

Three Approaches to Linking Childhood Cancer and the Environment

Wisconsin Environmental Public
Health Tracking

A photograph of the Golden Gate Bridge in San Francisco, viewed from a low angle looking up at the tower and the bridge deck. The bridge is orange-red, and the water below is a dark greenish-grey. The sky is a pale, overcast blue.

Wisconsin's Goals for Tracking Childhood Cancer

BUILD BRIDGES FOR FUTURE DATA LINKAGE EFFORTS

- Increase timeliness of data acquisition
- Facilitate data exchange with environmental partners
- Expand ability to identify potential exposures

Increase timeliness of data acquisition

- Issue

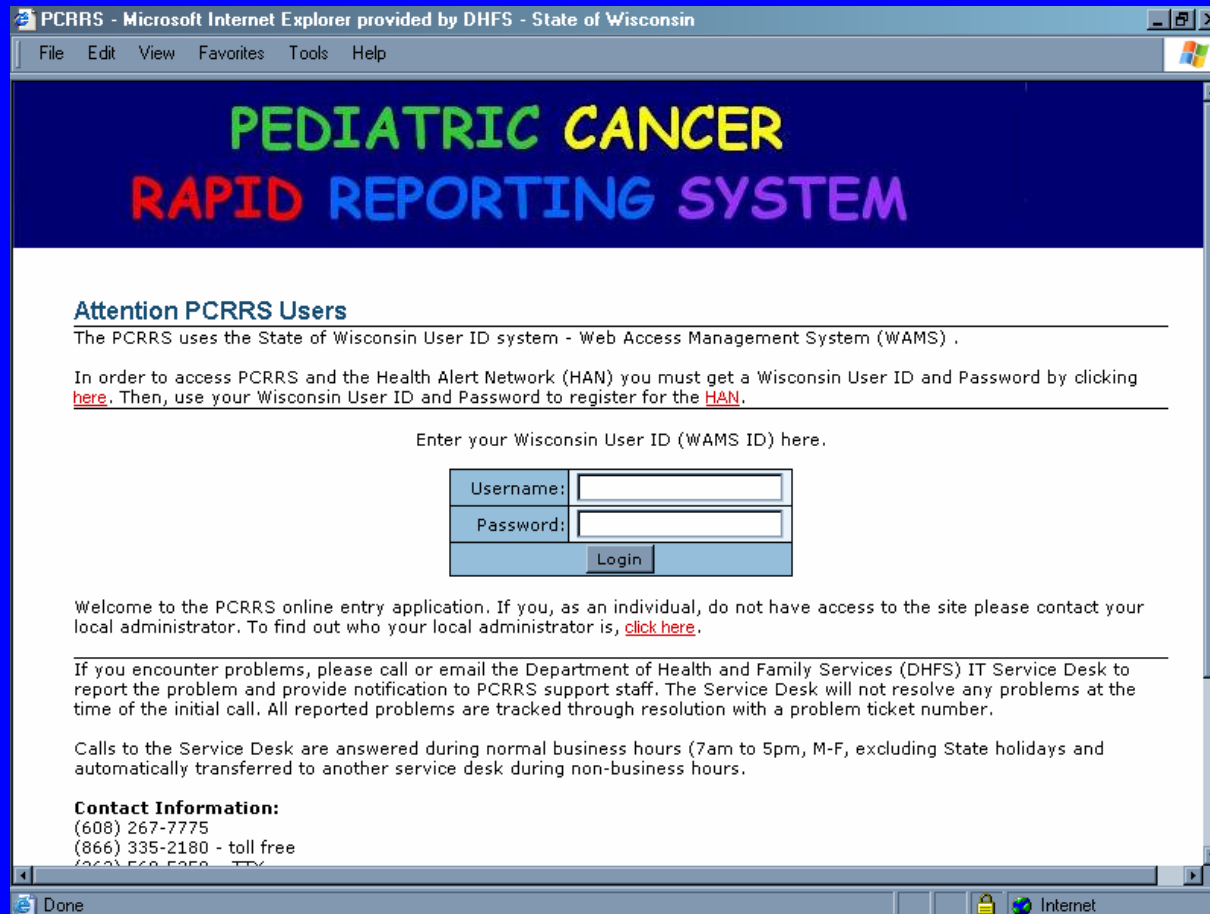
- Delay in getting information from cancer registry hinders follow-back

- Approach

- Web-based application for timely data entry

Application Description

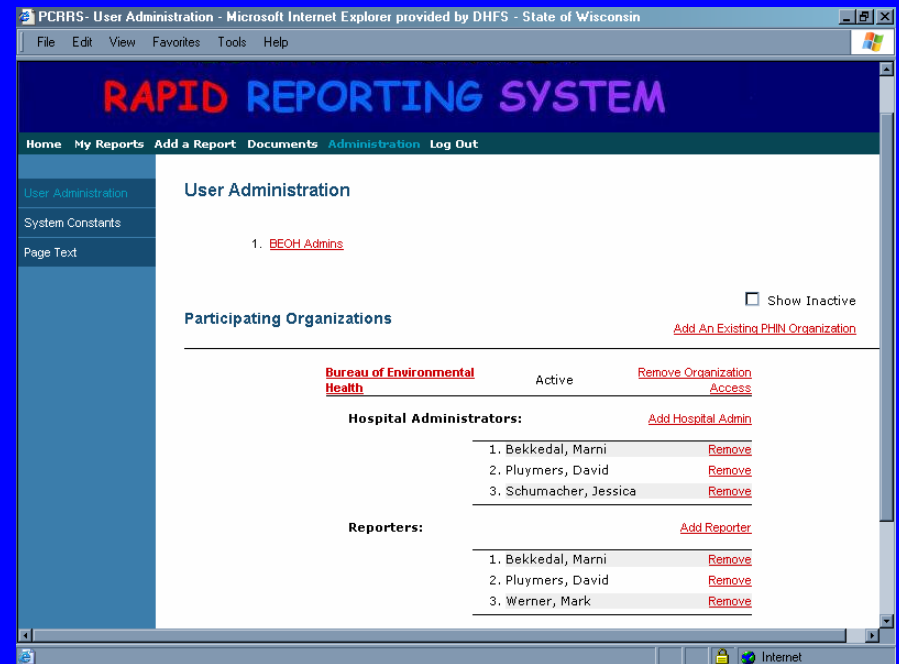
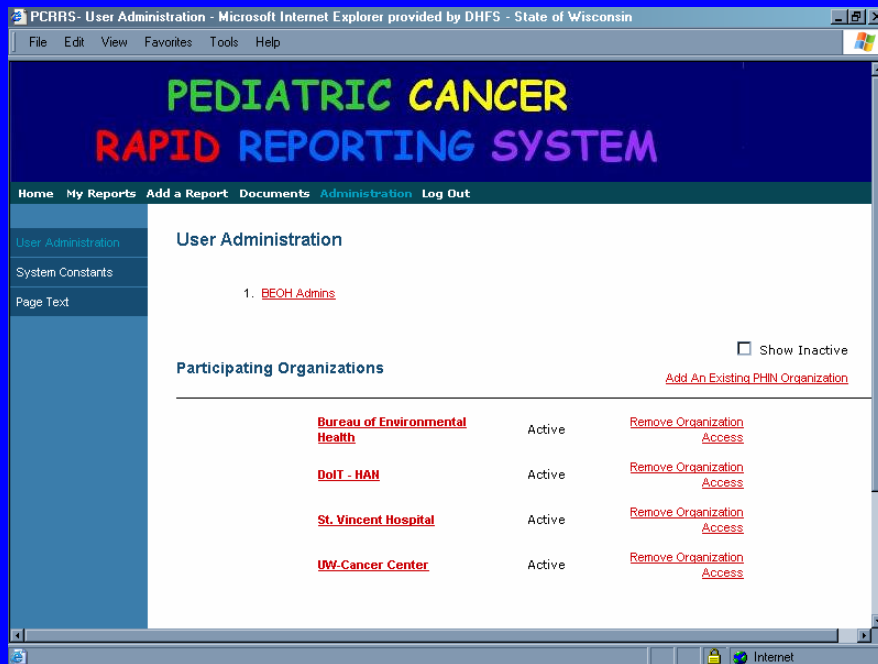
(User authentication, Role-based Access, Specific permissions)



The screenshot shows a web browser window titled "PCRRS - Microsoft Internet Explorer provided by DHFS - State of Wisconsin". The browser's address bar is empty, and the menu bar includes "File", "Edit", "View", "Favorites", "Tools", and "Help". The main content area features a dark blue header with the text "PEDIATRIC CANCER" in green and yellow, and "RAPID REPORTING SYSTEM" in red and purple. Below the header, there is a section titled "Attention PCRRS Users" with a horizontal line underneath. The text reads: "The PCRRS uses the State of Wisconsin User ID system - Web Access Management System (WAMS) . In order to access PCRRS and the Health Alert Network (HAN) you must get a Wisconsin User ID and Password by clicking [here](#). Then, use your Wisconsin User ID and Password to register for the [HAN](#)." Below this text is a prompt: "Enter your Wisconsin User ID (WAMS ID) here." followed by a login form. The form consists of two input fields: "Username:" and "Password:", each with a corresponding text box. Below these fields is a "Login" button. Underneath the login form, there is a paragraph: "Welcome to the PCRRS online entry application. If you, as an individual, do not have access to the site please contact your local administrator. To find out who your local administrator is, [click here](#)." This is followed by another horizontal line and a paragraph: "If you encounter problems, please call or email the Department of Health and Family Services (DHFS) IT Service Desk to report the problem and provide notification to PCRRS support staff. The Service Desk will not resolve any problems at the time of the initial call. All reported problems are tracked through resolution with a problem ticket number." Below this is another paragraph: "Calls to the Service Desk are answered during normal business hours (7am to 5pm, M-F, excluding State holidays and automatically transferred to another service desk during non-business hours." At the bottom of the page, there is a "Contact Information:" section with the following text: "(608) 267-7775", "(866) 335-2180 - toll free", and "(262) 560-5350 - TTY". The browser's status bar at the bottom shows "Done" on the left and "Internet" on the right.

Application Description

(User authentication, Role-based Access, Specific permissions)



Application Description

(Adding Reports)

PEDIATRIC CANCER
RAPID REPORTING SYSTEM

[Home](#) [My Reports](#) [Add a Report](#) [Documents](#) [Administration](#) [Log Out](#)

[Patient Info](#)
[Contact Person](#)
[Submit Report](#)

Report - General and Child Information

Reporter		Reporting Source	
Date:	1/19/2005	Facility:	Bureau of Environmental Health
Reporter:	Marni Bekkedal Epidemiologist bekkemy@dhs.state.wi.us		Madison, WI

Parental Consent * - indicates required field

Has Parent/Guardian given consent to be contacted for followup survey?*

Yes
 No
 Unknown

Child's Information

Last Name*:			
First Name*:		MI:	
Date of Birth*:	[]/[]/[] (mm/dd/yyyy)		
Sex:	<input type="radio"/> Female <input type="radio"/> Male <input type="radio"/> Undesignated		
Race:	<input type="checkbox"/> Amer Indian or Native Alaskan <input type="checkbox"/> Asian <input type="checkbox"/> Black <input type="checkbox"/> Hawaiian or Pacific Island <input type="checkbox"/> White <input type="checkbox"/> Other [] <input type="checkbox"/> Unknown	Ethnicity:	<input type="radio"/> Hispanic or Latino <input type="radio"/> Not Hispanic or Latino

Diagnosis

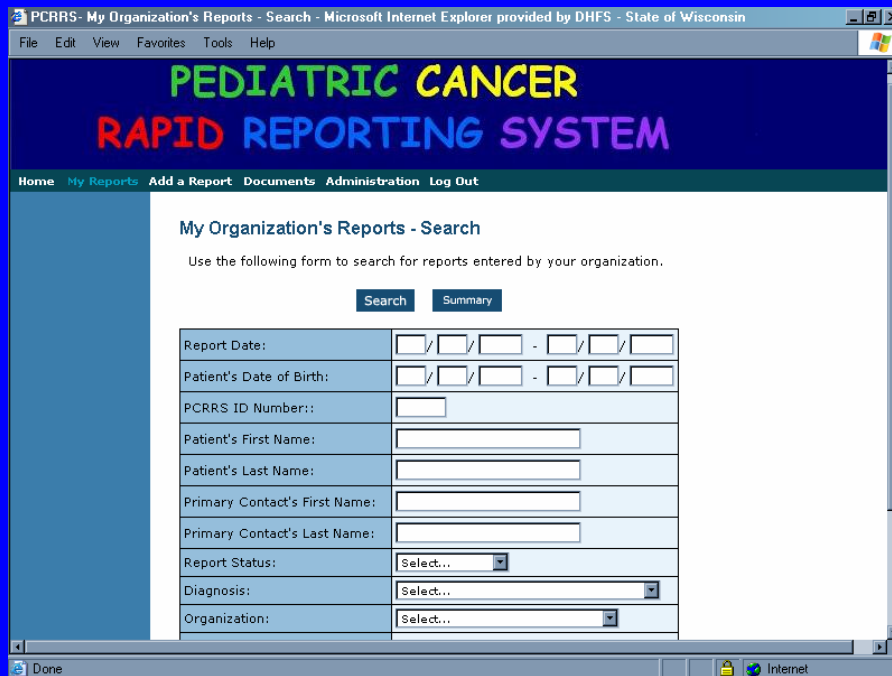
Date of Diagnosis*:	[]/[]/[] (mm/dd/yyyy)
General Cancer Type:	Not Available
Cancer Type Notes:	

Address and Phone

Address Type:	Home	<input type="checkbox"/> No Street Address Available
Street Address:		
City*:	State: WI	Zip: []
County:	PO Box:	
Phone Number:	[] [] [] - [] []	Home <input type="checkbox"/> Do not call
Contact Notes:		

Application Description

(Querying for Reports)



PCRRS - My Organization's Reports - Search - Microsoft Internet Explorer provided by DHFS - State of Wisconsin

File Edit View Favorites Tools Help

PEDIATRIC CANCER RAPID REPORTING SYSTEM

Home My Reports Add a Report Documents Administration Log Out

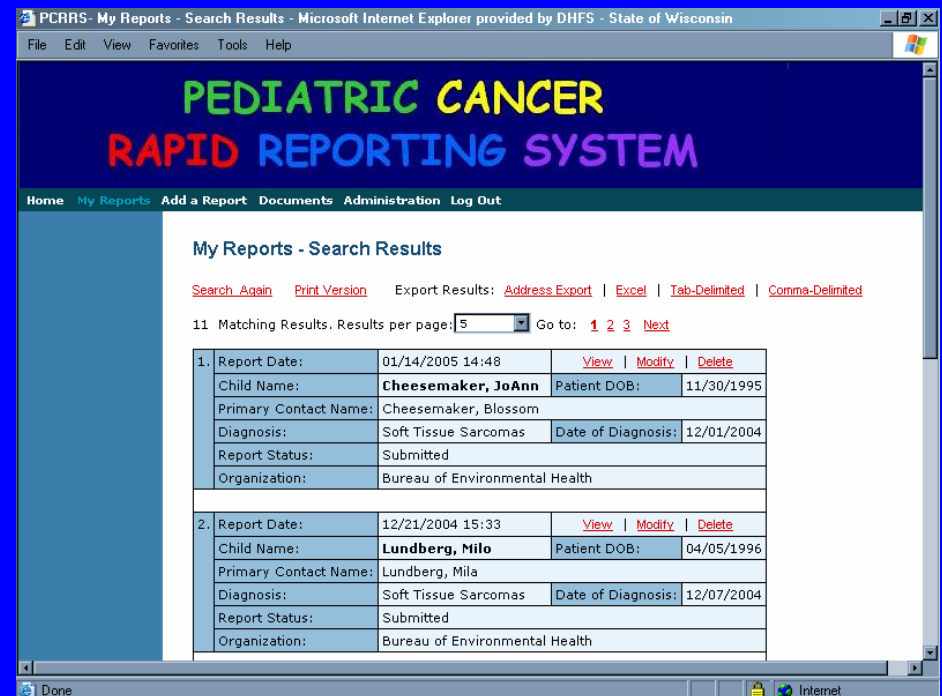
My Organization's Reports - Search

Use the following form to search for reports entered by your organization.

Search Summary

Report Date:	<input type="text"/> / <input type="text"/> / <input type="text"/> - <input type="text"/> / <input type="text"/> / <input type="text"/>
Patient's Date of Birth:	<input type="text"/> / <input type="text"/> / <input type="text"/> - <input type="text"/> / <input type="text"/> / <input type="text"/>
PCRRS ID Number::	<input type="text"/>
Patient's First Name:	<input type="text"/>
Patient's Last Name:	<input type="text"/>
Primary Contact's First Name:	<input type="text"/>
Primary Contact's Last Name:	<input type="text"/>
Report Status:	Select...
Diagnosis:	Select...
Organization:	Select...

Done Internet



PCRRS - My Reports - Search Results - Microsoft Internet Explorer provided by DHFS - State of Wisconsin

File Edit View Favorites Tools Help

PEDIATRIC CANCER RAPID REPORTING SYSTEM

Home My Reports Add a Report Documents Administration Log Out

My Reports - Search Results

[Search Again](#) [Print Version](#) Export Results: [Address Export](#) | [Excel](#) | [Tab-Delimited](#) | [Comma-Delimited](#)

11 Matching Results. Results per page: 5 Go to: [1](#) [2](#) [3](#) [Next](#)

1.	Report Date:	01/14/2005 14:48	View Modify Delete
	Child Name:	Cheesemaker, JoAnn	Patient DOB: 11/30/1995
	Primary Contact Name:	Cheesemaker, Blossom	
	Diagnosis:	Soft Tissue Sarcomas	Date of Diagnosis: 12/01/2004
	Report Status:	Submitted	
	Organization:	Bureau of Environmental Health	
2.	Report Date:	12/21/2004 15:33	View Modify Delete
	Child Name:	Lundberg, Milo	Patient DOB: 04/05/1996
	Primary Contact Name:	Lundberg, Mila	
	Diagnosis:	Soft Tissue Sarcomas	Date of Diagnosis: 12/07/2004
	Report Status:	Submitted	
	Organization:	Bureau of Environmental Health	

Done Internet

Application Description

(Printing Reports)

PCRRS - Microsoft Internet Explorer provided by DHFS - State of Wisconsin

File Edit View Favorites Tools Help

Pediatric Cancer Rapid Reporting System

1/19/2005

[Search Again](#) [Back to Search Results](#)

1.	Report Date:	01/14/2005 14:48		
	Child Name:	Cheesemaker, JoAnn	Patient DOB:	11/30/1995
	Primary Contact Name:	Cheesemaker, Blossom		
	Diagnosis:	Soft Tissue Sarcomas	Date of Diagnosis:	12/01/2004
	Report Status:	Submitted		
	Organization:	Bureau of Environmental Health		
2.	Report Date:	12/21/2004 15:33		
	Child Name:	Lundberg, Milo	Patient DOB:	04/05/1996
	Primary Contact Name:	Lundberg, Mila		
	Diagnosis:	Soft Tissue Sarcomas	Date of Diagnosis:	12/07/2004
	Report Status:	Submitted		
	Organization:	Bureau of Environmental Health		
3.	Report Date:	12/21/2004 15:14		
	Child Name:	Riverdance, Brunhilde	Patient DOB:	01/25/1988
	Primary Contact Name:	Riverdance, Barnard		
	Diagnosis:	Soft Tissue Sarcomas	Date of Diagnosis:	10/22/2004
	Report Status:	Submitted		
	Organization:	Bureau of Environmental Health		

Done Internet

Increase timeliness of data acquisition

- Obstacles:

- hospitals volunteering for double data entry
- cumbersome IT acquisition process
- Normal bumps associated with application development

- Solutions:

- find a “carrot” for them
- Like Nike says, “Just do it.”
- regular meetings and updates with developers; strong testing team

Facilitate data exchange with environmental partners

- Issue
 - No previous attempts to routinely link environmental and health data
- Approach
 - Work together to build tools and construct datasets that can work now and into the future for data linkage purposes

Tools Development

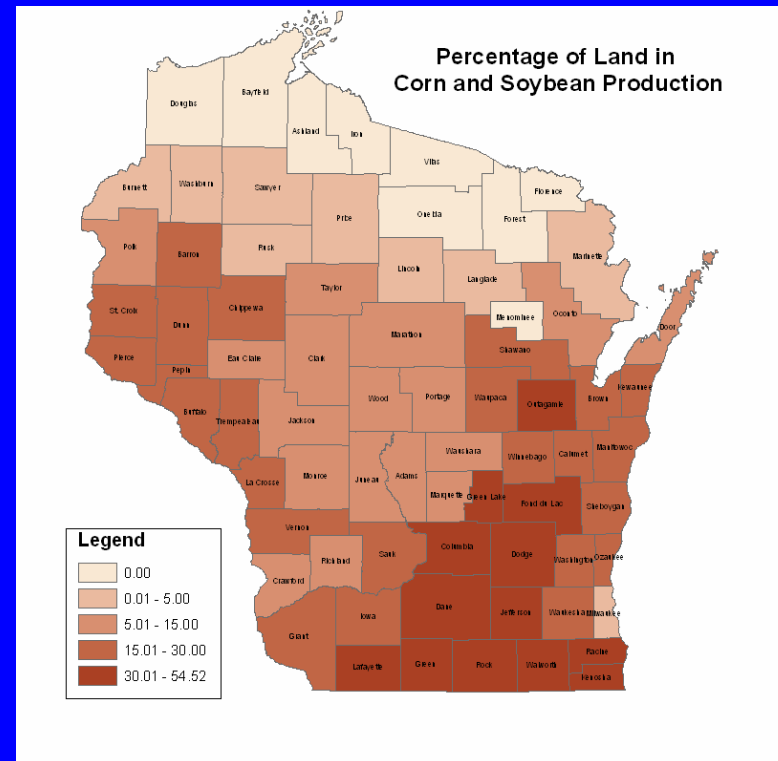
- Surveillance of pesticides in drinking water
- Other potential pesticide exposure
- Modeling of HAPs
- GIS coding algorithms
- Mapping templates

Tools Development

Pesticides in Drinking Water

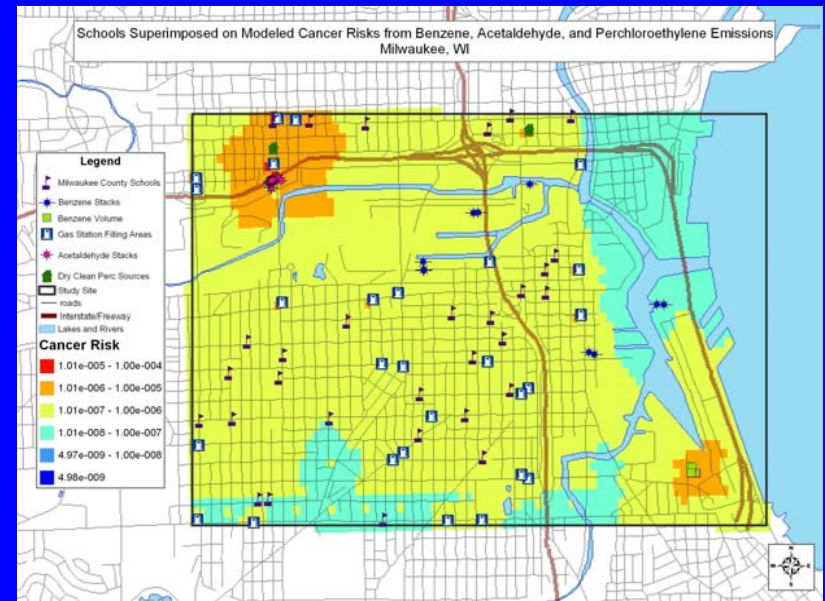
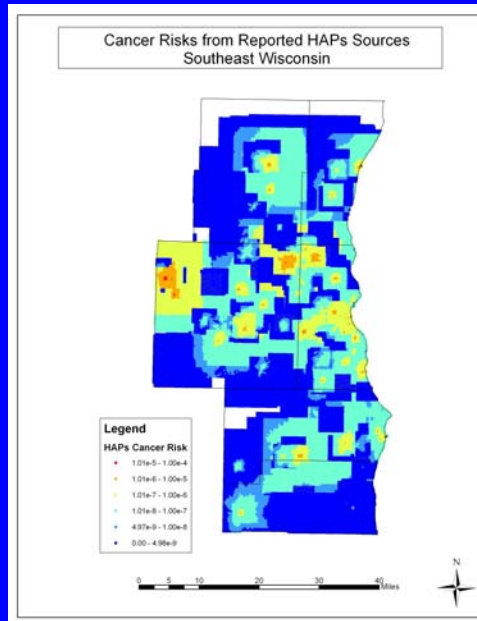
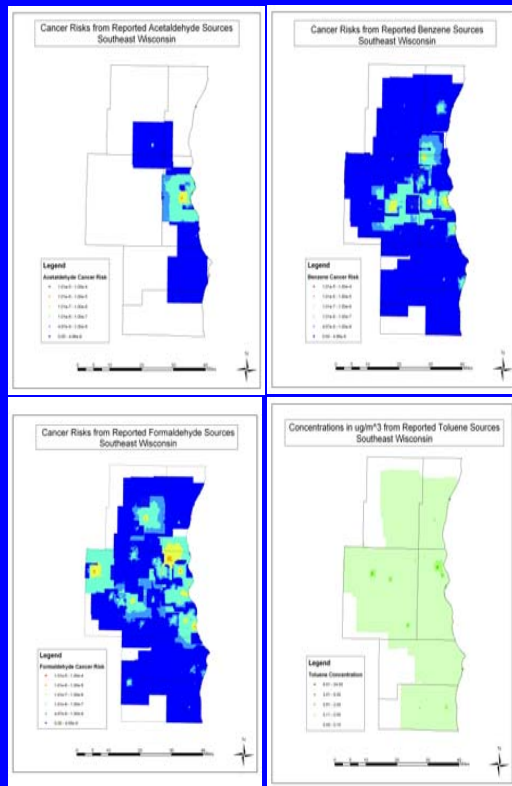
Tools Development

Other Potential Pesticide Exposure



Tools Development

Modeling HAPs



Facilitate data exchange with environmental partners

- Obstacles
 - Don't know what environmental data are available, or who has them
 - Geographic matching
 - State statutes
- Solutions
 - Many meetings to inventory people and data
 - fund projects to address geographic information
 - Hire as \$0 LTE

Expand ability to identify potential exposures

- Issue
 - Estimate, assign, and aggregate potential environmental exposures for chronic disease
- Approach
 - Attempt to quantify “transience” of children
 - Environmental Exposure Profile

Quantify “transience”

- Would like to have more geographical information than residence at time of diagnosis.
- Would like to have some estimate of how far these children move prior to diagnosis
- Pilot project to match birth certificate address with date of diagnosis address
 - will be doing some linkages with environmental factors

Environmental Exposure Profile

- Identify cases
- Conduct follow-back survey
- Identify geography corresponding to history
- Link geography with potential exposure(s)
- Establish individual Environmental Exposure Profile
- Aggregate into matrix

ENVIRONMENTAL EXPOSURE PROFILE MATRIX FOR HEALTH OUTCOME X			
Environmental Factors	Exposure Estimate (frequencies)		
	Low	Moderate	High
Benzene	(3)	(5)	(7)
Ozone	(4)	(8)	(3)
PM	(3)	(4)	(8)
Pesticides	(13)	(1)	(1)

Expand ability to identify potential exposures

- Obstacles
 - No electronic survey available
 - Difficulties matching and sharing vital records and cancer data
 - State Statutes
- Solutions
 - Combine surveys and put into interactive, electronic format
 - Negotiate data sharing agreements
 - Hire as \$0 LTE

Major Products

- Web-based application for timely identification of childhood cancer cases, follow-back survey administration, and sharing of data with environmental partners
- Quantification of transience to assist with exposure estimation
- Preliminary linkages of historical cases with HAP and pesticide data
- Environmental Exposure Profile survey and template

Lessons Learned

- Important to fund environmental partners to facilitate data collection, and improve dataset quality and compatibility
- There is value in building sustainable tools for long-term use in linkage efforts
- Data sharing and integration requires significant negotiation