

Efforts to develop a CP state registry

Developing multi-center collaborative research with the cerebral palsy community
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Outline

- CSHCN/CSHCS definition and program
- Efforts to develop CP surveillance and registry
 - Planning
 - Surveillance plan
 - Lessons learned
- Surveillance and registry: two slightly different concepts but same partners
- Collaboration and partnership: basic rules
- Suggested next step for developing a CP state surveillance and registry

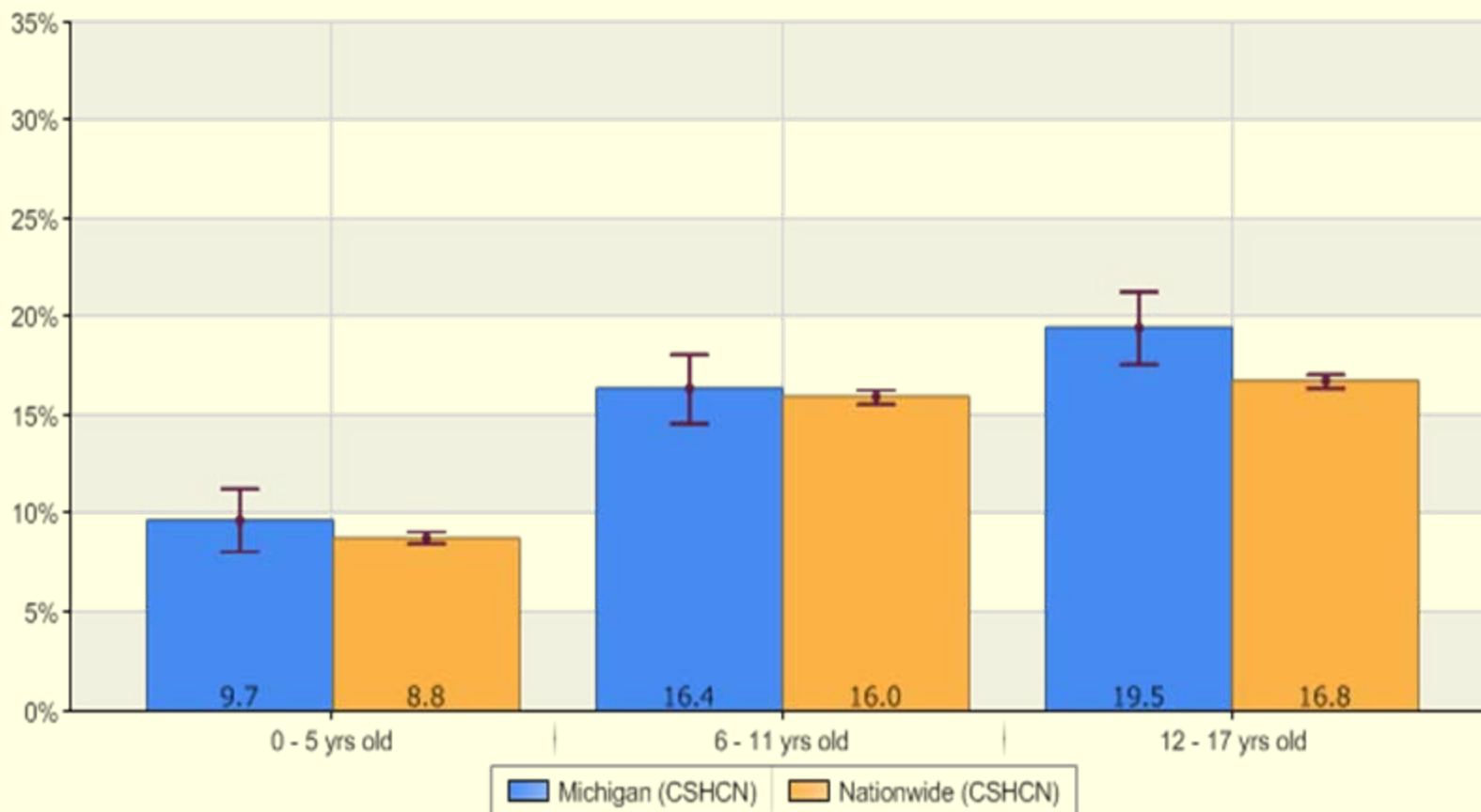
CSHCN Definition

- States are funded under Title V to implement service systems for children with special health care needs (CSHCN).
- **Federal (MCHB):** “Children with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”
- **Michigan:** A person under age 21 “whose activity is or may become so restricted by disease or deformity as to reduce the individual’s normal capacity for education and self-support.”

Prevalence of CSHCN: overall and by age

Overall: Michigan 15.4%

Nationwide 13.9%



Michigan's CSHCS Program

- ICD9-based eligibility: 2600+ codes
- Frequent dual-enrollment in Medicaid
- A final payer source for services
- Care coordination for specialty services and medical equipment

CSHCS Population Demographics

- Serves ~35,000 children per year
- 69% White, 21% Black
- 55% Male, 45% Female
- Most prevalent conditions are:
 - congenital anomalies,
 - cerebral palsy, and
 - hearing loss

Source: Michigan Data Warehouse, 2002-03

More about CP in CSHCS program

- 2002-2003 CSHCS program data: 12.7%
- 2004 CSHCS program data: 13.9%

- Is this a real increase in prevalence of cerebral palsy in CSHCS population?
- What type of CP is more frequent in this population of CSHCS?

Identified issues

- CP the second most prevalent condition among MI CSHCS population
- Increased CP prevalence in 2004
- Unknown severity and type of CP among those enrolled in MI CSHCS program
- Unknown association with other eligible CSHCS conditions

Cerebral Palsy Surveillance and Registry: public health approach

- **Engage stakeholders:** experts in the field, public health, parents, etc.
- **Use CSHCS program data** to identify the population of children with CP in Michigan followed by chart review for validation
- **Develop a surveillance plan** with goal and objectives to further explore:
 - Type and severity
 - Associated co-morbidities
 - Length of enrollment and use of services
- **Summarize and use the findings** to:
 - Develop and/or improve the case definition
 - Make recommendations when appropriate
 - Inform decision makers
 - Plan for developing a registry

Progress in developing and implementing the CP surveillance

- Epi studies with MI population of children enrolled in CSHCS program:
 - Grigorescu et al: **Contribution of Preterm Births to the Population of Michigan's Children's Special Health Care Services Program**: First poster award at the National MCH Epi Conference and published in the Journal of Registry Management
 - Prevalence of different diseases among CSHCS enrolled children
- Meetings held with:
 - experts in the field: June 2005
 - CSHCS program leaders at MDCH: Jan 2006
- Surveillance plan and data collection tools developed
 - Accomplished and chart abstraction performed for 17 cases
- Reports and presentations developed to keep the communication open with partners and decision makers at MDCH

CP Surveillance Goals and Objectives

1. **Develop data collections methods**
 - Identify children enrolled in Children's Special Health Care Services (CSHCS) with cerebral palsy
 - Perform abstraction of medical information pertaining to the development and therapeutic treatment of cerebral palsy from CSHCS charts
 - Survey parents about development and treatment of cerebral palsy
2. **Monitor the prevalence and impact of cerebral palsy in Michigan**
 - Identify disparities associated with the burden of cerebral palsy in Michigan
 - Track changes in the occurrence of cerebral palsy
3. **Assess risk factors for cerebral palsy to improve preventive and rehabilitative efforts**
 - Develop advisory board to provide recommendations
 - Help design interventions appropriate for prevention of cerebral palsy in Michigan
 - Assess the impact of therapies aimed at ameliorating the effects of cerebral palsy

No progress since. WHY?

- Lack of funding to support the epidemiology work that is crucial for this process
- Changes in the CSHCS program system: no access to program data and to charts
- Lack of well understood roles of each partner in this collaborative effort:
 - Program leaders and decision makers
 - Public health epidemiologists
 - Researchers and experts in the field
 - Patients and parents
- Competing priorities

Lessons Learned

- Establish ground rules and define the roles of core partners from the very beginning
- Get the buy-in and commitment from program leaders by promoting the science and evidence based: surveillance is an epi function
- Seek opportunities and/or offer solutions to adjust an existing plan to any administrative changes (i.e., program data collection)
- Do not offer voluntary work but rather find more resources to jump start the process

Different times and new evolving technologies

- Do we need both, surveillance and registry?
 - YES
 - Different functions and different use of data
- Could we have the same data system(s) source for both?
 - Maybe
 - Clinical and social information is needed
- Are there other similarities between these two slightly different concepts?
 - Same Ground Rules and Same Partners

Surveillance and Registry – two slightly different concepts

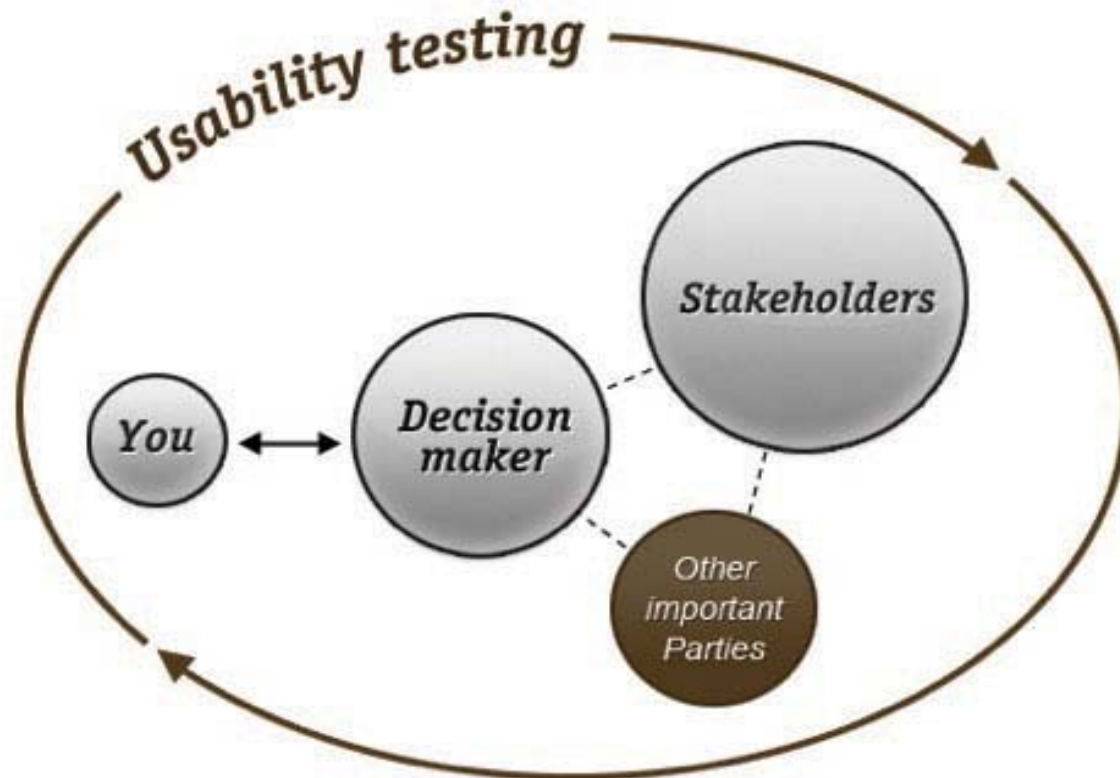
- **Disease surveillance***: an epidemiological practice by which the spread of disease is monitored in order to establish patterns of progression.
 - The main role of disease surveillance is to predict, observe, and minimize the harm caused by outbreak, epidemic, and pandemic situations, as well as increase our knowledge as to what factors might contribute to such circumstances.
 - A key part of modern disease surveillance is the practice of disease case reporting
- **Disease registries**: collections of secondary and more extensive data related to patients with a specific diagnosis, condition, or procedure.
 - Most frequently registries vary in sophistication from simple spreadsheets that only can be accessed by a small group of physicians to very complex databases that are accessed online across multiple institutions.
 - They can provide health providers (or even patients) with reminders to check certain tests in order to reach certain quality goals

* The word surveillance comes from the French word for "watching over".

Surveillance and Registry - Who are the partners?

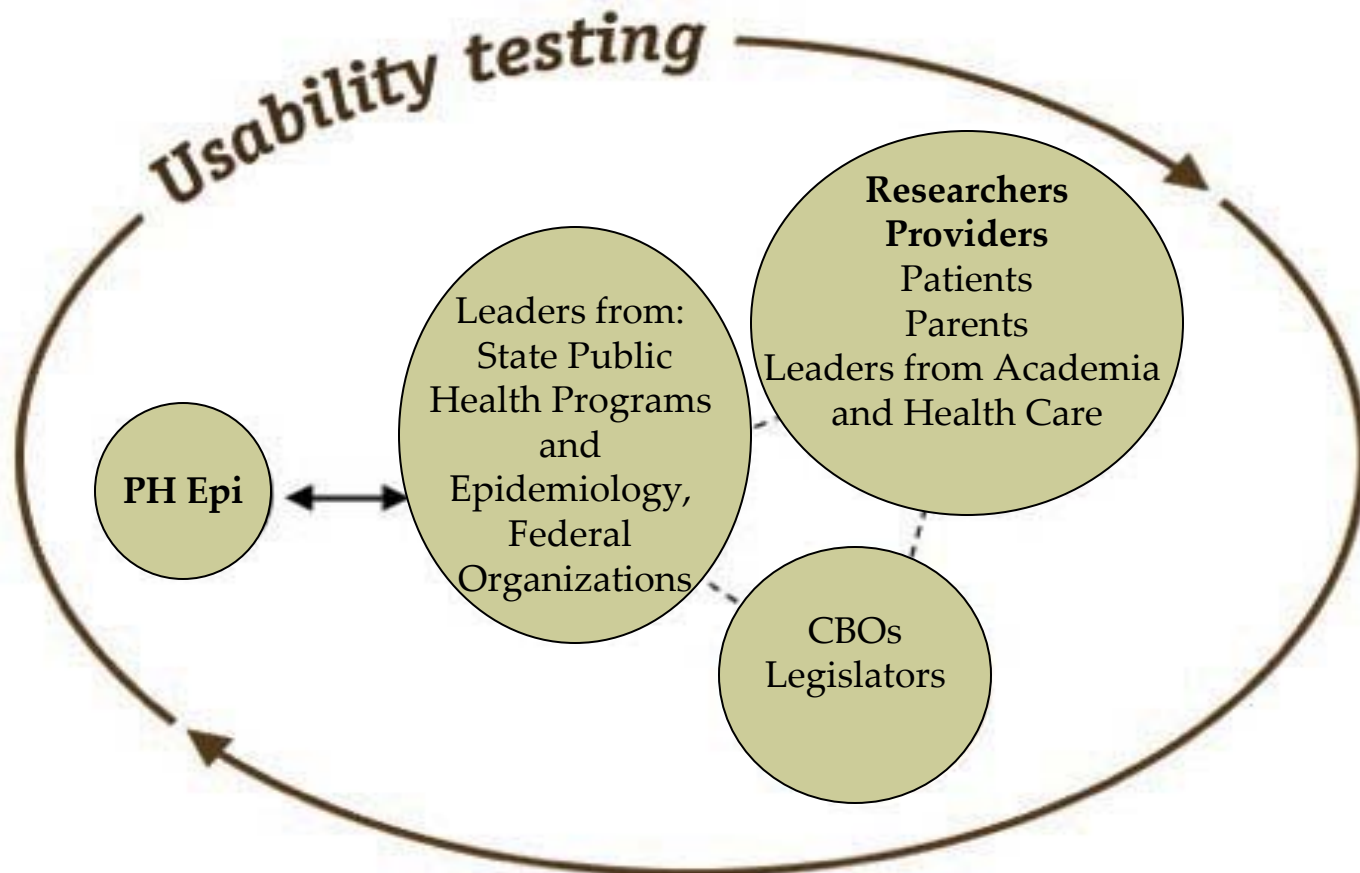
General Management Ground Rules on How to Achieve Positive Outcomes with Collaboration

Jacob Creech is a usability geek at IntuitionHQ.com



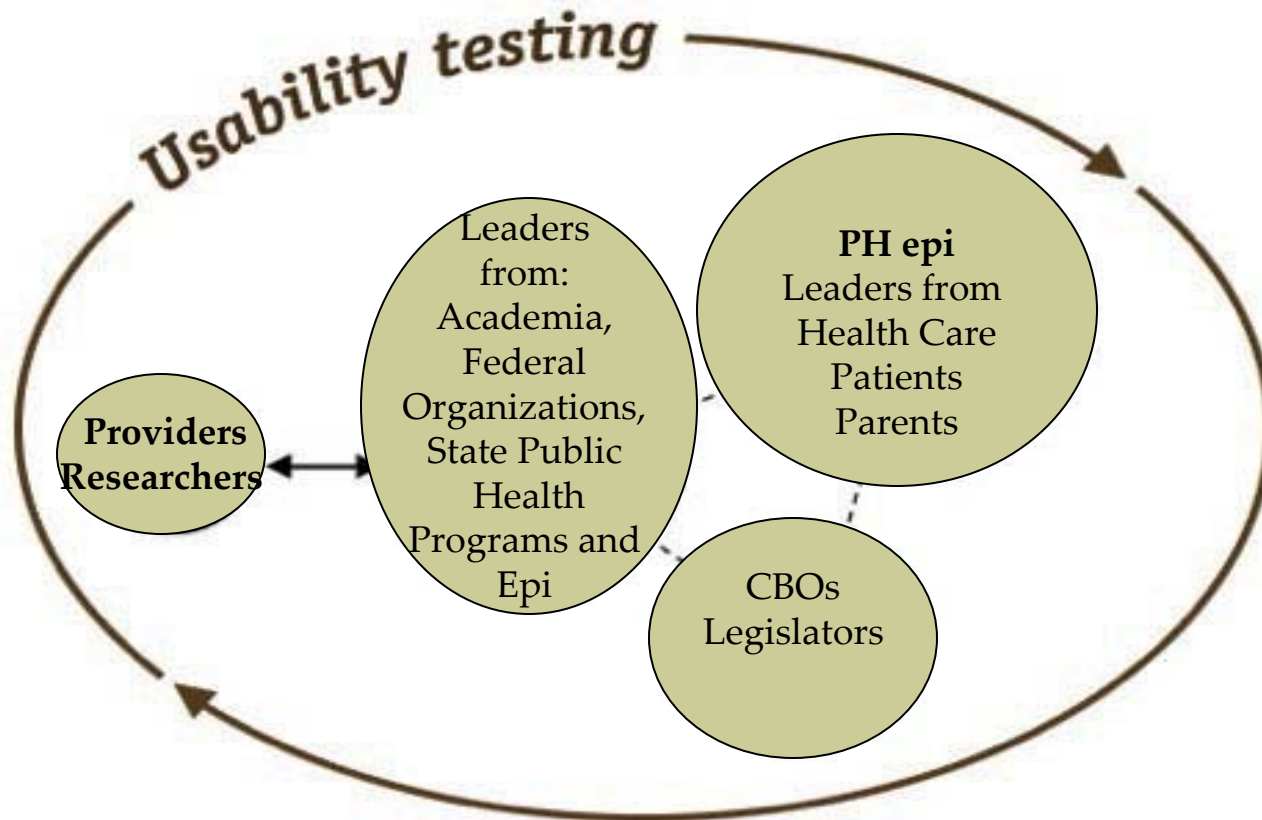
Surveillance and Registry Management ground rules: Same partners but Different roles

One Scenario for Surveillance



Surveillance and Registry Management ground rules: Same partners but Different roles

One Scenario for Registry



Successful collaboration

Violanda's basic rules

- Use scientific evidence
- Share and learn
- Have a good understanding of the unique skills each partner may bring
- Develop strong ground rules
- Define the roles of each partner and so the Shared ownership
- Promote and adopt:
 - professionalism
 - transparency and honesty
 - commitment
- Open communication path
- Remember that it is all about **GIVE** and **GET**

Ten Simple Rules for a Successful Collaboration in Research

Quentin Vicens, Philip E. Bourne - PLoS Computational Biology

- Rule 1: Do Not Be Lured into Just Any Collaboration
- Rule 2: Decide at the Beginning Who Will Work on What Tasks
- Rule 3: Stick to Your Tasks
- Rule 4: Be Open and Honest
- Rule 5: Feel Respect, Get Respect
- Rule 6: Communicate, Communicate, and Communicate
- Rule 7: Protect Yourself from a Collaboration That Turns Sour
- Rule 8: Always Acknowledge and Cite Your Collaborators
- Rule 9: Seek Advice from Experienced Scientists
- Rule 10: If Your Collaboration Satisfies You, Keep It Going

Effective collaboration in the context of the 4 Ps Framework for Effective Collaboration

All Collaboration: Connect, Collaborate, Create

Purpose	<ul style="list-style-type: none">• Define goals, roles, timelines and deliverables clearly (29%)• Take the time to create the context for the project (8%)
People	<ul style="list-style-type: none">• Select team members who play well with others (6%)• Ensure that team members are trained and comfortable with using collaboration tools (5%)• Recognize and resolve conflicts quickly (3%)
Process	<ul style="list-style-type: none">• Communicate the process and progress clearly and frequently (17%)• Spend more time working together rather than independently (3%)
Place	<ul style="list-style-type: none">• Select the right collaboration tools based on project needs (7%)• Get the team together several times for face-to-face contact (5%)• Make full use of the collaboration tools available (4%)

Michigan Hemoglobinopathy Surveillance and Quality Improvement as example

Planning:

- One voice to promote the same interest:
 - Advisory Committee created: members include public health professionals, providers, health insurance representatives, researchers, parents
 - Operating procedures in place
- Scientific evidence and existing resources used to promote the need
- Surveillance promoted as a follow up strategy

Final Results:

- NHLBI/NIH funded **RuSH** through a cooperative agreement with CDC: MiHemSQIP=Mi RuSH
- Overarching goal - Use of surveillance for:
 - continued health assessment and monitoring
 - informing the needs for registry and research

RuSH: Registry and Surveillance System in Hemoglobinopathies

- First phase of RuSH: public health surveillance to collect and analyze the information on demographics, morbidities and mortality, health care service utilization and cost
- Next phase of RuSH: develop registries with detailed clinical information

“Data collected from the \$27 million **Registry and Surveillance System in Hemoglobinopathies (RuSH)** project will help researchers determine the most effective plans for developing future hemoglobinopathy registries. Research findings based on data from disease registries may provide new ideas for drug therapies and can spur the development of tests that can determine severity of diseases over the **lifespan.**”

<http://www.nih.gov/news/health/feb2010/nhlbi-18.htm>

Suggested Next Steps for a CP State Surveillance and Registry

- One voice to promote same interest:
 - Create an Advisory Committee with core partners, including public health professionals
- Develop effective collaboration among expert users of public and clinical data systems
 - Public health epidemiologists and clinical researchers
- Develop ground rules for long term partnership/collaboration
- Review and Improve the developed surveillance plan: include the registry development
- Seek funding sources to jump start the process