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Tailoring and evaluating treatment with the Patient-Specific Needs Evaluation: A Patient-Centered Approach

Running head: Patient-Specific Needs Evaluation

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ABSTRACT

Background: No patient-reported instrument assesses patient-specific information needs, treatment goals, and Personal Meaningful Gain (PMG, a novel construct evaluating individualized, clinically relevant improvement). This study reports the development of the Patient-Specific Needs Evaluation (PSN) and examines its discriminative validity (i.e., its ability to distinguish satisfied from dissatisfied patients) and test-retest reliability in patients with hand or wrist conditions.

Methods: A mixed-methods approach was used to develop and validate the PSN, following COSMIN guidelines, including pilot testing, a survey (pilot: n=223, final PSN: n=275), cognitive debriefing (n=16), expert input, and validation. Discriminative validity was assessed by comparing the satisfaction level of patients who did or did not achieve their PMG (n=1,985) and test-retest reliability using absolute agreement, Cohen's kappa, and ICCs (n=102). We used a sample of 2,860 patients to describe responses to the final PSN.

Results: The PSN has only five questions (completion time ± 3 minutes) and is freely accessible online. The items and response options were considered understandable by 90-92% and complete by 84-89% of the end-users. The PSN had excellent discriminative validity (Cramer's V: 0.48, $p < 0.001$) and moderate to high test-retest reliability (Kappa: 0.46-0.68, ICCs: 0.53-0.73).

Conclusions: The PSN is a freely available patient-centered decision-support tool that helps clinicians tailor their consultations to the patient's individual needs and goals. It contains the PMG, a novel construct evaluating individualized, clinically relevant treatment outcomes. The PSN may function as a conversation starter, facilitate expectation management, and aid shared decision-making. The PSN is implementation-ready and can be readily adapted to other patient populations.

Level of evidence: I

INTRODUCTION

Patient-centered and value-based healthcare frameworks have gained global recognition in recent years, aiming to put the patient first and achieve better outcomes at lower costs¹⁻⁴. Key in these frameworks is responding to individual information needs and treatment goals⁵, aiming for high satisfaction with the treatment results⁶⁻¹². It is, therefore, important for clinicians to be well-informed about the patient's information needs and treatment goals. Clinicians aim to meet patients' needs and goals, but sometimes a misalignment occurs. For instance, a surgeon may prioritize pain relief with a joint replacement while the patient prioritizes hand appearance. This misalignment can induce a treatment plan not fully meeting the patient's needs or goals.

In routine care, clinicians must understand each patient's information needs, as patients require information to comprehend their medical situation, participate in decision-making, and manage expectations. Providing targeted, patient-specific information improves shared decision making¹³, daily functioning¹⁴, treatment adherence¹⁵, quality of life, the patient's mindset, pretreatment expectations¹⁶⁻²⁴, and satisfaction with care and treatment results²⁵. Since information provision is modifiable²⁶⁻²⁹, outcomes can be improved. There is a lack of concise, patient-reported tools that focus on patients' information needs and treatment goals. These needs and goals may be, for example, understanding the diagnosis or regaining the ability to perform daily activities. Setting goals enhances patient participation, treatment adherence, and motivation, ultimately improving outcomes and satisfaction with treatment results³⁰⁻³². There are several limitations to existing tools assessing patient-specific limitations or goals, including the Canadian Occupational Performance Measure³³, Goal Attainment Scaling³⁴, Patient-Specific Goalsetting Method³⁵, and the Patient-Specific Functional Scale³⁶. These limitations depend on the specific tool and include being time-consuming³², having the potential for therapist bias³³⁻³⁵, and only focusing on the activities and participation levels

instead of all levels of the International Classification of Functioning, Disability, and Health (ICF)³³⁻³⁷. Moreover, they do not assess patient-specific improvement goals, i.e., when is the patient satisfied with the treatment results? Patient-specific improvement goals may depend on condition, treatment type, baseline score, and other patient-specific factors. For example, a recreational tennis player may consider a change from 4 to 8 on a 0-10 scale satisfactory, whereas a professional tennis player may not. We introduce the Personal Meaningful Gain (PMG) to represent the improvement an individual wants to obtain in a domain relevant to that individual, given the baseline score. Knowing 1) the information needs, 2) the individual goal, and 3) the PMG before treatment will allow clinicians to improve decision support and facilitate expectation management.

This study introduces a brief patient-reported tool assessing patient-specific information needs, treatment goals, and Personal Meaningful Gain before a first clinician consultation: the Patient-Specific Needs Evaluation (PSN). Specifically, the first objective of this study was to describe the development of the brief, easy-to-use, patient-reported tool to assess 1) patient-specific information needs, 2) treatment goals, and 3) Personal Meaningful Gain (PMG). This tool was initially developed for patients with hand and wrist conditions, but we designed it to be easily adopted in other patient populations. The second study objective was to examine the PSN's discriminative validity (i.e., its ability to distinguish satisfied from dissatisfied patients) and test-retest reliability. The third study objective was to describe the results of the final

PSN.METHODS

Study design

This was a user-centered mixed-methods study in patients with hand or wrist conditions, healthcare providers, and other stakeholders. We used the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines on PROM development³⁸ and measurement properties³⁸.

Setting

We developed the Patient-Specific Needs Evaluation (PSN) at Erasmus MC (an academic hospital) and Xpert Clinics (a specialized clinic for hand and wrist care) in The Netherlands. Data were collected at Xpert Clinics²¹ between July and August 2023. The medical ethical review committee of Erasmus MC approved this study; all participants provided informed consent.

Research team

The core research team consisted of hand surgeons and therapists (WR, YK, RW, SH, GRA, AR, GV, JMD), professionals with experience in developing measurement sets and tools (RW, SH, HS, JMD, RS)^{12, 39-42}, and electronic data capturing and implementation (HS, YK, RW, RS, SH, JMD, GV, WR)^{21, 43}. We consulted other clinicians, language experts, and native English speakers.

PSN development process

The development was iterative and comprised five overlapping stages, each informing subsequent stage(s) (Figure 1). Stage 1 included literature studies and expert meetings. After developing an item bank, we conducted a pilot study and survey on completeness and understandability in Stage 2. Stage 3 included cognitive debriefing of patients and clinicians and refining the item bank. We gathered expert input in Stage 4 and consulted a language expert, performed cross-cultural translation, and repeated the survey for the final PSN in Stage 5 (more details in Figure 1).

Participants

We used different samples to develop the PSN and establish the discriminative validity and test-retest reliability (Figure 1). For all samples, patients were eligible if they were adults, had any hand or wrist condition, completed our intake questionnaire, and understood Dutch language. All questionnaires were completed digitally.

For the survey, we excluded patients who gave inconsistent answers, e.g., stating fair on understandability but stating that all is clear in the associated comments box.

For discriminative validity, we included patients who completed the PSN at baseline and three months follow-up, as well as the Satisfaction with Treatment Results Questionnaire at three months^{11, 12}. We prospectively invited patients to participate in a test-retest study and complete the PSN for a second time 3-5 days after initial completion. The retest remained accessible for six days, i.e., a possible time interval of 3-11 days. We hypothesized that patient needs and goals remained stable during this period. We included patients in the test-retest analysis if they completed both the primary and retest PSN before clinician consultation. COSMIN advises a sample size of >100 participants for examining test-retest reliability⁴⁴. To describe the results of the final PSN, we included all patients that completed the PSN at baseline and three months follow-up. There were no additional exclusion criteria. All samples reflected the target population (patients with hand and wrist conditions) and differed in age, sex, and treatment location.

Discriminative validity, test-retest reliability, and statistical analysis

We evaluated discriminative validity by comparing the satisfaction with treatment results level of patients that did or did not obtain their PMG. We used a Satisfaction with Treatment Results Questionnaire^{11, 12} at three months, which evaluates satisfaction using a 7-point Likert scale, ranging from extremely dissatisfied to extremely satisfied. Using Chi-squared tests, we determined the PMG's discriminative power. We computed Cramer's V to interpret the effect size, where 0.10 reflects a small effect size, 0.30 a medium effect size, and 0.50 a large effect size⁴⁵.

We evaluated test-retest reliability by computing absolute agreement and Cohen's kappa. We computed intraclass correlation coefficients (ICCs) for all variables, including the goal domain, baseline score, the score needed to be satisfied with the most important goal domain,

and the PMG. Kappa scores lie between -1 and 1, where ≤ 0 indicates no agreement, 0.01-0.20 none to slight, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80 substantial, and 0.81-1.00 is almost-perfect agreement⁴⁶. We calculated ICCs using a two-way mixed-effects model⁴⁷. ICCs range from 0 to 1, 1 being perfect reliability, 0.90-0.99 very high, 0.70-0.89 high, 0.50-0.69 moderate, 0.26-0.49 low, and 0.00-0.25 indicates little if any, reliability⁴⁸⁻⁵⁰.

There were no missing data in the final PSN, as completing it before clinician consultation is mandatory in our clinical setting. We analyzed missing data patterns for the test-retest analyses; patients who completed both the primary and retest tests were responders, whereas patients without a retest were non-responders. We compared baseline characteristics of responders and non-responders using significance testing and calculating standardized mean differences to investigate if they systematically differed. We used R statistical software version 4.1.1 for the quantitative analyses and considered a p-value <0.05 significant. We tested the Dutch version of the PSN.

SOURCE OF FUNDING

NA.

RESULTS

Development process: cognitive debriefing and survey data

We performed sixteen cognitive interviews among nine patients and seven clinicians. All patients (three men, six women, aged 21-71 years (median: 51 years)) had different diagnoses. We also included patients with lower levels of education. Amongst clinicians, we interviewed one occupational hand therapist, two physical hand therapists, and four hand surgeons (five men, two women, aged 27-70 years (median: 40 years)). We iteratively improved the PSN, alternating between interviewing and adjusting, e.g., we shortened the introduction and explanation texts, changed the answer scale for pain, tingling, and sensitivity, and simplified the text with a language expert (Supplemental Digital Content (SDC) 1-2).

The survey on the final PSN indicated that the questions and response options were rated entirely or mostly understandable by 90-92% and fully or mostly complete by 84-89% of the 275 participants (SDC 3A-F). These were 89-93% and 86-91% for the pilot PSN (n=223).

The final PSN

Because of the dependencies within the PSN, it works best in digital form. It can be accessed here:

<https://personeel.equipezorgbedrijven.nl/ls/index.php?r=survey/index&sid=587344&lang=en>

(See Table 1 for a non-digital version). The intake PSN has five questions and takes approximately three minutes to complete. The information need part asks an open question about the patient's reason for making an appointment at the clinic (their request for help), followed by a single-select question where respondents pick their most important information need category. Subsequently, respondents select a predefined sub-answer based on that category to specify their information need in more detail. The treatment goal part of the PSN asks respondents to choose which domain they would most like to improve if they were to be treated and rate their baseline score on that domain on a 0-10 scale (e.g., the baseline pain score). Two secondary goal domains can optionally be selected. The final question asks for the score they think they need to achieve with treatment to be satisfied. The Personal Meaningful Gain (PMG) is then automatically generated as the difference between the respondent's baseline performance rating and their score needed to be satisfied (Figure 2). The follow-up PSN evaluates the previously selected information needs and treatment and improvement goals in only two questions and takes less than one minute to complete. The final PSN was completed by 2,860 patients (Table 2). Figure 3 shows the selected information need categories, and Figure 4 shows the distribution of the selected treatment goals. The rating on the most important domain was normally distributed with a median of 4 (Figure 5). The median score needed to be satisfied with the treatment result was 9 (Figure 5).

Discriminative validity and test-retest reliability

We included 1985 patients for the discriminative validity analysis (Table 2). Patients who obtained the PMG had better satisfaction with treatment results than those who did not (Figure 6, $p < 0.001$). There was a medium to large effect size (Cramer's V: 0.48), indicating that the PMG has excellent discriminative validity, i.e., the ability to distinguish satisfied from dissatisfied patients.

For the test-retest reliability, 102 of the 139 invited patients completed both the primary test and the retest within a median interval of 7 days (range 3-11 days). We found small differences between responders and non-responders in age and type of work (SDC 4). There was moderate agreement and reliability for the most important goal domain (Table 3, SDC 5). Considering it also agreement when the most important goal domain was chosen as a secondary goal domain in the retest, the test-retest improved to substantial agreement and high reliability (Table 3, SDC 6). We found moderate reliability for the baseline score on the most important goal domain, for the score needed to be satisfied, and the PMG (Table 3).

DISCUSSION

The Patient-Specific Needs Evaluation (PSN) focuses on patient-specific information needs and treatment goals and supports patient-centered care. Although developed in hand and wrist patients, the PSN can be modified easily to unlock its potential for generalization by altering answer options. As part of the PSN, we introduce the Personal Meaningful Gain (PMG) as a valid parameter of the improvement an individual wants to obtain in a domain relevant to that individual, given the pre-treatment score.

How to use the PSN

The PSN can be used as a conversation starter, decision-support tool, and expectation management tool during the first consultation. The information needs part facilitates clinicians to effectively provide information and tailor information provision to the individual patient,

e.g., knowing a patient's tendency towards surgery may guide how a clinician proposes non-invasive treatment when more appropriate. The treatment goal aids realistic goal setting, e.g., if a patient with Dupuytren's disease wants to improve the hand appearance, but it is unlikely that this will be achieved with treatment. The PMG helps to identify and discuss expectations, e.g., if one wants to improve from 2 to 10 to be satisfied, while this may be unrealistic due to comorbidity or symptom duration. The PSN also evaluates treatment success at a personal level.

There was moderate agreement and reliability for the most important goal domain. However, these improved to a substantial agreement and high reliability when also considering agreement if the most important goal domain was a secondary goal domain in the retest. This indicates that the PSN's reliability is good enough to identify all patient-relevant goals. Thus, patients find it hard to distinguish between their most important and secondary goals, which may overlap. Our finding that most patients who obtained their PMG were satisfied with their treatment results suggests that their satisfaction was independent of whether their PMG was on their factual primary goal, confirming the PSN's useability. Clinicians should always consider all goals, and not only the most important goal domain.

Key considerations

User participation during the development, the iterative approach, pilot testing, and mixed-methods resulted in a content-valid, discriminative, and reliable patient-centered tool. The PSN was easily implemented, and patients deemed it relevant, complete, and understandable. The PSN helps patients prepare for their first consultation, enhances awareness, empowers them to take control of their treatment, and aids shared decision-making. The clinicians indicated that the PSN helps them to identify patients with high or low expectations and respond accordingly. These aspects may improve patients' experience, expectation management, satisfaction with treatment results, and clinical outcomes⁵¹.

Compared to existing tools³³⁻³⁶, the PSN adds value. For example, the COPM, GAS, and PSGM are completed together with a healthcare provider. Therefore, they are relatively time-consuming in clinical practice, and there is a risk of “therapist bias” as a practitioner may influence these goals. Other tools do not assess patient-specific improvement goals and their relation with satisfaction with treatment results, while the PSN does (i.e., the PMG).

Furthermore, in contrast with current tools such as the PSFS, COPM, and PSGM, the PSN allows distinct ICF domains and not only focuses on the activities and participation levels. None of the aforementioned tools assesses information needs, while the PSN does measure these. Altogether, the PSN is a unique tool with added value in daily clinic and research.

The distribution of the information need category and the goal domain indicates that patients have different needs and goals. This highlights that a personalized treatment strategy is essential, which can be informed by the PSN. Further, although most people wanted to reach a 9 to be satisfied, many patients consider lower scores satisfactory, i.e., not all patients aim for the maximum score. The wide distribution indicates that this is indeed a personalized score, which further adds to the value of the PSN.

The PMG distinguished satisfied patients from dissatisfied patients very well, indicating that it can be used to evaluate the clinical relevance of treatment effects. The PMG is especially beneficial as it is determined before clinician consultation, providing a proxy for satisfaction with treatment results at a very early stage, presuming what patients think they want is what they will be satisfied with. Future research may investigate whether the PMG has a greater discriminative capacity for satisfaction than traditional values such as the Minimal Important Change or Patient Acceptable Symptom State.

At our sites, a clinician dashboard is used, which displays, e.g., patient characteristics, PROMs, clinician-reported outcomes (e.g., goniometry), and prediction models. With the PSN added, healthcare can be further personalized and data-driven. Nevertheless, the PSN is also

valuable as a stand-alone tool.

We distribute the PSN before surgeon consultation. If treatment is scheduled (e.g., surgery or therapy), we allow patients to change previous answers. For example, the patient's goal may have changed following expectation management during consultation. This strategy is, of course, optional.

Limitations

Respondents indicate their most important needs and goals without knowing their diagnosis. It may also be difficult for individuals to accurately predict how a future score would feel, such as a 9 or 10, since this is an abstract idea that may not match their actual experience when they reach that level. However, focusing on the patient's most important needs and goals at this early stage benefits clinicians, as they may use these in decision-making and expectation management. Although some items may be moving targets (i.e., a response shift: goals may change over time), the PSN discriminated effectively between satisfied and dissatisfied patients. Future research could investigate how needs and goals change over time.

Also, the PSN does not replace traditional outcome measures, and additional time investment should be considered when using it.

Another limitation is the test-retest non-response. The small differences between responders and nonresponders seem clinically irrelevant, as age and type of work are unlikely to influence test-retest reliability. Still, although inevitable in test-retest studies, this may have influenced our findings.

We addressed most issues mentioned by respondents but kept the maximum number of information need categories respondents could choose. Obviously, patients have more questions, and clinicians should try to answer them all. However, we considered it essential that, at least, the most important question is identified and answered as there is a maximum

information load persons absorb. Therefore, it is essential to see the PSN as a conversation starter. Also, patients might be better prepared by knowing their most important question⁵¹. Another limitation is that we excluded patients with inconsistent answers on the survey. This may have influenced our findings on the understandability of the PSN. However, if we had included these patients, our findings would also have been biased; thus, we believe that our decision was the best solution to minimize bias. Also, although the participants had different educational levels (including lower levels), it remains challenging to reach lower literacy patients. Future research may specifically target these.

Although we performed a cross-cultural translation to English, we only tested the Dutch version. Future studies may investigate the PSN in different languages and cultural settings.

Conclusion

The PSN is a novel, brief patient-reported tool identifying individual patient needs and goals. By identifying these, clinicians are better equipped to tailor information provision and treatment to the individual patient, enhancing the quality of care. The PSN can help patients to take control of their treatment. It is valid, reliable, and easy to use, especially but not only in digital form. The PSN is implementation-ready for hand and wrist care and can easily be generalized to other fields. The PSN is provided with open access and is free to use.

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FIGURE LEGENDS

Fig 1. Flow chart of the development (in blue) and the validation (in orange) of the PSN, describing the sample and most important goals and activities per stage.

Fig. 2: Visualization of the Patient-Specific Needs (PSN) treatment goal and Personal Meaningful Gain (PMG) parts. In this example, the patient entered that the most important treatment goal was to improve the performance of activities. The score at baseline was 3 on a 0-10 scale (high scores indicate better performance), and the patient indicated that a score of 7 is needed to become satisfied with the treatment result. After this is filled in, the digital PSN automatically generates a statement on the treatment goal, and PMG, for the patient to be able to check whether it is correct or needs modification.

Fig. 3: Distribution of the information need in the final version of the Patient-Specific Needs Evaluation (PSN). The patient chooses one of the following options: I do not need information; Diagnosis (I have questions about the diagnosis); Advice (I want to know what is the best thing to do in my situation); Treatment (I have questions about the treatment); Perspective (I want to know what to expect in the future).

Fig. 4: Goal domains chosen as most important in the final version of the Patient-Specific Needs Evaluation (PSN).

Fig. 5: Distribution of the score on the most important goal domain at baseline and the score patient reported that they needed to achieve to be satisfied with the treatment results in the final version of the Patient-Specific Needs Evaluation (PSN). The figures indicate that not all patients want to obtain the maximum score on their most important outcome domain to become satisfied with the treatment results. The median score needed to be satisfied with the treatment result was 9 in the final version. For ease of interpretation, we converted each domain score to the same scale (i.e., reversing the scores on the domains pain, numbness, and tingling).

Fig. 6: Discriminative validity of the Personal Meaningful Gain (PMG) in n = 1985 patients, demonstrating that patients that obtained their PMG were much more often satisfied with their treatment results compared to patients who did not obtain their PMG (with a medium to large effect size (Cramer's V: 0.48, $p < 0.001$).

Supplemental Digital Content Legend

Supplemental Digital Content 1: Conceptual framework of the PSN derived from cognitive interviews with patients (n=9).

Supplemental Digital Content 2: Conceptual framework of the PSN derived from cognitive interviews with clinicians (n=7).

Supplemental Digital Content 3A-F: These pie charts indicate the understandability and completeness of the questions and response options on information needs (3A-C), treatment goals, and PMG (3D-F). The survey indicated that 90% considered the question on information need entirely or mostly understandable, 91% considered the answer options entirely or mostly understandable, and 84% rated the answer options as entirely or mostly complete. For the treatment goals and PMG: this was 92%, 91%, and 89%, respectively.

Supplemental Digital Content 4: Non-responder analysis for the test-retest study.

Supplemental Digital Content 5. Cross table demonstrating how often the most important goal domain was chosen at the primary test as well as at the retest. The values correspond to the number of patients and the percentage of the row total, except for the "Row total" column, where the percentages correspond to the percentage of the column total.

Supplemental Digital Content 6. This cross table demonstrates how often the most important goal domain was chosen at the primary test and also as the most important or as secondary goal domain at the retest. The values correspond to the number of patients and the percentage of the row total, except for the "Row total" column, where the percentages correspond to the percentage of the column total.

Table 1: The non-digital version of the Patient-Specific Needs questionnaire (PSN). The PSN is best administered in digital form and can be accessed digitally and open access here: <https://personeel.equipezorgbedrijven.nl/ls/index.php?r=survey/index&sid=587344&lang=en>. This table displays each question and the associated response options, which, in some specific domains, are slightly different than displayed. After question 4, respondents can optionally pick two secondary domains.

| Part | Question | Response options |
|-------------------|--|---|
| Information needs | 1. What is the reason that you have made an appointment with us? In other words: what is your request for help from the doctor? | [Open text] |
| | 2A. What is your most important information need? | Choose one of the following options: <ul style="list-style-type: none"> • I do not need information • Diagnosis (I have questions about the diagnosis) • Advice (I want to know what is the best thing to do in my situation) • Treatment (I have questions about the treatment) • Perspective (I want to know what to expect in the future) |
| | 2B. Specifying question based on information need: <ul style="list-style-type: none"> • On which topic would you like advice? OR • What would you like to know about the diagnosis? OR | [Choose one of the response options dependent on information need category, see digital PSN for all options] |

| | | |
|---------------------------------|---|--|
| | <ul style="list-style-type: none"> • What would you like to know about the treatment? OR • What would you like to know about your perspective? | |
| Treatment and improvement goals | 3. If you were treated, which domain would you most like to improve? | <p>Choose one of the following options:</p> <ul style="list-style-type: none"> • I do not want to be treated • Numbness (loss of sensation) • Mobility / flexibility of my hand • Strength • Pain • Tingling • Performance of activities (e.g., housekeeping, hobby, sports...) • Appearance of my hand / wrist • Ability to work |
| | 4. How would you rate your [domain from question 3] at this moment? | Score range 0-10; higher scores indicate better performance except for the items “Numbness (loss of sensation)”, “Pain”, and “Tingling” |
| | <p>5. What is the minimum score on [domain] that you want to achieve with your treatment?</p> <p>With what score would you be satisfied with the treatment result? Assume that your score on all other domains is (already) satisfactory.</p> | Score range 0-10; higher scores indicate better performance except for the items “Numbness (loss of sensation)”, “Pain”, and “Tingling” |

Table 2. Baseline characteristics of the patients that completed the final PSN (n = 2,860), the discriminative validity sample (n = 1,985), and patients that participated in the test-retest sample (n = 102).

| Variable | Sample that completed the final PSN (n = 2,860) | Discriminative validity sample (n = 1,985) | Test-retest sample (n = 102) |
|---|--|---|---|
| Age, mean (SD) | 54 (16.3) | 59 (13.9) | 61 (15.5) |
| Sex = male, n (%) | 1086 (38.0) | 704 (35.5) | 46 (45.1) |
| Duration of symptoms in months, mean (SD) | 18 (38.2) | 17 (33.5) | 21 (39.6) |
| Type of work, n (%) | | | |
| Unemployed due retirement | 695 (24.3) | 570 (28.7) | 41 (40.2) |
| Unemployed due other reason | 339 (11.9) | 214 (10.8) | 6 (5.9) |
| Light physical labor (e.g., office work) | 735 (25.7) | 468 (23.6) | 22 (21.6) |
| Moderate physical labor (e.g., working in a store) | 648 (22.7) | 438 (22.1) | 16 (15.7) |
| Heavy physical labor (e.g., working in construction) | 443 (15.5) | 295 (14.9) | 17 (16.7) |
| Level of education (%) | | | |
| None | 34 (1.2) | 12 (0.6) | 1 (1.0) |
| Primary education (primary school, special primary education) | 71 (2.5) | 31 (1.6) | 1 (1.0) |

| | | | |
|--|-------------|-------------|------------|
| Primary or pre-vocational education (such as (in Dutch) LTS, LEAO, LHNO, Huishoudschool, VMBO) | 323 (11.3) | 252 (12.7) | 12 (11.8) |
| Secondary general secondary education (such as (in Dutch) MAVO, (M)ULO, MBO-short, VMBO-t) | 517 (18.1) | 356 (17.9) | 24 (23.5) |
| Secondary vocational education and vocational training (such as (in Dutch) MKBO-long, MTS, MEAO, BOL, BBL, INAS) | 599 (20.9) | 429 (21.6) | 20 (19.6) |
| Higher general and pre-university education (such as (in Dutch)HAVO, VWO, Atheneum, Gymnasium, HBS, MMS) | 251 (8.8) | 198 (10.0) | 9 (8.8) |
| Higher vocational education (such as (in Dutch) HBO, HTS, HEAO, HBO-V, university graduates) | 608 (21.3) | 466 (23.5) | 21 (20.6) |
| Scientific education (e.g., MSc.) | 299 (10.5) | 164 (8.3) | 8 (7.8) |
| Prefer not to say | 158 (5.5) | 77 (3.9) | 6 (5.9) |
| Body Mass Index, mean (SD) | 26.5 (4.7) | 27.2 (4.9) | 26.5 (4.4) |
| Smoking status, n (%) | | | |
| Yes, daily smoker | 367 (12.8) | 207 (10.4) | 10 (9.8) |
| Yes, passive smoker | 15 (0.5) | 8 (0.4) | 2 (2.0) |
| Yes, sometimes | 140 (4.9) | 76 (3.8) | 6 (5.9) |
| No | 2338 (81.7) | 1694 (85.3) | 84 (82.4) |
| Affected side, n (%) | | | |

| | | | |
|-------------------------------------|-------------|-------------|------------|
| Left | 930 (32.5) | 607 (30.6) | 33 (32.4) |
| Right | 1106 (38.7) | 743 (37.4) | 40 (39.2) |
| Both | 824 (28.8) | 635 (32.0) | 29 (28.4) |
| Dominance, n (%) | | | |
| Left | 299 (10.5) | 199 (10.0) | 11 (10.8) |
| Right | 2395 (83.7) | 1676 (84.4) | 84 (82.4) |
| Both | 166 (5.8) | 110 (5.5) | 7 (6.9) |
| Second opinion = no, n (%) | 2475 (86.5) | 1781 (89.7) | 87 (85.3) |
| Personal injury lawsuit = no, n (%) | 2801 (97.9) | 1960 (98.7) | 100 (98.0) |

| Test-retest variable | Absolute agreement | Cohen's Kappa (95% CI) | ICC (95% CI) | Conclusion |
|---|---------------------------|-------------------------------|---------------------|--|
| Most important goal domain | 58% | 0.46 (0.34 to 0.58) | 0.53 (0.38 to 0.66) | Moderate agreement and reliability |
| Most important goal domain chosen as most important goal domain or as secondary goal domain at retest | 75% | 0.68 (0.58 to 0.79) | 0.73 (0.62 to 0.81) | Substantial agreement and high reliability |
| Baseline score on most important goal domain | - | - | 0.57 (0.42 to 0.69) | Moderate reliability |
| Score needed to be satisfied at most important goal domain | - | - | 0.64 (0.51 to 0.74) | Moderate reliability |
| Personal Meaningful Gain (PMG) at most important goal domain | - | - | 0.65 (0.53 to 0.75) | Moderate reliability |

Table 3. Test-retest reliability of the Patient-Specific Needs Questionnaire (PSN).

Figure 1



Figure 3

*How would you rate your performance of activities at this moment?

| Very poor | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Excellent |
|-----------|-----------------------|-----------------------|-----------------------|----------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

ⓘ ATTENTION! A higher score means better performance of activities.

*You currently rate performance of activities: 3

What is the minimum score on the performance of activities that you want to achieve with your treatment? With what score on the performance of activities would you be satisfied with the treatment result?

Assume that your score on all other domains is (already) satisfactory.

| Very poor | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | Excellent |
|-----------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|----------------------------------|-----------------------|-----------------------|-----------------------|
| | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

ⓘ ATTENTION! A higher score means better performance of activities.

I am satisfied if I improve on the performance of activities from a 3 to a 7.

Figure 3

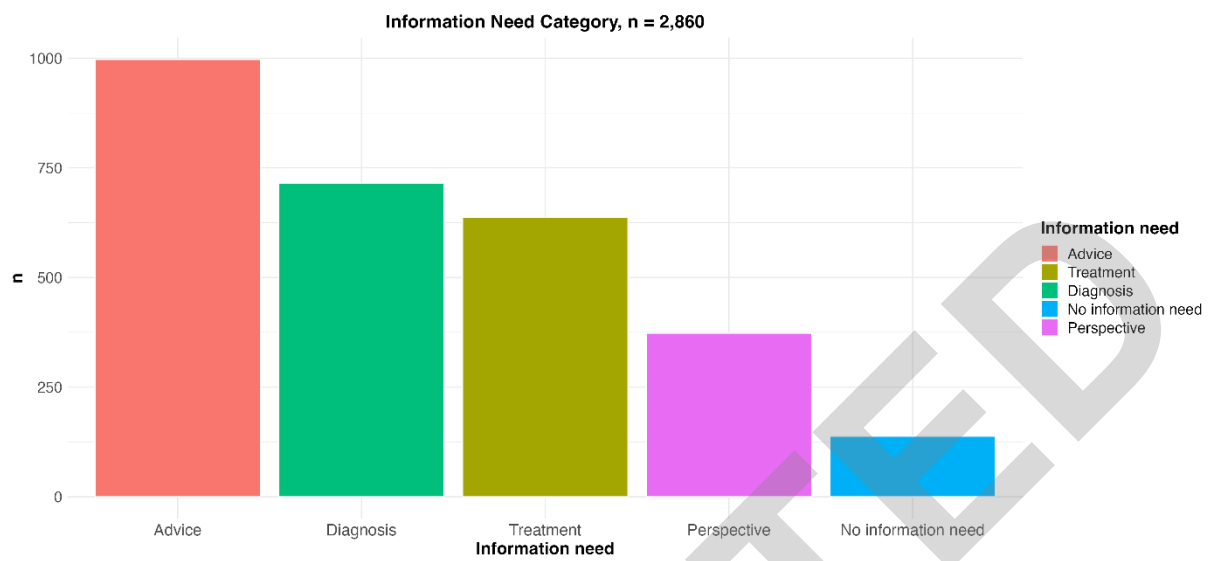
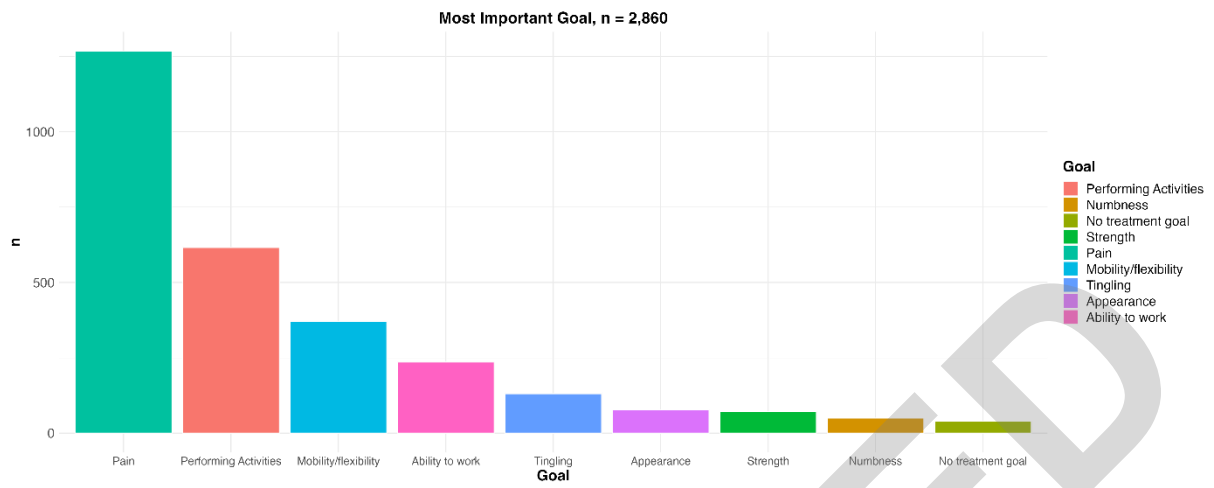
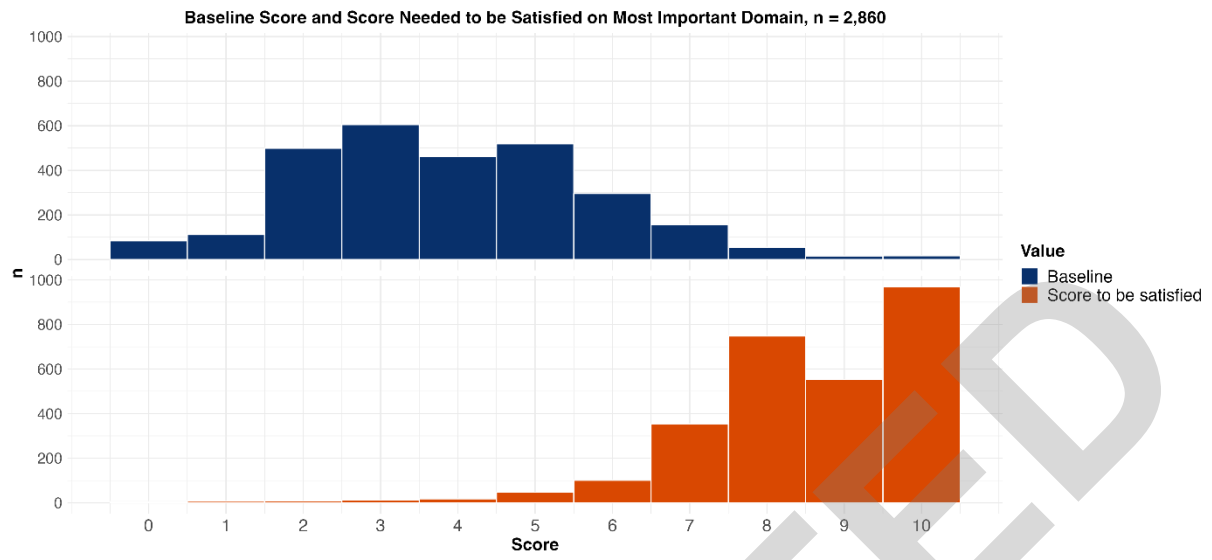


Figure 4



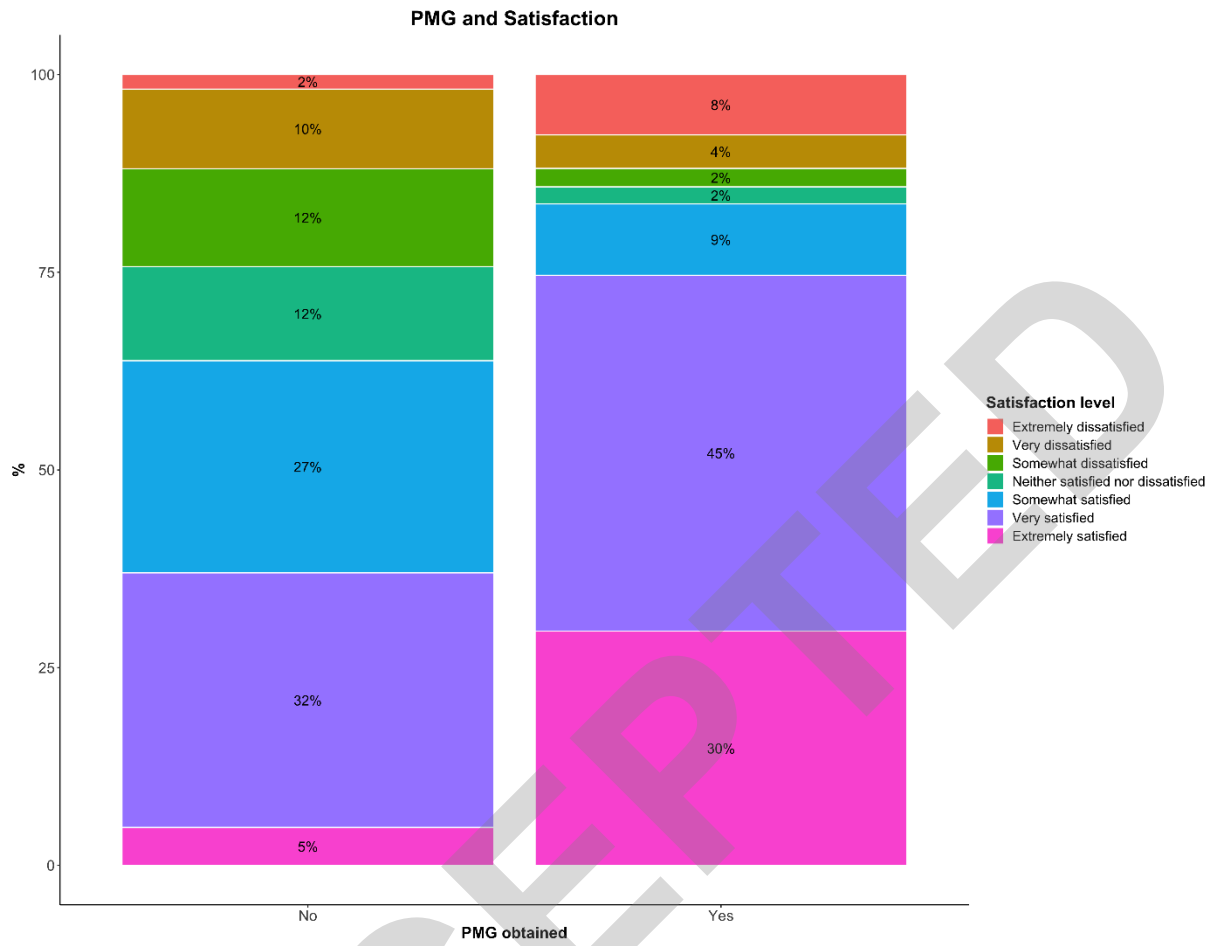
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Figure 5



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Figure 6



SDC 1

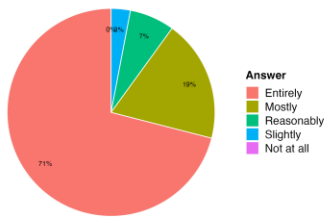
| Main categories | Findings | Quotes |
|---|---|--|
| 1: Relevance | 1.1: Most participants found it relevant that their answers could direct the conversation | 1.1.1 "I think it's important for a doctor to know that in advance. Know what the situation is" (P1) 1.1.2 "easy to give direction to the conversation" (P1) 1.1.3 "Time efficient" (P2) |
| | 1.2: Most participants found it relevant that the clinician could respond to expectations | 1.2.1 "If you absolutely want to reach a 10, that says something about you" (P1) 1.2.2 "It is easier for the doctor to estimate the patient's expectations" (P3) 1.2.3 "I can imagine that it is nice for the practitioner to already know what someone would most like to improve" (P4) |
| | 1.3: Some participants felt well prepared and empowered by filling in the questionnaire | 1.3.1 "Yes, also nice for myself to already think about what I would like to know during such a first intake, for example" (P5) 1.3.2 "You feel that you are taken seriously" (P6) |
| 2: Completeness: information need | 2.1 Some participants seem worried about whether the clinician would answer all their questions | 2.1.1 FIELD NOTES |
| | 2.2 Many participants deemed it impossible to choose just one answer option | 2.2.1 "To me, everything was important" (P2) 2.2.2 "asking multiple questions to arrive at an opinion" (P6) |
| 3: Completeness: treatment goal and improvement goal | 3.1 All participants thought the questions and answer options were complete | 3.1.1 "I believe everyone can find his or her complaint in here" (P7) 3.1.2 "Seems all right to me, yes, I can't see one missing" (P1) |
| 4: Understandability: introductory texts | 4.1 Many participants thought the welcome text was too elaborate | 4.1.1 "It could also be said in two sentences" (P7) 4.1.2 "Yes, just a good clear explanation" (P6) |
| | 4.2 Some participants missed a sentence on how many options they were allowed to pick at 'treatment goal' | 4.2.1 "It literally says pick one" (P3) 4.2.2 "for some people I think it is annoying to have to focus on one thing again" (P3) |
| 5: Understandability: information need | 5.1 Most participants found the question and answer options clear | 5.1.1 "Give me a second... No, it's clear like this" (P8) |
| 6: Understandability: treatment goal and improvement goal | 5.2 Some participants thought they couldn't answer the question without more information beforehand | 5.2.1 "You can't really ask about treatment if a diagnosis has not yet been determined" (P3) |
| | 6.1 Many participants thought the answer scale for pain was too complicated | 6.1.1 "You need to switch the scale" (P3) 6.1.2 "With smiley faces for people who think it is complicated" (P6) 6.1.3 "I would say 'unbearable pain' and 'no pain' instead of 'very bad' and 'excellent'" (P3) |
| | 6.2 Some participants found specific words in the domain section too complicated | 6.2.1 "Well, I didn't know what piliability was" (P2) |

SDC 2

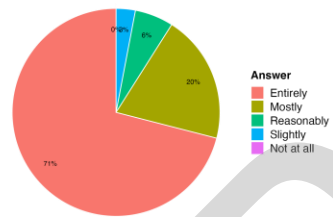
| Main categories | Findings | Quotes |
|--|--|--|
| 1: Relevance | 1.1 Many clinicians thought the open question for aid and the conversation itself provide enough information to understand what the patients needs are | 1.1.1 "you can just have this conversation and then you will get this information too" (C2) 1.1.2 "I'm quite satisfied with the information that we already have" (C4) |
| | 1.2 Some clinicians thought the questionnaire might help them to formulate a relevant treatment goal | 1.2.1 "I would definitely look it over and see what the patients goal was prior to their visit to the doctor. And of course I would discuss that with them, before coming here, your goal was this, is that still your goal or do you now want something else?" (C1) |
| | 1.3 Many clinicians thought it useful to know what the patients goal is to become satisfied with the treatment results | 1.3.1 "If the expectations aren't realistic then I would use it. (...) If it is just regular, then I won't do much with it" (C4) 1.3.2 "you can filter out those extremes nicely"(C2) |
| | 1.4 Some clinicians thought it useful that the patient fills in the questionnaire before the first consultation | 1.4.1 "I actually think this is a good one, because the patient can tell his own story. So one is a little less likely to be overwhelmed by the opinion of a clinician" (C3) |
| | 1.5 Some clinicians thought it useful to have an image of the patient before the first consultation | 1.5.1 "It's interesting, by certain answers, you also get to see a kind of personality" (C5) |
| 2: Completeness: information need | 2.1 All clinicians think the part on information need is complete | 2.1.1 "It's definitely complete, especially the first question" (C1) |
| 3: Completeness: treatment goal and improvement goal | 3.1 Most clinicians think the part on the treatment goal is complete | 3.1.1 "Yes, yes, I think it is fairly complete in terms of complaints" (C3) |
| 4: Usability for the clinician | 4.1 Barrier: Most clinicians are afraid the questionnaire will cost them more time | 4.1.1 "because of course you don't have forever to prepare so I'm not sure I would look at this" (C2) 4.1.2 "Example given, 'oh yes, I saw that you are a bricklayer or something' and then you immediately have a conversation and someone also has the feeling that his information is used" (C3) |
| | 4.2 Risk: Some clinicians fear being biased | 4.2.1 "Well, I think I have to be very careful not to start with prejudices. Someone has discussed his profession and his complaints, so I'm already starting with a tunnel vision" (C3) 4.2.2 "And especially a conversation is dynamic. You can't put at person in a box" (C4) |
| | 4.3 Risk: some clinicians fear that clinicians will only answer the most important answer | 4.3.1 "If I look at it quickly, I could just be put on the wrong track when I see that they can only indicate one" 4.3.2 "You have to let therapists know that patients are only asked to only choose one answer" (C1) |
| | 4.4 Barrier: Some clinicians thought it hard to use the patients answer to the information need in their consult | 4.4.1 "And vice versa, you choose diagnosis and treatment, or advice and future, but that is usually also a multi-question" (C4) 4.4.2 "Yeah, I honestly don't know if I'll be using this when they can only choose one option, because then I know okay, they will ask more questions anyway. Do you understand what I mean?" (C2) |
| | 5: Usability/ understandability for patients | 5.1 All clinicians thought the answer scale to pain was too complicated |
| | 5.2 Some clinicians think several words and questions are too hard for patients to understand | 5.2.1 FIELD NOTE: suggestion to put answers in sentences (narrative mode) (C4, C5, C6) 5.2.2 "We have a certain level of intelligence, it's not that I feel elevated, but a majority of patients do not even understand some of the words" (C3) |
| | 5.3 Some clinicians wonder whether the patient answers honestly | 5.3.1 "All patients want their doctor to put maximum effort in it" (C5) 5.3.2 "But is that realistic?" (C1) |
| | 5.4 Risk: many clinicians are afraid that patients have to answer too many overlapping questions | 5.4.1 "Yes, you know, whatever, 'I already filled this in' and then you fill in the question differently than the other one. So then you give a score, you don't look at it carefully, while you might have done that other list very carefully" (C3) |

SDC 3

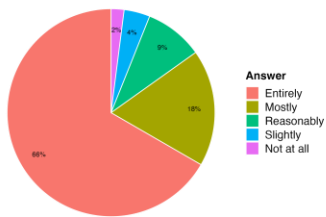
A Did you find the question about your information need understandable?



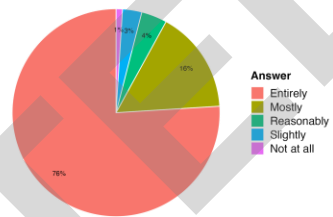
B Did you find the response options on your information need understandable?



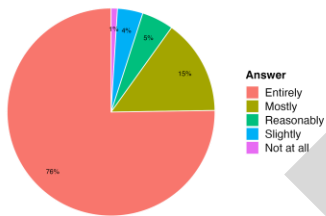
C Are the response options on your information need complete?



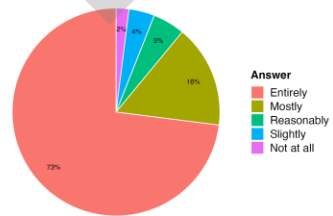
D Were the questions about your treatment goals understandable?



E Did you find the response options on your treatment goals understandable?



F Are the response options on your treatment goals complete?



ACCEPTED

Supplemental Digital Content 4. Non-responder analysis for the test-retest study.

| Variable | Non-Responders (n = 37) | Responders (n = 102) | p-value* | SMD |
|--|------------------------------------|---------------------------------|-----------------|------------|
| Age, median [IQR] | 53.00 [36.00, 63.00] | 64.00 [51.25, 73.75] | <0.001 | 0.691 |
| Sex = male, n (%) | 13 (35.1) | 46 (45.1) | 0.392 | 0.204 |
| Duration of symptoms in months, median [IQR] | 12.00 [6.00, 28.00] | 11.00 [5.00, 18.75] | 0.171 | 0.305 |
| Type of work, n (%) | | | 0.009 | 0.745 |
| Unemployed due retirement | 6 (16.2) | 41 (40.2) | | |
| Unemployed due other reason | 4 (10.8) | 6 (5.9) | | |
| Light physical labor (e.g., office work) | 10 (27.0) | 22 (21.6) | | |
| Moderate physical labor (e.g., working in a store) | 14 (37.8) | 16 (15.7) | | |
| Heavy physical labor (e.g., working in construction) | 3 (8.1) | 17 (16.7) | | |
| Level of education (%) | | | 0.950 | 0.328 |
| None | 1 (2.7) | 1 (1.0) | | |

| | | | | |
|--|----------------------|----------------------|-------|-------|
| Primary education (primary school, special primary education) | 0 (0.0) | 1 (1.0) | | |
| Primary or pre-vocational education (such as (in Dutch) LTS, LEAO, LHNO, Huishoudschool, VMBO) | 4 (10.8) | 12 (11.8) | | |
| Secondary general secondary education (such as (in Dutch) MAVO, (M)ULO, MBO-short, VMBO-t) | 6 (16.2) | 24 (23.5) | | |
| Secondary vocational education and vocational training (such as (in Dutch) MKBO-long, MTS, MEAO, BOL, BBL, INAS) | 8 (21.6) | 20 (19.6) | | |
| Higher general and pre-university education (such as (in Dutch) HAVO, VWO, Atheneum, Gymnasium, HBS, MMS) | 2 (5.4) | 9 (8.8) | | |
| Higher vocational education (such as (in Dutch) HBO, HTS, HEAO, HBO-V, university graduates) | 9 (24.3) | 21 (20.6) | | |
| Scientific education (e.g., MSc.) | 4 (10.8) | 8 (7.8) | | |
| Prefer not to say | 3 (8.1) | 6 (5.9) | | |
| Body Mass Index, median [IQR] | 26.00 [23.00, 28.00] | 26.00 [23.00, 29.00] | 0.617 | 0.042 |

| | | | | |
|-------------------------------------|-----------|------------|-------|-------|
| Smoking status, n (%) | | | 0.366 | 0.356 |
| Yes, daily smoker | 7 (18.9) | 10 (9.8) | | |
| Yes, passive smoker | 0 (0.0) | 2 (2.0) | | |
| Yes, sometimes | 1 (2.7) | 6 (5.9) | | |
| No | 29 (78.4) | 84 (82.4) | | |
| Affected side, n (%) | | | 0.953 | 0.059 |
| Left | 13 (35.1) | 33 (32.4) | | |
| Right | 14 (37.8) | 40 (39.2) | | |
| Both | 10 (27.0) | 29 (28.4) | | |
| Dominance, n (%) | | | 0.560 | 0.223 |
| Left | 3 (8.1) | 11 (10.8) | | |
| Right | 33 (89.2) | 84 (82.4) | | |
| Both | 1 (2.7) | 7 (6.9) | | |
| Second opinion = no, n (%) | 34 (91.9) | 87 (85.3) | 0.460 | 0.209 |
| Personal injury lawsuit = no, n (%) | 36 (97.3) | 100 (98.0) | 1.000 | 0.049 |

*Continuous variables were compared using the Kruskal-Wallis Rank Sum Test and dichotomous or categorical variables using a Chi-Square test.

ACCEPTED

Supplemental Digital Content 5. Cross table demonstrating how often the most important goal domain was chosen at the primary test as well as at the retest. The values correspond to the number of patients and the percentage of the row total, except for the “Row total” column, where the percentages correspond to the percentage of the column total.

| | Most important goal domain at retest | | | | | | | | |
|--|--------------------------------------|-------------------|-----------------------------|-------------|-----------------|-----------------|-------------------|---------------------------|------------------|
| Most important goal domain at primary test | <i>Pain</i> | <i>Activities</i> | <i>Flexibility/Mobility</i> | <i>Work</i> | <i>Tingling</i> | <i>Strength</i> | <i>Appearance</i> | <i>Numbness/Sensation</i> | <i>Row total</i> |
| <i>Pain</i> | 24 (69%) | 5 (0,14%) | 3 (9%) | 2 (6%) | 0 (0%) | 0 (0%) | 1 (3%) | 0 (0%) | 35 (34%) |
| <i>Activities</i> | 7 (29%) | 15 (63%) | 0 (0%) | 1 (4%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (4%) | 24 (24%) |
| <i>Flexibility/Mobility</i> | 2 (13%) | 3 (20%) | 8 (53%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (13%) | 0 (0%) | 15 (15%) |
| <i>Work</i> | 1 (13%) | 2 (25%) | 1 (13%) | 3 (38%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (13%) | 8 (8%) |
| <i>Tingling</i> | 0 (0%) | 1 (17%) | 0 (0%) | 0 (0%) | 5 (8%) | 0 (0%) | 0 (0%) | 0 (0%) | 6 (6%) |
| <i>Strength</i> | 2 (33%) | 2 (33%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (0,167) | 1 (17%) | 0 (0%) | 6 (6%) |
| <i>Appearance</i> | 0 (0%) | 0 (0%) | 1 (50%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (50%) | 0 (0%) | 2 (2%) |
| <i>Numbness/Sensation</i> | 0 (0%) | 1 (20%) | 1 (20%) | 0 (0%) | 1 (20%) | 0 (0%) | 0 (0%) | 2 (40%) | 5 (5%) |
| <i>No treatment goal</i> | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (100%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (1%) |
| <i>Column total</i> | 36 (35%) | 29 (28%) | 14 (14%) | 6 (6%) | 7 (7%) | 1 (1%) | 5 (5%) | 4 (4%) | 102 (100%) |

Supplemental Digital Content 6. This cross table demonstrates how often the most important goal domain was chosen at the primary test and also as the most important or as secondary goal domain at the retest. The values correspond to the number of patients and the percentage of the row total, except for the “Row total” column, where the percentages correspond to the percentage of the column total.

| | Most important or secondary goal domain chosen at the retest | | | | | | | | |
|--|---|-------------------|-----------------------------|-------------|-----------------|-----------------|-------------------|---------------------------|------------------|
| Most important goal domain chosen at primary test | <i>Pain</i> | <i>Activities</i> | <i>Flexibility/Mobility</i> | <i>Work</i> | <i>Tingling</i> | <i>Strength</i> | <i>Appearance</i> | <i>Numbness/Sensation</i> | <i>Row total</i> |
| <i>Pain</i> | 31 (89%) | 2 (6%) | 1 (3%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (3%) | 0 (0%) | 35 (34%) |
| <i>Activities</i> | 5 (21%) | 19 (79%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 24 (24%) |
| <i>Flexibility/Mobility</i> | 1 (7%) | 3 (20%) | 9 (60%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (13%) | 0 (0%) | 15 (15%) |
| <i>Work</i> | 1 (13%) | 1 (13%) | 0 (0%) | 5 (63%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (13%) | 8 (8%) |
| <i>Tingling</i> | 0 (0%) | 1 (17%) | 0 (0%) | 0 (0%) | 5 (80%) | 0 (0%) | 0 (0%) | 0 (0%) | 6 (6%) |
| <i>Strength</i> | 2 (33%) | 1 (17%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (33%) | 1 (17%) | 0 (0%) | 6 (6%) |
| <i>Appearance</i> | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (100%) | 0 (0%) | 2 (2%) |
| <i>Numbness/Sensation</i> | 0 (0%) | 1 (20%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 4 (80%) | 5 (5%) |
| <i>No treatment goal</i> | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (100%) | 0 (0%) | 0 (0%) | 0 (0%) | 1 (1%) |
| <i>Column total</i> | 40 (39%) | 28 (28%) | 10 (10%) | 5 (5%) | 6 (6%) | 2 (2%) | 6 (6%) | 5 (5%) | 102 (100%) |