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STATE HEALTH ACCESS REFORM EVALUATION

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Issues with the Survey-based Measure for Patient Centered Medical Homes for Children

Authors

Victoria Lynch
Urban Institute, Washington, DC

Lisa Clemans-Cope
Urban Institute, Washington, DC

Summary

Several provisions of the Affordable Care Act (ACA) are directed at the establishment and promotion of the Patient Centered Medical Home (PCMH), a model for evaluating health care quality that originated in the field of pediatrics. With this increasing emphasis on the PCMH concept, it is important to ensure policymakers have a valid measure for evaluating it, particularly at the state level, which is where national policy goals are primarily evaluated.

This brief considers the current standard measure used to study the patient centered medical home (PCMH) for children in the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN). Using this composite measure as it is currently computed, children with special health care needs (CSHCN) are less likely to be identified as having a medical home compared to children without such needs. However, the treatment of missing information in the surveys calls this finding into question. This is because non-response due to inapplicability for any of the PCMH composite domains is treated as through the criterion for that domain is satisfied, and well-children have substantially more of this non-response. In addition, this treatment means that states with a higher proportion of children needing the range of services covered by the PCMH domains will appear to have lower proportions of children with a medical home compared to states with a lower proportion of these needy children, everything else being equal.

The authors call for a revision to the current standard PCMH measure and suggest that, as computed, it should be interpreted as a measure of whether the medical care that children received conformed to the PCMH model *as far as it could be measured given the rage of care the children received.*

While the authors acknowledge that there are no simple solutions to this measurement issue, their findings should be taken into consideration when designing and interpreting survey measures of PCMH, whether for children or adults, particularly as the PCMH gains broader traction under health reform.

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Introduction

For the past several decades it has been a national goal to ensure that children receive patient centered care within a medical home (PCMH), and there has been widespread effort to develop consensus on how to define and measure the PCMH concept (Sia, Tonniges, Osterus, & Taba, 2004; US Department of Health and Human Services, 2010). The ideal PCMH is said to provide care that is "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective" (Health Resources and Services Administration, n.d.). The PCMH was first proposed by the American Association of Pediatrics as a model for an organization of pediatric care that delivers the core functions of primary health care (American Academy of Pediatrics, Medical Home Initiative s for Children with Special Needs Project Advisory Committee, 2004). It was originally developed for children with special health care needs (SHCN) and later extended to all children.

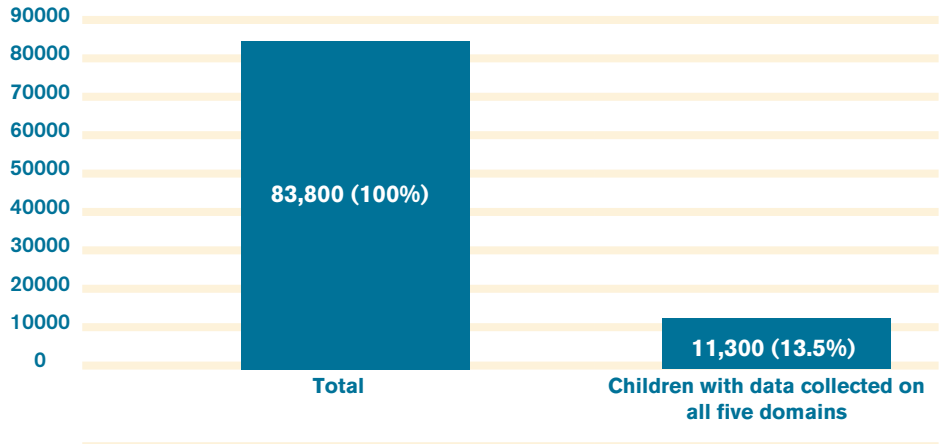
Measuring the Survey-based PCMH

The Child and Adolescent Health Measurement Initiative (CAHMI) notes that future work is needed to refine the measurement of the medical home (2009), but there is general consensus that the current standard is the National Quality Forum (NQF)-endorsed measure in the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN). The NSCH and the NS-CSHCN measures are nearly identical in design and cover the following five domains (CAHMI, 2009):

- Child has a personal doctor or nurse
- Child has a usual source of care
- Child had no problem getting needed referrals when needed
- Child's parent/guardian gets help with care coordination when needed
- Child has family-centered, culturally effective care

Based on the parent's/guardian's responses to one or more survey questions, each sample child receives a value of "yes," "no," or "legitimate skip because care not needed"—referred to in this brief as "no response"—for each of the five domains. Several questions used to derive medical home status may not be applicable to children in good health because they ask about services that the children did not need. For the surveys' standard measure of PCMH, cases that have no response on a medical home domain because care was not needed are treated as though they meet the criteria for that domain.

Exhibit 1. Total sample children in the 2007 National Survey of Children's Health (NSCH) and the proportion with data collected on all five domains of the patient centered medical home



Note: Domains include: 1) Personal doctor or nurse 2) Has a usual source of care 3) No problem getting needed referrals 4) Providers help coordinate care when needed 5) Family centered care.

It is known that small variations in the ways that survey items are used to construct measures of PCMH can affect estimates of the prevalence of medical homes (Bethel, Read, & Brockwood, 2004). However, the extent to which researchers take this possibility into account when making inferences is unclear. In this brief we describe how the standard measure of PCMH in the NSCH and the NS-CSHCN is sensitive to the treatment of missing information on the PCMH domains and how this raises questions about what the PCMH estimates represent. We largely report on findings from the 2007 NSCH, and we focus on the sensitivity of the PCMH measure to missing information.

Challenges in Measuring Patient Centered Medical Home Domains

We found high levels of missingness[1] on the domains of the PCMH measure in the NSCH. Exhibit 1 shows that only 13.5 percent of NSCH sample children[2] in 2007 had responses on all five domains. Less than 4 percent of our NSCH analytical sample children were characterized as missing because the respondent did not know or refused to answer questions on at least one domain, while 82.8 percent were characterized as having at least one "legitimate skip" (i.e., legitimate non-response) because the child was determined to not need the service asked about in a domain. The domains that are missing for a large share of the sample are 1) whether they have a problem getting referrals to the specialist that their parent/guardian thinks they need and 2) whether the parent/guardian gets extra help coordinating care among providers and school/daycare when needed. Referrals to specialists were only measured for children whose parent/guardian reported that they needed a referral in the last year. Care coordination was only observed for children whose parents reported that they went to a specialist[3] and had at least two services.

Exhibit 2. Hypothetical Values for the Five Domains of the PCMH, Two Example Children

	Child 2	Child 1
Personal doctor or nurse	Yes	Yes
Has usual source of care	Yes	Yes
No problem getting needed referrals	No response	Yes
Providers help coordinate care when needed	No response	No
Family centered care	Yes	Yes
Has a medical home?	Yes	No

High levels of missingness in surveys are not always an indicator of a problem, but there is reason to believe that it is problematic for the PCMH measure. The high levels of domain missingness may bias estimates of PCMH because the measure is computed by treating cases for which there is no response as though they meet the criteria for that domain. What this treatment means is that children who are by definition less likely to need a referral or care coordination are more likely to be classified as having a PCMH.

The mechanics of this potential problem are demonstrated in Exhibit 2. Example Child 1 did not need the full range of health services measured in the PCMH model, so two of the five domains had no response and are treated as if the child received care that met the PCMH criterion in those domains. In contrast, Child 2 needed the range of health services measured in the survey-based PCMH model, so

Children who are by definition *less* likely to need a referral or care coordination are *more* likely to be classified as having a PCMH.

[1] "Missingness" refers to the existence of missing data.

[2] Our analytical sample included only those who were insured or uninsured the full year (n=83,754).

[3] Mental health service provider or other specialist including therapists and home health care providers.

Exhibit 3. Estimated Prevalence of Children with a Medical Home among States Before and After Adjusting for Relatively High[1]/Low Rates[2] of Response on the Referral and Coordination Domains of the Medical Home

States with Relatively High Rates of Response	Original	Adjusted
Virginia	68.8	75.4
Maine	67.8	73.6
Massachusetts	66.2	72.1
Delaware	50.2	56.3
New Jersey	69.7	76.6
States with Relatively Low Rates of Response	**Original**	**Adjusted**
Utah	65.3	62.7
Montana	64.1	60.4
Nevada	65.2	63
Illinois	57.2	53.2
Wyoming	61.1	58.5

[1] Adjusted by assuming the same rate of response as in the state with the **lowest** rate of response.

[2] Adjusted by assuming the same rate of response as in the state with the **highest** rate of response.

information could be ascertained about the health care available to the child in all five domains. In effect, Child 1 had three opportunities to be identified as not having care that met the PCMH model, while Child 2 had five opportunities and thus a higher probability of being identified as not having a PCMH. The exhibit shows that Child 1 was identified as having a medical home even though the child received less care in the PCHM model compared to Child 2. This is different from determining that Child 1 had access to care that reflects the PCMH model (i.e., that the child would get PCMH care if he or she needed it). If the sample children with no response on the referral and coordination domains had needed those types of services, we do not know what proportion of the children would have received the services. However, we can be fairly certain that not all the children would have received the services, which is what is assumed by treating "no response" on the domain as satisfying the domain criteria and what is, therefore, reflected in the estimates. If we assumed, for example, that 80 percent of the children with no information on the referral and coordination domains would have gotten care that satisfied the PCMH criteria, then the estimate for the prevalence of medical home care would fall from 59.4 percent to 48.8 percent.[4]

We can infer from the logic demonstrated in Exhibit 2 that children with special health care needs (SHCN) will be less likely to be identified as having a medical home because they are more likely than other children to need services on all five domains and thus less likely to be treated as a "no response" on a domain. In fact, 28.7 percent of the sample children with SHCN had responses on all the domains, compared to 9.6 percent of the children with no SHCN in 2007. That more children *without* SHCN are assumed to satisfy the criteria of the PCMH domains raises the question of whether it is true that children without SHCN are more likely to have a medical home than children with SHCN, as previous research has asserted (Zickafoose and Davis, 2013).

[4]This estimate is computed for children who were uninsured or insured for the full year.

Implications for State Rankings from the Patient Centered Medical Home Care Methodology

We can infer from the logic demonstrated in Exhibit 2 that states with relatively less missingness on the domains—i.e., states with children who have relatively more health care needs—will appear to have lower proportions of children with medical homes compared to other states. We found empirical evidence that the degree of missingness on the domains affects state estimates of the prevalence of children with a PCMH.

The estimated prevalence of children with a medical home among states changed when we assumed higher or lower rates of response on the referral and coordination domains (Exhibit 3). For the five states with the highest rates of response, we assumed that their rate of response was the same as the state with the lowest level. We then moved the corresponding proportion of children in their samples to "no response", which are counted as satisfying the domain criteria. For the five states with the lowest rates of response, we assumed that their rate of response was the same as the state with the highest level. We also assumed that the random sample of children we moved from "no response" had the same rate of satisfying the criteria of the domains as the children who originally had responded.[5]

For example, Virginia has relatively high rates of response on the two key domains. When we assumed Virginia's rates were low, we found that the estimate for the prevalence of children with a medical home increased from 68.8 percent to 75.4 percent. Conversely, Utah had relatively low rates of response. When we assumed that it had high rates, we found that the estimated prevalence of children with a medical home fell from 65.3 percent to 62.7 percent. On average, the estimated prevalence of having a medical home increased by more than six percentage points among the states with relatively high rates of response and decreased by three points among states with relatively low rates of response when their response rates were adjusted in the opposite direction.

Conclusion

In this study we demonstrated that when survey data on some of the domains of the medical home are missing, there is not enough information available to determine whether a sample child has a medical home where he or she can get PCMH care should they need it. Given the high levels of missingness on two domains of the medical home measure in the NSCH, we conclude that the standard PCMH estimates for children should be interpreted as a measure of whether the medical care that children received conformed to the PCMH model *as far as it could be measured given the range of care the children received.* We also demonstrated that the treatment of cases with missing information on the PCMH domains affects the estimates of the prevalence of children with a medical home and that this treatment logically means that CSHCN are less likely to be determined to have a medical home. Finally, we found that assuming higher or lower rates of missingness on the domains affects conclusions regarding the relative prevalence of children with a PCMH across states.

The extensive collaboration of experts involved in developing the survey-based medical home measure for children implies that there are no simple solutions to measuring the complex concepts defining the PCMH model. However, these findings suggest that the measure should be evolved on the treatment of missing data on the PCHM domains.

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Report Authors

Victoria Lynch, MS

Victoria Lynch is a research associate in the Health Policy Center at the Urban Institute in Washington, D.C. Her current analytical focus is simulating eligibility for Medicaid/CHIP using state-based eligibility rules, state enrollment data, and survey data from the American Community Survey (ACS). Ms. Lynch's current survey methodological focus is on the validity of health coverage related data from the ACS and developing methods and recommendations for maximizing the ACS's utility for studying the impacts of health reform at the state and local level.

Lisa Clemans-Cope, PhD

Clemans-Cope is a senior research associate and health economist at the Urban Institute. Dr. Clemans-Cope's areas of expertise include health insurance; health spending; Medicaid and CHIP programs; Medicaid/Medicare "dual" eligibles; access to health care; health insurance reform initiatives and legislation; health-related survey data; and Medicaid claims data. Her recent work includes both quantitative and qualitative analyses of federal regulation and state implementation of the Affordable Care Act.

Other Contributors:

Andrea Stronghart and Carrie Au-Yeung provided assistance with document layout and graphics.

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