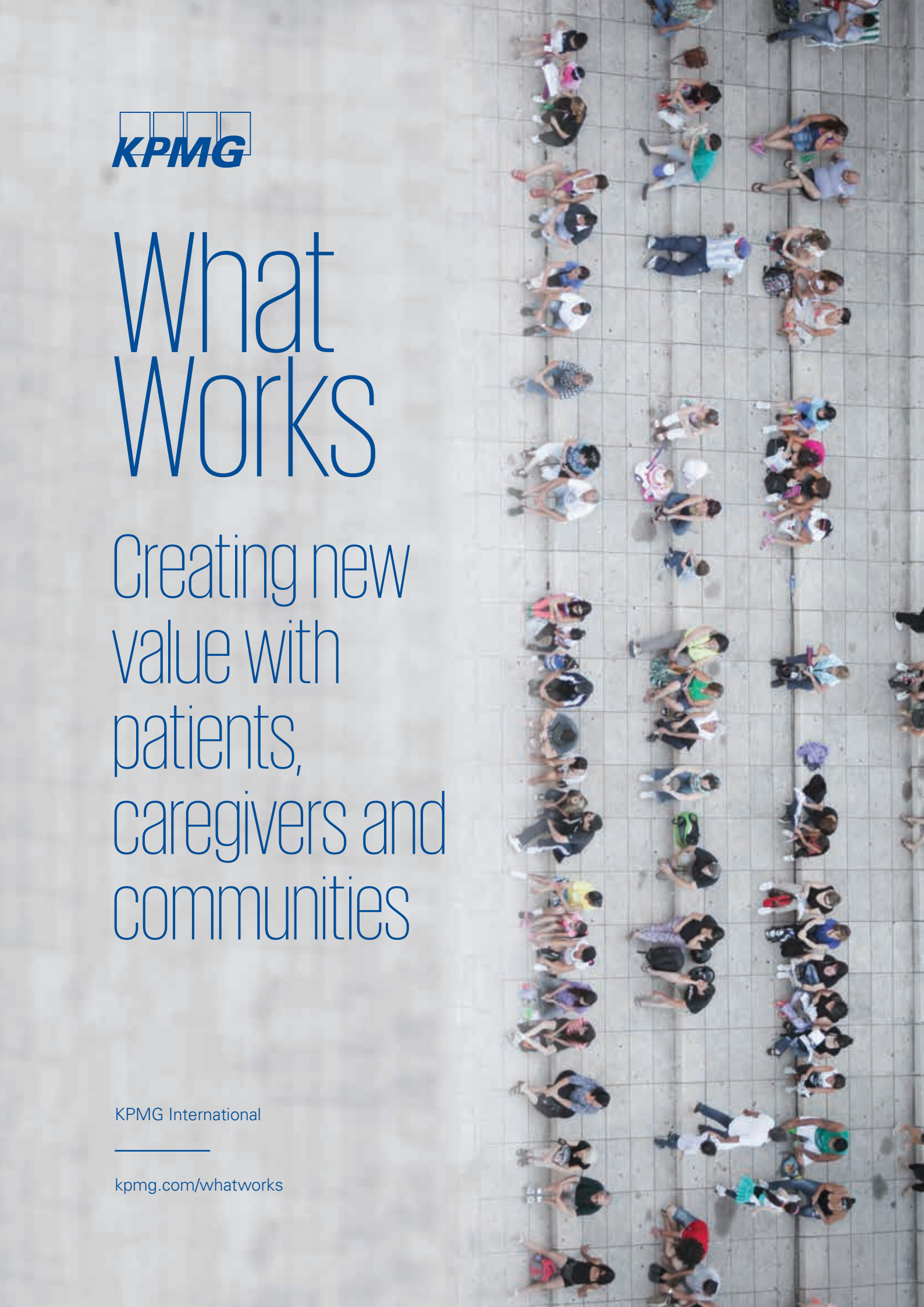

What Works

Creating new value with patients, caregivers and communities

KPMG International

kpmg.com/whatworks

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Mark Britnell has a pioneering and global vision of the future of healthcare in both the developed and developing worlds. Mark has a unique level of knowledge and insight and management experience at every level of the system. As Chairman of the Global Health Practice, he has global responsibility for KPMG's more than 3,000 practitioners in 45 countries.

Drawing on his 20 years of health service experience, Mark advocates that personalization, patient " co-production" and eHealth will be central to the future. Mark believes in the power of putting ideas into action — adhering to a "more brown mud, less blue sky" approach to strategy and transformation. Mark joined KPMG in the UK in 2009 as a partner following a career within the UK's NHS, grounding his approach to empowering, motivating and inspiring healthcare innovation. He has advised Governments and business leaders and has worked in public and private sector organizations.

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As Senior Vice President and Chief Medical Officer of a large Blue Cross/Blue Shield (BCBS) plan in New York, she led a cardiac surgical care evaluation program that challenged the physicians to think differently about the care process, driving major improvements in the quality of these services for more than two million people.

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Hilary Thomas, Partner and Clinical Lead — Healthcare and Life Sciences Advisory and Global Center of Excellence, is a leader in care system redesign working across regional health ecosystems to redesign inter-organizational patient pathways and shift the provision of care to more appropriate settings.

Hilary also leads on clinical engagement and clinical service redesign across a range of engagements including whole system transformation programs across several health economies to deliver reconfiguration to ensure sustainable aligned services. As the most senior clinician in the UK practice, she leads on telemedicine, e-health and m-health and has overseen nearly 40 quality governance reviews in the NHS.

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Introduction

Over the last two decades many industries have changed their value proposition by developing their customers' capacity to create value. Healthcare is only just understanding how this might transform its own value proposition.

Healthcare has missed out mainly because it has seen patient involvement in their own care as a moral rather than an economic issue.

Globally some parts of healthcare are beginning to make the changes that will involve patients, caregivers and their communities more fully in their own healthcare. Here, using our experience across the world, we outline the answers that you need to develop to fully realize the value inherent in better patient involvement and communities to improve care.

Payers, providers and other health and life sciences organizations that want to transform, need to rethink the way they engage with patients. This is the case in the conduct of research, in the offer made to patients and in the design of services.

In many cases, the alignment between what patients want and what is provided is poor. The goals of patients are not given enough recognition in treatment choices and the benefits of shared decision making and patient and caregiver involvement are not being realized. As a result, over-diagnosis and over-treatment are now a frequent hazard and a serious cost in many parts of the world. Communities can also offer much more and can add value to healthcare. In research, the knowledge that patients have is not being used and payers are only just starting to realize the opportunities of harnessing patient power to put pressure on costs, to improve lifestyles and drive quality.

Over the last two decades, many other industries and services have used their customers to strongly improve their value proposition. In retail banking, communications and retail, customers now routinely deliver value that had previously been delivered by paid staff.

Given the economics of the industry, healthcare leaders recognize that it is time for the healthcare industry to change in their value proposition.

Here we demonstrate that a further change in the value proposition for healthcare will occur when the industry recognizes the efficacy of extending its work from healthcare to health and well-being. Delaying the onset of long-term conditions into later old age will need very different interventions from traditional healthcare and will improve the value proposition for population health considerably.

We report on original research carried out by KPMG to find out what patient organizations in different countries believed patients needed and how that compared with the health service they received. We use that research[1] throughout this document.

Where we argue that if organizations want to involve patients in their own healthcare there are a number of tangible actions required. We will suggest answers to the following questions:

1. Is there work to create a new culture centered on the patient?
2. Is there patient and caregiver input into service design?
3. Are systems in place to support shared decision-making?
4. Does the model support self-care and help the professionals adapt to this?
5. Are the assets and capabilities of patients and caregivers recognized and mobilized?
6. Can patients get and use the information they need?
7. Are patients involved in teaching and research?
8. Are the assets that communities can contribute to healthcare being used effectively?
9. Are there measurement systems to support this?

We look at each of these and the steps required to move forward.

At the end we suggest a set of immediate and practical actions that flow from the answers to these questions.

We also outline a maturity index (see page 20) that demonstrates how to self-assess your organization on each of these questions.

Delaying the onset of long term conditions into later old age will need very different interventions from traditional healthcare and will improve the **value proposition** for population health considerably.

1. KPMG International carried out 27 interviews in USA, UK, Canada, Brazil, Hong Kong and the Netherlands with patient groups covering a range of different conditions

The use of the narrative story of a typical patient to give this somewhat **abstract idea** some concrete meaning is an effective way to align different parts of the organization.

1. Is there work to create a new culture centered on the patient?

Creating a patient-centered culture needs a recognition that patients, their caregivers and communities are different from each other. Therefore action in this area requires a sophisticated understanding of the different attitudes, desires and characteristics of different patient segments.

That is why most customer-facing industries recognize the importance of segmenting their population. Healthcare leaders recognize that having recognized the differences between segments of patients, it is important that everyone from the leadership to clinical teams have goals that are aligned with creating high quality outcomes and experiences for those segments of patients. Healthcare organizations will understand that that there will need to be continuous work to improve this.

In many organizations, goals relate to the work of individuals or departments, not to the overall value streams that relate to the patient's journey the use of the narrative story of a typical patient to give this somewhat abstract idea some concrete meaning is an effective way to align different parts of the organization.

In Ryhow Hospital an individual narrative around a patient Esther was used to mobilize change throughout the hospital. This has become so much a part of the whole story of the hospital that parts of the patient pathway are now named after her.

The importance of segmentation

Segmentation is a strategy that acknowledges and understands that "one size does not fit all." Consumers vary widely in their preferences, what is meaningful, what choices they will make and how they want to access services. Segmentation is a tool that the industry uses to categorize their consumer population into groups that define the groups' experiences, needs or even demographic… By segmenting consumers by preference or demographic information, companies are able to drive sales by personalizing products to meet the specialized needs of each consumer segment…

The complexity of healthcare systems is significant, unlike other sectors such as retail banking, travel, grocery or retail. However, segmentation tools focused on understanding value associated with experiences in health systems may offer an important strategy for health systems to achieve value.[2]

Jönköping County Council and Ryhov Hospital, Sweden

Jönköping's use of virtual patient Esther symbolizes the importance of care redesign focused on the needs and preferences of patients. In its initial development, the idea of Esther was used to focus discussions of system changes on patient needs. 'Esther coaches' help to bring the patient perspective into daily practice. These coaches are primarily nursing assistants charged with helping their colleagues to stay focused on improving care to serve the need of patients.

2. *Snowden Schnarr and Alessi. "It's All About me": The Personalization of Health Systems Ivey Business School February 2014, page 6*

2. Is there patient and caregiver input into service design?

In other customer-facing industries such as communications, successful firms spend considerable resources to ensure that their product is designed around their customers experience. As the healthcare system shifts from volume to value, healthcare organizations will need to ensure that patients and caregivers help to design services to deliver better value. Involving patients and their caregivers in the design of services, in identifying priorities for change or for research and in understanding how they perceive different components of services, will not just improve their experience but helps to remove non-value adding steps and improve efficiency. Using interviews, observations, diaries, stories and ethnography to supplement the standard methods to collect patient insight is important: having a culture willing to listen even more so.

This is not simply a set of soft skills.If patients and their caregivers are allowed to input across the health and social care system, they will be in a position to create extra value for organizations in that system.

Patient groups across the world not only want to represent patients in designing healthcare for political reasons, but also have strong economic arguments for so doing. In some countries this is already happening and resources are being saved. In others they are on the verge of making this happen.

Hong Kong

"We input about US$10 billion a year into healthcare services in Hong Kong. But we still don't make best use of these resources. If the government decision-makers and the patients got together to think about how we can make best use of these resources it would be productive," King Pin Tsang, HKAPO, Hong Kong.

The Netherlands

"The Dutch Government…is currently working on a number of 'pacts' between different groups (insurers, patient groups, providers etc) as part of a major cost control exercise. They are designed to look at the benefits packages that are available to people and explore not just what's in them but how they can be used more effectively — e.g. to prioritize preventative measures ahead of treatments. These 'pacts' are demonstrating the cost benefit of involving patients in benefits package design," Petra Shout, Dutch Patients and Consumers' Association, The Netherlands.

UK

"If we really tried to get into the shoes of patients and…tried to really understand them, understand about (their) experience and what they really want and need…you would get a lot of added benefits. Safety would fall out. Money would fall out, because you stop doing non value-added things because people tell you what they actually want and don't want. So there are all sorts of added benefits," Dr Fran Woodard, Director for England, Macmillan Cancer Support.

There is also growing concern that there is an increasing amount of **'over-diagnosis'** in which patients are over investigated and screened and may be harmed as a result.

3. Are systems in place to support shared decision-making?

According to Professor Al Mulley of the Dartmouth Institute, there is a widespread failure by clinicians to properly understand the preferences of their patients and how the proposed interventions will affect their lives.[3] He calls this "preference misdiagnosis" which wastes resources and can harm patients. There is also growing concern that there is an increasing amount of "over-diagnosis" in which patients are over-investigated and screened and may be harmed as a result. An informed patient who is aware of the risks may be less likely to agree to these procedures and as a result is more likely to get an outcome they will be content with.

There are a number of advantages to this approach. Patients often make different decisions about their care when they are fully informed about their treatment options — often more conservative and lower cost than those chosen by their physician.

Developing the skills to involve patients in decision-making, training staff or developing health coaches, providing decision aids and documenting and tracking preferences are key competencies.

Our research on patient organizations showed that medical professionals would like to involve their patients but feel they did not have the time.

Not having the time to work with patients to reduce the demand for healthcare will almost certainly cost resources.

A key area that is highlighted as one of the characteristics of low cost high quality organizations is that they spend time and care to help patients plan ahead — including advanced planning for the end of life. This is an area where a large amount of high cost but often futile care is delivered because the appropriate conversations did not take place at the right time.

The way in which healthcare organizations talk about whether patients take their medicines or not (the language of compliance or adherence) shows how little thought has been given to the patient as a consumer of services and medicines. No consumer-orientated industry would expect its consumers to 'comply' with the industry's wishes — they would have an approach that recognized the power of the consumer over their own choices.

This example of the Royal College of General Practitioners in England (previous page) shows how a doctor's organization can frame this argument and practice.

UK

"What we really need is good multi-professional assessment of people, or more developed social prescriber models of care (e.g. adopting a wait and see approach to knee surgery to see if other social interventions might work just as well to achieve the desired end goal, at less cost and less pain to the individual)," Jeremy Taylor, National Voices, UK.

3. Mulley A, Trimble C, Elwyn G. Patients' Preferences Matter: stop the silent misdiagnosis. King's Fund. 2012

4. Does the model support self-care and help the professionals adapt to this?

From our research patient organizations recognized the cultural change that is necessary here. Having the ability to support patients in caring for themselves is increasingly going to be an organizational competency needed by all providers, payers and many life sciences companies. This includes a range of tools and techniques, for example:

- Encouraging healthy behaviors — both through a focus on high risk behavior and longer term lifestyle change through direct support such as coaching, incentives and mechanisms such as text message reminders.
- Supporting self-diagnosis and management through phone and web services, the use of retail pharmacy, community workers, etc.
- Helping patients make decisions and navigate the system through apps and decision aids, and care navigators.

For most patients, for most of their illness, the person who spends the most time and effort caring for them are the patients themselves, their family or their caregiver. Patients are caring for themselves and their condition for about 5,800 hours, yet will spend less than 10 hours with a healthcare professional. Often the considerable resource contained in that time and effort does not provide as much return as it might because professionals have not recognized how they can invest their skills to improve its capacity.

Other industries — most of retail and most retail banking — have recognized how some investment will make customers into co-producers of value, rather than simply a set of costs. In social care services, users have been systemic

US

"Doctors are still on a pedestal here in the US and many people, however brilliant and highly educated, will tend to defer to them. We need to help providers understand why it matters to listen to the patient. For example, some medics are more approachable and open-minded about alternative therapies etc., but not all. It's still not generally accepted in the medical profession. But some patients feel these things help them, so doctors need to listen," Laura Windgate, Crohns and Colitis, US.

co-producers of value for some time. This has transformed the way these industries work but healthcare has some way to go in understanding how much patients put into this co-production and how better investment from healthcare professionals in supporting patient self-care can improve the outcomes from this work. Even when some recognition is given to how much 'work' patients carry out in their own self-care, very few healthcare organizations would for example invest any real training resource on patients when compared to their paid staff.

UK

"Most GPs say they'd love to do shared decision-making but they don't have the time. We need to think more carefully about how we can liberate people to do the right thing, to see that integrated care is better care, that it can help professionals and delivery organizations as well as patients," Jeremy Taylor, National Voices, UK

Royal College of General Practitioners, UK

The Royal College of General Practitioners in England has recognized that if patients are to take their drugs they need to be more involved in discussions with their GP about the drugs themselves. In 2009 they recommended new guidelines for involving patients in the prescribing of drugs.

"Medicine taking is a complex human behavior, and patients evaluate medicines and the risks and benefits of medicines according to the resources available to them. Unwanted and unused medicines reflect inadequate communication between professionals and patients about health problems and how they might be treated and about patients' ongoing assessment and experience of treatment. This guidance will be of help to all professionals by providing guidance on how to involve patients in the decision to prescribe medicine and on how to support patients in their subsequent use of medicines …"

It is thought that between a half and a third of all medicines prescribed for long term conditions are not taken as recommended.[4]

4. *Medicines adherence involving patients in decisions about prescribed medicines and supporting adherence published by the RCGP January 2009 England*

5. Are the assets and capabilities of patients and caregivers recognized and mobilized?

The growth in multi-morbidity and chronic conditions requires a major shift in outlook from a focus on achieving biomedical indicators to one where the goals of the patient define success. Successful healthcare needs active rather than passive patients. In creating more active patients it will be necessary to not only work with medical issues, but to include functional, social and psychological issues (see patient activation page 9).

To develop active patients, healthcare organizations need to understand the assets that the patient's family and caregiver possess that can be mobilized to better manage their healthcare.

The development of new services that invest in the development of skills and capabilities of patients, their caregivers and communities to support self-management is a challenge for traditional providers and payers. It may involve:

- New skills and job roles such as coaching and motivational interviewing
- New ways of engaging to identify patients' assets and develop the different options available to them
- Social prescribing — sign-posting patients to non-healthcare services, for example to reduce social isolation
- Incentives and new interventions to change behaviors including using social proof and insights from behavioral economics
- Remote monitoring using technology backed up with case managers
- Intensive intervention to support the vulnerable or chaotic patients
- Building and supporting peer networks so patients can provide mutual support.

Goal-oriented care

One important issue for providers relates to what we believe to be the primary goal of the care delivered by a healthcare system. Patients can be caught in a clash between goal-oriented and problem-oriented perspectives. De Maeseneer describes the case of an older patient with osteoarthritis, hypertension, type 2 diabetes and chronic airways disease who articulated what mattered most: "On Tuesdays and Thursdays I want to visit my friends… and play cards with them. On Saturday I want to go to the supermarket with my daughter. Foremost, I just want peace. I don't want to continually change the therapy anymore, especially not having to do this and do that." A doctor focusing on solving clinical problems by titrating multiple medications to make the patient normotensive, reduce HbA1C to levels defined by national guidelines, and achieve lung function tests that are normal for age and body habitus will miss the point. The patient's goals are primarily cognitive clarity and a certain amount of mobility.

Goal-oriented care is care that "encourages each individual to achieve the highest level of health as defined by that individual".

The majority of the tools help patients achieve their goals rather than solve physiologic problems. Hence providers who choose to mobilize these tools in pursuit of a strategy of patient engagement and promotion of self-care will have to first clarify their purpose for doing so and recognize the implied change in their goals as providers.

The emphasis in the discussion of this has tended to be about the technical capabilities to support self-care. The change in culture and in the practice of medicine that is implied by this is at least as significant. Simply adding technology to existing delivery models will not succeed.

Both self-care and shared decision-making make demands on patients. In particular they require a greater degree of health literacy and to become 'activated patients'.

Goal-orientated healthcare provides the healthcare organization with the capacity to work with patients to achieve their own life goals. This builds on the purely

Patient activation

Many studies have shown that patients who are activated — i.e. have the skills, ability and willingness to manage their own health and healthcare have better health outcomes at lower costs compared with less activated patients. Judith Hibbard of the University of Oregon has developed a "patient activation measure" — a validated survey that scores the degree to which patients see themselves as a manager of their health and care.

Patients with the lowest activation scores, that is, people with the least skills and confidence to actively engage in their own healthcare, cost 8 to 21 percent more than patients with the highest activation levels, even after adjusting for health status and other factors. And patient activation scores were shown to be significant predictors of healthcare costs.[5]

Predicted per capita costs of patients by patient activation level[6]

2010 patient activation level	Predicted per capita billed costs (US$)	Ratio of predicted costs relative to level 4 Patient Activation Measure (PAM)
Level 1 (lowest)	966**	1.21**
Level 2	840	1.05
Level 3	783	0.97
Level 4 (highest)	799	1.00

5. Health Policy Brief: Patient Engagement, Health Affairs, February 14, 2013. http://www.healthaffairs.org/healthpolicybriefs/
6. Hibbard J H, Greene J, Overton V (2013) 'Patients with lower activation associated with higher costs; delivery systems should know their patients' "scores". Health Affairs, 32, no (2013): 216–22. Notes: Authors' analysis of Fairview Health Services billing and electronic health record data, Jan-Jun 2011. Inpatient and pharmacy costs were not included

biomedical view of goals and will often gain impetus from the patient's own greater motivation to achieve something that they want and can recognize.

The point of the patient activation measures is that patients can learn to become more active in working with their own healthcare. Healthcare organizations could work to ensure that every interaction that they have with their patients would include increasing the capacity to be active in their own healthcare. Our argument explores the different ways that this can be achieved, from involving patients in service design, to providing them with better relevant information and investing in the assets in the families and communities around them. The above statistics demonstrate the value of investing in patients' capacity to better self manage.

Often the clinical explanation is fine **but it rarely helps to alleviate the fear** and anxiety that comes with a diagnosis.

6. Can patients get and use the information they need?

Patients need information that is often very different from the information that doctors think they need. Our research into patient groups across the world consistently showed that what patients felt was crucial information was ignored by clinicians. In fact, for some patient groups the biggest gap between what patients needed and what they got was information.

If patients do not receive what they need to know, they will not be able to be as active in their own care as we need them to be.

Information for patients that they can use improves clinical effectiveness, safety and patient experience. It needs to adhere to quality standards, be user-tested, and to be useful it needs to be co-designed and co-produced. Information must also be designed to meet different levels of health literacy.

Canada

"The biggest gap is information provision — pretty much at every stage of the pathway, but particularly at point of diagnosis. Specialists rarely spend more than 15 minutes with [patients] and that's never enough time to properly discuss implications, options etc.

There's a big psychological gap between the information that the clinician thinks their patient needs and what they themselves say they need. Often the clinical explanation is fine but it rarely helps to alleviate the fear and anxiety that comes with a diagnosis.

There's also a practical gap in information provision…no one at diagnosis goes into practical info about the financial situation — both what it might mean from a work perspective and insurance/funding standpoint," Cathy Ammendolea and Niya Chari, Canadian Breast Cancer Network.

It is now a basic requirement for organizations to have ways of communicating online and through mobile phone technology. Using clinically accredited apps to support chronic conditions and individual episodes of care, such as maternity care, is the next step. To make full use of this, it will be important to improve health literacy and activation — there is some evidence about how to do this. See below.

Promising interventions for improving health literacy:[7]

Intervention	Benefits
Personalized patient information (paper and electronic) reinforced by professional or lay support	— Improvements in patients' knowledge and understanding of their condition — Increased sense of empowerment — Greater ability to cope with the effects of illness — Improved patient satisfaction — May lead to improvements in health behavior — May contribute to better health outcomes
Preoperative and predischarge information	— May lead to shorter length of stay and fewer follow-up visits
Telephone counseling and helpliness	— May lead to shorter length of stay and fewer follow-up visits — Less social isolation — Improved self-efficacy and satisfaction — Reduced mortality and fewer hospitalizations for some patient groups — May improve diagnostic accuracy — May contribute to improved health status and better quality of life
Motivational interviewing	— Better adherence to treatment recommendations — Improved health behaviors — Reduced risk factors — Improved health outcomes

Emerging idea: Using serious games

There is growing interest in using various types of games to engage patients differently. Computer games are forming an increasingly vibrant part of popular leisure culture. Games can encourage goal setting, support adherence to treatment, develop cognitive or motor skills, and provide education or support exercises, diet management and other forms of self-care. The use of applications on mobile phones or tablets greatly helps this. Some models introduce some element of collaboration and rivalry between groups of patients — for example in rehabilitation or lifestyle change. Using games provides a different route to changing cognitive habits and behaviors than more conventional and passive interventions.

7. See http://informedmedicaldecisions.org/wp-content/uploads/2012/04/Patient_Engagement_What_Works_.3.pdf

7. Are patients involved in teaching and research?

Using patients to educate clinical professionals has potential to change the culture of the organization and decisions about treatment. They also are a potentially important contributor to clinical research.

The Seventh Framework Programme (FP7), the European Union's current research-funding instrument, stresses the importance of patient and public involvement.[8] And the Patient-Centered Outcomes Research Institute in Washington DC has allocated US$68 million to a research network predicated on the principle that "the interests of patients will be central to decision-making".[9] The opportunities for engaging patients in research are also being explored in a number of different ways by less conventional actors such as Shift MS which brings young people with multiple sclerosis together and 'PatientsLikeMe'[10] — a patient network where people connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, life sciences companies, purchasers and providers to develop more effective products, services and care.

In the process, **they generate data about the real-world nature of disease** that help researchers, life sciences companies, purchasers and providers to develop more effective products, services and care.

Survivors Teaching Students — USA

The goal of Survivors Teaching Students is for future physicians, nurse practitioners, nurses and physician assistants to be able to diagnose the disease when it is in its earlier, most treatable stages. This program brings ovarian cancer survivors into the classroom, where they present their unique stories along with facts about the disease. Students are able to interact with and learn from actual patients.

Survivors Teaching Students is offered in 82 medical schools, seven nurse practitioner programs, 13 physician assistant programs, 50 nursing schools and six other allied health professional schools across 29 states in the USA. In 2012, the program educated 9,446 students, a 52 percent increase over the previous year.[11]

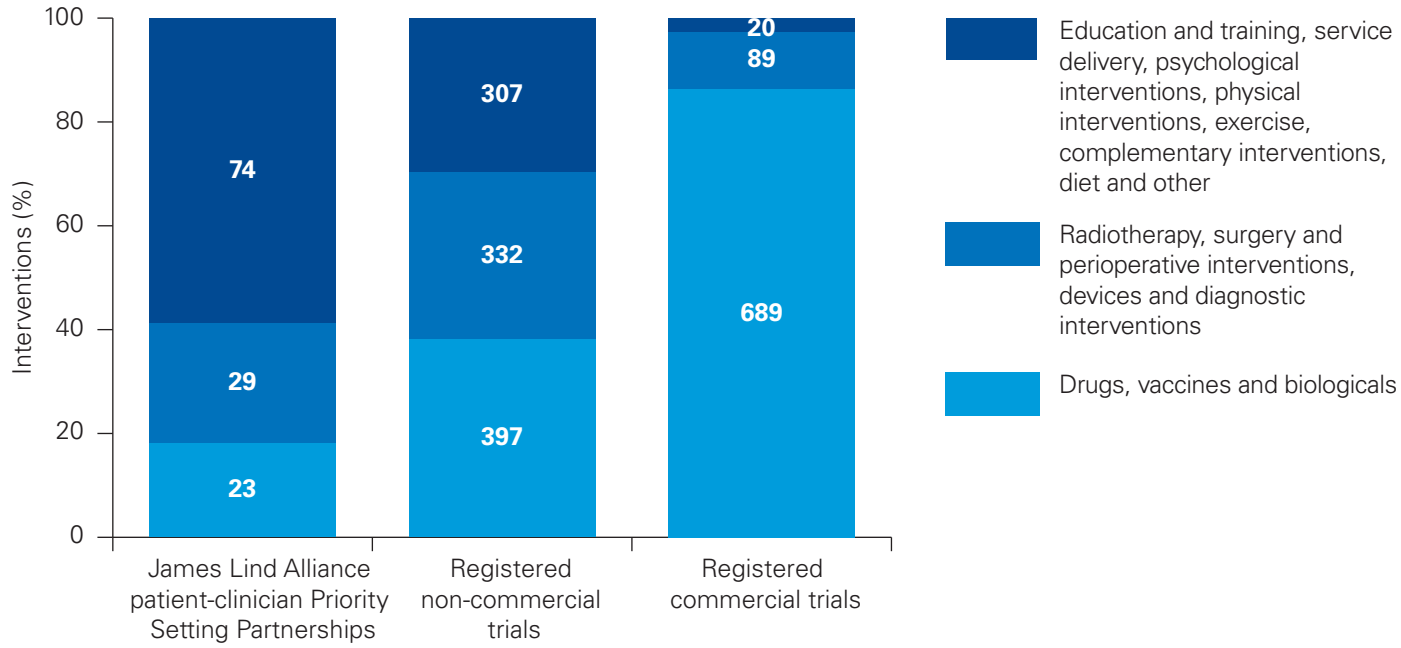
8. European Commission. *FP7 Cooperation Work Programme: Health 2013 (EC, 2012)*
9. http://www.nature.com/news/health-care-bring-on-the-evidence-1.13697
10. www.patientslikeme.com
11. Interventions mentioned in research priorities identified by James Lind Alliance patient — clinician Priority Setting Partnerships and in registered trials, 2003–12

We know that research does not currently mirror the priorities that patients think are important and that there is limited evidence that patient views are really making an impact.

But in a world in which patient value will increasingly become part of the decision-making process for spending and investment this will need to be dealt with.

The example of Survivors Teaching Students (page 11) demonstrates a simple way in which patients can influence the education of medical professionals.

Patient priorities vs. research activity[12]



Source: How to increase value and reduce waste when research priorities are set Iain Chalmers DSc, Prof Michael B Bracken PhD, Prof Ben Djulbegovic PhD, Silvio Garattini MD, Jonathan Grant PhD, A Metin Gülmezoglu PhD, David W Howells PhD, Prof John P A Ioannidis MD, Sandy Oliver PhD

12. The Lancet, Volume 383, Issue 9912, Pages 156–165, 11 January 2014 Published Online: 08 January 2014

8. Are the assets that communities can contribute to healthcare being used effectively?

The chronic care model developed by Ed Wagner and colleagues is the definitive description of how to deliver high quality care for people with chronic disease. The component that has tended to be most under-developed has been that related to the engagement of the resources of the wider community. Healthcare tends to ask the question, "what's the problem?" community development has a different mindset — it asks, "what are the assets we can use and build on?" The resources of the community are free or at least very cheap and no one is exploited or made to do something they would rather not. Cultural sensitivity is important in many communities particularly in ensuring treatments are accepted and followed, and community engagement strategies greatly improve this. Building sustainable communities to support patients have huge additional spin offs and can also support strategies for recruiting and training local workers, economic development and other social programs.

The Nuka healthcare system in Alaska provides a clear example of this approach. It recognizes that disease and its treatment are social, psychological and cultural components as well as the traditional biomedical issues.

The patient is treated as a customer and as an owner of their healthcare and their healthcare system and it infuses the healthcare system with the specific culture of this region.

Any healthcare system can start down this path by first searching for the assets that exist in the community they work with and secondly by developing their healthcare services to work with and realize the value of those assets.

This can only take place if the healthcare organization and its professional staff cede some power to those communities and the individuals in them.

Our research into patients groups backs this up with a recognition that there is a clear gap in health systems' understanding of community assets.

The Netherlands

"The gap here is mainly around support structures and systems to help people live independently with their condition. A lot of patients tell [us] they want to manage their conditions at home and by and large home care is pretty good in clinical terms.

What's lacking is a coordinated network of community facilities in the neighborhood that patients can access when they want to, together with the support to help them navigate this system," Petra Shout, Dutch Patients and Consumers' Association, The Netherlands

Southcentral Foundation Nuka System of Care, Anchorage, Alaska, USA

Southcentral Foundation's (SCF) Nuka System of Care is an alternative approach to healthcare delivery. It is a relationship-based system comprised of organizational strategies and processes; medical, behavioral, dental and traditional practices; and supporting infrastructure that strives to address the needs of the whole person. It is a system of care driven by direct feedback from Alaska Native people receiving services in the system — referred to as customer-owners. And it is built on a foundation of long-term relationships, transfer of control to the customer-owner, integration of the mind, body and spirit, and a commitment to measurement and quality. This is SCF's Nuka System of Care.

SCF is an Alaska Native nonprofit healthcare organization, established in 1982 by Cook Inlet Region, Inc., one of 12 Alaska Native regional corporations created by the Alaska Native Claims Settlement Act of 1971. SCF is an organization owned and managed by Alaska Native people.

The Indian Self-Determination and Education Assistance Act of 1975 put Tribes at the center of the choice of whether or not to assume ownership and management of programs previously operated and administered by the Bureau of Indian Affairs and Indian Health Service. Alaska Native people chose to take on this responsibility and became "customer-owners" of their own healthcare delivery system through compact agreements with the US Government. Through these alliances, and the paradigm shift from 'professionals know best' to 'customers know best' and the commitment to a relationship-based delivery system, SCF has redefined what it means to achieve wellness through health and related services.

The Nuka System of Care includes:

Customer-ownership

— The customer-owner is in the 'driver's seat' and voices needs and preferences through multiple feedback channels.
— Ownership is a shared responsibility.

Relationships

— Operational Principles spell out R-E-L-A-T-I-O-N-S-H-I-P-S.
— By connecting with the same people at every visit, strong relationships can be formed with the teams that support you on your wellness journey. These teams get to know your values, goals, priorities and strengths.

Whole-person wellness

— Promotes wellness beyond the absence of illness and prevention of disease.
— Addresses the physical, mental, emotional and spiritual dimensions of whole-person wellness.

Reflecting the values of the community they serve, customer-owners have the option of allowing their families to accompany them during visits with their primary care provider team in talking rooms, which are like living rooms with comfortable seating and no exam tables. The team includes a primary care provider, an RN case manager (who assists with care coordination and referrals, medication refills and test results), a certified medical assistant (who checks blood pressure, weight and height) and a case management support person who helps coordinate future appointments and navigate through the primary care center. The integrated care team's members take pride in their ability to work together.

"Our community owns their healthcare system," says SCF President/CEO Katherine Gottlieb. "Customer-owners become engaged by making personal behavioral choices on their journey of wellness."

"SCF providers stop seeing themselves as the heroes who are going to save the patient, who do things to and for people," Katherine Gottlieb explains. "Instead," she says, "they partner with customer-owners on their journey to wellness."

Many other health professionals are integrated into the primary care setting that make up a customer-owner's wider integrated care team. For example, if customer-owners need to see a specialist, such as a nutritionist, behavioral health consultant or dietitian, these individuals rotate throughout the clinic teams to offer additional support to the customer-owner. Other medical specialists, such as cardiologists, are available on referral the same day at the Alaska Native Medical Center. Clinical options also include a Traditional Healing Clinic, which is available on a referral basis and encouraged as a complement to western medical treatment.

Strong and effective relationships are necessary across the organization to accomplish goals, objectives and work plans. Building a culture of trust, based on relationships, encourages shared decision-making and supports innovation and creativity. A three-day mandatory Core Concepts training, led by the president/CEO, helps employees understand how their relational styles impact others, how their experiences affect how they approach and build relationships, and how to articulate and respond to each story in everyday work and life.

While SCF's employee and customer-owner satisfaction are well above national averages, the Nuka System of Care has reached a number of highly impressive outcomes since its inception in 1982:

— A 50 percent reduction in emergency room and urgent care visits
— Cultural respect is 99.2 percent
— Three quarters of measures for illness prevention, screening, and chronic disease measurement are in the top 25 percent.

9. Are there measurement systems to support this?

All of the practices described here need to be underpinned by the measurement and monitoring of patient experience. This has greater impact and creates greater value if it can be collected and utilized in real time.

This information needs to be collected on a number of dimensions including:

— Perceived humanity of care

— Pain and dignity

— Patient-reported outcomes

— Complaints, comments and complements.

These need to be measured at different times (humanity and dignity in real time or shortly after, outcomes at a later point). Satisfaction is now seen as an inadequate way of capturing information and prone to a number of biases, the patient's actual experience provides richer and more actionable information.

A range of qualitative and quantitative methods are required ranging from individual patient stories and interviews through to real-time data capture through electronic devices.

It is important that these are not treated as a set of add ons to the 'real data system'. Patient experience and involvement needs to be embedded in the quality framework of organizations and woven through Board strategy, contractual arrangements, staff training, individual performance targets, etc. Executive and clinical leadership that can create a culture where patient experience is continually improved and where concerns and complaints are welcomed and learned from, needs to be in place.

The Board should be aware of the complaints and key quality concerns within the organization and the actions being undertaken to address these. A key point is that data created by clinical teams needs to be fed back rapidly with support in identifying trends and solutions.

For payers and life science organizations the lessons are the same — what has been focused on may not be what is of most importance to patients, what has been measured may not be what really matters, and rich data about how patients actually experience care is vital.

The example below of iWantGreatCare, demonstrates patients by using a technologically based feedback system can provide speedy feedback to healthcare organizations and their staff.

iWant Great Care, UK

iWantGreatCare bills itself the 'TripAdvisor of health', collecting information from patients about the quality of care they receive from their doctor or other healthcare professional. Since its launch in 2008, it has grown to be the largest online repository of patient experience feedback in the UK. More than 80,000 reviews a month are being added to the 800,000 already stored on the website.

A scoring system, using objective criteria derived from the patient satisfaction evidence base, allows iWantGreatCare users to rate and compare care experiences in areas such as 'trust' and 'listening ability', as well as to indicate how highly they recommend their doctor.

The number and nature of providers covered by iWantGreatCare has grown steadily since launch. In 2010 the service was extended to cover dental patients and the following year national pharmacy chain Lloyds announced that it would enable its customers to give real-time feedback on their in-branch experience. Other partnerships have included a customer experience pilot with international renal care provider Diaverum and a unique service for the Terence Higgins Trust to help HIV patients identify sympathetic healthcare professionals.

Following the UK Government's announcement of the NHS Friends and Family Test in April 2013, iWantGreatCare offered to provide the infrastructure for NHS Trusts to capture the patient experience data prescribed by the new legislation. The system will also be used to allow patients to rate the care they receive from their GP when the Friends and Family Test is rolled out to cover primary care in December 2014.

Users **rate and compare care** experiences in areas such as **'trust'** and **'listening ability'**, as well as to indicate how highly they recommend their doctor.

Preparing to change

It's time to use patient power and involve families and communities and work with them to improve value, safety and quality and potentially to reduce costs.

What needs to be done

At the core of our argument is changing the way in which healthcare works with patients in order to ensure they are more active in their own healthcare. We believe that the economic argument for this is clear. Here we outline four next steps to take in realizing the extra value that patients can contribute.

1. Since we want to increase patient activation make every interaction with patients count

Healthcare spends most of its resource in developing its interaction with patients. If we want to increase patients' activity we need to review all of these interactions to ensure that each of them increases the capacity of patients to be more active in their own healthcare. At the end of a consultation does the patient always leave with greater skills to self-manage than they had at the beginning of that consultation? Does every letter, email or phone call leave them with greater capacity to know what they have to do next? Are you checking up that these attempts at improving patient capacity actually work with the patients and are not just empty instructions from medical professionals that have no impact on behavior?

2. If you want to allow patients to add value to their own healthcare make sure the healthcare is designed with them in mind

Successful industries that encourage consumers to create value design their products with those that consume them. Healthcare needs to fully involve patients, their caregivers and communities in all healthcare redesign. Our research shows that few patient organizations think that happens at the moment.

3. Develop your workforce to search for and realize assets in patients, their caregivers and their communities

The practice of most medical professionals is based upon seeing patients as a set of deficits. For medical professionals to recognize the possibilities of self-management and to see patients, their families and their communities as a set of assets is a departure from the deficit model. One of the best ways of developing the workforce in this direction is to use individual or groups of expert patients to carry out that development. The workforce will also need new technical skills to work with, a number of tools such as decision aids, telehealth and other self-care technology and with real-time information about patient experience. All of the components need to be built into recruitment, induction, appraisal and reward strategies.

4. Payment systems will need to be reorganized to recognize the value-creating possibilities of patients, their caregivers and the communities

Compared to most medical interventions, the investment in better patient self-management is not expensive. But it still calls for some resource. If the payment system is organized in such a way as to see self-management as just another form of episodic cost, then it is difficult to see where the return on this investment comes from. If however, the payment system is organized to cover an entire patient pathway or population, the return on the investment in better patient self-management is potentially significant.

Last word

It's time to use patient power and involve families and communities and work with them to improve value, safety and quality and potentially to reduce costs. New skills, technology and approaches are required to do this. Being able to do this will be a differentiating factor for payers, providers and life science companies. But, apart from that, it is the right thing to do.

KPMG maturity matrix

Throughout this argument we have been providing answers to the nine different questions that are at the core of greater involvement of patients in the creation of value in their own healthcare. While the actions that follow from each answer is important, it is important to bring these answers together into an overarching plan for greater patient involvement in their own healthcare. The following a maturity matrix for a healthcare organization describes how the answers to the nine key questions can grow together into an overall and coherent plan for transformation. Answering each question is not necessary. But answering them together will ensure that your organization has the opportunity to create much more patient-created value. If you have any questions about the matrix, or your self-assessment, please contact any one of our professionals listed on the back cover.

	5	4	3	2	1	0
Work to create a new culture centered on the patient culture	Absolute focus on patient involvement and experience at all leadership level	Some focus on patient involvement and experience	Key principles for patient engagement enacted and communicated	Strong narrative about what good patient experience looks like	Recognition that there needs to be a narrative about patient experience and outcomes and some work carried out on it	No focus on patient involvement and outcomes
Patient input into service design	Sophisticated methods for understanding patient experience and preferences are in regular use	Patients involved in most service design	Patients beginning to be involved in some service design	Some pilots of patient involvement in service design	Recognition that patients should be involved in service design and some contact with patients to achieve this	Patients not involved in design at all
Systems to support shared decision-making	Patients are offered coaching, decision aids and other support to be involved in all decision-making. No decision about me without me	Routine advanced planning including escalation and end of life	Shared decision-making is standard	Some pilots for shared decision making	Recognition that shared decision-making with patients produces better decisions and creates more value and the beginnings of a plan to implement that	No shared decision-making taking place
Models support self-care and help the professionals adapt	All medical staff are part of models of care that support self-care	Models of care are developed that are based upon a high level of measured patient activation with increasing patient social independence	Models of care are developed that need peer support networks and tools for self-management routinely available for patients	Some pilots that develop new models of healthcare that need retraining of medical staff to foreground improving patient care	Recognition that existing models of care may limit the ability of patients to self-manage and an exploration of the possibilities of different models	No recognition of the way in which existing models of healthcare limit the ability of patients to self-manage
Are patients assets mobilized?	Patients recognized as value creators by the organization and the Board, and their assets are invested in such	The Board systematically audits patients assets as potentially adding value to patients healthcare	Medical professionals lead the investment in patients assets across several care pathways	Some pilots which audit the patient assets that are available to add value to healthcare	Recognition that patients have assets that can contribute to healthcare value creation and that investment in those assets can gather returns	Patients are seen as lacking in assets to contribute to their own healthcare

	5	4	3	2	1	0
Can patients get and use information?	All healthcare information available to the organization about individual patients is also available to those patients in a form that patients can understand	Several patient pathways are redeveloped based upon sharing patients' information with them	Medical staff recognize the need to provide patients with information about their condition and work with patients to find ways to translate that information	Some pilots where all the information about their condition is shared with patients in a form they can understand	Recognition that patients can use information about their healthcare to add value to healthcare and an analysis of different ways of doing this	No recognition that information should be available to patients
Are patients involved in teaching and research?	Patients involved in teaching all clinicians	Patient defined priorities and goal-based outcomes embedded in research processes	Training for patients to be involved in teaching and research	Pilots involving patients in some research and teaching	Recognition that patients should be involved in research and teaching and some plans to implement	No recognition of any patient role in teaching or research
Are the assets that communities can contribute mobilized?	Understanding across the organization with all medical pathways of how communities have resources that can add value to healthcare	The Board systematically audits community assets as potentially adding value to patient healthcare	Medical staff realize that communities can provide assets that can add value to healthcare and work with patients to find ways to realize that value	Some pilots which audit the community assets that are available to add value to healthcare	Recognition that the communities that patients live in could have assets to add to healthcare value and an analysis of different ways in which these assets could be realized	No idea that communities have assets that can add value to healthcare
Are there measurements systems to support this?	Patient experience and outcome data embedded in all performance management and governance	Patient experience and outcome data embedded in performance management of medical staff	Real-time collection data used at front line for improvement	Systematic collection of data reported to boards	Recognition that the collection of data on patient experience and outcomes will provide a basis for understanding progress in delivering healthcare outcomes and an analysis of different ways of doing this	No data on patient experience or outcome data collected

Contributors

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Georgina Black is an Advisory Partner, National Sector Lead for Health and member of KPMG's Global Healthcare Steering Committee. She has 20 years of experience advising organizations in the areas of executive governance and leadership, strategic planning, performance improvement and complex organizational change.

Georgina's area of focus is working closely with boards, executive teams and diverse stakeholder groups to develop strategies to improve performance. She is an accomplished strategist and facilitator with a reputation for getting results. Clients appreciate her attention to the realities of implementation, political acuity and the discipline she brings from 10 years focused on the private sector.

Throughout her career, Georgina has led several transformational projects (mergers and acquisitions, restructuring, governance and program reviews, shared services and organizational design) in the public sector to improve effectiveness and efficiencies within complex stakeholder environments. Through her work with provincial, local governments, not-for-profits and healthcare organizations, Georgina brings a systems perspective to identifying and addressing cross function, organization and sector opportunities.

Liz Forsyth, Partner, KPMG in Australia

Liz Forsyth is a Partner in the KPMG Health and Human Services Practice, and has 10 years experience as an advisor to Government.

Liz Forsyth has 13 years experience in the public sector, 6 years of which were in a range of senior positions within both State and Commonwealth Departments. Liz has had extensive experience in consultation, disability, child and family services, community services, homelessness, performance management, evaluation and review. She has strong skills in policy, organizational and program review, service reform, strategic corporate planning and communications.

Prior to KPMG, Liz held senior and executive positions in the Commonwealth Department of Community Services and Health, the NSW Department of Transport and the NSW Department of Community Services. Liz has extensive experience in working with senior bureaucrats, politicians and a range of stakeholder groups including non-government service providers and consumers.

Nancy Valley, Partner, Advisory, Government Line of Business Leader

Nancy Valley is a Partner and KPMG's National Government Line of Business Leader. She is responsible for strategic direction and management for the firm's Federal Government and State and Local Government practices, as well as KPMG's Higher Education, Research and Other Nonprofit practice. Nancy has over two decades' experience in State and Local government. In addition to her current leadership of KPMG's Government Sector, she continues to serve as the overall lead partner for the State of New York. She is a member of AGA's Albany Chapter. As an industry subject matter professional, Nancy is actively involved at various national conferences. Nancy has played a major role in the creation and development of the KPMG Government Institute for which she serves as Chair of the Advisory Committee.

KPMG healthcare

We have drawn this argument from the international work that KPMG healthcare is engaged with in 40 different countries. In most healthcare systems there is a recognition that healthcare would be more effective if patients played a much greater role in their healthcare. Our international work in this area concentrates on three different themes.

1. As integrated and coordinated care is developed, it is vital to ensure that this new model of care is developed around the patient and not as in the past around organizations. Coordinated care will mainly add value to healthcare by utilizing the patient's own capacity to add-value to their healthcare.
2. We are working in several countries on the development of outcome-based commissioning and healthcare. The outcomes developed in this process have to be developed by patients to have any meaning that goes beyond a purely medical model.
3. In many parts of the world patients have a developed relationship with mobile communications that healthcare systems have failed to exploit. Given that in their non-healthcare behavior patients are used to utilizing their own technology, healthcare systems have to find ways to exploit this to add more value.

What Works

A series of thought leading reports from KPMG Global Healthcare

The need for change in healthcare is well understood. There is also an increasing consensus about what needs to be done to address these challenges:

— a focus on quality, safety, controlling costs and improving population health

— a move from the emphasis being on the volume of treatment towards ensuring high-value care

— activist payers working with patients and providers to reshape the system

— the development of new models of delivery including increasing convergence between healthcare payers, providers and the life sciences industry

— reaching out to patients and communities in new ways.

The question is how to make these changes happen. This is one in a series of reports that looks at the practical steps organizations need to take to turn their ambitions for major change into reality. We argue that there are a number of changes of both mind-set and capability that are required across a number of areas. These include:

— creating systems to drive clinical and operational excellence

— creating new partnerships and networks

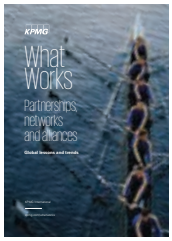
— developing new models for coordinated care and population health

— growing the ability to contract for value

— working with patients, caregivers and communities.

This report looks at the last of these and makes a strong case that there is a lot of work for healthcare organizations to be truly aligned to the interests of patients.

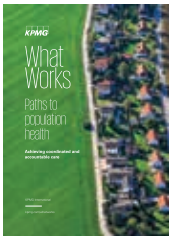
For more information, or to reserve your copy of future **What Works** reports, please contact your national partner, see back cover, or email: healthcare@kpmg.com or visit **kpmg.com/whatworks** for the latest report.



What Works: Partnerships, networks and alliances

As hospitals and healthcare organizations around the world struggle to address growing volumes of patients, reduce per capita costs, and improve the patient experience of quality and satisfaction, consolidation in healthcare has accelerated significantly. This report highlights six practical tips that together help organizations realize long-term success.

kpmg.com/partnerships



What Works: Paths to population health — Achieving coordinated and accountable care

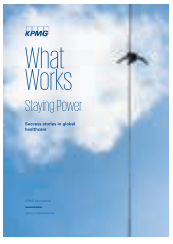
Health needs are changing fast, but systems are simply not keeping up. It is clear that organizations are struggling to convert theory into practice. This report describes the practical steps that organizations need to go through to reshape themselves and their services.

kpmg.com/pophealth

What Works: As strong as the weakest link — Creating value-based healthcare organizations

Organizing care to deliver value for patients requires change in five main areas. Start with a clear vision and understanding of what value means and focus energy on cohesive action across all the areas. This report focuses on the different lessons drawn from work done with clients and discussions with providers from all over the world.

kpmg.com/valuebasedcare



What Works: Staying Power — Success stories in global healthcare

KPMG gathered together 65 healthcare leaders from 30 countries across 6 continents to discuss effective strategies for successful transformation. These discussions were centered around 7 key themes ranging from population health and accountable care to clinical and operational excellence. This report summarizes the insights shared between organizations, cultures and countries.

kpmg.com/stayingpower

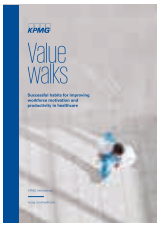
KPMG healthcare

Thought Leadership

We invite you to visit KPMG Global Healthcare (kpmg.com/healthcare) to access our global thought leadership. Here you can gain valuable insights on a range of topics that we hope add to the global dialogue on healthcare. Should you prefer a printed copy of the publication, please email us at healthcare@kpmg.com.

The more I know, the less I sleep — Global perspectives on clinical governance
This report explores best practices to provide oversight and assurance, govern, as well as measure and monitor quality and safety.

kpmg.com/clinicalgovernance



Value walks — Successful habits for improving workforce motivation and productivity
This report examines the potential for supportive public policy measures and identifies five key attributes that have proven to help health systems successfully manage the workforce challenge.

kpmg.com/valuewalks

Something to Teach, Something to Learn — Global perspectives on healthcare
The root causes of sub-optimal healthcare and outlines three core principles that — taken together — can deliver a clear path to driving value for patients, providers and payers.

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An uncertain age — Reimagining long term care in the 21st century
This report brings together expert commentary and global insights from 46 long-term care thought leaders on the current state and future impacts of eldercare.

kpmg.com/anuncertainage

Necessity: The mother of innovation — Low-cost, high-quality healthcare
This report explores how emerging health economies are challenging traditional models of care and succeeding with innovative, low-cost alternatives.

kpmg.com/healthcareinnovation

Contracting value: Shifting paradigms
This report explores how payers, providers and policy-makers are coping with the combined challenge of rising costs, demand and patient expectations.

kpmg.com/value

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