The Australian Corneal Graft Registry (ACGR)

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Financial disclosures: none to report
Goals of the ACGR

- Measurement of outcomes: graft survival and visual acuity
- Investigation of risk factors for graft failure
- Tracking of changing patterns of practice (especially new lamellar procedures)
Guiding principles of the ACGR

- Primary clients are contributing ophthalmologists, each of whom “owns” her or her own data
- Security and confidentiality are taken seriously
- The ACGR meets ophthalmologists’ and eye bankers’ needs wherever possible (requires flexibility of approach)
- Iterative changes are based primarily on consensus decisions made by contributors
Snapshot of the ACGR database, 1985-2015

- ≈ 1500 corneal grafts registered per year (PK, DALK, DSEK, DSAEK, DMEK, limbal stem cell graft)
- Archival follow-up requested at yearly intervals until graft failure, recipient death, or loss to follow-up
- > 900 ophthalmologists in a variety of public and private practices, and 5 Australian Eye Banks, have contributed data

- Total registered grafts: 29,526
- Total grafts followed: 23,326
- Total graft failures: 5,786
- Total recipient deaths: 7,426
- Total grafts lost to follow-up: 8,622 (77% after follow-up)
Information sought at registration

- Recipient
- Donor
- Eye Bank practice
- Surgical procedure
- Surgeon, location, and follow-up practitioner
  (recipient, surgeon, location, and Eye Bank are identified)

Information sought at follow-up

- Graft surviving?
- Best-corrected visual acuity?
- Date of specified event (eg. when last seen, failure, death, lost to follow-up, suture removal, rejection episode)
- Relevant ophthalmic events and complications
ACGR outputs

De-identified and amalgamated analyses returned to all contributing surgeons

Personalised analyses provided to individual contributors for audit, benchmarking and CME purposes

Reports published in the open literature, to increase the available evidence-base on real-world outcomes of corneal transplantation

Reports lodged in permanent D-space institutional repository: http://hdl.handle.net/2328/25859
Enablers and barriers

**Enablers**
- Contributors: personal analyses
- Eye Banks: data to satisfy Regulator
- Publications
- Readily usable, de-identified data
- Flexible approach by ACGR staff
- Voluntary and free
- Trust and goodwill

**Barriers**
- Time involved in provision of data
- Concern that data may be used out of context by external bodies
Changing practice

A. All indications

B. Keratoconus

C. Fuchs’ dystrophy

D. Pseudophakic bullous keratopathy

YEAR GRAFT PERFORMED

Penetrating  DALK  Endothelial
In the Eye Bank .....
PK compared with DALK for keratoconus

Penetrating grafts performed for keratoconus do better than DALKs
PK compared with DSE(A)K for Fuchs’ dystrophy

Penetrating grafts performed for Fuchs’ dystrophy do better than DSE(A)Ks
Acknowledgments

- All contributors to the Registry
- Staff of Australian Eye Banks
- DonateLife and NHMRC