



How to Guide – For Regional Data Collectors

This Guide has been developed by the Global Alliance of Eye Bank Associations (GAEBA) - Data Collection Working Party, to assist the assigned partner or collector to collect and submit statistical data (data) to the GAEBA.

Supplied with this How to Guide

- A. GAEBA Data Definition Guide
- B. GAEBA Data Country Reporting Tool (Template)

Introduction

This project seeks to understand the overall global ocular tissue donor numbers, utilization rates, and sectorial gaps. The collection of this information will assist our sector and our peers to examine how we, as a global community, can work towards the World Health Organization (WHO) and International Association for the Prevention of Blindness (IAPB) goals of eliminating treatable and preventable blindness, while simultaneously ensuring donor and tissue management practices are not compromised.

Background: In 2014, GAEBA formally incorporated. At that time, one of the key objectives was to develop global mapping and to capture statistical data regarding donation and transplantation. This has been encouraged by the WHO and promoted as a key component of understanding, learning from, and improving the sector's global service provision.

GAEBA's Partner Associations agreed that a key aspect of the Global Alliance would be to implement an ongoing global data registry regarding human tissue for ocular application. Commencing with a small data set, the system has been designed to allow for additional data-sets and adaptation by the sector over the years – and as individuals become more familiar with the reporting process.

Over the first few years of reporting, the data-set will be minimal, and reporting will be conducted via an Excel data sheet. It is anticipated long-term that an electronic data tool may be implemented.

The data is intended to be publically available, in order to allow the wider ophthalmology and transplant sector to benefit from the results. In adherence to privacy requirements and the intent of the data, we will only be reporting on a country-by-country basis. GAEBA will not be publishing the names of the organisations or individuals involved in the collection. For example, there are multiple eye bank providers in the USA. Their data will be displayed as one single country.

Role of the Data Collection Working Party (DCWP) and Contact Details

The GAEBA Data Collection Working Party (DCWP) is responsible for the development, implementation and collation of data. This includes the maintenance of collection templates and systems, how-to-guides, data dictionaries and end-data presentation to the GAEBA Representatives and/or external bodies. The DCWP has a responsibility to ensure that data is, to the best of their ability, submitted as accurately as possible. The DCWP is also available to assist individuals, countries, regions, their designated Data Collectors/Reports with the project, and enlist and work with volunteer Data Champions who – through their employers, are actively assisting with the project. All members of the DCWP shall adhere to privacy requirements.

The DCWP Contacts are:

- Heather Machin: heather.machin@unimelb.edu.au Development and Administrative Lead.
- Brian Philippy: brianp@lionseyebank.org Data Set and Collator Lead.

The Key DCWP Contacts may, as required, enlist appropriate volunteers to assist them behind the scenes. Such an individual may do so independently. In this instance, they shall not represent their own association, employer or affiliated group and are required to retain all confidentiality around the data provided by individuals from around the world.

Data Champions

Data Champions are individuals identified by eye tissue organizations that are involved in transnational activity, tissue provision, or capacity development within another country. These are voluntary appointments and carry no obligation to participate in all areas of the project. They are responsible for sharing and promoting the value of data capturing and assisting the global community to identifying in-country reporters. The DCWP will liaise with interested organizations to examine the Data Champions' potential within their own organization.

How will data be collected

For those already submitting data to an eye bank association - they will not need to submit data to the DCWP. The designated Data Collector of the *Association* will automatically be the contact providing the data set to the DCWP. Should an association represent multiple countries, the data will be separated to represent those jurisdictional differences.

For those not providing data to an eye bank association, the DCWP will work independently to determine collection via a national collective or via multiple individual providers. In this instance, the 'Collector/s' shall be provided with a data definition guide (Appendix A) and a data collection template - which is to be completed and returned to the DCWP annually. Collection options are:

	Country/Regional Association	No Eye Bank or Association in your country/region
Member	via your Association's Data Collector	The DCWP will liaise with known individual importers, or the local ophthalmological societies on a country-by-country basis.
Not-a-Member	Please connect to the DCWP	
Broker/distributor	Please connect to the DCWP	

Data Privacy

Individual data will not be released to any other party, and will be published only as part of a cumulated nationwide data set. Where necessary, Data Transfer Agreements between GAEBA and the data provider will be completed.

Data will be stored on the server of the Eye Bank Association of America (EBAA), located in Washington DC, USA. It will be accessible to the DCWP only. It will be backed-up, stored and managed in accordance with the data and privacy policies and laws governing the EBAA. EBAA, as the data storage point will also be outlined in any Data Transfer Agreements.

Only de-identified national data will be publically presented. It will be provided publically on the website of the Global Alliance of Eye Bank Associations <http://www.gaeba.org/data/> .

Collection Period

Data collection periods cover one calendar year at a time (January-December). The data for that period is to be submitted by email to the *Data Set and Collator Lead* with a subject line identifying that the email contains *GAEBA data*. With the exception of the first few years of development, the long term goal is for the prior year to be submitted by June 1st of the following year.

What to Collect

The data collection set will evolve as members and partners become familiar with the process or as sectorial need changes. The collection will commence with two questions and slowly increase over time. Partner Associations are to report on the total number of each item for each country during that entire calendar year.

On the next page, we provide a snap-shot of what will be reported initially, for the first few years, and then potentially over time. Please see the accompanied Data Definition Guide for sub-set explanations.

2019	add-on data set 1	add-on data set 2	add-on data set 4
Total corneal transplants	Total corneal transplants	Total corneal transplants	Total corneal transplants
Total domestic donors	Total domestic donors	Total domestic donors	Total domestic donors
Imports and exports	Imports and exports	Imports and exports	Imports and exports
	Number of adverse reactions (total number - we are not yet differentiating them)	Number of adverse reactions (total number - we are not yet differentiating them)	Number of adverse reactions (total number - we are not yet differentiating them)
	Total scleral transplants	Total scleral transplants	Total scleral transplants
	Tissue for research	Tissue for research	Tissue for research
	Wasted	Wasted	Wasted
	Eligible donors not collected	Eligible donors not collected	Eligible donors not collected
	Waitlist	Waitlist	Waitlist
		Number of whole eye recoveries (enucleations)	Number of whole eye recoveries (enucleations)
		Number of cornea-only recoveries (in situ excisions)	Number of cornea-only recoveries (in situ excisions)
		Storage solutions used	Storage solutions used
		Number of Penetrating Keratoplasties	Number of Penetrating Keratoplasties
		Number of Descemet's Stripping Endothelial Keratoplasties (e.g. DSAEK, DSEK)	Number of Descemet's Stripping Endothelial Keratoplasties (e.g. DSAEK, DSEK)
		Number of Descemet's Membrane Endothelial Keratoplasties (e.g. DMEK, DMAEK)	Number of Descemet's Membrane Endothelial Keratoplasties (e.g. DMEK, DMAEK)
		Number of Anterior Lamellar Keratoplasties (e.g. DALK, ALK)	Number of Anterior Lamellar Keratoplasties (e.g. DALK, ALK)
		Number of Keratolimbal Allografts (e.g. KLA, KLAL, ocular stem cell transplants)	Number of Keratolimbal Allografts (e.g. KLA, KLAL, ocular stem cell transplants)
		Number of other Keratoplasties	Number of other Keratoplasties
			Number of tissues processed by the eye bank
			Number of injectable corneas
			Number of Amniotic Membrane Grafts