Establishing a Spina Bifida Community-Centered Research Agenda

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Goal: Engage the community of people living with Spina Bifida to identify and prioritize research gaps.

2016 - 2018

Guidelines for the Care of People with Spina Bifida

Dicianno BE, Beierwaltes P, Dosa N, et al. Scientific methodology of the development of the Guidelines for the Care of People with Spina Bifida: An initiative of the Spina Bifida Association. Disabil Health J. 2020 Aor;13(2):100816. PMID: 31248776.

Steering Committee

- Comprised of a Medical Director, DNP, and Physicians
- Set overall strategy and

25 Volunteer Workgroups

- Reviewed literature summaries (Including NSBPR Publications)
- Revised Guidelines
- Identified research gaps
- Completed process documents
- Vetted Guidelines at Consensus Meeting
- Received public input
- Developed final manuscript

2020

- Research Advisory Council (RAC) formed to address 6 topic areas of importance
- RAC included a mix of parents of children with Spina Bifida, adults with Spina Bifida, care partners of adults with Spina Bifida, and health care professionals/researchers

Research Topics of Importance:

Mental health Self-management Weight management/nutrition Transition

Bowel incontinence Urinary incontinence

2020 - 2021

- RAC identified 10-12 research questions for each topic perceived as most impactful/in need of research
- 12 virtual discussion groups, 2 for each of the 6 topics, clarified research questions and ranked the most important questions for research
- Discussion groups consisted of adults with Spina Bifida and, parents and care partners of adults with Spina Bifida
- The first Spina Bifida Community-Centered Research Workshop was held November 6, 2021
- The Workshop had 200+ registered participants who subsequently formed research topic working groups to:
 - Address specific research questions
 - Consider use of Spina Bifida Registry data where appropriate
 - Develop proposals for funding

Culmination

Publication

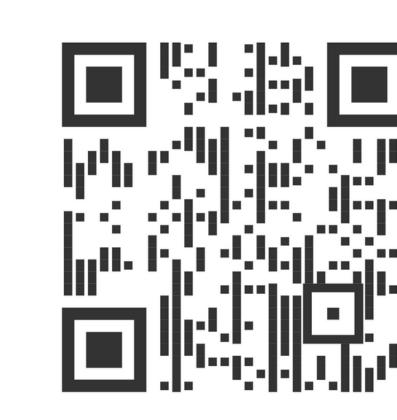
Dissemination

2019

Quantitative Survey

- Based on research gaps identified during the development of the Guidelines
- 1,607 respondents
 - Adults with Spina Bifida
 - Parents of children and adults with Spina Bifida

Parents of Child <18 with SB	%	Parents of Child 18+ with SB	%	Adults with SB	%
Bowel Incontinence		Finding Doctors	50%	Finding Doctors	55%
Urinary Incontinence		Bowel Incontinence	49%	Bowel Incontinence	51%
Independence		Independence	50%	Managing Weight	44%
Encourage Self-Management		Managing Weight	40%	Urinary Incontinence	43%
Learning Disabilities/Attention Disorders		Learning Disabilities/Attention Disorders	32%	Depression/Mental Health	42%



For information about or a copy of the Spina Bifida Association Community-Centered Research Agenda please scan the QR code or visit



organization for individuals with Spina Bifida.

