Health Promotion and Preventive Healthcare Services
SPINA BIFIDA HEALTHCARE GUIDELINES
Margaret Turk, Chair
Ellen Fremion
David Kanter
Jonathon Tolentino
Jason Woodward

NOTE: Health promotion and preventive services overlap significantly with other topic areas. This Working Group hopes that where there is overlap, the concepts noted here be incorporated into the other topic questions and guidelines, rather than just being omitted from this topic.

Overall outcomes
Primary:
- Maximize physical and mental health for individuals with spina bifida (SB) within the context of the underlying condition.
- Identify risks for and presence of common or known secondary conditions early.
Secondary:
- Limit preventable Emergency Department (ED) visits and hospitalizations for individuals with spina bifida.
- Monitor trends of identified and newly emerging secondary conditions.
Tertiary:
- Provide patient-centered general health monitoring, based on United States preventive Services Task Force (USPSTF) Recommendations and SB-specific biomedical information.

Infant-Toddler-Preschool (0-5 years)
Clinical questions:
- Do infants-children ages 0-5 years with spina bifida receive typical USPSTF recommended preventive healthcare?\(^1\)

Guidelines
- Educate families about the importance of their infant/child with spina bifida receiving typical preventative care and screening (i.e., immunizations; newborn screening labs; screenings for hearing, vision, dental, and speech and language)\(^1\)
- Ensure age-typical health promotion counseling. (i.e., above listing, counseling for motor vehicle occupant restraint, water safety, and age-typical skill development).\(^1\) Counseling should be individualized to accommodate for SB-comorbidities (shunt, bowel, bladder, mobility impairment, skeletal deformity, developmental delay).
Counsel families about possible future medical and social needs related to SB, such as latex allergies, chronic urinary issues, problems with shunts, achieving an inclusive environment, overweight/obesity risk, importance of physical and recreational activity, managing unexpected changes in function, keeping regular appointments, presence of pain complaints.

Monitor for neglect and/or abuse.

School Age (5-12 years)

Clinical questions:
- Does early discussion about maintaining health and using health promotion and prevention strategies assist with later participation in those activities?
- Do children ages 5-12 years with spina bifida receive typical USPSTF recommended preventive healthcare?
- When does pain become a common secondary condition? What are the characteristics that increase risk for pain complaints?
- What are the characteristics that increase the risk for hypertension?

Guidelines:
- Monitor for receipt of typical age appropriate health promotion and preventive services, such as screening for hypertension, iron deficiency, lipid disorders, overweight/obesity, abuse/violence. Screen for motor vehicle occupant safety (including wheelchairs); neglect, abuse, violence; depression.
- Counsel about tobacco/illicit drug use, skin cancer prevention, adaptive physical and recreational activity, as appropriate.
- Provide information about accessible physical activity and recreational opportunities in the community.
- Monitor for pain and pain changes, and proceed with appropriate evaluation and treatment.
- Monitor for spina bifida specific comorbid conditions during SB-specific visits as well as well child visits including shunt concerns, skeletal/limb deformity, sleep apnea, constipation, urinary tract infections, renal function, problems with bowel and bladder regimens, skin ulcers, and adaptive equipment needs (orthotics, crutches, walkers, and wheelchairs). Make referrals to necessary subspecialists.
- Ensure care coordination between SB-specific subspecialists and primary care providers.
- Ensure that families know how to detect early signs of problems due to SB-related chronic conditions.

Teenage (13-19 years)

Clinical questions:
- Does early discussion about maintaining health and using health promotion and prevention strategies assist with later participation in those activities?
- Do teenagers with spina bifida receive typical USPSTF recommended preventive healthcare?
- What are the parameters to begin screening for metabolic syndrome?
• What are parameters and modifications (if any) for beginning sexuality education related to sexually transmitted infections, partner violence, human papillomavirus (HPV) immunization?

• What are the characteristics that may increase the risk for decreasing self-rated health and health related quality of life (HRQOL)? Do increasing acute medical conditions affect this? Are there interventions or supports that may mitigate this?

• When does sleep apnea become notable and what are the risks?

• Do interventions make a difference for weight control, participation in physical or recreational activity, pain control?

• Can ED or hospital admissions be avoided?

Guidelines:

• Monitor for receipt of typical age appropriate health promotion and preventive services, such as screening for hypertension, lipid disorders, overweight/obesity, abuse/violence.

• Monitor for spina bifida specific comorbid conditions during SB-specific visits as well as well child visits including shunt concerns, skeletal/limb deformity, pain, sleep apnea, urinary tract infections, renal function, problems with bowel and bladder regimens, skin ulcers, and adaptive equipment needs (orthotics, crutches, walkers, and wheelchairs). Make referrals to necessary subspecialists.

• Ensure care coordination between SB-specific subspecialists and primary care providers.

• Ensure that families know how to detect early signs of problems due to SB-related chronic conditions and that teens are learning to monitor their own health condition.

• Counsel about tobacco/illicit drug use, skin cancer prevention, adaptive physical and recreational activity, nutrition as appropriate.

• Provide information about accessible physical activity and recreational opportunities in the community.

• Promote self-management for health and healthcare services (i.e. by age 14, patients should discuss planning for transition to adult care including providers and funding changes. They should also begin to meet with their doctors independently).

Adults

Clinical questions:

• Does early discussion about maintaining health and using health promotion and prevention strategies assist with later participation in those activities?

• Do adults with spina bifida receive typical USPSTF recommended preventive healthcare?

• What are the characteristics that may increase the risk for decreasing self-rated health and HRQOL? Do increasing acute medical conditions affect this? Are there interventions or supports that may mitigate this?

• Can future health issues and health care utilization be predicted? What is
prevalence and risks for common and SB-related conditions? What is the expected cost of care?

- Can ED or hospital admissions be avoided?

Guidelines:

- Monitor for receipt of typical and age-related health promotion and preventive services, such as screening for or counseling about hypertension, lipid/cholesterol disorders, overweight and obesity, cancer, diabetes/metabolic syndrome, falls prevention, adaptive physical activity and nutrition, depression/anxiety, skin cancer, smoking/illicit drugs, and hearing/vision.
- Monitor for spina bifida specific comorbid conditions during SB-specific visits as well as well child visits including shunt concerns, skeletal/limb deformity, pain, sleep apnea, urinary tract infections, renal function, problems with bowel and bladder regimens, skin ulcers, lymphedema, and adaptive equipment needs (orthotics, crutches, walkers, and wheelchairs). Make referrals to necessary subspecialists.
- Ensure care coordination between SB-specific subspecialists and primary care providers.
- Ensure that patients know how to detect early signs of problems due to SB-related chronic conditions.
- For sexually active men and women, counsel about and monitor for sexually transmitted infections, intimate partner violence.
- For individuals interested in pregnancy, counsel about family planning, probabilities of conceiving (men and women), pre-pregnancy health assessments for women (folic acid, smoking, infection, pre-eclampsia), breastfeeding, preparation for assistance post delivery if needed.
- Promote self-management for health and healthcare services (i.e. assess patients’ ability to perform routine care needs such as bowel, bladder, and skin check regimens; ability to detect change in health status; and need for provider services to maximize independence).

Research gaps:

- Can future health issues and health care utilization be predicted? What are the common health conditions that are preventable or easily amenable to interventions? What is prevalence and risks for common and SB-related conditions? What are the common causes for preventable or unanticipated mortality? What is the expected cost of care?
- What are the common physical and mental health conditions associated with ED visits and hospitalizations? What are key anticipatory guidance or management strategies to prevent the need for higher levels of care? Can ED or hospital admissions be avoided – and how? Does a medical home help to avoid?
- What are the characteristics that may increase the risk for decreasing self-rated health and HRQOL? Do increasing acute medical conditions affect this? Are there interventions or supports that may mitigate this?
• What adaptations to general care practice and the USPSTF Recommendations do individuals with SB need, taking into account patient-centered perspectives and biomedical information?
• What long term care planning is needed to support best health into adulthood for individuals with SB?

