Background

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) standards in Title XIX of the Social Security Act provide a guide for the appropriate care of children and youth covered by Medicaid.1 Recently issued Federal policy guidance includes updated standards that build on previously issued regulations and State Medicaid Manuals and address the periodicity schedule as well as developmental and mental health screening.2 State periodicity standards must meet reasonable standards of medical practice. States can either develop standards in consultation with recognized medical organizations involved with child health care, or they can use nationally recognized standards such as Bright Futures.3

Care for children with special needs, such as mental or behavioral health problems or developmental disabilities calls for particular attention to screening, referrals for specialty care, follow-up treatment, and care coordination. Medicaid programs often have difficulty in tracking the provision of such complicated care protocols. Without careful coordination, the care provided may be less than optimal, resulting in poor outcomes, unnecessary hardship and suffering for beneficiaries and their families, and increased costs for the Medicaid program. Electronic health records (EHRs) offer the possibility of improved tracking and coordination of care for all beneficiaries under the EPSDT benefit. Children and youth with special needs are particularly likely to benefit from more widespread use of EHRs. The Medicaid EHR incentive program provides an opportunity to expand EHR use to support improved care for this population.

EHRs, however, are simply a tool, and electronic tools and resources are only as useful as the content they contain. In order to achieve the potential gains in care processes and health outcomes, EHRs must reflect appropriate standards of care. The Medicaid EHR incentive program is making EHRs more widely available to pediatricians and others who care for children with special health care needs.4 However, the appropriate content to be incorporated has yet to be determined and is still being discussed. In this paper, we explore whether states feel that progress has been made in the development of consensus standards for EHRs as they apply to care for children and youth. We also examine the level to which these standards are being incorporated into the certified EHR technology that is available through the Medicaid EHR incentive program. Particular attention is paid to care for children with developmental disabilities or mental or behavioral health issues.

Methods

We interviewed national experts from three organizations concerned with the development of consensus standards for pediatric EHRs. We interviewed Medicaid officials involved in HIT development and child health issues in five states—Arizona, Illinois, Maine, Michigan, and North Carolina—in order to understand how such efforts are viewed by state Medicaid agencies. These states were chosen to represent varying degrees of progress in adoption of EHRs in order to reflect a range of state experience. A list of participants is provided in the appendix.

For each set of interviews, we used a semi-structured interview protocol. All three authors participated in each of the interviews. One team member was assigned to take notes, which were then transcribed and reviewed for completeness and accuracy by the remaining team members. We assured all interviewees we would not directly attribute any of their opinions without their permission.
Findings

We present our findings from these interviews in six broad categories:

1) Awareness of and attitude toward national efforts to develop consensus standards
2) The role of concurrent health system reform initiatives
3) The role of Certified Electronic Health Record Technology (CEHRT) vendors
4) Adoption of EHRs by pediatric providers
5) Practice-level issues related to provision of care and workflow
6) The challenges to use of EHR data in the treatment of children with special needs

1. National efforts

There are several ongoing national level efforts to develop consensus on the appropriate content for pediatric EHRs, some through federal agencies, such as the Centers for Disease Control and Prevention (CDC) and the Agency for Healthcare Research and Quality (AHRQ), and others by private groups, such as the American Academy of Pediatrics (AAP). In addition, there are some state-level efforts, such as those that have been developed in North Carolina and Arizona. Finally, some EHR vendors, such as Office Practicum and EPIC, are developing commercial products focused on pediatricians. Some national quality initiatives, particularly the Children’s Health Insurance Program Re-authorization Act of 2009 (CHIPRA) quality demonstration with its broad quality focus, will likely affect pediatric standards.

Specific findings on state awareness of and attitude toward national efforts to develop consensus standards follow:

- State knowledge of efforts to develop consensus standards varies widely from vague awareness to detailed information. No state appeared to be aware of all ongoing efforts.
- States with detailed knowledge of the many efforts were concerned by the lack of consistency across these standards, both in what standards were included and in how they were measured.
  - For example, until recently, CDC and EPSDT standards differed on lead screening; other measures differ between Stage 1 meaningful use (MU) and Bright Futures.
- Physician practices participating in both Improving Health Outcomes for Children and CHIPRA are getting two different sets of standards on some measures.
- Often, the issue is in a difference in the level of detail and the specificity with regard to children.
- There was widespread concern expressed about the bias towards measures relevant only for adults in existing CEHRTs and in MU requirements.
- States feel that consensus on content especially for developmental and mental health assessments is important, but so is functionality and ease of use at the practice level.

2. Role of concurrent reform initiatives

Many initiatives underway at the state level, both within Medicaid and in the privately insured market, may affect states’ ability to focus on pediatric EHR standards. Some, such as medical homes and health homes, are complementary, or will be when fully developed; and many, such as the CHIPRA quality demonstrations, include specific HIT components. All require State Medicaid Agency staff time and attention.

Specific findings on the role of concurrent health system reform initiatives follow:

- Different states have different priorities among various quality improvement and health system reform initiatives and with respect to EPSDT and EHRs.
- For some states, EPSDT and EHRs are part of a general quality improvement effort.
- State efforts to develop health information exchanges (HIE) and to promote data flows between practices and public health agencies, including immunization registries, also affect attitudes toward the urgency of standardizing the content of pediatric EHRs.

3. The role of vendors

For the most part, vendors develop products to serve particular markets. The EPSDT standards were originally developed by the AAP in partnership with the Health Care Financing Administration (now CMS) to apply to care for all children. Providers are required to meet these standards for Medicaid beneficiaries, but no such requirement exists for children with other coverage. Thus, the market for
EPSDT-based EHRs is relatively small. The Medicaid expansion in 2014 under the Affordable Care Act (ACA) will provide vendors with a larger Medicaid market, although the bulk of new enrollees are likely to be adults. In addition, the requirements of the EHR incentive program are being phased in under the meaningful use standards, and these standards focus more directly on adult care. The bar for meeting MU standards will continue to be raised, providing additional incentives to vendors to meet the new requirements. The effort on pediatric EHRs will depend on the extent to which future MU stages incorporate child-focused measures.

Specific findings on the role of CEHRT vendors follow:

- Vendors are working to meet ONC standards for products, which is a large job.
- Vendors are generally focused on helping providers qualify for incentives by meeting MU Stage 1 and 2 standards, which have few requirements for children.
- Available standards, such as Bright Futures, which includes a very large set of indicators, are not always mutually compatible with one other. Vendors may be reluctant to commit to a certain set of standards if they are not sure that the set will continue to be accepted for certification.
- States have received little guidance on the relative weights to give the various components of EHRs in certifying vendor products, which may have resulted in a lack of emphasis on pediatric measures.
- Interviewees report that due to the lack of emphasis on pediatric products, many are cumbersome, difficult to use, and incomplete.
- Despite these obstacles, some child-focused products are being developed (e.g., Office Practicum) and supported (e.g., EPIC’s KidShare).
- Federal grants have helped some states develop local products, such as the product developed by the University of Southern Arizona, that meet state-recognized standards for children’s care.
- Some vendors offer customization of CEHRTs to meet the requirements of pediatric practices but may charge each practice for this service rather than providing a pediatric module as a standard component or option.

4. Adoption of EHRs by pediatricians

Providers differ in their willingness to adopt EHRs. Some interviewees felt that it was important for providers to see that EHRs will be widely used so that they begin to adapt their practices to accommodate the use of this tool. There was, however, disagreement on whether it was more important to define the standards to which providers would then conform or to concentrate on the expansion of EHRs as a tool that providers could then adapt to the way they practice.

Specific findings on adoption of EHRs by pediatric providers follow:

- Some interviewees predict there will be a gradual evolution toward greater EHR use as providers begin to use this tool and come to understand its potential for better care and cost-saving workflow improvements.
- Under this scenario, providers will adopt EHRs and work to adapt them to the way they provide care; the standards incorporated in the EHRs will develop organically as the tool matures and providers demand and come to expect certain features.
- Promotion of adoption will thus lead to development of standards. For example, Arizona has developed an “EHR-lite” product for providers who find the prospect of adopting full EHRs too challenging and hopes this will lead to adoption of more sophisticated systems in the future.
- Others see a revolution of widespread standardization and adoption after which EHRs will be the norm.
- Under this scenario, the development of consensus standards plays a greater role. Developing clear standards for EHRs and mandating these standards for EHR certification on the state or national level will give vendors the motivation to create standardized and comprehensive products that facilitate the provision of higher quality care with the same resource use. The result will be to encourage more widespread provider adoption.

The share of children covered by Medicaid may influence which path a state’s providers take. In Arizona, the large share of children covered by Medicaid contributes to a high level of awareness of the need for pediatric standards for EHRs.
5. Practice-level issues

The standards incorporated into EHRs will tend to define how care is provided; therefore, the process of consensus development remains contentious, particularly with respect to the details of care for different populations. However, equally important is the availability of the desired functionalities at the practice level so that providers see the contribution of EHRs to the way they provide care.

Specific findings on practice-level issues related to provision of care and workflow follow:

- Doctors want useful clinical data at the point of care, easily viewed without “too many” click-throughs. Many of the available products are seen as “clunky.”
- There is tension between standardization of functions and tailoring products to meet the provider preferences. Different providers may want different measures or different levels of detail depending on their patient panel and style of practice. The challenge is to support workflow, but workflow differs across a range of factors.
- Tying payment for services to the adoption and use of EHRs as a reporting tool, as has been done in pharmacy for many years, could promote EHR expansion.

6. EHRs and the treatment of children with special healthcare needs

There is enormous potential for improving care for children with special health care needs through expanded use of EHRs. Communication between specialty providers and a child’s primary care provider is key to meeting all of the child’s many needs. In addition, because care for these children is expensive, the lack of coordination contributes to a higher financial burden for states. Interviewees identified several barriers to better communication among providers.

Specific findings on the challenges to use of EHR data in the treatment of children with special needs follow:

- Mental/behavioral health providers and primary care providers have different data needs at the point of care. Pediatricians have an incomplete picture of patients with special health needs.
- Mental/behavioral health is often provided as a carve-out service, which inhibits integration and increases the importance of health information exchanges in the coordination of care.

- The use of health information technology by behavioral health providers is much less advanced than that of physical health providers. Intensive effort will be required to level the playing field across providers.
- Mental/behavioral health providers are not eligible for incentives under the Medicaid EHR incentive program, which reduces the likelihood that they will adopt EHRs.
- Because of lower adoption and ineligibility for incentives, CEHRTs are not designed to meet the needs of mental/behavioral health providers or coordination of these providers with pediatricians.
- There are some fundamental disagreements about standards in mental/behavioral health. For example, there is no consensus on how and when to screen for developmental disabilities. There is greater consensus around mental health screening.
- Existing standards, such as the Certification Commission for Health Information Technology and Bright Futures were reported to offer little in the area of mental/behavioral health.

Summary and Conclusions

States are aware of some efforts to develop standards, and many would be willing to contribute to these efforts. They are not aware of all of the current work being done in this area. Furthermore, they are not convinced that the standards being developed will adequately reflect the needs of children and youth generally or, more specifically, those of children and youth with special health care needs.

The development of consensus standards for incorporation into EHRs is critical to achieving gains in health care processes and outcomes for children and youth. Because the standards incorporated into EHRs will tend to define how care is provided, the process of consensus development remains contentious, particularly with respect to the details of care for different populations. The current lack of pediatric standards and the considerable uncertainty about whether and when such standards might be promulgated puts vendors in a difficult position.
States perceive reluctance on the part of vendors to develop products that, though responsive to pediatric providers, might not conform to some future standard for the incentive program. States that are far along in their thinking about care coordination for children with special needs are urgently concerned with the development of standards so that they can move forward with their plans for improving care through the use of this tool.

It is also important for providers to understand that EHRs will be widely used so that they begin to adapt their practices to accommodate the use of this tool. There is some disagreement on whether it is more important to define the standards to which providers will then conform or to concentrate on the expansion of EHRs as a tool that providers can adapt to the way they practice. The certified EHRs currently available under the incentive program do not have adequate functionality to support care and care coordination for children and more specifically for children with special needs.

One finding is clear: this is an important area of concern for states as they move forward in the implementation of EHRs in their Medicaid programs. States indicated that national-level support for the development of consensus standards and their incorporation into certified EHRs would contribute to progress in expanding EHR adoption and use in practices caring for children with special health care needs.

Endnotes

1. Title XIX of the Social Security Act, §1905( r) (1) – (4)
2. State Medicaid Manual, HCFA-Pub 45-5 § 5123.1 EPSDT Service Requirements and §5123.2 Screening Service Content
4. The EHR Incentive Program was authorized under the HITECH Act of 2009. For information, see http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/ehrincentiveprograms/
5. The CHIPRA quality demonstration grants are intended to explore ways to improve the quality of care provided to children under Medicaid and CHIP. See https://www.cms.gov/Outreach-and-Education/Outreach/OpenDoorForums/downloads/DemoLiHAPresentation032310.pdf.
6. After these interviews were conducted, CMS has now aligned lead screening to comport with the current recommendations of the CDC. See http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html
8. Improving Health Outcomes for Children is a 5-year demonstration grant authorized under CHIPRA. It includes collecting and reporting on the use of evidenced-based child health quality measures and expanding the use of HIT to improve data flows in support of child health.
9. The Certification Commission for Health Information Technology (CCHIT®) is an independent, nonprofit organization that certifies EHR technology. See http://www.cchit.org/.

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About the Authors and Acknowledgments

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Appendix: Interviews

National experts

Dr. Andrew Spooner, Chief Medical Information Officer at Cincinnati Children’s Hospital and representative of the American Academy of Pediatrics (AAP) Council on Clinical Information Technology (COCIT)

Dr. Eric Tham, Children’s Hospital Colorado, member of the AAP COCIT

Dr. Jeffery Thompson, Chief Medical Officer of Washington State Health Care Authority and Medicaid Medical Directors Learning Network

State representatives

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Jim Parker, Deputy Administrator of Medical Programs, Illinois Department of Healthcare and Family Services

Maine

Aimée Campbell-O’Connor, CHIP manager for Maine Children and Waiver Services Program Manager--MaineCare Services

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