



Through the looking glass

**A practical path to improving
healthcare through transparency**

KPMG International



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Executive summary

Transparency in healthcare matters, but to date has failed to live up to its promise of transforming quality and cost. Too often progress has been symbolic and has given rise to bitter disputes between political ideologues and resistant provider and professional groups. Even countries that have led the field are now facing difficult questions about what value is really created for all their effort. Awash with data, some systems are finding it more difficult than ever to work out what is going but used strategically, this study suggests there is considerable potential waiting to be unlocked from health system transparency.



The objective of this study is to establish what health systems need to do to make transparency into the powerful, positive change agent that it can be. We present insightful research into the state of play of global health system transparency; explore what makes a health system transparent; examine the benefits, risks and opportunities; and delve into what the optimum future for transparency could look like and how to achieve this.

We begin by explaining what makes a health system transparent and comparing the world's major health systems by their level of progress on some of the most important dimensions of the concept.

Transparency in healthcare: Good governance or political distraction?

Evidence from our research shows that, like any tool, transparency can be used to create benefit or harm, or a bit of both. On the one hand, there is good evidence of data publication leading to quality improvement drives, better data collection and even improved health outcomes. On the other, it can undermine trust, lead to too much focus on particular measures, and lead to erroneous conclusions and policies.

If current trends continue, it is easy to imagine health systems overwhelmed

by data requirements that distract from the real business of healthcare improvement and support punitive cultures of naming-and-shaming, ultimately leading to less transparent performance and decision making. This report signals a different, far more positive way forward. Where transparency is applied in a disciplined way by national and local health systems we believe it can make a substantial contribution to the quality and value of healthcare. Key features of this strategic approach include a selective, phased approach to data publication, learning from innovative providers and promoting high trust cultures alongside independent narratives from selected groups.

We highlight where this future is happening now, with 16 global case studies from countries such as Australia, Denmark, Germany, the Netherlands, UK and US.

While our global index of health system transparency shows huge variation in progress, no country's health system is truly pursuing transparency in a strategic way. To realize the full value of this trend, a whole-system approach is needed that aligns the different dimensions of transparency, the means to deliver these dimensions, the methods for communicating this information, and the levers to facilitate positive change.

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 health practices in 32 countries
- Transparency scorecard data collected and analyzed by country

What should your organization be doing to successfully apply transparency

1. A consistent strategy
2. Take the lead from innovative providers
3. Measure what matters to patients
4. Fewer measures, more meaningful data
5. Provide personalized price transparency
6. A give-and-take approach to safeguarding patient data
7. Promote independent narratives to improve understanding



What is a transparent health system?

Transparency in healthcare is a contested concept, with a wide range of interpretations based on country, care setting, and stakeholder group. This diversity of terminology is symptomatic of a lack of strategic clarity about what constitutes an effective, transparent health system. Here we present a unified definition of the most important components.

Across the literature reviewed and our interviews, six main dimensions of health system transparency recurred.^{1,2,3,4,5,6} These dimensions cover the main issues of concern according to health systems, organizations and stakeholder groups globally and form the basis of our definition of transparency, as well as foundation for the global health systems transparency scorecard:

- 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 patients' 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.

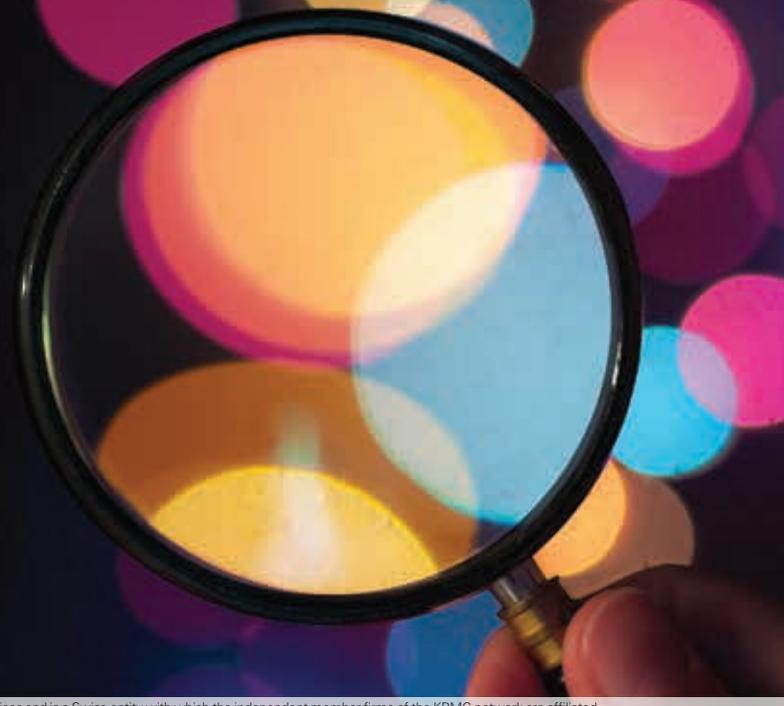


Drawing these concepts together, our definition of transparency in global health systems is:

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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 judgement on its fairness. ”

The global health systems transparency index



To understand how different countries’ health systems compared against this framework, we constructed a scorecard of key indicators by which to measure their progress on each of the six dimensions. After validation with a reference group of transparency experts and health system leaders, KPMG health practices in 32 countries completed the scorecard based on their knowledge of what data was published, sometimes with assistance from the Ministry of Health or other authorities.

While the full scorecard and scoring methodology can be found in the appendix, the grid below gives a summary of its 27 key indicators. These were selected by considering: the practices of leading healthcare organizations and systems; measures likely to highlight meaningful variation across health systems; concepts likely to translate easily across different health system types; and policies identified as important by our interviewees. Most indicators used a

very simple scoring system that asked whether a minority, majority or all providers (or hospitals) in the system routinely followed a particular practice, with each indicator weighted equally.⁷

Results

Completed transparency framework scorecards were received from 32 countries, covering most OECD and G20 countries. Composite scores for each dimension and an overall score were then compiled to give a global

state of play for most of the world’s major health systems. From this, several conclusions can be drawn:

- There is a high level of variation across countries in overall health system transparency, with scores ranging from 74 percent to 32 percent. The average score of 55 percent is relatively low, suggesting that there is still much, much more that countries have not yet done.

| Dimension | | | | | |
|--|---|--|---|---|---|
|  Quality of Healthcare |  Patient Experience |  Finance |  Governance |  Personal Healthcare Data |  Communication of Healthcare Data |
| Mortality/ survival rates for individual medical conditions and treatments | Patient reported outcome measures | Financial performance | Freedom of Information legislation | Electronic patient records system | An accessible data portal |
| All-cause mortality/ survival rates | Patient satisfaction | Prices patients are charged | Patient rights | Shared clinical documentation | Extent to which data is up-to-date |
| Hospital re-admission rates | Patient approval | Prices health insurers/ payers are charged | Procurement processes and decision-making | Patient data privacy and safeguarding policy | Ease of comparing providers and services |
| Waiting times for emergency care | Patient complaints | Disclosure of payments, gifts and hospitality to healthcare staff | Public decision making | Information on use of patient data | Use of open data file formats |
| 'Adverse event' reporting | | | Patient/Public involvement | | |
| Hospital-acquired infection rates | | | | | |
| Indicators: To what extent is information publicly available⁸ on... | | | | | |

- Comparing performance across the different dimensions, the highest scores go to 'Governance' and 'Finance' (averaging 67 percent and 66 percent respectively). The lowest scores are for transparency on 'Quality of Healthcare' (averaging 44 percent), suggesting this is where transparency is less advanced across health systems, and countries have been more reticent to make progress.
- The four Scandinavian countries — **Denmark, Finland, Sweden and Norway** — achieved the highest overall scores — little surprise to those that know these systems well. A dive into the dimension-specific results shows that this impressive performance reflects particularly strong scores on 'Finance', 'Governance', and 'Personal Healthcare Data'. However, these top ranking countries do not perform consistently well. There is still room for improvement in the way that healthcare data is communicated, and ongoing policy debates in several of these countries highlight an open question over what value is really being generated from all this progress.
- The second tier of countries comprises **Australia, Netherlands, New Zealand, the UK, Portugal and Singapore**, followed by **Brazil, Canada** and **Spain**. Those lower down the rankings despite having otherwise high performing health systems include **Germany, Italy, Switzerland, Korea, Ireland and Japan**. These may feel they should be doing better in comparison to their peers.
- The lowest tier of performers includes **China, India, South Africa, Saudi Arabia** and **Mexico**. However, these should not be judged too harshly as they are lower income members of the OECD or G20, included purely because of their size and global importance. Hence they are being compared against countries that mostly spend many times what they do on healthcare.
- Beyond the headline scores, many countries perform highly inconsistently across different dimensions. For example, **Iceland** scores particularly well on transparency of 'Finance' (75 percent) but less well on other categories.

Similarly, **Canada** performs strongly on transparency of 'Governance' (81 percent) and 'Communication of Healthcare Data' (79 percent), but less strongly across other categories.

New Zealand reported the most extreme variation across dimensions, with a score of 94 percent for transparency of 'Governance' but only 38 percent for 'Quality of Healthcare'.

- In terms of the specific policies which indicators measured for each country, the highest scoring (and therefore most widely practiced) measures were:
 - Presence of national patient data privacy and safeguarding policy
 - Explicit patient rights setting out exactly what patients are entitled to and can expect from providers
 - Existence of a 'Freedom of information' law
- The lowest scoring, and therefore least common, practices are:

Health warning

When interpreting these scores, it is important to remember that:

- It is not necessarily good to have a high ranking 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 bad results
- Disclosure of payments, gifts and hospitality made to healthcare staff
- Shared clinical documentation — a patient portal where patients can contribute to or edit their personal health data
- Publication of patient reported outcome measures or approval ratings

Healthcare transparency in the USA: Leaders and laggards

The scoring methodology for this study involved taking an overall snapshot of healthcare data publication practices in each of the countries studied, and summarizing these into overall scores. While internal variation existed to some extent in all countries, in no system did we find such a high degree of internal dissimilarity and fragmentation than the US.

Due to the state-based nature of many healthcare regulations, but also the coexistence of many large and complex payer and pricing systems — both private and public (operating at federal and state levels) — a summary score for the entire country was not felt to be a helpful guide as to progress.

While absent from the results table below, the US undoubtedly exhibits many of the leading transparency practices described in this report, as well as falling victim to many of the pitfalls. The issue is high profile and rapidly evolving — healthcare systems regularly report on more than 500 different indicators to payers, regulators and other bodies. However, there are no objective standards for many of these measures (such as quality, patient satisfaction, etc.) and few organizations are well positioned to integrate them — although many publish data about their own particular piece of the system.

The Affordable Care Act had some impact by making pricing more transparent — especially to the patient. Similarly, evolving payment models such as 'value based' pricing are likely to drive greater integration of data across different silos. Still, there is great uncertainty around how the Trump Administration will revise regulations in this area, and whether this will lead to an acceleration or stalling of progress.

US case studies and evidence are drawn throughout this report to demonstrate good and bad practice. But given the unique complexity of this picture, the current system does not easily lend itself to our single score method.

Table 1: 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%

Health system transparency: A powerful force for good or ill

To inform the often fractious political debate that surrounds healthcare transparency, we searched the literature for evidence about its real world impact. What emerged is that there is no doubt transparency has the potential to significantly change behaviour, although this can both enhance and undermine value.

Evidence was concentrated around six main effects:

1. Public reporting encourages quality improvement efforts

There is good evidence that public reporting stimulates quality improvement activities, particularly at hospital level.^{9,10} For example, Canadian hospitals were found significantly more likely to report quality improvement initiatives in response to publication of mortality rates; initiatives included new clinical pathways, and care maps for clinical management.¹¹ Similarly, large clinical practices in Wisconsin, US were found to have engaged in quality improvement efforts as a result of comparative public reporting.¹² In the Dutch hospital setting, care quality appears to have improved faster in hospitals mandated by government to publish patient experience data than in hospitals that were not.¹³ Several studies also report clinician-level quality improvement activity. A US national survey, for instance, found that patients with vascular disease were prescribed aspirin by fewer than 50 percent of physicians, but in Minnesota which publicly reported use of aspirin, the rate was 95 percent.¹⁴

2. Transparency is associated with mostly improved, but sometimes poorer outcomes

Publishing performance data has had differential effects in terms of improved health outcomes, with evidence from systematic reviews showing mixed results.^{15,16} Some research studies record a positive impact, for example, reporting of cardiac mortality data for individual surgeons in the UK is viewed a success, being linked with clear improvements in mortality.^{17,18} Other studies demonstrate no beneficial effects, for instance analysis of claims data for US Medicare patients discharged from hospital showed public reporting had no impact on readmissions or mortality outcomes.¹⁹ A few studies suggest negative effects. For example, a recent US study found that publishing mortality rates for acute conditions was associated with poorer outcomes than for non-reported conditions.²⁰

3. Publishing poor quality data diminishes transparency

Publishing data about a health system is not helpful if that data is incomplete, inaccurate, out-of-date, or not comparable. The wrong conclusions will be drawn and inappropriate actions taken. In the UK, the Vascular Society was the first medical association to release outcomes data and the publication of poor data led to mistaken assumptions.²¹ Surgeons have been incorrectly identified as poorly performing because of mistakes in how data is reported.^{22,23} For example, first publication of named surgeon-specific outcomes in England was based on raw data without risk adjustment and from pre-existing national surgical audit databases not designed for this purpose.²¹ False identification creates suspicion and resistance to transparency because of the associated stigma that results from 'naming and shaming'.²⁴ Therefore, attention and resources should be given to data quality and completeness and to validation processes that will achieve this, particularly for clinical databases.²¹ Published data is also unhelpful if it is not measuring meaningful indicators.

Badly communicated data prevents necessary improvements in care quality. Hence, comparative performance data has little value if all reported scores are average with no real differentiation. For example, until recently Centers for Medicare and Medicaid Services (CMS) in the US displayed performance ratings for hospitals in three major categories compared with

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There's no virtue in benchmarking yourself to a substandard norm.”

Paul Levy

Former President and CEO, Beth Israel Deaconess Medical Centre, Boston, currently Senior Advisor Lax Sebenius LLC, Massachusetts



Price data are not always what they seem to be. There is sometimes information on costs and charges but almost nobody pays either of these amounts, and costs are rarely known. Even when there is transparency of charges, the closest thing we have to prices, it isn't necessarily useful because it doesn't mean anything.

Helen Darling

Interim President and CEO National Quality Forum, Washington

the national average (worse, no different, and better). Since most hospitals were labelled 'average' and fewer than 5 percent 'worse', and the data was often more than two years old, there was little motivation for providers to invest resources in improving outcomes.²⁵

Much of the price data published in the US can mislead since it bears little relation to what patients will end up paying for their care. It frequently fails to take account of 'out-of-pocket' costs for premiums or deductibles, or total costs across the care pathway.

4. Transparency improves the quality of healthcare data reported

Despite the risks of making initially imperfect health data transparent, it will improve the quality of the data reported. Giving stakeholders open access to the information allows critical response. Publication of imperfect data by its very existence enables attention and debate on what, how, and why the data is measured. UK experience from cardiac surgery shows that publication helped improve data quality.²⁶

Transparent electronic patient records provide another example. The process of making patients' records available electronically has magnified the flaws of the current medical record, and accelerated clinicians' desire for improvement.²⁷ Publication also pushes professional societies responsible for data measurement and collection to set clear performance standards.²⁸ Additionally, several of our interviewees argued it is better to trigger change and improvement through publication than hold back from reporting to participate in a lengthy, time-consuming quest for the perfect measure or method.

5. Some gaming but not as widespread as the rhetoric suggests

Fears have been expressed that public reporting of performance data will lead to gaming by providers, for

example surgeons selecting only low-risk patients in order to improve their mortality rates.²⁹ While some clinicians express reluctance to operate on high-risk patients after the implementation of public reporting³⁰, such 'gaming' has not proved widespread. No country has shown evidence of systematic risk-averse behaviour through avoidance of high-risk cases following new publication practices.

There are also concerns that providers might take actions to improve performance without actually improving quality, such as focusing on reported measures to the detriment of other areas of care, or changing the way data is recorded. Again the evidence shows this is not a widespread practice, however there are a few studies which suggest such actions occur, for example, providers changing how they assess pain in order to improve performance scores.³¹

6. Transparency can become a distraction if not targeted carefully

The number of metrics reported has expanded greatly over time in many health systems. This is often in response to provider and clinician demands for more accurate and specific measures. While these measures may provide reliable and detailed understanding of what is happening at the clinical level, the sheer weight of data can make identification of what is important in terms of patient outcomes, more difficult. Since data collection is frequently cost and resource-intensive there is the additional risk that by focusing on the little rather than big things, transparency turns into a demotivating waste of resources.³² There are active debates about the burden and cost of publishing increasingly large numbers of metrics. In the Netherlands, hospitals deliver up to a thousand quality indicators to external parties each year, the vast majority of which are structural and process measures — often with poor data quality.³³

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Publishing a plethora of data is time consuming and doesn't add to real transparency — in fact it can even undermine it. Many countries end up not seeing the wood for the trees, so it's important to think about the value and true meaning of data, not just the quantity.”

David Ikkersheim

KPMG in the Netherlands



What does the future of healthcare transparency look like?

It is clear that across the world's health systems — both high and middle income — there is a steady rise in calls for transparency and implementation of new policies to promote it. To some this represents a growing encroachment into professional autonomy that at best distracts from the real work of caring for patients and at worst creates a fear-based culture of public exposure and blame. It is easy to imagine a dystopian future if this kind of transparency is left to run unchecked — with systems awash with meaningless or actively misleading data, providers averse to any risks that might lead to their being named-and-shamed and an increase in top-down micro-management of frontline delivery.

This is not the future we foresee, however. Increasing understanding of the risks and benefits of transparency should give cause for cautious optimism about its use in health systems of the future. There is no doubt that the trends towards greater transparency will continue — the explosion in the amount of healthcare data and rising consumer expectations of patients and the public make that almost inevitable. For those providers and payers that are prepared, the opportunities will outweigh the threats. The following is our considered prediction of the world we can reasonably expect to see develop over the next five years, with case studies interspersed of where this is happening already.

Less name and shame

While some of the movement to publish more healthcare data has been ideologically led, and often associated with rooting

out poor performance, the limitations of this approach are becoming more apparent. Resistance among providers — much of it justifiable — and the lack of supportive evidence for 'name and shame' strategies is forcing health systems to tip the balance in favour of partnership, not penalty. Transparency will come to be seen more as a strategic enabler of smarter decision making: whether it be government policy and investment decisions; civic organizations judging the fairness of the allocation process; purchasers deciding which services to commission or providers designing care pathways.

Since the most significant improvements resulting from transparency have come through peer-to-peer learning and review, this is something that is likely to be seen as a more common first stage in future (exemplified by global movements such as ICHOM). Clinicians have proved far more willing to share performance information within their



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As a nation, we don't always have a particularly mature attitude to transparency. We're not yet consistently talking in the language of signals and verification, we're still talking the language of judgement.”

Emma Doyle

Head of Data Policy, NHS England

own clinical communities at first than straight to public reporting. It is felt this approach creates a safer, non-judgemental environment on which to focus on improvement. They will also tolerate less robust data when using it for internal quality improvement.

At Helios, a 112-hospital group in Germany, they have used peer review for over 10 years to guide clinician-led improvements. Quality indicators, derived from routine data and referenced against the averages from all German hospitals, are publically reported for each hospital in the group. Whenever an indicator shows below-average outcomes for a Helios hospital, the peer review process is initiated: clinician colleagues from other Helios hospitals analyse the medical records of deceased patients treated in the hospital concerned and provide improvement suggestions in detailed protocols. Evidence indicates this peer review process has had significant impact on mortality rates for a range of conditions, with 710 'saved lives' over the study period 2004–2011.³⁴

When even sharing among peers is perceived to be sensitive, an alternative approach is to individually show providers their relative performance without naming others. For example, at the Beth Israel Deaconess Medical Center, Massachusetts, they collected data on withdrawal times of colonoscopy scopes since some doctors were thought to do it too quickly and miss things. Each doctor was sent a bell curve of the range of times done by everyone in the hospital with only their individual position highlighted. This confidential approach prompted measurable improvement in quality, without the need for anyone to feel discredited.

Real-time data with expanded formats and forms

A common complaint about published health system data is that they are out of date — often by years. As data platforms among providers improve it will be possible to turn this into more real time diagnostics, making it far more useful and accessible. For example, the East Kent Hospitals University NHS Foundation Trust uses a business intelligence system to display on its website, live A&E waiting times and the number of people waiting at each of the Trust's four hospitals. The information is also available to hospital staff through a smart phone app. This real-time data system helps control patient flow into A&E, and enables managers and clinicians to manage demand by

knowing when to redirect patients to other less busy Trust hospitals.

The types of data which could potentially be made transparent are also expanding thanks to new technology, such as live-streamed video through the eyes of the clinician. In Michigan, twenty bariatric surgeons recently agreed to have their technical skills rated anonymously by peers using a video of themselves performing a surgical procedure. Skill ratings were then assessed against clinical outcomes. The results showed higher peer ratings of surgical skill were associated with lower rates of post-operation adverse events.³⁵ Video can also be used to make decision making transparent — the board meetings of England's top executive agency for the NHS, for example, are now routinely live streamed to the public.

One area of potential threat to transparency from the big data revolution is the rise of algorithms and artificial intelligence to drive decision making in the system. While the evolution of these systems is undoubtedly helped by data transparency, they are often so complex that they are often barely understood even by the organizations that use them. Concerns have been expressed about the possibility of such an 'algocracy' arising if AI becomes widespread in making health decisions — it could result in care systems even less transparent than before.³⁶



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With doctors you can say we've done this data analysis and we know it's not perfect, but it gives you a reflection of how you benchmark against yourself six months ago or how you benchmark against your colleagues. And doctors will say that's very interesting I'm going to use that, it's going to change what I do.”

Brian Ruff

CEO Partner Professional Provider Organization Services, Johannesburg

More consumer access and use of data

One of the most widely shared conclusions of the transparency movement so far is that patients are not making widespread use of health system data. Very few patients currently use comparative performance information to inform their provider or treatment choices.^{37,38} As a result, there is minimal consumer pressure on providers to improve outcomes.

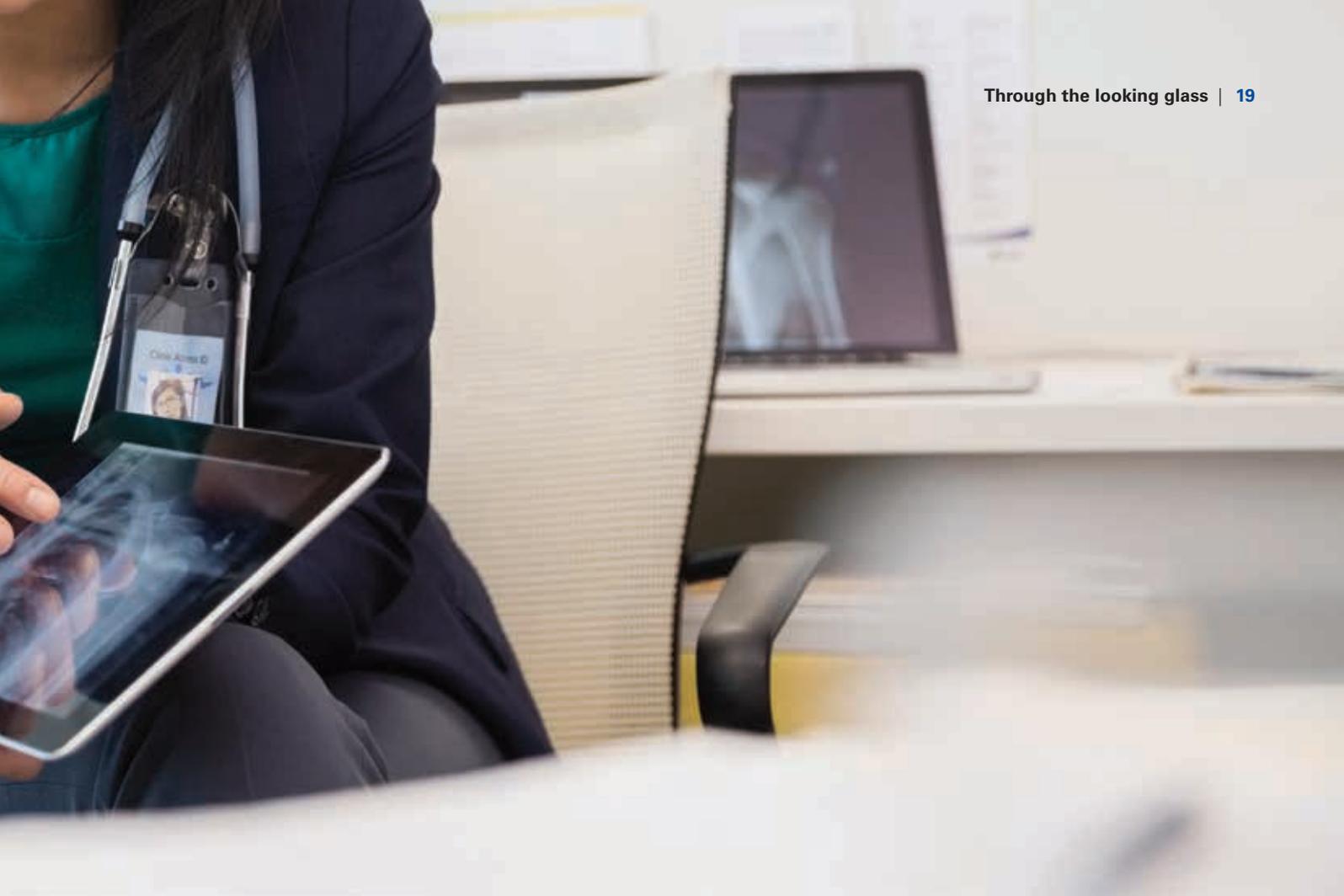
While consumers now use price and quality review sites routinely for almost every form of purchasing, there has not been a surge in interest to carry this behavior over when they need healthcare. Reasons include lack of skills to comprehend the data, inappropriate data being published, the urgency of many treatment decisions and lack of options to act on information. The 'army of armchair auditors' has not materialized, so that even in the most transparent countries healthcare still remains a black box to most people.

Lessons are gradually being learned that will make healthcare information more

accessible to consumers, however. Firstly, information portals are learning which measures are really of value to patients (and having them select the things to measure themselves), how to visualize and explain concepts in a way that is easy to understand. The provision of decision aids and brokers/advocates also makes it much easier for patients to process healthcare data into actionable information.

Perhaps the most important lessons of recent years is that patients are particularly receptive to information associated with their personal situation, such as the costs and quality outcomes for a particular procedure tailored to their specific circumstances.^{39,40,41} Patient accessible and editable electronic medical records are another great example.

The OpenNotes initiative in the US gives patients access not only to their medical records, but the appointment notes written by their clinicians. Evaluation studies report improved communication and trust between patients and clinicians, confidence in self-care, better medication adherence and compliance,



and accuracy of records.^{42,43} Having begun in 2010 with just 100 doctors and 19,000 of their patients, OpenNotes is now used by health systems across the US, giving more than 6 million patients unrestricted access to their medical records. Kaiser Permanente has found that this combination of personalization, interactivity and transparency has attracted patient engagement like no other system before.

Open data for independent third party narratives

Health systems will see the rise of privileged or approved ‘challenger’ organizations acting as independent interpreters of healthcare data for the system. The ability to challenge official narratives about what is going on is one of the fundamental foundations of healthcare transparency but it is currently hard for organizations to do this when only some health system data can be published — often with individual level data only available to government.

Health systems will increasingly begin publishing data in machine-readable formats under open licence, which

will increase the ability of outsiders to conduct their own analysis and bring together different data silos. Even then, there will always be some data — individual health outcomes, for example — which cannot be published. In these cases, responsible third parties (either not-for-profit or for-profit) will be given special permission to have access to this data in order to form an independent view and conduct the kind of sophisticated analyses that are possible with big data but many governments simply do not have the resources or expertise to conduct themselves.

The Leapfrog Group in the US is one example of an organization that has successfully pushed and advocated for such access.⁴⁴ Every six months, this independent national non-profit organization publishes the Hospital Safety Score, grading hospitals based on their patient safety performance. In response to their campaigning efforts, the number of hospitals providing performance measures has increased over 15 years from 200 to 2,500, and Leapfrog are also able to access

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Much more needs to be done to enable consumers or purchasers of care to understand their own healthcare experience, or to make choices in healthcare. I would say we’re very much at the beginning of a transparency process here.”

Dr. David Blumenthal

President,
Commonwealth Fund
New York

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They (Kaiser Permanente) found that if patients sign on to portals they can be managed more efficiently, and OpenNotes is what gets them onto the portals. It also makes them more likely to stick with the health system.”

Dr Tom Delbanco

Co-Director OpenNotes,
Professor of General Medicine and
Primary Care, Harvard Medical School,
Boston

data from several national agencies collecting metrics on healthcare quality. A panel of patient safety experts oversees the selection of measures used and the scoring methodology. The Safety Score gets significant media coverage which prompts attention and interest from hospital board members and hospital staff as well as community and patient organisations. ‘Exposing providers to themselves’, on a regular basis, has proved beneficial in driving hospitals to be continuously more vigilant about safety.

Price transparency tools to reduce health spending

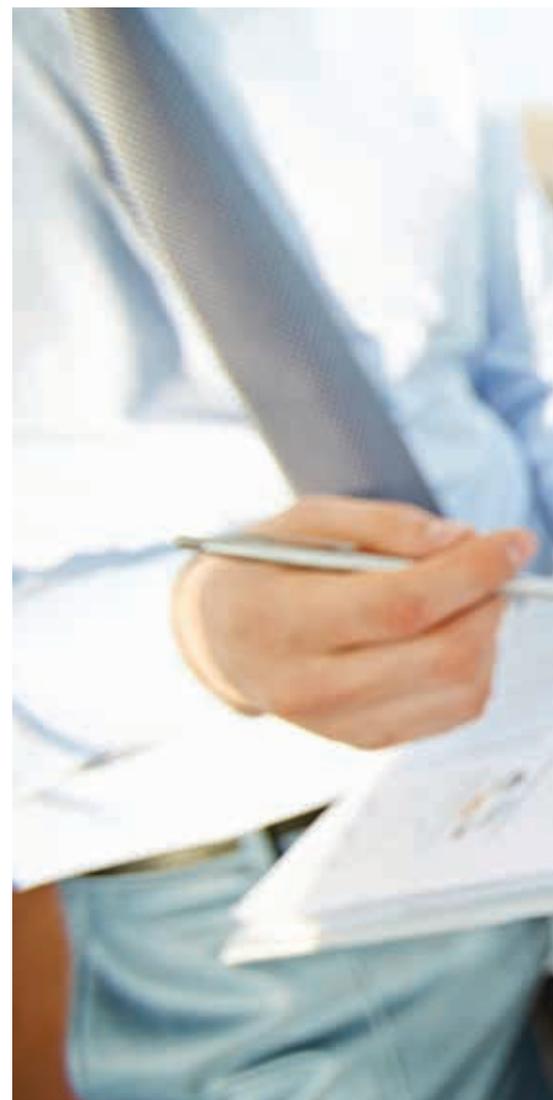
In some systems the potential financial rewards from price transparency tools, offering consumers price information on health services, are considerable. One organization estimated reduced health spending in the US of US\$18 billion over 10 years⁴⁵, another calculated that only a 3 percent uplift each year could save US\$16 billion by 2020.⁴⁶ Nevertheless, price transparency tools have so far failed to lower healthcare spending. Most patients are not using the data to choose best value services and continue to rely on their doctors’ recommendations. A key reason is low take-up.^{47,48} The current product offering fails to engage patients: price data is frequently provided without data on service quality, it is not personalized, and there is often no information on out-of-pocket costs. To be helpful price information needs to provide a meaningful estimate of a patient’s total expected costs.^{49,50}

Recent developments, particularly in the US, are prompting change. Adjustments in the US health insurance market have meant commercially insured patients now bear a larger proportion of spending through increased deductibles, co-payments and co-insurance. More than half of US states have passed legislation establishing price transparency websites or mandated that hospitals or health plans make

price information available for patients. Price transparency initiatives have developed in the private sector with some insurance companies providing cost estimates via online calculators. A few companies now offer personalized price information.

Open and honest responses to adverse events

While the threat of sanction and legal action has deterred many providers from being too open about failures in care, many healthcare systems and individual providers are beginning to buck this trend. Recognizing the importance of giving context to cold statistics and getting ahead of a media



environment that is all too ready to ascribe blame, policies that promote a proactive approach to error will become more common.

An example of one such 'proactive' approach that is quickly spreading is Sykehuset Østfold, a private hospital organization in Norway. If there is an adverse event, the hospital's patient harm group will meet to consider all the collected evidence, decide what should be done differently to prevent repeat occurrence, and help ensure necessary changes are implemented. A full report of the incident and improvement policy and practice is placed on the hospital website (except in the case of suicides or birth/infant

deaths which being rare makes patient identification likely). The management view is that adverse events are system not individual-related and should be used to learn and improve not penalize. New employees are informed on their introductory day that if they report adverse events they will always be supported. Within a year of its introduction other Norwegian hospitals started following this model and it has recently been adopted as government policy for all hospitals.

Still, there is a long way to go globally: only 38 percent of countries completing the transparency scorecard said there was public reporting of adverse events by hospital providers.

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Transparency will only be a meaningful and effective policy if third parties have the ability to construct their own narratives of fairness.”

Tim Kelsey

CEO Australian Digital Health Agency, Australia



Seven features of successful healthcare transparency

We have highlighted a critical need for transparency to be far better managed if it is to deliver its future potential. The largely optimistic scenario painted in the previous chapter will not materialize if health systems continue to misunderstand the benefits and risks of transparency and misuse it as an ideological symbol rather than a strategic tool. Our research identifies seven different features of successful approaches that health systems should pay attention to. We illustrate each of these features with case studies of where health systems have got this right or wrong.

1 A consistent strategy

While piecemeal progress is better than none at all, to fully unlock the benefits of transparency at scale it helps to take a strategic and planned approach that ensures every initiative is pushing in the same direction according to the same values. The government of Denmark — the highest scoring country in our index — acts as an excellent example of this strategic approach, having successfully created a positive policy and legislative environment, supported by a governance model that focuses on quality of care and quality management. It incorporates several national-level transparency initiatives:⁵¹

- i. *Public reporting on quality of care* — Care quality data, including information on patient experience, waiting times, and hospital ratings, is publically available on the official Danish e-health portal, Sundhed.dk. The data is updated daily. This enables patients, clinicians, policy officials and politicians to freely access all available healthcare information. In a secure part of the portal, patients can access their personal medical record.
- ii. *National surveys on patient experience* — A key aspect of healthcare policy, reflected in Danish legislation, is to measure and report patient experience in order to develop services for patient benefit. Results from the Danish National Survey of Patient Experience are publicly reported at unit, hospital, regional and national level. At the unit level, the data is used for identification of improvement areas, benchmarking, and monitoring of improvement efforts over time.

iii. *National agency for patients' rights and complaints, and reporting of adverse events* —

This operates as a one-stop portal for patients wishing to file a complaint about diagnostics, care, treatment, or rehabilitation in the Danish healthcare system, or report an adverse event. Patient safety legislation mandates that healthcare professionals report all adverse events they become aware of in connection with treatment and care; this process is blame and sanction free. The agency also administers the reporting system for adverse events and ensures that knowledge gained from all incidents is used system-wide to improve care quality.

iv. *National system measurement using patients' unique identifier* —

Denmark has well-developed health registries and a unique patient identifier that enables all registries to include patient-level data, and combine the data across care pathways into sophisticated quality performance measurements. Results are adjusted for case mix to ensure comparability of data at unit, hospital, region, and national levels. Clinicians and managers receive the results on a monthly basis. Structured audits are undertaken including interpretation and evaluation of the results and suggestions for improvements. After auditing the results are released publicly.

2 Take the lead from innovative providers

While examples abound of unintended consequences from centrally-designed, top down transparency initiatives, the track record is much better where policy is led by what the best payers and

1



Key actions for governments:

- Develop a whole-system approach to transparency with a positive policy and legislative environment, underpinned by governance focused on quality of care
- Legislate to measure and report quality of healthcare data including patient experience and PROMS, at unit and provider level
- Ensure communication of care quality data is accessible, understandable and up-to-date
- Publicly set out the individual rights of patients
- Ensure there is public reporting of adverse events
- Establish a clear patient complaints system

1



Key actions for providers:

- Measure and report patient experience data including PROMS
- Establish and publish a policy to protect whistleblowers (staff who report concerns about the quality or safety of healthcare) from any negative repercussions
- Ensure communication of care quality data is accessible, understandable and up-to-date

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The biggest push is from an elite group of providers who really want to get better and better. They're amazing and they push us all on transparency.”

Leah Binder

Chief Executive, The Leapfrog Group, Washington

2



Key actions for governments:

- Encourage recruitment of provider CEOs who will lead on promoting internal and external transparency
- Offer policy incentives and funding for provider initiatives on transparency
- Spread learning nationally from good local provider transparency models and innovations

2



Key actions for providers:

- Include the role and responsibility to lead on promoting internal and external transparency in job descriptions for CEOs and other leadership posts
- Reward CEOs who introduce transparency initiatives that successfully improve care quality

providers in a system are already doing. Regulation and legislation alone do not change hearts and minds, and 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. Even if a system has laggards and those that resist change, it is always safer to look at what is already working well somewhere and expand it, than impose new practices that sound good on paper but create unnecessary burden and confusion on the front line.

Just Ebbeson, CEO of Sykehuset Østfold in Norway is one such innovative provider leader. In 2016 he personally won the Norwegian transparency award (åpenhet), from across all Norwegian organisations not just healthcare. Sykehuset Østfold, a publicly-owned healthcare group, provides specialist healthcare services to around 280,000 people through three hospital sites in Østfold County in south east Norway. Just Ebbeson's leadership approach is a mix of challenge and support, underpinned by the view that transparency must be used to build a learning organization. For him transparency is not an ideology but a strategic tool to drive the behaviour changes that enable continuous improvements in safety and quality. When he 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 helped establish the culture that mistakes and errors are systemic, not individual, failures. Two staff members were under review for malpractice by the national quality inspectorate. Just immediately complained that the hospital, not the staff, should be held to account for these harms. When this did not

work he took the case to the Civil Ombudsman and won; the hospital was blamed for the incidents. This sent a clear message, not just to his workforce but across Norway, that staff would be protected if they reported errors — the important thing was to learn from them.

Other strategic actions that have helped Sykehuset Østfold embed a culture of transparency are:

- when national comparative performance results data showed Sykehuset Østfold scoring less than average on 30-day survival outcomes, Just Ebbesen did not question the figures, but stated it was important the transparent data was made available
- an internal peer-review improvement programme used to highlight variations has led to quality improvements e.g. two sites had 40 percent differences on stroke survival, so they closed the smaller one and saw instant increases in survival levels
- bringing in Transparency International to help reform purchasing and procurement practice to reduce suspicion about conflicts of interest
- all staff have tablet computers linked to patients they are responsible for, so they can get personal alert messages

The experience of Just Ebbeson provides some valuable lessons about 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 (see page 14)
- Data can be used effectively to improve care quality if clinicians are on side and feel a sense of ownership in development of the measures

- To raise care quality, it was judged more important to focus on the hospital's internal improvement targets and benchmarking, than comparative performance with other Norwegian hospitals (the size and situations being so varied)
- Team competence and organizational systems determine outcomes, not individual performance
- Being open and transparent changes the approach of the media; they are less inclined to attack and more prepared to present the steps being taken to avoid the same mistake again

3 Measure what matters to patients

Information on patient experience is a key motivator in attracting more consumers to use performance data in healthcare decisions, and should be a prime concern in deciding what data to measure and publish.⁵² Social media platforms such as TripAdvisor, RateMyTeachers, 311, and Yelp, where people can share and review their service experiences have proved popular as well as effective in improving service standards.

PROMS are a particularly rich source of information, having been linked to care quality improvements, predicting the likelihood of hospital re-admission⁵³, and identifying safety issues. Yet currently process measures are more likely to be reported than patient outcomes. Patient outcome and experience data is routinely published by only 22 percent of the countries completing our transparency scorecard.

In this context, the English NHS introduced the Friends and Family Test (FFT) in 2013, offering patients the opportunity to rate local services they use by providing real-time information on their experience. The primary objective was to make this

feedback publicly available on NHS websites in order that patients and the public could use the information to make choices about hospital care. The FFT asks a single question as to whether the user would recommend the service to friends and family if they needed similar care or treatment, and offers a range of responses. The methodology is based on the Net Promoter Score, developed as a measure of brand loyalty, and widely employed in the private sector to evaluate customer satisfaction.

Although individual hospitals had been using the FFT for some time, early reviews of its national implementation were highly critical, raising several concerns — test scores misunderstood by the public, data being 'gamed'; provider comparison being unreliable because there was no standardized way of administering the FFT, and the results being published without adjustment for patient mix. In response, NHS England introduced several significant modifications to the methodology, implementation, and use of the FFT⁵⁴:

- Clearly set out what was appropriate use of the data: to gather feedback from people using services that can be fed directly to the staff that provide their care; to provide a broad measure of patient experience that can be used alongside other data to inform patient choice; and, to identify areas where improvements can be made so practical action can be taken
- Sophisticated analytical tools used to identify when test data has been 'gamed'
- Publication of the number of responses alongside the FFT scores to indicate levels of participation within an organization

“

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

The friends and family question

We would like you to think about your recent experience of our services. How likely are you to recommend our (ward/practice etc) to friends and family if they need similar treatment?

3



Key actions for governments:

- Publicly report patient ratings on whether they would recommend health services they have used to others
- Use patient experience data alongside other quality data to inform patient choice
- Provide real-time feedback to staff of patient experience data to enable rapid quality improvements where necessary
- Communicate clearly to citizens how patient experience data will be used

3



Key actions for providers:

- Measure whether patients would recommend health services they have used to others
- Communicate clearly to patients how the patient experience data will be used
- Use patient experience data internally to empower staff to make patient-led changes and stimulate local improvements
- Publicly report any changes made in response to findings from patient experience data

- A clear message that it should not be used as a comparative measure of quality of care across the country
- The addition of a free text comments box

The FFT has subsequently been rolled out across most English NHS services. It has proved a powerful tool for service improvement, by increasing the emphasis placed on patient experience, and promoting a better staff culture of responsiveness to patient feedback. The FFT is also popular among patients as a data source about the quality of services. Since 2013, the FFT has collected more than 25 million ratings from patients of their healthcare experience, making it the biggest source of patient opinion in the world. Machine learning techniques employing predictive algorithms are being considered to analyze and make more use of the open text data collected by the FFT, potentially a rich source of patient experience information.⁵⁵

4 Fewer measures, more meaningful data

There is a difficult balance to be struck between the increasing ease with which healthcare data can be collected and published and the realization of many service leaders that transparency is most powerful when focused on a smaller number of indicators that really matter. While transparency is blamed in many countries for creating a huge burden of data collection, for the most part the opposite is true — it draws attention to how much data was being collected anyway, allowing for a more intelligent debate about what should be collected and why.

Such a debate is currently ongoing in the Netherlands. At the start of the decade hospitals there were reporting a large volume of

indicators to clinical registries. The majority of these indicators related to process and structure, very few to clinical outcomes. In the main they had limited relevance to quality improvement, and their collection, costly in terms of time and effort, was resented. Santeon Hospitals, an association of seven teaching hospitals, decided the number of reported metrics needed to be cut and that only indicators of value to patients and the quality of their care should be measured and reported. In 2013 they introduced the 'Care for Outcome' programme, initially for a range of different cancer types and followed later by other diseases. The ambition is to have outcome indicator sets for the 25 most expensive diseases that currently account for 45 percent of Santeon Hospitals' costs, by 2020.

Key features of the program include:

- Agreement on a compact set of 6–7 relevant and measurable indicators for each condition, in consultation with patients and clinicians — based on patient-relevant measures identified from existing literature and informed by value-based healthcare theory
- A scorecard for each condition with the selected indicators and what and how these should be measured
- Results for every indicator publicly reported by every Santeon hospital
- Variation identified and analyzed, and possible improvements discussed by multi-disciplinary teams including doctors, nurses, patients and a health insurer (to initiate discussion on outcome payment linked to quality)
- Shared learning across clinical teams about which quality improvements introduced in response to variation, work and do not work

- Benchmarking the outcomes of local innovations, and then implementing the best across all Santeon hospitals

The program has shown that with a minimal set of published outcome indicators, which reduces the administrative burden for hospitals and clinicians, care quality can improve across clinician teams. For example, as a result of identified poor outcomes from the low volume of prostatectomies conducted at Eindhoven hospital, operations were relocated to one of the other Santeon hospitals, Canisius Wilhelmina. This centre was undertaking a high volume of prostatectomies using robotic facilities. The Eindhoven Hospital clinicians were trained to use the robot and supervised by their Canisius Wilhelmina colleagues. The two clinician groups shared learning and experience about what worked well and what did not. Subsequently, serious complications declined at both hospitals from 8 to zero percent. The rate of positive surgical margins also declined: at the low volume hospital from 51 to 24 percent and notably at the high volume hospital too, from 40 to 22 percent.

5 Provide personalized price transparency

Price transparency can play a significant role in stimulating provider choice among consumers and ensuring they are not 'ripped off'. This is particularly important in countries such as the USA where the private sector dominates health care provision, but also in single-payer health systems where there are some private providers. However, price transparency can be challenging to achieve; some private insurers and providers are reluctant to make prices transparent for fear it will result in loss of market share.

Price transparency tools offering personalized information to patients

have been a recent introduction in the private sector. In line with evidence on what consumers seek from price data to support choice, the information made available reflects actual costs for individual patients. Castlight Health in the US is one such company providing this type of price transparency tool. It offers a personalized benefits platform to employees of client companies (self-insured employers). Employees can compare prices and quality across healthcare services and providers. The data shown in the toolbox is sourced from the insurance claims of health plan administrators, and a range of national organizations providing information on care quality. Employees can add their own satisfaction scores.

Castlight Health has had to manage complex challenges in implementing its price transparency tool. There are several important lessons associated with this experience:

- They started with larger employer clients because they needed large amounts of data and wanted the employers' advocacy power in making the case to health plan administrators

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Just work with the outcome measures and ignore all the indicators that are not relevant... Our doctors are very happy because they see the relevance of the measures and they really can use them to analyze and to study because of the variation, and learn from each others' best practice. This is working very well to improve the quality of care.”

Leonique Niessen

Director, Santeon Hospitals,
Netherlands

4



Key actions for governments:

- Assess the relevance and value of reported healthcare metrics to quality improvement, and whether they can be reduced in number
- Put focus on reporting measures to identify variation where quality improvements might be possible, not on performance management

4



Key actions for providers:

- Involve patients and clinicians in deciding the most important outcome measures
- Work collaboratively with clinical registries and regulators to determine the most meaningful measures to collect and report
- Use a limited number of key outcome measures internally to drive improvement among clinician groups

5



Key actions for governments:

- Legislate for providers to clearly and promptly give patients total prices they should expect to pay for individual medical conditions
- Legislate for insurance companies to provide personalized price transparency tools
- Publicly report total prices health insurers/payers are charged by healthcare providers for individual medical conditions and treatments
- Legislate against contractual arrangements between health insurers and providers that restrict price transparency

5



Key actions for providers:

- Publicly report total prices patients should expect to be charged for individual medical conditions and treatments (and where appropriate, care pathways)
- Challenge contractual arrangements with health insurers that restrict price transparency

- More progressive clients, who really want to drive price consumerism, have most supported employee use of the Castlight Health platform, educating them in its benefits and how to use it
- To support wider adoption, clients need to see cost savings from their employee use of the platform — this is not immediate and takes time
- Using data from across a range of different health plan administrators and care quality information sources is difficult and complex; data quality varies considerably, there are data gaps, and a lack of consistency — making the data transparent has however, resulted in data quality improvements
- Contractual arrangements between some large health insurers and providers restrict Castlight Health in the price data they can show consumers, the provider may even prevent them showing anything; market power being used to limit transparency

Nevertheless, among users the price transparency tool appears successful in reducing costs for some healthcare services. A recent study showed that its use was associated with lower total claims payments for laboratory tests, advanced imaging, and to a lesser extent, clinician office visits. The study analyzed the 2010–2013 medical claims of over half a million patients, insured by 18 employers providing the platform for their employees.⁵⁶

6 A give-and-take approach to safeguarding patient data

Health systems must walk a fine line in their treatment of patient data. On the one hand, there is widespread recognition of the potential benefits of allowing

some sharing and wider access of individual-level health data in terms of service improvement, developing new treatments and predicting who is likely to become ill. On the other hand, the possibilities of bio banking and big data come at a time where there is decreasing expectation that any organization can keep its data fully protected, and suspicion of the motivations of some stakeholders that wish to access it.^{57,58} As the differences between patient access to records (13 percent of countries) and patient privacy legislation (91 percent of countries), personal privacy is usually the more powerful of these two camps. Transparent data security and information governance has become a necessity, but how to manage it in the right way?

Such concerns were manifest in the recent backlash to the proposed implementation of care.data in the UK. This was a program to link data between general practitioners (GPs) and hospitals, launched in 2013 by NHS England. It was explained to the public that data was to be extracted from GP practices with certain personal identifiers available and others removed, for example the patient's NHS number but not their name or address. The data would be made available to a public body, allowed by law to manage sensitive personal data, which would link the data to hospital records; enabling patient outcomes to be tracked across the care pathway. All personal identifiers would be removed as soon as the data was linked and only 'authorized' organizations would have this data released to them. There would be complete transparency concerning how the data was used so the public could see the benefits of data sharing. However, since the program raised concerns about patient privacy, all patients were given the right to 'opt out' of the initiative.

During this process, the media reported two influential news stories. First, that individual-level data could be accessed by authorized pharmaceutical and insurance companies. Second, an NHS organization had released individual-level data to third parties, at least one of which was passing it on to other organizations. The media and public outcry, alongside more than one million people opting out of the scheme, led NHS England to postpone the program.

In response, the government introduced legislation permitting use of patient data for only health and care purposes. They also launched two parallel reviews of data security across the NHS.^{59,60} The review findings showed there to be broad support for personal data being used in running the health and social care system when the benefits of doing so are clearly explained, but people did not fully understand what options they have in relation to use of their information, and found the system difficult to comprehend. After publication of these findings, the care.data program was closed.

A wholly different approach was taken in Australia, which relaunched its My Health Record in 2016, and was able to learn from the care.data story. Promotion of its new tool puts emphasis on personal as well as organizational access — the program includes a secure summary of a person's health information that they can access online, control what goes into it, and who has access to it. Secondary use of My Health Record data for beneficial research, policy and planning purposes is currently open to community consultation.⁶¹

Lessons for future initiatives to share individual level health data include:

- Extensive public dialogue is needed about how health and

care information will be used, but benefits shouldn't just be theoretical or for the system — tangible personal improvements for patients are effective at allaying many concerns.

- Unlocking the benefits of mass individual level health data requires a completely transparent approach to data security and governance
- Patients must be closely involved in the design and continuous evaluation of the system
- While the popularity of social media has led to a cultural shift in terms of willingness to self-publish personal data, there is still widespread concern around sharing personal health data
- A consent/opt-out model should be made available to give people a clear choice about how their data is used for purposes beyond their direct care
- Emphasis in public communications should be on people having access to their own personal health record and control over what goes into this, and who can access it; not on third party access which is difficult to explain and comprehend

7 Promote independent narratives to improve understanding

Independent data assessment and interpretation enables better understanding of the impact and outcomes of healthcare policies, performance, and markets. Having informed, alternative narratives to those provided by executive authorities requires the sharing of data in open and machine readable formats. This is challenging for governments because it involves the loosening of control over how data will be used.

6



Key actions for governments:

- Develop a data privacy and safeguarding strategy for personal patient data, including obligations and responsibilities of all stakeholders
- Involve patients and their families as well as other stakeholders in determining this strategy
- Put legislative safeguards in place for personal patient data sharing with clear consent/opt out arrangements
- In communications, put emphasis on patients having access to their own personal medical record summary, control over its contents, and who can access it

6



Key actions for providers:

- Provide clear communications to patients about the data privacy and safeguarding strategy for personal patient data, including consent/opt out arrangements
- In communications, put emphasis on patients having access to their own personal medical record summary, control over its contents, and who can access it

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That whole debate, that whole concern about privacy wasn't managed.”

Charlotte Alldritt

Director
RSA Public Services and
Communities, and Open Public
Services Network
UK

7



Key actions for governments:

- Publish data in open and machine readable formats and under an open licence, allowing independent data processing and analysis
- Publish methodology and calculations used to report data (including underlying data used in algorithms), to allow other organizations to replicate, verify or challenge interpretations
- Set up agreements with third parties over how information is released

7



Key actions for providers:

- Publish data in open and machine readable formats

Dr Foster was one of the first organizations to provide this function for a national health system. They launched their first Hospital Guide to English hospitals in 2001, providing information and analysis of variation in healthcare outcomes, for patients, the public and professionals. The project was founded on the basis it would serve the public interest. This was underlined by the creation of an independent committee to oversee its work, with rights to curtail activities if found counter to the public interest. A key aspect of making data sharing possible was the agreement Dr Foster struck with government, whereby they would give several days' advance notice of any publication.

Despite strong reactions from both those who agreed and disagreed with the information Dr Foster published, it had significant impact on the debate around care quality improvement in England. In some

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It's creating a lack of transparency if all you have is one account of what data means. With Dr Foster we said can we have the underlying data, and when we re-analysed it in quite a different way, it showed where there was a problem. Simply publishing mortality or survival rates does not create transparency.”

Roger Taylor

Chair
Open Public Services Network,
London

cases hospitals identified as sub-standard were investigated, and the public enquiry into mortality outcomes at Stafford hospital concluded that without Dr Foster, comparative mortality statistics would not be published as quickly or as fully as they are now.⁶²

In the US, the Health Care Incentives Improvement Institute (HCI³) uses advanced analytic techniques to provide valuable independent third party narratives. For example, they published an analysis of New Hampshire's claims data for hysterectomies, showing indicators of low quality care.⁶³ HCI³ were facilitated in doing this analysis by New Hampshire providing their health databases in machine readable format. New Hampshire also allows publication of third party data narratives as long as they are shared with the state prior to publication.

How KPMG can help

Transparency of information can be a powerful positive change agent that can reduce the cost and improve the quality of healthcare. However, there are potential challenges that need to be addressed or overcome to realize the benefits transparency can create.

Transparency of information can be a powerful positive change agent that can reduce the cost and improve the quality of healthcare. However, there are potential challenges that need to be addressed or overcome to realize the benefits transparency can create.

The healthcare industry is impacted by many factors, such as aging populations, budget pressures, increased costs of treatments and rising demands from patients. The availability of timely, accurate and relevant data to provide and evaluate the effectiveness of care provided to patients is essential to ensure consistent, efficiency, effectiveness, and quality of care. However, this information will not have the appropriate impact if unavailable to the appropriate stakeholders.

Although there are no standardized data sets nor processes for accumulating, analyzing, and distributing health information today, there are various initiatives across the globe to create standardized frameworks to enhance the consistency and transparency of health data to improve the efficiency and quality of care.

However, even without national or global standards, to be successful and competitive over the long-term, healthcare systems need to focus on ensuring the transparency of relevant data (e.g. cost, operating results, mortality, medical mistakes, etc.) to each of their stakeholders.

KPMG's Global Healthcare practice is a leader in healthcare, assisting organizations across the healthcare ecosystem to work together in new ways to help transform the business of healthcare. Our vision is to bring the best of global practice to your organization through our network of 4,500 dedicated healthcare professionals across 152 countries. Our teams offer a market leading portfolio of tools and services focused on helping our clients establish appropriate strategies, design and implement new business models, leverage technology, and data and analytics to guide them on their path to providing timely, accurate and relevant data to each of their stakeholders to reduce the cost and improve the quality of care.

To learn more about the lessons and examples in this report, please contact the KPMG Head of Healthcare in your local region.

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Mark has dedicated his professional life to healthcare and has led organizations at local, regional, national and global levels. He was CEO of high-performing University Hospitals in Birmingham and master-minded the largest new hospital build in the NHS. He also ran the NHS from Oxford to the Isle of Wight before joining the NHS Management Board as a Director-General. He developed High Quality Care for All with Lord Darzi and recently published his first book 'In Search of the Perfect Health System', which won Best Health and Social Care Book 2016 at the BMA Book Awards. @markbritnell



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Dee Dee Owens, Partner, KPMG in the US

Dee Dee is a partner in KPMG's Los Angeles office. She has over 15 years of project advisory and audit experience with particular specialization in IT project management and IS governance. Dee Dee focuses on advising her clients on highly technical skills related to large IT enabled technology transformations, project management and quality assurance, third-party reporting, privacy and security, control design, risk management and internal audit advisory, and internal audit and co-sourcing engagements. She specializes in healthcare, state and local government industries and has worked with the largest US health plans and healthcare providers, as well as many large state and local government agencies.



Dan Harradine, Partner, KPMG in Australia

Dan is a Partner in KPMG Australia's Health, Ageing and Human Services (HAHS) Practice. Prior to joining the firm in 2013, Dan held a range of senior government roles in Australia. He has over 17 years' experience working across the public and private sectors, and combines his understanding of government and the public sector, private sector service provision and the broader healthcare environment to support strategy, operational improvement, risk and issues management and large-scale healthcare transformation projects. Dan has led major health system reform and improvement initiatives across a number of Australian jurisdictions, including the implementation of national health reforms in one of Australia's largest States, Queensland. Dan is a member of the HAHS national leadership team, and leads KPMG's health advisory services in Queensland and the Northern Territory.

With special thanks to Francesca Taylor and Jonty Roland who led the research and report drafting.

Interviewees

Charlotte Alldritt, Director, RSA Public Services and Communities, and Open Public Services Network, UK

Dr Sharon Arnold, Director, Agency for Healthcare Research and Quality, Washington

Leah Binder, CEO, The Leapfrog Group, Washington

Dr David Blumenthal, President, Commonwealth Fund, New York

Sheila Burke, Research Fellow, Malcolm Weiner Centre for Social Policy, John F Kennedy School of Government, Harvard University, Massachusetts

Helen Darling, Interim President and CEO National Quality Forum, Washington

Dr Tom Delbanco, Co-Director Open Notes, Professor of General Medicine and Primary Care, Harvard Medical School, Boston

Emma Doyle, Head of Data Policy, NHS England, UK

Andrea Ducas, Programme Officer, Robert Wood Johnson Foundation, New Jersey

Just Ebbesen, CEO Østfold Sykehuset, Norway

Carlos Iglesias, Senior Researcher, Open Data, World Wide Web Foundation, Washington

Tim Kelsey, CEO Australian Digital Health Agency, Australia

Dr Ralf Kuhlen, Managing Medicine, Helios Kliniken GmbH, Germany

Paul Levy, Former President and CEO, Beth Israel Deaconess Medical Center, Boston currently Senior Advisor Lax Sebenius LLC, Massachusetts

Malcolm Lowe Lauri, Executive Director, Cambridge University Health Partners

Jayne Lux, Head Global Business Group Health, Washington

Elizabeth Mitchell, President and Chief Executive Officer, Network for Regional Healthcare Improvement, Maine

Kristin Torres Mowat, SVP Health Plan Development & Data Operations, Castlight Health, California

Leonique Niessen, Director, Santeon Hospitals, Netherlands

Dr Ricardo Rodrigues, European Centre for Social Welfare Policy and Research, Austria

Dr Brian Ruff, CEO and Partner, Professional Provider Organisation Services (PPO Serve), South Africa

Dr Lewis Sandy, Senior Vice President, Clinical Advancement, United Health Group, Minnesota

Roger Taylor, Chair, Open Public Services Network, UK

Dr Juan Tello, Programme Manager, Health Governance, Division of Health Systems and Public Health, WHO Regional Office for Europe, Denmark

Matthias Wismar, Senior Health Policy Analyst, European Observatory on Health Systems and Policies, Belgium

Appendix 1

Global Health Systems Transparency Framework Results

Table 2: Quality of Healthcare scores by country (Indicator Score)

| Dimension 1: Quality of Healthcare | | | | | | |
|------------------------------------|---|---|---|--|---|---|
| | 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 |
| Austria | 1 | 1 | 1 | 1 | 1 | 1 |
| Australia | 1 | 1 | 2 | 3 | 2 | 2 |
| Brazil | 3 | 1 | 1 | 1 | 1 | 3 |
| Canada | 1 | 3 | 3 | 3 | 1 | 1 |
| China | 1 | 1 | 1 | 1 | 1 | 1 |
| Denmark | 3 | 1 | 3 | 3 | 3 | 1 |
| Finland | 3 | 1 | 1 | 1 | 1 | 3 |
| France | 3 | 3 | 1 | 1 | 1 | 1 |
| Germany | 1 | 1 | 1 | 1 | 1 | 1 |
| Greece | 1 | 1 | 1 | 1 | 1 | 1 |
| Iceland | 1 | 1 | 2 | 2 | 2 | 1 |
| India | 1 | 1 | 1 | 1 | 1 | 1 |
| Israel | 1 | 1 | 3 | 3 | 1 | 1 |
| Italy | 3 | 1 | 3 | 1 | 3 | 1 |
| Japan | 1 | 1 | 1 | 1 | 3 | 3 |
| K. of Saudi Arabia | 1 | 1 | 1 | 1 | 1 | 1 |
| Luxembourg | 1 | 1 | 1 | 1 | 1 | 1 |
| Mexico | 1 | 1 | 1 | 1 | 1 | 2 |
| New Zealand | 1 | 1 | 1 | 1 | 2 | 2 |
| Netherlands | 3 | 3 | 1 | 1 | 2 | 2 |
| Norway | 3 | 3 | 1 | 1 | 3 | 3 |
| Poland | 1 | 1 | 1 | 1 | 1 | 1 |
| Portugal | 1 | 3 | 1 | 3 | 1 | 1 |
| Republic of Ireland | 1 | 1 | 1 | 1 | 1 | 1 |
| Republic of Korea | 1 | 1 | 1 | 1 | 1 | 1 |
| Russia | 2 | 1 | 1 | 1 | 1 | 1 |
| Singapore | 1 | 3 | 2 | 2 | 3 | 1 |
| South Africa | 1 | 1 | 1 | 1 | 1 | 1 |
| Spain | 3 | 3 | 3 | 3 | 2 | 2 |
| Sweden | 3 | 1 | 3 | 3 | 3 | 4 |
| Switzerland | 1 | 3 | 1 | 1 | 1 | 1 |
| UK | 3 | 2 | 2 | 2 | 2 | 1 |

Table 3: Patient Experience scores by country (Indicator Score)

| Dimension 2: Patient Experience | | | | |
|--|---|--|--------------------------------------|--|
| | 2.1. Patient reported outcome measures | 2.2. Patient satisfaction | 2.3. Patient approval | 2.4. Patient complaints |
| Austria | 1 | 1 | 1 | 1 |
| Australia | 1 | 3 | 1 | 3 |
| Brazil | 2 | 2 | 1 | 4 |
| Canada | 1 | 2 | 1 | 2 |
| China | 1 | 1 | 1 | 1 |
| Denmark | 1 | 3 | 1 | 3 |
| Finland | 1 | 1 | 1 | 3 |
| France | 1 | 3 | 1 | 3 |
| Germany | 2 | 2 | 2 | 1 |
| Greece | 1 | 1 | 1 | 2 |
| Iceland | 2 | 2 | 1 | 2 |
| India | 1 | 1 | 1 | 1 |
| Israel | 3 | 3 | 3 | 3 |
| Italy | 1 | 1 | 1 | 1 |
| Japan | 1 | 1 | 1 | 1 |
| K. of Saudi Arabia | 1 | 1 | 1 | 1 |
| Luxembourg | 1 | 2 | 1 | 2 |
| Mexico | 1 | 3 | 1 | 1 |
| New Zealand | 1 | 1 | 1 | 4 |
| Netherlands | 2 | 3 | 3 | 3 |
| Norway | 1 | 3 | 1 | 3 |
| Poland | 1 | 1 | 1 | 3 |
| Portugal | 1 | 1 | 1 | 3 |
| Republic of Ireland | 1 | 1 | 1 | 1 |
| Republic of Korea | 1 | 1 | 1 | 1 |
| Russia | 1 | 1 | 1 | 2 |
| Singapore | 1 | 3 | 3 | 3 |
| South Africa | 1 | 1 | 1 | 1 |
| Spain | 1 | 2 | 1 | 2 |
| Sweden | 2 | 3 | 1 | 3 |
| Switzerland | 1 | 3 | 3 | 2 |
| UK | 3 | 2 | 3 | 3 |

Table 4: Finance scores by country (Indicator Score)

| Dimension 3: Finance | | | | |
|----------------------|----------------------------------|--|---|--|
| | 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 |
| Austria | 3 | 2 | 1 | 1 |
| Australia | 3 | 2 | 2 | 3 |
| Brazil | 1 | 3 | 3 | 1 |
| Canada | 3 | 1 | 1 | 1 |
| China | 1 | 2 | 2 | 1 |
| Denmark | 3 | 3 | 3 | 1 |
| Finland | 3 | 3 | 3 | 1 |
| France | 3 | 1 | 3 | 1 |
| Germany | 2 | 3 | 3 | 1 |
| Greece | 1 | 2 | 2 | 1 |
| Iceland | 2 | 3 | 3 | 1 |
| India | 2 | 1 | 1 | 1 |
| Israel | 1 | 3 | 1 | 1 |
| Italy | 1 | 3 | 3 | 1 |
| Japan | 1 | 3 | 3 | 1 |
| K. of Saudi Arabia | 1 | 2 | 2 | 1 |
| Luxembourg | 1 | 3 | 1 | 1 |
| Mexico | 2 | 1 | 1 | 1 |
| New Zealand | 1 | 3 | 3 | 3 |
| Netherlands | 3 | 1 | 2 | 3 |
| Norway | 3 | 3 | 3 | 1 |
| Poland | 1 | 3 | 3 | 1 |
| Portugal | 3 | 3 | 3 | 1 |
| Republic of Ireland | 3 | 3 | 1 | 1 |
| Republic of Korea | 3 | 3 | 3 | 1 |
| Russia | 1 | 3 | 3 | 1 |
| Singapore | 3 | 3 | 3 | 1 |
| South Africa | 1 | 1 | 1 | 1 |
| Spain | 2 | 1 | 1 | 1 |
| Sweden | 3 | 3 | 2 | 1 |
| Switzerland | 1 | 3 | 3 | 1 |
| UK | 3 | 3 | 3 | 1 |

Table 5: Governance scores by country (Indicator Score)

| Dimension 4: Governance | | | | | |
|--------------------------------|--|--------------------------------|---|---|--|
| | 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 |
| Austria | 3 | 3 | 1 | 1 | 1 |
| Australia | 2 | 3 | 4 | 2 | 3 |
| Brazil | 2 | 3 | 4 | 2 | 2 |
| Canada | 3 | 3 | 3 | 2 | 2 |
| China | 1 | 1 | 1 | 1 | 1 |
| Denmark | 3 | 3 | 4 | 2 | 3 |
| Finland | 3 | 3 | 3 | 3 | 2 |
| France | 3 | 3 | 2 | 1 | 3 |
| Germany | 3 | 3 | 1 | 1 | 2 |
| Greece | 2 | 2 | 4 | 2 | 1 |
| Iceland | 3 | 3 | 1 | 1 | 2 |
| India | 2 | 2 | 1 | 1 | 1 |
| Israel | 2 | 3 | 2 | 1 | 1 |
| Italy | 2 | 3 | 2 | 1 | 1 |
| Japan | 3 | 3 | 1 | 1 | 1 |
| K. of Saudi Arabia | 1 | 3 | 2 | 1 | 1 |
| Luxembourg | 3 | 3 | 2 | 1 | 1 |
| Mexico | 2 | 2 | 2 | 1 | 1 |
| New Zealand | 3 | 3 | 4 | 3 | 2 |
| Netherlands | 2 | 3 | 3 | 1 | 2 |
| Norway | 3 | 3 | 1 | 3 | 3 |
| Poland | 2 | 3 | 2 | 1 | 1 |
| Portugal | 3 | 3 | 2 | 1 | 1 |
| Republic of Ireland | 3 | 3 | 1 | 3 | 2 |
| Republic of Korea | 3 | 3 | 1 | 1 | 1 |
| Russia | 2 | 2 | 4 | 1 | 1 |
| Singapore | 3 | 3 | 3 | 1 | 3 |
| South Africa | 2 | 2 | 1 | 1 | 1 |
| Spain | 3 | 3 | 4 | 1 | 1 |
| Sweden | 2 | 3 | 2 | 3 | 1 |
| Switzerland | 3 | 3 | 3 | 1 | 1 |
| UK | 2 | 3 | 2 | 3 | 3 |

Table 6: Personal Health Care Data scores by country (Indicator Score)

| Dimension 5: Personal Healthcare Data | | | | |
|--|---|---|--|--|
| Indicators | 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 |
| Austria | 1 | 1 | 4 | 3 |
| Australia | 2 | 1 | 4 | 2 |
| Brazil | 1 | 1 | 4 | 3 |
| Canada | 1 | 1 | 4 | 1 |
| China | 1 | 1 | 1 | 1 |
| Denmark | 3 | 3 | 4 | 3 |
| Finland | 4 | 1 | 4 | 3 |
| France | 1 | 1 | 4 | 1 |
| Germany | 1 | 1 | 4 | 3 |
| Greece | 1 | 1 | 4 | 1 |
| Iceland | 1 | 1 | 4 | 1 |
| India | 1 | 1 | 2 | 2 |
| Israel | 3 | 1 | 4 | 3 |
| Italy | 1 | 1 | 4 | 3 |
| Japan | 1 | 1 | 3 | 1 |
| K. of Saudi Arabia | 1 | 1 | 3 | 1 |
| Luxembourg | 1 | 1 | 4 | 1 |
| Mexico | 1 | 1 | 2 | 1 |
| New Zealand | 1 | 1 | 4 | 3 |
| Netherlands | 1 | 1 | 4 | 1 |
| Norway | 1 | 2 | 4 | 3 |
| Poland | 1 | 1 | 3 | 3 |
| Portugal | 3 | 3 | 3 | 3 |
| Republic of Ireland | 1 | 1 | 4 | 2 |
| Republic of Korea | 1 | 1 | 4 | 1 |
| Russia | 1 | 1 | 4 | 1 |
| Singapore | 1 | 1 | 3 | 1 |
| South Africa | 1 | 1 | 4 | 2 |
| Spain | 2 | 1 | 4 | 3 |
| Sweden | 2 | 2 | 4 | 3 |
| Switzerland | 1 | 1 | 3 | 3 |
| UK | 2 | 1 | 4 | 1 |

Table 7: Communication of Healthcare Data scores by country (Indicator Score)

| Dimension 6: Communication of Healthcare Data | | | | |
|--|---------------------------------|---------------------------------|---|-----------------------------------|
| Indicators | 6.1. Accessible data | 6.2. Up-to-date data | 6.3. Direct comparison of providers and services | 6.4. Open data formats |
| Austria | 2 | 1 | 1 | 2 |
| Australia | 2 | 2 | 2 | 3 |
| Brazil | 1 | 2 | 1 | 2 |
| Canada | 3 | 1 | 3 | 4 |
| China | 1 | 1 | 1 | 1 |
| Denmark | 1 | 3 | 2 | 1 |
| Finland | 3 | 3 | 3 | 4 |
| France | 3 | 2 | 3 | 1 |
| Germany | 2 | 3 | 2 | 2 |
| Greece | 1 | 1 | 1 | 1 |
| Iceland | 1 | 3 | 1 | 1 |
| India | 1 | 1 | 1 | 1 |
| Israel | 3 | 2 | 1 | 2 |
| Italy | 1 | 2 | 1 | 3 |
| Japan | 1 | 1 | 1 | 1 |
| K. of Saudi Arabia | 1 | 1 | 1 | 1 |
| Luxembourg | 3 | 2 | 1 | 1 |
| Mexico | 2 | 1 | 2 | 2 |
| New Zealand | 3 | 3 | 2 | 3 |
| Netherlands | 1 | 3 | 3 | 3 |
| Norway | 2 | 1 | 2 | 2 |
| Poland | 3 | 3 | 1 | 1 |
| Portugal | 3 | 2 | 2 | 3 |
| Republic of Ireland | 1 | 2 | 1 | 2 |
| Republic of Korea | 3 | 3 | 2 | 3 |
| Russia | 1 | 1 | 1 | 2 |
| Singapore | 2 | 1 | 2 | 1 |
| South Africa | 1 | 1 | 1 | 1 |
| Spain | 1 | 2 | 2 | 1 |
| Sweden | 2 | 2 | 1 | 2 |
| Switzerland | 1 | 1 | 2 | 1 |
| UK | 3 | 2 | 2 | 1 |

Appendix 2

Scoring methodology for the Global Health Systems Transparency Framework

The scoring methodology is simple and straightforward, making the scorecard accessible and easy to complete, as well as suitable for replication over time. There is a three-grade scale of 1 to 3 for each indicator, plus a bonus point on some indicators to reward excellence. Overall, *'no, or only a few/rarely'* earns 1 point; *'most/mostly'* earns 2 points; and, *'all/always'* earns 3 points. Actual numbers need not be counted for each indicator, but as a guide *'most/mostly'* = more than 50 percent.

The majority of indicators are scored in relation to *'hospital providers'*, intended to include public and private hospital providers, but exclude small health clinics, niche or specialist providers just catering to a small population.

A few indicators are scored in relation to *'healthcare providers'*, intended to encompass any organizations providing healthcare services (including hospital, community, ambulatory, and mental health providers). Again, small specialist or niche providers can be excluded e.g. if all major providers follow a particular regulation but small e.g. private elective providers are exempt, tick *'all'*.

We acknowledge that in some countries different health systems exist with different levels of transparency (e.g. Ontario vs. Quebec in Canada). In these instances judgement should be used to discern the best score to give for overall performance across the country.

Additional advice provided

Where the private sector in a country is very *'niche'* (maybe, less than 10 percent of activity), scoring should focus on the public sector. Where private healthcare is more common than that, and it can be argued an important part of the healthcare delivery system, then it should be included.

To score *'3'* on indicators 1.1–1.6, data should be published by individual hospital provider (not aggregated at provincial, regional or Trust level). We have selected this scoring approach because only data published this way will enable patient choice between individual providers on the basis of quality. It also allows for identification of hospital provider outliers where performance is relatively poor and improvement is likely to support better quality healthcare.

Appendix 3

KPMG Global Health Systems Transparency Framework

| 1. Quality of Healthcare | | | | |
|---|--|--|----------------------------------|--|
| Indicator | Description | Score card | | |
| | | 1 | 2 | 3 |
| 1.1. Mortality/survival rates for individual medical conditions and treatments <i>(total possible score = 4 points)</i> | Is there public reporting of risk-adjusted in-hospital mortality or survival rates for a range of common acute medical conditions or treatments (e.g. stroke, cancer, transplants, hip replacement)? | No, or for only a few hospital providers | Yes, for most hospital providers | Yes, for all hospital providers Bonus point: Also for all individual clinical teams or physicians providing in-hospital treatment |
| 1.2. All-cause mortality/survival rates <i>(total possible score = 3 points)</i> | Is there public reporting of risk-adjusted all-cause mortality or survival rates, either in hospital or within 30-days of discharge? | No, or for only a few hospital providers | Yes, for most hospital providers | Yes, for all hospital providers |
| 1.3. Hospital re-admission rates <i>(total possible score = 3 points)</i> | Is there public reporting of unplanned hospital re-admission rates for a range of acute medical conditions or treatments (e.g. stroke, cancer, transplants, hip replacement)? | No, or for only a few hospital providers | Yes, for most hospital providers | Yes, for all hospital providers |
| 1.4. Waiting times for emergency care <i>(total possible score = 3 points)</i> | Is there public reporting of average waiting times for emergency care (e.g. between arrival and treatment at an Emergency Room) | No, or for only a few hospital providers | Yes, for most hospital providers | Yes, for all hospital providers |
| 1.5. 'Adverse event' reporting <i>(total possible score = 4 points)</i> | Is there public reporting of 'adverse events' (an occurrence during treatment that results in patient harm or death)? | No, or by only a few hospital providers | Yes, by most hospital providers | Yes, by all hospital providers Bonus point: For each incident, the improvement process followed as a result is also published |
| 1.6. Hospital-acquired infections <i>(total possible score = 4 points)</i> | Is there public reporting of three or more hospital-acquired infections (e.g. catheter-associated urinary tract infections; clostridium difficile (c.diff) or methicillin-resistant staphylococcus aureus [MRSA])? | No, or for only a few hospital providers | Yes, for most hospital providers | Yes, for all hospital providers Bonus point: This data is also published at ward or clinical team level |

| 2. Patient Experience | | | | |
|---|--|--|------------------------------------|---|
| Indicator | Description | Score card | | |
| | | 1 | 2 | 3 |
| 2.1. Patient reported outcome measures <i>(total possible score = 3 points)</i> | Is there public reporting of patient reported outcome measures (PROMS) for a range of inpatient and outpatient medical treatments (e.g. hip replacements, transplants). | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |
| 2.2. Patient satisfaction <i>(total possible score = 3 points)</i> | Are patient satisfaction measures published, based on surveys of patients' health care experience (e.g. how well staff communicated; whether pain was well controlled; how clean and quiet the care environment was)? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |
| 2.3. Patient approval <i>(total possible score = 3 points)</i> | Is there public reporting of ratings from patients on whether they would recommend the health service they have used to others e.g. friends and family? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |
| 2.4. Patient complaints <i>(total possible score = 4 points)</i> | Is there a clear complaints system with details published of who patients can make a complaint to about problems with their healthcare, how a complaint will be handled, and a named person/organisation who can help them make the complaint? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |
| | | | | Bonus point: Information on learning and action taken in response to complaints is also published |

| 3. Finance | | | | |
|---|--|--|---|--|
| Indicator | Description | Score card | | |
| | | 1 | 2 | 3 |
| 3.1. Financial performance <i>(total possible score = 3 points)</i> | Do healthcare providers publish an annual report with independently audited financial accounts? | No, or only a few healthcare providers | Yes, most healthcare providers | Yes, all healthcare providers |
| 3.2. Prices patients are charged <i>(total possible score = 3 points)</i> | Is there public reporting of total prices patients should expect to be charged for individual medical conditions and treatments? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |
| 3.3. Prices health insurers/payers are charged <i>(total possible score = 3 points)</i> | Is there public reporting of total prices health insurers/payers are charged by healthcare providers for individual medical conditions and treatments? | No, or for only a few healthcare providers or payers | Yes, by most healthcare providers or payers | Yes, by all healthcare providers or payers |
| 3.4. Disclosure of payments, gifts and hospitality to healthcare staff <i>(total possible score = 3 points)</i> | Is there public reporting of all payments, gifts and hospitality to healthcare staff? | No, or by only a few healthcare providers | Yes, by most healthcare providers | Yes, by all healthcare providers |

4. Governance

| Indicator | Description | Score card | | |
|---|--|--|--|---|
| | | 1 | 2 | 3 |
| 4.1. Freedom of Information legislation <i>(total possible score = 3 points)</i> | Does the country have a right-to-information law that applies to organizations providing, paying for or regulating healthcare services (this entitles citizens to ask questions and receive information about local or national services)? | No, or applies only to <i>national</i> organizations providing, paying for or regulating healthcare services | Yes, but applies only to all <i>public</i> organizations providing, paying for or regulating healthcare services | Yes, this applies to all <i>public and private</i> organizations providing, paying for or regulating healthcare services |
| 4.2. Patient rights <i>(total possible score = 3 points)</i> | Are the rights of patients publicly set out, stating what individual patients are entitled to and can expect from providers in the healthcare system including information, privacy, and consent to treatment? | No, or applies only to a few healthcare providers | Yes, applies to most healthcare providers | Yes, applies to all healthcare providers |
| 4.3. Procurement processes and decision-making <i>(total possible score = 4 points)</i> | Is there publicly available information about health service procurement processes including offers to tender, terms and conditions, and the decision-making process? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers Bonus point: Procurement prices and contracts are also routinely published |
| 4.4. Public decision-making <i>(total possible score = 3 points)</i> | Are the minutes from board and committee meetings, including decisions made, published online? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |
| 4.5. Patient/Public involvement <i>(total possible score = 3 points)</i> | Are patient/public representatives involved in the strategic decision making of healthcare providers (e.g. patient/public representatives on the boards or senior committees of healthcare providers, or invited to specific sub-committees to share their views on planning and performance)? | No, or for only a few healthcare providers | Yes, for most healthcare providers | Yes, for all healthcare providers |

5. Personal Healthcare Data

| Indicator | Description | Score card | | |
|--|---|---------------------------------|-------------------------|---|
| | | 1 | 2 | 3 |
| 5.1. Electronic patient records system <i>(total possible score = 4 points)</i> | Is there free and easy access for patients to their up-to-date patient record online, including clinical test results? | No, or only a few patients | Yes, most patients | Yes, all patients |
| | | | | Bonus point: If patients can share access to their electronic patient record with any other organizations of their choice |
| 5.2. Shared clinical documentation <i>(total possible score = 3 points)</i> | Is there a patient portal where patients can contribute to or edit their personal health data such as medical notes? | No, or for only a few patients | Yes, for most patients | Yes, for all patients |
| 5.3. Patient data privacy and safeguarding policy <i>(total possible score = 4 points)</i> | Is there a published patient data privacy and safeguarding policy setting out the obligations and responsibilities of all stakeholders for the protection of patient data, including how breaches of confidentiality or security will be managed? | No, or for only a few providers | Yes, for most providers | Yes, for all providers |
| | | | | Bonus point: If this is a legal obligation (as opposed to a policy or guideline) |
| 5.4. Information on use of patient data <i>(total possible score = 3 points)</i> | Are patients informed about third-party uses of their individual health data through an up-to-date confidential report or website on how it has been used by other organizations? | No, or only a few patients | Yes, most patients | Yes, all patients |

| 6. Communication of Healthcare Data | | | | |
|---|--|---|---------------------------|--|
| Indicator | Description | Score card | | |
| | | 1 | 2 | 3 |
| 6.1. Accessible data <i>(total possible score = 3 points)</i> | Where metrics for 'Quality of Healthcare' and 'Patient Experience' indicators are reported Is the data publicly available through a dedicated website(s) that is: easily located through a standard internet search, free to access, and easy to navigate with a site search function? | No, or only a limited amount of healthcare data | Yes, most healthcare data | Yes, all healthcare data |
| 6.2. Up-to-date data <i>(total possible score = 4 points)</i> | Is the data reported kept regularly up-to-date (e.g. data reported annually is no more than a year old; data reported monthly is no more than a month old)? | No, or rarely | Yes, mostly | Yes, always Bonus point: If the data is always reported in real-time |
| 6.3. Direct comparison of providers and services <i>(total possible score = 3 points)</i> | Can the data be customized to a specific set of circumstances (by geography and service) to enable patients and doctors to make an informed choice between different providers through direct comparison? | No, or rarely | Yes, for most of the data | Yes, for all of the data |
| 6.4. Open data formats <i>(total possible score = 4 points)</i> | Is the data published in open and machine readable formats e.g. .csv, .xlsx, .xml? | No, or rarely | Yes, mostly | Yes, always Bonus point: If data also published under an open licence allowing independent data processing and analysis |

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- ⁷ The reason for selecting hospitals as the unit of measurement in many indicators is that this is an easily transferrable concept across many different health systems, whereas understandings of community or primary care can vary dramatically.
- ⁸ Where publicly available is defined as published without access restrictions or the need to lodge requests (such as FOI) with agencies
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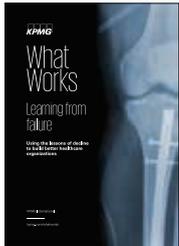
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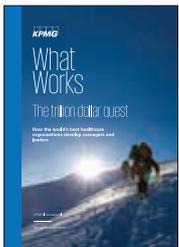
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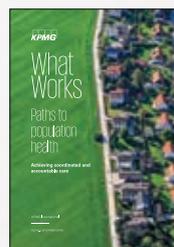
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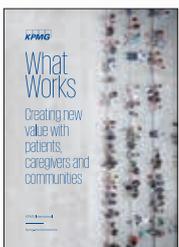
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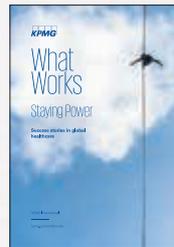
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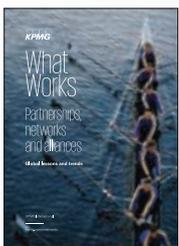
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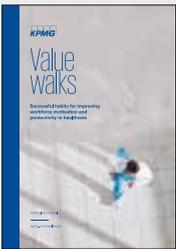


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