

Enhancing Value in European Health Systems

The Role of Outcomes Measurement

Consensus document





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This report is the output of a multi-stakeholder initiative, and has been endorsed by:

- **the European Brain Council**
- **the European Patients' Forum**
- **the European AIDS Treatment Group**
- **the European Liver Patients Association**
- **the European Federation of Pharmaceutical Industries and Associations**
- **the European Institute for Innovation through Health Data**
- **Active Citizenship Network**
- **Cancer Research UK**
- **Royal College of Nursing**
- **Warwick Medical School**
- **the International Consortium for Health Outcomes Measurement**
- **Celsus Academy for Sustainable Healthcare**

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Foreword



This Vision Document is not just an interesting report - it is a compelling illustration of the role of health for Europe's sustainable growth and prosperity, a convincing call for a stronger focus on the outcomes of health systems to improve the quality of care and public health - and a clear demonstration of the importance of measuring those outcomes for greater transparency and accountability for health system performance.

Good health is beneficial to our economies and societies: healthy citizens are more productive, work longer and more continuously; a healthier population with longer life expectancy is more prone to invest, including in human capital.

But there is a simpler, more important factor that justifies the importance given to health in the policy debate in Europe, of course: irrespective of its contribution to the economy, health is a value in itself - and that's why we have to do our best to help people maintain and improve their health. With this goal in mind, the European Commission adopted in 2014 an agenda for Europe's health systems, proposing actions to help countries strengthen their effectiveness, increase their accessibility, and improve their resilience.

I'm happy and reassured to see that this Vision Document confirms many of the key findings we identified, while at the same time proposing new interesting and valuable recommendations on how to move forward.

It is hard to disagree with the key assumption that drives the report: if we want to improve the performance of our health systems, we have first to assess them. And in particular, we should focus on measuring outcomes; this will give us the perspective of European citizens in understanding the quality and effectiveness of health services.

Most of the indicators we use today focus on inputs and processes. In some occasions we measure outputs, such as the number of operations. But what really matters for citizens and patients are outcomes: it's not the number of operations; it's their result.

In some areas, we already collect some statistics on outcomes, as pointed out in this Vision Document. In these cases we see marked variations - both between countries and within them. We know that variations mean possibilities of improvement: this gives us a stimulus to build more solid evidence,

“Measuring outcomes is close to a change of paradigm; it will require time and dedication, and a common effort by all players in this field.”



collecting relevant and valuable information, and thus help realise these improvements. At the same time, we cannot impose an excessive burden to those who will have to collect the data. ICT technologies and effective networks among providers of care will be instrumental.

Measuring outcomes is close to a change of paradigm; it will require time and dedication, and a common effort by all players in this field. We are already working with other international organisations to improve our capacity to assess the performance of health systems, and in particular to develop measures of patients' reported experiences and outcomes.

This Vision Document provides an outstanding contribution to the debate on health outcomes, and proposed valuable recommendations on how to move forward: it's now up to all of us to accept the challenge and translate these recommendations into actions. The European Commission cannot and should not tell countries how they should organise their health care systems: this is a national competence. But we have a mandate to develop, particularly within the Directorate General for Health and Food Safety, the necessary expertise on the performance of health systems, to build up solid country-specific and cross-country knowledge which can inform policies at national and European level.

This Vision Document will help us greatly in this task.

Xavier Prats Monné

Director-General for Health and Food Safety, European Commission

Executive Summary

Health systems across the European Union are confronting numerous challenges – from ageing populations and the sustainable financing of health care, to wide variations in clinical practice, a necessary and increasing emphasis on patient experience, and significant public health problems. This report shows how a **greater focus on health outcomes**, and in particular the use of **health outcome measures**, can help to **drive improvements** across the health system – be it at the clinical level, the healthcare system level, or in relation to public health policies / interventions.

The report also shows that health outcomes measures are essential to well-designed frameworks for **health system performance assessment** (HSPA). Too often, analyses of the health system performance focus on structural, process and expenditure measures. While all these data types can be useful, outcomes data is unique in providing information about the performance of the system in relation to its fundamental goal: improving patient and population health.

Improving health outcomes should not simply be seen as a matter for health policy. Better **health can make a very important contribution to economic and social goals** through longer working lives, greater productivity, reduced disability claims, better educational outcomes, and reduced social exclusion.¹ While ‘health and well-being’ is the third of the UN’s revised sustainable development goals², it does not feature among the priorities of the EU 2020 Strategy – the EU’s ten-year sustainable economic growth strategy (agreed in 2010).

The absence of health from the Europe 2020 Strategy was surprising not simply because of the link between health and economic performance, but also because health spending accounts for a significant share of public spending in all EU Member States.³ For that reason, recommendations aiming to contain the growth of health expenditure have featured prominently in Europe’s annual cycle of economic policy coordination – the European Semester.

A central argument of this report is that health should be included among the priorities of any new sustainable growth policy at European level. Given the importance of ensuring value for money in health spending, and the contribution that high performing health systems can make to economic and social outcomes, **the development of robust national HSPA frameworks should be identified as a key tool for economic, social and health policy.**

In addition, by improving quality of care for patients, and strengthening public health interventions, greater use of health outcome measures can also make an important contribution to the **sustainability of health systems.**

Making the development and use of health system performance assessment an objective of Europe’s sustainable growth policies does not imply the standardisation of HSPA across countries. Responsibility for the organisation of health systems rests with Member States, and the design of HSPA should

¹ ‘The Tallinn Charter: Health Systems for Health and Wealth’, WHO European Ministerial Conference, June 2008; J. Figueras and M. McKee, *Health Systems, health, wealth and societal well-being: Assessing the case for investing in health systems* (Open University Press, 2011); European Commission, ‘Investing in Health’ (Commission Staff Working Document, February 2013).

² See United Nations Sustainable Development Goals: <https://sustainabledevelopment.un.org/sdgs>

³ European Commission, ‘The 2015 Ageing Report: Economic and budgetary projections for the 28 EU Member States, 2013-60’ (2015).



therefore reflect national preferences and specificities.

However, and as this report will show, comparison of health outcomes based on **standardised indicators** can be a very powerful tool for use in national HSPA frameworks. The work of the OECD's Health Care Quality Indicators project is highly important in this respect, and should be further enhanced.⁴

Transparency of outcomes data – by publishing HSPA findings and conclusions – can also strengthen **accountability** for health outcomes within countries, and incentivise performance improvements by the different actors within health systems.

Chapters 1 and 2 focus on the use of outcome measures in relation to health care and public health respectively. **Chapter 1** shows that outcome measures can be a **multi-purpose tool for improving quality of care**. Using the OECD definition for quality of care (effectiveness, safety and patient-centredness), the chapter shows how outcome measures can be used to drive quality improvement initiatives both at the health care provider level (through 'continuous improvement' cycles) and at the health system level through performance assessment.

Chapter 1 also shows how outcomes measurement can contribute to **more patient-centred health care** – in particular **patient empowerment** – through the routine use of patient-reported outcome measures in clinical practice, and the involvement of patients in the selection of measures to be used as part of quality improvement strategies.

The chapter then outlines the **main challenges** relating to the use of outcome measures to improve quality of care, focusing on the need for:

- i. Efficient **health information systems** (e.g. electronic health records and patient registries);
- ii. Robust **data governance frameworks** that enable the use of health care data for performance improvement purposes whilst protecting patient privacy;
- iii. **Training and analytical support** for medical professionals in using outcome measures for quality improvement.

Chapter 2 focuses on the use of public health outcome measures to **support and improve public health policy and interventions**. It shows how outcome measures can be used to:

- i. **Tailor policies and interventions** to local population requirements – be that at the community, regional or national level;
- ii. Strengthen the **follow up and review** of past interventions with a view to evaluating their effectiveness and determining how future interventions can be improved;
- iii. Strengthening **transparency and accountability** for public health outcomes.

The chapter then sets out some of the key **challenges and opportunities** relating to the use of outcome measures for improving public health. These relate to: the need to differentiate data according to population sub-groups (for example, on the basis of gender, education and income levels); the need to take account of the time lags that may be involved between an intervention and a change in outcome indicators; and the potential for new digital technologies and Big Data analytics to further strengthen public health outcomes measurement.

Both chapters 1 and 2 conclude by making a number of recommendations for policy actions to

⁴ On the OECD Health Care Quality Indicators Project see: <http://www.oecd.org/health/health-systems/health-care-quality-indicators.htm>

support progress towards outcomes focused health systems across Europe (see the Summary of Recommendations at the end of this report).

This report is the output of a series of multi-stakeholder seminars focusing on health outcomes and the role of health outcomes measurement in improving and assessing the value of investments in health. The seminars will continue in 2016, focusing on three main topics:

- i. The use of outcomes data to **improve care pathways**
- ii. Harnessing the potential of **innovative technologies** as enablers of better outcomes;
- iii. **International standardisation** of outcomes indicators – especially at the OECD.

The final chapter of this report provides an introduction to these topics, and a starting point for the discussions in the next series of multi-stakeholder seminars. The seminars will lead to an updated version of this report, with new chapters added in late 2016.



Introduction

Health systems are increasingly in the political spotlight. The long-term trend of rising health spending as a share of GDP, short-term pressures on public finances due to the economic crisis, and the challenges associated with ageing populations, have combined to put health systems high on the economic reform agendas both of national governments and the European Union.

At national level, this is reflected in the raft of cost-containment measures introduced by governments during the economic crisis.⁵ At the European level, it can be seen in the strong focus on the sustainability of health systems in context of EU economic policy coordination, formally known as the European Semester.⁶

The financing of health systems is, however, just one of a number of critical health-related challenges that need to be addressed by policy makers. In addition, there is a need to focus on: reducing the wide variations in clinical practice both within and between countries⁷; enhancing patient experience and patient-centredness within health systems⁸; tackling a range of significant public health issues (obesity levels and diabetes prevalence, for example); reducing inequalities in health outcomes between different population groups.

The common theme running through all these challenges is the crucial importance of ensuring that health systems deliver maximum value for the resources invested in them – whether that means better resource allocation within the system, improving quality of care for patients, or more effective public health interventions. This report shows how the measurement of health outcomes (whether at the patient or population level) can be a vital tool for enhancing value.

Health outcomes and sustainable growth policies: the role of health system performance assessment

Better value in health spending is not only a primary objective for health policy; it has an increasingly vital role to play in economic policy as well. This is only partly related to the share of public expenditure invested in health systems and the need to ensure that spending levels do not become unsustainable. Equally important is the contribution that better health outcomes can make to economic goals – a contribution which, while often acknowledged in principle, is all too rarely taken into account when decisions about health spending are made.

⁵ OECD, 'Focus on Health Spending: OECD Health Statistics 2015', available at: <http://www.oecd.org/health/health-systems/Focus-Health-Spending-2015.pdf>; T. Clemens et al., 'European Hospital Reforms in times of crisis: Aligning cost containment needs with plans for structural re-design?', *Health Policy* 117 (2014); F. Houyes, L. Tessier, D. Synodinos, 'Health care cost-containment measures in the context of the economic crisis: impact analysis', *Orphanet Journal of Rare Diseases*, 2014, 9.

⁶ On the European Semester and country-specific recommendations, see: http://ec.europa.eu/europe2020/making-it-happen/country-specific-recommendations/index_en.htm.

⁷ OECD, 'Geographic Variations in Health Care: What do we know and what can be done to improve health systems performance' (OECD Health Policy Studies, 2014); H. Aldewick et al., 'Better Value in the NHS: the role of changes in clinical practice' (July 2015); J. Birkmeyer, 'Understanding Regional Variation in the Use of Surgery', *Lancet*, 382. 2013

⁸ For example: WHO European Conference on Patient Empowerment, April 2012; EMPATHiE project – Empowering Patients in the Management of Chronic Diseases, *Final Summary Report* (2014); OECD, 'Improving Value in Health Care: Measuring Quality' (2010).

The Tallinn Charter on 'Health Systems for Health and Wealth', agreed by health ministers of the WHO European region in 2008, emphasised that 'improved health contributes to social well-being through its impact on economic development, competitiveness and productivity'.⁹ Only two years later, however, in the midst of the economic and financial crisis, health spending in the EU (as a proportion of GDP) fell for the first time in decades.¹⁰

In a context of ageing populations, high performing health systems and improved health outcomes (in particular, by enabling people to remain fit and active for longer, and preventing or delaying morbidities) is more economically relevant than ever. At the global level, 'Good health and well-being' is the third of the UN's revised sustainable development goals.¹¹ At the European level, however, health and health systems were notable for their absence among the priorities of Europe's sustainable growth strategy – the Europe 2020 Strategy.¹²

During the review of the Europe 2020 Strategy in the second half of 2014, health ministers recognised that **'health is not only an important factor for social well-being but also makes an important contribution to economic growth and employment'**.¹³ The Italian Presidency's synthesis report on the Europe 2020 review further elaborated on the conclusions of the health ministers' discussion – noting that: *'More attention at national level should be given to the outcomes that health systems deliver. To achieve this, it will be necessary to develop indicators and promote the use of Health System Performance Assessment ... adapted to national circumstances'*.¹⁴

Health system performance assessment is the term used to describe a variety of national and international frameworks for evaluating the performance of the health system in relation to key goals and objectives – for example: quality of care (including outcomes), efficiency, access, and equity.¹⁵

HSPA as a concept began to attract significant attention following the publication of the WHO's World Health Report 2000 (WHR 2000), 'Health Systems: Improving performance', which included a scoreboard showing countries' performance in relation to a series of health indicators.¹⁶ WHR 2000 generated considerable controversy at the time, in particular due to criticisms regarding the underlying methodology. However, it was successful in generating a discussion about the appropriate design of HSPA, and a focus on its potential value as a tool for health policy.¹⁷

Today, HSPA has come a long way from the methodology used in WHR 2000. Three national examples of HSPA are discussed in Chapter 1 (the Netherlands, Sweden, and NHS England), which show how the use of outcomes data within HSPA can be used to drive quality improvement.

HSPA has also become an area of increasing interest within the EU. Developing expertise on HSPA was one of the priorities included by President of the European Commission, Jean-Claude Juncker, in his mission letter to the new European Commissioner for Health, Vytenis Andriukaitis in November

⁹ 'The Tallinn Charter: Health Systems for Health and Wealth', WHO European Ministerial Conference, June 2008

¹⁰ OECD, *Health Spending in Europe falls for the first time in decades* (2012)

¹¹ UN Sustainable Development Goals

¹² European Commission, *Europe 2020 Strategy*

¹³ Council of the EU, *Outcome of EPSCO (Health) Council*, 1 December 2014

¹⁴ Council of the EU, *Note by the Presidency: 'Europe 2020 Strategy mid-term review – Synthesis report*, 15 December 2014

¹⁵ See P. Smith, 'Health System Performance Assessment: Synthesis Report' (European Commission, 2014)

¹⁶ WHO, 'World Health Report 2000: Health Systems: Improving Performance' (2000)

¹⁷ C. Murray and D. Evans (ed.), *Health Systems Performance Assessment: Debates, Methods and Empiricism* (WHO, 2003)



2014.¹⁸

A Member State Expert Group on HSPA, chaired by Sweden and the European Commission, has also been created with the aim of: *'identify[ing] tools and methodologies for Member States, which might be implemented in order to further improve their health system performance'*, as well as *'searching for ways to improve comparability of information through an agreed working framework'*.¹⁹ Two thematic sub-groups have been established: the first on quality of care and the second on integrated care. Chapter 1 of this report is therefore closely related to the work of the HSPA Expert Group.

In April 2014 the European Commission adopted a Communication to propose an EU agenda on effective, accessible and resilient health systems.²⁰ The Communication makes the case for HSPA, which is presented as one of the key actions to improve the effectiveness of health systems, i.e. their capacity to produce positive health outcomes. The Communication suggests that an EU-wide collaboration in this area may allow more targeted work to reduce inequalities by providing support to Member States that are performing below the EU average to help improve their situation.

Performance assessment is also central to the focus on health systems in the European Semester process of economic coordination, which focuses above all on the 'efficiency' and sustainability of health spending. The Semester culminates each year with economic reform recommendations to Member States, many of which call for actions to improve the efficiency ('cost-effectiveness' is the phrase used in many of the country-specific recommendations) of Member State health systems.

However, the methodology used in the European Semester performance assessments has proved controversial. It is based on a 'thematic assessment framework' developed by the Directorate-General responsible for Economic and Financial Affairs (DG ECFIN), which is strongly focused on expenditure related indicators (including structural and process measures) in order to identify outliers in relation to certain types of health spending (e.g. hospital care, primary care, and pharmaceutical spending).²¹ Very few outcome indicators are used in the framework – reflecting the relative paucity of comparable data – which means that there is a very limited evidence base for making assessments about the effectiveness of national health systems.

The outcome indicators included in the thematic assessment framework are: i. life expectancy – which is determined by a large number of factors, many of which lie outside the health system (and even more so the health care system); ii. amenable mortality, which is a composite indicator of health care quality, but has a number of limitations as a performance indicator, particularly if it is not supplemented by indicators at the medical condition level²²; and iii. infant mortality, which, albeit very important, reflects outcomes in relation to only one area of health care.

Nonetheless, and as this report will go on to show, well-designed HSPA can be a powerful tool for improving health system performance. Well-designed HSPA frameworks should include robust measurements of health outcomes – providing a high level overview of the effectiveness of the health

¹⁸ Jean-Claude Juncker, President of the European Commission, [Mission Letter](#) to Vytenis Andriukaitis, 1 November 2014

¹⁹ Council of the EU, 'Health systems performance assessment (HSPA) – terms of reference for an expert group', 9 September 2014

²⁰ Communication from the Commission on effective, accessible and resilient health systems, Brussels, 4.4.2014, COM(2014) 215

²¹ The thematic assessment framework can be found in: Social Protection Committee, 'Progress Report on the Joint Assessment Framework in the Area of Health', 17 February 2015.

²² See for example: J. Gay and V. Paris, 'Mortality Amenable to Health Care in 31 OECD Countries: Estimates and methodological issues' *OECD Health Working Papers* No. 55 (2011).

system as a whole, as well as enabling detailed assessments of performance in relation to key medical conditions and public health challenges.

Frameworks for HSPA which contain a strong foundation of outcomes data will also be much more useful and valid as way of assessing the value of health spending. Given the strong links between health and the economy, well-designed HSPA should be seen as an essential tool for sound economic governance within countries.

EU health policy: the role of outcomes measurement

In addition to the contribution outcomes measurement can make to well-designed HSPA, and thereby to sustainable economic policies, this report highlights the relevance of outcomes measurements to numerous other EU policies and initiatives. In this context, it should be underlined that the responsibility for the organisation and delivery of health systems sits with Member States. The work of the EU focuses on supporting Member States to address common challenges and objectives.

The **EU Health Programme, 2014-20** is used to implement the 2007 EU health strategy.²³ It contains four main objectives related to:

1. Health promotion and disease prevention;
2. Protection from cross-border health threats;
3. Contributing to innovative, efficient and sustainable health systems;
4. Facilitating access to better and safer health care.

By showing how health care outcome measures can be used to improve quality of care, the first chapter of this report relates directly to objectives 3 and 4 of the EU Health Programme. In the same way, Chapter 2, which shows how outcome measures in public health can be used to support the design and follow up of effective public health interventions, is closely aligned with objectives 1 and 3.

A greater focus on health outcomes is also highly relevant to EU work on:

- **Health information** – by supporting the development of health information systems at national level;
- **The cross-border healthcare directive** – by facilitating the development and sharing of quality standards for Member State health systems;
- **Personalised medicine** – the December 2015 Council Conclusions highlight the contribution that personalised medicine could make to ‘improving health outcomes’²⁴;
- **Tackling health inequalities** – through the further development of the Joint Assessment Framework on Health (JAF Health) as a tool for social protection.

The report also focuses on the development of digital tools for the measurement and analysis of outcomes data (for example electronic health records and Big Data analytics) – a theme highly relevant to the EU’s Digital Single Market initiative.

²³ Regulation 282/2014, EU Health Programme, 2014-20

²⁴ Council of the EU, Outcomes of the Council Meeting, EPSCO, 7 December 2015



Strengthening health system accountability

Another key theme of this report is that transparency of outcomes data can strengthen accountability for health system performance. This may mean the accountability of health care providers, public health authorities, policy makers, or governments. Transparency of outcomes data provides an opportunity for all stakeholders to monitor and assess how effectively resources are being used, and what the results of investments in the health system have been. Greater accountability can lead to better priority setting, and incentivise improvement initiatives across the health system. The development of 'effective, accountable and transparent institutions' is also one of the targets included in the revised UN Sustainable Development Goals (see goal 16: 'just, peaceful and inclusive societies').²⁵

²⁵ UN Sustainable Development Goals

1 Health Care Outcomes Measurement

Improving quality of care

Improving quality of care is a high priority across EU health systems. Variations in clinical practice and outcomes are significant both within countries and between them, and there is increasing evidence regarding the extent of inappropriate or unsafe care.²⁶ Poor quality is both wasteful (using resources ineffectively when other treatments would have been more appropriate or beneficial) and can increase health care costs (for example, through avoidable hospital readmissions or reoperations).²⁷ High quality care, by contrast, can create savings for the health system by reducing the need for further interventions, and entails wider economic benefits – for example through longer working lives, reduced absenteeism, and reduced claims for other forms of welfare (such as disability benefits). In short, high quality care is a pre-requisite for health systems that are sustainable and deliver value.

The development of tools to help Member States improve quality of care is a key objective of the EU Health Programme, 2014–2020.²⁸ Quality of care is a priority area for the EU Expert Group on Health System Performance Assessment, as well as a major theme in the development of international health care indicators at the OECD.

While the term ‘quality of care’ is not always defined consistently, this chapter employs the OECD definition, which distinguishes between three aspects / dimensions of health care quality: effectiveness, safety, and patient-centredness / responsiveness.²⁹ Effectiveness and safety both reflect outcomes of care: effectiveness concerns the extent to which health care interventions actually improve the health of patients; safety focuses on the prevention of medical errors and adverse events (e.g. hospital related infections). Patient-centredness / responsiveness is not an outcome per se; it concerns the way in which care is delivered – e.g. whether it is attentive to patients’ needs, preferences, and expectations.

This chapter will show that health care outcome measures are a **multi-purpose tool** for improving quality of care:

- Outcomes data can be used to drive **continuous improvement** initiatives within individual or groups of health care providers.
- The inclusion of outcomes data in **performance monitoring** and transparency can:
 - enable the identification of best practice

²⁶ OECD, ‘Geographic Variations in Health Care: What do we know and what can be done to improve health systems performance’ (OECD Health Policy Studies, 2014)

²⁷ OECD, ‘Improving Value in Health Care: Measuring Quality’ (2010).

²⁸ Regulation 282/2014, EU Health Programme, 2014–20

²⁹ E. Kelley and J. Hurst, ‘Health Care Quality Indicators Project: Conceptual Framework Paper’ (OECD Health Working Papers, 23, 2006).



- inform policies and recommendations aimed at improving health care quality
- and incentivise quality improvement across providers
- Measurement of outcomes can also contribute to making health care more **patient-centred** – for example:
 - by using patient-reported outcome measures (PROMs) to empower patients in clinical settings³⁰
 - by involving patients in the selection of outcome measures for use in quality improvement initiatives³¹

The chapter will also outline some of the key challenges that need to be addressed if the full potential of outcome measures is to be realised. These include: the creation of **efficient health information systems** (such as patient registries, electronic health records); the need for **data governance frameworks** that allow patient data to be used for health care quality improvement whilst at the same time protecting patient privacy; and the need to continue developing **standardised outcome measures / indicators** that can facilitate international quality comparisons.

The chapter will conclude by outlining a number of recommendations for EU level actions to advance the agenda of outcomes measurement for better quality of care.

1. Measuring health care quality: the role of outcomes

A variety of different health care measures are available that can be used to assess quality. Using an adapted Donabedian model,³² these can be categorised as:

- **Structural measures:** which provide information about the resources (human, infrastructural and technological) available within a health care organisation or system. For example: the availability of CT scanners or relevant medical specialists.
- **Process measures:** these provide information about activities carried out in the delivery of health care services – for example: screenings, pharmaceutical prescriptions, or surgical interventions. They are often used to assess how far the delivery of care is compliant with clinical guidelines.
- **Outcome measures:** provide information about the effectiveness or safety of health care (e.g. mortality and surgical complications), and its impact on patients' quality of life and well-being. More information about the different types of outcome measures can be found below.
- **Experience measures:** provide information about whether patients were treated in a humane and dignified way, and whether care was attentive to individual patients needs and expectations.

While all of these data types have a role to play in monitoring and improving health care quality, the

³⁰ Greenhalgh J, Long AF, Flynn R, 'The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory'. *Social Science & Medicine* 60, 4 (2005), pp. 833-843; Haywood K, Marshall S, Fitzpatrick R, 'Patient participation in the consultation process: a structured review of intervention strategies', *Patient Education and Counseling*, 63, 1-2 (2006), pp.12-23.

³¹ Staniszewska S, Haywood K, Brett J, Tutton L, 'Patient and public involvement in patient-reported outcome measures: evolution not revolution', *Patient* 5, 2 (2012), pp.79-87.

³² Avdis Donabedian was the first person to distinguish between information about structures, processes and outcomes in health care.

focus in this report is on the unique role of outcome measures as a driver for quality improvement. Of the four types of measure outlined above, only outcome measures provide information on the success of treatment and care in relation to its fundamental task – improving the health and well-being of patients. In spite of this, outcome measures remain an underused tool for quality improvement.

Within the broad category of outcomes measures, four types of data can be identified:

- i. **Clinical data:** scientific measurements used by medical professionals to monitor and evaluate a patient's health status, and to inform treatment decisions
- ii. **Mortality data:** births and deaths
- iii. **Administrative data:** e.g. admissions, discharges and readmissions, prescriptions, and outpatient medical appointments
- iv. **Patient-reported data:** information provided directly by patients about symptoms, quality of life and mental well-being

A key argument of this chapter is that, in order to contribute to the patient-centredness of health care (a key component of quality), outcome measures should, as far as possible, be patient-centred. Patient-centred outcomes may be based upon clinical, mortality, administrative or patient-reported data – the key point is that they reflect outcomes that patients themselves consider to be meaningful and relevant. At the same time, outcome measures must be useful for medical professionals in routine care. If clinicians do not consider the data to be valuable for clinical practice, the risk is that it will not be collected

There are a number of organisations active in developing measurement sets for health outcomes in relation to key medical conditions, and which also ensure patients are closely involved in the 'outcome set' development process. The International Consortium for Health Outcome Measurement was founded in 2012 with the aim of creating a 'common language' on patient-centred outcomes by developing standard sets by medical condition. In the ICHOM vision, there should be a standard way of looking at outcomes for every condition, and these standards should reflect what is most important to patients. ICHOM develops its standard sets by bringing together leading clinicians, registry staff and patients for key medical conditions. They then discuss and agree upon the outcomes that are most relevant and important from a patient perspective (and ensure that medical evidence exists to support the selection of measures). Once the group has agreed on the most relevant outcomes (a process which takes approximately six months), the results are published in leading journals, and the standard sets made freely available on the ICHOM website. Each standard set is likely to include both outcomes measures and risk indicators, such as age, lifestyle factors (e.g. whether a patient smokes) and comorbidities.³³

Outcome Measures in Rheumatology is another organisation active in this field since 1998, focusing on the development of clinical and radiographic outcome measures for rheumatoid arthritis, osteoarthritis, psoriatic arthritis, fibromyalgia, and other rheumatic diseases. While the initiative is led by an international group of health professionals, it involves Patient Research Partners at every stage of the OMERACT process.³⁴

At the level of clinical research, the COMET-initiative (Core Outcome Measures in Effectiveness Trials) supports groups in the development of standardised core outcome sets (COS), representing

³³ For further information on ICHOM see: <http://www.ichom.org/>

³⁴ For further information on OMERACT see: <http://www.omeract.org/index.html>



the minimum set of outcomes that should be measured and reported (for a given medical condition) in clinical trials. The logic is that standardised measurements should enable improved comparison of clinical trial outcomes and reduce reporting bias, whilst enabling researchers to supplement the core set with additional outcome measures they consider relevant to the condition.³⁵

2. Enhancing quality within health care units: outcomes measurement for continuous improvement

Measuring outcomes is just the first step. The next question is how that data can be used to drive improvements in health care quality. The next section of this report focuses on how outcomes data can be used as part of quality improvement initiatives at the health care unit level – through ongoing routines of data collection and analysis in order to identify opportunities to improve outcomes for patients. This cycle of data collection and analysis is sometime referred to as ‘continuous improvement’ and is often supported by patient registries, which enable organisational data to be compared against national averages and best performers (on patient registries, see section 6). Examples of continuous improvement are now available from a number of countries. This chapter will focus on three case studies in particular: i. the now classic example of prostate cancer care at the Martini Klinik; ii. NHS England’s PROMs Programme; and iii. provider collaboration to improve cardiac care in Michigan (US).

Example 1: Prostate cancer care at the Martini Klinik³⁶

Outcomes measurement for prostate cancer began at the Martini Klinik in 1994, with data initially recorded using an Excel table, but now via an electronic database. A range different outcomes data is collected: clinical (e.g. positive surgical margin – used after surgery to determine whether further treatment/surgery may be required), mortality, administrative (e.g. surgery and radiotherapy), and patient-reported (e.g. urinary function, and quality of life). Every six months, risk adjusted data for each surgeon is shared with the full team. A three-hour quality review meeting is held to analyse the results, and a biostatistician is tasked with analysing the data to help frame the discussion. As a result of these meetings, surgeons with the best results may observe surgeons with below average results, and those with higher complication rates may be assisted in surgery by more experienced surgeons. The outcomes produced by Martini Klinik are impressive – performing significantly better than the national (German) average on a number of measures. For example, the proportion of patients reporting:

- Any incontinence:
 - Martini Klinik: 6.5%
 - National average: 43.3%
- Severe urinary incontinence:
 - Martini Klinik: 0.4%
 - National average: 4.5%
- Severe erectile dysfunction:

³⁵ For further information on COMET see: <http://www.comet-initiative.org/about/overview>

³⁶ Example based upon: M. Porter, J. Deerberg-Wittram, C. Marks. “Martini Klinik: Prostate Cancer Care”, Harvard Business School Case (2014); M. Porter, J. Deerberg, and R. Kaplan, ‘Outcomes Measurement’.

- Martini Klinik: 34.7%
- National average: 75.5%

Martini Klinik's five-year survival rates for prostate cancer are also above the national average.

Example 2: the NHS England PROMs Programme³⁷

Mandatory use of patient-reported outcome measures for hip and knee replacements, varicose vein, and groin hernia surgeries was introduced in NHS England in 2009. Patients are asked to complete questionnaires (the generic EQ-5D and a condition specific PROM) before surgery, and again at three and six months after treatment.

Two examples below – one relating to a low performing provider (Barnsley Hospital NHS Foundation), and the other to a high performing provider (CircleBath) – show how PROMs data have been used to support the redesign of care for hip and knee replacements based on the principles of the 'Enhanced Recovery Programme'.

Barnsley Hospital NHS Foundation

A negative outlier relative to other health care providers for hip replacements in 2011/12, patient-reported outcomes data was used to identify activities that patients found particularly difficult following discharge. Specific exercises, designed to reduce these difficulties, were then included in post-operation appointments. PRO data was also used to help make the case for an additional physiotherapist. PRO data was used to measure the effectiveness of the changes made to the care pathway since 2010. The data shows a year-on-year improvement in the Foundation's hip replacement PROMs scores, and it is now no longer a negative outlier relative to other providers.

CircleBath

In late 2011, CircleBath (a private health care provider) introduced a series of changes to its care pathway, a number of which were influenced by PROMs data. For example: the introduction of a clinical pathway booklet with information on daily goals of inpatient care; the use of variance forms to record pathway deviations (reviewed weekly to identify unwanted trends and take corrective action); and the creation of a clinical network to standardise the surgical process and reduce variation. PROMs data is shared with an operational team in order to monitor and assess the impact of these changes. CircleBath's PROMs scores for hip and knee replacement have both improved. In the case of hip replacements, it is now a positive outlier within England.

Example 3: provider collaboration to measure and improve outcomes in cardiovascular care: Blue Cross Blue Shield in Michigan³⁸

The Blue Cross Blue Shield (BCBS) quality improvement initiative in cardiovascular care began as a pilot initiative, funded by the Blue Cross Blue Shield (a health insurer) Foundation. The quality improvement model is based upon collaboration between different health care providers within Michigan. In this instance, the specific focus was on angioplasty (or percutaneous coronary intervention). Quality data from the six hospitals participating in the original pilot was collected in a central registry, and then

³⁷ M. Bassar, 'Patient-Reported Outcome Measures (PROMs)' outputs: Benefits case study (2015). Available at: http://www.hscic.gov.uk/media/16547/full-PROMs-benefits-case-study/pdf/Benefits_Case_Study_-_PROMs.pdf

³⁸ International Consortium for Health Outcomes Measurement, 'Aligning payers and providers around value: Blue Cross Blue Shield of Michigan's Collaborative Quality Initiatives' (2015).



analysed to provide feedback to the clinical teams within participating hospitals.

The pilot produced important findings related to patient risk factors and the impact of specific processes of care on patient outcomes. The data showed, for example, which patients were at greatest risk of kidney damage due to the use of contrast dye from angioplasty (used to help physicians identify coronary artery blockages on x-ray). This led in turn to the development of guidelines designed to reduce the use of contrast dyes and identify further measures to reduce the risk of kidney damage. As a result of the pilot, participating hospitals experienced a 56% reduction in complications due to contrast dye. The pilot also demonstrated significant improvements in a range of other outcomes.

There are now 33 health care units participating in the quality improvement programme for angioplasty (as well as 17 BCBS quality improvement initiatives for other conditions / interventions). Improvements recorded during the angioplasty quality improvement programme include:

- a 59.3% reduction in emergent coronary artery bypass grafts (CABG), and a 46.2% reduction in all CABG procedures
- a 57.9% reduction in transfusions
- a 27.7% reduction in vascular complications

In addition to improvements in outcomes, the various BCBS quality improvement initiatives have led to significant savings as a result of cost offsets (i.e. costs that are avoided due to more effective or appropriate care at an earlier stage). For example, costs avoided in relation to vascular complications, and unnecessary biopsies.

3. Improving quality at the system level: outcomes measurement and health system performance assessment

Health system performance assessment (HSPA) is a term used to describe a variety of approaches to monitoring and evaluating how well health systems or individual health care units (such as hospitals) perform in relation to core health system goals. These goals may include: quality, access, equity, and efficiency.

This section of the chapter will begin by briefly describing three country specific approaches to health system performance assessment – the Netherlands, Sweden and NHS England – before looking at the comparative international quality indicators developed by the OECD. It will then focus on the central question of how HSPA can be used to improve quality of care for patients.

While the focus here is upon national and international frameworks for performance assessment, it should be emphasised that HSPA also occurs at the sub-national level. For example, the Catalan Health System Observatory publishes annual comparisons of hospital performance (including quality indicators) within Catalonia,³⁹ with quality indicators relating to patient-centredness, appropriateness, effectiveness, and safety.

³⁹ Catalan Health System Observatory, 'Report of the Results Centre: Hospital Care: 2014 data', available at: http://observatorisalut.gencat.cat/en/central_de_resultats/informes_cdr/dades_actuats/

3i. National frameworks for health system performance assessment

Netherlands: the Dutch Health Care Performance Report⁴⁰

The Dutch Health Care Performance Report, initiated in 2002 with the first report published in 2006, comprises approximately 150 indicators.⁴¹ It has a strong focus on the following goals:

- **Quality of care:** the Netherlands developed the definition of quality currently used by the OECD: effectiveness, safety and patient-centredness/responsiveness
- **Access:** geographic, financial, and time-related
- **Affordability:** assessed primarily in terms of the growth of health care expenditure

Many of the quality measures are presented either as part of a time series (to show trends over time) or compared against other countries using standardised OECD health care quality data. In other cases, use is made of patient or carer reported information with inherent performance indicators (such as the proportion of patients that were satisfied with the care that they received). In a more limited number of cases, geographic comparisons are also used (e.g. ambulance response times).

Sweden: Regional Comparisons of Quality and Efficiency in Swedish Health care⁴²

By contrast, the approach taken in Sweden's 'Regional Comparisons of Quality and Efficiency in Swedish Health Care' focuses primarily on geographic comparisons. The comparisons relate to health care quality data for the twenty-one councils and regions, which are responsible for health care provision in Sweden's decentralised health system. The creation of Regional Comparisons in the mid-2000s was enabled by the existence of a very strong health information infrastructure based on patient registries.

The 2012 Regional Comparisons report featured 169 indicators, focusing primarily on quality of care (outcomes, processes, patient experience, and waiting time measures) and cost. In addition to geographic comparisons, national trends over time were also presented (however, international comparisons are not included). The report is divided according to overall health system indicators (e.g. avoidable mortality and health care associated infections) and indicators relating to specific medical areas – e.g. musculoskeletal diseases, cardiac care, cancer care, and psychiatric care.

England: the NHS Outcomes Framework⁴³

The NHS Outcomes Framework in England has its origins in the 2008 NHS Next Stage Review, which included a proposal to systematically measure and publish information about quality of care.⁴⁴ It was developed in late 2010 following a public consultation. It is designed to give an 'overarching picture of the current state of health and care services in England'.⁴⁵ The approach to indicator selection is described as 'parsimonious' – meaning that the number of indicators is relatively small (68) in order that the framework provides a clear focus for accountability and improvement.

⁴⁰ See: National Institute for Public Health and the Environment, *Dutch Health Care Performance Report 2014*

⁴¹ M. van den Berg et al., 'The Dutch health care performance report: seven years of health care performance assessment in the Netherlands', *Health Research Policy and Systems* 12, 1, (2014)

⁴² See: Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare, *Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012*

⁴³ See: Department of Health, 'The NHS Outcomes Framework 2015/16' (December 2014)

⁴⁴ Department of Health, 'High Quality Care for All: NHS Next Stage Review Final Report' (2008).

⁴⁵ Ibid.



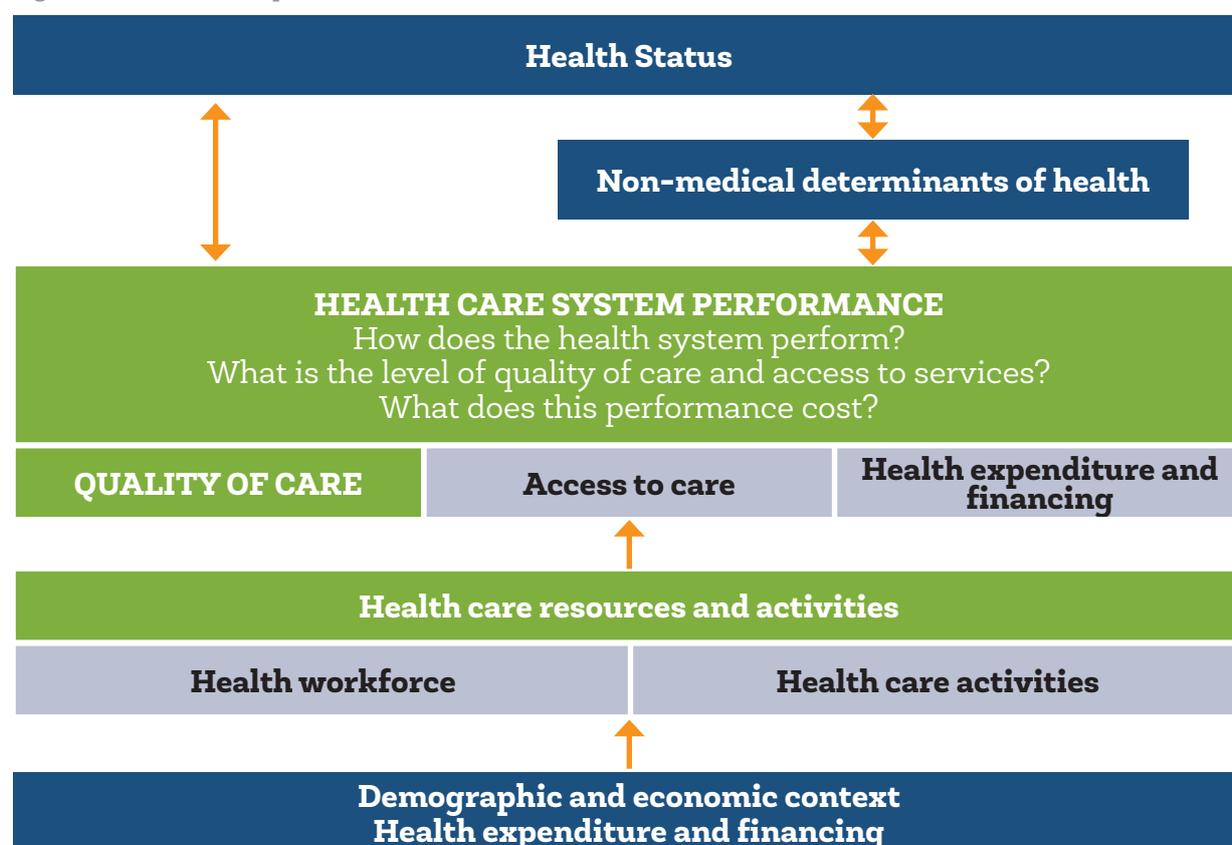
The indicators are grouped into five outcome 'domains':

1. Preventing people from dying prematurely
2. Enhancing quality of life for people with long-term conditions
3. Helping people to recover from episodes of ill health or following injury
4. Ensuring that people have a positive experience of care
5. Treating and caring for people in a safe environment and protecting them from avoidable harm

The NHS Outcomes Framework is also used to strengthen accountability within the health system, and is used by the Department of Health to hold NHS England to account for performance in relation to the five outcome domains. NHS England in turn monitors and compares the performance of regional Clinical Commissioning Groups (CCGs). CCGs use the indicators to identify local priorities and to demonstrate progress over time.

Figure 1 below shows the conceptual model for health system performance assessment developed by the OECD – highlighting the role of quality of care within that conceptual framework. Figure 2 then highlights a selection of the outcome indicators used in the three HSPA frameworks discussed above, to show how the OECD model can be further elaborated (according to national priorities and preferences). In each case the categories (or 'domains') under which the indicators are grouped reflects the categorisations used in the three national HSPA frameworks.

Figure 1: OECD conceptual framework for HSPA⁴⁶



⁴⁶ OECD Health at a Glance 2015, p.14 (adapted from Edward Kelley and Jeremy Hurst, 'Health Care Quality Indicators Project: Conceptual Framework Paper', OECD Health Working Papers, 2006)

Figure 2

EXAMPLES OF OUTCOMES INDICATORS USED IN NATIONAL HSPA

(indicator categories / 'domains' are based on those used in each framework)

Dutch Health Care Performance Report 2014

- *Antenatal, perinatal and postpartum care:*
 - Foetal and neonatal mortality
 - Rate of perineal tears
- *Acute care:*
 - Percentage of patients dying within 30 days of hospital admission for:
 - i. acute myocardial infarction
 - ii. ischaemic and haemorrhagic stroke
- *Non-acute curative health care:*
 - Relative five year survival rates for cancer
 - Mental health care (short-term) with positive treatment effects
 - Percentages of patents experiencing medical diagnostic errors
- *Living with long-term illness or functional limitation:*
 - Changes in perceived self-reliance and social participation
 - Percentages of informal carers reporting problems with their own social participation

Regional Comparisons of Quality and Efficiency in Swedish Health Care 2012

- *Overall indicators:*
 - Avoidable mortality
 - Health care associated infections
- *Musculoskeletal diseases:*
 - Reoperation within two years after total hip arthroplasty
 - Patient-reported improvement after spinal stenosis surgery
 - Effect after commencement of biologic drug therapy
- *Cardiac care:*
 - Survival after cardiac arrest outside hospital
 - Complications after pacemaker implantation
- *Cancer care:*
 - Relative five year survival rates



- Curative treatment of patients (aged 75 and younger) with prostate cancer
- *Psychiatric care:*
 - Readmission within 14 and 28 days after treatment for schizophrenia

NHS (England) Outcomes Framework

- *Reducing premature mortality:*
 - from the major causes of death
 - in people with mental illness
 - in children
 - in people with a learning disability
- *Enhancing quality of life for people with long-term conditions:*
 - Employment of people with long-term conditions
 - Employment of people with mental illness
 - Health-related quality of life (HRQoL) for carers
 - HRQoL for people with three or more long-term conditions (under development)
- *Helping people to recover from episodes of ill health or following injury:*
 - Health gain as assessed by patients for elective procedures
 - Recovery of mobility / walking after hip fracture
 - Improvement in activity / lifestyle following stroke
- *Treating and caring for people in a safe environment and protecting them from avoidable harm:*
 - deaths and severe harm attributable to problems in health care

3ii. International performance comparisons

In addition to national performance assessment frameworks, international comparisons of health care outcomes can make an important contribution to quality improvement by highlighting performance variations between countries. Care delivery within countries is always influenced by national tradition. International comparisons can provide opportunities for cross-country learning and exchange of best practice.

International comparisons are, however, a technically complex task. The necessary data must first be available in a sufficient number of countries to make comparison a valuable exercise. Even where the data does exist, there may be differences in the way it is collected and recorded, which can impact upon comparability and the interpretation of the results. Where data is used for international comparison, it is crucial that guidelines are provided to ensure the data collection process is standardised, thus enabling reliable and valid interpretation of the comparisons.

Just as within countries, there are likely to be differences in risk factors related to population

demographics. Case mix adjustment is therefore also very important to ensure the validity of the comparisons.

The OECD Health Care Quality Indicators (HCQIs) project is the principal forum for the development of internationally comparable outcomes data. The project began in 2003 among a group of 16 countries, initially focusing on a limited number of priority areas where comparable data was likely to be available (e.g. cancer survival and vaccination rates).

Over time, additional indicators have been developed and research into comparability issues has improved the quality of the data. The comparisons are now regularly published in *Health at a Glance* and *Health at a Glance Europe*.

Figure 3

HEALTH CARE OUTCOME INDICATORS INCLUDED IN HEALTH AT A GLANCE 2015

- *Cardiovascular disease and stroke:*
 - 30 day mortality after admission to hospital for acute myocardial infarction
 - 30 day mortality after admission to hospital for ischaemic stroke
- *Cancer (breast, cervical and colorectal):*
 - Mortality
 - Five year relative survival
- *Mental health:*
 - Excess mortality from: i. schizophrenia; ii. bipolar disorder
 - Inpatient suicide among patients with a psychiatric disorder
 - Suicide following hospitalisation for a psychiatric disorder (within 30 days and one year of discharge)
- *Diabetes:*
 - Major lower extremity amputation in adults
- *Avoidable hospital admissions for:*
 - Asthma
 - Chronic obstructive pulmonary disease
 - Congestive heart failure
- *Safety:*
 - Surgical complications
 - Obstetric trauma during child birth



The OECD HCQIs have enabled the identification of important performance variations between countries, as well as opportunities to improve quality of care. Health at a Glance 2015 found that 'no country consistently performs in the top group on all indicators' (for example, Portugal, Spain and Switzerland were found to have relatively low rates of hospital admission for certain chronic conditions, but relatively high rates of mortality for patients admitted to hospital for heart attack or stroke), and specific issues / opportunities for improvement were highlighted.

For example, attention was drawn to Ireland, Poland, and the United Kingdom in relation to cancer survival (breast, cervical and colorectal), as each ranks among the bottom third of countries. With regard to cervical and colorectal cancer survival in Poland, it was noted that access to care is limited due to fewer cancer care centres and radiotherapy facilities.

The future agenda for the Health Care Quality Indicators project includes a greater focus on patient-reported outcome and experience measures (both of which are very important for enhancing patient-centredness within health care), the strengthening of health information infrastructures to facilitate data collection at the patient level, as well as linkage between different data sources to enable more robust risk adjustment (for example, to take account of co-morbidities).

3iii. Using HSPA to improve health care quality: case studies

The use of outcome measures as part of performance monitoring, comparison, and assessment can be a key tool for improving quality of care. As noted in the introduction, there are wide variations in clinical practice and patient outcomes both within countries and between them. Comparing outcomes enables identification of high quality care, creating opportunities to learn from high performing providers.

Understanding the drivers of different performance levels can also be used to inform policy and clinical guidelines. Where undesirable outcomes are identified – particularly at a national or regional level – this can trigger a thorough investigation into the causes, and in turn lead to policy responses. Transparency of outcomes data can also incentivise performance improvements among health care providers.

To illustrate these mechanisms of quality improvement in practice, three examples of HSPA being used for performance improvement purposes are outlined below.

I. Thematic HSPA leading to recommendations for better stroke care in Sweden

In 2011, the Swedish National Board for Health and Welfare published a performance assessment focusing specifically on stroke care.⁴⁷ Utilising a series of indicators (both outcome and process measures), as well as qualitative information, the thematic HSPA made a number of recommendations for improving quality of care. The use of process measures enabled identification of variations in the way that stroke care was delivered, as well as non-compliance with clinical guidelines.

Outcome measures then included:

- Mortality
- The proportion of patients who could handle their activities of daily living independently three months after stroke

⁴⁷ National Board of Health and Welfare, 'Quality and Efficiency of Stroke Care in Sweden: National Performance Assessment 2011' (published in 2013)

- The proportion of patients reporting being often or always depressed three months after stroke care.

On the basis of the indicators, it was found that collaboration between different tiers of government within Sweden (county councils and municipalities) led to better outcomes for people who had received stroke care.

Patient-reported outcomes appeared better for people who received day or team rehabilitation, as compared with those who received home-based rehabilitative care. There was also significant variation between municipalities, both in terms of the way that care was delivered, and in terms of outcomes.

Recommendations made in the HSPA included actions to: increase the proportion of patients receiving care in designated stroke units; improve secondary preventative pharmaceutical treatment, and improve psycho-social support.

Similar thematic performance assessments have also been produced for: cardiac care, diabetes care, and psychiatric care.

II. International comparisons leading to improved perinatal outcomes in the Netherlands

In 2003 and again in 2008 the international Euro-Peristat report showed that the Netherlands had a relatively high perinatal mortality rate (defined by the WHO as the number of stillbirths and deaths in the first week of life per 1,000 live births). This prompted quality improvement initiatives among a number of health care stakeholders in the Netherlands – including the development of recommendations by the Steering Committee on Pregnancy and Birth.

The impact of these initiatives included a significant increase in the number of participants in perinatal audits, a decreasing number of women smoking during pregnancy, and increasing numbers of pregnant women (particularly in deprived neighbourhoods) providing timely notification of their pregnancy to general practitioners or midwives.⁴⁸

Data for 2010 (published in Euro-Peristat 2013) showed that there had been a marked decrease in perinatal mortality in the Netherlands. For example, with respect to foetal mortality at or after 28 weeks, the Netherlands improved from approximately 4.3 deaths per 1000 births in 2004, to 2.9 deaths per 1000 births in 2010.⁴⁹ Other countries also saw improvements, indicating that a similar mechanism of quality improvement might also be happening in other participating countries. The Netherlands reported one of the strongest performance improvements.

III. Transparency of data leading to better quality cardiac care in Sweden

Transparency of outcomes data creates incentives for health care organisations to improve their performance relative to other providers, and in so doing improve quality of care and outcomes for patients. A particularly powerful example of how transparency can incentivise such improvements is provided by cardiac care in Sweden.

In 2005, the Swedish heart attack registry created a quality index showing hospitals' compliance with cardiac care guidelines. Between 2005 and 2007 (during which period the data was not public) hospitals improved their quality index scores by an annual average of 13%. Among hospitals with below average scores, the improvement rate was only 7% (pointing to an increasing quality gap between high

⁴⁸ National Institute for Public Health and the Environment, *Dutch Health Care Performance Report 2014*, p.10.

⁴⁹ Euro-Peristat, *European Perinatal Health Report: Health and Care of Pregnant Women and Babies in Europe in 2010* (published 2013); and *European Perinatal Health Report 2004* (published in 2008).



and low performing hospitals).

Following the introduction of Regional Comparisons in 2006 – when quality index scores and patient survival rates became public – this changed. In the period 2007 to 2009, the overall improvement rate increased to 22%. Moreover, the performance gap between high and low performing hospitals was significantly reduced, with below average hospitals improving their performance by as much as 40%. These improvements are also considered to have contributed to the decline in short and long-term mortality following heart attack.⁵⁰

Provider comparisons have also been used in the United States for performance-based contracting by health insurers. This involves health insurers making risk-adjusted annual payments per patient (for patients considered to be higher risk higher payments are awarded). Insurers also award bonuses for high-quality care. There is evidence indicating that this model may both slow the growth of health care expenditure and contribute to improvements in quality of care.⁵¹

4. Making health care more patient-centred: outcomes measurement and patient empowerment

As has been seen, patient-centredness is one of the three aspects of quality included in the OECD definition of quality of care. There are, however, different interpretations and definitions of the term. One of the most often cited definitions is that contained in the Institute of Medicine's (IoM) now famous study on 'Crossing the Quality Chasm: A New Health System for the 21st Century', which included patient-centred care among its six aims for 'The 21st Century Health Care System'.

The IoM defined patient-centredness as: *'providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.'*⁵² In other cases, the term is applied more specifically in relation to: communication and information provision (for example regarding different treatment and care options); coordinated and integrated care; and treating patients in a dignified way (particularly in the context of long-term care).⁵³

Patient empowerment can be understood as a specific component of patient-centred care. Again, there is no standard definition for the term, but the main themes highlighted in the literature on patient empowerment are: involvement of patients in health care decision-making, and viewing patients as a key partner in the co-production of health care (alongside medical professionals and policy makers). In its recent campaign on Patient Empowerment, the European Patients' Forum identified five E's as key components of patient empowerment (see Figure 4).⁵⁴

⁵⁰ G. Hagglund, 'Fine-Tuning Health Care – improved outcomes and cost efficiency using quality registries', Swedish Ministry of Health and Social Affairs Conference (May 2013).

⁵¹ P. van der Wees et al. 'Governing healthcare through performance measurement in Massachusetts and the Netherlands', *Health Policy* (2013); also see 'The Alternative Quality Contract', Based on a Global Budget, Lowered Medical Spending and Improved Quality' *Health Affairs* 31, 8 (2012).

⁵² Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001)

⁵³ On definitions see: International Alliance of Patient's Organisations, 'What is patient-centred health care' (2007).

⁵⁴ European Patients' Forum, Patient Empowerment Campaign: <http://www.eu-patient.eu/campaign/PatientsprescribE/>

Figure 4

THE FIVE E'S OF PATIENT EMPOWERMENT

European Patients' Forum Campaign on Patient Empowerment

■ Education

Patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.

■ Expertise

Patients self-manage their condition every day so they have a unique expertise on health care which needs to be supported.

■ Equality

Patients need support to become equal partners with health professionals in the management of their condition.

■ Experience

Individual patients work with patient organisations to represent them, and channel their experience and collective voice.

■ Engagement

Patients need to be involved in designing more effective health care for all, and in research to deliver new and better treatments and services.

Outcome measures can contribute to more patient-centred health care, including patient empowerment, in two main ways: first, the use of patient-reported outcome measures (PROMs) in routine clinical practice; and second, the involvement of patients in the selection of measures for use in quality improvement initiatives.⁵⁵

I. PROMs as a tool for more patient-centred care and patient empowerment

PROMs are standardised questionnaires, completed by patients to ascertain their view about their health and health-related quality of life. When completed before and at regular intervals after treatment, they can be used to assess the outcome of that intervention from the patient's perspective. A patient-reported outcome (PRO) is shown by the change in a patient's responses to a PROM questionnaire following a health care intervention.

Routine use of PROMs as part of clinical care can: improve patient-clinician communication, and increase patient satisfaction (experience); facilitate shared decision-making and goal-setting (education); and enable patients to better monitor their own conditions (equality).⁵⁶

⁵⁵ Greenhalgh J, Long AF, Flynn R, 'The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory'. *Social Science & Medicine* 60, 4 (2005), pp. 833-843; Haywood K, Marshall S, Fitzpatrick R, 'Patient participation in the consultation process: a structured review of intervention strategies'. *Patient Education and Counseling*, 63, 1-2 (2006), pp.12-23; Staniszewska S, Haywood K, Brett J, Tutton L, 'Patient and public involvement in patient-reported outcome measures: evolution not revolution'. *Patient* 5, 2 (2012), pp.79-87.

⁵⁶ Chen et al., 'A systematic review of the impact of routine collection of patient reported outcome measures on patients,



Figure 5

PATIENT-REPORTED OUTCOME MEASURES (PROMs)

PROMs can be both generic and medical condition-specific. For many medical conditions both a generic and condition-specific PROMs may be used.

Generic PROMs focus on general aspects of a patient's health, and are used across a variety of conditions. Examples of generic PROMs include the EQ-5D and SF-36 - both include questions on:

- physical functioning / mobility (e.g. walking or cycling);
- symptoms (such as pain and fatigue);
- psychological well-being (e.g. anxiety / depression);
- the ability to perform normal day-to-day activities (e.g. shopping / cleaning);
- social well-being (e.g. at work, family, sports).

Condition-specific PROMs (as the term implies) address aspects of health that are particularly relevant to a given medical condition.

Examples of condition-specific PROMs (which are vast in number) include:

- the Asthma Quality of Life Questionnaire
- the Oxford Hip Score (for hip replacements)
- the Burn Specific Health Scale
- the Health of the Nation Outcome Scales (used in psychiatric care)
- and the PTSD checklist (for post-traumatic stress disorder).

Alongside patient-reported outcome measures, care giver reported outcome measures can be used to understand the impact of informal care provision on those providing care to friends or relatives, as well as to assess the effectiveness of interventions designed to reduce the impact.

Care giver reported outcomes can be particularly relevant in relation to long-term conditions. In dementia, for example, there is a clear association between the burden experienced by informal carers and whether the dementia sufferer will be moved to institutionalised care – entailing costs for the formal care system.

Outcome measures for caregivers fall into the following broad categories:

- burden – e.g. the carers physical health, psychological well-being, finances, and relationship with the person receiving care
- mood – whether the carer experiences anxiety or depression

providers and health organisations in an oncologic setting' *BMC Health Services Research* (2013), 13:211; N. Black, 'Patient-reported outcome measures could help transform healthcare', *British Medical Journal* (January 2013); Karolinska Institute, The Dartmouth Institute for Health Policy and Clinical Practice, and Group Health Research Institute, 'Using Patient-Reported Information to Improve Health Outcomes and Health Care Value', p.15. Also see Jensen, RE and Snyder, CF, 'PRO-cision medicine: Personalising Patient Care Using Patient-Reported Outcomes', *Journal of Clinical Oncology*, 20, 34 (6) (2015), pp. 527-9.

- mastery – the satisfaction of the carer with their performance
- the impact of care provision on the personal life of the carer
- generic quality of life measures.⁵⁷

The European Psychiatric Association's recent guidance on quality assurance in mental healthcare recommended that outcome measures should be used not only in relation to mortality, but also 'symptom severity, social functioning and patient or caregiver satisfaction'.⁵⁸

II. Involving patients in the selection of patient-centric outcome measures to be used in quality improvement initiatives

Engaging patients in the selection of outcome measures to be used in quality improvement initiatives can also help to ensure that such initiatives are themselves patient-centred, and contribute to improving outcomes that are meaningful from the patient perspective. Examples of this type of collaborative approach can be seen in the strong emphasis on patient involvement in the development of outcome sets that is central to the work of ICHOM and OMERACT – as well as COMET in relation to trials.

A report by the Independent Cancer Taskforce in the UK recently recommended that NHS England and Public Health England should 'work with charities, patients and carers to develop a national metric on quality of life by 2017 which would enable better evaluation of quality of life after treatment', and called for PROMs to be 'rolled out across breast, colorectal and prostate cancer by 2020'.⁵⁹ Similarly, consultation with patient groups regarding the outcome indicators to be included in HSPA frameworks can ensure performance assessment frameworks, and quality improvement efforts based upon them, reflect the concerns of patients.

It should be noted that many of the PROMs used in clinical settings today are 'legacy' measures – developed for clinical trials without the involvement of patients. Guidance from the US Food and Drug Administration in 2009 highlighted the need to actively engage with patients as participants throughout the development and evaluation process to improve content validity, and hence relevance, of new outcome measures.⁶⁰ It also highlighted the need for a clear audit trail illustrating how qualitative patient data had been used to inform PROM development and final content. Thus, while legacy PROMs should continue to be used in clinical settings for improving health care quality, there is also value in supporting research to investigate the relevance of these measures from the patient perspective. The co-production of new patient-reported outcome measures, with the active involvement of patients as partners in the process, should also be supported.⁶¹

⁵⁷ C. Jones, 'Health economics research into supporting carers of people with dementia: A systematic review of outcome measures', *Health and Quality of Life Outcomes* (2012), 10:142.

⁵⁸ W. Gaebel, 'European Psychiatric Association (EPA guidance) on quality assurance in mental healthcare', *European Psychiatry* 30 (2015).

⁵⁹ Independent Cancer Taskforce, 'Achieving World-Class Cancer Outcomes: A Strategy for England, 2015-20'.

⁶⁰ See US FDA Guidance on PROMs (2009); and Patrick, DL et al 'Content validity--establishing and reporting the evidence in newly developed patient-reported outcomes (PRO) instruments for medical product evaluation: ISPOR PRO good research practices task force report: part 1--eliciting concepts for a new PRO instrument', *Value in Health*, 14, 8 (2011), pp.967-77.

⁶¹ Staniszewska S, Haywood K, Brett J, Tutton L, 'Patient and public involvement in patient-reported outcome measures: evolution not revolution', *Patient* 5, 2 (2012), pp.79-87; de Wit, M. et al. 'Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences', *BMJ Open* 3, 5 (2013).



5. Challenges and opportunities for health care outcomes measurement

Efficient health information systems

In order to exploit the potential of health care outcomes measurement to drive quality improvement in health systems, it is vital that countries put in place efficient health information systems / infrastructures. As has been seen, patient registries have been central to a number of the quality improvement initiatives documented in this chapter. Registries collect information about patients with a specific condition and about speciality health care services such as surgery (see Figure 6).

In some countries, data privacy rules can pose challenges to the use of patient registries (and other databases) for HSPA – in particular when it comes to linking data from different databases in order to follow patient pathways over time and through different parts of the health and social care system. The implementation of sound data governance frameworks is therefore vital to ensure that data can be used for health care improvement purposes whilst also protecting patient privacy. Unique patient identifiers can be a key tool in this respect.

Figure 6

PATIENT REGISTRIES

Patient registries (also referred to as quality registries or disease registries) are a key tool for the collection of data on patient-centric outcomes and to support the use of that data for quality improvement purposes. Registries collect a variety of data about patients who have received the same diagnosis or who have undergone the same medical procedure. They collect data about the patient and their risk factors, the care that they receive, as well as the outcomes of care.

Registries enable clinicians and patient groups to use the data for quality improvement activities:

- Medical professionals can use the data to identify and share best practice, and to compare their outcomes against those of other providers.
- Patient groups can use the information to strengthen dialogue with both medical professionals and policy makers with a view to improving quality of care.

Sweden: use of registries in Sweden dates back to the 1970s. Since 1990 registries have been funded by Swedish government, and in 2011 the funding was increased with a view to further improving the quality of the data and the proportion of patients participating.

Netherlands: in recent years, there has been a proliferation of new patient registries in the Netherlands. The Dutch Institute for Clinical Auditing (DICA) – the result of an initiative by the Association of Health Insurance Companies – currently maintains 18 registries. It supports registries in relation to methodological and privacy challenges, data analysis and presentation (such as setting up data ‘dashboards’), communication with stakeholders.

Another very valuable tool for data collection and analysis is electronic health records (EHRs), which enable all relevant information about an individual patient (including age, lifestyle factors, co-morbidities, previous treatments, etc.) to be collected and stored in one place. To get the most out of EHRs, it is necessary for data to be collected in a structured and standardised way, and that

medical professionals see value in the data they are being asked to collect. Top-down data collection requirements that are not deemed to be valuable at the clinical level risk undermining the value of EHRs as a tool for health care improvement.

EHRs, and in future personal health records (PHRs), can also enable the development of new outcome indicators that are derived directly from routinely collected clinical data. This requires data to be entered in a coded and structured way, but can ultimately reduce workload for medical professionals by avoiding duplication of data recording requirements, and ensure integrated data collection systems – meaning that outcomes data can be used both at the clinical level and for performance monitoring.⁶² Indicators that are directly derived from patient data can also contribute to the transparency of health outcomes across European health systems.

Standardisation

As has been seen, comparison of outcomes data can be a powerful tool for driving quality improvement and identification of best practice both at a health care unit level, and at a health system level through performance monitoring and transparency. Some standardisation of outcomes measurement is essential if the full benefits of those measures are to be captured and outcomes are to be compared across health care settings. It is at the same time important that medical professionals should have the flexibility to use the measures that they consider most useful for their routine practice and most relevant in their local context.

Progress towards alignment on ‘core’ sets of outcome measures – which most or all providers would use – offers a way of meeting both these objectives. Core outcome sets provide the possibility for clinicians to collect agreed outcomes measurements in a standardised way in order to facilitate comparison, whilst being able to supplement these with additional measurements that they consider particularly important in their clinical practice.

Training and analytical support

Getting the most out of outcome measures requires that medical professionals are properly trained and supported to use them for quality improvement purposes. While medical professionals will be comfortable about using outcome measures for clinical purposes, they may be less confident about using and interpreting aggregate data to compare their performance against national averages, or for continuous improvement within their health care organisation.⁶³

Training is also very important to support and encourage the use of patient-reported outcome measures at the clinical level. Research has shown that medical professionals can be anxious about, and even resistant to, administering PROMs in clinical practice – either because they are uncertain about what the measure is designed to assess, or due to a lack of confidence about how to use it. Training can lead to more positive attitudes among medical professionals, and thereby encourage the use of PROMs within routine clinical care.

⁶² On the value of integrated data collection systems see: P. van der Wees, ‘Integrating the use of Patient-Reported Outcomes for both Clinical Practice and Performance Measurement’, *The Milbank Quarterly*, 92, 4 (2014)

⁶³ Santana MJ et al, ‘Training clinicians in how to use patient-reported outcome measures in clinical practice’ *Quality of Life Research* 24,7 (2015), pp.1707-18



Conclusions and Recommendations

Improving quality of care is a high priority across countries, and a key component of enhancing value in European health systems. Outcome measures provide a multi-purpose tool for improving quality of care – either through continuous improvement initiatives (such as those at the Martini Klinik, within NHS England’s PROMs programme, and the collaboration between health care providers to improve cardiac care in Michigan), or through performance monitoring and transparency.

HSPA offers significant opportunities to improve health care quality by enabling the identification of best practice, informing policies and recommendations aimed at improving quality, and by incentivising performance improvements across providers. Examples highlighted in this report include the stroke care recommendations developed on the basis of Sweden’s thematic HSPA on stroke, and the improvements in perinatal outcomes in the Netherlands that were prompted by international comparisons of perinatal mortality.

Outcome measures can also contribute to making health care more patient-centred – in particular through patient empowerment. This can include: i. using patient-reported outcome measures in clinical practice (empowering patients to better monitor their own conditions, and participate in shared decision-making); and ii. the involvement of patients in the selection of outcome measures for use in continuous improvement initiatives and HSPA.

In order to capture the full potential of outcome measures to drive improvements in health care quality, a number of key challenges require the attention of policy makers: i. the creation of efficient health information systems and infrastructures (for example patient registries and electronic health records) to facilitate data collection and analysis; ii. the implementation of data governance frameworks that permit the use of health care data for quality improvement whilst protecting patient privacy; and continuing to develop standardised health care outcome measures that will enable international comparisons of health care quality. Attention should also be given to the training of medical professionals in the use of outcome measures for quality improvement purposes.

Recommendations

Health system performance assessment

NATIONAL LEVEL

■ **Develop and use health system performance assessment**

HSPA can be a powerful tool for designing policies to improve quality of care and public health. Member States should design, develop and use HSPA as a key tool for health system and national economic governance. HSPA data and conclusions should be made transparent in order to strengthen the accountability of the health system, and to incentivise improvements in health system performance.

■ **Ensure outcomes data is a central component of HSPA**

Outcome measures are unique in providing information about the performance of the health system in relation to its fundamental goal: improving patient and population health. Member States should include in HSPA both composite outcome indicators – relating to the performance of the health system as a whole – and outcome indicators for key medical conditions.

- **Patient involvement and patient-centredness**

Patients should be involved in the selection of outcome indicators for use in national HSPA frameworks to ensure that these frameworks are themselves patient-centred (i.e. meaningful and relevant to patients), and that policies arising out of HSPA address issues that are important from the patient perspective.

Countries should make greater use of patient-reported outcome measures in routine clinical care, in order to: enhance patient experience; improve patient-clinician communication and provide a basis for shared-decision-making (to the extent that this is what the patient wants); and enable patients to better monitor their own conditions.

EUROPEAN LEVEL

- **Prioritise outcomes measurement as a tool for improving quality of care**

Quality of care is a principal theme in the work of the EU Expert Group on Health System Performance Assessment. In that context, outcome measures should be prioritised as being essential to assessments of health care quality.

- **Identify ‘core’ outcome measures for use in HSPA**

EU work on HSPA should aim to identify indicators that can be used in a standardised way across national HSPA frameworks. Whilst Member States need flexibility to tailor HSPA to national contexts and preferences, the inclusion of common, standardised indicators will facilitate international comparisons and enhance the value of HSPA for all countries. The Dutch Health Care Performance Report provides an excellent template for integrating internationally standardised indicators in a national performance assessment framework.

INTERNATIONAL LEVEL

- **Continue to develop internationally standardised outcome indicators at OECD level**

The OECD Health Care Quality Indicators project is playing a key role in the development of internationally standardised measurements of health care quality. This work should continue, focusing in particular on the development of new, internationally comparable outcome indicators across different medical conditions.

The development of standardised indicators should be extended to include patient-reported outcome and experience measures (PROMs / PREMs) in particular.

The development of internationally standardised indicators can also support the development of quality standards in relation to the EU Directive on patients’ rights in cross-border healthcare.

European Semester

- **Refocus country-specific recommendations**

Country-specific recommendations (CSRs) should be refocused on the need for Member States to develop and use well-designed national HSPA frameworks, as well as efficient health information systems.

By re-focusing CSRs on the tools required to design and implement high quality health care reforms, the European Semester can make a vital contribution to Member States’ capacity to enhance the value and sustainability of their health spending.



Sharing best practice

EUROPEAN LEVEL

■ Outcomes measurement for quality improvement

Outcome measures offer significant opportunities to drive improvements in quality of care. However, the potential to use outcome measures for this purpose is neither widely understood nor recognised. The EU can raise awareness by collecting and disseminating case studies showing real world use of outcomes measures for quality improvement in different national settings. Case studies should include examples of both: continuous improvements at the health care provider level; and HSPA incentivising and enabling quality improvements across the health system.

Health information policy

EUROPEAN AND NATIONAL LEVEL

■ Develop efficient health information infrastructures

Efficient health information systems are essential to the collection and use of outcomes data at a policy level. The development of health information infrastructures should therefore be a key objective of national governments in the development of HSPA frameworks.

EU health information policy should also aim to support Member States with the development of efficient systems for the collection and use of national health outcome data.

Data collection systems should be integrated, so that data collected for use at the clinical level can also be used at the aggregate level for performance assessment and transparency.

Research and innovation for health outcomes measurement

EUROPEAN LEVEL

■ Support pilot projects that compare outcomes across countries and regions

EU Research and Innovation funds should be used to support projects that measure, compare and analyse differences in health care outcome across countries (or between regions / hospitals within different countries). A previous example of this type of initiative was European Health Care Outcomes Performance and Efficiency (EuroHOPE) project, which took place between 2010 and 2014 and was funded by the European Commission's Framework Programme 7. EuroHOPE compared health care performance in relation to acute myocardial infarction, stroke, hip fracture, breast cancer, and low birth weight infants.

The EuroHOPE project provides an excellent template for future projects, which could look to expand coverage geographically and with regard to medical conditions, as well as broadening the types of outcome measures used. For example, the EuroHOPE project did not make use of any patient-reported outcomes – an area where there is a distinct need for research into the comparability of international data and the potential impact of cultural differences on patient responses.

■ Support the development of new outcome measures

EU research funds should also be used to support the development of new health outcome measures – in particular patient-reported outcome measures (PROMs).

Data governance for health system performance improvement

NATIONAL LEVEL

■ **Implement robust data governance frameworks**

Data governance is very important to ensure that health data can be used as part of quality improvement strategies whilst protecting patient privacy. Member states should develop data governance frameworks in accordance with the mechanisms identified by the OECD expert panel on health data governance in 2015.

EUROPEAN LEVEL

■ **Develop guidelines on the implementation of EU data protection regulation**

It is crucial that the implementation of the EU data protection regulation should not create additional barriers to the use of health data for health system performance improvement. The European Commission should provide guidelines to Member States on the implementation of the regulation with respect to the use of patient data, and support Member States with the design of data governance frameworks that enable the data to be used for performance improvement purposes.



2 Public Health Outcomes Measurement

For more effective interventions

Most of the resources in health systems are directed towards the treatment and care of patients with specific medical conditions. For the health and well-being of populations as a whole, however, effective public health policies are just as essential.

Public health policies and interventions address the determinants of health (social, environmental, economic, and behavioural) and take many different forms – such as ensuring safe and hygienic conditions at work, safe transport, adequate housing, health education, and measures to prevent and alleviate poverty and social exclusion.

Public health policies must also take account of inequalities between different population groups. In particular, levels of education and income can be key determinants of health outcomes. The health status of ethnic minorities, people who were not born in the country in which they live, and persons with disabilities, is also likely to be worse, on average, than that of the population as a whole.⁶⁴

Improving public health outcomes can have important economic benefits, in particular through labour market participation, reduced absenteeism and better educational outcomes. By preventing or delaying morbidity, public health policies can also help to reduce future costs within the health care system, and therefore contribute to the sustainability of health spending.

Designing public health policies that are both effective in addressing the causes of ill health, and responsive to health inequalities and the needs of vulnerable groups, is far from straight forward. Public health authorities are confronted with multiple public health challenges simultaneously, yet have limited resources in order to address them. The OECD estimates that prevention and related public health actions account on average for only 3% of total health spending among member countries.⁶⁵

To focus these limited resources where they are most needed, public health authorities will often prioritise specific public health threats and challenges. Even then, however, there may be a multitude of potential interventions, and varying levels of evidence to support decisions about which interventions are most appropriate and most likely to be effective.

Once specific interventions have been designed and implemented, those interventions have to be followed up and evaluated to know whether they contributed to improvements in public health or changes in risk factors. For all of these tasks, the ability to measure and monitor public health outcomes over time is extremely valuable.

This chapter focuses on how public health outcomes measurement can be used to improve the design,

⁶⁴ A. Linell, M. Richardson, and S. Wamala, 'The Swedish National Public Health Policy Report, 2010', *Scandinavian Journal of Public Health* (2013), 41.

⁶⁵ OECD, 'Health Spending in Europe Falls for the First Time in Decades': <http://www.oecd.org/newsroom/healthspendingineuropefallsforthefirsttimeindecades.htm>

follow up, and ultimately the effectiveness of public health policies. In particular, it focuses on how data about public health outcomes and risk factors can be used to:

- **Tailor public health policies and interventions to local needs** – through a better understanding of outcomes within geographically defined populations and population sub-groups.
- **Strengthen the follow up and evaluation of implemented interventions** – using outcomes data to inform analyses of the effectiveness of past interventions and how they might be improved.
- **Monitor the performance of public health policies** – by tracking changes in outcomes and risk factors over time, between different public health authorities, and in relation to public health targets.
- **Enhance the accountability of public health policy makers and institutions** – through transparency of outcomes data.

The chapter is divided into three parts. The first provides a short introduction to public health policy and interventions, outlines the different types of public health data that can be used to support public health policy, and explains how improvements in the health of the populations can have important economic benefits – including by contributing to the sustainability of health systems.

The second part shows how data about health outcomes and risk factors can be used to strengthen the design and implementation of public health policies. The analysis is based on three country-specific case studies, where information about the use of public health outcome measures is readily available: Sweden, the Netherlands, and the UK.

The third part of the chapter then outlines a number of the key opportunities and challenges associated with health outcomes measurement to support public health policy.

1. Public health: policies, indicators, and health system sustainability

What are public health policies?

Public health – as distinct from health care, which focuses on treatment and care for patients with specific medical conditions – aims at improving the health of populations as a whole. Some public health policies/interventions are designed and implemented by the health sector itself, while others are provided by wider sectors – for example, social care, education, employment, environment, housing and transport.

Within the health sector, public health policies fall into three types: i. **Health Protection** – directed at communicable disease, including monitoring and surveillance systems, vaccination, protection from natural and man-made disasters; ii. **Health Promotion** – directed at providing health information, education and support to enable people to lead healthy lives; and iii. **Prevention** – which includes many different types of intervention, and is categorised in terms of:

- **Primary prevention:** preventing people becoming ill – e.g. through better diets and exercise to prevent obesity, provision of statins to reduce cholesterol, and tobacco control.
- **Secondary prevention:** which aims to reduce the impact of a condition that has already occurred by identifying and treating people as quickly as possible, and slowing or halting the progress of that condition. For example: cancer screenings, and use of protease inhibitors in HIV and Hepatitis C treatment to prevent viral replication



- **Tertiary prevention:** in particular, managing long-term conditions by limiting deterioration in people's health and preventing complications – e.g. frailty related interventions, such as nutritional supplements and assisting physical exercise.

Beyond the health sector, important contributions to public health are made by a number of other sectors – many of which can be as important as the interventions provided by the health system itself. These include:

- **Youth / education policy:** ensuring that children have the best possible start in life and are well supported – e.g. through measures to combat child poverty, and providing school counselling services.
- **Transport:** measures to promote road safety, such as wearing motorcycle helmets and to deter driving after alcohol consumption.
- **Environment:** measures to combat pollution in urban areas, and to provide spaces for recreational activities and sports.
- **Fiscal policy:** taxation to deter risky behaviours related to smoking, alcohol and diet

The importance of interventions made by government ministries or government funded organisations outside the health sector highlights the relevance of the concept of 'Health in All Policies'. Health in All Policies means that health objectives should be factored into policy making across all sectors (be at the local, national, or international level).

Health in All Policies is included as a principle in the EU treaties: Article 168 of the Treaty on Functioning of the European Union states that “A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities”.⁶⁶ However, there is scope to improve the application of this principle at EU level, and Health in All Policies remains far from being universally applied within Member States.

For many public health issues, there are likely to be a range of effective interventions available (some within and some outside of the health sector) highlighting the need for inter-sectorial cooperation in order to design and implement comprehensive public strategies. This can be illustrated by reference to two of the main public health issues confronting EU Member States: tobacco consumption and obesity.

Tobacco consumption

Smoking is a key risk factor in relation to a range of medical conditions, including heart disease, stroke, lung and other types of cancer, and chronic obstructive pulmonary disease, while smoking among pregnant women can lead to low birth weight and illness among infants.

The daily smoking rate in the EU is nearly 23%, but there are wide differences between countries (Greece has the highest rate at 38%, while Sweden has the lowest at 13.1%). Tobacco consumption was typically very high in European countries from the Second World War up to the 1970s, and from the 1980s began to decline.

In the period 2002-12, the largest declines among EU Member States were seen in Denmark (39%), Luxembourg (35%) and the Netherlands (33%), and the decline in mortality from ischemic heart disease in the UK and the Netherlands is attributed to a significant degree to declining tobacco consumption.⁶⁷

⁶⁶ Treaty on the Functioning of the European Union, Official Journal of the European Union

⁶⁷ OECD, European Commission, *Health at a Glance Europe 2014*

Public health interventions are considered to have made a significant contribution to these outcomes.⁶⁸

The World Bank's 'Tobacco Control at a Glance' identifies six types of intervention that are 'highly cost-effective' in reducing consumption – a number of which require action outside of the traditional health sector i. higher taxes on cigarettes and tobacco products; ii. bans on smoking in public places; iii. advertising bans; iv. better consumer information; v. warning labels (e.g. on cigarette boxes); and iv. cessation therapies such as nicotine replacement.⁶⁹

Obesity

Obesity is now a major public health issue in many EU Member States. In 2012, one in six adults in EU Member States were obese (16.7%), compared with one in eight in 2002.⁷⁰ The OECD study, 'Obesity and the Economics of Prevention: Fit not Fat', found that obesity doubles the likelihood of a person being unable to live a normal active life, and that severely obese people die 8-10 years earlier than people with normal weight.

Within OECD countries, an obese person incurs 25% higher health expenditures (over the course of a year) than a person of normal weight. Obesity is also linked to wider societal inequalities – for example: women with a low level of education are two to three times more likely to be overweight than women with a high level of education; and obesity is associated with lower earnings.

The study argued that a comprehensive obesity prevention strategy would: 'delay or prevent the onset of chronic diseases, cutting disability and improving quality of life', and that the single most effective intervention is individual counselling by family doctors, although government regulation [and] taxes can generate health gains at a much lower cost.⁷¹ Other interventions that can be used as part of such a strategy include: advertising limits or bans, labelling, consumer information on health diets, and encouraging physical activity.

The important role that family doctors can play in tackling obesity highlights the key role of primary care as an integral component of both public health system and the health care system. Primary care also makes a crucial contribution to public health strategies in relation to: vaccination programmes, screening and early diagnosis, awareness raising, and promotion of health lifestyles, among others.⁷²

Public health indicators

The most widely used definition of health is that contained in the World Health Organisation constitution of 1946: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". The range of possible health measurements related to this definition is vast, and the standard population health indicators (such as life expectancy, mortality and disease prevalence), whilst important, are clearly insufficient.

For the design of effective public health policies, it is also crucial to understand risk factors, such as socio-economic status, living environments, and lifestyles, as well as outcomes for vulnerable groups (such as children, elderly people, people with learning disorders, ethnic minorities, and immigrants).

⁶⁸ Ibid.

⁶⁹ World Bank, 'Tobacco Control at a Glance', (2011)

⁷⁰ OECD, European Commission, *Health at a Glance Europe 2014*

⁷¹ F. Sassi, *Obesity and the Economics of Prevention: Fit not Fat* (OECD, 2010)

⁷² J-F Levesque, 'The Interaction of Public Health and Primary Care: Functional Models and Organisational Models that Bridge Individual and Population Perspectives', *Public Health Reviews*, 35, 1 (2013).



Population-wide data is also likely to conceal socio-economic inequalities, so it is important that data can be disaggregated to take account of differences in health outcomes based on gender, ethnicity, education and income levels.

This chapter will distinguish between four main types of outcome indicator:

- **Life expectancy and healthy life expectancy**
- **Public health outcomes** – e.g. cancer incidence; diabetes prevalence; HIV / AIDS diagnoses; mortality from preventable causes
- **Societal Outcomes** – child development; domestic violence; winter deaths; suicide rate.
- **Changes in risk factors** – e.g. daily smoking rate; alcohol consumption; obesity; air pollution

The economic dimension: the contribution of public health to economic performance and the sustainability of health systems

As noted above, public health accounts for only a small share of total health spending in EU Member States. However, the potential contribution of effective public health to economic goals is much greater than the small share of resources devoted to them would imply. Effective public health interventions can increase both life expectancy and healthy life years by preventing or ensuring early treatment for premature or avoidable morbidities.⁷³ These benefits can in turn feed into economic outcomes such as longer working lives, higher employment market participation and reduced absenteeism. Wider societal benefits associated with improving public health include better educational outcomes, as well as increased social participation and social cohesion.

By addressing the determinants of ill health and reducing the future burden of morbidity, public health policies can also reduce health care costs and make an important contribution to the sustainability of health systems. This consideration was, for example, central to NHS England's Five Year Forward, which called for a 'radical upgrade in prevention and public health'.⁷⁴ The report highlighted the continuing prevalence of risk factors – one in five adults smoke, a third of men and half of women don't get enough exercise, nearly two thirds of adults are overweight or obese, and the obesity rate among children doubles while they are at primary school.⁷⁵

The way in which failure to effectively address public health challenges can create significant costs for the health system and society more broadly has been strikingly demonstrated in the area of mental health. The OECD has highlighted that, each year, over a quarter of adults are affected by at least one mental disorder, with serious mental illness accounting for the largest share of that (e.g. severe depression, schizophrenia, bipolar disorder, and alcohol or drug dependence).⁷⁶

Mental illness also creates significant costs outside of the health sector – for example through reduced productivity, absenteeism and sick leave, and the provision of disability benefits. The International Labour Organisation has estimated that the economic and social cost of mental health problems amounts to 3-4% of GDP in the EU.⁷⁷

⁷³ J. Figueras and M. McKee, 'Health Systems, Health, Wealth and Societal Well-being, Assessing the case for investing in health systems' (2012).

⁷⁴ NHS, *Five Year Forward View* (October 2014)

⁷⁵ Ibid.

⁷⁶ OECD, 'Improving Value in Health Care: Measuring Quality' (2010)

⁷⁷ Ibid.

Effective mental health interventions – be it community based interventions to address the causes of mental illness, psycho-social support, peer-to-peer contact, psychotherapy, or medication – can thus represent high value investments in health.

An LSE study for the European Brain Council on ‘the ‘Cost and impact of not-treating severe mental illnesses (SMIs): the case study of schizophrenia’ sought to investigate the cost on society of non-treatment of schizophrenia, taking into account the impact on: co-morbidities, homelessness, use of criminal justice resources, education, employment issues, violence and use of health care resources. Failures in diagnosis is one of the main reasons for the non-treatment of schizophrenia: either people are not diagnosed, are only diagnosed with delays, or do not receive an appropriate diagnosis. While the study acknowledged major gaps in the evidence base, it estimated the worldwide economic burden of non-treatment of schizophrenia to be US\$ 56 billion.⁷⁸

2. Improving public health policies by measuring outcomes

This section of the report will focus on how the measurement of public health outcomes and risk factors can be used to support the design and implementation of public health policies. The analysis will focus on examples from three countries: Sweden, the Netherlands, and England. Each of the countries has a decentralised public health system, in which primary responsibility for the delivery of public health services rests with local authorities. However, in each country, central institutions (the health ministry or government agencies) are responsible for setting overall national priorities, and ensuring that local authorities are supported through the provision expertise and information from specialised institutes. Data about public health outcomes is used to inform policy both at the central and local level.

The three countries all perform well with respect to the main indicators of health outcomes – such as life expectancy and healthy life expectancy – but in each country there are specific problems requiring action. For example, in the Netherlands mortality from cancer is above the EU average, while obesity prevalence in the UK is the second highest of all EU Member States. Reducing health inequalities is also a key challenge in each.⁷⁹

Case studies from Sweden and the Netherlands will be used to show how the measurement of public health outcomes can be used to tailor public health policies to local challenges and risk factors, as well to strengthen the follow up and evaluation of past interventions. An example from England will then be used to demonstrate how public health outcomes measurement can be used to monitor the performance of, and strengthen accountability within, the public health system as a whole.

Tailoring public health policies to population requirements

The case studies for Sweden and the Netherlands below demonstrate the importance of data as a tool to understand public health issues affecting the population as a whole, population sub-groups and defined geographic areas, and then to tailor policies and interventions in order to address those challenges.

The case of Sweden demonstrates how detailed information about public health can be used to develop recommendations responding to specific issues. In the Netherlands, on the other hand, there was recognition that more usable data – in particular comparable data – was desirable in order to better assess the interventions that may be needed.

⁷⁸ M. Tinelli and P. Kanavos, ‘Cost and impact of non-treating severe mental illnesses (SMIs): the case study of schizophrenia’ (presentation at EBC, 19 June 2015).

⁷⁹ OECD, European Commission, ‘Health at a Glance: Europe 2014’



In **Sweden**, a *Public Health Policy Report* is produced every few years by the Swedish National Institute of Public Health. The report provides a detailed analysis of Swedish population health, including inequalities between different population sub-groups.

In relation to inequalities, for example, it was found that:

- the gap in life expectancy at 30 between people with a high and low level of education was three years for women and four years for men
- people with a lower level of education are at greater risk of cardiovascular disease, cancer, and death from injuries
- ethnic minorities experience poorer health than the majority of the population (in particular mental health) – as do people with disabilities⁸⁰

Based upon this extensive data, the Swedish Public Health Policy Report then reviews recent public health initiatives at the national level, and proposes a significant number of additional actions.

The 2011 report *Public Health Policy Report* included recommendations on:

- developing youth counselling centres and school health services
- developing national guidelines to support outreach and preventative home visits for the elderly
- strengthening labour market policy measures for the long-term unemployed, or those at risk of long-term unemployment – e.g. more apprenticeships, step-in jobs, and new-start jobs
- initiating collaboration between agencies to develop the physical environment – with the aim of increasing the level of physical activity in the population
- investigating the possibility of using economic policy instruments to promote healthy eating habits⁸¹

Vital to the collection and use of public health data for policy purposes is the fact that Sweden has an efficient health information infrastructure, which ensures that information about health and risk factors is available both at the level of the population as a whole, and for important sub-groups.

The case of the **Netherlands**, on the other hand, highlights the challenges to public health policy that may be posed by not having the type of data needed to inform policy. While the Netherlands has an advanced public health system, in 2011 there was a recognition at the policy level that health information systems were as yet insufficient to enable the type of fine-grain analysis considered necessary.

A *Public Health Status and Forecasts Report* is published every four years by the Dutch National Institute for Public Health and the Environment.⁸² The report is used to inform the Ministry of Health's National Policy Document on Health – also produced once every four years. The 2011 National Policy Document on Health acknowledged that while *'a significant body of data is collected in the Netherlands, it remains difficult to obtain reliable statistics on the health of the Dutch population in a form which allows ready comparison.'*

As a result, the Institute for Public Health and the Environment has been instructed to:

⁸⁰ A. Linell, 'Swedish Public Health Policy Report 2010'

⁸¹ Ibid.

⁸² National Institute for Public Health and the Environment (RIVM), 'Public Health Status and Forecasts Report 2010'

- i. streamline the collection of health information, with a view to generating more comparable data at the national, regional and local level; and
- ii. develop practical tools which give an immediate impression of the state of public health, and interventions that may be necessary.⁸³

Strengthening the follow up and evaluation of past interventions

Data about population health can also be used to support the follow up of previous interventions, and to evaluate their effectiveness. This function of outcomes data poses a number of methodological challenges due to the time lags that may be involved (between interventions and consequent changes in health outcomes), and the fact that a change in a health indicator may be influenced by a number of factors – not only the public health intervention itself.

The impact of policies / interventions aimed at modifying behaviours may be easier to assess – such as policies to reduce smoking and alcohol consumption, and influence diet – but again, time lags are inevitable. Despite these limitations, outcome measures can be an invaluable tool for the follow up, review and evaluation of public health policies and interventions in order to determine their effectiveness. Follow up activities are inevitably much more difficult if data is not available to support them.

In 2013, a **review of Swedish public health policy** found that over half of local public health authorities and municipalities used specific indicators to measure their public health efforts. However, a number of the authorities emphasised that statistics on health determinants needed to be more closely linked to specific activities, and that it was not always possible to relate indicators to interventions.

Those authorities that did not use indicators in the follow up of public health policies acknowledged that they had problems in organising and managing the follow up work. Local authorities also expressed a desire for more data to be made available at regional / local level, in order to be able to compare it with national level data.⁸⁴

The case of **meningitis vaccination in the Netherlands** provides a strong example of how data can be used to support follow up and evaluation of public health interventions. In 2000-2001, an upswing in the number of new meningococcal C meningitis cases led public health authorities to begin vaccinating against it. In the immediately following years, data showed the number of new cases had declined sharply, and to a very low level (in 2012, only two people contracted meningococcal C meningitis).⁸⁵

In the case of pneumococcal meningitis, a vaccine was introduced in 2006. While the incidence declined in subsequent years, the decline was not as sharp as that seen for meningococcal C meningitis. In 2012, there were approximately 130-140 new cases. One explanation suggested for the difference in outcome is the fact that a 'catch-up' campaign for children and adolescents was introduced for meningococcal C meningitis, but not for pneumococcal.⁸⁶

This type of follow up evaluation was only possible due to the availability of detailed data about the incidence of different types of meningitis over time, which could be linked to specific interventions.

⁸³ Dutch Ministry of Health, Welfare and Sport, 'Health Close to People', National Policy Document on Health, 2011

⁸⁴ Swedish National Institute of Public Health, 'Ten years of Swedish public health policy – Summary report' (2013)

⁸⁵ National Institute for Public Health and the Environment, *Dutch Health Care Performance Report*, 2014

⁸⁶ Ibid.



Monitoring the performance of public health policy and strengthening accountability

Public health outcomes data can also be used to monitor the performance of public health policies – either by tracking changes in outcomes over time, by comparing the outcomes of different regions / localities, or by measuring outcomes against specific targets.

Given the multi-sectoral nature of public health, it is important that governments as a whole are accountable for population outcomes. By making performance information transparent and accessible to the public, it is possible to strengthen this accountability mechanism, and incentivise a stronger focus on public health and the importance of investing in it.

A strong example of using performance monitoring for accountability purposes is provided by the creation of the **Public Health Outcomes Framework in England**.

The Public Health Outcomes Framework was created as a result of the 2012 Health and Social Care Act. Its explicit purpose is to provide transparency and accountability across the public health system (where responsibilities are divided between Public Health England – the national executive agency under the Department of Health, local authorities, and the NHS).

The framework features approximately 70 indicators, which are published in a transparent format online, and can be viewed either at the local level, the regional level, or the national level. The intention is that local authorities should aim to deliver improvements in public health outcomes, demonstrated via the agreed Outcomes Framework indicators. Central government can also incentivise progress by awarding increased funding for improvements against specific indicators.

The overarching objectives of the framework are:

- i. Increased healthy life expectancy – taking account of health quality as well as length of life
- ii. Reduced differences in life expectancy and healthy life expectancy between communities – through greater improvements in more disadvantaged communities

In addition, there are four thematic public health ‘domains’, supported by a range of indicators:

I. Improving the Wider Determinants of Health

Indicators include:

- children in poverty
- first time entrants to the youth justice system
- domestic abuse
- homelessness
- social isolation

II. Health Improvement

Indicators include:

- low birth weight infants
- excess weight in 4-5 and 10-11 year olds
- smoking prevalence

- cancer diagnosed at stage 1 and 2
- falls and injuries in people aged 65 and over

III. Health Protection

Indicators include:

- population vaccine coverage
- people presenting with HIV at a late stage of infection
- treatment completion for Tuberculosis

IV. Healthcare public health & preventing premature mortality

Indicators include:

- mortality from causes considered preventable
- mortality from: i. cardiovascular diseases; ii. cancer; iii. liver disease; iv. communicable diseases
- excess under 75 mortality in adults with serious mental illness⁸⁷

The health system in England also produces a number of annual reports, including by the Chief Medical Officer and Public Health England respectively. These highlight particular public health issues and how they are being addressed. *Health Trends* also provides a compendium of public health data, which can be broken down to local authority level.

3. Challenges and opportunities for public health outcomes measurement

The final section of this report focuses on key challenges and opportunities associated with the measurement of public health. Some of the main **challenges** were highlighted in section 2 – for example: the time lags between an intervention and any resulting change in public health indicators.

An additional challenge is to ensure that data collection practices at local level are standardised. Without standardisation, opportunities to compare data between regions / localities, or to compare local level data against national averages, will be much more limited.

Effective public health policies also rely on the ability to differentiate between the challenges affecting different population groups. When developing indicators and data collection practices, it is crucial to be able to differentiate according to gender, education, income, ethnicity, persons with LGBT (lesbian, gay, bisexual, and transgender) identity, and persons with a disability.

A further challenge relates to the planning of public health policies and interventions. All too often, public health actions are not implemented in a way that allows for subsequent measurement and analysis – sometimes because baseline measurements were not collected at the outset.

It is therefore vital that in the planning stage, consideration should be given to how the interventions will be monitored and evaluated in order to determine their effectiveness, and how the intervention

⁸⁷ Department for Health, 'Improving Outcomes and Supporting Transparency: A public health outcomes framework for England, 2013-16' (2013)



could have been improved.

With regard to **opportunities**, the rise of Big Data analytics has the potential to significantly strengthen public health policy making. New approaches to collecting and analysing large data sets may enable a more sophisticated understanding of the determinants of population health and risk factors, as well as a better appreciation of the effects of specific interventions.

Related to this is the availability of new data sources. In traditional epidemiological studies, data was often collected through interviews and surveys. As a result of new digital technologies, however, information generated by social media (such as Twitter) or mobile apps may be able to make an important contribution to monitoring health-related behaviours and trends.

As with the use of health care data, it is important that well designed data governance systems are put in place that ensure such data can be used to improve public health, whilst also protecting privacy.

Conclusion

Effective public health policies are crucial for improving health outcomes among populations, and for reducing health inequalities within them. Well-designed public health policies and interventions can also have a direct impact on economic outcomes (such as longer working lives, reduced absenteeism and improved educational outcomes). By preventing or delaying morbidity, public health systems can make a vital contribution to the sustainability of health systems.

The measurement of public health outcomes is a crucial tool for improving public health. Good public health measurements enable public health practitioners to tailor policies and interventions to local population requirements, support the follow up and evaluation of past interventions, and – through transparency – can strengthen accountability for public health outcomes.

The measurements of public health outcomes needs to go well beyond the classic indicators such as life expectancy and disease prevalence, and include broader societal outcomes. This is important not only in order to understand the links between health and wider socio-economic outcomes, but also in order to demonstrate the value of investments in public health – through the contribution they make to economic and societal goals.

For the same reason, it is also very important that public health policies / interventions are designed and planned in a way that enables their effectiveness to be monitored and evaluated afterwards. Ensuring that baseline measurements are made at the outset is vital to demonstrate effectiveness.

Finally, measurement of public health outcomes should be designed in a way that enables differentiation according to different population sub-groups. The reduction of health inequalities is a key challenge for all Member States, but without data that enables those challenges to be properly identified and understood, it will be much more difficult to design appropriate policies and interventions to address them.

Recommendations

■ Improving the collection of public health outcomes data in Member States

EU health information policy and structural funds should be used to support Member States in strengthening their health information infrastructures, as well as their data collection capacities. Given the relationship between public health and the sustainability of health systems, this can also make an important contribution to the objectives of the European Semester.

■ Sharing best practice at EU level

The EU can play an important role in enabling the sharing and dissemination of best practice among Member States. In particular, best practice should be shared with respect to:

- i. The design of public health outcomes measurement frameworks and reporting
- ii. The use of measurements to tailor and evaluate public health interventions
- iii. Designing public health interventions in ways that enable their effectiveness to be evaluated subsequently

■ Further develop the Joint Assessment Framework on Health

The Joint Assessment Framework on Health, developed by the Social Protection Committee in collaboration with Member States, can become an important tool for the identification of key public health challenges within and across Member States.

The further development of the framework should pay particular attention to inequalities in health outcomes between population groups, as this dimension has received less attention in other international HSPA frameworks.



Future Chapters

Improving Care Pathways, Innovative Technologies, and International Standardisation

Achieving high quality outcomes for patients and for health care systems requires health systems to be well organised and to function in ways that ensure patients receive the treatment and care they need, when they need it, and that the care and treatment provided is efficient and effective. In recent years, this has led to a focus on innovation in healthcare processes, alongside innovation in technologies.

In 2016, the multi-stakeholder seminars upon which this report is based will continue to address themes relating to improving outcomes and enhancing value in European health systems. Three themes in particular have been identified:

1. **Improving care pathways** – through outcomes measurement
2. **Harnessing the potential of innovative technologies** – as enablers of better outcomes
3. **International standardisation** – for comparable outcomes data

The purpose of this chapter is to provide an introduction to these topics, and to act as a starting point for the discussions in the 2016 seminars. Based on those meetings and the expert input provided, further chapters will be added to the Vision Document.

Improving care pathways

There are many ways in which healthcare service provision and processes have been reconfigured with a view to optimising outcomes. These include the physical reconfiguration of health services, such as the development of ultra-specialised facilities (e.g. the Martini Klinik in Hamburg – which focuses exclusively on treating prostate cancer), and the development of specialist hospitals (such as Moorfields Eye Hospital in the UK), which function as referral centres for particularly difficult cases or rare conditions. In primary care, it can be seen in the development of multi-professional practices and polyclinics.

Other ways to improve processes depend less on changing physical configuration than on changing methods of working and thinking. For example, the concept of value-based health care is increasingly influential. It begins with the proposition that health care services should aim to maximise value (defined as outcomes produced over the costs per patient). Value based health care requires measurement of both costs and outcomes, and clarity about how to improve outcomes whilst controlling or reducing costs.⁸⁸

⁸⁸ The concept of value-based healthcare, as developed in Michael Porter's work, is also supposed to govern how healthcare is costed and how services are paid for and reimbursed. This is not within the scope of this chapter.

Another approach that is becoming more widely employed is the use of care pathways (also called clinical pathways, patient pathways, care maps and integrated care pathways⁸⁹). Care pathways are designed to show how to achieve optimal results for patients with specific conditions by specifying a standardised approach to treatment and care (i.e. what should be done, by whom, and when).

The pathway design is based on the best evidence and clinical guidelines. Once the model is established, it is then adapted to real conditions by setting out a process of steps for the patient journey. In order to work effectively, care pathways rely on multi-disciplinary and multi-agency cooperation, the routine recording of data and information at all stages, and its analysis and communication to the professionals and organisations involved in the process. They must also fully involve patients in decisions concerning their treatment and care.

Care pathways can offer a number of benefits. They enable the best evidence-based medicine and effective new technologies to be adopted in local practice, including the use of personalised medicine. Other potential benefits of care pathways include:

- reducing / eliminating practices shown to be less effective
- providing support for the management of care and decision-making
- ensuring that patients receive clinical interventions and assessments that are appropriate and timely
- reducing unnecessary variations in treatment for particular conditions
- improving information about the goals and likely outcomes of treatment
- improving communication between the professionals involved and the patient
- ensuring decisions are made with the full involvement of patients
- ensuring integration of care between the different parts of the health system - primary and secondary care services, in-patient and community care (even health and social care)
- reducing duplication of work and wastage of resources
- avoiding the possibility of gaps in service

The care pathways concept has been gradually gaining ground in Europe, particularly as multi-disciplinary guidelines have been created in many countries. For example, some care pathways were created in Belgium, Catalonia and Germany in the 1990s. In 2005, the Welsh Government published a policy document on how they should be set up⁹⁰, and some integrated cancer care pathways were established in the Netherlands in 2009.⁹¹

The use of pathways has become particularly well established in England,⁹² and in Sweden a number of local areas and hospitals, such as the Karolinska and Uppsala Akademiska Hospital, use them. At EU level the role of care pathways has been discussed in meetings to develop networks of European

⁸⁹ The idea of care pathways goes back to the 1980s in the US where it was first introduced in Boston in 1985 and then developed in a number of other states for surgical patients.

⁹⁰ Integrated Care Pathways: A guide to Good Practice, National Leadership and Innovation Agency for Healthcare September 2005

⁹¹ See 'The care pathway: concepts and theories: an introduction' by Schrijvers, van Hoorn and Huiskesin the International Journal of Integrated Care Vol 12. Special edition Integrated Care Pathways September 2012

⁹² The University of Birmingham carried out a study of the operation of 61 care pathways in the early 2000s



reference centres, set up in the framework of the 2011 Directive on patients rights in cross-border healthcare. The European Brain Council is also undertaking a project to develop models of care for brain disorders, supported by examples of evidence-based interventions.

While care pathways can be an effective means of ensuring that high quality care and treatment is delivered in an efficient way, it is important that real world outcomes are measured and evaluated. This information can be used to adapt and further improve the pathways – as was seen, for example, in the case of the Enhanced Recovery Programme for elective surgery in England (chapter 1 of this report).

At the same time, it is important to recognise that the care pathways approach may have limitations. In particular, they are aimed at optimising patient care and treatment where a particular condition has been diagnosed. It is less clear that they can be used in cases – increasingly common with population ageing – of multi-morbidity. Nor do they deal with how patients access health services for initial diagnosis.

Moreover, the standardisation of processes of care should not reduce ‘good variation’ – i.e. the introduction of innovative practices that may further improve quality. The key is that the outcomes of the innovative practices should be measured, analysed and, if successful, publicly documented.

Harnessing the potential of Innovative technologies: enablers for better outcomes

eHealth

The rapid development and deployment of innovative technologies is having an increasing effect on how healthcare systems are organised, how they function, their costs and their outputs and outcomes. A particularly significant trend is the use of digital technologies (or eHealth) in relation to public health and health care.

eHealth tools and services can be used for health promotion, prevention, diagnosis, treatment, monitoring and surveillance, and health care management. eHealth offers ways to provide more accessible and effective healthcare, which can produce better outcomes for patients and more effective and cost effective healthcare systems.

The EU is giving considerable attention to eHealth, which is seen as playing an important role in the development and sustainability of European health systems. The Digital Agenda for Europe under the Europe 2020 economic strategy contains targets for eHealth in relation to promoting online access to medical data, interoperability standards, and a common set of patient data.

The European Commission’s Digital Single Market Strategy⁹³ also refers to developing priorities for standards and interoperability in relation to eHealth. In addition, the Commission has provided funding for many projects on uses of eHealth in the areas of prevention, treatment of specific diseases, chronic disease management, patient empowerment and patient literacy.⁹⁴

Moreover, in the framework of the Directive on cross-border healthcare, an eHealth Network of national authorities responsible for eHealth was set up⁹⁵, which aims to draw up guidelines for eHealth intended to help ensure continuity of care and access to safe and high quality healthcare. Areas of

⁹³ A Digital Single Market for Europe, 6 May 2015

⁹⁴ eHealth Projects – Research and Innovation in the field of ICT for Health and Wellbeing: an overview. EU Publications Office 2014

⁹⁵ Directive 2011/24/EU. Article 14 provides for the setting up of a voluntary network.

work being undertaken in relation to the Directive include: consideration of electronic health records, patient summary records, and ePrescriptions that can be communicated between countries.

Three specific areas of eHealth can give an indication its potential:

1. **mHealth:** mHealth, which makes use of mobile technology (especially mobile phones), has a particular advantage in addressing healthcare access issues. It can for example be used for remote diagnosis, monitoring of symptoms and diseases progression, for the provision of health information and advice, and consultation with health professionals.⁹⁶
2. **Big Data:** Big Data is the combination of huge amounts of data being routinely generated and put in databases and the ability to use technology to analyse it rapidly so that it can inform decisions and policy. In the EU a large number of patient and disease registries have been set up. The European Commission's PARENT project (the Cross Border Patient Registries Initiative) estimates that there are over 1000. In the US the trend towards the creation of massive health databases which can be mined by health authorities, companies and organisations has gone further.⁹⁷ For example, Kaiser Permanente, which provides healthcare to over 8 million people, has a computer system that links data across all its medical facilities, and is used to improve outcomes of healthcare and reduce costs. Another company is tracking the use of inhalers by asthmatics. Their data are then merged with Centers for Disease Control and Prevention (CDC) information about asthma catalysts in various localities, and used to develop prevention programmes.
3. **eHealth for health literacy:** electronic tools can provide people with more information about health promotion, disease prevention, and navigation of health systems and structures. They can also enable patients to understand their symptoms, make choices about care and treatment, and help in the management of chronic diseases. In this way, vulnerable groups can be helped to cope, and access to appropriate care can be improved. Together this contributes to better-informed, empowered patients, and should lead to better health outcomes for them and for health systems.

Personalised medicine

Alongside eHealth there are also major Innovative technologies in relation to genetics and genomics, notably personalised medicine (or precision medicine) – i.e. new combinations of genetically based diagnostics / medical technologies and pharmaceuticals. These can provide more precise diagnoses, more accurate monitoring of disease progression and tailored treatments, all of which can lead to better outcomes for the individual patient. Moreover by reducing use of less effective, or even inappropriate, therapies, they can also improve the cost-effectiveness and outcomes of healthcare facilities and of the healthcare system as a whole.

Medical devices

Similarly, there are a growing number of innovative medical devices/bioengineering products and services, which are offering new ways of screening for disease and safer and more effective treatment options. These include new kinds of scanners, robotic surgical tools, artificial limbs and organs etc.

Many of these innovative technologies not only improve the safety and effectiveness of treatment and care, but also lead to reductions in disability and give people a better quality of life and more functional independence. They can thus have a major impact on health and social care and related costs.

As with eHealth, the development of these innovative technologies has led to a number of EU policy

⁹⁶ See the EU Green Paper and consultation on mHealth April 2014

⁹⁷ McKinsey's report 'The big data revolution in US healthcare' of April 2013 is a good overview



responses. The new Horizon research programme includes a focus on personalised medicine. More generally, there are reviews of both EU pharmaceutical and medical devices legislation, and efforts are being made to expand health technology assessment (HTA) as a way of evaluating the effectiveness and impact of technologies.

Introducing these innovative technologies can offer significant benefits in terms of improving outcomes for patients and health systems. However, they also give rise to a number of important issues, which need to be addressed for them to achieve their full potential. These include: finding ways to enable data to be collected and shared while meeting concerns about privacy, financing the costs of implementing the technologies, and trying to ensure equity of access to them and benefit from them.

A particularly significant challenge is taking full account of the technologies' disruptive effect on current health organisations, processes and systems. It is too often overlooked that these technologies may not just make present systems work faster or more effectively; they may mean changing them.

International Standardisation

Chapter 1 (Health Care Outcomes Measurement) highlighted the importance of international quality comparisons as a means to identify best practice across countries, and to trigger quality improvement initiatives at a national level. International comparisons are technically complex, however, requiring standardised measures and appropriate risk adjustment in order to ensure the comparisons are valid.

The main forum for the development of internationally standardised indicators is the OECD's Health Care Quality Indicators (HCQI) Project. HCQI project began in 2003 among a group of just 16 countries, covering a limited number of medical areas (such as cancer survival and vaccination rates). Since then, both the number of participating countries and range of indicators has expanded considerably, and the comparisons are published in the OECD's annual *Health at a Glance* publication.

Consideration is now being given to the development of new indicators. A High Level Reflection Group on Health Statistics was recently established with a view to identifying future directions and priorities, including the possible inclusion of patient reported data, which until now has not been part of the HCQI work.

An important area for standardisation work to focus on is mental health care. In particular, there is a need to identify outcome measures that are meaningful and relevant to patients, and to help ensure their adoption at national level. In a context of ageing populations, it is also important that attention is paid to the measurement of outcomes for people with multiple morbidities.

There is potential scope for collaboration between the OECD HCQI project and expert organisations involved in the development of outcome standard sets – such as the International Consortium for Health Outcomes Measurement (which has a broad focus across many medical conditions), Outcome Measures in Rheumatology (OMERACT), as well as other organisations focusing on specific medical conditions.

In addition to the identification of the most important and patient-relevant indicators for development at the international level, there may be potential for cooperation in supporting countries with the development of optimal health information infrastructures – in particular with respect to data collection processes at the clinical level.

Summary of Recommendations

Health outcomes and economic performance

EUROPEAN LEVEL

1. Including health as a priority for EU sustainable growth

Improving health outcomes is not only of intrinsic value, it can make an important contribution to economic goals, such as longer working lives, reduced disability, and increased productivity.

In line with the UN Sustainable Development Goals, health and well-being should be included among the priorities of any new or updated EU sustainable growth strategy. In this context, the development and use of national health system performance assessment frameworks (HSPA) should be identified as a key tool for economic and health system governance.

2. European Semester: refocus country-specific recommendations

Country-specific recommendations (CSRs) should be refocused on the need for Member States to develop and use well-designed national HSPA frameworks, as well as efficient health information systems.

By re-focusing CSRs on the tools required to design and implement high quality health system reforms, the European Semester can make a vital contribution to Member States' capacity to enhance the value and sustainability of their health spending.

Health system performance assessment

NATIONAL LEVEL

3. Develop and use health system performance assessment

Member States should design, develop and use HSPA as a key tool for improving health system performance. HSPA should include both tailored indicators that are considered particularly relevant in the country concerned, as well as standardised indicators that enable cross-country comparisons. HSPA data and conclusions should be made transparent in order to strengthen accountability within the health system, and to incentivise improvements in health system performance.

4. Ensure outcomes data is a central component of HSPA

Outcome measures are unique in providing information about the performance of the health system in relation to its fundamental goal: improving patient and population health.



Member States should include in HSPA both composite outcome indicators – relating to the performance of the health system as a whole – and outcome indicators for key medical conditions.

5. Patient involvement and patient-centredness

Patients should be involved in the selection of outcome indicators for use in national HSPA frameworks to ensure that these frameworks are themselves patient-centred (i.e. meaningful and relevant to patients), and that policies arising out of HSPA address issues that are important from the patient perspective.

Member States should also make greater use of patient reported outcome and experience measures (PROMs/PREMs). At the clinical level, this can contribute to: improved patient experience; enhanced patient-clinician communication (including by providing a basis for shared-decision-making – to the extent that this is what the patient wants); and enable patients to better monitor their own conditions.

Patient reported data should also be included in HSPA.

EUROPEAN LEVEL

6. Prioritise outcomes measurement as a tool for improving quality of care

Quality of care is a principal theme in the work of the EU Expert Group on Health System Performance Assessment. In that context, outcome measures should be prioritised as being essential to assessments of health care quality.

7. Identify 'core' outcome measures for use in HSPA

EU work on HSPA should aim to identify indicators that can be used in a standardised way across national HSPA frameworks. Whilst it is important that Member States should be free to tailor HSPA to national contexts and preferences, identification of common indicators can facilitate international comparisons and enhance the value of HSPA for all countries. The Dutch Health Care Performance Report provides an excellent template for integrating internationally standardised indicators in a national performance assessment framework.

INTERNATIONAL LEVEL

8. Continue to develop internationally standardised outcome indicators at OECD level

The OECD Health Care Quality Indicators project is playing a key role in the development of internationally standardised measurements of health care quality. This work should continue, focusing in particular on the development of new, internationally comparable outcome indicators across different medical conditions.

The development of standardised indicators should include patient-reported outcome and experience measures (PROMs / PREMs), in particular.

The development of internationally standardised indicators can also support the development of quality standards in relation to the EU Directive on patients' rights in cross-border healthcare.

Sharing best practice: outcomes measurement for quality improvement

EUROPEAN LEVEL

9. Health Care Outcomes Measurement

Outcome measures offer significant opportunities to drive improvements in quality of care. However, the potential to use outcome measures for this purpose is neither widely understood nor recognised. The EU can raise awareness by collecting and disseminating case studies showing real world use of outcomes measures for quality improvement in different national settings. Case studies should include examples of both: continuous improvements at the health care provider level; and HSPA incentivising and enabling quality improvements across the health system.

10. Public Health Outcomes Measurement

Sharing best practice can also be highly valuable in the context of public health outcomes measurement. In particular, best practice examples should be identified and disseminated in relation to: i. the design of public health outcomes measurement frameworks and reporting; ii. the use of measurements to tailor and evaluate public health interventions; iii. designing public health interventions in ways that enable their effectiveness to be evaluated subsequently.

Health information policy

EUROPEAN AND NATIONAL LEVEL

11. Develop efficient health information infrastructures

Efficient health information systems are essential to the collection and use of outcomes data at a policy level. The development of health information infrastructure should therefore be a key objective of national governments and EU health information policy should aim to support Member States with this.

In the health care context, data collection systems should be integrated, so that data collected for use at the clinical level can also be used at an aggregate level for performance assessment and transparency.

Reducing inequalities in public health outcomes

EUROPEAN LEVEL

12. Further develop the Joint Assessment Framework on Health

The Joint Assessment Framework on Health, developed by the Social Protection Committee in collaboration with Member States, can become an important tool for the identification of key public health challenges within and across Member States.

The further development of the framework should pay particular attention to inequalities in health outcomes between population groups, as this dimension has received less attention in other international HSPA frameworks.



Research and innovation for health outcomes measurement

EUROPEAN LEVEL

13. Support pilot projects that compare outcomes across countries and regions

EU Research and Innovation funds should be used to support projects that measure, compare and analyse differences in health care outcome across countries (or between regions / hospitals within different countries). A previous example of this type of initiative was European Health Care Outcomes Performance and Efficiency (EuroHOPE) project, which took place between 2010 and 2014 and was funded by the European Commission's Framework Programme 7. EuroHOPE compared health care performance in relation to acute myocardial infarction, stroke, hip fracture, breast cancer, and low birth weight infants.

The EuroHOPE project provides an excellent template for future projects, which could look to expand coverage geographically and with regard to medical conditions, as well as broadening the types of outcome measures used. For example, the EuroHOPE project did not make use of any patient-reported outcomes – an area where there is a distinct need for research into the comparability of international data and the potential impact of cultural differences on patient responses.

14. Support the development of new outcome measures

EU research funds should also be used to support the development of new health outcome measures – in particular patient-reported outcome measures (PROMs).

Data governance for health system performance improvement

NATIONAL LEVEL

15. Implement robust data governance frameworks

Data governance is very important to ensure that health data can be used as part of quality improvement strategies whilst protecting patient privacy. Member states should develop data governance frameworks in accordance with the mechanisms identified by the OECD expert panel on health data governance in 2015.

EUROPEAN LEVEL

16. Develop guidelines on the implementation of EU data protection regulation

It is crucial that the implementation of the EU data protection regulation should not create additional barriers to the use of health data for health system performance improvement. The European Commission should provide guidelines to Member States on the implementation of the regulation with respect to the use of patient data, and support Member States with the design of data governance frameworks that enable the data to be used for performance improvement purposes.



The Value of Health
Improving Outcomes