
Training on management of FGS in primary health care

Day 1

Day 1 Overview

Introduction and agenda setting

Pre-test

Overview of FGS prevalence

Introduction to the care package for management of FGS

Diagnosis pathway

Presentation of FGS epidemiology, prevalence, transmission, treatment and tools

Aim of the session

- The aim of this session is to introduce health workers to the tools and the prevalence of FGS within Ogun and explain why the care pathway is important for women and girls with FGS, health workers and the community. By the end of this session, health workers should be able:
- To ensure that the participants can define and explain what FGS is, how it is transmitted and the prevalence in Ogun state.
- To recognise the value and benefits for women, girls and the community of treating FGS and the consequences of not treating.
- To recognise and understand the impact on women and girls of misdiagnosis.

Introduction: What is schistosomiasis?

- Schistosomiasis is a water-borne disease, caused by worms that live in infected water (such as lakes and rivers). People become infected when they come into contact with this water when the parasitic worm is present.
- The disease is present in 75 countries and over 200 million people are infected: 95% of infected persons are in Sub-Saharan Africa.
- Nigeria has the highest burden of the disease, with around 29 million cases across the country.
- It is typically prevalent among persons in rural environments where access to adequate sanitation and hygiene is poor
- Because there is often little attention given to this disease, it is considered a neglected tropical disease by the World Health Organisation

How schistosomiasis affects people: medical

- There are two forms of schistosomiasis: Intestinal (*S.mansoni*) and urogenital (*S. haematobium*) that can affect both males and females

Intestinal

Worms in blood vessels that surround the intestine

Symptoms include diarrhoea, abdominal pain and swelling, tiredness, and blood in faeces.

Urinary

Worms in blood vessels of the bladder, and cause inflammation

Typical symptom is often blood in urine

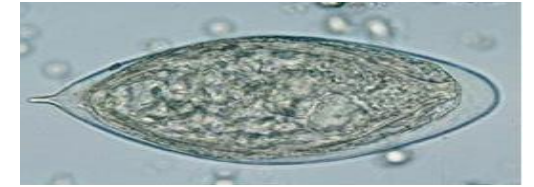
Gendered interactions with water

Fulani community, Ogun State, Nigeria

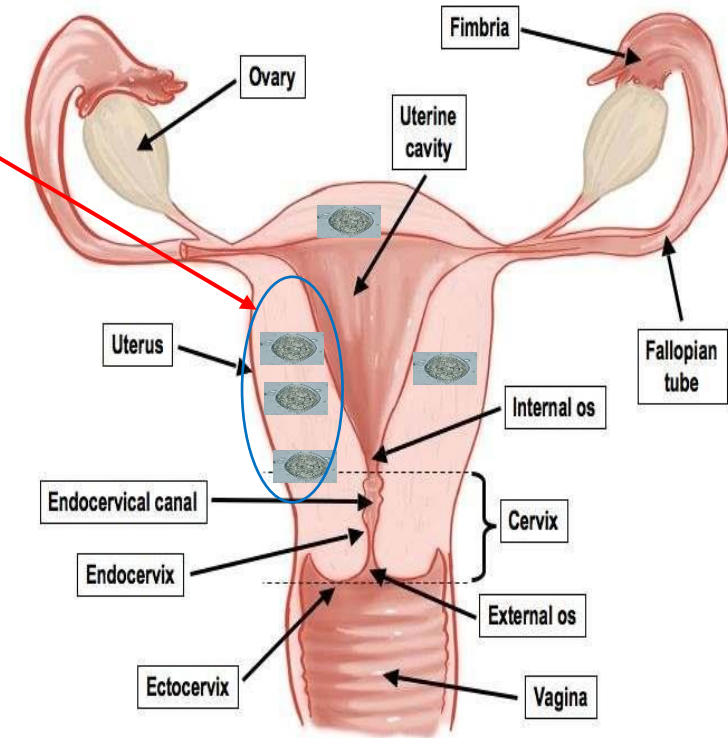


Female Genital Schistosomiasis (FGS): Overview

- Female Genital Schistosomiasis (FGS) is a common complication of schistosomiasis caused by the presence of eggs in genital tissue
- Left untreated, the damage that FGS causes include infertility, miscarriage, ectopic pregnancies, spontaneous abortions, social stigma, depression, and genital and cervical lesions
- In Nigeria it is estimated that 70% of female living in schistosomiasis endemic area have FGS



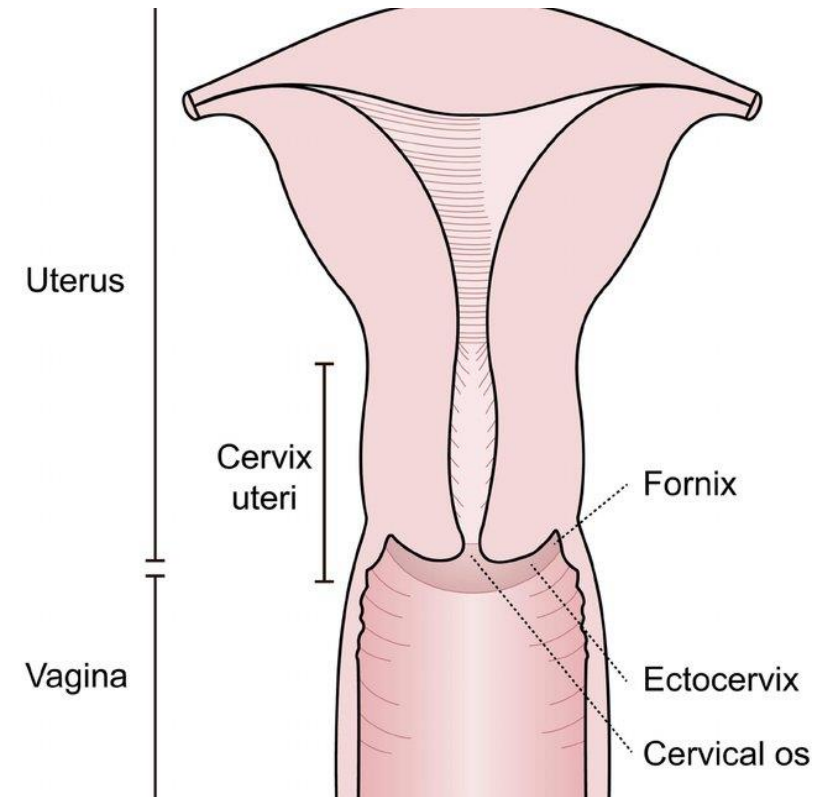
Schistosoma egg



Female genital part

How does FGS present?

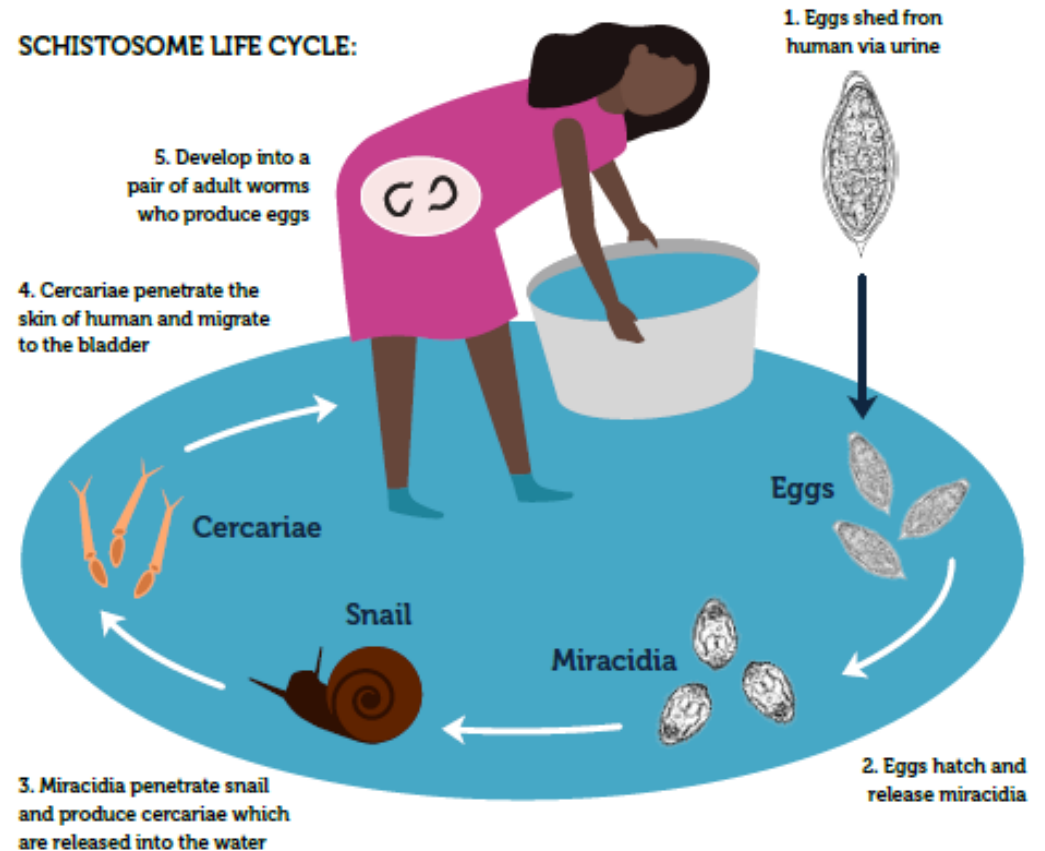
- Common symptoms of FGS can be quite general to other gynaecological diseases, including vaginal discharge, vaginal bleeding, vaginal discomfort and pain during sex
- Therefore, although FGS may be the most common gynecological condition in schistosomiasis-endemic areas, it remains undiagnosed in most cases



Most affected sites by schistosomiasis

Who is at risk of developing FGS?

- Women and girls living in areas with poor access to portable water coupled with poor sanitation and hygiene practices
- Women and girls living in fishing and agriculture communities



What are some of the consequences of FGS?

Medical

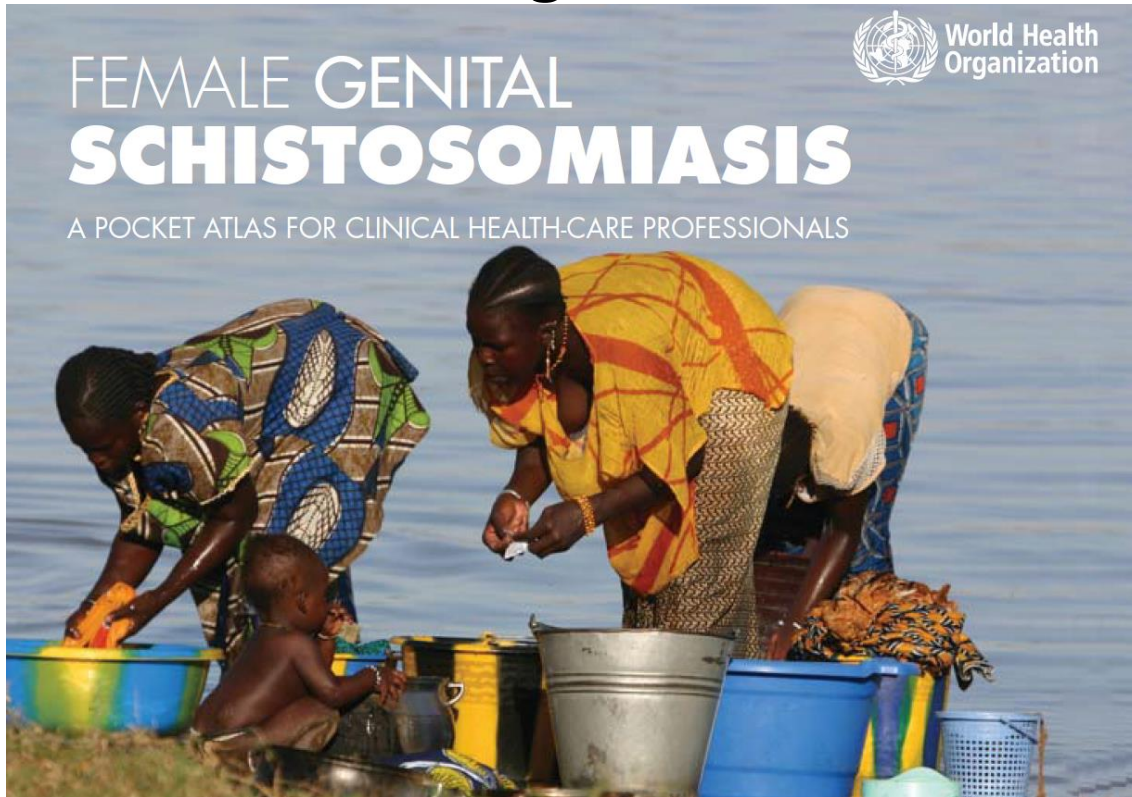
- Bleeding during intercourse (contact bleeding)
- Infertility
- Miscarriage or ectopic pregnancy
- Involuntary urination when coughing, laughing or jumping, etc.
- Genital ulcers
- Tumours or swelling (vulva, vagina, cervix)

Social

- Social stigma and embarrassment
- Isolation and fear of losing social network
- Depression and feelings of shame

How is FGS currently diagnosed and treated?

WHO guidelines



There is a WHO FGS pocket but most frontline health worker are not aware and do not have access to it

National guidelines

No national guideline on FGS diagnosis and treatment yet

- School-based treatment campaigns

What are some of the challenges affecting early and effective diagnosis and treatment of FGS (facility)?

- General focus on MDA strategies in schools - girls not attending school may miss opportunity for treatment
- Current lack of evidence work exploring health workers understanding and management of the disease
- Challenge obtaining praziquantel outside on MDA
- Lack of awareness among health workers- misdiagnoses and stigmatization – STI
- Lack of diagnostic tools suitable for primary health care

What are some of the challenges affecting early and effective diagnosis and treatment of FGS?

Girls and women affected by FGS have no idea of what is wrong with them

Many young girls affected go to chemist to do self medication instead of going to the health facility because of fear of stigmatization

Health implications of FGS such as Infertility and contact bleeding during intercourse result may affect women wellbeing and relationships

What do we need to do?

We need to educate the health workers and Health professionals about the challenge of FGS

We have developed diagnostic algorithm and treatment care package and training guide for the management of FGS at the primary health care level

We need to train the Frontline health workers on the use of the diagnostic algorithm and treatment care package

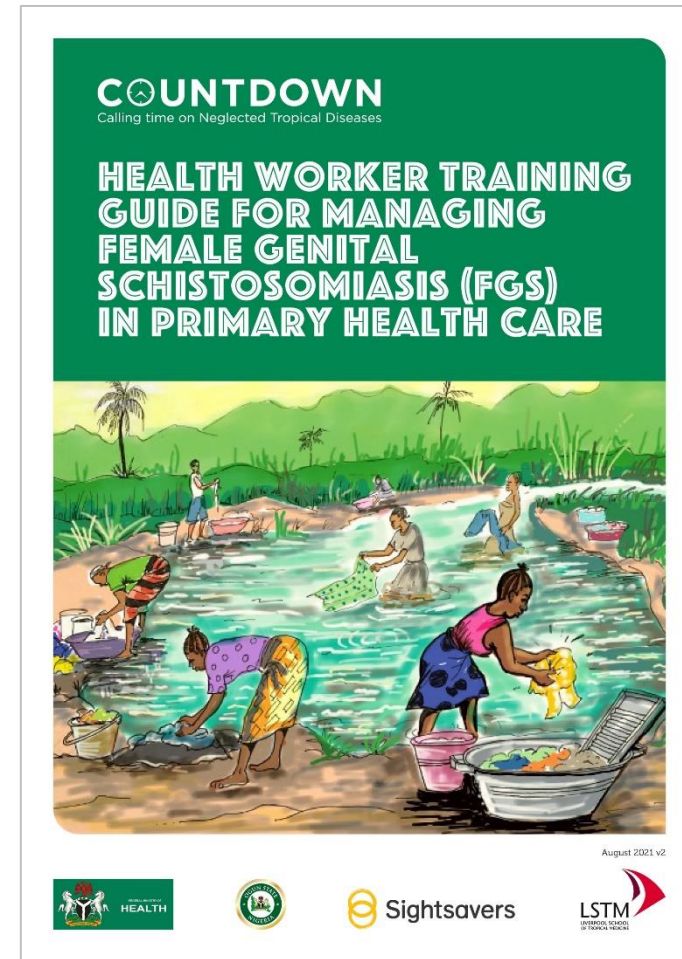
We need to be evaluate the effectiveness of the diagnostic algorithm and treatment care package

Overview of the training guide and tools

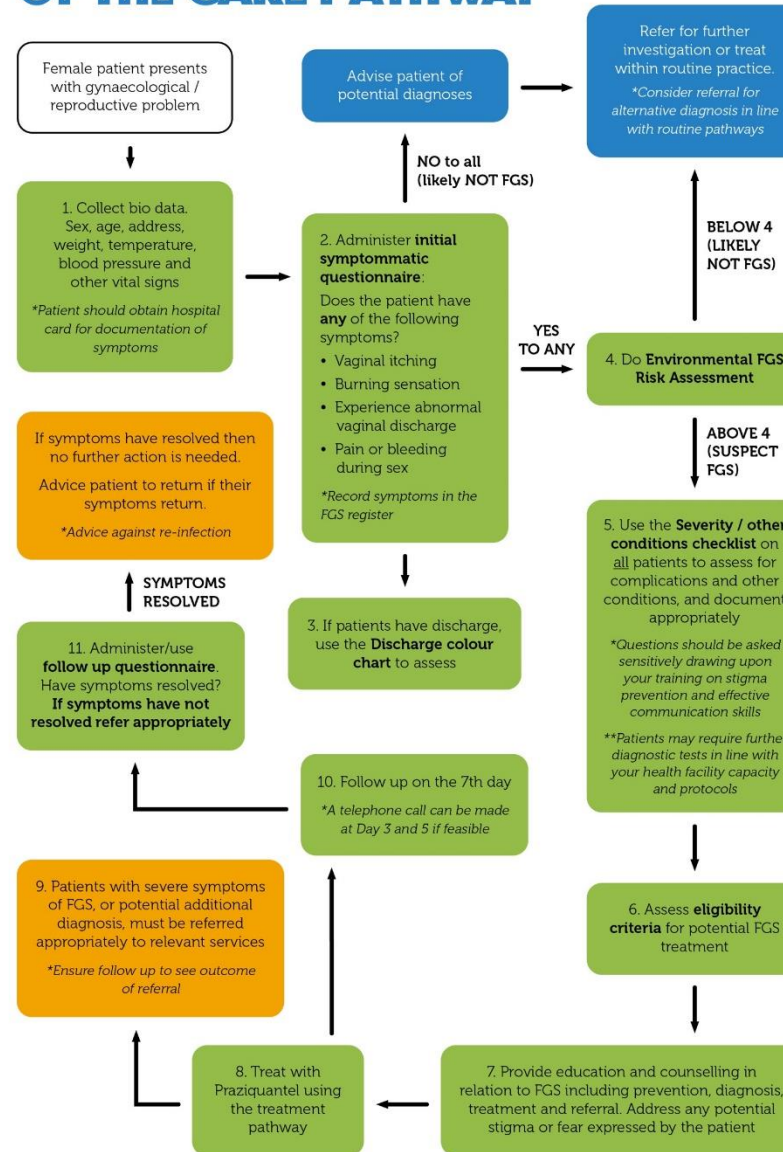
A package of care has been developed to support health workers to diagnose, treat, counsel, follow-up and refer women and girls with FGS.

This package includes:

- Four day participatory training
- Health worker Guide
 - Diagnosis pathway
 - Treatment pathway
 - Referral pathway
 - Counselling guidelines



OVERALL FLOW DIAGRAM OF THE CARE PATHWAY



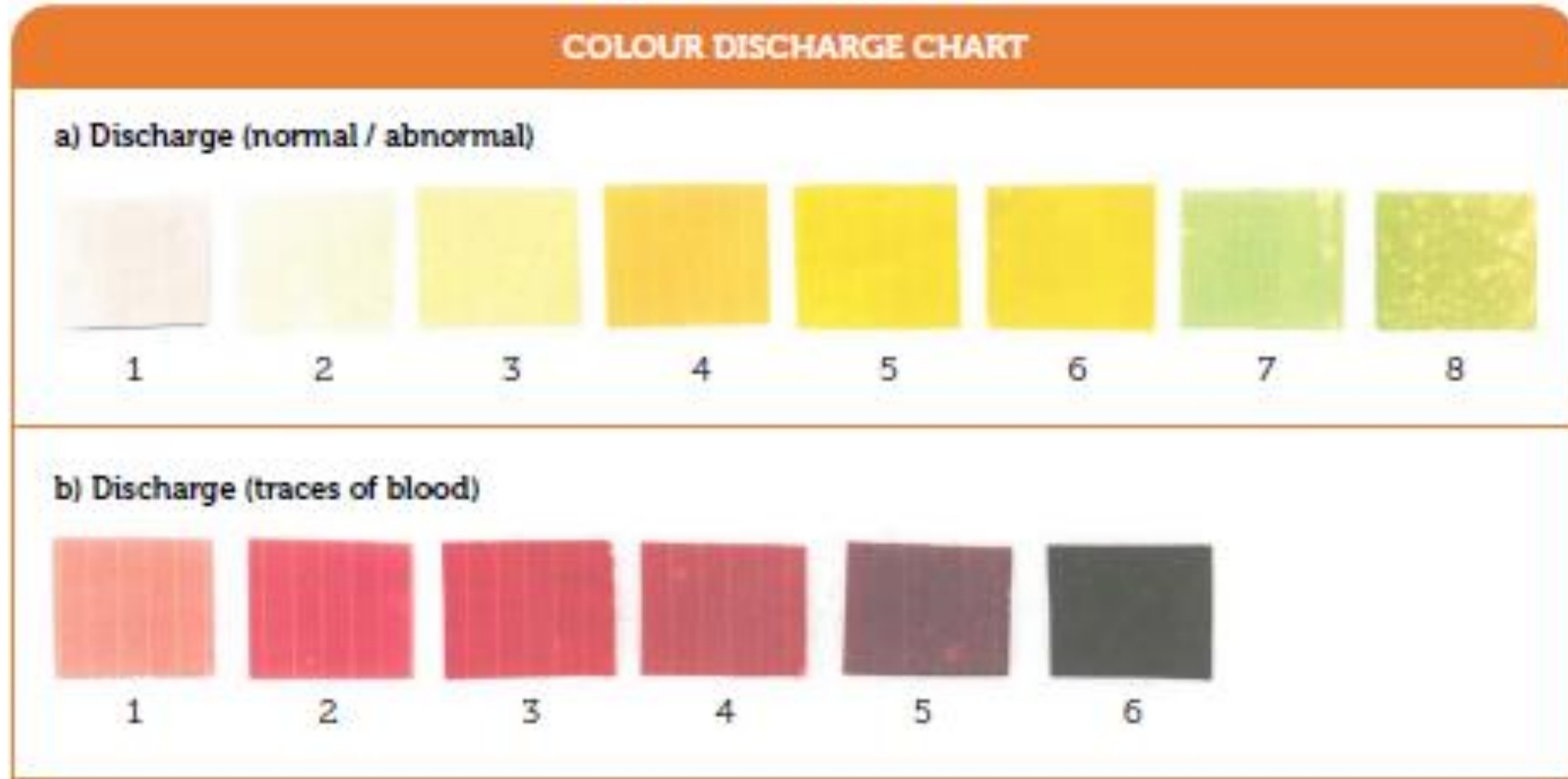
Diagnosis steps

1. Collect bio-data, including weight and vital signs (blood pressure and temperature)
2. Administer the initial symptoms questionnaire and record symptoms in FGS register.
3. If patient answers yes to having vaginal discharge, use vaginal discharge colour chart
4. Conduct the environmental risk assessment
5. Use the severity / other condition checklist on all patients and document as appropriate.

Initial symptom questionnaire

QUESTION	CIRCLE THE RESPONSE			
Do you have genital itching or burning?	Yes	No		
If yes, how severe is the itching / burning?	Mild	Moderate	Severe	
Do you have vaginal discharge?	Yes	No		
If yes, how heavy is the discharge?	Mild	Moderate	Severe	
Do you have pain during sex?	N/A	Rarely	Occasionally	All the time
Do you have spotting / bleeding during / after sex?	N/A	Rarely	Occasionally	All the time

Discharge Colour Chart



Environmental Risk Assessment

FGS RISK ASSESSMENT QUESTIONS	YES	NOT SURE	NO
<p>Have you had direct (active) or indirect (passive) contact with river / stream water now or in the past?</p> <p><input type="checkbox"/> Fishing</p> <p><input type="checkbox"/> Washing cloth</p> <p><input type="checkbox"/> Bathing*</p> <p><input type="checkbox"/> Walking through / crossing</p> <p><input type="checkbox"/> Swimming</p> <p><input type="checkbox"/> Defecating</p>	4	2	0
Have you had painful urination or bloody / cloudy urine in the past?	2	1	0
Is there anybody in the family or anyone you lived with that has history of blood in urine or reported cloudy urine?	2	1	0
Is there anybody in the community suffering from this?	2	1	0

Severity/Other conditions checklist

1. Do you involuntarily pass urine?
2. Do you find it difficult to get pregnant?
3. Have you experienced any previous pregnancy loss?
4. Do you have any genital sores or genital ulcers?
5. If yes, do the ulcers/sores bleed?
6. Do you have any genital swelling?

***Confidential and sensitive questions require effective communication which is non stigmatising**

Referral for severe FGS or potential other conditions



Summary

- If the woman or girl scores 4 and above in the risk assessment and has any of the conditions in the symptoms checklist, the woman or girl has suspected FGS and will proceed to the treatment checklist to see if she is eligible for treatment. Pregnancy test should be conducted to know the patient's pregnancy status.
- If she answered that she has one of her symptoms were severe then treat and observe, or if she had multiple symptoms which were either moderate or severe, then she may need further investigation (treat and refer immediately). If one of these symptoms was abnormal discharge, then present the colour discharge chart, and ask what colour her discharge is. This should be documented on any referral forms for further investigations.
- If you are unsure if the patient should be treated or referred, then please discuss with your supervisor.

Day 2

Day 2 Overview

Stigma management

Psychological distress

Gender-based violence

Health education and counselling

Communication skills

Stigma, Mental Wellbeing and Female Genital Schistosomiasis



Session Learning Objectives

- To be able to explain why stigma might exist in different forms (e.g. felt, feared, internalised and discrimination) and what these types of stigma may look like in relation to FGS.
- To understand what causes stigma related to FGS and the influence of societal judgements related to gender, religion, and health.
- To explore the effects of stigma, including the relationship between mental wellbeing and stigma.
- To develop skills that can support you to reduce stigma, particularly when supporting women and girls affected by FGS.
- To recognise when women and girls may need further support to improve their mental wellbeing or to seek support for gender-based violence

Activity One

What is Stigma?

- A negative response to our differences.
- They can be obvious for example name calling or making someone sit somewhere else because of who they are

OR

- They may be well meaning intentions but where we haven't thought through the potential negative impact of our response. For example, asking them why they look like that or why they don't have children.
- When we do these things because someone has a health condition, like FGS, we call it **'health related stigma'**

Types of Stigma

WE OFTEN LABEL OR STEREOTYPE PEOPLE. THIS CAN MAKE US TREAT THEM DIFFERENTLY AS WE SEE THE LABEL NOT THE HUMAN BEING.

Experienced Stigma

Someone is treated differently because of their health condition.
E.g. loses their job

Anticipated Stigma

When someone is scared that people will treat them differently because of their health condition

Internalised Stigma

When someone holds a negative belief about a health condition and diagnosed with it they apply these feelings to themselves.

Adeola's husband thinks she is not a virgin or is having an affair because of the symptoms of FGS and so shouts at her.

Chiyere is worried that people will think she can't have children because she has had FGS and no one will marry her.

Kadijat is hiding from people in her community because she thinks she has been cursed by a witch and can't have children.

Activity Two

What Causes Stigma?

- A social process that lead to a group being labelled or thought of as 'different' and can lead to social isolation or rejection. Society sees people as inferior based on their difference.
- Normally because of
 - physical appearance
 - Behaviours
 - Social characteristic

So why do we stigmatise?

Fear

- Catching the disease, physical impacts, of infecting others, disclosure

Unease

- People may not know how to react toward another person

Association

- Health condition perceived to be undesirable or linked to a specific job, for example, sex work, poverty. Often people are blamed for their condition.

Values and Beliefs

- Religious values related to sex and marriage may cause stigma if FGS perceived as a result of infidelity. These may be unconscious thoughts or ideas.

Policies or Legislation

- About where and how conditions are treated. Laws that are discriminatory e.g. allowing divorce as the result of a specific health condition.

Use of inappropriate pictures of language, comments from health workers

- The way in which diseases are presented visually, talked about in the community and or media is important. Labelling and negative language can lead to stigma.

Activity Three

Who Stigmatises?

EVERYONE

Often we don't realise we are doing it.

We might use certain words to describe people or avoid talking to someone because of a specific health condition because we do not know how to respond.

Ask yourself:

- Would I accept a glass of water from someone who is HIV positive?
- Would I assume that someone who shows signs of FGS is not a virgin?
 - Would I go for dinner at someone's house who has leprosy?

Who Stigmatises?

Anthony is a health care worker who is based at the clinic. A young women comes to him and says she has just got married but is struggling to have child and she gets pain when she has man and women business. Anthony thinks he has seen this before and she must have been sleeping with other men. He believes that she has been involved in sinful behaviour. Anthony feels strongly about women who behave like this in his community and so decides not to offer her care but to ask one of his colleagues to do it instead.

- In this example, Anthony has a negative attitude toward women and girls who may be experiencing signs and symptoms of FGS.
- Anthony is stereotyping toward certain health conditions.
- Our own personal emotional reactions can compromise the type of care we provide.

Activity Four

The Impacts of Stigma

Every person will experience stigma differently but often it can lead to negative thoughts and feelings. These feelings may not be constant but will depend on the situation that we find ourselves in. Stigma can often affect a person's mental wellbeing and how we respond becomes really important.

Mental Wellbeing

A state of **well-being in which the individual realises their own ability**, can manage the daily stressors of life, can work productively and fruitfully, and are able to make contribution to the community.

Psychological Distress

Comprises of the **worry, fear, sadness and insecurity often experienced by people with FGS and the associated stigma**. Can lead to reduced social functioning and self-isolation.

Mental Health Condition

Characterised by **changes in thoughts, perceptions, emotions or behaviour that affect relationships and ability to perform expected social roles**. Can cause significant functional impairment. For example, depression, anxiety, harmful use of alcohol.

Psychosocial Disability

Interaction between impairment caused by mental health conditions and barriers to participation in society experienced by many people with these conditions.

How should we Respond?

Think about the way that we communicate diagnosis

Listen to patient's distress and let them ask questions

Share with them the facts about transmission and treatment

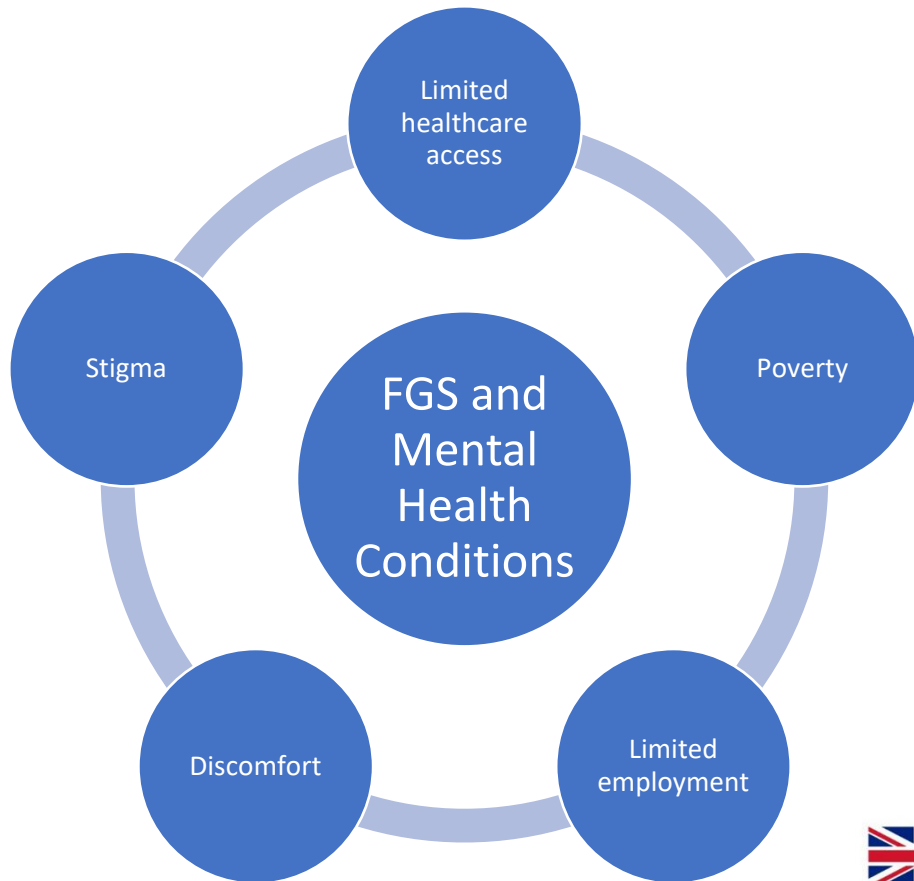
Give feedback to help them decide who they want to tell and how

Encourage expression of feelings and emotions

Help the person explore options of how they want to manage the situation

Psychosocial Support

People with FGS are at risk of developing mental health conditions; and people with mental health conditions are at risk of FGS. This is because many of the social factors that shape vulnerability are the same.



- Psychosocial support is a supportive relationship that involves allowing a person to address the feelings (emotions), thoughts and beliefs, behaviours and relationships that are associated with the diagnosis.
- We can provide this initial support by:
 - Listening: pay attention to words people use.
 - Watching: pay attention to non-verbal body language.
 - Empathising: be supportive and give hope.
- Sometimes you will identify people in psychological distress that need more support. In these cases you should refer.

Gender Based Violence: What is it?

Physical

Verbal

Emotional

Sexual

Based on
gender

All forms of violence and abuse can be harmful to a persons mental wellbeing

Questions?

Health Education and Counselling



Aim of the session

The focus of this session will be to guide the health workers on how to counsel a woman or girl with suspected FGS and to reduce feelings of stigmatisation, prevent reinfection and understand what to expect with treatment and or referral. By the end of this session the health worker should be able:

- To understand the difference between education and counselling.
- To understand why education and counselling are so vital in FGS case management.
- To be competent in a range of communication skills for education and counselling.
- To be able to explain to the woman/girl the importance of each step along the care pathway for FGS Management.
- To know how to communicate effectively to remove fear from the woman/girl and reassure her of how treatment will help reduce symptoms
- To understand the importance of maintaining confidentiality
- To be able to offer advice about preventive measures against re-infection.

Communication skills and counselling practice

Aim of the session

The aim of this session is to reflect on the importance of communication skills to support education and counselling. By the end of this session, health workers should be able:

- To demonstrate and reflect on effective communication and counselling skills
- Be confident and competent to educate and counsel women on the FGS care pathway and recognise and reduce stigma related to FGS.

Day 3

Day 3 Overview

Review day 1 and 2

Treatment criteria

Treatment pathway

Side effects monitoring

Referral pathway

Follow-up procedures

Eligibility criteria

Aim of the session

The focus of this session is eligibility criteria for administering praziquantel to women and girls with FGS. By the end of this session, health workers should be able:

- To understand the inclusion and exclusion criteria for treatment of FGS.
- To understand the importance of the eligibility criteria and why it is included.
- To apply the inclusion/exclusion criteria to decide who is eligible for treatment and what the next steps are.
- To apply the inclusion/exclusion criteria to identify who is not eligible for treatment, and what the next actions should be.
- To recognise the importance of communication and counselling to assess eligibility for treatment.

Inclusion/Exclusion criteria

INCLUSION (TREAT):

- ✓ Woman / girl 15 years and older
- ✓ Consented to treatment
- ✓ Has not taken praziquantel during last 6 months
- ✓ Has symptoms of FGS and has FGS environmental risk assessment score of 4 and above
- ✓ Has recently eaten food

EXCLUSION (DO NOT TREAT):

- ✗ Is pregnant or currently breastfeeding
- ✗ Has a history of epilepsy, central nervous system disorders or sickle cell anaemia
- ✗ Is taking a medication which may interfere with treatment
**See FGS Training Guide Annex page 39*
- ✗ Is currently unwell or sick
- ✗ Does not consent to treatment

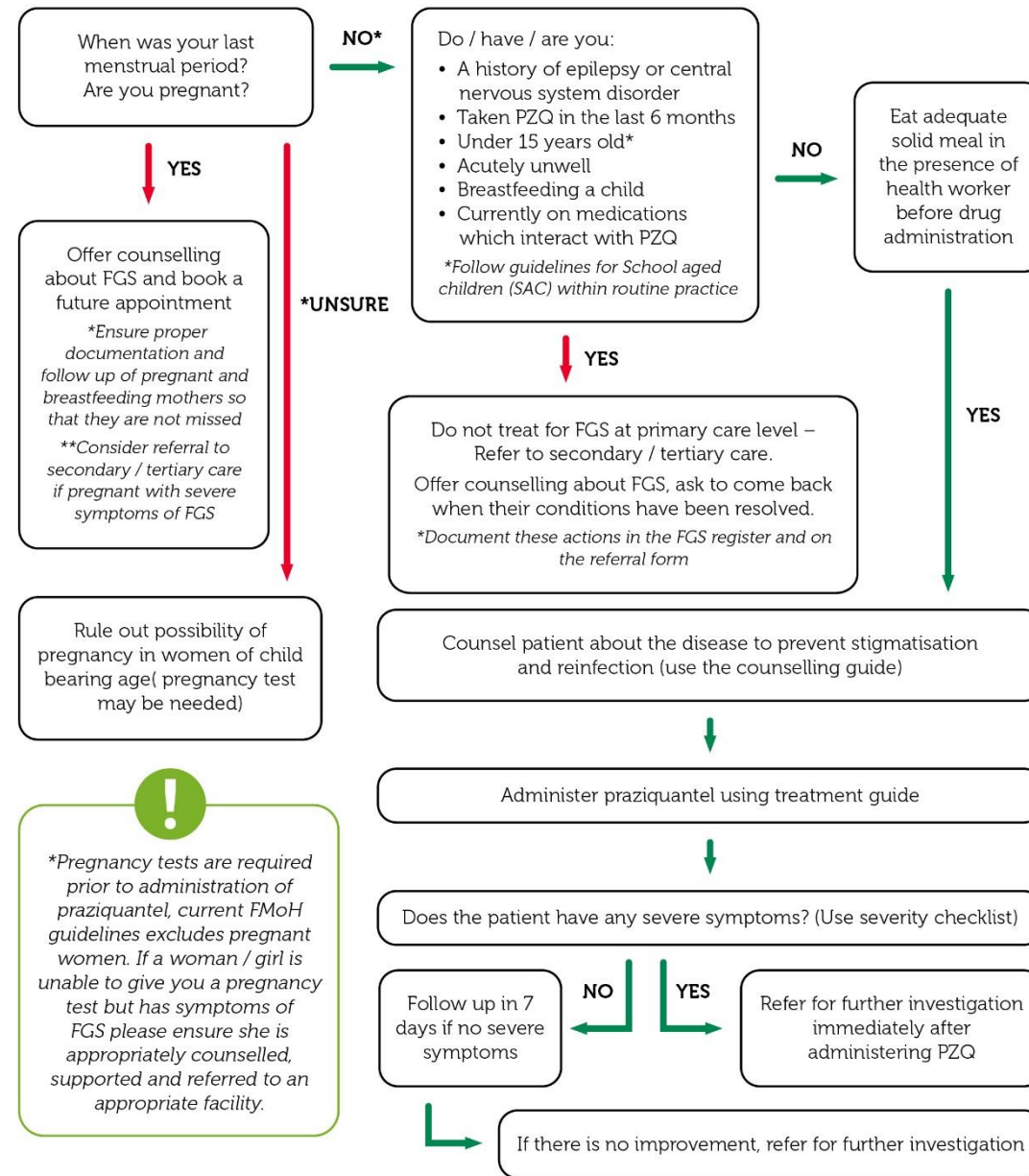
Treatment Steps

Aim of the session

The focus of this session will be on how to administer the praziquantel and other treatment appropriately to the patients that were found eligibly for treatment. Facilitator will follow the participatory steps and the activity outlined for this session. By the end of this session, the health worker should be able:

- To know how to carry out treatment appropriately.
- Be able to follow the treatment guideline for Praziquantel administration.
- Understand how to measure height using the dose pole (or weighing scales) to determine the corresponding dosage to be administered

Treatment pathway



Administering Praziquantel

What do you understand by DOTs administration of PZQ?

What will you do if a patient has not had a meal before presenting at the health facility/ not ready to take a meal in front of the health worker?

How long will you observe the woman/girl after she has taken the praziquantel?

What advice will you give the woman/girl after they have taken treatment?

How will you document the dosage given?

Side effect monitoring

Aim of the session

The focus of this session will be to guide the health workers on how to monitor side effects that may occur after administration of praziquantel to the patients that were found eligible for treatment. By the end of this session, the health worker should be able to:

- Understand how to monitor treated patients for side effects, and what potential side effects they may be.
- Be able to take the appropriate action for any noticed side effects.
- Be able to take appropriate steps to address Severe Adverse Effects (SAE)
- Recognise how to document and report SAEs.

Referral and Follow up

Aims of the session

This session will guide the health workers on how to follow up with women and girls with symptoms of FGS who received treatment. This is important to know if symptoms have resolved, or if the woman or girl needs further investigations or a different type of treatment. The facilitator should also recap on who should be referred, where referral should be made and how they should be documented and followed up. By the end of this session, health workers should be able:

- To use the follow up questionnaire accurately.
- Determine if the woman or girl requires further investigation and or referral.
- Determine if the woman or girl may have an additional or concurrent condition which requires treatment in line with health facility protocol.
- Advise the woman or girl appropriately to reduce her chances of re-infection.
- Advise the woman or girl to come back again to the health facility if symptoms return.

Follow up assessment questions

How would you differentiate between a resolved or improved symptom?

What advice would you give a woman or girl whose symptoms had resolved?

What advice would you give a women or girl whose symptoms had not resolved?

Questions?

Day 4

Day 4 Overview



REPORTING AND
DOCUMENTATION



SUPERVISION AND
MONITORING



SENSITIZING THE
COMMUNITY

Reporting and Documentation

Aim of the session

This session will guide the health workers on how to complete reporting and documentation appropriately. They will be taken through the various data capturing tools that will be used for the FGS management at Health Facilities. The importance of data integrity and completeness will be stressed. By the end of the session the health worker should:

- Understand the importance of completing documentation accurately.
- Identify which forms to complete and how to complete them.

Supervision and monitoring

Aim of the session

This session will ensure health workers are aware of the types of supervision and guidance to support them, and who to contact for advice. By the end of this session, health workers should:

- Understand what supervision mechanisms are in place.
- Who to contact if they require advice about a woman or girl with suspected FGS
- How often data will be reported and how.

Activity Post-test

Scenarios for pre and post test

Question	Scenario
1	Taiwo is an adolescent girl of sixteen (16 years) who just came to town to stay with her aunt. She shyly opened up to the aunt that she is having itchy vaginal discharge which is always accompanied by painful urination and that she also has ulcers on her vulva. What steps will you follow to help the girl?
2	Awero is a 34-year-old woman who has been married for 5 years now, she works in a fishpond and has been experiencing pain and bleeding during sex. What would you do to help her?
3	25-year-old Afusat who lives in Atako village complains of a bloody discharge accompanied by painful urination. She has had this for two weeks and it is getting worse. She does not know whether her partner has penile discharge because she has not seen him for three months. She has no other symptom.
4	A 22-year-old woman married for one month appeared at the clinic with history indicating pain during sex and vulvar pruritis (itching). How will you go about diagnosis and treatment?

Sensitisation strategies

Aim of the session

This session explores the importance of sensitization and mobilization of FGS patients to the health facility. By the end of this session, health workers should:

- Identify what types of sensitisation may be used within their own health facilities.

Question and answer session

- 3 key learnings of the training sessions
- 2 things you found very interesting
- Anything that you are still not yet clear about

Questions?



COUNTDOWN

Calling time on Neglected Tropical Diseases



COUNTDOWN

Calling time on Neglected Tropical Diseases