

## Chapter 2

# Measuring what matters for people-centred health systems

*The key objective of a health system is to improve the health of patients and populations. However, few health systems routinely ask patients about the outcomes and the experience of their care. This chapter presents patient-reported outcomes following hip and knee replacement, and breast cancer surgery, as well as patient-reported experiences of people with mental health problems, from a subset of OECD countries. Patients who underwent joint replacement surgery reported, on average, improved function and quality of life with hip replacements generating slightly higher gains. Women who underwent autologous breast reconstruction surgery reported, on average, better outcomes than women who underwent implant reconstruction. Meanwhile results of a 2016 Commonwealth Fund survey of 11 countries suggest that people with a mental health problem report a worse experience in some aspects of care. Such information is valuable for other health service users, for clinicians, providers, payers and policymakers.*

The statistical data for Israel are supplied by and under the responsibility of the relevant Israeli authorities. The use of such data by the OECD is without prejudice to the status of the Golan Heights, East Jerusalem and Israeli settlements in the West Bank under the terms of international law.

## Introduction

The primary objective of any health system, service or organisation is to maximise the health of the individuals and populations they serve, and to do so in an equitable way within budgetary parameters.

Good health is not just important in its own right. It also promotes personal, social and economic well-being. Healthy people create healthy communities and contribute towards a well-functioning, prosperous and more productive society. For example, good health can enhance a person's lifetime earnings by up to 25% (OECD, 2017[1]; OECD, 2018[2]).

Yet very few health systems assess their impacts on health and well-being from the perspective of the people they serve. While the concept of health-related quality of life (QoL) has existed for almost three decades, it is not measured or reported systematically. Performance metrics in health tend to focus principally on inputs and outputs. Outcomes such as life expectancy are important, but they are silent on a range of other things valued by patients, including pain, function and QoL as well as the experience of care itself. This means that the picture of health care and health system performance is missing an essential part.

The patient perspective on the outcomes and experience of their care is essential in driving continuous quality improvement of health services. It is also increasingly relevant in overcoming the broader demographic, epidemiological and economic challenges faced by all health systems. The rise of chronic conditions as the main source of disease burden, coupled with better but also more expensive technologies to manage them and prolong life, heightens the need for a more people-centred approach to both policy and practice. But people-centred health systems remain an empty promise without more information on how health care and health policy actually affect the lives of individual patients.

This chapter presents the results of a preliminary data collection on patient-reported outcomes from a sample of OECD countries. The areas covered are joint replacement surgery and breast cancer surgery. The next section discusses the importance of using patient-reported data in mental health. These areas of work are part of a broader OECD initiative – the Patient-Reported Indicator Surveys (PaRIS) – which aims to promote systematic use of these important metrics in health systems (see <https://www.oecd.org/health/paris.htm>).

### A people-centred health system needs to measure what matters to patients

People's assessment of their health, and the outcomes of their care, go beyond whether they survive a disease or medical intervention. A range of inter-related physical and mental health domains including pain, mobility, fatigue, anxiety and depression all contribute to person's health-related QoL. Patients also value their care experience, which includes having one's autonomy respected, feeling invited and empowered to participate in decisions about one's care, and if organisational aspects of the care pathway are well coordinated or disjointed and burdensome.

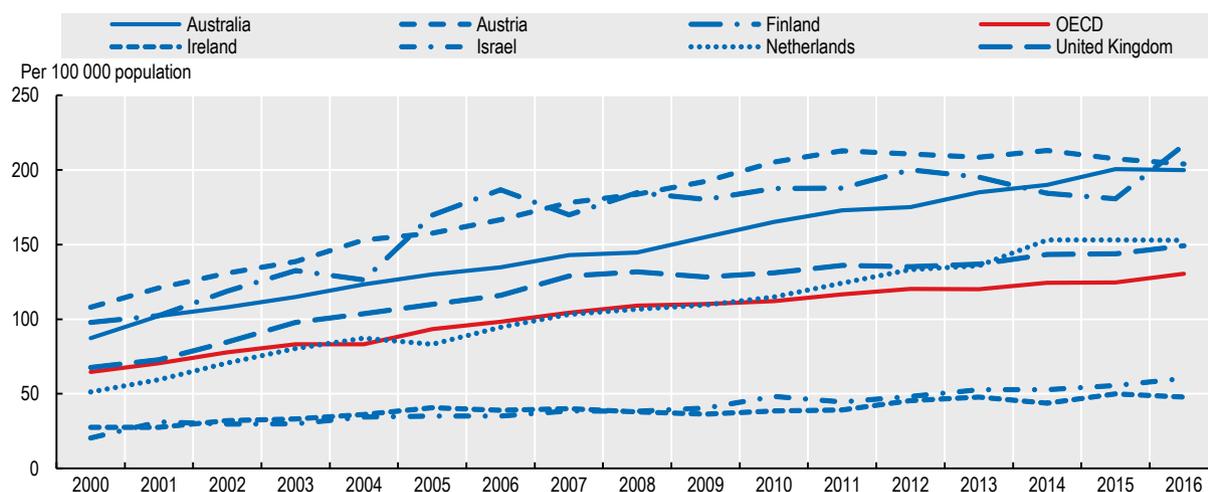
It makes sense to capture this knowledge in a way that is systematic and useful for decision-making. Yet the health sector has been remiss at measuring the effects of its activities on outcomes and experiences as reported by patients. Forward thinking provider organisations, disease registries and in some health systems have been collecting this information for some conditions or procedures. However, coherent and systematic patient reporting across the entire range of health system activities and interventions is not yet in place.

### Outputs provide only a partial picture of health system performance

Processes and activities, on the other hand, are routinely collected and reported. While these are an important part of the overall picture, in isolation they reveal quite little about performance, quality and value. For example, the average rate of total knee replacement in OECD countries doubled between 2000 and 2016 (Figure 2.1). Rates also vary up to 5-fold between and within countries (OECD, 2014[3]). Are the increased rates and the variation warranted? Do these operations make a difference to people's lives, or are some of them performed unnecessarily? What is the effect of waiting times for knee replacement, and patient's age at surgery? Are some patients better off choosing other treatments for their symptoms?

Figure 2.1. **Total knee replacement rates have doubled since 2000**

Total knee replacement rates per 100 000 population – adjusted for population ageing – selected countries and OECD average



Note: OECD is age-adjusted rate of countries submitting data. Countries chosen based on data availability over this period.

Source: OECD Health Statistics 2019.

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Such questions cannot be answered without knowing care outcomes. Case fatality or hospital re-admission are useful measures but are becoming rare in routine procedures such as joint replacement. They are also silent on other outcomes valued by these patients such as reduction in pain, and increase of mobility and function.

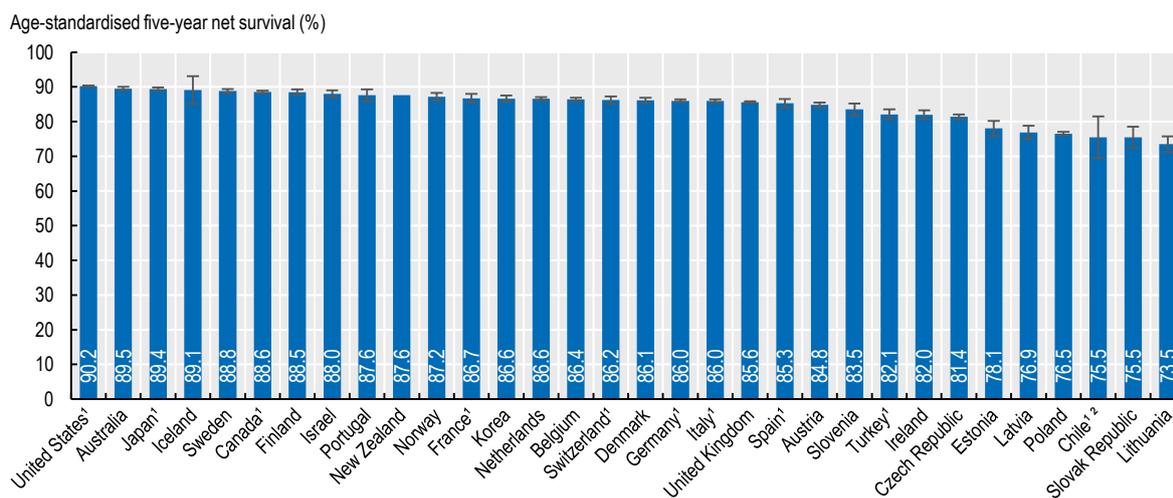
### We know how medicine treats diseases but what about the patient's quality of life?

Traditional outcome measures like survival or mortality will remain useful but cannot capture more subtle yet important effects. For example, people diagnosed with cancer

value survival highly, but therapeutic success entails more than just survival (Abahussin et al., 2018[4]). Survival and mortality say little about nausea, pain, sleep quality, body image, sexual function, independence and time spent with loved ones. Also, for some conditions, mortality and survival are now similar between OECD countries (Figure 2.2), with little separating the ‘best from the rest’. This hinders continued learning about best therapeutic approaches, techniques and interventions (Donovan et al., 2016[5]; Hamdy et al., 2016[6]).

Figure 2.2. **Cancer survival is similar between countries**

Breast cancer age-standardised five-year survival of patients diagnosed from 2010-2014



Note: H lines show 95% confidence intervals. 1. Coverage less than 100% of national population. 2. Survival estimates considered less reliable.

Source: CONCORD programme, London School of Hygiene and Tropical Medicine.

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That medicine has become quite successful at treating disease should be celebrated. However, continual improvement must include assessment of the impact treatments have on people’s lives. This makes outcomes valued by patients a key indicator of success. Men diagnosed with prostate cancer are now very likely to survive this condition. Beyond survival they also highly value preserving erectile function and avoiding incontinence (Nag et al., 2018[7]) – outcomes of significant interest to patients, providers as well as policymakers.

### **A good care experience contributes to better outcomes and is also an end in itself**

In addition to outcomes, *how* people are treated also matters. This includes being treated with respect and compassion and being supported, listened to and involved in decision-making. It also means that care is better integrated across teams who communicate well with each other and with the patient.

A positive care experience is a strong signal of quality care and is instrumental in outcomes achieved, especially for those who manage multiple chronic conditions (Stein et al., 2014[8]; Trzeciak et al., 2016[9]; Luxford, Safran and Delbanco, 2011[10]). In mental health, for example, a positive care experience influences the relationship with the care team, manifesting in better communication, therapeutic continuity, adherence and health outcomes (Wong et al., 2019[11]). But it is also an important end in itself. All patients expect

and deserve to be treated with respect. In some sectors, such as palliative care, being cared for with compassion and dignity are among the most important components of care.

Yet despite considerable progress in some specific cases, the care experience is not captured systematically. This needs to change, given the growing importance of this dimension of service delivery.

### **Shared decision making requires patient-reporting**

In the clinical setting, measuring patient-reported metrics helps to focus the health care interaction on the needs of the individual. The discussion moves from ‘what’s the matter with you?’ to ‘what matters to you?’ – a critical first step in shared decision making, a core principle of people-centred care. Aggregated patient-reported outcomes can inform care decisions and help choose the right therapeutic option where various interventions (including ‘watchful waiting’) are available (Veroff, Marr and Wennberg, 2013[12]). People see what the most likely outcomes of an intervention may be and can decide accordingly.

Regular reporting by patients throughout their care journey adds structure and rigour to assessment, decision-making and action. Care can be better tailored to individual needs, and enables a rapid and accurate response to clinical deterioration. For example, reporting of symptoms by patients during chemotherapy has been found to significantly prolong survival and reduce hospitalisation (Basch, 2017[13]; Basch et al., 2017[14]).

Knowledge derived from patient-reported data can be used to develop decision aids and update clinical practice guidelines. It also informs providers on how their work affects patient health and well-being. Patient-reported outcome measures, for example, provide a way to measure clinical progress more objectively. They can complement other metrics to provide a fuller assessment of performance of therapies and services. If implemented well, benchmarking and even public reporting can be a powerful driver of quality improvement (Greenhalgh et al., 2017[15]).

Data generated by patients can also contribute towards assessing the performance of medical products, combination therapies, care pathways, health services and the health system as a whole. Combined with other data, these can furnish researchers, regulators, health technology agencies, payers, researchers and policy makers with the knowledge to make more informed decisions to maximise health system performance, and meet the expectations of patients, citizens and communities (Calvert, O’Connor and Basch, 2019[16]).

### **Patient-reported measures are robust and reliable**

The ability to elicit information from individuals on their health status, quality of life and care experience is now decades old. The available instruments and surveys have undergone rigorous psychometric testing and statistical validation, with results published in the peer-reviewed literature. The field is mature and evidence supports that these instruments reliably measure what is intended (Black, 2013[17]). Box 2.1 outlines the different types of patient-reported outcome and experience measures (PROMs and PREMs) as well as some of the technical aspects of how these are collected, interpreted and used.

In the end, no single data source can provide information for a complete assessment of how a highly complex, adaptive health system performs. Patient-reported data need to be interpreted in the context of other metrics on health system activity and performance. They are not meant to supplant but to complement existing data that are collected in an effort to avoid tunnel vision and generate a more complete picture of performance for all involved: patients, providers, regulators and policy makers. In order for patient-reported

### Box 2.1. Measuring patient-reported outcomes and experiences of care

Instruments to elicit information from patients on self-reported health status, outcomes and experiences of care typically comprise questionnaires of varying length and format. These are administered in a range of ways (verbally, electronically or on paper). The two main categories of patient-reported outcome measures (PROMs) are condition-specific PROM instruments and health-related Quality of Life (QoL) instruments – commonly termed ‘generic’ PROMs.

#### Condition-specific PROMs

These are designed specifically for a condition (e.g. osteoarthritis) or a procedure (e.g. joint replacement). These PROMs are tailored to the symptoms of a specific condition, or those that a specific procedure tries to address. As such their advantage is sensitivity and specificity. Their key limitation is a lack of generalisability – that is, their results cannot be directly compared with results from instruments designed for other conditions or procedures, unless validated mapping algorithms (‘crosswalks’) exist to convert scores between one and the other.

#### Health-related QoL instruments (‘generic’ PROMs)

‘Generic’ PROMs instruments attempt to capture a broader range of physical and psychosocial domains that are considered important determinants of health-related QoL. Their advantage is that they can be compared across different conditions, procedures and interventions. For this reason they are often used in cost-utility analysis and health technology assessment (HTA).

#### Patient-reported experience measures (PREMs)

The patient experience is also measured using surveys or questionnaires. These can be administered in various ways and a number of approaches and questions have been developed. Questions can be tailored to a certain setting (e.g. primary, hospital, long-term care) or assess a specific aspect of care (e.g. continuity, autonomy, information provision). PREMs are now sophisticated and anchored to objective events, having moved well beyond the more subjective patient ‘satisfaction’ surveys of the past. They elicit scaled data across a range of dimensions including accessibility, communication, continuity and confidence. These data are now used to inform assessment and international comparisons of health systems (Schneider W, 2017[18]).

#### Collecting and using patient-reported data

A range of factors influence the outcomes of care as reported by patients. These factors include behaviour, adherence, age and comorbidities. But more traditional outcome measures such as readmission and mortality are subject to the same confounding variables. All data, whether patient-reported or not, have limitations and should be interpreted with the necessary caution. Like any outcome data that are used for benchmarking, confounders for patient-reported indicators should usually be adjusted in order to enable meaningful comparisons (Nuttall, Parkin and Devlin, 2013[19]).

measures to fulfil their promise in service provision, research and policy, standardisation of methods for data collection, analysis and reporting are essential. This relies heavily on international collaboration (Calvert, O’Connor and Basch, 2019[16]).

### Joint replacement rates are rising but are patients reporting improvement?

Each year, over 2.2 million people undergo an elective hip or knee replacement in OECD countries. Knee replacement rates have doubled since the year 2000 (Figure 2.1), while hip replacements have increased by 30%. Inter- and intra-country variation in rates can be as high as 5-fold (OECD, 2014[3]).

Patients typically undergo these procedures to manage symptoms of osteoarthritis such as pain and loss of mobility and function, which have a considerable impact on health-related QoL. Both procedures are invasive and, like all surgery, involve a degree of risk. They require a long period of rehabilitation. They are also expensive. In Australia, for example, they account for over 2% of total health expenditure.<sup>1</sup>

Given that alternative non-surgical ways of managing hip and knee pain exist (physical therapy, exercise and medication) patients should be able to base their decision to proceed with surgery on the expected outcomes including pain, mobility and capacity to perform daily activities following a period of recovery. Payers should expect that the procedures represent value compared to the alternatives.

The orthopaedic community has been among the most active in encouraging the collection of patient-reported data. Nevertheless, national-level reporting is the exception. Most patient-reported data collections are part of regional and local programmes, or voluntary registries covering a subset of a country's providers and hospitals.

A range of instruments measuring dimensions such as pain, function and QoL are in use around the world. Questionnaires are typically completed by the patient pre-surgery and then at a specified time point after the operation (usually 6 or 12 months). The numerical difference between the pre-operative and post-operative scores is the key value of interest.

The OECD has been working with a range of stakeholders and experts, including patients and clinicians, to collect PROM data internationally. Ten programmes across eight countries contributed to a recent pilot data collection. These included national initiatives (England, Netherlands, Sweden), regional (Canada – Alberta and Manitoba, Switzerland – Geneva), sub-national registries (the Australian Clinical Outcomes Registry – ACORN – which collects data from providers in two States) and single hospitals (Coxa hospital, Finland;<sup>2</sup> the Galeazzi Institute Italy). Various PROM instruments are used among the contributing programmes, and the post-operative data were collected at either 6 or 12 months.

Adult patients with a diagnosis of osteoarthritis<sup>3</sup> who underwent a unilateral, primary elective total replacement procedure were included in the data collection. The three most recent years of data were collected and aggregated to provide one result per participating programme.

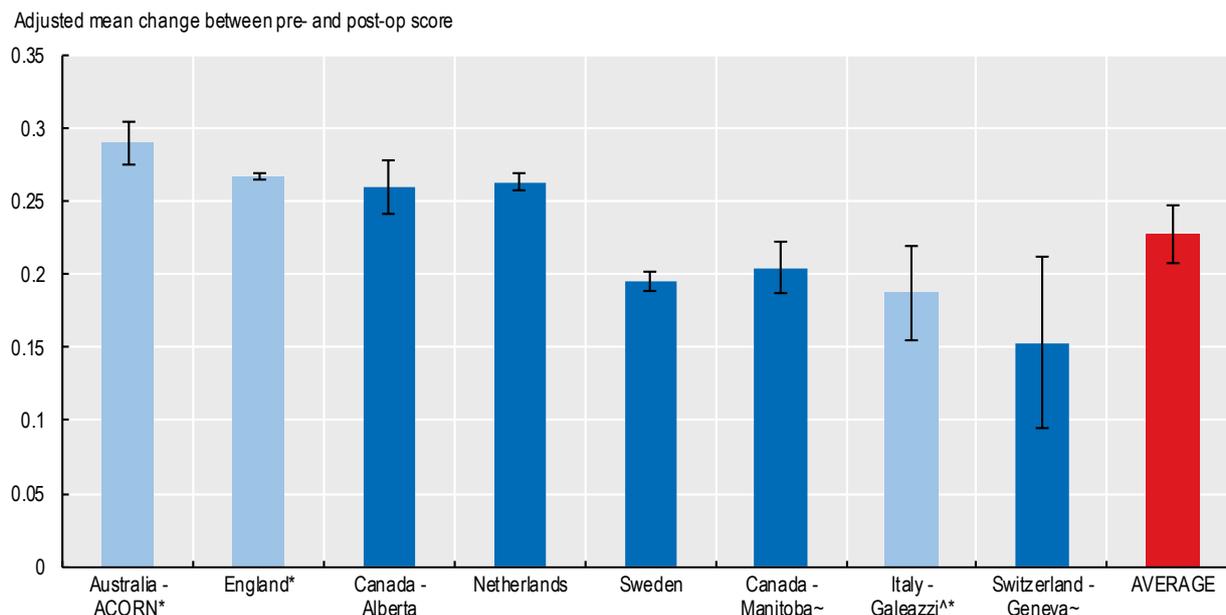
### **On average, hip replacement patients reported improvement**

Hip replacement results derived from the generic instruments (EQ-5D-3L, EQ-5D-5L and SF12) are presented on a common scale – the EQ-5D-3L index with a United States-derived valuation (Shaw JW, 2005[20]). The maximum score on the EQ-5D scale, is 1.0 (denoting optimal health-related QoL) while a negative score suggests health-related QoL rated as worse than death (Box 2.2).

Figure 2.3 presents the average difference between the pre- and post-operative scores<sup>4</sup> – i.e. the mean change in QoL – adjusted for patients' age, sex and pre-operative score (Box 2.2).<sup>5</sup> Results suggest that the average patient in each programme reported improvement in their health-related QoL following a hip replacement. The average mean adjusted change across the programmes was +0.23, which equates to approximately 21% improvement on this index at the respective post-operative time points of 6 or 12 months.<sup>6,7,8</sup>

The adjusted changes between pre-and post-operative scores derived from condition-specific instruments (Oxford Hip Score, HOOS-PS)<sup>9</sup> are presented in Figure 2.4. These need to be displayed on separate axes because algorithms to convert scores from one to the other are not available at present. The Oxford scale ranges from 0 to 48, the HOOS-PS from 0 to 100. In both cases a higher value represents a more desirable outcome.<sup>10</sup> Results suggest, on average, improvement of similar magnitude in all programmes. The average adjusted

Figure 2.3. **Hip replacement: adjusted mean change between pre- and post-operative EQ-5D-3L scores (US valuation), 2013-16 (or nearest years)**



Note: ^ results converted from SF-12v1 instrument; ~converted from SF-12v2 instrument; \*6-month post-op collection - lighter shade blue (all others are 12 months). H lines show 95% confidence intervals.

Source: PaRIS Hip/Knee Replacement Pilot Data Collection.

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mean change (not shown) was +23 on the Oxford scale and +32 on the HOOS-PS scale, which equates to about 48% and 32% improvement respectively.<sup>11</sup> More condition-specific results are provided in Chapter 6.

### Improvements reported following knee replacement were more modest

The adjusted changes between pre-and post-operative knee replacement scores derived from condition-specific instruments are presented in Figure 2.5 (the scales are the same as for hip replacement). On average, patients in each programme reported improvement of similar magnitude. The average adjusted mean change (not shown) was +17 on the Oxford scale and +22 for KOOS-PS,<sup>12</sup> or 36% and 22% improvement respectively (the corresponding values for hip replacement were 48% and 32%).<sup>13</sup>

Knee replacement results derived from generic instruments are presented using the EQ-5D-3L index with US valuation (see Box 2.2). Data derived from EQ-5D-5L and SF-12 scales were converted using validated algorithms (van Hout et al., 2012[21]; Sullivan and Ghushchyan, 2006[22]; Le, 2013[23]). Figure 2.6 shows the mean changes between pre- and post-op scores, adjusted for age, sex and pre-operative score (Box 2.2). On average, patients in each programme reported improvement ranging from +0.08 to +0.22. The average adjusted mean change across all programmes was +0.18 (about 16% improvement).<sup>14</sup> In comparison, as shown above, the hip replacement equivalent value was +0.23 (21%), a statistically significant difference at the 95% level.

The EQ-5D results suggest that – all other things being equal – the average 65-year-old patient undergoing a knee replacement in the contributing programmes gained an additional (incremental) 3.3 quality adjusted life years (QALYs).<sup>15</sup> In other words, the gain

### Box 2.2. The common EQ-5D index and data standardisation

Different instruments and measures of health-related QoL are used in the participant programmes and countries. Here, data derived from the EQ-5D-5L, and the SF-12 version 1 and version 2 instruments were converted to the EQ-5D-3L scale using validated mapping algorithms (van Hout et al., 2012[21]; Sullivan and Ghushchyan, 2006[22]; Le, 2013[23]).

#### The EQ-5D instrument

The EQ-5D health-related QoL instrument comprises questions covering five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The patient rates each from 1-3 (on the 3L version) or 1-5 (on the 5L version) with 1 being best and 3 or 5 worst. The output is a five-digit 'health state' – e.g. 11111 (perfect health), 33333 or 55555 (worst possible state for 3L and 5L respectively) and a range of permutations in between.

The health states are converted to a single index by referring to so-called valuations specific to a population or country. These valuations have been determined by asking a sample of that population about how they would rate a particular health state against being in perfect health (1.0) and death (0) using a method called time trade-off (TTO). The resulting function is called a valuation or value set. Currently, over a dozen national valuations exist for the 3L version, but fewer have been completed for the newer 5L. The functions can differ considerably between countries (Zhuo et al., 2018[24]). Some remain above zero, others decline into negative values at the worst possible health states. This means respondents rated these states as worse than death, and were willing to trade off time in good health to avoid that health state.

The EQ-5D was designed to generate quality-adjusted life years (QALYs) - a measure that combines morbidity and mortality and is often used to assess the effectiveness of medical interventions. For example, living in a health state of 0.8 on the index for 10 years equates to 8 QALYs.

#### The EQ-5D-3L index (US valuation) as the common scale

The EQ-5D-3L index was chosen as the common metric because (a) the majority of countries use this instrument; (b) algorithms exist to convert – or map – scores from other generic instruments to the EQ-5D-3L. Score conversions were conducted using patient-level data.

'Native' EQ-5D-3L health state valuations (see above) exist for most participation programmes. A single valuation, rather than a mix of respective native value sets, is preferred because it goes some way to mitigate cultural, demographic, socio-economic and other confounders of self-reported health status (Devlin, 2019[25]). It *de facto* presents results consistent with their underlying health state, and removes the additional variability created by a country's unique valuation of these states.

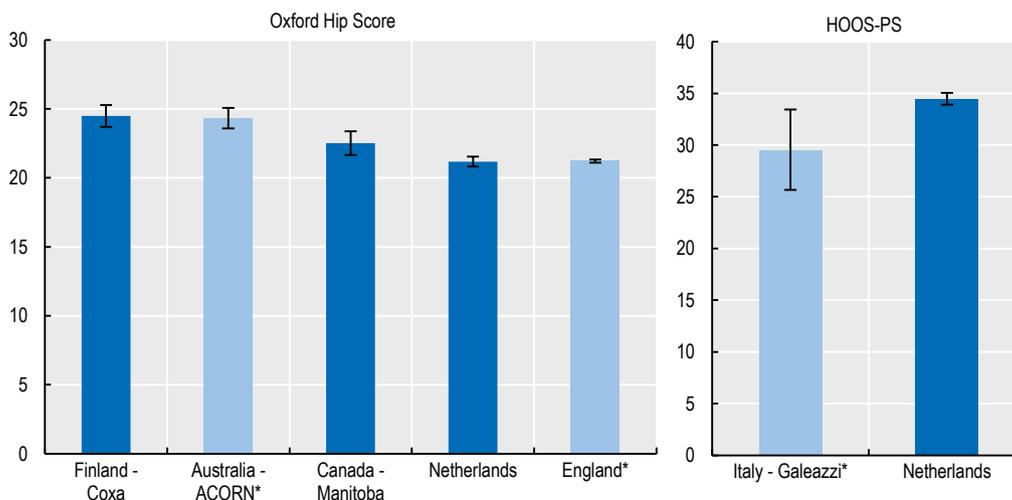
The choice of the US valuation was pragmatic. It was the only 'end point' of the available algorithms to generate EQ-5D-3L scores from the other instruments used by the contributing programmes (van Hout et al., 2012[21]; Sullivan and Ghushchyan, 2006[22]; Le, 2013[23]).

#### Standardising results to enhance comparability

To enhance comparability and mitigate the effect of demographic and other variables, results shown (derived from both generic and condition-specific tools) were adjusted for age, sex as well as the reported pre-operative PROM score, to a population based on the pooled data of the contributing programmes. Three age categories and two pre-operative score categories were used. Differences between crude and adjusted results were small in the majority of cases. Results were not adjusted for co-morbidity or socio-economic status due to the lack of consistent data.

was the equivalent of 3.3 years with 'full' health-related QoL over the expected remainder of their life compared to the pre-operative status quo (i.e. a 'no intervention alternative'). The corresponding figure for hip replacement is higher at 4.3 QALYs (Figure 2.7).<sup>16</sup> The difference between the procedures is consistent with existing literature (Konopka et al., 2018[26]). It should be noted, however, that knee replacement procedures typically have a longer recovery period than hip replacements. This may explain some of the difference.

Figure 2.4. **Adjusted mean change between pre- and post-operative Oxford Hip Score and HOOS-PS scores, 2013-16 (or nearest years)**

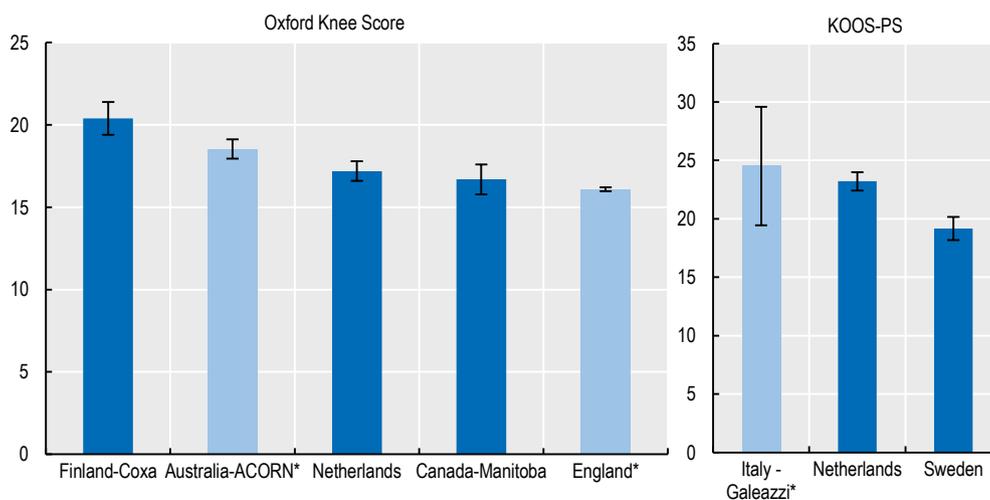


Note: \*post-op collection at 6 months – lighter shade blue (all others at 12 months); Scales: Oxford 0-48; HOOS-PS 0-100. H lines show 95% confidence intervals.

Source: PaRIS Hip/Knee Replacement Pilot Data Collection.

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Figure 2.5. **Adjusted mean change between pre- and post-operative Oxford Knee Score and KOOS-PS scores, 2013-16 (or nearest years)**



Note: \*post-op collection at 6 months – lighter shade BLUE (all others at 12 months); Scales: Oxford 0-48; KOOS-PS 0-100. H lines show 95% confidence intervals.

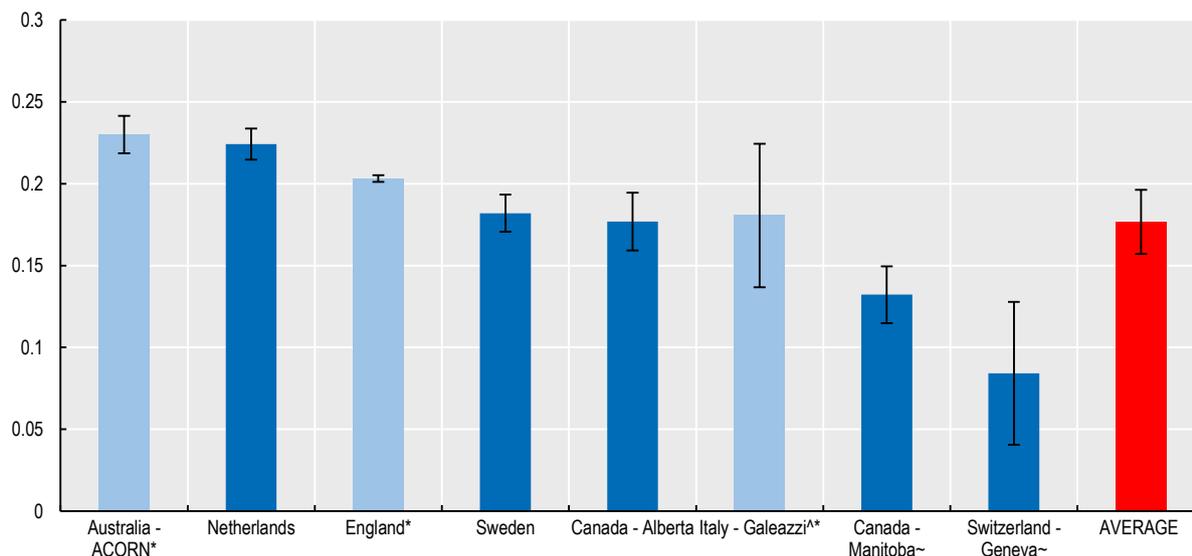
Source: PaRIS Hip/Knee Replacement Pilot Data Collection.

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### Results should be interpreted with caution

On average, patients undergoing hip or knee replacement procedures in the participating programmes reported an improvement in their symptoms and health-related QoL. This does not mean that all patients improved. In fact, a small but significant proportion reported no change or a worsening in their symptoms and health-related QoL for both procedures across the participating programmes. While this may still be a better

Figure 2.6. **Knee replacement: adjusted mean change between pre- and post-operative EQ-5D-3L scores (US valuation), 2013-16 (or nearest years)**

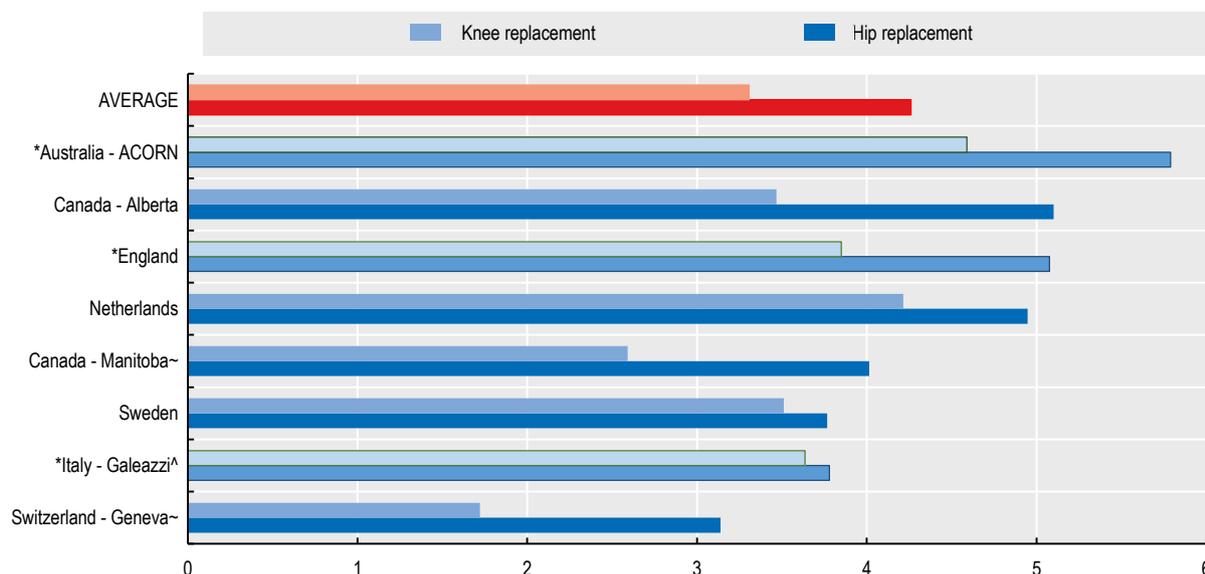


Note: ^ results converted from SF-12v1 instrument; ~converted from SF-12v2 instrument; \*6-month post-op collection – lighter shade green (all others are 12 months). H lines show 95% confidence intervals.

Source: PaRIS Hip/Knee Replacement Pilot Data Collection.

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Figure 2.7. **Both hip and knee replacements generate additional QALYs for patients**



Note: ^ results converted from SF-12v1 instrument; ~converted from SF-12v2 instrument; \*6-month post-op collection (all others are 12 months).

Source: PaRIS Hip/Knee Replacement Pilot Data Collection.

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outcome compared to the counterfactual (the status quo), receiving no intervention is unlikely given the availability of other treatment modalities in most health systems.

Results presented here are, in fact, silent on how the outcomes of hip and knee replacement surgery compare with other, more conservative surgical or non-surgical

treatments including exercise therapy and pharmaceuticals. This would require expanding the study cohort to patients who choose non-surgical therapy for joint pain. The literature suggests that non-surgical interventions indeed improve joint pain and function in people suffering from osteoarthritis, although joint replacement (followed by exercise therapy) results in greater patient-reported improvement (Skou, Bricca and Roos, 2018[27]; Skou et al., 2018[28]). However, joint replacement is associated with a higher number of serious adverse events such as infection than non-surgical treatment (Skou et al., 2015[29]).

Although results were standardised for age, sex and pre-operative score, a number of programme-specific variables limit their comparability. The number of patients differ considerably in each programme. Some of the contributing programmes collect post-operative scores at 6 months, others at 12 months. The latter is considered to be the optimal time for post-operative assessment as full recovery is expected 1 year after surgery. It is unknown how outcomes change beyond the respective time points when data are collected post-operatively. Programmes also deploy different modes of collecting data (paper, electronic, telephone) which is known to influence results. The response rates vary between programmes. Despite adjustment for pre-operative score, differences in wait times between countries may also influence results. Finally, results from three programmes were converted from, EQ-5D-5L and SF-12 to the EQ-5D-3L index (US valuation), which may bias the final results.

In addition, results have not been adjusted for casemix and co-morbidities because consistent data were not available across all programs. A range of cultural, demographic and socio-economic factors influence self-reported health status and will also influence the comparability of results, even when a common index and valuation are used.

### Better information on breast cancer care outcomes helps patients facing difficult treatment choices

Breast cancer is the most prevalent form of cancer in women worldwide, with about 2.1 million newly diagnosed cases in 2018 accounting for almost 1 in 4 cancer cases among women (Bray et al., 2018[30]). While an increase in the incidence of breast cancer over the past decade has been observed, mortality has declined in most OECD countries. Early diagnosis as well as improved treatments have contributed to this result, with most OECD countries now having 5-year net survival rates of 80% (see earlier discussion and Figure 2.2).

Although surgery is the preferred local treatment for the majority of early breast cancer patients, a range of treatment options exist when considering the specific approach for each woman's care. For example, primary systemic treatment with chemotherapy or hormonal therapy can improve surgical options by reducing tumour size before surgery. Post-surgical radiation therapy, chemotherapy, and/or hormonal therapy can lower the risk of recurrence of the cancer.

The three main surgical interventions for breast cancer are:

- **Breast conserving therapy (BCT)** involves a surgical operation to remove the cancer while leaving as much of the breast as possible – commonly an option in early-stage cancer. This is the primary surgical choice for breast cancer, with 60%–80% of newly diagnosed cancers amenable to breast conservation at diagnosis or after primary systemic therapy for women in Western Europe (Cardoso et al., 2019[31]).
- **Mastectomy** involves complete removal of the breast surgically and is often undertaken when a woman cannot be treated with breast conserving therapy. However, a woman

may prefer a mastectomy over a breast conserving therapy and women at very high risk of getting a second cancer sometimes have both breasts removed.

- **Breast reconstruction** may be chosen by women who have had mastectomy of their breast to rebuild the shape and look of the breast. The two main types of breast reconstruction are: 1) **implant** reconstruction surgery which involves the insertion of a silicone implant after the removal of the woman's breast tissue; and 2) **autologous** reconstruction surgery, which uses tissue from other parts of the woman's body, such as her belly, back, thighs, or buttocks to rebuild the breast shape. This form of reconstruction is generally considered to look more natural and behave more like natural breast tissue than breast implants.

The choice of treatment and outcomes for women with cancer are influenced by a number of factors including the size and location of the tumour, biology or type and characteristic of the tumour, age, general health status, service availability, related health risks and patient preferences.

As such, the choice of surgical approach can influence a woman's subsequent quality of life. Women diagnosed with breast cancer can therefore face difficult decisions when considering treatment options. While factors such as age, general health status and the size and location of primary tumour are important to clinical decision making, the preferences of the patient are also central to the choice of treatment strategy (Cardoso et al., 2019[31]).

Beyond the overarching objective to stay alive, QoL is also a key consideration. In weighing treatment options, information about the outcomes of other women who have been in similar circumstances can potentially be of great help in the decision making process and ongoing reflection of progress during and after treatment and into survivorship.

### **The collection and use of PROMs in breast cancer care is growing**

Motivated providers and patients across OECD countries are increasingly measuring patient-reported care outcomes to help inform difficult clinical decisions. The utility of such measurement is increasingly appreciated. For example, in the Netherlands breast cancer has been identified as one of the possible priority areas as part of a current national policy effort to measure patient-reported outcomes systematically and implement 'value-based' care (van Egdom et al., 2019[32]). Nevertheless, a variety of different PROM instruments are used, making comparability of outcomes more difficult. In addition, the scale of uptake is still largely localised and isolated to specific initiatives and clinical champions at specific sites.

In an effort to address this emerging priority, the OECD worked with a group of experts (including patients, clinicians, policymakers and industry representatives) and collaborating organisations to understand the current state of the art in breast cancer PROMS and to explore opportunities for international data collections and comparisons.

These efforts have culminated in a preliminary international data collection involving 11 clinical sites from 8 countries (Flinders Medical Centre, Adelaide, Australia; Angers Cancer Centres, Nantes, France; Charité – Universitätsmedizin Berlin, Germany; Erasmus Medical Center, Rotterdam, Netherlands; Capio St Göran Breast Unit, Södersjukhuset Bröstcentrum and Karolinska Univ.sjukhuset Bröst Endokrin och Sarkom, Stockholm, Sweden; Universitätsspital Basel, Basel, Switzerland; Manchester University Hospitals NHS Foundation Trust, Manchester, UK; Memorial Sloan Kettering Cancer Center, New York, US and Brigham and Women's Hospital, Boston, US).

The postoperative breast satisfaction scale of the breast conserving therapy and breast reconstruction modules of the Breast Q tool was used. This is an internationally validated instrument used to measure breast surgery outcomes reported by patients (Pusic et al., 2009[33]) (Box 2.3).

The data collection involved women aged 15 years and older who received unilateral breast conserving therapy or a breast reconstruction following a mastectomy during the primary treatment of breast cancer. Women undergoing bilateral breast surgery were excluded, given the possible differential impact this surgery may have on breast satisfaction.

### Box 2.3. Breast Q Postoperative Breast Satisfaction Scales

The Breast Q suite of tools is one of the more widely used amidst the range of instruments currently in use internationally to measure patient-reported outcomes from breast cancer surgery (Tevis et al., 2018[34]).

The breast satisfaction scales of the Breast Q tools measure body image in terms of a woman's satisfaction with her breasts and asks questions regarding how comfortably bras fit and how satisfied a woman is with her breast area both clothed and unclothed. Postoperative items ask about breast appearance (e.g., size, symmetry, softness), clothing issues (e.g., how bras fit; being able to wear fitted clothes) and location and appearance of scars. There are separate modules for lumpectomies, mastectomies and reconstructions, with each module consisting of multiple separate scales covering such issues as psychosocial wellbeing, sexual wellbeing, physical wellbeing, satisfaction with breasts and satisfaction with care. There are also implant-specific items, including the amount of rippling that can be seen or felt.

The scores from each scale of the breast conserving therapy and reconstruction scales, along with the other Breast Q scales can be transformed to an Equivalent Rasch Transformed Score of 1-100 to allow direct comparison between scales.

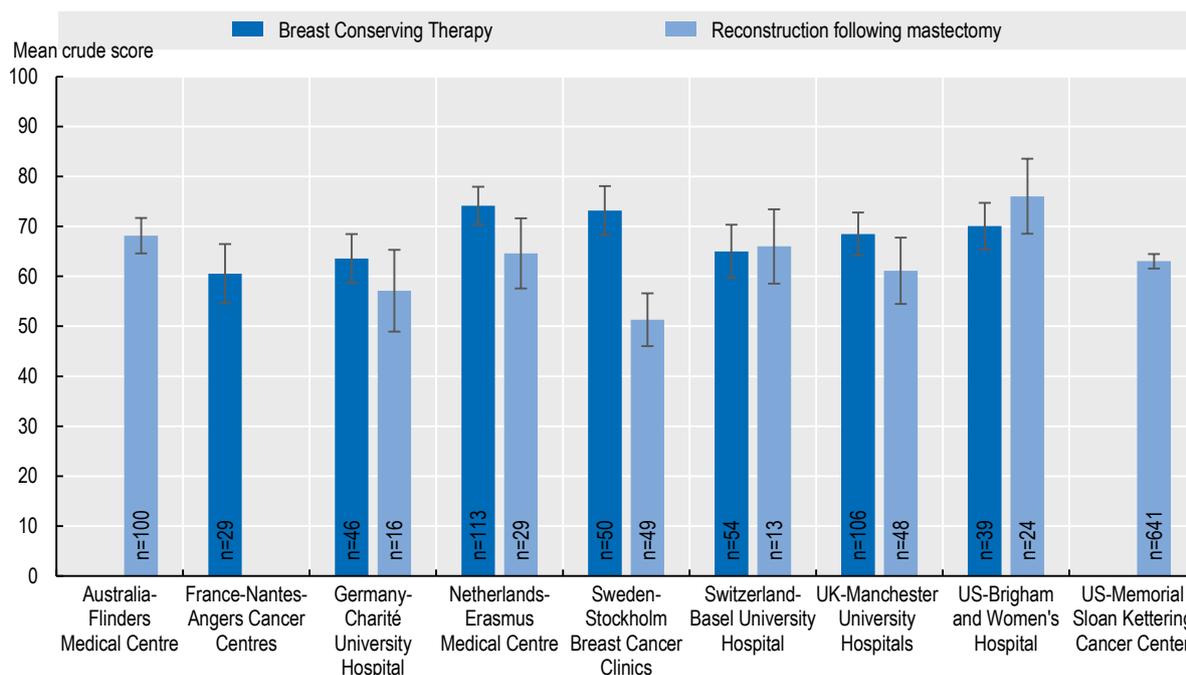
See <http://qportfolio.org/breast-q/breast-cancer/> for more details.

## Results suggest higher breast satisfaction outcomes after breast conserving therapy in some, but not all sites

The crude (unadjusted) outcomes scores at 6-12 months following breast conserving therapy, breast reconstruction, and the aggregate of the two are provided in Figure 2.8. Results are from relatively small samples and are not intended to be representative of the outcomes of breast cancer patients across each country. However, they demonstrate the capacity for metrics of this kind to be reported internationally.

Crude data from sites that reported scores for breast conserving therapy and reconstruction suggest that women in most sites may have higher breast satisfaction outcomes after breast conserving therapy, aligning with conventional wisdom in this area (for example (Flanagan et al., 2019[35])). However, in some sites women may have higher satisfaction scores for reconstruction. Further work and more extensive data collection are needed to validate this observation and consider the generalisability of the data outcomes, but these early observations may provide some basis for further sharing and learning of outcomes across sites. For example, follow up beyond 6-12 months may be warranted, given the timing of outcomes for women can vary as a result of differences in the duration and impact of the usual treatment pathways for BCT and breast reconstruction.

A number of personal factors can influence a woman's postoperative satisfaction with the outcomes of her breast cancer surgery, including age, smoking, obesity, tumour burden, education level, cultural background and overall satisfaction with breasts and physical health before surgery. For example, smoking and obesity can impair tissue healing and

Figure 2.8. **Crude PROM scores for breast cancer point to variations in surgical outcomes**

Note: Measurement extended beyond 12 months after surgery for sites in both Sweden and Switzerland. The data labels at the base of the histogram refer to the sample size at each site. H lines show 95% confidence intervals.

Source: PaRIS Breast Cancer PROMS Pilot Data Collection, 2019.

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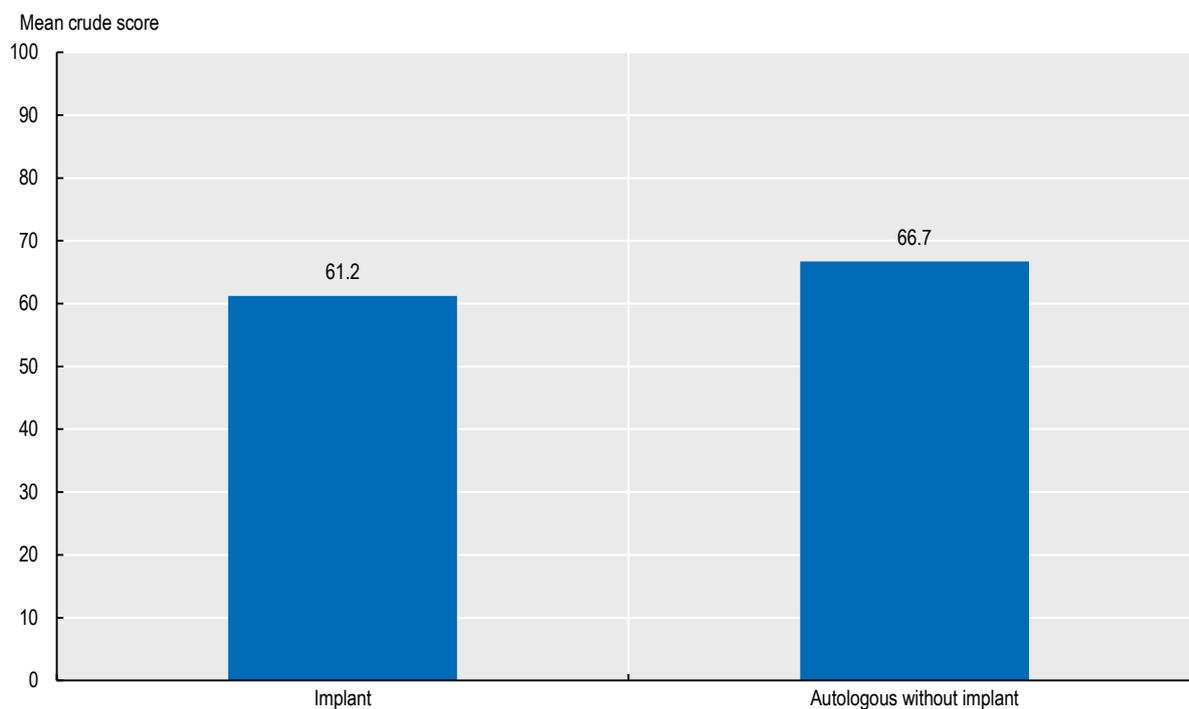
have a negative impact on implant reconstruction results, including aesthetic outcomes (Kern et al., 2015[36]). These factors are largely outside of the health service's direct influence and their impact should ideally be taken into account when comparing the quality of care across sites. Data were collected from participating sites on key patient variables, including age, smoking and obesity but limitations on sample size and incomplete capacity for reporting by all sites prevented risk-adjusting results for the time being.

### **Women report slightly more satisfaction following autologous than implant breast reconstruction**

Consolidated crude scores from the participating sites indicate that women are 6% more satisfied with their breasts after autologous reconstruction surgery than women after a breast implant (Figure 2.9). This result aligns with existing evidence (Matros et al., 2015[37]) and can be an important consideration where choice of surgical intervention is possible.

It follows that the variation in breast satisfaction scores presented in Figure 2.8 may be influenced, among other factors, by the proportion of women undergoing autologous reconstruction surgery. Table 2.1 presents the sample size of women and the proportion undergoing autologous reconstruction reported by each site. The proportion ranges from 100% of women receiving autologous reconstructions (Dutch and Swiss sites) to 0% in the Swedish site, where all women would have received implant reconstructions. However, it is likely some sites have not included all women undergoing reconstruction. For example, data may have been only provided by the plastics surgery unit in some sites and so not include the implant reconstructions performed by the breast surgeons and vice versa.

**Figure 2.9. Crude patient-reported outcomes for implants and autologous reconstructions**  
Self-reported satisfaction with breasts by type of reconstruction surgery, 2017-18 (or nearest years)



Note: Derived from consolidated data from all 11 participating sites.  
Source: PaRIS Breast Cancer PROMS Pilot Data Collection, 2019.

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While no clear relationship between the proportion of women undergoing autologous reconstruction and the overall crude outcomes scores (Figure 2.8) is apparent, further consideration of the factors contributing to the observed wide variation across sites may be warranted, particularly given the conventional wisdom regarding care outcomes. For example, the role of each site within the broader service arrangements for women with breast cancer or the representativeness of the sites' data.

**Table 2.1. Total breast reconstructions and the proportion of autologous reconstructions by site**

	Total breast reconstructions	Autologous reconstructions without implant
	No. of Women	% of total reconstructions
Australia-Flinders Medical Centre	100	57% (57)
Germany-Charité University Hospital	16	19% (3)
Netherlands-Erasmus Medical Centre	29	100% (29)
Sweden-Stockholm Breast Cancer Clinics	49	0% (0)
Switzerland-Basel University Hospital	13	100% (13)
UK-Manchester University Hospitals	48	25% (12)
US-Brigham and Women's Hospital	24	38% (9)
US-Memorial Sloan Kettering Cancer Center	641	24% (153)

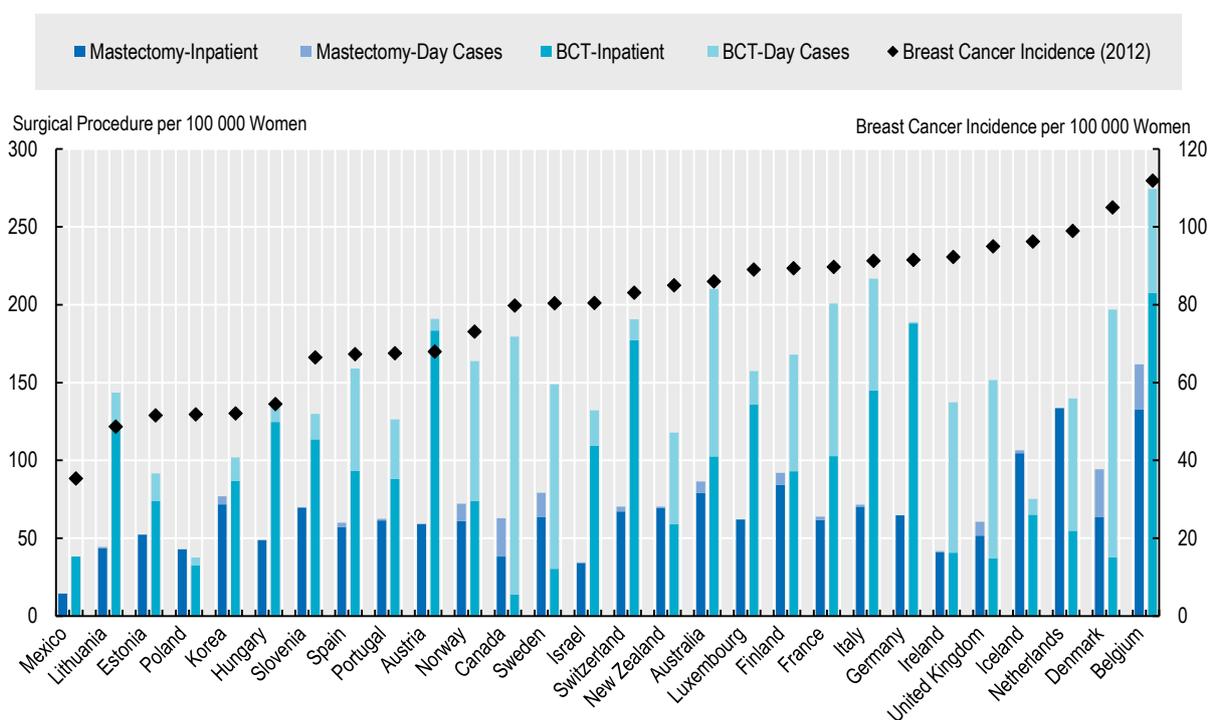
Source: PaRIS Breast Cancer PROMS Pilot Data Collection, 2019.

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### Recent use of PROMs indicates that autologous reconstruction may be cost-effective

Significant variation in treatment pathways and practices persists for women with breast cancer, including the use of different surgical approaches, even in the face of established clinical practice guidelines (Cardoso et al., 2019[31]; OECD, 2013[38]). Figure 2.10 presents the rates, setting and mix of breast conserving therapy and mastectomy surgery across OECD countries. This Figure suggests that different treatment patterns are evident, even across countries showing a very similar level of cancer incidence. Data need of course to be interpreted cautiously as patients' cancer stages, comorbidity and pre-operative patient performance status may also vary.

Figure 2.10. **Breast cancer surgery type and setting (2017) and incidence (2012) per 100 000 women**



Source: OECD Health Statistics 2019.

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Variation in the treatment patterns can also be affected by a number of other factors. For example, regional differences in breast reconstruction surgery in Sweden have recently been attributed to variation in patient information, availability of plastic surgery services and the involvement of women in decision-making (Frisell, Lagergren and de Boniface, 2016[39]).

Treatment choices made by patients in consultation with their clinical teams have not only consequences for survival and QoL, but also financial implications. For example, after a mastectomy a woman faces the choice of whether to have breast reconstruction (as an immediate or delayed procedure) or not and if she proceeds with breast reconstructive surgery, what type of reconstruction she should have. While the outcomes in terms of survival of having a breast reconstruction or not after a mastectomy are generally

comparable (Platt et al., 2015[40]), the choice of reconstruction can lead to different outcomes that are important to women, such as quality of life or satisfaction with breasts as well as different costs faced by the women and the health system.

While autologous reconstructions appear to result in better patient outcomes than implant surgery, they tend to be more complex and expensive, raises questions about value for money (Scurci et al., 2017[41]). A recent study in the United States compared the Breast Q scores of patients who had implant and those who underwent autologous reconstructions and calculated the average additional cost for obtaining 1 year of perfect breast-related health for a unilateral autologous reconstruction at just under USD 12 000 in 2010, compared with implant reconstruction, with lower additional costs for younger patients and earlier stage breast cancer (Matros et al., 2015[37]).

Although society's value for a year of perfect breast-related quality of life is unknown, a threshold of USD 50 000 to USD 100 000 for a year in perfect overall health is commonly used to classify interventions as cost-effective and considered as acceptable for adoption of new technologies or techniques in OECD countries (Cameron, Ubels and Norström, 2018[42]). On this basis, further consideration of the relative cost-effectiveness of autologous reconstructions may be warranted, along with broader economic evaluation of both BCT and breast reconstruction surgery.

Routine collection of data on outcomes that matter for breast cancer patients is useful not only for direct patient care but also for system improvement through better understanding of the impact of different care pathways. They complement traditional measures such as survival, mortality, complications and readmissions. Bringing measures of what matters to patients into the equation creates potential to evaluate alternative modes of treatment both in terms of outcome and value for patients, policy makers and third party payers (Cardoso et al., 2019[31]).

### **Existing mental health measures say little about experiences and outcomes of care**

Mental health is a vital component of individual well-being as well as social and economic participation. However, many OECD countries consider that their mental health care is inadequate. It is estimated that about one in five people experience a mental health problem in any given year, while every second individual will experience a mental health problem in their lifetime (Institute for Health Metrics and Evaluation, 2019[43]). The most common mental health problems are anxiety disorder (5.1% of the population), followed by depressive disorders (4.5%), and drug and alcohol use disorders (2.9%) (ibid.).

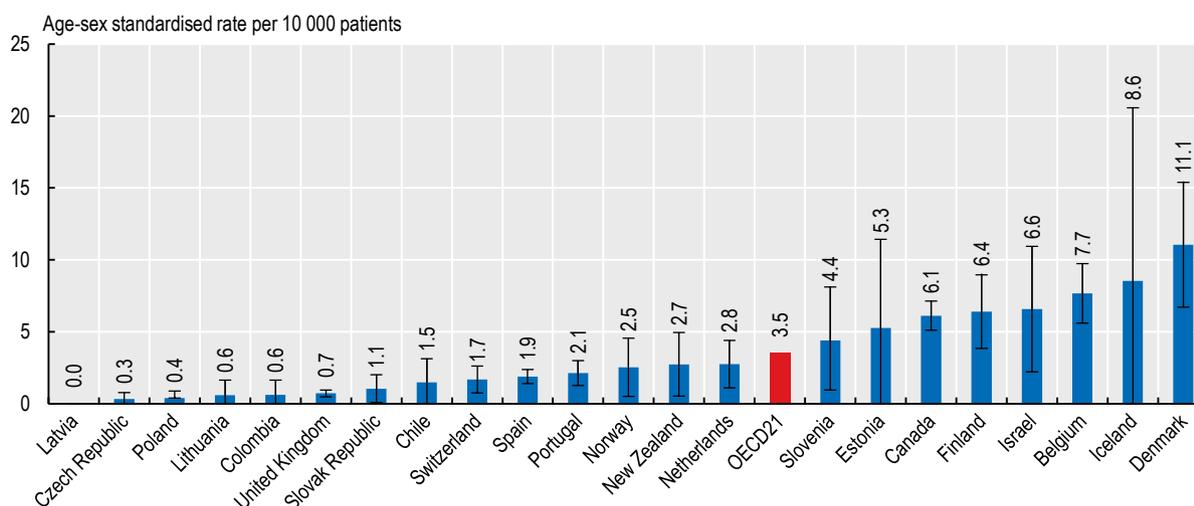
The economic and social costs of mental ill-health are significant. Direct spending on mental health services was estimated to account for around 13% of total health spending – or 1.3% of GDP – across EU countries in 2015 (OECD/EU, 2018[44]). But larger costs are also borne outside of the health system. Lower employment rates and productivity of people with mental health issues incur economic impact equivalent to 1.6% of GDP in EU countries; with greater spending on social security programmes, such as disability benefits or paid sick leave, accounting for a further 1.2% of GDP (OECD/EU, 2018[44]).

Comparable cost estimates have been established in OECD countries beyond the EU. In Australia, for example, the total costs of mental ill-health amount to 4% of GDP, 45% of which are indirect costs (Australian Government - National Mental Health Commission, 2016[45]). Similar figures are reported in Canada and Japan (Sado et al., 2013[46]; Sado et al., 2013[47]; Mental Health Commission of Canada, 2012[48]).

The impact of mental health problems on individuals' lives, and on societies and economies, can be addressed through more effective policies and interventions to prevent and manage them. However, understanding of the impact that mental health care makes on service users' lives is still weak; there is a pressing need to measure the effects and impact of prevention and treatment approaches more consistently and methodically.

Traditional measures say little about the lasting impact that mental health care has on the patient. For example, inpatient suicide is a critical safety measure which indicates when something has gone terribly wrong (Figure 2.11), and is one of the limited measures of care quality that can currently be reported internationally. Thankfully inpatient suicide is very rare, which means for the vast majority of psychiatric patients we do not have a meaningful insight into their experience or outcomes of care.

Figure 2.11. **Inpatient suicide among patients with a psychiatric disorder, 2015-2017**



Note: H line shows 95% confidence intervals. Three year average except for New Zealand.  
Source: OECD Health Statistics 2019.

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Patient-reported measures are a critical tool for improving policy and practice in mental health care. An example of how patient-reported measures (in this case PREMs) can shed light on potential problems with mental health care is provided in Box 2.4, which report survey data on the care experience of people who report having been told by a doctor that they have a mental health condition, compared to those who have not.

### Collaboration to enhance patient-reporting in mental health

Given the health and economic impact of mental ill-health, it is important to assess the quality and outcomes of care in this area. Existing outcome and process indicators – while very useful in some circumstances – do not provide the entire picture of quality and performance. This information gap impedes efforts to improve care, practice and policy.

However, patient-reporting in mental health is still at a relatively nascent stage. Data collection is patchy, and routine reporting and use of the information is far from the norm. As of 2018, only five of the twelve countries surveyed (Australia, Israel, Netherlands, Sweden, United Kingdom – England) reported that PROMs and PREMs were collected regularly in the mental health setting. Only Australia, the Netherlands and England

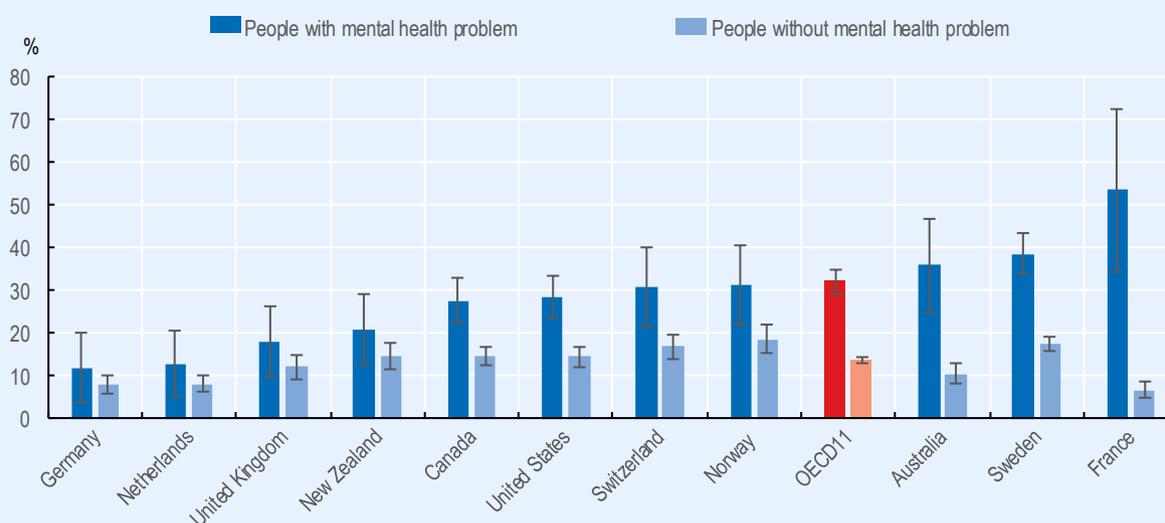
### Box 2.4. The Commonwealth Fund International Health Policy Survey of Adults

The Commonwealth Fund 2016 International Health Policy Survey of Adults (The Commonwealth Fund, 2016[49]) was conducted in 11 countries - Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States - with a total of 26 863 adults interviewed by phone about their experiences with their country's health care system, their health and well-being.

The survey included the question **“Have you ever been told by a doctor that you have depression, anxiety or other mental health problems”**. While there are some methodological challenges in using the survey in this way, including around comparability of response groups and sample sizes, comparing responses across all the survey questions for respondents who answered ‘yes’ with those who responded ‘no’ to the mental health question can shed light on how people who manage a mental health condition in the participating countries experience their health care journey.

Respondents who answered ‘yes’ reported similar experiences to the remaining respondents in some areas of care. In others, their reported care experience appears to be inferior. In several countries, for example, people with a mental health problem were significantly more likely to report having received conflicting information from different health care professionals (Figure 2.12). The differences were most pronounced in Australia, Sweden and France.

Figure 2.12. **People who have been told by a doctor that they have depression, anxiety or other mental health problems are more likely to report receipt of conflicting information from health care professionals**



Note: ‘People with a mental health problem’ are the respondents who answered “yes” to the question “thinking about the past 2 years, when receiving care for a medical problem, was there EVER a time when you received conflicting information from different doctors or health care professionals?” Data limitations. The number of respondents in the 11 countries ranged from 1 000 (Germany) to 7 124 (Sweden). Lowest response rates were observed in Norway (10.9%), Sweden (16.9%), and the United States (18.1%) and the highest were in the New Zealand (31.1%), the Netherlands (32.4%) and Switzerland (46.9%). The sample sizes of respondents who answered ‘yes’ to the mental health question were therefore small, which is reflected in the large confidence intervals (H refers to 95% confidence intervals). In addition, the mental health survey question does not permit distinguishing between individuals who were suffering from a mental health problem at the time of the survey, and those who had experienced mental ill-health in the past but have since recovered. Cultural and linguistic differences in how the question was interpreted could also influence responses. Results have not been risk-adjusted for co-morbidities and socio-economic status.

Source: OECD analysis based on Commonwealth Fund 2016 International Health Policy Survey (The Commonwealth Fund, 2016[49]).

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reported collecting and routinely reporting both. As such, a limited pool of national data exists that are not readily comparable at an international level.

This needs to change, and the OECD has been working with patients, clinicians and policymakers and other experts from 13 countries to develop PREM and PROM data collection standards in mental health to enable international reporting, and foster the capacity to collect and use this important information in OECD countries.

## Conclusion

A fundamental objective of health care is to improve the health and wellbeing of patients and populations. Yet, collecting information from patients on how successful health systems are in this endeavour is not the norm. In addition, emerging demographic, epidemiological and financial challenges are increasing the need to orient health systems around the needs of people and communities. This will not be possible without knowledge sourced directly from patients themselves to complement existing information on health system performance.

Results from preliminary data on patient-reported outcomes were presented in the areas of hip/knee replacement and breast cancer care, while work is underway in the area of mental health.

Over 2.2 million patients undergo a hip or a knee replacement each year in OECD countries. Since 2000, age-adjusted knee replacement rates have doubled in OECD countries, while hip replacement rates have grown by a third. The international landscape for collecting outcomes data from people undergoing hip or knee replacement is varied. Nevertheless, ten programmes from eight OECD countries contributed data reported by adult patients following an elective hip or knee replacement procedure. Results suggest that:

- In each country, both hip and knee replacement surgery improved the pain, function and health-related QoL as reported by patients, with results adjusted for age, sex and pre-operative score.
- Greater gains were reported by patients who underwent a hip replacement. If performed at age 65, hip replacement would, on average, generate an additional 4.3 QALYs compared to of 3.3 QALYs for the average knee replacement (although the longer recovery period following knee replacement surgery must be noted).
- Inter-country variation was modest, suggesting that methods to collect and analyse the pilot data were sound.

Public knowledge of these types of results are very important as a way to improve informed decision-making by patients, and to calibrate patients' goals and expectations when deciding to undergo elective procedures. Results also enable policy decisions and assessing the cost-effectiveness, cost-utility and value from the patient perspective. More patient-reported data will enable solid, temporal analysis and inter-country comparisons in the future. It is important that countries harmonise their data collection at national level.

Breast cancer is the most prevalent form of cancer in women worldwide. While an increase in the incidence has been observed over the past decade, most OECD countries display 5-year net survival rates of 80% or higher. A range of surgical interventions can be deployed to treat breast cancer but relatively little is known about their outcomes valued by women such as pain, breast satisfaction and QoL. Ten sites spanning 7 countries participated in a pilot collection of patient-reported outcomes data for women undergoing surgical breast cancer treatment. The preliminary results from this data collection - which have not been risk-adjusted - generate the following tentative observations:

- Postoperative breast satisfaction of women may vary by type of surgery (whether this be a mastectomy or breast conserving therapy) and by the site of surgery, with some sites reporting higher scores for lumpectomies and others higher scores for reconstructions. This may offer additional opportunities for sharing and learning across sites and countries.
- Of the women who had a breast reconstruction after a mastectomy, the women who underwent *autologous* breast reconstruction surgery reported, on average, slightly better outcomes to women who underwent *implant* reconstruction. This aligns with conventional wisdom, providing women with potentially greater assurance in the use of such information to help assess treatment options.
- Autologous reconstruction may be a cost-effective alternative to implant surgery, when the additional costs for an additional year of perfect breast-related health is compared with broadly accepted cost-effectiveness thresholds.

A number of clinical factors need to be taken into account when considering these observations and ongoing data collection and analytical refinement is required to explore their veracity. However, these results illustrate how this type of information derived directly from patients can potentially be very useful for other women when making difficult decisions and trade-offs on the optimal treatment pathway for their individual needs and preferences, providers when assessing the ‘success’ of various interventions, and payers and policymakers when considering the comparative cost-effectiveness and cost-utility of various treatments.

Mental ill-health exerts a considerable health and economic burden across the world, but systematic collection of patient-reported outcomes and experiences in mental health is at a nascent stage. Despite limitations in the data, the 2016 Commonwealth Fund survey of 11 countries suggests that people with a mental health problem report a worse care experience than those without mental health problems in some aspects of health care, such as receiving consistent information from providers. The OECD is working with international stakeholders including patients, clinicians and policymakers to advance measurement of mental health outcomes and experiences.

Overall, these results demonstrate that presenting valid and comparable results from patient-reported data at international level is eminently possible. However, capacity within and among countries must be increased to collect and report these data in a consistent and harmonised way. OECD will continue to work with countries to promote consistent collection and reporting of these data, in partnership with national and international stakeholders including patients and health care professionals.

## Notes

1. Based on 45 600 hip replacements and 49 500 knee replacements reported in 2016 and 2017 respectively, at a ‘national efficient price’ (NEP) -- the official price paid by the national payer for conducting these procedures in the public sector. The 2019-20 NEP is just under AUD 20 000 for each procedure (<https://www.ihsa.gov.au/publications/national-efficient-price-determination-2019-20>). The overall national figure is likely to be higher because approximately half of procedures are carried out in the private sector where higher prices are typically paid.
2. Coxa hospital has a patient catchment covering an entire region of Finland.
3. With the exception of Galeazzi, which included all principal diagnoses.
4. The value is derived by subtracting the pre-operative score from the post-operative score. A positive value therefore represents an improvement in QoL.

5. Charts showing the average pre- and post-operative results for each participating programme are presented in Chapter 6 (Section: Hip and knee surgery).
6. The degree of improvement was statistically significant at the 95% confidence level in all programmes and in aggregate.
7. The generic and condition-specific scales are not linear – i.e. a change from 0.2 to 0.3 is not necessarily the same magnitude in terms of health-related QoL than 0.7 to 0.8. The percentage improvements are provided for illustrative purposes and should be interpreted cautiously.
8. This does not mean that a joint replacement results in greater health gain than other, more conservative interventions for joint pain, which may be equivalent or even superior in this regard for some patients and on average. This comparison is beyond the scope of this chapter (Section: A good care experience contributes to better outcomes and is also an end in itself).
9. HOOS-PS: Hip disability and Osteoarthritis Outcome Score–Physical Function Shortform.
10. An alternative scoring system exists for both instruments where a lower value represents a better result.
11. See 6 and 7.
12. KOOS-PS: Knee injury and Osteoarthritis Outcome Score-Physical Function Shortform.
13. See 6 and 7.
14. See 6 and 7.
15. As valued by a US population sample (Shaw JW, 2005).
16. The incremental QALYs are derived by multiplying the adjusted mean change by 20.5 years -- the average life expectancy at age 65 in the countries of the contributing programs , minus one year to account for recovery and rehabilitation (OECD, 2019[50]).

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