1.

1.1 Why Family ART adherence clubs?

1.2 Family ART clubs in brief

1.3 Family ART club outcomes

1.4 Benefits of Family ART clubs

FAMILY ART ADHERENCE CLUBS: AN OVERVIEW

1.1 WHY FAMILY ART CLUBS?

South Africa's National Strategic Plan 2012-2016 targets:

- 90% of children eligible for ART to be initiated and maintained on ART
- Strengthening health services to offer child- and adolescent- friendly HIV service packages including adherence support programmes

Children and young adolescents also require quick simplified access to care and treatment to make it easier to stay on ART while completing their schooling and participating in their family and social lives.

1.2 FAMILY ART CLUBS IN BRIEF

1. Family ART adherence clubs (family clubs) are a long term retention model of care catering for children stable on ART and their caregivers.
2. Not all caregivers have to be ART patients to join a family club but the caregivers that are on ART must be stable on treatment.
3. 15 ART stable children and their caregivers meet once every 2 months.
4. A lay healthcare worker provides:
   - quick clinical assessment
   - referral where necessary
   - peer support and
   - distribution of pre-packed ART.
5. A nurse assesses each child under 40kg and prescribes appropriate ART dose according to their new weight at each club session.
6. Once a year a nurse provides follow up clinical management to caregivers and children >5 years.
7. For children <5 years follow up clinical management happens twice a year.
8. Family clubs support child disclosure

Child disclosure is the process of telling an HIV positive child that he/ she is HIV positive. The process starts with partial disclosure and progresses on to full disclosure. See pg.4 for more information.

FAMILY CLUB STAFF RESPONSIBILITIES

COUNSELLOR/ PEER EDUCATOR RUN

Every 2 months

1. Quick clinical assessment
2. Collection and distribution of 2 month ART supply
3. Quick optimised group support
4. Simplified monitoring

NURSE SUPPORTED

Every 2 months, during family clubs:

1. Write pharmacy script for children <40kg based on quick weight assessment

Once annually for caregivers and children >5 years on ART and twice annually for children <5 years

2. Blood taken for viral load and CD4 monitoring
3. Clinical consultation

1.3 FAMILY CLUB OUTCOMES

Between March 2011 and September 2013, 146 children and 71 caregivers on ART enrolled in family clubs. Overall 136 (93%) children were retained in care, 96 (66%) in family club care, 33 (23%) in clinic care, 7 (5%) transferred out and 10 (7%) were lost to follow up.

Of the children retained in family club care, 100% between 7 and 10 years achieved partial disclosure and 57 (79%) children over the age of 10 years achieved full disclosure. 91 (95%) had suppressed viral loads (<400) in the last 12 months.

No disclosure is when a child does not know that s/he is HIV positive. This is appropriate for small children not yet at school.

Partial disclosure is when a child is told some information about their health and why they take medication, but the word HIV is not used. In Khayelitsha, we encourage caregivers to tell their child that s/he has a germ in their blood and that the medication s/he takes puts the germ to sleep so that it doesn't make the child sick. This is appropriate for children who are between the age of 5 and 9 years.

Full disclosure is the step after partial disclosure. It is when a child is told that s/he is HIV positive and is helped to understand what this means, the need to take ART, disclosure to others and transmission. This is appropriate for children of school-going age and should preferably happen by the age of 10. (See Annexure 2 child disclosure pamphlet)

1.4 BENEFITS OF FAMILY CLUBS

HEALTH FACILITY AND SYSTEM

1. Reduces paediatric patient load in mainstream care
2. Increases available capacity for clinicians to initiate new paediatric patients on ART and manage clinically unstable patients and patients at risk of failing ART
3. Can reduce pharmacy load by utilising central dispensing service for pre-packing caregiver's and older children's ART supply

PATIENT

1. Quick, easy ART access so children have less time off school
2. Child disclosure better supported through shared peer experiences
3. Child and caregiver seen on same date and managed as a family
4. Provides community network for tracing patients not attending their family club
5. Ensures continued access to clinical care and support through appropriate referral mechanism
6. Improves retention in care and virological outcomes

2.

2.1 Family club basics

2.1.1 Family club organogram

2.1.2 Who is eligible to enter a family club?

2.1.3 Family club sessions planning

2.2 Family club planning and set-up in your facility

2.2.1 Ensure buy-in

2.2.2 Family club meeting space

2.2.3 Recruitment

2.2.4 Scheduling of family club dates

2.2.5 How to run family clubs

2.2.5.1 Preparation

2.2.5.2 Running the family club

2.2.5.3 After family club sessions

2.2.5.4 Family club attendance

2.2.5.5 Clinical oversight by family club nurse

2.2.5.6 When are family club patients referred back to mainstream care?

2.2.5.7 Monitoring of family club patients and club outcomes

HOW TO IMPLEMENT FAMILY ART CLUBS IN YOUR FACILITY:
A PRACTICAL GUIDE

2.1 CLUB BASICS

2.1.1 FAMILY CLUB ORGANOGRAM (see ART ADHERENCE CLUB REPORT AND TOOLKIT pg 10)

ROLES & RESPONSIBILITIES

It is very important that the family club facilitator and club nurse have a special interest in children and are capable of creating a child-friendly environment.

CLUBS MANAGER

Nurse responsible for the activities required to run successful ART clubs, including family ART clubs.

see ART ADHERENCE CLUB REPORT AND TOOLKIT

FAMILY CLUBS FACILITATOR

Counsellor/ peer educator responsible for preparing and running the family club sessions.

see ART ADHERENCE CLUB REPORT AND TOOLKIT

Where resources permit 2 club facilitators would be most beneficial. This will allow for separate but concurrent sessions for caregiver and child. One facilitator runs the family club session and discusses child disclosure with caregivers while the other engages children in basic, fun activities, thus creating a child-friendly setting (see Annexure 3).

FAMILY CLUB NURSE

Must be competent to manage children on ART

Assess the weight of each child <40kgs in order to prescribe appropriate ART dose at each club session.

See symptomatic patients during or after club session

Conduct annual blood taking and clinical consultation visits for adults and children over 5 years.

Conduct blood and clinical visits twice annually for children under 5 years.

PHARMACIST

Pharmacist/ pharmacy assistant is responsible for pre-packing ART for family clubs.

see ART ADHERENCE CLUB REPORT AND TOOLKIT

Packing ART for children under 40kg on the same day as club session after receiving scripts from club nurse

DATA CAPTURER

Data capturer is responsible for capturing family club patient visits from the family club paper register into the facility electronic register.

2.1.2 WHO IS ELIGIBLE TO ENTER A FAMILY CLUB

The family club model aims to benefit children and their caregivers who are stable on ART. In many instances a caregiver may not be the biological parent; therefore not all caregivers in the family club will be on ART, but those that are, must be stable ART patients. Clinicians apply the following criteria to determine whether patients qualify for the family club:

CHILDREN ELIGIBILITY

1. On the same ART regimen for at least 12 months (regimen 1 or 2)
2. 2 most recent consecutive viral loads undetectable
3. No medical conditions requiring regular clinical follow-up
5. Age of the child to align with the following age criteria of each club
    a. 4-7 years
    b. 7-10 years
    c. 11-15 years

CAREGIVER ELIGIBILITY

see ART ADHERENCE CLUB REPORT AND TOOLKIT

If the caregiver is not on ART s/he must be one of the child's primary caregivers.

2.1.3 FAMILY CLUB SESSIONS PLANNING

Family club sessions are structured to ensure that annual blood investigations and consultations are aligned for all caregivers and children older than 5 years while twice annual scripting is aligned for all adults and children weighing more than 40kg.

Blood investigations and consultations for children younger than 5 years are aligned to take place twice annually, while scripting for all children weighing less than 40kg happens at every family club visit as doses are weight dependent.

CHILDREN <5YRS AND <40KGS

Visit no.	Type of club visit	Activities	Script
Month -1		Recruitment + club PN scripting for 3 months	1 month supplied by pharmacy
Month 0	Enrolment visit	Club PNs script for 2 months*	1 x 2 month supplied by pharmacy
Month 2	Routine visit	Club PNs script for 2 months*	1 x 2 month supplied by pharmacy
Month 4	Blood visit (for all)	Bloods taken & 2 month script*	1 x 2 month supplied by pharmacy
Month 6	Clinical visit	Clinical consultation with caregiver & 2 month script*	1 x 2 month supplied by pharmacy
Month 8	Routine visit	Club PNs script for 2 months*	1 x 2 month supplied by pharmacy
Month 10	Routine visit	<5yrs bloods taken & 2 month script*	1 x 2 month supplied by pharmacy
Month 12	Routine visit	<5yrs clinical consultation with caregiver & 2 month script*	1 x 2 month supplied by pharmacy

*Appropriate ART drug dosing determined with reference to child's current weight

FOR CLUB SESSION PLAN OF CAREGIVERS AND CHILDREN >5YRS AND >40KG

see ART ADHERENCE CLUB REPORT AND TOOLKIT

2.2
FAMILY CLUB PLANNING AND SET-UP IN YOUR FACILITY

2.2.1 ENSURE BUY-IN OF ALL FACILITY STAFF

Remember to obtain buy-in from the facility team before starting family clubs in a facility.

see ART ADHERENCE CLUB REPORT AND TOOLKIT

2.2.2 FAMILY CLUB MEETING SPACE

Family clubs should happen at or close to the facility in order for children <40kg to be weighed, have their dosing assessed by the nurse and for the pharmacy to quickly pack their ART packages.

If possible, 2 separate spaces are recommended; one for caregivers to discuss child disclosure and one for children to engage in fun activities

Options within the facility

1. Support group room
2. Outside courtyard or NPO structure on facility grounds (ideal space for children)
3. General waiting area if family club meets after-hours

2.2.3 RECRUITMENT

see ART ADHERENCE CLUB REPORT AND TOOLKIT

Family clubs are age specific to allow for child disclosure support. It is therefore important to assign age ranges to family clubs. MSF recommends 3 age-group categories:

1. 4-7 years
2. 7-10 years
3. 11-15 years

When children and their caregivers are allocated to family clubs, the child's age at club enrolment will determine which club they are allocated to.

Clinician assesses disclosure status as no disclosure (none), partial disclosure (PD) or full disclosure (FD) at the time of recruitment and communicates the child's disclosure status with the family club facilitator.

Club :.................... Club manager:..............................

Sticker	Phone Number Private (PVT) or Shared (S)	Drug Regimen / Baseline CD		Standard Session
Club Month				0
Club date				2010/02/10
Place Patient sticker here, Or write Folder number First Name, Last Name Gender, Date of Birth	Write patient's cell phone number Write "PVT" or "S"	ART drugs Baseline Disclosure Status	Weight (W) Symptoms (S)	Weight or outcome N or RTC
56789099 Bulima Tataloko Female, 05/05/1982	0823334625	AZT, 3TC, EFV	W	63
	PVT	None	S	N
100005436 Bizikala Tolominta Female, 01/05/1977	078145628	D4T, 3TC, EFV	W	75
	PVT	PD	S	N

2.2.4 SCHEDULING OF FAMILY CLUB DATES

When implementing family clubs, the clubs manager needs to determine how many clubs will be implemented over a given period and schedule family club session dates accordingly. If the clinic has a specific day for paediatrics, family clubs could be scheduled on that day, but this is not a prerequisite. Family club dates for the year can be reflected in table format with blood, clinical and scripting visits clearly marked to simplify for family club staff.

Differences in blood, clinical and scripting visit scheduling can be noted in the following groups:

Caregivers & children >5yrs blood and clinical visit (B/C) 1x annually

Children <5yrs blood and clinical visit (B/C) 2x annually

Caregivers (and children >40kgs) scripting visit (S) 2x annually

Children <40kg scripting (S) every family club (every 2 months)

TUES	FRI	MON
Family club 1 <7yrs	Family club 2 7-10yrs	Family club 3 >10yrs
2013/11/01		
(B <5yrs) 2013/12/11	(B all) 2013/12/09	
(S caregivers, C<5yrs)2014/01/24	(S caregivers, C all)2014/02/03	2014/02/10
2014/03/20	2014/03/30	(S caregivers) 2014/04/13
(B all) 2014/05/15	2014/05/25	2014/06/08
(S caregivers, C all)2014/07/10	(S caregivers) 2014/07/20	(B all) 2014/08/03
2014/09/04	2014/09/14	(S caregivers, C all) 2014/09/28
(B <5yrs) 2014/10/30	(B all) 2014/11/09	2014/11/23
(S caregivers, C<5yrs) 2015/01/22	(S caregivers, C all) 2015/02/01	2015/02/15

B = blood visit
C = clinical visit
S = scripting visit

2.2.5 HOW TO RUN FAMILY CLUBS

A detailed description of preparing for and running the clubs, including discussion guide examples can be found in Annexures 1 and 3

2.2.5.1 PREPARATION

PREPARATION FOR THE FIRST FAMILY CLUB

1. All family club members' files are pulled for scripting purposes

2. Family club members' scripts are taken from the patient file and placed in two separate club files; one for children and one for caregivers (and any children >40kgs). The caregiver's (and children >40kgs) club file is then sent to pharmacy to pre-pack 2 months ART supply. It's important to establish the time-period with the pharmacy that they will need to pre-pack i.e. 1-3 days before family club session. The children's files are kept ready for weight review and scripting at the family club session.

3. Blank family club register is available

4. Family club facilitator reviews introductory club session plan (see Annexure 3 with club session plan suggestions)

5. 30 clinic scripts are available for completion with patient stickers

PREPARATION FOR ROUTINE, BLOOD AND CLINICAL FAMILY CLUB VISITS

1. Caregivers club file to pharmacy for pre-packing

2. Children's club file is ready for weight review and scripting first thing on club date

3. Family clubs facilitator collects caregivers pre-packed ART from pharmacy on the morning of the club session

4. The family club register is ready for the club session

5. The family club facilitator has reviewed club session plan and prepared accordingly (see Annexure 3 with family club session plan suggestions)

6. Blood visit: appropriate blood forms have been completed by family clubs facilitator

7. Clinical visit: all patients files to be drawn. Blood results need to be included in patient file for club nurse review.

8. Caregiver scripting visit: caregiver's files drawn for club nurse to complete next 6 months script.

2.2.5.2 RUNNING OF ROUTINE FAMILY CLUB SESSION

REGISTRATION
Caregivers & children hand in patient cards as they arrive

CHILDREN WEIGHT AND SYMPTON CHECK
Clubs facilitator weighs children, enters weights on scripts & conducts symptom check

SCRIPT SUBMISSION
Scripts submitted to club nurse

DOSING CHECK
Club nurse checks weight and amends script where necessary to correct dose, submits to pharmacy

PHARMACY CHILDREN PRE-PACK
Pharmacy packs children meds
Club facilitator collects children and caregiver meds from pharmacy

GROUP SESSION
Club facilitator facilitates group discussion
Options: split children & caregivers to discuss child disclosure with caregivers while the children play games

CAREGIVER WEIGHT AND SYMPTOM CHECK
Caregiver group weight & symptom check

ART DISTRIBUTION
Club facilitator distributes meds to family club members, next club date noted on patient card

CLUB REGISTER
Club register completed

CLUB NURSE REFERRALS
Symptomatic patients seen immediately after club session by club nurse

ADDITIONAL ACTIVITIES FOR SCRIPTING, BLOOD AND CLINICAL VISITS

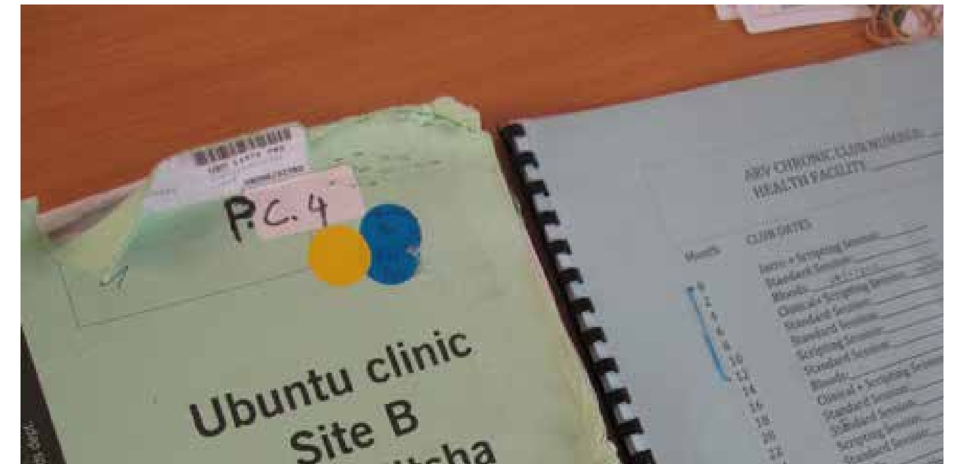
1. FIRST FAMILY CLUB VISIT: Family club nurse scripts all caregivers and weighs and scripts all children who attended the club using their patient files. These scripts then replace those in the club file. The family club facilitator clearly marks on the front of all patient's files that the patient is now a family club patient reflecting the club number on the front of the patient's file and on patient-held card.

2. AT FIRST BLOOD VISIT: Family club nurse takes all family club patients routine annual blood investigation, irrespective of how recently the routine bloods were taken. This is done in order to align all family club patients' blood visits going forward.

3. AT CLINICAL VISIT: Family club facilitator asks caregivers for updated child disclosure status and indicates this in the register. Family club nurse sees each club patient with the patient's blood results for their annual clinical review (see Annexure 4 for paediatric clinical review SOP). The clinician should check that the children's disclosure status is reflected in the register and on the file. Clinician to review blood results with caregiver alone if child not fully disclosed. Clinician to include caregiver and child in clinical review if child is fully disclosed.

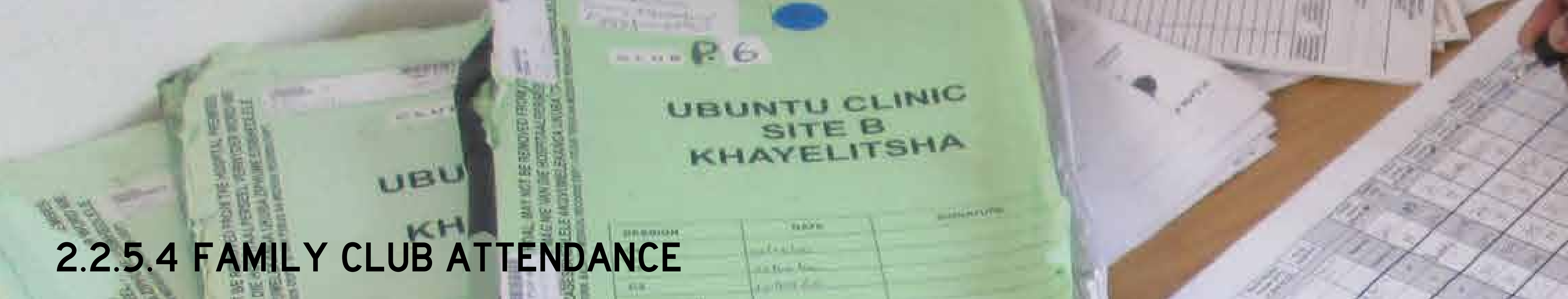
4. AT SCRIPTING VISIT: Family club nurse scripts caregivers and children over 40kg every 6 months. One out of two annual caregiver scripting visits will coincide with their clinical visit. Children under 40kgs are weighed and scripted at every club session.

In Khayelitsha we place a blue sticker on the front of the child's file to indicate partial disclosure and a yellow sticker to indicate full disclosure. The yellow sticker is an indication to the clinical team to include the child in all discussions about HIV, thus empowering him/ her to start to take responsibility for his/her health. The family club facilitator and nurse encourage caregivers to partially disclose to their children from about age 6 before progressing to full disclosure.



2.2.5.3 AFTER FAMILY CLUB SESSION

see ART ADHERENCE CLUB REPORT AND TOOLKIT



2.2.5.4 FAMILY CLUB ATTENDANCE

Caregivers on ART can send a buddy to collect their treatment from the club. Caregivers can also collect their child's treatment on the child's behalf if the child is unable to attend the club visit, for example during exam time. **BUT** a buddy cannot be sent to the blood or clinical visits and all children must be present on both these visits.

2.2.5.5 CLINICAL OVERSIGHT BY FAMILY CLUB NURSE

A nurse should be allocated as the family club nurse on each day that a family club is scheduled. This nurse needs to be available to script for every child under 40kg based on the child's weight at the time of his/ her family club session.The family club nurse should be able to continue seeing mainstream patients after she has completed this task but will be available to see any referred symptomatic caregivers or children immediately after the family club session. As the family clubs are meant for stable patients there should be very few symptomatic children and caregivers who need to be seen by the club nurse.

When it is a blood, clinical or caregiver scripting visit the allocated nurse will have an increased workload for that day and will need to plan his/ her day accordingly. The children and caregivers will complete the family club session and then see the nurse for their bloods to be taken or for their clinical visit (see Annexure 4 for paediatric clinical SOP).

During the clinical visit the nurse should ensure the prescription remains appropriate and that the child's disclosure status is correctly reflected on the front of the child's file. The caregiver scripting process can be completed after the club session once the clinic quietens down.

2.2.5.6 WHEN ARE FAMILY CLUB PATIENTS REFERRED BACK TO MAINSTREAM CARE?

Family clubs are a model of care for children and their caregivers who are stable and adherent on ART.If the child becomes clinically unstable it is recommended that both caregiver and child be referred back to mainstream clinic care for increased support. A child's poor adherence is the responsibility of their caregiver and both need to be monitored more closely by clinic staff to address the cause of poor adherence.

If the caregiver is no longer clinically stable or has missed a club session without sending a buddy, s/he no longer qualifies to be a family club member and returns to mainstream clinic care for enhanced clinical or adherence support. The child in this instance is still eligible to remain in the family club. It is the facilities discretion whether to remove both child and caregiver or to allow the child to continue to be a family club member in which case the caregiver may accompany the child to club sessions, but will not be seen as a family club patient until stable again.

2.2.5.7 MONITORING OF FAMILY CLUB PATIENTS AND CLUB OUTCOMES

Patient files are only drawn at the clinical and caregiver scripting visit. Each family club has a club register which is completed by the clubs facilitator in which patient's attendance is recorded for each club session. The family club register is divided into 2 sections, one for children (further split between children younger and older than 5 years) and one for caregivers who are on ART.

The family club register template can be found in Annexure 5. The register is similar to the ART club register. The only differences are:

1. An additional indicator for checking child disclosure status is reflected at each clinical visit.

This is completed with:

- None - no disclosure
- PD - partial disclosure
- FD - full disclosure

2. For children <5 years a blood and clinical visit will be indicated every 6 months. Their first, and thereafter every second blood and clinical visit will coincide with all family club patients' blood and clinical visits.

ARV FAMILY CLUB NUMBER: ____________________
HEALTH FACILITY: ____________________

Month	CLUB DATES	Data Captured
__	Intro Session: ____________	DC________
__	Standard Session: ____________	DC________
__	ALL Bloods: ____________	DC________
__	ALL Clinical + Caregiver Scripting Session: ________	DC________
__	Standard Session: ____________	DC________
__	<5 yrs Bloods / Standard Session: ________	DC________
__	< 5yrs Clinical / Caregiver Scripting Session: ______	DC________
__	Standard Session: ____________	DC________
	ALL Bloods:	DC
__	ALL Clinical + Caregiver Scripting Session: ________	DC________
__	Standard Session: ____________	DC________
__	<5 yrs Bloods / Standard Session: ________	DC________
__	< 5yrs Clinical / Caregiver Scripting Session: ______	DC________
__	Standard Session: ____________	DC________
__	ALL Bloods: ____________	DC________
__	ALL Clinical + Caregiver Scripting Session: ________	DC________
__	Standard Session: ____________	DC________
__	<5 yrs Bloods / Standard Session: ________	DC________

ANNEXURES

Annexure 1: Family club SOP

Annexure 2: Child disclosure pamphlet

Annexure 3: Family Club session plan examples – caregiver and child

Annexure 4: Clinical visit SOP for children

Annexure 5: Family Club register

For any family club queries please email:
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