

## HARTWIG MEDICAL FOUNDATION - PRIVACY POLICY

Version: 5.0

This privacy policy was most recently updated as per 1 April 2020. 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.

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### 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 (*Algemene Verordening Gegevensbescherming*) and the Dutch Implementing Act General Data Protection Regulation (*Uitvoeringswet Algemene verordening gegevensbescherming*) (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](http://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, analysing and reporting on 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 online portal (see paragraph 6);
- 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. Subsequently, we analyse the sequencing results and report the sequencing results and our analysis to the hospitals, treatment centers and research institutes that have assigned us the sequencing task. The genetic information about patients that we generate by means of sequencing and analyzing thereof 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) and analyzing the sequencing results. When sequencing biological material, we perform so-called 'Whole Genome Sequencing'.

**3.1 Sequencing in the context of clinical research**

First, 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**). This mostly happens in the context of a clinical research conducted by these Providing Institutions, whereby the sequencing of biological material of the patients enrolled in such research is essential. 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. Hartwig Medical Foundation's lab performing the sequencing of biological material is accredited for compliance with ISO-17025.

This genetic data is subsequently analyzed by us. 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.

In certain instances (if requested by the Providing Institutions) we compose a patient report based upon the analyzed genetic data. This patient report is an overview of the specific defects in the patient's DNA and provides information on the tumor-specific mutations, amplifications and deletions, the mutational load, microsatellite instability, the presence of fusion genes as a result of translocations and possible

relevant clinical evidence items and clinical studies (based on publicly available research data). In order to compose this patient report and in order for it to have an added-value, we process certain clinical data of the patient, such as detailed tumor type, primary tumor location and biopsy location. These clinical data are provided to us by the Providing Institutions.

The sequencing of biological material and the generating, analyzing of and reporting on 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, genetic data and clinical data and that we are bound to the instructions of the Providing Institutions. We enter into (data processing) agreements with the Providing Institutions about the use, confidentiality and security of the biological material, the clinical data and the genetic data that we generate and are analyzed by us.

The Providing Institutions provide us with the biological material and clinical data 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 to what patient the clinical data relate. Hence, we 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.

Once we have performed the sequencing on the instructions of a Providing Institution, we either destroy or return any remaining biological material to the Providing Institution. We also delete the clinical data.

In some cases where we sequence biological material on the instructions of a Providing Institution in the context of clinical research, we may agree upon certain arrangements with such Providing Institution that enable us to also record certain data in the database (as further described in paragraph 4 of this privacy policy). Currently, this only happens in the context of the clinical studies named CPCT-02, DRUP, WIDE, PEGASUS and OMICS-predict.

### ***3.2 Sequencing in the context of the treatment of a patient***

As mentioned in the previous paragraph, we mostly sequence biological material of patients with cancer in the context of clinical researches conducted by hospitals, treatment centers and research institutes with whom we collaborate. More recently, we have been receiving requests from hospitals, treatment centers and specific patients who, in the context of the treatment of a patient, wish to obtain a patient report based upon the biological material sequenced and analysed by us.

Hartwig Medical Foundation only sequences biological material of cancer patients with the cooperation of and upon the instructions of the hospital or treatment center where the specific patient is being treated. We do not sequence biological material upon the (mere) request of a patient. Once a hospital or treatment

center requests us to sequence biological material of one of its patient and we accept this request, we will sequence the biological material of this patient similarly as in the context of a clinical research in our capacity as 'processor' (as described above). We do this on the basis of a contract with the hospital or treatment center, not with the patient.

Unfortunately, the costs of sequencing of biological material by us (Whole Genome Sequencing) are not reimbursed by health care insurers at this moment. Consequently, this may mean that a patient whose biological material is sequenced in the context of his/her treatment, has to pay for the costs him/herself.

In order to send this patient an invoice for the costs of sequencing and for our administration purposes, each patient is given a registration number/reference (which includes the name of the treating hospital or center), which we process together with the patient's (email)address. We will keep this data for five (5) years after we have sent the patient an invoice or, longer, if this is necessary to uphold our legitimate interests (such as establishing, exercising or defending our legal position). Only in the event that we have to invoice the patient for the costs of sequencing (and in that respect we are provided with the name and the address of the patient), we can relate the genetic data and clinical data to this specific patient.

Once we have performed the sequencing on the instructions of the hospital or treatment center, we either destroy or return any remaining biological material to the hospital or treatment center pursuant to the arrangements with the hospital or treatment center. We also delete the clinical data. These data will not be stored in the database (as described in paragraph 4 of this privacy policy).

#### **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 and analysed on the instructions of a Providing Institution in the context of clinical research (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 do not record in our database the genetic data which we have generated and analysed on the instructions of a hospital or treatment center in the context of the treatment of a specific patient (see the previous paragraph).

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, with the exception of the patient report that we compose. The patient report (see paragraph 3 for more details) is not recorded in our Database.

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 in the context of clinical research conducted by these 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 perform (statistical) analyses on the Database in order to make statistical data available through Scientific Data portals as ICGC;
- 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 11 of this privacy policy;
- We process (certain) personal data in order to demonstrate that we comply with our obligations under the Laws and Regulations, for example we may share (certain) personal data in order to comply with orders of competent authorities (such as the Dutch Data Protection Authority);
- 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?***

We process personal data of patients based on their explicit consent. 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 paragraph of the 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 order to ensure the privacy of the patients as much as possible, we generally do not have access to any of these informed consents that are obtained and recorded by the Providing Institutions (as we do not need to know who the patient is). However, we must under the Laws and Regulations be able to demonstrate that any patient whose data is included in the Database has given his/her informed consent hereto. In view hereof, we ensure that the Providing Institution with whom we collaborate monitors the informed consents on a 100% basis, periodically reports to us on the status and administration of the informed consents and provides copies of the relevant informed consent forms to a competent authority in the event such authority would request so.

***Withdrawal of consent***

Patients who have given their explicit consent to record their data in the Database, can at all times withdraw such consent. Such withdrawal of consent only has future effect. This means that we will delete the patient’s data from the Database, however, it is impossible to undo the use (including the transfer to third parties) that has already taken place. As we only record encoded data of patients in the Database and we do not know to what specific patient what data relates, patients who wish to withdraw their consent, should contact the relevant Providing Institution. In this respect, please also see paragraph 12 of this privacy policy.

***Other legal basis***

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 Access request**). This is possible only for pre-defined, specific (research) purposes that have been preapproved by us.

It is hard to predict for what (type of) researches we will make available the data in the Database. Hartwig Medical Foundation will only make available data in the Database to external parties if the research for which a Data Access Request is submitted may enhance, develop or increase the knowledge on cancer or can improve the care for future (cancer) patients. As mentioned above, the external parties to whom we may make available the data in the Database may be independent researchers, (research) institutions, hospitals, universities and commercial parties such as pharmaceutical companies (as far as this is allowed under the Laws and Regulations). We may make available data from the Database to international collaborations, whereby the involved researching parties are established in a country outside the EU. In this case, 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 external parties access to the requested data from the Database automatically. We have a Scientific (advisory) Board and a Data Access Board in order to ensure this. The Scientific (advisory) Board and the Data Access Board assess Data Access 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, for example the receiving parties are only allowed to use the data for a limited period of time and only for the purposes of a certain research project. 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. The IT infrastructure of Hartwig Medical Foundation is maintained by a professional party offering state-of-the-art data security, being Google Ireland Limited. Both our sequencing services (such as the bio-informatic analysis of sequencing data through our IT pipeline) as well as our database will be processed and hosted on the Google Cloud Platform. For more details, please see paragraph 0 of this privacy policy.

**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 / newsletters
phone number	to keep guest lists
results survey	to send a (monthly) newsletter

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. We process these data based on our legitimate interests to (among others) inform and keep updated interested parties on our activities and to improve our services and activities.

**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 relating to) 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 via 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 online 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. We process these data based on our legitimate interests to execute the agreements we have entered into with our business relations and to establish, exercise or defend our legal position.

## **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.

<b>Name Cookie</b>	<b>Source</b>	<b>Purpose of the cookie</b>	<b>Retention period</b>
_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 Analytics	This cookie is used to throttle the request rate so as to improve the Website's operation.	10 minutes.
_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	10 minutes from set or update.

		functionality.	
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_I NFO1_LIV E	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 Security

Particularly in view of the highly sensitive data that Hartwig Medical Foundation processes on a day-to-day basis, Hartwig Medical Foundation strives to have in place a high standard IT environment to ensure it processes these data in a reliable, careful, safe and transparent manner and in compliance with this privacy policy, the Laws and Regulations and applicable standards. In view hereof, we take various technical and organizational security measures as necessary to protect your personal data against loss, misuse, amendment, disclosure, destruction, theft or unauthorized access and/or processing.

Hartwig Medical Foundation IT infrastructure is hosted on the Google Cloud Platform, which ensures the processing of your personal data in a careful and secure manner taking account of the state of the art and the latest insights in the field of data security. Hartwig Medical Foundation has agreed upon detailed arrangements on the applicable technical security regarding the Google Cloud Platform. These arrangements relate to such matters as access control, encryption, backups and compliance with security standards. Below, please find a list of the most important arrangements made with Google in this respect:

- The contracting party of Hartwig Medical Foundation is the EU subsidiary of Google, Google Ireland Limited (and not Google, Inc. in the US).
- All encoded data will be processed and hosted on servers of Google in the Netherlands.
- Any person who may have access to the encoded data must be authenticated by (at least) two factor authentication.
- Any access to the encoded data will be logged.
- All encoded data is encrypted. Encoded data in transit are encrypted by Google and the encoded data at rest are encrypted by means of Customer Managed Encryption (CMEK), whereby the key for encryption and decryption is only known to Hartwig Medical Foundation. Hence, Google cannot access the actual encoded data.
- Google cannot use the encoded data for its own purposes.
- The Google Cloud Platform is secured and certified in accordance with the standards of ISO27001 (Information Security Management), ISO27017 (Cloud Security), ISO 27018 (Cloud Privacy) and SSAE16 / ISAE 3402 (SOC 2/3).
- Hartwig Medical Foundation has the right to audit compliance of Google with the agreed arrangements.

Further, we 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.

In order for future users of Google Cloud Platform to optimize the use thereof, the Data Request form asks the requesting party to grant Hartwig permission to establish contact between them and Google and/or selected Google Partners, in order to walk through the onboarding steps of the Google Cloud Platform.

## 10 Data transfer

It is possible that, in the context of a Data Access 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. You may always contact us by email at [info@hartwigmedicalfoundation.nl](mailto:info@hartwigmedicalfoundation.nl) if you have specific questions in this respect.

## **11 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 maintained as long as indicated to us by the Providing Institution. For example, we may keep the generated genetic data and patient reports during the (entire) term of a clinical research and 15 years after termination of the clinical research to keep these available for the Providing Institutions.

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 online 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 Access 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 Access 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.

## **12 Exercising your rights and contact**

If we process your personal data on the basis of your consent, you have the right to withdraw this consent. Further, if we process your personal data, you have under certain circumstances 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. As mentioned in the previous paragraphs, 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](mailto: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](http://www.autoriteitpersoonsgegevens.nl)).

## **13 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. Contact details are as follows:

Data Protection Officer Hartwig Medical Foundation  
Considerati DPO services B.V.  
De Boelelaan 7 (1083 HJ) Amsterdam  
Email: [hoovers@considerati.com](mailto:hoovers@considerati.com)