POLICY STATEMENT

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children





DEDICATED TO THE HEALTH OF ALL CHILDREN™

# Achieving Quality Health Services for Adolescents

COMMITTEE ON ADOLESCENCE

This update of the 2008 statement from the American Academy of Pediatrics redirects the discussion of quality health care from the theoretical to the practical within the medical home. This statement reviews the evolution of the medical home concept and challenges to the provision of quality adolescent health care within the patient-centered medical home. Areas of attention for quality adolescent health care are reviewed, including developmentally appropriate care, confidentiality, location of adolescent care, providers who offer such care, the role of research in advancing care, and the transition to adult care.

## abstract

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#### **INTRODUCTION**

The American Academy of Pediatrics (AAP)-endorsed patient-centered medical home (PCMH) model has transformed the delivery of primary care in the United States and offers newly defined measures of quality.<sup>1</sup> Coupled with *Bright Futures*,<sup>2</sup> an evidence- and expert opinion-based guide on how best to provide clinical care for adolescents, a new blueprint for quality health services has emerged. Advanced and open-access models of care delivery have improved efficiency and decreased wait time for patients. Continuity of care with a primary care provider, electronic health record use for population management, and implementation of evidence-based guidelines for preventive care have significantly progressed. Focus on preventive care with attention to specific quality measures, such as those within the Healthcare Effectiveness Data and Information Set (HEDIS),<sup>3</sup> which consists of 81 measures across 5 domains of care, allow for an objective measurement of quality care delivery. A renewed attention to patient satisfaction strengthens the provider-patient relationship. In addition, greater attention to transition of care may allow the opportunity for an easier move from adolescent to adult care. Despite these significant advances, unique challenges to achieving quality health care for adolescents remain in areas such as access to care, provider availability, confidentiality, the

electronic health record, and adult transitions for adolescents with chronic health conditions.

# EVOLUTION OF THE MEDICAL HOME AS QUALITY HEALTH CARE

The conceptual framework by which a primary care practice intends to improve the quality, efficiency, and patient experience of care has evolved since the middle of the 20th century. The AAP first introduced the term "medical home" in 1967 to describe the need for a central location of archiving a child's medical records. This medical home primarily focused on children with special health care needs.<sup>4</sup> By 1992, the AAP broadened the concept of a medical home to include an identifiable, well-trained primary care physician to promote quality care for all children and adolescents. In the 2002 revision of its 1992 statement, the AAP reiterated and enhanced its explanation of care under this model known as the medical home, retaining the 1992 principles of medical care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective, and then expanded an operational definition to include 37 specific activities that should occur within a medical home.<sup>5</sup> Similar models of adult primary care were concurrently proposed by other medical organizations.

In 2007, the AAP joined the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association to endorse the "Joint Principals of the Patient-Centered Medical Home,"<sup>1</sup> which describes 7 core characteristics:

- 1. Personal physician for every patient.
- 2. Physician-directed medical practice.
- 3. Whole-person orientation.

- 4. Care is coordinated and/or integrated.
- 5. Quality and safety are hallmarks of PCMH care.
- 6. Enhanced access to care.
- 7. Appropriate payment for providing PCMH care.

The PCMH, a physician-led, teambased model of whole-person primary care intended to improve quality and efficiency of care, has been adopted by many stakeholders in addition to professional associations, including payers and policy makers.<sup>6</sup> The Agency for Healthcare Research and Quality defines the PCMH as a way to improve health care in America by transforming how primary care is organized and delivered.<sup>7</sup> Increased focus on improving the quality of health services in the United States through the PCMH model has led to a directed effort toward improving access to care, with more timely delivery of services, continuity of care with a primary care provider, patient satisfaction with care, and positive measurable outcomes resulting from care.<sup>8-15</sup> The PCMH uses these quality elements as its cornerstone and is a widely accepted means of achieving quality health service reform.<sup>1,5</sup> Voluntary certification of PCMH status assesses practice structural capabilities to meet the requirements of PCMHs. Certification is provided by a number of organizations, including the National Committee on Quality Assurance,<sup>16</sup> The Joint Commission,<sup>17</sup> the United States Military Health System,<sup>18</sup> and other certifying organizations.

# THE PCMH SHIFTS FOCUS FROM QUANTITY TO QUALITY

Traditional productivity measures of quantity of care focus on business outcomes, which, in a fee-forservice system, assist in measuring revenue generation and complexity of care delivered. In such a model, the health care system is rewarded when providing a high volume of care, particularly face-to-face care, because those visits generate the most revenue. From the patient's vantage point, this model promotes brief, episodic, discontinuous, acute illness-centric care. The result can be care that is not cost-effective. efficient, or guided by published recommendations, without sufficient regard for quality in the context of the whole patient. Access to care, continuity of care, and satisfaction with care are potentially excluded. This system may perpetuate a health and wellness trajectory in a negative direction.19

In contrast, the PCMH revolves around the patient-physician relationship. In this model, patientbased outcomes are at the forefront: access to care, continuity of care, confidentiality of care, preventive care, and measurable health outcomes, such as HEDIS quality measures. The PCMH reorients outcome measures of care away from provider- and system-based metrics of quantity of care and toward patient-centered metrics of quality of care. This model of care, if it includes appropriate payment by private-sector and government payers, encourages continuous, comprehensive, and preventive care that promotes wellness. This system rewards cost-effective care and promotes improvement in patient health to promote high-quality health care at reduced costs. This model transforms a health care system to a system of health.<sup>19</sup>

### **EFFECTIVENESS OF THE PCMH**

The nascent research on the effectiveness of PCMH for child and adult health care is promising.<sup>20</sup> PCMHs with open-access scheduling have been shown, in multiple managed care systems, to increase access and continuity of care; improve outcomes; increase productivity, with relative value unit gains of as much as 17% per encounter; raise total revenue per visit; increase physician compensation; provide more efficient clinic operations, with decreased use of urgent-care services; and improve patient and provider satisfaction, all while reducing health care costs.<sup>21-26</sup> Not all studies have found short-term cost-savings, however.<sup>27,28</sup> By using claims data, one study found that participation in a multipayer medical home pilot of National Committee for Quality Assurance-certified adult practices was associated with limited improvements in quality and was not associated with reductions in utilization of hospital, emergency department, or ambulatory care services or total costs over 3 years. The authors suggested that there may be a need for continued refinement of PCMH practice models within complex health systems.<sup>29</sup> This study reveals the complexity of evaluating PCMH interventions in large multipayer systems and may support the lack of uniformity of success among PCMH practices or a variable latency period between initiating quality improvements and reaching desired outcomes.<sup>30</sup> Transition toward a fully operational PCMH has inherent challenges, and it may take several years to reach maturity and reduce costs in a managed care system.<sup>31-33</sup>

The future direction and modifications of PCMHs will rely on continued research and rigorous evaluation, particularly for health care outcomes for adolescents within PCMHs, for whom little research exists to date. Consistent with lack of research in this area, the ability of the medical home to address the unique health service needs of adolescents is not well defined, and there remain differing approaches to the care of adolescents, such as length of appointment times; availability of confidential time with the pediatric provider; access to confidential

services, including confidentiality within the electronic health record and explanation of benefits; and access to adolescent medicine specialists within the PCMH and neighborhood.

Medical organizations recommend that health services provided to adolescents be adolescent oriented, comprehensive, and coordinated and that they promote healthful behavior, manage chronic health conditions, and focus on prevention.<sup>34–36</sup> Bright Futures contains evidence-based and expert-informed practice guidelines for adolescent health care providers.<sup>2</sup> However, health services in the United States often are not designed around the adolescent, nor do they usually take into account the unique issues of adolescence that affect their health. As a result, some adolescents face gaps in care, fragmented services, less-thanideal medical management, missed opportunities for health promotion and disease prevention, and challenges in transition to adult care for young people with chronic health conditions.37

#### **ISSUES SPECIFIC TO ADOLESCENCE**

Adolescents engage in high-risk behaviors that cause significant morbidity and mortality. Adolescents and young adults have higher incidences of reckless driving, substance abuse, unprotected sex, and violent behavior, compared with adults. Unintentional injuries are the leading cause of death for children, adolescents, and young adults, and alcohol use plays a role in many injuries. Homicide and suicide are the next leading causes of death for adolescents. Recent US high school data reveal that 4 in 10 high school students text or E-mail while driving. Thirty-five percent of high school students drink alcohol, and 23% have used marijuana. In the past year, nearly 15% of high school students were electronically bullied,

nearly 20% were bullied on school property, and 8% attempted suicide. Nearly half (46.8%) of US high school students have had sexual intercourse, 34% are currently sexually active, and 15% had sexual intercourse with 4 or more persons during their life. Among currently sexually active students, 59% used a condom during their last sexual intercourse.<sup>38</sup>

Risky and healthy behaviors that are associated with adult morbidity, such as cardiovascular disease, cancer, and diabetes, also have their origins during the adolescent years. Fifteen percent of high school students smoke cigarettes, and nearly 9% have used smokeless tobacco. Few adolescents consume the recommended amount of daily fruits and vegetables, and in the past week, 5% had not consumed any fruit or 100% fruit juice, and 6.6% had not eaten any vegetables. Fortyone percent had played video or computer games or used a computer for something not related to school work for 3 or more hours per day on an average school day.<sup>38</sup> In the context of these and other health behaviors, the PCMH, centered on the patient-pediatrician relationship, may have a significant impact on adolescent and young adult health.

Within the PCMH model of care as well as other health systems, adolescents receive care within a variety of delivery systems with varying access to comprehensive care, specialty care, and coordination of care and from a variety of providers with varied levels of training in adolescent care. The consequences of these variations are largely unknown for the adolescent population.<sup>10</sup> Issues unique to adolescence that are either incompletely or nonspecifically addressed with the PCMH model include developmentally appropriate care, confidentiality, location where adolescents receive care, providers who offer such care, the role of research in advancing care,

and transition to adult care. These measures need to exist within the PCMH to address adolescent care effectively.

The AAP, American Academy of Family Physicians, and American College of Physicians purport that optimal health care is achieved when each person, at every age, receives developmentally appropriate care.<sup>39</sup> Providing quality health care for adolescents requires that pediatricians maintain relationships with families and with community institutions, such as schools or youth development organizations, while maintaining the relationship with each patient.<sup>34,40</sup> In providing quality care for adolescents, pediatricians help patients develop autonomy, responsibility, and an adult identity, and therefore, care should be developmentally appropriate. Developmentally appropriate care for adolescents may require longer appointment times, which may be a challenge to accommodate within a PCMH that serves a broad age spectrum.<sup>13</sup>

Confidentiality, both in determining whether youth receive what they need and whether there are opportunities for private one-onone time during health care visits, is a major factor that determines the extent to which adolescents receive appropriate care.41 Confidentiality and privacy issues can pose significant barriers to successful screening, assessment, compliance, and follow-up for adolescents and, therefore, is inextricably intertwined with quality health care for this population.<sup>42-45</sup> Moreover, lack of confidential billing for patients with commercial health insurance provides an obstacle to recommended screening and treatment, particularly for sexually transmitted infections and contraception care.46

Even within certified PCMHs, a range of providers may care for adolescents. A common clinical

management approach within PCMH is for teenagers to be assigned advanced clinical practitioners, such as nurse practitioners and physician assistants, as primary care providers, because of relatively low utilization rates and generally well health status of this population overall to maximally leverage open- and advanced-access model systems of clinical care.<sup>21,47</sup> With the advent of excellent guidelines for provision of adolescent health care, such as Bright Futures, and use of validated quality measures, such as data from HEDIS, this may be an appropriate delivery model for well teenagers, presuming providers are adequately trained in provision of adolescent health care, but research on this topic is lacking. A primary concern is that elements necessary for highest-quality adolescent preventive health care, including additional time for confidential interview and discussion, may not be available in a medical home model focused on short-term cost benefits, when such care limits enrollment numbers and the number of patients available to be seen per day, further limiting access to preventive care in a population that often fails to receive preventive care.48

Supporting the health care transition from adolescence to adulthood in the medical home is another challenge for quality adolescent health care. In 2011, a clinical report authored by the AAP, American Academy of Family Physicians, and American College of Physicians reviewed the importance of supporting and facilitating the transition of adolescents with special health care needs into adulthood.<sup>49</sup> Despite renewed attention and effort, widespread implementation of health transition supports as a basic standard of high-quality care has not been realized and has not yet been incorporated into routine adolescent health care in the PCMH.<sup>39</sup>

Within the medical home model of care, and in comparison with other age groups, little research exists regarding adolescent health care. As a result, the impact of the medical home in delivery of quality adolescent health care is still unclear, because it is largely unstudied. Although more research is clearly needed, concerns also exist regarding the ability for the medical home to maintain clinical research activities to produce the types of outcomes data helpful in optimization of the model for adolescents.<sup>50</sup> Addressing these issues now is critical for the future success of adolescent care within the medical home, which remains early in its implementation in the United States.

## PRIMARY CARE ACCESS AND UTILIZATION

Adolescents and young adults are among those least likely to have access to preventive health care, and they historically have the lowest rate of primary care use of any age group in the United States.<sup>48,51</sup> One analysis based on claims data from a 700 000-member health plan in Minnesota revealed that one-third of adolescents with 4 or more years of continuous enrollment had no preventive care visits from age 13 through 17 years, and another 40% had only a single preventive care visit.<sup>52</sup> National surveys with past-year preventive visit measures show significant variation across adolescents (43% to 81%) and young adults (26% to 58%).<sup>53</sup> Those with behavioral health diagnoses are especially lacking in access to care, as fewer than half of all adolescents with psychiatric disorders received care within the past year.<sup>54</sup> In 2012, more than 8% of adolescents lacked insurance, and as of 2014, 18.3% of 18- to 24-year-olds are uninsured in the United States.<sup>55</sup> Health disparities are well described among subgroups of adolescents, including those who are homeless or in the

state child welfare or juvenile justice systems.56,57 Lesbian, gay, bisexual, and transgender adolescents are at highest risk of lacking access to primary care and behavioral health services.<sup>58</sup> Further access challenges exist for adolescents in more rural areas, as well as those who have difficulty negotiating the health care system or live in poverty and lack insurance coverage.<sup>57</sup> The Patient Protection and Affordable Care Act<sup>59</sup> shows promise in improving preventive care of young adults and adolescents.<sup>60</sup> Among those 10 to 17 years old, Healthy People 2020 data reveal that the proportion of adolescents who have had a wellpatient visit in the past 12 months increased by 9.6% from 2008 to 2013.61 The Affordable Care Act may continue to improve access to preventive health care for many adolescents, but its implementation and access to services provided vary by state.

School-based health centers (SBHCs) provide convenient preventive health services for a small number of adolescents and young adults. They serve as a model for improving the linkage between health and education and community systems to improve preventive and primary care. SBHCs may further provide an entry point and source of primary care, with ongoing connections to a medical home, for children who do not otherwise have access to consistent care.<sup>62</sup> There are more than 130 000 schools in the United States serving students in kindergarten through 12th grade. According to the School-Based Health Alliance 2013-2014 census report, there are 2315 SBHCs that serve US students and communities in 49 of 50 states and the District of Columbia. Eighty percent of SBHCs provide care for students in grade 6 and above. More than half of SBHCs serve populations in addition to students in the school, such as students from other schools, family members of

student users, out-of-school youth, school faculty and staff, and other people in the community. Although half of SBHCs are in urban areas, the largest growth of SBHCs has been in rural areas, accounting for nearly 60% of new SBHCs since 2010, and addressing unique challenges to rural youth access to quality primary, behavioral, and oral health care.<sup>63</sup>

Although household surveys indicate that most adolescents receive their primary care in a doctor's office or clinic, approximately 10% of adolescents rely on the hospital or emergency department as their usual source of care.<sup>10</sup> Among adolescents who received care, studies using national compliance rates data from the Medical Expenditures Panel Survey have shown that rates of preventive counseling, health promotion, and screening were low. Only half of adolescents received care that followed recommended guidelines, such as those for annual well-patient visits, confidential and comprehensive health screening, and immunizations.48,64,65

Adolescents with chronic medical needs face additional challenges within the medical home model.<sup>39</sup> The ability of primary care providers within a medical home to effectively manage chronic disease, considering time requirements, has been questioned.<sup>66</sup> Models of care encouraged in PCMH that address chronic health care needs include dedicated care coordinators and patient-care teams,<sup>14</sup> as well as population health registries, such as chronic disease, high-risk, highutilizer, and transition registries. Solutions within the medical home for adults who have complex health needs and require both medical and social services and support from a wide variety of providers and caregivers have been proposed, but the feasibility for smaller practices, including those that care for pediatric and adolescent patients with complex needs, remain unclear.<sup>67</sup>

A further complicating factor is that adolescents and young adults, especially those living in poverty, are more likely to be uninsured than any other age group. Beginning in 2014, the Affordable Care Act required state Medicaid programs to cover adolescents 16 through 18 years of age in families with incomes up to 133% of the federal poverty level. States can also choose to expand their Medicaid programs to 133% of the federal poverty level for late adolescents and young adults starting at 19 years of age. Even under the Affordable Care Act, which provides this extended eligibility for Medicaid and access to private coverage through state exchanges, people living in poverty may remain uninsured, particularly in states that opt to not expand Medicaid.

## ELECTRONIC HEALTH RECORDS AND HEALTH INFORMATION TECHNOLOGY

The electronic health record offers remarkable opportunity to improve the quality of care for adolescents within a PCMH and also offers unique challenges. The AAP, among other organizations, recommends standards for health information technology to help protect adolescent privacy.<sup>68–70</sup> Challenges to privacy for adolescents posed by commercial health information technology systems require the creation and implementation of electronic health record systems that do not impede access, continuity, privacy/ confidentiality, or quality of care for adolescents. The AAP also offers specific recommendations for health information and the medical home to promote confidentiality, continuity of care, patient-care transitions, and overall quality of care. These include criteria for electronic health records that encompass flexibility and specific technological capabilities and are compatible with state-specific laws as well as billing systems.<sup>69</sup> **Requirements regarding explanations** of benefits add additional

confidentiality concerns relevant to the medical visit for the privately insured adolescent, and strategies to address or mitigate the potential for inadvertent confidentiality breeches associated with explanations of benefits vary widely by state.<sup>71</sup> Current electronic health record and billing systems afford an opportunity to prompt providers to address adolescent-specific needs of the patient, to document adolescent health care compatible with current recommendations, and to provide data for process improvement in care for adolescents. Electronic health record and billing systems also allow for meaningful use of data, portals for patients to access their own electronic health records, secure messaging systems to expand access for adolescents to their health care team, and the opportunity for improved patient education through patient instruction sheets and other electronic means. Despite many systems in place, these opportunities are, as yet, not fully realized, and their effectiveness has not been well studied.<sup>70–72</sup>

#### QUALITY MEASURES FOR ADOLESCENT HEALTH CARE

Although multiple data sets and measures currently exist in the United States, there is no robust national information system that can provide timely, comprehensive, and valid and reliable indicators of health and health care quality specifically for adolescents. The health of adolescents is influenced by multiple factors, including biology, behavior, and social and physical environments. It is also influenced by the availability, use, and quality of health care services, especially for those with life-threatening conditions or special health care needs who require frequent interactions with health care providers. Therefore, understanding the health status of adolescents is closely intertwined with understanding the quality of

health care they receive. Health and health care measures can be used to assess the effects of many variables and inform improvements to adolescent health quality. In response to a mandate in the Children's Health Insurance Program Reauthorization Act of 2009 (Pub L No. 111-3), the Institute of Medicine and the National Research Council of the National Academies, under contract with the US Department of Health and Human Services, conducted an 18-month study concluding that, although multiple and independent federal, state, and private data sources exist that include measures of health and health care quality of children and adolescents, the existing data sources are fragmented, not timely, and insufficiently robust as a whole; lack standardization in measurements: and reveal an absence of common definitions.<sup>73</sup> The recommendations of that study included setting goals for child and adolescent quality measures, including adolescent measures in annual reports; standardizing measurement disparities in health and health care quality; improving data collection, reporting, and analysis; and improving public and private capacities to use and report data.

HEDIS outcomes within an adolescent medical home-enrolled population allow a practice to monitor the preventive health status for specific disease elements deemed important to the practice. HEDIS provides objective measurement of patient-centered quality care delivery. Limitations of HEDIS measures as markers of quality adolescent care are that they are relatively few in number, disease specific, and dependent on the practice to record and track the data. Similarly, a set of quality health care measures for Medicaid and the Children's Health Insurance Program, known as the child core set, allow for states to voluntarily report their quality metrics and may

serve as reasonable early measures for a practice to adopt (http:// www.medicaid.gov/medicaid-chipprogram-information/by-topics/ quality-of-care/downloads/2015child-core-set.pdf).

One area for improvement of quality measures includes using adolescents themselves as sources of measurement data. Adolescents have been found to be more valid and reliable than chart review and other data sources in reporting their experiences with preventive care.74-76 However, even health systems that measure patient satisfaction with care do not directly query adolescents younger than 18 years. Although standardization of clinical care and the process of care within the medical home may provide much progress toward the goals outlined in this policy statement, it is important that this process be accompanied by similarly standardized and rigorous research methods in measures of quality and quality services for adolescents.23,77

#### **RECOMMENDATIONS**

The AAP recommends the following:

- 1. Adolescents should receive comprehensive, appropriately confidential, developmentally appropriate primary care, as recommended by AAP guidelines (*Bright Futures*), within a medical home.
- 2. Feasible, valid, and reliable quality measures should be developed and implemented that use adolescent self-reported data to help assess the quality of preventive care provided to youth. In addition, existing measures that were developed in association with initiatives designed to improve the care delivered to adolescent patients should be cataloged and improved for use by external quality-measurement organizations.

- 3. Research on the effectiveness of the PCMH to achieve specific adolescent quality outcome measures is necessary to gauge the impact, and guide the future direction, of the medical home on the health of adolescents.
- 4. Adolescent access to care, continuity of care, confidentiality of care, preventive care, and desired measurable health outcomes should be rewarded by private-sector and government payers to promote high-quality adolescent health care.
- 5. Electronic health records and associated billing and notification systems should protect the confidentiality of care for adolescents. Electronic health records should be configured with templates that are compliant with *Bright Futures* and HEDIS measures.
- 6. PCMHs that care for adolescents should plan for a well-timed and well-executed transition to adult care, especially for adolescents with chronic health conditions.
- 7. Pediatricians and other adolescent health care providers from multiple disciplines should receive professional education about effective strategies for delivery of high-quality adolescent primary care, in accordance with *Bright Futures* guidelines. Educational opportunities currently exist to improve quality through Maintenance of Certification part IV activities as offered by the American Board of Pediatrics.

#### **LEAD AUTHORS**

William Adelman, MD

#### **COMMITTEE ON ADOLESCENCE**, 2014–2015

Paula K. Braverman, MD, Chairperson Elizabeth M. Alderman, MD, FSAHM Cora C. Breuner, MD, MPH David A. Levine, MD Arik V. Marcell, MD, MPH Rebecca Flynn O'Brien, MD

#### LIAISONS

Laurie L. Hornberger, MD, MPH – Section on Adolescent Health Margo Lane, MD – Canadian Pediatric Society Julie Strickland, MD – American College of Obstetricians and Gynecologists Benjamin Shain, MD, PhD – American Academy of Child and Adolescent Psychiatry

#### STAFF

Karen Smith James Baumberger, MPP

#### **ABBREVIATIONS**

AAP: American Academy of Pediatrics
HEDIS: Healthcare Effectiveness Data and Information Set
PCMH: patient-centered medical home
SBHC: school-based health centers

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