

## IHS Data Privacy Policy

The **International Headache Society**, a charity registered with the Charity Commission for England and Wales, and **IHS Trading Company Ltd** are committed to protecting and respecting your privacy. In this policy, we refer to either the International Headache Society, and IHS Trading Company Ltd as **IHS, we, our** or **us**.

The International Headache Society is an international membership organisation for those with a professional commitment to helping people affected by headache. As a charity, the purpose of IHS is to advance headache science, education, and management, and promote headache awareness worldwide.

This policy, together with our **cookie policy** and any other document referred to in it (if applicable), sets out the basis on which any data collected about you will be processed by us.

### 1. Scope of this policy

This policy applies to all personal data we collect and process through your use of this website, or as a result of your membership with us (for example, grant applications or use of journals), and any other services offered by IHS (regardless of where you visit or access this website from). This website is not intended for children and we do not knowingly collect data relating to children.

This policy does not apply to services offered by other companies or individuals and does not cover the information practices of other companies and organisations who advertise IHS services or any third party operating any website to which the IHS website or other digital asset may contain a link. Clicking on any third party links or enabling those connections may allow third parties to collect or share data about you. We do not control these third-party websites and are not responsible for their privacy statements. When you leave our website, we encourage you to read the privacy policy of every website you visit.

### 2. Data collected and method of collection

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

**Data collected.** We may collect, use, store and transfer different kinds of personal data about you which we have grouped together as follows:

- **Identity Data** includes first name, last name, username or similar identifier, qualifications, CV, title, date of birth, gender, passport details, photographs, conflict of interest information, organisation or company of employment and job title.
- **Contact Data** includes your or your organisation's address, email address, fax numbers and telephone numbers.
- **Financial Data** includes bank account and payment card details.
- **Transaction Data** includes details about payments to and from you and other details of services you have purchased from us.

- **Technical Data** includes internet protocol (IP) address, your login data, browser type and version, time zone setting and location, browser plug-in types and versions, operating system and platform, and other technology on the devices you use to access this website.
- **Profile Data** includes your username and password, field of activity and/or interest (for example, purely clinical, basic research or clinical research), purchases or orders made by you, your interests, preferences, feedback and survey responses.
- **Usage Data** includes information about how you use our website.
- **Marketing and Communications Data** includes your preferences in receiving marketing from us and our third parties and your communication preferences.

We also collect, use and share **Aggregated Data** such as statistical or demographic data for any purpose. Aggregated Data could be derived from your personal data but is not considered personal data in law as this data will not directly or indirectly reveal your identity. For example, we may aggregate your Usage Data to calculate the percentage of users accessing a specific website feature. However, if we combine or connect Aggregated Data with your personal data so that it can directly or indirectly identify you, we treat the combined data as personal data which will be used in accordance with this privacy policy.

We do not collect any **Special Categories of Personal Data** about you (this includes details about your race or ethnicity, religious or philosophical beliefs, sex life, sexual orientation, political opinions, trade union membership, information about your health, and genetic and biometric data). Nor do we collect any information about criminal convictions and offences.

**If you fail to provide personal data.** Where we need to collect personal data by law, or under the terms of a contract we have with you, and you fail to provide that data when requested, we may not be able to perform the contract we have or are trying to enter into with you (for example, to provide you with goods or services). In this case, we may have to cancel your membership or grant application, your subscription to our publication(s), or attendance of the IHS International Headache Congress, but we will notify you if this is the case at the time.

**How is your personal data collected.** We use different methods to collect data from and about you including through:

- **Direct interactions.** You may give us your Identity, Contact and Financial Data by filling in forms or by corresponding with us by post, phone, email or otherwise. This includes personal data you provide when you:
  - apply for a membership with us;
  - create an account on our website;
  - subscribe to our service or publications;
  - sign up to attend a conference;
  - request marketing to be sent to you;
  - enter a survey; or
  - give us feedback or contact us.
- **Automated technologies or interactions.** As you interact with our website, we will automatically collect Technical Data about your equipment, browsing actions and patterns. We collect this personal data by using cookies, server logs and other similar technologies. We may also receive Technical Data about you if you visit other websites employing our cookies. Please see our **cookie policy** for further details.
- **Third parties or publicly available sources.** We will receive personal data about you from various third parties and public sources.

### 3. Purpose of data collection

We will only use your personal data when the law allows us to. Most commonly, we will use your personal data in the following circumstances:

- Where we **need to perform the contract** we are about to enter into or have entered into with you.
- Where it is **necessary for our legitimate interests** (or those of a third party) and your interests and fundamental rights do not override those interests.
- Where we need to comply with a **legal obligation**.

**Further information about the lawful basis of processing.** The types of lawful basis of processing that we use are described further below:

- **Performance of Contract** means processing your data where it is necessary for the performance of a contract to which you are a party or to take steps at your request before entering into such a contract.
- **Legitimate Interest** means the interest of our organisation in conducting and managing our organisation to enable us to give you the best service/product and the best and most secure experience. We make sure we consider and balance any potential impact on you (both positive and negative) and your rights before we process your personal data for our legitimate interests. We do not use your personal data for activities where our interests are overridden by the impact on you (unless we have your consent or are otherwise required or permitted to by law). You can obtain further information about how we assess our legitimate interests against any potential impact on you in respect of specific activities by contacting us.
- **Comply with a legal obligation** means processing your personal data where it is necessary for compliance with a legal obligation that we are subject to.

Generally, we do not rely on consent as a legal basis for processing your personal data. We may send third party direct marketing communications (for example, on behalf of IHC or an affiliated headache society) to you via email or text message. You have the right to unsubscribe from receiving such marketing at any time by contacting us.

We have set out below, in a table format, a description of all the ways we plan to use your personal data, and which of the legal bases we rely on to do so. We have also identified what our legitimate interests are where appropriate.

Note that we may process your personal data for more than one lawful ground depending on the specific purpose for which we are using your data. Please contact us if you need details about the specific legal ground we are relying on to process your personal data where more than one ground has been set out in the table below.

Purpose/Activity	Type of data	Lawful basis for processing including basis of legitimate interest
<b>Visitors to our website</b>		
To contact IHS (including the editorial manager of Cephalalgia)	(a) Identity (b) Contact	Necessary for our legitimate interest (for running IHS)
To submit a manuscript to Cephalalgia	(a) Identity (b) Contact	Necessary for our legitimate interest (to redirect you to the Cephalalgia website to enable you to submit a manuscript)

To receive support services from SAGE with regards to Cephalalgia	(a) Identity (b) Contact	Necessary for our legitimate interest (to provide access to Cephalalgia)
<b>Members of IHS</b>		
To register you as a new member	(a) Identity (b) Contact	(a) Performance of a contract with you (if our contract is with you)  (b) Necessary for our legitimate interest (perform our contract with the organisation or company that you represent)
To process your membership application / renewal including: (a) Manage payments, fees and charges (b) Collect and recover money owed to us	(a) Identity (b) Contact (c) Financial (d) Transaction (e) Marketing and Communications	(a) Performance of a contract with you (if our contract is with you)  (b) Necessary for our legitimate interests (if our contract is with the organisation or company that you represent to recover debts due to us)
To enable you to sign up to attend IHC conferences	a) Identity (b) Contact (c) Financial (d) Transaction (e) Usage	(a) Performance of a contract with you (if our contract is with you)  (b) Necessary for our legitimate interests (if our contract is with the organisation or company that you represent to recover debts due to us)
To enable you to present at an IHC conference. This includes the sharing with attendees / individuals watching recordings of such conference any conflict of interests information)	(a) Identity (b) Contact	Necessary for our legitimate interest (to have appropriate speakers presenting at IHC conferences)
To provide you with membership benefits (including the sharing with third parties for the provision of membership services)	(a) Identity (b) Contact (c) Profile (d) Marketing and Communications (e) Technical Data	(a) Performance of a contract with you (if our contract is with you)  (b) Necessary for our legitimate interest (perform our contract with the organisation or company that you represent)
To manage our relationship with you which will include:  (b) Notifying you about changes to our terms or privacy policy (b) Asking you to take a survey	(a) Identity (b) Contact (c) Profile (d) Marketing and Communications	(a) Performance of a contract with you  (b) Necessary to comply with a legal obligation  (c) Necessary for our legitimate interests (to keep our records updated and to study how customers use our products/services, to develop them or grow our organisation)
To include your details in the IHS Membership Directory	(a) Identity (b) Contact	(a) Performance of a contract with you (if our contract is with you)

		(b) Necessary for our legitimate interest (perform our contract with the organisation or company that you represent)
To assess whether you are eligible or suitable for services that we provide, for example, assessing your grant application and making payments of any grants	(a) Identity (b) Contact (c) Usage (d) Profile (e) Marketing and Communications (f) Financial Data	(a) Performance of a contract with you (if our contract is with you)  (b) Necessary for our legitimate interests (if our contract is with the organisation or company that you represent to perform our contract with them)
To comply with our governance obligations and operation of IHS	(a) Identity (b) Contact (c) Profile (d) Marketing and Communications (e) Technical (f) Financial and Transaction (g) Usage	Necessary for our legitimate interest (to manage our governance and operation of IHS)
<b>Visitors to the website and members (and former members)</b>		
To administer and protect our organisation and this website (including troubleshooting, data analysis, testing, system maintenance, support, reporting and hosting of data)	(a) Identity (b) Contact (c) Technical	(a) Necessary for our legitimate interests (for running our organisation, provision of administration and IT services or network security)  (b) Necessary to comply with a legal obligation
To deliver relevant website content and advertisements to you and measure or understand the effectiveness of the advertising we serve to you	(a) Identity (b) Contact (c) Profile (d) Usage (e) Marketing and Communications (f) Technical	Necessary for our legitimate interests (to study how customers use our products/services, to develop them, to grow the organisation and to inform our marketing strategy)
To use data analytics to improve our website, memberships, products/services, marketing, relationships and experiences of our members and prospective members	(a) Technical (b) Usage	Necessary for our legitimate interests (to define types of members / customers for our memberships, products and services, to keep our website updated and relevant, to develop our organisation and to inform our marketing strategy)
To make suggestions and recommendations to you about services that may be of interest to you	(a) Identity (b) Contact (c) Technical (d) Usage (e) Profile (f) Marketing and Communications	Necessary for our legitimate interests (to develop our membership and products/services and grow our organisation)

**Marketing.** We strive to provide you with choices regarding certain personal data uses, particularly around marketing and advertising.

- **Promotional materials from us** (for example, information and news about events or conferences, or grant opportunities). You will receive marketing communications from us if you have requested information from us or have signed up to become a member and you have not opted out of receiving that marketing.
- **Promotional materials on behalf of third parties** (for example, IHC or affiliated headache societies). We may from time to time send you information and news (for example, information about conferences) on behalf of a third party.
- **Lawful basis.** It is in our (or the third party's) legitimate interest to contact you for this purpose (to promote IHS or the interests of the third party). However, if you do not represent an institution or company then we would need your consent for contacting you for these purposes.
- **Opting out.** You can ask us to stop sending you marketing messages at any time by following the opt-out links on any marketing message sent to you or by contacting us at any time. Where you opt out of receiving these marketing messages, this will not apply to personal data provided to us as a result of becoming a member.

**Cookies.** You can set your browser to refuse all or some browser cookies, or to alert you when websites set or access cookies. If you disable or refuse cookies, please note that some parts of this website may become inaccessible or not function properly. For more information about the cookies we use, please see our *cookie policy*.

**Change of purpose.** We will only use your personal data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another reason and that reason is compatible with the original purpose. If you wish to get an explanation as to how the processing for the new purpose is compatible with the original purpose, please contact us.

If we need to use your personal data for an unrelated purpose, we will notify you and we will explain the legal basis which allows us to do so.

Please note that we may process your personal data without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

#### **4. Data retention**

We will only retain your personal data for as long as reasonably necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, regulatory, tax, accounting or reporting requirements. We may retain your personal data for a longer period in the event of a complaint or if we reasonably believe there is a prospect of litigation in respect to our relationship with you.

To determine the appropriate retention period for personal data, we consider the amount, nature and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of your personal data, the purposes for which we process your personal data

and whether we can achieve those purposes through other means, and the applicable legal, regulatory, tax, accounting or other requirements.

Details of retention periods for different aspects of your personal data are available in our retention policy which you can request from us by contacting us.

## 5. Disclosure of your personal data

We may share your personal data with the parties set out below for the purposes set out in paragraph 3 above.

- **Other companies within our organisation.** We may provide information to other companies within our organisation if they provide a service to us.
- **Local headache societies.** We may provide information to local headache societies if you join us and them through IHS.
- **Suppliers of membership services.** We may provide your information to third party organisation to provide you with membership services, for example, the publisher Cephalalgia and Cephalalgia Reports, the provider of the Cephalalgia app, the IHC congress organiser or representatives and staff of IHS Affiliate Member Societies
- **Service providers and suppliers.** We may provide information to service providers and suppliers who provide services to us, for example, IT services or marketing services.
- **Professional advisers and other external parties.** We may provide information to our professional advisers and other external third parties, including lawyers, bankers, auditors and insurers, who provide professional services to us.
- **Legal, supervisory, and regulatory authorities.** We may share information with legal, supervisory, and regulatory authorities and any government agencies and law enforcement bodies if we are under a duty to disclose or share your personal data with them.

We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third-party service providers to use your personal data for their own purposes and only permit them to process your personal data for specified purposes and in accordance with our instructions.

## 6. International transfers

Whenever we transfer your personal data out of the UK and the European Economic Area (EEA), we ensure a similar degree of protection is afforded to it by ensuring at least one of the following safeguards is implemented:

- We will only transfer your personal data to countries that have been deemed to provide an adequate level of protection for personal data.
- We may use specific contracts approved for use in the UK which give personal data the same protection it has in the UK and the EEA.

Please contact us if you want further information on the specific mechanism used by us when transferring your personal data out of the UK.

## 7. Data security

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. In addition, we limit access to your personal data to those employees, agents, contractors and other third parties who have a business need to know. They will only process your personal data on our instructions and they are subject to a duty of confidentiality.

We have put in place procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

## 8. Your legal rights

Under certain circumstances, you have rights under data protection laws in relation to your personal data. You have the right to:

- **Request access** to your personal data (commonly known as a "data subject access request"). This enables you to receive a copy of the personal data we hold about you and to check that we are lawfully processing it.
- **Request correction** of the personal data that we hold about you. This enables you to have any incomplete or inaccurate data we hold about you corrected, though we may need to verify the accuracy of the new data you provide to us.
- **Request erasure** of your personal data. This enables you to ask us to delete or remove personal data where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal data where you have successfully exercised your right to object to processing (see below), where we may have processed your information unlawfully or where we are required to erase your personal data to comply with local law. Note, however, that we may not always be able to comply with your request of erasure for specific legal reasons which will be notified to you, if applicable, at the time of your request.
- **Object to processing** of your personal data where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground as you feel it impacts on your fundamental rights and freedoms. You also have the right to object where we are processing your personal data for direct marketing purposes. In some cases, we may demonstrate that we have compelling legitimate grounds to process your information which override your rights and freedoms.
- **Request restriction** of processing of your personal data. This enables you to ask us to suspend the processing of your personal data in the following scenarios:
  - If you want us to establish the data's accuracy.
  - Where our use of the data is unlawful but you do not want us to erase it.
  - Where you need us to hold the data even if we no longer require it as you need it to establish, exercise or defend legal claims.
  - You have objected to our use of your data but we need to verify whether we have overriding legitimate grounds to use it.



- **Request the transfer** of your personal data to you or to a third party. We will provide to you, or a third party you have chosen, your personal data in a structured, commonly used, machine-readable format. Note that this right only applies to automated information which you initially provided consent for us to use or where we used the information to perform a contract with you.
- **Withdraw consent** at any time where we are relying on consent to process your personal data. However, this will not affect the lawfulness of any processing carried out before you withdraw your consent. If you withdraw your consent, we may not be able to provide certain products or services to you. We will advise you if this is the case at the time you withdraw your consent.

If you wish to exercise any of the rights set out above, please [ihsoffice@i-h-s.org](mailto:ihsoffice@i-h-s.org).

**No fee usually required.** You will not have to pay a fee to access your personal data (or to exercise any of the other rights). However, we may charge a reasonable fee if your request is clearly unfounded, repetitive or excessive. Alternatively, we could refuse to comply with your request in these circumstances.

**What we may need from you.** We may need to request specific information from you to help us confirm your identity and ensure your right to access your personal data (or to exercise any of your other rights). This is a security measure to ensure that personal data is not disclosed to any person who has no right to receive it. We may also contact you to ask you for further information in relation to your request to speed up our response.

**Time limit to respond.** We try to respond to all legitimate requests within one month. Occasionally it could take us longer than a month if your request is particularly complex or you have made a number of requests. In this case, we will notify you and keep you updated.

## 9. Changes to this policy and your duty to inform us of changes

**Changes to this policy.** We keep this policy under regular review and this policy may be revised and updated by IHS from time to time. IHS will post any statement changes on the IHS website.

**Duty to inform us of changes.** It is important that the personal data we hold about you is accurate and current. Please keep us informed if your personal data changes during your relationship with us.

## 10. How to contact us and complaints

We are the data controller in respect of your personal data. Our registered office is at 2 London Wall Place, 6<sup>th</sup> Floor, London, England EC2Y 5AU, UK.

If you have any questions about this privacy policy, how we handle personal data or you are for any reason not happy with the way that we have handled your personal data, please contact us at [ihsoffice@i-h-s.org](mailto:ihsoffice@i-h-s.org) or at 2 London Wall Place, 6<sup>th</sup> Floor, London, England EC2Y 5AU, UK. If you are still not happy, you have the right to make a make a complaint to the Information Commissioner's Office (ICO), the UK regulator for data protection issues (<https://ico.org.uk>) or if you are based within the EEA, you can also complain to your regulator (as applicable). We would, however, appreciate the chance to deal with your

concerns before you approach the ICO or another regulator so please contact us in the first instance.

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