

The Internet Empowers Swedish Healthcare Consumers

Waiting list info shapes patient choices



By Johan Hjertqvist

Knowledge is power, states the time-tested saying. As the Scandinavian public becomes familiar with the success of Stockholm's health-care revolution, the clamour grows to replicate it throughout northern Europe. An expanding service that posts waiting lists on the Internet will amplify the noise, as more and more people compare the quality of health services in different regions and demand the best. Now a truly visionary electronic system to personalize medical services is about to be launched.

All the Nordic countries face similar challenges: a more demanding consumer of health services, aging populations needing increased service levels, an increasing shortage of health care personnel and the financial restrictions of strapped health-care budgets. When one region – Greater Stockholm – takes the lead in systems reform and meets those challenges, its neighbours are sure to notice. Stockholm's health-care consumers are already in a much stronger position than their fellow Swedes. The consumer focus in the capital city has developed quickly as providers decentralize, and interest in the model is increasing within and beyond Sweden's borders.

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Every Stockholm resident has access to all producers regardless of where he or she lives in the region. The city's large concentration of health services gives them a unique freedom of choice within the tax-financed system. No payment is required to get access to specialists. Many other regions have reduced the public's range of options with the use of gatekeepers and other restrictions like waiting lists, as in Canada. Compared to almost every other large city in Sweden, waiting lists for examination and treatment are short. A consumer guarantee states that you must get your operation within three months time. If you don't, you are entitled to treatment anywhere with quicker access, in Sweden or abroad.

Waiting lists – a part of the culture

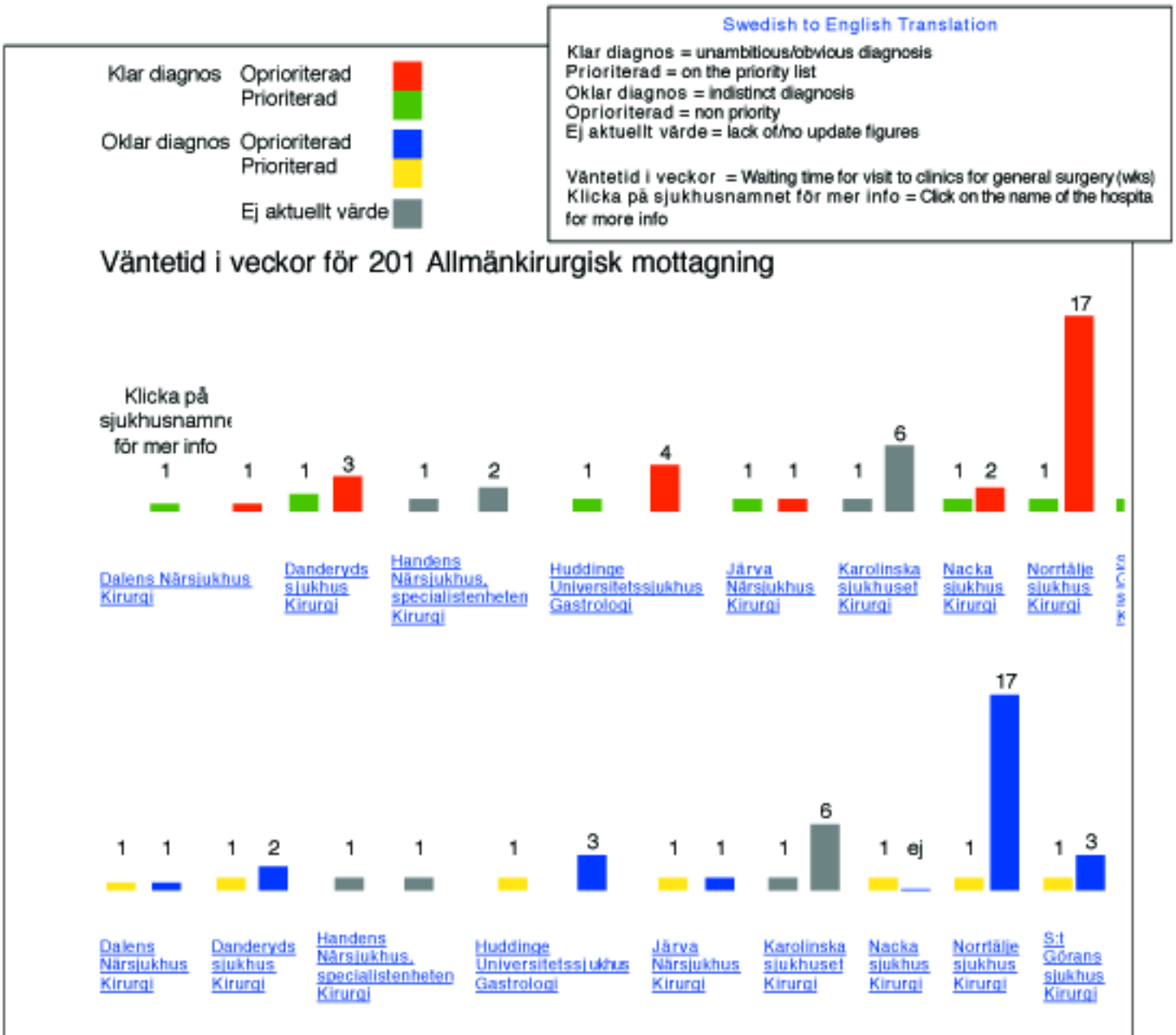
Like Canada, Sweden has a tradition of waiting lists for specialist treatment and surgery. National guidelines say you ought to be able to get in touch with your local doctor on the phone within 24 hours and meet the doctor personally within another five days. But these recommendations contain no sanctions. Regional authorities are supposed to comply with the requirement, but if they don't, they face no penalty. Poor access to primary care is a topic of daily discussion outside the capital region. Just like Canada, the national government has pledged more money to help the regions reducing waiting lists; whether higher budgets will do the trick remains to be seen. The problem may not be money, but attitudes.

Want to wait six or 104 weeks?

Today, patients can already reduce their waiting time by consulting available Internet tools. The Confederation of Greater Councils posts estimated waiting lists for many –

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A webview of waiting list times in weeks for access to general surgery clinics, both private and public, found by clicking on www.sll.se/w_vanta/17592.cs. Consumers cut delays by choosing facilities with shorter waiting lists in the Stockholm region.

but not all – Swedish hospitals and clinics. If you are prepared to travel to another city, you can cut your waiting time quite dramatically.

Take one common surgery, a primary plastic hip replacement. In Stockholm and a couple of other cities you can be treated within a maximum of six weeks. Four out of five of the most available clinics are found in the Stockholm area. But if you insist on going to the nearest hospital and live in Gothenburg, Umeå or Arvika, you can count on waiting at least 104 weeks. For ordinary prostate surgery, you wait four weeks in Stockholm and between 90 and 156 weeks in most parts of Sweden. (Details for a variety of services are posted in Swedish at http://sas.lf.se/appl/html/rapport/start_behandling.)

Only few patients or doctors are currently using this information to access faster service. Local hospitals still seem more trustworthy to most, so the continuing marketization of health services in Stockholm hasn't created much movement. But statistics show that mobility is on the increase, most evidently among younger people. To new generations, the "Swedish heritage" of long waiting lists is no longer acceptable. And in economic terms, the growing willingness to migrate holds out the hope of a more efficient use of resources.

Worth comparing also within Stockholm

Within the Stockholm region, citizens with urgent needs can compare waiting lists for different providers on the

Internet. Here people are more willing to use facilities in other parts of the region. (The somewhat more understandable web address is www.sll.se/w_vanta/17592.cs.) Waiting times for hip replacements differ from one to 34 weeks among the clinics in Stockholm. For ordinary prostate surgery, the spread is between four and 14 weeks.

None of this information is yet available in English. To maximize the spearhead effect for change, the portal content must be translated into a number of languages, providing large ethnic minorities with the same platform of informed choice.

Does consumer information press producers to stress efficiency and increase access? The history of active opportunities for choice is too short to provide undisputable evidence of the connection. But the chance to compare generally short waiting lists in Stockholm with often quite long ones in other regions strengthens the perception that a climate of informed choice matters.

No alternative

This is the reality to which the demanding and generally well-educated public in Stockholm is becoming accustomed. Obtaining more information about the number and availability of producers allows the transparency and openness of the health care system to grow. Widely available information on the health care market is a critical component that gives individuals the power to make active choices.

An interesting pattern is emerging: reform agenda politicians are trying to build alliances with health care consumers to pressure the administration to speed up the transition towards a patient focus. The success of newly entrepreneurial health-care providers, who have simultaneously improved the speed and quality of service and reduced unit costs, makes them natural allies in the search for higher productivity. Stockholm's regional government has gradually become aware that it cannot centrally plan a market. It must find new ways to make its visions come true.

By international standards, the region has a very advanced level of penetration by information technology. Internet-based tools are therefore the natural choice of reformist politicians. When exposed to a large amount of information, consumers tend to become more and more demanding and capable of well-informed choices. They are asking for more influence, a better quality of treatment and a service focus among producers. These forces are forming a health-care market and the only possible way to channel them successfully is through an industry organized along market principles. The traditional top-down bureaucratic system can't do it.

Supporting active choice

Beginning in autumn 2001, health-care consumers in the metropolitan area will be able to use a new device – the



**Your Personal Healthcare Portal at
www.varldguiden.nu**

Guide to Health Care (www.varldguiden.nu, not yet available in English). The Internet portal of the Greater Stockholm Council already provides health care-related information but the structure and content of the information is built from the administrative point of view. There is a large divide between what directors and doctors find appropriate to tell and what the individual, a group of patients or a consumer organization want to know. The logic is poor; you must use many links and queries. The terminology is vague and complicated. And a lot of the most relevant questions lack answers. But this is set to change.

Over the last year, a large team of specialists and information staff have been creating the new tool. In phase one, ready for launch in a couple of months, all present information will be organized and presented in a much clearer fashion. The service will be launched in a low-key manner, to avoid antagonizing doctors and other providers who are not yet ready for this first step. "We start by putting together and exposing mainly 'harmless' kinds of material," says Ms. Dagmar Fornander, project manager for the Guide to Health Care. "Examining the information needs, we discovered, for example, there is no complete catalogue covering every health care institution in the region. Attacking this problem we soon learned there are a number of different vocabularies naming institutions for child care, primary health care stations and so on, complicating an overview of the system. Now we are sorting out that issue."

Cultural revolution to come

The project's goal? From this autumn on, patients and citizens for the first time will need only one portal to survey the whole of health care. It will provide a view of all units and producers, conditions for treatment, ways to get in contact with clinics and local doctors, advice services and inquiries. But here we still talk about information from the system to the consumer.

"The big step comes in phase two," explains Ms. Fornander. "From next year on, we will focus on communication. By gradually expanding the system citizens will be allowed to build individual channels for dialogue. Depending on your needs, you will have access to relevant knowledge and communications facilities."

Using the communications tool you prefer – a personal computer, a cell phone, WAP (wireless application protocol) – you will be able to subscribe to the kind of information you want. It might be a monthly electronic newsletter,



weekly medical advice or a symptoms guide. You will be able to get updated news on waiting times for the kind of treatment you might need. The opportunity to reach your doctor on line will be quite revolutionary for Sweden; this anonymous, inaccessible person will have to communicate. Some doctors look upon this as a blatant threat.

Within the framework of the Guide, patients will be able to create their own entry page to the portal, distinguishing the needs, for example, of allergic patients from those suffering from heart problems, as well as those of parents with small children from overweight patients. With these kinds of identifiers, you will be able to quickly access the relevant place in the huge guide system.

Create your own patient profile

If you suffer from asthma, you can build your own bank of knowledge, including lists of clinics and providers, relevant medication therapies, crisis instructions, forecasts on air pollution, support groups and research reports. This means you will get your own library on how to treat your disease. Better conditions for self-treatment are the Guide's main objective.

Another new service will be electronic matrixes for patient documentation where the patient gives preparatory information about weight, health conditions, the use of pharmaceuticals and medical history. These will reduce the provider's paperwork burden and thereby allow more time during patient visits for doctors or nurses to focus on diagnosis and treatment. The privacy and security of this personal documentation will be strongly guarded. Every patient will have his or her own password protection.

The Guide's impact will gradually strengthen the consumer's position. Obliging doctors to answer e-mail requests is quite a revolution, and building your own health

and/or treatment profile on the Internet is another. The opportunity to compare all contracted service producers from the Guide's quality ranking will not only put pressure on the contractors to improve but will also for the first time allow consumers to make a truly informed choice.

A struggle of perspectives and approaches

This new environment taking shape step by step in the Stockholm region is light years away from the old monopoly culture, based on the conception that patients are satisfied with what they traditionally have been offered. If not, the system used to say, who cares? The system knows best. With only one producer you can ask for diversity all right. The car you buy will still be delivered in black only. Is health care a package of services to be demanded by individuals, available under market-like conditions (but with public funding)? Or are the needs to be satisfied (or denied) by authorities, focusing on avoiding "over-consumption" by rationing access? In the first alternative, top quality information is self evident, in the latter case rather a complication. Here perspectives and ideologies conflict, in Sweden as in many other countries. The practical consequences will be scrutinized in Sweden's general elections to come next autumn.



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AIMS Activities on ...Health Care

Recent Publications

Operating in the Dark: The Gathering Crisis in Canada's Public Health Care System offers a guide to Canadians and their policymakers in thinking through the roots of medicare's current difficulties, and a toolkit for resolving those difficulties as they intensify in the years to come. This publication won the Sir Antony Fisher Prize for excellence in think tank publications. Operating in the Dark can be found on the AIMS website at www.aims.ca (requires Adobe Acrobat Reader).

Upcoming Events

Lunch with **Johan Hvertquist**, Tuesday, 25 September 2001, noon, Bluenose Room, Delta Halifax, Halifax NS. Registration information is available under the heading "Events/Activities" on the AIMS website at www.aims.ca.

To Watch For

AIMS website to add a new **Health Policy Page** in October 2001. AIMS new Health Policy Page will soon become a must-read for those interested in being informed participants in the ongoing debate on securing health care in Canada.

Working papers on **health policy issues** to be released in coming months. Beginning in October AIMS will begin releasing a series of working papers on various issues within the health care field.