

UK General Data Protection Regulation (GDPR)

Even though the UK has left the EU, GDPR has been retained in UK domestic law, renamed as 'UK GDPR'. This means the key principles, rights and obligations remain the same. The UK now has the independence to keep this under review. The UK Data Protection Act 2018 remains in place and sits alongside UK GDPR.

Parkinson's UK is defined as a 'data controller' and the groups support Parkinson's UK by owning their local information assets, for example membership or mailing lists/databases. Whatever the size of your group, if you collect and store personal data - like names and addresses - you'll have to manage the data in accordance with strong data protection principles.

What does this mean for individuals?

In order to keep in touch with anyone, you must have their consent. If they are members of Parkinson's UK and they appear on your membership list, then they have given us consent for their local group to get in touch with them and you may do so.

If an individual is not a member, they may still give you consent to keep in touch with them. They must complete [this form](#), and then you will need to keep a record of these people's details, securely.

You don't need to have an individual's permission if you have a *need* to contact them - for example they have signed up to a class that is cancelled or having emergency contacts in case there is an urgent safety concern - but must have their consent for general mailings, for example, to send them newsletters.

Permission is also needed for a person's picture or video too - and we have dedicated guidance around this.

Individuals have the right, at any point, to request copies of their personal data and how it is being used - this is called a Subject Access request. If anyone submits a request for their personal data, let the [Data Protection Officer](#) know as soon as possible - we must respond within a month and they can coordinate this.

What are the key things to consider for local groups?

All local groups need to ensure that any personal data is:

- Processed and stored securely
- Updated regularly and accurately
- Limited to what the local group needs
- Used only for the purpose for which it is collected

Handling data

Electronically	Manually
<p>Make sure that any electronic files that contain personal data are password protected, particularly when sharing them. And don't share the password in the same way as you are sharing the data.</p>	<p>Make sure any manual files that contain personal data are kept securely, for example, in a locked filing cabinet and are not left lying out unattended at any time.</p>
<p>Emails, unless they are from one Parkinson's email address to another, are not secure. They should be thought of as postcards – the contents can be easily read. Please be particularly thoughtful when sharing information, even with fellow committee members, by email.</p>	<p>If you do share manual files that contain personal data, such as by post or by hand, make sure you take the necessary steps to ensure it arrives safely. For example, keep it in a sealed envelope, consider whether the package will fit through the recipient's letter box or whether email would be safer.</p>
<p>Always BCC (Blind Carbon Copy) email addresses when sending emails to a group of people. If you're not sure how to do this, ask your staff contact.</p>	<p>If you must send manual files that contain sensitive personal data by post, this must always be sent by recorded delivery or courier.</p>

Always delete files when they are no longer needed - from the hard drive and the 'recycle bin' on a laptop or desktop computer. This is also the case when a volunteer leaves their role.

Make sure all paper files that contain personal data are securely destroyed when no longer needed. For example, by using a cross cut shredder or giving them to your staff contact. This is also the case when a volunteer leaves their role.

We'd encourage you to limit the amount of paperwork you manage - keeping your data electronically is often more secure, as it can't fall into the wrong hands and is easier to protect.

What can I do locally to enhance cyber security?

- If you're using your home laptop/PC, please ensure the antivirus software is up to date and active and make sure you're running the latest version of your chosen browser. Don't install 2 antivirus programmes, as they'll conflict and may become ineffective as a result.
- Be suspicious of emails or web addresses that don't look quite right, whether because it's come from someone you don't recognise, has poor spelling, grammar or punctuation, or logos don't match what you would expect to see. If in doubt, don't open the email and delete it - and don't click on attachments or links. If you have concerns, you can forward these to phishing@parkinsons.org.uk
- Always lock your computer if you leave it unattended - even at home - and make sure you use strong and random passwords i.e. use at least 12 characters, including numbers and letters, both upper and lower case. And use 2 factor authentication where you can - this is where you need a second piece of information as well as your password, for example answering a security question, or where you need to approve the login on your mobile as well.
- If getting rid of your computer or tablet with any personal data stored on it, make sure it's properly deleted before disposal.
- Use 3G/4G for confidential browsing instead of free public WiFi. And change the default password for your home WiFi to something that is strong and random.
- Do not enter personal information on a website that has no padlock displayed before the URL address in the browser or https:// at the beginning of the web address.
- Be aware of USBs containing malware that can run without your knowledge.

For more information on how you can protect yourself online, take a look at the [National Cyber Security Centre's advice](#).

Sharing data

You can only use data for the purpose it is collected, so if you've collected that data to keep in touch with an individual, you shouldn't share it with other organisations or individuals to enable them to contact that individual for marketing purposes. This includes sharing that data with Parkinson's UK.

You may need to share data with a third party to achieve the purpose that you have collected the data for, for example getting a print house to mail your newsletter - if so, you should have a local contract in place.

Data retention

You should only keep data for as long as necessary, or until the individual 'opts out' of communications, and you should let individuals know how long you will keep their data. For example, if you send a newsletter to an individual but you have not heard from them, consider a re-consent exercise every few years. If you don't hear back from them still, you should remove them from your list at this point.

Privacy notice

Under GDPR, you need to tell people about how and what you do with their data at the point you collect it. An overarching [Privacy Notice](#) is now available on the Parkinson's UK website and we also have a [bespoke Privacy Notice](#) for local groups.

If you have your own website, you should make sure there is a link connecting to the Parkinson's UK Privacy Notice on the main charity website and upload the bespoke one to your site. You don't require this on social media pages.

Data breaches

If you are aware of a data breach, contact the Data Protection Officer as soon as possible. As a charity, we will only have 72 hours from being aware of a breach to report it to the Information Commissioner's Office if it meets the threshold criteria for reporting to the regulator. This will be

decided by the Data Protection Officer. For example, if an email is sent out without 'BCCing' email addresses.

Who to contact for more information

You can find out more about the training available and required around data protection [here](#). For further information and support on GDPR in general, please contact Douglas Smith, our data protection officer, at dataprotection@parkinsons.org.uk or on 020 7963 9388.

Useful links

[Communicating with your local group](#) [Media consent](#) [Team Parkinson's membership](#)
[Local Contracts](#) [Membership Lists](#) [Training](#)