

The Value of Health: Improving Outcomes

Final Report

A multi-stakeholder perspective on value in health systems
and the use of health outcome measures to enhance value







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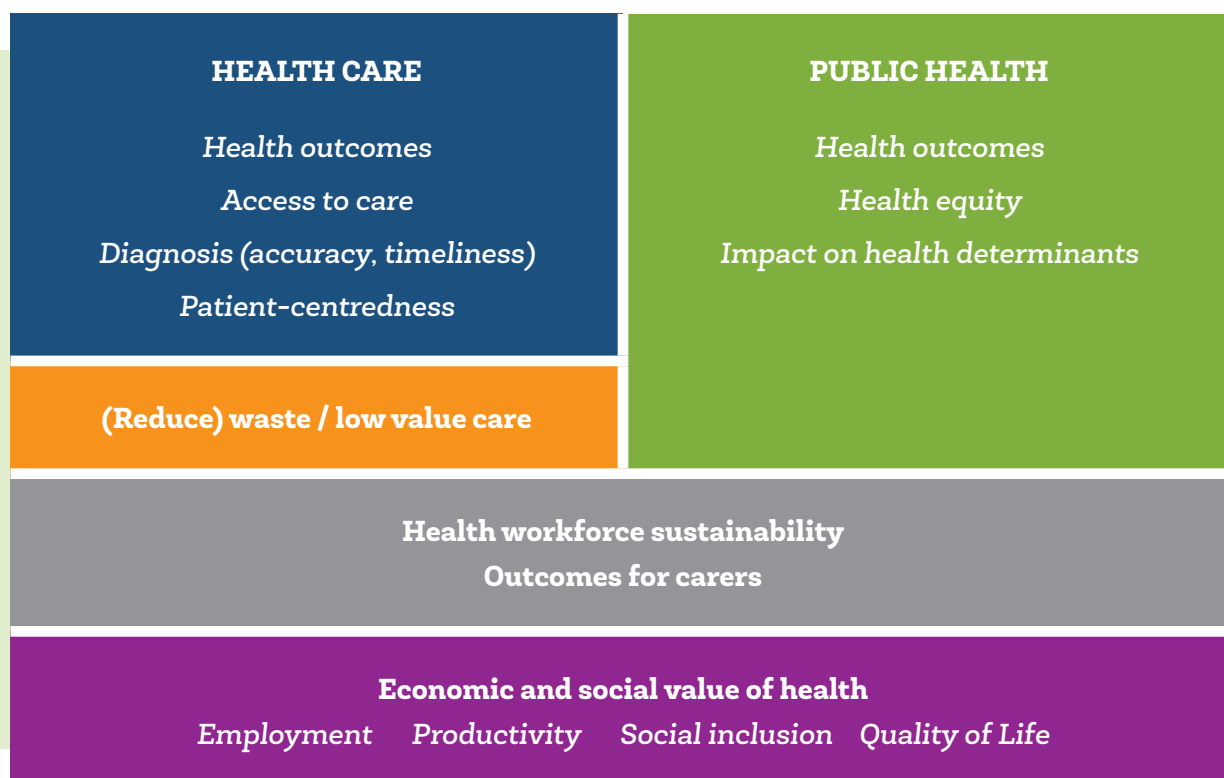
Executive Summary

Value has become a central concept in the analysis and reform of health systems. The fiscal sustainability of health systems has been called into question by the combination of: i) upward pressure on health budgets resulting from ageing populations, technological change, rising levels of multi-morbidity, and increasing public expectations; and ii) sharp constraints on public expenditure in many European countries. As a consequence, there is an increasing focus on the need to ensure better value for money from health spending.

At the same time, there is no single or universally accepted definition for 'value' in relation to health systems. Across stakeholders, the term carries a variety of meanings and associations, and as a result, discussions on how to improve value often lack conceptual common ground. The first chapter of this report therefore provides a multi-stakeholder perspective on the meaning of value.

Health outcomes are at the core of this perspective. At the same time, it is argued that there are other important health system objectives and goals that must be included as part of a comprehensive definition. Box 1 below provides a (non-exhaustive) overview of the different 'dimensions' of value in health systems: within health care and public health, as well as health workforce sustainability, outcomes for carers, and the economic and social benefits of good health.

Box 1: Value in health systems: a multi-stakeholder perspective





Enhancing value through health outcomes data: methods and benefits

The second chapter focuses on how health outcomes data can be used to improve value for money in health systems by enabling improvements in health care quality and public health. It highlights five main ways in which health outcome measures can be used for this purpose:

1. Learning from health outcomes variation

Measuring and comparing health outcomes can help to pinpoint potential areas for improvement through the analysis of outcomes variation. By identifying the reasons for the variation, action can be taken to improve care quality by sharing best practices and addressing instances of low value or sub-optimal care.

Standardised measurements, data collection and coding, as well as case-mix adjustment (i.e. adjusting the data to ensure comparisons reflect a similar 'risk' profile – for example, with respect to the age, gender, and overall health status of patients included), are pre-requisites for successful variation analysis.

2. Continuous improvement at the clinical level

Health outcomes data can be used by clinical teams, working with patients, to identify areas for improvement and to assess the benefits and impact of any clinical practice/care pathway changes introduced. Patients should be involved in both the selection of outcome measures used, and the analysis of the data, to help ensure that improvements reflect patient concerns and priorities.

Many of today's patient-reported outcome measures (PROMs) were developed without patient involvement. Moving forward, it is important that patients should be closely involved in the design of new PROMs to ensure that they measure the things that matter to patients.

3. Improving the effectiveness of public health interventions

Health outcome measures can be used to: i. Tailor public health policies and interventions to local needs; ii. Strengthen the follow up and evaluation of implemented interventions; and iii. Enhance the accountability among public health policy makers for their public health strategies.

4. Performance monitoring and transparency

Health outcome measures are an important tool for performance monitoring (for example, at the hospital, regional, national and international level), and can support health authorities in designing policies to improve health care quality and efficiency. Transparent publication of results can also help to improve health literacy, strengthen the accountability of the health system, and (where the system permit it) support patient choice between providers.

Using patient-centred health outcomes data can help to ensure performance monitoring and assessment is itself patient-centred, and reflects what matters to the users of the health system.

5. Supporting the implementation of integrated care

Health outcomes data can support the design and implementation of integrated care pathways. Health outcome measures are a key tool to demonstrate the impact and benefits of new models of care, and therefore the potential for return on investment in implementing such models at scale. Patient-reported outcomes can also bridge the gap between health and social care by enabling the measurement of the social and economic impact of health interventions

Key recommendations

The Value of Health initiative makes the following key recommendations, which should inform the future work of the European Union on health systems:

1. Continue to invest in the Patient-Reported Indicators Survey (PaRIS) & broaden the disease-specific indicators to include more health conditions

The OECD PaRIS initiative is an important step in providing comparable data on the outcomes and experience of care from the patient perspective (using patient-reported outcome and experience measures: PROMs and PREMs). The initial condition-specific focus on outcomes for elective surgery, cancer and mental health is welcome, and should be progressively widened to include other chronic conditions. In addition, the new comparative international survey on patient-reported outcomes and experiences for people with multiple chronic conditions, currently in development, promises to add significantly to the knowledge of how well health systems perform from the user perspective, and should be supported.

2. Integrate more health outcomes data into analyses of health system performance at EU level

The European Semester has relied upon a relatively narrow range of health outcome indicators, which are of only limited use in analysing health system performance for policy making. The State of Health in the EU cycle represents an important step towards a more balanced analysis of health system performance at EU level, including from a health outcomes perspective (for example through the use of condition specific mortality and survival data). The inclusion of patient-reported indicators (as these become available via PaRIS) would further strengthen the focus on outcomes. The EU Expert Group on Health System Performance Assessment can also provide a forum for exchanging experiences and best practices in using health outcomes data for performance monitoring and improvement.

3. Support the development of health information infrastructure (such as electronic health records)

The collection and use of health outcomes data for quality improvement requires strong health information systems that enable data linkage as part of an ambitious digital health strategy. They should be underpinned by standardised data collection/recording methods, interoperability principles, as well as robust data governance frameworks to enable privacy protective data use for health care improvement. The EU should support the development and implementation of health information systems across Member States as a key tool in ensuring ongoing improvements in quality of care and value in health systems. The 2018 Commission Communication on the 'digital transformation of health and care in the Digital Single Market' provides an important basis for further EU action in this area.



Introduction

The Value of Health: Improving Outcomes multi-stakeholder initiative began in 2014 with the aim of providing a European level, health community response to debates on health system performance and reform. Confronted by the need to control public spending in the immediate aftermath of the economic crisis, governments across Europe were faced with the challenge of containing health expenditure growth whilst continuing to improve the quality and effectiveness of services provided. At European level, these objectives were reflected in EU's economic governance process (the European Semester), which each year publishes structural reform recommendations – including on improving the cost-effectiveness of health spending.

Among health stakeholders, there was concern that the policy response focused too much on cost-containment, with too little attention given to the overall performance of the health system – in particular with respect to quality of care and health outcomes. Over time the European Semester has adopted a more balanced approach: a less prescriptive approach to cost savings, and a broader view of health system performance that recognises the importance of health outcomes, access to care, and quality of care. However, further improvements are still possible (see recommendations).

A first Value of Health consensus document was released in March 2016, with contributions and endorsement by fourteen health sector stakeholders. The report showed how health outcome measures can be used to improve quality of care and public health, and included a strong focus on the importance of patient-reported outcome measures (PROMs) as a tool to capture outcomes from the patient perspective.

For that reason, the Value of Health initiative also strongly supported the January 2017 decision of OECD health ministers to begin collecting patient-reported data across countries (see the OECD PaRIS initiative: <http://www.oecd.org/health/paris.htm>).¹ Following the June 2018 decision by the OECD Member States, the PaRIS survey on patient-reported outcomes and experiences for people with chronic conditions is now starting and likely to be ready for implementation by 2023.²

This final report is based on the discussions and findings of the Value of Health initiative over the past four years, including seven multi-stakeholder roundtables, and working groups on patient-centred outcomes, public health outcomes, and the analysis of health outcomes variation. While many of the case studies in the report are taken from projects and initiatives in West European countries, the findings and perspectives provided by the report are relevant to health systems in all EU Member States.

The report is divided into two main chapters: the first provides a multi-stakeholder perspective on the concept of value in health systems; the second explores how health outcome measures can be used to improve value.

1 Also see: OECD, 'Recommendations to OECD Ministers of Health from the High Level Reflection Group on the Future of Health Statistics: Strengthening the international comparison of health system performance through patient-reported indicators' (January 2017); and OECD, 'Ministerial Statement: The Next Generation of Health Reforms', OECD Health Ministerial Meeting, 17 January 2017.

2 See: <http://www.oecd.org/health/paris.htm>

Value in health systems: A multi-stakeholder perspective

The term ‘value’ is widely used in health policy debates, yet very often appears to hold different meanings or associations for different stakeholders. As a result, discussions on how to improve value often lack conceptual common ground. This chapter provides a multi-stakeholder perspective on the meaning of ‘value’ in relation to health systems.

Health outcomes, both health care and public health outcomes, are at the core of this perspective. Other aspects of care quality³ are also emphasised – in particular, patient-centredness, the accuracy and timeliness of diagnosis, and the need to reduce wasteful practices. The multi-stakeholder perspective also highlights the importance of access to care; health equity; health workforce sustainability; outcomes for carers; and the economic and social benefits of good population health.

The chapter begins by explaining why the concept of value has become central to health policy debates during the past decade. It then explains why health outcomes must be at the centre of any value definition, and how those outcomes can be measured. Finally, it outlines the wider objectives and potential benefits that must form part of a comprehensive definition of value in health systems.

I. Value for money in health spending: the political and economic context

The economic crisis of the late 2000s resulted in a much greater focus on the control of public expenditure, including health spending. With increased pressure on health budgets, the need to ensure value for money became a crucial goal. In 2009, for example, a policy brief by the European Observatory on Health Systems, prepared for the Czech Presidency of the EU conference on ‘The Financial Sustainability of Health Systems in Europe’, argued that: *“Attempting to enhance value by doing more with the resources being devoted to health care ought to be the first choice for government. Because this task involves identifying and addressing underlying inefficiencies, it is most likely to lessen the pressure facing the public budget at the same time as it places the emphasis squarely on improving the health system’s performance”*.⁴ Similarly, an analysis prepared by the OECD Health Division for the 2010 OECD Health Ministerial Meeting argued that: *“getting greater value for money in the longer-run is the biggest challenge facing health systems”*.⁵

While budget deficits and debts continue to act as constraints on public spending overall (particularly within the Euro Area), past experience suggests that there will be ongoing upward pressure on health expenditure. Between 1993 and 2008, for example, total public health spending grew at a faster rate than GDP in almost every OECD country. The main drivers of expenditure growth are ageing

3 For definitions of quality of care, see: OECD, ‘Quality of Care: a process for making strategic choices in health systems’ (2006); E. Kelley & J. Hurst, ‘Health Care Quality Indicators Project: Conceptual Framework Paper’ (2006).

4 S. Thomson et al., ‘Addressing Financial Sustainability in Health Systems’, European Observatory on Health Systems (2009), p.36.

5 OECD, ‘Health System Priorities When Money is Tight’, OECD Health Ministerial Meeting (2010), p.5.



populations, an increasing burden of chronic disease, new technologies, and rising public expectations about how health systems should respond to people's needs.⁶

At European level, the relevance of health spending to the sustainability of public finances has produced a strong focus the 'efficiency' of health spending. The Commission estimates that annual efficiency gains of 0.5% would result in public health expenditure rising to 9.6% of GDP (across the EU), compared with 11.5% without efficiency gains.⁷

This focus on the efficiency of health spending has been reflected in the European Semester process (the EU's annual cycle of economic policy coordination). Numerous EU Member States have received recommendations from the Commission highlighting the need to improve the cost-effectiveness of health spending – for example by strengthening primary care, reducing hospital care, or by investing in prevention.⁸

However, a focus on how health budgets cannot in itself answer the question: is health spending delivering value for money. For that, it is necessary to assess whether, and how far, the fundamental objectives of the health systems are being achieved.

II. Value for money in health systems

The principal aim of health systems is to improve the health and well-being of patients and the population. The WHO Constitution of 1946 famously refers to: "the highest attainable standard of health as a fundamental right of every human being". Good health outcomes are the central goal of health systems, and must therefore be central to any definition of value. For analytical purposes, it is necessary to distinguish between the outcomes of care and public health outcomes.

Health care outcomes

Health care outcomes are changes (be it improvements, no change, or harm) in patient health resulting from treatment and care. Health outcomes include mortality/survival, clinical measurements of treatment effectiveness, and quality of life, often captured through patient-reported outcomes (such as symptoms, pain, mobility, and ability to carry out normal day-to-day activities). Another important source of information on health outcomes is administrative data (for example, hospital admissions and readmissions)

Value can be enhanced by improving outcomes relative to spending, or by reducing spending whilst maintaining the same quality of care (as measured in terms of health outcomes). Chapter 2 will show that there are often wide variations both within countries (for example at the level of hospitals and regions), and between countries with relatively similar income levels and spending on health. This suggest that there is significant potential to improve value by addressing instances of sub-optimal quality of care, and by sharing best practices.

Throughout the value of health initiative, emphasis has been placed on the concept of patient-centred health outcomes. This reflects the idea that the outcomes measured by health care providers should reflect what is important from the patient's perspective. In that context, patient-reported outcome measures have an important role to play.

6 OECD, *Fiscal Sustainability of Health Systems: Bridging Health and Finance Perspectives* (2015).

7 J. Medeiros and C. Schwierz, 'Efficiency estimates of health care systems', European Commission Economic Papers 549 (2015).

8 See N. Azzopardi Muscat et al., 'EU Country Specific Recommendations for health systems in the European Semester process: Trends, discourse and predictors', *Health Policy* 119, 3 (2015).

IN FOCUS: PATIENT-REPORTED OUTCOME MEASURES

Patient-reported outcome measures (PROMs) are standardised instruments used to ascertain patients' perspectives on their health and health-related quality of life. PROMs can be both generic (such as the EQ-5D) and used across multiple conditions, or disease-specific (e.g. the 'Oxford Knee Score' or the 'Burn Specific Health Scale'). By using the same measure (or measures) before treatment and at regular intervals after treatment, the outcome of the intervention can be determined.

Health outcomes captured by PROMs (and depending on the medical condition) include:

- physical functioning / mobility (e.g. walking or cycling)
- symptoms (e.g. pain and fatigue)
- psychological well-being (e.g. anxiety / depression)
- ability to perform usual activities (e.g. shopping/cleaning)
- social well-being (e.g. family, sports)
- health-economic endpoints (e.g. return to work)

Routine use of PROMs as part of clinical care can: enhance patient-clinician communication; improve patients' experience of care; elicit patients' individual priorities, including what is most relevant/important to them at different points in time; facilitate shared decision-making and goal-setting with the care team; and enable patients to better monitor and manage their own conditions.⁹

As Chapter 2 demonstrates, PRO data (as with other types of outcome data), can also be used to analyse variation in the results of treatment and care, and to support continuous improvement initiatives at the clinical level.¹⁰ Aggregate PRO can also be used for performance monitoring and transparency.

Not all PROMs used today were developed with patient involvement – some are legacy measures that were developed for use in clinical trials. For that reason, it is important that the validity of PROMs should be rigorously tested to ensure that the responses genuinely reflect what matters to patients for the relevant medical condition.¹¹

The co-production of new patient-reported outcome measures, reflecting patient-prioritised outcomes, should be based on the active involvement of patients as partners in the PROM development process. 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.¹²

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

10 On continuous improvement, also see P. van der Wees, 'Patient-reported health outcomes after total hip and knee surgery in a Dutch University Hospital Setting: results of twenty years clinical registry', *BMC Musculoskeletal Disorders* 18, 1 (2017).

11 K.L. Haywood, et al. 'Using PROMs in Healthcare: Who Should Be in the Driving Seat – Policy Makers, Health Professionals, Methodologists or Patients?', *The Patient*, 9, 6 (2016).

12 US FDA Guidance on PROMs (2009)



For health outcomes to be comparable, whether at the level of clinicians, providers, or countries (systems), it is important that the same measurement tools are used, and that data collection and coding practices are standardised. A number of organisations are active in developing standard sets of health outcome measures for key medical conditions:

- **The International Consortium for Health Outcome Measurement (ICHOM)** 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.¹³
- **Outcome Measures in Rheumatology (OMERACT)** 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.¹⁴
- 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 the minimum set of outcomes that should be measured and reported (for a given medical condition) in clinical trials. 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.¹⁵

Training and equipping trained medical professionals for quality improvement activities

Medical education often does not include training in quality improvement techniques, which have their origins in other disciplines (notably management). If the benefits of quality improvement methods are to be fully exploited in healthcare, it is crucial that medical professionals are equipped with the knowledge, skills and tools to lead such improvement activities.

Case study I focuses on the RCP Quality Improvement Hub, which was established in 2016 in order to engage doctors in quality improvement work at an early stage in their training, and encourage the use of appropriate data as a driver for that improvement.

13 See for example: R.L. McNamara et al., 'Standardized Outcome Measurement for Patients with Coronary Artery Disease: Consensus from the International Consortium for Health Outcomes Measurement (ICHOM)', *Journal of the American Heart Association* 4, 5 (2015); Wee Loon Ong, 'A Standard Set of Value-Based Patient-Centred Outcomes for Breast Cancer: the International Consortium for Health Outcomes Measurement (ICHOM) initiative', *JAMA Oncology* 3,5, (2017). Also see: <http://www.ichom.org/medical-conditions>

14 See P. Tugwell, 'OMERACT: An international initiative to improve outcome measurement in rheumatology', *Trials* 38, 8 (2007). For further information on OMERACT see: <https://omeract.org>

15 See: 'The Comet Initiative', *BMJ Blogs* (March 2010): <https://blogs.bmj.com/bmj/2010/03/08/the-comet-initiative>. Also: <http://www.comet-initiative.org>

CASE STUDY I

ROYAL COLLEGE OF PHYSICIANS QUALITY IMPROVEMENT HUB

Based on M Choudry, K. Stewart, T. Woodhead, 'The Royal College of Physician's Quality Improvement Hub – how can it help physicians to improve patient care?', Future Healthcare Journal 3, 3 (2016)

In a context of increasingly complex health systems, and ageing populations with multiple needs and morbidities, there is a growing need for clinical leadership in delivering changes to health care processes. However, it is still too rarely the case that doctors are appropriately trained in quality improvement (QI) leadership and management, or in the analysis of health care processes to support QI.

To help address this gap, the Royal College of Physicians (RCP) has established a Quality Improvement Hub. The aim of the Hub is to engage clinicians at an early stage of their training in order to integrate quality improvement methods in their day-to-day working practices, and encourage the use of appropriate data as a driver for that improvement.

By acting as a repository for QI tools, the hub aims to make quality improvement accessible to all doctors. The hub will pool knowledge, including from other systems and organisations, make it available for learning, and seek to encourage a culture of quality improvement among doctors.

Tools and resources already available through the hub include:

- **Healthcare data for quality improvement:** sources of healthcare data that clinicians and their teams can use in QI projects – including information on clinical audits with tools, templates, surveys and outcome measures to assist reporting and improvement.
- **Educational courses** for clinicians and their teams who are interested in learning more about various aspects of quality improvement.
- **Guides, case studies and toolkits** to assist with the planning and implementation of improvements to healthcare services.

Public health outcomes

Public health policy aims to improve the health and well-being of the population as a whole, as well as specific population sub-groups (for example, children, older people, ethnic minorities and other minority groups). This includes policies and interventions designed to promote healthy behaviours, to prevent or delay the onset of ill health, and to protecting people against specific health threats. Public health interventions can take many different forms – for example, vaccination programmes, smoking cessation plans, ensuring safe and hygienic conditions at work, to safe transport, adequate housing, and measures to prevent and alleviate poverty and social exclusion.

Determining value for money in public health spending requires assessments to be made of the effectiveness of public health policies and interventions in relation to the core objectives outlined above. Given that public health policy aims at preventing (or delaying) sickness and ill health, rather than treating and caring for people once they have developed a particular condition or conditions, the



data needed to support and assess public health policy and practice is inevitably different from that used in health care.

Standard population health indicators (such as life expectancy and mortality) are essential, but must be complemented with a broader range of data, including:

- **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

Due to time lags between public health interventions and subsequent changes in public health outcomes (as well as the difficulty in many cases in isolating the specific cause of changes in outcomes) ensuring value for money in public health spending must also include a focus on changes in risk factors (behaviours or activities that increase the likelihood of developing specific health conditions) – such as obesity, smoking, alcohol consumption, and air pollution. Changes in risk factors can be viewed as a form of ‘intermediate outcomes’, as effective interventions should over time lead to improvements in health outcomes.

Health equity

Public health policy also often aims to tackle health inequalities that result from socio-economic differences. For example, differences in life expectancy that are linked to income, education and ethnicity. In this context, specific attention should be paid to population sub-groups (such as children, elderly people, and migrants).¹⁶ Actions to address these health inequalities through public health interventions, including by improving access to care and the equity of access, can make an important contribution to reducing societal inequalities.

Action to address health inequalities requires many policies to be designed and implemented by actors outside the health sector, including youth and education policy (for example, measures to combat child poverty, and providing school counselling services) and environment policy (reducing pollution, providing spaces for recreational activities and sports). Such an intersectorial approach to health is also known as Health in All Policies.¹⁷

III. Additional dimensions of value

Access to care

Universal access to health is a core principle of European health systems, and one of the targets included in Goal 3 (Good Health and Well-Being) of the Sustainable Development Goals – to which all Member States have committed. It has been incorporated in the EU Charter on Fundamental Rights (Article 35), as well as the European Pillar of Social Rights (co-signed by the European Commission, Council, and Parliament in November 2017).¹⁸ Financial barriers which compromise universal access, should therefore be seen as contrary to the objectives of the system, and therefore reducing the value that the system provides.

¹⁶ WHO Europe, ‘Review of social determinants and the health divide in the WHO European Region: final report (2014).

¹⁷ For example, see the Helsinki Statement on Health in All Policies, June 2013:
http://www.who.int/healthpromotion/conferences/8gchp/statement_2013/en

¹⁸ Article 35, Charter on Fundamental Rights of the European Union; for the European Pillar of Social Rights see:
https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights_en

OECD data indicates that, in 2014, most European countries achieved universal or close to universal coverage of health care costs for a core set of services.¹⁹ However, in some countries (for example, Bulgaria, Romania and Greece), the proportion of the population covered was below 90% (in Poland the figure was 91%). Moreover, patient testimony from Member States can result in a less positive picture.

Depth of coverage is critical in this context, and therefore for assessments of value. Services not included in public coverage may need to be purchased through out-of-pocket payments, raising questions both affordability and equity (even if affordable, the cost of paying for additional services may particularly disadvantage groups on lower incomes, and thereby further deepen social inequalities).

Another form of access barrier is waiting times. Waiting times may present a risk to health outcomes if patients do not receive timely treatment and care. In 2018, the British Medical Association warned that significant numbers of patients with severe mental illness were waiting more than six months to access mental health services known as ‘talking therapies’). Such delays increase the risk of self-harm or suicide.²⁰ Another example is waiting times for certain surgical procedures (often referred to as elective surgery), such as joint replacements, which can result in patients experiencing pain and reduced quality of life (including anxiety) for longer than would otherwise have been the case.²¹

Accuracy and timeliness of diagnosis

A 2015 report on ‘Improving Diagnosis in Health Care’ by the US National Academy of Medicine (formerly the Institute of Medicine) showed that that diagnostic errors can be harmful because they ‘prevent or delay appropriate treatment, lead to unnecessary or harmful treatment, or result in psychological or harmful repercussions’. These harms may not necessarily be captured or taken into account in routine health outcome measurement. A patient survey by the European Patients’ Forum in 2016 on how patients see ‘quality’ in healthcare showed that accurate and timely diagnosis is a key priority, and that access to diagnosis was problematic for many.²² For these reasons, accurate and timely diagnosis must be included as an aspect of value in its own right.

The National Academy report defined diagnostic error as the failure to establish an accurate and timely explanation of the patient’s health problem or the failure to communicate that explanation to the patient. A diagnosis is inaccurate if it ‘differs from the true condition a patient has (or does not have) or if it is imprecise and incomplete’.²³ Timely diagnosis is defined in the report as a diagnosis that is not ‘meaningfully delayed’.

Case study II (below) highlights the importance of early diagnosis in relation to ischemic stroke. The case study is taken from the European Brain Council’s ‘The Value of Treatment’ project (for more information see: <http://www.braincouncil.eu/VOTWP>).

19 OECD, *Health at a Glance: Europe 2016 – The State of Health in the EU Cycle* (2016), pp.152-55

20 British Medical Association, ‘The devastating cost of treatment delays’ (February 2018): <https://www.bma.org.uk/news/2018/february/the-devastating-cost-of-treatment-delays>

21 J.P. Oudhoff et al., ‘Waiting for elective general surgery: impact on health related quality of life and psychosocial consequences’, *BMC Public Health* 7 (2007).

22 ‘Patients’ Perceptions of Quality in Healthcare’, report of a survey conducted by EPF in 2016. Published February 2017. Available at <http://www.eu-patient.eu/whatwedo/Policy/quality-of-care>

23 Ibid., p.4.



CASE STUDY II

THE VALUE OF EARLY DIAGNOSIS

Vinciane Quoidbach, *Value of Treatment Project Manager, The European Brain Council*

In June 2017, the European Brain Council (EBC) published the findings of a two-year research project on 'The Value of Treatment' (VoT). The aim of the project was to provide evidence-based policy recommendations for a cost-effective, patient-centred and seamless care model for brain disorders. The project covered nine disorders of the brain, including both mental disorders (schizophrenia) and neurological disorders (Alzheimer's disease, Parkinson's Disease, Multiple Sclerosis, Restless Legs Syndrome, Epilepsy, Normal Pressure Hydrocephalus, Headaches, Stroke).

Value of Treatment built on past EBC research, in particular a study of "The Economic Costs of Brain Disorders in Europe" (Balak N and Elmaci I 2007²⁴), updated in 2010 (Gustavson A et al. 2011²⁵, Olesen J et al. 2012²⁶, Di Luca M et al. 2014²⁷) and conclusions which revealed the escalating costs not only for health systems in Europe but also for society.

The Value of Treatment project's research framework focused on testing an integrated model of care, including the development of a series of qualitative and quantitative benchmarks to identify treatment gaps and causal factors along the continuum of care in a patient care pathway analysis.

VoT also estimated the socio-economic impact and health gains from best practice healthcare interventions using an economic evaluation. The benefits of best practice interventions were compared with the current standard of care or, where appropriate, non-treatment. Comparisons took into account cost burdens (including socio-economic costs) in order to assess value.

Care for brain disorders usually involves multiple specialties and numerous interventions, with final outcomes determined by interventions across the full cycle of care. Measuring, reporting, and comparing outcomes is crucial in order to improve results, and to make informed choices about how to reduce costs.

The case studies were analysed in collaboration with hundreds of experts from EBC's network, and applied empirical evidence from different European countries.

VoT example: improving care for ischemic stroke patients

An illustration of the EBC approach, and one of the VoT case studies, is acute stroke care in stroke units.

Intravenous thrombolysis (IVT) with recombinant tissue plasminogen activator (rt-PA) is one of very few effective treatments for acute ischemic stroke. In most centres, however, only a small proportion (2%–7%) of patients with ischemic stroke receive this treatment.

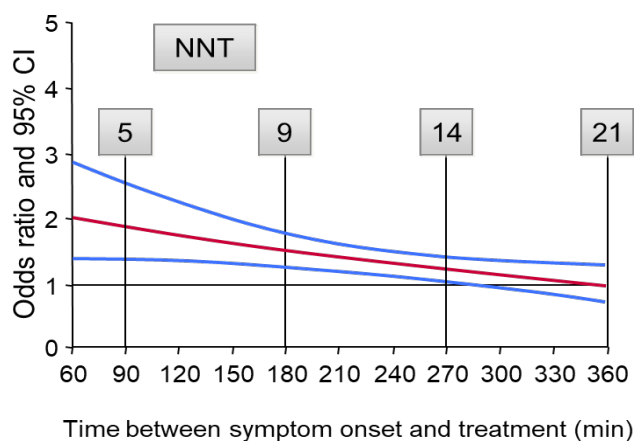
The most important factor limiting IVT administration is time. It has to be administered within 4.5 hours of symptom onset. Even within that window, reducing 'time-to-needle' (the time between symptom onset and IVT administration) can improve functionality and reduce complications.

24 N. Balak, I. Elmaci, 'Cost of disorders of the brain Europe', *European Journal of Neurology* 14, 2 (2007)

25 A. Gustavsson et al. 'Cost of disorders of the brain in Europe 2010' *European Neuropsychopharmacology* 21 (2011), available at <http://www.braincouncil.eu/wp-content/uploads/2015/07/Cost-of-Disorders-of-the-Brain-in-Europe-EurNeuro2011.pdf>

26 J. Olesen et al. *European Journal of Neurology*, 'The economic cost of brain disorders in Europe' 19, 1 (2012) <https://www.ncbi.nlm.nih.gov/pubmed/22175760>

27 M. Di Luca, J. Olesen, 'The cost of brain diseases: a burden or a challenge?' *Neuron*, 82, 6 (2014). Available at <https://www.sciencedirect.com/science/article/pii/S0896627314004887>



Lees KR, Bluhmki E, von Kummer R, et al. Lancet 2010;375:1695-1703

Figure 1: the longer the time between symptom onset and treatment, the larger the number of patients that will need to be treated (NNT) in order to achieve an excellent clinical outcome

- If IVT is started within 90 minutes after stroke onset, the number of patients that need to be treated ('NTT') in order to achieve an excellent clinical outcome (based on modified Rankin scale – a measure of disability and dependence in daily activities) is 5.
- Within the 180–270-minute time window, the number of patients that need to be treated to achieve an excellent outcome increases dramatically – to 14.

Put simply, a shorter delay from symptom to IVT (the so-called symptom-to-needle time) can make the difference between being independent and being dependent. Time is brain, and every minute counts.

Policy implications

Reducing the symptom-to-needle is vital. While most time is lost in the prehospital period (because patients wait before they seek medical attention), awareness campaigns have been found to have only limited impact in addressing this. Inside the hospital, the focus should be on decreasing the time from arrival to IVT administration – the so-called 'door-to-needle time' (DNT).

In most countries, national guidelines recommend that the DNT should not exceed 60 minutes. However, 15 years after IVT was proven to be clinically effective, in most institutions the DNT is still more than 60 minutes for the majority of patients. Reducing DNT will also increase the proportion of patients eligible for IVT, because more patients can be treated within the 4.5-hour time window.

Effective implementation of early diagnosis and treatment for acute stroke care varies widely across health systems and many European countries are still lagging a long way behind, with clinical practice variations even within countries (across Europe, it is estimated that only 30% of patients receive stroke unit care according to SAFE²⁸).

Please see EBC Value of Treatment Policy White Paper at http://www.braincouncil.eu/wp-content/uploads/2017/06/EBC_white_policy_paper_DEF26072017_Low.pdf.

28 Stroke Alliance for Europe, 'The Burden of Stroke in Europe' (2016), available at <http://strokeeurope.eu/report-info/foreword>



Patient centred care

Patient-centred health care is widely recognised as a key dimension of quality in healthcare,²⁹ and one of the central objectives of health care organisation and delivery. Patient-centred can be broadly defined as care that is responsive to individual patient needs, expectations and preferences. Common principles associated with patient-centred care include:

- i. **information** – providing patients (and informal care givers) with information about their condition and prognosis, as well as treatment options and care pathways, so that patients can jointly manage their own condition and participate in decision-making;
- ii. **communication** between patients and care providers in order that can express their individual preferences and concerns;
- iii. **participation** – enabling patients to become active partners in healthcare, in particular through shared decision making.

A definition developed by global patient organisations (IAPO, 2005) outlines the principles of patient-centred care as being:

1. **Respect** for patients' unique needs, preferences, autonomy;
2. **Choice** of appropriate treatment option that best fits patients' needs;
3. **Patient empowerment and involvement** in decisions that concern their health;
4. **Access** to safe, high-quality, appropriate services and support;
5. **Information** that is reliable, relevant and understandable; and
6. **Patient involvement in health policy** to ensure services are designed with the patient at the centre.³⁰

While concepts of patient-centred care have been central to health care reform debates for several decades, there is a recognition that European health systems often fall short of the principles and aspirations with which the term is associated. For example, a 2017 study by National Voices in the UK found that less than half of inpatients said that they did not get enough support to recover or manage their condition after leaving hospital, while just over half (56%) of inpatients said that they were definitely as involved as they wanted to be in decisions about treatments.³¹

Patient-centred care often goes hand-in-hand with the concepts of integrated care and coordination of care.³² Patients frequently have a variety of needs, requiring the involvement of a range of disciplines and specialists – from hospital to community-based care, physiotherapy to psychosocial support. A recent Commonwealth Fund Report by a group of leading international experts ('Designing a High Performing Health Care System for People with Complex Needs'), placed a strong emphasis on the need for care coordination and called for 'paradigm shifts ... away from disease-specific care delivery

29 Quality of Care. A process for making strategic choices in health systems. WHO, 2006. Pp. 9-10. Available at http://www.who.int/management/quality/assurance/QualityCare_B.Def.pdf; Crossing the Quality Chasm: A New Health System for the 21st Century. Institute of Medicine (US) Committee on Quality of Health Care in America, Washington (DC): National Academies Press (US); 2001. Available at <https://www.ncbi.nlm.nih.gov/books/NBK222265>

30 IAPO, Declaration on Patient-Centred Healthcare (2005), available at https://www.iapo.org.uk/sites/default/files/files/IAPO_declaration_ENG_2016.pdf

31 National Voices, 'Person-centred care in 2017: Evidence from Service Users' (2017), p.19.

32 For a patient perspective, see National Voices (2013), 'A Narrative for Person-Centred Coordinated Care', available at <https://www.nationalvoices.org.uk/publications/our-publications/narrative-person-centred-coordinated-care>

and toward more patient-centred approaches, or away from the single-provider model and toward cooperation and teamwork'.³³

Case study III below is based on the Royal College of Physicians' pioneering Future Hospital Programme, which implemented collaborative, coordinated, and patient-centred approaches to care at a range of development sites in England. The model of care was based on the recommendations of RCP's Future Hospital Commission.

CASE STUDY III

THE ROYAL COLLEGE OF PHYSICIANS' FUTURE HOSPITAL PROGRAMME

Based on 'Delivering the Future Hospital' report (November 2017)³⁴

In 2013, the Future Hospital Commission, established by the Royal College of Physicians under the Chairmanship of Sir Michael Rawlins, published a ground-breaking report on the future of hospital care in the NHS. The establishment of the Commission was a response to the increasing pressure on hospitals resulting from ever increasing demand. For example, the preceding decade had seen a 37% rise in emergency admissions alone. Two thirds of those admitted to hospital were over 65, and an increasing number were frail or had a diagnosis for dementia. The starting point for the Future Hospital Commission was to review all aspects of the design and delivery of inpatient hospital care, and to make recommendations to provide patients with safe, high quality care.

The final recommendations were based on principles of collaboration, coordination, and patient-centredness, and set out a new model of hospital care, structured around:

- **A Medical Division:** responsible for all medical services across the hospital
- **An Acute Care Hub** with an acute care coordinator; and
- **A Clinical Coordination Centre** that would act as an 'operational command' for the hospital, including medical teams working in the community.

The Clinical Coordination Centre would hold 'detailed, real-time information on patients' care needs and clinical status, and coordinate staff and services so that they could be met'.

Following the publication of the Future Hospital Commission report, the RCP invested in a three-year Future Hospitals Programme to implement its recommendations at 'development sites', and provide proof of concept through measurable improvements in patient care. The results of this implementation programme were published in late 2017 in **Delivering the Future Hospital**.

Delivering the Future Hospital highlighted a number of important successes, including:

- Patients with frailty who received specialist care in the community experienced fewer emergency hospital visits

³³ The Commonwealth Fund, 'Designing a High Performing Healthcare System for People with Complex Needs: Ten Recommendations for Policy Makers' (2017).

³⁴ Royal College of Physicians, *Delivering the Future Hospital* (2017). Available here:

<https://www.rcplondon.ac.uk/projects/outputs/future-hospital-programme-delivering-future-hospital>



- Patients with respiratory illness experienced longer intervals between emergency admissions once specialist services were integrated
- Frail, older patients given enhanced community assessment, experienced a reduction in hospital admissions due to falls.

As significant as the successes, was the knowledge and learning generated by through implementation project. Three key areas of learning are highlighted below:

1. Patients and carers

From the outset, the Future Hospital Programme (FHP) championed patient involvement. Patients were involved in the design and delivery of all development site improvement projects. While it was recognised that meaningful integration of patient representatives into clinical teams remains a challenge, FHP showed that successful patient involvement in service design and delivery can be achieved by:

- harnessing the individual strengths and skills of patient representatives;
- appointing at least two patient representatives to each clinical team and fostering mutual support and cross cover, to maintain continuity and to obtain a wider viewpoint;
- peer support provided by an organised patient group;
- ensuring that clinical teams continuously reflect on, and refine the role of patient representatives
- identifying a member of the clinical team to act as a main point of contact for patient representatives;
- ensuring that the patient's voice is heard and not marginalised by terminology, clinical decision making, professional relationships and hierarchy.

2. Collaborative Learning

The FHP refined a series of educational and supportive interventions to help individuals and teams successfully implement improvement projects, including:

- fostering a wider community of interest to share best practice and learning;
- building peer support, particularly valued by chief registrars embarking on a unique and new role
- training in improvement methodology;
- training in developing and implementing patient experience data collection and disseminating this to drive improvement.

3. Collect and analyse data on patient care

The FHP provided all development site teams with training and support from experts in quality improvement and data analysis from the outset. These analysts helped to upskill clinical colleagues to utilise data to improve the care delivered to patients. However, there remains limited expertise in the wider NHS in applying 'measurement for improvement'. Action is needed to:

- recruit and upskill data analysts;
- data analysts into clinical teams at the outset of improvement projects;

- support and train clinical teams to ensure the right data are collected, analysed and interpreted to measure the improvement in care sought;
- support clinical teams in collecting and interpreting patient experience data.

Attention is also needed to ensure the focus is on data that captures the true impact of clinically-led improvement, and data that enables clinical teams to improve patient-centred care and outcomes.

These learnings are now being taken forward as part of the Royal College of Physicians' Quality Improvement Programme (see Case Study I).

Case study IV below provides a condition-specific example of a coordinated and patient-centred care – namely, long-term care for people living with HIV. The case study outlines the recommendations of the HIV Outcomes multi-stakeholder initiative, published at the end of 2017. While developed primarily by HIV clinicians, patients and scientific experts, the principles underpinning the recommendations are also highly relevant to other conditions, and in particular to care for people with complex comorbidities.

CASE STUDY IV

INTEGRATED AND PATIENT-CENTRED CARE FOR PEOPLE LIVING WITH HIV

Nikos Dedes, Chair of European AIDS Treatment Group

The last two decades have seen remarkable scientific progress made in understanding and treating HIV, transforming it from a fatal disease into a long-term chronic condition. However, people living with HIV are at higher risk than the general population of developing a number of other serious conditions, and of doing so at an earlier age. These include: cardiovascular diseases, cancers, bone loss, respiratory, renal and liver diseases, mental health conditions, and co-infections such as tuberculosis, hepatitis and sexually-transmitted infections. If these conditions are not properly treated and managed in a timely manner they can greatly complicate HIV care, and have a negative impact on health and health-related quality of life for PLHIV.

Studies in the Netherlands and Italy, for example, have shown that PLHIV have a significantly higher level of comorbidities than demographically similar groups of people without HIV.³⁵ A recent Irish study of PLHIV found that for those with symptoms from HIV and comorbidities, quality of life was impaired. Many PLHIV experience a lack of energy, limited mobility and social isolation.³⁶ A Terrence Higgins Trust report found that older PLHIV were more than three times as likely to experience high levels of loneliness as the general population.³⁷

35 J.V. Lazarus et al. 'Improving Outcomes for People Living with HIV and Fostering Innovative Health System Approaches to Long-Term HIV Care in Europe – Research Report' (2017)

36 G Sherly et al., 'Health-related quality of life and associated factors in people with HIV: an Irish cohort study' (2016) Health and Quality of Life Outcomes (2016)

37 Terrence Higgins Trust, 'Uncharted Territory, A report into the first generation growing older with HIV' (2017)



People living with HIV therefore require access to a range of health services beyond just their HIV treatment. This includes services for: prevention, treatment and management of comorbidities; mental health and neurocognitive impairment; and advice and support in relation to sexual and reproductive health. Such multidisciplinary, multi-specialist care requires systematic coordination and a personalised approach – not only to ensure that all relevant services are provided, but also streamline service provision, ensure patient-safety, and to enable effective communication between the different care providers involved.

In 2017, a group of stakeholders from across the HIV community (patients, clinicians, public health practitioners, industry, and academic experts) launched recommendations on long-term health, well-being and chronic care for people living with HIV. This included five recommendations as part of an **integrated and patient-centred approach to long-term care**.³⁸

1. Place comorbidity prevention, treatment and management at the centre of long-term HIV care

Prevention, diagnosis, treatment and ongoing management of comorbidities should therefore be core components of long-term care for all PLHIV – including through public health interventions (encouraging beneficial steps such as a healthy diet and exercise), and routine screening.

2. Coordinate care using a personalised care plan

For each person diagnosed with HIV, there should be a designated healthcare professional responsible for coordinating that person's care and ensuring efficient communication between the different disciplines and specialists involved. The care plan should be developed in partnership with the patient and be regularly reviewed and updated in light of that person's changing needs.

3. Integrate services for mental health and neurocognitive impairment

Mental health issues, such as depression, and neurocognitive impairment are prominent among PLHIV. These conditions impact upon individuals' energy levels, mood, and ability to perform daily life activities and engage in social relationships. They can add significantly to the burden of living with HIV and severely compromise health-related quality of life.

4. Ensure an ongoing focus on sexual and reproductive health

Access to accurate information and advice on HIV transmission and methods of contraception should be complemented with services relating to conception, childbirth, and parenting options available for all. PLHIV should have access to regular sexual health assessments, as well as counselling and support services that are sensitive to the particular needs of individuals in different population groups.

5. Increase systematic participation of PLHIV in decisions about their care

Decision aids explaining the advantages and disadvantages of different treatment options can empower PLHIV to discuss these options with care providers, and make informed choices in the light of personal circumstances.

³⁸ See HIV Outcomes recommendations here:

<http://www.hivoutcomes.eu/recommendations/adopt-an-integrated-outcomes-focused-and-patient-centred-approach-to-long-term-hiv-care>

Patient involvement in quality improvement

Case study V below from Uppsala University Hospital shows how patients can be included in continuous improvement activities. Specifically, at Uppsala patients are invited to participate in the review data on outcomes and experiences with clinical teams. The aim is to support the identification of improvements to care pathways that will deliver benefits from the patient perspective. Health outcome and patient experience measures are used at the start and the end of the improvement cycles – at the beginning to help identify what improvements are needed, and at the end to evaluate the impact of the changes made.

CASE STUDY V

CONTINUOUS IMPROVEMENT AND PATIENT INVOLVEMENT AT UPPSALA UNIVERSITY HOSPITAL, AKADEMISKA SJUKHUSET

Morten Kildal, Strategic lead, Value Based Healthcare at Uppsala University Hospital

Uppsala University Hospital is a teaching hospital and one of Sweden's four largest hospitals with a primary catchment area of 350,000 people, providing highly specialised care to 2.1 million people. It has 8500 employees and cooperates closely with 13 other local hospitals.

Uppsala has adopted a value based health care approach, gradually increasing the number of involved diagnostic groups. Presently there are 43 groups, including areas such as burn care, diabetes, heart failure, stroke, maternity care, three areas of psychiatric care and 32 care pathways for specific cancer diagnoses. This is only part of the total number of diagnostic groups at a university hospital, and the diagnostic groups are at different levels of adopting value based care.

Continuous improvement at Uppsala is divided into two domains:

- i. Quality of care:** improving medical results through the analysis of patient-centred quality data - including health outcome data.
- ii. Patient flow:** improving continuity of care, patient centredness, patient safety, and efficiency.

At the centre of Uppsala's approach to continuous improvement is patient involvement, as part of the care team, in the improvement activities.

Collection of health outcomes and patient experience data is just the beginning of that process. The next challenge is to identify what changes need to be made to existing processes in order to: achieve the desired improvements; monitor the outcome of these improvements; and make further adjustments when necessary.

The base of the improvement methods is the classical improvement cycle of Deming: Plan-Do-Study-Act. Improvement methods are therefore not specific for value based health care, but rather based on previous and present experiences and knowledge of improvement work.



At the core of the value based approach is a specific focus on patient relevant outcomes, patient engagement in improvement work, and interprofessional teams working together to identify and implement improvements.

Patient representatives participate in meetings, with the care team, to review the health outcomes, experiences and processes, and to identify potential changes to the care pathway for that specific patient group. They are considered as experts among other health care experts. For example, they are experts on their own disease, and the experience of their own patient pathway – meeting with health care workers in different departments and health care institutions.

Working in this way, it also becomes possible to determine whether the patient outcome and experience data is itself appropriate and of sufficient quality to underpin improvement decisions. If it is not, as is often the case today, care teams work with registries to produce higher quality data that they can rely on for this improvement work.

Once changes/adaptations to care processes and pathways have been introduced, it is critical that they are followed up and that the impacts and benefits of those changes are assessed. In addition to daily steering rounds, many of the care teams at Uppsala hold short weekly meetings to analyse quality data – focusing on questions such as:

- What are the outcomes of care and how are they developing?
- Did the patients have a good or a bad experience?
- Did the patient feel pain or anxiety?
- What worked well?
- Could we do something different and better tomorrow?

Health outcome and experience measures thus form part of a continuous improvement loop: they are used to identify improvement needs, to assess the impact of any changes made, and then again to identify further opportunities for improvement.

A focus area in the coming work at the Uppsala University Hospital is to further develop the ways that patient representatives are engaged in improvement work – for example, by designing the care pathways together with the care teams, and in evaluating outcomes.

Engaging patient representatives in the care teams and the use of patient reported outcomes as we do today should be only one part of patient engagement. With increasing demands from well informed patients we need to discuss new approaches such as: increasing the use of patient focus groups; the use of principles of service design when improving care paths; engaging local patient organisations on a regular, structured basis; and consideration of how to include patient representatives and patient perspectives in management. So the work at Uppsala University Hospital is still very much a continuous “work in progress”.

Reducing waste and low value care

Ensuring value for money also means reducing wasteful practices, such as care that does not deliver benefits for patients (or may even cause harm) or the use of more expensive interventions when cheaper, equally suitable alternatives are available – thereby improving resource allocation within the health system.

In its 2017 report 'Tackling Wasteful Spending on Health', the OECD highlighted the following types of waste:

- **Clinical waste:** repeated diagnostic tests or services (due to lack of information sharing); use of ineffective interventions, interventions which only work for some groups of patients, or which the patient may not have wanted had they been informed about the likely effects; serious complications which could have been avoided;
- **Operational waste:** use of branded pharmaceuticals when generic alternatives are available; overuse of hospital care
- **Governance related waste:** high administrative costs, fraud and corruption.³⁹

The provision of care that is either unnecessary, or for which cheaper alternatives may be available, is also known as **low value care**. This is illustrated in the case study below by the European Collaboration for Healthcare Optimization (ECHO), focusing on the use of caesarean section (C-section) for low risk births.

C-Sections for low risk births entail health risks for both mother and baby (including unavoidable surgery risk for the mother) and are more expensive than normal deliveries. Clinical guidelines recommend C-section use only in cases of need. The use of C-section for low-risk births is therefore considered a form of low value care.

CASE STUDY VI

C-SECTIONS IN LOW-RISK DELIVERIES: IDENTIFYING LOW VALUE CARE

Enrique Bernal-Delgado and Sandra García-Armesto on behalf of the ECHO consortium⁴⁰

Uppsala University Hospital is a teaching hospital and one of Sweden's four largest hospitals with a primary catchment area of 350,000 people, providing highly specialised care to 2.1 million people. It has 8500 employees and cooperates closely with 13 other local hospitals.

The ECHO (European Collaboration for Healthcare Optimization) Project has its origins in the year 2002 in Spain with the 'Atlas VPM Project'. Atlas VPM was a nationwide Health Services Research Program focusing on the analysis of unwarranted variations in medical practice and healthcare outcomes in

39 OECD. Tackling Wasteful Spending on Health (2017). Also see the 'Choosing Wisely' initiative: <http://www.choosingwisely.org>

40 See García-Armesto S, Angulo-Pueyo E, Martínez-Lizaga N, Mateus C, Joaquim I, Bernal-Delgado E; ECHO Consortium. 'Potential of geographical variation analysis for realigning providers to value-based care. ECHO case study on lower-value indications of C-section in five European countries'. Eur J Public Health. 2015 Feb; 25 Suppl 1:44-51

Spain. The aim was to compare healthcare geographically – region by region – and to provide powerful feedback to policy decision-makers and managers across the country.

The ECHO project aimed to build upon the Atlas VPM experience by conducting a similar project on a European scale. ECHO was an effort to bring together national hospital databases in several European countries, supported by a European Union FP7 research grant.

In this case study, the ECHO project set out to answer the following questions: are pregnant women treated differently depending on their place of residence? What are the excess cases of C-section that could be avoided without risking maternal health?

Objective & methods

To map areas showing excess-usage of low value C-sections (C-sections for low risk deliveries) and to estimate excess-expenditure as a proxy of the opportunity costs borne by health care systems. 1.2 million deliveries were allocated to the 913 health areas composing five health care systems in Europe. Unwarranted variation in C-section rates in low-risk deliveries and consequent excess-cases were elicited, taking best performers as a reference.

Findings

- Cross-country comparison of lower-value C-section leaves Denmark with 10% and Portugal with 2% (the highest and lowest rates).
- Variation within countries ranged from:
 - Denmark: 3.2-fold variation
 - Spain: 41-fold variation
- Such behaviour was stable over the period of analysis.
- Within each country, the scattered geographical patterns of use intensity speak for local drivers playing a major role within the national trend (see Figure 3).

Policy lessons

The analysis indicates that there is significant scope for enhancing value (and reducing waste) in obstetric care, and improving equity in women's access to high value care. Comparing decision-making and pathways of care between high and low performers may be a powerful driver for improvement.

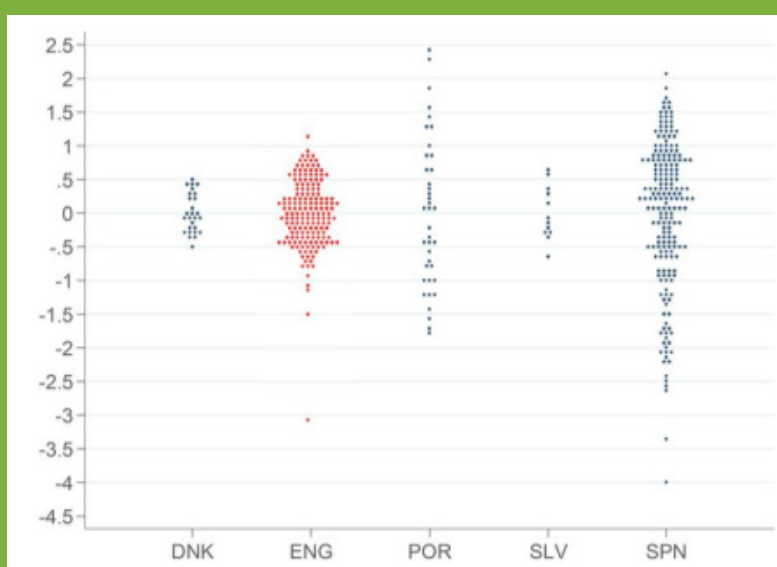


Figure 2: C-section in low risk deliveries
Variation between areas (represented by dots)

Case study VII presents the 'To Do or Not to Do' project in the Netherlands which aims to identify and reduce low value care. The project was based on a two-step process: first, the development of a list of low value interventions; second, the identification of strategies to 'de-adopt' low value practices.

CASE STUDY VII

IDENTIFYING AND DE-ADOPTING LOW VALUE CARE IN THE NETHERLANDS

Simone van Dulmen and Tijn Kool, Radboud University Medical Centre, The Netherlands

Overuse of unnecessary care is widespread around the world. Low value care provides minimal or no benefit for patients, but wastes limited resources and may cause physical, psychological and financial harm to patients.⁴¹ Estimates of the proportion of health care that is unnecessary or potentially harmful range from 10% to 30%.⁴²

There is an increasing number of initiatives around the world that aim to identify and reduce low value care, the largest of them being Choosing Wisely.⁴³ The UK's National Institute for Health and Care Excellence (NICE) started working on de-adoption of low value care in 2005,⁴⁴ and Australian activities are centred on the Medicare Benefits Schedule.

This case study focuses on the development of a do-not-do-list in the Netherlands, which formed part of a broader, nationwide program entitled: 'To do or not to do. Reducing low value care'. The program aims at identifying low value care practices and learning how to de-implement them (<https://www.doenoflaten.nl/en/>).

The first step is the development of a do-not-do list. A second step involves identification of strategies to reduce low value care. In 2016, eight programs were launched to de-adopt low value practices. (see box 2).

Step 1: Developing the do-not-do list

The basis of de-adoption programs is usually a (long) list of lower value services and sometimes a prioritization process to identify candidate practices for de-adoption. The methods for creating these lists are diverse, and prioritization based on impact often proves difficult.

A prominent problem in overuse is that interventions which are high-value for a specific subpopulation are inappropriately applied to other populations.⁴⁵ Prioritization of low value services for de-adoption for specific subgroups is warranted and there is need for an objective approach to identify and prioritize low value services for practical de-adoption.

In the Netherlands, potential low value care interventions are identified by listing explicit do-not-do recommendations in clinical guidelines. In 2016, a list was developed based on do-not-do

41 S. Brownlee, K. Chalkidou, J. Doust, et al. 'Evidence for overuse of medical services around the world', *Lancet* 390 (2017)

42 C.H. Colla, A.J. Mainor, C. Hargreaves, T. Sequist, N. Morden, 'Interventions Aimed at Reducing Use of Low Value Health Services: A Systematic Review. *Medical care research and review*', MCCR (2016); R. Grol, J. Grimshaw, 'From best evidence to best practice: effective implementation of change in patients' care', *Lancet* (2003); D.J. Morgan, S. Brownlee, A.L. Leppin, et al., 'Setting a research agenda for medical overuse', *BMJ* (2015).

43 W. Levinson, M. Kallewaard, R.S. Bhatia, et al., 'Choosing Wisely': a growing international campaign. *BMJ Quality & Safety* 24, 2 (2015)

44 S. Garner, P. Littlejohns, 'Disinvestment from low value clinical interventions: NICEly done?', *BMJ* (2011); G. MacKean, et al. 'Health technology reassessment: the art of the possible', *International Journal of Technology Assessment in Health Care*, 29, 4, (2013).

45 I.A. Scott, A.G. Elshaug, 'Foregoing low value care: how much evidence is needed to change beliefs?' *Internal Medicine Journal*, 43, 2 (2013).



Box 2: Eight de-adoption programs in The Netherlands

- Inappropriate prescribing of inhaled corticosteroids for patients with mild COPD
- Surveillance CT scans in asymptomatic patients after treatment for lymphoma
- Knee arthroscopies and MRIs for patients with orthopedic conditions older than 50 years
- Inappropriate use of intravenous and urinary catheters
- Vitamin D and B12 tests within general practice
- Inappropriate diagnostic testing by internal medicine doctors
- Inappropriate gastroscopies for patients who are dyspeptic
- Surveillance visits after treatment for basal cell carcinoma.

recommendations from 193 Dutch medical specialist clinical practice guidelines. The aim was to provide a comprehensive list of potential low value services in Dutch hospital care.

A total of 1366 lower value services were found in the 193 Dutch guidelines.⁴⁶ Of the lower value services, 30% covered diagnostics, 29% were related to surgical and medical treatment without drugs, and 39% were related to medication treatment. The majority (77%) of all low value services concerned care that should not be offered at all, whereas the other 23% concerned care that should not be offered routinely.

Figure 4 shows low value services in Dutch and UK guidelines categorized by International Classification of Diseases (ICD 10) chapters. In the Netherlands, the largest number of identified low value services related to neoplasms and diseases of the nervous system. In the NICE do-not-do list the largest number of low value services identified related to diseases of the nervous system and mental behavioural disorders.⁴⁷

The prioritization processes revealed several health conditions, including back pain, chronic obstructive pulmonary disease, and ischemic heart diseases, where low value services most likely occur, and de-adoption is warranted. The next step is that the professional societies, the Dutch Federation of Medical Specialist and the Dutch Medical Specialist Societies, are working on more detailed specification of the list focusing on the strength of the evidence of the do-not-do recommendations, and defining clear target patient groups, in order to measure the volume of low value care and developing tailor-made de-adoption programs.

Step 2: de-adoption of low value care

De-adoption is often hampered by implementation barriers. These often exist at different levels, and there is limited knowledge about which interventions to stimulate de-adoption are most successful.

To support the Dutch program, two literature reviews were conducted to gain more knowledge about barriers and facilitators in reducing unnecessary care and the strategies that are used. The results of these studies can help healthcare professionals and policymakers in developing, implementing and evaluating a de-adoption project.

46 J.J.G. Wammes, M.E. van den Akker-van Marle, E.W. Verkerk, S.a. van Dulmen, G.P. Westert, A.D.I. van Asselt en R.B. Kool, 'Identifying and prioritizing lower value services from Dutch specialist guidelines and a comparison with the UK do-not-do list', *BMC Medicine*, 14, 196 (2016).

47 NICE, Do-not-do webpage. <https://www.nice.org.uk/savingsandproductivity/collection>

The first literature review focused on barriers and facilitators for continuation of low value care or de-adoption. Key factors influencing the success of de-implementation were found to include:

- patient-provider communication
- the attitude of individual healthcare providers and team towards the project
- medical leadership
- fear of litigation or criticism
- changing of habits or routines in clinical practice
- continued reimbursement for low value care

The second literature review was aimed at assessing to what extent de-adoption strategies can reduce low value care and what strategies are used. Overall, de-adoption strategies reduced the proportion of low value care with a median of 15%. Many different (combinations of) interventions are used on different levels (patient, healthcare provider, organisation and system), such as education, audit and feedback, reminders, organisational or financial interventions.

The majority of the de-adoption studies were successful and there was no intervention superior compared to others. Multifaceted strategies involving multiple targets seems to be more effective than single intervention strategies; hereby not only targeting healthcare providers, but also patients and the organisational context.

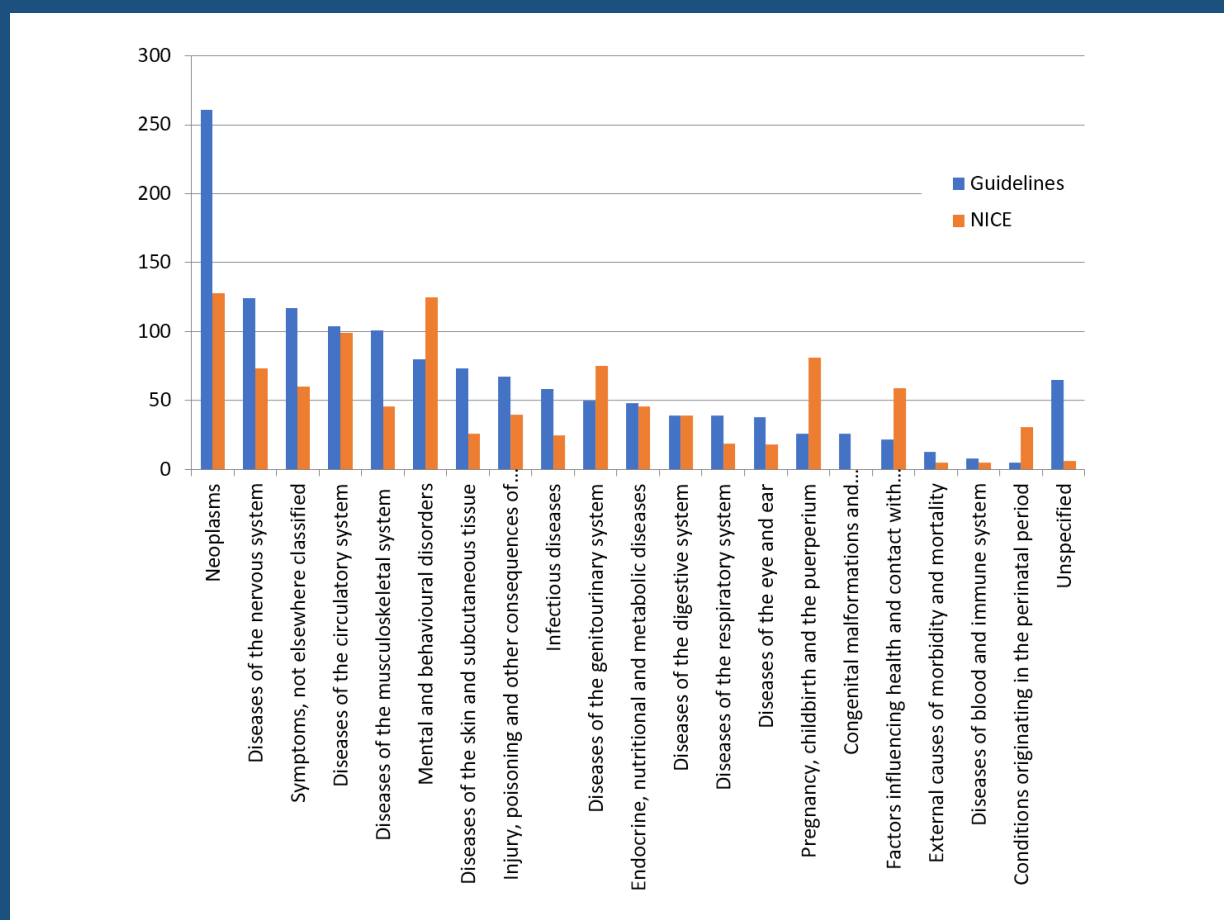


Figure 3: Number of lower-value services per ICD-10 group for Dutch guidelines and NICE do-not-do list



Health workforce and carers

Sustainability of health workforce

The focus up to this point has been on value from the perspective of those who use / benefit from health services. To ensure quality of care, over the medium and long-term, value for money assessments must also take into account care providers. In this respect, two aspects are highlighted below: i. health workforce skills and sustainability; and ii. the impact of care provision on informal carers.

Developing and maintaining a health workforce that is appropriate to the needs of the population requires planning, policies to ensure that doctors, nurses, and other practitioners are educated to meet current and future needs, and are managed in a way that avoids placing excessive demands on individuals.⁴⁸ Poor management of the health workforce may lead to shortages (problems retaining staff), health impacts as a result of stress and burnout.

In some countries, the International mobility of the health workforce has led to a 'brain drain', with medical professions trained in their native country finding employment in systems with better salaries and conditions. This may act as a disincentive for both host and source countries to invest in the future health workforce.⁴⁹ Ensuring value for money in health spending should encompass measures to ensure that the health workforce is appropriately educated and can be retained.⁵⁰

Outcomes for informal carers

The physical, psychological, economic and social impacts of informal care are also an often overlooked aspect of health system performance. Informal carers, often family members or friends, may devote significant time and resources to looking after someone that is unwell. They may give up regular employment in order to do so, while the psychological impact of ongoing care and reduced social interactions may impact negatively on carers own health and well-being.⁵¹

Value for money will not be attained if, as a consequence of the burden of care, informal carers themselves become unwell. This consideration is increasingly important in a context of ageing populations with rising levels of chronic disease and comorbidity. Furthermore, in dementia there is a clear association between the burden experienced by informal carers and the likelihood that the dementia sufferer will be moved to institutionalised care – entailing significant costs for the formal care system.⁵²

Informal carer-reported outcomes are one tool for assessing the impact of health care provision on those providing informal care. Outcome measures for caregivers fall into the following broad categories:

- Burden: the carers' physical health, finances, and impact on personal life
- Mood: whether the carer experiences anxiety or depression

48 See EU Joint Action on Health Workforce Planning and Forecasting: <http://healthworkforce.eu>

49 See WHO Europe, 'Towards a sustainable health workforce in the WHO European Region: framework for action', 11-14 September 2017: http://www.euro.who.int/__data/assets/pdf_file/0011/343946/67wd10e_HRH_Framework_170677.pdf?ua=1

50 I. Portoghesi et al., 'Burnout and Workload Among Health Care Workers: The Moderating Role of Job Control', *Safety and Health at Work* 5, 3 (2014)

51 See for example: M.F. Bevans, E.M. Sternberg, 'Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients', *JAMA*, 4, 307 (2012); V. Lambert-Obry, 'Real-world patient- and caregiver-reported outcomes in advanced breast cancer', *Current Oncology*, 25, 4 (2018)

52 C. Jones, 'Health economics research into supporting carers of people with dementia: A systematic review of outcome measures', *Health and Quality of Life Outcomes* 10, 142 (2012); J. La Fontaine et al., 'The experiences, needs and outcomes for carers of people with dementia', Association for Dementia Studies, https://www.dora.dmu.ac.uk/bitstream/handle/2086/14058/RSAS%20Worcester%20li%20terature%20review_08.04.16.pdf?sequence=1&isAllowed=y

- Mastery: the satisfaction of the carer with their own performance
- Generic quality of life measures.

The economic and social benefits of good health

The third dimension of value in relation to health spending is the economic and social benefits generated by improved health and well-being. The economic and social benefits of health spending can primarily be understood in relation to the following categories: employment (or workforce participation), productivity, poverty reduction, social inclusion. Each of these categories is discussed in further detail below.⁵³

Employment, productivity and longer working lives

Many people living with chronic diseases experience difficulties in staying in employment, or returning to work after having a period of treatment. They also often report experiencing discrimination and stigma. For young patients, being able to complete their education provides similar hurdles, with potentially severe impact on their lives.⁵⁴

Among older workers, health status and major health-related events, such as a heart attack or stroke, will be determinants of labour market participation and decisions about when to retire. Research suggests that people in poor health are likely to retire between 1 and 3 years earlier than people in good health.

Sickness related absences can also impose significant costs on firms. In the UK, for example, 137.3 million working days were lost due to sickness or injury in 2016. Minor illnesses (such as coughs and colds) were the most common cause, representing 24.8% of the total days lost. This was followed by musculoskeletal problems, including back pain, neck and upper limb problems at 22.4% (30.8 million days lost). Mental health issues, including stress, depression, anxiety, accounted for 15.8 million days lost (11.5%).⁵⁵

Health status and health-related behaviours are clearly associated with higher rates of sickness absence: the sickness absence rate among those with long-term health conditions was 4.4%, compared with 1.2% for those without; among smokers, the sickness absence rate was 2.5% compared with 1.6% for people who have never smoked. In addition, the sickness absence rate among those aged over 65 was twice that of people under 34 (2.9% compared with 1.5%).⁵⁶

The cost of exclusion from the workforce of people with partial capacity has a serious impact on public expenditure. In some countries, expenditure on disability benefits is more than 2.5 times what is spent on unemployment benefits.

53 For an introduction to this topic, see: J. Figueras and M. McKee, 'Health Systems, Health, Wealth and Societal Well-being, Assessing the case for investing in health systems' (2012).

54 European Patients' Forum position paper 'Equal treatment for patients in education and employment. Tackling discrimination in education and in the workplace' (2015), available at http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf

55 European Patients' Forum position paper 'Equal treatment for patients in education and employment. Tackling discrimination in education and in the workplace' (2015), available at http://www.eu-patient.eu/globalassets/policy/anti-discrimination/epf-position-paper_equal-treatment-in-education-and-employment.pdf

56 Ibid.



Poverty and social exclusion

The European Commission's 2016 Annual Growth Survey stated that 'protecting the population from falling into poverty or social exclusion due to ill-health and related expenditure is essential'.⁵⁷ In 2013, a Commission staff working document entitled 'Investing in Health' also argued that 'healthcare plays a significant role in reducing the at-risk-of-poverty rate'.⁵⁸

Disability and ill-health are both a cause and consequence of poverty. Having one or more chronic conditions means people are at higher risk of reduced income, social exclusion and poverty.⁵⁹ On average the incomes of people with disabilities are 12% lower than the rest of the population. In some countries, the incomes can be as much as 30% less.⁶⁰

Universal healthcare coverage reduces the risk that people will fall into hardship as a result of healthcare costs (or forgo healthcare on cost grounds). Informal carers (such as family members) tend to work less, are more likely to be at risk of poverty, and may experience ill health as a result of the burden of care.⁶¹

57 European Commission, 'Annual Growth Survey 2016' (November 2015)

58 European Commission, 'Investing in Health', Commission Staff Working Document (February 2013)

59 J. Arsenijevic et al., 'Catastrophic Health Care Expenditure among Older People with Chronic Diseases in 15 European Countries', PLOS One (2016), available at <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0157765>

60 OECD, 'Sickness, Disability and Work: Keeping on Track in the Economic Downturn', Background Paper (2009), available at <https://www.oecd.org/els/emp/42699911.pdf>

61 Ibid., p.12.; OECD, 'The Impact of Caring on Family Carers', 2011

Enhancing value through health outcomes data: methods and benefits

This chapter focuses on how health outcomes data can be used to improve quality of care and public health policy, and thereby strengthen value for money within health systems. It highlights five main ways in which outcomes data can be used for this purpose:

- i. learning from health outcomes variation (e.g. between hospitals, regions, and countries);
- ii. continuous improvement at the clinical level
- iii. improving the effectiveness of public health interventions
- iv. performance monitoring and transparency
- v. supporting the implementation of integrated care

The chapter features a series of case studies based on presentations that have been given to Value of Health multi-stakeholder roundtables, including: the European Collaboration for Healthcare Optimization, the International Cancer Benchmarking Partnership, Northumbria NHS Health Care Foundation True, the International Consortium for Health Outcomes Measurement, and the Catalan Health System Observatory.

I. Learning from variation

Summary

- The analysis of health outcomes variation can be a powerful tool for quality improvement.
- If the factors driving the variation can be identified, that knowledge can be used to improve quality – in particular by sharing best practices and by further investigating cases of potentially low or sub-optimal care.
- Standardised measurements, data collection and coding, and case-mix adjustment, are all pre-requisites for successful variation analysis.

Introduction

In health care, the term ‘variation’ is used to refer to differences in the way that treatment and care is organised and delivered, as well as differences in patient outcomes. The concept has its origins in John Wennberg’s work in the 1960s on US Medicare data. In recent decades, ‘atlases’ of variation have become a popular tool for illustrating geographic differences. Most atlases focus primarily on clinical practice variation (where data is more readily available), which can be used to indicate instances of ‘underuse’ and ‘overuse’ of health care resources (or ‘low value’ care).⁶² To date, there has been relatively less focus on variation in health outcomes.

⁶² OECD, ‘Geographic Variations in Health Care: What do we know and what can be done to improve health system performance?’ (2014)



Clinical practice variation

Some variation in clinical practices will always be inevitable, and indeed may be desirable if care providers and medical professionals are to have the opportunity to innovate and adjust practices to improve outcomes. However, where clinical practice variation is significant and systematic, it may reflect sub-optimal care in some cases. Some of the drivers of clinical practice variation include:

- differences in medical training and traditions of care (especially important between countries);
- differing levels of adherence to clinical guidelines;
- quality improvement initiatives leading to new approaches and practices;
- specialised and integrated services may result in higher quality care;
- incentives (e.g. payment and reimbursement models);
- changes in the underlying patient population (sub-groups).

Health outcomes variation

Health outcomes variation refers to differences in the impact of treatment and care on the health and well-being of patients. Variation in outcomes will often be due to differences in clinical practice, but may also be due factors such as access to care (for example, waiting times and proximity to health services) and patient behaviours (such as adherence). If the data is not risk-adjusted, it can also reflect differences in patient characteristics (such as age and prevalence of comorbidities).

If the factors contributing to health outcomes variation can be successfully identified, that knowledge can in turn be used to improve quality of care across providers, and even countries. Even where the causes of the variation cannot be readily ascertained, awareness of variation can trigger deeper investigations and research that may in time lead to improvements.

Case mix adjustment is a pre-requisite to successful variation analysis. It is used to take account of differences in patient characteristics (such as age, gender, co-morbidities, disease severity, and lifestyle factors). If the data were not adjusted, it would not be possible to differentiate between variation caused by patient characteristics, and variation caused by differences in clinical practices or access to care.

To illustrate the potential benefits of health outcomes variation analysis as a tool for learning and improvement, two case studies are provided below.

1. European Collaboration for Healthcare Optimization (ECHO)

Case study VIII focuses on the relationship between mortality rates following coronary artery bypass graft (CABG) surgery and 'surgical volume':

- Based on data from five countries, mortality was found to be significantly higher among 'low' volume hospitals (as compared with 'high' volume hospitals).
- In England, where a policy decision had already been taken to concentrate CABG provision, mortality rates were lower and the variation between hospitals was smaller.
- Based on these findings, ECHO recommended that CABG provision should be concentrated (or 'regionalised') with a view to improving outcomes.

2. International Cancer Benchmarking Partnership (ICBP)

Case study IX is provided by the International Cancer Benchmarking Partnership. It shows how an initial benchmarking of cancer survival (across countries) has provided a basis for deeper investigation into the drivers of variation.

- The initial benchmarking exercise (covering data from the years 1995–2007) found that overall survival for breast, colorectal, lung and ovarian cancer patients was:
 - higher in Australia, Canada and Sweden, and intermediate in Norway
 - lower in England, Northern Ireland, Wales and Denmark
- ICBP findings to date suggest that variation in cancer outcomes may be due to factors such as access to diagnostic tests and the organisation of treatment services.
- These findings have provided supporting evidence for changes in cancer policy, including initiatives aiming to address barriers to help-seeking and to introduce innovative diagnostic referral pathways.

CASE STUDY VIII

THE EUROPEAN COLLABORATION FOR HEALTHCARE OPTIMIZATION

Enrique Bernal-Delgado and Sandra García-Armesto on behalf of the ECHO consortium⁶³

ECHO uses a broad definition of ‘outcomes’, namely: the effect of care interventions on clinical, patient-centric, and economic outcomes – both at the patient and population level. This definition is used to analyse performance in five European health systems: Denmark, England, Portugal, Slovenia and Spain. The unit of analysis in ECHO is not the individual but the institution or care system in which the patient is treated.

Using real world data, including hospital discharges, demographic and socioeconomic data, ECHO was able to show significant variation in outcomes within and across health care systems. The example below focuses on hospital mortality after coronary artery by-pass (CABG), and shows systematic and unwarranted variation in low-quality care.

In-hospital mortality after coronary artery by-pass graft (CABG)

The objective of the analysis was to determine whether health outcomes may be dependent on the place where the patient is treated, and in particular whether ‘surgical volume’ is a factor that might help to improve outcomes. To estimate a safe minimum volume for hospitals performing coronary artery bypass graft (CABG) surgery, ECHO used hospital data on all publicly funded CABG in five European countries (2007–2009).

⁶³ Also see N. Gutacker, K. Bloor, R. Cookson, C.P. Gale, A. Maynard, D. Pagano, J. Pomar, E. Bernal-Delgado, ‘Hospital surgical volumes and mortality after coronary artery bypass grafting: using international comparisons to determine a safe threshold’. *Health Services Research*, 52, 2 (2017).

Findings

The 30-day in-hospital mortality rate was

- Overall: 3.0% overall
- Low-volume hospitals: 5.2% (95%CI: 4.0–6.4)
- High volume hospitals: 2.1% (95%CI: 1.8–2.3)

There is a significant curvilinear relationship between volume and mortality, flatter above 415 cases per hospital per year.

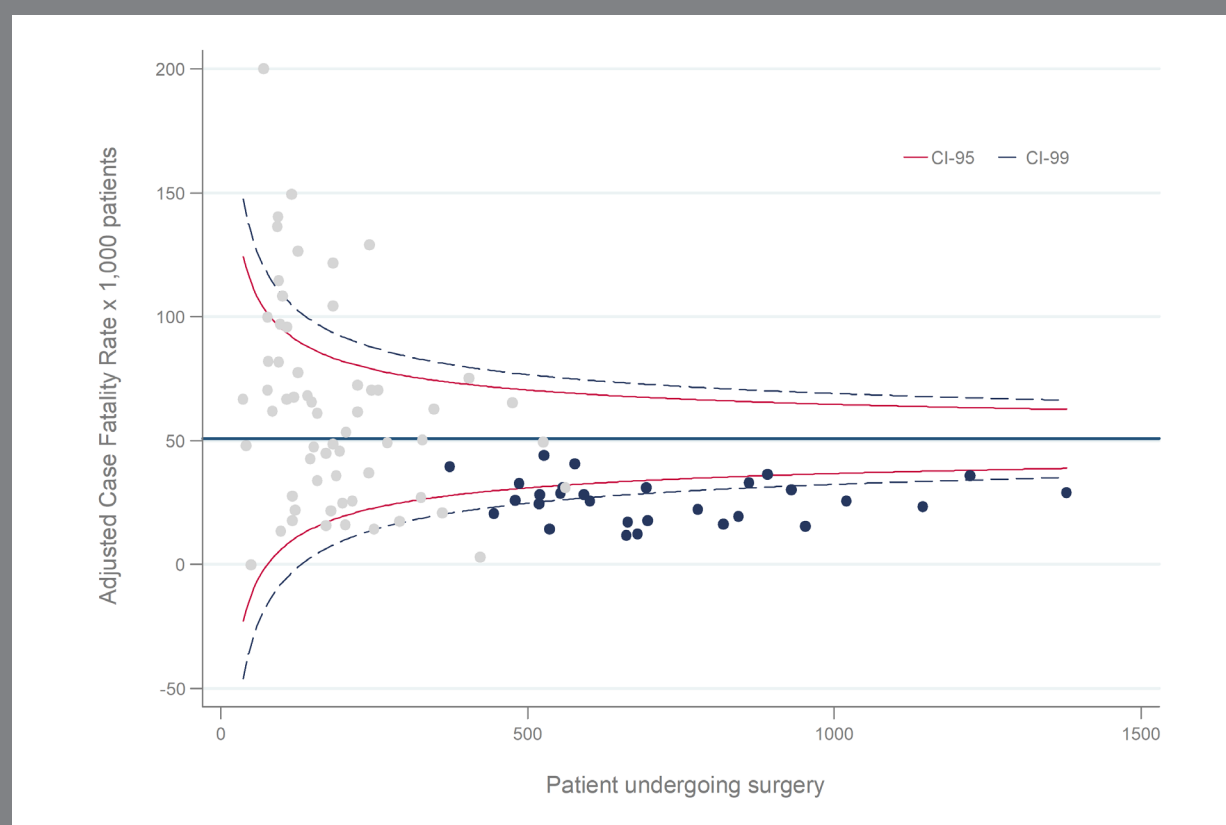


Figure 4: Mortality after CABG: Spanish (grey) and UK (blue) hospitals

Policy lessons

The provision of CABG should be regionalized to improve results. As CABG utilization is steadily decreasing (but remains the superior treatment for multi vessel coronary disease), the number of hospitals performing it above the safety threshold is also reducing. The concentration of interventions in a fewer number of centres should become the rule in the upcoming decades.

A broader finding from the ECHO project was that, within Europe, there is an uneven interest in the secondary use of the data collected routinely in the care system. The highest propensity of use is found in those countries with a large and consolidated evaluative tradition, where transparency is the rule. Logistical and technical capacity to deal with large amounts of data also plays a role. The development of high quality health information systems is crucial in order to create opportunities to learn from health outcomes variation.

CASE STUDY IX

INTERNATIONAL CANCER BENCHMARKING PARTNERSHIP (ICBP)

Lucie Hooper and Irene Reguilon, International Cancer Benchmarking Partnership⁶⁴

The International Cancer Benchmarking Partnership began in 2009 and is a multidisciplinary partnership of clinicians, academics, data experts and policymakers. It seeks to understand the factors that may contribute to variation in international cancer survival, using data from a range of sources. It is hoped that through understanding why some countries have higher cancer survival and better outcomes, partners can learn from each other and promote policy and practice changes rooted in evidence-based outputs. Criteria for joining the ICBP include population-based cancer registries with similar spend and access to healthcare.

The initial benchmarking (covering 1995-2007) found that overall survival for breast, colorectal, lung and ovarian cancer patients was:

- **higher** in Australia, Canada and Sweden
- **intermediate** in Norway
- **lower** in England, Northern Ireland, Wales and Denmark.



Figure 5: ICBP initial benchmarking (1995-2007)

A further study revealed that there was no significant difference in public awareness about cancer symptoms, suggesting this is not a major factor affecting cancer survival variation. One study revealed

⁶⁴ For more information contact the ICBP Programme Management team (ICBP@cancer.org.uk) or visit www.icbp.org.uk; for more information on the ACE Programme visit www.CRUK.org.uk/ACE

a correlation between a primary care physician's readiness to refer a patient for further investigation upon presentation of symptoms and survival differences for some studied cancer types (Figure 6).

ICBP findings to date suggest that differences in cancer outcomes may be due to different factors along the patient pathway (such as access to diagnostic tests or organisation of treatment services). These findings have provided supporting evidence for changes in cancer policy, including initiatives aiming to address barriers to help-seeking and to introduce innovative diagnostic referral pathways – for example, the Accelerate, Coordinate, Evaluate (ACE) Programme: <https://www.cancerresearchuk.org/health-professional/diagnosis/accelerate-coordinate-evaluate-ace-programme>.

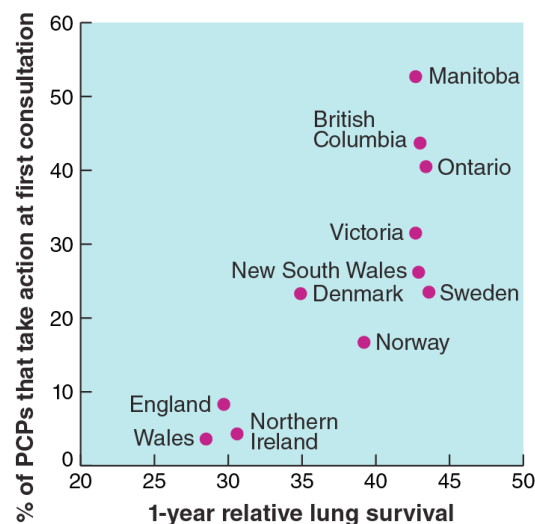
Across jurisdictions, projects have been carried out to improve cancer data completeness and availability. This was highlighted as a key issue in the original cancer survival benchmark and subsequent studies. Although data has improved, there are still gaps internationally, both in cancer registries and from health system data more widely.

Most of the studies published to date required data collection via surveys. This was due to the fact that much of the data required did not exist or was not available routinely in a comparable way. One published ICBP study, which tried to use existing data to determine if routine hospital admission data could be used to predict 1-year lung cancer survival, was limited by challenges in comparing international comorbidity data.

While the ICBP has made significant inroads into understanding the factors driving international cancer survival differences, there are still unanswered questions and areas requiring further exploration. Now ICBP is building on previous success, expanding the number of jurisdictions involved and cancer types studied.

An updated survival benchmark, covering 1995-2014, will produce policy and clinically-relevant metrics. There will also be a report detailing variation in practices in cancer registries, with recommendations for standardisation. This aims to address ICBP findings showing the impact of different registry practices on survival estimates.

Differences in cancer patient pathways and health systems will be explored, alongside access to diagnostics and optimal treatment in the 21 jurisdictions involved. Underpinning this research is the need to continue improving and standardising data collections and definitions. Initial scoping activity into the availability of relevant data relating to diagnostic tests from each jurisdiction has revealed that there is a lack of standardised and comprehensive data across all countries. This work reinforces existing calls for action on improving data collections.



Readiness of PCPs to investigate low risk symptoms that could be indicative of lung cancer and 1-year relative survival.

Figure 6: Readiness of primary care practitioners to investigate low risk symptoms that could be indicative of lung cancer and 1-year relative cancer survival

Enablers of variation analysis

As the ICBP case study illustrates, robust analysis of health outcomes variation requires standardised approaches to measurement, as well as standardised data collection and coding. Without such methods and tools, opportunities to learn from variation, and thereby improve health care, will be lost.

The use of standardised measures does not preclude local adoption of additional, complimentary measures based upon specific needs and preferences.⁶⁵

II. Continuous improvement at the clinical level

Summary

- Continuous improvement at the clinical level is a key method for enhancing quality of care and value for money.
- Health outcomes data can be used to identify areas for improvement in clinical practices and processes, and to assess the benefits of any changes introduced.
- Patients should be directly involved in continuous improvement processes to help ensure that they respond to patient concerns and priorities.
- It is crucial that medical professionals are equipped with the tools and techniques needed to support continuous improvement work.

Introduction

Continuous improvement is an approach to quality improvement that is generally led by medical professionals. In his famous 1989 article in the *New England Journal of Medicine*, Don Berwick translated the management theory of continuous improvement into a methodology applicable to health care. According to this theory, “Every process produces information on the basis of which the process can be improved”.⁶⁶ Continuous improvement thus relies upon data to identify areas for improvement, such as in clinical practice and management processes, as well as *ex post* evaluation of the effects of the changes introduced.

Health outcomes data is a powerful tool for supporting continuous improvement activities in health care. Patients should be involved in the improvement work from the outset, and the data used should prioritise what is most relevant and meaningful from the patient perspective. To this end, the outcome standard sets produced by organisations such as ICHOM and OMERACT can be an important tool.

Case study X focuses on the use of PROMs to improve outcomes for knee replacements at Northumbria NHS Healthcare Foundation Trust. The example combines the use of continuous improvement methodology at the clinical level, the use of outcomes data for variation analysis (to identify the implant brand associated with the best PROM scores), and the transparent publication of results as part of the NHS PROMs programme.

As the case study shows, Northumbria went from below average results within England (based on the Oxford Knee Score) to being a ‘positive outlier’ – in other words, a high performer.

⁶⁵ On the value of integrated data collection systems for clinical practice and performance monitoring 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).

⁶⁶ D. Berwick, ‘Continuous Improvement as an Ideal in Health Care’, *The New England Journal of Medicine*, 320 (1989).



CASE STUDY X

CONTINUOUS IMPROVEMENT IN HEALTH OUTCOMES FOLLOWING TOTAL KNEE REPLACEMENT AT NORTHUMBRIA HEALTHCARE NHS FOUNDATION TRUST

Based on presentation by Mike Reed, Consultant Orthopaedic Surgeon, to the March 2016 Value of Health consensus document launch (European Parliament)⁶⁷

Northumbria Healthcare NHS Foundation Trust in the Northeast of England has 14 Orthopaedic surgeons performing more than 1200 knee replacements each year. In 2009, the NHS PROMs programme mandated the use of patient-reported outcome measures for total knee replacements (as well as hip replacements, varicose vein surgery and groin hernia surgery) across England.

Specifically, NHS Trusts and independent providers are required to use: i. the 'Oxford Knee Score' (OKS) – a condition-specific PROM, which captures the patient perspective on their functional status and pain; and ii. the EQ-5D – a generic measure of health status. Patient responses to each PROM produce a score.

Patients are asked to complete the OKS before surgery and then six months afterwards (at the end of the recovery period). The improvement in the score after surgery represents the 'health gain' (or loss) of the patient – a proxy for the health outcome.

Through the analysis of Trust and surgeon level data, it becomes possible to monitor performance over time, and to assess the impact of changes in clinical practice/care pathways. In addition, risk adjusted data for all Trusts and providers across England is made transparently available online, making it possible to compare performance between one Trust/provider and another.

Quality improvement initiatives at Northumbria

Between 2011 and 2014, two quality improvement initiatives were implemented at Northumbria NHS Foundation Trust. The first was triggered by the participation of a Northumbria-based surgeon in a study group to investigate the relationship between PROM scores and a range of surgical factors. A key finding was that a specific implant brand was associated with significantly better health outcomes (based on the Oxford Knee Score).

As a result of this finding, all Northumbria based surgeons shifted to use of the superior implant, with a six-month changeover implemented between September 2011 and March 2012. Northumbria's own analysis of average PROM scores before and after the changeover subsequently indicated an improvement in patient outcomes based on both the OKS and EQ5D.

The second quality improvement initiative centred on the preservation of the infrapatella fatpad (IFP), which is situated below and behind the kneecap. In 2014, a study of outcomes for 1400 knee replacements was published in a medical journal. It demonstrated improved results when the IFP was preserved.

The study findings led Northumbria to analyse its own surgeon-level data. This revealed that, of the 14 surgeons at the Trust, the four that routinely preserved the IFP achieved significantly better PROM scores. This data encouraged a change across the Trust, with the majority of surgeons routinely preserving the IFP. Internal analysis again showed an improvement in average outcome scores as a result of the change.

⁶⁷ For more information see: Case study based on: Partridge, T. et al., 'Improving patient reported outcome measures (PROMs) in total knee replacement by changing implant and preserving the infrapatella fatpad: a quality improvement project' *BMJ Quality Improvement Report* (2016; 5)

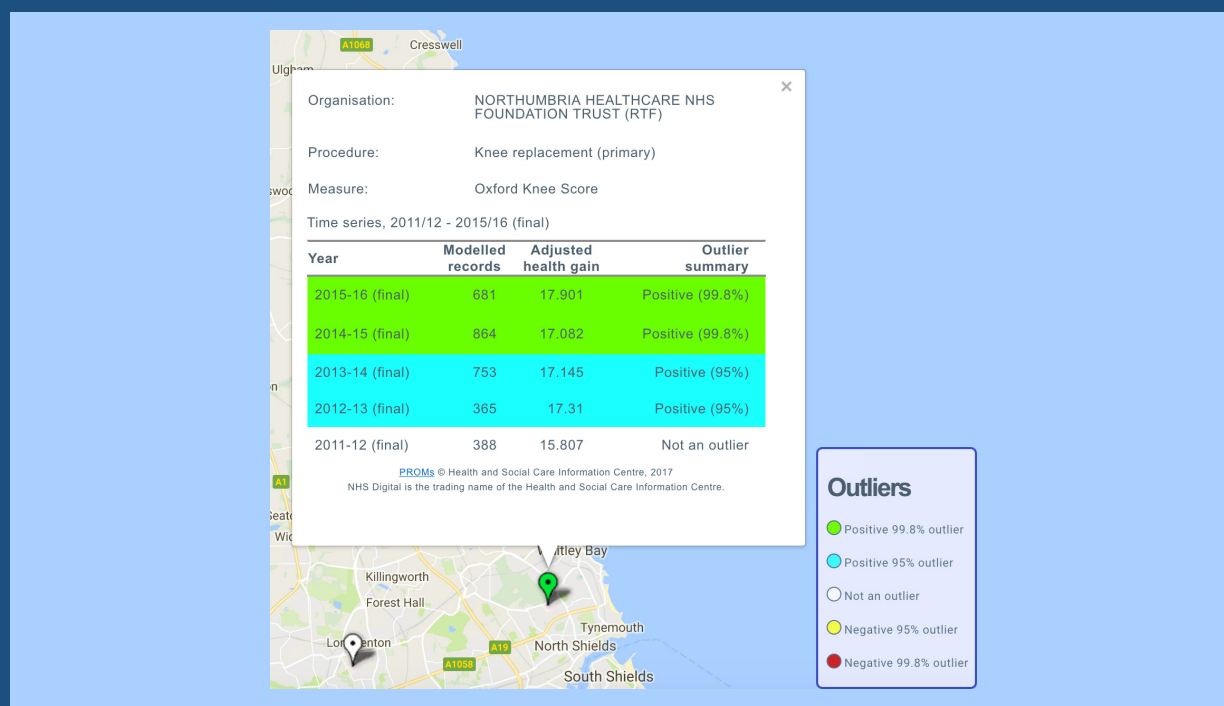


Figure 7: Performance improvement at Northumbria NHS Trust

Northumbria's improvement confirmed by NHS PROMs Programme

The improvement in outcome scores indicated by Northumbria's internal analysis was subsequently confirmed when annual data was published as part of the NHS PROMs programme. Even more strikingly, Northumbria saw a marked improvement relative to Trusts and providers across England.

In 2010/11, Northumbria's average risk-adjusted OKS score was 14.68 compared with a national average of 14.87 (i.e. it was below average within England). By 2013/14, following the shift to the superior implant, the average health gain had increased to 17.31. That compared with a national average of 16.25, making Northumbria a positive outlier within England (see Figure 7 below).

Following the shift to routine preservation of the IFP, there was a further improvement in OKS scores to 17.9. Improvement can also be observed in Northumbria's EQ-5D scores, in relation to which Northumbria has also become a positive outlier within England.

The use of PROs to support continuous improvement in prostate cancer care at the Martini Klink

Another, well known example of continuous improvement in healthcare is the Martini Klink, which specialises in treatment for prostate cancer.

At Martini Klinik in Hamburg, prostate cancer patients are asked to complete a 13-page quality of life survey (QLQ-C30) and the International Index of Erectile Function (IIEF-5) before surgery. They do this upon leaving hospital, upon removal of a urinary catheter, and at regular intervals thereafter (three months, and then one-year, two-years, and three-years after surgery). In addition to using these



outcome measures as part of clinical practice, Martini Klinik also uses the aggregate data (at the level of individual surgeons and the clinic as a whole) to support continuous quality improvement.

For example, when three Martini Klinik surgeons – informed by research by a group of Korean radiologists – adjusted surgical technique with the aim of improving urinary continence rates, it was possible to measure the impact using PROMs. After adoption of the new technique, one-week urinary continence rates rose from 50% to 70% of patients. As a result, all surgeons at Martini Klinik began to use that technique.

Reducing waste through continuous improvement

The same methods of quality improvement can also be used to improve the efficiency of care – in particular by reducing wasteful practices. By enabling the identification of unnecessary, inappropriate, or even harmful interventions, health outcome measurement can be a powerful tool to improve the efficiency of care and resource allocation within health systems.

Case study XI focuses on continuous improvement in cardiovascular care as a result of the Blue Cross Blue Shield programme in Michigan. In this example, outcome measures were used to identify which patients were at greatest risk of complications due to the use of contrast dyes in angioplasty, leading to a reduction in contrast-dye induced kidney damage.

CASE STUDY XI

CONTINUOUS IMPROVEMENT IN CARDIOVASCULAR CARE: BLUE CROSS BLUE SHIELD IN MICHIGAN

Based on ICHOM case study by Jason Arora and Jessica Aisenbrey⁶⁸

The Blue Cross Blue Shield 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 (also known as percutaneous coronary intervention).

Quality data from the six hospitals participating in the pilot was collected in a central registry, and 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.

For example, the data showed 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 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.

68 J. Arora and J. Aisenbrey, 'Aligning payers and providers around value: Blue Cross Blue Shield of Michigan's Collaborative Quality Initiatives' Cambridge, MA: International Consortium for Health Outcomes Measurement, June 2015 (available at www.ichom.org).

III. Improving the effectiveness of public health interventions

Summary

- Public health outcomes are measures of the health status of the population as a whole, as well as population sub-groups.
- Public health outcomes indicators can be used in a variety of ways to support public health policy and practice – for example by tailoring interventions to local needs, strengthening the follow up and evaluation of interventions, and for performance monitoring and accountability.

Introduction

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.

The first Value of Health consensus document highlighted the different ways in which health outcome measures can be used to strengthen and support public health policy, for example:

- **Tailoring public health policies and interventions to local needs** – through a better understanding of outcomes within geographically defined populations and population sub-groups.
- **Strengthening 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.
- **Monitoring 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.
- **Enhancing the accountability of public health policy makers and institutions** – through transparency of outcomes data.⁶⁹

Case study XII focuses on improvements in perinatal (the period immediately before and after birth) in the Netherlands. After international comparisons indicated an unexpectedly high perinatal mortality rate in the mid-2000s, a number of steps were taken to improve perinatal care services. Subsequent assessment, both within the Netherlands and on the basis of international comparisons, showed a marked improvement in Dutch performance.

69 See The Value of Health: Improving Outcomes, 'Enhancing Value in European Health Systems: the role of outcomes measurement', Consensus Document (2016), available at <http://www.eu-patient.eu/globalassets/policy/patientssafety/value-of-health-consensus-document.pdf>

CASE STUDY XII

IMPROVING THE EFFECTIVENESS OF PERINATAL CARE IN THE NETHERLANDS

Based on presentation by Michael van den Berg, the Netherlands' National Institute for Public Health and the Environment at the launch of the Value of Health consensus document (European Parliament, March 2016)

The National Institute for Public Health and the Environment (RIVM) in the Netherlands produces independent research, publishes policy advice, and provides national coordination – for example screening and immunization programs. It also produces a number of monitoring reports on public health and health care performance in the Netherlands, including: 'Public Health Status and Forecasts', 'Dutch Healthcare Performance Report', and 'State of public health and healthcare'.

RIVM also participates in several international data collection initiatives, including OECD health care quality indicators, and European Core Health Indicators. One such initiative is Euro-Peristat, which monitors and evaluates maternal and child health in the perinatal period (pregnancy, childbirth and postpartum). The Dutch experience with Euro-Peristat provides an excellent example of the use of outcomes data as a tool to support improvement in public health policy and practice.

In the mid-1980s, the Netherlands had one of the lowest perinatal mortality rates in Europe. However, in the 1990s' Dutch performance relative to other countries appeared less strong.

The Euro-Peristat reports (data for 2004 and 2008) then came as both a shock and a trigger for action. 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) – leading to increased political and media attention on the issue.

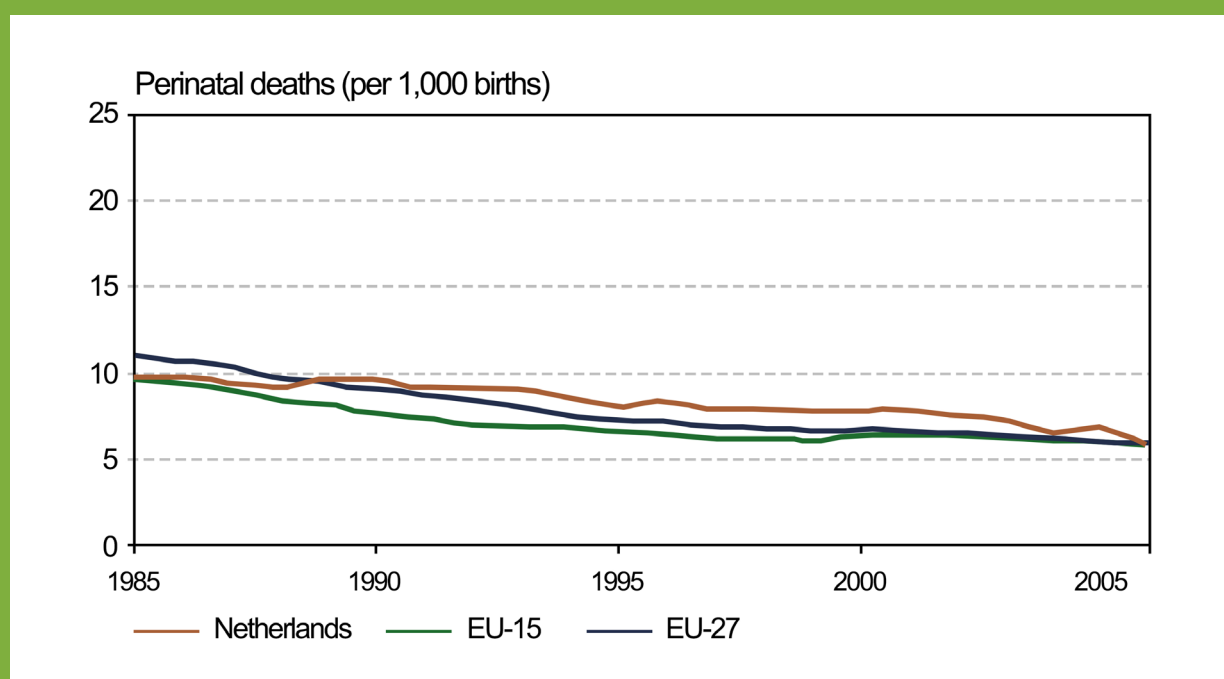


Figure 8: Perinatal outcomes: longitudinal performance analysis

The reports prompted a range of quality improvement activities for perinatal care in the Netherlands. Actions taken included:

- the introduction of preconception visits
- the establishing the Steering Committee on Pregnancy and Birth
- the creation of a Perinatal Audit in The Netherlands
- the introduction of the 20-week ultrasound (anomaly scan)
- the Netherlands Organisation for Health Research and Development initiated a research programme on 'Pregnancy and Birth'

The Steering committee made a number of recommendations to reduce by 50% the number of maternal and perinatal deaths due to sub-standard (care) factors. The perinatal audit had two aims: (i) to determine to what extent the actual care provided was in line with accepted standards; (ii) to identify sub-optimal practices and determine how far they contributed to negative health outcomes, including death.

Following these improvement initiatives, the Dutch Health Care Performance Report for 2014 showed that: the percentage of pregnant women that had their first prenatal visit before 10 weeks of pregnancy

has risen substantially; a decreasing number of women were smoking during pregnancy; participation in the perinatal audit progressively increased (up to almost 100%); and there was a lower percentage of preterm births delivered in maternity units without an on-site neonatal intensive care unit (NICU).⁷⁰

Euro-Peristat 2013 (based on 2010 data) also showed that there had been a marked improvement 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 2010.⁷¹

The Netherlands reported one of the strongest performance improvements in Europe. Other countries also improved their performance, indicating that a similar mechanism of quality improvement might be occurring in other participating countries.

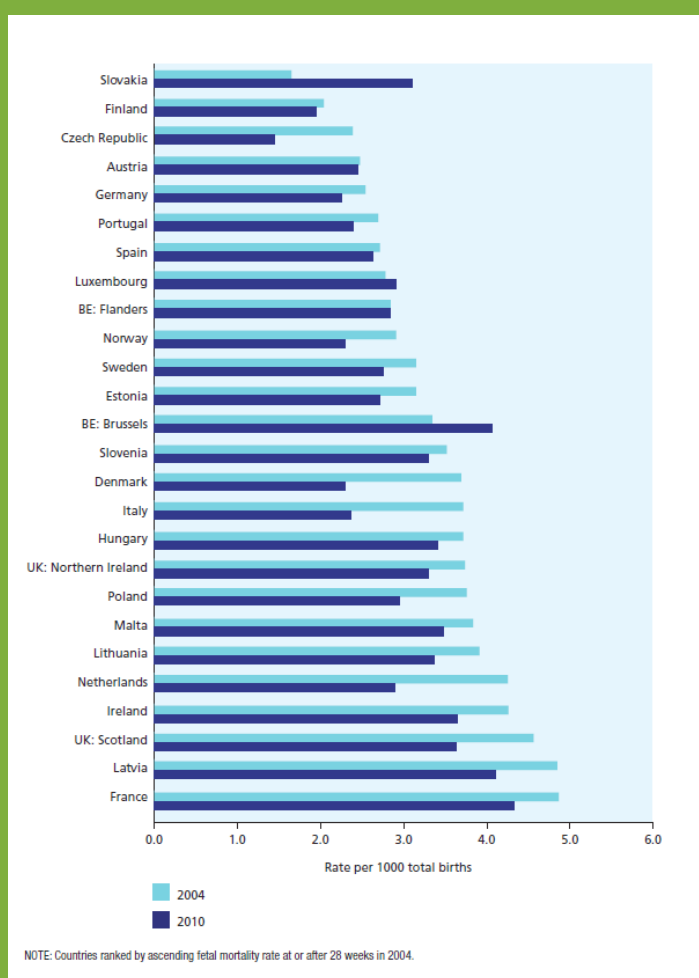


Figure 9: foetal mortality at or after 28 weeks

⁷⁰ National Institute for Public Health and the Environment, 'Dutch Health Care Performance Report 2014' (2015).

⁷¹ Euro-Peristat, 'European Perinatal Health Report: Health and Care of Pregnant Women and Babies in Europe in 2010' (2013).



IV. Performance monitoring and transparency

Summary

- Health outcomes data should play an important role in monitoring health care performance.
- Performance monitoring / assessment can be both a trigger for, and support the development of, policies designed to improve quality of care, health outcomes, and health system efficiency.
- Transparent publication of results can enhance health care accountability, act as an incentive for quality improvement, help to improve health literacy, and facilitate patient choice of health care provider.

Introduction

Health care performance monitoring and assessment refers to a variety of approaches to analysing and evaluating how far the health system is achieving its objectives (for example in relation to quality of care, health outcomes, and the efficiency of care).

Different approaches are used in different countries and contexts, including longitudinal analysis (changes in performance over time); comparisons of hospital, regional, and national performance; and performance in relation to targets.

Performance monitoring can be used to identify instances of potentially sub-optimal care, triggering investigation into the underlying causes. In addition, transparent publication of results can act as a powerful incentive for performance improvement, and patients can use the data to inform decisions about treatment options and (where the system permits) to enable choice between providers.

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.⁷²

Transparency as a tool for patient empowerment and accountability

Transparent publication of results can inform and empower patients, and strengthen health system accountability. For example, information about outcomes can enable patients to better understand their condition and the risks/benefits associated with a particular intervention. It can thereby support shared decision making with care providers. Where health systems allow patients to choose between providers, transparency of data can be an important tool to support patient choice.

In order to achieve these objectives, performance/quality data must be presented in a way that is easy to understand, using health literacy and numeracy principles, and readily accessible.

The link between transparency and patient choice is especially important in relation to safety. If there are patient safety issues at a particular hospital or clinic, it is crucial that this information is made available to patients so that they can make informed choices about where and whether they wish to

⁷² P. van der Wees et al. 'Governing healthcare through performance measurement in Massachusetts and the Netherlands', *Health Policy* (2013); Z. Song, 'The Alternative Quality Contract', Based on a Global Budget, Lowered Medical Spending and Improved Quality' *Health Affairs* 31, 8 (2012).

receive a specific treatment. In addition, transparency of results is also likely to incentivise swift action to address patient safety concerns if they do arise.

Case studies

Case Study XIII below focuses on an example of performance monitoring at the hospital level. The Results Center of the Catalan Health System Observatory aims to be a reference tool for citizens, healthcare centres / hospitals, and administrators.

Since 2009, a yearly report has been produced for hospitals. Each report employs around 60 quality indicators, grouped into thematic domains, such as: patient-centred care; effectiveness; appropriateness; efficiency; and safety. Against each indicator, individual provider results are reported.

The results are also published in 'open data' format to ensure public accessibility (made possible by high quality electronic health information systems). Reports are now also produced for primary care, long-term care, mental healthcare, and public health activities.

CASE STUDY XIII

THE 'RESULTS CENTRE' OF THE CATALAN HEALTHCARE SYSTEM

Anna García Altés, Catalan Health System Observatory

The Results Centre of the Catalan healthcare system measures and disseminates data on the performance of the different healthcare centres in Catalonia. Comparison between healthcare centres and the transparent feedback of results to professionals and citizens contributes directly to quality improvement.

The Results Centre offers a comprehensive and transparent system of measurement and evaluation of the results achieved by the different accountable agents that make up the Catalan health care system. It uses comparison (benchmarking) between health care centres, and disseminates best practices.

- **For citizens:** the Results Centre promotes a wider and better understanding of the field of health, and allows them to interact with the healthcare system and participate in decisions that affect their health.
- **For healthcare centres:** it enables comparison the results achieved, identification and sharing of best practices, and consideration of opportunities for improvement and cooperation between institutions.
- **For health administrators:** the reports respond to the demand for transparency in health policy decisions, as well as for accountability in the use of resources.

Yearly reports are produced covering hospital results, primary care, long-term care, mental healthcare, and public health activities. For each topic, around 60 indicators are used – these include indicators for: patient centred care, effectiveness, appropriateness, efficiency, safety, IT and communication systems.

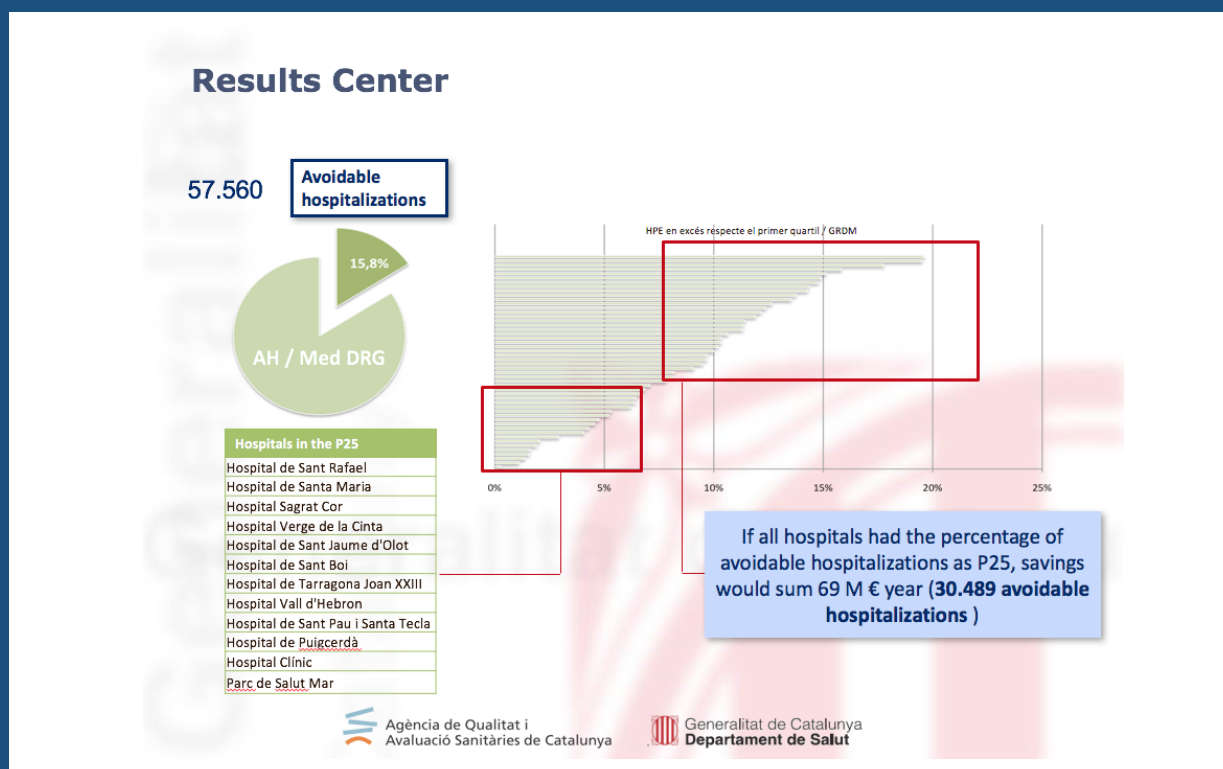


Figure 10: The Results Center: Avoidable Hospital Admissions

The reports also feature experiences from some of the centres with better results, as well as the opinions of experts, and a version for citizens. All detailed results are available in tables, together with technical definitions are published at: <http://observatorisalut.gencat.cat>.

In addition, the results are also made available to citizens in open data format (see Figure 8), responding to the objective of the Catalan government to ensure transparency and proximity to citizens by establishing the most suitable and simple ways to access public information. All this is possible due to the high level of development of health information systems, all of them in electronic format.

Regional Comparisons of Quality and Efficiency in Swedish Health Care

Another example of the use of health outcomes for performance monitoring and transparency is Regional Comparisons of Quality and Efficiency in Swedish Health Care. Regional Comparisons is a joint initiative by the Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare.

First published in 2006, Regional Comparisons is a product of the long tradition of quality registries in Sweden. The comparisons focus on the performance of the twenty-one country councils and regions that are responsible for health care provision in Sweden. Regional Comparisons has evolved over time. Originally a single written report, there are now several different reports and online systems, published in an accessible format. The comparisons make use of overall indicators (such as mortality

rates and avoidable mortality), as well as disease specific indicators of health care quality (for example, avoidable hospital admissions, patient-reported outcomes, and adverse events).⁷³

A Public Health Regional Comparisons report is also published.⁷⁴ This provides indicator-based comparisons of population health (including life expectancy, disease incidence, and mental ill health), social conditions and living conditions (for example: education, employment, and the environment), as well as lifestyle and living habits (such as physical activity, eating habits, alcohol and tobacco use, and sexual and reproductive health and rights).

Transparency leading to improved results in Swedish cardiac care

The potential for transparency to drive performance improvement is highlighted by an example from regional comparisons in cardiac care. In 2005, the Swedish heart attack registry created a quality index showing hospitals compliance with cardiac care guidelines. Between 2005 and 2007 (when the data was not made publicly available) hospitals improved their quality index scores by an annual average of 13%. Among hospitals with below average scores, however, the improvement rate was only 7%.

Following the introduction of Regional Comparisons in 2006 – when quality index scores and survival rates became public – this changed. In the period 2007-09, the overall improvement rate increased to 22%. In addition, the performance gap between the high and low performance hospitals was significantly reduced (below average hospitals improved their performance by as much as 40%). These improvements are considered to have contributed to the decline in short and long-term mortality following heart attack.⁷⁵

V. Supporting the Implementation of Integrated Care

Summary

- Integrated care is a ‘design principle’ at the centre of many of today’s healthcare reforms. It is closely linked to concepts of patient-centred and participatory care.
- If upfront investments are to be made in implementing new, integrated models of care, it is crucial that the benefits can be robustly demonstrated in advance.
- Health outcome and experience measures have a key role to play in this context. By enabling benefits to be assessed, outcome and experience data can be used to support decisions on implementing integrated care.

Introduction

Integrated care is a concept at the forefront of many of today’s health care reforms. The International Foundation for Integrated Care describes integrated care as a ‘fundamental design principle’, without which ‘care experiences and outcomes are unlikely to be as good as they should be’.⁷⁶ In a number of respects, it is closely

⁷³ See for example, Socialstyrelsen, ‘Regional comparisons 2016: Six questions about Swedish health care’ (2017), available at <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20666/2017-9-8.pdf>

⁷⁴ See for example, Socialstyrelsen, Public Health Agency of Sweden, and Swedish Association of Local Authorities and Regions, ‘Public Health: Regional Comparisons 2014’ (2015), available at <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19912/2015-9-2.pdf>

⁷⁵ G. Hagglund, ‘Fine-Tuning Health Care – improved outcomes and cost efficiency using quality registries’, Swedish Ministry of Health and Social Affairs Conference (May 2013)

⁷⁶ See International Foundation for Integrated Care: <https://integratedcarefoundation.org/about-ific>



related to patient-centred care: integration aims to ensure that care services will be responsive to individual patient needs, and thereby improve experience. Integrated care is closely related to participatory care, in that the patient is expected to be included as a part of the healthcare team, including shared decision-making and shared care planning.

In its 2016 report on integrated care, the EU Expert Group on Health System Performance Assessment defined integrated care: “initiatives seeking to improve outcomes of care by overcoming issues of fragmentation through linkage or co-ordination of services of providers along the continuum of care.”⁷⁷

Integration can be particularly important in the case of patients with complex needs or more than one chronic condition. These patients may have frequent interactions with the health system, making it particularly important that care is well co-ordinated.

‘Care pathways’ are an example of an approach to integrated care that aims to ensure that care provision is both coordinated and patient-centred. The European Pathways Association has identified the following characteristics of care pathways:

- i. An explicit statement of the goals and key elements of care based on evidence, best practice, and patients’ expectations and characteristics;
- ii. The coordination of the care process by coordinating the roles and sequencing of the activities of the multidisciplinary care team, patients and their relatives;
- iii. The facilitation of communication among team members and with patients and their families;
- iv. The documentation, monitoring, and evaluation of variances and outcomes⁷⁸

However, designing and implementing integrated care models is far from straight forward. If upfront investments are to be made in service integration with a view to improving experience and health outcomes, the effectiveness and efficiency of new models of care must be rigorously assessed to assess value for money (in particular relative to the existing model of care).

Health outcome measures are therefore a vital tool in supporting the implementation of integrated care. While it may be possible to track the extent of integration through process measures, only health outcome measures will demonstrate the return on investment with respect to effectiveness. Case Study XIV focuses on an integrated care model for chronic obstructive pulmonary disease (COPD) used by Whittington Health NHS Trust in London. It shows how the impact of the care model was successfully demonstrated in relation to mortality, length of stay in hospital, and health-related quality of life.

⁷⁷ European Commission, ‘Blocks: Tools and Methodologies to Assess Integrated Care in Europe’, Report by the EU Expert Group on Health System Performance Assessment’, (2017), p.2.

⁷⁸ See European Pathways Association: <http://e-p-a.org/care-pathways>

CASE STUDY XIV

INTEGRATED CARE FOR PEOPLE WITH COPD AT WHITTINGTON HEALTH NHS TRUST

*Based on King's Fund 'Ideas that change health care' series: Whittington Respiratory Service (October 2014)*⁷⁹

COPD is a major health problem in Europe, with annual mortality expected to continue to rise in the coming decades. Whittington Health is an integrated care organisation in London, with a respiratory service that provides integrated care for people with COPD. The service includes a specialist outpatient clinic, a 21-bed acute in-patient ward, and a multi-disciplinary 'community' team that supports patients in their homes following discharge from hospital or referral from GPs. The community team is composed of two respiratory consultants, respiratory nurse specialists, physiotherapists, clinical psychologists, a smoking cessation adviser, and a specialist registrar.

At Whittington, patients admitted to hospital with an acute COPD exacerbation receive a COPD discharge 'bundle' - a set of evidence-based interventions delivered to all patients. The interventions include smoking cessation advice and treatment, an assessment for pulmonary rehabilitation classes, self-management support, a review of inhaler use, and follow-up by a respiratory specialist within one month of discharge. Complex patients may be placed onto the 'enhanced recovery' pathway - whose purpose is to diagnose and treat co-morbid patients, and to involve other specialists, mental health practitioners, general practitioners and social care as required.

In advance of discharge, a multi-disciplinary case meeting is held with the patient and their family in order to review medications and (when appropriate) a smoking cessation plan, and to develop an 'action plan' for avoiding further admissions. A respiratory nurse specialist attends the meeting, and visits the patient after discharge in order to monitor progress and provide additional treatments. Locality based multi-disciplinary teams led by a consultant or specialist registrar meet weekly to review cases. The meeting notes are recorded on an electronic database (HanDBase) and shared with all team members by email (they can also be uploaded to the hospital system).

Crucially, the impacts of the care model (compared to pre-existing model of care) have been rigorously assessed using health outcomes data. The assessment of impacts led to the following findings:

- In 2010-11, in-hospital mortality for the Whittington service was 1.6%, compared to 6.5% nationally. There were also significantly fewer days spent in hospital among patients who completed pulmonary rehabilitation within 12 months of referral compared to those who did not.
- Participation in a long-term exercise group increased the duration of benefit from pulmonary rehabilitation. Based on a COPD Assessment Test scores (a questionnaire on the impact of COPD on a person's life), attendees of the long-term exercise group reported a 35% improvement, compared to 14% among non-attendees. After six months, 'attendees demonstrated a clinically significant ongoing improvement in all health-related quality of life domains'.

⁷⁹ The King's Fund, 'Whittington Respiratory Service', Ideas that change health care: Case Study (2014).



Conclusions and Recommendations

The pursuit of value is at the forefront of many of today's debates on health system reform. However, value can often mean different things to different actors and stakeholders within the system – be they policy makers, patients, medical professionals, hospital managers, public health practitioners, informal carers, health technology providers, or others. This lack of conceptual common ground can in turn inhibit discussions about how to strengthen and improve value.

Health outcomes (for individual patients and for populations as a whole) are at the centre of the multi-stakeholder perspective on value provided by this report. At the same time, numerous other objectives, and potential benefits, of healthspending need to form part of any comprehensive definition. These include: access to care; patient-centred care (including patient safety); accuracy and timeliness of diagnosis; health equity; health workforce sustainability; outcomes for carers; and the economic and social benefits of good health.

The report has also shown that health outcome measures are a crucial tool for improving value in health systems. In particular, health outcomes data can be used to: analyse and learn from variation (between hospitals, regions, or countries); enhance continuous improvement at the clinical level; improve the effectiveness of public health interventions; monitor health system performance; promote health system transparency and accountability; and support the implementation of integrated care.

A recurring theme of the report has been the need to measure the outcomes that are most meaningful and relevant to patients (patient-centred outcomes), as well as the need for standardised measurement instruments – and data collection practices – to ensure that outcomes data is comparable and can be used for the different purposes described above.

The Value of Health initiative makes the following key recommendations, which should inform the future work of the European Union on health systems:

1. Continue to invest in the Patient-Reported Indicators Survey (PaRIS) & broaden the disease-specific indicators to include more health conditions

The OECD PaRIS initiative is an important step in providing comparable data on the outcomes and experience of care from the patient perspective (using patient-reported outcome and experience measures: PROMs and PREMs). The initial condition-specific focus on outcomes for elective surgery, cancer and mental health is welcome, and should be progressively widened to include other chronic conditions. In addition, the new comparative international survey on patient-reported outcomes and experiences for people with multiple chronic conditions, currently in development, promises to add significantly to the knowledge of how well health systems perform from the user perspective, and should be supported.

2. Integrate more health outcomes data into analyses of health system performance at EU level

The European Semester has relied upon a relatively narrow range of health outcome indicators, which are of only limited use in analysing health system performance for policy making. The State of Health in the EU cycle represents an important step towards a more balanced analysis of health system performance at EU level, including from a health outcomes perspective (for example through the use of condition specific mortality and survival data). The inclusion of patient-reported indicators (as these become available via PaRIS) would further strengthen the focus on outcomes. The EU Expert Group on Health System Performance Assessment can also provide a forum for exchanging experiences and best practices in using health outcomes data for performance monitoring and improvement.

3. Support the development of health information infrastructure (such as electronic health records)

The collection and use of health outcomes data for quality improvement requires strong health information systems that enable data linkage as part of an ambitious digital health strategy. They should be underpinned by standardised data collection/recording methods, interoperability principles, as well as robust data governance frameworks to enable privacy protective data use for health care improvement. The EU should support the development and implementation of health information systems across Member States as a key tool in ensuring ongoing improvements in quality of care and value in health systems. The 2018 Commission Communication on the 'digital transformation of health and care in the Digital Single Market' provides an important basis for further EU action in this area.







www.valueofhealth.eu