



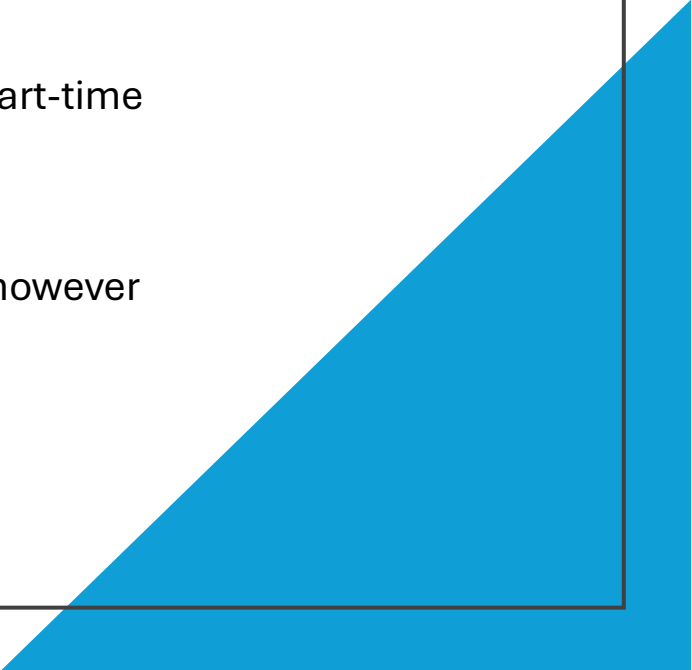
MMCUP

Kvalitetsregistret för MMC
och annan neuralrörsdefekt

Swedish national registry
för Spina Bifida and other
neural tube deficiencies

- Annika Lundkvist Josenby, head of the registry
- RPT, PhD

Introduction -MMCUP

- **National follow-up program** for Spina Bifida- initiated in 2004
 - **National quality register** since 2012
 - Financed by the Association Swedish Countys and Regions
 - Costs for register platform -3C, continuous development of the register & part-time employment of coordinating professionals
 - Spina Bifida- **myelomeningocele, lipo-meningocele and myeloschisis**
 - Participants with **other types of neural tube defects may also be registered**, however no specific follow-up program is available
 - The registry serves as **a common database**- accessible by professionals in re-/habilitation and specialized health care (hospital)
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Goals— MMCUP



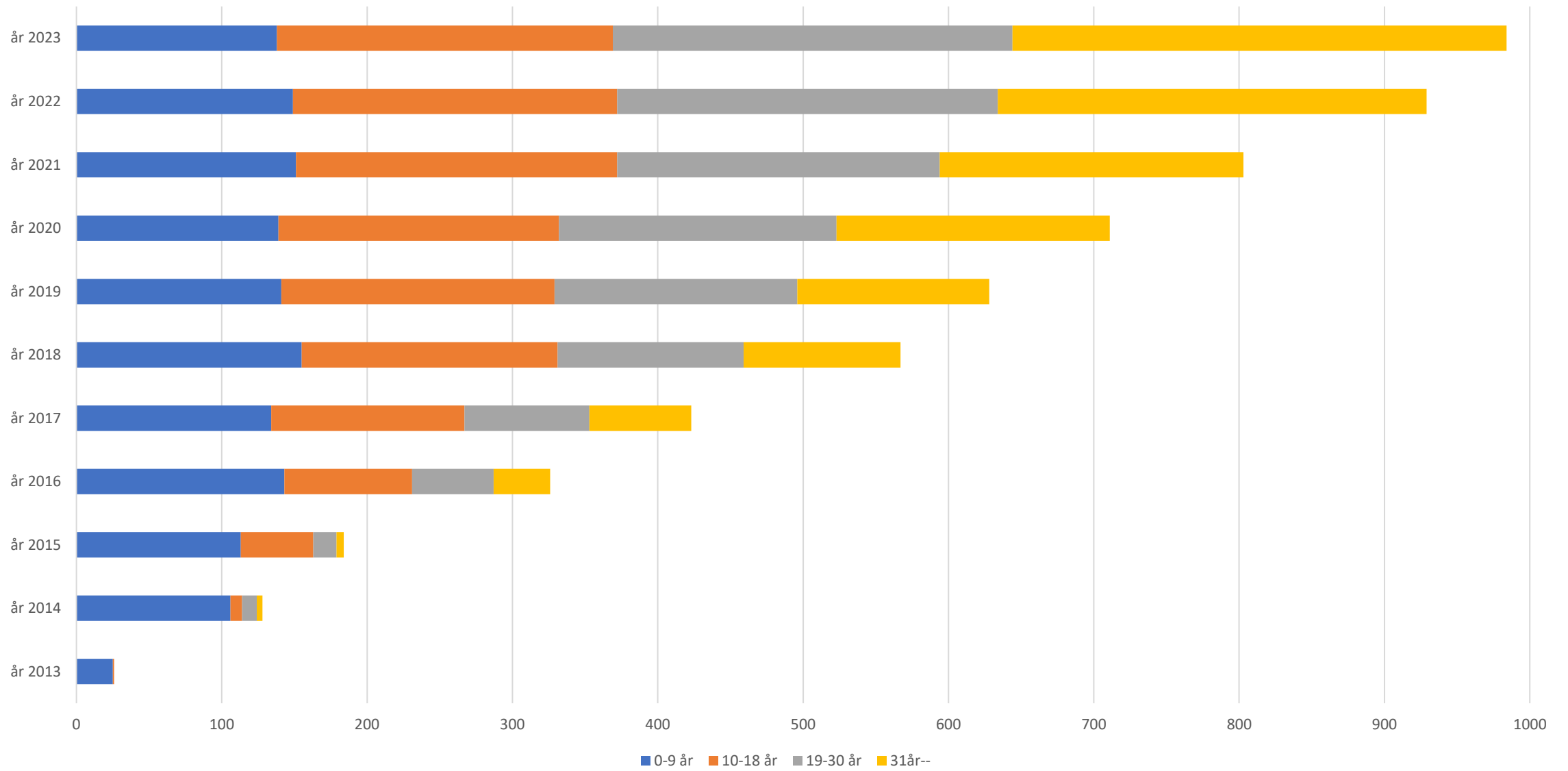
to prevent secondary loss of function, morbidity, pain and reduced quality of life as a complication of spina bifida and other neural tube defects through preventive follow-up, early detection and early intervention



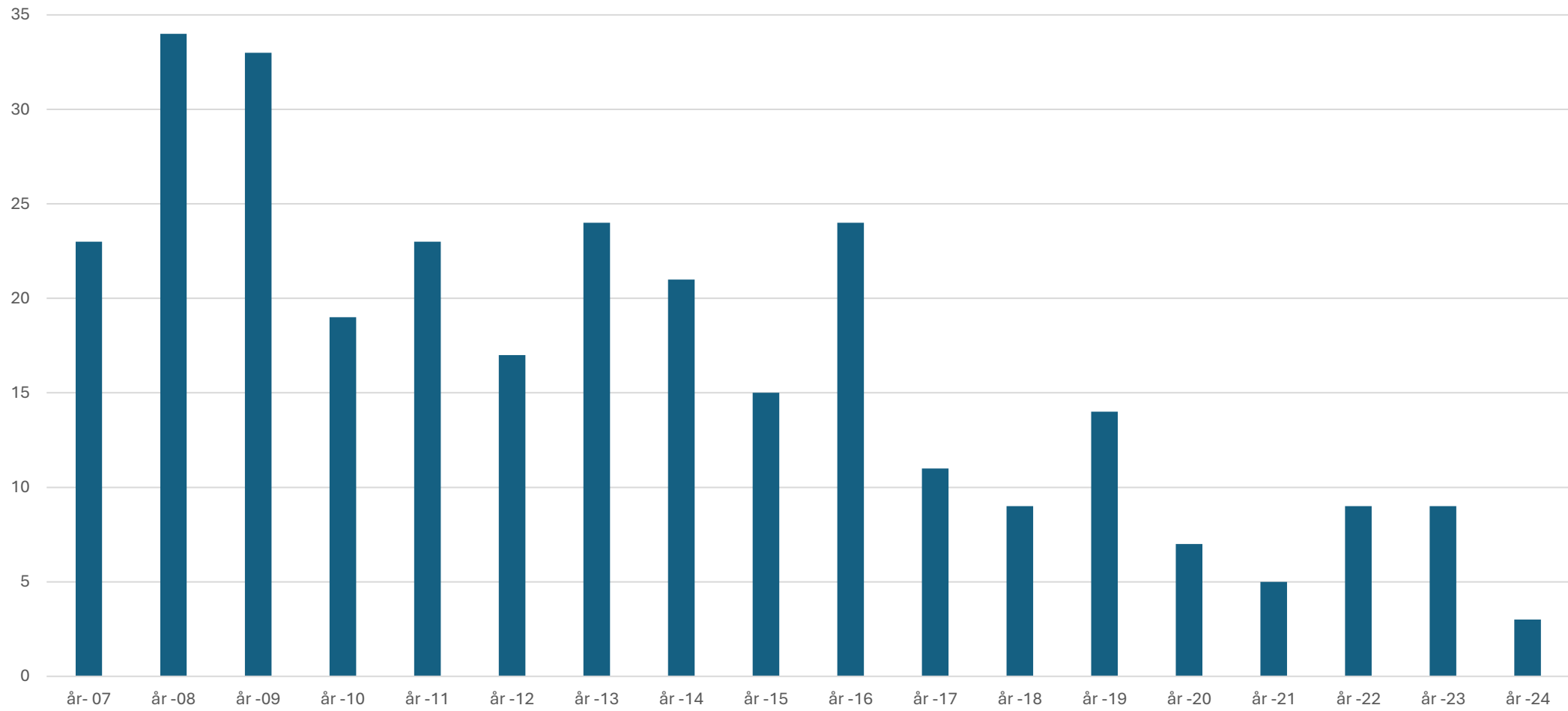
different treatments that prove less beneficial or harmful are discarded in favor of effective ones



ensuring high standards of care across the country



Antal deltagare med MMC/ födelseår



Data collected in the MMCUP

Forms	Child	Teenage	Adult
Participant info	x	x	x
Medical background	x	(x)	x
Urology-bowel function	x	x	
Surgery	x	(x)	
Physiotherapist	x	x	x
Occupational therapist	x	x	(x)
Cognition	x	x	(x)
Screening		(x)	x

MMCUP forms

Neuro

- Medical history-pregnancy and birth, subtype of SB, functional capacity, comorbidities.

Physiotherapy

- Range of motion, muscle strength, functional capacity, check for presence of pressure ulcers and pain, use of assistive devices and splints/orthotics

Urotherapy

- Assessments of ability to urinate and defecate and related functions
- Kidney and bladder function measurements
- Check for presence of pressure ulcers

Occupational therapy

- Standardized assessments of functional ability in everyday activities, grip function, eye-hand coordination, skills to plan, initiate and complete an activity and time management.

MMCUP forms, cont.

Cognition

- Standardized NP testing at 4, 6, 11 and 15 yrs.
- Testing of adults

Surgery

- Information on the procedure itself
- specific forms for neurosurgical, orthopaedic, urological and gastrointestinal operations

Health screening

- A summary review of important functions and medical status.
- May be performed by any health professional for an overview of participant's health and phycho-social situation

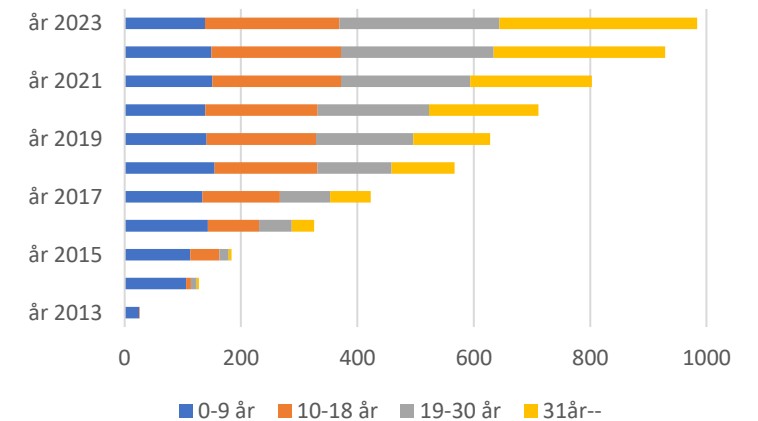
Population coverage

Participants born 2007 and later

- A total population followed according to the national guidelines -MMCUP
- Habilitation and health care
 - Available throughout Sweden

Participants > 17 years

- Population size- unknown
- Yearly increasing number of participants in registry
- Habilitation and health care
 - Regional differences in how/if services are provided



	MMC					Annand NTD
	0-9 år (2023-2014)	10-18 år (2013-2005)	19-30 år (2004-1993)	31 år – (1992-)	Totalt	Totalt (1973-2023)
Stockholm	23	34	27	28	112	8
Blekinge	<5	<5	6	<5	12	<5
Skåne	14	34	30	34	112	20
Halland	<5	6	17	12	37	<5
Västra Götaland	15	29	62	113	219	23
Värmland	<5	9	5	13	29	5
Örebro	<5	6	<5	<5	11	0
Västmanland	<5	5	7	20	33	0
Dalarna	6	<5	8	<5	22	<5
Gävleborg	<5	6	0	0	7	0
Västernorrland	<5	8	6	6	21	0
Jämtland	0	<5	<5	7	14	8
Västerbotten	6	7	13	17	43	0
Norbotten	0	<5	<5	0	5	0
Uppsala	<5	8	11	9	28	<5
Södermanland	10	<5	13	<5	28	<5
Östergötland	8	11	17	25	61	<5
Jönköping	<5	5	10	<5	21	<5
Kronoberg	<5	<5	6	22	35	8
Kalmar	5	9	15	12	41	<5
Gotland	<5	<5	<5	<5	<5	0
Sverige 2023	107	198	262	328	895	87
Sverige 2022	149	225	262	295	851	79
Sverige 2021	151	221	222	209	734	68

Participants born 2007 and later

Region	AT	FT	UT	Psyk	Neuro	LG
Sthlm (n=52)	0	8%	90%	0	78%	2%
Blekinge (n<5)	0	67%	67%	0	67%	0
Skåne (n=41)	56%	90%	83%	34%	89%	0
Halland (n=8)	38%	100%	75%	25%	88%	0
Västra Götaland (n=46)	54%	76%	87%	9%	91%	6%
Värmland (n=8)	100%	100%	100%	25%	75%	0
Örebro (n=9)	0	78%	89%	0	100%	0
Västmanland (n<5)	33%	100%	33%	0	100%	0
Dalarna (n=9)	56%	89%	89%	22%	89%	0
Gävleborg (n=7)	29%	86%	43%	0	86%	0
Västernorrland (n=7)	0	86%	0	0	71%	0
Jämtland (n<5)	67%	67%	100%	67%	100%	0
Västerbotten (n=14)	57%	86%	86%	57%	86%	0
Norrbottn (n<5)	0	0	0	0	50%	0
Uppsala (n=8)	63%	100%	88%	0	63%	0
Södermanland (n=13)	85%	92%	62%	8%	69%	0
Östergötland (n=16)	19%	75%	100%	38%	94%	6%
Jönköping (n=10)	30%	50%	100%	20%	90%	0
Kronoberg (n=7)	0	71%	100%	42%	71%	0
Kalmar (n=13)	38%	62%	92%	23%	92%	8%
Gotland (n<5)	0	0	100%	0	0	0
Sverige 2023 (n=255)	37%	67%	83%	18%	84%	2%

Participants > 17 years

Region	AT	FT	UT	Psyk	LG	Neuro Ä
Stockholm (n=58)	0	2%	26%	0	72%	0
Blekinge (n=8)	0	86%	75%	0	38%	25%
Skåne (n=68)	10%	87%	66%	4%	72%	57%
Halland (n=29)	3%	69%	17%	0	38%	17%
Västra Götaland (n=176)	0	38%	3%	0	57%	76%
Värmland (n=21)	19%	94%	0%	0	93%	71%
Örebro (n>5)	0	100%	0	0	50%	0
Västmanland (n=29)	3%	17%	0	0	93%	93%
Dalarna (n=12)	8%	58%	0	0	36%	50%
V-norrland (n=14)	0	81%	0	0	36%	7%
Jämtland (n=11)	18%	100%	91%	0	91%	54%
Västerbotten (n=30)	0	0	10%	0	77%	0
Norrbottnen (n>5)	0	0	0	0	0	0
Uppsala (n=19)	10%	58%	0	5%	89%	0
Södermanland (n=15)	0	87%	53%	0	13%	13%
Östergötland (n=45)	4%	89%	71%	2%	80%	38%
Jönköping (n=12)	0	25%	67%	0	0	0
Kronoberg (n=28)	0	89%	85%	0	96%	71%
Kalmar (n=28)	21%	71%	61%	0	79%	46%
Gotland (n>5)	0	50%	50%	0	0	0
Sverige 2023	4%	52%	30%	1%	45%	47%

Website- www.mmcup.se

Accessible without codes

- Information

- Health professionals

- Manuals and forms
 - Useful links – clinical guidelines and information
 - Registry platform- access via personal login

- Participants

- Information of the follow-up program and registry
 - Information of MMC/SB

**COGNITIVE FUNCTIONS IN SPINA
BIFIDA**

The cognitive is just as important as the physical



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In collaboration with



Thank You for listening!



MMCUP

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annan neuralrörsdefekt och hydrocefalus