MS Center Amsterdam

MS-Studie: Amsterdam MS Cohort and MS-biobank (Engelse vertaling)

Locatie VUmc

In this brochure you will find information about the Amsterdam MS Cohort and in brief about the MS biobank. You will also find information about the MS quality registration. This is a separate database with medical data of all people with MS in the Netherlands. Extensive information about the MS biobank and the MS quality registration can be found in separate information leaflets.

MS Center Amsterdam

The MS Center Amsterdam was founded in 1998 and conducts scientific research into the diagnosis, course and treatment of MS and diseases similar to MS. For this purpose we collect medical data and samples from a large group of people with MS and from people with diseases similar to MS. We call this the 'Amsterdam MS cohort'. The samples, such as blood and cerebrospinal fluid, are stored in the MS-biobank.

Wat do we ask of you?

If you visit the MS Center Amsterdam for an appointment with a neurologist, we will ask your to participate in two different studies: Amsterdam MS Cohort and the Amsterdam UMC MS-biobank.

1. **Participation in the Amsterdam MS Cohort - permission to retrieve your medical data and MRI scans and use them for scientific research**
   We may also request additional information from your general practitioner, municipal personal records database, Statistics Netherlands (CBS), other treating specialists and/or healthcare institutions.
2. **Participation in the MS-biobank - permission to take additional blood samples of your blood**
   a. **Permission to take blood and save for future scientific research**
      To diagnose your condition properly or to follow-up on the effects of treatment, blood is usually taken from you. We would like to ask you to donate a few extra blood samples for the MS-biobank. This is used for scientific research. In most cases, this will involve using only one needle. Some of the blood you donate can be used to isolate DNA. This makes it possible research genetic factors that might play a role in causing diseases. You can read more information detailed brochure about participation in the MS-biobank.

b. **Permission to take extra samples and save for future scientific research <u>if this is already taken for medical reasons</u>**
   You do not need to undergo a lumber puncture to participate in the Amsterdam MS cohort. But in case you need to undergo a lumber puncture for your health, we do ask your permission to collect some extra cerebrospinal fluid for the MS-biobank. This is used for scientific research. Because the cerebrospinal fluid is in direct contact with the brain, it has important information about what occurs in the brain.

Participating to MS quality registration (MSR)

In the Amsterdam MS Cohort, medical data is only collected from people who have visited the MS Center Amsterdam. The MS quality registration was established in 2016. Medical data of all people with MS in the Netherlands are collected in this registration. The goal of the MS quality registration is to improve the care for people with MS in the Netherlands. All medical data required for the MS quality registration is already collected in the Amsterdam MS Cohort. If you give permission to also participate in the MS quality registration, a limited set of medical data will be automatically linked to the MS quality registration. You will give your permission on a separate consent form.
More detailed information about the MS quality registration can be found in a separate letter.

Permission to contact you in the future for additional data and samples or other research projects

It is very important to learn more about the causes of your symptoms and how they develop over time. We also like to monitor our patients as closely as possible. With these goals in mind, we sometimes have additional questions. Therefore, you may receive an invitation for a follow-up appointment at our center to see how you are doing. In certain cases, we would like to take additional blood and/or other samples during a follow-up visit. We will of course ask your permission in advance each time you come to see us and the decision on whether to participate in each part of our research is always yours.

Possible inconvenience and risks

Participation in the Amsterdam MS Cohort will not take up any more of your time. You do not need to go to the hospital for an extra. For the MS-biobank we take additional blood samples from you as much as possible during routine medical procedures. A lumbar puncture is only performed if medically necessary. Taking additional samples of cerebrospinal fluid does not pose any added risk. Less than 10% of patients suffer from a headache after a lumbar puncture. Other possible complications such as meningitis and bleeding in the spinal canal are extremely rare.

What are the possible benefits?

You will noy benefit directly from participating in the Amsterdam MS Cohort. But by taking part you can contribute to a better understanding of the diagnosing MS and similar conditions, their progression and how to treat them.

Findings of interest to you

You will not be informed of any research results that have no immediate impact on your personal situation. Nor will these results be passed to your attending physician. In the event of results that may have direct consequences, you will be informed by your attending physician.

What will happen to my data and samples?

All your data are subject to medical confidentiality. The only people who can view your file are the research team of the MS Center Amsterdam, a member of staff at Amsterdam UMC, location VUmc who monitors the implementations of the study, and the Healthcare and Youth Care Inspectorate. All of these people are obliged to treat your information in the strictest confidence.

The scientific research is being carried out by the research team of the MS Center Amsterdam. Some of the samples you have donated may be stored separately in the MS-biobank along with the relevant medical data, as described above. Your medical data and samples are coded before they are passed om to the person who wants to use the data for scientific research. This means that any data published in a (scientific) journal cannot be traced to you. Research may also be carried out in close collaboration with other academic and non-academic partners in the Netherlands or abroad. This may involve sharing your coded medical data and samples with these research partners. Under all circumstances, the MS Center Amsterdam research team remains responsible for the medical data, the samples and the scientific data derived from them.

Both the coded medical data and the samples will be stored for a maximum of 50 years. At some point in the future, they may be used for a research objective related to your own particular disease. This could be research that is carried out in a collaborative context in the Netherlands or abroad with academic and non-academic partners. Different rules governing privacy may apply abroad. Your medical data and the samples collected for research will be used for this purpose until you withdraw your consent. If you withdraw consent, your remaining samples will be destroyed. Any samples that have already been processed as part of a scientific study cannot be destroyed. The same applies to the medical data that has already been used in research. In the event of your death while your samples are still in storage, your consent will remain valid.

More information about rights when data is processed

You can ask the researcher to provide you with an electronic copy of data you have submitted or resulting from any measurements taken. For more information about your rights when your personal data is processed, you should contact the researchers of the Amsterdam MS Cohort at the MS Center Amsterdam by calling Dr. E.M.M. Strijbis on telephone number 020-4442834. The MS Centrum Amsterdam is responsible for ensuring compliance with the rules for processing your personal data. If you are dissatisfied with how your privacy is handled, you can submit a complaint to the Data Protection Officer at privacy@vumc.nl. You can also look at the Privacy statement of Amsterdam UMC.

If you do not want to participate or want to withdraw from the study

It’s up to you to if you want to participate in our research. Participation is entirely voluntary. Even if you have already agreed to take part, you are always free to change your mind. You can withdraw from the study and you are under no obligation to say why. Your decision on whether or not to participate will have no impact on your medical treatment. A form for withdrawal consent that you have previously granted is available. However, we do ask you to inform the researchers of your decision. The data collected up to that point will be used for research. If you wish, all samples that have not yet been used will be destroyed.

Do I receive a fee for participating?

You will not be reimbursed for any expenses incurred when participating in this research.

Any questions?

If you have any questions, you can contact the research team at MS Center Amsterdam by calling Dr. E.M.M. Strijbis on +31 (0)20 4442834 or by sending an email to: msonderzoek@amsterdamumc.nl. Alternatively, you can get in touch with your attending physician. If you would like to obtain information about this study from an independent physician, Dr. Y.A.L. Pijnenburg is willing to answer your question. She can be reached via the neurology secretary on +31 (0)20 4442834.

More MS-information

For current MS information and news about MS research, visit the website: www.mscentrumamsterdam.nl (Dutch).

Support MS research

'We want to give people with MS a normal daily life.'
We cannot do this without your support!
You can donate via www.steunmscentrumamsterdam.nl

Amsterdam MS Cohort (2020.269), Amsterdam UMC MS Biobank (2016.554) en MS-kwaliteitsregistratie (2021.0506).