

Digesting Science Privacy and Data Protection Policy

We at Digesting Science care about those who facilitate and attend our events. Our privacy and data protection policy is important to us as we know our families may not want to disclose that they are affected by MS. As children attend our events, their privacy and dignity is our priority.

About collecting personal information

We keep information in order to communicate with you about upcoming events, project updates, research from the MS world that is pertinent to families, and information that may help or be of interest to families affected by MS.

We will never share personal data with others (unless requested by you or discussed with you in advance for a specific purpose (e.g. to introduce a facilitator to another Barts-MS project)).

Our mailing system records include your email address and your name if you have given it.

We also collect information from our events on the number of children, adults and volunteers who attend our Digesting Science events.

And we collect names and email addresses from people we meet at conferences and professional gatherings.

We don't take anything you don't voluntarily share with us — we never participate in "data mining" to collect personal data.

Some of the data that we may ask you for (this is not an exhaustive list):

Name

Phone Number (only of event organisers, never of attendees)

Email address

Number and ages of your children where relevant

How you found out about the project

Photographs

We encourage our facilitators to take photographs of the event, with attendees' permissions. These photos may be used on social media, in email newsletters and in printed project materials (e.g. manuals or evaluation posters). This is not an exhaustive list of the uses of these photos. Facilitators may also take photos of activities that include the first names of children written out. If you are at all uncomfortable with any of this, please speak to your facilitator about this and come to an arrangement you are happy with. We don't want to use photos that have been taken without consent or full understanding.

If you are receiving emails from Digesting Science, this will be because you requested to hear updates about the project. You may have sent an email, filled in a 'subscribe' form for

the newsletter, attended an event or met us at a conference. If you would rather not receive this information, please click 'unsubscribe' at the bottom of the newsletter.

How personal information is used and stored

We use your email address to contact you with a monthly newsletter about the project and relevant research news. We will never share this data with anyone else.

Your email addresses are stored in our MailChimp account.

We collect information on numbers of attendees and feedback from our events. We collect this information by phoning or emailing facilitators. They also complete an online form.

We collect evaluation forms from people that attend our events. Forms have an optional email address. If you fill this in you will be added to our newsletter list (as detailed on the form). You don't have to share your name or any other information with us. It is not asked for on the form.

These paper forms are sent back to us. They are scanned and the feedback is entered into spreadsheets. Email addresses are added to our MailChimp list. The paper forms are stored in a locked cabinet, in a restricted-entry office. The digital copies are kept on a Queen Mary University computer.

Security and Protection

We use tools and third party companies that are committed to high levels of security encryption. All technology is kept up-to-date in as reasonable time-frame as is possible.

Your data: your control

You can unsubscribe at any time. You may let us know that you don't wish us to use your data and we will honour your request.