Improving allied health and nursing outcomes through best practice guidelines for Duchenne muscular dystrophy

Zoë E Davidson, Paula Bray, Monique Ryan, Merryn Pearce, Joshua Burns on behalf of the Australasian Neuromuscular Network Guideline Development Group.

**Background**
There are inconsistencies in allied health and nursing management for people with Duchenne muscular dystrophy (DMD), despite published evidence. The primary goal of management and care for people with DMD is anticipatory and preventative management, much of which is delivered by allied health and nursing professionals.

**Aims**
1. To provide evidence-based guidance specific to allied health and nursing practice for the assessment and management of those with DMD.
2. Where appropriate evidence does not exist, to obtain consensus for allied health and nursing practice for assessment and management of those with DMD.
3. To disseminate and translate the guidelines widely across Australia and New Zealand.

**Methods**
A guideline development group was formed consisting of members from Australian and New Zealand (Figure 1). The guideline methodology will be conducted in accordance with the requirements of National Health and Medical Research Council of Australia (NHMRC). An overview is presented in Figure 2.

**Box 1. Key Focus Areas**
- Musculoskeletal status
- Muscle weakness
- Functional mobility
- Upper limb function
- Activities of daily living
- Respiratory function
- Weight management
- Swallowing difficulties
- Pressure care
- Emotional and social adjustment
- Learning difficulties
- Behavioural difficulties
- Facilitate the transition to adulthood

**Results**
The key focus areas that will be addressed in the guidelines are summarised in Box 1. The systematic literature review are due to be completed by December 2015. Delphi surveys will commence in January 2016, with a final consensus meeting to be held in March 2016.

**Conclusion**
Our vision is to improve and standardise allied health and nursing practice to enable better health outcomes and improved quality of life for those living with DMD in Australia and New Zealand.

**Want more information or interested in being involved? Contact:** zoe.davidson@monash.edu

---

**Figure 1. Structure of the guideline development group**

**Figure 2. Overview of guideline development process**

*Funding support: Neuromuscular Research Foundation Trust, The Richdale Charitable Trust, NHMRC RARE-Bestpractices grant no. 1055131*