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Funding Immunization Registries in Minnesota  
*Recommendations of the Commissioner's Task Force  
on Immunization Registry Funding*  
August, 2000

## Executive Summary

Immunization registries exist to prevent infectious diseases. They do this by centrally and securely storing individual immunization information that would otherwise be scattered across many health care providers. Registries alert patients and providers when shots are coming due or are past due. They can quickly assess the immunization status of a patient, a group of patients, or the entire population in a given area. Immunization registries are a powerful tool to better and more efficiently manage and protect data that is needed by the patients themselves, their health care providers, schools, day care facilities, and public health – all with the goal of preventing disease and disease outbreaks.

Currently, 57 of the 87 Minnesota counties are participating in regional registries, one of which recently received a prestigious top national honor for its high level of service and functionality.

But funding to date has been piecemeal and fragmented. The sources of funds through 2000 have included:

- Federal, through Section 317 Immunization funds to the state, reallocated by MDH to local health departments through Immunization Action Plan grants (1995-1998), registry demonstration grants (1994-1996), targeted registry operational grants (1996-2000), and support for MDH registry staff. Two rural registries also received direct assistance through the federal Office of Rural Health.
- State and local public health funds allocated by local health departments toward registry development and operations.
- Medical Assistance funding for children in the registry who are on MA.
- Health plan funding, either through direct support of some registries or through grants from health plan foundations.
- Private foundations, which supported several registries during critical expansion or software development phases.

In early 2000, the Center For Population Health, a public-private non-profit organization focused on collaborative approaches to achieving public health goals, was spearheading metro registry development, and urged the Commissioner of Health to convene a high-level registry funding task force. Commissioner Jan Malcolm readily agreed, and proceeded to convene a broad-based Task Force.

The charge to this Task Force was to “develop a comprehensive plan to secure adequate and sustainable funding for community immunization registries statewide.” The products of the Task Force were to include:

- a report and recommendations to the Commissioner of Health;

- updated cost estimates to fully operate a system of community registries across the state;
- a proposal for sharing the ongoing operational costs of registries, specifying the most appropriate mix of public and private funds;
- fact sheets on various aspects of the plan, such as the funding formula, the need for registries, and data privacy protections; and
- a communication strategy to ensure appropriate input during the development of the plan, and a broad base of organizational support in its implementation.

The Task Force was comprised of representatives from those organizations most closely allied to the operational and financial aspects of registries. Each of the seven regional registries also had representatives to ensure their input on both the operational status of registries and the funding needs.

Over the course of three meetings during the summer of 2000, the Task Force came to the following conclusions and recommendations:

- The goal for registries will be to include all age groups and all vaccines (eventually including influenza vaccine) but to approach this goal incrementally, starting with the 0-21 year olds.
- Since registries support the public good, they ought to be funded at the broadest level possible.
- The most appropriate model for ongoing stable funding registries includes both public and private funds.
- Key to any sustained funding is a statewide system of coordinated, "harmonized" regional registries with a state hub in place.
- The projected annual costs for registries in Minnesota will be based on an estimate of \$8.00/child/year through age six. That amounts to \$56 per pre-schooler to securely store and exchange their data, and send reminder-recall notices. That \$8.00 per child estimate will also be used as the basis for calculating costs in other age groups.
- Using the estimate above, total annual costs for community registries to include all children 0 – 6 years of age would be \$3.64 million. Total annual costs to include the entire population would be \$6.3 million, assuming no flu shots are tracked. Adding flu shots would raise the total to \$8.6 million annually
- An innovative approach to funding ought to be pursued, such a state tax on vaccines or negotiating lower vaccine costs for all Minnesota providers and using those cost savings to fund registries.

To assist the Commissioner of Health in crafting a strategy for securing stable funding for registries, the Task Force made the following recommendations:

1. The Task Force defines adequate funding as a level of stable, on-going funds sufficient for every regional registry and the state hub to meet national and state minimum standards for data security and operational functionality.
2. The amount needed for a statewide system that includes all residents and meets all standards is estimated by the Task Force to be \$7.3 million per year. Of this

amount, \$6.3 million is for regional registry operations and \$1 million for the state hub. This translates to \$1.53 a year or \$122 over a lifetime for each Minnesota resident to securely store their immunization record.

3. In seeking adequate funding for a registry system, the task force recommends the following principles to guide the Commissioner:
  - ⌘ Because the benefits of registries are broad-based, the sources of financial support should also be as broad-based as possible.
  - ⌘ Registry funding should not be over-reliant on any one funding source, nor comprised of too many sources.
  - ⌘ Because the benefits of a statewide system of registries accrue to both the public and private sectors, both sectors have an ongoing obligation to financially support registries. A per-time access fee as a source of registry funding should not be considered because it is an inherent disincentive to participating in the registry.
  - ⌘ Both collecting and distributing the funds should be as administratively simple as possible.
  - ⌘ Allocating the funds to community registries should be formula-based and non-competitive.
4. The funding sources analyzed by the Task Force which best balance the principles listed above are:
  - the current Medical Assistance/Child and Teen Check-up funding used to support registries,
  - a local immunization registry subsidy appropriated from the state general fund;
  - a state surcharge on all vaccines ordered by Minnesota providers, collected by the vaccine manufacturers at the time of ordering; and
  - a modest annual fee for all clinics and other entities using the registry.
5. An additional longer-term strategy that meets the funding principles is to encourage other states currently cooperating in the multi-state vaccine purchase cooperative to consider expanding the contract negotiations to include all vaccines for all providers, capturing the resulting savings in purchase price and applying them to registry operations. Because this is a long-term strategy with many factors outside of Minnesota's control, we recommend consideration of this as a back-up strategy if other sources fail to materialize.
6. Development and operational costs for registries should be kept to a minimum by standardizing key elements of registry design and operations, and sharing technical resources both across and within the agencies that operate registries.
7. Funding must be used to ensure registry operations meet national and state standards for data practices, and fully protect the privacy of all individuals participating in registries.

8. The Minnesota Department of Health must provide the necessary leadership in convening a broad-based coalition of supporters that can be successful in securing stable and adequate funding for immunization registries.

## Background

*[Note to Task Force: The body of the report will include pull-quotes and sidebars with background information on registries, such as that on the left.]*

Immunization registries exist to prevent infectious diseases. They do this by centrally and securely storing individual immunization information that would otherwise be scattered across many health care providers. Registries alert patients and providers when shots are coming due or are past due. They can quickly assess the immunization status of a patient, a group of patients, or the entire population in a given area. Immunization registries are a powerful tool to better and more efficiently manage and protect data that is needed by the patients themselves, their health care providers, schools, day care facilities, and public health – all with the goal of preventing disease and disease outbreaks. The vision for immunization registries for Minnesota was first articulated in 1993, then acted and built upon through the present. The vision calls for a decentralized and voluntary system consisting of provider-based immunization registries feeding into community (regional) registries, which in turn would link to a state hub. The vision standardized on data and registry functions, not on hardware and software.

Since 1993, we have been in a period of experimentation, growth, and evolution. Through the hard work and creativity of many public and private partners across the state, we have all learned a great deal about provider needs, the difficulties in merging and managing records from many sources, concerns about privacy, and a broad range of other challenging issues. We've certainly learned that registries are easy to grasp in concept but surprisingly hard to implement in practice.

How far have we progressed since 1993? In addition to the highlights noted in the sidebar, we have community registries operating or in planning stages in almost every county in the state. By the year 2000, 57 of the 87 counties were participating in regional registries, one of which received a prestigious top national honor for its high level of service and functionality. (See the registry fact sheet and maps in Attachment A.)

If the 1990's represented the first phase of registry development – a period of experimentation and learning – we are clearly in the second phase of registry development now. The focus today is on using best practices from the first phase

### *Chronology of immunization registry activity in Minnesota*

*1993 — Robert Wood Johnson registry planning grant*

*January, 1994 — Registry Work Group convened under the Commissioner's Task Force on Immunization Practices. Work group charged to develop guidelines for provider- and population-based registries.*

*April, 1994 — Part I of registry guidelines, Background and General Recommendations completed and approved.*

*December 1994 — Part II – Guidelines for Provider-based Registries completed and approved.*

*November 1994 — First local health department receives Acclaim ITS software. By 1998, a total of 41 agencies using Acclaim ITS.*

*1994 – 1996 — Registry demonstration grants.*

*1995 – 1998 — Statewide Immunization Action Plan grant program*

*1995 – 1996 — Supplemental funds to local health departments for provider-based registry development.*

*November, 1996 — Immunization registry conference*

*1997 — Part III guidelines on population-based registries completed and approved.*

*Chronology of immunization registry activity in Minnesota (cont.)*

*September, 1998 — Community Immunization Registry Toolkit released.*

*1998 — HumanSoft bankruptcy; loss of vendor technical support for Acclaim*

*April, 1999 — National All Kids Count conference held in St. Paul.*

*May, 1999 — Meeting of registry operators to begin discussion of Phase II state plan.*

*July, 1999 — Meeting of registry operators to set minimum functions for registries.*

*August, 1999 — Meeting of registry stakeholders to discuss ongoing funding strategies.*

*January, 2000 — Minnesota's Medicaid Program begins financial support for registries.*

*January, 2000 — The Blue Cross Foundation and MDH create a joint grants program for registry support in 2000*

*May, 2000 — The Southwest Minnesota Immunization Information System ties for first place nationally for "most fully functioning registry."*

*May, 2000 — Commissioner of Health convenes the Task Force for Immunization Registry Funding.*

to create more uniformity and consistency across registries. The focus today is also on regional versus individual county systems, and the design of the state hub has begun.

Having a coordinated statewide registry system is important for a number of reasons, including:

1. demonstrating to potential funding sources that a statewide system exists and that their clients will receive similar services no matter where they live or receive health care in the state;
2. creating greater efficiency in registry planning and implementation by adopting a core set of uniform functions and more readily learning from each other's experiences; and
3. responding to national surveys on the status of registry progress in Minnesota.

What is the vision for registries in Minnesota?

The vision for registries is that, by 2003, Minnesota will have 8 – 12 partially or fully operational regional registries that include every county in the state. These registries will have:

- 100% of local health departments participating;
- at least 65% of private providers actively participating;
- at least 75% of children 0 – 5 years of age enrolled and with immunization records;
- at least 25% of children 6 – 21 years of age;
- at least 25% of pneumococcal and Td vaccines recorded for adults 50 years of age and older;
- a lead local health department from each region coordinating\directing registry policies and operations;
- a public-private advisory or governing body;
- an "end user" advisory group to help ensure the registry is addressing providers' and other users' needs;
- the ability to meet all the minimum registry functions for Minnesota as defined by MDH (see *Minimum Functions for Community Immunization Registries* in **Attachment A**), including notification for enrollees;
- stable on-going funding from a minimum of different funding streams;
- the ability to securely exchange data with other registries, at least two of which can use standard formats such as HL7; and
- the authority and funding to create a state hub, all relevant policies in place, the design and testing complete, and most functionality implemented.

By 2005, Minnesota's regional registries will have:

- 100% of local health departments participating;
- at least 95% of private providers actively participating;
- at least 95% of children 0 – 5 years of age with immunization records;
- at least 65% of children 6 – 21 years of age; and
- at least 85% of pneumococcal and Td vaccines recorded for adults 50 years of age and older.

How have registries been funded to date?

Funding to date has been piecemeal and fragmented. Given that, it is all the more impressive how far regional registries in Minnesota have advanced. The sources of funds through 2000 have included:

- Federal, through Section 317 Immunization funds to the state, reallocated by MDH to local health departments through Immunization Action Plan grants (1995-1998), registry demonstration grants (1994-1996), targeted registry operational grants (1996-2000), and support for MDH registry staff. Two rural registries also received direct assistance through the federal Office of Rural Health.
- State public health subsidy allocated by local health departments toward registry development and operations.
- Local taxes allocated by local health departments toward registry operations.
- Medical Assistance funding for children in the registry who are on MA.
- Health plan funding, either through direct support of some registries or through grants from health plan foundations.
- Private foundations, which supported several registries during critical expansion or software development phases.

An estimated \$5 million has been spent on community immunization registries from 1993 through mid-2000 – a surprisingly small amount given the progress to date, particularly when viewed on an average cost per year basis.

## Responding to the Funding Need

Such piecemeal funding clearly cannot persist if we are to meet state and national goals for registry development in Minnesota. In early 2000, the Center For Population Health, a public-private non-profit organization focused on collaborative approaches to achieving public health goals was spearheading metro registry development, and urged the Commissioner of Health to convene a high-level registry funding task force. Commissioner Jan Malcolm readily agreed, and proceeded to convene a broad-based Task Force.

The charge to the Task Force members was to “develop a comprehensive plan to secure adequate and sustainable funding for community immunization registries statewide.” The products of the Task Force were to include:

- a report and recommendations to the Commissioner of Health;

- updated cost estimates to fully operate a system of community registries across the state;
- a proposal for sharing the ongoing operational costs of registries, specifying the most appropriate mix of public and private funds;
- fact sheets on various aspects of the plan, such as the funding formula, the need for registries, and data privacy protections; and
- a communication strategy to ensure appropriate input during the development of the plan, and a broad base of organizational support in its implementation.

The Task Force was comprised of representatives from those organizations most closely allied to the operational and financial aspects of registries (see charge and membership in [Attachment X](#)). Each of the seven regional registries also had representatives to ensure their input on both the operational status of registries and the funding needs.

## Summary of Task Force Meetings

Following are highlights and outcomes of each of the three two-hour meetings held by the Task Force.

### Meeting One: May 31, 2000

- Reviewed the history and purposes of immunization registries, and their cost, cost-offsets, and financing.
- Discussed various approaches to establishing a per child/person cost for registries.
- Decided that registries must include all vaccines given at all ages, phasing in by age groups beginning with children 0 – 21 years of age.
- Discussed what costs to include and exclude, particularly in terms of participating clinics and for public health follow-up of children behind in their shots.

### Meeting Two: June 27, 2000

The Task Force agreed on the following items:

- The goal for registries will be to include all age groups and all vaccines (eventually including influenza vaccine) but to approach this goal incrementally, starting with the 0-21 year olds.
- Since registries support the public good, they ought to be funded at the broadest level possible.
- The most appropriate model for ongoing stable funding registries includes both public and private funds.
- Key to any sustained funding is a statewide system of coordinated, “harmonized” regional registries with a state hub in place.
- The projected annual costs for registries in Minnesota will be based on an estimate of \$8.00/child/year through age six. That amounts to \$56 per pre-schooler to securely store and exchange their data, and send reminder-recall notices. That \$8.00 per child estimate will also be used as the basis for calculating costs in other age groups.
- Using the estimate above, total annual costs for community registries to include all children 0 – 6 years of age would be \$3.64 million. Total annual costs to include the entire population would be \$6.3 million, assuming no flu shots are tracked. Adding flu shots would raise the total to \$8.6 million annually

- An innovative approach to funding ought to be pursued, such a state tax on vaccines or negotiating lower vaccine costs for all Minnesota providers and using those cost savings to fund registries.

Meeting Three: July 27, 2000

In its final meeting, the Task Force accomplished the following:

- Developed principles for funding registries.
- Explored the advantages and disadvantages of various sources of public and private funds.
- Selected four funding strategies which best met the funding principles.
- Developed recommendations to the Commissioner.

## Issues in Funding Registries

The following issues were among the most critical or challenging during Task Force deliberations. They are presented here to reflect the thinking and conclusions of the Task Force.

*What is the annual financial need?*

The first critical issue was, of course, “how much are we talking about?” Finding that answer was not simple. Building community immunization registries is a complex task with many challenges. Since registries are still developing nationally, our knowledge of both operational costs and cost savings, while continually improving, is still incomplete. Two factors that have significant impact on costs are the level of registry functionality and the level of provider interaction.

Minnesota’s model for community immunization registries emphasizes strong relationships and effective use of both clinic-specific and population-based data. Because of these standards, it is expected costs in our state will be somewhat higher than systems in other states. Also, our decentralized approach to building community immunization registries – while important for community buy-in – has inherent inefficiencies which will likely affect costs.

The widely used standard for describing registry costs is to state them as a cost per year per child for ages 0 through 6 years. The figure most often cited nationally is \$5.00 per child per year, or an average of \$35 to manage the timely, complete, and accurate recording of a pre-schooler’s immunization record and making it available to authorized users.

Based in part on reported annual registry expenditures, and in part on the costs of Minnesota’s most mature registry (the Southwest Immunization Information System), MDH staff estimated \$8.00 per child 0 – 6 years of age as the cost of having fully operational registries across the state. That amounts to \$56 per child from birth through age six.

Among the reasons for using an estimate that is higher than the national average are:

- Minnesota's decentralized system calls for both regional registries and a state hub, while the national estimates are for single registry systems only.
- The national registries estimates are already several years old and reflected many registries with few services for users.
- The national average is just that—an average, with many registries costing more than the \$5.00 per child per year.
- Few of our current registries have expended much yet in the way of ongoing equipment outlays and technical support contracts.
- More and more vaccines are being approved, which complicates even more an already complicated immunization schedule, increasing costs in all major areas of registry operations, especially assuring data quality and conducting reminder-recall.
- The financial impact of national confidentiality standards (as part of the Health Insurance Portability and Accountability Act) on providers and public health information systems is still not known.
- The financial impact of creating interfaces with clinic practice management/billing systems and school information systems is unknown.
- The impact of a likely national certification/accreditation is unknown.
- Adding an inflationary factor is prudent.

For these reasons, MDH recommended the Task Force use \$8.00 per child as the cost figure for Minnesota, and to use that figure as the basis for calculating the cost per enrollee for all other age groups. Attachment C contains the calculations for each group, as well as the cumulative costs over the life span. MDH estimates that a person's immunization data will be submitted to a community registry 18 times during his/her lifetime, and disclosed from the registry (to providers, parent/enrollees, day care facilities, schools) 45 times, for a total of 63 data exchanges. Using the \$8/person figure, each of these exchanges would cost ~\$1.50, for a lifetime cost per person of \$98.63. In other words, for less than a hundred dollars, every Minnesotan can have his or her immunization record stored in a secure regional system that will ensure its completeness, its accuracy, and its availability to that person and to any authorized entity. State hub costs add another \$23.37 for a total lifetime cost per person of \$122.

*What registry –related costs are included in this estimate?*

The costs described in this report have been to directly operate community registries and a state hub. There are, however, other activities and costs that are critical to registry effectiveness. Foremost among them are costs of clinic participation and local public health follow-up on individuals who are seriously behind in their shots. The table on the next page details some of the other costs, which are considered to be in-kind contributions to making a community registry effective for all the users. Note that the center column specifies the minimum registry functions being addressed by the Task Force. Community registries which want to go beyond the minimums need to find other sources of funding to support those activities.

*What age span would be included in registries?*

The initial focus of registries has universally been pre-school age children. But as registries mature, the question of adding other age groups naturally arises. The rationale for other age groups discussed by the Task Force include:

6 – 21 year olds: Including adolescent immunizations would support enforcement of the school immunization law and also support documentation requirements for college entrance. Also, registries currently receive funding from the state Medicaid Program for children in this age group who are on Medical Assistance or Minnesota Care.

21 – 50 year olds: Few adults can state with much certainty when their last tetanus shots was. Emergency room access to this data will prevent unnecessary booster immunizations. Health care workers and other occupations can also more readily document their immunizations against measles, mumps, rubella, and hepatitis B. Adding this age group adds little to the overall cost of registries because there is little reminder-recall or other activity.

51+ year olds: Pneumococcal vaccine is recommended for all people over the age of 65. One to two doses are recommended to prevent life-threatening disease. Yet tracking whether this vaccine was given has been very challenging because of the number of health care providers seniors typically see, often in more than one state. Registry tracking of pneumococcal vaccines, as well as tetanus boosters, could both prevent disease in a vulnerable population and reduce unnecessary immunization due to the absence of documentation. Both would help contain health care costs.

Task Force members quickly concluded that, even though adding other age groups would greatly expand the scope and costs of the registries in Minnesota, achieving the full cost-effectiveness of registries would only come when all ages were included.

*What about tracking flu shots?*

The question of tracking influenza vaccines was one of the few issues the Task Force had difficulty resolving. Tracking flu shots in just the 50+ age group would increase total annual registry costs by more than a third, almost \$2.5 million a year. This for a vaccine that is repeated yearly, has lots of publicity, many traditional and non-traditional settings to receive it in, and little economic or health consequences if two doses are given in a year.

The number of flu doses given in non-traditional settings both argues for and against including flu tracking. The lack of any system for getting patient data to a registry would involve establishing new reporting and training systems statewide. On the other hand, the need for a central location for recording this data is particularly acute given the variety of settings in which flu shots are given.

## Costs/Activity Areas Related to Community Immunization Registries

Clinic Activities/Costs to Participate in a Registry	Community Registry Operational Activities/Costs	Local Public Health Activities/Costs
<p>Minimum Activities:</p> <ul style="list-style-type: none"> <li>• Send timely, accurate, and complete medical record or billing data to the registry.</li> <li>• Query the registry for records.</li> <li>• Verify/correct questionable data returned to the clinic by the registry.</li> <li>• Review and act on clinic-specific reports identifying quality improvement strategies suggested by the data.</li> </ul> <p><i>These costs will vary greatly depending upon factors such as the method for submitting data to a registry, how accurate and complete the data is, staff salary levels, decision-making processes, and the degree of annual patient "churning." For all practical purposes, these costs are inestimable. While most of these activities would be new to a clinic, participating in a registry would save considerable time in other related activities such as chart pulls, copying immunization records for parents, etc.</i></p>	<p>Minimum Activities (from <i>Minimum Functions for Community Immunization Registries in Minnesota</i>):</p> <ul style="list-style-type: none"> <li>• Involve providers and the community.</li> <li>• Store core data set.</li> <li>• Establish records on all newborns.</li> <li>• Notify all individuals included in the registry.</li> <li>• Permit parent/individual right to opt out without penalty.</li> <li>• Record access; audit trails.</li> <li>• Ensure timely provider reporting.</li> <li>• Ensure timely access to data by authorized users, including schools.</li> <li>• Authorized users of immunization registry data.</li> <li>• Protect confidential medical information.</li> <li>• Provide data privacy training.</li> <li>• Predict immunizations.</li> <li>• Provide reminder and recall notices.</li> <li>• Clinic-specific (HEDIS and other QI) and population-based (e.g., county, regional, zip code) reports.</li> <li>• Produce individual immunization records.</li> <li>• Merge and deduplicate immunization records.</li> <li>• Have and practice a plan for recovering lost data.</li> <li>• Exchange records securely.</li> </ul> <p><i>These are the costs the Commissioner has convened the Task Force to address.</i></p>	<p>Minimum Activities:</p> <p><i>[NOTE: The first four bullets would also pertain to schools that administer shots.]</i></p> <ul style="list-style-type: none"> <li>• Send timely, accurate, and complete medical record or billing data to the registry.</li> <li>• Query the registry for needed records.</li> <li>• Verify/correct questionable data returned to the clinic by the registry.</li> <li>• Review and act on county-specific reports.</li> <li>• Conduct follow-up on children more than two months behind.</li> <li>• Assure located children receive due immunizations and other well-child care.</li> </ul> <p><i>These costs include both those related to being a provider of immunizations and those unique to a health department; namely, assuring those not presenting for immunizations/well-child care are located, any barriers addressed, and then encouraged to present to their medical home. The portion of the latter costs related to families on Medical Assistance is currently covered through the Child &amp; Teen Checkup program.</i></p>
<p>Optional Activities:</p> <ul style="list-style-type: none"> <li>• Send reminder notices to patients.</li> <li>• Send recall notices to patients.</li> <li>• Serve on registry governing or advisory groups.</li> </ul>	<p>Optional Activities:</p> <ul style="list-style-type: none"> <li>• Produce immunization status reports for WIC.</li> </ul>	<p>Optional Activities:</p> <ul style="list-style-type: none"> <li>• Meet with private clinic staff on clinic-specific and other reports, identifying quality improvement strategies.</li> <li>• Serve on registry governing or advisory groups.</li> </ul>

After much discussion, most Task Force members believed the prudent course of action was to focus on all other universally recommended vaccines in all age groups before systematically collecting influenza vaccine data for any age group.

*Will the annual estimate include the costs for a state hub?*

Task Force members were resolute in wanting a statewide system of registries that included a state hub. Such a hub would enable a single point of access for statewide entities like health plans and the Medicaid Program. It would also facilitate secure exchange of immunization records as families move within and outside the state. Based on this belief, the Task Force recommendations to the Commissioner include adequate funds to support state hub operations, estimated to be around \$1 million a year (see Attachment D for estimated state hub costs.)

*Who should provide ongoing financial support for registries?*

Because the issue of “who should pay?” was a delicate one, the Task Force was asked through a survey to score their level of agreement or disagreement with a series of value statements. The value statements are included below and in Attachment E.

*“Because the primary rationale for registries is to protect the public health, it is most appropriate that registry funding be provided primarily or entirely by the public sector (that is, a mix of federal, state, local, and Medical Assistance funds).”*

*“Because the private sector (individual clinics, health systems, and health plans) benefits most from registries (including financially), it is most appropriate that registry funding be provided primarily or entirely by the private sector.”*

*“Because both public health and the private sector benefit from registries, it is most appropriate that funding be provided by some combination of both public and private funding.”*

*“Because active clinic participation is critical to an effective registry, anything that acts as a disincentive to clinics, such as fee for service arrangement, is inappropriate as a long-term funding source.”*

*“Private funds are too subject to the vagaries of the economy, politics, and the health care business environment to be considered stable and ongoing.”*

*“Schools could see a significant reduction in staff time spent collecting and recording immunization data, so schools should also contribute financially to the ongoing support of registries on either a fee-for-service or other basis.”*

*"We can't expect the private sector, either health care delivery or philanthropic side, to maintain a long-term commitment to registries, so it makes sense to have it invest up-front to complete a statewide system.*

*"The current clinical benefits of registries may largely disappear in the future as electronic medical records become more of a reality. Therefore, we can't assume that long-term private sector funding of registries is appropriate.*

*"The rationale behind the Health Care Provider Tax was one of equity, assessing a fee that would apply proportionally to self-funded, commercial, and government plans. That rationale, through whatever mechanism, also makes sense for funding registries."*

Respondents favored a mix of public and private funds, strongly disagreeing with private sector only funding and leaning slightly away from public sector only. Neither fees for clinics nor schools were looked at favorably, based on an assumption the fee would be an access or "click on" fee. Members were open to an equitable tax but not to private funds completing and sustaining the work done to date through public funds. While private funds generally were not seen as being stable, only one member thought private funds should be excluded from the mix.

The advantages and disadvantages of different funding models were also discussed (see *Analysis of Public and Private Funds for Registries* in Attachment F). Based on this discussion, the members reached consensus on four models that best fit the principles they outlined for the Commissioner. Each is discussed below.

#### Medical Assistance

This funding stream was created by the Department of Human Services in 1999 to financially support registry activity for children 0 – 21 years of age who are on Medical Assistance or MinnesotaCare. Funding levels are determined by establishing a statewide reimbursement rate based on previous calendar year registry expenditures. Any registry that meets the minimum functional requirements is eligible for these funds.

#### Local Registry Subsidy (Grant? Aid? Endowment?)

This annual appropriation would come from the state general fund to MDH for allocation on a formula basis to all eligible registries. While a new categorical grant is not consistent with the Department's principles for financing local public health programs, creating a new block grant is perhaps preferable to attaching "strings" to any increase to the Community Health Services Subsidy. Rolling the registry funding into a larger disease prevention and control or maternal-child health funding initiative is also possible.

#### State Vaccine Surcharge

This funding option would add a surcharge to every vaccine purchased in the state. The surcharge would not apply to the federally provided vaccines through the Vaccines for Children program, which provide approximately 25% of the vaccine

used in the state. The surcharge would be either paid or collected by the vaccine manufacturers, transferred to the state Department of Revenue, who would forward it to MDH for allocation to the registries. If this source were to support the total cost of registry operations statewide, including the state hub, the surcharge would amount to \$1.80 per antigen. In other words, a dose of measles-mumps-rubella vaccine would have a surcharge of \$5.40 (\$1.80 x 3 antigens). (See *Exploring the Vaccine Surcharge Option* in Attachment G for more information on how the surcharge amount was calculated.) A similar per-antigen surcharge is used nationally to fund the Vaccine Injury Compensation Fund. A national registry surcharge has been proposed but not acted upon to date.

Such an approach is consistent with the “user tax” approach currently favored by many policy makers. It also would provide stable funds that automatically increase as new vaccines are added and need to be tracked by registries. Finally, once established, this funding mechanism would basically be automatic and “institutionalized.”

The biggest disadvantage is obviously the likely increase in vaccine cost for Minnesota residents. This is an issue particularly for those individuals whose health insurance does not cover vaccines. Even if the intent of the surcharge were that it come from vaccine manufacturers, it is hard to imagine those costs would not be passed on to health care providers and ultimately to payors and consumers.

Task Force members were quite concerned about the potential for increasing the costs of vaccines, and were clear that, if enacted, this funding mechanism could not provide the entire annual funding need. An intriguing prospect, however, lies in a possible reduction in the national vaccine injury surcharge. If that happens, Minnesota could add a registry surcharge in the same amount as the national surcharge reduction, achieving both level vaccine costs and ongoing financial support for registries.

#### Annual User Fee

This funding mechanism ensures those who benefit from registries also help support registry operations. For this approach, the Task Force envisioned:

- a modest annual fee, low enough to not serve as a disincentive to any user;
- that the “user” would be at the organization/entity level, not at the individual level; and
- all users would pay, including clinics, local public health, schools, and health plans.

The Task Force did not discuss whether the fee would differ for different levels of participation in a registry (for example, a school versus a clinic), nor did it discuss whether regional registries or MDH would collect the fee.

## Funding Principles and Other Recommendations

To assist the Commissioner of Health in crafting a strategy for securing stable funding for registries, the Task Force made the following recommendations:

1. The Task Force defines adequate funding as a level of stable, on-going funds sufficient for every regional registry and the state hub to meet national and state minimum standards for data security and operational functionality.
2. The amount needed for a statewide system that includes all residents and meets all standards is estimated by the Task Force to be \$7.3 million per year. Of this amount, \$6.3 million is for regional registry operations and \$1 million for the state hub. This translates to \$1.53 a year or \$122 over a lifetime for each Minnesota resident to securely store their immunization record.
3. In seeking adequate funding for a registry system, the task force recommends the following principles to guide the Commissioner:
  - Because the benefits of registries are broad-based, the sources of financial support should also be as broad-based as possible.
  - Registry funding should not be over-reliant on any one funding source, nor comprised of too many sources.
  - Because the benefits of a statewide system of registries accrue to both the public and private sectors, both sectors have an ongoing obligation to financially support registries. A per-time access fee as a source of registry funding should not be considered because it is an inherent disincentive to participating in the registry.
  - Both collecting and distributing the funds should be as administratively simple as possible.
  - Allocating the funds to community registries should be formula-based and non-competitive.
4. The funding sources analyzed by the Task Force which best balance the principles listed above are:
  - the current Medical Assistance/Child and Teen Check-up funding used to support registries;
  - a local immunization registry subsidy appropriated from the state general fund;
  - a state surcharge on all vaccines ordered by Minnesota providers, collected by the vaccine manufacturers at the time of ordering; and
  - a modest annual fee for all clinics and other entities using the registry.
5. An additional longer-term strategy that meets the funding principles is to encourage other states currently cooperating in the multi-state vaccine purchase cooperative to consider expanding the contract negotiations to include all vaccines for all providers, capturing the resulting savings in purchase price and applying them to registry operations. Because this is a

long-term strategy with many factors outside of Minnesota's control, we recommend consideration of this as a back-up strategy if other sources fail to materialize.

6. Development and operational costs for registries should be kept to a minimum by standardizing key elements of registry design and operations, and sharing technical resources both across and within the agencies that operate registries.
7. Funding must be used to ensure registry operations meet national and state standards for data practices, and fully protect the privacy of all individuals participating in registries.
8. The Minnesota Department of Health must provide the necessary leadership in convening a broad-based coalition of supporters that can be successful in securing stable and adequate funding for immunization registries.

## Attachments

Attachment A – Fact sheets on registries in Minnesota and maps depicting registry progress

Attachment B – *Minimum Functions for Community Immunization Registries in Minnesota*

Attachment C – “Estimated Costs for Community Immunization Registries by Age Group”

Attachment D – “Minnesota State Hub Budget Estimate”

Attachment E – Survey on Task Force members values and preferred funding models

Attachment F – “Analysis of Public and Private Sources of Funds”

Attachment G – “Exploring the Vaccine Surcharge Option”

Attachment H – All Kids Count policy brief on funding registries