



Through the looking glass

A practical path to improving
healthcare through transparency

Country report card:
**Scandinavia (Denmark,
Finland, Norway and
Sweden)**

KPMG International

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Foreword

Each of the four Scandinavian countries has a distinct word for transparency: 'åpenhet' (Norway), 'gennemsigtighed' (Denmark), 'genomskinlighet' (Sweden) and 'läpinäkyvyys' (Finland). In the four Scandinavian countries these are themes that have been and still are high on the agenda of health care policymakers and institutes. And not without results: Scandinavia dominates the top of KPMG's first global transparency ranking. The global health systems transparency index show a high level of variation across 32 participating countries and the average score of 55 percent is low. But this is not the case for **Denmark, Finland, Sweden and Norway**, who achieved the top overall scores ranging from 69 percent to 74 percent. Those familiar with Scandinavian healthcare systems may not be surprised by these findings, which come, however, with a note of caution as transparency has two sides. On the one hand, there is good evidence that data publication drives quality improvement, better data collection and even improved health outcomes. On the other hand, transparency can undermine trust, create too much focus on particular measures, and lead to erroneous conclusions and policies.

Strategic transparency, a positive way forward

It is easy to imagine health systems awash with data that distracts from the real business of healthcare improvement and supports punitive cultures of 'naming and shaming', ultimately resulting in less transparent performance and decision-making. In this report we signal better practices that can bring a far more positive way forward. Our Scandinavian examples show that if transparency is applied strategically, it can make a substantial contribution to the quality and value of care.

In this report, we highlight the outcomes of each Scandinavian country and how each experience the value of transparency. We highlight good practices in order to give better insights into why the Scandinavian performance is so good — and what we can learn from each other. Through four case studies, we discuss the importance of a consistent strategy for personal healthcare data in Denmark; how Finland is creating meaningful data; quality of healthcare and measuring what matters from a Swedish perspective; and finally, how Norwegian players are taking the lead from innovative providers.



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What is a transparent health system?

Transparency of health systems matters, but progress to date has been more symbolic than substantive. KPMG International's recent report 'Through the Looking Glass' showed the wide variation that exists in how far different countries have pursued transparency in healthcare, with the central message that every system needs to improve how strategically it uses this powerful but potentially damaging tool.

What constitutes 'transparency' in healthcare is hotly contested around the world, but following a global literature search and interviews with experts around the world, the following six dimensions surfaced as the most important:

1. **Quality of healthcare:** transparency of provider-level performance measures, especially the quality of outcomes and processes.
2. **Patient experience:** patient perceptions of their healthcare experience and outcomes.
3. **Finance:** price and payments transparency, and the public nature of accounts for healthcare organizations.
4. **Governance:** open decision making, rights and responsibilities, resource allocation, assurance processes and accountability mechanisms.
5. **Personal healthcare data:** access, ownership, and safeguarding of patient's individual health data.
6. **Communication of healthcare data:** the extent to which all the above is presented in an accessible, reliable and useful way to all relevant stakeholders.

Using these six dimensions we constructed a scorecard to measure each of the world's major health systems. Twenty-seven indicators were measured for each country tracking the extent to which different transparency practices were in effect on a systemic level. Selection of the indicators was on the basis of published evidence and interviews with experts, under the guidance of a twelve-member global health system transparency steering group. We considered indicators that were: employed by other organizations to measure transparency; likely to highlight meaningful variation across health systems; used by stakeholders to effect positive change; and, identified as important by interviewees.

Completed transparency scorecards were received from 32 countries, covering most OECD and G20 countries. A composite overall ranking score was created by summing each country's score for every indicator.

Methodology

This study involved several research stages:

- Summary literature review of the evidence on health systems transparency
- 25 interviews with experts
- Development of the transparency framework and sense-testing with KPMG heads of health and interviewees
- Completion of the transparency scorecard by leaders of KPMG's major health practices
- Transparency scorecard data collected and analyzed by country

Data health warning

- It is not necessarily good to have a high score because transparency can be harmful as well as beneficial
- The data shows what health systems are currently doing, not whether the transparency is well managed, or achieving good or ill

“

A health system that provides accessible, reliable, useful and up-to-date information to all interested stakeholders so they can acquire meaningful understanding of the quality, patient experience, finance, governance, and individual health data associated with the health system, and make judgements on its fairness. ”

KPMG International definition of healthcare transparency, Through the Looking Glass (2017)

Global health systems transparency index – composite results (%)

	Overall Score	1. Quality of Healthcare	2. Patient Experience	3. Finance	4. Governance	5. Personal Healthcare Data	6. Communication of Healthcare Data
Denmark	74	67	62	83	94	93	50
Finland	72	48	46	83	88	86	93
Sweden	71	81	69	75	69	79	50
Norway	69	67	62	83	81	71	50
UK	69	57	85	83	81	57	57
Australia	68	52	62	83	88	64	64
New Zealand	67	38	54	83	94	64	79
Netherlands	67	57	85	75	69	50	71
Portugal	64	48	46	83	63	86	71
Singapore	63	57	77	83	81	43	43
Israel	62	48	92	50	56	79	57
Brazil	61	48	69	67	81	64	43
Canada	61	57	46	50	81	50	79
Spain	61	76	46	42	75	71	43
France	60	48	62	67	75	50	64
Germany	56	29	54	75	63	64	64
Italy	54	57	31	67	56	64	50
Iceland	53	43	54	75	63	50	43
Switzerland	53	33	69	67	69	57	36
R. of Korea	52	29	31	83	56	50	79
Poland	50	29	46	67	56	57	57
R. of Ireland	49	29	31	67	75	79	43
Luxembourg	47	29	46	50	63	50	50
Russia	47	33	38	67	63	50	36
Austria	46	29	31	58	56	64	43
Japan	46	48	31	67	56	43	29
Greece	43	29	38	50	69	50	29
Mexico	42	33	46	42	50	36	50
K. Saudi Arabia	38	29	31	50	50	43	29
South Africa	37	33	31	33	44	50	29
India	36	29	31	42	44	43	29
China	32	29	31	50	31	29	29
Average Score	55	44	51	66	67	59	52

■ 70% and over
■ 60% and over
■ 50% and over
■ 40% and over
■ Lower than 40%

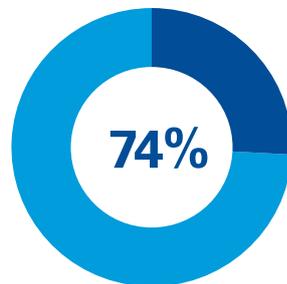
In depth reflections on Scandinavian countries' results



Globally, the average score on the transparency matrix is 55 percent, which is relatively low and suggests that there is still much more to be done. The high Scandinavian scores (from 69 to 74 percent) reflect specific structural investments by government and institutes to make these systems more transparent. Scandinavian countries score especially high in areas that reflect 'Finance,' 'Governance,' and 'Personal Healthcare Data.' Of course, there is also room for improvement, for example in the way that healthcare data is communicated. Ongoing policy debates in several Scandinavian countries highlight questions over the value being generated from these large investments into transparency. In this chapter we give a brief summary of the results per country and value that transparency brings.

Denmark

Overall transparency score =



Brief summary

Although Denmark achieved an excellent overall score, making it the top performing country in the entire index, its scores vary across the six dimensions of transparency measured. It rates particularly high on transparency of 'Governance' (94 percent), 'Personal Healthcare Data' (93 percent) and 'Finance' (83 percent). Scores for 'Quality of Healthcare' (67 percent) and 'Patient Experience' (62 percent) were lower but still above average, whereas transparency around the 'Communication of Healthcare Data' (50 percent) was the lowest performing dimension.

As one of only four countries to provide free online access for all patients to their up-to-date medical records, Denmark is well positioned to further expand transparency. However, significant improvements could be made by better navigation methods for users, increased allocation and publication of patient-reported outcomes, and publishing data in open and machine-readable formats, allowing independent data processing and analysis.

Upsides and downsides of transparency

The transparency of personal healthcare data allows patients to report errors —

for instance adjusting vaccination records — and enriches trust between doctors and patients. On the other hand, giving all patients access to all their data without consultation can create unnecessary anxiety, as the data is only quantitatively filtered against standard measures and does not communicate the full picture (e.g. one parameter falling outside standard measures with all other parameters being 'in the green'). This consequence will furthermore be biased to different patient groups, possibly working against the level of doctor/patient trust established by the same transparency in other patient groups.

 <p>Dimension 1 Quality of Healthcare</p> <p>Total result: 67%</p>	Indicator	1.1. Mortality/survival rates for individual medical conditions & treatments	1.2. All- cause mortality/survival rates	1.3. Hospital re-admission rates	1.4. Waiting times for emergency care	1.5. 'Adverse event' reporting	1.6. Hospital-acquired infections
		(total possible score = 4)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 4)
	Score	3	1	3	3	3	1

 <p>Dimension 2 Patient Experience</p> <p>Total result: 62%</p>	Indicator	2.1. Patient reported outcome measures	2.2. Patient satisfaction	2.3. Patient approval	2.4. Patient complaints
		(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)
	Score	1	3	1	3

 <p>Dimension 3 Finance</p> <p>Total result: 83%</p>	Indicator	3.1. Financial performance	3.2. Prices patients are charged	3.3. Prices health insurers/payers are charged	3.4. Disclosure of payments, gifts and hospitality to healthcare staff
		(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)
	Score	3	3	3	1



Dimension 4
Governance

Total result:
94%

Indicator	4.1.	4.2.	4.3.	4.4.	4.5.
	Freedom of Information legislation	Patient rights	Procurement processes and decision-making	Public decision making	Patient/ Public involvement
	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 3)
Score	3	3	4	2	3



Dimension 5
Personal Healthcare Data

Total result:
93%

Indicator	5.1.	5.2.	5.3.	5.4.
	Electronic patient records system	Shared clinical documentation	Patient data privacy and safeguarding policy	Information on use of patient data
	(total possible score = 4)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)
Score	3	3	4	3



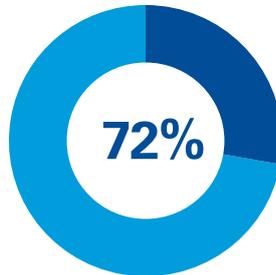
Dimension 6
Communication of Healthcare Data

Total result:
50%

Indicator	6.1.	6.2.	6.3.	6.4.
	Accessible data	Up-to-date data	Direct comparison of providers and services	Open data formats
	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 4)
Score	1	3	2	1

Finland

Overall transparency score =



Brief summary

Finland’s excellent score of 72 percent placed it in the top tier of countries on the transparency index. Finland scored exceptionally high on ‘Communication of Healthcare Data’ (93 percent), transparency of ‘Governance’ (88 percent), ‘Personal Healthcare Data’ (86 percent) and ‘Finance’ (83 percent). Whereas transparency scores were far lower on ‘Patient Experience’ (46 percent), and ‘Quality of Healthcare’ (48 percent).

‘Communication of Healthcare Data’ relies heavily on patients’ free and easy access to their electronic medical records and on a wide database of healthcare data available on a national level. The Finnish National Institute

for Health and Welfare maintains a national database that includes records of all healthcare visits across the entire country. Furthermore, Finland publishes healthcare data under an open licence as well as in machine readable formats, allowing independent data processing and analysis. The database enables decision-making and research based on comprehensive and up-to-date statistics.

On the other hand, Finland is weak in ‘Patient Experience’ transparency. There is a particular need for measurement and publication of patient-reported outcomes, and patient satisfaction and approval ratings. Public reporting of this data would further advance transparency of the overall Finnish healthcare system.

Upsides and downsides of transparency

The amount of data collected and available is generally seen as positive, but also represents quite an administrative burden. Additionally, stakeholders may also be concerned about the relevance of the data collected and the security of highly personal information. Questions have been raised about the impact of data collection on patient wait lists, and whether Finland should also concentrate more on client experiences. Also, there are fears that security breaches may limit the gathering of personal information in the future. Finland has benefited in several ways from its high transparency, but needs to ensure that it continues to focus on areas seen as central to the development of the country’s healthcare system further.

 <p>Dimension 1 Quality of Healthcare</p> <p>Total result: 48%</p>	Indicator	1.1.	1.2.	1.3.	1.4.	1.5.	1.6.
		Mortality/ survival rates for individual medical conditions & treatments	All- cause mortality/ survival rates	Hospital re-admission rates	Waiting times for emergency care	‘Adverse event’ reporting	Hospital-acquired infections
		(total possible score = 4)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 4)
	Score	3	1	1	1	1	3

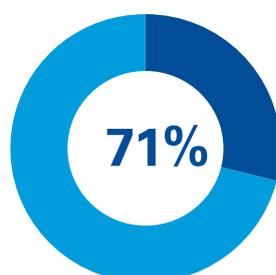
 <p>Dimension 2 Patient Experience</p> <p>Total result: 46%</p>	<p>Indicator</p> <p>2.1. Patient reported outcome measures</p> <p>(total possible score = 3)</p> <p>Score</p>	<p>2.2. Patient satisfaction</p> <p>(total possible score = 3)</p> <p>1</p>	<p>2.3. Patient approval</p> <p>(total possible score = 3)</p> <p>1</p>	<p>2.4. Patient complaints</p> <p>(total possible score = 4)</p> <p>1</p>	<p>3</p>
 <p>Dimension 3 Finance</p> <p>Total result: 83%</p>	<p>Indicator</p> <p>3.1. Financial performance</p> <p>(total possible score = 3)</p> <p>Score</p>	<p>3.2. Prices patients are charged</p> <p>(total possible score = 3)</p> <p>3</p>	<p>3.3. Prices health insurers/ payers are charged</p> <p>(total possible score = 3)</p> <p>3</p>	<p>3.4. Disclosure of payments, gifts and hospitality to healthcare staff</p> <p>(total possible score = 3)</p> <p>1</p>	<p>3</p>
 <p>Dimension 4 Governance</p> <p>Total result: 88%</p>	<p>Indicator</p> <p>4.1. Freedom of Information legislation</p> <p>(total possible score = 3)</p> <p>Score</p>	<p>4.2. Patient rights</p> <p>(total possible score = 3)</p> <p>3</p>	<p>4.3. Procurement processes and decision-making</p> <p>(total possible score = 4)</p> <p>3</p>	<p>4.4. Public decision making</p> <p>(total possible score = 3)</p> <p>3</p>	<p>4.5. Patient/ Public involvement</p> <p>(total possible score = 3)</p> <p>2</p>

 <p>Dimension 5 Personal Healthcare Data</p> <p>Total result: 86%</p>	Indicator	5.1.	5.2.	5.3.	5.4.
		Electronic patient records system	Shared clinical documentation	Patient data privacy and safeguarding policy	Information on use of patient data
		(total possible score = 4)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)
	Score	4	1	4	3

 <p>Dimension 6 Communication of Healthcare Data</p> <p>Total result: 93%</p>	Indicator	6.1.	6.2.	6.3.	6.4.
		Accessible data	Up-to-date data	Direct comparison of providers and services	Open data formats
		(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 4)
	Score	3	3	3	4

Sweden

Overall transparency score =



Brief summary

Like the other top-performing countries, Sweden's scores vary across the six dimensions of transparency measured. The 'Quality of Healthcare' dimension (scoring 81 percent) is a particular strength, with Sweden being the only country in the index to achieve a bonus point for publishing hospital-acquired infections (HAI) at the ward or clinical level, thanks to an annual national prevalence survey of HAI within all hospitals (results are publicly reported).

The comparatively strong performance for transparency of 'Personal Healthcare Data' (79 percent) was achieved because patient data privacy and safeguarding is a legal obligation in the country, with the law regulating who can access patient data. Transparency could still be further advanced however, since most (but not all) patients are able to access

their up-to-date medical records online. As yet, there is no national coordinated electronic patient record system. 'Finance' is another positive performer (scoring 75 percent), with all healthcare providers publishing annual reports with independently audited financial accounts. An even higher score could be achieved on this dimension if there was public reporting of all payments, gifts and hospitality made to healthcare staff.

In terms of transparency of 'Patient Experience' (69 percent), a nationwide patient experience survey is conducted bi-annually, covering all primary care, emergency care, special somatic care and psychiatric care providers. Although more frequent surveys are preferable, the results still give an indication of the patient experience. Stakeholders can now compare individual care providers in terms of patient experience, through the "1177," national care guidance

service. However, outcomes in terms of medical results in anonymized form are not yet publicly available. Apart from legislative challenges in publishing outcomes, the practice of connecting care outcomes with providers is viewed by some stakeholders as sensitive and underdeveloped.

Upsides and downsides of transparency

In Sweden transparency has increased pressure on the healthcare sector for clear and continuous improvement. The fact that patients and other stakeholders have become more informed should be seen as an opportunity rather than a threat. Transparency enables healthcare systems to utilize and involve patients in new ways in order to co-create solutions and effective care.

Indicator	1.1.	1.2.	1.3.	1.4.	1.5.	1.6.
	Mortality/survival rates for individual medical conditions & treatments	All- cause mortality/survival rates	Hospital re-admission rates	Waiting times for emergency care	'Adverse event' reporting	Hospital-acquired infections
	(total possible score = 4)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 4)
Score	3	1	3	3	3	4



Dimension 1 Quality of Healthcare

Total result:
81%

 <p>Dimension 2 Patient Experience</p> <p>Total result: 69%</p>	Indicator	2.1.	2.2.	2.3.	2.4.
		Patient reported outcome measures	Patient satisfaction	Patient approval	Patient complaints
		(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)
	Score	2	3	1	3

 <p>Dimension 3 Finance</p> <p>Total result: 75%</p>	Indicator	3.1.	3.2.	3.3.	3.4.
		Financial performance	Prices patients are charged	Prices health insurers/ payers are charged	Disclosure of payments, gifts and hospitality to healthcare staff
		(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)
	Score	3	3	2	1

 <p>Dimension 4 Governance</p> <p>Total result: 69%</p>	Indicator	4.1.	4.2.	4.3.	4.4.	4.5.
		Freedom of Information legislation	Patient rights	Procurement processes and decision-making	Public decision making	Patient/ Public involvement
		(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 3)
	Score	2	3	2	3	1



Dimension 5

Personal Healthcare Data

Total result:

79%

Indicator	5.1.	5.2.	5.3.	5.4.
	Electronic patient records system	Shared clinical documentation	Patient data privacy and safeguarding policy	Information on use of patient data
	(total possible score = 4)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)
Score	2	2	4	3



Dimension 6

Communication of Healthcare Data

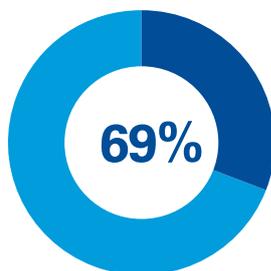
Total result:

50%

Indicator	6.1.	6.2.	6.3.	6.4.
	Accessible data	Up-to-date data	Direct comparison of providers and services	Open data formats
	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 4)
Score	2	2	1	2

Norway

Overall transparency score =



Brief summary

Norway's overall score of 69 percent places the country fourth in the transparency index. Once more, there is some variation in how Norway performs across the six dimensions of transparency. Norway recorded very high scores for transparency of 'Finance' and 'Governance' (83 percent and 81 percent respectively). Relatively good scores were achieved for transparency of 'Personal Healthcare Data' (71 percent), 'Quality of Healthcare' (67 percent), and 'Patient Experience' (62 percent). However, the transparency score was significantly lower on 'Communication of Healthcare Data' (50 percent).

In relation to 'Personal Healthcare Data,' it is encouraging to note that patient data privacy and safeguarding is a legal obligation in the country. At the time of measurement, about 70 percent of Norwegian patients were able to access information about their health through a new electronic platform 'kjernejournal.' Patients are also able to add/edit this information and include

notes. Transparency is advancing on this dimension as more and more patients get access to their up-to-date electronic medical records through the portal 'My Health' at Helsenorge. Access to medical records, however, still varies according to health region.

Transparency of 'Patient Experience' could be advanced further through the publication of patient reported outcomes (PROMS) for a range of inpatient and outpatient medical treatments. There is also room for improvement in 'Communication of Healthcare Data.' While most data on quality of healthcare is easily accessible through the Helsenorge portal, patient experience data is not kept on a dedicated website and has to be accessed through individual hospitals' websites, with published data not regularly kept up-to-date.

Upsides and downsides of transparency

In general, Norway has a transparent health system. Outcomes are published,

giving patients access to their own medical data; avoidable events are discussed and published; even doctors' salaries are public information. But there is an ongoing national debate about the downside of this transparency. People working in healthcare experience a very high administrative burden, which has led to discussions about the use of the data and indicators. Although it has enjoyed improvements in quality and efficiency, Norway has also seen some adverse events. For example the publication of wait times, and the monitoring of "number of patients that were not getting an appointment before a certain period" appears to have created internal and therefore "invisible" waiting lists.

Doctors have also raised concerns about the consequences of patients accessing their medical records, as they feel restricted in making notes, fearing that they may cause unnecessary anxiety amongst patients and their families.

 <p>Dimension 1 Quality of Healthcare</p> <p>Total result: 67%</p>	Indicator	1.1.	1.2.	1.3.	1.4.	1.5.	1.6.
		Mortality/survival rates for individual medical conditions & treatments	All- cause mortality/survival rates	Hospital re-admission rates	Waiting times for emergency care	'Adverse event' reporting	Hospital-acquired infections
		(total possible score = 4)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 4)
	Score	3	3	1	1	3	3

 <p>Dimension 2 Patient Experience</p> <p>Total result: 62%</p>	Indicator	2.1.	2.2.	2.3.	2.4.
		Patient reported outcome measures	Patient satisfaction	Patient approval	Patient complaints
		(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 4)
	Score	1	3	1	3

 <p>Dimension 3 Finance</p> <p>Total result: 83%</p>	Indicator	3.1.	3.2.	3.3.	3.4.
		Financial performance	Prices patients are charged	Prices health insurers/payers are charged	Disclosure of payments, gifts and hospitality to healthcare staff
		(total possible score = 3)	(total possible score = 3)	(total possible score = 3)	(total possible score = 3)
	Score	3	3	3	1

 <p>Dimension 4 Governance</p> <p>Total result: 81%</p>	Indicator	4.1. Freedom of Information legislation	4.2. Patient rights	4.3. Procurement processes and decision-making	4.4. Public decision making	4.5. Patient/ Public involvement
		(total possible score = 3)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 3)
	Score	3	3	1	3	3

 <p>Dimension 5 Personal Healthcare Data</p> <p>Total result: 71%</p>	Indicator	5.1. Electronic patient records system	5.2. Shared clinical documentation	5.3. Patient data privacy and safeguarding policy	5.4. Information on use of patient data
		(total possible score = 4)	(total possible score = 3)	(total possible score = 4)	(total possible score = 3)
	Score	1	2	4	3

 <p>Dimension 6 Communication of Healthcare Data</p> <p>Total result: 50%</p>	Indicator	6.1. Accessible data	6.2. Up-to-date data	6.3. Direct comparison of providers and services	6.4. Open data formats
		(total possible score = 3)	(total possible score = 4)	(total possible score = 3)	(total possible score = 4)
	Score	2	1	2	2

Scandinavian examples of successful healthcare transparency

If transparency is to deliver its future potential, it must be better managed. Our global research identifies seven different features that all health systems should consider more seriously to unlock these benefits — and avoid the risks — of transparency. In this mini report we highlight one case study for each of the four Scandinavian countries.

Case 1:

Personal Healthcare data — a consistent strategy from Denmark

The government of Denmark offers a good example of how a consistent strategy for data transparency and ICT-based interactions between the public sector and citizens can create transparency across the board. Denmark has successfully created a positive policy and legislative environment, supported by a governance model that focuses on high quality of services and management, which in healthcare translates to quality of care.

The high level of transparency of personal healthcare data in Denmark is an achievement built on three key stepping stones.

Firstly, since 1968 Denmark has given all nationals (and people with a residence permit) a personal identification number (Central Personal Registration (CPR) number) used as a common identifier across the public sector as well as part of the private sector.

Secondly, in 1977 Denmark established a national patient registry. Every time a patient has recorded contact with a hospital, selected data related to the contact is registered and incorporated into the National Patient Registry (LPR). The data is gathered and reported in a strictly structured format based on

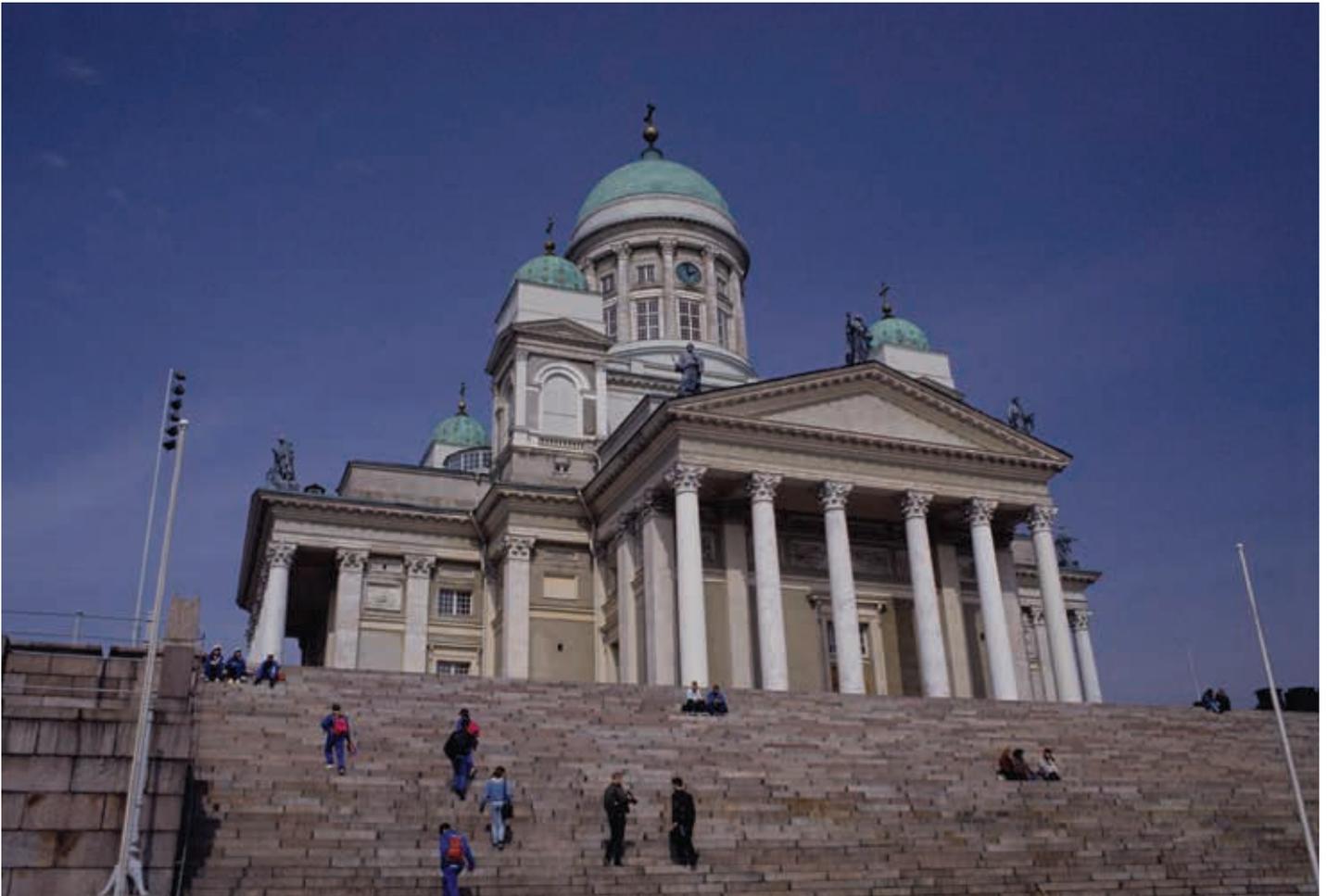
a national clinical and administrative standard (known as SKS). Data from LPR is used in several ways, including a number of national health registers (like cancer and birth records), as a basis for central and local funding models, clinical quality databases, and health research. The breadth and depth of the data effectively makes the whole nation a cohort.

Building on this foundation, Denmark has seen a significant roll-out of IT services within the whole healthcare sector, with hospitals, general practitioners and municipalities leading the way. A key player has been MedCom, a public funded, non-profit cooperation that facilitates cooperation between authorities, organizations and private firms linked to the Danish healthcare sector, by developing standards and profiles regarding exchange of healthcare related data throughout the entire Danish healthcare sector.

Thirdly, Denmark has a robust and carefully planned information and communications technology (ICT) infrastructure, with good, reliable solutions. Since 2001, Denmark has had a nationwide digitization strategy, covering increasingly complex parts of the interaction between citizens and the public sector.

In order to make communication and information exchange between the public sector, businesses, and citizens as easy as possible, the government supports a wide variety of digital tools and solutions, ranging from the implementation of an electronic signature to specific websites aimed at citizens. NemID (EasyID), a digital signature for single log-in for both public and private self-service solutions (based on Public Key Infrastructure), gives access to all public authority self-service solutions. These include Sundhed.dk, the official portal for the public Danish Healthcare Services, and enable citizens and healthcare professionals to find information and communicate with the sector. The portal facilitates patient-centered digital services that provide access to and information about Danish healthcare services.

With a personal registration number as identifier, a national registry and administrative standard providing the structured data foundation, and a consistent cross-national ICT infrastructure to make data available to the public (in aggregated format) and the patient (via micro data), Denmark has established a pathway to a high level of transparency in personal healthcare data.



Case 2: Meaningful data from Finland

Healthcare in Finland is strongly guided by legislation. This steers professionals to systematically register patient information and treatment. All healthcare providers are obligated to register healthcare visits into a national register (called Hilmo and AvoHilmo) provided by the National Institute for Health and Welfare. Recent national reforms of information systems have promoted the availability of patients' health information and improved the processes for data collecting. Today, all of the public and most of the private healthcare providers use the national data system, Kanta. Kanta services include the electronic prescription, Pharmaceutical Database, My Kanta pages, and Patient Data Repository. The National data system allows patients to view and edit their own

healthcare data and make up-to-date online requests for prescription renewals. (<http://www.kanta.fi/>).

Finland has a long tradition of healthcare data collecting, with established procedures for service providers for reporting and registering healthcare actions. This culture of conscientious reporting and registering is the basis for a nationwide database of healthcare data.

The task of collecting healthcare statistics has been entrusted to the National Institute for Health and Welfare, which also maintains the national database for healthcare visits. All these statistics are part of a centralized national register for healthcare data. The database works on open licence and provides up-

to-date information about the use of healthcare services, availability of treatment, population health problems, epidemics, services for promoting health and practices of treatment, and responsibilities of professionals. Information is available under an open licence and is used primarily for decision-making, research and development.

All healthcare providers must report healthcare actions to the national database (Hilmo, Avohilmo). In most cases data collecting is automated, with interfaces to patient information systems. Standardized and centralized data collecting makes the data comprehensive and comparable.

** KPMG in Finland interviewed Mr. Pasi Pohjola, Senior Specialist at Ministry of Social Affairs and Health.*

Case 3:

Quality of healthcare measuring what matters in Sweden

With its long history of science and engineering Sweden remains among the world's top five countries in terms of percentage of gross domestic product (GDP) invested in research and development. In parallel and throughout the 20th century, Sweden has promoted and protected public health and medical care, through reforms and a political vision. Evidence-based medicine, where measurement is central, has been driven by legislation, for instance the Patient Safety Act, which demands that healthcare professionals provide care in line with scientific and tested experience. As a result of close cooperation between science, entrepreneurs and clinical research, innovation in medical technology and pharmaceuticals has accelerated and provides an important basis for development of the Swedish healthcare system.

However, increasing costs, limited resources and lack of coordination have forced medical professions to focus on efficiency. One way to

control costs has been to compare best practice by exchanging information about outcomes and identifying the best intervention for a given type of diagnosis. Influenced by American practices in evidence-based medicine, Sweden started its first quality register in 1975 within knee replacement, shortly followed by a registry for hip replacement. Being given access to the growing set of data, Swedish orthopedic professionals could identify what replacement types and working methods were most effective. Today, Sweden is a world leader in orthopedics, thanks in large part to shared outcomes data.

The work with evidence-based medicine and quality registers has continued and expanded. In the 1990s, initiatives were taken to coordinate quality work, including registers via a national forum, a cooperation between The National Board of Health and Welfare (Socialstyrelsen) and county councils. Today there are some

110 national quality registers in Sweden containing individualized data about medical interventions, procedures and outcomes. Apart from being integrated into clinical workflows, each registry is supported by an organization of healthcare professionals, researchers and patient representatives.

National quality registries in Sweden have had an important and positive impact on healthcare results, where the country has among the best survival rates following heart attacks, strokes, breast and colorectal cancer.

The Swedish example shows that transparency and coordinated sharing of outcomes can contribute significantly to improved nationwide healthcare. To follow the Swedish example, development of quality registers should start small, focus on a limited number of diagnoses and assure good data governance. Today, international quality data is starting to become available and is sought after by many healthcare systems.



Case 4: Taking the lead from innovative providers in Norway

Why is Norway performing so well on governance? And what is a key success factor in taking the lead from innovative providers?

What we have seen in Norway is that regulation and legislation alone do not change hearts and minds; healthcare is simply too complex for transparency initiatives to be successful if they are 'done to' the system. Most constructive innovation happens locally by individual organizations that are inspired to improve.

One of the examples is Sykehuset Østfold. Their CEO, Just Ebbeson, personally won the transparency award (åpenhet) in 2016 competing against all Norwegian organizations across all sectors. When Ebbeson started as CEO in 2009, the hospital group did not score well on quality performance indicators and he looked for 'early wins' to change the culture. One of his first actions was to help all staff recognize that mistakes and errors are systemic, not individual, failures. When two staff members were placed under review for malpractice by the national quality inspectorate, the Board immediately complained that the hospital, not the staff, should be held

to account. The hospital even took the case to the Civil Ombudsman and won; the hospital was blamed for the incidents. This sent a clear message, not just to the workforce but across Norway, that staff would be protected if they reported errors. The important lesson was not to apportion blame for errors, but to learn from them.

Another great development is the structural way Sykehuset Østfold now deals with adverse events. When reported, an event is discussed in the hospital's patient harm group, which agrees what should be done differently to prevent a repeat occurrence, and helps ensure necessary changes are implemented. A full report of the incident and improvement policy and practice is placed on the hospital website. Within a year of the introduction of this practice, other Norwegian hospitals started following this model, which has recently been adopted as government policy for all hospitals.

The experience of Sykehuset Østfold provides some valuable lessons in transparency at the individual provider level:

- strong visionary leadership from innovative providers is a good basis for national policy, such as the hospitals adverse events system which is now common practice across Norway
- data can be used effectively to improve care quality if clinicians are 'on side' and feel a sense of ownership in developing the measures
- to raise care quality, it is more important to focus on the hospital's internal improvement targets and benchmarking, than on comparative performance with other Norwegian hospitals (given the huge variation in size of institution and range of medical situations)
- outcomes are determined by team competence and organizational systems — not by individual performance; and
- being open and transparent changes the approach of the media; they are less inclined to attack and more prepared to acknowledge steps are being taken to prevent a re-occurrence.

“

The population is increasingly expecting this kind of transparency. Either we react to it slowly and it happens to us...or we are active and drive it, and shape it ourselves, which helps us to learn and build trust and a better conversation around healthcare.”

Just Ebbesen, CEO, Sykehuset Østfold, Norway



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