



## WICKENSTONES

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### **Privacy notice to patients and carers**

Wickenstones collects personal data about individuals who are patients of a disease or who care for those patients. This notice will refer to these individuals collectively as patients.

This notice gives information about how patient data are processed. You can find further information on Wickenstones' data protection policy on our web site.

The person responsible for these data, and for ensuring that all processes in this privacy notice are followed, is the office manager, who can be contacted at [sarah@wickenstones.com](mailto:sarah@wickenstones.com).

#### **The data we collect and how we collect them**

We collect patient data either by gathering them first hand through surveys, questionnaires or interviews. Sometimes clients give us data for analysis, but these data are always fully anonymised before we receive them and therefore do not qualify as personal data.

The personal data we collect varies from project to project, and if you are involved in a project you will be given a separate, specific notice. In general, they may include an internet provider (IP) address, email address, and the age range, gender, location and health condition of the patient. IP addresses are often collected automatically by online survey providers; all other data we will ask you to provide. Your participation in research is always optional.

#### **Why we collect/store data**

We collect data about you to learn about a particular health condition and report back to our clients. Sometimes we collect IP addresses in order to ensure that we don't get duplicate survey responses from the same person or household which would adversely affect the validity of our results. At other times we are given the IP addresses by the survey provider, even though we don't require them. If we can, we will ask the survey provider not to collect your IP address if we don't require it. We may ask you for your email address so that we can contact you directly about your survey responses or provide you with a personalised report. This is usually optional and we will tell you this if we ask you for your email address.

#### **Data storage and processing**

Registered office: Wickenstones, Chalkwood house, Cold Harbour, RG8 7SZ, UK

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If you complete an online survey or questionnaire, your raw data will initially be stored by a survey provider. We will make sure you have access to the survey provider's privacy policy before you complete the survey. One team member will be able to access your data on the survey provider's site and they will be responsible for downloading them and anonymising them before anyone else in the team can access them. If you participate in an email questionnaire or an interview, we will initially store notes in a Microsoft OneDrive folder which is only accessible to the person conducting the interview or questionnaire, who will then summarise and anonymise your data before sharing it with the project team. We will keep the raw data securely, until the results of the study have been published. After that, within one month the raw data will be archived with only the office manager and CEO having access, and after 10 years they will be destroyed.

The process of anonymising the data we collect is likely to involve removing the IP addresses if not necessary to the project, and/or creating a separate list of IP addresses and email addresses that only the person doing the anonymisation can access. The exact process will vary between projects, and we will inform you of the process before we collect your data. The data will be considered to be pseudo-anonymised if one person can match your data back to you, or if some of the demographics you belong to are specific enough that with effort and inclination someone with access to the data could feasibly identify you. If that is the case, we will continue to treat the data as personal data, and the same process as outlined above for the raw data will be followed.

### **Third parties**

- As mentioned above, we may use an online survey provider to collect your data. If that is the case, we will let you know this.
- Microsoft is a data processor for our patient data because they provide storage and the functionality to sort, filter and share data internally. Microsoft adheres to the GDPR and their data protection policy can be accessed [here](#).
- CTS is a data processor for our patient data because they are our Internet Service Provider. CTS adheres to the GDPR and their privacy policy can be accessed by emailing [support@cts-group.co.uk](mailto:support@cts-group.co.uk).

### **Right to erasure and access requests**

You can read about your rights to erasure and access [here](#) and [here](#). If you wish to make a request under your right to access or right to erasure, please email [GDPR@wickenstones.co.uk](mailto:GDPR@wickenstones.co.uk).

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