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# Smart governance for health and well-being: the evidence





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# **Smart governance for health and well-being: the evidence**

Edited by:

Ilona Kickbusch, Director, Global Health Programme, Graduate Institute of International and Development Studies, Geneva, Switzerland

*and*

David Gleicher, Project Officer, Global Health Europe, Graduate Institute of International and Development Studies, Geneva, Switzerland

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# Abstract

Governance for health describes the attempts of governments and other actors to steer communities, whole countries or even groups of countries in the pursuit of health as integral to well-being. This study tracks recent governance innovations to address the priority determinants of health and categorizes them into five strategic approaches to smart governance for health. It relates the emergence of joint action by the health and non-health sectors, public and private actors and citizens, all of whom have an increasing role to play in achieving seminal changes in 21st century societies. The chapters presented here were initially commissioned as papers to provide the evidence base for the new European policy framework for health and well-being, Health 2020. Calling for a health-in-all-policies, whole-of-government and whole-of-society approach, Health 2020 uses governance as a lens through which to view all technical areas of health.

## Keywords

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## Foreword

*As our societies change and face new challenges, they need to revisit approaches to governance. My goal as WHO Regional Director for Europe is to ensure that health is positioned as an overarching goal shared by the whole of government and the whole of society. That is why the WHO Regional Office for Europe commissioned a study on governance for health in the 21st century.*

*Mind-sets on how we view and address health and its determinants have shifted. Two challenges go hand in hand:*

- *the governance of the health system and health systems strengthening (what we refer to as health governance); and*
- *the joint action of health and non-health sectors, the public, private sector and citizens in common interest (what we call governance for health).*

*The latter is the subject of this study.*

*As WHO's constitution makes clear, governments have a responsibility for the health of their people. Ministries of health have a strong leadership role to play, particularly in providing evidence for policies that make the healthier choice the easier choice. But living in a knowledge society means that power and authority are no longer concentrated in governments. Informed citizens, conscientious businesses, independent agencies and expert bodies increasingly have a role to play. The health system alone does not have the tools to solve all our health challenges; the highest levels of government and society must recognize that health is a common objective and that achieving it requires coherence.*

*The governance for health in the 21st century study informed the WHO European policy framework for health and well-being, Health 2020. This book provides access to background papers for the study prepared by eminent experts, which provide further detail on the issues raised, and culminates in a comprehensive depiction of what constitutes smart governance for health in the 21st century, based on examples and insights from the book.*

**Zsuzsanna Jakab**

WHO Regional Director for Europe





## Contributors

### Editors

**Ilona Kickbusch**, a political scientist with a PhD from the University of Konstanz, Germany, is recognized throughout the world for her contribution to health promotion and global health. She is currently Adjunct Professor at the Graduate Institute of International and Development Studies, Geneva and Director of the Global Health Programme. She advises organizations, government agencies and the private sector on policies and strategies to promote health at national, European and international levels, has published widely and is a member of a number of advisory boards in academic and health policy arenas. Her career with WHO at regional and global levels is long and distinguished and includes initiating the Ottawa Charter for Health Promotion and a range of settings projects, such as Healthy Cities.

**David Gleicher** is Senior Programme Manager at the World Economic Forum, where he is responsible for all science and technology-related sessions at the Forum's annual meetings in Davos and China. He has held research positions in the Forum's global risks and scenario-planning teams and managed the work of the Forum's global agenda councils on personalized and precision medicine, and space security. Prior to joining the Forum, he worked in WHO's offices at the European Union and for Global Health Europe.

### Authors

**Edward Andersson** (Chapter 3) works for, and helped set up, the Involve Foundation, a British think tank specializing in participative decision-making. He helped set up Participationcompass.org – one of Europe's public engagement sites – and has advised a number of organizations on public engagement strategies. He is a professional facilitator (certified by the International Association of Facilitators) and a board member of the international not-for-profit e-Democracy.org.

**Anders Diseberg** (Chapter 4) has an MSc in Biotechnology from Chalmers University of Technology and is enrolled in the transdisciplinary Master's programme, Ecosystems, Resilience and Governance, at the Stockholm Resilience Centre, Stockholm University, Sweden. He is an intern at the Medical Management Centre, Department of Learning, Informatics, Management and Ethics, Karolinska Institute, Stockholm.

**Armin Fidler** (Chapter 5) is Lead Adviser, Health Policy and Strategy, Global Health Practice at the World Bank Group, Washington DC, United States.

**Eva Jané-Llopis** (Chapter 6) has a PhD in Health Sciences from the University of Nijmegen, Netherlands. She has held several senior positions in the Netherlands, the WHO Regional Office for Europe, the Government of Catalonia, Spain and the European Commission. She is currently Director, Head of Health Programmes, World Economic Forum, Geneva.

**Maged N. Kamel Boulos** (Chapter 7) is Associate Professor of Health Informatics at Plymouth University, United Kingdom. In addition to his medical degree and Master's in Dermatology, he holds a Master's in Medical Informatics from King's College, University

of London and a PhD in Measurement & Information in Medicine from City University London. He teaches and has over 100 publications on a specialist range of medical/public health informatics topics. He is the founder and Editor-in-Chief of the MEDLINE-indexed *International Journal of Health Geographics*.

**Bartha Maria Knoppers** (Chapter 2) is Professor and Director of the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, McGill University, Montreal, Canada. She is a graduate of McMaster University (BA), University of Alberta (MA), McGill University (LL.B, BCL), Cambridge University (DLS) and Sorbonne, Paris (PhD). She was admitted to the Bar of Québec in 1985.

**David McQueen** (Chapter 8) is Senior Biomedical Research Scientist and Associate Director for Global Health Promotion, the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, Georgia, United States.

**Vural Özdemir** (Chapter 2) is Vice Dean, Faculty of Communications and Adviser to the President on International Affairs and Global Development Strategy, Office of the President, Gaziantep University, Turkey. He is a transdisciplinary scholar in anticipatory technology governance and foresight, innovation ecosystem design and science diplomacy and Editor-in-Chief of *OMICS: a Journal of Integrative Biology* (New York, United States).

**Jessica Påfs** (Chapter 4) has a Master's degree in Medical Science in Global Health from the Karolinska Institute, Stockholm, Sweden. She is temporary Research Assistant, Division of Global Health in the Department of Public Health Sciences at the Institutet and is now a PhD student at Uppsala University.

**Olivier Raynaud** (Chapter 6) is Senior Director and Head, Global Health and Healthcare Industries, World Economic Forum, Geneva, Switzerland.

**Tünde Szabó** (Chapter 5) is a Senior Health Economist at the European Investment Bank, Luxembourg.

**Göran Tomson** (Chapter 4) is Professor of International Health Systems Research at the Karolinska Institute, Stockholm, Sweden. He is a member of the Research for Development Committee of the Swedish Research Council and a cofounder of the International Network for Rational Use of Drugs and the ReAct Network, focusing on containing antimicrobial resistance. He chairs the STAC Alliance Health Policy Systems Research and serves as a member on WHO's Expert Panel on Drug Policy and Management and the European Advisory Committee on Health Research.





## Abbreviations and acronyms

AG	anticipatory governance
BBP	basic benefits package
BSE	bovine spongiform encephalopathy
CCEE	countries of central and eastern Europe
CDC	Centers for Disease Control and Prevention (United States)
CPIA	(World Bank) Country Policy and Institutional Assessment (measure)
CSDH	WHO Commission on Social Determinants of Health
DAH	development assistance for health
DDT	dichlorodiphenyltrichloroethane
ECA <sup>a</sup>	Europe and central Asia (Region)
EU	European Union
EU15	countries belonging to the EU before May 2004
EU27	countries belonging to the EU after January 2007
eWOM	electronic word of mouth
FCTC	WHO Framework Convention on Tobacco Control
GAVI	Global Alliance for Vaccine Immunization
GDP	gross domestic product
GMOs	genetically modified organisms
GSMA	Global System for Mobile Communications Association
HiAP	health in all policies
HTAs	health technology assessments
ISO	International Organization for Standardization
IT	information technology
LMICs	low- and middle-income countries
MAP	medical assistance programme (Georgia)
MDGs	(United Nations) Millennium Development Goals
NCDs	noncommunicable diseases
NGO	nongovernmental organization
NHS	National Health Service (United Kingdom)
NICE	National Institute for Health and Clinical Excellence (United Kingdom)
NSM	networked social media
OECD	Organisation for Economic Co-operation and Development
PNS	post-normal science
QRA	quantitative risk assessment
ReAct	Action on Antibiotic Resistance
SARS	severe acute respiratory syndrome
UNAIDS	Joint United Nations Programme on HIV and AIDS
VGI	volunteered geographic information
WGIs	(World Bank) Worldwide Governance Indicators

<sup>a</sup>ECA is used by the United Nations and the World Bank. WHO refers to the European Region.



# Part 1. Introduction

# 1.

# Governance for health and well-being

Ilona Kickbusch and David Gleicher

## 1.1 Background and context

How will countries wish to define success as the century progresses? In a time of fiscal crises and shifting demographics, when economic growth is far from guaranteed, it becomes evident just how much nations will be shaped by the health of their populations. People, with their potential and capabilities, are the key resources of knowledge societies: investment in their health and education is critical. Societies' success should be measured in terms of citizens' health and well-being and their quality of life. In such a perspective, health is not only relevant to many areas of society and policy, but also becomes a defining factor of good governance.

Governance reflects how governments and other social organizations interact, how they relate to citizens and how decisions are taken in a complex world. This book argues that the main changes in governance at the beginning of the 21st century are also manifesting in relation to health and its governance and will be critical for achieving health gains in the decades to come. It identifies three key contextual drivers – interdependence, complexity and coproduction – and three new governance dynamics, summarized as diffusion, democratization and shared value.

The wider role of health in society tends to surface at critical points of societal change, such as the rise of the industrial society in the 19th century and the development of the European welfare state after the Second World War. Health has not only shaped the modern state and its social institutions in Europe over the past 150 years, but has also powered social movements, defined the rights of citizens and contributed to the construction of the concept of the modern *self* and its aspirations (Kickbusch, 2007).

Despite health being essential to individuals' well-being and the progress of whole societies, policy discussions too often consider it only from within the limited context of health service provision and related rising costs. This undeniably deserves serious attention. The financial stability of some health systems will be threatened to the point of insolvency over the next decade or two. Health expenditure across the countries of the Organisation for Economic Co-operation and Development (OECD) has on average exceeded the rate of economic growth by 2% annually for the past 60 years; health systems in these countries are projected to consume 13–27% of gross domestic product (GDP) by 2050 (Darzi et al., 2012). Rising costs will be compounded by the struggle to address changing population needs, acquire adequate numbers of health professionals and provide access to the best life-saving treatments and technologies.

At the same time, many countries, especially those with low incomes, still lack an effective health system and others struggle with basic health governance mechanisms, such as guaranteeing financial protection for service users. Wealthier countries must also remain vigilant in protecting universal access and addressing health inequities while introducing innovations and cutting waste. These types of concerns and central functions of ministries of health, which come under the term *health governance*, are of the utmost importance and will present key challenges for the next decade.

The focus of this book, however, is different. Its chapters explore various dimensions of what is called *governance for health* – that is, the attempts of government or other actors to steer communities, countries or groups of countries to perceive health as being integral to well-being and a key feature of a successful society and vibrant 21st century economy (WHO Regional Office for Europe, 2011).

## 1.2 Drivers of transformation

A series of long-term trends has affected overall social development and, of course, health over the last 50 years (Nye & Kamarck, 2002): globalization, marketization, the increasing power and impact of the business sector and information technology (IT). The most important trend, however, may be the rise of citizens and consumers as active participants in governance at all levels.

These trends present a new context within which societies evolve in the face of new challenges. Three key drivers of transformation are increasingly recognized as being critical within the present context and are therefore highly relevant to the development of governance for health: interdependence, complexity and coproduction. Each is part of the global transition from industrial societies to what are referred to as knowledge societies.<sup>1</sup> They are considered transformational because they are drivers of change at systems level and therefore catalyse change on a transformative scale.

### 1.2.1 Interdependence: the context for governing health has changed

Governments today operate in entirely new contexts that are, above all, dynamic, complex and interdependent,<sup>2</sup> as are the problems they have to address. Each context appears to be unique, but they are increasingly understood to have underlying patterns and interconnections that require global and whole-of-society, whole-of-government responses. The crisis in the international financial and monetary system, outbreaks such as severe acute respiratory syndrome (SARS), other health challenges (including HIV infection and AIDS), hurricanes, tsunamis and earthquakes have hit some nations harder than others, but the after-effects, often unforeseen and unpredictable, have transcended political borders, government sectors, businesses and civil society. Risks associated with damage to the Fukushima nuclear reactor in Japan have changed policy perspectives throughout the world, with the threat to human health being the main factor in the debate about controlling atomic energy production. These problems can no longer be resolved by any single government, yet it remains difficult to achieve joint commitment to resolving complex, multilayered issues of relevance to all societies.

The failure of global governance is one of the greatest risks to a sustainable future for human civilization. The World Economic Forum's annual report on global risks surveys the perceptions of a global community of experts and leaders from government, business and civil society, asking them to rate the likelihood and impact of 50 global risks and characterize the relationships these risks share with each other within a network of interconnections. The risk of global governance failure is consistently viewed in this report as the most highly interconnected of all risks (World Economic Forum, 2014).

<sup>1</sup> Knowledge societies are those in which the capabilities to identify, produce, process, transform, disseminate and use information to build and apply knowledge become the main engines behind economic growth and human development (Willke, 2007).

<sup>2</sup> Keohane & Nye (1989) state: "Interdependence' refers to situations characterized by reciprocal effects among countries or among actors in different countries. Interdependence exists where there are reciprocal – not necessarily symmetrical – costly effects of transactions. When interactions do not have significant costly effects, there is simply interconnectedness. Interdependence does not mean mutual benefit; interdependent relationships always involve costs, as interdependence restricts autonomy. It is nevertheless impossible to specify a priori whether the benefits of a relationship will exceed the costs. This will depend on the values of the actors and on the nature of the relationship."

The finding that the failure of the institutions, policies and safeguards humanity has collectively put in place would have greater systemic repercussions than any number of large-scale natural hazards is testament to how interdependent societies have become. Many of today's most pressing risks, from water-supply crises and climate change to the collapse of financial systems and food shortages, are largely products of governance's failure to create sustainability at global- or even regional-systems level.

Just as the health problems that governments confront today transcend national borders and are part of complex webs of interdependence, the separation between domestic and foreign policy agendas has also become blurred. New geopolitical constellations have a significant effect on the role and position of many countries in regional contexts and within the global arena. Many advanced economies are facing deeply rooted fiscal imbalances and have to make hard choices about health and health systems in new contexts of fiscal austerity. Health ministries do not have much bargaining power in this critical situation.

To resolve these problems, health ministries find themselves working at several levels with overlapping networks of actors who have competing agendas, be it other ministries such as foreign affairs or finance, private sector actors or civil society coalitions at home and abroad. Many international organizations and countries, however, are ill prepared for the complex processes of multistakeholder diplomacy necessary in the health arena. Health ministries are increasingly involved with ministries of foreign affairs and economic cooperation and development and with international financial bodies that now consider health as part of their so-called toolbox, because of its new relevance (Kickbusch, 2011). An additional level of power and complexity has been added for countries through the European Union (EU), as they are bound by a growing number of multilateral agreements related to health but not primarily health-focused. Other countries have been challenged through the development of trade agreements that weaken commitments to population health (Médecins Sans Frontières, 2013); most lack coherence among these many portfolios, with the health sector, on its own, frequently having insufficient power to cement commitments for a health agenda.

The economic impact of health and health security on other sectors and the whole of society is becoming increasingly evident in an interdependent world and is changing societal approaches to health. Stakeholders affected negatively by health challenges will increasingly call for governance and institutions that can respond and deliver as health gains new political and economic relevance in a knowledge society. Governments are rediscovering the extent to which health and well-being drive economic growth and prosperity (Henke & Martin, 2009).

Health in the 21st century is not only a pivotal variable for public finance, but also constitutes an essential sector of the global economy and national economies in its own right, just as it contributes to labour productivity and economic performance in all other sectors. In Germany, for example, health is the second largest industry, larger than the automobile industry: its macroeconomic importance in terms of innovation and productivity led the government to establish a division of health within the Ministry of Economic Development (Aizcorbe et al., 2008; Schneider et al., 2010). Strong arguments for investments in health have recently been put forward by a Lancet commission, which has calculated that "reductions in mortality account for about 11% of recent economic growth in low-income and middle-income countries as measured in their national income accounts" and could account for up to 24% if a broader calculation that includes the "value of additional life years" is made (Jamison et al., 2013).

The health sector's impact and capacity are also becoming relevant in relation to outbreaks of, for example, SARS, avian influenza, pandemic (H1N1) influenza and the outbreak in Europe of infection with a deadly strain of *Escherichia coli* in 2011. The economic cost of the SARS outbreak was estimated to be €7–21 billion, while the locally contained outbreak



of plague in Surat, India in 1994 was estimated to have cost €1.4 billion. The 1997 avian influenza epidemic in China, Hong Kong Special Administrative Region was estimated to have cost hundreds of millions of euros in lost poultry production, commerce and tourism (Robertson, 2003). The 2013 outbreak of avian influenza (H7N9) is reported to have cost the Chinese economy US\$ 6.5 billion (Nebhay, 2013).

### 1.2.2 Complexity: understanding of health has changed and expanded

WHO's definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946) goes beyond disease categories. It is reinforced today by a perception of health as an outcome of a wide range of political, social and economic developments and as an asset linked to individuals, communities and societies' capabilities and resources. Accepting this complexity is a key characteristic of a 21st century perspective of health and health risks.

This view is recognized in a number of ways in the world of health. Widespread tobacco use and obesity, for example, are referred to as social epidemics, so-called communicated diseases or commodity-driven pandemics because of the many factors that contribute to their spread. In terms of complexity, strategies to control such epidemics must work at many levels and their impact will reach far beyond health outcomes: they will also have economic, social and political effects and unintended consequences, a fact frequently neglected in many health-centred analyses.

Society's resilience is tested not only by systemic shocks and outbreaks, but also by challenges that have been gathering momentum for over a century. Rapid urbanization, epidemiological shifts, demographic transitions, climate change, competition for scarce natural resources, commercialization of everyday life, widening economic disparities and the integration of new technologies such as the Internet and social media into daily lives are profoundly affecting societies' health and well-being in positive and negative ways. The cumulative effects of all these developments are impossible to describe through linear logic alone. For example, there is increasing scientific evidence that speculation in commodity futures markets and the conversion of food into biofuel are driving extreme volatility in global food prices, and that this volatility was in turn a driver of the widespread hunger and social unrest that exploded in headlines in 2011 (Lagi et al., 2012).

Understanding complexity first requires that populations and leaders become more willing to consider apparent counterfactuals as potentially plausible explanations. Today's world is one in which the behaviour of options traders in Chicago, United States can unwittingly determine the availability of nutritional inputs and the resulting health and well-being trajectories of entire generations of children living in countries thousands of miles away.

Some authors have suggested that health should be understood as a complex adaptive system that results from multiple interactions and dynamic processes embedded in other complex systems. Many modern-day health problems and the complex nature of chronic diseases therefore require a systems perspective that includes understanding of the overall interdependence of all stakeholders and the social nature of risk, its equity dimensions and individual motivations. Changes at policy, organizational, community and individual levels will be required, as expressed in many health policy documents. Yet despite this knowledge and evidence, many governments have not yet opened up to innovative multistakeholder governance arrangements.

The report of the WHO Commission on Social Determinants of Health (CSDH) (2008) shows that health is itself a property of other complex systems (from employment and work to transport and housing) and that it relates to the social stages of industrialization, urbanization and globalization and, most importantly, to differential exposure to risks

and differential coping capabilities determined by the distribution of power, money and resources in society. These causes of the causes require a new approach to measurement and a new perspective of policy on equity, one that recognizes how positive health effects are achieved through other sectors with no involvement of the health sector. This is particularly true of certain fiscal measures and redistributive policies, with countries that have less social inequality also tending to have less health inequality and enjoying higher overall health status (Wilkinson & Pickett, 2009). Similarly, negative trends in population health have been seen in countries undertaking strict austerity measures (Karanikolos et al., 2013).

### 1.2.3 Coproduction: the new role of citizens and civil society

Health activism, from local action to address environmental health risks to global action on HIV infection and AIDS, access to medicines and tobacco control, has been pivotal in bringing about changes in how societies govern health and disease. Citizens changed the ways they approached health and governance as individuals, civil society communities and organizations during the 20th century. Many present-day health challenges require a unique mixture of structural and behavioural change and agency and political action. Individual choices contribute to health successes and failures, but they are embedded in socioeconomic and cultural environments.

The concept of obesogenic, which describes environments that encourage unhealthy eating or discourage physical activity, expresses this clearly and points to the interventions people must make in their lives, particularly at local level. Understanding of obesity governance is itself a result of experience gained in 30 years of tobacco control. The governance of health cannot be understood without civil society action at all levels in what Keane (2003) describes as “a vast, interconnected and multilayered non-governmental space”. This form of democratization of health is linked to new participatory features of modern democracy.

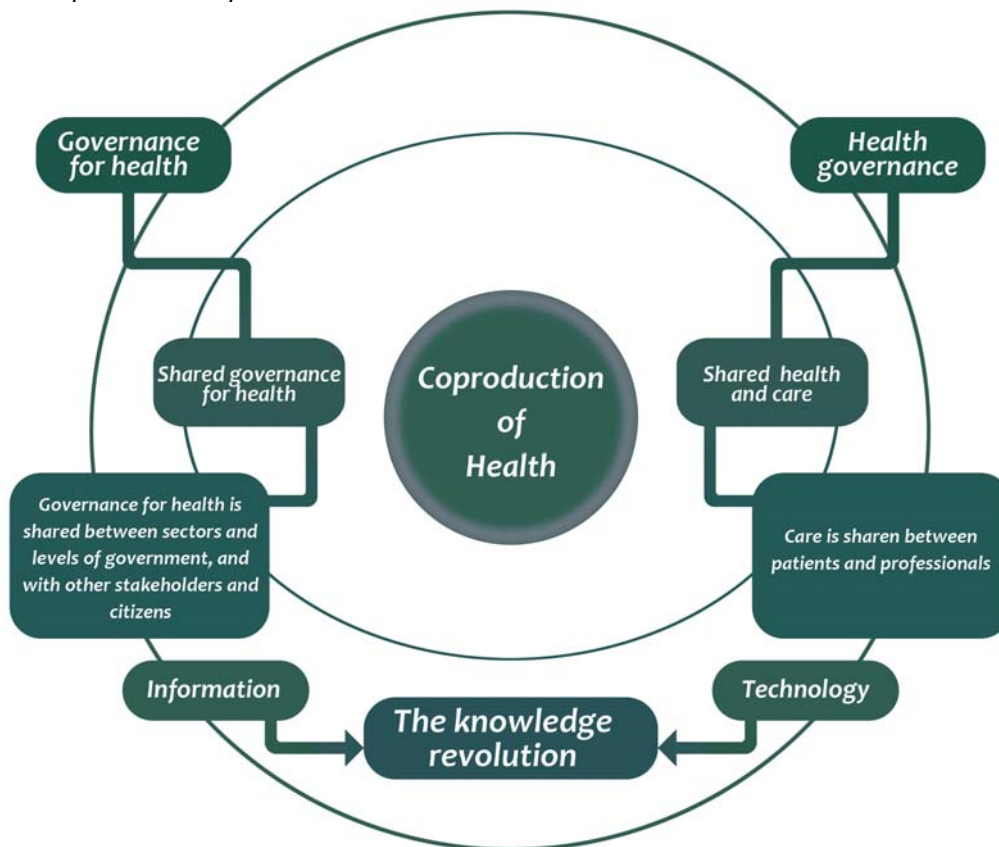
There is something inherently new about the way individuals in the 21st century, empowered by novel technologies and forms of communication, are taking charge of their health and demanding more from governments, health professionals and industry. Citizens are activists involved in the coproduction of health through engagement in two simultaneous and often interacting approaches: shared governance for health, which incorporates awareness that success requires commitment to a whole-of-government and whole-of-society approach, and shared health and care, which relates to the collaborative communicative relationships between individuals within the more narrowly defined health sector in their capacity as citizens, patients, carers, consumers or health care professionals.

Coproduction of health implies coproduction of knowledge. Governance for health must be participatory and include, but go beyond, expert opinion. People’s experience and perceptions are beginning to count in new ways. A knowledge society requires anticipatory governance (AG), which responds to uncertainty by mobilizing as many viewpoints as possible from experts and laypeople, to examine the value and power systems that shape public policies and institutions safeguarding public health and safety.

Change based on coproduction of health and knowledge is occurring in all sectors and areas of life (Fig. 1.1), in the demand for healthier food, greener technologies and cleaner streets, faster development of new medicines and treatments, and more participatory forms of health care. People can be empowered to act. Shared governance for health, the focus of this book, is both a driver of change and a response to the changing political contexts of the 21st century: it “envisions individuals, providers and institutions [working] together to create a social system and environment enabling all to be

healthy” (Ruger, 2010). The challenge for governments is to build capacity for efficient coproduction of public value in complex, interdependent networks of organizations and systems across public, private and not-for-profit sectors (World Economic Forum, 2011) and to measure the value produced in new ways that allow evaluation of societies’ movements towards greater well-being.

Fig. 1.1. Coproduction of health



Source: Kickbusch & Gleicher (2012).

## 1.3 Book structure

The three drivers – interdependence, complexity and coproduction – are mutually reinforcing and overlap to produce the context from which governance for health is emerging. The chapters explore these drivers of transformation by tracing policy innovations manifest in governance for health.

Following this introduction, Part 2 discusses changing approaches to governance in an interdependent world. Ozdemir & Knoppers explore the concept of AG for emerging technologies, a public policy method that creates incremental regulations through iterative processes between regulators and the regulated. The notion of foresight with participation is central to AG. Andersson reflects this by providing an overview of health engagement, looking at drivers of, and challenges and opportunities in, involvement of patients, service users, citizens and members of the public in public services and decision-making. Andersson outlines the transformation of participatory approaches to governance that engage individuals as patients and citizens in promoting healthier living.

Part 3 draws out the complex contexts from which governance for health is emerging. The chapter from Tomson, Påfs & Diseberg explores the multiple levels of governance, from local to global, necessary to achieve real gains for health. They use

EU tobacco control policy and the challenge of antimicrobial resistance as illustrative examples. Their chapter is followed by Fidler & Szabó, who look at the context of transitioning economies in eastern Europe, highlighting governance for health as a “missing middle piece” to the top-down and bottom-up policies driving health reforms in that region.

Part 4 features two chapters that discuss new and evolving modes for coproduction of health and governance. Raynaud & Jané-Llopis discuss how the shift in the understanding of health from being a moral issue to an economic imperative has led to new interpretations of responsibility for the creation of health and well-being in society. They outline clear principles and describe a framework for more inclusive, efficient, accountable and shared governance for health that the World Economic Forum has been implementing with its members and constituents. Kamel Boulos follows with a detailed overview of the many advances in social media and Internet-based technologies that are revolutionizing the way individuals engage with governments and health systems as patients and activists, giving whole new meaning to the notion of coproduction of health policies, services and outcomes.

In Part 5, McQueen provides a provocative discussion on the role of social values and ethics in the creation of health policy and governance for health. He raises a series of challenges for the future on the incorporation of value-driven decision-making into all aspects of governance for health, from multistakeholder collaboration to the division of resources and investment in infrastructure. Finally, Kickbusch & Gleicher lay out a comprehensive depiction of what constitutes smart governance for health in the 21st century, based on examples and insights from the book.

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## **Part 2.**

# **Interdependence**

# 2.

## From government to AG: responding to the challenges of innovation and emerging technologies

Vural Özdemir and Bartha M. Knoppers

### 2.1 Knowledge societies and innovation in the governance of science

The concept of the knowledge society has been in existence for more than two decades (Böhme & Stehr, 1986). Today, research funding and development aid agencies, policy-makers and governments promote knowledge-based innovations and the emerging technologies that enable them as key drivers of nations' prosperity (Bement, 2007; European Commission, 2011). Indeed, the Europe 2020 economic reform and growth agenda in the EU is defined to a large extent by science and technology, with research, development and innovation being one of the five EU-wide targets (European Commission, 2011; Jakab, 2011).

Data-intensive 21st century sciences such as ecogenomics, synthetic biology and human embryonic stem cell research have increased the scale and throughput of knowledge production by several orders of magnitude (Kolker, 2010; Knoppers et al., 2011; Özdemir et al., 2011a). This is evidenced by recent large-scale initiatives such as the Human Genome Project (International Human Genome Sequencing Consortium, 2001), the Sloan Digital Sky Survey (the equivalent of the Human Genome Project in astronomy: see Raddick & Szalay, 2010) and, most recently, the call for the Human Proteome Project (Human Proteome Organization, 2010).

These new forms of data-intensive science and technology, with their attendant need for global data-sharing, challenge many governance mechanisms currently in place (Kaye, 2012; Knoppers et al., 2011). They also demand an understanding of the ways in which science–technology–society are interwoven in coproduction of knowledge on a day-to-day basis (Ravetz, 1971; Bijker et al., 1987; Bijker, 1995; Yearley, 2005; Jasanoff, 2006; Barben et al., 2008; Özdemir et al., 2011b).

The focus in responding to uncertainties of science and technology future(s), however, has tended to be on expert knowledge and quantitative sciences that do not take into account the broader ways of knowing or local/tacit knowledge and human values in which science and technology are already embedded. Innovation is therefore crucial not only in science and technology, but also in new ways of knowledge production (Cook & Brown, 1999; Nowotny et al., 2003; Carlile, 2004; Fisher, 2011; Jasanoff, 2011; Wynne, 2009; Özdemir et al., 2012), governance of emerging technologies and in the way risk and uncertainty are approached. This need is felt more acutely in the current era of so-called liquid modernity (Bauman, 2000), which refers to the failure of the grand narratives of the past four centuries, such as scientific determinism, and the attendant feeling of insecurity precipitated by science and technology uncertainties.

Transformative cross-cutting technologies in 21st century science are accompanied by potential consequences for society in contexts that can be both negative and positive. Yet the rapid pace of technology development does not afford the luxury of waiting for the science to mature prior to societal and policy engagement. Uncertainties are not necessarily entirely technical in nature: policy-makers and societies increasingly have to act when facts are uncertain, values are in dispute, stakes are high and decisions urgent (Ravetz, 1987).

EU Member States and world governments are facing the need for innovation in governance to effectively respond to challenges set by scientific discoveries and emerging technologies. What kind of transformation in governance of science and technology is needed to ensure that innovations are not the problems, but rather the solutions, to the pressing health priorities affecting global society?

Governance in the health context is defined as “the attempts of governments or other actors to steer communities, whole countries, or even groups of countries in the pursuit of health and well-being as a collective goal” (Kickbusch, 2011). In the past, governance of innovations and emerging technologies (such as genetically modified organisms (GMOs)) has been reactive in nature, responding to policy crises or breaches of public trust in scientific practice (Ingram & McDonald, 2002; Knoppers, 2009). Such approaches to governance are not sustainable; they do not provide an opportunity to intervene and constructively shape science and technology innovation trajectories (Özdemir et al., 2010).

AG presents a new approach to managing uncertainties embedded in an innovation trajectory with foresight to devise mechanisms for collective steering of science and technology. In contrast to narrowly framed, purely technical predictions or downstream impact assessments for emerging technologies, AG adopts a broader approach based on collective, adaptive and iterative learning among the constituents of an innovation ecosystem. It includes in its process an understanding of upstream factors to the innovation trajectory, such as negotiation and cocultivation of the aims, motives, funding, design and direction of science and technology by experts and public(s).

This chapter introduces the concept of AG and considers its promise and the challenges it faces as a new approach to health governance. The discussion is developed against a background of extant strategies for policy-relevant decision-making in the face of uncertainty. This is timely, not only due to the development of the new European policy framework for health and well-being, Health 2020 (WHO Regional Office for Europe, 2012) and the final report of the review of social determinants and the health divide in the WHO European Region (WHO Regional Office for Europe, 2014), but also because of past governance frameworks, such as the precautionary principle, which have proven ineffective in dealing with emerging technologies like GMOs. The chapter situates AG’s application in a broader context of global health, including low- and middle-income countries (LMICs).

## 2.2 Emerging technologies and the Collingridge dilemma

Technology assessments emerged in the 1960s in business and public policy fields before being transformed into health technology assessments (HTAs) – decision-support tools for the implementation of new technologies in clinical practice – in the 1970s. Technology assessment/HTA efforts have focused on ways to keep a given technology controllable. Emerging technologies and transformative innovations present a two-pronged control conundrum known as the Collingridge dilemma (Collingridge, 1980), which holds that:

The social consequences of a technology cannot be predicted early in the life of the technology. By the time undesirable consequences are discovered, however, the technology is often so much part of the whole economics and social fabric that its control is extremely difficult. This is the *dilemma of control*. When change is easy, the need for it cannot be foreseen; when the need for change is apparent, change has become expensive, difficult and time consuming.

The first part of the Collingridge dilemma is concerned with technologies' notorious resistance to changing trajectory in later stages. A reactive approach to governance, or waiting until a technology's future trajectory is locked into a certain path before adopting it, might result in greater knowledge on social impacts, but attempts to modify the technology at a later stage become difficult as it is entrenched (a word used by Collingridge) in a complex nexus of sociotechnical, economic and political dependencies.

Collingridge borrowed in part from the classic (and often contested) linear model of innovations (Ogburn, 1922; Godin, 2006), but his observations on technology entrenchment remain pertinent today (Marris & Rose, 2010). Even the staunchest critiques of the linear model of innovations would agree that cemented beliefs and pathway dependencies pose rigid constraints to shaping an entrenched technology. Such social systems do not permit flexibility in stakeholder values for effective negotiation of science and technology policy.

The predicament of an entrenched technology is consistent with an observation made by Professor Sir Michael Marmot (Marmot, 2004): "Scientific findings do not fall on blank minds that get made up as a result. Science engages with busy minds that have strong views about how things are and ought to be".

Given the problem of technology entrenchment, a wait-and-see approach in a context of responsible innovation with emerging technologies is untenable (Owen & Goldberg, 2010). An alternative is to engage with science and technology from the outset to predict their long-term social impacts – the so-called customary response to the dilemma (Collingridge, 1980), which has taken the form of decision-analytic frameworks and quantitative predictive algorithms. Such a predict-and-control approach is not, however, without its problems. Many emerging transformative technologies, such as synthetic biology or novel applications of existing technologies (ecogenomics and metagenomics), affect diverse environmental, ecological and social systems with complex intertwined effects that cannot be predicted a priori.

Collingridge (1980) presciently acknowledged the manifest challenge of predicting long-term social impacts:

The prediction of social effects with such confidence demands a vastly greater appreciation of the interplay between society and technology than is presently possessed. I doubt that our understanding will ever reach such a sophisticated level, but even if this is possible it will only be as the outcome of many years of research. Thus even an optimistic view leaves us with the problem of how to improve the control of technology in the period needed for the development and testing of adequate forecasting methods.

Collingridge has also argued for a theory of decision-making under ignorance and uncertainty, recognizing that "a whole bundle of unknown factors" makes the task of sociotechnical prediction untenable (Collingridge, 1980). Similarly, our inability to understand the natural world is captured in the statement "prediction is very difficult, especially about the future", attributed to the physicist Niels Bohr (1885–1962).

Uncertainty about the future does not arise simply as a consequence of shortcomings from scientific descriptions of the natural world. Social factors such as human values and ways of knowing – what we choose to know and how we know it – expressly affect the production of scientific knowledge. The choice and framing of scientific hypotheses, experimental methodology and interpretation of data can each be influenced by experts' and institutions' value systems, which often remain implicit in scientific decision-making (Özdemir et al., 2009a). Consider, for example, risk analyses for environmental toxicants conducted by the United States Office of Science and Technology Policy in the 1980s, in which the neat separation of facts and values was subsequently contested (Whittemore, 1983). In other words, it is impossible to separate the knowledge and the knower (Macfarlane, 2003; Özdemir et al., 2009a).

## 2.3 Traditional responses to the dilemma

The dilemma of technology control astutely described by Collingridge (1980) has been (and still is) considered within a narrow technocratic vision guided primarily by quantitative sciences or conservative regulatory measures (such as the precautionary principle) developed to address the risk-society framework (Beck, 1992) that has prevailed, particularly in Europe. This section contextualizes two competing approaches extensively employed in the policy-making process in response to risks and uncertainties associated with emerging technologies and innovations. These responses to the Collingridge dilemma are often inadequate and ill-suited, however, especially in a context of transformative innovations and highly complex novel technologies such as synthetic biology, ecogenomics and nanotechnology.

### 2.3.1 Quantitative risk assessment

Quantitative risk assessment (QRA) was developed in the 1960s to address the governance crisis associated with the loss of public trust in science at that time, typified by the controversy around dichlorodiphenyltrichloroethane (DDT). DDT was an effective pesticide, but it had a long half-life in the environment and caused a decline in the bird population in the late 1950s due to thinning of their eggshells (Newton, 1979; Newton, 1986). QRA and related quantitative sciences subsequently emerged as a rational basis for governance of large technological systems, including nuclear power reactors, space systems, systems concerned with environmental and occupational safety, water quality and food production, and the Concorde supersonic aircraft (Ingram & McDonald, 2002; Lantos & Fuller, 2003; Apostolakis, 2004).

QRA is based on statistical calculation of probabilities associated with adverse outcomes. It emerged from industry and government insurance practices, where subscription and compensation rates are commensurate with the statistical likelihood of experiencing an adverse outcome from potentially hazardous exposures. QRA consists of:

1. identifying risk;
2. establishing a quantitative relationship between the magnitude and time-course of exposure to a hazard and the occurrence of a particular adverse outcome;
3. assessing exposure, where a given person or population is assessed for the amount and duration of exposure to a hazard; and
4. calculating risk, where steps 2 and 3 are integrated.

QRA has found acceptance, particularly in North America, as an alternative to the more conservative precautionary principle (see below) widely adopted in Europe. While it appears to offer a strong scientific remedy to managing the unanticipated societal consequences of technology and innovation, it has two notable shortcomings.

First, neither rapidly emerging technologies nor their risks are static. By the time a QRA is available, technology has already evolved to new configurations or local application contexts, meaning previous risk measures are no longer applicable. This is particularly the case in highly dynamic fields of innovation or when the social context of an innovation is rapidly changing (Özdemir, 2009). QRA assumes that innovations and scientific evidence mature and stabilize, leading to universal generalizations, an assumption that runs squarely against the inherently dynamic nature of science and technology and their sensitivity to locally situated knowledge in different contexts (Wynne, 1992a).

Second, QRA creates false binaries, such as fact/value and science/policy separations, while adopting a positivist view that science is a value-neutral autonomous activity distinctly separated from (and ostensibly uninfluenced by) social systems that shape scientific practice. This view de facto disregards the value-loaded and uncertain nature of scientific inquiry, in which social systems and institutional procedures operate with science and technology to coproduce knowledge (Jasanoff, 2006; Özdemir et al., 2011b). Indeed, coproduction occurs in all facets of scientific inquiry by humans, ranging from choice and framing of a hypothesis and experimental methodology to interpretation of data and decisions to publish (or not to publish) scientific findings.

The embedded values and the concept of coproduction of knowledge remain implicit and unquestioned in QRA and quantitative science more generally, so the robustness and sustainability of QRA findings are compromised upon diffusion to various local contexts. In addition, the misconception of the natural world and social worlds as being separate creates false confidence in QRA, resulting in loss of public trust in science (consider, for example, the Chernobyl incident or bovine spongiform encephalopathy (BSE)). Indeed, QRA predictions are continually contested because the social and natural worlds in which emerging technologies and transformative innovations evolve are also subject to rapid flux and plasticity (Özdemir, 2009).

### 2.3.2 The precautionary principle

The precautionary principle is a widely adopted (yet widely contested) strategy for management of risks associated with science and technology. The principle (or the precautionary approach, as it is framed in North America) has been deployed as a response to the alleged irreversible adverse consequences of technological change in developed and developing countries.

Principle 15 of the Rio Declaration on Environment and Development from the Earth Summit in Rio de Janeiro, Brazil in June 1992 introduced the precautionary principle, though initially as a precautionary approach (United Nations, 1992):

In order to protect the environment, the precautionary approach shall be widely applied by States according to their capabilities. Where there are threats of serious or irreversible damages, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environment degradations.

The precautionary principle fundamentally contests QRA and scientific approaches to risk analysis and management. The customary notion that scientific communities (via hard facts) instigate change in international law is turned around (Ingram et al., 2004): instead, uncertainty is addressed by law, not sciences. The precautionary principle has changed the neutral legal position towards science, creating a bias in favour of safety.

A psychological foundation based on the heuristics of fear is a key tenet of the precautionary principle (Jonas, 1985; Tallachini, 2005). According to Jonas (1985), when faced with scientific uncertainty, it is more responsible to accept the priority of fear over predictions of hope to prevent potential irreversible damage. As section 2.4 discusses in the context of AG, the principle also creates asymmetry in technology assessment by focusing on risks alone rather than risks and benefits.

Various environmental and community groups at supranational and grassroots levels have exerted pressure on countries to adopt the precautionary principle regardless of the presence or absence of scientific evidence for acute or long-term damage by technology to the environment and social systems (Tallachini, 2005; Renn, 2007). Not surprisingly, the precautionary principle has therefore found acceptance in the industrialized global north and in LMICs in the global south.



It is important to be cognizant of the origins and foundations of the precautionary principle to be clearer on how new approaches (such as AG) bring about innovation in governance. The precautionary principle has so far played a dominant role in governance of health, technology and the environment in Europe as a defining feature of an “emerging European epistemological identity in science policy” (Tallachini, 2002), but it is not innovative from the standpoint of governance or health policy-making. Most notably, it flatly ignores the value-loading of scientific facts by the social world, the importance of the values of end users of knowledge (user pull) and locally situated or tacit knowledge found in society’s adoption or rejection of knowledge-based innovations.

Perhaps most concerning is that the principle can be “institutionally evoked only by the European Commission and no legal power is granted to citizens about it” (Tallachini, 2005). Even though modified versions based on public consultation have been proposed (for an overview, see Renn (2007)), the principle remains authoritarian in practice. By contrast, shared governance and democratic engagement are essential for innovation in governance of emerging technologies and 21st century science.

### 2.3.3 Type III errors: a barrier to good governance

Relying solely on unproblematic facts or the quest for truth is unlikely to provide sustainable solutions for policy-making under uncertainty for governance challenges raised by 21st century knowledge-based innovations such as synthetic biology (Gibson et al., 2010) and personalized medicines (Özdemir et al., 2011b). Lack of recognition of the highly politicized and inherently value-laden nature of scientific inquiry presents a major difficulty. Modern-day emerging technologies and innovations require collaboration among multiple actors – universities, governments, industry and product-development partnerships – who differ vastly in their objectives, values and priorities. These complex scientific practices are examples of how the recognition of knowledge as a coproduct of science and society is particularly important. Conversely, the view of science as an autonomous activity isolated from society and stakeholder values creates what is known as a type III error that is often not recognized.

Dunn (1997) has defined this form of error as:

Assessing the wrong problem by incorrectly accepting the false meta-hypothesis that there is no difference between the boundaries of a problem, as defined by the analyst, and the actual boundaries of the problem.

In other words, type III error involves the incorrect framing of a problem, a form of upstream error in the course of scientific inquiry that in turn leads to the wrong question being answered. This contrasts with the more widely known type I (assessing as important an unimportant factor to produce false positives) and type II (assessing as unimportant an important factor to produce false negatives) errors.

Omitting to study the social context that coproduces knowledge with the natural world sets the ground for type III framing errors that can incorrectly lead to calls for more research on the wrong problem. It is necessary to make the attendant value structures transparent so they can be deliberated through an extended peer community of experts and public(s). Engagement of this kind can reduce type III errors by allowing a broader range of upstream inputs to ensure appropriate framing of research aims and directions (Kloprogge & van Der Sluijs, 2006). As an example, involving patients allowed scientists assessing treatments for rheumatoid arthritis to discover that fatigue, not pain, was the dominant symptom of concern for most patients, contrary to what the researchers had assumed (Hewlett et al., 2006). Frequent exchange between knowledge generators and end users can constructively refine an innovation trajectory (Kato et al., 2010).

Taken together, 21st century innovations demand skills of governance well beyond extant technocratic approaches based on expert opinions and sole reliance on quantitative sciences. A keen appreciation of the notion of knowledge coproduction is therefore at the heart of good governance. Not surprisingly, numerous fields of science, including medicine and computing, are increasingly recognizing that false distinctions such as fact/value or science/policy are illusory and are no longer tenable (Kernick & Sweeney, 2001). Value-loaded decisions that drive science, technology and policy require pluralistic, transparent and participatory engagement among stakeholders for innovation in health governance. The following section introduces one such potential strategy, the concept of AG with foresight, to enable innovation in governance of science and technology.

## 2.4 AG with foresight

### 2.4.1 Expertise and lay knowledge: contested and fluid boundaries

The Collingridge dilemma remains relevant for health technology assessment in developed and developing countries (Kahveci, 2009; Kolker, 2010; Marris & Rose, 2010; Özdemir et al., 2011b). Expert opinion is usually sought to forecast the innovation and technology trajectory as a response to the dilemma, but a range of uncertainties associated with specialized expert knowledge can coexist (Wynne, 1992b; Wynne, 1996; Wynne, 2009; Taleb, 2010). Some of these are listed in Box 2.1 in increasing order of uncertainty.

#### Box 2.1. Uncertainties associated with specialized expert knowledge

**Risk** refers to a situation where the system parameters and their associated probabilities are known in relation to a hazard or cognate outcome.

**Uncertainty** is when the system parameters are known, but their probability in relation to a hazard is not.

**Ignorance** is when neither the system parameters nor their odds in relation to a hazard are known – that is, unknown unknowns.

**Indeterminacy** is the case of an open system that includes a social or human agent with an entirely unchecked social behaviour that acts on technological predictions. Hazards can occur in such open systems despite expert assurances in favour of safety.

**Black Swans** are rare outlier events that cannot be predicted a priori (often they have no precedence) and consequently fall outside usual cognitive imaginative capacities and expectations, but with massive effects on society: the earthquake in Japan on 11 March 2011, for example, can be considered a Black Swan event.

Experts, by virtue of their disciplinary brackets, have an inherent tendency to develop professional blind spots or “trained incapacity” (Veblen, 1914), similar to how technologies can lock in or become entrenched (consider also type III errors explained in section 2.3.3). Events such as Black Swans, ignorance or indeterminacy fall outside the extant dominant technology discourse or the innovation master narrative. As Choi et al. (2005) state: “A scientific expert is someone who knows more and more about less and less, until finally knowing (almost) everything about (almost) nothing”. Collingridge (1980) comments:

An expert is traditionally seen as neutral, disinterested, unbiased and likely to agree with his peers. On the view proposed here, none of these qualities can be attributed. Instead, an

expert is best seen as a committed advocate, matching his opinions with other experts who take a different view of the data available to them in a critical battle.

Reliance solely on expert knowledge in relation to governance is problematic, as expertise is a highly contested and fluid construct. Experts are not necessarily value-neutral, disinterested and objective: indeed, the importance of local knowledge and context in the validation and revision (or rejection) of expert knowledge has been empirically documented in studies of radioactive contamination in the wake of the Chernobyl incident (Wynne, 1992a), governance of health effects of hazardous agricultural sprays (Irwin, 1989) and BSE (Yearley, 1992; Jasanoff, 1997). Additionally, public(s) may be “much more interested in issues of distribution, power relations, and a generic sense of fairness” (Yearley, 2000). It is interesting to note that the claims of advocacy or activist groups that are supposedly designed to protect citizens might also rely on expert opinion, with scientific measures obtained without citizen participation (see Yearley (2000)).

Efforts to broaden and complement expert knowledge are supported by the move away from the regulatory state or government to shared governance based on the idea of coevolution of science and society. Traditional governance questions such as, “Do we adopt/reject a technology, given that it is now well developed and mature?”, are being replaced with: “How can a new technology and its applications be codesigned and governed collaboratively early on, together with innovators and anticipated end users?” (Özdemir et al., 2010). This signals an upstream shift for shared (and anticipatory) governance at the technology design stage, before its applications enter society (Table 2.1).

Table 2.1. Comparative approaches to governance for science and technology

Via government	Via AG
Influenced by technological determinism	Coproduction of science, technology and society
Forecast	Foresight
Predict	Anticipate
Control technology	Steer or shape technology
Envision a singular deterministic future for an innovation trajectory	Envision possible multiplex future(s) for an innovation trajectory
Rely on expert knowledge	Rely on expert knowledge as well as public engagement and tacit/locally situated knowledge
	solicit wider debate about the implications of health products and interventions
Certainty is attainable; scientific evidence is the only authority that can justify policy action (scientism)	Need to make policy-relevant decisions under uncertainty; public policy issues have dimensions beyond technology such as social benefits and justice as well as science; uncertainty is sociotechnical
Assess impacts downstream in the innovation trajectory	Integrate technoscience and society upstream in the innovation trajectory
Adopt the so-called risk society model	Study of coproduction of knowledge by both the natural world and the social world opens up the implicit process of scientific inquiry for participatory foresight, deliberation and policy-relevant decision-making under uncertainty

Source: authors.

In relation to democratization of expert knowledge and shared governance, engaging a broad set of stakeholders with different ways of knowing creates epistemic cultures (Knorr-Cetina, 1999), which are necessary for a rich discourse on innovations. As section 2.4.2 describes, broadly constructed epistemic cultures contribute to a foundation for robust and negotiated anticipatory knowledge (Selin, 2006; Selin, 2008) in relation to plausible innovation trajectories.

## 2.4.2 Forecast is dead: long live foresight

### 2.4.2.1 Steering innovations

Individuals, groups and communities need to develop broad capacity early on to prepare for the future impacts of transformative events such as an emerging technology, health care innovation, climate change or environmental and economic crisis. Responses to these ever-present societal challenges have tended to focus on prediction or, alternatively, the creation of policies that forecast a deterministic future. Yet social events with long-lasting impacts, such as emerging health technologies, environmental change or military conflicts, are by their very nature unpredictable. Multiple possible futures commonly exist for a given innovation trajectory. The traditional predict-and-control framework by the regulatory state or government is inadequate for complex social change and transformative innovations (Miles, 2010; Quay, 2010).

Put another way: what do people do when they do not exactly know what the future holds? How can they best prepare against unanticipated effects of new technologies (including cases of ignorance, indeterminacy or Black Swan events) so that they can not only characterize them in real time, but also intervene on the innovation trajectory with new information on emerging impacts of technology in society? Governance mechanisms that recognize the ever-present uncertainty in knowledge systems and its social and technical dimensions are necessary.

Collingridge (1980) noted: “Since the future is extremely uncertain, options which allow the decision maker to respond to whatever the future brings are to be favoured”. This sentiment, articulated over 30 years ago, still resonates in the postgenomics era of the second decade of the 21st century. If prediction of the future is not feasible, the next best alternative is to closely follow the actors of an innovation system from the outset of a technology or scientific discovery (Irwin, 2008).

Because innovation future(s) are ostensibly uncertain in sociotechnical systems that coproduce scientific knowledge (Jasanoff, 2006), decision-makers ideally ought to continually monitor a technology in real time as it coevolves with society to understand the ways in which science–technology–society are interwoven in the course of an innovation (Özdemir et al., 2009b; Özdemir et al., 2011b). This provides stakeholders with flexibility and resilience to enable them to better adapt and promptly respond to whatever consequences might emerge on innovation trajectories.

### 2.4.2.2 What is foresight?

Foresight is a human cognitive capability that has existed since time immemorial (Miles, 2010), yet this fundamental aspect of cognitive creativity has not been utilized in the governance of science and technology or knowledge-based innovations. Etymological origins date to 17th century Renaissance England in the Restoration Period. The English playwright and poet William Congreve used it in his comedy *Love for love* (1694), in which the character Mr Foresight was engaged with the alleged signs and symbols of the future.

Chia (2004) defines foresight as:

A refined sensitivity for detecting and disclosing invisible, inarticulate or unconscious societal motives, aspirations, and preferences and of articulating them in such a way as to create novel opportunities hitherto unthought and hence unavailable to a society or organization.

Selin (2008), in a discussion on foresight and sociology of the future as an emerging field of study, commented:

Foresight is a means to analyse the explicit and implicit stories embraced and circulated to cope with futures known and unknown. By 'stories', I highlight from a postmodernist perspective, the difficulties about talking about a world of forces 'out there'. Instead, tacitly understood interpretative frameworks are organized into stories that characterize experience and perceptions. Foresight practices bring these stories out into the open for examination. Such stories of the future are potent sources of legitimization, inspiration, and construction in an emerging technoscience like nanotechnology.

Foresight in part depends on broadening and integrating expert knowledge with other ways of knowing, including locally situated and tacit knowledge, together with enhanced reflexivity – that is, a broad cognizance and acknowledgement of how values, beliefs and political commitments, as well as the choice of research questions and methodologies, contribute to construction of meanings from science and technology. Foresight is essential to contextualize emerging technologies and scientific discoveries over time periods extending well beyond the immediate future, such as over a course of 10 years or several decades (Giles, 2011).

#### 2.4.2.3 AG with foresight

AG with foresight has emerged in the broader context of policy-relevant decision-making under uncertainty. AG is a new approach to managing uncertainties posed by the future(s) of innovations and the prospective understanding of transformative social changes in rapidly moving and dynamic fields. With its origins in an eclectic blend of literature from the fields of future(s) studies (Bell, 1997; Miles, 2010), constructive (Rip et al., 1995; Douma et al., 2007) and real-time (Guston & Sarewitz, 2002) technology assessment, sociology of expectations, management sciences and strategic planning (Schoemaker & van der Heijden, 1992; van der Heijden, 1996; Ratcliffe, 2002) and social studies of science and technology (Barben et al., 2008), AG has recently attracted attention in diverse fields such as nanotechnology, public administration, climate change, military adaptive capacity, personalized medicine and social risks attendant to clinical trials in marginalized populations (Barben et al., 2008; Özdemir, 2009; Özdemir et al., 2009b; Quay, 2010).

A key concept underpinning AG is that the best way to definitively predict the future of a complex system is to run it, but not under *laissez-faire* conditions without engagement or monitoring. A collective and reflexive learning experience can materialize, provided a complex innovation system with embedded technical and social uncertainties is allowed to run iteratively in increments and under conditions of open access connectivity in which multistakeholder values (expert and lay), knowledge and modes of knowing are characterized transparently, deliberated and discursively fed back to the stakeholders of an innovation ecosystem.

Participatory foresight, a key ingredient of AG enabled by multistakeholder engagement (as described above), frames innovations as a shared collective learning exercise under complex contingent conditions in which stakeholders have mutual interdependencies. It builds on the principle of incremental recursive learning and explores representations of multiple possible futures in the present as perceived by a diverse set of expert and lay stakeholders. As such, it signals a shift in favour of looking at, rather than the prediction-oriented looking into, the future(s) (McGrail, 2010).



Instead of generating predictive what-if or if-then statements on the future, AG aims to understand how the future(s) are being constructed in the present (by asking, for example, which values are shaping the imaginations of the future in the present?) and how the intersection and interaction of such values/imaginings might influence innovation trajectories or result in societal transformation (such as social consensus or conflict). This allows the values embedded in future vision(s) to be made explicit and to be deliberated before a social change introduced by a technology, environmental or other crisis locks into a deterministic path. It also contributes to a foundation for anticipatory knowledge (Selin, 2008), as noted above.

The goal of AG is not to predict or forecast a single future, but to develop participatory foresight and broad capacity within society to respond to multiple possible futures. Guston (2007) describes AG as: “the ability of a variety of stakeholders, including the lay public, to prepare for the issues that [nanoscience and engineering] may present before those issues are manifest or reified in particular technologies”. As observed by Quay (2010) in the case of climate change, “rather than trying to tame or ignore uncertainty, this approach explores uncertainty and its implications for current and future decision making”.

AG underscores shared governance, the coproduction of knowledge by science and society and the inseparable nature of facts and values where both of these elements need to be made explicit and deliberated to achieve innovation in governance. It responds to uncertainty beyond traditional expert knowledge by mobilizing (through an extended peer community of epistemic cultures) local and tacit knowledge and ways of knowing to enable a more robust and enriched framing of science and technology, enabling type III errors to be minimized (Kloprogge & van Der Sluijs, 2006). This broader approach to knowledge (including, but beyond, expert opinion) permits an examination of the value and power systems that shape visions of the sociotechnical future(s).

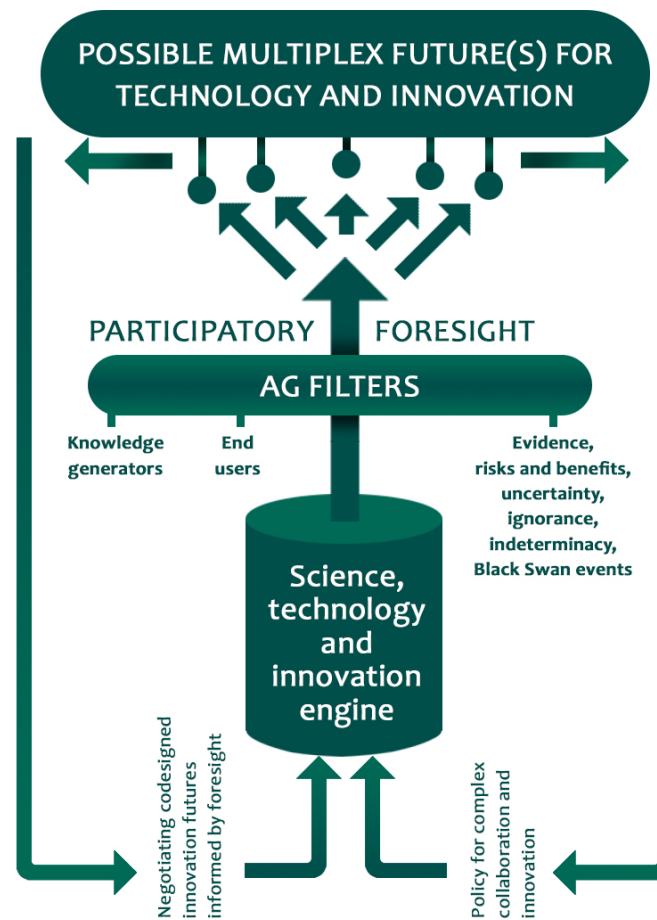
Fig. 2.1 presents a general schema for AG of science and technology with participatory foresight. Notably, several themes can be explored in the course of multistakeholder engagement between, for example, knowledge generator and end users, including the type and extent of evidence perceived to be adequate to transition a basic science discovery to the clinic, the risks and benefits of an emerging technology and attitudes towards different configurations of uncertainty. Broad engagement concerning stakeholder attitudes towards evidence is particularly timely for complex 21st century innovations. Synthetic biology, for example, may change the basic operating system of biology and ways in which molecules such as proteins are organized from their building-block amino acids. A diverse set of expectations and attitudes in relation to the appropriateness of the extant evidentiary frameworks and regulatory review mechanisms vis à vis synthetic biology is likely to emerge (Hogle, 2009).

It is interesting to note that the social construction of scientific evidence has been understudied, particularly across the emerging, highly dynamic and contested postgenomics fields of innovation such as pharmacoproteomics, metagenomics and nutrigenomics. To the extent that scientific evidence serves as an innovation filter or accelerator, examination of the sociotechnical forces that shape or construct evidence through an AG lens appears more than essential. Foresight exercises can help induce a multistakeholder collaborative transformation in such contested novel technologies to negotiate and, when possible, codesign the future(s) of innovations (among innovators and end users of innovations, for example).

This cultivates a broad capacity for scientists, funding agencies, governments and citizens to understand how the decisions they make today might affect the future, and therefore allows decision-making on innovations that are more likely to survive future uncertainties. Importantly, the AG model presented Fig. 2.1 has the novel aspect of including the social study of evidence as a construct between knowledge generators and end users.



Fig. 2.1. AG of science and technology with participatory foresight



Source: authors.

Evidence has tended to remain a so-called silent domain in past discussions about public engagement or AG, as noted above. Differences in perceptions on evidence deemed to be necessary to transition an alleged scientific discovery to societal applications are part of the sociotechnical uncertainties associated with innovations. Through iterative, continuous and real-time analysis, such sociotechnical drivers of innovations and, importantly, scenarios of multiple possible perceived imaginations of the sociotechnical future(s) by stakeholders, governments, firms or nongovernmental organizations (NGOs) can inform decisions on the suite of mechanisms (such as precompetitive collaboration regulation, licensing, intellectual property, tax credits and treaties) necessary to govern a complex innovations ecosystem.

Engagement exercises using the scenario method can help form a shared mental model of innovation trajectories among stakeholders (Ratcliffe, 2002) and, where disagreements exist, create a platform to negotiate and calibrate conflicting expectations towards the future(s) among an innovation ecosystem's constituents. The scenario method is also valuable for broadening imaginations regarding the future(s) of an emerging technology. Such enhancement of collective cognitive visions in an innovation ecosystem for multiple possible (multiplex) future(s) and their putative configurations is noteworthy: it can serve as an insurance mechanism against the technologies' notorious tendency to be entrenched or locked in a rigid course that can stall their adaptability and progression towards socially desirable outcomes. The scenario method expands the cognitive armamentarium to respond to the challenges of innovations and emerging technologies in a versatile manner.

Deployment of social science methods such as Delphi surveys, focus groups and citizens' juries from the outset of a technology can provide iterative ongoing feedback to stakeholders so that a real-time broad discussion of the innovation future(s) can be initiated and sustained over time and societal contexts. Innovative examples of public and stakeholder engagement methodologies are presented in the chapters in this book by Andersson and Kamel Boulos.

In contrast to the precautionary principle that focuses on risks, AG aims to develop capacity for understanding of, and responding to, the adverse and beneficial effects of technology and innovations. AG emphasizes coproduction of knowledge by science and society, recognizing that science is not an autonomous enterprise; it also works towards enabling coproduction through social learning that becomes possible through upstream engagement of science and society from the outset of an innovation, before cognitive lock-in develops among stakeholders.

### 2.4.3 Future promise and caveats

AG should not be viewed as a panacea for the challenges of innovations and emerging technologies, and there will probably be successive generations of AG frames. A wholesale application of AG may be neither realistic nor desirable. Adjustments will be necessary depending on the specific context (the type of technology and its present degree of entrenchment, the range of stakeholders involved and how versatile the future technology applications might be, for instance). Developing a broad capacity to respond to the uncertainties of innovation future(s) by AG nevertheless warrants attention, particularly in the case of post-normal science (PNS).

In contrast to what Kuhn (1962) called "normal science", PNS aims to address knowledge production and scientific inquiry where "facts are uncertain, values in dispute, stakes high and decisions urgent and where no single one of these dimensions can be managed in isolation from the rest" (Ravetz, 1987; see also Turnpenny et al. (2009, 2011)). Funtowicz & Ravetz (1991) termed these characteristics as PNS, while others have named similar forms of complex knowledge production processes as Mode 2 (Gibbons et al., 1994). An example of PNS is vaccigenomics, the application of genomics for directed vaccine development in public health, a field of inquiry where convergence of long-standing tensions in genomics, vaccines and public health collectively create the qualities of PNS.

Some recent examples of demands by research funding agencies to anticipate the broad impacts of proposed research – that is, at a very upstream stage at the time of the research funding application – suggest that AG may offer a way of showing how scientific practice might transform in the future towards responsible innovation (Owen & Goldberg, 2010). Despite these promises, the following caveats of AG should be born in mind; they also constitute potential focus areas for innovation in governance of science and technology.

1. While there might be some resemblance between efforts to study public understanding of science and AG, the latter has a proactive interventionist (normative) goal to feed the complex linkages between social change and technology back to stakeholders for real-time sociotechnical integration.
2. AG should be considered as an incremental, iterative and continuous approach to building capacity among a complex range of stakeholders while the innovation system is evolving.
3. Upstream engagement among stakeholders early in the course of a technology and innovation trajectory (or even at the stage of research funding application) is essential for an AG approach.

4. Steering an innovation trajectory in a sustainable manner warrants mechanisms for both acceleration and deceleration, in much the same way as a complex aerodynamic system like an aeroplane requires these qualities to take off. AG findings may at times suggest ways to accelerate the science and innovation engine, but it may also find in other contexts that momentary deceleration of a discovery engine might be prudent for long-term acceleration and multistakeholder sustainability. How could stakeholders with existing political and economic commitments (and research funders) view such recommendations as deceleration and acceleration of technology applications?
5. AG might serve as a mechanism to create a valuable real-time archive (or observatory) of technical and social aspects (such as human values) of scientific knowledge and ignorance as they emerge and evolve. Social scientists have long focused on the social construction of scientific knowledge, but there is a parallel need to examine the social construction of ignorance that contributes to type III errors. With interest in the AG of technology and scientific uncertainty in knowledge-based societies growing, sociotechnical archives can serve to trace the lineages or genealogy of scientific knowledge and ignorance in the current era of liquid modernity. They can also be creatively mined and shared as public goods in the future to inform how best to steer an emerging innovation trajectory (Özdemir et al., 2011a).
6. In relation to public engagement, the goal of such an exercise for AG should not be about pacifying public resistance or making the public(s) accept an emerging technology. By framing public responses to science and innovation as resistance or acceptance, scientific enterprise in the 20th century was quick to (incorrectly) bring to the fore the public knowledge-deficit thesis, an idea that has been contested and rejected for a long time in the social studies of science and technology (Lehoux, 2011). Instead, the scientific enterprise ought to reflect beyond a simplistic dichotomy of public acceptance or resistance to emerging technologies to focus upstream on ways in which scientific priorities and questions are framed by experts without citizen participation, and how this one-sided practice might lead to type III errors and vastly undermine the future sustainability of innovations.
7. Instead of presenting a prediction of the future, participatory foresight studies aim to understand the sociotechnical forces shaping the supply and demand of scientific knowledge and technology and facilitate frequent exchange of key strategic interactions among stakeholders. In a traditional policy environment that often demands if-then predictions of the future, however, will there be adequate funding for, and commitment by governments to act on, such anticipatory knowledge to build broad capacity for responsible innovation?
8. Social sciences have been reluctant to take on the task of studying the future. How can an empirical discipline such as sociology study a construct like the future, which has not yet materialized? How future(s) are being constructed in the present can be studied empirically using valid social science methods, with symmetries and asymmetries in stakeholder imaginations building a broad capacity to anticipate the future, but will social sciences be willing to take on the task of being social architects by studying the future(s) in the present?

## 2.5 Conclusions and the way forward

The image and framing of science as an invariably beneficial, objective, value-neutral and intrinsically ethical activity have endured since the origins of modern thought over

300 years ago. This view was immortalized by Polanyi's idea of the Republic of Science (1962) and the works of Merton (1968) throughout the 20th century (see: Guston, 1992; Tallachini, 2005; Özdemir et al., 2009a; Özdemir et al., 2011b). The need for a more intense, reflexive and open dialogue between science and society from the outset of innovations at an upstream stage, and the integration of this dialogue to actively shape the technology and innovation trajectories, sit at the core of AG. Its emergence as an approach to innovation policy firmly recognizes the politics of technology policy (Özdemir et al., 2012) and consequently symbolizes a new relationship among 21st century science, publics, governments and research funders in which "science is understood as being embedded in social and political life, rather than separated from it" (Guston, 1992).

AG does not advocate for a hollowed-out government or deregulation of science, technology and innovation, but calls for a move beyond a neat (and false) separation of fact/value and science/policy. It underscores the need to amend the self-accountable and autonomous vision of science in a deliberated and socially contextualized idea of values and choices that ultimately serves the purpose of creating socially robust knowledge-based innovations. AG makes the human values that affect science transparent and explicit, thereby creating an opportunity for their deliberation through an extended community of peers that includes experts and citizens. This reflects a general shift from government to governance in which a range of actors, governmental but also nongovernmental, play a more significant role in knowledge production than in the past (Table 2.1).

Saltelli & Funtowicz (2004) have aptly noted that uncertainty is not an accident of the scientific method, but its very substance. AG offers a mechanism to respond to uncertainty by making the coproduction of knowledge by the natural world and social systems transparent. The following excerpt from *Borderliners*, a novel by the Danish writer Høeg (1995), speaks well to the need for this openness:

That is what we mean by science. That both question and answer are tied up with uncertainty, and that they are painful. But that there is no way around them. And that you hide nothing; instead, everything is brought out into the open.

Openness is needed not only in the understanding of uncertainty in scientific output, but also in upstream elements such as how and why a research question is framed in a certain direction. In addition to such openness, health policy-makers are demanding a broader range of evidence, including that produced locally in LMICs (Pang, 2007). Combining expert opinion with tacit and locally situated knowledge and with social systems interacting with science and technology is receiving increasing attention for innovation in the governance of uncertainty (Wilson & Willis, 2004; *Nature*, 2010). This should not be seen as a threat to science, as social systems already greatly affect the entire scientific process, thereby coproducing knowledge. Science and its governance would be well served by a genuine acknowledgement of the inseparable interaction between science and the social. Conversely, scientism – the idea that scientific evidence is the only (autonomous) authority that can justify policy action – limits the impact of science on policy and good governance (Wynne, 2010).

Science will become a stronger partner for innovative governance when it moves beyond solely supplying facts to expressing the coconstitutive nature of knowledge and normative assumptions (such as values, beliefs and political commitments) that collectively define the uncertainties of, and solutions to, public policy issues. Such recognition is necessary to steer innovations and emerging technologies in a manner closely attuned to social values. In a health context, AG is a new form of reflexive governance (Bourdieu & Wacquant, 1992) which underscores that the choices we make (in health) are "political in their own right and have political consequences not only of a local but of a global nature" (Kickbusch, 2007).

While AG examines the multiple possible future(s) of science and technology, its own future as an innovation in governance is also developing. The extent to which AG with foresight may be adopted by EU Member States as a new form of governance is yet to be identified. Life sciences innovation in countries of central and eastern Europe (CCEE) has reportedly been challenged by institutional lock-in developed through years of state control and path dependencies (Huzair & Robbins, 2008). Together with the present and historically dominant role of the precautionary principle across the EU, these may turn out to be important roadblocks to adaptive and AG approaches.

On the other hand, concrete examples in which AG or adaptive governance approaches akin to it are being used in the process of knowledge creation and in responding to uncertainties associated with innovations or dynamic social changes are emerging. These governance strategies are occasionally framed under a vision to promote responsible innovation in democratic societies. For example, the United Kingdom Engineering and Physical Sciences Research Council, the largest public funder of basic innovation research in the country, has for the first time requested applicants to identify the wider potential impacts of their proposed research on nanoscience for carbon capture and utilization (Owen & Goldberg, 2010). The council in effect has moved towards promoting the AG of innovations and continuous reflexivity by researchers in the course of their knowledge creation by virtue of engagement with broad future(s) of proposed new research at an upstream stage. Nanotechnology in North America has been one of the leading areas in which the AG approach has been intensively utilized, in part led by pioneering work at the University of Arizona (see: Fisher et al., 2006; Selin, 2008; Guston, 2011).

AG is not limited to applications in the context of emerging technologies or knowledge-based innovations. Any dynamic social change, climate change or so-called wicked problem well known in the business and management science communities can be amenable to AG approaches. The Hawaii sustainability plan to 2050, for example, aims to chart a visible and lasting course for the islands over the next four decades (Hawaii Sustainability Plan Task Force, 2007). It should be emphasized in this context, however, that AG has a normative intent to influence (steer) the innovation technology well beyond describing linkages between innovations and society. This aim for sociotechnical integration in part differentiates AG approaches from previous studies of public understanding of science or impact analyses of new technologies. Studies that consider foresight-oriented activities without the aim of integration will fall short of meeting AG's overarching goals of dynamic nonlinear social changes, whether introduced by emerging technologies, climate change, economic crisis or military conflicts.

Notwithstanding the importance of the integration component, broadly framed, transparent and inclusive public engagement rests at the heart of AG, but it may not always be feasible, particularly in states where governments pose authoritarian limitations on the media, the public(s) and civil liberties more generally. The pace of technology and science is markedly faster than people's ability to grasp or map out the attendant social dimensions, so considerable work has to be done on how best to integrate technology foresight into the day-to-day fabric of scientific practice so that the innovation trajectory can be usefully amended. The chapters by Andersson and Kamel Boulos in this book suggest ways forward and concrete solutions.

These future challenges to AG aside, current governance options, QRA and the precautionary principle are vastly underpowered to meet the demands of 21st century innovations, some of which fall under the category of PNS. Action is frequently required when facts are uncertain, values in dispute, stakes high and decisions urgent. AG with foresight provides a strategy to bring about innovation in governance of science and technology for integrated and dynamic policy responses across portfolio boundaries in the coming decade, and deserves further evaluation.



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# 3.

## Engagement in health: roles for the public and patients

Edward Andersson

### 3.1 Engagement

Engagement is an umbrella term covering a broad spectrum of activities that aim to include lay people in aspects of health care decision-making, service delivery or accountability. Engagement encompasses a span of activities, ranging from patient involvement in individual treatment decisions, through patient consultation and lay membership of advocacy committees, to the lobbying of collective organizations and actions to influence health care policy-makers' decisions (Small & Rhodes, 2000).

Patient- and public-centric health policy and decision-making is a governance theme of growing importance. This chapter provides an overview of health engagement, looking at the drivers, challenges and opportunities for the involvement of patients, users, citizens and members of the public in services and decisions.

Numerous terms overlap with engagement, such as HTAs, service-led design, health scrutiny and coproduction. Involving patients in their own care is very distinct from public involvement. The multiple terms used can sometimes lead to confusion between, for example, rights-based approaches and those emerging from a more consumerist world view.

Activities that aspire to empower individual patients in their own care and structures put in place to allow the public (either as interested individuals or elected representatives) to hold health structures to account have important differences. Chapter 1 speaks of the difference between shared governance for health and shared health and care: this chapter focuses on the former.

Engagement covers widely different approaches in terms of who participates and why. Differing practices include individual-focused initiatives such as appointed expert health ombudsmen and elected lay board members, deliberative group processes (including consensus conferences and citizens' juries, in which randomly selected citizens are asked to consider issues in depth) and processes that reach thousands of people, such as surveys and consultations (Smith, 2009). A plethora of examples of good public engagement in health exists across Europe; Table 3.1 shows some that provide an overview of reasons for engaging.

### 3.2 Developments

The OECD and the WHO Regional Office for Europe have identified increased participation of citizens in health care as a key goal (OECD, 2009). International comparisons also reveal a growing interest in this topic (Coulter, 2006).

Efforts to improve public involvement in health policy and services date back to the 1970s with community health councils in United Kingdom (England) (Forster & Gabe, 2008) and WHO's early interest (WHO, 1978), but the idea of engaging and empowering citizens and service users in health has only become a truly important concept in health policy since the mid-1990s (Baggott, 2005). Engagement practice tends to be more systematic



Table 3.1. Examples of engagement in Europe

Issue	Event/initiative and country setting	Comment
Exploring public perceptions of emerging policy areas	“Testing our genes” consensus conference, Denmark, 2002	Denmark has been pioneering the development and use of deliberative engagement methods in which randomly selected members of the public engage with and assess emerging policy areas. This example asked a small group of citizens to consider how the government should relate to ethical issues related to genetic testing.
Supporting implementation of existing policies	Workshop on tobacco control, Armenia, 2007	This meeting brought together governmental and international agencies, NGOs, practitioners and researchers under the auspices of the Coalition for a Tobacco-free Armenia to discuss how civil society could support the development and implementation of the national tobacco control strategy.
Gathering public feedback on service quality	Social Support Act boards, the Netherlands, 2008 (ongoing)	The Social Support Act 2007 requires that citizens be involved by municipalities in the delivery of social care services. Many municipalities have established a Social Support Act board to provide solicited and unsolicited advice on policy in relation to the act.
Empowering citizens to assess health services	“People’s voice” project, Ukraine, 1999	The World Bank funded a project to use citizen report cards, conferences, public hearings, surveys and joint training of NGO groups and civil servants to empower citizens to hold health services to account. The civic audit method has been used in numerous European countries in recent years to evaluate the quality of health performance from citizen perspectives, led by the Italian NGO Cittadinanzattiva.
Citizens allocating funding and making spending priorities	Participatory budgeting, Seville, Spain, 2004 (ongoing)	Participatory budgeting allows citizens to make or influence spending decisions directly at city or neighbourhood level. Arising in Latin America, it has been used in France, Germany, Italy, Spain, the United Kingdom and other European countries. The process in Seville involves thousands of residents each year in making decisions about spending on health, transport, culture and many other services.

Source: author.

and advanced in western and northern Europe, with the public's culture of deference towards, and dependence on, the expertise of health professionals (particularly doctors) and the dismissive culture of professionals towards the public posing significant barriers to engagement in other parts of the world (Gagliardia et al., 2008).

Engagement growth has manifested in a number of ways. Governments are investing in engagement structures and institutions (Hogg, 2007) by, for example, funding ombudsman services, patient advocacy groups and specialist engagement institutions, such as the Danish Board of Technology and the Sciencewise programme in the United Kingdom. New structures for engagement have been set up at local level in many countries to link citizens and services across health and social care, including Local Health Watch in United Kingdom (England) and Social Support Act boards in the Netherlands. Legislation has established a new role for elected members of local authorities to scrutinize health on behalf of local people (Coleman & Glendinning, 2004), building on the power of local authority overview and scrutiny committees. Some governments have also put in place legal requirements for patients and citizens to influence health governance.

### 3.3 Concepts

Engagement appears to be an area that is likely to become more important in the future. It can be conceptualized in many different ways. Understanding the purpose, participants and timing of engagement is vital to making sense of the diverse activities taking place. It is not about identifying one approach that is better than others: rather, it is about developing an ecosystem of engagement approaches that serve different purposes and reach numerous people in varying circumstances.

One model (Jakubowski & Liste, 2006) divides public participation into three categories:

- voice, in which patient and public views are articulated through, for example, surveys, focus groups and citizens' juries;
- representation, with individuals representing patient or public views either indirectly through councillors or patient groups or directly via lay representatives and having a formal governance role on boards and other structures; and
- choice, whereby individual patients are given the ability to directly affect the health services they receive through, for example, coproduction and service-led design processes.

Engagement is undertaken for many different reasons. A useful categorization can be found in Fiorino (1990), who provides a framework of three types of benefits:

- normative (empowering citizens in agenda-setting and decision-making in accordance with their democratic rights);
- substantive (improving agendas and decisions through the inclusion of diverse views, kinds of knowledge and value and belief systems); and
- instrumental (engagement as a means of endorsing favoured decisions and outcomes, such as citizens' trust, consent and behaviour change).

The framework was developed to increase understanding of public engagement in science and technology, but is also relevant to health. Other important benefits from the academic literature, such as the so-called voice–choice dichotomy common in the United Kingdom, are also listed.

Tenbenschel et al. (2010) identify two rationales for engagement: increasing democratic legitimacy and making more intelligent policy decisions informed by better information.

Fishkin (2009) highlights the changes in public perspectives that occur due to deliberation and discussion as another benefit to individuals and governments.

Justifications for engagement occupy a continuum between democratic and consumerist models. Typically, distinctions relate to rights inherent in citizenship versus those of individual choice in the marketplace (Rogers & Robinson, 2004).

Engagement can be classified by who is included and what role they play, but differences are found across Europe in who is asked to participate and in what capacity. For example, it is useful to differentiate between public and user engagement (Coulter, 2005): public involvement is the involvement of people in their wider role as citizens in health care decision-making; user involvement relates to people in their role as current or future patients. In theory, the former is motivated by the greater good, as represented by health commissioning decisions, while the latter is taken to be more motivated by self-interest in aiming to improve services and treatment outcomes (Weale, 2006). There is no consensus on whom the public might be: they can be considered to be represented by elected representatives, randomly selected citizens, NGOs or local activists. There is also a difference between engagement in collective versus individual decisions.

Table 3.2 outlines reasons for engaging with the public and patients.

Table 3.2. Why encourage patient and public involvement?

Patients	Public
Patient engagement should be encouraged to: <ul style="list-style-type: none"> <li>• ensure appropriate treatment and care</li> <li>• improve health outcomes</li> <li>• reduce risk factors and prevent ill health</li> <li>• improve safety</li> <li>• reduce complaints and litigation.</li> </ul>	Patient engagement should be encouraged to: <ul style="list-style-type: none"> <li>• improve service design</li> <li>• determine priorities for commissioning</li> <li>• manage demand</li> <li>• meet expectations</li> <li>• strengthen accountability</li> </ul>

Source: reproduced from *British Medical Journal*, Angela Coulter, What do patients and the public want from primary care? 331(1199), doi: 10.1136/, ©2005, with permission from BMJ Publishing Group Ltd.

Distinctions go beyond the public–patient dichotomy: the issue of representation is also important. Despite the increasing ubiquity of the Internet, which has increased the potential for direct citizen engagement, it is not always possible to engage the intended participant group directly due to time, geographic or technological constraints. Representatives are often needed in these cases and they appear in many forms – political representatives, NGOs or elected lay members, for example.

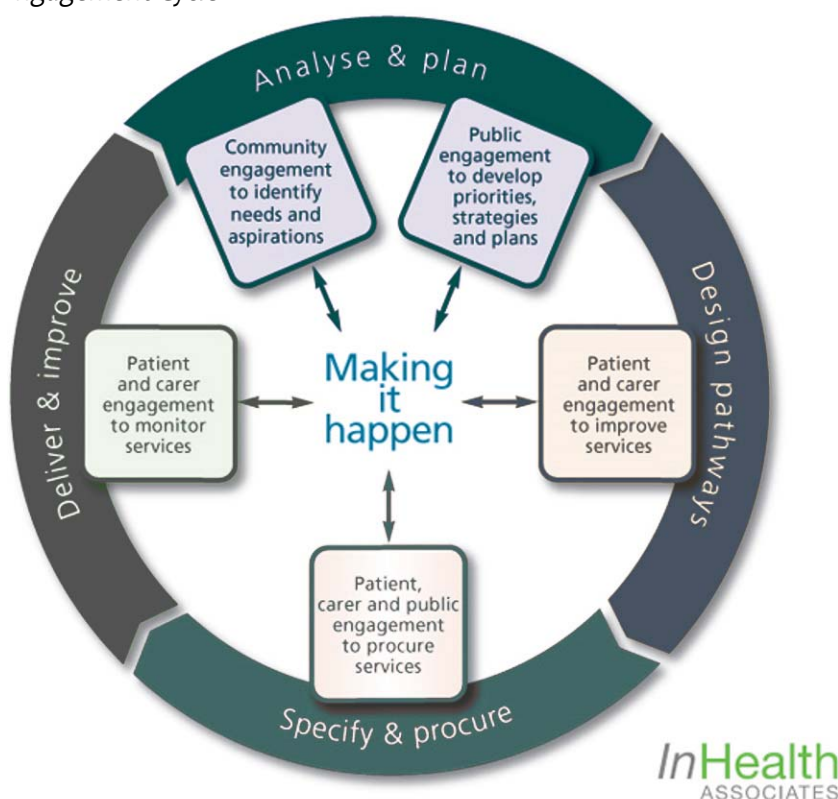
Elected representatives can play a role in acting for local people, such as in health overview and scrutiny committees in the United Kingdom. Politicians have the strength of being democratically elected and consequently have a mandate to act. Trust in representative democracy and politicians seems to be falling in many European nations, however, meaning the respect that politicians command as representatives of the public may be overestimated.

Civil society groups and NGOs can also play an important role. Representative groups (such as patient associations) straddle the divide between patient and public by being patient-focused but collective and are able to articulate and represent collective needs. Patient associations in France, for example, are represented on the boards of national health insurance funds (Jakubowski & Liste, 2006). A third option is to elect (or in some cases appoint) lay representatives, such as nonexecutive board members on foundation trust boards in United Kingdom (England) who are elected by local member schemes to

ensure that current users' views are not prioritized over those of other residents (Lewis & Hinton, 2008). These roles have the benefit of bringing people's voices into boardrooms, but have been criticized for being tokenistic and lacking adequate support (Milewa, 2004). It is hard for one individual to hold his or her own against experts without training and support; power relations can hinder genuine engagement.

Another way of understanding forms of engagement is to look at the timing of the process. Engagement will happen sometime during a decision-making, service-delivery or commissioning cycle. This will have a big impact on what role it is possible for participants to play. The Engagement Cycle, a model developed by InHealth Associates for the Department of Health in United Kingdom (England), enables engagement to be tracked across the commissioning cycle and the identification of various levels at which engagement might happen. Where a person is situated in the commissioning cycle may determine whether or not information-gathering or information-giving is appropriate (Fig. 3.1) (Department of Health, 2009).

Fig. 3.1. The Engagement Cycle



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## 3.4 Drivers

A range of drivers enhances the effect of engagement.

### 3.4.1 Decrease in deference

Professionals across Europe are finding they need to come to terms with more vocal patients and publics. Patients' traditional role as passive recipients of care delivered by doctors is increasingly being challenged (Schoen et al., 2005). As Kennedy (2001) notes:

Society is changing and involvement by proxy is no longer seen to be enough. The public are no longer prepared to be passive, trusting and grateful recipients of what is made

available. They are no longer prepared to hope that their views will be fully reflected by the professionals. That is not a criticism of professionals; it is just a reflection of the way the world has changed. Increasingly, with public services as with commercial services, the public are ready to challenge, prepared to question, and have come to expect that services will be responsive to their needs.

Health care professionals and politicians are finding engagement important in responding to increasingly educated, vocal and challenging patients. Surveys by the Picker Institute show that patient expectations of being listened to are growing (Coulter & Jenkinson, 2005).

### 3.4.2 Need for legitimacy

High-profile health care scandals (such as those linked to contaminated blood or food standards) and the resulting decline in trust in health services provide a powerful driver for increased engagement in many countries. High mortality among infants at the Bristol Royal Infirmary in United Kingdom (England) in the early 2000s and the contamination of blood products in Italy show the risks to health systems (financially and in relation to reputational damage) of being out of touch. European health systems are increasingly finding themselves under intense media and public scrutiny.

Engagement fulfils two roles in this respect: it is sometimes undertaken as a trust-building exercise after a scandal has emerged, but it can also function as a risk-minimizing strategy by improving the quality of information gathered. Post-scandal inquiries have found that effective listening to patient and public feedback could in many cases have averted the crisis (Kennedy, 2001; Francis, 2010). Engagement can therefore offer a means of eliciting feedback to identify and/or avoid scandals at an early stage.

### 3.4.3 Need to encourage behaviour change

Many health care systems across Europe are financially unsustainable in the long term due to the increasing incidence of chronic conditions and the population's ageing demographic (Lister & Jakubowski, 2008). Health care systems' financial base is under threat due to rapidly increasing costs (which are often linked to individuals' lifestyle decisions). Proposed solutions include shifting health care towards a focus on preventive care. Engagement has been highlighted as a way of motivating the public to adopt more healthy and sustainable behaviours or, where costs must rise, building popular support and acceptance of the need for an increased tax burden (Wanless, 2004).

### 3.4.4 Consumerism

Increasingly across the EU (even when health care is predominantly delivered through the public sector), health care systems treat their patients as consumers of services, giving increased importance to concepts such as choice and satisfaction and creating quasi-market solutions. In this situation, engagement functions for the public sector in the way that market research and complaints management does for the private. The rise in patient satisfaction surveys and focus groups is testimony to this development (Robinson, 2005).

### 3.4.5 Rise of rights-based focus

Engagement is also linked to the concepts of rights and voice. For some, engagement is an inalienable democratic right that enables people to influence decisions. Movements for people with long-term illnesses and disabilities have gained in strength and have sought greater influence. Disabled people's groups have demanded a say over their care under the slogan "Nothing about us without us" (Charlton, 2000). This has led to, for example, personal budgets being introduced in some countries, placing purchasing power in the hands of service users. The growing size and influence of patient groups across Europe will further extend this trend in the future. Examples include the work of Salvea Zavieti in Romania and the Movement for Public Health in Slovenia.



### 3.5 Benefits and challenges

The evidence base for the benefits of engagement is mixed, in large part because trials are difficult to carry out in this area of health policy. It is stronger for individual patient-based engagement than for collective citizen involvement (Coulter & Ellins, 2006). The body of academic evidence on the benefits of engagement is growing, although it is much harder to evaluate than traditional medical interventions.

Some reviews of engagement have found evidence or indications of better outcomes for governments, health care systems and patients. It is recommended as good practice by the United Kingdom National Institute for Health and Clinical Excellence (NICE), which found that “community engagement may have a positive impact on a range of intermediate and long-term health outcomes” (NICE, 2008).

Coulter & Ellins (2006) identified some evidence of improved quality of life, life problems and social functioning among mental health service users in engagement projects and “positive effects on service use in terms of longer time between hospital visits, reduced need for hospital admission and shorter hospital stays.” Coulter’s (2007) review found that “public involvement in service development can lead to improvements in quality and responsiveness” and that “more intensive efforts to secure lay involvement in determining priorities are more effective than traditional consultation methods”. In addition, the body of research demonstrating the positive impacts of deliberation on citizens and government institutions is growing (Barabas, 2004).

Engagement is not, however, without difficulties. It challenges professional groups’ established ways of working and structures that are often resistant to change. Health care has traditionally been an expert-dominated field and increased engagement has been resisted by some professionals (Cayton, 2004).

Studies of engagement reveal a number of problems with implementation (Gagliardi et al., 2008). Outcomes in the United Kingdom have been mixed despite a long history of promoting patient and public engagement, partly due to lack of clarity on engagement’s nature and purpose leading to confusion and squandered resources. Key challenges include limited knowledge and support from junior and senior staff, lack of resources and cultural factors (professional and public) that discourage engagement (Creasy et al., 2007).

A key determinant for success appears to be structural, with results depending in large part on the support provided by senior leaders and engagement’s position within organizations. Factors that determine sustainability include how engagement is perceived (whether it is viewed as being central to the organization as a whole or as a specialist area) and whether the focus is on short-term projects or long-term strategy (Bishop, 2006).

Issues linked to equity also pose problems, as users are not equally equipped to participate. Concrete or subjective barriers (such as confidence) can be a problem for some groups. Interventions to build user groups’ capacity and health literacy are therefore of growing importance. Countries also have different starting points: what is possible for some may not be practical for others due to institutional, cultural or political factors.

Other potential criticisms focus on the risk of engagement empowering those who already have a strong voice (Greenhalgh et al., 2010). Some have warned of a so-called postcode lottery in which benefits are unevenly distributed, with those in areas with more educated and affluent populations gaining most and what has been described as the usual suspects (those who are already vocal and influential locally) attaining



disproportionate influence (May, 2007). Many community development programmes attempt to provide the support necessary for those who most need a voice on policy to be able to take advantage of engagement opportunities.

Diverse engagement practices can lead to conflicts around legitimacy. Patient groups, politicians and individual citizens can all claim to speak for the public. Effective representation requires a clear mandate and an ongoing process of active engagement with users and the public (Abelson et al., 2004). Confusion about purpose, participants and timing undermines engagement by alienating key stakeholders and giving the public the impression that engagement is a waste of time (Andersson et al., 2005).

Some evidence suggests that public cynicism can lead to wider unwillingness to participate. Only a minority are active in engagement; evaluations have found widespread cynicism among the public and difficulties for organizations in recruiting and retaining users as participants (Rowe & Shepherd, 2002). Cynicism is fuelled by manipulative engagement and consultation: in 2007, for example, the United Kingdom High Court found that the government's consultation into the future energy mix for the country was "misleading", furthering the view that government engagement was manipulative (Lehtonen, 2010).

Recent research into what motivates people to take part has found that participation planners tend to focus solely on the benefits public sector organizations gain from engagement. This organization-centric view is problematic, as the public does not tend to define or divide the issues that matter most to them along lines that mirror the division of responsibility between individual public sector departments or bodies (Brodie et al., 2009).

As has been suggested above, professional cultural barriers also exist. Shaw & Baker (2004) state: "For ... anxious and overworked medics, the expert patient is the demanding patient, the unreasonable patient, the time consuming patient, or the patient who knows it all". Health care practitioners tend to be trained to view themselves as experts and patients as passive beneficiaries. Bureaucrats and managers can often have a similar perspective in relation to engagement, viewing it as costly and time-consuming and showing little appreciation of its benefits.

## 3.6 Future trends

Engagement still appears high on the agenda, despite economic turmoil across the world. Some sources have actually emphasized engagement's importance in controlling cost increases (Boyle et al., 2010).

Löffler (2008) highlights the fact that older age groups tend to engage more than younger people. It is likely that engagement will increase over time as the European population ages.

Growing numbers of European countries have implemented laws to define citizen engagement rights. NGOs are likely to exert ongoing pressure for this to increase over time, building their case on experience from other countries: tobacco control advocates, for instance, have used laws in other countries as an argument for further legislation in their own states. Governments will be under pressure to convert laws and regulations into reality through dedicated support structures, training and funding.

Engagement can be understood to take place on a continuum extending from information provision to empowerment, and from consultation to coproduction, delegated power and ultimate control of decisions (Table 3.3).

Table 3.3. Engagement continuum

Level of engagement	Outcome sought
Inform	To provide information to the public
Consult	To obtain feedback from the public on an issue or decision
Involve	To work together with the public to explore an issue or decision
Collaborate	To work in partnership with the public, sharing decision-making power
Empower	To place final decision-making power in the hands of the public

Source: authors.

Much engagement in health is currently limited to informing or consulting, rather than empowering or involving, citizens or patients. Some research suggests that engaging processes such as deliberative dialogue and collaborative practice provide more useful results than limited consultations (Simces et al., 2003). A shift towards engagement that hands more power to participants is possible. Participatory budgeting, which gives financial decision-making power and budgets to citizens, is one example; authorities in Hull and Southampton, United Kingdom (England) have allocated funds for community health projects in this way (Participatory Budgeting Unit, 2013) and, as was shown in Table 3.1, similar processes are underway in Seville, Spain. Commissioning decisions are also being pushed towards direct patient and public engagement rather than vague prioritization exercises.

Some authorities on engagement have started to come to grips with the idea of it being an activity that in part can be delegated to the voluntary sector. The concepts of distributed dialogue (Andersson et al., 2010) and the big society, in which the impetus for engagement comes from citizens, may become more important in the coming decade. Engagement does not have to be initiated by government on topics of their choosing; impetus can also come from citizens and NGOs. NGOs already play an important role in this regard in countries with the least formal engagement structures (often in eastern Europe), while the United Kingdom has been pursuing a move away from formal structured engagement to involving a relatively small number of people in informal activities run in community spaces, using a flexible approach to collect data when and where communities gather. This will not replace formal consultation, but is likely to complement it (Andersson & Shahrokh, 2010).

New forms of communication technology will affect engagement at numerous levels (the chapter by Kamel Boulos discusses the impacts of the Internet and social media on health services). New technologies are likely to make it easier for a large number of people to be consulted and to collaborate on an issue and will facilitate the involvement of people who have little spare time, work irregular hours or live with mobility issues. There are nevertheless limitations to what is possible using online engagement. Face-to-face engagement has particular benefits that will be difficult to replicate online and there will often be a need to provide an offline engagement alternative until access to the Internet is universal.

New cross-cutting challenges, such as climate change and the ageing society, will affect health engagement practice. These so-called grand challenges facing Europe have health aspects, meaning they can only be addressed through partnerships involving public, private and not-for-profit sectors. Engagement will not just be about health, but also about numerous related issues. Health engagement forms part of a broader trend of increased democratic engagement in many topic areas, including science and technology, environmental conflict resolution and citizenship. It cannot be understood in isolation, but must be seen as a part of a broader field of public sector reform.

## 3.7 Conclusions and recommendations

The next decade will be challenging for European health systems. Ageing populations, decreased deference towards authority figures, consumerization of public services, growth of the rights agenda, increase in the prevalence of complex chronic conditions and new technological developments will combine to make the old ways of taking decisions and delivering services increasingly unsustainable. Despite resistance in some quarters, user and citizen engagement in health care looks set to continue to rise. It is not the sole solution to all these problems, but will play a role in defining new working relationships and addressing challenges.

Engagement marks a shift in medical practice and public management. Twin challenges for the future will be how to make engagement worthwhile for all involved while supporting patients and professionals to build their capacity to involve and be involved. Research has identified positive outcomes, including heightened feelings of empowerment, better quality of life, increased satisfaction with services, improved public legitimacy of decisions, more positive health outcomes and lower health care costs.

Engagement needs to be adapted to local circumstances to reflect different starting points across Europe, but there are no so-called hopeless cases. It is more difficult in countries with top-down administrative cultures, a lack of resources and weak civil society institutions, but there are always things that can be done, starting small and scaling-up over time. This is a policy area with relevance across Europe and the rest of the world.

Engagement is a broad concept, covering individual patient coproduction, collective advocacy by patient groups, deliberative research through consensus conferences and many other approaches. Structures and processes should be seen as a series of connected ecosystems, stretching from local accountability mechanisms that link care providers to patients and the community and which in turn link to regional, national and, in some cases, international structures. This will be particularly important as provision diversity leads to more geographically dispersed provider networks.

A legal framework for engagement is important, as are support structures and adequate resourcing, but these alone are insufficient. Governments should invest in the long term, with systems being given time to establish themselves and to operate under clear mandates, frameworks and understandings set from the outset. Engagement should not be viewed as a quick fix, but as a fundamental shift in service. It should not be a job for one unit while everyone else continues with business as usual, but rather be seen as part of the work of mainstream staff (Creasy et al., 2007). Where engagement is legally required, it must be followed up, measured and enforced if it is to be meaningful.

The commitment to engagement should be mainstreamed across government and embedded in processes such as service contracting and commissioning. It needs to become entrenched as a culture.

Engagement systems at all levels must take account of different forms of marginalization. This undermines opportunities for participation by individuals such as members of minority ethnic communities, faith communities, homeless people, older people and people who are isolated by sickness or disability. Partnerships with voluntary health organizations, patient groups and local authorities provide a vital channel for empowering diverse local voices. WHO, the EU and OECD also have a role in providing weaker health care systems with advice and capacity-building support.

Gathering more information from patients and the public through, for example, surveys is in many ways the easy bit. A core challenge is to build health care systems that are able to gather and, more importantly, respond to patient and public views in a timely fashion. The idea of patient-centred institutions is popular but can be difficult to realize.

Convincing more doctors and other professionals that engagement is important and not a threat to their positions is a key area of work for the coming decade. Allowing professionals to experience engagement first hand is influential in this regard (Creasy, 2007). High-quality training and exposure to engagement theory and practice at an early stage in careers will also be important. It is perhaps fitting that one of the best ways to convince policy-makers of the relevance of participation is to have them participate themselves – there really is no replacement for this first-hand experience.

### 3.8 References

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# Part 3. Complexity

# 4.

## The challenges of multilevel governance: the impact of global and regional processes on health and health systems in Europe

Göran Tomson, Jessica Påfs and Anders Diseberg

### 4.1 Global and regional processes

Globalization is not a new phenomenon, but the increasing pace of global processes is posing new challenges and creating new opportunities. Palmowski (2008) defined globalization as “the growing interconnectedness between political, social, and economic systems beyond national or regional borders”, arguing that while the international regulation of politics and the global conduct of commerce and finance are as old as the establishment of individual states, new developments are characterized by:

- an unprecedented and ever-increasing pace of communication and information-sharing through channels such as the Internet;
- the spread of global cultures of consumerism and popular culture;
- the homogenization of the global political economy, where states organize around capitalism;
- the internationalization of domestic problems (through, for instance, migration and social movements); and
- a culture of dramatic innovation and fluctuation in the workplace, a shift that causes a great sense of dislocation as jobs and social systems become insecure.

The most obvious effects of global processes, at least in recent decades, have arguably been driven primarily by economic globalization (Woodward et al., 2001). This movement has substantially stimulated the global mobility of capital, goods, services and labour and has supported such transnational actors as multinational corporations and NGOs. The effects have extended to issues such as regulations, rights, risks and responsibilities on multiple levels (local to international) and consequently to global governance and legal agreements. Economic processes have had substantial influence on the ideological workings behind globalization, which encompass economic liberalization and relationships between policy priorities (Koivusalo, 2006). Under these conditions, globalization leads partly to the erosion of power within the state in favour of financial markets and multinational companies. This transfer of power is nevertheless contested, as states clearly have the ability to influence and control corporations not only through domestic regulation, but also with intergovernmental agreements.

### 4.2 Health, health systems and the impact of globalization

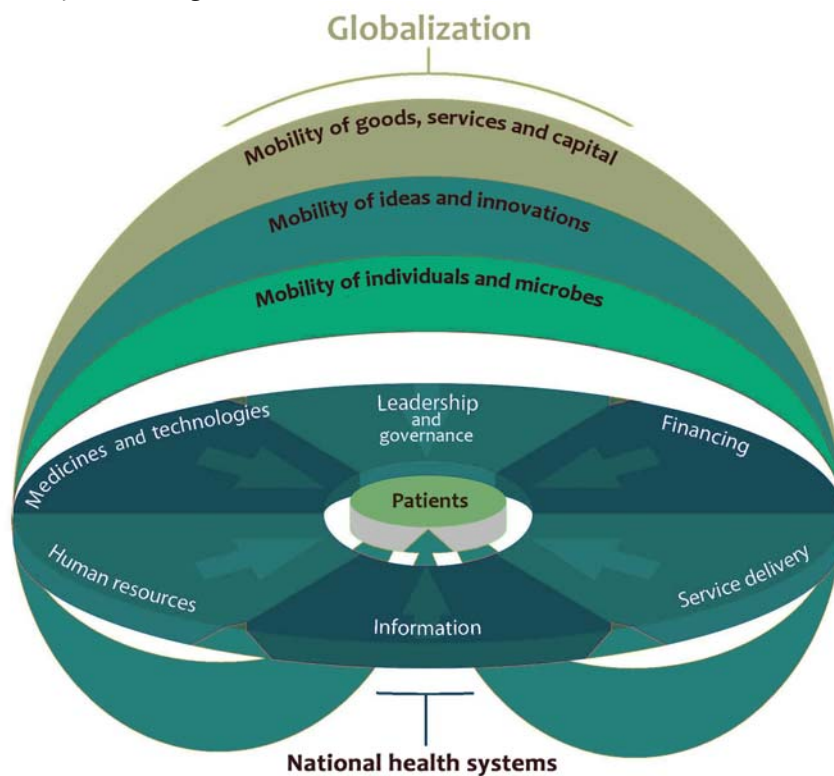
Health systems have existed for as long as people have endeavoured to protect their health. As Chapter 1 explained, WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946). WHO implicitly acknowledges through this definition the comprehensive nature of health promotion as an issue that goes beyond the health sector.

A health system constitutes the totality of “organizations, people and actions whose primary intent is to promote, restore or maintain health” (WHO, 2007) – including the

determinants of health – and whose performance is best measured by their impact on health outcomes (WHO, 2007). The complexity surrounding the basic requirements for good health nevertheless makes health status difficult to predict. Several determinants of importance for human health have been defined, such as socioeconomic status, food, water and sanitation, ecosystem functioning, human behaviour and health services (Dahlgren & Whitehead, 1991). These determinants transcend boundaries between sectors and disciplines, entailing the necessity of a governing system with a holistic approach to human health.

WHO has characterized health systems as comprising six basic layers or subsystems (service delivery; health workforce; information; medical products, vaccines and technologies; financing; and leadership/governance) working towards four overall goals: improved health, responsiveness, social and financial risk protection, and improved efficiency (WHO, 2007). This model is somewhat limiting, as health promotion and prevention tend to be underemphasized. The conceptual ecological framework presented in Fig. 4.1 incorporates these aspects but goes further to fully depict the complex nature of health and health systems. System components in this model interact dynamically, creating a complex patient-centred system influenced by, and influential of, external drivers. A thorough description of the characteristics of a well-performing health system is summarized in Box 4.1.

Fig. 4.1. Health system in a globalized world



Source: Tomson (2010) reproduced by permission of Global Health Europe.

Initiatives aiming to strengthen the performance of existing national health care systems and investigate the role played by global actors, not least in resource-poor settings, are underway. Frenk (2010) underlined the importance of having a clear concept of national health systems, seeking a more dynamic view of the role of populations and individual patients as beneficiaries and active participants. Frenk's prescription for better performance contains four elements: leadership, institutions, systems design and technologies. He emphasizes the importance of coordination of resources (human, financial and technological) through good systems design to deliver good-quality services to those in need (Frenk, 2010).



**Box 4.1. Characteristics of a well-performing health system**

A well-performing health system:

- delivers qualitative, equitable, efficient and safe medical interventions in a timely and geographically appropriate manner;
- holds a competent, responsive, fair and efficiently working health workforce to achieve the best health outcomes possible (given available resources and circumstances);
- uses an information system that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status;
- ensures equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy and cost-effectiveness;
- builds on a health financing system that raises adequate funds for health services to ensure access to appropriate health care, while minimizing the risk of financial hardship or impoverishment associated with medical expenses; and
- has a governance and leadership structure that ensures the existence of strategic policy frameworks, combined with effective oversight, coalition building, regulation, attention to system design and accountability.

Source: WHO (2007).

Having a sound understanding of the different system parts, subsystems and functions, as Frenk points out, is truly important for policy development and implementation. A growing body of literature describes interventions that attempt to render the so-called black box nature of health systems less opaque. Transferring an implemented policy from one system to another is not, however, as straightforward as one might think. A new environment inexorably introduces differences in interactions and connections.

The problem is that health cannot be compartmentalized within a society, and the environment in which the system resides is context-specific. System function does not lie so much in the parts, but in their interactions. It is therefore important to appreciate that evidence and informed system design should be seen as a starting point for ad hoc measures and not as a copy-paste solution.

Frenk's arguments for increasing health system performance are valid, with the caveat that good system design tends to implicitly convey the need for controlling individual system parts and functions through micromanagement. Such efforts tend to be counterproductive (in this case lowering system performance). It is therefore suggested that system design should focus on creating a suitable environment that can facilitate a well-functioning system that is sufficiently flexible and adaptive to readily accommodate evidence-based policy decisions.

Many tools for achieving a good health system environment are available, but promotion of basic qualities such as transparency, well-functioning institutions (rules and regulations), capacity to deal with failure and room for adaptation have proven good investments in time, finances and energy.

Traditionally, health systems and policy have been viewed as being bounded by the state, but recent decades have seen the emergence of a more global focus on health policy and management (Woodward et al., 2001). Globalization is being perceived under

increasingly comprehensive conditions (Huynen et al., 2005), meaning modern medical practice has to be pursued within the context, and under the influence, of powerful global social and cultural forces (Benatar et al., 2010). More specifically, globalization influences patient options and choice of medical interventions, patient mobility, health worker migration and the development of health innovations and technology through global economic factors. As a result, it affects not only the mobility of goods, people and capital, but also the rules and grounds on which these are regulated, creating the need for a more holistic system perspective (Huynen et al., 2005; Young et al., 2006).

Plsek & Greenhalgh (2001) apply the theory of complex adaptive systems to capture emerging and nonlinear characteristics of health systems. This approach fits well with the multilevel governance framework, as complex adaptive systems are networks of diverse, interdependent and interacting agents (such as countries, firms, NGOs and individuals) acting on local information and subscribing to different agendas (Norberg & Cumming, 2008). System components can act in unpredictable ways: their activities are interconnected, so one agent's actions set the context for others. By responding and adapting to changes in the system, agents and their interactions may create positive or negative feedbacks that have the potential to cause significant shifts in the overall system. Self-organization and coevolution, tipping points and multiple and moving equilibriums are therefore key features that lead to dynamic and unpredictable system behaviours (Norberg & Cumming, 2008). Plsek & Greenhalgh (2001) contend that health care management based on linear system models is unable to cope with the inherent complexity of health care and respond effectively to emerging problems and opportunities.

The idea of a complex system perspective also finds support in research on polycentricity by the political economist Elinor Ostrom, who received the Nobel Memorial Prize in Economic Sciences in 2009. Polycentric systems can be defined as those consisting of multiple semi-autonomous decision-making centres operating over different scales and levels (Ostrom, 2010), as in the case of municipality boards and state agencies. It has been argued that such systems promote innovation, cooperation, collective action, conflict resolution and trust among actors, increasing the potential for successful management of resources and building resilience in social-ecological systems (Dietz et al., 2003; Olsson et al., 2004; Folke et al., 2005; Ostrom, 2010).

The time is therefore ripe for critical thinkers on globalization to embrace its effects in their entirety. Applying Ostrom's work to health systems actors helps to define the complexity resulting from global processes that have been influenced over time by internal and external forces of various actors, eventually linking with each other to form potential outcomes and net costs and benefits (Young et al., 2006). The ultimate pay-off is that successful costs and benefits create longevity within the system.

Ostrom's model also finds a place for diversity and redundancy, as unsuccessful investments and failures are seen as part of the underlying practices of a successful and resilient system. In relation to health systems, demand created by the boundaries between health users and health resources become clearly defined over time and thereby offer congruence between costs and benefits. Health users at individual level in this ecological framework are entrusted to collectively make their own rules for use, but are still clearly defined within the boundaries constructed by the health system, which is also entrusted with making its own beneficial rules.

According to Ostrom, part of this system-level trust involves regular monitoring of individual use and resource utility and ensuring that resource conditions continue to create benefits (Ostrom, 1993). An ecologically driven health system would maximize conflict resolution and assume that individual (as well as large-scale) cooperation exists within common-pool resources. The complex and adaptive nature of health systems

is therefore acknowledged in spite of the individuality presented by local or national characteristics. Ostrom (1993) and Plesk & Greenhalgh (2001) conclude that to cope with the complexity of a system, one must abandon linear thinking and accept unpredictability and uncertainty, elements covered by concepts such as polycentricity and adaptive and multilevel governance in network-based management models.

### 4.3 Multilevel governance

The term multilevel governance was coined in the early 1990s to describe the emerging structure of policy- and decision-making in the EU (Bache & Flinders, 2004). It has since been applied to a number of policy areas, including environmental protection (Jordan & Lenschow, 2000) and economics (Eising, 2004). The concept is only briefly reviewed here as a complete description is well beyond the scope of this chapter.

In condensed form, the concept of multilevel governance tries to capture the notion that governance emerges from the interactions among a range of state and non-state actors operating on different jurisdictional, geographic and organizational levels and enjoying different forms and degrees of authority (Hooghe & Marks, 2003). The shift in focus from a central decision-making authority to a more fragmented network-based governance system has several implications for how governance is viewed, such as the dissemination of power and responsibility and the creation of competing and nested institutions (Dietz et al., 2003; Ostrom, 2010).

The typology of multilevel governance can be empirically analysed in two contrasting ways: as a system of relatively stable relationships demarcated by territorial borders with minimal overlap among jurisdictions in terms of policy-making, authority and responsibility; or the allocation of responsibilities according to the nature of the specific policy rather than territory, producing a more complex and integrated process (Hooghe & Marks, 2003).

One of the most important aspects of multilevel governance theory is arguably the development of a framework for analysing and understanding complex interactions among actors at (and between) different levels. From a country perspective, the vertical dimension refers to higher (supranational) and lower (regional) government levels, while the horizontal constitutes interactions with other states, NGOs and novel forms of public-private partnerships. The temporal dimension of governance is less well articulated and partly overlooked, but is nevertheless significant. It elucidates the heterogeneous involvement of actors on multiple levels at different stages of the decision-making/policy-generating process, from identification and communication of issues to policy development, implementation, monitoring and evaluation.

Benefits related to attributes of multilevel governance have been suggested and researched, including: increased rule compliance and trust building (Ostrom, 2010); facilitation of knowledge generation and innovation (Folke et al., 2005; Berkes, 2009); and decreased risk of institutional misfits (Galaz et al., 2008). The concept's apparent success can (at least partly) be explained by the distribution of traditionally viewed core governmental functions such as security and health care to non-state actors (Bache & Flinders, 2004). It highlights the importance of the shift away from command and control by states and high-level organizations towards a governing-for-governance approach (Jessop, 2004). Countries in a multilevel system should generate efforts to facilitate good governance by providing the environment in which a wide variety of actors (including the state) can interact in a constructive way.

### 4.3.1 Tobacco control and the EU

The case of tobacco control in the EU illustrates two key aspects of multilevel governance: different levels of government, and the role of NGOs.

Tobacco use is a major health concern. It constitutes the main underlying cause of preventable deaths and disease in EU Member States (Rehm et al., 2006), with almost 700 000 people dying each year as a result of smoking. Issues related to public health have traditionally been viewed as the responsibility of individual EU countries, but growing information about health implications associated with tobacco use, together with the global positioning of the tobacco industry, initiated a push for transnational regulation of tobacco within the EU (Mamudu & Studlar, 2009). The process was highly influenced by NGOs and networks of tobacco control advocates, particularly in relation to providing and communicating information on tobacco-associated health risks to the public and governments (Mamudu & Studlar, 2009). The tobacco industry generated substantial lobbying efforts to counteract this movement.

The EU has actively encouraged civil society groups to take part in the process by subsidizing their involvement through, for example, the European Network for Smoking and Tobacco Prevention (ASPECT Consortium, 2004). Observed through the lens of multilevel governance, such initiatives clearly reflect the importance of contributions from non-state actors in policy-making, particularly in areas characterized by high complexity and uncertainty.

Decision-making capacity on tobacco control policy is now shared by the EU and individual Member States, with directives having to be adopted into state laws within a defined period. Directives on warning labels, toxic substance content, advertising and a minimum taxation level for cigarettes have been passed (European Commission, 2009a). The EU also has the option of offering recommendations in areas such as smoke-free environments (European Council, 2009) when its powers are less clearly demarcated or when there is insufficient consensus to pass binding directives (ASPECT Consortium, 2004). Some directives have been modified over the years, focusing on issues such as increasing the size of cigarette pack warning labels (European Commission, 2008a) and changing health warning messages (European Commission, 2012). While EU directives have to be implemented through state law, Member States retain a significant level of authority to create national policy within the EU tobacco control framework. They may, for example, impose higher tax rates on tobacco than the required EU minimum (European Commission, 2008b).

At global level, EU Member States and the EU (through the European Commission) are full signatory members of the WHO Framework Convention on Tobacco Control (FCTC), an international health treaty providing an internationally coordinated response to combating the tobacco epidemic that represents a milestone for the promotion of public health and provides new legal dimensions for international health cooperation (WHO, 2003; Faid & Gleicher, 2011). Some FCTC articles are obligatory but others have a more exhortative tone: there are, however, no sanctions for noncompliance. The EU is the first and so-far only regional economic organization to become a full signatory member (Faid & Gleicher, 2011).

The EU has embarked on an important learning process on how to conduct international negotiations in a policy field in which legal competence is mostly shared through work within the FCTC. Working relationships between Member States and the European Commission, for example, have reflected a fluid partnership largely based on trust and solidarity that cannot be understood from a reading of the division of legal competence alone. The EU is a unique entity, but its experience in international diplomacy may provide a model for other non-traditional actors, be they similar unions or from academia,

business or civil society, to achieve a more integrated voice in multilateral negotiations (Faid & Gleicher, 2011).

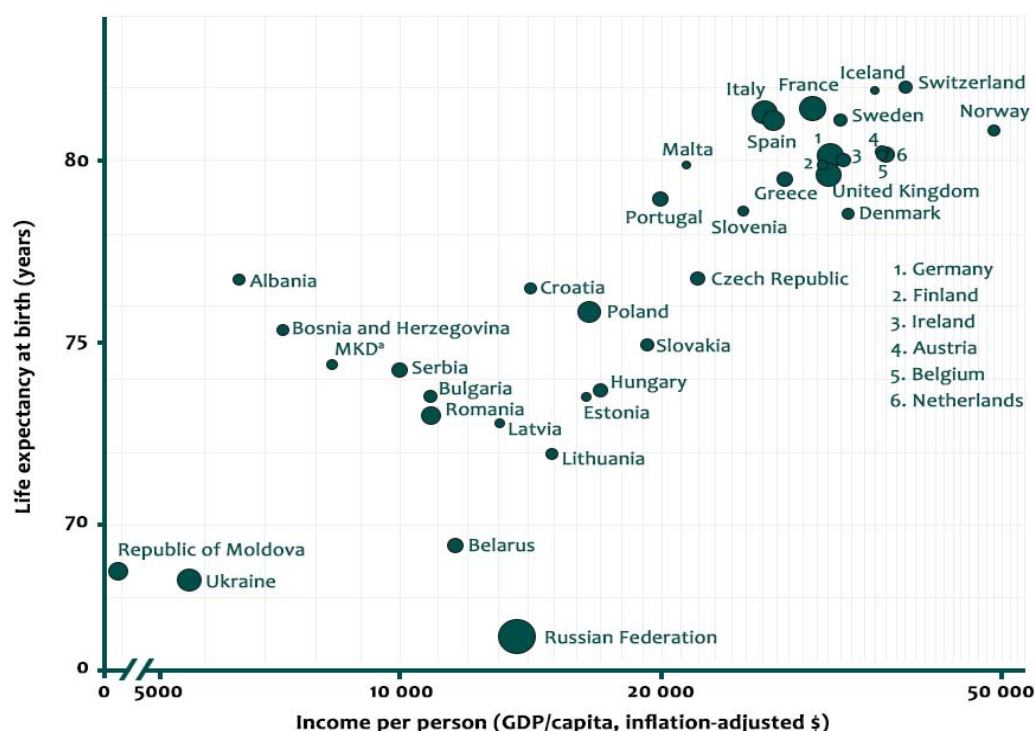
Applying the multilevel governance concept to tobacco control policy in the EU highlights the vertical interactions and shared authority and responsibilities among regions, countries and intergovernmental organizations and the importance of non-state actors at all levels. It also emphasizes the importance of integrating different sectors, such as health care, agriculture and international trade, to appropriate and effective policy-making.

## 4.4 Europe and its health systems

Defining Europe and its borders is complicated. This chapter uses the definition of the United Nations Population Division, which divides Europe into four regions: eastern, northern, southern and western (United Nations, 2009).

Fig. 4.2 shows that countries continue to experience varying health and financial conditions. European countries (with a few exceptions) generally score well in terms of health (measured as life expectancy at birth) compared to the global situation. Maintaining population health is essential to sustain economic and social development, something that was recognized over 30 years ago in the Declaration of Alma-Ata (WHO, 1978). Well-functioning health systems contribute to economic development and wealth (WHO Regional Office for Europe, 2008), a fact that is clearly recognized by European countries, but cannot be achieved without a well-functioning health financing system.

Fig. 4.2. Life expectancy and income per person in Europe



<sup>a</sup> MKD (the former Yugoslav Republic of Macedonia) is an abbreviation of the International Organization for Standardization (ISO).

Source: Gapminder (2010) reproduced by permission of Global Health Europe.

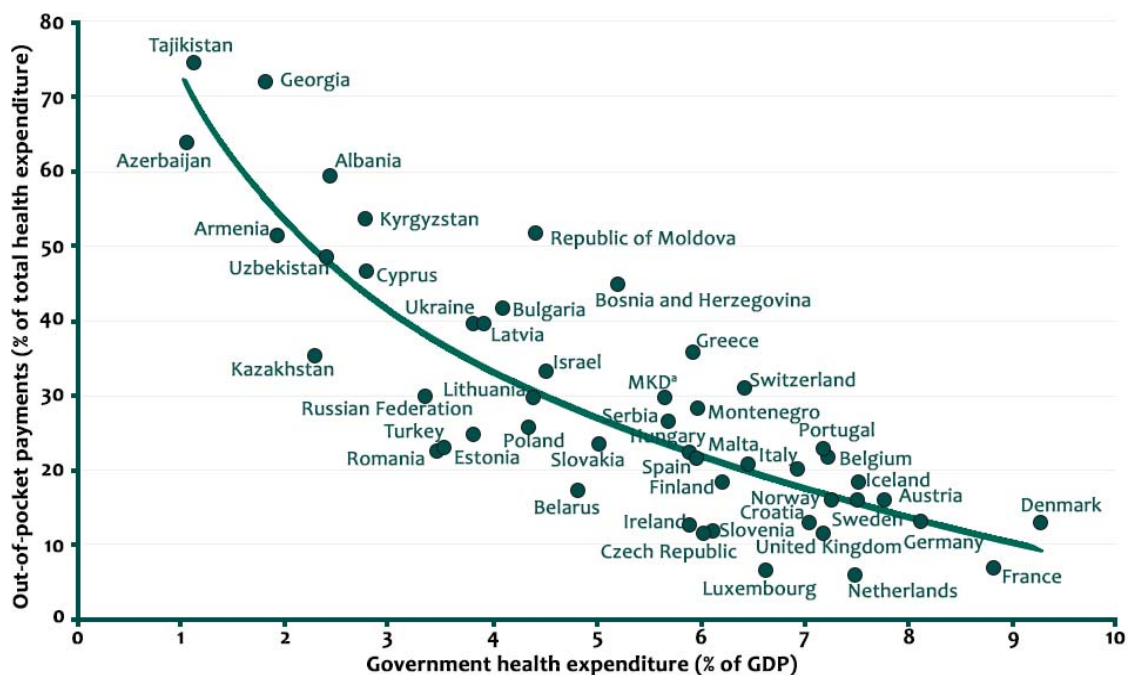
Health expenditure within Europe varies from 3% of gross national product in Ukraine to 11% in Germany. Health systems are sociohistoric constructs and their typologies can crudely be described as Beveridge (mostly publicly funded) or Bismarck (largely funded by mandatory health insurance). A consequence of this is that geographic location plays



a role, with, for example, Poland being influenced by its close proximity to Germany (Bismarck) and Baltic states having a natural orientation towards the Scandinavian publicly financed model.

Public taxation and social health insurance are the main sources of funding in almost all European countries, but voluntary insurance and out-of-pocket schemes play an important part. In the Republic of Moldova, for example, out-of-pocket payments represent over 40% of total expenditure. Social insurance contributions are the main source of funding in Croatia, the Czech Republic, Estonia, France, Germany, Hungary, Luxembourg, the Netherlands, Slovakia and Slovenia (Mossialos et al., 2002). Informal payment schemes exist in western and eastern Europe, but are more significant in the east (Figueras et al., 2004). Fig. 4.3 depicts the relationship between government spending and the share of total health expenditure from out-of-pocket payments. Out-of-pocket spending represents more than one third of total health care expenditure in several European countries, although the world health report of 2000 (WHO, 2000) marked the onset of a concerted effort to move away from direct to prepayment health care financing mechanisms.

Fig. 4.3. Relationship between level of government health spending and share of total health expenditure from out-of-pocket payments, European Region, 2006



<sup>a</sup> MKD (the former Yugoslav Republic of Macedonia) is an abbreviation of the ISO.

Source: WHO Regional Office for Europe (2009).

The core ideals of health care systems are similar among European countries and include efficiency, high-quality services, responsiveness and universal access. All Member States share the common value of highest attainable standard of health as a fundamental human right (WHO Regional Office for Europe, 2008), but approaches to health systems vary depending on the individual country's culture, history and politics and its institutional and legal traditions (Dubois et al., 2007).

All WHO Member States committed to developing their health financing systems to reach universal coverage in 2005, which meant giving all people access to health services without putting them at risk of financial hardship (WHO, 2010). The need for universal coverage and financing strategies has never been greater as growing demands due to globalization of diseases and increased need for chronic care as the population ages increasingly strain health systems (WHO, 2010). Strong leadership is therefore needed: European governments have a responsibility to ensure that all providers operate

appropriately, that everyone can obtain services and that they are protected from financial risks. Universal coverage is essential to avoid an increase in medical tourism, which is the movement of people across national borders in search of high-quality, alternative and affordable medical interventions (Carrera, 2006).

EU Member States have additional agreements related to public health. Under Article 152(5) EC, each Member State has the responsibility to provide a high level of care for citizens. Countries decide the goals they wish to pursue, such as effective care, and then implement them consistent with EU law (Mossialos et al., 2010). Meanwhile, so-called Europeanization, which gradually redraws national and European identities and dismantles each Member State's social policy (Ferrera, 2005), is taking place within Europe (Bache & Jordan, 2008). Regulation, redistribution and stabilization are main features of the modern state and are necessary for public policy and maintaining a welfare system, but closer integration in Europe might mean loss of national control over welfare entitlements, including health-related regulation (Mossialos et al., 2010). EU countries take different approaches to health policy, especially in relation to the delivery and funding of health care services (Mossialos et al., 2010), and it is of course possible for patients to seek care across borders throughout the EU, indirectly influencing national health systems in many ways (European Council, 2011).

Health systems blocks are interconnected and create the need for coordinated action to reach desired results. The emergence and re-emergence of communicable diseases such as SARS and H1N1 influenza put increasing demands on health systems and societies. The outbreak of H1N1 in spring 2009 required the involvement of many state and non-state actors globally and nationally. Countries had to collaborate with the pharmaceutical industry to initiate and ensure adequate vaccine production and information campaigns through media and other outlets (such as schools and workplaces) encouraged individuals around the world to take precautionary measures such as getting vaccinated and practising good hygiene (Kaul & Gleicher, 2011).

#### 4.4.1 Antibiotic resistance: a major global health challenge

Antibiotic resistance poses one of the greatest challenges to global health in the 21st century (Cars et al., 2008). At least 25 000 patients per year in Europe die due to bacterial infections that can no longer be treated using currently available antibiotics (European Centre for Disease Prevention and Control/European Medicines Agency, 2009). It has become increasingly obvious that collective responsibility, system thinking and good governance are needed in an era of globalization in which microbes move more freely across national borders (see Fig. 4.1). Collaboration at all levels is needed not only to promote the correct use of existing antibiotics, but also to develop new antibiotics and reduce the spread of bacterial infections (Cars et al., 2008).

Substantial knowledge on antibiotic resistance existed during the 1990s and well into the 21st century, but little global action was taken. Action on Antibiotic Resistance (ReAct) was therefore established in 2005 by the Dag Hammarskjöld Foundation, Uppsala University and Karolinska Institutet, Sweden. ReAct is an independent global network aiming to “create, support and integrate both bottom-up and top-down processes by bringing partners together, catalysing action and helping to shape processes at several levels in society depending on contexts” (ReAct, 2013). The Swedish Government, facilitated by ReAct, liaised with other governments to initiate World Health Assembly resolution WHA58.27 (WHO, 2005) to strengthen WHO's leadership role and urge Member States and the WHO Director-General to take action and restrain microbial resistance.

Sweden has been a leading actor in the fight against antibiotic resistance, as it has in relation to curtailing tobacco use. The Swedish Strategic Programme against Antibiotic Resistance has worked at national level since 1995, promoting interdisciplinary collaboration to

reduce antibiotic prescriptions, consumption and, consequently, resistance (Mölstad et al., 2008). The EU action plan on antibiotic resistance was implemented in 2009, providing (among other important elements) concrete proposals on incentives to develop new and effective antibiotics. Several other European projects are currently underway, including the European Surveillance of Antimicrobial Consumption, which is funded by the European Centre for Disease Prevention and Control and includes EU Member States and other European countries with national networks of experts.

The issue has still not been given sufficient attention internationally, however, and a fundamentally changed view of antibiotics is needed (Cars et al., 2008). Efforts to realize this changed view are ongoing, including World Health Day 2011, which focused on the spread of antibiotic resistance. In China, the home of a quarter of the world's population, the government has initiated health sector reforms (Hedini et al., 2009) and is stepping up plans to manage resistance by developing a new policy that aims to significantly decrease hospital use of antibiotics. National surveillance activities through the Ministry of Health's National Antibiotic Resistance Investigation Network expanded from 150 to 500 hospitals during 2011.

Many believe that political measures to control antibiotic use have only negligible short-term effects. Health care regulation nevertheless has the power to influence antibiotic use in many ways and in different settings. Countries such as China, Ghana and India have recently undertaken steps to develop national policies to tackle the threat posed by antibiotic resistance. Denmark (Hammerum et al., 2007), France (Aubry et al., 2000), Israel (Schwaber et al., 2011), the Netherlands (Prins et al., 2008) and Sweden (Mölstad et al., 2008) have developed and implemented very practical policies for management of resistance and/or its components at various levels over the last 15 years, and many examples of the effects of local antibiotic stewardship programmes in hospitals and health centres exist. The cross-cutting nature of antibiotic resistance, however, requires a multipronged approach in which all relevant sectors of society are engaged, including health care professionals at all levels, pharmacists, the private sector, civil society organizations, academia and policy-makers representing health, science and technology, environment and education.

Health systems vary, so there is no one-size-fits-all approach. Each country needs to develop its own working model that allows multiple partners to come together in a coordinated national effort targeting key barriers that may be present in specific contexts. This poses formidable challenges, as it entails convening a diverse group of actors with different remits and who are not used to working together. In addition, the truly global nature of the problem and the need for transnational cooperation to enable learning from successful initiatives means that international cooperation is fundamental to the long-term management of antibiotic resistance.

The emergence of antibiotic resistance as a serious global health problem highlights the need for improved leadership within a multilevel governance structure to provide an arena in which actors can interact in a constructive way to better manage this growing health concern.

## 4.5 European health systems and governance for the future

As the discussion of antibiotic resistance above suggests, identifying and understanding a problem does not necessarily mean that the interdisciplinary collaboration and joint action needed to address it will materialize. The rate of social and technological innovation development nevertheless holds great promise for creating novel solutions to known and unknown challenges in the future. Governance systems therefore have

to be capable of managing a wide range of society-related issues of all dimensions, both temporal and spatial, while facilitating knowledge and innovation generation and building resilience for future challenges.

Building on the theories of complex adaptive systems, polycentricity and nested institutions, the diversity of system components and functions creates the very foundation for dealing with uncertainties, nonlinearity and emerging problems. These properties are essential for managing future challenges. This view redefines the concept of efficiency in that an increase in diversity, even by seemingly redundant and obsolete components, may still increase the adaptive capacity of a system.

Local solutions to health issues will have to continue adapting or transforming due to the influence of global forces. Health systems' interconnections, and therefore interrelationships, should be considered most important in minimizing the implementation of specific agenda-driven schemes. The conceptual ecological framework presented here, and depicted in Fig. 4.1, aims to provide an analytical tool for this view.

In relation to global processes, movement of people, goods or services over jurisdictional borders creates challenges for government structures, particularly for rigid systems confined to specific regions or issues. A multilevel approach, if applied appropriately, may create the structure for actors to mitigate issues transcending boundaries. Implementing a particular policy in one area may have detrimental and unpredictable effects elsewhere in other regions or sectors. Subsidizing a medical intervention may, for example, create an inflow of patients and potentially overstress a local system. Such effects could conceivably be controlled more appropriately at regional level by implementing policies on, for instance, patient mobility, or by creating incentives to provide similar treatments throughout the region.

The above argument holds true for issues transcending sectoral boundaries. Drivers of human health are not constrained to the health care system, so policy implementation and governance for health need to be considered in all sectors. This requires engagement from actors primarily concerned with human health in other policy fields, such as the education and transport sectors, especially in raising awareness of the implications of policy implementation on public health and building cross-sectoral partnerships and collaboration to mitigate such effects. The problem of antibiotic resistance provides a prime example of an area in which sectors such as livestock production, transportation and health need to agree on jointly developed measures – from the local health practitioner or veterinary officer to international trade agreements and disease surveillance.

Drawing knowledge and ideas from other sectors and encouraging and facilitating novel innovations in promoting health and well-being are also important. An example is the Clinical Innovation Fellowship scheme introduced by Karolinska Institutet, the Royal Institute of Technology and Stockholm County Council in Sweden (Centre for Technology in Medicine and Health, 2013). These partners set up a multidisciplinary expert team to identify innovative solutions to meet future hospital-level challenges in the Stockholm region. The fellowship is the first of its kind in Sweden and is being implemented in cooperation with Stanford University, United States, which started a multidisciplinary biodesign fellowship programme in 2003.

The explosion in access to health information through Internet forums dedicated to self-diagnosing disease and hosting discussions on causes, prevention and treatment options is related to issues on patient mobility and asymmetries in health care. Access to readily available information is creating a power shift among actors involved in the health arena. Information raises people's expectations and gives patients the ability to better compare health services across borders (Kerssens et al., 2004). National policy-makers should be aware of this phenomenon and take it into consideration.



As earlier chapters have noted, patients in Europe and the wider international setting are no longer passive recipients of care, but are informed and demanding consumers who will ask for information about the performance of health providers and their staff. The IT revolution has led to situations where the patient is sometimes better informed about his or her disease than the doctor – a phenomenon referred to as patient empowerment. This obviously has an impact on power relationships and makes possible the creation of well-informed individuals and groups of patients capable of influencing not only their own preferred treatment, but also the wider health care system.

To set the stage for the following discussion, the intimate relations between the depicted layers in Fig. 4.1 raise the question of system component demarcations, especially in terms of policy-making. The focus here is on the role of leadership, health financing and information, innovation and technology, but the interconnectedness and blurring of boundaries remains an important factor within a social–ecological perspective on health and health systems that advocates for health being reflected in all sectors and at all levels.

### 4.5.1 Leadership

Leadership is considered a crucial component of a national health system, but despite its critical importance in meeting health system challenges (Frenk, 2010), and in contrast to technologies such as medical interventions, it has been little studied. The importance of strong leaders is consolidated by drawing from literature on other complex issues requiring integrated management perspectives, particularly ecosystem governance, but leaders' roles remain ambiguous. This can in part be ascribed to their wide range of responsibilities and the ad hoc nature of the different sectors, locations, cultures, political systems and time periods in which they operate.

Looking through a social–ecological lens inevitably raises the question of leadership in relation to emerging features in complex systems. Plowman et al. (2007) proposed that leaders have roles as sense-makers and enablers rather than directors of change. This view is generally supported by literature concerning ecosystem management, which emphasizes that strong leadership is essential for fostering innovation, transferring ideas and creating clear visions and momentum for necessary policy implementation (Biggs et al., 2010). The direction of change in this context is towards the identification of issues (that is, sense-making) and general and overarching visions to deal with problems rather than specific routes to changing system behaviour.

This means that leaders and European health systems should assess health systems' performance in areas other than efficiency and cost savings. Health ministers in Europe should have a clear vision of the desired general characteristics of future health systems, but also articulate potential future problems. Health-related system thinking (de Savigny & Adam, 2009) means addressing the full range of system elements and interactions. As previous sections have suggested, reforms to reduce out-of-pocket spending in European health systems should be a top priority. A vision such as this creates a need for well functioning and easy-to-understand information systems for the general public and a plan to manage reactions from the health workforce (to avoid negative impacts on their performance), ensure supply of technology and provide effective leadership at all levels.

The discussion so far clearly mimics ecological adaptation in relation to external drivers originating at higher levels. It promotes investment in the appropriate mix of local human and material resources. Value-driven policy that emphasizes social justice, equity and responsiveness needs to take the forces of globalization into consideration. Strong leaders and leadership are necessary in this international context to strike a balance between globalization and the privatization of health care to ensure that the values



inherently imposed upon national health systems remain firmly grounded in the public sector.

Leadership within the framework of network-based governance raises issues and opportunities. Problems stemming from accountability, power structures, incompatible agendas and ambiguity around leaders' roles pose challenges to effective governance (Peters & Pierre, 2006). Opportunities nevertheless exist to create enhanced collaboration and integration of heterogeneous actors with different perspectives, promoting social learning and minimizing risks of neglecting potential issues down the line: this is considered to be characteristic of good leadership (Berkes et al., 2003).

It can be difficult to define appropriate accountability and responsibility for leaders and organizations in a fragmented network-based governance system. Peters & Pierre (2006) studied this issue in the context of multilevel governance and democracy. Their research highlights accountability as a key issue for policy-makers and high-level leaders, particularly those whose decisions greatly influence human health, with implications that could have detrimental effects from individual to global levels. Leaders involved in governance for health can therefore favourably be seen in the light of PNS, a concept created to describe situations where high-stake decisions need to be based on uncertain and/or incomplete information (Funtowicz & Ravetz, 1991).

Leaders' role as enablers and facilitators of governance has emerged in this discussion. It is therefore important to raise leadership's role in creating and maintaining bridging and boundary organizations (Bodin & Crona, 2009). These act as the glue between system components, creating an arena for conflict resolution, information sharing and planning for joint initiatives (Berkes, 2009). This may prove pivotal for good health-system governance in the future and requires strong leadership to be effective. The mitigation of complex challenges such as institutional misfits and the impact of external processes can be achieved through such collaboration (Young et al., 2006; Galaz et al., 2008). It should also be noted that participation is key in this process: health ministers in Europe should be aware of the potential benefits of stakeholder involvement.

Addressing comprehensively the big issues that demand integrated collaboration and leadership, such as patient and health workforce mobility, financing of health interventions and emerging threats from antibiotic resistance, also has the potential to bring synergistic effects. The thinking behind this is that by inviting actors operating on different scales and from a range of sectors to interact, a more complete picture of the system – its vulnerabilities and opportunities – will be produced and areas suitable for cooperation and joint operations will be identified (Folke et al., 2005; Olsson et al., 2007). Perceptive leaders are important in promoting awareness of, and initiating action on, issues that are currently perceived as small and insignificant but which may cause problems in the future. Finding potential synergies in areas such as collaboration in surveillance of multiple emerging infectious diseases may prove highly beneficial for health and the economy.

#### 4.5.2 Information, innovation and technology

Social innovations include new ways of organizing human resources, information and decision-making processes within health systems (Gardner et al., 2007). They are also required in health systems to maximize take-up of new drugs and diagnostics and to find the best ways of delivering services and promoting healthy behaviours. Innovation systems for health and social care should include putting the results of research and new knowledge into practice. More evidence from health systems research on social innovations is required to increase their effectiveness and equity. Knowledge networks, learning sites and close collaboration between researchers and practitioners are major enabling factors. Outcomes-oriented management and leadership, patient-centred

care processes and professional practice improvement are just some of the innovation-related projects currently being evaluated within the Swedish health care system.

There is a growing consensus that IT's effect on health systems will be revolutionary, but much less agreement exists as to its likely nature (Oh et al., 2005). Some see IT as being used as a tool to reinforce existing health systems, while others see it as having the potential to transform them. IT's role in the doctor–patient relationship is also increasingly being discussed. If health systems are seen as “ways of organizing access to expert knowledge” (Bloom & Standing, 2008), then issues of access to knowledge and its organization (and how it can be withdrawn) are important.

Technological innovation has the potential to provide enormous benefits for health and health systems management in the future. It offers a forum for the momentum constructed in the social–ecological framework (Fig. 4.1). The benefits offered by innovation and IT are not automatic, however, and require governance consideration on three issues: monetary cost, policy and utility.

The cost implications of new innovations for health systems apply not only to pharmaceuticals, but also to other new technologies and IT. New technologies create substantial financial pressures within health systems at the outset, with expected benefits arriving only later. Particular concerns relate to very expensive new products with limited evidence of improved life expectancy or those that are intended for large predominantly healthy populations, such as new vaccines. Products' high costs are usually accompanied by a high-cost necessity to support the innovation.

The second issue is policy. The need to consider technology assessment as part of innovation policies is critical, as it is now recognized that some health innovations show moderately incremental benefits with relatively little clinical value (OECD, 2008). Keeping abreast of the high speed of health innovation and IT requires EU-level policy-based assessments of the clinical value and cost–effectiveness of new technologies to be made early. Efforts to enhance the scope for technology assessment in the field of pharmaceuticals are already in place within the EU and attention to other forms of health innovation should ensue.

The third issue to consider is a lack of forethought on new innovations' end-utility and longevity. Some, for example, are developed purely on the basis of economic considerations. The European Commission sectoral inquiry highlighted this problem in relation to competition within the health sector, alongside more immediate concerns about costs borne by consumers and national health systems (European Commission, 2009b). Innovation in itself is not sufficient; policies that enhance innovation also need to represent the wise use of public funds, enable access to knowledge and result in products that are affordable.

### 4.5.3 Financing

A well-functioning health system is essential to an effective market economy, but as Mackintosh & Koivusalo (2005) argue, making a health system work in a market economy does not simply imply the commercialization of the health care sector. In fact, certain areas of health are inherently unprofitable and are therefore left in the sole care of governments and philanthropic initiatives.

Ensuring that unprofitable and neglected health problems are raised and kept on the agenda, and that marginalized groups are sufficiently empowered to voice their concerns and are not shadowed by powerful economic interests, are major challenges for governance in market-driven societies. From a multilevel governance perspective, this implies the creation of incentives and infrastructure to facilitate information-sharing, learning and collective action among individuals and organizations. Health systems underpin health policies, so the way they are organized has fundamental implications

for how policies are developed and implemented. They therefore hold a key position in building an inclusive governance system for the future and are essential in capturing the expression of societies' values, priorities and expectations and providing the basis for ethical, efficient and equitable policy-making.

Economic aspects of health care and commercialization do not solely concern the exchange of goods and services, but also reflect medical tourism (Carrera, 2006). The forces of globalization related to patient mobility include the interconnectedness of health economics with national and international politics, the social elements of patient choice, availability of information to empower patients, the ability to pay and variations in technical developments found across the globe. Questions around the health workforce are also of great importance for health systems, with several countries currently facing a severe workforce crisis. International migration of health professionals has increased in recent decades, especially in OECD countries (OECD/WHO, 2010), and the workforce in Europe is ageing. Demographic considerations should become inherent components of workforce planning. The creation of a single market within the EU has important implications for health workforce migration for countries that recruit foreign workers and those that face increasing emigration (Mossialos et al., 2002).

Health systems not only provide health services, but are also responsible for public health, health protection, health promotion and tackling the health implications of other policies. It is therefore important that sufficient capacity remains within the public sector not only to absorb external processes, but also to inform and influence other areas of society that indirectly affect human health. The financial crisis has shown that processes related to globalization affect health systems' and governments' resource base and, as a consequence, public health outcomes (Tomson, 2010). Health systems in Europe therefore face a major challenge in maintaining the resource base and expanding capacities to predict, negotiate, cope with and provide balance to some of the impacts of globalization, including the social determinants of health. This has implications for how health systems are financed and organized to ensure that services are available and affordable in areas where their provision may not be economically profitable.

Some health system functions may not be adequately served in more commercially oriented models. Highly complex and non-profitable issues of relatively low public awareness and political will (but with implications stretching far into the future) are especially ill suited to a commercial context. Antibiotic resistance stands as a prime example, although recent efforts at multiple levels, such as WHO initiatives and the formation of the ReAct independent global network, have pushed it further up the agenda. Emergency preparedness and services also fall into the commercially neglected category, as does response mechanisms to epidemic outbreaks. Tobacco control in the EU has been cited as a good example of how intergovernmental collaboration helps to mitigate health issues originating from a field with highly influential and powerful economic interests.

## 4.6 Conclusions

Multilevel governance could offer a potential framework for analysing contemporary societal and political trends in the context of a world in which groups, organizations and countries are simultaneously integrating and fragmenting. Strong and perceptive leaders are needed in this context to provide the necessary integration of different fields, highlighting issues and enabling solutions to be developed and implemented. Social and technological innovations are providing, and will continue to provide, opportunities and challenges for the future of public health and society in general. The way social media and IT have been used to coordinate demonstrations and protests in conflicts in different parts of the world clearly shows the impact of open communication systems in linking

people. Financing is also a topic for the future: much thought and effort will have to go into balancing private and public interests in building an efficient, ethical and equitable health care system.

It is important for health systems to recognize that globalization starts at home, as emphasized by the International Labour Organization globalization report (International Labour Organization, 2004). This process requires cooperation among those responsible for health and a focus on the appropriate level of governance. In this context, the focus on health in all policies (HiAP) highlights the need to include the health system implications of other policies and to move health up the political agenda so that priorities can be set transparently as part of broader political decision-making. Future challenges for public health and health systems will therefore require concerted actions on many fronts and collaboration across territorial and sectoral borders, calling for a governance structure with a comprehensive and holistic perspective on health.

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# 5.

## Bridging the gap: governance challenges for the health sector in CCEE and former Soviet Union countries

Armin Fidler and Tünde Szabó

### 5.1 Historical context

Countries of the former Soviet Union share a significant part of their recent history. Most emerged from over 50 years of the Soviet regime to gain independence between 1989 and 1993. Governments of Warsaw Pact countries introduced purposeful equalizing policies during this period, resulting in their economic development levels, social structures and policies, levels of education and governance cultures becoming similar, despite historic and cultural heterogeneity. Alongside national defence, education and health systems were consistently the top priorities on government agendas.

Central European and Soviet Union health systems were organized under the Semashko system (named after its intellectual creator, Nikolai Semashko), characterized by centrally planned public provision of health care. Health systems were based on the principles of universality, equity of access and solidarity. Countries made important gains in public health during the decades after the Second World War, gaining control over infectious diseases and achieving universal childhood vaccination.

In hindsight, however, it can be seen that health systems organized on the Semashko model shared negative features. They tended to be oversized, overstaffed, characterized by corruption and inefficiency and commonly consumed over 15% of total government outlays. Eventually, they became unsustainable: financing arrears increased and illegal so-called under-the-table payments to health staff became an integral part of health system structures, eroding earlier achievements in relation to equity of access to services.

Transition economies inherited these inefficient health systems after the fall of the Soviet Union, with each country having to cope with the economic, quality and management problems they had created. Some, especially those that gained accession to the EU, experienced robust and sustained economic growth. It was therefore not surprising that health workers began to demand higher salaries, closer in nature to those in other EU countries (Fidler & Mikkelsen-Lopez, 2010). Patients who were able to access better information began to demand higher quality and more modern medical care featuring state-of-the-art medical technology and new brand-name pharmaceuticals.

Despite the large amount of information collected by central governments and an extensive network of public health institutes, new EU Member States such as Slovenia had little capacity to analyse epidemiologic, demographic and economic data to promote priority-setting and decision-making processes (Fidler & Mikkelsen-Lopez, 2010). This was coupled with lack of capacity for good health sector stewardship and governance and a dearth of skills in economic evaluation of health system performance. Challenges from the past, combined with increasing public and private health spending and growing consumer demand, the need to invest in modern medical technology and pharmaceuticals and wage pressures from health workers, resulted in rapidly rising costs in the new Member States (Fidler & Mikkelsen-Lopez, 2010). Unsustainable internal debt and contingent liabilities followed, which in turn negatively affected the path of fiscal

austerity and prudent debt management pursued by governments in fulfilment of the Maastricht Criteria<sup>3</sup> during EU accession.

Policy assessments by international organizations (European Community, World Bank, WHO, OECD, United Nations Development Programme) and sectoral reports and analyses suggest that most central European and former Soviet Union countries still have a long way to go compared to other EU countries to reduce the inherited gap in good governance. This is the case not only in health, but also across most sectors of the economy.

It is nevertheless difficult to quantify existing gaps in good governance, especially in relation to the health system. Information permitting comparisons with countries belonging to the EU before May 2004 (EU15) or OECD countries is scarce for developing and transition economies, or does not yet exist. Reliable reports, indicators or published case studies that contain robust governance quality analysis corroborated by adequate country data are difficult to find in an environment fraught with governance challenges.

## 5.2 Analysis approach

Despite these limitations (particularly in relation to data-driven empirical analysis), this chapter aims to assess health governance in Europe and central Asia (ECA),<sup>4</sup> focusing on:

- how different actors within transition countries' health systems have evolved over the last 20 years;
- what areas are of specific concern to EU and OECD countries in terms of governance for health;
- to what extent transition countries' health systems qualify for recognition of good governance; and
- the principal challenges for the next decades in terms of cross-sectoral policy-making aimed at improving governance and reducing the gap between transition countries and the more advanced economies of the EU.

The chapter also examines how health systems in ECA fared in the context of the global economic crisis, which was a stress test for cross-sectoral governance.

The chapter comprises three parts:

1. a comparison of transition countries from an overall governance perspective, including health systems (top-down approach);
2. an assessment of gaps and definition of challenges in different dimensions of health governance (bottom-up approach); and
3. a review of resilience and governance challenges in the face of the recent global economic crisis.

The approach has inherent advantages and limitations. A top-down lens is perhaps too broad and may miss the idiosyncrasies of countries' health systems. Population health and well-being is not determined by the health sector alone, however, but is a result of biological, personal and societal determinants that include the interaction of many agents whose primary mission is not managing and/or providing public health or curative care to the population; health outcomes are to a large extent determined by the influence of sectors such as education, infrastructure, energy, nutrition and social protection.

<sup>3</sup> Maastricht Criteria are the rules that determine whether a country is ready to adopt the euro as its national currency. They include targets or rules for inflation, limits for budget deficits, national debt, interest rates and exchange rates. The inflation rate should be no more than 1.5% above the rate for the three EU Member States with the lowest inflation over the previous year.

<sup>4</sup> ECA is used by the United Nations and the World Bank. WHO refers to the European Region.

A bottom-up lens focuses on particular areas of the health system, but might be incomplete. It does not cover all aspects of health governance and ignores the fact that a population's health status is affected by the interaction of multiple agents. Governance indicators for the health sector usually provide information on a very narrow dimension of governance, such as health worker absenteeism or prevalence of illegal out-of-pocket payments.

The so-called missing middle – measures of governance for health – includes exogenous factors and determinants focusing on specific roles of other areas that may affect health system performance and, consequently, the health status of the population. These include finance, trade, public administration and consumer protection.

Most CCEE and former Soviet Union countries face a pending task – implementing a whole-of-government approach to health (better known in the literature as the HiAP model) – that will pose an even greater challenge for leadership and cross-sectoral governance in the interest of achieving and sustaining specific health outcomes. This policy model refers to interlinking the process of accountable decision-making and operating in society by sectors that have the potential to influence the population's health and well-being. The ultimate goal of the HiAP principle is to maximize positive effects on health equity and sustainability by coordinating and intensifying the efforts of policy-makers, businesses and citizens. While studies of target-setting indicate that the role of the health sector proper is perceived to remain dominant in most countries, the development of comprehensive intersectoral policies for health remains a distinct leadership and governance challenge in many (Ståhl et al., 2006).

### 5.3 Comparison of overall governance indicators in ECA

Plumptre & Graham (2000) propose that “governance is the process whereby, within accepted traditions and institutional frameworks, interests are articulated by different sectors of society, decisions are taken, and decision makers are held to account”. Governance in this view is more a process than an institution, a means of ensuring accountable decision-making in society that interlinks different sectors.

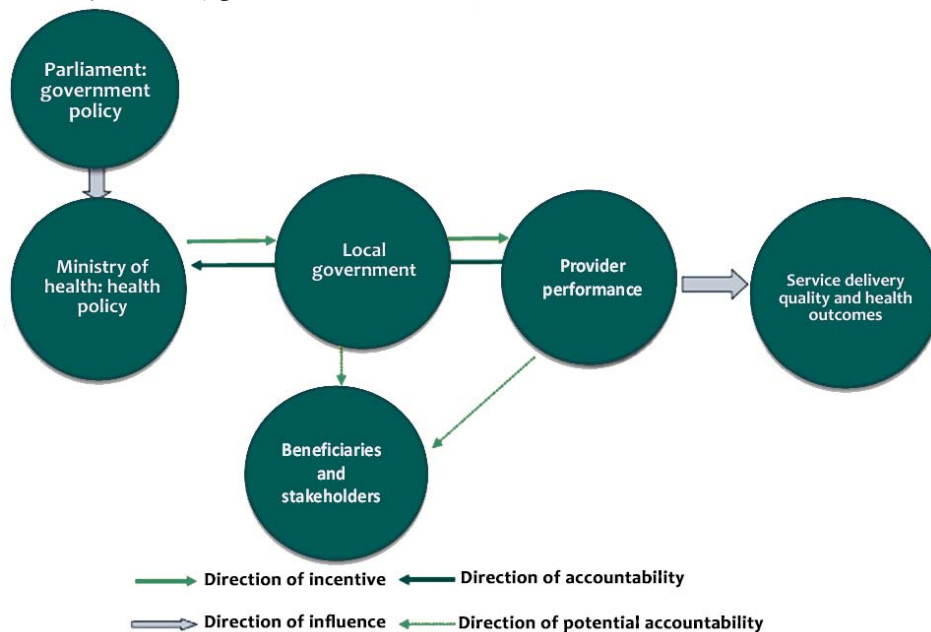
Good health governance, among other things, promotes effective delivery of health services. The process must provide appropriate incentives, performance information and accountability mechanisms at each level of the health system to attain and sustain desired performance standards (Lewis & Pettersson, 2009) (Fig. 5.1).

Only a limited number of readily available, reliable and broadly applied standard aggregate measures of governance is available, with those that exist tending to refer to overall governance and not being health-specific. A key question to be asked is: to what extent might these indicators be informative as a reflection on health governance?

Good governance in the health sector implies that health care systems function effectively and with a reasonable level of efficiency. Improvement of the efficiency and effectiveness of a health system as a whole can usually only be achieved with an effective government, given the public–private nature of most health systems. Well-intentioned additional spending on health care delivery or health technology might, however, have little effect on the population's health status. There is ample evidence to show that health priorities cannot be met if government and public institutions do not function efficiently and scarce resources are wasted. For instance, Wagstaff & Claeson (2004) found that increased spending reduced under-5 mortality, but only where governance,



Fig. 5.1. The process of governance in health care



Source: Lewis, Maureen; Pettersson, Gunilla. 2009. Governance in Health Care Delivery: Raising Performance. World Bank. © World Bank. <https://openknowledge.worldbank.org/handle/10986/4266> License: Creative Commons Attribution CC BY 3.0.

as measured by the World Bank's Country Policy and Institutional Assessment measure (CPIA) score,<sup>5</sup> was sound (that is, above 3.25). The authors explored the implications of additional spending for attaining the United Nations Millennium Development Goals (MDGs) and concluded that more spending in medium- and low-scoring CPIA countries (as a proxy for performance in governance across sectors) would not be expected to reduce child mortality, and that per capita income growth offered a better investment when mortality reduction was the main objective (Wagstaff & Claeson, 2004; Bashir & Lewis, 2006).

It is therefore reasonable to use aggregate governance measures for international comparisons of differences in health governance performance, but these should be complemented by specific health indicators to give a complete picture of health governance quality. This is discussed in the second part of the chapter.

Standard (as opposed to health-specific) measures of good governance are defined in the Worldwide Governance Indicators (WGIs) project (World Bank, 2013), which reports aggregate and individual governance indicators for 215 economies over the period 1996–2012 for the following six dimensions of governance:

- government effectiveness across sectors
- control of corruption
- consumer voice and accountability
- political stability and lack of violence
- rule of law
- regulatory quality.

These dimensions affect populations' overall quality of life, including health status, expressed through morbidity and mortality. This chapter focuses on two that have a direct and documented effect on morbidity and mortality (Bashir & Lewis, 2006): government effectiveness across sectors and control of corruption. The next two sections discuss these indicators in ECA.

<sup>5</sup> The CPIA measure is scored between 1 and 5 depending on performance, part of which relates to corruption and governance.

### 5.3.1 Government effectiveness across sectors

Good governance for health combines financial, material and human resources to deliver timely and good-quality services to citizens, involving them in decision-making, provision and monitoring processes. This requires a system that mobilizes and distributes resources, processes information (and acts upon it) and motivates appropriate behaviour by health care and other workers and administrators. Good governance is a critical factor in making such a system function well.

Government effectiveness includes efficiency in administration, role distribution and defining local and regional government responsibilities. Good governance requires government staff with strong administrative and technical skills who are capable of formulating and implementing policies and programmes, governing capacity and using resources effectively.

Repeated business environment and enterprise performance surveys carried out by the World Bank and the European Bank for Reconstruction and Development in ECA countries capture (among other things) business managers' perceptions of health service quality. Across 20 countries, positive assessments from 60% or more of respondents were achieved only in the Czech Republic and Slovenia, indicating management and governance problems in most of the other 18 health systems (Ryterman et al., 2000). The survey also highlighted negative perceptions prevalent in a number of EU15 countries, such as Italy and Greece.

Fig. 5.2 illustrates the ranking of government effectiveness in countries in Europe in 2012, using measures of perceptions of the quality of public services, the civil service and its independence from political pressures and policy formulation and implementation, and the credibility of the government's commitment to policies. The WGI point estimate gives the country's score on the aggregate indicator in units of a standard normal distribution, ranging from approximately -2.5 (lowest effectiveness) to 2.5 (highest effectiveness). Transition countries are highlighted in brown.

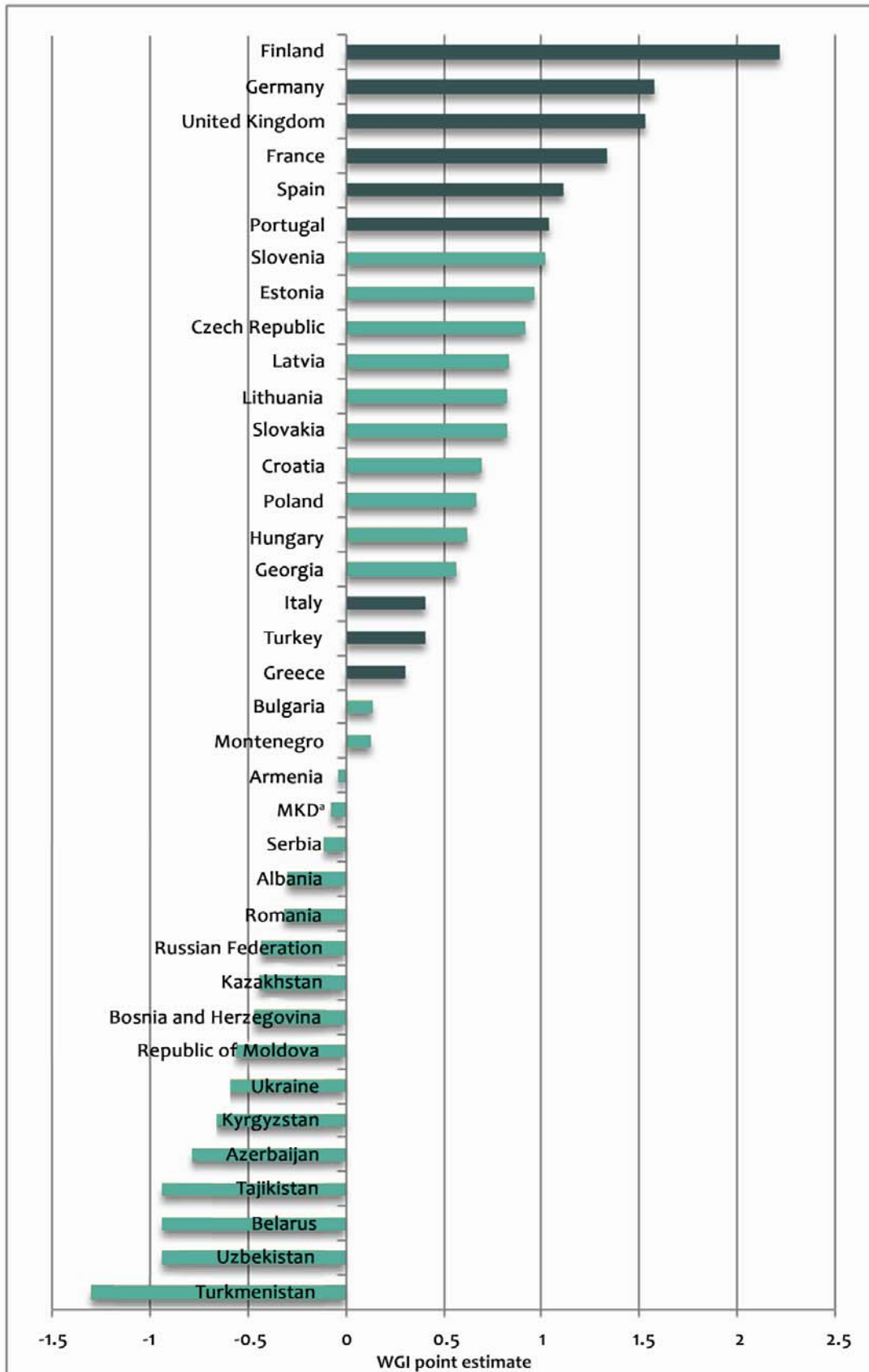
Fig. 5.2 shows that more than half of transition countries in Europe have negative government effectiveness indicators, with the bottom five having scores ranging from -1.29 (Turkmenistan) to -0.78 (Azerbaijan).

Countries that joined the EU in May 2004, such as the Czech Republic, Estonia, Hungary, Lithuania, Poland, Slovakia and Slovenia, did relatively well, ranging from 0.62 (Hungary) to 1.0 (Slovenia).

It is difficult to explain the full range of reasons for such vast differences in government effectiveness of previously relatively similar societies without specific empirical analysis. A possible explanation offered anecdotally among experts is the process of acquiring EU membership, with governance in the EU requiring transparency in policy-making, funding allocation and public purchasing. All of these good governance dimensions were nevertheless EU accession criteria used during evaluation of country candidacies prior to gaining full EU membership: this means that these countries were performing better even before joining the EU, as failure to fulfil these basic criteria would have resulted in their candidacy being rejected.

Sustained leadership and good managerial practices are hallmarks of good stewardship in health: as Lewis (2006) notes, "although a chronic weakness of health systems, management is critical to performance and improved effectiveness". The basic ingredients for improving management and overall health care delivery are ensuring the availability of funds, hiring and deploying staff, maintaining basic record systems and tracking facility performance (Lewis, 2006).

Fig. 5.2. Government effectiveness, Europe: estimate, 2012



<sup>a</sup> MKD (the former Yugoslav Republic of Macedonia) is an abbreviation of the ISO.

Source: authors' calculation based on World Bank data.

### 5.3.2 Control of corruption

Corruption can be defined as the use of public resources for private gains. Bribes, corrupt officials and inappropriate procurement undermine health care delivery and compromise its functions through poor governance, for which corruption can be used as a proxy measure. Researchers have shown a correlation between corruption indicators and child and infant mortality and immunization levels even after controlling for mothers' education, health care spending and urbanization (Gupta et al., 2000; Bashir & Lewis, 2006). The leakage of resources for education, for example, has the potential to indirectly affect health outcomes by lowering educational attainment and negatively affecting families' health status (Reinikka & Smith, 2004). As was stated in section 5.3 above, under-5 mortality has been shown to improve with additional funding, but only in the presence of good governance and low corruption (Wagstaff & Claeson, 2004). Improved per capita income per se is unlikely to improve public health status unless it is accompanied by good governance, examples of which can be demonstrated in a number of ECA countries.

Lewis (2006) analysed a set of corruption surveys conducted between 1998 and 2002 in which public officials, business executives and the general public in 23 countries were interviewed. Within ECA countries, health ranked first as the most corrupt sector in the Republic of Moldova, Slovakia and Tajikistan and among the top four in half of the other countries surveyed. Lack of transparency, lack of accountability and monopolization were cited as corruption's main driving forces. These countries, for the most part, also ranked highly on the percentage of the population perceiving high levels of corruption in health, going as high as 85% in Tajikistan and 82% in the Republic of Moldova. Expectations on paying for public care corresponded to perceptions of corruption, which in turn were closely related to the need for informal payments.

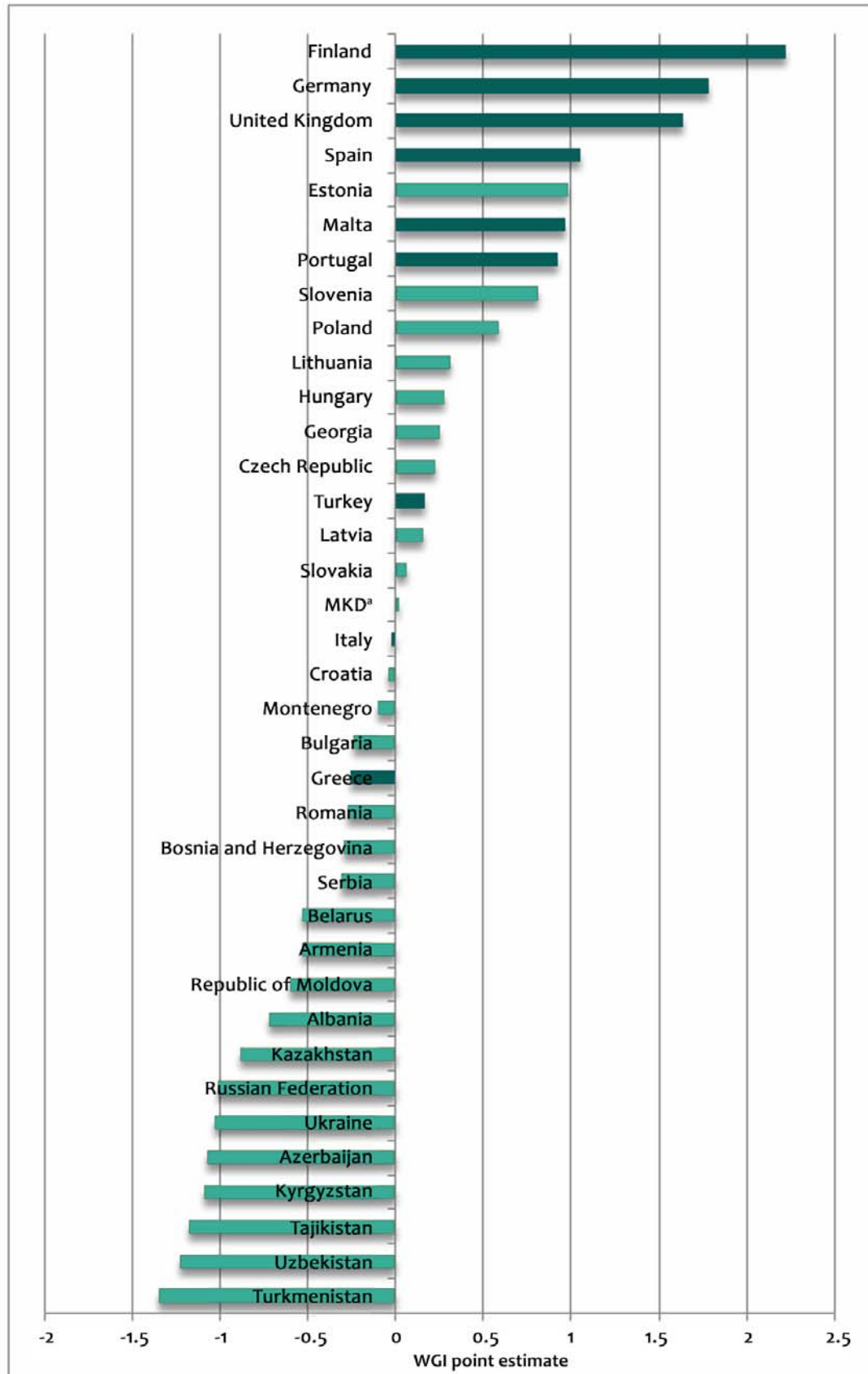
A related survey of perceptions of corruption among public officials in Bosnia and Herzegovina, Bulgaria, Croatia, Montenegro, Romania and the former Yugoslav Republic of Macedonia conducted in 2001 by the United States Agency for International Development showed that 45–55% of respondents felt that corruption among doctors was widespread. Albania and Serbia showed much higher levels (in the 61–71% range). Albania's perception score for doctors was an outlier relative to its score for other public officials, but Serbia exhibited levels above those of other countries for most categories of officials, suggesting a relatively more corrupt environment.

Fig. 5.3 illustrates the ranking of countries from a control-of-corruption perspective in Europe in 2010. It captures perceptions of the extent to which public power is exercised for private gain, including petty and grand forms of corruption and the so-called capture of the state by elites and private interests. The WGI estimate gives the country's score on the aggregate indicator in units of a standard normal distribution, ranging from approximately –2.5 (highest corruption) to 2.5 (absence of corruption). Transition countries are highlighted in brown.

Fig. 5.3 shows that two thirds of transition countries have negative control-of-corruption indicators, with the bottom 5 in the ranking ranging from –1.3 (Turkmenistan) to –1.1 (Azerbaijan). As in relation to government effectiveness (Fig. 5.2), countries that joined the EU in May 2004 did relatively well in controlling corruption compared to others but scored slightly worse than in the area of government effectiveness, ranging from 0.1 (Slovakia) to 1.0 (Estonia).

Most of the lowest-ranking countries in terms of good governance had common negative features, such as: low per-capita GDP; low per-capita health care spending; low share of government spending on health, reflecting other government priorities; high corruption combined with lack of anticorruption measures; low government effectiveness; lack of universality in access to care; and lack of financial protection for the population.

Fig. 5.3. Control of corruption: estimate for Europe, 2012



<sup>a</sup> MKD (the former Yugoslav Republic of Macedonia) is an abbreviation of the ISO.

Source: authors' calculation based on World Bank data.



Pharmaceuticals and medical technology (including IT) have been shown to be particularly problematic within the health sector. Forzley (2004) estimates that 25% of drugs consumed in poor countries are either counterfeit or substandard, stating: “Counterfeit drugs are a global public health problem causing death, disability and injury affecting adults and children. No country is free of this problem, which plagues developing and developed countries alike”.

The literature presents diverse recommendations on potential mitigating measures based on empirical research and case studies. Some positive examples include success in combating unregistered drugs in Azerbaijan through a range of sustained policy measures. Albania (among other countries) has made significant strides in introducing a more transparent international tendering system after rapid deregulation and privatization of the pharmaceutical sector which, combined with an unstable economic and political environment in the western Balkans, created a number of governance challenges in the pharmaceutical sector.

Improved governance and government leadership across sectors in Slovakia (Fidler et al., 2009) resulted in a modernized drug procurement system featuring a competitive, transparent, online pharmaceutical procurement process, combined with substantially higher patient copayments. These resulted in the proportion of the cost of pharmaceuticals falling from 38.5% to 32% of total health expenditure between 2003 and 2005. The drug expenditure minimization policy was, however, too aggressive with respect to consumers and had some undesirable side-effects, with the financial shock derived from patient copayments hitting the lowest two income quintiles of the population hardest. A new price control policy was implemented in 2008, combining administrative regulation of prices on the production side with regulation of markups on the distribution. Demand-side measures became less aggressive through upper limits on individuals' quarterly out-of-pocket drug expenditure. A regressive margin was implemented as an effective instrument to decrease costs associated with pharmaceuticals: drugs were classified according to price and the maximum permitted supplier margins were decreased with price (the total markup by the distribution chain ranged from 47% to 6%). Some estimates suggest the regressive margin policy saved an additional €30 million (Filko & Kiss, 2009).

A stricter second wave of reforming the procurement process was implemented in autumn 2009 after it was discovered that despite the more transparent price-negotiation process, prices of numerous essential drugs were still substantially higher in Slovakia than in considerably wealthier EU countries. A likely explanation is that before 2009, as a rule, the outcome of negotiations between producer and regulator depended largely on the negotiation skills of the two parties. Basically, a resourceful negotiator could easily pass through any price proposal. Since autumn 2009, total transparency of negotiation mechanisms has been assured by mandatory prior discussion of the relevant parameters for drug pricing between the Ministry of Health and pharmaceutical associations and a requirement for immediate online publication of the outcome of the discussions. The Ministry of Health has opened a database of internationally comparable drug prices in countries belonging to the EU after January 2007 (EU27) that is accessible to the entire population. The new law establishes that no drug price can exceed the average of the six lowest prices in EU27 countries.

The role of the regulator in Slovakia was substantially enhanced. Instead of negotiating prices with pharmaceutical producers, the regulator now forms clear prior rules for price setting. While the change of policy provoked substantial resistance from some pharmaceutical producers, some estimates suggest it has brought 7.3% of savings on national drug expenditure additional to those described above (Filko & Kiss, 2009).

These examples suggest that it is possible to attain significant improvements in controlling corruption in a reasonable period of time with relatively simple measures,

provided there is a common understanding of the relevance of the problem and coordinated action among different actors.

## 5.4 Challenges in health governance in ECA countries

The principles and characteristics of good health governance are based on a set of declared values:

- universality
- solidarity
- protection against health-care-related financial risks for all
- equity of access to good-quality care
- transparency and accountability
- sustainability.

A HiAP approach and operational embodiment of the health care system into an overarching multisectoral governance-for-health process is lacking in countries of the former Soviet Union. Public health is not yet regarded as a global concern, but rather as a task or competence of ministries of health. The absence of governance for health, lack of holistic understanding of the importance of public health and social determinants for health outcomes and a health system that focuses on curative medicine as the main instrument for achieving health goals mean that population health outcomes lag behind those of higher-income economies. Evaluating the gaps in equity, universality, transparency, quality and sustainability is limited to detecting health system failures and highlighting the potential role of other sectors in achieving improvements.

The lack of a single indicator to measure universality, solidarity, financial protection, equity, transparency and sustainability presents a further limitation in assessing health systems. There is no clear measure of what constitutes a functioning system. Each country tends to have its own unique health system with a mix of public and private financing, delivery and regulations. Comparisons of system performance tend to be limited to gross measures such as spending levels, morbidity and mortality statistics and assessments of service quality and user satisfaction where relevant data exist.

Gaps in universal access to health care, the unavailability of financial protection and lack of sustainability will be analyzed and explained through examples and case studies. Regarding transparency, there are no health-care-specific indicators available, additional to the corruption measures explained in the previous section.

### 5.4.1 Bridging gaps in equity

Equal access to health care is a central objective of most governments, and its attainment can be regarded as a robust indicator of good governance for health. Universal coverage is defined as a situation in which the whole population of a country has access to good-quality services according to needs and preferences and regardless of income level, social status or residency. It implies two key features – equity of access to services of a minimum quality standard and financial risk protection for individuals and families in case of a catastrophic health event – and may be financed through taxes or contributory insurance schemes and organized either through a single national scheme or a number of public and private initiatives (Gottret & Schieber, 2006).

It is usually assumed that a universal system implies equity in financing, although this is not inherent within a definition of universality. Equity in financing means that contributions are made on the basis of ability to pay irrespective of need or level of consumption of services.

Social solidarity is a key enabling factor behind many European risk protection arrangements, most of which have roots dating back to the late 19th and early 20th centuries. Numerous former Soviet Union countries have gradually lost the notion of social solidarity in their health systems since the early 1990s but still maintain the principle of equity through their status or constitution, perhaps through cultural influences (Ensor, 1999).

In Armenia, for instance, official user charges were introduced in 1997 alongside the introduction of the basic benefits package (BBP), a publicly funded package of services free of charge for the entire population that stipulates population groups entitled to receive health care services for free (Ensor, 1999). All other residents must pay out of pocket – in full, at point of use – for care and pharmaceuticals not listed in the BBP.

The BBP has been reviewed periodically, with the range of services and/or population groups covered being extended or reduced, depending on the level of funding available. This has resulted in considerable uncertainty, creating wariness among service users and health care providers. Similar practices can be also seen in other former Soviet Union countries (European Observatory on Health Systems and Policies, 2006).

Many households in Ukraine – nearly one in five – incur catastrophic health expenditures through high out-of-pocket spending. Spending from public sources appears to favour higher-income groups, resulting in an unfair cross-subsidy from poor to rich population segments (World Bank, 2008a).

These and similar countries tend to consider the absence of solidarity and equity as a temporary problem that will be addressed over the medium-to-long term, arguing that population coverage with free-of-charge essential services will gradually expand with growing national income. Countries such as Albania, Armenia and the Republic of Moldova have started with the formal employment sector (state employees and big companies) and gradually scaled-up contributory coverage to the entire population.

International evidence nevertheless shows that real progress on universal coverage can only be achieved when state transfers from general budget revenues play a strong role from the beginning. Starting with the formal sector and gradually scaling-up contributory coverage was a common strategy 60 years ago, but problems due to political capture by the initially insured (which tended to prevent the later inclusion of new population groups), fragmentation and efficiency and equity concerns expose the approach's serious limitations (Kutzin, 2009). Examples from the Czech Republic, Kyrgyzstan and the Republic of Moldova show that ensuring stable flows of budget revenues into the insurance pool requires a switch from subsidizing supply to subsidizing purchase of services for the population (Kutzin, 2009).

Kutzin et al. (2010) suggest that reform of the package (and associated policies on copayments) is unlikely to be successful without necessary changes in pooling arrangements and the incentive environment being created beforehand. They recommend that structural efficiency problems should be addressed first, before attempting to target other objectives such as equity and transparency.

The values of solidarity and equity of access are shared by social insurance and health promotion. First steps to include prevention and health promotion under the scope of activity of social insurance have been taken (Ståhl et al., 2006); this could be considered by countries currently building their social insurance system.

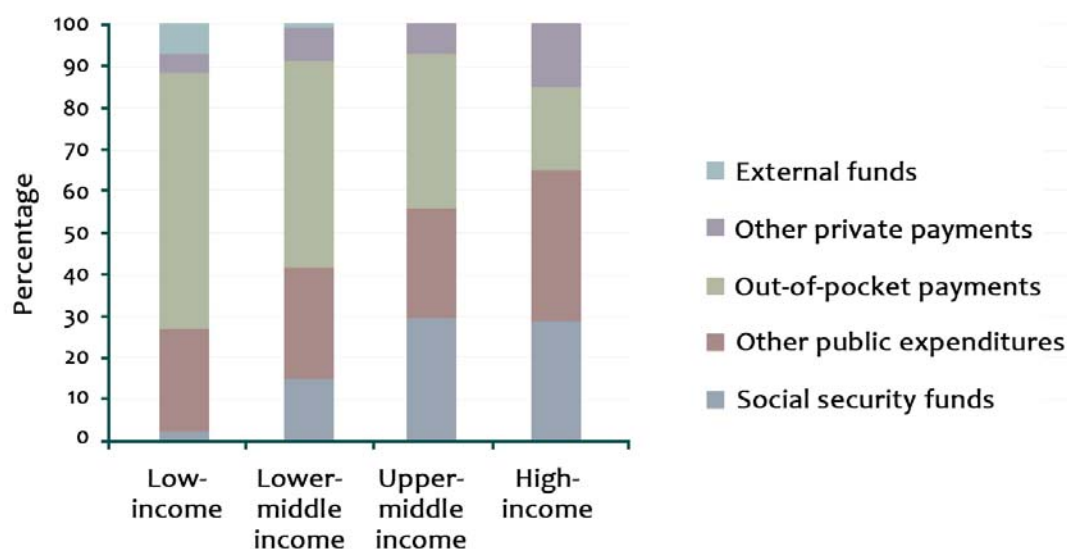
## 5.4.2 Bridging gaps in protection against health-care-related financial risks

Fundamental principles of good governance for health include protection of the population against health-care-related financial risks. Financial protection means protecting poor households from falling into poverty as a result of catastrophic spending on essential health services. The proportion of households facing catastrophic medical expenses can be used as one of the outcome indicators for evaluating health governance.

Out-of-pocket payments are an important source of health financing in many countries. They usually constitute direct payment to providers independent of other sources of funding and can be formal or informal, although it is sometimes difficult to distinguish between them in some countries.

Direct payments are usually regressive, as they may be unaffordable to the poorest. International evidence shows that out-of-pocket payments are inversely related to income: as countries become more affluent, the proportion of health financing from public sources increases (Gottret & Schieber, 2006) (Fig. 5.4). This might be a reflection of good governance, expressed through citizens' voices and choices.

Fig. 5.4. Composition of health expenditures in high-, middle-, and low-income countries, population-weighted averages, 2002



Source: authors, based on data in Gottret & Schieber (2006).

Informal and out-of-pocket payments dominate over other forms of health spending in some CCEE and former Soviet Union countries, including Armenia, Azerbaijan, Georgia, Kazakhstan, Kyrgyzstan, the Republic of Moldova and Tajikistan. They are also of major concern in many other countries:

- the percentage of households impoverished by out-of-pocket health spending raised from 1% in 1992 to 1.4% in 2002 in Estonia (Habicht et al., 2006);
- informal payments were so important in Kazakhstan that they had negative impacts on access to care and the functioning of formal payment systems (Ensor & Savelyeva, 1998);
- evidence from Kazakhstan showed that the lowest-income households spent more than twice their monthly income on health care for major illnesses while the wealthiest households spent the equivalent of half, reflecting the lack of exemptions for people on lower incomes (Sari et al., 2000);

- significant differences in utilization rates by socioeconomic groups were detected in Tajikistan, related to ability to pay (Falkingham, 2004); and
- the 2003 World Bank poverty assessment in Azerbaijan estimated that unofficial charges for childbirth varied from US\$ 100 to US\$ 150 in smaller towns, to US\$ 300 to US\$ 700 in Baku hospitals, which were up to 14 times the average monthly salary; informal fees were estimated to constitute 20% of all health expenditures, creating important problems of access to health care for people on lower incomes (Gottret & Schieber, 2006).

The literature also presents some positive country examples, including success in formalizing informal payments in Kyrgyzstan and achieving enhanced access to care among low-income populations in Georgia (Fidler et al., 2009).

The Kyrgyz approach to limiting widespread informal payments (including so-called envelope payments to physicians and contributions to hospitals as well as the value of medical supplies and drugs purchased by patients but intended as part of government-financed health care services) in public facilities where care is supposed to be free was to introduce formal above-the-table user fees in 2004. A BBP was introduced under the single-payer reform to provide free primary care through a general practitioner, with copayment being required only for inpatient care. It was hoped that by increasing the transparency of the copayment system and improving the flow of resources to health care providers, these health financing reforms would reduce, or even eliminate, informal payments, particularly in hospitals. Analyses of data from the 2001 and 2004 waves of the Kyrgyz household health financing survey and the health module of the 2007 household budget survey showed encouraging results. Out-of-pocket payments for drugs and medical supplies had fallen sharply within the first six months of the programme, being replaced by formal copayments. Less than half of hospitalized patients were making cash payments above the copayment threshold by 2004.

Seventy-seven per cent of total health expenditure in Georgia in 2005 was in the form of out-of-pocket expenditure, higher than in any other ECA country. The government launched the medical assistance programme (MAP) in 2006, targeted at poor people using welfare scores based on 80 variables, eliminating user fees for services included in a defined BBP and introducing a cash assistance programme for poor families. The scheme is still evolving, but in 2007 included acute out- and inpatient treatment, planned inpatient services, outpatient examinations below approximately US\$ 100 per beneficiary per year, institutional deliveries and other select services. An impact evaluation conducted by the World Bank found that the utilization of acute surgery/inpatient services was 10 times higher among MAP beneficiaries than among nonbeneficiaries with similar characteristics. A three-part model (the probability of seeking care, the number of services utilized and the expenditure incurred are modelled as sequential decisions) revealed that beneficiaries in the poorest quintile were significantly more likely to use acute surgery/inpatient services than those in the wealthiest. The number of services utilized did not differ across quintiles, but poorer people had slightly lower expenditure than those who had high incomes.

Despite Georgia's sophisticated poverty mapping, there is evidence that the MAP suffers from errors of inclusion (leakage) and exclusion (undercoverage). The government is exploring MAP expansion by raising the eligibility threshold to include less-poor and other vulnerable population groups.

The above examples suggest that protection against health-care-related financial risks can have positive effects in very different economic and political environments. Such means gain special importance in times of economic crisis.



### 5.4.3 Bridging gaps in sustainability

The sustainability of a health care system is an important governance outcome. It refers principally to the long-term stability of the financing mechanism and the affordability of costs it generates: the mechanism cannot be regarded as reliable if the revenue it generates is subject to considerable fluctuations. Sustainability also relates to the ability of a financing mechanism to maintain its level of funding in the long term and to expand funding over time as health care needs grow, with ongoing and purposeful planning for gradual increases in domestic funding for health services.

The determinants of health financing are a complex amalgam of institutional, demographic, socioeconomic, environmental, external and political factors (Gottret & Schieber, 2006) that go far beyond the scope of activity of ministries of health and which call for the adoption of HiAP and governance-for-health principles. Mossialos et al. (2002) (as reported in Gottret & Schieber (2006)) summarized these factors (Fig. 5.5). Demographic profiles, social values, environmental factors and economic activity are import determinants of mandated and voluntary health financing, but political structures and external pressures are also key to the nature, scale and effectiveness of mandated health financing.

Fig. 5.5. Determinants of health financing



Source: Gottret, Pablo; Schieber, George. 2006. Health Financing Revisited: A Practitioner's Guide. Washington, DC: World Bank. © World Bank. <https://openknowledge.worldbank.org/handle/10986/7094> License: Creative Commons Attribution CC BY 3.0 IGO.

Public spending levels on health depend highly on government policy priorities, even in constrained fiscal contexts. Several ECA country governments give health low priority, making already underprovisioned health care and weak financial protection of the population unsustainable. Low prioritization of health by governments hurts the poorest most, with indiscriminate cuts in government health expenditure being associated with reduced health status (Hopkins, 2006). Understanding the priority-setting mechanism is challenging, however, given the special position of ministries of finance in these countries. While ministries of health are committed to increasing health budgets, ministries of finance have at times reduced health financing in the presence of substantial external development assistance for health to government (substitution effect) (Chunling et al., 2010).

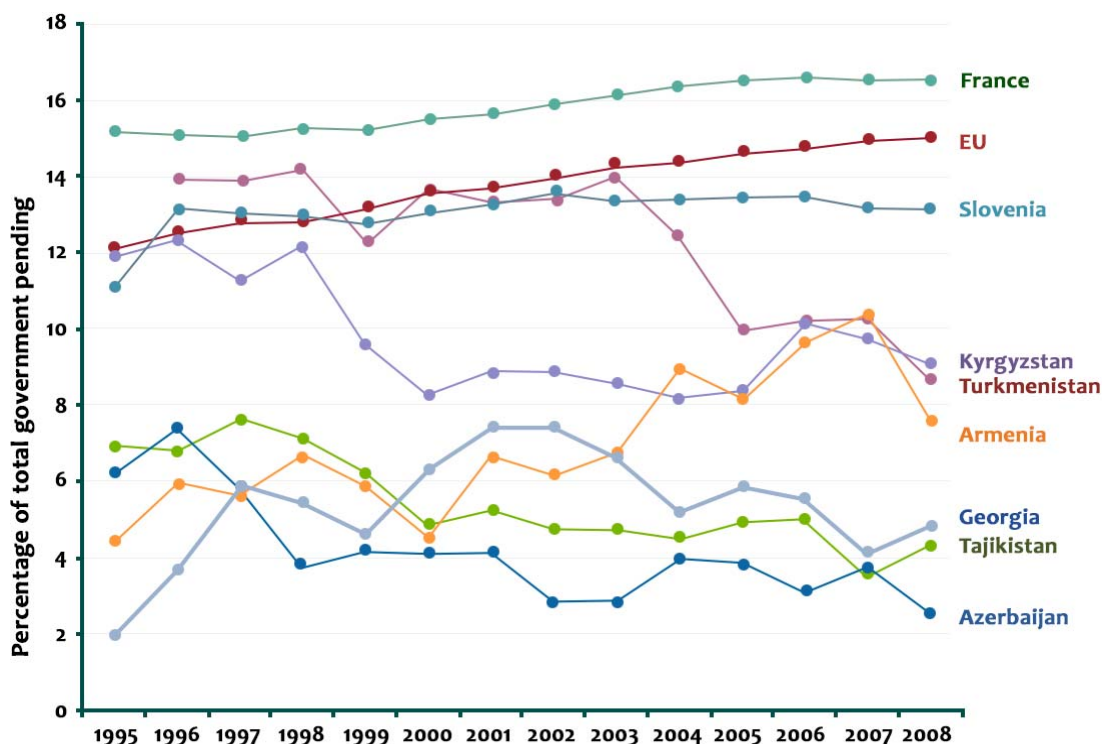
The literature suggests that it is not population health status but country GDP, government size and external health resources that most affect government health expenditures (Musgrove et al., 2002; Falkingham, 2004; Yontcheva & Masud, 2005; Baldacci et al., 2008; Mishra & Newhouse, 2009; Chunling et al., 2010). Some studies have also shown that international donor funding to a developing country is often fully translated into a reduction in government health spending (Chunling et al., 2010).

Chunling et al. (2010) found that development assistance for health (DAH) to government as a share of GDP showed a significant negative effect on government health spending as a share of GDP worldwide. Results for all developing countries suggested that for every US\$ 1 of DAH, the government reduced spending from its own sources by US\$ 0.46. This is probably an underestimate, with equilibrium-corrected coefficients suggesting even greater substitutability: every US\$ 1 of DAH to government might lead to a reduction of US\$ 1 or more in domestic government health spending.

Sustainable public financing of the health sector is important for the long-term financial viability of care. Countries that treat health aid as a substitution for, rather than as an addition to, government health spending run a higher risk of worsening their health system's performance, meaning households might be forced to pay more out of pocket and, if forced to make catastrophic health payments, be pushed below the poverty line.

Fig. 5.6 shows a comparison of selected countries' public sector expenditure as a share of total government expenditure.

Fig. 5.6. Public sector expenditure for health as percentage of total government expenditure, selected countries and EU



Source: authors' calculation based on WHO Regional Office for Europe (2013).

For the sake of simplicity, Fig. 5.6 refers only to a small number of countries, but its message is quite representative. While high-income EU countries such as France and Slovenia tend to have a smooth line and a high proportion of total government expenditure on health, many LMICs, including most Caucasian and central Asian nations, have a low and very volatile share devoted to health care. Government spending cuts in these countries tend to be indiscriminate and fail to preserve health governance elements that have the

strongest long-term benefits for health. People may be at risk of being pushed below the poverty line due to catastrophic health care spending on essential care.

As far back as 1993, the World Bank's world development report (World Bank, 1993) stipulated that household decisions to improve health status were constrained by household members' income and education levels. The challenge for most governments is to concentrate resources on compensating for market failures and financing health services that particularly benefit poorer people. The world development report recommended that governments pursue sound macroeconomic policies that emphasize poverty reduction, as overall economic growth – particularly poverty-reducing growth and social protection – and education are central to good health. Spending on health is a profitable investment: good health is both a key objective and a means for its acceleration. Targeting health as a multisectoral development effort is an effective way to improve overall welfare, particularly in LMICs.

Average public health spending (including by ministries other than health) as a percentage of total government expenditure was 15% for the EU and 13% for ECA in 2008. Most transition countries are below the EU average and also below the average for ECA countries, including EU accession nations. Exceptions are Bosnia and Herzegovina, Croatia, the Czech Republic, Lithuania, Montenegro, Serbia and Slovenia.

Although Slovenia faces some concerns and looming challenges in relation to health financing and modern care delivery, the country has shown that it is feasible to evolve from one form of health system to another and overcome obstacles without suffering substantial disadvantages (Fidler & Mikkelsen-Lopez, 2010). It has done this by engaging in healthy political and technical debate and by ensuring strong economic monitoring policies and fiscal prudence. Although the health system may not be perfect in the eyes of the consumer, it has managed to achieve and maintain comprehensive and equitable health coverage for the entire population and good access to well-distributed medical practitioners and hospitals around the country with reasonable outcomes and customer satisfaction (Fidler & Mikkelsen-Lopez, 2010).

## 5.5 Resilience and governance challenges in the face of the economic crisis

HiAP may be even more important in times of financial crisis. Governments are increasingly aware of the negative effects of the global financial crisis on population health and realize that the problem needs a collaborative response from a broad spectrum of policy-makers (Plumptre & Graham, 2000; Ståhl et al., 2006; European Commission, 2009a; Fidler et al., 2009; Hofmarcher, 2009; Stuckler et al., 2009).

The global financial crisis affected countries at all levels of income throughout Europe and the world. Different from previous regional economic crises, it displayed a global dimension in that it started in the most developed countries and spread to LMICs.

Regardless of the income category of the affected countries, the crisis hit low-income households hardest and caused substantial negative effects on the health status of populations. The World Bank estimates that an additional 50 million people were placed in extreme poverty in 2009 and 64 million by 2010 relative to a no-crisis scenario. Eighty per cent of these people could be undernourished due to parallel increasing food and fuel costs (World Bank, 2008b).

A Red Cross study of its European administrative region revealed that certain groups in society were more vulnerable to the adverse effects of the crisis, including children and young people, elderly people, those who were unemployed, migrants and refugees, and asylum seekers (International Association of Red Cross and Red Crescent Societies, 2009).

Real government spending on health care in countries of all income ranges tends to decline at times of crisis due to reduced tax revenues, currency devaluations and, in the case of middle-income countries, potential reductions in external assistance and lower remittances. Negative impacts on employment will have spill-over effects for health systems primarily financed by social health insurance. Compulsory health insurance funds in Austria, Estonia and Slovenia experienced deficits in 2008 and 2009 and have formulated various cost-saving measures to restore solvency (Hofmarcher, 2009; Albrecht, 2010; Kruus & Aaviksoo, 2010).

Some governments in the OECD decided to include health as a component of their fiscal stimulus packages, reflecting the significant role played by health in national economies (Table 5.1).

*Table 5.1. Measures taken in relation to health in fiscal stimulus package in selected OECD countries*

Country	Measures taken in relation to health in fiscal stimulus package
Denmark	Higher taxes on consumption and production of products that are harmful to the environment and health
Germany	Lower social contributions for health insurance
The Netherlands	Financial help to citizens (low-income, disabled and with chronic health problems)
Sweden	Increased resources to health and aged care providers.

Source: OECD (2009).

Europe's demographic challenge further compounds the situation. The European Commission (2009b) argues that the economic downturn accentuates the demographic challenges created by ageing societies, such as a rising dependency burden and threats to public finances through expenditure pressure on pensions, health and social services. A 10-year window for structural reforms to health, pension and education systems exists as a large reduction in the size of the labour force is predicted in the next decade. Some countries, including France and Greece, have introduced unpopular reforms to increase the retirement age to reduce pressure on public finances.

Previous economic crises have shown that health and social expenditure tends to recover slower than the rest of the economy, which will put poor and vulnerable people at most risk (Gottret et al., 2009). Sixteen per cent of the EU population is considered at risk of officially defined poverty even after social transfers, ranging from 10% in Nordic countries to 25% in Italy and the Baltic states (European Commission, 2008). Unemployment-related income reductions will affect household nutrition, transport and health care expenditure. Citizens of new EU Member States who aspired successfully to enter the middle class during the transition years are at risk of falling back into poverty, particularly when a catastrophic health event occurs in the absence of social safety nets.

Past financial crises have also shown a direct impact on households, negatively affecting demand for, and use of, health services (WHO Regional Office for Europe, 2009). Devaluation of local currencies may result in reduced consumption of essential drugs as local currency prices increase. All this may contribute to deteriorating health status. It should also be noted that in times of stress, people tend to indulge in less-healthy behaviours, such as consuming higher proportions of fat in the diet, taking part in

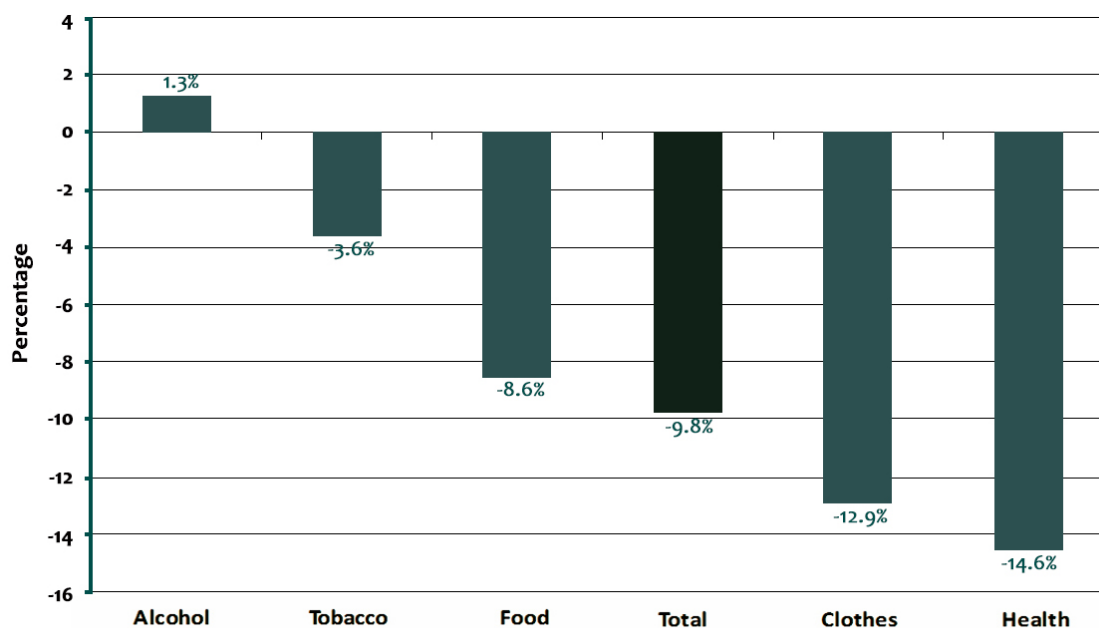
physical activity less frequently and increasing their tobacco and alcohol intakes. Those in lower-income categories may need to take on extra low-paying jobs, consequently having less leisure time with their family and children and taking less exercise. People may consume less-nutritious food due to household income reductions and forego necessary preventative and curative care.

Armenian households have been forced to change the following aspects of their lifestyle due to the current economic crisis (National Statistical Service of the Republic of Armenia, 2009):

- less expenditure on entertainment, reported by 65.7% of households
- expensive food substituted by cheaper options (57.8%)
- fewer or no visits to health centres (42.6%)
- fewer or no purchases of medications (36.4%)
- lower food consumption (34.5%).

This so-called forced change of lifestyle caused changes in real per capita household consumption (Fig. 5.7), including a 14.6% decrease in purchasing health care services and 1.3% increase in alcohol consumption. Such behaviour changes could entail adverse health outcomes in the future.

Fig. 5.7. Armenia: changes in real per capita household consumption, 2008/2009 (Quarter 1–Quarter 3, year over year)



Source: authors' calculations based on data from the National Statistical Service of the Republic of Armenia (2009).

Evidence suggests that increases in unemployment are associated with premature mortality from suicide in age groups less than 65 years (Stuckler et al., 2009), but empirical evidence from Europe has so far revealed only limited changes in effective health service utilization (WHO Regional Office for Europe, 2009).

Evidence and case studies from around the world suggest that the impact of the crisis on households and the health status of vulnerable populations can be alleviated through appropriate social protection and social risk mitigation measures, with parallel creation of new policies and effective responses to employment and social cohesion challenges presented by the economic downturn. In recognizing the importance of jobs for family health and welfare, governments not only need to tackle unemployment through active labour-market policies, but also adapt and modernize social assistance, health care and



public health services. Income support programmes, conditional cash transfers and active labour-market policies can stimulate demand, facilitate transition back to work and avoid social exclusion. They will also cushion the potential negative health effects of the crisis as they support households to cover basic needs and provide much-needed social safety nets. Barriers to formal labour markets in developing countries need to be reduced to ensure that workers have more opportunities to find decent jobs and are protected by labour-market institutions, including social protection measures (International Labour Organization, 2009).

In this context, the crisis provides a unique opportunity for many countries to continue reforming health and social sectors to improve governance for health and increase health and social spending efficiency. In Estonia, for example, responsibility for covering short-term sick-leave benefits was shifted in mid-2009 from the health insurance fund to employers and employees, with funds no longer used for sick-leave coverage being reallocated to health care.

Governments must maintain adequate revenues for the health sector, but should be circumspect in how this is achieved. It is not advisable, for instance, to increase payroll taxes due to the negative impact for labour markets, but rather experiment with increases in indirect (sometimes known as *sin*) taxes on tobacco, alcohol and unhealthy foods to compensate for potential revenue shortfalls and protect pre-crisis levels of public spending on health. Countries such as Poland and Slovenia have enacted such measures, with the former using revenues from increased excise taxes on alcohol to finance a social solidarity fund and the latter increasing excise taxes on alcohol and tobacco (WHO Regional Office for Europe, 2009).

Governments may also face the necessity of containing costs and curtailing public expenditure in times of economic downturn. Instead of applying indiscriminate budget cuts across the board, this can be achieved in social sectors by postponing selected capital investments and reducing overheads and overcapacity by rationalizing hospitals and improving social programme efficiency.

Other measures may include transparent pharmaceutical policies to exercise expenditure control, public tendering of health goods for economies of scale, sound registration and prescription practices and investment in cost-effective public health programmes, epidemiologic surveillance and health technology assessments to provide decision-makers with up-to-date intelligence on how to improve allocative efficiency.

Past crises teach valuable lessons on how to protect health outcomes and reduce financial risks. Protecting the most vulnerable households by safeguarding pro-poor spending on health, maintaining primary health care, protecting against catastrophic health expenditures and ensuring the use of transparent, formal cost-sharing, including exception policies for people with low incomes in lieu of under-the-table payments, is of the utmost importance for governments and policy-makers. These and other public policies should be implemented in line with the principle of governance for health, resulting in improved social solidarity and social protection.

All stakeholders in society should be involved in the common goal of protecting poor and vulnerable people and simultaneously maximizing society's health and well-being. Societies are interdependent: the economic impact of health on other sectors and on the whole of society is becoming increasingly evident. Citizens' role as active participants in governance should also be greatly enhanced.

## 5.6 Conclusions and recommendations

Analysis of existing gaps in governance for health in CCEE and former Soviet Union countries suggest four key messages.

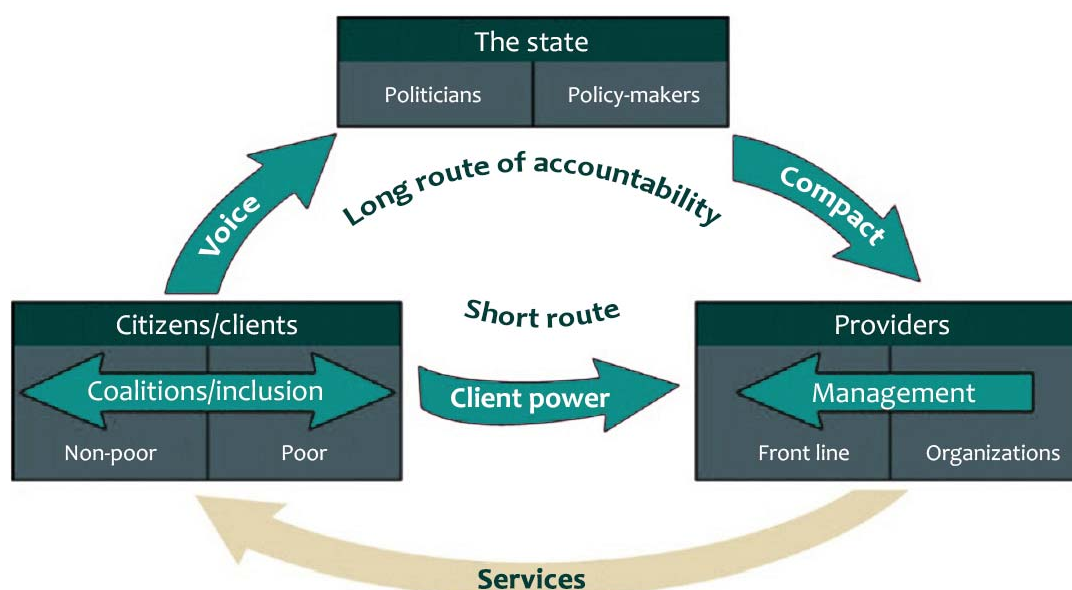
### 5.6.1 Leadership for HiAP

The population's health should be a priority governance issue for all sectors, not only for health. The notion of HiAP should be introduced into policy-making at all administrative levels (in line with a whole-of-government approach). Sectors that have the potential to influence population health and well-being should be identified, related policies and programmes interlinked and decision-making within and across all sectors coordinated.

### 5.6.2 Improved accountability of health providers

Better accountability of agents with an influence on population health should be assured. The World Bank's world development report in 2004 (World Bank, 2004) (as reported by Lewis & Pettersson (2009)) featured an accountability triangle that included policy-makers, providers and citizens. Health service providers' accountability is achieved either by the short route, involving direct feedback from citizens, or the long, which requires altruistic politicians and policy-makers to act as intermediaries for their citizens (Fig. 5.8).

Fig. 5.8. The long and short routes of accountability



Source: Lewis, Maureen; Pettersson, Gunilla. 2009. Governance in Health Care Delivery: Raising Performance. World Bank. © World Bank. <https://openknowledge.worldbank.org/handle/10986/4266> License: Creative Commons Attribution CC BY 3.0.

Effective health provider training and supervision at all levels and community involvement results in greater professionalism, more accountability and improved quality and outcomes, including those related to user satisfaction.

### 5.6.3 Focus on fiduciary management and control

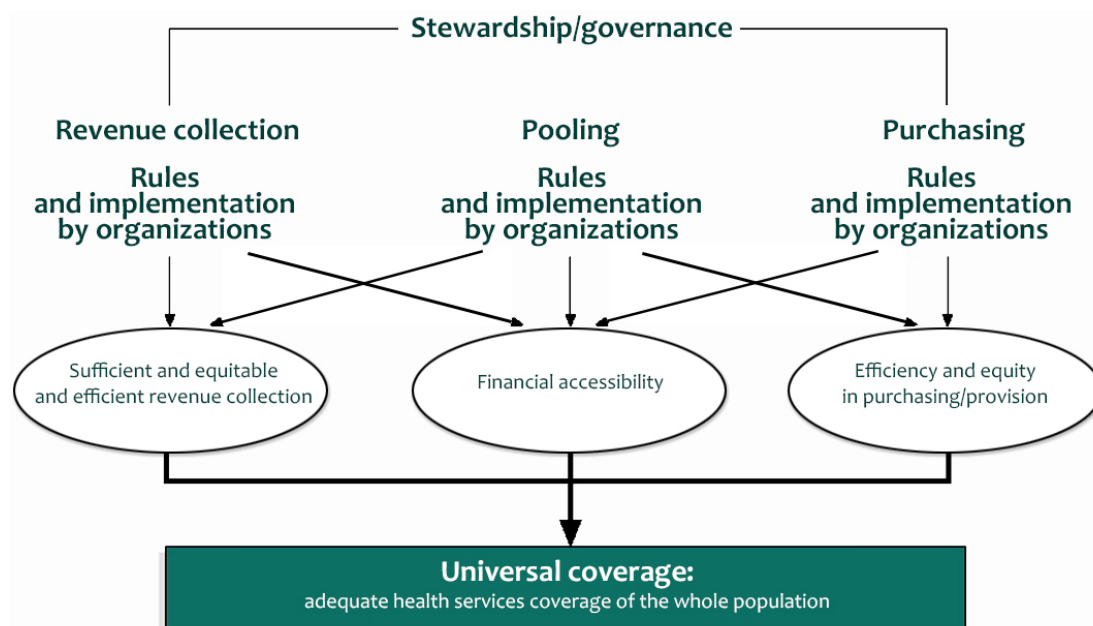
Improving health governance and better fiduciary oversight maximizes control of corruption, including limiting its extent and nature among public officials, tracking the incidence of nepotism and bribes among civil servants, identifying irregularities in public purchasing and increasing the extent to which governments manage corruption. Fear of being caught and expected sanctions are discouraging factors.

Many government bodies, not just the courts and prosecutors, can play important roles in anticorruption, including public sector ethics boards and ministry inspection boards, as is the case in Turkey (World Bank, 2008c). A decentralized system of enforcement of various provisions, including asset monitoring and conflict regulation, is an important feature of several EU countries. Routine audits of all aspects of fiduciary transactions should be ensured and improved records and record-keeping of public purchases should be implemented to provide systematic data necessary to control organizations. Citizens should be involved in decision-making and health care delivery and monitoring. Although not strongly associated with health outcomes, consumer involvement enables citizens to access information, challenge governments and ensure that services meet their needs.

### 5.6.4 Social protection and social risk mitigation

Governments should continue to build universal coverage. A combination of specific revenue collection rules, pooling and purchasing, and organizations' effectiveness in implementation will determine the efficiency and equity of the health financing system, but it is necessary to assess and understand the existing situation before rules and organizational arrangements can be optimized. The framework shown in Fig. 5.9 facilitates a focus on rules and organizational arrangements currently in force in different countries and helps in assessing how they contribute to, or detract from, the achievement of universal coverage. This framework should form the basis of plans to modify existing rules or introduce new ones.

Fig 5.9. Basic components of the framework to guide health financing system reform



Source: Carrin et al. (2008).

Health care financing should parallel economic growth and improvements in revenue collection. While it will be impossible to completely shield the health and social sectors from the impact of economic downturns, appropriate policies should be deployed to avoid a breakdown in health care financing specifically and social safety nets more generally.

Concerning DAH, health care financing sustainability should be maintained, keeping in mind negative externalities in case of spikes in funding flows. International donor inflows should be regarded as complementary to, and not substitutes for, government funds for health care.

International donor organizations should use strong standardized methods to:

- monitor government health expenditure and spending in other health-related sectors;
- establish collaborative targets to maintain or increase the share of government expenditure going to health;
- invest in the capacity of developing countries to effectively receive and use development assistance for health; and
- perform a careful assessment of the risks and benefits of expanded development assistance for health to nongovernmental sectors.

Governments are encouraged to protect social safety nets during and after an economic downturn as part of an overall HiAP approach. Focused efforts to sustain the supply of basic services combined with targeted demand-side approaches (such as conditional cash transfers) and active labour-market policies can be very effective. Health governance is a broad and far-reaching topic in CCEE and former Soviet Union countries; as such, it is often top of national governments' and multinational organizations' agendas, but all too often the concept of governance for health – a holistic understanding of public health that recognizes the interdependent role of diverse agents including government, health care providers, citizenry, finance and trade and public administration, among others – is not fully understood.

The chapter has used currently available data and literature to show that it is possible to evaluate health systems performance in CCEE and former Soviet Union countries in two ways:

- in a top-down way, looking at overall governance indicators (not only health care) and deliberately not taking into account components that affect the health and well-being of the population; and
- in a bottom-up way, looking at single health system performance/outcome indicators and arriving at an overall assessment in a synthetic way.

More research is needed, however, to tackle the missing middle. It is not currently possible to carry out a comprehensive analysis of governance for health from a multisectoral, interdependent and participatory governance perspective because of the lack of standard outcome indicators. In line with recommendations from WHO, the World Bank (and the European Commission in the case of EU Member States) and following the trend in most developed societies, CCEE and former Soviet Union countries should put more attention on broader aspects of governance for health in recognition that health, well-being and prosperity are not only concerns of ministries of health, but are common goals for all stakeholders in society.

### *Author disclaimer*

*Opinions expressed by the authors in this chapter are personal and may not necessarily reflect the positions or policies of the World Bank or the European Investment Bank.*

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## Part 4. Coproduction

# 6.

## Partnering for health governance transformation

Olivier Raynaud and Eva Jané-Llopis

### 6.1 Health as an economic imperative

Recent developments in the global economic landscape have helped to highlight health as an economic issue and an integral part of economic growth and development (Bloom et al., 2011). While health is intrinsically a right of global citizenship and has inherent value, proposing and translating it in economic terms promotes a universal understanding that makes participation in the health debate possible for all actors and helps political considerations, societal impacts and economic sense in investing in health to converge (Bloom et al., 2011; WHO, 2011a; World Bank, 2011).

The importance of making economic arguments for health is not new. When asked about the fundamental reasons for his engagement in the fight against malaria, the entrepreneur and philanthropist Bill Gates said (Gates B, unpublished observations, World Economic Forum Annual Meeting, Davos-Klosters, Switzerland, 2010):

It was not enough to know that people suffer and die; it was not enough that efficient control and care interventions were available. What made it compelling was the fact that investing in the prevention and control of malaria was one of the best buys of any development interventions.

Arguments on return of investment on vaccine and immunization programmes (Bloom et al., 2005) spearheaded renewed interest in expanded immunization programmes and the establishment of the Global Alliance for Vaccine Immunization (GAVI) and associated funding mechanisms. More recently, increased support announced by the United Kingdom Department for International Development earmarking aid for immunization programmes was based on the same argument of demonstrated economic value and measurable impact.

This is particularly important in health financing situations, where competition for resources (either within government or when engaging corporate communities, private actors or NGOs) requires that health interventions make good use of resources from taxpayers, donors or shareholders. Equitable and fair allocation of resources for health can best be decided using a league table that ranks health interventions on their health and economic merits. Access to clean water and sanitation, for example, often ranks first, bringing a clear case for social and economic investment even in the most resource-constrained environments. League tables of all interventions, not only those that link to development, would support decision-making and choice of interventions: the cost-benefit-conscious approach they promote is essential in ensuring interventions' economic value in terms of their societal impact is taken into account, rather than a health-payer perspective only. Most important, such considerations also need to reflect the broad consequences of some health-based decisions (even when direct economic value makes sense from a health perspective) and their indirect knock-on effects beyond health (to, for instance, trade, environment and agriculture) to ensure a broad understanding of the trade-offs these decisions imply in relation to costs and the benefits to all stakeholders and sectors (such as subsidies, jobs, deforestation and biodiversity).

The economic argument has proven extremely useful in placing noncommunicable diseases (NCDs)<sup>6</sup> at the top of the international agenda, raising awareness and triggering the broad coalition necessary to address this growing problem. The 2009 World Economic Forum global risks report identified NCDs as one of the top five economic risks, transforming what had been a health issue into an economic one (World Economic Forum, 2009). NCDs remained at the top of perceived global risks in 2010, highlighting their impacts not only on individuals and communities, but also on health systems, overall competitiveness and, ultimately, economic growth and fiscal balance (World Economic Forum, 2010). A collaboration involving the World Economic Forum and the Harvard School of Public Health in the United States that set out to estimate the concrete global costs of NCDs highlighted that they account for over US\$ 30 trillion of lost economic output, with mental health yielding another US\$ 16 trillion economic loss (Bloom et al., 2011).

The translation of disease incidence, morbidity and premature deaths into impacts on productivity, health budgets, social sectors and GDP in recent NCD debates has clearly contributed to mobilizing actors and decision-makers who had previously believed this health issue had to be solved at health-system level. The ability to make the economic argument is, however, only one small piece of what is necessary for the cocreation of modern health governance. Raising political awareness of NCDs at all levels and to all actors so it becomes a cross-sector and cross-ministerial responsibility will need to be strongly supported by a set of implementation options detailing their costs and benefits (WHO, 2011a) and a list of worked-through innovative mechanisms defining actions and accountability in the cocreation of health. This relates to, and builds on, previous definitions of health governance, describing a function that mapped burden of disease parameters into a set of collective societal responses and then mapped the reactions back to disease burden (Stuckler et al., 2009).

## 6.2 The multistakeholder nature of health

Health requires a cross-sectoral response that lies largely outside the health sector and involves trade policy, tax incentives, international regulation, the agriculture and environment sectors and general working and living conditions (Nishtar & Jané-Llopis, 2011), as was evident in the development of the WHO FCTC, the first international treaty negotiated under the auspices of WHO, which demonstrated the importance of intersectoral collaboration and action (WHO, 2003).

While the multistakeholder nature of health is understood globally, independently of country income or culture, few efforts to mainstream health or adjust new governance mechanisms to its creation have been successful. Governance for health is being distributed to stakeholders at different levels, starting with individuals. Greater health-informed and health-conscious populations, supported by wider access to health information, result in empowered individuals and movements towards a more person-centred approach to health and control of disease. Environmental influences – the contexts in which individuals learn and adopt behaviours – also influence and inform consumers to be, for example, more health-conscious in their spending patterns (Euromonitor International, 2010). The health and wellness segment in packaged foods in the United States food and beverage market is 2.3 times higher than that of conventional segments. As Smith (2009) notes:

Globalization has increasingly turned health and health care into cross-national issues, raising questions as to which collective action problems to prioritize as well as how to mobilize

<sup>6</sup> NCDs include cardiovascular diseases, respiratory diseases, diabetes and cancer and are driven by four major risk factors: tobacco use, unhealthy diet, lack of physical activity and harmful use of alcohol.



and coordinate the numerous actors who have some potential, yet critical role in delivering collective solutions.

The multistakeholder nature of health calls for new mechanisms and platforms that support and stimulate collaboration across the academic, political, nongovernmental and corporate worlds. This need has been recognized through the high-level United Nations political declaration on NCDs (United Nations Secretary-General, 2011) and the First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control (WHO, 2011b), which called for the engagement of all key stakeholders, including private and public sectors, in collaborative partnerships against NCDs and the establishment of HiAP (Box 6.1) (Hospedales & Jané-Llopis, 2011).

**Box 6.1. Coproduction of health: developing multistakeholder governance platforms for NCDs with ensured accountability of all players**

The problem of NCDs is caused by ageing of the population and widespread shared risk factors – unhealthy diet, physical inactivity, tobacco use and harmful use of alcohol – associated with globalization, urbanization and socioeconomic and environmental trends. Issues like poverty, culture, education, gender and ethnicity, workplace and school settings, and access to health services are important underlying determinants. As a consequence, most people eat too much salt, fat and sugar and do not get the minimum daily recommended 30 minutes physical activity, or five servings of fruits or vegetables. And most people with early stage of chronic conditions, do not know, are not diagnosed, or are not taking appropriate measures to prevent complications and maintain health.

This challenge requires new models of partnership within and among governments, private sector, and civil society, as interventions span individual/family level (behavioural changes), health systems (primary prevention, screening and early detection, and long term care) and policy level in finance, agriculture, education, trade, workplace, etc., and through actions in private sector and civil society levels.

Hampering this promising progress in action from government, civil society and private sector that has started in recent years, is a worrisome problem of fragmentation of initiatives, within and between sectors, and lack of coordination and efficiency loss. Currently there is no mechanism in place either globally or regionally, to ensure that the response to NCDs is optimized, existing stakeholders and initiatives mapped and duplication of efforts minimized. Such mechanism, could integrate ongoing efforts on different areas and across diseases, rather than opting for a vertical approach that is disease specific, as seen in the infectious diseases arena with partnerships like Stop TB partnership and Roll Back Malaria. For NCDs, given that addressing common risk factors can lead to synergistic effects in preventing NCDs, such platforms at local, national, regional or global levels, with appropriate governance and accountability by different stakeholders could provide synergies across existing actions against NCDs and foster horizontal and integrative policy and practice approaches for efficiency optimization. One such example being currently developed by the Pan American Health Organization (PAHO), with the World Economic Forum as a core partner, the **Pan American Forum for Action on Chronic Disease**, was launched during the United Nations high-level meeting on NCDs (September 2011).

Source: A multi-stakeholder platform to promote health and prevent NCDs in the region of the Americas: Pan American Health Organization Partners Forum for Action, Hospedales J, Jané-Llopis E, *Journal of Health Communication*, 2011, Taylor & Francis Ltd, reprinted by permission of the publisher (Taylor & Francis Ltd, <http://www.tandf.co.uk/journals>).

Such platforms are necessary, but efforts to promote new governance mechanisms reflecting stakeholder responsibility and accountability to break out of the classic way health is created and governed at local, country and global levels are struggling to succeed.

## 6.3 Principles for modern health governance: coordinating all players who contribute to health improvement

Given the multistakeholder nature of health, a few dimensions and principles should be considered when defining governance for health in the 21st century. These are:

- collectivity – different leadership levels for inclusive governance;
- management – the need for efficient and accountable governance; and
- shared responsibility – health as a shared issue and the need for participatory governance.

### 6.3.1 Collectivity

The first relevant principle refers to collectivity of the different players who contribute to and determine health. It highlights the complexity of who governs health (from individuals to governments and multilateral agencies) and the consequent complexity that is necessary to develop modern health governance.

Health starts with the family, with mothers at the centre. The important role women play in health in high-income countries and LMICs is evident (OECD, 2008). The framework for health governance should reflect this role by encompassing girls' empowerment and promoting higher representation of women on health-governing bodies.

Village and urban communities also represent key health collectivities. Village and urban leaders have important roles to play in health-governance, especially as they tend to have a closer relationship with their constituents than national leaders have with their voters. Mayors, for example, usually have longer terms in office than many other groups of politicians, which gives them the opportunity to integrate long-term health considerations into local policies. Citizens are strongest when determining and influencing their immediate health environment and are key to supporting and cocreating governance for health locally.

Cities represent an important level of society in which regulations and policies affect people. Urbanization is clearly identified as a major determinant of health, so urban settings are relevant for the design and implementation of interventions (Cooper et al., 2011). Several major cities, including New York, Vancouver and Mexico City, provide good examples of the pioneering role urban leaders can play in health.

Collectivity also implies striving towards an inclusive way of addressing and managing an issue. In this respect, health governance has for too long been kept in the hands of health experts. "War is too serious a matter to entrust to the military," former French Prime Minister Georges Clemenceau once famously said, and there is an interesting parallel to be made here with health governance. Improvements in health governance will have to address how better to include non-health experts and many other non-state actors, from city mayors to company chief executives, while having clear transparency and accountability rules for all players.

Private sector skills and know-how need to be integrated with global health organizations to improve health governance, an approach affirmed by WHO (WHO, 2010) in calling for the need to strengthen governments' capacity to constructively engage the private sector in providing essential health care services.

### 6.3.2 Management

Management in health tends to be characterized by excess fragmentation, failure to set clear objectives and accomplish desired common goals, and chronic insolvency (most health systems use more resources than are made available to them and consequently run a deficit). The health sector has resisted attempts to measure its efficiency and effectiveness, focusing the debate on availability of means rather than generation of results.

Principles for proper health governance should therefore address the need for:

- integration (as opposed to fragmentation)
- accountability (as opposed to shifting responsibility)
- efficiency (as opposed to a primary focus on additional funding mechanisms).

The root cause of gaps, and possibly the common prerequisite to addressing them, is lack of information. "You cannot manage what you cannot describe," goes a common management adage. Comprehensive health information should be a prerequisite for establishing proper governance. It can be achieved through accountability and transparency, performance measurements and benchmarking, and incentives. It is striking how these fundamental pillars of good management have only recently made their way into the health lexicon.

Health information also has to be accurate and accessible online; it is no longer acceptable to see biased, fragmented, incomplete or outdated health data being used to make decisions. Accurate health data are commonly not available when and where needed, but the efficiency of health systems relies on the quality and accessibility of data collected or received. The World Economic Forum has facilitated the development of a global health data charter (World Economic Forum, 2010) to drive improvements in how health data are captured and used. If the 20th century led to the development of evidence-based medicine, the 21st should mark the start of the data-based health era. The experience of several large health organizations suggests that improvement in the availability and sharing of health data enables integration and transformation in the way health is managed.

### 6.3.3 Shared responsibility, or interdependent accountability

Health issues need to be a shared responsibility for all stakeholders and sectors of society, but what if this responsibility is not recognized, measured or incentivized?

First, measuring the health footprint of each stakeholder seems to be a good way to start to ensure accountability is redistributed and acknowledged, metrics and trends are available and incentives are designed. A health footprint could be a fundamental tool for adequately distributing roles and responsibilities across all sectors and actors involved in prevention efforts, tracking progress in production and shifts towards healthy options, and reflecting the interdependence of most players and forces that determine or influence health. It can be developed at individual, industry, community and government levels and could represent a model for integrating the evidence on burden of disease, providing insights about the drivers of consumer behaviour, tracking progress over time of interventions' effects and supporting the alignment of health incentives (Harrison et al., 2011). It would speak to the accountability of all

actors and provide a framework to identify gaps and match necessary interventions, leading towards the cocreation of health governance.

Second, the concept of health issues being reflected in cross-sector policies is commendable, but needs to be implemented through, and supported by, a simple commonly agreed measurement system. HiAP requires that an accountability system is put in place through which, in the words of Professor Sir Michael Marmot, “every minister is a health minister” (Epimonitor, 2011). If education, for example, is such a powerful health determinant, perhaps the content of health education could be defined and delivered through the education system, regularly measuring health literacy levels in students and providing funding and incentives to the education sector in proportion to their positive impact on health. Health could therefore become an integral part of teachers’ job descriptions and an indicator to measure school performance; progress could easily be tracked and regularly communicated.

Third, understanding the potential future is key to determining direction for defining joint governance, recognizing different impacts of (and for) all stakeholders and justifying multistakeholder governance mechanisms. HIV/AIDS was the first major global health issue in which the need for a broad coalition was recognized early, with the development of a global scenario (Joint United Nations Programme on HIV and AIDS (UNAIDS), 2005) being a main contributing factor. Scenario development is a powerful tool for forecasting a possible future and addressing complex multistakeholder issues, allowing experts and other relevant actors to identify major trends and factors and the trade-offs and impacts of potential actions, and explore possible solutions and pathways to a desirable future through a collaborative approach. New governance in health could benefit greatly from scenarios that would unpack the main health threats currently facing systems and futures. In addition to fostering agreement on issues and promoting collaborative design for possible solutions, scenarios can also describe what key choices and decisions are needed today to put the world on track for the best future and establish accountability.

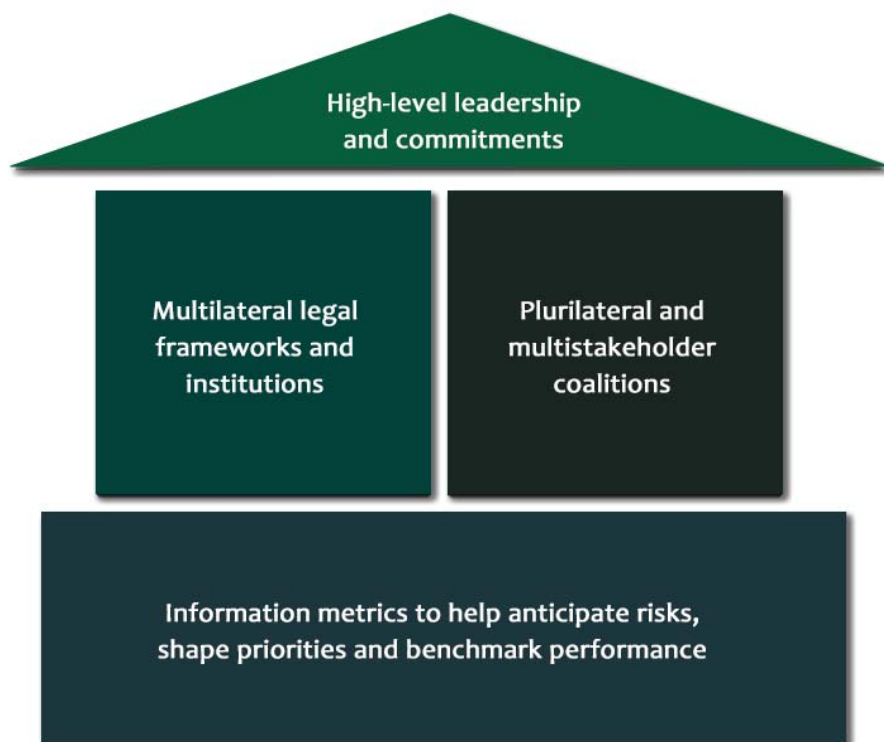
## 6.4 Partnering for transformation: a framework for integrated health governance

Fig. 6.1 proposes a simple framework as the basis for the architecture of new forms of governance and shows how it could apply to health. The framework was developed under the World Economic Forum global redesign initiative, a multistakeholder dialogue on the future of international cooperation (World Economic Forum, 2010). Set up in the midst of the global financial recession, its purpose was to stimulate thinking and debate about how the international community and its institutions and organizations (in the widest sense) can be adapted to contemporary challenges and devise potential responses to a new global business and social environment.

Applied to health, this framework proposes that new governance for health builds on its multistakeholder nature to promote coproduction of health (building health and effective health systems) from local to global levels.

The framework resonates with recent debates on international global health governance in which clear reference is made to how a “new multilateralism has emerged, which moves out of the realms of traditional diplomacy and is characterised as multi-actor, multi-issue, multi-role and multi-valued” (Kickbusch, 2009).

Fig. 6.1. Partnering for transformation: a framework for integrated health governance



Source: World Economic Forum (2010) (reproduced with permission).

Box 6.2 looks at each of the framework's modular building blocks, highlighting examples of successful initiatives where appropriate. The great transformation societies must undergo to achieve modern governance for health requires a fluid combination of all the building blocks when addressing health and beyond, truly taking into account the three main underlying principles of complexity, interdependence and coproduction (Kickbusch & Gleicher, 2012).

### **Box 6.2. Building blocks for integrative health governance**

#### **High-level leadership and commitments**

The MDGs helped set new priorities and triggered international actions complemented by concrete and results-oriented actions on the ground. Measurement is critical to ensuring commitments are followed up and accomplishments accounted. Many stakeholders are key to this development and joint action has supported implementation and promoted success.

#### **Multilateral legal frameworks and institutions**

Regulatory frameworks developed by governments or jointly with stakeholders have set the right conditions for advancement in health (in some cases). It is essential to set accountability and enforcement mechanisms to ensure success. The WHO FCTC is a good example of how to establish a new level playing field and give formal expression of new norms and principles to the international community. Such an initiative can be developed at global, national or even local level.

#### **Plurilateral and multistakeholder coalitions**

All stakeholders have a role and responsibility in the creation of health. Core competencies of all players and rules and transparency for joint action need to



**Box 6.2 contd**

be defined and agreed to unlock the power of multistakeholder action. The GAVI Alliance demonstrates that such alliances can achieve considerable results by coalescing the most relevant actors around a common cause.

**Information metrics to help anticipate risks, shape priorities and benchmark performance**

Strong metrics and continuous monitoring are essential for all of the above, as they can assist with anticipating risks, shaping priorities and benchmarking performance and progress. They can also be extremely powerful in influencing political debate and agendas, shaping policy, supporting planning and resource allocation, and tracking results. Greater impact is achieved by making information metrics independent and neutral. Metrics should reflect new frameworks of health governance and measures for all stakeholders to track progress and accountability.

## 6.5 Whole-of-society approach underpinning health governance

Health solutions require multiple actors to achieve the best outcomes for the largest number of people. Challenges in health, such as financing health services and influencing social determinants, are beyond the control of current decision-makers, yet the health sector is surprisingly poorly connected with other sectors, businesses and civil society, resulting in many missed opportunities to improve health outcomes.

Meeting the global health challenge of the 21st century will require two movements in current health governance: a shift from health as a moral issue to an economic imperative, addressing not only well-being and development but also competitiveness, fiscal situation and sovereign debt; and a shift from a mainly political and technical agenda to one in which civil society will be invited to take ownership. Rather than trying to rally other sectors around an agenda entirely conceived and driven by health professionals, the time has come to involve other sectors from the planning stage to improve the effect of curative and (particularly) preventive health activities, realize cobenefits and cocreate a new framework of governance to which all sectors and actors can contribute and benefit.

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# 7.

## Social media and Web 2.0: effect on governance for health

Maged N. Kamel Boulos

### 7.1 Introduction

#### 7.1.1 Sociable tools and activities

The Social Web, or networked social media (NSM), consists of mediated environments in which people can use their computers or mobile phones to connect with others, share information and generate content. NSM is sometimes inaccurately referred to as Web 2.0, but such versioning of the web is better avoided. It has been conceived as a social medium and a sharing and communication platform from the very start and has simply grown more popular, affordable and usable over the past two decades, to become what it is today and what can currently be observed as its prominent social aspects and opportunities. The core principles and concepts of online communities' and users' sharing, repackaging and repurposing of online content, however, have been there in one form or another since the very early days of the web – the first wiki, WikiWikiWeb, for example, appeared in 1994 – and pre-date the web (they could even be recognized in the 1980s CompuServe dialup service).

Examples of NSM tools include:

- social network sites, such as Facebook, Myspace and LinkedIn
- media-sharing platforms, such as YouTube, Vimeo and Flickr
- blogging and microblogging platforms, as in Twitter and Tumblr.com
- social bookmarking tools, such as Delicious.com, CiteULike.org and Connotea.org
- content creation through wiki platforms such as Wikipedia.org
- 3D virtual worlds and virtual globes, such as Second Life® and Google Earth.

Practices involved in NSM include discussions and collaboration, user-generated content, content distribution/sharing and signposting on user-curated pinboards (such as Scoop.it and Pinterest.com), copy/paste code creation, code and content remixing (known as mashups), content tagging (using loose, user-created vocabularies (folksonomies)), social voting and rating (such as digg.com), lobbying for various causes to effect change (through, for instance, online petition sites – see Sunday Morning (2012)), among others (Kamel Boulos et al., 2006; Kamel Boulos & Wheeler, 2007; Wheeler & Kamel Boulos, 2007; Kamel Boulos, 2010).

Social media and social networking now reach 80% of active Internet users in the United States (The Nielsen Company, 2012), with citizens of the United States spending more time on Facebook (53.5 billion minutes a month) than on Yahoo!, Google, YouTube, Blogger, Tumblr and Twitter (most of which also belong to the Social Web) combined. Despite the commonly held belief that Facebook is mainly used by teenagers and young adults, a survey in August 2011 reported that its use (and that of other social networking sites) is on the rise among those aged 50–64 years (51% of Internet users in this age group use social networking sites), with 33% of Internet users in the 65+ age group also using such sites (Madden & Zickuhr, 2011). Some have described that observation as the so-called greying of social networking sites. Introductory courses that teach the use of Facebook and Twitter are now available for those aged 60 and older, providing yet further testimony to the growing popularity of social networking tools among older

generations. Almost all doctors in the United States are believed to be on social media, particularly Facebook and Twitter.

Many health and social care providers, particularly in the United States, are using NSM extensively. Examples include the United States Centers for Disease Control and Prevention (CDC) (CDC, 2013) and a good number of hospitals: according to the Found in Cache web site, 1229 United States hospitals were using social networking tools as at October 2011, with 4118 hospital social networking sites spread between them, including 1068 Facebook pages, 814 Twitter accounts, 946 Foursquare, 575 YouTube channels, 566 LinkedIn accounts and 149 blogs (Hinmon, 2011). Even organizations with the strictest Internet access and user policies and regulations in place, such as the United States Department of Defence (2013), could not bypass the latest NSM wave.

The technologies that enable NSM are rapidly changing the way people interact, get information and do business in the health and social care sectors. Health care social networking can readily be seen today on the clinician side with professional networking sites such as Sermo (Sermo, 2013), a United States-based physician collaboration network, and on the patient front with support group sites such as the United States-based PatientsLikeMe (Wicks et al., 2010). NSM are excellent enablers of participatory health care and patient-centred care in which patients' engagement and empowerment are keys to improving clinical outcomes. Patients' self-help also has strategic importance in that it can help relieve some of the increasing burden on already constrained conventional health care systems (such as acute care hospitals), but engaging patients in care poses many challenges.

The least difficult of these challenges is related to access. A study found that people fighting chronic illnesses are less likely to have Internet access; once online, however, they are more likely to blog or participate in online discussions about health problems (Fox & Purcell, 2010). Tougher challenges include NSM's potential to rapidly spread misinformation (incomplete and/or wrong or inaccurate) and the related difficulties in moderating and controlling the quality of the vast amounts of user-generated content (Clauson et al., 2008; Scanfled et al., 2010; Steinberg et al., 2010; Knösel & Jung, 2011; Liang & Mackey, 2011; Briones et al., 2012).

Analysing Social Web post aggregates in real or near-real time can provide a good indication of the prevailing public opinion(s), attitude(s) or knowledge of corresponding communities on different matters of interest (Kamel Boulos et al., 2010a; Kamel Boulos, 2011). It indicates the general public mood or understanding of a given topic and where the so-called wisdom of the (online) crowds is pointing, acting like a measure of the pulse and beat of online societies, including measuring public satisfaction with health care services (Greaves et al., 2012). As more and more people all over the world get connected to the Internet, online societies are rapidly becoming a good mirror of conventional (offline) societies. The Social Web is a strategic place of choice to reach out to them and influence in ways that were not possible a few decades ago through, for instance, using viral (rapidly spreading) videos, electronic word-of-mouth (eWOM) and other forms of viral social marketing techniques (Gosselin & Poitras, 2008; Purdy, 2011). Tracking the change in Social Web post aggregates over time after some Social Web opinion/attitude-shaping or knowledge-changing intervention has been made enables monitoring and assessment of the effectiveness of the intervention and tweaking or retargeting as necessary.

### **7.1.2 Virtual worlds, virtual workplaces, virtual globes (mirror worlds) and gaming consoles**

Multi-user 3D online environments, such as Second Life®, MPK20 and Google Earth, represent a viable venue for professional collaboration, participatory health care,



public health education and many other applications. They have been likened to vast collaborative 3D wikis, offering unique and immersive audiovisual spatial experiences that enable multiple users to experiment and edit together, seeing changes in real time (Kamel Boulos & Burden, 2007; Kamel Boulos et al., 2007; Huang et al., 2008; Kamel Boulos et al., 2008a; Kamel Boulos, 2009; Kamel Boulos & Toth-Cohen, 2009; Toro-Troconis & Kamel Boulos, 2009).

The rich experiences such environments offer combine many of the features of the so-called flat Social Web, such as group instant messaging, voice chat, user profiles and real-time social networking. They also provide unique forms of online social interaction, cobrowsing and copresence that involve sharing and remixing various objects and building and running places and services collaboratively in the virtual world (user-generated content). The latest generations of home 3D-gaming consoles also feature similar prominent Social Web elements via their corresponding online social networks and are being successfully tested and used in a number of health/fitness and health care-related scenarios in, for instance, home telemanagement of congestive heart failure (Finkelstein & Wood, 2011).

The functionalities of virtual worlds such as Second Life® and mirror worlds like Google Earth are starting to merge, opening many new possibilities and applications, including novel emergency and public health virtual situation rooms (Kamel Boulos, 2009). The Digital Birmingham project commissioned by Birmingham City Council in the United Kingdom (England) provides another example of combining virtual and mirror worlds (Kamel Boulos et al., 2008b). True stereoscopic 3D is now possible in these environments, adding to their realism and immersiveness (Kamel Boulos & Robinson, 2009); this is necessary in many serious applications of these worlds, such as in virtual situation rooms. Running virtual and mirror worlds on small-form factor mobile devices such as smartphones and tablet computers is becoming technically feasible thanks to a number of developments, including the latest generations of multiuser 3D virtual worlds that can directly run in standard web browsers (and can easily be embedded in social network sites and other web pages), cloud computing and server-side graphics processing (Ross, 2009) and newer smartphone and tablet chipsets supporting advanced and stereoscopic 3D graphics.

The convergence of web-based geospatial technologies and virtual globes and the growing practices of user-generated georeferenced content disseminated via Social Web tools and services (such as the FixMyStreet and LoveCleanStreets citizens' reports about neighbourhood problems, described below) are also changing the way citizens help each other and wider society and interact with their local government. Google Earth, for example, has become known as a Wikipedia of the Earth, with very large amounts of user-generated content and layers being added continuously. Kamel Boulos (2005a) predicted this in 2005, coining the phrase-terms "online consumer geoinformatics services" and "wikification of geographic information systems by the masses". The public, sometimes knowingly and at other times unknowingly, is generating a remarkable new form of georeferenced information for local government and public health/public services research and practice called volunteered geographic information (VGI) (Kamel Boulos et al., 2011a). A good example of VGI can be seen in the collaborative OpenStreetMap project (OpenStreetMap Foundation, 2013), a free editable map of the whole world made by ordinary people. This VGI phenomenon represents a major paradigm shift not only in georeference content and characteristics, but also in how information is created and shared (and by whom) and through the new opportunities it presents for creating all kinds of useful mashups and serious data-mining of information aggregates.

Another closely related area, location-based augmented reality on mobile phones, can also include different kinds of VGI and wisdom of the crowds (useful crowdsourced intelligence about a given place). Layar (2013) is an example of this technology, with

layers being added all the time, including many that are health-related. Also worth mentioning in this context is the Google Open Spot crowd concept, which is meant to help citizens assist each other in finding parking space so they can save time and fuel and reduce pollution.

### 7.1.3 The Internet of things and crowd-sensing

Crowd-sensing and citizen reporting of incidents are becoming increasingly common, with applications ranging from distributed air-quality monitoring and building a crowdsourced database of all the automated external defibrillators in a major city to protest movements, political activism and citizen journalism (citizens equipped with Internet-enabled mobile phone cameras), as witnessed, for example, in the 2011/2012 Occupy movement and so-called Arab spring events. Kamel Boulos et al. (2011a) published a comprehensive review of the main technologies and standards involved in this domain of citizen-sensing.

In this age of the Internet of things, it is becoming increasingly common to find volunteer citizens carrying various kinds of Internet-enabled sensors serving different purposes, such as distributed radiation-sensing and monitoring of environmental pollution. These Internet-connected sensors can either be embedded in smartphones (many of the latest models already include a range of useful sensors and can additionally detect and automatically attach geolocation information to reports and other data sent by the user) or are provided as special devices (with built-in suitable means of communication to relay and upload measurements to the Internet either directly or via a nearby Internet-connected computing device or smartphone) to be worn or carried around by the user, fixed somewhere in their living space, or mounted on their bicycle or car.

Xively is an online database service allowing developers to connect sensor-derived data to the web and to build their own (mapping) applications based on those data. Following Japan's Fukushima Daiichi nuclear accident in March 2011, Xively was used to monitor and map radiation levels in real time by interlinking live radiation measurement feeds obtained from portable Geiger counters (radiation sensors) owned by concerned individuals from across the country. The Japan Geigermap created by Haiyan Zhang is a good example of a Xively-powered, crowdsourced, real-time radiation map of Japan.

### 7.1.4 The mobile Social Web on smartphones and tablet computers

A December 2010 report on phone use by the United States National Center for Health Statistics at the CDC found that more than half of people in the United States aged 25–29 lived in households with mobile phones but no traditional landline telephones (Blumberg & Luke, 2010). The same study also identified that the younger children were, the more likely they were to live in homes that only had wireless phones, suggesting that younger parents are becoming increasingly reliant on mobile phones even as they adjust from being single to a more settled family lifestyle.

Smartphones are increasingly viewed as handheld computers rather than as phones due to their powerful on-board computing capability, capacious memories, large colour (and often multi-touch-enabled) screens and open operating system architectures that encourage third-party application development. The potential for the creation of simple and easy-to-download applications (apps) for smartphones and tablets has created a vibrant new industry. The mobile Social Web is enabling people to easily share, rate, recommend and find software apps about almost any topic. Before the advent of smartphones, small-form-factor tablets and the latest generations of operating systems and web browsers that support the concept of apps and associated app stores or markets, downloading and installing software was neither easy nor popular (among

average Internet users). There is now an app for just about every social, entertainment and educational requirement, with great scope to harness the potential of the mobile Internet to improve many aspects of society (including health care and health care governance) through, for example, apps supporting distributed communities of clinical practice or mobile Social Web tools aimed at enhancing citizen and patient empowerment (Kamel Boulos et al., 2011b).

Smartphones have now achieved such a pervasive presence in society that users find it easy to self-organize across wide geographic areas. Many have adopted a culture in which they are always connected to their peer groups, communities of practice and information. The Internet-enabled mobile phone provides an essential any time, any place portal to the entire World Wide Web of knowledge. Such continuous and pervasive social connectivity has important implications for society and holds much potential for use in professional and patient education and other aspects of health care and medicine. GPS and location-enabled smartphones offer many additional application opportunities that can further support independent living for people with disabilities and/or multiple chronic conditions (Kamel Boulos et al., 2011c), epidemiology and public health surveillance, and community data collection (Aanensen et al., 2009).

Kailas et al. (2010) claim that there are already in excess of 7000 documented cases of smartphone health applications. Extensive reviews of mobile phone and handheld computing device use in health and clinical practice can be found in the published literature (see, for instance: Terry (2010); Sarasohn-Kahn (2010)). Reviewers highlighted several key features that give mobile phones the advantage over other information and communication technologies, including portability, continuous uninterrupted data stream/always-on Internet, capability to support multimedia software applications through sufficient computing power, and the potential to connect medical sensors/devices (such as a glucometer) to smartphones, either directly (using a special cable) or wirelessly. Significant economic benefits (or the potential for such benefits) and improvements in clinical outcomes have also been reported in the literature (Liang et al., 2011), with mobile communication being employed in the provision of remote health care advice and telemedicine.

Notwithstanding the benefits, smartphone use in health care and clinical practice is not without its problems and limitations. The small internal storage capacity, processing power and screen size of mobile phones compared to laptop computers often requires applications to be run in reduced format (Kailas et al., (2010), but cloud computing resources (which are external to the mobile device) may obviate restrictive processing speeds and memory requirements in the future. Mobile phones are nevertheless smaller, more portable and less obtrusive than standard notebooks, so it could be argued that this is a reasonable trade-off. Although much mobile phone communication is now conducted using text, voice communication still necessitates the securing of space within which vocal communication can be made in private. This may be essential to maintaining the confidentiality of patient information if used in public spaces. Other factors, such as loss or theft of devices, may affect the security of confidential digital health records or data held on smartphones and tablets. The security and privacy of patient and other sensitive data held on mobile phones and pads has been a concern for some time (Sarasohn-Kahn, 2010), while some studies warn of the security risks of using mobile instant messaging in health care (Barnes et al., 2007).

Malware distribution and privacy invasion are also serious risks. Individual privacy risks led the Global System for Mobile Communications Association (GSMA) to publish privacy design guidelines for mobile application development (GSMA, 2012). Issues of smartphone app content quality and provenance (in, for example, the case of patient education apps) have also been raised, and the United States Food and Drug Administration (2013) proposed review procedures and guidelines for mobile medical apps.

## 7.2 Social Web and NSM governance-related work

### 7.2.1 United Kingdom initiatives and commitment

#### 7.2.1.1 National Health Service web accelerator initiative

National Health Service (NHS) North West launched the NHS web accelerator initiative, a partnership involving several NHS organizations and a web software agency working exclusively with the NHS. The initiative focuses on quickly introducing creative and low-cost ways of using the Social Web and social media for the benefit of patients, clinicians and NHS managers and has produced NHS Web Tools, a comprehensive online catalogue listing and describing many Social Web tools that can be used in health care.

#### 7.2.1.2 “Show us a better way” competition

The government showed its strong commitment to empowering citizens and encouraging their participation in decisions that can shape their present and future by making available gigabytes of new or previously invisible public information (this is also a good step towards transparency for better governance) and launching a £20 000 data mashup competition in June 2008, “Show us a better way”, that was open to all members of the public (Cabinet Office, 2010a). In launching the competition, the government said it wanted “to hear [the public’s] ideas for new products that could improve the way public information is communicated”. Citizens responded very positively, with excellent ideas on tackling health care, environmental pollution, crime and many other issues and aspects of society and civic life (Cabinet Office, 2010b).

#### 7.2.1.3 Executive director of the government digital service

The government now has a dedicated executive director of the government digital service (the so-called Director for Digital) to manage and integrate NSM digital technology into the infrastructure of daily government communication and practice. The post aims to support and encourage all government departments to become excellent in using digital engagement techniques, such as communicating through social media sites, alongside traditional engagement methods.

#### 7.2.1.4 Data.gov.uk portal

Launched in September 2009, this is an ambitious project that aims to open up (for free reuse by members of the general public) almost all nonpersonal data acquired for official purposes. The portal is making freely available to its visitors thousands of government datasets and over 100 apps harnessing public data.

#### 7.2.1.5 Police.uk

The new police mapping service was launched online in January 2011 to map crime levels throughout the United Kingdom (England and Wales). The online service uses Google Maps and displays media feeds tracking crime developments in local areas. The site also

offers all the underpinning raw data for downloading, in addition to a mobile phone app and an experimental London crime heatmap that uses the latest HTML5 markup language and base layer for rendering (for an overview of HTML5, a core technology of the Social Web today, see: Kamel Boulos et al. (2010b)). Members of the public are also encouraged to suggest mobile phone app ideas or build and add their own apps using police application programming interface data made available for this purpose.

### *7.2.1.6 Improving communication between local councils and the people they serve and supporting local renewal*

Some local councils are now using Social Web tools for reaching out to engage with local people on their own terms, rather than waiting for people to come to the council to participate in conversations and air their opinions. The London Borough of Barnet, for example, appointed a social media manager in 2008 to scope out and implement the council's social media strategy: this was a first at that time in the United Kingdom. The council decided to embrace the latest Social Web technologies as a means of engaging with existing online social networks and embedding the council within them. Video recording and broadcasting its meetings and other council-related material is making the world of the council far more open, transparent and accessible to the people it is serving, thereby helping to establish trust and participation as the basis for meaningful future conversations. The council is now running its own broadcast channel on YouTube and using social media to communicate with the public.

### *7.2.1.7 FixMyStreet and LoveCleanStreets*

The London Borough of Barnet is also benefiting from FixMyStreet (mySociety Ltd, 2013), a very handy Social Web service that encourages people to report local neighbourhood problems such as graffiti, fly-tipping, broken paving slabs or inoperative street lighting in a few easy steps. The user starts by entering a nearby postcode or street name and area, then locates the problem on a map of the area and inputs the details of the problem. FixMyStreet then sends a report to the council on behalf of the user. Other councils in the United Kingdom are also using the service, with very positive results. Lowering the barrier to interacting with councils has resulted in a barrage of citizens' e-mail reports via the service and corresponding repairs of reported problems.

LoveCleanStreets (Bbits, 2013) is a FixMyStreets-like application that is able to use mobile phones' built-in GPS and camera. Features include:

- direct reporting to local authority of environmental/neighbourhood issues by mobile phone;
- automatic location detection and attachment to reports (via GPS);
- capacity to send a photograph with the report (using the mobile phone camera); and
- facility for users to visit the web site to review the progress of their reports and corresponding actions taken by the council.

City councils across the United Kingdom are responding very well and promptly to citizens' reports, encouraging citizens' active and continuing participation in the process, fostering vibrant responsible communities around the service, and preventing people from simply giving up.

Older people's engagement via participatory reporting platforms is likely to contribute positively to their psychosocial well-being and help relieve some of the feelings of isolation and lack of value that are common in this age group (provided the tools can be made to suit the special usability and other needs of older people and communities); this also fits nicely into the concept of e-inclusion, which holds that no one is left behind in reaping and enjoying the benefits of information and communication technologies.



### 7.2.1.8 Patientopinion.org.uk

This not-for-profit web site, which is independent of the NHS and government, was founded by Sheffield general practitioner Dr Paul Hodgkin to enable NHS managers to put to good use insights and ideas from patients' feedback. Patients can rate and share their NHS experiences online, helping other patients and perhaps even improving NHS services (Kamel Boulos & Wheeler, 2007), through an easy-to-use online platform that allows them to tell their stories about what happened to them or their family when they received care at any NHS facility and make suggestions about how services could be made better. Patients and carers can also find out what others are thinking of local hospitals, hospices and mental health services. NHS service managers receiving users' postings from the service can gauge patient satisfaction levels and use the real experiences of NHS users to identify and rectify problems and improve care services. Managers will often post replies on the site explaining how they have improved a particular service.

### 7.2.1.9 NHS Choices

One way to widen the reach of health care service providers' messages is to take the messages to the places where people go, rather than wait for people to visit the provider's web site or pick up a printed leaflet at the reception desk. Health and social care organizations are beginning to exploit the unprecedented consumer reach and power of viral marketing techniques (Gosselin & Poitras, 2008) enabled by Social Web tools. The NHS Choices team, for example, established a successful broadcast channel on YouTube (also available on social media) hosting a growing number of videos with health-related messages, exploiting popular online places the target audiences frequently visit to broadcast health education and promotion content. The ease with which tools such as YouTube are enabling users to share this content and their experiences, comments and opinions with progressively larger audiences (by, for instance, e-mailing it to others, making links to it or embedding it in their own posts, blogs and social network sites) makes these tools extremely powerful as viral marketing channels.

The NHS in United Kingdom (England) has also made available a free NHS Direct app for smartphones and tablets (there is a mobile web version for web-enabled smartphones). The app provides health and symptom checkers, covering a comprehensive range of problems such as diarrhoea and vomiting, abdominal pain, chest pain, rashes and burns among others, based on the same algorithms used in the NHS Direct popular online symptom checkers and nurse-led telephone-based triage system. The app is also linked to NHS Direct's telephone service so that if further assessment is deemed necessary, the user is asked to submit his or her contact details for a nurse advisor to call back.

### 7.2.1.10 Hospitals using the Social Web

Hawker's (2010) quantitative analysis investigated the online identities of primary care trusts in the NHS in United Kingdom (England) to inspect their use of social tools and found that 61 organizations (40.13%) used at least one, with the most popular being Twitter (n = 30). The study noted, however, that organizations appeared to be failing to take advantage of the interactive nature of social media and were instead using it as unidirectional information-push channels.

### 7.2.1.11 Second Health

Second Health invites members of the general public to join "the 3D virtual world of Second Life® to explore, discuss and shape a shared vision of the future [of health care]", moving towards a "health system centred on each patient's specific needs" (Second Health, 2013). For those unable to join Second Life® (due, for instance, to lack of the

necessary computer graphics hardware or skills), a series of documentary machinimas (movie clips produced in Second Life®) is available to show them what the 3D virtual world versions of the Second Health hospital and polyclinic plans and patient scenarios look like. The designs realized in Second Life® are based on the vision, principles and recommendations outlined in the 2007 *Healthcare for London: a framework for action* report (NHS London, 2007). The visual, spatial and immersive nature of the Second Health experience in Second Life® is potentially a better way to convey to laypersons the key vision and plans from the report and engage the general public.

### 7.2.2 Examples from continental Europe (France, Norway and Spain)

The French site “Le guide santé” offers a service similar to that of the patientopinion.org.uk site, where patients can read and post comments about their hospital services and rate services.

Projects similar to the data.gov.uk portal and “Show us a better way” competition in the United Kingdom have been developed in Norway. The Ministry of Government Administration, Reform and Church Affairs launched a national data portal and catalogue offering a growing range of public sector data and mobile apps, supported by a licence for open data to facilitate reuse (in, for example, customized user-created data mashups that combine and link distributed data from different government agencies for all sorts of useful purposes). In addition, Nkr 2.5 million was made available in 2010 to NGOs, schools, universities, private individuals and companies who were able to apply for support/scholarships for amounts ranging from Nkr 10 000 to Nkr 250 000 for projects harnessing the potential of social media, Social Web technologies, volunteered web information and open data.

“Internet & salud: migrando hacia la Red 2.0” [“Internet & health: moving to Web 2.0”] is a Spanish project that analyses Social Web developments in the health field through an observatory and portal. The observatory gathers information and prepares reports on Social Web uses in the health sector and has published a report on the presence of Spanish hospitals in social media, using qualitative and quantitative descriptive methodologies (Andalusian School of Public Health, 2010).

### 7.2.3 Cross-sector mashup examples

Mashups have gone mainstream in supporting interagency collaboration, joined-up government and a better-informed citizenry. Government agencies, including health care organizations in many developed countries, are now regularly mixing their data with social media and linking and sharing their distributed information silos in unprecedented ways (Kamel Boulos et al., 2008a; Yasin, 2010). A good example is the “London profiler” service, a maps mashup that combines comprehensive higher education, health, crime, transport, house prices, multiple deprivation and other data about London and its individual boroughs (Giben et al., 2009). Other (mainly United States) government data mashup examples can be browsed online on the ProgrammableWeb web site (ProgrammableWeb, 2013).

### 7.2.4 HealthMap (mashup and apps)

HealthMap offers a unique mashup of disparate data sources to provide a real-time global view of emerging infectious diseases and their effect on health (Brownstein & Freifeld, 2007). This freely available online resource integrates outbreak data of varying reliability, ranging from news sources and crowdsourced users’ reports, to curated personal accounts (such as the International Society for Infectious Diseases’ Program

for Monitoring Emerging Diseases), to validated official alerts (such as those issued by WHO, EuroSurveillance and the European Centre for Disease Prevention and Control).

An automated text processing system allows the data to be aggregated by disease and displayed by geographic location using mapping technology. A user-friendly interactive visual map provides a jumping-off point for real-time information on emerging outbreaks and should prove useful to public health officials and international travellers, among others. Smartphone users are also able to access HealthMap on their devices and contribute their own outbreak reports by downloading and running a free app called “Outbreaks near me” (Freifeld et al., 2010).

The HealthMap team also created MedWatcher, a mobile app for health care professionals and the general public that allows users to submit adverse drug event reports to the United States Food and Drug Administration. Clark Freifeld of the Children’s Hospital Informatics Program, Boston, who jointly led the app’s development, stated (PR Newswire Association LLC, 2013):

[It is hoped MedWatcher would] prompt increased participation in surveillance, empowering people to participate in the public health process, but also potentially allowing us to crowdsource problem drugs, which will lead to better understandings of side effects of medicines, and possibly even bring about earlier detection and prevention.

“Outbreaks near me” and MedWatcher represent excellent examples of apps that leverage the power of the crowds for real-time participatory epidemiology and health care.

### 7.2.5 Medpedia (wiki)

This is a global, specialized wiki for unbiased, evidence-based medical information, edited by qualified experts from all over the world. It is a long-term project that aims to evolve a new model for sharing and advancing knowledge about health and medicine among medical professionals and the general public. Harvard Medical School, Stanford School of Medicine, Berkeley School of Public Health, the University of Michigan Medical School and other leading global health organizations are contributing. Since the announcement of the project’s launch in July 2008, over 100 organizations have contributed or pledged thousands of pages of content to the knowledge base, and thousands of verified expert editors and others have joined the community. The goal is to develop a repository of current unbiased medical information contributed and maintained by medical and health experts around the world, made freely available.

Another wiki with a global nature that is worth noting in this context is Flu Wiki, which is intended to help local communities prepare for (and perhaps cope with) an influenza pandemic.

### 7.2.6 WaterEngage

This Social Web tool for public engagement on global water issues and associated health challenges is a versatile, interactive engagement platform. The Social Web has the potential to unite people globally around relevant health issues, and Cohen et al. (2008) describe WaterEngage as a web-based community seeking to both inform and engage youth and the broader public on global water issues and their health impacts. They also outline a possible course for future action to scale up this sort of online public engagement, listing a number of benefits of public engagement to society. These include creating an informed citizenry, generating new ideas from the public, increasing the chances of research being adopted, promoting public trust, answering ethical research questions, fostering global communication, enabling shared experiences and methodology, standardizing strategies, generating global viewpoints and encouraging previously marginalized populations to participate on a global stage.

## 7.3 Discussion

### 7.3.1 Harnessing the potential of the Social Web and NSM in governance for health

Reid et al. (2010) provide a good example of clinical governance, the system through which health care organizations can be held accountable for continuously improving the quality of their services and safeguarding high standards of care by nurturing an environment in which clinical excellence and best practices will flourish. The Social Web (or Web 2.0) and social media communications can help health care organizations reach and refine a strategic vision by:

- improving information and business intelligence-gathering and sharing;
- encouraging better participation and engagement of all stakeholders;
- building consensus and identifying priorities; and
- ensuring transparency, proper monitoring, responsiveness, equity and inclusiveness, effectiveness and efficiency, accountability and ethical operation.

The Social Web and social media communications can act as enablers of better collaboration and coordination among large numbers of players in complex health care systems and provide ways to identify and manage partnership and data-sharing opportunities by, for instance, using mashups that combine data silos from multiple health and social care organizations and government agencies to display the bigger picture and promote better policy formulation and decision-making. The Social Web is also enabling unprecedented multiway communications and engagement to take place between and among government agencies and the communities they serve, empowering citizens by helping create an informed citizenry, increasing public trust and encouraging participation in shaping their own services by seeking feedback and generating new ideas (wisdom of the crowds and demands of the public).

Such approaches and associated properties are crucial to successful health systems governance (Gostin & Mok, 2009; Siddiqi et al., 2009). NSM's success in the context of health care governance will always, however, depend largely on the way these tools are implemented in specific situations. Social tools per se do not guarantee success and can in fact introduce many threats and risks if not used properly.

Technological developments such as online social networks and mobile computing have made it easier to initiate and nurture community and citizen-led innovation and activism. According to Shirky (2008), these technologies permit “ridiculously easy group forming” and have led to civic engagement of citizens on a scale and with an efficiency never seen before. In these times of economic instability, citizens are being asked to do more for less; one consequence is that they are now expected to become more active participants in solving local problems and in positively transforming society. Governments (such as that in the United Kingdom) are opening up public data to facilitate this in a drive for transparency that puts information into the hands of citizens in a way never before imagined.

Social media and crowdsourcing/citizen-sensing are rapidly becoming pivotal tools in shared governance (citizen engagement) and the democratization of health. Crowdsourced maps powered by free tools and pulling their data (often in real time) from different sources (social media and citizen reports via mobile phone SMS and specialized sensors carried or operated by volunteering individuals), coupled with appropriate geovisual analytics tools such as the ability to interactively spot trends and clusters in crowdsourced data and filter the data by time and/or other parameters (Kamel Boulos

et al., 2011d), have demonstrated the power of the crowds and citizen engagement in various distributed sensing and incident-reporting scenarios. High numbers of sampling points (citizens acting as sensors and reporters) and sampling locations (such as covering an entire country) are needed to more accurately draw and continuously update the complete picture of a given situation. This is essential to provide the public and decision-makers with better and much-needed situational awareness of the problems at hand and assist in various management and prevention operations (Kamel Boulos et al., 2011a).

Online social tools' success in these new citizen-led governance tasks depends on citizens' behaviour and needs from such tools (what stimulates people to participate, why and how?) being examined and understood. Appropriate tools for the desired change (what current or next-generation technologies can best support how people want to innovate) can then be selected. This is particularly important: although sociable technologies and social software tools have been extremely effective in many ways in promoting citizen-led activism and participatory governance, they were not designed specifically for such tasks. It is therefore crucial to ask what the tools and applications should look like and to design them and implement usage scenarios with the actual wants and needs of participatory citizens firmly in mind.

Fundamental barriers and risks need to be overcome and mitigated in relation to:

- social software usability and accessibility;
- security and privacy issues (such as social media accounts being taken over by hackers or the inadvertent release of sensitive, patient-identifiable details on social media or a blog post);
- copyright infringement issues in social media posts;
- risks of spreading misinformation (Clauson et al., 2008; Scandfeld et al., 2010; Steinberg et al., 2010; Briones et al., 2011; Knösel & Jung, 2011; Liang & Mackey, 2011) and the associated potential patient harm and/or losses of organizational reputation and trustworthiness;
- knowledge management (search and retrieval) issues caused by the loose nature of folksonomies (user-generated NSM tags);
- information overload (partially solvable by using appropriate content aggregators and user-customizable/collaborative filtering tools); and
- risks of negative effects on productivity, such as employees spending time browsing social profiles.

These undesirable effects and risks are, however, counterbalanced by social tools' potential to enhance collaboration, communication, transparency and responsiveness and increase work efficiency and cost savings, coupled with the generally low cost of adoption.

Challenges also include designing and running social media in such a way that fosters true multiway communications, rather than merely using social tools as one-way information-push channels, and moderation of user-generated posts and content to, for instance, prevent spammers and other forms of inappropriate content (this can become a real challenge with large volumes of user-contributed posts: organizations should be prepared to allocate sufficient personnel, time and resources to deal with it). The viral nature of the Social Web means that (mis)information can travel and get boosted (known as the water ripple effect) very quickly, especially during times of mass stress.

The concept of self-correction of misinformation by the community over time is a process sometimes referred to as Darwikinism (Kamel Boulos et al., 2006; Kamel Boulos & Wheeler, 2007; Kamel Boulos et al., 2011a). But a person might read and make decisions based on wrong, inaccurate or incomplete information in a way that causes harm before the information is taken off by the site's administrator or corrected by the community (or without the person finding any corrections that followed the original message; the



Internet is very vast and can be confusing or difficult for some users to navigate and locate related pieces of information and follow-on replies). There might be a liability issue here that requires careful attention and watchfulness by online health information providers, particularly those running sites that include extensive Social Web elements. Moderating and facilitating conventional web forums and discussion boards is not exactly the same as moderating social media feeds, which pose their own additional set of challenges. It is not always possible or straightforward, for example, to keep users' posts to a social media page hidden until approved or deleted by a moderator; turning off all user posting and commenting is not a good option, as this will remove the social element from social media and transform it into a one-way information-push channel.

The tension between innovation and inclusion/e-inclusion ("e" in this case standing for digital media) needs to be addressed by, for instance:

- ensuring messages are understandable to lower reading-age populations (Kamel Boulos, 2005b; Chan et al., 2009; Norman, 2011);
- ensuring technology accessibility for all and the participation of older people with lower access rates to the Internet and lacking the necessary skills to use the various Social Web tools; and
- including other marginalized or disadvantaged groups in society (Fox & Purcell, 2010).

All of these could prove difficult tasks to achieve. Regularly involving a truly representative sample of the target audiences in planning, implementing, updating, disseminating and evaluating Web 2.0 health information material and services is critical to successfully fulfilling these important e-inclusion, health literacy and accessibility tasks.

### 7.3.2 The need for clear social media policies

Clear strategies, policies and protocols must be formulated and enforced to ensure proper use of social media by governments and health care organizations, unambiguously define roles and functions (who should/can post, what can be posted and when), and avoid or mitigate any potential side-effects, such as the risks of posting inaccurate information or information that might be misinterpreted by readers, information security breaches, posting private patient-identifiable details, or the premature disclosure of embargoed news items. Different social media will require different approaches, although general rules and broad lines can also be drawn: a draft strategy for corporate use of a micro-blogging service by United Kingdom government departments and other public sector organizations has been developed, for example, and the Ohio State Medical Association published a set of social networking guidelines for physicians, office staff and patients (OSMA Legal Services Group, 2010).

Lists of Web 2.0 governance policies and best practices from a number of United States government and other agencies are also available, and the NHS (in United Kingdom (England)) information governance toolkit, although not specifically focused on the Social Web, identifies useful information governance requirements (and corresponding actions) that may prove helpful to other health care organizations in Europe when formulating and implementing their own policies (Department of Health, 2000–2010). HONcode, a voluntary code of conduct and ethics for health web sites published by the Geneva-based Health on the Net Foundation (2011), has a version specifically tailored for social media sites.

Openness about privacy issues and financial/business model and sponsorship disclosure (answering questions such as "how do we use your data?", "how do we make money?", and "who are our partners?") are also important, especially for privately-owned/for-profit Social Web services.

### 7.3.3 Choosing the right tool (or combination of tools) for a given task

In this era of the Social Web, establishing a conventional web presence for the organization is no longer sufficient, particularly in the health care sector, where organizations need to engage and open a dialogue with the public, patients and other stakeholders. Users' information-seeking behaviour on the Internet is going through rapid and significant change. The importance and roles of conventional search engines and the search-engine optimization of an organization's web site have been shaken, with users now increasingly discovering and sourcing new information through social network sites and other social media outlets rather than searching using classic search engines. Searching and learning on the web have become crowdsourced. People ask other people and interact with real, intelligent humans. They follow them on social media and create specific lists for this purpose. They source information in many different ways. Signposting is the name of the new (Social Web) game, but this was the librarian's or teacher's conventional role in the days before search engines and the web. Humans are back in the driving seat, but the Social Web has unprecedented powers in amplifying what a single human can say or teach.

The affordances of various social media classes and services (such as blogs and wikis) are different; they are not necessarily mutually exclusive or a substitute for one another, but can rather be complementary and synergistic in many ways, depending on the task at hand and the audience(s) being targeted. For example, wikis can be perfect tools to enable organizations to document information about data governance projects and other cross-functional or cross-organizational initiatives (Moseley, 2009). A data governance wiki would make the best forum for collaboratively reviewing and refining data policies and documenting their evolution throughout a project's lifetime.

Sociable tools' best assets – those things and scenarios that can only be delivered in a certain medium (and not via any other “e” option) and which also determine the optimal formulae for blended approaches that combine different networked social media – need to be identified and capitalized. User demographics of different online communities of sociable tools will determine the choice of tools to use in a given situation; developers need to carefully investigate where best to go online (identifying Social Web places to take their message to) if they want, for example, to target teenagers, or single mothers or middle-class, middle-aged people.

Designers and developers of Social Web presences need to decide on which device(s) to focus, whether conventional personal computers and notebooks, public touchscreen kiosks, Internet-connected home television screens and/or small-form-factor devices such as smartphones (for which they also need to consider which mobile platform(s) they are going to support). Such a decision will depend on identifying the target audiences and their usability and accessibility needs, studying the ownership profiles of different devices among them, and considering any typical use scenario(s) of the social application at hand that might call for supporting or favouring a particular device.

Social Web presences can be created using publicly available tools and free blog providers and/or with in-house grown (ad hoc) or hosted (commercial or open source) packages. The decision will depend on a number of factors, including available budget and in-house technical expertise, as well as any special tool requirements that might dictate a particular choice. For example, a secure enterprise setup of social software such as a corporate/intranet installation of MediaWiki can be used to run a private/internal and more secure wiki or a fully administrable public wiki on the organization's own server. On the other hand, the use of existing publicly available and popular tools can provide a

golden and unique opportunity to reach out to the vibrant online communities already established and thriving around these tools.

The CDC has published a practical toolkit (CDC, 2011) covering Social Web media options. It is meant to help public health practitioners and managers make informed choices and formulate a more effective social media communication strategy and evaluation plan for using these media. The tools–resources (time, staff and costs) table of the toolkit is particularly helpful; it shows, for example, that virtual-world experiences do not consume as much time or staff resources (once deployed) as other media but could be more costly to develop, while some of the very low-cost social media require extensive time and staff resources to run and maintain. There is always the possibility of using more than one medium in a given programme to reach out to even wider populations or different communities and achieve a healthy balance between message dissemination and audience engagement.

### 7.3.4 The mobile apps phenomenon

Smartphones are now seen as the next big medium for web content access and delivery. They are rapidly and radically transforming health care, enabling it to become more mobile at the point of need and more participatory by engaging all involved stakeholders, including patients, nonclinical carers, the general public, clinicians and various organizations (Kamel Boulos et al., 2011b). Smartphone sales overtook personal computers, including notebooks, in 2011, and it is predicted that mobile web access via smartphones and other small-form-factor Internet devices, such as small touch-screen tablets, will overtake conventional desktop Internet use by 2015 (Meeker et al., 2010). The world’s largest mobile operator is very well aware of this and has commissioned a large study of current and future mobile health care and health promotion applications and their use in China and elsewhere (Leslie et al., 2011).

The main implication of this phenomenon is that governance software application developers and providers must now carefully consider smartphones as a key target medium (rather than a mere development option that can be dismissed). Many of the governance examples described in this chapter already include a smartphone app version or component, but the decision regarding which smartphone platform to support can be difficult. Many apps are designed to run on only one platform: porting the same app to different platforms is not a trivial task and can prove costly for app developers. Cross-platform coding is currently most successful for mobile web apps (those that run in smartphone web browsers and/or are using Java for Mobile Devices and are consequently generally smartphone-platform-neutral), which can partly solve the developer’s platform dilemma. Web apps can nevertheless sometimes prove a bit restrictive (in what they can be coded to do) compared to the functionalities that can be implemented in native apps (those designed for a specific smartphone operating system and chipset).

### 7.3.5 Building capability: the “Armchair involvement” project

The NHS Institute for Innovation and Improvement<sup>7</sup> in the United Kingdom has been exploring how new (participatory Social Web) technologies can be applied to old problems to dramatically improve services since 2006. It launched its “Armchair involvement” project to identify opportunities for public and staff involvement in the NHS through the latest web and mobile phone technologies and uncover whether these advances will help in reaching those at risk of exclusion from involvement using traditional methods. An inspiring 10-minute video can be viewed on the project’s homepage (NHS Institute for Innovation and Improvement, 2006–2013), discussing how participatory Social Web

<sup>7</sup> Involve took over the “Armchair involvement” toolkit when the NHS Institute for Innovation and Improvement closed.

technologies can transform health services and help engage the public, patients, staff and carers in new and more effective ways for service improvement.

The project's main report (Wilson & Casey, 2007) found much enthusiasm across the NHS for using these tools to reach people, better understand their opinions and encourage involvement in service improvement. The project produced guidance material to highlight the benefits of investing stakeholders' time and energy in new interactive Social Web and mobile phone formats, stimulate improved communication and enable provision of tailored health advice and service information on the individual's own terms (from their own armchair or anywhere else they may find it convenient).

Perhaps the best elements of the "Armchair involvement" materials, however, are the practical parts focusing on how to choose the most appropriate sociable or mobile technology (or mix of technologies) for a specific scenario at hand. The project is also linking to a social strategy wiki for crowdsourced advice on overcoming some of the barriers to using social media and online technology in public services.

"Armchair involvement" has evolved to become an online capacity-building platform in which users can develop their skills, review best practice, share information about their own projects and learn from the work of others in the field of online health engagement and technology. It currently has a repository of 80 user-contributed projects and case studies that can be browsed and searched online. There is also a highly recommended archived audio masterclass.

It should be noted here that capacity-building also implies preparing the necessary in-house technical expertise (or outsourcing it, where appropriate) to build and maintain dynamic and vibrant social media presences. Although anyone with average web-browsing skills can create a simple social media page, developing effective organizational presences on social media will often require a team of professionals suitably trained in social media marketing, including one or more dedicated developers with adequate knowledge and practical coding experience in the increasingly complex and rapidly evolving programming interfaces and mark-up languages of today's social media (Stay, 2011).

## 7.4 References

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# Part 5. Conclusions

# 8.

## Value base, ethics and key challenges of health governance for health protection, prevention and promotion

David McQueen

### 8.1 Setting the stage

It is not easy to write about values and ethics in health-related governance. It is a so-called wicked problem mired in a rich, centuries-old discourse. The distance between conceptual and philosophical discussions and values in modern-day health governance is vast: on the one hand are lofty and complicated treatises by renowned and ancient philosophers and, on the other, a seemingly new-found recognition that values and ethics might be at the very foundation of the practice and conduct of contemporary public health.

Recognizing the complexity of the problem is challenging enough, but considering it from a European perspective and identifying specific European challenges for health in the 21st century make it even more wicked. Perhaps it is time to think beyond wickedness.

While appreciating the complexity, this chapter examines some of the conceptual components involved. Some are ancient, but many arise from current debates on health, health policy and health governance. Key terms in the debate and discussion often lack clarity, with most being used without precise definition but being shaped by their use in a particular context (see author's note at the end of the chapter). Most people who discuss values in health are neither trained philosophers nor skilled logicians, which shows in the ambiguous applications of terms that might otherwise be more tightly defined. It is therefore difficult to separate the discussions and debates from those who are pursuing them. Analysis of discussions and debates is not free of the need to understand who the actors are in their context and what shapes their interest.

The following quotation from the President of the European Commission (Barroso, 2007) refers to the difficulties of the current times and the major economic and social changes taking place:

Our record shows that we have held fast to the core values and core goals that have made the [EU] so successful, and will leave a powerful contribution to the future development of the European project. ... The European Union is now taking the lead in shaping globalisation with European values ...

What were the values to which President Barosso referred? Earlier, in commenting on the celebration of 50 years of the EU, he made them explicit: "shared values, like freedom, democracy, the rule of law, tolerance and mutual respect" (Barosso, 2007). This type of statement from a person at high political level promotes key values that have been asserted in public health over the years and are continuing to the present day. Chief among them are notions of equity, social justice, dignity and a human-rights-based approach. They are reflected in numerous documents, such as Staley (2001) and the more recent comprehensive report of the CSDH (2008). Documents such as these have been guided substantially from a European perspective that reflects the deep discussions in moral philosophy characterizing thinking in major European countries in the past two to three centuries.

While discussion on the notion of values is ancient, the term's use in the academic sphere is more recent, with a strong base in 19th century German philosophy. This development

has been extensively reviewed by writers such as Kuhn (1975), Schnädelbach (2008) and Joas (2000). The values discussion stems from the collective works of key German figures such as Hermann Lotze, Immanuel Kant and, in particular, the works of Friedrich Nietzsche, which emphasize the contextual or contingency nature of values. The emerging discussion followed ancient philosophical and teleological discourse dating to medieval concerns with realism and nominalism, which in turn reverts to classical antiquity and debates between Aristotelian and Platonic perspectives. This elaborate and ancient discourse has meaning for the chapter. The problem is whether values are fundamental concepts that exist independently of humans perceiving them, or whether they are highly contextual and bound to an ever-developing and changing perspective.

The perspective adopted in this chapter is that values in health relating to prevention and health promotion stem mostly from the contextual position: that is, they are created *sui generis*. It therefore becomes possible to introduce the idea that health itself is a value. Allowing for health as a value opens the door for public health and health promotion to fully incorporate the idea of values as being fundamental to the conduct of public health and for the full incorporation of equity, social justice and women's rights as values. The notion over the past three decades (enhanced by the Ottawa Charter for Health Promotion (WHO, 1986), a largely European-derived document) that health promotion was driven by values allowed it to be distinguished from more technical and biomedical approaches to health. This perspective on health promotion and its attendant values stimulated a wider debate that brought in the value perspectives of such key thinkers as Amartya Sen and Jennifer Ruger and allowed the incorporation of a contextual value-based ethics, as elaborated by Rawls (1971) and others.

Equity, which has been a subject of considerable debate and discussion globally (Braveman, 2006), is one of the key value concepts that characterize present-day thinking on European health values. The precise definition of health equity remains elusive, but the idea has been key for at least two decades in European discussions about health disparities, inequalities and other forms of apparent maldistribution of health resources in populations. The concept is actually (and potentially) shaped by government policies and therefore becomes a particular challenge for governance. Health inequities in most countries are highly related to systematic decisions by government actors to distribute resources unequally in the population, favouring some components over others in terms of the experience of health and disease.

The concept of health equity owes much to the writings of Sen, who, in his Tanner Lecture of 1979 (Sen, 1979), laid out most of the essential components of equity in terms of the interpretation of equality in moral philosophy. In critiquing then-predominant types of equality (utilitarian, utility and Rawlsian), Sen, an economist, introduced concepts of equality that stemmed from welfare economics. This was a critical step that moved considerations of equality out of the more classical philosophical realm and into the world of economic ideas. This horizontal movement would be replicated in time by the adaptation of such thinking to the idea world of health, health economics and ultimately health promotion and prevention. In the same decade in which health promotion embraced cross-discipline thinking in health, Sen moved to what is termed a capabilities approach that began to tie resources to the individual, grouping efforts to distribute resources in an ethically driven effort to achieve equitable distribution. These efforts created a paradigm shift that would bring together equity with human and economic development, a shift in thinking that accelerated in the new millennium.

Current values of health equity therefore inherit a substantial ideological base in moral philosophy that leads to the integration of health equity into concrete policy related to development. Efforts of those concerned with the social determinants of health and their incorporation into broad policy goals (such as the MDGs) can, it may be argued, be traced to the fundamental shifts in value concepts arising from the 1980s and the subsequent discussion on inequalities and health. The extension of the value concept of

health equity leads inevitably to discussions on living a full, lengthy and relatively disease-free life and concepts such as salutogenesis, but most of all to those related to resources at individual and group levels, which are part of the capabilities shaped by governance.

Despite Sen's rejection, to a certain extent, of the Rawlsian approach to equality, Rawl's approach should be considered further. He wrote in 1971 what was and still is considered by many as the definitive treatise on social justice, *A theory of justice* (Rawls, 1971). This seminal work ties the political process into the value concept of equity and consequently leads to cross-fertilization of the equity concept from another discipline area. He argued from a notion of what he called "original position" that individuals acting in a group who lack awareness of the resources of other group members would move to an egalitarian position of distributive justice. The point here is not to delve into the thought processes that would lead to such an outcome, but to accept the Rawlsian position as one that has influenced the equity discussion. The Rawlsian position is certainly not naïve, and he carefully modified the egalitarian perspective to accept that the real world would have both liberty and difference, resulting in some real and perceived inequities. The value, however, is still to minimize the impact of the differences. The critical point arising from Rawls is that social justice (and consequently equity) is tied to agency and therefore becomes an ethical concern.

Discussions around the works of Sen and Rawls and their explication over recent years have once again pinpointed classical concerns with the interaction of structure and agency. It is not this chapter's role to delve into complicated sociological debate around structure and agency, but it is important to keep in mind that a value concept such as health equity usually resorts to a discussion of structural change (distribution of government resources, for instance) versus agency (including actors, individuals and civil society) in which an observer sees the focus for actions to address equity as being driven by the individual's belief that one approach may be more effective than the other. The structure versus agency discussion introduces the question of whether those concerned with health equity should focus on values or ethics in an effort to improve human health. Ruger (2004, 2010) has reviewed this discussion of social justice in detail over the last decade, successfully linking it to health and health care. Her work further integrates that of Sen and political theory and provides considerable guidance for health policy.

Finally, individual versus social values needs to be considered. It can be argued that values belong only to the individual, which is part of a larger philosophical question of whether values exist independently from a conscious mind that can conceptualize them. This is not a trivial question. In the consideration of values related to health, the issue is whether values are within individuals, or whether groups and societies can have shared values and whether, indeed, a government can have values. This is essentially the problem of anthropomorphism and the question of whether structural entities (such as governments) can have human characteristics (such as values).

The easy answer at first glance appears to be yes. Governments can be conceptualized as having values and being ethical, but it becomes more difficult when another collective structure, such as big business, is considered. Ethical statements from businesses, such as those that may be posted in the produce sections of stores for the public to see, can raise cynicism when people consider them in relation to the industry's perceived negative effects on the environment.

There are no fixed solutions to this question, but many would argue that organizations have social values as long as there are individuals or groups to validate them. If this transformation is acceptable, it can be assumed that governance can be undertaken with ethical considerations, but the discussion of social values in this context inevitably leads to the conclusion that the discourse on values and ethics in governance is somehow relegated more to the pragmatic and less to the realm of deep moral philosophy. In many ways, the elaborate work and discussion of values in health in the past three decades has



focused on efforts to pull the deeper philosophical debate on values into the realm of the pragmatic, which is the field of governance.

## 8.2 The European focus on values

The question of whether European health-related values are unique or decidedly different from, for instance, those in North America is interesting, but could be the subject of a long treatise and a lifetime of investigation by a distinguished professor of philosophy. As in all realms of endeavour, aspects that are peculiarly European and which distinguish the European perspective from other geographic regions undoubtedly exist, but it is probably equally true that there is great variation on values within and across Europe. By analogy, few would have difficulty in recognizing that health values in North America, which includes nations as diverse as Canada, the United States and Mexico, might vary considerably. Indeed, much has been written about the particular role of values in health in the Canadian context (Giacomini et al., 2001) in which the health care system itself is seen as a core Canadian value, while debate has been ongoing for decades in the United States on whether health and, by implication, health care are human rights or privileges.

Returning to the European context, it would appear that European thinking is highly in line with WHO's perspective of health as a human right and a public good. Comments such as those of Staley that directly link health to the public good and to a public value and further argue that the values are "concerned with state intervention to promote morally desirable ends" (Staley, 2001) are therefore quite common: such a statement is unambiguous and is quite distinct from the discussion of health as a privilege. It is also quite clear that discussion of health as a fundamental value has been dynamic in the European discourse over the past decade (Staley, 2001; McKee, 2002; Byrne, 2004).

If health itself is seen as a value, the first question arising is what are its specific components, and the second remains how its components are explicitly recognized in policies, documents, programmes and advocacy statements. In answer to the first, much European discussion centres on tacit agreement that the components are dignity, liberty, democracy, equality, rule of law, human rights, pluralism, tolerance, justice, solidarity and nondiscrimination, as set out in the Treaty establishing a Constitution for Europe (EU, 2004). The EU Constitution is not a short, explicitly framed document and, like the far shorter Constitution of the United States, is open to considerable interpretation that is often bound to the current context of political thinking, but its fundamentals are quite clear. Yet despite agreement on fundamentals, European values around health are subject to possible value conflicts (especially when considering health across sectors), including value trade-offs in the policy-translation process. Trade-offs and translation move the value-based ideology into the realm of ethical actions regarding health, health prevention and health promotion, with potential value conflicts leading inevitably to confrontation with parallel values such as accountability and civil participation. A notable value conflict arises with values in science and technology, explicitly in relation to the role of evidence, particularly on health promotion and prevention effectiveness (McQueen & Jones, 2007).

It can easily be asserted that belief in science is a strongly held value in European thought. The deep structure of modern scientific thinking is firmly embedded in European history. Science seeks clear explanations of what works and why. Insofar as medicine is seen as a science and public health as a science-driven field of work, these disciplines are held accountable to the rigours of scientific proof. Almost parallel to the rise of such value concerns as equity and social justice in the world of health has been the rise of accountability, framed in terms such as evidence-based medicine and effective

knowledge translation. At first glance, these would appear to be in line with the chief values discussed above, but science values have inherent measurement theories rarely found in the discussion of value concepts. The theoretical background of values such as equity, social justice and human rights have their underlying epistemology in moral philosophy, but for evidence, it is in the philosophy of logic and science. These may be seen as very distinct traditions and ones that have often been at odds in European history. The 18th century philosopher David Hume wrote that all assumptions of value involve projections of one's own sentiments onto whatever is said to have value. The choice between morality and science depends on one's stance.

Unfortunately, such choices are often not transparent for decision-taking efforts. The CSDH report (2008) directly addresses conflicted value approaches. The scientific, epidemiologically-based evidence in the report clearly lays out the causal connections between health-related values such as health equity, social justice, education and human dignity, and good health. Despite public health recognizing for a long time the strong relationship between social and cultural factors and good health, it was this report that solidified the knowledge into a position beyond scientific doubt. Knowledge, however, is not enough for effective action on the value-related causes of poor health: it is only the precursor to action. The science of how these causes can effectively be changed is highly problematic. In reality, significant changes in the attributable causes may imply political philosophies that are themselves tied to values that may not be in concert with those of the underlying values relating to good health. Very basic value concepts, such as freedom of choice and public democracy, may be inimical to addressing some key causal values. It is not the point of this chapter to debate this, but merely to lay out why governance and ethical considerations to deal with health inequities face such extraordinary challenges.

### 8.2.1 Ethics

Ethics and values are obviously related, but ethics deals with decisions to take action on values and the underlying principles for these decisions. Most ethical considerations in the health field deal with what is generally termed normative ethics. Normative ethics is the part of historical ethical philosophy that is concerned with how to act, taking into account value concepts. It views ethical considerations as largely a prescriptive effort. In some thinking, normative ethics are interpreted simply as applied ethics. As has been shown, value-based thinking related to health has become more complex in recent decades and now includes judgements of right and wrong in actions; this in turn has led to considerations of partial rightness, a concept developed in ethical writings, but Rawls' work tends to move the focus in health directly to moral arguments underpinning action.

Values are turned into ethical considerations when they become verbal – that is, when one makes an effort to protect the health of a population, prevent the spread of disease, promote the health of a community, reduce poverty that leads to poor health or increase health literacy, for instance. It is this verbalization of efforts to effect change based on values that ties values and ethics directly to governance, which in sum can be imagined as the verbalization or action component of government structure.

The values and ethics discussion in Europe is largely dominated by a western European literature and perspective, a fact that is undoubtedly connected to the rise of the EU and its efforts to address health values and the common concerns of public health, prevention and health promotion. With value concepts such as equity and social justice, efforts to address the so-called social determinants of health have had a decidedly western focus, notably championed by the work of the CSDH, as has leadership related to HiAP governance in the Scandinavian part of Europe, notably in Norway (which is not an EU Member State), where explicit and deep concerns with values such as health equity can be witnessed. This was reflected by Bjarne Hanssen (2009), Minister of Health and Care Services in Norway, who wrote:

Reducing health inequity is a whole-of-government challenge. It requires intersectoral action, which is demanding. Nevertheless, it is the only way forward if we are to achieve our aim of reducing health inequity that is socially produced and unfair. The Norwegian Government is committed to action for a society in which there is equal opportunity for a healthy life for every individual.

Strand et al. (2009) describe in their report on setting the political agenda to tackle health inequity in Norway the most clear and compelling analyses of the historical development of a nation's efforts to come to grips with the key values and ethical challenges attached to addressing the value of health inequity. Of particular importance is the discussion of mechanisms to implement governance in this area, postulating the horizontal and vertical mechanisms needed. Critical to their interpretation of the governance directive is recognition of the structure and agency of governance.

Moving the focus to the eastern part of Europe, particularly to the Russian Federation and former Soviet Union states, reveals a distinctively less clear pattern of engagement with the fundamental values and ethics addressed in contemporary health promotion, although the literature base is small. Efforts to focus on addressing NCDs in ways similar to the MDGs have been supported by the Government of the Russian Federation and were discussed at the First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control, held in Moscow on 28 and 29 April 2011, much of the work from which was followed up at the United Nations high-level meeting on NCDs in September 2011. Values and ethics have nevertheless generally been addressed within the health care sector rather than the prevention and promotion area. Issues with particular reference to the Russian Federation and its European identity have been explored by Manning & Tikhonova (2009), who examined the government's role in addressing social policies during the 1990s. They suggest that central government has had difficulties in addressing inequities and civil society organizations are not currently strong enough to provide alternative social policy options. In addition, Mansurov et al. (2009) collected views and articles from many of the leading social scientists in the Russian Federation. An article by Gorina (2009) argues:

Over last years the relationships between [the Russian Federation] and its neighbors — countries of European Union and the [Commonwealth of Independent States] — have notably changed. Along with the changing political regimes, foreign policy priorities and values, the attitudes of the Russians towards those countries have also transformed. Today in the mass consciousness of the Russians, the EU has become, perhaps, closer than before, but some [Commonwealth of Independent States] countries are moving away to the second place. This trend is evidenced in the results of the international sociological research 'Russia and the EU' conducted by the Center for Sociological Studies [of Lomonosov Moscow State University] in November 2008.

Zaborova & Markova (2009) discuss in the same collection the role of health culture in forming values and implicitly argue the value case that might apply to governance, although the argument is not direct:

Many famous national scientists ... speak about the need to develop individual health culture in the modern society as the task and requirement of today. Health culture, being a kind of panhuman culture, is a system phenomenon consisting of a number of interdependent elements.

Zaborova & Markova (2009) describe a primary component of health culture as:

... the complex of values and standards: health culture is a certain commonly shared system of values, meanings and standards with regards to the external environment of the nature and society and to the internal environment of the human body, which is assimilated by the individual in the process of socialization and living, and on the basis of which they form their health-related behaviour ...

This is obviously just a brief review, but it is clear that throughout the Region, from Albania through Israel to Uzbekistan, there is engagement in varying degrees with the social determinants of health, HiAP, inequities and all the areas of current public health and health promotion that include either explicit or implicit values and ethical considerations. This engagement remains a key consideration in how governance related to health is viewed in Europe today.

### 8.3 Distinguishing policy from governance and the role of values in each

It is useful to briefly characterize policy as it is generally understood in discussions on health. At the highest levels, it may be seen as aspirational or visionary: major policy documents of international organizations, including United Nations agencies such as WHO, and those from government ministries belong to this category. They tend to be collective works crafted after many hours of debate and dialogue and have corporate authorship. Policy documents, often presented as statements, resolutions, charters or agreements, draw on value principles rather than ethics: they are primarily visionary and rarely state the ethical means by which the vision is to be achieved. Occasionally they may state policy goals, but without specification of means. The statements' visionary level may incline some of those outside the visioning process to consider them somewhat vague, so the challenge for policy at this level is to translate vision into collective action. This process is generally left to others, often bureaucrats and broader collectives such as civil society, with bureaucrats well positioned within government being charged with governance responsibilities.

As with all characterizations, this is a simplification. Civil society's role in creating the impetus for visionary statements has been well recognized in recent years and is appreciated chiefly by those examining policy, although less so by policy-makers. Civil society, particularly NGOs, has nevertheless impressed its own sets of values on governments, with NGOs sometimes being organized around a value that directly relates to health or health promotion and working to persuade standing governmental institutions to adopt value-based visionary statements in their area of interest.

Governance relates to policy in many ways. Often it is difficult to distinguish when the primary operation is one of policy or governance, but expressions of governance and policy within government are seen in day-to-day operations of management, legislation, procurement, resource allocation, communication and other government activities. Policy, governance and the institutions of government ultimately reflect back to the value concepts that underlie government functioning: in essence, government's role is to make values explicit to the governed.

### 8.4 Governance challenges

In considering key challenges for governance resulting from this discussion of values and ethics and their translation into the everyday commitments of governments and institutions, six critical challenge dimensions arise. There may be more, but these six are based on the author's experience of working in government for many years coupled with an academic appreciation of the complexity of making firm decisions on what needs to be done. They involve the translation of stated values to the possibility for action. Above all, the need to take action must itself be a governance value.

The first challenge is that of the allocation of resources to the value area. Ministerial and international governmental health agencies have argued for many years that funding to address the present-day burden of disease is inadequate. This is particularly true in the area of chronic disease, where the burden in most European countries is very high, but resource allocation to prevention of chronic disease and promotion of health-related actions to mitigate their occurrence has been small in comparison to that allotted to the care of people who already have advanced chronic illness. Health is argued as a value; prevention is argued as a value; but resources do not flow in the direction of the burden. It is not simply about the allocation of new resources harvested from other sectors of the government budget: it is also about the fact that there has been little redistribution of resources in the health system. Why does it continue to be the case that public health is the mere stepchild of medical care and that resources for prevention and health promotion are low on the allocation table, even within the allocation of funding for public health? What specifically is the relationship between lofty value statements and resource allocation? The challenge is to change this picture, locally and globally.

The second challenge is related closely to the first and concerns the building of infrastructure to carry out the value-laden policy. This is a long-term challenge, but one that can be implemented fairly rapidly if the governance structure so desires. Deep infrastructure capacity requires restructuring other systems in some depth: there is no use, for example, trying to hire postgraduate-level people trained in health promotion, social epidemiology and political science if there is no university infrastructure supporting these fields. This is less of a problem within the European context – the training capacity is in place and many institutions can produce well-trained individuals to work in the health arena – but government institutions must hire these people and have the internal bureaucratic structure to properly utilize their skills and knowledge. Even today, many well-trained staff work in health institutions in roles that do not exploit their skills.

The third challenge is that of sustainability, which may also be interpreted as the long-term continuous provision of financial and human resources to develop appropriate programmes and address responses to the value-based challenges. Parto (2005) has written rather disparagingly about the lack of EU institutions to sustain programmes. This chapter argues that values are long term, enduring and theoretically sustainable, yet the sustainability of programmes, policies and health-related values seems a major challenge. This partly explains why efforts are made to tie these kinds of aspirations to lofty goals such as the MDGs and why the NCD area hopes to buy into the argument for development and sustainability. In addition, the current debate on health systems strengthening, particularly as addressed in *The Tallinn Charter: "Health Systems for Health and Wealth"* (WHO Regional Office for Europe, 2008), has taken up values as a subcurrent, but not the broader values of health. Clearly, part of the challenge for the health sector is the need to link with other sectors to put together a comprehensive package that has health as one of its focuses.

The fourth challenge is a bit of a conundrum. The challenges of capacity and sustainability would seem to imply high growth in financing of the public health sector: the new challenge is to seek reasonable limitation of what can be done. It is not simply a matter of prioritizing, but of deciding what value-laden actions need to be taken in the short, medium and long terms. The public health sector managed to meet the challenge of tobacco use (in some sense) by focusing on a single cause that appeared to be highly tied to medical and social values. The result has been one of the success stories of modern public health and health promotion, but the fact that this success did not occur overnight is often overlooked: it was the product of reallocation of resources, capacity-building and sustainability over half a century of tireless work. Currently, the priority of what to address remains fluid.



The fifth challenge relates to the fourth and concerns the role of key actors in the fields of health protection, health promotion and prevention. They are to be found in civil society as well as in government and, some would add, the market place. The challenge is for these different actors to clarify their unique and distinct roles. At present, each appears to want to carry out all necessary actions, resulting in many cases in the development of agencies with little strength in any specific area and a diffuse mission concept.

The sixth and final challenge has been alluded to above and that is the challenge of evidence or, as some would state it, accountability. The basic question is: how does one know that they have effectively translated a value into practice and that practice is reinforcing it? What, after all, is the point of stating values that are considered vital, then having no way of knowing whether there has been a positive effect on that value? It is not the role of this brief chapter to go into the details of this challenge: suffice to say that both government and civil society want some evidence that their values are being upheld and sustained.

### Author's note on general terms in this chapter

*This chapter uses a number of terms, including values, ethics, structure, agency, policy, governance and concepts. Each is open to considerable discussion as to meaning and may vary in use in English or when translated. It is not possible to reach definitions in a manner that would yield consensus among those who regularly use them. Meanings are heavily influenced by the author's graduate and doctoral training in the history, sociology and philosophy of science and his public health career in academia and government of over four decades. The terms therefore have particular meaning and nuance to the author. For example, values is a largely conceptual idea often translated into cultural, political or moral values, which tend to be broad enduring constructs regarded as fundamental to being human. They can often be contextual, but many would regard some values as beyond context (Dworkin, 2011). Health is a fundamental value, but ethics relates much more to moral philosophy and concerns about how an individual or collective acts in relation to values. Ethics is about how one takes a course of action; it is even more contextual than values and relates highly to concepts of justice. With regard to structure and agency, it can be argued that (Wikipedia, The Free Encyclopedia, 2013):*

*The debate concerning the primacy of either structure or agency with regard to human behaviour is a central ontological issue in sociology, political science, and the other social sciences. In this context, 'agency' refers to the capacity of individuals to act independently and to make their own free choices. 'Structure', by contrast, refers to the recurrent patterned arrangements which seem to influence or limit the choices and opportunities that individuals possess ... The structure versus agency debate may therefore be understood simply as the issue of socialisation against autonomy.*

*This debate is central to the whole understanding of inequity as it relates to health.*

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# 9.

## Smart governance for health

Ilona Kickbusch and David Gleicher

### 9.1 Smart governance

Smart governance is one way to describe the major institutional adaptations observed in public and international organizations in the face of increasing interdependence. Smart governance, coined by Willke (2007), is “an abbreviation for the ensemble of principles, factors and capacities that constitute a form of governance able to cope with the conditions and exigencies of the knowledge society”. Policy decisions in a knowledge society that are based on purely normative considerations lose ground to those based on evidence. At the same time, decision-making requires new methods for coping with, and accounting for, the associated uncertainties that abound when knowledge – always questionable, always revisable – supersedes majority values as the basis for authority.

The central feature of 21st century governance arrangements is that collaboration is the new imperative: the multidimensional and complex character of health challenges and their wicked-problem nature needs an integrated and dynamic response across portfolio boundaries, making health a shared goal of all parts of government and linking it more explicitly than hitherto to the well-being agenda.

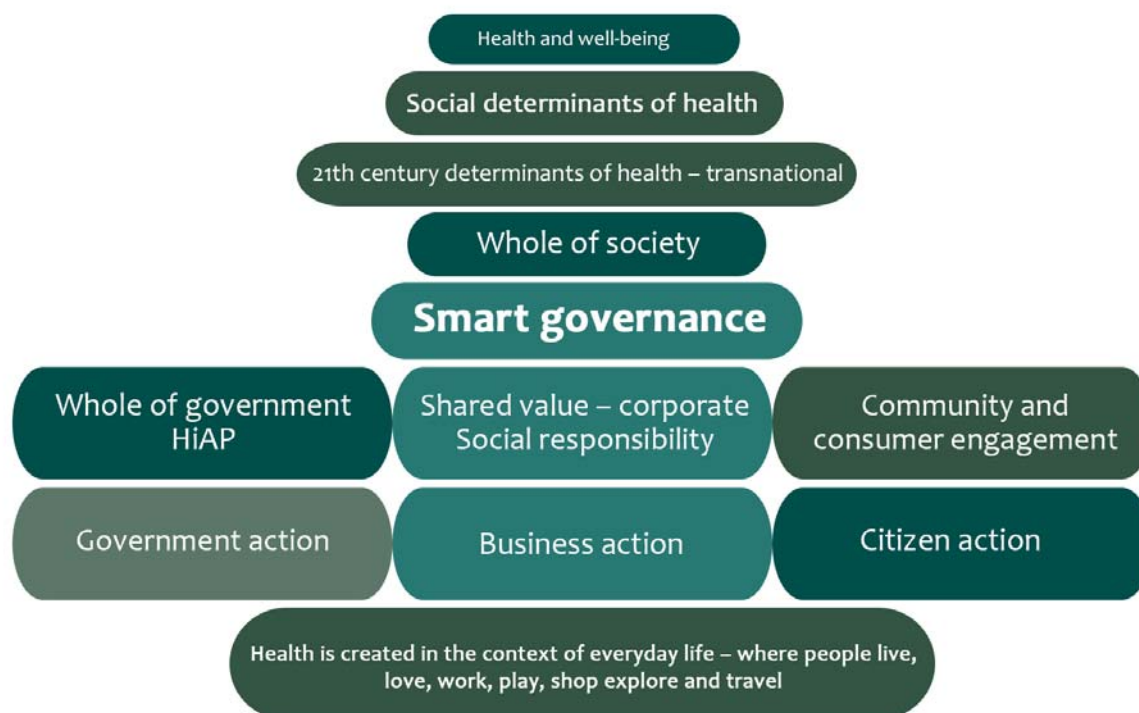
Communicative and collaborative approaches to governance are gaining traction, with two features being particularly highlighted.

1. Power and responsibility throughout government levels and in society have been diffused. This trend is coming together with shifts in approaches to democracy and shared value in new whole-of-government and whole-of-society approaches that provide a new framework in which public policy for health is designed and implemented.
2. The concept of good governance is expanded to include aspirations such as health and well-being. Value systems like human rights, well-being, global public goods and social justice/equity provide the principles to guide ethical policy-making for health.

These challenges are not only faced by the health sector: sector-based approaches to governance do not generally fit the interdependent world of the 21st century. Just as health seeks the support of other sectors, so must the health sector begin to consider how health contributes to, or hinders, other sectors’ agendas and how it adds to overall societal well-being. It is not sufficient to exert leadership for health, as is so frequently stated in health policy documents. All sectors have a responsibility for the whole, particularly in the face of economic crisis, as recent experiences with European austerity politics have shown.

Governments under increasing pressure to maintain legitimacy and increase performance gradually add new forms of governance, mainly by forging new strategic relationships within government and with non-state actors. The term smart governance has been chosen to describe such an innovative set of approaches to address the most challenging health problems (Kickbusch, 2011) (Fig. 9.1).

Fig. 9.1. Governance for health in the 21st century



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Smart governance for health is already happening in Europe and other parts of the world. Many governments are approaching governance for health in new and innovative ways, informed by increased understanding of health and transitions in how states and societies work together. Health sector boundaries are being redefined. Health impact assessments in Europe, for example, are enabling policy-makers to make better-informed and forward-thinking decisions to avoid unintentional consequences for health, regardless of the sector from which the policy emerges. The health sector in South Australia is lending its particular expertise to all other sectors by providing a health-lens analysis to a wide range of challenges, from water security to sustainable transport systems. This approach to HiAP, which is institutionalized through the whole-of-government strategic plan, supports other sectors to achieve their goals while promoting health, rather than giving them an additional burden.

Health impact assessments are seen as a universally applicable decision-support tool for policy-making at local, federal/provincial, national and supranational levels across sectors. They are sensitive to the determinants of health inequities. Wismar et al. (2007) explored their use in Europe through research and 17 case studies that focus on their effectiveness in areas such as air quality in United Kingdom (Northern Ireland) and Ticino, Switzerland, to the food production and nutrition impacts of Slovenia adapting EU agricultural policy.

## 9.2 Key characteristics of smart governance for health and well-being

Smart governance can be understood as the application of so-called smart power, defined by Nye (2011) as “the combination of the hard power of coercion and payment with the soft power of persuasion and attraction”. Hard power (such as use or threat of military intervention or economic sanctions) and soft power (diplomacy, economic assistance and



communication, for instance) are wholly descriptive, but smart power is also evaluative. Smart governance for health is about how governments respond strategically to health challenges, the choices they make regarding which mix of instruments to use, which partners to choose, which levels of government/society to engage, and when.

Smart governance for health and well-being means that the state is involved in more complex relationships with other governmental and societal actors, but this does not inevitably reduce its role or power. Indeed, some argue that states (including ministries of health and the health sector) have expanded their power through the new collaborative arrangements. They remain responsible for ensuring that governance arrangements for health are effective, accountable, legitimate and democratic, but many are expanding their regulatory power in relation to a number of health challenges and extending their reach into everyday life and control of markets. This has become even more complex in Europe, where governance dynamics have changed with the EU's role. How to balance the interests of health with those of the market, the public good and individual interests is a key conflict for 21st century governance for health, but in relation to the EU, it requires a constant balancing act between market efficiency and social (and health) protection (Scharpf, 2002).

### 9.2.1 Multistakeholder deliberation

Multistakeholder deliberations feed into nearly every aspect of smart governance for health. Swanson et al. (2009) describe it as:

... a collective and collaborative public effort to examine an issue from different points of view prior to taking a decision. Deliberative processes strengthen policy design by building recognition of common values, shared commitment and emerging issues, and by providing a comprehensive understanding of causal relationships.

It is also critical for effective AG and reintroduces the notion of balancing evidence and values in a complex and knowledge-based society. In Chapter 2, Özdemir & Knoppers emphasize that AG must be participatory to be effective, including but going beyond expert opinions. Including as many viewpoints from experts and lay persons as possible is necessary to minimize the risk that problems are incorrectly defined or framed by unknown biases. This broader approach to knowledge also allows examination of value and power systems (Kloprogge & van Der Sluijs, 2006).

## 9.3 Smart governance for health

Built on an expanded understanding of health and the contexts that drive new governance for health, it is proposed that smart governance for health is composed of five interrelated aspects:

- collaboration
- citizen engagement
- a mix of regulation and persuasion
- independent agencies and expert bodies
- adaptive policies, resilient structures and foresight.

Each of these aspects interacts and manifests differently, depending on the contexts in which they are set.

### 9.3.1 Governing through collaboration

WHO (2014) states that a health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. This primary intent must

be better prioritized and coordinated within the wider health system and the health sector, but the boundaries of the health care sector have become increasingly fluid. Health can be perceived not only as a sector of public policy and the economy or as an individual or population's physical and mental attributes, but also as an emergent property of complex systems and multiple nested dynamic networks and relationships with many spillover effects (such as the interconnected systems of transport, utilities and public services that define urban living). This view goes beyond the concept of primary-intent health into other sectors and systems that contribute to or endanger health (such as the food system), or which consider health to be a significant part of their own mission but tangential to their primary goals (the economic development aid sector and foreign policy, for example).

Health is increasingly being shaped by issues and forces such as the speed of modern societies, globalization of markets, individuals' increasing mobility and insecurity, energy expenditure and climate change, food security, concerns regarding risk and safety, and the reach of the media. These are called 21st century health determinants, as they cut across many of the acknowledged social, environmental and economic determinants of health. Their interfaces will lead the health sector to work with an equally diverse range of actors to jointly explore policy innovation, novel mechanisms and instruments, and better regulatory frameworks. For example, it is critical that the health sector works with the environmental sector on climate change and food security. As Raynaud & Jané-Llopis explain in Chapter 6, coproduction means achieving outcomes by working together across sectors and stakeholder groups: in principle, it is irrelevant who is in the lead, as the goals pursued cannot be realized by acting unilaterally.

### 9.3.2 Governing through citizen engagement

Expansions in governance for health and understanding of what health is and how it is produced imply that the views of a wider range of actors are important. The health sector must work with other policy sectors (as described above), the private sector and nongovernmental actors, but increasingly it must also engage with individuals in their roles as patients, consumers and citizens and in their everyday lives. Policy can no longer just be delivered – success requires coproduction and citizens' involvement and cooperation.

Andersson discusses in Chapter 3 how patient engagement has become not only an integral aspect of health care in Europe, but also a model for citizen engagement. Successful prevention, diagnosis and treatment of diseases are only possible with citizens and European governments' active participation. As Andersson states, however, “activities that aspire to empower individual patients in their own care and structures put in place to allow the public (either as interested individuals or elected representatives) to hold health structures to account have important differences” (page 34).

#### 9.3.2.1 How technology can boost engagement

Citizen engagement is a vital aspect of smart governance for health. Recent advances in consumer technology and innovations from the private sector (including foundations) can facilitate this greatly: organizations such as *AmericaSpeaks*, for example, have piloted what they call the 21st century town hall meeting, which brings together thousands of randomly selected citizens in one location or across multiple settings to input on public debates. Up to 10 participants sit at tables with a trained facilitator discussing questions that build to create a set of collective priorities by the end of the meeting. Participatory technology is utilized to make sure every voice in the room is heard: this includes a computer on each table serving as an electronic flipchart, allowing agreements to be

instantly transmitted and enabling participants to vote electronically on what they believe are the most important priorities.

Similar initiatives called consensus conferences have been organized in Europe on local and regional scales. This model has been applied to health in a variety of ways. In the United Kingdom, the global arm of *AmericaSpeaks*, Global Voices, teamed up with the NHS and the firm Opinion Leader Research to hold a national dialogue on health policy in 2005 called “Your health, your care, your say”, which produced a road map and commitments from the Prime Minister. The high-profile meeting was broadcast live on the Internet, received day-long coverage on channels of the national public service broadcaster and made the national press. A more focused conference, the “European citizens’ deliberation on brain science”, was held one year later in partnership with German communications firm IFOK and the King Baudouin Foundation. Conducted in nine languages, it was the first example of a transnational consensus conference, developing 37 consensus recommendations for the European Parliament on brain science research and regulation priorities. The recommendations set the framework for national and international meetings and informed research and policy papers. The body of research demonstrating the positive effects of deliberation on citizens and government institutions is growing (Barabas, 2004).

In addition to engaging for intelligence-collecting, knowledge-sharing and shared care, technology is also enabling and facilitating citizens to actively coproduce governance for health as independent agents, as Kamel Boulos demonstrated extensively in Chapter 7.

Smart governance for health needs to be about better and deeper engagement with a range of societal actors, facilitated by better transparency and held accountable by social values. The media has an important role to play in this regard. Information-sharing in general needs to be understood as one of the most effective tools for coordination, legitimacy and accountability (Hernández-Aguado & Parker, 2009). The same is true for businesses, which are often perceived as contributing significantly to creating wicked problems, but minimally to finding their solutions. Hard regulations may ultimately be needed, but businesses are taking the initiative in realigning their operational philosophies in accordance with social values and self-reporting on progress made. The move towards a shared-values approach provides businesses with a smart governance option to contribute to the solution more actively, thereby stemming the implementation of harder regulations while catering to consumer preferences for healthier and safer products.

The International Food and Beverage Alliance was formed in May 2008 when the chief executive officers of eight major manufacturers signed a letter to the WHO Director-General committing their companies to support WHO’s global strategy on diet, physical activity and health (WHO, 2004). The chief executives acknowledged the private sector’s role by pledging to expand efforts already underway within individual companies to realize what they called five commitments in five years (International Food and Beverage Alliance, 2009):

1. continue to reformulate products and develop new products that support the goals of improving diets;
2. provide easily understandable nutrition information to all consumers;
3. extend responsible advertising and marketing to children initiatives globally;
4. raise awareness of balanced diets and increased levels of physical activity; and
5. actively support public–private partnerships that support WHO’s global strategy.

Annual reports in 2009, 2010 and 2011 and an independent audit of commitment 3 in 2012 suggest that the partnership is compliant (International Food and Beverage Alliance, 2013). Despite this, conflicts are increasing as WHO pays more attention to the

commercial determinants of health and is increasingly critical of what it calls “big food” and “big soda”. At the 8th Global Conference on Health Promotion in Helsinki, Finland on 10 June 2013, the WHO Director-General (Chan, 2013) stated:

It is not just Big Tobacco anymore. Public health must also contend with Big Food, Big Soda, and Big Alcohol. All of these industries fear regulation, and protect themselves by using the same tactics.

### 9.3.3 Governing through a mix of regulation and persuasion

#### 9.3.3.1 *How hierarchical governance still matters*

HiAP implies that health and risk are everywhere. This has significant consequences for how health policies are framed, where responsibilities for health in society are assigned and where major conflicts of interest emerge. If health and risk are everywhere, every place or setting in society can support or endanger it. Stakeholders in the big health debate are not only the producers of unhealthy products and substances, but also those that populate the arenas of everyday life where they are bought or consumed: supermarkets, restaurants, fast-food outlets, kiosks and such like.

This implies a shift from material entities and organizations that are clearly defined as health organizations to an increased dependence on institutional mechanisms that apply throughout society and which regulate behaviours and access to (or consumption of) products. Typical examples are smoking regulations: they not only regulate who can buy tobacco products, where and at what price, but also where smoking is permitted. Smoking restrictions have expanded over time to all settings in society: first, schools and hospitals, then major public places, then all forms of transport, then restaurants and bars until finally, as is the case now in the State of New York, smoking is permitted in practically no space outside the home. Smoking laws also regulate access to images and messages through restrictions on advertising for tobacco products.

Health, it turns out, really is everybody’s business in both a symbolic and real sense: owners of bars and restaurants, retailers, managers of airports and railway lines, to name but a few, need to be concerned with health. Everyday life settings become healthy settings through a commitment to norms and standards and patterns of appropriate behaviour, with laws and regulations sometimes promoting (and sometimes following) cultural shifts (Kickbusch, 2003).

Hill & Lynn’s (2005) comprehensive review of governance literature concluded that while market- and network-related government activities have increased in importance, hierarchical government is by no means in decline, and the role of government is just as pivotal as it ever was. Bell & Hindmoor (2009) argue that governments have recently extended hierarchical controls in governing at national and regional levels in areas such as mobile phones, genetic cloning, the Internet, genetically modified organisms, performance-enhancing drugs for sportspersons, in vitro fertilization, traffic congestion, population imbalances, antisocial behaviour and the threat of terrorism. An increasing willingness to regulate in relation to health – especially through applying fiscal policies – can be seen; the most recent example is the taxing of soft drinks that are high in sugar content.

#### 9.3.3.2 *How multilevel governance and steering instruments are evolving*

The expansion of top-down authority is visible in governments’ reliance on multilevel governance to address an increasing number of challenges, the solutions for which require that collective action beyond the state be effectively coordinated with implementation at national and local levels. Governing through networks captures the

horizontal cross-sector and interjurisdictional aspects of smart governance for health and governing through engagement describes the diffusion of governance for health roles to multiple new actors, but multilevel governance aims to describe the vertical relationships between governance actors and arenas.

Europe has seen a particularly large rise in multilevel regulatory agreements since the 1990s, almost entirely due to a new authority at regional level of governance. Fewer than 20 agreements were signed every three years when the European Economic Community was formulating policies on trade and agriculture in the 1970s, but 260 such agreements were signed between 2002 and 2005 (Bell & Hindmoor, 2009). The EU has successfully been able to provide health promoting regulations under its powers of consumer protection in some cases, such as the 2006 regulation on nutrition and health claims made on foods, which calls for measures “to ensure that any claim made on foods’ labelling, presentation or marketing in the European Union is clear, accurate and based on evidence accepted by the whole scientific community” (European Commission, 2006). The increasing attention industry lobbyists pay to the European Parliament is testament to its growing influence and authority. This can have implications for governance for health, as was exemplified in 2010 when food industry lobbying saw the European Parliament vote down proposals to force food manufacturers to add so-called traffic-light labels to the front of packaging to help consumers work out their daily intake of salt, sugar and fat.

The EU’s best-know work in smart governance for health, however, arises from its steering instruments, which are used as “alternatives to legislation” (Senden, 2005; Greer & Vanhercke, 2010). Examples include the platform on diet, nutrition and physical activity, the high-level group on health services and medical care, and the open method of coordination (Greer & Vanhercke, 2010). The last of these particularly demonstrates how traditional forms of hierarchical governance have to be incorporated into new governance methods to ensure that the so-called soft-law practices of the EU do not degrade into a sharing of ideas without follow-through. Greer & Vanhercke (2010) consider the looming possibility that the European Court of Justice can intervene with hard law through Article 49 jurisprudence (provision of services), state aid and competition cases (that are assimilating health into the internal market) as being integral to the success of regulatory approaches that rely less and less on command-and-control approaches. The potential use of hard law provides incentives for Member States to make the most of softer consensus-based mechanisms (Greer & Vanhercke, 2010). Bell & Hindmoor (2009) refer to this approach as “self-regulation in the shadow of hierarchy”.

The move to more mixed and multilevel forms of governance is driven by an increasing deterritorialization of problems and solutions and increasing differentiation within the international political system (Zürn, 2010). Differentiation refers to the development of new legitimate actors and arenas beyond the state where decision-making and regulatory action, policy implementation and resource allocation, and acceptance and recognition of actors and functions – the traditional business of governments – is also taking place. As Zürn (2010) argues, “nation states have increasing difficulties in designing unilateral policies or regulations that are of use in attaining governance goals such as security, legal certainty, legitimacy or social welfare,” for which they must turn to multilateral collaboration and international and regional institutions. Tomson, Påfs & Diseberg demonstrate this in Chapter 4 with examples of European policies to tackle tobacco consumption and antimicrobial resistance.

### *9.3.3.3 The softer side of the state: how states govern through persuasion*

A softer side of top-down authority has been developed in new forms of what is known as welfare contractualism, in which the state uses its centralized power and resources



to provide incentives through reward rather than sanction. Bell & Hindmoor (2009), for example, describe how:

... states have used tax incentives, subsidised nursery places and job-sharing schemes to encourage mothers to return to work. In Mexico, Brazil and other South American countries, conditional cash transfers provide financial incentives for mothers to take nutritional supplements, keep their children in school, and ensure they attend regular health check-ups. Parents are paid only if they effectively police their own activities.

One step further down the continuum from approaches that reward good behaviour is governance through persuasion. This goes beyond modifying people's behaviour through rewards and sanctions to changing their ideas of how they ought to behave (Bell & Hindmoor, 2009). The health sector has extensive experience in governing through persuasion and in teaming up with non-state actors to do so: HIV peer education and prevention programmes are a case in point.

#### 9.3.3.4 Nudge policies

Traditional hierarchical means of governing are becoming more fluid and adaptive. Regulation is no longer solely a top-down process, as soft power and soft law expand their influence. This includes self-regulation and growing interest in so-called nudge policies, which build on health promotion approaches such as making the healthier choice the easier choice.

Thaler & Sunstein (2008) describe nudge as: “any aspect of the choice architecture that alters people's behaviour in a predictable way without forbidding any options or significantly changing their economic incentives”. Examples would include making salad rather than chips the default side dish, or making stairs rather than lifts more architecturally prominent in public buildings. Another applied technique for nudge policies is called social norm feedback, in which information on what others are doing is shared.

Examples of nudging and regulating actions as described by Marteau et al. (2011) are shown in Table 9.1.

Nudging may not have convinced all public health professionals of its value (Bonell et al., 2011) and more research into its effectiveness is needed, but it represents an important shift in governance that does not treat individuals only as perfect specimens of *Homo economicus*, always rational and calculating. Rather than using incentives directed at people's wallets, nudge policies interface with people “within the settings of their everyday life; where they learn, work, play and love” (WHO, 1986), subtly influencing the norms by which they live and the psychosocial cues that can promote healthier behaviour or hinder unhealthy habits.

Smart governance for health is therefore not about choosing between governing through networks or through hierarchies, but is about the smart use of both approaches. As the Government of Australia (2007) notes:

For many wicked policy problems the effectiveness of traditional policy approaches to influencing behaviour (legislation, sanctions, regulations, taxes and subsidies) may be limited without some additional tools and understanding of how to engage citizens in cooperative behavioural change.

While traditional categories for policy tools, such as hard and soft (in the case of law, for instance), are descriptive in their function, smart governance is evaluative: it describes not only the tool in use, but also its choice and application within the context of a plurality of tools and modes of application.

Table 9.1. Examples of nudging and regulating actions

	Nudging	Regulating
<b>Smoking</b>	<p>Make non-smoking more visible through mass media campaigns communicating that the majority do not smoke and most smokers want to stop</p> <p>Reduce cues for smoking by keeping cigarettes, lighters and ashtrays out of sight</p>	<p>Ban smoking in public places</p> <p>Increase price of cigarettes</p>
<b>Alcohol</b>	<p>Serve drinks in smaller glasses</p> <p>Make lower alcohol consumption more visible through highlighting in mass media campaigns that the majority do not drink to excess</p>	<p>Regulate pricing through duty or minimum pricing per unit</p> <p>Raise the minimum age for purchase of alcohol</p>
<b>Diet</b>	<p>Designate sections of supermarket trolleys for fruit and vegetables</p> <p>Make salad rather than chips the default side order</p>	<p>Restrict food advertising in media directed at children</p> <p>Ban industrially produced transfatty acids</p>
<b>Physical activity</b>	<p>Make stairs, not lifts, more prominent and attractive in public buildings</p> <p>Make cycling more visible as a means of transport through, for instance, city bike-hire schemes</p>	<p>Increase duty on petrol year on year (fuel price escalator)</p> <p>Enforce car drop-off exclusion zones around schools</p>

Source: reproduced from *British Medical Journal*, Theresa M Marteau, David Ogilvie, Martin Roland, Marc Suhrcke, Michael P Kelly, Judging nudging: can nudging improve population health?, 342, d228, ©2011, with permission from BMJ Publishing Group Ltd.

### 9.3.4 Governing through independent agencies and expert bodies

New mechanisms have emerged with developments in approaches to democracy since 1945. Keane's (2009) monitory democracy is distinguished from previous forms of representative or assembly democracy through:

... the way all fields of social and political life come to be scrutinized, not just by the standard machinery of representative democracy, but by a whole host of non-party, extra-parliamentary and often unelected bodies operating within and underneath and beyond the boundaries of territorial states.

These new power-scrutinizing institutions are manifold and vary to a degree that challenges attempts to group them as a common phenomenon (Keane, 2009):

Monitory mechanisms are not just information-providing mechanisms. They operate in different ways, on different fronts. Some scrutinise power primarily at the level of citizen input to government or civil society bodies; other monitory mechanisms are preoccupied with monitoring and contesting what are called policy throughputs; still others concentrate on scrutinising policy outputs produced by governmental or nongovernmental organisations. Quite a few of the inventions concentrate simultaneously on all three dimensions. Monitory mechanisms also come in different sizes and operate on various spatial scales, ranging from 'just round the corner' bodies with merely local footprints to global networks aimed at keeping tabs on those who exercise power over great distances.

Types of monitory mechanisms are shown in Box 9.1.

**Box 9.1. Types of monitory mechanisms**

- Citizens' juries
- Participatory budgeting
- Teach-ins
- Archive and research facilities
- Conflict of interest boards
- Railway courts
- Consumer testing agencies
- Democracy clubs
- Protestivals (a specialty of the Republic of Korea)
- Deliberative polls
- Public consultations
- Social forums
- Web logs
- Electronic civil disobedience (often referred to as hacktivism)
- Advisory boards
- "Talkaoke" (local/global talk shows broadcast live on the Internet)
- Public memorials
- Opportunities for professional networking
- Public meeting trigger clauses
- Lok adalats in India
- Consumer councils
- Democracy cafés
- Summits
- Boards of accountancy
- Public scorecards
- Tendency of increasing numbers of NGOs to adopt written constitutions, with an elected component
- International criminal courts
- Bioregional assemblies
- Think tanks
- Local community consultation schemes
- Citizens' assemblies
- Global association of parliamentarians against corruption
- Public interest litigation
- Online petitions
- Public vigils
- Global watchdog organizations
- Experts' councils (such as the so-called five wise men of the Council of Economic Advisers in Germany)
- Global social forums
- Unofficial ballots (text-messaged straw polls, for instance)
- Focus groups
- Consensus conferences
- Open houses that offer information and advisory and advocacy services
- Brainstorming conferences
- Constitutional safaris (famously used by the drafters of the new South African constitution to examine best practice elsewhere)
- Satyagraha (non-violent) methods of civil resistance
- Chat rooms
- Peaceful sieges
- Independent religious courts
- Public planning exercises
- Web sites dedicated to monitoring the abuse of power (such as Bully OnLine, an initiative in the United Kingdom that aims to tackle workplace bullying and related issues)
- Self-selected opinion polls

Source: Keane (2009).

One subcategory, which Vibert (2007) refers to as "the unelected", is of particular importance within this wide range of new democratic mechanisms.

The focus on evidence-based policy has led to the creation of agencies such as NICE in the United Kingdom, an independent body for providing national guidelines on treatment, use of medicines and quality of care, and its sister organization in Germany, the Institute for Quality and Efficiency in Health Care. The EU has created a number of specialized agencies at regional level that bridge the interests of the EU, Member States and, ultimately, citizens. Permanand & Vos (2010) suggest that they have proliferated on numerous grounds in practical terms but mainly "in response to an increased demand for information, expert advice and coordination at the community level, as well as the need to lessen the Commission's workload and its search for more efficient and effective decision making." EU Member States support these multilevel expert agencies primarily as means of facilitating collective action and improved governance without further strengthening the European Commission, but also because "EU agencies are generally networks functioning to a 'hub and spoke' model, which directly involves national level counterparts" (Permanand & Vos, 2010). It is also important to note that some of these unelected expert bodies have developed approaches to listening to public and patient opinions (such as NICE's citizens' panel) (Dolan et al., 2003).

When these new and highly capable unelected actors are coupled with the increasing involvement and growing demands of informed citizens, more traditional elected forms of government must react, "propelled to change both the way they discharge their problem-solving role and the way in which they provide an arena for the expression of values in society" (Vibert, 2007). Government's steering role must facilitate, and adapt to, the new distribution of power. Public debates in Germany on the future of nuclear energy following events in Japan led to an ethical commission on safe energy provision, chaired by the former head of the United Nations Environment Programme,

being established: the government's decision to opt out of nuclear energy was based on its results. The High Court in the United Kingdom found in 2007 that the government's consultation on the future energy mix for the country was "misleading" and required the government to redo it. Increasingly, established ways of taking controversial decisions are being called into question.

In the EU context, regulatory agencies such as the European Medicines Agency and the European Food Safety Authority fill an important gap between regional-level regulation and regulatory implementation in Member States (Mossialos et al., 2010):

Many of the [EU] agencies represent the formalization into a single structure of what had previously been a series of loosely connected committees. This single committee structure can then work independently of both the Commission and the Member States – though this is not to say that the main committees are not subject to pressures from both, nor that their decisions or recommendations have never reflected these pressures – a fact that, in turn, generates its own credibility.

The agency approach therefore represents a new mode of EU governance which shifts away from "the long-standing, essentially top-down, rule-based 'community method'" (Mossialos et al., 2010) and aims to foster credibility of EU scientific decision-making depoliticizing processes such as risk assessment for health protection .

The expansion of the unelected into governance for health is also occurring in lower-income areas of the European Region. The Global Fund to Fight AIDS, Tuberculosis and Malaria, for example, a multilateral, multistakeholder donor agency, has established multistakeholder forums in Bulgaria, Romania and Tajikistan through their country coordinating mechanisms. These forums are responsible for governing global fund investments within countries in a manner analogous to the fund's own board of directors, which includes representatives from donor and recipient governments, NGOs, the private sector (including businesses and foundations) and affected communities.

### 9.3.5 Governing through adaptive policies, resilient structures and foresight

Fuerth (2009) states:

Most human misery arises from our own ignorance, rather than from the inherent organization of the natural world. Science and technology are ladders allowing us either to climb higher out of this condition, or to descend further. At the societal level, we express our choice through governance. But the default condition of governance is for the most part that it is myopic and fragmented.

#### 9.3.5.1. *How complexity science can inform better governance for health and well-being*

Addressing wicked problems requires a high level of systems thinking. If there is a single lesson to be drawn from the first decade of the 21st century, it is that surprise, instability and extraordinary change will continue to be regular features of our lives in the future (Swanson et al., 2009). Theories of complexity science are consequently increasingly being seen as relevant to public policy in sectors beyond environment, where they have so far mostly been applied (OECD Global Science Forum, 2009). Interdisciplinary systems approaches are critical for analysis and attempts to improve health and well-being and prevent future crises.

Systems approaches require understanding of the system as a whole, interaction between its elements and the potential for intervention. Understanding the system as a

whole in complex systems may include acknowledging the extent of our ignorance and limited grasp of the implications of nonlinear relationships within the system.

The systems approach is particularly valuable in child road safety, because it “moves away from placing the onus on children to adapt their behaviour to cope with traffic, to recognizing that children’s need for safe mobility must instead be addressed in the design and management of the whole transport system” (WHO & UNICEF, 2008). More than 260 000 children die as the result of road traffic accidents each year, and it is estimated that up to 10 million more are injured (WHO & UNICEF, 2008). Preventing child injury requires an understanding of the system and the interactions between its elements. Effective interventions need a mix of policies that extend to engineering and urban planning: these include reducing and enforcing speed limits and building separate infrastructure (the designation of exclusive motorcycle lanes in Malaysia reduced crashes by 27%), vehicle design and safety equipment (from running day lamps on vehicles to access to bicycle helmets), legislative action and implementation of standards, and better education and skill development for children, parents and the general population. System responses can be further strengthened with AG with foresight, as discussed below, helping policy-makers to explore how proposed policy interventions would stand up to future scenarios presented by, for example, demographic change and further urbanization.

Complex adaptive systems are characterized by nonlinear and self-organizing relations between agents that give rise to uncertainty and unanticipated consequences, or emergent properties or behaviours: in other words, the whole is greater than the sum of its parts. Urban planners, for example, understand that (Glouberman et al., 2003):

... the characteristics of a neighbourhood are different from, and not just the sum of, the individual elements of houses, streets, parks and shops. What makes a neighbourhood work, or not, is not the result of its particular parts, but rather, of the complex interactions of the individual elements.

The same can be said of human health, which is not just a function of an individual’s biological characteristics. The study of interconnections (weak links) and interdependencies (strong links) within the system and how small-scale interventions can impact the system as a whole are therefore paramount.

In brief, complexity science teaches that there is no simple causality or simple solution to wicked problems; indeed, interventions in one area could have unintended deleterious effects in another. Strategies for complexity-informed public policies have been developed (Glouberman et al., 2003; Swanson et al., 2009). Complex adaptive systems should be approached by policies that mirror the characteristics of complexity: decision-making should be decentralized and self-organizing/social networking should be enabled to ensure stakeholders can respond quickly to unanticipated events in innovative ways. Interventions should be iterative and should integrate continuous learning, multistakeholder knowledge-gathering and sharing and mechanisms for automatic policy adjustment or to trigger deliberations. They should also promote wide variation in policies, promoting the idea that delivering many smaller-scale interventions for the same problem offers greater hope of finding an appropriate and effective solution (or solutions) than a single, top-down, rationally planned approach.

This is particularly important to bear in mind as governance for health shifts to more collaborative whole-of-society and whole-of-government approaches, which should not be misinterpreted as a return to top-down large-scale initiatives. Although the role of leadership at the highest level of government and society is crucial, diffusion of governance must remain the critical paradigm for policy design and implementation.



Preserving and promoting system resilience should also be a fundamental characteristic of smart governance for health, but it is easy when talking about resilience to misunderstand it as merely the ability to quickly bounce back from systemic shocks to the old system. This is not possible, or even desirable, in many instances. Resilience is less about sustaining the existing system and more about a system's adaptive capacity to evolve with challenges – to roll with the punches – in the least disruptive way.

In summary, mirroring complexity means:

- promoting policies that are holistic and enable self-organization and social networking in the communities that design, implement and receive the end-services of public policy;
- decentralizing decision-making to the lowest effective and accountable unit of governance, whether existing or newly created;
- promoting variation and diversity in responses to common problems; and
- institutionalizing continuous learning and formal policy review and integrating automatic policy adjustment by defining signposts and triggers for changes in policy or for new discussions on policy renewal or adaptation.

Each of these methods has proven to strengthen communities and stakeholders to better respond to unanticipated events, increase policies' capacity to perform successfully when encountering unforeseen events, and manage risk more efficiently in the face of unanticipated conditions (Swanson et al., 2009). Paramount among them, however, is the use of integrated forward-looking analysis and multistakeholder deliberations.

### *9.3.5.2 How to govern anticipatorily: integrated and forward-looking analysis*

Swanson et al. (2009) comment:

By identifying key factors that affect policy performance and identifying scenarios for how these factors might evolve in the future, policies can be made robust to a range of anticipated conditions, and indicators developed to help trigger important policy adjustments when needed.

This describes a need for foresight and AG. Foresight is “the capacity to anticipate alternative futures, based on sensitivity to weak signals, and an ability to visualize their consequences, in the form of multiple possible outcomes” (Fuerth, 2009). AG employs foresight in policy design and implementation processes. Integrated and forward-looking analysis should lead to policies and policy-makers that are better able to “sense and execute changes ahead of the cusp of major events; the better to blunt threats and harvest opportunities” (Fuerth, 2009). Rather than a forecast that has a highly deterministic outlook on one high-probability outcome or singular trajectory, AG aims to build broad stakeholder capacity to imagine multiple possible future scenarios, including ignorance (unknown unknowns or so-called Black Swans). AG aims to address uncertainty head-on, signaling a shift from risks to addressing more fundamental challenges (such as ignorance) in the ways people conceive of, and respond to, the future(s) of innovations and how they live, work, love and relate to each other as a society.

Fuerth (2009) conceptualizes AG as a “system of systems” comprising a foresight system, a networked system for integrating foresight in the policy process, a feedback system to gauge performance and manage institutional knowledge, and an open-minded institutional culture. Integrated foresight analysis can be seen as complementary to initiatives to institutionalize health impact assessments and health lens analysis. AG with participatory foresight is discussed by Özdemir & Knoppers in Chapter 2.

## 9.4 New governance for health

This book has examined how governance for health in the 21st century is evolving alongside notions of health, democracy and the roles of state and society. It has argued for a new and expanded approach to good governance guided by values for health and well-being and described critical characteristics of smart governance for health that is collaborative, coproduced in government and throughout society, incorporates new actors and methods for scrutinizing power and authority and uses new methods to boost resilience and adaptability.

Governance for health is part of how 21st century societies are shaped. This means that governments need to change their approaches. It is now well understood that health requires action at whole-of-government level and by ministers and ministries of health. It is also recognized that partnerships and participation are critical mechanisms for the new governance, as expressed in whole-of-society approaches. The Moscow Declaration from the First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control held in Moscow on 28 and 29 April 2011 reflects this type of thinking clearly (WHO, 2011):

Effective NCD prevention and control require leadership and concerted whole of government action at all levels (national, sub-national and local) and across a number of sectors, such as health, education, energy, agriculture, sports, transport and urban planning, environment, labour, industry and trade, finance and economic development. ... Effective NCD prevention and control require the active and informed participation and leadership of individuals, families and communities, civil society organizations, private sector where appropriate, employers, health care providers and the international community.

This book has discussed the many reasons why another approach to governance is needed to promote and protect health and well-being in the 21st century. It has explored the role government and society play in the coproduction of governance for health to propose new roles for ministers and ministries of health and has compared the developments in health with the analysis of general trends in new governance.

As the editors of the book, we have aligned ourselves with the conclusions of Hill & Lynn's (2005) comprehensive review of governance literature: that while market- and network-related government activities have increased in importance, the role of government is as pivotal as it ever was. The role of governments in health remains fundamental; indeed, the changing nature of health has seen a clear – often contested – expansion of its regulatory controls into new areas of policy in different sectors.

We concur with the position that governments today are involved in exploring new approaches in metagovernance which, as Bell & Hindmoor (2009) describe, covers the range of functions governments assume in relation to:

... the support of governance arrangements, which include overseeing, steering and coordinating governance arrangements; selecting and supporting the key participants in governance arrangements; mobilising resources; ensuring that wider systems of governance are operating fairly and efficiently; and taking prime carriage of democracy and accountability issues.

Growth in new mechanisms and approaches to governance for health at all levels and involving many different actors has been exponential. We see a clear trend in health towards new forms of collaboration and monitory democracy, with increased levels of accountability for health impact.

We agree with arguments that health can no longer be considered a sectoral goal to be produced by a single ministry. Indeed, we believe health emerges from complex adaptive systems primarily dependent on social and political determinants of health. This requires a shift in mindset throughout society and government in three main ways, in which health is recognized by:

1. heads of government as a priority for joined-up-government;
2. all sectors and levels of government and within society as a means to reach their own goals but also as a responsibility towards the whole of society; and
3. the health sector as requiring a greater leadership and outreach role.

Governance for health requires whole-of-government and whole-of-society approaches and a new positioning and role for ministers and ministries of health. New forms of transitional leadership are beginning to emerge. We believe this is possible to achieve not as a utopian ideal, but as a form of what Stewart (2014) describes as good-enough governance, which is characterized by its diversity and adaptability.

## 9.5 New role for the health sector

We concur that for health, the role of governments and government agencies is far from dried up, and that the dichotomy between state-centred and society-centred relational governance is somewhat false; they remain distinct approaches, but coexist (and even mix in most cases). Capable and informed ministries are still crucial whether actions are hierarchal or designed for more fluid systems of communication and collaboration, but they need to change. Considering the transformations society has been undergoing over the last 35 years, many governments and ministries of health appear slow to adapt. Too many national governments and agencies within governments continue to conduct business as usual and “assume the role of coal shufflers on electric trains” (Willke, 2007). Instead, the state must play new roles and become involved in problem-solving as a broker, catalyst, animator, educator and partner in much more participatory and so-called flat processes (OECD, 2001). This also applies to ministries of health and the agencies aligned to them. In particular, interaction with the citizenry has become critical, lending new vigour to concepts of subsidiarity and health action at local level and the importance of mesoinstitutions that allow for participation in debate.

Ministers of health, permanent secretaries, secretaries of state and equivalents have a key role in good governance for health by engaging in transformational leadership within government and by:

- giving the message (and creating the environment) within their sphere of influence that they want to see cross-cutting approaches and wish to move away from territorial identities;
- taking positions for health at the cabinet table and initiating cross-departmental cooperation with support at ministerial level;
- using their authority to reach out to other actors for joint initiatives, setting the framework for health for microdecisions through nudge policies directed at society as well as government; and
- seeking exchange with citizens and community-based action groups to understand people’s concerns and contributions through developing a civil society strategy.

Senior civil servants in ministries of health and heads of health agencies need to initiate a process that develops their organizations’ capacities in smart governance for health.

They need to:

- adopt an expanded understanding of health that:
  - looks outward from the health sector as well as inward;
  - abandons linear thinking and accepts unpredictability and uncertainty brought on by complexity; and
  - calls for health policies and institutions to reflect a better use of foresight, multistakeholder deliberation, promotion of variation, self-organizing networks, decentralized decision-making and continuous learning and review to manage risks and create more enduring policies;
- assign resources and, above all, time to:
  - building-up intersectoral trust and understanding;
  - jointly identifying areas of goal interdependence with partners in other ministries, the private sector and communities; and
  - taking on the critical role of network manager with skill and respect for network partners; and
- support national-, regional- and global-level dialogues on societal values and goals with health and well-being as an essential component by facilitating universal ownership for the health agenda, which in some cases may mean that the ministry of health does not lead.

It is important to note the distinction between the powers of politics, which sit with ministers, and the powers of policy, which sit with ministries, agencies and the experts on whom they call. This book has argued that health politics is paramount, and it is often politics that have most influence over good governance for health and its four key dimensions: human rights, well-being, global public goods and social justice.

Ministers should recognize the need, and their responsibility, for action on the political determinants of health beyond the scope of public policy. Parliamentarians should engage in governance for health in new and proactive ways. This is critical if we consider, for example, the recommendations from the First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control (WHO, 2011), which identify and distinguish the responsibilities that lie at whole-of-government and ministry of health levels.

The power to initiate smart governance for health sits mainly with ministries. Ministries of health and health agencies must assume new roles as metagovernors of relationships – that is, taking responsibility for building trust and managing networks through improved communication for collaboration.

The health sector must learn to work in partnership with other sectors to advance governance for health, which means jointly exploring policy innovation, novel mechanisms and instruments and better regulatory frameworks. This requires a health sector that is outward-oriented, open to others and equipped with the necessary knowledge, skills and mandate to take a systems approach to health and partner ministry priorities. It also means improving coordination and supporting champions within the health sector itself.

Health departments' new responsibilities in support of a HiAP approach were summarized in the 2010 Adelaide statement (WHO, 2010) (Table 9.2).

Table 9.2. Adelaide statement on HiAP

New responsibilities of health departments in support of a HiAP approach will need to include:	Comment
<ul style="list-style-type: none"> <li>understanding the political agendas and administrative imperatives of other sectors, building capacity to practice intersectoral approaches and working with other arms of government to achieve their goals and, in so doing, advance health and well-being;</li> <li>building the knowledge and evidence base of policy options and strategies;</li> </ul>	<p>This is essential for successful collaborative governance, which requires the building of trust between sectors and appropriate framing of interdependent policy goals, challenges and solutions.</p>
<ul style="list-style-type: none"> <li>assessing comparative health consequences of options within the policy development process;</li> </ul>	<p>More information and evidence need to be developed and shared. The health sector should set an example of greater transparency by providing information on how resources are allocated and used, identifying successful institutions and those with problems, and sharing epidemiological research on health trends, among other data. This offers a point of departure for intersectoral analysis of health problems (Castell Florit, 2010).</p>
<ul style="list-style-type: none"> <li>creating regular platforms for dialogue and problem-solving with other sectors;</li> </ul>	<p>This can be accomplished through integrated forward-looking analysis, such as foresight and AG, health impact assessments and health-lens analysis.</p>
<ul style="list-style-type: none"> <li>evaluating the effectiveness of intersectoral work and integrated policy-making; and</li> </ul>	<p>Engaging with a wide range of viewpoints in multistakeholder deliberations is critical to all aspects of smart governance for health.</p>
<ul style="list-style-type: none"> <li>building capacity through better mechanisms, resources, agency support and skilled and dedicated staff</li> </ul>	<p>Policies can become more adaptive and address problems before they turn into a crisis through integrated review and continuous learning.</p>

Source: WHO (2010).

## 9.6 Political engagement and leadership

Health is a political choice. Change processes need to be led within governments, organizations and civil society. Leadership can be shown at the top of an organization and it can emerge bottom-up as agendas are set in civil society and through the media. The term political will is used frequently in the health arena to describe the ability to effect change. It is a composite of many dimensions that requires a sufficient set of political actors with a common understanding of a particular problem on the public policy agenda and who genuinely intend to support a potentially effective policy solution (Post et al., 2010). Assuring political will is a complex process usually developed over time and influenced by contextual factors such as the media and social acceptance of an issue. Kingdon (1995), in his work on agenda-setting, identified three streams that need to come together to effect policy change: the problem, politics and policies streams.

Leaders can be seen as policy entrepreneurs by helping to develop understanding of an issue, framing it and acting as facilitators. Leaders today are not always individuals:



they can also be organizations and movements that exert pressure on politicians and policy-makers to act. The health arena has many examples of leadership through social movements, such as those for women's health and HIV/AIDS, which are developing new dimensions through technological advances. Leadership becomes increasingly consultative and democratized as new forms of participation develop. Monitory democracy requires good ethical judgement and transparency from leaders in relation to conflicts of interest.

Nye (2011) underlines that leadership is changing in a 21st century context. He applies his concept of soft and hard power and sees effective leadership as a successful mix of skills of both kinds, which he calls smart power. Leaders today are enablers: they help a group create and achieve shared goals. This is critical in relation to multistakeholder governance, as one of the most highly regarded leadership skills is to enlarge the sense of "we" and create a common purpose, a principle fully reflected in health promotion's notion of empowerment, which is about enabling people to improve their health and address its determinants. This is called transformational leadership – it mobilizes power for change based on goals that serve a higher purpose, in this case increased health and well-being as a societal goal.

New leadership needs a range of critical skills. One of the most important has been termed contextual intelligence (Mayo & Nohria, 2005), which describes the ability to discern trends in the face of complexity and adaptability and capitalize on them. It is a skill that allows a leader to align tactics with objectives and create smart strategies in an evolving environment. Transformational leaders make good use of windows of opportunity and apply a mix of hard and soft power strategies to achieve change. It is these skills that need to be strengthened to drive better governance for health.

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## The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

# Smart governance for health and well-being: the evidence

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UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark

Tel.: +45 45 33 70 00 Fax: +45 45 33 70 01 E-mail: [contact@euro.who.int](mailto:contact@euro.who.int)

Web site: [www.euro.who.int](http://www.euro.who.int)