



Data Protection / Privacy Policy

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The objective of this policy is to ensure that all Personal Data under the control of IPPOSI is stored, processed and used in compliance with the Irish Data Protection Act 2018 (the “DPA”) and the EU General Data Protection Regulation (GDPR).

This is an active document which is open to revision and adjustment on an ongoing basis.

Table of Contents

Reason and scope of this policy	2
What information do we collect from you?	4
Who might we share this information with?	5
How long do we keep hold of your information?	6
What will happen if we change our privacy policy?	6
How can you contact us?	6
Membership Records.....	7
Personnel Records	7
Prospective employees.....	9
Tax Records.....	10
Legal and Insurance Records	10

Who we are

We are the Irish Platform for Patients’ Organisations, Science and Industry (IPPOSI) with an address at 77 Camden St. Lower, Dublin, D02XE80, Ireland.

IPPOSI is a unique, patient-led partnership in Ireland and internationally which brings together patient groups, scientists, clinicians, industry and other key decision makers to build consensus on issues relevant to all involved in delivering treatments and innovations to people with unmet medical needs.

Reason and scope of this policy

IPPOSI are firmly committed to complying with our data protection obligations. This policy sets out the basis on which any Personal Data we collect, or that is provided to us, will be stored, processed and used by us. This policy applies to all staff in IPPOSI.

This policy applies to all data which can include: Names of individuals, postal addresses, email addresses, telephone numbers, bank account numbers, and any other Personal information relating to individuals.

Definitions used in this document

Personal data

This means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;

Special categories of Personal Data and Sensitive personal data

This means information revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.

Cookies

Cookies are small text files that can be used by websites to make a user's experience more efficient. The law states that we can store cookies on your device if they are strictly necessary for the operation of our website. For all other types of cookies we need your permission. The IPPOSI website uses different types of cookies. Some cookies are placed by third party services that appear on our pages. You can at any time change or withdraw your consent from the Cookie Declaration on our website -

<https://www.ipposi.ie/cookies/>

For the purpose of the DPA and the GDPR, the data controller is IPPOSI.

Our data protection officer for the purpose of the DPA and GDPR is: the IPPOSI Chief Executive Officer.

What are your rights with respect to your information?

You have the following rights:

- The right to access the information we hold about you.

- The right to require us to rectify any inaccurate information about you without undue delay.
- The right to have us erase any information we hold about you in circumstances such as where it is no longer necessary for us to hold the information or if you have withdrawn your consent to the processing.
- The right to object to us processing information about you such as processing for profiling or direct marketing.
- The right to ask us to provide your information to you in a portable format or, where technically feasible, for us to port that information to another provider provided it does not result in a disclosure of information relating to other people.
- The right to request a restriction of the processing of your information.

Where our processing of your information is based on your consent to that processing, you have the right to withdraw that consent at any time but any processing that we have carried out before you withdrew your consent remains lawful.

You may exercise any of the above rights by: writing to the IPPOSI CEO at info@ipposi.ie or by post to IPPOSI, 77 Camden St. Lower, Dublin D02XE80.

You may lodge a complaint with your local supervisory authority with respect to our processing of your information. In Ireland, the local Supervisory Authority is the Office of the Data Protection Commissioner with an address at Canal House, Station Road, Portarlinton, Co. Laois.

What information do we collect from you?

You may give us information by:

- corresponding with us by phone, e-mail or otherwise. We ask you to disclose only as much information as is necessary for the purpose of your interaction with us or when submitting a question/suggestion/comment in relation to our website or our activities.
- applying to work with us as an employee or contractor or to act as an advisor on an IPPOSI working group/advisory board. The type of information you may provide includes your CV, a cover letter, your name, address, e-mail address and phone number. CVs should include information relevant to your employment history and education (degrees obtained, places worked, positions held, relevant awards, and so forth). We ask that you do not disclose sensitive personal information (e.g. gender, height, weight, medical information, religion, philosophical or political beliefs, financial data) in your application.
- Navigating online to our website – www.ipposi.ie

Why do we collect this information?

We collect the information in order to improve our website, to recruit staff, to engage the IPPOSI membership and external bodies and organisations. We will use this information:

- to liaise with you about initiatives that we are undertaking with you;
- to communicate any upcoming IPPOSI events and activities;
- to carry out our obligations arising from any contracts entered into between you and us;
- to administer and improve our website and for internal operations, including troubleshooting, data analysis, testing, research, statistical and survey purposes. For further information please see our Cookie Policy on our website: <https://www.ipposi.ie/cookies/>
- as part of our efforts to keep our website safe and secure.

The legal bases for the processing of your data are:

1. that you have provided consent for the processing for one or more specific purposes. For example, when you subscribe to our online newsletter which you submit to us.
2. processing necessary for the performance of a contract which you have entered into with us or to take steps at your request prior to entering into a contract;
3. processing necessary for compliance with a legal obligation to which we are subject.

Who might we share this information with?

Disclosure of your information

We may share your information with selected third parties including:

- Business partners, suppliers and sub-contractors for the performance of any contract we enter into with them or you.

We have set out below a list of third parties with whom we share your data:

1. Sub-contractors (i.e. service providers who sign a contract agreement with IPPOSI. An example would be technical support for an elearning website)
2. Cloud Service Providers
3. IT Back-up Providers
4. Email and IT service providers
5. Auditors

6. Accounting software
7. Cookie analytics service provider

How long do we keep hold of your information?

The time periods for which we retain your information depends on the type of information and the purposes for which we use it. We will keep your information for no longer than is required or permitted. For further information please see the IPPOSI Data Retention Schedule in Annex I. We do not transfer your data outside of the EU.

What will happen if we change our privacy policy?

This policy may change from time to time, and any changes will be posted on our website and will be effective when posted. Please review this policy each time you use our website or our services. This notice was last updated on the date appearing on the cover hereof.

How can you contact us?

You can contact us:

by phone: 01-556-8269

website or by email: info@ipposi.ie

Our Data Protection Officer can be contacted by email at info@ipposi.ie or by post to IPPOSI, 77 Camden St. Lower, Dublin D02XE80.

Annex I - Data Retention Schedule

IPPOSI Employees will give special consideration to the categories of documents listed in the retention schedule below. Employees will avoid retaining records if there is no legitimate reason for doing so and will consult with the Data Protection Officer if unsure.

Membership Records

Record	Retention Period	Justification for time frame
IPPOSI Membership Application Forms	7 years from receipt of completed form	Membership renewal to take place within a 7 year period

Personnel Records

Record	Retention Period	Justification for time frame
Benefits descriptions per employee	Permanent	Irish employment law and for pension calculation and record keeping
Employee applications and resumes	6 years or where successful, for the duration of the employment plus 7 years from the date of termination of employment	Section 11 of The Statute of Limitations Act 1957
Employee benefit plans	6 years from when the record was required to be disclosed save pension detail requirements	Benefit of the employee
Employee offer letters (and other documentation regarding hiring, promotion, demotion, transfer, termination or selection for training)	6 years from date of making record or action involved, whichever is later, or 1 year from date of involuntary termination	Benefit of the employee
Records relating to background checks on employees	6 years from when the background check is conducted	

Employment contracts; employment and termination agreements	7 years from the date of expiry of the contract or agreement	Benefit of the employee
Employee records with information on pay rate or weekly compensation	3 years	Benefit of the employee
Tax forms	6 years after date of hire	Revenue obligation
Injury and Illness Incident Reports and related Annual Summaries; Logs of work-related injuries and illnesses	6 years following the end of the calendar year that these records cover	Statute of Limitations
Supplemental record for each occupational injury or illness; Log and Summary of Occupational Injuries and Illnesses	6 years following the year to which they relate	Statute of Limitations
Job descriptions, performance goals and reviews; garnishment records	For the duration of the employment plus 7 years from the date of termination of employment	Benefit of employee
Employee tax records	6 years from the date tax is due or paid	Revenue obligations
Medical exams required by law	Duration of employment + 30 years	Benefit of employee
Personnel or employment records	6 years from the date the record was made	Benefit of employee
Pension plan and retirement records	Permanent	Benefit of employee
Pre-employment tests and test results	2 years from date of termination	Benefit of employee
Salary schedules; ranges for each job description	2 years	Benefit of employee
Time reports	Termination + 3 years	Benefit of employee

Training agreements, summaries of applicants' qualifications, job criteria, interview records	Duration of training + 4 years	Benefit of employee
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Payroll Records

Record	Retention Period	Justification for time frame
Payroll registers (gross and net)	3 years from the last date of entry	Benefit of employee
Time cards; piece work tickets; wage rate tables; pay rates; work + time schedules; earnings records; records of additions to or deductions from wages; records on which wage computations are based	7 years	Benefit of employee

Prospective employees

Record	Retention Period	Justification for time frame
Curriculum vitae	1 year	For future employment opportunities

Accounting and Finance

Record	Retention Period	Justification for time frame
Accounts Payable and Receivables ledgers and schedules	7 years	Revenue Requirements

Annual audit reports and financial statements	Permanent	Revenue Requirements
Annual plans and budgets	2 years	Revenue Requirements
Bank statements, cancelled checks, deposit slips	7 years	Revenue Requirements
Business expense records	7 years	Revenue Requirements
Cash receipts	2 years	Revenue Requirements
Electronic fund transfer documents	7 years	Revenue Requirements
Employee expense reports	7 years	Revenue Requirements
General ledgers	Permanent	Revenue Requirements
Journal entries	7 years	Revenue Requirements
Invoices	7 years	Revenue Requirements

Tax Records

Record	Retention Period	Justification for time frame
All tax records	7 years	

Legal and Insurance Records

Record	Retention Period	Justification
Appraisals	6 years from termination	
Insurance claims/ applications	Permanent	
Insurance disbursements and denials	Permanent	
Insurance contracts and policies (Director and Officers, General Liability, Property, Workers' Compensation)		
Leases	6 years after expiration	
Patents, patent applications, supporting documents		
Warranties	Duration of warranty + 7 years	