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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OBJECTIVES
To review and categorize the body of research produced by cerebral palsy registries from 2006-2012 in order to characterize the influence these registries have on our overall understanding of cerebral palsy (CP).
To compare the database variables of global CP registries that were compiled for the 2009 World CP Register Congress with the International Classification of Functioning, Disability and Health (ICF) for Children and Youth developmental code sets.

METHODS
A literature review using key words cerebral palsy, registry, population-based study, and known names of CP registries and regions was conducted. Criteria for included articles were publication date between 2006 and 2012, use of a CP registry for study data and articles written in English.

Two authors independently reviewed the articles then assigned them into one of the five collaboratively defined CP Registry and Surveillance Groups Aims as well as the geographical region of the first author. The reviewers compared their results for consistency and discussed discrepancies until an agreement was achieved. Each article was assigned to the one aim that best described the article’s main purpose.

Secondly, variables collected by world registries were categorized by the ICF for Children and Youth developmental code sets. Database variables were available for 14 CP registries. Items that were addressed in each area of the ICF model were assigned by age band.

RESULTS
Literature review resulted 129 articles that met inclusion criteria and were classified according to aim: Resource for CP Research (n=54), Surveillance (n=44), Prevention (n=17), Planning (n=7) and Raising the Profile of Cerebral Palsy (n=7).

Articles per geographical region: Europe (56) United Kingdom (28) Australia (25) Canada (13) United States (7).

CP registries variables were addressed: Body, Structure, Function ages 0-5 years (21/34); 6-12 years (14/36); Activities and Participation ages 0-5 years (16/31), 6-12 years (5/56); Environment ages 0-5 years (9/24), 6-12 years (5/29).

DISCUSSION
This preliminary literature search had a limited scope and appeared to under-represented the magnitude of research contributions global CP registries have contributed to the field of CP.
However, because this pilot data was significant, a full systematic review on the topic of research contributions generated from global CP registries was performed in 2014, resulting in an increase of articles and novel uses for CP registries.

CONCLUSION
Journal publications produced from international CP registries continue to grow in quantity, quality and range of scientific and social themes that significantly contribute to the understanding of how CP affects families, individuals and society.

In order to get a complete profile of this heterogeneous and complicated condition, new CP registries should include variables that address medical associated conditions that impact body Structure and function, functional activities in mobility, manipulation communication, and participation in family and community roles as demonstrated in the ICF model of Functioning, Disability & Health.

Core datasets of CP registries need to be carefully planned and developed to maximize the amount of data collected while minimizing burden on the registrant.