

## Outcome Measures Adolescent and Family Questionnaire (AFQ) by ICF domain ([Figure 1](#))

### PART/BOOKLET 1: DEMOGRAPHICS & PHYSICAL HEALTH

**To be completed by Adolescent with choice of assistance by principal researcher/volunteer/parent**

<i>Factors -Variables</i>	<i>Outcome Measure</i>	<i>Intent/Reason</i>	<i>Reference for Psychometric Properties/ Source/Relevant Permissions</i>
<b>Overall self-perception of health and wellbeing</b>	<b>Global Rating Scale of Physical Health and Social &amp; Emotional Wellbeing</b>  <b>Kidscreen-10 Global Rating Scale</b>	To explore individual participant's overall feeling of health and wellbeing with their detailed measures of health & wellbeing described in relation to the mean of all participants	Written permission Health Behaviours of School Age Children (HBSC) Study Protocol 2013/14 (The KIDSCREEN Group, 2004)
<b>Screen of Health Complaints</b> <i>Replaces Peds-QOL Generic</i>	<b>HBSC MQ 55</b>	Summary/Screen of Health Outcomes DEPENDANT VARIABLES	(Currie et al., 2014)
<b>SECTION 1: ABOUT YOU, YOUR FAMILY and HIGH SCHOOL</b>			
<i>Factors -Variables</i>	<i>Outcome Measure</i>	<i>Intent/Reason</i>	<i>Reference for Psychometric Properties/ Source/Relevant Permissions</i>
<b>A: ABOUT ME</b> Demographics			
Age	Date of Birth	CO-VARIATES	
Diagnosis	Rare Disease Code if available	If DMD & SMA, possibility to link with Genotype via Registry	(Orphanet, 2014)
Personal context -	Age of diagnosis	DEPENDANT VARIABLE May relate to coping/acceptance of condition	Common data element with Australian Neuromuscular Disease Registry (ANMDR)
Cultural background	Ethnicity Country of Birth Language Background Other than English (LBOTE)	CO-VARIATES May relate to understanding of condition	(ACARA, 2012)
<b>B: MY FAMILY</b> Environmental context:	Living arrangements Family make-up Family History of NMD	CO-VARIATES May relate to family coping/stress - in Family QoL	De novo questions

<b>C: MY PARENTS</b> Environmental context:			
Parental socio-educational context Socio-economic context	ICSEA - Index of Community SocioEducational Advantage incl: Parental education, occupation & employment based on Australian Qualifications Framework (AQF)	CO-VARIATES	(ACARA, 2012)  Common data element with Care-NMD survey (Kirschner et al., 2012)
	Parental physical activity	May relate to parental health	De novo questions
<b>D: MY SCHOOL</b> Personal context:			
School attendance			De novo question
Participation & Personal Factors: Academic Performance	NAPLAN results Year 9	DEPENDANT VARIABLE May relate to MES-HS score	(ACARA, 2014), (ACARA, 2011) De Novo Questions
Health Condition - cognitive ability	Learning support needs	CO-VARIATES	De novo question & Sub-section of PCMT-QOL (Ramchandren, Finkel, Reilly, Burns, & Shy, 2013) written permission from author

	<b>SECTION 2:YOUR MOVEMENT</b> Physical <b>Functional</b> Ability		
<b>Factors –Variables</b>	<b>Outcome Measure</b>	<b>Intent/Reason</b>	<b>Reference for Psychometric Properties/ Source/Relevant Permissions</b>
Ability to sit, stand, walk, mobilize using wheelchair	Egen Klassifikation -2 (EK2) scale  And Peds-QL Neuromuscular Module	CO-VARIATES Function De Novo questions based on North Star Assessment for Non-Ambulant boys with DMD (DMD NA), Functional Motor Scale (FMS)	(Brunherotti et al., 2007; Mayhew, Eagle, & Steffenson, 2012; Steffensen, Hyde, Attermann, & Mattsson, 2002) (Davis et al., 2010; Harvey, Morris, Graham, Wolfe, & Baker, 2010; Iannaccone et al., 2009)
A: MUSCLES, JOINTS AND BONES Joint Range of Motion - contracture Behaviour - use of splints	Self-report of Joint Range of Motion De Novo questions	DEPENDANT VARIABLE	Australian and International specialist NMD Physiotherapists. North Star Assessment for Non-Ambulant boys with DMD

SECTION 3: YOUR PHYSICAL HEALTH severity of <b>Body Systems</b> Co-morbidities			
<i>Factors –Variables</i>	<i>Outcome Measure</i>	<i>Intent/Reason</i>	<i>Reference for Psychometric Properties/ Source/Relevant Permissions</i>
<b>B: RESPIRATORY SYSTEM</b>			
Lung function	EK2 scale Peds-QL Neuromuscular Module	CO-VARIATE DEPENDANT VARIABLE	Public domain (Steffensen et al., 2002)
Spirometry	Vital Capacity: SVC&FVC Cough Peak Flow	DEPENDANT VARIABLE	ANMDR Common Data (Hull et al., 2012)
Use of Non-Invasive Ventilation & respiratory support	As per ANMDR & Care-NMD data elements	DEPENDANT VARIABLE	ANMDR Common Data Care-NMD survey NZ
Cough effectiveness	EK Scale	CO-VARIATE	(Steffensen et al., 2002)
Recurrent chest infections	Hospitalisation	DEPENDANT VARIABLE	Care-NMD survey (Kirschner et al., 2012)
Symptoms of nocturnal hypoventilation	Paediatric Daytime Sleepiness Scale (PDSS)	DEPENDANT VARIABLE	(Drake et al., 2003)
Sleep	positioning	DEPENDANT VARIABLE	De novo questions - Sue McCabe, OT
<b>C: BONES AND SPINE</b>			
Spinal scoliosis	Cobb angle Spinal fusion	DEPENDANT VARIABLE	ANMDR Common Data
Behaviour: use of positioning aides & splints	Spinal Mx: surgery, brace, seating/24hr postural Mx	DEPENDANT VARIABLE	De novo questions
Bone density Behaviour: Mx of bone health	Incidence of fractures Medical management	DEPENDANT VARIABLE	De novo questions (Bushby & Connor, 2011; Bushby et al., 2010; Wang et al., 2012)
<b>D: HEART HEALTH</b>			
Diagnosis of Cardiomyopathy			ANMDR Common Data
Cardiac Function	Left Ventricular Ejection Fraction - LVEF	DEPENDANT VARIABLE	ANMDR Common Data
	Symptoms of Heart Failure	DEPENDANT VARIABLE	Advised by Dr Larry Markham
<b>E: NUTRITION: EATING &amp; DRINKING</b>			
Ability to self-feed	EK scale	DEPENDANT VARIABLE	(Steffensen et al., 2002)
Ability to swallow	Incidence of aspiration	DEPENDANT VARIABLE	De Novo Questions
Nutritional Intake	Number of limitations to intake Weight in kg & maintenance	DEPENDANT VARIABLE	Advised by Zoe Davidson, PhD, specialist NMD Dietician
<b>F: DIGESTION, BLADDER AND BOWEL HEALTH</b>			
Bladder health and function	Incidence of Urinary Tract Infection	DEPENDANT VARIABLE	Public domain

	Urinary continence - ICIQ		(Bristol Urological Institute, 2014)
Bowel health and function	Constipation : Rome III Criteria for Function Gastrointestinal Disorders	DEPENDANT VARIABLE	Public domain (Backhouse & Harding, 2006; Ying-Chih, Deutscher, Sheng-Che, Werneke, & Mioduski, 2014)
<b>G: SKIN HEALTH</b>			
Incidence of pressure injuries	De novo questions	DEPENDANT VARIABLE	(The Australian Wound Management Association, 2012)
Cause of pressure injuries	De novo questions	CO-VARIABLE	Advised by expert clinicians & parents
<b>H: PAIN</b>			
Prevalence, Source & Rating of pain	De novo questions with Wong-Baker Faces Pain Rating Scale	DEPENDANT VARIABLE	(Ramchandren et al., 2013; Zebracki & Drotar, 2008)
<b>I: MEDICATIONS</b>			
Steroid management	Type & prescription	DEPENDANT VARIABLE	Common Data element ANMDR & Treat-NMD
<b>J: THERAPY SERVICES</b>			
Env. Factor: health service prvn	Service provision	CO-VARIATE	De novo questions
Pers. Factor: Behaviour - participation in Mx	Home therapy activities	DEPENDANT VARIABLE May relate to MES-HS constructs	(AussieRett, 2011)
<b>K: KNOWLEDGE OF THE CONDITION</b>			
Personal factor: knowledge	CARE-NMD survey NZ		CARE-NMD survey NZ

## PART/BOOKLET 2: SOCIAL AND EMOTIONAL WELLBEING

**To be completed INDEPENDENTLY by Adolescent**

### Dependent and Independent Variables

### What you do, think and feel

<i>Factors -Variables</i>	<i>Outcome Measure</i>	<i>Intent/Reason</i>	<i>Reference for Psychometric Properties/ Source/Relevant Permissions</i>
<b>Global Rating Scale Wellbeing</b>	Wellbeing MQ 57	Summary/Screen of Health Outcomes DEPENDANT VARIABLES	Written permission Health Behaviours of School Age Children (HBSC) Study Protocol 2013/14 Cantril (1965) adapted for HBSC surveys
<b>A: QUALITY OF LIFE</b> Disease specific Perceived QoL Communication with Health Professionals Family Resources	Peds -QL 3.0 Neuromuscular Module	DEPENDANT VARIABLE	Written permission from Mapi Research Trust (Iannaccone et al., 2009) (Davis et al., 2010)
<b>B: FEELING SUPPORTED</b> Community and School Family Friends	From Child and Youth Resilience Measure – CYRM 12 MQ46 Family, MQ47 Friends HBSC study protocol	DEPENDANT VARIABLE	(Liebenberg, Ungar, & LeBlanc, 2013) public domain  (Currie et al., 2014)
<b>C: PARTICIPATION</b> In Educational, Social and Recreational and Health Care activities	Questionnaire of Young People's Participation Version 2.0 (Feb 2011)	CO-VARIATE	(Tuffrey, Bateman, & Colver, 2013) written permission
<b>D: PLANNING FOR ADULthood</b> Knowledge Peer Culture, Peer Support	De novo questions	CO-VARIATE	(Sonneveld, Strating, van Staa, & Nieboer, 2013) & Young Adults with NMD
<b>E: MOTIVATION AND ENGAGEMENT</b> & perceptions of school support	MQ58, 61 & 62 of HBSC Study Protocol  Motivation and Engagement Scale - High School (MES -HS)	DEPENDANT VARIABLE	With permission (Currie et al., 2014)  Purchased from Lifelong Learning (Liem & Martin, 2012)
<b>E: MENTAL WELLBEING</b> Positive Affect PROMIS Subjective Wellbeing Items	WEMWBS Domains of Wellbeing: Life Satisfaction Positive Affect Meaning and Purpose	DEPENDANT VARIABLE	(Clarke et al., 2010) public domain

## PART/BOOKLET 3: PARENT' HEALTH & FAMILY WELLBEING

To be completed by Parent/Primary Carer

SECTION 4: FAMILY LIFE			
<i>Factors -Variables</i> <b>CO-VARIATES</b>	<i>Outcome Measure</i>	<i>Intent/Reason</i>	<i>Reference for Psychometric Properties/ Source/Relevant Permissions</i>
<b>A: DAY TIME CARE</b>	Parental involvement Support & Respite	CO-VARIATE	Adapted From: (Down Syndrome NOW Needs Opinions Wishes, 2011)
<b>B: SLEEP AND NIGHT TIME CARE</b>			
comfort	Positioning	DEPENDANT VARIABLE	De-novo questions In consultation with Sue McCabe
Symptoms of nocturnal hypoventilation	<i>Sleep Disturbance Scale for Children</i>	DEPENDANT VARIABLE	Public domain (Bruni et al., 1996)
<b>C: CARER QUALITY OF LIFE</b>	Adult Carer Quality of Life Questionnaire (AC-QoL) (UK)	CO-VARIATE	Public domain (Elwick, Joseph, Becker, & Becker 2010)

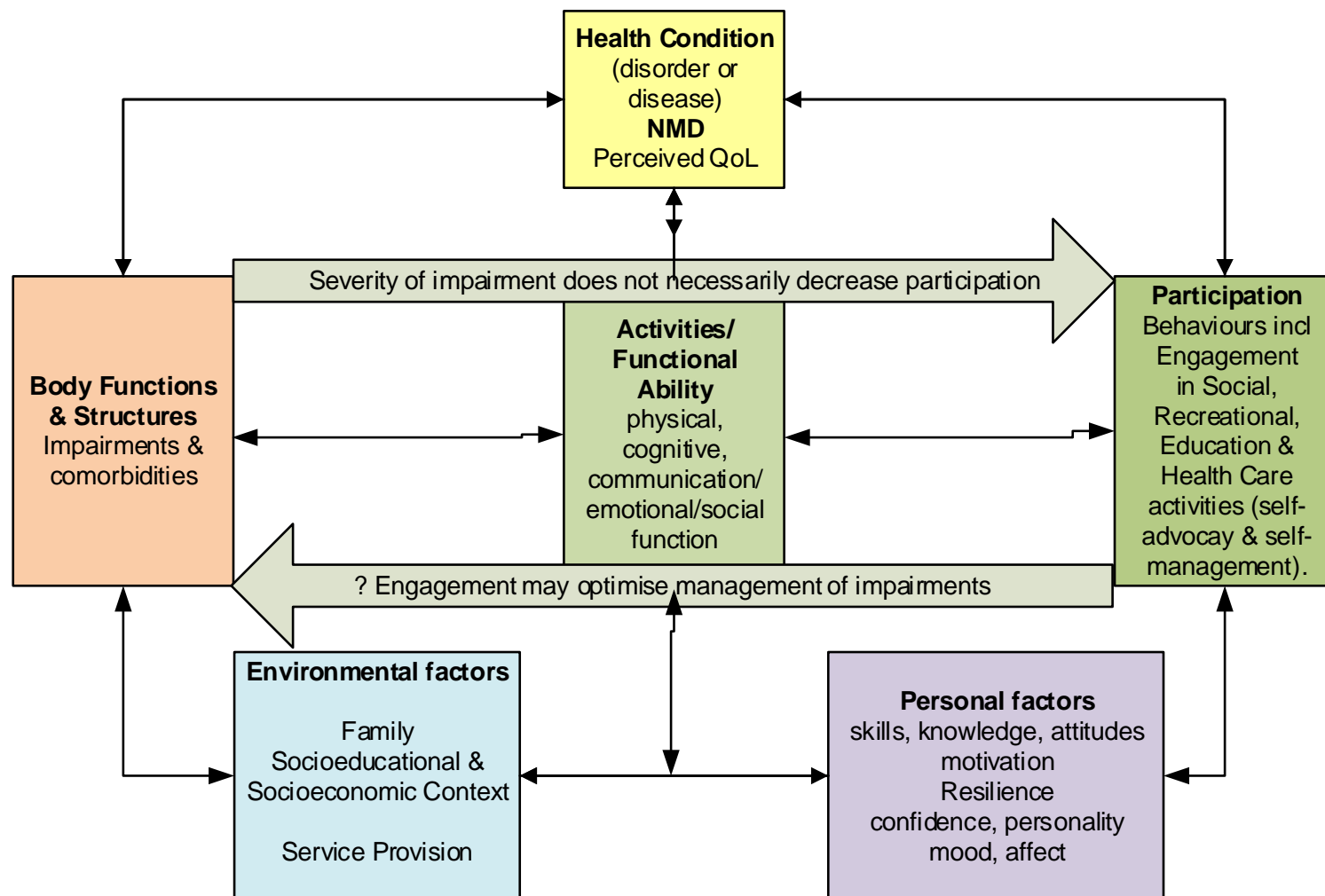


Figure 1: International Classification of Functioning, Disability and Health (ICF) Conceptual model of factors influencing health and wellbeing in adolescents with NMD

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