Data Definition for Retinoblastoma Registry
Version date Nov 5 2008

| Section | Domain | No | Data elements or Variables | Data Definition | Core data? |
|---|---|---|---|---|---|
| 1 | Identifier | 1. | Patient Name | | Yes |
| | | 2. | IC number * | MyKid | Yes (must fill) |
| | | 3. | Other identifying document # * | | Yes |
| | | 4. | Address | Only postcode, town/city and state are required<br>Must fill for state | Yes, (must fill for state ) |
| | | 5. | Contact numbers | Either home, office or hand phone number | No |
| | Demographics | 6. | Date of birth / Age * | Date of birth (auto from MyKid)<br>Age (auto-calculated) | Yes (must fill) Pop up massage if more than 20 years) |
| | | 7. | Gender | | Yes(must fill) |
| | | 8. | Ethnic* | | Yes(must fill) |
| 2 | Ocular history and presentation | 9. | Age of onset | | Yes |
| | | 10. | Duration of disease | | Yes |
| | | 11. | Eye affected * | • Right eye<br>• Left eye<br>• Both eyes | Yes (must fill) |
| | | 12. | Family history | • Yes<br>• No | Yes |
| | | 13. | Vision – unaided<br>With glasses/ pin hole | Pull down from 6/6 to NPL | Yes (must fill at least one vision- either unaided or with glasses/pin hole) |
| 3 | | 14. | Refer to tertiary centre* | No<br>Yes, If yes, hospital name | Yes (must fill) |
| 4 | Investigations and Classification | 15. | CT Scan | No- not done<br>Yes - done<br>If yes, state imaging findings:<br>Presence of mass<br>Presence of calcification | Yes |

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|---|---|---|---|---|---|
| | | | | Extraocular extension to<br>- Optic pathway<br>- Orbit & adnexa<br>- Intracranial | |
| | | 16. | MRI | No- not done<br>Yes- done<br>If yes, state imaging findings:<br><br>Presence of mass<br>Presence of calcification<br>Extraocular extension to<br>- Optic pathway<br>- Orbit & adnexa<br>- Intracranial | Yes |
| | | 17. | Genetic testing (blood) | No- not done<br>Ye- , done<br>If yes, state positive or negative | Yes |
| | | 18. | Classification * | Based on International Intraocular Retinoblastoma Classification (IIRC) (see attachment below)<br>• Group A/B/C/D/E for each affected eye- | Yes |
| 5 | Management<br>( to be filled after 3 months of clinical presentation) | 19. | Chemotherapy | No- not done<br>Ye- done<br><br>If yes,<br>• systemic -state how many cycles<br>• local - either subtenon or intravitreal injection, state how many times of local injection for each affected eye | Yes |
| | | 20. | Enucleation | Yes /No for each affected eye<br>If yes, state HPE result of enucleated eye:<br>• Intraocular- confined to the globe<br>• Extension - Extension outside the globe<br>• If Extension outside the globe , state extend of extension :<br>▪ Lamina cribrosa<br>▪ Bruch's membrane<br>▪ Superficial choroids<br>▪ Deep choroids<br>▪ Sclera<br>▪ Optic nerve end | Yes |
| | | 21. | Focal therapy: | Yes /No for each affected eye | Yes |
| | | 22. | Radiotherapy | Yes /No for each affected eye<br>If yes, state<br>• External beam radiation (EBRT)-<br>• intensity modulated radiotherapy (IMRT)<br>• Plaque brachytherapy | Yes |
| | | 23. | Traditional complimentary medicine | Tick if patient refused conventional therapy and decide for Traditional complimentary medicine | No |
| 6 | Outcome and complications<br>( to be filled after 1 year of clinical presentation) | 24. | Vision after 1 year | • Vision pull down for affected eye or eyes | Yes |
| | | 25. | Remission | State status of response to treatment in affected eye (s)<br>Either:<br>• No regression -means no response to treatment<br>• Complete - complete remission | Yes |

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|---|---|---|---|---|---|
| | | | | • Partial regression<br>o If partial, type of regression:<br>▪ Flat scar<br>▪ calcification/<br>▪ fish-flesh/<br>▪ mixed | |
| | | 26. | Recurrence | Yes /No for each affected eye<br>If yes, duration from first treatment in months | Yes |
| | | 27. | Complications | Yes /No for each affected eye<br>If yes, complication related to:<br>• Socket/ prosthesis related, specify<br>• Chemo related- specify<br>• Radiation related, specify<br>• Disease related- specify | Yes |
| | | 28. | Los to follow up* | Yes /No | Yes (must fill) |

The International Retinoblastoma Classification
(Based on the natural history of intraocular retinoblastoma and consensus of appropriate therapies for stages of disease)

**Table 50.3 International Intraocular Retinoblastoma Classification**

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|---|
| **Group A**<br>Small intraretinal tumors away from foveola and disc<br>All tumors 3 mm or smaller in greatest dimension, confined to the retina *and*<br>All tumors located further than 3 mm from the foveola and 1.5 mm from the optic disc |
| **Group B**<br>All remaining discrete tumors confined to the retina<br>All tumors confined to the retina not in Group A<br>Any tumor-associated subretinal fluid less than 3 mm from the tumor with no subretinal seeding |
| **Group C**<br>Discrete local disease with minimal subretinal or vitreous seeding<br>Tumor(s) discrete<br>Subretinal fluid, present or past, without seeding, involving up to 1/4 retina<br>Local subretinal seeding, present or past, less than 3 mm (2 DD) from the tumor<br>Local fine vitreous seeding close to discrete tumor |
| **Group D**<br>Diffuse disease with significant vitreous or subretinal seeding<br>Tumor(s) may be massive or diffuse<br>Subretinal fluid, present or past, without seeding, involving up to total retinal detachment<br>Diffuse subretinal seeding, present or past, may include subretinal plaques or tumor nodules<br>Diffuse or massive vitreous disease may include "greasy" seeds or avascular tumor masses |
| **Group E**<br>Presence of any one or more of these poor prognosis features<br>Tumor touching the lens<br>Neovascular glaucoma<br>Tumor anterior to anterior vitreous face involving ciliary body or anterior segment<br>Diffuse infiltrating retinoblastoma<br>Opaque media from hemorrhage<br>Tumor necrosis with aseptic orbital cellulitis<br>Phthisis bulbi |

# International Intraocular Retinoblastoma Classification (IIRC)