

Implications For Dataset Linkage

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PLEASE PRINT

2011-05



Lab I.D.

192718516

NEWBORN SCREENING BLOOD COLLECTION FORM
DO NOT USE AFTER MAY - 2011

DOH USE ONLY

DO NOT WRITE IN OR COVER SHADED AREA

192718516

Infant's Last Name

AKA

Date of Birth

Mo. Day Yr.

Birth Weight

Grams

Infant's First Name

Date of Specimen

1 ☐ Male

☐ Single Birth

Ethnicity/Race

1 ☐ Whl. 4 ☐ Asian

2 ☐ Female

☐ Twin A or B

2 ☐ Blk.

5 ☐ Other

☐ Other

3 ☐ Hisp.

6 ☐ Native Amer.

Infant's Age When Specimen Collected:

1 ☐ Less than 24 hrs. of age

2 ☐ 24 hrs. of age

HIV TESTING

A B C D E F G

Infant's Medical Record No.

TPN:

☐ Antibiotic:

1 ☐ Pos

2 ☐ Neg. 3 ☐ Unk.

Mother's Social Security No.

Mother's Age

Gestational Age (Wks/Days)

Hospital of Birth?

1 ☐ Yes 2 ☐ No

1 ☐ Initial Specimen

Physician License No.

2 ☐ Repeat Specimen

Mother's Name:

Last

First

Hospital PFI Code

☐ Homebirth

Infant's Primary Care Physician:

Address:

Apt. #

Hospital Name and Address:

Address:

Zip:

City

Zip:

Tel. ()

Tel. ()

County of Residence

PRINT CLEARLY

FILTER COPY

192718516

SEE REVERSE SIDE FOR INSTRUCTIONS

SATURATE ALL CIRCLES COMPLETELY

Size (inches)

1/2

1/4

1/8

1/16

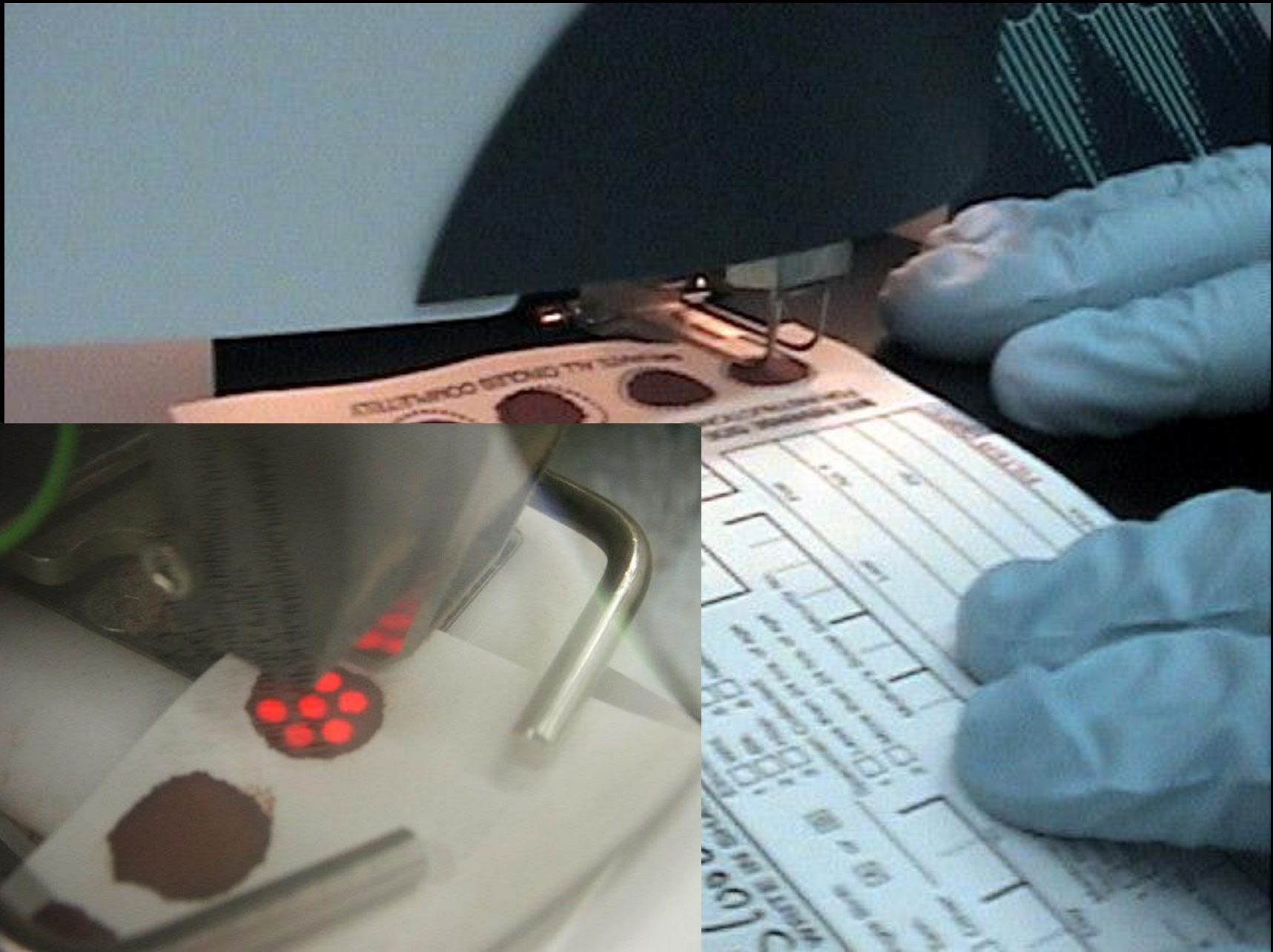
Blood (µl)

50

12.5

3.1

0.8



Why Perform Newborn Screening?

Pre-symptomatic screening results in a change in health status

World Health Organization Criteria – 1968

ü Prevalence in population, public health

ü Marker in the blood

ü Assay to detect the marker

ü Therapy for the child

Ø Legislation

Ø Commissioner's Declaration

The program cannot add diseases to the test panel

PHENYLKETONURIA IN PUBLIC HEALTH LAW

§ 2500 a

" It shall be the duty of (1) the administrative officer or other person in charge of each institution caring for infants twenty-eight days or less of age and (2) the person required ... to register the birth of a child, to cause to have administered to every such infant or child in its or his care a test for phenylketonuria in accordance with rules or regulations prescribed by the commissioner. ...

§ 2. This act shall take effect January first, nineteen hundred sixty-five. "

Part 69
Duties of birth
hospitals,
CEOs,
physicians,
and STCs

Newborn Screening

What to do after the completion of screening?





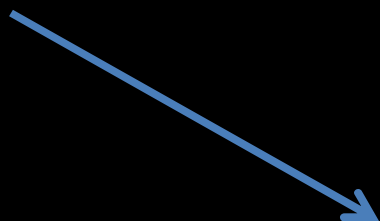
Immunizations
Lead screening



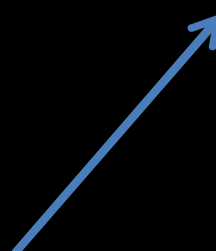
Health
Record



Metabolic screening
Hearing screening



Childhood diseases
Hospitalizations
Medications



Exposures?
Risk of disease to unborn?



What is CHI²?

Child Health Information Integration

- CHI² seeks to create a **Virtual Child Health Profile**
- *Authorized users* access to a consolidated view of comprehensive information about the health of an individual child , including but not limited to:
 - NBS results, referral and required follow-up
 - NBHS results, referrals and required follow-ups
 - NICU admission and treatment
 - Immunizations (birth and beyond)
 - Referrals to early intervention programs or other specialized care
 - Lead testing results and need for follow-up

Why is CHI² important?

- Ø Provide comprehensive, timely and accurate child health information to support the provision of service through medical home, public health programs, and decision-making at the point of service
- Ø Ensure newborn screening tests have accurate diagnoses, short and long-term follow-up and children receive treatment as needed
- Ø Coordinate medical care and public health activities and program services
- Ø Ensure children receive needed preventive, screening, therapeutic and follow-up services
- Ø Eliminate duplicative work and services

CHI² in Action 1

- A child is born and is admitted to the Neonatal Intensive Care Unit (NICU) due to transient tachypnea and poor O₂ saturation following delivery.
 - The child's details are added into the Hospital's systems and all the systems of DOH that capture NICU and screening data (CHI² System).



- The child is determined to have no recurrent problem and is transferred to newborn nursery for routine hospital care and Hepatitis B vaccine is administered.

CHI² in Action 2

Ø The NBS heel stick is performed, the vital statistics work book is completed, the child receives a hearing screening exam and the child is discharged from the hospital.

Ø The NBS DBS sample is sent to Wadsworth Center.

Ø Dr. Goodfriend schedules a 1-week check-up at her private practice office in the community.



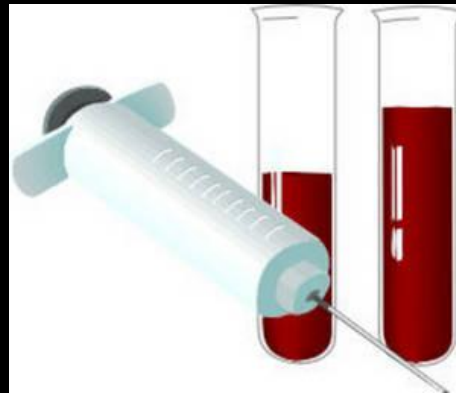
Wadsworth Center

New York State Department of Health

Sarah Goff, M.S., PMP

CHI² in Action 3

- Ø Dr. Goodfriend is notified by NBS at the Wadsworth Center of a positive screen for congenital hypothyroidism (CH).



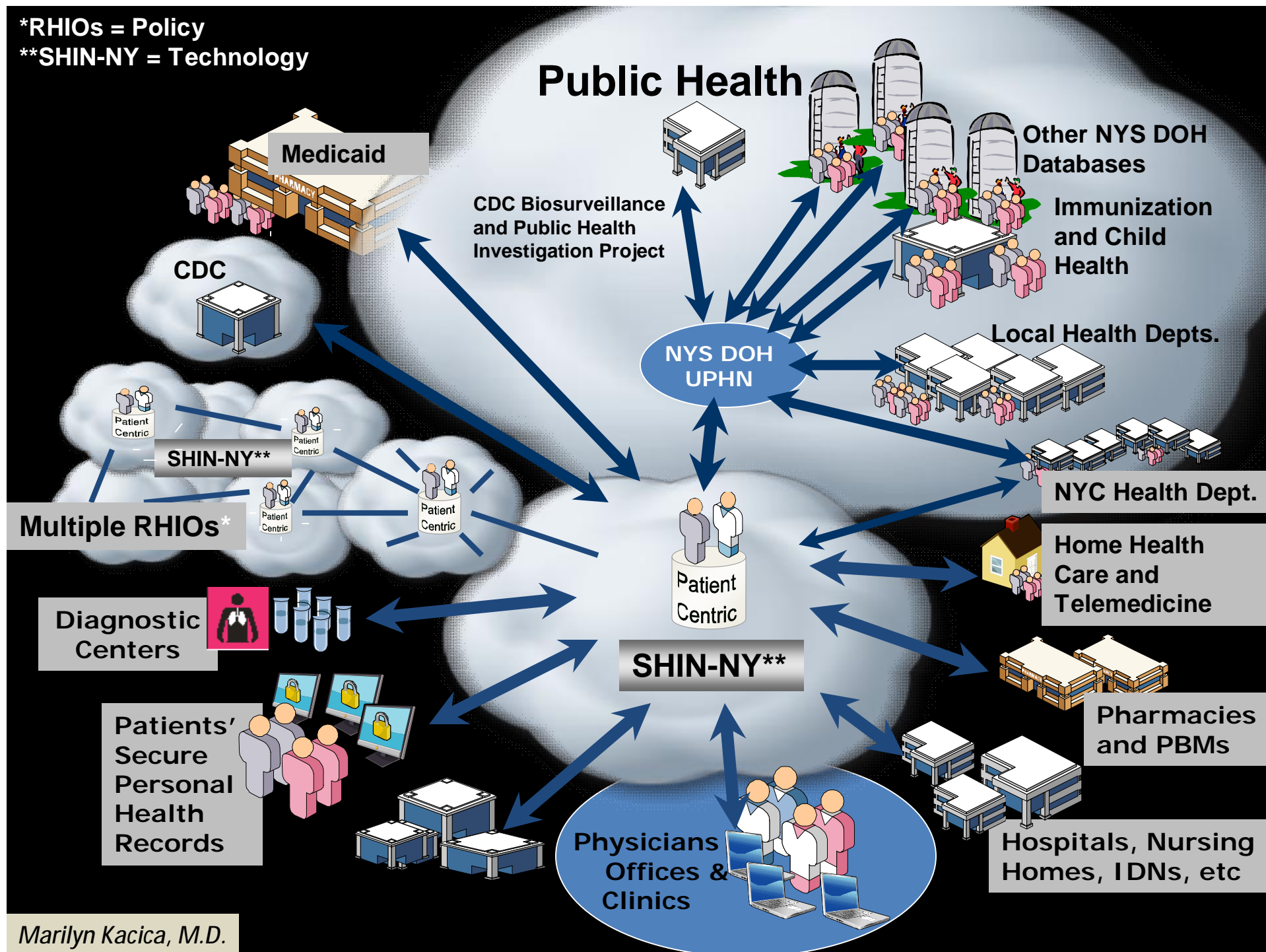
- Ø Dr. Goodfriend tells the family about the positive newborn CH test at the 1-week visit, orders follow-up test and draws all the necessary blood samples at the clinic.
- Ø Dr. Goodfriend accesses the CHI² data system and verifies the Hepatitis B vaccine was administered in the hospital.



CHI² in Action 4

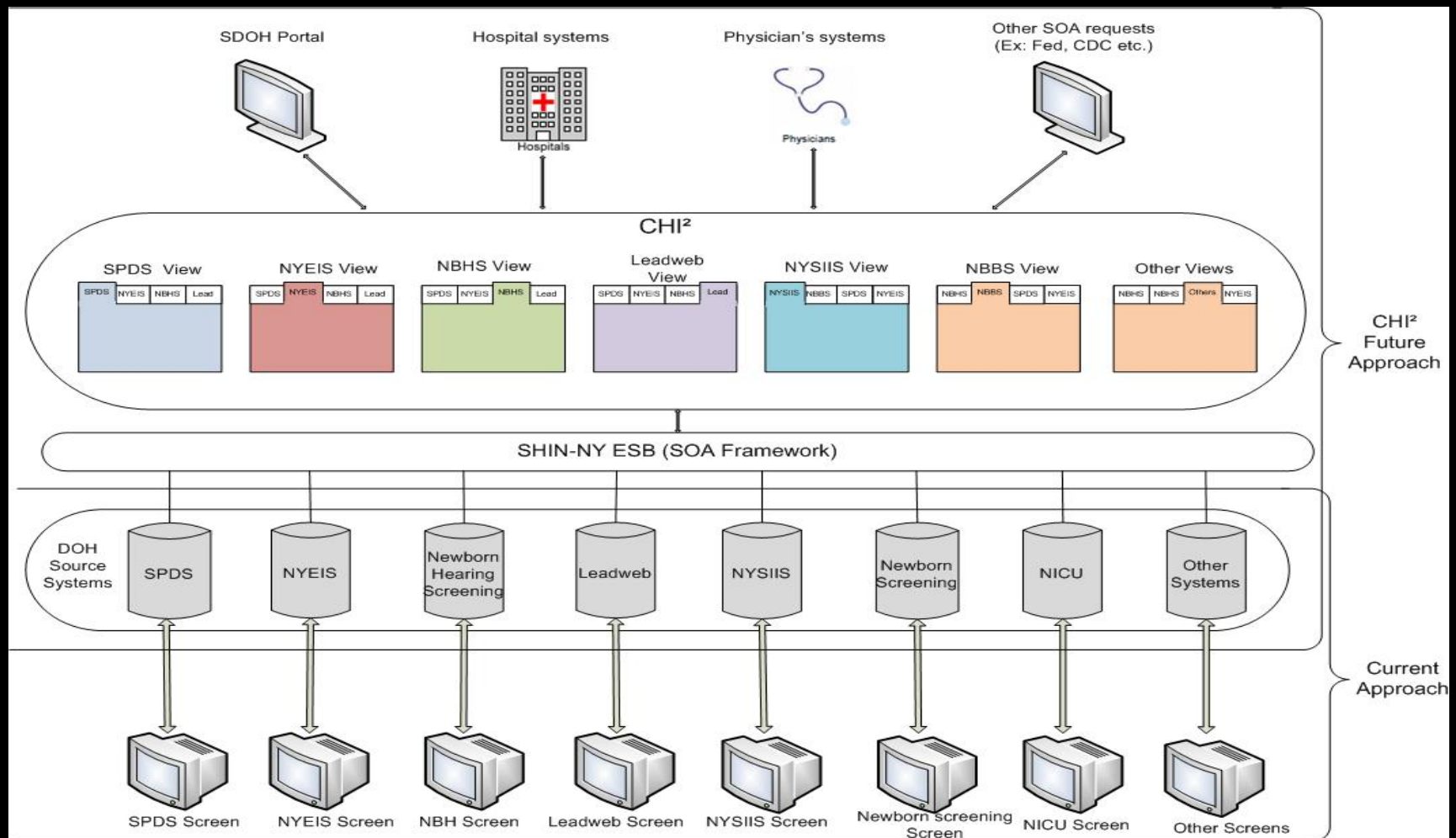
- Ø Several days later , the pediatrician's office calls the family to let them know that the follow-up laboratory tests were all within normal limits and the child does not have CH, and documents the outcome in the CHI² system.
- Ø After a few months the family moves to a different county. The child is taken to a new pediatrician, Dr. Wellness for a six month visit.
- Ø Dr. Wellness accesses the CHI² system and determines with the use of CHI² that the child missed one set of vaccinations. Dr. Wellness arranges for the child to receive the missing vaccinations.

****SHIN-NY = Technology**

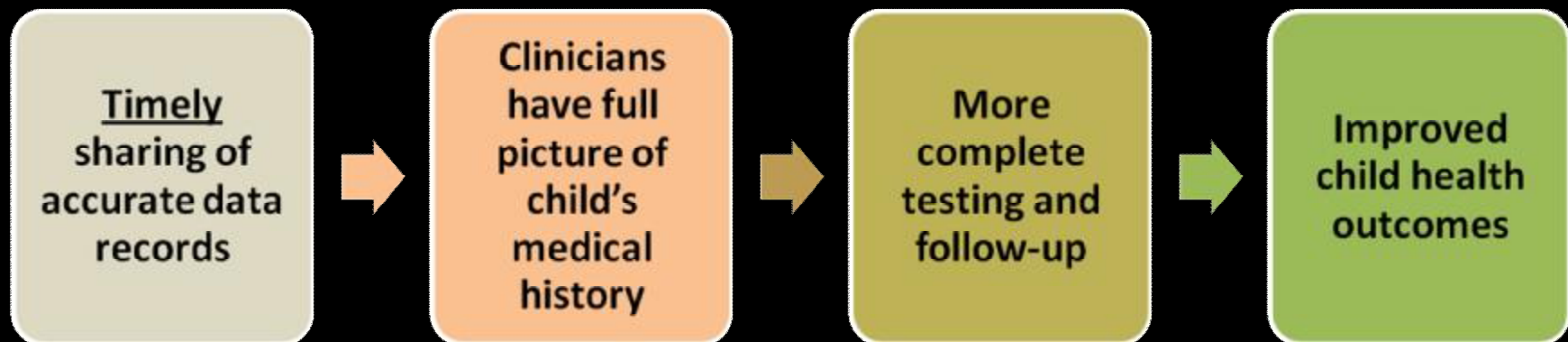


Marilyn Kacica, M.D.

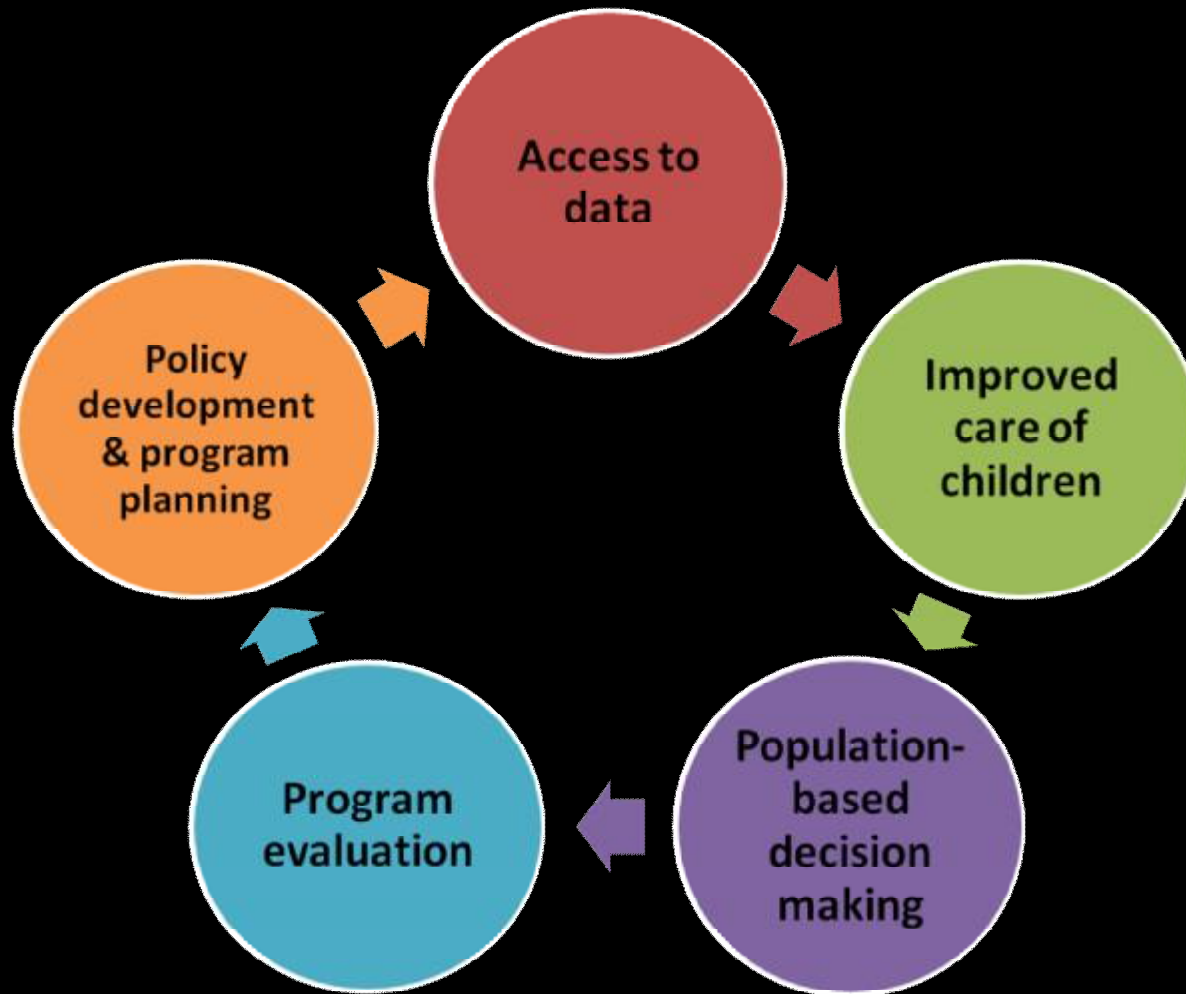
Benefits of the Future: Integration of Current Approach and CHI² Future Concepts



A Path for Improved Child Outcomes



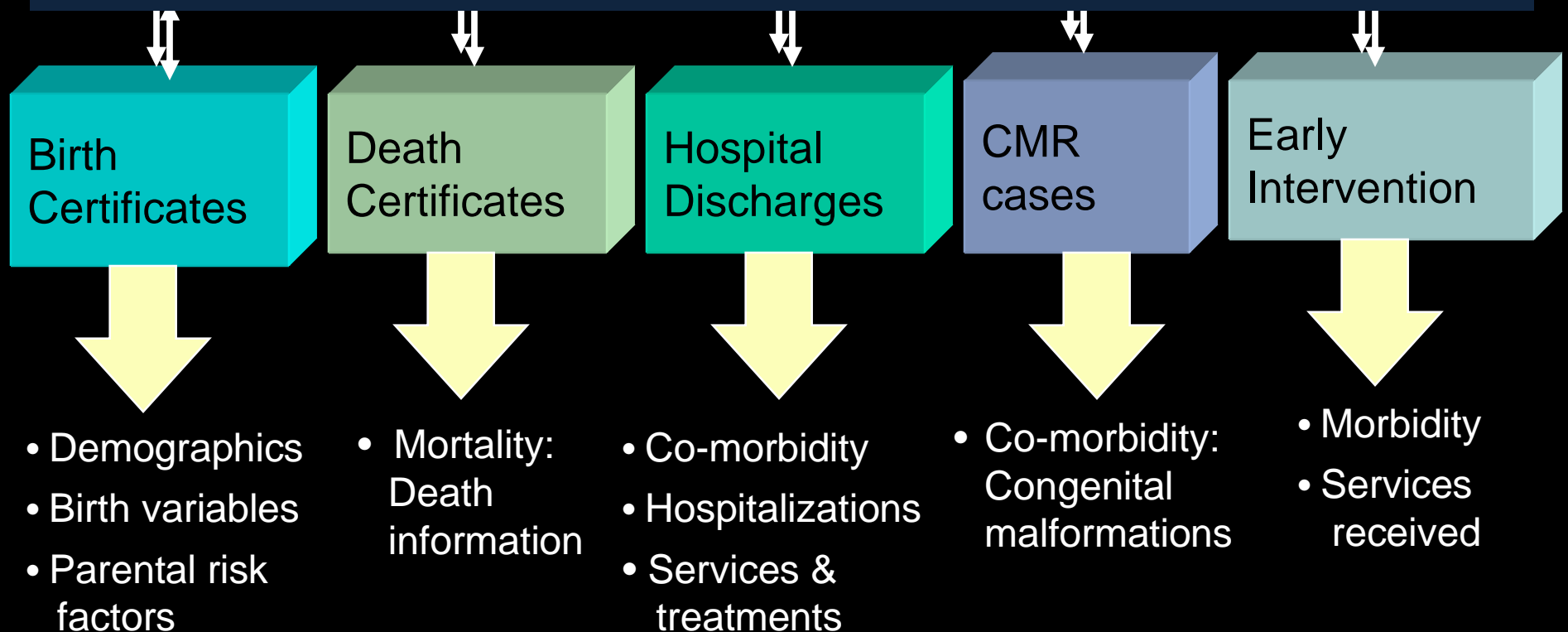
An Asset for Public Health Officials



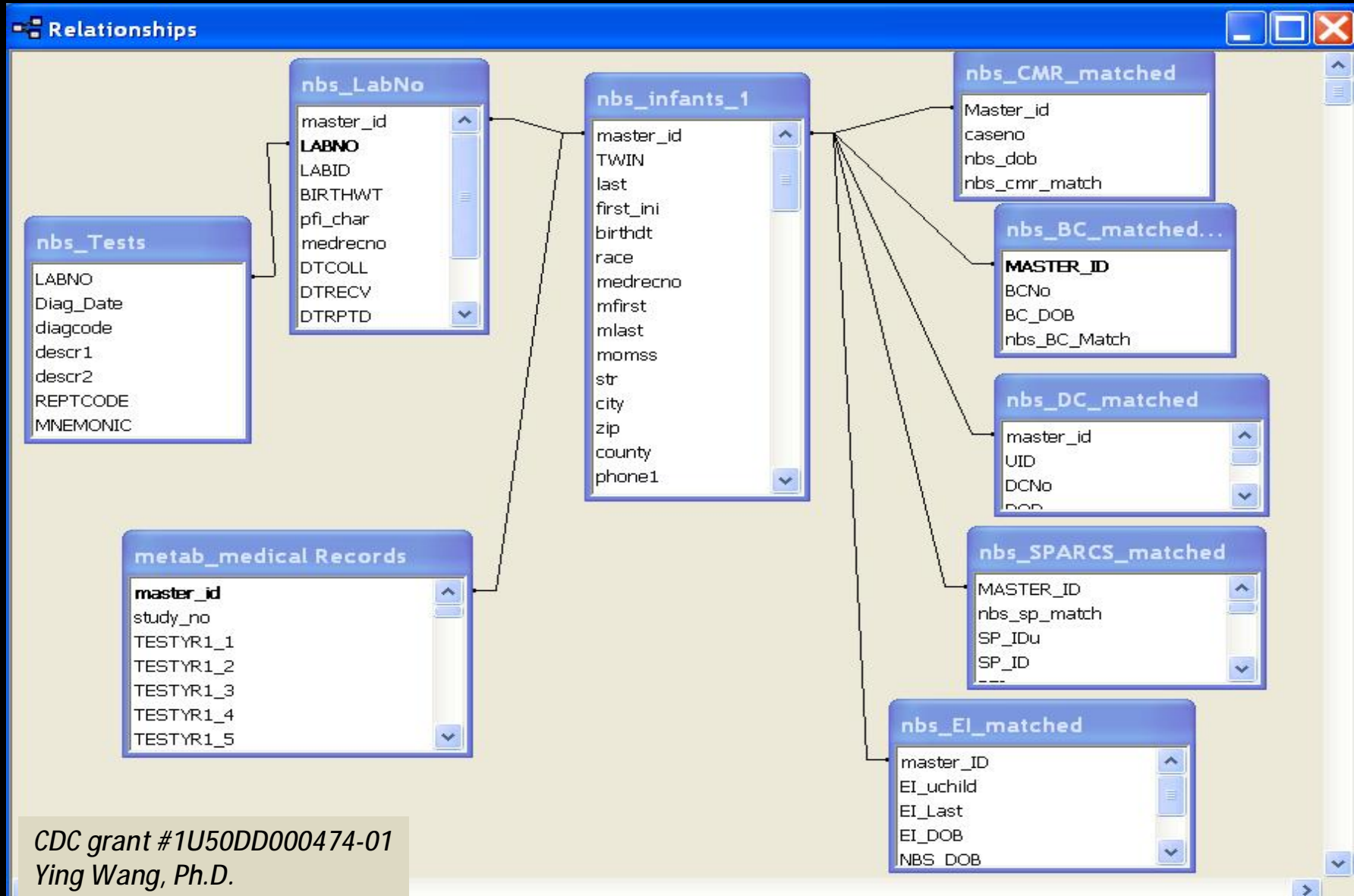
Long-term Follow-up: Record Linkage

Birth Cohort: Children born in 2006 & 2007
with confirmed NBS disorders

Follow-up: up to 2yrs

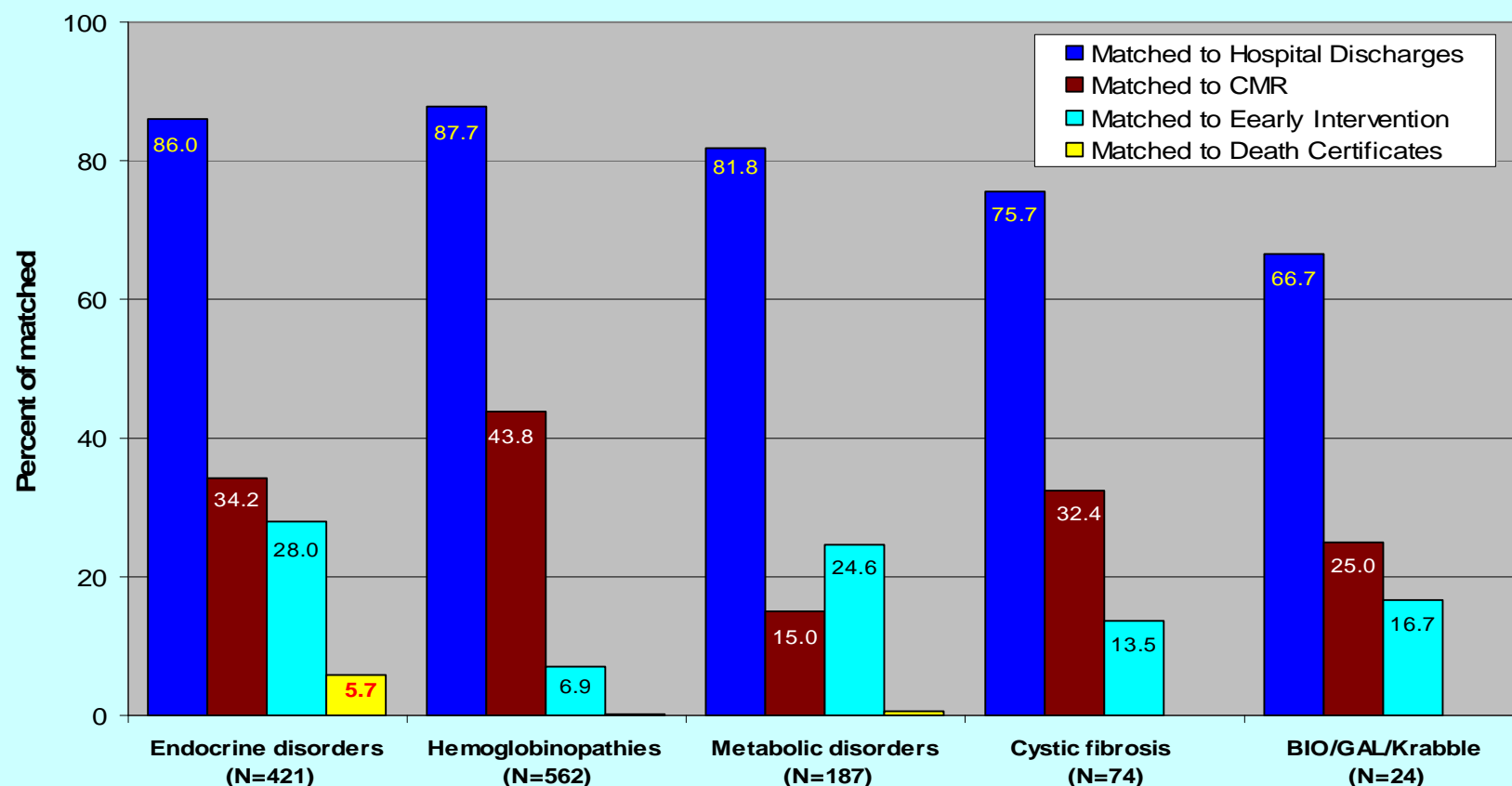


Long-term Follow-up: Integrated Database



Long-term Follow-up: Results

The results from data linkage of children with confirmed NBS conditions to hospital discharges, Congenital Malformations Registry, Early Intervention and death certificates (Birth cohort: 2006 & 2007 New York State live births)



Results of Improved Data Quality/Access

- Ø Clinicians and public health officials will share in *meaningful health information exchange*, reduced reporting burden & duplications
- Ø Data and diagnostic criteria will be standardized
- Ø PH communication, diagnosis, and infant quality of care will improve
- Ø Location data for environment
- Ø Missed children can be located



Challenges

- Currently, no formal solution exists that enables the NYSDOH to link systems containing child specific data.
- *Challenges faced by the CHP² project include:*
 - **Privacy** – Careful consideration of the need to maintain individual privacy/security. Particularly, must ensure that health data is secure and the system complies with HIPAA and FERPA. Use of role-based access
 - **Legal/regulatory**- Current legislation and regulations restrict data-sharing among NYSDOH systems and with health care providers. New regulations to allow data exchange while still protecting patient privacy and security are required
 - **Technology** - compatibility issues and data sharing (including from the electronic medical records (EMR) systems and RHIOs) among systems

...But Without CHI²

- Ø Data from electronic medical records (EMR) systems and RHIOS will be *more difficult and costly to utilize* for public reporting purposes
- Ø Lack of a coordinated approach increases *difficulty of sharing integrated child data* held by the department with health care providers
- Ø *Loss of opportunity* - practicing clinicians and public health programs are unable to effectively utilize existing DOH information to improve the clinical and public health outcomes of New York's children

Current NBS Projects

Ø *Short term, quick rewards*

- Establish number of infants born who are not screened ; establish number of screened babies not born in NY (transfers etc.)
- Improve quality of demographic data
- Improve tracking; intense follow-up measures
- NBS program aware when infant dies
- Integrated childhood medical record

Ø *Long term follow-up*

- Long term outcomes of screening are largely unknown; Compliance? Do treatments work? Standardized treatments?

