Who is our internal data guardian

How is the data reviewed/updated/permissions updated

How long do we keep data

How and when is data deleted

Introduction

The Cure Parkinson’s Trust (“we”) promises to respect any personal data you share with us, or that we get from other organisations and keep it safe\*.  We aim to be clear when we collect your data what happens to it, how it is kept and how we use it.. Parkinson’s Movement is part of The Cure Parkinson’s Trust so information collected through Parkinson’s Movement is kept and stored with data collected through The Cure Parkinson’s Trust

Developing a better understanding of our supporters through their personal data allows us make better research decisions, fundraise more efficiently and, ultimately, helps us to reach our goal of finding a cure for Parkinson’s.  We have made improvements to this policy to make it more understandable to supporters.

In March 2018, we will be moving to be an ‘opt-in only’ communication policy. This means that we will only send communications to those that have explicitly stated that they are happy for us to do so via their preferred channel(s) (email, SMS, phone or post). Our communications are divided into research (including Parkinson’s Movement) and fundraising and you will only receive the communications you have selected.

Our communications include information about our latest breakthroughs, campaigns and lifesaving work. If you would like to receive such communications but have not opted in please contact us on.

We collect information in the following ways:

* When you give it to us DIRECTLY

You may give us your information in order to sign up for one of our events, tell us your story, sign up to take part in research, complete surveys via Parkinson’s Movement, make a donation, purchase our products or communicate with us.  Sometimes when you support us, your information is collected by an organisation working for us (e.g. a professional fundraising agency), but we are responsible for your data at all times.

* When you give it to us INDIRECTLY \* (see intro)

Your information may be shared with us by independent event organisers, for example the London Marathon or fundraising sites like Just Giving or Virgin Money Giving.  These independent third parties will only do so when you have indicated that you wish to support Cancer Research UK and with your consent. You should check their Privacy Policy when you provide your information to understand fully how they will process your data.

* When you give permission to OTHER ORGANISATIONS to share or it is available publicly

We may combine information you provide to us with information available from external sources in order to gain a better understanding of our supporters to improve our work.

**Social Media**
Depending on your settings or the privacy policies for social media and messaging services like Facebook, WhatsApp or Twitter, you might give us permission to access information from those accounts or services.

**Information available publicly**
This may include information found in places such as Companies House and information that has been published in articles/ newspapers.

* When we collect it as you use our WEBSITES OR APPS

Like most websites, we use “cookies” to help us make our site – and the way you use it – better. Cookies mean that a website will remember you. They’re small text files that sites transfer to your computer (or phone or tablet). They make interacting with a website faster and easier – for example by automatically filling your name and address in text fields. There are more details in our [Cookie Policy](http://www.cancerresearchuk.org/terms-and-conditions/cookies-policy).

In addition, the type of device you’re using to access our website or apps and the settings on that device may provide us with information about your device, including what type of device it is, what specific device you have, what operating system you’re using, what your device settings are, and why a crash has happened. Your device manufacturer or operating system provider will have more details about what information your device makes available to us.

The type and quantity of information we collect and how we use it depends on why you are providing it.

**Supporters**

If you support us, for example make a donation, volunteer, register to fundraise,  sign up for an event or buy something from our shop, we will usually collect:

* Your name
* Your contact details
* Your date of birth
* Your bank or credit card details
* Your contact preferences

Where it is appropriate we (CPT and PM) may also ask for:

* Information relating to connection with Parkinson’s which might include information relating to your health Why you have decided to donate to us. We will never make this question mandatory, and only want to know the answer if you are comfortable telling us.

We will mainly use your data to:

* Provide you with the information you asked for
* Administer your donation or support your fundraising, including processing gift aid
* Keep a record of your relationship with us
* Ensure we know how you prefer to be contacted
* Understand how we can improve our work.

If you enter your details onto one of our online forms, and you don’t ‘send’ or ‘submit’ the form, we may contact you to see if we can help with any problems you may be experiencing with the form or our websites.

Only with your prior consent, we may also need to use your personal information to detect and reduce fraud and credit risk.

**Building profiles of supporters and targeting communications – this needs reworking**

We use profiling and screening techniques to ensure communications are relevant and timely, and to provide an improved experience for our supporters.  Profiling also allows us to target our resources effectively, which donors consistently tell us is a key priority for them.  We do this because it allows us to understand the background of the people who support us and helps us to make appropriate requests to supporters who may be able and willing to give more than they already do.  Importantly, it enables us to raise more funds, sooner, and more cost-effectively, than we otherwise would.

When building a profile we may analyse geographic, demographic and other information relating to you in order to better understand your interests and preferences in order to contact you with the most relevant communications.  In doing this, we may use additional information from third party sources when it is available.  Such information is compiled using publicly available data about you, for example addresses, listed Directorships or typical earnings in a given area.

**Direct Marketing**

With your consent, we will contact you to let you know about the progress we are making and to ask for donations or other support.  Ocassionally, we may include information from partner organisations or organisations who support us in these communications.  We make it easy for you to tell us how you want us to communicate, in a way that suits you. Our forms have clear marketing preference questions and we include information on how to opt out when we send you marketing. If you don’t want to hear from us, that’s fine.  Just let us know when you provide your data or contact us on.

We do not sell or share personal details to third parties.  But, if we run an event in partnership with another named organisation your details may need to be shared. We will be very clear what will happen to your data when you register.

**Being an Ambassador and / or being part of Parkinson’s Movement**

Some people choose to tell us about their experiences with Parkinson’s to help further our work.  They may take on a role as an Ambassador, attend our patient focused events or sit on our committees.  This may include them sharing sensitive information related to their health and family life in addition to their biographical and contact information.

We monitor the types of people who are involved to ensure that the views we hear are representative of all people affected by Parkinson’s.

If we have the explicit involvement and informed consent of the individuals, this information may be made public by us at events, in materials promoting our campaigning and fundraising work, or in documents such as our annual report.

 **Forums and Surveys**Parkinson’s Movement hosts a forum via health forum specialist Health Unlocked. You will be asked to provide your email address when you register and we may contact you about administrative issues and changes to the forum.
Posts to the forum are anonymous but are likely to contain sensitive information.  We advise users to be careful not to post information which would allow them to be identified.We regularly run surveys as part of our work in Parkinson’s Movement. This is to uncover research clues. If you take part, we will ask you if you would like to receive the results of the survey and to do so you will be asked for your email address. All other data collected via these surveys is anonymised.

If you have expressed an interest in taking part in clinical trials, we also have created a short survey which again seeks your contact permission and preferences and so we are able to notify you of any research opportunities.

We will only share your details, and with your permission, in exceptional circumstances.

We may also collect and retain your information if you send feedback about our services or make a complaint.

How we keep your data safe

We ensure that there are appropriate technical controls in place to protect your personal details.  For example our online forms are always encrypted (can they be??) and our network is protected and routinely monitored.

We undertake regular reviews of who has access to information that we hold to ensure that your information is only accessible by appropriately trained staff, volunteers and contractors.

We use external companies to collect or process personal data on our behalf. We do comprehensive checks on these companies before we work with them, and put a contract in place that sets out our expectations and requirements, especially regarding how they manage the personal data they have collect or have access to.

Some of our suppliers run their operations outside the European Economic Area (EEA).  Although they may not be subject to same data protection laws as companies based in the UK, we will take steps to make sure they provide an adequate level of protection in accordance with UK data protection law. By submitting your personal information to us you agree to this transfer, storing or processing at a location outside the EEA.check

We may need to disclose your details if required to the police, regulatory bodies or legal advisors.

We will only ever share your data in other circumstances if we have your explicit and informed consent.

Keeping your information up to date

Where possible we use publicly available sources to keep your records up to date; But we really appreciate it if you let us know if your contact details change.

You have a right to ask us to stop processing your personal data, and if it’s not necessary for the purpose you provided it to us for (e.g. processing your donation or registering you for an event) we will do so.   if you have any concerns.

You have a right to ask for a copy of the information we hold about you, although we may charge £10 to cover the costs involved.  If there are any discrepancies in the information we provide, please let us know and we will correct them.

If you want to access your information, send a description of the information you want to see and proof of your identity by post to.   We do not accept these requests by email so we can ensure that we only provide personal data to the right person.

If you have any questions please send these to , and for further information see the [Information Commissioner’s guidance here(link is external)](https://ico.org.uk/for-the-public/personal-information/).