

**THE PROGRAMMATIC REGISTRY OPERATIONS WORKGROUP (PROW)
PROJECT FOCUS GROUP**

**PROMOTING PARTNERSHIPS BETWEEN IMMUNIZATION REGISTRIES
AND IMMUNIZATION PROGRAMS**

Immunization Program Needs and the Role of Immunization Registries

A Report on the Focus Group Conducted at the Program Managers Annual Meeting

Conducted by: **The American Immunization Registry Association (AIRA)
with support from the Centers for Disease Control and
Prevention (CDC).**



I. PURPOSE

As part of the deliverables for the AIRA/CDC/PROW (Programmatic Registry Operations Workgroup) Project, a focus group was held on Friday, January 25, 2002 in Atlanta at the Immunization Program Managers Annual Meeting. The purpose of the group was to discuss key findings of the PROW Survey on *Immunization Registry Support of Immunization Programs* and to seek input on the PROW Project. The outcomes from the focus group will provide additional data for the work of the PROW who will be charged with the planning and development of registry programmatic standards to support immunization program core functions.

II. FORMAT

The focus group was a one hour and forty-five minute session. It was co-facilitated by Sue Salkowitz, Consultant and AIRA Board member and Cindy Sutliff, AIRA Executive Director. The format was designed to be informal and interactive and included the following:

- Opening: Group Introductions
- Introduction: Purpose of Focus Group
- Transition: Questions that Frame Key Areas
- Key Questions: Questions designed to get insight into key issues
- Ending: Brings closure to discussion.
- Summary: Identifies common themes; notes different views; things not mentioned. Includes a final question and thanks.

III. QUESTIONS

The focus group used a series of questions that were designed to expand on the information gathered from the PROW survey and to get a sense from the group regarding the concept of programmatic registry standards. There were three main transition questions and 10 key questions. The entire questioning period was recorded to assist in the final analysis.

See attached list of Focus Group Questions

IV. KEY FINDINGS

Registry Functions

- Although survey responses indicated that there was uncertainty regarding *registry functions*, focus group participants indicated that basic registry functions are clear to immunization program managers. Responses on the survey may have been a result of how the question was phrased.
- Focus group participants identified prioritization as an issue. Funding issues often create a “pull” on registry priorities.

Program Core Functions

- Respondents did not rank **vaccine safety** in the top five on the survey, as a function that they felt immunization registries would be helpful in supporting. Focus group participants felt that registries should have the ability within the system to support vaccine safety core functions citing again that perhaps the phrasing of the question may have resulted in the survey outcome. Some issues they identified related to vaccine safety included provider reporting of manufacturer and lot number data, legal issues in some states about how records are classified and the recording of adverse events.
- Using immunization registries in supporting immunization program **provider and consumer education** core functions appeared to be a low priority based on the survey responses. Focus group participants felt that web-based registry systems are effective in provider education. Those registries that are moving toward a Web-based system also expressed hope for high usage by school nurses and day care providers. Other ways of supporting consumer communication/education cited included broadcast fax capability. WIC access/integration was cited as working in some registries and as an issue for others.
- The survey results indicated a high percentage of registries currently collect data on adult immunizations. Although few registries were used during the recent **bioterrorism** activities following the September 11, 2001 terrorist attacks, respondents to the survey indicated that they expected to use their registry in future bioterrorism activities if required. Focus group participants were supportive of incorporating registries into their **bioterrorism preparedness** plans and submissions for grant funding and for having registries become a part of the larger, integrated public health information system.

PROW Project

- Developing and recommending programmatic registry operations standards to the CDC is a key activity of the Programmatic Registry Operations Workgroup (PROW). Focus group participants in general were supportive of this initiative citing, however, that programmatic standards should have a low threshold for meeting minimum requirements so that all registries, no matter what stage of development they are at, have the opportunity to reach those goals.
- Utilizing a “lessons learned” model via a specific Web page on a designated Web site that would also allow for information exchange and the testing of different systems/models was cited by the participants as something that would be helpful and would add to the success of the initiative. Creating a mentor (peer-to-peer) support group was another suggestion for ways to increase the success of the project.
- Advantages to the PROW initiative were seen as a way to build capacity within registries, increase communication between registries and immunization programs, more productively establish collaboration with private providers and create a model for collecting and sharing best practices that continue to support and give credence to the benefits of registries.
- Issues as opposed to disadvantages that were raised included finding a way to rate/evaluate the standards. Participants raised the question: What happens if programmatic standards are not met?

V. CONCLUSIONS

- Programmatic registry operations standards will be useful in improving registry capacity and enhancing the overall effectiveness of immunization programs.
- Guidelines for assessment/evaluation of the standards should reflect a simple self-assessment, goal-setting model that might also incorporate a peer-to-peer evaluation process.
- Best practices should be used to provide models of “lessons learned” and to promote replication.
- Integrating registries into the larger public health information infrastructure is a desirable outcome.

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FOCUS GROUP
January 25, 2002

Immunization Program Needs and the Role of Immunization Registries

Conducted by: The American Immunization Registry Association (AIRA)

QUESTIONS

Opening: 10 min

1. Tell us your name.

2. **Introduction: 5 min**

The purpose of the focus group is for us to further discuss the key findings of the survey on *Immunization Registry Support of Immunization Programs* and to seek your input on the Programmatic Registry Operations Workgroup (PROW) project. (Show slide # one of Amy's presentation again for project background and project activity review). Information from this focus group will be used to inform the work of the PROW.

Transition: 20 min

- **As Program Manager what do you expect from your registry?**
- **What are you currently getting?**
- **What do you want to get in the future?**

Key Questions: 40 min

1. 68% of all responses on the survey indicated that *registry functions were not clear*. When you hear "immunization registry" what comes to mind?
2. The survey asked you to rank the core functions that you feel Immunization Registries would be most helpful in supporting. The functions that emerged as most useful to you were:
 - Reminder/Recall
 - Coverage Assessments
 - Provider visits-AFIX

Vaccine safety was NOT ranked as a priority. Do you see a role for the immunization registry in supporting this function? What activities do you see registries doing?

3. Consumer and provider education were barely mentioned. Should they have been? How could the immunization registry be used to help in your program provider and consumer education function?
4. How else would you like to be helped by the immunization registry?
5. What changes are necessary for your program to be able to get this type of support from the immunization registry?

Ending: 20 min

1. One of the key activities of the PROW is to recommend programmatic registry operations standards to the CDC. Do you see a need for programmatic operations standards for registries?
2. What do you see as the advantages/positive aspects of the PROW project?
3. What do you see as the disadvantages/negative aspects of the PROW project?
4. For the PROW project to be successful what do you think needs to happen?
5. Would you be interested in participating on the PROW?

Summary: 5 min

Summarize common themes, different views from the discussion.

Final Question: Think about what we discussed today. Have we missed anything?

Thank you.