The National Institutes of Neurological Disease and Stroke (NINDS) and the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) Cerebral Palsy Common Data Elements (CDE) Recommendations

IC #10 Thursday, September 14, 2017

Project Background

Eileen Fowler, PhD, PT
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Thursday, September 14, 2017

Disclosure Information

AACPDM 71st Annual Meeting | September 11-16, 2017

Speaker Name: Eileen Fowler PhD, PT

Disclosure of Relevant Financial Relationships
I have no financial relationships to disclose.

Disclosure of Off-Label and/or investigative uses:
I will not discuss off label use and/or investigational use in my presentation

“I love strategic planning!”

Maureen O’Donnell
Past President

AACPDM Strategic Plan
2013 - 2017

AACPDM is a leader in fostering research that will generate new knowledge and evidence to inform the care of people with cerebral palsy and other childhood-onset disabilities.
AACPDM STRATEGIC PLAN GOALS

Evolution

Initial meeting AACPDM San Diego meeting, October 2014
2 separate groups
- MOMS Lead: Eileen Fowler
- CDE Lead: Rich Stevenson
Suggestion made to explore a relationship with NINDS CDE project
Realized that NINDS CDEs incorporate our definitions of CDEs and Outcomes
NINDS CP Planning meeting held in DC in Fall, 2014

NINDS CDEs Examples

Characteristic
C00007 Birth date
Outcome Measurement
C10974 Manual muscle testing muscle score

Steering Committee & WG Leads
Annual Meeting in Austin 2015

AACPDM CDE Steering Committee

Eileen Fowler, PT, PhD, Co-chair
Richard Stevenson, MD, Co-chair
Diane Damiano, PT, PhD
Sharon Ramey, PhD
Jessica Rose, PhD
Elaine Stashinko, PhD, RN
Laura Vogtle, OT, PhD

Engagement and Quality of Life Assessments/Data Working Group

Susan Sienko, PhD (WG Lead)
Kristie Bjornson, PT, PhD
Stephanie DeLuca, PhD
Margaret Wallen, OT, PhD
Laura Vogtle, OT, PhD
Health/Growth/Genetics/Comorbidities/Labs Working Group
Theresa Moulton, DPT, PhD (WG Lead)
James Blackman, MD
Kathleen Kolaski, MD
Sebastian Schroeder, MD
Benjamin Shore, MD
Richard Stevenson, MD
Gordon Worley, MD

Integrated Across Working Groups
Veronica Schiariti, MD, PhD (WG Lead)
Eileen Fowler, PT, PhD
Mary Gannotti, PT, PhD
Bernadette Gillick, PT, PhD
Sylvia Õunpuu, MSc

Neurocognitive, Social, and Emotional Assessments Working Group
Sharon Ramey, PhD (WG Lead)
Roslyn Boyd, PT, PhD
Michael Msall, MD
Seth Warschausky, PhD
Kathi Zebracki, PhD

Neuroimaging and Diagnostics Working Group
Eric Levey, MD (WG Lead)
Patrick Barnes, MD
Roslyn Boyd, PT, PhD
Hannah Glass, MD
Andrea Poretti, MD
Jessica Rose, PhD

Neuromotor Skill and Functional Assessments Working Group
Joline Brandenburg, MD (WG Lead)
Michael Aiona, MD
Mary Jo Cooley Hidecker, PhD
Diane Damiano, PT, PhD
Christopher Joseph, MS, PT
Claire Morress, OT, PhD
Laura Prosser, PT PhD
Katherine Steele, PhD

Participant Characteristics and Disease/Injury Related Events Working Group
Sarah McIntyre, PhD (WG Lead)
Katharine Alter, MD
Elaine Stashinko, PhD, RN
Deborah Thorpe, PT, PhD
NINDS CDE Team
(The Emes Corporation)
Joy Esterlitz, MS
Sherita Ala'i, MS
Robin Feldman, BS, MBA

Tracy scheduled meetings - primarily conference calls. She and Robin were both on most conference calls taking minutes and answering questions. Working group leads ran the meetings.

38 AACPDM Volunteers

Tracy Burr
AACPDM Executive Director

NINDS CDE Development Timeline

Fall 2015 CDE development had begun
Midyear meeting in March 2016
  • CDE, CRFs, instruments completed by 6 WGs
  • Integrative working group began review
June: Steering committee and all WG members reviewed
July: NIH received draft to prepare for public review
August: Incorporated internal group feedback
September
  • Public review began
  • Presented at annual meeting in Florida

https://www.commondataelements.ninds.nih.gov