An Editorial on Tailoring Patient-Reported Outcomes to the Individual Patient: Precision PROs

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Abstract

Patient-reported outcomes (PROs) have the potential to improve clinical care. One barrier to implementing PROs and maximizing their effectiveness is difficulty individualizing PROs. To address this barrier, we propose a precision PRO methodology. By this approach, patients would first define a minimally important difference for themselves. Patients would then choose which items within a PRO item bank are most important to them; these items would be used to monitor patients' progress. Patients could be compared to each other – even if they chose different questions – using modern psychometric methods. We propose future research to guide how to determine the simplest and most effective precision PRO methodology.

Keywords: measurement-based care; minimally important difference; outcome monitoring; progress monitoring; responder

1 Patient reported outcomes (PROs) bring the patient voice into evaluations of medical care
2 and can help monitor patients' well-being during various treatments (Administration, 2009;
3 Basch et al., 2017; Basch et al., 2016; Guo et al., 2015; Scott & Lewis, 2015). PROs are
4 questionnaire-based measures that ask patients directly about their symptoms and feelings
5 (Administration, 2009). The clinical utility of PROs has been highlighted by recent studies
6 showing survival benefits for cancer patients monitored with PROs during systemic therapy
7 (Basch et al., 2017; Basch et al., 2016; Denis, Lethrosne, et al., 2017; Denis, Yossi, et al.,
8 2017). The mechanism for benefit could be improved communication with the provider team
9 about the patient's health status (Basch et al., 2017; Basch et al., 2016; Denis, Lethrosne, et al.,
10 2017; Denis, Yossi, et al., 2017), although other mechanisms are possible (Greenhalgh et al.,
11 2017).

12 PROs can be integrated into routine patient management to provide vital information to
13 guide treatment (Scott & Lewis, 2015). For instance, a patient with chronic cancer-related pain
14 may complete a pain PRO routinely to screen for flares and to assess if current treatment is
15 working. If a new pain medication is started but the patient's pain levels remain stable, the
16 physician might then consider whether to add an additional medication, increase the dose or
17 switch to a different medication. Increasing pain scores may aide in early detection of tumor
18 progression by prompting oncologists to order re-staging examinations that potentially change
19 the oncologic treatment plan. Many professional organizations have called for wider use of
20 PROs in oncology and other medical fields (2015; Gordon et al., 2005). Yet even in fields with a
21 long research and clinical history of PROs such as mental health care, uptake of PROs in
22 clinical care is low (Fortney et al., 2015; Nelson et al., 2015). This begs the question: why are
23 PROs, despite their demonstrated benefits when used to monitor patients, not used widely in
24 clinical care?

25 We believe one reason for the limited use of PROs in practice is that physicians struggle to
26 interpret PRO results for their individual patients (Snyder et al., 2017), particularly when it

comes to determining a meaningful change (Uryniak et al., 2011). This is unsurprising, since standard PROs are not tailored or individualized to each patient, which limits their utility in a practice setting (Jensen-Doss et al., 2018). Although patients value both standardized and individualized PROs (Greenhalgh et al., 2017), the majority of research and clinical care has focused on standardized PROs. To address these substantial barriers, we propose an approach we call precision PROs as a potential solution.

The Minimally Important Difference

Most PROs are scored on a continuous scale (Haslam, Holland, & Kuppens, 2012). While continuous physiological measures like blood pressure can be linked to dichotomous outcomes like morbidity and mortality, PRO outcomes are not so clearly anchored to a clinically important outcome. In addition, PROs are not calibrated to the specific patient who completes them (Grossman, 2018). As a result, interpreting changes in PRO scores for individuals may lead to misclassifying a patient as improved, worsened or unchanged when their experience is actually different and this misclassification could lead to incorrect changes in management (Donaldson, 2008).

The challenge to using PROs in practice is highlighted by the concept of the minimally important difference (MID) to define meaningful changes in PRO scores. The MID is the smallest amount of change that is meaningful to the patient. In theory, exceeding the MID might warrant a change in management (Jaeschke, Singer, & Guyatt, 1989). Currently, two methods are used to define the MID. The first is the anchor-based method, which links PROs to another outcome such as death, cancer recurrence, or some other quantifiable change in health status (Streiner & Norman, 2008). The intention is to identify categories of PRO responses that reliably correspond to identifiable health states. One problem is that there are no meaningful anchors for many measures of quality of life or symptom status, since these constructs are themselves delineated using patient-reported questionnaires. For our patient with chronic cancer-related

1 pain, pain is a subjective experience and relieving pain the ultimate endpoint so there is no
2 physiological correlate. Similar issues arise for mental health outcomes such as depression and
3 anxiety. The second approach is the distributional method, which defines the MID by a statistical
4 threshold such as half a standard deviation (Jacobson & Truax, 1991; Streiner & Norman,
5 2008). The distribution method can be difficult to interpret in clinical situations since the
6 threshold is not anchored to a measure of health status change, does not involve patient input
7 and therefore may not represent a change that is meaningful to many patients. A problem with
8 both approaches to determining MID is that they focus on differences between groups (such as
9 control and intervention groups), while in practice, what is considered a meaningful difference
10 will vary from patient to patient (C. E. Cook, 2008; Gatchel & Mayer, 2010). The focus on group-
11 based change may be a reason why PROs often have limited ability to detect statistically
12 significant response for individual patients in clinical practice (Donaldson, 2008; Jones, Crane, &
13 Simon, 2019; Moynihan et al., 2017). Currently, the only options for clinicians trying to use PROs
14 in clinical care is to use the group-based MID at the individual level (King, Dueck, & Revicki,
15 2019).

16 To extend our example, consider a cancer pain PRO with scores ranging from 0 to 100. On
17 a return visit, the patient records a 5-point increase. Is this change meaningful? If the MID for
18 the pain PRO (derived by the distribution-method) is 14 points (Tashjian, Deloach, Porucznik, &
19 Powell, 2009), the increase would not be considered meaningful. But what if a patient's pain
20 scores are highly variable, changing by up to 30 points a week? For this patient, a 14-point
21 change might just be normal variability. In contrast, for patients with extremely stable pain
22 scores (e.g., rarely changing by more than 2 points), the 5-point change may in fact be
23 meaningful.

24
25 PRO Items

1 A second problem that we believe hinders the use of PROs in practice is the uniform use of
2 the same PRO question sets for every patient, regardless of their clinical situation (Jensen-Doss
3 et al., 2018). This means the PRO may not reflect what is most important to the patient. PROs
4 are often chosen because they have been widely published and validated in populations, such
5 as the General Health Questionnaire, but this does not mean that the PRO measures what
6 actually matters to an individual patient (Calvert, Kyte, Price, Valderas, & Hjollund, 2019;
7 Grossman, 2018; Marshall, Haywood, & Fitzpatrick, 2006). For example, many clinical practices
8 are using the Patient Health Questionnaire-9 to regularly screen for and monitor depression
9 (Moore et al., 2012), which represents a great improvement in addressing mental health needs.
10 However, general anxiety and other forms of distress may be missed entirely if the same items
11 are applied to all patients.

12 PROs can be nomothetic or idiographic. Nomothetic means the same PRO questions are
13 used for all patients and the data can be analyzed at the group-level. This can be useful in
14 situations like clinical trials that use group-based analyses (Lyon et al., 2017). Idiographic
15 means the PRO is specific to what the patient finds important but the data cannot be directly
16 compared to other patients (Lyon et al., 2017). While idiographic measures are rarely used in
17 oncology and medicine, they have a long history in psychology. One example is the subjective
18 units of distress scale (SUDS) in which a patient defines distress (or another outcome such as
19 pain) for themselves and then rates their distress on a 0 to 100 or 0 to 10 scale, depending on
20 their preference (Wolpe, 1969). The differences between nomothetic and idiographic measures
21 creates an unresolved tension between making a PRO meaningful to the patient (and clinician)
22 versus allowing comparison between groups of patients, such as for practice profiling, quality
23 assessment, analysis of administrative data, evaluating treatments in clinical trials or for
24 comparison of a patient to published norms (Lyon et al., 2017).

1 To address these problems, we propose redefining the way that PROs are used in clinical
2 practice. We call this approach precision PROs, because it is similar to the concept of precision
3 medicine—selecting, using, and interpreting PROs tailored to the individual patient. For the MID,
4 a precision PRO would involve prospectively asking patients to define how much change is
5 personally meaningful to them on a specific PRO scale, and then using that patient-specified
6 definition of change as a benchmark going forward. For PRO questionnaires, this would involve
7 having patients select the items or questions that their PRO contains, based on what is
8 important to them.

9 Newer methods of determining a group-based MID rely on a personally defined measure of
10 meaningful change, consistent with the notion of precision PROs. One study asked patients to
11 review case studies and say whether each case had worse or better fatigue than their own level
12 (K. F. Cook, Kallen, Coon, Victorson, & Miller, 2017). Another study asked patients and
13 providers to review case reports with a PRO at baseline and one month later and judge whether
14 the case's change over time was meaningful (Thissen et al., 2016). In the aforementioned
15 studies, what patients considered a meaningful change on a PRO varied widely. In one,
16 meaningful change ranged from 1/100th of a standard deviation to 1.5 times the standard
17 deviation (K. F. Cook et al., 2017). These widely discrepant specifications of meaningful change
18 are consistent with our underlying premise that precision PROs are necessary in the presence
19 of high levels of variation in patient experiences of symptoms or quality of life (Jaeschke et al.,
20 1989).

21 Item response theory (IRT) could help tailor PROs to specific patients (Samejima, 1969).
22 IRT differs from conventional PRO scoring methods in that it weights each item by severity and
23 accuracy, rather than treating all items as equal measures of a patient's health. IRT can be used
24 to create item banks with all items scored on the same metric so each patient does not have to
25 answer the same questions (Pilkonis et al., 2011). Typically, the items banks are administered
26 using computerized adaptive testing (CAT). In CAT, patients answer a question around the

1 population mean of the scale and, based on their response, only answer additional questions
2 tailored to their level of the construct, such as pain. The choice of items is not based on which
3 are personally meaningful for the patient; rather, a computer algorithm chooses the questions
4 for each patient to optimize reliability. For example, the PROMIS pain interference item bank
5 contains questions on pain interfering with daily activities (hygiene, housework, walking), social
6 activities and physical labor. For a patient who is introverted, the social activities questions
7 might not be relevant. Similarly for depression, some patients express the condition in somatic
8 symptoms while others experience mainly psychological symptoms (Cheng, Chan, & Fung,
9 2006). We would propose to modify this method by allowing the patient to select those items
10 most relevant to them. IRT would allow one patient's precision PRO to still be compared to
11 another patient's PRO, even though they are answering different questions because patients
12 already answer different questions with CAT. This would also address one of the problems with
13 current idiographic measures not being comparable between patients or to population norms
14 and cutpoints. It would also allow a patient to change the items they answer if their goals shift
15 over time (for example, from daily activities to social activities as function improves). These
16 scores would still be comparable within the patient across time even though different items are
17 answered. Item banks commonly have 20 or more items (Pilkonis et al., 2011), providing
18 sufficient numbers to allow most patients to build their own PRO. Theoretically, item banks that
19 measure different dimensions of a common construct could be used. To date, IRT has not been
20 used to allow patients to select the items most important to them while still enabling group-
21 based analyses, but item banks could – in theory – be used in this fashion.

22 By continuing to treat patients as groups rather than individuals, it is inevitable that important
23 elements of individual patient's quality of life will not be identified. A paradigm shift is needed in
24 which new methods are developed to precisely measure each individual patient's preferences
25 and values, while still allowing comparisons between patients. We propose these new precision
26 PRO methods as a starting point for subsequent research to address this issue.

Challenges to the Precision PRO Approach and Recommendations for Future Research

We propose a research agenda to develop precision PRO methods for clinical practice.

Although we focused here on individualized measures and precision PROs, it is important to acknowledge that this is only one possible barrier to clinical use of PROs with others including concerns about PROs being used to determine care eligibility and healthcare professionals perceiving PROs to be outside the traditional scope of their practice (Greenhalgh et al., 2017).

We recognize it is premature to suggest that precision PROs be included in clinical trials evaluating treatments or quality improvements, and that important challenges to developing a precision PRO approach need to be addressed.

One potential problem with precision PROs is that patients may have difficulty providing a personal MID. Our own pilot data shows that patients can provide a personal MID in response to two simple questions, one asking patients to define worsening and the other asking them to define meaningful improvement in symptoms (Jones, Du, Bell-Brown, Bolt, & Unger, In press). Across two studies using the scale judgment method mentioned above, 20% of responses were paradoxical (K. F. Cook et al., 2017; Thissen et al., 2016). Paradoxical responses occur when a patient is asked to define a personal MID but responds in the opposite direction, such as indicating worsening symptoms are meaningful when asked about improvement. Whether or not paradoxical responding occurs likely depends on how the personal MID is elicited, and importantly, does not represent a mistake on the part of the patient; instead it should be considered a sign that psychometricians need to design better questions. Some patients will be unable to define a personal MID for themselves regardless of how well questions are written. Options may include time series methods from case studies and other statistical methods for patients unable to self-report a personal MID (Borckardt et al., 2008).

Some might argue that rather than using precision PROs, clinicians should instead have a conversation with patients to define the personal MID. But we see this as not realistic. Clinicians

1 already are pressed for time and the addition of another task should be avoided (Tai-Seale et
2 al., 2017). Additionally, some patient populations might not be seen often enough by their
3 physician, such as cancer survivors, to allow time for discussion to define a personal MID
4 (Smith et al., 2019). Given the number of studies leveraging remote patient monitoring with
5 PROs (Breen et al., 2015; Maguire et al., 2015) and electronic completion of PROs (Basch et
6 al., 2016), it seems eminently feasible that electronic methods could be leveraged to solicit a
7 personal MID, rather than using valuable consultation time. Self-administered methods for
8 precision PROs would also help reduce non-medical costs for patients as this could reduce the
9 number of office visits (Fortner et al., 2003).

10 One key question that will have to be addressed by future research is how to score a
11 personal MID. In clinical practice, this may be straightforward: if the PRO score increased or
12 decreased more than the personal MID, this would be interpreted as a change and the clinician
13 would use their clinical judgment to decide whether treatment should be changed or continued.
14 However, if a personal MID were to be used in clinical trials, scoring methods would have to be
15 developed and tested. One possibility is to create a conversion of amount of change to a
16 standardized measure similar to the Goal Attainment Scaling method, which converts each
17 patients unique functional goals to the same metric (Kiresuk & Sherman, 1968). Another method
18 is to classify study participants as responders or non-responders based on their personal MID
19 (Uryniak et al., 2011). One criticism of a responder analysis approach has been that power is
20 lost through dichotomization (Royston, Altman, & Sauerbrei, 2006). However, we argue that this
21 may more accurately mirror clinical practice where clinical decisions are often dichotomous (for
22 instance, physicians and their patients choose to either change treatment or not to change
23 treatment).

24 Another argument that stands in opposition to the idea of using a pre-specified, personal
25 MID to help guide decision-making is based on the idea that meaningful differences are better
26 determined by the assessment of statistical significance, rather than absolute differences in

1 scores. This argument assumes a high level of measurement error at the individual level
2 (Donaldson, 2008; Moinpour et al., 2017). However, in the absence of expected variation, even
3 trivial differences between groups could conceivably achieve statistical significance. Indeed,
4 with the advent of item response theory, a psychometrician could conceivably construct an item
5 bank with enough precision at various levels of a construct to make even small (e.g. 1/100th of a
6 standard deviation) differences statistically significant.

7 Another challenge is that the use of precision PROs will likely create a greater respondent
8 burden. Most item banks are 20 to 40 items long, which will likely be too burdensome for
9 patients to review often. Careful attention will be required to determining the optimal
10 assessment times and choosing the PRO items would most likely only be possible at the
11 beginning of treatment or at discrete timepoints throughout care (e.g. once every three months).
12 Again, future research would need to determine the feasibility of this method.

13 The statistical assumptions underlying IRT models may also present a challenge for
14 developing precision PROs. Most IRT models and computerized adaptive testing are premised
15 on the idea that patterns of non-response cohere to the MAR (missing at random) assumption.
16 Research on multidimensional adaptive testing has shown that violations of the missing-at-
17 random assumption will decrease accuracy, although it has been suggested this issue can be
18 addressed, at least in part, by increasing the number of items (Han & Guo, 2014). Future
19 research will need to determine the extent to which violations of the missingness at random
20 assumption will influence results and will need to identify approaches to compensate for such
21 scenarios. Future studies should also examine whether having patients choose PRO questions
22 from item banks violates the other statistical assumptions of the IRT models (unidimensional,
23 local dependence) used to develop the banks and whether it is possible to combine scores from
24 related item banks (like depression and anxiety) into an overarching score (like mental health
25 quality of life).

While the precision PRO premise may be easily translatable to clinical care following studies on initial feasibility, the translation to clinical trials and quality improvement would require additional development. With the personal MID, methods for scoring and usage in group-based analyses would need to be developed that preserve power. One approach would be to include the personal MID as a secondary outcome for trials or as a measure for quality improvement. One challenge in using precision PROs in clinical trials is that the process of patients choosing their own items might not be feasible in the context of the study goals. In quality improvement, physician and other provider belief in the validity of precision PROs would need to be ensured if precision PROs are used as a performance measure (Greenhalgh et al., 2017).

Future research should also examine the stability of precision PROs over time to determine how often patients may need to redefine their personal MID and chose their PRO questions. A phenomenon called response shift (Oort, Visser, & Sprangers, 2009) in which respondents change their valuing of different aspects of a PRO over time suggests precision PROs may need to be periodically reassessed over the course of clinical care.

Summary

In summary, creating precision MIDs and precision PROs provides an opportunity to make clinical care more patient-centered. Modern psychometric statistical models like IRT make it possible to create PROs that are both meaningful to the individual patient and comparable between patients. Allowing patients to individually select PRO questions and creating their own MID would permit tailoring of PROs and clinical management to what is important for that patient. The future research agenda for PROs should include a focus on making these measures, and interpretation guidelines like the MID, as individualized to the patient as possible.

References

- . (2015). In D. Blumenthal, E. Malphrus, & J. M. McGinnis (Eds.), *Vital Signs: Core Metrics for Health and Health Care Progress*. Washington (DC).
- Administration, F. a. D. (2009). *Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims*. Rockville, MD: Food and Drug Administration
- Basch, E., Deal, A. M., Dueck, A. C., Scher, H. I., Kris, M. G., Hudis, C., & Schrag, D. (2017). Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. *JAMA*, *318*(2), 197-198.
doi:10.1001/jama.2017.7156
- Basch, E., Deal, A. M., Kris, M. G., Scher, H. I., Hudis, C. A., Sabbatini, P., . . . Schrag, D. (2016). Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol*, *34*(6), 557-565.
doi:10.1200/JCO.2015.63.0830
- Borckardt, J. J., Nash, M. R., Murphy, M. D., Moore, M., Shaw, D., & O'Neil, P. (2008). Clinical practice as natural laboratory for psychotherapy research: a guide to case-based time-series analysis. *Am Psychol*, *63*(2), 77-95. doi:10.1037/0003-066X.63.2.77
- Breen, S., Ritchie, D., Schofield, P., Hsueh, Y. S., Gough, K., Santamaria, N., . . . Aranda, S. (2015). The Patient Remote Intervention and Symptom Management System (PRISMS) - a Telehealth- mediated intervention enabling real-time monitoring of chemotherapy side-effects in patients with haematological malignancies: study protocol for a randomised controlled trial. *Trials*, *16*, 472. doi:10.1186/s13063-015-0970-0
- Calvert, M., Kyte, D., Price, G., Valderas, J. M., & Hjollund, N. H. (2019). Maximising the impact of patient reported outcome assessment for patients and society. *BMJ*, *364*, k5267.
doi:10.1136/bmj.k5267

- Cheng, S. T., Chan, A. C., & Fung, H. H. (2006). Factorial structure of a short version of the Center for Epidemiologic Studies Depression Scale. *Int J Geriatr Psychiatry*, 21(4), 333-336. doi:10.1002/gps.1467
- Cook, C. E. (2008). Clinimetrics Corner: The Minimal Clinically Important Change Score (MCID): A Necessary Pretense. *J Man Manip Ther*, 16(4), E82-83. doi:10.1179/jmt.2008.16.4.82E
- Cook, K. F., Kallen, M. A., Coon, C. D., Victorson, D., & Miller, D. M. (2017). Idio Scale Judgment: evaluation of a new method for estimating responder thresholds. *Qual Life Res*, 26(11), 2961-2971. doi:10.1007/s11136-017-1625-2
- Denis, F., Lethrosne, C., Pourel, N., Molinier, O., Pointreau, Y., Domont, J., . . . Letellier, C. (2017). Randomized Trial Comparing a Web-Mediated Follow-up With Routine Surveillance in Lung Cancer Patients. *J Natl Cancer Inst*, 109(9). doi:10.1093/jnci/djx029
- Denis, F., Yossi, S., Septans, A. L., Charron, A., Voog, E., Dupuis, O., . . . Letellier, C. (2017). Improving Survival in Patients Treated for a Lung Cancer Using Self-Evaluated Symptoms Reported Through a Web Application. *Am J Clin Oncol*, 40(5), 464-469. doi:10.1097/COC.0000000000000189
- Donaldson, G. (2008). Patient-reported outcomes and the mandate of measurement. *Qual Life Res*, 17(10), 1303-1313. doi:10.1007/s11136-008-9408-4
- Fortner, B. V., Demarco, G., Irving, G., Ashley, J., Keppler, G., Chavez, J., & Munk, J. (2003). Description and predictors of direct and indirect costs of pain reported by cancer patients. *J Pain Symptom Manage*, 25(1), 9-18.
- Fortney, J., Sladek, R., Unützer, J., Kennedy, P., Harbin, H., Emmet, B., . . . Carneal, G. (2015). *Fixing Behavioral Health Care in America: A National Call for Measurement-Based Care in the Delivery of Behavioral Health Services*. Retrieved from

- 1 Gatchel, R. J., & Mayer, T. G. (2010). Testing minimal clinically important difference: additional
 2 comments and scientific reality testing. *Spine J*, 10(4), 330-332.
 3 doi:10.1016/j.spinee.2010.01.019
- 4 Gordon, D. B., Dahl, J. L., Miaskowski, C., McCarberg, B., Todd, K. H., Paice, J. A., . . . Carr, D.
 5 B. (2005). American pain society recommendations for improving the quality of acute
 6 and cancer pain management: American Pain Society Quality of Care Task Force. *Arch*
 7 *Intern Med*, 165(14), 1574-1580. doi:10.1001/archinte.165.14.1574
- 8 Greenhalgh, J., Dalkin, S., Gooding, K., Gibbons, E., Wright, J., Meads, D., . . . Pawson, R.
 9 (2017). Functionality and feedback: a realist synthesis of the collation, interpretation and
 10 utilisation of patient-reported outcome measures data to improve patient care. *Health*
 11 *Services and Delivery Research*, 5(2), 1-280.
- 12 Grossman, C. (2018). *Patient-Reported Outcomes: Design with the End in Mind*. Retrieved from
- 13 Guo, T., Xiang, Y. T., Xiao, L., Hu, C. Q., Chiu, H. F., Ungvari, G. S., . . . Wang, G. (2015).
 14 Measurement-Based Care Versus Standard Care for Major Depression: A Randomized
 15 Controlled Trial With Blind Raters. *Am J Psychiatry*, 172(10), 1004-1013.
 16 doi:10.1176/appi.ajp.2015.14050652
- 17 Han, K. T., & Guo, F. (2014). Impact of violation of the missing-at-random assumption on full-
 18 information maximum likelihood method in multidimensional adaptive testing. *Practical*
 19 *Assessment, Research and Evaluation*, 19(2), 1-11.
- 20 Haslam, N., Holland, E., & Kuppens, P. (2012). Categories versus dimensions in personality
 21 and psychopathology: a quantitative review of taxometric research. *Psychol Med*, 42(5),
 22 903-920. doi:10.1017/s0033291711001966
- 23 Jacobson, N. S., & Truax, P. (1991). Clinical significance: A statistical approach to defining
 24 meaningful change in psychotherapy research. *Journal of Consulting and Clinical*
 25 *Psychology*, 59, 12-19.

- Jaeschke, R., Singer, J., & Guyatt, G. H. (1989). Measurement of health status. Ascertaining the minimal clinically important difference. *Control Clin Trials*, 10(4), 407-415.
- Jensen-Doss, A., Smith, A. M., Becker-Haimes, E. M., Mora Ringle, V., Walsh, L. M., Nanda, M., . . . Lyon, A. R. (2018). Individualized Progress Measures Are More Acceptable to Clinicians Than Standardized Measures: Results of a National Survey. *Adm Policy Ment Health*, 45(3), 392-403. doi:10.1007/s10488-017-0833-y
- Jones, S. M. W., Crane, P. K., & Simon, G. E. (2019). A comparison of individual change using Item Response Theory and sum scoring on the Patient Health Questionnaire-9. *Annals of Depression and Anxiety*, 6(1), 1098.
- Jones, S. M. W., Du, Y., Bell-Brown, A., Bolt, K., & Unger, J. M. (In press). Feasibility and Validity of Asking Patients to Define Individual Levels of Meaningful Change on Patient-Reported Outcomes. *Journal of Patient Centered Research and Reviews*.
- King, M. T., Dueck, A. C., & Revicki, D. A. (2019). Can Methods Developed for Interpreting Group-level Patient-reported Outcome Data be Applied to Individual Patient Management? *Med Care*, 57 Suppl 5 Suppl 1, S38-S45. doi:10.1097/MLR.0000000000001111
- Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Ment Health J*, 4(6), 443-453. doi:10.1007/BF01530764
- Lyon, A. R., Connors, E., Jensen-Doss, A., Landes, S. J., Lewis, C. C., McLeod, B. D., . . . Weiner, B. J. (2017). Intentional research design in implementation science: implications for the use of nomothetic and idiographic assessment. *Transl Behav Med*, 7(3), 567-580. doi:10.1007/s13142-017-0464-6
- Maguire, R., Ream, E., Richardson, A., Connaghan, J., Johnston, B., Kotronoulas, G., . . . Kearney, N. (2015). Development of a novel remote patient monitoring system: the advanced symptom management system for radiotherapy to improve the symptom

- experience of patients with lung cancer receiving radiotherapy. *Cancer Nurs*, 38(2), E37-47. doi:10.1097/NCC.0000000000000150
- Marshall, S., Haywood, K., & Fitzpatrick, R. (2006). Impact of patient-reported outcome measures on routine practice: a structured review. *Journal of Evaluation in Clinical Practice*, 12(5), 559-568. doi:DOI 10.1111/j.1365-2753.2006.00650.x
- Moinpour, C. M., Donaldson, G. W., Davis, K. M., Potosky, A. L., Jensen, R. E., Gralow, J. R., . . . Cella, D. (2017). The challenge of measuring intra-individual change in fatigue during cancer treatment. *Qual Life Res*, 26(2), 259-271. doi:10.1007/s11136-016-1372-9
- Moore, M., Ali, S., Stuart, B., Leydon, G. M., Ovens, J., Goodall, C., & Kendrick, T. (2012). Depression management in primary care: an observational study of management changes related to PHQ-9 score for depression monitoring. *Br J Gen Pract*, 62(599), e451-457. doi:10.3399/bjgp12X649151
- Nelson, E. C., Eftimovska, E., Lind, C., Hager, A., Wasson, J. H., & Lindblad, S. (2015). Patient reported outcome measures in practice. *BMJ*, 350, g7818. doi:10.1136/bmj.g7818
- Oort, F. J., Visser, M. R., & Sprangers, M. A. (2009). Formal definitions of measurement bias and explanation bias clarify measurement and conceptual perspectives on response shift. *J Clin Epidemiol*, 62(11), 1126-1137. doi:10.1016/j.jclinepi.2009.03.013
- Pilkonis, P. A., Choi, S. W., Reise, S. P., Stover, A. M., Riley, W. T., Cella, D., & Group, P. C. (2011). Item banks for measuring emotional distress from the Patient-Reported Outcomes Measurement Information System (PROMIS®): depression, anxiety, and anger. *Assessment*, 18(3), 263-283. doi:10.1177/1073191111411667
- Royston, P., Altman, D. G., & Sauerbrei, W. (2006). Dichotomizing continuous predictors in multiple regression: a bad idea. *Stat Med*, 25(1), 127-141. doi:10.1002/sim.2331
- Samejima, F. (1969). Estimation of a latent ability using a response pattern of graded scores. 34 (suppl 4).

- 1 Scott, K., & Lewis, C. C. (2015). Using measurement-based care to enhance any treatment.
2 *Cognitive and Behavioral Practice*, 22(1), 49-59.
- 3 Smith, T. G., Troeschel, A. N., Castro, K. M., Arora, N. K., Stein, K., Lipscomb, J., . . . Ward, E.
4 (2019). Perceptions of Patients With Breast and Colon Cancer of the Management of
5 Cancer-Related Pain, Fatigue, and Emotional Distress in Community Oncology. *J Clin*
6 *Oncol*, JCO1801579. doi:10.1200/JCO.18.01579
- 7 Snyder, C. F., Smith, K. C., Bantug, E. T., Tolbert, E. E., Blackford, A. L., Brundage, M. D., &
8 Board, P. R. O. D. P. S. A. (2017). What do these scores mean? Presenting patient-
9 reported outcomes data to patients and clinicians to improve interpretability. *Cancer*,
10 123(10), 1848-1859. doi:10.1002/cncr.30530
- 11 Streiner, D. L., & Norman, G. R. (2008). *Health Measurement Scales: A practical guide to their*
12 *development and use* (4th ed.): Oxford University Press.
- 13 Tai-Seale, M., Olson, C. W., Li, J., Chan, A. S., Morikawa, C., Durbin, M., . . . Luft, H. S. (2017).
14 Electronic Health Record Logs Indicate That Physicians Split Time Evenly Between
15 Seeing Patients And Desktop Medicine. *Health Aff (Millwood)*, 36(4), 655-662.
16 doi:10.1377/hlthaff.2016.0811
- 17 Tashjian, R. Z., Deloach, J., Porucznik, C. A., & Powell, A. P. (2009). Minimal clinically
18 important differences (MCID) and patient acceptable symptomatic state (PASS) for
19 visual analog scales (VAS) measuring pain in patients treated for rotator cuff disease. *J*
20 *Shoulder Elbow Surg*, 18(6), 927-932. doi:10.1016/j.jse.2009.03.021
- 21 Thissen, D., Liu, Y., Magnus, B., Quinn, H., Gipson, D. S., Dampier, C., . . . DeWalt, D. A.
22 (2016). Estimating minimally important difference (MID) in PROMIS pediatric measures
23 using the scale-judgment method. *Qual Life Res*, 25(1), 13-23. doi:10.1007/s11136-015-
24 1058-8

- 1 Uryniak, T., Chan, I. S. F., Fedorov, V. V., Jiang, Q., Oppenheimer, L., Snapinn, S. M., . . .
- 2 Zhang, J. (2011). Responder Analyses-A PhRMA Position Paper. *Statistics in*
- 3 *Biopharmaceutical Research*, 3(3), 476-487. doi:10.1198/sbr.2011.10070
- 4 Wolpe, J. (1969). *The Practice of Behavior Therapy*. New York: Pergamon Press.

5