Registry-Based BMI Surveillance: A Guide to System Preparation, Design, and Implementation
This guide was made possible with support provided by Altarum Institute’s Childhood Obesity Prevention Mission Project (CHOMP). CHOMP is an internally funded 2-year, $2.5 million effort designed to develop and catalyze systems changes to affect childhood obesity and make healthy, active lifestyles easier for children and families to pursue. CHOMP is one of three projects in Altarum’s Mission Projects Initiative. The initiative aims to solve pressing health care issues using systems methods at the institutional, organizational, and community levels in partnership with the public and private sector.

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Registry-Based BMI Surveillance: A Guide to System Preparation, Design, and Implementation

June 2011

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Acknowledgements

The authors would like to thank organizational partners in Michigan and San Diego County who provided invaluable support to projects that have advanced the development of the registry-based BMI surveillance model. In Michigan, these partners include: the Michigan Department of Community Health (MDCH) Immunization Program, the Cardiovascular Health, Nutrition and Physical Activity Section, the Bureau of Epidemiology, and the Division of Medicaid; the Child Health Evaluation and Research Unit of the Division of General Pediatrics at the University of Michigan; the Midwest Affiliate of the American Heart Association; the American Academy of Pediatrics-Michigan Chapter; and other members of the Healthy Kids, Healthy Michigan Coalition. In San Diego, these partners include the San Diego County Childhood Obesity Initiative, and the San Diego County Health Department and its affiliated community health clinics. The projects we have undertaken together resulted in many lessons learned and led to this report.

We also wish to thank individuals who work within those organizations and who have given so much of their time and energy to this emerging model. Former Michigan Care Improvement Registry Manager Therese Hoyle provided technical guidance and a national perspective on work in both locations. Without her vision, the registry-based model would not have been developed in Michigan, been advanced in San Diego, or received the national attention that it has. Persistent support by colleagues within MDCH was essential in building bridges and consensus across the department—key requirements for designing and testing the state’s registry-based BMI surveillance system. Among many others, these colleagues included Shannon Carney-Oleksyk, Patricia Heiler, Bea Salada, Kevin Garnett, Rochelle Hurst, and Jean Chabut. Leading clinicians and advocates who partnered with us include: Sarah Poole, Susan Woolford, Tom Peterson, Chris Pohlod, and Jonathan Gold in Michigan; and Philip Nader, Ann Cordon, Heidi DeGuzman, Cheryl Moder, and Maria Sebiane in San Diego. Staff from clinics involved in pilot testing in Michigan and in San Diego County provided invaluable input while volunteering to pilot test these systems.

Lastly, we thank our colleagues at Altarum Institute who helped advance pieces of this work and pull this report together, including Gerry Bragg, Ruth Morgan, John Christensen, Iza Bobowski, Roy Quini, and Liz Ritter. We also thank Altarum President and Chief Executive Officer Linc Smith for his early and enthusiastic support for this work.
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1. Introduction

The childhood obesity epidemic in the United States is threatening to reverse decades of improvements to human health. Rates of childhood obesity have tripled in the last three decades, and pediatric overweight and obesity have been correlated with increased risk for type 2 diabetes mellitus, high blood cholesterol levels, high blood pressure, asthma, liver disease, sleep apnea, depression, and social discrimination.\(^1\) Disparities in the rates of pediatric obesity exist, with Latino boys and African American girls at the highest risk.\(^2\) As today's cohort of children ages, disparities in obesity prevalence will likely contribute to continued and growing differences in health and longevity between demographic groups and communities.\(^3\) The burden obesity is placing on our entire health system is also significant; annual medical costs of treating adult obesity have been estimated at $147 billion, or roughly 10% of all national health care expenditures.\(^4\)

The increases in childhood obesity prevalence noted above have been identified and monitored by federal surveillance systems that capture height and weight information from national-level samples of children. Body mass index (BMI), an indirect measure of body fatness calculated from height and weight, is the most widely used measurement from which population-level obesity prevalence rates are determined. The surveys and systems generating these data include the National Health and Nutrition Examination Survey, the National Survey of Children's Health, and the Pediatric Nutrition Surveillance System (PedNSS). Recent reports from these data sources suggest the national epidemic has leveled off, but the available datasets are not sufficiently robust to determine how rates in local communities are changing.\(^2,5,6\) The urgent need to address the childhood obesity epidemic has spawned thousands of interventions at local, state, and national levels. Local-level data on obesity prevalence and trends are needed to ensure that prevention and treatment resources are allocated where most needed, and to inform efforts to plan and evaluate interventions.

National and state datasets used to assess obesity rates have significant gaps in coverage, validity, and analytic power. Telephone and in-person surveys collecting parent-reported obesity data are subject to the difficulties parents face in accurately and precisely recalling the height and weight of rapidly growing children.\(^7\) Self-reported height and weight data from surveys of teens have also been shown to be inaccurate.\(^8\) Data collected from direct measurements of children by trained personnel are of better quality, but are more expensive to obtain. Thus, fewer children may be measured than would be needed for obtaining childhood obesity prevalence data among subgroups at the local level. When considered together, these systems produce a relative dearth of state and local data for 5- to 14-year-olds. For children ages 0–5, they only provide information for those who are eligible for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC; which is the setting in which PedNSS data are collected),\(^9\) but this data will also soon be unavailable. CDC announced plans to discontinue operation of PedNSS in 2012. In sum, existing sources of BMI surveillance data do not allow organizations operating on the front lines of the epidemic to optimally mobilize childhood obesity prevention resources, or to monitor and evaluate effects that state and local policies and interventions might have on childhood obesity rates.
A growing number of states are passing legislation to address the gaps in local and state childhood obesity data by creating their own BMI surveillance systems. One emerging model of state and local BMI surveillance uses existing registries. In registry-based BMI surveillance systems, height and weight data are collected in an ongoing and systematic manner by health care providers. Measurements are then entered into an existing public health registry, such as an immunization registry (also known as an immunization information system or IIS). The data from these systems are then available to public health authorities for monitoring obesity trends among populations and geographic areas. This model also offers other potential benefits beyond BMI surveillance, such as preventing and managing pediatric obesity by promoting the increased screening of children for obesity in the health care setting.

Over the past two years, Altarum Institute has worked with stakeholders in Michigan to develop BMI surveillance capacity in the Michigan Care Improvement Registry (MCIR; Michigan's IIS) and to expand functionality and utilization of an existing registry-based BMI surveillance system in the San Diego County Regional Immunization Registry (SDIR; San Diego County's IIS). Altarum’s work on these projects was internally funded through the Childhood Obesity Prevention Mission Project (CHOMP), a 2-year, $2.5 million initiative designed to catalyze, implement, and evaluate systems changes designed to prevent obesity among young children. The content of this guide reflects experience gained and lessons learned while supporting these efforts. The guide has also been informed by a parallel CHOMP effort to assess the readiness of states across the country to adopt registry-based BMI surveillance.

The guide is chiefly written to serve an audience that may be evaluating the possible benefits of a registry-based BMI surveillance model or that is implementing this kind of system. It provides information, analysis, resources, and a potential roadmap for anyone interested in creating or implementing a registry-based childhood obesity surveillance system built upon a state’s immunization information system. Most of the information provided would also apply to city or county-level registries. Because the registry-based surveillance model offers potential benefits beyond surveillance (e.g., functionality for program planning and evaluation, clinical quality improvement) a number of additional audiences may benefit from this guide, such as the following:

- **Chronic disease prevention personnel** working in health departments who are interested in developing a BMI surveillance system;
- **Members of coalitions** focused on children’s health and obesity prevention whose advocacy may be needed to support development of such a system and whose members desire information to plan interventions, assess their effectiveness, and promote policy change to support children’s health;
- **Epidemiologists** charged with ensuring data quality and with analyzing data collected through state and local disease surveillance systems;
Immunization registry managers in state and county health departments who are interested in or are being asked to add height and weight to their registry;

Vendors of electronic health records and immunization registry software who are interested in facilitating aggregation of height and weight data;

Health plan administrators interested in using registry data to promote the quality of obesity prevention, screening, and care; and

Clinical providers who may be seeking clinical tools and resources or answers to questions about how a state’s registry-based BMI surveillance system might affect their clinical care delivery, operations, and quality improvement efforts.

Organization of This Guide

Throughout the guide, we use the term “IIS” interchangeably with “immunization registry” or “registry.” This guide begins by providing background information on the existing state-level BMI surveillance models, and their advantages and disadvantages. Chapters 3 and 4 outline practical processes and design decisions that should be considered when exploring a registry-based BMI surveillance model. Chapter 5 presents information on features that, if programmed into a registry-based BMI surveillance system, would facilitate the practice of evidence-based pediatric obesity management by primary care provider system users. Chapters 6 and 7 describe approaches to testing and implementing new capacities of an immunization registry and to integrating data collection and reporting activities into clinic operations. Included in chapter 7 are examples of how data can be used for surveillance, program planning and evaluation, and clinical quality improvement purposes. Chapter 8 presents considerations for further development and dissemination of the registry-based obesity surveillance model. Finally, a number of key terms used in the guide are included in the appendix for audiences who are less familiar with health information systems.
2. Background

This chapter orients readers to the advantages and disadvantages of various BMI surveillance systems.

Comparing Models of Childhood Obesity Surveillance

As noted above, numerous states have, or are considering, mandates to collect children's height and weight for public health surveillance purposes. Three basic models of surveillance merit review, as knowledge of their features, strengths, and limitations is useful in understanding design options for registry-based BMI surveillance. Key features of the three models are summarized below and in table 1.

School-Based

Most state BMI surveillance systems that are in place or under exploration are connected with schools. Modeled after a successful effort in Arkansas, schools are an obvious setting to consider because children are readily accessible and precedent exists for data collection and screening from school-based scoliosis, vision, and hearing screenings. However, other states have had difficulty replicating the Arkansas model due to the resources needed to train and deploy data collection staff, to collect and analyze data, etc. Alternative models are needed.

Registry-Based

A few states have been exploring registry-based BMI surveillance systems. The idea is to leverage existing immunization registries whose benefits for public health surveillance, improved clinical care, and privacy protections are well established. With the addition of height and weight data to IISs, systematic reporting of data collected from routine clinical visits is possible. Obesity rates for localities across the country could be determined from these measurements, comparable to how immunization coverage rates are determined. No state has fully implemented this model, but it is thought to hold great promise based on assumptions of low development and maintenance costs, high quality data produced, and broad population coverage. Further, the model is well aligned with federal and market-based incentives that are accelerating the use of electronic medical records (EMR), which are expected to communicate with public health registries. With the inclusion of some clinical functions such as tracking of weight-related counseling, the registry could also be used to demonstrate obesity care quality by its ability to generate reports for the Healthcare Effectiveness Data and Information Set (HEDIS), a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service.
Hybrid

In this model, height and weight are measured and recorded by health care providers on health examination forms required for school entry. These data are then extracted and aggregated into a database for surveillance purposes. There are a few states that have passed policies with this model of surveillance in mind (e.g., Illinois, New York). Pilot data collection activities are underway, but early evaluations have revealed challenges connecting education and public health databases for obesity surveillance.13

Table 1. Description, Advantages, and Disadvantages of Three Models of BMI Surveillance

<table>
<thead>
<tr>
<th></th>
<th>School-Based</th>
<th>Registry-Based</th>
<th>Hybrid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Features</td>
<td>Teachers or health personnel are trained and equipped to measure children.</td>
<td>Height and weight measurements routinely taken by health care providers are entered manually into IIS or submitted through automated transfers from electronic health records.</td>
<td>Height and weight measurements are taken in health care settings and recorded on required school forms.</td>
</tr>
<tr>
<td></td>
<td>Data aggregated at schools are submitted to health agencies.</td>
<td></td>
<td>Data are extracted from forms by schools and transmitted to public health authority.</td>
</tr>
<tr>
<td>Pros</td>
<td>Children are easily reached in schools.</td>
<td>Children are measured by trained personnel in a clinical setting where evaluation and management of obesity can continue.</td>
<td>It takes advantage of school mandates for children to have health exams for school entry and possibly at other ages as well.</td>
</tr>
<tr>
<td></td>
<td>Height and weight measurements can be integrated with other health screenings.</td>
<td>Data are most likely to be captured on children under age 6, a strategic population to reach for obesity prevention.</td>
<td>It uses measurements obtained in a clinical setting.</td>
</tr>
<tr>
<td></td>
<td>School is the primary source of health care for some children.</td>
<td>Funding for health information technology may support automated transfer of height and weight data into registries.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Data to improve clinical quality are related to obesity prevention and treatment.</td>
<td></td>
</tr>
<tr>
<td>Cons</td>
<td>Young and absent children are missed.</td>
<td>The technical capacities of state registries vary.</td>
<td>Educational privacy laws may complicate the transfer of data for use by health departments.</td>
</tr>
<tr>
<td></td>
<td>It is not part of the schools’ core education mission so issues related to school funding may arise.</td>
<td>Legislative or regulatory changes may be required to permit providers to report data or obtain consent.</td>
<td>A mechanism to aggregate data is needed.</td>
</tr>
<tr>
<td></td>
<td>Specific training and mobile staff and equipment are required.</td>
<td>A proliferation of electronic health records may reduce provider motivation to participate in surveillance, if voluntary.</td>
<td>Errors are common in extracting data from paper forms.</td>
</tr>
<tr>
<td></td>
<td>Overweight children would need to be referred to clinical care.</td>
<td>Only information on children presenting for care is captured.</td>
<td>Information is only available when health exams are required.</td>
</tr>
<tr>
<td></td>
<td>Overweight children could be stigmatized.</td>
<td>Older children and those lacking access to health care may be missed.</td>
<td>There are concerns about stigmatizing overweight children in school setting.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>There are privacy concerns about the government having BMI data.</td>
<td>There are privacy concerns about the government having BMI data.</td>
</tr>
</tbody>
</table>

Source: Adapted from Longjohn, et al., 20109
When considering development of a registry-based BMI surveillance system, it is important to recognize that each state has a unique set of circumstances and factors that will influence many aspects of the system. These will need to be understood prior to launching a formal effort to add BMI functionality to an IIS. This chapter describes factors that should be considered early in these efforts and will help structure the planning and assessment phases for developing a registry-based BMI surveillance system. Based on our experience, early steps should include the following:

- **Engage stakeholders** to provide opportunities for collaboration in the assessment, design, testing, implementation, advocacy, and fundraising to support the development of BMI functions within a registry;

- **Assess the registry's technical capacity** to determine early in the process whether your state’s registry has or is developing features that will impact the design or effectiveness of the system;

- **Assess the legal environment**, including local and state laws and regulations, which may need to change to implement the system;

- **Assess interest in including clinical functions** beyond surveillance that stakeholders in your state might find additional value in;

- **Identify objectives** for the system; and

- **Establish leadership** for work necessary to develop the system.

Each of these steps is discussed in more detail below.

**Engage Stakeholders**

Successful development and implementation of registry-based BMI surveillance requires a coordinated approach, likely involving many stakeholders. This section identifies the types of organizations and partners that should be sought out as early as possible. Their early engagement is essential because individuals and organizations whose interests and strategies are not routinely or consistently aligned may need significant time spent together to establish consensus on the goals and features of the system to be developed.

Early and consistent interaction between those primarily focused on obesity prevention and those focused on immunization registries is crucial for ensuring that the system can feasibly be developed and implemented to meet users’ needs. Ideally, the registry programmer and manager should be included throughout the design, development, and planning process to ensure that their insight and experience informs the development of the BMI surveillance capacity.

State and local health department staff members who are working in the field of childhood obesity prevention are essential partners. Others within government who should
be engaged early include epidemiologists involved in surveillance or chronic disease, the
immunization program director or registry manager, a legislative affairs staff member, and
an individual involved in state-level health information technology development. Organizations
or individuals focused on improving nutrition, physical activity and childhood obesity rates in communities, child care centers, schools, and health care settings should also be sought. Academics, clinicians, and state-level chapters of professional medical associations (e.g., American Academy of Pediatrics) and nonprofit organizations (e.g., American Heart Association) will offer valuable perspectives on relevant clinical standards.

In addition to these traditional partners, persons with legal expertise or who come
from research agencies, health plans, and organizations focused on improving clinical quality should be considered as potential partners. Those planning registry-based BMI surveillance should also connect with Health Information Technology Regional Extension Centers or Beacon Communities funded by the Office of the National Coordinator for Health Information Technology to promote provider adoption of electronic health records (EHR). Considerable resources are being devoted to helping providers demonstrate meaningful use of certified EHRs. Use of EHRs to record height and weight, calculate BMI, display growth charts, and transmit data to immunization registries are ways that providers can demonstrate meaningful use of certified EHR products to receive financial incentives beginning in 2012 and avoid financial penalties in future years. See chapter 5 for more information on registries and meaningful use.

Many partners focused on obesity surveillance may already be part of an existing obesity prevention coalition. Approaching stakeholders who have already come together in such a coalition might facilitate the identification of “champions” to advance this work. A coalition structure is also useful for distributing tasks discussed throughout this guide. In our work in Michigan and San Diego County, registry-based BMI surveillance was advanced by existing childhood obesity prevention coalitions. The Healthy Kids Healthy Michigan (HKHM) coalition and the San Diego County Childhood Obesity Initiative both sought local-level BMI surveillance data to support their efforts to advance policy, environment, and systems changes to prevent childhood obesity. Examples of partners who may be important in developing a registry-based BMI surveillance system are shown in figure 1.

Example

In Michigan, registry-based BMI surveillance was taken on by the Healthy Kids, Healthy Michigan (HKHM) coalition, which sought to identify a method to evaluate the success of their state-level childhood obesity prevention policy agenda. HKHM is a coalition of approximately 100 organizations. BMI surveillance was advanced by one of the coalition’s three policy action teams, the Health, Family, and Child Care Services Policy Action Team. Within this team, a smaller workgroup formed to develop Michigan’s registry-based BMI surveillance module. This workgroup included state health department obesity and chronic disease prevention staff members, IIS staff members, physicians, medical association representatives, and nonprofit organization representatives (including Altarum Institute and the American Heart Association).
Assess the Registry’s Technical Capacity

A number of registry characteristics affect whether and how BMI could be added, and how useful the data would be for surveillance purposes. Therefore, learning about the capacity of your state’s IIS is an essential first step in determining the viability of using it for BMI surveillance purposes. The IIS program manager for your state can assist you in learning more about your registry. (State contacts are listed at: http://www.cdc.gov/vaccines/programs/iis/contact-state.htm.)

Availability of Information Needed for BMI Percentiles

BMI values are calculated from height and weight. However, to assess the weight category for a child (i.e., underweight, healthy weight, overweight, or obese), calculated BMI values must be compared against those of children of the same age and gender in a reference population. Therefore, the registry must have the child’s age at measurement, gender, height, and weight. Age at measurement can be calculated as the difference between the birth date and the measurement date. Date of birth is a required field in the CDC IIS Core Data Set, a set of elements representing the fundamental attributes necessary for identifying individuals and describing immunization events. Thus, the date field would already exist, as would a field for clinic visit date, as it is required for documenting vaccine administration. Although gender is also included in the CDC IIS Core Data Set and all registries track gender, the information may be missing or not displayed to registry users.
Key IISAR Survey Data Elements

Many registry characteristics that are relevant to assess for BMI surveillance purposes are reported annually by each state. Results are presented in the CDC’s Immunization Information System Annual Report (IISAR), available at: http://www.cdc.gov/vaccines/programs/iis/rates/default.htm. Annual reports assessing progress in meeting each decade’s Healthy People goals for registries are published annually in the CDC’s Morbidity and Mortality Weekly Report. IISAR data can also be used to help determine which new data fields would need to be added to any state’s IIS to incorporate BMI surveillance functionality. Below, we discuss the IISAR data elements we feel are the most relevant to adding BMI functionality to registries. These elements are summarized in table 2.

Is the registry populated by birth data?

Ideally, the answer should be “yes.” When registry records are created directly from birth records, there are fewer chances for children to be missed or have duplicated records. In addition, birth dates, one of the data elements required to determine a child’s BMI percentile, would be available from all birth records. Thus, if a registry is populated by birth data (i.e., from vital records), BMI data will likely be more comprehensive, data entry errors will be minimized, the need for quality checks will be lower, and analysis will be easier.

Proportion of children with gender recorded

As noted, gender is needed to calculate BMI percentiles, and all registries have patient gender data. However, the proportion of children on whom gender data is available varies. As of the 2009 IISAR report, nine registries had gender data on fewer than 95% of children. A number of contemporary issues such as gender reassignment, gay marriage, surrogate births, and the President’s birthplace are generating legislative initiatives that involve birth certificates. On a population basis, lack of access to birth certificate information on a small number of children has little impact on BMI surveillance capacity. However, if such legislation restricts the ability of a registry to access birth certificate gender data on all children, BMI surveillance would be impossible. Therefore, it is important to monitor any proposed legislation involving birth certificates to ensure that the registry’s access to the needed data fields is preserved for all children. (See the next section on assessing the legal environment related to BMI surveillance.)

Proportion of children with ≥2 shots recorded in registry

Another key determinant of a registry’s utility for BMI surveillance purposes is the extent to which it includes data on all children in the state. Optimal surveillance data would be based on measurements from all individuals in the population of interest. Systematic variation in the likelihood of a child’s data being in a registry will lead to biased estimations of obesity prevalence in a state. IISAR reports various measures of child participation in registries. On average, registries report coverage of 77% of all children under 6, well below the Healthy People 2020 performance goal of 95%. However, 23 states reported that over 95% of children under 6 were covered by the registry. States with higher coverage will likely have more robust BMI data, allowing for greater precision of obesity estimates at local levels (i.e., county, ZIP Code, census tract). Obesity prevalence rates are likely to be more accurate if they are based on data from a registry with near universal coverage. Coverage rates for younger children may be lower than for older children due to the possibility of delay in creating records for newborns. Therefore, the IISAR indicator for children 19–35 months may be a more accurate indicator of coverage than the indicator for all children under 6 years.

These measures have some limitations in assessing actual coverage. First, IISAR data on the proportion of children covered are calculated based on the number of children’s records in the IIS divided by census data on the number of children in that age group.
The numerator may be inaccurate due to duplicate IIS records or failure to eliminate records for children who have moved out of state. The denominator may be inaccurate due to large population movements that may have occurred since the census. Thus, it is not uncommon to see states reporting that records exist for more than 100 percent of children. Although not all registries achieve federal targets for 95% coverage for children, data can still be invaluable for surveillance purposes when coverage biases are understood.

**Proportion of public and private providers who submitted data to registry in past 6 months**

IISAR reports the proportion of public and private providers who submit data to the registry. Higher provider participation rates indicate the widespread incorporation of IISs into clinical systems within a state. At present, public and private provider participation rates fall significantly below the Healthy People 2020 performance goal of 50%. Large differences in participation rates by provider type may indicate that coverage rates will be different for children who have public versus private insurance coverage, introducing bias in the assessment of obesity statewide. However, in states where most or very few children see public providers, differences in provider participation rates may have minimal effect on validity.

It should be noted that provider coverage determination is hampered by the difficulty in enumerating the number of providers in a state because some may be missed or double counted if they practice in multiple locations. Nevertheless, the numbers and proportion of children and providers participating in a registry are key drivers of registry cost and efficiency and may affect the feasibility of adding BMI functionality. Thus, while IISAR child and provider coverage are important dimensions of capacity, it is also useful to understand factors affecting the accuracy of IISAR coverage data in individual states.

**Capacity to process and return HL7 messages**

HL7 messaging standards allow health care providers to easily share information across different types of computer systems to support the clinical care of patients. Ideally, the IIS should be able to both process and return HL7 messages. As the emerging standard for data exchange, this is one indication of the likelihood that a registry will be populated directly from EHRs. Federal incentives for providers to use EHRs mean that registries will increasingly be populated by data coming directly from EHRs, and that clinical systems will be better integrated with IISs. In 2010, 20 CDC immunization program grantees received awards to enhance electronic interchanges between EHRs and IISs. Thus, registries may be poised to adopt this standard soon, even if it is not reflected in the current IISAR report.

**Data system linkages**

IISs are increasingly seen as vehicles for improving child health outcomes and the cost-efficiency of surveillance efforts related to children’s health. Understanding which other systems integrate with a registry is important for design purposes. The IISAR survey reports whether registries include information on health data beyond immunizations (such as newborn hearing or lead screening) and whether other programs or facilities (such as Medicaid or WIC) have access to registry data.

Of the linkages reported in various survey years, we believe that the following connections demonstrate capacity (and, possibly, political will) to add surveillance for health conditions unrelated to immunizations: links by hospitals, elementary schools, health plans, WIC, and Medicaid, and tracking of newborn hearing and lead screening program results. These connections may also indicate that the registry has access to the data items needed to calculate children’s BMI percentiles. At least one-third of state registries have some connection with newborn hearing screening or lead screening, both of which
have been included in some years’ annual IIS surveys. A state that has already added at least one health condition or assessment may be more amenable to adding BMI than would a state that had not integrated any other health topics. Additionally, if data elements needed for calculating BMI are already being tracked for other purposes, efforts should be made to avoid having staff enter the same information in multiple systems.

**Table 2. Registry Characteristics Most Relevant to BMI Surveillance That Are Reported in IISAR**

<table>
<thead>
<tr>
<th>IISAR Data Field</th>
<th>Relevance for Registry-Based BMI Surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the registry populated by birth data?</td>
<td>If the registry is populated with information from the vital record of the birth, there is less likelihood of having missed or duplicate records on children. Also, date of birth, required to determine a child’s BMI percentile, will already be in the system. Registries in 39 states plus the District of Columbia are populated by vital records.</td>
</tr>
<tr>
<td>Proportion of records with gender reported</td>
<td>All registries track gender, another data element required to calculate BMI percentile. However, registries in 9 states have gender information missing on more than 5% of children.</td>
</tr>
<tr>
<td>Proportion of children with &gt; 2 shots recorded in registry</td>
<td>This is an indicator of the extent to which registry data are representative of all children in a state. The higher the value, the more robust BMI data will be, allowing for detailed analyses at local levels (i.e., county, ZIP Code, census tract). IISAR publishes coverage rates for all children younger than age 6 and for children ages 19–35 months of age.</td>
</tr>
<tr>
<td>Proportion of public and private providers who submitted data to registry in past 6 months</td>
<td>Higher provider participation rates indicate the widespread incorporation of IISs into clinical systems within a state.</td>
</tr>
<tr>
<td>Capacity to process and return HL7 messages</td>
<td>Ideally, the IIS should be able to both process and return HL7 messages. As the emerging standard for data exchange, this is one indication of the likelihood that registry will be populated directly from EHRs.</td>
</tr>
<tr>
<td>Data system linkages</td>
<td>Connections to other data systems may indicate that the registry has access to the data items needed to calculate children’s BMI percentiles.</td>
</tr>
</tbody>
</table>

**Other Relevant IISAR Data Elements**

Beyond the IISAR data elements discussed above, which are thought to be most relevant to using registries for BMI surveillance, there are several other IISAR elements that may or may not be relevant depending on specific design decisions (discussed in later chapters) that are made. Table 3 summarizes these data elements and their potential relevance.
Table 3. Less Critical IISAR Data Related to BMI Surveillance

<table>
<thead>
<tr>
<th>IISAR Data Field(s)</th>
<th>Relevance for Registry-Based BMI Surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of children with race, ethnicity and ZIP Code recorded</td>
<td>IISAR reports whether or not registries track this information and the proportion of records with the characteristic recorded. Data from registries lacking information on these characteristics will be less useful for understanding obesity disparities. All registries track race, for example, but only 17 state registries have race on at least 80% of children.</td>
</tr>
<tr>
<td>Average time in weeks between birth and establishing IIS record; % with record established within 6 weeks of birth; % immunizations entered within a day, week, and month</td>
<td>These are indicators of the timeliness of data being captured in an IIS. To be useful for providers, the child’s record must be created promptly so that a record of the first hepatitis B immunization is available for the child’s first well-child office visit during the first week of life.</td>
</tr>
<tr>
<td>Automated ability to flag children needing immunizations</td>
<td>This indicates that the registry has a capacity to alert providers if children should be recalled to receive immunizations. If clinical features are being considered for a registry-based BMI surveillance system (see chapter 5), the immunization alert could be modified to recall children for annual BMI assessments.</td>
</tr>
<tr>
<td>Use registry data for HEDIS reporting</td>
<td>BMI screening and weight counseling is a new HEDIS measure (as of 2009) of children’s health care quality. IISs have been used in many states to report HEDIS data. Thus, the capacity to report BMI HEDIS data to health plans could be a cost-effective method for assessing provider compliance with BMI screening guidelines. If clinical features are being considered in a registry-based BMI surveillance system, this might also allow the registry to be useful for programs to improve clinical quality.</td>
</tr>
</tbody>
</table>

The IISAR reports the proportion of records in a registry for which gender is recorded. If registries track birth weight, then a weight field would already exist, although the field would need to be changed to allow entry of multiple measurements as the child ages. Thus, in addition to information already likely to be in registries (date of birth, gender, and measurement date), calculation of BMI percentiles for children will likely only require the addition of height and weight data fields, plus the capacity to compare the result with a table with BMI values from the reference population. The CDC provides this table online at: www.cdc.gov/nccdphp/dnpa/healthyweight/assessing/bmi/00binaries/bmi-tables.pdf.

Integration with Other Systems

Understanding which other data systems integrate with a registry is important for design purposes. It is particularly important to determine whether other systems contain data fields needed to calculate BMI percentiles to avoid having providers enter duplicate information into multiple systems. It is also useful to know whether the registry is able to use those data fields and whether providers have access to that information in real time while using the registry. Such factors affect decisions about which features to include in the registry and whether registry data fields are populated from other systems or need to be entered for each child.
**Method of Data Collection and Entry**

In addition to reviewing IISAR survey data elements, it is vital to understand how, when, and by whom data are entered into a registry. These features affect which processes need to be changed, who needs to be involved in making the changes, and how much the changes will cost. States may use one or multiple methods to enter data into registries or to transfer it from EHRs. Data may be recorded on paper forms and then submitted to a central location for hand entry or to be scanned by a program. Most often, clinic personnel will enter information into a web-based program from paper forms or in real time during the course of a patient visit. Finally, data could be entered into registries via automated uploads of data extracted from electronic health records or other data systems. Where paper forms are used, the addition of BMI would require modification to paper forms and scan forms to allow for recording of information needed to calculate BMI. Data entry screens would also need to be modified to accept the additional information into the registry. File format specifications that are required for HL7 messaging or flat file import programs would have to be modified to include height and weight.

When providers enter information directly into a computer, they will access the registry via the Internet. Thus, programmers need only modify the registry on the central server location to provide users with access to new the data fields required for BMI. Programming costs for software modifications to support BMI surveillance in Michigan and San Diego County were accommodated within the context of routine software maintenance.

Finally, when data are extracted from electronic health records and shared with the registry through automated transfers, each user setting (e.g., clinic) may have to modify the software required to support these extractions. Some registries may provide a program to accomplish this change whereas in other cases, providers might need to work with the vendors who either support their medical records or write data extraction programs, to provide the additional information to a registry.

**Administration and Management**

Registries may be run and managed by state health departments, or may be administered through partnerships with regional or local health departments, or through public/private partnerships. In addition, registries may use software that they have developed internally or adapted from that used in other states; or they may use a system provided by a commercial vendor. The All Kids Count project, which supported initial establishment of 16 immunization registries, offers many lessons pertinent to adding a new function to an existing registry. In addition, a report on best practices in overcoming barriers in registry management consolidates a decade of progress into lessons easily applied to an effort to add BMI surveillance.

Understanding how your IIS is managed, and how best to engage that management in adding BMI functionality to it, is a critical step. Involvement of the IIS leadership is crucial to successful addition of BMI to a registry. Consider setting up key informant interviews to identify perspectives of IIS management. A presentation on the need for, and use of, local obesity surveillance data can help IIS staff understand the value of the proposed system change.
Assess the Legal Environment

In addition to the legal issues described earlier in this chapter regarding whether registries can access birth certificate information, legal and regulatory language on a number of other topics may allow for, or preclude, adding BMI information to registries. The permissiveness and specificity of language governing the IIS or BMI data collection may determine whether and how BMI could be added to a registry. Following is some background information to guide the search for, and interpretation of, relevant language. In any event, legal counsel with oversight for registries should be engaged to determine whether and what policy changes are required before BMI could be added to registries in your state.

Privacy law is a main consideration in the design of a registry-based BMI surveillance system. Health plans and health care providers, considered “covered entities” under the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA), are allowed to share protected health information (PHI) with public health officials without patient consent when such reporting is required by law or for public health protection purposes. Federal law provides states with the authority to require reporting of PHI for various public health functions. However, whether this authority would cover reporting of body mass index surveillance for obesity prevention is a matter untested by court challenges. Small but vocal organizations have generated publicity around the potential for government misuse of BMI data. Ensuring the legal basis for a state’s registry to collect body mass index measurements that is or could be linked to specific individuals is an essential first step in assessing the legal environment.

Detailed instructions for assessing the legal basis for registry-based surveillance exceed the scope of this guide. However, basic information is provided, along with references that offer additional guidance. Relevant legal language to be examined may appear in either state legislative code or in regulations promulgated by state health departments under authority delegated by the legislature.

Language pertaining to BMI reporting in registries might appear in statutes or administrative code (i.e., regulations) which do the following:

- Govern the creation of registries;
- Provide authority to public health entities to conduct disease surveillance or to take other actions to protect public health;
- Mandate provider reporting of information for public health purposes;
- Establish requirements concerning school-based immunizations and reporting thereof; or
- Establish requirements concerning patient consent for disclosure of health information from providers to public health authorities.

In addition, states may have legislation mandating BMI screening that affects the potential for adding BMI to immunization registries.

Review state laws and departmental regulations regarding:

- State exercise of public health authority
- Mandates regarding provider reporting of PHI
- Requirements regarding provider notifications when PHI is shared
- Obligations regarding patient consent for sharing of PHI
Particular attention should be paid to whether legal or regulatory language includes words such as “may” versus “shall” in connection with providers’ obligations to report PHI to public health officials or to notify patients when their PHI is being disclosed. This terminology, along with broader notions of the state’s use of its public health authority, factor into whether and how patient consent need be obtained before BMI information can be shared by providers with an IIS.Providers may also be mandated to report immunization or other health data to an immunization registry or to other databases. Generally speaking, when providers are mandated to report PHI, individual patient consent is not required. However, requirements differ from state to state and may even be internally inconsistent within a state.

Regulations often are in place to address how consent must be obtained for registry reporting. States may have “opt-in” regulations whereby patients have to provide specific consent about their willingness to have their data included in the registry, or they may have “opt-out” regulations whereby patients are presumed to consent unless they specifically object. In states requiring specific consent for information to be included in the registry, coverage is likely to be lower, and costs higher, compared to data that are entered in states with opt-out legislation.22,30

Additional considerations may apply under either opt-in or opt-out scenarios. Topics commonly addressed in legislation are described below.

**Passive or active consent.** Passive consent requires providers to notify patients (via the responsible adult) that their health information is being shared by the provider—with public health authorities in this case. Providers would customarily be asked to inform patients how to express their desire to have their data withheld or removed from the registry. When active consent is required, providers are required to obtain a patient’s approval so that data may be entered into an IIS.

**Notification format.** Depending on state laws, notification requirements about the registry could be satisfied by a wall poster informing patients that data are being shared. Other states may require that patients sign a form indicating their awareness, or approval, that their data is to be shared with registries.

The Michigan Care Improvement Registry website (www.MCIR.org) provides a number of documents pertaining to the sharing of patient data with registries.

**Specificity of notification language.** Providers may be required merely to indicate that some of their PHI is being shared with public health officials or to specify exactly what data are being shared, with whom, and by what process.

**Frequency of notification or consent.** Regardless of whether notification and consent are active or passive, specific or general, some states may require that patients be notified every time data are shared, while others may accept a one-time notification.

**Putting consent into action.** The onus may fall on providers to retain records of patients’ affirmation or withholding of consent, or to pass those documents along to state officials. Similarly, providers may be responsible for removing information from non-consenting patients from registries, or to prohibit its electronic transmission. In other cases, registry operators bear the responsibility of rejecting electronic transmissions of data from non-consenting patients, or deleting or prohibiting entry of information when consent is withheld or withdrawn.
Further information regarding legal and consent issues pertinent to registries is available from professional associations such as the American Immunization Registry Association, the Association of Immunization Managers, Every Child by Two; academic literature;31-34 the Centers for Disease Control and Prevention’s IIS section;35 and websites specific to each state registry. Additionally, several organizations track legislation pertaining to childhood obesity, issuing periodic reports or providing web-based access to legislation.36-38 Other organizations that provide assistance or information to facilitate access to state legislation include the National Policy and Legal Analysis Network to Prevent Childhood Obesity and Washington University’s Prevention Research Center’s State Legislative Search Guide. It should be noted that rules are just being established in relation to the Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted as part of the American Recovery and Reinvestment Act of 2009.39 Intended to speed the adoption and standardization of health information technology, HITECH requires that federal rules pertaining to HIPAA privacy and security be modified. Such changes may well preempt existing state laws pertaining to data sharing, or otherwise change consent and notification requirements related to sharing data with registries. Thus, those interested in registry-based BMI surveillance must be alert to implications of emerging rules. The results of legal analysis may determine whether advocacy is required to change statutes, or regulations in a state. Specific legislative change strategies are beyond the scope of this guide; however, it is worth noting that regulatory changes are frequently accomplished without legislative involvement. Depending on the leadership provided by department directors, policy barriers such as these may be addressed with relatively little debate.

Assess Interest in Including Clinical Functions

Before beginning to determine the desired surveillance system specifications, it may be useful to assess whether there is interest in including clinically relevant features in the system, so that these items may be built into the design specifications. This guide focuses on developing a system for obesity surveillance purposes. However, the system could plausibly support clinical objectives of improving obesity screening and care quality. In Michigan, a focus group discussion was held with pediatricians to determine their perspectives on how a BMI surveillance system connected with their clinical duties. Feeling inadequately positioned to screen and counsel all children, providers noted that addition of clinical support features would make them more likely to assess children’s BMI and report the data for surveillance purposes. Chapter 5 provides a thorough discussion on assessing interest in clinical features. Since clinical features could add significant complexity to programming, details regarding design of clinical features are discussed separately (in chapter 5) from design of the surveillance capacities (in chapter 4).
Identify Objectives

After engaging stakeholders and assessing factors that may affect how BMI data might be included in the registry, consensus on stakeholders’ shared objectives should be defined. The following are examples of objectives that may be of interest in developing a registry-based BMI surveillance system:

- Obtaining local- or county-level obesity prevalence data;
- Analyzing obesity prevalence data by gender and racial and ethnic subgroups;
- Evaluating the effects of public health policies, environmental changes, and interventions; and
- Improving childhood obesity screening rates.

Figure 2 presents a logic model describing benefits of registry-based surveillance to various stakeholder groups. The specific objectives in a state will determine which stakeholders will be needed to plan, design and implement the system.
Establish Leadership

Once the preparatory and assessment activities have been completed, it will be useful to determine who will be responsible for overseeing the system’s design, development, testing, and roll-out. It is logical that a state health department would take the overall lead, but when advocacy is called for or if resources are scarce, other organizations may lead specific activities. Within a health department, it is important to clarify which divisions or sections are responsible for which activities. For example, most registries have “help desk” staff members who are accustomed to resolving registry software issues but refer content questions to immunization staff. New referral mechanisms may need to be established so that chronic disease staff members can answer queries specific to obesity.

Leaders will be responsible for establishing project timelines and work plans, identifying costs and sources of funding, and ensuring that relevant stakeholders are involved when needed. Regularly scheduled meetings of this project team offer an opportunity to make assignments, review progress, and identify stakeholders who need to be included at each step. Ideally, the registry manager and a programmer should be included throughout the design and development process to ensure that their insights and experiences inform the BMI surveillance effort.

Example

In both Michigan and San Diego County, it was invaluable to have a single individual designated to be responsible for system development and implementation. This person ensured that action items were assigned and that progress was reported during regularly scheduled meetings of stakeholders.
4. Surveillance System Design

After gathering input from stakeholders and identifying objectives to be accomplished through a registry-based BMI surveillance system, key features of the system design should be articulated. The selected design features will then be codified into a set of functional specifications that will describe which features are needed by the system users. In this chapter, we describe potential features and their implications for system design.

Functional Specifications

Software development projects follow certain protocols to ensure that the system will ultimately meet the needs of the users with an eye toward efficiency and ease of use.

A functional specification document describes the desired features of the surveillance system, its appearance, and the user interface.

Requirements are a narrative expression of what developers believe users want in a system.

Functional specifications serve as a record of the project team’s consensus on the program’s desired features, but do not specify the actual system design. That is, the functional specifications describe what the system will do, but not how that functionality is achieved. The IIS programmers will determine how the tool will achieve the functional requirements.

The primary requirement of a registry-based BMI tool is to receive pediatric patient height and weight measurements and then to compute BMI values. This may seem straightforward, but there are a variety of nuances that make receiving this data more challenging. For example, there are natural changes in BMI as children grow and differences between boys and girls; children’s weight status is assessed in relation to others of their own age and gender. The CDC growth curves allow BMI values that are specific to age and gender to be assigned BMI percentiles for children ages 2–20 years. The registry program will thus calculate a child’s BMI, compare it to a table of BMI values for a standard reference population of children of that age and gender, and produce the associated BMI percentile value. This percentile represents the child’s BMI value ranking in comparison with children of the same age and gender in the reference population. The weight classification associated with that percentile is then made.

Considerations pertaining to key requirements needed to support surveillance are presented below. Specifications for features useful for clinical purposes (discussed more fully in chapter 5) are also provided. While many of these elements may be standard from state to state, a number of specifications will need to be customized either to meet local needs and objectives, or to accommodate differences among registries. In addition, it

Those planning surveillance systems should monitor recommendations from medical societies and other advisory groups to ensure that system design is consistent with the most current obesity screening, prevention, and treatment guidelines.
should be recognized that not all of those involved in planning the system may be aware of recent changes in reference populations for assessment of weight and growth. Those planning surveillance systems should monitor recommendations from medical societies and other advisory groups to ensure that system design is consistent with the most current obesity screening, prevention, and treatment guidelines.

Following is a description of key topics to be covered in the functional specifications.

Age Coverage

The functional specifications should be clear about the ages for which data will be collected into the registry. The measurement, reporting, and interpretation of growth data for children under age 2 differ in significant ways from those for older children, but evidence is emerging that obesity should be recognized and managed even at these early ages. At the upper end of the age range, certain idiosyncrasies also apply. Some registries are becoming lifespan registries by retaining data on children who become adults, and accepting data on individuals who reached adulthood after registries began. States may have different consent requirements for retention of childhood data after individuals reach age 18, or for entry of data on adults who were not previously in the registry. See chapter 7 for more details on consent requirements for data sharing.

Growth Indicators

For systems focused solely on surveillance, BMI percentile is the metric of primary interest and has traditionally been used only for children over age 2. BMI is calculated from a formula based on weight and height, and then assessed in relation to a designated population of same-age children to determine a child's BMI percentile:

\[ \text{BMI} = \frac{\text{weight (lb) } \cdot 703}{\text{height}^2 \text{ (in}^2)} \quad \text{OR} \quad \frac{\text{weight (kg)}}{\text{height}^2 \text{ (m}^2)} \]

If a system is meant to be used clinically, however, metrics focused on growth per se, rather than BMI, might be tracked and made available for display or used on printed growth charts for discussion with families. For children younger than age 2, growth is assessed by looking at length, rather than standing height, in relation to age. During the third year of life, providers have tracked length on charts for children ages 0–36 months or height using charts that began at age 2 years. Because children’s length is longer than their height, a disjunction could be seen on a growth chart when, during the third year of life, providers transitioned from measuring children in the recumbent to the standing position. A child could have been classified as normal weight based on length at age 2, but as overweight based on their height at the same date. Therefore, some clinicians may prefer to continue using length into a child’s third year for continuity. This issue is further confusing because of different standards in use by the CDC and the World Health Organization (WHO), as will be discussed in the next section.

To track growth on children under age 2, there needs to be a way to enter length, rather than height. If providers are offered a choice between measuring length and height during the third year, then a designation of which measurement has been obtained should be available. Systems meant to be clinically useful should ideally offer providers the option to choose whether to track and print head circumference, and, during the second year of life, to choose whether to print length or height growth charts as well. For children over age 2, while BMI-for-age is the metric used for weight screening and surveillance, clinicians may want to review height and weight in relation to age for general growth assessment and review with families. Thus, the capacity for computing height- and weight-for-age percentiles and for displaying or printing weight-for-age and height-for-age growth charts would be needed.
If you assessed the interest in your state for including clinical features, the debate over growth indicators may be settled by the stance or preference of your local constituency.

Reference Population

There has long been consensus on use of the standard CDC reference population for assessment of growth for children. Until recently, weight-for-age, length-for-age, and head-circumference-for-age charts were available for children ages 0–36 months, and a weight-for-length chart was used for children 45–103 centimeters in length. Weight-for-age and height-for-age charts derived from a different population were available for children ages 2–17 years, and a weight-for-height chart was available for children 77–121 centimeters. Updated growth charts were issued in 2000 based on inclusion of additional measurement data and use of more advanced statistical techniques for calculation of growth curves. The new charts addressed limitations particularly significant for those in the youngest age groups and reflected data from a more diverse and representative population. Weight- and height-for-age charts were extended to age 20. For children ages 2–20 years, gender-specific BMI percentile charts were introduced for the first time, supplementing weight-for-height charts geared for children 77–121 centimeters in length.

In September 2010, the CDC began recommending use of the WHO international growth standard, released in 2006, to assess growth on children ages 0–2, instead of charts based on the CDC standard reference population used since 2000. The WHO standard reflects growth expected for healthy children living in optimal environments. In contrast with the CDC reference population made up of persons who were more likely to have been formula fed, the new standard is derived from populations made up of persons who followed international feeding standards that were heavily reliant on breastfeeding during the early months. Therefore, the new WHO standards reflect faster growth in the first few months and slower thereafter, when compared with growth curves of children in the CDC reference population.

The new standard has a number of other differences relevant to establishing an obesity surveillance system. BMI-for-age charts are available from birth onward, enabling the assessment of BMI percentiles for children younger than age 2. To date, the CDC has remained silent on the use of BMI in children under age 2, and clinical guidelines for their interpretation do not exist. Also, the WHO data have addressed the disjunction occurring in the transition from length to height. Therefore, they recommend switching from length to height at age 2 rather than giving providers the option of switching during the third year of life as desired.

Those planning a registry system should monitor whether the CDC and the American Academy of Pediatrics have issued or changed recommendations on pertinent matters such as use of BMI in children under 2 years of age, use of length versus height for children ages 25–36 months, and reference populations to use in determining growth percentiles.
Because of the evolving nature of the debate about how to handle the different WHO and CDC perspectives, current standards should be reviewed when designing the system. As most state funding for obesity prevention programs is tied to CDC standard practices, it will most likely be strategic to follow their guidance.

**Weight Classification**

Unless and until standards for weight classification of infants become available, the registry should only classify weight status for children ages 2–20 years. For both weight screening and surveillance, the BMI percentile is categorized using defined cutoffs from the gender-specific BMI-for-age charts (table 4).

<table>
<thead>
<tr>
<th>Weight Status</th>
<th>BMI Percentile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underweight</td>
<td>&lt;5th percentile</td>
</tr>
<tr>
<td>Healthy weight</td>
<td>5th – &lt;85th percentile</td>
</tr>
<tr>
<td>Overweight</td>
<td>85th – &lt;95th percentile</td>
</tr>
<tr>
<td>Obese</td>
<td>≥95th percentile</td>
</tr>
</tbody>
</table>

Table 4. Pediatric Weight Status Classification by BMI Percentiles

As noted, weight classification has heretofore not been assigned for children less than age 2, regardless of which growth metric was used (e.g., weight-for-length or BMI-for-age). However, the WHO growth standard, which uses 5th and 95th percentile cutoffs for abnormal weight, would classify more children as having suspect growth problems than would the CDC reference population, using the same percentile cutoffs. Therefore, the CDC now recommends use of the 2.3 and 97.7 percentiles of the WHO reference population to identify children less than age 2 whose weight alone (not BMI) might reflect a health condition of concern. In the absence of consensus recommendations, those planning a registry system should decide how to handle assessment of weight status in the youngest age groups, staying alert to the emergence of new recommendations from the CDC or the American Academy of Pediatrics (AAP).

If adults are included in the registry, weight classification is based on BMI alone for those ages 20 and above, rather than BMI percentiles. Weight classifications for men and women are based on the BMI values shown in table 5.

<table>
<thead>
<tr>
<th>Weight Status</th>
<th>BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underweight</td>
<td>&lt;18.5</td>
</tr>
<tr>
<td>Normal weight</td>
<td>18.5 – 24.9</td>
</tr>
<tr>
<td>Overweight</td>
<td>25.0 – 29.9</td>
</tr>
<tr>
<td>Obese</td>
<td>≥30.0</td>
</tr>
</tbody>
</table>

Table 5. Adult Weight Status Categories by BMI Values

**Frequency of and Indications for Reporting Height and Weight**

To enhance data quality, a protocol should be established to give providers clear guidance on when height and weight data should be reported for surveillance purposes. If provider reporting of height and weight is mandated, these specifications must be clearly articulated so that providers know when they are obligated to report data. This protocol would also be used to determine which height and weight values would be extracted from electronic medical records for incorporation into the registry dataset. While not necessarily required as part of the functional specifications, careful definition of the
reporting protocol would allow developers the opportunity to build in alerts to remind providers when BMI assessments are due for children in their practice.

In establishing the reporting protocol, attention should be paid to balancing data quality and improving clinical care against disruption to clinic procedures. For optimal data quality and surveillance utility, BMI data would be obtained annually from all children. However, not all children visit providers annually, and differences in patient visit patterns are not random. For example, children lacking health insurance may be less likely to visit clinics than children with insurance, younger children tend to visit more frequently than older children due to the need to obtain immunizations for school entry, and sick children may visit more frequently than well children. Therefore, the reporting protocol should seek to minimize the likelihood that non-random factors associated with visit patterns would affect the likelihood of a child’s data being reported to the registry.

In addition, the reporting protocol should seek to minimize sampling or ascertainment bias that would occur due to known tendencies of providers to screen children selectively for reasons such as the visual appearance of obesity. Providers may also differ in screening practices based on their own demographic characteristics, specialty, or sense of self-efficacy in providing obesity prevention counseling. Therefore, the reporting protocol should seek to ensure that all providers who are expected to report data have an equal likelihood of screening, and that all children have an equal likelihood of being screened. Thus, the reporting protocol should specify which types of providers are expected to report data and under what circumstances.

Considerations in developing a reporting protocol should include the following factors:

**Example**

In Michigan, a draft rule governing height and weight reporting reflected the consensus of the BMI surveillance workgroup: If a child had data recorded in the system within the prior 12 months, then height and weight values did not need to be reported.

### Age and grade

The protocol might call for making a single report per child per year, or could focus on reporting data for children of specific ages or grades. Assessment might be prioritized for grades where school immunization or physical examination requirements drive children to clinics. Alternatively, surveillance might focus on children at ages thought most important for early recognition of obesity risk or when behavioral counseling might be most important or effective. Selection of reporting priorities might also take into consideration changes in the predictive value of a BMI screen in light of growth dynamics, such as the adiposity rebound that occurs around age 5 or where the normal rate of BMI change is stable or similar for boys and girls, and across different race and ethnic groups.

### Visit type

Consideration might be given to usual provider practices regarding weighing and measuring children. Providers may weigh children at all visits, but might only measure height at annual well child visits. A protocol that minimizes changes to customary office practices is more likely to be well-received than one for which substantial changes to usual practice would be required. Thus, consideration might be given to harmonizing BMI surveillance reporting requirements with clinical practice, such as at well child visits. As a related matter, the protocol should specify how to handle reporting for children making multiple visits during a single reporting period (e.g., year). For a system that serves both screening and surveillance purposes, there are advantages to encouraging providers to report height and weight whenever both are assessed. Such an approach, however, would require analysts to select a single observation from among several for surveillance reports. For example, children undergoing obesity treatment are likely to be measured frequently during a year. If all of their measures were included, selection of the
last measure during a year could introduce bias if those children succeeded in losing weight during the course of their treatment.

Example

Pilot testing in Michigan and San Diego County revealed differences in use of BMI surveillance systems according to how practices managed obesity in general and how easy it was to access computers in general and the registry software in particular.

In determining visit types for which reporting would be expected, care quality guidelines should also be considered. The HEDIS measure of obesity care quality expects BMI assessments to be undertaken at a variety of visit types beyond annual well-child visits. See chapter 5 for more information about the HEDIS measure.

Provider and facility type. Provider types and practice settings should be specified in the reporting protocol. The list of provider types should focus on providers of primary care, including, for example, family medicine specialists and pediatric nurse practitioners. Local considerations would factor into whether to include other providers such as school-based clinics, clinics associated with commercial pharmacies, and hospitals. In selecting provider types, consideration should be given to harmonization with the types of providers falling under an immunization reporting mandate and with requirements for demonstration of meaningful use of electronic health records.

Alerts

Alerts can be detailed in the functional specifications to indicate to providers that children visiting their clinics are due or overdue for BMI assessment. Two approaches could be used for generating alerts—one based on the time since a particular provider reported a child’s height and weight, and the other based on the time since a child’s height and weight values were entered by any provider. The capacity to generate clinical alerts is among the ways that providers can demonstrate meaningful use of EHRs.

Exceptions

Handling of exceptions—situations where BMI percentiles may not be valid indicators of weight status—should also be considered. Examples include babies born prematurely, teens who are pregnant or postpartum, or children with missing body parts. The specifications should indicate whether or not data should be entered on individuals for whom BMI values may not be accurate indicators of obesity. Premature infants may be considered of normal weight, or to be growing normally, even though their BMI percentiles might put them in the underweight category. Similarly, BMI percentiles should not be calculated on pregnant females. The specifications might call for recording of estimated dates of conception and delivery, actual pregnancy end dates, and alerts to providers for when BMI assessment should resume in the postpartum period. Guidelines do not currently exist for adjustment of weight, height, or BMI for individuals with missing body parts or various dysmorphic conditions. Should those be developed, specifications could be provided accordingly. Thus, provision could be made to designate individuals for whom adjustments should be made to the BMI calculation, or that a different reference population should be used for determination of BMI percentile and weight classification.
Reports
Specifications should be provided for reports that will be used at the following levels:

- Local and state levels, for program planning, evaluation, and surveillance purposes;
- The clinic level, to facilitate delivery of obesity prevention and management services; and
- The health plan level, to assess, improve, and report (e.g., for HEDIS) on health care quality.

Specifications should detail which reports are available to each class of registry users. For example, individual providers might have access to reports on all of their own patients while site administrators could access reports on all patients of that facility. Details for the query capacity for each type of report should be presented as well. Specifications could offer the opportunity to restrict inclusion of data by characteristics such as ZIP Code or insurance coverage or to aggregate data by characteristics such as age or gender. Additional detail about system reports appears in chapter 7.

Data Quality
Data quality is an essential component of an effective surveillance system, and should be a consideration in the design of any BMI surveillance system. Systematic bias in coverage, measurement, or reporting must be minimized or avoided.

The system’s external validity reflects the extent to which data on the population included in the registry accurately represents that for the entire population. In a clinically based registry, a number of factors affect whether or not children’s data will be included. For example, observations will be obtained only from children who visit clinician offices. Younger children are more likely to visit providers to obtain immunizations needed to enter school; they are also more likely to have insurance coverage for well child care. External validity would also be compromised if providers were more likely to report BMI values on children who appeared overweight. Therefore, knowing how children in the registry differ from children not in the registry is important in interpreting the external validity of registry surveillance data.

A key dimension of internal validity is the extent to which obesity prevalence results accurately represent the population that is included in the registry. Internal validity would be compromised if there were systematic inaccuracies in measurements taken by some providers or on some groups of children. For example, use of the “paper and pencil” method of measuring children on an examination table overestimates the length of children younger than two when compared with use of recumbent length boards. Thus, a surveillance system would underestimate the prevalence of elevated body mass of younger children relative to that for older children who are more likely measured on stadiometers. Assessment of the registry’s features and capacity should give a sense of the limitations of data in your state and the tradeoffs that might need to be considered during the design phase. Other examples are discussed above, particularly in relation to the frequency of and indications for height and weight reporting. A complete review of bias is beyond the scope of this report, but excellent resources are available to guide surveillance system design to minimize and assess coverage bias and to adjust for it in analysis.

Data quality control features can be constructed and implemented in a number of ways. Methods such as the following can be used to restrict or eliminate erroneous data from the system:

- Specified values may be prohibited outright from being entered if deemed biologically implausible.
- Values could be entered but flagged to alert a clinician or analyst to confirm a plausible but suspect value.
Values to be designated as implausible or suspect may be defined in fixed or variable terms. In other words, one set of fixed height and weight extremes applies to children of all ages, while variable extremes only apply to children of certain ages. For example, a height of two inches could be part of a fixed range considered as biologically implausible at any age. By contrast, a weight value of 100 pounds might be acceptable for children over a defined age but deemed implausible for children below that age.

Values falling in these predetermined ranges may be excluded from entry altogether, or flagged for further investigation. In a situation where data are entered directly into the registry, an alert can pop up to indicate that a value is refused or that it requires the user to confirm that the value is valid. Alternatively, suspect and implausible values may be allowed into the system but identified subsequently through an editing process that is run either at the clinic or centrally. Edit reports are then reviewed by clinic staff and either corrected or confirmed as correct. Either way, once a clinic has confirmed that a suspect value is accurate for a particular patient, the tool could allow a one-time override so that further confirmations of the same value are not required. That alert would then be deactivated for that particular value for that patient.

When data come in to the system through transfers from EHRs rather than by direct entry, biologically implausible or suspect values could be rejected entirely, or flagged for further investigation. Data quality editing routines would generate summary reports of values that need to be replaced or confirmed by clinic staff. Analysts may choose to exclude from analysis data that were identified at any or all levels of quality review.

The CDC has published a guide and SAS program to exclude growth values deemed as biologically implausible. Values used by a national system tracking growth of school-age children in the United Kingdom have also been published. A recent change to the growth chart standard population used for children ages 0–2 may mean that these standards will need to be updated. In a partnership between the CDC and the American Immunization Registry Association, the Modeling of Immunization Registry Operations Workgroup maintains a best practice guide for registries. This group, augmented with individuals familiar with the analysis of BMI data, would be a logical one to establish data quality standards for registry-based BMI data.

Figure 3 presents a sample decision tree for review and revision of data outside specific limits. This example should be modified to reflect data quality procedures already in use by a particular registry.

Biologically implausible and suspect values may be excluded from entry or flagged for verification or correction. Fixed and variable ranges may be used to designate cutoffs.
In addition to flags for height, weight, or calculated BMI values falling outside of defined ranges, data on growth velocity might also be flagged for biological implausibility. Growth velocity is determined by comparing the height, weight, BMI, or BMI percentile values for two time periods. Potential scenarios include any decreases in height, absolute increases in height or increases or decreases in weight or BMI beyond a defined threshold for a particular amount of time, or excessive changes in BMI percentiles (or Z-scores values). Age- and interval-specific growth velocity limits have not been systematically identified for obesity, although some general guidelines appear in the literature. Such limits do exist for assessing concern about or progress in cases of malnutrition and of weight, length, and head circumference for children younger than 24 months.

Other data quality routines may be incorporated to look for quality control issues arising among specific registry users. For example, an excessive proportion of values with terminal digits “0” and “5” might indicate that measurements are being rounded when taken or entered. A large proportion of flagged values that are either overridden or deleted and left as missing values might indicate inadequate attention to resolution of suspect data.

You may choose to flag cases of implausible growth velocity, such as a child whose height decreases, or suspect cases, such as a child whose BMI percentile increased from 22 to 84 in one year.

Source: Data Quality Standards for Body Mass Index Surveillance in Children
5. Design Considerations for Clinical Capacities

Registry-based BMI surveillance systems present an opportunity to provide clinical benefits to providers that are not directly related to the surveillance function. These features may allow for improvements in the frequency and quality of obesity screening and management efforts in the clinical setting, linkages between screening efforts and reimbursement or HEDIS reporting, and improved interfacing with electronic health records and data systems. After summarizing current clinical care practices, these features will be discussed in this chapter.

Methods of Assessing Clinical Sector Needs

As discussed in chapter 3, once key stakeholders have been identified, a needs assessment should be undertaken to understand in greater detail which features users would like to have included in a system, and what sort of reports they would like access to. Inclusion of clinical features may increase providers’ willingness to report data to the registry, if such reporting is voluntary. This section describes needs assessment specific to clinical functions, if they are to be included in the surveillance system.

Information on stakeholder needs can be obtained through one-on-one interviews with key informants, focus group discussions, or surveys of groups of prospective users. Potential groups of greatest interest include clinicians, clinic staff members and administrators, health plan quality directors, state medical professional associations, and state government officials responsible for Medicaid, obesity prevention, immunizations, and epidemiology. Local government officials can offer a valuable perspective on needs for data to plan or evaluate programs at the community or local level. Guidance on how to conduct these assessments, and examples provided, come from our experiences supporting the addition of clinical features to the Michigan Care Improvement Registry BMI Growth Module and supporting expanded clinician use and clinical functionality of the BMI module that had already been incorporated into the San Diego County Regional Immunization Registry.78,79

User perspectives should be obtained on whether a system should offer clinical support to improve the quality of obesity prevention and treatment care. Stakeholder perspectives should also be ascertained regarding whether surveillance reporting should be mandated and under what circumstances.
Clinicians’ views should be elicited regarding the types of clinical support features that might be desired or needed to ensure robust reporting of BMI data for surveillance. Clinicians might point to national guidelines or recommendations that should be incorporated. For example, representatives of a state medical society may want to ensure that clinical guidance is consistent with that endorsed by their national body.

Clinic administrators may see opportunities to simplify reporting of pediatric care quality required by Children’s Health Insurance Program Reauthorization Act (CHIPRA) of 2006, documentation of meaningful use of EHRs per the HITECH Act, and indicators of the impact of health reform through the Affordable Care Act’s Prevention and Public Health Fund. These discussions may also provide insights into legislative issues that need to be considered in developing a statewide BMI registry. Various stakeholders may have strong views about whether reporting of BMI should be mandated. These areas of disagreement should be brought to the forefront early in the project to elicit constructive discussions and informed decisions.

Clinic staff will provide insights regarding how entry of data into the registry fits into current clinic flow processes. Important considerations include whether and how electronic medical records are used and existing and planned arrangements for exchange of data between EHRs and the registry. The goal of this assessment will be to inform the BMI registry design and development process with early insights from clinicians, staff members, and administrators on the needs, attitudes, opportunities, and challenges they perceive for a registry-based BMI surveillance system. The feedback from these groups will lead to requirements that are included in the functional specifications to help guide the design and development of the BMI registry.

Interviews of or discussions with the IIS registry programmer and manager will unearth issues and considerations for the development, rollout, and implementation of the BMI registry. Aside from information gleaned from reviewing legislation and published IISAR data, these individuals can provide crucial information about the ease of adding new functions to a registry, other priorities under consideration, and whether other major changes to the registry are being contemplated. Such changes could include whether or which vendors are supporting the registry, how changes are made to data extractions from EMRs, etc. The registry manager may also be aware of whether legal or regulatory changes would be needed to add BMI data collection.
Obesity Screening and Prevention Efforts in the Clinic Setting

The AAP Expert Committee recommendations suggest that all children be screened annually for obesity and that tailored counseling be provided to all patients. The needs assessments undertaken with providers in Michigan and San Diego County revealed limited familiarity with the recommendations and a desire for assistance in tailoring the guidelines for streamlined use during patient visits. These findings demonstrate that there were opportunities to use the BMI surveillance system infrastructures to do more than just collect surveillance data. Thus, a key decision to make is whether a system will support only surveillance features or whether clinical needs will also be addressed.

This decision may depend on the extent to which providers are able to access computers easily during visits, and whether the flow of typical patient visits could be modified to allow for the generation and use of customized information during the course of a patient visit.

Specific resources that could be included in the system to aid clinicians in obesity screening, counseling and treatment include the following:

Growth charts. In addition to the BMI-for-age percentile chart, clinicians commonly use length-for-age, height-for-age, weight-for-age, weight-for-length, and head-circumference-for-age percentile charts for children in various age groups.

Identification of patient goals. Patients can be given surveys to assess their behavioral risks and their physical activity and nutrition goals prior to the visit. Such assessments could, with permission, be based on existing products, such as the AAP’s Pediatric Obesity Clinical Decision Support Chart. Survey responses can be used to help the provider customize prevention counseling around a child’s particular risks and goals. If certified, this function could be used by providers to demonstrate meaningful use of an EHR to identify patient-specific education resources and to provide those resources to patients.

Decision support. Tools can be included to guide providers regarding the clinical and laboratory assessment and referrals as well as counseling efforts specific to a child’s age, gender, and weight status. The patient’s success or lack thereof with prior prevention or treatment efforts could also be factored into patient-specific plans. As above, existing, widely accepted tools should be used when possible. The tools developed for the Michigan Care Improvement Registry (MCIR) BMI Module, based on the AAP Expert Committee Guidelines, are available upon request. Figures 4a–c present examples of surveys and clinical guidance from the Michigan tools. Again, if certified, this feature could be used by providers to demonstrate meaningful use of an EHR to implement one clinical decision support rule.

Example

A needs assessment undertaken with providers in Michigan and San Diego County revealed limited familiarity with obesity screening and counseling recommendations and a desire for assistance in tailoring and streamlining the guidelines for use during patient visits. Plans for system implementation in San Diego County and for system design in Michigan were made accordingly to incorporate support for clinical efforts.
Figure 4a. Behavior Survey Customized for a Normal Weight Child
Age 12-18

| Survey for Patients Ages 12-18 Years Old | Patient Name: ____________________  
| Age: ______  Date: ________________  |

In our office, we are interested in discussing the aspects of a healthy lifestyle with all of our patients. Please take a moment to answer the following questions. We realize how busy families and children are and how difficult it is to do all the right things! The questions below reflect only a small number of the challenges that face individuals each day.

| 1. I eat 5 or more servings of fruits and vegetables on most days. | True  False |
| 2. I eat a healthy breakfast every day. | True  False |
| 3. I usually eat dinner at the table with other family members. | True  False |
| 4. I eat take out, fast food, or other restaurant food less than two times per week. | True  False |
| 5. I participate in physical activity for at least 1 hour each day. *This would include sports as well as general play where you are up and moving. | True  False |
| 6. I drink fat free or 1% milk rather than 2% or whole milk. | True  False |
| 7. I drink less than 12 ounces of 100% fruit juice every day. | True  False |
| 8. I spend more than 2 hours per day in front of the TV or computer. | True  False |
| 9. I have a TV in my bedroom. | True  False |
| 10. I have drinks with sugar (punch, fruit drinks, sports drinks, soda, ices, etc) on most days of the week. | True  False |

I have (circle the correct answer):

| Parent or sibling who is overweight or obese. | Yes  No |
| Siblings, parents, grandparents, aunts or uncles with: |  
| Diabetes Type 2 | Yes  No |
| High blood pressure | Yes  No |
| High cholesterol | Yes  No |
| Heart attack before age 55 | Yes  No |
| Stroke before age 55 | Yes  No |

Circle the number which best reflects where you are at on the number continuum.

| How concerned are you about your diet and physical activity habits? |
| Not concerned  Very concerned | 1 2 3 4 5 6 7 8 9 10 |

| How ready are you to make changes? |
| Not ready  Very ready | 1 2 3 4 5 6 7 8 9 10 |

| How confident are you that you can make changes? |
| Not confident  Very confident | 1 2 3 4 5 6 7 8 9 10 |
Figure 4b. Guidance for Assessing the Current and Future Weight-Related Disease Burden for an Obese Child Age 2–5

**Weight Status:** This 2-5 year old’s BMI percentile puts her/him in the obese category (BMI >95th percentile)

**STEP 1: ASSESS THE CURRENT AND FUTURE WEIGHT-RELATED DISEASE BURDEN.**

a. Assess Vitals: Is the patient hypertensive?

b. Is the child taking any of these obesogenic medications?

Antipsychotics____ Mood Stabilizers____ TCA____ Anticonvulsants____ Prednisone____ SSRI____

c. Laboratory Assessment - Are any levels above borderline or higher?

Total Cholesterol > 170 ___ LDL > 110 ___ Triglycerides > 110 ___ HDL < 40 ___

d. Assess Comorbidities and ROS – Is there presence of comorbidities from the ROS?

- Anxiety, school avoidance, social isolation (Depression)
- Polyuria, polydipsia, wt loss (DM)
- Abdominal pain (GERD, gall bladder disease, constipation)
- Hip/ knee pain (SCFE)
- Daytime sleepiness (Sleep apnea, hypoventilation syndrome, depression)
- Headaches (Pseudotumor cerebri)
- Night breathing problems (Sleep apnea, hypoventilation syndrome, asthma)

**Potential Causes of Obesity**

- Violaceous striae (Cushing’s syndrome)
- Undescended testicle (Prader-Willi syndrome)
- Osteoporotic features (Genetic disorders)
- Poor linear growth (Hyphenothyroidism, Cushing’s, Prader-Willi)

**Potential Complications of Obesity**

- Transsial hypertension (Sleep apnea)
- Abdominal tenderness (Gall bladder disease, GERD, NAF/DO)
- Acanthous mucus (NIDDM, insulin resistance)
- Lower leg bowing (Blount’s disease)
- Hepatomegaly (Nonalcoholic fatty liver disease [NAFI/O])
- Limited hip range of motion (Slipped capital femoral epiphysis)

**Physical Exam – Are comorbidities noted on the physical exam?**

f. Review assessment tool – is family history positive for any of the following?

Family Hx: Obesity___ HTN___ Type 2 DM___ Hyperlipidemia___ Early MI___ Early Stroke___

If any above medical risks are noted refer as appropriate.
Figure 4c. Guidance for Tailoring Behavioral Counseling, Clinical Assessment, and Planning Future Treatment for an Overweight Child Age 6–11

### STEP 2: REVIEW BEHAVIOR TARGETS & FAMILY READINESS FOR CHANGE

**a.** Reinforce positive behaviors noted on survey tool and note risky behaviors below.

- Eats <5 servings fruit & veggies every day.
- Does not eat a healthy breakfast every day.
- Does not usually eat meals at the table with family.
- Eats take out or fast food ≥2 times per week.
- Spends >2 hours TV & computer time per day.
- Physical activity less than 1 hr per day.
- Drinks >1 sugar sweetened beverage per day.
- Drinks 2% or greater milk.
- Drinks >6 oz 100% fruit juice per day.
- TV in bedroom.

**b.** Assess readiness for change – Record numbers from survey tool

<table>
<thead>
<tr>
<th>Concern about child’s diet &amp; physical activity habits?</th>
<th>Ready to make changes?</th>
<th>Confidence in ability to make changes?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3=Not Ready</td>
<td>4=Unsure</td>
<td>7-10=Ready</td>
</tr>
</tbody>
</table>

### STEP 3: TAILOR APPROACH TO FAMILY/PATIENT

START WITH STAGE 1 (PREVENTION PLUS) AND PROGRESS AS NOTED TO STAGES 2, 3 OR 4

<table>
<thead>
<tr>
<th>Stage 1: Prevention Plus</th>
<th>Stage 2: Structured Weight Management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GOAL</strong></td>
<td><strong>RECOMMENDATIONS</strong></td>
</tr>
<tr>
<td>Weight maintenance (weight loss of up to 1 lb/mo may be acceptable if BMI is &gt;21 or 22kg/m²)</td>
<td>• Counsel and guide parents through goals they set themselves.</td>
</tr>
<tr>
<td></td>
<td>• If low parental concern (i.e., pre-contemplation) attempt to motivate by educating family regarding medical risk factors associated with obesity.</td>
</tr>
<tr>
<td></td>
<td>• Refer or order appropriate follow-up testing for comorbidities.</td>
</tr>
<tr>
<td><strong>LABS</strong></td>
<td><strong>FOLLOW UP</strong></td>
</tr>
<tr>
<td>Obtain fasting lipid profile. Repeat every 2 years if normal.</td>
<td>Monthly ideally. If no progress is made in 6 months, advance to Stage 2 (Structured Weight Management) if family is ready.</td>
</tr>
</tbody>
</table>

### Labs (check those obtained during visit)

- Fasting lipid profile
- Other (specify)

**Recommended Follow Up**

- Weeks
- Months

**Referrals:**

- None
- Dietician
- Physical Therapist
- Behavioral Counselor
- Other

**Counseling occurred for _____ minutes and comprised 50% or more of visit.**

- Yes
- No

**Topics addressed:**

- Weight counseling
- Physical activity counseling
- Other (specify)

**Agreed upon goals for target behaviors from 2a:**

<table>
<thead>
<tr>
<th>Goal</th>
<th>Patient's Action</th>
<th>Provider's Role</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

**OTHER NOTES:**

**Provider Signature:**

**Date:**

### Billing Information

- This section is for information only and cannot be taken as a guarantee of payment for services.
- Check with patient’s health plan directly to determine eligibility and billing requirements.

**Prevalence**

<table>
<thead>
<tr>
<th>Type</th>
<th>Prevalence %</th>
</tr>
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<td></td>
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</table>

**Screening**

<table>
<thead>
<tr>
<th>Type</th>
<th>Screening %</th>
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**Assessment**

<table>
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<th>Type</th>
<th>Assessment %</th>
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**Intervention**

<table>
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<th>Type</th>
<th>Intervention %</th>
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**Follow-up**

<table>
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<tr>
<th>Type</th>
<th>Follow-up %</th>
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### Resources & References

Reimbursement Linkages

Because clinical BMI assessment is the essential starting point for management of excess weight and reinforcement of preventive behaviors among those at a healthy weight, many efforts are converging to encourage annual BMI screening and weight counseling. While current federal and clinical practice guidelines call for annual BMI screening of all children,80,84 reimbursement for such screening is variable.85,86 Actual and perceived barriers to reimbursement have been widely documented87,88 and persist.48 Registry-based BMI surveillance offers several opportunities for leveraging increased reimbursement for BMI screening and counseling. If providers are confident they will be reimbursed for their services, they may be more likely to regularly engage in BMI screening and counseling with families. Examples include the following:

- **Clarification and expansion of Medicaid coverage.** Providers in Michigan expressed reluctance to screen patients because of a perception that they would not be reimbursed. Working through the Healthy Kids, Healthy Michigan coalition, examples of denied requests for reimbursement were presented to Medicaid officials. In response, the state issued a letter to providers clarifying policies for obesity screening and counseling reimbursement.89 The coalition is monitoring Medicaid claims data to compare the number of children with documented obesity diagnoses with approved and rejected claims for BMI screening and counseling. Once populated, registry data could be examined alongside claims data to assess the relationship of coverage to service provision and obesity trends and disparities. Such analysis could enable advocates to push for further clarifying or expanding Medicaid coverage for obesity care.

The Affordable Care Act (Public Law 111-148) and CHIPRA include a number of initiatives to increase access to quality obesity screening and treatment services.90,91 Annual BMI screening and counseling are likely to be included in the CHIPRA Pediatric Quality Measures Program as measures of care quality and access to care. If there is interest in using the registry to document provision of quality obesity care, the registry should track whether counseling is provided in addition to recording BMI values.

- **Increase provider awareness of methods to obtain reimbursement for obesity screening and counseling.** Because the Michigan Medicaid coverage clarification memo was thought not to have been widely read by providers, the childhood obesity prevention advocacy coalition circulated it via various electronic and print means to further increase provider awareness.92 Professional associations and other organizations offer tip sheets about obesity coding and provide training as part of continuing education events.93-95

- **Display reimbursement codes in registry interface.** Where clinicians or their staff have access to computers, the registry could display diagnosis and procedure codes to facilitate provider billing for BMI screening and weight counseling services. Figure 5 shows how these codes are displayed in the Michigan Care Improvement Registry (MCIR) BMI interface. Codes may also be shown on printed clinical decision support sheets, as shown in figure 4c. An interface could be established with the Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program to document that children are receiving mandated obesity preventive and treatment services.
Other Electronic Data Exchange

Interfaces with other electronic systems can be developed to populate or update specific data fields, to facilitate clinical care, to exchange information on patients relocating in or out of the state, or to analyze data. The move toward electronic health records may enhance the value of registry data while lowering data collection costs. A suite of advanced registry analytic capacities that was recently pilot tested demonstrated the enormous potential value for data interchanges. Several key linkage opportunities are described below.

HEDIS Reporting

Immunization registries are increasingly being used as a cost-effective method of obtaining data that health plans use to attain quality ratings. Documentation of BMI screening and counseling are required for a number of provisions in the Affordable Care Act. For registries already providing HEDIS data to health plans, supplying the documentation required for the HEDIS Weight Assessment and Counseling for Nutrition and Physical Activity for Children/Adolescents (WCC) measure is fairly straightforward. The National Committee on Quality Assurance, which administers HEDIS, provides a certification process to enable registry data to be used for HEDIS assessment. This clearance would need to be obtained to certify an IIS for reporting the HEDIS WCC measure.

The HEDIS BMI measure is based not just on BMI assessment but also on documentation that counseling about weight, nutrition, and physical activity occurred as well (see

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**Figure 5. MCIR BMI Tool to Facilitate Provider Billing and HEDIS Reporting of Obesity Screening and Counseling**

Source: Michigan Care Improvement Registry BMI Growth Module

Note: These codes should be verified in light of changes to the HEDIS specifications, and inconsistencies between HEDIS reporting and billing requirements.
figure 5 for MCIR tracking of the HEDIS WCC counseling components). Therefore, if a decision is made to have the registry provide data for the HEDIS BMI measure, careful attention should be given to ensuring that all the required elements for the HEDIS measure have been included. General specifications for the measure are available online, but the detailed specifications required for certification are published in copyrighted volumes, updated annually. To obtain registry data extracts for HEDIS reporting, providers submit a query listing the patient identification numbers and visit dates for which information is requested. An example of a query form can be found on the MCIR website at http://www.mcir.org/forms/MCIR%20HEDIS%20query%20return%20formats.xls. Those seeking more information about obtaining data from registries for HEDIS reporting in general are referred to an excellent resource whose content is updated online as needed.101

**Vital Records**

As noted earlier, registries where records are initially created through downloads of vital record birth certificate data may have fewer problems with duplicate and erroneous data than registries where records are established in clinician offices. Additionally, birth certificates contain many of the core data elements used in the computation of BMI percentiles, including date of birth and gender. Birth weight and birth length, included routinely on birth certificates, are of substantial analytic interest for study of development of obesity and would be useful in plotting longitudinal growth charts on children in the clinical setting. Registries already connected with vital records, then, should consider transferring birth weight and length when other data are being transmitted. The height and weight fields could then be created as repeated sections in the registry to allow for multiple measures as the child ages.

**Electronic Health Records**

Recent legislation offers incentives to providers who achieve “meaningful use” of certified electronic health records.102 To obtain certification, EHRs must be able to track children’s growth and produce growth charts.103 One of several criteria used in assessing whether a threshold of meaningful use has been achieved is exchange of data between an EHR and an immunization registry. Data can be transferred from EHRs to registries in a number of ways. Data can be exported from the EHR into a file using specifications provided by the registry. The method for transferring the file, and the frequency for transfers, will be defined most likely as daily or weekly. In some cases, registries or EHR vendors provide programs to extract the data from the EHR.104

National standards are emerging to guide systematic data exchange, and specifications are available for all of the data needed to calculate BMI percentiles.105 However, guidance specific to using HL7 messaging to transmit data to registries does not cover requirements for transfer of height and weight data (other than birth weight).106,107 Registry officials in Rhode Island have attempted to articulate HL7 standards for transmission of BMI information.108 States may also wish to exchange data on individual patients who move between states. Guidance is available for state-to-state data exchange using HL7 messaging, but again, specifications for BMI data exchange are not provided.109

Registries already connected with vital records should consider including birth weight and length when other vital record data fields are being accessed.
**Women, Infants, and Children Data Systems**

State WIC systems capture length/height and weight measurements for children who participate in this federally funded nutrition program. In 2009, this comprised nearly one-half of infants and one-quarter of children ages 1–4 years. Immunization registries have played an important role in coordination of care by serving as a bridge between providers and the WIC program for the exchange of immunization data. Since 2000, the U.S. Department of Agriculture and the CDC have collaborated to improve immunization rates among children enrolled in WIC. Thus, many states have established links to facilitate sharing of data between WIC and immunization programs. Because WIC is concerned with the growth of young children, clients must be measured at periodic visits either at WIC clinics or at provider offices. Therefore, if the registry can be used to share this information, the burden on clients for obtaining the measurements is reduced, as is the burden on WIC and clinic staff who can avoid duplicate measurements. Like other methods of electronic data transfer, patient consent may be required for exchange of BMI data between WIC and a registry. Consent information could be stored electronically using an unused field in a WIC data entry screen. After consent has been obtained, the WIC staff member could enter a code established to indicate whether patient consent was obtained, refused, or not ascertained into an agreed-upon unused data field. At an established interval, the state WIC data manager would extract data for clients on whom consent was obtained to share with the registry. Other guidance regarding exchange of WIC and registry data is available in the CDC’s Immunization Program Operations Manual.111

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**Example**

San Diego WIC staff members highly valued being able to access the San Diego Immunization Registry (SDIR) to see their clients’ immunization data. They requested that a capacity be developed so they could see SDIR BMI data as well, to show patients their BMI growth charts and print them out for clients to take home.

Figure 6 shows an example of unused data fields that could be used to store the record of patient consent.
Other Data Systems

The Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT) is designed to ensure that children covered by Medicaid receive certain services, including weight assessment and counseling. However, lack of specificity in state Medicaid handbooks raises questions about the likelihood of providers actually obtaining reimbursement for such services. Numerous states have been sued for failure to provide mandated EPSDT services. In response, some are exploring creation of registries modeled on, or linked with, existing registries to document that services are, in fact, being provided. Because BMI assessments are included in EPSDT coverage, similar efficiencies could be seen by exchanging EPSDT data with registries.

Attention must be paid to ensuring that providers have obtained patient consent, if needed, to transfer BMI-related patient information among such systems. Families may have particular concerns about having their BMI information shared with their health plan, as might occur in using registry data for HEDIS reporting. It is essential to ensure that provider notifications of data sharing and consent forms cover any additional information being collected for BMI surveillance. Legal and political considerations related to family or public privacy concerns are discussed in chapters 3 and 7.
6. Preliminary System Testing and Refinement

After key design decisions have been made and functional specifications and requirements are drafted and programmed, comprehensive testing should be performed prior to launching a registry-based BMI surveillance system. This chapter describes recommended testing procedures illustrated with examples of what was learned during testing of systems in Michigan and San Diego County.

User Testing

There are several types of internal user testing that can take place during the system development process. The main purpose of user testing is to identify and document programming bugs and defects and then re-test and close defects following adjustments to programming.

Different types of testing include the following:

- **Regression testing** can be undertaken by almost any member of a development team, including external coalition members or other volunteers. It occurs as the system is being developed to uncover software errors. Defects are noted and reported after each round of testing. Each time the software program has been modified, regression testing will seek to reproduce defects seen previously, plus ensure that no new defects have been generated.

- **Internal testing** is conducted by developers and key stakeholders to determine whether the system achieves the objectives laid out in the functional specifications. The objective is to identify situations where the tool does not behave as required or expected. At this stage, testers may determine that specifications do not meet user needs in certain areas and request revisions or enhancements.

- **Provider testing** is undertaken in clinical settings by prototypical users. Physicians are asked to use the system as they would in routine clinic practice, while striving to identify defects by using all of the system’s capacities for all types of patients. In addition to noting defects, providers offer input on the design and functionality of the tool.

When user testing is completed and the system has been modified accordingly, the internal testing team should confirm that all of the identified issues have been fixed prior to pilot testing.

Example

At one pilot test clinic, after discovering an unreasonable BMI value, system testers determined that a 16-year-old child had been entered as 5 inches tall. This finding led designers to add in data quality controls prohibiting entry of implausible values.

Providers testing the system in one state requested that the default units should be inches and pounds, with metric offered as an alternative option.
Pilot Testing

Planning and Selection of Testers

Pilot testing is undertaken to assess how the tool performs during actual clinical conditions. Ideally, the tool should be tested in settings that, collectively, include wide variation in provider and client characteristics. Important dimensions to consider include the following:

- Settings with and without electronic health records;
- Public and private facilities;
- Settings that use state-of-the-art obesity screening procedures and settings where minimal attention is typically paid to obesity screening;
- Urban and rural locations;
- Pediatric, family medicine, and other specialty settings; and
- Facilities with heavy Medicaid caseloads and those with primarily privately insured patients.

Example

In Michigan, providers were reluctant to participate in pilot testing because of the burden on staff members and patients to obtain patient consent. Where testing did go forward, no patients objected to having their data shared, and families were generally enthusiastic about being included.

Ideally, it would be useful to test all procedures as they would occur during actual tool deployment. However, the consent requirements that pertain to a pilot test may differ from those expected to be in effect during statewide deployment. For example, administrative rules allowing providers to share height and weight data with the registry may not be in place at the time of testing, necessitating special informed consent procedures for the pilot test. Conversely, data collected in the pilot may not actually be submitted to the surveillance system—for example, they could be collected in a test environment but never actually considered as data that are being shared by providers with public health officials. With such a scenario, consent might not be required for the pilot but could be required for actual registry deployment when data are being shared. In a situation like this, it would be best to test the informed consent procedures during the pilot, even if consent was not required. In considering consent requirements for the trial, keep in mind that different components of a system—such as use of behavioral surveys, clinical decision support sheets, and growth charts—could trigger different consent requirements.

Tailoring Pilot Test Protocol

Initial interviews or meetings should be held with administrators at pilot test sites to determine how the tool might best be tested in a particular setting. Based on this information, an ideal clinic flow can be mapped out for testing the registry BMI tool. For example, a clinic might be interested in accessing the clinical decision support tools in the registry if they are superior to those available in their EMR. That clinic would have to perform double entry of height and weight information during the pilot test period to provide feedback on using the BMI registry during a patient visit. If a clinic measures height and weight in a location far from computers, many changes to typical processes may be required to accommodate testing of the registry features. Recommended approaches to developing an optimal clinic flow are discussed in a later section of this guide.
Training

Organizers might choose to offer extensive training to some pilot test sites, while seeing how others perform in a situation likely to be more typical of startup of a new function in the real world—with minimal training. At least some sites, however, should receive hands-on training to ensure that they are fully familiar with all of the features they are expected to test.

Assessment

After sites begin using the system, it is beneficial to check in periodically to identify issues, answer questions, and understand how the pilot testing is progressing. The pilot testers may also have identified new defects that were unseen during internal testing.

Following the pilot test period, it is advisable to set up a focus group session with all clinic staff members and clinicians involved with or affected by the pilot testing process. This enables staff members to provide input and collectively identify barriers, benefits, or other feedback. There is also an opportunity to work with providers to understand the effectiveness of the clinical guidance tools for updates, clinic flow modifications, and patient feedback. Important feedback that can be gained during focus group sessions includes the following:

- The way BMI registry height and weight data entry fit into—or interfered with—clinic flow patterns;
- The final clinic flow that proved to be efficient for the clinic (with rationale);
- Provider (and staff) attitudes toward and experience with using the reporting functions;
- Physician and patient/family reactions to generating and using basic tools such as BMI growth charts during appointments;
- Physician and staff attitudes toward generation and use of the clinical decision support functions;
- Impact of the implementation of the BMI reporting and clinical features on childhood obesity prevention and management practices; and
- Clinic administrator interest in and use of summary reports from the registry.

Example

In Michigan, clinics that had ready access to computers were easily able to access the BMI screening tools and enter data for surveillance. By contrast, in clinics that did not have electronic health records, many changes were required to clinic flow to be able to access the registry during patient visits.
Feedback of Pilot Results for System Design and Implementation Planning

Example

Deploying the clinical decision support tools with the BMI surveillance system was not sufficient to overcome barriers providers face in conducting BMI screening and counseling. However, access to new tools can also generate considerable enthusiasm.

“I had no idea when I started this how excited the parents would be…[Printed growth charts were] so well received, regardless of the patient’s educational level. They have something to take home. That has been the most surprising thing for me. It also gives me an opportunity to give them support and say, wow, your kid is right in the groove! It also lets me be able to counsel them and give them additional support. For some patients, the dot isn’t even on the graph. I say, ‘See, your number is 39 and this graph only goes up to 32 and your dot would be here.’ They say, ‘What?’ It has created a lot of aha moments. Sad, but powerful.”

Source: SDIR BMI Pilot Test Results

Following completion of the post-pilot assessments, a report should be written to summarize findings from the pilot assessment. Implications for system revision and roll-out planning should be identified, including the following:

- Defects that must be fixed or that could be handled with instructions for simple work-arounds;
- High priority changes to make prior to deployment, including development of additional desired features that had not been identified during earlier needs assessment phases; and
- Communication and training priorities.

Once decisions have been made about which changes, if any, will be implemented, a timetable should be prepared or revised to plan for system deployment.

Sample pilot test protocols, and results of pilot testing are available upon request.79,81,113
7. Implementation

Plans for roll-out of the system should begin during late stages of system development. Several activities may proceed in tandem with pilot testing and final system revisions. Implementation planning will likely focus on ensuring that clinicians and their staff are prepared in the following ways:

- Understand why BMI data are being collected for surveillance purposes and how they will be used;
- Are familiar with clinical recommendations regarding BMI screening and know where to obtain additional training or referral resources, if needed;
- Understand their obligations to report height and weight measurements (if mandated);
- Understand requirements regarding patient notification and/or informed consent for exchange of height and weight data, if needed;
- Understand how to process patient opt-out requests or refusals to allow their height/weight data to be shared with the registry; and
- Are prepared to explain BMI screening and the rationale for surveillance to families.

Obesity prevention coalition partner organizations should be mobilized to support plans for system launch. Medical societies, state education and advocacy organizations, and government agencies should all be prepared to offer training in obesity screening and counseling. Health plans should clarify expectations regarding the importance of BMI screening and counseling in health care quality. Insurers should also clarify reimbursement policies.

Tips for Successful Implementation:

- Obesity prevention coalition partner organizations should be mobilized to support plans for system launch.
- Medical societies should be prepared to offer training in obesity screening and counseling.
- Health plans should clarify expectations regarding the importance of BMI screening and counseling in health care quality.
- Insurers should also clarify reimbursement policies.
Finally, staff members from various divisions within the health department should be prepared as needed to do the following:

- Train immunization registry personnel in the field to enter data into the system;
- Provide specifications for data extractions from electronic health records;
- Answer questions from data entry staff members and clinicians regarding obesity screening and referrals, reporting requirements, etc.;
- Monitor data collection for suspect data flags and overrides, coverage rates, accuracy, timeliness, and refusals/opt-out requests; and
- Ensure that data from families opting out are not included in the surveillance dataset.

The project team should plan to meet frequently during early implementation stages to address issues that arise and disseminate best practices as they become evident.

A couple of issues merit special consideration when planning for system deployment. These are discussed below.

### Integrating Surveillance and Clinical Tools into Clinic Flow

For settings where data will be entered into the registry manually (versus through automated extractions from electronic health records), consideration should be given to helping clinics think through optimal methods of organizing patient visits to accommodate entry of data into the registry. To maximize the efficiency and effectiveness of clinical tools, if included in the surveillance system, significant changes may be needed in how clinics process patients during visits. The model appropriate for one clinic may be very different from that of another.

Staff concerns with adding new processes for BMI surveillance often grow from a sense of exasperation at the thought of adding anything to an already overburdened system. Such frustrations were commonly noted when immunization registries were initially introduced. Yet experience shows that common sources of waste in clinical settings may be readily identified and eliminated. Techniques developed for reducing waste and error in manufacturing, such as lean production (Lean), can be applied to help clinics determine optimal ways to integrate BMI surveillance reporting into their usual procedures. Regional extension centers (REC) are using these techniques to help providers integrate EHRs into their clinics. The RECs might be a source of expertise for this process and, indeed, the EHR conversion might be an optimal time to build in more time for BMI screening and reporting.

Categories of waste identified in the manufacturing sector have been adapted for application to the health care sector. Shown below are examples of waste that could be eliminated through use of registry BMI tools or of waste in related processes whose elimination would free up time that could be used for BMI reporting.

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**During a Lean exercise, staff members who are involved in a particular process are asked to map out the “current state” showing how a particular process occurs. Once they identify where wasteful processes can be eliminated, a “future state” map is drawn to show how the process could be implemented more efficiently.**
Waste of overproduction (e.g., giving unneeded immunizations because not all
immunizations given in the past have been entered into the registry)

Waste of time (e.g., waiting for equipment or room cleaning)

Waste in transportation (e.g., needing to move scales or measuring boards across
the clinic area)

Waste of processing (e.g., hand calculating BMI values)

Waste of stock on hand (e.g., poor control of immunization inventory)

Waste of movement (e.g., staff member searching for charts or medication, fre-
quently needed supplies located far away)

Waste of making defective products (e.g., re-doing BMI percentile assessments
because they were computed incorrectly)

Lean value stream maps can be combined with Six Sigma (methods to reduce variation
and improve clinical quality) analyses to identify waste, minimize error, and improve
process flow. During a planned mapping exercise, staff members who are involved in
a particular process are asked to map out the “current state” showing how a particular
process occurs. Once they identify where wasteful processes can be eliminated, a
“future state” map is drawn to show how the process could be implemented more
efficiently. Software tools are widely available to represent these processes using charts,
graphs, and “spaghetti diagrams.”115 Tools specific to clinical settings have also been
developed to improve patient and office visit cycle times.116-118

Key steps needed to undertake process mapping and waste elimination are described
below.

A designated coordinator should pull together a team whose duties collectively represent
all functions involved in clinic visits. Ideally, the team would include an individual experi-
enced with Lean facilitation or process mapping, plus a clinic administrator, a physician,
a nurse, a medical assistant, a data entry clerk, and a patient representative. The team
begins by establishing a charter specifying the project goals, scope, and timetable.

The coordinator will plan and implement a session whereby team members identify
sources of error and waste—time spent that does not involve adding value to the patient
flow process. Team members diagram every step involved in a simulated patient visit.
Participants then note where waste occurs and when and how errors are introduced.
Findings from this “waste walk,” known as a “Gemba Walk” in Lean parlance, are
summarized in a current state value stream map. The map can be accompanied by a
chart listing the amount of time required for various team members for each step in the
process, and other direct costs such as immunization supplies.

Example

Using Lean methods, staff in a clinic were able to map out a process that reduced
the average time required for patient visits from 75 minutes to 45 minutes, resulting
in increased patient satisfaction, increased provider time with patients, and more
complete patient charting and billing.

Source: SDIR BMI Pilot Test Results79

Team members then suggest revised processes to reduce error and waste to capture
time that can be used for priorities identified by staff such as having clerks enter data into
the registry, print growth charts, and allow providers additional time to discuss growth
charts during patient visits. A model revised process is then diagramed as a future
state map, along with a chart showing the time required (plus direct expenses) for each
step using the new process. Total time for each staff member, plus costs, can then be
compared in the current and future maps to estimate the savings that could be expected
from new processes. Figure 7 illustrates the dramatic reduction in steps travelled by each staff person in the current state and future state models for patient flow.

Making change has costs as well. Therefore, the team must prioritize which changes should be made, and in what order. These decisions should be recorded in an action plan that identifies who is responsible for making each agreed-upon change, the resources required for the change, a timetable for making the change, and an indicator that will be used to assess the impact of the change once it has been made. The team should meet periodically to assess progress, holding team members accountable for their commitments on the action plan.

Figure 7. Illustrative Foot Path Taken by Staff Before and After Clinic Flow Re-engineering

![Illustrative Foot Path Taken by Staff Before and After Clinic Flow Re-engineering](image)

Wasteful processes identified: incomplete charting, billing, and registry data entry.
Improvements documented: wait time, patient satisfaction, and provider time spent with patients.
Source: Drawings courtesy of North County Health Services Lean Clinic Flow Re-engineering Team

Addressing Confidentiality and Data Sharing

The need to protect patient data has been recognized since the initiation of immunization registries dating back to the mid-1990s. National registry implementation guidelines have been updated regularly as federal information privacy standards have evolved to ensure the privacy and confidentiality of registry data. Nevertheless, patients may have particular concerns about having their weight data shared due to stigma and fear of discrimination in employment, insurance coverage, etc. In fact, a recent analysis found that 11 states allowed insurance companies to set higher rates for, or determine eligibility based on, obesity or health status (that would include obesity). While health insurance reforms expected to come into effect in the latter part of this decade will forbid these practices, concern about discrimination based on obesity data must be considered, whether or not it is based in fact.

As discussed in chapter 3, each registry operates within a unique legal environment. Rules and laws regarding a broad array of topics may have implications for ensuring that BMI data are legally shared with a registry. Guidance on changing laws and regulations to allow BMI reporting is beyond the scope of this guide. However, some of the more crucial steps needed to ensure that the addition of BMI data is compliant with federal and state laws, regulations, and registry implementation guidelines are described below. Key documents that may need to be developed or modified include the following:

- **Registry confidentiality policies.** Policies are maintained by every registry to define user responsibility and penalties for violating confidentiality.

- **Registry user agreements.** These documents are signed by individuals or organizations with access to registry data spelling out obligations and responsibilities of users and registry officials. A written statement certifying that users understand the
confidentiality requirements may be included with, or be separate from, user agreements. Special consideration might be given to user agreements with health plans regarding their access to individual-level patient BMI data due to consumer concerns about the potential misuse of weight-related information in making coverage decisions or setting plan rates.

- **Notices to families.** Notification is sent to families that their data are included in the registry. Families must be notified regarding the existence, purpose, and potential uses of the registry, and the information contained therein. These notices are based on a 1999 recommendation by the National Vaccine Advisory Committee and guidelines for their use have been updated regularly. If families receive stand-alone notices about the sharing of data for BMI surveillance, clinics should have available basic information about BMI, BMI surveillance, and measures taken to protect the privacy—and guard against misuse—of their information. Frequently asked questions have been developed for this purpose (http://www.altarum.org/research-initiatives-health-systems-health-care/improving-human-health-systems-mission-projects/BMI-FAQs).

- **“Opt-out” forms to decline participation in the registry.** Registries for which active consent is not required likely have notification procedures informing patients of their right to opt out of having their immunization data shared with the registry. In such settings, it would be useful to offer patients the opportunity to opt out of immunizations and not height and weight reporting, and vice versa. In other words, registries should take steps to ensure that patients who choose to opt out of reporting on one topic do not automatically opt out of the other.

- **HIPAA privacy notifications.** Patients sign privacy notifications to indicate their awareness of what data their providers share and with whom. If these notices mention data being shared with registries, the language might need to be updated to mention sharing height and weight data.

### Training

Outreach, promotion, and training should be planned prior to implementing registry-based BMI surveillance. Whether or not reporting is mandated, resources should be made available to train providers and their staff members in how to report height and weight data to the registry. In addition, whether or not clinical tools are included in the registry, training about the registry might be expanded to address considerable gaps in provider awareness of, comfort with, and effectiveness in implementing obesity screening, prevention, and treatment guidelines. While a review of general obesity training is beyond the scope of this effort, it should be noted that training has been shown to improve obesity screening and counseling practices. As health reform legislation might result in increased reimbursement for prevention counseling and obesity treatment, broader provider training might be especially timely.

There are many options for developing a training program to incorporate the registry-based BMI into clinic practice. Information from pilot testing should inform plans for widespread training (e.g., regarding efficient ways to use the registry in patient weight assessment and obesity prevention counseling). Training materials and processes should be developed in light of the likelihood that the registry will be used in different ways in different settings. Thus, in some settings, providers may enter data directly into the registry in the course of documenting the patient visit. In other settings, providers never see or touch the system and data entry is completed by clerks or medical assistants before or after patient visits.

Training may be conducted as hands-on sessions during medical education seminars, through regular meetings of registry user groups, through on-demand web-based videos or interactive methods, or through dissemination of print material. Many registries share...
information through user listservs or post training guides or online demonstrations on their websites.

**Using BMI Data**

**Data for Surveillance**

Existing registry query and reporting capacity varies considerably. All registries are supposed to meet minimum functional standards, which include the capacity for automated production of immunization coverage rates by provider, age group, and geographic area. Minimal effort should thus be required to generate the same reports but substituting obesity prevalence for immunization coverage. Clinic administrators could then generate prevalence and trend reports on all of their patients whereas health department users could do so for the state as a whole, or for various geographic regions. Collectively, these analyses should enable public health officials to better allocate resources to areas and populations in greatest need, and to assess progress in addressing the epidemic.

On the most basic level, aggregation of patient BMI data should facilitate assessment of overweight and obesity prevalence and trends. The registry’s query function should allow designated users to assess the distribution of a specified population into weight categories associated with BMI percentiles for those children. Obesity prevalence could also be explored according to various population characteristics of interest. If available in the registry, background characteristics such as ethnicity or health insurance status can be especially valuable for analyzing obesity prevalence and trends. As has been discussed previously in this guide, obesity trends could be explored in two ways: by looking at within-child differences (e.g., the proportion of children whose BMI percentile increased, decreased, or remained the same) or by looking at group differences over time.

The state’s epidemiologists and academic partners should collaborate with stakeholders to develop these core surveillance reports. For each report, protocols will be needed to determine which measurement to use on a given child if multiple measurements have been entered for a child in the given time period. Thus, for a report on the distribution of children by weight category, one might specify that the first measurement taken after a child’s birthday or after a specified calendar date would be the one used for analysis. Epidemiologist input will be crucial for understanding the extent to which data quality and quantity limit use of data for surveillance. Some may wish reports based on z-score values rather than percentiles. These scores reflect the standard deviation of a child’s value from the mean value in the reference population. This standardizes a child’s deviation from the mean by gender and age. Clinically and analytically, there may be times where raw BMI values, BMI percentiles or BMI percentile z-scores are most useful, particularly when assessing growth over time or changes in response to a treatment intervention. Thus, clinicians and analysts should provide input into how data are displayed on screen and in reports. A number of sources offer guidance on the strengths and limitations of various analytic approaches to BMI data.
Some registries have geo-spatial analytic tools that can provide powerful ways to understand links between environment, behavior, and human health. They can be particularly valuable in understanding and addressing disparities in immunization rates—an important national priority. Figure 8 shows a prototypical (i.e., fictitious) map illustrating the association between obesity and poverty. A recent report by Sage et al. includes maps showing the relationship between the concentration of obesity among San Antonio students and environmental factors such as the density of fast food outlets, green recreation space and availability of fresh produce. Notably, the authors describe the powerful effect the maps had on mobilizing community members to take action. The Department of Health and Human Services is making local-level health data and mapping applications widely available at www.data.gov/health. These resources could dramatically increase the value of real-time BMI data collected through a registry because of the opportunity to examine relationships between obesity and a host of health determinants and outcomes. However, it is crucial to ensure that conventions regarding privacy and data security be followed to ensure that reports—whether or not they incorporate spatial characteristics—are at a sufficient level of aggregation to preclude identifying individual patients.

Figure 8. Illustrations of Geographic Display of Obesity Prevalence Surveillance Data
Data for Program Planning and Evaluation

Surveillance reports of obesity prevalence and trends can be instrumental in planning, budgeting, directing, and evaluating local, regional, and state obesity interventions and policy changes. Cross-sectional looks at obesity prevalence could reveal geographic areas or population groups at higher or lower risk for obesity. Such information might lead to recognition that certain environmental characteristics are associated with lower rates of obesity in children, and in turn lead to more effective advocacy and mobilization of local resources. With relatively high or low obesity documented at a local level, these data might then be used to advocate for changes such as stronger school district nutrition and physical education policies, access to safe places for outdoor recreation, zoning laws that limit fast food establishments in communities, and more clear and generous reimbursement policies from health plans for obesity counseling.

Data for Clinical Systems Changes

If the surveillance system includes clinical features, there are a number of ways BMI data could be used to push for systems improvements. Minimum functional standards call for immunization registries to be able to produce reports to help providers ensure that children are fully immunized. Production of such reports is one way for providers to demonstrate meaningful use of a certified EHR. These reports could serve as templates for reports to ensure that all children receive annual BMI screening and counseling. Thus, reports generated at the patient, provider, and clinic levels could be used in the following ways:

- **BMI/counseling recall list by patient roster.** This report could produce a list of patients who have not had BMI screening for over a year and generate reminder letters to alert families to bring children in for assessments.
- **Current profile by provider.** This report could identify which children on the roster of visits on a specific day are due or overdue for BMI screening or counseling.
- **Current profile by patient ID.** This report could show the history of measurements and counseling activity to help providers know, at a glance, whether a specific patient is due for routine counseling or might require progression to more intensive efforts such as referrals to a nutritionist.
- **BMI profile by provider or clinic.** This report could provide a snapshot of patients in each BMI percentile category broken out by age, gender, or other criteria to help a clinic plan for service delivery to the patient population.
Data to Assess Clinical Quality

Various reports may be created for use in assessing the extent to which providers follow recommendations for BMI screening and counseling. While reports could also be generated to assess the relationship between weight change and receipt of counseling, caution is needed in drawing conclusions about differences in effectiveness because providers are unlikely to see similar patient populations. Established methodologies should be used to adjust for case mix and other factors unrelated to the quality of counseling that may affect the likelihood of weight change among patients. Nevertheless, as discussed previously, aggregate data on BMI screening and counseling are a promising new means of assessing obesity care quality, and registries are well-equipped to produce data for this purpose. Specific reports that could be useful for clinic administrators or health plan quality managers include the following:

- **Provider roster reports.** These could be used to show the proportion of a provider’s patients who have been screened and counseled in the prior year.

- **Clinic roster reports.** Could be used to assess disparities in screening and counseling rates according to sociodemographic characteristics such as age, gender, and health insurance status.

Evaluating the Impact of Better Surveillance Data

It may be useful to collect baseline data so that the impact of the registry could be determined, once the surveillance system is in use. Assessment topics and methods, of course, would be chosen to address the specific goals of a registry. Table 6 summarizes key topics that might be addressed and illustrative methods of collecting baseline data. A follow-up assessment would then be repeated after the registry is deployed. The time between baseline and follow-up assessments would differ according to the goal in question. Examples of assessment questions administered as part of a baseline provider survey in Michigan are available upon request. Resources developed to evaluate immunization registries offer excellent guidance for designing a baseline assessment. Consider collecting baseline data so that the impact of the registry can be assessed following its introduction. Progress toward meeting some goals may be assessed within a year while other goals may take several years until impact might be seen.
### Table 6. Baseline Assessment Topics and Methods

<table>
<thead>
<tr>
<th>Registry Goal</th>
<th>Key Assessment Topic</th>
<th>Assessment Method</th>
<th>Timeframe for Follow-up Assessments</th>
<th>Partner Organizations for Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase provider awareness of, comfort with, and self-efficacy in following screening guidelines</td>
<td>Provider knowledge of guidelines, comfort with, and feeling of self-efficacy in following screening guidelines</td>
<td>Surveys of providers</td>
<td>1–2 years following system introduction</td>
<td>State medical societies, health plan quality directors</td>
</tr>
<tr>
<td></td>
<td>Provider awareness of reimbursement methods, belief that screening and counseling will be reimbursed, and rates of reimbursement denials</td>
<td>Surveys of providers, Analysis of claims data</td>
<td>1–2 years following system introduction</td>
<td>State medical societies; health plans, Medicaid agency</td>
</tr>
<tr>
<td>Increase efficacy of obesity prevention and care</td>
<td>Do families recall providers discussing weight assessment and obesity prevention?</td>
<td>Survey of families</td>
<td>1–2 years following system introduction</td>
<td>Clinical practices</td>
</tr>
<tr>
<td></td>
<td>Is there a relationship between obesity screening and counseling and obesity rates?</td>
<td>Review of aggregate surveillance reports to correlate obesity prevalence rates and screening and counseling rates</td>
<td>Several years following system introduction</td>
<td>Medical societies; health plan quality directors</td>
</tr>
<tr>
<td>Improve quality of obesity prevention care</td>
<td>What proportion of providers screen and counsel families according to practice guidelines? What proportion of children with positive BMI screening results are referred for and receive appropriate follow-up care?</td>
<td>Review of claims data, Analysis of provider-level and practice-level registry data, Health plan and claims data</td>
<td>1–2 years following system introduction</td>
<td>State medical societies; health plan quality directors</td>
</tr>
<tr>
<td>Increase use of surveillance data by government and community stakeholders</td>
<td>To what extent are BMI data being used in program planning, evaluation, grant seeking, etc.?</td>
<td>Key informant interviews with stakeholders such as government officials and those working in organizations involved in obesity prevention. Number of requests for custom surveillance reports. Review of grant proposals, strategic plans, and annual reports indicating the extent to which data are being used in decision-making.</td>
<td>Years—once system is fully populated with data that could be used for surveillance</td>
<td>Health department staff, Nonprofit and academic organizations, Obesity prevention coalition members</td>
</tr>
</tbody>
</table>
Data on obesity in children are urgently needed to assess progress, understand disparities, and plan and evaluate obesity prevention programs. Immunization registries offer the potential to create a national BMI surveillance system based on state registries. Experience in planning for statewide adoption of BMI surveillance built on Michigan’s Care Improvement Registry and in expanding use of the BMI feature in San Diego County’s Immunization Registry offer a roadmap for further deployment of this promising strategy. Clinicians using the registry with limited features wanted more clinical features to be added. Some who had access to a system with more comprehensive clinical features were unable to take full advantage of them due to provider-related and logistical barriers. Those exploring the registry-based BMI surveillance model for use in other locations will make unique design choices. It is our hope that the results and thinking that have come out of the first two registries to attempt this model prove useful as the model continues to evolve.

Establishing a Common Standard

To create a national surveillance system, data from states must be aggregated. In the absence of national standards for reporting height and weight data to registries, efforts to add BMI to registries are proceeding on an ad hoc basis. States seeking to develop this capacity may do so in ways that could preclude ready aggregation for national-level analysis or exchange of individual patient data between states. At a minimum, defined standards for electronic exchange of height and weight should be followed. General specifications for HL7 exchange of registry data have been developed. However, while these specifications do cover birth weight, they do not cover all of the fields needed for BMI percentile calculation. More effective, however, would be the establishment of national standards in the form used for designated optional or required registry data elements.

Legislative Opportunities

In grappling with the need to better understand and efficiently address burgeoning rates of childhood obesity, numerous states have considered or enacted legislation to conduct surveillance of obesity in children. Most such efforts have been focused on aggregating information from measurements obtained from school settings. To date, few states have succeeded in generating comprehensive, high quality data for surveillance purposes based on this approach.

In recognition of the potential advantages of the registry-based approach, a number of bills were introduced in 2009–2010 that would support pilot testing of registry-based BMI surveillance in a number of states. At present, none has passed or received funding.
At the federal level, however, registry-based obesity surveillance could be encouraged, if not funded, through authorizations or appropriations to existing and emerging efforts including the following:

- Meaningful use incentives for providers to utilize electronic health records and to registries to improve linkages with EHRs;
- Evaluation requirements associated with funded programs related to obesity prevention including nutrition support, medical assistance, and managed care quality;
- Support to section 317b of the Public Health Service Act that provides funding for IISs to help states achieve Healthy People objectives around immunization coverage rates;
- Efforts to assess the impact of health reform through augmenting existing health surveillance systems with other existing data sources; and
- Evaluations of community level and policy interventions underway in communities around the country such as the Department of Health and Human Services’ flagship Community Health Data Initiative (http://www.hhs.gov/open/datasets/community-healthdata.html).

Those interested in pursuing legislative approaches are referred to an excellent resource for planning and assessing progress toward policy change. Even if registry-based surveillance were to be supported through federal legislation as described above, states pursuing registry-based surveillance would likely still need to address privacy and consent issues in state statutes and regulations.

**Sharing Knowledge Through Communities of Practice**

Communities of practice, groups of individuals and organizations with a common domain of interest, can be effective settings for sharing knowledge and generating innovative approaches and best practices. Immunization registry users have numerous venues for exchanging information about best practices in quality control and analysis, defining new standards for BMI data collection, communicating with families, etc. Examples focused on promoting immunization include the following:

- **Websites, newsletters, and task forces of professional associations:**
  - Every Child by Two—http://www.ecbt.org/
  - American Immunization Registry Association—http://www.immregistries.org/
  - Association of Immunization Managers—http://www.immunizationmanagers.org/
  - Immunization Action Coalition—http://www.immunize.org/
  - Partnership for Prevention—http://www.prevent.org/

- **Communication channels established by vendors of registry software.** HLN Consulting, for example, prepares “Insights”—briefs on issues of interest to the registries they support. HP regularly convenes users of the Wisconsin Immunization Registry (WIR) software from multiple states. Developed by EDS, HP currently provides additional programming and other support when contracted by states using WIR software. Similarly, Scientific Technologies Corporation issues white papers on topics of interest to the many states whose registries the company supports.

- **Efforts fostered by the CDC relevant to registries.** The CDC-sponsored annual National Immunization Conference brings together professionals from many sectors involved in immunizations, from product manufacturers to health professionals. The CDC also supports the Modeling of Immunization Registry Operations Workgroup.
to identify and disseminate best practices for registries. CDC’s National Center for Public Health Informatics, part of the Coordinating Center for Health Information and Service, sponsors Communities of Practice for those with common interests in public health information networks.

One CDC-supported effort is particularly well-positioned to foster knowledge transfer regarding registry-based obesity surveillance. The nonprofit Public Health Informatics Institute (PHII) promotes effective use of public health information and has projects focusing on both IISs and obesity prevention. They provide technical assistance to registries nationwide, and, through an arrangement with the Health Resources and Services Administration’s Maternal and Child Health Bureau, support Connections Communities of Practice to promote integrated child health systems. Numerous publications are available to support involvement of many types of stakeholders in the use of information systems for children’s health. Notably, PHII has recently completed an activity focused on the need for better information to support childhood obesity prevention efforts. With a grant from the Robert Wood Johnson Foundation, “Planning for the Development of Information Systems for Childhood Obesity Programs,” PHII produced a number of reports that, collectively, called for creation of a national strategy to increase availability of data to guide obesity prevention efforts and recognized the need for better methods to promote information exchange among professionals involved in obesity prevention.144-146

Most of the efforts described above are focused around immunizations and would not ordinarily attract professionals whose primary interest is in obesity prevention. Because registries are likely largely unknown to those concerned with obesity prevention outside the clinical realm, work needs to begin with building awareness of the potential for the registry-based obesity surveillance model. Potentially productive venues include the following:

- Communities of practice,147 conferences, webinars, listservs, or other dissemination vehicles related to health care quality, such as the annual HEDIS updates, or events sponsored by organizations such as AcademyHealth or the National Initiative for Children’s Healthcare Quality;

- Continuing education (and training) efforts directed at increasing provider awareness of, and effectiveness in, implementing obesity prevention guidelines—such activities are likely to be sponsored by state chapters of national medical societies such as the American Academy of Pediatrics, the American Medical Association, and the American College of Preventive Medicine148-151; and

- Multisector national and regional obesity prevention conferences, such as the CDC's Weight of the Nation or the Southern Obesity Summit.

Best practices in establishing new communities of practice have been articulated for those interested in learning more about this emerging method for knowledge creation and transfer.152
Appendix A. Definitions of Key Terms

**Body mass index (BMI)**

BMI is a number calculated from a person’s weight and height using this formula (Centers for Disease Control and Prevention, 2009a):

$$BMI = \frac{\text{weight (lb) \cdot 703}}{\text{height}^2 \text{ (in}^2)} \quad \text{OR} \quad \frac{\text{weight (kg)}}{\text{height}^2 \text{ (m}^2)}$$

BMI provides a reliable indicator of body fatness for most people and is used to screen for weight status categories that are correlated with increased risk for health problems. In children, BMI values are compared to a reference population to determine the child’s percentile in relation to other children of the same gender and age. Children with BMI values between the 85th and 95th percentiles are considered overweight, and those with BMI values that are above the 95th percentile are considered obese.153

**CDC IIS Core Data Set**

These elements represent fundamental attributes necessary for identifying individuals and for describing immunization events. Required elements are critical for record exchange purposes, client de-duplication, vaccine management, immunization status evaluation, reminder/recall, and data analysis or use purposes. The core data items fall into two categories: required and optional. Optional core data elements are less important for record exchange. Some optional items (e.g., address) may be useful only at the local level. The purpose of the core data element is to facilitate record exchange between IISs.16

**Clinical decision support**

Clinical decision support systems provide clinicians, staff, patients, and other individuals with knowledge and person-specific information, intelligently filtered and presented at appropriate times, to enhance health and health care. It encompasses a variety of tools and interventions such as computerized alerts and reminders, clinical guidelines, order sets, patient data reports and dashboards, documentation templates, diagnostic support, and clinical workflow tools.154

**Functional specification**

A document that describes the desired features of the surveillance system, its appearance, and the user interface.

**Healthcare Effectiveness Data and Information Set (HEDIS)**

HEDIS is a tool used by more than 90% of America’s health plans to measure performance on important dimensions of care and service. Altogether, HEDIS consists of 71 measures across eight domains of care.155
Health Level 7 (HL7)

Founded in 1987, Health Level Seven International (HL7) is a not-for-profit, ANSI (American National Standards Institute)-accredited standards developing organization dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery, and evaluation of health services.155

Immunization Information System (IIS)

Immunization information systems are confidential, population-based, computerized information systems that attempt to collect vaccination data about all children within a geographic area.156 Nearly every state has an immunization registry used by health care providers to track immunizations given to children. IISs are secure and efficient methods of ensuring that children are fully vaccinated for school entry, and that they do not receive duplicative services when seeing multiple providers. IISs currently permit states to assess the success of immunization programs, allocate vaccine supply, and rapidly assess immunization needs in the event of an outbreak.

Immunization Information Systems Annual Report (IISAR)

Available online, the IISAR presents results of an annual assessment conducted by CDC’s National Center for Immunization and Respiratory Diseases of IIS activity among recipients of funding from section 317b of the Public Health Service Act. Grantees include the 50 states, 5 cities, the District of Columbia, and 8 territories.156

Interoperability

Having the capacity for electronic health information exchange.

Lean Six Sigma

A continuous performance improvement methodology aimed at reducing waste and cutting lead time (Lean) while reducing variation and improving quality (Six Sigma). Lean Six Sigma is a balanced process that can be implemented at all levels and in any organization type to enable improved productivity and quality within a set time frame.

Meaningful use

The term “meaningful use” is used often when discussing electronic health records or electronic medical records. The Medicare and Medicaid EHR Incentive Programs, administered by the Centers for Medicare and Medicaid Services, provide a financial incentive for the “meaningful use” of certified EHR technology to achieve health and efficiency goals. The American Recovery and Reinvestment Act of 2009 specified three main components of meaningful use: (1) the use of a certified EHR in a meaningful manner, such as e-prescribing; (2) the use of certified EHR technology for electronic exchange of health information to improve the quality of health care; and (3) the use of certified EHR technology to submit clinical quality and other measures. “Meaningful use” means providers need to show they are using certified EHR technology in ways that can be measured significantly in quality and in quantity.157
References


