice is a priority (Open Comparisons 2009).

Winblad and Andersson (2011) assessed information being produced to support patients' free choice of provider and found that the county councils have made good efforts to inform citizens and patients about the possibility of choosing health care providers, and how to choose such a provider. However, the information currently available falls short of the ideal if its purpose is to support patients in making rational choices of health care providers. To a large extent, the information does not provide patients with data such as similarities and differences in medical quality between providers. Furthermore, the information is fragmented among different health care providers, county councils and national actors.

A report from the Swedish Competition Authority (2012) (*Konkurrensverket*) also investigated the question of patient information on free choice of provider. A survey of citizens in all county councils included questions about whether existing information was sufficient for making an active choice of provider. Two out of three respondents considered that they had sufficient information to make an active choice of a healthcare center. However, there are



differences among the county councils. In the county council of Örebro and Uppsala, only 45 and 48 percent stated that they had enough information to make an active choice; however, in the counties of Blekinge and Jönköping, 79 and 81 percent reported having sufficient information.

### *Patients' rights to control information contained in medical records*

An ongoing debate in Sweden relates to ownership of information in patient medical records. Physicians have traditionally viewed these records as a professional tool, whereas patient representatives argue that patients should own their records and the information they contains, with broad authority to decide who should see the information and under what circumstances, and to add information considered by the patient to be pertinent. In a similar vein, patients reportedly continue to have great difficulty accessing their records. The records are not always accessible electronically and providers reportedly can be reluctant and slow to respond to patient requests for a copy.

One of the goals of the National Strategy on eHealth (S2010.020) (*Nationell eHälsa – strategin för tillgänglig och säker information inom vård och omsorg*) is to ensure that patients are able to benefit from their own medical records online, extracting information and actively take part in their own care and treatment. The Center for eHealth (CeHis) – governed by representatives from county councils and regions, the Swedish Association of Local Authorities and Regions, municipalities, and private care providers – has been formed to coordinate and develop the national technical infrastructure to improve factors such as accessibility of information, quality and patient safety (Inera 2011).

## **Shortfalls in meeting patient demands and expectations**

### *Issues relating to patient/provider communications*

The provision of information about medications and their side effects and about warning signs associated with a condition or treatment is a particular area identified as requiring further attention, problematic for primary care and inpatient specialty care patients, as well as inpatient psychiatric patients. Representatives of patient organizations reported that physicians often fail to provide this information, possibly due to the view that this is the role of the pharmacist, or out of concern that knowing about side effects might result in poor patient compliance.

Time pressure (partly due to a move to activity-based financing and cost-

control constraints) may also limit the extent of information sharing between health care provider and patient, generally, and the quality of communication that takes place in a patient encounter. More than one in ten (12 percent) of sicker Swedish patients said that their doctor rarely or never spent enough time with them, a higher share than in any other country but Norway, among the 11 countries surveyed (IHP, 2012). Encounters in which patients feel constrained in asking questions and feel that options are not presented may be partly explained by such constraints. Experts also noted that Sweden has a paternalistic culture in terms of the historical patient/doctor relationship, which can limit open communication and has been slow to change, although it is now reportedly changing.

While patient surveys show that patients report a high degree of understanding in the communications they have with health care providers, this is an area to watch in that Sweden is an increasingly multicultural country and some experts felt that not enough has been done to ensure linguistically appropriate and culturally competent communication, education and information programs. It may be the case that the same people who face problems with understanding are underrepresented among the survey respondents, leading to incomplete information on the scope of this problem.

### *Information needed to support health care decisions is not always available*

According to the experts interviewed for this study, relatively little information, education and support for decision-making is as yet available to support Swedish patients faced with making a treatment choice, and the information that is available is not provided in the most useful ways to foster and support informed patient decision-making. This observation was supported by a comprehensive report on available information by Winblad and Andersson (2011), who concluded that there is a lack of web-based decision aids to support patients who face a choice of alternative treatments. Experts who were interviewed pointed to what they saw as 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, and group seminars. While examples of such initiatives can be found in Sweden, experts asserted that progress in this area was slow, small-scale, and far from meeting patients' real needs for decision support.



### *Legally required information is not always furnished*

Representatives of patient associations interviewed for this study asserted that patients were often unaware of the legal obligations of providers with respect to meeting patient information needs, and of the guarantees afforded to them in the Swedish health system. For example, patients were recently given the authority to obtain what is known as a point of contact associated with their episode of treatment. This reform was enacted to address the perceived problem of difficulties navigating the health system and obtaining information needed to achieve good outcomes. However, many experts interviewed for this study were themselves unfamiliar with this relatively new opportunity and stated that they believed most patients were also unaware. These results were recently supported by a report from the National Board of Health and Welfare (2012), which reported that insecurity prevails in the health care sector about how to interpret the new legislation and what kind of mandate the point of contact actually has.

Another good example of the discontinuity between the law and current practice is the obligation to inform patients about the health care guarantee. A recent report from the National Board of Health and Welfare (2012) concluded that the provision of information about this reform to patients remained a challenge. A population survey revealed that the provisions of the guarantee are inadequate to ensure that patients get the help and support to which they are entitled. Moreover, the survey showed that information furnished to patients likely to have a waiting time longer than 90 days, varies among county councils. Also, not all patients with longer waiting times even received the required information. According to the report, although most county councils declared that providing information about the guarantee was a priority, few had evaluated their communication efforts. Many counties lack information in languages other than Swedish, and many have not adapted the information to groups that could have difficulties in understanding it. Even administrative staff members know too little about what the guarantee entails, making it difficult for health care providers to explain and assist patients.

According to the National Board of Health and Welfare, physicians have taken an ambivalent wait-and-see attitude towards the guarantee, a factor that has had a negative effect on the reform's impact. In the same vein, a report from the Expert Group for Public Economics (*Expertgruppen för studier i offentlig ekonomi*) (Winblad & Andersson, 2010) showed that a large share of orthopedic doctors did not routinely provide information about the guarantee, and did not consider doing so to be part of their professional duties. The report pointed to the variation in county councils' management and policy

regarding the implementation efforts, and lack of clarity concerning what role the health professionals should play in the implementation of the reform.

## **Conclusions and main implications of findings**

Although Sweden has made good recent progress in strengthening and improving legal provisions pertaining to patient information and education, important gaps in information and education are evident, in terms of how well those efforts have contributed to patients' understanding and satisfaction with the information and education obtained. An overall conclusion is that there is a vast amount of innovative work to be done in informing, educating and supporting patients and that, while there is a foundation to build upon, many would like to see more rapid improvement to address problems and to improve upon strengths.

The results of this assessment point to some strengths of Sweden's health care system, in terms of serving patient needs for information and education. A number of potentially important initiatives have been launched, ranging from efforts to establish legal information obligations, to efforts to give patients more access to, and control over, their medical records, and to efforts to inform patient decision-making with respect to choice of treatment and health care providers. A considerable share of the experts interviewed for this study expressed confidence that efforts such as the drive to expand patient choice of health care providers would eventually drive further development, innovation, enhancement and use of information about health care providers and treatments.

However, one area in particular need of further attention is support for patients who require better information to cope with their condition, navigate the health care system and make appropriate treatment choices. Lagging information in this area may in part reflect a cultural tradition in Sweden for patients to be advised by their providers as to the course of care, rather than being consulted with, as discussed in more detail in the next section, and as suggested by the finding from an international survey that Swedish patients were among the least likely to say that their physician gave them treatment options.

To date, the numerous public and private initiatives to inform and educate patients have yet to yield demonstrable benefits in terms of outcomes. However, judging from findings from patient surveys and expert reports, Sicker Swedish patients do better than patients in some other nations in terms of receiving good responses to the questions they pose by telephone. But otherwise, Swedish patients are less well off than most, according to numerous measures



gauging patient information and education. Whether this is because Swedish patients have relatively high expectations or whether it relates primarily to relatively low performance in meeting those expectations is unknown, but a sizeable minority of patients clearly perceives problems relating to the information available to them and/or the education they receive about their condition and treatment.

Similarly, there is a need to ensure that the move to Internet-based platforms, and any future development of smart phone-based apps drawing upon Sweden's extensive health databases, does not leave behind some groups who can benefit most from better information, including the elderly and the cognitively impaired.

An issue that emerged in the course of this assessment was the need to further delineate responsibilities between the national government and the county councils in setting priorities and to ensure that priorities for improving information and education are achieved. There are problems across many county councils related to in providers meeting their stipulated requirements to inform patients of their legal protection, especially in the case of psychiatric patients.

Issues relating to electronic medical records are under study by the Swedish government, as indicated above. With respect to resolving issues connected with the ownership of the medical records, and the authority to add to or suppress information included in them, further public discussion may be required to find satisfactory policy and technical solutions.

## 5.2 DIMENSION 2: RESPECTING PATIENTS' NEEDS, PREFERENCES AND VALUES AS INDIVIDUALS

► *Sweden's health care system often fails to anticipate and respond to patients as individuals with particular needs, values and preferences. Failure to involve patients in their own health care has demonstrable costs to patients, the health system and public finances.*

### 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 de-



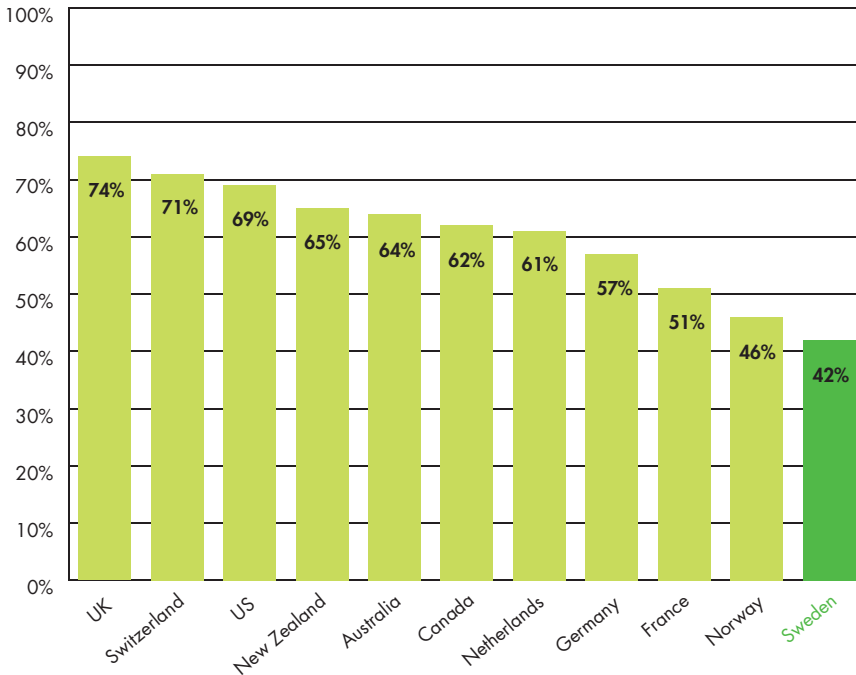
signed so as to anticipate and respond to patients' particular concerns, and to solicit meaningful patient input into all decisions about how health care is furnished.

## An overarching look at patient views

### *Sweden's relatively poor international performance*

International comparisons reveal that Swedish patients experience relatively poor care, in terms of how well it meets their individual needs, preferences and values. A 2011 survey of sicker patients in 11 countries found that Swedish patients were least likely to report positive experiences (see Figure 8). In fact, Sweden had the lowest performance on each of four relevant measures included in the survey, failing to reach even 50 percent patient satisfaction on three of the measures (see Figure 9).

**Figure 8.** Percentage of patients answering the most preferable answer on each question concerning preferences and needs\* *Source: IHP International Survey of Sicker Adults, 2011.*

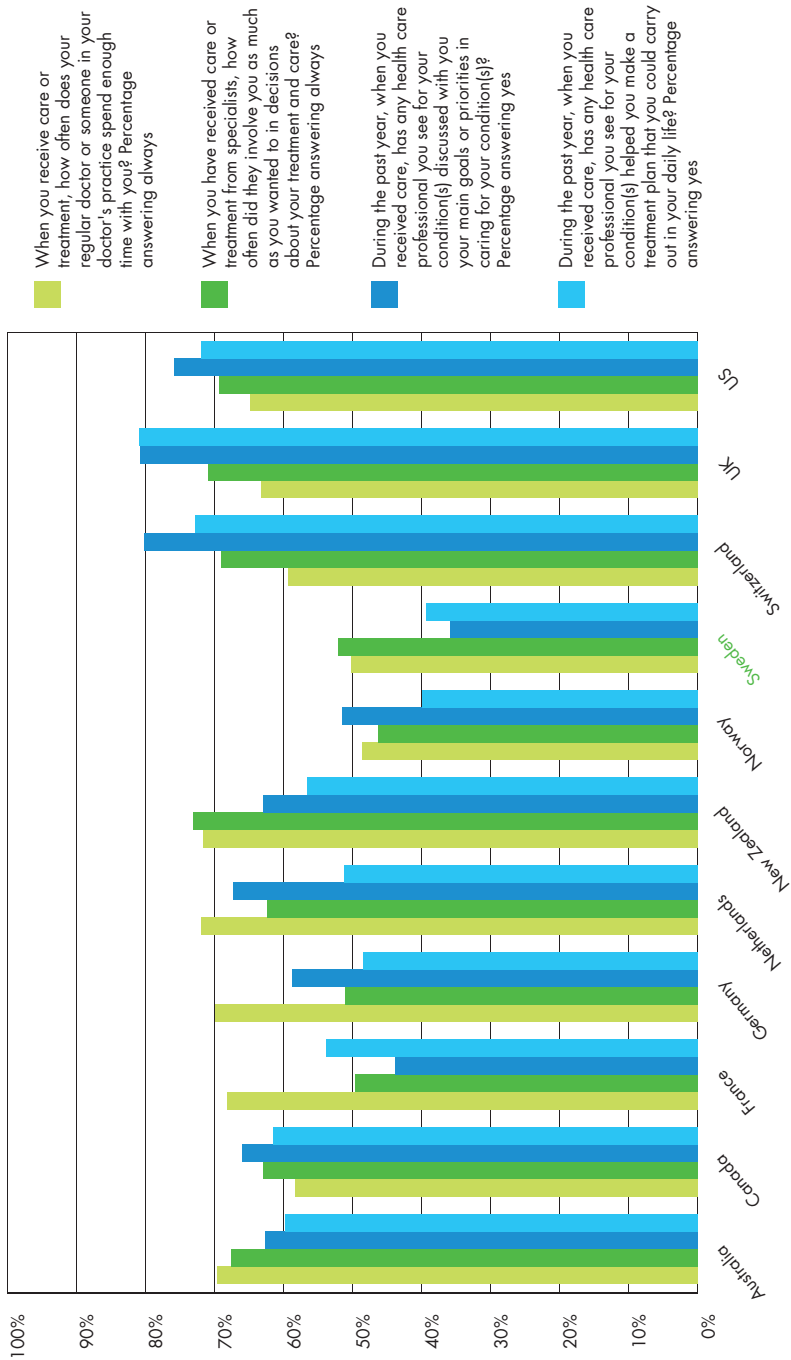


\* Unweighted index. For a description of the elements of the index, see figure 13.

How patient-centered is Sweden's health care today?

**Figure 9.** Sicker adults reporting positive experiences relating to preferences and needs. (Percentage of patients in Sweden and 10 other countries.)

Source: IHP International Survey of Sicker Adults, 2011.



### *National Patient Surveys reveal areas for improvement*

Findings from the Swedish National Patient Survey modules on primary care, inpatient and outpatient specialty care, and psychiatric care also reveal areas in which patient-experienced quality in terms of respect for patients' individual needs, preferences and values, can be improved.

However, certain problems appear less widespread in the national versus the international survey results. For example, the median patient-experienced quality score in terms of patients who felt as though they were able to participate as much as they would like in decisions about their treatment was considerably high especially for primary care and specialty care patients. It is likely to be the case that the international survey's focus on heaviest users of health care (i.e. sicker adults) found more problems by virtue of its sample design plan.

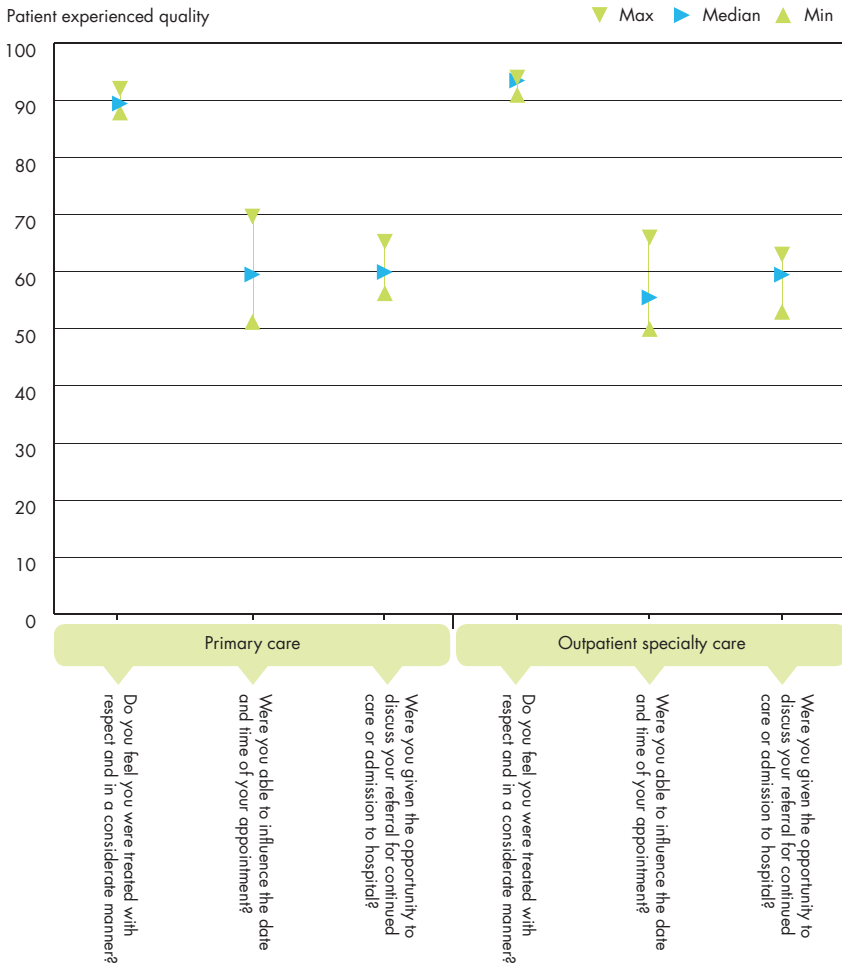
#### PRIMARY AND SPECIALTY CARE

A notable finding related to problems with the perceived convenience of health services in meeting individual needs. A finding that was common across both primary care and specialty care was relatively low patient-experienced quality scores in terms of the ability to influence the date and time of appointment. Variation across counties was relatively high for these measures, as well – about 20 points – as compared with 5-10 points for most of the measures relevant to this dimension in the primary care and specialty care modules. Another shortfall concerned the opportunity for primary care and outpatient specialty care patients to discuss their referral for continued care or admission to hospital (see Figure 10).

Some relatively positive findings were also evident. For example, a common outcome across the surveys was that some of the positive scores related to the important question of whether the doctor listened to what the patient had to say, and whether the patient felt that he or she was treated with respect and in a considerate manner. For these questions, cross county variation was low (see Figure 10 and Appendix III).

**Figure 10.** Primary care and outpatient speciality care patients' experiences relating to needs, preferences and values in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*.)

Source: National Patient Survey, primary and outpatient speciality care (2011, 2010)



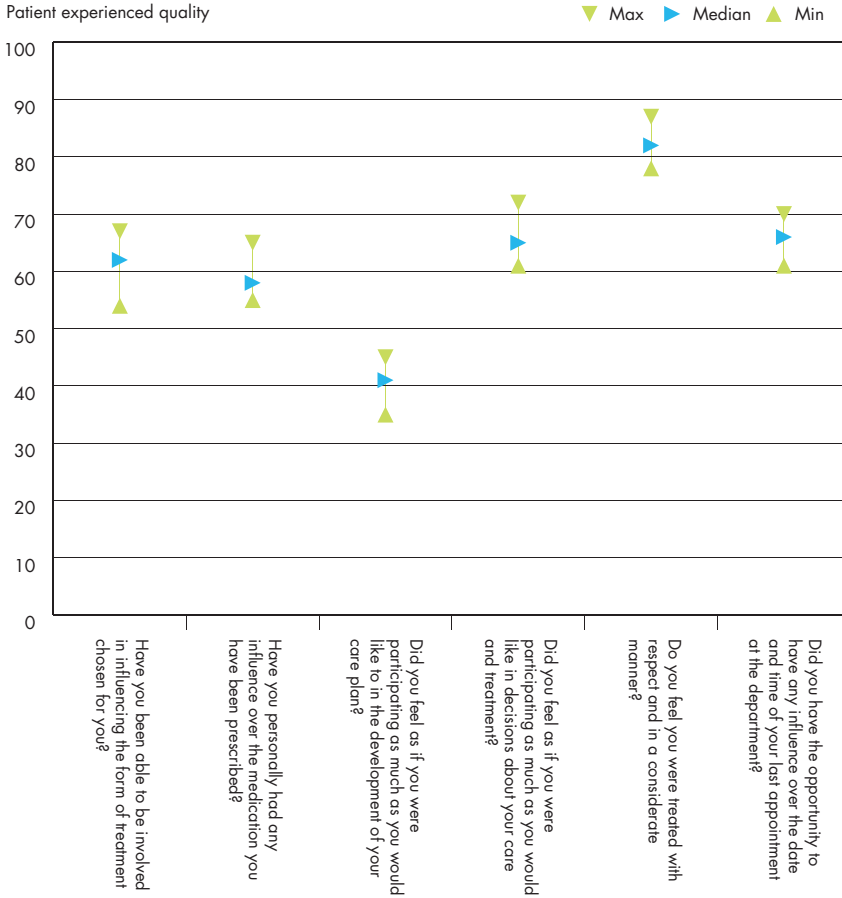
\* See Appendix III for a more detailed description.

#### OUTPATIENT AND INPATIENT PSYCHIATRIC CARE

Findings for inpatient and outpatient psychiatric patients showed a different pattern. Questions concerning outpatients' involvement in influencing form of treatment, medication prescribed, or the time and date of appointments, showed relatively low scores, around 60 and below. In addition, there is considerable room for improvement concerning patient participation in decisions

about care and treatment and in the development of care plans. Most of the relevant questions asked of outpatient psychiatric patients had median scores between 60 and 80 points, with fairly small variation across counties (see Figure 11).

**Figure 11.** Outpatient psychiatric care patients' experiences relating to needs, preferences and values in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*.) Source: National Patient Survey, outpatient psychiatric care (2010).



\* See Appendix III for a more detailed description.

However, the findings for the relevant questions asked of inpatient psychiatric patients show enormous variation across counties. For example, a question as to whether the doctors showed sufficient understanding and respect for the patient and his or her disease or complaints had a median score in the low 70s, with a range of 35 to 96 across counties (see Appendix III).

## **Legal framework, recent initiatives and reforms**

The Health and Medical Service Act and Patient Safety Act both include provisions that specify the need to respect patients' needs, preferences, and values. For example, the Health and Medical Service Act stipulates that health care must be managed to comply with the obligations of a good care, which means that it must be built on respect for the patient's self-determination and integrity. Also, care and treatment, as much as possible, must be planned and implemented in consultation with the patient. It is further stated that when there are several treatment alternatives that are in compliance with science and proven experience, the county council shall give the patient the opportunity to choose the alternative that he or she prefers. The Patient Safety Act specifies that the person who is responsible for the health and medical care of a patient shall assist in the patient being given an opportunity to choose the alternative that he or she prefers.

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 events. This is partly due to limits on enforceability. To the extent that patients find that their care does not meet the legal standard established, they can complain to designated bodies (the local Patient Advisory Committee and the National Board of Health and Welfare), but have no legal grounds to obtain redress.

### *Patient choice reforms aim to spur competition to meet patients' needs and preferences*

In this vein, reforms by the current and previous governments were geared toward establishing and expanding the patients' choice of health care provider were, in part, intended to spur competition to meet patients' needs and preferences, and to give patients an out when service is unsatisfactory. Choice of provider has not traditionally been a feature of the Swedish health care system. Up to the beginning of the 21st century, Swedish patients have been assigned the provider closest to their home address. Changing one's health care provider within the county or outside the county has almost been impossible due to administrative and financial barriers in the system. Also, Sweden's health care system has been based on public finance and public provision of care, with a very limited tradition of private caregivers. In light of this, expanding choice of health care providers and providing more opportunities for private healthcare are reforms that have fundamentally changed the Swedish system and how it views patients (Anell, 2012; Winblad, 2003).

While many steps toward increasing choice and private options have been

put in place, it is clear that the implementation of the reforms is not being accomplished in a uniform and regular manner. For example, some counties, with respect to the legislation on free choice of provider (2008:962), have gone further than required, expanding choice to specialty care, for example. Furthermore, results point to shortfalls in the implementation of enhanced choice, a recommendation issued by the former Federation of County Councils, currently known as the Swedish Association of Local Authorities and Regions, which is supposed to allow patients to seek care outside their own county council (Dir.2011:25). Furthermore, some county councils have erected implicit administrative barriers to choice, stipulating that they will not pay for certain services that they do not consider to be necessary. The current government has asked the Commission on Patient Empowerment (S 2011:03) to put forward proposals on how to further strengthen patients' ability to choose providers.

### *Initiatives aim to strengthen the role and prominence of patients*

Beyond this legal basis, some movement towards increasing the role and prominence of individual patients as unique individuals is evident.

Notably, the University of Gothenburg's Person-Centred Care Institute, established in 2010, conducts research and assists hospitals in implementing patient-centered pathways. Institute researchers have undertaken a number of studies in which implementation of new practice pathways involving detailed information gathering from patients, and developing patient-provider partnerships in devising and carrying out treatment plans, were tried out (see, for example, Ekman et al., 2007; Olsson et al., 2006; Olsson et al., 2009; Ekman et al., 2011; Ekman et al., 2012). Findings from the research have demonstrated very significant improvements in both health outcomes (e.g., better maintenance of functional ability among heart failure patients) and costs (e.g., 40 percent reduction in costs of caring for hip fracture patients) in studies comparing use of the pathways to control groups following regular practice.

According to a recent government report on national quality registers (Rosén et al. 2010), many of Sweden's quality registries, especially those concerning chronically ill patients, are also increasingly being used to raise the level of patient participation in care as active partners with their physician. The rheumatoid arthritis registry uses a module that enables patients, on their own and prior to their medical appointment, to feed information about their health into the registry. This data is discussed between the doctor and the patient during the appointment. The diabetic registry has an individual diabetic

profile that is created automatically, based on all data and is complemented together with the patient. Data from the registry for children with cerebral palsy show children's development over time and can be used in communication with the whole family. These types of methods contribute to making patients co-producers in their own health care. They receive support for a holistic view of their health situation, and can see results and connections between complying with the prescribed treatment and their own health results.

Another promising development relates to efforts to place patients at the center of planning in terms of design of structure and process. One example of this is the ongoing efforts at a new hospital being developed as part of the Karolinska University Hospital system. Efforts to consider impact of decisions from the patient's perspective are being made in choosing both design features and delivery system features.

On a smaller scale, quality improvement initiatives such as a "Tell Us" campaign inviting hospital patients to provide on-site feedback, has reportedly helped to improve patient experience and promote a more responsive and positive care environment.

## **Shortfalls in meeting patient demands and expectations**

### *Problems with how care is structured and organized, and with processes used in care delivery*

Patient complaints about the rules and resources associated with health care delivery account for about one-quarter of all patient complaints lodged with the Patient Advisory Committees in recent years. Examples of the types of problems cited include issues relating to choice, access and waiting times, administrative procedures, and privacy and confidentiality issues, some of which can relate to problems in respecting patients' needs, preferences and values. Emergency room triage procedures are a reportedly problematic area, according to experts interviewed for this study, and studies have found dissatisfaction with postnatal care procedures (Hildingsson, 2007, 2005).

### *Insufficient attention to patient convenience*

Although there is reportedly quite significant variation in organizational and procedural characteristics across counties, health care in Sweden has often been characterized by experts as being structured primarily for administrative convenience, secondarily for providers' convenience, with patient convenience



nience at the bottom of the list. This is evidenced in the difficulty patients have in obtaining appointments on convenient dates and times, long waits for appointments due to poor scheduling, obstacles preventing patients from seeing the same practitioner, and other problems. 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; examples of multidisciplinary or multispecialty practices that specialize in providing comprehensive care for patients with particular conditions (e.g., diabetes, stroke rehabilitation) are rare.

Findings from the National Patient Survey document the problem. The median patient-experienced quality score based on emergency care patients being informed about how long they would need to wait to see a doctor was 35. A finding that was common across both primary care and outpatient specialty care was relatively low (55–60 median) patient-experienced quality scores in terms of the ability to influence the date and time of appointment. And the median score pertaining to the opportunity to influence the hospital admission was even lower (38). Variation across counties was relatively high for these measures, as well.

### *Providers need to do more to tap patient knowledge*

Processes used in the provision of care also fail to support the tailoring of health care services to the individual and unique case. For example, representatives of patient organizations noted that physicians often fail to take advantage of the knowledge patients with rare or complex conditions might have about their own symptoms and conditions. Because of time constraints associated with appointments or for other reasons, patients do not tend to be properly tapped as a resource for improving health care decision-making. In addition, patient representatives reported that “advance directives,” (basically, living wills) in which patients specify their preferences regarding employment of life-sustaining technology such as artificial respirators and feeding tubes in the event of their being rendered unable to consent to treatment, are not commonly used in Sweden.

### *Limited patient engagement in informed, shared-decision making*

Osborn and Squires (2012) found that Swedish patients were among the least engaged in their health care decision-making. Sicker adults were asked how

often the specialist physicians treating them provided opportunities to ask questions about recommended treatments, told them about their treatment choices, and involved them as much as they would like in decisions about their care. Four-fifths of patients in Switzerland and the U.K. replied “always” or “often” to all three questions, as did two-thirds or more of Dutch, New Zealand, and American respondents. Respondents in France, Germany, Norway, and Sweden were the least likely to report participating together with their specialists in shared health care decision-making. In Sweden, as in seven of the eleven countries studied, lower income patients were more likely to report not having been given an opportunity to participate by their providers. Notably, the survey also found that patients who were given this opportunity by their providers were less likely to report a medical, medication, or lab test error in the past two years, and had more positive views of the health system as a whole (Osborn and Squires, 2012).

Problems of inadequate patient participation appear less widespread in the national versus the international survey results. For example, the median patient experience score in terms of patients who felt as though they were able to participate as much as they would like in decisions about their treatment was between 78 and 81 for primary care patients and for inpatient and outpatient specialty care patients, and 65 for outpatient psychiatric patients and 55 for inpatient psychiatric patients. It is likely to be the case that the international survey's focus on heaviest users of health care (i.e. sicker adults) found more problems by virtue of its sample design plan.

But there is widespread agreement among experts that, as yet, there is relatively limited opportunity for many Swedish patients to engage with doctors as partners in their own care. By all accounts, the paternalistic model of physician-patient relationship still prevails in Sweden. This contrasts with some countries, such as the United States, where, for a number of years, a partner relationship has been presented as an ideal, albeit one that is only inconsistently met. Formal processes of informed shared decision-making for treatments highly dependent on patient preferences, such as screening and treatment for prostate cancer, are not yet widely employed by health care providers for use with patients, although decision aids such as pamphlets and online resources have been developed. In one exceptional example of physician-patient partnership cited by a number of experts interviewed, some Swedish rheumatologists have begun to routinely collect and employ information from patients on their symptoms and changes in the progression of their conditions, in the interest of improving care and outcomes.

Certainly not all patients are both capable and interested in sharing de-

cision-making responsibilities with their health care providers, but health care providers will need to ask about patient preferences in order to enable patients to participate to the extent they desire. A study by Ekdahl and colleagues (2010) found that most frail elderly patients wish to be informed and to have good communication with their providers, but do not wish to participate in decisions about medical treatments. Another study of elderly patients (Ekdahl et al., 2011) found that about half of elderly patients surveyed said that they were as involved in their care decisions to the extent they desired, whereas about one-third reported less participation than they wanted and about a quarter reported more than they wanted.

### *Unsatisfactory patient encounters have poor implications for outcomes*

Swedish patients are often unsatisfied with some aspects of the patient encounter. For instance, fewer than 36 percent of Swedish patients surveyed said the health care professionals they consulted in the past year had discussed with them their main goals or priorities for treatment (IHP, 2011).

Some experts expressed concern about the impact of growing administrative requirements or incentives that were viewed as potentially interfering with the patient-physician relationship. One example cited by several experts was a guideline that physicians ask about alcohol use, physical activity and smoking, behaviors that could be viewed as embarrassing for some patients.

Furthermore, the IHP survey found that Swedish patients were, together with Norwegian patients, those most likely to be dissatisfied with the amount of time their physicians spent with them (IHP, 2011). Of Swedish patients, 12 percent said the time spent was rarely or never sufficient. By contrast, only two percent of British patients reported this problem.

Nevertheless, some aspects of the patient encounter appear to be working generally well for patients. A common finding across the surveys was that some of the positive scores related to the important questions of whether the doctor listened to what the patient had to say, and whether the patient felt that he or she was treated with respect and in a considerate manner.

The importance of positive patient encounters for outcomes has been underscored by recent research. Based on a cross-sectional study of 10,000 long-term sick-listed people, Niels Lynøe and colleagues (2011) found that negative patient encounters characterized by problems with empathy, respect, and failure to listen were associated with a reduced self-estimated ability to return to work.



## Conclusions and implications of findings

Sweden's health care system often fails to anticipate and respond to patients as individuals with particular needs, values and preferences to an extent that makes Sweden a relatively poor performer in this respect in international comparisons. This failure reduces patient satisfaction with their encounters with the health care system and their providers, and may well have a negative effect on health care costs and health outcomes, via channels such as reduced compliance with treatment protocols or otherwise. This is, in part, due to observable structural problems (e.g., time constraints, burdensome administrative data-collection requirements) that are subject to change through policy, although attitudinal changes are also important.

The shortfalls are evident. While legal standards exist, there is little recourse when they are not met. Expanded patient choice may help, but there are barriers to achieving choice of health care provider and treatment that remain to be addressed. At present, patients are not often encouraged to participate as partners with their physicians in their care, and are not invited or encouraged to engage in joint decision-making. And health care is, by and large, not organized in ways that cater to patients in terms of respecting them and their time.

There is evidence to suggest that health care in Sweden is moving in the direction of being more responsive to patients' individual needs, preferences and values, manifest in initiatives like those described above. The fact that patients see their doctors as respectful and engaged in active listening provides a basis for a more active future partnership. Findings from this assessment suggest that health care administrators and those managers who are responsible for the design of care delivery organizations and processes are less far along in terms of being respectfully engaged with the patients they serve, however.

On the other hand, threats to progress are also evident. While some experts pointed to changing attitudes among younger, newly trained physicians as being more amenable to active engagement with patients, others noted that the move to standardize practice through administrative incentives to follow clinical practice guidelines and formularies has influenced some physicians to be less willing to deviate from prescribed approaches and thereby tailor care to the preferences and values of individual patients. Time pressures on physicians, reflecting increased use of activity-based reimbursement methods, and increased administrative requirements that interfere with the physician-patient relationship were also cited as potential threats.

### 5.3 DIMENSION 3: COORDINATING CARE ACROSS SERVICE PROVIDERS AND ENSURING CONTINUITY OF CARE

- ▶ *Inadequate coordination across healthcare providers is a major, widespread and persistent 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

Coordinating care, so as to obtain optimal service in a particular episode of treatment, and ensure good continuity of care over the long term, is a core conceptual dimension of patient-centered 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.

#### An overarching look at patient views

Below, we review recent survey findings that compare Swedish patients with patients in other countries, in terms of their satisfaction with health care coordination and continuity of care, and review findings from selected modules of the National Patient Survey

*International survey of sicker adults shows shortfalls in care coordination, although the impact on quality is less than would be expected*

Findings from the 2011 Commonwealth Fund survey of sicker adults in 11 countries reveal evidence of shortfalls in processes used to coordinate treatments and ensure good continuity in care (Schoen et al., 2011). Sweden scored below the median on three out of five relevant process measures included in the survey (see Figure 12). Assessing the share of patients who responded with the most favorable answer on the five coordination-related questions, Sweden's performance was second-lowest, after Germany (see Figure 13).

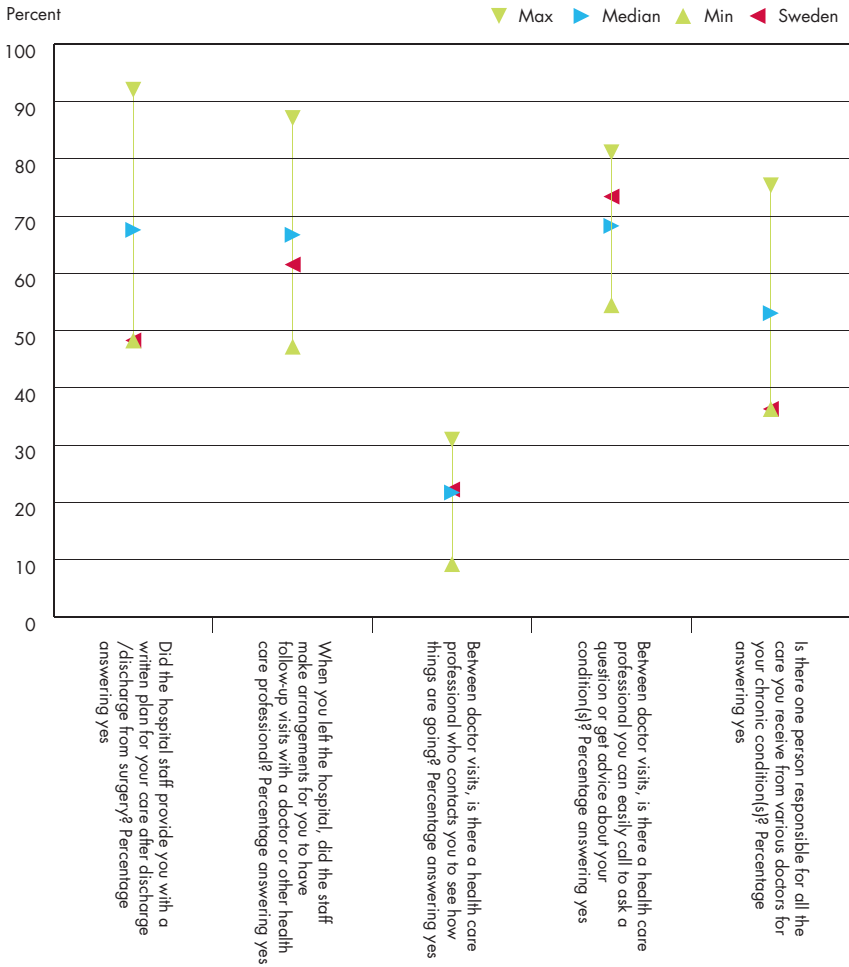
The poor performance partly reflects a structural characteristic of Swedish health care in which most patients get their primary care at a particular clinic, but not all patients see a particular provider at that clinic. Swedish patients were least likely of patients from any country to report that they have a personal physician whom they usually see for care, and more likely to report



How patient-centered is Sweden's health care today?

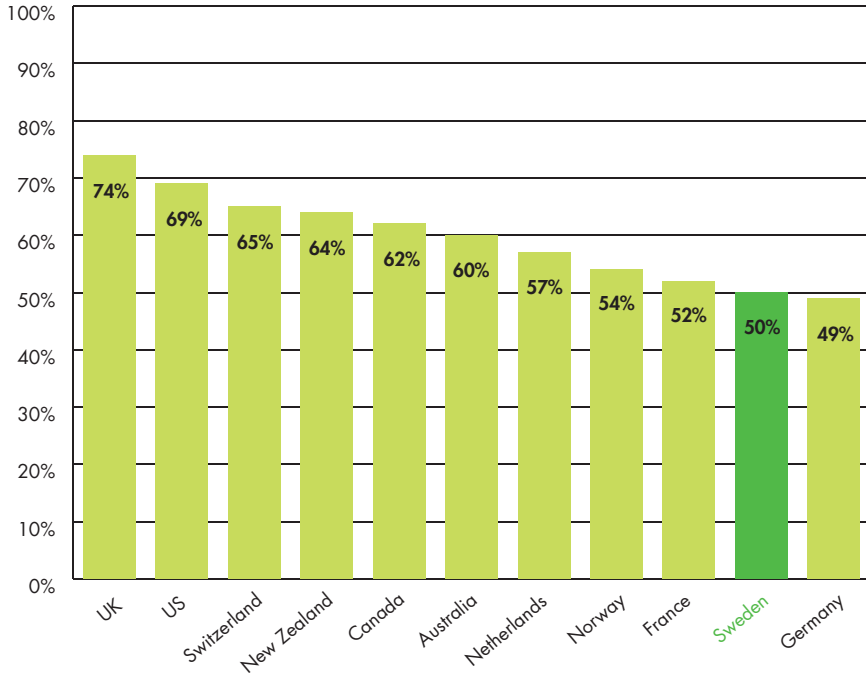
that they had a particular clinic at which they obtained care (Schoen et al., 2011).

**Figure 12.** Sicker adults reporting positive experiences relating to care coordination. (Percentage of patients in Sweden and ten other countries answering "yes".) Source: IHP International Survey of Sicker Adults, 2011.



How patient-centered is Sweden's health care today?

**Figure 13.** Percentage of patients answering the most positive answer on each question concerning coordination and continuity.\*  
Source: IHP International Survey of Sicker Adults (2011).



\*Unweighted index. For a description of the elements of the index, see Appendix IIII.

A total of 39 percent of Swedish patients had experienced gaps in coordination – defined as patients having experienced a situation in which their test results or records were not available at time of appointment, their doctors ordered tests that had already been done, providers failed to share important information with each other, specialists did not have information about medical history, and/or regular doctor was not informed about specialist care – over the past two years, resulting in a ranking of sixth place out of 11 countries. The most problems were experienced in Germany, where 56 percent of sicker patients experienced gaps, and the fewest in the United Kingdom, where just 20 percent reported gaps (Shoen et al., 2011).



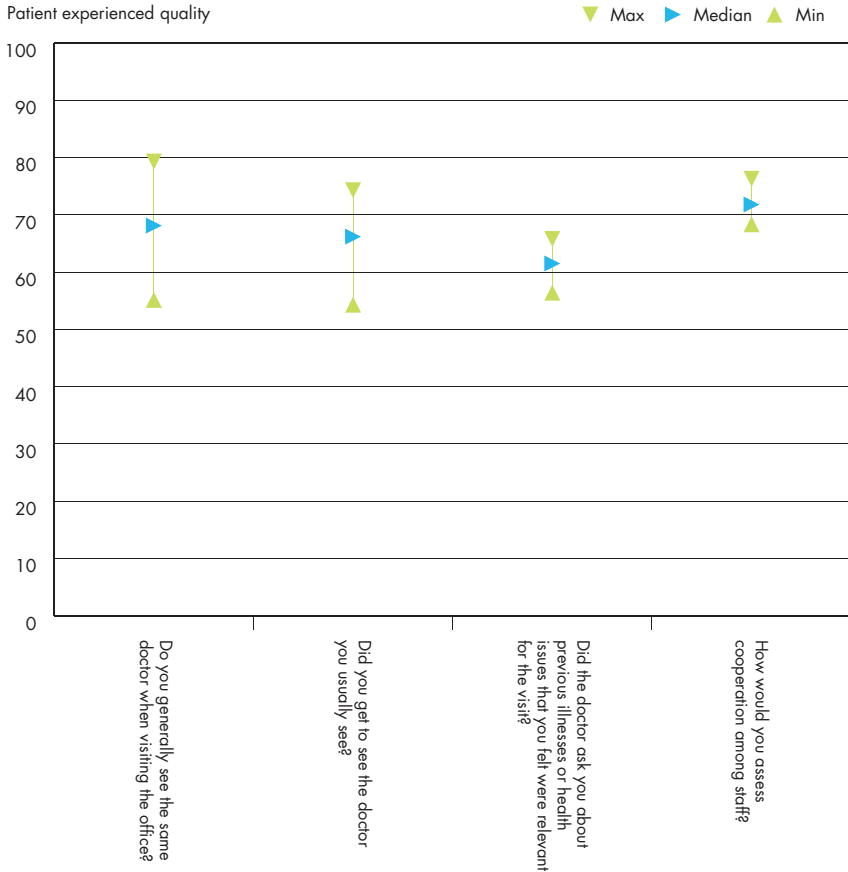
*The Swedish National Patient Survey documents room for improvement in coordination and continuity of care*

PRIMARY CARE

As a patient's primary care provider generally serves as the locus of coordination across the different providers a patient sees, it is notable that the primary care module of Sweden's National Patient Survey does not include questions to assess how well the primary care physician (or clinic) performs this care coordination function. With respect to four questions that could be considered instrumental in promoting care coordination (e.g., generally seeing the same doctor, cooperation among clinic staff), the results indicated considerable room for improvement. The range of scores across counties was particularly large for the measure of generally seeing the same doctor when visiting the office, suggesting that there are important structural or procedural differences in primary care across Sweden (see Figure 14).



**Figure 14.** Primary care patients' experiences relating to care coordination and continuity in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*.)  
 Source: National Patient Survey, primary care (2011).

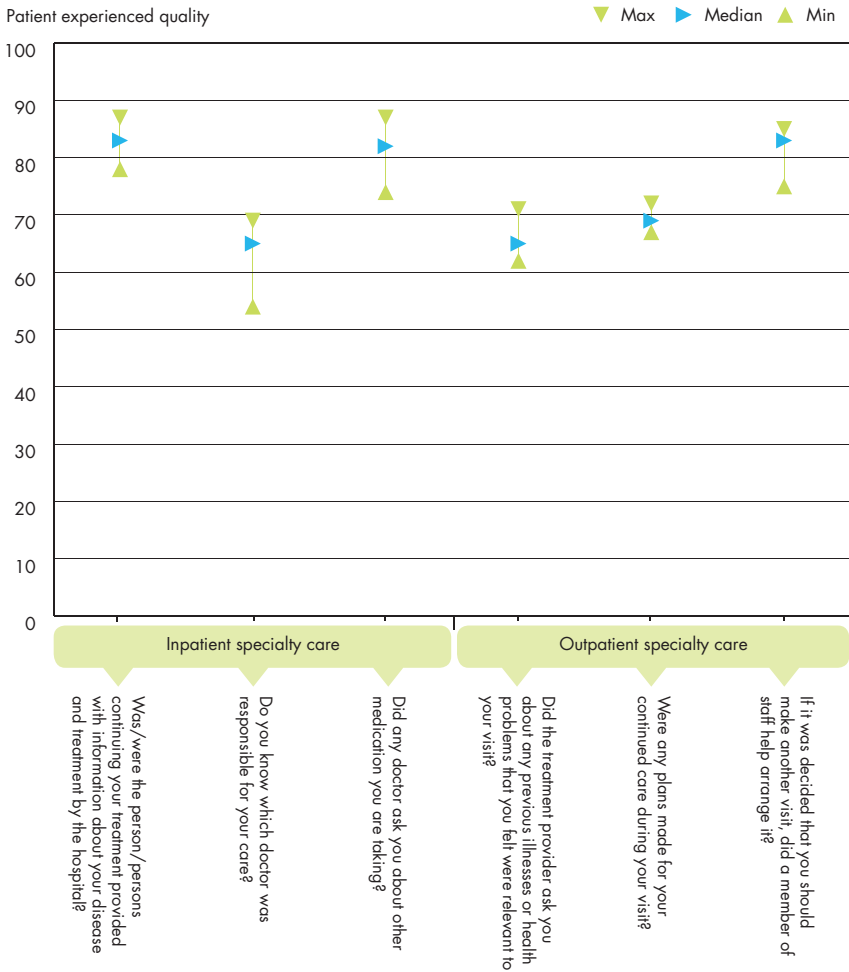


\* See Appendix III for a more detailed description.

#### INPATIENT AND OUTPATIENT SPECIALTY CARE

With respect to inpatient and outpatient specialty care, county performance on questions such as whether plans were made for continuing care or whether health professionals continuing treatment asked about medical history or were provided with relevant information about previous diseases or treatments, was only slightly better, although the range of variation across counties in performance was much smaller. Notable was a finding that the median score on a question as to whether inpatients knew which doctor was responsible for their care stood at only 65 (see Figure 15).

**Figure 15.** Inpatient and outpatient specialty care patients' experiences relating to care coordination and continuity in Sweden's county councils. (Patient-experienced quality measures on a 0–100 scale\*.)  
 Source: National Patient Survey, inpatient specialty care (2010) and outpatient specialty care (2010).



\*See Appendix III for a more detailed description.

OUTPATIENT AND INPATIENT PSYCHIATRIC CARE

With respect to coordination and continuity of care experienced by outpatient psychiatric patients, median experience across counties was notably lower than for somatic specialist care. An area of relatively poor performance was in work by the patient and provider on a plan for continued care, with relatively little variation across counties. Greater variation across counties was

seen with respect to a question on whether the patient thinks that his doctor and psychiatric treatment provider collaborate in a satisfactory way: Patient experience scores ranged from 45 to 73, with median performance at 64 (see Figure 16).

With respect to inpatient psychiatric care, variation across counties was over 30 points for each of the questions concerning information of where to turn after discharge, planning for continued care, and collaboration between the clinic and other agencies, such as social insurance offices and social services. A particular concern is that the median patient experience score on a question about planning for continued care was only 45, with the lowest scoring county at 23 and even the best performer only reaching 59 (see Figure 16).

### **Legal framework, recent initiatives and reforms**

Sweden's Health and Medical Services Act includes provisions that establish legal requirements to coordinate care. For example, in specifying what constitutes "good care," the Act requires that care be managed in such a way as to "accommodate the patient's need of continuity." It further specifies that different health care activities for a patient be "coordinated (so as) to be adapted to its purpose."

It is evident that there is room for improvement in achieving the legislation's objectives, but making improvements will require addressing key obstacles including the functional independence of health care actors, problems with health information systems and reimbursement mechanisms that fail to incentivize or reward coordination in health care. Below we review key obstacles to achieving the legislation's objectives and describe initiatives aimed at enhancing health care coordination and continuity of care in Sweden.

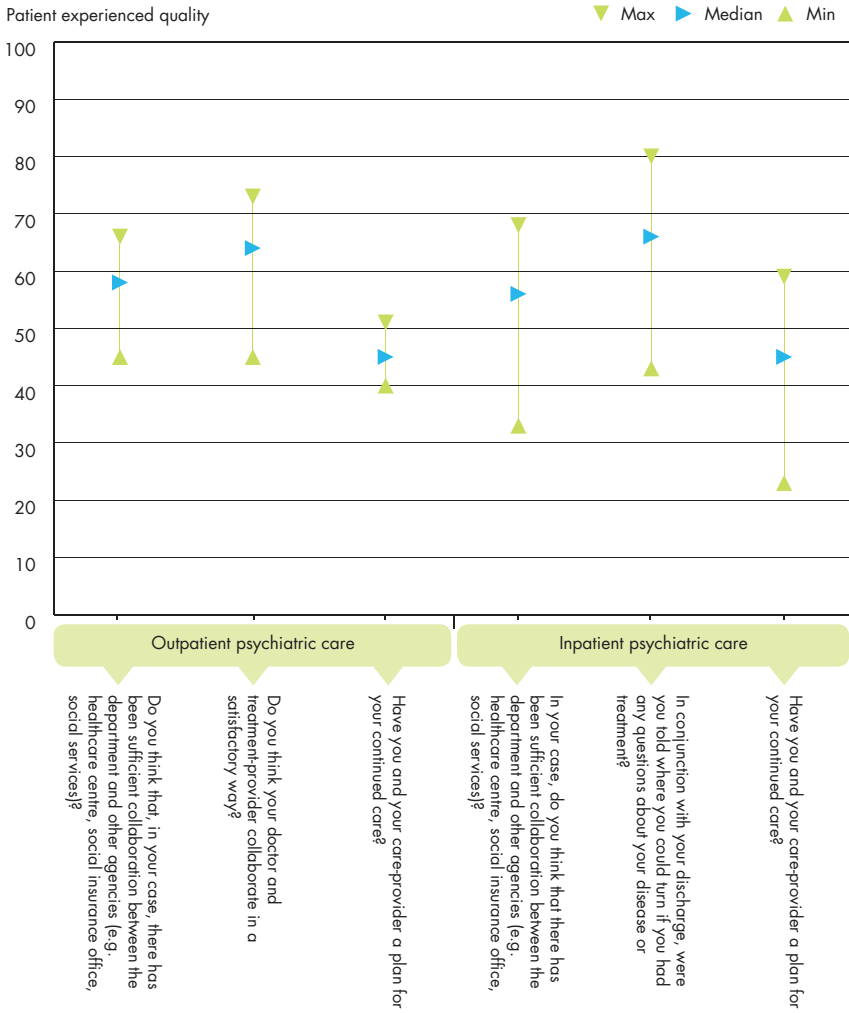
### *Organization of health care services*

The organization of Sweden's health care, typically structured by function in a vertical manner, presents an obstacle to coordination of care. Every clinic and hospital unit manages its own resources and strives to reach its own goals (KEFU, 2012). As a result, cooperation within health care and between health and social services suffer, making it hard to create coordinated health care processes horizontally (Krohwinkel, Karlsson & Winberg Eds., 2012).

However, various reforms, on both national and local level, have been enacted in efforts to strengthen cooperation within and between county councils, responsible for administration of health services, and municipalities, respon-

**Figure 16.** Outpatient and inpatient psychiatric care patients' experiences relating to care coordination and continuity in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*.)

Source: National Patient Survey, outpatient psychiatric care (2010).



\*See Appendix III for a more detailed description.

sible for administration of social services. For instance, county councils and municipalities are supposed to establish "cooperation agreements" to clarify how care is functionally organized, and to delineate the different roles and responsibilities of actors in the health and social services chain (NBHW 2011).

Other local and national reforms aim to bypass structural obstacles by aiding the patient in maneuvering successfully through the system and acting to coordinate care on his or her own behalf. Specific local examples include:

- **Case management;** in which a designated case manager has overarching responsibility for all health care provided to a patient, is sometimes employed; for example, for patients with severe mental disabilities.
- **Health care attendant;** Stockholm County Council launched an initiative featuring registered nurses who support and assist very sick patients with multiple diagnoses and chronic diseases.
- **Multi-professional teams;** these are used to facilitate assessments that require different perspectives and competences and to meet patient care needs from a holistic perspective. The constellation of multi-professional teams varies depending on the special needs of patients. There are different ways to organize the teams; one example is the dementia-teams that some county councils and municipalities have created.

At the national level, a recently enacted (2010) provision of the Health and Medical Services Act gives Swedish patients the right to have a point of contact within the system who will serve as a resource and coordinator. The chief executive of the health care organization is to ensure that patients' needs for security, continuity, coordination and safety are met. If deemed necessary, or upon request from the patient, the chief executive shall appoint a permanent point of contact for the patient. However, most experts interviewed for this study were either unfamiliar with the law or stated that it had not yet had an impact on practice. These results are supported by a report from the National Board of Health and Welfare (2012), which stated that a majority of the primary care centers and about half of the hospital clinics had not had any patients that had been assigned a point of contact. The report also noted that insecurity prevails in the health care sector about how to interpret the new legislation and what kind of mandate the point of contact actually has. Some experts observed that providers lacked financial or other incentives to act as a point of contact, in that no reimbursement was associated with acting in a coordinating role.

After the 2010 reforms, the Health and Medical Services Act provides that county councils and municipalities are required to establish a plan to meet

an individual's needs in cases where both health care and social services are necessary. The plan must be established if the county council or municipality in question deems this necessary in order for the individual's needs to be accommodated, and if the individual consents to its establishment. The law also stipulates that the plan must specify the responsible authorities of the different activities as well as who has the main responsibility of the plan.

An issue of particular interest to the current national government is improving coordination and continuity of care for the sickest elderly, a group (like people with neuropsychiatric disorders and people with alcohol problems) that has been identified as one suffering from shortfalls in provider cooperation and problems with continuity of care. This interest has produced initiatives such as annual agreements (since 2010) between the national government and local authorities and regions intended to support more coherent health care and better welfare for the sickest elderly (i.e., people aged 65 or older who have substantial functional limitations caused by aging, injury or illness). The agreement links certain government grants to support local governments and other stakeholders in developing long-term, systematic improvements in designated areas. The funds allocated from 2012 and forward are to be divided according to a performance- and result-based model in which requirements and goals will gradually be raised (Ministry of Health and Social Affairs, 2011).

The performance-based agreements are interesting in that they may provide an example of how to obtain better and more timely congruence between national health care goals and local implementation and practice.

### *Initiatives to strengthen health information systems*

Functioning information systems are crucial to support cooperation by actors in health care service delivery processes. Yet by all accounts, existing health information systems in Sweden fall short in terms of what is desirable and achievable. A report from the Karolinska Institute (Andreasson et al., 2009) finds that existing information systems do not support adequate cooperation within and between health care and social services. That report, as well as reports from experts interviewed for this study, pointed to important problems in recording, retrieving and sharing data through the systems of electronic medical records employed in Sweden.

The Patient Data Act (2008:355) (*Patientdatalagen*) regulates information management in the health care system. This act provides health care workers with the ability to access information from other providers across



organizational borders electronically. One of the prerequisites is that the patient has given his consent to various care facilities accessing the journal. There are two ways to access records: - by care providers within a county council sharing a database, or through NPÖ, the "national patient overview" (another e-Health solution, under authority of the Center for e-Health). By the end of 2012, all county councils and regions are to have incorporated the NPÖ system.

In an investigation, the National Audit Office (*Riksrevisionen*) (2011) concluded that although the Patient Data Act creates new opportunities for data sharing, it is still constrained in many respects. Data sharing is limited and especially problematic in the exchange of information between health and social services providers because the legal framework does not enable sharing of patient information through electronic direct access between social services and health care. Improving access to personal data within and between health care and social services is an issue currently being studied by a national commission (S 2011:13).

In addition to the not-yet-fully utilized opportunities presented by electronic medical records, other types of technology may assist in facilitating better coordination and continuity of care for Swedish patients in the future. For example, electronic decision aids can not only help health care providers consider the evidence relating to alternative approaches to health care for particular patients, but also might contribute to coordination in care decision-making across different providers involved with a particular episode of treatment. One of the tasks of Sweden's National eHealth strategy (S2010.020) (led by the Ministry of Health and Social Affairs in cooperation with other actors) is to ensure that health care providers are equipped with well-functioning and coordinated decision aids.

### *Reimbursement systems to strengthen coordination*

The reimbursement system is one of the causes of care coordination problems. Reimbursement focuses on every unit's specific goal, which consolidates a vertical structure and prevents cooperation. One way to use the reimbursement system as an incentive for coordination between units and professionals is to define payments for the whole care episode, for example, from emergency care to rehabilitation. This is currently being done under the auspices of the Stockholm County Council for knee and hip surgery. In the Skåne region, reimbursement for stroke is based on how well the patient functions in daily activities three months after the incident. However, the use of these kinds of



reimbursement systems is not common in Sweden, and there is a need for evaluation of how reimbursement affects outcomes in practice.

### **Shortfalls in meeting patient demands and expectations**

A problem commonly cited by patient representatives is the lack of assistance available to patients who are 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. Patients in transition often feel they are given inadequate support, and even within a hospital setting may face challenges in coordinating post-discharge care. This is reportedly an increasing problem due to reductions in the length of hospital stays.

Coordination problems are especially evident in the cases of the frailest elderly patients and in psychiatry, rehabilitation, care for patients with disabilities and care for patients with drug abuse problems. All these patients require care involving different health and social service providers, contributing to boundary problems over defined responsibilities. Several reports from the National Board of Health and Welfare show that this is a pertinent and ongoing structural problem in Sweden's health care (NBHW, 2009, 2010, and 2012). Problems relating to coordination and continuity also make up a considerable share of complaints compiled by the Patient Advisory Committees serving each county.

Sweden's reliance on local financing and administration of health care presents some challenges to good coordination of services, particularly when patients' needs require use of services outside the local area. Patient representatives report that cost considerations make it difficult for patients to make convincing cases of the need to see non-local experts specializing in particular conditions. Other problems include a lack of interoperability in electronic medical record systems, impeding the sharing of data between providers.

Findings from the patient surveys make clear that health care planning is a problem area in Swedish health care. Additional evidence comes from a 2012 report by the Swedish Association of Local Authorities and Regions about the sickest elderly, which reported that health care planning at the time of discharge of patients occurred in only 30 percent of the cases.

### **Conclusions and implications of findings**

Poor coordination across health-care providers is a problem that is relatively common in Sweden's health system, as it is in many countries. Such problems



are likely to have a negative impact on health outcomes and costs, as well as on patient-experienced quality of service. Key problems identified in the course of the present study include:

- Poor performance in terms of international comparisons on structural and procedural instruments for care 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;
- 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 care providers and between health and social services;
- Technical problems in the functioning of electronic medical records that impede their full use to better coordinate and ensure continuity of care; and
- Problems in continuity and coordination for particular populations, such as the sickest elderly.

Coordination of care and collaboration across providers is important in any health system, but it is arguably particularly important in a country like Sweden, where a significant portion of patients rely on a clinic, rather than a particular physician, as their usual source of care. The clinic-based approach presumably offers advantages, such as improved accessibility of services, in contrast to individual practices, but structural or procedural changes (e.g., more powerful information systems) may be needed to counter the evident disadvantages for coordination and continuity of care.

A number of targeted initiatives have been launched and are promising, in particular, efforts to strengthen the health information systems that are essential to cross-provider cooperation, although problems in implementation are evident and will require both time and attention to development. Coordination is a complex area and in order to have successful outcomes from invested resources it is important that decision-makers pay attention to reimbursement systems, information, organization and regulations – factors that together are important prerequisites for collaboration and coordination in health care.

As is true in many countries, Sweden's provider reimbursement systems do not reward various activities that ensure good coordination and continuity of

care, including collaboration across providers and care planning, in that there is limited use of pay for performance in meeting process or outcome measures. Financial or other types of administrative incentives may be needed to reward collaborative care for patients with complex conditions.

#### **5.4 DIMENSION 4: TAKING A HOLISTIC APPROACH TO PATIENTS AS PEOPLE WITH MEDICAL AND NONMEDICAL (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**

Health care is a profoundly important and personal experience that 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 takes a holistic approach to patient needs, rather than a disease-centered approach.

#### **An overarching look at patient views**

##### *The Swedish National Patient Survey*

##### OUTPATIENT AND INPATIENT SPECIALTY CARE

In terms of taking a sufficiently holistic view of patients' situations, Sweden's specialty care providers perform fairly consistently across counties (see Figure 17). With respect to outpatient specialty care, patient-experienced quality scores for the different counties were tightly clustered around 80 points, with little variation. Greater variation was seen for inpatient specialty care, with scores ranging from the low 70s to the low 80s.

#### **Legal framework, recent initiatives and reforms**

In comparison with other dimensions of patient-centered care, holistic treatment is not well addressed in Sweden's legal framework, and no initiatives or reforms relevant to this concern were identified in the course of work on



this study. This may indicate that this concern is a relatively lower priority to Swedish patients or that the issues have not been subject to significant public and political discourse.

### **Shortfalls in meeting patient demands and expectations**

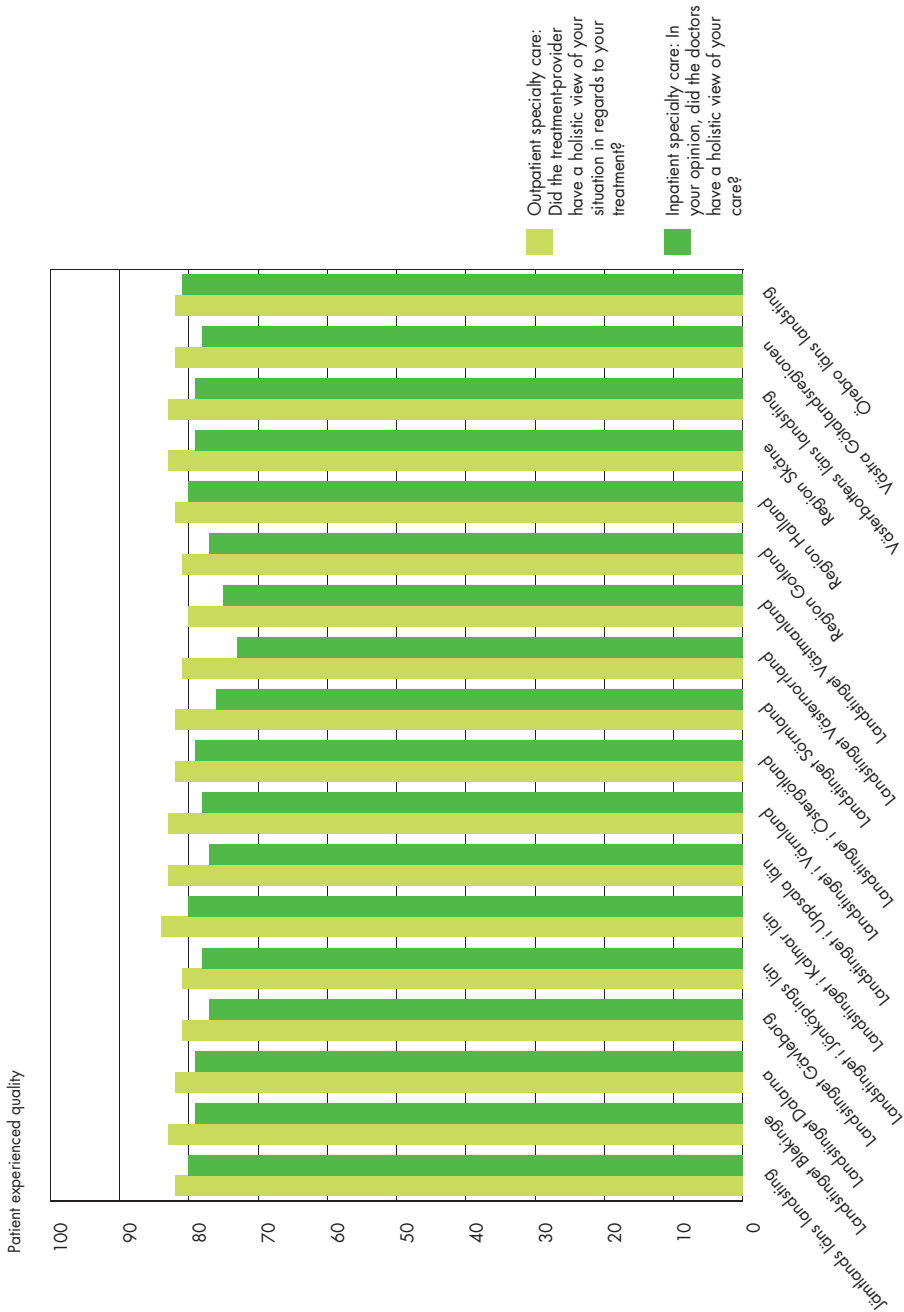
Some problems in terms of taking an insufficiently holistic approach to patients were identified in the course of work on this study.

One area in which experts pointed to problems lies in the area of post-acute care transitions. Patients with need for chronic follow-up care following an acute episode, such as a cardiovascular incident (stroke, heart attack), reportedly often lack the guidance and support needed to transition from the acute hospitalization phase to the critical follow-up care and lifestyle changes that may be required in the aftermath. Patients in the hospital are treated appropriately as acute care patients, but a holistic view of patients and their current and future needs is needed to help them prepare for and prosper in the post-acute phase. This becomes more and more of an issue as the period of hospitalization shrinks due to technological improvements that allow for less invasive procedures and less required recuperation as an inpatient, as well as cost pressures that encourage providers to reduce lengths of stay. One possible question for follow-up investigation is whether better-performing hospitals have instituted specific policies and practices that could be replicated to improve performance elsewhere.

Some patient representatives interviewed for this study reported that psychological and emotional support for patients is not what it needs to be, in terms of meeting patient needs. For example, certain types of cancer diagnoses may be viewed by patients as a “death sentence,” so it is very important that care processes acknowledge patient concerns and aid in reducing them to the extent possible, by minimizing waits for results post-biopsy, for example, and minimizing waits for specialty appointments and surgery in the aftermath of a biopsy finding of malignancy.

As a predominantly secular, and increasingly multicultural, country with a relatively strong social service sector, the value of integrating social and spiritual services within the context of health care provision is a matter deserving of consideration. Such issues were not prominent among the concerns raised by patient representatives interviewed for this study. Nevertheless, there is some indication of a need for improvement reported by some patient representatives and in studies from the academic research literature. In a small study, Koslander and Arvidsson (2007) found that Swedish mental health care

**Figure 17.** Specialty care patients' experiences relating to holistic care in Sweden's participating county councils. (Patient-experienced quality measures on a 0-100 scale\*.)  
 Source: National Patient Survey, inpatient specialty care, 2010 and outpatient specialty care, 2010.



\* See Appendix III for a more detailed description.

patients reported unmet spiritual needs and were frustrated in their attempts to obtain assistance from nurses in meeting those needs. Another area potentially benefiting from a similar study would relate to families of patients who are terminally ill.

## Conclusions and implications of findings

Our findings suggest that specialist physicians, hospital staff, and hospital administrators can do more to take a sufficiently holistic view of patients, so as to better meet their needs. Our findings of relatively low variation across counties suggest that this may not be an area in the administration of health care by the county councils that has had a particular impact. Therefore, in order to find models for improvement, so as to close the gap between what is ideal (100 points in terms of patient reported experience measures) and what has been accomplished to date, it may be useful to look instead at particular hospitals that scored highest in terms of providing holistic care for examples of best practices.

Our findings also suggest the need for further work to explore what the concept of holistic care means to Swedish patients. In particular, it would be useful to examine what is expected, particularly in terms of health care's 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 coordinated 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.

### 5.5 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

The involvement of family and friends in a patient's health care experience is an important determinant of patient experience and outcomes of patient-centered care. Patient focus groups conducted as part of development of the Picker Institute model of patient-centered care revealed that a patient's family members and close friends played a central role in the 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 (Gerteis et al., 1993).

## An overarching look at patient views

### *Results from the Swedish National Patient Survey*

#### INPATIENT SPECIALTY CARE

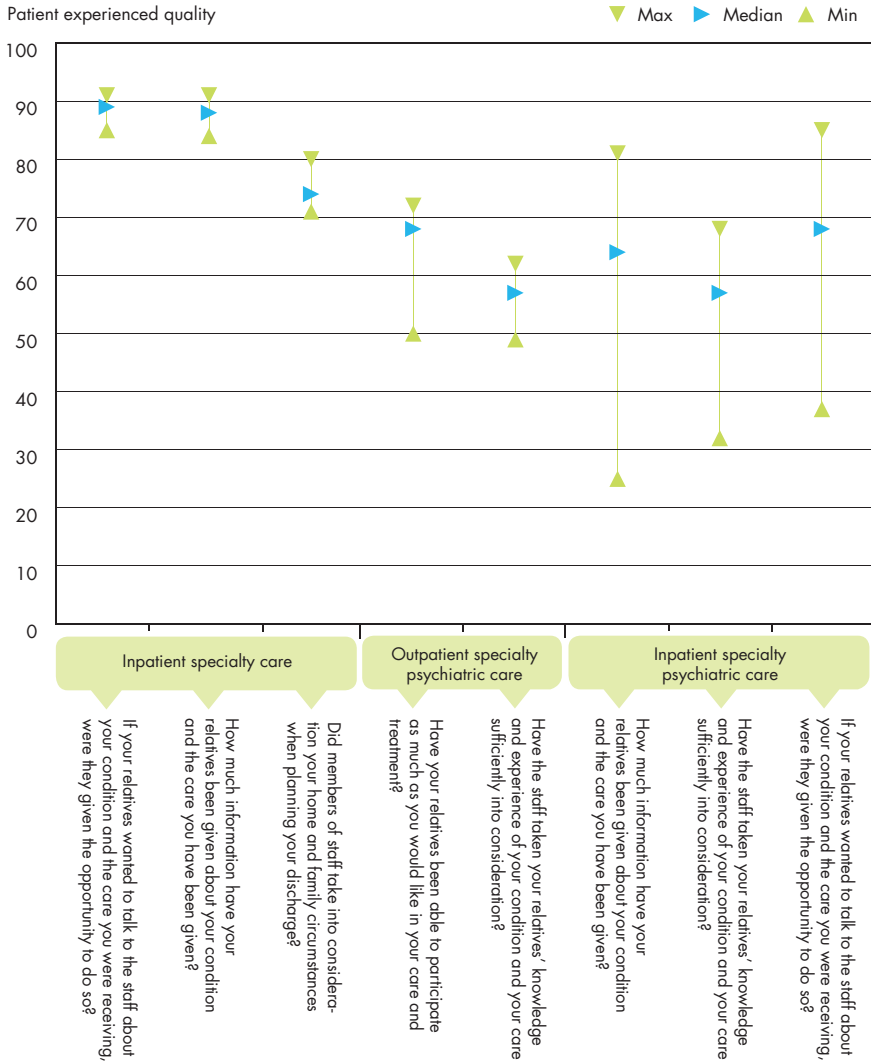
Patient experience measures from recent modules of the National Patient Survey show a mixed performance, in terms of involving family and friends in a patient's health care experience (see Figure 18). Counties had median patient experience scores of close to 90 points on two measures of performance evaluated by inpatient specialty care patients: measures of communication with and information provided to relatives of patients. Performance was markedly lower, with a median score of 74 points, with respect to a question about how well patients' home and family circumstances were taken into account in discharge planning.

#### OUTPATIENT AND INPATIENT PSYCHIATRIC CARE

For outpatient and (especially) inpatient psychiatric patients, median performance on the relevant measures was lower and the range of variation in performance across counties was considerably greater (see Figure 18). For example, with respect to a measure of whether relatives interested in talking to hospital staff about a psychiatric patient's condition and care were given the opportunity to do so, counties showed patient experience measures ranging from below 40 to above 80. The measure of amount of information given to relatives about an inpatient's care and condition had an even larger range, from 25 to 81, indicating very significant differences in performance – as well as potentially different relevant policies – across counties. Measures of how well physicians used input from psychiatric patients' friends and families received the lowest median scores (below 60), consistent with earlier findings that practitioners often fail to tap the expertise and perspective of their patients.



**Figure 18.** Inpatient somatic and in- and outpatient psychiatric patients' experiences relating to involvement of family and friends in Sweden's county councils. (Patient-experienced quality measures on a 0-100 scale\*.) Source: National Patient Survey, Inpatient specialty care (2010), Outpatient specialty psychiatric care (2010), Inpatient specialty psychiatric care (2010).



\* See Appendix III for a more detailed description.



The National Patient Survey findings documented possible problems in other areas of health care, as well. For instance, analysis of the reports from emergency care patients (2010) revealed that county councils showed patient experience quality measures of only between 46 and 71 points on an indicator that related to whether they were offered help to contact relatives while at the emergency department.

### **Legal framework, recent initiatives and reforms**

Sweden's health care laws include provisions intended to define a role for patients' family members in certain aspects of health care, to the extent desired by the patient. Both the Health and Medical Services Act and the Patient Safety Act oblige health care providers, with some exceptions intended to protect privacy, to give to a person closely related to the patient the information to which the patient is entitled (i.e., individually tailored information about health status, methods to be used in examination, care and treatment, options to choose care providers and the health care guarantee) at times when it is not possible to provide the information directly to the patient. Similarly, Swedish law includes provisions that promote the inclusion of patients' relatives in efforts to formulate a patient's individual health care plan, when appropriate and when such collaboration is not opposed by the patient. In 2009 a new provision was enacted in the Social Services Act (2009:549) (*Socialtjänstlagen*) obligating municipalities to offer assistance to people who provide care and support for a close relative who is sick, elderly, or with disabilities. The kind of support available varies across municipalities, but may include temporary relief by a professional who fills in for the family caregiver on occasion, individual counseling and support groups.

### **Shortfalls in meeting patient demands and expectations**

In the research undertaken for the present study, less information was found by which to assess Sweden's health system performance according to this dimension, in comparison with the amount of information uncovered for assessing other dimensions. The research literature appears fairly thin and this was not an issue emphasized, relative to others, by patient representatives and other experts interviewed. This may reflect limitations in research to date, or in the priority accorded to this dimension, relative to others. Alternatively, it could mean that problems in this area were less common or judged to be somewhat lower in priority, relative to problems in other areas.



Nevertheless, involvement of family and friends is likely to be important to at least a share of the Swedish patient population, given the prominent role of family caregivers in aiding individuals with dementia and other conditions. Furthermore, some municipalities provide for family caregivers to be compensated financially so as to allow them to serve in this important function.

The present study identified several problem areas. For example, several studies pointed to problems in treatment of male partners to women giving birth. One study by Ellberg and colleagues (2010) based on a survey of new parents found that close emotional attachment by parents was not always supported by health care providers, with fathers of babies being treated as outsiders in postnatal care.

An area that could benefit from further investigation is facilitating patients' abilities to authorize proxies to represent them and act on their behalf when they are unable to make health care decisions. Patient representatives interviewed for this study noted that problems have arisen when patients are incapacitated and unable to provide informed consent. It may not always be possible for patients to empower a family member or friend to act as a proxy in making decisions on their behalf, leaving the patient unrepresented. In a similar vein, the National Board of Health and Welfare (2011) noted that an unclear legal framework created challenges for family members of patients with dementia who could unwittingly impede their relatives from getting the support needed in cases where a patient is unable to apply for support himself.

Yet another problem cited by experts interviewed for this study was in a lack of engagement in outreach to family requiring support in caring for seriously ill patients. Municipal coordinators responsible for family support might provide a business card with contact information, rather than seeking out families and conducting follow-up, which is often important in informing patient families who might not be aware of the possible support available to assist them in caring for their seriously ill relatives. A report by the National Board of Health and Welfare (2011) concluded that it was not possible to evaluate the effects of the 2009 caregiver support law (2009:549) and to assess improvement areas, as little information was available for assessment outside of the municipalities' own reports. Lacking was information from patients' families about whether they had been offered or accepted support from the social services. In the report's conclusions, the Board stated that there is a need for developmental work within all areas of social services to ensure that staff apply a family/relative perspective in their work.

## Conclusions and main implications of findings

While 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 (and opportunities for making international comparisons using recent data were not found), available data (including cross-county variation in survey performance) 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;
  - 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; and
  - Provision of support to family members caring for seriously ill patients.
- In addition, there may well be as-yet unidentified needs to improve involvement of friends and family that pertain to different patient groups.

As with other dimensions, a prominent barrier to improvement in this area appears to be knowledge of protections and support afforded by law. For example, only six of eighteen patient organizations consulted by the National Board of Health and Welfare in 2011 were familiar with the legal protections provided for patient families in the Social Services Act. And as with other dimensions, there appears to be a discontinuity or lag between the enactment of protections and the implementation of those protections in actual practice. Finally, this appears to be an area in which improved cooperation between national government authorities and local health care administrators has the potential to yield important benefits.

The activities of the many patient organizations in Sweden that receive public funding can facilitate increased involvement of close family and friends in health care. Many of these patient organizations are already active in providing education about diseases and support to patients' relatives.

## 5.6 CROSS-CUTTING ISSUES: FACILITATORS AND BARRIERS TO ACHIEVING A MORE PATIENT-CENTERED HEALTH CARE IN SWEDEN

In the course of this study, 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 were 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 (European Observatory, 2012), 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 good 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 2010, a share comparable to many of the country's European neighbors and significantly less than the highest-spending systems (OECD, 2012). Nevertheless, reliance on local financing as a main source of funding stands to contribute to inequitable progress in meeting national goals. Many of the experts interviewed for this study commented on the inequities created by regional differences in resources and priorities, resulting 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 utilize patient data**

A second important facilitator of progress in Sweden lies in its extensive system of data collection. The quality registers of Sweden serve as an internation-

al example of best practice in terms of tracking patient care and outcomes over time. The relatively new National Patient Survey includes modules focused on many populations and categories of provider services, as well as comprehensive instruments based on Picker Institute surveys that are designed to assess the patient experience of care in ways that matter most to patients. As a result, the National Patient Survey provides an invaluable source of data that have yet to be fully utilized 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. So far, not all county councils have participated in all surveys, rendering comparisons more difficult. Also, each county council has owned its own data, making it 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, the Indicator Institute and the Swedish Association of Local Authorities and Regions, thus resulting in an inconsistent understanding of overall findings.

There are a variety of ways of allocating responsibilities relating to developing, administering and reporting on patient experiences with health care among different actors. One interesting example is the Dutch model. Following a set of reforms that moved the Netherlands' health system to a competition model among insurers, the government sought to enhance the information basis for health care consumer choice. One step was to develop an independent agency charged with setting standards for the measurement of patient experiences with the health system, including accreditation of instruments and data collection methods.

In addition to enhancing patient surveys, there is an evident need to develop additional sources of information, such as focus groups, and opportunities to provide input and feedback on line and through applications for smart phones, for example. Progress in terms of electronic medical records, albeit still burdened by technical and policy issues that are not yet resolved (subject to a currently ongoing inquiry commissioned by the national government), puts Sweden at the forefront of developed countries, and stands to be a critically important facilitator of future improvements in patient-centered care. Such a data infrastructure presents myriad opportunities for Sweden to make major advances in patient-centeredness. For example, such data could serve to support a range of applications for consumer use via smart phones to aid in making informed choices about health care treatments and providers. Such data should also inspire provider initiatives geared toward improving perfor-



mance 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 increase patient-centeredness, such as recent provisions allowing patients to name 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 and rank priority areas, and to ensure consistency across goals, might 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 have invested 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. In addition, Sweden's participation in international benchmarking efforts, such as international surveys fielded annually by the Commonwealth Fund and work

by the Organization for Economic Cooperation and Development, 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 by allowing for the participation of more private health care providers, and by 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, international experience has shown that competition in health care is not a panacea and carries costs (Newhouse, 1993; Schneider, 2009). Moreover, competition alone will not serve to ensure patient-centered care for all patients. The most vulnerable may be incapable 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 may not consider it valuable to compete 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 with regard to qualities valued by patients.

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

Another facilitator of patient-centered care is mechanisms for patient protection, including the Patient Advisory Committees and the National Board of Health and Welfare, which investigate and seek to resolve patient 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 that were injured during care or treatment had little knowledge of where to file a complaint. For example, only six percent of the patients knew that complaints concerning bad encounters (*dåligt bemötande*) should be filed with patient



committees. Another study found that patient complaints are filed by only a very small share of patients who have experienced problems in their encounters or experiences with the health care services (Wessel and Lynöe, 2011). The main barriers to making complaints are the feeling on the part of that they are not strong enough to lodge complaint, don't know who to contact, or don't find it worthwhile, as they believe it will make no difference.

Also needed are the adoption of better mechanisms for enforcing the legal requirements that are established and remedies for patients who have not been treated in the manner legally prescribed, and ensuring that laws enacted promptly translate into changes in health care practice.

Furthermore, while patient organizations in Sweden are active and empowered via public funding, they could be more effective if they operated collectively on issues of common concern. It is also far from clear that these organizations are being utilized by actors in national and local government and in health care organizations to get patients' perspective and input on decision-making. It appears that patient consultations remain pro forma and involve using the groups to disseminate and publicize efforts relating to patients more often than they actual efforts 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 technology to get real-time feedback and input from patients on line, as well as using smart phone technology.

### **Local administration of health services carries both benefits and disadvantages for patient-centeredness**

One of the reasons why there appears to be a lag between the passage of laws and changes in practice is the local administration and financing of health care in Sweden. This situation provides the national government with relatively little leverage 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, was cited by experts as presenting 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 would be to identify investments in patient-centered care that can potentially reduce costs, by 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**

A barrier to progress that was cited by numerous experts interviewed for this study is the question of attitudes. Advancing 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 in 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, however, slowly. More leadership, greater attention to 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.









## 6

## Policy implications of the study

The present study identifies a number of shortfalls in Sweden's health care in terms of how well the system meets five dimensions of patient-centered health care, and discusses 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 internationally derived framework serves as an initial foundation to conceptualize and operationalize a definition of patient-centered care. Also, 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 providing information for 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 (a) the need for further work to validate the framework for assessment used in this study (comprising five core dimensions used in leading international frameworks, in terms of its consistency with Swedish patients' expectations and priorities; (b) the need for additional work linking specific dimensions of patient-centeredness with satisfaction, health and cost outcomes; (c) the presence of certain 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 (d) limited availability, at present, 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 im-



provements in performance. Other limitations will require some investment of resources to address.

## 6.1 POLICY RECOMMENDATIONS: SIX STEPS TOWARD A MORE PATIENT-CENTERED CARE

Below we describe areas that warrant attention 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 encounter. The existing laws and regulations are too often not complied with, and the system for accountability is not effective, in practice, particularly 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 these better known to patients and their representatives, thereby strengthening their positions. 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 of this lack of compliance be better understood, and that appropriate measures to address these are developed. Such avenues for improvement might 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 the development of 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, little 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 are open to patients wishing to share information with providers on health status and symptoms, these opportunities 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, real demand for these supports is required 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, 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 like 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 for the Swedish health care system and is 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 are meaningful to patients in terms of meeting their needs. Other promising initiatives include 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 for 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 fully utilize and benefit from 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.









## 7

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# Appendix 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 (Vårdanalys) commissioned 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 ac-

tivities undertaken by international organizations and government actors in the United States and in Sweden.

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.

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

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 survey is conducted every year and Sweden has earlier participated in 2009 and 2010. The survey is conducted on request by the Commonwealth Fund, an American foundation, and is coordinated by Harris International Inc. Ramböll Management Consulting conducted the Swedish part of the study on behalf of the Ministry of Health and Social Affairs (IHP, 2011).

The target group of the study, "sicker adults", has been identified through screening questions in the survey. In order to participate in the study the respondents had to fulfill some of the following criteria:

- Considers oneself to be in poor or very poor health;
- Has received medical care for a serious or chronic condition, injury or disability during the past year;
- Has been hospitalized any time during the last two years for other conditions than a normal, uncomplicated delivery;
- Has undergone a surgery any time during the last two years

4 800 respondents participated in the survey, conducted by phone. The interviews were clustered geographically with 200 undertaken in each county,



plus Gotland, except for Stockholm, Skåne and Västra Götaland where 400 interviews were conducted in each county/region. A new survey of the quality of health care as experienced by Swedish patients, the National Patient Survey (or Nationell Patientenkät) was launched in 2009. It is authorized by the Swedish Association of Local Authorities and Regions (SALAR) and administered by Sweden's Institute for Quality Indicators. Results are available reflecting administration of the survey to patients beginning in 2009. The written survey is sent to people who have recently been patients, for example, in primary care or specialized inpatient or outpatient care. The results are used to develop and improve health care, and used in comparisons of the quality in different health care provider organizations (e.g., primary care units, hospitals). The National Patient Survey has grown over time to include components focus on a range of health care settings and subgroups of the population. The surveys, administered by the Institute for Quality Indicators, are based upon Picker Institute surveys, which are available for use in the public domain.

Results from the following modules have been used in this study:

- **Emergency Care**, fall 2010, Nationwide, Counties, hospitals. More than 15,000 patients participated in the survey
- **Primary Care**, spring 2011, 130,000 patients responded
- **Psychiatric Inpatient Care**, spring 2010, 2,100 patients responded
- **Psychiatric Outpatient Care**, spring 2010, 16,700 patients responded
- **Specialized Inpatient Care**, spring 2010, 34,600 patients responded
- **Specialized Outpatient Care**, spring 2010, 88,3000 patients responded

Another source of new data generated for this phase of the study was information obtained from interviews with 34 Swedish experts (see list of experts and their affiliations in Appendix II). Therefore, an important component of this phase was to define the types of experts and the specific information (including both objective information and expert opinion) that were sought. For example, 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.

The findings were further informed by review of relevant legislation, regu-

lations and recent public inquiries undertaken in Sweden.

A final source of information used for the assessment was a review of academic and policy research literature. The review included English-language publications in the academic literature as well as Swedish-language publications in the policy or “grey” literature. The literature searches included broad searches for studies on the PubMed database/search engine using the terms “patient-centered” (and “patient-centred”) and “Sweden,” as well as more specific terms (e.g., patient satisfaction, patient experience, patient survey, patient education, patient preferences, patient rights, patient information, shared decision-making, patient decision support, patient family, end of life care, care coordination, transparency, physician communication) relating to the five core conceptual elements used in the framework for assessment. The review generated a large quantity of articles based on numerous studies undertaken in Sweden; however, most were very narrow in scope (e.g., reporting on the process of implementing a particular intervention in a particular hospital) and of limited value for the present comprehensive assessment.

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.

A parallel process was used for review of preliminary findings and draft recommendations produced in the study’s assessment phase.

The final report from this study was evaluated by the staff and Board of Directors of the Swedish Agency for Health and Care Services Analysis.

## Appendix 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 Acad-  
emy 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, Karo-  
linska Institute

Åke Hedin, Association Secretary, Heart and Lung Association

Kerstin Holmberg, Gothenburg Patient Advisory Committee

Inger Holmström, Professor, Department of Health and Medical Sciences,  
Örebro 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, 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 Anaesthesiology 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 Trevett, Chair, Social and Mental Health Association

Sven Wählin, Specialist in General Medicine, Stockholm

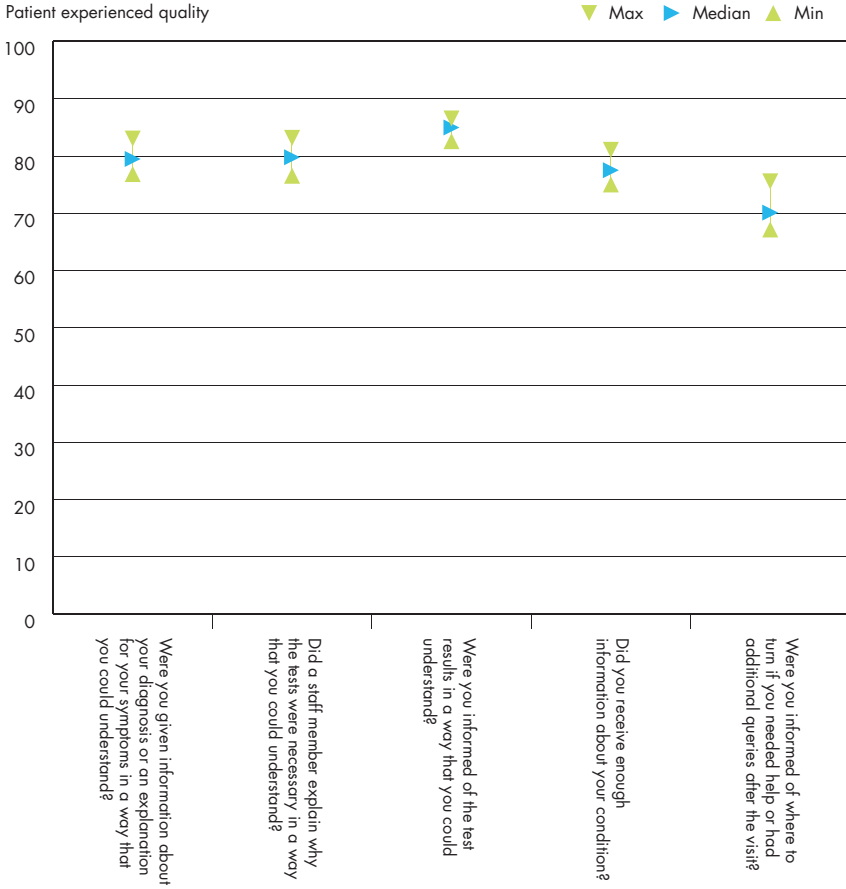
## Appendix III

### RESULTS FROM THE SWEDISH NATIONAL PATIENT SURVEY, PATIENT-EXPERIENCED QUALITY MEASURES IN SWEDEN'S COUNTY COUNCILS

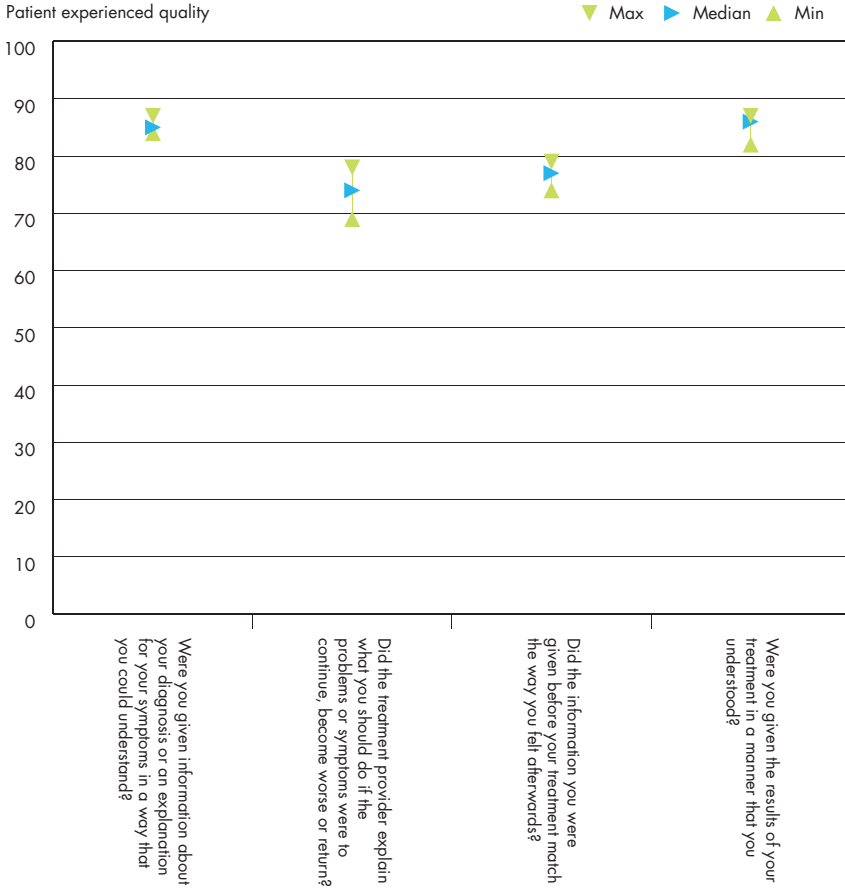
Each figure below demonstrates the median patient-experienced quality measures in Sweden's county councils concerning questions relating to the different dimensions as presented in the framework. The "max" value represents the county council with the highest score of patient-experienced quality and the "min" value represents the county council with the lowest score. The categorical response alternatives are in each question given numerical values on a 0-100 scale, where the most preferable answer is ranked as 100. The numerical value of patient-experienced quality index is then the product sum of the proportion of answers in each category times the 0-100 ranking.

## Patients' experiences relating to dimension 1: Information and education

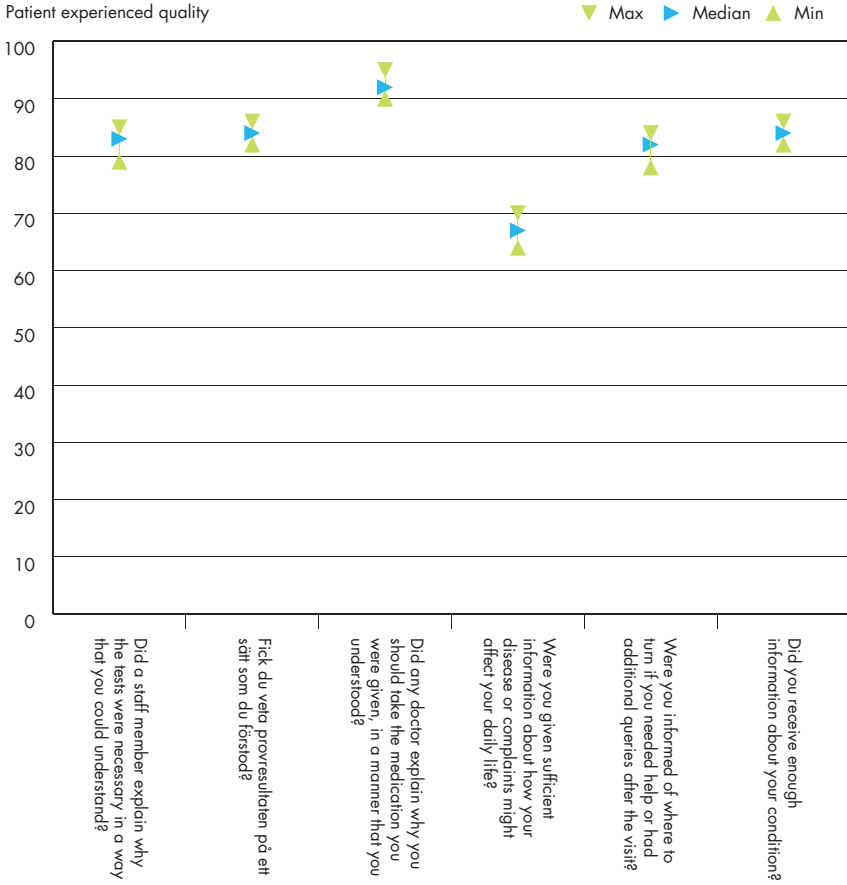
### Primary care 2011



**Outpatient specialty care 2010**



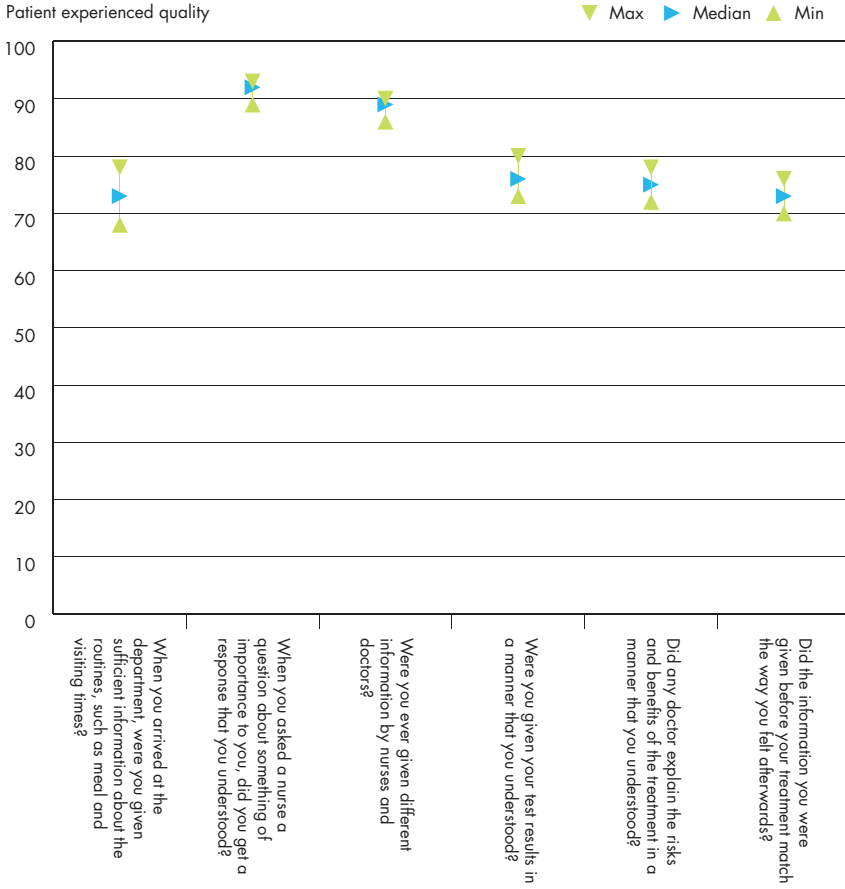
**Outpatient specialty care 2010**



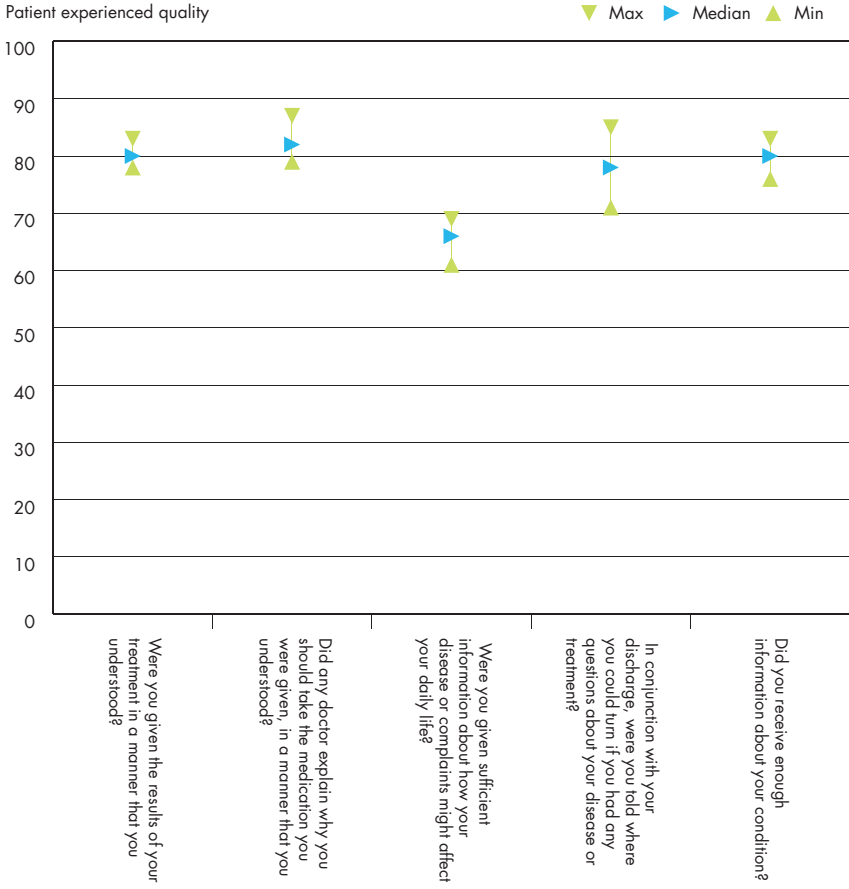


**Inpatient specialty care 2010**

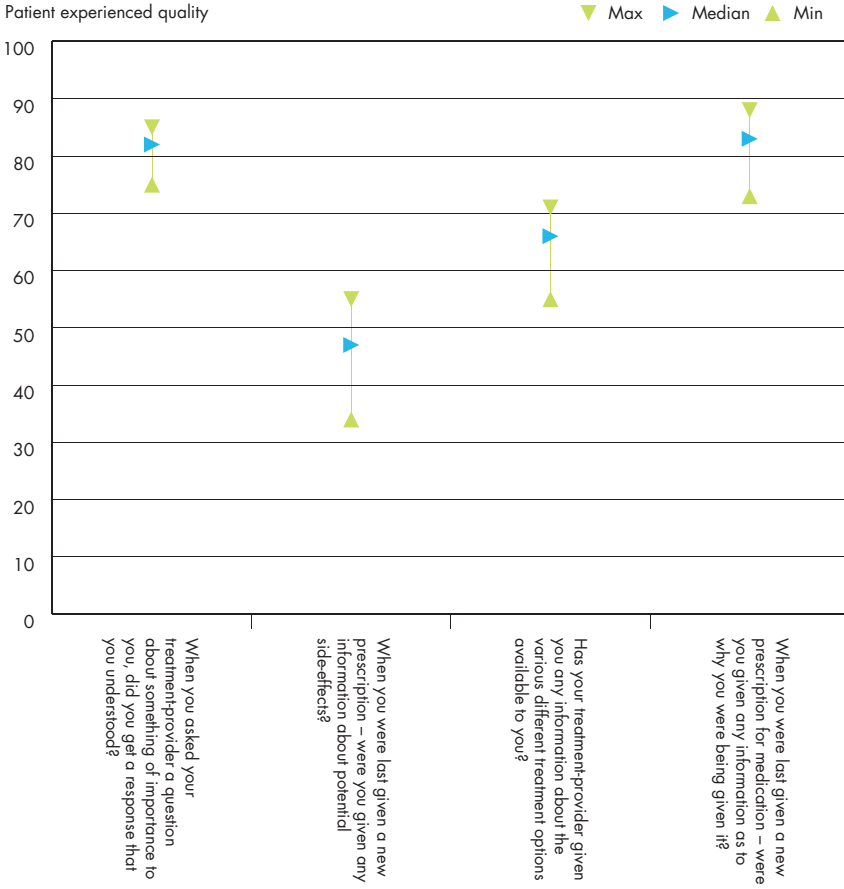
Patient experienced quality



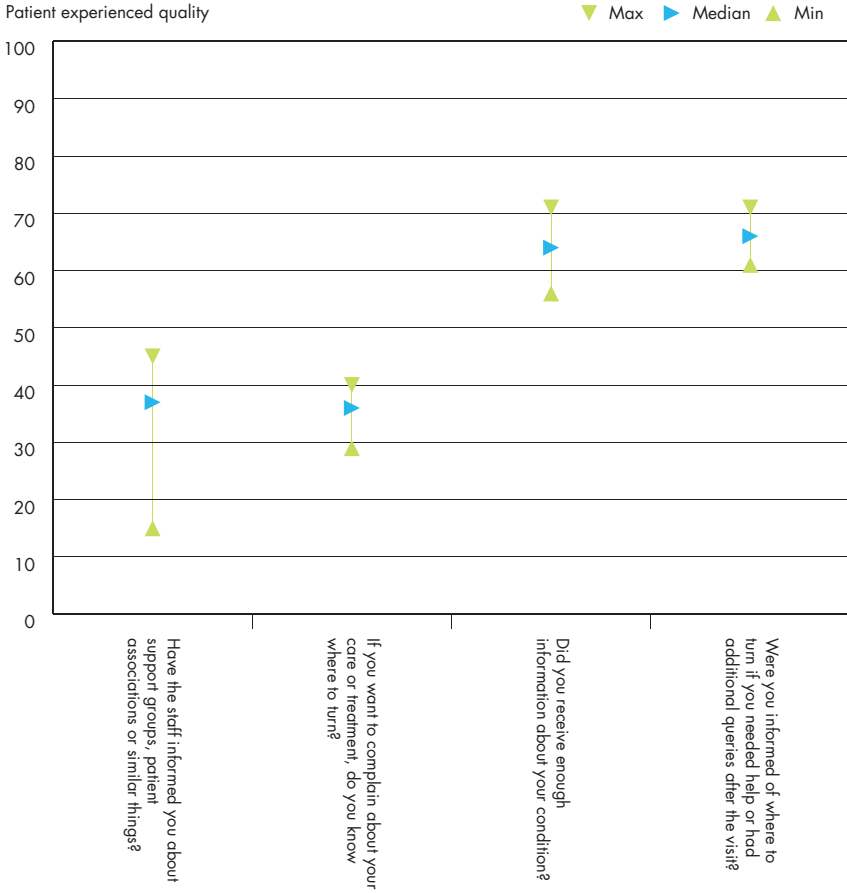
**Inpatient specialty care 2010**



**Outpatient psychiatric care 2010**



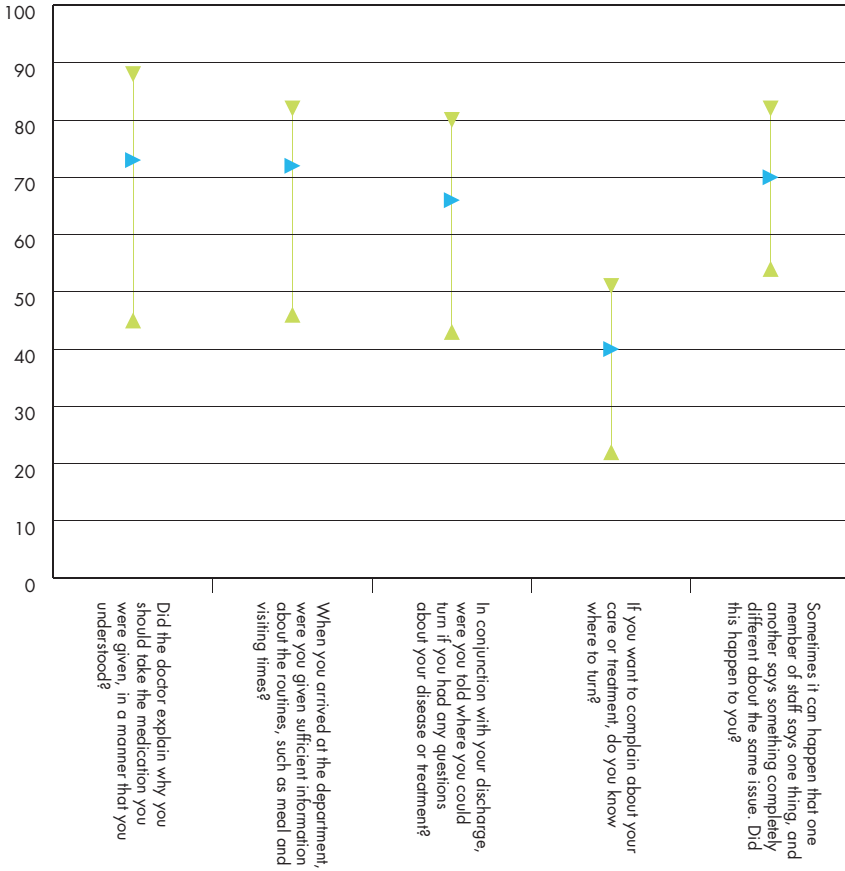
### Outpatient psychiatric care 2010



### Inpatient psychiatric care 2010

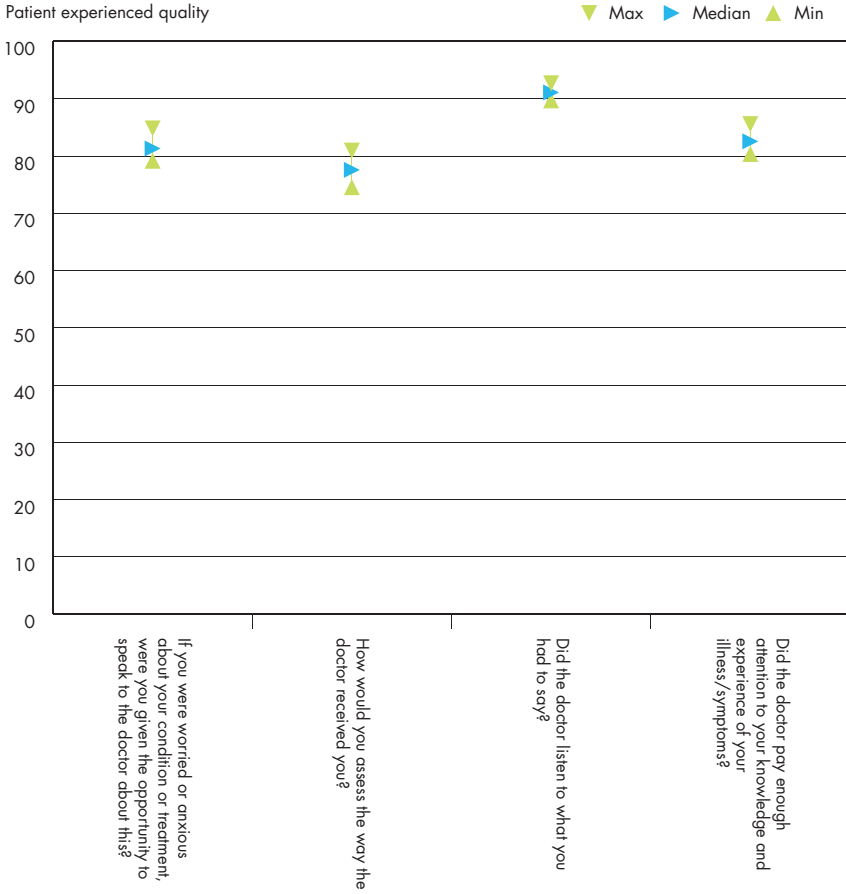
Patient experienced quality

▼ Max ▲ Min ◆ Median

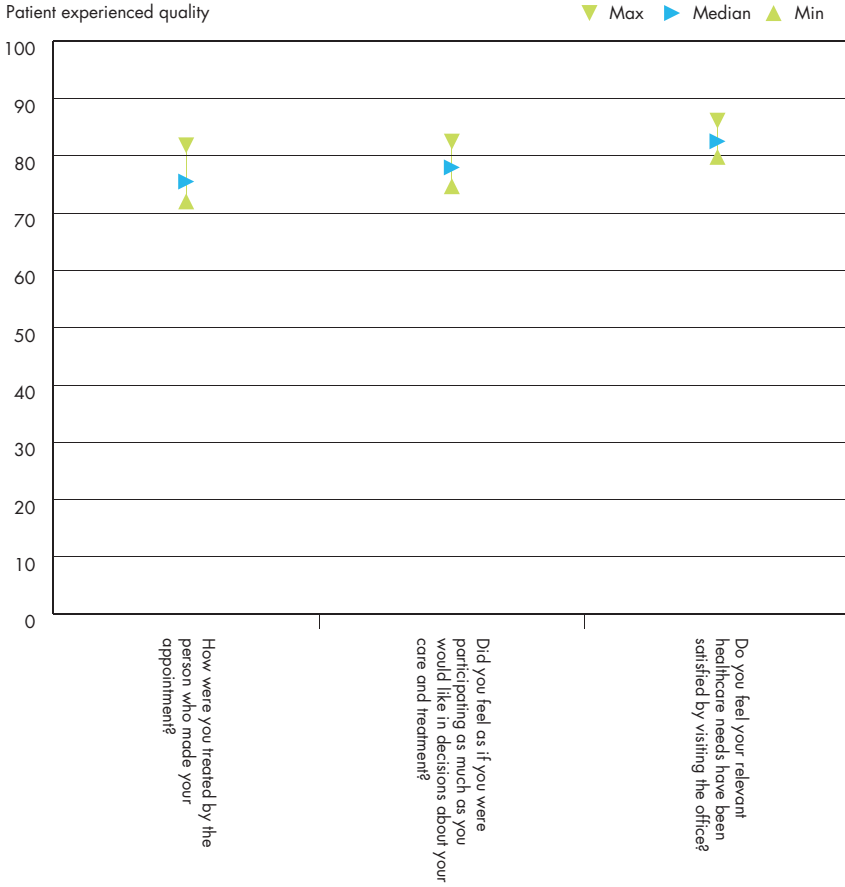


## Patients' experiences relating to dimension 2: Needs, preferences and values

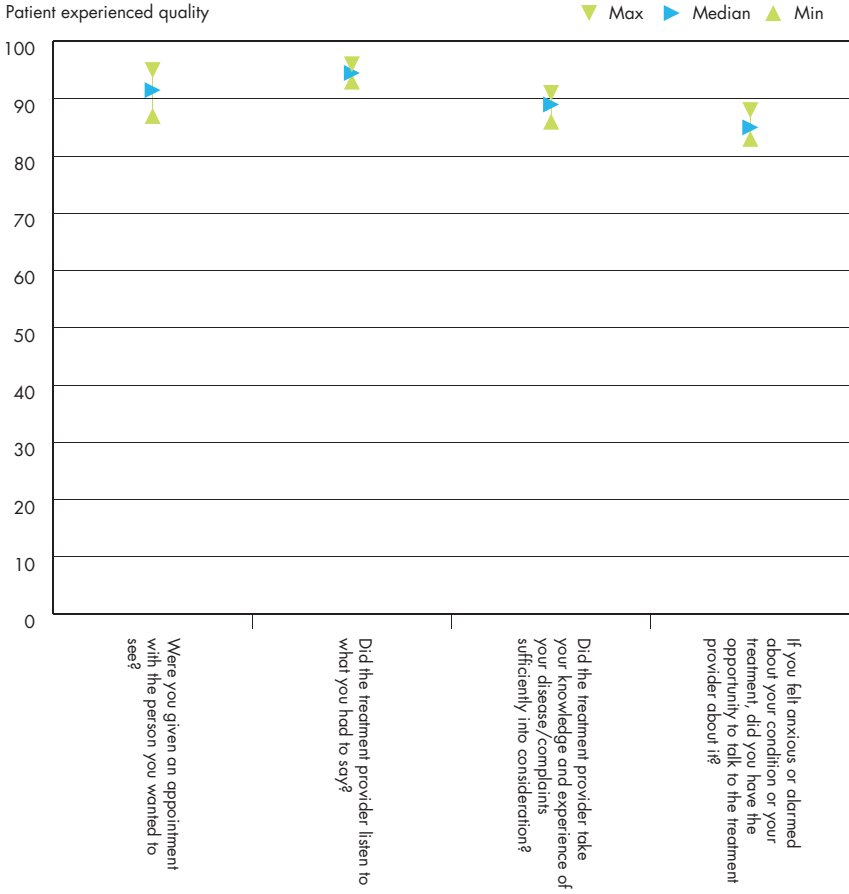
### Primary care 2011



Primary care 2011

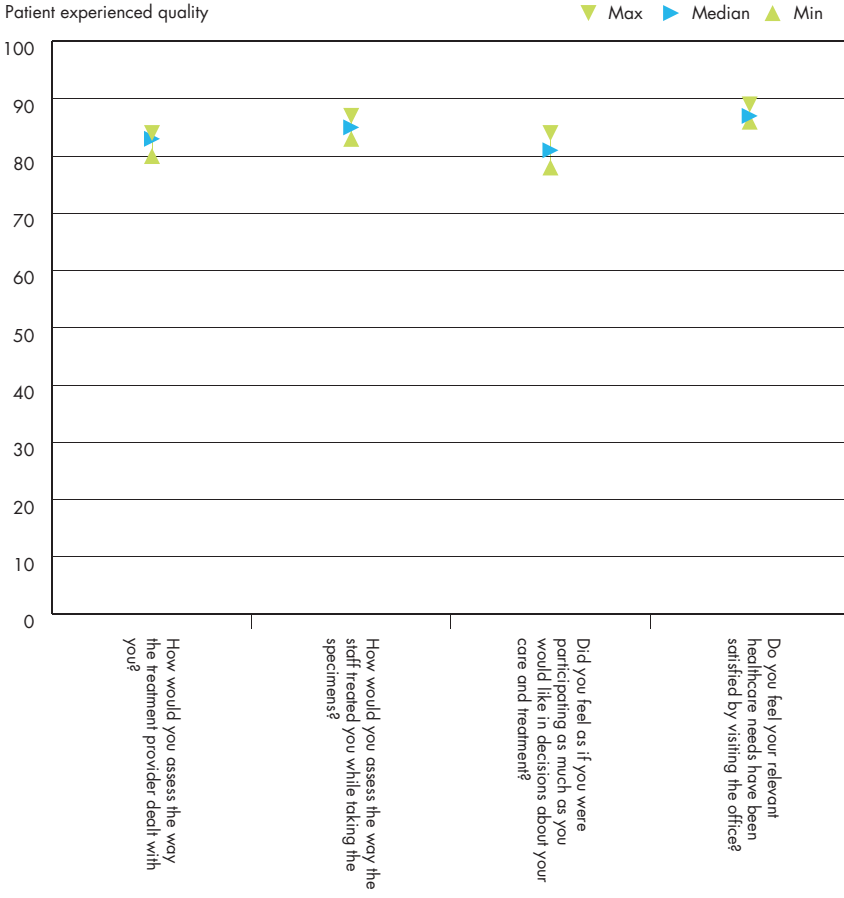


**Outpatient specialty care 2010**

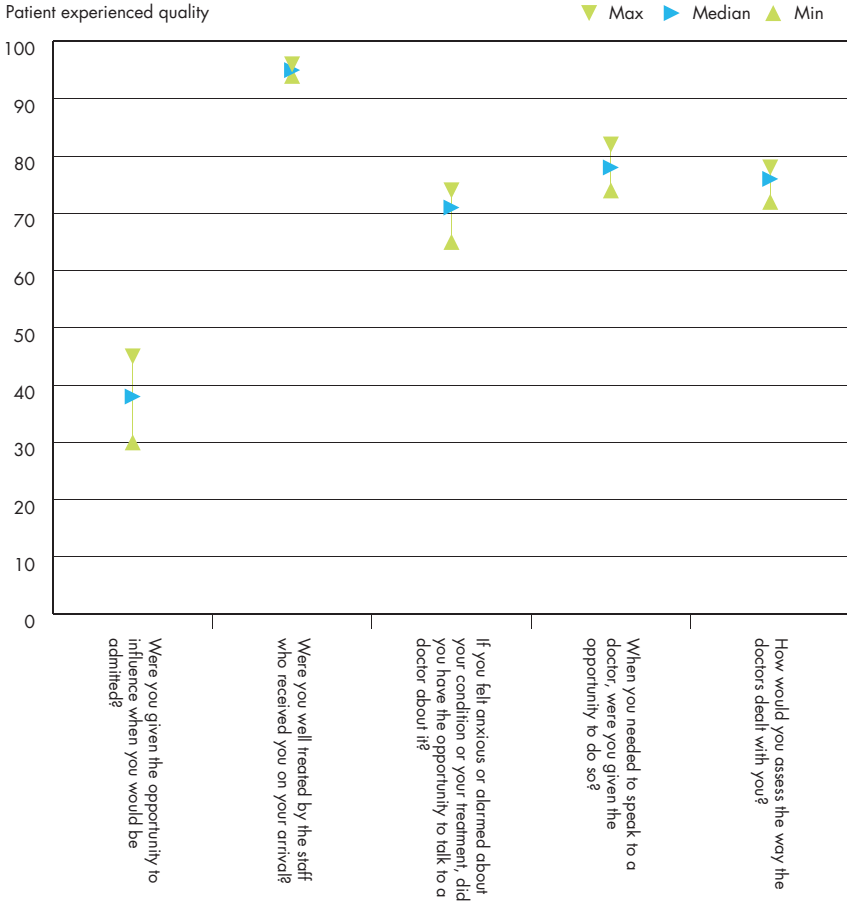




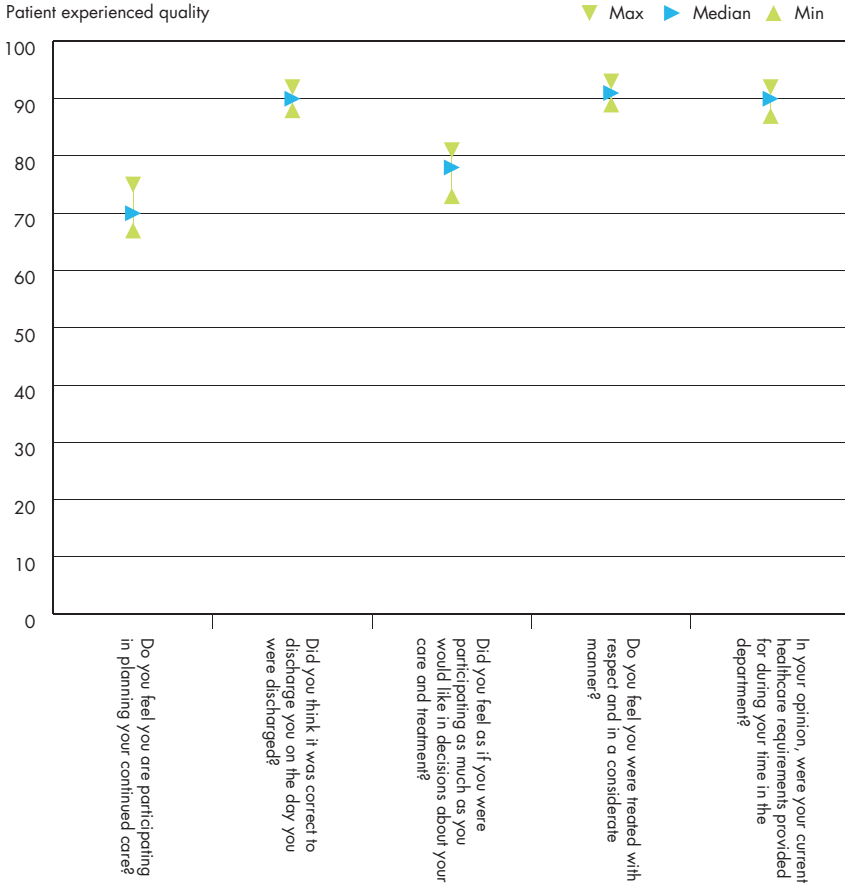
**Outpatient specialty care 2010**



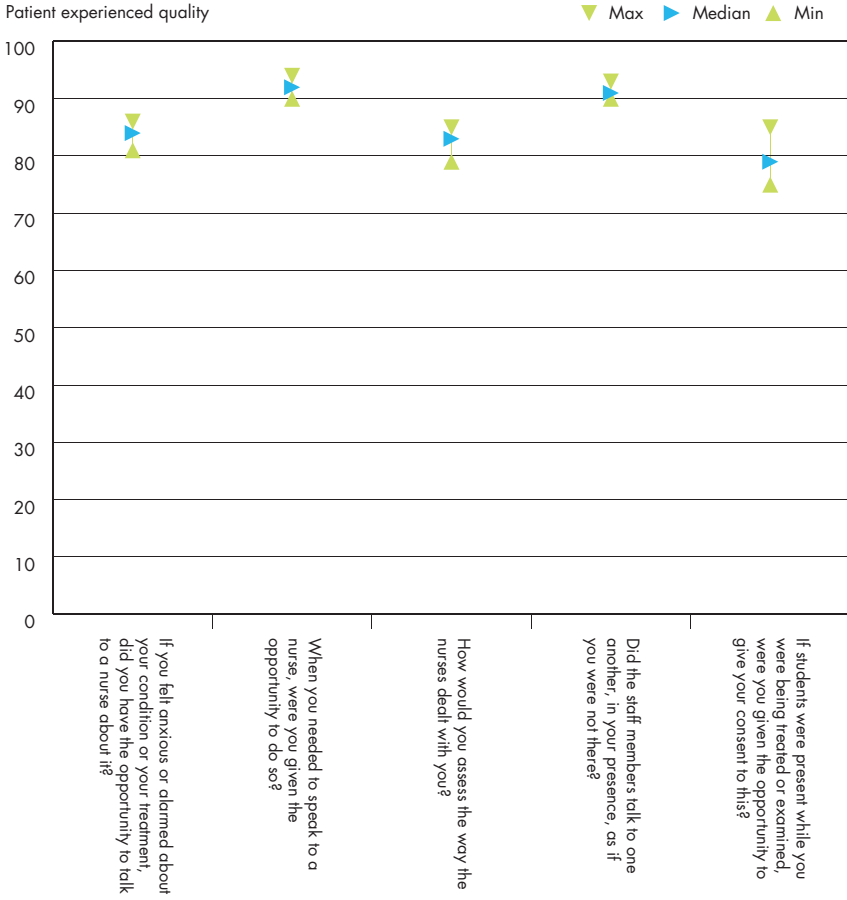
**Inpatient specialty care 2010**



**Inpatient specialty care 2010**



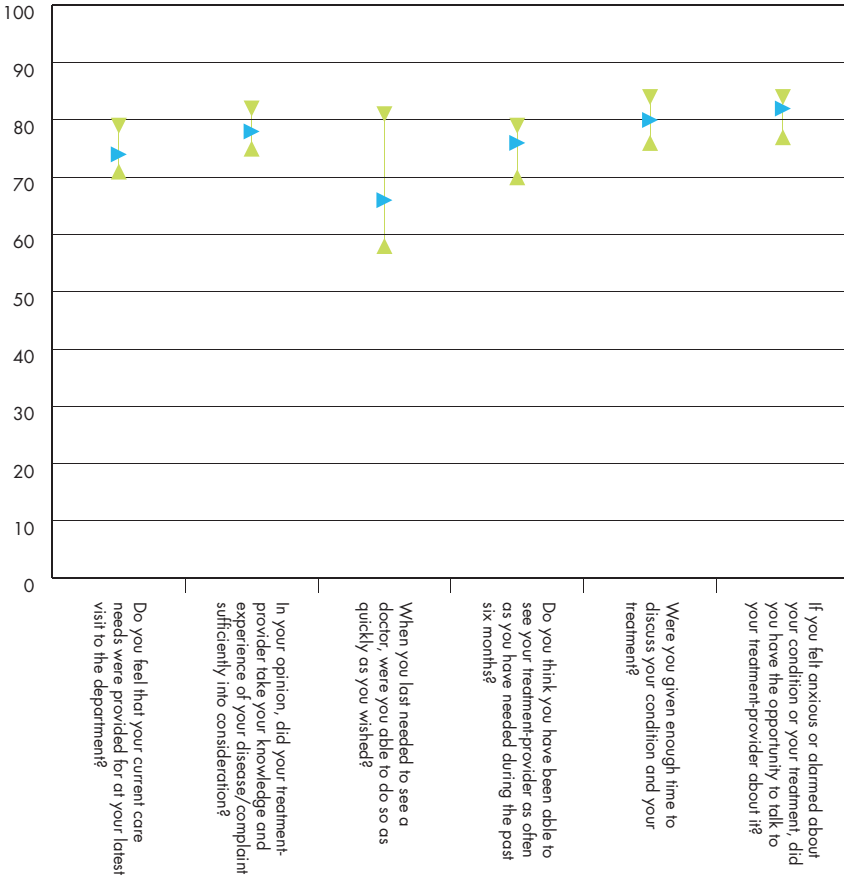
**Inpatient specialty care 2010**



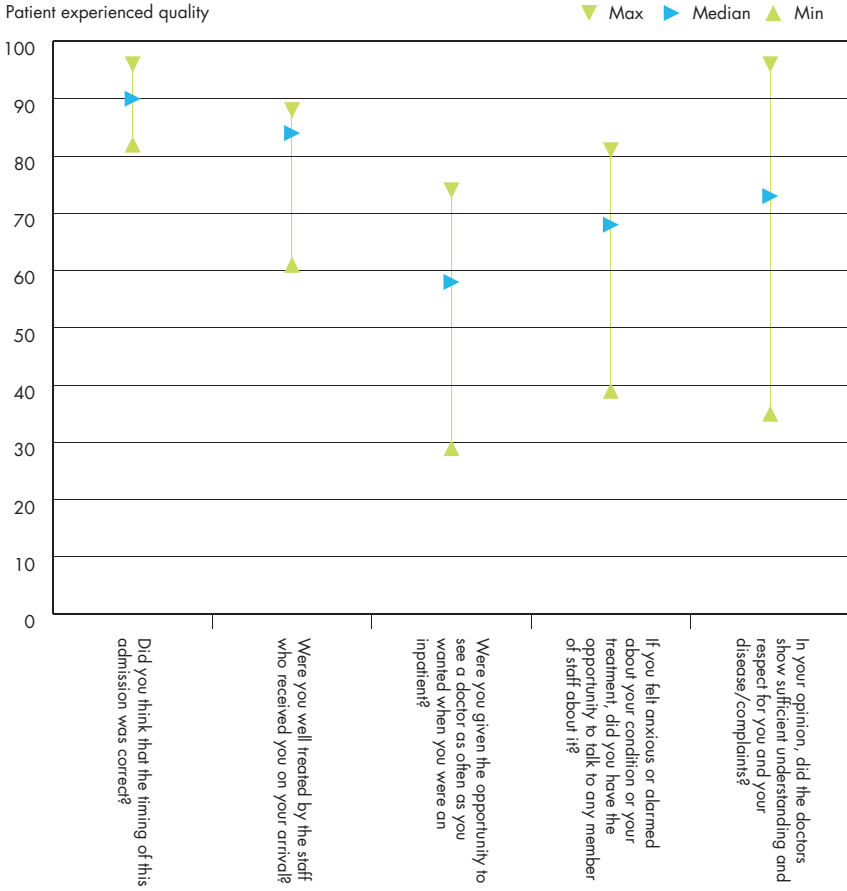
**Outpatient psychiatric care 2010**

Patient experienced quality

▼ Max ▲ Median ▲ Min



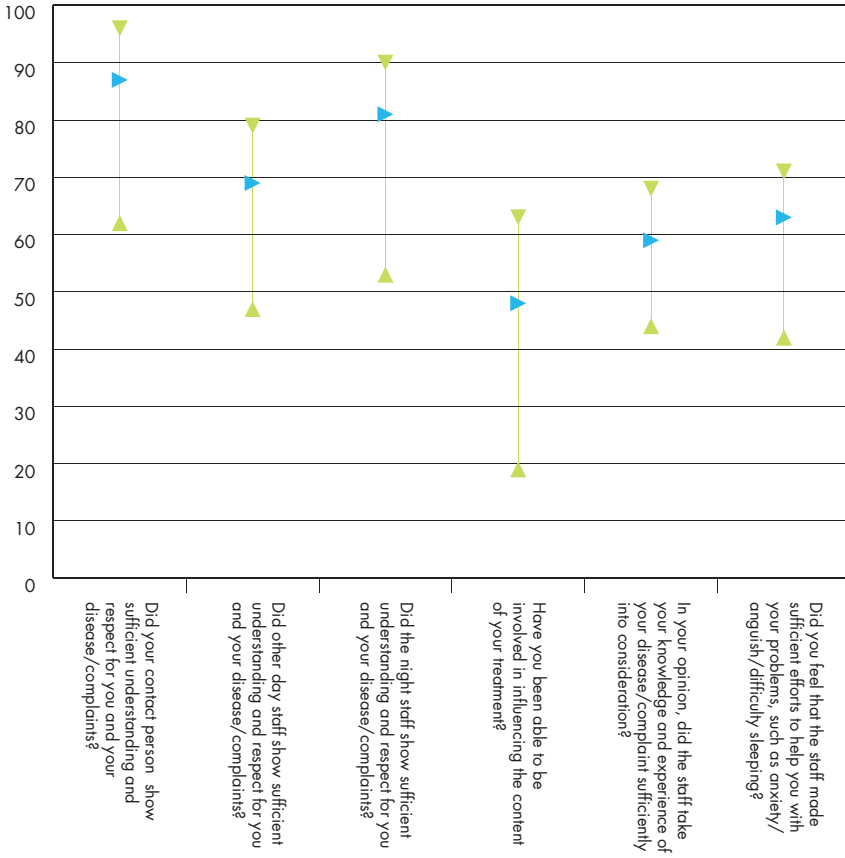
**Inpatient psychiatric care 2010**



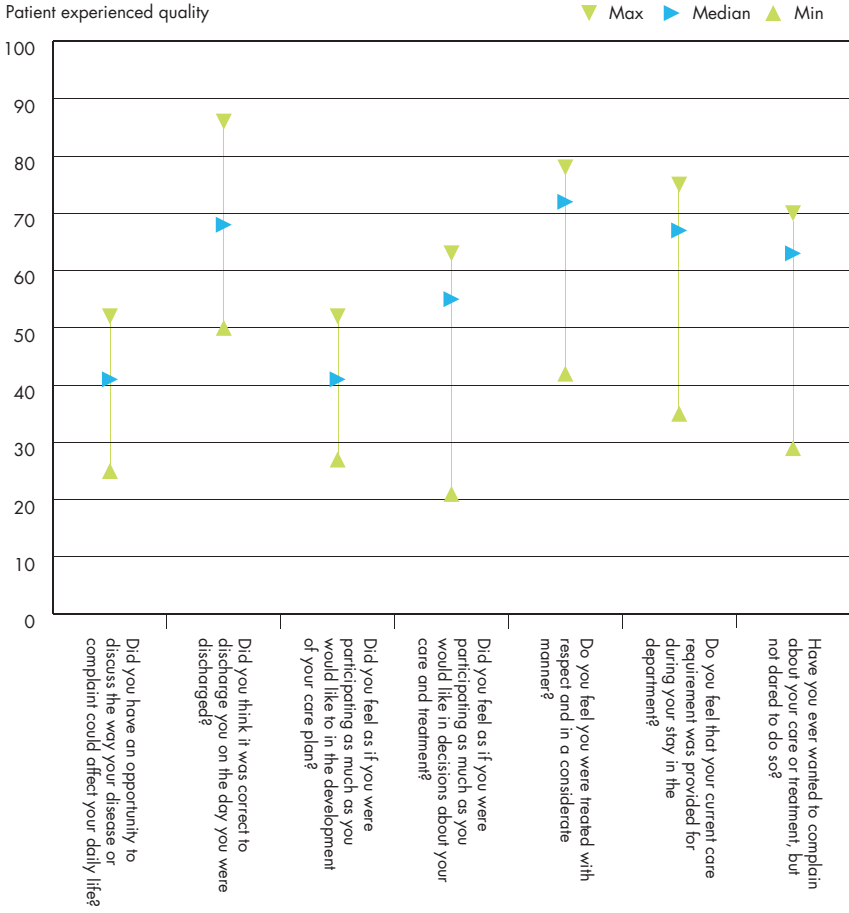
### Inpatient psychiatric care 2010

Patient experienced quality

▼ Max ▲ Min ◆ Median



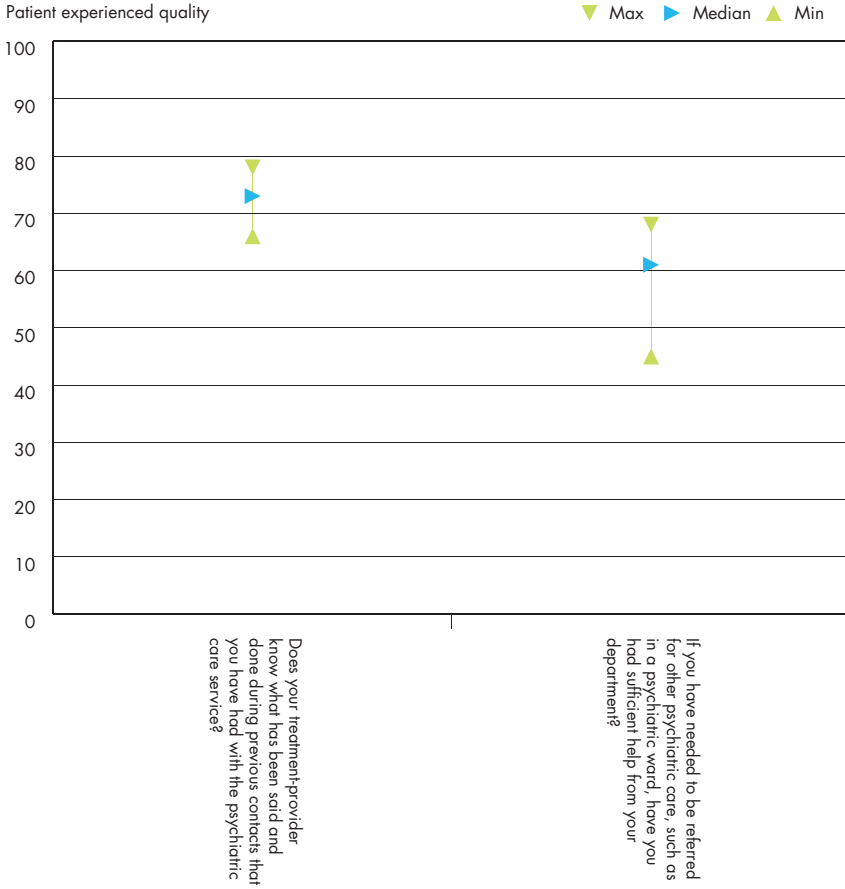
**Inpatient psychiatric care 2010**





## Patients' experiences relating to dimension 3: Coordination and continuity of care

### Outpatient psychiatric care 2010





## Appendix IV

### **SURVEY QUESTIONS INCLUDED IN UNWEIGHTED INDEX FOR DIMENSION 3 – COORDINATING CARE ACROSS SERVICE PROVIDERS AND ENSURING CONTINUITY OF CARE (IHP 2011)**

- In the past two 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.”
- When you left the hospital, did the staff make arrangements for you to have follow-up visits with a doctor or other health care professionals? Percentage answering “yes.”
- Between doctor visits, is there a health care professional, who contacts you to see how things are going? Percentage answering “yes.”
- Between doctor visits, is there a health care professional you can easily call

to ask a question or get advice about your health condition(s)? Percentage answering “yes.”

- Is there one person responsible for all the care you receive from various doctors for your chronic condition(s)? 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. The Agency takes the needs of the patients and the users as the starting-point in the investigations. The mission of the Agency is to contribute to quality and efficiency improvements that benefit patients and citizens.

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

The Swedish Agency for Health and Care Services Analysis gave two international experts the assignment to make an external evaluation of patient-centeredness in the Swedish health care system. In this report, the independent experts produced a framework consisting of five dimensions that can serve as a basis for defining and assessing the degree of patient-centeredness. The framework was then applied to make a first, preliminary assessment of patient-centeredness in Sweden. On the basis of the conclusions drawn from the assessment, the experts developed six recommendations that can serve to strengthen progress towards a more patient-centered health care system in Sweden.

