HIV CLINICS

KHAYELITSHA

COUNSELLING GUIDELINE

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Contents

Acronyms

AIDS	Acquired Immunodeficiency syndrome
ARV	Antiretrovirals
ATICC	AIDS training, information and counselling center
CHSO	Community Health Services Organization
DG	Disability grant
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
ID	Identification
MSF	Médecins Sans Frontières
TB	Tuberculosis
VCT	Voluntary counselling and testing

1. Background

Médecins Sans Frontières (MSF) started clinics for patients with HIV-related problems within three Community Health Clinics in Khayelitsha in mid 2000. The clinics provide counselling, support, prophylaxis, treatment, screening and referral for conditions related to HIV/AIDS. The aim is to provide comprehensive care for HIV infected patients in the primary health care setting.

In addition to these services MSF started providing HAART in May 2001. The aim of this pilot project was to test the effectiveness, feasibility, acceptability and cost-effectiveness of providing HAART in a primary health setting. The first patient was started on HAART therapy in May 2001. The programme started enrolling children at the end of 2001, once the programme for adults was fully operational. In September 2001 MSF received a section 21 authorisation of the Medicines Control Council to use generic versions of antiretroviral drugs in order to test, not only the feasibility of providing antiretroviral therapy, but also its affordability. The use of generic antiretrovirals started in January 2002.

2. The antiretroviral therapy programme

Only patients who attend the HIV clinic regularly and who live in Khayelitsha are considered for HAART in the MSF clinics. Clinical, biological, adherence and social criteria have to be fulfilled to be eligible for HAART. Only patients in stage 3 or 4 according to the World Health Organization classification AND with a CD4 cell count of less than 200 /mm^3 are eligible. Prior adherence to cotrimoxazole prophylaxis and to TB treatment, and regular attendance at clinic appointments are used to assess ability to adhere to HAART. After the patient has been counselled about HAART and provided informed consent, a clinic worker assesses the social and support structures available to the patient by conducting a home visit. The home visit verifies the patient's residence and disclosure to at least one person. The doctor and the nurse counsellor present eligible candidates to a committee of community representatives who make the final decision on enrolment. The committee includes persons living with HIV/AIDS, a private general practitioner, nurses, and counsellors. Only candidates who provide written informed consent are enrolled in the HAART programme.

Once selected a doctor assesses the patient by reviewing the past medical history, including prior ARV use, and by physical examination. Appropriate laboratory tests are also performed to determine which regimen should be used and to provide a baseline to monitor the response to therapy and adverse events. These tests assess liver function, haematology, CD4 cell count and viral load (hereafter called baseline). Standardised triple therapy regimens are used.

A patient-centred programme has been developed to support adherence to HAART, which consists of three parts - Individual support, peer support and material support. Individual support: Trained counsellors are available at all times during clinic hours to assist patients having difficulties with any aspect of HAART; All patients are requested to identify a "treatment assistant," usually someone living in their household, who can assist them with adherence issues; Home visits are performed as needed for more thorough follow-up of patients having problems. Peer support: Support groups exclusively for patients on HAART therapy facilitate discussions on barriers to adherence, adverse events, disclosure and other psychosocial issues, and also serve as forums for health promotion and education (other support groups are also available for patients not on HAART). Materials support: Patients are provided with pillboxes and drug identification charts, daily schedules, diaries and educational materials explaining the risks and benefits of HAART.

The patient-centred support program have been supplemented with additional strategies. These include drug-related strategies (low pill counts and ARV agents with a limited side-effects profile), health care worker strategies (primarily, standardising communication strategies to both ARV and non-ARV clients and to develop a team-based approach), clinic strategies (scheduling ARV and non-ARV visits; access to community education initiatives) and influencing popular discourse (integration of clinic services into community discourse on HIV treatment, rights etc.) It is the interplay of these strategies that determine the nature of the program.

3. Counselling

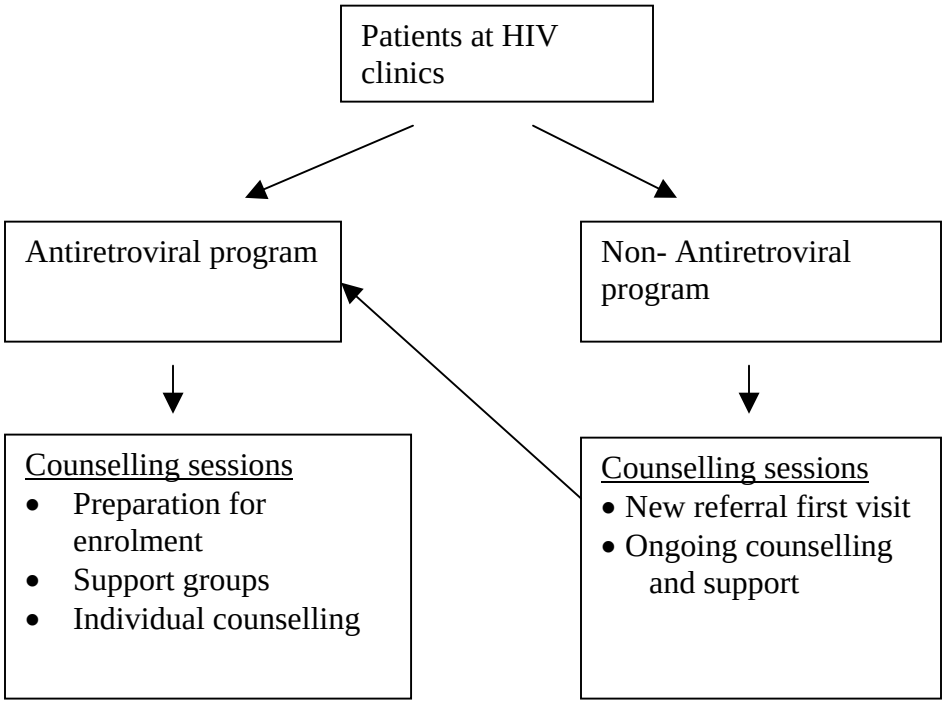
Counselling is a dynamic process based on developing a relationship with patients. Counselling is essential to assist patients in coming to terms with their HIV status, in disclosing and in empowering them to live positively with HIV. Counselling forms the backbone of ensuring patients are fully informed about HIV/AIDS and related conditions, on how antiretrovirals and other medication used in their treatment work. Individual and group support facilitated by counsellors are integral to support adherence to HAART.

Counsellors at the HIV clinics are contracted from Lifeline. Lifeline trained all counsellors on personal growth and HIV counselling over a six-month period. After this training they are selected by Lifeline as counsellors. They also did the ATICC AIDS awareness (4 day) course and then started working at the HIV clinics. Once there, they received training on HIV, Infectious diseases and Antiretrovirals. Counsellors work as part of the clinic team (consisting of doctors, nurses, administrator and counsellors) and receive mentoring at Lifeline.

4. Objective of this document

To develop guidelines for counselling within the HIV Clinics to aid with standardisation of practise across clinics.

Patients attending the HIV clinics fall into one of two groups and counselling sessions for each group is outlined below.



5. Counselling guideline

5a. Non- Antiretroviral program

i. New referral to the clinic

The counsellors will open a folder (at site C and Michael M where there are no administrators) and collect baseline information. Counselling is provided on an individual basis as per patient request.

The nurse will then clinically stage the patient and draw bloods. The patient gets asked to return two weeks later. The number of new patients booked per day should not exceed five.

On presentation two weeks later, staging will be reviewed taking into account laboratory results.

- Stage 1 and 2 patients will be referred to CHSO. Will be given follow-up appointment at MSF clinics ranging from within 3 months to 1 year.
- Stage 3 and 4 patients will be followed-up at the HIV clinic.

Patient to be followed up at MSF, will be seen by the counsellor for individual counselling. All these patients are aware of the HIV status. The individual counselling session will therefore cover:

- Issues related to the HIV clinic
  - Explain clinic procedures
  - Explain expected management at the clinic

Expected Management for Stage 3 and 4:

- Treatment
  - Taking blood for CD4 and other tests
  - Providing prophylactic and therapeutic medication
  - Receiving counselling as needed
- Follow-up
  - Uncomplicated cases to be followed up every 3 months
  - Inter-current problems will be attended to at MSF clinics, however unscheduled appointments will only be seen at the end of the day, unless very ill
- Screening during each consultation by clinicians (doctors and nurses) with counsellor's feedback for potential candidates for ARV – if identified as potential candidate will be called back more regularly to assess adherence and compliance with visits.

- Topics as guided by the needs of the patient.
  - Post test counselling (if the patient requires it)
  - Counselling on disclosure
  - Relationship with family and with partner
  - Feelings, fears, hope....
  - Nutrition
  - Safe sexual practices
  - Opportunistic infections
  - Family planning
  - Alcohol, drugs....
  - Referral to other sectors e.g. for DG grant / support groups

ii. Ongoing counselling and support

Patients who are stage 1 and 2 and have existing MSF folders are followed up every 6 months. Uncomplicated stage 3 and 4 (not on ARVs) are followed up every 3 months.

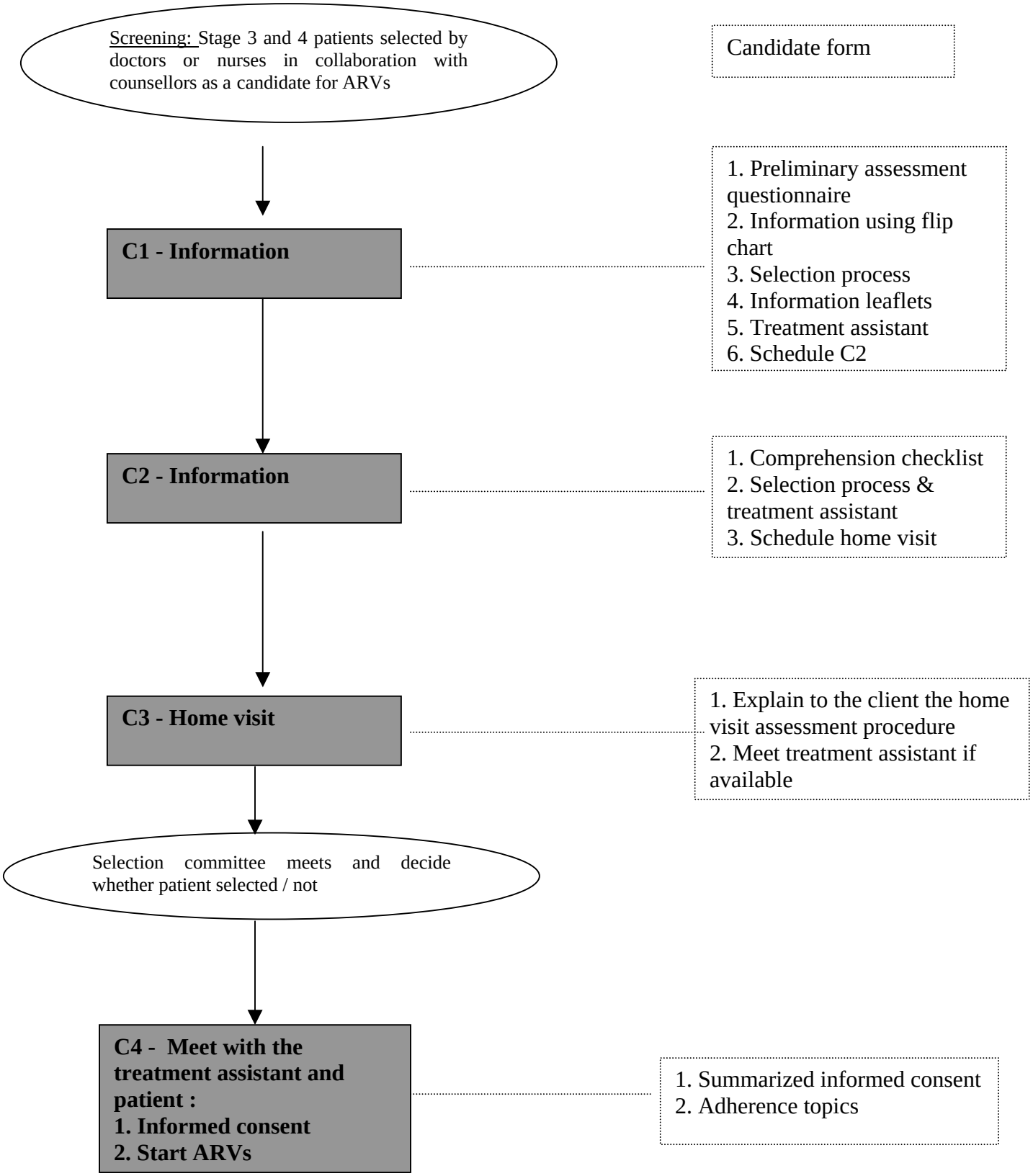
Individual counselling should be conducted as per patient request / as per referral from a clinician. There are also situations where family members of patients request individual counselling. Partners of patients also request VCT. MSF counsellors will either refer partners to the VCT center at the community health center or conduct pre and post test counselling at the MSF clinic with testing also being conducted there (Site C and Site B)

Support groups presented by the VCT counsellors at the three community health centers run once a week and all patients should be encouraged to attend these. Patients should also be referred to income generation groups, voluntarywork and other CBO-run activities.

It is important that persons at this stage of disease progression also get exposed to information and education around ARVs. This could be located outside of clinic-time and run by community for a or can take place in the form of waiting room education sessions.

5b. Anti retroviral program

i. Preparation for enrolment into the Anti-retroviral program



Screening

Potential candidates will be identified by doctors or nurses in collaboration with the counsellors according to regular clinic attendance, openness, biological and clinical criteria. This process needs to be standardised using Michael M format as a guideline. The doctor or nurse introduces the notion of ARV and explain the selection criteria and refers the patient to the counsellor. The counsellor sees the patient (if possible the same day/week) for individual counselling (C1) and start filling in the "candidate form" which must be stapled on the inside of the patient's folder. (Appendix A)

C1 - Information

The objective is to give basic information on HIV infection and antiretroviral drugs, and to assess social selection criteria. Information about ARVs will empower patients to make decisions about treatment, and will improve their motivation and intention to adhere to the regimen as prescribed.

Firstly: Administer the preliminary assessment questionnaire (Appendix B). This will give the counsellor an indication of the level of knowledge that the patient has as well as whether the patient full-fill the social selection criteria. If the patients does not fit any of the criteria, assist patient in working out ways to address criteria not fulfilled e.g. presenting on time for visits, attending the support group, disclosure.

Secondly: The counsellor then structures the information session taking into account previous experience and knowledge of the patient.

Topics to cover:

- Educate patient about ARV triple therapy using the flip chart (Appendix C):

- Explain the Selection process
  - Selection criteria (Appendix D)
  - Selection committee

Encourage the patient to ask questions on anything that he/she does not understand.

Thirdly: Give the patient information leaflets ("Antiretrovirals as easy as ABC" and "People's Stories on ARVs") to read in their own time. Ask whether the patient has a relative or a friend who could be his/her treatment assistant. Explain the role of the treatment assistant, that the treatment assistant can accompany the patient on C2, and should be present at the home visit, and when informed consent is signed.

Schedule the C2.

C2 - Information

Objective of this meeting is to review information on HIV and ARVs, and to assess the patient's motivation and expectation regarding ARVs.

Firstly: Administer comprehension checklist (Appendix E) to

- Check if information given at first session has been understood,

- Assess if patient still agrees to take ARV
- Assess patient motivation to take ARV
- Assess expectation regarding ARV treatment (misconception, belief, safer sex)
- Assess whether patient can come regularly to HIV clinic

In case of misunderstanding, correct these.

Secondly: Explain the role of the treatment assistant and the selection process and answer any questions.

Confirm home visit date

C3 - Home visit

Objective of the home visit is to assess the home environment of the patient and to meet the treatment assistant.

The counsellor accompanies Ms Nozi Skefile (home visit assessor) on the home visit and

a. Introduces Ms Nozi Skefile to the patient and treatment assistant
b. Re explain the selection criteria
c. Explain to the client the home visit assessment procedure
d. Meet treatment assistant
e. Ms Nozi Skefile will complete a Home visit form (Appendix F)

Following the home visit, the counsellor write notes in MSF folder, prepare folder for selection committee visit.

Selection committee meets and decide whether patient selected / not

C4 - Informed consent and start of ARVs

Objective of this meeting is to obtain informed consent and to explain and discuss treatment adherence measures.

If patient is selected:

- Explain the informed consent form (Appendix G) to the patient and treatment assistant
- Clarify any questions and make sure all details are understood
- Ask the patient to sign and date the informed consent form (or parent of child selected for ARVs)
- Ask the treatment assistant to sign and date as the witness
- If the patient is not ready to sign, give the informed consent form to the patient to read at home and arrange a follow-up appointment in 1 to 2 weeks time.

If the patient is not selected:

- Candidates who were not selected for anti-retrovirals need to be explained the reasons for this.
- Measures that can be taken to address these reasons must be explored and encouraged.

Once the informed consent form is signed, the patient will see the doctor/nurse who will prescribe and issue the ARVs.

The patient will be send back to the counsellor to explain and discuss the adherence measures (see table below). This will either happen the same day as informed consent or if the patient had to have blood tests first it will be done when the patient return for ARV issuing.

Topic to cover	**Tool**
Check the prescription	
Explain to the patient how to recognize the different drugs prescribed.	The drug ID chart has visual representation of individual drugs, written and visual description of drug doses and potential common and life threatening drug adverse events. (Appendix H1)
According to the regimen prescribed by the doctor educate the patient on how to take the ARV drug using the daily planner. -Cite the name of each drug to be taken -Explain the number of pills to be taken -Advise to bring the stock drugs back on every visit	The daily planner is used to review the patient's daily routine every hour. Two events that occur daily approximately 12 hours apart are linked to taking morning and evening doses. (Appendix H2)
Explain the importance of drug adherence. Explain the use of the tick sheets and the pill box	Tick sheets - patient or treatment assistant reports on a daily basis doses taken and any adverse events experienced in 2 day period (Appendix H3) Pill box - each day has a separate box which fits into the main holder. Each day can also be detached from the larger holder. Helps to reinforce twice daily dosing of drugs
Explain what to do if the patient forget to take 1 dose	Time delay between 2 doses and when is it too late to take a forgotten dose. Reporting of forgotten doses.
Explain what to do if the patient vomit after taking drugs	Precise importance of vomiting. Potential role of traditional medicines Anti-emetic drugs. No need for additional dose
Who to contact in case of problem with the treatment	Clinic number and when to come for inter-current visit. 24h emergency in site B
Explain how the follow up visits will be planned	Clinician: Every second week for 2 months then, every month till 12 months then every 2 – 3 months. Counsellor: Support groups – at least once per month Individual counselling – as per need

Patient ID card are issued by counsellors upon initiation of treatment – documents patients name, current medications and contact doctor/number for medical management of patients outside of the HIV clinics. (Appendix H4):

ii. Support groups

- Support groups (maximum of 20 participants / group) are run by the one or two counsellors at each HIV clinic.
- Patients at the clinics should be divided into 4 groups and frequency of meetings are linked to ARV clinical attendance.
    - Children
    - 0-3 months on ARVs
    - 4-11 months on ARVs
    - 12 + months on ARVs
- It is important that the content covered in the support groups are standardised. Information sheets should be developed on issues such as disability grants, family planning, ARV, Nutrition, STIs, OIs, adherence, etc.
- If irregular attendance / increased viral load – individual counselling should be done and the patients should not be placed in the 0-3 months group.
- Treatment assistants can join individual sessions not support groups.

1. CHILDREN

- When: Meet once per month
- Content:
    - The first hour of the support group is spent discussing treatment - how treatment is taken, possible side effects, and adherence measures are emphasized.
    - The second hour is spend discussing a topic which was determined by the group / the counsellor. Either participants present / speakers from outside give input.
- Should be structured to include games, play, reading, etc.

Content to cover	
Disclosure	- Strategies on how, when, and where AND to whom: partners, family members, and friends. - How to respond to gossip about your HIV status.
Drug Identification, and adverse events	- Daily routine exercise: Using others suggestions for daily routine - What happens if the child vomit a few minutes after taking medications - Are there recommended diets for persons living with HIV on antiretrovirals - Co-use of Cotrimoxazole and/or TB drugs with ARVs - Adverse events in blood results: anaemia, neutropaenia, and transaminitis - Using traditional medicines and ARVs: advice given in this situation
Opportunistic infections	
HIV in general	

2. **0-3 MONTHS ON ARVS**

- When: Meet twice per month.
- Content:
  - The first hour of the support group is spent discussing treatment - how treatment is taken, packing pill boxes, possible side effects, and adherence measures are emphasized.
  - A questionnaire is used at every session – each participant in the support group is asked questions and responses are documented.
  - The second hour is spend discussing a topic which was determined by the group / the counsellor. Either participants present / speakers from outside give input.
  - The standardised input is very important for this group and takes up most of the support group session. If the patients want to participate in other activities e.g. Memory box project, Drama or income generation projects this have to be done outside of the scheduled support group time.

Content to cover	
Disclosure	- Strategies on how, when, and where AND to whom: partners, family members, and friends. - Denial about partner's own HIV status/ convincing partner to go for VCT. - How to respond to gossip about your HIV status.
Condom use (male and female), other contraception and T.O.P.	- How to use condoms and where to get them - Multiple partners: why, how, how to discuss - Difference between government supply and brand condoms - Falling pregnant while on HAART, PMTCT - Michael Mapongwana MOU is the designated TOP site for Khayelitsha
Drug Identification, pill-box packing and adverse events	- Using the drug id and side effects sheet - Packing the pillbox exercise - Daily routine exercise: Using others suggestions for daily routine - What happens if I vomit a few minutes after taking my medications - Drinking alcohol and taking ART - Is there any problem with my smoking affecting the effectiveness of ART - Are there recommended diets for persons living with HIV on antiretrovirals - Co-use of Cotrimoxazole &/or TB drugs with ARVs - Adverse events in my blood results: anaemia, neutropaenia, and transaminitis - "Cleaning the stomach" and "Responding to tasting gall" - Using traditional medicines and ARVs: advice given in this situation
Support services or counselling for persons with suspected or confirmed substance abuse (alcohol dependency or abuse)	
You and your treatment assistant's visit at month 3.	
Opportunistic infections	
HIV in general	

3. 4-11 MONTHS ON ARVS

- When: Once per month
- Content:
  - The first hour of the support group is spent discussing treatment - how treatment is taken, packing pill boxes, possible side effects, and adherence measures are emphasized.
  - The second hour is spend discussing a topic which was determined by the group / the counsellor. Either participants present / speakers from outside give input.
  - Once standardised input has been given, other activities can also take place in the support group. Examples include the Memory box project, Drama or income generation projects.

Content to cover	
Drug Identification, pill-box packing and adverse events	- Using the drug id and side effects sheet - Packing the pillbox exercise - Changing regimens: reasons for changing, benefits of not changing regimens
Discussion of month 6 CD4 count and viral load results	
Workplace rights, rights to confidentiality	
Sexual violence: Women, gender and culture; rape and rape survivor services	
Drama development	Ekwezi drama group gives workshops to provide participants with drama skills and facilitate the development of a play.
Memory box project	Memory boxes and books are used for people to record their own life stories. For further details see the Memory Box manual by the AIDS and society research unit, Centre for Social Science Research, University of Cape Town.
You and your treatment assistant's visit at month 6.	

4. 12 + MONTHS ON ARVS

- When: once per month
- Content:
  - The first hour of the support group is spent discussing treatment issues.
  - The second hour is spend discussing a topic which was determined by the group / the counsellor. Once standardised input has been given, other activities can also take place in the support group. Examples include the Memory box project, Drama or income generation projects.

Content to cover	
Discussion of month 12 CD4 count and viral load results	Understanding why a viral load can increase - even though I have taken my medications correctly; - because I have missed doses; - checking if I need support
Progress in life: relating stories of change and plans for the future	
Drama development	
Memory box project	
You and your treatment assistant's visit at month 12 and 18	

iii. Follow-up individual counselling

Once enrolled in the anti-retroviral treatment program patients visit the clinic according to the schedule. At each of these visits, patients are seen by both the counsellors and the medical staff. While waiting in the waiting room patients receive group education on treatment adherence and other topics related to HIV by treatment educators.

Patients will receive individual counselling as per request or referral.

<u>One special case of referral is when there is an increased viral load:</u>

All patients on ARVs have blood drawn for viral loads at 3 monthly intervals. If a patient is found to have an increased viral load while on treatment the patient will be asked to attend the clinic on a weekly basis and be referred to the counsellors.

Possible reasons for increased viral load:

- Not adhering to treatment regimen
- Resistance

Increased viral load at 18 months on treatment is probably the result of resistance. First check adherence for 1 month and redo viral load after 1 month.
If increased viral load at 3 months – mainly adherence problem.

The counsellors need to

1. Explore how the patient has been taking his/her treatment including checking if the client has seen any other Health care workers (outside of the MSF clinics). Encourage patients to inform staff at the MSF clinics if they are seeing/have seen other HCWs
2. Book 3 appointments with the patient and the treatment assistant for individual counselling. Topics to be covered in individual counselling:
   - Explain how ARVs work
   - Explain all the adherence measures (tick sheet, pill box)
   - Explain the importance of adhering to the treatment regimen

The counsellor then provides feedback to the attending doctor/nurse.

6. Documentation and Monitoring

Counsellors should keep notes on interactions with the patients. During the 0-3 months support group sessions a questionnaire is used. Counsellors also need to keep an attendance register for each support group and then fill in monitoring register.

7. **References**

1. Médecins Sans Frontières (MSF), School of Public Health and Primary Health Care, University of Cape Town Providing Antiretroviral Therapy at Primary Health Care Clinics in Resource Poor Settings Preliminary Report: May 2001 – May 2002

2. Patient education/counselling to patients under ARV tgerapy: Guideline intended for drug educators working at the adherence consultation for patients under ARV therapy, Surin Provincial Hospital & MSF FRANCE Surin, Thailand, September 2002

8. APPENDICES

A. CANDIDATE FORM – to track enrolment into ARV program

Antiretroviral program

Candidate form

Folder number:…….

Address:……

Phone number: (h)…….(cell)……..(w)…….……

Date of first visit: ……./……/…….

Income: Yes ☐ No ☐

Children (age):

Latest CD4 count: ……./mm^3. Date: ……./……/…….

WHO Stage: …….

	YES	NO
Last four visits on time:		
Disclosure of HIV status If yes, to whom? …… ……		
Regular support group attendance		
Using contraceptives		
Using condoms		
Partner / child on ARVs		
Belong to medical aid that covers ARVs		
Lived in Khayelitsha for more than 3 months		
Adherence to Cotrimoxazole / TB treatment		

Counselling enrolment session	**Date**
C1 – Information	……./……/…….
C2 - Information	……./……/…….
C3 – Home visit	……./……/…….
Selection committee meeting	……./……/…….
C4 - Informed consent & Adherence	……./……/…….

B. PRELIMINARY KNOWLEDGE AND SOCIAL SELECTION CRITERIA ASSESSMENT

(Adapted from Surin Provincial Hospital & MSF FRANCE Surin Thailand Guideline for drug educators)

QUESTIONS		
What is HIV infection?		
What is CD4? Viral load?		
What do you know about anti-retroviral medicines (ARV)?		
Do you know names of any ARV medicines?		
Do you know how ARVs work?		
Do you know how long people should normally take ARV medicines?		
What are the benefits of ARV?		
What do you know about side effects of ARVs?		
Social election criteria checklist	**YES**	**NO**
Are you able to take medication regularly?		
For how long have you lived in greater Khayelitsha? _____ if more than 3 months tick "yes"		
Do you have a friend or family member who can be your treatment assistant?		
Do you belong to a Medical Aid Scheme that covers antiretroviral therapy?		
Will you be able to regularly attend a support group?		
Have you disclosed your HIV status? If yes, to whom_____		
Are you ready to commit to long-term antiretroviral therapy?		

If answers in shaded areas – not eligible

C: CONTENTS OF FLIP CHART

D. SELECTION CRITERIA

SELECTION CRITERIA FOR ADULTS **All criteria should be met for inclusion**

1. Clinical criteria
   - WHO stages 3 or 4 or asymptomatic patient with CD4 CELL $^{+}$ T cells less than 50/mm^3
   - Karnofsky Performance Score greater 40%

2. Biological criteria
   - 2 tests confirming HIV serostatus (either ELISA or rapid tests)
   - CD4^{+} T cell counts from 0 to 200/mm^3

3. Ability to adhere to therapy
   - Attended the clinic for at least 3 months
   - Presented on time to the 4 last visits
   - Able to take medication regularly.

4. Social criteria
   - A fixed address in greater Khayelitsha for more than 3 months
   - Stable home environment and treatment support structure
   - No Medical Aid Scheme that covers antiretroviral therapy
   - Commitment to regularly attend a support group
   - Open about HIV status and ready to commit to long term antiretroviral therapy. Disclosure to the partner and if not present to have at least disclosed to one family member.

S*ELECTION CRITERIA FOR CHILDREN*

1.Clinical criteria
- Paediatric stages B or C

2. Biological criteria
- If less than 18 months of age, two positive tests (rapid or ELISA) confirmed by a PCR test.
  If greater than 18 months of age, two positive tests (rapid or ELISA)
- If less than one year, the CD4+T cell count is not a criterion.
  If more than one year, CD4+ T CELL + cell count less than 24 % of the total lymphocyte count

The other criteria for children relate to their parents and are the same as for adults outlined above.

E. COMPREHENSION CHECKLIST FOR C3

(Source - Surin Provincial Hospital & MSF FRANCE Surin Thailand Guideline for drug educators)

QUESTIONS	PURPOSE
What do you know about anti-retroviral medicines ?	Check if information given at the 1st visit has been understood
Do you know names of any anti-retroviral medicines ?	Check if patient knows that AZT, DDI, etc are anti-retroviral, but Co-trimoxazole, herbal medicines are not.
Do you know how anti-retroviral work ?	Check patient knows anti-retroviral medicines inhibit HIV reproduction, but do not cure AIDS.
Do you know how long people should normally take anti-retroviral medicines?	Check patient know that anti-retroviral treatment is life long
What do you know about side effects of anti-retrovirals?	Check patient is prepared to tolerate some side effects
Do you know the purpose of the CD4 count? Viral load?	Check patient know that CD4 count is an important indicator to follow the effectiveness of anti-retroviral treatment.
Do you have any more questions in relation to anti-retroviral medicines?	Answers other question of patient if needed
Are you still interested in taking anti-retroviral treatment?	Check patient motivation to take anti-retroviral
If yes, what are your expectations from anti-retroviral treatment ?	Check patients have realistic expectations such as giving longer life, keeping them well enough to care for their children, etc. Correct false hopes such as anti-retroviral medicines will cure blindness, hemiplegia, etc
Ask the patient : - distance from home - financial difficulties - transport difficulties	Assess whether patient can come regularly to HIV clinic for Follow up.
Ask the patient : - If he feels ready to take treatment for long run. - If he could come regularly to HIV `clinic for follow up.	Assess commitment for long run treatment.

F. HOME VISIT FORM

Patient ID Number :…… Date of home visit: (dd/mm/yyyy): / /200

Gender : male / female Age: years

HOME SITUATION

1. Here in Khayelitsha are you living: (TICK the appropriate answer(s))

With a partner	
With a friend or friends	
With family	
Alone	

2. How many people eat and sleep regularly in this house ?

3. How many children do you have ?

3.1 What are their ages ? …….....

3.2 How many are living with you ?

4. In your household who is aware of your HIV status ? (TICK the appropriate answer)

No one	
Some members	
Everyone	

5. Who do you depend upon financially ? (TICK the appropriate answer(s))

Disability grant	
Family member living in household	
Family member living elsewhere	
Salary	
Neighbour/friends	

5.1How many people depend financially on you ?

6. Last year how many times did you leave Khayelitsha for more than a week?

6.1 On average, how long do you stay away when you travel ?:……days/weeks

7. Please name your treatment assistant:…….

7.1 Has he/she been to the clinic with you ? YES / NO

8. Please show me the number of bactrim tablets you have with you.

8.1 Number tablets:

8.2 Date last visit in clinic when bactrim dispensed: / /200

8.3 Difference between the two:…….

9. Counsellors Impressions and Comments (on the home, the client, the Rx assistant and on knowledge of ARV's, acceptance of support groups, safer sex, family planning etc…)

G. SUMMARIZED INFORMED CONSENT FORM

You are hereby considering taking antiretrovirals (ARVs) as part of the MSF Antiretroviral Programme in Khayelitsha. ARVs are proven to work elsewhere, and we plan to assess whether it can work in Khayelitsha. ARVs are not a cure for HIV and must be taken for the rest of your life. This makes ARVs difficult to take and needs much commitment on your part. You have the choice to join this programme or not. If you join the programme you can choose to stop receiving ARVs once you have started and still continue to attend the MSF Infectious Diseases Clinics (IDC).

You hereby indicate that you have been informed about HIV, your immune system, viral load, CD4-cells, the effect of HIV on CD4-cells, causes and types of opportunistic infections, the way ARVs work and the need to take ARVs in the correct amounts at the right times everyday. You have had an opportunity to ask questions about these issues and will have an opportunity to do so in future as well.

The main reason why ARVs have not been used before in Khayelitsha or South Africa on a large scale is because of the cost. This programme will try to show that the use of "generic" ARVs can bring the cost of ARVs treatment down. Generics are cheaper copies of "brand" name drugs and work as well as the brand name drug. MSF guarantees that treatment will be provided for 5 years and has an agreement with the provincial government to provide your treatment beyond this period.

When you start ARVs, you will visit your clinic to see your doctor and counsellor weekly for the first month, then every two weeks for the second month and monthly thereafter. You will have to attend your support group at least once a month for the first year and then every two months. Blood will be drawn for tests linked to the safety and effectiveness of the ARVs you will take. This will happen at least at your first visit, then at 2, 4 and 6 weeks, as well as 3, 6, 12, and 18 months after starting ARVs. Your clinic will inform you about which tests will be done and what purpose it serves. ARVs help the immune system to recover. If this happens, you have a better chance of not getting opportunistic infections. You would also have a better chance of living longer. You stand a better chance of the benefits of ART if you take your medications very regularly.

There are different drug regimens. You will start ARVs with a first line regimen containing three drugs: AZT+3TC+ Efavirenz or AZT+3TC+Nevirapine. ARVs can cause side effects - some side effects are minor, some are very severe. Some appear soon after starting and some develop after a long while. One cannot tell at the beginning of treatment who will get side effects and who will not. AZT can cause headache, nausea, fatigue, and problems with the blood; 3TC, nausea, vomiting, headache; Nevirapine, rash, liver inflammation and Efavirenz, vivid dreams, rash. Inform the IDC about these if you experience it or any other form of sickness. It is important to know that some ARVs can affect your pregnancy in a bad way therefore women must be on family planning before being started on EFV, d4T or ddI. It is important to always practice safe sex. Changes to the regimen can be because you cannot tolerate the side effects or because the drugs are not working. When this happens your clinic will inform you and you will be given other ARVs, which can be difficult if the reason for changing is due to a failing regimen.

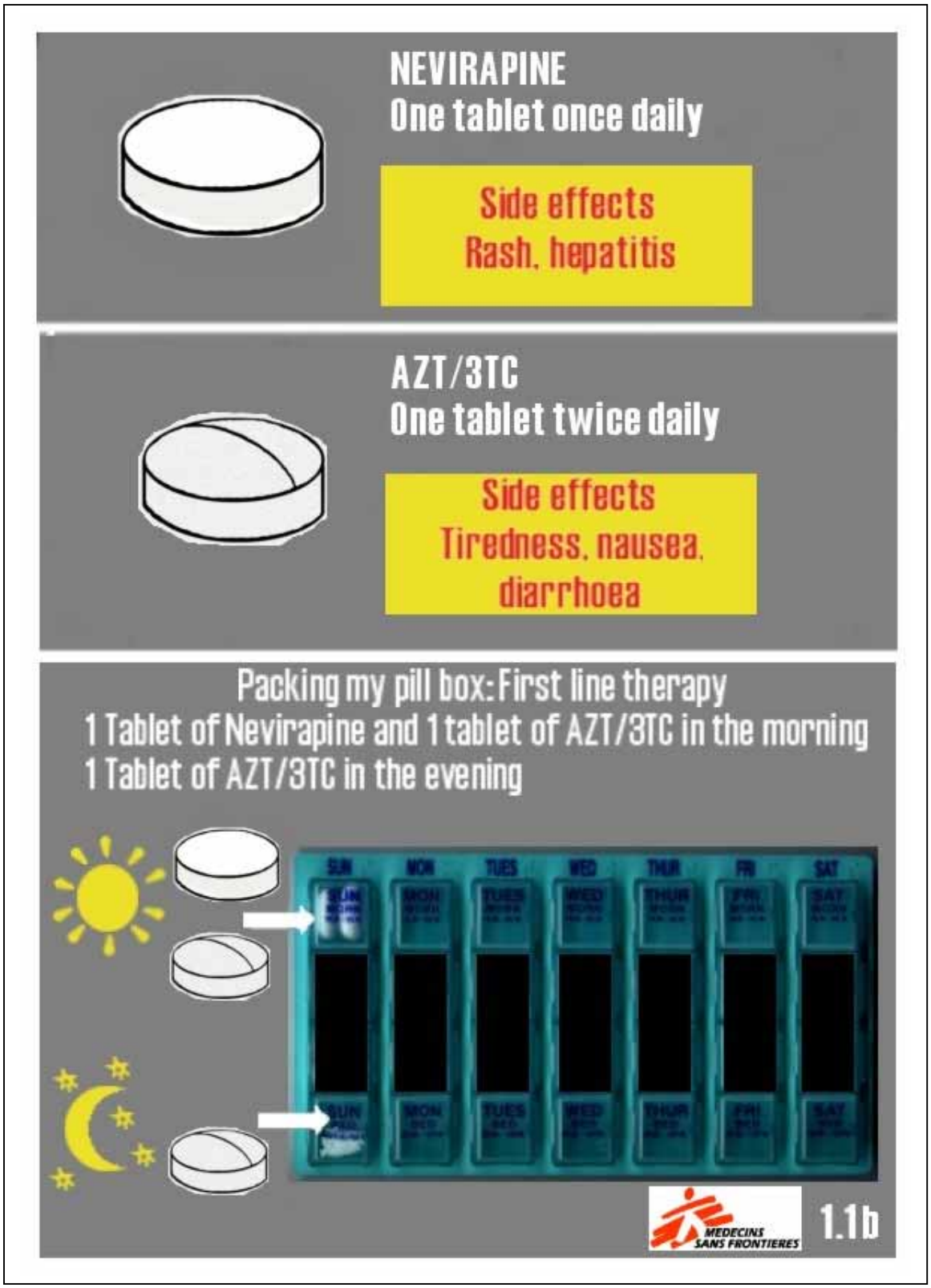
If you have any problems or questions, you can contact the staff working at the MSF infectious disease clinics:

- Michael Mapongwana: 021 363 0144
- Site C: 021 387 1038
- Site B: 021 364 9836

In an emergency after regular working hours, you can contact Dr. XXXXXX on (cell phone number here).

_____	_____	_____
Signature/mark of study volunteer/ caregiver of child	Printed name of study volunteer/ caregiver of child	Date
_____	_____	_____
Signature/mark of doctor	Printed name of doctor	Date
_____	_____	_____
Signature/mark of witness	Printed name of witness	Date

H. H1. DRUG ID CHART



H2. DAILY PLANNER

Daily Schedule

1h00 _____

2h00 _____

3h00 _____

4h00 _____

5h00 _____

6h00 _____

7h00 _____

8h00 _____

9h00 _____

10h00 _____

11h00 _____

12h00 _____

13h00 _____

14h00 _____

15h00 _____

16h00 _____

17h00 _____

18h00 _____

19h00 _____

20h00 _____

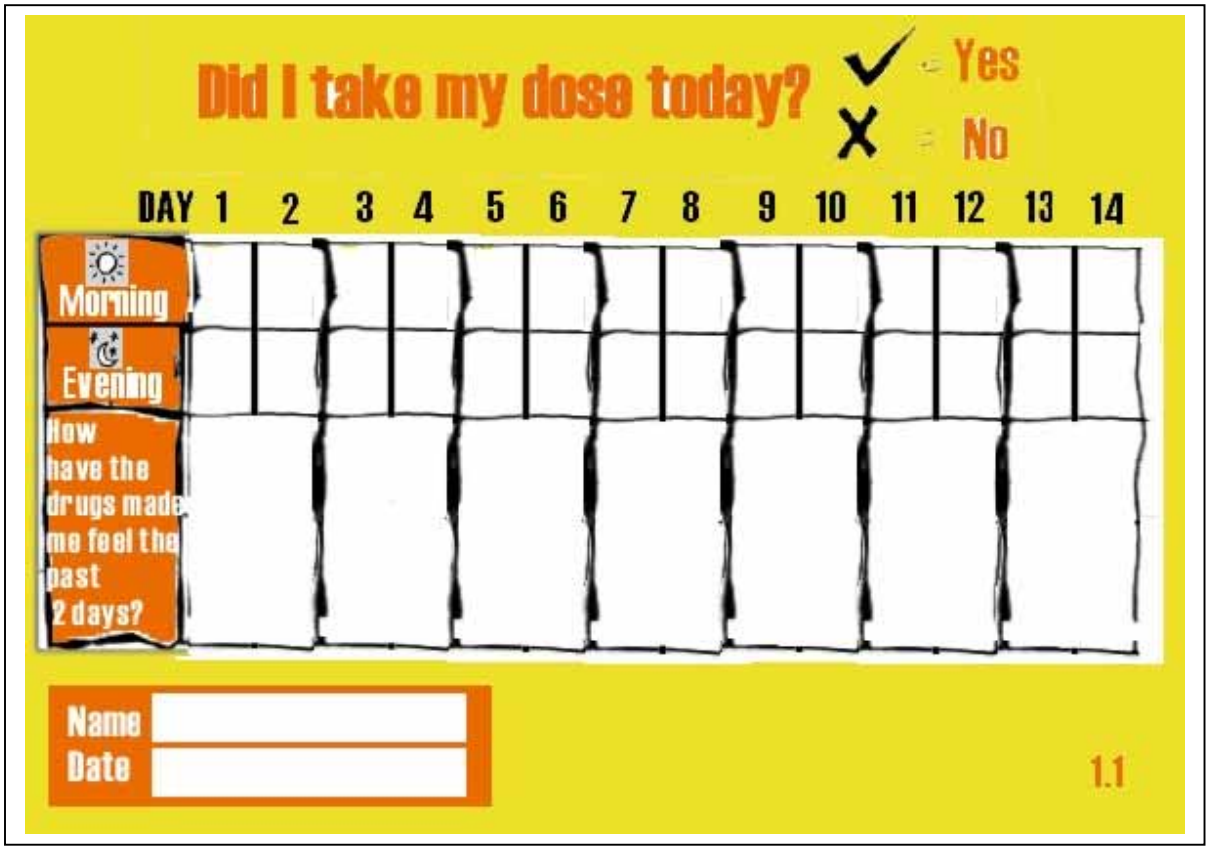
21h00 _____

22h00 _____

23h00 _____

24h00 _____

H3. TICK SHEET



H4. PATIENT ID CARD

MEDECINS SANS FRONTIERES

Name: _____

Current Medications: _____

_____

Please contact Dr. _____at _____