Future of CP CDE

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Disclosure Information
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Speaker Name: Joline Brandenburg, MD

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

Current CP CDE
• Version 1.0
  • Built upon:
    • Other Disease Group CDEs
    • Expert Review and Consensus
    • Basic Data Collection
    • Creating a Common Language for CP Clinical Research
• More Information
  • Shiarti et al. submitted for publication

Future Considerations
• Creating/Advancing CP Research Networks
• Filling Gaps:
  • CDE for CP Surgical Data
  • Hypotonia Measures
  • DME
  • Outcome Measures for Adults with CP
  • Inclusion of patient stakeholders, caregivers, parents/guardians
• Level of Recommendations

Other Applications
• Standardizing Clinical Practice
  • PT/OT/Speech Therapy Documentation
  • Standardized Language for Physician Documentation for EMR
  • Validated outcome measures for following response to therapy, medical interventions, or surgical interventions.
  • Quality Improvement Projects
• Functional Outcome Measures for Other Disorders

CP CDE Review Process
• Version 2.0
• CP CDE Oversight Committee

Feedback — Meet/Discuss — Review — Recs — Publish
Feedback

Thank you

- Attendees
- Members of the CP CDE Work Groups and Steering Committee
- AACPDM
- NINDS
- EMMES