



MMCUP

a secondary prevention follow-up
program in spinal dysraphism and
hydrocephalus

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Swedish professional network for MMC/
Lena Westbom





Why follow up program?

- lifelong risk for complications
- complex medical needs *remember everything
- coordinated health care *stay healthy
- best treatment? *evidence missing
- new survivors, new health care personnel

PROCESS

Swedish professional network for MMC; 2004 →

Priority:

1. Transition to adulthood
2. Evidence based treatment recommendations
3. Follow-up program +
a health care quality registry

MMC+lipoMMC

Hydrocephalus

Other congenital/early acquired spinal disorders



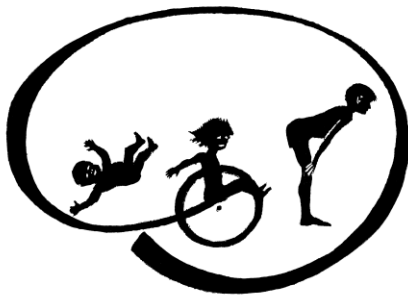
Aims MMCUP

- 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
2009-2013***

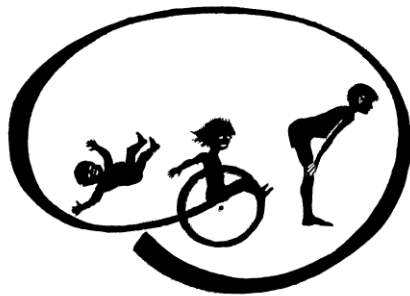
Guidelines PT and OT follow-up

See links from www.mmcup.se

Methods



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



***Guidelines for medical follow-up
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Guidelines PT and OT follow-up

See links from www.mmcup.se

Measurements on body structure and function (PT, OT, UT)

Recording of interventions + indications (+ neurosurg, urol, ort)

Reports on daily function, activities and health (PROM)

Methods



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

Comparisons

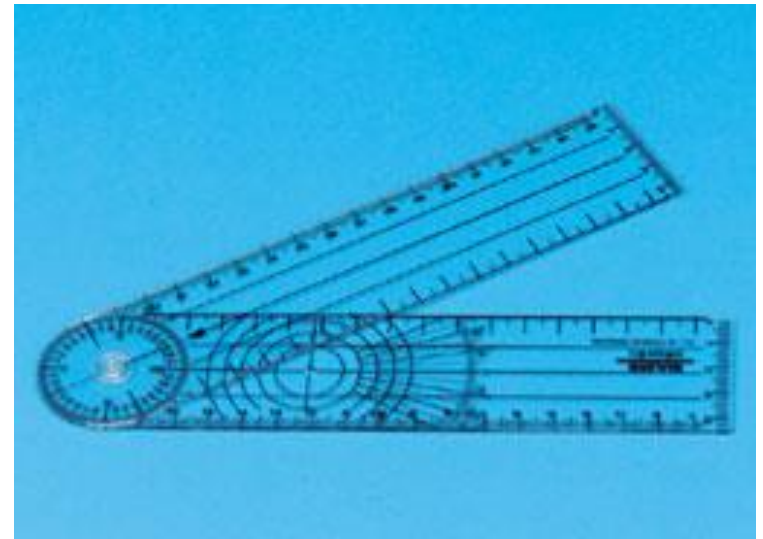
...maybe a little more stiff

...probably no difference

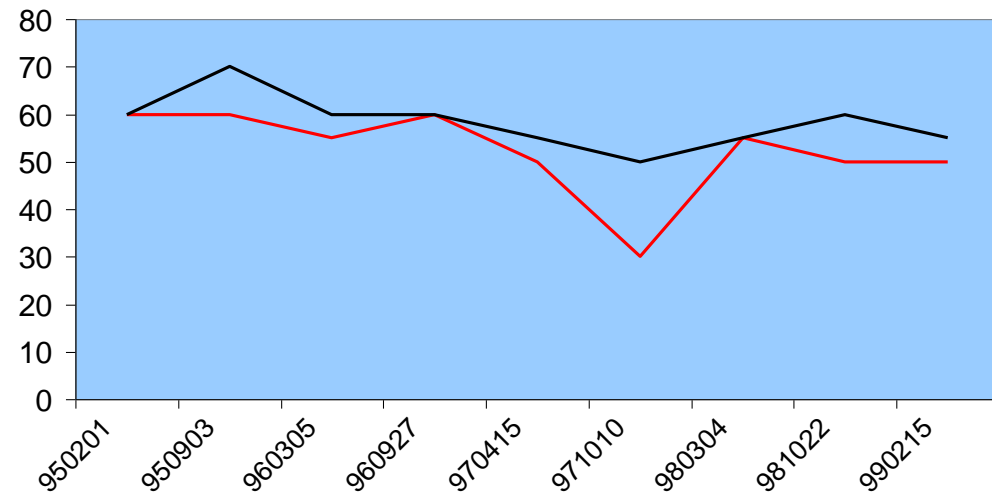
...unclear if new symptom

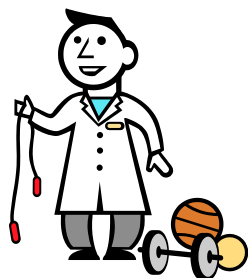
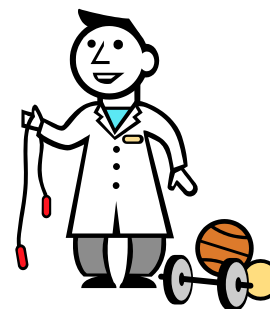
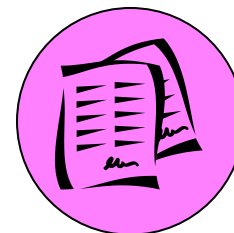
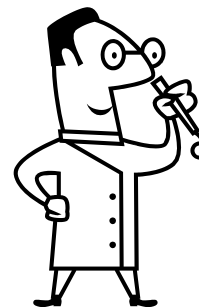
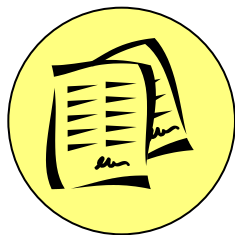
...have not met him before,
don't know previous
function

MEASURE
RECORD
COMMON LANGUAGE

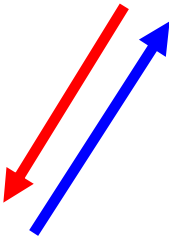
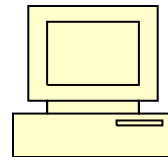
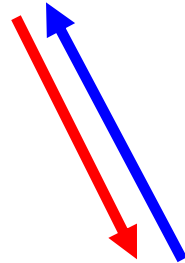
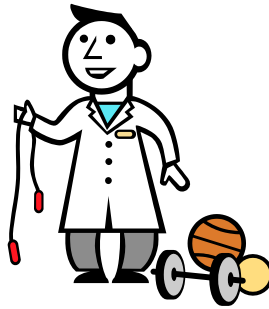
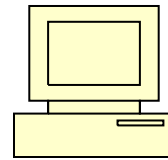
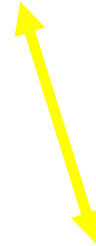
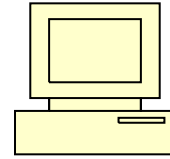
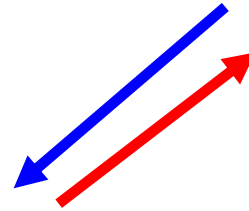
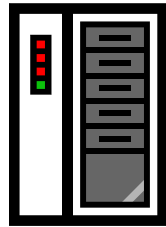
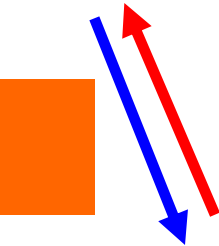
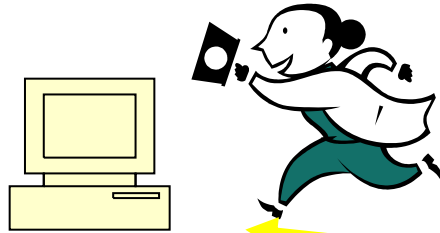
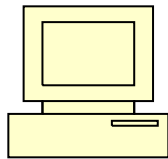
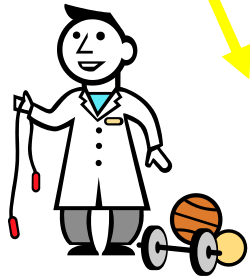
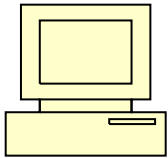


Abduktion höger och vänster höft

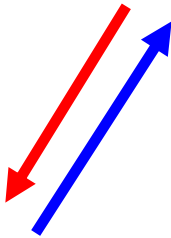
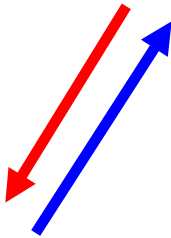
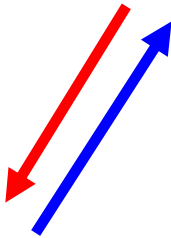
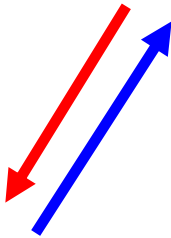
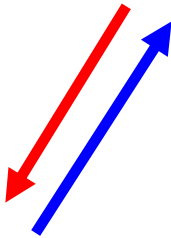
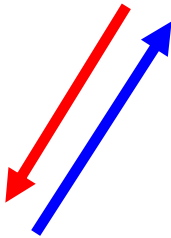
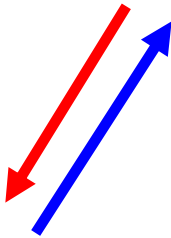
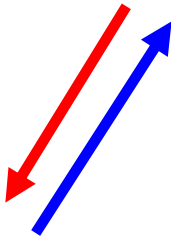
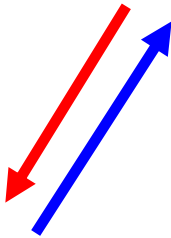
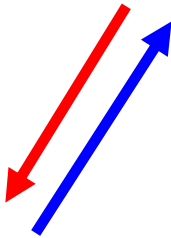
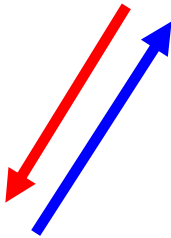
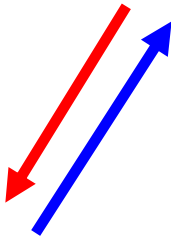
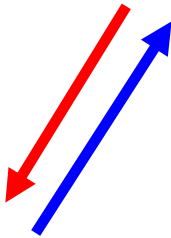
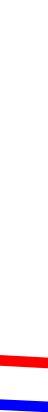
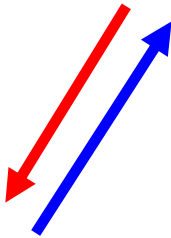
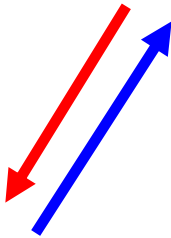
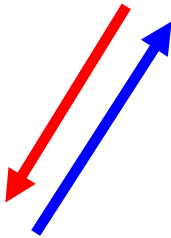
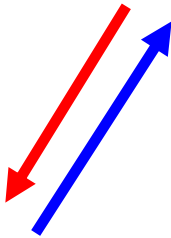
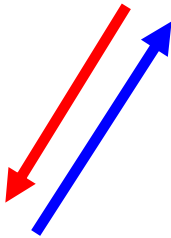
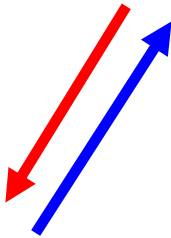
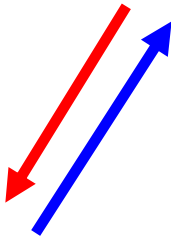
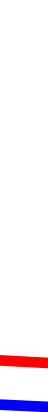
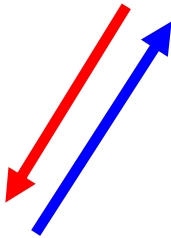
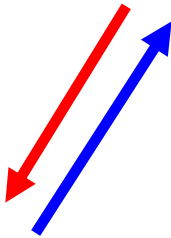
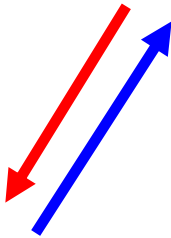
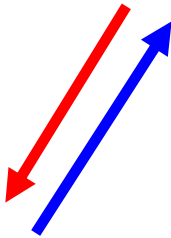
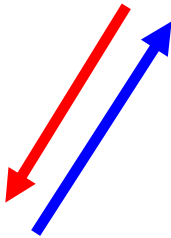
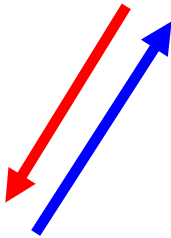
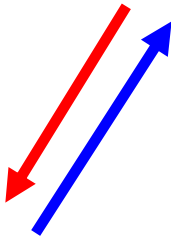
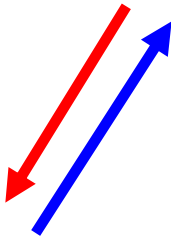
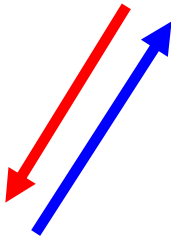
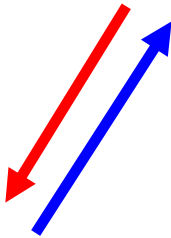
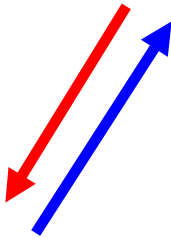
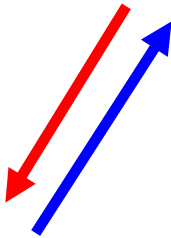
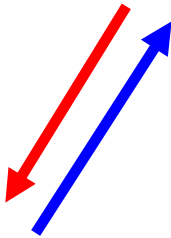
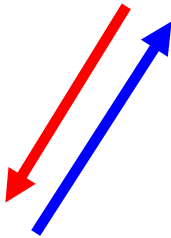
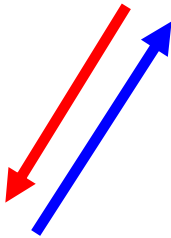
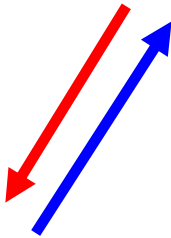
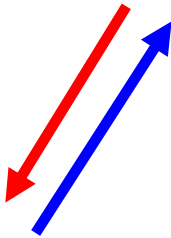
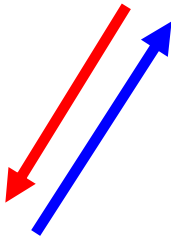
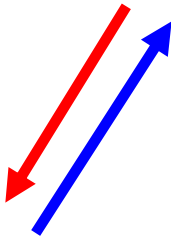
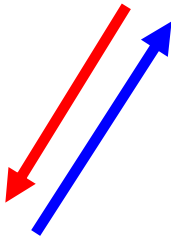
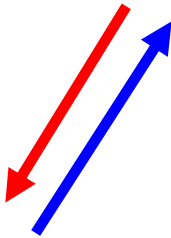
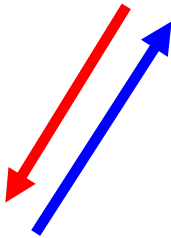
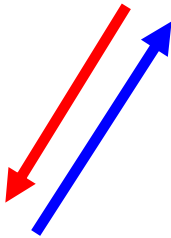
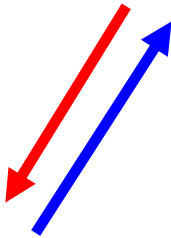
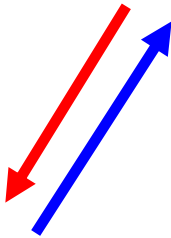
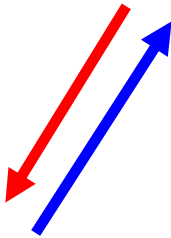
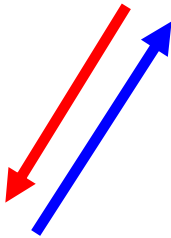
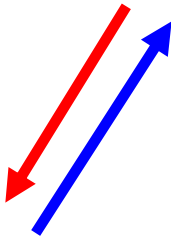
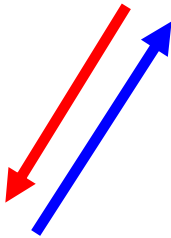
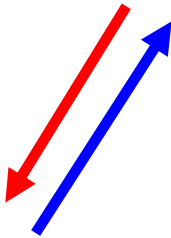
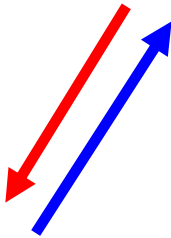
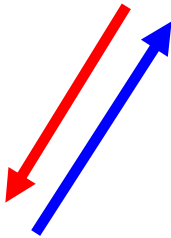
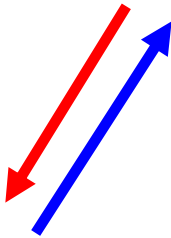
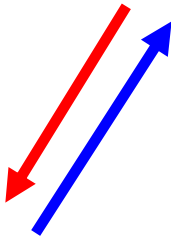
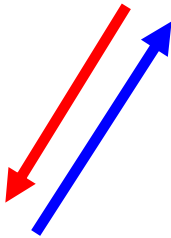
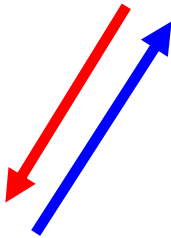
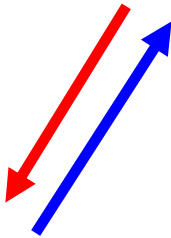
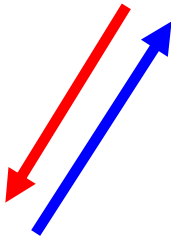
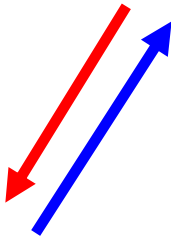
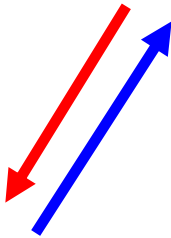
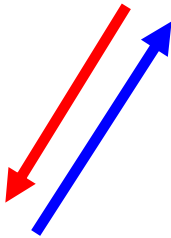
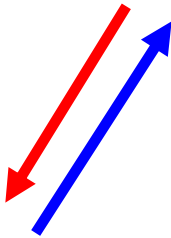
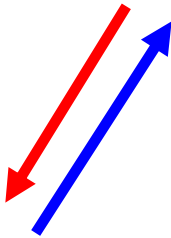
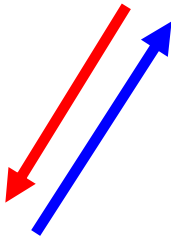
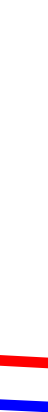
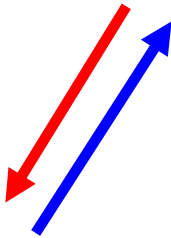
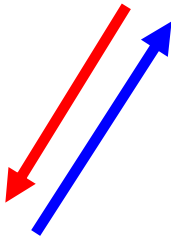
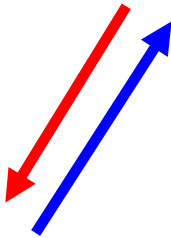
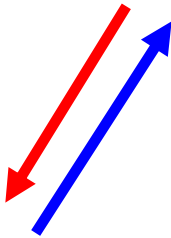
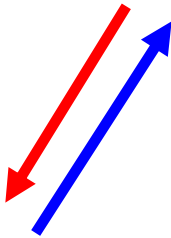
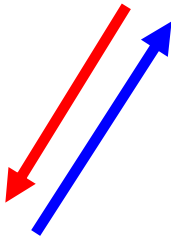
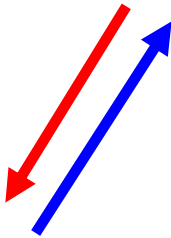
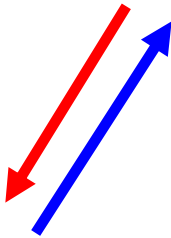
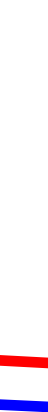
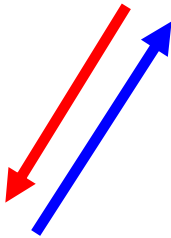
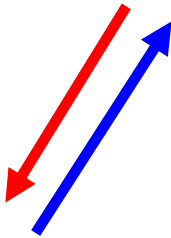
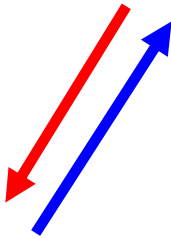
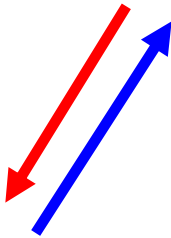
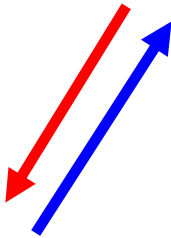
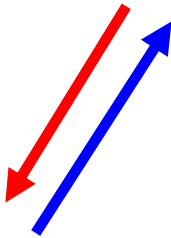
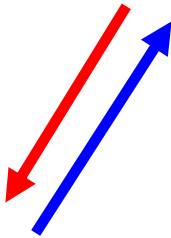
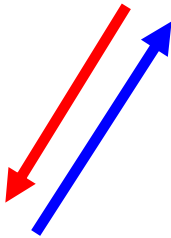
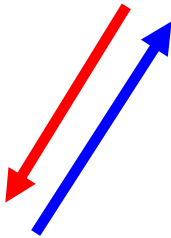
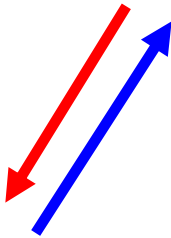
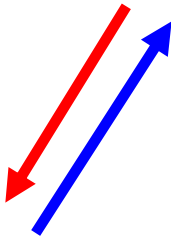
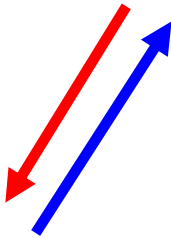
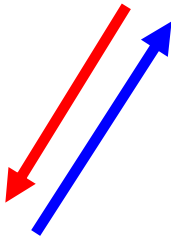
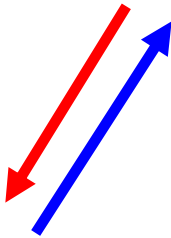
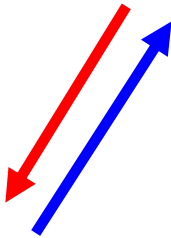
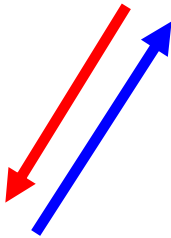
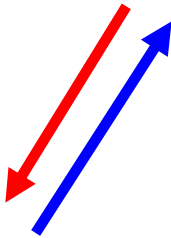
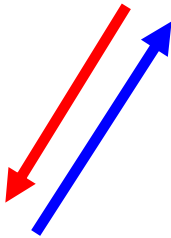
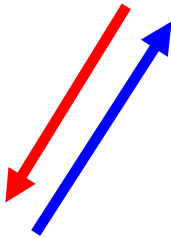
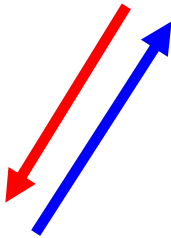
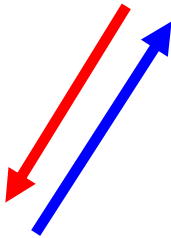
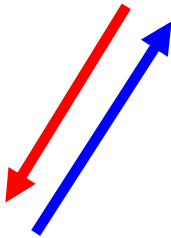
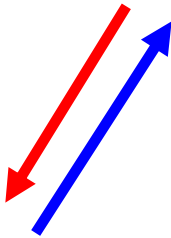
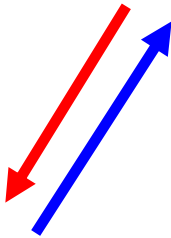
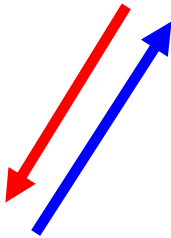
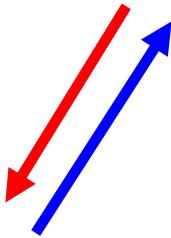
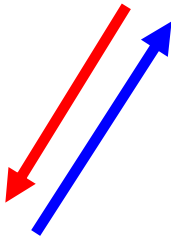
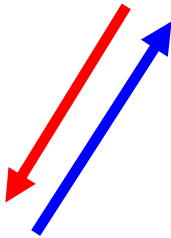
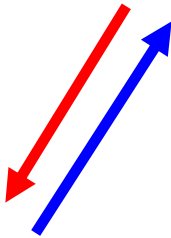
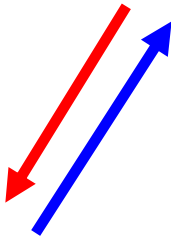
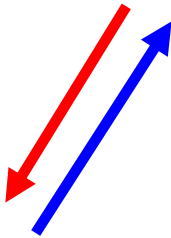
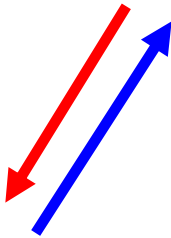
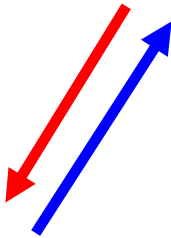
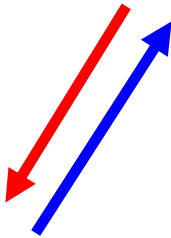
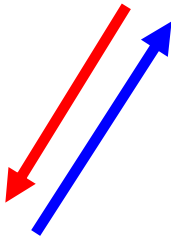
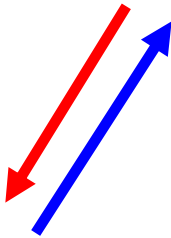
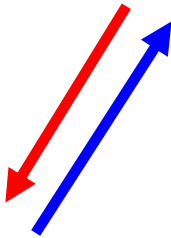
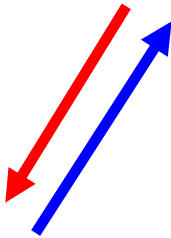
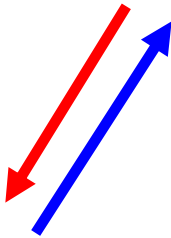
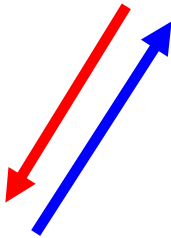
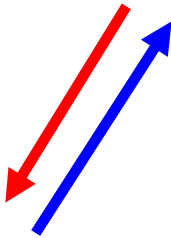
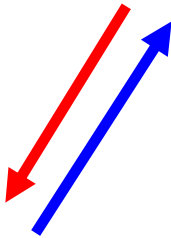
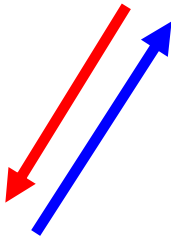
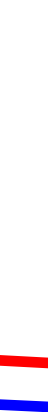
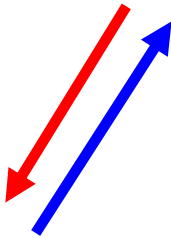
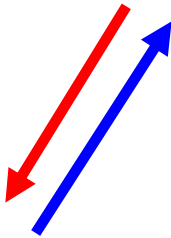
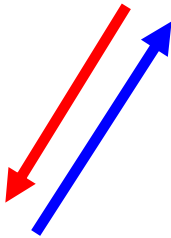
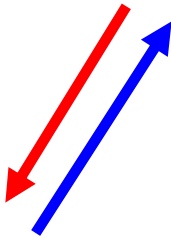
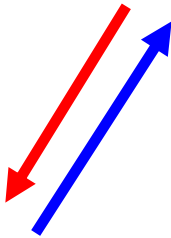
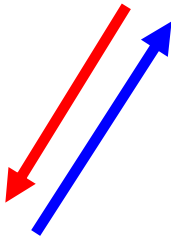
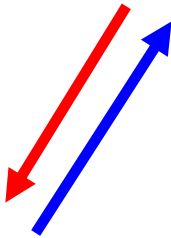
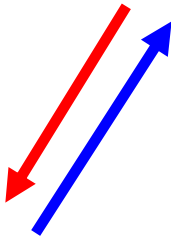
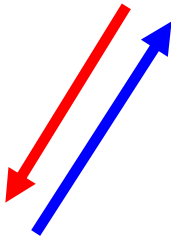
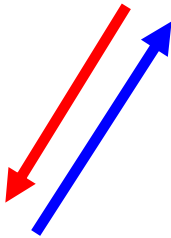
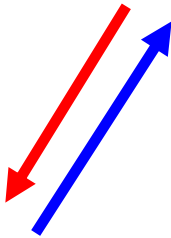
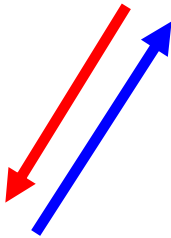
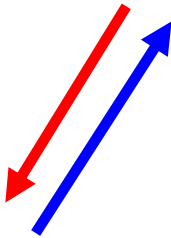
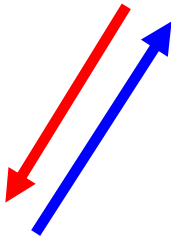
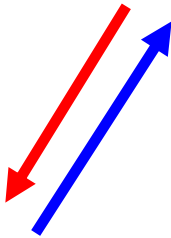
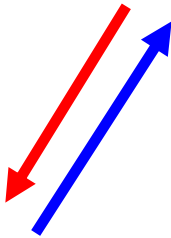
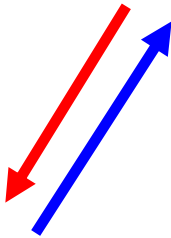
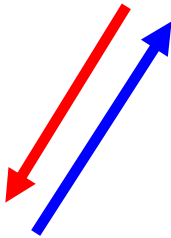
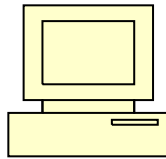
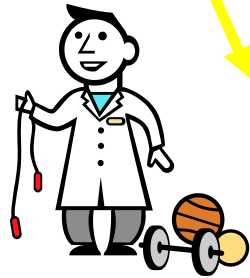
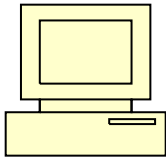
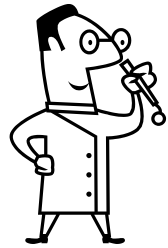
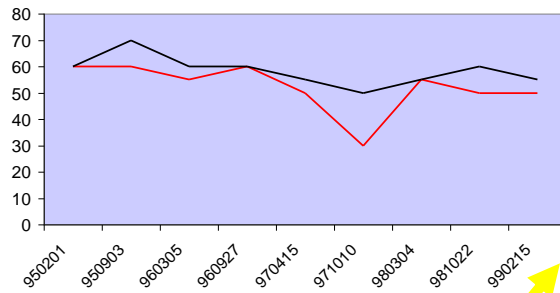




A computerised registry



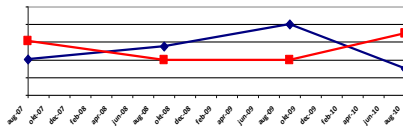
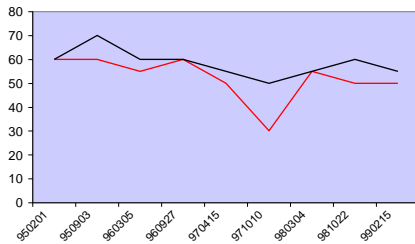
Abduktion hö resp vä höftled



Follow-up program in SB/HC



Support in the choice of
treatment for each person
with SB/HC



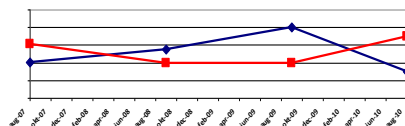
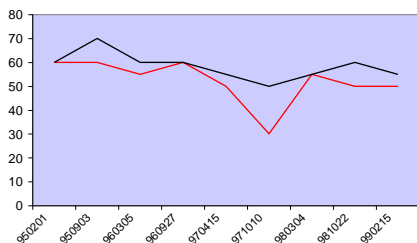
Hip abduction ROM and
functional bladder volume
and detrusor pressure
over time
Self-reports

Follow-up program in SB/HC



Support in the choice of
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Support process of care –
lists of planned investigations,
treatments, visits to the clinic



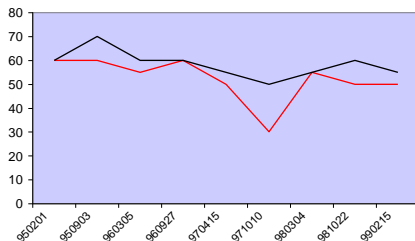
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2011, april	2011, april	010101-0345 M Karlsson
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2011, aug	2012, aug	010101-0345 M Karlsson

Follow-up program in SB/HC

Support in the choice of
treatment for each person
with SB/HC

Support process of care –
lists of planned investigations,
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National quality of care registry
- comparisons of results of
medical care and surgical
interventions



Hip abduction ROM and
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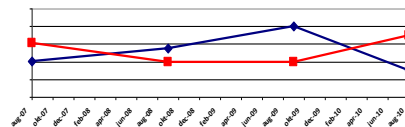
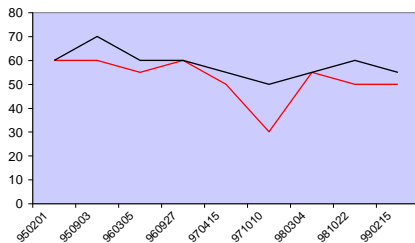
Follow-up program in SB/HC

Research
Health care
improvements

National quality of care registry
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MMC/lipoMMC – prio 1

Born \geq 2007 - start 2012

Older children and adults - prio 2

Hydrocephalus without MMC; all spinal dysrafism

MMCUP –Sweden

Local habilitation centres
Hospitals

Regional MMCUP-teams/

Coordinator (UT, nurses)

Central team/RCSYD

Registry holder

Competence groups:

UTs/Urol

PTs

OTs

Ort

Nsurg

Nped/Neurol/Rehab drs

Pslg, Ped



2012-2014

6 reg.forms

Process form PT

www.mmcup.se

Results – from annual report 2013

91 children born 2007-2012 MMC/lipoMMC

84 were born in Sweden – 50 girls, 34 boys

Incidence 1.26/10 000

1/3 of the celes were closed

Conclusion

An unselected total population with MMC/lipoMMC today 100 children 0-7 years of age is now followed.

Personal data, neonatal, PT assessment and operations forms are now internet based. Next to follow: the UT form and the first form for for older children and adult.

"Retrospective MMCUP-data" for > 700 with MMC born 1986 – 2006 available and they will be offered participation in the prospective follow up program