

# Terms of Use

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If you continue to browse and use this website, you are agreeing to comply with the following terms and conditions of use and with the WMDA Privacy Policy. If you are a registered user or active member of WMDA, your use of the WMDA services is also governed by the Membership Agreement. If you disagree with any of these terms and conditions, please do not use our services.

The term WMDA (World Marrow Donor Association) or 'us' or 'we' refers to the owner of the website whose registered office is Schipholweg 55, 1st floor, unit 2, 2316ZL Leiden, The Netherlands. Our company registration number is 40448326. The term 'you' refers to the user or viewer of our website.

## Web-based services provided by WMDA

This includes the WMDA website (<https://wmda.info/>), all subdomains of the website, and other sites as listed below:

- <https://wmda.info/>: General information about the organisation
- <https://share.wmda.info/>: More specific information regarding the activities of the four WMDA pillars
- <https://education.wmda.info/>: E-learning platform
- <https://searchmatch.wmda.info/>: Searchable database of adult donors and cord blood units for hematopoietic stem cell transplantation, accessible only for registered users.
- <https://questionnaire.wmda.info/>: Service to export global trends data provided by participating organisations
- WMDA meeting websites: Information on upcoming virtual and in-person meetings
- <https://worldmarrowdonorday.org/>: Information on this annual event acknowledging donors
- <https://crm-data.wmda.info/>: Published data for registries
- <https://statistics.wmda.info/>: Statistical information
- <https://spear.wmda.info/>: Reporting system for serious adverse events and reactions by participating organisations
- <https://connect.wmda.info/api/>: Registry to registry communication system

The information on some of these sites is subject to change without notice.

## Access to WMDA online services

WMDA operates two types of services:

- Public. No user account is needed
- Restricted. A personal user account is needed. MFA is used or will soon be implemented for all WMDA online services.

The right for personal access cannot be transferred, sold or rented to anyone else. We reserve the right to suspend or terminate any account that we believe is being used for illegal or unauthorised activities, or any account violating these terms. Please remember that we are not responsible for any breaches of security that occur outside of our platforms.

## Account sharing

Sharing of user accounts on any web-based service provided by WMDA is strictly prohibited. Each user must create and maintain their individual account. Users are responsible for maintaining the confidentiality of their account information, including login credentials. Any unauthorised sharing of accounts may result in the suspension or termination of access to the service.

## Accuracy and operation of services

We will make every effort to keep WMDA websites current and to correct errors brought to our attention. Documents published on the sites might not be in the final or formally accepted version. WMDA does not warrant the error-free operation of its services. WMDA accepts no responsibility or liability whatsoever with regard to material accessed, operated on or downloaded from its services.

## Use of information and resources

Information on WMDA websites is not intended to provide specific advice unless it is stated otherwise. Neither WMDA nor any person acting on its behalf is responsible for the use that might be made of the information or resources contained in these services. Users act at their own risk when using information or resources on the websites and they are hereby urged to take necessary precautions when evaluating the usefulness and applicability of information or resources for their intended purposes.

## Privacy Policy

The WMDA is committed to user privacy. The WMDA services have been structured so that users have to identify themselves with a username and a password. Completion of the online membership form requires the submission of personally identifiable information. WMDA will use the information for the purpose of membership administration (e.g., sending WMDA communications including the invoice for services requested). In case of the online learning platform, personal information related to participation and test scores are recorded so that the user can pass a course and/or obtain a diploma.

### Members' Rights Regarding Personal Data:

1. Confirmation as to whether data related to him or her are being processed
2. Information about the purposes of the processing operations, the categories of data concerned, and the recipients or categories of recipients to whom the data are disclosed
3. Communication of the data undergoing processing
4. Knowledge of the logic involved in any decision process concerning the use of personal data.

### Users' Rights Regarding Their Personal Data:

1. Access to information on his or her processed personal data
2. Rectification of any inaccurate or incomplete personal data
3. Withdrawal of consent so that personal data will no longer be processed
4. Request that his or her personal data be completely erased from the WMDA services to which the data has been exported.

Users and viewers also have the right to lodge a complaint with a supervisory authority:

Data Protection Officer  
Schipholweg 55, 1st floor, unit 2  
2316ZL Leiden, The Netherlands

## Important message on data minimisation and security

Unless stated otherwise, visitors to WMDA services are not allowed to submit sensitive personally identifiable information related to donors, patients, or other individuals who may not be members or users of WMDA services or its member registries. See below for specific terms regarding SPEAR and MatchConnect.

## Reporting Serious Adverse Events and Reactions (SPEAR) to WMDA

Please note that SPEAR reports may contain privileged and confidential information. It is intended only for the use of the person(s) belonging to the reporting registry and/or their affiliated organisation(s). The data downloaded from the SPEAR online reporting tool remains confidential and should be treated as such. The dissemination, distribution or duplication of the data downloaded from the SPEAR online reporting tool outside of your own registry or organization is therefore prohibited. The WMDA shall not be liable for any indirect, incidental, consequential or punitive damages, whether incurred directly or indirectly, or any loss of data, use, goodwill, or other intangible losses resulting from any content obtained from the SPEAR online reporting tool or due to unauthorized access, use or alteration of downloaded content.

## Search, Match & Connect

The Match-Connect service consists of several components. For all components it is not allowed to send information that is not required in order to perform the work that needs to be done on the service. Below we make some specific claims that always count on this platform:

## Search & Match Service

URLs: <https://searchmatch.wmda.info/> and <https://sandbox-search.wmda.info/>

In concordance with the general data minimisation principles described above, the following data is never allowed to be entered on this service for a patient or any other person:

- First name
- Last name
- Any reference to the initials
- Any location information regarding where the person lives

## Dataupload

URLs: <https://dataupload.wmda.info/> and <https://staging-dataupload.wmda.info/>

In concordance with the general data minimisation principles described above, the following data is never allowed to be entered on this service for a donor or any other person:

- First name
- Last name
- Any reference to the initials
- Any location information regarding where the person lives

## Registry-to-registry communication system (connect APIs)

URLs: <https://connect.wmda.info/api/> and <https://sandbox-connect.wmda.info/api/>

Depending on the messages being exchanged on this system, there may be differences in the level of personally identifiable information required in order to allow for successful and useful information exchange. Always make sure that the receiving organisation absolutely requires this information at this stage of the communication. If the receiving registry does not require the information, it should not be sent.

## Data retention

In adherence to the principles of transparency, accountability, and privacy, the World Marrow Donor Association (WMDA) has established a comprehensive Data Retention Policy as an integral component of its Terms of Use. This policy outlines the guidelines and procedures governing the retention, storage, and disposal of user data collected through the WMDA platform.

### Purpose of Data Retention:

The primary objective of data retention within the WMDA framework is to facilitate the efficient operation of the organization's services and to support its mission of connecting donors and patients worldwide. Retained data is utilized for communication, research, and statistical analysis aimed at enhancing the effectiveness of the WMDA's operations.

### Types of Retained Data:

WMDA may collect and retain various types of user data, including but not limited to personal information, medical information, communication history, and donor/patient matching details. The organization ensures that the collection and retention of such data are conducted in compliance with relevant data protection regulations.

### Retention Period:

Data will be retained for a period deemed necessary for the fulfilment of WMDA's operational objectives, legal obligations, and the provision of ongoing services. The retention period may vary based on the nature of the data, its relevance, and the applicable legal requirements.

The table below describes the retention periods for some of the various WMDA services.

| Service                                                                                                     | Data type                  | Retention period                                                                                                                                                                                                                                                    |
|-------------------------------------------------------------------------------------------------------------|----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>• Search &amp; Match</li><li>• Patient</li><li>• Search API</li></ul> | Patient information        | 42 days + 6 months of no user interaction with patient or its searches: the patient is anonymised by replacing the patient ID with a random string and the birth date with birth year. Patient is no longer accessible by any organisation, except for WMDA admins. |
|                                                                                                             | Search results information | Search results are removed when the patient is "inactivated" (set to the "STP" status). Statistical data regarding number of search results and type of search are retained for analysis purposes.                                                                  |

|               |                                                                                                                                                                 |                                                                                                                                                                                                              |
|---------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|               | Logs regarding API and website use and associated error messages.                                                                                               | Up to 3 years.                                                                                                                                                                                               |
| • Connect API | Encrypted message contents for non-retrieved messages                                                                                                           | Messages are available for retrieval for 90 days. After that they are marked as "retrieved" and handled as such. See below for information on retention and destruction information on "retrieved" messages. |
|               | Encrypted message contents for retrieved messages                                                                                                               | In order to facilitate recovery of retrieved messages, these messages are retained for 72 hours after retrieval.                                                                                             |
|               | Logs regarding message sending and retrieval. Contains meta information on messages, such as the sending and receiving organisation and validation information. | Up to 3 years.                                                                                                                                                                                               |

## Security Measures:

WMDA utilizes standard security measures and encryption practices to protect stored data from unauthorized access, disclosure, alteration, or destruction. The organization is dedicated to upholding the confidentiality and integrity of user information through the implementation of encryption, access controls, and regular security assessments. It's important to note that while these measures are industry-standard, no system is entirely foolproof. As such, we cannot offer absolute guarantees regarding the security of the data. WMDA cannot be held responsible for any breaches or data loss. You can contribute to the safety of the system by using strong passwords, proper device security and by not sharing your passwords.

## Access and Rectification:

Users have the right to access their personal data stored by WMDA and rectify any inaccuracies. The organization will provide mechanisms for users to review and update their information, ensuring that the data retained remains accurate and up-to-date.

## Data Disposal:

Upon expiration of the designated retention period or upon request for deletion by the user (where applicable), WMDA will systematically dispose of data in a secure and irreversible manner. This process will adhere to industry best practices and legal requirements to ensure the permanent removal of user information from WMDA's systems.

## Compliance with Applicable Laws:

The data retention practices of WMDA will consistently align with the requirements of relevant data protection laws and regulations, ensuring a legal and ethical framework for the collection, storage, and processing of user data.

By adhering to this Data Retention Policy, WMDA aims to balance the necessity of retaining information for operational purposes with the commitment to safeguarding user privacy and maintaining the highest standards of data protection. This policy is subject to periodic review and updates to align with evolving legal standards and organizational needs. Users are encouraged to review this policy regularly to stay informed about how their data is managed within the WMDA ecosystem.

## Copyright

Whilst content may be accessed, downloaded and used, visitors are not allowed to publish any material from these websites for public consumption without permission.

## Links to other websites

These websites include links to other websites. These links are provided for your convenience to provide further information. We have no responsibility for the content of any linked website(s).

## Use of cookies

We use cookies to enhance your user experience. By clicking the accept button, you are giving your consent to the [use of cookies](#).

## Amendments

WMDA is free to unilaterally change the Terms of Use without giving further notice to the individual member or user. Such changes will, unless otherwise stated, take immediate effect and will be published on WMDA Share, in the "Stem Cell Matters" newsletter and on the web sites of the relevant WMDA online services. Members or users are responsible for keeping themselves updated in relation to any changes to the Terms of Use.

## Governing law and jurisdiction

These Terms of Use and any dispute or claim relating to the Terms of Use or the services provided by the WMDA website are governed by the laws of The Netherlands. Any dispute arising out of, or related to, these Terms of Use or the services, whether contractual or arising from an unlawful act, must be brought exclusively before the courts of The Hague in The Netherlands.

## Contact Us

Your access to and use of the services is conditioned on your acceptance of and compliance with these Terms. These Terms apply to members, users and others who access or use our services. If you have any questions about these Terms of Use, please contact the WMDA office by email [mail@wmda.info](mailto:mail@wmda.info).