

English Translation of the general terms and conditions of use for the HGQN database of the "Berufsverband Deutscher Humangenetiker e.V."

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1. Applicability

1.1. The "Berufsverband Deutscher Humangenetiker e.V." (herein after "BVDH") operates the online platform "Human Genetic Quality Network"(herein after "HGQN") for institutions in the human genetic field to present themselves. These general terms and conditions of use include fundamental rules for use of the HGQN. The rules are applicable for all aspects of business between each user of the HGQN and the BVDH. There is no possibility of alternative conditions.

1.2. A German original of the general terms and conditions is available on the HGQN internet site. However, this English version is only envisaged to provide guidance. It is the German version of the general terms and conditions of use that is binding.

2. Services of the HGQN, definitions, fees

2.1. The profile of a human genetic institution is a publicly accessible collection of data and statements from the institution, used to provide details about it. The detailed description includes contact data of institutions and contact persons, diagnostic achievements and quality control activities of the institution.

2.2. All HGQN users can register themselves personally (as an individual doctor /scientist) or as an institution and thereby apply for access (Account) if they represent a human genetic institution.

2.3. The registration of a profile with all contact details, the classification in category "Genetic Counselling" and accessing data is free of charge.

2.4. In addition to the cost free services, HGQN offers the following services that are liable to costs:

1. A fee is charged for the "Institutions categorisation" with the exception of classification in category "Genetic Counselling"

2. A fee is charged for disease entries in the diagnostic list of the institutions profile.

3. Participation in BVDH EQASs also carries a fee.

3. Registration, completing the agreement

3.1. Use of HGQN is open to all human genetic institutions (universities, laboratories, medical practices, genetics counsellors, etc.). Prerequisites for acceptance into the database are provision of correct data for your institution and business in at least one of the fields of activity specific to human genetics.

3.2. Prerequisite for the profile of an institution to be accepted in the database is registration of the institution. The data provided by the individual making the registration (hereinafter the "Operator") must be factual and complete. In the case of changes to the data provided after successful registration, the operator must immediately update these details. Should this not be possible, HGQN must be immediately informed of the changes. The operator is responsible for all entries concerning the institution's profile that have been entered by him or nominated persons from the institution.

3.3. Multiple registrations are not possible.

3.4. By transferring the completed registration form to HGQN, the operator is making a contingent request for registration. After transferring the data, the operator is provided with personal access data by email. The institution's profile remains hidden from public access until released by HGQN. An institutions profile is only released, after receipt of a signed licence agreement from the head of the institution and subsequent verification by a HGQN scientific consultant.

3.5. The contractual agreement is established by the contractual leader of the institution returning the signed, legally binding licence agreement. By signing the contract, the institution automatically agrees to their data being publicised.

3.6. HGQN reserves the right to reject or delete an institution's profile without justification. This particularly applies in the case of inaccurate or incomplete data entries, as well as provision of entries that are ethically or morally not in accordance with the BVDH principles.

4. Access data

4.1. On registration, a user name and password are provide by HGQN (hereinafter access data). The access data is provided to the operator by email. The access data are to be kept secret and protected from unauthorised access. Operators are to be aware that the access data enables third parties to delete or manipulate data stored at HGQN. If the access data are misplaced or use, or suspected use by a third party is detected, the operator must immediately inform HGQN and change the password.

4.2. The operator can create access to HGQN for other users. The operator must be aware that each individual, for whom user access is created, must be informed of the general terms and conditions of use. The operator is responsible for any contravention by this person of the general terms and conditions of use.

4.3. On suspicion of improper use of access data, HGQN is authorised to immediately block the user account.

5. Institution profiles

5.1. Any individual with user access (hereinafter "user") has the possibility to change the profile of their institution within the constraints of the allocated user rights.

5.2. All entries made in the profile must be factual.

5.3. Entries can only be made in the appropriate field of the form. Limitations made by or identified in the form must be observed. In addition issues of the federal regulations governing pharmaceutical advertisements (German law: "Heilmittelwerbegesetz") are to be observed. In the "Homepage" field only the address of the official business homepage may be entered.

5.4. Concerning presentation of an institution, reference can only be made to achievements that the institution itself can claim. Only areas of expertise that the institution itself is active in, can be identified.

5.5. The operator is responsible for all entries concerning the profile of their institution that they themselves or another authorised user from the institution have made.

5.6. The user must ensure that they are authorised by all the people about whom details are entered in the HGQN database. This particularly applies to details of their email addresses and telephone numbers. The user must inform the third party before entering their details, that they are liable to automatically receive system emails from HGQN.

5.7. The user must observe possible copyright or other protection rights of others. HGQN draws attention to the fact that the use of texts, pictures and photos, even if only extracts are used, is only allowed with the permission of the respective copyright holder. Should the user enter protected material into the platform, then HGQN is authorised to require evidence of authorisation for use from the copyright holder.

5.8. The user is obliged not to insert or refer to any unlawful contents. This particularly refers to representations that glorify violence or war, incite race hatred, are pornographic or are of a nature that poses a youth risk or has content that infringes personal privacy rights.

5.9. HGQN reserves the right to decline activation of profiles as well as to remove entered profiles out of the platform without justification.

6. Diseases

6.1. An institution's profile offers the possibility to link diseases with the institution's diagnostic list. This link is identified as a "Diagnostic entry". The prerequisite for this is that the corresponding disease is already stored in the HGQN database. Any user at an institution with the appropriate user rights can make this type of link. Every diagnostic entry is liable for costs. By inputting a diagnostic entry, an institution's operator automatically is informed about related forthcoming EQASs.

6.2. HGQN reserves the right to delete diagnostic entries or entries about diseases without justification. This particularly applies if no standardised diagnosis methods exist for an entered disease or entries provided by a user do not correspond to the truth.

6.3. If an entry for a disease does not already exist in the HGQN database, the user can make this entry. Points 5.2 to 5.8 inclusive apply accordingly. Once a disease has been entered by a user, it cannot be deleted.

6.4. All inputs from a user concerning an entry for a disease or a diagnostic entry must be factual.

6.5. If a user identifies that a diagnostic entry contains incorrect details, the user must immediately inform HGQN and make the necessary corrections.

6.6. An institution's user with appropriate user rights has the possibility to modify or delete their institution's diagnostic entries.

7. External Quality Assessment Schemes (EQAS)

7.1. An institution's profile offers the possibility to link external quality assessment schemes to the profile of the institution as evidence of quality control. Prerequisite is that the corresponding EQAS is already stored in the HGQN database. Any user at an institution with the appropriate user rights can make this type of link. The user is obliged to provide HGQN with a certificate about the participation in external quality assessment schemes of the institution.

7.2. Links between an EQAS and the profile of an institution are not immediately visible to the public. HGQN reserves the right to delete EQAS entries or links without justification. This applies in particular to when there is no certificate for an EQAS participation at HGQN.

7.3. If a user identifies that an EQAS entry contains incorrect details, this must be immediately identified to HGQN.

7.4. If an entry for an EQAS does not already exist in the HGQN database, the user can enter it. Points 5.2 to 5.8 inclusive apply accordingly. Once an entry has been established by a user for an EQAS, it can no longer be modified or deleted.

7.5. All inputs from a user concerning an entry for an EQAS must be factual.

7.6. HGQN offers the user the possibility to register themselves or another person for a forthcoming EQAS via an online form. The registered person participates on behalf of the institution of the user that made the registration. Participation in EQASs is liable for costs. Registration for an EQAS is binding.

8. Research platform (Research)

8.1. Research projects are always linked to an institution's profile. An institution can only enter those research projects in the HGQN Research area of the database, that the institution itself is participating in.

8.2. Points 5.2 to 5.8 inclusive apply accordingly for entering research projects. HGQN reserves the right to change or delete entered details without justification.

8.3. HGQN reserves the right without justification at any time, to modify, limit or remove this service.

8.4. The user of an institution requires the written permission of people for whom personal data is to be input.

8.5. It is not allowed for personal data of patients to be entered.

9. List of self help groups

9.1. Points 5.2 to 5.8 inclusive apply accordingly for the input of self help groups into the HGQN Service area. HGQN reserves the right at any time to change or delete input data without justification.

9.2. HGQN reserves the right at any time, to modify limit or cancel this service.

10. Blocking and deleting of details

In the case of a user contravening these general terms and conditions of use, HGQN is authorised to block or delete user access, their profile and any of their other details.

11. Use of personal details

It is forbidden to use contact details or other personal information of individuals for advertising purposes, to transmit to them unsolicited email, fax, SMS or postal adverts or to enter into unsolicited telephone contact.

12. Information service

By entering email addresses in the fields of the form the user authorises HGQN to send emails related to the information service to the owner of the email address. The user must be in possession of the corresponding authorisation from the email address owner.

13. Fees and payment conditions

13.1. HGQN users can make use of cost incurring services. Cost incurred will be charged monthly, corresponding to the current price list defined by the provider.

13.2. Issued invoices are immediately due and payable without reduction. All invoices are payable within the time period detailed on the invoice, if no time period is on the invoice, the time period is 14 days from the date on the date invoice.

13.3. The monthly fee due per diagnostic entry is imposed on input of a diagnostic entry in the institutions profile. If the user deletes the corresponding diagnostic entry from the institution's profile, the fee is due for the current month.

14. Duration of the contract, terminating the licence agreement

14.1. The contractual agreement between the user and HGQN concerning use of the platform runs for an unspecified time.

14.2. The operator of an institution can delete the institution from the HGQN database at any time or request deletion. In this way, the licence agreement between the institution and HGQN will be cancelled. During deletion, all diagnostic entries of the corresponding institution are removed. Not yet invoiced services will be billed. After settlement of all outstanding invoices, all remaining data concerning the institution will be removed from the HGQN database.

15. Liability exclusion, activation, publication rights

15.1. The user alone is responsible for content, pictures, documents, external hyperlinks and any other data that they have entered. HGQN provides no guarantee for the correctness of data entered by a user.

15.2. The user is obliged to take responsibility for archiving and producing backups of their documents, entries and other data on their own data carriers. In the case of data loss, HGQN takes no responsibility for the effort necessary to recreate the data.

15.3. The user releases HGQN from any third party claims made against HGQN concerning entered content, pictures, documents, texts and other data.

15.4. HGQN is authorised to publish content and other data entered by users in the internet and print media.

16. Concluding regulations

16.1. Should individual definitions of these general terms and condition of use be inoperative or impracticable, the remaining definitions are nevertheless applicable. Instead of an impracticable definition or to fill a gap, a ruling applies that so far as possible the next achievable definition is achieved that legally or commercially can be. As far as definitions of the federal regulations governing terms and conditions of use compel additional definitions, or dictate something else (German law: "AGB-Gesetz", AGBG), the AGBG applies, in so far as its use is imperative.

16.2. HGQN retains the right at any time to change the general terms and conditions of use, without justification. The new conditions will be conveyed to the user by email at the latest one month before they take effect. The new conditions are considered as accepted, if the user does not present written disagreement within 14 days.

16.3. Sole responsible court of law for all claims arising from the licence agreement is Munich, Germany.

16.4. German law is applicable.