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Outcomes for Children with Chronic Conditions Associated with Parent- and Provider-reported Measures of the Medical Home

Jean L. Raphael, MD, MPH,

Department of Pediatrics, Baylor College of Medicine, Academic General Pediatrics, Houston, TX

W. Carl Cooley, MD,

Center for Medical Home Improvement, Crotched Mountain Foundation, Greenfield, NH and the Department of Pediatrics and Psychiatry, Dartmouth Medical School, Hanover, NH

Amanda Vega, BA,

Department of Pediatrics, Baylor College of Medicine, Academic General Pediatrics, Houston, TX

Marc A. Kowalkowski, PhD,

Department of Medicine, Baylor College of Medicine, Houston, TX

Xuan Tran, MHA,

Texas Children's Health Plan, Houston, TX

Janet Treadwell, MSN, PhD,

Texas Children's Health Plan, Houston, TX

Angelo P. Giardino, MD, PhD, MPH, and

Department of Pediatrics, Baylor College of Medicine, Academic General Pediatrics, Houston, TX and the Texas Children's Health Plan, Houston, TX

Thomas P. Giordano, MD, MPH

Department of Medicine, Baylor College of Medicine, Houston, TX

Abstract

Purpose—Assess relationships between having a patient-centered medical home (PCMH) and health care utilization among low-income children with chronic conditions using parent and practice perspectives.

Methods—We analyzed data from 240 publicly insured children with chronic conditions. Parents completed surveys assessing PCMH access and their child's primary care practice completed the Medical Home Index (MHI) self-assessment. Multivariate negative binomial analyses were conducted to investigate relationships between PCMH and service use.

Results—Parent-report of a usual source of care was associated with lower rates of emergency care (ED) encounters and hospitalizations. Practice report of higher organizational capacity (e.g., communication, staff education) was associated with lower rates of ED visits and hospitalizations. Parent report of a PCMH was positively associated with practice MHI score.

Jean L. Raphael is the corresponding author and can be reached at Suite 1540.00; Texas Children's Hospital; 6701 Fannin Street Houston, TX 77030; (832) 822-1791; Raphael@bcm.edu.

Conclusions—Among low-income children with chronic conditions, having a usual source of care and higher quality organizational capacity were associated with lower rates of ED visits and hospitalizations.

Keywords

Medical home; primary care; children; disparities

The patient-centered medical home (PCMH) is emerging as a cornerstone of efforts to reform chronic disease management in the U.S. health care system and transform primary care into a centerpiece for improving health care quality. ^{1–4} Built upon the core principles of primary care, the PCMH has evolved into a conceptual framework for an integrated health care delivery system. ^{5,6} The American Academy of Pediatrics describes the PCMH as a model of care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. ⁷ While the PCMH is recommended for all children, its implementation may be particularly relevant for children with chronic conditions who have a diverse set of medical needs and account for a significant proportion of medical expenditures among the general pediatric population. ^{8–10}

Over the past decade, the pediatric literature on the PCMH for children with chronic conditions has rapidly advanced, largely due to the availability of large, population-based surveys on children. Survey instruments, including the National Survey of Children's Health¹¹ and the National Survey of Children with Special Health Care Needs,¹² have provided researchers and policymakers the ability to assess relationships between parent-reported experience with a PCMH and health outcomes. Such studies have found the PCMH to be associated with increased utilization of primary care services¹³ and decreased emergency care encounters,^{14,15} family burden,¹⁶ and out-of-pocket expenses.¹⁷

While these studies have contributed new insights to the evidence base supporting the PCMH for children with chronic conditions, they have been lacking in key areas. First, they rely entirely on parent report for health outcomes and are therefore subject to recall bias. Second, these studies have largely lacked any practice report of PCMH. Third, few studies have focused on the PCMH experience of racial/ethnic minority and low-income children with chronic conditions. ^{15,18–20} More targeted study of these underserved groups of children is warranted given that the demographic makeup of U.S. children increasingly comprises greater proportions of children belonging to racial/ethnic minority groups and children from low-income households. ^{21,22}

Obtaining PCMH feedback from multiple stakeholders—families and practices—may help to generate comprehensive insights on what PCMH activities lead to better outcomes. The aims of this study were 1) to assess the PCMH experience of low-income children with chronic conditions and 2) to determine associations with health care utilization, using a combination of parent-report, primary care practice self-assessment, and administrative claims data.

Methods

We conducted a cross-sectional, retrospective analysis of administrative claims data from Texas Children's Health Plan (TCHP), a managed care organization and the largest insurance provider for children with Medicaid and State Children's Insurance Program (SCHIP) in Houston, Texas. The TCHP database contains comprehensive enrollment, demographic, clinical, and financial data on over 300,000 members annually, all of whom are publicly insured. Members within the TCHP database have unique medical identification numbers, allowing patients to be followed over time. Study methods were reviewed and approved by the Institutional Review Board of Baylor College of Medicine. Informed consent and child assent (when appropriate) were obtained for all participants.

Study population

Health plan members—Members with chronic conditions were identified according to a published algorithm in which pediatric chronic conditions are defined categorically on the basis of *International Classification of Diseases 9th Revision Clinical Modification* (ICD-9) diagnosis codes most prevalent and chronic among Medicaid and commercially-insured children. ^{23–25} This tracer methodology allows for focused investigation of selected conditions. Based on previous pediatric studies using this approach, ^{23–25} we generated a representative list of chronic conditions: asthma, attention deficit hyperactivity disorder (ADHD), autism, cerebral palsy, cystic fibrosis, diabetes, seizure disorder, and sickle cell disease. These chronic conditions constitute the full list of conditions selected for this study. To qualify for inclusion, a member was required to have two claims with the ICD-9 code in the last 12 months.

Sample size was determined using previously published data on access to PCMH and emergency care (ED) utilization.¹⁵ To find a minimum detectable difference of 18% for ED utilization between those with and without aspects of a PCMH, we determined that 220 subjects were required, assuming power = 80% and a two-sided significance test with an alpha of .05. A one-time query of the TCHP database was conducted in August 2011 for members, 1–17 years of age, meeting the above categorical criteria for chronic conditions, and having continuous enrollment at TCHP for the previous 12 months (Figure 1). As shown in the figure, the majority of children with one of the eight selected conditions did not meet eligibility criteria due to lack of continuous enrollment for 12 months. In total, 452 children met complete inclusion criteria. We attempted to contact the households of all 452 children eligible for the study. Parents were initially informed of the study by TCHP staff by telephone. Those interested in participating were subsequently recruited by the research coordinator. Parents were asked to complete a survey instrument by phone and provide consent for review of their child's administrative claims record for the 12 months prior to survey completion.

Primary care practices—After parents completed the survey instrument, their child's assigned primary care practice for the past 12 months as documented by TCHP was contacted by TCHP Physician Relations representatives for participation. If the practices agreed to participate, they were provided a survey packet with instructions for its completion

by a practice leader and staff. Cross-validation of TCHP assigned primary care practices with parent-report was not conducted since TCHP members are restricted to their assigned practices.

Measures

Parent survey—The parent survey was administered to families and consisted of 38 questions about the child, the family, and the primary care practice. The survey included questions regarding experiences with different components of a PCMH, all of which were taken directly from the 2005/2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). The remaining survey items on demographic characteristics were also derived from the NS-CSHCN.¹² Surveys were administered in both English and Spanish. Families were given a \$20 gift card for completing the survey.

We assessed PCMH items reflective of the AAP criteria for a PCMH using questions from the 2005/2006 NS-CSHCN. ²⁶ Of the 19 PCMH-based questions in the NS-CSHCN, we selected a representative subset of 10 questions that assessed facets of having a regular provider, comprehensive care, family-centered care, coordinated care, and culturally effective care. While other measures of the PCMH exist, ²⁷ the NS-CSHCN was selected for several reasons. First, it examines multiple aspects of the PCMH concept, allowing evaluation of a wide spectrum of primary care functions. Second, numerous population-based studies have used this measure, providing the opportunity to compare findings. Lastly, the NS-CSHCN definition of the PCMH has been endorsed by the National Quality Forum. ²⁸

The survey also collected data on child covariates including age, race/ethnicity, gender, and parent-reported child health status. Race/ethnicity was defined as non-Hispanic White, non-Hispanic Black, Hispanic, and non-Hispanic Other (hereafter White, Black, Hispanic, Other). To assess health status, we used the NS-CSHCN question asking parents, "Overall, how would you rate the severity of difficulties caused by child's health problems? Would you say minor, moderate, or severe?" Parent covariates surveyed included relationship to child, primary parent status, employment status, education level, and household primary language.

Practice survey—The Medical Home Index (MHI) is a validated, self-administered, quality improvement instrument designed to translate the broad indicators defining a PCMH into tangible behaviors and processes of care within a primary care setting. ²⁹ The MHI contains 25 themes organized into 6 domains: (1) organizational capacity; (2) chronic condition management; (3) care coordination; (4) community outreach; (5) data management; and (6) quality improvement (Table 1). All 25 MHI items are scored on a scale of 1 to 8, with higher scores representing more comprehensive care. Possible domain score ranges are shown in Table 1. Mean item scores were calculated for the entire MHI as well as domains comprising the MHI. The overall MHI score was standardized on a scale of 1 to 100, with higher scores indicating better delivery of PCMH functions. Practices were not offered incentives to complete the MHI given that TCHP affiliated practices historically participated in similar assessments without compensation and the logistical challenges of

distributing incentives in practices where multiple individuals contributed to MHI completion.

Utilization review—We abstracted utilization claims data for all children for the 12 months prior to parent survey completion. We collected all data on ED and inpatient encounters.

Data analysis

Statistical analyses were performed using SAS® 9.2 (SAS Institute Inc, Cary, NC). Summary statistics were used to determine the percentage of children with chronic conditions having access to individual components of a PCMH. Multivariate negative binomial regression analyses, which can correct for over-dispersed count data, were used to assess associations between PCMH items (parent report, MHI) and health care utilization. Through a series of multivariate regression analyses, the primary independent variables (PCMH items) were systematically evaluated to determine their relationships with ED encounters and hospitalizations. Separate regression models were created for each individual parent-reported PCMH item (10 models), overall practice MHI score (one model), and each individual MHI domain (seven models) with the two utilization categories as the dependent variable. Results were calculated as incidence rate ratios (IRRs) for the number of encounters per child with 95% confidence intervals (95% CI). All analyses were controlled for child and parent co-variables.

We also conducted exploratory analyses using the Wilcoxon signed-rank test to assess associations between components from the parent-reported PCMH items and the overall practice-based MHI. This analysis was conducted for the subset of children who had both parent survey data and practice MHI data (n= 135). For parent-reported items, we created a composite score from the 10 items that measured parent-reported PCMH experience in this study. We allotted one point for each of parent's 10 responses related to the presence of key variables (e.g., regular provider [Yes vs. No]), care coordination (Usually/Always vs. Sometimes/Never), satisfaction with communication (Very Satisfied/Somewhat Satisfied vs. Somewhat Dissatisfied/Very Dissatisfied) or the absence of certain barriers (e.g., problems with referrals [None vs. Small/Big]). The maximum possible score was 10. For practice overall MHI scores, we designated the highest quartile (75%) as high scores and scores below the highest quartile (<75%) as low scores. We compared the mean parental composite score for PCMH items in a specific practice with the practice reported MHI score for that practice. To assess for potential bias in practices completing the MHI versus those that did not, we also compared the mean parental composite score for PCMH between participating practices and those refusing study participation.

Results

Patient and family demographic characteristics

Of the 259 parents whom we reached, 240 agreed to complete the survey instrument, yielding a participation rate of 53% overall and 93% among parents we could contact (Figure 1). Socio-demographic characteristics of the study participants are shown in Table 2.

Mean child age was 8.9 years. The majority of children were Hispanic (68.3%). Almost half the sample of children was reported to experience health problems of moderate severity. There were no statistically significant differences in demographics between children in the study and those who could not be reached or refused participation.

Parent-reported experience with PCMH

The results showed wide variation in receipt of PCMH components (Table 3). Over 95% of children were reported to have a regular provider and over 90% had a usual source of care. For family-centered care, greater than 80% of parents reported that their provider usually/always spends enough time, listens carefully, and provides needed information. For care coordination, 52% of parents reported that they got help as wanted in coordinating care. Less than 30% of parents were very satisfied with the communication between their health care providers.

Primary care practices and MHI

Of the 122 practices that accounted for the study sample of 240 children, 51 (n=135 children) completed the MHI, yielding a practice participation rate of 42%. The remaining 71 practices (n=105 children) either never responded to requests or refused to complete the MHI citing lack of time or prior completion. Of the 51 practices completing the MHI, the majority (28/51) were multi-provider practices while the remainder (23/51) were single provider. The mean panel size of TCHP members for these practices was 1,496 (range 1,300–2,000). There were no statistically significant differences between participating practices and those refusing participation in panel size or number of providers. Table 4 presents the descriptive information for MHI scores. Higher scores indicated greater levels of medical home-ness. For individual domains, mean scores were highest for organizational capacity and care coordination and lowest for community outreach.

Associations between PCMH and health care utilization

Thirty-two percent of children had one or more ED encounters while 60.4% had one or more hospitalizations. Both patient report of PCMH items and MHI were separately assessed for their association with documented health care utilization in multivariate regression models. Having a usual source of care per parent-report was associated with a lower rate of documented ED visits and hospitalizations (Table 5). While overall MHI summary score was not associated with health care utilization, mean domain scores showed variable relationships. Higher mean score for organizational capacity was significantly associated with both lower rates of ED visits and hospitalizations (Table 6). Higher data management mean score was significantly associated with lower rates of ED visits. Higher chronic condition management mean score was significantly associated with a higher rate of ED visits.

Association between parent-report of PCMH and practice MHI

A significant relationship was found between the parent-reported composite of PCMH items and the practice overall MHI score. The parent-reported composite mean was 7.46 (95% CI 7.12–7.80) for practices with low overall MHI scores and 8.23 (95%CI 7.76–8.71) for

practices with high overall MHI scores (p=.02). In comparison of practices completing the MHI and those refusing, the parent-reported composite mean was 7.66 (95%CI=7.38–7.94) for participating practices and 7.48 (95%CI=7.12–7.84) for non-participating practices (p=.63).

Discussion

While numerous survey-based studies have highlighted the potential benefits of the PCMH for children with chronic conditions, this study builds on prior work by focusing on underserved children, utilizing feedback from multiple stakeholders, and employing administrative claims as a source for health outcomes. Several general findings among our sample of underserved children were notable. Over 95% of parents reported that their children had a regular provider. Although the percentage of children with a regular provider might be anticipated to be lower among marginalized populations, this study's finding is supported by multiple population-based studies of children with special health care needs. In prior studies, 87-94% of these children are reported to have a regular provider, regardless of race/ethnicity, household income, or primary household language. 30,31 These high percentages may be due to children with chronic conditions having more frequent contact with the health care system secondary to medical need. In our study, a minority of parents reported being very satisfied with the communication surrounding care coordination. These findings are consistent with prior work demonstrating that only half of children with special health care needs are reported to receive comprehensive and coordinated care through a PCMH.³⁰ However, poor care coordination for low-income and racial/ethnic minority children with chronic conditions poses additional challenges given that these children already encounter barriers related to access and navigation through a complex health care system.

Our study found several associations between components of a PCMH and health care utilization. Among patient experience measures, parent report of a usual source of care was associated with lower rates of ED encounters and hospitalizations. This finding has been supported by previous studies that also show lower rates of acute care encounters among those reporting a usual source of care.³² From the practice perspective, MHI mean domain scores demonstrated variable associations with utilization. Higher organizational capacity was associated with lower rates of ED encounters and hospitalizations while higher quality chronic condition management was associated with higher rates of ED encounters. Organizational capacity is defined as the practice's commitment to patient-centered care as demonstrated by solicitation of patient feedback, multiple mechanisms for communication with families, patient access to medical records, and continual staff education and training. In previous studies, characteristics of organizational capacity, including access and communication, have been associated with lower rates of non-urgent ED utilization.³³ While the results regarding organizational capacity were anticipated, the relationship between chronic condition management and utilization was surprising. It may be that practices with highly effective chronic condition management may attract more medically complex, potentially high resource using children.

Our results differ from a previous study by Cooley *et al.* in which higher MHI scores and higher domain scores for organizational capacity, care coordination, chronic-condition management, and data management (availability of electronic data system, production of electronic reports to measure quality) were associated with lower hospitalization rates for children with chronic conditions.²⁴ Higher mean scores for the chronic condition management and care coordination domains on the MHI were also associated with lower ED rates in the Cooley study. While the work by Cooley *et al.* comprised a larger study sample for utilization review (880 children), the findings were modest and influenced by the two most prevalent conditions (asthma and ADHD) which made up approximately 90% of the children who underwent utilization review.

Although our study found several relationships between PCMH items and health care utilization, the majority of PCMH items (both parent and practice) did not show associations with utilization. Several reasons may explain these negative findings. First, it is possible that while some encounters may be preventable, others are not, especially for children with chronic conditions who may have illnesses that require more urgent attention. We did not have data available to determine whether encounters were preventable. Second, it is possible that our sample size was not sufficiently large enough to detect small differences. Third, it is possible that the PCMH components measured do not influence health care utilization. A recent systematic review has shown mixed findings regarding the association between PCMH measures and utilization.³⁴

Several associations found between PCMH and utilization were unexpected and may represent spurious results. Parents who were somewhat satisfied with communication between their provider and the community had higher ED visit rates for their children relative to those who were very satisfied with communication. It would be expected that more satisfaction would be associated with lower ED encounter rates. Among MHI domains, community outreach was positively associated with a higher rate of ED encounters. An inverse relationship would have been expected given the assumption that more community outreach by a practice to provide children with services would decrease ED use. No previous studies support our findings between communication satisfaction, community outreach and ED use. Larger studies are warranted to determine if these findings are spurious.

In our exploratory analysis, parent-report of a PCMH was positively associated with practice MHI score. To our knowledge, this is the first study to demonstrate a relationship between parent- and practice-report of a PCMH. A previous study found poor correlations between family perceptions of care and the MHI.²⁴ Our novel finding is significant in that it indicates some overlap in what parents and practices determine to be a high quality PCMH. Future studies with more rigorous methodology are necessary to gain greater understanding of the correlations between parent- and practice-report. While use of both practice self-assessment and patient experience offers a comprehensive strategy for assessing PCMH, practical implementation of this strategy remains a challenge for policy makers.^{35,36} Assessing PCMH status by measuring a practice's standard structural components and a patient's perception may yield different results. At the state level, Medicaid and CHIP agencies are taking different approaches to measuring the PCMH construct. Many states are currently

measuring the structural elements of PCMH through the National Committee for Quality Assurance Physician Practice Connections-Patient Centered Medical Home (NCQA PPC-PCMH) tool—either alone or in combination with other state requirements. Given concerns about the specificity of the NCQA PPC-PCMH for pediatrics and its limited attention to family-centeredness of care, other state pilot programs have elected to develop their own medical home recognition standards, employing both structural and consumer experience data. ³⁵

This study had a number of strengths including a specific focus on low-income and largely minority children with chronic conditions, the combination of both parent and practice report measures of medical home-ness, and the use of claims data for outcomes. However, several limitations of the study should be noted. First, the number of subjects eligible for this study was significantly limited by failure of potential subjects to meet the 12-month continuous eligibility criterion. The substantial turnover in the publicly insured population observed in this study has been well documented in prior studies. ^{37,38} While our study findings showed deficiencies in PCMH care for enrolled subjects, the outcomes for those who did not meet eligibility criteria due to continuous enrollment may be worse due to turnover or gaps in coverage. Future studies should assess PCMH among those with disruptions in health care coverage.

Second, our study sample size was small relative to national population studies of children assessing experience with a PCMH. Third, our measures of PCMH differ from other instruments. Although endorsed by NQF, the PCMH measure from the NS-CSHCN differ from other measures both in terms of components assessed and validation of its contents. We did not use all the PCMH questions from the NS-CSHCN due to concerns regarding survey burden. It is possible that our selection of questions introduced bias into the study. While the MHI has historically provided a measure by which primary care practices can improve care quality, the number of available tools to measure and certify the structural elements of the PCMH has rapidly expanded. Alternative choices to measure family experience included the Medical Home Family Index (MHFI), Consumer Assessment of Healthcare Providers and Systems (CAHPS), and Clinical and Group Consumer Assessment of Healthcare Providers and Systems (CG-CAHPS). We chose to use the MHI given its wide use in pediatrics and limited assessment of patient-centeredness with other tools (e.g., NCQA PPC-PCMH). Fourth, because the individual practices participated voluntarily, selection bias may have affected the results. Fifth, while claims data may provide more objective data relative to parent report, it is subject to misclassification and coding errors. Lastly, due to its cross-sectional design, this study could not determine causality.

Conclusions

Despite limited data demonstrating health outcomes associated with PCMH care for low-income children with chronic conditions, state Medicaid and CHIP agencies continue to advance medical homes through implementation of pediatric demonstration projects. Such programs will largely influence the design of primary care practices and the alignment of incentives and reimbursement with performance. This study demonstrated that measurement of the PCMH through consumer experience, practice structure, and documented health

outcomes provides a comprehensive strategy for assessing and guiding system improvement. Based on our study, key PCMH components for reducing health care utilization include having a usual source of care, organizational capacity, and data management. Future studies should be prospective in nature with larger sample sizes to determine the long-term impact of PCMH care for vulnerable children with chronic conditions. Further studies are also warranted to assess how having a PCMH could have different meanings for parents of children with different conditions.

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References

- 1. Landon BE, Gill JM, Antonelli RC, et al. Prospects for rebuilding primary care using the patient-centered medical home. Health Aff (Millwood). 2010 May; 29(5):827–34. http://dx.doi.org/10.1377/hlthaff.2010.0016. [PubMed: 20439868]
- 2. Rittenhouse DR, Thom DH, Schmittdiel JA. Developing a policy-relevant research agenda for the patient-centered medical home: a focus on outcomes. J Gen Intern Med. 2010 Jun; 25(6):593–600. http://dx.doi.org/10.1007/s11606-010-1289-x. [PubMed: 20467908]
- 3. Homer CJ, Cooley WC, Strickland B. Medical home 2009: what it is, where we were, and where we are today. Pediatr Ann. 2009 Sep; 38(9):483–90. http://dx.doi.org/10.3928/00904481-20090820-06. [PubMed: 19772234]
- 4. Zickafoose JS, Clark SJ, Sakshaug JW, et al. Readiness of primary care practices for medical home certification. Pediatrics. 2013 Mar; 131(3):473–82. Epub 2013 Feb 4. http://dx.doi.org/10.1542/peds.2012-2029. [PubMed: 23382438]
- Stille C, Turchi RM, Antonelli R, et al. The family-centered medical home: specific considerations for child health research and policy. Acad Pediatr. 2010 Jul-Aug;10(4):211–7. http://dx.doi.org/ 10.1016/j.acap.2010.05.002. [PubMed: 20605546]
- McAllister JW, Cooley WC, Van Cleave J, et al. Medical home transformation in pediatric primary care—what drives change? Ann Fam Med. 2013 May-Jun;11(Suppl 1):S90–8. http://dx.doi.org/ 10.1370/afm.1528. [PubMed: 23690392]
- Medical Home Initiatives for Children With Special Needs Project Advisory Committee, American Academy of Pediatrics. . The medical home. Pediatrics. 2002 Jul; 110(1 Pt 1):184–6. [PubMed: 12093969]
- Cooley WC, McAllister JW. Building medical homes: improvement strategies in primary care for children with special health care needs. Pediatrics. 2004 May; 113(5 Suppl):1499–506. [PubMed: 15121918]
- Bethell CD, Read D, Brockwood K. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. Pediatrics. 2004 May; 113(5 Suppl):1529–37. [PubMed: 15121922]
- Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. Arch Pediatr Adolesc Med. 2005 Jan; 159(1):10–7. http:// dx.doi.org/10.1001/archpedi.159.1.10. [PubMed: 15630052]
- Data Resource Center for Child and Adolescent Health. National Survey of Children's Health (NSCH). Rockville, MD: Data Resource Center for Child and Adolescent Health; 2008. Available at: http://www.nschdata.org/learn/NSCH
- 12. Data Resource Center for Child and Adolescent Health. The National Survey of Children with Special Health Care Needs chartbook 2005–2006. Rockville, Maryland: Data Resource Center for Child and Adolescent Health; 2008. Available at: http://www.nschdata.org/learn/NS-CSHCN

13. Willits KA, Platonova EA, Nies MA, et al. Medical home and pediatric primary care utilization among children with special health care needs. J Pediatr Health Care. 2013 May-Jun;27(3):202–8. Epub 2012 Jan 13. http://dx.doi.org/10.1016/j.pedhc.2011.11.004. [PubMed: 22243921]

- 14. Willits KA, Nies MA, Racine EF, et al. Medical home and emergency department utilization among children with special health care needs: an analysis of the 2005–2006 National Survey of Children with Special Health Care Needs. J Ambul Care Manage. 2012 Jul-Sep;35(3):238–46. http://dx.doi.org/10.1097/JAC.0b013e318249c5ca. [PubMed: 22668613]
- 15. Raphael JL, Zhang Y, Liu H, et al. Association of medical home care and disparities in emergency care utilization among children with special health care needs. Acad Pediatr. 2009 Jul-Aug;9(4): 242–8. http://dx.doi.org/10.1016/j.acap.2009.05.002. [PubMed: 19608125]
- 16. Katz ML, Laffel LM, Perrin JM, et al. Impact of type 1 diabetes mellitus on the family is reduced with the medical home, care coordination, and family-centered care. J Pediatr. 2012 May; 160(5): 861–7. Epub 2011 Dec 1. http://dx.doi.org/10.1016/j.jpeds.2011.10.010. [PubMed: 22133424]
- Porterfield SL, DeRigne L. Medical home and out-of-pocket medical costs for children with special health care needs. Pediatrics. 2011 Nov; 128(5):892–900. Epub 2011 Oct 17. http:// dx.doi.org/10.1542/peds.2010-1307. [PubMed: 22007014]
- Raphael JL, Guadagnolo BA, Beal AC, et al. Racial and ethnic disparities in indicators of a primary care medical home for children. Acad Pediatr. 2009 Jul-Aug;9(4):221–7. Epub 2009 May 31. http://dx.doi.org/10.1016/j.acap.2009.01.011. [PubMed: 19487171]
- Raphael JL, Rattler TL, Kowalkowski MA, et al. The medical home experience among children with sickle cell disease. Pediatr Blood Cancer. 2013 Feb; 60(2):275–80. Epub 2012 Apr 22. http:// dx.doi.org/10.1002/pbc.24184. [PubMed: 22522496]
- Zickafoose JS, Davis MM. Medical home disparities are not created equal: differences in the medical home for children from different vulnerable groups. J Health Care Poor Underserved. 2013 Aug; 24(3):1331–43. http://dx.doi.org/10.1353/hpu.2013.0117. [PubMed: 23974402]
- 21. Horn IB, Beal AC. Child health disparities: framing a research agenda. Ambul Pediatr. 2004 Jul-Aug;4(4):269–75. http://dx.doi.org/10.1367/1539-4409(2004)4<269:CHDFAR>2.0.CO;2. [PubMed: 15264953]
- Addy, S.; Engelhardt, W.; Skinner, C. Basic facts about low-income children. New York, NY: National Center for Children in Poverty; 2013. Available at: http://www.nccp.org/publications/pdf/text_1074.pdf
- 23. Shatin D, Levin R, Ireys HT, et al. Health care utilization by children with chronic illnesses: a comparison of Medicaid and employer-insured managed care. Pediatrics. 1998 Oct.102(4):E44. http://dx.doi.org/10.1542/peds.102.4.e44. [PubMed: 9755281]
- 24. Cooley WC, McAllister JW, Sherrieb K, et al. Improved outcomes associated with medical home implementation in pediatric primary care. Pediatrics. 2009 Jul; 124(1):358–64. http://dx.doi.org/10.1542/peds.2008-2600. [PubMed: 19564320]
- 25. Ireys HT, Anderson GF, Shaffer TJ, et al. Expenditures for care of children with chronic illnesses in the Washington State Medicaid program, fiscal year 1993. Pediatrics. 1997 Aug; 100(2 Pt 1): 197–204. http://dx.doi.org/10.1542/peds.100.2.197. [PubMed: 9240799]
- 26. The Child and Adolescent Health Measurement Initiative. Measuring medical home for children and youth: methods and findings from the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health. Rockville, Maryland: Data Resource Center for Child and Adolescent Health; 2009. Available at: http://www.childhealthdata.org/docs/medical-home/mhmanual_withappendices-updated-12-7-10-pdf.pdf
- 27. Malouin, RA.; Merten, SL. Measuring medical homes: tools to evaluate the pediatric patient and family-centered medical home. Elk Grove Village, IL: National Center for Medical Home Implementation; 2010. Available at: http://www.medicalhomeinfo.org/downloads/pdfs/MonographFINAL3.29.10.pdf
- 28. National Quality Forum. Measure of medical home for children and adolescents. Washington, DC: National Quality Forum; 2015. Available at: http://www.qualityforum.org/MeasureDetails.aspx? actid=0&SubmissionId=84#k=medical+home
- 29. Cooley WC, McAllister JW, Sherrieb K, et al. The Medical Home Index: development and validation of a new practice-level measure of implementation of the Medical Home model. Ambul

- Pediatr. 2003 Jul-Aug;3(4):173–80. http://dx.doi.org/ 10.1367/1539-4409(2003)003<0173:TMHIDA>2.0.CO;2. [PubMed: 12882594]
- 30. Strickland BB, Singh GK, Kogan MD, et al. Access to the medical home: new findings from the 2005–2006 National Survey of Children with Special Health Care Needs. Pediatrics. Jun; 123(6):e996–1004. 200. [PubMed: 19482751]
- 31. Strickland BB, Jones JR, Ghandour RM, et al. The medical home: health care access and impact for children and youth in the United States. Pediatrics. 2011 Apr; 127(4):604–11. Epub 2011 Mar 14. http://dx.doi.org/10.1542/peds.2009-3555. [PubMed: 21402643]
- 32. Ryan S, Riley A, Kang M, et al. The effects of regular source of care and health need on medical care use among rural adolescents. Arch Pediatr Adolesc Med. 2001 Feb; 155(2):184–90. http://dx.doi.org/10.1001/archpedi.155.2.184. [PubMed: 11177095]
- 33. Brousseau DC, Hoffmann RG, Nattinger AB, et al. Quality of primary care and subsequent pediatric emergency department utilization. Pediatrics. 2007 Jun; 119(6):1131–8. http://dx.doi.org/10.1542/peds.2006-3518. [PubMed: 17545380]
- 34. Peikes D, Zutshi A, Genevro JL, et al. Early evaluations of the medical home: building on a promising start. Am J Manag Care. 2012 Feb; 18(2):105–16. [PubMed: 22435838]
- 35. Sternberg SB, Co JP, Homer CJ. Review of quality measures of the most integrated health care settings for children and the need for improved measures: recommendations for initial core measurement set for CHIPRA. Acad Pediatr. 2011 May-Jun;11(3 Suppl):S49–S58.e3. [PubMed: 21570017]
- Co JP, Sternberg SB, Homer CJ. Measuring patient and family experiences of health care for children. Acad Pediatr. 2011 May-Jun;11(3 Suppl):S59–67. http://dx.doi.org/10.1016/j.acap. 2011.01.009. [PubMed: 21570018]
- 37. Carrasquillo O, Himmelstein DU, Woolhandler S, et al. Can Medicaid managed care provide continuity of care to new Medicaid enrollees? An analysis of tenure on Medicaid. Am J Public Health. 1998 Mar; 88(3):464–6. http://dx.doi.org/10.2105/AJPH.88.3.464. [PubMed: 9518985]
- 38. Sommers BD. From Medicaid to uninsured: drop-out among children in public insurance programs. Health Serv Res. 2005 Feb; 40(1):59–78. http://dx.doi.org/10.1111/j. 1475-6773.2005.00342.x. [PubMed: 15663702]

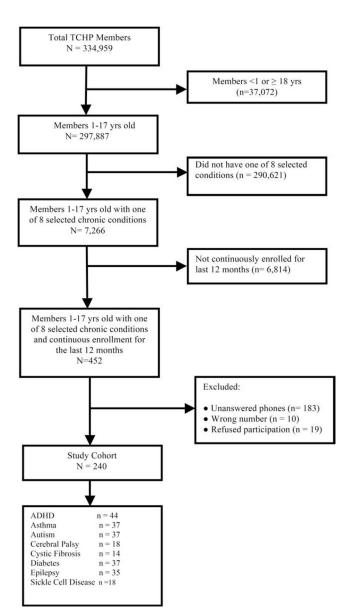


Figure 1. Patient enrollment algorithm.

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Table 1

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MEDICAL HOME INDEX DOMAINS AND THEMES

Domains	Score Range	Themes	
1. Organizational capacity	(7–42)	1.1	Mission of the practice
		1.2	Communication/access
		1.3	Access to medical records
		1.4	Office environment
		1.5	Family feedback
		1.6	Cultural competence
		1.7	Staff education
2. Chronic condition management	(6–24)	2.1	Identification of CSHCN
		2.2	Care continuity
		2.3	Continuity across settings
		2.4	Cooperative management with specialists
		2.5	Supporting transition to adult services
		2.6	Family support
3. Care coordination	(6–24)	3.1	Role definition
		3.2	Family involvement
		3.3	Child and family education
		3.4	Assessment of needs/plans of care
		3.5	Resource information and referrals
		3.6	Advocacy
4. Community outreach	(2–16)	4.1	Community assessment of needs of CSHCN
		4.2	Community outreach to agencies and schools
5. Data management	(2–16)	5.1	Electronic data support
		5.2	Data retrieval capacity
6. Quality improvement	(2–16)	6.1	Quality standards (structures)
		6.2	Quality activities (processes)

Note: CSHCN = Children with Special Health Care Needs

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Table 2

CHILD AND PARENT CHARACTERISTICS OF PARTICIPATING FAMILIES (N=240)

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Variable	Overall N (%)			
Child characteristics				
Age in years				
Mean (SD)	8.9 (4.8)			
Race				
White	27 (11)			
Black	47 (20)			
Hispanic	164 (68)			
Other	2(1)			
Gender				
Male	141 (59)			
Female	99 (41)			
Severity of difficulties due to health condition				
Mild	45 (19)			
Moderate	110 (46)			
Severe	85 (35)			
Parent characteristics				
Relationship to child				
Parent	228 (95)			
Grandparent	4(2)			
Legal guardian	3 (1)			
Other	5 (2)			
Primary caregiver				
Yes	238 (99)			
No	2(1)			
Employment status				
Employed	141 (59)			
Unemployed	99 (41)			
Education				
< High school	120 (50)			
High school diploma/GED	75 (31)			
Some college	35 (15)			
College and above	10 (4)			
Primary language				
English	119 (49)			
Spanish	119 (49)			
Other	2 (2)			

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 $\label{table 3} \textbf{PARENT PERCEPTIONS OF EXPERIENCE WITH A PATIENT-CENTERED MEDICAL HOME}$

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General Domain ^a	% (N)
Has Personal Provider	96 (230/240)
Comprehensive Care	
Referral not a big problem if needed	88 (125/142)
Usual source of care	91 (218/240)
Family Centered Care	
Spent enough time b	81 (195/240)
Listened carefully b	88 (211/240)
Provided needed information b	88 (211/240)
Care Coordination (if needed)	
Got help coordinating care b	52 (125/240)
Very satisfied with communication among providers	28 (68/240)
Satisfied with communication between provider and outside programs/school	52 (124/240)
Culturally Effective Care	
Sensitive to family's values and $customs^b$	88 (210/240)

 $^{^{}a}$ If specific services were not needed, dominators reflect total population having the need.

 $b_{\mbox{Responses}}$ were Usually/Always (vs. Sometimes/Never).

Table 4
SUMMARY OF MEDICAL HOME INDEX SCORES FOR PARTICIPATING PRACTICES

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Measurement	Mean (SD)	Median	Minimum	Maximum
MHI (n=51 practices)				
MHI standard summary score	63.5 (16.3)	67.5	30.0	92.5
Domain score				
Organizational capacity	5.2 (1.1)	5.4	2.0	7.1
Chronic condition management	5.0 (1.4)	5.3	2.2	7.8
Care coordination	5.3 (1.6)	5.8	1.3	8.0
Community outreach	4.3 (2.0)	4.5	1.0	8.0
Data management	5.2 (2.0)	6.0	1.5	8.0
Quality improvement	5.0 (2.0)	6.0	1.0	8.0

MHI=Medical Home Index

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 $\label{thm:condition} \textbf{Table 5}$ MULTIVARIATE ANALYSIS OF PARENT-REPORTED PCMH AND HEALTH CARE UTILIZATION $(N=240~\text{CHILDREN})^a$

	Health Care Utilization		
	ED Use IRR (95%CI)	Hospitalization IRR (95%CI)	
PCMH Component			
Regular Provider			
Yes	Reference	Reference	
No	1.83(0.55-6.08)	1.04(0.50-2.17)	
Usual Source of Care			
Yes	Reference	Reference	
No	0.35(0.19-0.64)*	0.38(0.25-0.59)	
Problem with Referrals			
Small/Big	Reference	Reference	
None	1.18(0.70-2.00)	0.88(0.62-1.26)	
Spends Enough Time			
Always	Reference	Reference	
Usually	0.63(0.36-1.09)	0.89(0.60-1.30)	
Sometimes	1.07(0.57-2.02)	1.19(0.76–1.88)	
Never	2.12(0.75-5.96)	1.56(0.69-3.50)	
Listens Carefully			
Always	Reference	Reference	
Usually	1.12(0.66-1.91)	0.96(0.669-1.40)	
Sometimes	1.58(0.79–3.15)	1.62(1.00-2.65)	
Never	0.71(0.06-8.17)	1.06(0.20-5.52)	
Provides Information			
Always	Reference	Reference	
Usually	0.81(0.48-1.37)	1.15(0.80–1.65)	
Sometimes	0.82(0.38-1.78)	1.36(0.81-2.30)	
Never	0.88(0.21-3.58)	0.94(0.30-2.90)	
Helps coordinate care			
Always	Reference	Reference	
Usually	1.65(0.80-3.40)	1.44(0.89–2.32)	
Sometimes	1.36(0.64–2.88)	1.28(0.78–2.09)	
Never	1.24(0.48–3.16)	1.35(0.73-2.50)	
Satisfaction with Communication Among Providers			
Very Satisfied	Reference	Reference	
Somewhat Satisfied	1.28(0.78-2.08)	0.92(0.64-1.33)	
Somewhat Dissatisfied	0.64(0.23–1.78)	1.17(0.62-2.19)	
Very Dissatisfied	1.09(0.30-3.91)	1.40(0.59-3.33)	
Satisfaction with Communication Between Provider and Outside Groups			

Health Care Utilization ED Use Hospitalization IRR (95%CI) IRR (95%CI) Very Satisfied Reference Reference Somewhat Satisfied 2.55(1.30-4.99)*** 1.22(0.74-2.00) Somewhat Dissatisfied 0.68(0.15-3.14) 0.48(0.18-1.28) Very Dissatisfied 2.46(0.86-7.00) 2.08(0.70-6.13) Sensitive to Values Always Reference Reference 1.13(0.67-1.90) 1.19(0.84-1.68) Usually 1.11(0.51-2.39) 0.54(0.29-1.01) Sometimes Never 1.23(0.37-4.02) 1.03(0.39-2.71) Page 19

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ED=Emergency Care

PCMH=Patient-Centered Medical Home

IRR=Incidence Rate Ratios

[★]p=.0006

^{**}p<.0001

^{***} p=.0063

^aCovariates consisted of child age, race/ethnicity, gender, health status and parent relationship to child, primary parent status, employment status, education level, and household primary language. Individual survey items assessed in separate models.

 $\label{eq:Table 6} \mbox{MULTIVARIATE ANALYSIS OF PRACTICE-REPORTED PCMH AND HEALTH CARE UTILIZATION } (N=135~\text{CHILDREN}, 51~\text{PRACTICES})^a$

	Health Care Utilization		
	ED IRR (95%CI)	Inpatient IRR (95%CI)	
PCMH Component ^b			
Overall MHI Score	0.99(0.98-1.02)	1.00(0.99-1.02)	
Organizational Capacity	0.38(0.23-0.64)	0.62(0.43-0.88)	
Chronic Condition Management	1.59(1.04-2.42)	1.28(0.95-1.72)	
Care Coordination	0.94(0.61-1.43)	1.29(0.97-1.72)	
Community Outreach	1.50(1.11-2.02)	1.01(0.82–1.25)	
Data Management	0.82(0.69-0.99)	0.88(0.77-1.02)	
Quality Improvement	1.05(0.75-1.45)	0.96(0.78-1.20)	

^aCovariates consisted of child age, race/ethnicity, gender, health status and parent relationship to child, primary parent status, employment status, education level, and household primary language.

ED=Emergency Care

PCMH=Patient-Centered Medical Home

IRR=Incidence Rate Ratios

 $[^]b\!$ All PCMH Components are continuous variables