

Terms and Conditions of SEEK by Haemnet

These Terms govern

- the use of this Application, and,
- any other related Agreement or legal relationship with the Owner

in a legally binding way. Capitalised words are defined in the relevant dedicated section of this document.

The User must read this document carefully.

Nothing in these Terms creates any relationship of employment, agency, or partnership between the involved parties.

This Application is provided by:

Haemnet Ltd a company registered in England and Wales with company number 12211003. The registered offices are located at 74 Glenwood Road, London, England, N15 3JR, United Kingdom. Haemnet Ltd is registered with the Information Commissioners Office (ICO) with registration number ZA708768.

Owner contact email: digital@haemnet.com

What the User should know at a glance

- Usage of this Application and the Service is age restricted, as detailed in the relevant section of this document.
- The Service/this Application is only intended for Consumers.

Information about this Application

SEEK stands for 'Sharing Experience, Expanding Knowledge'.

Created by a professional team of researchers and patient experts, SEEK provides a safe and secure environment in which people living with rare disorders and their carers can share their experience to expand knowledge and be rewarded for doing so.

Please read these Terms & Conditions carefully. If you wish to know more about how we handle your data, please see our Privacy Policy.

SEEK ("SEEK") is owned and operated by Haemnet Ltd ("company", "us", "we", "our"). SEEK can be accessed via various platforms and devices, as either a mobile application or a web application.

The following sets out the information you will need to provide to register on SEEK.

SEEK is intended for use by those who fulfil at least two of the following criteria:

- Those with a given health condition diagnosed by a medical professional. We reserve the right to ask for verification should it be required for a particular research project.
- Carer of a person with a given health condition.
- Those over the age of consent for research in their country of residence (e.g. over 16 years of age in the United Kingdom). We reserve the right to ask for verification.

To access SEEK and to take part in its activities, you will need to register on the platform by creating an account. To do this you must enter a unique username and password and a valid email address.

As part of the onboarding process we will ask you to complete the following profile details:

- Name
- Date of birth
- Location / Country of residence Gender
- Health condition Treatment information

- Potentially further information about your primary condition or any other condition(s) you may have.

We use this information to:

- Determine which activities are relevant to you. This means that we will only contact you about activities that are relevant to you and your condition.
- Confirm that you are a real person. Due to the nature of our activities and the reimbursement involved, people may pretend to have a condition or may develop software (“bots”) to mimic humans and respond to surveys. This can compromise the quality and viability of research data. Completing this information will help us to ensure the data we collect is robust, of high quality, and from real people.

We store this information on a third-party cloud-based server located in the United Kingdom. Users who register on SEEK will be sent invitations to take part in Haemnet research and communications activities that may be of interest to them. These will be sent by push notification, email and potentially post.

By creating an account on SEEK you consent to Haemnet storing your personal data for the purposes described. In addition, you consent to Haemnet sending you communications via the methods described. You also agree to be bound by the SEEK Terms & Conditions, which will take immediate effect upon the creation of your account. For more information on how Haemnet handles your data, please see our Privacy Policy. If you do not agree with these Terms & Conditions, you should not use or access SEEK.

"This Application" refers to

- this website, including its subdomains and any other website through which the Owner makes its Service available;
- applications for mobile, tablet and other smart device systems;
- the Service;

TERMS OF USE

Unless otherwise specified, the terms of use detailed in this section apply generally when using this Application.

Single or additional conditions of use or access may apply in specific scenarios and in such cases are additionally indicated within this document.

By using this Application, Users confirm to meet the following requirements:

- Users must qualify as Consumers;
- Users must be older than 16;

Account registration

To use the Service Users must register or create a User account, providing all required data or information in a complete and truthful manner.

Failure to do so will cause unavailability of the Service.

Users are responsible for keeping their login credentials confidential and safe. For this reason, Users are also required to choose passwords that meet the highest standards of strength permitted by this Application.

By registering, Users agree to be fully responsible for all activities that occur under their username and password.

Users are required to immediately and unambiguously inform the Owner via the contact details indicated in this document, if they think their personal information, including but not limited to User accounts, access credentials or personal data, have been violated, unduly disclosed or stolen.

Conditions for account registration

Registration of User accounts on this Application is subject to the conditions outlined below. By registering, Users agree to meet such conditions.

- Accounts registered by bots or any other automated methods are not permitted.
- Unless otherwise specified, each User must register only one account.

- Unless explicitly permitted, a User account may not be shared with other persons.

Account termination

Users can terminate their account and stop using the Service at any time by doing the following:

- By using the tools provided for account termination on this Application.
- By directly contacting the Owner at the contact details provided in this document.

Account suspension and deletion

The Owner reserves the right, at its sole discretion, to suspend or delete at any time and without notice, User accounts which it deems inappropriate, offensive or in violation of these Terms.

The suspension or deletion of User accounts shall not entitle Users to any claims for compensation, damages or reimbursement.

The suspension or deletion of accounts due to causes attributable to the User does not exempt the User from paying any applicable fees or prices.

Content on this Application

Unless where otherwise specified or clearly recognisable, all content available on this Application is owned or provided by the Owner or its licensors.

The Owner undertakes its utmost effort to ensure that the content provided on this Application infringes no applicable legal provisions or third-party rights. However, it may not always be possible to achieve such a result.

In such cases, without prejudice to any legal prerogatives of Users to enforce their rights, Users are kindly asked to preferably report related complaints using the contact details provided in this document.

Rights regarding content on this Application - All rights reserved

The Owner holds and reserves all intellectual property rights for any such content.

Users may not therefore use such content in any way that is not necessary or implicit in the proper use of the Service.

In particular, but without limitation, Users may not copy, download, share (beyond the limits set forth below), modify, translate, transform, publish, transmit, sell, sublicense, edit, transfer/assign to third parties or create derivative works from the content available on this Application, nor allow any third party to do so through the User or their device, even without the User's knowledge.

Where explicitly stated on this Application, the User may download, copy and/or share some content available through this Application for its sole personal and non-commercial use and provided that the copyright attributions and all the other attributions requested by the Owner are correctly implemented.

Any applicable statutory limitation or exception to copyright shall stay unaffected.

Content provided by Users

The Owner allows Users to upload, share or provide their own content to this Application.

By providing content to this Application, Users confirm that they are legally allowed to do so and that they are not infringing any statutory provisions and/or third-party rights.

Rights regarding content provided by Users

Users acknowledge and accept that by providing their own content on this Application they grant the Owner a non-exclusive, fully paid-up and royalty-free licence to process such content solely for the operation and maintenance of this Application as contractually required.

To the extent permitted by applicable law, Users waive any moral rights in connection with content they provide to this Application.

Users acknowledge, accept and confirm that all content they provide through this Application is provided subject to the same general conditions set forth for content on this Application.

Liability for provided content

Users are solely liable for any content they upload, post, share, or provide through this Application. Users acknowledge and accept that **the Owner does not filter or moderate such content**.

However, the Owner reserves the right to remove, delete or block such content at its own discretion and, without prior notice, to deny the uploading User access to this Application:

- upon becoming aware of any (alleged) violation of these Terms, any third-party rights, or applicable law, based on such content;
- if a notice of infringement of intellectual property rights is received;
- if a notice of violation of a third party's privacy, including their intimate privacy, is received;
- upon order of a public authority; or
- where the Owner is made aware that the content, while being accessible via this Application, may represent a risk for Users, third parties and/or the availability of the Service.

The removal, deletion or blocking of content shall not entitle Users that have provided such content or that are liable for it, to any claims for compensation, damages or reimbursement.

Users agree to hold the Owner harmless from and against any claim asserted and/or damage suffered due to content they provided to or provided through this Application.

Access to external resources

Through this Application Users may have access to external resources provided by third parties. Users acknowledge and accept that the Owner has no control over such resources and is therefore not responsible for their content and availability.

Conditions applicable to any resources provided by third parties, including those applicable to any possible grant of rights in content, result from each such third parties' terms and conditions or, in the absence of those, applicable statutory law.

Acceptable use

This Application and the Service may only be used within the scope of what they are provided for, under these Terms and applicable law.

Users are solely responsible for making sure that their use of this Application and/or the Service violates no applicable law, regulations or third-party rights.

Therefore, **the Owner reserves the right to take any appropriate measure to protect its legitimate interests including by denying Users access to this Application or the Service, terminating contracts, reporting any misconduct performed through this Application or the Service to the competent authorities - such as judicial or administrative authorities - whenever Users engage or are suspected to engage in any of the following activities:**

- violate laws, regulations and/or these Terms;
- infringe any third-party rights;
- considerably impair the Owner's legitimate interests;
- offend the Owner or any third party.

Liability and indemnification

Indemnification

The User agrees to indemnify and hold the Owner and its subsidiaries, affiliates, officers, directors, agents, co-branders, partners and employees harmless from and against any claim or demand — including but not limited to lawyer's fees and costs — made by any third party due to or in relation with any culpable use of or connection to the Service, violation of these Terms, infringement of any third-party rights or statutory provision by the User or its affiliates, officers, directors, agents, co-branders, partners and employees to the extent allowed by applicable law.

Limitation of liability

Unless otherwise explicitly stated and without prejudice to applicable statutory product liability provisions, Users shall have no right to claim damages against the Owner (or any natural or legal person acting on its behalf).

This does not apply to damages to life, health or physical integrity, damages resulting from the breach of an

essential contractual obligation such as any obligation strictly necessary to achieve the purpose of the contract, and/or damages resulting from intent or gross negligence, as long as this Application has been appropriately and correctly used by the User.

Unless damages have been caused by way of intent or gross negligence, or they affect life, health or physical integrity, the Owner shall only be liable to the extent of typical and foreseeable damages at the moment the contract was entered into.

In particular, within the limits stated above, the Owner shall not be liable for:

- any losses that are not the direct consequence of a breach of the Terms by the Owner;
- any loss of business opportunities and any other loss, even indirect, that may be incurred by the User (such as, but not limited to, trading losses, loss of revenue, income, profits or anticipated savings, loss of contracts or business relationships, loss of reputation or goodwill, etc.);
- damages or losses resulting from interruptions or malfunctions of this Application due to acts of force majeure, or unforeseen and unforeseeable events and, in any case, independent of the will and beyond the control of the Owner, such as, but not limited to, failures or disruptions of telephone or electrical lines, the Internet and / or other means of transmission, unavailability of websites, strikes, natural disasters, viruses and cyber attacks, interruptions in the delivery of products, third-party services or applications;

Australian Users

Limitation of liability

Nothing in these Terms excludes, restricts or modifies any guarantee, condition, warranty, right or remedy which the User may have under the Competition and Consumer Act 2010 (Cth) or any similar State and Territory legislation and which cannot be excluded, restricted or modified (non-excludable right). To the fullest extent permitted by law, our liability to the User, including liability for a breach of a non-excludable right and liability which is not otherwise excluded under these Terms of Use, is limited, at the Owner's sole discretion, to the re-performance of the services or the payment of the cost of having the services supplied again.

US Users

Disclaimer of Warranties

This Application is provided strictly on an "as is" and "as available" basis. Use of the Service is at Users' own risk. To the maximum extent permitted by applicable law, the Owner expressly disclaims all conditions, representations, and warranties — whether express, implied, statutory or otherwise, including, but not limited to, any implied warranty of merchantability, fitness for a particular purpose, or non-infringement of third-party rights. No advice or information, whether oral or written, obtained by user from owner or through the Service will create any warranty not expressly stated herein.

Without limiting the foregoing, the Owner, its subsidiaries, affiliates, licensors, officers, directors, agents, co-branders, partners, suppliers and employees do not warrant that the content is accurate, reliable or correct; that the Service will meet Users' requirements; that the Service will be available at any particular time or location, uninterrupted or secure; that any defects or errors will be corrected; or that the Service is free of viruses or other harmful components. Any content downloaded or otherwise obtained through the use of the Service is downloaded at users own risk and users shall be solely responsible for any damage to Users' computer system or mobile device or loss of data that results from such download or Users' use of the Service.

The Owner does not warrant, endorse, guarantee, or assume responsibility for any product or service advertised or offered by a third party through the Service or any hyperlinked website or service, and the Owner shall not be a party to or in any way monitor any transaction between Users and third-party providers of products or services.

The Service may become inaccessible or it may not function properly with Users' web browser, mobile device, and/or operating system. The owner cannot be held liable for any perceived or actual damages arising from Service content, operation, or use of this Service.

Federal law, some states, and other jurisdictions, do not allow the exclusion and limitations of certain implied warranties. The above exclusions may not apply to Users. This Agreement gives Users specific legal rights, and Users may also have other rights which vary from state to state.

The disclaimers and exclusions under this agreement shall not apply to the extent prohibited by applicable law.

Limitations of liability

To the maximum extent permitted by applicable law, in no event shall the Owner, and its subsidiaries, affiliates, officers, directors, agents, co-branders, partners, suppliers and employees be liable for

- any indirect, punitive, incidental, special, consequential or exemplary damages, including without limitation damages for loss of profits, goodwill, use, data or other intangible losses, arising out of or relating to the use of, or inability to use, the Service; and
- any damage, loss or injury resulting from hacking, tampering or other unauthorised access or use of the Service or User account or the information contained therein;
- any errors, mistakes, or inaccuracies of content;
- personal injury or property damage, of any nature whatsoever, resulting from User access to or use of the Service;
- any unauthorised access to or use of the Owner's secure servers and/or any and all personal information stored therein;
- any interruption or cessation of transmission to or from the Service;
- any bugs, viruses, trojan horses, or the like that may be transmitted to or through the Service;
- any errors or omissions in any content or for any loss or damage incurred as a result of the use of any content posted, emailed, transmitted, or otherwise made available through the Service; and/or
- the defamatory, offensive, or illegal conduct of any User or third party. In no event shall the Owner, and its subsidiaries, affiliates, officers, directors, agents, co-branders, partners, suppliers and employees be liable for any claims, proceedings, liabilities, obligations, damages, losses or costs in an amount exceeding the amount paid by User to the Owner hereunder in the preceding 12 months, or the period of duration of this agreement between the Owner and User, whichever is shorter.

This limitation of liability section shall apply to the fullest extent permitted by law in the applicable jurisdiction whether the alleged liability is based on contract, tort, negligence, strict liability, or any other basis, even if company has been advised of the possibility of such damage.

Some jurisdictions do not allow the exclusion or limitation of incidental or consequential damages, therefore the above limitations or exclusions may not apply to User. The terms give User specific legal rights, and User may also have other rights which vary from jurisdiction to jurisdiction. The disclaimers, exclusions, and limitations of liability under the terms shall not apply to the extent prohibited by applicable law.

Indemnification

The User agrees to defend, indemnify and hold the Owner and its subsidiaries, affiliates, officers, directors, agents, co-branders, partners, suppliers and employees harmless from and against any and all claims or demands, damages, obligations, losses, liabilities, costs or debt, and expenses, including, but not limited to, legal fees and expenses, arising from

- User's use of and access to the Service, including any data or content transmitted or received by User;
- User's violation of these terms, including, but not limited to, User's breach of any of the representations and warranties set forth in these terms;
- User's violation of any third-party rights, including, but not limited to, any right of privacy or intellectual property rights;
- User's violation of any statutory law, rule, or regulation;
- any content that is submitted from User's account, including third party access with User's unique username, password or other security measure, if applicable, including, but not limited to, misleading, false, or inaccurate information;
- User's willful misconduct; or
- statutory provision by User or its affiliates, officers, directors, agents, co-branders, partners, suppliers and employees to the extent allowed by applicable law.

Common provisions

No Waiver

The Owner's failure to assert any right or provision under these Terms shall not constitute a waiver of any

such right or provision. No waiver shall be considered a further or continuing waiver of such term or any other term.

Service interruption

To ensure the best possible service level, the Owner reserves the right to interrupt the Service for maintenance, system updates or any other changes, informing the Users appropriately.

Within the limits of law, the Owner may also decide to suspend or discontinue the Service altogether. If the Service is discontinued, the Owner will cooperate with Users to enable them to withdraw Personal Data or information and will respect Users' rights relating to continued product use and/or compensation, as provided for by applicable law.

Additionally, the Service might not be available due to reasons outside the Owner's reasonable control, such as "force majeure" events(infrastructural breakdowns or blackouts etc.).

Service reselling

Users may not reproduce, duplicate, copy, sell, resell or exploit any portion of this Application and of its Service without the Owner's express prior written permission, granted either directly or through a legitimate reselling program.

Privacy policy

To learn more about the use of their Personal Data, Users may refer to the privacy policy of this Application.

Intellectual property rights

Without prejudice to any more specific provision of these Terms, any intellectual property rights, such as copyrights, trademark rights, patent rights and design rights related to this Application are the exclusive property of the Owner or its licensors and are subject to the protection granted by applicable laws or international treaties relating to intellectual property.

All trademarks — nominal or figurative — and all other marks, trade names, service marks, word marks, illustrations, images, or logos appearing in connection with this Application are, and remain, the exclusive property of the Owner or its licensors and are subject to the protection granted by applicable laws or international treaties related to intellectual property.

Changes to these Terms

The Owner reserves the right to amend or otherwise modify these Terms at any time. In such cases, the Owner will appropriately inform the User of these changes.

Such changes will only affect the relationship with the User from the date communicated to Users onwards.

The continued use of the Service will signify the User's acceptance of the revised Terms. If Users do not wish to be bound by the changes, they must stop using the Service and may terminate the Agreement.

The applicable previous version will govern the relationship prior to the User's acceptance. The User can obtain any previous version from the Owner.

If legally required, the Owner will notify Users in advance of when the modified Terms will take effect.

Assignment of contract

The Owner reserves the right to transfer, assign, dispose of by novation, or subcontract any or all rights or obligations under these Terms, taking the User's legitimate interests into account. Provisions regarding changes of these Terms will apply accordingly.

Users may not assign or transfer their rights or obligations under these Terms in any way, without the written permission of the Owner.

Contacts

All communications relating to the use of this Application must be sent using the contact information stated in this document.

Severability

Should any provision of these Terms be deemed or become invalid or unenforceable under applicable law, the invalidity or unenforceability of such provision shall not affect the validity of the remaining provisions, which shall remain in full force and effect.

US Users

Any such invalid or unenforceable provision will be interpreted, construed and reformed to the extent reasonably required to render it valid, enforceable and consistent with its original intent. These Terms constitute the entire Agreement between Users and the Owner with respect to the subject matter hereof, and supersede all other communications, including but not limited to all prior agreements, between the parties with respect to such subject matter. These Terms will be enforced to the fullest extent permitted by law.

EU Users

Should any provision of these Terms be or be deemed void, invalid or unenforceable, the parties shall do their best to find, in an amicable way, an agreement on valid and enforceable provisions thereby substituting the void, invalid or unenforceable parts.

In case of failure to do so, the void, invalid or unenforceable provisions shall be replaced by the applicable statutory provisions, if so permitted or stated under the applicable law.

Without prejudice to the above, the nullity, invalidity or the impossibility to enforce a particular provision of these Terms shall not nullify the entire Agreement, unless the severed provisions are essential to the Agreement, or of such importance that the parties would not have entered into the contract if they had known that the provision would not be valid, or in cases where the remaining provisions would translate into an unacceptable hardship on any of the parties.

Governing law

These Terms are governed by the law of the place where the Owner is based, as disclosed in the relevant section of this document, without regard to conflict of laws principles.

Prevalence of national law

However, regardless of the above, if the law of the country that the User is located in provides for a higher applicable consumer protection standard, such higher standards shall prevail.

Venue of jurisdiction

The exclusive competence to decide on any controversy resulting from or connected to these Terms lies with the courts of the place where the Owner is based, as displayed in the relevant section of this document.

Exception for Consumers in Europe

The above does not apply to any Users that qualify as European Consumers, nor to Consumers based in the United Kingdom, Switzerland, Norway or Iceland.

The Haemnet Limited privacy policy can be found at the following website address:
<https://www.haemnet.com/privacy-policy/>

Definitions and legal references

This Application (or this Application)

The property that enables the provision of the Service.

Agreement

Any legally binding or contractual relationship between the Owner and the User, governed by these Terms.

European (or Europe)

Applies where a User, regardless of nationality, is in the EU.

Owner (or We)

Indicates the natural person(s) or legal entity that provides this Application and/or the Service to Users.

Service

The service provided by this Application as described in these Terms and on this Application.

Terms

All provisions applicable to the use of this Application and/or the Service as described in this document, including any other related documents or agreements, and as updated from time to time.

User (or You)

Indicates any natural person or legal entity using this Application.

Consumer

Consumer is any User qualifying as such under applicable law.

Latest update: 26 May 2023