# The Challenges in Measuring Local Immunization Coverage: A Statewide Case Study

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There are many forms of existing immunization surveillance in the United States and Washington state, but all are limited in their ability to provide timely identification of clusters of unimmunized individuals and assess the risk of vaccine-preventable diseases. This article aims to: (1) describe challenges to measuring immunization coverage at a local level in the United States using Washington State as a case study; and (2) propose improvements to existing surveillance systems that address the challenges identified.

## CASE

As a pediatrician, you see a 12-monthold girl for her well-child visit. Her parents are unsure about giving her the measles-mumps-rubella vaccine. They are specifically concerned about measles and ask you if their daughter is really at risk for this disease. You tell them that although measles is not endemic to the United States, imported cases can occur at any time. You explain that the risk of developing measles depends on whether she comes into contact with someone who has measles, and that likelihood depends in part on the number of people around her who remain unimmunized. You try to look for local data regarding immunization coverage in their area, but give up because it is too difficult to find. Despite continued conversation with the family during the remainder of the visit about the importance of the measles-mumpsrubella vaccine, the parents ultimately decide against immunizing their daughter.

In early 2015, a traveler who had contracted measles overseas visited Disneyland while still infectious. Over

the next 4 months, 189 people across 24 states subsequently developed measles.<sup>1,2</sup> The scope of the outbreak was largely unanticipated since the United States and California, specifically, have high rates of immunization against measles. Before the outbreak, the proportion of children in California statewide who were adequately immunized against measles was 96% among children in daycare and 93% among children in kindergarten.<sup>3</sup> During the investigation of the measles outbreak, however, public health officials discovered that among the 16 measles cases in California who were 1 to 3 years old, only 6 (38%) were vaccinated against measles and among the 2 measles cases who were 4 to 6 years old, none were vaccinated against measles (J. Zipprich, PhD, personal communication, 2015).

The Disneyland measles epidemic demonstrates once again that outbreaks of vaccine-preventable diseases (VPDs) can occur when unimmunized individuals cluster together despite high rates of overall immunization.<sup>4</sup> Unimmunized

# abstract

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**To cite:** Wolf E, Rowhani-Rahbar A, Duchin J, et al. The Challenges in Measuring Local Immunization Coverage: A Statewide Case Study. *Pediatrics*. 2016; 137(5):e20153755 individuals can spread VPDs by living in the same neighborhood,<sup>5</sup> going to the same school,<sup>6,7</sup> attending the same church<sup>8</sup> or in the case of the Disneyland outbreak, frequenting the same tourist attraction.<sup>9</sup> Existing surveillance systems often do not have enough granularity to detect these clusters of unvaccinated individuals. In fact, the World Health Organization has identified heterogeneity in immunization coverage as a major risk factor for the spread of VPDs and note that this heterogeneity may not be evident through routine monitoring.<sup>10</sup>

Lack of timely and accurate local immunization coverage information limits the ability of public health agencies to identify clusters of unimmunized children who might be susceptible to VPDs and prevents healthcare providers from gauging the risk of VPDs in their patients. In addition, as the case in the beginning of this article illustrates, lack of precise information about VPD risk can promote a so-called "ambiguity aversion" against immunizations in parents. Ambiguity aversion regarding immunizations occurs when missing or conflicting scientific risk information leads a person to construct their own subjective risk assessments, which maximize the risk of immunizations and minimize the risk of VPDs.<sup>11</sup> This distorted risk assessment can therefore result in immunization refusal.

Like California, Washington state represents an opportunity to review challenges to childhood immunization surveillance, especially regarding the identification of clusters of underimmunized individuals. Washington has one of the highest nonmedical exemption rates for required kindergarten immunizations in the United States,<sup>12</sup> and similar to California, there is wide variation in immunization coverage<sup>13</sup> with proportions of unimmunized kindergarteners ranging from 0% to 50% among schools of different types and different geographic locations.<sup>14</sup> This article aims to: (1) describe challenges to measuring immunization coverage at a local level in the United States using Washington state as a case study; and (2) propose improvements to existing surveillance systems that address the challenges identified.

## CHALLENGES TO EXISTING IMMUNIZATION SURVEILLANCE SYSTEMS

The National Immunization Survey is designed to capture immunization trends in all 50 states, the District of Columbia, and 27 other high-interest urban areas.<sup>15</sup> Currently, only state-level estimates with relatively large margins of error are available for Washington State.<sup>16</sup> To gauge smaller-scale immunization trends, 1 of 3 data sources is typically used: (1) an integrated healthcare delivery database, (2) school exemption data, or (3) a state immunization registry.

# Integrated Healthcare Delivery Databases

Group Health and Kaiser Permanente are 2 examples of organizations that measure immunization uptake among their members in Washington state. These integrated healthcare databases can be quite useful in identifying clusters of unimmunized individuals who are enrolled in their plans.<sup>5</sup> However, Group Health and Kaiser Permanente contain only 16% and 2% of Washington State's market share, respectively.<sup>17</sup> These databases typically include proportionally fewer low-income families and may not be generalizable to the entire state. Furthermore, these data are not typically available to individuals outside these organizations.

# School Exemption Data

School exemption data make it possible for schools to identify which students are up to date with required immunizations, the proportion out of compliance but in the process of coming into compliance, and the proportion of students with immunization exemptions. Schools report their findings to the state, which, in turn, reports to the Centers for Disease Control and Prevention. Currently, all US states permit medical exemptions to immunization. Forty-seven states (with the exception of Mississippi, West Virginia, and, recently, California) also allow exemptions for religious reasons.<sup>18,19</sup> Washington is 1 of 19 states that also permits philosophical exemptions.<sup>12,18</sup> Washington State school exemption data can be helpful in understanding trends in reasons for immunization refusal (ie, medical, religious, or philosophical), and because these data are not subject to the same geographic and socioeconomic constraints as integrated healthcare databases, they are more generalizable.

Several problems exist with school exemption data quality, however, and these problems often vary by state. First, Washington is 1 of a few states that permit school data to be entered by families themselves, which can result in inaccuracies.<sup>20</sup> Second, reporting of school data often occurs before final immunization statuses are complete (thus leading to potential underestimates of coverage). Third, most states do not include homeschooled children in their school exemption data<sup>21</sup>; yet, vaccine refusal can be particularly pronounced among families that homeschool,<sup>22,23</sup> and VPDs are known to occur in these settings.<sup>23,24</sup> Fourth, exemption data from private schools, though required by law, can be more difficult to obtain. The logistic capability required to record and track immunization data is frequently lacking in private schools (L. Page, MPH, personal communication, 2016). This can be a substantial problem because certain private schools, although accounting

for a relatively small fraction of all students, usually have higher proportions of underimmunized children.<sup>25</sup> Lastly, budgetary constraints and inadequate staffing can prevent sufficient follow-up of underimmunized children.<sup>26,27</sup>

#### **State Immunization Registries**

## An alternative to school exemption data is a state immunization registry, also known as an immunization information system (IIS). IIS's

are "confidential, computerized, population-based systems that collect and consolidate immunization data from immunization providers."28 The Washington State Immunization Information System (WAIIS) is populated by birth certificates and includes every child born in Washington State. State registries are not subject to the same age limitations as school exemption data. In addition, data are generally entered by medical staff at the time that immunizations are given, so the databases are kept relatively up-to-date. There has been a notable increase in the use of state immunization registries in the past decade within Washington<sup>29</sup> and across the United States,<sup>28</sup> driven by the Affordable Care Act and so-called "meaningful use" incentives.30

There are, however, limitations to WAIIS and the other statebased registries. First, although participation, based on the percentage of children  $\leq 6$  years old with  $\geq 2$  immunizations, is high (96%) in WAIIS, it is as low as 16% in some state registries.<sup>31</sup> Indeed, New Hampshire is still in the process of establishing its IIS.<sup>32</sup> Second, what data are contained in a state immunization registry varies from state to state. Many registries, for example, do not record the child's school, which can make outbreak investigation quite challenging. Third, because registries operate at the state, rather than national, level, it is often impossible to distinguish

between an underimmunized child and one who has simply moved out of state.

## IMPROVING IMMUNIZATION SURVEILLANCE

### Establishment of a National Immunization Registry

One way to improve immunization surveillance is to establish a national registry. The Childhood Immunization Initiative Act of 1993 was originally introduced to Congress with language to do just this, but this language was later changed to instead allocate funding for states to establish their own registries.<sup>20,33</sup> The main benefit of a national registry is that it can help medical and public health officials more easily gauge local trends in immunization and detect clusters of unimmunized individuals.<sup>34</sup> This is evident from the experience of countries with national immunization registries, including Australia and many countries in Western Europe.<sup>35</sup> In the United Kingdom, for example, all administered immunizations are linked to local and national public health systems. Immunization data can also be disaggregated based on clinical characteristics or location. In the event of an epidemic, general practitioners can interrogate the system and contact underimmunized individuals (D. Salisbury, CB, FRCP, personal communication, 2015). Some national registries can also be linked with disease surveillance to help detect adverse events after immunization.36

Although well suited for surveillance purposes, a national immunization registry is unlikely to be established in the United States in the near future. The 10th amendment is frequently interpreted as allowing states to control their own immunization registries,<sup>37</sup> and 15 states have statutes that specifically prohibit immunization data sharing There are also several antivaccination groups that oppose a national registry out of fear of being "tracked" by the government.<sup>40,41</sup>

### Strengthening and Integrating State Immunization Registries

As an alternative strategy to establishing a national immunization registry, the federal government is attempting to strengthen and standardize state registries.<sup>42</sup> The National Vaccine Advisory Committee established functional standards for state immunization systems in 2001, which were updated recently by the Centers for Disease Control and Prevention.<sup>43</sup> These standards outline data quality goals and recommend that information should be available "to a wide range of stakeholders, including public and private care providers, public health programs, emergency responders, and many others." However, access to registry data by local health jurisdictions, physicians, and the general public can be quite limited since stakeholders are dictated by state law.43

Ideally, state registries would be compatible with one another and able to share information so that national assessments could be made and account for individuals moving from state to state.<sup>44</sup> Currently, 36 states permit immunization data to be shared between states and 29 of these report active data sharing data across state lines.<sup>38</sup> To expand data sharing between states, the nonprofit, Every Child by Two, in conjunction with the Department of Health Policy at George Washington University, drafted a model statute for data sharing that can be adopted by each individual state. Some groups have proposed the creation of a single data sharing agreement for all states similar to that governing the North American Association of Central Cancer Registries.<sup>39</sup> In 2014, the Office of the National Coordinator for Health Information Technology

outside of their own jurisdictions.<sup>38,39</sup>

launched a pilot program to exchange immunization data between Oregon and Washington State (2 states that had pre-existing data exchange agreements) through an Office of the National Coordinator for Health Information Technology–developed data hub.<sup>39,45</sup> This pilot program will allow for bidirectional data queries and real-time data sharing between the 2 states.<sup>46</sup> In the future, other states with compatible systems may also be connected to this data hub.

#### **Enhancing School Exemption Data**

In addition to improving the quality, accessibility, and compatibility of state registries, a key component to improving immunization surveillance is providing support to schools to improve the accuracy and timeliness of exemption data.

There is also a need to enhance reporting and enforcement of state immunization requirements in vounger children because outbreaks of VPDs are known to occur in early child care settings,47 and younger children can be at particularly high risk of complications from VPDs.48 Improving immunization coverage in early child care settings has even been shown to reduce the morbidity of VPDs in household contacts.<sup>49</sup> Although all states have immunization requirements for licensed daycares, head start programs, and preschools, there is currently great variability in the reporting and enforcement of these requirements.<sup>3,50–52</sup>

#### **Predicting Risk of VPD**

Because state registries typically include an individual's address, geospatial statistical techniques could be employed to identify underimmunized "hotspots." A good illustration of these techniques is a study that assessed the relationship between immunization and proximity to pediatric providers using the Washington, DC Immunization Information System.<sup>53</sup> Geospatial techniques could also be used to gather the data necessary to develop highly specific prediction models regarding which individuals are at risk for a VPD during an outbreak, because these predictions not only include the proportion of unimmunized (susceptible) individuals within a population, but also how likely susceptible individuals are to come into contact with one another.

### CONCLUSIONS

There are many forms of existing immunization surveillance in the United States and Washington state, but all are limited in their ability to provide the timely identification of geographic clusters of unimmunized individuals and assess the risk

of VPDs. Yet, these 2 features are emerging as important components of public health and clinical practice. Other developed countries are able to use national immunization registries to efficiently identify clusters of unimmunized individuals that are at risk for outbreaks of VPDs. In the absence of widespread support for such a national immunization registry within the United States, there should be renewed support for state and federal programs that enhance school exemption data and improve and integrate state immunization registries.

#### **ABBREVIATIONS**

 IIS: immunization information system
VPD: vaccine-preventable disease
WAIIS: Washington State Immunization Information System

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