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Assessing Patient Activation among High-Need, High-Cost Patients in Urban Safety Net Care Settings

Tessa M. Napoles · Nancy J. Burke · Janet K. Shim · Elizabeth Davis · David Moskowitz · Irene H. Yen

Abstract We sought to examine the literature using the Patient Activation Measure (PAM) or the Patient Enablement Instrument (PEI) with high-need, high-cost (HNHC) patients receiving care in urban safety net settings. Urban safety net care management programs serve low-income, racially/ethnically diverse patients living with multiple chronic conditions. Although many care management programs track patient progress with the PAM or the PEI, it is not clear whether the PAM or the PEI is an effective and appropriate tool for HNHC patients receiving care in urban safety net settings in the United States. We searched PubMed, EMBASE, Web of Science, and PsycINFO for articles published between 2004 and 2015 that used the PAM and between 1998 and 2015 that used the PEI. The search was limited to English-language articles conducted in the United States and published in peer-reviewed journals. To assess the utility of the PAM and the PEI in urban safety net care settings, we defined a HNHC patient sample as racially/ethnically diverse, low socioeconomic status (SES), and multimorbid. One hundred fourteen articles used the PAM. All articles using the PEI were conducted outside the U.S. and therefore were excluded. Nine PAM studies (8%) included participants similar to those receiving care in urban safety net settings, three of which were longitudinal. Two of the three longitudinal studies reported positive changes following interventions. Our results indicate that research on patient activation is not commonly conducted on racially and ethnically diverse, low SES, and multimorbid patients; therefore, there are few opportunities to assess the appro-

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priateness of the PAM in such populations. Investigators expressed concerns with the potential unreliability and inappropriate nature of the PAM on multimorbid, older, and low-literacy patients. Thus, the PAM may not be able to accurately assess patient progress among HNHC patients receiving care in urban safety net settings. Assessing progress in the urban safety net care setting requires measures that account for the social and structural challenges and competing demands of HNHC patients.

Keywords Patient activation measure · Patient enablement instrument · Complex care management · Safety net · Urban · Super-utilizer · High-need, high-cost · HNHC · Health disparities

Introduction

In the U.S., 1% of the population accounts for approximately 20% of total healthcare expenditures [1]. Attention to improving healthcare quality and decreasing costs has identified "super-utilizers" or high-need, high-cost (HNHC) patients as a population whose care is particularly costly and often fragmented [1–3]. HNHC patients are defined as individuals with multiple chronic conditions and frequent acute care use, whose conditions are compounded by both the limited ability to care for themselves independently and by their complex social needs such as lack of housing, food, and supportive personal relationships [3]. In response to the recognition that a small number of complex patients drive a disproportionate share of cost and utilization, counties and states are funding care management initiatives that integrate team-based care with primary care to improve outcomes and reduce expenditures [4]. Urban safety net providers, which include safety net hospitals and community health centers (CHCs), provide a disproportionate amount of care to HNHC patients. Patients receiving care in the U.S. urban safety net are disproportionately low-income (e.g., eligible for Medicaid or dually eligible for Medicaid and Medicare), report lower educational attainment, demonstrate lower health literacy, are predominately non-White, and have higher rates of comorbidity [5].

Care management initiatives for complex patients receiving care in urban safety net settings provide team-based care and health coaching for symptom management, support patients in managing their medical, social, and behavioral health needs, track patient progress, and graduate patients if they reach milestones they set for

themselves and providers deem them able to self-manage their conditions. As self-management is a focus of these new initiatives, patient activation—defined as one's ability and willingness to manage one's health and healthcare—emerged as a key construct to track patient progress [6]. Studies report that patient activation is an important predictor of health outcomes and healthcare usage [7]. Therefore, new care management initiatives that seek to better manage and coordinate care for urban HNHC patients require standardized patient tracking tools and means of assessing progress and such attributes as patient activation.

The Patient Activation Measure (PAM) was developed in 2004 to assess patient knowledge, skill, and confidence for self-management [8] and is now widely employed to manage patient panels and identify patients most likely to improve after clinical intervention. Respondents are asked to indicate their level of agreement with 22 statements, or 13 statements with the PAM short-form [9]. Questions inquire about an individual's role in healthcare and their relationship with their provider such as *I know what each of my prescribed medications do* and *I am confident that I can tell a doctor concerns I have even when he or she does not ask*. The raw PAM score is converted to an activation score between 0 and 100, where a higher score equates to a higher level of activation. The activation score is then used to classify respondents into one of four activation levels, or stages, based on cut-off points. If respondents score at stage 1 ($\leq$47), they are categorized as "believing the patient role is important (but not having the confidence to take action)." Likewise, if a respondent scores at the highest level, stage 4 ($\geq$67.1), they are "taking action to maintain and improve one's health" and able to "maintain these behaviors even under stress." The PAM was developed and validated in a national random sample of individuals living with and without chronic illnesses (80% reported at least one chronic disease). The sample included individuals who were 45 and older, 88% were White, 60% had completed at least some college, and 80% rated their health as good, very good, or excellent. The Patient Enablement Instrument (PEI) focuses on the concept of "enablement," defined as "patient centeredness and empowerment" and "ability to understand and cope with the health and illness," and like the PAM, has been used to assess the quality of primary care among chronically ill individuals [10, 11].

Despite the routine use of the PAM and the PEI, it is unclear whether these measures are an appropriate means to capture changes in patient knowledge and

self-management skills among HNHC patient populations receiving care in urban safety net settings. Anecdotal evidence from complex care management programs in two urban safety net institutions in California indicates that although patients do progress in terms of their willingness and ability to manage their own health issues, the PAM does not detect improvements that safety net staff believe have clinical relevance. Therefore, we reviewed the PAM and PEI literature to determine whether, and to what extent, the measures have been administered in populations whose characteristics mirror those of HNHC patients receiving care in urban safety net settings and whether the measures could discern changes in activation, or enablement, in this population.

Methods

Search Methods

We searched PubMed, EMBASE, Web of Science, and PsycINFO for articles published between January 1, 2004 and December 31, 2015 using the search term "patient activation measure" and for articles published between January 1, 1998 and December 31, 2015 using the search term "patient enablement instrument." The search was limited to English-language articles published in peer-reviewed journals.

Eligibility Criteria

Article eligibility was based on the following inclusion criteria: (1) published in a peer-reviewed journal; (2) English-language article; and (3) used the PAM or the PEI as a measure of patient activation or enablement, respectively. Studies conducted outside of the U.S., among children, or that examined the psychometric properties of either instrument in other languages were excluded.

Study Selection

PAM. After identification of relevant studies ($n = 509$) and removal of duplicates ($n = 250$), one author (TMN) screened 259 titles and abstracts to determine appropriateness for full review. One hundred twenty-eight records were excluded for the following reasons: conducted outside of the U.S. or with children, conference

abstracts, study protocols, and articles using the Patient Activation Measure for Mental Health (PAM-MH) or Clinician Support (CS-PAM). Two authors (TMN, IHY) then screened the full text of relevant articles ($n = 131$) to determine whether they met the eligibility criteria; at this stage, another 25 articles were excluded for similar reasons. A secondary search of reference lists of the included articles yielded an additional eight studies.

PEI. The search identified 136 records. After removal of duplicates ($n = 83$), the titles and abstracts of 53 records were screened by two authors (TMN, IHY); all 53 records were conducted outside the U.S. and excluded.

We contacted authors for additional information when needed.

Data Abstraction and Selection

Two authors (TMN, IHY) recorded study details which included the following: (1) characteristics of the sample (race/ethnicity, socioeconomic status (SES), language, insurance, health literacy, multimorbidity, and mean PAM score) and (2) whether the study sample could be categorized as a HNHC urban safety net sample (see below). A third author (NJB) reviewed a subset of ten articles to verify article extractions.

Definition of High-Need, High-Cost Patients Who Receive Care in an Urban Safety Net Setting

Documentation of the demographic characteristics of safety net patients is elusive. Harris et al. characterized patients in Memphis, TN who were targeted for a care transition program as community-dwelling super-utilizers of hospital-based services (e.g., three or more hospitalizations within a six-month period) without major social risk factors (e.g., mental illness, substance abuse, or homelessness) [12]. Seventy-four percent of the patient cohort was African American. The authors did not report socioeconomic status characteristics. Johnson et al. described safety net patients in Denver and reported that they were primarily Black or Hispanic men living with multiple chronic conditions, many of whom were uninsured, non-English-speaking, and homeless [13]. The U.S. Department of Health and Human Services framework defines multiple concurrent chronic conditions (MCC), or multimorbidity, as two or more chronic conditions [14].

To assess the inclusion of HNHC populations in patient activation research, we created the following inclusive definition for HNHC patient samples: Racially/ethnically diverse = at least 33% of the sample are people of color or non-White. Low SES = either low income (at least 33% of the sample have an annual income of ≤$25,000, which is about 200% of the federal poverty guidelines for one individual in the household [15]) or low educational attainment (at least 33% of the sample completed high school or less). Chronic disease comorbidity = at least 33% of the sample have at least two chronic diseases, or the mean number of chronic conditions in the sample was ≥2 [14].

Results

Of the 645 records included in our initial search, 114 met our inclusion criteria (see Fig. 1). Characteristics of the study samples are presented in Table 1. Of the 114 records included in our search, only nine studies (8%) included HNHC populations who receive care in urban safety net settings as defined herein (see Table 2). In addition, only three of the nine studies were conducted longitudinally, two of which reported that the PAM was able to discern change over time; the third study did not see changes in patient activation scores over time or between the intervention and control groups. Below, we describe how the PAM was used in each of the nine studies.

Studies that Included HNHC Patient Populations Receiving Care in Urban Safety Net Settings ($n = 9$)

Cabassa et al. conducted a cross-sectional mixed method study examining the primary healthcare experiences of 40 Latino patients living with serious mental illness (SMI; e.g., schizophrenia, bipolar disorder) at an outpatient public mental health clinic in New York City [16]. The study participants responded to the PAM along with other measures of patient-centered care, including perceptions of chronic illness care quality and self-efficacy. Analyses revealed that positive relationships with primary care providers (based on focus group interviews) were associated with higher patient activation scores.

In Crowley et al., 963 participants living with type 2 diabetes and poor blood pressure control were assessed at baseline of a cluster randomized controlled trial of a hypertension intervention [17]. Participants with persistent poorly controlled diabetes mellitus (PPDM) were compared to participants with intermittent poorly controlled diabetes mellitus (IPDM) and well-controlled diabetes mellitus. The authors sought to identify patient factors associated with PPDM by analyzing available demographic/socioeconomic, clinical, psychosocial, and healthcare utilization data. Psychosocial data included the PAM, Patient Health Questionnaire (PHQ-2) depression screen, Perceived Competence Scale for self-efficacy, components of the Patient Assessment of Chronic Illness Care (PACIC) scale, and an internally developed healthcare satisfaction scale. While PPDM patients were more likely than patients with IPDM and well-controlled DM to have a positive depression screen, higher PACIC score, and lower general healthcare satisfaction, no differences in PAM scores were seen across groups.

Dattalo et al. enrolled 241 multimorbid adults in a cluster randomized controlled trial of a chronic disease self-management (CDSM) program with the objective of determining the characteristics of those who were more likely to participate [18]. Baseline information on demographics, health status, health activities, and quality of care was available for program participants and nonparticipants. Dattalo et al. hypothesized that patient activation in addition to patient perception of quality of chronic illness care and difficulty with health activities would be associated with participation in CDSM programs. The authors did not find an association between the PAM score and participation in CDSM. The authors note that among their sample of multimorbid older adults, "self-care motivation may be limited by physical capacity to follow through with intended behaviors."

Druss et al. randomized 80 participants living with serious mental illness (SMI) to either a chronic disease self-management (CDSM) program or usual care [19]. The authors administered the PAM at baseline and six-month follow-up because "positive changes in patient activation have been found to be associated with improved self-management behaviors, medication adherence and outcomes including quality of life." At six-month follow-up, patient activation was "clinically and significantly higher" in the program group compared with the usual care group ($p = 0.01$). PAM scores in the usual care group declined by 17% from 48 at baseline to 45 at follow-up ($p = 0.04$). Due to improvements in PAM scores in the CDSM program participants, Druss et al. concluded that the chronic disease management program has the "potential to improve other more downstream health outcomes."
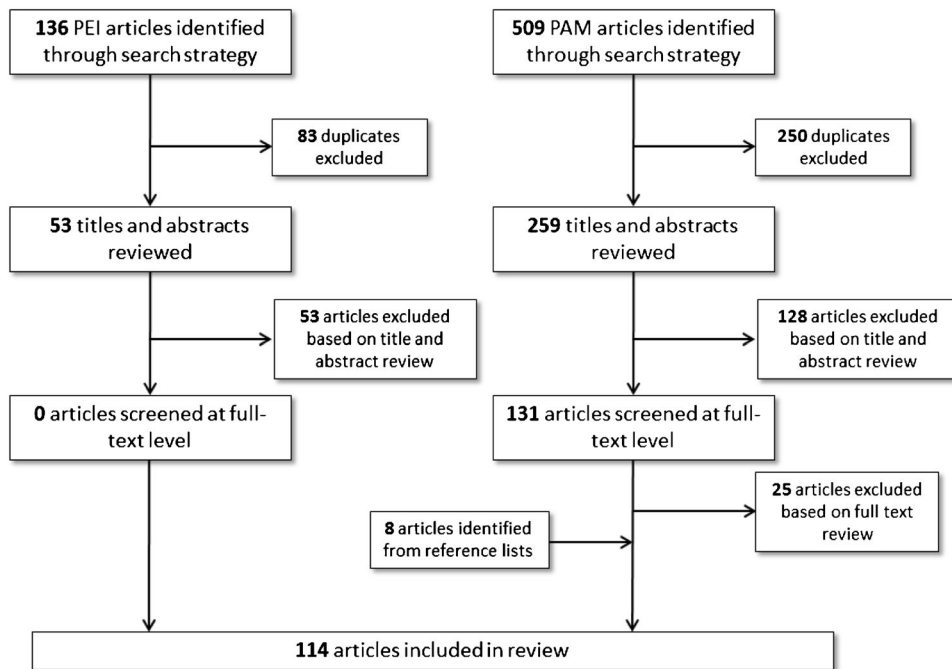
Fig. 1 Flow chart of article selection and exclusion

Druss et al. randomized 170 individuals with a serious mental disorder and a comorbid medical condition to a personal health record or usual care to test the quality of medical care received in an urban community mental health center [20]. The PAM measure was administered at baseline and one-year follow-up along with measures of medical care quality, service use, and health-related quality of life. Analyses showed that both the intervention and usual care groups did not exhibit improvement in patient activation. The authors concluded that having a personal health record provided "no evident benefits regarding patient activation."

Evangelista et al. examined the effects of a remote monitoring system (RMS) on patient activation among 42 older patients living with chronic heart failure from a tertiary care center in Southern California using a quasi-experimental design [21]. The authors note that symptoms of heart failure can result in "loss of control over. Health outcomes or inadequate self-care knowledge, skills, and self-efficacy" and, in particular, older adults with heart failure "experience an inability to engage in self-care …." The PAM measure was administered at baseline and three-month follow-up along with measures of self-care and quality of life. At follow-up, participants in both the RMS and standard heart failure care groups

showed greater improvements in patient activation over time ($p < 0.001$).

Kawi examined self-management (SM) among 230 participants living with chronic low back pain (CLBP) using a cross-sectional, descriptive design [22]. The authors outline that SM strategies, defined as "the performance of tasks and skills with self-efficacy so that patients are activated to make appropriate decisions and engage in health-directed behaviors," are recommended in pain care guidelines to help address CLBP but the evidence of SM effectiveness in CLBP remains unclear. Kawi analyzed secondary data to identify variables that could predict which patients would respond best to SM of CLBP; data included the PAM, Patient Assessment of Chronic Illness Care (PACIC), Oswestry Disability Index, and mental health state from the SF-36. Kawi reported that the mean PAM score for the sample was 58 (SD = 16), which corresponds to PAM level 3, indicating that participants were already beginning to take action in SM.

Maeng et al. cross-sectionally measured participants' self-report of care coordination problems and level of activation using the PAM [23]. Care coordination problems were assessed using a one-item survey question: *In general, do you think that coordination among all of the different health care professionals that you see is …?* with

Table 1 Characteristics of study samples included in the review (*n* = 114)

	n (%)
Sample size	
Range	[16; 144,625]
PAM measured at two time points	49 (43)
Version of PAM used	
PAM-13	93 (82)
PAM-22	7 (6)
PAM-MH[a]	7 (6)
Adapted PAM	2 (2)
Did not report	1 (1)
Psychometric studies	8 (9)
Race/ethnicity	
Reported race/ethnicity	90 (79)
≥33% non-White sample	56 (49)
Socioeconomic status (SES)[b]	
Reported income	43 (38)
Reported education	87 (76)
Low-income sample[c]	26 (23)
Low-education attainment sample[d]	51 (45)
Language	
Reported language of sample	15 (13)
100% English-speaking sample	45 (39)
≥33% non-English-speaking sample	6 (5)
Multimorbidity	
Reported chronic disease status of sample	81 (71)
≥1 chronic disease	66 (58)
≥2 chronic diseases	15 (13)
Reported a mean number of chronic diseases ≥ 2	15 (13)
PAM scores	
Reported a mean PAM score	78 (68)
Weighted PAM score, mean (SD)[e]	58 (7)
Percent of sample at PAM stage 1, mean (SD)	17 (12)
Percent of sample at PAM stage 2, mean (SD)	20 (9)
Percent of sample at PAM stage 3, mean (SD)	29 (9)
Percent of sample at PAM stage 4, mean (SD)	34 (17)

[a] Patient Activation Measure for Mental Health

[b] SES includes income and education

[c] Low income is defined as at least 33% of the sample had an annual income of ≤$25,000

[d] Low education attainment is defined as at least 33% of the sample completed high school or less

[e] Weighted by sample size

response options "major problem," "minor problem," or "not a problem at all." Results showed that the highest activation stage had lower odds of reporting care coordination problems compared to those in the lowest stage ($p < 0.01$). In addition, participants with multiple chronic conditions were more likely to report coordination problems than those with hypertension only. Seventy-five percent of the sample scored at PAM levels 3 and 4 indicating already high levels of patient activation.

Lastly, Skolasky et al. assessed the psychometric properties of PAM among 855 multimorbid older adults, a population that will soon make up a significant proportion of the U.S. population. The authors concluded that the PAM is a reliable and potentially clinically useful measure of patient activation for multimorbid older adults [24].

Studies that Discussed the Appropriateness and Utility of PAM

While the nine articles that fit our HNHC patient definition did not all discuss the appropriateness and utility of the PAM to discern changes over time with vulnerable patient populations, a number of other articles within the 114 that the search retrieved did. Among 587 Black home care patients with uncontrolled hypertension enrolled in a randomized controlled trial of a home-based hypertension control intervention, Ryvicker et al. found that the interventions (basic or augmented) did not lead to positive change in patients' PAM scores compared to those in usual care. The authors questioned "whether the large variation in PAM change seen in [the] sample [was] a reflection of actual fluctuation in activation levels over time or of unreliability of the measure in [the] study population" [25]. Ryvicker et al. posited that the PAM may not be culturally appropriate for an older Black population. In another study by Ryvicker et al., among predominantly non-White (59%) participants (*n* = 249) with an average of 1.7 chronic conditions, the investigators expressed misgivings about their participants' ability to comprehend the PAM instrument [26]. The authors noted that "it is possible that the questions were less well understood by individuals in our sample with lower literacy levels." A third study of 313 acute care patients with three or more chronic diseases, Schmaderer et al. criticized PAM items 10, 12, and 13 (i.e., *I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising*; *I am confident I can figure out solutions when new problems arise with my health*; and *I am confident that I can maintain lifestyle changes, like eating right and*

Table 2 Summary of articles meeting the HNHC urban safety net sample definition (n = 9)

Author	Study design	Location(s)	Sample size	PAM version	% non-White	% low income or mean annual income[a]	% low educational attainment[b]	% ≥2 chronic conditions or mean # of chronic conditions ≥2	Mean PAM score(s)[c]
Cabassa [16]	Cross-sectional	NYC	40	PAM-13	100%	NR	60%[d]	Mean = 4.2 (SD = 2.3)	55 (SD = 18)
Crowley [17]	Cross-sectional	Ann Arbor & Detroit, MI; Toledo, OH; Oakland & San Francisco, CA[d]	963	PAM-13	34%	53%[e]	44%	All participants had type 2 diabetes and poor blood pressure control	Persistently poorly controlled diabetes mellitus: 71 (SD = 14); Intermittent poorly controlled diabetes mellitus: 70 (SD = 13); Well-controlled diabetes mellitus: 71 (SD = 14)
Dattalo [18]	Cross-sectional	Baltimore—DC area[d]	241	PAM-13	52%	44%[f]	74%	Number of chronic conditions > median 4: attendees = 47%; non-attendees = 42%	Attendees: 36% > median 60; Non-attendees: 30% > median 60
Druss [19]	RCT	NR	80	PAM-13	84%	$7704 [$2520, $12,306]	NR	All participants had a severe mental illness and one or more chronic medical conditions	**Baseline:** Intervention: 48 (SD = 12) Usual care: 48 (SD = 12); **6-months:** Intervention: 52 (SD = 10) Usual care: 45 (SD = 10)
Druss [20]	RCT	NR	170	PAM-22	85%	$6966 (SD = $4985)	NR	Intervention: mean = 2.3 (SD = 1.5) Usual care: mean = 2.3 (SD = 1.3)	**Baseline:** Intervention: 56 (SD = 14) Usual care: 56 (SD = 14) **12-month:** Intervention: 59 (SD = 13) Usual care: 59(SD = 16)
Evangelista [21]	RCT	CA	42	PAM-13	48%	NR	41%	Charlson Comorbidity Index = 3.4 (1.4)	**Baseline:** Intervention: 38 (SD = 7) Standard care: 38 (SD = 7) **3-month:** Intervention: 54 (SD = 9) Standard care: 43(SD = 7)

Table 2 (continued)

Author	Study design	Location(s)	Sample size	PAM version	% non-White	% low income or mean annual income[a]	% low educational attainment[b]	% ≥2 chronic conditions or mean # of chronic conditions ≥2	Mean PAM score(s)[c]
Kawi [22]	Cross-sectional	NV	230	PAM-22	50%	47%[g]	46%	Mean = 4.1 (SD = 3)	58 (SD = 16)
Maeng [23]	Cross-sectional	17 communities across the U.S.	10,038	PAM-13	40%	42%[e]	Mean years of education = 14 (SD = 3)	42%	Stage 1 = 7% Stage 2 = 19% Stage 3 = 34% Stage 4 = 41%[h]
Skolasky [24]	Psychometric	Baltimore—DC area	855	PAM-13	~ 50%[i]	~50%[e,i]	26%[j]	Mean = 4	57 (SD = 13)

NR not reported

[a] Low income is defined as at least 33% of the sample had an annual income of ≤$25,000

[b] Low education attainment is defined as at least 33% of the sample completed high school or less

[c] Values have been rounded to the nearest whole number

[d] Personal communication with author

[e] Studies that reported ≤$30,000

[f] Percentage of sample who reported "financial strain" defined as "not enough money to make ends meet" at the end of each month (compared with some money left over or just enough to make ends meet)

[g] 47% reported income <$15,000; 75% reported income <$35,000

[h] Based on the PAM score (0 to 100), respondents are assigned to one of four "stages" of activation where the first stage corresponds to the lowest level of activation and the fourth stage corresponds to the highest level

[i] Authors only reported approximations

[j] Only reported percent of respondents who had less than a high school education

exercising, even during times of stress) as inappropriate, indicating that patients may not be confident or able to make lifestyle changes with a recent diagnosis [27]. As suggested by the authors, the PAM may not be relevant for an acute hospital setting. Moreover, Schmaderer et al. conducted a confirmatory factor analysis (CFA) to assess whether PAM is a "unidimensional instrument measuring the overarching construct of being in charge of one's health." The CFA found that "a single-factor structure of the PAM did not fit well in this population," suggesting an instrument that can assess additional dimensions (e.g., appointment logistics, meeting basic needs) not considered by the PAM would be more useful. Taken together, these studies suggest that PAM may not be an appropriate measure for chronically ill, older, and low-literacy populations of color.

Discussion

The primary goal of the current review was to determine whether, and to what extent, the PAM and PEI measures have been administered, tested, and validated in populations whose characteristics mirror those of HNHC patients receiving care in U.S. urban safety net settings, and whether the measures could discern changes in activation and enablement, respectively, in this population. Our results indicated that research on patient activation is not commonly conducted on racially and ethnically diverse, low SES, and multimorbid patients in the U.S.; therefore, there were few opportunities to assess the appropriateness of the PAM in such populations. While recent studies using the PAM have documented its ability to predict important outcomes such as patient satisfaction, hospitalizations and emergency department use [28], and overall cost of care [29], PAM studies are still by and large conducted among White, college educated, and insured samples reporting higher incomes and good to excellent health.

Despite less documented use of the PAM in underserved populations, the PAM is recognized as the gold standard for assessing a person's health management abilities [30, 31]. It is widely deployed by major health systems, hospitals, insurers, and population health organizations in the U.S. and England to measure and improve health outcomes and reduce costs by improving patient-centered care. As part of the Centers for Medicare and Medicaid Services (CMS) shifts toward a value-based care reimbursement model, the PAM was identified as a Merit-based Incentive Payment System (MIPS) measure within the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) [32]. Implementation of the PAM seeks to help clinicians and other healthcare professionals meet MIPS requirements while increasing patient activation in a number of states including New York and Washington. In New York State, the administration of the PAM through the Delivery System Reform Incentive Payment (DSRIP) program mechanism seeks to "fundamentally restructure the health care delivery system by reinvesting in the Medicaid program, with the primary goal of reducing avoidable hospital use by 25% over 5 years" [33, 34]. Similarly, the Washington State Health Homes Program, part of HealthPath Washington's Medicare–Medicaid initiatives, which provides care coordination services to HNHC Medicaid and Medicare/Medicaid dually eligible patients, requires care coordinators to administer the PAM and based on the PAM score, develop a tailored healthcare action plan [35]. Washington State's Health Homes Program predicts a 6% savings, or $21.6 million, in Medicare spending by focusing on patient activation [35].

Likewise, as part of the National Health Service (NHS) Five Year Forward View, which sets out to better help people manage their health and grant greater access to person-centered care in England, local NHS organizations and their partners were provided free access to PAM licenses with the expectation that "measuring and supporting improvements in patient activation will lead to patients having better outcomes, improved patient experience, increased engagement in healthier behavior (such as those linked to smoking and obesity), and fewer episodes of unplanned and emergency care" [36, 37]. An interim report from the independent evaluation of the PAM by the University of Leicester sought to provide insights about the PAM in order to "support the wider roll-out of [the] patient activation measurement" under the NHS Self-Care Program [37]. Notably, given the scope of this paper, the report identified "some concerns about the appropriateness of using PAM as an outcome measure" among "patients with comorbidities" who may provide variable answers "depending on which health condition they are most focused on" [37]. In addition, the report posited that a program could "deliver no immediately measurable change in PAM score yet still be effective" [37]. Indeed, anecdotal experience from care management programs supporting HNHC patients located in safety net

institutions indicates that although patients do progress in terms of their willingness and ability to manage their own health issues, the PAM does not register improvements that care management staff feel to be real. Given the system-wide deployments of the PAM by Medicaid and the NHS England, there is a need to ensure that the tool, used to capture the extent to which people feel engaged and confident in taking care of their health, accurately assesses patient progress in a diversity of settings, including the urban safety net. An appropriate tool for the measure of patient activation is needed in the urban safety net care setting for HNHC patients.

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