

National Spina Bifida Patient Registry (NSBPR)

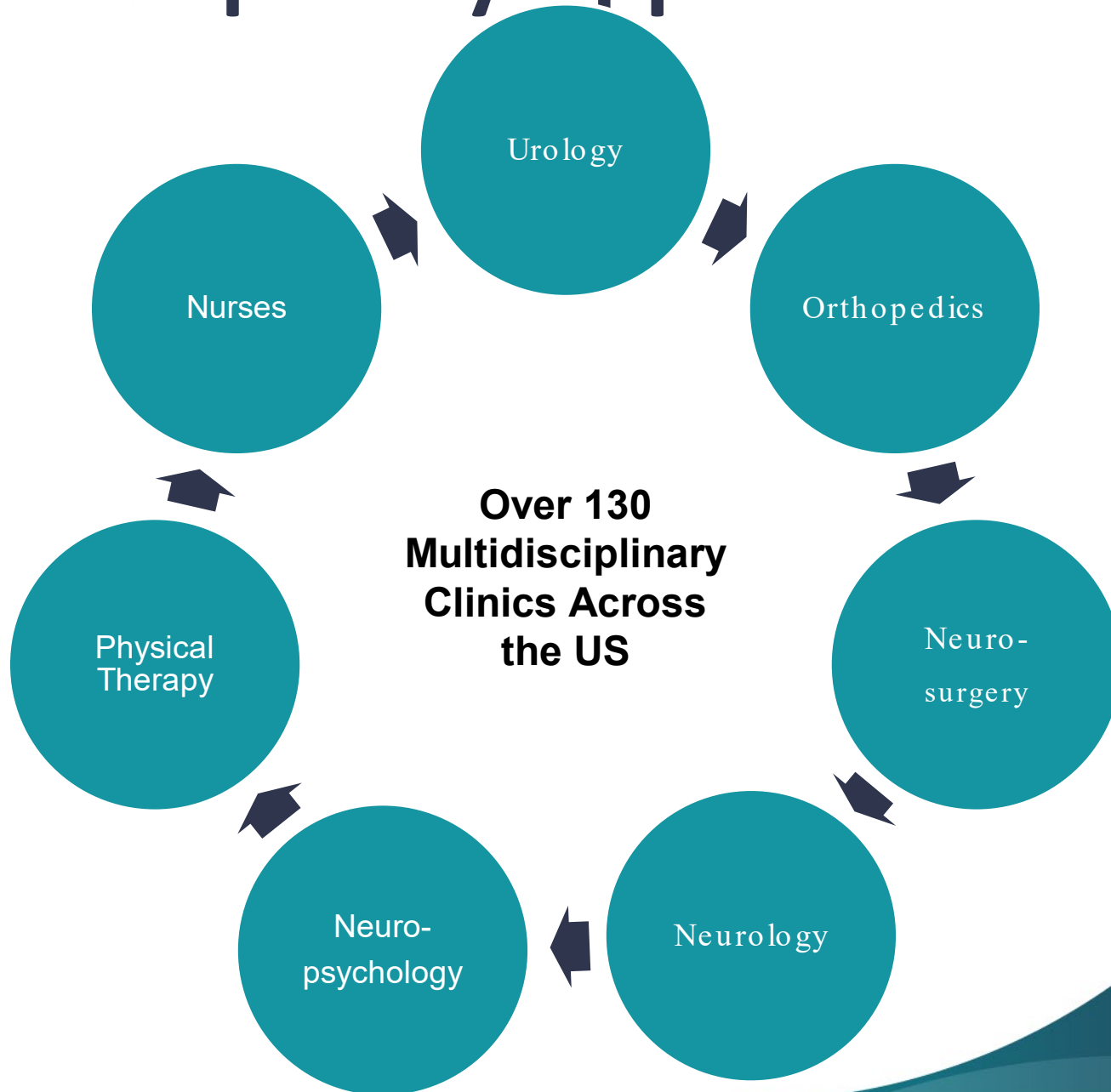
Sara Struwe, MPA
President & CEO



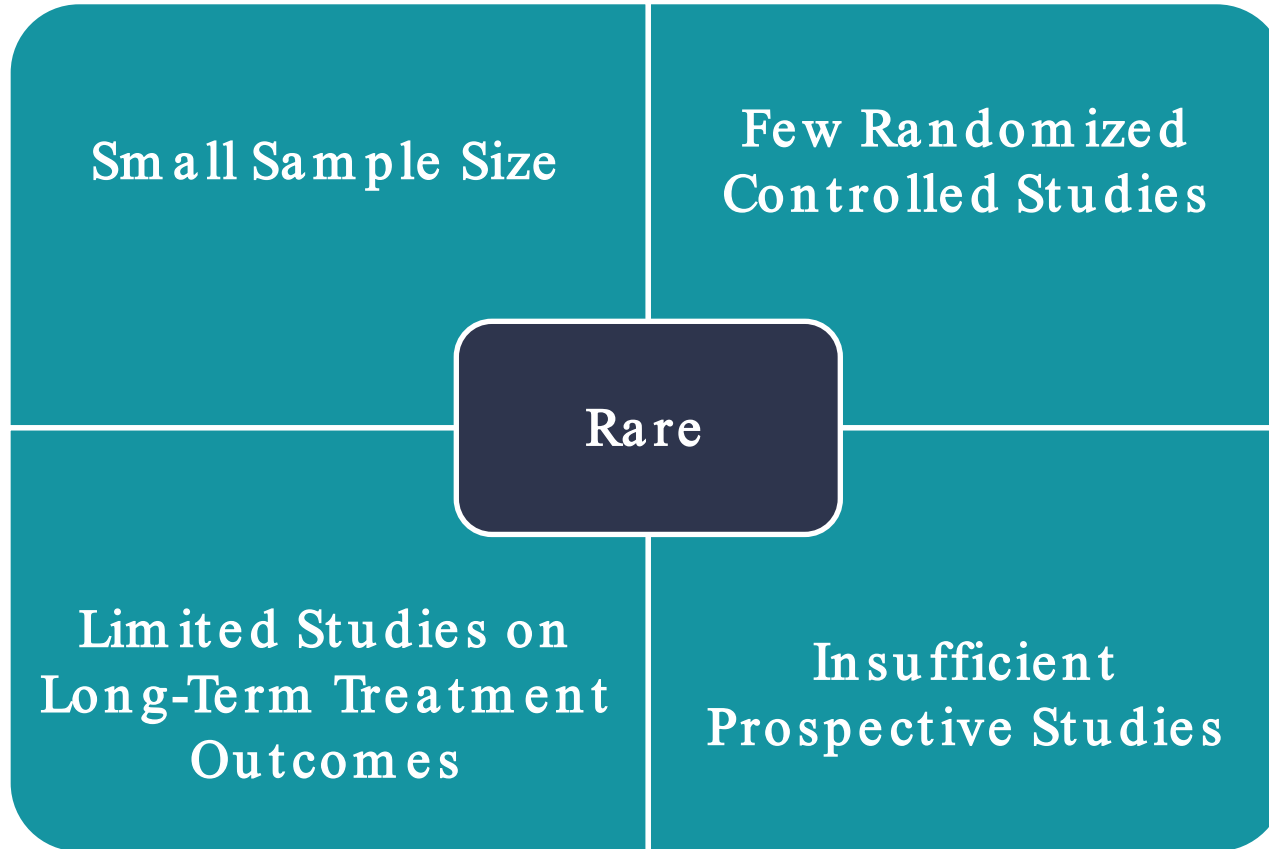
SPINA BIFIDA
ASSOCIATION

Birth of NSBPR

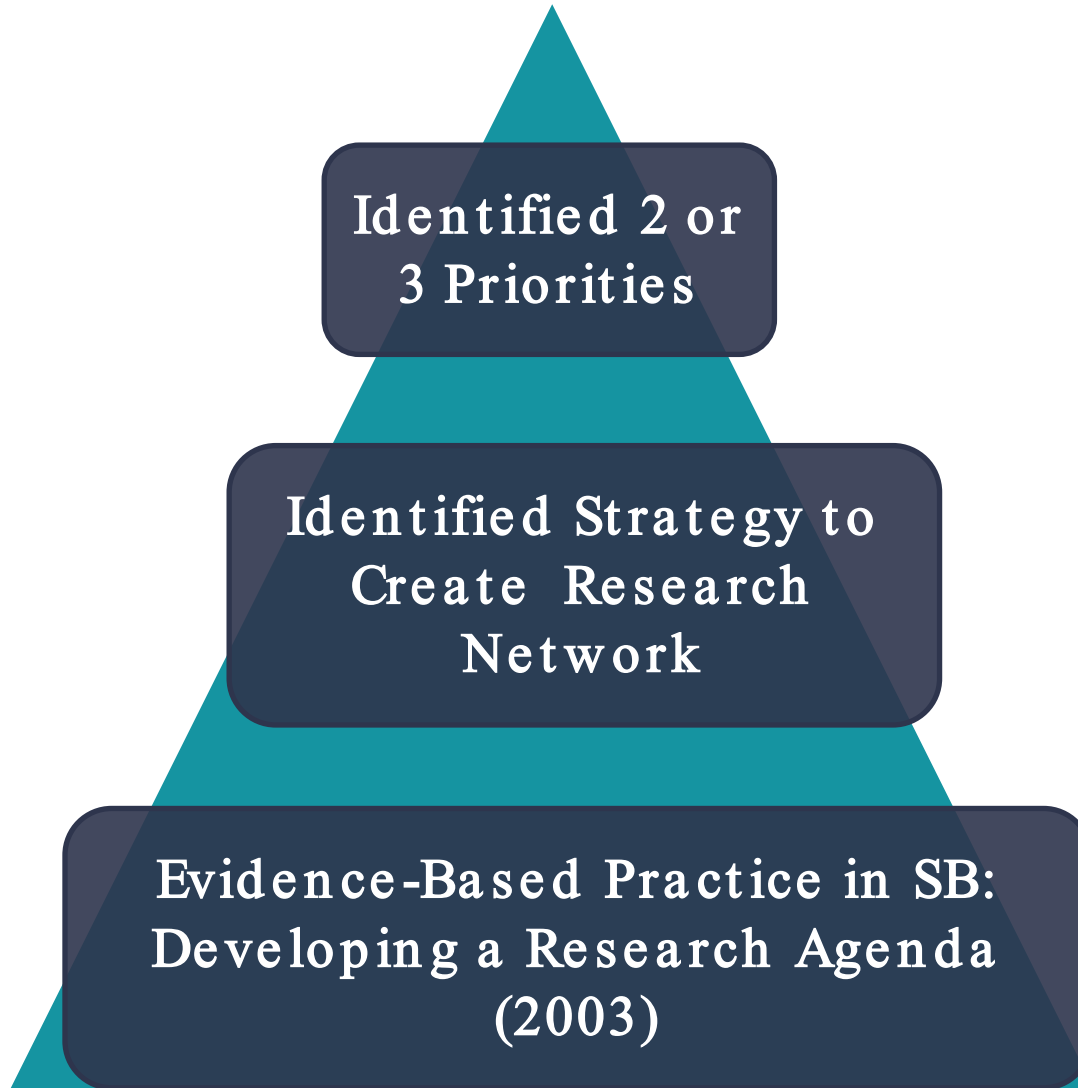
Multidisciplinary Approach



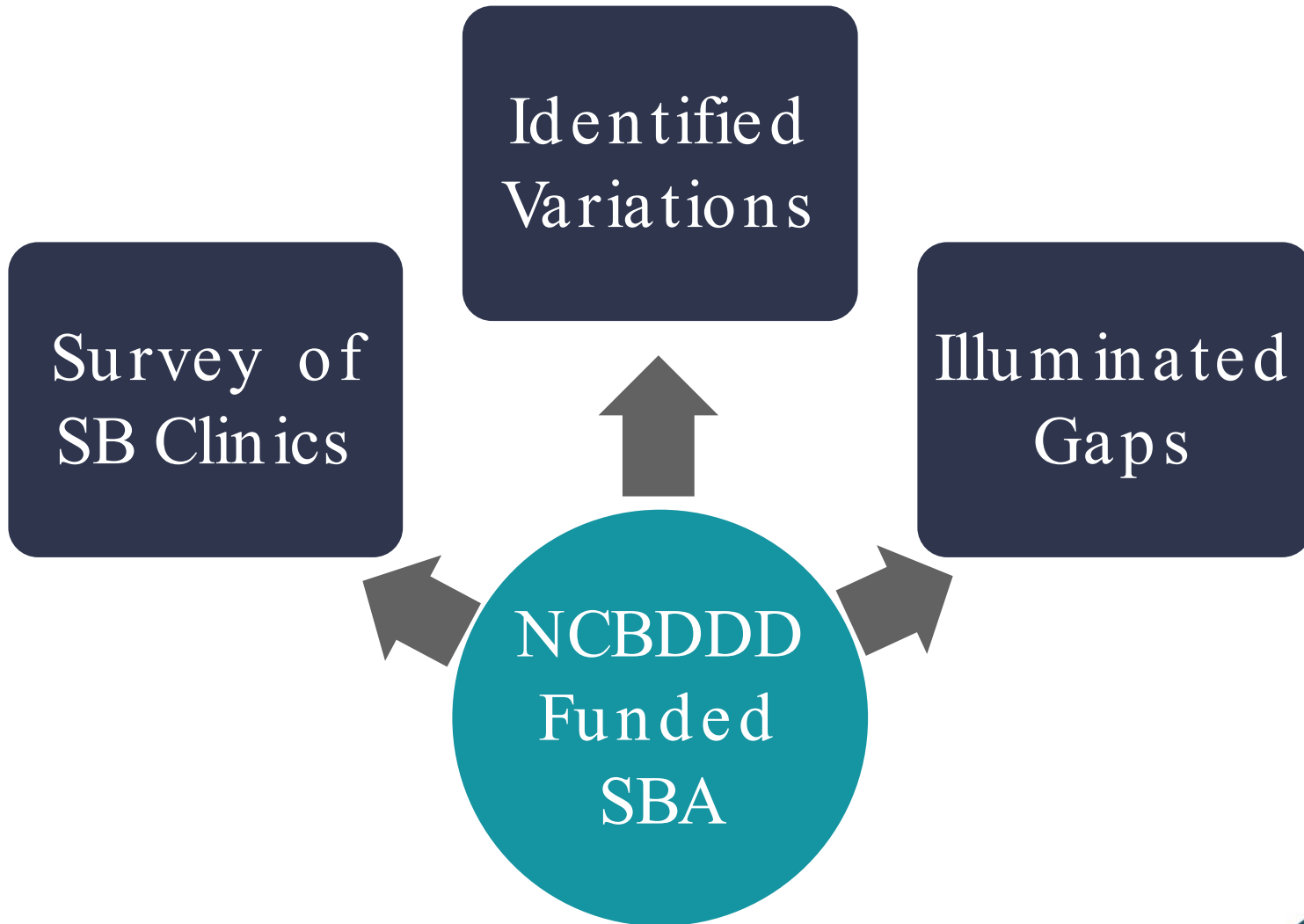
SB Research Limitations



NSBPR Beginnings

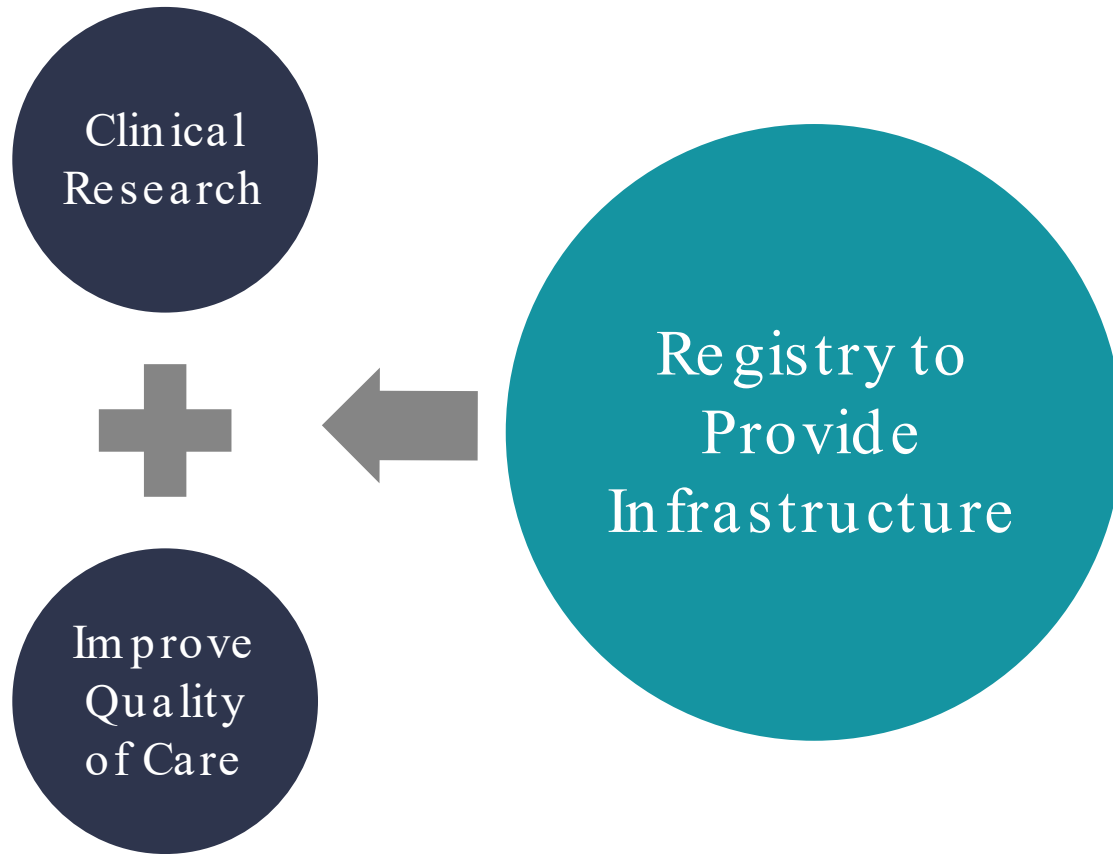


NSBPR Beginnings



NSBPR Beginnings

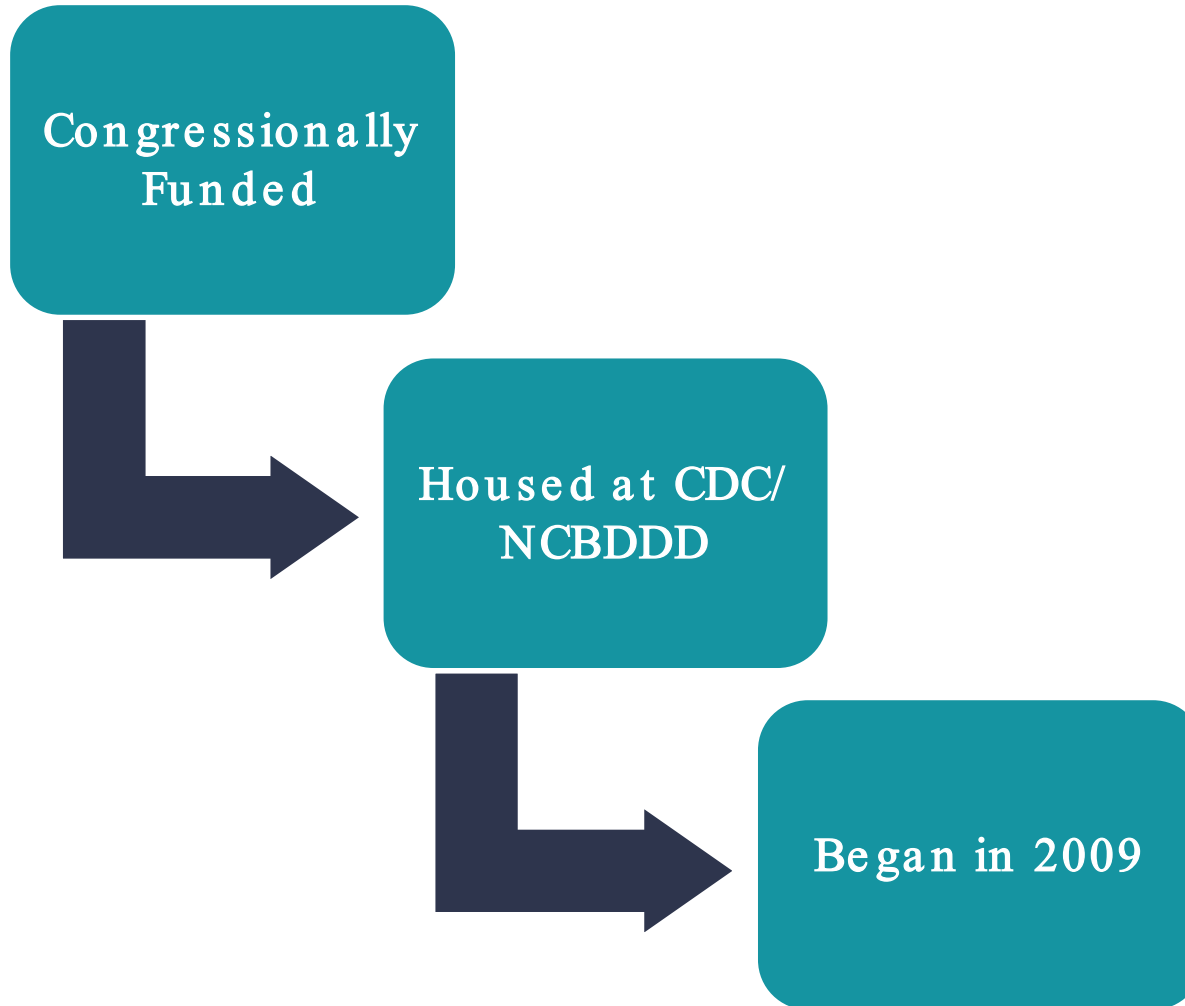
SBA Endorse the Establishment of a SB Patient Registry



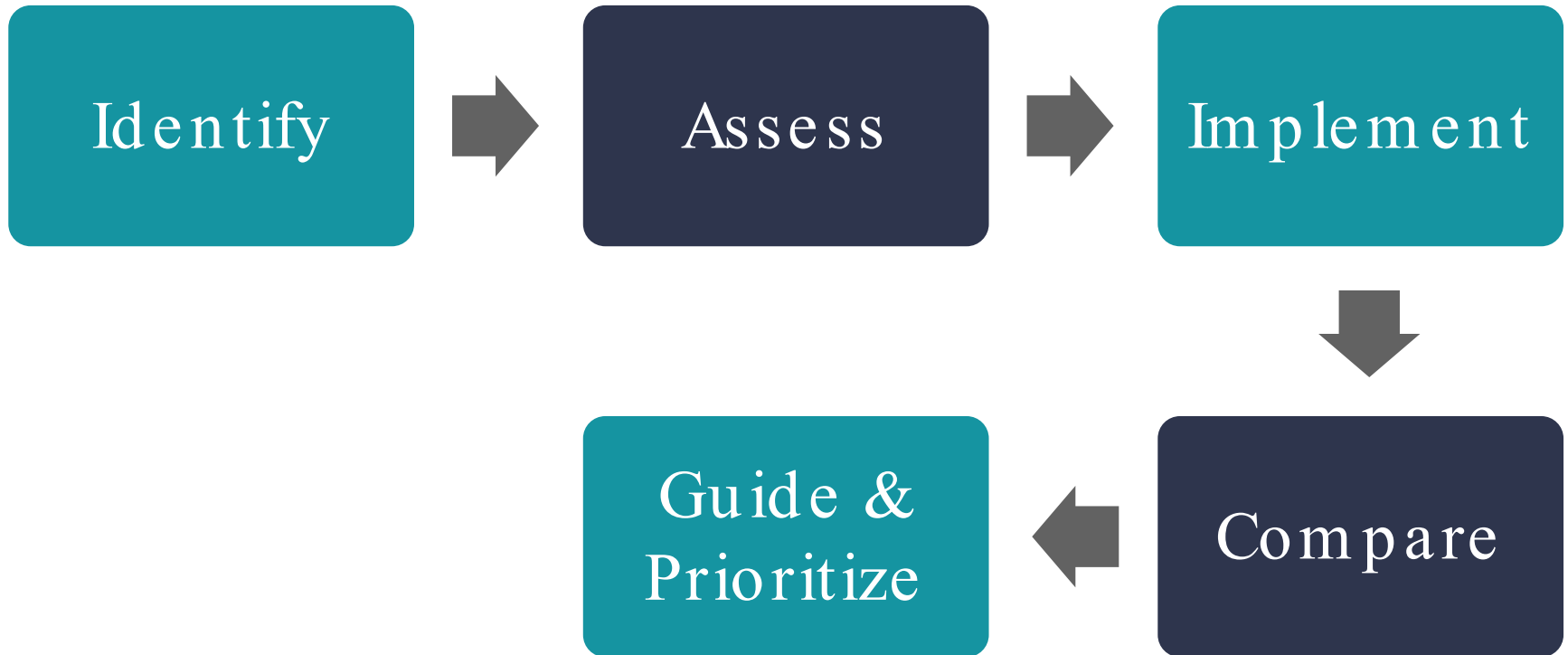
NSBPR

Early Days

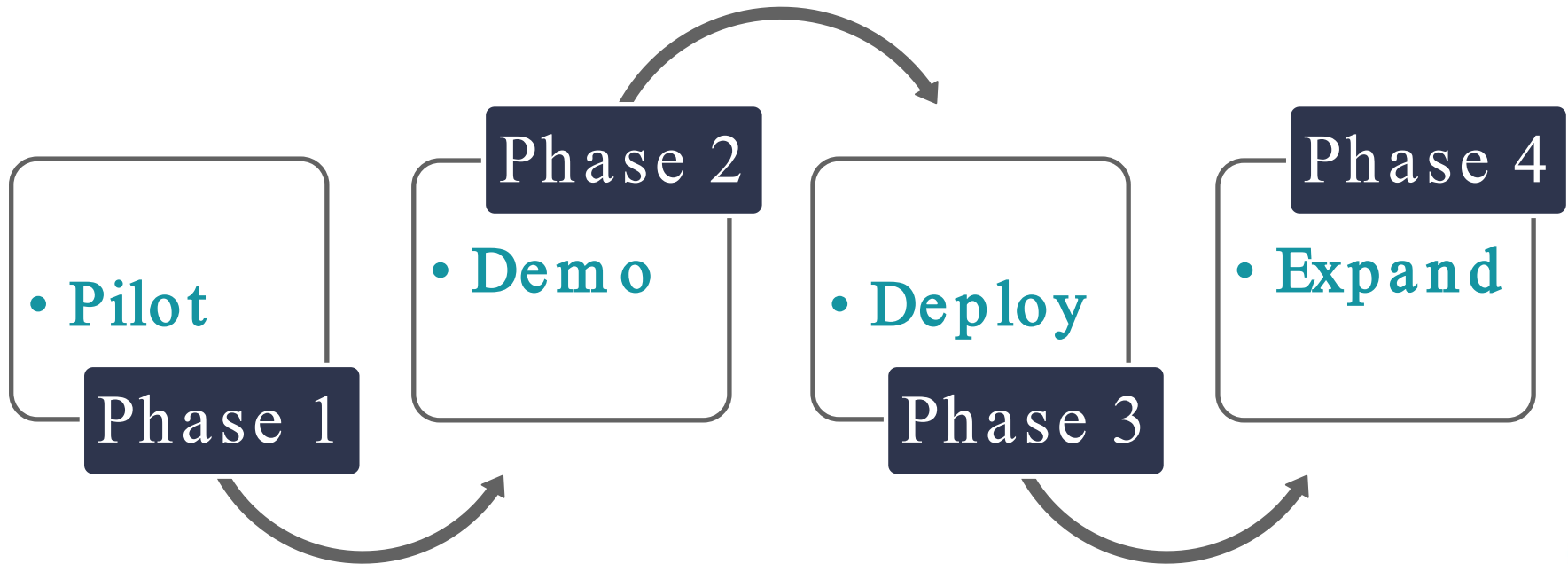
NSBPR



NSBPR Objectives



NSBPR Development



Phase 1: Pilot

Developed a Diagnosis-
Specific EMR



Identified 20 Registry
Variables



Funded Children's Hospitals
of Alabama & Cincinnati

Phase 2: Demo



Funded 9
SB Clinics



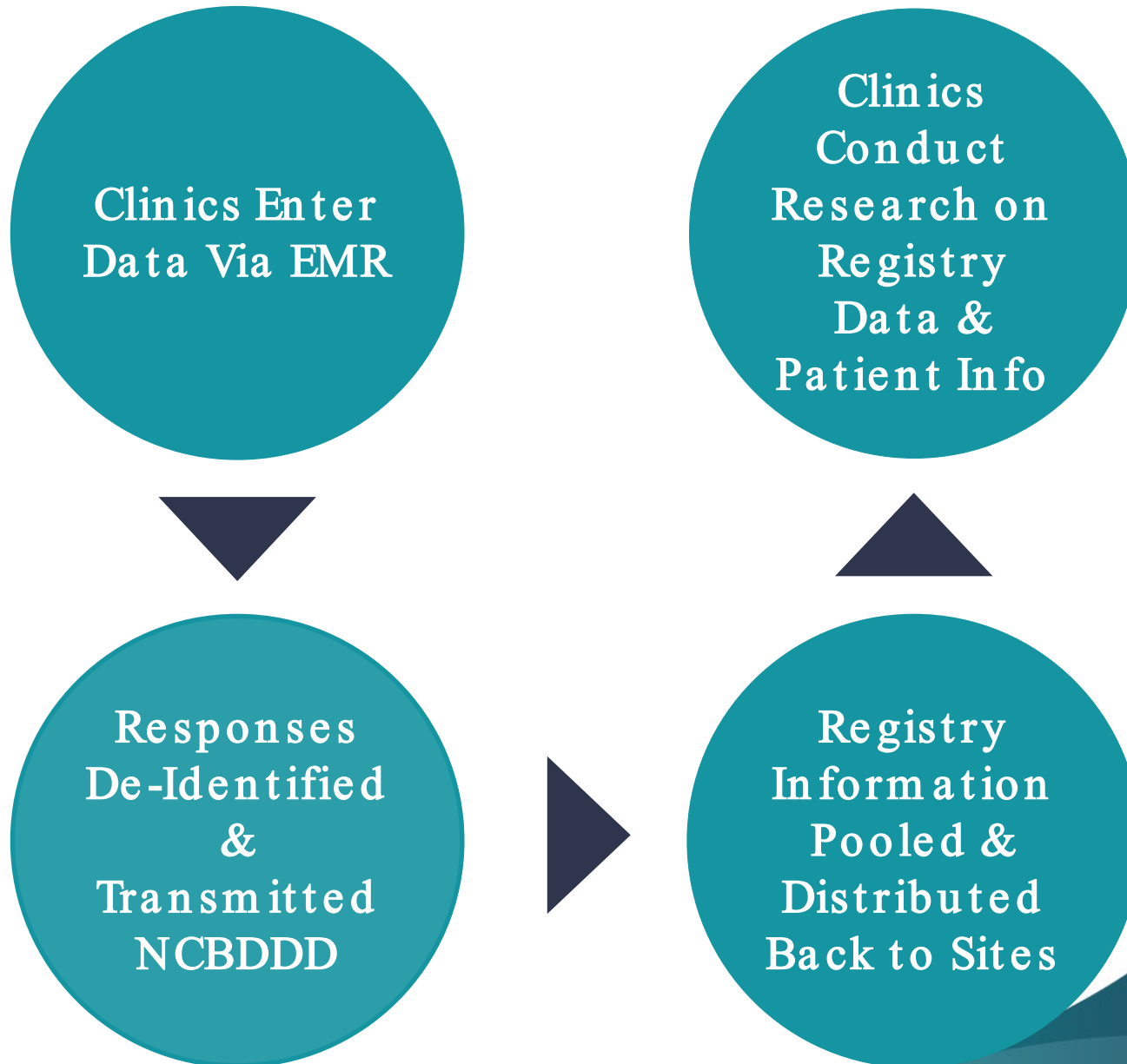
Required
125 People
with SB



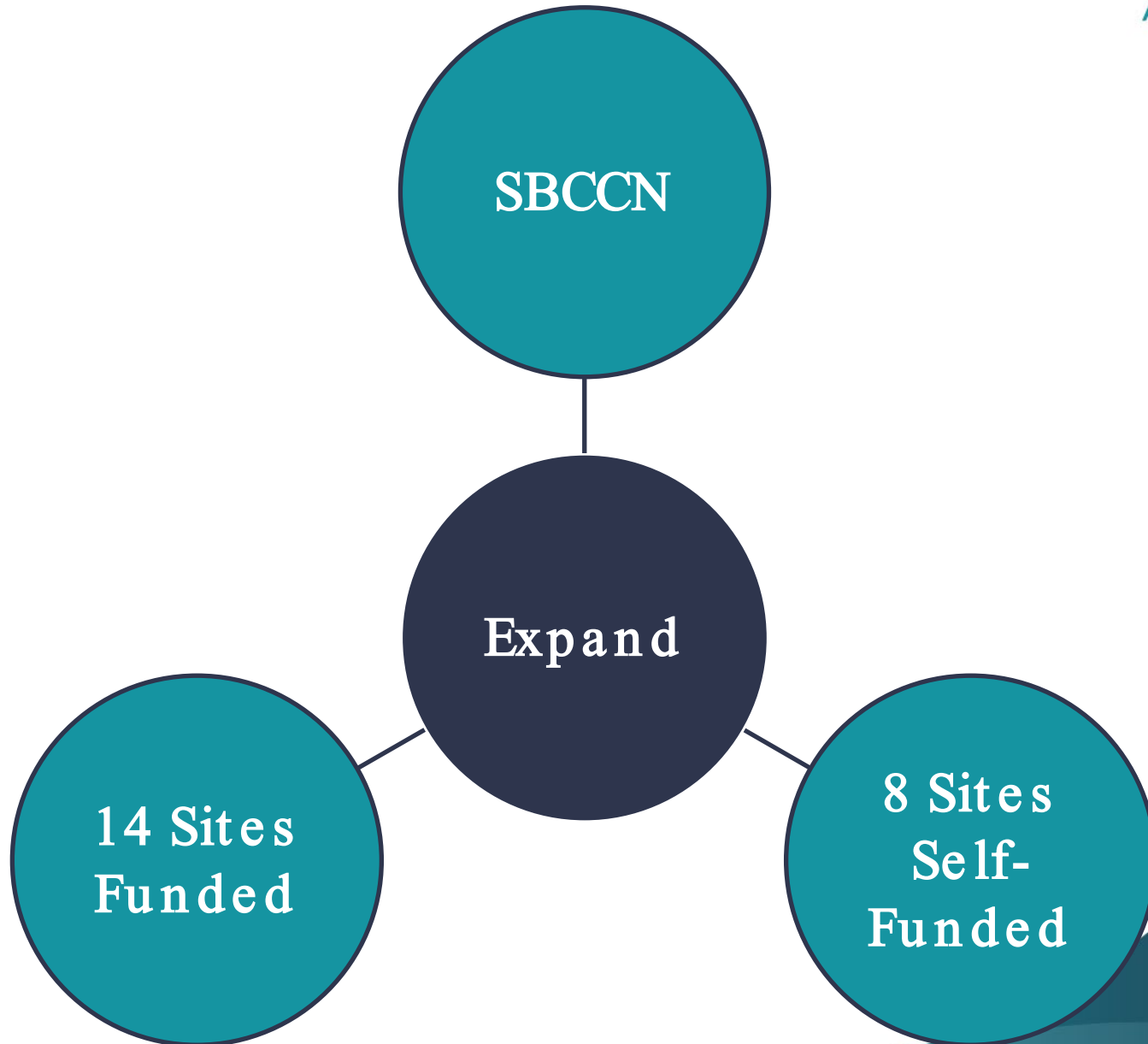
Established
Coordinating
Committee



Phase 3: Deploy



Phase 4: Expand 2014-2019



**Identify & Facilitate Expert
Clinical Care & Educate
People with SB**

**Monitor, Track, and
Evaluate the Care in SB**

**To Improve the
Health of
People with SB**

**Identify Research Priorities
in SB**

**Advocate for the Best Care
Practices in Treatment of
SB**

NSBPR Today

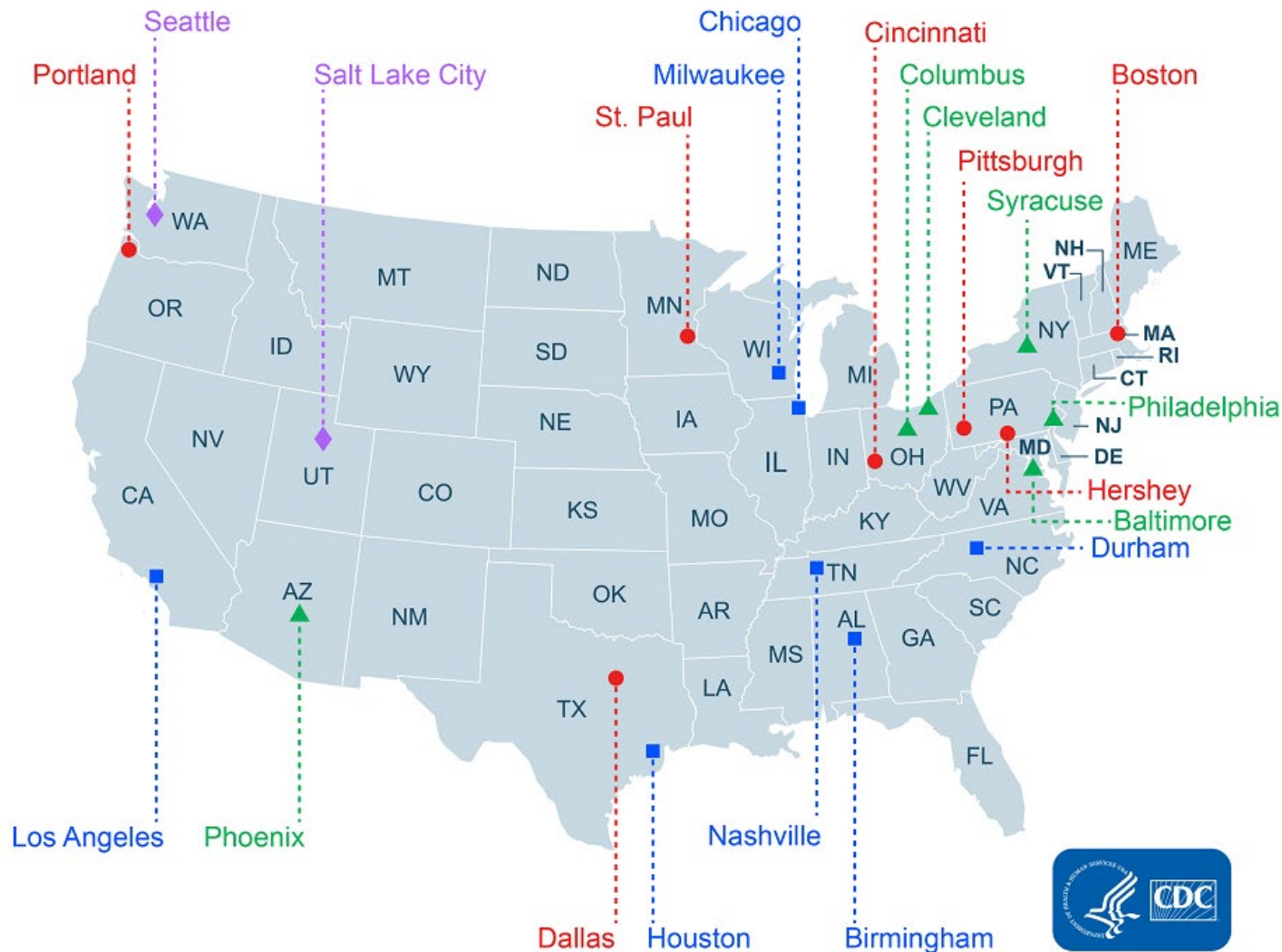
Current Phase of NSBPR



2020 NSBPR MAP



SPINA BIFIDA
ASSOCIATION



<https://www.cdc.gov/ncbddd/spinabifida/map/sb-clinic-map.html>

NSBPR Data

SUBMITTED ANNUALLY ON CHILDREN AND ADULTS

Characteristics

Child

Family

Adults

Interventions

Prenatal
Closure

Shunts

Outcomes

Urinary
Continence

Bowel
Continence

Pressure
Sores

Mobility

Tests

Serum
Creatinine

Urodynamics

Sleep Study

NSBPR Demographics

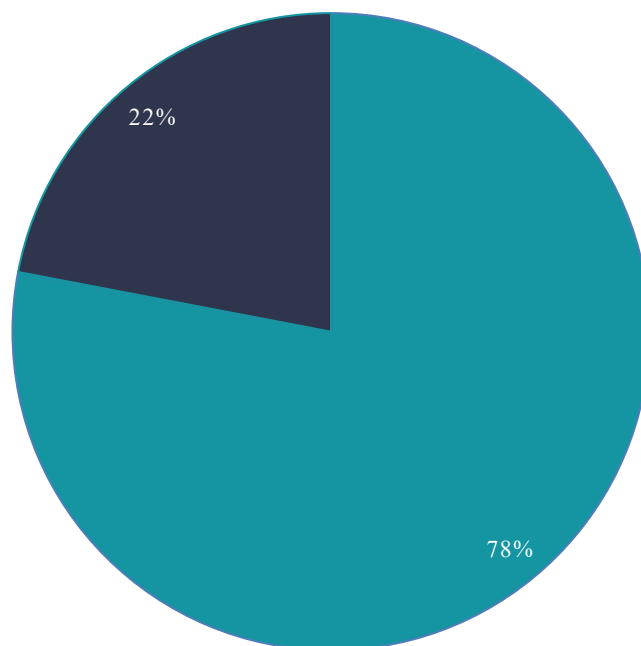
Over 10,000
Participants
in the
NSBPR

9,545
Registry
Participants
at Last Visit

Birth to 80+

NSBPR Demographics

TYPES OF SPINA BIFIDA



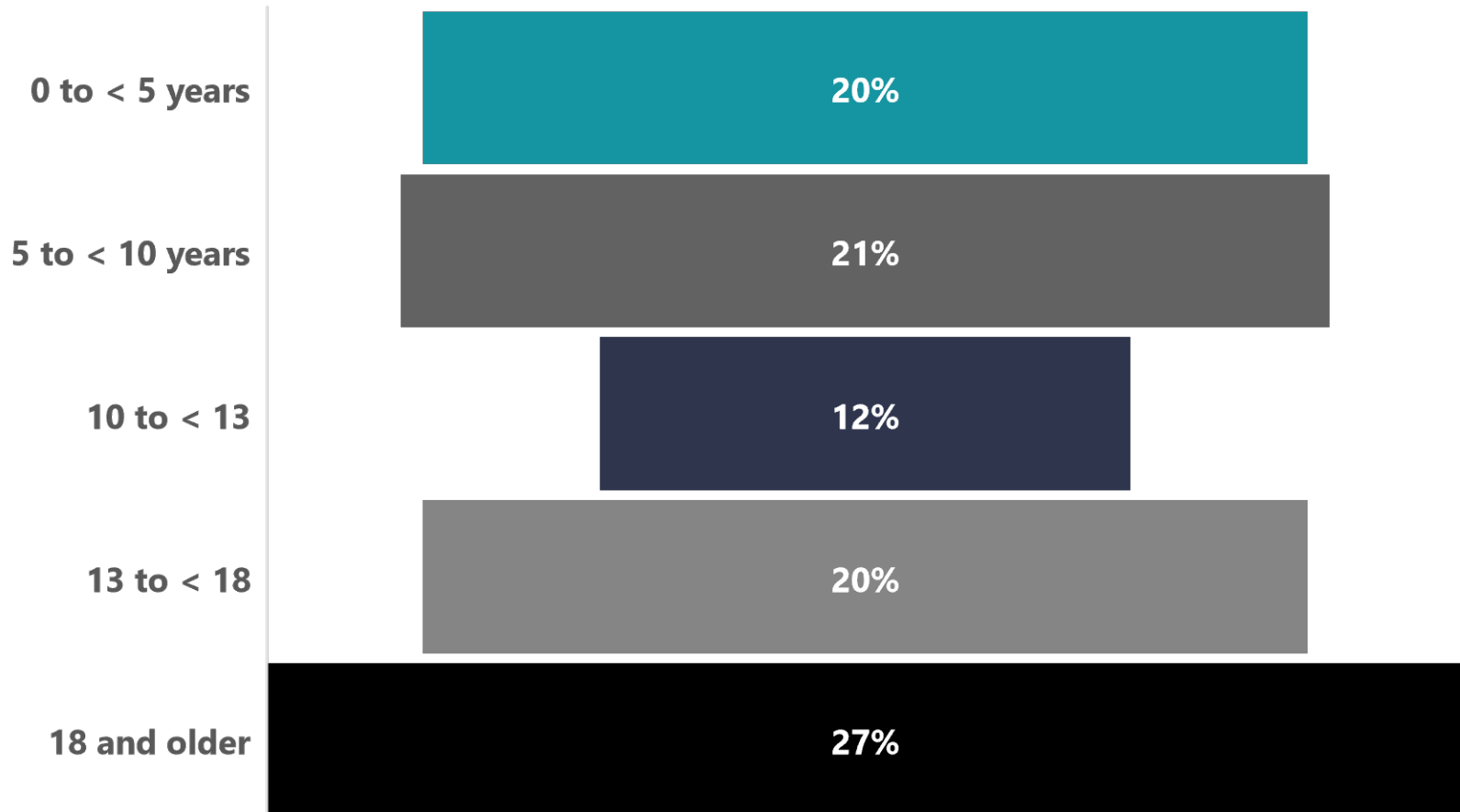
■ Myelomeningocele ■ Non-myelomeningocele

Non-myelomeningocele includes lipomyelomeningocele, fatty filum terminale, meningocele, split cord malformation, terminal myelocystocele)

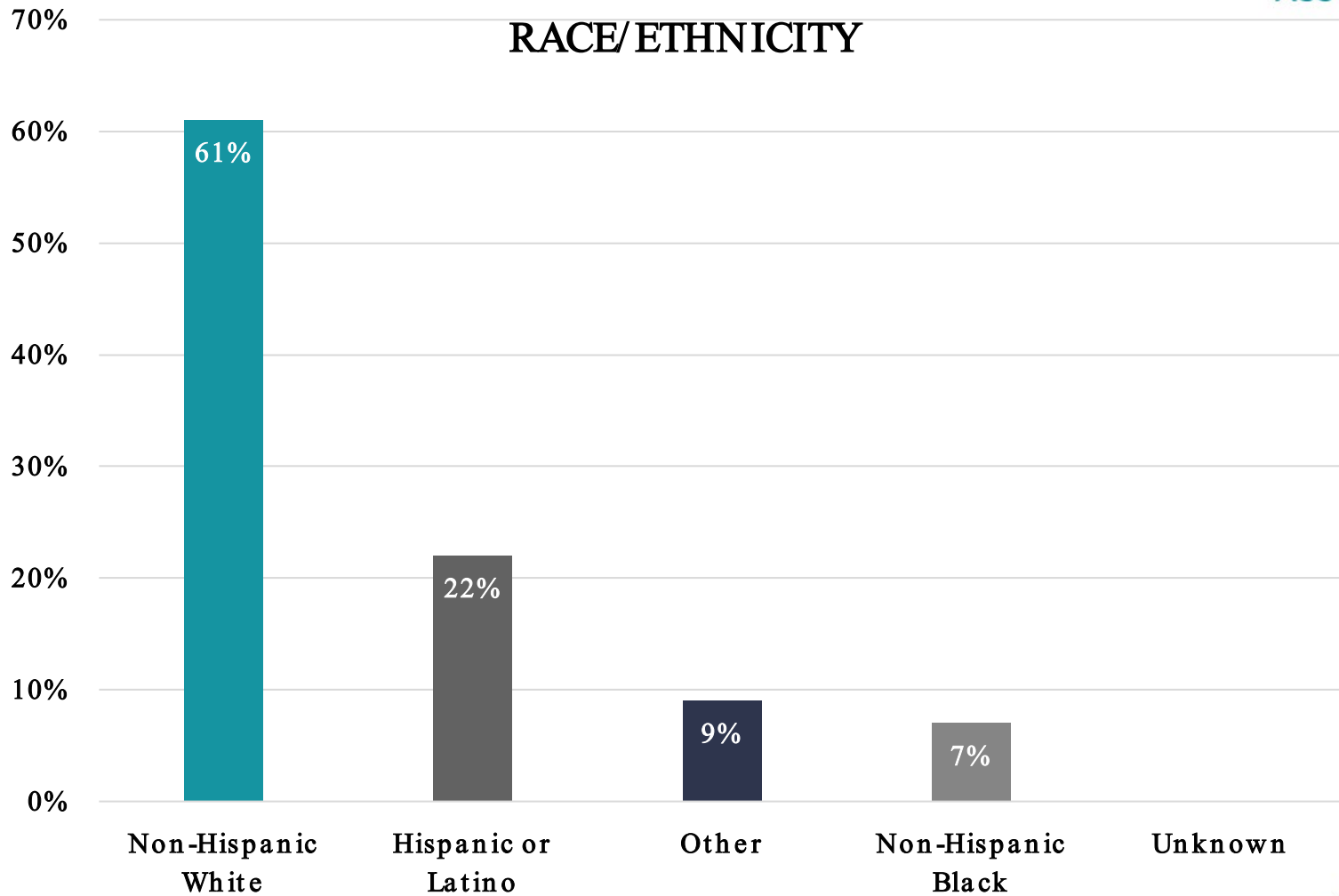
NSBPR Demographics



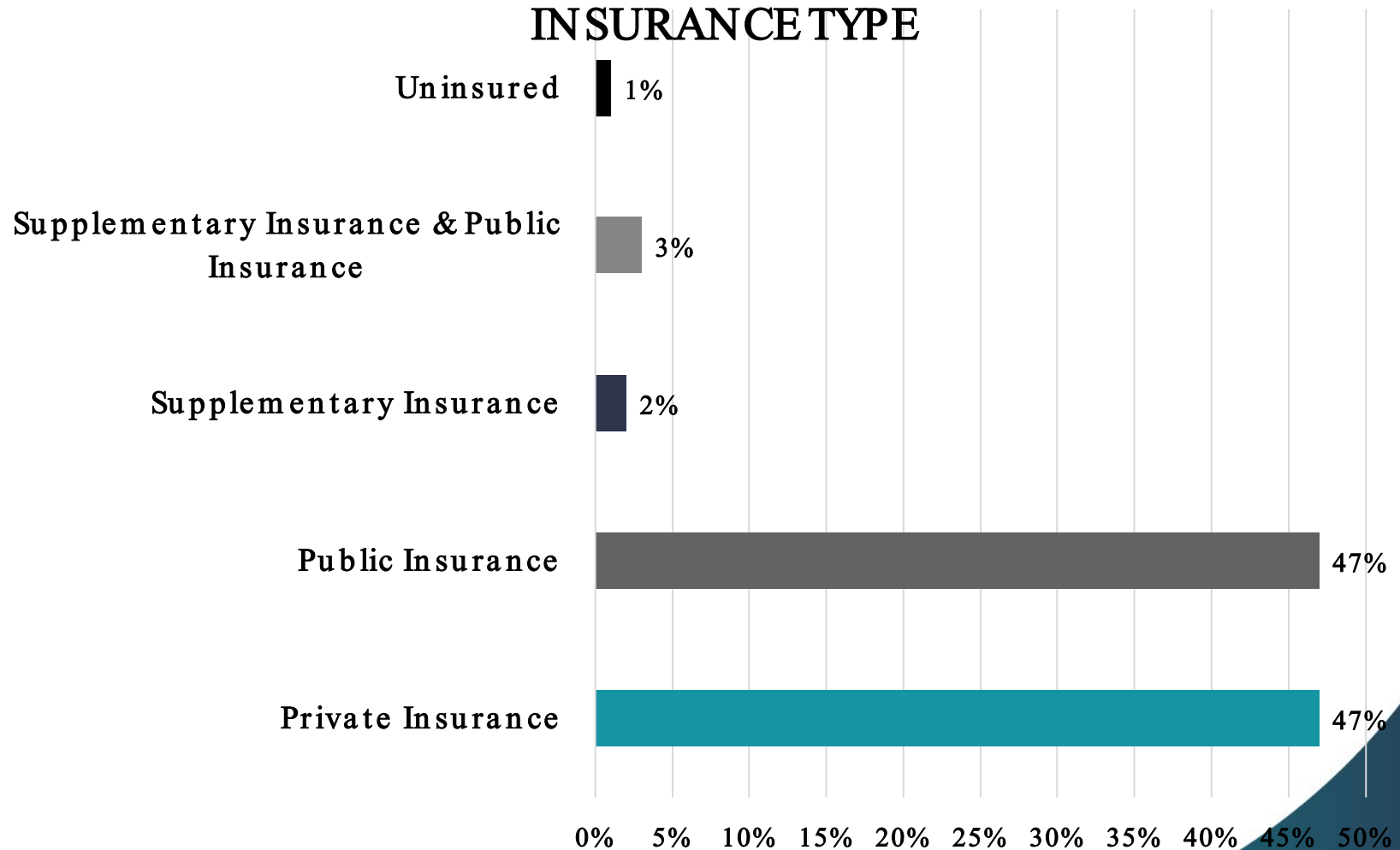
AGE BREAKDOWN



NSBPR Demographics

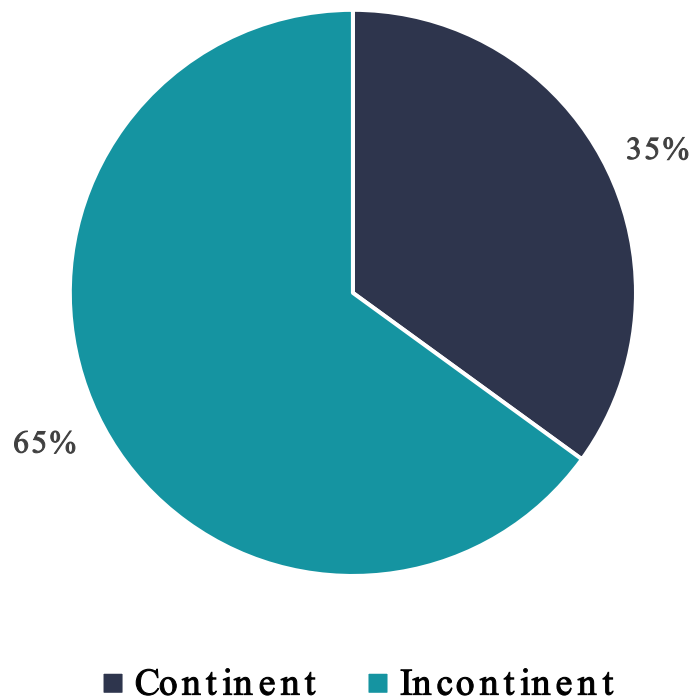


NSBPR Demographics



NSBPR Demographics

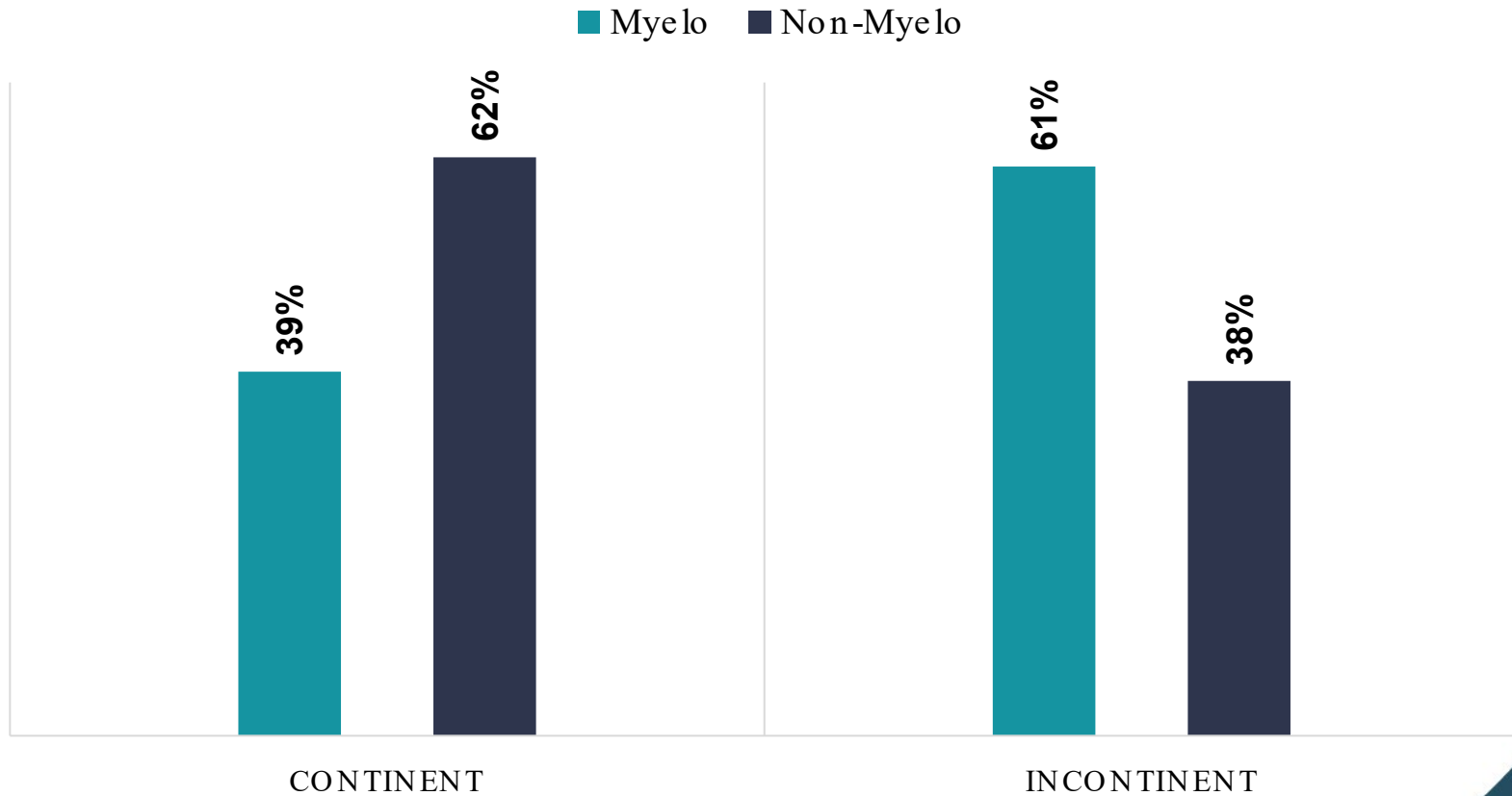
BLADDER CONTINENCE OVERALL



Continence is defined as dry during the day in the last month.

NSBPR Demographics

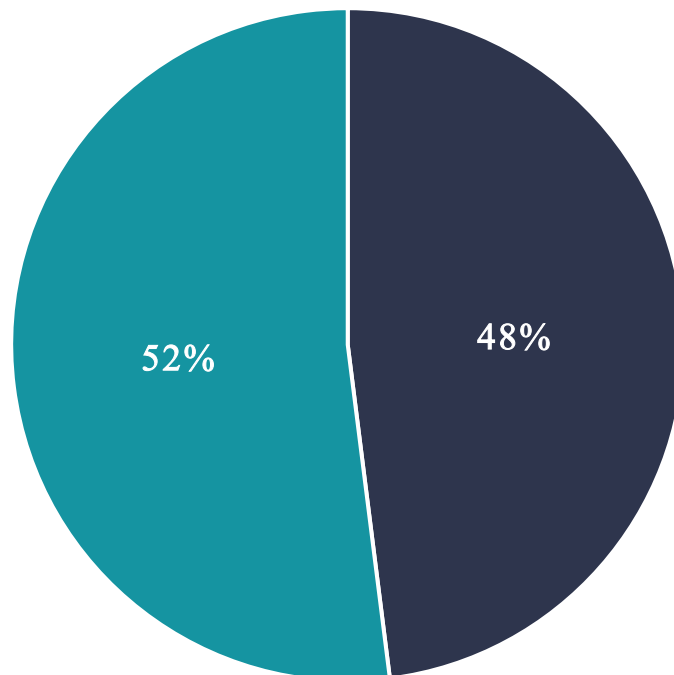
BLADDER CONTINENCE BY TYPE OF SB



Among Participants 5 YOA and Older

NSBPR Demographics

BOWEL CONTINENCE



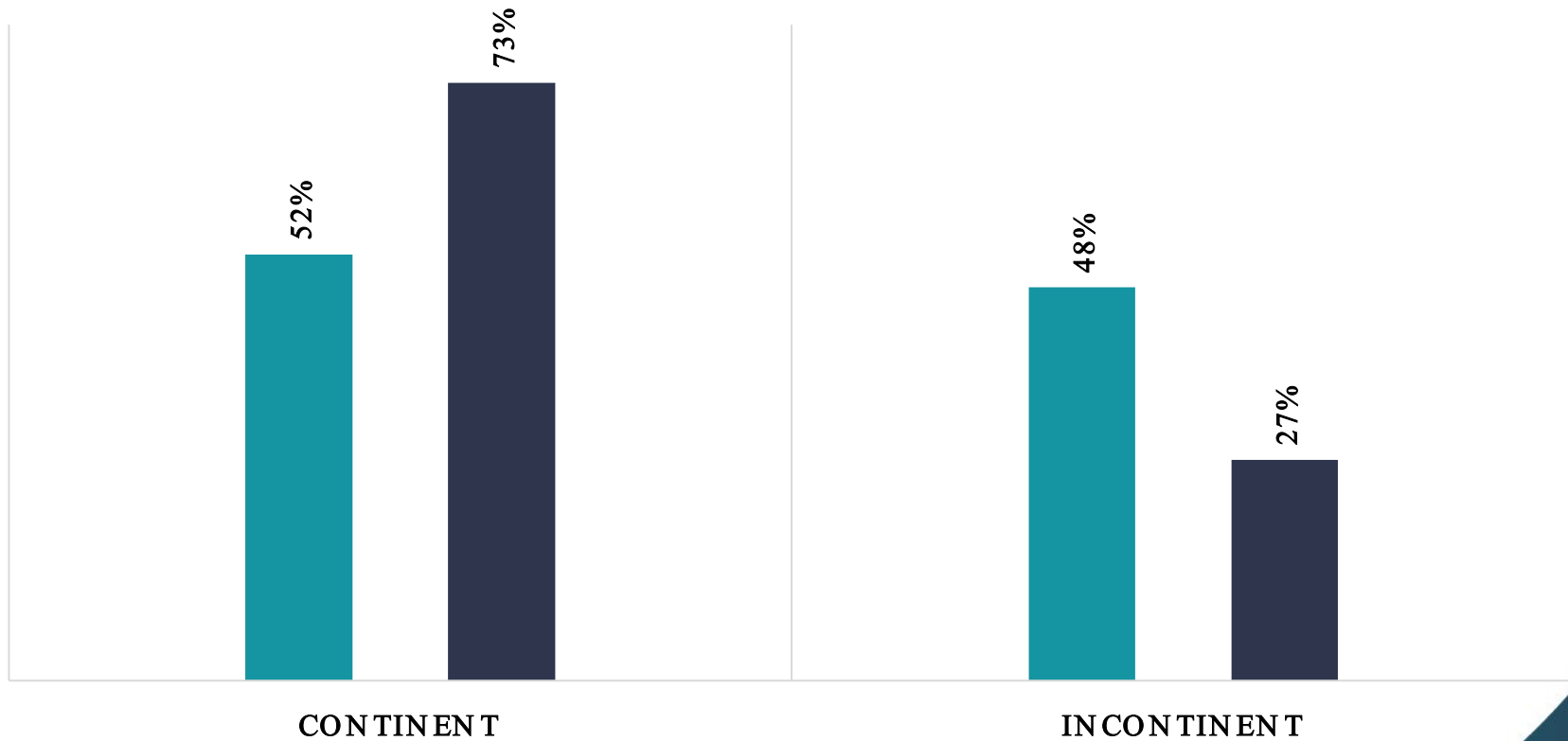
■ Continent ■ Incontinent

NSBPR Demographics



BOWEL CONTINENCE BY TYPE OF SB

■ Myelo ■ Non-myelo



Among Participants 5 YOA and Older

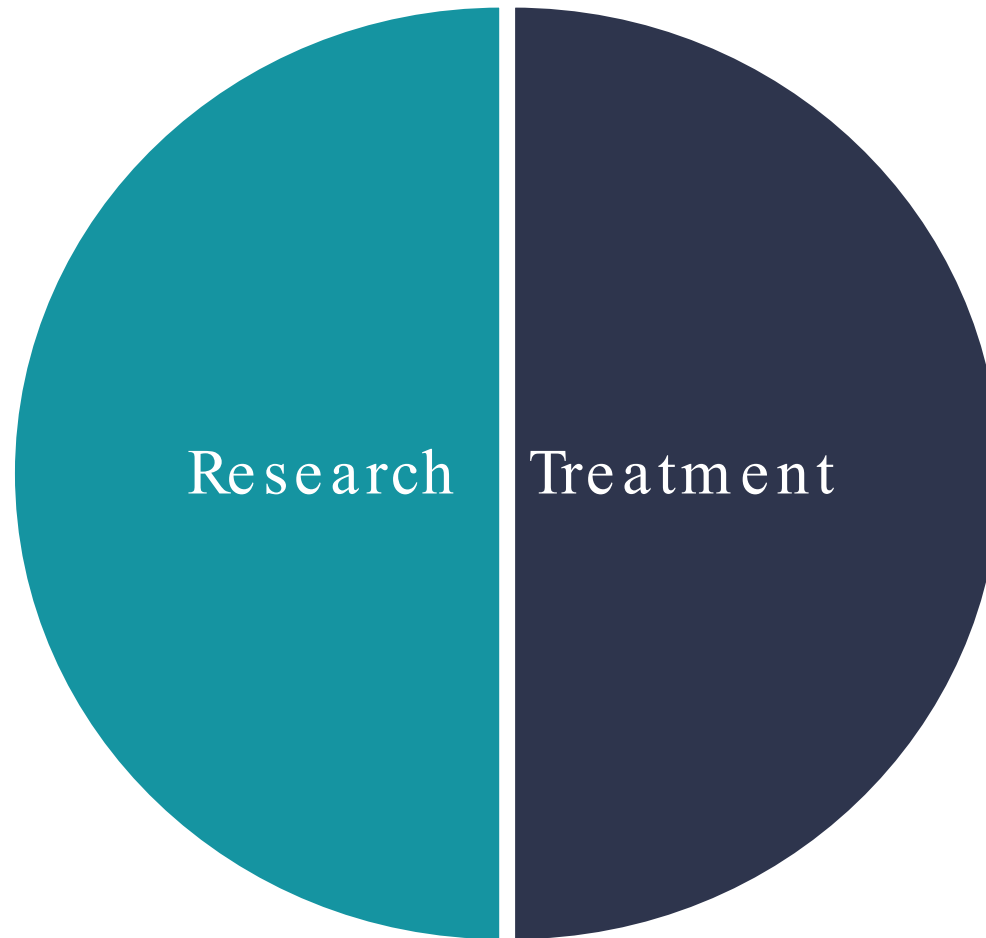
NSBPR Findings



Statistics and Findings are Located at:

<https://www.cdc.gov/ncbddd/spina-bifida/nsbprregistryfindings.html>

NSBPR Data Uses



NSBPR Research

NSBPR Committee for Science & Publication



NSBPR Research by the #s

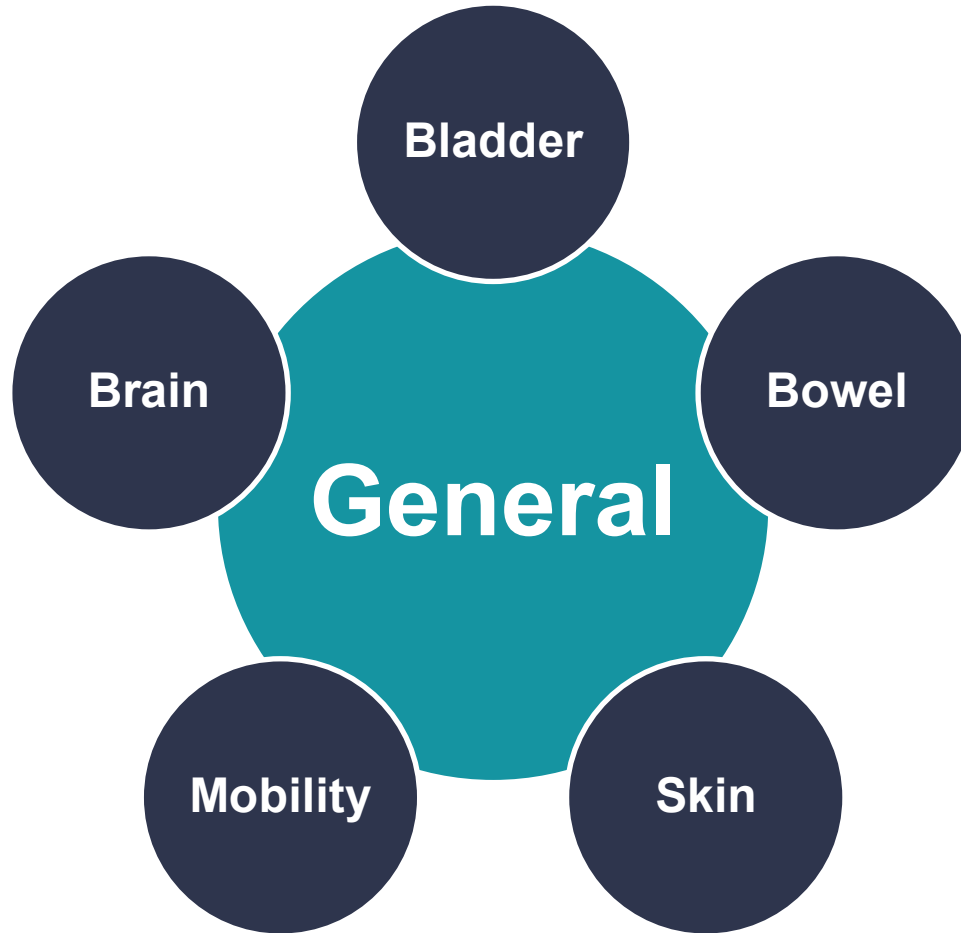


7
Years

24
Projects

6 Topical
Areas

NSBPR Research: Topics



NSBPR Research: Bladder

Bladder & Bowel
Continence Among
Clinics

Bladder Continence
in Adults

Longitudinal Study:
Bladder Continence

Bladder
Reconstruction
Rates

Ethnic Difference in
Continence Rates

Baseline Urinary
Imaging in Infants
(UMPIRE)

Kidney Function
Surveillance

NSBPR Research: Bowel



Bladder & Bowel Continence Among Clinics



Surgical Management Variations in
Neurogenic Bowel



Bowel Continence in Adults with SB



Ethnic Difference in Continence Rates

Pressure Ulcers

NSBPR Research: Mobility

- Mobility
- Neurologic Impairments & Ambulation in Adults with SB
- Ambulation Longitudinal Study
- Mobility Transfer & Wheelchair Transfer Ability



Chiari II
Malformation



Hydrocephalus

NSBPR Research: General



Feasibility

Socio-demographics
& Outcomes

Participant Profiles in
10 SB Clinics

Status Report

Comparison of EMR
& Patient Reported
Data

10 Year Review of
NSBPR

Surgeries & Health
Outcomes

Philosophy of Care
Delivery

NSBPR Research



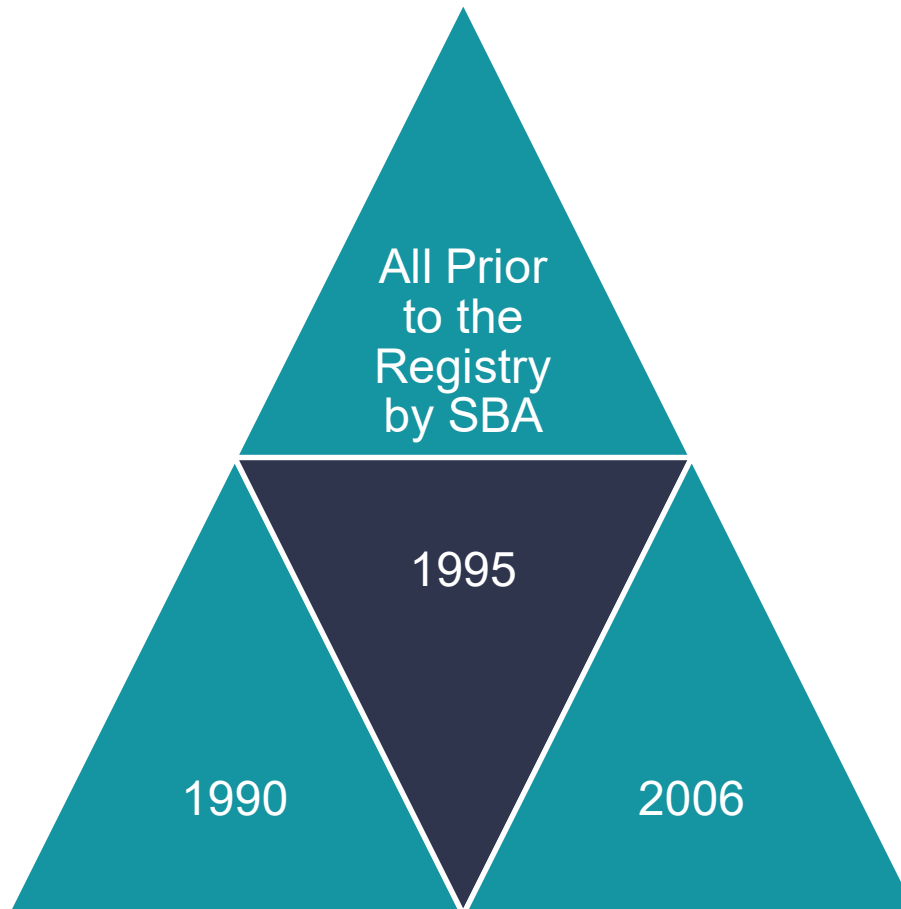
Publications, Authors, and
Summaries are Located at:

<https://www.cdc.gov/ncbddd/spina-bifida/nsbpr-registry-publications.html>

NSBPR

Treatment

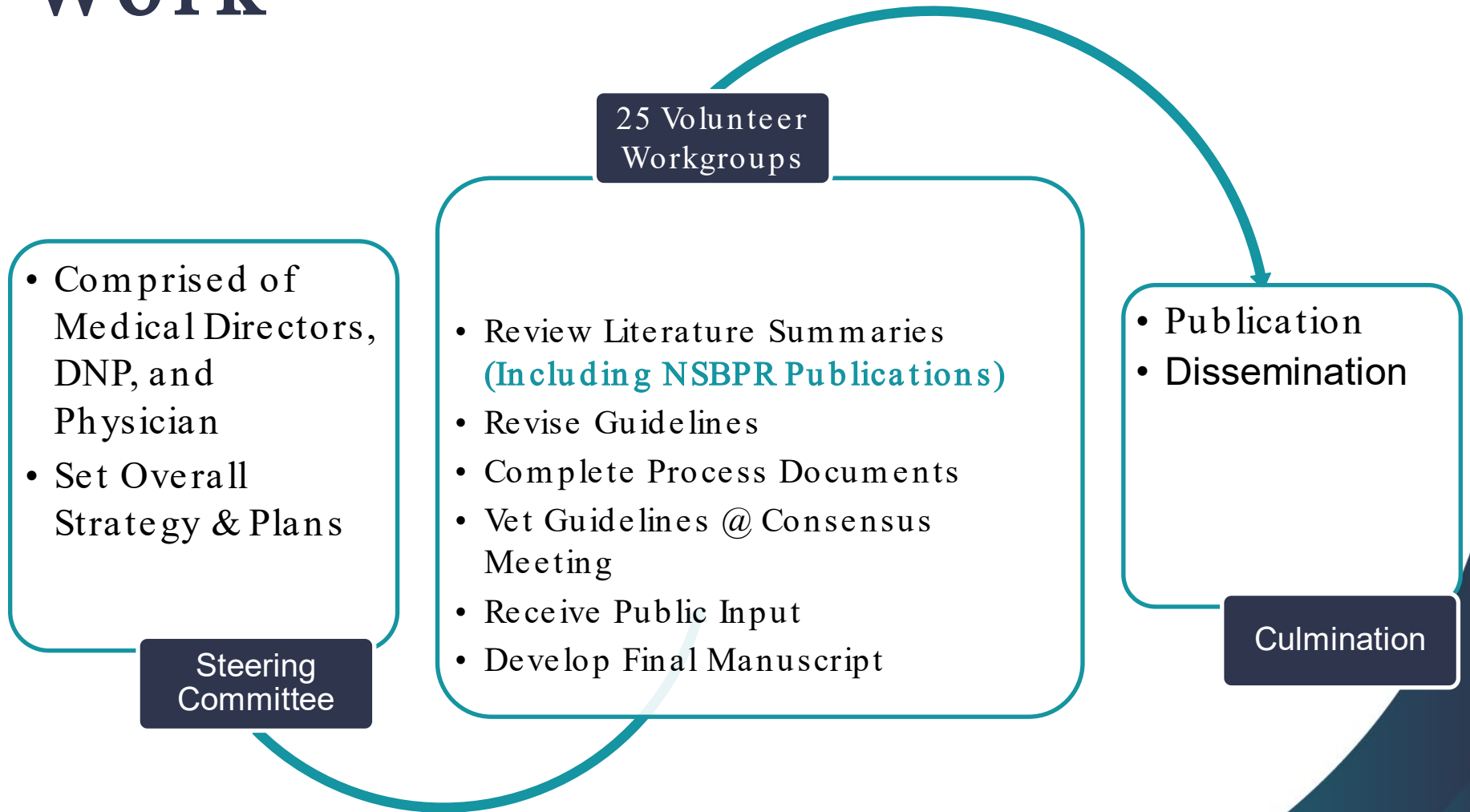
Guidelines for Spina Bifida Health Care Services Throughout the Lifespan



Guidelines Recent Revision Work



SPINA BIFIDA
ASSOCIATION



Guidelines



SPINA BIFIDA
ASSOCIATION

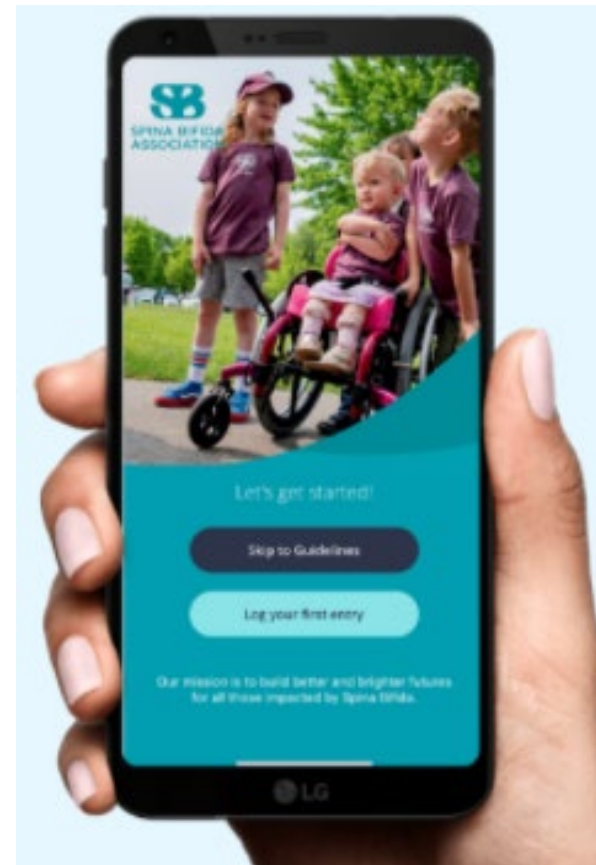
GUIDELINES FOR THE CARE OF PEOPLE WITH **SPINA BIFIDA**



SPINA BIFIDA
ASSOCIATION

<https://www.spinabifidaassociation.org/resource/guidelinespdf/>

<https://www.spinabifidaassociation.org/mobile-application/>



Urologic & Renal Background

Bladder Function

- Normal at Birth
- Dysfunctional Early

Renal Function

- Deterioration Begins Early
- Not Monitored Early

In the Field

- Diagnostic Management Similar
- No Standardized Frequency of Testing

Additional CDC/NCBDDD Research Findings

No Significant Mortality Increase for
People with SB in ESRD

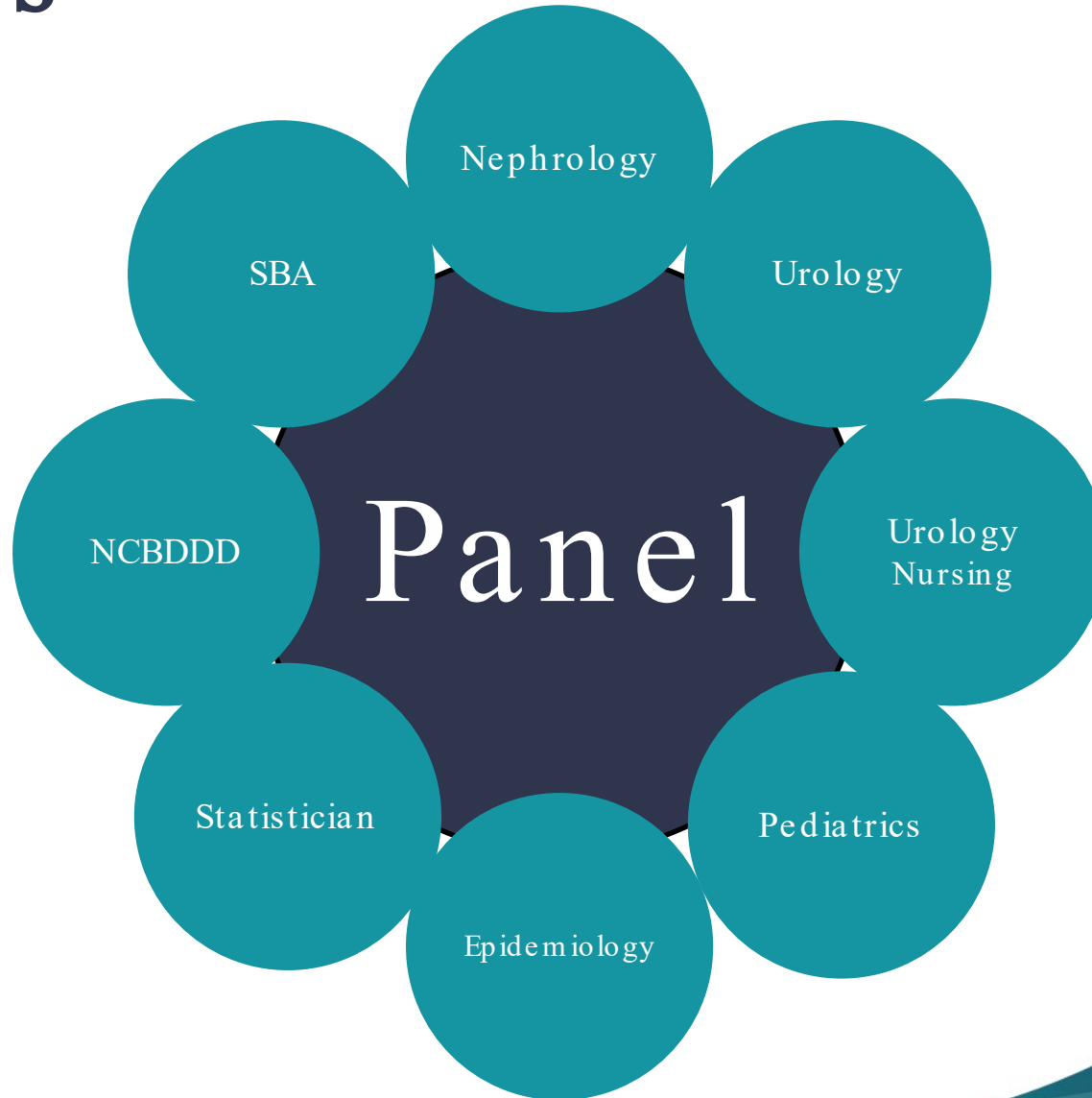


ESRD Younger in SB

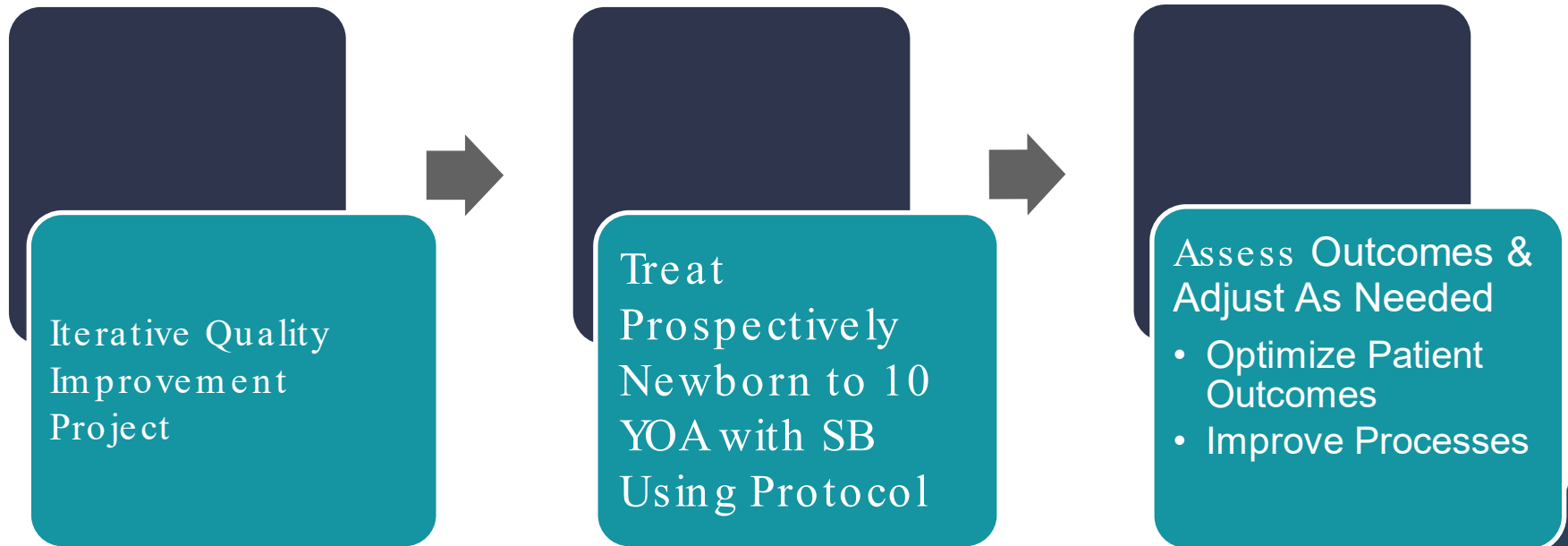


Need to Monitor Renal Function
Aggressively in Young People with
SB

Panel to Address Renal Issues



NSBPR Urologic Protocol (UMPIRE)



SBCCN Outcomes

Determine Attributes of NSBPR Clinics Associated with Best Patient Outcomes.

Identify NSBPR Clinics with Good Outcomes



Develop & Implement Plan to Determine Causes of Difference



Use findings to Improve Outcomes in ALL SB Clinics

SBCCN Clinic Care Partners



<https://www.spinabifidaassociation.org/clinics/clinic-care-partner/>

SBCCN Transition & Adult Care

Transition

Support NSBPR Clinics to Prepare People with SB to Transfer to Adult HCPs

Adults

Conduct Follow-up Survey(s) of Adults with SB

Develop Models of Care for Adults with SB

Conduct HCP Training on Caring for Adults with SB



SPINA BIFIDA
ASSOCIATION

What Can You
Do?

Get Involved: SBA Education & Support



Education Days

<https://www.spinabifidaassociation.org/education/education-days/>



WNRs

<https://www.spinabifidaassociation.org/walk-n-roll-for-spina-bifida/>



SB-YOU

<https://www.spinabifidaassociation.org/education/sb-you/>

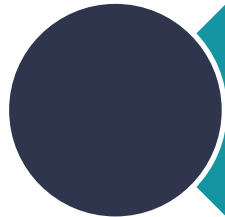
Get Involved: SBA Clinical Care



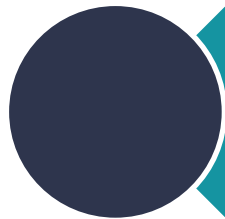
Attend Clinical Care Meeting
<https://www.spinabifidaassociation.org/clinical-care-meeting/>



Sign Up for List Serv
<https://www.spinabifidaassociation.org/for-health-care-professionals/sb-professionals-listserv/>



Volunteer for PAC & Committees
jhibadeau@sbaa.org



Become a Clinic Care Partner
<https://www.spinabifidaassociation.org/clinics/clinic-care-partner/>

Get Involved: Research

SBA PAC & Sub-
Committees

Contact

Dr. Tonya Williams

tis5@cdc.gov

SB
Research

SBA RAC

Contact SBA if YOU
Do Research Related
to SB

Get Involved: Advocacy



SPINA BIFIDA
ASSOCIATION



TEAL
ON THE
HILL

If You Need More Info



Sara Struwe

sstruwe@sbaa.org

Judy Thibadeau

jthibadeau@sbaa.org

Dr. Tonya Williams

tis5@cdc.gov