

A common data language for clinical research studies: the art and science of uncertainty

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This commentary is on the review by Schiariti et al. on pages 976–986 of this issue.

The development of an analytical common structure for data collection is a valuable step forward in both research and the commissioning of services for the children and young people we try to help and support. The valid and reliable conceptual framework provided by the US National Institute of Neurological Disorders and Stroke, and the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)¹ seems to be an excellent starting point. The incorporation of elements of the International Classification of Functioning, Disability and Health (ICF) into the framework is both logical and progressive. The impact of the ICF has been huge and there is no doubt that activity and participation have quietly revolutionized clinical practice.

Much of what we consider routine practice is currently based purely on expert opinion rather than factual evidence; something that became obvious in the development of the recent UK National Institute for Health and Care Excellence (NICE) guidelines on cerebral palsy in children and young people from birth up to their 25th birthday (<https://www.nice.org.uk/guidance/ng62>). With the current development of the NICE guidelines for adults with cerebral palsy over 25 years of age, we have become increasingly aware that the grade, quality, and depth of published research could be better. The need to provide quality evidence of high or moderate grading requires collaboration using

agreed, validated tools, to ensure confidence in the estimate of effect and to reduce any confounding heterogeneity. Any benchmarking of standards and the commissioning of appropriate, equitable cost-effective clinical services is based on our ability to code and acquire relevant data metrics on the populations of children and young people we see in our locally agreed pathways of care. Again, any possible constructs that help us in these aspects of our practice are invaluable.

The clear and comprehensive review by Schiariti et al. is an incredible tour de force of analysis. In their open constructive discussion, they recognize the limitations of the process while sharing their drive to improve data quality acquisition and collaboration.

We all need to work on doing things better. However, I am personally wary that too much structure may prompt inflexible application both in research and service design. Reflective clinical practice requires many other skills that cannot necessarily be scored or easily implemented. The time in which we can provide guidance and support for our children and families is increasingly limited. Frameworks, traffic-lights, and toolboxes are all useful (particularly in the world of construction), but are generally quite time-consuming and uncompromising in their nature. Families require individualized care with skills that cannot be taken off the shelf. We need always to maintain a free, open, and questioning approach.

If, especially in our clinical practice, services are purely driven by standardized tools we run the risk of focussing on the science and losing the flexible art of medicine and surgery. In such, the empathic care we provide is likely to lose as much as it gains. This important paper by Schiariti et al. shows that this new conceptual framework is not an end in itself – but only a beginning.

REFERENCE

1. Schiariti V, Fowler E, Brandenburg JE, et al. A common data language for clinical research studies: the National Institute of Neurological Disorders and Stroke and American Academy for Cerebral Palsy and Developmental Medicine Cerebral Palsy Common Data Elements Version 1.0 recommendations. *Dev Med Child Neurol* 2018; **60**: 976–86.

The power of mobility

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There is growing evidence of the importance of mobility for the overall development of children. Children with mobility