

# THE IMPORTANCE OF USER-REPORTED INDICATORS OF HEALTH SYSTEM PERFORMANCE

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EPA Forum 2018: Person Centered Mental Health Care: Outcomes That Matter to Patients and Their Carers
Nice March 3 2018





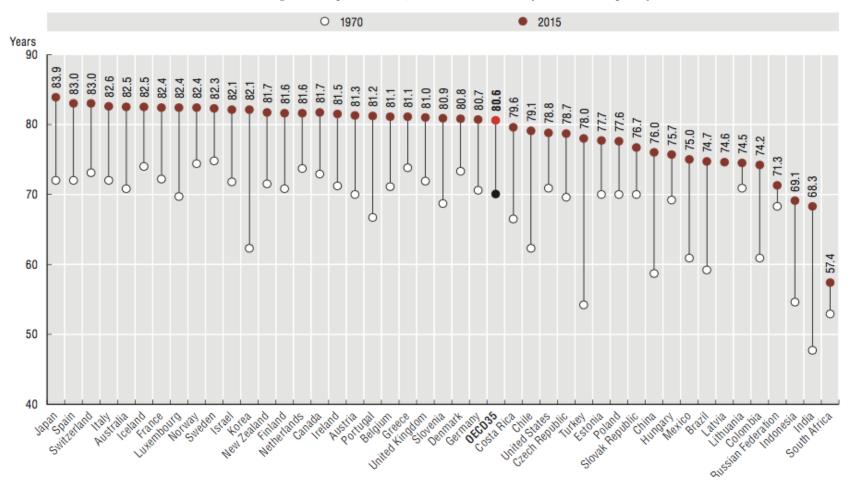
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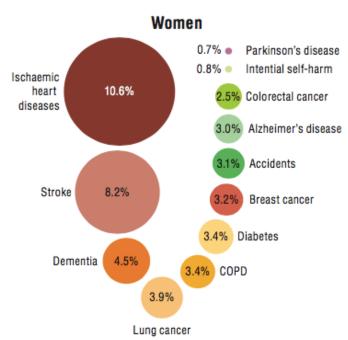
#### HAG 2017 life expectancy at birth

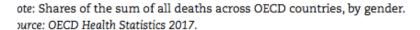
#### 3.1. Life expectancy at birth, 1970 and 2015 (or nearest year)

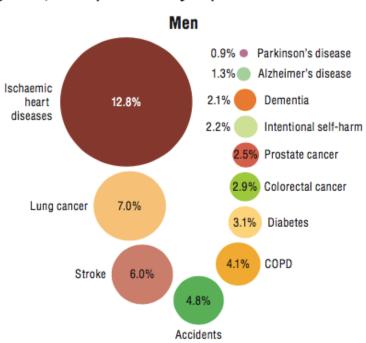




#### 3.7. Main causes of mortality by gender, 2015 (or nearest year)

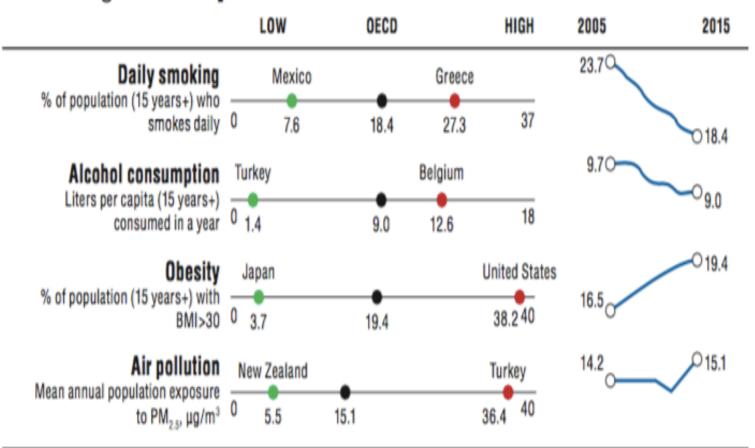






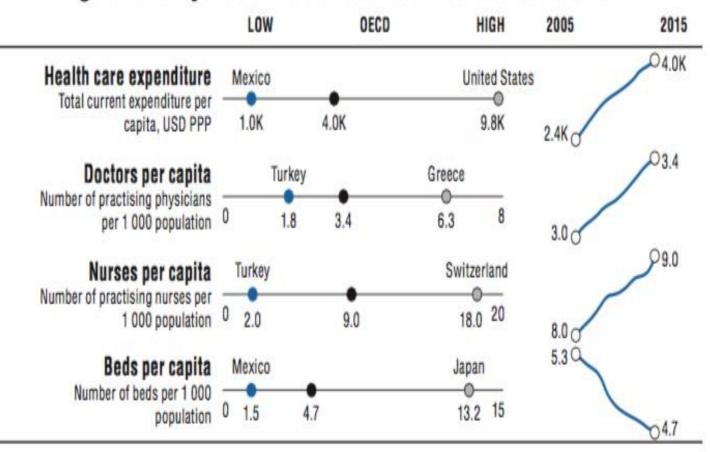
StatLink | http://dx.doi.org/10.1787/888933602

Figure 1.2. Snapshot on risk factors for health across the OECD



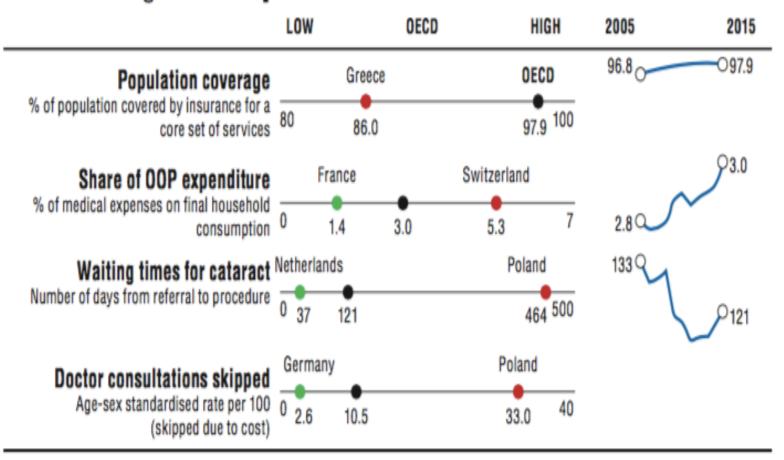
Note: The Y-axis for OECD trends is standardised to have fixed height, based on the minimum and maximum values of the indicator. The high-low X-axis is standardised with constant distance from the OECD average whenever the indicator is not truncated at 0. Air pollution shows data for 2005 and 2010 to 2015.

Figure 1.5. Snapshot on health care resources across the OECD



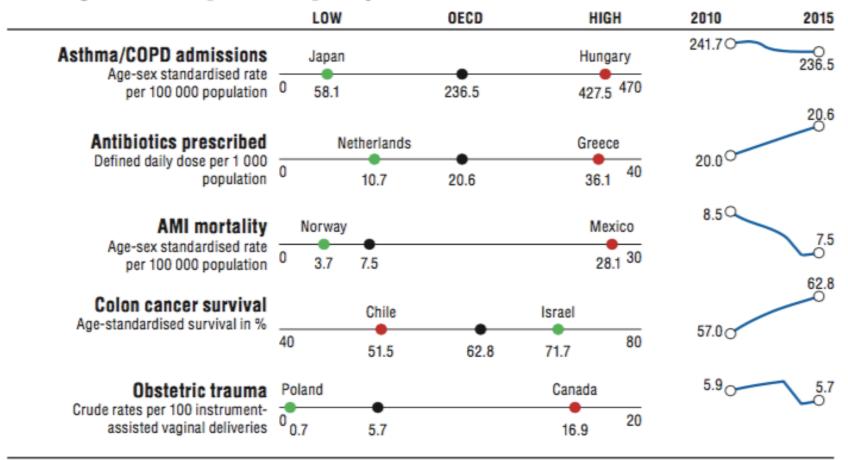
Note: the Y-axis for OECD trends is standardised to have fixed height, based on the minimum and maximum values of the indicator. The high-low X-axis is standardised with constant distance from the OECD average whenever the indicator is not truncated at 0.

Figure 1.3. Snapshot on access to care across the OECD



Note: the Y-axis for OECD trends is standardised to have fixed height, based on the minimum and maximum values of the indicator. The high-low X-axis is standardised with constant distance from the OECD average whenever the indicator is not truncated at 0.

Figure 1.4. Snapshot on quality and outcomes of care across the OECD

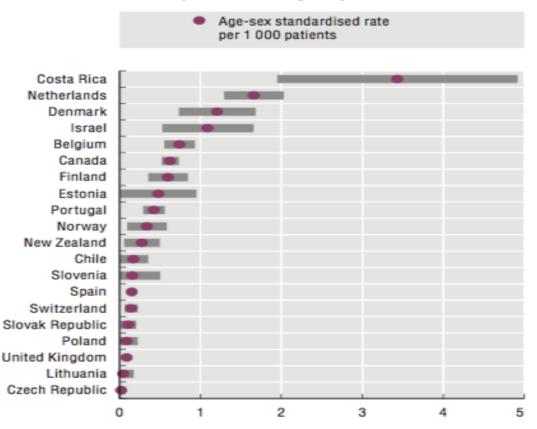


Note: the Y-axis for OECD trends is standardised to have fixed height, based on the minimum and maximum values of the indicator. The high-low X-axis is standardised with constant distance from the OECD average whenever the indicator is not truncated at 0. Asthma/COPD admissions and antibiotics prescribed report 2011 as the baseline year. Obstetric trauma reports 2010.



## Inpatient suicide amongst patients with a psychiatric disorder

### 6.29. Inpatient suicide amongst patients with a psychiatric disorder, 2014 (or nearest year)



Note: multiple year average when data available. 95% confidence intervals have been calculated for all countries, represented by grey areas.

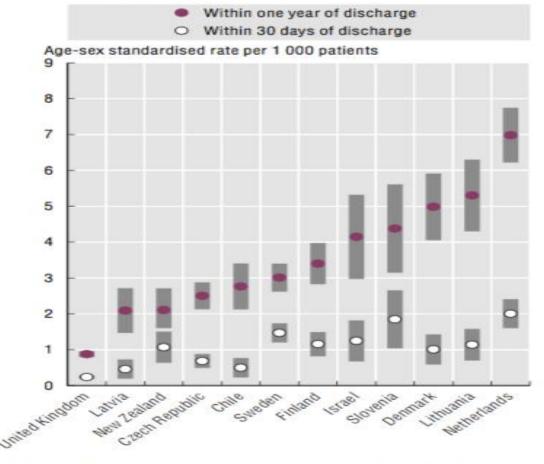
Source: OECD Health Statistics 2017.

StatLink http://dx.doi.org/10.1787/888933603887



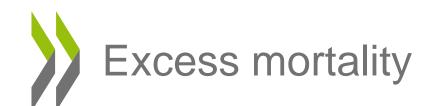
### Suicide following hospitalization

6.30. Suicide following hospitalisation for a psychiatric disorder, within 30 days and one year of discharge, 2015 (or nearest year)

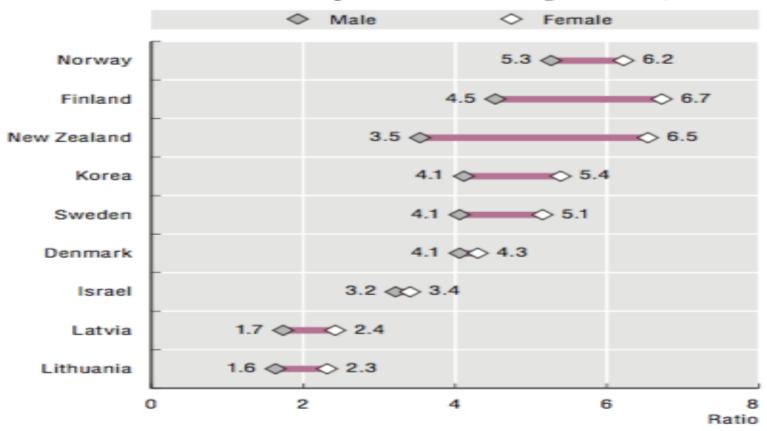


Note: 95% confidence intervals have been calculated for all countries, represented by grey areas.

Source: OECD Health Statistics 2017



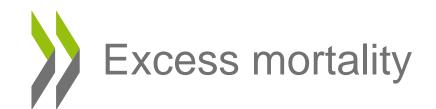
#### 6.31. Excess mortality from schizophrenia, 2014



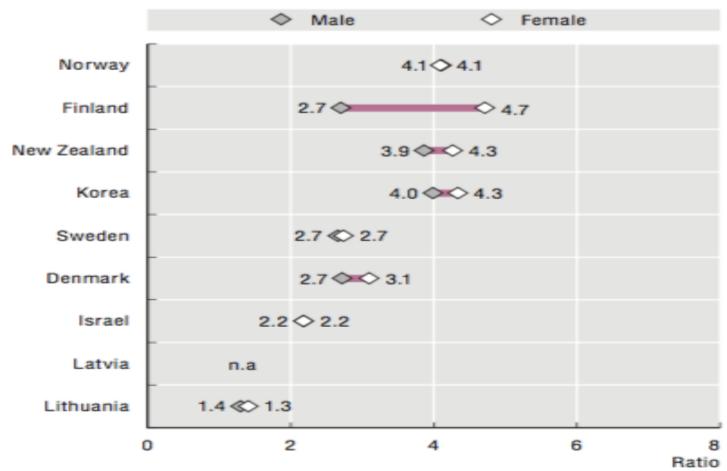
Note: Three-year average for all countries.

Source: OECD Health Statistics 2017.

StatLink | http://dx.doi.org/10.1787/888933603925



#### 6.32. Excess mortality from bipolar disorder, 2014

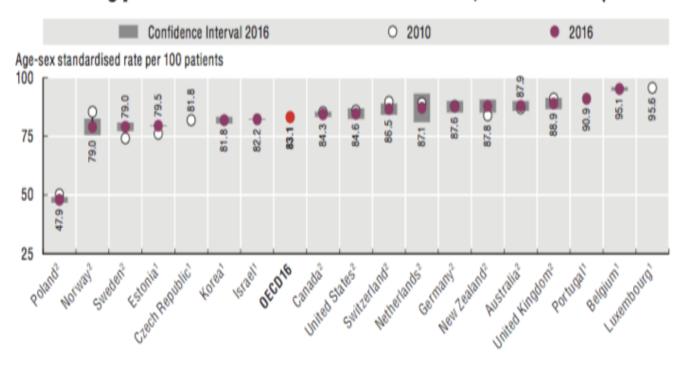


Note: Three-year average for all countries.

Source: OECD Health Statistics 2017.



#### 6.3. Doctor involving patient in decisions about care and treatment, 2010 and 2016 (or nearest year)



Note: 95% confidence intervals have been calculated for all countries, represented by grey areas.

- National sources.
- 2. Data refer to patient experiences with regular doctor.

Source: Commonwealth Fund International Health Policy Survey 2016 and other national sources.



### OECD work on Mental Health

- Mainly based on mortality data
- Difficulties using re-admission and prescription data
- Limited availability of clinical registries
- Analyses on mental health system design (in-hospital versus community based, workforce and relation to employment)



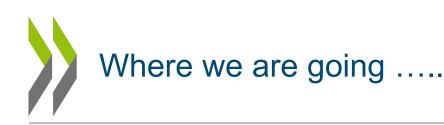
### OECD Policy Forum and Ministerial, January 2017

- Patients
- Health professionals
- Civil society
- Providers & payers
- Policy makers
- Ministers



#### Strategic direction --- People-centred health services

- → modernise delivery
- → build knowledge & capacity
- → systematise patient-reported measurement



#### **Deaths**



#### **Diseases**



#### **Disability**



#### Wellbeing

- Mortality and life-expectancy
  - data source: death registries
- Prevalence and incidence of diseases
  - medical/clinical perspective
  - data source: administrative & clinical data
- How health system deals with disabilities
  - DALY, QALYs, SF36
  - data sources: registries and surveys
- Things that matter to <u>patients</u>, <u>carers</u>, <u>families</u> & <u>populations</u>
  - Wellbeing, function, pain,
  - Quality of Life
  - Generic (e.g. EQ-5d; SF-12; Picker) and disease specific (HOOS, Oxford....)
  - Validated, sensitive & objective tools



#### Patient-reported <u>outcomes</u>

### People report about their health and quality of life before, during and after treatment or intervention



To what extent are patients in **pain** after **hip surgery**?

What is the **health- related quality of life** for people receiving **cancer**treatment?





Can patients live independently after a stroke?

How well can people with a mental health condition live independently?





### ICHOM: Depression and Anxiety Standard 2015



### ICHOM: Depression and Anxiety Standard 2015

- 1 Recommended to track via the Patient Health Questionnaire (PHQ-9).
- 2 Includes symptoms of general anxiety, social phobia, agoraphobia, post-traumatic stress disorder, panic disorder, and obsessive-compulsive disorder.
- 3 Recommended to track via the Generalized Anxiety Disorder (GAD-7), and for those with specific anxiety disorders: the Social Phobia Inventory (SPIN), the Mobility Inventory for Agoraphobia (MIA), the Impact of Event Scale Revised for Post-Traumatic Stress Disorder (IES-R), the Panic Disorder Severity Scale (PDSS-SR), and the Obsessive-Compulsive Inventory (OCI-R).
- 4 Recommended to track via the World Health Organization Disability Assessment 2.0 (WHODAS 2.0).
- 5 Includes work status and disease-related absenteeism

JAMA. 2017 Jul 11;318(2):197-198. doi: 10.1001/jama.2017.7156.

## Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment.

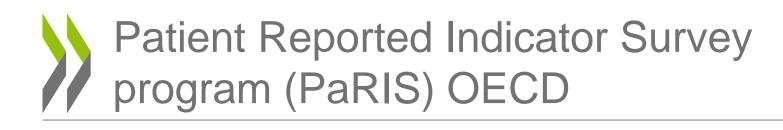
Basch E<sup>1</sup>, Deal AM<sup>2</sup>, Dueck AC<sup>3</sup>, Scher HI<sup>4</sup>, Kris MG<sup>4</sup>, Hudis C<sup>5</sup>, Schrag D<sup>6</sup>.

Author information

#### Comment in

Patient-Reported Symptom Monitoring During Chemotherapy. [JAMA. 2017]

PMID: 28586821 DOI: 10.1001/jama.2017.7156



Building on work ICHOM and CWF

Working Group on Breast Cancer Working Group on Hip/Knee Working Group on Mental Health

New survey development on patients with chronic diseases in primary care



### Dilemma's to be addressed.

- Different purposes of using PROMS
- shared decision making
- quality improvement mental health services (formative function)
- comparison of performance (accountability/summative function)
- International benchmarking
- Effectiveness research



### Dilemmas to be addressed

- Choice of specific PROMS
- Choice of generic PROMS
- Mapping between (domains of) PROMS
- Computer Adaptive Testing approach PROMIS PROMIS® (Patient-Reported Outcomes Measurement Information System) is a set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. It can be used with the general population and with individuals living with chronic conditions



### Cancer Specific PROMS surveys (n=10)

		Cancer Specific							
	EORTC QLQ-C30	EORTC BR23	FACT-B	BreastQ	PRO-CTCAE	ESAS	MSAS	None	
Currently Used		Australia	Australia	Australia					
						Canada			
	Denmark	Denmark			Denmark				
					Finland				
	Netherlands	Netherlands	Netherlands	Netherlands					
lon	Israel	Israel	Israel						
derat								Luexenbourg	
Under Consideration								Malta	
	Norway	Norway	Norway						
	Sweden	Sweden	Sweden				Sweden		

## Generic PROMS surveys (n=10)

	Generic PROMS							
	EQ-5D	SF-36	PROMIS-10	None				
	Australia	Australia						
Used				Canada				
ently				Denmark				
Currently Used								
	Netherlands							
ion	Israel		Israel					
derat				Luxembourg				
onsi				Malta				
Under Consideration	Norway							
5			Sweden					

• Building PROMS and PREMS in the datainfrastructure

- How and when to collect the data (app-based, web-based, before every consultation with a professional...)
- Link with Electronic Health Records
- Link with Clinical Registries



## EPA 2018 principles for using PROMS to achieve person centered care

- Assure involvement patients in standards containing PROMS and PREMS
- Assure data on PROMS and PREMS in mental health are actually used for shared decision making
- Contribute to embedding of PROMS and PREMS data in regular data-systems
- Contribute to international benchmarking





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