

MMCUP – The National MMC Follow-Up Program and Quality of Care Registry

ERN ITHACA Spina Bifida clinicians workshop
Stockholm, 25 Nov 2017

Swedish professionals and users network for
MMC /

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MMCUP registry holder





Aims MMCUP

- to prevent complications and loss of function
- to increase knowledge
- to improve cooperation
- to boost high quality of care
 - effective interventions at the right time
 - skip in-effective treatments

Methods



Follow-up according to the
Swedish national guidelines in MMC/HC



***Guidelines for medical follow-up
Swedish neuropaediatric society***

***Guidelines PT, OT, Psychol follow-up
See links from mmcup.se***

Investigations and measurements on body structure and
function (Drs, UT, PT, OT, Pslg)
Recording of interventions/operations, indications, complications
Reports on function, activities and HRQoL (PROM)

Methods



standardised follow-up →
 early detection →
 early intervention →
 standardised evaluation →
 standardised follow-up →

Comparisons

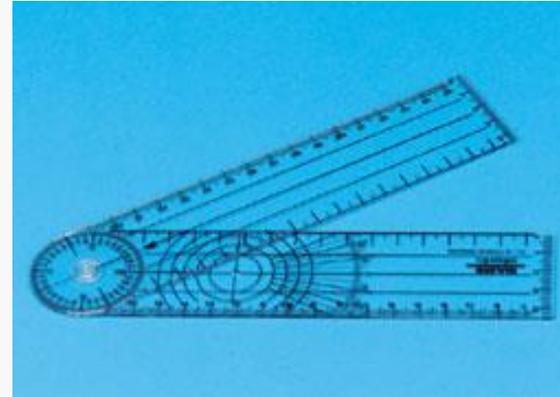
...maybe a little more stiff

...probably no difference

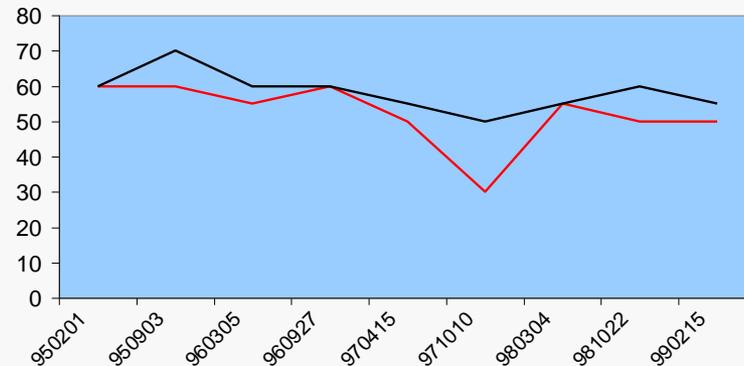
...unclear if new symptom

...have not met him before,
don't know previous
function

MEASURE
RECORD
COMMON LANGUAGE



Abduktion höger och vänster höft





Tertiary care university hospitals

MMC-specialized:
Neuropediatrician
Neurosurgeons
Paediatric surgeons
Urologists
Urotherapists
Orthopaedics
Obstetrics
Neonatal dpt
...



Primary care

General care
physicians,
nurses, OTs,
PTs,



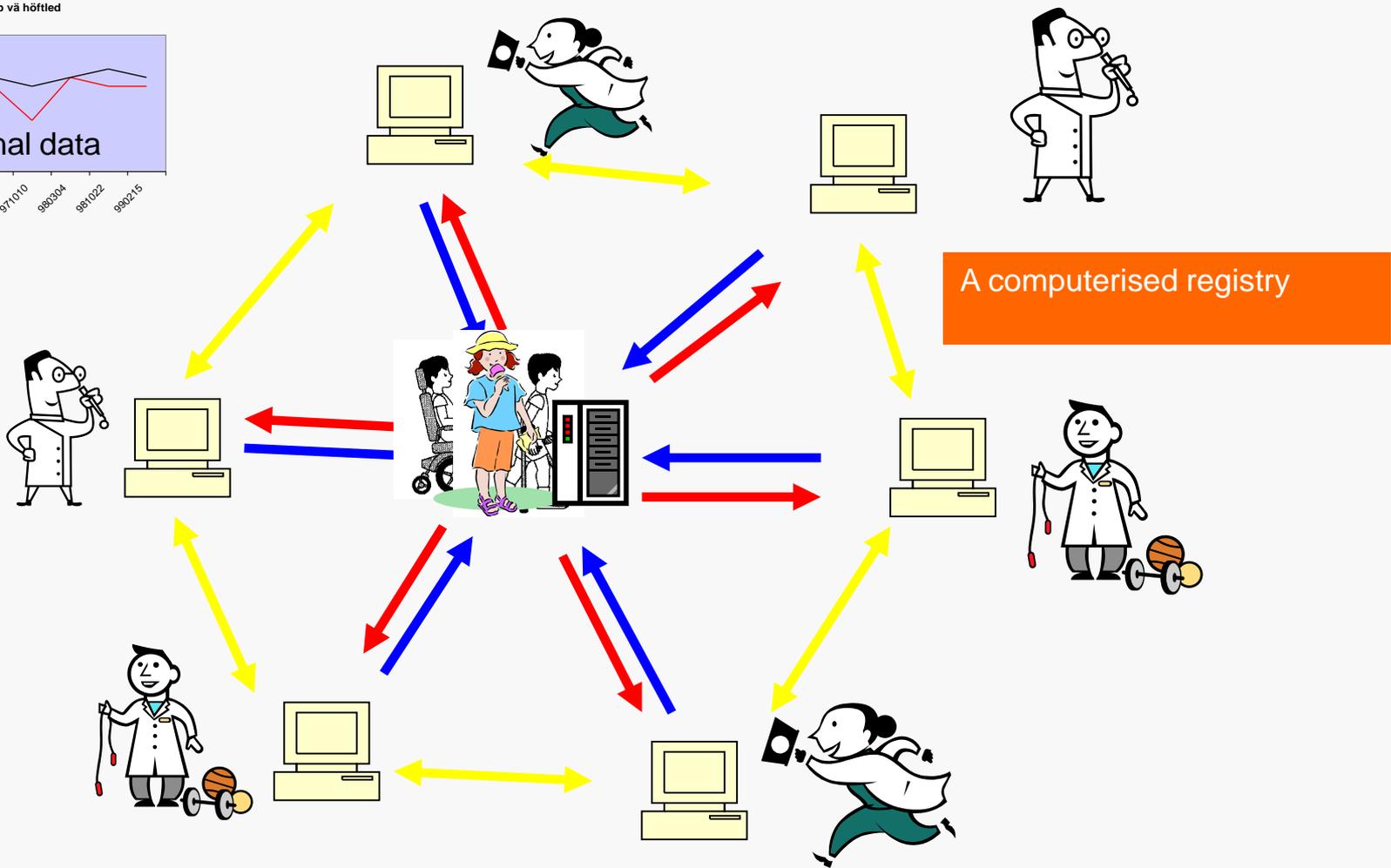
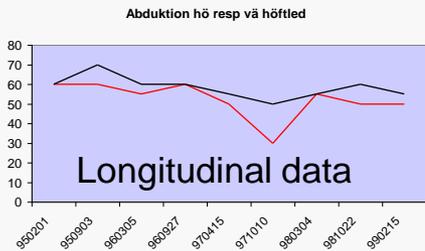
Local hospitals

Emergency, medicine &
general surgery dpts
Orthopaedic dpt
Urology dpt

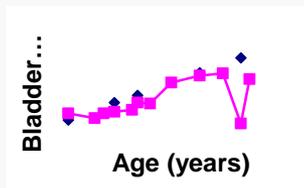


Local rehab units

PT, OT, psychol,
social workers, drs,
nurses



MMCUP



e.g. functional bladder volume and detrusor pressure over time

Senaste us	Nästa us	Pnr Namn
2010, Jan	2011, jan	020101-0011 M Jönsson
2011, april	2011, april	010101-0345 M Karlsson
2011, juli	2012, juli	040506-1234 S Pettersson
2011, aug	2012, aug	010101-0345 M Karlsson
2011, oktober	2012, oktober	000101-0135



Sweden

10 000 000 inhabitants

110 000 births/year

Taxes include health care insurance fee for all citizens

Multiprofessional habilitation teams in each municipality (290)

21 counties – health care responsibility

6 tertiary health care regions



MMCUP – organisation



National steering group

Representatives from:

- patient org - 2 adults with MMC, 2 parents
each professional organization (FT, OT, UT, psychol
rehabdr, neuroped, neurosurg, orthop)

Local habilitation centres

The *university hospital* in each region (6)

Regional MMCUP-teams (6)

Coordinator (UT, nurses)

Nped/rehab dr, Nsurg, Ort, Child surg/urologist

Central team (Lund)

Registry holder + registry coordinator (PT)

Psychol-fundraiser, UT coordinator, secr.

All working only few hours with MMCUP

MMCUP – organisation



RCSYD – Registry centre southern region –
Registry development and support, data
managing, IT platforms

”Personal integrity responsible authority” (CPUA)
- Region Skåne

Funding – Swedish government and SALAR
(Swedish Assoc of Local Authorities and Regions)

MMCUP –Sweden



National working groups for MMCUP:

Patients/relatives

UTs/Urol

PTs

OTs

Ort

Nsurg

Nped/Neurol/Rehab drs

Pslg,

Special teachers

MMC/"lipoMMC" – prio 1

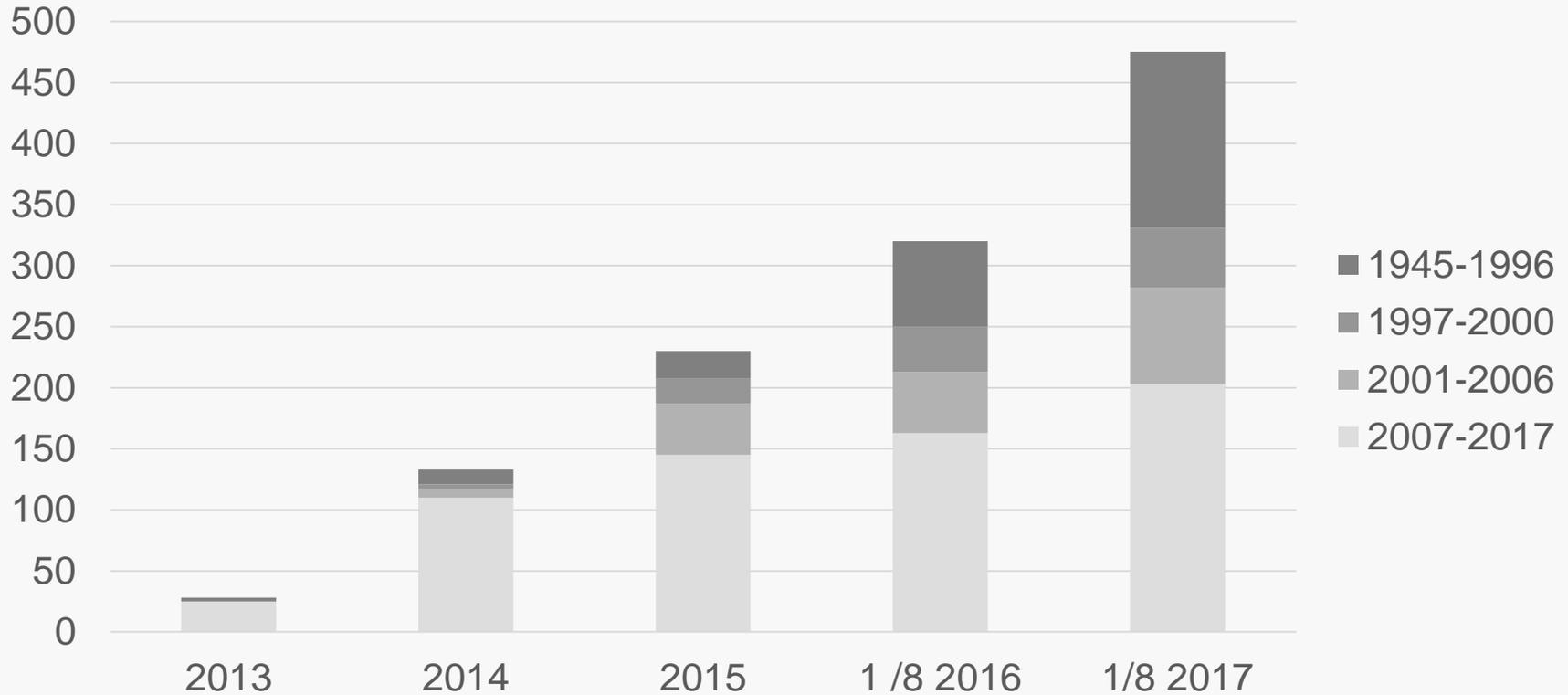
Born \geq 2007 – 100% coverage

Older children and adults – prio 2

other spinal NTDs – prio 3

Cong or early aq. hydrocephalus without NTD

Number of participants in MMCUP database per birth cohort since start Nov 2013



MMCU - Degree of covering

Participating persons with MMC 31/12 2016

Children 0-9 yrs 97%

Teenagers 15-18 yrs 94%

Adults 19-30 yrs 16%

Adults > 30 yrs ??

Participating units 1/8 2017

County regions – 21/21

Tertiary care university hospitals - 6/6

Habilitation units from 16/21 counties

...

> 200 professionals log in and contribute with assessments/data

Examples results:

Children born 2007-2016 with MMC/"lipoMMC"

0-9 years of age	160
Born in Sweden	132
Moved in	28 (18 %)
Moved out	1
Died	6 (4 neon)

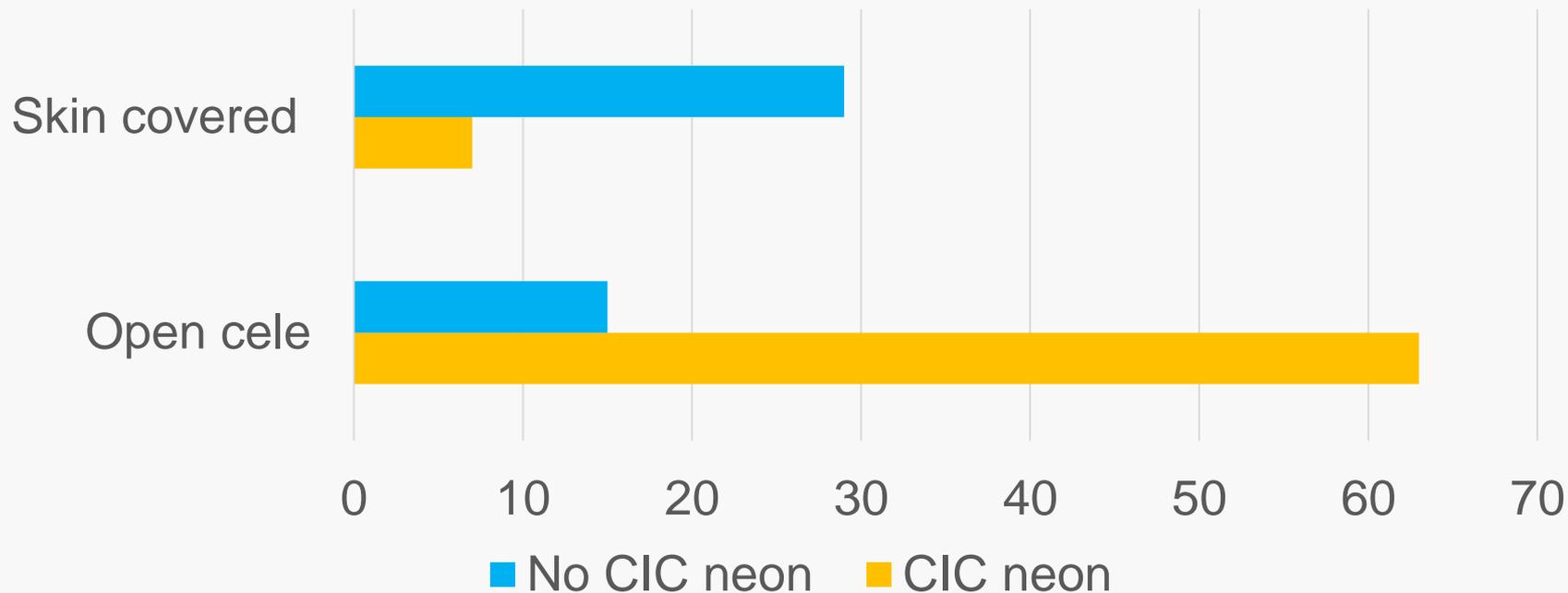
Prevalence 1.44/10 000 (95% CI 1.22-1.66)
Incidence 1.24/10 000

Termination of pregnancies MMC 65%

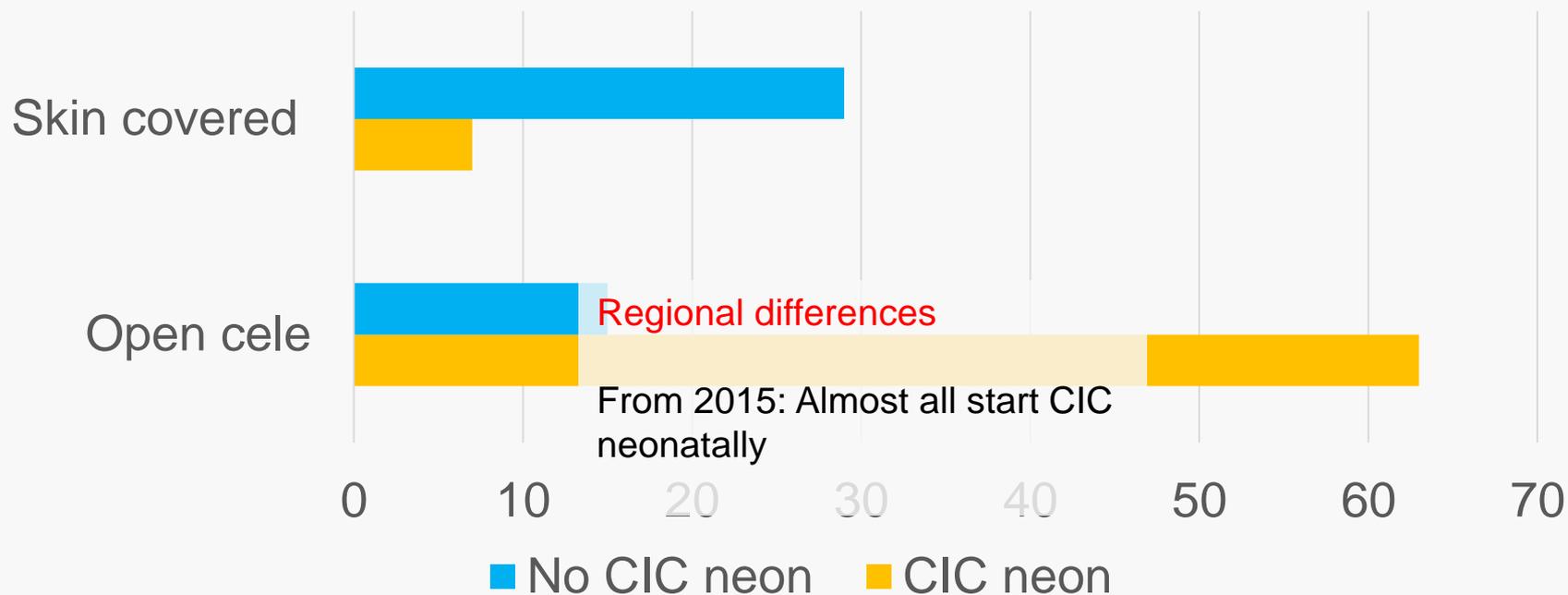
Children born 2007-2016 with MMC/"lipo-MMC"
(n=60, PT latest assessment)

- Orthoses LE 45 (75%)
- Spinal orthosis 7 (12%)
- Pressure sores 0
- Pressure marks hindering orthosis use 8 (13%)
- Pressure marks hindering spinal orthosis 1
- Pain now 10 (17%)
- Pain every day or often last 4 weeks 9 (15%)
- Leading pain sites spine/back (9) and lower legs/feet (7)
- Most often pain both in activity and during rest/night (11)

Number of children born 2007-2015 in Sweden starting CIC neonatally (MMC/"lipo-MMC" n=114)



Number of children born 2007-2015 in Sweden starting CIC neonatally (MMC/"lipo-MMC" n=114)



Operations

(Children born 2007-2016 with MMC/"lipo-MMC", n=160)

• Primary op cele	134
• Hydrocephalus	198
• Untethering	47
• OC decompression	7
• Urologic (incl BxA)	95
• Orthopaedic	114

Regional differences (6 regions)

One region larger proportion shunted although a higher proportion of skin covered celes

One region higher proportion of shunt re-operations than the others

5/6 deaths occurred in one region

Project 2017. All six neurosurgeon units perform retrospective review of cases in MMCUP-forms

Quality of care indicators in MMCUP –

Number and proportion of persons without

- pain interfering with sleep or activities
- pressure sores
- urine- or bowel incontinence interfering with activities
- severe obesity and/or malnutrition
- perioperative complications
- hospitalizations for preventable health problems
- loss of function (ex. motor f, kidney f, continence, growth, respiration, vision, cognition)
- preventable mortality causes

Quality of care indicators in MMCUP –

planned – but not easy to find validated reliable instruments.....

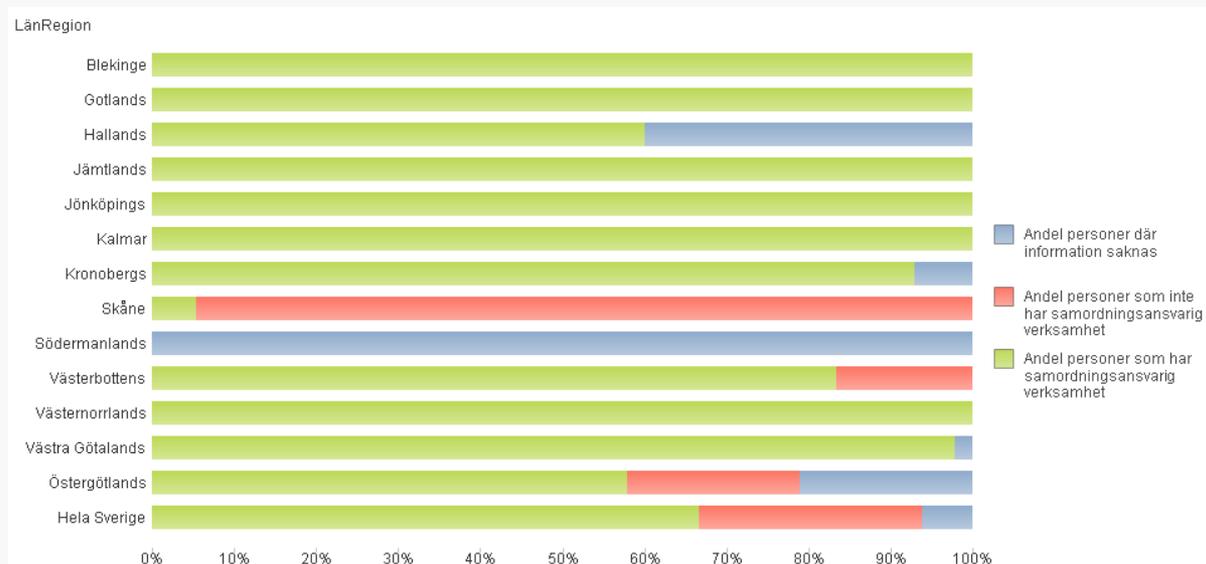
PREM (Patient-Reported Experience Measures)

Self reported QoL (EQ5D-5L used now)

Participation, Activity, and Function

Quality indicator 1 – Process item: Coordinated care?

Ex adults with MMC



IMPROVEMENTS 2012-2017

KNOWLEDGE

- Inter- and multiprofessional networking in creating guidelines and the registry

STATUS

- Appointment of MMCUP as a national quality of care registry

COMMON LANGUAGE

- definition of terms used, classification of spinal NTDs,

IMPLEMENTED FOLLOW UP

Almost all children born \geq 2007 with MMC/"lipoMMC" included

COMPARISONS for improved management started

FUTURE

- More habilitation units need to start with PT, OT and psychol assessments
- Continue....and go on include adults and teenagers;
- Money – government and SALAR campagne investments in national quality of care registries 2012-2016 finished (extension 2017, 2018?)
- Improved IT; no double registration MMCUP ↔ medical records



MMCUP

secondary prevention
life-span perspective

for all persons with SB



Thank you!