

scQA – Societat Catalana de Qualitat Assistencial

# PREMS I PROMS Experiència i resultats del pacient en salut

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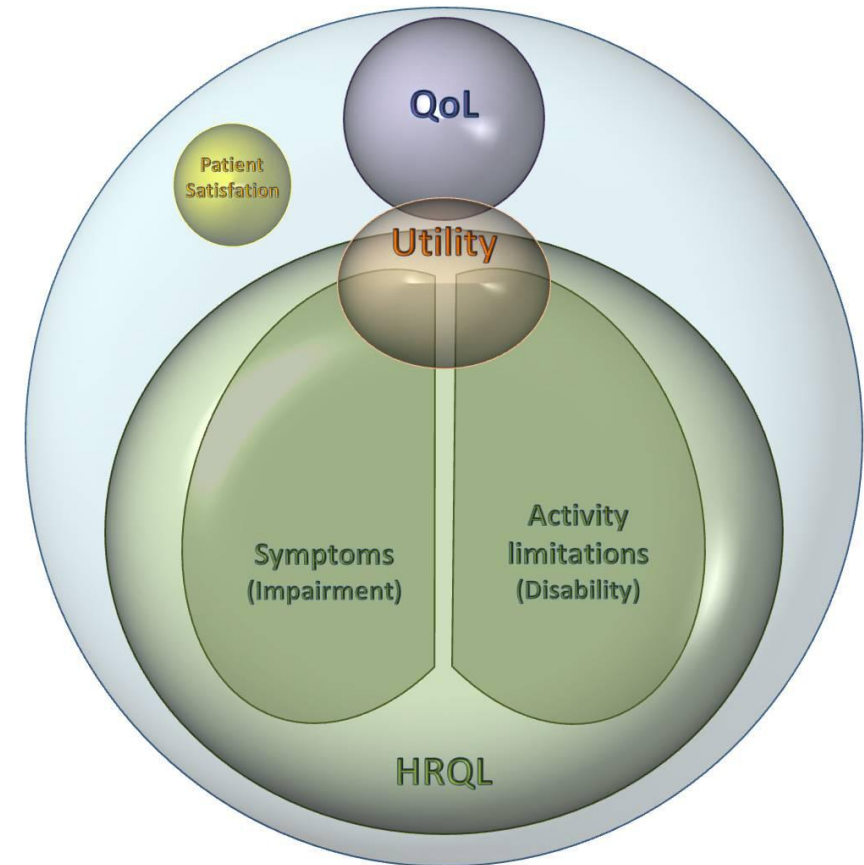
[\(mferrer@imim.es\)](mailto:mferrer@imim.es)

Sessió scQA , 16 de Març, 2023

# Resultados Reportados por los Pacientes

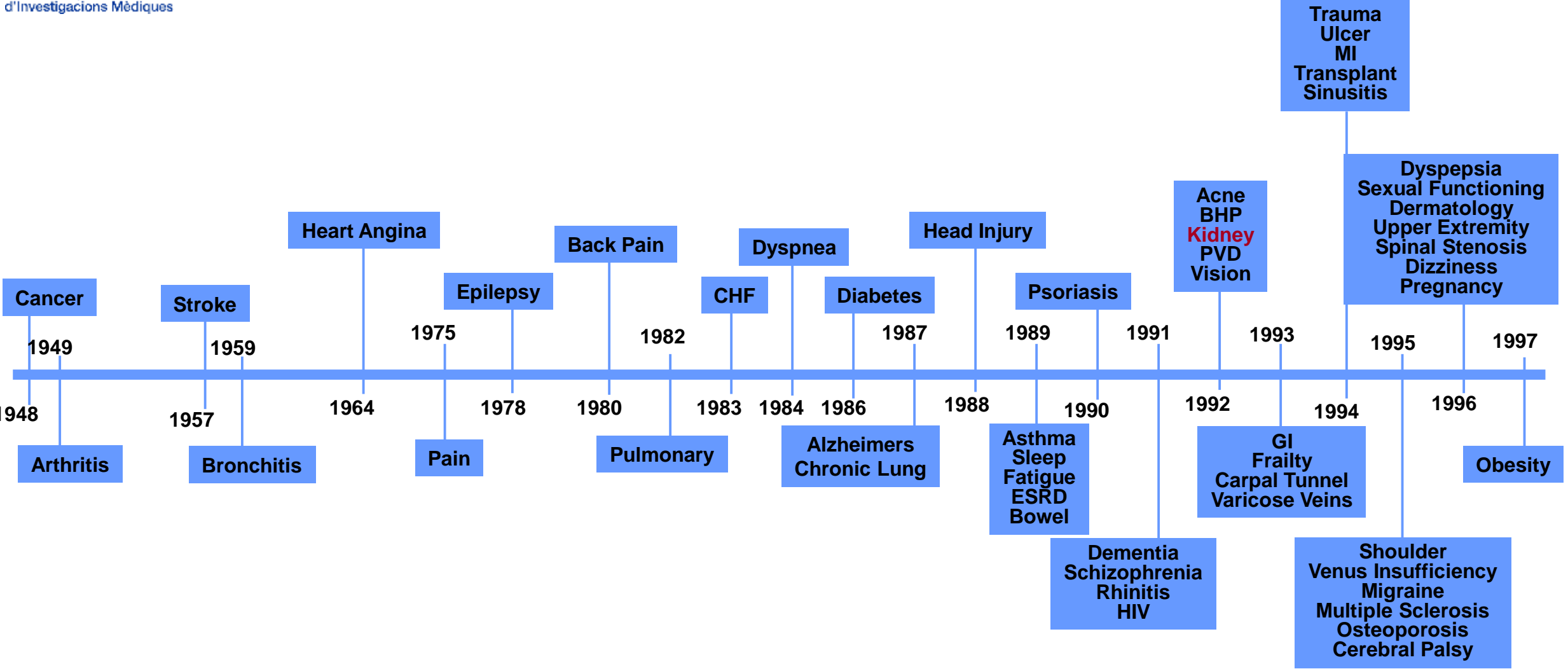
**PROs:** Patient Reported Outcomes  
**PROMs:** measure based on PROs

“Un PRO es cualquier informe del estado de salud de un paciente, que proviene directamente del paciente, sin interpretación de la respuesta del paciente por parte de un médico o cualquier otra persona”.

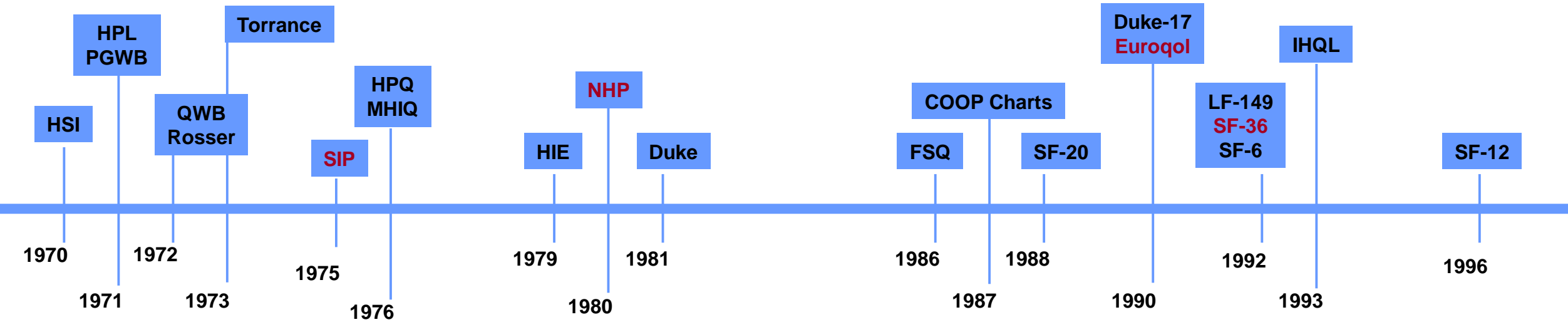


McKenna SP, BMC Med 2011.

# PROs Específicos

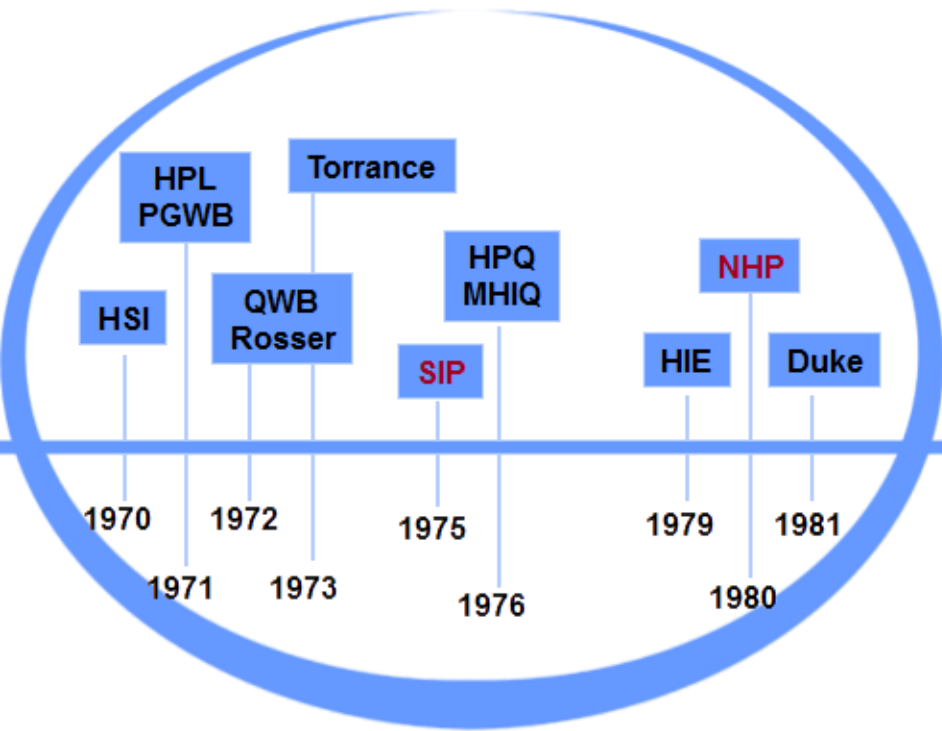


# PROs Genèrics

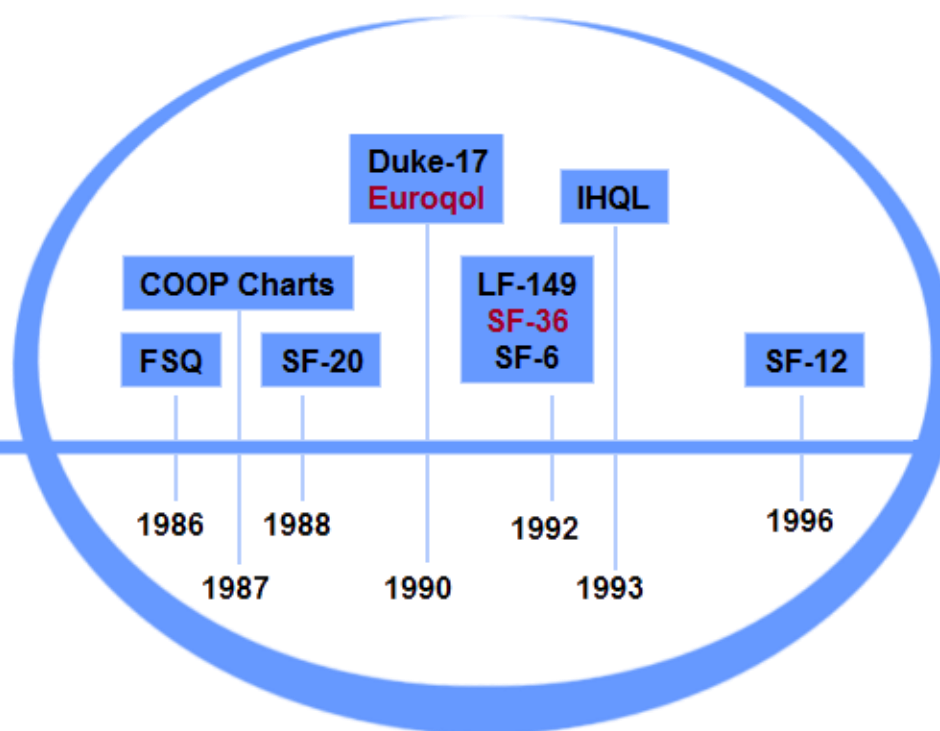


# PROs Genèrics

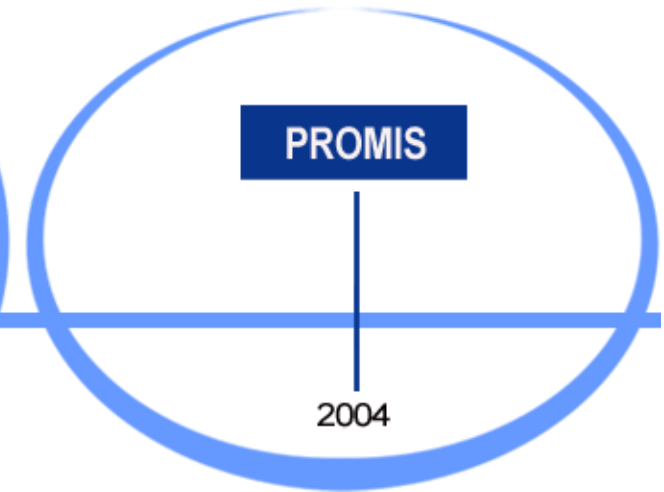
## DESARROLLO METODOLÓGICO



## REDUCCIÓN DE ÍTEMS



## TESTS ADAPTATIVOS





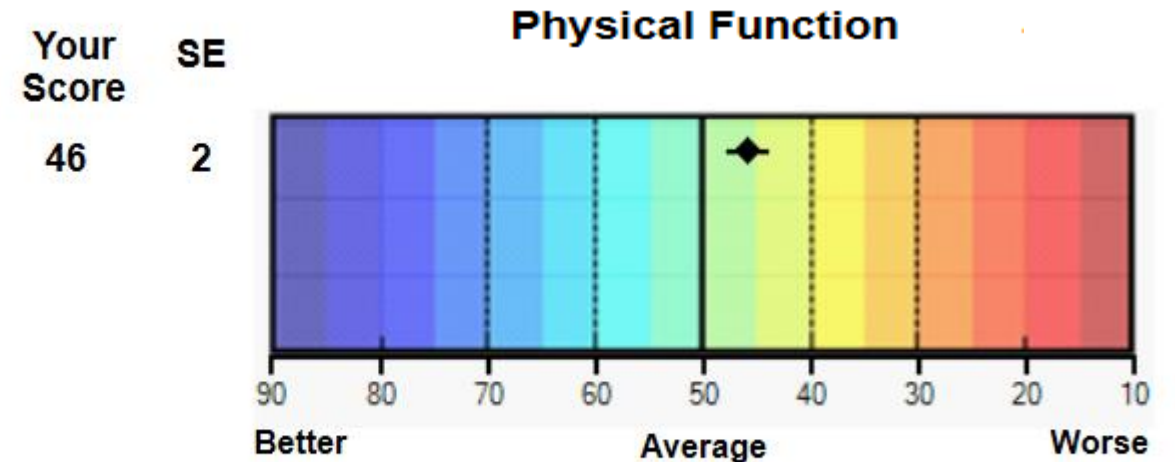
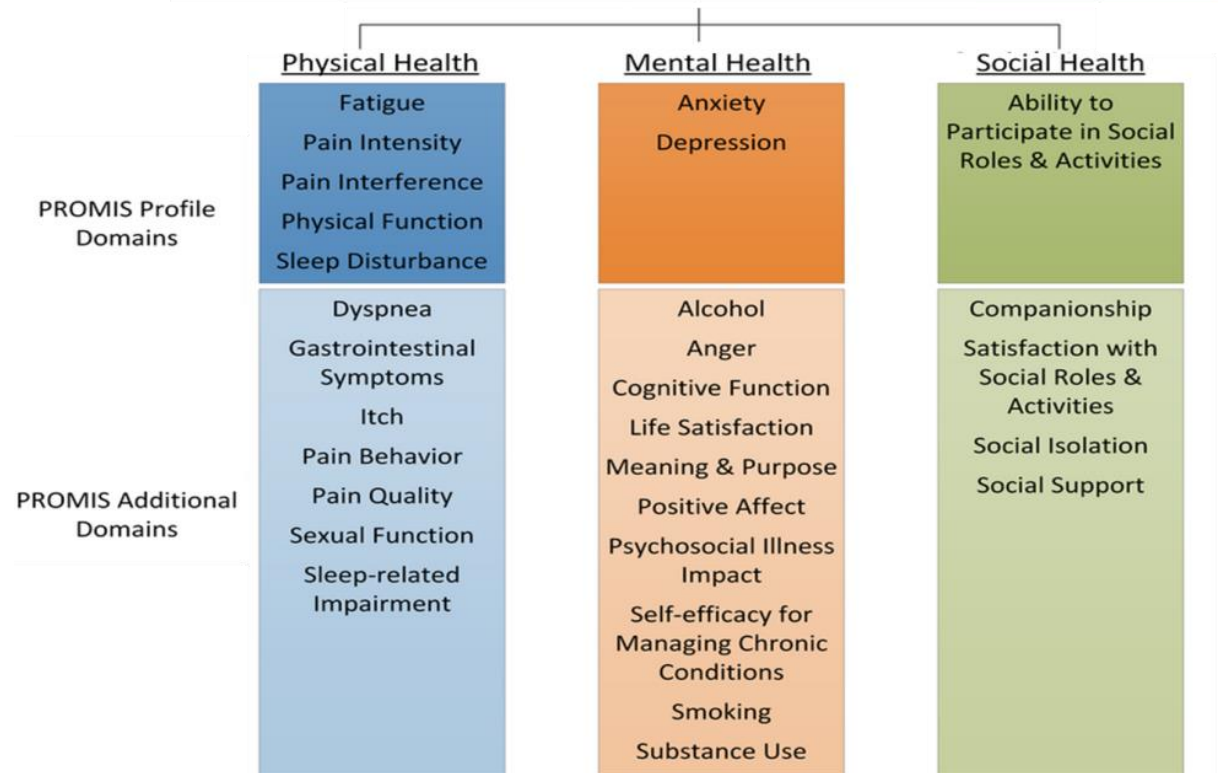
Computer Adaptive Tests (CATs): items are dynamically selected for administration from an item bank based upon the respondent's previous answers. Usually 4-12 items with a high level of measurement precision.

Your scores for the CATs you completed are shown below.

The diamond ♦ is placed where we think your score lies. This diamond is placed on your T-Score, which is a standardized score that is based on an average score of 50, based on responses to the same questions in the United States general population. The T-score also has a standard deviation of 10 points, so a score of 40 or 60 represents a score that is one standard deviation away from the average score of the general US population.

The Standard Error (SE) is a statistical measure of variance and represents the possible range of your score. The lines on either side of the diamond in your profile report show the possible range of your actual score around this estimated score. It is very likely that your score is in the range of these lines.

## PROMIS<sup>®</sup> Adult Self-Reported Health — Global Health



# Aplicaciones de los PROs

- Evaluación (transversal) de la salud de la población general o de grupos específicos de población
- Monitorización (longitudinal) de la salud de la población general o de grupos específicos de población **A NIVEL POBLACIONAL**
- Evaluación del impacto de intervenciones de salud y/o de políticas sanitarias
- Evaluación de la eficacia y efectividad de las intervenciones **INVESTIGACIÓN**
- Evaluación económica de las intervenciones sanitarias
- Análisis de la calidad de las intervenciones sanitarias **GESTIÓN SANITARIA**
- Cribado de problemas de salud
- Diagnóstico de problemas de salud
- Monitorización del estado de salud individual **PRÁCTICA CLÍNICA**



# Patient reported outcome measures could help transform healthcare



Nick Black *professor of health services research*

London School of Hygiene and Tropical Medicine, London WC1H 9SH, UK

BMJ 2013;346:f167 doi: 10.1136/bmj.f167 (Published 28 January 2013)

## Box 3: National PROMs programme in England for elective surgery

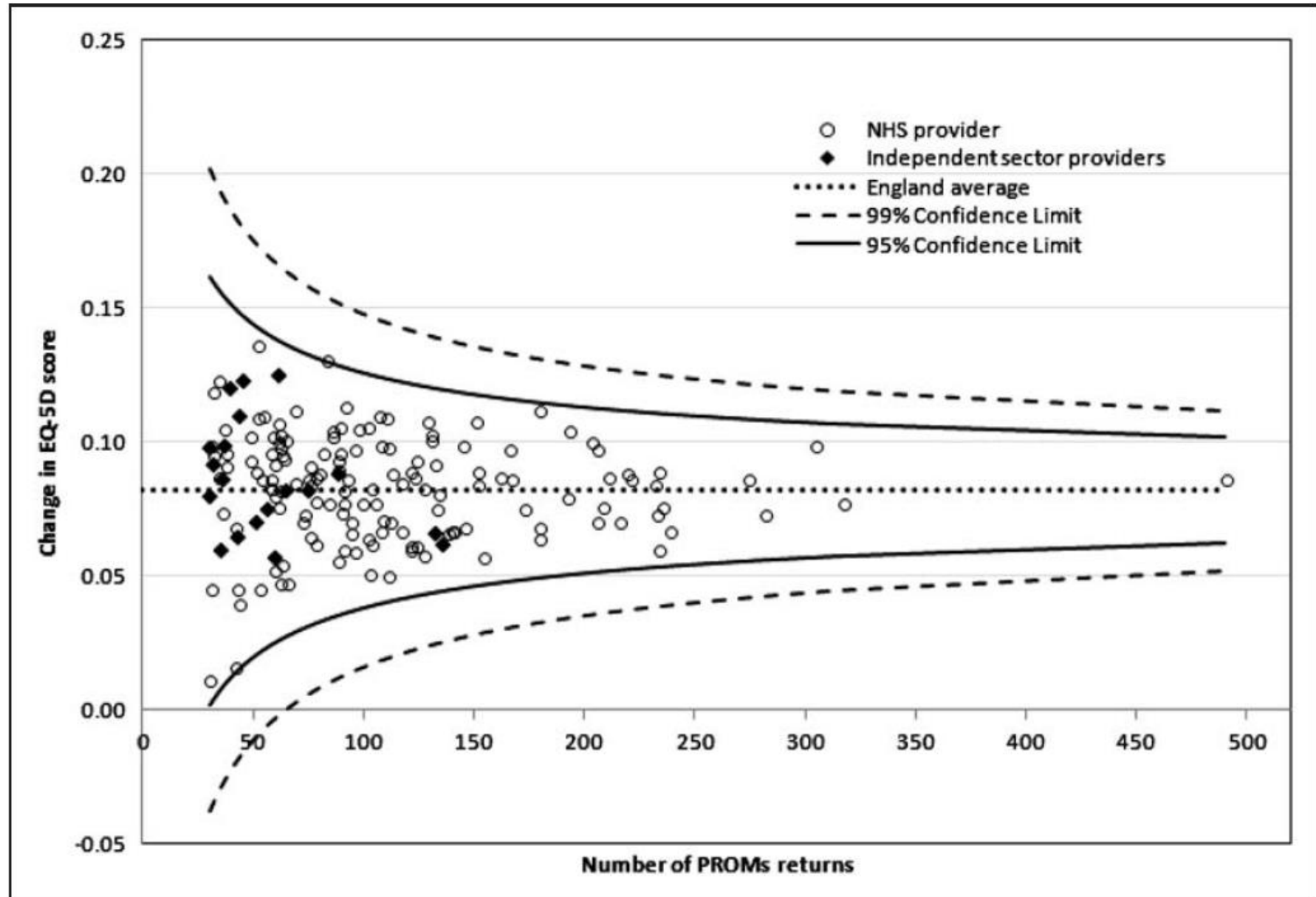
From April 2009 it has been mandatory for all providers (NHS hospitals, independent sector treatment centres, private hospitals) treating NHS patients for any of four elective procedures to participate in the national PROMs programme. All patients undergoing a hip or knee replacement, groin hernia repair, or varicose vein surgery should be invited to complete a questionnaire before surgery, either at the pre-assessment clinic or on the day of admission.

The preoperative questionnaire collects data on the patient's sociodemographic characteristics, the duration of their condition, their general health, any comorbidities, and whether they are undergoing a repeat/revision procedure. In addition, they are asked to complete a disease specific PROM (Oxford Hip Score, Oxford Knee Score, or Aberdeen Varicose Vein Score; there is no available instrument for hernia repair) and a generic PROM (EQ-5D index and EQ-Visual Analogue Scale).

Patient reported outcome measures (PROMs) can drive the changes in how healthcare is organised and delivered. Key to this will be to link doctors' use of PROMs in the treatment of their patients with collection and aggregation of the data for assessing and comparing the performance of providers—all to improve healthcare quality.

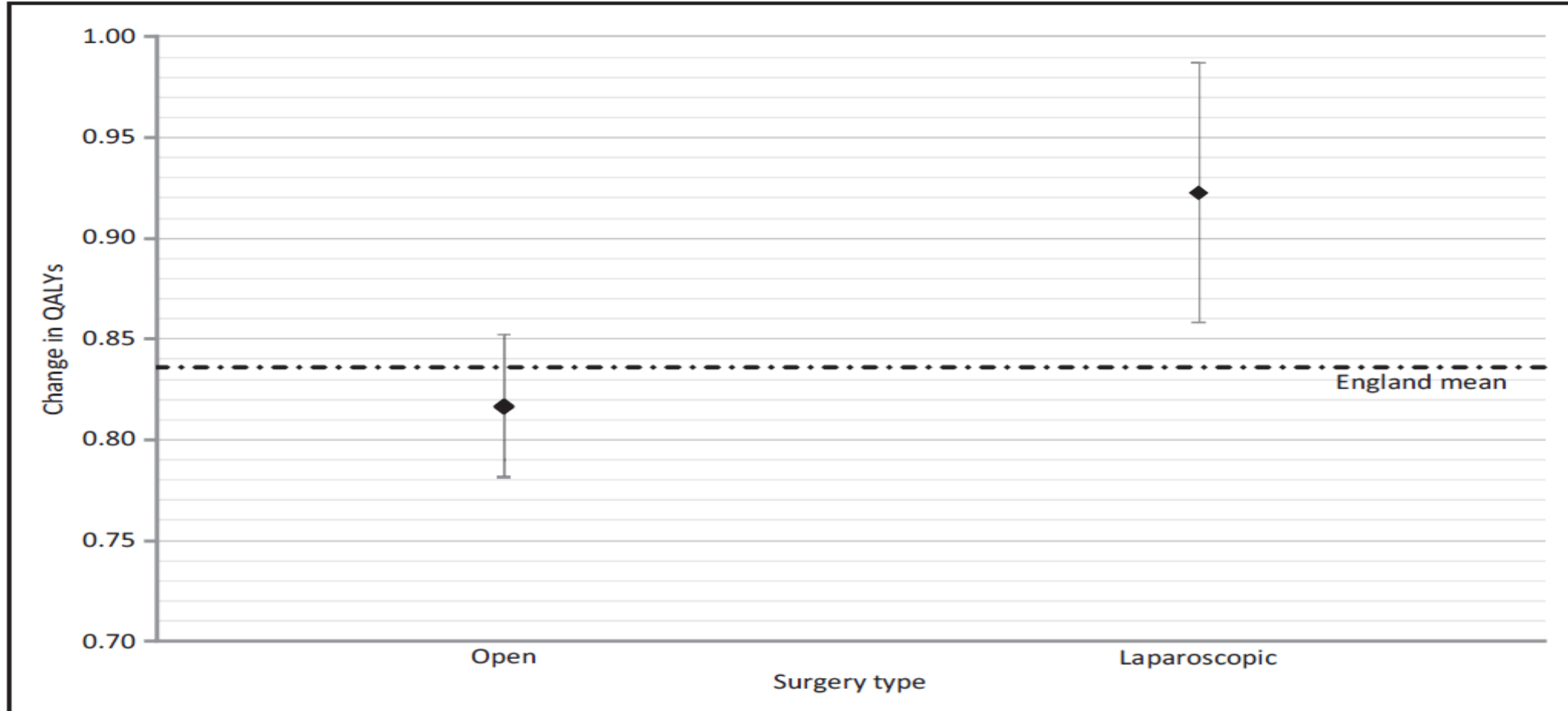


**Figure 2** Funnel plot of adjusted EQ-5D change against number of PROMs returns (min.  $n = 30$ ) received from NHS ( $n = 145$ ) and independent sector ( $n = 19$ ) hospitals providing hernia surgery for NHS patients in 2009–2010, with 95% and 99% upper and lower confidence limits, respectively



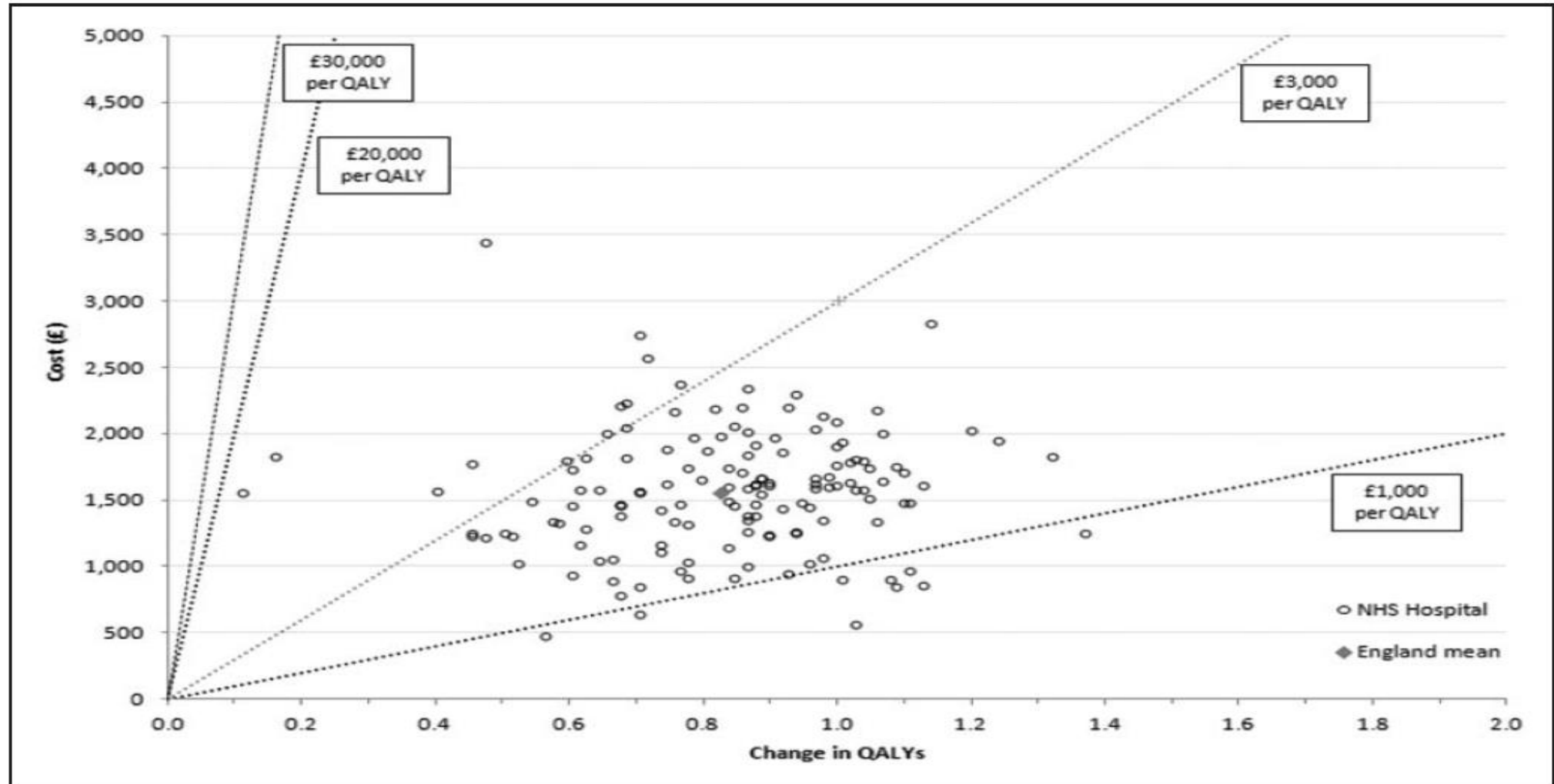
Coronini-  
Cronberg et al.  
J R Soc Med  
2013  
106:278-287.

# REAL WORLD DATA



**Figure 5** Mean change in discounted (at 3.5%) and degraded (over 25 years) QALYs with 95% confidence intervals by type of surgery

## REAL WORLD DATA

Institut Hospital del Mar  
d'Investigacions Mèdiques

**Figure 4** Cost-effectiveness plane showing discounted (at 3%) and degraded (over 25 years) mean QALYs change after hernia surgery, and associated average cost among NHS providers ( $n = 145$ ) with  $\geq 30$  PROMs returns, 2009–2010

# INICIATIVES INTERNACIONALES



# International Consortium for Health Outcomes Measurement - ICHOM



- Three organizations with the desire to unlock the potential of **Value - Based HealthCare (VBHC)** founded ICHOM in 2012 as non-profit.
- Formed to drive health care systems towards **VBHC** by defining FREE Standard Sets
- Data owned by patients



# International Consortium for Health Outcomes Measurement - ICHOM

ALL    CARDIOVASCULAR AND CIRCULATORY    CONGENITAL ANOMALIES    DIABETES, BLOOD AND ENDOCRINE    DIGESTIVE    MALIGNANT NEOPLASMS    MATERNAL AND NEONATAL    MENTAL AND BEHAVIORAL DISORDERS    MENTAL HEALTH

MUSCULOSKELETAL    NERVOUS SYSTEM    NEUROLOGICAL    PRIMARY/PREVENTATIVE CARE    SENSE ORGAN    UROGENITAL

**IN PROGRESS**

HIV & AIDS

Externally Developed Sets



OSTEOGENESIS IMPERFECTA




The Patient - Patient-Centered Outcomes Research (2022) 15:341–351  
<https://doi.org/10.1007/s40271-021-00554-8>

ORIGINAL RESEARCH ARTICLE



## A Standard Set of Value-Based Patient-Centered Outcomes and Measures of Overall Health in Adults

Jaheeda Gangannagaripalli<sup>1,2</sup> · Andrea Albagli<sup>3</sup> · Stacie N. Myers<sup>3</sup> · Sarah Whittaker<sup>3</sup> · Andria Joseph<sup>3</sup> · Anna Clarke<sup>3</sup> · Lucy Matkin<sup>3</sup> · Jordi Alonso<sup>4</sup> · Ira Byock<sup>5</sup> · Michael van den Berg<sup>6</sup> · Carolyn Canfield<sup>7</sup> · John Chaplin<sup>8</sup> · Juan Dapuerto<sup>9</sup> · Marcelo Pio de Almedia Fleck<sup>10</sup> · Chris Sidey-Gibbons<sup>11</sup> · Jan Hazelzet<sup>12</sup> · Rachel Hess<sup>13</sup> · Kaisa Immonen<sup>14</sup> · Serena Joyner<sup>15</sup> · Catherine Katz<sup>16</sup> · Carolyn Kerrigan<sup>17</sup> · Cindy Lam<sup>18</sup> · Joanne Lunn<sup>19</sup> · Fiona McKenzie<sup>20</sup> · Alastair Rieves<sup>21</sup> · Caleb Stowell<sup>5</sup> · Timothy Switaj<sup>22</sup> · Melissa Tinsley<sup>23</sup> · Eyal Zimlichman<sup>24</sup> · Jose M. Valderas<sup>1,25</sup> 

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# Ejemplo: conjunto estándar para salud general adultos

## OVERALL ADULT HEALTH

1. Defined by Self-reported Health Status
2. Defined by Physical Health/Well-being/Physical Functioning
3. Defined by Functional Health  
Status/Disability/Autonomy/Dependence/Activities of Daily Living
4. Defined by Role/(Psycho) Social Functioning
5. Defined by Interpersonal Functioning/Defined by Work Related Functioning/Limitations
6. Tracked via the PROMIS Scale v1.2- Global Health
7. Tracked via the WHO (Five) Wellbeing Index (WHO5)
8. Tracked via the WHO Disability Assessment Schedule 2.0 (WHO-DAS 12)
9. Outcomes will not have an individual score



# Ejemplo: conjunto estándar salud adultos

## Collecting Patient-Reported Outcome Measures

Overall Adult Health Survey Used	Licensing Information
PROMIS Global Health 10	Free for use in clinical practice and a license is not required. Information on available translations can be found here: <a href="https://www.healthmeasures.net/search-view-measures">https://www.healthmeasures.net/search-view-measures</a>
WHO-5	The WHO-5 is free for all health care organizations, and a license is not needed. There are translations available. More information may be found at <a href="http://www.who-5.org">www.who-5.org</a>
WHO Disability Assessment Schedule 2.0 (WHODAS 12)	The WHODAS 12 can be used for non-commercial purposes following the completion of a free user agreement found at: <a href="https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule">https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule</a> . The inclusion of the WHODAS 12 in an electronic records or data capture system requires a license, available at: <a href="https://www.who.int/about/policies/publishing/permissions">https://www.who.int/about/policies/publishing/permissions</a>

# Ejemplo: conjunto estándar salud adultos

## Follow-Up Algorithm

The following algorithm illustrates when Standard Set variables should be collected from patients and clinicians.



# International Consortium for Health Outcomes Measurement - ICHOM

## Data Dictionary

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<b>Variable ID:</b>	PROMCHOICE_PAIN
<b>Variable:</b>	PROM Choice - Pain
<b>Definition:</b>	Which Patient-Reported Outcome Measure are you using to measure pain?
<b>Supporting Definition:</b>	Choose one from: Numerical Rating Scale Visual Analogue Scale SF-36 Bodily Pain PROMIS Pain Interference PedsQL Pain and Hurt
<b>Inclusion Criteria:</b>	All patients
<b>Timing:</b>	Baseline and annually
<b>Data Source:</b>	Patient-reported
<b>Type:</b>	Single answer
<b>Response Options:</b>	1 = Numerical Rating Scale 2 = Visual Analogue Scale 3 = SF-36 Bodily Pain 4 = PROMIS Pain Interference 5 = PedsQL Pain and Hurt

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# Patient-reported outcome and experience measures for quality improvement in pregnancy and childbirth care: a retrospective cohort study

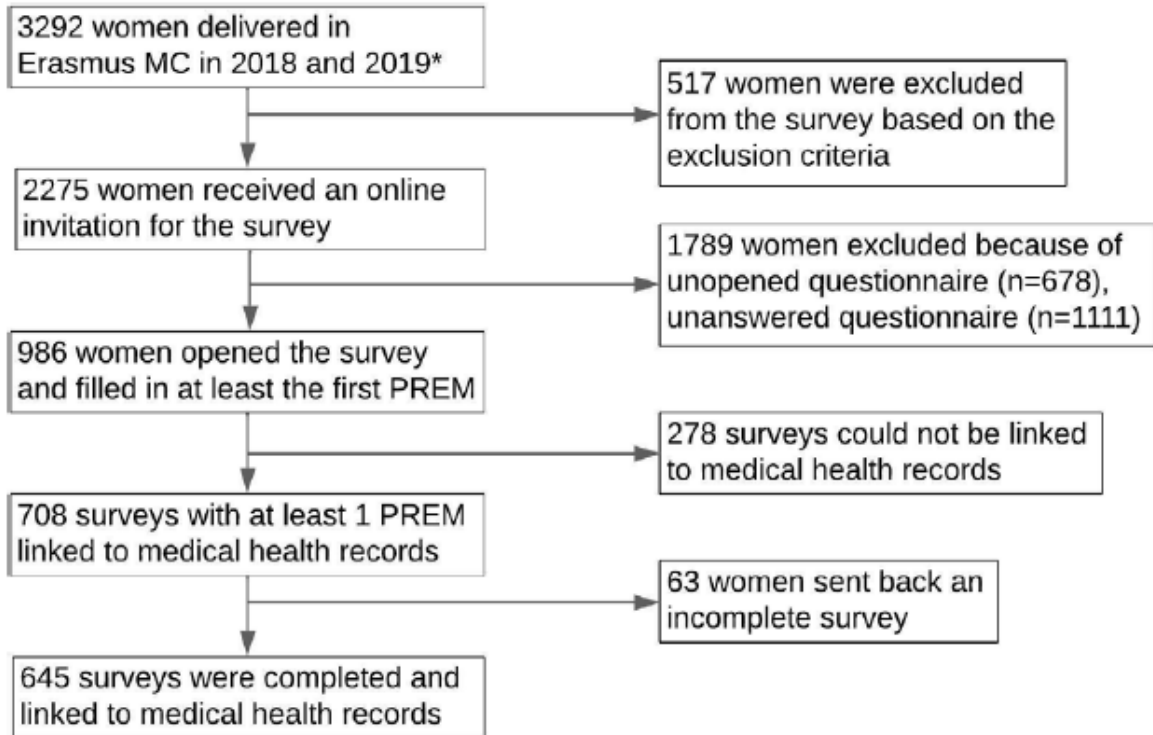
Klootwijk A, *et al. BMJ Open Quality* 2023;12:e001922. doi:10.1136/bmjog-2022-001922

## ABSTRACT

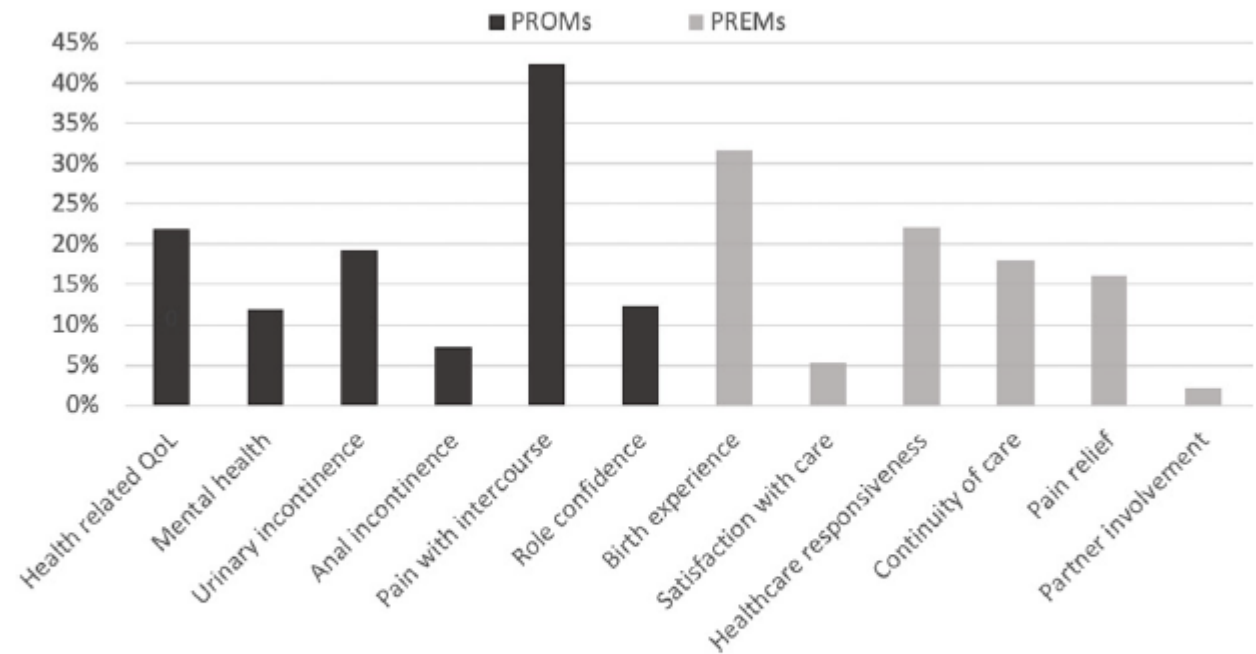
**Background** Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) can highlight issues that remain unnoticed when using standard clinical quality indicators. However, estimations of the potential power of measuring PROMs and PREMs to identify unrecognised areas suitable for quality improvement are often limited by a lack of reliable real-world data. Here, we report on how the indicator set for PROMs and PREMs that was recently developed by the International Consortium for Health Outcome Measures can change perspectives on quality assessment in women receiving care for pregnancy and childbirth.

**Methods** PROMs and PREMs were captured 6 months after childbirth via an online survey in a single academic maternity unit in the Netherlands between 2018 and 2019. Indicators of abnormality were scored using predefined cut-off values established by a national consensus group. We used regression analysis to identify associations between PROMs, PREMs and healthcare use, and further stratified data to explore the distribution of indicators among relevant patient subgroups.

# Patient-reported outcome and experience measures for quality improvement in pregnancy and childbirth care: a retrospective cohort study



**Figure 1** Recruitment of respondents. \*Women with >1 pregnancy in 2018 and 2019 and women who had a termination of pregnancy were excluded. PREM, patient-reported experience measure.



**Figure 2** Share of respondents with suboptimal scores, for each PROM and PREM (%). PREM, patient-reported experience measure; PROM, patient-reported outcome measure.



## Ministerial Statement

### THE NEXT GENERATION of HEALTH REFORMS

OECD Health Ministerial Meeting

17 January 2017

In their [Ministerial Statement](#) in 2017, Health Ministers from over 40 countries called on the OECD to invest in better cross-country comparative measures of patients' own experience of medical care and health care outcomes, and to further engage in the analysis and development of such comparative measures.

## Patient-reported Indicator Surveys (PaRIS)

PaRIS is the OECD's Patient-Reported Indicator Surveys initiative where countries work together on developing, standardising and implementing a new generation of indicators that measure the **outcomes and experiences of health care that matter most to people**.

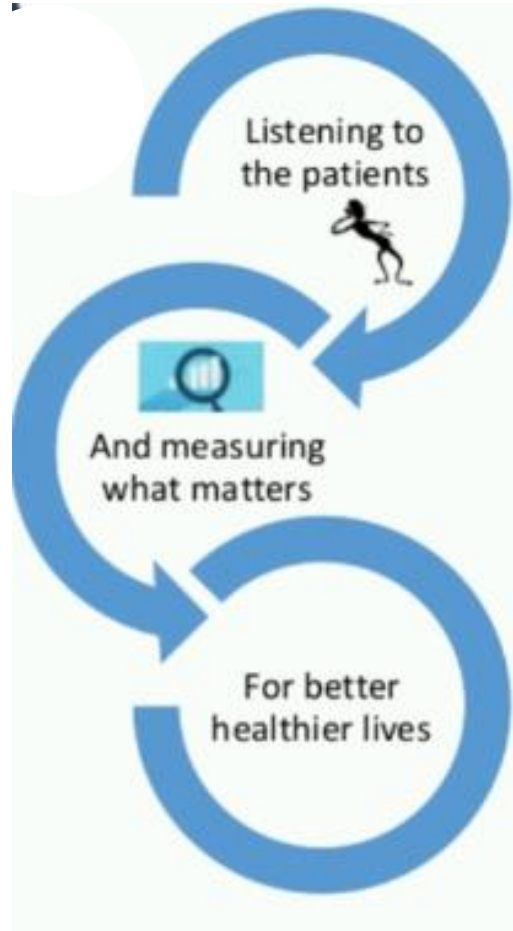
The [International Survey of People Living with Chronic Conditions](#) will be the first of its kind to assess the outcomes and experiences of patients managed in primary care across countries. The PaRIS survey aims to fill a critical gap in primary health care, by asking about aspects like access to health care & waiting times, as well as quality of life, pain, physical functioning & psychological well-being. [Contact us](#) to join the survey.



## How will it work?

The PaRIS conceptual framework links the **two sources of data** in the main survey;

- **data provided by the patient** about the patient demographics, health conditions, health literacy level, and health behaviours, the patient-reported measures on general, physical, mental, social health outcomes and experiences of health care.
- **data by the health care providers** about the demographics, clinic characteristics, remuneration and care models.

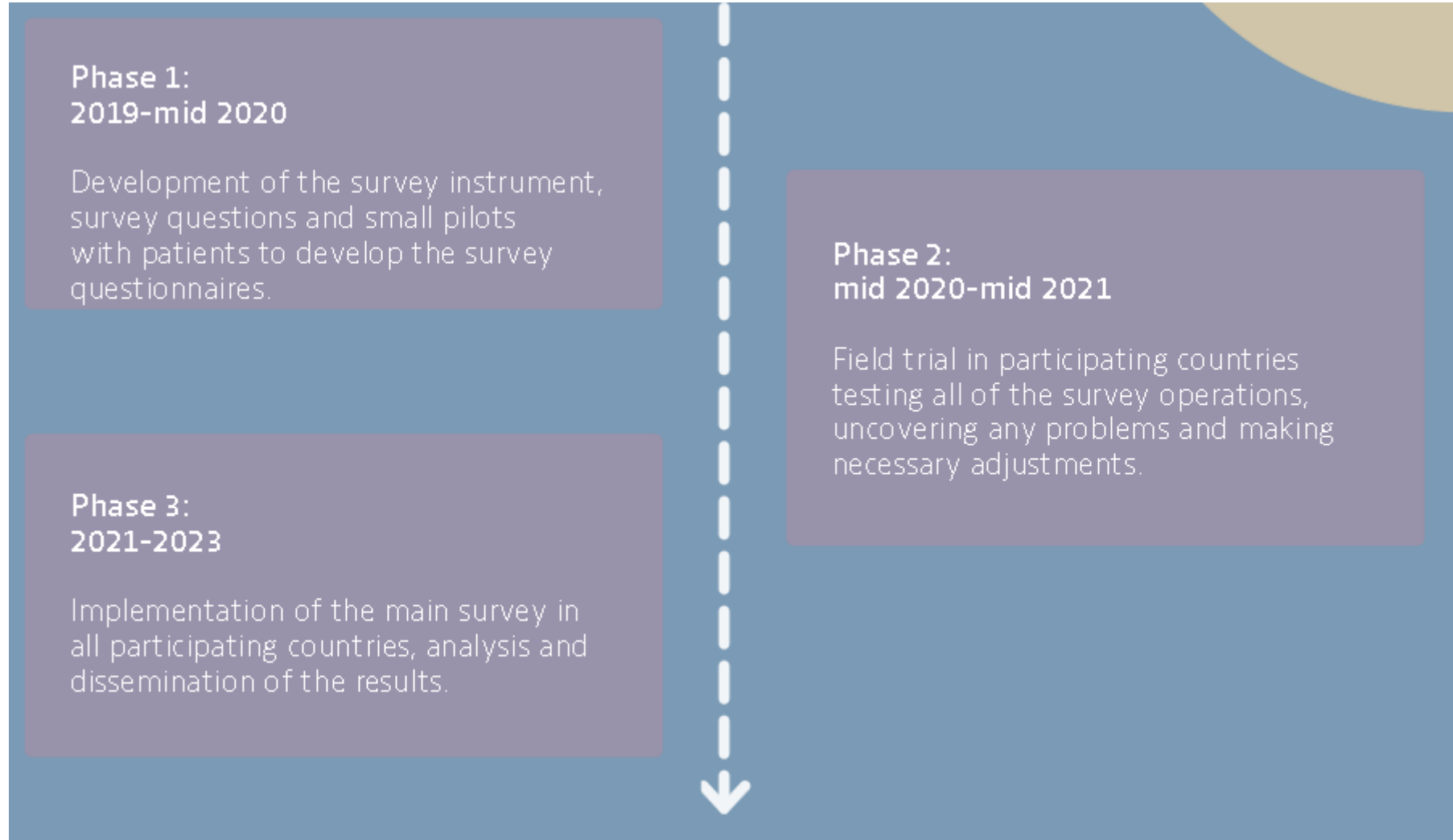


## Who will PaRIS help?

- **POLICY MAKERS**, by having better information on where to focus quality improvement efforts and prioritise spending
- **PATIENTS**, by having their say on what treatments work best for them
- **HEALTH CARE PROVIDERS**, by better understanding how to improve the quality of the care they provide

# Patient-reported Indicator Surveys (PaRIS)

## International Survey of People Living with Chronic Conditions



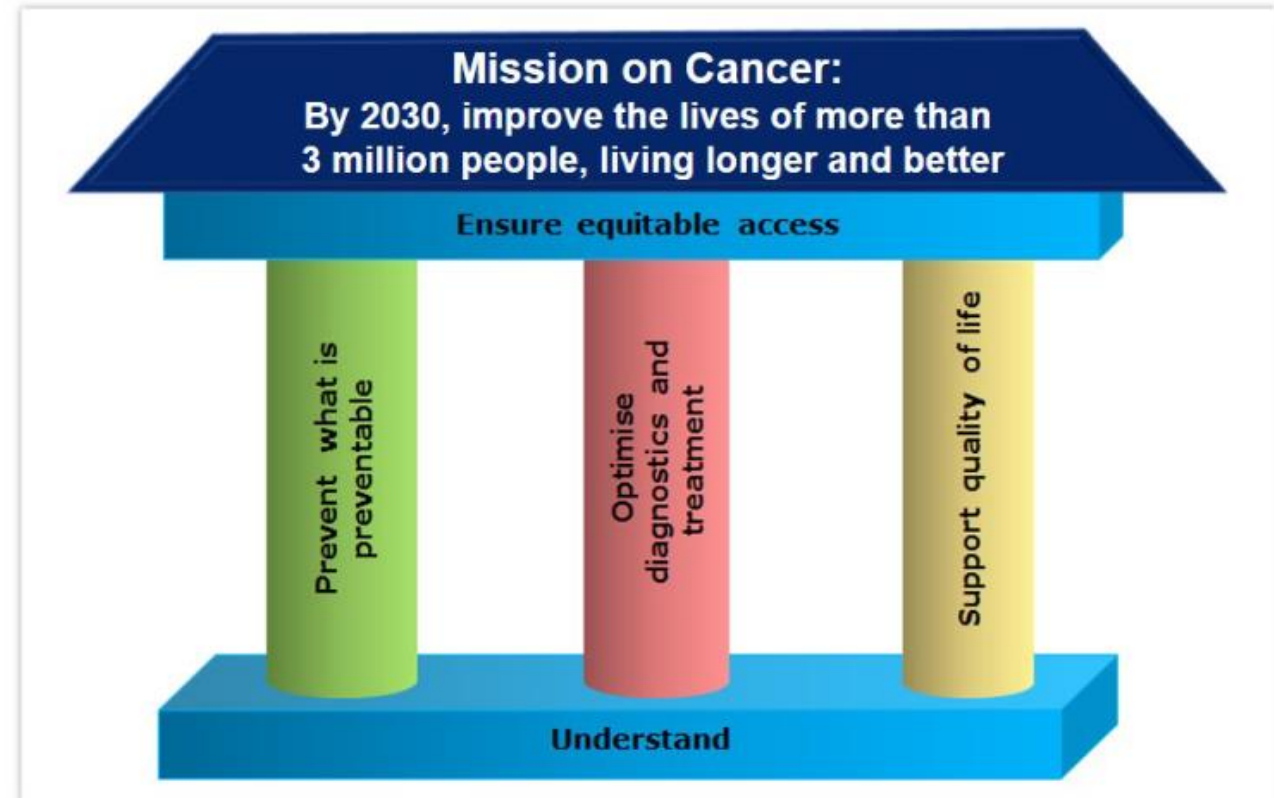
# HORIZON-MISS-2021-CANCER-02-02: Develop and validate a set of quality of life and patient preference measures for cancer patients and survivors



Horizon Europe

Work Programme 2021-2022

In parallel with prevention and treatment of cancer, the **improvement or preservation of patients quality of life** is one of the three pillars of the EC Mission on Cancer.



It is aimed at developing, validating, and disseminating the **EUropean oncology Quality of Life tool-Kit (EUonQoL)** to be used with:

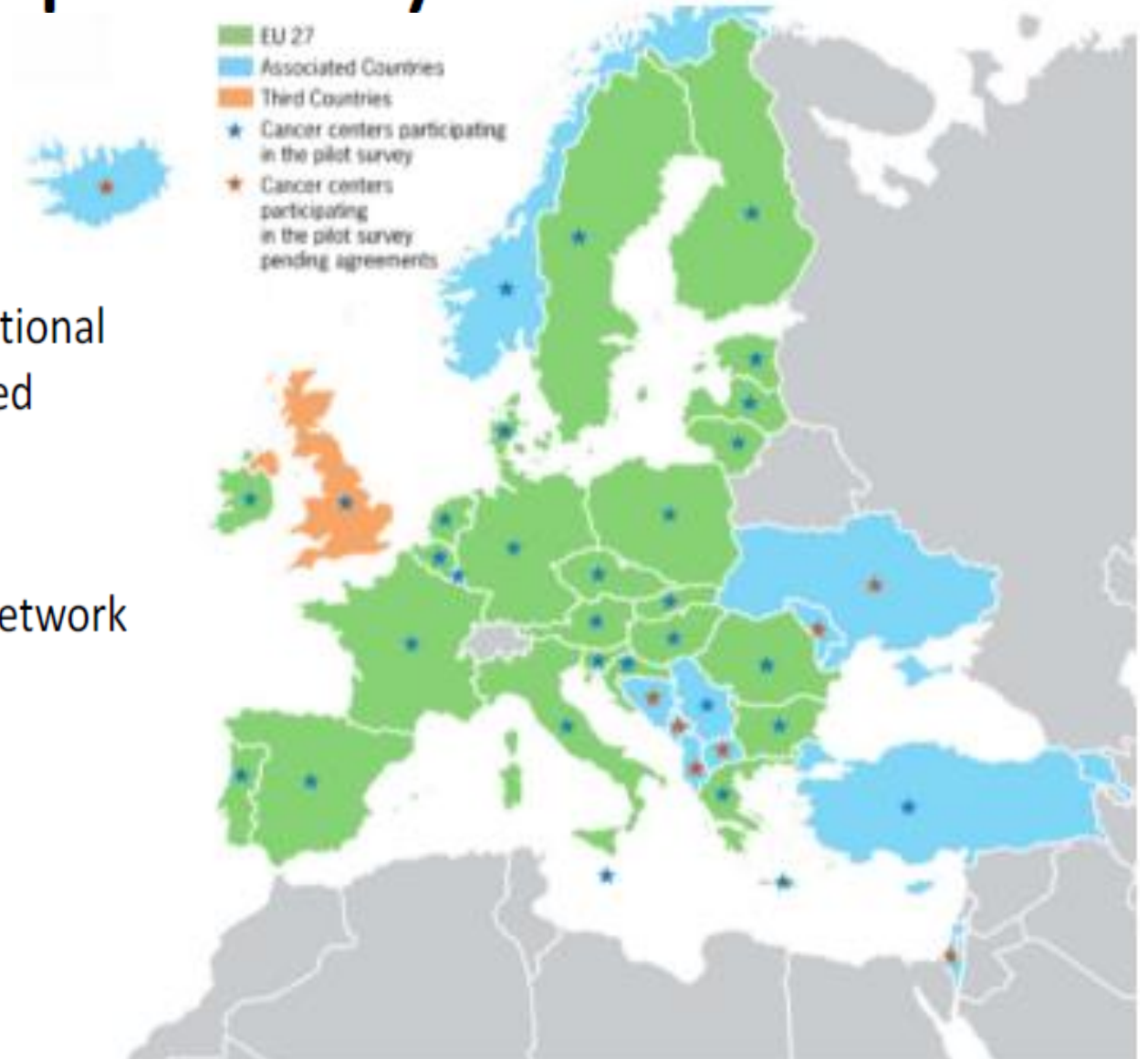
- Patients in active treatment
- Survivors
- Patients in palliative services

- developed from the patient perspective
- available in several European languages
- psychometrically sound
- based on CAT (Computer Adaptive Testing)
- digitally administrable
- applicable in future periodic surveys for health policy intervention evaluation
- Developed and validated by M24

# To validate the EUonQoL-Kit in a pan European pilot survey.

“The EUonQoL-Kit will be validated in a pilot cross-sectional survey involving the EU27 member states and Associated Countries.”

This was addressed thank to OECD and its pre-existing network of cancer centres





The screenshot shows the top navigation bar of the Bibliopro website. It includes the 'Bibliopro' logo, a 'Login' button, a 'Registro' button, and the 'Fundació IMIM ciberesp' logo. Below the navigation bar is a main banner featuring a photograph of a modern building with a curved facade. The banner text reads 'Biblioteca de Patient Reported Outcomes (PRO) en español'.

[Cómo funciona >>](#)

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- Por Qué
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- Patient Reported Outcomes y Calidad de Vida relacionada con la Salud
- Derechos de los autores
- América Latina

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Grup de Recerca en Serveis Sanitaris

