

HARTWIG MEDICAL FOUNDATION - PRIVACY POLICY

Version: 3.0

This privacy policy applies from 25 May 2018. The Hartwig Medical Foundation (**Hartwig Medical Foundation**, 'we' or 'us') can amend this privacy policy at any time by publishing an amended version on its website.

1 Introduction

This privacy policy applies to the processing of personal data by Hartwig Medical Foundation.

This privacy policy provides insight into the manner in which Hartwig Medical Foundation collects, protects, uses and transfers personal data. This privacy policy also provides you information about your rights with regard to the processing of your personal data by Hartwig Medical Foundation.

We respect your privacy and process your personal data with the utmost care and in accordance with the General Data Protection Regulation and the Dutch Implementing Act General Data Protection Regulation (hereinafter: the **Laws and Regulations**).

Please read this privacy policy carefully.

We may change this privacy policy from time to time. The most recent version of this privacy policy can be found on our website www.hartwigmedicalfoundation.nl (the **Website**). We recommend you to regularly review the privacy policy on our Website. In case of significant changes to our privacy policy we will expressly bring this to your attention.

2 For what activities does Hartwig Medical Foundation process personal data?

We may process your personal data for multiple activities and in multiple manners. That happens:

- when sequencing biological material from patients with cancer (see paragraph 3);
- when managing a database with data from cancer patients (see paragraph 4);
- when creating an account for access to the HMF Data Portal;
- when organizing events and meetings, conducting surveys and sending our newsletter (see paragraph 5);
- when engaging in and executing business relations, such as with (external) suppliers and customers (see paragraph 6); and
- when you visit our Website (see paragraph 8).

On the Website you will find further information about our activities. Below, we will elaborate, per activity, on which personal data of yours we may process, for which purposes and our role in that respect.

3 What personal data does Hartwig Medical Foundation process when sequencing patients' biological material, how do we process these data and what happens with the personal data?

In short: we sequence biological material of patients with cancer on the instructions of hospitals, treatment centers and research institutes. This happens only with the knowledge and consent of the patient. By means of sequencing we generate (unique) genetic information of the patients. This information is transferred to the hospitals, treatment centers and research institutes that have assigned us the sequencing task. This genetic information about patients that we generate by means of sequencing cannot be traced back to the patient by us (but can be by the hospitals, treatment centers and research institutes that have assigned us the sequencing task).

Cancer is caused by (multiple) defects in the genetic material (DNA) of a patient. In assessing what the best treatment would be, it can be of importance to determine the defects in the DNA (of the tumor) of the patient. This is possible by 'sequencing' biological material of the patient (such as tumor tissue and blood).

We sequence biological material of patients with cancer on the instructions of organizations with whom we collaborate, such as hospitals, treatment centers and research institutes (the **Providing Institutions**) and only as part of clinical research. This happens only with knowledge and consent of (or on behalf of) the patient.

By means of sequencing we generate genetic data from biological material of cancer patients. This biological material is provided to us by the Providing Institutions. Sequencing unveils the complete genetic composition (also: the genome) of the patient and makes it available. Unique information about (the defects) in the DNA of the tumor of the patient is simultaneously determined.

This genetic data is analyzed by us. Based upon this analysis we compose a report. All information that we generate by sequencing is transferred to the Providing Institution. Every Providing Institution has and will continue to have disposal of the data of its 'own' patients. We provide an online portal for this, giving Providing Institutions the opportunity to check and download the generated genetic data. Obviously this online portal is well secured. For example, by logging we keep track of which Providing Institution checks upon what data and when. We do this with the assistance of our IT service provider.

The sequencing of biological material and the generating and analyzing of genetic data is done for and on the instructions of the Providing Institutions. In this respect, we operate as 'processor' within the meaning of the the Laws and Regulations. The Providing Institution is the controller within the meaning of the the Laws and Regulations.

This means (among other things) that we do not have independent control over the use of the biological material and genetic data and that we are bound to the instructions of the Providing Institutions. We enter into agreements with the Providing Institutions about the use, confidentiality and security of the biological material (that we receive from the Providing Institutions to sequence) and the genetic data that we

generate as a result of sequencing thereof.

The Providing Institutions provide us with the biological material encoded, so without a name, date of birth or social security number of the patient, but with a code only. Only the Providing Institution knows which patient corresponds with the code. That means that we are unaware from which patient the biological material comes and (subsequently) are unable to trace the generated genetic data back to the patient. The Providing Institution can trace the genetic data with which we have provided them back to the patient.

We have no direct contact with the patients of whom we sequence biological material. Only the Providing Institutions have this contact. In case of questions, complaints or remarks about the sequencing of your biological material and the generating, analyzing and further use of your genetic data, we ask that you contact the Providing Institution.

4 We maintain a database

In short: we maintain a database in which we record encoded genetic and clinical data of cancer patients. In the database we record among other things the genetic data which we have generated by sequencing biological material on the instructions of a Providing Institution (see the previous paragraph). This happens only in collaboration with the Providing Institution and with consent of the patient (only in extraordinary circumstances can this happen without the patient's consent). Please note: we only record data in the database. We are not a biobank. The data in the database are meant to be made available to researchers for research purposes to further develop the knowledge on cancer and the treatment thereof and to improve the care of cancer patients.

We maintain a database in which we record genetic and clinical data of cancer patients in the Netherlands and make this available for research (the **Database**). This Database was set up to (further) develop the knowledge of cancer and the treatment thereof. Hartwig Medical Foundation wants to improve the care of (future) cancer patients (for example by developing new treatment methods and the (more) efficient usage of cancer medicine).

What personal data does Hartwig Medical Foundation process in the Database?

In the Database we record the following data:

- gender and age of cancer patients;
- clinical data of cancer patients, such as data about the characteristics of the tumor of the patient, treatment history, treatment data (including choice of therapy and medicine), and results of the treatment; and
- genetic data of cancer patients that we have generated by sequencing biological material and that have subsequently been analysed (see paragraph 3 for more details).

We receive these data (just like the biological material) exclusively in an encoded form. We cannot (independently) track the data to an individual and, thus, we are unaware of what data corresponds with which patient. This way Hartwig Medical foundation safeguards the patient's privacy as much as possible. It is not necessary for Hartwig Medical Foundation and for the researchers to whom the data from the Database is provided to know who the patient is.

In the Database we record only the aforementioned data. We do not store biological (rest) material of patients in the Database. We return to the Providing Institution or destroy all unused biological material. **In other words: we have and are no biobank.**

How does Hartwig Medical Foundation collect the personal data?

We receive the data in the Database from the Providing Institutions. We collect no data about cancer patients in any other way.

The Providing Institutions transfer the data to us in accordance with their own privacy policy. If a Providing Institution transfers your data to us, the Providing Institution will inform you about this and ask for your consent (see hereafter for more).

For what purposes does Hartwig Medical Foundation collect and use the personal data?

The overarching goal for which we collect and use data in the Database is stimulating progress in research on (the treatment of) cancer in order to improve the care for (future) cancer patients. We process the clinical and genetic data for setting up, using, making accessible and maintaining the Database. We do so (among other things) for the following activities:

- We collect the data to record and store these data in the Database, in order to create a useful Database that is as complete as it can possibly be;
- We consult, organize, rubricate and sort the data, to make the maintenance and use of the Database as efficient and practical as possible;
- We consult, organize, sort and analyse the data to identify (possible) correlations in the data in the Database;
- We consult, use and analyse the data to improve the algorithms that we use with the analysis of the genetic data that is generated by sequencing;
- We perform (statistical) analyses on the Database for research purposes, to inform third parties about the (valuable) information that is recorded in the Database and to (keep) improving our Database and our internal processes (for example analysis software);
- We make the data available to third parties for research, but solely under predetermined conditions and in the manner as described hereinafter in this privacy policy under paragraph "*When is data transferred to third parties?*";
- We keep data up to date and delete data if a patient requests us to do so, based on his or her legal rights thereto;
- We strive to eventually connect or make connectable the data in the Database to data in other databases, that are comparable to the Database, such as the Nederlandse Kankerregistratie (NKR) and the Pathologisch-Anatomisch Landelijk Geautomatiseerd Archief (PALGA);

- We retain and delete personal data in accordance with paragraph 12 of this privacy policy.
- In case we stop existing or stop maintaining the Database, we can decide to transfer the Database to another organization with the same mission, purpose and safeguards as Hartwig Medical Foundation.

Hartwig Medical Foundation does not use personal data for other purposes, such as marketing purposes or to advertise for products or services.

On what basis does Hartwig Medical Foundation process the personal data?

The Providing Institutions must ensure that a data subject gives explicit consent for the provision of his or her personal data to HMF for the purposes referred to in this Privacy Policy. This happens through 'informed consent'. In so far as possible, Hartwig Medical Foundation will ensure that this has been complied with, and will then process the personal data exclusively within the parameters of the informed consent. In addition, we only use the personal data for scientific research that serves a public interest and we take such safeguards that the privacy of the patients is guaranteed. For example, we only process encoded personal data.

In extraordinary circumstances, Hartwig Medical Foundation works with data from data subjects whose tissue was taken quite some time ago (in the case of retrospective studies). In those cases, the informed consent pursuant to which the human tissue was obtained might be inadequate to serve as a basis for our processing activities. This can for instance be the case when the relevant human tissue was taken at a time when Hartwig Medical Foundation did not yet exist.

In such cases and in so far as possible, Hartwig Medical Foundation will attempt to obtain adequate informed consent through the Providing Institution. However, that is not always possible or practically feasible, for example where the data subject in question has passed away in the interim.

The public interest that Hartwig Medical Foundation seeks to serve (stimulating the research on (the treatment of) cancer to improve the care of (future) cancer patients), as well as the processing purposes described above, justify (in some cases) that we record personal data in the Database in such situations as well. In these cases we base its processing on the exception of the prohibition to process health data and genetic data that applies to conducting scientific research in the public interest. Naturally, we ensure (in these cases as well) that there is no unauthorized infringement of the data subjects' privacy. It does so by, for example, only processing data in encoded form.

When does Hartwig Medical Foundation share data from the Databank with third parties?

The data in our Database are intended to be made available for (further) research to external parties, such as (research) institutions, hospitals, universities and commercial parties such as pharmaceutical companies (but only for scientific research that serves a public interest). Such parties may ask us for certain information from the Database (a **Data request**). This is possible only for pre-defined, specific (research) purposes that have been preapproved by us.

Hartwig Medical Foundation does not give these parties access to the requested data from the Database automatically. We have a Scientific Council and a Data Access Board in order to ensure this. The Scientific Council and the Data Access Board assess Data requests according to a strict procedure that is codified in the Rules of Procedure. The Rules of Procedure Data Access Requests can be found on our Website.

We only provide specific and encoded data (we never provide access to the entire Database) and impose strict contractual rules and obligations on the receiving parties, such as the obligation to adequately secure the data they obtain. We also impose strict requirements regarding (restrictions on) use of the data by the receiving parties. They are obviously not allowed to use personal data for marketing purposes.

Who helps us maintaining the Database?

We engage third parties for technical support and to help us maintaining the Database. Our IT service provider helps us to maintain the Database, our systems and the company processes and to keep them functioning well. Thus, it is possible that our IT service provider has access to the data in the Database, but exclusively on our behalf and for the purposes described above. Our IT service provider does not use the data for his own purposes.

5 Organizing of events and meetings, conducting surveys and sending our newsletter

We regularly organize events and meetings, we can conduct surveys on our Website (optionally in collaboration with other parties) and we send a monthly newsletter. When doing this we process personal data of participants, respondents and recipients of our newsletter for the following purposes:

Personal data	Purpose
name	to approach parties (such as patients or employees of Providing Institutions) with information about events and meetings, in order to correctly address the (monthly) newsletter
function	to approach respondents of a survey to disclose results of a survey
organisation and section	to share results of a survey with the party with whom we have developed the survey
e-mailadres	to send invitations / newsletter
phone number	to keep guest lists
results survey	to send a (monthly) news letter

We may engage third parties who help us to organize events and meetings or to conduct surveys. We may share the aforementioned information with these parties for the purposes listed.

6 Processing personal data of (contact persons of) business relations

Like any organization we also process personal data of (contact persons of) parties with whom we engage in business activities. This can concern among others (contact persons of) our suppliers, (contact persons of) Providing Institutions and scientists/researchers to whom we make the data in the Database available. We collect and use this personal data for the following purposes:

Personal data	Purposes
name	(to enter into agreements about) maintenance of our apparatus or in order to maintain contact with a contact person of a Providing Institution or a researcher
function	to discuss contracts and the execution thereof with suppliers and clients or in order to maintain contact with a contact person of a Providing Institution or a researcher
organisation and section	for the placement, execution and/or cancellation of orders or in order to maintain contact with a contact person of a Providing Institution or a researcher
e-mailadres	to create an account to grant authorized persons access to our online portal, the HMF Data Portal by which we (i) give access to the Providing Institution to the genetic data generated by us and (ii) provide the researchers with data from the Database, or to maintain contact with a contact person of a Providing Institution or a researcher
phone number	in order to maintain contact with a contact person of a supplier, client, a Providing Institution or a researcher
log in data	in order to grant access to the HMF Data Portal

We may engage third parties to help us manage our systems and company processes and to keep them functioning well. We may share the aforementioned information with these parties for the purposes listed.

7 Sharing data with third parties

In as far as we share personal data with third parties it has explicitly been mentioned in the previous paragraphs of this privacy policy. We will only share your personal data with parties other than those mentioned above (such as authorized authorities) if we are obliged to do so by law, and/or in consultation with a Providing Institution that is obliged to do so or if this is necessary to protect our rights, property or safety. This always happens within the parameters of the Laws and Regulations.

We exclusively provide personal data to third parties if and in so far as these parties consent to treat the personal data they receive confidentially and if they provide sufficient safeguards for the safety of your data. Where necessary and relevant we enter into a data processing agreement with these parties.

8 Cookies

The use of cookies

If you use our Website, third parties (such as Google, Vimeo and YouTube) may place cookies on your computer, telephone or other device with which you visit the Website. Some cookies are essential for the Website to work properly; others serve to provide you with a better, faster and safer user experience.

A cookie is a small text file that is stored on your computer, telephone or other device that you use to visit the Website, allowing the Website to remember who you are and/or what your preferred language is for the Website.

By using the Website, cookies from the following third parties can be placed:

- Google;
- Vimeo; and
- YouTube

Each of these third parties has its own separate and independent privacy policy. We recommend that you read these third parties' privacy policies before accepting their cookies. With respect to Google Analytics: we have entered into a data processing agreement with Google, your IP address is partly masked, Google will not use your data for advertising purposes and we do not use other Google services in combination with the Google Analytics cookie.

Below, we have set out an overview of the third party cookies that you will encounter in any event when you use the Website.

Name Cookie	Source	Purpose of the cookie	Retention period
_utma	Google Analytics	This cookie collects information on the Website's use, users and user sessions.	2 years from set or update.
_utmb	Google Analytics	This cookie collects information on the Website's use, users and user sessions.	30 minutes from set or update.
_utmc	Google Analytics	This cookie collects information on the Website's use, users and user sessions.	End of browser session.
_utmt	Google	This cookie is used to throttle the request	10 minutes.

	Analytics	rate so as to improve the Website's operation.	
_utmv	Google Analytics	Used to track and to enable optimal functionality of user-custom variables for use of the Website.	2 years from set or update.
_umtz	Google Analytics	The functional cookie tracks how a user reached the Website (e.g. via a search engine or a link on another website).	2 years from set or update.
_ga	Google Analytics	Used to distinguish users from each other.	2 years from set or update.
_gat	Google Analytics	This cookie is used to throttle the request rate so as to improve the Website's functionality.	10 minutes from set or update.
PREF	YouTube	This cookie is used to remember preferences and user settings (such as preferred language) for YouTube clips on the Website.	8 months.
VISITOR_INFO1_LIVE	YouTube	This cookie measures your bandwidth to determine which YouTube interface to apply.	8 months.
vuid	Vimeo	These cookies are used to display Vimeo videos on the Website and to save preferences and user settings (such as the preferred language) for Vimeo videos on the Website.	2 years from set or update.

How do you manage / delete these cookies?

All major internet browsers offer the possibility to manage the cookies that are installed on your computer or mobile device.

If you do not want our Website to place cookies on your computer, you can easily restrict or delete them

by adjusting your mobile or browser settings. You can also set your mobile or browser settings so that you are notified each time you receive a cookie on your computer or device, so that you can decide whether you want to accept this cookie or not.

We note that when you disable certain cookies that we use, there is a possibility that certain parts of our Website may not function properly and you will no longer enjoy an optimal user experience.

Links/services from third parties

The Website may contain links to third party websites and services, such as links to social media platforms. We are in no way responsible or liable for the processing of personal data by these third parties. Each of these third parties has its own separate and independent privacy policy. We recommend that you read these third parties' privacy policies before visiting their websites or using their services.

9 Personal data protection

We take various technical and organizational security measures as necessary to process your personal data securely and in accordance with this Privacy Policy and the Laws and Regulations. These measures serve to protect your personal data against loss, misuse, amendment, disclosure, destruction, theft or unauthorized access and/or processing.

For the technical security of patients' data, we have engaged a reputable IT service provider, with which detailed arrangements have been made regarding the applicable technical security. These arrangements relate to such matters as access control, backups, application of the ISO 27001:2013 information security standard NEN7510, etc.

We also make confidentiality arrangements with our employees and ensure that only a limited number of (authorized) persons obtain access to patients' data. When relevant, we enter into (data processing and licensing) agreements with third parties that (could) obtain access to personal data that we process. In such agreements arrangements can be made about what these parties can and cannot with this personal data and how they must secure this.

10 Location of the servers

We use servers to store our information (including personal data). These servers are managed by Schuberg Philis and are located in The Netherlands.

11 Data transfer

It is possible that, in the context of a Data request, personal data stored in the Database are transferred to receiving parties located in countries outside the European Union. We take adequate measures to guarantee that your personal data are always exchanged in accordance with the Laws and Regulations, for example by concluding EU Model Contracts.

12 Retention of your personal data

Sequencing data and data in the Database

All information we generate through sequencing in assignment of a Providing Institution (and which is not stored in the Database) is destroyed ultimately a month after we made the information accessible for the third party. It is inherent to the purposes of the Database that the personal data stored therein are retained for as long as the Database is maintained.

For the rest we apply the following retention periods for the types of personal data we process:

Personal data of people visiting events and meetings, participants of surveys and recipients of our newsletter:

- as long as the people concerned are still employed by the same employer or by another employer in the same sector;
- as long as the people concerned still have an interest in receiving invitations for events and/or meetings (because, for example, they are still patients or they have indicated that they are interested);
- as long as the people concerned would like to receive the newsletter or have indicated that they wish to be kept abreast of developments;
- as long as necessary to fulfill the purpose of the survey.

Naturally, this applies under the condition that these persons made no objection to their personal data being processed.

Personal data of (contacts of) business relations:

- Personal data (name, position, organization, department and email address) are retained as long as we have a (contractual) relationship with the relevant supplier, customer, contact person or researcher and as long as the relevant person is still working with the supplier, customer or Providing Institution. Possibly the data can be kept for a longer period if we have a conflict with the relevant supplier, customer, contact person or researcher.

Account information (for access to the HMF Data Portal):

- Account information (name, email address and log data) of persons working at a Providing Institution, researchers or persons working at a research organization that has submitted a Data request will be retained as long as we have a contractual relationship with the Providing Institution, the researcher or the researching organization. In case of a cooperation agreement or a Data request, the log files will be saved in order to investigate and handle irregularities (afterwards). In the case of a service agreement, the log files are destroyed one month after the data have been made available.

13 Exercising your rights and contact

If we process your personal data, you may have the right to object to this and to request us (i) to allow

inspection of your data, (ii) to correct these data if they contain errors, (iii) to remove these data, (iv) to restrict the use of these data and (v) to transfer (or arrange for the transfer of) your data to another party.

We emphasize that exercising the aforementioned rights can only affect future events. It is not possible to undo the use (including the transfer to third parties) that has already taken place.

If we have stored your data in the Database, we recommend that you contact the Providing Institution if you wish to exercise your rights or have questions or complaints. We do not know of which patients we have stored data in the Database. The Providing Institution will then handle your question, complaint or request in consultation with us.

If we process your data in any other way, you can contact us by sending an email to info@hartwigmedicalfoundation.nl to exercise your rights or for questions or complaints concerning the use of your data.

If you are not satisfied with the manner in which we deal with your personal data, you can contact the Dutch Data Protection Authority (www.autoriteitpersoonsgegevens.nl).

14 Data Protection Officer

We have appointed a 'Data Protection Officer'. If you have questions, comments or complaints about this privacy policy or the processing of your personal data by us, do not hesitate to contact our Data Protection Officer. Her contact details are as follows:

Data Protection Officer Hartwig Medical Foundation
Carolien Heemskerk
De Boelelaan 7 (1083 HJ) Amsterdam
Email: heemskerk@considerati.com
Telephone: +316 53 897 018
