Cerebral palsy registers and surveillance systems: why they are useful, how to start one and what to do next!

Sarah McIntyre, Sue Reid, Hayley Smithers-Sheedy, Eve Blair Australian CP Register); Eva Nordmark and Lena Westbom (CPUP Sweden); Kate Himmelmann and Guro Andersen (Surveillance of CP Europe); Marshalyn Yeargin-Allsopp, Kim Van Naarden-Braun, Daisy Christensen, Alyson Goodman (CDC, MADDSP and ADDM Network); Michael Msall and Donna Hurley (Cerebral Palsy Research Registry); Maryam Oskoui and Michael Shevell (Canadian CP Register).

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http://impact.cerebralpalsy.org.au/activities/research-activities/cp-register-and-surveillance/

IMPACT for Cerebral Palsy | Connecting people globally for prevention and cure

CP REGISTERS AND SURVEILLANCE

Schedule

1.00pm	Introduction
1.20pm	Major contribution of registers
1.30pm	What is a CP Register? Purposes?
1.50pm	Governance and funding
2.00pm	Group work and report back
2.40pm	Break

Schedule

2.55pm	Scope and Minimum Data Set
3.05pm	Data collection
3.15pm	Group work and report back
3.45pm	Break
4.00pm	Overview of current registers and
4.30pm	Networks and resources and panel discussion
4.55pm	Wrap up and thanks

Survey report


World CP Register | Congress
19 February 2009

SURVEY REPORT

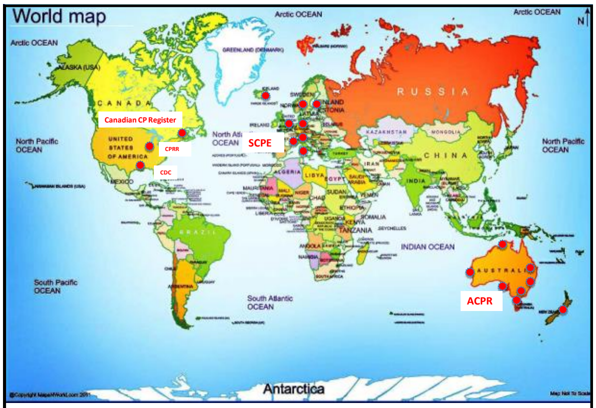
Acknowledgment

AUSTRALIA

EUROPE

EUROPE - UNITED KINGDOM

World map



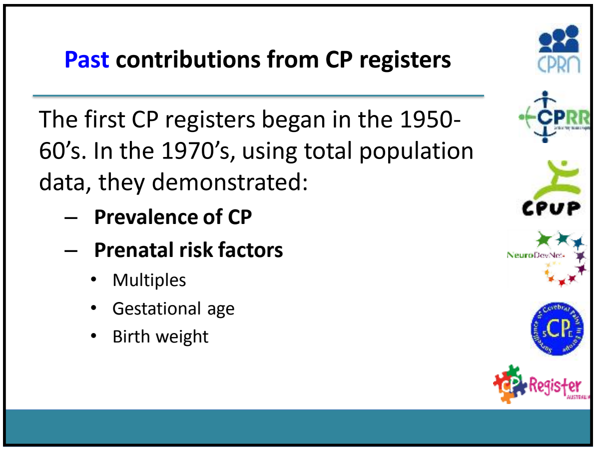
Major contributions from CP registers: past, present and future

DONNA S. HURLEY, PT, DPT & MICHAEL E. MSALL, MD
CEREBRAL PALSY RESEARCH REGISTRY, CHICAGO ILLINOIS

Contributions from CP registers

CP registers have been increasing our knowledge of cerebral palsy for the past 60 years.

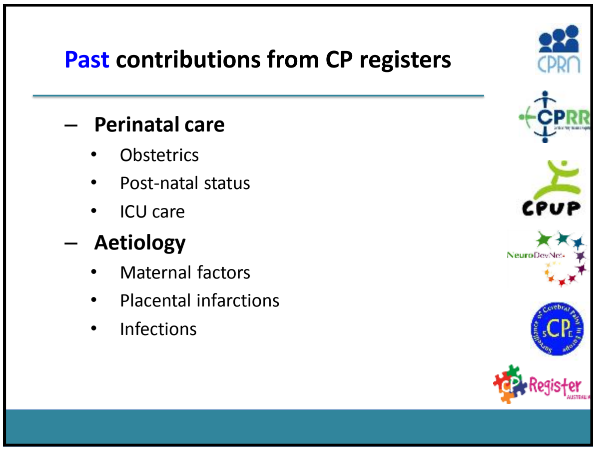
Early epidemiological contributions have provided a **foundation** for researchers to expand upon.



Past contributions from CP registers

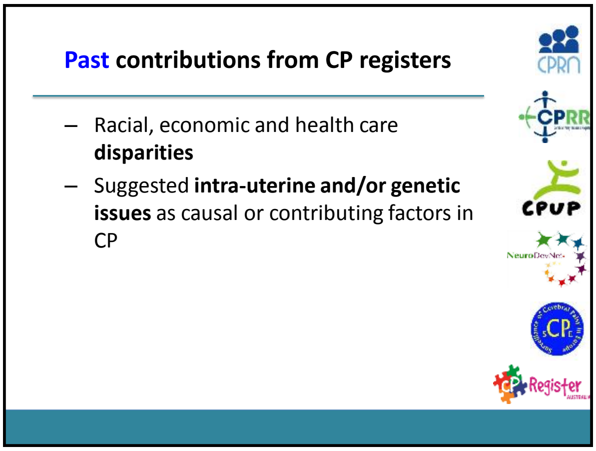
The first CP registers began in the 1950-60’s. In the 1970’s, using total population data, they demonstrated:

- **Prevalence of CP**
- **Prenatal risk factors**
  - Multiples
  - Gestational age
  - Birth weight



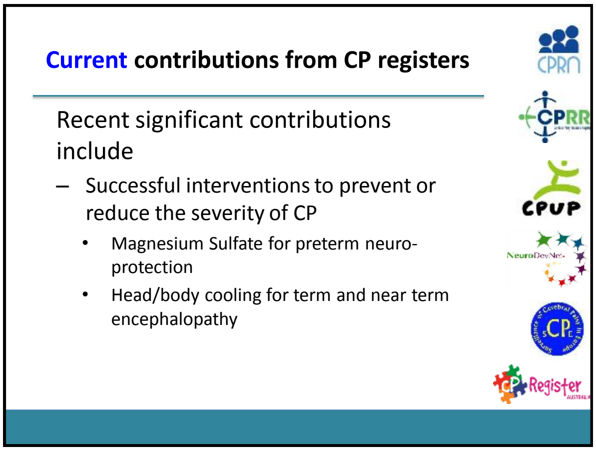
Past contributions from CP registers

- **Perinatal care**
  - Obstetrics
  - Post-natal status
  - ICU care
- **Aetiology**
  - Maternal factors
  - Placental infarctions
  - Infections



Past contributions from CP registers

- Racial, economic and health care **disparities**
- Suggested **intra-uterine and/or genetic issues** as causal or contributing factors in CP



Current contributions from CP registers

Recent significant contributions include

- Successful interventions to prevent or reduce the severity of CP
  - Magnesium Sulfate for preterm neuro-protection
  - Head/body cooling for term and near term encephalopathy

Current contributions from CP registers

- Genetic expression and biomarkers
- Maternal and paternal risk factors
- Neuroimaging antecedents
- Hip surveillance
- Social and environmental influences on persons with CP
- Economic implications of CP: individual, family and society
- Interventions addressing pain, spasticity, therapeutic needs, stress, co-morbidities

Current contributions from CP registers

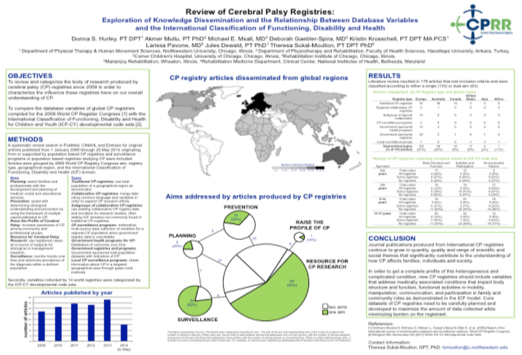
Documented studies on

- Decline of CP in birthweight 1000-1499 G but stable prevalence in full term and late preterm births over past 50 years
- Importance of multiple births especially with the intrauterine death of sibling
- Most common antecedent in term CP is unknown, not neonatal encephalopathy

Current contributions from CP registers

CP registers have enabled us to see contributions to CP that **are less likely to be clinically obvious.**

This is performed by **charting** various **post neonatal causes** that put the clinically obvious risk factors (very preterm birth, asphyxia) **into perspective** and investigating infants that are **neonatally asymptomatic**.



Review of Cerebral Palsy Registries:
Exploration of Knowledge Dissemination and the Relationship Between Database Variables and the International Classification of Functioning, Disability and Health

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Larissa Pavone, MD[5] Jules Dewald, PT PhD[1] Theresa Sukal-Moulton, PT DPT PhD[6]

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OBJECTIVES

To review and categorize the body of research produced by cerebral palsy (CP) registries since 2009 in order to characterize the influence these registries have on our overall understanding of CP.

To compare the database variables of global CP registries compiled for the 2009 World CP Register Congress [1] with the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) developmental code sets [2].

SP 26: Systematic Review of CP Registers and disseminated CP research

Future contributions from CP registers

CP registers have a unique position within the scientific community and can assist with accelerated discovery.

This can be accomplished with collaboration, registry expansion, inclusion of variables covering the lifespan and a willingness to embrace new technology.

Future contributions from CP registers- Accelerated Discovery

- Clinical trial networks for neuro-protection
- Placenta research; maternal risk factors
- Research on full-term asymptomatic infants with non informative MRIs
- Lifespan approaches in research studies
- Genetics
- Community interventions to improve maternal health and early child health in developing countries

Future contributions from CP registers- Collaboration

Collaboration within and between countries can lead to shared **resources**, improved social awareness that can **raise the profile of CP** and being a **support** for global and rural initiatives.

Future contributions from CP registers- Collaboration

Collaboration between CP registers and state/government registries will promote **a holistic and comprehensive life-course view** of persons with CP emphasizing wellness, functioning, participation and caregiver well being.

Future contributions from CP registers- Expansion of Registers

Expansion of CP registers can

- Ask additional questions not on the original register questionnaire
  - How the physical, social, economic, QOL change over time for persons with CP.
  - What technology promotes participation and independent living?
  - **SPARCLE** (Study of Participation of Children with Cerebral Palsy Living in Europe)

Future contributions from CP registers- Expansion of Registers

Expansion of CP registers can

- Provide longitudinal information
  - Surveillance of hip dislocations, scoliosis and contractures.
    - **CPUP** and **CPOP** in Sweden, Norway, New South Wales, Demark, Iceland & Scotland
  - What interventions are working? What reduces obesity? What optimizes seizure control? What optimizes behavioral health? What promotes self-efficacy?

Future contributions from CP registers- Include Lifespan Variables

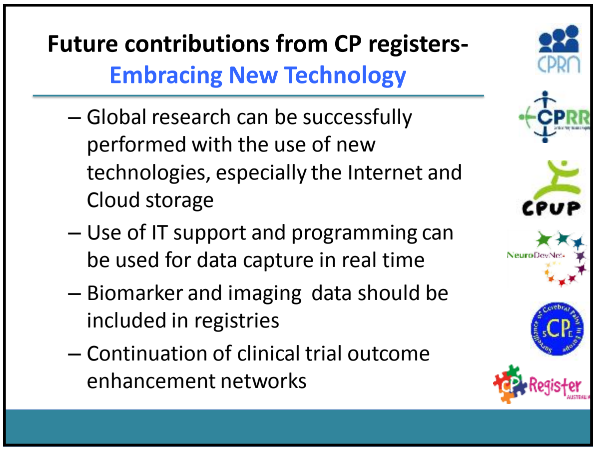
With the inclusion of variables that address adolescent and adult issues, CP registers can contribute to the understanding of

- School precursors necessary for independent living
- Successes and difficulties faced by adolescents and adults with CP
- Social and economic planning for persons with CP

Future contributions from CP registers- Include Lifespan Variables

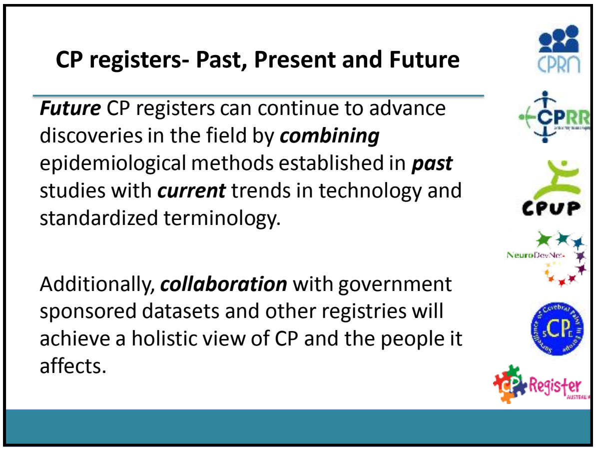
New CP registers should include variables addressed in the International Classification of Functioning, Disability and Health (ICF) and American Association on Intellectual & Developmental Disabilities (AAIDD) models

- ICF: ICF Adult
- ICF-CP: ICF core sets for children and youth with CP (replacing the ICF-CY- Child and Youth)
- AAIDD: Core Measures of Adaptive Behavior: practical, conceptual, and social



Future contributions from CP registers- Embracing New Technology

- Global research can be successfully performed with the use of new technologies, especially the Internet and Cloud storage
- Use of IT support and programming can be used for data capture in real time
- Biomarker and imaging data should be included in registries
- Continuation of clinical trial outcome enhancement networks



CP registers- Past, Present and Future

Future CP registers can continue to advance discoveries in the field by ***combining*** epidemiological methods established in ***past*** studies with ***current*** trends in technology and standardized terminology.

Additionally, ***collaboration*** with government sponsored datasets and other registries will achieve a holistic view of CP and the people it affects.

Thank you for your attention!

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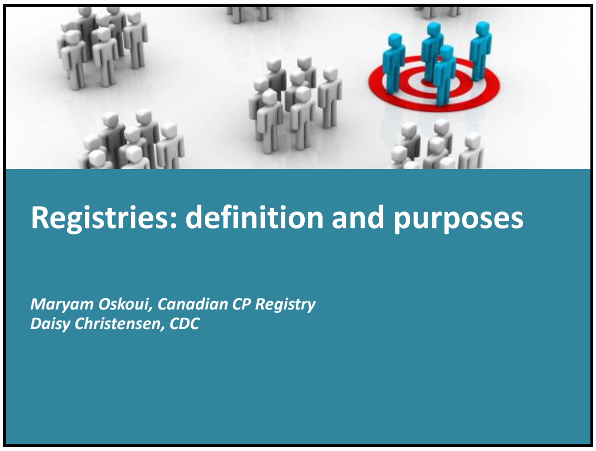


Registries: definition and purposes

Maryam Oskoui, Canadian CP Registry
Daisy Christensen, CDC

What is a Registry?

Register or Registry?

Oxford dictionary (English UK):

- Register: an official list or record of names or items
- Registry: a place where registers or records are kept

Register or Registry?

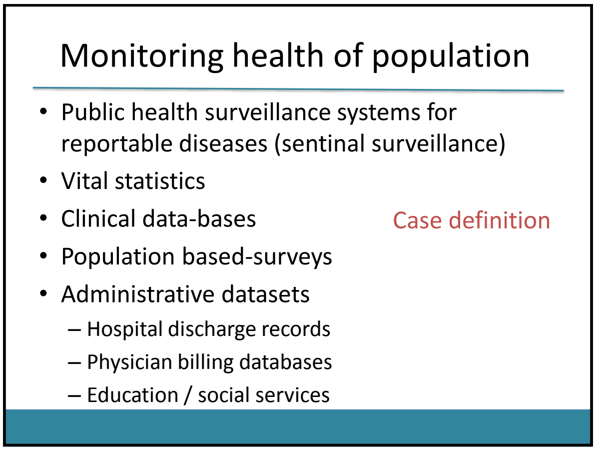
Oxford dictionary (English US):

- Register: an official list or record of names or items
- Registry: (1) a place where registers or records are kept. (2) An official list or register.

Definition of a patient registry

- WHO
  "a file of documents containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a pre-determined scientific, clinical or policy purpose".

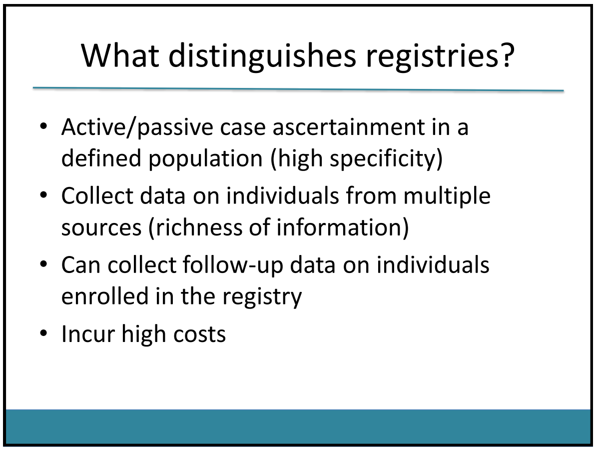
- US National Committee on Vital and Health Statistics
  "an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individual persons who have either a particular disease, a condition (e.g., a risk factor) that predisposes (them) to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects".



Monitoring health of population

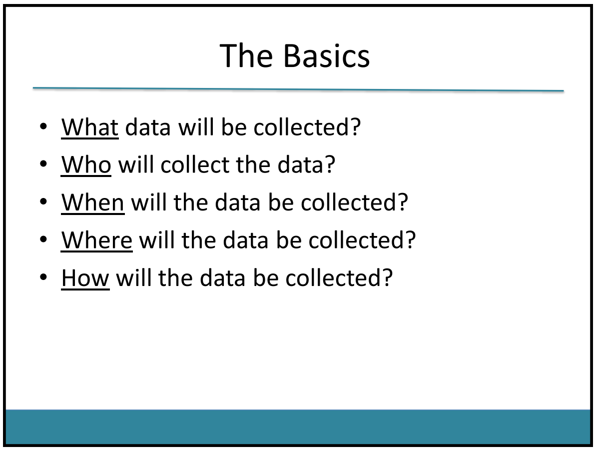
- Public health surveillance systems for reportable diseases (sentinal surveillance)
- Vital statistics
- Clinical data-bases
- Population based-surveys
- Administrative datasets
  - Hospital discharge records
  - Physician billing databases
  - Education / social services

Case definition



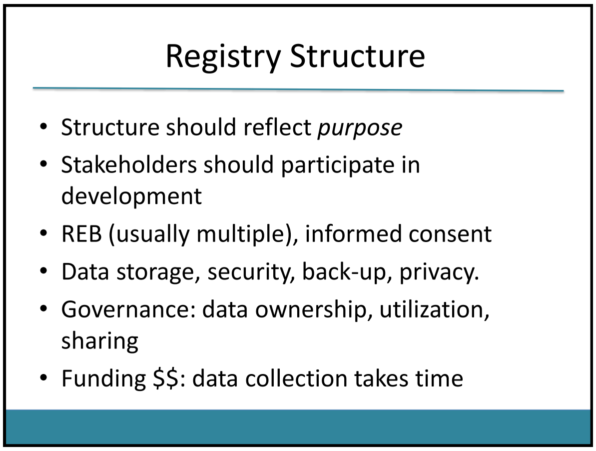
What distinguishes registries?

- Active/passive case ascertainment in a defined population (high specificity)
- Collect data on individuals from multiple sources (richness of information)
- Can collect follow-up data on individuals enrolled in the registry
- Incur high costs



The Basics

- What data will be collected?
- Who will collect the data?
- When will the data be collected?
- Where will the data be collected?
- How will the data be collected?



Registry Structure

- Structure should reflect *purpose*
- Stakeholders should participate in development
- REB (usually multiple), informed consent
- Data storage, security, back-up, privacy.
- Governance: data ownership, utilization, sharing
- Funding $$: data collection takes time

What are the purposes of Registries?

- Describe characteristics
- Assess service provision and needs
- Examine treatments and outcomes
- Provide information to public
- Increase awareness
  - → **Identify and collect information on cases**

Purpose

- Determine incidence/prevalence
- Analyze trends over time
- Identify risk factors
  - →**Identify and collect data on cases**
  - →**Identify underlying population**
  - →**Collect data on population or controls**

Key Considerations

- Passive versus active data collection
- Population-based versus practice-based
- Consent
- Extent of data collection
- Data on underlying population
- Ability to collaborate/pool data with others
- Resources

Ascertainment of Individuals

- Reports from healthcare providers
- School records
- Administrative records
- Parent- or self-report

Data Collection

- Demographics
- Physical findings/subtype
- Co-occurring conditions
- Treatments and services
- Outcomes
- Function and participation
- Prenatal/perinatal factors
- Neuroimaging findings

Underlying Population

- Live-births/1-year survivors
- Children of a specified age
- Ability to follow children who migrate out of the birth cohort
- Characterized using existing sources (e.g. birth records)
- Selected controls/comparison group

Examples

- If your purpose is to…

Describe Population

- Ascertain cases from a practice or population
- May follow individuals over time
- Data elements may be few or many

Evaluate treatments

- Ascertain cases from practice or population
- Follow individuals over time
  - Population stability/follow-up issues
- Data on covariates
- Subgroups
- Research study recruitment

Estimate Prevalence

- Ascertain as many cases as possible
- Account for imperfect sensitivity
- Choice of denominator
  - Birth prevalence – use live-births/survivors
  - Period prevalence – use census data
- Representative of underlying population
- Estimation in subgroups of interest

Assess Trends

- Consistent ascertainment over time/across regions
- Consistency of underlying population
- Choice of denominator
  - Birth prevalence trends
  - Period prevalence trends

Investigate Etiology

- Obtain comparison group
  - Birth cohort
  - Population controls
- Data on potential risk factors and covariates

Know the Purpose!

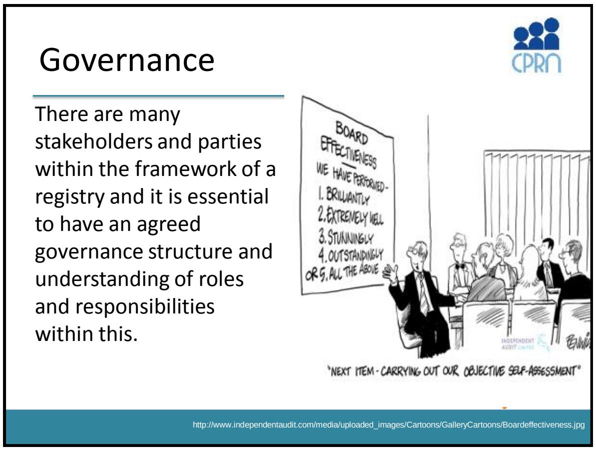
- Why you are collecting data informs
  - Who
  - What
  - Where
  - When
  - How
- Know the interests and priorities of your stakeholders

Governance models and funding

Sue Reid, Sarah McIntyre, Eve Blair, Hayley Smithers-Sheedy

Australian Cerebral Palsy Register

GOVERNANCE



Governance

There are many stakeholders and parties within the framework of a registry and it is essential to have an agreed governance structure and understanding of roles and responsibilities within this.

http://www.independentaudit.com/media/uploaded_images/Cartoons/GalleryCartoons/Boardeffectiveness.jpg

Definitions of Governance

European commission: *Rules and behaviour by which interests are articulated, resources are managed and power is exercised*

WHO: *…involves ensuring that strategic policy frameworks exist and are combined with effective oversight, coalition building, regulation, attention to system-design and accountability.*

A data linkage unit: …. *refers to who has the authority to establish, manage, monitor and review the Data Linkage Units, and how they will do this. It includes all the structures, rules, laws, processes, policies, systems, and controls that are used to safeguard the Data Linkage Units, participants and researchers.*

E. Barbazza, J.E. Tello / Health Policy 116 (2014) 1–11

Registry governance:

- **Includes stakeholders** who manage and analyse personal medical information;
- **An independent management structure**;
- **Supports development of a research environment;**
- Receives **adequate funding** to ensure continuity of data collection & QA.

Williamson, O.D., Cameron, P.A., & McNeil, J.J. (2004). Medical registry governance and patient privacy. *Medical Journal of Australia*, 181(3): 125-126.

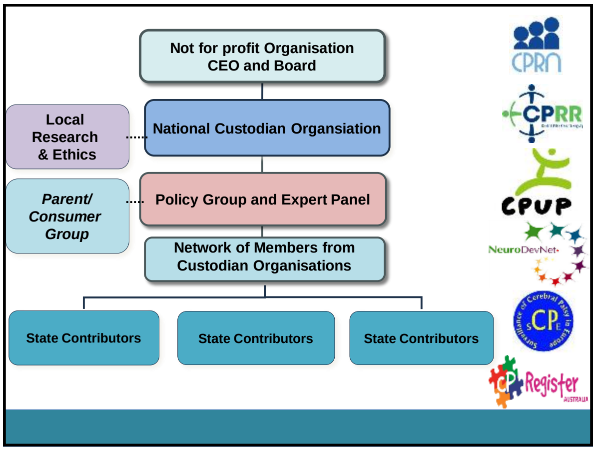
ACPR Governance

- Data management
- Legislation
- Reporting
- Meeting structures
- Operational rules
- Ethics
- Audit
- Communication/ publications/ media

E.g. population ascertainment

Method reported	Number of groups
Comparison to other registers/health care sources	3
Rates compared to long standing population registers	6
Capture-recapture techniques	1

46% of the 24 respondents report having a procedure for assessing the completeness of population ascertainment



Not for profit Organisation
CEO and Board

Local
Research
& Ethics

National Custodian Organsiation

*Parent/
Consumer
Group*

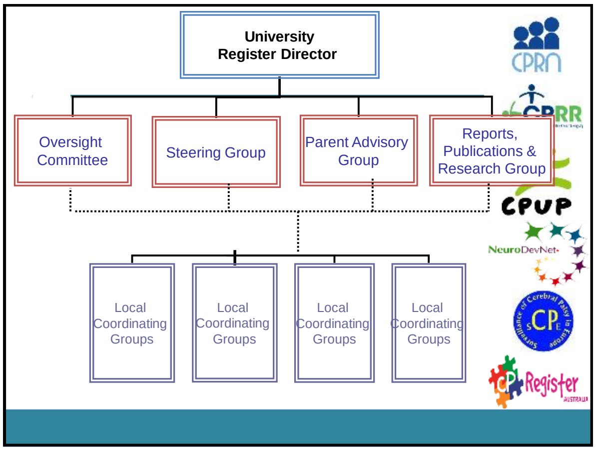
Policy Group and Expert Panel

Network of Members from
Custodian Organisations

State Contributors

State Contributors

State Contributors



University
Register Director

Oversight
Committee

Steering Group

Parent Advisory
Group

Reports,
Publications &
Research Group

Local
Coordinating
Groups

Local
Coordinating
Groups

Local
Coordinating
Groups

Local
Coordinating
Groups

Other examples

National Diabetes Surveillance System (NDSS) in Canada ***http://www.phac-aspc.gc.ca/ccdpc-cpcmc/ndss-snsd/english/pubs_reports/pdf/NDSS_English_Report_FINAL.pdf***

Australian Twins Registry

http://www.twins.org.au/about-us/governance/structure

National Cancer Registry Ireland

http://www.ncri.ie/about/governance

FUNDING

Funding

It is essential to have continuity and security of funding.

Registers can't run on determination alone!

- Development /maintenance of data platform
- Data linkages
- Staff wages
- Administrator for central collection / coordination site
- Staff time re in-servicing data collectors

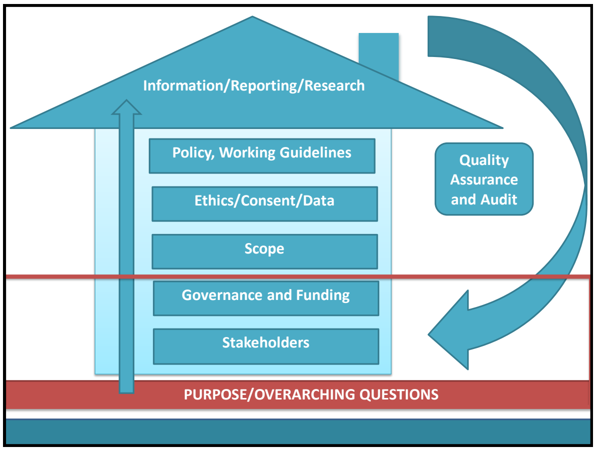
Funding

- Development of promotional material / data forms
- Meeting costs: airfares / accommodation if register administrators are across states / geographically spread
- Professional development of staff where specific new competencies are required.

Funding

Source of Funding	Number of groups
Government (health/education/research)	18
Research grants	2
Not for profit/charity	4
No specific funding	2

? Corporate funding



Information/Reporting/Research

Policy, Working Guidelines

Ethics/Consent/Data

Scope

Governance and Funding

Stakeholders

Quality Assurance and Audit

PURPOSE/OVERARCHING QUESTIONS

PURPOSE/OVERARCHING QUESTIONS

Green Workstation

- What questions do you want to answer in your (real or fictitious) register?
- What would your overarching purpose for your register be?
- Is a register the best way to answer your questions?

⏱ 15 minutes

Sue, Eve, Guro, Kate, Donna, Maryam, Daisy, Kim

Stakeholders

Blue Workstation

- Who could be the key stakeholders for your (real or fictitious) register?
- Can you think of any funding bodies who may be able to assist in funding your register/ surveillance program?
- Are there any existing groups/programs that could be important to engage with early during the time you are planning the development of your register? e.g. congenital anomalies register

⏱ 15 minutes

Eva, Lena, Sarah, Hayley, Michael S, Michael M, Marshalyn, Alyson

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Scope of a register

Kate Himmelmann MD PhD

Associate Professor, University of Gothenburg
CP register of western Sweden
Surveillance of Cerebral Palsy in Europe

Geographical region

- Area: Is it possible to define an area
- Is the area relevant/logical /representative for the population
- Migration in and out of the area

- *Make sure your population is big enough!*
  - *The area included in your survey or register should have >10,000 births per year*

Birth years

- From what birth years are data accessible?
- Sustainability/funding
- legal & ethical issues
- Sources
- Appropriate denominator data
- Ascertainment metod?
- Quality control

Define a minimal pre-, peri-, neo- and postneonatal data set

Use a standardised collection form to ensure you record the same information from each case in the same way

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Inclusion

- Age at inclusion in the register
- *The minimal age at diagnosis when data are entered into registers must be 3 years, and the optimal age is 5 years*

- What about those who died before inclusion age?
- *Children with clear signs of cerebral palsy who die between the ages of 2 years and 5 years may be included*

Cases

How to identify and collect information on cases?

- active (e.g. regularly ask all clinical staff about new cases)
- passive (e.g. rely on clinical staff to report cases when they see them)

Clinical data can be collected by

- record abstraction
- Clinical examination

Harmonisation work

- Guidelines for inclusion/exclusion
- Decision and classification trees

- Standardised Data Coll. Form

- Reference and training Manual including imaging results

- Guideline for data collection on congenital anomalies, jointly with EUROCAT

→ Sharing, translating and disseminating these tools

The CP register survey 2014 – data collection

Data collected by all

- Date of birth
- Gender
- Gestational age
- Birth weight
- Diagnosis/CP type
- Postneonatal timing/cause
- Epilepsy
- Syndrome/cong malform
- GMFCS
- MRI

Data collected by >80%

- No. of fetuses
- Place of delivery
- Vision
- Hearing
- Intellectual function

The CP register survey 2014

Age at inclusion	4-5 years (survival minimum varied)
Reference for inclusion	Smithers-Sheedy 2013/ Badawi 1998/ Rosenbaum 2007/ SCPE/ Smith's
CP classification	USCP/Hemiplegia BSCP/diplegia/quadriplegia/tetraplegia Dyskinetic/Athetoid/dystonic Ataxic Hypotonic CP included by Australia, US and Canada
Postneonatal CP upper age limit (n)	2 years (most common) – no upper limit
Neuroimaging	3 classfications From reports/scans. By radiologist/neuroped
Interventions	17 registers recorded this, 8 did not

Data management

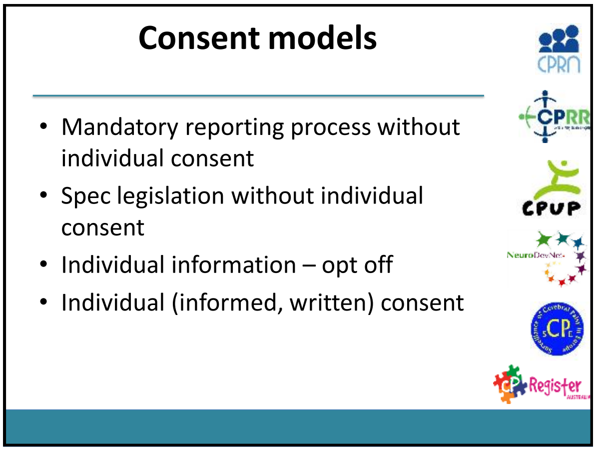
- *Setting up and maintaining a register takes time and money; check you have enough of each*
- *90% of the effort is required for 10% of the data, but with that data missing, the rest is of limited use*
- Definitions are important (gestational age, stillbirth, neonatal mortality, parity, syndromes, congenital anomalies…)

The special case of post-neonatal CP

- What upper age limit?
- Example: Sweden and Norway 2 years, other registers up to 7 years
- *It is useful to separate 'CP cases of post-neonatal origin' defined as cases arising from an aetiological event occurring after 27 completed days following birth*

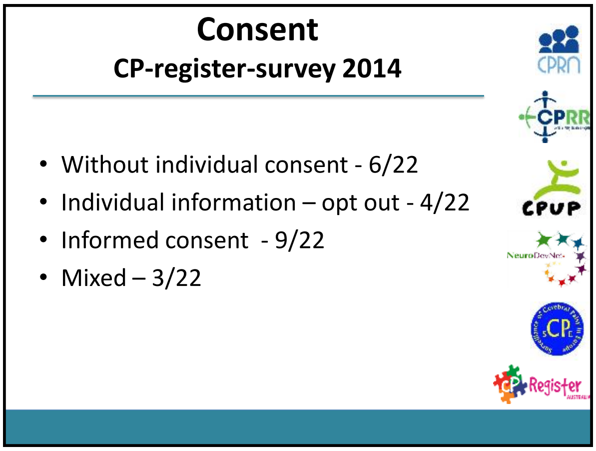
Data collection

Lena Westbom, Lund, Sweden



Consent models

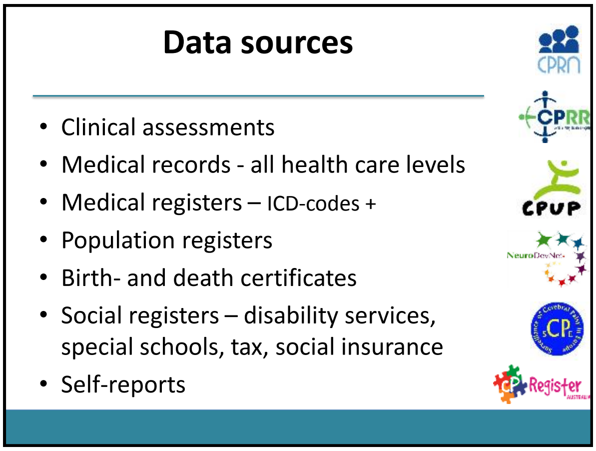
- Mandatory reporting process without individual consent
- Spec legislation without individual consent
- Individual information – opt off
- Individual (informed, written) consent



Consent

CP-register-survey 2014

- Without individual consent - 6/22
- Individual information – opt out - 4/22
- Informed consent - 9/22
- Mixed – 3/22



Data sources

- Clinical assessments
- Medical records - all health care levels
- Medical registers – ICD-codes +
- Population registers
- Birth- and death certificates
- Social registers – disability services, special schools, tax, social insurance
- Self-reports

Data sources

CP-registry survey 2014

17 sources + 1 “other”

- Medical professionals – all 22 registries
- Hospital records in/outpat – 17/15 registers

Range 3-13 sources, median 6 sources per register

Ascertainment methods

- 19 registries clinical contacts – primary info at medical appointment
- 3 registries no primary info
- Range 1 - 9 sources of 13 (median 4)
- The 3 registries with a single method were based on medical appointments

Data quality

- Data accuracy (registered data conforms to the truth)
- Data completeness (proportion of all necessary data that could have been registered is actually registered)

Data quality assurance

Planned and systematic procedures

before – during – after data collection

to guarantee data qaulity

Data quality assurance

Planned and systematic procedures

before – during – after data collection

to guarantee data quality

Arts, Keizer, Scheffer. Defining and improving data q,
J Am Med Inform Assoc 2002
Ranstam J. Data handling… Acta Radiologica 2008

Data quality assurance

At onset of a registry:

- minimum data set necessary items
- define each variable describe characteristics
- data dictionnary with coding list
- design a quality assurance plan
  periodical, central and local automatic and manual procedures;
  inconsistent and incomplete responses
  compare with primary data sources

A perfect data set – an utopia?

A good-enough data set to answer your question!

Consult an epidemiologist/statistician – BEFORE start

KNOW YOUR SOURCES

KNOW YOUR own data set

- strengths and weaknesses, and describe them in your reports

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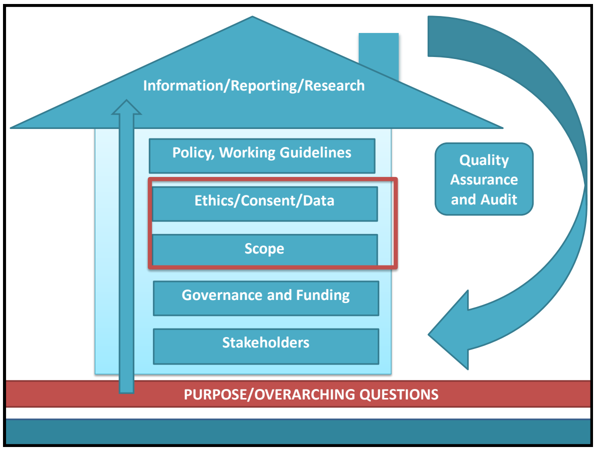
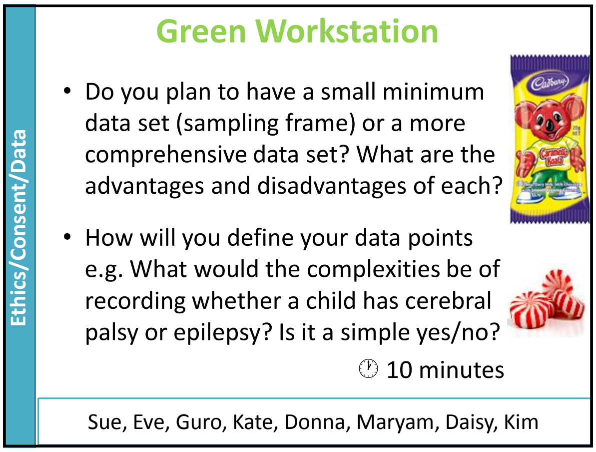




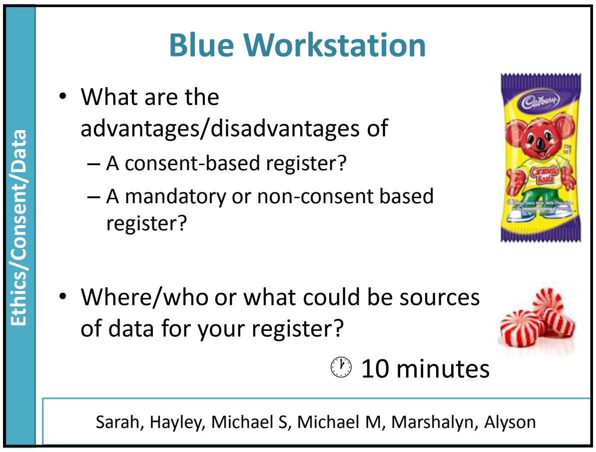
Ethics/Consent/Data

Green Workstation

- Do you plan to have a small minimum data set (sampling frame) or a more comprehensive data set? What are the advantages and disadvantages of each?
- How will you define your data points e.g. What would the complexities be of recording whether a child has cerebral palsy or epilepsy? Is it a simple yes/no?

🕐 10 minutes

Sue, Eve, Guro, Kate, Donna, Maryam, Daisy, Kim



Ethics/Consent/Data

Blue Workstation

- What are the advantages/disadvantages of
  - A consent-based register?
  - A mandatory or non-consent based register?
- Where/who or what could be sources of data for your register?

🕐 10 minutes

Sarah, Hayley, Michael S, Michael M, Marshalyn, Alyson

Ethics/Consent/Data

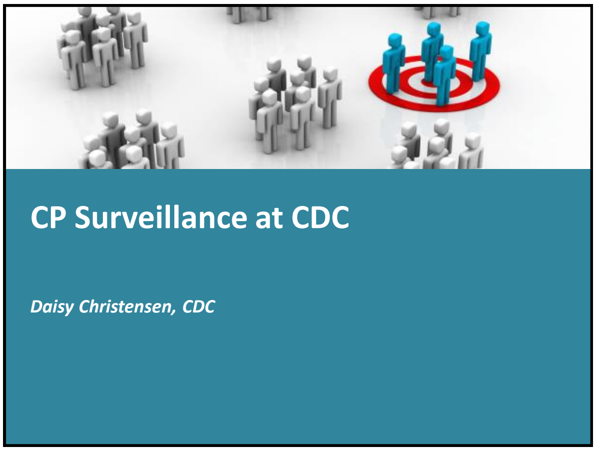
Yellow Workstation

ACTIVE SURVEILLANCE

- Parent and child perspectives
  - Participating in an active surveillance program - pros and cons?
  - Individual versus community benefits

🕐 10 minutes

Eva and Lena



CP Surveillance at CDC

Daisy Christensen, CDC

Purpose of MADDSP/ADDM

- To provide regular and systematic monitoring of CP prevalence
- To assess the possible relationships between selected maternal and child characteristics noted on birth certificates and CP
- Provide a framework for initiating special studies of children with CP through establishment of a large case series

Key Findings

- CP prevalence appears to be higher in the US compared with other areas
  - Distribution of risk factors
  - Migration issues
- Frequency of autism spectrum disorder higher among children with CP
  - Implications for clinical practice
  - Need for tools

Advice

- Maintain close ties with community and stakeholders
  - Understand the needs
  - Assist with data collection
  - Advocate for resources
  - Data dissemination
- Collaborate with other researchers
  - Structure data collection to allow comparisons or data pooling

Good Luck!

Daisy Christensen, PhD
Division of Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Road NE
MS E-86
Atlanta, GA, United States
404-498-3860

Active Surveillance CPUP

Eva Nordmark
RPT, Ass Professor, Senior lecturer in Disability studies

Aims

The main goal of the CPUP- follow up program/National Quality Registry by The National Board of Health and Welfare in Sweden is to:

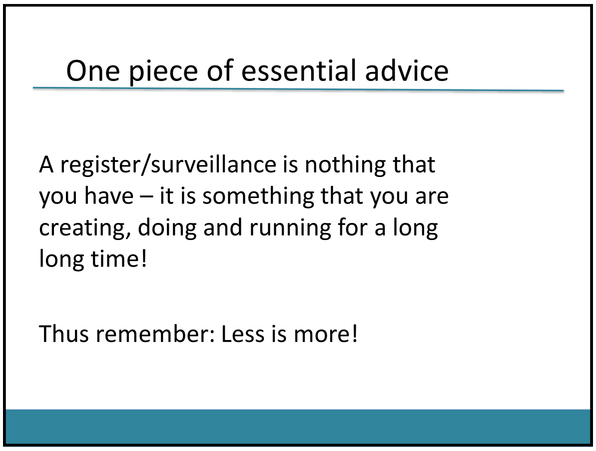
Prevent hip dislocation and severe contractures through early detection and early intervention.

Additional Aims

- describe the **"natural" development** and course of functioning during the lifespan
- **evaluate** interventions
- increase **cooperation** and knowledge between health care professionals, children and young people with CP and their families

Most important finding/roles

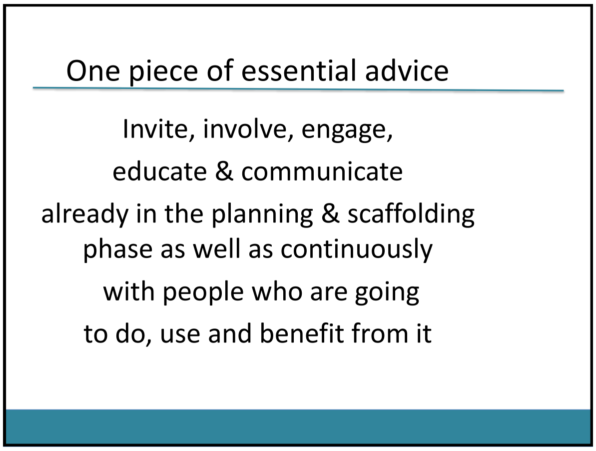
- All children/adults with CP
- Multidisciplinary
- Secondary prevention program



One piece of essential advice

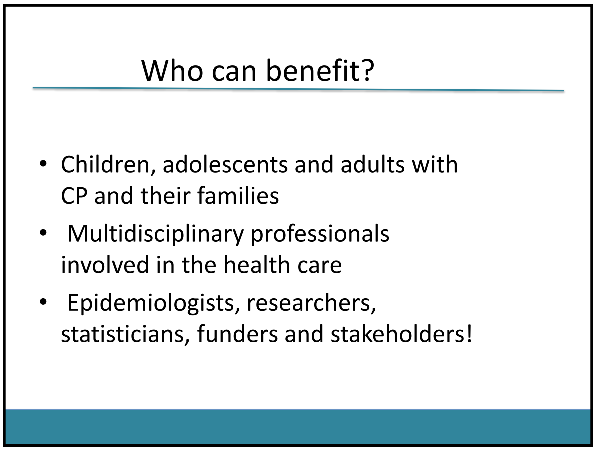
A register/surveillance is nothing that you have – it is something that you are creating, doing and running for a long long time!

Thus remember: Less is more!



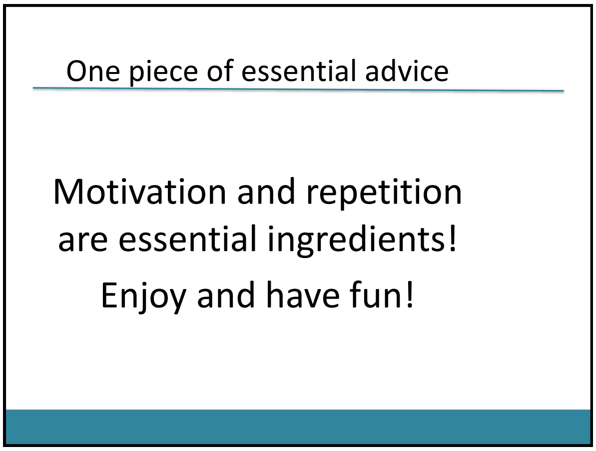
One piece of essential advice

Invite, involve, engage,
educate & communicate
already in the planning & scaffolding phase as well as continuously
with people who are going
to do, use and benefit from it



Who can benefit?

- Children, adolescents and adults with CP and their families
- Multidisciplinary professionals involved in the health care
- Epidemiologists, researchers, statisticians, funders and stakeholders!



One piece of essential advice

Motivation and repetition are essential ingredients!

Enjoy and have fun!

CPUP – A preventive follow-up programme for children with cerebral palsy or suspected cerebral palsy and a National Quality Registry by The National Board of Health and Welfare, Sweden

To boldly follow CPUP – 20 years in the making
Thursday 2 pm General session
Presidential Guest Lecturer Gunnar Hägglund
Professor, MD,PhD, Orthopedic surgeon

20 år!
CPUP

Cerebral Palsy Research Registry

Donna S. Hurley, PT, DPT & Michael E. Msall, MD
Chicago, Illinois USA

CPRR- Cerebral Palsy Research Registry

The CPRR is a **collaborative registry** between Northwestern University Department of Physical Therapy & Human Movement Sciences, the Rehabilitation Institute of Chicago and the University of Chicago, Comer Children's Hospital.

CPRR- Cerebral Palsy Research Registry

The CPRR is an encrypted, secure, **expandable** online database. Northwestern University's Biomedical Informatics Center houses the database and server.

Our **long-term goal** is to collaborate with institutions across the country to create a National US-CP Registry.

CPRR- Cerebral Palsy Research Registry

The **Aim** of the CPRR is to **promote cerebral palsy research across the lifespan.**

We do this by **connecting** researchers with CPRR participants for studies as well as performing our own research using CPRR data.

CPRR- Cerebral Palsy Research Registry

The CPRR began in 2008 with 35 children. It currently has **1000 participants**, ages 2-68, living in **38 different US states.**

The CPRR is a voluntary registry that uses both direct and in-direct methods for recruitment. Consenting into the registry is mandatory.

CPRR- Cerebral Palsy Research Registry

The CPRR has **supported** 20 research studies with subject recruitment. Studies range from interventions, robotics, genetics to social skills and parental support.

We communicate with our participants and the public via email and our website **www.cpregistry.org.**

CPRR- Cerebral Palsy Research Registry

The CPRR has both pediatric and adult enrollment questionnaires. **Variables** include contact information, birth history, co-morbidities, school/employment/housing, medical procedures, adaptive technology/equipment, interventions/therapies,

CP subtype, tone, MACS, GMFCS and FMS scores.

CPRR

Most Important Finding

The **Internet** is a powerful tool. With online registration, we are able to enroll and support children and adults in remote areas of the US that do not have access to large, urban research facilities.

The Internet **levels the playing field** for **ALL** people, no matter where they live. A person in a town of 300 has the same opportunity to learn about and participate in research studies, as someone from a town of 3 million.

CPRR

Essential Advise

- A **multi-disciplinary team** will make for a robust registry; increasing your perspective, resources and opportunities for research projects.
- **Stay in contact with persons with CP and their families**. Not only will this remind you of why your work is important, but their insights and appreciation of your efforts will carry you forward.

Thank you

The Victorian Cerebral Palsy Register

Sue Reid

CP Register Victoria

The Children's
Excellence in clinical care, research and education

The Royal Children's Hospital Melbourne

Murdoch Childrens Research Institute

The University of Melbourne

The VCPR

- Established in 1987
- Includes persons with CP born or living in Australian state of Victoria from 1970 (80-140 Vic-born per year)
- Current *n* of 5200
- Consent not required (but sought)
- MS Access database

Location and staffing

- Melbourne Children's campus
  - Murdoch Childrens Research Institute
  - Royal Children's Hospital
  - University of Melbourne
- Staffing
  - Manager (.4 FTE)
  - RA (.4 FTE)
  - Advisory Committee

Distinguishing features

Advantages	Disadvantages
Large geographical area	
Large sample sizes for epidemiological studies	Case ascertainment and data collection more challenging
Use as sampling frame for research	
Creates a 'hot spot' for CP research / doctoral studies Facilitates information transfer	Work involved in keeping data and contacts up to date Additional work to identify and contact eligible families
Campus location	
Encourages collaboration and educational opportunities	None

Study recruitment

- VCPR staff identify sample and make first contact on behalf of researchers
  - Require ethics approval
- Contact consented families directly
  - Keep in touch via newsletters
- Contact other families via hospital departments/state-wide rehab service
  - Requires ongoing info on clinical contacts

Questions?

SCPE - Surveillance of cerebral palsy in Europe

Guro L. Andersen, MD, PhD
Leader, Cerebral Palsy Register of Norway
Associate Professor, The Norwegian University of Science & Technology
Second Deputy, SCPE Steering Committee

What is SCPE?

- Established 1998
- Multiprofessional, multidisciplinary collaborative network
  - Monitor trends
  - Provide information for service planning
  - Provide framework for collaborative research
- Central database of children with cerebral palsy

www.scpenetwork.eu

- Reaching today 26 registers from 16 countries = 9 % of European births
- 18 active population-based registers

www.scpenetwork.eu

The aim of the SCPE

- To disseminate knowledge about cerebral palsy through epidemiological data
- To develop best practice in monitoring trends in CP
- To raise standards of care for children with cerebral palsy

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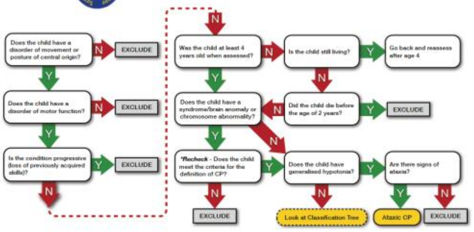
Essential advice

- Use developed standardized tools
  - For classification of cerebral palsy
    - Decision Tree for Cerebral Palsy
    - Classification Tree for Sub-Types of Cerebral Palsy
  - For classification of neuroimaging results
  - For associated impairments
    - Vision/hearing
    - Viking Speech Scale
- Reference & Training Manual

Decision tree for Cerebral Palsy



Does the child have a disorder of movement or posture of central origin?

EXCLUDE

Does the child have a disorder of motor function?

EXCLUDE

Is the condition progressive (loss of previously acquired skills)?

EXCLUDE

Was the child at least 4 years old when assessed?

Is the child still living?

Go back and reassess after age 4

Does the child have a syndrome/brain anomaly or chromosome abnormality?

Did the child die before the age of 2 years?

EXCLUDE

*Recheck - Does the child meet the criteria for the definition of CP?

Does the child have generalised hypotonia?

Are there signs of ataxia?

EXCLUDE

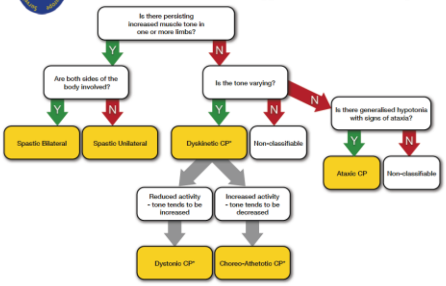
Look at Classification Tree

Ataxic CP

EXCLUDE

SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine and Child Neurology*. 2000;42:816-24.

Classification tree for sub-types of Cerebral Palsy



Is there persisting increased muscle tone in one or more limbs?

Are both sides of the body involved?

Is the tone varying?

Is there generalised hypotonia with signs of ataxia?

Spastic Bilateral

Spastic Unilateral

Dyskinetic CP*

Non-classifiable

Ataxic CP

Non-classifiable

Reduced activity - tone tends to be increased

Increased activity - tone tends to be decreased

Dystonic CP*

Choreo-Athetotic CP*

SCPE Collaborative Group. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine and Child Neurology*. 2000;42:816-24.

Viking Speech Scale, 2010©

I. Speech is not affected by motor disorder.

II. Speech is imprecise but usually understandable to unfamiliar listeners.

III. Speech is unclear and not usually understandable to unfamiliar listeners out of context.

IV. No understandable speech.

Name of Child ………………………… Date of birth……………………

Name of person completing Viking Speech Scale …………………………

Relationship to child ………………………… Date of classification ……………

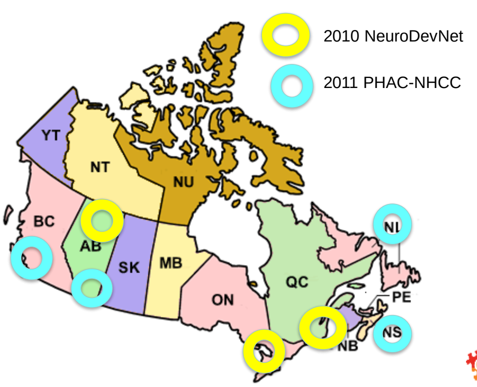
THANK YOU

Canadian Cerebral Palsy Registry

Maryam Oskoui, MD, MSc, FCRPC
Michael Shevell, MDCM, FRCPC, FAAN
Montreal Children's Hospital
McGill University

History of Canadian CP Registry

- 1991-2001 Delphi consultation process
- 2003 pilot at one centre
- 2004-2006 REPACQ in 7/16 regions QC
- 2009 re-establish in 1 region
- 2010 NeuroDevNet: re-establish in 7 QC regions and expand to N AB + GTA
- 2011 PHAC-NHCC: expand to BC, S AB, NS, NFL



Aims

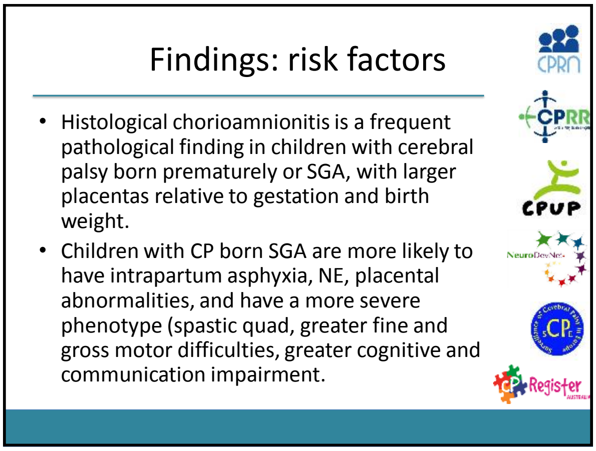
1. Provide an epidemiologic profile of CP in Canada reflecting the full heterogeneity of the disorder and possible regional variations;
2. Provide a platform for population-based research on CP that promotes a greater understanding of the disorder from mechanistic to family and community perspectives;
3. Promote research into causal pathways, prevention and treatment of this disorder;
4. Facilitate planning and support rapid and precise enrolment of patients in new research studies.

#1 Role

Bring together a multidisciplinary network of researchers and clinicians from across Canada, serving as a catalyst for collaborative efforts in CP

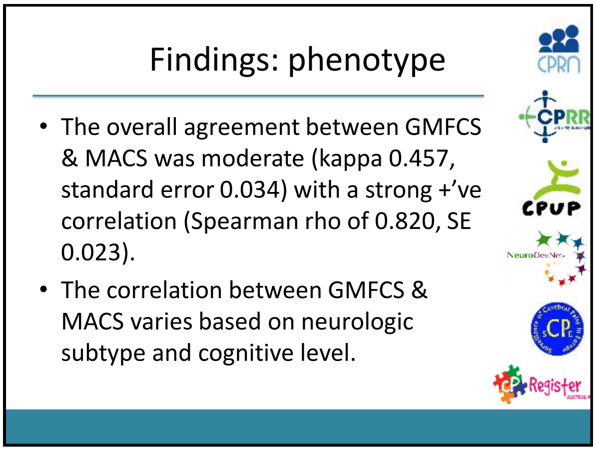
Findings: context

- Contextual socioeconomic factors can impact disease severity in CP
- Socioeconomic gradient in mobility (GMFCS) using both individual and area-based measures of socioeconomic deprivation, despite adjusting for differences in maternal and perinatal factors.



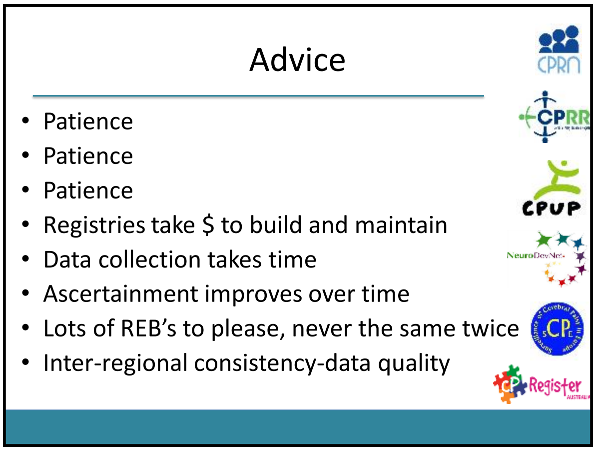
Findings: risk factors

- Histological chorioamnionitis is a frequent pathological finding in children with cerebral palsy born prematurely or SGA, with larger placentas relative to gestation and birth weight.
- Children with CP born SGA are more likely to have intrapartum asphyxia, NE, placental abnormalities, and have a more severe phenotype (spastic quad, greater fine and gross motor difficulties, greater cognitive and communication impairment.



Findings: phenotype

- The overall agreement between GMFCS & MACS was moderate (kappa 0.457, standard error 0.034) with a strong +'ve correlation (Spearman rho of 0.820, SE 0.023).
- The correlation between GMFCS & MACS varies based on neurologic subtype and cognitive level.



Advice

- Patience
- Patience
- Patience
- Registries take $ to build and maintain
- Data collection takes time
- Ascertainment improves over time
- Lots of REB's to please, never the same twice
- Inter-regional consistency-data quality