HIV AND YOUR COMMUNITY

A facilitator's supplementary guide to Umoja

tearfund

HIV AND YOUR COMMUNITY A FACILITATOR'S SUPPLEMENTARY GUIDE TO UMOJA

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CONTENTS

Introduction	4
The role of the facilitator	6
HIV facts and related issues	11
Stage 1: Envisioning and equipping the church	18
Stage 2: Envisioning the community	25
Stage 3: Planning for action	32
Stage 4: Taking action	39
Stage 5: Evaluation	40
Useful resources	42
Appendix – A checklist of community awareness and response	44
Glossary	46

INTRODUCTION

The aim of this supplementary guide is to provide information and resources that enable the church to understand its role and its responsibility to work with its local community both to prevent the spread of HIV and reduce its devastating impacts. It also aims to equip the church to understand its community's vulnerabilities to HIV.

The Umoja process helps churches and communities to find ways in which they can work together to serve each other better.

This supplement is specifically designed to provide additional HIV-related information to build better understanding of the local HIV epidemic.

As with the Umoja process, a facilitator is required to work through this supplement, envisioning, guiding and supporting churches and communities through the process.

Why is this resource important?

HIV is one of the more difficult issues for churches and communities to identify and prioritise because it is often hidden, not spoken about or discussed, even if people in the community are living with or affected by HIV.



This resource seeks to equip Umoja facilitators with basic information about HIV, as well as provide some simple tools for gathering and analysing information. It enables the facilitator to help churches and communities identify HIV-related issues, discuss them and think about the right response. The resources are designed to equip facilitators with tools such as Bible studies and methods for gathering and analysing information about HIV in their community.

It is important that facilitators feel confident about the supplement content and also take time to consider their personal views on HIV, challenging themselves about any prejudices they may hold.

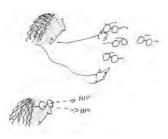
How does it fit into the Umoja process?

The following diagram shows the key stages of Umoja and how the supplementary guide has additional material for each of these stages.



	STAGES					
	Envisioning the church	Envisioning the community	Dreaming dreams and planning for action	Taking action	Evaluation	
Content of Umoja	Foundational Bible studies Celebrating what we have Using our own resources	Describing our community Gathering information Analysis	Dreaming dreams Clarifying what is next Planning	Key skills for supporting an initiative	Learning from experience Accountability Celebration	
Content of supplementary HIV guide	Bible study on stigma	Using indicators to identify HIV- related issues and advice on analysing the results	Ideas for churches and communities to respond to HIV-related issues		Tips for evaluating HIV- related initiatives and options for strengthening future responses	

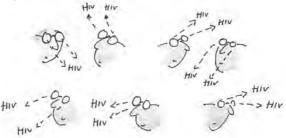
THE ROLE OF THE FACILITATOR





The facilitator needs to be aware of four key things when working in the context of HIV:

- It is important that the facilitator is able to look at community issues from an HIV perspective. It is essential that all facilitators have some training in the basic facts and issues surrounding HIV and AIDS.
- 2. The facilitator needs to listen to the community in their everyday discussions about their lives and work, to identify HIV-related issues which may lie below the surface. For example, community members may talk about the shortage of labour for farming because of sickness or the increased number of orphans and singleparent households, and these may be indicators of HIV.
- 3. A key role of the facilitator is to raise awareness of HIV, if it is an issue in the community. This can be done through focus group discussions using drama or pictures. The key thing here is not for the facilitator to tell people what the problem is, but instead to help the group explore it for themselves through the careful use of questions.



4. Once the group has identified HIV-related issues in their community and has understood their root causes, the facilitator should help them look at options for addressing these issues.

How to facilitate discussions around sensitive issues

HIV is a sensitive topic, therefore it is important for the facilitator to create the right environment for an open and productive discussion. Consider the following tips when facilitating groups:

- When introducing a sensitive topic, think about different ways to present it, such as a monologue or role play, telling a story, showing some pictures that demonstrate a problem or highlighting an issue for groups to discuss.
- Consider breaking up large groups into smaller groups of five or six people. This may need to be done on the basis of gender or age.
- Nominate a leader for each group who is confident enough to give feedback on discussion points or answers to questions.
- Where possible, try to record people's feedback on paper or blackboards so there is a record of the discussions.
- Try not to let individuals dominate group discussions. Make sure everyone's voice is heard.
- Try to stop and summarise what has been said at frequent intervals. Check that everyone has an understanding of what has been discussed.
- Ensure there are plenty of breaks and fun activities to relieve any tension left by the discussions.



How to facilitate Bible studies around HIV-related issues

In this supplement we include one Bible study on stigma and discrimination (on page 19). It is taken from Tearfund's HIV resource *Hand in Hand* which contains Bible studies on different HIV-related subjects. The publication is available from the Tearfund International Learning Zone (TILZ) website to download free of charge: www.tearfund.org/tilz

How could this study change us?

The Bible is transformative. You may want to list the ways you would hope to see this transformation taking place. Transformation could be within three areas:

KNOWING – these describe the practical knowledge and learning to be gained through reading the Bible.	BEING – these describe changes to our thinking and understanding, changing our hearts and our responses.	ACTING – these are the practical responses we can make as a result of our learning.
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These transformative areas provide a good introduction to the Bible study. They can be discussed before each study and then used to summarise the discussions at the end.



Discussion: in biblical times

First look at the passage by considering who it was written for and the situation at that time. Use the questions provided in Stage 1 (on page 21) to help the group learn about the passage and understand what God is saying through it.



Discussion: in the time of HIV

Then move on to consider what the Bible passage is saying to us today – how is this relevant to us today and what is it saying about the issue of HIV?



Key learning points

Check that these points have come out through the discussion. These should provide a good summary of the learning gained from the study. They can also help people think of things they can do in their community.

Further passages for reading

Several other related passages are provided. These can be referred to during the study or used for personal study.

Prayer

Always end with prayer. Pray for each others' personal situations and pray that the learning and understanding you have gained will be put into practice.

When facilitating Bible studies, consider the following points:

- Some of the studies are very sensitive and it may help to divide men and women or girls and boys for separate discussions. (Remember you will need an additional facilitator for this.)
- After small group discussion, always come back into the large group to share learning. Agree on the key issues in the small groups before sharing these with the large group. Pray together before finishing in the larger group.
- When dealing with sensitive issues, the group must agree to respect each other's confidences. They must not pass on stories and secrets.
- Make clear what specific words mean if individuals do not understand them. This will enable everyone to participate in discussions.

- Encourage quieter people to share their views and prevent talkative people from taking over the discussion. Ask everyone in the group to speak in turn in discussions, in order to draw out points from everyone present.
- Open discussion is valuable even if participants may not agree on all the points raised. However, the facilitator should not allow the discussion to become angry or aggressive. If this happens, they should take control, summarise the differences, suggest further opportunities to discover more information on disputed subjects/ topics and move the discussion to another topic.
- Avoid 'teaching'. Allow everyone to share their knowledge and experience. Everyone's opinion is equally valid, so include everyone in discussions.
- Provide correct factual information where there is confusion. The facilitator's role is to gently help people discover what the passage is saying – and more importantly what it is saying to the group.
 If necessary, summarise a long discussion before moving to another question.

Ideas for practical response

These studies may change our understanding or how we feel about certain issues. However, this may not be enough. Ideally the studies should lead to action too. As the discussion on the Bible passages finishes, help people to focus on the practical responses they could make in light of the study. Point out to the group that as they go through the Umoja process, there will be opportunities to identify simple things the church and community can do to help and support people living with HIV.





HIV FACTS AND RELATED ISSUES

Key facts for the church to know and communicate about HIV

How our body works to protect us

How HIV affects our bodies

HIV and AIDS

Each of us has a shield that helps our body to fight illnesses. Our shield is known as our 'immune system': this helps to fight infections and minimise the impact of illnesses on our body. We keep our shield strong by taking care of our health through good nutrition, exercise, managing stress etc.

HIV (Human Immunodeficiency Virus) is a virus that damages our immune system so that infections such as Tuberculosis (TB) and malaria have a greater impact on our body. These infections are often called opportunistic infections. When HIV first enters the body, the body is still strong, but over time the virus destroys the immune system, which causes the body to become weaker and more vulnerable to infections and diseases.

HIV and AIDS are not the same. Without antiretroviral treatment HIV can start to break down a person's immune system. The person is then more susceptible to infections and the body becomes very weak. People die from these infections because the body is no longer able to fight them. AIDS is a stage when a collection of diseases affect the body together as the immune system is very weak. AIDS stands for Acquired Immune Deficiency Syndrome.



Living positively

HIV and CD4 tests

Antiretroviral treatment

HIV transmission

A person living with HIV can stay healthy for many years as their immune system is able to fight off infections. To stay healthy they need to take care of themselves: physically, emotionally and socially. Stigma and discrimination have a negative impact on wellbeing and often make people too scared to go for testing and access the help that they need. People with HIV can continue to work and be involved in their families and communities. However, although an individual is not ill and looks fine, they can still infect others during this time. This is why it is important to encourage one another to go for HIV testing regularly so that people can know their status and look after themselves and others.

In most countries the government provides free HIV tests. In addition people might have another test called the CD4 test. This test helps check the strength of the immune system and is the key indicator to help decide whether the person needs to start antiretroviral treatment (ART), the life-long treatment available for people living with HIV.

Treatment is freely available in many places. It enables a person to remain healthier for longer and to have a good quality of life. People on treatment can live a long time and do all the things they were doing before. Treatment is lifelong and the medicines need to be taken every day without any breaks. If someone stops taking the treatment the body can become weak very quickly.

HIV is passed on only in the following ways:

- when a person with HIV has unprotected sex with another person
- through infected blood and blood products (blood infected with HIV can be transmitted through a blood transfusion, although hospitals should have checked that blood is HIV-free); or by using non-sterile injecting equipment or other instruments that cut the skin



The effects of stigma

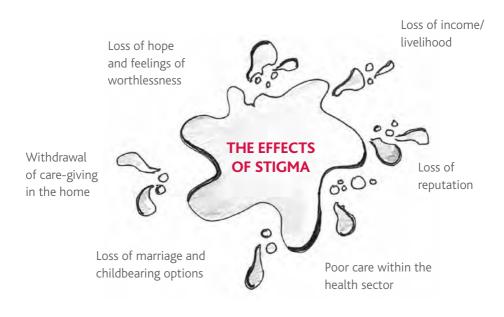
 from a mother to her child. If the mother is living with HIV, the child can get HIV during pregnancy or through breastfeeding. Not all children born to women with HIV get the virus but on average one in three children are born with HIV.

You **cannot** become infected by:

- shaking or holding hands, touching or hugging
- normal work or school contact
- using telephones
- sharing cups, glasses, plates and utensils
- coughing or sneezing
- insect bites, mosquitoes and bed bugs
- sharing water or food
- sharing toilets and latrines
- sharing bedding and clothing

Stigma is described as the isolation of someone or the creation of negative attitudes towards them 'on the basis of particular attributes such as their gender, HIV status, sexuality or behaviour'. Stigma can be 'felt' – for example it can be anticipated, feared or 'experienced'. Stigma such as exclusion from church activities or leadership positions still occurs.

HIV-related stigma has a profound effect on people. Stigma and discrimination are the main reasons why people don't want to be tested, be open about their HIV status or come forward to take treatment for HIV. These factors all contribute to the spread of HIV and a high number of HIVrelated deaths. An unwillingness to take an HIV test means that people can infect others unwittingly and when people are diagnosed late, their immune system may already be very weak, making treatment less effective and increasing the risk of early death.



Below is a diagram highlighting the main effects of stigma on individuals and their families.

'Many people suffering with AIDS are not killed by the disease itself but by the stigma surrounding it.'

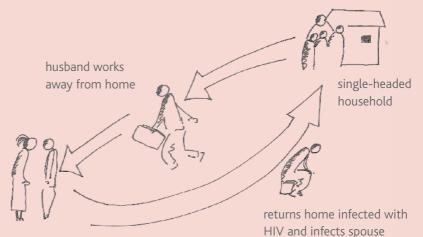
Nelson Mandela

Why HIV may be an issue in the community

There are many things that make communities vulnerable to HIV. Poverty and lack of awareness are two critical factors. Here are some common examples of how people could be at risk:

 Poverty and increased vulnerability of women. In many situations women are responsible for providing food and money for their families, as well as caring for the sick. With increased food insecurity and economic hardship, they sometimes have to make difficult choices and may be forced to exchange sex for money or food. Migration. Where communities are situated near main transport routes, migrant populations pass through on a regular basis; for example truck drivers may be looking for casual sex in the community. This increases the risk for both the local community and their wives/partners at home.

In communities where men have to work away from their families, there is a higher risk of them becoming infected with HIV if they have multiple sexual relationships while away. When they return home they may infect their partners.



husband visits sex worker

- Harmful cultural practices and beliefs. With low awareness about HIV, people continue to follow cultural practices that increase the risk of HIV infection. For example:
 - polygamy, a marriage which includes more than two partners
 - unprotected sex
 - some harmful practices related to sexual initiation, such as encouraging a young boy or girl to have sex with many people as part of their grooming, or female genital mutilation carried out with infected instruments

- Misinformation. In some situations where individuals know that they are living with HIV, they may be given false information about how to treat it. For example, some believe the lie that they could be cured by sleeping with a virgin child.
- Low awareness and access to services. Stigma and lack of access to health services result in people not knowing their HIV status. This leads to an increased risk of HIV transmission, including to unborn and newborn children.

Common dangers of not knowing one's HIV status

When a person knows they are living with HIV, they can actually live a normal life whilst at the same time protecting their family. However, lack of awareness about one's HIV status can have a massive impact on individuals, their families and the wider community. Some of these are listed below:

- Increased spread of HIV. The biggest danger associated with not knowing one's HIV status is that people can unknowingly infect others.
- Impact of sickness on family. Frequent sickness, long-term illness and AIDS-related deaths have a massive impact on children and other dependent family members. Families affected by HIV have the additional stress of caring for the sick and finding extra income to pay for medicines and support. When a family member is ill, their emotional, social and economic contribution is affected, which increases the burden on other family members.

• Reduced productivity. Individuals living with HIV who do not have access to treatment are more likely to become vulnerable to other infections and diseases, which often means they are unable to work. This affects their families, as well as the productivity of the community. In rural areas, reduced food production leads to lowered food intake and malnutrition.

Why the community may not see HIV as an issue

- Low awareness or understanding of HIV. HIV is hard to identify when people do not have access to appropriate information because people living with HIV often look healthy unless their symptoms are serious. Where there are few facilities encouraging and offering an HIV test, there is also often a general lack of awareness of HIV status.
- Myths. There may be many myths and negative beliefs in the community about the causes and origins of longterm illnesses.
- Stigma. Where there is some awareness of HIV, there may also be a fear of being stigmatised and rejected by families and the community, or a fear of losing employment.

STAGE 1: ENVISIONING AND EQUIPPING THE CHURCH

Stage 1 of the Umoja process is about envisioning the church to work together with the local community to meet their needs. It is important that the church follows the Bible studies in the main Umoja manual first before introducing the HIV-specific Bible study on stigma and discrimination detailed on page 21. This stage in the process will give the bigger picture of what the church is called to be and to do. This also provides a foundation for discussing sensitive issues such as stigma, denial and discrimination.

Issues to be aware of in church contexts

- Not everyone in the church will understand what HIV is and how it impacts people in the community, so it may be important to provide a basic introduction to HIV.
- Sometimes people can read the Bible out of context and select verses to support views which may be discriminatory and harmful.
- Some of the questions in the Bible study may be difficult for some to consider or answer. Therefore it is important to use small groups with a facilitator in each group. This provides a safe environment in which everyone can participate in discussions. Sometimes it is good to organise small groups based on age or gender.

Do not rush the study in order to complete it by a certain time but rather take it in short sections so that everyone is moving together in their understanding. If the group members are finding the Bible study difficult to understand and apply, spread it over a number of sessions or days.



 If you know there are members of the church who are living with HIV themselves, then meet with them confidentially to understand the issues they face in the community. Explore how comfortable they would be to participate in the group discussions and if they would like to contribute from their experience. It may require courage from them, as well as support from you, and therefore needs to be considered carefully.

Introduction to stigma, discrimination and denial



Background information

Three key factors – **stigma, discrimination and denial** – contribute to the spread of HIV worldwide.

STIGMA is a feeling of being socially unacceptable, resulting in isolation, rejection and shame. It can be revealed through the disapproval, condemnation and rejection of people living with HIV.

SELF-STIGMA means that some people living with HIV feel unworthy or ashamed.

Discrimination

DISCRIMINATION means to treat someone unfairly because of prejudice or wrong information, for example people of a different race or religion, or people living with HIV.

Stigma

Denial

DENIAL means refusing to accept something is true (such as the existence of HIV in one's family or community), despite evidence. Because of the enormous stigma attached to HIV and AIDS, many people living with HIV suffer discrimination from their family members, friends, workmates, health workers and faith communities. This negative environment leads to widespread denial of the reality of HIV. If people are in denial about HIV, they are less likely to go for HIV testing and change their behaviour to reduce the risk of being infected. Often women face greater discrimination and are unfairly blamed for their HIV status (even though they may have been infected by their husbands/partners).

How could this study change us?



We will KNOW...

and understand the effects that stigma, discrimination and denial have on the spread of HIV.



We will BE...

able to care for and support people living with HIV and their families by addressing issues of stigma, discrimination and denial.

We will ACT...

to help foster unconditional love, care and compassion for people living with HIV and their families.

Advice for facilitators

Focus on the practical ways in which people living with HIV experience stigma and discrimination in our churches and communities. Examine what impact that has on us and on others. Are we aware of denial about HIV in our churches and families? How can we challenge such denial and encourage openness?

Ideas for practical response

Help people to be clear about the consequences of stigma, discrimination and denial in their churches and communities. Discuss ways of dealing with each of these.

Bible study on stigma, discrimination and denial



Read John 8:1–11

This story takes place in the temple after the Feast of Tabernacles. The Pharisees and teachers of the Law brought this woman to Jesus in order to trap and discredit him.



Discussion: in biblical times

- 1 Who are the main people in the story?
- 2 What do you think the story is really about?
- 3 Verse 4 of this passage states that the woman 'was caught in the act of committing adultery'. Why, therefore, was it only the woman, and not the man she was with, who was accused of adultery and brought before Jesus and a crowd of people?
- 4 Why did Jesus answer in the way he did?
- 5 Why did the Pharisees and teachers of the Law walk away?



Discussion: in the time of HIV

- 6 If a married woman in our community tests positive for HIV before her husband, how is she treated by her husband and the members of his family?
- 7 How do attitudes in our community towards a pregnant woman living with HIV affect her chances of receiving good medical care during pregnancy and childbirth?
- 8 How do these attitudes affect the chances of a baby becoming infected with HIV from its mother during childbirth?



Key learning points

- Do not rush to judge others, for all of us have fallen short of the glory of God and sinned in many ways. (See Romans 3:23–24).
- Women are often blamed for the spread of HIV because they are often the first to discover their HIV positive status, but they may well have contracted the virus from their husband/partner.
- As Christians, we have a responsibility to lead efforts to challenge stigma, discrimination and denial.
- If people living with HIV suffer from stigma in the community, they may not receive the healthcare they need, particularly during pregnancy and childbirth.

+

Prayer points

• Give thanks that Jesus came into the world to save it, not to condemn it. We all need to be saved, just like this woman, in order to begin a new life.

Further passages for reading:

John 4:1–26 Jesus and the Samaritan woman

John 5:1–15 Jesus heals a paralysed man

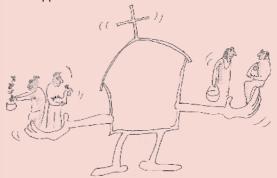
Practical action for churches

Below is a list of suggestions for how churches might respond after going through the Bible study.

What can the local church do to promote safe and healthy lives?

The church can play a key role in ensuring individuals and families have safe and healthy lives. This means looking at all aspects of life including health, education, emotional development and income generation.

Where there are individuals or groups living with HIV, the church can help them to have a life that is productive and fulfilling, and one that can even contribute to an improvement in their physical health. Key initiatives such as home gardens, which enable people living with HIV to grow their own food, are one area where the church could help. The church could also mobilise volunteers to provide home-based care: visiting the sick on a regular basis to provide physical, emotional and spiritual care and support.



'Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world'

UN Secretary-General Ban Ki-Moon What can the local church do to address stigma and discrimination?



As long as stigma exists, people will be afraid to ask and learn about HIV and they will not come forward to access testing and treatment services. They will live in fear and isolation.

Churches need to consider if they have played a part in creating stigma around HIV. If this has been the case, they may need to work hard to reverse this and deal with the root causes of stigma. Below are some ideas for tackling this issue:

- Provide training for key leaders and church members on understanding and tackling stigma and discrimination.
- Ensure the participation of people living with HIV in church activities by first creating a supportive environment.







- Set up a support group for people living with HIV in the church and community.
- Challenge stigma when preaching and in other areas of church and community life.
- Invite other churches which have overcome stigma issues to share their stories.

What can the local church do to prevent the spread of HIV?

- Create awareness and a supportive environment.
- Understand the facts about HIV and approaches to prevention. Use every opportunity to share this with the community.
- Promote Christian values, life skills and a sense of self-worth among young people. Provide them with opportunities so that they feel motivated and strengthened to make healthy choices about their future lives and sexual health.
- Promote an understanding of gender issues and why gender inequality puts girls and women at risk of HIV.
 Promote gender equality in church activities.
- Encourage people to get tested and know their HIV status. The church leader can do the same and lead by example.

What can the local church do to promote access to treatment?

- If the health services are short of space, consider offering the church building as a testing and treatment centre for the community. Local people may feel less stigmatised visiting a church than a test clinic, especially if the church is a welcoming caring community.
- Give information on how to counsel and accompany people as they go for testing, access timely support services to treat opportunistic infections and start ARV treatment. Become treatment 'buddies', supporting people to take their medication consistently and motivating them when they are feeling low.

STAGE 2: ENVISIONING THE COMMUNITY

This section provides different tools and methods to gather information with the community and help them explore if HIV is an issue for them. This information is then analysed and prioritised by those involved to define the most important needs. The Umoja process encourages the church to build relationships with the local community as they work together.

When it comes to gathering information about HIV, the facilitator needs to understand the following points:

- In many community situations it is difficult to talk directly to people about HIV so the facilitator must look for 'proxy indicators'. A 'proxy indicator' is an indirect way of measuring the impact of an issue. On page 26 to 31 there are a number of indicators which may show you the presence and prevalence of HIV in the community.
- It is important that the facilitator follows the Umoja information gathering process and also includes the additional indicators on pages 26 to 31. This ensures that other important issues that are not HIV related do not get missed.
- 3. It is essential that the facilitator understands all the 'proxy indicators' so that he or she can facilitate confidently. In addition, it would be useful if the facilitator could train those involved in information gathering (the information gathering team) in the importance and value of the indicators. This training may need to wait until the members are more confident in their understanding of HIV and related issues.

Essential proxy indicators that may indicate HIV prevalence in a community

The 'proxy indicators' are to be applied to the situation in individual households as well as the situation in the whole community.

Migration and trading

Possible proxy indicator	Questions to ask
Main transport routes	 What are the main transport routes nearby? Do these routes bring visitors into the community? Do visitors stay overnight in the community?
Trading points	 Do people have to travel long distances to trading points? Do truck drivers or those travelling to nearby trading points stay overnight in your community? How frequently does this happen?
Presence of bars and drinking spaces	Where are the bars and drinking spaces nearest to your community?

Illness and death

Asking about work patterns before individuals became ill helps to illustrate the relative impact of illness and may relate to the vulnerability of the household.

Possible proxy indicator	Timeframes	Comments on use
Chronic illness, especially in the working age group of 24–50 years	Condition prevents individual living a normal life for periods of 3–4 weeks at a time; this occurs 2–3 times a year	 Record sex, age and type of condition This does not distinguish AIDS from other chronic illnesses
Number of chronically ill adults	Age range	 Record sex, age and type of condition This does not distinguish AIDS from other chronic illnesses
Recent death of a household member	Last 12 months	 Record actual date of death, sex, age and cause of death if possible Record if death was caused by TB
Recent death of an adult	Age range	 Record actual date of death, sex, age and cause of death if possible Try and explore what is known about the person's sexual relationships
Household member not been able to carry out normal responsibilites	For 3 of the last 12 months	 This may indicate chronic illness Clarify that the condition is not long term since birth or as a result of an accident

Orphans

Possible proxy indicator	Comments on use
Presence and number of orphans	 Age, sex and number of orphans Explore whether the orphan is originally from the household Ask if one or both of his/her parents died Specify which parent(s) died Explore if the child has lost other siblings

Livelihoods and demographics of households

Possible proxy indicator	Comments on use
Recent loss of labour in household	This is a useful indicator when combined with other indicators, for example child- headed households, elderly-headed households and chronically ill households
Changes in livelihoods	This is a good indicator for showing how stressed households look for alternative ways of generating income, some of which may be negative (for example crime, sex work or sale of drugs)
Female-headed households	A high number of female-headed households can indicate the prevalence of HIV in the community
Child-headed households	This is a good indicator for showing the long-term impact of HIV on a community. However, you need to look at the other indicators to decide on the cause
Grandparents with grandchildren	This is a strong indicator showing the change in the local population as the elderly have to take on a parenting role because of parents dying in the community
Reduced productivity	 The following are strong indicators showing the impact of HIV on the community. These could all point to a loss of labour in households: reduced land sizes reduced productivity use of small implements rather than bigger mechanisms for agriculture, which links with reduced food production



Information gathering tables

The tables below are similar to those used in the initial Umoja information gathering stage but they have been enhanced with questions that will help dig deeper to explore HIV-related issues in the community. These are to be used as a guide to community-based discussions but also as a way of documenting the information once it has been gathered. The indicators above can be integrated into these charts as well.

a) Demography

Questions and indicators for exploring HIV issues:

- 1. Numbers of widows, widowers, orphans, single mothers
- 2. Are elderly people caring for children?
- 3. Explore causes of death. Is there a trend or common pattern?
- 4. Is this pattern increasing? Decreasing?
- 5. Which age group is most affected?
- 6. Who is looking after the widows? Is there a tradition of widow cleansing that occurs in the community?
- 7. What happens to the orphans? What happens to orphans who are teenage girls?
- 8. Has land use and ownership of land changed due to individuals suffering from long-term disease?

When using the table below, it is useful to bear in mind these proxy indicators which identify possible HIV-related trends. The questions are also useful for the community to discuss once the table has been completed.

AGE	VILLAGE/TOWN Male	Female	TOTAL
0–5			
6–15			
16–21			
22–49			
50–65			
66+			
Total			

	MALE	FEMALE	TOTAL
Widows			
Widowers			
Orphans			
Disabled			
Single mothers			

b) Household information

Questions for exploring HIV issues:

- 1. How many households have orphans from other relatives or families?
- 2. How many single-headed households are there? What are the challenges for these households? What future risks might they face?
- 3. How secure is their food source?
- 4. What coping strategies do they use? How does the wider community support them?

	Total	Average size of household
Male-headed households		
Female-headed households		
Total		



c) Common diseases

Questions for exploring HIV issues:

Section 1 – Is HIV mentioned? If so, explore how it is affecting the community and how the community is responding to it:

- 1. Which group is most affected?
- 2. What is the prevalence in the general population? In antenatal clinics?
- 3. What is the prevalence of sexually transmitted infections (STIs) and other opportunistic infections like tuberculosis (TB)?
- 4. What is the average age of men/women with HIV?
- 5. What are the current attitudes and responses in the community?
- 6. Can you get data about HIV infections from the antenatal clinic and health facility where they do blood screening and testing for HIV?
- 7. Can one access antiretroviral (ARV) treatment?

Section 2 – TB is a proxy indicator for HIV infection. Ask the questions in Section 1 again, replacing TB for HIV.

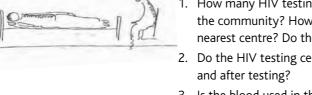
Disease	Category of people affected	Number affected in the last 6 months	Effect in the community

d) Health services

Questions for exploring HIV issues:

- 1. How many HIV testing centres are there in or near to the community? How far from the community is the nearest centre? Do the testing centres do CD4 tests?
- 2. Do the HIV testing centres provide counselling before and after testing?
- 3. Is the blood used in these centres screened for HIV?
- 4. Do the health centres use new/sterilised needles?
- 5. What sort of ongoing support is there in the community?
- 6. Where in the community can you buy condoms?
- 7. Is there access to treatment for HIV (antiretrovirals)?
- 8. What are people's attitudes to voluntary counselling and testing (VCT)? If negative or fearful, how could this be addressed?
- 9. How is VCT promoted in the community?

Facility	Number	Where located	Distance from village	Who owns/ controls
Hospital				
Health centre				
Dispensary				
Mobile clinic				
Private clinic				
Village pharmacy				
Doctor				
Nurse				
Clinical officer				
Community health worker				
Trained traditional birthing attendant (TBA) ¹				



¹A trained TBA has an understanding of complications that can occur during birth and is able to take pregnant mothers to hospital when required.

Facility	Number	Where located	Distance from village	Who owns/ controls
Untrained TBA				
Registered herbalist				
Unregistered herbalist				
Traditional healer Witch doctor				

e) Education

Questions and issues around HIV:

- 1. Find out the primary and secondary school attendance rates in the area.
- 2. Track the age of children, especially girls, attending primary school. Explore at what age they drop out of school and why.

Reasons for school drop-out are an indicator of some issues, for example early marriages (often to older men), sexual initiation at a young age or sickness in the family (the child may be forced to drop out of school to take on the burden of care). Sometimes it may be that the child is ill due to HIV.

- 3. Is HIV discussed and taught in both primary and secondary schools?
- 4. What forms of support and education take place among children?

Class	1	2	3	4	5	6	7	8	9		
	Primary school 1										
Male											
Female											
Total											
	Primary school 2										
Male											
Female											
Total											

5. Are schools open to educating children with HIV?



STAGE 3: PLANNING FOR ACTION

'They made me realise that I can experience love again. They listened and prayed with me, and then they campaigned for me, writing letters, talking to all the important people on my behalf. It has made me feel part of the world community of God.'

Doris, a Zimbabwean living with HIV in London

If HIV is a priority for the church and community, the next stage is to plan a response. If the church and community do not yet feel confident in addressing HIV-related issues, the facilitator can continue with the initial Umoia process and re-evaluate the situation after those involved have built up their confidence.

In planning a response, it is important to bear in mind that the first step is to educate the church and community and enable them to include and support people living with HIV.

Changing attitudes is a big challenge and cannot be done as a 'project' but more through teaching, creating space for open discussions and reflecting on what it is like to live with HIV. The following checklist is a useful guide to looking at the attitude of the church and can help to identify areas which need to be changed.

When there is a positive attitude and a supportive environment, the church and community are able to respond effectively to HIV-related issues, addressing the most important needs that have been identified at the time. The action plan at the end of this section will help guide the planning of any response.

The local churches working with their community need to look at what resources already exist in their community; these resources can help decide what action points they could begin with. The resources could be financial, physical or more abstract such as an individual's time. It is also very important to involve the government and other groups involved in HIV in the community. Below are a few ideas of what the church and community could do together to address HIV-related issues.

A) WHAT LOCAL CHURCHES AND COMMUNITIES CAN DO TO HELP PREVENT THE SPREAD OF HIV Information



Make sure that everyone understands the facts about HIV and the common approaches to prevention.



- Analyse the context and vulnerabilities of different people groups in the community by age, gender and education etc. For example, there are differences in vulnerability and HIV risk between: girls and boys, orphans and children with families, and children living in a home or living on the street.
- Discuss the impact of relationships between the various groups and the unequal power different groups have to protect themselves. Share this understanding and insight with youth groups and the wider community.

Training and equipping others

- Provide teaching on prevention and promote inclusion of those on the edge of community. Ensure this does not lead to the stigmatisation of people living with HIV.
- Provide training on how to make right choices regarding life skills, sexual health and healthy living.
- Share facts using materials produced by the health services or organisations with a good reputation.
- Ensure that people can raise questions and express doubts.



Actions that can be undertaken

- Encourage individuals to think about how they can respond to HIV-related issues in the community.
- Link with local NGOs and government organisations promoting HIV education and behaviour change programmes.
- Work with parents, guardians and other leaders in the community to create a supportive environment for people, especially for those who are most vulnerable.
 Ensure they are not left out and develop services that reach out and engage with them.

B) WHAT CHURCHES AND COMMUNITIES CAN DO TOGETHER TO END STIGMA AND DISCRIMINATION



Information

Invite the health service and other agencies working in your area to do media campaigns and training in the community.

- Make information on rights available to people living with HIV, with advice and practical support if they have been discriminated against. Where possible, this may be through independent advocacy services or by referral to other agencies such as legal services, human rights organisations and unions.
- Provide public opportunities to discuss HIV and address fears and wrong ideas about how people are infected with HIV.



Training and equipping others

- Access and distribute information about HIV and AIDS and associated services so that people know the facts.
- Train church and community leaders and members in ways of challenging stigma and discrimination and explore theology that is inclusive of marginalised people.
- Encourage people to lead by example: getting themselves tested and speaking out against stigma and discrimination in the church and community.

Actions that can be undertaken

- Ensure active participation of people living with HIV at all levels of church and community activities.
- Encourage community involvement in education on HIV transmission, care and support and stimulate discussions on stigma and its consequences.
- Develop partnerships with the health services or NGOs to ensure services reach the people who need them.
- Facilitate the setting up of a support group for people living with HIV in church and the community.
- Provide support to people who have suffered from discrimination, which may include peer support (in groups or one to one), counselling and referral to housing, employment, schooling, social and other related services.
- Support the development of community-based initiatives that will help provide food and better livelihoods for the most vulnerable families.

C) WHAT CHURCHES AND COMMUNITIES CAN DO TO PREVENT MOTHER (PARENT)-TO-CHILD TRANSMISSION (PMTCT/PPTCT) OF HIV

Information

- Learn about the issues of HIV PMTCT/PPTCT, caring for the health of mothers and babies, and treatment beyond delivery (if needed). Get advice on breastfeeding and HIV testing of babies.
- Find out how local government, church, health services and NGOs provide support to mothers and families in accessing these services.
- Provide expectant mothers and fathers with information on the need for testing to enable them to give their babies the best protection from HIV.

Training and equipping others

 Train key leaders and church members in PMTCT/PPTCT so that they themselves know what to do, can inform others and provide counselling and accompaniment to mothers and fathers through pregnancy and after delivery.

Actions that can be undertaken

 Set up a network of women willing to befriend and accompany mothers through their antenatal checks and testing, continuing to the post-natal period to promote the health of mother and baby. Such counselling must remain confidential.

Set up a support group for fathers to promote their responsibility for protecting both mother and baby from HIV, including through sexual faithfulness. This will help to avoid the father infecting the mother during this period. Discuss ways in which both parents can support one another and deal with negative attitudes within the wider family.

Support communities or lead advocacy initiatives if access to services is limited or non-existent.





D) WHAT LOCAL CHURCHES AND COMMUNITIES CAN DO TO PROMOTE ACCESS AND ADHERENCE TO TREATMENT

i

Information

- Link with local government, church and NGO health service providers to understand the issues around HIV testing, treatment and living healthily with HIV.
- Share any available material that explains treatment issues and provides information about where to access it. Often this material can be displayed in public spaces.

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Training and equipping others

- Get training for key leaders and church members to understand the importance of ART (antiretroviral treatment).
- Enable them to counsel others on ART, especially equipping them with skills to help discordant couples (couples where only one person has HIV), people who are preparing to get married etc.
- Train volunteers on appropriate and ethical approaches to informal counselling, including the importance of confidentiality, but stress that pre- and post-test counselling is best given by trained people.

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Actions that can be undertaken

- Set up a post-test club in church for those who test positive so they can support each other and learn more about healthy living.
- Establish a network of volunteers, including people who are living with HIV, to encourage and accompany people during testing.
- Set up a network to give care and support to those living with HIV, especially to help them access treatment for any associated illness and to adhere to the regular regime of ART (if available).
- Work with the community to advocate for testing and treatment if such services are limited or unavailable.
- Find out whether people on ART have enough food. If not, set up community gardens to improve nutrition.

E) WHAT LOCAL CHURCHES AND COMMUNITIES CAN DO FOR THOSE LIVING WITH OR AFFECTED BY HIV



Information

 Focus on those who are most vulnerable in the community, not just people affected by HIV. This is a more inclusive and effective response.



Training and equipping others

- Access training for church leaders and members to understand the needs and issues faced by people with HIV and their families.
- Understand the guidelines for providing good care and support to those living with or affected by HIV.

Actions that can be undertaken

- If children are involved in caring for sick members of their family, the church can consider practical ways to help them continue their education. This may include one of the following options:
 - negotiate with the school to waive school fees
 - set up a fund to pay for the school fees
 - establish informal classes for literacy and numeracy which run at a suitable time for children to attend
 - Provide palliative care services by referring those who are unwell to a health service and ensuring they get access to pain relief.
- Encourage and invest in income-generation activities that will bring resources to the affected families.
- Mobilise a network of volunteers to provide effective care and support to individuals and families in the community who are living with and affected by HIV. They can provide practical support, such as help with food and healthcare, but also vital psycho-social support, offering love and counselling.
- Provide extra support to the most vulnerable, for example to households headed by children or the elderly.









- Gather resources, such as clothes, food and household items, for distribution to vulnerable families. You can also use local skills such as repairing homes or growing vegetables to help these families.
- Consider community-wide responses, such as a communal garden for providing healthy food to the sick and vulnerable. Use gardening methods that are sensitive to the physical limitations of people living with HIV.
- Consider joint saving schemes (groups saving small amounts of money each week, enabling a different group member every week to receive some money every week) to provide opportunities for financing an income-generating activity.

Action plan

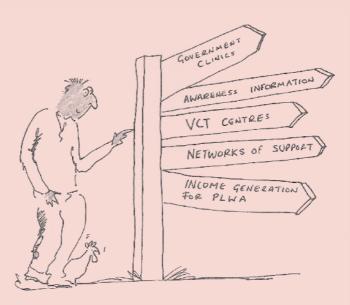
Once the church and community have decided on an issue they can address, they need to develop an action plan. The following questions will help them to do this. For more details on this, see the minibus exercise in the *Umoja Facilitator's Guide*, pages 118–120.

Plan	Details
Which HIV issue do we want to address?	
What do we want to do to address it?	
What resources do we have?	
How are we going to do it?	
Who do we need to participate?	
What could prevent us from starting the project?	
What could get in our way once the project has started?	
When are we going to start?	

STAGE 4: TAKING ACTION

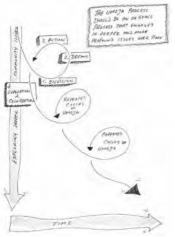
For this stage, please refer to the 'Taking Action' section in the Umoja manual which provides you with tips and ideas to help you with the day-to-day running of a project. For example, in that section there is material on how to delegate, how to value volunteers, how to stay motivated and motivate others and how to have an effective meeting. These are all essential skills for any church and community involved in HIV and community work.

This booklet is an additional resource to support the existing Umoja process. As you go through the material, you may have further need of specific information and training on HIV. If so, we recommend you to contact your local government health department and local NGOs for support and information.



PLWA stands for 'people living with AIDS'

STAGE 5: EVALUATION



Introduction

For this stage, please refer to the 'Evaluation' pages in the Umoja manual. Most of the principles and practical details are covered in that section. However, it is important to note that you need to include any proxy indicators that you identified in your evaluation of your HIV work.

Umoja is run as a series of cycles during which the church and community gain confidence in addressing issues in their community. At the end of each cycle the church and community reflect together on what they have learned and what has changed, as well as exploring new opportunities and issues they can take on. In the case of HIV, the first cycle may just address some basic issues of awareness and education. In future cycles, a more confident church and community may decide to equip themselves to tackle more challenging issues such as stigma and discrimination or cultural beliefs and practices.

Self-evaluation tool

The following table is designed to help churches and communities assess their level of knowledge and response to HIV work. Once scores have been entered into the table, the church and community can then discuss areas that need to be strengthened and improved. There are no right or wrong answers, however: please answer truthfully. This section can be revisited every few months to map progress and to reflect on how the church and community have changed over time.

Key areas	Score 0	Score 1	Score 2	Score 3
Understanding of HIV	There is no understanding	Know some basic facts	Good understanding	Able to teach and train others
Teaching, preaching and prayer on HIV	None	Mentioned occasionally	Regular reference to HIV	Well established pattern of focused support and awareness-raising
Leadership	No interest whatsoever from leadership	Leaders have some understanding	Leaders actively promote and support any HIV- related issues	Leaders are actively involved in raising awareness in other churches and the community
Inclusion of people with HIV	No interest in including people with HIV	There is an awareness of people living with HIV but little attempt to include them in activities	Active inclusion of people living with HIV in activities	People living with HIV are actively involved in leading activities and events
Care and support	None	Awareness of people who may need support but little support is given	Fully recognise the need to support people living with HIV and affected by HIV. The support is given when needed	Have established support groups and initiatives to support people living with HIV and those affected by HIV
Prevention	No HIV prevention	The basic facts of HIV prevention are known	Full recognition of the need for prevention strategies and active promotion of them	Prevention strategies are promoted and taught in the church and throughout the community
Testing and treatment	No testing or treatment	Some knowledge of where testing and treatment can be accessed	Widespread understanding of the value of testing and treatment and where they can be accessed	People living with HIV are accompanied to testing and treatment and fully supported

USEFUL RESOURCES

The following free toolkits are available for more specific information on running different types of projects. All these are available from www.tearfund.org/tilz

- Palliative care: how to provide end-of-life support to people living with HIV
- Sustainable Livelihoods A toolkit is available for use enabling individuals and communities to understand their local assets and how they can achieve a sustainable livelihood
- Prevention of Parent to Child Transmission (PPTCT) A toolkit called Guardians of Our Children's Health (GOOCH) is available for churches and communities to help prevent transmission of HIV from parent to child.
- A toolkit called *Let your light shine* is available for guidance on working with children affected by HIV.
- Footsteps 69 Tackling taboo subjects
- ROOTS 4 HIV and AIDS
- PILLARS Responding more effectively to HIV and AIDS

Resources for general topics

- Hand in Hand Bible studies
- Gender Toolkit (currently being developed)
- Channels of Hope (a World Vision Toolkit)

It will be very helpful to have some of these resources available within your church and community.

Guide to further resources

The Child-to-Child Trust

Website: www.child-to-child.org Email: ccenquiries@ioe.ac.uk Address: Institute of Education, 20 Bedford Way, London, WC1H 0AL, UK

The Child-to-Child Trust's website provides information about child-friendly approaches to health promotion. It contains a useful directory of all known projects using these approaches around the world, as well as an annual international newsletter and new publications on Child-to-Child activities for preventing and coping with HIV and AIDS.

International HIV/AIDS Alliance

Website: www.aidsalliance.org Email: publications@aidsalliance.org Address: International HIV/AIDS Alliance (Secretariat), 1st and 2nd Floor, Preece House, 91–101 Davigdor Road, Hove, BN3 1RE, UK

The mission of the International HIV/AIDS Alliance is to support communities in developing countries to play a full and effective role in the global response to HIV and AIDS. All Alliance publications can be found on its website and downloaded as PDFs or viewed as plain text.

ACET (AIDS Care Education and Training) Uganda

Website: www.acetug.org Email: acet@acet-uganda.org Address: PO Box 9710, Kampala, Uganda

ACET provides training and support to a range of NGOs in Uganda and other areas of Africa, especially in life skills-based education and promoting communication between children and their parents and guardians.

TALC (Teaching-aids at Low Cost)

Website: www.talcuk.org Email: info@talcuk.org / e-talc@talcuk.org Address: PO Box 49, St Albans, Herts, AL1 5TX, UK

TALC distributes books, presentations and accessories relating to health and community issues to health workers throughout the world. The website includes a full list of TALC materials including titles related to HIV and AIDS. Its electronic publishing division, e-TALC, produces and distributes CD-ROMS that contain large quantities of up-to-date health and development information.

UNAIDS (Joint United Nations Programme on HIV and AIDS)

Website: www.unaids.org Address: 20, Avenue Appia, CH-1211 Geneva 27, Switzerland

UNAIDS has published an extensive range of materials on a variety of topics related to HIV and AIDS. Most of these, and other HIV and AIDS related titles published by other organisations in the UN system, are contained in a bibliographic database that can be searched by title, author, keyword, ISBN, topic, language and global area.

APPENDIX

A checklist of community awareness and response

Use the tick boxes below to assess your response to HIV. What are you currently doing and what would you like to improve? It is important to involve people who are living with HIV in these discussions.

Acknowledgement and recognition		
1	We know the basic facts about HIV – how it spreads and its effects.	
2	We recognise that HIV is more than just a health problem.	
3	We recognise that HIV is affecting us as a community and we discuss it among ourselves.	
4	We acknowledge openly our concerns about and the challenges of HIV. We seek others for mutual support and learning. We seek HIV testing for individuals.	
Ном	v can we improve our acknowledgement and recognition of people with HIV?	

Inclu	sion of people living with HIV	Tick
1	We are aware of people living with HIV.	
2	We co-operate with some people who help us understand the issues.	
3	We actively encourage initiatives to support people living with HIV.	
4	People living with HIV in our church or community are actively involved in leadership and in planning our response.	
Ном	v can we be more inclusive of people living with HIV?	

Care and prevention Tick		Tick
1	We communicate messages about care and prevention to the community.	
2	We look after those unable to care for themselves (sick, orphaned, elderly).	
3	We discuss the need to change behaviours. We take action because we need to and we have a process to care for others in the long term.	
4	As a community we initiate comprehensive care and prevention activities.	
Hov	v are we caring for people living with HIV and helping to prevent others becoming ill?	

Access to treatment		
1	We know very little about treatment and do not know anybody who is on antiretroviral treatment (ART).	
2	We know where treatment can be accessed.	
3	We find out if there are any in our local community who struggle to access treatment and we support them.	
4	We talk openly about HIV testing and treatment and will accompany and advise any in the community who wish for help.	

Identify and address vulnerability Tick		Tick
1	We are aware of the general factors associated with why people are vulnerable to HIV.	
2	We understand the specific factors which make people vulnerable in our communities.	
3	We have a clear approach to support and protect those who are vulnerable.	
4	We are addressing vulnerability in other aspects of the life of our community.	
How can we improve the way we support vulnerable people?		

Tackling stigma and discrimination Tick		Tick
1	We are aware that there is a general problem about HIV stigma and discrimination.	
2	We have reflected on our own attitudes and behaviour and seen where we can transform these.	
3	We actively tackle HIV stigma and discrimination and are recognised as a welcoming and open church for those living with HIV.	
4	We address other issues of stigma and discrimination which exclude people from the life of the church and community.	
What other steps can we take to remove the effects of stigma and discrimination?		

GLOSSARY

The glossary explains the meaning of certain words according to the way they are used in this book.

advocacy/to advocate	speaking out about an issue to those in power with and on behalf of others
AIDS	Acquired Immune Deficiency Syndrome
antiretroviral therapy (ART)	using special drugs that slow down the development of HIV and AIDS
blood transfusion	the transfer of blood from a healthy person to somebody who has lost some of their own blood as a result of an accident, illness or an operation
buddy	a friend or supportive person who encourages you to take your medication every day
circumcision	to cut away skin from the sexual organs of boys and girls
condom	a fine rubber covering worn over the penis during sex to prevent pregnancy or infection. Female condoms, which fit inside the vagina, are becoming increasingly available
discordant couple	a relationship between two people, one of whom is living with HIV and the other of whom is free of HIV $% \mathcal{A}(\mathcal{A})$
discrimination	when one group of people is treated worse than others because of prejudice or incorrect information
facilitator	a leader who encourages others to share their knowledge, experience and thinking so that people can learn through sharing together
female genital mutilation	the practice of circumcising young women which involves removing of the sex organ
gender	the social differences between men and women, or boys and girls, that are learned (rather than the sexual differences which are biological)
HIV	Human Immunodeficiency Virus
monologue	when the character (eg in a play) is speaking his or her thoughts aloud, directly addressing another character, or speaking to an audience
orphan	a child under 18 who has lost one or both parents
participants	people taking part in any kind of activity
penis	the male sex organ, also used to pass urine
proxy indicators	an indirect way to highlight an issue. This can be used if there are no direct ways of measuring the impact of this issue. For example, in a desert the presence of trees/ bushes highlights that there is a water source nearby, even if you cannot see the water
rape	forcing a person to have sex against their wishes
ritual	a well established pattern of behaviour or religious practice
sex	in this book, sex means penetrative sexual activity: the act of placing a man's penis inside a woman's vagina or person's anus, resulting in the exchange of bodily fluids
stigma	a feeling of being socially unacceptable, resulting in isolation, rejection and shame
taboo	a subject that is rarely discussed for social or cultural reasons
virus	a microscopic parasite which can be spread among people



www.tearfund.org/tilz

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