HARTWIG MEDICAL FOUNDATION - PRIVACY STATEMENT

This privacy statement was last updated on 05 October 2023. Hartwig Medical Foundation ("**Hartwig Medical Foundation**", "**we**" or "**us**") may amend this privacy statement at any time by publishing an amended version on its website.

1 Introduction

This privacy statement applies to the processing of personal data in the context of Hartwig Medical Foundation's various activities.

The mission of Hartwig Medical Foundation is to act in the public interest by promoting scientific research to combat and treat cancer and other diseases, in the broadest sense of the word.

Hartwig Medical Foundation seeks to achieve this goal by:

- establishing and maintaining a database and a central medical DNA/RNA sequencing facility;
- facilitating timely and responsible clinical implementation of - genomics technology-based - diagnostics;
- applying large-scale sequencing technologies on patient material for the identification and development of biomarkers;
- building and valorising knowledge and intellectual property, which will flow back into Hartwig Medical Foundation for the benefit of the goal and the activities that contribute to the goal.

This privacy statement provides insight into how Hartwig Medical Foundation collects, protects, uses and transmits personal data. This privacy statement also contains information about the rights of persons whose data Hartwig Medical Foundation processes.

We respect privacy and process personal data with the utmost care and in accordance with the General Data Protection Regulation (GDPR) and the GDPR Implementation Act ("**Laws and Regulations**").

Hartwig Medical Foundation may amend this privacy statement from time to time. The most recent version of the privacy statement can be found on our website hartwigmedicalfoundation.nl ("**Website**"). We advise you to regularly consult the privacy statement on the Website.

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

We may process personal data about you for different activities and in different ways. This happens when:

- performing DNA/RNA testing (**Sequencing**) on biological material from patients with cancer for diagnosis or for clinical research (see paragraph 3);
- managing a database of cancer patient data and issuing data from the database for scientific research (see paragraph 4);
- carrying out static analyses and quality and validation projects (see paragraph 4);
- organising events and meetings and conducting surveys (see section 5);

- entering into and performing contracts with business partners, such as with external or other suppliers and customers (see paragraph 6);
- sharing data with third parties (see paragraph 7);
- visiting the Website (see paragraph 8); and
- applying for a job with Hartwig Medical Foundation (see paragraph 9).

The Website provides further information about our activities. Below, for each activity, we explain which of your personal data may be processed by us, for what purposes and what role we have the processing.

3 What personal data does Hartwig Medical Foundation process for Sequencing, for what purpose and what happens to the personal data?

In summary, we Sequence biological material from cancer patients on behalf of hospitals and other medical institutions. This is done only with the patient's knowledge and consent. With Sequencing, we generate (unique) genetic information from those patients. We provide this information to the hospital or medical institution that commissioned the Sequencing.

3.1 What personal data does Hartwig Medical Foundation process during Sequencing and how does Hartwig Medical Foundation collect this data and for what purpose?

During Sequencing, we generate genetic data from biological material from cancer patients. We receive this biological material from hospitals or other medical institutions ("**Providing Institutions**"). Through Sequencing, a patient's complete genetic makeup, also called a genome, becomes known and available. At the same time, unique information about the DNA of the patient's tumour and its abnormalities is established. Hartwig Medical Foundation's laboratory that performs Sequencing of biological material does so according to a strict procedure and is accredited for compliance with ISO 17025:2017.

We analyse the genetic data that is generated. Based on that analysis, we prepare a patient report. To prepare this patient report and to give it added value for the treating physician, we process certain health data, also called registration data, from the patient, such as detailed tumour type, primary tumour location and biopsy site. This registration data is provided to us by the Providing Institutions. We provide all information generated by Sequencing to the Providing Institutions. Each Providing Institution has and keeps access to this data of its 'own' patients.

We Sequence biological material and generate and analyse genetic and health data on behalf of the Providing Institutions. In doing so, we act as joint controllers within the meaning of the Laws and Regulations.

The Providing Institutions provide us with the biological material of their patients, coded or with some personal data (surname, initials, gender, date of birth, postal code, hospital identification number) indicated. This depends on the specific agreements made about this with the Providing Institution.

We make agreements with the Providing Institutions regarding the use, confidentiality and security of the personal data and biological material (which we receive from the Providing Institution for Sequencing) as well as the genetic data we generate by Sequencing it. Hartwig Medical Foundation is responsible for

high-quality security of the data it processes and manages. Hartwig Medical Foundation is ISO 27001 accredited for this purpose.

After we have carried out the Sequencing on behalf of the Providing Institution, we destroy or return any remaining biological material to the Providing Institution in accordance with the agreements with the Providing Institution. We store the results of Sequencing in our Database, provided a patient has given consent. Inclusion of data in the Database is for an indefinite period of time, during which we periodically review whether keeping the data longer is still relevant and useful for the purpose of the Database. You will read more about the Database in paragraph 4 below. Providing Institutions can request the data of their own patients from Hartwig at any time. Hartwig will facilitate this.

3.2 On what basis does Hartwig Medical Foundation process personal data during Sequencing?

3.2.1. Basis (Article 6 GDPR)

The processing of personal data during Sequencing to produce both health data and genetic data is necessary for the treatment of patients.

3.2.2. Grounds for exception for the processing of health and genetic data (Article 9 General Data Protection Regulation (Implementation) Act)

Health data

The processing of health data is necessary for the proper treatment of patients.

Genetic data

In summary: we manage a database in which we store coded genetic, clinical data and some other personal data of cancer patients. Among other things, we store in that database genetic data generated by Sequencing of biological material on behalf of a Providing Institution (see paragraph 3). This is always done in cooperation with the Providing Institution and only with the patient's consent. Note that we only store data in the database and no human bodily material. We are not a biobank. The data in the database are intended to be made available to researchers for research to improve

The processing of genetic data takes place in relation to the patient from whom the relevant data was obtained.

4 We manage a database

We manage a database in which we store genetic,clinical data and some other personal data of cancer patients in the Netherlands and make it available for research ("**Database**"). We set up this Database to further expand knowledge about cancer and its treatment. Hartwig Medical Foundation aims to improve care for current and future cancer patients (e.g. by developing new treatment methods and the more targeted use of cancer drugs).

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

In the Database, we collect the following personal data:

- clinical data of cancer patients, such as patient gender and age, data on patient tumour characteristics, treatment history, treatment data (including choice of therapy and medication) and treatment outcomes;
- genetic data of cancer patients that we have generated through Sequencing and the subsequent analysis of biological material. This does not include the patient report we prepare for the treating physician. This patient report (see paragraph 3 for more details) is not included in our Database; and
- some other personal data of cancer patients (surname, initials, gender, date of birth, postal code, hospital identification number).

In the Database, we only store the data mentioned above. We do not store any biological material or residual biological materials from patients. We return all unused biological material to the Providing Institution or destroy it in consultation with the Providing Institution.

We include the above data in the Database in coded form. In this way, Hartwig Medical Foundation safeguards patient privacy as much as possible. Researchers to whom the data from the Database are provided do not know which patient is involved.

4.2 How does Hartwig Medical Foundation collect the personal data?

We receive the clinical data and other personal data in the database from the Providing Institutions; we generate the genetic data ourselves through Sequencing.

The Providing Institutions provide patient data to us in accordance with their own privacy policies. If a Providing Institution provides data to us for inclusion in the Database, the Providing Institution will inform the patient about this, partly on behalf of Hartwig Medical Foundation, and will seek consent to do so. Hartwig, together with the hospital (as the Providing Institution), has prepared an information letter with a consent form for this purpose, which is shared with patients as soon as the decision is made to have Sequencing performed.

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

The overarching purpose for which we collect and use the data in the Database is to promote research into cancer and its treatment in order to improve care for current and future cancer patients. We process clinical and genetic data to set up, use, manage and make accessible the data in the Database. We do this through various activities, such as:

- collecting the data for storage and retention in the Database, in order to create a usable and as complete as possible Database;
- consulting, organising, classifying and sorting the data to make the management and use of the Database as efficient and practical as possible;
- consulting, organising, sorting and analysing the data in order to identify possible links in the data in the Database;
- consulting, using and analysing the data to improve the algorithms we use when analysing the genetic data generated by Sequencing;
- performing statistical and other analyses on the Database for research purposes, to inform third parties about the valuable information contained in the Database and to continue to improve our Database and our internal processes (e.g. analysis software);
- performing statistical and other analyses on the Database to make statistical data available through Scientific Data portals, such as International Cancer Genome Consortium (ICGC) and through our own Database;
- performing work and tests for quality and validation purposes;
- making the data available to third parties for research purposes, but only under strict conditions and in the manner further described below in this privacy statement under section "When are data from the Database provided to third parties?";
- cooperating to link or make linkable the data in the Database with data in other databases comparable to the Database, such as the Dutch Cancer Registry (NKR) and the Pathological-Anatomical National Automated Archive (PALGA) for the purpose of research into improving cancer treatment;
- processing certain personal data to demonstrate compliance with our obligations under the Laws and Regulations, for example, we may share certain personal data to comply with orders of competent authorities (such as the Personal Data Authority);
- in case we cease to exist or stop managing the Database, we will decide to transfer the Database to another organisation with the same mission, objective and safeguards as Hartwig Medical Foundation.

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

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

Processing of clinical and genetic data in the Database requires explicit patient consent. The Providing Institutions must ensure that a patient is asked for this explicit consent. This is done through an information letter with a consent form. Hartwig Medical Foundation ensures, to the extent possible, that this requirement has been met. We then process the personal data only within the framework of the consent given.

To ensure patient privacy as much as possible, we generally do not have access to these consents obtained and recorded by the Providing Institutions.

4.5 Withdrawal of consent

Patients who have given their express consent for their data to be included in the Database may withdraw

such consent at any time. Such withdrawal of consent only has future consequences. This means that we remove the patient's data from the Database, but it is impossible to undo the use (including transfer to third parties) that has already taken place.

4.6 When will data from the Database be provided to third parties by Hartwig Medical Foundation?

The data from our Database may be made available for further research to external parties, such as research institutions, hospitals, universities and companies, but only for scientific research that serves a public interest. These parties can submit a request to us to obtain certain data from the Database ("Data Request"). This can only be done for predefined, well-determined, (research) purposes approved by us.

Hartwig Medical Foundation will only make data in the Database available to external parties if the research for which a Data Request has been submitted can increase, develop cancer knowledge or improve care for current and future cancer patients. As mentioned above, the external parties to whom we make the data in the Database available may include independent researchers, research and other institutions, hospitals, universities and companies (to the extent permitted under the Laws and Regulations). We may also make data from the Database available to research parties based in a country outside the EU. In such cases, Hartwig Medical Foundation will always ensure that the necessary measures are taken to comply with the Laws and Regulations.

Hartwig Medical Foundation does not give the parties who make a Data Request, access to the requested data from the Database without question. This is done only for specific, research or other purposes that have been approved by us. To ensure this, we have established a Scientific Board and a Data Access Board. The Scientific Board assesses Data Requests on the scientific value of the proposed research. The Data Access Board assesses the ethical, social and legal aspects of Data Requests according to a strict procedure laid down in the Rules of Procedure Data Access Requests. Moreover, when Hartwig Medical Foundation was founded, it established Guiding Principles, which include the basic principles for data sharing. The Guiding Principles and the Rules of Procedure Data Access Requests can be found on our Website.

We provide only specific and encrypted data to third parties (we never give third parties access to the entire Database) and impose strict contractual rules and obligations on the third parties who obtain data, such as the obligation to properly secure the data they obtain. We also impose strict requirements on the use of the data and the restrictions on it, by the third parties. They may only use personal or other data for research purposes and obviously not for commercial purposes.

4.7 Who helps us manage the Database?

We engage third parties to provide us with technical support and help in managing the Database. Hartwig Medical Foundation's IT infrastructure is maintained by a professional party that provides state-of-the-art data security, namely Google Ireland Limited. Both our Sequencing services (such as bioinformatic analysis of Sequencing data through our IT pipeline) and our database are processed and hosted on the Google Cloud Platform. See paragraph 10 of this privacy statement for more information on data security in the Database.

4.8 Sharing of personal data outside the European Economic Area

In the context of a Data Request, personal data stored in the Database may be transferred to a recipient outside the European Economic Area. We will then take adequate measures to ensure that provision of encrypted personal data is always made in accordance with the Laws and Regulations, for example by concluding the EU Model Contracts. For specific questions, you can always contact us at privacy@hartwigmedicalfoundation.nl.

5 Organising events and meetings and conducting surveys

We organise events and meetings and may also conduct surveys through our Website (possibly in cooperation with other parties). In doing so, we process personal data of participants and respondents for the following purposes:

Personal data	Purposes	Legal basis
Name, position, organisation and department, email address, telephone number and survey results	to approach parties (such as patient representatives or employees of Providing Institutions) with information about events and meetings, to register your participation in an event or meeting, to correctly address the monthly newsletter and to answer questions to approach survey respondents to disclose survey results to share survey results with the party with whom we developed the survey to send invitations/newsletters and answer questions to maintain guest lists to send a monthly newsletter	- Consent, or - Hartwig's legitimate interests to (among other things) inform and keep interested parties informed about our activities, to improve our services and activities and to communicate about them

We may engage third parties to help us organise events and meetings or conduct surveys. We may share the aforementioned information with these parties for the purposes listed. We process this data on the basis of our legitimate interests in order (among other things) to inform and keep interested parties informed of our activities and to improve our services and activities.

6 Processing of personal data of business partners and their contacts

Like any organisation, we also process personal data of parties with whom we cooperate or do business and their contacts. These may include our suppliers and their contacts, Providing Institutions and researchers and their contacts to whom we make data from the Database available. In this context, we collect and use the following personal data for the following purposes:

Personal data	Examples of purposes	Legal basis
Name, position, organisation and department, email address and telephone number	to make agreements about maintenance of our equipment to discuss and execute contracts with Providing Institutions, suppliers and service providers to place, handle and/or call for orders or services	Performance of an agreement or a legitimate interest of Hartwig to conduct its activities and/or provide services.

We may engage third parties to help us manage and properly operate our systems and business processes. We may share the aforementioned information with these parties for the purposes listed. We process this data based on our legitimate interests to perform the agreements we have entered into with our business partners and to establish, exercise or defend our legal position.

7 Sharing of personal data with third parties

Insofar as we share personal data with third parties, this has already been explicitly stated in the previous paragraphs of this privacy statement. We will only share personal data with parties other than those mentioned above (such as authorised regulators) 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 is always done within the framework of Laws and Regulations.

For example, we only provide personal data to third parties if and to the extent that these parties agree to keep the personal data they receive confidential and if they provide sufficient guarantees for the security of the data. Where necessary and relevant, we conclude a processing agreement with these parties.

8 Visiting the Website (Cookies)

8.1 Use of cookies

When visiting our Website, cookies may be placed on the computer, phone or other device used to visit the Website. Some cookies are essential for the Website to work properly, others serve to provide a better, faster and safer user experience.

A cookie is a small text file that is stored on the computer, phone or other device used to visit the Website so that the Website can, for example, remember who visits the Website and/or what the preferred

language for the Website is. On our Website you will find an overview of the cookies used by the Website, for what purposes and how long the respective cookie remains active. You can read additional information about cookies in the paragraphs below.

8.2 Purposes of the use of cookies

The Website uses cookies for the following purposes:

- Essential purposes: to enable the Website to function properly. These cookies cannot be disabled.
- Functional purposes: to provide visitors with a functioning Website.
- Analytical purposes: to collect and analyse information about the use of the Website, the number of visitors to the Website and the sources of traffic to the Website (i.e. how visitors were directed or redirected to the Website) and to improve the functioning of the Website based on the information collected and analysed.
- Performance purposes: to collect information about the performance of the Website and to improve its functionality.
- Marketing purposes: The Website does not display advertisements. The Website does feature 'embedded' YouTube videos. YouTube places cookies for this purpose to record video preferences.

8.3. How do you manage/delete cookies?

You can disable the use of non-essential cookies via the opt-out function or in your browser settings.

You can consent to the use and placement of other cookies, unless the cookies are essential for the proper functioning of the Website or serve to provide you with a better, faster and safer user experience. Consent is not sought for placement of these essential cookies.

We note that if you disable certain cookies that we use, there is a possibility that certain parts of our Website may not function as well as they should. This may affect the user experience.

8.4. Links/services of 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. These third parties each have separate and independent privacy policies. We advise you to read the privacy policies of these third parties before visiting these websites or using these services.

9 Applicants

When applying for a job at Hartwig, we process personal data of applicants. This includes at least the applicant's name, email address and telephone number. When we receive a CV, we also have additional data, such as date of birth and residential address. These data are naturally treated with the utmost confidentiality. Only those persons directly involved in job applications at Hartwig have access to this

data.

If an application does not lead to an employment contract, Hartwig will delete the obtained data after completion of the application procedure. However, it is possible that we ask whether we may keep a CV for one year, in order to possibly approach the applicant in question in the future. If consent is granted, we will delete the CV after one year.

If an application does lead to an employment contract, data processing falls under our responsibility as employer. How we as an employer handle personal data of our employees is included in internal documents.

10 Security

Particularly in view of the highly sensitive data that Hartwig Medical Foundation processes on a daily basis, Hartwig Medical Foundation strives for a high-quality IT environment to ensure that this data is processed reliably, carefully, securely and transparently in accordance with this privacy statement, the Laws and Regulations and applicable standards. To this end, we take various technical and organisational security measures to protect personal data against loss, misuse, alteration, disclosure, destruction, theft or unauthorised access and/or processing. Hartwig has implemented an information security quality system and is also certified for ISO27001 (Information Security Management).

Furthermore, we make confidentiality agreements with our employees and ensure that only a limited number of authorised persons are given access to patient data. Strict internal conditions and processes apply for access to personal data. Where relevant, we enter into data processing and licensing or other agreements with third parties who have or may have access to personal data we process. Such agreements include strict agreements on what these parties may and may not do with these personal data and how they must secure them. Personal data are always provided in encrypted form.

11 Retention periods

Sequencing data not in the Database

All information that we generate by Sequencing on behalf of a Providing Institution (and which is not included in the Database) we destroy after a minimum of three (3) months and no later than four (4) months after we have made such information available to the Providing Institution.

We keep data recorded upon receipt of biological material for at least twenty (20) years. In principle, we also retain the patient report for twenty (20) years, unless different agreements are made with a Providing Institution.

Sequencing data in the Database

The data stored in the Database will be kept there as long as it is relevant for the purposes for which the Database is intended. Hartwig evaluates on an ongoing basis whether the storage of the personal data retained is still relevant for the purposes in question.

Otherwise, we apply the following retention periods for the different types of personal data we process:

Personal data of visitors to events and meetings and survey participants:

- as long as the relevant individuals are employed by the same employer or for another employer in the relevant sector and Hartwig is informed of any departure from the relevant employer;
- as long as the persons concerned have an interest in receiving invitations to events and/or meetings (e.g. because they have indicated an interest);
- as long as the relevant persons wish to receive the newsletter or have indicated that they wish to be kept informed of developments;
- as long as necessary to carry out the purpose of the survey.

This is of course done on condition that the person concerned has not objected to the processing of his/her personal data by Hartwig and keeps Hartwig informed of any changes.

Personal data of business partners and their contacts:

personal data (name, position and email address) will be kept for as long as we have a contractual relationship with the supplier, Providing Institution, customer, contact or researcher concerned and for as long as the person concerned still performs work for the supplier, Providing Institution, customer, contact or researcher.

Account information for online access to systems:

Hartwig uses online accessible programmes for various purposes, processes personal data and applies retention periods as shown in the table below.

Who	**Application**	**Program**	**Personal data**	**Retention period**
Data requestors	Submit Data Request	Bizzmine	Username and IP address	Six months
Data requestors	Access to data in Database	Google Cloud Platform	GCP account details and IP address	Six months
Physicians and pathologists employed by Providing Institutions	Access to Sequencing results and reporting	Nextcloud OKTA	None Username, email address, IP address	NVT Six months

Applicants

- we delete applicants' data, including CV, no later than one year after receipt.

12 Exercise of rights and contact

If we process your personal data, in some cases you have the right to object to this and, in certain situations, you have the right to request us (i) to access your data, (ii) to correct or supplement this data, (iii) to delete this data, (iv) to restrict the use of this data and (v) to receive your data in a structured form and transfer it (or have it transferred) to another party.

We emphasise that invoking the above rights only has consequences for the future. For example, it is not possible to undo any use (including disclosure to third parties) of your data that has already taken place.

If you are a patient, please contact the relevant Providing Institution if you wish to exercise your rights or have any questions or complaints. The Providing Institution will then deal with your question, complaint or request in consultation with us.

If we otherwise process data about you, to exercise your rights or in case of complaints and questions about the use of your data, contact us by sending an email to privacy@hartwigmedicalfoundation.nl.

If you are not satisfied with the way we handle your personal data, you can file a complaint about it with the Personal Data Authority (autoriteitpersoonsgegevens.nl).

13 Data protection officer

We have appointed a Data Protection Officer. If you have any questions, comments or complaints regarding this privacy statement or our processing of your personal data please do not hesitate to contact our Data Protection Officer. The contact details are:

Data Protection Officer Hartwig Medical Foundation
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Email: hoovers@considerati.com