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Themed Section: PhRMA Foundation Challenge Awards

Improving Value for Patients with Eczema

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ABSTRACT

Objective: Chronic diseases now represent a cost majority in the United States health care system. Contributing factors to rising costs include expensive novel and emerging therapies, under-treatment of disease, under-management of comorbidities, and patient dissatisfaction with care results. Critical to identifying replicable improvement methods is a reliable model to measure value. **Study Design:** If we understand value within healthcare consumerism to be equal to a patient's health outcome improvement over costs associated with care (Value=Outcomes/Costs), we can use this equation to measure the improvement of value. **Methods:** Research and literature show that patient activation—the skills and confidence that equip patients to become actively engaged in their health care—impact health outcomes, costs, and patient experience. Reaching patient activation through engagement methods including shared decision-making (SDM) lead to improved value of care received.

The National Eczema Association (NEA) Shared Decision-Making Resource Center can be a transformative strategy to measure and evaluate value of health care interventions for eczema patients to advance a value-driven health care system in the United States. **Results:** Through this Resource Center, NEA will measure patient value through their own perceptions using validated PRO instruments and other patient-generated health data. **Conclusions:** Assessment of this data will reveal findings that can assist researchers in evaluating the impact this care framework on patient-perceived value across other chronic diseases. **Keywords:** chronic disease, eczema, health care intervention, patient activation, patient-reported outcomes, shared decision making, value.

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The Value of Measuring Value

In the traditional study of consumerism, “value” is defined by the customer and measured against the customer's perception of value. In other words, “value” is measured through the “eyes” of the consumer (Fig. 1) [1].

Applied to health care consumerism, Michael Porter famously described value measurement as “health outcomes achieved per dollar spent,” an equation where value equals outcomes over costs (Fig. 2) [2].

In the evolving U.S. health care landscape, the role of the “consumer” has also evolved. Value as described from the perspective of the consumer, or patient, has become synonymous with improved outcomes or efficiencies, but these often describe costs to the health care system and not from the perspective of the patient. Rising costs in the denominator of this equation result from rising expenditure associated with full cycles of care for medical conditions or patient populations but may be offset by upstream investments of prevention or integrated care. Chronic illnesses, including eczema, now represent a cost majority in the U.S. health care system [3]. These diseases are costly and difficult to treat. Novel and emerging therapies, which offer

hope and new options for the very first time to many patients with eczema, are sophisticated and expensive. For example, Dupixent, the first-ever biologic indicated to treat moderate to severe atopic dermatitis (AD; a chronic, systemic form of eczema) was launched in March 2017 with a sticker price of \$37,000 per year.

For patients with AD, “costs” hit closer to home. Eucrisa, a topical nonsteroidal phosphodiesterase 4 indicated to treat mild to moderate AD also launched in the past 12 months costing the consumer over \$600 per 60-g tube. In addition to out-of-pocket costs, poor outcomes may have an impact on patients' perception of value. Undertreatment of disease and undermanagement of comorbidities by coordinated care teams can lead to more costly interventions [4,5]. Delays in care can also result in unchecked disease progression [6]. Last, patient dissatisfaction with care results in “doctor shopping,” leading to further inefficiencies [7]. A patient-centered framework for measuring $v = o/c$ may augment the assessment of value in a larger health care value framework.

In the numerator of this “patient centered” value equation is improved health outcomes. Although different stakeholders in the health care system may have differing motives in the value equation, measurably improving patient health outcomes is a

Conflict of Interest: The authors have indicated that they have no conflicts of interest with regard to the content of this article.

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1098-3015/\$36.00 – see front matter Copyright © 2018, International Society for Pharmacoeconomics and Outcomes Research (ISPOR).

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<https://doi.org/10.1016/j.jval.2018.01.014>

Value=Benefits/Costs

Fig. 1 – Measuring patient-perceived value.

unifying factor, and one where the National Eczema Association (NEA) has an important role. NEA, whose mission is to improve the health and quality of life for individuals with eczema, operates in the numerator of patient-centered value and acts as an advocate for the improved health outcomes of its patient members. Research and the literature support these efforts, showing that patient activation—the skills and confidence that equip patients to become actively engaged in their health care—impact health outcomes, costs, and patient experience [8]. As such, NEA provides patient-centric tools and resources to complement traditional care models, inspiring active participation in one's care and creating an understanding of shared responsibility in one's outcomes (Fig. 3).

Patient perception of health care value has real impact on treatment choices and behaviors, leading to effective management and improved outcomes. Shrestha et al. evaluated the burden of AD conducting a large-scale analysis of claims data in the commercial ($n = 83,106$), Medicare ($n = 31,060$), and local Medi-Cal ($n = 5550$) databases [9]. Patients with higher AD severity had increased risk of comorbid conditions, such as asthma, allergic rhinitis, chronic pulmonary disease, and chronic rhinosinusitis, which are associated with increased total costs (Fig. 3) [9]. Per-patient costs were higher for commercial insurance (US\$14,580 vs US\$7192 non-AD matched controls), Medicare (US\$21,779 vs US\$12,490 non-AD matched controls), and Medi-Cal (US\$22,123 vs US\$16,639 non-AD matched controls) ($P < 0.0001$).

Patient perceptions of not only their diagnosis and disease trajectory but also their experience of care and impact on quality of life can be assessed through validated patient-reported outcome (PRO) instruments and other patient-generated health data, such as lifestyle activity or symptom reporting.

PROs have been defined as “any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else” enabling assessment of patient-reported health status for physical, mental, and social well-being [10,11]. By collecting, assessing, and analyzing the PROs of its members, the NEA acts as the data-driven eyes of patients with eczema, measuring patient-centered value and being the voice of these patients by using the data to impact the health care outcomes of its members.

An Opportunity to Impact Value

Patient-provider communication is an important area of patient engagement. Studies show that well-done patient-provider communication produces a therapeutic effect for the patient. Strong patient-provider communication has been tied to decreased emotional stress, improved treatment adherence, improved health outcomes, and increased patient satisfaction [12]. Formal provider training programs have been created to enhance and measure specific communication skills. Many of these efforts, however, focus on medical schools and early postgraduate years isolated in academic settings. The communication skills of busy professionals often remain poorly addressed and the need for providers to have access to communication and engagement tools and resources persists.

Patient barriers also exist. Language, health literacy, and cultural differences may be obvious impediments, but there are less obvious barriers, particularly for patients with eczema. In a study of patients with chronic disease, 30% of surveyed patients reported reluctance to discuss self-care with their physicians for

fear of being judged, not wanting to disappoint their doctors, guilt, and shame [13]. Compounding these barriers are the characteristics of dermatologic care. A review in the *Journal of Cutaneous and Aesthetic Surgery* [14] describes the issues that dermatology practices encounter. Patients may visit dermatologists with high expectations of a definitive cure of their skin disorder, but because of the heterogeneous nature of chronic skin disease, it is not possible for providers to guarantee solutions. This creates a gap between the service provider and the service seeker, leading to reduced patient satisfaction and perceived value of the intervention.

Thus, improving patient-provider communication is a starting point for improving patient engagement and value. Patient engagement is more broadly defined as “patients, families, their representatives, and health professionals working in active partnership ... to improve health and health care [15].” This partnership in direct patient care involves patients receiving information about a condition and determining their preferences for treatment. This form of active engagement allows patients and providers to make decisions based on the medical evidence, patients' preferences, and clinical judgment. Consistent with this strategy of engagement is shared decision making (SDM), whereby patients and providers together consider the patient's condition, treatment options, medical evidence behind treatment options, benefits and risks of treatment, and patients' preferences and then arrive at and execute a treatment plan [16].

Improving Value through SDM

Patients are experts in their condition—their lives are directly affected by their illness. Health care providers are experts in the treatment and management of the conditions of their patients. These are the precepts of SDM—by acknowledging these fundamental principles, SDM presents an actionable framework, whereby patients and providers co-create effective solution strategies to complex issues [17].

SDM is purported to promote patient autonomy, trust in physicians, and realistic expectations; improve patient safety and health outcomes; enhance patient satisfaction and ratings of health care quality; reduce costs; and improve quality of life [16]. SDM is now recognized as an integral part of treatment by the Institute of Medicine, the Centers for Medicare & Medicaid Services [18], the U.S. Preventive Services Task Force (USPSTF) [19], the Affordable Care Act [20], and other entities in the United States. Unfortunately, there is lack of robust SDM tools outside of the clinical trial environment. A variety of instruments, such as PATIENT-Oriented Eczema Measure and Scoring Atopic Dermatitis [21], or efforts, such as Harmonising Outcome Measures for Eczema, seeking a core set of measures; however, currently there are no validated instruments that are developed with patients and meet quality and performance measures [22].

The innovation of SDM is the use of evidence-based tools, known as *patient decision aids*, to inform patients and help them set their own goals and to clarify their values [16]. The International Patient Decision Aid Standards (IPDAS) have evolved since 2003 to help guide the development of robust and effective frameworks for broad dissemination. Patients with eczema have access to a variety of sources for such comprehensive information, including the website nationaleczema.org, physicians, friends and family, and printed materials, such as pamphlets, from the NEA. Integrating guidance from IPDAS criteria leads to quality-assurance to guide decision making at the point of care, although additional development and testing of

Value=Outcomes/Costs

Fig. 2 – Measuring value-based care

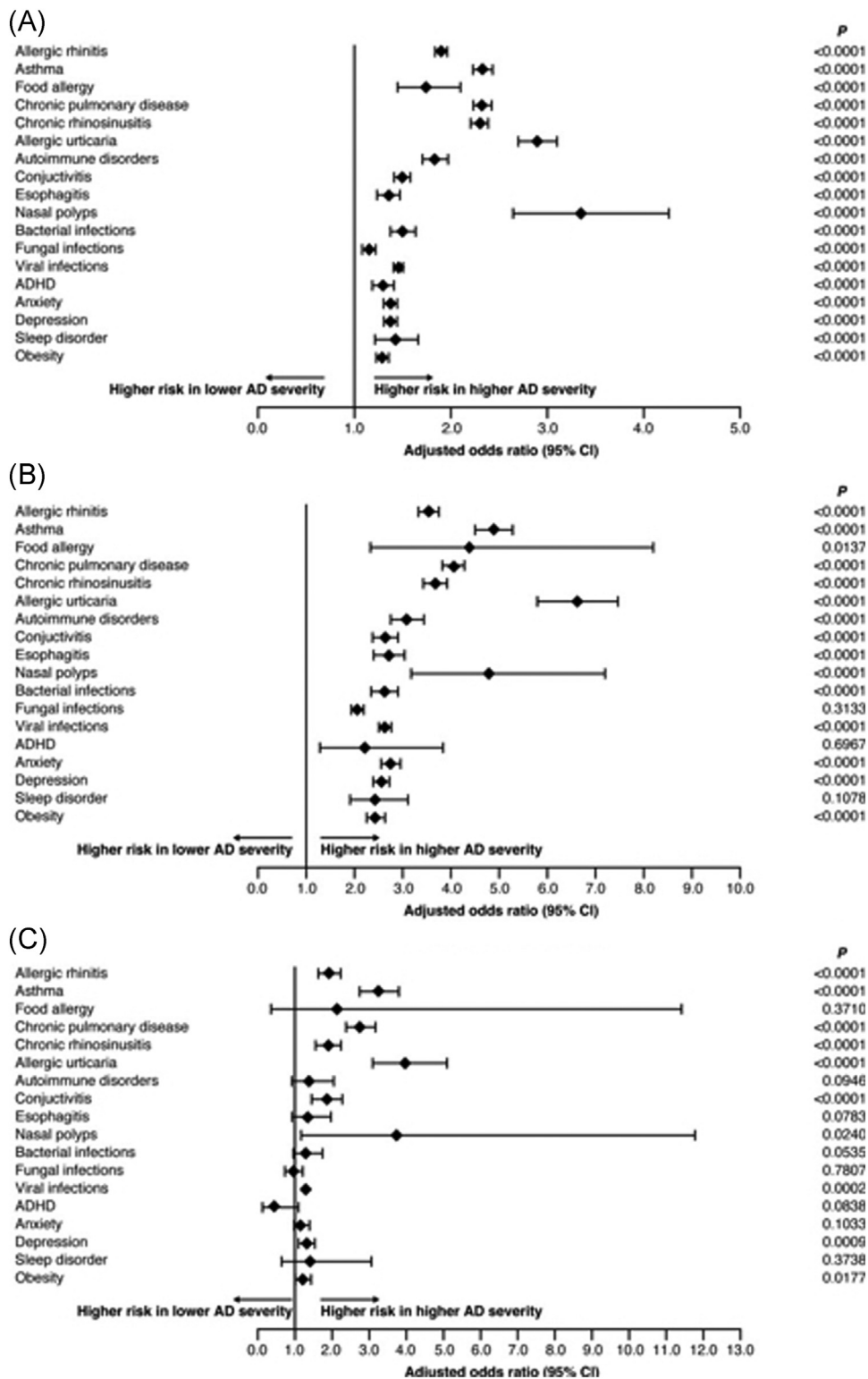


Fig. 3 – Adjusted odds ratios of prespecified comorbidities in atopic dermatitis (AD) patients and matched non-AD controls in: (A) Commercial, (B) Medicare, and (C) Medi-Cal populations. Variables included in the generalized linear model: age, gender, race, and non-AD-related comorbidities. ADHD attention deficit hyperactivity disorder, CI confidence interval [9].

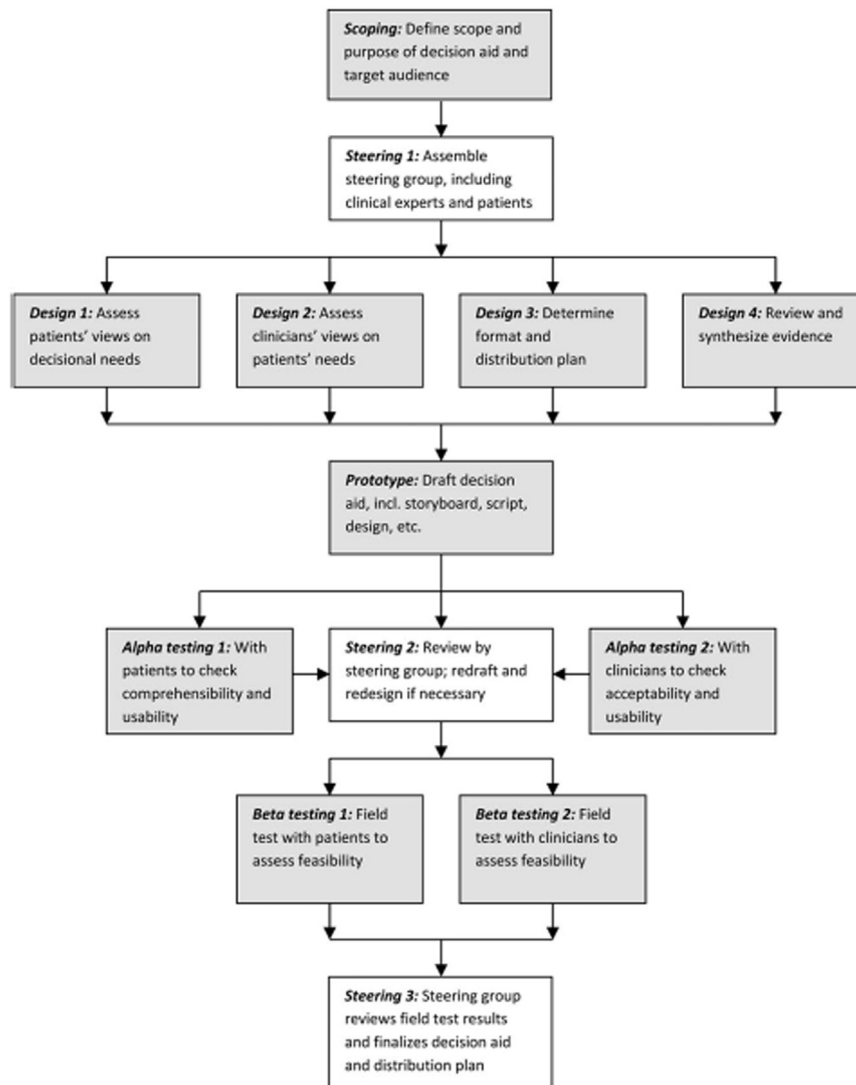


Fig. 4 – Model development process for decision aids [23].

recommendations are needed to develop the current model elements from pragmatic criteria to evidence-based ones. A draft process flow for the development of patient decision aids is presented in Figure 4 [23]. As the Agency for Healthcare Quality and Research describes, SDM aids expand this learning to explain the issues fairly and clearly, highlighting the pros and cons of each option, and providing support for users to clarify and express their personal values, goals, and preferences (Fig. 4).

Although patient checklists and action plans are important resources that support the framework of SDM, consensus statements on the quality of interventions have presented a wide range of quality scores [24,25]. Durand et al. recommend that minimum standards be introduced to increase consistency and reduce the risk of bias [26]. The IPDAS collaboration has developed a checklist and actual instrument, which can create a framework for acceptable quality [26] and guidance for developing SDM tools and resources for patients with eczema [24].

Patients who are empowered to participate in decision making about their health in ways that better reflect their personal values often experience more favorable health outcomes, such as decreased anxiety, quicker recovery, and benefits yielded from

increased compliance with treatment regimens [27]. Greater patient involvement in decision making leads to lower demand for health care resources [28].

Patients with eczema need access to an SDM resource center developed specifically for patients with eczema and their care providers. In 2017, the NEA will develop and launch an SDM resource center for patients with eczema.

Building an SDM Resource Center

Fulfilling its mission as a trusted source of information for patients with eczema, the NEA is developing a web-based SDM resource center. Through the NEA SDM resource center, patients with eczema will access resources to better share information and to initiate informed conversations about available options with their health care provider [6], as well as tools to help them develop actionable self-care strategies.

The first step in developing a resource for patients with eczema is to engage patients in their care decisions. In accordance with recommendations for patient engagement processes

by the National Health Council [29], the NEA has assembled a panel of co-creators, including patients, caregivers, and health care providers. This panel will assist in the development of tools by providing feedback, needs, gaps, and insights into issues that can be asked of a larger sample of end users. Panel feedback is critical during design, development, instrumentation, validation, and testing. Additionally, larger populations of patients with eczema will be engaged during the validation, testing, and quality assurance phases. The structure for the resource center follows the evidence-based framework provided by the Agency for Healthcare Research and Quality's guidelines for improved SDM [30], as well as IPDAS recommendations [24], but the panel and other patient co-creators will assist in providing the lens through which these resources focus on the specific needs of over six million patients with eczema and their families impacted by the NEA.

In addition to patients, caregivers, and care providers, the NEA has assembled a team of collaborators, including patient engagement experts, data scientists, programmers, digital engagement experts, and researchers. These experts will further develop the resource center by identifying known and unknown barriers to its success. Kristin Carman, Director of Public and Patient Engagement at the Patient-Centered Outcomes Research Institute, described some of these real-world barriers in her book, *Framework for Patient and Family Engagement in Health and Healthcare*. These barriers are related to web access, the health literacy of patients, cultural differences, sex, age, education, and limitations to human decision-making skills.

There are also significant real-world barriers to the provider-side use of the SDM model. In a recent study, RAND Corporation and coauthors reported three main barriers to implementing SDM: overworked physicians, insufficient provider training, and clinical information systems that fail to track patients throughout the decision-making process [31]. In another meta-analysis of SDM barriers, the study found that most physicians cite "lack of time" as a major roadblock, even though SDM may provide some time-saving process-of-care tools. In this systematic review of 38 studies by Légaré and Witteman, clinicians most often cited time constraints as the primary barrier, even though there was "no robust evidence that more time is required to engage in shared decision making in clinical practice than to offer usual care [32]." Both the above-mentioned studies noted that payment reforms and incentives may be needed for the concept of SDM to take hold. The Merit-Based Incentive Payment System of the Centers for Medicare and Medicaid Services may be a vehicle for provider incentive, but additional study on this is needed. In the development of the resource center, inclusion of providers in the panel of co-creators is critical to gaining insights into these barriers and incentives to SDM adoption and solutions for overcoming or maximizing them.

Measurement

As it builds the resource center, the NEA will also develop the ability to assess the effect of the tools and resources on improved health outcomes. Validated PRO instruments, such as Patient-Reported Outcomes Measurement Information System and Scoring Atopic Dermatitis, will be assessed to determine appropriate instrumentation of the data collection tool. By using validated PROs to assess longitudinal health outcomes, before and after clinical visits, the NEA will be able to evaluate the impact of the health care interventions. Collecting and storing large data sets of PRO and other patient-generated health data will provide opportunities to connect data to interventions and will provide data scientists and researchers with the ability to conduct and present relevant sensitivity and scenario analyses and account for

selection bias. These instruments were created for clinical trial assessment, and their utility in the real-world setting will also be assessed.

The collection and reporting of PRO data are described in a research plan to be submitted for Internal Review Board approval. Informed consent, Health Insurance Portability and Accountability Act compliance, and privacy policy acceptance are offered to participating patients and families. Patients will be able to opt out of sharing data and still use the resource center.

Analysis, interpretation, and visualization of anonymized patient data will reveal the resource center's true impact. The NEA hypothesizes that SDM will demonstrate a positive impact on health outcome domains, including coping and self-care, and may, eventually, impact symptom domains over time.

Summary

Eczema affects more than 30 million Americans today (nearly one in 10) [33], and as every case is different, a treatment strategy that is effective for one patient may not be appropriate for another. Each eczema patient's condition is unique and requires comprehensive care strategies to ensure success. To increase patient-perceived value, an outcomes-driven, patient-centric model of care toward achieving individualized goals in their chronic disease management is necessary [34].

The overall goal of creating an SDM resource center is to engage patients so that they can actively manage their health care. This patient participation may lead to increases in the perceived value of care received as interventions become a facilitated exchange that leads to improve individual health outcomes. As a first step toward identifying strategies that improve this patient-centric value, building and maintaining a leading-edge SDM resource center is essential for the NEA to support patient-centric, value-driven health care delivery. Measuring its utility can be an effective strategy for assessing patient-perceived value of point-of-care interventions.

The high variability in health care management for patients living with eczema offers researchers a chance to assess successful methods, and this effort may be replicable in other populations within the health care landscape. As a chronic inflammatory disease that is heterogeneous in its effect, eczema can provide a unique opportunity to test and measure the impact of SDM on the patient-perceived value of interventions.

Funding

Funding was provided through the PhRMA Foundation Challenge Award.

Acknowledgments

The author is grateful to Archie Frink, Stephen Chavez, and Lisa Butler not affiliated with PhRMA Foundation, for their assistance.

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