

DR TB Counseling

Training Pack

Contents

DR-TB Counseling Model Overview.....3

Routine DR TB Treatment Counseling 6

- Session Plan- Session 1
- Session Plan- Session 2
- Session Plan- Session 3
- Session Plan- Session 4
- Adherence Plan - Session 1- 4

DR TB Treatment Interruption Counseling38

- Background and Rationale
- Session Plan - Treatment Interruption Counseling
- Adherence Plan - Treatment Interruption Counseling

XDR TB Counseling53

- Session Plan - XDR TB
- Adherence Plan - XDR TB

DR TB Palliative Care Counseling 61

- Session Plan - DR TB Palliative Care
- Adherence Plan - DR TB Palliative Care

Competency Assessment Form for DR TB Counselors 70

The DR-TB Treatment Adherence model

The DR-TB Treatment Adherence model has been adapted from the ARV treatment adherence counseling model.

The model consists of 3 initial counseling sessions and additional sessions dependent on treatment adherence and treatment success.

Rationale for new model:

- Bring structure to counseling sessions
- Integrate with ARV counseling model
- Patient centered model
- Provide baseline knowledge and support to prevent treatment interruption
- Increased number of sessions allows for treatment literacy to be split and patient has time to process information

Tools:

- Session guide for counselors
- Adherence plans
- DR-TB flip chart

Training:

- Training of counselors (3-5 Day training):
 - Theoretical training on initiation and adherence counseling model, guidelines and tools.
 - Practical training based on the use of the guideline and tools through role –plays and case studies

MSF DR TB Counseling Model consists of:

1. Session 1-3: 3 initial counseling sessions completed ideally within the 1st month of DR TB treatment initiation
2. Session 4: Completed at the start of the continuation phase of DR TB treatment
3. Treatment Interrupter session – for patients that have interrupted DR TB treatment for 2 consecutive weeks or longer or have had short frequent interruptions
4. XDR treatment session – for patients with pre XDR or XDR TB diagnosis
5. Palliative Care session – for patient in whom DR TB treatment has failed

DR TB Counseling
Content of Counseling sessions

Session	Target	Timing and location	Session Content
Session 1	Newly diagnosed DR-TB patients at treatment	First day of treatment initiation Clinic	Treatment literacy Basic TB and DR- TB information regarding definition, when and where to take treatment, clinic visits, basic awareness of side effects and some other treatment related challenges, basic Infection control and pt. support Adherence steps Identify 3 reasons to stay healthy and alive Step 1- Getting to the clinic daily Step 2- Dealing with side effects Step 3- Getting support at home Step 4- Getting support at the clinic Step 5 - Audio
Session 2 – (may be combined with Session 3)	Newly diagnosed DR-TB patients having received counselling session 1	Within one week of treatment initiation Home or clinic	Treatment literacy Basic information regarding adherence, What to expect if adherent versus non adherent. Discuss importance of identifying drugs and dosages. What is culture and sputum culture conversion? Completing your treatment journey} Adherence steps Step 6- Completing your treatment journey Step 7-Identify a treatment partner Step 8 -Communicating with treatment team Step 9- How to manage w/e doses Step 10- Conclusion Reminder strategies
Session 3 – (may be combined with Session 2)	Newly diagnosed DR-TB patients having received counselling sessions 1, Session 2 may follow session 3.	Within first month of treatment initiation Home If patient refuses a home visit this may be done in the clinic with a family member joining the patient	Treatment literacy : Basic TB and DR-TB information, TB infection control and spread, Time off work and school, Patient journey, details on those at risk and contacts in the home, TB and pregnancy, traditional medication and alcohol use with treatment. Adherence steps: Step 11- How to protect my family Step 12-How to deal with drug/alcohol use Step 13-Planning for travel
Session 4 –	DR-TB patient who has completed the intensive phase-	Clinic	Revision of Treatment Literacy messages Revisit Adherence Steps:
Treatment Interruption Session	Patent who has interrupted DR-TB treatment for two consecutive weeks or who	Clinic or home	Treatment literacy What is adherence, What happens if you take your treatment, what happens if you stop taking your treatment,

DR TB Counseling

	frequently interrupts treatment for short time periods.		
Treatment interruption follow-up sessions	Patient who had the treatment interruption session	Clinic	Follow-up session Monitor goals achieved, set new goals
XDR-TB	Patient with a pre-XDR or XDR diagnosis- only when a doctor refers patient to a counselor with the relevant patient history	Clinic	Treatment Literacy
Palliative Care Session	Patient diagnosed as treatment failing	Clinic or at patient's home	Explanation about current diagnosis , What happens with treatment of other diseases, conditions that patient has? What happens when need to see a doctor or nurse? What is Palliative Care? Family Support? How do you protect your family? How to travel safely if patient intends to migrate

Routine DR TB Treatment Counseling

DR TB Counseling

NB! These sessions may not suite every context; please review for necessary adaptations

Session Plan

Session 1: DR TB Education Session and Adherence Counselling	
Target group	Patients newly diagnosed with DR-TB
Timing	Within the first few days of patient starting DR-TB treatment
Objectives	Understand basic principles of DR-TB and treatment
Duration	30 to 45 minutes
Mode	Individual (The treatment literacy section can be completed in a small group setting)
Tools	DR-TB flipchart and Adherence Plan
<p>Blue/Grey text: reflects what the counsellor needs to say Black text: reflects prompts, instructions or any information that is helpful for the counsellor</p> <p>A: Overview of Session</p> <p>1. Introduction of facilitator and objective of session Introduce yourself and acknowledge that right now the patient is probably finding it difficult to accept diagnosis. It must be difficult for you to accept your diagnosis, but acceptance will help you to get through the rest of your treatment journey. You will receive 3 counselling sessions and one of them will be a home visit with the family to cover everything you need to know about DR-TB and also to help you figure out how to keep taking treatment every day.</p> <p style="padding-left: 20px;">[Session Objective] Daily adherence</p> <p>2. Give patient an outline of session: During this session we will cover</p> <ul style="list-style-type: none"> • What you need to know about DR-TB • Planning your DR-TB Treatment Adherence together • The way forward – what happens from here <p>(Counsellors have the option of completing the adherence plan at appropriate points [see prompts] during the treatment literacy section or completing adherence step after treatment literacy section.)</p> <p>B: Treatment Literacy</p> <p>This is the part where you learn about your disease.</p> <p>1. <u>Do you know what infection you have?</u> You have drug resistant tuberculosis.</p> <p>2. <u>What do you understand about tuberculosis (TB)?</u> <u>(Optional, only if patient does not know or has never had TB before)</u></p> <ul style="list-style-type: none"> • TB is an infection caused by a germ that you breathe in 	

DR TB Counseling

- It gets into the lungs and grows there
- It can make holes in the lungs
- It can also affect other parts of the body
- People who have had TB before can get it again
- TB is curable with the correct treatment

3. What do you know about Drug Resistant TB?

- Drug resistant TB is disease caused by TB germs, but the germs are **resistant** to the normal TB drugs; this means that normal TB drugs do not work to cure the disease
- The drug resistant TB germs are more difficult to treat than the regular TB germs
- Different drugs have to be used to treat drug resistant TB
- It takes much longer to treat drug resistant TB – usually 2 years and sometimes longer

4. How and when will you be taking your treatment?

- Your doctor will decide what treatment to give you – the treatment may be different from other patients depending on the type of DR-TB that you have (i.e. which drugs your TB is resistant to)
- You will receive injections as well as tablets initially.
- The injection has to be given to you by the nurse in the clinic every week day (Monday to Friday) for at least 6 months, sometimes longer
- You also have to swallow tablets every single day of the week for about 2 years – this will be in front of the nurse in the clinic most days, but you will be given your tablets to take at home over the weekend.
- It is best to take the tablets first thing in the morning
- Every time you take your tablets, it must be recorded on your treatment card

The counsellor has the option to continue with **Adherence Step 1: Getting to the clinic** at this point in the session. Alternatively all the adherence steps can be completed at the end of the session.

5. What are some of the challenges you might experience with the treatment

- There are lots of pills to swallow, and the injection has to be given Monday to Friday for at for at least 6 months – it will not be easy to continue your treatment but we are here to help you get through this.
- Do you need to eat first?- It is not necessary to eat first, it is safe to take your treatment on an empty stomach

DR TB Counseling

- You might vomit your tablets after you have taken them:
 - ⇒ If you vomit while you are at the clinic or just after you have left the clinic, you need to go back and tell the nurse so you can get more tablets
 - ⇒ If you are already at home, come back the next day for your next dose as usual and tell the nurse that you vomited the day before

6. Do you know what side effects you might experience with the treatment?

- Not all patients get side effects
- Mild side effects are normal initially for most patients taking DR-TB treatment and these usually improve over time, so it's best to try and continue treatment.
- These might include: nausea, vomiting, stomach pains, dizziness, diarrhea, ringing in the ears, painful or burning feet, rash and aching joints.
- Many of these side effects are easily treated, so if they are bothering you, always report them to your clinic nurse or doctor before you decide to stop any treatment – there may be something that they can do to help you.
- **Some side effects are more serious**, hearing loss is a potentially serious side effect of the injections:
 - [It is important to have your hearing tested every month while you are receiving injections to identify early if you are starting to lose your hearing
 - The doctor can then change your medication to try to stop you losing any further hearing.]
 - Serious side effects are not that common, but they do happen, so look out for
 - Problems with sight or hearing loss
 - Seizures /fits
 - Blistering or peeling of skin
 - Feelings of extreme sadness (depression)
 - Confusion

The counsellor has the option to continue with **Adherence Step 2: Dealing with side effects** at this point in the session. Alternatively all the adherence steps can be completed at the end of the session.

7. How often do you need to come to the clinic?

- It is important to attend the clinic every day, Monday to Friday, for your treatment.
- Every month you will have a check up at the clinic, the monthly checkups are important to check if the treatment is working and give you feedback regarding your medical progress
- During these monthly visits you will:
 - Be weighed
 - Have Sputum collected, your sputum has to be taken around the same time (date and / or day) every month
 - Monthly sputum checks are very important as this is how the doctor monitors your response to treatment and this is how he/she decides when to stop your injection
 - If the TB nurse forgets to ask you to give sputum please ask

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- Be examined by the clinic doctor who will check your latest sputum, blood and hearing results
- It is best not to plan for any other appointments on the day you have your doctors appointment
- Some months extra test might be needed e.g. Chest X-Rays, Blood test...
 - On the days that you need to stay for test, you have to plan for a longer stay at the clinic as it will take some time
- Try not to stay away from the clinic without telling anyone.
- If for some reason you will not be able to come to the clinic, talk to the TB nurse so that a plan can be made for you to still get your treatment.

8. Why do you need to wear a mask?

TB is spread by people who cough, sneeze and spit the germs into the air.

- These germs can be breathed in by other people who might then also get the disease.
- You need to wear a mask when you are indoors and when you are around other people to reduce the amount of TB you cough into the air.
- People living in the same house as you or who have regular contact with you can wear a mask to protect themselves from breathing in the TB germs in the air.
- As far as possible, you need to try to sleep alone/ separately
- As far as possible try to keep doors and windows open so that fresh air can flow through your home
- We will talk more about how you can protect your family and others at a later counselling session

9. Do your family / those close to you know that you have DR-TB?

It is important to have the support of family and friends during the next 2 years.

Your support system could encourage you in taking your drugs, be a listening ear, accompany you to the clinic and be there when you are feeling sick.

- It is important to tell your family or close friend that you have DR-TB
- The family need to understand what is happening with you so that they can support you and learn how to protect themselves.
- Your family or close friend can then encourage you to take your treatment, accompany you to clinic and be there to help you when you are feeling sick.
- It is important to identify someone you trust and are close to you like a family member or a close friend, to provide encouragement and motivation to take your treatment every day, complete 24 months of treatment and help you take your treatment on weekends

The counsellor has the option to continue with **Adherence Step 3: Patient Support System** at this point in the session. Alternatively all the adherence steps can be completed at the end of the session.

Ask the patient to start thinking of which person from his/her support system could be his/her treatment supporter for the rest of his/her treatment journey. The patient can give you the person's name during the next counselling session or during the home visit.

10. Who else is going to support you?

At the clinic

It is important that you know your treatment team; they are here to help you get through this difficult time.

The clinic TB team is here to help you complete the treatment and to get well
Although we can help you, completing your treatment is your responsibility

The Clinic TB Nurse

- The clinic TB nurse will give you your treatment every day in the clinic.
- S/he will ask you to give a sputum sample every month. If s/he forgets remind him/her please
- You should report any problems you have with your treatment to the nurse and she will decide if you need to go to see the doctor.
- The clinic TB nurse is available to see you at any time if you have problems
- It will also help to get to know the names of nurses in the TB room and the DR-TB counsellor

The DR-TB Counselor

- The counsellor will do another counselling session with you at the clinic and visit you at home soon (to see you with your family if possible)
- (This is a good time to check if the patient is open to a home visit) Can the counsellor visit you at home
- The DR-TB counsellor will run support groups for DR-TB patients at your local clinic and you are welcome to attend any time.
- You can contact the DR-TB counsellor through the clinic at any time if you have any further questions or worries.

The Clinic Doctor

- You will have to visit the clinic doctor each month so he/she can examine you and look at your latest results.
- The doctor will decide when to stop your injection, and how long your treatment will be for.

The DR-TB Professional Nurse

- There is a DR-TB nurse working in your area to help clinic staff look after you in the community.
- If there are any problems with your treatment the DR-TB nurse might come and see you to try to resolve the problems.

The counsellor has the option to continue with **Adherence Step 4: The DR-TB support team** at this point in the session. Alternatively all the adherence steps can be completed at the end of the session.

The Audiologist

- This is the health professional who will test your hearing monthly.
- It is important to have your first hearing test as soon as possible so that any problems that occur with your hearing can be detected earlier.
- This is an important part of your care and we have to plan how you will get to the audiometrist for your hearing test every month while you are receiving injections.
- Once your injections are completed you will still need to go for a hearing test

The counsellor has the option to continue with **Adherence Step 5: Going for hearing screening every month** at this point in the session. Alternatively all the adherence steps can be completed at the end of the session.

C: Adherence

Now we talk about why you want to stay healthy and alive and we are going to make a plan together of how you are going to manage taking your treatment every day. (The section regarding making a plan together to stay on treatment refers to your adherence plan- if this was completed during the session it does not need to be repeated here.)

Identify Life Goals:

Can you tell me 3 main reasons for you to remain healthy and alive?

What are your goals or the dreams you still want to achieve?

Who are the important people in your life you want to live for?

Let the patient write down their 3 reasons to stay alive on their adherence form. If the patient cannot write, assist them in drawing their 3 reasons.

Add a sticker to the top of the page where patients wrote their 3 reasons.

As you complete each adherence step with the patient, allow the patient to right down their plans and assist the patient who cannot write.

For a patient who is illiterate discuss who would assist her/him at home with reading her /his adherence plans.

Adherence Step 1 – Getting to the clinic	
Review adherence goal	To treat DR-TB you need your treatment every day. It is important that you come to the clinic daily to get your medication (injection and pills) Once a month you will also have a check up with the doctor in the clinic when you come to take your medication.
Identify barriers	What would stop you from coming to the clinic every day? (No money for taxi, train not working, its raining when you usually walk, sick child, you feel quite sick yourself.)

DR TB Counseling

Make a concrete plan	<p>Identify a way the patient will get to the clinic daily <i>How will you get to the clinic every day?</i></p> <p>Identify a backup method of reaching the clinic daily if the patient experiences a problem <i>What solutions can you think of that would work best if one of these things happen?</i> (Some can help with money, transport, umbrella/ raincoat can be used, a neighbour watch child, inform doctor you too sick to come to clinic-)</p>
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Adherence Step 2 – Dealing with side effects

Review adherence goal	As I just said, some side effects are more serious and should be reported to the clinic nurse or doctor as soon as possible
Identify barriers	<p><i>What would make it difficult to tell the nurse or doctor that you are experiencing side effects?</i></p> <p>Reassure the patient that it is best to check with the nurse or doctor if they are worrying about any symptom. The team is there to support the patient and answer any questions they may have.</p>
Make a concrete plan	<p>Help the patient identify and plan what to do with mild side effects and side effects that worry him/her.</p> <ul style="list-style-type: none"> - With mild side effects the aim is to report and continue treatment even if side effect persists. - With serious side effects the aim is to report to the nurse and doctor as soon as possible.

Adherence Step 3 – Getting Support

Review adherence goal	<p>It is important to have the support of family and friends during the next 2 years. Your support system could encourage you in taking your drugs, be a listening ear, accompany you to the clinic and be there when you are feeling sick.</p> <p><i>It is important to tell your family that you have DR-TB.</i></p>
Identify barriers	<p><i>Have you told your family that you have DR-TB</i> <i>Did you experience any problems with family because you have DR-TB?</i> If the patient haven't told the family ask: <i>What would make it difficult to tell the family that you have DR-TB?</i></p>
Make a concrete plan	<p>Ask the patient to list those s/he told and name those they think who would support them.</p> <p>Only if the patient has not told any one: Help the patient identify members of his/her support team who s/he needs to tell his/her news to.</p> <p>Help the patient identify a time and words to tell his/her family that s/he has DR-TB <i>When do you think will be a good time to talk to your family about your TB? Who in the family will you talk to? What will you say to them?</i></p>

DR TB Counseling

Adherence Step 4– The DR-TB support Team

Review adherence goal	It is important that you know your treatment team, they are here to help you get through this difficult time. If you experience any problems with your treatment during your treatment journey, please let them know, so that they can assist you.
Action	Assist the patient to make a note of the contact details of the DR-TB counsellor/ clinic. { Put the numbers on the patient cell phone}

Adherence Step 5 – Going for hearing screening every month

Review adherence goal	It is important to go to the hearing screener at the clinic [have the schedule available] each month to have your hearing tested
Identify barriers	What would stop you from going to the clinic (mention the appropriate clinic) for hearing screenings every month? (No money for taxi, train not working, its raining when you usually walk, sick child, you feel quite sick yourself.)
Make a concrete plan	Identify a way the patient will get to the clinic for hearing screenings every month Help the patient identify how s/he will remember his/her audiometry appointments, and how s/he will get there. Help the patient identify a back up plan to get to audiometry What solutions can you think of that would work best if one of these things happen? (some one can help with money, transport, umbrella/ raincoat can be used, a neighbour watch child, inform doctor you're too sick to come to clinic)

D: Review

Closure of session (Let the patient know that the session is nearing an end)
The session is almost at an end. Let's review what we discussed today.

Take Home messages:

- A. Do you know what is wrong with your health?
- B. Do you know when and how you need to take your treatment?
- C. What will help you take your treatment well?
- D. Why do you need to wear a mask?

Remember to wear your mask at home and at the clinic

NB! Being diagnosed with DR-TB is very difficult and right now it must be hard. We are here and we want to support you.

DR TB Counseling

- **Check if patient wants to talk about any other issue or have further questions**
- **Give positive reinforcement**

I can hear that you have taken a decision to take care of your health and you can be proud of that. I am looking forward to see you next time and hear how it has been going. And even if you struggle with things, come back so that we can find solutions for them together.

Plan with the patient the date and time of the next session.

Session Plan

Session 2: DR TB Education Session and Adherence Counselling	
Target group	Patients newly diagnosed with DR-TB
Timing	After Session 1 (can be 1 week later)
Objectives	Understand basic principles of DR-TB and treatment
Duration	30 min
Mode	Individual/Group
Tools	DR-TB flipchart/Adherence Plan, stickers- same colour as sticker on patients adherence plan

Blue text: reflects what the counsellor needs to say

Black text: reflects prompts, instructions or any information that is helpful for the counsellor

A: Overview of Session

3. Introduction of facilitator and objective of session

Welcome patient to the second session.

4. Give patient an outline of session:

- Today we will review key messages from Session 1
- What else do you need to know about DR-TB
- Planning your DR-TB Treatment Adherence together
- The way forward – what happens next

Review of session 1 take home messages

A. What TB do you have?

B. Do you know when and how you need to take your treatment?

C. Why do you need to wear a mask?

Remember to wear your mask at home and at the clinic

Review adherence Plan

Now you have been on treatment for a week, can you tell me how it has been working out for you?

Were you able to come to the clinic daily?

Let's look at your adherence plan and you can tell me how you have managed to implement each plan.

What were the difficulties you have faced since you started treatment?

What have you done to overcome them?

If patient talk's about difficulties faced ask the patient to explain what solutions was used, ask if the solutions worked.

If solution worked, congratulate patient.

If the solution did not work help the patient find a solution.

B: Treatment Literacy

This is the part where you learn more about your disease.

1. What is adherence?

- Taking all the tablets you should, every day at the same time

2.What happens if you take your treatment well?

- You should start feeling better
- You should start gaining weight
- You will be healthier
- Your sputum tests should come back negative

Aim to take all your treatment everyday.

3.What happens to you if you stop your treatment?

- If you do not take your DR-TB treatment, you give the germs a chance to grow again
- Every time the germs grow again there is a chance that further resistance will develop. This means that the Drug Resistant TB germs will continue to grow and multiply and will eventually make you sick again.
- If the Drug Resistant TB germs gets a chance to grow further you may become extensively drug resistant (XDR TB), this means the DR-TB drugs you were using before may not work anymore
- Treatment will take longer and you may need to restart the injection
- You may become infectious again and spread the drug resistant TB germs to other people, including your children, family, friends and others in the community
- There is only a small number of drugs available to treat XDR-TB: once they are all used up, there will be no more treatment options available for you- you will then most likely die from your disease.

4.Do you know the names of the tablets and injections you will be taking?

- All the DR-TB drugs have long (generic names) and brand names
- If a different company makes the tablets, the brand name and the colour and shape of the tablet might change
- Your doctor will choose at least 4 of the following tablets to make up your treatment:
 - Pyrazinamide (PZA)
 - Ethambutol (EMB)
 - Isoniazid (INH)
 - Moxifloxacin
 - Ethionamide
 - Teridizone
 - PAS

DR TB Counseling

- Your doctor will also choose one injection that will be given to you by the TB nurse
- It is important that you learn to recognise the shape and colour of the tablets and also how much of each you have to take.
- If the shape or colour change at any point check with the nurse to see if it is still the right treatment you are getting.

5.Sputum and Culture conversion

There are 2 types of sputum test that will need to be done every month while you are on treatment.

Smear microscopy

- It is when the laboratory looks at your sputum under a microscope and counts how many germs are still in your sputum
- It is a quick test and results are available within days

(Tell the patient that this test is routinely done and when they are told that they are smear negative they should be careful not to confuse it with the sputum culture result. The sputum culture result is the most important result and the patient needs to know the culture result as it will help the doctor make decisions about their treatment.)

Sputum culture

- Sputum culture is a specimen of your sputum that has been sent to the lab. Your sputum is placed in a special incubator with a special growth medium to see if TB germs are still active; this takes up to six weeks.
- 'Culture' means growth
 - if the sputum culture is **positive**, it means that TB is still growing in the sputum, and you could possibly still infect other people; if the cultures remain positive while you are on treatment then it could mean that the drugs are not working and your disease is not getting better;
 - if the sputum culture is **negative**, it means that no more TB is growing in the sputum, and you are unlikely to infect other people; negative cultures indicate that the drugs are working and you are getting better. However, it is important to continue your treatment till the end
- Right now there is a sputum culture growing at the lab. After 4-8 weeks we will hear if there are any other drugs your TB is resistant to. This will tell us what kind of Drug Resistant TB you have. E.g. XDR TB
- **What is sputum culture conversion and why is it important to find out if your sputum has converted to culture negative?**
 - Culture conversion is when your sputum culture(change from positive to negative) is negative 2 months in a row
 - The injections will be stopped 4 months after your sputum culture has converted to negative
 - You still have to take injections for a minimum of 6 months, even if your cultures become negative right away.
 - It is important that you give the clinic nurse a sputum specimen monthly.

- Your sputum have to be taken around the same time (date and/or day) every month.
- Ask the patient how s/he will remember to take there sputum monthly.

6.Completing your treatment journey

- Many things get in the way of people taking treatment regularly and completing the total of 24 month treatment journey
- These are normal events that need to be planned for
- Some people stop their treatment journey because
 - They still feel unwell
 - They may feel tired, depressed and have a poor sex drive
 - They may have pain in the chest
 - Due to pain from injections
 - Due to side effects from the tablets
- They start to feel better before they are rid of all their drug resistant TB
- These problems are frequent and it is important to express it if you are tempted to stop the treatment for one of these reasons.

Note: The flip chart covers more questions in this section (What to do if you are going away, moving) - some will be dealt with in Session 3 adherence step 13.

C: Adherence

Now we are going to make a plan together of how you are going to manage taking your treatment every day.

Adherence Step 6 – Completing the treatment journey	
Review adherence goal	We spoke about the importance of completing the treatment during our last session. We understand that the treatment journey is a long one. People make mistakes and you might stop taking treatment for a while. It is important that you restart treatment as soon as possible.
Identify barriers	What could stop you from going back to the clinic for treatment after you interrupted your treatment” The patient may feel like s/he failed, stress that everyone makes mistakes. The patient may feel anxiety because the staff might be unfriendly towards the patient upon his/her return. Explain to the patient that staff are only acting in their best interest and staff are reacting out of concern.

DR TB Counseling

Make a concrete plan	Help the patient plan what they will do in future if the patient makes a mistake. <i>What will I do if I make a mistake ,and don't come to the clinic for a while to take my treatment</i>
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Adherence Step 7 – Treatment Partner

Review adherence goal	<i>During the last session we spoke about how important it is that you have support during this time and during the next 24 months of taking treatment. Have you thought of a person that could be your treatment partner?</i>
Identify barriers	<i>What would make it difficult to find a treatment partner</i> Ask the patient if s/he has a close friend or family member that can be a treatment partner. A spouse or partner may not be the best person because when their relationship experience difficulties it will affect the patient's treatment journey. If the patient cannot identify anyone, do not insist. Write in the form that the patient could not identify someone. Maybe someone can be identified from the support group at a later stage.
Make a concrete plan –	Identify a person and write down the name and contact details.

Adherence Step 8 – Communicating with the treatment team

Review adherence goal	<i>It is important that you are able to speak to someone at the clinic when you have concerns or need assistance</i>
Identify barriers	<i>What could stop you from talking to a member of the clinic team</i> Talk to the patient of the realities of what happens in the clinic. The clinic gets busy, patients sometimes need to wait, staff at times seems to lecture at patients. Reassure patients that the clinic team has their best interest at heart and want to see the patient cured. They may at times lecture patients but they will listen to patient's problem and concerns. The patient is welcome to complain if they feel unheard.
Make a concrete plan	Help the patient identify a focal person at the clinic that they might feel comfortable with. <i>Who at the clinic do you think you can trust or think you can talk to when you have an issue</i>

Adherence Step 9 – Management of weekend doses

Review adherence goal	<i>You will need to take treatment on the weekends by yourself (not the injections). Are you taking ARVs on the weekend?</i>
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DR TB Counseling

Identify barriers	What could stop you from taking your DR-TB treatment on the weekend?
Make a concrete plan	<p>How will you remember to take your DR-TB treatment? Help the patient identify reminders including family assistance, linking with taking ART if it is appropriate</p> <p>Where will you store medication on the weekend at home? – link to ART (if appropriate).</p>

Adherence Step 10 – Reminder strategies

Review adherence goal	<p>Having reminders can help you focus on the reasons to stay healthy and alive. What are your 3 reasons to stay healthy and alive?</p> <p>You also have to remember to take your treatment.</p> <ul style="list-style-type: none"> • Daily, Monday to Friday at the clinic • On weekends at home
Identify barriers	<p>What difficulties have you previously faced with remembering to take medicine (like antibiotics or others)</p> <p>How have you previously reminded yourself to take these medications?</p>
Make a concrete plan	<p>Identify reminder tools (propose stickers or whatever they want like a piece of fabric) and link them to the 3 reasons to stay healthy and alive on the adherence plan</p> <p>The reminders can be put in your house to remind you of your reasons to stay healthy and to take your Treatment</p> <p>Where can you place these reminders so that you see them at the time that you need to take your treatment?</p> <p><u>Ask:</u> What are you doing around the time your treatment is due? Most patients would say they are waking up, brushing teeth, having breakfast. This gives various options for placement of reminder stickers.</p> <p>Show the patient the sticker on the patient’s adherence plan next to the 3 main reasons for staying healthy and alive.</p> <p>Encourage the patient to read their 3 reasons everyday, preferably before they need to go to the clinic or take their treatment, or just before they sleep at night or upon waking up.</p> <p>What other things could you use to remind you to go to the clinic or take your treatment (set cell phone alarm, get family members to remind you)?</p>

D: Review

Closure of session [Let the patient know that the session is nearing an end]

Take home messages

Congratulations on participating in this session.

Lets look at what you remember about DR TB

A. What happens if you take your treatment well?

B. Why do you need to have monthly sputum?

C. When can you stop treatment?

Aim for negative sputum cultures

Complete you treatment journey

- You have good reasons to live for. You have shown this last few days that you have a strong will by getting up daily and making your way to the clinic. You can do this!
- And Congratulations on completing your 2nd session

Plan with the patient the date and time of the next session.

Session Plan

Session 3: DR TB Education Session and Adherence Counselling and Infection Control assessment	
Target group	Patients newly diagnosed with DR-TB
Timing	After Session 2
Objectives	Creating understanding of the basic principles of DR-TB and treatment and Infection control by the family Creating a family support base for the patient
Duration	30 min
Mode	Family and patient if possible
Tools	DR-TB flipchart , Adherence plan Pamphlet with general DR-TB information.
<p>This session is designed to be a family session but if for some reason a home visit is not possible immediately this can be done with patient only.</p> <p>Blue/Grey text: reflects what the counsellor needs to say Black text: reflects prompts, instructions or any information that is helpful for the counsellor</p> <p>A: Overview of Session</p> <p>5. Introduction of facilitator and objective of session</p> <p>Introduce yourself thank the patient and family for allowing you into their home. Tell the family that the patient has DR-TB. This disease takes a long time to treat and the patient is starting a very long treatment journey that s/he needs support with.</p> <p>It is important that the family is aware of the some issues that the patient will face during the treatment journey. The family also need to be aware that TB is infectious and they need to know how to protect themselves.</p> <ul style="list-style-type: none"> • Ask the patient if you can see the home, see where patient sleeps in order to do a quick Infection control assessment. • At this point ask the patient if you could see where s/he placed the stickers to help him/her remember there 3 reasons to stay healthy and alive. Congratulate patient if stickers in the home. Review reminder strategies – Adherence step 8 if no stickers displayed. <p>6. Give patient/ family an outline of session:</p> <ul style="list-style-type: none"> • What the family and you need to know about DR-TB • Planning the patient’s DR-TB Treatment Adherence together • The way forward <p>B: Treatment Literacy This is the part where you learn more about DR TB disease</p> <p>1. What do you understand about tuberculosis (TB)? (This section is extra for family)</p> <ul style="list-style-type: none"> • TB is an infectious disease caused by a germ that you breathe in • It gets into the lungs and grows there 	

- It can make holes in the lungs
- It can also affect other parts of the body
- People who have had TB before can get it again
- TB is curable with the correct treatment

2. What do you know about Drug Resistant TB? (This section is extra for family)

- Drug resistant TB is disease caused by TB germs, but the germs are **resistant** to the normal TB drugs; this means that normal TB drugs do not work to cure the disease
- The drug resistant TB germs are more difficult to treat than the regular TB germs
- Different drugs have to be used to treat drug resistant TB
- It takes much longer to treat drug resistant TB – up to 24 months

3. How is TB spread?

- All TB is spread by people who have TB in their lungs, who cough, sneeze and spit the germs into the air
- The TB germs in the air can be breathed in by anyone
- This happens especially in small crowded spaces which are poorly ventilated, i.e. no movement of air (windows and doors closed)
- Drug sensitive TB and drug resistant TB are spread in the same way
- DR- TB is **NOT** more contagious than TB

4. What would make you think that someone at home has TB?

The signs and symptoms of DR-TB are the same as normal TB

- 2 weeks or more loss of appetite
- loss of weight
- fever
- drenching night sweats
- chest pain
- Anyone with these problems would need to go to the clinic for sputum test to see if they have TB
- People can have TB even if they do not have a cough

5. What are important ways to protect others and not spread TB? [Ask both the patient and family if they can think of ways to protect others]

- You are still infectious until your sputum culture is negative

DR TB Counseling

- The most important way to avoid spreading TB is to take the TB treatment every day and complete the full course.
- Avoid close contact with others, especially children under 5 years, until your sputum culture test is negative.
- At home the spread can be reduced by opening the windows and letting the sunshine and fresh air move through the house
- Spend as much time outside as possible if you are around other people.
- The patient has to try to wear a mask if s/he is in a room with many other people and the air flow is poor.
- If possible sleep in a bedroom on your own or at least try not to share a bed.
- Spend as much time outside as possible if you are around other people
- Wear a mask or cover your mouth with your hand or sleeve when you cough
- Do not spit in the ground; spit into a tissue and throw it in the bin
- Ask anyone with a cough to go to clinic for a TB test
- TB **cannot** be spread by sharing cups or eating utensils, shaking hands, peoples clothes

The counsellor has the option to continue with **Adherence Step 11: How to protect my family** at this point in the session. Alternatively all the adherence steps can be completed at the end of the session.

6. Who is most at risk?

- You can be infected with DR-TB even if you have never had TB before
- Those who spend lots of time around people with TB and DR-TB are at higher risk of being infected and getting sick – e.g. laboratory and health care workers, people in mines and prisons

Who lives at home with you?

- People who are in close contact with you on a daily basis, such as those living in the same house, may be at increased risk of being infected with TB and DR-TB.
- This means that they should go to the clinic and tell the TB nurse that they are a contact of a DR-TB patient
- The TB nurse and the clinic doctor will examine and decide what test need to be done and they will also offer an HIV test

Are there any children under 5 years of age who live in your house?

DR TB Counseling

- Children under 5 years are most at risk of developing TB and DR-TB disease.
- All children living in your house who are under 5, or older children who are HIV positive, should be screened for TB.
- This means that they should go to the clinic and tell the nurse that they are a contact of a DR-TB patients.
- The nurse and doctor will do an examination, a CXR, a skin test for TB, and they will also offer an HIV test for the child.
- Any child who is a contact of a DR-TB patients but who does not have active TB disease should be offered tablets to prevent them from developing DR- TB.

Are there any children <5 years of age who live in your house?

7. Does the patient need to take time off work or school?

Yes

Remember that TB is infectious and just as the family needs protection, the people at work/school need protection too.

- You need to take time off work/school until your sputum cultures are negative; this will protect those you work with/attend school with
- Ask your clinic staff to tell you about the social assistance options that are available.
- The clinic doctor or TB nurse are not able to assist you in making an application for a grant, but they can tell you where the nearest social services offices are.
- Ask your clinic doctor or TB nurse to assist you with a sick certificate.
- You will need to speak to your employer about long sick leave and UIF benefits.

8. What happens if [patient name] falls pregnant?

- Women should avoid falling pregnant while on DR TB treatment, as it means that some of the drugs will have to be stopped and this will reduce your chance of being cured from your disease.
- It is important to have a reliable family planning method- the 3 month injection is safe to use with DR-TB
- Having a baby during this time could be difficult for the family, especially if you are sick, than the family need to care for both you and the baby.
- If however you are pregnant or suspect that it possible, it is important that the nurse and doctor are informed as soon as possible.

9. Do you know about the link between TB and HIV?

DR TB Counseling

- People with HIV have a weakened immune system and are more likely to get TB
- TB and HIV are spread in different ways :
 1. TB Germs are breathed in
 2. HIV is most commonly spread through unprotected sex
- The only way that we can tell whether you have HIV is through a HIV test. A HIV test is strongly advised for everyone with TB so that we can provide the extra care that is required for those with both TB and HIV
- If you have HIV :
 1. TB and DR-TB are still curable with the correct treatment
 2. You may need additional tablets to prevent other infections
 3. You should start ARVs as soon as possible after you have started DR-TB treatment, regardless of your CD4 count
 4. If you are already on ARVs, you might need to change one of the tablets while you have the injection as part of your DR-TB treatment
- If your HIV test is negative then you should re-test again in three months time, and ensure you stay HIV negative through practicing safe sex

10. Can [patient name] use traditional medication with the DR-TB treatment?

As counsellors our role is to advise. We cannot tell patients they may not use traditional medication but you can advise them that

- They should discuss it with the nurse/doctor first
- It may be dangerous to use them with DR-TB treatment
- They may make the DR-TB treatment not work properly
- Any traditional medication that causes vomiting and diarrhoea should be avoided.

Tell patients that if they decide to use traditional medication they should carry on with their DR-TB treatment as well.

11. Can [patient name] use alcohol/ drugs when you take DR-TB treatment?

This can be a difficult session to discuss in front of family as some family members may react negative ; especially if the patient has a problem with alcohol or drugs. Make it clear that you are not blaming the patient if they struggle with alcohol or drugs. Your aim is to ensure that the patient still has enough support to get to the clinic daily for his/her treatment. If the patient wants help to stop we can refer the patient but this session is not to force patients to stop drinking.

- Taking drugs and alcohol can make a person less likely to remember to attend the clinic daily to take their treatment.
- It can also reduce the effectiveness of the DR TB drugs.

DR TB Counseling

- If the patient has difficulty managing how much alcohol or drugs they take, they will need the support of the family help them with their treatment.
- Try to cut down or avoid it as much as possible.
- There are support organizations that we can refer you to that can assist and support you in cutting down alcohol and drug use.
- If it is very difficult for you to cut down or avoid taking alcohol and drugs, it is important that you plan ways to remember to get to the clinic in the morning before you take anything.
- If you use alcohol and drugs on the weekend it is important to plan how you will remember to take your weekend medication.

C : Adherence

Now we are going to make a plan together of how you are going to manage taking your treatment every day.

Adherence Step 11: How do you protect your family?	
Review adherence goal	It is important that you do not spread the TB germs to your family and others.
Identify barriers	<p>What would make it difficult to protect others and your family? Help the patient think of situations like work, school, sharing a bed at home, and limited space at home. These things will make following infection control guidelines difficult.</p>
Make a concrete plan	<p>Help the patient make plans to Sleep alone; if not in a separate room at least in a separate bed. Where can you sleep to ensure the family stays safe? Take sick leave- Talk about asking the doctor/nurse for a sick certificate</p>

Adherence Step 12– Dealing with substance use	
Review adherence goal	<p>It is important that you take your treatment everyday. Using alcohol drugs make it difficult to remember to take treatment We advise you to avoid alcohol and drugs while you are on DR TB treatment but if this is not possible, you still need to take your DR TB treatment.</p>
Identify barriers	<p>What would make it difficult to take your treatment and get to the clinic when you have taken a substance Ask the patient to identify what would make coming for his/her treatment difficult if s/he has taken a substance. Discuss whether the patient can't delay taking a substance till after treatment has been taken. Discuss the possibility of a friend or family member escorting the patient to the clinic when a substance was taken.</p>
Make a concrete plan	<p>Help the patient make a plan to ensure s/he takes the treatment over weekends and daily at the clinic. How will you remember to take your medication over weekend? Where will you keep your weekend medication?</p>

DR TB Counseling

Adherence Step 13 – Planning for travel	
Review adherence goal	<p>As explained you will need to attend your clinic each day to get your DR-TB treatment including a daily injection for at least 6 months. Now that you have started DR-TB treatment, it is important to discuss travelling away from your home.</p> <p>Share information</p> <ul style="list-style-type: none"> – It is important to know that all clinics and hospitals in other districts, provinces and or countries may not have DR-TB treatment. Your clinic might have to send you to a specific TB hospital in the area you plan to visit if it is appropriate. The DR-TB drugs may be ordered from the central special hospital but you will have to discuss this with your clinician. This all takes time, so it wont be possible to get DR-TB treatment immediately – It is not possible for your clinic to give you a supply of DR-TB treatment as we cannot give you the injection to take with you. It may be possible to get a treatment supply for travel when you finish the injection and start continuation phase. We will make a new plan for you at that time.
Identify barriers	<p>As explained you will need to attend your clinic each day to get your DR-TB treatment including a daily injection for at least 6 months. Now that you have started DR-TB treatment, it is important to discuss travelling away from your home.</p> <p>Ask the patient to think of emergency situations that may require urgent travelling</p>
Make a concrete plan	<p>If you have to travel due to an emergency, it is best to come to this clinic in advance so that your treatment team can help make a plan for you. This plan will depend on how long you have already been getting the injection and whether your culture has converted to negative. If for any reason your travels are unplanned and it is impossible for you to come to this clinic:</p> <ul style="list-style-type: none"> – If you think you will be somewhere for an extended period, it is important to go to your closest clinic in that area, as soon as possible after arrival – tell them that you have DR-TB, you have started DR-TB treatment but have no treatment with you, so that they arrange transport to the hospital or order the treatment you need. They will need to phone us to confirm your treatment.” – If you are not getting help from the clinic , please contact your DRT-TB counsellor or nurse and ask them to speak to the nurse in that clinic where you are. – Help patient program into their cell phone: <ul style="list-style-type: none"> » phone number of TB nurse, DR-TB counsellor and clinic » their file/clinic number – Please remember that it is very important that you protect other people you are travelling with by ensuring the windows are open and you are wearing your mask while in the car or bus" <p>It is important to know that we are here to help you stay on your treatment, if there has been a problem and you had to travel as an emergency and you have stopped your treatment, please come back to us when you return so that we can help you get back onto your treatment immediately</p>

D: Review

Closure of session [Let the patient know that the session is nearing an end]

Take Home Messages

A. How to protect the family?

B. Who is most at risk?

C. When can the patient stop the treatment?

Give a short motivational speech to the family – The patient can only do this with your support. You will be a great help by supporting him/her in the treatment. If you need more information, we are there to support you.

Session Plan

Session 4: End of Injectable Phase of DR-TB Treatment	
Target group	DR-TB Patients who completed the intensive phase
Timing	At 4–6 months on treatment – culture converted, injection finished
Objectives	Identify gaps in DR-TB knowledge To acknowledge milestone and provide on-going treatment literacy
Duration	30-60 min
Mode	Individual
Tools	Original adherence plan; DR-TB flip chart
<p>Blue text: reflects what the counsellor needs to say Black text: reflects prompts, instructions or any information that is helpful for the counsellor</p> <p>A: Overview of Session</p> <p>1.Introduction of facilitator and objective of session</p> <p>Introduce yourself and thank the patient for being open to having this session.</p> <p>Congratulate patient on reaching this milestone</p> <p>Congratulations for staying on your treatment this far! You are at the end of the first phase of your treatment and you no longer need injections. That is a big achievement! It is not the end of your treatment journey though.</p> <p>2.Give patient an outline of session:</p> <ul style="list-style-type: none"> • During this session we will talk about some important information that you need to remember about DR-TB treatment • Review some messages from previous counselling sessions • The next steps in your treatment journey <p>B: Treatment Literacy</p> <p>This is the part where we talk about some information that is important for you to remember about DR TB.</p> <p>Assess gaps in knowledge</p> <p>Is there anything you still want to know about DR-TB disease or DR-TB treatment, or anything you want me to repeat from previous counselling sessions?</p> <p>Counselling Sessions 1-3 and other education tools may be used again as necessary (e.g. DR-TB flipchart and patient information leaflets).</p> <p>1. Are you feeling better?</p> <ul style="list-style-type: none"> • Even though you are probably feeling much better than when you started treatment, we know that there may still be some TB germs left in your body. 	

- You need to complete the full 2-year treatment course to completely kill all of the remaining TB germs. This might be difficult, because when people feel better they usually want to stop taking their treatment.

2. Do you know how far you are in your treatment journey?

- You have already finished the first phase of your treatment and you are now in the 'continuation phase'.
- This means that you do not need injections any more but you must still take your tablets every day for the rest of your treatment journey.

3. For how long do you still have to be on treatment?

- Treatment for drug resistant TB is up to 2 years in total, sometimes longer.
- You had to have the injection for at least 6 months, and now you have to continue taking the tablets every day for the rest of the course.
- The doctor in the clinic is the one who decided when to stop your injection and will also decide when to stop the treatment completely. The decision is based on:
 - how you are feeling when he/she sees you in clinic every month,
 - how well you are taking your treatment every day,
 - and the results of your sputum cultures every month.

It is very important that you continue to take your tablets every day until your doctor tells you that you can stop.

4. What will happen if you DO NOT complete the rest of my treatment properly?

- If you stop taking treatment before the doctor tells you to, this is called "treatment interruption" or "lost to follow-up"
- We know it is difficult to continue this treatment for 2 years and there are lots of reasons why people stop taking their treatment. But if you don't finish your treatment properly, those few TB germs left in your body will start to grow and you will become sick again.
- You will also start to spread the TB germs to other people around you.
- If you stop taking your treatment before the doctor tells you to, then someone from the clinic will try to come and find you to see what the problem is and how they can help you.
- They will ask you to come back to the clinic to see the doctor, who will examine you and ask if you are having any problems with the drugs.
- The doctor might decide to either:
 - Restart your treatment from the beginning (with injections again);
 - Continue your treatment with just the tablets, but then extend the total duration of treatment to make up for the missed months;
 - Withhold all treatment until more tests are done at the lab to see if your TB has become more resistant to even more drugs.

5. Monitoring progress through treatment

- The tablets can still affect your internal organs without you realising it, and so the doctor might still need to do some **blood tests** every few months to check
- You still have to give sputum to send to the lab **every month** for the rest of treatment.

Sputum culture

- ‘Culture’ means growth. When your sputum is sent to the lab, they keep it in a warm environment to see if any TB grows in your sputum sample.
 - If the sputum culture result is **positive**, it means that the TB germs are still alive and are growing in that sputum sample;
 - Usually people’s sputum cultures are only positive for the first few months of treatment, and it means they can still infect other people at that time.
 - If the sputum culture result is **negative**, it means that no more TB is growing in that sputum sample;
 - Negative cultures indicate that the drugs are working properly to kill the TB and that the person is no longer infectious to other people.
- Your doctor will check your sputum results every time you see him/her in clinic – your sputum culture results have to be negative for at least 18 months before you can stop your treatment
- If you do not give sputum to the clinic staff every month to send to the lab, the doctor will not know when to stop your treatment
- If you do not take your treatment properly every day for the full course, then the TB will start growing again and your sputum cultures will become positive. You will eventually get sick again and you will infect other people.

6. What tablets will you be taking for the rest of your treatment?

- The tablets to treat your DR-TB will stay the same as before
- The doctor might increase the number of these tablets if you gain weight
- Let us review the different tablets that you are taking

Go through the picture chart of all the different pills for DR-TB and go through the names and variations of colours and shapes. Check that the patient knows which ones they should be taking.

7. Staying healthy and protecting yourself and others from getting sick again

- Continue ARVs – this will improve your chances of being cured from TB
- Encourage contacts to be screened – if any of your close contacts become unwell with TB symptoms, they should go to clinic to be screened for TB

DR TB Counseling

- Contraception – women should avoid falling pregnant while on DR-TB treatment, because the tablets can still harm the baby
- Avoid alcohol – drinking alcohol makes you less likely to remember to take your treatment, and also reduces the effectiveness of your DR-TB drugs. Try to cut down as much as you can while you are still on DR-TB treatment.

8. Do I still need to come to the clinic every day and see the doctor every month?

- Yes, you still need to come to the clinic every day to collect your tablets to eat them in front of the nurse in the TB room. This is called Directly Observed Therapy, or DOT.
- You still need to give a sputum sample in the clinic once a month (at the same time of month as before)
- The doctor may still want to do a blood test sometimes
- You will still see the doctor once a month so he/she can assess how you are feeling and to review the results of your sputum and blood tests, and then decide when to stop your treatment.

C : Adherence

So let's go through your adherence plan from when you started treatment

- Tell me again your three reasons to stay healthy and alive.
- Step 1 - How do you get to your clinic / appointments every day?
- Step 2 - Are you still having problems with side effects?
- Step 3 - Who are the members of your support system at home now?
- Step 4 - Who in your clinic is supporting you through your treatment?
- Step 5 - Do you have any more appointments planned to test your hearing again?
- Step 6 - What did you do when you made a mistake and missed any of your clinic visits in the last 6 months?
- Step 7 - Who is your Treatment Partner now?
- Step 8 - Who is the main person you speak to in the clinic when you have concerns or need assistance relating to your treatment?
- Step 9 - Explain to me how you remember to take your medication on the weekend.
- Step 10 - How do you remind yourself to take treatment or remember appointments?
- Step 11 - How do you and your family protect yourselves from DR-TB?

DR TB Counseling

- Step 12 - How do you manage to remember to take your treatment whenever you have a drink of alcohol or use other drugs?
- Step 13 – Did you need to travel in the last six months? What arrangements did you make with your clinic when you needed to travel?

If any problems raised you can go back and repeat the relevant Adherence Steps from Counselling Sessions 1-3.

Now let's review a few important adherence steps again to make sure you have a plan for completing your treatment journey, and also to make a plan for if you have to go away on a long trip or want to go back to work at some point:

Adherence Step – Completing the treatment journey	
Review adherence goal	We spoke about the importance of completing the treatment during our last session. We understand that the treatment journey is a long one. People make mistakes and you might stop taking treatment for a while. It is important that you restart treatment as soon as possible.
Identify barriers	What could stop you from going back to the clinic for treatment after you interrupted your treatment” The patient may feel like s/he failed, stress that everyone makes mistakes. The patient may feel anxiety because the staff might be unfriendly towards the patient upon his/her return. Explain to the patient that staff are only acting in their best interest and staff are reacting out of concern.
Make a concrete plan	Help the patient plan what they will do in future if the patient makes a mistake. What will I do if I make a mistake ,and don't come to the clinic for a while to take my treatment

Adherence Step – Planning for travel	
Review adherence goal	As explained you will need to attend your clinic each day to get your DR-TB treatment including a daily injection for at least 6 months. Now that you have started DR-TB treatment, it is important to discuss travelling away from your home. Share information <ul style="list-style-type: none"> – It is important to know that all clinics and hospitals in other districts, provinces and or countries may not have DR-TB treatment. Your clinic might have to send you to a specific TB hospital in the area you plan to visit if it is appropriate. The DR-TB drugs may be ordered from the central special hospital but you will have to discuss this with your clinician. This all takes time, so it wont be possible to get DR-TB treatment immediately – It is not possible for your clinic to give you a supply of DR-TB treatment as we cannot give you the injection to take with you. It may be possible to get a treatment supply for travel when you finish the injection and start continuation phase. We will make a new plan for you at that time.

DR TB Counseling

Identify barriers	<p>As explained you will need to attend your clinic each day to get your DR-TB treatment including a daily injection for at least 6 months. Now that you have started DR-TB treatment, it is important to discuss travelling away from your home.</p> <p>Ask the patient to think of emergency situations that may require urgent travelling</p>
Make a concrete plan	<p>If you have to travel due to an emergency, it is best to come to this clinic in advance so that your treatment team can help make a plan for you. This plan will depend on how long you have already been getting the injection and whether your culture has converted to negative.</p> <p>If for any reason your travels are unplanned and it is impossible for you to come to this clinic:</p> <ul style="list-style-type: none"> – If you think you will be somewhere for an extended period, it is important to go to your closest clinic in that area, as soon as possible after arrival – tell them that you have DR-TB, you have started DR-TB treatment but have no treatment with you, so that they arrange transport to the hospital or order the treatment you need. They will need to phone us to confirm your treatment.” – If you are not getting help from the clinic , please contact your DRT-TB counsellor or nurse and ask them to speak to the nurse in that clinic where you are. – Help patient program into their cell phone: <ul style="list-style-type: none"> » phone number of TB nurse, DR-TB counsellor and clinic » their file/clinic number – Please remember that it is very important that you protect other people you are travelling with by ensuring the windows are open and you are wearing your mask while in the car or bus" <p>It is important to know that we are here to help you stay on your treatment, if there has been a problem and you had to travel as an emergency and you have stopped your treatment, please come back to us when you return so that we can help you get back onto your treatment immediately</p>

D: Review

Closure of session [Let the patient know that the session is nearing an end]

Take Home Messages:

Congratulations for getting this far in your treatment!

- Keep taking your tablets every day to complete your treatment journey
- Continue giving a sputum sample every month in your clinic so that the doctor knows when to stop your treatment
- Try not to interrupt your treatment – rather talk to your counsellors or clinic staff about any challenges that might make it difficult to continuing taking your treatment.

You can do this!

DR TB Counseling

Please staple a copy to patient treatment card, second copy to patient file

Adherence plan (for patient and carbon copy for patient's file)

Patient name:

My 3 reasons to stay healthy and alive:

1.
2.
3.

Session 1 after DR TB education session (date)	
Adherence Step 1 A– DR TB Education done <input type="checkbox"/>	
Adherence Step 1 – Getting to appointments How are you going to get to clinic every day..... Back up plan to get to appointments daily.....	
Adherence Step 2 – Dealing with side-effects My plan for minor side effects is:..... My plan for side effects that worry me is:.....	
Adherence Step 3 – Patient Support system	Agree to a home Visit: Yes <input type="checkbox"/> No <input type="checkbox"/>
Members of my support system:..... Who else can support me in my treatment.....	
Adherence Step 4 – The DR TB Support team Contact details of the clinic:	
Adherence Step 5 – Getting to my Audiology appointment How to remember Audiometry appointments:..... How to get to Audiometry appointment..... Back up plan to get to appointments:.....	
Session 2 (date)	
Adherence Step 6 A– DR TB Education	
Adherence Step 6–Preventing any future mistakes and completing my treatment journey What will I do if I make a mistake, and don't come to the clinic for a while to take my treatment:.....	
Adherence Step 7 – Treatment Partner My treatment partner is	
Adherence Step 8 - Communicating with treatment team My focal person in clinic is:.....	
Adherence Step 9– Management of weekend doses How will I remember to take my weekend medication	
Where will I keep my weekend medication.....	
Adherence Step 10 –Reminder Strategies I will put my reminder stickers on:..... I will read my reasons for taking my treatment at :..... My other reminder tools are:.....	
Session 3 (date)	
Adherence Step 11 A– DR TB Education	
Adherence Step 11: How do I protect my family? I will sleep.....	
Adherence Step 12 – Dealing with substance use My plan to make sure I take my drugs if I used alcohol or drugs is:.....	
Adherence Step 13- Managing unplanned trips My folder Number:..... My regular travel location..... Closest clinic at regular travel location.....	

GOAL: To be Sputum Negative

DR TB Treatment Interruption Counseling

Identifying treatment interrupters

Background:

All DR-TB diagnosed patients on DR-TB treatment receives daily DOTs- Directly observed treatment at their local clinic daily.

The TB Nurse assigned to the TB room ensure patient gets the prescribed medication.

The TB nurse also has an additional role:

- Record patients daily medication administration in appropriate records
 - Patient treatment card
 - Patient file
 - Clinic compliance sheet
- Sputum collection monthly
 - Check compliance sheet to see sputum date
 - Take sputum specimen
 - Send sputum specimen off to lab
- Ensure patient sees Medical Officer monthly
- Ensure new patients are registered
- Ensure patient details are updated in the DR-TB patient treatment register

There are various points in the patient care process where the nurse has the opportunity to note if a patient is interrupting treatment.

- Patient file
- Clinic compliance sheet
- Sputum date missed
- Doctor's appointment

The patient would be identified within 2 to 3 days of missed treatment at the clinic.

What is the process with initial identification:

- TB Nurse identify that patient has missed 2to 3 days of DOTs
- The counsellor who provides DR-TB counseling gets informed
- Next step:
 - If a telephone number is available-the patient is called and the counsellor tries to find out what the reason for the interruption is. Patient is asked to return to the clinic.
 - If no telephone number available- A home visit is done. The counsellor tries to establish the reason for treatment interruption.
 - Patient either returns to clinic or continues interruption.
- Follow- up monitoring is done in the clinic by the TB nurse who checks if the patient had returned to the clinic for treatment.
- If patient return to clinic continue treatment
- If patient's treatment interruption continue the patient will be referred to the MSF Treatment Interrupter counselor.

Definition of treatment interrupter for purpose of counselling support intervention:

- Patient interrupting treatment for 2 weeks
- Attempt to recall patient has been unsuccessful
- Treatment interruption is not due to weakness and unwell patient

DR TB Counseling

The role of the MSF Treatment Interrupter counselor:

- The counselor does a home visit and request the patient meet with the counselor at the clinic
- During the Treatment Interruption session the counsellor
 - Completes a SAMISS (Substance Abuse and Mental Illness Symptom Screener){ Screening for mental illness and substance abuse is helpful as it identifies some risk factors for treatment interruption}
 - Completes the Treatment Interrupter counseling session with the patient
 - Completes adherence steps with the patient
 - Completes modified short term adherence goals with the patient
- The patient is then referred to the nurse for further follow-up sessions
- Patients with Substance abuse related SAMISS positive result are included in a 4 week patient support group looking at the effects of substance abuse on the patient's life
- Patients with a Mental illness related SAMISS positive result are referred back to the medical officer for further assessment and management
- Patient with a SAMISS negative result only receive follow from the nurse

The role of the TB nurse/doctor

- Receives patient back at the clinic post treatment interruption
- Week to week intervention- Discuss goals achieved or not achieved. Discuss barriers to adherence and facilitate problem solving around these specific barriers. Uses motivating language and positive reinforcement. Make new short term goals for patients.
- Monitor patient's for further treatment interruptions and initiates additional intervention if treatment interruption continues
- Additional Interventions:
 - Family meetings with interdisciplinary team with the goal
 - to get the family to support patient more actively if the patient is struggling
 - to get the family to rally around the patient and assist the patient in making decisions regarding treatment
 - to get the family to understand infection control implication if treatment interruption continue
 - Home visit with an Environmental officer to ensure the patient and the family understands infection control implication for all the close contacts of the patient who continues to interrupt treatment.
 - Referral:
 - Substance Abuse Intervention programme like Matrix
 - Social worker
 - Psychologist
 - Centralized TB facility for long term adherence support if appropriate
 - Local DR-TB short stay facility for social support or adherence support

DR TB Counseling

Session Plan

This session is appropriate for patients interrupting treatment due to

- Feeling better
- Need to work/ school
- Pill burden
- Treatment too long
- Want a baby
- Alcohol/ Drug use (Note – use only over weekends, special days, parties)

Session Plan

Treatment Interrupter Session : Adherence Counselling	
Target group	DR-TB Patients interrupting treatment
Timing	Patient who has interrupted DR-TB treatment for two consecutive weeks or who frequently interrupts treatment for short time periods
Objectives	Encouraging adherence and completion of treatment journey
Duration	30 to 40 min
Mode	Individual
Tools	DR-TB flip chart/ Adherence Plan/ patient card/ stickers
<p>Blue text: reflects what the counsellor needs to say Red text: reflects key address that must be addressed Black text: reflects prompts, instructions or any information that is helpful for the counsellor</p> <p>A: Overview of Session</p> <p>7. Introduction of facilitator and objective of session</p> <p>Introduce yourself thank the patient for being open to having this session. Ensure confidentiality Before the start of the session make sure that you check the patient file for:</p> <ul style="list-style-type: none"> (a) How long the patient has been on treatment (b) Whether the patient has culture converted or not (c) Whether the patient has a history of treatment interruption and default <p>It is important that you know your patient before you start the session. The patient’s history may guide you to respond more appropriately if the patient ask questions or express concerns.</p> <p>We realise that taking DR-TB treatment is hard. But it is necessary to take the treatment every day to be cured. Some times people stop treatment for various reasons but with this session we are going to work together and plan ways to keep you taking your treatment even though things do not always go as planned.</p> <p>8. Give patient an outline of session:</p> <ul style="list-style-type: none"> ● Talk about challenges that made coming to the clinic difficult and look at the old adherence plan ● Complete a DR-TB Treatment Adherence plan together ● The way forward <p>B: Treatment Literacy This is the part where we are going to talk about your disease.</p>	

DR TB Counseling

Your patient who is interrupting treatment should already know some of this information. This is a good time to check what they remember.

11. What is adherence?

- Taking all the tablets (and injections if still on intensive phase) you should, every day

12. What happens if you take your treatment well?

- You should start feeling better and healthier
- You should start gaining weight
- Your sputum tests should come back negative

13. What happens to you if you stop your treatment?

- Every time you do not take your DR-TB treatment, you give the germs a chance to grow again
- Every time the germs grow again there is a chance that further resistance will develop. This means that the virus changes and the drug is no longer working and you will eventually become sick again..
- If the Drug Resistant TB germs gets a chance to grow further you may become extensively drug resistant (XDR TB), this means the DR-TB drugs you are using may stop working.
- There are few drugs that work against XDR-TB. Starting XDR treatment will mean:
 - taking treatment for even longer than the months you have left on DR-TB treatment
 - it can include a daily injection again
 - often it does not workYour best chance to beat TB is to complete your MDR-TB treatment.
- You may become infectious again and spread the drug resistant TB germs to other people, including your children, family, friends and others in the community.

Let's talk through some of the problems you might be experiencing with your treatment?

Pill burden:

- There are lots of pills to swallow, and the daily injections during the first phase.
- **Is this a major problem for you?**
- It will not be easy to continue your treatment but we are here to help you get through this.

Eating before taking treatment:

- You may feel that you need to eat before you can take your treatment and may not have food
- **Is this a problem for you?**
- Remember that it is safe to take your treatment on an empty stomach

Vomiting after taking treatment

- It is common vomit or feel like you will vomit your tablets – this is a horrible part of taking DR-TB treatment,
- **Is this a problem for you?**

DR TB Counseling

- It is really important to not let this stop you from carrying on with your treatment even though it is so difficult. Some of our patients finding that eating or drinking something sweet straight after taking the tablets helps to keep them down.
- If you do vomit:
 - At the clinic or just after you have left the clinic, you need to go back and tell the nurse so that she can give you your tablets again
 - If you are already at home, come back the next day for your next dose as usual and tell the nurse that you vomited the day before

Experiencing side effects

- Mild side effects are normal for most patients taking DR-TB treatment.
- These might include: nausea, vomiting, stomach pains, dizziness, diarrhea, ringing in the ears, painful or burning feet, rash and aching joints.
- Mild side effects usually improve over time.
- Some side effects are more serious such as:
 - Problems with sight, or hearing loss
 - Seizures/fits
 - Blistering or peeling of the skin
 - Feelings of extreme sadness (depression)
 - Confusion
- **Do you have any side effects or symptoms that you are worried about now?**
- **We will discuss planning around side effects later in the session again.**
- Many of the milder side effects are easily treated, and the severe ones need your doctor's immediate attention. Always report them to your clinic nurse or doctor before you decide to stop any treatment – there may be something that they can do to help you.

Have you experienced any other problem that made it difficult for you to take your treatment?

{ If it is something that is covered in the treatment literacy or adherence steps- say

It does happen that people stop treatment because of certain issues that arise in their lives, the most important thing to remember is to restart the treatment as soon as possible

If the patient's reason for stopping is not covered and it needs further management- say

I can hear that you had difficulty staying on treatment because of your situation. You might need further support. Can I have permission to discuss your challenge with the doctor/ DR-TB Nurse?

(Patient may live in unhealthy environment, may struggle with mental illness...)

Why do you need to take time off work or school?

Remember that DR-TB is infectious and just as the family needs protection, the people at work/school need protection too.

- There is social assistance available for the full 24 months of treatment. Ask your clinic staff to tell you about the social assistance options that are available.
- There is a special clinician that can help you in making an application for a grant. Ask the nurse how you get an appointment with this special clinician?
- Ask your clinic staff to assist you with a sick certificate. You will need to speak to your employer about long sick leave and Unemployment Fund benefits.
- You might feel better and urgently want to return to work, if this is the case, you need to speak to your doctor/ nurse so that s/he can plan with you when it is safe for you to go back.

DR TB Counseling

You need to know what the relevant procedures are in your district, region, country; that patients need to follow to access social aid if appropriate. Explain the relevant procedures in your context to the patient.

Are you worried about being away from work or school?

4. What happens if you fall pregnant? (Female)

- Women should avoid falling pregnant while on DR TB treatment, as it means that some of the drugs will have to be stopped and this will reduce your chance of being cured from your disease.
- Having a baby during this time could be difficult for the family, especially if you are sick, than the family need to care for both you and the baby.
- If however you are pregnant or suspect that it possible, it is important that the nurse and doctor are informed as soon as possible.

Being asked to delay starting a family can be difficult to accept. If you and your partner are struggling with this issue it is important to speak about it to the counsellor or the nurse.

Is this a concern for you?

Using alcohol/ drugs when you take DR TB treatment?

- Taking alcohol or drugs can make a person less likely to remember to attend the clinic daily to take their treatment.
- It can also reduce the effectiveness of the DR TB drugs.
- If the patient has difficulty managing how much alcohol or drugs they take, they will need the support of the family to help them with their treatment.
- If you are struggling to cut down, there are support organizations that we can refer you to that can assist and support you in cutting down alcohol and drug use.
- It is also then important to make use of your treatment partner as much as possible, so that s/he can help you get to the clinic in the morning each day before you take anything.
- If you only use alcohol and drugs on the weekend, your treatment partner will need to help remind you to take your treatment when you wake up on Saturday and Sunday.
- We will discuss planning around substance use again later in the session.

It is very important that you complete your DR-TB treatment. It the best chance your have to be cured so you can get back to life as it was before you were infected with TB.

C: Adherence

Now we are going to make a plan together of how you are going to get back to taking your treatment every day.

Identify Life Goals:

You will remember that we discussed your life goals when you started DR-TB treatment, can you remind both of us what your main reasons for wanting to be cured were?

Here you can take out the patients initial Adherence form and ask the patient if the patients goals are still the same. If the goals have not changed, help the patient rewrite the goals on the New adherence form.

If this hasn't been done before:

"Can you tell me 3 main reasons for you to be cured, become healthy again?"

DR TB Counseling

“What are your goals or the dreams you still want to achieve?”

“Who are the important people in your life you want to live for?”

[Let the patient write down their 3 reasons to stay alive on their adherence form. If the patient cannot write, assist them in drawing their 3 reasons.]

When you started DR-TB treatment we went through a few steps that can help you to take your treatment, today we are going to go through a revised version of the adherence steps to work out a plan for you to help you get back to taking your DR-TB treatment every day

Have the old adherence document with you as you go through the new adherence steps. Check what the patient’s plan was initially and ask the patient if it was helpful or what did not work for them. Then help the patient make a new plan or repeat the old plan on their New adherence form.

Adherence Step 1: Reminder strategies	
Review adherence goal	<p>Having reminders can help you focus on the reasons to beat DR-TB, get cured, become healthy and stay alive.</p> <p>These reminders will also help you to remember to take your treatment.</p>
Identify Barriers	<p>What difficulties have you previously faced with remembering to come to the clinic daily for your medication?</p> <p>How have you previously reminded yourself to go to the clinic?”</p> <p>Have you put reminders up around your house – tell me about these?</p>
Make a concrete plan	<p>If patient has not put reminders up around house – carry out plan below, if patient has put up reminders, go through where they have been put, determine possible other places that may work better.</p> <p>Identify reminder tools (propose stickers or whatever they want like a piece of fabric) and link them to the 3 reasons on the adherence plan</p> <p>The reminders can be put in your house to remind you of your reasons to be cured and to take your Treatment</p> <p>Where can you place these reminders so that you see them at the time that you need to take your treatment?</p> <p>Ask: What are you doing around the time your treatment is due? Most patients would say they’re waking up, brushing teeth, having breakfast. This gives various options for placement of reminder stickers.</p> <p>Place the sticker/ fabric on the patient’s adherence plan next to the 3 main reasons for staying healthy and alive.</p> <p>Encourage the patient to read their 3 reasons everyday, preferably before they need to go to the clinic or take their treatment.</p> <p>What other things could you use to remind you to go to the clinic or take your treatment (set cell phone alarm, get family members to remind you)?</p> <p>You can use the same reminders over the weekend to take the medication the nurse gave you to take at home.</p>

Adherence Step 2 – Getting to the clinic	
Review adherence goal	<p>To treat DR-TB you need your treatment every day. It is important that you come to the clinic daily to get your medication</p>

DR TB Counseling

Identify barriers	<p>What has been stopping you from coming to the clinic every day?</p> <p>Encourage patient to think of issues such as work, children, weather, and staff at the clinic?</p>
Make a concrete plan	<p>Identify a way the patient will get to the clinic daily</p> <p>How have you been getting to the clinic daily?</p> <p>Can you continue coming to the clinic this way?</p> <p>What plan can you make when your usual way of coming to the clinic is difficult.(e.g. no money for taxi, it's raining and you have to walk, your child is sick, you are feeling too sick)</p> <p>Go through the patients back up method of reaching the clinic daily if the patient experiences a problem</p> <p>What can you do if transport cost is an issue? Can you ask family to help?, can you use a rain coat/ umbrella in the rain/ can a neighbour take care of your child?}</p> <p>Who could help you to come to the clinic if you have a problem?</p>

Adherence Step 3 – Getting Support at home

Review adherence goal	<p>It is important to have the support of family and friends during this time. Your support system will encourage you to take your treatment.</p>
Identify barriers	<p>Who in your family has provided you with support till now?</p> <p>Does..... (Insert name of family member mentioned/ if no family member ask if partner, parent) know that you stopped taking your treatment?</p> <p>How do you feel about telling your family that you have been having a difficult time with the treatment and getting their support to help you get back on daily treatment?</p> <p>What would make it difficult to ask a family member or a friend to support you?</p>
Make a concrete plan	<p>Who can you talk to you about your struggles with staying on your treatment and ask for additional support and care?</p> <p>Write down the names of family support and the treatment partner.</p>

Adherence Step 4– The DR-TB support at the clinic

Review adherence goal	<p><i>It is important to feel you can trust your treatment team at the clinic, so that you can talk to them about your problems with staying on your treatment."</i></p> <p><i>Another Important part of the treatment team at the clinic is the support group. The support group is made up of patients from the clinic that is also on DR-TB treatment.</i></p>
Identify Barriers	<p><i>What would make it difficult for you to join a support group?</i></p> <p><i>Are you shy, afraid of what people will think of you? , you don't like talking about your problems</i></p> <p><i>- The idea is to attend, listen to others struggles, maybe you have something that could help someone else, and maybe someone else can help you. In this meeting no one judges anyone because it is hard for everyone.</i></p>
Action Plan-	<p>Assist the patient to make a note of the contact details of the DR TB counsellor/ clinic.{ Put the numbers on the patient cell phone}</p> <p>Support groups: Give the date and time</p>

DR TB Counseling

	Plan with the patient to join one session to see what it is like.
Adherence Step 5 – Dealing with side effects	
Review adherence goal	<p>As we discussed earlier, mild side effects affect most patients and some side effects are more serious and should be reported to the clinic nurse or doctor as soon as possible.</p> <p>If you stop your treatment because of mild side effects you are taking a risk with your life. You need the treatment to cure your TB as TB can kill.</p>
Identify barriers	<p>You told me about the side effects you are experiencing, these were.....</p> <p>What would make it difficult to tell the nurse or doctor?"</p> <p>Some time you not sure if you are really experiencing a side effect and feel that the doctor or nurse might think you are silly, you feel shy or fearful of telling the nurse and doctor.</p> <p>Are there any other side effects you are worried about?</p> <p>Allow the patient to mention any side effect they have and listen attentively. Thank the patient for trusting you.</p> <p>Would you like some help going to the nurse and talk about the side effects that you are struggling with?</p>
Make a concrete plan	<p>Help the patient identify and plan what to do with mild side effects and side effects that worry him/her.</p> <ul style="list-style-type: none"> - With mild side effects the aim is to report and continue treatment even if side effect persists. - With serious side effects the aim is to report to the nurse and doctor as soon as possible.
Adherence Step 6 – Dealing with substance use	
Review adherence goal	<p>Taking alcohol and drugs makes it difficult to get to your clinic each day for your treatment. If it is not possible to avoid alcohol and drugs while you are on DR TB treatment, you will need more support from your clinic team and those close to you.</p>
Identify barriers	<p>We all go to parties or visit friends on weekends or even in the evenings. During these visits when we are having a nice time we all would enjoy a drink, or a beer or a glass of wine?</p> <p>Do you have ‘babalas’ or a hangover the next morning? (‘Babalas’ is the slang word for hangover and can identify with the term as they know it well. Use terms appropriate to your context.)</p> <p>If yes: continue otherwise move onto to next adherence step:</p> <p>Would the ‘babalas’ make going to the clinic difficult?</p> <p>Are you scared of going to the clinic when you have taken substances or have a babalas?</p> <p>What happens if you drink at a party, over the weekend at a friends place?</p> <p>Ask the patient to identify what would make coming for his/her treatment difficult if s/he has taken a substance.</p> <p>Discuss the possibility of going to the clinic first thing in the morning before taking any substance</p> <p>Discuss the possibility of a friend or family member escorting the patient to the clinic.</p>

DR TB Counseling

<p>Make a concrete plan</p>	<p>Identify a person who lives with or close to the patient, who can check if the patient is okay in the morning and support them to get to the clinic Write down any other plan the patient proposes to ensure they get to their clinic for their treatment.</p>
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Adherence Step 7 – Completing the treatment journey

<p>Review adherence goal</p>	<p>We spoke about the importance of completing the treatment during our last session. We understand that the treatment journey is a long one. People make mistakes and might stop taking treatment for a while.</p> <p>It is important that you restart treatment as soon as possible and focus on your 3 reasons to be cured and regain your health. Your reasons to stay healthy and alive will help you focus on what is important.</p>
<p>Identify barriers</p>	<p>What could stop you from going back to the clinic for treatment after you interrupted your treatment The patient may feel like s/he failed, stress that everyone makes mistakes.</p>
<p>Make a concrete plan</p>	<p>Help the patient plan what they will do in future if the patient makes a mistake. What will I do if I make a mistake ,and don't come to the clinic for a while to take my treatment After the answer is filled in on the adherence plan continue with-</p> <p>You can do this! - One WEEK at a time – People get overwhelmed with the fact that the treatment can take so long. But let's only focus on taking your treatment for this week, can we do this?</p> <p>For this week, until our next session-</p> <ul style="list-style-type: none"> ○ Come to the clinic daily for your treatment ○ Tell some one in your family that you need more support with your treatment journey ○ Come to 1 support group. <p>Next..... (mention a day exactly one week away) you will bring your card to the nurse. The nurse will check how things have been going. Is there any specific nurse in the TB room you feel more comfortable talking with? If patient identify someone say- After we finish off here, I will walk with you to the TB nurse if she is available and tell her that we need her to support you in completing your treatment journey. If patient cannot identify someone say- After we finish off here, I will walk with you to the TB nurse if she is available and tell her that we need her to support you in completing your treatment journey.</p> <p>Identify person they are trusting most at clinic to get in touch with? Or add in communication step again here as patient was not comfortable to address issues with HCW before</p>

D: Review

DR TB Counseling

Closure of session [*Let the patient know that the session is nearing an end*]

1. What will happen if you stop your treatment
2. What will help you to get back to taking your treatment every day?

End with: (MY WEEK to WEEK)

Congratulations on participating in this session.

It shows you are serious about living for(mention the patients 3 reasons to stay healthy and alive)

End:

You have come this far and I know that you can do this. I am looking forward to seeing you in the support group and hearing how things have been going. If you are struggling at any point please feel free to contact the clinic and arrange to talk to me. We want to help you through this!

Further Monitoring of patient:

- Check to see if patient attends support group
- If patient at support group, congratulate (Note: Do not draw attention to patient as treatment interrupter. Welcome patient to group. Encourage members to make patient feel welcome).

DR TB Counseling

Treatment Interruption Adherence plan

Patient Name: _____

Please staple a copy to patient treatment card, second copy to patient file

My 3 reasons to stay healthy and alive:

- 1.....
 2.....
 3.....

Session after DR TB Treatment Interruption session(date)
DR TB Education <input type="checkbox"/>
Adherence Step 1 - Reminder Strategies I will put my reminder stickers on..... I will read my reasons for taking my treatment at..... My other reminder tools are.....
Adherence Step 2 - Getting to appointments How am I going to get to clinic every day..... Back up plan to get to appointments daily.....
Adherence Step 3 - Patient Support system Members of my support system..... My treatment partner is.....
Adherence Step 4 - The DR TB Support team Support Group Time slot.....
Adherence Step 5 - Dealing with side effects in the future- My plan for minor side effects is..... My plan for side effects that worry me is..... For the side effects that worry me today I will.....
Adherence Step 6 - Dealing with substance use My plan to make sure I come to the clinic to take my treatment if I had some beer/ wine or have babalas.....
Adherence Step 7-Completing my treatment journey If I do if I make a mistake, and don't come to the clinic to take my treatment, I will

My week to Week:

Aim:
Week 1 Date _____ ○ Come to the clinic daily for treatment for 1 week ○ Make sure the nurse ticks your clinic card ○ Tell some one in the family that you need support ○ Join 1 support group
Week 3 Date _____ ○ Come to clinic daily for 2 weeks ○ Make sure the nurse ticks your clinic card ○ Attend another support group session
Week 6 Date _____ ○ Come to the clinic daily for 3 weeks ○ Make sure the nurse ticks your clinic card ○ Attend 2 support group sessions
Week 12 Date _____

DR TB Counseling

- Come to the clinic daily for 6 weeks
- Make sure the nurse ticks your clinic card
- Attend 3 support group sessions

Reminder: Mistakes happen and this plan is not a magic solution. When you struggle, always remind yourself of your 3 reasons to stay healthy and alive. Do not stop trying to take your treatment daily. Aim for completing 1 week at a time. Check your clinic card to see your progress.

DR TB Counseling

Treatment Interruption Adherence monitoring sheet for Nurses

Patient Name:

Patient sticker

Initial Session completed by DR-TB counsellor:

Counsellor Name:

Date:

Comments:

.....

My week to Week:

Aim:	Date	Done	Not done	Sign
<p>Week 1: Check that the patient achieved the following (This is done 1 week after the treatment interruption counseling session)</p> <ul style="list-style-type: none"> ○ Attend clinic daily for treatment for 1 week (give a date) _____ ○ Clinic card ticked ○ Who in the family did you tell: _____ ○ Join 1 support group <p>Congratulate the patient if goals were achieved/ Encourage patient to continue trying if patient had difficulties.</p>				
<p>Week 3 : Check that the patient achieved the following (This is done 3 weeks after the treatment interruption counseling session)</p> <ul style="list-style-type: none"> ○ Attend clinic daily for treatment for 2 weeks (give a date) _____ ○ Clinic card ticked ○ Attended 1 support group <p>Congratulate the patient if goals were achieved/ Encourage patient to continue trying if pt had difficulties.</p>				
<p>Week 6: Check that the patient achieved the following (This is done 6 weeks after the treatment interruption counseling session)</p> <ul style="list-style-type: none"> ○ Attend clinic daily for treatment for 3 weeks (give a date) _____ ○ Clinic card ticked ○ Attended 2 support group <p>Congratulate the patient if goals were achieved/ Encourage patient to continue trying if patient had difficulties.</p>				
<p>Week 12: Check that the patient achieved the following (This is done 12 week after the treatment interruption counseling session)</p> <ul style="list-style-type: none"> ○ Attend clinic daily for treatment for 6 weeks (give a date) _____ ○ Clinic card ticked ○ Attended at least 3 support group <p>Congratulate the patient if goals were achieved/ Encourage patient to continue trying if patient had difficulties.</p>				

Reminder: Mistakes happen and this plan is not a magic solution. When patients struggle, remind patients of their 3 reasons to stay healthy and alive. Tell the patient to Aim for completing 1 week at a time. Tick their clinic card so they may be able to see their progress. Refer back to counsellor if more support needed.

XDR TB

Treatment

Counseling

Session Plan

Counselling Session: Diagnosis of extensively drug-resistant TB (XDR-TB)	
Target group	Patients identified with extensive TB drug resistance
Timing	As soon as possible after detection of 2 nd line drug resistance
Objectives	Educate on XDR-TB and further treatment options Assess potential suitability for access to specific drugs (BDQ, DEL, LZD, etc)
Duration	30 – 60 minutes
Mode	Individual, +/- family member or trusted companion
Tools	Session plan XDR-TB Plan and Centralised Hospital Social Assessment Form
<p>Blue text: reflects what the counsellor needs to say Red text: reflects key address that must be addressed Black text: reflects prompts, instructions or any information that is helpful for the counsellor</p> <p>A: Overview of Session</p> <p>9. Introduction of DR-TB counsellor and preparation for the session</p> <ul style="list-style-type: none"> ➤ Prepare the environment for this session – look for a quiet area with minimal chance of interruption; turn off your phone; have everything you need near you. ➤ Introduce yourself. ➤ Ask the patient if they would like a family member or significant other to join. ➤ Tell the patient if you have any time constraints or if there will be any interruptions. <p>10. Give patient an outline of session:</p> <ul style="list-style-type: none"> • I have some important information to tell you about your DR-TB • We will take it slowly, you can stop and ask me questions at any time, and we can meet again to talk some more if the information is too much to take in now. • During this session we will also talk about your DR-TB treatment and what will happen from here. <p>[Session Objective] Understand diagnosis and future treatment options</p> <p>11. Share the information with the patient:</p> <ul style="list-style-type: none"> • The lab has done some more tests on your sputum, and the results show that you have a form of XDR-TB, which is Extreme or Extensively Drug Resistant TB. • The TB is resistant to at least FOUR of the usual TB or MDR-TB drugs, and so some of the medications that you are currently taking will not work to kill this TB bug. 	

DR TB Counseling

- This is serious because there are not that many treatment options available for XDR-TB. If we do not find better drugs to treat your TB, then you may eventually get sicker again and you might die from the disease.

STOP here and allow the patient to take in the information and ask any questions.

Check emotional state, e.g.....:

- Do you understand what I have told you?
- How are you feeling?

Recognise the emotions, e.g.....:

- I can see that this is making you feel (angry / sad / shocked etc.)
- This must be difficult for you to hear.

Normalise the emotions, e.g.....:

- It is normal to feel this way after such news. We are here to support you.

Give the patient some time alone if needed – to cry / talk with family / sit alone... etc.

Make sure tissues are available.

Are you ready for me to tell you more about XDR-TB and the treatment options?

B: Treatment Literacy

This is the part where you learn about XDR-TB.

Assess gaps in knowledge:

Can you tell me what you understand about DR-TB from what people have told you before?

Listen to everything the patient knows about their disease and answer any specific questions that they raise at this point.

Explain about pre-XDR and XDR-TB:

- Pre-XDR-TB stands for Pre-Extensively Drug Resistant Tuberculosis.
- XDR-TB stands for Extensively Drug Resistant Tuberculosis.
- XDR or pre-XDR-TB is similar to TB and multi-drug resistant TB (MDR-TB) because it is an infection or a disease caused by a TB germ.
- There are two ways that you can get pre-XDR or XDR-TB:
 - You can breathe in XDR-TB from someone else who has the same disease – this is the most common way that people get XDR-TB. You can become sick with XDR-TB for the first time, even if you have never had TB before.

OR

DR TB Counseling

- You might be infected with a normal TB bug which *becomes* more resistant while you are taking TB treatment. This could happen if your regular TB treatment is not working for some reason, or if you are not able to take your TB treatment properly every day for any reason.
- Just like other types of TB, the XDR-TB germ usually grows in the lungs but it can also grow in other parts of the body. If it grows in the lungs, you can also spread XDR-TB directly to other people through coughing, laughing, sneezing, spitting and singing.
- The reason we know that you have pre-XDR or XDR-TB is because the lab did some more tests on your sputum.
- The test for pre-XDR and XDR-TB are difficult and usually takes a long time. The test for MDR-TB is usually a bit quicker and easier and so the MDR result often comes back to the clinic first. The clinic staff will then start MDR treatment based on that result.
- However, because the test for pre-XDR and XDR-TB takes much longer, that result might only reach the clinic a few months later, after you have already started MDR-TB treatment.
- Pre-XDR and XDR-TB is more serious than MDR-TB because it is resistant to even more drugs
 - Multi-Drug Resistant TB (MDR-TB) is resistant to TWO common TB drugs
 - Pre-XDR TB is resistant to THREE drugs
 - XDR-TB is resistant to FOUR or more drugs
- That means the drugs you are currently taking will not work to kill your pre-XDR or XDR-TB.

STOP here and check if the patient has any questions about pre-XDR or XDR-TB.

- This is a lot of information.
- Can you tell me what you understand about what I have just told you?
- Do you have any questions about your diagnosis at this stage?
- Are you ready for me to tell you about the treatment of pre-XDR and XDR-TB?

TREATMENT of pre-XDR and XDR-TB:

- It is possible to cure XDR-TB, but only if it is treated with a combination of effective drugs.
- It is better to change your treatment to include more effective drugs as soon as possible because this will give you the best chance of being cured.
- If you wait until you get sick first before changing to more effective treatment, then your chance of cure will be much lower.
- Not everyone gets exactly the same treatment for pre-XDR and XDR-TB. If you are willing to change the treatment for your XDR-TB, then your doctor will work out which combination of drugs will work best for **you**. The choice of drugs will depend on:
 - the results from the lab showing which drugs your TB is resistant to

DR TB Counseling

- the types of medications you have already received before this
 - any other diseases that you have, and other medications that you are taking
 - your commitment to treatment for a full 2 years.
-
- If you are feeling very unwell, or if your doctor thinks that there is a medical problem s/he cannot manage in your clinic, you may need to be admitted to hospital for further treatment of your pre-XDR or XDR-TB.
 - If you and your doctor both feel that you can take your treatment every day at your local clinic, then you will only have to go to the hospital out-patients department every few months to be seen by the specialist doctor there.
 - Some medications for pre-XDR and XDR-TB can cause serious side effects at the beginning of treatment. Your doctor will be able to tell you more about these side effects.
 - If your doctor is worried that you might experience serious side effects, s/he might refer you for admission to a hospital or other inpatient facility to monitor you more closely. This is usually just for a short time at the start of your treatment to make sure that you can tolerate the drugs – it might be longer if you experience problems at the beginning.
 - It is sometimes possible to offer surgery to people who have limited treatment options. Surgery can help to remove some of the TB bugs in your lungs. Your doctor will look at your CXR and discuss with you whether this is an option for you or not.

STOP here and check if the patient has any questions about treatment options.

Review of KEY MESSAGES:

- You have (pre) extensively drug-resistant TB (pre-XDR or XDR-TB)
- There is no guarantee that you will definitely be cured of this TB, but your chance of cure is higher if your doctor changes your treatment to give you more effective drugs. The sooner you start this treatment, the better your chance of success.
- These drugs are usually difficult to take and you have to continue treatment for 2 year. Therefore you and your doctor have to be sure that you are committed to completing this treatment before you start.
- If you do want better treatment for your pre-XDR or XDR-TB, your doctor will try to find the best combination of drugs specifically for you – this may be different to treatment that other people take.
- The drugs you might be offered could have serious side effects, and so you may need to be admitted to a hospital or other inpatient facility for a short time at the start of your treatment for closer clinical care and support. Your family can visit you there.

C: Re-Assessment of Social Circumstances and Preparing for XDR Treatment

In this section I will ask you about your home and social circumstances. If this was already done before, I want to do it again to see if anything is new or has changed. This will help me to better support you and your family through the rest of your treatment journey.

- **Step 1: Confirming the patient’s support system at home**

<p>Inform</p>	<p>Treatment for pre-XDR and XDR-TB is often more difficult to take than the treatment for TB and MDR-TB. You will need the support from your friends and family to continue going to the clinic every day for your treatment.</p> <p>So your family needs to know why you are taking this treatment, and also how to protect themselves from getting pre-XDR or XDR-TB.</p>
<p>Assess</p>	<p>Does a family member or friend know that you are taking DR-TB treatment? How are you going to tell them?</p> <p>Is there someone who you live with or who you are close to who can support you and look out for you in the coming months?</p> <p>I would like to visit your home to meet your family members and see if they are able to support you or have any questions. Is this OK?</p>
<p>Action</p>	<p>Help the patient to find a way to tell at least one of their family and friends about their diagnosis and treatment.</p> <p>Write down the details of the family member or friend who can support the patient through treatment.</p> <p>Offer to do this counseling session again with a friend or family member present (if patient is alone).</p> <p>Make a date to do a home visit to meet and educate the family, assess infection control and identify contacts.</p>

- **Step 2: Reviewing contacts for screening**

<p>Inform</p>	<p>Your close contacts need to know about your diagnosis so that they can protect themselves from getting sick. Close contacts are people who spend time with you on a regular basis.</p> <p>Children <5 years and people who are HIV positive are at higher risk of getting the disease, and they should be assessed by a doctor to see if they also have DR-TB.</p>
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DR TB Counseling

Assess	<p>Are any of your close contacts sick or having any symptoms of cough, night sweats, weight loss or fever?</p> <p>Have any of your close contacts been to the clinic to be screened for TB?</p>
Action	<p>Write down the names of the close contacts living in the house and also anyone else who has regular contact with the patient (like school friends, work colleagues, or other people's children).</p> <p>Check these names and ages at the home visit and ask if each one has any TB symptoms or if they have been assessed in clinic (sputum or paed's clinic).</p>

- **Step 3: SOS Plan for emergencies**

Inform	<p>In case of any emergency, you may have to go to a clinic or hospital.</p> <p>It is useful for the staff to know that you have XDR-TB so that they can make sure you get the right care and also to reduce the infectious risk to others. The staff might also want to find out more about your current XDR treatment.</p>
Assess	<p>What will you do if you have an emergency – who will you call or tell?</p> <p>Where is your nearest hospital? How will you get there? What is the ambulance number?</p> <p>How will you remember to tell the hospital staff that you have XDR-TB?</p> <p>Do you know the contact details of your local clinic and nurse or doctor so that you can give this information to the hospital staff?</p>
Action	<p>Discuss with the patient what they will do if they suddenly become unwell or have to go to hospital in an emergency.</p> <p>Suggest possible plans to help the patient to remember to tell someone that s/he is going to hospital.</p> <p>Make sure the patient writes down any information which might be useful (ambulance number, contact details of clinic staff and others, your number).</p>

Put a copy of the XDR Plan in the patient's file.

D: Closure of Session

- Do you have any further questions?
- It can be difficult to cope with a diagnosis of XDR-TB and you may have more questions later. The clinic staff and I are here to support you as much as we can, and we will answer your questions at any time.
- The next step for you is to go back to your clinic doctor when you are ready to discuss your treatment options and the way forward.

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Re-Assessment of Social Circumstances and Preparing for XDR Treatment

Patient name: _____ Cell no: _____

Clinic: _____ Date of counselling session: _____

Step 1 – Confirming the patient’s support system at home

Does a family member or friend know that the patient is taking DR-TB treatment? **Y / N**
 If not, how and when is s/he going to tell them?

Who will be able to continue to support the patient at home?

Name: Cell number:

Relationship to patient: Agree to home visit: **Y / N**

Step 2 – Reviewing contacts for screening - (can be completed at home visit)

Name of contact	Age <5yrs Y / N	Symptoms Y / N	Sputum Y / N	Outreach Y / N
.....
.....
.....
.....
.....
.....
.....

Step 3 – SOS Plan for Emergencies – in case patient needs emergency admission to hospital

Make suggestions for the patient and help him/her to carry out:

Give the patient their sputum result to carry with them or give it to a family member to show staff in any hospital.

Ask the MO to write a letter with the diagnosis and clinic contact details for the patient to carry with their health card.

Write down the name of the local health centre or district hospital for the patient and their family to go to in case of emergency.

Put the local ambulance number into the patient’s phone.

Write down the name and numbers of the patient’s local clinic and MO.

Palliative Care Counseling

Session Plan

Counselling Session: Patient in whom DR-TB treatment has failed	
Target group	Patients identified with drug-resistant TB treatment failure
Timing	The medical officer needs to indicate to counselor that this patient is not for further DR-TB treatment before this session may be done.
Objectives	Understand diagnosis/ prognosis and future treatment/ psychosocial support options
Duration	30 – 60 minutes
Mode	Individual, +/- family member or trusted companion
Tools	Patient Referral letter- For patient to keep in case of emergency admission.
<p>Blue text: reflects what the counsellor needs to say Red text: reflects important information that the counselor need to take note off Black text: reflects prompts, instructions or any information that is helpful for the counsellor</p> <p><u>A: Overview of Session</u></p> <p>12. Introduction of DR-TB counsellor and objective of session</p> <ul style="list-style-type: none"> ➤ Gather information from the doctor or the patient file about the patient’s sputum cultures, Chest X-ray and patient’s clinical condition. Gathering information about whether the patient was discussed at the BCH Review board and the outcomes of the discussions, other treatment or conditions that the patient has is important to note before having the counselling session with the patient. To speak to the patient about what is happening to them you need to have all the relevant information. ➤ Prepare the environment for this session – look for a quiet area with minimal chance of interruption and allow enough time; turn off your phone; have everything you need near you. ➤ Introduce yourself. ➤ Explain that you have some more information about the patient’s diagnosis of DR-TB. ➤ Acknowledge that they may be confused about this but that you will take it slow, they can ask questions any time, and that you can do it in two sessions if the information is too much to take in now. <p>[Session Objective] Understand diagnosis/ prognosis and future treatment/ psychosocial support options</p> <p>13. Give patient an outline of session:</p> <ul style="list-style-type: none"> • We will talk about what has been happening to your DR-TB and the treatment. • We will talk about the care and support options that are available to you. <p><u>B: Informing patient about the treatment failure diagnosis</u></p> <p>1. Assess patients knowledge of diagnosis/ prognosis:</p>	

Can you tell me about your disease so far- what has been happening to you and your health (allow the patient to talk about experiences)

Listen to everything the patient knows about their disease and answer any specific questions that they raise at this point. The patient may mention key points: Being on treatment for 5 months +, not getting better, still sputum positive, not picking up weight.

Can you tell me what the doctor or the nurse told you about your disease.

The patient may be aware of diagnosis of treatment failure and have insight into what that means. Patient may indicate that they have not been told anything by the medical staff.

2. Ask permission before you go further:

In some cultures context talking about the possibility of dying is frowned upon and patients avoid the topic indefinitely. A more direct approach may be needed where the patient is informed about their condition without the counselor seeking the patient's permission before hand.

Please proceed in a manner that is appropriate in your context.

If you choose a more direct approach- Do not ask permission to go further.

Can I tell you about what is happening with your disease and your treatment?

14. Tell the patient about their diagnosis

- When you were diagnosed with DR-TB initially, you were started on a treatment regimen which the doctors thought was the most effective treatment available for you at the time.
- The doctors may have changed some of the drugs throughout your treatment journey depending on: further information that became available about the type of TB that you have, how you reacted to the treatment and the progress of your TB disease
- While you have been taking the treatment you have been seeing the doctor regularly for him / her to check if your treatment is working to kill the TB bugs
- The doctor thinks that your treatment is no longer working because:
- (Explain the following to the patient using the information from the patient file and the information from the doctor/ nurse. Only mention the parts that pertain to the patient.)
 - Your sputum cultures are still positive (that means TB is still growing in your sputum) after many months on treatment
 - Your X-ray is showing signs of more disease in your lungs
 - You are not feeling better and are showing some of the signs of active TB disease, like: you are feeling sick again, losing weight, sweating at night, coughing, fevers, chest pains

Pause and give the patient a moment to answer or react.

Encourage the patient to express feelings (crying freely, talking about concerns, fear, anger, etc.) and respond with empathy

Never lie or avoid embarrassing topics (e. g. questions about death, about worsening symptoms)

How do you feel about this?

Are you ready for me to tell you more about your condition?

Explain further:

Share the information with the patient:

- Your treatment is not working and the DR- TB inside you is still growing. This is called treatment failure because the treatment fails to work.
- This is serious because without treatment you will probably get sicker and you will most likely eventually die from this disease.

STOP here and allow the patient to take in the information and ask any questions.

Some patients want to know how long they will live for – no-one really knows, but you should speak to your doctor about this.

If patient asks about treatment refer patient back to the doctor.-

If the Patient was discussed at the Review Board and there is an outcome stating that treatment has been stopped, you may mention it here but add that the patient should discuss this with the doctor further.

- Your doctor will be able to tell you what will happen with your Drug Resistant TB treatment.

(You may need to take a break at this point or even end the session and continue another time).

For Closing at this point:

I can see that hearing all this information is quite difficult for you.

Do you want to stop here today? We can make an appointment to have a second session

When will you be available? (Make a date)

If the patient is willing to continue with session-

Check if the patient has any questions about what happens next.

C: Future Care and Support Options

What happens with treatment of other diseases, conditions that patient has? (if nothing, skip this)

- You will still be able to take your treatment for your (mention the condition the patient has- e.g. diabetes, HIV, hypertension, asthma) if you want to.
- You should discuss this further with your doctor and make the decision together.
- Although it will not stop the TB from spreading in your body, the other treatment will stop you from getting sicker more quickly due to other problems.

What happens when you get sick and need to see a doctor or nurse?

- It is important to understand that no matter what the doctor decides about your TB treatment, you are still entitled to receive medical care if you are sick or unwell.

If you need to go to the clinic

- If you have to see a doctor, you can still go to the clinic and see the doctor. It is best to phone the clinic or me or some one you trust at the clinic, before going, so that the best time to see the doctor can be arranged and you can avoid waiting in long queues.
- Remember to wear your mask at the clinic during your visits to protect others from breathing in the TB

If you need to urgently go to hospital

DR TB Counseling

- Your doctor will give you a letter. It is important that you keep this letter with you when you have to go to hospital.
- At the hospital you have to give this letter to the nurse or doctor immediately.
- This letter will tell the doctors and nurses at the hospital that your TB treatment is not working and this stops the doctor from giving you TB treatment that wont work, again
- This letter also lets the doctor know that you still need care and the doctor may give you medications to help relief some of the signs and symptoms you have.
- This letter will also tell the doctor to put you in a separate room from other patients to protect them from breathing in TB germs.

What is Palliative Care?

- When a person has a life threatening disease they have very special needs. Palliative Care aims to cater to their special needs and ensures that patient receives the care and support they need.
- These needs include -Treatment and relief for any symptoms such as difficulty breathing, chest pains, weakness and tiredness, coughing up blood some times.
- These special needs also include social support. The patient will need support and assistance to access social aid, like a grant. A social work assistant will work with the patient to ensure that the you access this type of support
- The needs also include emotional support. Patient experience a whole lot of emotions as they deal with their disease and having a support system available helps ease the burden and distress the patient might experience.

If you need Palliative Care

It is important that you find out what palliative care services are available in your area if any. Here you tell the patient what services they can access in their respective areas.

This support can come from Non-governmental organisations / Community care workers and others who provide home based care or in patient care for patients whose DR-TB treatment have failed to work.

See example of what patient's in Khayelitsha are told:

- If at any point you need palliative care you can be admitted to Lizo Nobanda (Nurse run unit that provides short term stay and palliative care) where you will receive good care and support from the nursing team. Your clinic doctor will still be involved in your care.
- The Lizo Nobanda has nurses available 24 hours a day to look after you.
- Your family can visit you at any time at Lizo Nobanda
- If you choose not to go Lizo Nobanda you may be able to have a home base care worker come to the house and provide you with some nursing care a few times a week.

It is important that you know that you will still receive care if you need it at any point.

Family Support?

- It is important that you have support from your family and those close to you at this time.
- Do you need help telling your family what I have told you today?

How do you protect your family?

DR TB Counseling

- The ways you keep your family safe is the safe principles as when you first started treatment.
- Open windows, wearing a mask, spending time outside, sleeping separately from other family members if possible ... if this is difficult speak to me or the clinic staff so that that we can try to arrange something for you.
- A nurse or counsellor can come to your family and talk to them about how to support you and protect themselves

People often move away from home for many reasons and when they find themselves unwell; their family may want them to return home and this will result in a need for them to travel.

What should you do if your family wants you to go to home?

- It is normal to want to be around family where you know you will get the best support and for your family to want you to be close.
- However you be aware that going home means travelling in a transport with others for a length of time and this will not be safe for others in the vehicle. (E.g. the taxi or bus) as they can breath in the TB germs.
- If you are going to travel, try as far as possible choose transport with as few people in as possible, like a car.
- Wear your mask all the time and take mask for the people in the car to wear from your clinic.
- Open the windows even if it is cold.
- When you need to eat, wait till the transport stops and eat out in the fresh air, avoid eating in crowded places along the trip. You can still go to the bathroom.
- When you arrive in the other district/ area, it is important that you go to your closest clinic as soon as possible after your arrival.
- Show the nurse/ doctor at the clinic your letter so that they can add details to your file.
- If you are not getting help from your clinic, please contact your counsellor or nurse in the clinic you traveled from and ask them to speak to the nurse in the clinic where you are.

(Help patient program into their cell phone:

- phone number of TB nurse, counsellor and clinic
- their file/clinic number
- It is important to remember that other districts has the same TB medication as this district and if they do start you on TB treatment it will be the same treatment that is not working.

C: Re-Assessment of Social Preparing Emergencies

In this section I will ask you about your home and social circumstances. If this was already done before, I want to do it again to see if anything is new or has changed. This will help me to better support you and your family through the rest of your treatment journey.

- **Step 1: Confirming the patient's support system at home**

DR TB Counseling

Inform	<p>This is a difficult time in your DR-TB journey. You will need the support from your friends and family.</p> <p>So your family needs to know why you might not continue to take your DR-TB treatment. They also need to know how to protect themselves from getting DR-TB.</p>
Assess	<p>Is there someone who you live with or who you are close to who can support you and look out for you in the coming months?</p> <p>I would like to visit your home to meet your family members and see if they are able to support you or have any questions. Is this OK?</p>
Action	<p>Help the patient to find a way to tell at least one of their family and friends about their prognosis.</p> <p>Write down the details of the family member or friend who can support the patient through treatment.</p> <p>Offer to do this counseling session again with a friend or family member present (if patient is alone).</p> <p>Make a date to do a home visit to meet and educate the family, assess infection control and identify contacts.</p>

- **Step 2: SOS Plan for emergencies**

Inform	<p>In case of any emergency, you may have to go to a clinic or hospital.</p> <p>It is useful for the staff to know that you have XDR-TB so that they can make sure you get the right care and also to reduce the infectious risk to others. The staff might also want to find out more about your other conditions that you might have.</p>
Assess	<p>What will you do if you have an emergency – who will you call or tell?</p> <p>Where is your nearest hospital? How will you get there? What is the ambulance number?</p> <p>How will you remember to tell the hospital staff that you have XDR-TB?</p> <p>Do you know the contact details of your local clinic and nurse or doctor so that you can give this information to the hospital staff?</p>
Action	<p>Discuss with the patient what they will do if they suddenly become unwell or have to go to hospital in an emergency.</p> <p>Suggest possible plans to help the patient to remember to tell someone that s/he is going to hospital.</p> <p>Make sure the patient writes down any information which might be useful (ambulance number, contact details of clinic staff and others, your number).</p>

Do you have any questions?

(The patient has received traumatic news and very little of what you said may have been retained.)

DR TB Counseling

Some patient may also appropriately be in denial. If patient have no questions do not push them. If patient refuse to accept any of the information, acknowledge that this is a lot to process and it is normal to not want it to be true.)

D: Closure of Session

- We are going to end today's session but I would like to see you next week. Can we set a date to meet?

The next meeting will be a home visit to check how patient is doing physically, socially (grant process started), family been informed and check if patient need support with any family issues that may have raised, or if patient need to talk about diagnosis as patient had time to process it and to assess infection control and identify contacts.

Patients Support System and SOS Plan

Patient name: _____ Cell no: _____

Clinic: _____ Date of counselling session: _____

Step 1 – Confirming the patient’s support system at home

Does a family member or friend know that the patient is taking DR-TB treatment? **Y / N**
If not, how and when is s/he going to tell them?
.....
Who will be able to continue to support the patient at home?

Name: Cell number:

Relationship to patient: Agree to home visit: **Y / N**

Step 2:

SOS Plan for Emergencies:

I have a letter from my doctor with the clinic contact details and the details of my condition:

I have a copy of my sputum result to carry with me to show staff in any hospital:

Emergency contact Details:

Local Clinic:

Name of Doctor:

Ambulance Number:

District Hospital emergency room:

DR TB Counseling

Competency Assessment for DR TB Counselling Session 1/ 2/ 3/4/XDR Session/ Palliative Care Session

Session observed:

Name of Facility:

Date of visit:

Name of person observed:

Cadre of person observed:

Starting time:

Finishing time:

Name of supervisor:

NOTE: Counsellors should seek permission from the client for the supervisor to observe the session.

Score: 0=Task not performed / 1=Task partially performed / 2=Task competently performed

Task	0	1	2	N/A	Comment
Greets client in a culturally appropriate way					
Introduces himself/herself to client					
For home visit, request permission to enter home and talk to family					
Describes counsellor's role and the main objective of the session					
Explain confidentiality, create a trustful relation with the patient					
Give information as per the session plan in a clear, audible manner					
Clarifies misconceptions respectfully and clearly					
Answer's any questions accurately					
Involves patient and illicit responses from patient					
Addresses patient in a non-judgemental, empathic manner					
Address issues in a supportive way (especially if patient is facing some difficulties to be adherent)					
Take the time needed to insure patient's understanding					
Give opportunity to the patient to express him/herself					
Follow sequence of steps					
Help patient complete adherence document					
Completes Session Form					
Agree with the patient on a date for the next appointment					
Transfer appropriate information to patient file					

TIP FOR FEEDBACK: Start from the counsellor opinion/feeling on the session, then the supervisor can give feedback

WHAT DO YOU THINK WENT WELL? / MAIN STRENGTH OBSERVED.....

WHAT DO YOU THINK DID NOT GO WELL? /MAIN WEAKNESSES OBSERVED.....

PLAN FOR IMPROVEMENT?

COUNSELLOR'S SIGNATURE

SUPERVISOR'S SIGNATURE
