

General privacy statement of Amsterdam UMC (Abridged)

Abridged version, September 2024

If you are a patient or visitor of Amsterdam UMC or if you participate in research your personal data will be saved in our systems. The same applies when you visit any of our websites or attend a course with us. It is only natural for you to want assurance that your data will be safe with us. We at Amsterdam UMC also consider your privacy extremely important.

This document explains how we handle your data. Do you wish to read the privacy statement in full? If so, click [here](#).

Information for (adult) patients: which of your data do we use?

We 'process' or 'use' data concerning all of the patients at our hospital. When you are examined by a doctor, the results of your treatment are noted in your patient record. Our doctors are required to do this because they have a statutory obligation to do so under the 'Medical Treatment Contracts Act (WGBO)'. Medical data includes data regarding your health, the results of examinations, diagnoses specifying your illness(es), and your treatment plan. In addition to your medical data, we also require other personal data about you, such as your name, address and date of birth. This data is required so that we avoid confusing you with any other patient. Under no circumstances will we use more data than is required in order to assist you appropriately. Most of the data relating to your healthcare has been provided to us by you yourself, or has been generated through any examinations we have carried out on you. Once we have received your approval for doing so, we may also receive data from your GP or other healthcare providers in order to enable us to provide you with appropriate healthcare.

How we handle your data

Amsterdam UMC takes the appropriate technical and organisational measures to protect your personal data against loss or unlawful use. Parties permitted access to your personal data on behalf of Amsterdam UMC are obliged to treat your data confidentially. Only employees who are involved in your treatment or care have access to your personal data. These employees are legally required to observe confidentiality in respect of your data. They will not share your data with anyone where doing so is unnecessary on legal or medical grounds. If we as your healthcare provider deem it important that your data be shared with others, then we will request your permission before doing so. The decision is yours as to whether or not we share your data with others. If you do not grant your permission, this will in no way affect your treatment at Amsterdam UMC.

In some cases, we have a statutory duty to share certain of your personal data with other parties. For example, when sending a letter containing the bill for your treatment to your healthcare insurer. Another example is that the hospital is required by law to audit the quality of care we provide. (In doing so, we help to improve Dutch healthcare.) For this purpose, we are sometimes required to share your data with national registries. If it is necessary for your treatment or health, we will inform your GP who referred you about the main results (outcomes) of your treatment.

We only share data if it is necessary to do so. In urgent cases or emergency situations, we may need to take a decision on your behalf. When taking such a decision, your health is always our number one consideration.

Where we store your data

We save your medical data in Amsterdam UMC's Electronic Patient Record (EPR) system. The healthcare providers who treat you can access your record (file) at both Amsterdam UMC locations (i.e. both AMC and VUmc buildings). This is necessary in order to ensure your safety and to be able to provide you with good care. You can view this data (or a portion thereof) yourself via the *Mijn Dossier* ('My Record') digital environment. Amsterdam UMC relies on the services of a US-based company in relation to electronic patient records. Personal data is only passed on to companies with which appropriate agreements have been made in accordance with privacy legislation.

How you can inspect your own data

You are permitted to inspect your own personal data and patient record at Amsterdam UMC. You can ask your doctor for permission to do this. Your doctor is obliged to grant you permission to inspect your data. Your doctor may however block certain portions of your record if they contain information about others, such as family members. Moreover, your doctor is not required to allow you to read his or her own notes. You can request a copy of your patient record. You can find out how this works on our website under the section [Rights and obligations](#).

How long we store your data for

We store your data for at least 20 years from the time your file has last been amended. Because Amsterdam UMC is a university hospital, we have a statutory duty to keep certain data from your medical record, known as the 'core documents', for a period of 115 years from your time and date of birth. The core documents include discharge letters, operation reports, anaesthesia records, results of pathological examinations and first aid reports.

Are you satisfied? Patient Experience Monitor (PEM)

The Dutch University Medical Centres (UMCs) measure the satisfaction of patients with their treatment annually. We do this by means of a questionnaire. Participation is entirely voluntary. We also send the questionnaire to children, or their parents/caregivers. Children of 8 years of age and over can also complete part of the questionnaire themselves. The questionnaire is also sent to adult patients and children following video or telephone appointments. By using the PEM to measure patient experiences at UMC level, Amsterdam UMC can compare its own results with those of other UMCs. By learning from good examples from both within and outside its own hospital, Amsterdam UMC is able to improve the quality of its patient care.

Additional information for children

If you come to Amsterdam UMC because you are ill, we will do everything in our power to help you get better. To make sure this is done properly, we will note down information such as your name, address and age. That way, we will know who you are and we can avoid getting you mixed up with anyone else. We also take notes about how you are feeling and what we have learned about your illness from the examinations and tests that have been done. We will put all of the data into your record. We look after all your data carefully and only share it with the people who take care of you, such as your doctor and nurse.

Are you under 12 years of age? Then your parents* are allowed to read what we have written down in your record about you and your condition. If there is anything in your record which is wrong, such as your address, they can ask us to change it. We keep your record for at least 20 years, starting from your 18th birthday. We are required to keep certain data for 115 years, starting from your time and date of birth. Your parents can, however, request to have your record deleted sooner than that. The doctor will find out first whether that is allowed. In some cases, it is important for your health that your record be retained. In that case, we will not delete your record.

Are you aged between 12 and 16? If so, you can ask the doctor for permission to look at your own record. Your parents are also allowed to request this. You can tell the doctor if you do not want your parents to see your record or have your data changed. We will keep your record for at least 20 years, starting from your 18th birthday. We are required to keep certain data for 115 years, starting from your time and date of birth.

Are you over 16 years of age? Then you are allowed to look at your own record. Your parents are not allowed to do this. You may also request changes to your data, for instance if the address in your record is wrong. You can also ask to have your record deleted. Your parents are not allowed to do this. The doctor will first check whether it is possible to have your record deleted. In some cases, it is important for your health that your record be retained. In that case, we will not delete your record. The doctor does, however, have to explain to you why it is important for us to keep your record. We keep your record for at least 20 years, starting from your 18th birthday. We are required to keep certain data for 115 years, starting from your time and date of birth. As a university hospital, we are required to do this by law. Do you want your parents to also be able to look at your record or be allowed to have something changed in it or to request to have it deleted? If so, please go to the central counter of the outpatient clinic with your parents. You can tell one of the employees there that you want your parents to have access to your record. You and your parents should bring your ID cards or passports with you.

** 'Parents' should in each case be taken to mean one or more of your parents or caregivers.*

Information for medical research participants

Medical research enables us to improve the care provision and knowledge of our doctors and nurses. At Amsterdam UMC, we carry out medical research. This research is aimed at discovering better treatments for illnesses, learning more about particular illnesses and finding ways to detect certain illnesses (or to detect them more easily). Amsterdam UMC is careful to ensure that all of the medical research carried out at the hospital takes place in an ethical (and

sensible) manner and in accordance with the law. We inform you fully of your rights in letters sent to you in respect of any scientific research.

Medical research involving humans (human subjects)

You may be asked to participate in a scientific study. You are of course entitled to say 'no'. This will in no way affect your treatment. You are also entitled to change your mind and cease your participation, even once the research has started. All data collected by the researcher during the research will remain confidential.

Medical research involving medical data and/or body material

In addition to medical research involving human subjects, research is also done at Amsterdam UMC using medical data in the record and/or body material. In such medical research, the researcher studies the medical data and/or body materials gathered. This research is subject to strict conditions. The researcher is not always obliged to request the consent of each participant separately in this type of research, for instance if the research data cannot be traced back to any specific individual. Our Medical Ethics Committee (METC) evaluates whether the researcher is required to request your consent. You can ask your attending doctor or the researcher for more information about the research and what will be done with your data or body materials during and after the research. However, under no circumstances will your data be shared with others without your consent.

If you do not want any of your medical data and/or body materials to be used for scientific research, you can inform your attending doctor or the department in which you are being treated of this. In such case, your data will not be used.

Information for course participants and students

If you are participating in a course of training at Amsterdam UMC, we will collect personal data about you, such as your name, address and date of birth. We need this data in order to ensure that we do not confuse you with another student or course participant. We also keep track of your study results. This data is suitably protected and secured and may only be examined by authorised persons. When the data is no longer needed, it is deleted.

The privacy of our visitors and of users of the emergency telephone hotline

We deploy cameras in and around our buildings and grounds in order to protect our visitors and employees as well as possible against theft, vandalism and other criminal offences, and also to ensure patient safety. Signs are used to indicate the deployment of camera monitoring.

Recordings may also be made of conversations held via the emergency hotline. We do this in order to improve our assistance in emergency situations.

Both camera images and recordings of conversations are retained for a maximum of four (4) weeks.

Information for website visitors: collection and use of your personal data

Amsterdam UMC only collects personal data via this website if such data is required in order to enable (or improve) your use of this website and the services provided through it. In order to do this, we use cookies. You can find information about cookies and how we use them here.

Your personal data will in principle only be used for the purposes for which it has been shared with us.

We use your personal data for other purposes in the following cases:

1. If we have received your express permission to use your personal data;
2. If we are required by law to use your personal data;
3. If we need your personal data for the assertion of the legitimate interests of Amsterdam UMC. The legitimate interests of Amsterdam UMC include: improving the quality of our services, informing you of Amsterdam UMC's other services, and defending Amsterdam UMC or one of its employees in the event of a complaint or legal action.

An example:

- If you send us an email asking for information about Amsterdam UMC, we will use your email address and other information you have shared with us to reply to your email.

Privacy rights

You have a number of rights with regard to the personal data which we collect from you:

- Right of access
- Right to rectification
- Right to restriction of processing
- Right to object
- Right to erasure
- Right to data portability

Should you wish to access your medical data, please contact the Healthcare Support Patient Service (PAZO) via dossierdesk@amsterdamumc.nl. You may also exercise your privacy rights by sending an email to the Data Protection Officer via privacy@amsterdamumc.nl. This is a free service. We will respond to your request within one month.

Contact

The employees of Amsterdam UMC do their utmost to provide you as a patient with the best possible treatment, care and support. However, there is still a possibility that you will have a negative experience, or that the treatment or organisation does not meet your expectations when it comes to the protection of your privacy.

If you have any questions, complaints or comments, there are various ways to communicate these:

1. If you have any questions or comments about the protection of your privacy, please contact Amsterdam UMC's Data Protection Officer by sending an email to privacy@amsterdamumc.nl.
2. Any [complaints you may have can be submitted to Amsterdam UMC](#).
3. You can also submit [any complaints you may have in relation to privacy to Autoriteit Persoonsgegevens, the Dutch Data Protection Authority](#).