
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 [here](#).

The team responsible for these data, and for ensuring that all processes in this privacy notice are followed, is administrative support, who can be contacted at admin@wickenstones.com.

The data we collect and how we collect them

We usually collect patient data 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 separate, specific information. In general, they may include an email address, internet provider (IP) 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 rely on legitimate interests as our lawful basis for processing patient data. We consider that someone voluntarily completing a survey about their/their loved one's health condition, will reasonably expect their data to be stored and analysed as we do. We also consider that doing so is unlikely to negatively impact on the subject's interests, and presents very little risk to them.

We collect the data you provide to us in your answers to survey questions, to learn about a particular health condition and report back to our clients.

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. 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.

Data storage and processing

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.

If you participate in an email questionnaire or an interview, we will initially store notes in a Microsoft SharePoint folder which is only accessible to the team conducting the project. We call this the raw data. At the earliest opportunity we will anonymise or pseudo-anonymise the data, and only work with that going forward.

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 securely archived for up to 10 years.

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 expert 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](#).
- AirIT is a data processor for our expert data because they are our IT support. AirIT adheres to the GDPR and their data protection policy can be found [here](#).

Your rights under GDPR

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.com.