

# PERSON- CENTRED CARE



- CO-CREATING A HEALTHCARE  
SECTOR FOR THE FUTURE





## ACKNOWLEDGEMENTS

DNV GL and Monday Morning / Sustainia would like to thank the following for their contribution to the guide.

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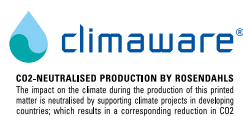
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Print: Rosendahls.

March 2014.



# FOREWORD

→ **The world has changed immeasurably over the last fifty years.** A visitor from the 1960s would be entirely bemused. An incredible pace of technological change has altered almost every aspect of life, particularly for people living in the richer countries of the world.

The healthcare that can be provided today is quite remarkable. When I was a medical student, the 'treatment' for a heart attack was bed-rest. Today, it is a minimally invasive procedure that directly re-opens the blocked coronary artery. Thanks to this and other advances, cardiovascular disease today causes just half the premature loss of life that it did just twenty years ago. My country founded its National Health Service in 1948, at a time when only half of the population lived beyond the age of 65 years. Today, people aged 65 have a life expectancy of another 20 years.

To deliver this, today's healthcare systems are vastly more complex than those of fifty years ago. Medical care has become increasingly sub-specialised. Many more healthcare professionals are involved in each patient's care. Amidst the complexity, the patient risks getting lost. The different parts of the system struggle to coordinate with one another. The personal touch is too often absent. Services are delivered in the way that fits with the system, rather than with what patients actually need and want.

The challenge now is to re-orientate today's healthcare around the patient. This Guide inspires and challenges

us to take up the quest for high quality, person-centred healthcare.

Today, healthcare is too often unsafe and fragmented. Healthcare systems around the world struggle whilst financial pressures worsen. Current systems are simply no longer sustainable nor do they provide the best quality of care for patients.

Yet around the world, in low-, middle- and high-income countries alike, services, users, health professionals, managers and policy makers are proving that change is possible. As the examples in this Guide show, adopting person-centred care approaches is a core part of transforming mindsets, cultures, structures and processes in the pursuit of quality care for all. Person-centred care is both a rallying cry to change and a first step to building better healthcare.

This Guide synthesises what is known about person-centred care and healthcare quality with inspiring interviews with leaders in the field as well as best practice examples from around the world. I think its content will intrigue and challenge you, whether you are a service user, a clinician, a manager or a policy maker.

I am sure that the pace of change in healthcare will continue. This Guide gives us considerable hope that, if the changes firmly place the patient at the centre, we can create healthcare that is highly effective, safe and the best possible experience for patients – something the care-givers can be proud of.



**PROFESSOR SIR LIAM DONALDSON**

Chair of Health Policy, Imperial College London

A handwritten signature in dark ink that reads "Liam Donaldson".

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# CHANGING OUR HEALTHCARE JOURNEYS

→ **DNV GL and Sustania share a vision: a vision of a smarter and safer healthcare, enabling people to live healthy, happy and independent lives.**

To achieve this, healthcare must change. Although millions of people around the world are successfully treated by health services every day, major challenges to the delivery of high quality care remain. Ageing populations, emerging disease patterns, fragmented services, rising costs, inequitable access and an unenviable safety record mean that business as usual is not an option. In short, current models of healthcare are unsustainable.

Person-centred care offers a way to change this. In person-centred care, the system is redesigned to focus on the service user's experience. Patients, practitioners, providers and policy makers become equal and active partners in co-producing the health journey. Each brings a different type of experience and expertise to the care process, and together they can create a culture where they question and challenge each other in an effort to drive improvement forward, a process where everyone takes responsibility for making healthcare sustainable.

This guide is a next step on the road to creating health journeys founded on genuine partnerships, where patients are no longer seen as passive recipients of care and where different stakeholders work together in en-

suring the best possible quality of care.

The transformation will not happen in a flash. Healthcare systems are arguably among the most complex and difficult systems to influence and change. But change is possible, if we work together to make it happen.

This guide aims to inspire and support that process of change by communicating best practice examples of healthcare solutions co-created by policy makers, providers, practitioners and, of course, the health consumer. It gathers existing knowledge, presents best practise examples from around the world, and lets global health leaders shed light on the obstacles to change – and on how to overcome them.

DNV GL and Sustania are committed to working with the healthcare community in order to achieve person-centred care and to make high quality, safe and sustainable healthcare standard practise for all. To that end, we issue a challenge. We ask each of you to join us on this journey. To share your best practices. To support one another in spreading and scaling solutions. Imagine the year 2020. Imagine what healthcare could look like. Imagine that you are there now, looking back on the first half of the 21st century. We must make sure that the years between now and then are not wasted. Rather, we must work together to make sure our vision becomes the reality for all.

**HENRIK O. MADSEN**

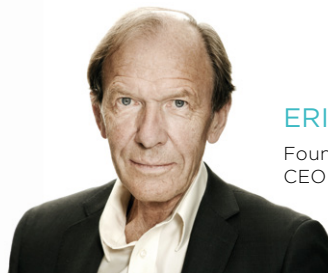
President & CEO  
DNV GL Group



*Henrik O. Madsen*

**ERIK RASMUSSEN**

Founder of Sustania and  
CEO of Monday Morning



*Erik Rasmussen*





## EXECUTIVE SUMMARY

→ **When professionals stop asking patients, “What is the matter?” and begin to ask: “What matters to you?”, the concept of care is expanded to encompass the patient as a person. Thus person-centred care is a way of understanding healthcare that empowers and engages the patient on their own healthcare journey and brings healthcare up to date with the needs of service-users today.**

The current system is based on a ‘fix-it’ understanding of healthcare. In much the same way you would call a mechanic if your car broke down, you make an appointment with a healthcare professional – expecting them to locate the problem and then fix it. However, increasing numbers of chronic diseases as well as improved health literacy amongst patients challenge the foundation of the ‘fix-it’ model. A chronic disease, for example, cannot, by definition, be fixed, and so the role of the healthcare professional becomes one of helping people manage their condition.

Extending the understanding of healthcare from a strictly biological one to one that includes a social and psychological dimension is not new. As early as 1948, the WHO defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.

But it has taken time for healthcare practices to follow suit. In general, current healthcare systems are still organized according to the old health paradigm and they often fail to recognize the greatest resource available in the health process, namely the person who is the patient.

Furthermore, healthcare systems around the world struggle with pressure from global inequality, an ageing population, and an alarming increase in patients with chronic diseases. This pressure is mirrored in projections of public spending on health and long-term care, which reveals a healthcare sector that swallows more and more of countries’ GDP. And so it becomes quite obvious that current

systems are no longer sustainable nor do they provide the best quality of care for patients.

Healthcare systems are very complex and by making small adjustments that address one issue at a time, we risk creating new problems in other areas. What is needed is a reconfiguration equivalent to Galileo’s restructuring of our solar system when he dared to proclaim that the earth was not its centre, but the sun was. Likewise, the rethinking of a healthcare model, which places the patient at the centre of care, represents a radical change that calls for new perspectives, new partnerships and new solutions.

For more than half a century, policy makers, providers, professionals and patient organizations have discussed how healthcare could be organized to focus more directly on patients’ needs rather than the concerns of professionals or institutions.

The difference now is the urgency felt in various sectors; in 2012, research on person-centred care amounted to more than 2,000 articles. 1990 produced a mere 58 articles, while in 1980, only 20 articles were published on the subject. Looking at the political arena over the last couple of years, we have witnessed the production of an increasing number of plans and strategies for the implementation of person-centred care within healthcare systems, a development that is embraced by developing countries and in some cases they are even leapfrogging ahead of our own initiatives. All things considered, the concept of person-centred care seems to be on the verge of a breakthrough.

### **Practical examples**

The growing interest in person-centred care is supported by cases from all over the world. Across countries and across continents, we find useful examples of what person-centred care could entail. From the person-centred transformation process of the US Veteran Health Admin-

istration to the innovative treatment of tuberculosis in Tanzania – these cases show the way to making person-centred care a reality.

### Research base

Additionally, the growing amount of research produced within the field reveals beneficial outcomes for all major stakeholders in the healthcare sector: patients, professionals, providers, and policy makers. Patients experience improved satisfaction and quality of life, improved patient safety and better health outcomes to name but a few benefits. Professionals achieve better job satisfaction, and providers experience better health finances and increased treatment compliance, while policy makers can show their electorate both an improved public health service and a stronger healthcare economy.

### Systems and risk-based thinking

As there are so many benefits to a person-centred approach – why is it not yet standard practice? Well, there are a number of obstacles to overcome before implementing person-centred care. These obstacles are to be found in all areas of the healthcare system: how is a healthcare system focused on person-centred care organized? What are the incentives? How do we train patients to expect person-centred care, and how do we educate the professionals to meet these expectations?

The solutions that show us the way forward are as interconnected as are the obstacles.

There are six primary focus areas that are vital for pushing forward person-centred care; in order for professionals and patients to co-create health, they require a new set of skills, enabling them to form these new partnerships. Clear goals and strong leadership are essential in keeping the transition on track, and at the same time,



incentives should reward person-centred care. Providers of healthcare need to find ways of gathering and using patient feedback more effectively while also using other service providers as inspiration for further development of healthcare. A more seamless data sharing process is key to ensuring continuity in care and everything has to be re-organized into new models and pathways that encourage the person-centred approach.

The transition will not be easy. It will have to build on the dedication of all major stakeholders who need to invest resources and time in order to make person-centred approaches a reality. Changes have to be made throughout health systems, including a change in culture and mind-sets, a change in structures and a change in processes.


Taking a systems based approach to the risks and hazards, and how to overcome them, offers a powerful framework for redesigning healthcare. Other sectors that have used such approaches have experienced significant improvement.

If we are able to catalyse these processes of change, we can create sustainable healthcare systems capable of addressing health issues of tomorrow.

# CHAPTER SUMMARY


CHAPTER 1 PAGE 14-19

## MAKING THE GUIDE

 To help the reader navigate through this guide, we have set a distinct frame; what did we aim for? How did we do it and why? And what should readers bear in mind while reading the report?


CHAPTER 2 PAGE 20-31

## RETHINKING HEALTHCARE

 Patients, professionals, policy makers and providers approach healthcare from different positions, with different objectives and by using different terminology. Patients do experience shared decision making with professionals to some extent, but it is not a prevailing phenomenon. Inspired by WHO and other distinguished institutions, we describe the concept of person-centred care. For person-centred care to become a reality the healthcare sector needs to establish new partnerships, to conduct the meeting between patients and professionals in a new way, and not least to develop a new language.


CHAPTER 3 PAGE 36-47

## THE STATE OF GLOBAL HEALTHCARE

 Existing healthcare systems around the world are no longer sustainable. Pressure on healthcare systems is increasing due to demographic change, new disease patterns, technological advances, increased expectations from patients and restrained public spending. Different regions face different challenges, but they all highlight the need for new solutions, new perspectives and new partnerships.


CHAPTER 4 PAGE 50-59

## THE NEXT BLOCKBUSTER

 The increasing amount of research, policy making and initiatives within the area of person-centred care indicate that this approach to healthcare is on the verge of a breakthrough. And although current work on this subject is focused more strongly on practices in developed countries, emerging economies and developing countries are following suit. However, despite the increased attention to person-centred care, it is far from standard practice yet and the accumulated knowledge still needs to be converted into action.


CHAPTER 5 PAGE 62-93

## INSPIRATIONAL PERFORMANCES

 Across countries and across continents, there are numerous stories of how person-centred care is developed; from battling maternal deaths in El Salvador, to national reform in England, to the restructuring of the US Veteran Health Administration. We present ten cases that outline how person-centred care can be brought to life. The cases also lead the way for others seeking directions.


CHAPTER 6 PAGE 100-113

## BENEFITS FOR ALL

 Every month, new research is presented in support of the benefits of person-centred care. Among the many positive effects of a person-centred approach to healthcare, we find increased satisfaction and a better quality of life for patients, improved job satisfaction for professionals, better health outcomes, a decline in medication errors and a stronger healthcare economy. But while there are indeed great benefits for stakeholders, there are still obstacles to the implementation of person-centred care as standard practice.


CHAPTER 7 PAGE 118-127

## A BUMPY ROAD AHEAD

 Identifying the obstacles that block the way for an implementation of person-centred care is as essential as highlighting the solutions. Experts and patients identify several barriers that need to be dealt with in a coordinated effort. Making organizational changes is not enough, you have to create the right incentives as well, and you cannot change patients' habits and expectations, if you do not train professionals to ask different questions than the ones they are used to asking. The obstacles are interconnected – and thus call for interconnected solutions.


CHAPTER 8 PAGE 130-153

## PARTNERS IN CARE

 Person-centred care constitutes much more than simply a good idea or an interesting area of research – it is an approach to care that is ready to be taken to the next level. Based on interviews with experts from around the globe, we have identified the most vital focus areas to take into consideration when pushing person-centred care forward. This new approach will include a thorough reconfiguration of the way we view partnerships, patients, care and leadership.


CHAPTER 9 PAGE 158-167

## RISK AND SYSTEMS THINKING

 Combining person-centred care with systems and risk thinking can improve the quality of care. Good quality healthcare depends on different systems working together. Unfortunately, healthcare systems frequently evolve without coordination and planning. Systems thinking is a way of addressing this problem, creating healthcare systems that are both more responsive to patients, safer and more reliable. This process can benefit from tools and procedures of risk assessment and management that have been developed in other high risk sectors.

CHAPTER 10 PAGE 170-181

## A PERSON-CENTRED FUTURE

 The year is 2020, and given that we apply existing knowledge, solutions and examples of best practice of person-centred care, what would the healthcare sector look like, feel like and how would it be organized? The experts, who have contributed to this guide, present their visions for a healthcare sector anno 2020. Looking to the future, we leave this edition of the guide.

CHAPTER 1

# MAKING THE GUIDE

WHAT WE DID,  
AND WHY



*THIS GUIDE SETS OUT TO DEMONSTRATE THE POTENTIALS OF PERSON-CENTRED CARE. IT COMBINES AN EXTENSIVE LITERATURE REVIEW, TEN CASE STUDIES FROM ACROSS THE WORLD, AND INTERVIEWS WITH MORE THAN FORTY THOUGHT LEADERS.*

→ **This guide is the result** of the collaborative efforts of Monday Morning Sustainia and the Healthcare Programme within DNV GL Strategic Research & Innovation. It began with a shared belief that person-centred care is the key to creating a safer, more effective and sustainable healthcare sector, able to provide high quality care that meets the increasing demands and needs of patients today.

Person-centred care is attracting attention, not just as an experimental approach but rather as an expected standard of care. But it is still far from being standard practice.

In this guide, we document, demonstrate and communicate the huge potential of person-centred care, we point out obstacles and we outline the way forward. We hope to provide an incentive for change and innovation, not just by giving a sober account of documented benefits, but also by telling inspiring real-life stories and analysing some of the preconditions that must be met to make person-centred care a reality within varying healthcare sectors across the globe.



# WHAT WE DID, AND WHY

→ In our research, we have focused on four main sources of knowledge and inspiration that have been the foundation of the entire guide. They are used as the basis for documenting the state and results of person-centred care, demonstrating real life examples and communicating insights, conclusions as well as recommendations.



## 1. MAPPING THE STATE OF PERSON-CENTRED CARE

A key pillar in our work has been an extensive literature review focused on international databases as well as journals on medicine and health. Furthermore, we have gathered knowledge and research on person-centred care from leading global healthcare organizations and institutions. This has provided us with the necessary insights and the essential overview of the history, the different results and surveys and also the current state of person-centred care.

We also studied international healthcare organizations' work on health and healthcare, in order to give a wider insight into the state of global health and the challenges that healthcare systems around the world face today.

## 2. INSPIRATIONAL PERFORMANCES



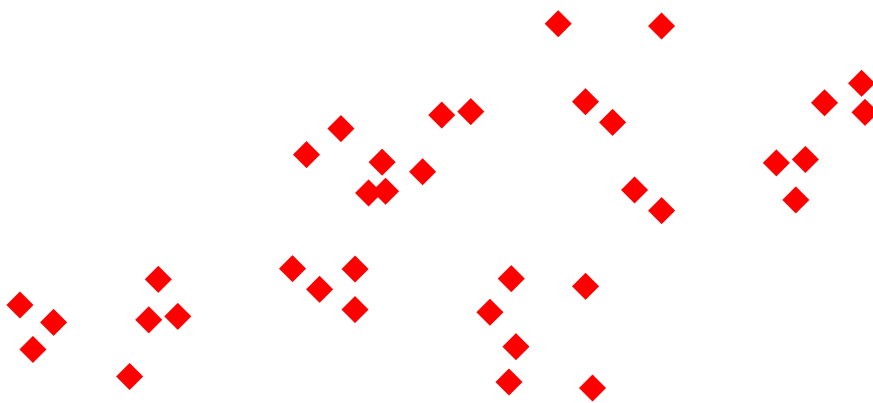
This guide includes ten best-case examples from across the globe. They illustrate how a person-centred approach to healthcare can become a reality, they serve as inspiration for others and they present some of the benefits of implementing a more person-centred system.

The ten case stories have been selected in accordance with three general criteria. Firstly, that they provide the reader with a global perspective. Consequently, the cases cover five continents and represent countries on different levels of development. Secondly, that they include perspectives from different stakeholders in the healthcare sector. Together, the cases show how patients and their organizations push the agenda in the direction of person-centred care, how governments encourage person-centred care, and how front runners in their daily work place patients at the centre of care and convince other stakeholders to follow suit. Thirdly, that they are recognised by thought leaders as important and credible examples of person-centred care. To ensure this, each case has been presented to several of the thought leaders interviewed for this guide.

This does not mean that the selected case stories constitute a final or authoritative list of best practice. Indeed, other inspiring examples of person-centred care could have been included.



*The cases show how patients and their organizations **push the agenda** in the direction of person-centred care.*



### 3. THE EXPERTS' DIAGNOSIS

We have conducted interviews and listening sessions with forty selected thought leaders and experts from both developed and developing countries. They contribute with vital insights and perspectives throughout the guide. The interviews are used as a base for outlining what person-centred care is, identifying obstacles for adopting person-centred healthcare, and investigating how we can move forward.

The selection of the forty thought leaders was based on a wish to present informed opinions from all over the world; from the US and Europe as well as countries in the developing world. The thought leaders also represent different stakeholders: patients, professionals, university researchers, experts from selected healthcare organizations, providers and policy makers. These criteria and our extensive desk research resulted in a list of more than 200 selected key persons, and from this list we created a short list of fifty of the most important experts in the field of person-centred care – according to criteria such as credentials, academic background, professional experience and involvement in political initiatives. The forty experts we finally interviewed are picked from that short list.

### 4. BRINGING THE PATIENT EXPERIENCE TO LIFE

Since the key issue is to place patients more at the centre of care, we have afforded patients a visible presence in the guide. Besides the experts who represent patient organizations, the guide presents accounts of seven patients' encounters with the healthcare system – describing "the patient journey" and demonstrating what different people feel, think, expect and experience when they meet the healthcare sector.

The accounts cover a wide a range of patients, representing different regions of the world, countries at different levels of national income and healthcare coverage, different age groups, both sexes, and finally different disease types (chronic/acute, communicable/non-communicable, rare/common, complicated/uncomplicated etc.).



# WHAT YOU SHOULD BEAR IN MIND WHEN READING THE GUIDE

→ **In order to present a readable and accessible guide**, we have had to focus our efforts with regard to structure and content. Sadly, the process of selecting also involves deselecting interesting aspects, surveys, research papers and even very good examples of best practice. This means that there are equally qualified cases, thought leaders and patients not presented here.

Among other things, we have narrowed our focus to include only the healthcare sector: this guide deals with healthcare provided after a person has been in contact with the healthcare system.

We acknowledge that other aspects of healthcare are equally important from a person-centred perspective. For instance, issues of prevention and health risks related to lifestyle are rising factors on the political agenda. These issues raise a wide range of questions and concerns, which are not dealt with in this guide.

This guide does not target one specific audience but aims to inspire stakeholders across healthcare sectors worldwide. Consequently, it does not favour patients, healthcare professionals, providers or policy makers exclusively. It is directed at all these stakeholders and seeks to describe what person-centred care entails from each of these different stakeholder perspectives. Finally, it does not focus on one specific element of person-centred care, one country, or one type of healthcare institution.

An important message is that person-centred care should not be understood as a set of isolated elements such as buildings, design, doctor-patient-relationship or sharing of data. It is an approach to healthcare that will affect the entire healthcare sector and it requires the involvement of all healthcare stakeholders.

We hope that the guide will help pave the way for a future healthcare sector within which person-centred care is an essential part.

*“All changes and new concepts that we initiate in order to make the healthcare sector **more person-centred** must include all stakeholders. We must make sure that **everybody is on board**, or we are not likely to succeed.”*

- Jacqueline Bowman-Busato, Executive Director of European Platform for Patients' Organisations, Science and Industry

NEXT  
RETHINKING  
HEALTHCARE



CHAPTER  
2/10

ALL CHAPTERS

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CHAPTER 2

# RETHINKING HEALTHCARE

WHAT IS PERSON-CENTRED CARE  
- AND WHY IS IT IMPORTANT?



*PERSON-CENTRED CARE IS FOCUSED AND ORGANIZED AROUND THE INDIVIDUAL'S HEALTH NEEDS, EXPECTATIONS AND RESOURCES. PROFESSIONALS AND PATIENTS ARE PARTNERS IN CARE WORKING TOGETHER TOWARDS A COMMON GOAL. THIS BEARS WITNESS TO A NEW APPROACH TO HEALTHCARE.*

→ **Zeny almost died giving birth to her first son. Today, Zeny is 43 years old and she lives in San Jose City, a small town in the northern part of the Philippines.**

When her son was nine, Zeny – then aged thirty-one – was finally given a diagnosis, a combination of two rare autoimmune diseases: scleroderma and lupus. Both attack healthy body cells and tissue, causing inflammation in different organs of the body. Common symptoms include fever, nausea, hair loss and vomiting. The more severe effects are muscle pain, kidney failure, stiff lungs and heart problems.

Zeny has suffered most of these complications, and the sheer number of symptoms is one reason why the two diseases are so difficult to diagnose.

Her condition is chronic, but there are ways to relieve pain and delay the destruction of her body cells. And so, she is always on the lookout for better ways to manage her condition. She has learned a lot from searching the Internet and emailing questions to top-researchers in the US. In the Philippines, help is hard to come by. And it took Zeny over a decade just to get a useful diagnosis.

“In 1998, when my son was six, I started to feel pain all over my body. I had multiple skin inflammations, and most

of the time I felt tired and just wanted to sleep,” she says. “At the time, I went to several doctors. But they all thought it was connected to my heart problem. They couldn’t find anything wrong with me.”

After consultations with several doctors in the city, Zeny and her family travelled to a nearby city, to see an arthritis specialist. However, this doctor could not come up with any specific conclusions either. Instead, she prescribed a chemotherapeutical drug for Zeny to take.

“She just told me to take the medicine, without explaining anything about its side effects. Everytime I took it, I felt sick. I would throw up, I couldn’t eat, and I could hardly get out of bed,” she says.

After one month, Zeny had lost one fifth of her body weight and was down to 49 kg. She seemed to fade away, day by day. Then her family decided to bring her to a doctor in Manila, a five hour drive from her home town. And this time around, she was more successful. The doctor discovered that Zeny most likely suffered from lupus. He tried explaining the effects of the rare disease.

“I didn’t know what lupus was. All I understood was when he said: ‘There is no cure for that’,” says Zeny.

The doctor referred her to another specialist, who diagnosed Zeny with scleroderma as well.

“I asked if there was any treatment. The doctor told me that there is no cure, and that we could only try mixing different sorts of medicine,” she says. “After three years of different treatments, I asked if we could stop doing the medicine, because it did not work.”

Then in 2005, Zeny took charge and started looking for answers to her problems on the Internet.

“I realized that since it is my body, I have to understand what is happening to me. So, I started looking for information about my illness on the Internet. I wrote emails to a lot of doctors in the US, who sometimes replied,” she explains.

Later, she came across the International Scleroderma Network where she found other patients with the same rare condition. This proved another useful source of information on how to cope with it.

Today, her illness is under control – primarily thanks to the information she has gathered herself. But she has also developed a closer relationship to her doctor.

“I have my scleroderma under control. I listen to what my body is telling me, and I pass on this information to my doctor. He knows the medical side of the illness. I know my body,” she concludes.

### Putting the patient in the centre

Patients and relatives from all over the world could tell stories like Zeny's. In surveys, patients all too often report that the healthcare system fails to involve patients in their own care and that care is provided to patients, rather than co-created in partnerships with them. See figure 1.

In recent years, an increasing number of researchers, politicians and patient organizations have acknowledged the need for a new approach – a concept of healthcare that gives a much more central role to the patient's needs, interests, life circumstances and personal relations.

In this guide, we have labeled this concept “person-centred care”.

With this term we refer to a basic philosophy of care, centred around the individual, in which the needs and

resources of the person define the process, in which individuals are supported and encouraged to make informed decisions about their treatment and health management; a process that is not only responsive to their physical abilities and medical needs, but also to the individual's social and psychological abilities, preferences and lifestyle.

Twenty years ago, a group of researchers from Harvard School of Medicine conducted a series of interviews with recently discharged patients, their family members, physicians and other health professionals. The result was the book “Through the Patient's Eyes”<sup>1</sup>, where the research team introduced some fundamental principles directing person-centred care.

- **Mutual respect** is the foundation of any genuine dialogue between human beings. Healthcare must begin with respect between professionals and patients who bring different experiences and knowledge to the relationship.
- **A coordinated effort** is essential. This is especially true when patients need care from different providers.
- **Involving the patient's network** can be of great benefit. In the Western world, this will typically include close relatives or friends, while in Asia, Africa and Latin-America, the local community and more distant family members may also play a supportive role.

These principles have, in different versions, been adopted by patient organizations all over the world. They are integrated in the Declaration of Patient Centred Health Care, issued by The International Alliance of Patients Organization (IAPO)<sup>2</sup>.

### The need for a new mindset

For more than half a century, politicians, providers, professionals and patient organizations have discussed how healthcare could be organized to focus more directly on the patient's needs rather than the concerns of professionals or institutions. See figure 2 on page 25.

The World Health Organization (WHO) was among the first to condense these discussions and call for a new approach to patients and patient care. In The World Health Report 2000, the WHO introduces the concept of “responsiveness”, signifying a concept of care that is not purely medical, but includes the relation between professionals and patients.

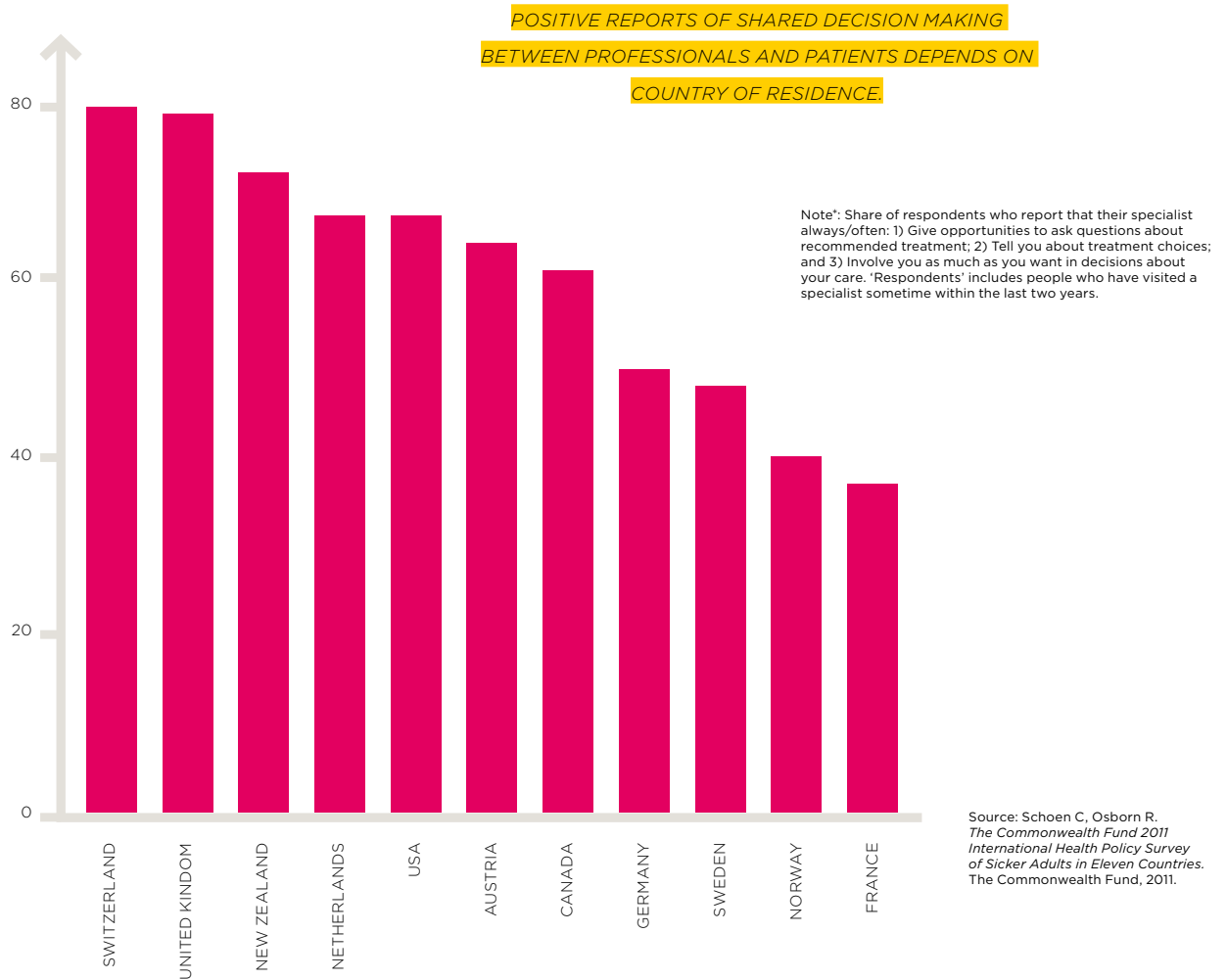
Note<sup>1</sup>: Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. *Through The Patient's Eyes: Understanding and promoting Patient-Centred Care*. San Francisco: Jossey-Bass; 1993.

Note<sup>2</sup>: International Alliance of Patients' Organization. *Declaration on Patient-Centred Healthcare*. 2006.

FIGURE 1

## SHARED DECISION MAKING: A MIXED PICTURE

SHARE OF PATIENTS WITH POSITIVE EXPERIENCES OF SHARED DECISION-MAKING WITH SPECIALISTS\*, PER CENT.



The WHO calls for a new mindset, where the traditional clinical encounter is only one element. And in a global perspective, the WHO has underlined the need to involve the patient's family, network and community as well.<sup>3</sup>

An important aspect of shared decision making is that

care will increasingly be co-created between professionals and patients; they will become partners in care.

In a thorough and much quoted study of the American health system from 2001, The Institute of Medicine (IOM) further discusses how this new partnership challenges

Note<sup>3</sup>: World Health Organization. *Health Systems Strengthening Glossary.*

Note<sup>4</sup>: Hurtado MP, Swift EK, Corrigan JM (eds.). *Envisioning the National Health Care Quality Report.* Institute of Medicine, 2001.

traditional assumptions about the roles of professionals and patients, e.g. during visits at a clinic or while being admitted to hospital.<sup>4</sup>

Some ten years after the IOM study, the Gothenburg University Centre for Person-centred Care, Europe's first University Centre in this field, further stresses the importance of partnerships.

"The most central aspect is the partnership, as this is about a mutual respect for the knowledge of each party; on the one hand the knowledge of what it is to live with the condition, on the other hand a generic knowledge of the condition."<sup>5</sup>

This condensed definition touches on another key aspect of person-centred care: care and treatment constitute only small parts of a person's life. Seen from the patient's point of view, an approach that confines care to a hospital or a clinic is neither sensible nor desirable.

### **An evolving concept**

The discussions above have taken place under different headlines, which signify different approaches, focus areas and perspectives. Throughout this guide, we synthesize and elaborate on insights gathered under all these labels.

We believe that all these terms share the same basic philosophy: placing the individual at the centre of care.

As a general rule, we have chosen to stick with the term "person-centred care" – not because we imply a wish to favour specific types of research or practices at the expense of others, but for two different reasons.

Firstly, this guide takes the individual's meeting with the healthcare system as its point of departure. By talking about a "person" rather than a "patient", we acknowledge the need for a holistic approach, seeing the individual as more than "just-a-patient" and emphasizing the fact that a patient is first and foremost a person with individual preferences, needs and abilities. Patients should not be reduced to their disease but viewed as partners in care.

As the Swedish professor and director of the University of Gothenburg Centre for Person-centred Care, Inger Ekman, explains:

"Patients should be seen as persons. That is one of the central points. Just like Martin Luther King demanded that Afro-Americans should be seen as persons. Or the wom-

en's rights movement that argued that women should be seen as persons".

Secondly, the term takes into consideration that an individual's healthcare needs do not vanish the moment he or she leaves the hospital and is no longer considered "a patient". Good care goes beyond medical treatment. It includes social and psychological aspects such as lifestyle, habits and family status. Healthcare is not limited to the patient's visits to a doctor's clinic.

### **Making the change: A new language**

One charismatic advocate of a person-centred approach is Dave deBronkart. Styling himself as "e-patient Dave", deBronkart is a businessman with a background in marketing and technology, and he has been treated for a severe case of kidney cancer. Today, he combines his two fields of experience and he is instinctively convinced that any service, including healthcare, should be delivered according to the needs of the user.

deBronkart is one of the first patients lecturing at professional conferences and he often begins his lectures with a pledge:

"I want to propose that we modify our language. We're all talking about patients as if they're not in the room. Well, I'm here to tell you, patient is not a third person word. Whether it's you yourself, your child, your spouse, your mother – your time will come, when you are the one in the hospital bed, or you're the one at the bedside, holding someone's hand and silently thinking, 'Dear God, I hope she makes it'.<sup>6</sup>"

As deBronkart points out, the call for new partnerships and a redistribution of roles challenges the traditional authority of doctors and other professionals, which is deeply embedded in the professional jargon that permeates the healthcare sector.

Many professionals still tend to talk about healthcare in a way that pays little attention to the patient's own preferences and opinions. A new mindset that places the individual at the centre of care must be based on new language that puts patients and professionals on a more equal footing.

On the following pages, you will see a phrasebook that applies a new terminology to the field of health, disease, care and treatment.

Note<sup>5</sup>: University of Gothenburg Centre for Person-centred Care. *Facts about GPCC*. 2013.

Note<sup>6</sup>: deBronkart RD. *Let patients help!*. CreateSpace Independent Publishing Platform; 2013. p3.



FIGURE 2

## A NEW UNDERSTANDING OF CARE

CONCEPT	WHO	WHAT	WHEN
RESPONSIVENESS	<i>World Health Organization: "The world health report 2000 - Health systems: improving performance"</i>	"Responsiveness is not a measure of how the system responds to health needs, which shows up in health outcomes, but of how the system performs relative to non-health aspects, meeting or not meeting a population's expectations of how it should be treated by providers of prevention, care or non-personal services"	2000
PERSON-CENTREDNESS	<i>Institute of Medicine: Envisioning the National Health Care Quality Report, Washington, D.C.: National Academies Press, 2001</i>	"Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care"	2001
PATIENT-CENTRED HEALTHCARE	<i>The International Alliance For Patients: Declaration on Patient-Centred Healthcare</i>	"The essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective."	2006
PEOPLE-CENTRED HEALTHCARE	<i>World Health Organization: People-centred care in low- and middle-income countries</i>	"Care that is focused and organized around the health needs and expectations of people and communities rather than on diseases. People-centred care extends the concept of patient-centred care to individuals, families, communities and society. Whereas patient-centred care is commonly understood as focusing on the individual seeking care—the patient—people-centred care encompasses these clinical encounters and also includes attention to the health of people in their communities and their crucial role in shaping health policy and health services."	2010
PERSON-CENTRED CARE	<i>DNV GL / Sustainia</i>	"A basic philosophy of care, centred around the individual - in which the needs and resources of the individual define the process, in which individuals are supported and encouraged to make informed decisions about their treatment and health management; it is a process that is not only responsive to the individual's physical abilities and medical needs, but also to the individual's social and psychological abilities, preferences and lifestyle."	2014

Source: DNV GL / Sustainia.

# PHRASE BOOK

A NEW LANGUAGE

■ INSTITUTIONALIZED CARE

■ PERSON-CENTRED CARE

## PATIENT – AND PERSON

Weakness ... and resource

Recipient ... and co-creator

Cost ... and investment

Taken care of ... and responsible

## NURSE

Care provider ... and health helper

Carer ... and advisor

Practitioner ... and trainer

Fire fighter ... and preventer

## DOCTOR

Clinician ... and service provider

Authority ... and partner

Fire fighter ... and preventer

## THE ENCOUNTER

Visits ... and a continuous relationship

At institutions ... and in network

Specialization ... and cooperation

Providing ... and empowering

## INFORMATION

Stored ... and shared

Controlled ... and flowing between partners

# EXPERTS DEFINE PERSON-CENTRED CARE

→ **There is growing consensus** on what person-centred care is and what it entails. This is one of the main conclusions from our many interviews with experts. Professionals, providers, policy makers and patients seem to share

an understanding of the basic elements that constitute a person-centred healthcare sector.

**Five key concepts** have been brought up in all interviews.

## HOLISM

*“As physicians we are trained in a biological model of disease. Now we have to supplant this model by a biological-psychological and sociological model and look at patients in a holistic way. We shall treat patients not only from a biological view but also understand his or her psychology and social environment.”*

- Sanjay Kalra, owner and chief clinician, Bharati Hospital, India

*“In Bhutan, we understand person-centred care in our cultural context. We follow Buddhism and have a focus on compassion within a holistic perspective. We are the only country not to focus on Gross National Product but on Gross National Happiness and we think that person-centred care is suitable to promote Gross National Happiness. For us, healthcare should begin with dignity and respect for patients.”*

- Rinchen Pelzang, doctoral student at Deakin University, Australia

## PARTNERSHIPS

*“Person-centred care is a form of power sharing between healthcare professionals and patients.”*

- Yang Jingqing, Institute for International Studies, University of Technology, Sydney

*“Person-centred care is a partnership between patients and professional care givers.”*

- Inger Ekman, Professor, Director of The Centre for Person-centred Care, Gothenburg University

*“The patient becomes a co-producer of health.”*

- Angela Coulter, Senior Research Scientist, Oxford University

## COHERENCE

*“Planning of care and making sure that all involved partners are informed is very important – this is a basic premise for ensuring that the patient’s meeting with the healthcare sector is as easy and smooth as possible.”*

- Jacqueline Bowman-Busato, Executive Director, European Platform for Patients’ Organisations, Science and Industry.

*“Continuity of care is one of the central points in patient-centred care. This is about the coordination of care and the collaboration of care as multiple people in the healthcare business are involved in the process.”*

- Yunan Chen, Assistant Professor, Department of Informatics and the Institute of Clinical and Translational Sciences, University of California.

## QUALITY CARE

*“Person-centred care is about improving the quality of care.”*

- Astrid Krag, former Minister of Health and Prevention in Denmark

*“My entrypoint in to the discussion of a person-centred care or a people centred care is patient safety. Essentially, somebody walking into a hospital or a healthcare facility should not walk away with something, that they did not have in the first place. A classical example is an infection or a surgical error meaning, that patients suffer from something which went wrong that can be classified as an error.”*

- Dr. Shams B. Syed is the Programme Manager for African Partnerships for Patient Safety, WHO

## EMPOWERMENT

*“Patients are involved actively in their own care. They actively participate.”*

- Senga Pemba, Director, the Tanzanian Training Centre for International Health

*“Person-centred care empowers patients – and it is important because it motivates people to take responsibility and engage in their own health.”*

- Asfandyar K. Niazi, researcher, Shifa College of Medicine in Islamabad, Pakistan.



*Person-centred care is **a basic philosophy of care, centred around the individual** – in which the needs and resources of the individual define the process, in which individuals are supported and encouraged to make informed decisions about their treatment and health management; a process that is not only responsive to their physical abilities and medical needs, but also to the individual’s social and psychological abilities, preferences and lifestyle.*

NEXT  
THE STATE OF  
GLOBAL HEALTHCARE



CHAPTER  
3/10

ALL CHAPTERS

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**Inger Ekman:** Professor and Director of the Centre for Person-centred Care (GPCC) at the University of Gothenburg in Sweden. GPCC employs around 100 researchers from a multitude of disciplines. GPCC is funded by the Swedish Government and the University of Gothenburg. With the programme “Towards Person-Centred Care in Long-term Illness: A Research Core Centre”, Inger Ekman and the GPCC are on their way to establishing a interdisciplinary research centre with the aim of improving communication between patients with long-term medical conditions and their care-givers. Inger Ekman has authored and co-authored 100 peer reviewed articles.



**Jerzy Kaczynski:** Senior physician at the Sahlgrenska University Hospital. Jerzy Kaczynski is an Associate Professor and specialist in internal medicine. For many years, he has worked at the Department of Internal Medicine, Sahlgrenska University Hospital/Östra in Göteborg, Sweden, and currently he holds the position as Head of one of the wards in this department. His research field is mainly hepatology. His ward had participated in some studies conducted by The Göteborg Centre for Person-centred Care (GPCC).



**Axel Wolf:** Researcher at Centre for Person-centred Care at the University of Gothenburg in Sweden. He has a background in anaesthesia and intensive care. His research taps into different aspects of person-centred care, such as exploring the prerequisites for and effects of person-centred care within a hospital setting. A current focus for Axel Wolf is the development of person-centred eHealth innovation, change-management and implementation of person-centred product-service innovations within the healthcare setting.



SWEDEN

INTERVIEW **INGER EKMAN, JERZY KACZYNSKI AND AXEL WOLF**

# CREATING A NEW PARTNERSHIP



→ **Person-centred care demands a new partnership between patients and professionals. Each party brings different skills and resources to the table and care will improve greatly if they are combined. This is the call from three Swedish experts from the University of Gothenburg Centre for Person-centred Care Research (GPCC).**

“The most vital aspect of person-centred care is the partnership, which is centred on mutual respect for each other’s expertise; on the one hand the knowledge of living with the condition – on the other hand the general knowledge of the condition,” says Inger Ekman, Professor in Nursing and Director of GPCC.

Together with her two colleagues, Jerzy Kaczynski and Axel Wolf, she elaborates on why a strong partnership between the professional and the patient is the essence of person-centred care and why it is important to strengthen this aspect today. Their critical analysis paints a picture of a healthcare sector where this kind of partnership is not the reality.

“It is still defined by the distinction between *us* and *them*,” Inger Ekman states.

Jerry Kaczynski elaborates: “Right now, we have three different tracks when the patient comes to the hospital. First, there is the doctor track: we look at the diagnosis, order tests and blood samples, inform the patient, and we treat the disease without thinking about anything else. Then there is the nurse track: caring for the patient. And finally there is the patient track. It is very passive. The patient will say: ‘Take care of me, you know best’. These tracks are not regarded as one unit but as separate parts.”

Following this analysis he advocates a “common track” where the different actors team up in a much stronger partnership.

#### **Different resources**

A person-centred partnership must acknowledge that healthcare professionals and patients have very differ-

ent perspectives, backgrounds and knowledge – and it must utilize this difference.

“Both the doctor and the patient can gain from each other. We doctors know more about medicine than the patient. But the patient knows more about themselves than we do,” as Jerzy Kaczynski puts it.

Inger Ekman points to patient empowerment as an important part of creating a fruitful partnership.

Axel Wolf elaborates: “The key factor is how we see each other. If I only see a person as a patient when I talk to him, I only seek my own answers”.

Instead, the doctor must acknowledge the patient as an essential resource, while the patient must acknowledge the doctor as an equal partner and take responsibility for her own care. According to Jerzy Kaczynski, this will eventually make the work of professionals easier.

“If you have no partnership, the doctor decides everything. This means that the patient will have very high expectations of the doctor and his/her ability to fix all medical, psychological and social problems. And then she will not be satisfied, if the doctor fails to meet them. In a partnership, the doctor can explain which problems he can and cannot help with.”

#### **The patient’s need in the centre**

“What we have missed completely is what the patients actually want. What are their expectations? Maybe they had different wishes. This is why it is so important to ask the patient on the first day: what do you want? What do you expect? It has to do with respect and listening more to the patient and not only focusing on the medical side of the problem,” Jerzy Kaczynski says.

He stresses that the new partnership between healthcare professionals and patients has to be founded on patients’ resources and needs – is has to be person-centred and take the person’s motivation and preferences into account. An important part of this is focusing on each patient as a person with an unique story.

“The decisions tend to be made without the patient being present. But if you partner up with somebody, you have to listen to their story. So the patient narrative is extremely important,” Inger Ekman explains.

“In the history of medicine, the patient narrative has become less and less important. If you look at a patient’s journal you can see almost no narrative and only hard data like biomarkers, blood pressure, heart rate, different tests, and you almost don’t need to see the patient because you can just read the test results.”

All three experts agree that in order to build this new kind of partnership, professionals have to learn how to engage patients in a whole new way.

“If you ask people who work in the health sector if they work with person-centred care, they would say ‘of course we do’. But they don’t know what person-centred care actually means. I didn’t know either. A lot of doctors and nurses think that being nice and friendly to the patient constitutes person-centred care,” Jerzy Kaczynski points out.

One issue that professionals will have to address is how to communicate with the patient.

“One of the central ideas in person-centred care is to utilise the patient’s resources. Talking with a patient should be based on dignity, willingness and responsibility. If you talk to a person in that way, you free up patient resources that you can use in the care. But this kind of partnership is not easy to obtain because you are in a structure that is very conservative,” says Inger Ekman.

One of the main things that can help push forward this idea is creating pathways and lines of communication that support the idea of doctors and patients partnering up.

“You need to support the partnership with e-health, architectural design, IT-solutions and everything else within the context,” Axel Wolf suggests.

*“She talked to  
me like a person.  
It made me feel  
normal – **almost  
healthy**”*



- **Brooke Billingsley**, USA, Breast cancer

**Age:** 53 years

**Occupation:** Business owner, perception researcher, speaker, author

**Family:** Married for 30 years with two children and two grandchildren

**Hobbies:** She has created a website for cancer patients full of free resources, she goes on cruises and she sings

→ **“I don’t know if there is any good way to hear that you have cancer,”** says Brooke Billingsley recalling that day in December 2011, when she was diagnosed with breast cancer. The physician doing the biopsy was direct but honest. Replying to Brooke’s question of whether she thought it might be cancer; the physician looked her straight in the eye and said without hesitation: “No, it is cancer.”

The tough message was not what Brooke wanted to hear just two days before Christmas. She is a long-time business professional and for 15 years she was the CEO of a Healthcare Consumer Research and Consulting Company, Perception Strategies, Inc. She has worked extensively with clients such as Cleveland Clinic and Johns Hopkins as well as many other organizations dedicated to improving patient experiences.

Entering the world of healthcare as a patient is one of the most challenging things Brooke has ever had to do. Diagnosed with stage two, triple positive breast cancer, her oncologist presented a 16-months treatment plan. She only made it through those months of chemotherapy, hair loss, surgery, 33 radiation treatments and emotional distress, she says, due to the kindness and understanding of her family as well as the healthcare professionals surrounding her.

“As a strong independent woman, it was amazing to me, how vulnerable and emotional cancer made me, I was almost like a helpless child at times.” The kindness of her caregivers had a huge impact on her care. Brooke calls it “survival kindness”.

However, the day she underwent surgery was very tough to get through. After an excellent MRI report that showed almost no cancer, she asked her surgeon what he would be cutting out. The doctor would not tell her straight out exactly what he was going to do.

“My doctor was very vague. He wouldn’t answer all my ques-



tions. I’d thought all along that after chemo, I was having two lymph nodes removed and a lumpectomy, so when the surgeon said, ‘I think we’ll be able to save the breast,’ that frightened me. As a patient, I don’t want the doctor to use language that is meant to be intentionally safe,” she says.

“I don’t just do things because people tell me to. It needs to make sense to me,” she says, explaining that the surgeon seemed focused only on the clinical procedure without seeing the person behind.

Luckily, a nurse took the time to explain the entire procedure, answering all of her questions, approaching her like a person. She experienced that kind of patient involvement continually throughout most of her cancer treatment.

“Psychologically, it matters how the hospital staff talk to you,” argues Brooke. “You are powerless, lying in a hospital bed. But it helps to talk about all kinds of normal things not related to cancer. It was feeding into my belief that this is all just temporary,” she says.

Brooke remembers one nurse who was particularly helpful. She spent 20 minutes talking to Brooke, just to get to know her. The hospital encouraged that. They made sure nurses had a patient ratio of no more than three or four, so they would not be too stressed when patients needed attention.

“She talked to me like a person. It made me feel normal – almost healthy,” says Brooke. “It helped me look forward.”

But it was not just the individual approach of one nurse that made the difference. It was also the cooperation of all the healthcare staff that seemed to work. “My experience was very positive at this hospital because of the care I received and the collaborative effort of everyone working together as a team,” she concludes.

CHAPTER 3

# THE STATE OF GLOBAL HEALTHCARE

- PRESSURE FOR A NEW  
APPROACH IS BUILDING



ACROSS THE GLOBE, HEALTHCARE SYSTEMS FACE TREMENDOUS PRESSURE. LOOKING TO THE FUTURE, THE CHALLENGES WILL ONLY GET BIGGER. A NEW HEALTHCARE MODEL IS NEEDED.

→ **A mismatch between demand and availability causes a strain on healthcare systems around the world.** Demographic change, new disease patterns, technological advances, increased expectations from patients, and restrained public spending steadily expose existing healthcare models as unsustainable. See figure 1.

In the Western hemisphere, healthcare systems are challenged by an ageing population as well as an alarming prevalence of chronic diseases. Combined, these challenges further pressurize an increasingly effective but also increasingly expensive healthcare sector.

At the same time, a new generation of self-confident and informed patients, born without a blind faith in professional authorities, is emerging as conscious and modern quality consumers.

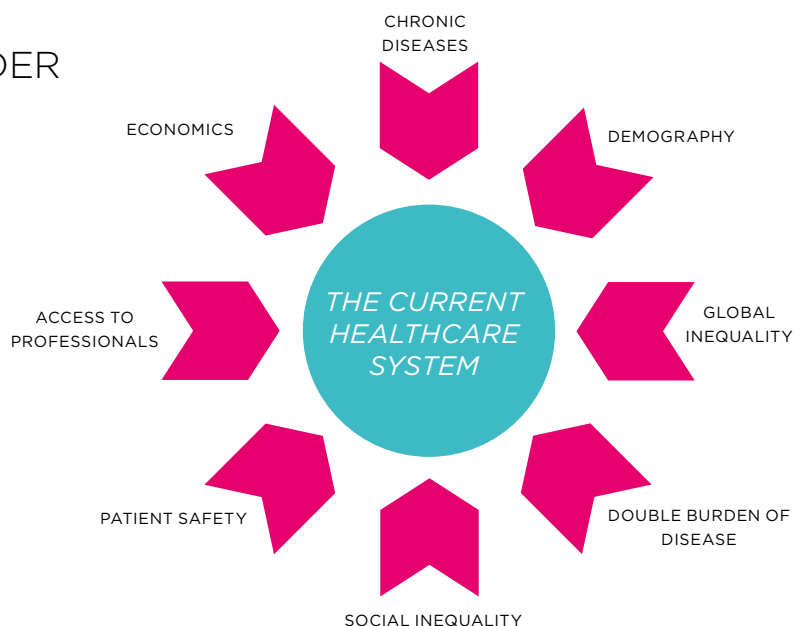
In the developing world, providing a basic healthcare infrastructure that complies with citizens' need for care still represents the most immediate challenge. Despite improvements in reducing child mortality rates, improving maternal health, combating HIV/AIDS, malaria and other infectious diseases; these diseases continue to have a firm grip on developing countries, where access to healthcare is often considered a luxury rather than a basic human right.

Across the globe the pressure for change will only increase. This calls for new solutions, new perspectives and new ideas that will help create a sustainable healthcare sector in the future. This opens the door to a new healthcare model based on a person-centred approach to become the dominant way of thinking, providing and structuring care.

FIGURE 1

## HEALTHCARE UNDER PRESSURE

TODAY, HEALTHCARE SYSTEMS AROUND THE WORLD FACE A LOOMING CROSS-PRESSURE - HAVING TO BALANCE INCREASING DEMANDS AND NEEDS WITHOUT THE HEALTHCARE BUDGET SKYROCKETING.



Source: DNV GL / Sustainia

# HEALTH SPENDING IS SKYROCKETING

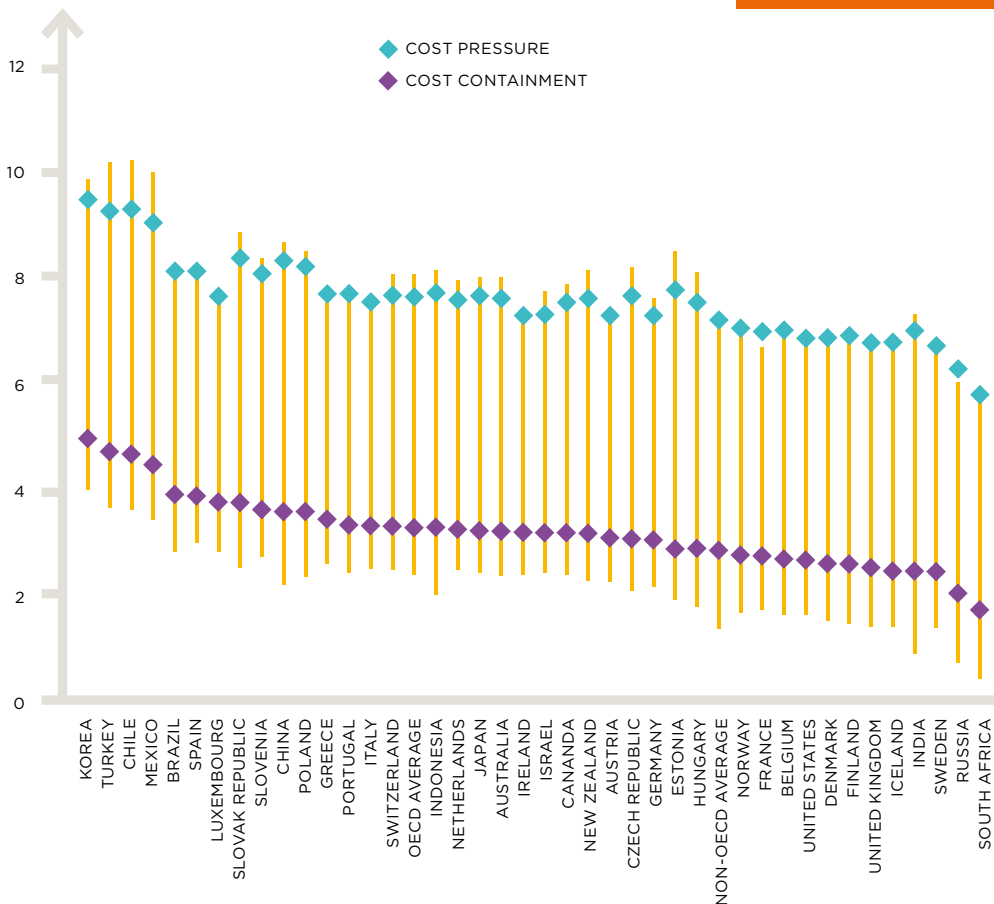
→ **During the last couple of decades**, the world has witnessed a massive increase in healthcare expenditure. Yet, we have only seen the tip of the iceberg. Projections of public spending on health and long-term care in OECD countries suggest a rapidly rising trend over the next fifty years. Moving from an average of 6 per cent of the GDP in 2006-10, the combined public health and long-term care expenditure is projected to reach 9.5 per cent in 2060 according to a cost-containment scenario – which assumes that policies, to a greater extent than previously, will rein in some of the expenditure growth. In a cost-pressure scenario, which does not make this assumption, spending could reach as high as 14 per cent of GDP. See figure 2.

**US IS THE NUMBER ONE LARGE-SCALE HEALTH CONSUMER**

- The US currently has the highest health expenditure in the world. It consumes 17 per cent of the American GDP – an increase of 4 per cent since 2000. Globally, healthcare expenditure has currently reached 10.4 per cent of the global GDP.
- Today, the US consumes 40 per cent of the total global spending on healthcare. Japan is number two on this list consuming 8 per cent of the global healthcare expenditure.
- However, the high spending does not mean that the US has the best healthcare. The US is currently doing relatively well in some areas—such as cancer care—and less well in others—such as mortality from treatable and preventable conditions.

Note: Docteur E, Berenson RA. *How Does the Quality of U.S. Health Care Compare Internationally?* Urban Institute, 2009.

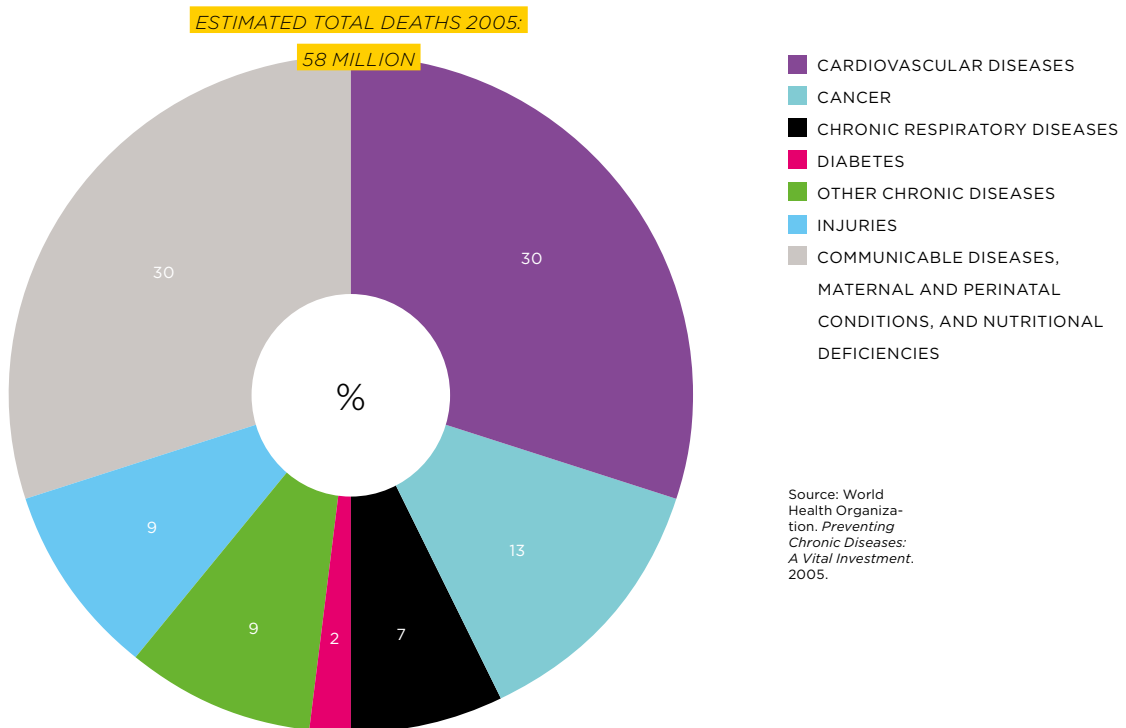
FIGURE 2  
**RISING HEALTH COSTS**  
PERCENTAGE POINT INCREASE IN TOTAL PUBLIC SPENDING ON HEALTH AND LONG-TERM CARE, 2010-2060



Source: Martins JO, de la Maisonneuve C. *Public spending on health and long-term care: a new set of projections.* OECD, 2012.

FIGURE 3

## PROJECTED MAIN CAUSES OF DEATH WORLDWIDE, ALL AGES, 2005



## THE CHRONIC DISEASE PANDEMIC

→ **Chronic diseases** account for approx. 46 per cent of the global burden of disease, and according to the WHO, this will rise to 57 per cent by 2020. 36 out of 58 million annual deaths worldwide are attributed to chronic diseases. Cardiovascular diseases account for nearly half, but deaths from obesity and diabetes are also showing worrying trends. According to the WHO, worldwide obesity has nearly doubled since 1980. According to the International Diabetes Federation, diabetes affects at least 383 million people worldwide today, and the number will rise to 592 million by 2035. See figure 3.

Chronic diseases demand long-term treatment, constant follow-up and supervision. This challenges the organization and mindset of existing healthcare systems and increases the need for new approaches to treatment and care.

### UK - THE CHRONIC CHALLENGE

- One third of the population now suffers from a long-term condition.
- Patients with long-term conditions account for more than 50 per cent of all GP appointments, 65 per cent of all outpatients' appointments and over 70 per cent of all inpatients' bed days.

Source: Department of Health: *Improving the health and well-being of people with long-term conditions*. 2010.

FIGURE 4

## THE WORLD IS GETTING OLDER... POPULATION AGED 60 OR MORE

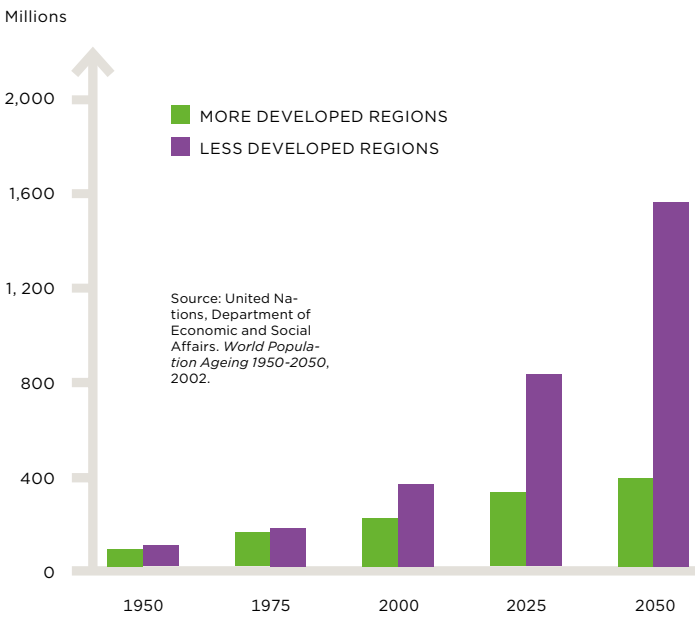
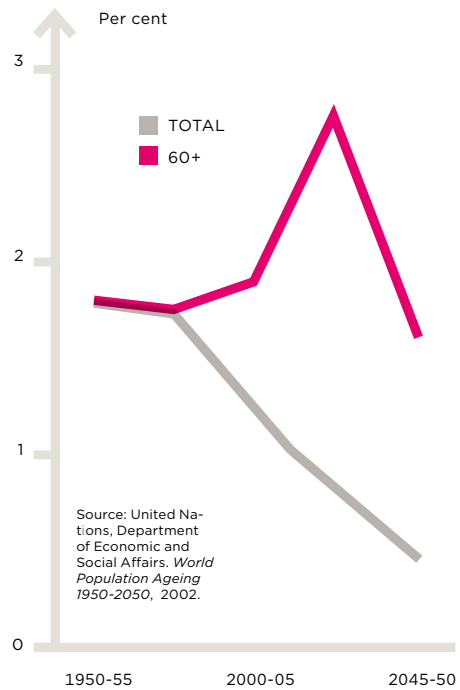


FIGURE 5

## ... AND THIS DEVELOPMENT WILL CONTINUE IN YEARS TO COME

AVERAGE ANNUAL GROWTH RATE OF WORLD  
POPULATION AGED 60 OR OVER



# THE AGEING POPULATION

→ **Between 1950 and 2000**, the number of people aged 60 years or over has tripled worldwide. By 2050, it will have tripled again. See figure 4. In practically every region of the world, the ageing population is growing faster than the population in total – and this difference in growth rate is on the rise.

Currently, the growth rate of the ageing population is 1.9 per cent compared to 1.2 per cent for the population in total. However, projections indicate that the population aged 60 and above will be growing 3.5 times as fast by 2025-2030 (2.8 per cent compared to 0.8 per cent). See figure 5.



# GLOBAL INEQUALITY

→ **Across the globe, healthcare spending is tremendously diverse.** The annual amount spent on healthcare per capita is 13 times higher in Europe than the amount spent in the Middle East and Africa.

North America is currently the region that spends most money on healthcare, amounting to USD 5,335 per capita annually. In the Asia-Pacific Region it is USD 303 and in

the Middle East and Africa the average annual expenditure is just USD 191 per capita. See figure 6.

This transfers directly to the actual access to healthcare. For instance, high-income countries have 56 hospital beds per 10,000 citizens. Upper-middle-income, lower-middle-income and low-income countries have 37, 21 and 12 respectively.<sup>1</sup>

FIGURE 6

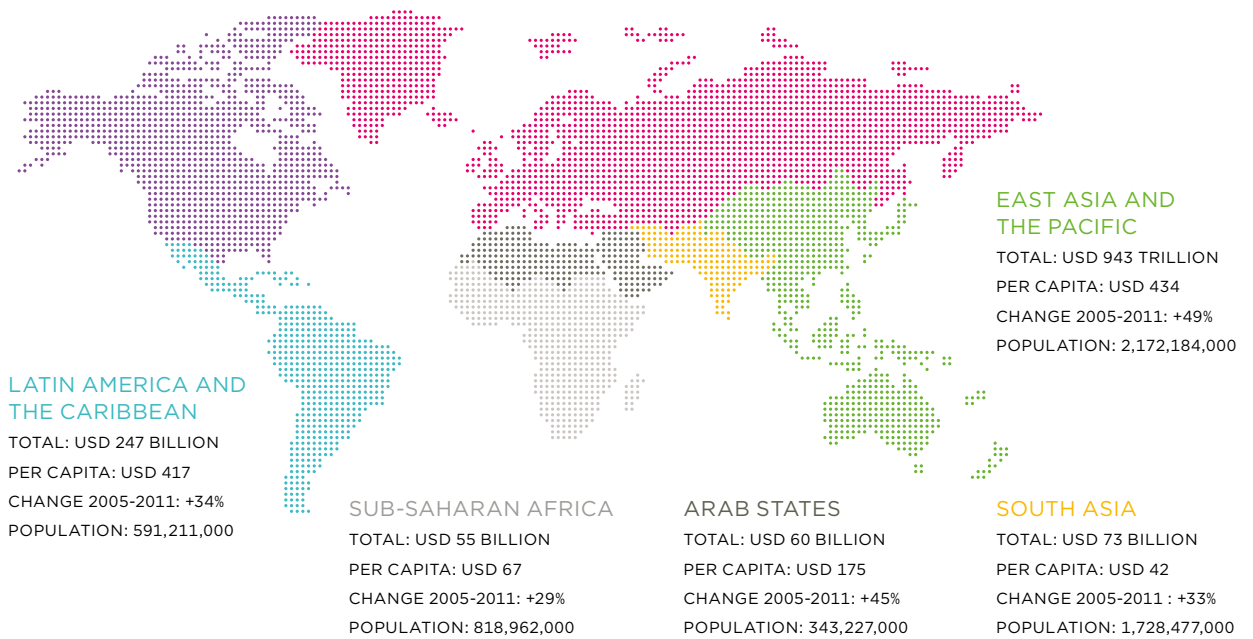
## THE GLOBAL HEALTH DISPARITY WORLDWIDE SPENDING ON HEALTHCARE

### US AND CANADA

TOTAL: USD 2,512 TRILLION<sup>1</sup>  
PER CAPITA: USD 7,228  
CHANGE 2005-2011: +20%  
POPULATION: 347,568,000

### EUROPE AND CENTRAL ASIA

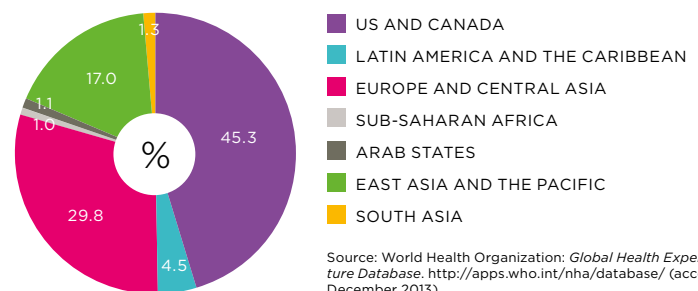
TOTAL: USD 1,652 TRILLION  
PER CAPITA: USD 1,837  
CHANGE 2005-2011: +12%  
POPULATION: 898,809,000



### WORLDWIDE

TOTAL: USD 5,542 TRILLION  
PER CAPITA: USD 803  
CHANGE 2005-2011: +22%  
POPULATION: 6,900,439,000

### PERCENTAGE OF GLOBAL SPENDING ON HEALTHCARE



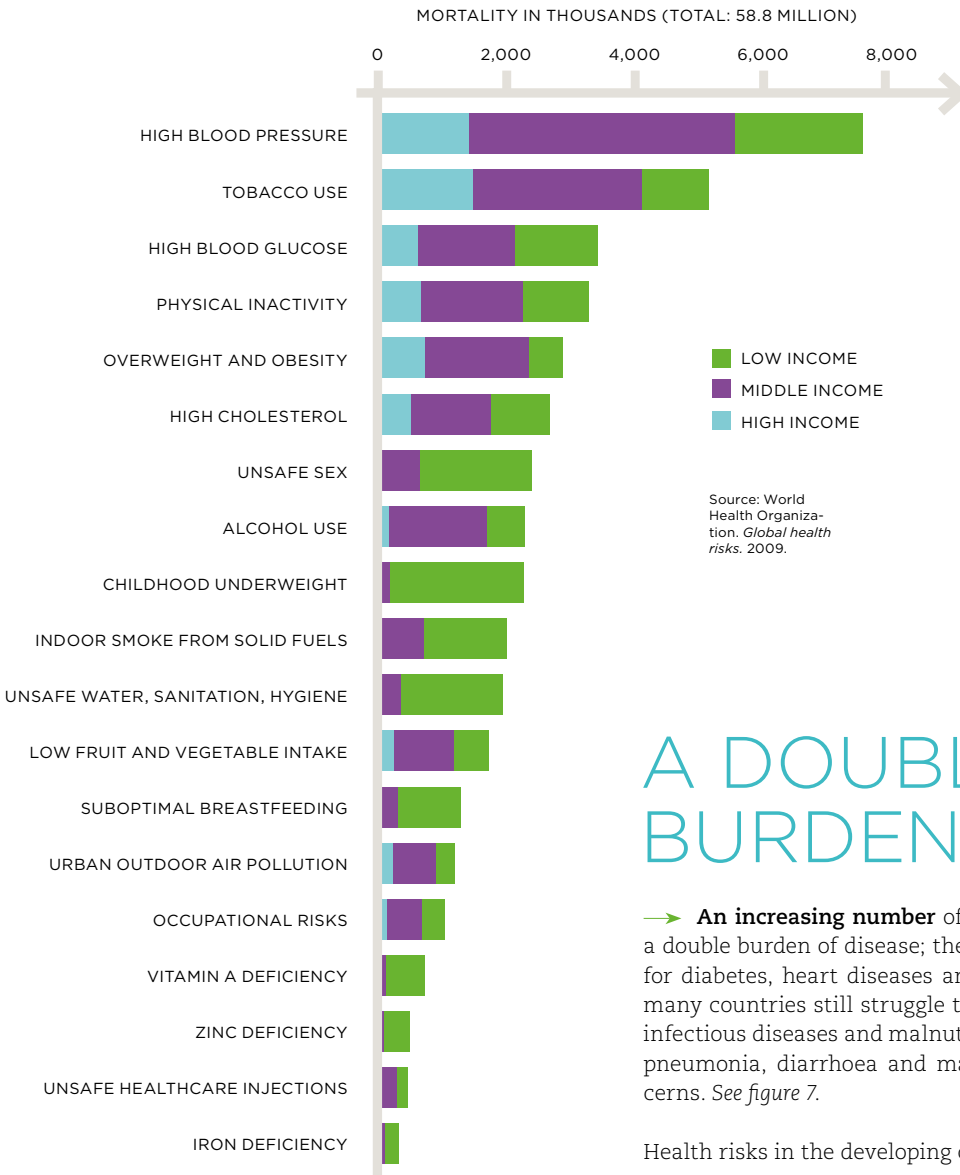
Source: World Health Organization: *Global Health Expenditure Database*. <http://apps.who.int/nha/database/> (accessed December 2013).

Note<sup>1</sup>: World Health Organization. *World Health Statistics 2013*. 2013: p219.

FIGURE 7

## HEALTH RISKS RELATING TO POVERTY

DEATHS ATTRIBUTED TO 19 LEADING RISK FACTORS, BY COUNTRY'S INCOME LEVEL, 2004



## A DOUBLE BURDEN

→ **An increasing number** of developing countries face a double burden of disease; the prevalence of risk factors for diabetes, heart diseases and cancer increases, while many countries still struggle to reduce deaths caused by infectious diseases and malnutrition. Furthermore, AIDS, pneumonia, diarrhoea and malaria are still major concerns. See figure 7.

Health risks in the developing countries include:

- More than 1 billion people suffer from infectious diseases.
- Easy-to-remedy nutritional deficiencies result in the fact that 1 in 38 new-born babies in low-income countries never reach the age of five.
- In 2010, an estimated total of 2.7 million people became infected with HIV. Every year, 1 million African women die from human papillomavirus, HIV or other sexually transmitted diseases.
- In 2010, an estimated 216 million cases of malaria led to approx. 655,000 deaths – 86 per cent of which were children under the age of five.

# SOCIAL INEQUALITY

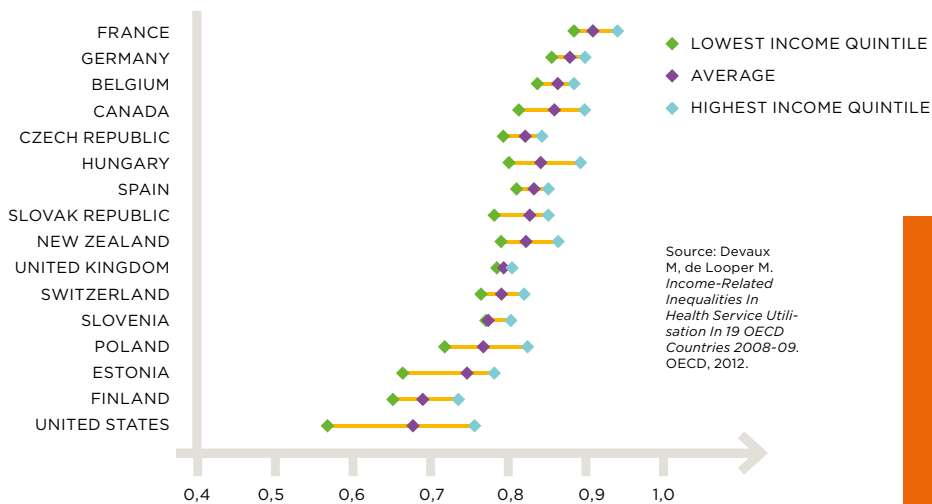
→ **Around the world** existing healthcare sectors are still characterized by social inequality. The so-called inverse care law<sup>2</sup> states that “the availability of good medical care tends to vary inversely with the need for it in the population served. This (...) operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced”. In many countries, the poorest part of the population *needs* healthcare services the most, while their wealthier countrymen have easier *access* to healthcare and make more use of it.

A study conducted by the OECD shows that the frequency of doctor visits rises in line with income level. See figure 8 and 9. In most countries, people with high income are more likely to visit a doctor than people with low income – even though they experience the same level of need for care. The same is true for the use of specialists. In all countries, wealthy people consult specialists more often than poor people do. In other words, the richer you are, the better access you have to the healthcare system.

FIGURE 8

## VARIATION IN VISITS TO DOCTORS...

NEEDS-ADJUSTED PROBABILITY OF A VISIT TO THE DOCTOR WITHIN THE LAST 12 MONTHS BY INCOME QUINTILE, 2009 (OR LATEST YEAR)



Source: Devaux M, de Looper M. *Income-Related Inequalities In Health Service Utilization In 19 OECD Countries 2008-09*. OECD, 2012.

### WOMEN HAVE MORE LIMITED ACCESS TO HEALTHCARE

Despite the fact that life expectancy is higher for women in many countries, the WHO concludes that “a number of health factors create a lower quality of life for women”<sup>\*</sup>.

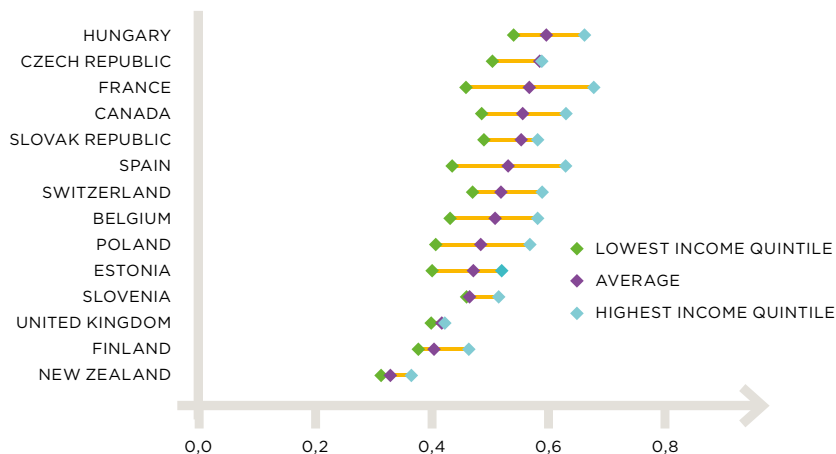
For instance, every day 1,600 women die from preventable complications during pregnancy and childbirth, almost 99 per cent of whom are found in the developing world. Many of these deaths could be prevented if the woman was able to leave her home to receive treatment, or if she had a skilled attendant by her side.

Note\*: World Health Organization. *10 Facts on Women's Health*. 2009.

FIGURE 9

## ... AND SPECIALISTS

NEEDS-ADJUSTED PROBABILITY OF A VISIT TO A SPECIALIST WITHIN THE LAST 12 MONTHS BY INCOME QUINTILE, 2009 (OR LATEST YEAR)



Note<sup>2</sup>: Hart JT. The Inverse Care Law. *The Lancet* 1971;297(7696): 1.



# PATIENT SAFETY

→ **Patient safety is a serious issue** in healthcare systems around the world. Globally, approximately 43 million patient safety incidents occur each year. They account for a staggering 23 million disability-adjusted life years. This makes patient safety incidents the 14th leading cause of morbidity and mortality – comparable to diseases like TB or malaria.

Patient safety issues affect all countries, regardless of income group. For example, in Latin America, a study showed that out of every 100 patients who experienced harmful incidents, 63 had to extend their hospital stay, 18 had to be readmitted and only 19 did not need to spend additional days in hospital. On average, harmful incidents extended the duration of hospitalization by more than 16 days per patient.<sup>3</sup>

In Denmark, 150,000 adverse events are reported each year, one fourth of which prompt renewed treatment or re-admission to hospital. That means that around 15 per cent of all hospitalized patients nationwide are victims of an adverse event. And according to The National Agency for Patients' Rights and Complaints, the authority which is responsible for registering and monitoring these events, this is just "the tip of the iceberg".<sup>4</sup> Between 1,000 and 5,000 of these events are lethal.

A recent American study, published in the *Journal of Patient Safety* in September 2013, estimates that the nation-

wide number of premature deaths caused by preventable harms amount to more than 400,000 each year.<sup>5</sup>

In addition to the unnecessary loss of lives and life quality, patient safety incidents represent a significant financial burden in terms of wasted resources and poor productivity.

The alarming number of harmful events is one thing – another concern is that we can not determine this number very accurately. It is almost impossible to find credible and comparable data on adverse events and fatalities or robust assessments of the "preventable" costs. One reason for this level of uncertainty is the lack of standardised measures and means to capture patient safety incidents.

As more people around the world live with multiple chronic co-morbidities, the challenge to deliver safe person-centered care will increase further. As a group of researchers state, patient safety incidents "no longer relate only to episodic errors and failures in procedures at specific times, but also to cumulative failures throughout a patient's journey within a health system".<sup>6</sup>

In later chapters we examine how risk based approaches to system design and delivery can enable the provision of safer person-centered care.

Note<sup>3</sup>: World Health Organization. *IBEAS: A pioneer study on patient safety in Latin America - towards safer healthcare*. 2011.

Note<sup>4</sup>: Rasmussen E. *Danskernes farligste rejse*. Mandag Morgen 2013.

Note<sup>5</sup>: James JT. A new evidence-based Estimate of Patient Harms Associated with Hospital Care. *Journal of Patient Safety*. 2013; Volume 9; Issue 3:122-128.

Note<sup>6</sup>: Degos L, Amalberti R, Bacou J, Cartlet J & Bruneau C. Breaking the mould in patient safety. *BMJ* 2009; 339:82-85, p84.

# LACK OF HEALTH PROFESSIONALS

→ **Globally there is a chronic shortage** of healthcare professionals. There are not enough physicians and nurses to meet the demands and needs of the global population. The shortage is most notable in the developing world. While high-income countries have 27 physicians and 72 nurses per 10,000 citizens, low-income and middle-income countries have 5 and 14 respectively. See figure 13.

According to the WHO, 57 of the world's 192 countries have a shortage of doctors, nurses and midwives – 26 of these are countries in the African region.

## CONCLUSION

→ **Demographic change**, the rise in chronic diseases, increasing demands from patients and restrained public spending produce challenges and demands that existing healthcare systems have difficulties dealing with. It is increasingly evident that the quality, safety and funding of global healthcare systems are under pressure – and that this pressure is mounting.

This calls for new ways of understanding and organizing healthcare services. Around the world, healthcare providers and political decision makers are beginning to recognize person-centred care as an essential part of this transformation – and a solution to some of the major healthcare challenges.

The following chapter examines how the concept of person-centred care has migrated from the domain of pioneering practitioners and scientists to the top of the political agenda.

FIGURE 12

### NOT A HOSPITAL BED FOR EVERYONE...

HOSPITAL BEDS PER 10,000 POPULATION

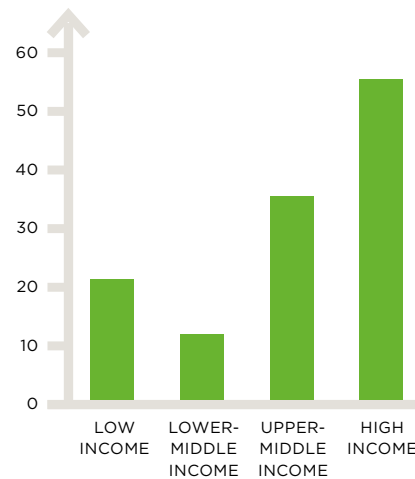
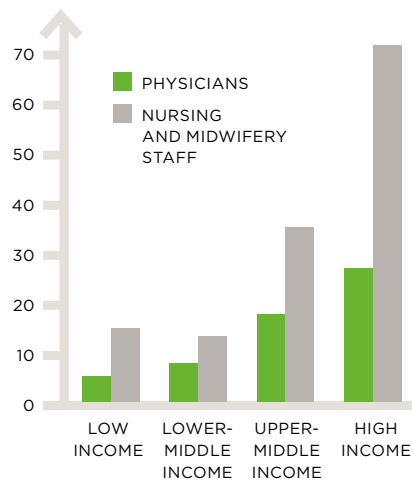


FIGURE 13

### ... AND NOT A HEALTH PROFESSIONAL FOR EVERYONE

PHYSICIANS, NURSES AND MIDWIVES PER 10,000 POPULATION



Source: World Health Organization, *World Health Statistics*, 2013.

NEXT  
THE NEXT  
BLOCKBUSTER



CHAPTER  
4/10

ALL CHAPTERS



*“My first meeting  
with the medical  
profession  
was **not good.**”*



- **Ann Steyn**, South Africa, Breast Cancer

**Age:** 73 years

**Occupation:** A former school teacher and lecturer at Cape Town University's faculty of education.

**Family:** Married, with three grown-up children

**Hobbies:** Likes walking and enjoys the wildlife of South Africa



→ **Ann Steyn is a two-time breast cancer survivor.** At the age of 50, she was diagnosed with cancer and had one of her breasts removed. 14 years later, cancer struck again. She describes two completely different encounters with South Africa's healthcare system.

"The first time, I felt let down by my health service," Ann says, thinking back on the hectic time in 1990. She remembers the fear and uncertainty.

"I had found a lump and I went to the doctors several times to have it looked at. But they kept telling me: 'No, there is nothing wrong, you are fine,'" she explains. The doctor just asked her to come back in six months time for another check-up.

But she came back just a couple of months later because, as she says, "I was absolutely convinced that there was something wrong."

Only then was she set up for a mammographic screening – something that had not been discussed earlier.

"In my ignorance, I never asked for one," she recalls with regret.

She had the screening, and as the doctor read the test results an hour later, he realized that Ann did indeed have cancer. She was hospitalized that same day.

"I went in that afternoon, and they did some more tests on me. And in the early hours of the next day, they removed a breast," she says. Today, she still wonders if that had in

fact been necessary. But it did not enter her mind to question the doctor's judgment. "He explained what he would do, and that was it. I had no say in the decisions whatsoever," she explains.

"My first meeting with the medical profession was not good."

Much had changed 16 years later when she was diagnosed with cancer again.

This time around, it was a young female surgeon, who was much more engaging with Ann, setting up different possibilities for treatment, asking about other aspects of her life. Compared to her first encounter, this was an entirely new approach. This time both she and her husband were involved in the decision-making process.

Ann firmly believes that supportive care plays a vital role in the patient's rehabilitation and should be a part of person-centred care.

"It is a very frightening and lonely thing, going to a hospital. And when you have cancer, it becomes even more frightening," says Ann. That is why a doctor who recognises the patient's emotional and psychological turmoil is so much better.

"I have seen a huge improvement in the way doctors and patients discuss things. There are still some doctors that will simply tell you 'this and this is going to happen'. But many doctors seem to engage much better and involve the patients in the decision-making," she says.

CHAPTER 4

# THE NEXT BLOCKBUSTER

- THE BIG BREAK FOR PERSON-  
CENTRED CARE



THE CONCEPT OF PERSON-CENTRED CARE IS ON THE VERGE OF A BREAKTHROUGH. HEALTHCARE SYSTEMS ARE ACTIVELY SEEKING WAYS TO PROMOTE A MORE INDIVIDUAL APPROACH.

→ **It took** the British navy 194 years from the initial discovery of the fact that lemons prevented scurvy to their inclusion in the dietary guidelines in 1795<sup>1</sup>. During that incubation period thousands of seamen met their death due to scurvy.

This very long incubation period is far from the reality today. Since then, healthcare professionals have been trained to adapt new insights at a still higher pace. This is a skill much in demand today - and increasingly so in the years to come.

“One of the most important advances in medicine has been the ability to adopt new ideas faster,” says Alan Manning, Chief Operating Officer at Planetree, a non-profit organization dedicated to spreading the idea of person-centred care. On a global scale, healthcare organizations in nearly twenty countries cooperate with Planetree on implementing the principles of person-centred care in their organizations.

“When our founder started to talk about patient-centred care in the 1970s, people thought we were lunatics. Today, part of the reimbursement to hospitals relies on patients’ satisfaction with their treatment,” says Alan Manning.

His assessments are shared by Carol Cronin, founder and

CEO of The Informed Patient Institute (IPI), another non-profit-organization that tries to facilitate access to credible online information about healthcare quality and patient safety.

“Twenty years ago hardly anyone talked about patient-centred care. Then, the concept was introduced in the literature, and in 2001 the Institute of Medicine defined patient-centred care as one of the decisive elements in quality of care,” she explains.

Like Alan Manning, she acknowledges that there is a gap between knowing and doing. But the strain on healthcare sectors around the world forces decision makers to look for new solutions, which could create a window of opportunity for the person-centred approach. *See chapter 3.* This was exactly the point made by Maureen Bisognano, president of the US-based Institute for Health Improvement, stating that “patient engagement is the next blockbuster drug.”<sup>2</sup>

This development from the periphery towards the centre of healthcare discussions is also observed by experts at the universities.

“Today, we see an increased focus on patient-centred approaches. Politicians and researchers are beginning to

Note<sup>1</sup>: Gillam M, et al (eds.). *The Fourth Paradigm: Data-Intensive Scientific Discovery*. Microsoft Research, 2009. p57-64.  
Note<sup>2</sup>: Britnell M. From god to guide: can patient-centred care become a reality in the NHS? *The Guardian*. May 14 2013.

FIGURE 1

## FROM IDEA TO POPULAR CONCEPT

PERSON-CENTRED CARE HAS EVOLVED FROM A GENERAL IDEA TO A SUBJECT OF IMMENSE POLITICAL INTEREST AND THOROUGH SCIENTIFIC RESEARCH.

Source: DNV GL / Sustainia

### 2006. ...AND CUTTING COST.

The International Alliance of Patients' Organizations (IAPO) issue the *Declaration of Patient-Centred Healthcare*. Taking account of patient's needs is also cutting costs.

### 2001. "CROSSING THE QUALITY CHASM"

The US Government's Institute of Medicine defines person-centred care as an aspect of healthcare quality.

**1998. A NEW HEADLINE.** At a Salzburg Global seminar 64 experts from 29 countries discuss person-centred care under a new popular headline: "Nothing about me without me".

**1993. NEW DIMENSIONS.** The book "Through the Patient's Eyes: Understanding and Promoting Patient-centered Care" defines the modern understanding of person-centred care in eight dimensions.

**1986. PROMOTING THE CONCEPT.** The Picker Institute — an American based non-profit organization — is founded.

**1978. A MANIFESTO.** An American initiative, Planetree, is founded by the former patient Angelica Thieriot.

**1950. CARE IS MORE THAN MEDICINE.** A Hungarian GP, Michael Balint, coins the concept and urges physicians to take a holistic rather than a strictly medical view on care.

**2012. NHS REFORM.** Patient-centredness is highlighted as a key principle in the UK's extensive reform of its national health services.

**2010. US HEALTH REFORM.** The Patient Protection and Affordable Care Act adopts a number of person-centred approaches to healthcare.

**2010. NOT ONLY FOR THE RICH.** WHO widen the scope and describe how people-centered care can be implemented and scaled-up in low- and middle-income countries.

**2009. A LONG LEAP FORWARD.** China's extensive healthcare reform includes a number of person-centred elements.

**2008. HOW-TO-DO-IT GUIDE.** Planetree and Picker institute publish *The Patient-Centered Care Improvement Guide*. The guide is a how-to-do-it tool to place patients at the centre of care.

realize the potential of putting the patient in the centre of treatment. This insight is the driving force in a line of initiatives and activities moving healthcare in a more patient-centred direction,” says Angela Coulter, Senior Research Scientist at Health Services Research Unit at Oxford University.

### A boom in research

Originally, the idea of person-centred care was a radical thought presented by the Hungarian physician, Michael Balint. See figure 1. More than 60 years later, it has become an established field of scientific study amongst researchers around the world.

The accumulated amount of research available demonstrates that person-centred care has become a popular – if not mainstream – field of research among medical scientists. In 1980 and 1990, the number of scientific articles focusing on different aspects and elements of person-centred care amounted to 20 and 58, respectively. However, in 2012 alone there were more than 2,000 scien-

tific articles on the subject. See figure 2.

“The idea of patient-centred care is gaining momentum among researchers – it is something that people within medical research are increasingly focusing on,” says Per Hasvold, Senior Researcher at the University Hospital of North Norway and manager of the Norwegian Centre for Integrated Care and Telemedicine.

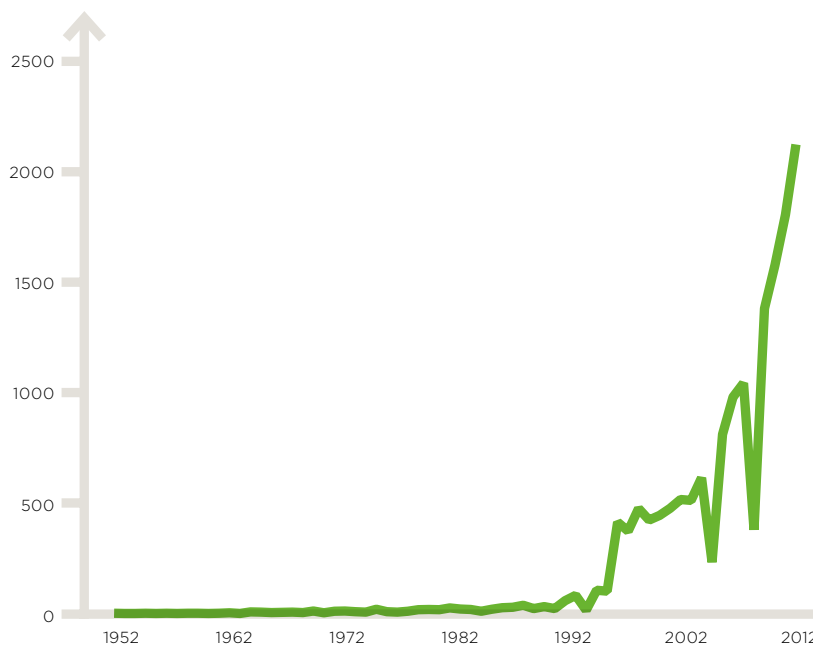
This development reveals a change in attitudes among medical researchers, indicating an acceptance of this approach as an important contributor to the development of the healthcare sector.

“I thought it was just another buzzword, when I first came across the idea. But I have come to realize that it does in fact represent a concept that is important and improves the quality of our healthcare,” says Saul Weiner, Professor of Medicine, Paediatrics and Medical Education at the Institute for Health Research and Policy at the University of Illinois.

FIGURE 2

## RESEARCHERS COVER NEW GROUND

ACCUMULATING NUMBERS OF ARTICLES FOCUSING ON ELEMENTS AND ASPECTS OF PERSON-CENTRED CARE IN THE MEDICAL DATABASE PUBMED\*



Source: DNV GL / Sustainia

Note\*: Search conducted on PubMed in May 2013 – based on “person centered”, “family centered”, “integrated care”, “patient centered”.

Within the last couple of years, several institutions and NGOs (such as The Health Foundation and King's Fund in the UK and PlaneTree in the US) as well as a growing number of universities (see text box) have set up departments and projects dedicated to research on person-centred care.

In recent years, the WHO has also increased its focus on person-centred care:

"WHO is currently focusing on the concepts of person-centred and integrated care as an important part of programmes and as a basis of how we can ensure better response to the health needs of the world's population," says Anayda Portela, Technical Officer at the Department of Maternal, Newborn, Child and Adolescent Health at WHO. She has been working with a person and community care oriented project improving maternal health in developing countries. See chapter 5, page 68.

#### Visions pave the way for political action

On the political stage, a similar momentum for person-centred care is building; in countries such as the US, the UK, Denmark, Sweden and Australia, the concept has played an important part in discussions on a possible restructuring of national healthcare systems for some time.

Furthermore, the elements and ideas behind person-centred care have also become more prominent contenders in the political debate, and several countries have produced more specific plans and strategies for implementing this approach within their healthcare systems in the last couple of years. See opposite page.

"Within the last 10-15 years, healthcare systems in developed countries have gradually recognized that the quality of care has to become a top priority and that money is not enough; they have to be more determined on managing health experience, patient safety and quality of treatment," says Jocelyn Cornwell. She is a senior fellow at The King's Fund and the director of the Point of Care Foundation – a foundation that strives to keep patients' experience of care high on the agenda of policy makers and boards.

Angela Coulter agrees: "There is an increased focus on patient-centred care. It is something that policy makers discuss and focus on. And it is being embedded directly in the healthcare policies of many countries as a vital part of how the future healthcare sector should be organized".

On the political level, person-centred care is regarded as

#### THE SWEDISH FRONT RUNNERS

One of the latest examples of the increasing focus on person-centred care from the field of research is the Centre for Person-centred Care at University of Gothenburg in Sweden. The centre was established in 2010 by Professor Inger Ekman with strategic funding from the Swedish Government. The aim was to establish a centre of excellence in person-centred care. This has made the university one of Europe's leading institutions in dealing with person-centred care.

The centre includes more than 100 researchers from a wide array of academic disciplines including medicine, nursing, economics, linguistics and drama, in a grand attempt to create a broad evidence-base for a sustainable change of healthcare.

The centre has recently initiated the EU-funded project WE-CARE, a collaboration between seven European universities and organizations with expertise in healthcare and technology.

a means of enhancing the quality of treatment, financial viability and patient safety. One example is the American National Strategy for Quality Improvement in Health Care, published in 2011. This strategy encompasses three broad aims, one of which is to create better care and improve "the overall quality, by making health care more patient-centred, reliable, accessible, and safe."<sup>3</sup>

#### PCC: Important for all countries

Expert statements, leading literature, best practice examples and current policy frameworks indicate that the concept of person-centred care has mainly caught the attention of professionals and decision makers in the more developed parts of the world.

But in developing countries and emerging economies, person-centred care has managed to obtain some attention – and in certain countries it has been a political priority for quite some time. In China, the ideas and thoughts of

Note<sup>3</sup>: U.S. Department of Health and Human Services. *National Strategy for Quality Improvement in Health Care*. 2012.

# STEPPING IT UP

➔ **Many countries are committing** to a more person-centred approach to healthcare:

- *Since April 2013, the UK National Health System (NHS) has been implementing a reform with three interconnected goals: placing patients at the centre, changing the emphasis of measurement to clinical outcomes and empowering general practitioners. The reform is framed as the most extensive since the foundation of the NHS<sup>4</sup>.*
- *In the US, the National Strategy for Quality Improvement in Health Care, published in March 2011, set three goals for quality improvement, and patient-centred care is listed as number one. In the National Healthcare Quality Report from 2011<sup>5</sup>, “patient centeredness” is one of seven measures of quality in the health-care sector.*
- *Sweden has made a great leap towards implementing person-centred care in the Swedish healthcare sector. In 2012, The Swedish Agency for Health and Care Services Analysis published a report with recommendations to promote person-centred care. In the spring of 2013, the Swedish National Audit Office published a report examining how Sweden can implement person-centred care through legislation and national guidelines. In June, a commission, Patientmaktutredningen, published a report proposing ways of how legislation could help empower patients<sup>6</sup>.*
- *Australia has implemented a long line of person-centred healthcare initiatives on a national policy level. Recent initiatives include national health reform arrangements such as the Performance and Accountability Framework of the 2010 National Health and Hospitals Network Agreement, aimed at providing incentives to improve focus on patients by linking it to performance and funding<sup>7</sup>.*
- *In Canada, the Ministry of Health and Long-Term Care in Ontario is working to “establish a patient-focused, results-driven, integrated and sustainable publicly funded health system”<sup>8</sup>.*
- *Since 1997, person-centred approaches have played a significant role in the development of China’s healthcare system<sup>9</sup>. In April 2009, the Chinese government unveiled a blueprint for developing healthcare over the next decade, kicking off a much-anticipated reform to fix the ailing medical system and to ensure “safe, effective, convenient and affordable” health services for its 1.3 billion citizens. The Chinese government has guaranteed that its new guiding principle will be “people-centered”<sup>10</sup>. Public, non-profit hospitals will continue to be the predominant providers of medical services, while increasing priority will be given to the development of grassroots-level hospitals and clinics in cities and rural areas.<sup>11</sup>*



Note<sup>4</sup>: Lansley A. *A Patient Centred NHS*. Speech at Guy’s and St Thomas hospital. 7 December 2011.

Note<sup>5</sup>: Agency for Healthcare Research and Quality. *National Healthcare Quality Report 2011*. 2012.

Note<sup>6</sup>: Socialdepartementet: Ansvarfull hälso- och sjukvård. Slutbetänkande av Patientmaktutredningen. 2013

Note<sup>7</sup>: Council of Australian Governments. *National Health and Hospitals Network Agreement*. 2010.

Note<sup>8</sup>: Ontario Ministry of Health and Long-term Care, [www.health.gov.on.ca/en/common/ministry/](http://www.health.gov.on.ca/en/common/ministry/) (accessed December 2013).

Note<sup>9</sup>: Yang J. *The side-effects of China’s patient-centred healthcare reform*. 2010.

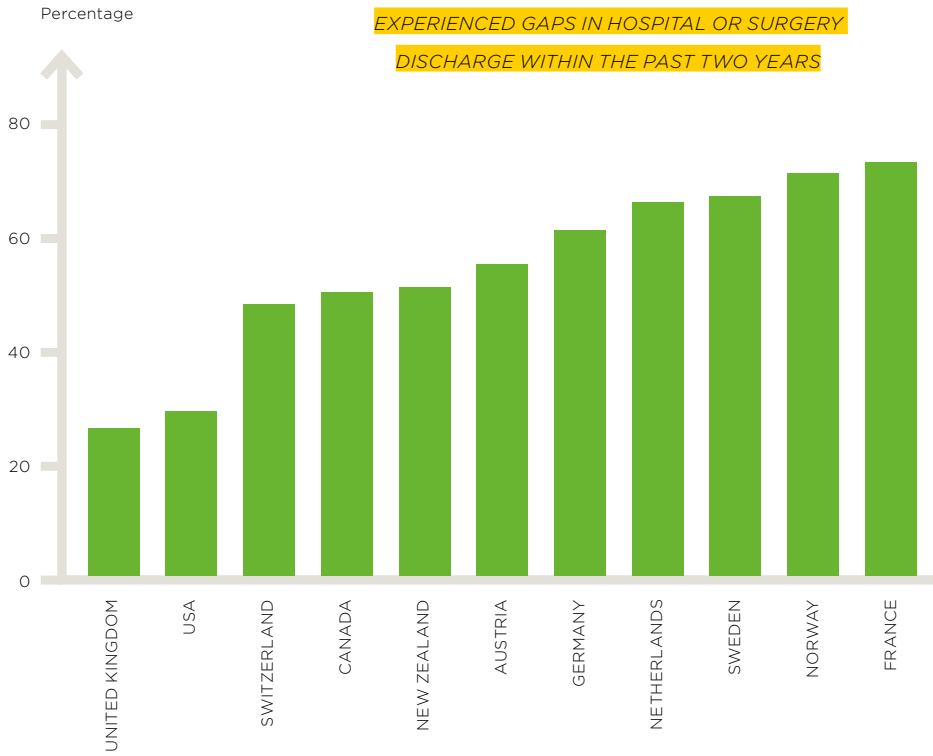
Note<sup>10</sup>: Yip W, Hsiao WC. The Chinese Health System At A Crossroads. *Health Affairs* 2008;27(2): 460-468.

Note<sup>11</sup>: People’s Daily Online. *China Unveils health-care reform guidelines*. 7 April 2009.

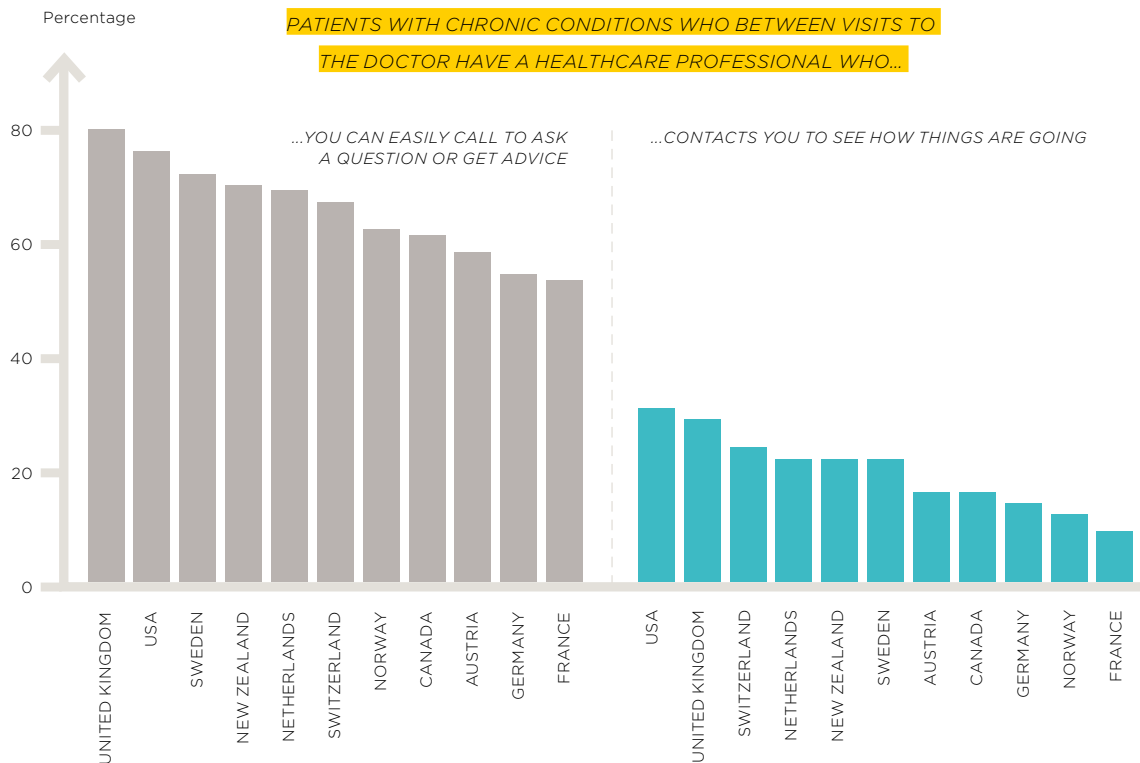
FIGURE 3

## NOT A REALITY YET

DESPITE POLITICAL AMBITIONS, THESE EXAMPLES OF GAPS IN THE CURRENT HEALTH SYSTEMS UNDERLINE THAT THERE IS STILL A LONG WAY TO GO IN MAKING PERSON-CENTRED CARE A REALITY.



Source: Schoen C, Osborn R. *The Commonwealth Fund 2011 International Health Policy Survey of Sicker Adults in Eleven Countries*. The Commonwealth Fund, 2011.





person-centred care became part of the national healthcare reform as early as 1997 and have remained the main theme of hospital management reform since 2005<sup>12</sup>.

“China was one of the first countries in the world to implement the idea of patient-centred care into their healthcare policy. It was organized through a top down approach, with healthcare policy makers imposing it on professionals – they were for instance forced to strengthen communication, respect privacy, treat patients like humans, smile more, be polite, explain illness more,” Jingqing Yang says. He has written several papers on the Chinese healthcare system and their person-centred healthcare reform. He currently works for the Institute for International Studies at the University of Technology in Sydney.

Today, he believes that the healthcare sector in China is still far from being person-centred, but he also acknowledges that the reform helped improve the rights of the patient.

“It provided some change in the way doctors and patients interact – and helped to create a culture that focuses more on patients, but the Chinese healthcare sector is not patient-centred through and through,” he concludes.

In Malaysia – a country of 27 million people with limited resources for healthcare – principles of person-centred care have been incorporated into national health policies<sup>13</sup>. In practice this means that the policy makers have decided to include a “personal focus” as one of the goals for Malaysia’s National Health Service. In order to meet this goal, The Ministry of Health has introduced a set of innovations to improve the quality of healthcare and person-centred care. By way of example, residents of the rural and more remote areas in the East Malaysian provinces have their own home-based health cards, which gives them ready access to their health records and allows them to seek healthcare at any facility.

The conclusion so far is that person-centred care is possible also in countries with limited resources. A recent study, “People-centred care in low and middle-income countries” undertaken by the WHO, looks at five different examples of people-centred care initiatives in developing countries and states that “people-centred care is feasible

in low- and middle-income countries. While approaches have differed, all have been able to make service delivery more people-centred in a context of competing priorities and scarce resources.”<sup>13</sup>

However, it is not something easily accomplished and introducing person-centred care in developing countries has a very different point of departure than in more developed countries

“In developing countries such as Pakistan, the ambitions with patient-centred care have to start at a very basic level – we have to teach patients the basic skills. Another important part is to secure access to treatment that is qualified and safe,” says Asfandiyar K. Niazi, researcher at the Shifa College of Medicine in Islamabad, Pakistan.

#### Still a long way to go

Despite the growing focus and attention afforded to person-centred care, it is still far from standard practice. No country has succeeded in creating a fully person-centred healthcare sector, “we have yet to see a healthcare system built around a person-centred approach,” as Per Hasvold states.

The same observation is made by Angela Coulter, “the US and the UK are taking some political and organizational steps towards this approach, as are countries in Scandinavia. But even in these countries, the patient-centred approach is not a cornerstone of the healthcare system.”

This is also revealed when looking at different models of funding and organizing healthcare. *See next page.* A survey from the Commonwealth Fund focusing on eleven countries that represent all four healthcare models concludes that person-centred care is a long way from becoming a reality in current healthcare systems – regardless of financing and structure. It also becomes evident when looking at cohesiveness in care and communication between patients and professionals. *See figure 3.*

“There is still a long way to go. We hear people saying that patient-centred care is the right thing, but they don’t always live by it. I think it is because people do not see a structure enabling it to be successful,” says Alan Manning.

Note<sup>12</sup>: Yang J. *The side-effects of China’s patient-centred healthcare reform.* 2010.

Note<sup>13</sup>: World Health Organization. *People-Centred care in low- and middle-income countries.* 2010. p17.

# FOUR FUNDING MODELS

## – NONE OF THEM PERSON-CENTRED

→ **“The sum of the people, institutions and resources arranged together to maintain and improve the health of the people they serve.”** This is how the WHO defines a healthcare system.<sup>14</sup> A healthcare system involves three major agents: patients or consumers, healthcare providers or producers, and third-party players.

As the broad definition suggests, countries around the world manage healthcare in different ways and with different resources. But despite the many local variations,

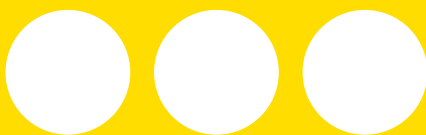
healthcare systems tend to follow general patterns when it comes to healthcare coverage, ownership, organization, financing, incentives and division of public/private providers. Based on these structures, the world’s healthcare systems are commonly divided into four models.

Mapping the state of person-centred care, it has become evident that none of the four models are leading when it comes to having person-centred care implemented as standard practice.



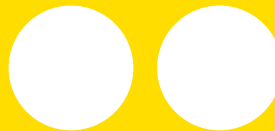
### THE BEVERIDGE MODEL

- Named after William Beveridge, a social reformer who designed Britain’s National Health Service.
- Healthcare is provided and financed by the government through tax payments, just like the police force or public libraries.
- The majority of hospitals and clinics are owned by the government; some doctors are government employees, but there are also private doctors, who collect their fees from the government.
- Countries that have implemented the Beveridge plan or variations of it include the UK, Spain, Scandinavia, New Zealand, Hong Kong and Cuba.



### THE NATIONAL HEALTH INSURANCE MODEL

- The NHI model combines elements from the Beveridge and the Bismarck models.
- Healthcare services are based on private-sector providers, but payment comes from a government-run insurance program that every citizen pays in to.
- Health insurance covers everybody
- The NHI system is found in Canada, and some newly industrialized countries - for example Taiwan and South Korea - have also adopted the model.



### THE BISMARCK MODEL

- Named after the Prussian Chancellor Otto von Bismarck, who invented the welfare state as part of Germany’s unification in the 19th century.
- Healthcare is provided and financed through an insurance system - “sickness funds” - usually financed jointly by employers and employees through payroll deduction.
- Health insurance plans have to cover everybody, and they do not generate a profit.
- The majority of doctors and hospitals are private.
- The Bismarck model is found in Germany, France, Belgium, the Netherlands, Japan, Switzerland, and, to a certain degree, Latin America.



### THE OUT-OF-POCKET MODEL

- The Out-Of-Pocket Model is essentially a kind of “non-system”; individual patients pay for medical treatment upfront.
- This model is the dominating model for the vast majority of developing countries. It could also be said to apply to parts of the population in developed countries, e.g. the 15 per cent of the American population, who have no health insurance.

Note<sup>14</sup>: World Health Organization. *Key components of a well functioning health system*. 2010

*NEXT*  
INSPIRATIONAL  
PERFORMANCES



*CHAPTER*  
5/10

*ALL CHAPTERS*



*“I wish patients would take **more responsibility** for their own health”*



- **Tifiro Cook**, USA, kidney transplant recipient

**Age:** 44 years

**Occupation:** Fitness consultant, health advocate, motivational speaker.

**Family:** Wife and two young children

**Hobbies:** American football, workout, riding a motorbike and watching movies

→ At the age of 17, Tifiro Cook was “strong as a horse”, as he puts it. He played American football at semi-professional level and had just received a scholarship from Hartnell College in Salinas California. Despite the intense workout and football practice several times a week, he was suddenly gaining weight around his ankles.

Then one day at practice, his dream of becoming a professional football player suffered a major blow.

“I was running, and suddenly I felt a sting of pain in my chest that forced me to stop. The coach was yelling and yelling, but I just couldn’t move because of the pain,” he recalls. His blood pressure was incredibly high, and he was taken to the local emergency ward immediately.

A biopsy soon revealed that Tifiro was suffering from a renal disease – his kidney did not adequately filter waste products from his blood, and so from one minute to the next, he became a patient.

That was Tifiro’s first encounter with the healthcare system. Since then, he has spent more than half his lifetime “being a patient”. He has spent more than ten years in dialysis, he has undergone thirty surgeries, and he is a two-time kidney transplant recipient.

The first few years, while he was still in his late teens, Tifiro lived in denial of his body’s shortcomings.

“At that age, you think you are invincible. A lot of my friends were drinking and partying. All I ever relied on was my body. I just wanted to play football forever. So, I couldn’t quite believe this was happening to me. I was seventeen years old and living in denial. But then I had a heart incident,” he explains.

That was a second blow to his dreams. His life changed dramatically, as he was forced to focus on his health. He was growing up much faster than his healthy friends.

“I was living a life of health worry. At some point I realised it and started acting on it,” he says.



Each week, Tifiro would go to the hospital or to see his doctor for dialysis and health checks. Throughout his life he has kept up a healthy lifestyle despite his condition. “I don’t know what was in me, being strong like that. I just kind of lived up to it,” he elaborates.

Tifiro has met many patients during his lifetime, and far too many place the responsibility for their health in the hands of doctors. Or worse: ignore the fact that they are ill.

“A lot of people don’t take responsibility, maybe because they are still living in denial. But you have to. You always have to put your health in your own hands,” he argues.

He recalls one bad encounter with the hospital. He was sick from an infection and lying in a hospital bed when a doctor entered the room. Without saying much, the doctor started preparing a penicillin injection. Tifiro told him it was a bad idea, as he was allergic to penicillin.

“He didn’t believe me at first and thought I was a smartass. So, I stood up and said out loud that I’m allergic to penicillin,” he says. Only after checking his papers did the doctor believe him.

“A lot of people think that when they are in the hospital, they are in good hands. They will think that they should just do what the doctors tell them. I wish patients would take more responsibility for their own health,” he explains.

Failing to do so can have fatal consequences, which is why Tifiro has these three simple guidelines for other patients:

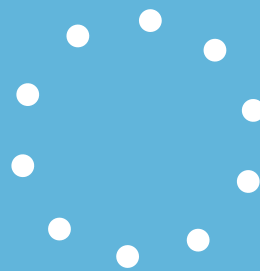
- 1. Ask doctors questions.** Ask until you feel enlightened and comfortable. Try to educate yourself.
- 2. Let doctors and nurses treat you as a person.** Talk to them. Show them that you are a person.
- 3. Take responsibility for your own health.** Every case is different, and no doctor knows all the specific circumstances related to your condition or how you feel.

“You are your own best advocate. You know your body better than anybody,” he concludes.

CHAPTER 5

# INSPIRA- TIONAL PERFOR- MANCES

- 10 EXAMPLES OF PERSON-  
CENTRED HEALTHCARE



*THE FRONT RUNNERS WITHIN PERSON-CENTRED CARE PRESENT A NEW WAY OF THINKING AND A NEW WAY OF WORKING. 10 CASES FROM AROUND THE WORLD TELL INSPIRING STORIES OF PERSON-CENTRED CARE IN PRACTICE - LEADING THE WAY FOR OTHERS TO FOLLOW SUIT.*

→ **From a project** to improve maternal health in El Salvador to a complete restructuring of the Veterans Health Administration in the US, the stories on the following pages show the possibilities and perspectives of person-centred care.

All over the world, healthcare providers, policy makers, professionals and patients team up in new ways, with the shared ambition of changing the system to improve the quality of healthcare by placing people at the centre. They are championing new ways of working, new poli-

cies, and new partnerships that involve patients, family members and resources in the community.

Across countries and continents, they show us what person-centred care can look like.

This chapter presents 10 stories which cover five continents and represent countries on different income levels. They provide inspiration and insight, not only on the “what”, but also the “how” of person-centred care and can hopefully lead the way for others.



# THE TEN CASES

→ The following chapter presents ten case studies from around the world that show how international front runners on different levels within the healthcare sector have developed, implemented and practiced concepts of

person-centred care. See figure 1. The stories are from different sectors, driven by different stakeholders, with different intentions and goals – allowing for different perspectives on how to make person-centred care a reality.

1

**Making maternal mortality a thing of the past.** A person-centred initiative has helped prevent maternal deaths in El Salvador.

2

**Leadership supports care focused on patients' needs.** Appointing a Director of Patient Experience paved the way for a more person-centred approach at the UK Northumbria Trust.

3

**Mapping family resources in health records.** Family records mobilise new resources and enable a more person-centred care in Thailand's primary care system.

4

**Physicians and nurses partner with patients.** A transformation from traditional single doctor practices to doctor-nurse health-care teams keeps patients out of hospitals in Israel.

5

**A how-to-do-it kit.** "The Patient Centred Care Improvement Guide" from Planetree and Picker Institute helps stakeholders along the road from first ideas to real-life praxis.

6

**Shared information – a cornerstone of coordinated care.** A unique platform for sharing data and patient information paves the way for more person-centred care in Denmark.

7

**A patient revolution.** A national healthcare reform aimed at creating a more person-centred healthcare sector is laid out by the National Health Service in England.

8

**A model for the future.** An innovative new person-centred treatment has proven successful in the treatment of tuberculosis in Tanzania.

9

**A cultural revolution in health-care.** The US Veteran Health Administration has initiated a radical transformation process in order to create a new healthcare system based on the principles of person-centred care.

10

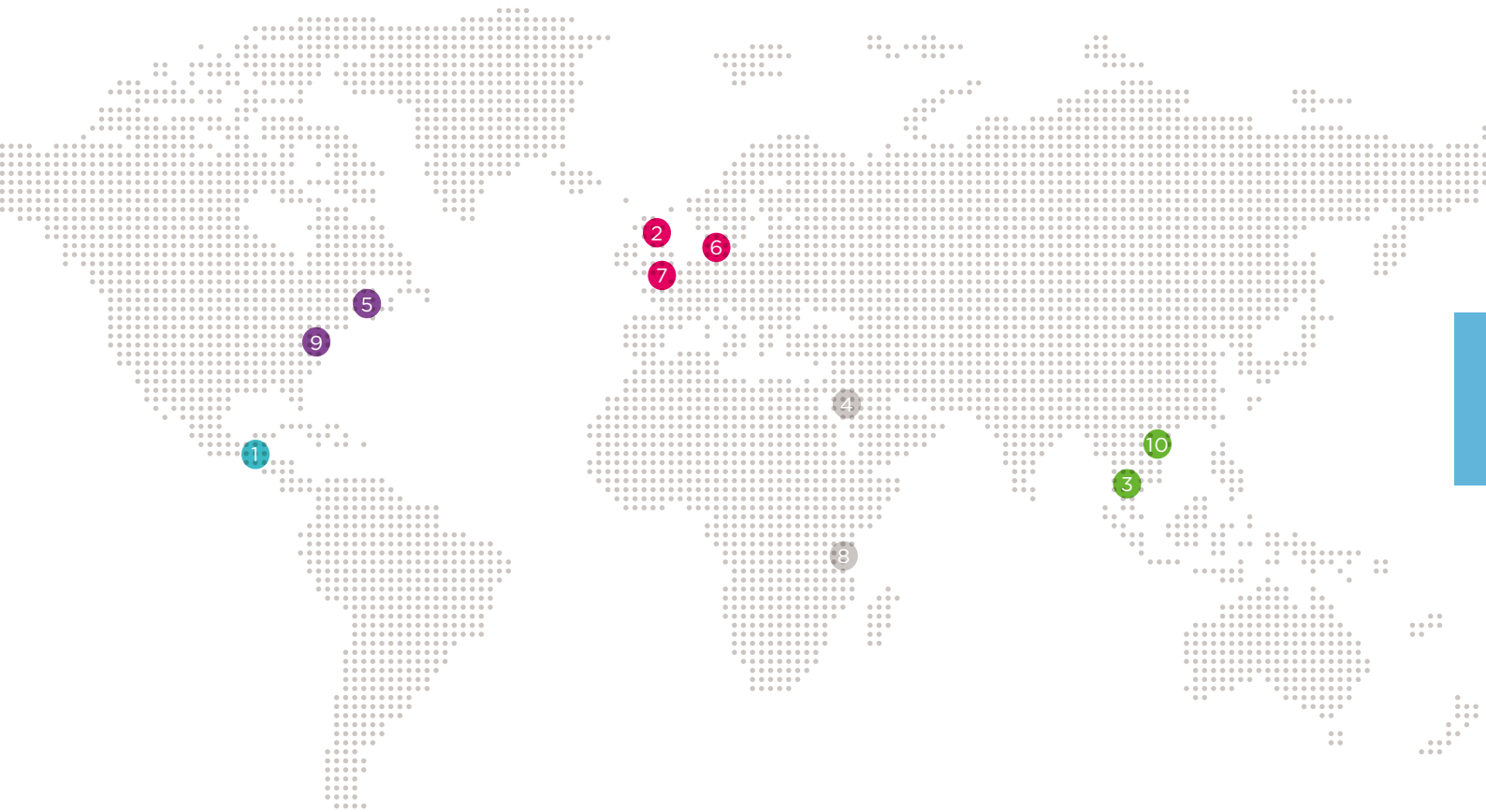
**Giving patients a voice.** The public is a powerful driver for person-centred care. This is the lesson learned from the Hong Kong patient organization the Alliance for Patients' Mutual Help Organizations.



FIGURE 1

## TEN CASES FROM AROUND THE WORLD

THE 10 STORIES COVER FIVE CONTINENTS AND REPRESENT COUNTRIES ON DIFFERENT LEVELS OF DEVELOPMENT UTILIZING DIFFERENT HEALTHCARE MODELS.



Source: DNV GL / Sustainia



# MAPPING THE CASES

→ **To guide the reader**, the cases are categorized in five main themes – outlining each story's main focus area – based on relevant perspectives of person-centred care.

## **POLICY – A NEW AGENDA**

Person-centred care has become a central part of national policies in several countries. One example is the UK, where person-centred care has been afforded a significant role in the on-going reform of the National Health Service (NHS).

**Cases:** [UK](#), [El Salvador](#), [Tanzania](#)

## **SHARING INFORMATION**

When patients demand continuity in treatment across sectors, departments or institutions, information has to be shared on a hitherto untried scale, and not only between professionals, but also between professionals and patients.

**Cases:** [Denmark](#), [Thailand](#), [US](#)

## **PROMOTING NEW PARTNERSHIPS**

As patients' needs change from acute interventions to continuous efforts, effective care must be based on new partnership structures – both between different groups of professionals as well as between professionals and patients.

**Cases:** [Israel](#), [Northumbria](#), [US](#)

## **SCALING**

All over the world, the development of person-centred care has relied on front runners who champion its cause. However, this is not a durable recipe for lasting changes on a larger scale. We need to move from good examples to standard practice.

**Cases:** [Thailand](#), [PlaneTree](#), [Israel](#)

## **INVOLVING PATIENTS AND THEIR FEEDBACK**

When companies want to improve their products or services, they obtain input from their customers. In much the same way, providers of healthcare can give their patient a voice when developing care.

**Cases:** [Hong Kong](#), [Northumbria](#)



CASE EL SALVADOR

# MAKING MATERNAL MORTALITY A THING OF THE PAST

## FACTS

**TYPE**  
COMMUNITY BASED PROJECT

**WHERE**  
EL SALVADOR



**LEVEL**  
MICRO AND EVENTUALLY MACRO

**PARTNERS**  
PATIENTS, FAMILIES,  
COMMUNITIES, HEALTH CARE  
WORKERS, POLICY MAKERS

**SCALE**  
FROM PILOT PROJECT TO  
NATIONAL POLICY

**GOAL**  
FEWER MATERNAL DEATHS

→ **The story of a great success: improved prevention of maternal deaths allows young mothers to look forward to giving birth without risking their lives in the process. This success boils down to a deliberate effort of involving local communities and asking them to help.**

“It is not just about improving care, but about creating a culture where women have a voice and are being heard. Only that ensures that the treatment, the initiatives and the help is focused on the individual woman’s needs and the broader community needs.”

According to Anayda Portela, Technical Officer at the Department of Maternal, Newborn, Child and Adolescent Health at WHO, this was the key reasoning behind a successful effort in El Salvador focused on bringing down the high number of maternal deaths. Every 3 in 1000 women die giving birth in El Salvador, while less than 3 in 10.000 woman in a developed country die giving birth. In addition, a higher number of underprivileged and poorly educated young El Salvadorian women die giving birth than do their middle class sisters.

In light of these facts, the Ministry of Health and the Ministry of Education in El Salvador partnered up with WHO and Enfants du Monde, a Swiss NGO, and initiated a pilot programme in 2006 with the aim of reducing maternal mortality through community involvement and community focused care. See text box.

“Women in these cultures are not used to be asked the question: ‘What do you need?’ Thus it is important to create a process enabling them to answer this question. But also to make sure that their needs are outlined and accepted as important – not just by the mom-to-be, but by all the people surrounding her,” Anayda Portela points out.

In order to nudge the prevailing attitudes within the community, all relevant stakeholders including the mothers-to-be, the mother-in-laws, the grandmothers and health workers as well as community and religious leaders were invited to a series of community consultations, where they were asked to bring their perspectives and ideas with regards to improving maternal health to the table – and thus help save more young women’s lives during their maternity.

### A PILOT PROJECT BASED ON THE WHO'S IFC (INDIVIDUALS, FAMILIES, COMMUNITIES) FRAMEWORK

In 2003, the Making Pregnancy Safer department at WHO developed the framework "Working with individuals, families and communities to improve maternal and newborn health", which aims at empowering individuals, families and communities to increase their control over maternal and newborn health, and at easing the access to quality health services.

Today, the initiative has become a national health

policy and as a result of this project, The Ministry of Health in El Salvador has started to reform the entire health sector based on the IFC framework; focusing on integrated care and mobilizing resources both at family and community level.

The project is not limited to El Salvador. the WHO framework is adopted by a number of developing countries including Burkina Faso and Bangladesh.

Based on these discussions, healthcare professionals and representatives of the three initiating organizations developed and implemented an action plan in collaboration with the local stakeholders. Three focus areas were considered most important:

- More births were attended to by skilled personnel
- Increased visits from the obstetrician-gynaecologist from a hospital
- Activities to improve men's awareness of danger signs were designed and carried out at men's clubs.

The outcomes of the project were successful. Altogether, the changes resulted in maternal deaths dropping to zero in 90 per cent of the municipalities involved.

Anayda Portela believes that the community-based approach was absolutely fundamental for the success and outcome of the project.

"Before the project we had the right goals, but we simply lacked a focus on the patient – in this case the woman. We were able to build the right capacity centred on responding to the woman, creating a community based support that ensured that the needs of the women were put in the centre", she explains.

Just as the meetings with stakeholders within the communities changed attitudes in the community itself and helped create a stronger sense of responsibility towards solving the problem with maternal deaths, it also changed attitudes amongst the staff involved.

At the beginning of the process, professionals joined hesitantly, questioning whether those kinds of meetings would be helpful. However, during the process, attitudes changed and the staff involved felt that including the greater community and asking them for assistance was actually very helpful in improving the level of care.

"We had to develop new skills so as not only to focus on clinical skills, but on organizational, cultural, interpersonal and management skills. This is key, if person-centred care is to become a common way of organizing and structuring healthcare services," says Anayda Portela.



CASE NORTHUMBRIA HEALTHCARE NHS FOUNDATION TRUST, UK

# LEADERSHIP SUPPORTS CARE FOCUSED ON PATIENTS' NEEDS



## FACTS

**TYPE**  
NEW LEADERSHIP, NEW ORGANIZATION

**WHERE**  
UK



**LEVEL**  
MESO

**PARTNERS**  
PATIENTS, DOCTORS, LEADERS

**SCALE**  
NEW TREATMENTS AND PROCESSES  
AT THE TRUST

**GOAL**  
BETTER TREATMENT, HIGHER PATIENT  
SATISFACTION

→ Bringing down the waiting time for patients and reducing the mortality rate are the impressive results of an ambitious person-centred turnaround at the Northumbria Healthcare NHS Foundation Trust in Northeast England. The Trust appointed a Director of Patient Experience who pushed forward a radical cultural change of the way patients are included in their treatment.

The turnaround and the award are the result of an ambitious organizational readjustment of the Trust – backed by a leadership determined to make person-centred care a cornerstone in all actions performed by staff members.

“The Trust managers have incorporated a whole new way of thinking and coordinating care based on the patient’s needs. This has promoted a whole new culture and a new way of looking at the patient”, says Angela Coulter, Senior Research Scientist at Health Services Research Unit at Oxford University and Head of Global Initiatives at the Foundation for Informed Medical Decision Making in Boston. *See interview on page 114.*

One of the Trust’s first steps, in 2009, was the appointment of Annie Lavery as “Director of Patient Experience”. While most hospitals and healthcare trusts have designated leaders for resource management and clinical governance, her job description and functions are pretty rare at this level of management in the healthcare sector.

One of Annie Lavery’s first initiatives was “Hip Qip” – a hip fracture quality improvement programme.

Due to a concerted effort, the 30-day mortality rate was reduced from 11.7 per cent to 7.7 per cent in just eighteen months.<sup>1</sup> On top of that, patients now spend fewer hours waiting for an operation, and in 2011, the Trust won one of the four categories in the yearly Patient Experience Network National Awards (PENNA).

A main feature of the programme was the introduction of several measures to enhance the inclusion of feedback from patients. Instead of getting results from feedback on a yearly basis, the Trust organized methods of collecting and acting upon feedback on a monthly basis. In addition to that, the Trust

Note<sup>1</sup>: NHS Networks. *The National Hip Fracture Database National Report*. 2011.



also gathered feedback from select patients within twenty-four to thirty-six hours after they had been discharged and then distributed the results directly to the appropriate wards.

The changes that followed included a number of organizational measures, ensuring, for instance, that a key clinician was present in all phases of care. Some of the changes dealt with what could seem like very small details, such as supplying “dignity boxes” with toiletries and nightwear to patients who may have been admitted to hospital without their personal belongings.<sup>2</sup>

Next, attention was turned to improving recovery and getting patients, often elderly, back on their feet.

The new approach to recovery led to a new nutrition programme, based on research showing that paying special attention to the nutritional needs of hip fracture patients could greatly aid recovery – an insight supplied by the staff.

“Two nutritional support workers were employed and special efforts were made to find out what types of food patients enjoyed and to make it available. The nutritional assistants made sure that it was presented attractively, in utensils that enabled people to eat with dignity,” Angela Coulter reports.<sup>3</sup>

Ward rounds were also banned at mealtimes, allowing the patients time to eat in peace and quiet.

The success of these efforts is utterly reliant on the positive support from members of staff. According to Angela Coulter, support from the board of directors and the strong focus on staff involvement have been key drivers in ensuring Annie Lavery free reins in her pursuit of pushing forward the necessary innovation and in order to make the different initiatives succeed.

“This kind of organizational change is not done in an instant – it is very difficult. The focus and backing from the board for the initiatives that Annie Lavery has introduced, has been very important. But the way the staff has been involved has ensured that there is support for new initiatives throughout the organization,” Angela Coulter explains.

The 2012 National NHS staff survey showed that 89 per cent of the staff employed by the Trust feel they make a difference to patients, 71 per cent felt able to contribute towards improvements at work and 91 per cent felt able to report errors or incidents. The Trust’s report may be “seen as evidence of a positive reporting culture and as supporting a learning environment”.<sup>4</sup>

Note<sup>2</sup>: Northumbria Healthcare. *Top for patient experience*. 2012.

Note<sup>3</sup>: Coulter A. *Leadership for patient engagement*. The King’s Fund. 2012.

Note<sup>4</sup>: Northumbria Healthcare. *Northumbria staff amongst most satisfied in country*. 2013.

CASE THAILAND

# CARING ABOUT RELATIONS



## FACTS

**TYPE**  
GOVERNMENTAL PROJECT

**WHERE**  
THAILAND



**LEVEL**  
MICRO AND NOW MACRO

**PARTNERS**  
PATIENTS, FAMILIES,  
COMMUNITIES, HEALTHCARE  
WORKERS, POLICY MAKERS

**SCALE**  
FROM PILOT PROJECT TO  
NATIONAL POLICY

**GOAL**  
INTEGRATING RESOURCES OF  
PATIENTS AND THEIR NETWORK  
WITH PRIMARY CARE

→ **Involving families and communities in healthcare has been a cornerstone of Thailand's successful healthcare reform. It has allowed a middle-income country to extend universal care to its large, and relatively poor rural population.**

Thailand's 2001 health reform extended universal health coverage to practically all of its citizens, including 18,5 million previously uninsured people<sup>5</sup>. The reform combined universal access to subsidised health care with a radical shift in funding from urban hospitals to primary care<sup>6</sup>.

This means that citizens in need of care do not have to leave their communities in order to receive treatment. And the government can reserve its expensive hospital facilities for the citizens most in need.

According to the WHO, the reform has been a success: "The network of health institutions provides good overall coverage with solid evidence of its 'pro-poor' effect."<sup>7</sup>

A key to this success is the way that local primary care units – the cornerstone of Thailand's health system – are able to involve patients' families and communities.

According to Dr. Yongyuth Pongsupap of the National Health Security Office, Thailand's success relies on a triple foundation which should inspire other healthcare providers.

- **New attitudes towards patients.** Professionals combine classical medical knowledge with respect for patients in order to establish a dialogue. This is a basic precondition for uncovering the resources of the patients and their families.
- **Integrating family data in the patient's journal.** "Family records are a really useful tool. If we can keep information about the patient and the family together, we can understand the patients better, make them feel that we know them very well, and have the opportunity to empower them to help each other," Dr. Yongyuth Pongsupap explains.
- **Involving the community.** Local healthcare units arrange community meetings about prevailing healthcare problems in rural areas. "It may be the professionals

Note<sup>5</sup>: Damrongplait K, Melnick G. Early Results From Thailand's 30 Baht Health Reform: Something To Smile About. *Health Affairs* 2009; 28(3): w457-w466.

Note<sup>6</sup>: Towse A, Mills A, Tangcharoensathien V. *Learning from Thailand's health reforms*. BMJ. 2004; 328(7431): 103-105.

Note<sup>7</sup>: World Health Organization. *Country Cooperation Strategy Thailand 2012-2016*. 2011.





Comprehensive family health records in Thailand allow doctors and other professionals to improve the quality of healthcare.

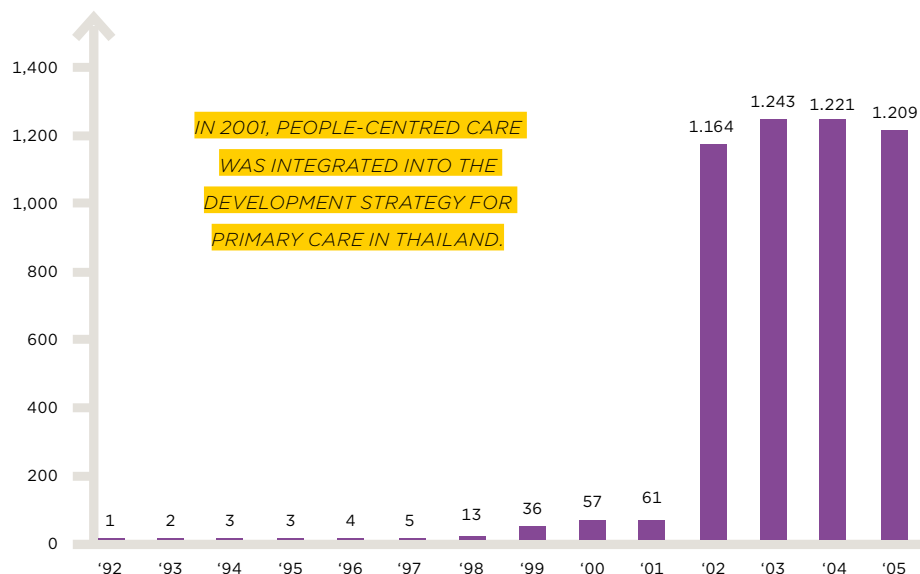
who ask for a meeting, or it may be the community. Local needs will dictate the agenda,” Dr. Yongyuth Pongsupap elaborates.

The transition did not come about automatically. Prior to the national health reform, pioneers across the country worked to establish clinics in remote areas, relying heavily on the principles of person-centred care.

Steadily, these front runners built political momentum, demonstrating their practices to politicians, representatives of civil society and consumer organizations as well as students and health workers.

Within one year after the reform, the number of local health centres had risen from 60, covering 600,000 people, to 1,164 covering 12 million people. See figure 1.

FIGURE 1  
THE GREAT LEAP FORWARD  
NUMBER OF PEOPLE-CENTRED PRIMARY CARE UNITS



Source: Pongsupap Y. Experience of people-centred care in Thailand: From demonstration diffusion to policy transformation. 2010.

CASE THE MACCABI HEALTHCARE SERVICE IN ISRAEL

# PHYSICIANS AND NURSES PARTNER WITH PATIENTS

## FACTS

**TYPE**  
STRUCTURAL CHANGE

**WHERE**  
ISRAEL



**LEVEL**  
MESO

**PARTNERS**  
PROVIDERS AND PROFESSIONALS

**SCALE**  
FROM TEST TO GENERAL IMPLEMENTATION

**GOAL**  
BETTER TREATMENT, LOWER COSTS

→ **In Israel, doctors and nurses in primary care team up with their patients. This marks an end to single doctor practice. OECD now lauds Israel as a nation doing what other countries struggle to do.**

When you visit a doctor in Israel, you may meet not only a physician but also a nurse. The doctor and the nurse constitute a small team that cooperates with you in diagnosing the problem and designing the best plan for care and treatment. If they need the help of other experts, i.e. a pharmacist or a physiotherapist, these will join the team.<sup>6</sup>

“We have encouraged doctors to partner up with other physicians and then we have made nurses part of their teams. We want the nurses to do what they are better at than doctors, which is to be responsible for the coordination of the entire process of care together with patients,” says Rachelle Kaye, consultant in R & D and former Deputy Director of the Division of Planning and Finance in Maccabi Healthcare Services.

The formation of these small units dates back to a government evaluation of delivered healthcare, at a time when primary care was based on independent practitioners providing reactive care for people who fell ill. Prevention and health promotion were sporadic and rarely regarded a vital task of primary care.

A reform passed in 2004 aimed at improving the quality of healthcare as well as the methods used to monitor and evaluate care.

“Year by year, our population is ageing, more citizens suffer from chronic diseases, and many suffer from more than one. If we don’t coordinate care, we may cause harm to the patient or just fail to deliver the care he needs. It is essential, that we coordinate care,” says Rachelle Kaye.

Since the beginning of the reform, more and more professionals and patients are forming partnerships in care.

“We think our model gives the patients more control of their destiny. We also think they have a better understanding of what is happening and ultimately, they have a better quality of life,” she continues.

Note<sup>6</sup>: In one of the four Israeli Health Plans (Clalit) it is standard practice for salaried Family Physicians, in another (Maccabi) it will, within the next few years, become standard practice for primary care among independently contracted physicians in their private clinics.



When the OECD evaluated healthcare in Israel in the fall of 2012, it concluded that the reform had provided policy makers “with a platform to do things that other OECD-countries are struggling to do, like regular monitoring of a patient’s health indicators, delivering follow-up support after a visit to the doctor, and tailoring preventative advice to the specific needs of communities.”<sup>7</sup>

The coordination of care relies heavily on an advanced IT-platform, developed since the end of the 1980’s.

“Our physicians, the nurses and the patient have access to the data in an electronic record for each patient. This promotes integrated care,” Rachelle Kaye explains.

The Maccabi IT-platform is more than just a database with information about each patient. The system also helps nurses keep track of patients and it informs them of when to call patients to, for example, ensure that they receive the care they need and that they indeed adhere to their care plan, or it could be to pro-actively invite them for a visit at the clinic in order to discuss how they may improve their health.

The platform helps both patients and doctors monitor selected health indicators such as the level of haemoglobin A1c (HbA1c) for diabetic patients. The OECD notes that the number of hospital admissions for patients with diabetes is lower in Israel than most other OECD-countries.

“I think our work with diabetic patients is unique. We do a lot of educational work with patients and our system makes sure that doctors remember to refer their patients for laboratory monitoring at required intervals. Our goal is to keep patients out of hospitals,” says Rachelle Kaye.

During the implementation of the model, the management at Maccabi committed themselves to a new approach to chronic care. Since a positive evaluation of 11 clinics piloting the model in 2007, the model has been implemented at more than 50 clinics.

The implementation was based on a highly detailed set of incentives for staff and physicians in the Maccabi HealthPlan – making restructuring a desirable path to choose.

#### ISRAEL’S HEALTH-CARE PLANS

Israel’s healthcare system is based on four non-profit healthcare plans: Clalit, Maccabi, Meuhedet and Leumit. The system is designed so that the four plans compete with each other and operate within tight budgetary constraints. Named after a famous group of Jewish freedom fighters from the second century AD, Maccabi is the second largest health plan, providing care for 25 per cent of the population.

Note<sup>7</sup>: OECD. *Reviews Of Health Care Quality: Israel*. 2012.

CASE "THE PATIENT CENTRED CARE IMPROVEMENT GUIDE"

# A HOW-TO-DO-IT KIT



## FACTS

**TYPE**  
GUIDE/REFERENCE POINT

**WHERE**  
THE US, GLOBAL



**LEVEL**  
MICRO, MESO, MACRO

**PARTNERS**  
PATIENTS, FAMILIES, DOCTORS,  
MANAGEMENT

**SCALE**  
FROM BEST PRACTICE TO  
STANDARD PRACTICE

**GOAL**  
BETTER CARE, MORE SATISFIED  
PATIENTS

→ The lack of knowledge on implementation often becomes an obstacle along the road to person-centred care. "The Patient Centred Care Improvement Guide"<sup>8</sup> from Planetree and Picker Institute helps stakeholders on the road from first ideas to integrated praxis.

A guide is something you need when you find yourself in unknown territory. A guide describes your destination, helps you choose the right route, and it ensures that you feel well equipped in your explorations.

For the vast majority of the healthcare sector, person-centred care is a road hitherto untraveled. What a person-centred approach actually entails remains blurred, and stakeholders struggle with the task of changing cultures of care and transforming these changes into actual practices and daily routines.

This is why two of the global pioneers within the area of person-centred care – Planetree and Picker Institute – joined forces and created a guide that translates "patient-centred care from a vague concept into a concrete one". See text box. Together, they set out to demonstrate "the what and the how" of person-centred care, which resulted in the "Patient-Centred Care Improvement Guide", published in 2008.

The guide is based on the understanding that developing a person-centred culture is a process that takes time – and that there is a direct link between person-centredness and staff-centredness, which supports the fact that the staff's professional and personal aspirations are vital for success.

"Patient-centred care is a direct extension of how you treat your staff. On the way to successful patient-centred care there are some absolutes: you have to

PERSON-CENTRED CARE

Note<sup>8</sup>: Planetree. *Patient-Centred Care Improvement Guide*. 2008.

## TWO PIONEERS

Planetree is a non-profit organization that partners with healthcare organizations to transform organizational cultures and improve the patient experience. The guide has been financed by The Picker Institute, an international non-profit organization that supported research in the field of person-centred care.

The Picker Institute ceased its operations in 2012, but some of its initiatives will be carried on by institutions like the Institute for Healthcare Improvement, the Arnold P. Gold Foundation and Planetree's Harvey Picker Center of Innovation and Applied Research in Long-Term Care. The institute's sister organization, Picker Institute Europe, remains active.

listen to the patient's voice and you have to engage the staff," says Alan Manning, Vice President of Operations at Planetree.

The 241-page guide seeks to inspire and push forth a more person-centred approach – not by communicating unattainable visions, but by telling the story of person-centred care and how it works in the real world. Thus, it not only recounts the stories of successes, but it also addresses some of the most common myths and obstacles: that it is too costly and time-consuming, that it should be a concern for nurses rather than doctors, that it collides with other care models and quality standards etc.

Targeted at individual healthcare organizations, the guide is a functional resource that provides practical and palpable guidance for initiating and sustaining a culture of person-centred care, step by step. It is primarily based on a self-assessment tool that helps identify and prioritise opportunities for introducing person-centred approaches into "your" organization. But it also presents concrete implementation tools for replicating best practices, many of which are straightforward initiatives that can inspire the process, or "journey" as Alan Manning calls it.

"The guide will operationalize patient-centred care, clarifying what the achievement of patient-centred care looks like. The ultimate bar – being a patient-centred organization – is quite high, but we understand that this is a long journey and we try to allow for points of achievement along the way so that organizations can pause and celebrate. In essence, our goal is to help people understand how to turn a very commonly supported principle into an actionable practice. Ultimately, we want to develop a practical approach that drives positive change," he explains.

According to Manning, the guide is also very much about setting a goal and pointing to structural changes that allow staff to establish new partnerships in care.

"Stakeholders have the desire to be patient-centred, but desire alone leaves you with just good intentions. We think that the key to success is desire plus new structures motivating the staff and allowing them to participate," says Alan Manning.

CASE E-HEALTH IN DENMARK

# SHARED INFORMATION – A CORNERSTONE OF COORDINATED CARE



FACTS

**TYPE**  
STRUCTURAL CHANGE

**WHERE**  
DENMARK



**LEVEL**  
MESO AND MACRO

**PARTNERS**  
PROVIDERS AND STAKEHOLDERS

**SCALE**  
FROM TEST TO NATIONAL IMPLEMENTATION

**GOAL**  
SHARED INFORMATION ACCORDING TO COMMONLY ACCEPTED, HARMONIZED STANDARDS

→ Rather than going for the grand national e-health system, Denmark has followed a step-by-step strategy, placing the country as one of the global front runners in terms of sharing patient data amongst providers.

Rarely does a grand vision collapse so heavily as it did, when the British Government dismantled its ambitious plans to digitalize UK health information in the fall of 2011. After six years of unsuccessful development, the bill reached GBP 12.7 billion or just below USD 20 billion. It was labelled a “colossal failure”.

But the need to transfer patient data from one professional to another remains the same all over the world.

“Our job is to make it possible to use and reuse the same data in every part of the healthcare system and across organizational boundaries. To us, that is the cornerstone of coordinated and patient-centred care. Without access to the same data, patients have to repeat the same data over and again. With access to the same data, relevant discussions about care can begin the moment patients visit a professional,” says Ib Johansen, deputy manager at Medcom<sup>9</sup>, the publicly funded organization assigned to develop, test and disseminate IT-standards of communication between different Danish providers of care.

In Denmark, the need to share data between providers is growing exponentially, as hospitals discharge patients faster and leave still bigger parts of care to GPs, physiotherapists and other care providers.

Professionals use many different standard formulas when communicating with each other; one for discharge letters from hospitals to other professionals, one for requests for laboratory tests and so on.

But instead of building one grand system of data exchange, Denmark started the other way round. Form by form, the way in which professionals hand over data to others is harmonised in order to ensure that the next provider receives the data in exactly the same format as it was originally drawn up.

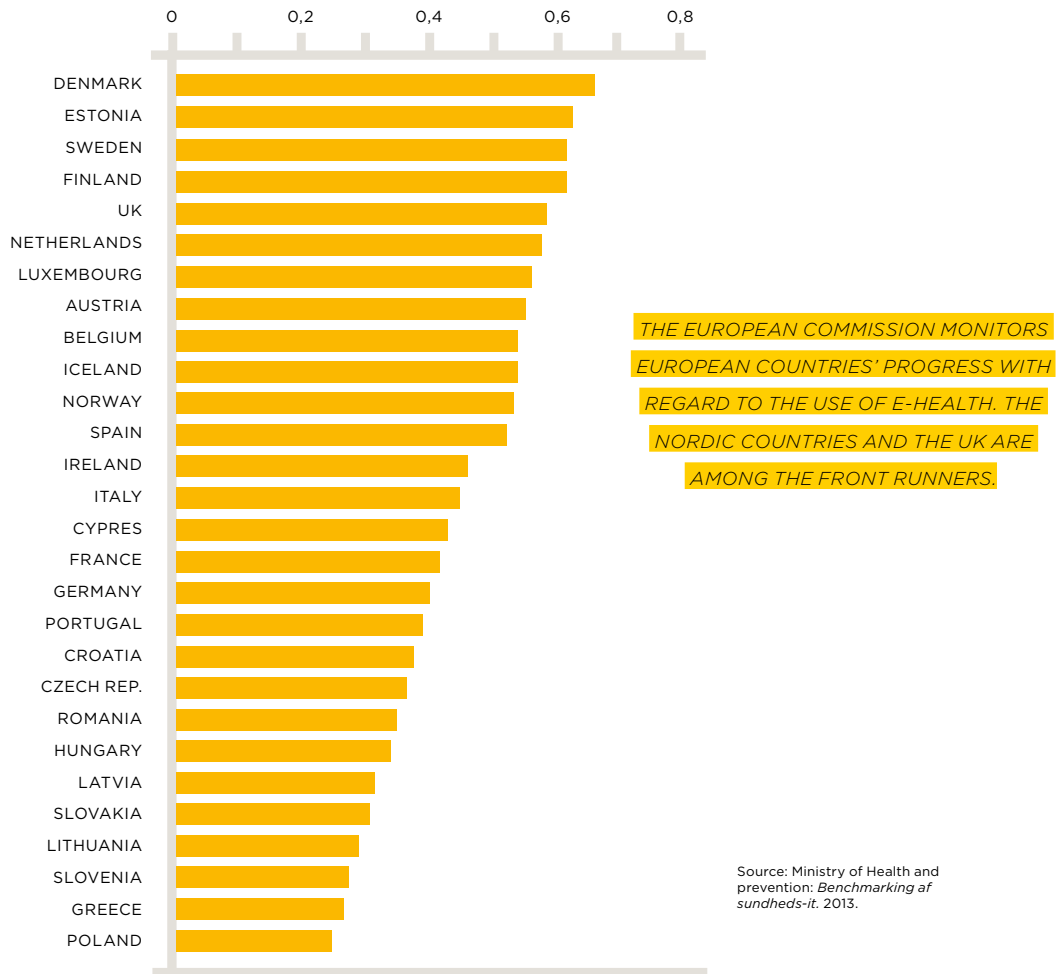
And it would seem that Medcom has done a good job, as Denmark takes the lead in the yearly European indicator, with a small margin to countries like Esto-

Note<sup>9</sup>: Medcom is owned by the Danish Government, the Regions and the Municipalities: the three main constituents of the Danish Public Sector and key agents of Denmark’s publicly funded healthcare system.

FIGURE 1

## DENMARK LEADS THE EUROPEAN PACK

INDEX FOR IMPLEMENTATION OF E-HEALTH, 2012



nia, Sweden, Finland and the UK. See figure 1.

For Ib Johansen, it is not enough to provide standards for professionals who are already convinced of the advantages of sharing health data though. “Our goal is to reach 100 per cent dissemination,” he states.

The main instrument to obtain that goal is establishing consensus between senders and receivers of data, as exemplified by the electronic transfer of laboratory tests such as blood samples.

“We ask stakeholders to sit around the same table and listen to each other. Physicians can state what kind of data they need, and the lab team can explain, what kind of data they can provide. After reaching a common understanding, it is our job to translate needs and possibilities into a new standard,” says Ib Johansen.

Apart from easing the process of sharing information, this standardized way



of providing information also reduces errors. According to Ib Johansen, one in every six traditional paper formulas following blood samples contained errors. After the introduction and total implementation of new harmonized standards that provide the same information via a computer, it is now less than one in fifty.

After professionals agreed on which standards to implement, Medcom cooperated with all market agents who could deliver solutions. If one company chooses to deliver products that do not live up to the set standards, Medcom will post a note on the website, stating that the product does not comply with required standards. And so in the end, most companies choose to develop solutions that respect the agreed standards and instead they compete on other parameters such as price, usability or services provided to users.

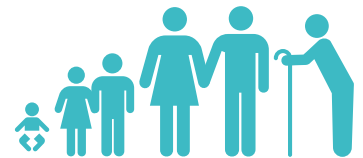
The biggest problem for this process is the fact that not all benefit equally from implementing the new standards.

“We have to find out if it’s the sender or the recipient who gets the benefits and the same goes for the costs,” Ib Johansen explains. But up until now, stakeholders have seen advantages attractive enough to participate in the development of new standards.



CASE ENGLAND

# A PATIENT REVOLUTION



FACTS

**TYPE**  
NATIONAL CARE REFORM

**WHERE**  
ENGLAND



**LEVEL**  
MACRO AND LATER MESO AND MICRO

**PARTNERS**  
POLICY MAKERS, MANAGERS, STAFF, PATIENTS

**SCALE**  
IMPLEMENTATION OF NATIONAL POLICY

**GOAL**  
RE-FOCUSING CARE WITH PATIENTS AT THE CENTRE

→ **“Putting Patients First” is the headline of the National Health Service’s business plan for the years 2013 to 2015. Systematic use of feedback from patients, the alignment of incentives and a new approach to the coordination of care are three important elements.**

The word “revolution” evokes images of people in the streets, waving banners and shouting slogans. But England’s on-going healthcare revolution is more about listening than shouting.

The aim is to “ensure sustainable improvements in patient and customer experience.” Providers of care are to put patients at the centre of their efforts, and one of the most important tools is listening to patients’ stories and utilizing their experiences with care as inspiration for change and improvement. See figure 1 on next page.

“We really do emphasize real-time feedback from patients. And when we receive it, it is directed to the ward or the service that the patient visited. We believe that for people to pay attention to feedback, it has to be relevant to them and their ward or their service and not a generalized feedback to hospitals,” says Neil Churchill, Director of Patient Experience at NHS England.

Since April 1st, it has been mandatory to collect feedback from patients and it is done in a standardized way, where patients simply have to answer the question: “How likely are you to recommend our service to friends and family if they needed similar care or treatment.”

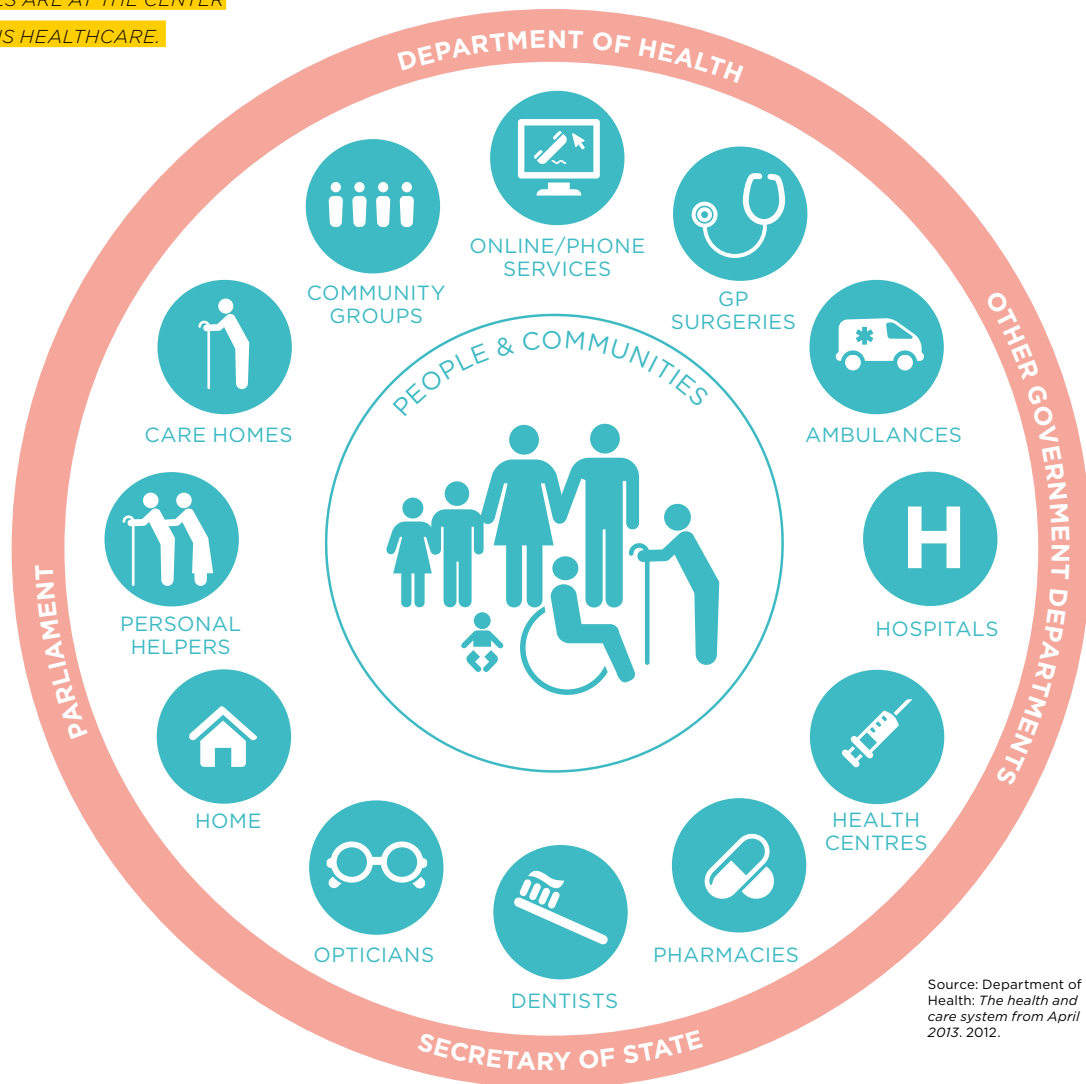


FIGURE 1

# PLACING PATIENTS AT THE CENTRE

THE ORGANIZATIONAL MODEL FOR THE NHS ENGLAND, APRIL 2013

**PATIENTS, FAMILIES AND  
COMMUNITIES ARE AT THE CENTER  
OF NHS HEALTHCARE.**



Source: Department of Health: *The health and care system from April 2013*. 2012.

Patients are asked to substantiate their assessment, and some do. Neil Churchill mentions a 91-year-old woman who reported that “the bell was answered promptly, but occasionally a smile and a kind word would have been welcome.” Another response, from a 14 year-old boy, just read: “Please try to interact more with patients, we are scared...”

Neil Churchill is not kidding when he talks about “real-time” feedback. To be of relevance to professionals, it has to be collected and delivered soon after discharge. In maternity services, for instance, the NHS expects feedback to be collected within 48 hours, at the latest.

The feedback is available to the public, and Churchill hopes that professionals will react positively.

“Professionals take pride in their work and if they see that they are doing less well than the service delivered by other wards or other services, I think it will encourage them to improve,” he clarifies.

But one thing is listening to patients; being rewarded for it is a different matter. Neil Churchill points to the need of aligning incentives to aim for the same result as the feedback, which is to improve patient experience.

“We haven’t aligned all incentives yet, but we are moving away from a model mainly incentivizing hospitals to do a certain number of interventions,” he explains.

In order to do so, general practitioners represented on local boards have been handed the responsibility of delivering overall care to the patients in need, and providers are then rewarded for delivering a specific part of this coordinated care.

Neil Churchill regards the transformation of NHS England as a cultural revolution.

“I have the responsibility of providing leadership and improving patient-centred care, and I feel we are at a crossroad right now. On one hand, we have the inertia of the system, the professionals and the managers, on the other hand, we have a strong coalition of forces wanting the transformation. Ultimately, I’m an optimist.”



CASE TB IN TANZANIA

# A MODEL FOR THE FUTURE



**FACTS**

**TYPE**  
NEW TREATMENT

**WHERE**  
TANZANIA



**LEVEL**  
MICRO - LATER MACRO

**PARTNERS**  
FOUNDATION, POLICY MAKERS,  
STAFF, PATIENTS, COMMUNITY

**SCALE**  
FROM PILOT PROJECT TO  
NATIONAL POLICY

**GOAL**  
ENABLING PATIENTS TO TREAT  
THEMSELVES

→ **An innovative person-centred care initiative gives TB patients in Tanzania the opportunity to treat themselves at home. The results are better treatment rates and less strain on both healthcare professionals and patients. The model is now being scaled as a best-case example – in Tanzania as well as other countries.**

What started out as a small pilot project focused on TB treatment in three regions of Tanzania has now become a new approach to treatment nationwide and it is used to inspire and help other countries improve their treatment of TB as well as a range of other diseases.

“The TB project is the first big patient-centred care initiative in the country. The experiences so far are very positive, and it is now serving as a model for how we can treat people with various kinds of diseases and as a way of teaching both staff and patients how to work together in new ways,” says professor Senga Pemba, Director of the Tanzanian Training Centre for International Health, and one of the initiators behind the TB project.

An innovative new treatment model – the Patient-Centred Treatment (PCT) – was launched in Tanzania in 2005. The PCT approach was designed to ensure adherence to TB treatment, while alleviating pressure on both healthcare professionals and patients. The model gives TB patients the choice between receiving daily treatment at a health facility, supervised by a medical professional, or at home, supported by a trained family or community member.

The approach is developed through the collaboration of Novartis Foundation for Sustainable Development and the National TB and Leprosy Programme of the Tanzanian Ministry of Health and Social Welfare.

In Tanzania, TB treatment used to put a tremendous strain on the healthcare system as well as the people suffering from the disease. *See text box.* Treating TB requires a combination of drugs to be taken over a period of six months. The WHO recommends a treatment based on the Directly Observed Treatment Short-course, requiring patients to take their medicine daily, under the supervision of a healthcare professional.

Although this approach ensures better patient adherence, it is not easy to deploy

### THE GREAT TB CHALLENGE

- Tanzania is one of 22 countries with a high TB burden countries
- TB is a major cause of morbidity and mortality in Tanzania
- 63,450 TB cases were reported in 2010, 1.3 per cent less than in 2009. 94 per cent were new cases.
- The average caseload has increased dramatically due to HIV/AIDS. It is 5.4 times higher than in 1983, when the number was 11,753 cases

Source: Training of Tutors from Medical Training Institutions Central Zone VETA – Dodoma: July 30th 2013 Dr. N. Range

in a country where the healthcare sector and patients only have scarce resources available: the scenario of TB patients going to a health facility on a daily basis to take their medication, not only represents a heavy workload for the healthcare staff, but also for the patients themselves.

The PCT model is designed to ease the following challenges:

Firstly, the model reduces the burden on health workers as they no longer have to provide every day supervision of all TB patients' treatment, an important factor bearing in mind the chronic shortage of health workers. Today, Tanzania has only one doctor for every 40,000 people – while Denmark has one per 294 people and England has one per 263 people.<sup>10</sup>

Secondly, it improves access to TB treatment for patients, many of whom are already in poor health (38 per cent are also infected with HIV), and if they have to walk long distances every day or find the money to pay for public transport, many will eventually drop out of treatment.

“This approach can help minimize the use of scarce resources in the healthcare sector, and also improve the access to and quality of treatment for each TB patient,” Senga Pemba explains.

In 2006, an evaluation of the three pilot districts showed a higher percentage of

Note<sup>10</sup>: The World Bank. *Physicians (per 1,000 people)*. <http://data.worldbank.org/indicator/SH.MED.PHYS.ZS> (accessed December 2013).



successful treatment outcomes under PCT compared to the conventional facility-based TB treatment, from 72 per cent in 2005 to 77.5 per cent in 2007.

Given these positive findings, the PCT-approach was rapidly adopted as national policy and applied across the country. So far, the positive effects have been replicated on the national level; the rate of successful treatment outcomes has increased from 72 per cent in 2005 to 87.7 per cent in 2007 and 88 per cent in 2009. A recent survey of patient experience revealed that 88 per cent of TB-patients chose home-based treatment, indicating a huge demand for the new treatment option. More than 95 per cent of patients followed the TB therapy.

Putting the patient in the center allows for resources to be dedicated to the patients who have the greatest need. According to Senga Pemba, the numbers alone tell the story of the positive effects that can be brought about by rethinking treatment and care with a patient focus.

“There are many benefits. It is very cost-effective: it allows you to give a much more effective treatment, while saving time and money. And it enables better care and quality of treatment.”

Tanzania's efforts do not stop with TB treatment though. In fact, PCT is now being laid out as a template for treatment of other diseases.

Senga Pemba stresses that an important part of the work to be done in the future includes teaching both professionals and patients to engage in a new partnership. Another important element has been information about the new approach, firstly, by distributing PCT guidelines and booklets to patients and treatment supporters and secondly, by training healthcare professionals and students at medical schools.

“We travelled the entire country telling the story of how to setup this kind of patient-centred treatment for TB patients. This is important to make sure that both professionals and patients understand what it takes”, Senga Pemba explains.

CASE THE VETERAN HEALTH ADMINISTRATION IN THE US

# A CULTURAL REVOLUTION IN HEALTHCARE



FACTS

**TYPE**  
 REVOLUTIONIZING A HEALTHCARE SYSTEM

**WHERE**  
 THE US



**LEVEL**  
 MESO

**PARTNERS**  
 POLICY MAKERS, MANAGERS, STAFF, PATIENTS

**SCALE**  
 IMPLEMENTATION OF A NEW STRATEGY

**GOAL**  
 A CULTURAL CHANGE TO PROMOTE PERSON-CENTRED CARE

→ The Veteran Health Administration in the US has embarked on a journey to improve quality and change their system from being disease-driven to being patient-driven.

Person-centred care calls for a radical revolution in the way care is organized and provided. This insight has been the driving force for the Veterans Health Administration (VA) in the US in its quest to make person-centred care a reality. See text box. Since the mid 1990s, the organization has worked towards changing the culture within the entire healthcare system, moving from a disease-centred to a person-centred approach. See figure 1.

FIGURE 1

## THE NEW PARADIGM

THE VETERANS' HEALTH ADMINISTRATION HAS SET OUT TO RESTRUCTURE ITS HEALTH SERVICES FROM FOCUSING ON DISEASE TO FOCUSING ON THE NEEDS OF THE PATIENT.

PAST	VA	PRESENT	VA	FUTURE	VA
"WHAT CAN I FIX?"		"HOW CAN WE HELP WHAT IS WRONG WITH YOU?"		"HOW CAN WE HELP YOU LIVE THE LIFE YOU WANT TO LIVE?"	
PHYSICIAN		CLINICAL TEAM		VETERAN, FAMILY AND HEALTHCARE TEAM	
CASE-BASED PAPER MEDICAL RECORD		DISEASE-BASED ELECTRONIC MEDICAL RECORD		WHOLE-PERSON ELECTRONIC HEALTH RECORD	
"WE'LL ADDRESS YOUR IMMEDIATE CONCERN."		"YOU HAVE A RISKY PROBLEM, PLEASE FOLLOW THIS PLAN TO IMPROVE BY YOUR NEXT VISIT."		"WE CAN DESIGN YOUR PERSONALIZED HEALTH PLAN TO MEET YOUR GOALS."	

Source: Noe CM. Integrating Audiology into PACT. Veterans Health Administration, 2012.

### THE VETERANS' HEALTH ADMINISTRATION

The Veterans' Health Administration is America's largest integrated healthcare system with over 1,700 sites of care, serving 8.3 million veterans each year. The VA is responsible for providing healthcare to US Military Veterans through 171 medical centres; more

than 350 outpatient community and outreach clinics; 126 nursing home care units; and 35 domiciliaries. VA healthcare facilities provide a broad spectrum of medical, surgical and rehabilitative care to the veteran population.

“The VA is embarking on a transformation of healthcare, to replace the current ‘find-it-and-fix-it’-model with a personalized, proactive approach, driven by the individual needs of the Veteran,” Dr. Tracy Gaudet, Director of VA’s Office of Patient Centered Care and Cultural Transformation, explains<sup>11</sup>.

As a part of this transformation, the VA has changed its nursing homes and made them into community living-centres where the staff’s primary mission is to deliver person-centred care in a homelike environment. The VA has implemented the person-centred medical home-model at all primary care clinics throughout its nationwide system. *See text box.* And it has launched My HealthVet – a personal health record that helps patients communicate with their healthcare providers.

All of these changes are based on the overall strategic goal of providing more comprehensive and coordinated as well as person-centred care.

In this manner, the VA has leapfrogged many other healthcare systems on the path to developing a model for person-centred care – and becoming a model of inspiration for others in the process.

“The VA is an example of a healthcare system that has successfully worked towards improving the quality of care through patient-centred care,” says Rinchen Pelzang, a doctoral student at Deakin University in Melbourne, Australia.

#### PATIENT-CENTRED MEDICAL HOMES ARE A SUCCESS

In 2010, the VA initiated a three-year project to build person-centred medical homes in more than 900 primary care clinics across the nation. They are manned by interdisciplinary provider teams that collaborate to improve chronic disease management for veterans.

The delivery of patient care is the collective responsibility of the team members, who include a primary care provider, a registered nurse, a licensed practical nurse and a medical clerk.

The program has shown positive results so far. The review “Benefits of Implementing the Primary Care Patient-Centered Medical Home: A Review of Cost & Quality Results” which evaluates 46 medical home

initiatives across the US, provides significant evidence that the medical home model improves quality of care and population health, while reducing healthcare costs.

At one of the medical homes, the Alaska Native Medical Center, the new organizational structure has resulted in 50 per cent fewer urgent care and emergency room visits, 53 per cent fewer hospital admissions and a 65 per cent reduction in specialist utilization.

At another medical home, the Maryland CareFirst Blue Cross Blue Shield, it has resulted in a 4.2 per cent reduction in patients’ overall healthcare costs and estimated cost savings of USD 40 million in 2011.<sup>12</sup>

Note<sup>11</sup>: Department of Veterans Affairs. *Transforming Health Care*. 2012.

Note<sup>12</sup>: Nielsen M, Langner B, Zema C, Hacker T, Grundy P. *Benefits of Implementing the Primary Care Patient-Centred Medical Home*. Patient-Centred Primary Care Collaborative, 2012.



Several experts came to the same conclusion last year, at the conference for Patient-Centeredness in Policy and Practice. Steven E. Weinberger, MD, Executive Vice President and Chief Executive officer of the American College of Physicians, praised the VA and its transformation to person-centred care as a model for others to look into: “Right now, the VA is used as a model of quality”<sup>13</sup>.

The VA was not completely changed overnight, however. In fact, the still ongoing process is characterised by many different steps, however five key areas have formed the cornerstones of this process.<sup>14</sup>

**Five key cornerstones to the VA’s transformation:**

**1. Strategic goals and leadership.** Person-centred care is an important part of the VA’s strategic goals and daily work. In 2011, the VA established the Office of Patient-Centred Care and Cultural Transformation, which promotes person-centred care as a way to change the present culture within the system.

**2. Structural and organizational transformation.** The VA has initiated a number of structural and organizational alterations in order to promote person-centred care. It has rationalized and relocated resources, established financial incentives to promote person-centred care, redesigned the primary care system and transformed in-house care to include more outpatient treatment. See figure 2. Today the VA manages approximately 150 medical centres, supplemented with 800 community-based outpatient clinics – as a strategic move to facilitate care closer to the veterans.

**3. Education and research.** Throughout the VA healthcare system, administrators have been asked to train their staff in person-centred care. The VA Employee Education System and Primary Care Central Office promote person-centred care within VA through meetings, conference calls and presentations. With regards to research, all alterations and changes are based on evaluations of pilot projects and demonstration laboratories.

**4. Creating a measurement culture.** The VA has invested in the collection of and feedback on data on clinical processes, outcomes and patients’ experiences, as a way of promoting person-centred care.

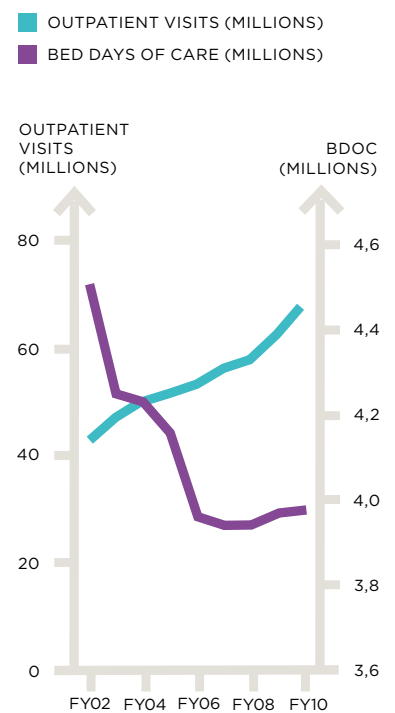
**5. Data.** New information systems have also been key factors – both as a way of monitoring and supporting performance, and as a way of ensuring better coordination of care between healthcare stakeholders. One example is the personal healthcare records MYHealtheVet.

The VA has not reached its final destination yet and further advancement of person-centred care remains a cornerstone of the VA’s strategy for 2013-2018.

FIGURE 2

## REDUCING HOSPITAL STAYS

THROUGH A DIRECT EFFORT TO CHANGE THE STRUCTURE AND FOCUS OF HEALTHCARE SERVICES, THE VA HAS SUCCEEDED IN REDUCING THE NUMBER OF BED DAYS REMARKABLY.



Source: Petzel RA. Health System Transformation. 2010.

Note<sup>13</sup>: Kuehn BM. Veterans Health System Cited by Experts as a Model for Patient-Centred Care. *The Journal of the American Medical Association*. 2012; 307(5):442-443.

Note<sup>14</sup>: Perlin JB, Kolodner RM, Roswell RH. *The Veterans Health Administration: quality, value, accountability, and information as transforming strategies for patient-centered care*. *HealthcarePapers* 2005; 5(4): 10-24.

CASE ALLIANCE FOR PATIENTS' MUTUAL HELP ORGANIZATIONS IN HONG KONG

# GIVING PATIENTS A VOICE



## FACTS

**TYPE**  
ADVOCACY

**WHERE**  
HONG KONG



**LEVEL**  
MICRO AND MACRO

**PARTNERS**  
ORGANIZATION/PATIENTS

**SCALE**  
PROMOTING NEW POLICIES AND  
KNOWLEDGE SHARING

**GOAL**  
IMPROVING PATIENT CONDITIONS

→ **The voice of the public can be a powerful driver of change – also when it comes to promoting person-centred healthcare as revealed by the Alliance for Patients' Mutual Help Organizations in Hong Kong.**

If we compare the different groups in the healthcare sector, patients and their personal networks easily outnumber the professionals, providers and policy makers. Potentially, this makes the coordinated and unified voices of patients a great force of power and influence. Patient-based advocacy and public pressure can become an important driver for change, not least in terms of promoting and creating a more person-centred healthcare sector.

Based on the motto “No decision about me, without me”, the patient organization the Alliance for Patients' Mutual Help Organizations (APMHO) works to endorse person-centred healthcare in Hong Kong and the Western Pacific region. For years, the organization has successfully used advocacy as a vehicle for influencing and pushing forth a more person-centred approach. By doing so, it has managed to challenge new laws, influence new policies and promote new guidelines that can help move the healthcare sector in a more person-centred direction.

Founded in 1993, the alliance represents more than forty-seven different patient groups. Its aim is to provide a united voice for patients with various chronic diseases like diabetes, cancer and multiple sclerosis and through its patient group memberships, it currently represents approx. 40,000 patients.

Since 2006, APMHO has been promoting the concept of person-centred healthcare through a line of different advocacy initiatives aimed at the government, healthcare service providers, and the media.

Among others, AMPHO has convinced the Hong Kong Government and major public healthcare providers that they should accept patient representatives' participation at all levels of the decision-making processes, from policy formulation and planning through concrete implementation and review. This has led to a complete transformation of the Hong Kong healthcare sector, where patient involvement has become an important part of the decision-making process. Furthermore, patient representatives now participate in

healthcare advisory committees to the government and in various steering committees at a number of hospitals.

The Alliance has ensured that patient opinions have been considered on a number of issues, e.g. smoking policies, the provision of vaccinations for children and regulations on pharmaceutical products.

One specific case that shows the organization's impact was when a government hospital authority planned to use a drug to treat colon cancer and age-related macular degeneration (AMD), because it was cheaper than its registered counterpart.

However, there were no studies to prove that the drug was safe to use, and it was not generally considered effective by drug regulators. With the support of healthcare professionals and patients' organizations, AMPHO spent over a

#### **THE ALLIANCE FOR PATIENTS' MUTUAL HELP ORGANIZATIONS**

In its work with promoting better patient conditions, APMHO has the following objectives:

- Supporting the growth of patient self help/mutual help groups.
- Promoting the participation of patient groups in designing healthcare policies.
- Advocating patient-centred healthcare services.
- Participating in local and international patient self-help movements.



year lobbying the government, the health authorities and the universities. As a result of the organization’s massive efforts, the hospital authority dropped its plans to use the drug and decided to use the registered drug instead.<sup>15</sup>

In December 2012, AMPHO published the report “Patient-Centred Healthcare in Hong Kong - An Exploratory Study Report”<sup>16</sup> in collaboration with the Community Rehabilitation Network of The Hong Kong Society for Rehabilitation.

It is the first time a study outlines the status of person-centred healthcare in Hong Kong with the declared goal of promoting person-centred care as an important part of policymaking: “Patient-Centred Healthcare and Patient Engagement must be two core pillars in policy-making, strategy forming, and program planning.”

The study provides an account of chronic patients’ and caregivers’ current view on person-centred services within the Hong Kong healthcare sector as well as their expectations. It shows that the present level of person-centred care is above average and it has been on a positive track for the last five years, but it also reveals that respondents still expect more. See figure 1.

FIGURE 1

## EXPECTATIONS RISE

RATINGS ON PERSON-CENTERED HEALTHCARE FROM THE CHRONICALLY ILL AND CAREGIVERS IN HONG KONG, 5-POINT SCALE (5=BEST)

CHRONICALLY ILL /CAREGIVER’S RATING OF SERVICES IN HONG KONG	5 YEARS AGO	PRESENT	COMING 5 YEARS
PATIENTS’ RIGHT AND ACCESS TO INFORMATION (DISEASE PROGRESS, TREATMENT METHODS, ETC.)	3.0	3.3	4.2
RESPECT AND COURTESY TOWARDS PATIENTS AND FAMILY MEMBERS	3.3	3.4	4.2
PATIENTS AND THEIR FAMILIES’ RIGHT OF CHOICES TO TREATMENT METHODS	2.9	3.2	4.2
CARING FOR AND ENCOURAGEMENT OF PATIENTS	3.1	3.3	4.2
PATIENT INVOLVEMENT IN THE FORMULATION OF HEALTHCARE POLICIES	2.4	2.7	4.0
RELEVANT SOCIAL RESOURCES AND INFORMATION FOR THE DISEASE GROUP	2.8	3.1	4.2

CHRONIC PATIENTS AND CAREGIVERS IN HONG KONG SHARE THE STRONG SENSE THAT PERSON-CENTRED CARE IS MOVING FORWARD. THEY HAVE SEEN A LOT OF IMPROVEMENTS OVER THE LAST FIVE YEARS AND EXPECT EVEN MORE LOOKING FIVE YEARS INTO THE FUTURE.

Source: Alliance for Patients’ Mutual Help Organizations and Community Rehabilitation Network of The Hong Kong Society for Rehabilitation. *Patient-Centred Healthcare in Hong Kong - An Exploratory Study*. 2012.

Note<sup>15</sup>: International Alliance of Patients’ Organizations. *IAPO Member Case Study: Promoting Patient-Centred Healthcare in the Western Pacific: the Experience of the Alliance for Patients’ Mutual Help Organizations*.

Note<sup>16</sup>: Alliance for Patients’ Mutual Help Organizations and Community Rehabilitation Network of The Hong Kong Society for Rehabilitation. *Patient-Centred Healthcare in Hong Kong - An Exploratory Study*. 2012.

NEXT  
BENEFITS  
FOR ALL



CHAPTER  
6/10

ALL CHAPTERS





**Sanjay Kalra:** Endocrinologist and Consultant & Head of Bharti Research Institute of Diabetes & Endocrinology at Bharti Hospital in Karnal, India. Awarded the DAWN International Award in 2009, Executive Editor of the Indian Journal of Endocrinology & Metabolism and Journal of Social Health in Diabetes, he has authored numerous editorials and reviews on the usage of person-centred care in diabetology and endocrinology practices.



**Dr. Rakesh Kumar Sahay:** Professor of Endocrinology at Osmania Medical College and Hyderabad and Consultant Endocrinologist at Sahay's Endocrine and Diabetes Centre. Furthermore, he is Secretary of the South Asian Federation of Endocrine Societies and Associate Editor for the Indian Journal of Endocrinology & Metabolism. He has co-authored the article: "Patient-Centred Approach To Diabetes Management: The Dawn Philosophy".



**Manash P. Baruah:** Editor-in-Chief of the Journal of Medical Nutrition & Nutraceuticals. He is also the Director and Consultant Endocrinologist at the Excel Centre (a unit of Excel Care Hospitals) in India. He is co-author of: "Patient-Centred Approach To Diabetes Management: The Dawn Philosophy", which discusses on supporting diabetes healthcare professionals in adopting new person-centred treatment strategies through facilitation of training programs, insights as well as practical tools and strategies.



INDIA

INTERVIEW **SANJAY KALRA, MANASH P. BARUAH AND DR. RAKESH KUMAR SAHAY**

# A FAREWELL TO *THE* BIOLOGICAL MODEL

→ **Person-centred care requires professionals in the healthcare sector to adapt a whole new model of treatment to meet the needs of today's patient. This calls for a change in training and mindsets, as three Indian endocrinologists advocating a more person-centred culture among professionals explain.**

"Today, doctors are trained in and used to looking at the biological aspects of a patient's disease and treatment. We think in terms of diseases, diagnoses, pills, tests. We explain everything in physiological terms, and we are not used to focusing on social and psychological aspects when we meet a patient. This must change in order to deliver care that is patient-centred," Sanjay Kalra says.

He believes that a holistic focus on each patient is a precondition for person-centred care. This is far from standard practice in the healthcare sector of today.

"You have to put yourself in the patient's shoes and understand the patient's needs and what they prefer. This means that you need to understand the whole person and make this the cornerstone of the treatment. This is not the way most doctors think and work today," kalra elaborates.

Along with two other Indian physicians, Manash P. Baruah and Rakesh Kumar Sahay, he is pioneering person-centred care as the way forward. They all practice this approach in their daily work as doctors, while also doing research on shared decision-making, doctor-patient relationships and diabetes management based on person-centred care.

They share the opinion that it is out of tune with the needs of patients today to look solely at the biological and physiological aspects of care – especially when dealing with patients with chronic and long-term conditions.

"Chronic diseases demand another kind of treatment.

It is not enough to give an instant treatment or a pill. When looking at these types of diseases, we have to understand that they are caused and affected not only by biological but also psychological and social factors. Therefore, we have to substitute the traditional biomedical model with a model that includes psychological and social aspects of a patient's life," says Manash P. Baruah.

#### **A cultural change**

This new model of treatment is not something that doctors and professionals will automatically adopt. Sanjay Kalra notes that there is widespread resistance and skepticism among physicians when it comes to including the more psycho-social aspects in their treatment of patients.

"When someone teaches us biological medicine, we look and we listen with both ears open. But when someone teaches us about social and physiological aspects of a medical issue or treatment, we do not. We think of it as something below our level of expertise," he says.

Elaborating further on this point, Rakesh Kumar Sahay stresses that adopting the new treatment model requires a change in attitude and culture among physicians.

"A change in the attitudes of the doctor is key. Today we have a very preconceived notion of how we should work and interact with patients. This is something that we have to rethink."

Not least because healthcare professionals tend to favour aspects that can be measured and communicated in numbers and facts, which dictates how medical issues are communicated, how treatments are structured and planned, and what is considered prestigious and valuable. It is more difficult for professionals to address "softer" issues.

"Biological training is more tangible: the facts can be monitored, so you know what to improve, what to do, and how to do it. This is more difficult when it involves social and psychological perspectives, but it is a way of thinking and working that doctors have to learn," Rakesh Kumar Sahay states.

#### **The way forward**

All three physicians agree that the key to making professionals accept and adopt a more person-centred approach is to build up its status and professional substance.

"We have to enhance the prestige of person-centred care and make it more desirable in order to get more people to accept it as the default for future medical care. We have to convince people that this is not only a vital part of good medical behavior, but high status also," Manash P. Baruah says.

One important element of this is to engage "champions" – respected professionals that can endorse person-centred care within the medical regime.

"It has to be someone with real results and clinical expertise. If you do not have this, people will not listen to you," says Manash P. Baruah.

Another important task is to ensure that the new generations of professionals are taught this model from the beginning.

"We have to tell medical students about patient-centred care and shared decision making. This is where we can make a difference. If you have been a clinician for some years, it is much more difficult to make this change. So for person-centred care to move forward, we have to begin with medical colleges and promote this approach throughout education programs and medical curricula. This will enable a change among the doctors," Sanjay Kalra predicts.

*“We cannot change  
the past. But we  
can use it to **inform**  
**the present.**”*



- **Margaret Murphy**, Ireland, Mother of Kevin who died from medical errors at the age of 21

**Age:** 72 years

**Occupation:** Retired administrator. External Lead Advisor, Patients for Patient Safety Programme, World Health Organization

**Family:** Married, two adult children besides Kevin



→ 14 years ago, Margaret Murphy lost her youngest son due to neglect and medical errors in the Irish healthcare system. Today, she is a dedicated and respected advocate of patient safety and person-centred care.

Her motivation for speaking about the tragic experience is the learning imperative and the prospect of preventing recurrence.

“Kevin’s death has value as a learning tool that can benefit healthcare,” she says.

When she speaks to policy makers, healthcare professionals and students about Kevin’s patient journey, she calls for greater involvement of patients and their families, which she considers to be an untapped resource in healthcare.

Kevin Murphy died at Cork University Hospital on a Sunday afternoon in September 1999, his mother and sister sitting at his bedside.

His death certificate lists multi-organ failure and hypercalcaemia due to a tumour in the hormone-producing parathyroid glands in the neck. Such a tumour affects the body’s hormone balance, altering the viscosity of the blood and depriving the bones of calcium.

The appropriate treatment for his condition has a 96 per cent success rate with a 1 per cent complication rate. But despite alarming test results almost two years previously, Kevin Murphy was not diagnosed correctly before the autopsy. He died only three days after he was finally admitted to hospital.

The first symptoms appeared in 1997. On several occasions, Kevin complained about persistent back pain, lack of concentration and lethargy. He also suffered from uncharacteristic mood swings.

“As a family, we noticed quite a change in Kevin,” Margaret explains. “We took him to the GP on a number of occasions and to a physiotherapist for the back pain. We were trying to address the symptoms, because that was all we could see.”



Kevin returned from each consultation seemingly healthy, with no further explanation for his erratic behaviour. But Margaret knew something was not right.

“As his mother, I felt that something was seriously wrong. But I had no idea what that might be,” she says: “Mothers have a sixth sense when things are not right with their children”

After some months, the GP finally referred Kevin to an orthopaedic consultant. A blood test revealed unusually high calcium levels. But in the letter sent back to the GP, the calcium numbers were downplayed and the intended consultation with Kevin later on was never scheduled.

Peer reviewers have later stated: “All the evidence indicates that the patient was suffering from a solitary parathyroid adenoma at that time and removal would have been curative with a normal life expectancy.”

### Neglect and closing ranks

Two years later, in the fall of 1999, Kevin once again complained of lethargy, occasional vomiting, and continuing bone pain. A blood test now showed even higher calcium levels, levels which were later described as “inconsistent with life”. These results were communicated by telephone to the GP and transcribed on a post-it note by the nurse who drew attention to the high calcium levels.

But the GP subsequently neglected the high calcium levels in the letter of referral to the hospital, instead highlighting other parameters in the tests supporting his own suggested diagnosis.

When the patient file was compiled in The Mercy Hospital, where a diagnosis of nephritis was made, the Post-it note on the critical calcium results was stuck to the back of the letter and was not discovered until six weeks after Kevin’s death.

Upon his transfer to Cork University Hospital, new tests re-



***Margaret's advice to healthcare professionals:***

- *Remember that care is only patient-centred when it is perceived as such by the patient.*
- *Listen to and respect patients and families. Practice dialogue and collaboration – meaningful engagement with patients and families. Create a coalition of healthcare professionals and patients.*
- *Know your personal limitations. Acknowledge error and allow learning. When things go wrong, be honest and open, and seize the opportunity to give some meaning to tragedy.*

vealed calcium levels so high that the doctors thought an error had occurred and had them repeated.

As the picture was becoming clearer and the correct diagnosis was finally offered, Kevin was managed at registrar level following a weekend admission to hospital. Senior personnel were not alerted and he did not benefit from emergency surgery. On September 26, Kevin suffered a heart attack and died.

After his death, Kevin's family looked for answers to what had gone wrong, but were met with excuses, absence of transparency and "closing ranks". Reluctantly, they embarked on what became a five-year litigation process, which culminated when the High Court judge declared: "It is very clear to me that Kevin Murphy should not have died".

Two GPs, the orthopaedic consultant and a hospital consultant conceded liability, expressing their regret and sympathy. The family eventually donated the compensation to two charities.

Since then, Margaret has reacted to the growing demand to learn from Kevin's patient experience in the hope that it can be a catalyst for change.

"We cannot change the past. But we can use the past to inform the present and then in the present we can influence a better future," she says.

"I believe that partnership and collaboration between health-care professionals, patients and relatives is the way forward."

### **Biography: Margaret Murphy**

Following the death of her son as a result of medical error, Margaret Murphy has been an active advocate of patient safety. She is the External Lead Advisor at WHO Patients for Patient Safety – a network of more than 200 patient safety champions from 51 countries with 19 collaborating organizations.

The pivotal point of her work is to see adverse events as potential catalysts for change; providing opportunities for learning, identifying areas for improvement and preventing recurrence.

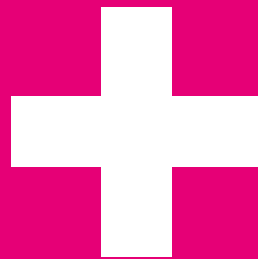
She promotes this viewpoint at local, national and international levels, when she is invited to speak at conferences, to hospital staff or to students. Her area of particular interest is education as a vehicle to achieve sustainable change of culture.

Considered a resource in relation to the inclusion of the patient perspective in a variety of initiatives and a range of fora, Margaret has been invited to partner and collaborate in the areas of:

- Policy-making (Commission on Patient Safety & Quality Assurance and implementation steering group; HSE National Risk Committee)
- Standard-setting (HIQA working group)
- Regulation (lay member of the Irish Medical Council, serving on the ethics committee and the preliminary proceedings committee)
- Education (lectures for students at UCC, Trinity, UHG, Queens)
- Research (collaborator on EU Handover Project, QUASER Project, Assessor final stage applications for NIHR funding for Translation Research Centres in UK)
- Conference speaker – often keynote (conferences, seminars and learning sets in Ireland, UK, Europe, US, Canada, Australia).
- Team member of critical incident reviews
- One of 70 designated ISQua Experts in 2012

# BENEFITS FOR ALL

– PERSON-CENTRED CARE  
SHOWS POSITIVE GAINS FOR ALL  
HEALTHCARE STAKEHOLDERS



RESEARCH SHOWS THE BENEFITS OF PERSON-CENTRED CARE FOR ALL MAJOR STAKEHOLDERS WITHIN THE HEALTHCARE SECTOR. FROM IMPROVED PATIENT AND EMPLOYER SATISFACTION TO BETTER HEALTH OUTCOMES AND HEALTH ECONOMY. A GROWING AMOUNT OF EVIDENCE YIELDS A POSITIVE ANSWER TO THE QUESTION THAT ALL HEALTHCARE STAKEHOLDERS ASK: “WHAT’S IN IT FOR ME?”

*“To develop and implement person-centred care, you have to face the question: ‘**what’s in it for me?**’ That’s the only way to convince doctors, nurses and hospital directors that it’s **a win-win-win situation.**”*

- Jerzy Kaczynski, Chief Physician,  
Sahlgrenska University Hospital

→ **Chief physician Jerzy Kaczynski** admits he is a bit of a sceptic when it comes to new ideas in healthcare. As head of the ward for emergency and cardiovascular medicine at the Sahlgrenska University Hospital in Gothenburg, he wants new ideas to be supported by scientific evidence and by a clear indication that the new concepts actually work.

This was also the case, when he first heard about person-centred care. But then he was approached by a respected colleague, Professor Inger Ekman, one of Europe’s leading experts in person-centred care. She presented him with the latest research and told him about plans to establish a national competence centre for person-centred care in Gothenburg.

“Almost all studies in this literature review, regardless of methodology, found **positive relationships** between patient-centred care processes and patient satisfaction and well-being”

- Patient-Centered Care and Outcomes:  
A Systematic Review of the Literature, 2012

Convinced by the evidence on the positive outcomes, Jerzy Kaczynski agreed to take on the challenge. Today, his ward is Sweden's front runner in the practical implementation of person-centred care.

“I was persuaded because it wasn't just another loose idea from management consultants. We doctors don't like all these new ideas that are not supported by science. We want scientific proof that ideas work. And person-centred care works. That convinced me,” says Jerzy Kaczynski.

His own experience tells him how hard it can be, convincing other doctors and healthcare professionals to adopt the idea of person-centred care.

“To develop and implement person-centred care, you have to face the question: ‘what's in it for me? That's the only way to convince doctors, nurses and hospital directors that it's a win-win-win-situation,” Jerzy Kaczynski argues.

#### Documented benefits

Every month since Inger Ekman and Jerzy Kaczynski first met, there has been new research adding to the body of evidence in support of person-centred care.

“There is very much research demonstrating the benefits and positive outcomes of this kind of thinking. We have the evidence and knowledge we need to prove that this approach works,” says Angela Coulter, professor at the Health Services Research Unit at Oxford University.

The range of benefits was recently documented, when a report from the UK's innovation fund, Nesta (National Endowment for Science, Technology and the Arts), did a review of 51 studies and real-life business case experiences at six different NHS localities in England.<sup>1</sup> Their conclusion was that person-centred care not only benefits patients but also other stakeholders.

The wide range of benefits suggest that person-centred care is valuable to all groups involved in the healthcare system. Some factors might have an isolated impact on only one group, but just as often, specific improvements benefit more than one group of stakeholders. By way of example, reduced length and number of hospital admissions have obvious benefits for everyone involved.

As the different agents within the healthcare sector have diverging interests and concerns, it all boils down to the question Jerzy Kaczynski posed earlier: *what's in it for me?*

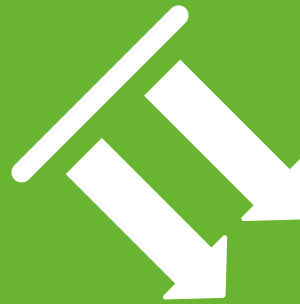
Note<sup>1</sup>: Nesta. *The Business Case for People Powered Health*. 2013.

# BENEFITS OF PERSON-CENTRED CARE



## IMPROVES

- Patient satisfaction by improving patient experience and effectiveness of clinical treatment
- Patient experience by involving patients in the delivery of their care
- Work satisfaction among healthcare professionals
- Treatment compliance as patients co-design and self-manage
- Health outcomes for patients as they are better able to manage their long-term condition
- Social capital by building networks of support around the patient
- Use of primary care by improving patients' ability to self-manage



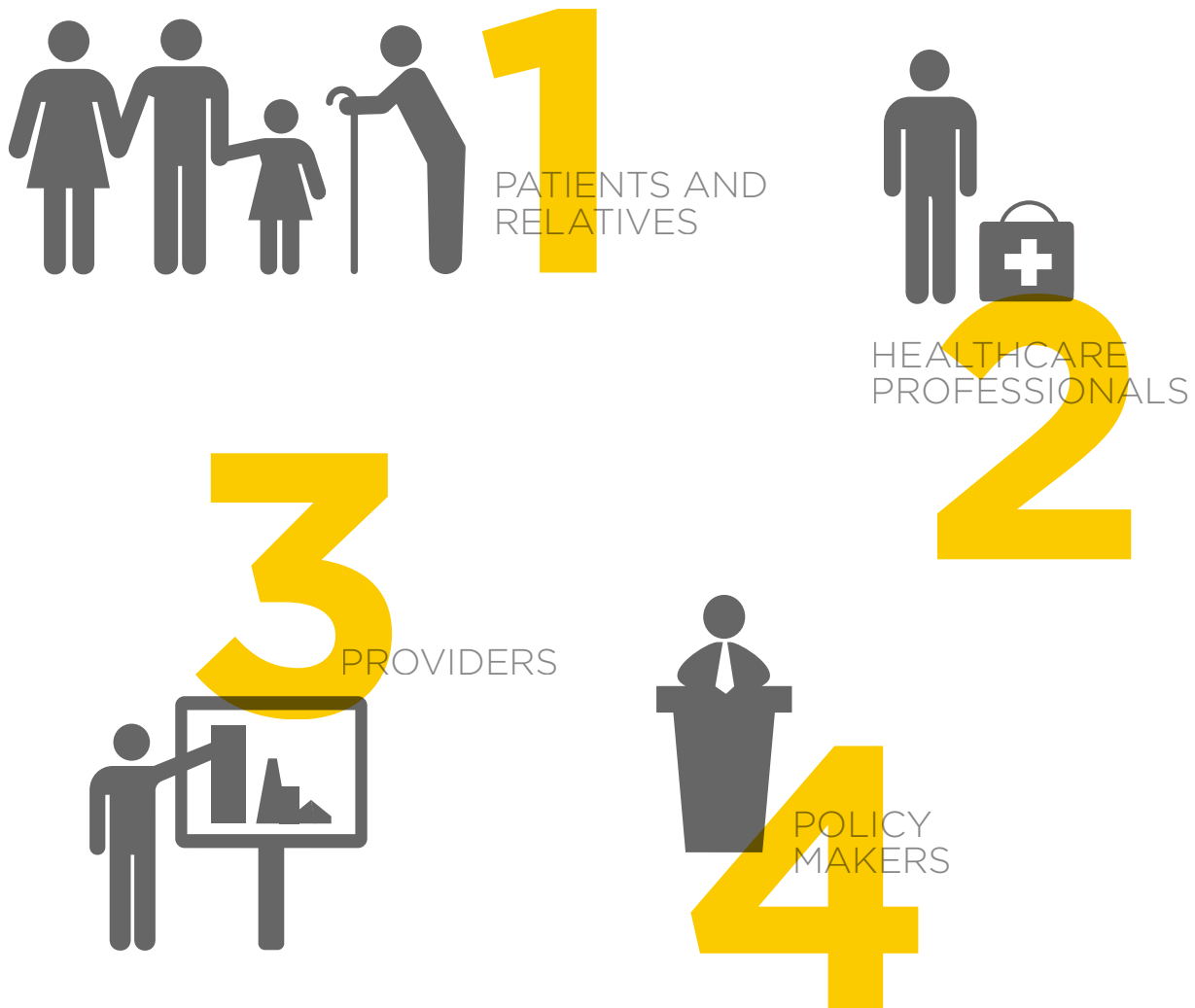
## REDUCES

- Rate of medication errors
- Number of hospital admissions and
- Re-admissions
- Length of stay at hospitals
- Need for primary and secondary care
- Cost of healthcare

FIGURE 1

## GROUPS OF STAKEHOLDERS IN HEALTHCARE

THE FOUR MAIN GROUPS OF STAKEHOLDERS WITH INTERESTS IN THE HEALTHCARE SECTOR



**PATIENTS AND THEIR FAMILIES HAVE OBVIOUS INTERESTS IN PROMOTING PERSON-CENTRED CARE. HOWEVER, RESEARCH AND STUDIES ALSO POINT TO BENEFITS FOR HEALTHCARE PROFESSIONALS, PROVIDERS AND POLICY MAKERS.**





# WHAT'S IN IT FOR THE PATIENTS?

→ For years, patient organizations have called for an improved focus on patients' needs and circumstances within the healthcare system and a growing amount of evidence supports their case.

### Patient satisfaction

Patient satisfaction is one of the most well-documented measurable outcomes of person-centred care. This message was carved in stone by a systematic literature review of 40 scientific studies<sup>2</sup> revealing evidence of a variety of outcomes, most significantly a strong positive correlation between person-centred care and patient satisfaction.

"Almost all studies in this literature review, regardless of methodology, found positive relationships between patient centred care processes and patient satisfaction

and well-being," the review concluded.

Patient satisfaction has become an important benchmark when US hospitals measure healthcare quality and report patient satisfaction scores online. On the official government website for Medicare in the US, everyone can access the scores and compare hospitals on a wide range of parameters and questions and in addition to that, a percentage of the reimbursement to hospitals is actually dependent upon the scores. This alone makes it hard for hospitals to ignore what patients think of them.

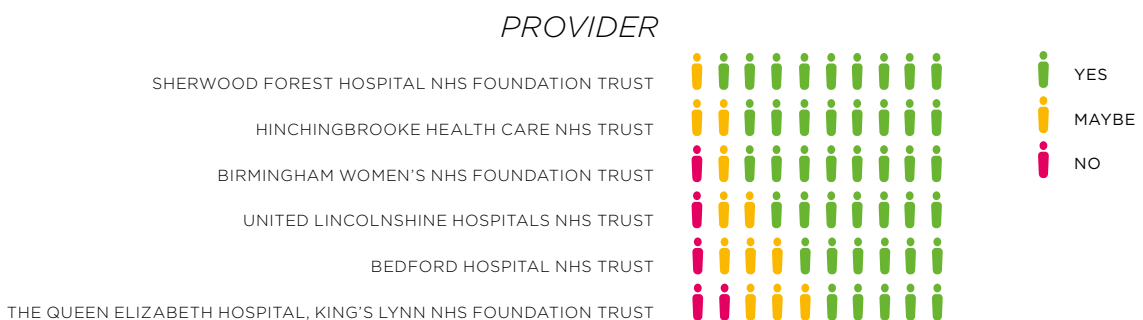
And the trend is spreading to other parts of the world, e.g. the NHS in Britain, where there is growing emphasis on the importance of feedback from patients, and not least how to use feedback to improve the services provided. See figure 2.

FIGURE 2

## HIGHLY VARIED ASSESSMENTS FROM PATIENTS

PATIENTS' FEEDBACK TO HOSPITALS IN NHS MIDLAND AND EAST, MARCH 2013

WITHIN 48 HOURS AFTER RECEIVING CARE, PATIENTS ARE ASKED IF THEY WOULD RECOMMEND THAT RELATIVES OR FRIENDS USE THE SAME PROVIDER. THE RESULT REVEALS BIG DIFFERENCES AMONG THE 46 HOSPITALS IN ONE NHS REGION (NHS MIDLAND AND EAST).



Source: [http://www.strategicprojectseoe.co.uk/index.php?id\\_sec=224](http://www.strategicprojectseoe.co.uk/index.php?id_sec=224) / Breakdown of March's results

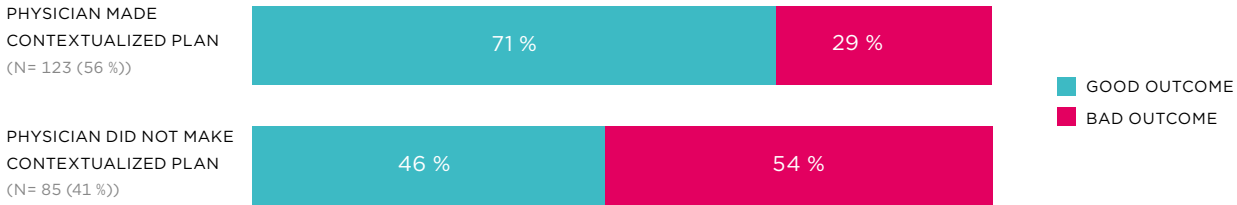
Note<sup>2</sup>: Rathert C, Wyrwich MD, Boren SA. Patient-Centered Care and Outcomes: A Systematic Review of the Literature. *Medical Care Research and Review* 2013;70(4): 351-379.

FIGURE 3

## BENEFITS FROM INCLUDING WHOLE LIFE EXPERIENCE

OUTCOME OF CARE PLANNING, WITH AND WITHOUT INCLUSION OF THE PATIENT'S WHOLE LIFE SITUATION

OUTCOME ACCORDING TO PERFORMANCE OF PHYSICIANS IN RELATION TO CONTEXTUALISING CARE



**THERE ARE SIGNIFICANT BENEFITS TO THE CLINICAL OUTCOME WHEN PHYSICIANS INCLUDES PATIENTS' WHOLE LIFE SITUATION INSTEAD OF SOLELY FOCUSING ON CLINICAL ASPECTS.**

Source: Weiner S, et al. Patient-Centered Decision Making and Health Care Outcomes: An Observational Study. *Annals of Internal Medicine* 2013;158(8): 573-580.

Some researchers suggest that improved patient satisfaction is also a sign of more palpable health benefits because it affects adherence and self-management behaviour<sup>3</sup>.

### Improved quality of life

Patients with long-term conditions such as diabetes, chronic lung diseases and heart diseases participating in the Expert Patients Programme in Britain, report an improved quality of life. They are turned into “experts” by receiving self-care support and developing self-care skills, confidence and motivation to manage their long-term conditions<sup>4</sup>.

On the other side of the globe, evidence points in the same direction. In Taiwan, a study found that support for patients’ self-directed recovery plans promoted patient satisfaction, trust and quality of life. By recognising the uniqueness of each patient’s preferences, healthcare professionals could improve outcomes for patients<sup>5</sup>.

### Improved health outcomes

Another benefit is the improved clinical outcome, which is indirectly indicated by studies showing higher patient satisfaction and reduced periods of hospitalization.

Furthermore, healthcare plans that are person-centred have a more beneficial outcome. This was pointed out in a recent study led by Dr. Saul Weiner of the University of Illinois in Chicago. The study shows that when doctors addressed underlying patient-specific circumstances as a basis for the care plan at the initial meeting with the patient, health outcomes would improve.

By way of example, deteriorating self-management of a chronic condition could reflect an underlying contextual factor such as loss of social support. When identified and included in the formulation of a care plan, healthcare outcome improved in 71 per cent of the cases compared to 46 per cent, where those underlying patient-specific issues were not addressed<sup>6</sup>. See figure 3.

According to Dr. Weiner, the emphasis in healthcare today is still too narrowly placed on the patient’s clinical history and on research evidence. What is needed is more attention to the patient’s life context and preferences.

“Today the healthcare sector and the doctors are very focused on the first two points. The last two tend to be overlooked,” he says pointing to four focus areas of healthcare: patients’ clinical history, research evidence, the patient’s life context and the patient’s preferences.

Note<sup>3</sup>: Kahn KL, Schneider EC, Malin JL, Adams JL, Epstein AM. Patient centered experiences in breast cancer: Predicting long-term adherence to tamoxifen use. *Medical care* 2007; 45(5):431-9 ; Lemmens KMM, Nieboer AP, Huijsman R. Designing patient-related interventions in COPD care: Empirical test of a theoretical model. *Patient Education and Counseling* 2008;72(2): 223-231.

Note<sup>4</sup>: Nesta. *The Business Case for People Powered Health*. 2013.

Note<sup>5</sup>: Lee YY, Lin JL. Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes. *Social Science & Medicine* 2010;71(10): 1811-1818.

Note<sup>6</sup>: Weiner S, et al. Patient-Centered Decision Making and Health Care Outcomes: An Observational Study. *Annals of Internal Medicine* 2013;158(8): 573-580.

### Improved patient safety

A person-centred work environment at hospitals can increase patient safety. For instance, a statistical study on nurses' perception of their work environment in the US found that person-centred care leads to fewer medication errors. In addition, the caregivers in the study said that they felt more comfortable reporting errors and near-misses than caregivers in units working traditionally<sup>7</sup>.

David Blumenthal, president of the US based Commonwealth Fund claims that problems with safety in care is one of the two major issues that need addressing.

"Unsafe care cannot be patient-centred, because it is not responsive to patients needs and wishes," he says.

Statistics tell us that one in ten patients is harmed because of failures in health systems<sup>8</sup>. A WHO report about patient safety notes that "estimates from developed nations suggest that between 7.5 and 10.4 per cent of hospitalized patients experience injuries due to medications alone and that has been estimated to contribute to 140,000 deaths each year in the US alone."<sup>9</sup>

A study encompassing eight countries in Africa and the Middle East revealed that adverse events at hospitals may cause the death of up to 4 per cent of all patients<sup>10</sup>.

"We have to create an environment, where the health facility places the patient at the heart. Health facilities should develop a culture, that is patient-centred and where patient safety is key," says Sham S. Syed, Programme Manager for African Partnerships for Patient Safety at WHO.

"My entry point is that patients should not leave a hospital, a physician or any other provider of care suffering because something went wrong during the process of care," Sham S. Syed explains.

### Improved communication and patient guidance

Improved communication between healthcare personnel and patients is one of the central strategies of person-centred care. Communication is particularly important in the healthcare sector as it is strongly dominated by professional jargon with a lot of expressions that non-professionals find hard to decode.

Often, treatment is insufficient because of a mismatch between patients' and doctors' expectations, which again is caused by poor communication, as Jerzy Kaczynski from Sahlgrenska University Hospital in Gothenburg argues:

"Usually, patients have many health issues that bother them. But it is only one particular reason that gets them to the hospital. So if the communication is not working well, the patient will complain at the end of the treatment because he still has pain."

At the ward he works on, a nurse is the first person the patients will meet. She will interview patients thoroughly and make sure that the communication is flowing from the beginning.

"Information is central. But patients are already well informed about their illness. What they miss is information about what is going to happen next: when can they go home and so on," Jerzy Kaczynski elaborates.

The same communication issue needs to be addressed in the primary health sector. A review has revealed that strategies to improve communication between service providers and patients in the primary sector are positively linked to health improvements<sup>11</sup>.

Note<sup>7</sup>: Rathert C, May DR. Healthcare work environments, employee satisfaction, and patient safety: Care provider perspectives. *Health Care Manage Review* 2007;32(1): 2-11.

Note<sup>8</sup>: National Patient Safety Agency. *Seven Steps to Patient Safety*. 2004.

Note<sup>9</sup>: Jha AK, Prasopa-Plaizier N, Larizgoitia I, Bates DW. Patient Safety Research: An Overview of The Global Evidence. *Quality & Safety in Health Care* 2010;19(1):42-7.

Note<sup>10</sup>: Wilson RM, et al. *Patient safety in developing countries: retrospective estimation of scale and nature of harm to patients in hospital*. *BMJ* 2012; 344

Note<sup>11</sup>: Powell-Davies G, Williams AM, Larsen K, Perkins D, Roland M, Harris MF. Coordinating primary healthcare: an analysis of the outcomes of a systematic review. *The Medical Journal of Australia* 2008;188(8): 65-68.



# WHAT'S IN IT FOR THE HEALTHCARE PROFESSIONALS?

→ **Some of the outcomes** mentioned above will naturally benefit doctors, caregivers and other healthcare professionals as well as patients. Other studies point directly to an increased satisfaction with the work environment among caregivers, if the work is person-centred.

## Improved work satisfaction

One of the most used textbooks on patient-centred interviews at medical schools in the US is “Smith’s Patient-Centred Interviewing”. The author, Robert C. Smith, a professor in internal medicine at Michigan State University, explains that doctors benefit tremendously from treating patients as human beings rather than just as patients. See chapter 8, page 134.

“Doctors are not like robots with a narrow focus on diagnosing diseases. It lightens up your day, when you are interacting with patients like a human being. It is simply much more fun to get to know the people, who visit your clinic. In the end, I think it helps to prevent burnout among doctors,” he says.

Research tells the same story. Caregivers who see their work as more person-centred are significantly more satisfied with their job than others, a study from the US concludes<sup>12</sup>.

A recent literature review on studies investigating links to job satisfaction is a bit more sceptical of the strength of the evidence but still highlights that “emotion-oriented” care and small-scale care show the most positive effects<sup>13</sup>.

## Increased understanding of patients

Healthcare professionals can also benefit from person-

centred care in the sense that they get an increased understanding of the patient’s individual needs and circumstances.

Professor Inger Ekman from Gothenburg University Hospital argues that there is an “information mismatch” between patient and healthcare professional:

“While the doctor is superior in his knowledge and understanding of medicine and healthcare in general, the patient has more knowledge about how it is to live with the condition in the specific case.”

This mismatch can be levelled out by patient and doctor entering into a partnership where mutual respect for the other’s area of expertise as well as an improved overall communication becomes the order of the day.

“It has to do with respect and is basically about listening more to the patient and not only focusing on the medical side of the problem,” Inger Ekman elaborates.

Following a disappointing patient satisfaction survey in 2009, North Middlesex University Hospital, UK, started a range of training initiatives, approaching person-centred care in a new way.

An external training provider was commissioned to deliver a course that enhanced skills of communication, respect, courteous behaviour, attentiveness and consideration of patients and their families.

This also included inter-professional learning and reflection on professionals’ attitudes. A post-training evaluation revealed that levels of knowledge and understanding among staff member had increased significantly due to the updated approach to person-centred care<sup>14</sup>.

Note<sup>12</sup>: Rathert C, May DR. Healthcare work environments, employee satisfaction, and patient safety: Care provider perspectives. *Health Care Manage Review* 2007;32(1): 2-11.

Note<sup>13</sup>: van den Pol-Grevelink A, Jukema JS, Smits CH. Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International Journal of Geriatric Psychiatry* 2012;27(3): 219-229.

Note<sup>14</sup>: Okougha M. Promoting patient-centred care through staff development. *Nursing Standard* 2013;27(34): 42-6.



# WHAT'S IN IT FOR THE PROVIDERS?

→ **As more studies reveal** effects such as shorter and less frequent hospitalizations, the business case is beginning to catch the interest of health commissioners, authorities and insurance companies. The financial benefits of person-centred care are intriguing, but they often require some sort of initial investment, studies conclude.

### Increased treatment compliance

Treatment compliance increases, when patients co-design and self-manage their health plans. An evidence report from the Health Foundation reviews the different strategies to support self-management in 550 high quality research papers<sup>15</sup>.

The review concludes that different clinical conditions re-

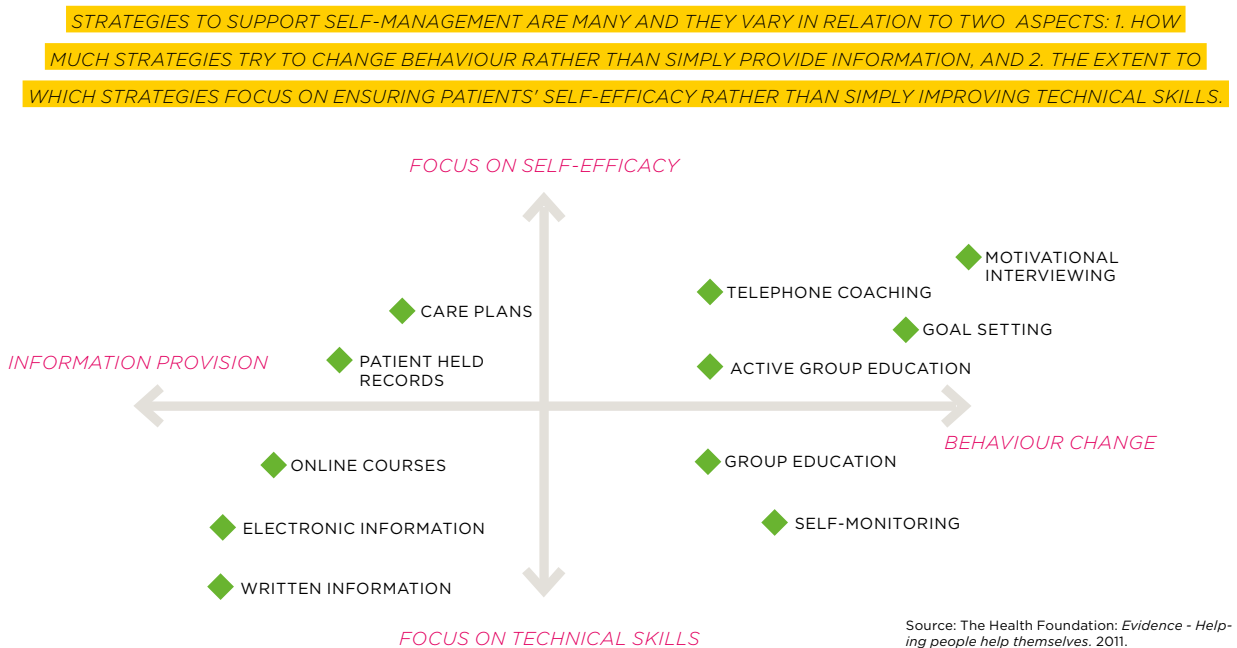
quire different approaches in support of self-management. For instance, while people with diabetes benefit from structured education about how to eat, exercise and handle medications, other conditions such as depression require less physical training and more cognitive and behavioural interventions.

Overall, evidence shows that strategies for more active goal setting, involvement of the patient, and behavioural change are more effective than just supplying the patient with information. However, a combination of different strategies proves even more effective. By way of example, supplying information about the facts of a disease should be complemented with active goal setting and management of individual recovery plans. The latter strategies are the ones with the most substantial long-term impact. See figure 4.

FIGURE 4

## STRATEGIES TO SUPPORT SELF MANAGEMENT

STRATEGIES FOR AND AIM OF SUPPORTING SELF-MANAGEMENT

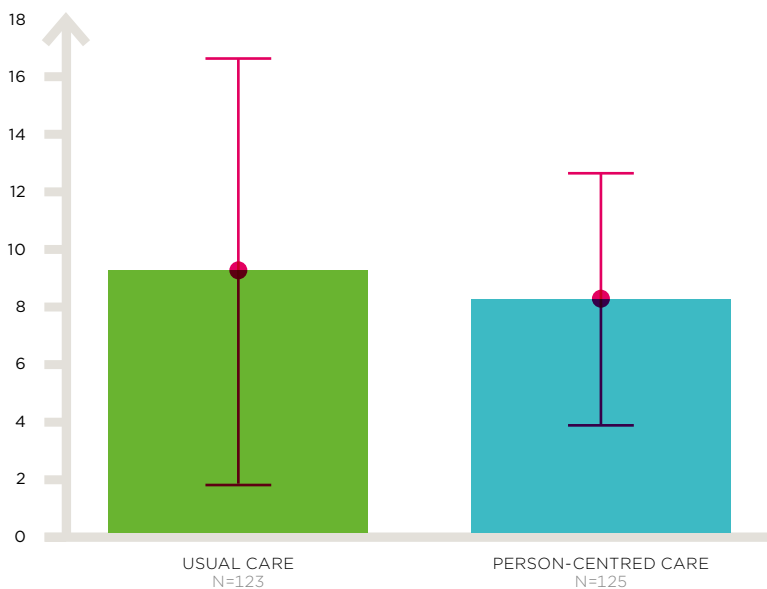


Note<sup>15</sup>: The Health Foundation. Evidence - Helping people help themselves. 2011.

FIGURE 5

## REDUCTION IN LENGTH OF STAY IN HOSPITALS

AVERAGE LENGTH OF HOSPITAL STAYS FOR PATIENTS WITH CHRONIC HEART FAILURE RECEIVING USUAL CARE AND PERSON-CENTRED CARE, DAYS



Source: Ekman I, et al. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *European Heart Journal*. 2012;33(9):1112-1119.

**THE AVERAGE LENGTH OF HOSPITAL STAY FOR PATIENTS IS SIGNIFICANTLY SHORTER FOR PATIENT GROUPS RECEIVING PERSON-CENTRED CARE SPECIFICALLY DESIGNED TO IDENTIFY EACH PATIENT'S RESOURCES FOR AND BARRIERS TO RECOVERY.**

Another example is a project in Denmark on self-managed rehabilitation of elderly within their own homes<sup>16</sup>. The municipality of Fredericia changed their overall focus in eldercare from *helping* the elderly to *enabling* them to help themselves.

The projects showed that individualised recovery plans and a focus on supporting self-help led to a higher rehabilitation rate, an increased satisfaction among 84 per cent of patients as well as higher job satisfaction among members of staff. What might also interest healthcare providers is the project's significant spending cut, which amounted to approximately 20 per cent.

### Shorter hospital stays

Evidence is beginning to show that person-centred care may reduce hospital stays with as much as one third. One

British study reveals reductions of around 32 per cent<sup>17</sup>, and a study from the US reveals that hospital admissions are significantly shortened when implementing person-centred practices.<sup>18</sup>

A third example is a study from Sweden, in which it is revealed how improved partnerships between patients and caretakers can result in shorter stays in hospital. A test-of-concept study focusing on patients with chronic heart failure showed that hospital stays were reduced by about 30 per cent with no increased risk of readmission<sup>19</sup>. See figure 5.

The improved partnerships were specifically designed to identify each patient's resources and obstacles in terms of recovery, thus guiding both the planning and performance of care. As such efforts pay off in the sense that patients stay in hospital for shorter lengths of time, because they recover faster, there is also an indirect economic effect.

Note<sup>16</sup>: Kjellberg J, Ibsen R. *Økonomisk evaluering af Længst Muligt i Eget Liv i Fredericia Kommune*. Dansk Sundhedsinstitut, 2010.

Note<sup>17</sup>: Nesta. *The Business Case for People Powered Health*. 2013.

Note<sup>18</sup>: Stone, S. A Retrospective Evaluation of the Planetree Patient-Centered Model of Care Program's Impact on Inpatient Quality Outcomes. *Health Environments Research and Design Journal* 2008;1(4): 55-69.

Note<sup>19</sup>: Ekman I, Wolf A, Olsson LE, Taft C, Dudas K, Schaufelberger M, Swedberg K. Effects of person-centred care in patients with chronic heart failure: the PCC-HF study. *European Heart Journal* 2012;33(9): 1112-1119.



# WHAT'S IN IT FOR THE POLICY MAKERS?

→ **Improvements** in healthcare ultimately benefit the policy makers with the overall responsibility for healthcare spending. They will benefit from an improved public health and higher satisfaction with the health system at large, and not only in economic terms (reduction of costs), but also because a dysfunctional health sector would put the careers of the responsible politicians at risk.

### Health finances

Nesta's 2013 report reviews the effects of 51 studies and real-life case experiences in six different NHS localities in England, revealing an intriguing business case with financial benefits of around 7 per cent of overall healthcare costs. Extrapolations from 21 of the studies with the highest evidence suggests that savings could add up to GBP 113 for each patient. At a national level for England this means annually saved healthcare expenses of GBP 4.4 billion<sup>20</sup>.

Another relevant estimate – based on the median of all studies – shows savings of 20 per cent on overall healthcare costs. See table 1.

However, achieving such substantial savings requires investments. "Ultimately, cashable savings will only be achieved if

commissioners are prepared to commission and invest in supporting clinicians and patients to make the shift; and in doing so, encourage providers to respond to the shifting pattern of demands, from high-cost, un-planned and hospital-based care models to more effective co-management of conditions in the community," Nesta concludes.

However, these investments are not necessarily very large. Nesta estimates that the typical intervention comes at an annual cost of between GBP 100 – GBP 450 per patient, depending on the type<sup>21</sup>.

Interventions like patient education programmes, mentoring schemes and patient self-management also require different amounts of time committed by doctors, volunteers and patients.

### Improved public health

It is clear that even small-scale health improvements will have some aggregated impact on public health as a whole. This is especially true, when it comes to increased treatment compliance and more self-management among the chronically ill. The WHO's "Global status report on non-communicable diseases" attributes an estimated 63 per cent of all deaths worldwide to non-communicable diseases –

TABLE 1

## CUTTING COSTS WITH PERSON-CENTRED CARE

MINIMUM, MEDIAN AND HIGHEST LEVEL OF EVIDENCE, 51 STUDIES\*

	TOTAL BENEFIT (MILLION GBP)	PERCENTAGE OF AVERAGE CCG BUDGET	BENEFIT PER PATIENT (GBP)
SCENARIO 1: MEDIAN OF ALL STUDIES	59	20%	322
SCENARIO 2: MINIMUM REPORTED IMPACT	12	4%	64
SCENARIO 3: HIGHEST LEVEL OF EVIDENCE	21	7%	113

**PERSON CENTRED CARE CAN CUT HEALTH EXPENDITURES WITH 7 PER CENT AND PROBABLY EVEN MORE.**

Note\*: The first two scenarios summarise all the available evidence for People Powered Health interventions based on their impact (minimum or median value), regardless of the relative merits of the studies. The third scenario uses only the most robust study for any particular benefit.

Source: Nesta. *The Business Case For People Powered Health*. 2013.

Note<sup>20</sup>: Nesta. *The Business Case for People Powered Health*. 2013.

Note<sup>21</sup>: Ibid.

principally cardiovascular and chronic respiratory diseases, diabetes and cancer<sup>22</sup>. Improved health outcomes and treatment compliance on such diseases will have an impact on the whole public health system.

**Reduced use of primary care**

Improving patients' ability to self-manage health plans can result in reductions in the demand for primary care. In the UK, a randomised controlled trial of self-management techniques for 203 patients with long-term conditions showed that the use of primary care could be reduced by one third<sup>23</sup>.

UK's innovation fund Nesta sums up the evidence from eight recent and ongoing programmes with varying reductions in the use of primary care, especially in the use of practice nurses and allied health professionals.

One programme is the Health and Well-being Centre in London, which offers a holistic view on healthcare, based on a commitment to address physical, mental and social wellbeing as well as delivering care that goes beyond simply treating medical conditions. On entering the centre, pa-

tients are met by so-called health and wellbeing navigators. These people listen to the patients and guide them to the right health and social care services – even if these services are not provided at the centre. If patients are not sure what kind of medical attention they need, the navigators can help them anyway. Calculations show that the programme can reduce unplanned admissions by up to 60 per cent and reduce the use of primary care by 34 per cent<sup>24</sup>.

**Benefits for all stakeholders**

Doctors and nurses do not necessarily share the same interest in cost-efficiency as healthcare providers or policy makers. And patients will often be more concerned with their own condition than the nurses' level of satisfaction with their work environment.

But as evidence clearly demonstrates that the effects of person-centred care benefit all stakeholders in the health sector – from patients and professionals to providers and policy makers – who would want to get in the way? There is unquestionably something in it for all stakeholders in healthcare. See figure 6.

FIGURE 6

**SOMETHING FOR EVERYONE**

THE CENTRAL BENEFITS IN PERSON-CENTRED CARE FOR DIFFERENT GROUPS OF STAKEHOLDERS.



PERSON-CENTRED CARE IS VALUABLE TO ALL GROUPS INVOLVED IN THE HEALTH SYSTEM. FROM INCREASED PATIENT SATISFACTION AND IMPROVED WORK ENVIRONMENTS FOR HEALTH PROFESSIONALS TO REDUCED LENGTHS OF HOSPITAL STAY AND IMPROVED HEALTH ECONOMIC EFFICIENCY.

Source: DNV GL / Sustainia

Note<sup>22</sup>: World Health Organization. *Global status report on noncommunicable diseases*. 2011.  
 Note<sup>23</sup>: The Health Foundation. *Evidence - Helping people help themselves*. 2011.  
 Note<sup>24</sup>: Nesta. *The Business Case for People Powered Health*. 2013.



NEXT  
A BUMPY  
ROAD AHEAD



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**Angela Coulter:** Senior Research Scientist at the Nuffield Department of Population Health at the University of Oxford, Director of Global Initiatives at the Informed Medical Decisions Foundation in Boston, and a Senior Visiting Fellow at the King's Fund. Angela Coulter has published more than 300 research papers and reports as well as several books. She was the founding editor of *Health Expectations*, an international peer-reviewed journal on patient and public involvement in healthcare and health policy. Her work has been recognized by the Donabedian Foundation of Barcelona in 2012 and the International Shared Decision Making Conference in 2013.



INTERVIEW **ANGELA COULTER**

“WE KNOW WHAT  
TO DO, *BUT WE ARE*  
*NOT DOING IT YET*”

→ **Person-centred care is gaining momentum. But healthcare sectors are still struggling with implementation and integration, says leading expert Angela Coulter.**

“Currently, there is a huge open window for person-centred care: healthcare sectors are under a tremendous strain, and people continuously demand better treatment. At the same time, a growing body of research uncovers the benefits to be gained from a more patient-centred healthcare sector. We are facing a tipping point for this approach: we should expect to see patient-centred care on a much bigger scale in the future.”

This is the clear-cut analysis provided by Dr Angela Coulter.

Based on her years of experience as Senior Scientist at Oxford University and director of the Picker Institute Europe and more, she is confident that the concept of person-centred care is not only here to stay, but it is rapidly becoming part of mainstream healthcare. It is becoming more and more accepted that person-

centred care will be an irrefutable element of future healthcare sectors.

“There is an increased focus on patient-centred care. Patient-centred care is being embedded in healthcare policy in many countries, as an important part of how the healthcare sector should be organized and focused. In the academic world more and more research is produced. And healthcare stakeholders generally acknowledge that this is an important part of the healthcare sector. For instance, The European Commission is becoming more willing to fund patient-centred care projects,” she elaborates.

#### **Implementation is key.**

Despite the extensive number of positive signs hinting at a future where healthcare takes on a more person-centred approach, we still have a long way to go, as Angela Coulter explains.

“We are faced with a great knowing-doing gap. The amount of evidence showing that this is good idea is tremendous and is getting still harder to ignore. But

mainstreaming these insights is still a struggle. We know what to do, but we are not yet doing it,” she says.

She points to the fact that the scaling of person-centred approaches requires cultural and organizational changes across the entire healthcare sector. Leaders, professionals and patients all have to adapt to new roles and new ways of thinking. This makes for a long and complicated process.

“The big challenge now is implementation. The process towards a healthcare sector based on person-centred care is not at all straightforward. It demands a whole new focus – and a fundamental transformation of the traditional way of thinking about patients. We need to move from a disease-focused to a patient-focused healthcare sector. This requires a new mindset, new services, and new organizational structures, including new technologies that allow information to be shared or new kinds of services funded by the health budget. This is not done in a trice. It demands a whole new mindset among patients, professionals and decision makers. This is the great transformation process that we are currently waiting for.”

Despite these obstacles, Angela Coulter is optimistic about the future. She believes that the key drivers for scaling person-centred approaches are within reach.

“It is important to realize the extent of transformation and innovation that a patient-centred healthcare sector calls for, and to ensure that it is based on broad support and strong teamwork between the partners involved. Thus, it is pivotal to focus on creating the right leadership and the right incentives in the implementation of this approach. This is key, if person-centred care is to become a common way of organizing and structuring healthcare services,” she predicts.

*“It is important to realize the extent of transformation and innovation that a patient-centred healthcare sector calls for.”*

*“I try **to listen**  
to my body.  
No doctor knows  
it like me”*



- **Maria Helmsby**, Denmark, lung disease

**Age:** 19 years

**Occupation:** Unemployed nursing assistant

**Family:** Lives with her mother and sister

**Hobbies:** Plays the drum in a music corps

→ **Maria travels by train to the other end of the country** every third month for a routine health check. Since the age of six, she has been one of just twenty Danes diagnosed with the rare lung disease PCD. Only few doctors in the country – most of them working at Rigshospitalet, the central hospital in Copenhagen – can help monitor this attention demanding chronic condition.

PCD causes a defect in the lungs' cilia, limiting respiratory functions and resulting in progressive lung destruction, chronic sinusitis and it even influences Maria's hearing. But most obviously, it prevents her from a lot of physical activities such as sports and going out with friends. In the local music corps, she plays the drum because it does not require much lung capacity.

If she strains her body – maybe just by doing everyday activities like climbing stairs – it can leave her exhausted and ill for days, which is why Maria constantly has to monitor her body, be on the lookout for signs and anticipate when she might be in need of rest.

"I'm much better at listening to my body now. When I was younger, I sort of ignored that I was ill," Maria explains. Even though she has had the condition since kindergarten, it is only within the last few years that she has truly accepted the consequences it brings to her life.

"I'm more open about it now, also explaining to my friends what it means and that I cannot always do all the stuff they want to," she says.

Four times a year, before every routine health check, Maria forwards samples of spit to the doctors at the hospital in Copenhagen. She then travels for three and a half hours by train to see the doctors.



"They are the leading experts in the country. And I have known them since I was a child," she explains.

Most often, they are well prepared for Maria's visits and for the scheduled thirty minutes talks. They listen to Maria and try to answer as many of her questions as possible. They gather information about how she lives with the rare disease, of which they still know relatively little.

"I try to listen to my body. No doctor knows it like me. So, they listen to what I tell them," Maria explains. She has realised that living with chronic lung failure presents her with a lot of responsibility. Most importantly, she has to take the medicine that helps her breathe on a daily basis.

"I know that I risk dying if I don't take my medicine," she says. It is a fact that is always at the back of her mind.

Maria would like to talk to other patients her own age, who suffer the same condition as she has noticed that sharing experiences with other patients instead of doctors is of a completely different value.

"I'm a member of an association for lung patients. But there aren't many other members my age," she says. Because the disease is so rare, it can be difficult to get in touch with other patients and to share experiences.

Recently, however, Maria met a girl, just one year younger than herself, with the same condition. They have met up once.

"It is nice to hear from another person in my situation how she copes with everything; it is comforting with this support," Maria concludes.

CHAPTER 7

# A BUMPY ROAD AHEAD

– OBSTACLES TO IMPLEMENTING  
PERSON-CENTRED CARE



A NUMBER OF OBSTACLES PREVENT A BREAKTHROUGH FOR PERSON-CENTRED CARE. THEY CANNOT BE DEALT WITH SEPARATELY, BUT CALL FOR A COORDINATED EFFORT ON ALL LEVELS WITHIN THE HEALTHCARE SYSTEM.

*“We will never get person-centred care without **rethinking** the entire system. The current ‘cure-focused’ system was designed **one hundred years ago** when the pathological picture looked completely different. Person-centred care is not possible before we change the entire structure to start with **the needs of the patient.**”*

- Albert van der Zeijden, Vice Chairman of the Dutch National Council of the European Disability Forum

→ **When hurricane Katrina hit New Orleans in 2005, the town was flooded, at least 1,833 people were killed and damages to buildings and the surrounding environment amounted to more than USD 81 billion.**

The tragedy presented the city’s healthcare system with the fundamental choice of either rebuilding or starting afresh: “After the hurricane nearly everything was de-

stroyed. We decided not to rebuild the system we had, but to start from scratch. It turned out to be a real opportunity to make some significant changes to our primary care,” says health commissioner Dr. Karen DeSalvo, New Orleans.

Even before Katrina, a reform was greatly needed “We had a terrible health outcome and at high costs,” says DeSalvo.

*“The process towards patient-centred care is not at all straightforward. The shift **from being disease-focused to being patient-focused** requires a new recognition, new services and a new organization. This is a **very big challenge** for the healthcare sector.”*

- Angela Coulter, Senior Research Scientist, Oxford University

Many citizens simply did not have access to healthcare, and doctors were overburdened within almost every aspect of care.

“Frankly speaking, before Katrina the doctor was responsible for educating patients, for social services and support. But we realized that doctors should not try to be social workers, and instead we invited social workers to be part of our team,” she continues.

The hurricane spurred a reform of primary care that enabled professionals to meet the needs of citizens. Creating teams of doctors and social workers was one measure, identifying and utilizing resources within the community and among users was another.

“Katrina was a rallying cry for all of us to come together and find a way to solve our problems as a community,” says DeSalvo. A concerted effort from the City’s Health Department, schools, businesses, and non-profit organizations put public health and prevention on the local agenda.

Some seven years after the hurricane, in 2012, New Orleans won an award honouring the city’s “outstanding

community partnerships, which are helping people live healthier lives”<sup>1</sup>

It should not take a devastating tragedy like Hurricane Katrina to initiate fundamental changes within a health-care system. However, there are those who claim that New Orleans illustrates how rethinking the healthcare system from scratch is in fact necessary in order to make it truly person-centred.

One reason for rethinking systems from scratch is the strength of tradition:

“We will never get person-centred care without rethinking the entire system. The current ‘cure-focused’ system was designed one hundred years ago when the pathological picture looked completely different. Person-centred care is not possible before we change the entire structure to start with the needs of the patient,” says Albert van der Zeijden, Vice Chairman of the Dutch National Council of the European Disability Forum and former Chairman of International Alliance of Patients Organizations (IAPO).

Another reason lies in the strong influence professionals

Note<sup>1</sup>: Robert Wood Johnson Foundation. *New Orleans, Louisiana: 2013 Roadmaps to Health Prize*. 21 February 2013.





*The current healthcare is built on a cure based paradigm – with patients checking in for treatment and signing out when cured*

have on the system. “Our system is designed to meet the needs of the providers and professionals – not the needs of the patient,” says Jocelyn Cornwell. She is Senior Fellow at The King’s Fund and Director of the Point of Care Foundation – a foundation that strives to keep patients’ experience of care high on the agenda of policy makers and relevant boards. However, on all levels, change will be opposed by strong forces striving to preserve the status quo.

As Angela Coulter, Senior Research Scientist at University of Oxford puts it, the shift from being disease-focused to being patient-focused is not at all straightforward, but requires a new mindset, new services, and new organizational structures. *See the interview on page 114.*

#### **Seven obstacles to person-centred care**

Experts and patients identify a number of obstacles to person-centred care, which can be categorized under seven headlines.

##### **1. Implementation,**

While many acknowledge the need for person-centred care, there is still an extensive vagueness when it comes

to ‘how’: How should we proceed? Where should we begin? Who should make this change come about? Person-centred care is stalled by the lack of specific recommendations, guides and models for implementation.

##### **2. Organization.**

The organization of healthcare is split into different “silos” – different sectors, disciplines and professions, each with their own logic, routines and incentives. A holistic, person-centred approach to healthcare requires vast improvements in cohesion, coordination and communication between these various systems.

##### **3. Mindsets and culture.**

The healthcare sector is based on strong traditions that go back over a hundred years. The transition towards person-centred care constitutes a huge challenge for the healthcare sector and healthcare professionals, as it demands a fundamental change of culture and mindset.

##### **4. Patients’ expectations.**

Person-centred care requires patients to take on a new role as active co-creators of care. For many patients, this change is difficult.

### 5. Education and training.

Professionals are trained within a bio-physical paradigm of medicine and do not view patients from a psycho-social perspective.

### 6. Incentives.

Current healthcare systems do not build upon incentives that encourage person-centred care.

### 7. Access and resources.

Access to high quality care is not a common good across the globe and resources are under tremendous strain. This hinders the necessary investments in person-centred care.

None of these obstacles to change are limited to one sector or one stakeholder alone; they are all interconnected in a complex pattern of obstacles that calls for coordinated action on all levels. See figure 1.

### Implementation

In spite of the fact that cumulative experiences reveal how person-centred care works in practice, several experts point to the fact that structured knowledge is still limited. They call for more palpable examples and replicable models to guide various healthcare stakeholders who seek to make care more person-centred.

“We need more evidence on how to do it. We don’t have enough replicable models and do not fully understand enough about how to implement this kind of change in different contexts in the healthcare sector,” says Jocelyn Cornwell.

Across healthcare sectors, experts and practitioners tend to agree with this analysis: tools and models for implementation are in short supply, which prevents the scaling, spreading and speeding of best practice routines.

“We are standing at a tipping point. We have the research and experience that proves the potential. The big remaining issue is implementation: How do we do this?” says Angela Coulter.

Scaling is a major hurdle, because most up-to-date examples are relatively limited and isolated. There is a need for larger projects and institutions to lead the way.

“We know little about how to implement person-centred care in a really structured way so you can really scale it

up. That is the big challenge. We lack knowledge and examples on how to scale it,” says Axel Wolf, researcher at the Centre for Person-centred Care at the University of Gothenburg.

### Organization

Cohesion and coordination across sectors are cornerstones of a person-centred approach to healthcare. In this field, today’s healthcare sectors have a lot to learn.

“Lack of cohesion is a primary barrier to person-centred care in today’s healthcare system. There is an enormous lack of coordination, making it difficult to deliver a connected and organized course of events with the patients in the centre,” says Jacqueline Bowman-Busato, Executive Director at the European Platform for Patients’ Organisations, Science and Industry.

The fragmentation of current healthcare systems reveals itself in a number of ways.

Firstly, funding usually relies on the division of healthcare into different sectors: the hospitals are responsible for and get paid for one kind of treatment while GPs have other areas of responsibility and so on. Different areas within the healthcare sector are staffed by diverse groups of professionals with differing perspectives on healthcare and their own role within the system.

Secondly, centuries of scientific advances have paved the way for extensive specialization within the field of medicine, so doctors are often specialized in one type of disease or focused on only one part of the body.

According to Senior Researcher and Section Manager at the Section for Research on Home-based and Personal Health Systems at the Norwegian Centre for Integrated Care and Telemedicine, Per Hasvold, these trends prevent a thorough coordination of care and complicate collaboration between the different sectors, disciplines and professions:

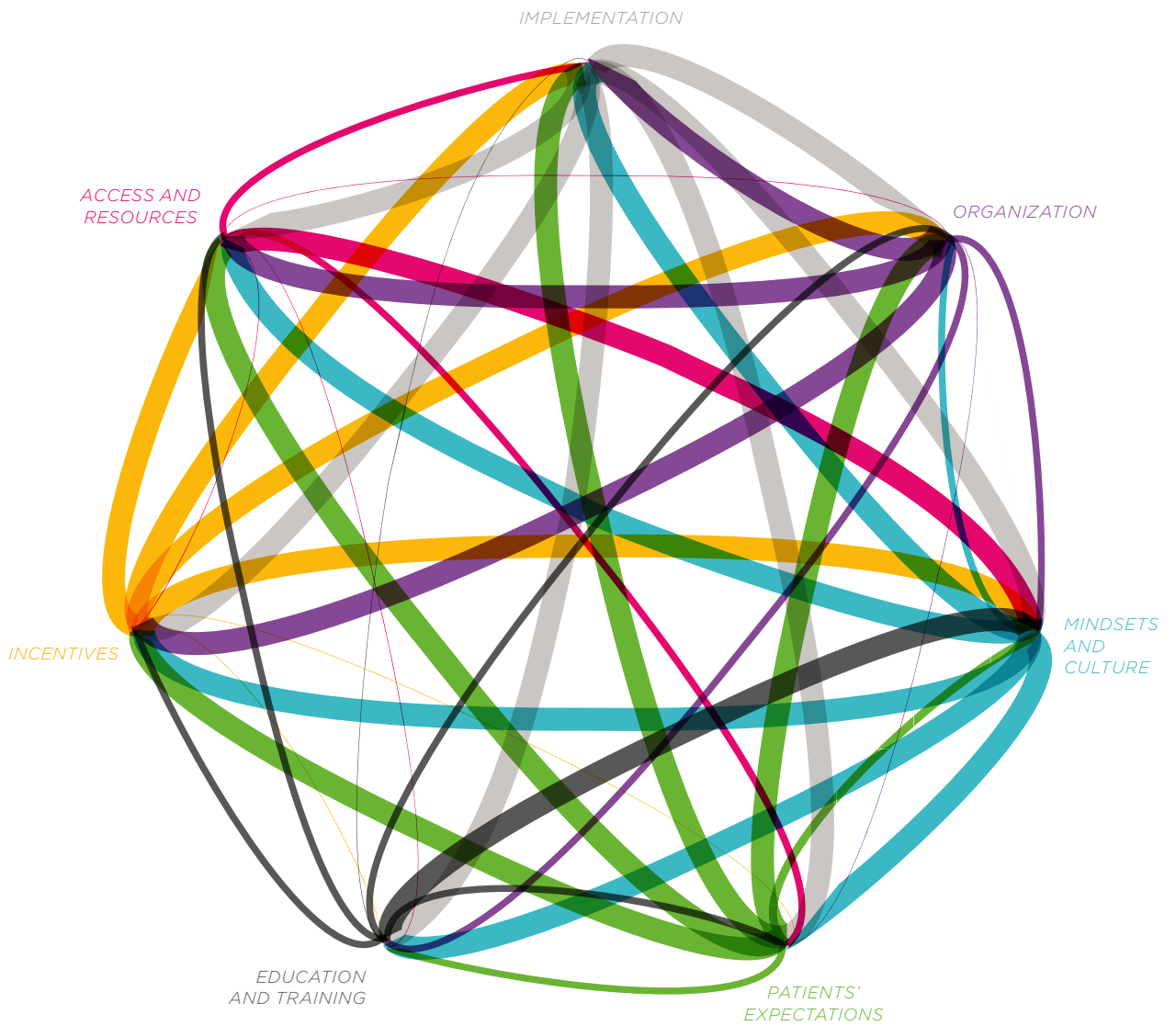
“We have a system very much based on ‘silos’ of care. The healthcare sector is split up into sectors and different medical specialties, which do not interact very often. This makes it difficult to create coherent and interconnected patient-centred care”.

As Angela Coulter puts it: “We have a healthcare system that is very much challenged by the lack of cohesion and coordination, making patient-centred care almost impossible within the current system.”

FIGURE 1

## SEVEN INTERCONNECTED OBSTACLES STANDING IN THE WAY

THE THICKNESS OF EACH LINE INDICATES HOW HEAVILY ONE OBSTACLE AFFECTS ANOTHER



SEVEN INTERCONNECTED OBSTACLES ARE CURRENTLY PREVENTING PERSON-CENTRED CARE FROM BECOMING NEW STANDARD PRACTICE FOR HEALTHCARE INSTITUTIONS. THEY AFFECT EACH OTHER IN A COMPLEX AND INTERRELATED PATTERN.

Source: DNV GL / Sustainia

*“We are going in the **right direction**, but we are moving **very slowly**. This is due to the fact that it is a very difficult process that faces great barriers and demands **great change** on every level and in every part of the healthcare system.”*

- Albert van der Zeijden, Vice Chairman of the Dutch National Council of the European Disability Forum

This makes it difficult to establish the collaboration and cohesion that is so vital for person-centred care.

“Establishing the capacity that will allow the implementation of this practice is not easy, as merging different cultures and approaches to work is always difficult,” Anayda Portala, Technical Officer at the Department of Maternal, Newborn, Child and Adolescent Health at WHO, explains.

#### **Mindsets and culture**

Person-centred care demands a whole new way of thinking when it comes to tasks, obligations, treatment and patients. This will challenge well-established patterns and attitudes, strong traditions, power structures and hierarchy. And old habits die hard.

“Traditions within the healthcare sector make it difficult to adapt to the thoughts and processes of patient-centred care,” as Albert van der Zeijden points out.

One example is the doctor-patient relationship. Traditionally, it has been framed within the doctor’s authority as the expert: the doctor talks, the patient listens. This well-established modus operandi has a strong foothold in today’s healthcare sector – affecting everything from organization (e.g. time reserved for an appointment, ward rounds and use of medical records) to how the individual

doctor meets and engages with patients (in terms of communication, focus area and sharing of medical journals).

“The traditional power structure blocks the way towards a more partnership-oriented approach,” says Yang Jingqing, who works for the Institute for International Studies, University of Technology in Sydney and has written a paper on person-centred care in China.

Angela Coulter stresses the fact that the healthcare sector is based on rigid hierarchies with a strong focus on avoiding mistakes. This leaves little room for innovation and new ideas. “The current healthcare system and its management do not promote innovation,” she explains.

#### **Patients’ expectations**

Even if patients generally are becoming better informed and more resourceful, they may still regard themselves as passive recipients of care.

“People are used to leaving the treatment and the decisions surrounding it to the doctor. Patients tend to take on a very passive role in regards to their own health and their own treatment,” says Albert van der Zeijden.

The consequence of such an attitude is that the idea of being an active partner, engaging in a co-creative pro-

cess, challenging or questioning professionals as well as taking responsibility for their own treatment is still a somewhat abstract phenomenon for the majority of patients.

“A lot of patients still do not really think they have to participate in their own healthcare and make sure that the doctors get the right information. I think that is a cultural issue,” says Yunan Chen, Assistant Professor at the Department of Informatics and the Institute of Clinical and Translational Sciences at the University of California.

On the other hand, many patients are not fully equipped for more active participation. “Some patients still need to learn more about what they gain from taking on a more active role”, according to Peter Hasvold.

Especially experts based in developing countries stress this point, and many underline poor literacy as an absolute key issue to be improved in order to establish and ensure a high level of patient involvement.

“Patient-centred care demands a change from patients – they must be educated to take a more active role in their treatment. The majority of patients are not trained or skilled to ask questions with regards to their own health. They need to learn to ask questions and not to be afraid of the doctor or nurse,” says Senga Pemba, Director of the Tanzania Training Centre for International Health.

### **Education and training**

Difficulties with implementing person-centred care are also maintained by a lack of knowledge and education among professionals.

“There is a huge lack of medical training and education – especially of doctors – on how to communicate with patients,” says Jacqueline Bowman-Busato.

Professionals are trained within a bio-physical paradigm of medicine and care. They are not trained to view patients from a psychological or social perspective, at least not to the same extent.

“Doctors are trained to look at objective rather than subjective information,” Albert van der Zeijden elaborates.

This is also the opinion of Saul Weiner, professor at the Institute for Health Research and Policy at the UIC Col-

lege of Medicine in the US. “Professionals are currently trained to focus on biomedical reasons for a patient’s condition, rather than their life circumstances – such as a lack of social support – that could be contributing to their problems.”

Weiner especially stresses the lack of education and training with regard to teamwork, which is a precondition for making person-centred care a reality.

“Professionals are not taught how to work in teams. There is limited, if any, inter-professional education.”

### **Incentives**

Today, incentives in the healthcare sector rarely promote person-centred care. Not least models for funding – how different healthcare providers and services are paid – reveal a lack of backing for person-centred care.

“For instance, doctors and hospitals are not rewarded for taking the time to do a long consultation or for making a preventive phone call to a patient,” says Albert van der Zeijden.

This has a very negative effect on the motivation and willingness to pursue person-centred care.

“Hospitals are paid to do a certain number of interventions rather than paid due to their outcomes. An example is that hospitals are paid for admitting a patient with asthma and treating him on a ward after an acute attack. Similarly a pharmacist is paid for dispensing prescriptions. These things curtail a person-centred approach because the hospital and the pharmacist are acting against their own interests if, for instance, the admission is prevented and prescriptions not dispensed,” says Neil Churchill, Director of Patient Experience, National Health Service, England.

### **Access and resources**

Person-centred care does not come free of charge, and the initial steps require investments that do not pay off instantly. Professionals will have to increase time spent with patients, empowering the patient to participate and thereby increasing the patient’s involvement in the process of care. And the majority of benefits in terms of health, economy, quality and safety do not emerge right away.

Another problem may be that the institutions investing in

person-centred care may not be the institutions reaping the benefits. Altogether this makes the decision to implement person-centred care a difficult one, as healthcare sectors across the world experience a massive strain on resources.

“We are faced with a seriously cost-constrained healthcare system. This makes it difficult to implement a whole new approach – and to create the window that allows patient-centred care,” Angela Coulter says.

Especially experts based in or focused on developing countries identify the problems with resources and access to healthcare as one of the major obstacles to adopting a more person-centred approach. These fragile healthcare systems are widely defined by lack of funding, lack of organizational structures, and also a lack of personnel with the required professional skills – making person-centred care difficult.

Among others, Anayda Portala points out that the lack of access to medical treatment and the lack of resources tends to push person-centred care way down the agenda: “Today person-centred care is often not a first priority. Limited budgets force us to prioritize what are deemed more critical efforts such as safe treatment, finding qualified professionals, access to clean water and medicines

which tend to overshadow a focus on person-centred care.”

#### **Moving forward**

And so, there are many obstacles to overcome in order to implement person-centred care as standard practice within healthcare sectors around the world.

Person-centred care does not become a reality by changing a working procedure, by passing a new healthcare policy or even by changing models of financing. There is a need for fundamental changes on all levels.

“We are going in the right direction, but we are moving very slowly. This is due to the fact that it is a very difficult process that faces great barriers and demands great change on every level and in every part of the healthcare system,” Albert van der Zeijden states.

The future of person-centred care lies in the hands of the change agents and their ability to understand interrelations between the different obstacles as well as their willingness to use these understandings as a basis for incorporating new solutions, ideas and initiatives within the healthcare sector.

NEXT  
PARTNERS  
IN CARE



CHAPTER  
8/10

ALL CHAPTERS



*“They discouraged  
my family from  
paying school fees,  
as I was **not going  
to survive**”*



- **Ruth Nankanja**, Uganda, sickle-cell disease

**Age:** 39 years old

**Occupation:** Founder and director of the Sickle cell Association of Uganda

**Family:** Married for 10 years, mother of two children

**Hobbies:** Reading novels



→ **“I grew up believing my parents didn’t love me,”** says Ruth Nankanja. Born in a small town in the northern suburb of Kampala, Uganda, she noticed early on that she was being treated differently than her three younger siblings. She was not allowed to play as wildly as the others, and her parents always seemed to be worried about her.

From birth, Ruth had sickle-cell disease, a hereditary blood disorder where the red blood cells assume an abnormal sickle shape because of mutations in the haemoglobin gene. This causes a wide array of complications such as a highly increased risk of infections, gallstones, strokes, and death of tissue and bones due to an interruption of the blood supply. And then there is the pain.

“If I’m dehydrated, it can trigger pain anywhere in the body,” she explains. Often it comes as a pain attack. In Uganda, children with sickle-cell disease rarely survive very long. This caused stigma in the small town.

“Society pointed fingers at my family, stereotyped us and discriminated me. They gave ages at which I was supposed to die,” Ruth explains. “They discouraged my family from paying school fees as I was not going to survive.”

It was a harsh way to grow up. “I was very sad. Every day I waited for the day I would die,” she elaborates.

Ruth tried to hide her condition during most of her childhood and youth. Society’s reaction was unbearable, and she met little understanding from the people she shared her experiences with.

“Eventually, I felt like a bomb about to explode, and I got tired of sitting on it. So I had to break the silence and come out publicly,” she explains. That was when she decided to form the Sickle Cell Association of Uganda. One of the organization’s aims is to educate people in Uganda about the disease in order to break the taboo.



When she got married years later, little had improved in the minds of her fellow citizens.

“I think something like 1,000 people attended my wedding just to witness a man foolish enough to marry a sick woman,” she says. Most people thought the disease was contagious.

Ruth tried to explain as much as she knew about the disease to her new husband. And that proved wise a few years later, when Ruth suddenly fell ill one day.

An infection of both parvovirus and malaria caused a cessation in the production of red blood cells in her body. Normally, it would go unnoticed because the cells have quite a long lifespan, but for people with sickle-cell disease, it can cause severe anaemia because their blood cells die fast.

And so Ruth suffered what is called an aplastic crisis where the body is emptied of red blood cells, but without them, her organs will shut down one by one.

“I felt sick and was just lying in my bed all the time. I was not manufacturing red blood cells at all,” Ruth explains.

She tried asking her husband to take her to the hospital as fast as possible. Then she realised she could not speak. She was locked in her body without the ability to communicate. “My brain was working, but I couldn’t speak.”

Luckily, her husband quickly realised what was happening and he ran to three different hospitals in town to find the right type of blood for Ruth. The first two blood banks did not have any. The third had just one unit of B+ blood – but it was enough to keep Ruth alive until the next delivery of blood supplies.

After three days in hospital, Ruth was sent back home. However, she still could not move her right leg and it took almost 16 months of physiotherapy, massage and steam baths before she was able walk properly again.

CHAPTER 8

# PARTNERS IN CARE

- CO-CREATING A HEALTHCARE  
SECTOR FOR THE FUTURE

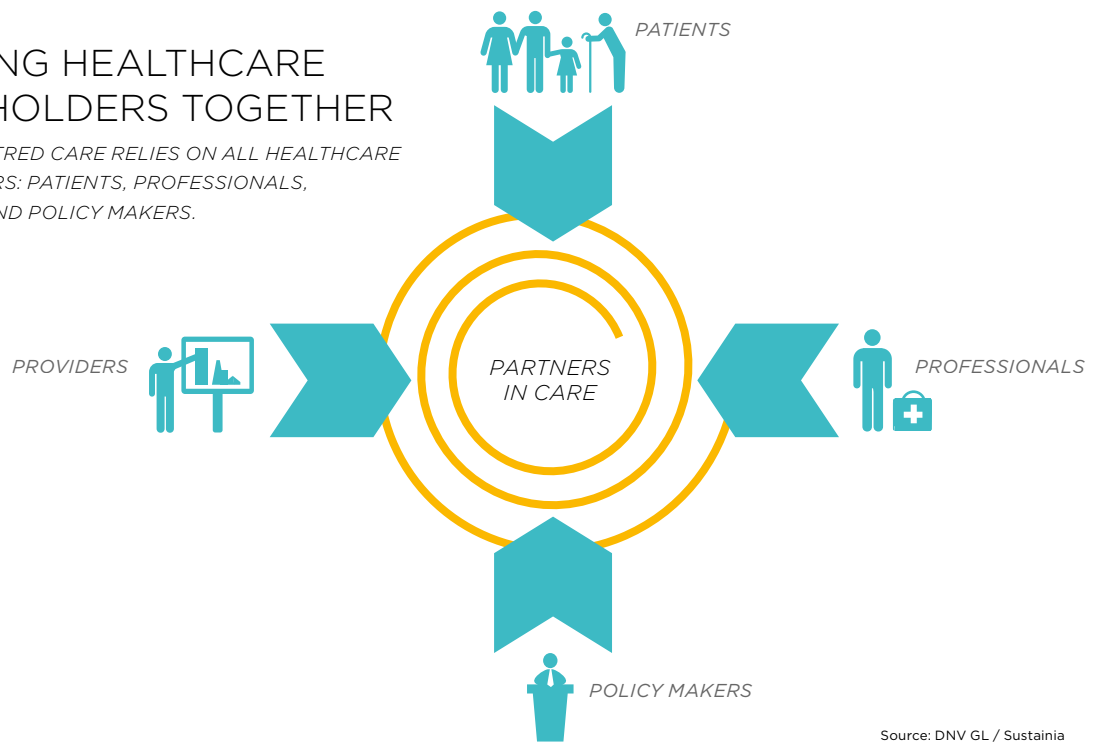


THE RECIPE FOR PUSHING PERSON-CENTRED CARE FORWARD IS TO CHALLENGE BOTH THE CULTURE AND STRUCTURE OF TODAY'S HEALTHCARE SECTOR. TO SUCCEED, ALL STAKEHOLDERS WITHIN THE HEALTHCARE SECTOR MUST TAKE ACTION.

FIGURE 1

## BRINGING HEALTHCARE STAKEHOLDERS TOGETHER

PERSON-CENTRED CARE RELIES ON ALL HEALTHCARE STAKEHOLDERS: PATIENTS, PROFESSIONALS, PROVIDERS AND POLICY MAKERS.



Source: DNV GL / Sustainia

→ **Making person-centred care a reality is no easy task.** It demands changes in the way we think, work, cooperate and communicate. It requires a new culture and new behaviour within the entire healthcare sector.

Some proponents of best practice champion the positive story of person-centred care and patient organizations strongly promote it. It is being integrated in local, regional and national political strategies, and it is becoming part of the curricula for doctors, nurses and other health professionals.

These initiatives are all noteworthy signs of positive change, but none of them can stand alone; transforming person-centred care from an ambitious idea to an essential

part of standard practice cannot rely on one single point of change or the efforts of one stakeholder. Moving forward relies on creating a positive spiral, in which all stakeholders change their attitudes as well as their actions.

Some parts of this process must be executed top-down to ensure that the change is organized and sustained: outlining strategies and visions, guiding the transformation, upscaling best practice, and creating incentives for other stakeholders to implement person-centred approaches.

However, policy leaders and managers cannot bring this change about on their own. Person-centred care relies equally on the involvement, support, and pressure from professionals and patients alike. See figure 1.



“There is no silver bullet – no easy way to make this kind of change happen. It demands changes and rethinking on micro, meso and macro level within the healthcare sector,” says Adrian Sieff, Assistant Director at the Health Foundation.

As Jacqueline Bowman-Busato, Executive Director at the European Platform for Patients’ Organisations, Science and Industry, puts it:

“All changes and new concepts that we initiate in order to make the healthcare sector more person-centred must in-

clude all stakeholders. We must make sure that everybody is on board, or we are not likely to succeed.”

The experts interviewed for this guide emphasize six areas of intervention that are vital to creating a healthcare sector centred around the needs, preferences and resources of the individual patient.

They call for a change of conduct from all stakeholders, even if the level of change, and the effort required to bring it about, depends upon whose perspective you apply.

# 1

## NEW PARTNERSHIPS – NEW SKILLS

Professionals and patients must define and practice care in a partnership. Both parties need new training and knowledge to engage in this co-creation of care.

# 2

## GOALS AND LEADERSHIP

The implementation of person-centred care is a complex process, which requires well-communicated goals, distinct leadership, and full commitment from policy makers.

# 3

## REDESIGNING INCENTIVES

Incentives must be realigned to support and reward person-centred care, thereby ensuring compatibility between goals and instruments.

# 4

## TAKE STOCK OF USER SATISFACTION

Just like any other service provider, providers of healthcare must focus on the outcome and implement feedback from ‘customers’ in order to improve the quality of care provided.

# 5

## SHARING INFORMATION

Exchanging health data between professionals and sharing the information with patients is a gateway to creating continuity in care. At the same time, patients are becoming increasingly knowledgeable and resourceful, making them a valuable resource of care.

# 6

## NEW PATHWAYS

Person-centred care calls for new ways of coordinating and organizing treatment, which makes it necessary to design new pathways and develop new models based on and supporting this approach to care.

# 1

## NEW PARTNERSHIPS – NEW SKILLS

→ **The scenario may appear simple:** a physician and a patient sitting side by side, going through relevant health information on the same screen. But moving to the same side of the table is in fact symbolic of an important partnership, where care is no longer “provided” but co-created.

Sitting side by side is one way to signal a new relation between professionals and patients. Alan Manning from Planetree points to another important aspect by stating that person-centred care begins when the professional sets a new tone when meeting patients.

“Professionals should sit down with patients and ask them questions, maybe the same question several times, to make sure, that the patient actually tells the whole story. I don’t think it takes any longer, but efficiency in healthcare will improve radically if we just slow down a little in the beginning of the process and actually start talking with patients,” he elaborates.

This new partnership is not only about empowering patients but also about determining to what extent the patient has the ability, the competences and the will to participate.

### INTERVIEW SKILLS

Before becoming a professor in medicine, Robert C. Smith was a general practitioner in Michigan, USA. He was overwhelmed by the number of patients who attended his clinic for not entirely medical reasons.

“I discovered that by attending to my patients and their needs, I simply learned more about them and also got a better understanding of what was going on. It could be a patient complaining about severe headaches and in the discussions we found out that they began shortly after her mother moved in. Then we had to address *that* problem,” says Robert C. Smith.

As a professor, Robert C. Smith has been a front runner for person-centred care by writing one of the most used textbooks at medical schools in the US – “*Smith’s Patient-Centered Interviewing, An*

*Evidence-Based Method*” - which teaches novice practitioners the art of interviewing and thus enabling them to understand the patient’s concern and apply their knowledge of pathophysiology more effectively. There is still some way to go before such “soft skills” are valued as highly as the “harder” sciences but the textbook is contributing to this development.

Underneath the actual skills of conducting better patient interviews lies a new understanding of how to react to patients.

“When the doctor and the patient interact in an empathetic way, they develop a shared meaning of what the problems is,” Smith says and emphasizes that care is much more than what the doctor says to patients.

*“If doctors just tell patients what to do, many patients do not comply. Professionals and patients have to agree on the outcome of care and to **share decisions**. Patients will feel much more responsible and there will be **higher rates of compliance**.”*

- Neil Churchill, Director of Patient Experience of the  
NHS Commissioning Board, England



*A strong patient-doctor partnership is vital for person-centred care.*

“The professional will have to assess how involved the patient wants to be, and not just assume that the patients want to or can be involved,” says Carol Cronin, CEO of The Informed Patients Institute.

Despite years of education and training, many professionals have never been trained in this kind of patient-relation.

“We have been teaching medicine for more than a hundred years, and in many areas, it has been a tremendous success. But we should add new skills, enabling professionals to attend to patients’ needs and interests, to understand the psychological and emotional situation of a patient,” says Robert C. Smith, Professor of Medicine at Michigan State University and author of a textbook on systematic patient interviews, which is widely used in American medical schools. See textbox on page 132.

Person-centred care fundamentally changes the relationship and interaction between professional and patient and this partnership calls for a new understanding and new skills on both sides of the table.



## TAKE RESPONSIBILITY

As chronic diseases become more prevalent, most patients cannot expect professionals to deliver a cure.

“Patients should realize that it is reasonable and important for them to be thinking, for them to be active and involved and to speak up, because doctors can’t do it alone,” says e-patient Dave deBronkart.

Therefore, patients must actively abandon their role as passive recipients of care and take on the role of participants. Patients must proactively deliver insights, involve themselves in the process and dare to ask questions. They must engage in self-care management and adhere to treatments and care decisions – also when they are not facing a doctor.

“We should enable patients’ health literacy so that they have a better understanding of their health and healthcare system,” says Dr. Lee Chien Earn, CEO of The Changi General Hospital in Singapore.

Education and self-education, through patient organiza-

tions as one example, is vital. “We have to educate people to focus and be prepared for a more active role,” says Albert van der Zeijden, a patient representative.

As the outcome of healthcare is often much less certain than many patients expect or at least hope for, they need to understand that care may imply a process of trial and error.

Dr. Lee Chien Earn elaborates: “In a partnership, patients should be able to have frank conversations with their doctor and understand that sometimes you will have to try something out and see if it works,” he says.



## LEARN TO LISTEN

Professionals all too often neglect the importance of the initial dialogue with patients:

“Start listening to patients and stop thinking that you know in advance what patients prefer,” says Lucien Engelen, Director at The Radboud REshape & Innovation Center at Radboud University Medical Centre in The Netherlands.

In order for this to happen, professionals must learn not only how to convey their message, but they have to develop what Lucien Engelen calls the single most important competence: the ability to listen.

“It should not be the doctor, but the patient who makes an informed choice, even if it is a tough decision. A patient with cancer may not have really good alternatives; one option could prolong her life but with heavy side effects, while another involves lighter medication, less side effects – and a shorter life,” he explains.

It is even more important when people suffer from one or more chronic diseases, because they only spend time with a professional occasionally, while their condition may need to be monitored constantly and so patients must fully understand their condition and how to live with it.

“If doctors just tell patients what to do, many patients do not comply. Professionals and patients have to agree on the outcome of care and to share decisions. Patients will feel much more responsible and there will be higher rates of compliance,” says Neil Churchill, Director of Patients



Experience at the UK National Health Service.

The flow of information should not be confined to the actual medical treatment but should also include social and psychological aspects of each patient's life as well as make room for a wider dialogue with family members and peers. This is not something professionals will simply take on. It requires a change of both actions and attitudes.

"The role of healthcare professionals has to be redefined – they have to be taught this new way of thinking and they have to learn to do things differently," as Adrian Sieff states.



PROVIDERS

## ENCOURAGE ALL EMPLOYEES TO PUT PATIENTS AT THE CENTRE

Person-centred care requires that all persons and institutions involved in healthcare put the patient at the centre at all times.

"What is needed right now is involvement of patients at all levels – in evaluating boards of hospitals and doctors, ethical committees and so on," says Antonio Gaudio, General Secretary of Cittadinanzattiva, an Italian non-profit consumer organization.

Healthcare providers have an important job in ensuring that members of staff adopt a new approach to care, in which patients are placed at the centre of every single action they perform. The idea of partnerships should be regarded as a precondition for good care throughout the healthcare sector. See text box.

Of course, patient satisfaction is not the product of a single encounter but an experience of the care process as a whole.

"In all patient encounters, even when the secretary answers the phone, the patient should not be met in a hurried way. Patient-centred care is simply a broader concept of care," says Robert C. Smith, Michigan State University.

To optimize this experience, members of staff have to cooperate across wards, departments and institutions. It is vital that managers ensure that the concept of partnership extends beyond the doctor-patient meeting and that it becomes the cultural and behavioural cornerstone of all interaction between colleagues as well.

### PERSON-CENTRED CARE IN THE PHYSICAL ENVIRONMENT

Developing a person-centred culture should also include the physical environment. It should signal and support the concept of partnership and co-creation. Dr. Lee Chien Earn from Changi General Hospital in Singapore urges providers to keep the patients' needs in mind whenever they build new hospital units or renew existing ones.

"For instance: when we build environments for elderly people, we should understand that they perceive colours and lighting differently than younger people," he says.

This philosophy formed the basis of the design and construction of a new ward at the hospital in Singapore.

Asking all stakeholders to contribute and even participate has also been the underlying prin-

ciple for the design and construction of a new University Hospital in Odense, Denmark:

"Twenty-five years ago, we would have built a hospital that favoured the chief physician. Our new hospital will not only be designed according to the needs of physicians but also to other staff members as well as patients and their families," says Carl Holst, Chairman of The Region of Southern Denmark, in charge of the new hospital.

Design centres like IDEA in San Francisco and G10 in Denmark offer developers facilities where they test the building environment through a process where patients and staff members are invited to contribute – from reviewing the first drafts on paper to creating rooms and inventory made of papier mâché or plywood.

*“The policy makers have to make the **public aware** of the care standards they should expect and the role that they can play. They must initiate political initiatives that can help **raise public expectations** of the care they receive”*

- Mike Spencer, Assistant Director for Patient Experience at Cardiff and Vale University Health Board, Wales



#### POLICY MAKERS

## SET CLEAR GOALS AND PROVIDE THE MEANS TO MEET THEM

When it comes to developing the skills of healthcare professionals, policy makers have the important task of setting the goals and adjusting the focus. In addition, they should ensure that education pays more attention to person-centred care.

“I am passionate about education. We have to start at medical schools and invite patients into the classroom to share their stories. It’s not good enough to lecture about the patient perspective during the first year at medical school, because students will have forgotten most of it by the time they graduate. It should be an integrated part of every single year of their education,” says Julie Ginn Moretz, Associate Vice Chancellor for Patient- and Family-Centred Care at the University of Arkansas for Medical Sciences in Little Rock.

Like all other medical skills, learning about person-centred care should not stop on graduation day, but it should remain an integral part of all further training for professionals.

“The training has to be continued into residency,” says Robert C. Smith, who urges policy makers to integrate new skills at medical schools and university colleges for nurses.

Policy makers also play a key role when it comes to widening the knowledge base among patients. They should contribute to public discussions of person-centred care and help create awareness about the expectations of patient participation.

“Communication is key – we need to get information about this new approach out to the public, so that people know what to expect and what rights they have. They need to be equipped for this kind of care,” says Senga Pemba, Director of the Tanzania Training Centre for International Health.

This is supported by Mike Spencer, Assistant Director for Patient Experience at Cardiff and Vale University Health Board in Wales.

“Policy makers have to make the public aware of the care standards they should expect and the role that they can play. They must initiate political initiatives that can help raise public expectations of the care they receive,” he suggests.



## GOALS AND LEADERSHIP

→ **Even though the concept** of person-centred care is gaining a foothold across the globe, the majority of healthcare sectors still have some way to go.

Experts stress that clear-cut support and commitment from management and politicians is crucial to pushing the agenda forward.

Leaders of the healthcare sector must provide the goals, visions and roadmaps of change.

“Leadership is important. We need clear visions and targets in order to push person-centred care forward,” says Anayda Portala, Technical Officer at the Department of Maternal, Newborn, Child and Adolescent Health at WHO. See chapter 5, page 68.

This is supported by Senior Research Scientist at Oxford University Angela Coulter, an expert that governments turn to for advice on healthcare reforms.

“Support from above is key. This allows professionals to take the necessary risks in order to make change happen. The current healthcare sector is weak on innovation. We have to create an environment where people dare to try new things. You need support throughout the organization in order to make this transformation happen: better teamwork based on better horizontal and vertical cooperation”.



### MAKE YOUR LEADERSHIP VISIBLE

When implementing person-centred care, healthcare providers lead the way for their staff with clear goals and strategies.

“The concept has to be worked all the way down through the organization, or person-centred care will remain something we talk about rather than practice,” says Jeni Bremner from the European Health Management Association.

She stresses that it is important for providers and managers to engage in a dialogue: “Managers should initiate discussions about person-centred care in a way, so everybody knows what this involves in their own particular ward or department.”

In turn, this means that the concept of person-centred care should be an important area of focus among providers and managers. “We need managers that are trained to think about the patient experience as a key to their success,” Jocelyn Cornwell, Director and Founder of the Point of Care Foundation in the UK, says.

Alan Manning supports her view: “You have to make sure leaders buy in. If they don’t, patient-centred care cannot be fully successful. Leaders should be willing to take every measure needed. First and foremost, they need to understand the commitment needed.”

Hospital CEO Dr. Lee Chien Earn stresses the need for providers to set down visions that challenge the fundamental understanding of healthcare. Today’s hospital is expected to attend to much more complex needs than previously.

“The need of patients is changing; therefore we need to evolve too. As care becomes more complex and more of it takes place outside the hospital, we have to provide care in a more coordinated and integrated way,” he says.

Healthcare providers and managers must also ensure the involvement and support of professionals and patients.

“It is a both a top-down and a bottom-up process. Most often, the person who knows how to make the right changes is the one closest to the bedside. I’m not saying that front-line staff always knows the right solution, but they know the right issues to be dealt with. Of course, we need the leaders on board, but they should give the staff the power to move ahead,” says Alan Manning.

In fact, most experts draw a direct line between professionals’ commitment and enhanced person-centred care.

“Patient-centred care will never work if you don’t touch the heart of the staff. We think it’s an extension of how management treats its staff,” he says.

Another expert in implementation, Julie Moretz, points out that changes may be less complex if everybody sticks to the new approach and “keeps patients and families at the centre of all they do.” To her, person-centred care has to be taken literally by providers and managers, meaning that it has to permeate every action in care.

“In every single meeting – with administrators, physicians, and nurses – where we are redesigning services or working on process improvement measures, we should be asking if the patient or the family was involved. It is so important that we go through all of our processes with the goal of keeping patients at the centre of what we do. Who is better to help us with quality improvement initiatives than those we serve?” she says.

One of the ways of ensuring this could be to begin all meetings with a patient’s story.

“It could be a professional or a personal story, but simply listening to that story makes us all think differently. It is all too easy to talk about statistics, mortality rates or the length of a stay—which are important to our business—at the ward, but we also need to focus on integrating our patients and families at the very core of what we do by engaging and empowering them as partners in care. This has a huge impact on everybody” she says.

As a former patient and a former businessman, e-patient Dave deBronkhardt encourages providers to understand that the process of change may take years and that implementation has to be included in their goals as well as in management in general.

“The first step is to understand that change is not a short

term project. It is complex and you can’t figure it all out in advance. You should not expect it to be perfect from day one and you will have to keep your eye on the goal and be clear about your commitment throughout the process”.



POLICY MAKERS

## DEFINE EVIDENT GOALS

Today, clinical performance and cost-effectiveness compete in being the defining feature of good healthcare. Person-centred care requires a different set of goals and criteria for success.

“To move healthcare forward, we have to recognize that quality of care and patient safety should have the same high priority as finance and clinical performance,” says Mike Spencer. When changing the standard of healthcare, policy makers must define expectations in much the same way, Singapore’s Minister of Health presented a vision of making healthcare “patient-centric”. Such goals seem relevant across the world.

“Policy makers have to set goals for patient-centred care and then create incentives supporting that goal. They should send very clear signals,” says Annette Wandel from Danish Patients.

Her recommendation is in accordance with suggestions from WHO: “Political will is key and can be developed through demonstrating that people-centred care is both possible and feasible in resource-constrained health systems.”<sup>1</sup>

The development of primary care in Thailand is an example of the importance of this. After a decade of engaged work by pioneers championing person-centred care, the breakthrough came when a national reform made it a national standard. See *chapter 5, page 72*.

The same goes for Tanzania: “We need to ensure that health policies include patient-centred approaches much more than they do today – that it becomes an inevitable part of health policies. We need the necessary leadership to support the change”, says Senga Pemba. See *chapter 5, page 84*.

Note<sup>1</sup>: World Health Organization. *People-centred care In low- and middle-income countries*. 2010.

*“Policy makers have to set goals for patient-centred care and then create incentives supporting those goals. They should send **very clear signals.**”*

- Annette Wandel, Danish Patients



# 3

## REDESIGNING INCENTIVES

→ **Setting the goal and outlining the strategy is one thing** – ensuring that incentives support the decisions made is another.

“Policy makers can outline the vision and strategy, but we also have to support this with concrete changes in the organization of the healthcare sector and with concrete incentives that can help support person-centred care”, says Denmark’s former Minister of Health Astrid Krag.

Incentives are one of the most effective instruments when transforming healthcare. In Denmark, for instance, a substantial appropriation introduced in 2002 has prompted hospitals to improve efficiency and reduce patients’ waiting time for a number of selected operations such as knee and hip replacements, cataracts and hernia. As a result, waiting times have been reduced by approximately 30 per cent, and hospital productivity has increased significantly.<sup>2</sup>

The reverse side of the coin was revealed in an evaluation of the Danish initiative in the summer of 2013<sup>3</sup>, which acknowledged the positive effects but also noted that hospitals are rewarded if the same patient is readmitted. Furthermore, the incentives neglect the patients’ demand for coherence by not rewarding collaboration between providers of care.

Following the evaluation, a revision of the economic incentives is now due. It sets out to reward the whole healthcare process rather than individual points of action, e.g.

operations, providing incentives for creating a positive patient experience.

“We have laid out a proposal that will include coherence, professionalism and quality of care as important factors in the future structure of the incentives in our healthcare sector”, the former Danish Health Minister explains.

This case illustrates the importance of aligning incentives with goals. To promote person-centred care it is necessary to link incentives much more to patients’ needs.

“It is both important to remove disincentives in the system and to renew other incentives in order to support a patient-centred care,” says Neil Churchill.

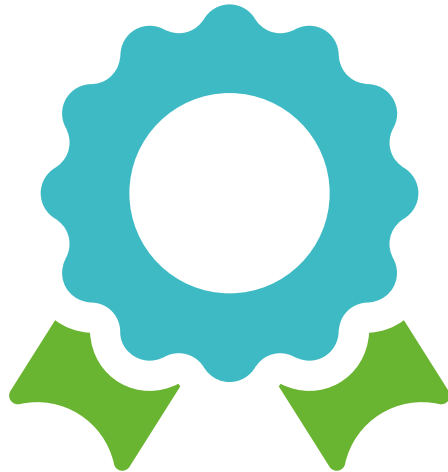
Albert van der Zeijden supports this call. He advocates a whole new incentive structure. “We have to rethink the incentive and payment structure within the healthcare sector,” he says.

Jacqueline Bowman-Busato elaborates: “Incentives are essential. Most people do not want to change routines unless there is something in it for them. The incentives do not need to be solely economic, and it is important that they are integrated and communicated to the stakeholders involved,” she says.

Redesigning incentives within the healthcare sector must be pushed forward primarily by policy makers and providers.

Note<sup>2</sup>: Statistics Denmark. *General Government Output and Productivity 2003-2010*. 2012.

Note<sup>3</sup>: Ministry of Health and Prevention. *Bedre incitamenter i sundhedsvæsenet*. 2013.



PROVIDERS

## REWARD PERSON-CENTRED CARE

Different providers of healthcare play an important part in creating a new model of care, where professionals are rewarded not only according to the number of operations, visits or diagnoses, but also according to patient satisfaction, patient experience, patient rehabilitation, and patient activation.

Anette Wandel suggests a model, where providers focus on incentives and rewards for professionals based on their ability to coordinate the entire treatment process.

“It is not enough to be a good surgeon if rehabilitation afterwards is not satisfactory. There has to be incentives to reward the whole process,” she states.

And that approach is exactly an integrated part of the current changes within the National Health Service in the UK.

“General practitioners are to commission care and they should keep an eye on the total outcome and not just the outcome in hospital care. When they commission care, they are rewarded for care that is coordinated around patients,” says Neil Churchill, NHS England. See *chapter 5, page 81*.

In the Maccabi Healthcare Service in Israel, the restructuring of the primary care sector around a more person-centred approach was supported by subsidising physicians to hire a nurse practitioner. See *chapter 5, page 74*.

But generally, the process of developing incentives to support person-centred care is still at its early stages.



POLICY MAKERS

## REALIGNING INCENTIVES WITH PERSON-CENTRED CARE

Changing the structures of payment and incentives within the healthcare sector demands political backing as well as political action – especially in countries where the healthcare sector is financed mainly through public funds.

In the countries currently championing person-centred care, the political determination to rethink incentives and rewards has been vital. New payment and incentive structures are an essential element in the national healthcare reforms in both the US and the UK.

According to several experts, a key factor in future funding models should be to promote prevention before actual treatment.

“Today, hospitals receive money for the number of patients that are admitted and treated. This is not a very good incentive for getting them to participate in more preventive and out of hospital care,” Jocelyn Cornwell explains.

Furthermore, policy makers should focus on incentives that support coordination of care between different actors and providers. In the reform process of the NHS in the United Kingdom, one of the main elements is putting the GP in charge of the care delivered to patients. It means that patients are only admitted to a hospital on advice from their doctor. The system is designed to focus on the coordination of care.

“The incentives will be organized in order to keep patients out of the hospital. There will be one provider who's accountable for the whole process of care,” says Neil Churchill.

# 4

## TAKE STOCK OF USER SATISFACTION

→ **Hotels, sports teams and restaurants.** Carolyn M. Clancy, a top official at the US Department of Health, has a surprising take on where professionals and providers should look for inspiration to improve healthcare.

Like many other healthcare administrators, she describes herself as a doctor first, but she is also Director of a branch of the US Department of Health, The Agency for Healthcare Research and Quality, which is a “scientific agency” responsible for monitoring quality of care throughout the country.

“At good hotels, staffs members are extremely service oriented. If you have a question, the person you ask will take care of your problem. They don’t want you to get ‘passed around’. There is a responsiveness, which ensures that no one you meet will ever say ‘that’s not my job’,” she points out.

A hotel is a business that relies entirely on satisfied consumers and within the American healthcare system, a

percentage of reimbursement to providers is already dependent on measured patient experience.

This means that suppliers of care have to take the experience of patients into consideration – and use their feedback in the internal process of performance enhancing.

In the end, it boils down to changing culture and routines – like any football team going through last Sunday’s game in order to improve their performance on the following Sunday.

“Of course, the hospitals don’t have the videotapes from the last match as the football teams have, but they may have complaints from patients,” Carolyn Clancy explains.

She expects that over time, suppliers of healthcare will be met by the same expectations as other providers of services.

*“You can’t **improve** something without **measuring** it.”*

- Dave deBronkhardt





## PROFESSIONALS

### PAY ATTENTION TO PATIENTS' EXPERIENCE

Many professionals look exclusively at the clinical outcome, when measuring their performance and do not hold the patient experience to be of equal importance. That is the estimation of Mike Spencer, who has co-authored a thorough evaluation of healthcare in Wales from the perspective of the patients.

"There is currently a lack of awareness amongst staff as to how to use feedback to shape and move towards person-centred care – we are far from a situation where the patients' views, feelings, preferences and experiences drive patient care."

He points out that clinical standards aside, many routines are simply carried out by force of habit. Treatment or procedures commonly used by staff members may be experienced as highly unusual by patients, and staff need to think about how they explain and engage patients in the routines of care. As a patient in his evaluation reports:

"The hoist was so undignified; I felt like a baby in a romper suit. I still squirm when I see others in it."<sup>4</sup>



## PROVIDERS

### MAKE FEEDBACK A KEY DRIVER FOR CHANGE

"You can't improve something without measuring it." This is e-patient Dave deBronkhardt's basic conclusion, which suggests that providers must include patient experience and feedback in order to move in a more person-centred direction.

The UK National Health Service, which is right in the middle of a transformation process regarded by analysts as the

most challenging since its inception in 1945,<sup>5</sup> uses feedback from patients as an important tool in improving care.

"We are introducing real-time feedback to more and more wards and emphasizing the meaning of it," says Neil Churchill.

Apart from being measured in real-time, the feedback has to be directed to the specific ward and not the hospital in general.

"Our experience is that if the surveys are too general, they do not result in any improvements. Surveys have to be delivered directly to the ward at discharge or very shortly after discharge," he explains.

Surveys directed straight at the wards have been the main tool in improving hip-operations and ensuring care to patients at the NHS Hospitals in Northumbria. See chapter 5, page 70.

The exact same intention is behind the Friends and Family Tests, which providers all over the UK use to question patients about the quality of care received. The tests were introduced in the NHS in April 2013, following the advice of the Nursing Quality Care Forum.

The hope is that they "can drive a culture change of continuous recognition of good practice and potential improvements in the quality of the care received by NHS patients and service users."<sup>6</sup>

The feedback should also be passed on to fellow patients. Carol Cronin, Founder and CEO of the Informed Patients Institute in the US, believes that easy access will empower patients and their relatives – in much the same way Tripadvisor has enhanced tourists' ability to choose the right destination, restaurant or hotel.

"Some providers in the US already ask their patients to comment upon received care online. When digital natives like my own kids grow up, they will comment on everything on the net, including providers of care," says Carol Cronin.

Note<sup>4</sup>: Williams A, et al. *The Listening Organisation - Ensuring care is person-centred in NHS Wales*. 2013.

Note<sup>5</sup>: Nick Triggle. *The changing NHS*. BBC News. 26 September 2012.

Note<sup>6</sup>: NHS England. *Introduction to the Friends and Family Test*.

# 5

## SHARING INFORMATION

→ **“Most people visit Dr. Google before they visit their doctor.** That is something of a paradigm shift,” say Lucien Engelen.

In some countries, “Dr. Google” actually entails professional doctors submitting popular comments on the most common diseases and their symptoms.

In Sweden, more than 100 professionals write articles and answer questions from users on Netdoktor.se, a website visited by approximately half a million citizens every month – more than 5 per cent of the entire population. They may urge patients to seek further information or even direct them to other websites after the consultation.

Another possibility is finding information about health issues at the Khan Academy. By clicking a mouse or swiping a finger across a screen, citizens can gain access to a pool of knowledge and data that used to be the exclusive domain of trained professionals.

Knowledge is power, and this marks a fundamental shift in the balance between patients and professionals.

Which is why e-patient Dave deBronkart calls on professionals to team up with patients in order to bring their knowledge into care. He often finishes his interventions at conferences by rapping a simple message to his audience: “Let patients help”.

To him patients are the “most under-utilized resource in healthcare today”. He thinks that the resources of patients may improve the partnership between patient and professional in care.

“Hundreds of thousands of articles are published every year. No one – not even the best doctor – can know everything, so it’s entirely reasonable for patients and families

to help seek information. It’s not an insult to the physician,” he explains.

Sharing data is an integrated part of partnerships between patients and professionals. At the same time there is a growing need for professionals to share data with other professionals in order to provide the best possible service to patients.

One vision includes electronic data journals following every single patient from provider to provider. Data-driven health is a constituent part of a person-centred care.




### ACTIVE USERS AND PRODUCERS OF DATA

Easy access to information provides patients with a new tool.

For instance, they can share their knowledge and experience with other patients. According to Dave deBronkart, knowledge gathered on the Internet from other patients helped him and his doctor choose the right dose of medication in their fight against cancer.

“During my own care, I turned to patient communities because I wanted to know as much about side effects as possible. My doctor told me that he was not sure I could have tolerated enough medicine to save me, if I hadn’t been so well informed to deal with the side effects,” says Dave deBronkart.

Note<sup>2</sup>: deBronkart RD. *Let patients help!* CreateSpace Independent Publishing Platform, 2013.

A close-up photograph of a silver stethoscope resting on a white tablet. The tablet screen displays a medical form with various fields and text. The background is a dark wooden surface.

*“New sources of information are around and that’s why **patients should help their doctors**, because the doctors can’t handle the information alone.”*

- Dave deBronkharts

There is also a rapidly emerging market of easy-to-use tools and applications allowing citizens to monitor their own health. Like joggers can monitor their speed and pulse, people with COPD can monitor their blood oxygen level and their respiratory rate on their smartphones.

This gives rise to another question: patients gather much information from devices bought on the consumer market, but what about their access to data collected from a professional device such as a defibrillator?

One American patient, Hugo Campus, suggests that data collected by professional devices should be shared not only with professionals but also with the patients themselves.

“This would help me and people with other medical devices to identify and prevent potential triggers of cardiac arrhythmias and other critical events. It's a tragedy when information exists that could have been used to prevent a problem. Such an app would give users of medical devices unprecedented access and insight into their health. Give us our data so we can take better care of ourselves and our families,” he reasons.<sup>8</sup>

When the Office of the National Coordinator for Health Information Technology (ONC) in the US issued one of its public challenges to push innovation forward, Hugo Campus' proposal to share data from professional devices with patients won.

Next step could be patients typing data into their own health records.

“Professionals are used to storing their own data about the patient. Within the coming years, they will also receive data from patients. We will take out a subscription on patients' data,” says Lucien Engelen.

The free flow of information on the Internet is in stark contrast to the stored information in the healthcare sector.

“When data does not follow the patient, the patient has to repeat the information again and again. But as humans, they will not repeat every detail in exactly the same way each time they meet a healthcare professional. In that process, pieces of information is lost,” Dr Lee Chien Earn notes.



PROFESSIONALS

## NAVIGATE AND SHARE DATA

Just like patients, professionals get access to a growing amount of relevant data and information.

The much-hyped transformation of data into big data has particularly extensive implications for the field of medicine.

“One hundred years ago, it is said that a physician might have reasonably expected to know everything in the field of medicine. Today, research librarians estimate that a physician in just one specialty, epidemiology, needs 21 hours of study per day just to stay current. Faced with this flood of medical information, clinicians routinely fall behind, despite specialization and sub-specialization.”

Despite that development, “many doctors think, that it is their responsibility to know everything within their field. But they can't possibly know everything – there's too much information,” says Dave deBronkart. See figure 2.

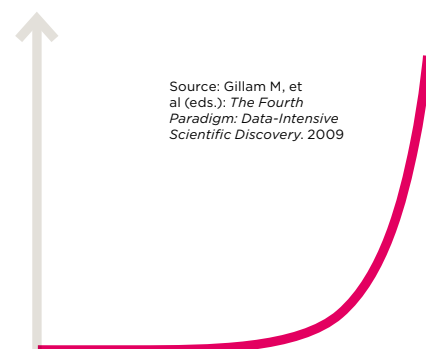
To him patients are the “most under-utilized resource in healthcare of today”, and he thinks that tapping into that the resource may improve the partnership between patient and professional.

“New sources of information are around and that's why patients should help their doctors, because the doctors can't handle the information alone,” he says.

FIGURE 2

## EXPONENTIAL GROWTH IN MEDICAL KNOWLEDGE

THE NUMBER OF BIOMEDICAL ARTICLES CATALOGUED EACH YEAR IS INCREASING RAPIDLY.



Note<sup>8</sup>: Health 2.0. *Blue Button Co-Design Challenge*. <http://www.health2con.com/devchallenge/blue-button-co-design-challenge/>

# 6

## NEW PATHWAYS

→ **The predominance of chronic diseases** and the high rate of co-morbidities point to the need for new kinds of treatment and care. Former Director of the Maccabi Institute for Health Services Research in Israel, Rachele Kaye describes the development of healthcare in three phases.

“In the past, the hospital was the centre of care, then it moved to the general practitioner, and today, patients are becoming the centre – in their home or wherever they happen to be,” she says.

To support this development, healthcare has to part with the idea of pathways founded only on the medical perception of care.

“Pathways can be a great force of good in moving person-centred care forward, but they can also have a negative effect. They have to be designed as people pathways and based on the patient’s journey,” says Adrian Sieff.

ferent steps of care; they should tell patients what the next steps are and outline the way forward. Today, the process of care is all too often a mystery to patients. It is a small thing to do but a big relief for patients,” says Carol Cronin from The Informed Patient Institute.

Pathways must be much more clear and cohesive, enabling different professionals to cooperate around the individual patient. Today, professionals are seldom held responsible for neglecting that kind of cooperation. Many experts stress the need for chief officers or “captains”, and most appraise the general practitioner as the one most suited to take on this role.

“Someone has to be responsible for the continuity of care for each patient. In England, it is the general practitioner, who commissions hospitals or communities when they are needed to support the single patient’s need”, Neil Churchill says.



### TAKE ON THE ROLE AS THE PATIENT’S GUIDE

A person-centred healthcare sector requires professionals to undertake a much more visible and active role of helping the patient navigate through a system of care provided by different agents. They must view each meeting with a patient as part of a consecutive care process and not as an isolated point of contact. By force of routine, professionals should outline the foreseeable care process for the patient and other participants.

“Professionals should help patients understand the dif-



### ENSURE COHESIVE PATHWAYS

Providers and politicians are the primary agents when it comes to developing and disseminating new pathways and models for care. Both can initiate actions that allow patients to be treated according to their needs much more systematically than today. They should challenge “what we usually do”, which means locating new approaches to how and where the healthcare sector provides care.

Angela Coulter believes that a stronger focus on cohesion in treatment plays an important part.



“Could we do more if we were, for instance, differently organized? Organized in a way that created new structures to allow stronger cooperation between primary care and hospitals? Today, there is a communication gap between primary care and hospitals. One solution could be multi-disciplinary teams that included the patient,” she explains.

A key element is ensuring that different actors and sectors share information and knowledge on each patient.

“We need better sharing of knowledge. Today, our system is characterized by a very fragmented treatment. It would be of great help, if the people doing the work were informed on what happens to the patient, when they are not with them. Thus, we need pathways designed deliberately to support this,” Jocelyn Cornwell suggests.

This is especially true for people with chronic diseases.

“We need to focus much more on the implementation of new treatment models and pathways for long term diseases,” Albert van der Zeijden states.

Established pathways in cancer and diabetes treatment in countries like Denmark and the UK are pointed out as models that could be applied to many different treatment and care processes. This could also be a way of relieving the economic strain on the healthcare sector.

“If a hospital like ours try to provide all care within the hospital, our system would simply break down due to costs even if we could handle the increased throughput. Care at acute hospitals is expensive. We should try to care for patients in the most appropriate setting. For example, we could serve patients with diabetes with simple messages provided to their smartphone or another screen in their home,” says Lee Chien Earn of Changi General Hospital in Singapore.

Astrid Krag, former Danish Minister of Health, agrees; she has outlined a political proposal where developing cohesive healthcare solutions – across sectors – is considered a key area of focus.

“We need to ensure that the healthcare sector is based on strong collaborations and cohesive pathways in order to ensure a care where the individual is placed at the centre”, she stresses.

One example of this could be the use of data and technology allowing providers to deliver healthcare services in completely new ways.

“We think that between 20 and 25 per cent of all visits to professionals may be virtual in the years to come. In rural areas of Israel, patients and their doctors or nurses may link up via Skype,” Rachele Kayes explains.



## CO-CREATING HEALTH

When Carolyn M. Clancy is asked to “diagnose” healthcare systems of today, she immediately thinks of one word: fragmentation. Describing the “cure”, the word that comes to mind is interdependence.

As more and more patients receive care from more than one provider, there is an obvious need for collaboration between professionals to ensure that the patient and not the interests of their own institutions or wards are placed at the centre of care.

But as the six points described on the previous pages show, understanding this interdependence is only a first step. The overall message from the experts is that for future healthcare to succeed, it has to be co-created by all stakeholders. *See figure 3 on next page.*

First of all, **patients** must take an active role in their own care. When it comes to chronic diseases, professionals can advise, present and discuss pathways and treatment plans as well as coach and even support difficult decisions, but they cannot decide the behaviour of patients. Patients must assume co-responsibility for care.

A new partnership between patients and professionals will build on the sharing and discussion of information and data. The patient’s own knowledge and input from online communities may have substantial value to care.

**Professionals** should reap the benefits of patients who are becoming still more educated, informed, and resourceful. Professionals should listen to patients’ needs and seek an understanding of their general life situation.

The partnership between these two parties is the cornerstone of person-centred care. But it has to be supported by other stakeholders.

At the start of such a transformation, **providers** have to demonstrate the willingness to place patients at the cen-

tre of care. As simple as this may sound, it will have profound implications for attitudes and practices as well as the organization of care.

Understanding that they will often be one of several agents of care, providers must ensure that pathways and models of treatment are cohesive and coordinated. It is not enough to optimize care within one institution; it has to be co-created across a network encompassing several institutions and experts.

In this process, feedback from patients is vital and must trigger adequate reactions from the healthcare system.

Today, **policy makers** perform varying roles; in some countries they are directly responsible for providing care, while they play a more limited part in other countries. However, they do share the common responsibility of setting the goals for the entire healthcare system.

In a number of countries, from Thailand to the UK, they are already highlighting the need to place patients at the centre of care.

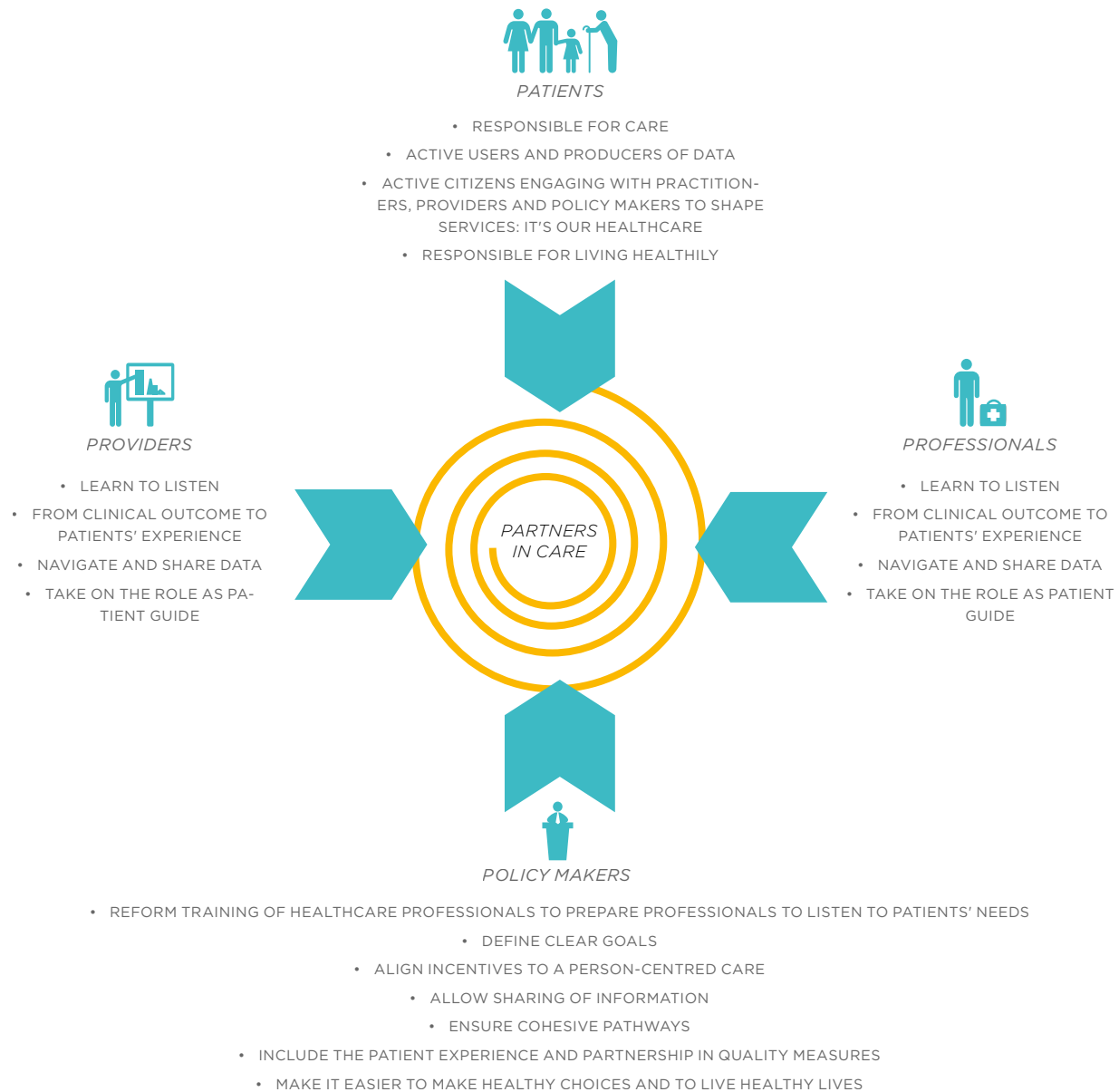
An important aspect of their mission is to promote a new public understanding of healthcare, clarifying what actions patients and other stakeholders should take to enable the change to become a reality. They are also key players in the facilitation of data sharing, which ultimately requires legislation that allows it.

It all boils down to a question of costs and incentives. In general, providers are not yet appropriately rewarded for cooperating with other providers or involving the patient. Reforms that realign the incentives of healthcare with the goal of person-centred care could be decisive to change.

FIGURE 3

## HEALTHCARE STAKEHOLDERS CAN MOVE PERSON-CENTRED CARE FORWARD

ALL HEALTHCARE STAKEHOLDERS - PATIENTS, PROFESSIONALS, PROVIDERS AND POLICY MAKERS - MUST CONTRIBUTE IN DIFFERENT WAYS TO MOVE PERSON-CENTRED CARE FORWARD.



Source: DNV GL / Sustainia



NEXT  
RISK AND  
SYSTEMS THINKING



CHAPTER  
9/10

ALL CHAPTERS

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*Durhane Wong-Rieger, President & CEO, Institute for Optimizing Health Outcomes in Canada and Chair of the Board of International Alliance of Patients. She is also President of the Canadian Organization for Rare Disorders and Head of Consumer Advocare Network, a national network that promotes patient engagement in healthcare policy and advocacy. Durhane Wong-Rieger has conducted training, workshops, and evaluation for patient groups in Canada and internationally on all aspects of patient engagement and advocacy. She has served on numerous health policy advisory committees and panels.*



INTERVIEW **DURHANE WONG-RIEGER**

“THE DEVELOPED  
WORLD CAN LEARN  
A LOT FROM AFRICA”

→ **Engaging and empowering patients has become a cornerstone in many developing countries' efforts to create universal healthcare. The "old healthcare systems" could learn a lot from this, says Durhane Wong-Rieger, an international expert on person-centred care and patient engagement.**

When Mozambique gained independence in 1974, all doctors except two left the country. The new independent nation faced the massive challenge of rebuilding a healthcare system from scratch. Today, this process is not yet completed, but their work so far bears witness to the fact that it is indeed possible to build a healthcare system that is different from the ones we know from developed countries.

Up until now, Mozambique has focused primarily on self-care and community-based healthcare. Besides building hospitals and clinics as well as training and recruiting nurses and physicians, they have invested in educating community workers and lay people.

Durhane Wong-Rieger points to Mozambique to explain how developing countries can inspire the rest of the world when it comes to creating a person-centred healthcare system from nothing.

"Many developing countries have come to realize that you could not do anything but patient-centred care. They are faced with a tremendous strain on resources and have no choice but to place the person at the centre of treatment – they simply need to engage and turn people into a resource that can be drawn on in order to ensure the right care."

And this, she argues, means that developing countries have the opportunity to implement healthcare that is much more up-to date and more sustainable, which makes it interesting for more established healthcare systems to look into.

"If we could start all over again in terms of building a healthcare system from the ground, would we put the

money were it is now? Probably not. We would do it differently. That is why the developed world can learn a lot from Africa. They are just now in the process of creating healthcare systems that provide universal care, and therefore they have the opportunity to make investments that are right for today – and build their healthcare on the reality of today. This gives them the opportunity to spend their money wisely."

#### **Person-centred care is key**

As Dr Wong-Rieger elaborates: many developing countries integrate person-centred care as a cornerstone, when they build or rebuild their healthcare systems.

"Africa is making patient-centred care a reality. They take the community as their starting point, train people to take care of themselves and invest in empowering the people. They are teaching us that if you want to create universal care, you better empower a whole lot more people than the professionals, and you better be using a whole lot more than just the latest medicine."

"They work with the idea of reducing care to the lowest professional level necessary. A lot of the care provided by professionals today is basic hands-on care that people in developing countries are still doing at home. They only go to professionals with problems beyond what you can do at home or in the community."

"For instance, patients travel 60 miles to get some tests done at a hospital, go back to their village and get the results on their mobile phone, and only then do they go to the village clinic to get the results interpreted. If they need more care than the village clinic can provide, they can get a new appointment at the hospital, but in many cases they do not – they only use the most professional and most expensive part of the system when other options are depleted."

Durhane Wong-Rieger believes that the lessons learned in Africa are very important for the future improvement of healthcare systems in the developed world.

"To be sustainable, it is necessary for healthcare systems around the world to consider patients as a resource. No healthcare system can provide the necessary care for the growing number of chronic patients without doing this."

#### **It is hard to change things**

This is exactly where the idea of community-based care becomes vital.

"We need to start focusing on embedding care within the community, including prevention, good education and so on. Different sectors must be involved in care, such as school systems, restaurants etc."

But this kind of change has proven hard for healthcare systems that have a long history as well as strong traditions and well-established structures.

"It is difficult to change an entrenched professional-based system. If we could start with nothing, we could build something that is going to be effective today, but that's not the case".

Wong-Rieger points to the funding of established healthcare sectors as a specific challenge.

"We don't have more money, but we could use the money we have better. When you place money in the wrong areas, it is difficult to take it away again. We have invested a lot in hospitals, high cost specialists and administration. Now we are faced with the challenge of pulling some of the money out again – so that we can reinvest it. Today, where chronic conditions account for the majority of morbidity, mortality, and healthcare costs, we must begin to invest in effective and cost-effective person-centred programs such as self-management and health-coaching which will empower patients and connect them to community resources. This is extremely difficult."

*“I was happy to survive, so I wanted to give something **in return**”*



- **Suphot Phithaksinachenkit**, Thailand, heart failure

**Age:** 62 years

**Occupation:** Former factory owner

**Family:** Wife and two children

**Hobbies:** Spending time in the patients' club

→ **For most of his life**, Suphot has worked hard in his small factory, producing bags for consumers in Thailand and Japan: whether it was backpacks, ladies' handbags or purses – Suphot's factory made them.

Then one day, at the age of 56, he suddenly fainted. His family took him to the hospital as fast as they could, and the doctor quickly discovered that the problem was with his heart and he would have to go into surgery.

Two weeks after the operation, Suphot was back home. He was still receiving advice and instructions from his doctors on how to rehabilitate properly.

He promptly decided – together with his wife – to sell the factory and retire early. With a lot of spare time on his hands, Suphot quickly regained strength and started wondering what to do with the rest of his life. Then he realised he wanted to help other patients within his community.

"I was happy to survive, so I wanted to give something in return," he explains. The care he had received at the hospital and the rehabilitation programme was simply excellent and it made him feel grateful.

Today, Suphot spends most of his time helping other patients through two small patients' organizations within his local community.

One of the organizations helps sick children prepare for a life of going in and out of hospitals. Suphot talks to the children as well as their parents in order to help them prepare for treatments that can seem so alien to everyday life.

The second organization, the New Heart Club, was founded by Suphot himself and there he helps other heart pa-



tients get through whatever problems they encounter both before and after heart surgery.

He sees it as a link between patients and health providers: "When patients come to the hospital, they have many worries about their health. So, we try to talk to both patients and doctors to moderate the relation between them," he explains.

Before patients are discharged from the hospital, he gives them advice on how to exercise, which will help them recover as fast as possible – as he himself did.

The philosophy is simple Suphot explains, "If patients have good information and a good understanding of their disease, they will get healthier faster."

He has developed several exercises for heart patients. But more important are the six guiding principles that he hands out to every new heart patient he comes across.

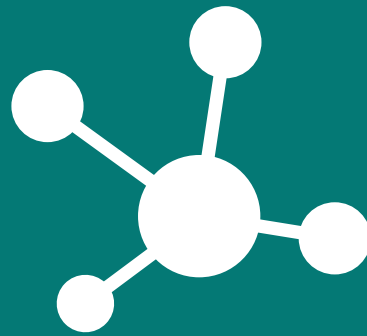
He calls them, "The six principles to make the patient happy":

1. Don't be afraid.
2. Keep up a good hygiene and good nutrition
3. Follow the advice of the doctors – remember to take your medicine
4. Exercise regularly
5. Make a schedule to follow
6. Include your family

Every week, about five of the patients discharged from the hospital will receive his guidelines, after which he meets up with them on a regular basis to ask how they are doing. "I would like to make other patients feel happy," he says.

# RISK AND SYSTEMS THINKING

- ENSURING THAT HEALTHCARE  
IS PERSON-CENTRED



COMBINING PERSON-CENTRED CARE WITH RISK AND SYSTEMS THINKING CAN IMPROVE THE QUALITY OF CARE, MAKE IT MORE RESPONSIVE TO PATIENTS, SAFER, AND MORE RELIABLE.

—> **Alice Mason was just two years old when she died from hydrocephalus.** The coroner’s verdict was that her death was preventable.<sup>1</sup> On nine separate occasions, things went wrong in Alice’s care and thus contributed to her death.<sup>2</sup> These “mistakes” included tests not being acted upon, information not shared effectively between clinical teams and hospitals, the lack of an overall care plan and Alice’s parents’ concerns not being taken seriously.

A story like this is heartrending but, unfortunately, not extraordinary.

Despite the best intentions of professionals, managers, policy makers and researchers, each year, millions of patients are injured while in the care of the health services whose aim it is to help them.

Of 421 million annual hospitalizations worldwide, an estimated 42.7 million are associated with adverse events to some degree. This makes unsafe care the “14<sup>th</sup> leading cause of morbidity and mortality, comparable to the bur-

den from tuberculosis or malaria”.<sup>3</sup>

Two-thirds of adverse events occur in low- and middle-income countries.<sup>4</sup>

This chapter examines how we can connect person-centred care to systems and risk thinking in order to improve the quality of care and minimize the occurrence of cases like Alice’s.

#### **PCC as a driver for improvement**

As Atul Gawande, Professor of Surgery at Harvard Medical School and Professor in the Department of Health Policy and Management at the Harvard School of Public Health, points out: healthcare is unsustainable.

“Our costs are soaring, service is typically mediocre, and the quality is unreliable. Every clinician has his or her own way of doing things, and the rates of failure and complication (not to mention the costs) for a given

Note<sup>1</sup>: BBC News. *Toddler’s tumour death was avoidable, coroner rules*. 14 October 2013.

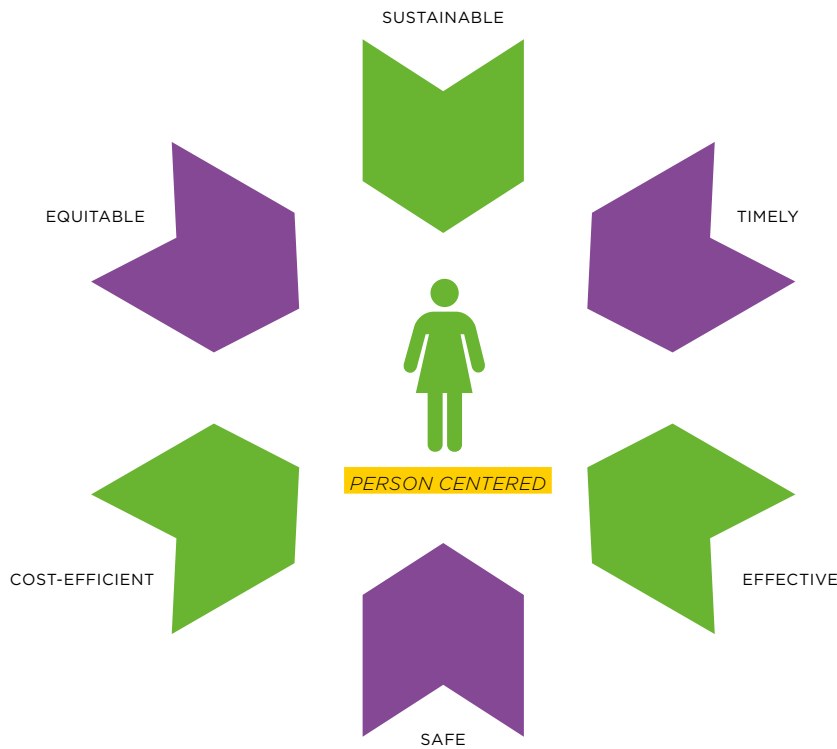
Note<sup>2</sup>: Donnelly L. *Doctors missed nine chances to save our toddler, claim parents*. *The Telegraph*, 24 March 2013.

Note<sup>3</sup>: Jha AK, Larizgoitia I, Audera-Lopez C, Prasopa-Plaizier N, Waters H, Bates DW. *The global burden of unsafe medical care: analytic modelling of observational studies*. *BMJ Quality and Safety* 2013;22(10): 809-815.

Note<sup>4</sup>: *Ibid.*

FIGURE 1

## PERSON-CENTRED CARE AS THE DRIVER FOR WIDER DIMENSIONS OF QUALITY



Source: DNV GL / Sustainia, adapted from: Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001.

service routinely vary by a factor of two or three, even within the same hospital.”<sup>5</sup>

In short, healthcare has to change and person-centred care offers a powerful narrative to drive that change and to improve the overall quality of health services worldwide. In person-centred care, dimensions of quality are focused on the perspective of the users of health services rather than on the needs of the providers. See figure 1.

### Where do we start?

Good quality healthcare depends on different systems working together. If we want to improve healthcare, we have to improve the systems.

Systems comprise a set of interrelated or interacting elements.<sup>6</sup> In healthcare, they constitute the sum of the

people, institutions and resources working together to maintain and improve the health of the people they serve.<sup>7</sup> In other words, the systems and the people who work within them deliver care to the patient. If they are focusing on the wrong things, then poor care will be provided. When systems lose their focus on the user of the service, the results can be devastating – as in the case of Alice Mason.

Systems encompass micro, meso and macro levels – ranging from the clinical through the organizational to the regional, national and international levels. They are dynamic and complex, and information, resources, time and people are continuously exchanged. See figure 2.

The boundaries of the systems are often blurred and parts of one system will frequently be embedded in other systems (e.g. patients commonly rely on healthcare and

Note<sup>5</sup>: Gawande A. Big Med. *The New Yorker*. 13 August 2012.

Note<sup>6</sup>: ISO. *ISO 9000 - Quality Management*. [www.iso.org/iso/iso\\_9000](http://www.iso.org/iso/iso_9000)

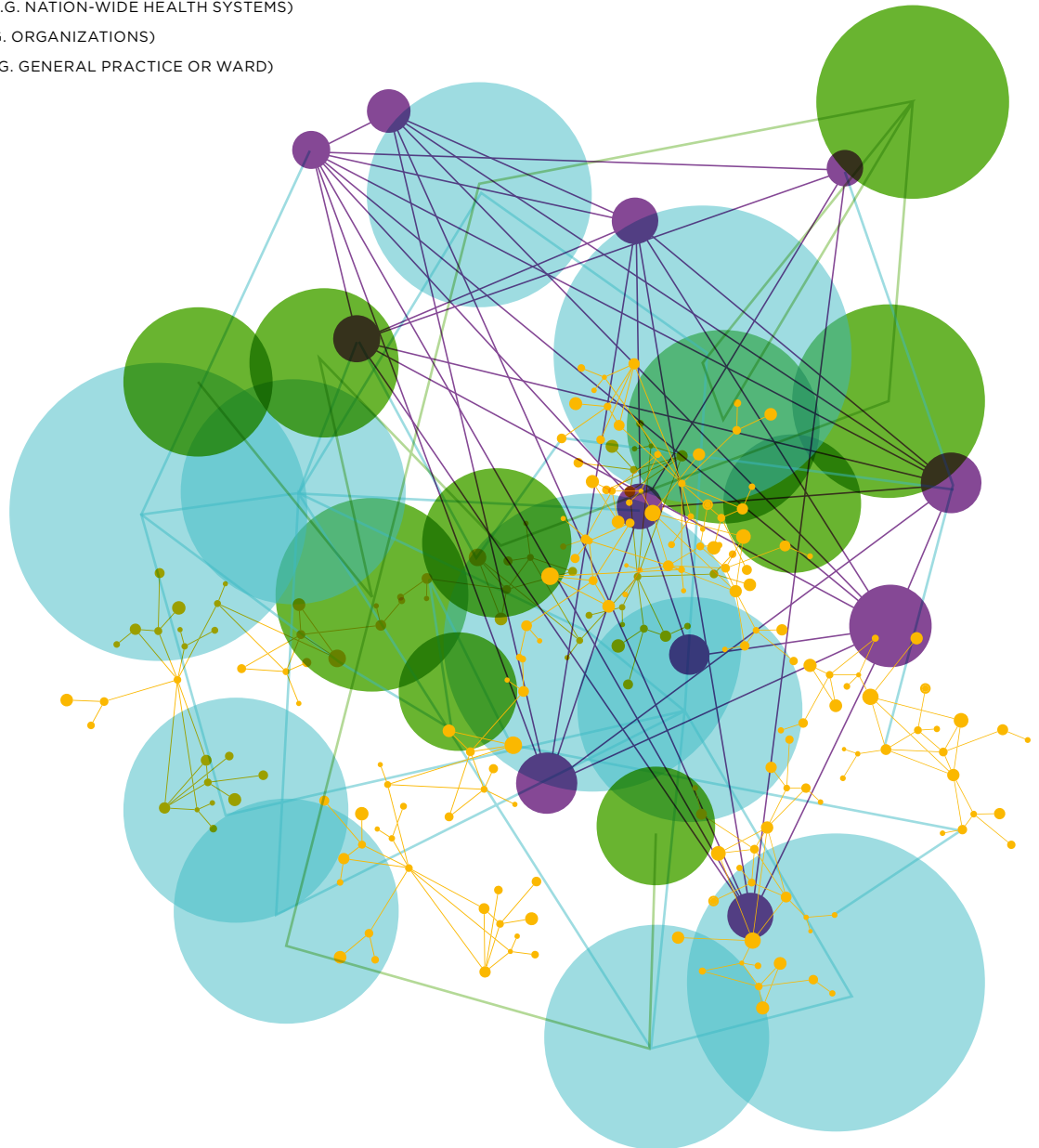
Note<sup>7</sup>: World Health Organization. *Key components of a well functioning health system*. 2010.



FIGURE 2

## MICRO, MESO AND MACRO SYSTEMS CONNECTING

- INTERNATIONAL LEVEL
- MACRO (E.G. NATION-WIDE HEALTH SYSTEMS)
- MESO (E.G. ORGANIZATIONS)
- MICRO (E.G. GENERAL PRACTICE OR WARD)



Source: DNV GL / Sustainia

social care working together). The results they provide are a product of the factors shown in figure 3.

**Addressing complexity through management systems**

It is sometimes easy to forget that systems are products of the humans who design them and work within them. But this also allows us to change them by organizing structures and processes in differently ordered sequences.

Unfortunately, this is not always the case in healthcare, as healthcare systems frequently evolve through piecemeal reactions to various changes without overall coordination and planning.

Systems thinking is one way of addressing this problem: identifying and describing key processes within and across organizations to ensure that these processes are implemented in a reliable way and that they interact with other processes in a coordinated manner.

A common approach to organizing and implementing sys-

tems thinking is the use of formal management systems. Management systems have been used in a wide variety of sectors to drive improvements in quality.

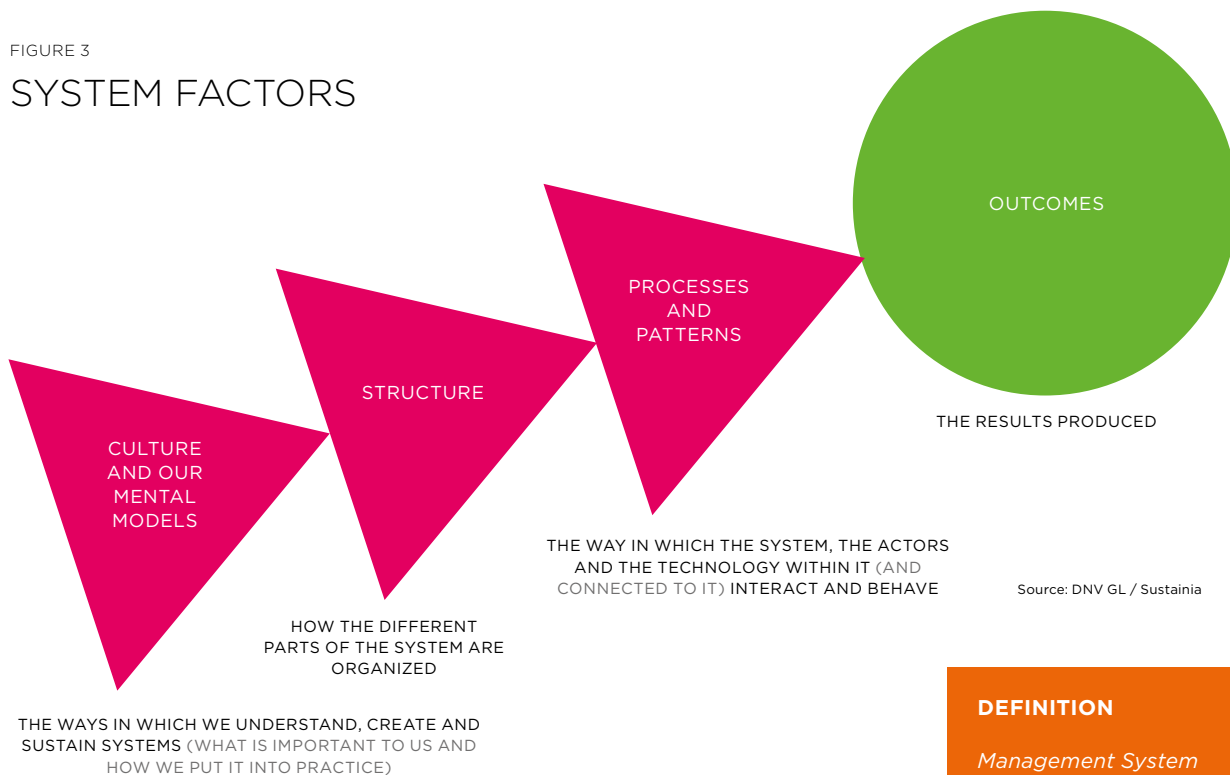
Evidence also suggests that healthcare can benefit from using system level approaches and standardization, both to reduce risks and to improve care. The pan-European MARQuIS project, for example, found that hospitals “that have either ISO certification or accreditation [i.e. hospitals that can demonstrate effective management systems] are safer and better than those which have neither.”<sup>8</sup>

By developing management systems that overcome the obstacles and build on the enablers of person-centred care identified in this guide, we have a real opportunity to create healthcare systems that are not only more responsive to patients but also safer and more reliable. See figure 4.

This will not just require healthcare organizations to adopt policies and objectives aligned to PCC goals. They

FIGURE 3

**SYSTEM FACTORS**



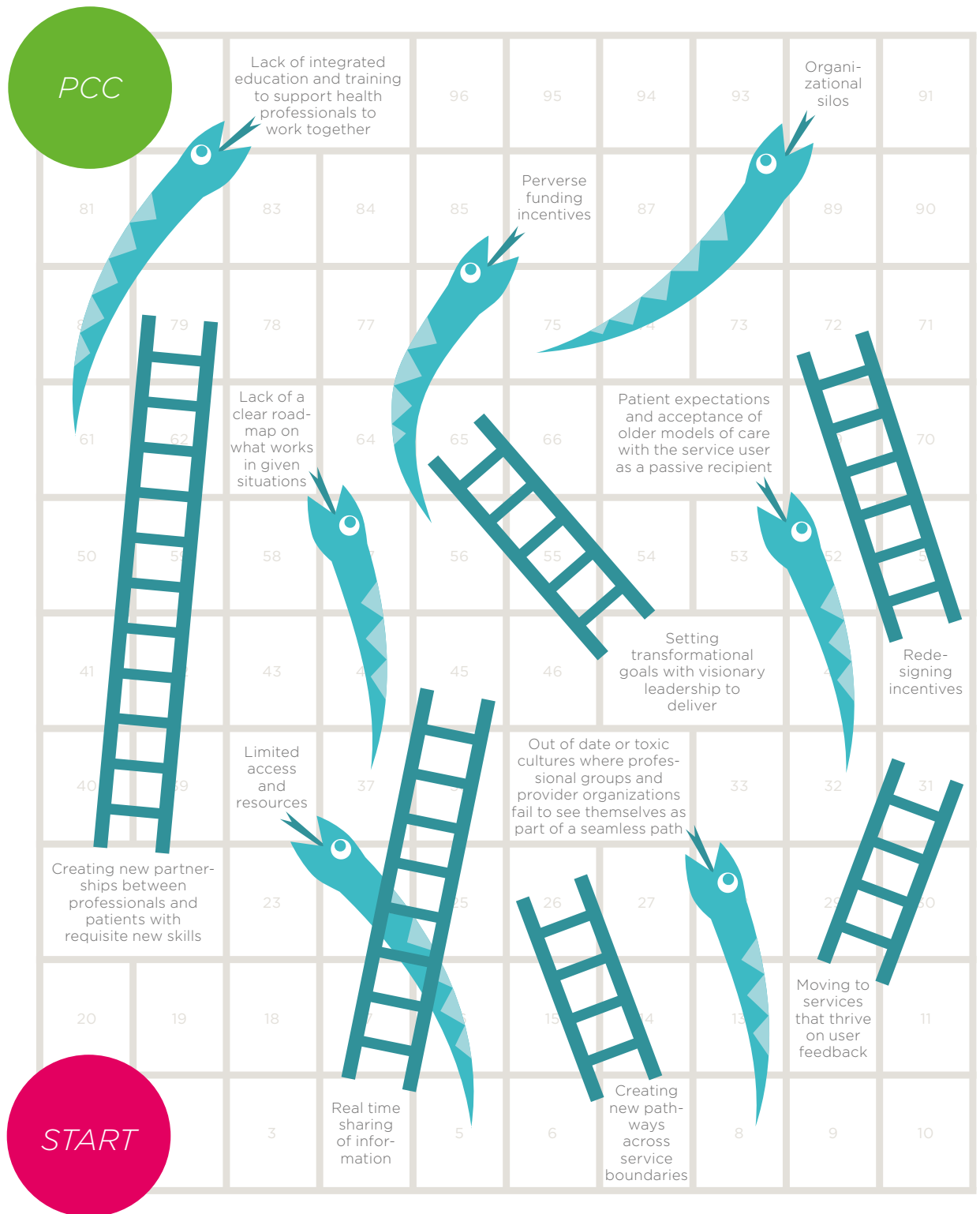
**DEFINITION**

*Management System* – a system that will establish policy and objectives and how to achieve those objectives

Note<sup>8</sup>: Shaw C, Groene O, Mora N, Sunol R. Accreditation and ISO certification: do they explain differences in quality management in European hospitals?. *International Journal for Quality in Health Care*. 2010;22(6): 445-451.

FIGURE 4

# THE SNAKES AND LADDERS OF PERSON-CENTRED CARE: OBSTACLES AND FACILITATORS



Source: DNV GL / Sustainia

“Every system is perfectly designed to achieve the results **it gets.**”

- Paul Batalden, Professor Emeritus,  
Dartmouth Institute for Health  
Policy and Clinical Practice

must also embrace the idea of utilizing patients' resources and experiences to help map, redesign and measure relevant outcomes of key processes within the organization, powering improvement where it has the greatest impact on both patient and staff.

Risk management provides the framework to accomplish this while also ensuring that the voices of patients, as well as those of staff, management and other interested stakeholders will be heard.

#### **The role of risk thinking**

Person-centred care and system level risk management may not be the most obvious bedfellows. But combining the two could provide the means to make high quality and safe care a reality for all.

Risk thinking is already a driver for continually improving systems outside of healthcare.

Evidence from other high-risk sectors supports this.<sup>9</sup> Major disasters, such as the Piper Alpha oil rig fire that

killed 167 men in 1988,<sup>10</sup> lead other sectors to take great strides in improving safety at system level by using risk based approaches.

They have been able to create a culture where organizations continuously try to be one step ahead of the obstacles and hazards they face; i.e. how those obstacles and hazards might prevent improvements or become harmful, and how systems can be designed to prevent or mitigate unintended results.

They make sure that any planned or performed activity begins with a risk recognition process, and then the activity becomes subject to a risk evaluation and a determination of the risk controls required, after which both risks and the risk management system itself are monitored. See figure 5.

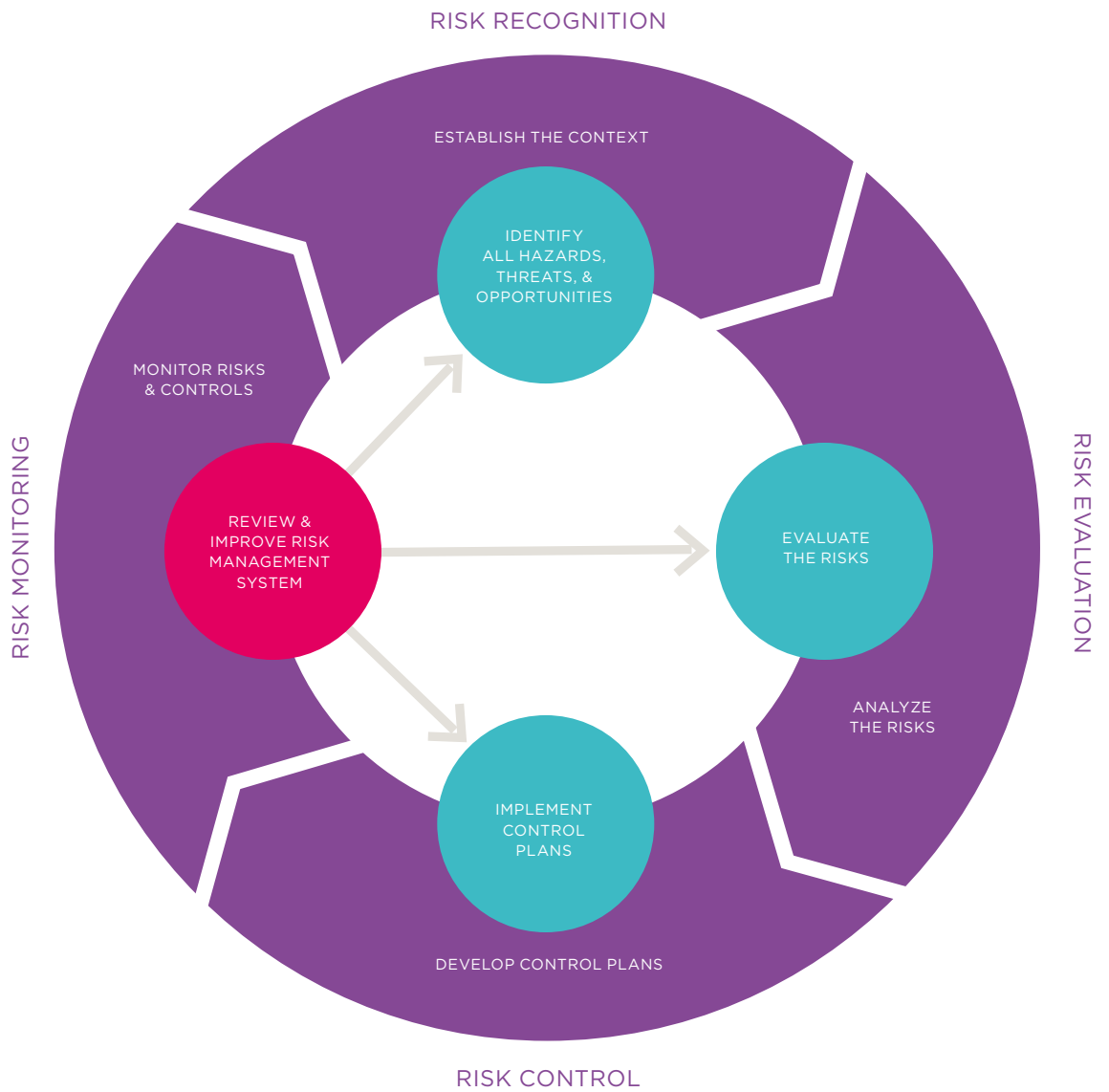
#### **Person-centred risk management**

The results of the risk assessment process must be documented together with associated action plans, and it is important that organizations follow-up and ensure that

Note<sup>9</sup>: The Health Foundation. *Evidence: Using safety cases in industry and health care*. 2012.

Note<sup>10</sup>: Cullen WD. *The Public Inquiry into the Piper Alpha disaster / The Hon Lord Cullen*. Volume 1 and Volume 2. London: HMSO; 1990.

FIGURE 5  
RISK MANAGEMENT



Source: DNV GL / Sustainia

actions are allocated to individuals and resolved appropriately.

This process should not be mistaken for mere bureaucracy: the very process of risk assessment can be very valuable.

Well performed risk assessments, independent of the particular approach, will improve communication across organizational and professional silos, increase risk awareness and facilitate cooperation along shared processes – whether within or between organizations.

To be effective, the risk management process must involve all relevant stakeholders.

Depending on scope and type of risk assessment, these should include clinical and non-clinical professional staff, management, facilities management, support staff (e.g. cleaning, administration etc.), contractors, volunteers – as well as patients and their families.

The latter provide a unique perspective on the patient journey and it stands to reason that they can, and should, play a key role in this process. Patients can identify potential sources of harm that they have observed during their patient journey, which healthcare staff, who only observe part of the journey, may not be aware of.<sup>11</sup>

Moreover, patient involvement in the entire risk management process, from mapping processes and setting acceptance criteria to following up action plans, demonstrates a hospital's commitment to openness and

transparency and it helps legitimize the process.

To date, healthcare has largely engaged patients only by seeking their feedback through satisfaction surveys<sup>12</sup>. This approach can be criticized for being passive and only providing after-the-fact data.

Tools that enable patients to become partners in the advancement of safe and compassionate care<sup>13</sup> are not prevalent.

But there is growing evidence that patients can play an important part in reducing avoidable harm and improving healthcare quality<sup>14</sup> in general. Engaging patients in on-going risk management alongside professionals, managers and policy makers will help ensure that service redesign and continuing provisions incorporate the service user's experiences and that any obstacles and hazards to those experiences are identified and managed before they cause harm.

### Conclusion

The time has come for healthcare systems to recognise the evidence base of what really makes a difference, and to make the most of this opportunity, service users, professionals, providers and policy makers all have to work together to create and sustain this historical momentum for change.

They must work as partners to design and deliver care with individual service users at the centre. To succeed requires a systems approach to identifying and managing risks and obstacles.

Note<sup>11</sup>: Giles SJ, Lawton RJ, Din I, McEachan RRC. Developing a measure of patient safety (PMOS). *BMJ Quality and Safety* 2013;22: 554-562.

Note<sup>12</sup>: The Health Foundation, Nuffield Trust. *Quality Watch*. [http://www.qualitywatch.org.uk/indicators-results?domain\[\]=10](http://www.qualitywatch.org.uk/indicators-results?domain[]=10) (accessed December 2013)

Note<sup>13</sup>: World Health Organization. *Patients for Patient Safety*. [www.who.int/patientsafety/patients\\_for\\_patient/en/](http://www.who.int/patientsafety/patients_for_patient/en/)

Note<sup>14</sup>: Lawton RJ, Armitage G. *Innovating for Patient Safety in Medicine*. London: SAGE; 2012.

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A PERSON-  
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**Astrid Krag**, former Minister for Health and Prevention, Denmark.

*Astrid Krag has been a Member of the Danish Parliament since 2007, serving as Minister for Health and Prevention from 2011-14. She stepped down as Minister when her party, the Socialist People's Party, left the government coalition. She has now joined one of the remaining coalition partners, the Social Democrats.*

*To improve the Danish healthcare sector, Astrid Krag launched a new political health initiative that focuses on how the healthcare sector can further emphasize placing the patient at the centre of treatment through new incentives and new cohesive and integrated healthcare solutions.*

*Astrid Krag holds a BA in political science.*



INTERVIEW **ASTRID KRAG**

“THE PATIENT HAS TO  
COME INTO PLAY  
ON ALL LEVELS OF THE  
HEALTHCARE SECTOR”



→ **“Patient empowerment and involvement are a true brainwave for our healthcare sector.”** This is the perspective laid out by former Danish Minister of Health, Astrid Krag.

In 2013, she spearheaded the government initiative “More citizen, less patient”, which set out visions, targets and tangible steps to kick-start a transformation of the Danish healthcare sector towards person-centred care.

Astrid Krag is a strong believer in the notion that person-centred care is not only a fundamental precondition for creating quality healthcare for all, but also for creating a healthcare sector that is economically sustainable.

“Person-centred care is vital when it comes to ensuring that we get as much healthcare as possible from our resources. The patient has to come into play on all levels of the healthcare sector,” she explains.

In recent years, the Danish healthcare sector has been moving quietly in the direction of person-centred care and Astrid Krag hopes that the initiative will help accelerate this transformation further.

In support of this, the proposal outlines a number of initiatives to be implemented between 2014 and 2017, including the implementation of new cohesive health solutions, increased access to GPs, active involvement of patients and their families as well as the development of a new incentive structure. *See text box.* And the proposal is not merely a “single shot”, but rather the beginning of a new, long-term political strategy.

“This kind of change takes time. It's not something that will become a reality overnight. Our initiative can set the direction and start a transformation

process, but it is not enough. This is the beginning of a long-term process with a number of new initiatives and concrete changes throughout the sector.” Astrid Krag believes that policy makers have a vital role to play.

“Politicians can put person-centred care on the political agenda, set out new standards, restructure funds, and support new projects. This initiative includes new legislation, new incentives, and new financial agreements that can help push this forth. For instance, we are currently rethinking the economic incentives for hospitals in order for them to incorporate quality and outcome as important factors.”

Having said this, she stresses that the political strategy and concrete political decisions are far from enough to create a more person-centred healthcare sector – all stakeholders must be involved.

“As politicians, we can outline the broad strategy and we have the political tools to change the organization and structure of the healthcare sector. But to implement these changes, the strategy must be embedded among the stakeholders. We have a responsibility to facilitate a dialogue which ensures that all stakeholders are included in the process.” In accordance with this line of thinking, political strategies have been based on input from the different stakeholders.

The strategy does not try to outline “a grand model” but to set off change, step by step. A great part of it is about creating the political framework that can initiate and support pilot projects.

“You cannot just outline a big-scale transformation without ensuring that you do it the right way. So we focused on sending out trial balloons in order to find out what would be effective in a Danish con-

text. This is vital to gaining ownership and support from the people involved,” Astrid Krag points out. She elaborates on the importance of having the right arguments and the right process in order to gain wide support.

“It is not possible to just push changes through without having a clear understanding of what it takes and what works. Creating person-centred care is a journey – and this initiative alone will not take us to our destination.”

#### CENTRAL INITIATIVES IN THE HEALTH PROPOSAL

Some of the initiatives listed in Astrid Krag's proposal are already being implemented. Others are subject to upcoming political negotiations with the Danish municipalities and regions, the main providers of healthcare in Denmark.

The five main themes in the proposal are:

- A coherent healthcare sector
- Increased health equality
- Stronger emergency standby and cancer treatment
- Improved quality and focus on results
- A modern and efficient healthcare sector

CHAPTER 10

# A PERSON- CENTRED FUTURE

- THE EXPERTS' VISIONS FOR 2020



*IN 2020 WE WILL HAVE TAKEN A BIG LEAP TOWARDS A MORE PERSON-CENTRED HEALTHCARE SECTOR. STRONGER PARTNERSHIPS, STRONGER COORDINATION, STRONGER COMMUNICATION AND STRONGER PERSON-CENTRED INCENTIVES WILL HAVE BECOME THE NEW NORM.*

→ **It is not often** that you use the words “warm” and “welcoming” to describe an emergency ward. But with carpets on the floor, coloured walls and calm professionals, moving at a comfortable pace, the emergency room at Griffin Hospital is not far off the mark.

At Griffin Hospital, located in the small town of Derby, in Connecticut, USA, the sense of emergency is all but non-existent. Here they proudly tell visitors that patients consider it the best hospital in the state – even above the renowned and highly skilled Yale New Haven Hospital, only a few miles away.

“Think about it this way: when people arrive here, they are extremely upset. They may have had an accident in their car or some other kind of emergency. They share one thing, anxiety. That is why we try to meet people in the most honourable way possible. We want to take some of their edge off,” says Alan Manning, Chief Operating Officer at Planetree, an organization instituted by, and still based at, Griffin Hospital.

The Planetree hospital network counts hundreds of hospitals in the US, Canada, South America, Japan and the Netherlands. Since 1992, management and staff have strived to live up to the vision of person-centred care – based on the principles strongly advocated by Planetree. Today, every aspect of care at Griffin Hospital is informed by the Planetree principles – from their welcome

procedure to comfortable interiors to their emphasis on patient and family education and involvement – establishing Griffin Hospital as an inspiring example of how to make person-centred care a reality.

This kind of hospital is far ahead in terms of general healthcare standards today. But it also tells an inspiring story of the future – of how advances towards person-centred care are within reach.

The experts interviewed for this guide agree that as soon as we reach 2020, we will have taken a big leap towards a more person-centred healthcare sector.

“Patients are at the centre of healthcare and they are given a much more pivotal role with appropriate support. Some coordinate their own care; some need more help and are guided through the different steps of treatment and prevention,” Senior Research Scientist at Oxford University, Angela Coulter, explains.

“In 2020, we will have found a new way of organizing the entire system based on the needs of the patient – and patient-centred care will have become reality,” according to Per Hasvold, Section Manager for the Homecare and Personalized Health Research Section at the Norwegian Centre for Integrated Care and Telemedicine at the University Hospital of North Norway.

# VISIONS FOR THE HEALTHCARE SECTOR IN 2020

## PERSON-CENTRED CARE HAS BECOME THE NEW NORMAL

The cultural change has been a success, and no one questions person-centred care anymore. It has evolved into the new standard practice for healthcare.

*“My vision is a healthcare system, where person-centred care is not a thing to talk about, but simply **the natural way** to understand and deliver care.”*

- Alan Manning, Chief Operating Officer, Planetree.

The shift from disease-focused care to person-centred care has become a reality.

*“Care is now person-based so that the entire healthcare sector helps you **as a person, not as a disease**”*

- Saul Weiner, Professor in medicine, University of Illinois.

## STRONGER COHESION AND COORDINATION

The healthcare sector is based on a focused coordination of care between different actors and silos.

*“Patients experience care as **continuous and coordinated**, within and across different sectors.”*

- Jocelyn Cornwell, Director, Point of Care programme at the King's Fund.

Multidisciplinary teams are widely used.

*“We have a healthcare sector that is coordinated and based on stronger communication. The healthcare sector is based much more on **multidisciplinary teams**, where primary care is much more involved through **the entire treatment process** – guiding the patients through a treatment, i.e. helping with the discharge and the process after”.*

- Angela Coulter, Senior Research Scientist, Oxford University.

## A LOUDER PATIENT VOICE

The healthcare sector is founded, structured and developed on the basis of a much louder patient voice.

*“Patients and their experiences are  
**a natural part** of the development  
of quality of care.”*

- Annette Wandel, Deputy Manager, Danske Patienter.

Patients know their rights and needs.

*“We will see a healthcare system where  
people are able to **express their needs** and  
where they know their patient rights”.*

- Senga Pemba, Director, Tanzanian Training Centre for International Health.

The GP is given the role of health guide.

*“The GP has become the process  
manager or a kind of **ombudsman for  
the patient** – guiding him through all the  
meetings with the healthcare sector.  
He is the point of contact”.*

- Per Hasvold, Section Manager, H0me care and PErsonalised health, Norwegian Centre for Integrated Care and Telemedicine.

## A STRONGER PARTNERSHIP

A main aspect of the healthcare sector of tomorrow is a strong partnership between the patient and the professional, where both parties take on new roles.

*“The patients and the doctors take on **new roles**; the patient as a responsible actor in his own treatment and the doctor as a partner helping the patient.”*

- Albert Van der Zeijden, vice president, Health First Europe and former chairman, International Alliance for patients.

The process of treatment is now co-created and based on shared decision making.

*“The healthcare sector is based on a **strong partnership** between professionals and patients. It is a process of co-creation.”*

- Jacqueline Bowman-Busato, Executive director, EPPOSI.

The traditional doctor-patient hierarchy has been replaced by an equal partnership.

*“There is a much more positive **sharing of power** between the doctors and the patients”.*

- Yang Jingqing, Responsible Academic Officer, China Studies Higher Degree Research Program, University of Technology, Sydney.

EMPOWERMENT OF PATIENTS AND PROFESSIONALS

*Patients are better prepared to embrace the person-centred approach...*

*“We will see many more **empowered patients** and they meet a new generation of doctors focused and trained in person-centred care”.*

*- Asfandyar K Niazi, Doctor, Shifa College of Medicine, Pakistan*

*... and so are professionals.*

*“People working in hospitals are **more comfortable, prepared and trained** to work with patients with multiple morbidity including cognitive impairment”.*

*- Jocelyn Cornwell, Director, Point of Care programme at the King's Fund.*



INCENTIVES WITH A STRONGER FOCUS ON PERSON-CENTRED CARE

Patient satisfaction and experience have become important incentives in the economic structure of the healthcare sector.

*“Patient-centred care has become an **important incentive** for the healthcare sector”.*

- Saul Weiner, Professor in medicine, University of Illinois.

... and a vital concern for healthcare leaders.

*“Managers are trained to think about and focus on **patient experience** as key to their success”.*

- Jocelyn Cornwell, Director, Point of Care programme at the King's Fund.

Person-centred incentives are reflected in and developed by precise measurement systems.

*“We are **much more rigorous** about measuring person-centred care. And it is used as an important factor when **rewarding** healthcare care institutions”.*

- Saul Weiner, Professor in medicine, University of Illinois.

STRONGER COMMUNICATION

The right kind and level of communication is given much more attention.

*“A lot of time is reserved for communication”.*

- Albert Van der Zeijden, vice president, Health First Europe and former chairman, International Alliance for patients.

The entire healthcare sector is based on better and more accessible information  
– tailored to the recipient’s needs.

*“We will see a much stronger dissemination of **plain language** medical knowledge”.*

- Yang Jingqing, Responsible Academic Officer, China Studies Higher Degree Research Program, University of Technology, Sydney.

Communication with patients is based much more on patients’ premises.

*“We have trained professionals in order to conduct an **emphatic and safe interview** with patients”.*

- Robert C. Smith, Professor in medicine, Michigan State University.

## SHARING OF DATA AND BETTER PATHWAYS / 1

The healthcare sector shares its data with patients and it develops models and pathways to ensure person-centred care.

*“Much more data is coming back to the teams on quality of treatment, risk and safety. And they are much better **trained to use this data** to improve processes of care”.*

- Jocelyn Cornwell, Director, Point of Care programme at the King's Fund.

The right pathways of data sharing are implemented.

*“My dream is that we **open up medical records** and other health data bases for patients and make it possible for patients to upload their own data. If it is in any way critical, we should ensure that professionals **get the information immediately** so as to react properly to the data.”*

- Ib Johansen, Department Manager of MedCom, Denmark's official health data network.

SHARING OF DATA AND BETTER PATHWAYS / 2

The models and pathways to secure person-centred care are much more developed.

*“There are more **clearly defined treatment routes** like the existing ones concerning cancer or diabetes.”*

- Per Hasvold, Section Manager, HHome care and PErsonalised health, Norwegian Centre for Integrated Care and Telemedicine.

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CONCLUSION



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# CONCLUSION

# MOVING MINDSETS – A JOURNEY BEGUN

→ **With this guide, we have travelled far.** We have seen person-centred care unfolding in different geographical settings, and looked at person-centred care from different stakeholders' points of view. So where does that leave us?

We have learned that there is a need for the person-centred approach in current healthcare systems; that different stakeholders – patients, professionals, policy makers and providers – approach and talk about healthcare in very different ways, constantly reproducing a fragmented healthcare sector; that this fragmented healthcare sector is unfit to deal with the mounting challenges that it will face in the near future; and that person-centred care is one way of coordinating and restructuring the healthcare system in line with this new reality.

We have seen that person-centred care has become an increasingly popular subject of scientific research and political initiatives. So why have we not yet arrived at our destination? Why is person-centred care not standard practice already? An important part of the answer lies with the fact that while it is easy to make small changes in structures and incentives, moving mindsets takes time.

The point of departure for changing the system is to identify the role models of the new mindset and communicate their stories. It is not possible to change the healthcare sector if we cannot imagine how it could be better.

## **But how do we move a mindset?**

The current healthcare sector is unsustainable and every projection indicates that care will get more expensive while quality will fail to improve accordingly. Faced with new challenges of greater complexity, we cannot stick to traditional methods – we need to rethink the entire system.

Albert Einstein once said that problems cannot be solved by the same mind that created them. Hence, the mindsets that will make person-centred care a reality should be our guiding stars on the journey forward. The first two destinations are clear: identifying the cases and then creating a new language to communicate them.

## **Communication is everything**

All over the world, healthcare policy makers, providers, professionals and patients partner up in new ways with amazing results. Our quest is to gather these examples from different stakeholders and different regions in the world until we have a community of front runners championing the person-centred approach. Identifying the cases is essential to proving that a person-centred healthcare sector is possible and actually already unfolding all over the world.

But identifying the best examples is not enough if the success stories are kept hidden in closed circles and silos; solutions must be communicated and shared in order for the person-centred care approach to become a success. In order to communicate, inspire and engage the varying stakeholders in a fragmented system, we need to create a new common language centred round the same approach, namely person-centred care.

Only when we succeed in gathering the most convincing cases of person-centred care and communicating the lessons learned from them, will we see a movement in the minds of those who create the healthcare sector every day.

This not only vouches for a better and more financially viable healthcare system, but also for a safer one.

On the following page, the key learnings from the cases and the patient interviews have been translated into 10 steps to promote person-centred care – key actions for decision makers to take to bring the change about.

We have embarked on a journey. It will not be easy or straightforward, but it will take us through many inspiring locations on the way to our common destination, a more quality-based, safe, economically sustainable, and person-centred healthcare sector.

**DEVELOP** a person centred culture from bedside to board – each member of an organization should routinely ask themselves how they can make care more person-centred and integrated.

10

**USE** continuous feedback from service users to rate their care and to identify and tackle areas for improvement.

9

**INVOLVE** service users as active partners in developing standards and means to assure compliance.

8

## KEY ACTIONS

10 STEPS TO PROMOTE PERSON-CENTRED CARE

**IMPROVE** safety and quality by using risk-based approaches to redesign systems and deliver services. This will enable hazards to be identified and managed at a local level before causing harm, which in turn means reducing variability, improving the service user experience and lowering costs.

7

**PROMOTE** health literacy (from individuals through communities to societies) to ensure that people have both the knowledge and the skills to manage their healthcare.

6



1

**INCENTIVIZE** what matters. Pay for the results of the full cycle of care rather than separate treatments. Use finances to drive improvements in quality and public health by moving from an emphasis on the tasks performed by providers to an emphasis on achieving outcomes in terms of sustained happiness, independence and productivity.

2

**INTEGRATE** care across specialities and providers, where it will add the most value. Healthcare is not the sole determinant of health. Care should be built around pathways that reflect the reality of service users with multiple needs rather than fragmented episodes in a hospital. Health, social care and civil society organizations should be rewarded by how well they work together in supporting individuals and communities in gaining and retaining happiness, independence and productivity.

3

**RECOGNIZE** that there is no “one way” to achieve person-centred and integrated care. The approach to establishing person-centred care in micro and meso systems in particular, must be built from the “bottom up” to meet local needs.

4

**INVEST** in and capitalize on the growth of technology (e.g. the ability to use and share increasingly large and complex data sets through cloud networks). Technology will be a key element to personalizing healthcare while achieving manageable costs across populations.

5

**FOCUS** care on ways to actively engage the individual service user rather than on diseases and physicians’ specialties. Use a dedicated team of both clinical and non-clinical staff to support the individual service user through coaching; providing counselling, education, encouraging adherence and supporting healthy behaviour.

# BIOGRAPHIES

- OF PERSONS INTERVIEWED





### ANNETTE WANDEL

Annette Wandel is Deputy Manager and Head of Quality and Policy in the patient organization Danish Patients. During the last 20 years she has worked with quality in healthcare on different levels and from different perspectives; as a supervisor in the clinical practice of physiotherapists and as a consultant in politics and quality development in healthcare from both a professional and a user perspective. She has entered a number of research and development projects and participated in a number of national projects focused on professional quality, consistency in healthcare and user involvement as focus. She is a Physiotherapist and holds a Master of Public Policy.



### ALBERT VAN DER ZEIJDEN

Albert Van der Zeijden has been an active patient advocate on national as well as international level since he was diagnosed with Crohns' disease and enkylosing spondylitis in the early 1980s. He is currently a board member of the European Health Forum Gastein, Vice President of Health First Europe and Chairman of the Dutch Steering Committee on Orphan Drugs and of the Dutch National Council of the European Disability Forum. He is also former Chairman of the International Alliance of Patients' Organizations.



### ANTONIO GAUDIOSO

Antonio Gaudio is the General Secretary of Cittadinanzattiva, an Italian non-profit consumer organization. Antonio Gaudio started his collaboration with Cittadinanzattiva in 1996 taking up the responsibility of launching the first PIT Salute: a free daily service offering information, advice and assistance to all citizens in order to safeguard their rights in the field of welfare and health, concerning both public and private facilities. He is currently a senior consultant for CSR and sustainability at the World Bank, a member of the Committee on Biotechnology and Bio Safety of the Presidency of the Council of Ministers and a member of several commissions and working groups on health in Italy and Europe.



### ANGELA COULTER

Angela Coulter is Senior Research Scientist at the Nuffield Department of Population Health at the University of Oxford, Director of Global Initiatives at the Informed Medical Decisions Foundation in Boston, and a Senior Visiting Fellow at the King's Fund. Angela Coulter has published more than 300 research papers and reports as well as several books. She was the founding editor of Health Expectations, an international peer-reviewed journal on patient and public involvement in healthcare and health policy. Her work has been awarded by the Donabedian Foundation of Barcelona in 2012 and the International Shared Decision Making Conference in 2013.



### ASTRID KRAG

Astrid Krag has been a Member of the Danish Parliament since 2007 and was Minister for Health and Prevention from 2011-14. To improve the Danish healthcare sector, Astrid Krag launched a new political health initiative that focuses on how the healthcare sector can further emphasize placing the patient at the centre of treatment through new incentives and new cohesive and integrated healthcare solutions. Astrid Krag holds a BA in political science.



### AXEL WOLF

Axel Wolf is a researcher at Centre for Person-centred Care at the University of Gothenburg in Sweden. He has a background in anaesthesia and intensive care. His research taps into different aspects of person-centred care, such as exploring the prerequisites and effects of person-centred care within a hospital setting. A current focus for Axel Wolf is the development of person-centred eHealth innovation, change-management and implementation of person-centred product-service innovations within the healthcare setting.



### INGER EKMAN

Inger Ekman is the Professor and Director of the Centre for Person-centred Care (GPCC) at the University of Gothenburg in Sweden. GPCC employs around 100 researchers from a multitude of disciplines. GPCC is funded by the Swedish Government and the University of Gothenburg. With the programme *Towards Person-Centred Care in Long-term Illness: A Research Core Centre*, Inger Ekman and the GPCC are on their way to establishing an interdisciplinary research centre with the aim of improving communication between patients with long-term medical conditions and their care-givers. Inger Ekman has authored and co-authored 100 peer reviewed articles.



### ADRIAN SIEFF

Adrian Sieff is the Assistant Director of the Health Foundation. The ambition of the Health Foundation is to inspire health services to make care person-centred, supporting people in making informed decisions about and successfully managing their own health and care. For many years Adrian has worked at the Department of Health, leading the development and delivery of policies in diabetes, mental health and reducing teenage pregnancy, as well as early thinking in the Department on Patient Empowerment and Stakeholder Engagement. He has worked for the Audit Commission, the Social Exclusion Unit and National Voices. Adrian was Vice-Chair of Tzedek, which works in partnership with local community organizations to support sustainable development projects in some of the world's poorest countries.



### JACQUELINE BOWMAN-BUSATO

Jacqueline Bowman-Busato is the Executive Director of European Platform for Patients' Organisations (Epposi), Science and Industry. Jacqueline Bowman-Busato has worked in the Brussels policy environment since 1996, both within the public and private sector. She specialises in multi-stakeholder engagement, particularly in the fields of public health and healthcare IT. Jacqueline is currently working as a change agent at Epposi, a multi-stakeholder think tank focused on bridging the gap between innovation and better health outcomes in Europe.



### IB JOHANSEN

Ib Johansen is the Deputy Manager at MedCom, Denmark's official health data network. It contributes to the development, testing, dissemination and quality assurance of electronic communication and information within the healthcare sector. He is responsible for the actual implementation of the Shared Medication Record in General Practice, for the development and dissemination of a National Laboratory Portal for professionals and citizens as well as for the e-referrals for hospital treatment. MedCom's work is essential in the transfer of patient data between different providers of care, thus enabling more continuity in care.



### JENI BREMNER

Jeni Bremner is the Director of European Health Management Association (EHMA). Within the organization, Jeni Bremner is in charge of its effort to enhance healthcare management capacity in Europe. She is responsible for setting a strategy as well as overseeing EHMA's policy work and operations across Europe working with and supporting the EHMA network of over 170 organizational members. Jeni Bremner has worked extensively with policy makers and during her time at the Local Government Association (LGA) she was in charge of health and social care, as well as services for children and young people including education and Criminal Justice.



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### MIKE SPENCER

Mike Spencer is the Assistant Director for Patient Experience at Cardiff and Vale University Health Board in Wales. He is responsible for volunteers, spiritual care services, infection prevention and control team, bereavement services, patient information and patient feedback. Mike Spencer is leading a process towards implementing person-centred care and developing a culture where the patient is being heard at The Cardiff and Vale University Health Board.



### JOCELYN CORNWELL

Jocelyn Cornwell is the Founder and Director of the Point of Care Foundation and Senior Fellow at The King's Fund. The mission of the Point of Care Foundation, building on work started at The Kings Fund in 2007, is to keep patients' experience of care high on the agenda of policy makers and boards, and to work with managers and front line staff to improve the experiences of both staff and patients. Jocelyn originally trained as a medical sociologist and ethnographer.



### NEIL CHURCHILL

Neil Churchill, Director of Patient Experience of the NHS Commissioning Board, is a patient and consumer advocate with 25 years' experience in the voluntary sector and in government work. His background is in policy development, service development and implementation, with particular focus on those most disadvantaged. Since 2007, Neil has been Chief Executive of Asthma UK, the UK's leading asthma charity, during which time the charity has secured some of its long-standing campaign goals, including quality standards, a national improvement strategy and a national inquiry into asthma deaths.



### LUCIEN ENGELEN

Lucien Engelen is the Head of the Regional Acute Healthcare Network at Radboud University Medical Center Nijmegen in the Netherlands. He also advises the Executive Board on changes in healthcare, enhancing patients' participation and he works towards participatory healthcare. Furthermore, he is the Initiator and Director of the Radboud REshape & Innovation Center in the Netherlands where they create and implement healthcare innovations in practice. He is also Founder and Curator of TEDx-Maastricht "The Future of Health", an independently organized TEDTalks event and the following TEDxMaastricht and TEDxRadboudU.



### PER HASVOLD

Per Hasvold is the Section Manager for the Homecare and Personalized Health Research Section at the Norwegian Centre for Integrated Care and Telemedicine (NST) at the University Hospital of Northern Norway. Per Hasvold holds a Master of Science degree in Physics and has worked at NST since 1995. He has been involved in user-centered and participatory design of care. Per Hasvold is currently involved in projects focusing on prevention and patient empowerment, self management, and patient pathways. He is also interested in enhancing the collaboration between different levels of health and care systems, paying special attention to how ICT can support these processes.



### RACHELLE KAYE

Rachelle Kaye is senior consultant, former Director of the Maccabi Institute for Health Services Research and former Deputy Director of the Department of Planning and Finance at Maccabi Healthcare Services in Israel. Maccabi Healthcare Services is one of four Israeli healthcare organizations operating as a full service provider of care comparable to Kaiser Permanente in the US or to the public funded healthcare systems of Scandinavia and in the UK. Maccabi Healthcare Services is reforming services with the goal of placing patients at the centre of care.



NORTH AMERICA



### ALAN MANNING

Alan Manning is the Chief Operating Officer at Planetree. The mission of Planetree is a personal mission for Alan Manning after caring for a critically ill child. After spending much time at their child's bedside in a pediatric ICU, Allan Manning and his wife started a non-profit organization supporting patients, families and care-givers, which he operates alongside his work at Planetree. Planetree has pioneered methods of personalizing, humanizing and demystifying the healthcare experience for patients and their families. Planetree has published a series of guides to patient-centred care and worked with more than 500 hospitals and other healthcare organizations around the world to help them implement patient-centred care based on the Planetree model.



### CAROLYN M. CLANCY

Carolyn M. Clancy is MD and Director of Agency for Healthcare Research and Quality (AHRQ) in the US. Dr. Clancy is a general internist and holds an academic appointment at the George Washington University School of Medicine and serves as Senior Associate Editor of the journal *Health Services Research*. She also serves multiple editorial boards, including the *American Journal of Medical Quality*. Dr. Clancy's main focus is research on improving healthcare quality and patient safety as well as reducing disparities in care associated with patients' race, ethnicity, gender, income, and education. As Director of AHRQ, she launched the first annual report to Congress on healthcare disparities and healthcare quality.



### CAROL CRONIN

Carol Cronin has over 20 years' experience in working with healthcare issues, with a particular interest in consumer health information, ageing, healthcare quality and patient safety. She is currently Executive Director of a Maryland-based non-profit organization, the Informed Patient Institute. Carol Cronin works in and around healthcare from a consumer/patient/family perspective. The Informed Patient Institute provides credible access to online information about healthcare quality and patient safety. Carol Cronin chairs the Joint Commission's Patient and Family Advisory Council, is President of a family foundation and serves on numerous other committees and task groups.



### DAVE DEBRONKART, "E-PATIENT DAVE"

In January 2007, Dave deBronkart Jr. was diagnosed with kidney cancer. During and after his illness he has been writing about his experiences on his blog; *e-PatientDave.com*. In February 2009, deBronkart was elected founding co-chair (with his physician, Dr. Danny Sands) of the Society for Participatory Medicine. At conferences and meetings e-Patient Dave is a frequent speaker about the "e-Patient" movement, also referred to as "patient engagement" and "participatory medicine". His compelling TEDx Talk "Let Patients Help" is in the top half of most-watched TED talks of all time. He is also author of the book: "Let Patients Help".





### DAVID BLUMENTHAL

David Blumenthal is the President of The Commonwealth Fund, a US based philanthropic foundation engaged in independent research on health and social policy issues. Blumenthal received his Undergraduate, Medical, and Public Policy degrees from Harvard University and completed his residency in internal medicine at Massachusetts General Hospital. From 2009 to 2011, he served as the National Coordinator for Health Information Technology, in charge of building an interoperable, private, and secure nationwide health information system while also supporting the widespread, meaningful use of health IT.



### SAUL WEINER

Saul Weiner is Professor in Medicine, Paediatrics and Medical Education at University of Illinois at Chicago (UIC) and staff physician at the Jesse Brown VA Medical Center. His primary research interest is focused on exploring and identifying ways to improve how physicians individualize treatment decisions. He has developed the concept of “contextual errors” to describe medical errors that result from failures to identify or take into account factors in patients’ lives and circumstances that are relevant to their care. Dr. Weiner also conducts research on access to care.



### DURHANE WONG-RIEGER

Durhane Wong-Rieger is the President and CEO of the Institute for Optimizing Health Outcomes in Canada and Chair of the Board of International Alliance of Patients. She is also President of the Canadian Organization for Rare Disorders and Head of Consumer Advocare Network, a national network that promotes patient engagement in healthcare policy and advocacy. Durhane Wong-Rieger has conducted training, workshops, and evaluation for patient groups in Canada and internationally on all aspects of patient engagement and advocacy. She has served on numerous health policy advisory committees and panels.



### JULIE GINN MORETZ

Inspired by her son’s battle with heart disease, his multiple heart surgeries and a heart transplant, Julie Ginn Moretz describes herself as a “professional parent” and has spent the better part of her career as a family leader passionate about improving healthcare for patients and families. She is the Associate Vice Chancellor for Patient- and Family-Centred Care at the University of Arkansas for Medical Sciences in Little Rock, where she has overall institution leadership responsibility for the development of clinical and academic programs related to patient- and family-centred care.



### ROBERT SMITH

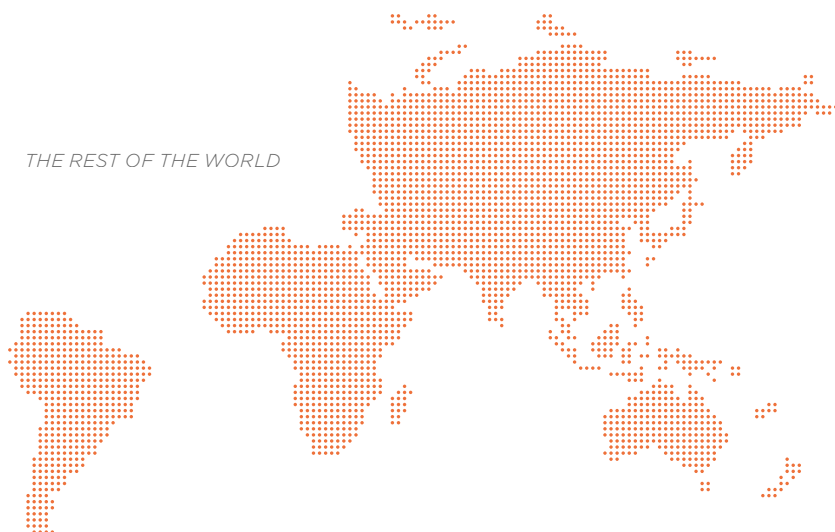
Robert C. Smith, MD is a Professor of Medicine and Psychiatry who does research in patient-centred care at Michigan State University in East Lansing. His focus is on the patient-centred conversation between doctor and patient. He and his colleagues were the first to systematize and define the patient-centred interview. Dr. Smith and his colleagues have written one of the most popular textbooks on interviews, *Smith’s Patient-Centered Interviewing: An Evidence-Based Method*, used in medical schools in the US to teach future professionals the art of interviewing and establishing the doctor-patient relationship, thus supplementing the qualifications of professionals.



### KAREN B. DESALVO

Karen B. DeSalvo is the Health Commissioner of New Orleans City and serves as Senior Health Policy advisor to the Mayor. Her responsibilities include leading the Health Department, whose mission it is to protect and promote the health of New Orleanians. Dr. DeSalvo has 20 years’ practice, research and policy experience aimed at improving access to quality, affordable community healthcare for all. Dr. DeSalvo has been a leader in health sector recovery and healthcare reform efforts since Hurricane Katrina. Part of this work includes the development of nationally award winning models for neighborhood-based care for low income, uninsured and other vulnerable populations.

THE REST OF THE WORLD



**ANAYDA PORTELA**

Anayda Portela is a Technical Officer in the Department of Maternal, Newborn, Child and Adolescent Health at the World Health Organization in Geneva. As a public health expert with over 20 years' experience in planning, implementation and evaluation of Reproductive-Maternal-Newborn-Child Health strategies at global, regional and national level, She has extensive knowledge in designing and leading implementation of health promotion and community-based programmes. Particular areas of focus include ensuring access to care for underserved populations and ensuring the participation of women and communities in the design of programmes and services. In order to achieve this, she has specialized in bringing together different stakeholders such as representatives of governments, health services, NGOs, local leaders, academia and international partners.

**ASFANDYAR K NIAZI**

Dr. Asfandiyar K. Niazi works at the Shifa College of Medicine in Islamabad in Pakistan. He is co-author of the paper *Patient Centred Care in Diabetology: an Islamic Perspective from South Asia* which focuses on the special need for person-centred care in Muslim communities.



**LEE CHIEN EARN**

Lee Chien Earn is CEO of Changi General Hospital (CGH) in Singapore. CGH is partnering with other healthcare providers in the region to improve care for patients. Dr Lee Chien Earn was previously Deputy Director of Medical Services for Healthcare Services and Performance in the Ministry of Health, Singapore. A veteran in the healthcare industry, his past appointments include Head of Health Services Finance at MOH and Director of Corporate Affairs at Singapore General Hospital. Dr Lee was awarded the Public Administration Medal (Silver) in 2011.



**MANASH P. BARUAH**

Manash P. Baruah is the Editor-in-Chief of the *Journal of Medical Nutrition & Nutraceuticals*. He is also the Director and Consultant Endocrinologist at the Excel Centre (a unit of Excel Care Hospitals) in India. He is co-author of *Patient-Centred Approach To Diabetes Management: The Dawn Philosophy*, which discusses the DAWN programme, which focuses on supporting diabetes healthcare professionals in adopting new person-centred treatment strategies through facilitation of training programs, insights as well as practical tools and strategies.





### RAKESH KUMAR SAHAY

Dr. Rakesh Kumar Sahay is Professor of Endocrinology at Osmania Medical College and Hyderabad and Consultant Endocrinologist at Sahay's Endocrine and Diabetes Centre. Furthermore, he is Secretary of South Asian Federation of Endocrine Societies and Associate Editor for the Indian Journal of Endocrinology & Metabolism. Has co-authored the article: *Patient Centred Approach To Diabetes Management: The Dawn Philosophy*.



### SANJAY KALRA

Sanjay Kalra is an endocrinologist and serves as Consultant & Head of Bharti Research Institute of Diabetes & Endocrinology at Bharti Hospital in Karnal, India. Awarded the DAWN International Award in 2009. Executive Editor of the Indian Journal of Endocrinology & Metabolism and Journal of Social Health in Diabetes. He has authored numerous editorials and reviews on the usage of patient-centred care in diabetology and endocrinology practices.



### RINCHEN PELZANG

Rinchen Pelzang is a doctoral student at the School of Nursing in Deakin University, Melbourne Australia. He worked as a Registered Nurse Midwife and Mental Health Nurse under the Ministry of Health at the Government of Bhutan for the past 17 years. As a nurse, he wanted to bring changes to the healthcare system in Bhutan in order to further patient-centred care and patient safety. He carried out several studies with a particular focus on patient-centred care, mental health and religious care of patients and families and published several articles in national as well as international journals. He is currently working on patient safety issues and risk management strategies in hospitals in Bhutan as part of his doctoral dissertation and thesis.



### SHAMS B. SYED

Dr. Shams Syed, Programme Manager, African Partnerships for Patient Safety, World Health Organization. Syed currently oversees African Partnerships for Patient Safety, based at WHO Headquarters in Geneva and has led the development of this innovative program since its inception in 2008. He assumed responsibility for global partnership development at WHO Patient Safety in early 2013. Syed is a US Board Certified Preventive Medicine Physician with a background in primary care and public health in the UK. He has a focused academic interest in reverse innovation in global health systems. His previous experiences include: involvement in a multi-country health systems research consortium; working at PAHO with seven Caribbean countries on strengthening surveillance systems; and working as the Advisor on Family & Community Health at the WHO Country Office in Trinidad and Tobago.



### SENGA PEMBA

Professor Senga Pemba is Director of the Training Centre for International Health based in Ifakara, Tanzania. Additionally, he has worked at various levels within the Tanzanian Ministry of Health and Social Welfare, Ugandan Ministries of Education and Health, College of Health Sciences at Moi University in Kenya and numerous Human Resource Development Projects in various countries. Professor Pemba is a member of a WHO Human Resource Expert Group (African Region) formed in Benin in 2003. At the Tanzanian Training Centre, Pemba has worked to develop models of excellence in training health professionals especially clinicians. Other engagements include the ongoing effort to upscale the training of health personnel in patient-centred care using the patient centred TB treatment as a model.



### YANG JINGQING

Yang Jingqing received two PhD degrees from the University of Sydney and University of New South Wales respectively. He is a Senior Lecturer in China Studies at the University of Technology, Sydney. His research areas include Chinese healthcare, welfare policies and politics. He is currently working on a project investigating the policies and implementation of patient-centred healthcare in China. Yang Jingqing has written a paper on patient-centred care in China, *The Side-Effects of China's Patient-Centred Healthcare Reform*.



### YUNAN CHEN

Yunan Chen is Assistant Professor in the Department of Informatics at the Donald Bren School of Information and Computer Sciences and the Institute for Clinical and Translational Science at the University of California in Irvine. Yunan is interested in designing and evaluating interactive systems to support information practices involving patients. In order to do so, she studies the documentation, communication, use, and reuse of health information in patient care processes. Yunan graduated with a Ph.D. from the iSchool at Drexel University in 2008 and a Medicine Degree from China Medical University in 2003.



### YONGYUTH PONGSUPAP

Yongyuth Pongsupap is a senior expert at the National Health Security Office, Thailand. His specific task is to work on the dissemination of family practice models throughout the country. He was assigned to work as a "self-styled family doctor" in a health centre in the Ayutthaya Province in 1991. This health centre has been considered the first demonstration health centre for a new approach to quality primary care in Thailand. Yongyuth Pongsupap has written several articles about health-care and person-centred care.



# WHO'S BEHIND THIS PUBLICATION

## Monday Morning / Sustainia

Sustainia is an innovation platform where companies, NGOs, foundations and thought leaders come together in creating a tangible approach to sustainability. With a focus on ready and available solutions, Sustainia's mission is to mature markets and sectors for sustainable models, products and services. The work of Sustainia equips decision makers, CEOs and citizens with the solutions, arguments, visions, facts and network needed to accelerate a sustainable transformation in sectors, industries and our everyday life.

The concept of Sustainia is developed by the Scandinavian think tank Monday Morning, in a collaborative effort with global companies and foundations, organizations and experts. Since 1989, Monday Morning has addressed megatrends in our society: sustainability, healthcare, welfare, and financial systems, to name but a few. On a national and international level, Monday Morning works for an innovative society where old barriers between sectors, institutions and leaders are torn down in a mission to locate shared solutions to common challenges. Monday Morning publishes numerous publications including a weekly magazine.

## DNV GL

Driven by its purpose of safeguarding life, property and the environment, DNV GL enables organizations to advance the safety and sustainability of their business. DNV GL provides classification and technical assurance along with software and independent expert advisory services to the maritime, oil & gas and energy industries.

It also provides certification services to customers across a wide range of industries. Combining leading technical and operational expertise, risk methodology and in-depth industry knowledge, DNV GL empowers its customers' decisions and actions with trust and confidence. The company continuously invests in research and collaborative innovation to provide customers and society with operational and technological foresight. DNV GL, whose origins date back to 1864, operates globally in more than 100 countries with its 16,000 professionals dedicated to helping their customers make the world safer, smarter and greener.

## DNV GL Strategic Research & Innovation

The objective of strategic research is to enable long term innovation and business growth in support of the overall strategy of DNV GL through new knowledge and services. Such research is carried out in selected areas that are believed to be of particular significance for DNV GL in the future.

## Our Commitment

DNV GL will seek out the best practices in risk thinking to support the further development of high quality, person-centred care. We welcome the opportunity to work with others to make this vision a reality for all. To learn more about our work or to establish a collaboration, please visit us at: [www.dnvgl.com/patientsafety](http://www.dnvgl.com/patientsafety)

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