INSTRUCTION BOOKLET

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Only Family information sheet and report form are included somewhere else in the thesis.

INSTRUCTIONS TO NURSES

A) Preparation for the Out-Reach

1) Informing the kitchen about the date of outreach.
2) Preparing the drops and checking if they require replacement (e.g. out of date or being open for more than a month, or the amount in the bottles are not enough.
3) Inform driver and check that car is full of petrol.

B) The morning of the out-reach

Get the CSSD box
Take equipments to the van
Collect cases from the BSS Office
Collect items from the kitchen

C) Nurse assisting in the Field Work

1) When helping the doctor

a) Bringing the patients to the examination room and looking after him or her.
b) Standing nearby the patient during examination. This is important, as they are usually nervous and anxious.
c) Putting drops when required.
d) Filling information regarding photographs taken.

2) Assisting in visual acuity checking SEE PROTOCOL PAGE

3) Assisting in the colour vision protocol SEE PROTOCOL PAGE

4) Helping in filling the questionnaire & the Family Information Sheet SEE PROTOCOL PAGE

5) Helping in drawing he genealogy tree SEE PROTOCOL PAGE

D) Dealing with patients in the out patient clinic

1) Dealing with families arriving at the hospital

a) Preparing their hospital card & the study protocol in advance. Receiving the families.
b) Approaching Dr.Jalili for instructions except when they already have a list of instructions. In this case they should be taken for various tests in the order written in the instruction notes, e.g. the orthoptist, etc.
c) Instilling the drops should be done by the nurse to avoid unnecessary delays.

d) Arrange for photography and fundus fluorescein angiography if needed.
e) Helping the research assistant in filling the family questionnaire and genealogy tree.
f) To co-ordinate with the secretary/research assistant.

INSTRUCTIONS TO SECRETARIES

A) PREPARATION FOR THE FIELD WORK

1) To ensure smooth running of the above preparation for the field work.
2) To ensure all communications are completed such as contacting the families, schools, and all people concerned.
3) Informing all parties concerned in the hospital about the date of the outreach and the number requiring food.
4) To ensure that there is sufficient stationery in the files by routine checking of files weekly especially the various forms used for recording the data.
5) Check the first available operating list for patients having examination under anaesthaesia and other procedures (from out-patient sister)

B) ON THE DAY OF THE OUT-REACH

1) To ensure that all equipment is taken to the van.
2) The stationery and files are her own responsibility to take to the van.

C) AT THE FIELD

1) Concentrating on family questionnaire and genealogy information.
2) Helping nurses in the other duties as above and in the abscence of a nurse taking over the duties mentioned above.

ARRANGEMENT FOR PATIENTS REQUIRE E.U.A OR FURTHER OUT-PATIENT ASSESSMENT:

1) Take a consent form signed by the father or mother.
2) Write patient(s) name and number on SJOH prescription form in 4 copies using carbon paper.
3) Let IJ write details of procedures required including any out-patient examination and assessment.
4) Patients for EUA :

   1 copy to the out-patient sister (ensure that the Family Name and study number is recorded in the out-patient's waiting list diary).

1 copy for the protocol form.
1 copy for the diary.
1 copy for the hospital card (notes).

5) Patients for assessment in the out-patient clinic :

1 copy for the protocol form.
1 copy for the diary.
1 copy for the hospital card (notes).
1 copy for the orthoptist.

6) Please don't over-book.
Choose a short list.
Make sure there are not many cases for GA (general anaesthaesia) on that operating session.

PATIENTS COMING FOR EUA / OUT-PATIENT ASSESSMENT

1) The Day Before
Get the study protocol and give it to IJ the day before
Prepare a patient examination form and add it to the protocol and give it a study number.

2) The Day of Surgery:
Complete any deficiencies in the family information sheet and the genealogy tree.

CARDS TAKEN FROM THE RECORDS

1) Write their numbers in duplicate, one copy for the Records Department and keep one in the BSS office.
2) Cards should be dealt with quickly and returned to the Records.
3) Remember to cross out the name and the number from both lists when cards are returned.

FILING THE PROTOCOL FORMS

- When completed show to IJ.
- Place the family information sheet FIS on the top followed by the patient(s) examination form
- Ask IJ to classify it if this has not already been done.
- File in the appropriate file (see section on filing)
- Never send the family home unless you clarify with IJ.

DEALING WITH FILMS TAKEN BY FUNDUS AND ORDINARY CAMERA

- Write the film number (#) in the two spaces (see below).
- Remove the adhesive backing from the top part of the label.

- Stick the top part on the film cartridge.
- Write the patient's card number in the prepared space only when dealing with the fundus colour photographs and FFA.

FILM NUMBERING

1) F1 BOBY

- Before October 1986

F/ then the film number as written on the film-recording sheet.
e.g F / B (Alphabetic in capitals are used)

- After October 1986

F1/ then the film number as written on the film-recording sheet.
e.g F1/A

2) T90 BODY

T90/ then the film number as written on the film-recording sheet.
e.g T90 / G = using T90 camera body. (Alphabetic in capitals are used)

3) Fundus photographs with colour films

F1/ 1.2.86 i.e film number 1 taken on the 1.2.86

4) FFA (Fundus Fluorescein Angiography)

FFA 1/ 1.2.86 i.e film number 1 taken on that date.

5) KOWA Fundus Camera

KW/1 etc. (use numbers)
Place a label indicating the film number, patient(s) numbers to be returned to us with the processed film.

FAMILY INFORMATION SHEET

SECTION A

1- FATHER'S HAMOULA If there is no Hamoula put a cross in the box
Est.#: Put an estimated number of the members

2- FATHER'S FAMILY
Est.#: Put an estimated number of the members

3- MOTHER'S HAMOULA If there is no Hamoula put a cross in box

4- MOTHER'S FAMILY
Est #: Put an estemated number of the members

In case there is more than one wife use a separate form. Don't mix the sibs

5- FATHER'S I.D # However if the patient has his own I.D card, then put this number.

6- RELIGION/SECT Such as Latin, Orthodox, etc.

7- CURRENT ADDRESS IN DETAIL AND TELEPHONE NUMBER (or the number of the
the nearest telephone.
Estimated number of population in the village or town.

SECTION B

1- FULL NAMES
a. The quadruple name of the father
b. The quadruple name of the mother
c. First names of sibs (Should any of the sibs have a family write the information on a separate form.
- in sequence according to age
- include any miscarriage (28 weeks) or abortion (after 28 weeks) and include period of pregnancy.

2. D.O.B (D/M/Y)
a. Father's Date of birth/ mention the day/month/year
b. Mother's Date of birth/ mention the day/month/year.
c. Sibs, also put the year of miscarriage
d. Deaths: put the year (and cause of death)

SEX
Include the sib's sex following the age in the special box.

3- DEGREE OF CONSANGUINITY See Diagram

of the :
- a. Parents
- b. GPp — the father's grand parents
- c. GPm — the mother's grand parents
- d. GGPp 1 — the father's father parents
- e. GGPp 2 — the father's mother parents
- f. GGPm 1 — the mother's father parents
- g. GGPm 2 — the mother's mother parents

The following abbreviations indicate;

C1 = 1st cousins,
C2 = 2nd cousins and so on.
C1Å = first cousin once removed, and so on
p = Paternal, (related to the father)
m = Maternal, (related to the mother)
SF = Same family
SH = Same Hamoula (if tribal mention which tribe or branch of a tribe.
ST = Same Town
SV = Same village
NV/T = Nearby village/town
DA = Distant area.
OC = Other country.
? = Unknown

4- PLACE OF ORIGIN & Population
a. the father
b. the mother

- Mention the distant origin of family(s), when left and the various places of residence over the years.
- When left the various places.
- Write the name(s) of village(s) and nearby town(s).
- Ask an estimate of population in that village if applicable.

5- JOB /EDUCATION of the
a. the father
b. the mother

- Mention the years in school
- Any certificates, degrees, and qualifications
- Present job and if unemployed previous ones.
- Mother: put housewife (H/W) if not employed.

6- OPHTHALMIC HISTORY (and SJOH # if applicable)

Any ocular condition, blindness, glasses, operations, night/day vision and preferences, photophobia (tolerance to light), small/big eyes, colour vision, etc. [Including onset and progression with dates]

of a- the mother b- the father c-all the sibs (sons and daughters) and 4a- any other relative.

7- MEDICAL HISTORY (including GYNAECOLOGICAL HISTORY OF THE MOTHER) AND ANY DENTAL PROBLEM

Any systemic disorder and disability, cardio-vascular disease (heart, blood pressure), neurological disorder, diabetes, kidney disorders and gynae-cological problems in women (in the past & present including any drugs taken & any allergies).

DENTAL HISTORY
also includes milk teeth, permanent teeth, and any problem in dentition.

of a- the mother b- the father c- all the sibs (sons and daughters) and 4b- any other relative

8- GENETIC HISTORY

Any congenital defects), deaf/ dumb, mental retardation/abnormality, (teeth abnormalities), hair colour, behaviour and language disorders, extra digits (hands & feet), abnormal faces & ears, hare lip abnormal chest shape etc.

of a- the mother b- the father c- all the sibs (sons and daughters) and 4c-Any other relative

9- INSTITUTE / SCHOOL / WORK

Where the patient studies and work

10- MARRIED ? (WIFE, SIBS ETC.)

- Unaffected individuals with unaffected sibs: write briefly the number of sibs and indicate them clearly in the family tree (including the wife).

- Affected members or unaffected members with affected sibs: use a separate form.

SECTION C (FAMILY HISTORY)

PD.C Ref.# = (pedigree chart reference number)

The reference number on the family tree which should include the generation number and the sequence number of the individual on the tree e.g VI 12 = individual # 12 in the seventh generation.

1- FULL NAME AND SJOH #

2- AGE Approximate age will suffice and SEX

3- RELATION TO THE PATIENT(S)

4- RELEVANT INFORMATION SEE 6, 7, & 8 for the questions

a) Ophthalmic (& onset)
b) Medical
c) Genetic

PENDINGS

Anything that requires sorting out.

SECION D PRENATAL /PERINATAL / POST NATAL HISTORY
(including miscarriages/abortions)

1- PRENATAL HISTORY (PREGNANCY)

Infections/viral illness (e.g German measles, any fever), drugs (any), x-rays (especially 1st 3 months (times, part(s) exposed), trauma, Toxaemia of pregnancy (high BP, oedema, protein in urine, fits), diabetes & length. Any medical supervision including blood tests e.g Hb., Rhesus incompatability.

2- PERINATAL HISTORY (DELIVERY) :

Nature of delivery,(normal, suction, forceps, Caesarean), duration, baby's colour & weight, Oxygen given & duration. Hospital / home delivery?

3- POST NATAL HISTORY

Health of baby, drugs given? Oxygen given? and for how long? Immediately, neonatal & any time afterward.
Diet (type), vitamins.

SECTION E (INTELLIGENCE, SCHOOL MARKS)

SUBJECTS (depending on the year and school)

Arabic Language, English Language, Science, Maths, Sociology, History Religious Studies, Music, Handicrafts, Arts, Sports, Home economics,

Average Art subj. Average Science, Average all subj. = average marks

ADDITONAL INFORMATION:
Any point you or the patients or their relatives wish to add.

NAME OF PERSON(S) FROM WHOM INFORMATION IS TAKEN AND THEIR RELATIONSHIP TO PATIENT(S) such as the parents, an uncle etc. AND HOW CO-OPERATIVE / INTELLIGENT ARE THEY

NAME & POSITION OF PERSON FILLING THIS FORM

DATE OF THE INTERVIEW WITH THE FAMILY

PENDINGS: Any further work required to be done in any aspect of this family.

PROTOCOL FOR GENETIC STUDIES [instructions]

* PLEASE ASK THE QUESTIONS IN THE FAMILY INFORMATION SHEET WHEN YOU COME ACROSS AN AFFECTED MEMBER.

ALSO emphasis on the following points throughout the work on the pedigree tree including those who marry into the family in question:

NAME: HAMOULA, FAMILY NAME, TRIBE? (if any)

AREA OF ORIGIN: & WHEN LEFT

AREA OF RESIDENCE: HOW LONG

GENETIC ANOMALY EMPHASIS ON THE PRESENCE OF ANY GENETIC ANOMALY

IN EACH GENERATION

- START from the family in question (the patints and their parents), then ascend through the older generations. When the furthest generation is reached, start descending down through the various branches of the family.

- When you draw the family tree: Don't mix between generations/ each on a line with a wide space between them.

- Write AGE RANGE in each generation especially the first ancestor. If deceased; mention approximate age the estimate year of of death.

- In the non-important sections of the enlarged family, just put the number of females and males in a circle or box according to the sex.

- Don't forget to put a footnote explaining each symbol used and details of the problem or condition.

- Patients with different conditions should have different symbols (new symblol for each).

- Patients with conditions thought to be similar but who have not been seen indicate by a separate consistent symbol.

- Start from left to write, in temporal sequence including any miscarriages, abortions and stillbirths.

WOMEN

- Exact ORIGIN OF WOMEN MARRIED into the family. HAMOULA, FAMILY, AREA ETC

- Enquire if any of her ancestors married into or from the family in question

MAKE SURE THAT ANY NAME OF ANY DIFFERENT FAMILY GIVEN IS NOT SIMPLY A ALTERNATIVE NAME OF THE SAME FAMILY OR A BRANCH OF IT.

CHECK WHETHER ANY DIFFERENT FAMILY GIVEN IS FROM THE SAME OR FROM A DIFFERENT HAMOULA

STUDY CAREFULLY THE ENCLOSED SYMBOLS USED IN DRAWING THE FAMILY TREE

VISUAL ASSESSMENT PROTOCOLE

The following methods of assessing the VA are used depending on the age:

1) Sheridan Gardiner from age of 3 upwards (3 books) with accessories
2) 100s and 1000s for the first year of life.
3) Snellen's chart (the Å size) at 3 meters for those who could read English letters.
4) Kays pictures with the photostatic copies of the pictures. For patients given appointments for follow up in the hospital, give a spare copy of the pictures to the child to practice with at home.

5) Near vision reading charts (in English)

<u>Instructions on doing the Sheridan Gardiner test:</u>

A) DISTANT VISION (Write on page 2 of the Patient's Examination Sheet)

- Check vision unaided at first.
- Check it again with the appropriate correction (if any).
- Always re-examine aphakic with the +10 d glasses or the appropriate correction (if any).
- If there is an increase in nystagmus on dissociation (covering one eye) then check vision with both eyes open.
- Use Sheridan-Gardiner as a standard at 6 meters especially with those who do not read ordinary letters or illiterate.
- Children under 2 yrs ue 100s & 1000s.
- ALWAYS keep the light source behind the patient i.e light projected on the chart or hand.
- A common mistake when a PL is interpreted as HM when the hand moves between the patient and a light source.

<u>PATIENT WITH CONE DYSFUNCTION:</u>

- Check vision indoor (not very bright) and compare with vision outdoor.

- Use the red glasses available outdoors and compare the degree of comfort with and without. Ask older patients how much more comfortable as (a percentage and do they feel that it is worth while to have a pair provided for a permanent pair - Look at the eyes in the sun with out and with the glasses and observe if the patient start opening them behind the glasses.

B) NEAR VISION

- Use the Sheridan-Gardiner book for near vision for this purpose.
- Keep the book at 1/3 meter from the patient.

- Ensure good illumination on the plates.

- Start from the largest plate.
- When reaching a plate too small for the patient to read, give them the available hand magnifier hand magnifier to hold near the print.

- Patients cannot read the largest plate, use the standard near vision in English and use the large letters on the plate made especially for this purpose.

COLOUR VISUAL ASSESSMENT PROTOCOL

- Do the test nearby a window as a natural source of light but avoid excessive light especially in patients with cone disorders

- Use the appropriate protocol forms.

- DO NOT ALLOW THE PATIENT TO TOUCH THE PLATES; NEITHER SHOULD THE EXAMINER TOUCH THEM.

- Men doing the test should be tested for colour deficiency.

ISHIHARA

- The first plate (No.12) is not included in the score and it only shows contrast.

- Start from the left of the book and as most patients do not read the English form of Arabic numbers and rely only on Braille, ask them to draw the number and proceed accordingly

- If you find difficulty in this, rely on the plates at the back of the book (the lines).

CITY UNIVERSITY

- Test each eye separately then both eyes together unless instructed otherwise.
- The small dots are difficult to be seen by most of the patients in this study because of their macular involvement.

COLOUR PLATES

- Use the plates in each corner on the following pages 1, 5, 9, 13, 17, 21, 25, 29 i.e odd numbered pages but miss ones in between.

- Write the colour given by the patient and compare.

PROTOCOL FOR HISTORY TAKING FOR THE CONE-ROD DISORDERS

ONSET
Age

Progression

PRESENTING SYMPTOMS

	Age noted	Progression	Change in severity (Age)
1-			
2-			
3-			

TOLERENCE TO LIGHT/PHOTOPHOBIA

Preference; shade, indoor [comfort & discomfort]

Desire and like to look at the sun disc or towards any light
or the contrary

Progression/improvement (Age)

NIGHT VISION (any unusual difficulty at night)

Unusual fear of the dark at childhood

Onset

Progression

COLOUR VISION

Has it deteriorated?

Age of onset of colour deterioration

Comparison to other sibs

Name of BSS personnel taking the information:

REGISTRATION BOOK AND CLASSIFICATION

SERIAL NUMBERS

- Start from 1 onward.
- The patients are registered according to the sequence they are being examined.
- If some of the relatives are seen later put their number in the remarks section of the Registration Book. (The Green Book).
- Only those patients who have ocular disorders are to be registered. Others screened are to be entered in the family information sheet and tick the appropriate box.

CLASS# = Classification number

e.g 8 (CO) 11 a - 1

8 = File number [in this case is the file on cone disorders.
(CO) = Abbreviation of the condition for the ease of rememberance.
11 = Family number or Hamoula when both are the same
a = Sub-family number
-1 = Patient number in the classification
M,F = If the patient is the mother or the father of the patient.

Reference numbers of Conditions

1 = Aniridia
2 = Coloboma
3 = Microphthalmia
4 = Congenital Cataract
5 = Congenital glaucoma
6 = Congenital corneal conditions
7 = Keratoconus
8 = Cone disorders
9 = Flecked retina
10 = Pigmentary retinopathy
11 = Leber's congenital amaurosis
12 = Vitreo-Retinopathy
13 = Albinism
14 = Myopia
15 = Psuedogliomas
16 = Congenital nystagmus
17 = Optic nerve disorders
18 = Retinoblastoma
19 = Syndromes
20 = Mental retardation
21 = Unclassified
22 = Undiagnosed
23 = Acquired
24 = Phthisical ofunknown aet.
25 = Trauma
26 = Macular degeneration
27 = Cong.corn.disord.[cancel]
28 = Miscellaneous
29 = Vasculitis
30 = Excluded from the study
31 = Extra digit
32 = Dislocated lens

STUDY SOURCE

The following abbreviations indicate:

BS = Blind school.
BW = Blind training and work centre.
BR = Blind residential home
OP = Out-patients
WL = Waiting list of BS recruits
HO = Home
OT = Others

Schools Abbreviation

A = Ala'iya school
B = Biera school (National Society for the Blind)
G = Gaza school/institute/WL
H = House of Hope
K = Hebron National Society
N = Nablus Noor Institute/school
R = Relative
S = Shuruque
O = Others

REGISTERY BOOK

Please enter data in the following sequence:

DATE - SERIAL # -CLASS.# - NAME – AGE –SEX - SJOH # -INSTITUTE-REMARKS /RELAT

RELIGION

M = Muslim, O = Orthodox, L = Latin, P = Protestant, T = Methodist

APPENDIX 1

LIST OF DROPS AND OTHER PHARMACEUTICAL PREPARATIONS REAUIRED ON EACH BSS FIELD WORK

A) Drops needed:

1) Mydriatics	Cyclopentolate i%, Mydramide 1%, Atropine 1%
2) Miotics	Pilocarpine 2%
3) Lubricants	Methylcellulose 1% (2 bottles)
4) Antibiotics	Chloromyxin drops, Chloromycetine ointments. Terramycin ointment.
5) Anaesthetics	Amethocain 1% drops.

B) Tablets

Diamox, Acamol (Paracetamol)

C) Injections

Diamox.
Few syringes and disposable needles.

D) Others

Disposable bags
Cotton wool
Soft tissues (Kleenex)
Bar of soap
Clean towel
Urine plastic cups

E Diagnostic

N-Multistix.
Blood samples containers

APPENDIX 2

DIAGNOSTIC EQUIPMENT TAKEN

1) OUT-REACH STANDARD EXAMINATION EQUIPMENT

Slit-lamp
Retinoscope
Refraction Set (lenses and trial frame)

2) HOSPITAL OPHTHALMIC EQUIPMENTS

INDIRECT OPHTHALMOSCOPE
Desmares retractors (2)
Calipers

3) MISCELLANEOUS ITEMS

Extension wire
Socket electric adaptor
Generator (when electricity not available)
Others: Clean towel
Bar of soap
Soft tissues (Kleenex)

4) KOWA fundus camera (kept in the operating theatre), ensure there is a spare plug).

5) MEDICINE CASE

PERSONAL OPHTHALMIC EQUIPMENTS

1) OPHTHALMIC CASE

Indirect ophthalmoscope with the rechargeable battery
Ophthalmoscope
Retinoscope
2 rechargeable battery handles
Nikon indirect lenses (20D & 28D)
Fundus diagnostic lenses: Goldmann's fundus lens 3 Mirror lenses (d10 & large), Keratoscope.

2) SYSTEMIC EXAMINATION EQUIPMENT (personal)

Stethoscope
Patellar hammer
Sphygmomanometer

3) CAMERA & ACCESSORIES

CANNON Bodies 2 (F1, T90)
Lenses 200mm MACRO
28 mm
50 mm
Flashguns CANNON 300 TL SPEEDLITE
MACRO RING LITE ML-2
STARBLITZ 1000 AUTO MACRO-LITE
Cannon microscope attachment
Tripods
Blue cotton sheets, 2 (large & small)

APPENDIX 3

VISUAL ASSESSMENT CASE (BOX)

a) Visual acuity

Charts

1) Sheridan Gardiner from age of 3 upwards (3 books) with accessories
   Red, Yellow, Blue books.
2) 100s and 1000s for the first year of life.
3) Snellen's 3 meters
4) Kays pictures with photostatic copies of the pictures
5) Near vision reading chart (in English)

b) Colour vision

1) Ishihara
2) City University
3) Colour atlas
4) Colour contrast book.

c) Others

Occluder
Pin-hole
+ 10D lens (aphakic)
Red glasses
Hand & stand magnifier
OKN tape

d) Visual Field

Targets

APPENDIX 4

STATIONERY & ACCESSORIES REQUIRED TO BE TAKEN IN THE BSS FIELD WORK

The GREEN BOOK (Registration Book)
Secretary diary

The following files:

1) Family Information Sheets.
2) Patient Examination Forms.
3) Patient continuation Forms.
4) Plain papers for the genealogy tree.
5) Questionnaire.
6) Carbon papers.
7) BSS Report Forms.
8) Photograghs records.
9) Colour vision protocol forms.
10) Retina drawing chart.
11) Consent forms.

**) The appropriate file(s) of the family(s) to be studied.

Dr.Jalili's Operating List.
Out-Reach Programme.
On-Call Rota.

Glasses prescriptions book
SJOH drugs prescription books (2)
SJOH patients cards and hospital continuation sheets(cards)
SJOH stationery, papers & envelopes

Pencils, dry ink pens (biros)- black, blue, & red, and colour pencils. Tipex
Eraser and pencil sharpener
Paper clips
Punch
Stapler with spares (one large , one small)
Ruler
Adhesive stickers
Cellotape

Pocket dictaphone & tapes

Spares required

Colour films FUJI 400 (3)
Spare batteries size (R6, 1.5v), 2 packets.
Slit-lamp bulb