

# The Australian Corneal Graft Registry (ACGR)

## Who are we and what do we do?

The ACGR was established to collect information about corneal transplantation in Australia.

The database has information on over 40 000 corneal transplants (also known as corneal grafts), performed in every State in Australia, since 1985.

Differences in a graft recipient's ophthalmic history, the surgical technique used, or the follow-up care given, might affect the success of the graft.

By collecting information on grafts performed by surgeons Australia-wide we are more able to detect what these factors might be.

***You don't need to do anything else.***

## Your Involvement

By agreeing to have information about your graft included in the ACGR you are helping us to help corneal surgeons improve the outcomes for corneal graft recipients like yourself.

We will request information from your surgeon at regular intervals (usually between every one to three years) about how your graft is going and whether there have been any complications or further surgeries needed.

Your surgeon can let us know if we should ask a different surgeon or eye-health professional (e.g. your optometrist) for follow-up information instead.

***It is your right to say you do not want your data included.  
Your surgeon will still provide you with the same level of care.***

## Your data

Your data are kept secure and will not be shared with anyone else.

The ACGR is committed to keeping your information safe, as we have for corneal graft recipients for over 35 years, with multiple levels of protection in place. We regularly review our security measures to ensure they operate at the highest level.

Your data will be de-identified and combined with that collected from other recipients for statistical analysis. No information that could identify you is used in this process or published in any scientific papers, reports, or presentations published by the ACGR.

The ACGR performs data-linkage with the National Death Index every five years, so that we know if graft recipients have died and we can stop seeking follow-up information. We do not provide any information about your health care during this process. The National Death Index only informs us of the date of a recipient's death, no other information is provided.

*Saying “yes” now, doesn’t mean you can’t say “no” later.*

## Your options

If you decide that you don't want any more information collected on your graft, we'll stop. If you decide that you no longer want your data kept in the ACGR database, we will remove it and it won't be included in any future analysis.

You can let us know what you want done with your data in two ways: via your surgeon who will let us know, or by contacting the ACGR directly on 08 8204 5321

## More information

The major reports and presentations produced by the ACGR are freely available online, so you can see what we do with your data:

<https://www.flinders.edu.au/fhmri-eye-vision/corneal-graft-registry>

You can contact the ACGR by phone, Monday to Thursday, on 08 8204 5321.