

### **MMCUP- What does it mean?**

MMCUP is short for **myelomeningocele follow-up** program. In many parts of the world they say myelomeningocele, or for short MMC, instead of spina bifida. The word myelomeningocele is Greek and means “membrane” and “hernia”. Spina bifida means “divided spine”. You may be used to SB but your healthcare provider may say MMC instead.

### **MMCUP- What is it?**

MMCUP is a follow-up program for persons with MMC and is also a health care quality registry. That means that certain information is collected and safely stored in a databank. Those who work at hospitals and clinics use different ways to care for persons with MMC. By collecting information from many persons with MMC all over Sweden we want to learn which treatment methods lead to the best health and quality of life. MMCUP has a webpage ([mmcup.se](http://mmcup.se)) that you can visit if you want to learn more.

### **What is the purpose of MMCUP?**

The most important goal for MMCUP is to make sure that persons with MMC, of any age, do **not** experience health problems that could have been prevented. Certain problems are more common in persons with MMC, such as allergic reactions to latex, fractures or joint dislocations, malformations of bone structures, problems with kidneys, bladders and stomach. These problems may get worse over time.

### **How does the data collection work?**

Persons with MMC meet many health professionals who work with them over the years. It may be occupational therapists, physical therapists, nurses specialized in urotherapy, psychologists and physicians from different specialties. After these professionals have examined the person they will enter the data into MMCUP. Information they may enter include outcomes after surgery, implanted materials (e.g., shunt), medications, different treatments and use of assistive devices. Participating in MMCUP does not require extra appointments but is built in to the regular health care.

Information will only be reported to the databank if the legal caregiver or the adult with MMC has been informed about MMCUP and wants to participate. If you do not want to participate or your data to be reported, all you have to do is tell us.

### **How is MMCUP being used?**

Specific information and results are collected in a database. A treating health care provider may review data from an individual’s MMCUP chart in order to follow the development of a patient’s specific functions over time. The programme has been set up to ‘alert’ the provider if there seems to be a cause for concern. These ‘alerts’ are very important to enable the provider to review or initiate new treatments in order to curb or prevent further deterioration.

An additional goal of MMCUP is to enable consistent high quality health care across the country. If everybody follows the same MMCUP assessment schedule, the outcomes can be compared across the country. This means that we will know if there are certain parts of the country that needs more resources in terms of caring for persons with MMC. The results are published in an annual report on [www.mmcup.se](http://www.mmcup.se)

**Can an individual person be identified in MMCUP?**

No, all results will be anonymous. Only those authorized will be allowed access to MMCUP data. Authorized persons need a specific log-in to access the MMCUP database. The log-in process is done in accordance with rules and regulation established by the Swedish Data Inspection Board.

MMCUP strives to ensure the quality of the health care provided to persons with MMC. Research on MMCUP data is allowed provided an independent ethics board has reviewed and approved a specific research project.

**Do you want more information?**

Feel free to contact the MMCUP secretary Ms. Gunilla Petersson. She will answer your questions. If she is unable to do so she will direct you to a person who can.

**Contact information for MMCUP**

Attention: Gunilla Petersson  
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