Data linkages in Michigan From Vision to Implementation

Violanda Grigorescu, MD, MSPH
State MCH Epidemiologist and Director

Mary Kleyn, MS
NBS Epidemiologist

Robin O'Neill MPH
MiHemSQIP Coordinator

Division of Genomics, Perinatal Health and Chronic Disease Epidemiology

Atlanta, November 3-4, 2010

Michigan Department of Community Health
MDCH
Jennifer M. Granholm, Governor
Janet Olszewski, Director

Public Health FOR MICHIGAN FOR YOU

Outline

- Data linkages:
  - History
  - Strategies
- Example of linkages
- MiHemSQIP
- MCIR

History - The basic questions

- Why?
- What?
- When?
- Where?
- Who?

- How?

WHY?

1. "Cluster" of many enthusiasts
2. Commitment to develop a science friendly infrastructure in public health
3. Interest to explore innovative approaches
4. New and challenging study questions that could have not been answered by the existing data sets

WHAT?

The decision on what files to be linked was prompted by:

1. Epidemiological study question and design
2. Program strategies targeted to improving the health status and outcomes

WHEN?

The time frame for developing the linkages depended on:

1. Study design and funding if available
2. Program framework and timelines for developing strategies targeted to improving the health status and outcomes
3. Staff availability

WHERE?

Data warehouse or Vital Records Office based on:

1. File location
2. Staff capacity and knowledge
3. Software available

WHO?

1. Staff from Vital Records Office: state registrar and other data analysts and statisticians
2. Epidemiologists
3. Data warehouse staff

HOW?

1. Probabilistic
2. Deterministic
3. Different software used depending on the staff skills but also the files location

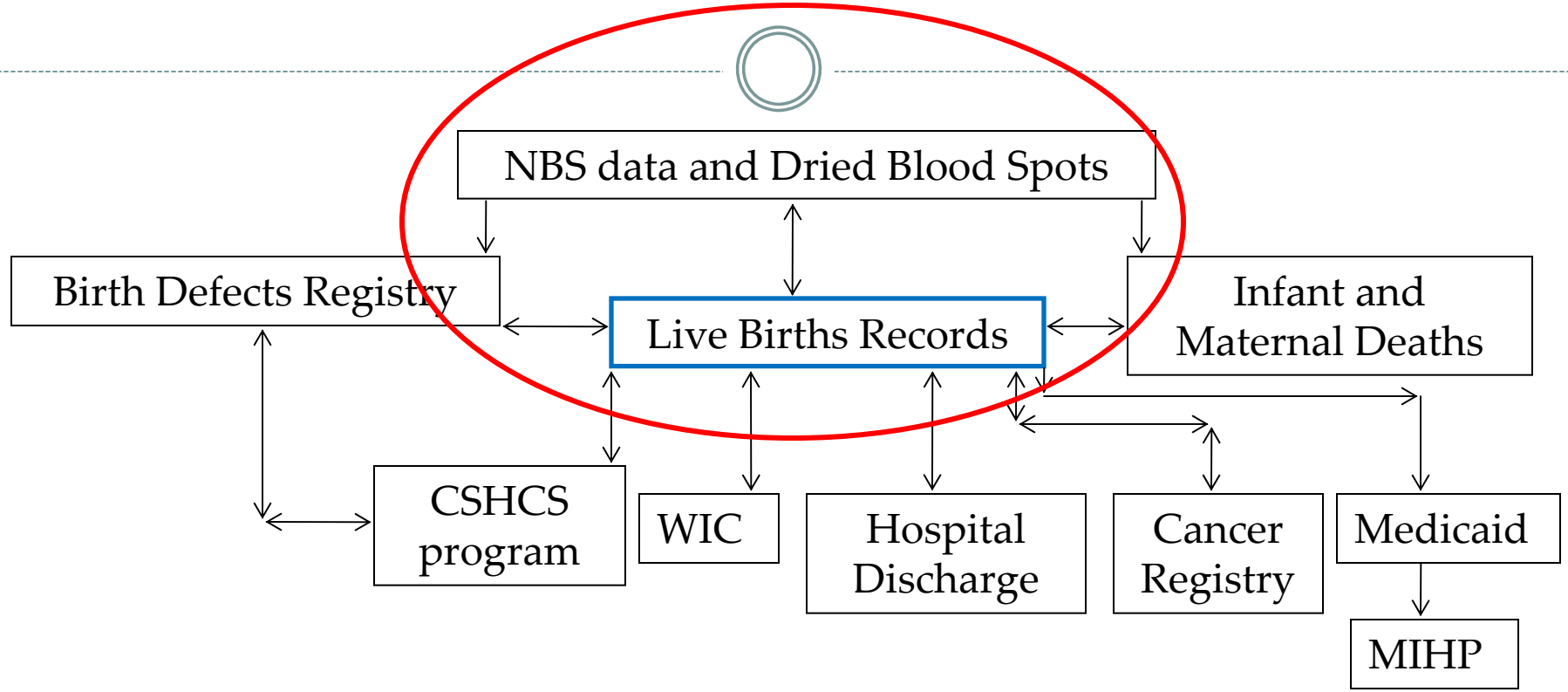
Overarching strategies in the past

- Not necessarily based on any vision
- Short term planning
- Vital Statistics Office with Data sharing process responsibility
- Department IRB in existence but less standardized process
- Epidemiologists had limited decision making roles

Current process

- More data and registries so more linkages developed
- Staff assigned to perform certain linkage
- More timely and better matching rate
- Standardized data sharing process
- Department IRB plays an important role – known, organized, respected
- Agreements between MDCH IRB and Universities IRBs
- Advisory groups to perform scientific reviews formed by the Department

Examples of data linkages



Current process

- More data and registries so more linkages developed
- Staff assigned to perform certain linkage
- More timely and better matching rate
- Standardized data sharing process
- Department IRB plays an important role – known, organized, respected
- Agreement between MDCH IRB and Michigan State University
- Advisory groups to perform scientific reviews formed by the Department

Short and Long Term Vision Principles

- Respect the "give and get" principle in any relationship
- Collaboration and partnership with academia to strengthen the process
- Collaboration and partnership with other institutions that own data needed for population based studies (i.e., Michigan Hospital Association) to strengthen the process
- Standardized data linkage and sharing process
- Standardized IRB approval process and Scientific reviews
- New collaborations and partnerships based on the same principle(s)
- Department as active participant in the implementation of new emerging technologies – Health Information Exchange (Michigan Health Information Network)
- Department continues to be:
  - Honest Broker for population based data files
  - Active collaborator in research

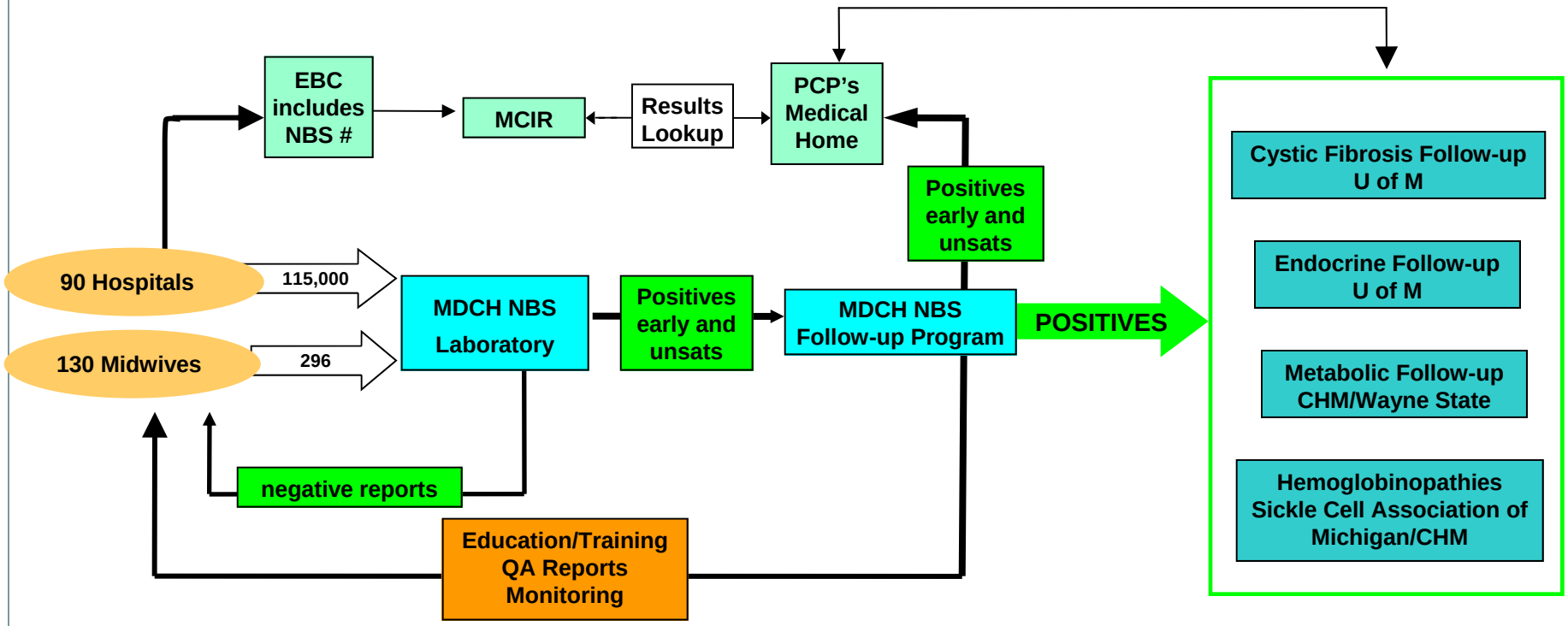
Barriers/Limitations

- Limited resources to meet the growing needs
- More competition and with former partners due to the budget deficit
- Still limited understanding of public health functions and services
- Non-infectious epidemiology still "new" and justifying its existence
- Public Health System – all of us but with better defined roles and responsibilities

Michigan Hemoglobinopathy Surveillance and Quality Improvement Program (MiHemSQIP)

MiHemSQIP= MI RuSH

Michigan Newborn Screening Overview



NBS Fee $86.86

More about Sickle cell Disease

- Screening started in 1987
- The Sickle cell Disease Association of America (SCDAA), Michigan Chapter is the coordinating center that provides comprehensive services to all newborns with hemoglobinopathies detected by NBS in Michigan.
- SCDAA located in Detroit and is directed by Dr. Wanda Whitten-Shurney
- SCDAA primary responsibilities are to assure that:
  - (1) all newborns referred with positive sickle cell screening results are appropriately diagnosed,
  - (2) penicillin prophylaxis is initiated,
  - (3) sickle cell counseling and social work services are available, and
  - (4) each newborn has a medical home
- In addition to the central office in Detroit the program maintains offices for social workers (patient advocates) in Grand Rapids, Benton Harbor, Kalamazoo, Lansing, and Saginaw.
- Not much for Sickle cell Traits (SCT) and adult population of both, SCD and SCT, due to lack of resources

MiHemSQIP Goals

Goal 1: Develop cross sectional and longitudinal data collection methods

Goal 2. Develop a model comprehensive surveillance System

Goal 3. Utilize the surveillance system to inform public health planning, services implementation, evaluation and policy development related to hemoglobinopathies across the life span

How do we define "life span"?

- Two-dimensional concept that involves recognizing that health and well-being along with other exposures and risks occur over a continuum from conception to death (horizontal dimension) but have also an impact on offspring (vertical dimension)
- Horizontal dimension:
  (1) longitudinal follow-up of the same cohort diagnosed at birth by newborn screening, which can be very challenging and requires resources and time; and
  (2) cross-sectional long term follow-up in order to assess and monitor sickle cell disease prevalence, mortality, co-morbidities, service utilization and costs at different stages across the lifespan, which entails the cross-sectional use of data from multiple sources.
- Vertical dimension: applies to those of reproductive age and reflects the impact of disease on offspring.

What do we need for implementation?

- Identify a process and do a plan:
  - **Surveillance process**
  - **Surveillance plan**

- Identify the existing data sources that could be useful:
  - **Multiple data sources for different issues and age groups,**
  - **Standard schedule for existing linkages and plan for new ones as needed**

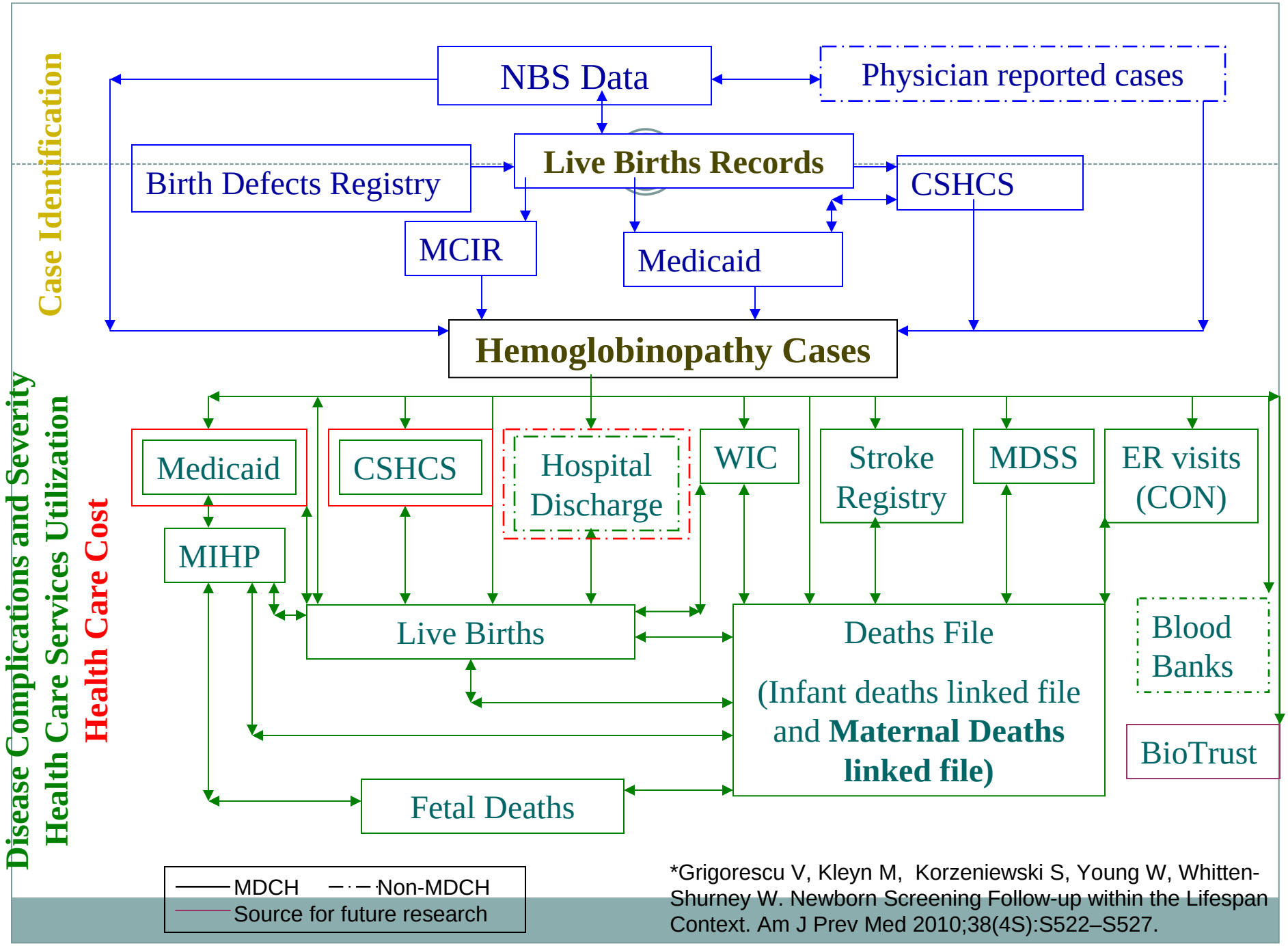
- Develop new data collection tools if need be:
  - **Sickle cell module in MCIR;**
  - **New question in BRFSS for estimating the prevalence**

- Find partners and engage them:
  - **Michigan Hemoglobinopathy Advisory Group**
  - **CBOs**
  - **Other programs and surveillance processes**

- Evaluate the plan to identify gaps and improve:
  - **CDC guidelines for surveillance evaluation**

Data sources to be used

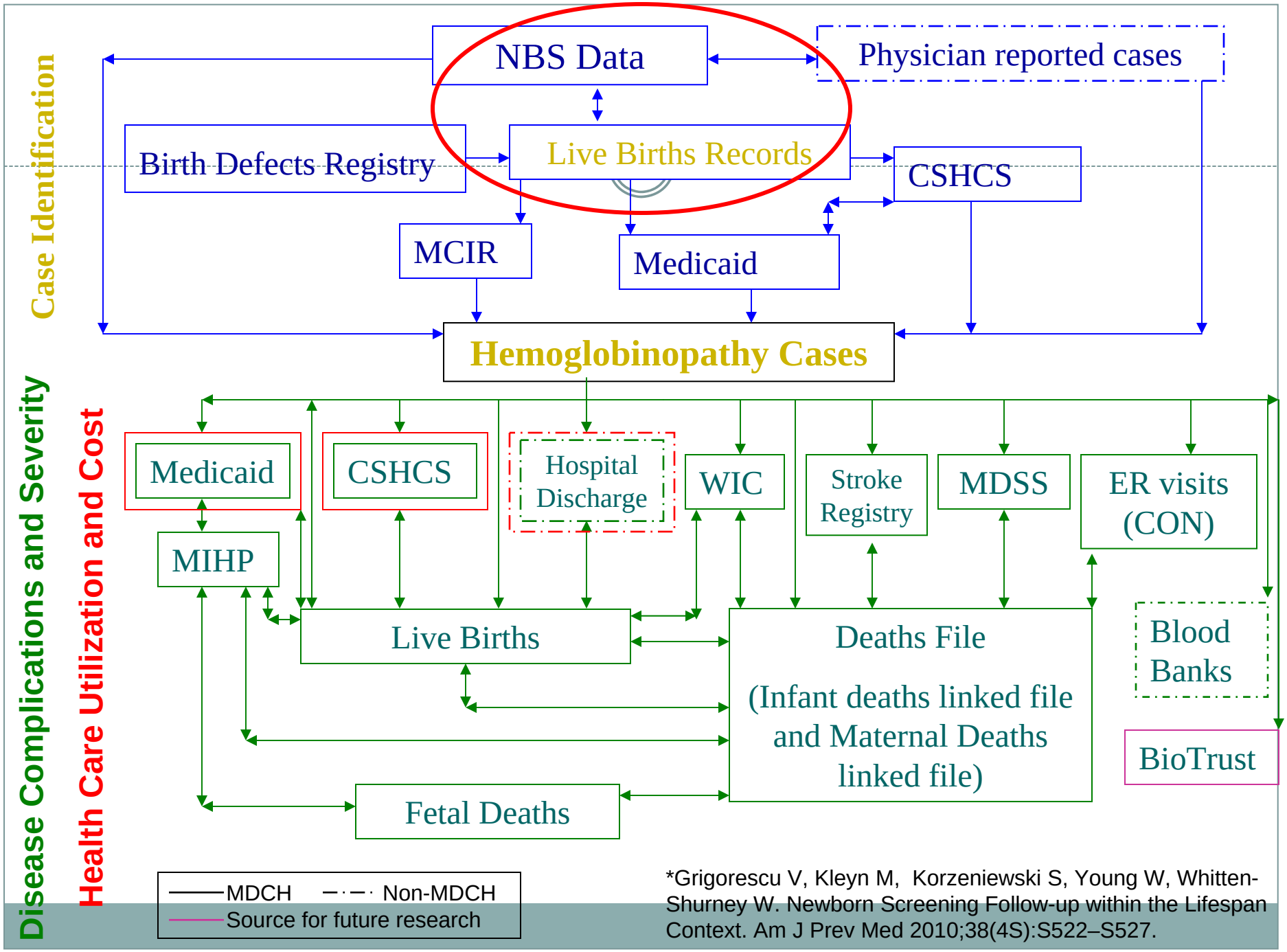
- NBS data and Patients roster for case identification
- Live births
- Birth defects registry
- Children's Special Health Care Services (CSHCS) program data
- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)
- Medicaid
- Michigan Inpatient Database provided by the Michigan Hospital Association, which contains hospital discharge records
- Stroke registry – future option
- Death certificates
- Different linked files



*Grigorescu V, Kleyn M, Korzeniewski S, Young W, Whitten-Shurney W. Newborn Screening Follow-up within the Lifespan Context. Am J Prev Med 2010;38(4S):S522–S527.

From vision to implementation

From linking to using the data



*Grigorescu V, Kleyn M, Korzeniewski S, Young W, Whitten-Shurney W. Newborn Screening Follow-up within the Lifespan Context. Am J Prev Med 2010;38(4S):S522–S527.

Linkage of Newborn Screening (NBS) and Birth Records

- Purposes:
  - Identify potentially unscreened infants
  - Provide the Division for Vital Records and Health Statistics a method for assessing data quality compared to NBS records
  - Assess the feasibility of linking NBS records to other administrative databases
- Process detailed in manuscript
  - Korzeniewski SJ, Grigorescu V, Copeland G, Gu G, Thoburn KK, Rogers JD, Young WI. Methodological Innovations in Data Gathering: Newborn Screening Linkage with Live Births Records, Michigan, 1/2007-3/2008. Matern Child Health J 2010;14(3):360-4.

Current Linkage Process

- Live birth records are received daily and linked to NBS records weekly
- SAS version 9.1 (Cary, N.C.) used for data preparation
- Link Plus used for linking
  - Blocking variables - used to 'block' the two files
  - Matching variables are compared between records that matched on the blocking variable
- Unmatched live birth records are sent to NBS Follow-up Program staff

Linkage Match Rates

- Match rate of each linkage is maintained in a spreadsheet.
  - Typically 99%+

Birth Year	Total Births*	Matched	
	N	N	%
2009	115,786	114,659	99.0

*Resident births, excluding 529 infants listed as deceased on the live birth record. Preliminary estimate.

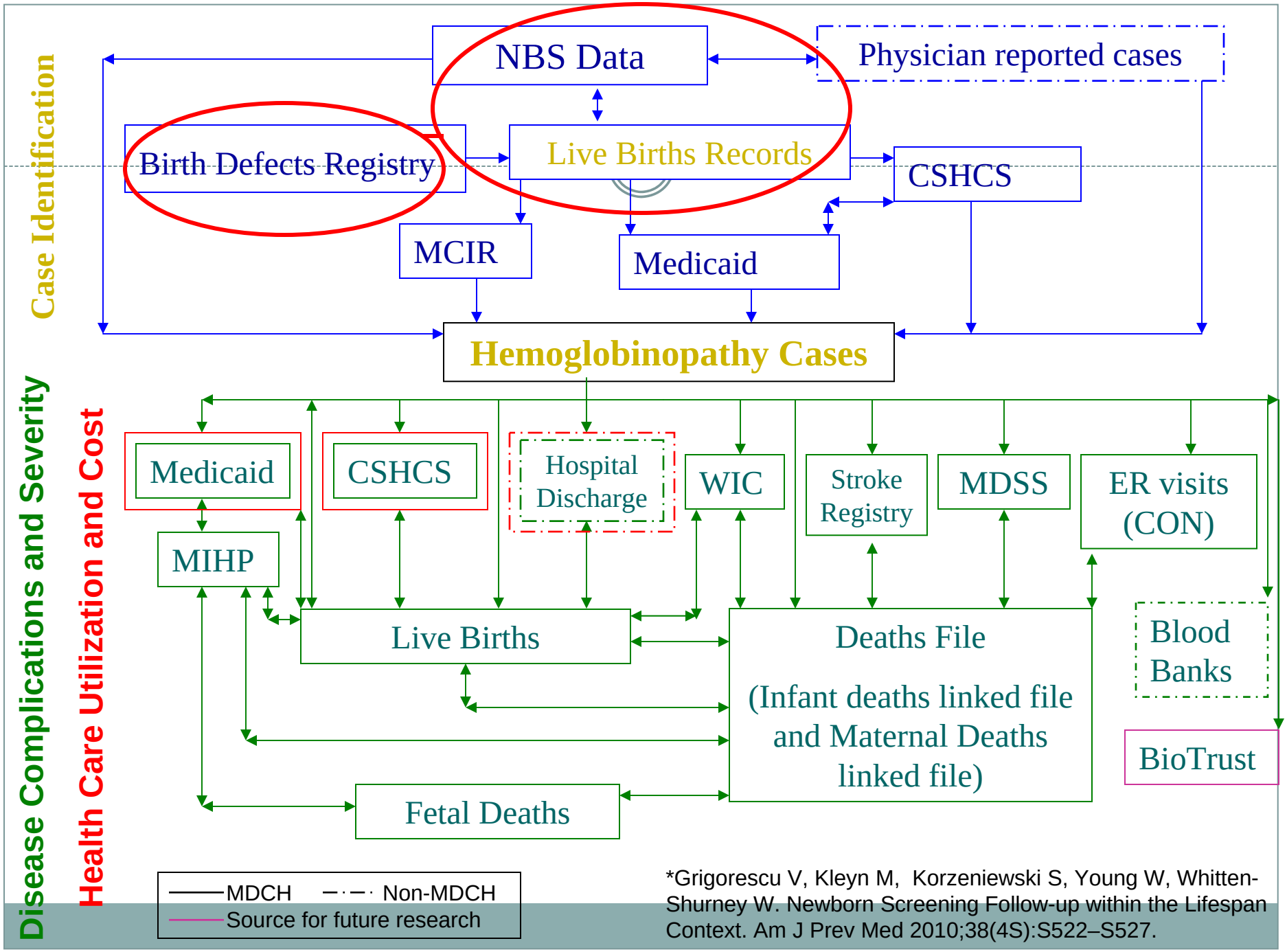
- Of the 1,127 unmatched records:
  - 504 (45%) were screened
  - 623 (55%) were not screened

Years Completed

- Linked Birth/NBS records
  - 2001 through present
- Plan to link as far back as possible
  - Goal: 1987

Importance of NBS/Live Births Linkage

- Through this probabilistic linkage, we can perform deterministic linkages with:
  - Michigan Birth Defects Registry (MBDR)
  - Michigan Care Improvement Registry (MCIR)
  - Michigan Inpatient Database (MIDB) for birth hospitalizations
  - Death certificates for infants
  - Medicaid
  - Women, Infants, & Children (WIC)



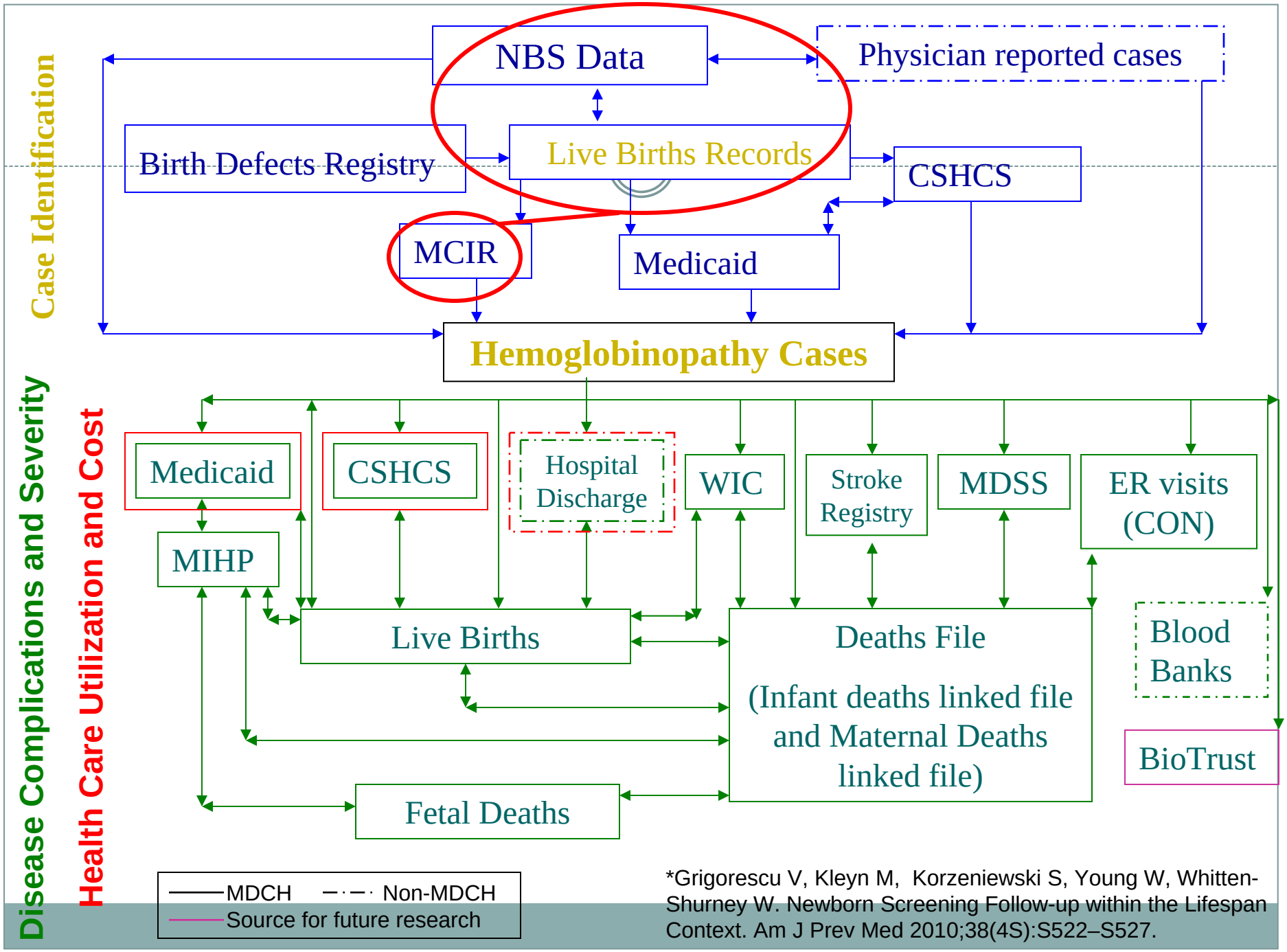
*Grigorescu V, Kleyn M, Korzeniewski S, Young W, Whitten-Shurney W. Newborn Screening Follow-up within the Lifespan Context. Am J Prev Med 2010;38(4S):S522–S527.

NBS and MBDR

- Study questions:
  - How many children with sickle cell disease (SCD) or trait (SCT) are missing or misclassified in MBDR compared to NBS records?
  - What birth defects are reported in children with SCD or SCT?

- MBDR epidemiologist given birth certificate identifier for all infants born 2004-2006 identified with SCD or SCT through NBS.
  - Linked 97% of NBS records with live birth records for this population

- Chart review for validation is currently on-going.

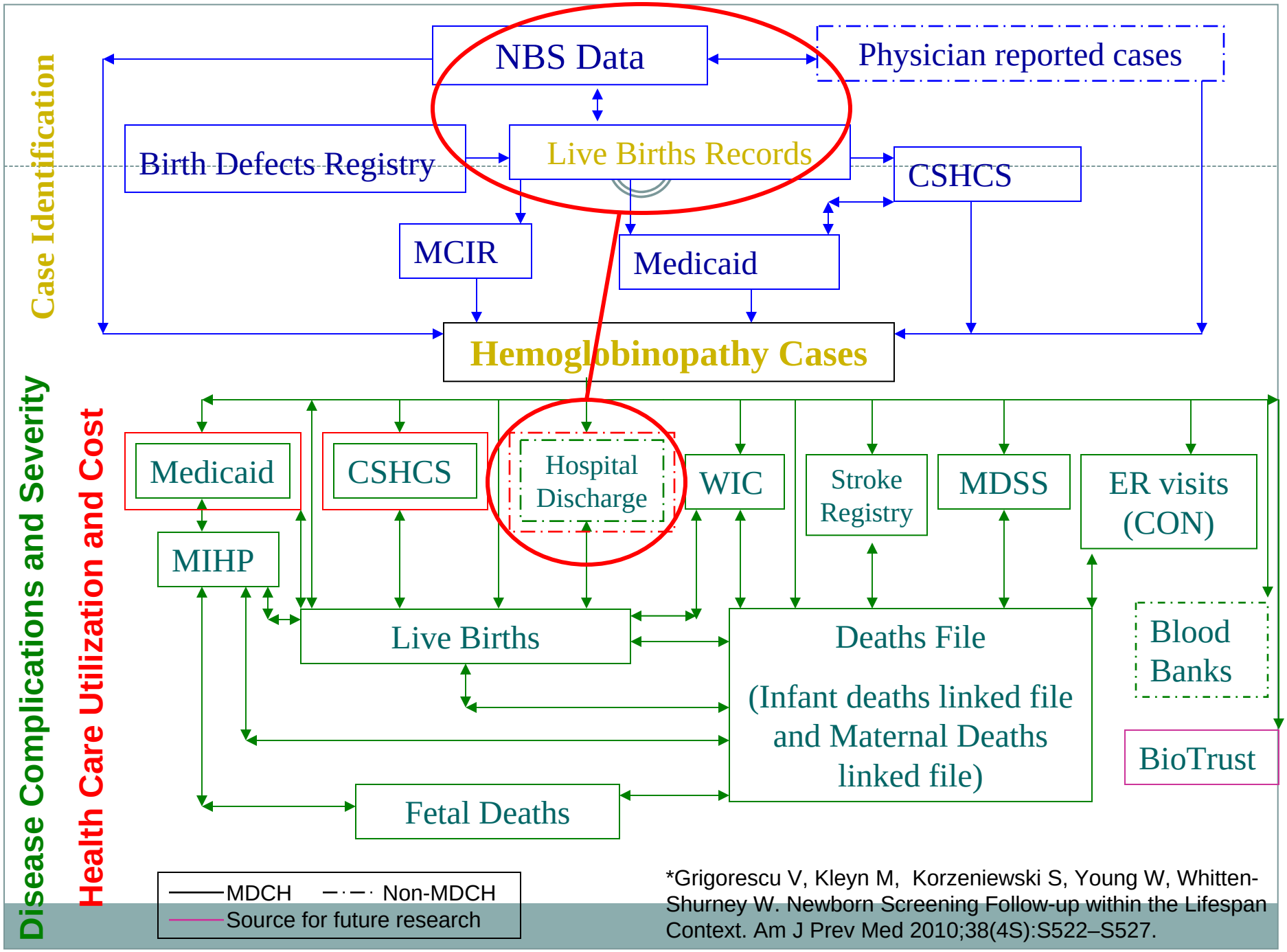


*Grigorescu V, Kleyn M, Korzeniewski S, Young W, Whitten-Shurney W. Newborn Screening Follow-up within the Lifespan Context. Am J Prev Med 2010;38(4S):S522–S527.

NBS and MCIR

- Study question:
  - What proportion of children with sickle cell disease (SCD) or trait (SCT) in Michigan is receiving appropriate immunizations in a timely manner?

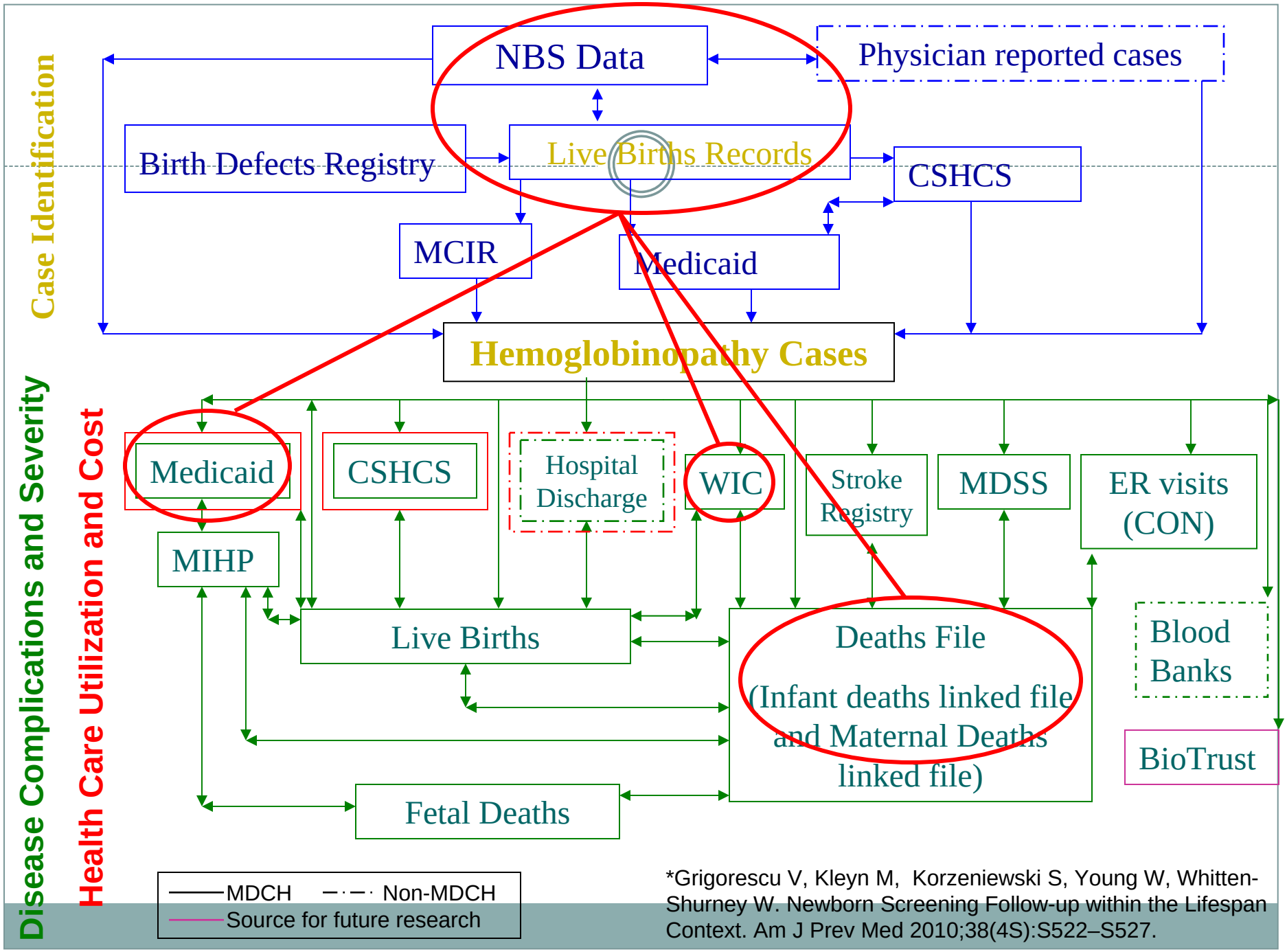
- MCIR epidemiologist given birth certificate identifier for all infants born 2004-2008 identified with SCD or SCT through NBS.
  - Linked 97% of NBS records with live birth records for this population
  - Linked immunization records for 90% of records with birth certificate identifier



*Grigorescu V, Kleyn M, Korzeniewski S, Young W, Whitten-Shurney W. Newborn Screening Follow-up within the Lifespan Context. Am J Prev Med 2010;38(4S):S522–S527.

NBS and MIDB

- Study questions:
  - Do perinatal characteristics or healthcare utilization after birth differ between newborns with SCD and newborns with SCT?
- Used birth certificate identifier for all infants born 2004-2008 identified with SCD or SCT through NBS
  - Linked 97% of NBS records with live birth records for this population
  - Linked hospitalization records for 94% of records with birth certificate identifier



*Grigorescu V, Kleyn M, Korzeniewski S, Young W, Whitten-Shurney W. Newborn Screening Follow-up within the Lifespan Context. Am J Prev Med 2010;38(4S):S522–S527.

NBS and Other Linkages

- In the process of linking NBS records with:
  - Medicaid
    - Working with Medicaid data analyst on data query
  - Deaths for infants
    - Working with state registrar to receive data
  - WIC
    - Working with WIC epidemiologist to develop WIC/live births linkage
      - Have already linked data for birth year 2007

MiHemSQIP - New data collection tools

- New question in BRFSS* for cross sectional prevalence estimate
- Sickle cell module in MCIR: longitudinal data collection for NBS cohort plus/minus cases identified in providers' offices
  - Patient level data
  - Annual health status assessment

* Behavioral Risk Factor Surveillance System

Michigan Care Improvement Registry

Web-based Hemoglobinopathy Follow-up

Sickle Cell Disease Follow-up Protocol using MCIR

Newborn Screening Follow-up
(Michigan Department of Community Health)

Long Term Follow-up
(Sickle Cell Disease Association of America, Michigan)

Electronic Live Birth Records sent to NBS

(Linked by NBS Epidemiologist)

Newborn Screening samples sent from hospital to MDCH NBS Lab, results entered into Perkin Elmer System

All Newborn Screening Follow-up results entered into MCIR with basic demographic information, contact information, NBS lab information

MDCH NBS sends letter to SCDAA (back-up)

SCDAA Center receives new case of newborn with sickle cell disease

New case is assigned in MCIR to SCDAA Center staff

MDCH NBS sends letter to physician

SCDAA sends letter to parents

SCDAA sends letter to physician

SCDAA assigns case in MCIR to regional patient advocate for follow-up

Patient Advocate begins follow-up

- Records family contact efforts in MCIR
- Records penicillin follow-up information in MCIR
- Records confirmatory lab test results in MCIR
- Conducts annual health status assessment

SCDAA notifies MDCH NBS of confirmatory results via e-mail

Confirmatory Test results recorded into MDCH records

Michigan Care Improvement Registry (MCIR)

- Web-based system established in 1998 to track immunizations
- Expanded in 2006 to include adults
- Healthcare providers are required to report childhood immunizations to MCIR within 72 hours of administration
- New "Follow-up" tab
  - Hemoglobinopathies
  - Early Hearing Detection and Intervention
  - Perinatal HIV
- http://www.mcir.org

General Information - Site: Sickle Cell Center - Microsoft Internet Explorer

Person | Follow Up | My Site | Admin | Reports | Other

Add/Find Roster Information Status History

Person Information : Edit — **MCIR ID : 30188999334**

Name: | Birthdate: 01/08/2002 | Gender: Male

Age: 8 Years 9 Months | County: Wayne (82) County

Address:

Resp. Party:

As of 02/03/2009 | Phone:

Immunizations | **Other**

Series	Dose 1	Dose 2	Dose 3	Dose 4	Dose 5	Dose 6+	Status
DTP/DTaP/ DT/Td/Tdap	04/05/2002 DTaP 2mos 28dys	08/10/2002 DTaP 7mos 2dys	12/07/2002 DTaP 10mos 29dys	01/27/2004 DTaP 2yrs	09/02/2006 DTaP 4yrs 7mos		Up-to-date Next Due 01/08/2013
Polio	04/10/2002 IPV 3mos 2dys	08/10/2002 IPV 7mos 2dys	01/27/2004 IPV 2yrs	09/02/2006 IPV 4yrs 7mos			Series Complete
MMR	07/26/2003 MMR 1yr 6mos	09/02/2006 MMR 4yrs 7mos					Series Complete
Hepatitis B	04/05/2002 Hib-HepB 2mos 28dys	08/10/2002 Hib-HepB 7mos 2dys	12/07/2002 Hib-HepB 10mos 29dys				Series Complete
Varicella	07/26/2003 Varicella 1yr 6mos	08/26/2008 Varicella 6yrs 7mos					Series Complete
Hepatitis A	08/18/2007 Hep A (ped) 5yrs 7mos	08/26/2008 Hep A (ped) 6yrs 7mos					Series Complete
Seasonal Influenza							Seasonal Influenza DUE NOW

Other Administrations

Series							Status
Hib	04/05/2002 Hib-HepB 2mos 28dys	08/10/2002 Hib-HepB 7mos 2dys	12/07/2002 Hib-HepB 10mos 29dys	07/26/2003 Hib-HibTITER 1yr 6mos			Not Available
Pneumococcal Conjugate	04/10/2002 PCV7 (Prevnar) 3mos 2dys	08/10/2002 PCV7 (Prevnar) 7mos 2dys	07/26/2003 PCV7 (Prevnar) 1yr 6mos				Not Available

Non-Administered Doses/Positive Immunity

Series/Antigen	Date	Reason	Entered by
No Non-Administered Doses/Positive Immunities Found			

Hemoglobinopathy Annual Health Status Assessment Form

SICKLE CELL HISTORY

8. Are you currently on Hydroxyurea therapy?

☐ Yes ☐ No ☐ Don't Know ☐ *Clinically Verified*

If no: Has a health professional talked to you about Hydroxyurea therapy in the past 12 months?

☐ Yes ☐ No ☐ Don't Know

9. In the past 12 months, have you been on a chronic transfusion program?

☐ Yes ☐ No ☐ Don't Know ☐ *Clinically Verified*

If yes: What was the reason for chronic treatment? (select 1)

☐ Stroke
☐ Abnormal TCD
☐ Silent Infarct
☐ Splenic sequestration
☐ Priapism
☐ Leg ulcer
☐ Recurrent Pain
☐ Don't know
☐ Other

☐ *Clinically Verified*

10. Are you currently on narcotic therapy? ☐ *Clinically Verified*

☐ Yes ☐ No ☐ Don't Know

If no: Has a healthcare professional talked to you about narcotic therapy in the past 12 months?

☐ Yes ☐ No ☐ Don't Know

11. Are you currently taking any vitamin supplements?

☐ Yes ☐ No ☐ Don't Know

If no: Has a healthcare professional talked to you about taking vitamin supplements in the past 12 months?

☐ Yes ☐ No ☐ Don't Know

"The future belongs to those who believe in the beauty of their dreams."

Eleanor Roosevelt