



Parkinson's Ireland Data Protection Policy

December 2025

Version	Purpose/ Change Summary	Approved by Board	Effective Date	Next Revision
1.0	Original Policy	2022	2022	2025
2.0	Updated policy – after periodic legal review by charity's solicitors	December 2025	December 2025	2028

1. INTRODUCTION

The purpose of this document is to provide a concise policy statement regarding the Data Protection obligations of Parkinson's Ireland. This includes obligations when dealing with personal data, in order to ensure that the organisation complies with the requirements of relevant Data Protection Legislation (as defined below).

The protection of natural persons in relation to the processing of personal data is a fundamental right. Article 8(1) of the Charter of Fundamental Rights of the European Union (the 'Charter') and Article 16(1) of the Treaty on the Functioning of the European Union (TFEU) provide that everyone has the right to the protection of personal data concerning themselves.

2. DEFINITIONS

The main terms used in this Policy are defined as follows:

- **Data Controller** means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of Personal Data. PI is Data Controller of the Personal Data processed under this Policy.
- **Data Processor** means a natural or legal person, public authority, agency or other body which processes Personal Data on behalf of PI.
- **Data Protection Legislation** means all applicable laws, orders and regulations relating to privacy and data protection including but not limited to the EU General Data Protection Regulation (2016/679) ("**GDPR**") and the Irish Data Protection Acts 1988 to 2018, each as many be amended, supplemented or replaced from time to time.
- **Data Subject** means a living, identified or identifiable individual about whom we hold Personal Data. This includes Board members, employees, members and volunteers.
- **PI** means Parkinson's Ireland.
- **Personal Data** means information relating to either:
 - a. an **identified** living individual *or*
 - b. a living individual **who can be identified from the data**, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data or online identifier, or one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of the individual.

3. RATIONALE

PI must comply with the data protection principles set out in the Data Protection Legislation.

This Policy applies to all Personal Data collected, processed and stored by PI in relation to its employees, service providers, contractors and volunteers in the course of its activities. PI makes no distinction between the rights of Data Subjects who are employees, and those who are not. All are treated equally under this Policy.

4. SCOPE

The policy covers both personal and special categories of personal data held in relation to Data Subjects by PI. The policy applies equally to Personal Data held in manual and online/digital form. Special categories of personal data receive greater protection under the Data Protection Legislation and refer to the following:

- racial or ethnic origin
- political opinions
- religious or philosophical beliefs
- trade union membership
- genetic data or biometric data for the purpose of uniquely identifying a person
- data concerning health
- data concerning a person's sex life or sexual orientation

Additional protections apply under Article 9 of the GDPR in relation to the processing of any such data.

5. AIMS / OBJECTIVES

In order to fully fulfil its aims and objectives, detailed below, PI needs from time to time to collect and process Personal Data about its Board, employees, members and volunteers (Data Subjects).

Objectives of Parkinson's Ireland

- help and support patients and carers by developing a support network of branches throughout the country
- make information freely available to patients and their families through seminars, magazines, information leaflets and meetings on a national and local level
- facilitate easy access to all appropriate services for people with Parkinson's and to lobby to improve those services
- help establish a network of Parkinson's Disease Nurse Specialists within a multidisciplinary setting, each in association with a neurologist and or a geriatrician.
- promote and encourage research into Parkinson's Disease.
- support through our Freephone Helpline, 1800 359359, which is open from 9am to 7pm

Monday to Thursday and 9am – 5pm Friday.

provide Information and advice from our Parkinson's Disease Nurse Specialist available through our Freephone helpline.

- raise awareness through educating the public, health professionals and influencers, to give a greater understanding and acceptance of Parkinson's.

Aims of Parkinson's Ireland

- to help and support patients and carers by developing a support network of branches throughout the country
- to make information available to patients and their families through seminars, newsletters and branch meetings on both a national and local level
- to facilitate easy access to all appropriate services for people with Parkinson's and to lobby to improve those services
- to help establish a network of PDNS, within a multidisciplinary setting, each in association with a neurologist and or a geriatrician.
- to promote and encourage research into Parkinson's.

Those individuals (Data Subjects) have privacy rights in relation to the processing of their Personal Data and PI must comply with the Data Protection Legislation when processing this Personal Data.

It is important to note that the Data Protection Legislation confers **rights** on individuals as well as **responsibilities** on those who process Personal Data.

6. PARKINSON'S IRELAND AS A DATA CONTROLLER

In the course of its daily organisational activities, PI collects, processes and stores personal data in relation to:

- Employees of PI
- Volunteers and Members of PI
- Third party service providers engaged by PI

In accordance with the Data Protection Legislation, this data must be processed fairly. Not all employees, members or volunteers will be expected to be experts in Data Protection Legislation. However, PI is committed to ensuring that its employees and volunteers have sufficient awareness of Data Protection Legislation in order to be able to anticipate and identify a data protection issue, should one arise. A Data Protection FAQ (Appendix 1) is issued to all

Branches.

Due to the nature of the services provided by PI, there is regular and active exchange of Personal Data between PI and its Data Subjects. In addition, PI exchanges Personal Data with Data Processors on the Data Subjects' behalf.

In terms of working with vulnerable adults some special category data needs to be processed in order to ensure relevant volunteer committee members/employees are fully vetted with An Garda Síochána. The main function of Board members (decision-making, policy creation, strategic planning) also does not involve one to one contact with members and therefore there is no need for Directors to be Garda vetted.

All Garda vetting is administered by the National Office in full compliance with the Data Protection Legislation.

7. THE DATA PROTECTION PRINCIPLES

The following key principles are enshrined in the Data Protection Legislation and are fundamental to PI's Data Protection Policy.

In its capacity as Data Controller, PI ensures that all data shall:

I. BE OBTAINED AND PROCESSED FAIRLY AND LAWFULLY.

For data to be obtained fairly, the data subject will, at the time of data collection and via our Privacy Statement, be made aware of:

- The identity of the Data Controller (PI)
- The purpose(s) for which the data is being collected
- The person(s) to whom the data may be disclosed by the Data Controller
- Any other relevant information.

PI meets this obligation in the following way:

- PI ensures that collection of the data is justified under one of the legal bases for processing under the GDPR – consent, legitimate interests, legal obligation, contractual necessity, etc.
- When processing is based on the consent of the Data Subject, the consent of the Data Subject will be sought before their data is processed either via an opt-in check box where digital or signed when in person. Verbal consent does not suffice.

- Processing of Personal Data is carried out only as part of PI's lawful activities, and PI safeguards the rights and freedoms of the Data Subject.
- The Data Subject's data will not be disclosed to a third party other than to a party contracted to PI and operating on its behalf (read 8. External Data Processors below).

II. BE OBTAINED ONLY FOR ONE OR MORE SPECIFIED, LEGITIMATE PURPOSES.

PI collects data for purposes which are specific, lawful and clearly stated. A Data Subject has the right to question the purpose(s) for which PI processes their data, and PI will provide all relevant details when queried.

III. NOT BE FURTHER PROCESSED IN A MANNER INCOMPATIBLE WITH THE SPECIFIED PURPOSE(S).

Any use of the data by PI is compatible with the purposes for which the data was collected.

IV. BE KEPT SAFE AND SECURE

PI employs high standards of security in order to protect the Personal Data it processes. Appropriate security measures are taken to protect against unauthorised access to, or alteration, destruction or disclosure of any Personal Data held by PI in its capacity as Data Controller.

Access to and management of employees and volunteer records is limited to those employees/volunteers who have appropriate authorisation and password access.

V. BE KEPT ACCURATE, COMPLETE AND UP-TO-DATE WHERE NECESSARY.

PI:

- ensures that administrative and IT validation processes are in place to conduct regular assessments of data accuracy;
- conducts periodic reviews and audits to seek to ensure that relevant data is kept accurate and up-to-date. PI conducts a review of sample data every six months to seek to ensure accuracy. Employees contact details and details on next-of-kin are reviewed and updated every year;
- conducts regular assessments in order to establish whether there is a need to keep certain Personal Data or whether it can be deleted.

VI. BE ADEQUATE, RELEVANT AND NOT EXCESSIVE IN RELATION TO THE PURPOSE(S) FOR WHICH THE DATA WERE COLLECTED AND PROCESSED.

PI ensures that the data it processes in relation to Data Subjects are relevant to the purposes for which those data are collected. Data which are not relevant to such processing will not be collected or processed.

VII. NOT BE KEPT FOR LONGER THAN IS NECESSARY TO SATISFY THE SPECIFIED PURPOSE(S).

Once the respective retention period has elapsed, PI undertakes to destroy, erase or otherwise put this data beyond use. On occasion, data may be anonymised or pseudonymised for reporting or statistical purposes. Our retention procedure is to only keep data while you are engaging with our services/are a member and to delete it following the end of this engagement, except where information is required to be held for legal purposes, for example the retention of financial information for a 6 year period following the end of this engagement, in accordance with our legal obligations.

VIII. BE MANAGED AND STORED IN SUCH A MANNER THAT, IN THE EVENT A DATA SUBJECT SUBMITS A VALID SUBJECT ACCESS REQUEST SEEKING A COPY OF THEIR PERSONAL DATA, THIS DATA CAN BE READILY RETRIEVED AND PROVIDED TO THEM.

PI has implemented a Subject Access Request procedure by which to manage such requests in an efficient and timely manner, within the timelines stipulated in the Data Protection Legislation. Read 7. Data Subject Access Requests.

8. DATA SUBJECT ACCESS REQUESTS

As part of the day-to-day operation of the organisation, PI's employees and volunteers engage in active and regular exchanges of information with Data Subjects. Where a request is submitted by a Data Subject in relation to the data held by PI, such a request gives rise to access rights in favour of the Data Subject.

Any request by a Data Subject for a copy of their personal data (a Subject Access Request) will be processed as soon as possible. PI employees will ensure that, where necessary, such requests are processed as quickly and efficiently as possible, and in any event, within one month from receipt of the request. Appendix 2 to 5 sets out template Subject Access Request Forms and standard responses for convenience.

9. RETENTION PERIOD

Our retention procedure is to only keep data while you are engaging with our services/are a

member and to delete it following the end of this engagement, except where information is required to be held for legal purposes, for example the retention of financial information for a 6 year period following the end of this engagement, in accordance with our legal obligations.

10. EXTERNAL DATA PROCESSORS

It is occasionally necessary for PI to engage the services of external processors. If the service involves the external hosting of Personal Data (such as staff, volunteer or member data) by the supplier on behalf of PI, PI ensures that full compliance is adhered to in the management of data in accordance with the Data Protection Legislation.

GDPR imposes restrictions on the transfer of Personal Data outside the European Union, to third countries or international organisations. These restrictions are in place to ensure that the level of protection of individuals afforded by the GDPR is not undermined. Personal Data may only be transferred outside of the EU in compliance with the conditions for transfer set out in [Chapter V](#) of the GDPR.

11. IMPLEMENTATION

As a Data Controller, PI ensures that any entity which processes Personal Data on its behalf (a Data Processor) does so in a manner compliant with the Data Protection Legislation. We ensure training is available and advice and guidance comes from our National Office. A PI Data Protection FAQ is available in Appendix 1 that serves as a useful guide to employees, volunteers and members.

12. DATA BREACH PROCEDURE

A personal data breach means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data. This includes breaches that are the result of both accidental and deliberate causes. It also means that a breach is more than just about losing personal data.

Personal data breaches can include (PI can add any other relevant examples that may be helpful to the reader): access by an unauthorised third party; deliberate or accidental action (or inaction) by a controller or processor; sending personal data to an incorrect recipient; computing devices containing personal data being lost or stolen; alteration of personal data without permission; and loss of availability of personal data.

In short, there will be a personal data breach whenever any personal data is accidentally lost, destroyed, corrupted or disclosed; if someone accesses the data or passes it on without proper authorisation; or if the data is made unavailable and this unavailability has a significant negative effect on individuals.

Where a data breach is likely to result in a risk to the rights and freedoms of a Data Subject, employees at PI will liaise with the Data Protection Commission (DPC) and report the breach within 72 hours of discovery. The CEO of PI will also recommend, where necessary, actions to inform Data Subjects and reduce risks to their privacy arising from the breach.

Employees/volunteers and members of PI who discover a personal data breach or who are in any doubt whether a data breach actually occurred must immediately inform nationaloffice@parkinsons.ie.

It is important that all employees/volunteers and members of PI act quickly and report any suspected incident without delay. It is also important to note that despite any action taken, the DPC must be contacted within **72 hours of discovery** even on a weekend so time is always of the essence.

All Data Breaches (even those not reportable to the DPC) must be logged in the Data Breach Notification Log which is stored at the National Office on a password protected workbook.

13. PRIVACY STATEMENT

A Privacy Statement is required when information is being collected directly from an individual and must be provided at the **point at which** the data is collected. In a case where information is obtained from another source, a Privacy Statement must be provided:

- at least one month after obtaining the data
- if Personal Data is to be used to communicate with the Data Subject at the latest at the time of the first communication with the Data Subject
- if disclosure to another recipient is envisaged, at the latest when Personal Data are first disclosed

The PI Privacy Statement is available on www.parkinsons.ie

Appendix 1

Data Protection Policy FAQ

Step 1: Fair collection:

- At the time when we collect information about individuals, are they made aware of the uses for that information?
- Are people made aware of any disclosures of their data to third parties?
- Have we obtained people's consent for any secondary uses of their personal data, which might not be obvious to them
- Can we describe our data-collection practices as open, transparent and up-front?

Parkinson's Ireland says: The Privacy Statement on www.parkinsons.ie is your go-to guide when it comes to GDPR for your branch – the main things to remember are: Do you **need** it? Have you obtained **permission to use it** (i.e: "I consent to the processing of my personal details as set out in the privacy statement for such purposes XYZ Parkinson's Ireland considers reasonable and appropriate.") Are you **upfront** that you will be processing their data? In addition, Parkinson's Ireland has an overarching Data Protection Policy which contains procedures on how we deal with data breaches, subject access requests and data retention.

Step 2: Purpose specification

- Are we clear about the purpose (or purposes) for which we keep personal information?
- Are the individuals on our database also clear about this purpose?
- Has responsibility been assigned for maintaining a list of all data sets and the purpose associated with each?

Parkinson's Ireland says: The GDPR that we have a clear purpose for the data we process. Do the individuals **know why** you are obtaining their data? Does one person in each branch (i.e. Secretary) **have responsibility** for ensuring the data is kept under lock and key or in the case of digital files, on a secure and password protected laptop/phone/tablet? Is a log maintained that clearly sets out the purpose of data processing of each data set?

Step 3: Use and disclosure of information

- Are there defined rules about the use and disclosure of information?
- Are all employees/volunteers aware of these rules?
- Are the individuals aware of the uses and disclosures of their personal data? Would they be surprised if they learned about them? Consider whether the consent of the individuals should be obtained for these uses and disclosures.
- If we are required to register with the Data Protection Commissioner, does our register entry include a full list of persons to whom we may need to disclose personal data?

Parkinson's Ireland says: Does everyone who gives us information **know** that they are giving it at the time of giving (ie: through a consent checkbox/cookie notice/link to Privacy Statement) and do they know how we process it? **Don't** pass on 3rd party information without prior consent or knowledge!

Step 4: Security

- Is there a list of security provisions in place for each data set?
- Is someone responsible for the development and review of these provisions?
- Are these provisions appropriate to the sensitivity of the personal data we keep?
- Are our computers and our databases password-protected, and encrypted if appropriate?
- Are our computers, servers, and files securely locked away from unauthorised people?

Parkinson's Ireland says: Every member of staff and volunteer on a committee needs to know about their obligations towards GDPR. Some simple GDPR best practices will ensure that you lead by example:

Always BCC when sending group emails especially when using personal email addresses.

If using WhatsApp be aware to not give out any personal information about anyone on the group. The phone number and name of the user is available to other people in the group so before setting up a group, make people aware of this and ask their permission.

Do not pass on the contact details of any person without the consent of that person

If someone needs their information changed or deleted you have 30 days to comply – in this case contact : nationaloffice@parkinsons.ie to request a subject access request form.

Always have a difficult to guess password on your phone/laptop/tablet.

Use your branch email address where possible

NEVER share your password with anyone

Information on members should only be shared internally where absolutely necessary, and if sent via email, should be protected with a strong password (communicated separately).

Double check before sending any data that a) you are sending it to the correct email address b) you are sending the correct information and c) it is necessary that this person receives this data

Step 5: Adequate, relevant and not excessive

- Do we collect all the information we need to serve our purpose effectively, and to deal with individuals in a fair and comprehensive manner?
- Have we checked to make sure that all the information we collect is relevant, and not excessive, for our specified purpose?
- If an individual asked us to justify every piece of information we hold about him or her, could we do so?
- Does a policy exist in this regard?

Parkinson's Ireland says: Is there any place where we can **cut down** on the amount of data being asked for/processed? Is every piece of information we gather used for legitimate purposes? For the purposes of volunteer and member registration, Parkinson's Ireland requires certain contact information about individuals and dates of birth. We will never ask for people's bank details, their sexual orientation, their relationship status or country of birth. Every piece of information gathered **must** have a legitimate purpose.

Step 6: Accurate and up-to-date

- Do we check our data for accuracy? Do we take steps to ensure our databases are kept up-to-date?
- Do we know how much of our personal data is time-sensitive, i.e. likely to become inaccurate over time unless it is updated?

Parkinson's Ireland says: The onus is on the individual if their contact information changes. You have **30 days to comply** once a request comes

in. A public notice on your Facebook Page or Website with "*Please contact xyz if your contact information has changed so that we can ensure our database is up to date.*" covers you here.

Step 7: Retention time

- Is there a clear statement on how long items of information are to be retained?
- Are we clear about any legal requirements on us to retain data for a certain period?
- Do we regularly purge our databases of data which we no longer need, such as data relating to former employees or members?
- Do we have a policy on deleting personal data as soon as the purpose for which we obtained the data has been completed?

Parkinson's Ireland says: The retention period is outlined in our Data Protection Policy but to boil it down to one sentence: *"Data will not be held for longer than is necessary for the purpose(s) for which they were obtained."*

Step 8: The Right of Access

- Is a named individual responsible for handling access requests?
- Are there clear procedures in place for dealing with such requests?
- Do these procedures guarantee compliance with the Act's requirements?

Parkinson's Ireland says: One person on your committee (Branch Secretary) should handle all Subject Access Requests – please email nationaloffice@parkinsons.ie for a form that you can modify and administer at local level. For national queries the CEO will be your point of contact at the same email address.

Step 9: Registration

- Are we clear about whether or not we need to be registered with the Data Protection Commissioner?
- If registration is required, is the registration kept up to date? Does the registration accurately reflect our practices for handling personal data? *[Remember, if your data-handling practices are out of line with the details set out in your register entry, you may be committing an offence.]*
- Is a named individual responsible for meeting our registration requirements?

Parkinson's Ireland says: We have consulted the [DPC guidelines](#) and deemed that we are not required to have a DPO registered with the DPC. At a National Level, the CEO of Parkinson's Ireland will act as a liaison between the organisation and the DPC. At Branch level the Secretary liaises with all things relating to GDPR.

Step 10: Training & Education

- Do we know about the levels of awareness of data protection in our organisation?
- Are our employees aware of their data protection responsibilities - including the need for confidentiality?
- Is data protection included as part of the training programme for our employees?

Parkinson's Ireland says: The Parkinson's Ireland Head Office can supply training on a needs-must basis. There are also courses available at www.thewheel.ie. Sign up to the Data Protection Commissioners newsletter to be aware of any updates: www.dataprotection.ie

GDPR can seem scary, but it is to protect EVERYONE including yourself. If in doubt contact nationaloffice@parkinsons.ie

Appendix 2

Current/Former Employee/Volunteer or Member - Subject Access Request (SAR) Form

The General Data Protection Regulation (GDPR) provides you (the data subject) with rights over how your personal data is processed. These rights entitle you to a description of your personal data which we hold. You are also entitled to obtain a copy of the personal data we hold on you, details of the purposes for which it is used; and various details in relation to the manner in which it is processed.

We will not charge a fee for responding to a Subject Access Request. We may, however, charge a reasonable fee where the data being provided is extremely voluminous (based on the administrative cost of providing the information).

To enable us to respond efficiently to your request, please:

- 1.** Complete all the relevant sections of this form;
- 2.** Send the completed form and copies of required identification documents to:

National Office
Parkinson's Ireland
Carmichael House
North Brunswick Street
Dublin

Section 1 – Data Subject Details	
Your Full Name:	
Address:	
Eircode:	
Tel:	Mobile:
Email:	
I am a current employee/former employee, volunteer or member*	
<i>*Delete as appropriate</i>	
Proof of identity	
<i>PI may have to authenticate your identity upon submission of this request.</i>	
Section 2: Personal Data you are requesting	
Please use this section to tell us what personal data you would like to see.	
“Personal Data” means information relating to the data subject as an individual. Please be as specific as possible and include any notes to help us locate the information you are requesting, eg: by listing the documents or information you would like disclosed or the dates you are interested in.	
Details of information requested (with dates)	
Section 3 – Declaration	
I confirm that I am the data subject and that the information given on this form is correct and supplied the proof of identity requested.	
Signed:	Date:

Checklist – Please ensure that you have provided us with the following:

- | | |
|--|--------|
| <input type="checkbox"/> Description of the data you require: | Yes/No |
| <input type="checkbox"/> Dates relating to the data you require: | Yes/No |
| <input type="checkbox"/> Proof of identity: | Yes/No |
| <input type="checkbox"/> Signed declaration: | Yes/No |

We reserve the right to obscure or suppress information that relates to third parties. Personal information collected on this form is required to enable your SAR to be processed and will only be used in connection with this request. In accordance with the GDPR, we may take up to **one month** to respond to your SAR beginning on the day it is received.

Office use only:

Received on:	Completed:	Notes:
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Appendix 3

SAMPLE LETTER ACKNOWLEDGING REQUEST

Subject Access Request:

Reference [Surname:MMYY]

Name

Address Line 1

Address Line 2

Address Line 3

Address Line 4

Insert date here

Dear Mr/Mrs *[insert name]*

Thank you for your correspondence dated **xx** requesting access to your/your child's (delete as applicable) personal information. I acknowledge receipt of your request and your proof of identity and address.

I can confirm that we received your request on **xx**. As set out in the General Data Protection Regulation, we have one month to provide you with this information, beginning on the day the request is received. We will therefore ensure we respond to you by **xx** at the latest. If we are able to locate your information sooner, we will send it to you as soon as it is available.

You can find out more about Subject Access Requests and your rights by visiting the Office of the Data Protection Commissioner/Information Commissioner's Office website at www.dataprotection.ie

Yours sincerely

XXX

Appendix 4

SAMPLE LETTER REQUESTING MORE INFORMATION

Reference: **[Surname:MMYY]**

Name
Address Line 1
Address Line 2
Address Line 3
Address Line 4

Insert date here

Dear Mr/Mrs **[insert name]**

Thank you for your correspondence dated **xx** requesting access to personal information.

Unfortunately, we are not able to process your request as we do not have the appropriate further details to identify the information you are requesting/authenticate your identity.*

Please provide:

Identification – **Include Details***

Further information – **Include Details ***

Under data protection legislation we are allowed to ask you for additional information to help us locate your data.

We would be grateful if you would provide the required information as detailed above. If you have any queries about this request, please contact us [by email](#) Please quote the reference provided at the top of this letter in all your future correspondence. You can find out more about Subject Access Requests and your rights by visiting the Office of the Data Protection Commissioner's website at www.dataprotection.ie or

Yours sincerely

Xxx

*Delete as appropriate

Appendix 5

SAMPLE LETTER RESPONDING TO REQUEST

Reference [Surname:MMYY]

Name

Address Line 1

Address Line 2

Address Line 3

Address Line 4

Insert date here

Dear Mr/Mrs [*insert name*]

[Further to your subject access request dated **xx** we have carried out a search of our filing systems and confirm that we do not hold the information you have requested]*

[Further to your subject access request dated **xx** please now find enclosed the requested personal information.] *

Please refer to www.parkinsons.ie for our privacy notice which provides details of how we process personal data.

You can find out more about Subject Access Requests and your rights by visiting the Office of the Data Protection Commissioner's website at www.dataprotection.ie

Yours sincerely

Xxx

*Delete as appropriate

