

# The MAMMI Study



## The General Data Protection Regulation (GDPR) - What it means for you.

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From everyone here at the MAMMI study, we hope that you and your family are all happy, healthy and well and enjoying the start of summer! It is always a pleasure to update you on the developments and progress of the study.

Follow us on *Twitter* @mammi\_tcd and on our new *Instagram* page [the\\_mammi\\_study\\_tcd](#) to keep up to date on MAMMI news and events!

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### General Data Protection Regulation (GDPR)

The General Data Protection Regulation is a Europe-wide data protection law, brought into effect in May 2018, to make sure that European citizens have more control over their personal data and how their information is used.

The GDPR means that healthcare researchers have to be completely clear with participants about how their data are being used, protected and stored, and we must show that we are using and handling data in a way that is GDPR compliant.

The MAMMI Study's Consent form was very detailed, as you know, but we have updated it, and the Participant Information Leaflet (PIL), to include the new and necessary details on the legal basis under which we are processing and storing your data. We sent these documents to a group of MAMMI Study participants for comment and review, and they were very happy with the wording.

We have published the updated Consent Form and PIL on our new website, and you can access them here: [www.tcd.ie/mammi/](http://www.tcd.ie/mammi/)

### What does GDPR and MAMMI participation mean for me?

As you know, the MAMMI Study is an ongoing longitudinal study. We are still analysing the data you gave to us during the year after your baby's birth and plan to publish the findings on what you told us about your health and health problems. We have retained your contact details (*but only if you gave us consent to do so*) to invite you to take part in the five-year follow-up study, the second baby study and the Public Participation in research Initiative (PPI).

GDPR means that we are obliged to let you know that we are *still* using your data for research purposes and ASK FOR YOUR CONSENT to CONTINUE using the data (You gave us consent to use your data previously).

**For this reason, the MAMMI Study team will be contacting participants about consent via phone over the next few weeks.**

Our understanding of GDPR is that you can give, or withhold, consent for us to continue using your data in the form of an email to [mammistudy@tcd.ie](mailto:mammistudy@tcd.ie), or it can be verbal when the team member calls.

### What is new in the Participant Information Leaflet?

As you know, the Consent Form and the Participant Information Leaflet (PIL) that you received when you first joined the MAMMI study were very detailed, and much of it complied with GDPR standards today.

In the updated PIL, we have added in the information on the legal basis for processing and storing your data, information on who to contact and how to make a data protection complaint, and the contact details of Trinity College's Data Protection Officer.

### Date Sharing:

The PIL also outlines our plan to share **anonymised study data** with researchers in the Australian Maternal Health Study (MHS) (the research that the MAMMI Study was modelled on when Deirdre Daly started it in 2011) and the Multidisciplinary Opinion and Democracy Research Group (MOD) at the University of Gothenburg, Sweden.

The data we plan to share with the MHS research group and the MOD group will only contain the information collected from the paper surveys in an electronic and numeric format, *it will not contain any personal details or any information that can identify you*. In other words, the MHS and MOD researchers will receive **fully anonymised data**.

The MHS and MOD research groups will not receive any information that might directly, or indirectly, lead researchers to identify any individual participant.

As the data being shared is anonymised, this does not affect the consent process because it falls outside the scope of GDPR and Health Research Regulations (HRR) 2018. However, we want to tell you that we are planning to share the data because we want to be open and transparent with you.

### Contact the MAMMI Study team!

If you are happy for the MAMMI study to continue using your data or if you have any questions about the protection of your data, you can contact us at [mammistudy@tcd.ie](mailto:mammistudy@tcd.ie) or call us on **087 118 6762**.