Macular Hole Data Set

Introduction

A data set comprises a set of defined variables representing clinical information about a patient with a given condition. Datasets already exist for cataract, macular degeneration, and retinal detachment. Collection of agreed datasets allows comparison of outcomes across different platforms, including paper notes, proprietary electronic patient records and open source databases. The benefits of this approach have already been seen in the national cataract dataset.

This document describes a proposed data set for macular hole surgery. The data set has been composed by a subcommittee of the Royal College of Ophthalmologists Informatics and Audit Sub-committee, comprising a representative selection of experts in vitreoretinal surgery working in different healthcare environments across the UK. The authors have a great deal of experience not only in the management of macular holes, but also in audit, electronic data collection, and research. The British and Eire Association of Vitreoretinal Surgeons (BEAVRS) gave their input through the BEAVRS Board, and were closely involved in drawing up the dataset.

Application

The purpose of this data set is to represent an agreed set of clinical information which can be collected on patients with macular holes. As well as defining the items to be collected, the data set also describes the format for each item. The data set can be used as a basis for clinical care, outcome analysis, clinical audit, revalidation, and research. Common use of the data set will ensure that information collected by different clinicians, using different paper or electronic systems in different locations, is easily transferable, and can therefore form the basis of large, anonymised databases for audit and outcomes research. Each data item is colour coded according to the following scheme;

Category	
Revalidation	Required for revalidation purposes
Mandatory	Data items which are essential for all applications, and must be collected
Optional	Data items which are required for some applications, and may be collected

NB The revalidation fields are advisory only. The selection of data for revalidation is determined by the RCOphth. However, it is likely that the data in the red fields will be sufficient for revalidation.

Scope

This dataset applies to idiopathic full thickness macular holes only. This excludes Stage 1 holes without a full thickness retinal defect. Macular hole surgery includes the use of injectable drugs, such as ocriplasmin, and is not limited to vitrectomy.

The following types of macular hole are also excluded:

- Traumatic macular hole, arising from direct physical trauma or laser exposure
- Macular hole associated with rhegmatogenous or tractional retinal detachment
- Macular hole associated with high myopia and foveoschisis
- Macular hole following vitrectomy for retinal detachment or other indication

Principles

The data set is designed to comply with the following principles

1. The data set should be a subset of information routinely collected

   The intention is not to burden already busy clinicians with additional work, so the data set should be constructed of items that are, or should be, recorded as part of the routine clinical management of the patient.

2. Items not required for likely analysis should be excluded

   The collection of data requires time and effort, and therefore the total number of items should be kept to a minimum. The range of analyses likely to be conducted on the data is largely predictable, and items not required for these analyses should be excluded.

3. Items in common with other College data sets should be congruent

A number of data items (for example visual acuity, IOP) will be common to other ophthalmic data sets. It makes sense to ensure that only one definition for each item is used throughout all data sets, particularly within a subspecialty. This dataset is therefore closely related to the existing retinal detachment dataset.

4. The data set should be capable of implementation in an electronic patient record

It is likely that the maximum benefit of the data set will only be achieved when information is being routinely collected using electronic patient record systems. It is therefore essential that it is capable of being implemented electronically.

Data types

Each item of the data set has a data type, from the list below. These correspond to data types available in most relational database management systems (RDMS), which generally form the core of EPR systems.

Type	Description
NULL	A special entity representing an uncertain or unassigned value
INTEGER	An integer value, normally unsigned (i.e. zero or positive values
FLOAT	A floating point value, positive or negative
BOOL	A value representing true or false
STRING	A value containing text (alphanumeric data) of unspecified length
ENUM	A value which represents one of a limited range of values
DATE	A value representing a date
DATETIME	A value representing a date and time

Macular hole surgery dataset

Item	Description	Values/format
Patient ID	An identifier which will uniquely identify the patient. In England and Wales this could be the NHS number. This would be removed in anonymised data sets	INTEGER
Age	The age of the patient in years at the time of presentation. Age provides sufficient information for scientific analysis, without also being patient identifiable data (PID), unlike date of birth	INTEGER
Sex	The patient's gender	ENUM (Male, Female)
Consultant	Identifier for consultant in charge of patient (to allow individual audits)	INTEGER
Ethnic category	The ethnicity of the patient using the classification used for the 2011 census[3]	ENUM (British, Irish, Any other White background, White and Black Caribbean, White and Black African, White and Asian, Any other mixed background, Indian, Pakistani, Bangladeshi, Any other Asian background, Caribbean, African, Any other Black background, Chinese, Any other ethnic

Item	Description	Values/format
Route of referral	Route by which patient arrived in the ophthalmic department, based on who made the initial diagnosis (e.g. if an Optometrist sends a patient via the GP with a suspected diagnosis of RRD, this item would have a value of 'Optometrist')	ENUM (Optometrist, GP, Ophthalmologist from other Trust, Ophthalmologist from same Trust, Ophthalmic A&E, New diagnosis in clinic, Other)

Initial assessment

Item	Description	Values/format
Assessment date	Date of this assessment	DATE
Blurred vision	Symptoms of blurred vision present	BOOL
Metamorphopsia	Symptoms of distortion present	BOOL
Date of onset of symptoms	Date when patient first noticed any symptoms, or NULL if no symptoms	DATE* or NULL
Eye laterality	Affected eye	ENUM (Right, Left)
Refraction	Refractive error as spherical equivalent	FLOAT
Prior refraction	Estimated refractive error prior to any form of refractive surgery (LASIK, cataract	ENUM (Myopia, Emmetropia, Hypermetropia)
Assessment Acuity	Best recorded acuity	Visual acuity*

Item	Description	Values/format
Lens	Status of lens of eye. (Phakic - cataract is defined as a lens opacity sufficient to warrant lens surgery at the same operation)	ENUM (Phakic, Phakic cataract, Aphakic, Aphakic Soemmerring ring, PC IOL, AC IOL, Phakic IOL, Angle supported IOL, Iris clip IOL)
Date of cataract surgery	If pseudophakic or aphakic, date of cataract surgery	DATE* or NULL
IOP	Intraocular pressure in mmHg	INTEGER
Vitreous	Attached or detached on clinical examination. (definition of PVD is at the discretion of examining ophthalmologist)	ENUM (Uncertain, PVD, No PVD, Vitrectomised eye)
Macular hole stage	Gass staging	ENUM (Stage 1,2,3, or 4)
Stage 2 Full thickness macular hole, <400□ diameter, Posterior vitreous attached.	Stage 3 Full thickness macular hole, operculum may be seen. Posterior vitreous attached, >400□ diameter.	Stage 4 Full thickness macular hole, >400□ diameter. Complete posterior vitreous detachment.
Vitreo foveal attachment	Attachment of vitreous to fovea	ENUM (attached with traction on fovea, detached from fovea, complete posterior vitreous detachment)
Internal Hole diameter	Maximum hole diameter at narrowest point (see diagram at end)	INTEGER
Basal Hole diameter	Maximum hole diameter at RPE photoreceptor junction (see diagram at end)	INTEGER
Ocriplasmin used		BOOL
Date of ocriplasmin injection		DATE* or NULL

Operation note

Common elements

Item	Description	Values/format
Admission type	Type of admission	ENUM (Outpatient, Day case, Inpatient)
Date and time	Date of surgery	DATE
Surgeon	Identifier for primary surgeon (to allow individual audits)	INTEGER
Surgeon grade	Grade of primary surgeon	ENUM (Consultant, Fellow, Specialist registrar, Associate specialist, Clinical
Anaesthetic	Type of anaesthetic	ENUM (Topical, Peribulbar, Subtenon, General)
Antisepsis	Preparation of eye prior to surgery	ENUM (Chlorhexidine, Povidone iodine, Other)

Surgery note

Item	Description	Values/format
Lens surgery	Phacoemulsifcation or lensectomy	ENUM (None, Phacoemulsification, Lensectomy)
IOL	Insertion of IOL	ENUM (None, AC IOL, Iris clip IOL, PC IOL rigid, PC IOL foldable)
IOL power		FLOAT

Intended final spherical error		FLOAT
Cataract surgery complications		ENUM (from list of complications in national cataract dataset)
Primary capsulotomy	Posterior capsulotomy carried out during vitrectomy	BOOL
Gauge	Gauge of vitrectomy system	ENUM (20g, 23g, 25g)
Sclerostomies sutured	Number of sclerostomies sutured	INTEGER
Induction of PVD	The creation of a PVD during surgery	BOOL
ILM Peel	Peeling of internal limiting membrane (complete ILM peel is 360 degrees)	ENUM (None, Incomplete, Complete)
ERM peel		BOOL
Triamcinolone	Use of triamcinolone to enhance visualisation during vitrectomy	BOOL
ILM stain 1		ENUM (None, Brilliant blue, Membrane Blue, ICG, Other)
ILM stain 2		ENUM (None, Brilliant blue, Membrane Blue, ICG, Other)
Comorbidity	Concurrent pathology with the potential to compromise central vision	ENUM (AMD, RVO, DMO, Amblyopia, Optic neuropathy, Other)

Breaks in attached retina	Number of breaks found in retina	INTEGER
Size of largest break	Size of largest retinal break in clock hours	ENUM (0.5, 1 - 12)
Position of lowest break	Position of most inferior break in detached retina in clock hours	ENUM (1 - 12)
Retinal detachment	Visible elevation of retina during surgery	BOOL
Cryotherapy	Cryotherapy used for retinopexy	BOOL
Endolaser	Endolaser used for retinopexy	BOOL
Indirect laser	Indirect laser used for retinopexy	BOOL
Trans scleral diode	Trans scleral diode used for retinopexy	BOOL

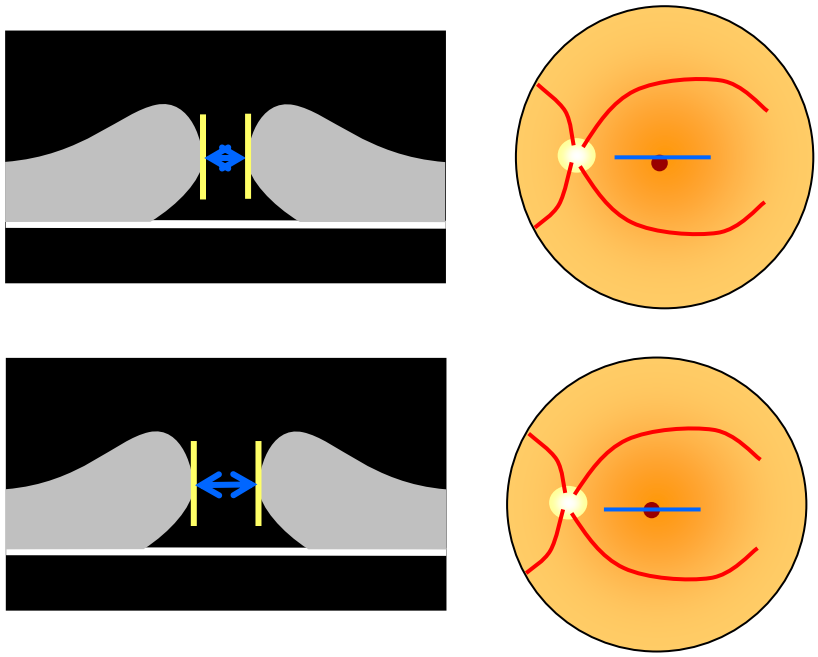
Item	Description	Values/format
Lens touch		BOOL
Choroidal haemorrhage		BOOL
Positioning instructions	Posturing instructions. Log roll is defined as a sequence of posturing positions intended to displace sub retinal fluid away from the macula	ENUM (None, Prone, Not supine, Sitting, One cheek, Alternate cheeks, Other)
Posturing duration	Number of days posturing to be maintained (No. of hours expressed as fraction of days e.g. 6 hours = 0.25)	FLOAT
Tamponade	Type of tamponade agent	ENUM (None, Air, SF6, C2F6, C3F8, 1000cS oil, 2000cS oil, 5000cS oil, Densiron, Oxane-HD)
Percent	Gas concentration used in percent	INTEGER

Outcome

Item	Description	Values/format
Date	Date of visit	DATE
Type	Discharge or ongoing follow up	ENUM (Discharge, Ongoing)
Readmission	Readmission within 28 days	BOOL
Number of operations	Total number of operations for macular hole	INTEGER
Re-do tamponade	Type of tamponade agent	ENUM (None, Air, SF6, C2F6, C3F8, 1000cS oil, 2000cS oil, 5000cS oil, Densiron, Oxane-HD)
Re-do percent	Gas concentration used in percent	INTEGER
Re-do Positioning instructions	Posturing instructions.	ENUM (None, Prone, Not supine, Sitting, One cheek, Alternate cheeks, Other)
Re-do posturing duration	Number of days posturing to be maintained (may need to clarify no. of hours per day)	INTEGER
Ocriplasmin hole closure	Closed outer retina on OCT, after one injection	ENUM (Closed, Open & elevated, Open & flat)
Primary hole closure	Closed outer retina on OCT, after one operation	ENUM (Closed, Open & elevated, Open & flat)
Final hole closure	Closed outer retina on OCT, after one or more operations	ENUM (Closed, Open & elevated, Open & flat)
Oil	Silicone oil tamponade present	BOOL
Acuity	Visual acuity	Visual acuity*
Final refraction	Spherical equivalent	FLOAT
Retinal detachment	Rhegmatogenous RD following macular hole surgery	BOOL

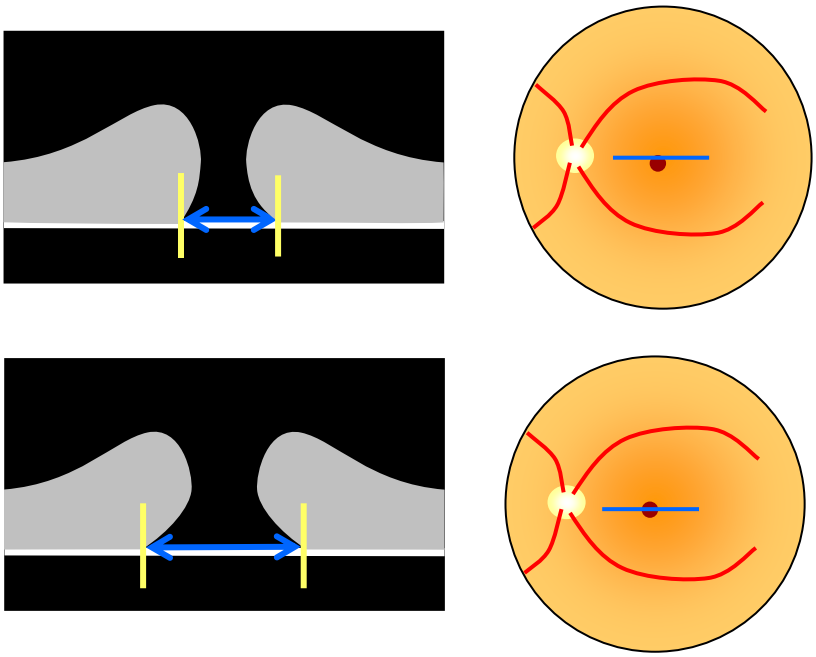
Cataract	Cataract sufficient to reduce visual acuity	BOOL
Late cataract complications	Include optic capture or displacement, PC opacity, corneal oedema etc.	STRING
Post-op refraction	Spherical equivalent	FLOAT
IOP problem	IOP requiring either monitoring or treatment in an eye that had neither pre-operatively	BOOL
CMO	Cystoid macular oedema requiring treatment following hole closure	BOOL

Maximum linear diameter



The measurement is taken from the section with the widest diameter. The hole should be measured at its narrowest point, where the sides are nearly parallel. This makes the measurement more reproducible, as small variations in the position of the callipers will have little effect on the width.

Basal hole diameter



The hole is measured at the widest point. The measurement is taken where the outer retina meets the retinal pigment epithelium as shown.

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