

## Immunoglobulin Home Therapy: Draft Privacy Policy

Last updated: March 2019

### TERMS OF SERVICE

### CONFIDENTIALITY AND SECURITY ON THE INTERNET

MDSAS (Medical Data Solutions and Services) has taken measures to ensure the security and confidentiality of any information that you provide to this site, the Internet is not an absolutely secure medium, and is not under MDSAS's control. Use of the Internet is solely at your own risk and is subject to the applicable laws and regulations. Haemtrack communication between your PC, Mac or smartphone and your Treatment Centre uses the internet and is encrypted using industry standard technologies as used in Internet banking. MDSAS has taken measures to ensure the security and confidentiality of any information that you provide to Haemtrack.

### PRIVACY POLICY

MDSAS are strongly committed to maintaining your privacy.

Medical Data Solutions and Services ("MDSAS", "we", "us", "our") operate the Immunoglobulin Haemtrack site ("the Site"). This Privacy Policy tells you how we use, share, and protect the privacy of the information that we collect from you during your use of the Site.

The Site is intended to be used by Healthcare Professionals, Patients and their Caregivers. It allows a Patient to record their personal health and treatment information and to share that information with their Health Care Professional(s) in a timely manner.

Your information may also be used in an anonymised way to carry out research and audit with an aim to improve treatment and care. By using the site, you agree to the collection and use of your information as set out in this Policy.

#### What information does the Immunoglobulin Haemtrack site collect from you?

The Immunoglobulin Haemtrack site requires you to enter data in order to provide its functionality. This includes data about you and your treatment when you or your Healthcare Professional enter it, and additionally it collects certain data about your visit when you use the Site. The data collected falls into three categories as described below.

#### **Personal Information**

In order to register an account with the Site, we ask you to enter Personal Information which is used by your health care professionals to identify you. This Personal Information may include (but is not limited to) your name, date of birth, NHS number and email address.

#### **Treatment Data**

Treatment Data is data you provide about your health and treatment which is linked to your user account but does not, on its own, identify you.

When you (as a Patient or Caregiver) enter Treatment Data on the Site, it is shared with your Healthcare Professional(s) as described in this Policy. Your Treatment Data may also be provided in an anonymised format to third parties for research and audit purposes as disclosed in this Policy. Treatment Data which is disclosed for research and audit purposes does not include personally identifiable Information.

## Log Data

When you use the Site, our server automatically records information about your visit ("Log Data"). This Log Data may include information such as your IP address, browser type and version, and pages that you visit. Log Data does not include Personal Information or Treatment Data. We use Log Data to monitor, maintain and improve the Site's operation, and do not provide it to anyone else except as otherwise disclosed in this Policy.

## How your information is used

You and your health care professionals can access your data. In addition, your data may be used in a de-identified (anonymous) way for research and audit purposes by third parties with an aim to improve treatment and care. This work may be funded by NHS commissioners or through third-party grants. To de-identify the data means to remove all personal identifiers so that you cannot be identified.

We will not allow access to your personal data with any outside parties, except as we have explained in this Privacy Statement or as we tell you at the time you provide the information.

## Your choices regarding the collection and use of your information

We want you to be confident that we are collecting only the information you are willing to share with us. We will indicate, at each data collection point, whether the information is required in order to use the Site or whether it is optional.

It is important for your Healthcare Professionals to have access to accurate information; therefore, we provide you with access to the data you have provided so that you can update it or correct errors to keep the data current and complete. We may not allow you to access certain information if doing so would harm, or put at risk, another person's privacy, or if we are entitled or obliged by law to withhold the information in the circumstances.

When you give us information at this site, you consent to the use and release of your data as we have explained in this Privacy Policy. You have the right to review and request the deletion of personal data collected at this Site. If you ever decide you do not wish to participate in the Haemtrack program, if you are unable to access your personal data, or if you would like to review your data, you may contact us by email at [support@mdsas.com](mailto:support@mdsas.com) or by mail at:

MDSAS  
City View House,  
5 Union Street,  
Manchester  
M12 4JD

Please note that, in addition to the rights set out in this Privacy Statement, you may have further rights in relation to the use, collection and disclosure of your personal information under the Data Protection Act of 2018.

## Security

We want your personal data to remain safe. However, there are no systems that are 100% secure or error-free and we therefore cannot guarantee the security or accuracy of the information we gather.

We have implemented security measures to protect the privacy and security of the data within the Site. For example, any treatment data you give us is transmitted to the Site over a secure, encrypted connection.

## Passwords

One way we protect your personal data is by requiring you to log in to the Site with your unique username and password before you can view or edit personal information. It is your responsibility to ensure that your password remains secret. The Site provides the ability to reset your password if you forget it or believe that it is no longer secret. If you suspect that someone else has unauthorised access to your account, you should reset your password and inform your Treatment Centre immediately.

It is important that you keep your contact email up to date, as we will use this to verify your identity and send you instructions to reset your password.

### **Cookies**

We use cookies as required to optimise the Site and to support the Site's functions, such as enabling you to log in to the Site. If you block cookies from the Site, you will not be able to use the Site or your access to its functions will be limited. We do not use tracking or advertising cookies.

### How Haemtrack protects the privacy of children and persons with legal guardians

Children and persons with guardians who are invited by health care professionals to use the Site are required to provide the same data as adult participants. This Privacy Statement applies equally to children and adults with guardians.

We require written parental or guardian consent before we allow children or persons with guardians to use the Site. If there are changes to this Policy, we will ask for the parent or guardian's consent before using or disclosing information about the child or adult.

We reserve the right to collect, use, and release a person's name and online contact information without parental or guardian consent, to the extent that it is necessary to protect the security of our Site, to protect us from liability, and as required by law. We always welcome questions from parents and guardians and encourage them to contact us at the address below.

Parents and guardians have the right to review and request the deletion of personal data collected at this Site. To review personal data, or to have data deleted, please notify your Healthcare Professional who will notify us to arrange this. You also have the right to revoke your consent to our collection of your child's information, or that of the adult to whom you are a guardian, or your information. To revoke consent, contact your Healthcare Professional.

### Withdrawing from Haemtrack

If you decide that you no longer want to participate in the Home Therapy programme, you can withdraw at any time by informing your Healthcare Professional.

### Clinical Research

Only observational research is conducted using data from the Haemtrack system. Observational research is non-interventional research consisting of observing and analysing patterns in normal treatment, and in patients of different age and severity. In such research the patient is not asked to change treatments or treatment regimen or given experimental treatment. By agreeing to this Policy, you are giving consent for your treatment data to be made available for observational research.

Data for research purposes will only be provided on a de-identified basis (that is, with all personal identifiers removed) and/or in an aggregate format (that is, as totals and summary figures rather than individual records). No third party will be provided with any data containing personal identifiers.

### Contacting MDSAS with questions or comments

If you have questions, comments, concerns or complaints about this Privacy Statement, or the information practices of this Site, you can contact us by email at [support@mdsas.com](mailto:support@mdsas.com) or by mail at:

MDSAS Support  
City View House  
5 Union Street  
Manchester  
M12 4JD

We welcome your comments and feedback and will do our best to answer your questions or concerns and to fix problems that you bring to our attention.

Please be aware that email may not be secure, and we suggest that you do not send clinical or medical information by email.

### Changes to this Policy

We may change this Privacy Policy at any time. If we do change the Policy, the new Policy will be posted here along with the date it was changed. You will be asked to agree to the new Policy by way of a notice that will appear when you log in to the Site for the first time after the change. Until you agree to the new Policy, any information you have previously provided to us will be treated in accordance with the last version of the Policy that you agreed to. If you do not agree to the new Policy, you will not be able to use the Site.

This Policy will be available on the Site for you to view at any time, and we encourage you review the Policy if you have any questions or concerns about entering your personal data.

### APPLICABLE LAWS

This site contains information about treatments and therapies, which may or may not be available in other countries. Each country has specific laws, regulations and medical practices governing the communication of medical or other information on the Internet. Nothing in this site should be viewed as a solicitation or promotion of any particular treatment or therapy, which is not authorised, by the laws and regulations of the country where the reader resides, or as a promotion or advertisement of any products or services.

The treatment log facility provided on this site is intended to supplement, but not to replace, communication with your health care professionals in respect of your Treatment Centre. Remember! Haemtrack is not an emergency notification tool! Contact your designated emergency number immediately should a serious or life-threatening event occur. This site is not intended to replace a medical record.