



Privacy Policy

Introduction

In this Privacy Policy, any reference to “ECPC”, “we”, “us”, “our” refers to the European Cancer Patient Coalition (ECPC), an international non-profit association, whose registered office is at Rue Montoyer 40, B-1000 Brussels, registered at the Crossroads Bank for Enterprises under number 0818.999.605. Online you can find us at <http://www.ecpc.org>.

This privacy policy is subject to the “Privacy legislation”

- I. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (“GDPR”);
- II. the Belgian Data Protection Act of 30th July 2018 on the protection of privacy in relation to the processing of personal data (as amended) (the “Privacy Act”); and/or
- III. All other applicable legislation regarding the protection of privacy and the processing of personal data;

For the purposes of the Privacy legislation –of the information you provide to us. This means that we handle the way the information is managed and processed while keeping your personal data secure and only using it for appropriate purposes. Applicant members and members act as “joint-controllers” when they share data such as the contact details of their employees, members, board members, staff, subcontractors, and contracting parties. This means that they will have the liability to undertake some specific roles and tasks described in this Privacy Policy in view of their ECPC’s membership.

What Personal Data does ECPC collect?

With this in mind, ECPC will treat your data with care and take steps to protect it. You may provide us with the following types of personal data when you interact with us:

- **Identity** – first name, last name, gender, date of birth, ID and/or passport details, photos, invoice attesting the domicile (for legal representative of ECPC);
- **Signature**
- **Contact** – email address, home address, phone number, social media accounts, job title, organisation you work for;
- **Financial** – paycheck and bank details;
- **Health and lifestyle**– medical information (**type of cancer** treatment and diagnosis), and dietary needs;
- **Professional life** CV, education, professional situation, photography, e-mail, phone number, certificate of good conduct, personal address





- **Pictures and videos** taken at meetings, statements made during meetings/events.

How does ECPC collect your Personal Data

The Personal data are collected via Google Form, Survey monkey, via e-mail and are obtained

- directly from you, or
- indirectly through third parties, such as your organisation

By agreeing to this Privacy Policy, members of ECPC that provide personal data of third parties (e.g. their employees, members, board members, staff, subcontractors, and contracting parties) to ECPC guarantee that (i) these personal data are lawfully obtained and (ii) that the member is authorized to transfer these personal data to ECPC. Members themselves comply with the Privacy Legislation and will indemnify, hold harmless and compensate ECPC for all claims resulting from non-compliance with the above.

For which purposes does ECPC process your Personal Data?

ECPC uses the information collected from you for the following purposes

- For the general administration and membership-related management providing services and sending communications.
 - to process job applications
 - for internal administration (including internal meeting and follow-up) and record-keeping
 - to process payments, invoices, and reimbursements
- To manage compliance and/or regulatory issues such as:
 - to comply with the rules of governance of the organisation (organisation of General Assemblies etc..)
 - to share information legally required to public authorities (Moniteur Belge, UBO registry, Data Protection Authority, etc.)
- To engage with our members and stakeholders (such as Members of European Parliament, officials from the European Commission and from EU Member States, academics, consultants and European affairs stakeholders, European and International Cancer Organisations):





- to inform about our activities, recent policy development, advocacy strategies and personalize our communication
 - to subscribe to our newsletters
 - to give the opportunity to provide us with feedback through surveys and other research
 - to answer your enquiries which may involve contacting by social media, virtual conference tool, post, e-mail, and/or phone.
 - to share our dissemination materials (White papers, reports, press release, scientific articles)
 - to share the results of surveys
 - to proceed registration for participation in events (conference, workshop, etc)
 - to send invitations to join trials
- To map the situation worldwide and within the EU by collecting data on treatments, innovative medicine, survivorship from our members based in different countries. Those personal data are collected through anonymization. The information collected is used then to prepare campaigns, advocacy strategies, prepare dissemination materials (White papers, reports, press release, scientific articles)
 - To notify of changes to this Privacy Policy
 - To administer our digital platforms
 - To verify identity, and to detect and prevent fraud
 - To interact with representatives and contact persons of third-party entities with which OECl has a contractual relationship (such as, services providers or consultancies).

On which legal basis your personal data are processed?

Your data are processed on the following basis:

- A contractual relationship as soon as you become a member of ECPC, enter in a work agreement ECPC (as an employee, consultant, trainee or other), a supplier of ECPC or any otherwise contractually linked to ECPC's activities; and/or
- a legal obligation; and/or
- your prior free, specific, informed and unambiguous consent to ECPC will be requested, by visiting our website, for registration to our newsletter to receive communication concerning membership-related services, promotional activities ; your consent will also be specifically asked for photos or multimedia content that may enable the recognition of participants at events.





- a legitimate interest of ECPC to achieve purposes within the framework of its activities that is not overridden by your fundamental rights and freedoms as data subject; ECPC commits to strictly limit its data and information collection to the abovementioned uses' type of legitimate interest.

What are your rights?

It is important that the personal information we hold about you is accurate and current. Please keep us informed if your personal information changes by keeping your details up to date.

Under certain circumstances, by law you have the right to:

- Right to erase – You have the right to ask ECPC to delete or remove Personal Data from our records.
- Right to transfer – You have the right to have the Personal Data we hold about you transferred to another organisation.
- Rights of access – You have the right to request a copy of the Personal data that we hold about you.
- Right of correction – You have the right to correct Personal Data that we hold about you that is inaccurate or incomplete.
- Right to object – You have the right to object to certain types of processing such as direct marketing
- Right to restrict – You have the right to restrict the processing of your Personal Data.

If you want to exercise these rights, please contact privacy@ecpc.org.

You will not have to pay a fee to ECPC to exercise any of the other rights listed above. However, we may charge you a reasonable fee or refuse to comply with your request if it is manifestly unfounded, repetitive, or excessive.

We may need to request specific information from you to help us confirm your identity for security reasons in order to ensure your right to exercise any of the rights listed above.

ECPC will try and respond to all legitimate requests within four weeks. If it is likely to take longer than four weeks to respond, ECPC will notify you.

By agreeing to this Privacy Policy, members providing personal data of third parties (e.g. their employees, members, board members, staff, subcontractors, contracting parties) guarantee that they will inform the aforementioned data subjects regarding the abovementioned rights and how to exercise these rights as well as answering their requests.

Who does ECPC share your Personal Data with?

ECPC guarantees that it does not transfer your personal data to third parties, unless:

- I. There is a legal obligation to transfer the personal data);





- II. It is necessary for the achievement of one of the Purposes here-above described (e.g. subcontractors, partners or contracting parties);
- III. ECPC has a legitimate interest to do so.

Third parties to whom ECPC may, or is obliged to, transfer personal data on the basis of the above categories, can be located within or outside the European Union. In such case OECl shall ensure that the Personal data will be treated fairly and lawfully. This will include ensuring OECl has a legal ground for sending the personal data outside the European Union and putting in place necessary safeguard for such arrangement.

ECPC cannot be held responsible regarding the transfer of personal data and cannot be liable for the further processing of the personal data by third parties

ECPC is located within the European Union (EU), however, if there is a time when any of our service providers are based outside the EU, we will make sure that your Personal Data is still treated fairly and lawfully. This will include ensuring we have a legal ground for sending your data outside the EU and putting in place necessary safeguards for such arrangement.

How long does ECPC keep your information?

We only store your personal data for that is strictly necessary to achieve the purpose(s) for which they were collected.

After that period, we will either delete it or anonymise it so it cannot be linked back to you. You can also exercise your deletion right at any time.

How do we secure your Personal Data?

All data collected through surveys made by ECPC are anonymized.

We undertake to keep your personal data confidential and have established reasonable technical and organisational security procedures aimed to avoid any loss, abuse or alteration to this personal data. However, since no method of transmission or forwarding over the internet, or any method of electronic storage is 100% secure, ECPC is, in this context, not in a position to guarantee absolute security.

Your consent to this Privacy Policy acknowledges and accept processing of data is never without risk and damages you may suffer from third parties in case they use your Personal Data unlawfully, is not the liability of ECPC.

Changes to the ECPC Privacy Policy

ECPC reserves the right to update this Privacy Policy at any time. We may also notify you in other ways from time to time about the processing of your personal information.

Any questions for ECPC?





European Cancer
Patient Coalition

If you have any questions about how ECPC handles Personal Data or this Privacy Policy notice, please contact ECPC at privacy@ecpc.org.

You have the right to make a complaint at any time to the Belgian Data Protection Authority:

<https://www.gegevensbeschermingsautoriteit.be>

<https://www.autoriteprotectiondonnees.be>



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