

# Data linkages in Michigan From Vision to Implementation



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# 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

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# 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



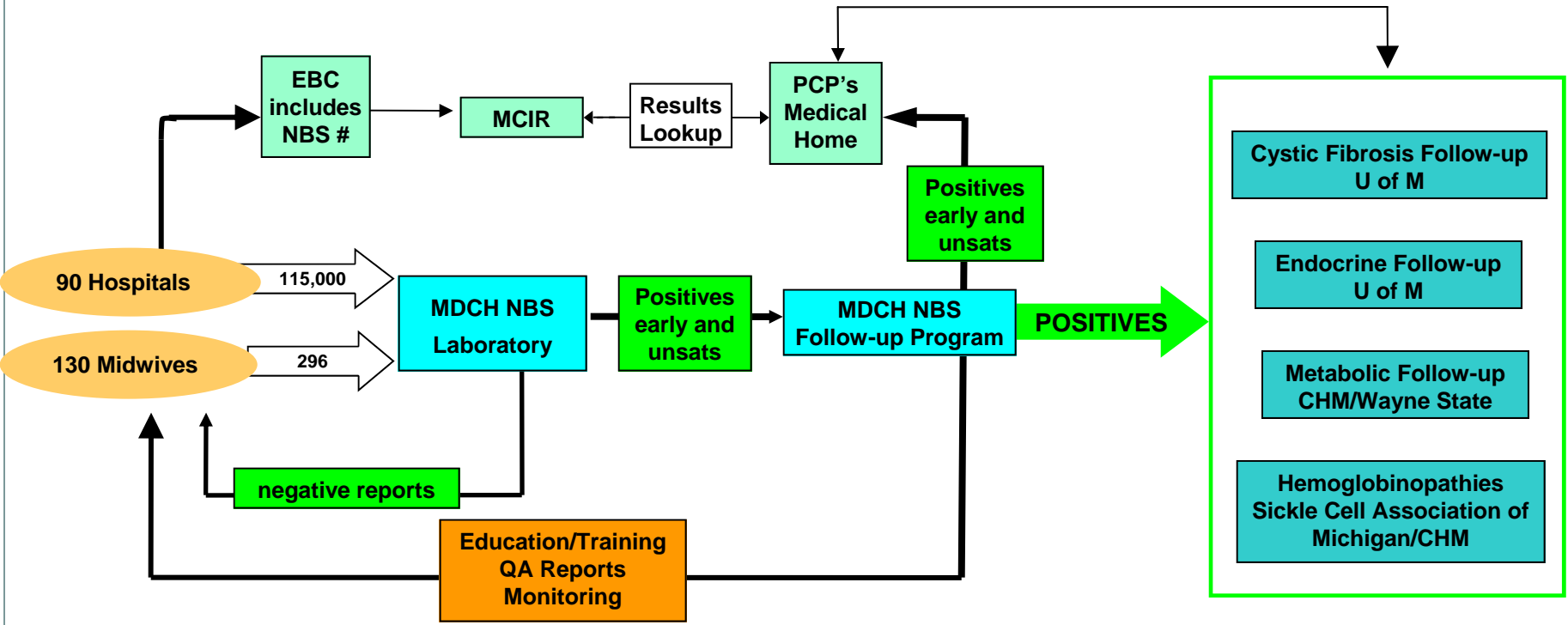
- Limited resources to meet the growing needs
- More competition and with former partners due to the budget deficit
- Still limited understanding of public health functions and services
- Non-infectious epidemiology still “new” and justifying its existence
- Public Health System – all of us but with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

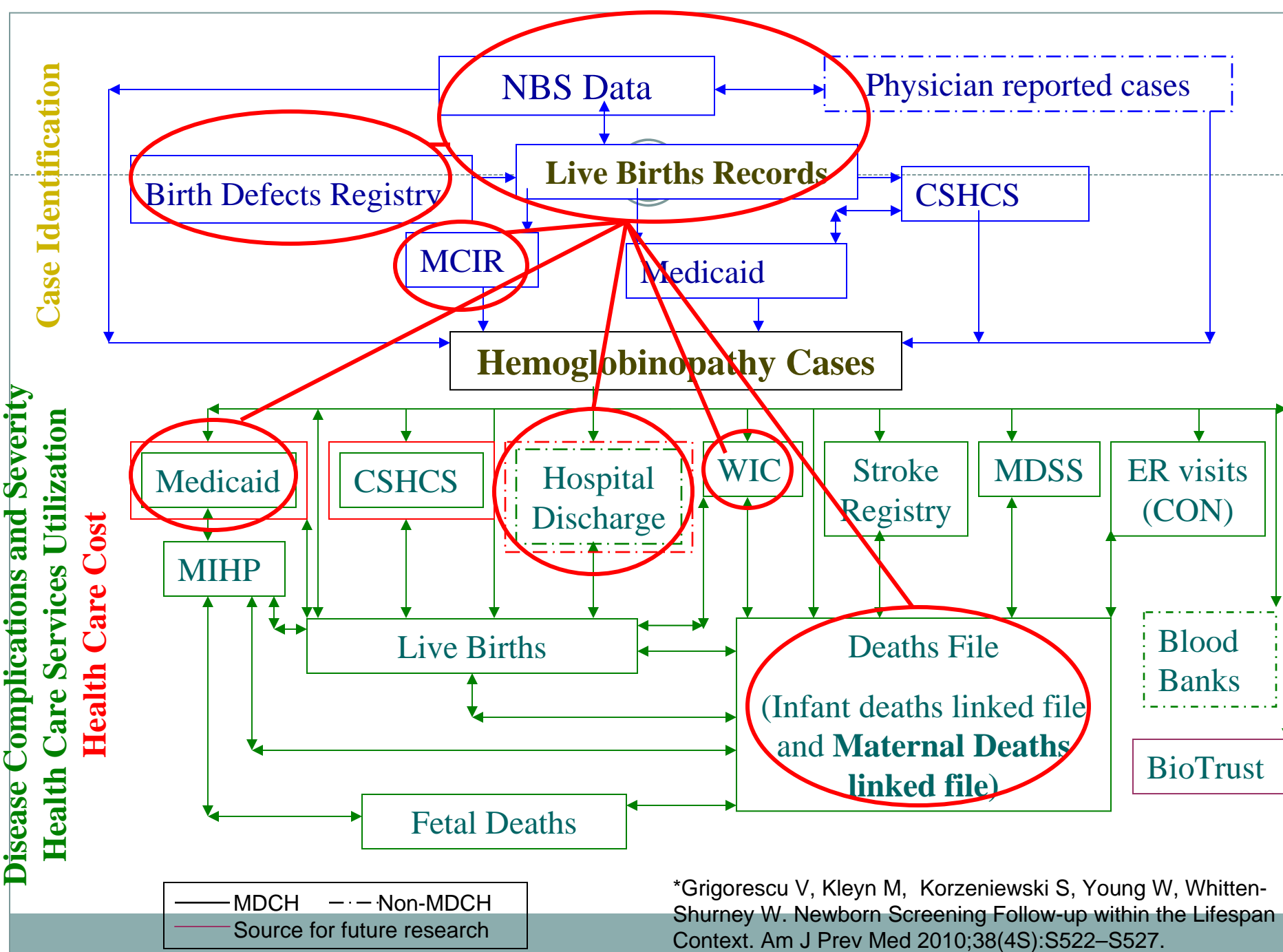


- Identify a process and do a plan:
  - Surveillance process
  - Surveillance plan
- Identify the existing data sources that could be useful:
  - Multiple data sources for different issues and age groups,
  - Standard schedule for existing linkages and plan for new ones as needed
- Develop new data collection 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 – **on going and very active**
  - CBOs – **different activities coordinated by the SCDAA MI Chapter**
  - Other programs and surveillance processes – **collaboration with Medicaid - ED visit**
- 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



Case Identification

Disease Complications and Severity  
Health Care Services Utilization  
Health Care Cost

— MDCH    - - - Non-MDCH  
— Source for future research

\*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.

# MiHemSQIP - New data collection tools



- New question in BRFSS\* for cross sectional prevalence estimate
- ED visits question in CON – experiment
- 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