

The NAACCR Showcase: The All Star Team

Distance Training – Fran Michaud

New Data Tool – Andy Lake

NAACCR 2005-06 Priorities – Betsy Kohler

NAACCR Research Program –

Holly L. Howe

Susan Preston-Martin



NAACCR

NAACCR Research Program

- NAACCR Narrative Updates
- Town Meetings with Members
- Defining Data Uses and Minimal Data Needs of Users
- NEXT: Define Quality Metrics for the Data Needs [for reporting only; not evaluation]
 - ◆ Activity of DECC [or HQD]
- NEXT: Gather process information on Researcher data access.

Data Access Processes, e.g.

...

- Do you have a standard form for researchers to use to request registry data?
- Do you require IRB approval for research proposals?
- Is the IRB form the same as the researcher data request form?

11 Process Questions in All

- Do you require physician consent before patient contact?
- Are there fees involved for researchers to obtain data?
- Do you routinely share cases among all neighboring states?
- To the best of your knowledge are there plans to revise any of your procedures within the next 12 months?

Registry Research Procedures

	Research Protocols			
		Registry	MD Consent	Patient
Registry	IRB Requirements	Request Form	Required	Consent
United States				
Alabama				
Alaska	Instn IRB accepted	Yes	No	
California			Active	
GBA				
CA - Los Ang	Yes	Same as IRB	Passive	Research

Research Amenities Matrix

		Ca control	Incid. Surv.
Registry	Incidence	target audience/	Research
United States			
Alabama	2002		
Alaska	1996-2002		
California	1988-2002	*	*
GBA	1973-2002		*
CA - Los Angeles	1972-2002		*

**Program is in
Development...
But also Operational.**

**Dr. Susan Preston – Martin:
Seventh Day Adventist
Study**

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