

1 **Validation of a brief, patient-reported index that guides care**
2 **for chronic conditions**
3 **and can substitute for computer generated risk models**
4 **(the What Matters Index)**

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21 **Abstract**

22

23 The notion that intensive management of chronic conditions should be based on a
24 patient’s risk for high future expenditures is entrenched in current practice. However,
25 prediction of one patient’s high risk based on complex, computer-generated risk models
26 constructed from insurance claims and medical record data is inaccurate, does not explicitly
27 guide care, and probably undercuts investment in management of the many patients at lesser
28 risk. We prospectively test an uncomplicated, broadly applicable alternative grounded on
29 patient report.

30 Five measures selected for evidence of impact on the use of health services are summed
31 to create a “what matters index”. These measures are: 1) insufficient confidence to self-manage
32 health problems, 2) pain, 3) bothersome emotions, 4) polypharmacy, and 5) adverse
33 medication effects. We compare the sensitivity and predictive values of this index with two
34 archetypical risk models in a population of 8619 Medicaid recipients. We also demonstrate how
35 the “what matters index” can guide care for all patients.

36 For “what matters index” sums of 1, 2 and ≥ 3 the corresponding odds ratios (with 95%
37 confidence intervals) for subsequent hospitalization within 1 year were 1.3 (1.1–1.6), 2.0 (1.6–
38 2.4), and 3.4 (2.9–4.0); for emergency room use, the corresponding odds ratios were 1.3 (1.1–
39 1.4), 1.9 (1.6–2.1), and 2.9 (2.6–3.3).

40 Both the “what matters index” and the archetypical risk models had similar sensitivity,
41 predictive values, and statistical measures for concordance (the c-statistic) for subsequent use

42 of the hospital or emergency room. However, the risk models' performance was inferior for the
43 majority whose needs were not identified.

44 In summary, when contrasted to typical computer-generated risk models a patient-
45 reported "what matters index" immediately and unambiguously identifies fundamental,
46 remediable needs for each patient. By empowering patients to express their needs, the "what
47 matters index" can also be used to guide the design and delivery of services for chronic
48 conditions.

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64 **Introduction**

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66 The growth of non-communicable, chronic disease is major global health problem.

67 Unfortunately, inadequacies of the dominant strategy for controlling the escalating costs of

68 chronic disease management are evident. [1-6] This dominant strategy depends on computer-

69 generated risk models (CRMs) constructed from insurance claims and medical record data that

70 designate a few patients at greatest risk for utilizing costly care. These patients become the

71 target for intensive interventions.

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73 Three deficiencies make high-user interventions inherently ill-advised. First, CRMs are not

74 accurate for individual patients. [7] A few reports provide sufficient raw data to illustrate the

75 implications of inaccuracy in clinical practice: a minority of the highest risk decile use the

76 hospital within two years in contrast to almost three times as many patients not designated

77 high risk. [8,9] The large false positive rate will cause scarce resources to be wasted on the

78 many patients in the highest-risk subgroup who will not use costly care, while care will be

79 relatively rationed for those not designated as at-risk, including the many “false negatives”

80 destined to use costly services. From a public policy perspective, targeting may perpetuate

81 underinvestment in chronic disease prevention and management across all risk strata of a

82 population. [10]

83

84 A second deficiency is that CRMs based on demographics, diagnoses, and past utilization do not

85 provide specific, real-time guidance for needs that matter to patients. Rather, CRM output is a

86 general, asynchronous designation of risk offered with the implicit assumption that the correct
87 action can be selected and applied to mitigate that risk. This generality does not support
88 clinicians and patients who, during a time-constrained visit, struggle to identify a few current
89 concerns that might respond to a management plan and thus decrease risk.

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91 Additionally, by being based on “what is the matter” (such as diagnoses and test results) rather
92 than “what matters” to patients (such as bothersome symptoms and specific functional limits),
93 CRMs are often too abstract, untimely, or irrelevant to support patient engagement in care.
94 Patient engagement in care is increasingly recognized as a very effective strategy for delivering
95 health care in the face of rising demand and shrinking budgets. [11]

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97 We recently tested the hypothesis that a clinical prediction rule based on a few self-reported
98 measures might address shortcomings of current high-user interventions for patients with
99 chronic conditions. [12] We named this clinical prediction rule for chronic condition
100 management the “What Matters Index” (WMI) because it proved to be a good indicator for
101 patients’ quality of life—that is, what matters to patients. The WMI is based on a parsimonious
102 set of memorable measures for which immediate actions and a management plan can be
103 implemented and for which there is good evidence that action can positively impact patient
104 outcomes. [13-20] The five WMI measures are listed in Table One.

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108 **Table One**

109 **[This is Table One Title] Patient-Reported Measures Within the “What Matters Index”***

Patient-Reported Measure
<p>Insufficient Health Confidence</p> <p>How confident are you that you can manage and control most of your health problems?</p> <p><i>(Not very confident or somewhat confident, scored as 1, versus very confident, scored as zero)</i></p>
<p>Pain</p> <p>During the past four weeks how much bodily pain have you generally had?</p> <p><i>(Extreme or moderate pain scored as 1, versus none, very mild, or mild, scored as zero)</i></p>
<p>Emotions</p> <p>During the past four weeks how much have you been bothered by emotional problems such as feeling anxious, irritable, depressed or sad?</p> <p><i>(Extremely or quite a bit scored as 1, versus not at all, a little, or somewhat, scored as zero)</i></p>
<p>Polypharmacy</p> <p>How many prescription medicines are you taking more than three days a week?</p> <p><i>(More than five scored as 1, versus 5 or less, scored as zero)</i></p>
<p>Adverse Effects from Medicines</p> <p>Do you think any of your pills are making you sick?</p> <p><i>(Yes or maybe scored as 1, versus no, scored as zero)</i></p>

This is Table One Footnote:

*** The “What Matters Index” is the sum of the five binary scores, with an index of 0 meaning lowest reported problems and an index of 5 meaning highest reported problems.**

In addition to its foundation in clinical evidence for likely impact on patient outcomes, when retrospectively tested in three populations aged 18–64 (n = 8,619), aged 50–64 (n = 7,408) and aged 65+ (n = 3,566), the WMI proved to be strongly associated with a history of emergency and hospital use. For example, regardless of patients' financial status, WMI ≥ 2 was associated with about twice the odds of costly utilization as a WMI = 0; for ≥ 3 , usage was about three times higher. Its positive predictive value was comparable to a CRM based on a multiple diagnoses and medications. These preliminary results suggest that the WMI can adequately stratify for risk (relative to a CRM) and immediately guide care that matters to patients. However, retrospective results guarantee neither future performance nor applicability in practice. Therefore, this report prospectively compares the WMI to two archetypical CRMs and illustrates how the WMI can be used to promote engagement of health care providers and patients in the improvement of health and health care.

Materials and Methods

Participants, Source of Data and Outcomes

Patient members of a Midwestern statewide Medicaid program were required to complete a comprehensive, free, online health assessment called HowsYourHealth (www.HowsYourHealth.org). [21] The branching logic of the assessment includes the five items of the WMI in addition to queries about demographics, symptoms, concerns, function, conditions, experience of care, preventive interventions, and past utilization. Of the 26,130 adults who completed the survey in 2014, 8771 fulfilled the eligibility criteria. Eligibility criteria for this prospective assessment were identical to those used for development of the WMI and were based on patient self-identification of at least one of five chronic conditions—hypertension, cardiovascular disease, diabetes, respiratory disease, arthritis—or use of at least one chronic medication. Outcome information based on insurance claims data was available for all patients, but the claims contained data only about any emergency or hospital use, not frequency of use.

Of the 8,771 eligible Medicaid patients who had information about subsequent use of emergency or hospital service, 152 had missing WMI variables and were eliminated from the analysis.

Predictors

The predictors listed in Table One are identical to those used for development of the WMI.

We selected five binary (yes or no, 1 or 0) measures from a previous distillation of patient-reported “vital signs.” [22] By design these measures are immediately available from patients without retrieval of data from electronic health records or insurance claims, easily interpretable, translatable, and limited in number so that they are memorable. (23) The sum of the five measures, a number from 0 to 5, constitutes the What Matters Index.

Insufficient health confidence is an easy-to-measure proxy for a patient’s lack of ability to manage health problems. A low level of self-management capacity predicts poor engagement in self-care and is associated with increased use of costly health care services. [13-16]

Emotional problems and pain significantly impact the attainment of health confidence over time. [16] These measures are fundamental to the human condition and have considerable influence on health and use of services. Emotional problems and pain often respond to simple behavioral interventions and are frequently assessed as vital signs in clinical settings. [18,19]

Polypharmacy and medication side effects account for a large percentage of preventable hospital and emergency department uses. [20] Multiple medications can give rise to harmful interactions; even without such interactions, side effects can reduce adherence. [14]

Archetypical CRMs

We used two archetypical CRMs commonly employed for patients with chronic conditions to examine comparative advantages or disadvantages of the WMI.

The Centers for Medicare and Medicaid Services in the United States suggest the use of a CRM to select patients for complex care reimbursement. For this report a patient is considered complex and at risk if they report both that they are taking three or more medications and they have two or more chronic conditions.

A proprietary CRM, the 3M™ Clinical Risk Groups, uses insurance claims to assign individuals to one of a set of risk groups based on historical clinical and demographic characteristics. The risk groups can be combined for prediction of costly care. [24]

Analysis

Prospective reliability of the WMI. Based on the number of patients expected to have emergency or hospital use, the number of patients easily surpassed the minimum suggested for development and validation of clinical prediction rules: i.e., at least five to ten observations for each measure, or 25–50 emergency or hospital uses. [25,26]

Odds ratios and 95% confidence intervals tested the association of the sum (between 0 and 5) of the five measures in the WMI with any use of emergency or hospital use during the year

after its completion. The contribution of the WMI to forecasting emergency or hospital use was also examined by logistic regression after inclusion of self-reported age, gender, number of chronic conditions (listed above), and poverty (i.e., sometimes or always not able to pay for essentials such as food, clothing, or housing).

Comparison of WMI to Archetypical CRMs. We make three comparisons between the WMI and archetypical CRMs: (i) sensitivity and positive predictive values for costly care, (ii) measures for concordance (the c-statistic) used to assess the relationship between the probability of detection and the probability of a false alarm, and (ii) distribution of the five WMI measures in patients designated to be at higher or lower risk by the CRMs. Because predictive values are influenced by prevalence, we calibrated the WMI test threshold to each CRM to produce similar proportions designated “at risk.”

An Illustration: Using the WMI to Plan Patient and Provider Engagement.

Every item of the WMI is meant to elicit an action for each patient’s needs. For example, patients who say they are not confident that they can control and manage most of their health problems are asked by medical assistants or the online health assessment (www.HowsYourHealth.org) to describe “what would it take for you to be able to say that you are very confident that you can control most of your health problems during the next two months?” [12,20] Their verbatim responses are included in a summary report for the clinicians who provide care to them. Examples of queries for the other items of the WMI are listed elsewhere. [9]

To illustrate how the WMI identifies population needs for a clinical setting, we sorted the verbatim responses of 1,915 adult patients from across the United States to the online assessment into 3 general categories as shown below. These patients met the identical selection criteria used for the Medicaid population.

1) Changes in Professional Health Care. Patients most often request better information and education. In addition, they seek clarification of diagnosis, timely sharing of test results, and when possible, additional relief of symptoms. Examples: (a) "Help of a doctor who will actually listen and take my problems seriously without just pushing medication." Michigan; WMI = 2. (b) "If I got an accurately diagnose of my illness, and able to get a specific course of treatment I could control and manage my health problems." Texas; WMI = 2.

2) Personal Changes. Patients acknowledge their need to improve time-management, motivation, and lifestyle. Examples: (a) "Staying focused on what is required to be healthier." New Hampshire; WMI = 2. (b) "More time and attention to my diabetes." North Carolina. WMI = 2]

3) Non-professional Support and Guidance. Includes coaching and possible support in the workplace, home, and community. Financial assistance may be needed. Examples: (a) "Finances are stopping me from getting medical help. Co-pays for doctors and medications has taken most of my life savings." Rhode Island; WMI = 2. (b) "Need some coaching." Minnesota; WMI = 2

Inability to specify a change, listing of multiple changes, and nonsense changes remained in a non-response category.

The contribution of the WMI to the distribution of the three categories was examined by logistic regression after inclusion of self-reported age, gender, number of chronic conditions, and poverty (i.e., sometimes or always not able to pay for essentials such as food, clothing, or housing).

Results

Patient Characteristics

Despite its youth (40% aged 18–49 and none over 65), this Medicaid population has a high prevalence of serious chronic conditions such as diabetes (31%), respiratory diseases (39%), and atherosclerosis (17%), and more than a third (35%) report taking more than 5 prescription medications. Most (70%) are unable to always pay for food, clothing, and housing. More than 40% report that they are not confident they can manage and control most of their health problems. Additional characteristics of this population are described in the Supporting Information.

Prospective Reliability of the WMI

During the year following completion of the WMI, half the patients used the emergency department and 20% were admitted to hospital. The association was strong between WMI magnitude and increased use of hospital or emergency services during the subsequent year (Figure 1). The odds ratios (with 95% CI compared to a WMI of 0) for subsequent hospitalization of WMIs 1, 2, and ≥ 3 were 1.3 (1.1–1.6), 2.0 (1.6–2.4), and 3.4 (2.9–4.0) and for emergency room use were 1.3 (1.1–1.4), 1.9 (1.6–2.1), and 2.9 (2.6–3.3). These findings validate the pattern observed during development of the WMI. [12]

Figure One

This is Figure One Title: Odds Ratios of a What Matters Index (WMI) for Subsequent Use of Costly Care Among 8619 Medicaid Patients

This is Figure One Legend: Odds Ratio Compared to a WMI of 0 (and 95% Confidence Interval)

Logistic regression models including age, gender, number of chronic conditions, and poverty indicated that WMI was the variable most highly associated ($p < 0.001$) with subsequent emergency or hospital use.

Comparison of WMI to Two Archetypical CRMs

For Table 2, the proportions of patients designated at-risk have been matched so that the sensitivity and predictive values of the WMI, Medicare CRM, and proprietary CRM can be compared. Specifically, the Medicare CRM identifies roughly half the population as being at risk. To approximate the Medicare CRM target population, the WMI threshold was set to ≥ 2 . For comparably sized populations, the WMI and Medicare CRM sensitivities and positive predictive values for future hospital use were essentially the same. Similarly, for comparably sized at-risk designations, the prospective performances of the proprietary CRM and the WMI were equivalent.

Table Two

This is Table Two Title: Sensitivity and Predictive Values for subsequent hospital use of a What Matters Index (WMI) and Two Claims-based Prediction Models (CRMs)

Method	WMI ≥ 2	Medicare CRM	WMI ≥ 3	Proprietary CRM
Proportion of all patients designated "at risk"	0.53	0.51	0.30	0.30
Sensitivity of method in the population	0.69	0.64	0.45	0.43
Positive predictive value *	0.26	0.25	0.30	0.28
Concordance statistic (area under the receiver operation curve)**				

This is Table Two Footnote:

WMI: The sum of five measures: insufficient confidence to manage health problems, level of pain, emotional problems, polypharmacy, and adverse medication effects.

Medicare CRM: The presence or absence of complexity as indicated by two or more diagnoses and three or more prescriptions or lack of either. The proportions of patients designated at-risk by the Medicare CRM and a WMI ≥ 2 are similar.

Proprietary CRM: A claims-based classification system for risk. The proportion of patients designated at risk by the Proprietary CRM and WMI ≥ 3 are similar.

***Positive Predictive Value: The proportion who were hospitalized in the following year among all patients with an “at risk for hospital use” designation by the method.**

**** A c-statistic expresses the relationship between the probability of detection and the probability of a false alarm. In general, a less than excellent “c statistic” (< 0.90) will often incorrectly classify individual patients in at risk and not at risk categories.**

However, low predictive values and a low concordance statistics are demonstrated regardless of method, a reminder that most “at-risk” designated ambulatory patients are not destined to use hospital services.

While either a CRM or the WMI can provide actuarial stratification for future costly care, allocation of resources based only on the forecast is inefficient because of low positive predictive value.

Figure 2 shows that WMI needs are distributed among all patients and are not confined to the higher risk groupings designated by the CRMs. For example, 984 and 1,586 patients reporting a WMI score ≥ 3 are in the higher and lower risk groups, respectively, for the proprietary CRM.

Figure Two

Figure Two Title: Distribution of Measures that Matter from the WMI for Medicaid Patients Based on Categorization by Computer-Generated Risk Models (CRMs)

Figure Two Legends: Number of Patients Number of Patients

Figure Two Footnote:

WMI: The sum of five measures: insufficient confidence to manage health problems, level of pain, emotional problems, polypharmacy, and adverse medication effects.

Medicare CRM: The presence or absence of complexity as indicated by two or more diagnoses and three or more prescriptions or lack of either.

Proprietary CRM: A claims-based classification system for risk. Set for highest predicted 30% of patients.

Thus, use of CRMs to target resources will ignore a large proportion of patients at risk for future utilization. Also, CRMs are agnostic to potentially remediable risk factors for utilization that are easily identifiable through patient self-report.

A Hybrid Prediction Model?

Hybrid prediction models based on the addition of self-report to administrative and clinical data do not seem to warrant the effort if the goal is high accuracy. (7,8,27) For example, within this Medicaid cohort, a combination of the proprietary CRM and WMI marginally increased the c-statistic from XXX and XXX to a hybrid level of XXXX. This improvement seems to be largely a difference that has no practical distinction since incorrect classification remains and considerable effort would be required to make the hybridized model timely and useful in a clinical practice.

An Illustration: Using the WMI to Plan Patient and Provider

Engagement

A very common remediable risk factor included in the WMI is lack of health confidence—that is, a perceived inability to manage most health problems and concerns. Lack of health confidence is associated with many adverse health experiences such as higher (and often avoidable) utilization of emergency or hospital care, lost time from work, and medical harm. [13]

Figure 3 illustrates 1,915 patients' verbatim responses for changes needed to improve health confidence and how their needs vary by the sum of the WMI.

Figure Three

Figure Three Title: Influence of What Matters Index (WMI) On Patient Report of Changes Needed to Improve Their Health Confidence*

Figure Three Footnote

*** Non-professional Support and Guidance: Includes coaching or less formal support in the workplace, home and community. A needed for financial assistance is also included.**

**** Personal Changes: Includes time management, lifestyle changes and motivation.**

***** Changes in Professional Health Care: Patients most often request better information and education. In addition, they may request clarification of diagnosis, timely sharing of test results, and relief of persistent symptoms.**

[Data Source: Coding of verbatim responses by 1,915 adult patients with chronic conditions from across the United States who, if they not confident that they could control and manage most of their health problems, were asked to describe “what would it take for you to be able to say that you are very confident that you can control most of your health problems during the next two months?” Refer to the Supporting Information for additional details.]

For this sample population of adult patients with chronic conditions, the higher the WMI the more likely the respondents write that professional assistance is needed and the less likely they are to consider their personal behavior as the primary remediable cause for their low confidence. Logistic regression confirms the persistence of this pattern ($p < 0.001$) regardless of patient age, gender, financial status, or number of chronic conditions. For patients who experienced hospital or emergency care in the past year and had a $WMI \geq 3$, half (70/142) believed that the utilization might have been avoidable; for those having a $WMI = 1$, about one in five (15/76) shared that belief.

Discussion

Despite extensive evidence of their inadequacies, the notion that CRMs should be the basis for high-user interventions is entrenched in current practice. This report prospectively demonstrates that when compared to two archetypical CRMs, the WMI is both reliable and comparable in its capacity to forecast risk for costly care. However, the WMI is superior to CRMs in providing specific care guidance for each patient and enhancing a practice's capacity to plan care for many patients. As an example, to improve their health confidence, patients with chronic conditions are likely to request behavioral change support if their WMI is low and more attention to medical diagnostics, therapeutics, and education if their WMI is high.

Additional Advantages of WMI

- It is equitable because it assesses remediable needs of all patients, not just a designated few.
- It is unambiguous. The lack of ambiguity makes it much less likely to evoke high variance in interpretation than a list of patients generated by a CRM.
- It correlates strongly with overall quality of life and can be used to monitor the impact of interventions designed to improve patients' quality of life.
- It has no direct cost.
- It applies in any setting because it is patient-reported and does not require insurance claims, electronic medical records, or complicated scoring methods.

Implications

There have been many validated, self-reported prediction instruments applicable for community-dwelling older adults at risk for hospitalization, functional decline, institutionalization and death. [28] The WMI differs from these in being broadly applicable to all adults with chronic conditions and specific in its focus on remediable needs.

The advantages of the WMI make it particularly suited for the improvement of public health. People do not need to have a high level of education, access to professional health care or English proficiency to use the WMI. A person simply answers each question and brings their responses to the attention of someone to help them address each problem. That someone might be a health professional, a support group or even a website such as the one used to develop the WMI. Service appropriate for “what matters” is the goal.

When the sum of the WMI is two or more the risk for costly emergency and hospital serves is high. Therefore, the What Matters Index should be brought to the attention of health professionals. Services appropriate for the level of risk based on “what matters” is the goal.

Limitations

Several limitations of the What Matters Index deserve comment.

First, its place relative to the alternative. While it is true that a small proportion of patients account for a large proportion of the costs of care, that CRMs can identify some patients who will cost more than others, and that payers can use computer algorithms to almost effortlessly generate lists of these patients and send them to office practices who will, with incentives, do something with the lists, there is evidence that this approach is not effective in controlling costs of care, does nothing to specifically guide care for individual patients, and probably has negative consequence for those not targeted. [1-6, 12] Similar inadequacies have been previously documented for intensive care management based on targeting distinct diseases, an antecedent to the current high-user interventions. [29] In other words, a critical sociologic limitation of the WMI is, ironically, the challenge it represents to the flawed but widely adopted status quo.

That these prospective results were derived from a large sample of Medicaid patients could represent a significant scientific limitation of the What Matters Index. Whether the WMI would perform similarly in non-Medicaid patients is a valid concern. To address this point, the Supporting Information shows similar results for a smaller sample of 1,061 older patients from nine private practices using the same patient selection criteria and assessment methods. Specifically, for the private practice patients with chronic conditions, the odds ratios (with 95% CI compared to a WMI of 0) for subsequent emergency room use were 1.8 (1.1–2.8), 2.1 (1.2–3.6), and 3.0 (1.4–6.3) when the WMI was 1, 2, or ≥ 3 respectively. For WMIs of 1 or ≥ 2 , the odds ratios of subsequent hospitalization were 1.4 (0.8–2.6) and 2.4 (1.2–4.5) respectively. Sensitivity and positive predictive values WMI were identical to those of the Medicare CRM.

Finally, although a controlled cost-effectiveness trial to compare the value of a WMI-based strategy to the CRM-based high-user paradigm has not yet been conducted and a description of the optimum types and timing of interventions for different WMI levels is not yet available, the WMI's advantages strongly suggest that it is ethically more justifiable and economically more sensible to implement simple, self-reported measures for learning about what matters to all patients and to use the results to guide care. Patient report as the basis for chronic care management is increasingly recognized for its ease of implementation and benefits for patients and the providers who serve them. [21, 30] Furthermore, as a guide for health care delivery and a possible substitute for claims-based predictive models the patient report for the few items of the WMI is not the final word. Rather the WMI validates the utility of parsimonious patient-reported measures in the delivering services that matter to patients with chronic conditions. [31] Additional measures may be useful for different circumstances.

Conclusion

By listening to what patients say about their health, the WMI identifies both important needs that matter and risk for costly health care utilization. Compared to the complex and opaque algorithms of computer-generated risk models, which leave the lion's share of expensive utilization in the low-risk bin and do not provide standardized follow-up for high-risk patients, the brief, unambiguous WMI points toward a care plan for mitigating risks of all patients with chronic conditions.

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