



SPINA BIFIDA
ASSOCIATION

The Spina Bifida Collaborative Care Network

Spina Bifida Clinical Care Meeting

June 29, 2019

Lurie Children's Hospital

Chicago

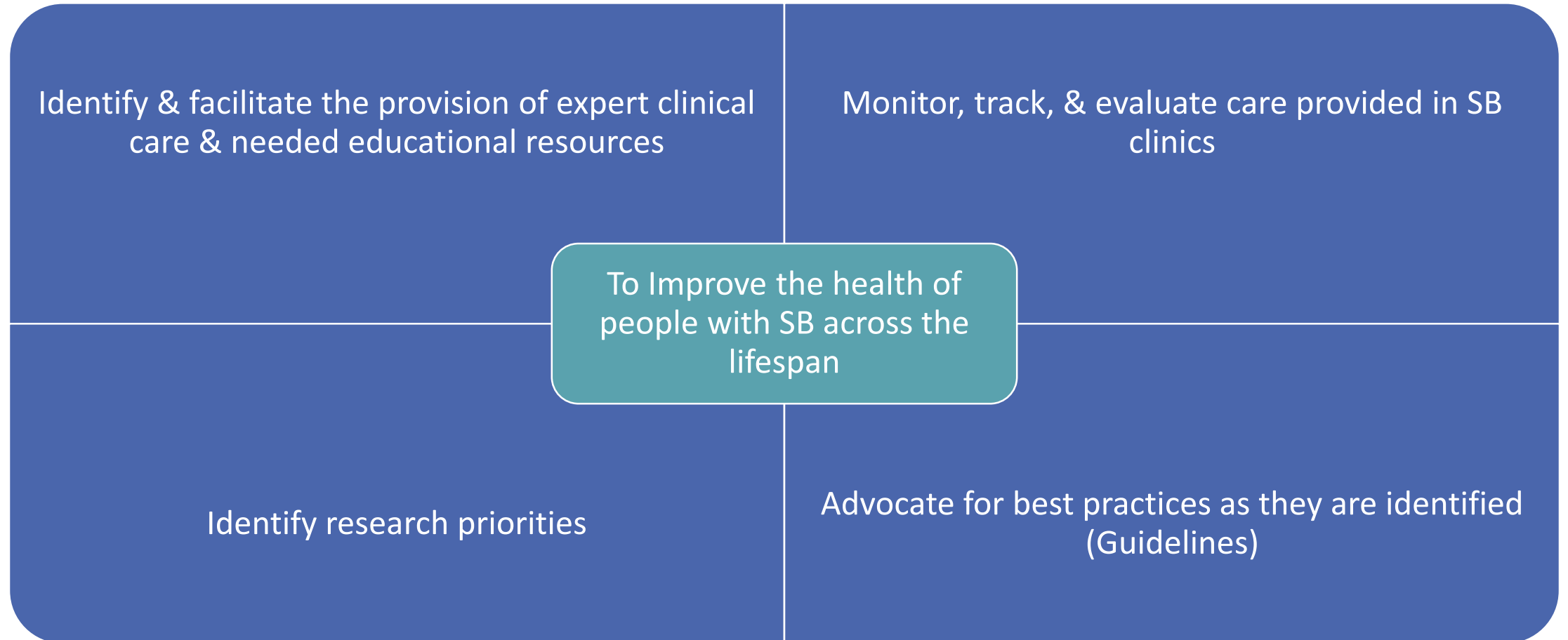
Agenda

- The Spina Bifida Collaborative Care Network
 - Development and Implementation
 - How to be involved
- Spina Bifida Association Clinic Care Partner Opportunity
 - Standards



The Spina Bifida Collaborative Care Network 2014-2019

Why the Spina Bifida Collaborative Care Network?






Identify & facilitate the
provision of expert clinical
care & needed
educational resources

Expert clinical care & educational resources

- Collaborate with CDC to identify Registry clinics with better clinical outcomes
- Develop a plan to meet with these clinics to learn about their approaches to care
- Develop and implement plans to address barriers to health care across the lifespan
- Encourage implementation of effective care coordination in SB clinics



Advocate for adoption of
best practices as they are
identified (Guidelines)

Guidelines for the Care of People with Spina Bifida

- Launched in October 2018
- Available on the SBA website
- Consumer Friendly Guidelines in development
- Mobile App in development
- Shared with all SB clinics, HCPs, people with SB and their families
- Included in presentations to SB chapters, Education Days, other medical specialties
 - Encourage people with SB to share with HCPS



Monitor, track, & evaluate
care provided in SB clinics

Care provided in SB clinics

- Advocate for use of the Guidelines for the care of People with SB
 - Explore where uptake can be measured via the NSBPR
- Include use of the Guidelines in SBA Care Partner Standards
 - Evidence of use provided annually



Identify research priorities

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- Using Research Gaps identified during Guidelines development process
 - On-line market research survey of parents and adults with SB
 - Guideline subject areas of most importance
 - Gaps identified most important
 - Other topics of importance
 - Focus Groups, parents and adults
 - Gain deeper understanding of on-line survey data
 - Monitor issues as they are conveyed, National Resource Center
 - Develop a Research Agenda
 - CDC and NSBPR
 - Other funding agencies

Spina Bifida Collaborative Care Network

People with SB will have access to knowledgeable, experienced health care professionals who are connected to SBA

Enhanced relationships with HCPs

Connections with others with SB, needed info, and resources

Access to HCPs via an established care network

Increased access to SB care via expanded network

Established collaboration among HCPs, Chapters, and SBA



Work of the Spina Collaborative Care Network

2019-2024

Purpose

Expand the work of the Spina Bifida Collaborative Care Network (SBCCN) to identify and encourage rapid adoption of best practices based on available evidence for the care of people with SB.

Through communication

Maintain
Clinic/Provider
database

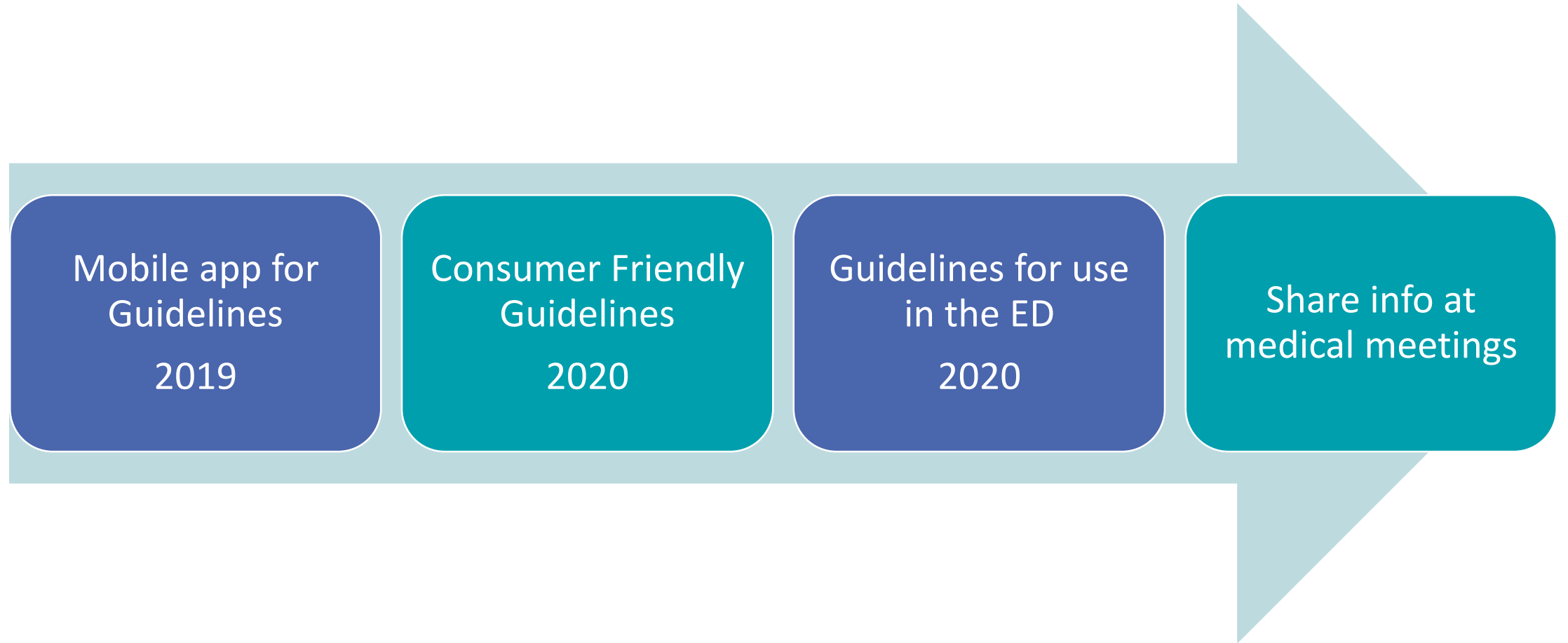
Identify HCPs

With/Through SBA
Chapters

Among families,
HCPs, adults

Through programs
(NRC, SB-Connect,
SB-YOU, Education
Days)

Promote/Disseminate Guidelines for Care



Promote/Disseminate Health Care Guidelines

Meetings About SB Care

- SB Clinical Care, June 28-30, 2019
- Education Days
- Local Chapter events
- World Congress 2022

Share information and research via

- Network
- List serv



Adoption of Best Practices

Attributes of SB Clinics with Best Outcomes

Identify using NSBPR data	Visit clinics with best outcomes	Share what is learned with other clinics
<ul style="list-style-type: none">• Bowel continence• Bladder continence• Skin breakdown• Mobility	<ul style="list-style-type: none">• Practices• Patterns• Attitudes	<ul style="list-style-type: none">• Incorporate into Care Partner Standards• Support to adopt

Influence Availability of Adult Care

Educate

Adults

Health Care
Providers

Listen

Adult
Survey

NRC

Advocate

AAP Project

T2C

Health Care Professionals Role in SBCCN

1	Become an SBA Clinic Care Partner
2	Become an SBA Provider Partner, future opportunity
3	Use Guidelines & download the app
4	Attend SB Clinical Care Meeting, World Congress on SB Care and Research
5	Join the Health Care Professionals Listserv
6	Support Chapter activities
7	Participate in Teal on the Hill, April 26-28, 2020
8	Support SB Awareness Month activities, October 2019
9	Speak at SBA Education Days

Spina Bifida Association Clinic Care Partner



Clinic Care Partnership

The heart of the work of the SBA's Spina Bifida Collaborative Care Network (SBCCN) is to improve health and outcomes of people living with SB so that they may realize their full potential and live long and well...

- Necessary to success

- Identify practices and processes that yield the best outcomes
- Recognize clinical programs that strive to accomplish them
- Support all programs to incorporate these practices and processes

Clinic Care Partnership

- Encourage inclusion of specific practices and processes in all SB programs
 - All receive care to optimize outcomes
- Practices and processes
 - Developed by SBA
 - Approved by the Professional Advisory Council/SBA
 - Basic standards that clinics must implement, SBA Clinic Care Partner

Network of Clinics

- Identified and recognized for providing exemplary services
 - Essential to enhance health and outcomes
 - Continual quality improvement
- Applications may be submitted by the end of each calendar year, December 2019
- Status of Standards reported annually
- Further discussion of this network at breakout sessions this afternoon

The Spina Bifida Clinic Care Partnerships

- People with SB will have access to HCPs
 - Knowledgeable
 - Experienced
 - Connected with SBA and/or chapters
- Ensuring the provision of
 - Care
 - Support
 - Information
 - Resources
- Optimize health and Quality of Life

In closing

To enhance the lives of all people affected by Spina Bifida

- The SBCCN
 - Identify expert clinical care
 - Provide needed educational resources
 - Identify research priorities
 - Advocate for best practices
- The SBA Clinic Care Partners Network
 - Identified best practice and process standards
 - Identify/Recognize programs that implement these standards
 - Encourage/Support all programs to implement these standards

Thank you for what
you do and for this
opportunity to share
with you why it is so
important



**SPINA BIFIDA
ASSOCIATION**