

International Pilot Survey of Childhood Glaucoma (IPSO CG)

Investigator's Manual Summary

Database URL: <http://c.glaucoma-research.net/>

A. Inclusion & Exclusion Criteria

Inclusion criteria:

1. **Any child with newly diagnosed glaucoma in at least one eye with no previous glaucoma laser or surgical procedures**
2. Fulfills the CGRN definition of childhood glaucoma (Appendix A)
3. Includes children seen as both public and private patients

Exclusion criteria:

1. **previous glaucoma laser or incisional surgery**
2. currently children with glaucoma under your care
3. glaucoma suspects
4. availability of follow up outcome data unlikely even by referring outside source

B. Data entry will occur at the time of: *diagnosis, any management action (i.e., medication, laser or surgical procedure, complication,) and for 6, 12, and 18 months outcomes after enrollment*

!!! A UUID will be generated for each patient along with a summary including a barcode – **print this summary and place it in the patient's hospital notes or record it in the EMR** - this will be the only link between the UUID and the patient

C. Patient Data

Date of birth (DOB) YYYY-MM-DD, the international standard date notation is to be used

Post/Zip code: Unknown postcode - insert '00000'

D. Baseline Assessment

Date Refers to the date **you are best able to complete all the requested findings. If EUA is required for accurate IOP measurements then correct date is EUA data.** **Vision within 3 weeks of EUA is valid.**

YYYY-MM-DD, the international standard date notation is used

Diagnosis As per CGRN classification (Appendix C)

IOP **Record the IOPs (average of 3) that you have taken and feel are the most accurate** (i.e., calm, relaxed child without a speculum and prior to dilation).

Do not record the referring doctor's IOPs.

Medications – must be documented with IOP – remember to record combination drops as 2 meds

E. Management Record all of your management actions from the time you meet the patient:

medical treatment: including the commencement or addition of meds prior to surgery (combo drops = 2 meds)

any laser or surgical procedures (glaucoma or non glaucoma related) as they occur

any complication including any surgery if necessary

F. Outcome [Record 6,12,18 month review (1 month)] **Measurements by "reliable referring doctor" allowed.**

Regarding IOP control - your assessment of IOP control is determined not just be the pressure but by the whole clinical scenario taking into account optic disc appearance, corneal diameter, axial length, refraction, visual field stability etc. Regarding medications, remember to record combination drops as 2 meds.

G. Miscellaneous

If entering data, moving to another page on the website may result in loss of data.

Data does not have to be entered in chronological order.

If you are having problems completing the dataset, please contact Tami Frank tf.glf@charter.net or

Jamie Neil at jamie.neil@openeyes.org.uk