International Association for the Study of Pain MULTIDISCIPLINARY PAINCENTER DEVELOPMENT MANUAL



Created by the IASP Multidisciplinary Pain Center Toolkit Advisory Group www.iasp-pain.org/MPCManual

EVALUATIONS AND MEASUREMENTS

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Patient Outcomes and Satisfaction

The primary purpose of outcome evaluation is to help improve services and outcomes for patients with chronic pain conditions. Since pain is conceptualized as a multidimensional phenomenon, the evaluation of treatments for pain needs to reflect—at minimum—changes to the key domains of pain quality (severity, extent), pain-related distress and emotional functioning, and pain interference in daily activities.

Other outcomes that are more specific may also be considered in particular populations. These may include changes in the use of certain medications, behavior changes such as resumption of valued activities (e.g., return to work), and improved quality of sleep. In addition, Centers may evaluate patient satisfaction with treatment services. Such evaluations should primarily examine service delivery factors such as cost, convenience, accessibility of services, and waiting times at the Center.

Broad Principles

- 1. Assessment of outcomes should be voluntary for patients, and the instruments used should not place undue burden on patients.
- 2. Assessment of outcomes should include self-reports by patients, using validated and reliable measures translated into their own languages where possible.
- 3. Patients should complete the self-report measures before and after treatments in order to determine if meaningful treatment changes have occurred.
- 4. Where possible, Centers should encourage follow-up evaluations to determine if any treatment effects are maintained.
- 5. Centers should record clinical metrics. These include patient wait times at the Center, number of patients assessed and treated, number of Center visits for treatment, and the nature of treatments provided.
- 6. Each Center should establish and actively use a secure, computerized database to maintain a record of all assessment data for each patient.

Dimensions and Possible Measures for Outcomes

Numerous outcome measures are available for each domain, but ideally, the pain services in each country or region should agree to use the same measures that widely accepted. This will enhance their ability to benchmark outcomes and help improve the outcomes achieved by all pain services.

It is beyond the scope of this manual to describe all possible measures (see Appendix 8 for suggested scales), but reviews of many have been published in PAIN. For example, a consensus review of self-report measures suitable for clinical trials [4] has been widely cited, but its utility in routine clinical practice requires additional considerations (see principles above) [5]. The British Pain Society has also published a list of recommended measures [1].

A clinical practice example is the ePPOC (electronic Persisting Pain Outcomes Collaboration) approach used in Australia and New Zealand [16]. The Australia and New Zealand faculty of pain medicine at the Pain Societies of Australia and New Zealand reached agreement on a core set of measures for all pain services in those countries. The measures include: the Brief Pain Inventory (BPI) [3], including two sub-scales: one assessing pain severity and the other the degree of pain interference in daily activities; the Depression Anxiety and Stress Scales (DASS) [10] assessing these domains; pain beliefs assessed by the Pain Self-Efficacy Questionnaire (PSEQ) [11]; and the Pain Catastrophizing Scale (PCS) [14]. Normative data on more than 13,000 chronic pain patients using the ePPOC measures in Australia and New Zealand were recently published [12].

Pain severity

Potential measures for pain severity include a Numerical Rating Scale (NRS) using a 0-10 scale, where 0 equals no pain and 10 equals the worst pain imaginable, and a Visual Analogue Scale (VAS), which employs a 10-cm horizontal line with similar anchor points to the NRS. The BPI includes four scales that assess the current intensity of pain (0-10), as well as at its least, worst, and average during the past week. Scores of each of the four items are averaged to provide a total pain score. Centers can also use the Faces Pain Scale (FPS) [7] for children.

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Pain Interference (pain-related disability)

If resources are limited, a basic set of measures that would be generally applicable could include the following:

- Pain Interference subscale of the BPI [3]
- Pain Interference scale of the Multidimensional Pain Inventory (MPI) [9]
- Pain Disability Index (PDI) [15]

Scales for site-specific pain interference include the Roland Morris Disability Questionnaire (RMDQ) [13] and the Oswestry Disability Index (ODI) [6] for back and the Neck Disability Index (NDI) [18] for neck pain.

A recent consensus review of the assessment of physical function by Taylor et al. [17] provides guidance on both self-report and behavioral measures for this domain. For example, the researchers did emphasize the importance of selecting specific measures for different groups of patients, rather than a single scale for all. Behavioral measures or performance (e.g., walking time, sit-to-stand repetitions, number of steps) may be suitable but only in those patients where these are limited by pain. New technologies are making these easier to record (e.g. smartphones).

Emotional functioning (mood and anxiety)

Dworkin et al. [5] recommend the Beck Depression Inventory (BDI) and the Profile of Mood States (POMS), but neither seems suitable for use in Southeast Asia. The BDI is subject to a fee, and the POMS is very long (65 items) and would add substantially to patient burden.

Alternative and briefer scales include the DASS, which has 21 items and is freely available. Health providers in Malaysia have already used it [2].

The Hospital Anxiety and Depression Scale (HADS) [19] is another brief measure that would be suitable for consideration since, like the DASS, it contains no somatic items that can be problematic for patients with physical illnesses.

Another commonly used brief measure of depressive symptom severity is the PHQ-9 [23]. It has nine items measuring symptoms of major depressive disorder based on the DSM-IV criteria for depression. Higher scores indicate greater severity [20, 23]. There is also a 2-item version [21].

The GAD-7 [20, 24] is a 7-item measure of anxiety that is used widely in research and clinical settings. It can be used to screen for anxiety disorders and can be scored to assess level of anxiety symptoms.

The PHQ-9 and GAD-7 are often used in clinical and research settings to monitor mood and anxiety levels and as treatment outcome measures.

Both the PHQ-9 and GAD-7 have 2-item short versions with demonstrated validity and utility in screening for mood and anxiety disorders [21].

Cognitive scales (pain-related beliefs)

The use of pain belief scales in Southeast Asia has not been studied, so their use should be treated with caution lest there be misinterpretations. Typically, these include a list of statements, whereby the patient responds on a scale ranging from complete disagreement to complete agreement or from never thinking to always thinking.

The statements are samples, not all thoughts patients have about their pain. However, they have been related to important outcomes including disability, depression, and medication use.

Two cognitive measures that have been translated into a range of languages and have been widely used are the **Pain Catastrophizing Scale (PCS)**, which asses the frequency of common, but unhelpful, beliefs about pain, such as "I worry all the time about whether the pain will end," and the **Pain Self-Efficacy Questionnaire (PSEQ)**, which assesses the strength of a person's confidence in their ability to function despite their pain [17]. The PSEQ has been shown to be understood by Malaysian patients with chronic pain [2].

Global Assessment of Outcomes

Some researchers have proposed that a measure reflecting a summary or overall degree of change could be useful. The IMMPACT group recommended the **Patient Global Impression of Change (PGIC)** scale for chronic pain clinical trials. In this case, the patients rate their improvement on a seven-point scale, where 0 equals "very much worse" and 6 equals "very much improved" [5]. This method, by itself, does not indicate what has improved [22].

Minimum Data Sets (self-reports by patients)

If resources are a problem for these evaluations of treatment outcomes, Centers could turn to another option: collect a minimal data set using basic Numerical Ratings Scales (NRS).

This might include

- Pain severity (NRS: 0-10)
- Pain interference (NRS: 0-10)
- Pain-related distress (NRS: 0-10)

Translated Versions

Some of these scales have already been translated into languages other than English. Where these are not currently available, translations should be sought.

LINKS TO PAIN QUESTIONNAIRES
Brief Pain Inventory (BPI) long
Brief Pain Inventory (BPI) short
Depression Anxiety and Stress Scales (DASS)
Pain Self-Efficacy Questionnaire (PSEQ)
Pain Catastrophizing Scale (PCS)
Numerical Rating Scale (NRS)
Visual Analogue Scale (VAS)
Faces Pain Scale (FPS)
West Haven-Yale Multidimensional Pain Inventory (WHYMPI)
Pain Disability Index (PDI)
Roland Morris Disability Questionnaire (RMDQ) Translations
Oswestry Disability Index (ODI)
Neck Disability Index (NDI)
Beck Depression Inventory (BDI)
Hospital Anxiety and Depression Scale (HADS)
Patient Global Impression of Change (PGIC)
Neck Disability Index (NDI)

(Also see Appendix 8)

Evaluation of Pain Services and Satisfaction

As indicated earlier, patient satisfaction with a clinical service can be useful for evaluating service delivery such as accessibility, cost, convenience, and appointment and service waiting times. This information can help Centers improve the delivery of their pain assessment, treatment, and management services.

Conducting Internal Self-Assessments

In addition to obtaining patient feedback, it is important that Centers monitor some key performance indicators. There are no specific forms for these, but the data can easily be collected and entered on a dataset established for this purpose (e.g. on an Excel file).

Commonly used Center performance metrics:

- Waiting time (from referral to attendance at the Center)
- Numbers of patients assessed in a set period (e.g., one year)
- **Treatment completions** (number of patients completing treatment and/or discharged in a year)
- Treatment dropout rate (percentage of patients withdrawing from treatment in a year)
- Follow-ups (percentage of patients completing follow-up measures)
- Audit of provided treatments and services (list and number of patients receiving each treatment and/or service)
- Mean, median, and maximum number of treatment sessions per patient

Establish and track staff measures

- Retention of staff for more than a year along with reasons for leaving
- Professional development (numbers and kinds of training undertaken in a year)

- Satisfaction with work and roles
- Recruitment issues (length of time and amount of effort needed to recruit new staff to the Center)
- Sick leave taken within a year and whether illnesses were work-related

Adopt a practice of benchmarking

As the name suggests, benchmarking is a method for evaluating a service according to agreed outcomes (or benchmarks). These outcomes are often the result of discussion between members of a service or several services where they come to an agreement on what a desirable outcome (or outcomes) should be for their services. Ideally, benchmarking MPCs should be done on a regional basis with participating Centers using the recommended minimum data set (above), with ICD-11 Pain Codes recorded and agreeing on a feasible or achievable outcome goal (e.g., patients achieving a 30 percent reduction in pain severity after treatment). Participating Centers should meet regularly (perhaps at an annual meeting and/or at the biennial Congress of the Association of South East Asian Pain Societies (ASEAPS)) to compare and discuss their results relative to the benchmarks.

If this option is available, the Centers could work with a university to establish a regional data hub to collate data collected by the Centers, perhaps presenting a report at the annual reviews. This hub could be used to help Centers learn from each other as part of an ongoing system of quality upgrading. Comparisons could be made for areas such as the following:

- Waiting time (from referral to attendance at Center)
- Numbers of patients assessed in a set period (e.g., one year)
- Follow-ups (percentage of patients completing follow-up measures)
- Audit of provided treatments and services (list and number of patients receiving each treatment and/or service)

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