

# HIV TREATMENT LITERACY TRAINING MANUAL

Designed and produced by Just Associates (JASS) for the Our Bodies, Our Lives Campaign, Malawi Supported by COWLHA and MANERELA+, funded by Comic Relief



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July 2018

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#### **HIV Literacy Training Manual**

Thanks to the women activists and WLWHIV of Malawi who richly contributed to the initial workshop design, pilot and refinement of workshop content and methodology. The manual is designed to be used with the flipchart, serving as a visual aid.

#### **July 2018**

#### **Acknowledgements**

Author: Dr Di Lavies

Editing: Dr Di Lavies, Dr Vuyeseka Dubula, Anna Davies and

Sibongile Chibwe Singini

**Key Contributions:** JASS, COWHLA, MANERELA+, Our Bodies Our Live Movement Members, MANET+ and Ministry of Health.

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#### **Introduction and Training Preparations**

#### Training material designed for:

- # 4 days of training
- groups of about 25-30 HIV positive women
- \* 3-4 Facilitators per group
- \* to be rolled out across all the 10 districts in Malawi 2017 2019

#### Content includes modifications of materials from:

- \* JASS Feminist Movement Builders school
- Medicins Sans Frontiers (MSF)
- Malawi Ministry of Health Education flip charts and Malawi Clinical HIV Guidelines 2018
- USAID (Community Treatment Literacy; 'Recognising Gender Issues in Adhering to HIV treatment', workshop manual)
- Desmond Tutu HIV Foundation
- \* TB/HIV Care

#### Stationery requirements (for 30 participants):

- \* 100 pages each of 3 different pastel-coloured A4 paper
- \* 100 pages each of 3 different brightly coloured A4 paper
- \* 10 booklets of sticky notes
- 30 ring-bound notepads/30 booklets
- 30 black ballpoint pens (one to each participant)
- 30 pencils with erasers (one to each participant)
- \* 5 Pencil sharpeners
- 5 pairs of scissors
- Flip chart stand and 4 flip chart sheet packs (of 50 sheets)
- \* 30 black flip chart pens check ink is fresh if used before
- 30 red flip chart pens check ink is fresh if used before
- 2 or 3 additional flip chart pens in different colours
- \* 3 x Prestik
- \* 1 roll of masking tape
- ball of string
- box of big white stickers for names tags

#### Other materials:

- register page one for each day (On letterhead of partner organisations)
- \* attendance certificates for each participant
- 30 consent forms (Annexure11, Page 69)
- 30 evaluation forms
- \* two printed HIV/ARV educational flip charts
- laminated contents pages for Day 1, Day 2, Day 3 and Day 4
- # 1 Dildo
- \* 30 male condoms (one for each participant)

- "Vagina"
- 30 female condoms (one for each participant)
- some example ARV pill bottles or boxes to demonstrate generics
- \* tissues, tampons and sanitary pads
- \* 2ml or 5ml syringe
- \* copy of latest Malawi Clinical HIV Guidelines
- \* 30 participant packs : Consisting of Annex 2 (double-sided), 3, 4 (double-sided), 5 (double-sided), 6,7,9 (double-sided, choose Option 1 or 2), 10 and 11
- Optional: 30 small 7-day pillboxes (one for each participant)
- Optional: 30 small mirrors (one for each participant)

#### At the start of the workshop, each participant to receive:

- \* notepad or booklet
- \* one black pen
- \* one pencil with eraser
- \* one participant pack

#### **Facilitator Information**

#### PREPARING IN ADVANCE FOR THE WORKSHOP

- \* Invite participants inform them if you are offering travel and accommodation costs or not
- \* Invite co-facilitators
- \* Book the venue for the training (is it accessible to all participants?)
- \* Two weeks before the workshop, make sure that all stationery and "other materials" on the workshop list are acquired. Print all training material.
- \* Carefully go through all the training material so that you are familiar with the program and activities.
- \* With the facilitation team decide which method options you choose or adaptations you need to make and agree on which facilitator will lead which activity. Prepare well.
- \* Prepare a register and an attendance certificate for each participant.

#### **PLANNING THE VENUE**

- \* Make sure that the room is big enough for 30 participants and 3-4 facilitators
- \* 2-3 tables around the side of the room
- \* Enough chairs, in a semi-circle. No tables in the middle.
- \* Lots of wall space
- \* Make sure there will be a flipchart stand available
- \* Arrange refreshments
- \* Inform the venue hosts that no male staff should enter the room during the training

#### PREPARING THE EVENING BEFORE

- \* Check that the venue is ready, including all materials readily accessible. Consider the room layout is it conducive to sharing and inclusion? Seating in a semi-circle. No tables in the middle.
- \* Prepare yourself for the process make sure you are clear on your tasks for the day and do any additional reading/research so you fully understand the topic(s).
- \* Consider a "gift" like a paper cut-out heart on each participant's chair (refer to it at the beginning of the first day "The heart shows that you are the centre of this process and signifies love for yourselves and for others").
- \* Confirm that no male staff will enter the room during the training.
- Make a question bowl with paper and pen available so that participants can write any unanswered questions for answering later in the day or the next morning.

#### PREPARING ON THE DAY

\* All facilitators to meet in the venue an hour before the workshop starts, every morning. Check in with each other. Set the intention for the day. Decide who will act as a monitor on the mood in the room.

#### **APPROACH**

- Use language that feels natural to you draw on appropriate examples
- \* Daily inclusion of Heart-Mind-Body focus
- \* Facilitators to check in with each other during the breaks
- \* Try to stick to the time allocation for each task if possible. Co-facilitator to monitor the time. However, the time assigned to each activity is a guideline only and could be adjusted if necessary in response to the group dynamics.

- \* If the day is running too much behind time, consider not breaking into groups for some activities, but rather answering the questions for the tasks in plenary.
- \* Any person who self-identifies as a woman is welcome here.
- Regarding prayer: If every participant comes from the same church/religion, then the group could begin with a short prayer together if they want to, but if not then it is advised that participants all pray privately in their rooms before the workshop begins.

#### **FEMINIST POPULAR EDUCATION CORE PRINCIPLES**

- \* Create a safe space of trust and solidarity
- \* Start with the concrete experiences of women's daily lives
- Use stories, art, theatre and other ways to generate open-ended questions that promote critical and creative thinking and deepen understanding about power
- \* Promote learning by doing, connected to concrete problems and practical solutions
- Prioritise reflection, dialogue and action as the primary way to learn
- \* Acknowledge and address diversity, power dynamics and conflict
- Recognise the need to challenge assumptions and probe alternatives
- Share new information and terms that enable participants to name what they are experiencing and see the global forces behind the local and personal
- \* Tap women's sense of hope, inspiration and joy
- Provide time for self-care and personal renewal
- \* Conflict leads to change, but encourage participants to challenge ideas, not individuals.

#### A NOTE ABOUT THE "FACILITATOR INFORMATION" BOXES IN THE MANUAL

- \* The content provided in these boxes is there to support the facilitator with information, background or approach for each activity. It will assist the facilitator to make sure that the information covered is thorough and can prompt the facilitator to "fill in the gaps" where necessary.
- \* It is to be read by the facilitators and well-understood beforehand. If necessary, facilitators can make their own notes in a form that works best for them.

#### A NOTE ABOUT THE HIV TREATMENT LITERACY TRAINING FLIPCHART

- \* Each page of the flipchart has information printed on the back to assist with explaining what the flipchart illustrates and also to give some additional information.
- \* The drawing can be shown to the participants while the facilitator refers to the information on the back.
- \* It is best if the facilitator is very familiar with all the information before presenting the flipchart pages so that the presentation is natural and professional.

#### **DEBRIEF**

- \* Facilitators to meet and debrief with each other at the end of each day and also at the end of the workshop.
- \* This is critical to ensure the facilitation team is shifting in response to what has come up during the day and reviewing (and revising if necessary) the day ahead.

#### **Facilitator resource**

#### WHAT IS A FACILITATOR?

A facilitator is someone responsible for managing, training, keeping participants engaged and on track with the learning process and ensuring each participant's voice is heard. This resource provides some tips for how to facilitate effectively.

#### WHAT IS FACILITATION?

To facilitate is to help bring about learning especially when training adults. The facilitators guide the participants within a particular topic and allow dialogue and keep track of time while allowing maximum participation.

#### **HOW TO FACILITATE EFFECTIVELY?**

Facilitators must have both personal characteristics and acquired skills that make them good at what they do. Many good facilitators make a difficult process seem very natural and intuitive, even when lots of planning and training goes into the craft. For example

- Good facilitators value people and their ideas
- \* Good facilitators think fast and reasonably
- Good facilitators are good communicators
- \* Good facilitator's focus both on the outcomes of the actual training and the process through which learning is facilitated.

#### PREPARE IN ADVANCE

Good facilitators make their work look effortless and natural, but prepare in advance to be effective.

#### **DURING THE TRAINING**

- \* State your objectives at the beginning of the event. Your job as a facilitator is to ensure that the group understands what needs to be accomplished.
- \* Look and sound interested in the topic. Be aware of body language and posture.
- \* Communication is critical in facilitation. You need to project your voice so that participants can hear you well.
- \* Speak and use local examples and language so that participants can follow you.
- \* Always keep an eye contact / face the participants when presenting.
- \* Use the training manual as a guide not a prescription.
- \* Be creative to keep participants engaged and able to follow your presentation well. For example use stories, people's experiences to make the issues you are presenting real.
- \* Appreciate and acknowledge participant's participation.
- \* Try to keep track of time.

#### **KEEPING THE PROCESS FLOWING**

- Participants will usually have a lot to say, but in the event of a lull in participation, you might want to use the following techniques to keep the conversation going:
- \* Use probing questions
- \* Invite the experts to speak up

- \* Call on individuals in the group
- Invite debate by using open questions
- Using Icebreakers to keep the room energised
- Use group work to encourage full participation from all

#### STAYING ON-TASK AND ON-TIME

Your group may have a lot to get accomplished in a short amount of time. With groups of passionate and knowledgeable people, it is easy to get side -tracked onto other topics or get stuck in the detail of a topic. To help the group stay focused, you may want to:

- Remind the group of the expectation to "keep focused"
- Don't be afraid to directly re-focus the group on a particular agenda item
- \* Try to close the item or set it aside in a "parking lot" for consideration later
- \* Let the community decide

#### DEALING WITH UNPRODUCTIVE BEHAVIOUR.

Difficult behaviour is often unintentional or occurs as the result of an emotionally charged situation. Or you might be dealing with inattentive members who are engaging in side conversations. You might also be dealing with personal agendas or disrespectful behaviour. Use gentle and appropriate humour for redirection.

- Restate the ground rules directly
- Direct your questions to the individual for clarification
- \* Seek help from the group
- \* Address the issue with individuals privately during a break

#### **Facilitator information**

#### **IDEAS FOR HEART-MIND-BODY ACTIVITIES**

(Second, third and fourth mornings and also if needed during the day to restore the group)

- 1. Meditative relaxation (Annex 12, Page 70)
- 2. Breathing for Well-being and Calm (Annex 13, Page 73)
- 3. Holds tools for calming and well-being (Annex 14, Page 76)

#### IDEAS FOR CLOSING THE DAY OR DEBRIEFING/RECAP THE NEXT DAY

- 1. Ask each participant: Which one word can you think of to describe how you feel right now?
- 2. Eyes, Ears, Hearts;

Pictures of ears, eyes and hearts are handed out.

Those with ears are asked: "What did you hear yesterday/today?"

Those with eyes are asked "What did you see yesterday/today?"

with hearts are asked: "What did you feel yesterday/today?"

3. Hot potato;

Use a ball, apple or make a ball out of paper/ tape. Group to stand in a circle.

Throw the "hot potato" to a participant and ask them quickly to say one thing they learned, then pass on to another person until everyone has spoken.

4. 2-4-8;

Two participants get together and share what they learned that day Join another group of 2 to make a group of 4. Share with each other what was learned Merge with another group to make a group of 8. Share again.

5. Complete the sentence;

"One thing I learned today/yesterday is...." or

"What made me feel good yesterday/today was..." or "What surprised me yesterday/today was..." or "One thing I'm not sure about is..." or

"One thing I feel grateful for is..."

6. Loaded paper ball;

Write concepts from the previous day on paper, scrunch it up and place the balls in the centre of the room, one for each participant.

Participants to take a ball, read the concept, make any point about that concept and throw the ball back in the centre of the room.

7. Graffiti wall;

Put key concepts on flip chart paper in different corners of the room. Ask participants to visit each sheet and write what that concept means to them or a question they still have about the concept.

- 8. The story of today/yesterday;
  - Sitting in a circle, get the group to tell the story of today/yesterday. The first prompt could be when I arrived I saw...and then (hand to the next person), keep going until the full story is told. The facilitator can ask questions to facilitate.
- 9. Barometer:
  - Create a barometer by drawing a thermometer (For example: hotter=happier and colder=sadder) to indicate how the participants are feeling. Ask participants to put their name or a line on the thermometer.
  - Alternatively write different words to measure feelings/thoughts under headings on flip chart sheets (For example: happy/sad, confused/clear, agree/disagree).
  - Ask participants to write their names or place a sticker under the appropriate column on the flip chart sheet.
  - Facilitator to sum up the trends For example: So most people are feeling unsure today, can someone tell me why? Some are feeling very happy, what made you happy today? Who would like to share from the sad group? Elicit answers from a few people willing to share in the group
- 10. In pairs, share what inspired you the most today/this week and how you plan to take that back to your community. Present each other's feedback to the group

TIME	ACTIVITY	DURATION	PAGE
08h30-09h15	INTRODUCTIONS  ACTIVITY 1 – Introductions  ACTIVITY 2 - Introduction to OBOL approach	45 minutes 40 minutes 5 minutes	11 11 11
09h15-09h45	WORKSHOP HOPES ACTIVITY 1 - Tree of Hope	30 minutes	12 12
09h45-10h10 10h10-10h15	CREATING A SAFE SPACE  ACTIVITY 1 – Creating a safe space  ACTIVITY 2 – Consent	25 minutes 5 minutes	13 13 14
10h15-10h35	TEA	20 minutes	
10h35-12h30	SESSION 1: OUR BODIES  ACTIVITY 1 – Body mapping: Which parts of my body give me pleasure/pain?	1 hour 55 mins	15 15
12h30-13h30	LUNCH	1 hour	
13h30-14h15	ACTIVITY 2 – Drawing our female sexual anatomy	45 minutes	17
14h15-15h00 15h00-15h30	SESSION 2: GENDER AND HIV  ACTIVITY 1 – Defining sex and gender  ACTIVITY 2 – The sex and gender spectra	45 minutes 30 minutes	17 17 19
15h30-15h50	TEA	20 minutes	
15h50-16h40	ACTIVITY 3 – Exploring how women's anatomy and gender role impacts on risk of HIV infection (Why did Grace become HIV infected?)	50 minutes	19
16h40-16h50	FACILITATOR INPUT/RECAP/CLOSING	10 minutes	21

TIME	ACTIVITY	DURATION	PAGE
08h30-09h00	HEART-MIND-BODY	30 minutes	23
09h00-09h10	DEBRIEF AND RECAP	10 minutes	23
09h10-10h40	SESSION 3 – THE WORLD WE LIVE IN  ACTIVITY 1 – The Master's House: Power and patriarchy	1 hour 30 mins	23 23
10h40-11h00	TEA	20 minutes	
11h00-11h30	ACTIVITY 2 - The Master's House: Power analysis	30 minutes	24
11h30-12h00	SESSION 4: WHY HIV TREATMENT LITERACY?  ACTIVITY 1 – The benefits of HIV treatment literacy	30 mins	27 27
12h30-13h30	LUNCH	1 hour	
13h30-14h00 14h00-15h30	ACTIVITY 2 – How to reduce the risk of HIV transmission ACTIVITY 3 – Understanding how HIV works in the body	30 minutes  1 hour 30 mins	28 30
15h30-15h50	TEA	20 minutes	
15450 174 20	SESSION 6: INTRODUCTION TO ANTIRETROVIRAL MEDICATION (ARVs)	20	32
15h50-16h20	ACTIVITY 1 – Learning about antiretrovirals	30 minutes	32
16h20-16h45	FACILITATOR RECAP/CLOSING	25 minutes	33

TIME	ACTIVITY	DURATION	PAGE
08h30-09h00	HEART-MIND-BODY	30 minutes	34
09h00-09h15	DEBRIEF AND RECAP	15 minutes	34
09h15-09h30	SESSION 7: VIRAL LOAD  ACTIVITY 1 – Understanding viral load	15 minutes	34 34
09h30-10h45	SESSION 8: ARV SIDE EFFECTS  ACTIVITY 1 – Learning about ARV side effects	1 hour 15 mins	34 34
10h45-11h05	TEA	20 minutes	
11h05-11h50	SESSION 9: ANTIRETROVIRAL RESISTANCE ACTIVITY 1 – Understanding antiretroviral resistance	45 minutes	35 35
11h50-12h30	SESSION 10: ADHERENCE TO ARVs  ACTIVITY 1 – Benefits of adherence to ARVs	40 minutes	36 36
12h30-13h30	LUNCH	1 hour	
13h30-14h45 14h45-15h30	ACTIVITY 2 – Factors affecting adherence (Why did Grace die?) ACTIVITY 3 – Formulating a personal adherence plan	1 hour 15 mins 45 minutes	38 41
15h30-15h50	TEA	20 minutes	
15h50-16h30	ACTIVITY 4 – Women collectively supporting each other as an aid to adherence	40 minutes	43
16h30-16h45	CLOSING/FACILITATOR RECAP	15 minutes	43

Optional: Informal evening for discussion about sex, sexuality and sexual pleasure

TIME	ACTIVITY	DURATION	PAGE
08h30-08h45	HEART-MIND-BODY	15 minutes	45
08h45-09h15	RECAP ACTIVITY 1 - Learning how best to take ARVs	30 minutes	45 45
09h15-10h15	SESSION 11: WELLNESS AND SELF-CARE ACTIVITY 1 – Healthy Heart-Mind-Body	1 hour	47 47
10h15-10h30	TEA	20 minutes	
10h30-11h00	SESSION 12: KNOWING THE HIV TREATMENT PROTOCOLS ACTIVITY 1 – Knowing the HIV treatment and blood test protocols in Malawi	30 minutes	49 49
11h00-11h30 11h30-12h30	SESSION 13: STRATEGY AND FEMINIST MOVEMENT BUILDING  ACTIVITY 1 - Update report on OBOL campaign  ACTIVITY 2 - Developing our strategies	30 mins 60 mins	49 49 51
12h30-13h30	LUNCH	1 hour	
13h30-13h50 13h50-14h10	ACTIVITY 3 - What do we take home? ACTIVITY 4 - Letting go of the Master's House	20 minutes 20 minutes	52 52
14h10-15h00	CLOSING Evaluation Certificates	50 minutes	52



# DAY 1

HIV TREATMENT LITERACY TRAINING MANUAL

#### **→ INTRODUCTIONS**

45 minutes

08h30 - 09h15

- \* Welcome participants into the space.
- \* Invite personal introductions.
- Consider pairing participants up so that each has a "guardian angel" to look out for them during the workshop.

#### **Facilitator Information**

#### **IDEAS FOR PERSONAL INTRODUCTIONS**

- Each participant to say their names and one thing that starts with the first letter of their name that makes them happy (very brief, preferably one word or one sentence). Also one thing that they don't like.
- \* Sing a song that includes introduction of each person's name.
- \* Stand in a circle. Each person to introduce themselves "My name is \*\*\*" and to do any clapping routine using any parts of their body. Everyone else to respond "Hello \*\*\*" and to copy the routine.
- \* Stand in a circle and each participant to have a turn to throw an orange to someone and the person catching says their own name. Everyone responds with "Hello...." and says the person's name.
- Introduce yourself using an adjective that starts with the same letter of your name For example: Cheerful Clara, Thoughtful Tiwonge, Amazing Ameela.

Facilitators to give information on JASS partnership with Manarela+ and COWLHA, the OBOL Campaign and the background of how the Treatment Literacy Project came about.

#### **Facilitator Information**

#### INTRODUCTION TO OBOL AND APPROACH

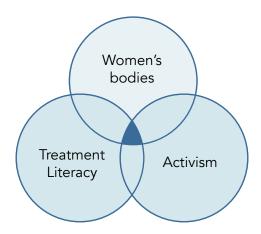
Just Associates (JASS) is an organisation that works with women leaders, activists and organisations across the world, in South-East Asia, Meso America and Southern Africa. We work with women on different issues in different places in order to equip them with the skills, knowledge and strategies to build movements for social change. We have been working with WLHIV in Malawi since 2006. In 2012, along with partner organisation, MANERELA+ we launched the Our Bodies, Our Lives (OBOL) Campaign in order to support women to mobilise for better anti-retroviral treatment and services. Throughout this work together, women have consistently raised the lack of treatment literacy training as a gap; this gap was reinforced by the participatory action research done in 2012 which indicated that almost all women on treatment had received no treatment literacy information beyond the need for lifetime adherence.

JASS, not a health or HIV organisation, has made various attempts to ensure that this demand has been responded to as part of a movement building approach. For example, by purchasing community Media Trust materials (in Chichewa and English) and contracting Johanna Ncala (former TAC national educator) to include elements of women-centred treatment literacy in the feminist movement builders schools (2013). In addition, Johanna supported the production of 2 women-centred treatment literacy factsheets in 2014 which were translated into Chichewa and distributed.

Based on the demands from OBOL members, a new proposal was submitted along with MANERELA+ adding a new partner COWLHA to the HIV/AIDS grant committee at Comic Relief which includes outcomes around treatment literacy and well-being for WLHIV in Malawi. Our analysis of existing materials and how change happens for women, has made us define this element of the movement building work as women-centred (focused on women's bodies) and is about more than treatment literacy/HIV. It is about our bodies and our sexual and reproductive health and is feminist (analysing the gendered power relations in which WLHIV exist). These materials did not exist, so we created a feminist treatment literacy task team - including WLHIV from OBOL, treatment literacy activists and educators, a doctor specialising in HIV treatment and JASS' team of organisers and feminist popular educators to create this curriculum.

This is not a training workshop like others, this is a feminist popular education workshop – in which we start with our experience, our bodies and our lives - and add layers of knowledge and information to build up ourselves and each other, using different methods including selfcare - so that we have the information, knowledge, skills and community we need to be well and to build the OBOL Campaign to reach more women.

#### Draw this illustration on a flipchart:



This training is an intersection where women's bodies, treatment literacy and activism meet.



Activity 1. Tree of Hone

- Activity 1: Iree	е от поре	30 minutes	091113-091143
Activity objectives	<ul> <li>To identify individual expectations and clarify the expectations in light of actual program goals.</li> <li>To begin creating a climate of creativity and solidarity.</li> </ul>		
Materials/preparation	<ul> <li>Draw a large tree on two flipchart sheets stuck together. Stick it on a wall.</li> <li>Cut out 30 paper leaf shapes in green and 30 bud shapes in pink.</li> <li>Flipchart Page with training objectives written on it (See Facilitator Information box below)</li> </ul>		
Activity	<ul> <li>Give a leaf and a bud to each parti</li> <li>On the leaf, ask participants to learn/achieve on this training.</li> <li>On the bud, ask participants to will benefit from the new</li> <li>knowledge.</li> <li>Each participant to read them alou (Credit for methodology: Nani Zulr</li> </ul>	write a hope for we write a hope for leading and stick them	how their bodies on the tree.

Facilitator to write training objectives (from Facilitator information box below) on a flipchart and clarify, especially if there are any major differences in participant expectations/hopes and what has been planned for the workshop.

Any hopes that cannot be met, stick them aside in a "parking lot" or "cookie jar" and explain that these topics may be covered in future training or informally during breaks.

Inform the participants that at the end of the workshop we will revisit the Tree of Hopes to see whether the hopes have been achieved.

#### **Facilitator Information**

#### TRAINING OBJECTIVES

- \* To create a safe space for learning and sharing
- \* For participants to explore the personal impact of gender and power imbalances on their health and lives
- \* For participants to acquire more knowledge about HIV and antiretroviral treatment
- \* For participants to identify, understand and address personal barriers to ARV treatment adherence
- \* To build alliances and mobilise women to demand quality services and treatment
- \* To empower participants to make decisions that will improve heart-mind-body and health.

09h15-09h45

30 minutes



→ Activity 1: Creating a safe space

•	5		
Activity objectives	To co-create a space that is intended for the safe expression, personal reflection, learning and sharing of every participant in the room.		
Materials/preparation	* Flipchart and pens		
Activity	Invite participants to close their eyes.  Ask: Think of a time in your life when you felt completely safe.  Participants to open eyes.  Ask: If we want that feeling here in this room, what would we need to do?  Participants to share responses and facilitator to add suggestions to the group agreements to make the space safe for all participants. Facilitator to write the list on a flipchart.  Ask: Do we all agree with this list? Can we hold ourselves and each other to these agreements?  Stick the flipchart page on the wall for the rest of the workshop.		

25 minutes

09h45-10h10

#### **Facilitator Information**

#### SAFE SPACES ARE CREATED WHEN PARTICIPANTS:

- \* Are in charge of how much they want to participate/share
- Feel respected and not judged
- \* Feel that they have as much right to be in the room as any other participant
- \* Know that what they share will be treated with confidentiality
- Feel that their views, experiences and voices are valued

#### **REMINDER:**

Any person who self-identifies as a woman is welcome here.

#### **AGREEMENTS MAY INCLUDE:**

- \* Confidentiality agreement
- Mobile phones to be switched off
- Not to leave the room except during breaks
- \* Being on time
- \* No interrupting
- \* Allowing every participant to have a voice
- \* Active positive participation by all participants
- \* No speaking to each other while someone is presenting
- \* Being respectful to others
- \* A space where we are open to being challenged
- Being kind, helpful and loving to each other

#### **REGARDING PRAYER:**

Activity 2: Consent

If every participant comes from the same church/religion, then the group could begin with a short prayer together if they want to, but if not then it is advised that participants all pray privately in their rooms before the workshop begins.

Activity objectives	To obtain consent from particip photographs or videos from the		nents, stories,
Materials/preparation	* 30 JASS consent forms (Annex	ure 11, Page 69)	
Activity	* Hand out JASS consent forms -	one to each part	icipant

#### **Facilitator Information**

#### **EXPLAIN**

In this workshop, we want to create a space that is safe for all of us – to share our experiences, our stories and our questions/concerns. For that reason, one of our agreements – above – should be that what we HEAR HERE, stays HERE! Each of us 'owns' our stories and it is not for others to share our stories unless they have our permission.

The same applies to those organising the workshop – sometimes we want to use your stories and the things you say (quotes) to share with others – to tell of the work the OBOL Campaign is doing in Malawi, to write stories of change, to write a report to share with you and sometimes to raise more money for this work.

We have to request your consent (your permission) to use your quotes, photos and even video clips. This is because they belong to you. Also sometimes when we share our stories we may share things that make us unsafe – so we each need to think about whether we are *comfortable* to give consent. And remember you can always change your mind.

10h10-10h15

5 minutes

If you do not want to use your name, we can anonymise your quotes – and say a "women's rights activist" or "OBOL member".

You are under no obligation to give consent. Before any quote, story or photograph is published, you will be called again to confirm that you agree.

- Ask the group Is it okay if we take photos and videos?
  Is it okay if we take notes for a report?
- \* Discuss any concerns and clarify the intention.
- Invite the group to decide if they are willing to sign the consent form.
- \* If yes, appoint someone to collect all signed forms during the first break. Make sure that support is provided to those who may not be able to read well it needs to be informed consent.

Tea	20 minutes	10h15 – 10h35
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→ Activity 1: Body mapping: Which
parts of my body give me pleasure/
pain?

1 hour 55 minutes

10h35 - 12h30

Activity learning objectives	<ul> <li>To reflect on our bodies and lives and how we experience pleasure and pain</li> <li>To think about who is in charge of our bodies and why.</li> </ul>
Materials/preparation	<ul> <li>2 large sheets of flipchart paper per participant, taped together</li> <li>Two poster pens of different colours per pair of participants</li> </ul>
	In pairs, participants to trace the outline of each other's bodies on the sheet of paper and to draw on their body maps which parts of their body give them pleasure (black pen) and which parts give them pain (red pen).
	Invite participants to share with the group. Stick the body maps up on the wall.
	Facilitate a discussion.
	Ask: What similarities can we see in our body maps?
	Are women encouraged to feel pleasure in our bodies?
Activity	Are women encouraged to pleasure ourselves?
	Who gets to decide what pleasurable or painful things happen to our bodies?
	What control do or don't we have over their bodies?
If we don't have control over our bodies, who does?	
	If there is enough wall space, leave the body maps up on the wall to refer back to when side effects are discussed on Day 3.
	Invite participants to thank each other for sharing by hugging their neighbours and anyone else in the room whose story touched them.

Facilitator to write training objectives (from Facilitator information box below) on a flipchart and clarify, especially if there are any major differences in participant expectations/hopes and what has been planned for the workshop.

#### **Facilitator Information**

#### A PROCESS TO RESPOND TO DEEP EMOTION

(Credit: Raising Voices/JASS facilitator workshop 2016)

In the event that this activity (or any other) elicits a deep emotional response, these are possible steps to guide the facilitator to manage this:

- \* Facilitator can acknowledge the value of safe space and inevitability of emotion; see it as part of the work and necessary for healing.
- \* Acknowledge the deep pain and sharing make sure the participant knows you are hearing them (e.g. make eye contact and if appropriate physical contact; repeat what they are saying and acknowledge it).
- \* After a few minutes, introduce a grounding exercise bringing the group together (e.g. breathing, holding hands etc).
- \* Ask group if they have anything to offer back to the people who shared (e.g. "I really appreciate your sharing; I think your mother must have been a really strong woman") BUT make sure no new stories!
- Processing next the facilitator could link what has been shared back to recognising the control or lack of control that we have over our bodies; speak to how deep emotion motivates us and moves us.
- \* Positive note a song or something uplifting draw on the skills of co-facilitators and participants.
- Move on in the process ask the group if that is okay; accept that some people may need to leave the space.
- \* Follow-up individual follow-up and provision of external support resources if necessary.

LUNCH		1 hour	12h30-13h30
→ Activity 2: Drawing our female sexual anatomy		45 minutes	13h30 – 14h15
Activity learning objectives	* To better know and understand our external and internal reproductive organs and how they work.		
Materials/preparation	<ul><li>Flipchart Pages 1-2</li><li>One small mirror per participant (optional)</li></ul>		
Activity	On a page in their books, ask participants to draw what they think the outside of their female sexual parts would look like if they used a mirror to look at them while lying on their back.  On another page, ask participants to draw the parts of our internal		ke if they used a
female reproductive organs (the sexual parts we can't see).  In pairs, ask participants to share their pictures with each other.			

Then facilitate a group discussion.

Ask: Was that easy/hard to do?

How did you feel during the activity?

Which parts did you feel unsure about?

Show the 2 diagrams on Flipchart Page 1 and 2. Cover the labels with a piece of paper and ask for the names of the labelled parts. Uncover the names. Clarify the parts of internal and external anatomy. **Note** that different women's labia and vaginas are not the same and can look very different from the drawings.

Ask: Are women allowed to know about these parts of our bodies?

Can we label these parts in our vernacular language?

Are we allowed to say these words? Are they good or bad words?

Optional:

Ask: Quietly ask yourselves which parts are important to you?

Are there other people who have a say about this part that's important to you?

Invite participants to share if they feel comfortable to do so.

Optional: Hand out a mirror to each participant and invite them to examine their own genitalia in the privacy of their rooms tonight.



→ Activity 1: Defining sex and gender roles		45 minutes	14h15 – 15h00
Activity learning objectives	<ul> <li>To clarify the difference between sex and gender role.</li> <li>To explore the implications of gender roles</li> </ul>		
Materials/preparation	<ul> <li>Flipchart page with two columns headed "Sex" and "Gender role" stuck on the wall.</li> <li>Page of 30 sex/gender statements, cut up individually (Annexure 1) (Note: do not include the "G"/"S" labels, only the statements) or write each statement on a piece of coloured paper</li> </ul>		
Activity	<ul> <li>Page of 30 sex/gender statements, cut up individually (Annexure 1)</li> <li>(Note: do not include the "G"/"S" labels, only the statements) or</li> </ul>		

#### **Facilitator Information**

**Sex** refers to the biological differences between male and female. Note: not all bodies are either male or female, some people have male *and* female characteristics and are called **intersex**.

**Gender role** is a social construct, shaped by society; it refers to the unequal power relations between men and women. It is about what it means to be a 'woman' or a 'man'; what is considered female/feminine and what is considered male/masculine. Society enforces these roles through a process called **socialisation** (learning by being in society) in which these rules are internalised (taken inside ourselves and seen as 'normal and natural').

Gender roles and attributes dictate what a person is able to do due to imposed beliefs and controls enforced by society onto a person of a particular gender. *Gender roles can be challenged*.

It is important to distinguish between sex and gender roles because men and women are not equal. Most constraints on women are gender-based and not sex-based. They differ in different countries, cultures and communities.

Note that it is not as simple as each person being either a man or a woman. As we will see in an upcoming activity, these statements that we have looked at about men and women can have exceptions. For example, a person may be biologically male, but may self-identify as a woman. Or a person may self-identify as neither a man nor a woman.

# → Activity 2: The sex and gender spectra

30 minutes

15h00 - 15h30)

Activity objectives	<ul> <li>To learn the differences between gender identity, gender expression, sex and sexual orientation</li> <li>To appreciate that these each exist on a spectrum and are not binary</li> </ul>	
Materials/preparation	* 30 copies of the Sex and Gender Spectra (Annexure 2) Page 54	
Activity	Show the participants Flipchart Page 3. Discuss each continuum. If a facilitator feels comfortable, they might talk about their own experience of fluidity on the various spectra. Or a facilitator could give examples that illustrate the non-binary experience on the spectra. Hand out Annexure 2 (The Sex and Gender spectra). Ask participants to privately plot where they are on the spectra and to think about if there has ever been a time in their lives when the plotted points would have been different?  Invite participants to share only if they feel comfortable doing so,	

#### **Facilitator Information**

Society tends to think of one's sex as binary – each person is either male or female. There is tremendous societal pressure to conform to one's birth-assigned sex and to heterosexuality and any tendency to deviate from these accepted (and learnt) norms is likely to be viewed with suspicion, anger or judgment.

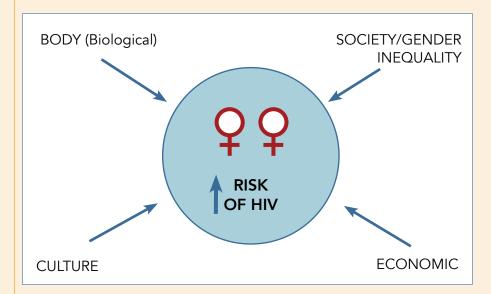
Sex, gender identity, gender expression and sexual orientation in fact *all exist naturally on a spectrum*. Any one person could be on any point on each spectrum. And the points may shift for any one person during their lifetime or even day to day.

TEA	20 mins	15h30-15h50
→ Activity3: Exploring how women's anatomy and gender role impacts on risk of HIV infection (Why did Grace become HIV infected?)	50 minutes	15h50-16h40

Activity learning objectives	To explore how female anatomy and gender role makes us vulnerable to risk of HIV infection.	
Materials/preparation	<ul> <li>30 copies of Case Study Exploring how women's anatomy and gender role impacts on risk of HIV infection (Annexure 3: CASE STUDY: Why did Grace become HIV infected?)</li> <li>30 factsheets about factors that make women vulnerable to HIV infection (Annexure 4)</li> <li>6 pieces of A4 paper</li> </ul>	
Activity	Women are more often infected with HIV than men are. We are going to explore ways in which women are more vulnerable to HIV infection.  Hand out and read the Case Study (Annexure 3) out aloud.  In groups of 4 or 5, discuss the following question:  Ask: Why did Grace become HIV infected? (Give all the factors that contributed to Grace getting infected with HIV)	

Then back in plenary:

Draw the following diagram on a large flipchart sheet.



Ask groups to feed back the reasons that they have identified in Grace's story for why she became HIV infected and write points under each heading on the flipchart as they are mentioned.

For every point that is made, the reason must be clearly identified for why this factor placed Grace at increased risk of infection.

Ask: Are Grace's challenges typical of women in our society? Are there any other reasons drawn from our own experiences that make women more likely than men to be infected with HIV? Add these further suggestions to the chart.

Ask: Is it Grace's fault that she contracted HIV?

#### **Facilitator Information**

#### WHY DID GRACE BECOME HIV INFECTED?

#### Body:

- \* As a woman, Grace is more at risk of HIV acquisition than a man (receptive partner, semen has higher concentration of HIV than vaginal fluid)
- Married at a young age so her mucosa is more sensitive and prone to small tears during
- \* Grace had an STI which makes it easier for her to contract HIV if exposed

#### **Culture:**

- \* Grace marries a man 15 years older than she is. He is likely to have had multiple sexual partners before and is at increased risk of having HIV already. She is then exposed.
- \* Grace is expected to work hard in the fields and look after her children so she did not have time to go to the clinic and have the STI treated

- \* Family planning including condoms is discouraged by their church, which places Grace at increased risk of HIV/STI exposure
- \* Grace's husband and family expect Grace to have another child, hoping for a son. Grace has no say about her fertility choices or the choice to use condoms.
- When her husband dies, Grace is forced to marry her brother-in-law, placing her at risk of exposure to HIV

#### Society (including gender inequality):

- Her husband drinks alcohol and gets drunk (risk of uninhibited behaviour including sexual)
- \* Husband verbally abusive, so Grace will be afraid of him and not be able to negotiate safe sexual practises
- Grace is too afraid to tell her husband she has an STI because she will be blamed, so he does not get treated and she is at risk of repeated reinfection and increased risk of HIV
- \* Grace lives in a remote village, 300km from the nearest clinic so she does not have easy access to health care services or accurate information

#### **Economic:**

- \* Husband does migrant labour to earn a living (risk of having other sexual partners)
- \* Grace is unemployed and therefore dependent on Paul for money. This means she is not in a position to insist on condom use or make other choices about her body.
- As Grace is unemployed, she would be financially dependent on Paul or his family for transport money to get to the clinic for treatment of her STI and for other health interventions
- \* The government could not provide the infrastructure, such as accessible clinics

Hand out a fact sheet to each participant (Annexure 4: Factors that make women vulnerable to HIV infection, stigma ad discrimination).



10 minutes

16h40-16h50

Facilitator to recap what was covered in the day. Reinforce key points in the box below.

#### **Facilitator Information**

#### **RECAP FOR DAY 1**

- When we think about women's health, it is important for us, as women, to start with our own bodies. As we have seen and heard today, we are often not in control of our bodies. When we are in control, we can get a lot of pleasure from our bodies (sexually, doing what we enjoy, working, looking after our children, etc) 22
- Sometimes we do not have the information we need to keep our bodies healthy, to enjoy our bodies and experience pleasure with our bodies. If we can get accurate information, we can keep healthy and protect ourselves from getting sick. However, having the information is not enough, we also need to take action – ourselves and also collectively with others.
- Men and women should be equal but women have less opportunities, reduced ability to earn money and less say about what happens to us or our bodies. This includes having less say over how we express ourselves sexually or what we find sexually pleasurable.
- \* Sometimes we need to unlearn or challenge some of the things we have learnt about being women, so that we can live our lives and be free to express ourselves without facing stigma, discrimination and violence.
- \* If women are HIV positive, there is additional stigma and discrimination that has a negative impact on our physical and mental health.
- \* This is why this Treatment Literacy training begins with women's bodies and who has control over them and then goes on to provide accurate information about HIV, its treatment and how we can keep ourselves healthy.

#### Homework (optional):

Each participant to take their mirror home and to have a look at what their female external genitalia look like.



# DAY 2

HIV TREATMENT LITERACY TRAINING MANUAL

→ HEART-MIND-BODY	30 minutes	08h30 – 09h00

Activity

See example activities on Annexures 12, 13 and 14

#### **→ DEBRIEF AND RECAP**

10 minutes

1 hour

09h00 - 09h10)

00610 10640

Recap what was covered yesterday (see ideas for DEBRIEF/RECAP on Page 5-6)

Stick the laminated Day 1's agenda on the wall.

Ask if participants used their mirrors last night to examine their external genitalia.

Ask if anyone would like to give feedback on how the experience was for them.

Ask if there are any questions from yesterday's activities.

→ Activity 1: The Master's House:



## Session 3: The world we live in

Power and patriarchy		30 minutes	09h10-10h40
Activity learning objectives	* To better understand how patriarchy works and how the whole world uses the same system to oppress women. This will be done by reflecting on women's experiences of "what women and men can and can't do" and then surfacing experiences and understandings of power		
Materials/preparation	<ul> <li>100 A5 papers (20 of each in 5 different colours)</li> <li>The shape of a "roof" for the Master's House, using 2-4 flipchart pages, stuck up on the wall</li> <li>10-15 white strips of paper</li> </ul>		
Activity	Ask: Where do we learn the things we know? Write on a flipchart and choose 5 key institutions of patriarchy to focus on (ie. Family/community, Religion, Formal education, Culture/Tradition, Media, Health facility) Participants break into 5 groups of 6. Give each group 20 "bricks" of coloured paper. Each group looks at a different place where we get information from.		

Ask: What does each place say about how **women with HIV** should behave/act and how **men with HIV** should behave/act?

Groups to write points on their coloured paper "bricks" – make one point per 'brick' and keep the points about women and men on different bricks.

Groups report back and as they do, facilitator to "build the walls" of the Master's House.

Ask: What do you notice?

Are there similarities across the different groups? Are there differences?

What does this house say about women's bodies?

Are we free in this house to decide what to do with our bodies?

Who controls our bodies?

Do all women and men have to follow these 'rules'?

What happens when you break the rules and step outside the Master's House?

Facilitator maps mechanisms used to enforce the behaviours on the walls of the house as they come up (e.g. violence, fear, financial insecurity) using white strips of paper

Ask: Whose house is this?

What do we think about the Master's House?

What feelings does it evoke in us?

What role do we play in maintaining the Master's House?

What does it mean to do the work of breaking down the

Master's House?

What does it mean to stay well in this house?

Facilitator to guide group discussion.

Invite participants privately to write down one way they feel they contribute to building the Master's House and place in a box until end of workshop.

#### **Facilitator Information**

Patriarchy is present in everything we do, in our sense of ourselves, how we think about sex, work, our bodies, the way we dress, etc. We are not born with this thinking – it is learned.

"PATRIARCHY is the system of male authority, which makes the oppression of women seem natural and eternal. Because this system appears so natural, it is almost invisible but patriarchy functions through political, economic, legal, cultural and religious institutions – and, if it is challenged – through violence. Patriarchy has changed over time, and has served ruling class interests under slavery, feudalism and capitalism. Thus to challenge patriarchy effectively also means challenging other systems of oppression and exploitation – like class oppression and racism – which frequently support each other." (FEMINISM FOR TODAY, ILRIG)

#### Moving from patriarchy to HIV and women and our bodies:

"My issue" becomes "our issue" – when we realise that these things are happening to us all, we realise that the things we face in our lives – like not having a job, or not having enough food to eat or not being able to stay on treatment – are not our fault; they are not personal problems, but political problems we need to solve together.

This helps to understand patriarchy as a system of oppression (although it plays out as personal problems). This results in seeing the system as political and prompts collective action.

TEA		20 mins	10h40 – 11h00)
→ Activity 2: The Master's House: Power analysis		30 minutes	11h00-11h30
Activity objectives	<ul> <li>To reflect on women's experiences and then surface understandings of power.</li> <li>To start to introduce the concepts and analysis of power</li> <li>To examine the reasons that we build transformative power.</li> </ul>		
Materials/preparation	<ul><li>A4 coloured paper</li><li>Flipchart sheet with table drawn on it, as below.</li></ul>		
Activity	<ul> <li>Flipchart sheet with table drawn on it, as below.</li> <li>We are now going to look at POWER ANALYSIS in the context of the Master's House</li> <li>Ask: Write down the first word that comes to mind when you hear the word "power".</li> <li>Facilitator groups the words into different types of power (positive, negative or both) and links back to the previous days' examples of when women felt powerful/powerless in regard to their body maps.</li> <li>Facilitator distils key themes and draws out the transformative forms of power (power within, power to and power with). Write the definitions on cards to stick on wall.</li> <li>Ask: Are women encouraged to have power?</li> <li>Facilitator introduces power analysis – visible, hidden and invisible power - reflecting back on Master's House</li> <li>Discuss the three faces of power (See Facilitator information box) and collective power analysis.</li> <li>Ask: When we think about the campaign, who are the visible actors,</li> </ul>		

the invisible actors and the hidden actors?

Then facilitate how the campaign is addressing the issues, using the following chart as an example.

POWER ANALYSIS	Actors	How are we addressing the issues?
Visible	MOH/Nurses/ Doctors/TL/FL	More training for health personnel/ engagement meetings
Hidden	Government and donor community	Advocating for increased domestic funding/ engagement meetings/advocacy
Invisible	Political will/MOH/ individuals or self	Demand for services/ advocacy/ engagement meetings

### **Facilitator Information**

Using the Power Framework: The Three Faces of Power, Adapted by JASS (adapted from Making Change Happen III: POWER).

**POWER:** Degree of control over material, human and financial resources, exercised by different sectors of society. The control of these resources becomes a source of individual and social power.

### **VISIBLE (FORMAL) POWER: MAKING DECISIONS & ENFORCING THE RULES**

This kind of power includes the most visible and definable aspects of political power — the formal rules, authorities, institutions, and procedures of decision-making and enforcing the rules.

Examples include elections, laws, legislatures, budgets, courts and policing, government from local to global. Strategies that target this kind of power are usually trying to change one or more of the following: who makes decisions, how decisions are made, and what the outcome of a particular decision will be.

### HIDDEN (SHADOW) POWER: SETTING THE POLITICAL AGENDA

Often operating behind the scenes, powerful people and institutions exercise their influence by controlling who gets to the decision-making table and whose concerns get on the public agenda.

Examples include: corporate interests, organised crime cartels, churches, social movements, paramilitaries. This form of power excludes and devalues the concerns of other less powerful groups, attacking and delegitimizing their leaders and ideas. By preventing important voices and issues from getting a fair public hearing, decision-making can be skewed to benefit the interests of a few. In response, strategies that focus on strengthening community organizations and movements can build collective power and new leadership to influence and shape the political agenda and increase their legitimacy and voice.

### INVISIBLE POWER: SHAPING MEANING, VALUES AND NORMS

Invisible power isn't really invisible – we see it all around us, if we know what to look for. Through processes of socialization, culture and ideology, invisible power works to legitimize certain ideas, beliefs and behaviors, and delegitimize others. By influencing how individuals think about their place in the world, this form of power shapes people's beliefs, sense of self and acceptance of the status quo. Significant problems and issues are not only kept from the public agenda, but also from the minds and consciousness of the people involved. Challenging power at this level requires strategies that help people share their experiences, build confidence and political awareness and challenge oppressive ideas - transforming not only the way they perceive themselves but also the way others perceive the world.

Power within: Capacity to imagine and have hope

Power with: Finding common ground in order to build collective strength

Power to: Power to make a difference which can be multiplied

### **WOMEN AND POWER**

\* Women are not encouraged to have power.

- \* Power can be positive or negative.
- \* No-one is completely powerless. Everyone has some power.
- \* Power can come from feelings, connections, relationships, position, control over resources, knowledge, etc.
- \* Power plays out across gender, race, class, ethnicity, age, sexuality privileging some excluding others. Often men are privileged and women are excluded.
- \* Power is relational and dynamic, and can change.
- \* This is important for us as activists so we can think about what kind of power we want to build and what kind of power we want to challenge



### Activity 1: The benefits of HIV **Treatment Literacy**

30 minutes

11h30-12h00

Activity learning objectives	* To explore the benefits of becoming HIV treatment literate
Materials/preparation	* Flipchart and pens
Activity	What's the one thing that you would really like to know about your HIV status or your treatment? Write answers on a flipchart. Explain that the word we use for knowing about HIV and its treatment is "treatment literacy". As a group, discuss the following questions one at a time and facilitate discussion Ask: Why is it important for us as individuals to be treatment literate? How might the Treatment Literacy knowledge impact on how we feel about ourselves and our status? Why would we, as a community of women, want to become HIV treatment literate? What do we think about this statement: "HIV Treatment literacy is as important as medication (ARVs)?"

### **Facilitator Information**

### **DEFINITION OF HIV TREATMENT LITERACY:**

Understanding the major issues related to HIV – such as the latest science, treatment, side effects and guidelines - so that individuals and communities can be more responsible for their own care and can demand their rights when proper care is not made available to them. (modified from Treatment Action Campaign definition)

### BENEFITS OF HIV TREATMENT LITERACY TRAINING FOR INDIVIDUAL WOMEN:

- To increase self-empowerment and feelings of self-confidence
- \* To increase understanding of HIV and the personal feeling of control over the management and treatment of our HIV
- To understand how ARVs treat HIV and protect our bodies and consequently to understand the reasons for optimum adherence to treatment - with improved adherence comes improved health and longevity

- \* To understand the science of HIV well enough to make the best decisions for our own health
- \* With this knowledge, we can be more responsible for our own care and can demand our rights when proper care is not offered to us.
- \* Accurate knowledge can translate into action.
- \* To become our own health advocates so we know when to seek healthcare; how to explain our symptoms and what tests to ask for.

## BENEFITS OF HIV TREATMENT LITERACY FOR THE COMMUNITY OF WOMEN AS A WHOLE:

- \* Opens up conversation with other women about our bodies, sex and sexuality that we are usually not encouraged to have.
- Puts our health back in our hands so we can be well and help other women in our community to be well
- \* To understand what treatments and tests to lobby the government for Treatment literacy work is essential to develop the sort of empowered activists who can become important allies for HIV programmes and to support the implementation of collaborative efforts.
- \* Treatment literacy is information that helps women to act, to remain healthy and to hold government accountable for access to the right drugs. It also helps women to hold healthcare workers accountable for the correct treatment and HIV management. If women have the knowledge then they can advocate if things are not right in the community.



→ Activity 1: What is HIV? How HIV

is transmitted an transmitted	d how it is NOT	30 minutes	12h00-12h30
Activity learning objectives	<ul> <li>To understand what HIV is.</li> <li>To understand the difference be</li> <li>To be clear about ways that HIV NOT transmitted.</li> </ul>		
Materials/preparation	<ul> <li>Pieces of coloured A6 paper – in two colours</li> <li>Two large sheets of paper headed "Ways that HIV is transmitted" and "Ways that HIV is NOT transmitted"</li> <li>Flipchart Page 4-6</li> </ul>		
Activity	Ask: What is HIV? Use Flipchart Page 4 Place a pile of coloured A6 paper (flipchart pens on the floor. Participants to stand in a circle around the HIV is transmitted and on the HIV is not transmitted (myths). Put middle of the circle. Ask participant Facilitator to take each paper and a on the correct sheet	und the papers. e colour paper wa other colour pape the papers on the ts <b>not to duplicat</b>	ays in which they er ways in which e floor in the te.

<b>LUNCH</b>	1 hour	12h30-13h30
→ Activity 2: How to reduce the risk of HIV transmission	30 minutes	13h30-14h00
Activity objectives * To understand how to reduce ri	sk of HIV transmis	sion.

HIV not transmitted?) to consolidate

Afterwards, use Flipchart 5 (How is HIV transmitted?) and 6 (How is

Materials/preparation	<ul> <li>One large sheet of paper headed "Reduce risk of HIV transmission" (sub-headings: "Through sex", "Through blood" and "Through Parent-to-Child Transmission")</li> <li>30 male condoms and dildo</li> <li>30 female condoms and female "vagina"</li> <li>Flipchart Page 7-8</li> </ul>
Activity	Ask: How can the risk of HIV transmission through sex be reduced?  How can the risk of HIV transmission through blood spread be reduced?  How can the risk of HIV transmission through parent-to-child transmission be reduced?  Write the answers on the flipchart sheet.  Explain that the reason that we use "parent-to-child transmission" rather than "mother-to-child transmission" is because often women are blamed for transmission of HIV (even though most women get infected through a male partner to whom they have been faithful) and we want to be careful about reinforcing the idea that mothers (women) are the sources of HIV and are to blame for children being infected. The term "parent-to-child" recognises the role of both parents in creating HIV negative babies.

### To reduce the risk of HIV transmission through sex

- \* Choose non-penetrative sex
- Use male or female condoms correctly every time for sex (vaginal, anal and oral sex)
- \* Early treatment of Sexually Transmitted Infections (because the risk of HIV transmission during sex is increased in the presence of STIs)
- If the HIV positive partner is taking anti-retroviral treatment correctly and their viral load is suppressed, this will greatly reduce the risk of transmission to HIV negative partner(s)
- Post-Exposure Prophylaxis (for example taking ARVs after rape) 30 day course of antiretroviral treatment started within 72 hours of the incident, will reduce the risk of acquiring HIV
- \* Voluntary Male Medical Circumcision (reduces transmission to men and therefore to their partners)
- Use lubricants to avoid cuts or abrasions to vaginal mucosa
- NOTE: Pre-exposure Prophylaxis (when an HIV negative person takes ARVs before exposure to prevent HIV acquisition) is not currently available in Malawi (2018 Clinical Management of HIV in Children and Adults)

### To reduce the risk of HIV transmission through blood

- Handle blood from others as though it is always potentially infected
- Do not share needles for intravenous drug use
- Healthcare workers to get post-exposure prophylaxis (30-day course of ART started within 72 hours of incident)in cases of needle stick injuries with HIV infected or unknown blood
- Do not share razors
- Do not share toothbrushes (there is sometimes bleeding from gums when teeth are brushed, although very low risk of transmission)
- \* Screen donated blood before blood transfusions (this is happening in Malawi)

### To reduce the risk of HIV transmission through parent-to-child transmission

- Mother to be on anti-retroviral treatment during pregnancy, delivery and breastfeeding (Risk is less than 5% when the mother's viral load is suppressed)
- \* Baby to receive anti-retrovirals (Nevirapine daily) as soon as possible after birth until six weeks of age, to further reduce risk of transmission
- Breastfeeding only for the first 6 months of baby's life. Early mixed feeding increases risk of transmission to the baby by causing gut inflammation. The Malawi Guideline for Clinical Management of HIV suggests exclusive breastfeeding for 6 months. Then gradually introduce nutritious hygienic food from 6 months of age. Aim to wean gradually from breastfeeding at about 22 months. Baby to be tested for HIV at around 24 months old.

Use Flipchart 7 and 8 to review how to use male and female condoms.

Give one female and one male condom to each participant.

Ask for a participant to volunteer to demonstrate how to use a male and a female condom on the male dildo and female "vagina"

Invite participants to practise using male and female condoms during the next break.

→ Activity 3: Understanding how HIV	1 hou
works in the body	30 minu

ur utes

14h00-15h30

Activity learning objectives	To understand how HIV replicates, how it damages the immune system and how that leads to opportunistic infections and ill- health.
Materials/preparation	<ul> <li>Flipchart Page 9-18</li> <li>For roleplay: Brightly coloured A4 paper, tied with string to put around participants' necks to label each participant's role during role-play:</li> <li>10 x "CD4"</li> <li>4 x "DNA"</li> <li>1 x "Germ"</li> <li>3 x "Immune cell"</li> </ul>

	<ul> <li>1x "HIV"</li> <li>1x "Reverse Transcriptase" (or "Helper 1")</li> <li>1x "Integrase" (or "Helper 2")</li> <li>1x "Protease" (or "Helper 3")</li> <li>2 pairs of scissors</li> <li>One short strip of paper ("RNA") stuck on the "HIV" neck label</li> <li>Several long strips of the same colour paper</li> </ul>
Activity	<ul> <li>Questions posed to whole group, participants volunteer to answer each question. Then use Flipchart Pages to illustrate and consolidate the answers.</li> <li>Flipchart Page 9: How does a healthy immune system work?</li> <li>Flipchart Page 10: What does HIV do to the immune system?</li> <li>Flipchart Page 11: How does HIV multiply inside and destroy the CD4 cells?</li> <li>Clear the centre of the room of chairs and demonstrate these slides using the following role-play</li> </ul>

Each participant in the role play to wear a labelled A4 paper around their necks to say which role they are playing.

### **ROLEPLAY 1: HOW CD4 CELLS FIGHT GERMS**

### Roleplayers:

- \* Room represents the body, door represents a break in the skin
- \* 10 participants in centre of the room, sitting on chairs and holding hands facing inwards, represent CD4 cell membrane
- \* 4 participants inside the CD4 cell, holding hands in a row, represent the genetic material (DNA) inside the nucleus of the CD4 cell
- \* 3 participants scattered around the room, represent other cells of the immune system
- \* 1 participant outside the room, represents an invading germ that is about to enter

### Method:

- \* "Invading germ" enters the room via the door (representing the skin)
- \* CD4 people see the germ enter and whistle or shout loudly
- \* Three other immune system cells "wake up" and come running to "arrest" the germ, surround it and "kill" it

### **ROLEPLAY 2: HOW HIV INFECTS A CD4 CELL**

### Roleplayers

- \* Room represents the body, door represents a break in the skin
- \* 10 participants in centre of the room, sitting on chairs and holding hands facing inwards represent CD4 cell membrane
- \* 4 participants inside the CD4 cell, holding hands in a row, represent the genetic material (DNA) inside the nucleus of the CD4 cell
- \* 3 participants scattered around the room represent other cells of the immune system
- \* 4 people to act as the HIV virus outside the room, about to enter: 1 is the HIV genetic information, 3 are the enzymes Reverse Transcriptase (Helper 1), Integrase (Helper 2) and Protease (Helper 3). Protease and Integrase carry scissors

### Method

- Invading HIV virus (4 participants holding hands) creeps into the room via the door(representing the skin)
- \* HIV virus moves towards CD4 cell and puts finger on lips of CD4 cell person before that person can whistle and alert other immune cells. The other immune cells continue to sleep.
- \* HIV virus uses a "Key" (hand) to open the "Lock" (where 2 CD4 people are holding hands)
- \* HIV virus (all 4 people) slips inside the CD4 ring
- \* The HIV particle separates into 4
- \* The Reverse Transcriptase enzyme (Helper 1) picks up a strip of paper and sticks it onto the neck label of the HIV. Explain that it is converting single stranded RNA into double stranded DNA so that it can be recognised by the CD4 cell.
- \* The Integrase enzyme (Helper 2) uses "scissors" to open the DNA of the CD4 cell and allows the HIV genetic material to "insert" itself
- Explain how the HIV genetic material inserts itself into the DNA genetic material and turns the CD4 cell into a factory for making more HIV
- Explain how the CD4 DNA starts manufacturing more and more HIV genetic material (illustrated by the strips of paper inside the cell)
- Explain that the Protease enzyme (Helper 3) cleaves ("cuts" with scissors) the new genetic material at the right places to create mature HIV genetic material (cut long strips of paper into shorter strips).
- \* Explain that the new HIV genetic material moves through the CD4 membrane, stealing some membrane from the CD4 cell (a CD4 membrane person takes a small strip of paperand moves away from the cell), ready to infect other cells (These are the "babies" of the HIV virus that first entered the CD4 cell)
- Whole CD4 cell "collapses" and dies.

Use the following flipcharts:

Flipchart Page 12: What happens when HIV destroys too many CD4 cells?

Flipchart Page 13: What are the stages of HIV infection?

Flipchart Page 14: What could happen in Stage 1?

Flipchart Page 15: What could happen in Stage 2?

Flipchart Page 16: What could happen in Stage 3?

Flipchart Page 17: What could happen in Stage 4?

Ask: In which stage is HIV most easily transmitted to someone else?

Facilitate group discussion.

Consolidate with Flipchart Page 18: In which stage is HIV most transmissible

TEA	20 mins	12h30-13h30
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# → Activity 1: Learning about antiretrovirals 30 minutes 15h50-16h20

Activity objectives	<ul><li>To know what ARVS are</li><li>To better understand how ARVs work</li></ul>
Materials/preparation	<ul> <li>Flipchart Page 19-20</li> <li>For roleplay: Brightly coloured A4 paper, tied with string to put around participants' necks to label each participant's role during role-play: <ul> <li>10 x "CD4"</li> <li>4 x "DNA"</li> <li>1 x "Germ"</li> <li>3 x "Immune cell"</li> <li>1x "HIV"</li> <li>1x "Reverse Transcriptase" (or "Helper 1")</li> <li>1x "Integrase" (or "Helper 2")</li> <li>1x "Protease" (or "Helper 3")</li> <li>3x "ARV"</li> <li>2 pairs of scissors</li> <li>One short strip of paper ("RNA") stuck on the "HIV" neck label</li> <li>Several long strips of the same colour paper</li> </ul> </li> </ul>

Questions posed to whole group, participants volunteer to answer each question. Then use

Flipchart Pages to illustrate the answers.

Flipchart Page 19: What are antiretrovirals?

Flipchart Page 20: How do ARVs work?

Facilitator to facilitate the following roleplay.

#### **Facilitator Information**

Each participant in the role play to wear a labelled A4 paper around their necks to say which role they are playing.

### **ROLEPLAY 3: HOW ARVS TREAT HIV INFECTION**

### **Roleplayers:**

- \* Room represents the body, door represents a break in the skin
- \* 10 participants in centre of the room, sitting on chairs and holding hands facing inwardsrepresent the CD4 cell membrane
- \* 4 participants inside the CD4 cell, holding hands in a row represents the genetic material (DNA) inside the nucleus of the CD4 cell
- 4 people to act as the HIV virus outside the room, about to enter: 1 is the HIV geneticinformation, 3 are the enzymes Reverse Transcriptase (Helper 1), Integrase (Helper 2) and Protease (Helper 3). Protease and Integrase carry scissors
- \* 3 participants represent ARVs

### Method:

- \* Invading HIV virus enters the room via the door (representing the skin), uses the key, divides into the different enzymes and enters the nucleus (as in Roleplay 2). Explain that the CD4 cell is now infected and the person is HIV positive.
- \* ARVs move into place (as if the PWHIV starts taking ARVs): 1 restrains Reverse Transcriptase (Helper 1), 1 restrains Integrase (Helper 2) and 1 restrains Protease (Helper 3).
- \* Explain that the HIV genetic material embedded in the CD4 DNA is alive, but the lifecycle is blocked at various points. All other viruses that were outside the CD4 cell die.
- \* Explain that if someone stops taking their ARVs the lifecycle will begin again (demonstrate by removing ARVs and the HIV begins to multiply again)

### → FACILITATOR INPUT/RECAP/ CLOSING

25 minutes

16h20-16h45

See Page 5-6 "IDEAS FOR CLOSING THE DAY"

### Homework (optional)

Each participant to learn how to spell and say the name of their medication (both the Tradename and the chemical name)

Invite the participants to practise inserting a female condom in the privacy of their rooms this evening.



HIV TREATMENT LITERACY TRAINING MANUAL

→ HEART-MIND-BODY		30 minutes	08h30 – 09h00
	C   L	40.40	
Activity	See example activities on Annexures 12, 13 and 14		

→ DEBRIEF AND RECAP	15 minutes	09h00 – 09h15
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Recap what was covered yesterday and stick the laminated Day 2's agenda on the wall.

Ask if participants tried to learn their medication Tradenames and chemical names. Ask if anyone would like to tell the group which medication they are taking?

Ask if there are any questions from yesterday's activities.



Activity 1: Understanding viral load		15 minutes	09h15-09h30
Session learning objectives	* To understand the viral load test result and implications		
Materials/preparation	* Flipchart Page 21-22		
Activity	Ask the following questions first and then use the Flipcharts:  Flipchart Page 21: What is the viral load test? (Demonstrate with a syringe how much 1ml of blood is)  Flipchart Page 22: What does a low or high viral load mean for me?		



→ Activity 1: Learning about ARV side

effects	15 minutes		
Session learning objectives	<ul> <li>To understand what side effects may occur on ARVs and how to manage them</li> <li>To understand and appreciate how each person has an individual medical history, preexisting conditions and vulnerabilities that will</li> </ul>		
	affect which medication choice is right for them and whether they are at risk of side effects		
Materials/preparation	<ul> <li>Flipchart Page 23-27</li> <li>30 Copies of Annexure 5 "Malawi ARV regimens, contraindications and possible side effects"</li> </ul>		
Activity	Use the following Flipchart pages to prompt discussion. Flipchart Page 23: Why are some people taking different ARV regimens? Ask: Can any of you tell us your story of side effects that you may have experienced on your medication? Flipchart Page 24: What possible side effects may I get on Regimen 5A? (less serious) Flipchart Page 25: What possible serious side effects may I get on Regimen 5A? (more serious) Flipchart Page 26: What possible side effects may I get on the new drug Dolutegravir? Flipchart Page 27: What should I do if I get side effects? Flipchart Page 28: What is IRIS?		

Hand out a copy each of Annexure 5 "Malawi ARV regimens, contraindications and possible side effects"

TEA	20 mins	10h45-11h05
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1 hour

09h30-10h45

antiretroviral resis	<b>-</b>	45 minutes	11h05-11h50
Activity learning objectives	<ul> <li>To understand the consequences of not adhering as prescribed to ARV medication and how this can lead to resistance of the HIV.</li> <li>To understand what HIV resistance is, the significance of resistance and how to prevent it.</li> </ul>		
Materials/preparation	<ul><li>* Flipchart Page 29-30</li><li>* Flipchart sheet with questions already written</li></ul>		
Activity	Participants in groups of 3 or 4 to discuss the answers to these questions. Stick up the flipchart sheet to display the questions.  Ask: What is HIV resistance?  Under what conditions does HIV become resistant?  Why is it bad for us if our HIV becomes resistant?  How do we prevent ourselves from having HIV that is resistant?  Participants to feed back in plenary.  Use the flipchart pages to consolidate  Flipchart Page 29: What is HIV resistance?		

Flipchart Page 30: How can we prevent viral resistance?

Use the flipchart pages to consolidate

Flipchart Page 29: What is HIV resistance?

Activity 1. Understanding

Flipchart Page 30: How can we prevent viral resistance?

### **Facilitator Information**

### **HIV Resistance**

- \* HIV can become "resistant" to certain ARVs
- \* This means that these ARVs will no longer work to control the HIV, even if they are taken correctly again

### How does HIV become resistant?

- \* Poor adherence to ARVs
- \* When ARVs are not taken regularly, it gives the HIV a chance to "learn" how to overcome the tablets.

### Why is it bad if the HIV becomes resistant to our ARVs?

- \* The ARVs will no longer work once our HIV is resistant, even if we take our ARVs correctly again
- \* This means our CD4 count could go down and we could get sick
- \* We will need to change to other tablets, which may be harder to take or have more side
- \* effects

### How do we prevent HIV resistance?

- \* Take ARVs correctly every day
- \* Always use condoms to prevent getting a resistant virus from someone else.
- \* Have your viral load done on schedule to detect early if viral load is detectable so that this can be addressed and corrected hopefully before viral load resistance develops

→ Activity 1: Benefits of adherence to	40 minutes	11h50-12h30
ARVs	40 millates	111130-121130

Session learning objectives	<ul> <li>For participants to have a broader understanding of what adherence means</li> <li>To understand the importance and benefits of adherence to ARVs</li> </ul>
Materials/preparation	<ul> <li>5 Flipchart sheets</li> <li>Draw the diagram below</li> <li>Flipchart Page 31</li> <li>Water bottle, with neck cut off. Two lines drawn on the bottle or two elastics around the bottle (for maximum and minimum therapeutic levels). A hole punched in the bottom of the bottle. Cup or bottle for pouring. A bowl to catch the water.</li> </ul>
Activity	Ask: How would we define "adherence" in the context of management of HIV?  Take 2 or 3 suggestions and then give the definition below.

### ADHERENCE IN THE CONTEXT OF MANAGEMENT OF HIV

- Sticking to the plan that is agreed between us as the client and health care worker
- \* Collecting our medication on the right dates
- \* Taking our medication exactly as prescribed: every day, at the right time, in the right doses. Good adherence is defined as taking more than 95% of the tablets every month (this means missing no more than one dose per month if you are taking one tablet once a day)
- \* Attending all medical appointments and having blood tests done on time

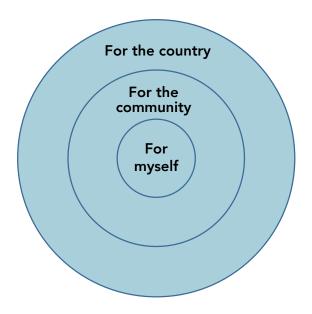
Break into small groups of 5 or 6. Participants to write onto the Flipchart page, in the circles.

Ask: Why do we take ARVs?

What is the benefit to us as individuals, communities and as a country?

Group discussion about what has been written.

Encourage participants to share their personal positive experiences of taking ART.



### **BENEFITS OF ART:**

### For individuals:

- \* To prolong life and improve quality of life
- \* To achieve my goals and dreams
- \* To prevent disease progression and immune system damage
- \* To prevent opportunistic infections
- \* To reduce parent-to-child transmission
- \* To stay well to care for our children
- \* To reduce the risk of infecting sexual partners
- \* To prevent transmission to partners
- \* To prevent ARV resistance

### For the community:

- \* To reduce the mortality rate
- To reduce the spread of HIV infections
- \* To minimise the number of orphans due to early parental death
- To increase awareness in the community as more people take treatment, which will encourage more people to test for HIV
- \* To reduce the burden to the community particularly women having to care for sick members
- To maintain the health of the breadwinners in the community and not to lose people who have skills

### For the country:

- \* For businesses to continue having a healthy workforce
- For fewer resources to be spent treating opportunistic infections and providing palliative care
- \* To reduce pressure on healthcare facilities
- \* To enhance the economy because healthy people can contribute to country development

- For fewer resources to be spent on disability grants, e.g. MASAF FUND
- To aim for the goal of an HIV-free generation and contribute to UNAIDS goal of 90:90:90
   90% of all PLWH to know their status
   90% of those to be on ARVs
   90% of those to have undetectable Viral Load

All these reasons are what keeps us motivated to take ARVs.

Ask: Why is it necessary to take ARVs correctly every day?

Use Flipchart Page 31 Why is it necessary to take ARVs at the right time every day?

DEMONSTRATION: Pour water into the top of the bottle. Stop when the level is between maximum and minimum therapeutic lines. Allow the water to trickle out of the bottle ("metabolising" of ARVs by kidney and liver), then pour more water in the top (taking a dose of medication). Demonstrate what happens if no more water is added (Dose is missed) – level falls below minimum level and risk of resistance. Demonstrate what happens if too much water is added (eg. Double dose taken) – level is above maximum level and risk of toxicity.

<b>LUNCH</b>	1 hour	12h30-13h30
→ Activity 2: Factors affecting adherence: Why did Grace die?	1 hour 15 minutes)	13h30-14h45

Session learning objectives	<ul> <li>For participants to identify the multifactorial reasons that result in difficulty with adherence to (any) medication</li> <li>To identify factors that can support adherence</li> </ul>
Materials/preparation	<ul> <li>30 copies of case study: CASE STUDY: Why did Grace die? (Annexure 6)</li> <li>Ball of string</li> <li>Scissors</li> <li>30 pieces of A6 coloured paper</li> </ul>
Activity	Hand out one copy to each participant of the case study of "Why did Grace die?" (Annexure 6) Facilitator to read through the case study aloud. Ask for one volunteer who will symbolise Grace. "Grace" to sit on a chair. Ask: What are the reasons that Grace found it difficult to adhere to medication? As each reason is suggested, participant to write it on a piece of paper and tie it with string to Grace Ask: What other reasons might prevent women in our own community from being adherent?

Encourage participants to draw from their own experience or the experience of other women around them, to identify other challenges to adherence. Keep writing the reasons on papers and tying them to "Grace" as each suggestion is made.

Once all ideas are exhausted, ask the group:

Ask: Is it Grace's fault that she did not adhere to treatment? Facilitate discussion

Now ask for suggestions for how each problem may be solved. Remove the strings one at a time as the suggestions are made, until "Grace" is free again (to be able to adhere to her medication).

### **Facilitator Information**

# FOR WOMEN, BARRIERS TO GOOD ADHERENCE TO ARVS MAY INCLUDE:STICKING TO THE PLAN THAT IS AGREED BETWEEN US AS THE CLIENT AND HEALTH CARE WORKER

### Individual/internal

- \* Internal stigma or shame
- Lack of treatment literacy knowledge and education
- \* Depression/mental illness
- \* Alcohol/substance abuse
- \* Forgetfulness
- \* Medication not with client when time to take them (eg when socialising)
- \* Too busy to collect or take medication
- \* Run out of medication
- \* Afraid to take medication in front of others
- Non-disclosure to those living in the house
- \* In denial does not want to believe or be reminded of infection
- \* Side effects to medication
- \* Frequent travel
- \* Domestic or childcare responsibilities
- \* Domestic violence
- Too occupied with survival like sourcing food
- \* No money for transport
- \* Feeling marginalised and therefore reluctant to seek health care (eg. LGBTQI community)
- \* Family members taking/sharing my medication
- Belief and use of herbal remedies instead

### Social:

- Fear of stigma and discrimination
- \* Fear of rejection
- Lack of emotional and practical support
- Social influence of family members (eg. Husband not allowing wives to take ARVs)
- Myths about HIV/ARVs
- \* Fears or rumours about side effects
- \* Gender-based violence
- \* Religious beliefs about having faith rather than taking ARVs. Promises of faith healing
- Beliefs that ARVs should not be taken if alcohol consumed
- \* Beliefs that ARVs cannot be taken on an empty stomach
- \* Family encouraging use of herbal or traditional remedies
- \* Work obligations
- \* Lack of access to resources such as food, money, transportation

### Healthcare system:

- \* Clinic/healthcare facility too far away
- \* Lack of ongoing adherence counselling
- \* Poor relationship or lack of trust with healthcare provider
- Service providers poorly trained
- \* Medication stockouts
- \* Long queues and waiting times
- \* Fears about lack of confidentiality
- \* Inadequate budgets allocated to healthcare

## FOR WOMEN, FACTORS THAT MAY SUPPORT GOOD ADHERENCE TO ARVS MAY INCLUDE:

### Individual/internal:

- Confidence in oneself
- Reminders such as phone alarm, tick-sheets, cues (For example regular television shows)
- Disclosure to trusted friends or family members
- \* To be able to take ARVs at home openly and without having to hide them
- \* Treatment of substance abuse problems
- Treatment of mental health problems
- \* Understanding about HIV, how ARVs work and what the viral load results mean

### Social:

- Support from friends and family
- Support from groups such as church and church leaders
- Build support groups of WLHIV within our communities
- \* Community feeding schemes
- Programs and campaigns to address gender-based violence

### Healthcare system:

- Good HIV, ARV and adherence education
- \* Programs and campaigns to reduce stigma
- \* Provision of free services and medication
- \* Non-judgmental and supportive attitude of healthcare providers
- \* Health services easily accessible
- \* Health services integrated
- \* Well-trained healthcare providers
- \* Reduced waiting times

Facilitator to refer back to POWER ANALYSIS and to code some of the barriers to adherence and solutions from Grace's story in terms of invisible/hidden/visible power (choose one example of each): For example:

POWER ANALYSIS	BARRIERS TO ADHERENCE	SOLUTIONS
Visible	Government – long distance to clinics Healthcare worker bad attitudes	Lobbying the government for increased budget allocation to build more clinics or provide mobile clinics Healthcare worker training
Hidden	District Health Officer (DHO) Government	Collective mobilisation Hold engagement meetings with health care workers
Invisible	Church – teaching that prayer alone will cure HIV	Engagement/community awareness and education Dialogue with faith community

→ Activity 3: Formulating a personal adherence plan	45 minutes	14h45-15h30
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Activity objectives	<ul> <li>To formulate a personal plan to optimise adherence to medication</li> <li>To identify personal actual and potential barriers to adherence and begin to formulate a plan to address those barriers</li> </ul>
Materials/preparation	<ul> <li>30 copies of a Personal Adherence Plan (Annex 7, Option 1 or Option 2)</li> <li>Optional: 30 pillboxes</li> </ul>
Activity	Hand out a Personal Adherence Plan page to each participant. Choose which Personal Adherence Plan will work best for the group (Annex 7, Option 1 or Option 2)

If Option 1: Facilitator to read out the guiding questions in the Facilitator information box below, one heading at a time, and allow a short time for participants to complete each block.

Each participant then to share their answers and plan with a partner.

### Back in the group:

Ask: What challenges for adherence did you identify?

Invite participants to share their challenges with the group and facilitate discussion

Hand out a pill box to each participant and explain how it is used.

### **Facilitator Information**

# PROMPTING QUESTIONS FOR PERSONAL ADHERENCE PLAN (ANNEX 7, OPTION 1):

### Support system:

- **\*** Who supports me?
- Who reminds me to take my treatment?
- Who can I rely / talk to when I have troubles with adherence?

### Disclosure - to whom and challenges:

- Who have I disclosed to?
- Who do I still want to disclose to?
- What are my challenges around disclosure?

### Names of ARVs:

Do I know the names of the ingredients in my ARVs?

### Time to take ARVs:

- What time do I take my ARVs?
- \* Does this time work for me?
- Do I need to change the time that I take my ARVs?

### Storage of ARVs:

- \* Where do I keep my ARVs?
- Am I trying to hide them from anyone?
- Are my ARVs safe? (eg. Out of reach of small children)

### Reminders for taking ARVs

- Do I always remember my ARVs?
- What methods do I use to remind myself to take my treatment?
- Do I need additional reminders?

### Plan to attend clinic

- Do I need to plan in advance for my clinic visits?
- \* Is my clinic easily accessible?
- If not, do I need to plan for transport (including transport money)?
- Do I need to plan for childcare or to take time off work?

### Travel plans for taking ARVs

- If I am travelling away from home (for example to a funeral or to visit friends/family) what special plans do I need to make for my treatment?
- Do I need to get extra medication in case I stay longer?
- Do I need to take my treatment passport with me?

During discussion, emphasise how women can support and help each other with optimal adherence to treatment and clinic attendance.

TEA	20 minutes	15h30-15h50
→ Activity 4: Women collectively supporting each other as an aid to adherence	40 minutes	15h50-16h30

* For participants to start thinking in a collective way, about he women can support each other			
Materials/preparation	* Continue using the Personal Adherence Plan page		
Activity	In 6 groups of 5 participants, the group to ask each member in that group "As women in your community, how could we support you?" Each participant to reply. Try to find answers that are as practical as possible.		
	Each participant to write or draw the answers in the last block of the Personal Adherence Plan. Each group to feed back to big group and share ideas. Write answers on flip chart and facilitate discussion.		

### **Facilitator Information**

### WAYS OF WOMEN SUPPORTING EACH OTHER MIGHT BE:

- \* Encourage and support each other
- \* Sharing personal stories and adherence plans to help each other
- \* Remind each other to take medication and to go to their clinic appointments
- \* Home visits to women who are defaulting, to provide extra support
- Share information with each other about HIV Treatment Literacy
- Plan to go to the clinic on the same day so that participants can check in with each other while they wait
- \* To send SMS reminders to each other to take medication
- \* To start a WhatsApp support group
- \* To meet once a month in a small group to talk about challenges (informal support groups) and encourage other women to join

- To look after each other's children on clinic attendance days
- \* To lend each other money when they can, for transport to the clinic on clinic days
- To form Community Action Groups to collect medication for each other
- Collective lobbying to the government for what is needed. For example, mobile ART clinics
- Lobbying for inclusion in public works programmes

### **→ CLOSING/FACILITATOR RECAP**

15 minutes

16h30-16h45

See ideas for closing on Page 5-6.

**Homework (optional):** Invite participants to learn to write and say the names of their ARVs and the ingredients

Informal evening discussion about sex, sexuality and sexual pleasure.

Note: This evening could also be used to answer questions that have been placed in the question bowl.

### **Facilitator Information**

The informal evening discussion should be guided by whatever the participants want to talk about, but possible prompts may be:

Prompts: Under what circumstances is sex for women likely to be

pleasurable/un-pleasurable?

What control do or don't we have over their bodies? If we don't have control over our bodies, who does?

What messages do girls and women in Malawi grow up learning about

women's sexual pleasure?

What is considered by society to be acceptable or unacceptable sexual expression for women? How are these expectations enforced by society?

Women are most likely to experience sex as pleasurable when they are in control of who they want to have sex with, how they want to have sex and what happens to their bodies during sex.

Women often have too little control over these decisions due to the following patriarchal pressures:

- \* Women are often not viewed as having legitimate sexual desires.
- \* Women's sexuality is considered less important than men's sexuality. Women are expected to pleasure men on demand.
- \* Women are taught that they are not meant to pursue their own sexual pleasure, initiate sex or be sexually assertive.

- \* Women are considered a failure if they do not produce children and are expected to want to have children. Their worth is connected to their fertility.
- \* Women are expected to dress and behave like women, and only to have or want to have sex with men.

If women do not comply with these societal expectations they are stigmatised, criticised, rejected or punished by society (which sometimes includes other women).









# DAY 4

HIV TREATMENT LITERACY TRAINING MANUAL

08h45-09h15

Activity

See example activities Annexures 12, 13 and 14



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Materials/preparation	<ul> <li>30 copies of "Learning how best to take ARVs questionnaire" (Annexure 8)</li> </ul>
	Recap what was covered yesterday and stick the laminated Day 3's agenda on the wall.
	Ask if there are any questions from yesterday's activities.
	Hand out the questionnaire (Annexure 8 "Learning how best to take ARVs")
Atiia	Write "True" and "False" on two flipchart sheets and place at either side of the room.
Activity	Then ask the questions one at a time and ask the group to "vote with their feet" (Move to the "True" or "False" papers depending on their answers)
	Elaborate as necessary.
	Optional: Add any myths or points of clarity that came up in previous days and read them out for
	participants to "vote with their feet" true or false.

Questions		Facilitator information
1.	In Malawi, all PLWH are eligible to start ARVs, regardless of CD4 count.	TRUE – This is beneficial for your own health and also helps prevent passing the virus onto others.
2.	ARVs are a lifelong treatment	TRUE – Taking ARV treatment is a lifelong commitment

3.	If I'm starting treatment for the first time, I will definitely be given one tablet once a day	FALSE - Your healthcare provider will choose the correct regimen for you. This will depend on other illnesses or conditions you may have and your history. Most people starting treatment will be given Regimen 5A or 13A but your healthcare provider may choose one of the other regimens if it is more suitable for you.
4.	It's OK to skip doses a few times a week	FALSE – It's normal to forget doses occasionally but you should make every effort to remember every day. If you skip doses you run the risk of developing resistant HIV. You need to take 95% or more of your tablets for best chance of it being effective. This means that forgetting any more than one or two tablets per month is putting you at risk of developing resistant HIV.
5.	I can take my tablets at varied times of the day, as long as I take them daily I can take my tablets at varied times of the day, as long as I take them daily	FALSE – Try to take your treatment as close to the same time every day as possible. Choose a time that best suits your schedule and then try to stick to that time.
6.	If I forget a dose, it's best to take it whenever I next remember it, even if it's close to my next dose	FALSE – It is normal sometimes to forget a dose or to take a dose late. With time, taking your ARVs will become easier. If you remember a skipped dose less than half way to your next dose, take the missed tablet as soon as you remember and then carry on as usual. If it is more than half way to your next dose, skip the missed dose and then continue as usual. Never take a double dose if you accidentally forgot a previous dose.
7.	It's alright to stop my treatment if I get side effects as long as I inform my Health care provider next time I see them	FALSE - If you want to stop your treatment for any reason, including side effects, please inform your health care provider before doing so. Your Health care provider will work with you to try and prevent interruptions to your treatment and any decisions to stop should be made together.
8.	If I experience severe abdominal pain, jaundice (yellow eyes) or severe rash, I should tell my healthcare worker at my next appointment	FALSE – those are symptoms of potential serious side effects and should be reported immediately.
9.	I always have to eat before taking ARVs	FALSE – It is safe to take ARVs on an empty stomach. However, some people still prefer to eat first. Having no food is not a reason to delay or skip doses. It is a myth that all tablets must be taken on a full stomach.

10.	If I vomit within 30 minutes of taking my ARVs, swallow a fresh tablet.	TRUE – If you vomit soon after swallowing your tablet then it was not absorbed into your body and you will need to take a fresh tablet. Even if you don't see the tablet come out when you vomit, the tablet may have dissolved in the stomach contents, but not yet been absorbed.
11.	If I drink alcohol, I should skip my treatment.	FALSE – It is better to minimise alcohol always, especially if you are taking ARVs, but if you do drink, then it is very important that you should take your ARVS as well. The harm from skipping a dose of medication is more than the harm of taking medication and alcohol together.
12.	It's safe to take traditional or herbal medicine at the same time as taking my ARVs, because they are 'natural' Substances	FALSE – Not much is known about how traditional medicines affect ARVs. It may interact with ARVs and cause the level of ARVs in your blood to go too high (toxic) or too low (ineffective). If you are taking traditional medicines consult with your health care worker.
13.	My ARV medication should be kept safe and away from children	TRUE – Children, especially younger children, are curious and may eat your tablets if they find them. This can be very dangerous for them. Please keep all tablets out of reach of children.
14.	If I get any medication from a doctor or pharmacist, I should always tell them I am also taking ARVs	TRUE – Other medication can also affect the level of ARVs in your blood, pushing it too high (toxic) or too low (ineffective). This even applies to some over-the-counter medication. Always 47 check with a healthcare provider before taking any other medication with your ARVs.
15.	It's OK to share tablets with my family members or my neighbours	FALSE – If you share tablets you may run out of medication before your next ARV collection. You also might be taking different medications. Tablets are prescribed for a specific person and should never be shared.
16.	My neighbour and I might have the same medical condition and be on the same medication, but the medication box or bottle may look different and the name of the medication may be different	TRUE – the tablets could be two generics of the same medication. The Trade names could be different, but the chemicals inside the tablets are the same.



→ ACTIVITY 1: He Body	ealthy Heart-Mind-	1 hour	09h15-10h15
Session learning objectives	<ul> <li>To understand the importance of strategies to build and strengthen women's bodies as well as their minds.</li> <li>To consider the different aspects of Heart, Mind and Body wellbeing and how these are all important for women's wellbeing and a positive outlook on the future.</li> <li>To put women's individual and collective wellness at the centre of organising</li> </ul>		
Materials/preparation			epicting Heart
Activity	<ul> <li>3 large flipchart posters with a picture on each depicting Heart (heart shape), Mind (brain) and Body (body)</li> <li>Visualisation: Ask participants to sit with their eyes closed and do a scan of their bodies. Then imagine themselves feeling perfectly well.</li> <li>Ask: What does it feel like to be well?</li> <li>Divide into 3 groups. Give each group one flipchart sheet (heart, mind or body)</li> <li>Ask: As a woman living with HIV, what can I do to promote wellness in my heart, my mind and my body?</li> <li>Ask participants to write their group suggestions directly onto the flipcharts. Try not to duplicate any that are already there.</li> <li>Once each group is finished, pass the posters around between the groups so that other groups have the opportunity to add.</li> <li>Once finished, stick the posters up on the wall and review in plenary Then participants to individually reflect and journal (writing or drawing), guided by the following questions:</li> <li>Ask: Which points from the lists am I already doing well?  Which 3 additional points would have the most impact on my well-being if I were to start practising them?  Which of these could I begin doing from next week?  Which of these would take some planning before I can begin?  What would I need to do to make them happen?</li> <li>Invite participants to share and facilitate discussion.</li> </ul>		

### Heart:

- Fulfilling relationship with partner
- \* Social interaction
- Do things that make you feel happy
- Share troubles with trusted friends/family
- Choose healthy friendships and relationships
- Spend time with loved ones
- \* Join a women's support group
- \* Prayer
- Do good for others and for oneself
- \* Be loved and loving others
- \* Love yourself

### Mind:

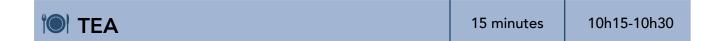
- Learn all you can about HIV, ARVs and healthy living
- Personal development: Improving knowledge and skills (keep learning new things)
- \* Manage stress
- \* Have a positive attitude
- Be prepared and organised
- \* Acceptance of status
- Disclosure to others (when appropriate)
- \* Good relationship with healthcare provider
- Seek help for depression, anxiety or other mental illness
- Seek support from friends and community
- \* Earn, spend and save money wisely to be economically empowered

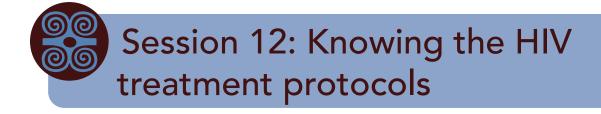
### Body:

- Eat healthily
- \* Exercise
- \* Drink enough water
- Get enough sleep (7-8 hours per night) and rest.
- \* Avoid work overload.
- \* Have good (safe) sex
- Good adherence to medication
- \* Good personal hygiene
- Diagnose and treat infections early (such as TB)
- \* Take prevention medication (such as Bactrim to prevent infections and INH to prevent TB)
- \* Don't smoke
- \* Minimise alcohol
- \* Protect against STIs (use condoms consistently) and treat STIs early if you get them
- Protect against re-infection with other strains of HIV (use condoms)

- \* Take Cotrimoxazole (Bactrim) to prevent PCP pneumonia, diarrhoea, malaria and other infections
- Take Family Planning to prevent unwanted pregnancies
- \* Take Isoniazid preventative therapy (IPT) to prevent TB if you live in a high prevalence region
- \* Regular health checks

Note: Emphasise the connection between heart/mind/body: For example, when I have a healthy body, I can have good sex and my heart is well. When I have good education or understanding about my health, I can make good decisions which will result in a healthy body.





→ ACTIVITY 1: Knowing the HIV		
treatment and blood test protocols in	30 minutes	10h30- 11h00
Malawi		

Activity learning objectives	To learn about the package of care in the Malawi Ministry of Health HIV Guidelines 2018 and evaluating whether this care is being provided in local clinics
Materials/preparation	<ul> <li>Handout page "Knowing the Malawi Ministry of Health HIV Treatment Guidelines 2018" (Annexure 9) – one to each participant)</li> </ul>
Activity	Give one handout (Annexure 9) to each participant. Facilitator to read the list aloud, one at a time.  Ask: Are each of these services offered in your clinic/healthcare facility?  Which services are not offered?  Participants to feed back to the group. Facilitate discussion.  Ask: What improvements would you like to see to the HIV Clinical Guidelines in Malawi?  What improvements would you like to see in your district regarding implementation of these guidelines?

### Possible ways in which the HIV Clinical Guidelines in Malawi could be improved:

- \* Annual viral loads, rather than 2-yearly
- \* Creatinine safety bloods (checking kidney function before and after starting Tenofovir which is part of Regimen 5A and 13A)
- \* ALT (liver test) to be more readily available in cases of suspected liver toxicity
- \* Pap smears rather than Acetic Acid Visualisation of cervix to screen for cervical cancer

→ ACTIVITY 1: Update report on OBOL campaign		30 minutes	11h00-11h30
Activity learning objectives	<ul> <li>To use the power analysis to strategise as part of the OBOL Campaign work</li> <li>To think about what we have learnt and what we want to share – in our communities and in the Campaign</li> <li>To commit ourselves to stepping out of the Master's House and to not creating the system that keeps women oppressed</li> </ul>		
Materials/preparation	<ul> <li>The box of papers on which each participant wrote down one way they feel they contribute to building the Master's House (from SESSION 5, Activity 1)</li> <li>3 different colour A6 pieces of paper (one of each colour to each participant)</li> </ul>		
Activity	Facilitator to remind participants that the reason we have come together is through the OBOL Campaign – so we need to start shifting to thinking about how we will use what we have learnt to build the campaign.		

### ABOUT THE OUR BODIES, OUR LIVES (OBOL) CAMPAIGN IN MALAWI

Through 6 years of support and efforts by Just Associates Southern Africa (JASS SNA) in

feminist organising, movement building and leadership-training with hundreds of women from across Malawi, women activists realized that their bodies matter, and through activating the power within them and collectively, the campaign for Better ARVs was launched in 2012. The Campaign was to organise women to put pressure on the Ministry of Health in Malawi to provide better quality anti-retrovirals (ARVs) for WLHIV in the country. The politics and motivation behind the Campaign was that women were experiencing and suffering from serious side effects as a result of a drug (ARV) that was part of the first-line regimen T30, called Stavudine. The Campaign in July 2013, made great strides in that the Ministry of Health started rolling out a more suitable first line regimen. The Ministry committed to ensuring all HIV+ people in Malawi had access to a new drug, Tenofovir, by December 2013. However, the concern still existed around HIV+ women being at risk of serious side effects that occur over time - the risk of irreversible deformities - if Stavudine was not changed to Tenofovir immediately.

In 2015, the *Our Bodies, Our Lives: the fight for better ARVs Campaign* (OBOL), was launched, with support from Comic Relief (UK-based funder). This allowed for more women living with HIV (WLHIV) to be mobilised. The Campaign also brought the Coalition of Women Living HIV/AIDS (COWLHA) on board, as a third institutional partner supporting the campaign, alongside MANERELA+ and JASS SNA. Although many COWLHA members have been part of the organising and mobilisation efforts from the very start, having the organisation fully on board and putting its weight behind the Campaign was an important and strategic moment. The OBOL Campaign could then also shift to focus on monitoring WLHIV's access to the new drug, Tenofovir, at the district level.

The OBOL Campaign continues to strengthen district committees across Malawi in order to ensure that WLHIV have access and are able to adhere to their antiretroviral treatment (ART). The partners – JASS SNA, MANERELA, COWLHA - are committed to sustain and grow the Campaign; to ensure that it is built, owned and led by WLHIV in Malawi to access the services and engage in issues affecting them so that they can live well and live positively.

### The 2015–2019 Campaign outcomes include:

- \* monitoring access and adherence to ARVs;
- improving well-being of WLHIV;
- \* strengthening Campaign district committees and WLHIV demands for rights and services;
- \* reducing stigma and discrimination and strengthening the capacity of implementing partners to represent and serve WLHIV

### What does the Campaign want to achieve?

- \* WLHIV should have the same rights to full and healthy lives as anyone else.
- \* A separate, nationally generated and controlled basket fund to ensure the new drug regimen can be sustained and reach all HIV positive people, as well as ensure decent healthcare for all Malawians.
- \* Access to treatment and care as stipulated by the World Health Organisation regulations which state that HIV positive people should have their viral load checked every six months.
- \* The provision of more mobile clinics to shorten the distance people travel to access medical help.
- \* Ensuring that government initiatives are also benefiting WLHIV (e.g. fertiliser coupons)
- \* That WLHIV are at the decision-making tables.

### Key Questions/Issues for the Our Bodies, Our Lives Campaign

- \* Why are women more affected and infected? What do we need to be healthy?
- \* Addressing HIV is more than medicine: women need access to food, fertilisers and land in order to survive and thrive.
- Pain and isolation: what is the personal impact?
- \* Who holds the power over us and resources in our communities, in our country and beyond?
- \* How can the government use money to support the procurement of antiretroviral drugs?

Divide the participants into groups – district traditional authority areas or regions

Ask: Think of 3 things you are doing as part of the Campaign?

Think of 2 problems that WLHIV in your community are facing?

Share in the broader group. Facilitator to help the group to choose one problem to focus on for the next activity.

60 minutes

11h30-12h30

Facilitator to draw a table, using the problem identified in Activity 1 and the example template below.

Refer back to the definitions of power, on Page 25-26, if necessary.

Example of template to develop strategies: For example: Poor Healthcare worker attitudes

POOR HEALTHCARE WORKER ATTITUDES	BARRIERS	ACTORS	STRATEGIES	TIMELINE	RESPONSIBLE
INVISIBLE	Healthcare workers do not care about WLHIV	Clinic staff	Go as a big group of women to get services and stand up for each other		
HIDDEN	The traditional chief has made statements about WLHIV being workthless	Chief, Paramount chief			
VISIBLE	The MoH does not train health workers to treat us well	МоН	Use the OBOL campaign to lobby for better training		

LUNCH	1 hour	12h30-13h30
→ ACTIVITY 3: What do we take home?	20 minutes	13h30-13h50

#### Participants to:

- Identify one thing for myself (write it on red pieces of paper)
- Identify one thing for the community (write it on green pieces of paper)
- \* Identify one thing for the campaign (write on yellow pieces of paper)

Participants to stand in a circle and each participant to put their red pieces of paper down first, saying what is on their paper. Then to put down green paper, then yellow.

Participants to stick their red papers on the Tree of Hopes.

Ask: Do you feel that your hopes for this workshop were met?

# → ACTIVITY 4: Letting go of the Master's House

20 minutes

13h50-14h10

Bring out the box of papers on which each participant wrote down one way they feel they contribute to building the Master's House (SESSION 3, Activity 1)

Invite each participant to take one (unopened) and throw it in a bin or burn it in a fire as a symbolic letting things go.

→ Closing	50 minutes	14h10-15h00
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#### Material/preparation

- \* 30 evaluation forms
- \* 30 signed attendance certificates

Hand out evaluation form. Participants to complete and hand in.

Hand out attendance certificates to each participant, one at a time.

Each participant to give a "gift" (hug, wish, affirmation, etc) to the next person in the circle.

Participants to congratulate themselves and each other.

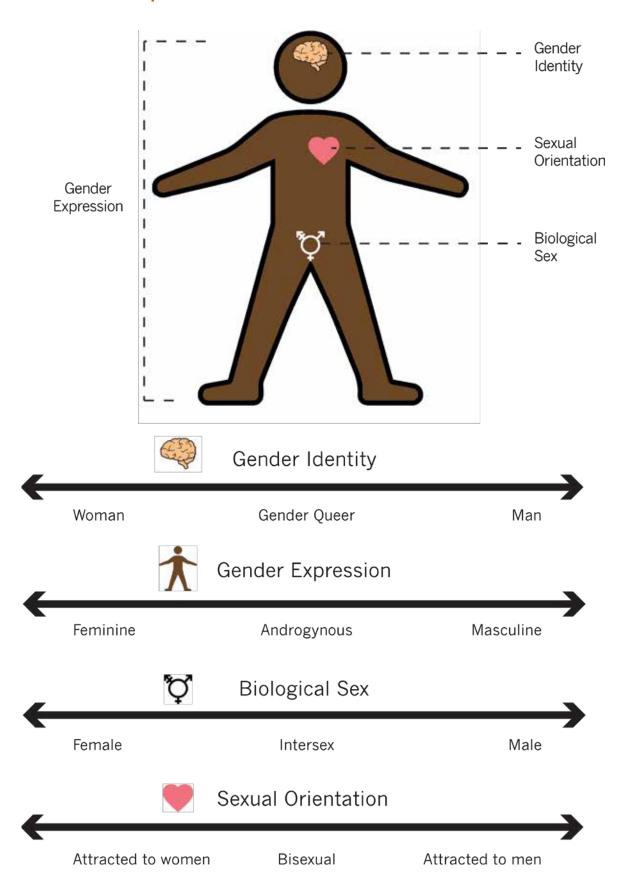
Celebrate, sing, dance!

#### **CLOSE**

# "Sex"/"Gender" Statements

Girls are gentle	G	Men are generally hairier than women	S
Boys are tough	G	Men are generally more muscular than women	S
Men are good drivers	G	Women can give birth to babies	S
Women are poor drivers	G	Men cannot give birth to babies	
Women have long hair		Men generally have deeper voices	S
Men have short hair	G	Women generally have higher Voices	S
Women don't like sex	G	Women have breasts	S
Men love sex	G	Women can breastfeed	S
Women do the cooking and housework	G	Men cannot breastfeed	S
Men are the breadwinners	G	Men have penises	S
Nurses are women	G	Women have vaginas	S
Doctors are men	G	Men have testes	S
Men don't cry	G	Women have ovaries	S
Women are not assertive	G	Women can menstruate	S
Men make good politicians	G	Men cannot menstruate	S

# The Sex and Gender Spectra



#### The Sex and Gender Spectra

Society tends to think of one's sex as binary – each person is either male or female. There is tremendous societal pressure to conform to one's birth-assigned sex and to heterosexuality and any tendency to deviate from these accepted (and learned) norms is likely to be viewed with anger or judgment.

Sex, gender identity, gender expression and sexual orientation in fact all exist naturally on a spectrum. Any one person could be on any point on each spectrum. And the points may shift for any one person during their lifetime or even day to day.

Gender identity: 'A personal conception of oneself as a man or woman (or rarely, both or neither)'. In other words, regardless of what a person's sex is at birth, gender identity is the internal experience of which gender we feel and identify ourselves as. It may be the same as or different from their birth-assigned sex. *Cisgender* refers to a person whose gender identity corresponds with their birth sex. *Genderqueer* refers to a person who does not subscribe to either one or other gender but identifies with neither or with both. *Transgender* refers to an individual whose gender identity does not match their assigned birth gender. For example, a person born a girl may self-identify as a boy or a man, even though they were born with female genitalia. For transgender people, as for everyone else, gender identity it is not a 'wish' to be a boy/man or a girl/woman, but simply 'who they are' and having their identity questioned, judged or denied can be deeply traumatising.

**Gender expression:** This means how a person publicly presents their gender – how one chooses to dress, talk or behave. For example, a person born female may self-identify as a woman, but choose a hairstyle and clothes that are considered more 'masculine'. **Androgenous** refers to a person who presents neither obviously feminine nor masculine.

**Biological sex:** This is the sex that we were assigned at birth and is based on the appearance of the external genitalia. The external genitalia of a baby may look like the baby is clearly born *male* or *female*. But it is also possible to look like a bit of both (*intersex*)

**Sexual orientation** is a description of which sex(es) one feels romantically or sexually attracted to. For example a woman may be sexually attracted to other women, or to men, or to both (*bisexual*) or neither (*asexual*).

#### Annex 3

#### **SESSION 2: GENDER AND HIV:**

#### Activity 3: Exploring how women's anatomy and gender role impacts on risk of HIV infection

#### **CASE STUDY: Why did Grace become HIV infected?**

Grace is a 33 year old woman. When she was 16 years old she got married to Paul, who was 15 years older than she was. He was her first and only sexual partner. Her family was very pleased when she married him as he was older and had a job. She moved to the village where his family comes from, which is some 300 kilometres away from the nearest town. She and Paul have built a small house, and it is right next door to Paul's parents. She works in their small field, growing maize, groundnuts and also vegetables in their small garden. Grace is always struggling for money as Paul does not give her a lot of money.

They have three daughters aged 6 years, 4 years and 2 years old. Paul works in a hotel in Johannesburg, because he could not find any jobs in Malawi. He comes home only three or four times a year, because coming more often is expensive and also he does not get a lot of time off from his job.

When Paul comes home for holidays, he goes out to drink with his friends. He often gets drunk and comes home late. He has never hit her but he is sometimes verbally abusive towards her when he has been drinking. He is easily irritable with the children and sometimes shouts at them or hits them when they are noisy or misbehave.

Last year she noticed a new, smelly vaginal discharge. It was 6 weeks before she gets a chance to visit a clinic, because the clinic is in the nearest town (300km away) and she is too busy every day looking after her children and working in the field. When she manages to get there she was told by the nurse that she had a sexually transmitted infection. She was treated for the infection and instructed always to use condoms and to tell her husband to come to the clinic for treatment as well. She is too scared to tell him that she has an STI because she may be accused of sleeping with other men.

Grace and Paul do not use any family planning method. They are members of the Roman Catholic Church which strongly discourages use of family planning between married couples. Grace does not want to have any more children, for health reasons. She tries to talk to Paul about using condoms, but he was very angry. He doesn't like using condoms and anyway he still wants a son. When Grace spoke to her Aunt, her mother and Paul's sister and Aunt all the women were absolutely shocked! How could she even think of stopping to produce children when she had not yet given Paul a son? When Paul heard that she had spoken to the other women, he said, "My dear, if you are tired of being married to me, you can go back to your family and return my lobola!"

One day Paul dies suddenly in a car accident. Her family-in-law tell her that she is to marry her husband's brother, which she does.

Grace falls pregnant for the fourth time. She goes to her antenatal clinic and as part of antenatal care she is tested positive for HIV.

How was Grace at increased risk for HIV infection?

#### Factors that make women vulnerable to HIV infection, stigma and discrimination

#### More women than men are infected with HIV in Malawi

\* The Malawi Population-Based HIV Impact Assessment (MPHIA) of 2015-2016 reports that the prevalence of HIV is higher among women than men. In the age group of 14-49 years, women have an HIV prevalence of 12.4%, compared with 7.5% in men. In the age group 25-29 years the disparity is especially prominent with 14.1% of women living with HIV compared to only 4.8% of men.

#### Women are biologically vulnerable to HIV infection

- \* As a receptive partner, women have a larger mucosal surface exposed during sexual intercourse.
- \* Semen has a higher concentration of HIV than does vaginal fluid.
- \* If intercourse takes place at an early age, the mucosal surface of the vagina is more tender and vulnerable to tears and infection.
- \* Women are even more vulnerable if their vaginal mucosa is damaged as a result of sexual violence such as rape.

#### Women are culturally vulnerable to HIV infection

- \* The practise of a women being expected to have sex with a male member of her deceased husband's family after his death (or a hired sexual cleanser if no male relative is available or willing) exposes her to possible sources of HIV infection. (*Kulowa Kufa*)
- \* Polygamy makes women more likely to contract HIV from her partner who has multiple other partners
- Women tend to marry or have sex with older men who may have had more sexual partners and are more likely to be infected with HIV than younger men
- \* Women are expected not to be assertive sexually and are therefore less empowered to insist on condom use to protect themselves during sex
- \* Initiation rituals of young girls (*chinamwali*) which sometimes includes having sex with a boy or a man (*fisi*)
- When a woman is in a childless union, she may be expected to have intercourse with another man if it is suspected that her husband is impotent or sterile (fisi) exposing her to potential HIV infection.
- \* The practise in which young men invade the girls' dormitory at night and rape them (gwamula)
- \* The practise of having 'dry' sex using herbs to dry out the vagina before having sex, for the pleasure of men. This makes the mucosa more vulnerable to tears
- Child marriage in which girls are married off to older men before they are 18 years old. The men are often sexually experienced and sometimes already living with HIV and transmit it to their young wives

# Women are more vulnerable to HIV infection due to societal factors, including gender inequality

\* The unequal power relationship between men and women means that women are often not in a position to negotiate safe sexual practises, thus making them vulnerable. Gender inequality often leads to intimate partner violence which further dis-empowers women, particularly young women, from protecting themselves.

- \* Women are less likely to be educated than men and therefore may lack the knowledge that enables them to make good health decisions
- \* There is societal pressure for women to bear children, necessitating unsafe sexual practises
- \* Women are expected to fulfill many time-consuming roles such as domestic chores, caring for children or elderly and thus may not have time to attend clinics/hospitals for appointments
- \* Women sometimes have their movements restricted by men and are denied the opportunity to visit health care centres to see to their sexual health
- In some districts, health care services are inadequate and inaccessible, resulting in lack of access to comprehensive HIV and sexual and reproductive health (SRH) services, so that women are less able to look after their sexual health to reduce their risk of HIV infection
- Many women lack access to accurate, relevant information on HIV and sexuality and therefore may be unaware of the risks

#### Economic factors that make women more likely to be infected with HIV

- Women in Malawi are frequently poor and unemployed, thus making them financially dependent on men and therefore: less likely to be able to negotiate safe-sex practises less empowered to leave abusive relationships
- Women may not have enough money for transport to health care facilities due to earning less than men, or having no income
- Migrant husbands, especially from the rural areas, work away from home for long periods in their work as miners, truckers or soldiers and may engage in unprotected sex while away. These men may get infected with HIV and transmit it to their wives when they come home.
- Pressure to provide for themselves or their children may lead women to engage in 'transactional' sex with men who give them money, school fees or gifts in exchange for sex. Under these circumstances women are not in a position to negotiate safe sex.

#### Women are more likely to suffer from stigma when diagnosed with HIV

- Women may be afraid to test for HIV for fear of suffering the effects of stigma should they test HIV positive
- \* Women are often diagnosed before their partners via antenatal services and are therefore blamed for infecting their partners, with consequent risk of abandonment or violence
- Women are more likely to be accused of prostitution or promiscuity if diagnosed with HIV and are therefore afraid to seek medical health care or to disclose to partners

#### Women living with HIV experience discrimination in Malawi

- Women living with HIV are excluded from many developmental and social projects such as the fertiliser subsidy programmes and food programmes
- Women living with HIV are denied social support, which is often fuelled by negative messages from faith healers and church leaders

#### Annex 5

#### Malawi ARV regimens, contraindications and possible side effects

#### Adult regimens in Malawi Clinical HIV Guidelines 2018:

Regimen	Ingredients	Line
0A	Abacavir/Lamivudine Nevirapine	1st
2A	Zidovudine/Lamivudine Nevirapine	1st
4A	Zidovudine/Lamivudine Efavirenz	1st
5A	Tenofovir/Lamivudine/Efavirenz	1st
6A	Tenofovir/Lamivudine Nevirapine	1st
7A	Tenofovir/Lamivudine Atazanavir/Ritonavir	2nd
8A	Zidovudine/Lamivudine Atazanavir/Ritonavir	2nd
9A	Abacavir/Lamivudine Lopinavir/Ritonovir	2nd
10A	Tenofovir/Lamivudine Lopinavir/Ritonovir	2nd
11A	Zidovudine/Lamivudine Lopinavir/Ritonovir	2nd
12A	Darunavir Ritonovir Dolutegravir	3rd
13A	Tenofovir/Lamivudine/Dolutegravir	1st
14A	Zidovudine/Lamivudine Dolutegravir	1st
15A	Abacavir/Lamivudine Dolutegravir	1st

#### NOTE:

- \* When ingredients are separated with a "/" it means that they are combined in the same pill
- Regimen 5A is the most common current First Line regimen. If someone fails 5A, they are usually changed to Second Line Regimen 8A
- \* From January 2018 all eligible PLWH will be transitioned to Dolutegravir-based regimens (most commonly Regimen 13A as it is a single tablet

#### Individual antiretroviral ingredients, contraindications and possible side effects:

INGREDIENT	CONTRAINDICATIONS	POSSIBLE SIDE EFFECTS	
Abacavir	Previous Abacavir hypersensitivity	Abacavir hypersensitivity: fever, body pains, vomiting, cough, sore throat, shortness of breath (serious)	
Lamivudine	None	Usually none, or mild such as nausea	
Nevirapine	Jaundice/hepatitis/liver failure	Liver damage (Abdominal pain, nausea, vomiting, fever, jaundice, dark urine) (serious) Rash (can be serious)	
Zidovudine	Anaemia	Anaemia (thin blood that can't carry oxygen well) Neutropenia (low white cells) Muscle weakness	
Efavirenz	History of psychosis or severe depression	Dizziness, poor concentration Nightmares Psychosis, depression, suicidality Liver damage (see above) (serious) Rash (can be serious)	
Tenofovir	Renal failure	Renal failure (Nausea, vomiting, tiredness, leg swelling, loss of appetite, drowsiness, shortness of breath)	
Atazanavir		Jaundice (usually harmless)	
Ritonavir		Diarrhoea	
Lopinavir		Usually none, or mild such as nausea	
Dolutegravir	Pregnancy Renal failure Severe liver damage Uncontrolled diabetes	Insomnia, headache, agitation Nausea, diarrhoea Skin rash	

#### Note:

- \* Many ARVs can cause tiredness, nausea, vomiting, stomach pain, muscle pain, headaches
- \* The list above is not complete. For a complete list please check the package insert that comes in the medication box. If you are not given one at the clinic, ask your healthcare provider to give you one.
- \* "Contraindications" means that if you have any of these conditions, then the medication should not be given to you.

#### Annexure 6: Barriers to ARV adherence

#### **CASE STUDY: Why did Grace die?**

Grace is now married to her brother-in-law and pregnant with her 4th child.

The clinic sister started her on ARVs. She is told to come every month for her supply. A trip to the clinic takes a full day. Initially she tells her family that she needs to go to the clinic for antenatal care every month because she is worried about what excuse she will use after her baby is born.

Grace has not disclosed her status to anyone. She is terrified that her current husband or her in - laws will find out that she is HIV positive because she is afraid that she will be rejected and sent away by them. Her husband is also sometimes verbally and physically abusive to her, so she is afraid of him.

She tries to hide her tablets in her home, but her home is small with no privacy. She puts them in a plastic bag under her mattress.

When she starts her tablets she gets terrible headaches initially and this makes it very difficult for her to look after her 3 small children or to work in the fields. After a week, her skin becomes itchy and she sees that she is getting a faint rash on her body. She stops her tablets because she is afraid that the rash will become worse. She can only get to the clinic again to report these side effects about a month later, when her husband gives her money for transport. The ARV nurse tells her to restart her tablets and that the side effects will pass after a week or two. Fortunately for Grace, the rash does not recur.

The ARV nurse told her to take her tablets at 8 o'clock every night, but her husband is home at that time and she is very busy cooking and feeding her family and getting her children to bed. Sometimes she manages to swallow her tablet while her husband is watching TV, but sometimes she does not get a chance. Grace thinks that as long as she takes her tablets more than half the time that this should be enough. On days when she misses the 8 o'clock time, she skips the dose.

Her baby is born premature and she now has additional responsibilities. She starts to feel very low in mood, tearful and forgetful. Her sleep is disturbed and her appetite is reduced.

At church one day, the priest preaches that all things are possible if people have enough faith. All illnesses can be cured by a miracle, if people pray hard enough and believe that it will happen. Grace is not sure what she believes, but the following month she cannot get to the clinic to collect her medication because she has to look after her sick child, so she prays hard every day instead.

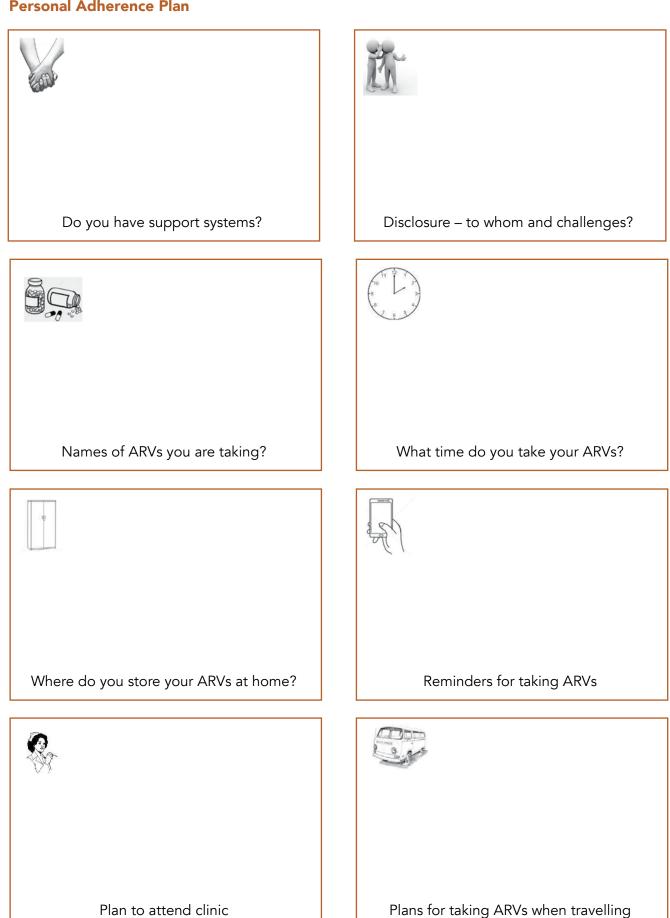
6 months after starting treatment, she has a blood test for viral load at the clinic. The following month the nurse tells her that her viral load is high and Grace gets severely scolded for not taking her medication correctly. A month later when she goes to collect her medication she is told that the clinic has not received the delivery of ARVs yet. She is told to come back the following week. She is unable to do that because her husband says she cannot be away from home for a full day again so soon, as her in- laws cannot be expected to look after her children again. She is afraid to return to the clinic after this because the nurse will shout at her for not having come back.

3 months later, Grace starts coughing, losing weight and having profuse night sweats. By the time she gets to the clinic again, she is very ill. She is diagnosed with TB. Her CD4 count is 52. She starts TB treatment, but after a few days she gets a severe headache and fevers (likely TB meningitis) and dies at home.

What were the barriers to adherence that resulted in Grace's death?

# Annexure 7 (Option 1)

#### **Personal Adherence Plan**



Choose 3 personal barriers to adherence	Possible solutions
QΦ	
¥	

# Annex 7 (Option 2)

# **Personal Adherence Plan**

Support:
Who is my support system currently?
Who else could support me in my treatment?
Disclosure:
Who have I disclosed to?
Who am I reluctant to disclose to?
Why am I reluctant to disclose?
Who do I still plan to disclose to?
Who could help me with disclosure?
Adherence:
The best time for me to take my medication is
Where will I store my medication?
How can I remember to take my medication?
During the week?
On weekends?
On holiday?
Who could help to remind me to take my medication?
Where could I keep spare medication in case of emergencies?
Clinic attendance to collect medication and see my health care professional:
How will I get to the clinic/hospital for appointments?
How will I remember my appointment dates?
Travel:
If I travel, what plan will I make for extra medication?
Where will my nearest clinic be?
Does it provide ARVs?

# Barriers to adherence:

I have the following challenges:

Not analysh assist support?	Yes	No
Not enough social support?	res	INO
Depression, anxiety or other mental health challenge?	Yes	No
Substance abuse problems?	Yes	No
Forget to take medication?	Yes	No
Afraid to take medication in front of others in the house?	Yes	No
Side effects to medication?	Yes	No
Food insecurity?	Yes	No
Too busy (with work or domestic chores) to attend the clinic?	Yes	No
Stigma causing reluctance to seek health care?	Yes	No
Family, community or church pressure not to take treatment?	Yes	No
Domestic violence?	Yes	No
Lack of money for transport to the clinic/hospital?	Yes	No
Clinic/health care facility too far away?	Yes	No
Attitude of my health care professionals?	Yes	No

For all answers of "Yes", what could I do to overcome that challenge?					

# Annex 8

# Learning how best to take ARVs

Qu	estions	TRUE / FALSE
1.	In Malawi, all PLWH are eligible to start ARVs, regardless of CD4 count.	
2.	ARVs are lifelong treatment	
3.	If I'm starting treatment for the first time, I will definitely be given one tablet once a day	
4.	It's OK to skip doses a few times a week	
5.	I can take my tablets at varied times of the day, as long as I take them daily	
6.	If I forget a dose, it's best to take it whenever I next remember it, even if it is close to my next dose	
7.	It's alright to stop my treatment if I get side effects as long as I inform my healthcare provider next time I see them	
8.	If I experience severe abdominal pain, jaundice (yellow eyes) or severe rash, I should tell my healthcare worker at my next appointment	
9.	I always have to eat before taking ARVs	
10.	If I vomit within 30 minutes of taking my ARVs, swallow a fresh tablet.	
11.	If I drink alcohol, I should still skip my treatment.	
12.	It's safe to take traditional or herbal medicine at the same time as taking my ARVs, because they are "natural" substances	
13.	My ARVs should be kept safe and away from children	
14.	If I get any medication from a doctor or pharmacist, I should always tell them I am also taking ARVs	
15.	It's OK to share tablets with my family members or my neighbours	
16.	My neighbour and I might have the same medical condition and be on the same medication, but the medication box or bottle may look different and the name of the medication may be different	

# **Knowing the Malawi Ministry of Health HIV Treatment Guidelines 2018**

	Malawi MOH HIV Treatment Guidelines 2018	Is this happening in my clinic/ healthcare facility?
Who is eligible for ARVs?	There are 8 standard first line, 5 standard second-line regimens and 1 standard third-line regimen. Most common first line currently is Regimen 5A including in pregnancy (start on same day if pregnant) From January 2019 all PLWH who are eligible will transition to Dolutegravir-based regimens (Dolutegravir will replace Efavirenz and Nevirapine). Some PLWH will not be prescribed Dolutegravir, including pregnant women or women who may fall pregnant (See Dolutegravir Stavudine-containing regimens have been discontinued Third-line can be prescribed by a specialist ARV Clinician	
CD4 count testing	CD4 was not previously routinely tested but the 2018 Guidelines say that CD4 should be tested at baseline, if available.  Thereafter, targeted CD4 may be requested by Health care providers for complicated cases	
Viral load testing	At 6 months on ARVs, 2 years, 4 years and every 2 years after that Health care providers can also request "targeted" viral load testing if clinically indicated	
Cervical cancer screening	Annual Acetic Acid visualisation (direct examination of the cervix after washing with acetic acid to identify areas of abnormal cells)	
Standard package of preventative services provided for all ART patients	Provider initiated Family Planning (at least condoms + Depo Provera), Cotrimoxazole (Bactrim) preventive therapy and Insecticide treated bed nets	
Cotrimoxazole (Bactrim)	To be given to all PLWH (including babies from 6 weeks of age) daily for life	
Isoniazid Preventative Treatment (prophylaxis for TB) - issued with Vitamin B6	Give for life to all children and adults living in the 5 high TB burden districts, provided they have no symptoms of TB: Lilongwe, Blantyre, Zomba, Thyolo and Chiradzulu	

National Strategic Plan for HIV (2015-2020) includes 90-90-90 Treatment Targets proposed by UNAIDS:

- \* 90% of all PLWH to know their status
- \* 90% of those to be on ARVs
- \* 90% of those to have undetectable Viral Load

#### Annex 10

#### **Dolutegravir (DTG) information sheet**

DTG-based ART regimens (Regimens 13A, 14A and 15A) have important advantages:

- Rapid viral load suppression within weeks
- \* High drug-resistance barrier (strains of HIV do not easily become resistant to DTG)
- Convenient: One small tablet taken once per day
- Better tolerated: very few patients experience significant side effects
- Fewer drug-interactions (see below): no interactions with hormonal contraceptives

#### (Relative) Contra-indications for DTG-based regimens:

- It is currently not confirmed that DTG is safe in early pregnancy and it is therefore not used in standard 1st line for girls/ women who may get pregnant while on ART
- Uncontrolled diabetes (problems with 'sugar')
- \* Kidney failure
- Severe liver damage

#### Potential **side-effects** (which are rare):

- Insomnia, headache, agitation (DTG-based regimens are usually taken in the morning to reduce risk of insomnia)
- \* Nausea, diarrhoea
- Skin rash
- \* Liver damage

#### Important DTG drug-interactions:

- Rifampicin (TB treatment): need to take double the daily dose of DTG (take an extra 50mg tablet of Dolutegravir every day as prescribed)
- Drugs with iron, magnesium, calcium, zinc (For example iron supplements, vitamins and antacids): take 2 hours before or 6 hours after DTG
- There may be interactions with some medications for diabetes
- DTG is not to be combined with Nevirapine or Etravirine (which are also ARVs)
- DTG is not to be combined with some anti-epilectic medications

#### DTG-based regimens:

- DTG may be used in 1st, 2nd and 3rd line ART regimens
- DTG is also effective for patients who have failed on other 1st and 2nd line regimens
- From 2019, for patients starting ARV treatment, Regimen 13A (Tenofovir/Lamivudine/Dolutegravir) will be prescribed for the following, unless there are contraindications:
  - \* most boys over 30kg of weight
  - \* most men
  - \* most women over 45 years of age
- Women under 45 years of age will still usually be prescribed Regimen 5A unless reliable contraception can be assured and they are not planning any pregnancies. This is because safety in pregnancy has not yet been established.
- Patients on other regimens will also be transitioned to DTG-based regimens from 2019 if they are eligible
- From 2019 DTG will also be used in Post Exposure Prophylaxis regimen



# **SS** Consent Form

JASS (Just Associates) is dedicated to raising the voices, visibility, and collective power of women around the world who are working for justice, equality and human rights in their communities and countries. We think your views, experiences and wisdom are valuable to social change movements worldwide, so we would like your permission to share them.

Event:		Date:		
communities, and b organizations world JASS to use) may ap website and social r	ortant role in creating soc uild support (solidarity an wide. I understand that m	ial change, inspire other of d funding) for JASS' move y quotes, photos, or vide and descriptions, research witter, Instagram, etc.).	line materials to raise awar women to be change-make ement-building efforts with os (cross out any that you on and training materials and	ers in their n women and do not want
Name (please put the full name you are comfortable with here):		· · · · · · · · · · · · · · · · · · ·	Event participant (e.g. JASS workshop participant)	
Women's rights activist		Feminist activ	Feminist activist	
By organisation affiliation		Other (please	Other (please state):	
JASS will contact		n and make sure you recei	lentifying or personal infor ve a copy of the final versi	
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If at any time you v	vould like to withdraw this	permission, please contact	adminsna@justassociates.or	g OR call the

If at any time you would like to withdraw this permission, please contact adminsna@justassociates.org OR call the JASS office at +27 218022519/ +27 218016779.



# Meditative Relaxation for Heart, Mind and Body

#### Overview:

In our work, we often contend with stress, difficulty and fear which impacts our bodies, minds and spirits. This activity helps us relax, center and find calm in a simple way.

Purpose: This activity is designed to help us relax our bodies and minds - to calm down after emotional process or to deal with conflict or to address difficult topics.

Materials: Meditation bell/bowl, wooden stick, chairs

Time: 5 - 20 minutes

Credit: JASS Southeast Asia (JASS SEA)

#### **Process:**

1. Prepare the room.

Make sure the room is spacious and comfortable, and that the seating is not located where the lights are too bright or there is a lot of noise.

Position the seats in circle with enough space so no one is not touching anyone else. If you have many participants, create two semi-circles one behind the other.

2. Welcome everyone and let them know that they will be invited to calm down, get centered and relax.

Ask the participants to sit quietly, not talking, and soften their gaze, looking at the floor in front of them, not looking at others.

Invite the participants to begin to relax, explaining that relaxing is not just about the body but also the mind. Begin to quiet the mind, just following the voice of the facilitator and bringing breath into and out of your chest. Ask the participants to let the mind and body relax in the silence.

3. Dim the light. Explain to the participants that there will be several steps and a sound will be made (with bowl or bell) to indicate each one:

When you hear the first bell close your eyes (if comfortable doing so) and focus internally. Let go of thoughts about events at home, in the community and in the news - neither bad nor good. Let it all pass by for now. It has already happened and is in the past. Now we sit with friends. See if you can breathe into your body and allow it to relax.

The second sound: Invite the participants to sit quietly at the edge of a chair or if more comfortable, navigate to kneeling or sitting cross-legged with your palms on your knees. Have them give time to the silence – about 2-3 minutes. As a thought or anxiety arises, let it go, see if you can relax into your breathing in the moment. You are surrounded by friends and allies.

Take them through a relaxation: Invite them to focus attention on the muscles and other body sensations on their body. Using a calm tone and clear voice: bring breath to each body part asking it to relax: brain relax, forehead relax, ears relax, two eyes relax, eyelids relax, nose relax, cheeks relax, lips relax, tongue relax, jaw relax, neck relax, shoulder relax, both upper arm relax, both forearm relax, both palm relax, both finger relax, torso relax, stomach relax, upper back relax, lower back relax, buttocks relax, both thighs relax, both knees relax, both calf relax, ankles relax, feet relax, toes relax. Body relax, mind relax. Mind relax, body relax.

Repeat relaxation process one more time - look to see if their faces look relaxed.

Third bell is for the last 1- 2 minute to invite a last stage of concentration on breath and being in the present moment. Give 2 minutes' silence. Hit the bell twice. When they hear the sound hit twice, that indicates we are done. Ask participant to move slightly. Move the arms, move the legs, move torso to the right and to the left, keeping the eyes closed.

4. Invite everyone to gently open their eyes. When they are ready they can acknowledge each other and move to a different position or space, completing the activity.



# Breathing for Wellbeing and Calm

#### Overview:

The health of body, mind and heart is continuously affected by trauma, violence, stress, fear, diet, environment, daily news, and the challenges of life. The following simple exercises are offered for use at times when we feel stressed, distressed, overwhelmed or scattered. These tools are for all of us, whether we are survivors of trauma, activists confronting injustice and oppression, caregivers working with others or persons overwhelmed and stressed by daily life.

#### Purpose:

Breath is the source of life, bringing fresh energy into the tissues and cells to nourish body, mind and the whole person. When we breathe out, accumulated stress and toxins are released. Breathing through a stressful time is an effective way to let go of the tension that accumulates in the body. A few long deep breaths at a difficult moment can completely change the way we handle a situation. Breath-work combined with images of light or nature can promote feelings of peace, calm and focus.

Simple breathing exercises are calming for both the nervous system and the overworked mind. Your exhale needs to be longer than your inhale, the vagus nerve (running from the neck down through the diaphragm) sends a signal to your brain to turn up your parasympathetic nervous system and turn down your sympathetic nervous system. The sympathetics command your fight or flight response, and when they fire, your heart rate and your breathing speed up, and stress hormones like cortisol start pumping through your bloodstream, preparing your body to face a threat. If the threat is, "A lion is chasing me and I need to run away," this is helpful. If the threat is, "I am late for work" or, "I'm so upset with my colleague" this is not particularly helpful, and in fact it can be damaging – when cortisol is elevated for too long or too frequently it disturbs all the hormonal systems of the body. The parasympathetics, on the other hand, control your rest, relax, and digest response. When the parasympathetic system is dominant, your breathing slows, your heart rate drops, your blood pressure lowers as the blood vessels relax, and your body is put into a state of calm and healing.

Time: 5 minutes – 1 hour

Credit: Adapted from the Capacitar Emergency Response Tool Kit www.capacitar.org

**Materials:** Quiet space, chair or if you prefer you can sit on the floor in which case you may require a cushion for comfort.

**Purpose:** The following simple exercises are offered to be used at times when we feel drained or scattered. These tools are for all of us, whether we are survivors of trauma, caregivers working with others or persons overwhelmed and stressed by daily life.

# Methodology:

#### **Breathing 1: Abdominal breathing**

#### **Process**

Breathe deeply and centre yourself, letting go of all worries and thoughts. Abdominal breathing can be practiced lying down on your back, sitting down or while standing.

Lie down. Separate your legs slightly and let the feet fall to the sides. Interlock the fingers and place the hands on your abdomen, palms facing downwards. Make a conscious effort to inhale deeply, so that your abdomen starts to expand your fingers separate. Allow your abdomen to expand as much as possible. As you begin to exhale, apply gentle pressure on your abdomen with your hands, pushing it downwards. Exhale fully. The secret to good breathing is in proper exhalation. With better exhalation, your inhalation will also get better.

Repeat this process several times. When you feel comfortable, take full abdominal breaths without using your hands. And make your breath long and smooth, for both inhalation and exhalation.

#### **Breathing 2: Breathing in Calm**

#### **Process**

To begin, sit still and tall somewhere comfortable. Close your eyes and being breathing through your nose.

Then, inhale for a count of two... hold the breath in for a count of one... exhale gently, counting out for four... and finish by holding the breath out for a count of one. Keep your breathing even and smooth.

If the 2-4 count feels too short try increasing the breath lengths to 4 in and 6 out, or 6 in and 8 out, and so on. But if longer breaths create any anxiety there is no need to push yourself. The most important thing is that the exhale is longer than the inhale, not the absolute length of the breath. Set a timer and breathe this way for at least five minutes. You will see a difference in your mood.

#### **Breathing 3: Breathing in Nature**

#### **Process**

Nature is a great resource for healing and grounding. With feet on the ground, breathe in deeply imagining that your feet are long roots running into the earth. Breathe in earth energy; breathe out stress, tension and pain. Slowly focus on tensing and relaxing each muscle group for two to three seconds each. Start with the feet and toes, then move up to the knees, thighs, rear, chest, arms, hands, neck, jaw and eyes — all while maintaining deep, slow breaths. Take a moment to listen to the sounds of nature while slowly bringing participants back into the present, asking them to slowly and gently open their eyes when they are ready.

#### **Breathing 4: Oxygenating your body**

#### **Process**

Stand with your feet firmly on the ground. Raise your arms in the air. Take a deep breath in. As you lower your arms breathe out in a vigorous manner, your elbows coming in close to the side of your body. Repeat in cycles of 8. Caution: This exercise causes a rapid intake of oxygen and could result in mild dizziness as a result.



# The Holds – Tools for Calming and Well-being

#### Overview:

This practice consists of several simple energy holds that may be done on oneself or another person for anxiety, emotional or physical pain, strong emotions such as anger, fear, and insomnia and for deep relaxation. Through the energy of our hands we have the power to bring harmony and healing to body, mind and heart. This is useful for introducing heart-mind-body as a critical part of movement building, by creating space for this type of practice during each day of a workshop but also to respond to any deep feelings/outside influence that is affecting the dynamic in the space.

#### Purpose:

To share a technique for managing our individual emotions as well as emotions/dynamics that surface in our work with groups as facilitators. In our feminist movement building work, there is often deep sadness/pain that is motivating our activism, this can be useful but we need to be careful to ensure that participants feel contained in the workshop space (safe space). The exercises serve to "ground" participants, making them more present to the workshop and feel relaxed/safe.

Time: 50 minutes, 10 minutes for the demonstration, 20 minutes for each set of partners

Credit: Adapted from the CAPCITAR Emergency Response Toolkit,

www.capacitar.org/kits/engcapemergkit.doc

#### Materials and Space Needed:

Large enough space for participants to pair off with one of them sitting on a chair and the other being able to move freely around them.

Essential oil or fresh herbs that have relaxing/energising fragrances (optional) e.g. lavender, lemongrass.

#### **Process:**

- 1. The facilitator will demonstrate this practice in front of the whole group.
- 2. She will then invite participants who would like to try it to get into pairs, find a chair and a space in which to work.
- 3. The facilitator will then guide you through the steps.
- 4. The facilitator will ask how did it feel to receive/give the head holds before swooping to within the pair.

**Facilitator Notes:** Explain to the group that this is a practice that can be used on oneself or on another person, hold in mind and heart a deep sense of peace, light and spaciousness. The holds can be done for several minutes each, accompanied by deep abdominal breathing to promote greater release. The touch is very light and if someone fears touch because of pain or their history of abuse, the holds may be done working slightly off the body. Always ask permission when you do any practice involving touch of another person. You can also do this hold several inches off the body respectful of the person's boundaries.

It is useful to demonstrate to the group first and then guide them through applying the practice encouraging them to take deep breathes throughout.

#### Step 1. Permission

First ask your partner if you have permission to touch them, and if you are using oil, if it is okay if you use the oil on them.

#### Step 2. Halo Hold

Stand behind your partner and hold your hands an inch away from their ears. This is a way of greeting the person's body before starting the practice. Tell the participants to take a few deep breathes together, in through the nose and out through the mouth. After a couple of breathes, ask them to move solely to the next position.

#### Step 3. Head Hold

One hand lightly holds the head high on the forehead; the other hand holds the base of the skull. The energy of the hands connects with parts of the brain related to memories and emotions. Instruct the participants to keep doing deep breathes.

#### Step 4. Shoulder Hold

The hands rest lightly on the shoulders, the place in the body related to anxiety, excess baggage or the burdens of life.

#### Step 5. Heart Hold

One hand rests across sternum high on chest. The other hand touches upper back behind the heart. The heart area often holds emotional pain, wounds of the past, grief and resentment. Breathe deeply and imagine the heart pain draining down into the earth. You can also do this hold several inches off the body respectful of the person's boundaries.

#### Step 6. Feet Hold

The tops of the feet may also be held to ground the person. Move around to the front of the body and kneel down in front of the receiver.

#### Tips:

- \* Strong smelling oils can affect people with sensitive chests so make sure you ask permission and open some windows.
- As you get more familiar with the techniques, it is nice to start threading through an imaginary for each step, as the giver of the practice to hold the receiver in their hearts thank them for their contribution to this workshop/to activism; acknowledge whatever they might be struggling with and give them good wishes for the future.





JASS (Just Associates) is an international network of activists, popular educators, and scholars in 26 countries working to strengthen and amplify the voice, visibility, and collective power of women for a just and sustainable world for all. Grounded in the Global South, JASS equips, accompanies and amplifies grassroots women activists and organizations with the tools, connections and resources they need to scale up their demands and solutions to problems of inequality and violence. We focus our work with women and organizations on the frontlines of crises and change (indigenous, rural, LGBTQ, young and poor women) in Mesoamerica, Southern Africa and Southeast Asia. While they rarely have a seat at the decision-making table, they are leading communities and building innovative solutions to the multiple crises in the world – often at great risk.

> www.justassociates.org jass@justassociates.org





