

# **QUALITY TOOL BOX**

#### Overview

QTBs are a resource for Academy members that include existing tools which may be useful in physiatric practice. Tools included in the Spina Bifida QTB were identified by subject matter experts who treat patients with this condition, and the Academy's Performance Metrics Committee has evaluated the tools for their methodological quality.

#### **ACKNOWLEDGMENTS**

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# Pediatric Rehabilitation/Developmental Disabilities Council

# Spina Bifida

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#### **Core Constructs**

Core Constructs were identified to help guide the selection of Assessment Instruments and Performance Measures. Core Constructs are based on the International Classification of Functioning, Disability and Health (ICF) framework.

More information on the ICF Framework can be found here.

The Core Constructs for this QTB related to Spina bifida are:

- Self Care
- Mobility
- Cognition
- Life Satisfaction
- Quality of Life

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### **Assessment Instruments**

- Pediatric Evaluation of Disability Inventory (PEDI) Was developed to
  evaluate functional skills and abilities. Has 3 subsets related to self care,
  mobility and social function. Age range is 6 months to 7.5 years. There is a
  computerized version available (CAT). \*NOT FREE
- Functional Independence Measure for Children (WeeFIM) Global
  assessment of disability and amount of care giver assistance required
  for functional tasks. In relations to spina bifida the self care and mobility
  domains are the most useful. \*NOT FREE
- Functional Independence Measure (FIM) Global assessment of disability and amount of care giver assistance. Age range 7 to adult. The domains include self care, mobility and cognition. \*NOT FREE
- Ages and Stages Questionnaires (ASQ) Screening toll for birth to 5½ years. Looks at 5 areas of development: communication, gross motor, fine motor, problem solving and personal-social. \*NOT FREE
- Trails making Test B Test of working memory and task shifting ability. Children with Spina bifida and especially with an associated hydrocephalus should have formal neuropsychology testing around school age.
- Vineland Adaptive Behavior Scale-II Assess adaptive behaviors in 4 areas: communication, daily living skills, socialization and motor skills. All ages. \*NOT FREE
- Pediatric Symptoms Checklist (PSC) Screening tool for psychosocial issues specifically around cognition, emotional and behavioral problems.
- Life Satisfaction Questionnaire 9 (LSQ-9) Assesses various aspects
  of life satisfaction.
- Pediatric Quality of Life Inventory (PEDS QL) measures health related quality of life items related to physical, emotional, social and school functioning. There are 23 items and the age range is 2–18 years. \*NOT FREE
- Pediatric Outcomes Data Collection Instruments (PODCI) —
   Tool is used to assess overall health, pain and the ability to participate in different levels of activity. Eight scales include: upper extremity and physical function, mobility and transfers, sports physical functioning, pain and comfort, treatment expectations, happiness, satisfaction and global functioning scale. Age range is under 19 years. \*NOT FREE
- Craig Hospital Inventory of Environmental Factors (CHIEF) Looks at impact from environmental barriers.

#### Performance Measures

- Pressure Ulcer: rate per 1,000 discharges
- Developmental Screening in the first 3 years of life
- Weight Assessment and Counseling for Nutrition and Physical Activity \*Measure included in EHR Incentive Program, and the Physician Quality Reporting System (PQRS)
- Screening for Clinical Depression and Follow-Up Plan \*Measure included in EHR Incentive Program, and the Physician Quality Reporting System (PQRS)



# **Review Articles**

- Fletcher JM, Brei TJ. Introduction: Spina Bifida—
   A Multidisciplinary Perspective. Developmental disabilities research reviews 2010;16(1):1-5. doi:10.1002/ddrr.101.
- Myelomeningocele (Spina Bifida)

# **Evidence-Based Clinical Practice Guidelines**

- National Institute for Health and Clinical Excellence (NICE):
   "Urinary incontinence in neurological disease: Management of lower urinary tract dysfunction in neurological disease"
- American Academy of Pediatrics: "Diagnosis and Management of Childhood Obstructive Sleep Apnea Syndrome"

## **Clinical Reports**

• American Academy of Pediatrics: Providing a Primary Care Medical Home for Children and Youth with Spina Bifida





### Spina Bifida Educational Resources

#### **General Knowledge:**

- Living With Spina Bifida: School-Aged Children
- Center for Parent Information and Resources: Spina Bifida
- Spina Bifida Association
- Spina Bifida Association: An Expectant Parent's Guide to Spina Bifida

#### **Spanish General Information:**

Center for Parent Information and Resources: La Espina Bífida

#### Folic Acid:

• Spina Bifida Association: Folic Acid

#### **Genetics:**

• Spina Bifida Association: Genetics and Spina Bifida

#### **Education:**

- Learning and Education
- Learning Among Children with Spina Bifida
- Mathematics
- Reading Comprehension
- College/University Education

#### **Types of Spina Bifida:**

• Spina Bifida Occulta

#### **Sports:**

- Disabled Sports USA
- Spina Bifida Association Camps & Recreation List INTERACTIVE LIST BY STATE

#### **Medical Care:**

- Spina Bifida Association: Obesity
- Spina Bifida Association: Obesity Among Persons with Spina Bifida
- Spina Bifida Association: Transitioning to Adult
- Spina Bifida Association General Information Sheets
- Spina Bifida Association: Depression & Anxiety
- Spina Bifida Association: Hip Function and Ambulation
- Spina Bifida Association: Hydrocephalus and Shunts
- Spina Bifida Association: Lipomyelocele
- Spina Bifida Association: Latex Allergy
- Spina Bifida Association: Pain
- Spina Bifida Association: Bowel and Bladder Needs and Care
- Spina Bifida Association: Urological Care and Management
- Spina Bifida Association: Urological Care and Management (PDF)
- Spina Bifida Association: Spinal Cord Tethering
- Spina Bifida Association: Symptomatic Chiari Malformation
- Spina Bifida Association: Traveling with a Disability



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# Other Resources

# **AAPM&R** Resources

- Evidence-Based Resources
- Vetted PQRS Measures
- Performance Measure Resources
- Endorsed Clinical Practice Guidelines
- Quality Glossary

## **External Resources**

#### **Evidence/Literature:**

Cochrane Library

An online collection of databases that brings together in one place rigorous and up-to-date research on the effectiveness of healthcare treatments and interventions, as well as methodology and diagnostic tests.

 Oxford Centre for Evidence-Based Medicine 2011 Levels of Evidence

Defines a process of finding appropriate evidence feasible and its results explicit.

#### **Clinical Practice Guidelines:**

National Guidelines Clearinghouse

A public resource for evidence-based clinical practice guidelines.

#### **Assessment Instruments/Performance Measures:**

• National Quality Measure Clearinghouse

A public resource for evidence-based quality measures and measure sets.

National Quality Forum (NQF) Quality Positioning System

NQF's measure search tool that helps you find the endorsed measures you need quickly and easily.

• Rehabilitation Measures Database

The rehabilitation clinician's place to find the best instruments to screen patients and monitor their progress.