

until 5 p.m. on Monday, Tuesday, Wednesday and from 8:30 a.m. until 12 noon on Thursday. The sessions will be held at the Washington National Airport Hilton, 2399 Jefferson Davis Highway, Arlington, Virginia 22202. The purpose of this meeting is to discuss the Federal Depository Library Program. The meeting is open to the public.

A limited number of hotel rooms have been reserved at the Washington National Airport Hilton for anyone needing hotel accommodations. Telephone: 800-HILTONS, 703-418-6800; FAX: 703-418-3763. Please specify the Depository Library Council when you contact the hotel. Room cost per night is \$124.

Michael F. DiMario,

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[FR Doc. 98-7615 Filed 3-23-98; 8:45 am]

BILLING CODE 1520-01-P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

National Vaccine Advisory Committee Meeting

The National Vaccine Program Office of the Centers for Disease Control and Prevention (CDC) announces the following meeting:

Name: National Vaccine Advisory Committee (NVAC) Immunization Registries Workgroup on Privacy and Confidentiality.

Time and Date: 9 a.m.-5:30 p.m., April 6, 1998.

Place: The Hilton at Riverside, 2 Poydras at the Mississippi River, New Orleans, Louisiana 70140, telephone 504/561-0500.

Status: Open to the public, limited only by space available. The meeting room accommodates approximately 400 people.

Purpose: During a White House ceremony on July 23, 1997, the President directed the Secretary of Health and Human Services (HHS) to work with the States on integrated immunization registries. As a result, NVAC has formed a workgroup, staffed by the National Immunization Program (NIP) which will gather information for development of a National Plan of Action for Immunization Registries.

To assist in the formulation of this work plan, a series of public meetings, relating to (1) privacy and confidentiality; (2) resource issues; (3) technology and operations; and (4) ensuring provider participation, will be held throughout the Nation. These meetings will provide an opportunity for input from all partners and stakeholders which include state and local public health agencies, professional organizations of private health agencies, managed care organizations, employer-funded health care plans, vaccine manufacturers and developers, vendors and developers of medical information systems,

information standards development organizations, parents, social welfare agencies, law enforcement agencies, legislators, privacy and consumer interest groups and other representatives of the public at large.

Based on the outcome of these meetings, a National Immunization Registry Plan of Action will be developed and proposed to NVAC for their deliberation and approval. This plan will identify registry barriers and solutions; strategies to build a registry network, resource requirements and commitments, and a target date for network completion.

Matters to be Discussed: Agenda items will include an overview of the Initiative on Immunization Registries and current immunization registry efforts and discussions by organizational representatives on privacy and confidentiality issues relevant to immunization registries.

Agenda items are subject to change as priorities dictate.

Terminology: Privacy—The right of an individual to limit access by others to some aspect of the person. Confidentiality—The treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure. Individually identifiable information—Information that can reasonably be used to identify an individual (by name or by inference).

Questions To Be Considered

1. Should immunization data have different privacy requirements than the rest of the medical record?

2. How can the disclosure and re-disclosure of immunization information be controlled through policies, procedures, and legislation?

3. Should consent to participate be implied or required? In what form?

4. Should different levels of disclosure be possible? What levels should be available to what groups?

5. Who should have access to immunization registry data?

6. What information should be disclosed to an immunization registry?

7. What other uses can immunization registry data have?

8. Would ability to produce a legal record be a desirable function for the registry?

9. What fair information practices should be implemented (e.g., ability to correct the record, notice of being put in registry to parent)?

10. How long should information be kept in a registry?

11. How will privacy issues affect the following groups: parents, immigrants, religious groups, HIV-positive and other immunocompromised health conditions, law enforcement, victims of domestic violence, and custodial parents?

12. How should registries ensure that privacy policies are followed?

13. Do you have any comment or recommendation for NVAC/CDC/HHS related to the implementation of the network of state and community based registries and do you have any concerns?

14. Do you feel that there is a need for the Federal Government to provide leadership in developing state and community based immunization registries? What should the role of the Federal Government be in this effort?

15. Given the mandate of Health Insurance Portability and Accountability Act (HIPPA) to create a unique health identifier, how should that goal be achieved while minimizing the probability of inappropriate use of the identifier?

16. What steps can be taken to prevent unauthorized re-disclosure of information already provided to an organization or person?

17. What data capture technology (e.g., bar codes, voice recognition, etc.) can minimize the negative impact on workflow?

18. What techniques (e.g., standard knowledge representation such as Arden Syntax) can be used to disseminate vaccination guidelines to individual registries quickly and with a minimum of new programming required to update automated reminder/recall and forecasting based on the guidelines?

19. What legal barriers exist that prevent data sharing by MCOs and how can they be obviated?

20. What mechanism should be available to allow parents to opt out of the registry?

21. What agency/organization should be responsible for maintaining registry information?

22. How should consent for inclusion in an immunization registry be obtained? Should it be implicit or explicit?

23. What information should be included in an immunization registry?

24. Should registries include (and release) information on contraindications, adverse events, etc.?

25. Who should have access to immunization registry data and how can restricted access be assured?

26. What information should be available to persons other than the client/patient and the direct health care provider (e.g., schools)?

27. What is the best way to protect privacy and ensure confidentiality within a registry?

28. How should individuals/parents have access to registry information on themselves/their children?

29. Should data maintained in a state and community based immunization registry be considered public information?

30. Would national privacy and confidentiality standards help ensure that data maintained in an immunization registry is protected?

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Dated: March 19, 1998.

Carolyn J. Russell,

Director, Management Analysis and Services Office, Centers for Disease Control and Prevention (CDC).

[FR Doc. 98-7694 Filed 3-23-98; 8:45 am]

BILLING CODE 4163-18-P