**Table S1. Characteristics of included PROMS**

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| **PROM\* (reference to first article)** | **Construct(s)** | **Target population and context PROM developed for** | **Conceptual framework** | **Mode of administration** (e.g. self-report, interview-based, proxy report etc) | **Recall period** | **(Sub)scale (s) (number of items)** | **Response options (number)** | **Range of scores/scoring** | **Administration time** | **Language (s) (Country) of development** | **Available translations** | **Access fee** | **Patient Involvement in concept elicitation** |
| BDI II 1,2 | Indicator of the presence and degree of depressive symptoms | Patients diagnosed with depression;  Clinical practice and research | Observations of attitudes and symptoms in patients with depression  Diagnostic and statistical manual of mental disorders Fifth edition (DSM-IV) | Self-administered | 2 weeks | 2 subscales with a total of 21 items.  Affective (8 items) and somatic (13 items) | Varies, 4 responses per item (rating scale 0-3), except items 16 and 18 which have 7 responses | Total score derived from calculating the sum of items.  Scores indicative of severity of depression; 0-13 mild, 14-19 moderate and 20-28 severe 29-63 | 5 -10 minutes | English (US) | Yes | Yes | **Yes** |
| BPI- Pain Interference subscale 3 | Measure of the severity and impact of cancer-related pain on functioning | Patients with cancer related pain; clinical practice, clinical trials, epidemiological research, | “sensory” dimension of pain (intensity or severity) and the “reactive” dimension of pain (interference with daily function) | Interview-based | 24 hours | 7 items measuring general activity, mood, walking ability, normal work, relations with other people, sleep and enjoyment of life | 11 responses per item, 0-10 numerical scale | Pain interference score derived from mean score of interference items  Range 0-10.  Higher scores indicate greater interference. | 5 minutes | English (US) | Yes | Yes | Yes |
| EHP 30 4 | Assessment of health related quality of life, “encompassing physical, psychologic and social aspects”, of women with endometriosis | Women with endometriosis; clinical practice and research | Interviews with patients | Self-administered | 4 weeks | Core questionnaire; 5 subscales, total 30 items: pain (11 items), control and powerlessness (6 items), social support (4 items), emotional well-being (6 items) and self-image (3 items)  Modular questionnaire; 6 subscales, total 23 items: intercourse (5 items), work (5 items), medical profession (4 items), infertility (4 items), relationship with children (2 items), treatment (3 items) | 5 responses per item (rating scale 0-4) | 0-100 per subscales; scores derived as sum of items in each scale, raw scores transformed into a scale 0-100  Lower scores indicate better health status | Not stated | English (UK) | Yes | Yes | Yes |
| EHP 5 4,5 | Assumed same as EHP-30 | Assumed same as EHP-30 | Assumed same as EHP-30 | Assumed same as EHP-30 | 4 weeks | Core questionnaire; 5 subscales, total 5 items: pain (1 item), control and powerlessness (1 item), social support (1 item), emotional well-being (1 item) and self-image (1 item)  Modular questionnaire; 6 subscales, total 6 items: intercourse (1 item), work (1 item), medical profession (1 item), infertility (1 item), relationship with children (1 item), treatment (1 item) | 5 responses per item (rating scale 0-4) | 0-100 per subscales; scores derived as sum of items in each scale, raw scores transformed into a scale 0-100  Lower scores indicate better health status | Not stated | English (UK) | Yes | Yes | Yes |
| EQ-5D-3L 6,7 | Generic measure of health related quality of life, no definition given. | Non-disease specific. Large-scale surveys of community. Complement other forms of quality of life measures to facilitate a common data set and generate cross-national comparisons of health state valuations | Review of existing health surveys, expert opinion | Self-administered, interview-based | Today | Descriptive system: 5 items measuring mobility, self-care, usual activities, pain/discomfort and anxiety/depression  EQ-VAS that scores “worse imaginable health” to “best imaginable heath’ | 3 response options per item (rating scale 1-3) | Single index derived from responses that is transformed into a utility score  VAS scored from 0-100 | Few minutes | Dutch  English (UK)  Finnish  Norwegian  Swedish | Yes | Yes | None |
| EQ-5D-5L 8,9  (2009) | Assumed same as EQ-5D-3L | Assumed same as EQ-5D-3L | Assumed same as EQ-5D-3L | Assumed same as EQ-5D-3L | Today | Assumed same as EQ-5D-3L | 5 responses per item (rating scale 1-5) | Single index derived from responses that is transformed into a utility score  VAS scored from 0-100 | Few minutes | English (UK)  Spanish (Spain) | Yes | Yes | Yes |
| FABQ 10 | Measure of patients’ fear of pain and consequent avoidance of physical activity and long-term disability. | Patients with chronic lower back pain; clinical practice and research | Fear avoidance model of exaggerated pain perception.  Concept of Disease conviction  Review of existing instruments  Patients with backpain | Self-administered | Not stated | 2 subscales, total of 11 items. FABQ- work scale (7 items).  FABQ physical activity scale (4 items). | 7 responses per item (rating scale 0-6) | Vary per subscale, Scores derived from sum of items. Higher scores indicate higher levels of fear-avoidance beliefs.  FABQ-work scale, range 0-42  FABQ physical activity, range 0-24 | Not stated | English (UK) | Yes | Not stated | Yes |
| HADS 11  (1983) | Measure to detect depression and anxiety | Patients in hospital clinics; clinical practice, research | Review of existing instruments | Self-administered | 1 week | 2 subscales, total of 14 items.  Depression subscale (7 items) and anxiety subscale (7 items) | 4 responses per item (rating scale 0-3) | Scores per subscale, derived from calculating the sum of items  Higher scores (> 7) indicate depression and/or anxiety | 2-5 minutes | English (UK) | Yes | Yes | **None** |
| IIP 64 12,13 | Measure of distress and determining source of interpersonal difficulties, by assessing 8 domains: Domineering/controlling, vindictive/self-centred, cold/distant, socially inhibited, nonassertive, overly accommodating, self-sacrificing and intrusive/needy.\*\* | Patients attending psychotherapy reporting interpersonal difficulties; clinical practice, research | Review of interviews in patients with reported interpersonal problems  Expert panel  Pilot studies of preliminary inventory in student population  Interpersonal theories, people from birth onward,  engage in interactions with others, and that each person's salient interpersonal  experiences are represented cognitively and emotionally in the nervous system. | Self-administered, interview-based | Undefined | 8 subscales, with a total of 64 items. Domineering/controlling (8 items), vindictive/self-centred (8 items), cold/distant (8 items), socially inhibited (8 items), nonassertive (8 items), overly accommodating (8 items), self-sacrificing (8 items), intrusive/needy (8 items) | 5 responses per item (rating scale 0-4) | Scores per domain (individual/ipsatized) calculated by sum of items, raw scores then converted into T scores  Total T score > 70 indicates distress greater in this domain than general population  Total score derived from calculating sum of subscales, raw total score then converted into T-scores,  Total T score > 70 indicates distress greater than general population | 10-15 minutes | English (US) | Yes | Yes | Yes |
| IIP 32 13,14 | Assumed same as IIP 64 | Assumed same as IIP 64 | Assumed same as IIP 64 | Self-administered, interview-based | Undefined | 8 subscales, with a total of 32 items. Domineering/controlling (4 items), vindictive/self-centred (4 items), cold/distant (4 items), socially inhibited (4 items), nonassertive (4 items), overly accommodating (4 items), self-sacrificing (4 items), intrusive/needy (4 items), | 5 responses per item (rating scale 0-4) | Scores per domain (individual/ipsatized) calculated by sum of items, raw scores then converted into scores  Total T score > 70 indicates distress greater in this domain than general population    Total score derived from calculating sum of subscales, raw total score then converted into T-scores.  Total T score > 70 indicates distress greater than general population | 10-15 minutes | English (US) | Yes | Yes | Yes |
| MPI 15 | Measure of the subjective distress caused by pain and impact of pain on patients’ lives | Patient with chronic pain (men and women) Clinical practice and research | Cognitive -behavioural perspective of pain | Self-administered, interview- based | Not stated | 12 subscales, total of 52 items  Subscales grouped into three parts.  Part 1 includes 5 subscales (perceived pain interference, support, pain severity, life-control and affective distress)  Part 2 includes 3 subscales (negative, solicitous and distracting responses)  Part 3 includes 4 subscales | 7 responses per item (rating scale 0-6) | Vary per subscale  Scores per subscale calculated as an average of items  Higher scores indicate greater subjective distress or impact of pain | 20 minutes | English (US) | Yes | None | None |
| ODI 1.0 16 | Disability defined as the limitations of a patient’s performance compared with that of a fit person | Patients with acute or chronic lower backpain; clinical, response to treatment | Review of interviews in patients with lower back pain | Self-adminstered | Not stated | 10 items measuring performance during activities of daily living pain intensity, personal care, lifting, walking, sitting, standing, sleeping, sex life, social life and travelling | 6 responses per item (0-5 rating scale) | Index score calculated by score achieved divided by possible score and converted into a percentage  Higher scores indicate more severe disability.  Range 0-100%.  0-20%; minimal disability, 21-40%; moderate disability,  41-60%; severe disability, 61-80% crippling backpain, 81-100%; bed-bound | 5 minutes | English (UK) | Yes | Yes | None |
| ODI 2.1a 17 | Assumed same as Oswestry Disability Index 1.0 | Assumed same as Oswestry Disability Index 1.0 | Assumed same as Oswestry Disability Index 1.0 | Assumed same as Oswestry Disability Index 1.0 | Not stated | Assumed same as Oswestry Disability Index 1.0 | 6 responses per item (0-5 rating scale) | Assumed same as Oswestry Disability Index 1.0 | 5 minutes | English (UK) | Yes | Yes | None |
| PBPI 18,19 | Measure of pain beliefs, assessing 4 domains: mystery, self-blame, constancy and permanence\*\* | Injured workers (Men and women) receiving compensation with chronic pain as a result of in- jury at work, not defined.  Clinical practice, research | Biopsychosocial model of pain. “Pain beliefs”, represent a personal understanding of the pain experienced.  Patients with chronic pain | Self-administered | Not stated | 4 subscales, total of 16 items. Pain constancy (4 items), pain permanence (5 items), pain as a mystery (4 items), self-blame (3 items) | 4 responses per item  (rating scale -2 - 2a) | Vary per domain  Scores per domain derived as an average of items.  Reverse scoring for items 5, 9 and 12 in the permanence domain and item 3 in constancy domain. | Not stated | English (US) | No | Not stated | **Yes** |
| SAQ 20 | Measure of sexual function, no definition given | Women on long-term Tamoxifen with a high risk of developing breast cancer. Unclear context, implied for clinical trials | Review of quality of life outcomes in a single clinical trial | Self-administered | Four weeks | 3 subscales, total of 10 items. Pleasure (6 items), discomfort (2 items) and habit (1 item). | 4 responses per item (rating scale 0-3) | Vary per subscale  Pleasure, range 0-18. High scores indicate greater pleasure  Discomfort, range 0-6, low scores indicate greater discomfort  Habit, range 0-3 | Not stated | English (UK) | No | Not stated | None |
| SF-36 21,22 | Generic health, 8 concepts, assessing physical functioning, social and role functioning, mental health, general health, perceptions, bodily pain and vitality\*\* | General and patient population; clinical practice, research, health policy evaluations and general population health survey | Medical Outcomes Survey (MOS), review of existing health surveys, expert opinion | Self-administered , interview administration | Various, current, past 4 weeks | 8 subscales with a total of 36 items.  Physical functioning (10 items), role limitations due to physical problems (4 items), social functioning (2 items), Bodily pain (2 items), general mental health (5 items), role limitations due to emotional problems (3 items), vitality (4 items), general health perceptions (5 items ) | Number of responses varies per subscale; uses rating scale, yes/no | 0-100 per subscale, higher scores indicate favourable health status. Summary scores: Physical (PCS) and mental health component summary (MCS) | 5-10 minutes | English (US) | Yes | None | None |
| SF-12 23 | Assumed same as SF-36 | Assumed same as SF-36 | Assumed same as SF-36 | Assumed same as SF-36 | Past 4 weeks | 8 subscales with a total of 12. Physical functioning (2 items), role limitations due to physical problems (2 items), social functioning (1 items), Bodily pain (1 items), general mental health (2 items), role limitations due to emotional problems (2 items), vitality (1 item) | Number of responses varies per subscale; uses rating scale, yes/no | Physical (PCS) and mental health component summary (MCS) | 2 minutes | English (US) | Yes | None | None |
| WHOQoL-100 24,25 | Generic measure of quality of life cross-culturally (definition given), 6 domains identified as core aspect of quality of life cross-culturally: physical, psychological, level of independence, social relationships, environment, personal beliefs/spiritualty \*\* | Patient groups in both developing and developed countries; clinical practice, clinical trials, epidemiological research, health policy. and service evaluation | WHOQol, Focus groups with patients (varying diseases), well persons, health personnel and quality of life researchers. Expert opinion | Self-administered, interview-based | Two weeks | Total 100 items, reflecting 24 specific facets (aspects of quality of life) and 1 general facet. Each facet is measured by 4 items. Facets grouped into 6 domains. | 5 responses per item (rating scale 1-5) | Score per domain derived from calculating mean that is transformed to a 0-100 scale  Higher scores indicate higher quality of life | 30 minutes | Various languages  -Over 30  Argentina  Australia  Brazil  China  Croatia  Germany  France  Japan  India  Israel  Netherlands  Panama  Russia  Spain  Thailand  United Kingdom  US  Zimbabwe | Yes | None | **Yes** |
| WHOQoL- Bref 24,26 | Generic measure of quality of life cross-culturally (definition given), 4 domains identified as core aspect of quality of life cross-culturally: physical, psychological, social relationships and environment, \*\* | Assumed same as WHOQol-100 | Assumed same as WHOQol-100 | Assumed same as WHOQol-100 | Two weeks | Total 26 items, reflecting 24 specific facets (aspects of quality of life) and 1 general facet. Each facet is measured by a single item and a further 2 items about overall quality of life and general health.  Facets grouped into 4 domains  physical health (7 facets), psychological (6 facets), social relationships (3 facets), environment (8 facets) | 5 responses per item (rating scale 1-5) | Score per domain derived from calculating mean that is transformed to a 0-100 scale.  Higher scores indicate higher quality of life | Not stated | Various languages  -over 30  Argentina  Australia  Brazil  China  Croatia  Germany  France  Japan  India  Israel  Netherlands  Panama  Russia  Spain  Thailand  United Kingdom  US  Zimbabwe | Yes | Yes | **Yes** |

*\*Each version of a PROM is considered a separate PROM.*

*\*\* These domains/concept have been defined, please refer to the reference*

a*0 not included*

**Abbreviations:** BDI; Becks Depression Inventory, BPI; Brief Pain Inventory, EHP 30; Endometriosis Health Profile 30, EHP-5; Endometriosis Health Profile 5, EuroQoL 5D 3L; EQ-5D 3L, EuroQoL 5D 5L; EQ-5D 5L, FABQ; Fears Avoidance Beliefs Questionnaire, HADS; Hospital Anxiety and Depression Scale, IIP 64; Inventory of Interpersonal Problems 64, IIP 32; Inventory of Interpersonal Problems 32, MPI; Multidimensional Pain Inventory, ODI 1.0; Oswestry Disability Index 1.0, ODI 2.1a; Oswestry Disability Index 2.1a, PBPQ; Pain beliefs and Perception Questionnaire, PROM; Patient reported outcome measures, Quality of life; QoL, SAQ; Sexual Activity Questionnaire, SF 36; Short Form Survey 36, SF 12; Short Form Survey 12; WHOQoL; World Health Organisation Quality of Life Questionnaire.

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