

Global Patient Survey - Data Privacy Statement

We recognise that it is important for you to understand how we use your personal data. Therefore, please read the following information carefully as it contains important information regarding the PVRI Global patient Survey and the way we use your personal data.

This Privacy Statement explains how we use personal data about visitors to our Global Patient Survey, including data provided by third parties and individuals that get in contact with us following on or in relation to the Global Patient Survey.

We will only use personal data in ways that are described in this statement and only ways that are consistent with our obligations and your rights under applicable data protection laws.

Who we are

For the purpose of applicable data protection laws, the data controller (in other words, the organisation that determines how and for what purposes your personal data is used) will be the Pulmonary Vascular Research Institute ('PVRI') with registered company number 05780068 and address 5 Tanner Street, London, SE1 3LE United Kingdom. Our Data Protection Lead is PVRI's Chief Executive, who can be contacted at admin@pvrinstitute.org. We have produced this privacy statement to tell you how we and our affiliates handle your personal data when you participate in our online Global Patient Survey.

All handling of your personal data is done in compliance with the UK Data Protection Act 2018 and, if and when applicable, the General Data Protection Regulation (EU) 2016/679 and UK General Data Protection Regulation ("**Data Protection Legislation**"). The terms "**Personal Data**", "**Special Categories of Personal Data**", "**Personal Data Breach**", "**Data Controller**", "**Data Processor**", "**Data Subject**" and "**process**" (in the context of usage of Personal Data) shall have the meanings given to them in the Data Protection Legislation.

What are your rights?

When reading this statement, it might be helpful to understand that your rights arising under Data Protection Legislation as set out below.

If you would like to exercise any of those rights (or if you have any queries about this policy or the way that we use your data, please contact us at admin@pvrinstitute.org..

RIGHT	DESCRIPTION OF RIGHT
Access	A right to access personal data held by us about you
Rectification	A right to require us to rectify any inaccurate personal data held by us about you

Erasure	A right to require us to erase personal data held by us about you. This right will only apply where (for example): we no longer need to use the personal data to achieve the purpose we collected it for; or where you withdraw your consent if we are using your personal data based on your consent; or where you object to the way we process your data (in line with your right to object, below).
Restriction	In certain circumstances, a right to restrict our processing of personal data held by us about you. This right will only apply where (for example): you dispute the accuracy of the personal data held by us; or where you would have the right to require us to erase the personal data but would prefer that our processing is restricted instead; or where we no longer need to use the personal data to achieve the purpose we collected it for, but you require the data for the purposes of dealing with legal claims
Portability	In certain circumstances, a right to receive personal data, which you have provided to us, in a structured, commonly used and machine-readable format. You also have the right to require us to transfer this personal data to another organisation, at your request
Objection	A right to object to our processing of personal data held by us about you where the processing of such data is necessary for the purposes of our legitimate interests, unless we are able to demonstrate, on balance, legitimate grounds for continuing to process personal data which override your rights or which are for the establishment, exercise or defence of legal claims
Not to be subject to automated processing	A right for you not to be subject to a decision based solely on an automated process, including profiling, which produces legal effects concerning you or similarly significantly affect you
Withdrawal of consent and objection to marketing	A right to withdraw your consent, where we are relying on it to use your personal data (for example, to provide you with marketing information about our services or products). You can object to direct marketing at any time.

You can also gain access to your personal data by emailing admin@pvrinstitute.org with the subject line: "Subject Access Request". When you submit a 'subject access request', you will need to provide confirmation of your identity by contacting us using the email address that you provided in the Global Patient Survey and another form of photo Identity verification. The data you requested will be provided free of charge and our response will be made within thirty (30) days unless our Data Protection Lead deems your request to be excessive or unfounded. If this is the case, we will inform you of our reasonable administration costs in advance and/or any associated delays, giving you the opportunity to choose whether you would like to pursue your request. If you believe we have made a mistake in evaluating your request, please see the section 'Who can you complain to?'

If you have questions about any of the rights mentioned in this section, please contact our Data Protection Lead at admin@pvrinstitute.org.



Who is the Data Controller?

Where we collect your personal data directly from you for our own purposes, we are the Data Controller.

What are the lawful bases for processing personal data?

Under Data Protection Legislation, there must be a 'lawful basis' for the use of personal data. The lawful bases are:

- a) 'your consent';
- b) 'performance of a contract';
- c) 'compliance with a legal obligation';
- d) 'protection of your, or another's vital interests';
- e) 'public interest/official authority'; and
- f) 'our legitimate interests'.

What are PVRI's 'legitimate interests'?

Legitimate interests are a flexible basis upon which the law permits the processing of an individual's personal data. To determine whether we have a legitimate interest in processing your data, we balance the needs and benefits to us against the risks and benefits for you of us processing your data. This balancing is performed as objectively as possible by our Data Protection Lead. You are able to object to our processing and we shall consider the extent to which this affects whether we have a legitimate interest. If you would like to find out more about our legitimate interests, please contact dataprotection@pvrinstitute.org.

Personal Data We May Collect From You And How We Collect It

Ways in which you might provide the data to us

This is personal data about you that you give us via our Global Patient Survey.

If you decide to participate on our online Global Patient Survey, we will only process the data if you input personal data such as your name and email address at the end of the Global Patient Survey, otherwise PVRI shall only hold pseudonymised data. The legal basis for such processing is Article 6(1)(f) GDPR since it is in our legitimate interests to do so and we make sure that your rights are protected.

About our processing of your data

We might collect, use, store and transfer different kinds of Personal Data about you which we have grouped together as follows:

Identity Data such as names, usernames or similar; marital status; title; date of birth; sex and gender.

Contact Data such as addresses; email addresses and telephone numbers.

Technical Data such as IP addresses; login data; browser info; time zone; location; browser plug-ins; operating systems; platforms and other technology on the device used to access the Global Patient Survey.

Marketing and Communications Data such as your preferences about receiving communications from us or third parties.

Special Categories of Data such as details about race or ethnic origins, religious or philosophical beliefs, sex life, sexual orientation, political opinions, trade union membership, information about your health, genetic or biometric data.

Children

This Global Patient Survey shall include questions that help to provide valuable health data of children (as defined by local law) with various health conditions. The Global Patient Survey shall be completed by parents and carers on behalf of children. PVRI shall not knowingly collect information from children without parental consent except where in compliance with applicable law.

We shall collect, use and share pseudonymised special category data e.g., health data based off the Global Patient Survey unless you choose to input your name and email address at the end of the Global Patient Survey. Pseudonymisation means the processing of personal data in such a manner that the personal data can no longer be attributed to any particular participant of the Global Patient Survey without the use of additional information. If pseudonymised data is ever used in combination with your Personal Data and becomes identifiable, it will be treated in accordance with this statement.

How Do We Use Your Personal Data and What Are Our Justifications For Doing So?

Whenever we use your personal data, we need to make sure that we have established a valid legal justification (known as a "lawful basis") for that use of data. We have described the ways that we use your data and the associated lawful basis below.

Reference	What categories of information about you do we process?	Why are we processing your data?	Where did we get your personal data from?
Client Correspondence and Professional Services	<ul style="list-style-type: none"> • Identity Data • Contact Data • Sensitive Personal Data 	We use the personal data you have given us in order to communicate with you in the event you share your contact information at the end of the Global Patient Survey. This processing is conducted lawfully on the basis of legitimate interests, it is in our interests to analyse medical data. Where we	Obtained directly from you.

<p>rely on legitimate interests, we will always make sure that we balance these interests against your rights. .</p>			
Direct Marketing	<ul style="list-style-type: none"> • Identity Data • Contact Data • Marketing and Communications Data 	<p>We use this personal data in order to market our products, services, updates, newsletters or other promotional and marketing information to you that we believe you will benefit from via email, telephone or post. This processing is conducted lawfully on the basis of 'our legitimate interests'.</p> <p>You can amend your preferences or opt out from marketing communications by using the unsubscribe links within our marketing messages or by sending a request to admin@pvrinstitute.org .</p>	Obtained directly from you.
External Companies	<ul style="list-style-type: none"> • Identity Data • Contract Data • Profile Data • Sensitive Personal Data 	<p>In order to invite you to participate in our online Global Patient Survey we use an external company, Survey Money, services offered under Momentive Europe UC, to collect your feedback. If you want to read more about how Survey Monkey process your data, you can find their Privacy Policy via this link; https://www.surveymonkey.com/mp/legal/privacy/</p>	Directly obtained from you.
Enquiries	<ul style="list-style-type: none"> • Identity Data • Contact Data • Any other unsolicited personal data that you choose to submit 	<p>We use the contact information sent to us in the Global Patient Survey in order to respond to any enquiries. This processing is conducted lawfully on the basis of 'our legitimate interests'.</p>	Directly obtained from you.

Security

We take the security of your personal data very seriously and have put physical, technical, operational and administrative strategies, controls and measures in place to help protect your personal data from unauthorised access, use or disclosure as required by law and in accordance with

accepted good industry practice. We will always keep these under review to make sure that the measures we have implemented remain appropriate.

Unfortunately (and as you will probably already know) the transmission of information via the internet is not completely secure. Although we will do our best to protect your personal data, we cannot guarantee the security of your data transmitted to our Global Patient Survey; any transmission is at your own risk.

What profiling or automated decision making does PVRI perform?

PVRI does not perform any profiling or automated decision making based on your personal data.

How long will your personal data be kept?

PVRI holds different categories of personal data for different periods of time. Wherever possible, we will endeavour to minimise the amount of personal data that we hold and the length of time for which it is held.

- If 'consent' is the basis for our lawful processing of your data, we will retain your data so long as both the purpose for which it was collected, and your consent, are still valid. Occasionally, we might identify a legitimate interest in retaining some of your personal data that has been obtained by consent. If we do, we will inform you that we intend to retain it under these conditions and identify the interest specifically.
- If we process your data on the basis of 'legitimate interests', we will retain your data for as long as the purpose for which it is processed remains active.
- All categories of personal data that are held by us because they are essential for the performance of a contract, will be held for a period of six years, or as otherwise required under applicable law, for the purposes of exercising or defending legal claims.

Who else will receive your personal data?

Third party suppliers and service providers involved in our contractual relationship with you:

Like most businesses, we work with third party suppliers and service providers as part of the day-to-day operation of our business. Some of these trusted suppliers will process your personal data on our behalf and provide services to us such as research, analytical health data, statistics.

We will always make sure that we require them to meet agreed standards for the protection of your data and they will only ever be allowed to use the data in order to provide services to us and not for their own commercial purposes. If any of these trusted third-party suppliers is based outside of the UK or EEA (i.e. in a territory where local laws may not provide the same level of protection for your data), we will implement safeguards to ensure that your personal data is protected in accordance with our obligations under data protection law.

PVRI may pass your data to the third parties listed in the section 'Third Party Interests' below.

Third Party Interests' below.

Where Your Personal Data May Be Processed

We may transfer your personal data outside of the UK, Switzerland and the European Economic Area ("EEA") where local laws may not provide legal protection for your personal data in the same way as is applicable in the UK, Switzerland or the EEA. Examples of when your personal data may be processed outside of the UK, Switzerland and the EEA include for the purposes of for example research and analysing health data. Similarly, some of our trusted third-party suppliers may transfer data outside of the UK/Switzerland /EEA and wherever this is the case, we will implement appropriate safeguards to protect your personal data.

Whenever we send (or permit a third party to send) your personal data outside of the UK, Switzerland and the EEA, we will make sure that we take steps necessary to protect your data as required by applicable laws. For example, we may require the overseas recipient (including any of our group companies) to enter into particular contract terms such as the European Commission's Standard Contractual Clauses or the UK IDTA.

Does your data leave the EU?

Yes. Details are included in the section ‘

Third Party Interests’ below.

Third Party Interests

Our Data Processors

Name or Category of Third Party Processor	Purposes for carrying out processing	If applicable – where does data leaving the EEA go and what safeguards are in place?
Web hosting providers	Hosting of our Global Patient Survey, including the storage of data forming the Global Patient Survey content and processing your Technical Data (and Profile Data, where applicable) in order to provide you with access to the Global Patient Survey.	In the interests of providing a quality service, we may use providers located in the United States. These providers are bound by the contractual provisions of the EU Commissions model clauses and UK model clauses.
Internal technology providers	<ul style="list-style-type: none"> • CRM software providers • Telephony providers. • Office software providers, such as email clients. 	In the interests of providing a quality service, we may use providers located in the United States. These providers are bound by the contractual provisions of the EU Commissions model clauses.



- IT Support services, who might require access to our systems (with our strict supervision) in order to remedy faults with our technology.

Marketing technology providers

Providers who enable us to send you our marketing emails.

In the interests of providing a quality service, we may use providers located in the United States. These providers are bound by the contractual provisions of the EU Commissions model clauses.

Who can you complain to?

In addition to sending us your complaints directly to admin@pvrinstitute.org, you can send complaints to our supervisory authority. As PVRI predominantly handles the personal data of UK nationals, our supervisory authority is the UK Information Commissioner's Office. If you believe that we have failed in our compliance with data protection legislation, complaints to this authority can be made by visiting <https://ico.org.uk/concerns/>.

If you are an EEA citizen, please contact your local supervisory authority.

Changes To Our Privacy Statement

We keep this privacy statement under regular review, and we will place any updates here on this page. This privacy statement was last updated on 23rd May 2023.