This section looks at the practicalities of implementing HIV testing for individuals. It discusses essential requirements, how to provide services if resources are limited, counselling for voluntary HIV testing and HIV testing of particular groups.

### 4.1 Requirements for testing individuals

HIV testing for individuals should only be carried out if certain essential requirements can be met, and if the capacity exists to provide effective, high quality services.

**Essential requirements of HIV testing**

These include pre-test counselling, post-test counselling, informed consent and confidentiality.

- **Pre-test counselling** must be given before HIV testing, to enable people to make an informed choice about whether to take the test.
- **Post-test counselling** should be provided after the test result is known, whether the result is positive or negative. Post-test counselling is essential to help those with HIV to cope and to live positively, and to advise those whose result is negative about how to prevent future HIV infection.
- **Informed consent** means that a person agrees to be tested and has a clear understanding of what the test involves, the advantages and disadvantages of testing, and the implications of a positive or a negative result. The person must show that they have understood that an HIV test will be carried out, and agree to this. The decision to take a test must be made by the person, without pressure or coercion from anyone else. If a doctor or counsellor makes the decision on a person’s behalf, this is not informed consent.
- **Confidentiality** means that information about a person is not passed on to anyone else without that person’s permission. Counselling, testing and test results must be confidential.

People are better able to discuss their feelings if they know that the counsellor will not tell anyone else without their permission. Breaking confidentiality can destroy a person’s confidence and trust in their...
counsellor or doctor, and expose them to discrimination and prejudice. In some countries, programmes are developing approaches to confidentiality, such as shared confidentiality (see Section 4.7), that may be more appropriate to the local culture and situation.

CONCERNS ABOUT CONFIDENTIALITY

A health worker in Tanzania, when asked about HIV testing, replied, "This question frightens me. Maybe I would go to a hospital some distance away for testing as I am nervous about confidentiality in spite of reassurance." Another health worker also said that she would not trust people in the hospital to keep her result confidential, and for that reason would not be tested.

Capacity to provide HIV testing

Ideally, voluntary counselling and testing services should be part of a continuum of care, linked to referral and support services. However, in practice, this often does not work well or breaks down at particular points – for example, between traditional and modern health systems, between hospitals and home-based care programmes. It is important to ensure that referral and support systems are in place before establishing voluntary HIV counselling and testing services.

The following questions can be used to find out whether there is the capacity to implement voluntary, confidential HIV counselling and testing, as part of a comprehensive programme of prevention and care.

Technical capacity

- Is there a regular, reliable and sufficient supply of HIV tests?
- Is there an appropriate testing strategy, including confirmatory testing of positive results?
- Are high-quality testing and laboratory procedures in place to ensure accurate results?
- Are quality control systems in place to identify and correct technical and clerical errors?

Staff capacity

- Are experienced health staff available who can take blood samples and who are trained to follow universal precautions?
- Can adequate training for counsellors be provided?
- Are enough trained counsellors available to provide pre-test and post-test counselling?
- Is there the capacity to provide support to health workers and counsellors?
- Are there laboratory staff trained in how to carry out the tests?

Capacity for treatment and care

- Is medical treatment available for people diagnosed with HIV?
- Can people who are diagnosed with HIV be referred for care and support?
- Is there family or community support for people with HIV?

Administrative capacity

- Is there adequate space for confidential counselling and testing?
- Does the capacity exist to maintain proper records and systems to ensure confidentiality, and to make sure that people are given the correct results?
- How will the quality of counselling and testing services be monitored?
- Can supplies, transport and storage be ensured?
- Is there a system for safe handling and disposal of contaminated needles and syringes?

Financial capacity

- Are there enough funds to set up services, including training and improving laboratory infrastructure?
- Are there enough funds to cover recurrent costs, such as purchase of tests and any additional staff salaries?
- Are there enough resources to run a comprehensive programme that includes education, follow-up counselling, care and support?

4.2 Situations with limited resources

In situations where the capacity for counselling and HIV testing is limited, services have adopted different strategies to ensure that resources are used effectively. These are some examples:

- Limit testing to situations in which a positive diagnosis will result in different treatment and clinical management – for example, offering counselling and tests to pregnant women if interventions are available to reduce mother-to-child transmission, or to all adults who may be exposed to TB if tuberculosis preventive therapy is available for HIV-positive people.
- Use counsellors to provide information to groups, in order to reach more people, educate communities and encourage greater acceptance of people with HIV, especially where the number of trained counsellors is limited, or in places where it is not possible to provide effective individual counselling. Experience has shown that a lot of basic information about risk reduction and safe behaviour that is relevant to everyone can be provided in a group setting, using videos, for example. However, if people choose to have an HIV test, they should have individual pre-test counselling to be able to discuss issues in confidence.
- Train existing health workers to provide people with basic information about HIV transmission, prevention and testing, using trained counsellors, peer educators and post-test clubs or support groups, to help people make decisions about testing and to provide post-test counselling.
- Consider charging for voluntary HIV tests, making sure that people can afford them.
COST OF TESTING AND COUNSELLING

Cost affects whether or not people seek counselling and testing. If charges are made for services, it is important to get the level of fees right. In Tanzania, the number of people using the Muhimbili centre fell when a fee of $3.00 was introduced. The numbers of people seeking tests increased again when the fee was halved. In Kenya, the fee of $0.35, which most people could afford, made little difference to the number of people seeking tests. YRG Care in India charges different fees for an HIV test, depending on people’s ability to pay. Higher payments subsidise the cost for people who are on a low income.

4.3 Counselling for voluntary HIV testing

HIV counselling is a confidential dialogue between a person and a counsellor. A counsellor is someone who is trained in the skills required and who has the personal qualities for the job. Counsellors need to have listening skills and to be able to explain things clearly. They should be non-judgemental, emotionally stable, able to respect the rights and dignity of others, and able to keep information confidential. A counsellor’s role is to listen and ask questions, and to provide relevant information, practical suggestions and emotional support.

It is important to understand what counselling aims to do, what it requires, and what training and support counsellors need.

What counselling is

HIV counselling aims to:
- help people to cope with their reactions to HIV infection and with any stress, fears and concerns they may have
- find realistic ways to solve problems
- help people make informed decisions
- protect others from infection.

Counselling is not about giving advice or telling people what to do. An effective counselling service requires:
- careful selection of counsellors
- training that includes supervised placement after initial training and follow-up training after a period of work experience
- support to retain trained counsellors and prevent burnout
- enough space to provide a confidential setting for counselling
- convenient opening times and easy access for people seeking counselling
- links to referral systems for medical treatment, family planning and other health care
- provision of condoms
- capacity to refer to services that provide ongoing care and support, including self-help groups, further counselling, legal services, and social support.

Training and support for counsellors

Good training is the most important factor in good counselling. Counsellors need good initial training, as well as regular refresher training and follow-up support to help them cope with their work. In many countries with limited resources, counselling training is done in one or two days or is of poor quality.

Counselling training should enable counsellors to:
- explain the facts clearly and simply and provide appropriate information
- discuss sexuality and sex in a non-judgemental and open way that encourages people to talk
- listen and give people time to voice their concerns
- understand the person’s situation
- give psychological support
- help a person to make realistic decisions and adjust to change
- establish trust
- understand about confidentiality and explain to people how confidentiality will be maintained.

Counselling training should involve several training sessions or workshops, spread over a period of time, that enable participants to practise the skills needed for good counselling, including exercises to explore their
Supervisors must make sure that counsellors are allowed time to meet with each other and reflect on their experience, and that they receive recognition for the work they are doing.

Health workers and counsellors themselves may be worried about or have HIV and need counselling. As the head of counselling at one Ugandan hospital noted, ‘Of 20 counsellors here, three are infected and two are suspected of being infected’.

4.4 Pre-test counselling

Individual pre-test counselling is mainly carried out to help a person make an informed decision about whether to take an HIV test. Pre-test counselling aims to:

- provide information about HIV and AIDS, HIV transmission and risk behaviour
- assess whether the person might have been at risk of HIV infection
- provide information about the HIV test and how it works
- explain about the window period
- explore the possible advantages and disadvantages of taking a test
- discuss the implications of a positive test result for relationships, employment and future health
- explain how confidentiality will be maintained
- assess the person’s ability to cope with a positive result, including the emotional and practical support available to them
- explore the possibility of shared confidentiality – sharing their test result with their partner, a friend or close relative
- provide information about services available to people with HIV
- discuss the implications of a negative result and prevention of HIV infection
- give the person enough time to consider whether or not to take a test
- obtain informed consent, if the person decides to take a test.

In some places, counsellors have found it useful during pre-test counselling to ask a person why they want to take a test and what they expect the result to be. This can help the counsellor to see how the person will cope with the result.

Assessing whether the person might have been at risk of HIV infection involves sensitive discussion of possible exposure to HIV and consideration of the following risk factors:

- unprotected sex with multiple sexual partners, or, for men, sex with other men
- non-sterile skin piercing
- blood transfusion
- intravenous drug use
- risk behaviour of sexual partner or spouse
- occupational risk, such as needlestick injuries.

**SELECTING, TRAINING AND SUPPORTING COUNSELLORS**

People in Tanzania, asked what qualities they would seek in a counsellor, mentioned warmth and genuineness, empathy and acceptance, and the ability to keep secrets.

In Malawi, counsellors said they needed regular upgrading of knowledge and information. They also wanted to discuss problems related to lack of cooperation between counselling and other health services, lack of privacy for counselling, lack of condoms to give to clients, handling aggressive patients, involving partners and other family members in counselling, stigma, and community mobilisation.

own values, fears and prejudices. Training should be practical and participatory, using a mixture of methods such as group exercises, role plays, demonstrations, short talks and visual aids.

During and after training, regular supervision and the opportunity to work together with an experienced counsellor are essential to help trainees to practise their new skills and deal with their reactions to counselling.

Counsellors often experience stress, sadness, low morale and burnout as a result of heavy workloads, fear of infection, the pressure of dealing with people’s problems, not being able to solve these problems because of limited resources, and coping with illness, pain and death.

Counsellors also often worry if clients deny their result or fail to change their sexual behaviour. Counsellors need help to recognise the influence of culture and community attitudes on people’s behaviour, and to find ways to try to overcome problems associated with these influences, without blaming themselves. Support groups for counsellors can help, allowing them to discuss problems, talk about their feelings of anger, stress and sadness, share new ideas and information, provide feedback, and discuss how to organise counselling services.

**HEALTH WORKERS WITH HIV**

‘My partner died six years ago. Before he died I counselled him and encouraged him to take an HIV test. He agreed but suggested that we both take a test. We visited a counsellor. Unfortunately we were both diagnosed HIV positive. The counselling we received then and afterwards helped us to accept the situation. Since that time I have faced problems both as a person and as a health worker. I am worried about my health and losing my job. When I see the suffering of people with AIDS I see what awaits me in the future. I worry about what people say about me, about losing my independence and about what will become of my family and dependants.’

Ugandan health worker
In some countries, group or community counselling has been used successfully to inform people about the test and the implications of being tested. However, group counselling is not appropriate for people to make decisions. Decisions should be made in private and confidential situations, to ensure that there is no pressure put on an individual.

Like individual counselling, community counselling is a dialogue, with communities learning new information and ways of behaving, and health workers learning about the social and cultural context of HIV prevention and care. Programmes based on community knowledge, priorities and resources are not only more effective, but also less expensive than other approaches.

Community counselling may be able to address issues that individual counselling cannot. In one area of Uganda which is badly affected by HIV/AIDS, counselling services need to take account of the needs of adolescents and children with HIV, who may be left to look after younger brothers and sisters, and of the worries and concerns of grandparents left to care for young children.

### WHY DO PEOPLE SEEK TESTING?

The Kara Counselling Centre in Zambia and the AIDS Information Centre in Uganda found that people wanted to find out their HIV status for reasons including: planning for marriage, planning for the future of their families, mistrust of their partner, having a partner with HIV symptoms or risk, having HIV-related symptoms and wanting to take better care of their health.

### APPROACHES TO COUNSELLING

ESPOIR, an NGO in Côte d’Ivoire, runs the Centre for AIDS Information and Prevention – a free, anonymous and voluntary counselling and testing service. First-time visitors receive a warm welcome from the receptionist. People are never asked their name or address but are given a number to ensure that they remain anonymous.

Pre-test counselling sessions last 30-45 minutes, because ESPOIR has found that proper pre-test counselling helps to reduce the shock of a positive result later, as well as helping people decide whether they really want to have the test. Clients are given their results almost immediately, because the centre has found that people are anxious to know. Post-test counselling emphasises living positively with HIV and suggests ways to avoid unsafe sex, as well as putting HIV-positive people who are interested in touch with a group of people with HIV.

The Ulam centre in Arusha, Tanzania, provides voluntary counselling and testing services. People often find out about the service through word of mouth or community volunteers. Following an initial discussion, people receive three pre-test counselling sessions. Children and people who are obviously ill with HIV-related symptoms are not tested. The centre carries out three HIV tests on each sample, using different laboratories if there is likely to be any doubt about the result.

Confidentiality is guaranteed by using a code number. Information about test results is not given to anyone without the consent of the person concerned. People are encouraged to share their result with someone and to bring that person for counselling before the result is given, but, if the person is reluctant, the counsellor does not insist on this.

One programme in Zambia that provides counselling for clients in hospital and provides home-based care has developed over time, as local needs have changed. Originally, a group of nurses, doctors, a nun and a laboratory worker provided hospital-based counselling. At first the hospital was not convinced that counselling was important. However, staff began to notice that counselling not only helped patients and their families, but also made it easier to discuss HIV/AIDS in the hospital wards.

Some of the counsellors then began offering home-based counselling and support to patients after discharge from hospital. Soon the counsellors realised that they needed to involve community health educators and other community leaders and service providers – such as teachers, churches and social workers – in organising and providing ‘counselling’ for whole communities. This helped communities to learn about HIV/AIDS as well as helping the counselling team to learn about community customs, needs and resources.

Links between health centre staff and communities are strengthened through regular visits. The provision of care and support, with the involvement of the community, has made it easier to develop prevention activities.

A counsellor in Côte d’Ivoire, offers a warm welcome.
4.5 Post-test counselling

HIV test results should always be given with post-test counselling, whether the result is positive or negative. Post-test counselling aims to:

- support the person who has been tested
- reduce the spread of HIV, through discussion of the result, sharing information, providing support and encouraging future safer sexual behaviour.

The specific objectives of post-test counselling depend on whether the test result is negative or positive.

When the test result is available, the person (or couple if both were tested) should be asked first if they wish to know their result. They should also be told that, whether or not they wish to know the result, it will be kept confidential.

Counselling for a negative result

When the result is negative, the counsellor needs to:

- deal with the feelings arising from the result
- discuss prevention of HIV infection.

Although the person will be relieved about a negative result, the counsellor needs to explain that, because of the window period, this may not necessarily mean that the person is not HIV infected. The counsellor should suggest the person considers returning for a repeat test after 3-6 months. Prevention of future infection and information about safer sex and condoms can also be discussed during post-test counselling.

Counselling for a positive result

There is no right way to tell a person that they have a positive result. It depends on the individual and the culture, and everyone reacts differently. How to disclose test results should be a regular training topic for counsellors, using real life examples. Counsellors can learn from more experienced colleagues and practise disclosing results through role plays.

When the result is positive, the counsellor should:

- inform the person (or couple) as clearly and gently as possible, and deal with the initial reactions
- give them time to understand and discuss the result
- provide information in a way that is easy to understand, give emotional support, and help them discuss how they will cope, including identifying what support is available at home
- refer the person, where possible, to a community support organisation and for follow-up care and counselling
- explain how the result will be kept confidential, so that no one else will know, unless the person who has been tested chooses to tell them
- discuss who the person may want to tell about the result, risks to sexual partners, and how to tell their partner. If a pregnant women has not been tested with her partner, find out whether she intends to tell her partner, and if so, how she might do this.
**4 IMPLEMENTING HIV TESTING FOR INDIVIDUALS**

- explain how the person can take care of their health, including advice about diet, exercise, rest, avoiding infections and when to seek advice
- tell the person where to get treatment and care, if required, and, if appropriate, help them decide about antiretroviral therapy, treatment for opportunistic infections and preventive therapy for tuberculosis
- with pregnant women, discuss how to feed their baby, help them make the decision that they feel is best for them, and refer them for further counselling
- discuss prevention of HIV transmission to partners who may be uninfected, and provide information about safer sex and condoms.

How to help people to live positively depends on the local culture. In many places, it is not helpful or culturally appropriate to tell people that they have a fatal illness. The emphasis in counselling is on giving people hope of staying well and living a normal life.

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**FINDING OUT YOU ARE HIV POSITIVE**

- 'I was working for an insurance company and as a staff member I needed to have insurance. So I had to go for tests. At that time I didn’t know what the test was for, they told me it was just a medical check-up. After 4 to 5 days, the doctor phoned and told me, “Your test came back HIV positive.” To me, HIV positive meant AIDS – death the next day or very soon. I was sent for counselling, but when I got there I couldn’t talk to the counsellor. I said, “No, I’m fine, I’m just angry.” I lost my job. I couldn’t talk to my parents. I couldn’t sleep at night and I wanted to kill myself. I lived a risky life, hoping that I would die, for six years. After that I told myself, “I’m six years with HIV and I’m still alive.” I decided to tell my mum and see whether she would help me. I worried that she would reject me, but instead she gave me a hug and supported me. She took me for proper counselling and I found out that a person can live with HIV for a long time.

  I think companies should look at this pre-test and post-test counselling. It is real exploitation to be forced to have a test without your consent and not to even know the implications.’

- ‘I was raped. The doctor suggested that I go for an HIV test. So they tested me at the hospital. The result of the test was negative. Then they said I should return in six weeks for another test. The second test was positive. When they told me I sat there silently. I couldn’t talk. I couldn’t do anything. It took some days before I could say, “This has really happened and I can’t go back.”

  I think what really helped me was the counselling. I joined a support group and it gave me strength to cope. Counselling says you must keep it confidential and you mustn’t share it, but I think this is not good because spiritually a person can’t cope.’


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**BENEFITS OF COUNSELLING**

The Kara Counselling Centre in Zambia asked the people who had used the centre about their experience. They found that people came for testing because they were either concerned about being infected or worried that their past behaviour may have put them at risk. About 60 per cent of people said that the counsellor had helped them make up their mind about having the test. Most people found counselling useful, whether their result was positive or negative, and valued being able to discuss issues with someone outside the family and community who was non-judgemental.

Many people who were diagnosed with HIV had seen relatives or friends with HIV suffer painful, undignified deaths, and feared that this would happen to them. Most said they valued the fact that their counsellor could link them to medical referral services, although a few felt let down because there was little to offer them. Most had not discussed death and dying with their counsellor, but said that this would have been helpful.

With the help of a counsellor, many people had been able to tell someone else about their HIV infection, and some had brought their partners for testing. Many also valued being able to plan for their dependants and to discuss these plans with a counsellor.

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**4.6 Being prepared for different situations**

Counsellors and health workers need to be prepared for a range of situations, such as people who have been tested without their knowledge or consent, people who decide not to have counselling, people who decide not to take a test, and people who choose not to know their result or who deny their result.

**Being tested without consent**

If the person is HIV positive but has been tested without their knowledge or consent, and they do not know the result, it is possible to start the process again. The person can be offered pre-test counselling. If they decide not to be tested or not to know the results, their wishes should be respected.

If someone already knows or suspects that they have been tested without their consent, it may be better for counsellors to use more than one counselling session. The counsellor could begin by explaining about the test and its implications and why the person’s blood has been tested, covering the issues that should have been discussed during pre-test counselling. Discussion of whether the person wants to know the results should be covered during a later, post-test counselling session.

**Deciding not to have counselling**

People who do not want pre-test counselling, or who do not have access to it, should not be prevented from
taking an HIV test if they want one. However, informed consent is always required.

Deciding not to take a test

A person may decide after pre-test counselling that they do not want to be tested. Counsellors and health workers should remember that HIV testing is not the objective of counselling, and should always accept a person’s decision. People should never be forced to take a test. People who come for counselling and testing who decide not to take a test should be provided with counselling about how to prevent HIV transmission.

Choosing not to know results

Some people may decide to take a test and then choose not to know the result. Their decision should be respected and they should not be told their result when they do not want to know. People may have good reasons for not wanting to know. For example, they may feel that knowing will make no difference to their health care or the choices they make, or that the risk of others finding out is too great.

Denying results

Sometimes a person may not seem to understand what being HIV positive means. Counsellors may need to find culturally appropriate ways to explain what the test result means. Some people may deny the result. Denial is often linked to feelings of extreme anxiety and helplessness and fears that life is over, and makes it difficult for a person to explore what they feel. The counsellor can offer additional counselling sessions, and try discussing how the person would feel if they did have HIV. With a supportive and understanding counsellor, a person may come to accept their diagnosis over time.
4.7 Confidentiality

Confidentiality is interpreted in different ways in different places. In some places it is interpreted as never telling anyone about your HIV status – but this secrecy is not the same thing as confidentiality. Secrecy can increase the sense that HIV is a taboo subject. It is vital not to discuss a person’s HIV status without permission, but too much emphasis on individual secrecy can make it hard for the person to be given appropriate support.

If a person does not tell anyone that they have HIV, they can feel more anxious and isolated. People are often more concerned about the social consequences of a positive diagnosis, for example about what will happen to their children, than about the medical implications. Social support plays an important role in helping to keep people healthy and in reducing stress. In many places, the only source of social support is the family and community.

Secrecy about HIV needs to be tackled through, for example, better public information about HIV, encouraging people to share results with others that they trust, encouraging openness about the cause of death, and, at the same time, respecting people’s rights, and preventing stigma and discrimination.

Individual counselling is an approach developed in industrialised countries, which focuses on the relationship between the counsellor and the person concerned. ‘Western’ models may not work so well in different cultures or in rural areas where there is a greater emphasis on the family and community than on individuals, and where there are no services, NGOs or other forms of support. In some places there is also a problem with people who know their HIV status infecting partners because they refuse to use condoms. Some health workers can therefore feel frustrated by the need to maintain strict confidentiality.

For these reasons, programmes in some African and Asian countries are promoting more culturally appropriate forms of confidentiality. These include ‘shared confidentiality’, using ‘lay’ counsellors (already trusted people who have been trained in counselling) rather than professional counsellors, counselling and testing couples, and group counselling and community education to remove the stigma of HIV and AIDS.

Shared confidentiality

Shared confidentiality means encouraging someone to identify a person they can trust, and telling them of their HIV status, for example their doctor or health worker, partner, close friend or family member, or traditional healer. Sharing confidentiality does not mean that confidentiality is not important, and the decision to disclose HIV status must still be under the control of the person with HIV.

However, deciding whether to tell a partner can be very difficult for some people. They may prefer to tell a close friend or family member, or to share the news of their HIV status with their partner through an intermediary, such as a friend or relative. Reasons for not wishing to tell partners may include fear or taboos about discussion of sexual matters. If a person is in a stable relationship, the counsellor can introduce the idea of shared confidentiality during pre-test counselling.

Some people may also be reluctant to tell their family that they have HIV. This is usually because of fear of rejection, although this is often over-estimated, and counselling can help them to assess the situation more realistically. If someone is still reluctant to tell a family member, the counsellor can encourage him or her to think of someone else they could trust.

If the person is still reluctant to tell anyone their HIV status after post-test counselling, the counsellor can offer more counselling sessions until the person is ready to share confidentiality. This can take many months. Counsellors should never put pressure on people to disclose their status.

Some health workers say that they find it difficult to accept the concept of confidentiality – for example, if a person who has tested positive and has been counselled does not use condoms, or fails to tell their sexual partners that they have HIV. In one community, nurses were aware that people with HIV were not practising safer sex, and were concerned that by protecting these
people's confidentiality, they were putting others in the community at risk.

However, regardless of people's behaviour, health workers must maintain confidentiality, but should offer additional counselling to help people consider their behaviour. Shared confidentiality can make it easier for counsellors to deal with some of these difficult issues.

Counselling and testing couples

Counselling and testing couples may sometimes be more appropriate than individual counselling and testing. Couples who are both HIV negative can plan to stay that way. Couples who are both HIV positive can support one another in decisions about fertility, care and other issues. Discordant couples (where one partner is HIV positive and the other is HIV negative) can discuss reducing the risk of transmission. Both men and women can acquire HIV from their partners, and studies of discordant couples have shown that number of partners, condom use and other sexually transmitted infections are important factors.

People who come for pre-test counselling could be invited to come back with their partner, so that the decision about testing is made together. Couple counselling provides a safe place to discuss difficult issues and it can be easier if both partners have an HIV test at the same time. This can be particularly helpful for women, who are often dependent on their partners and may be unwilling or afraid to reveal their HIV status to their partner.

If a person decides to have a test without telling their partner, and is found to be HIV positive, the counsellor could suggest that they have counselling and testing again, this time with their partner, as though they had not already had a test. While continuing to protect a person's right to confidentiality, counsellors can try to encourage shared confidentiality. They can explain that a person's partner may not yet be infected, and that safer sex will protect them from HIV. They can point out that not telling their partner will make it very difficult to, for example, practise safer sex, or discuss whether to have children.

However, counsellors should be aware that if one partner tests positive and the other tests negative, one partner may blame the other. Pre-test counselling needs to discuss the possibility of a couple having discordant (different) results and the importance of minimising the risk of transmission from one partner to the other.

Where one partner tests negative and one tests positive, post-test counselling can also help the couple to accept the partner who has HIV, rather than blaming them. It can help them to be more open and understanding about HIV and AIDS. They may want to discuss contraception and sexual issues, agree to try to use condoms, and plan for coping with future illness and its impact on the family.
4.8 Problems with implementing counselling services

Problems with implementing counselling services include low uptake and failing to return for the results. Steps can be taken to reduce these problems.

Low uptake of counselling and testing services

In some places, demand for services is increasing and people seek counselling and testing for a range of reasons. However, in many places people are reluctant to come for counselling and testing because they:

- believe that nothing can be done for people with HIV and that knowing their status would not improve treatment
- fear that if they know that they have HIV, they will get sick and die sooner because of worry and anxiety
- are concerned about confidentiality, or about being seen to visit a counselling and testing centre
- believe that there is no cause for concern, for example, because they are not ill or have recently had a healthy baby
- are worried about being told that they have HIV and having to face the implications of this
- prefer to cope with HIV-associated symptoms by believing that they are caused by illnesses other than HIV infection
- lack money to pay for testing and counselling, where there are fees for these services, particularly young people who may not have money of their own.

Group counselling

Some projects in Africa have extended the concept of confidentiality to ‘community confidentiality’, particularly in places where health and social services cannot provide the care and support people need. But this is only possible in communities that accept people living with HIV. Many people have lost their homes, jobs and – in extreme cases – their lives, because other community members do not accept them.

Although some types of group counselling can be successful, it is usually not possible for people to discuss their personal concerns with others present.
Failing to return for the test result
In some places a high proportion of people who come for counselling and testing do not return for their results. People may:
- change their mind and decide they do not want to know the result after thinking about it, especially if they have to wait a long time for the results
- decide not to come back after talking to a partner, friend or family member
- not really want to know their HIV status, but take the test to avoid offending the counsellor or health worker, or are pressured to come by someone in their community
- lack the time or money to travel back to a centre a week or two later (and would find it easier to receive the results the same day).

Overcoming barriers
Various steps can be taken to overcome barriers to counselling and testing and to encourage more people to return for their test results. Strategies should be appropriate for local circumstances. They could include:
- using simple/rapid tests so that results can be given the same day and the person does not need to come back a week or two later. (However, providing two simple/rapid tests is quite costly and it is very important to ensure that the person has time before having the test to think through the implications.)
- educating people so that they are aware of the potential benefits of knowing their HIV status, whether the result is negative or positive
- increasing awareness of care, treatment and support services available to people with HIV
- providing high quality counselling
- ensuring that measures to maintain confidentiality are effective and that clients are aware of these
- integrating HIV counselling and testing into existing health services, to reduce the stigma associated with being seen to visit a counselling and testing centre.
4.9 HIV testing for particular groups

Health services may decide to offer HIV testing to particular groups for public health reasons, for example, people with tuberculosis and pregnant women. However, before testing is targeted at specific groups, various issues need to be considered carefully. The needs of other groups, such as men who have sex with men, adolescents and injecting drug users, who are often forgotten, should also be considered in planning counselling and testing services.

Pregnant women

Testing for pregnant women is being promoted in some places, because of the possibility that the risk of HIV transmission from an HIV-positive woman to her baby can be significantly reduced. Some interventions that may reduce mother-to-child transmission benefit all pregnant women and do not require that the woman’s HIV status is known. These include malaria prophylaxis, vitamin supplements, iron supplements, and screening and treatment of sexually transmitted infections.

The risk of mother-to-child HIV transmission can be significantly reduced by giving antiretroviral (ARV) therapy during delivery to the baby, and by avoiding breastfeeding. For a pregnant woman to be able to make informed decisions about whether to take antiretroviral therapy during labour, where this is available, she will need to know that she has HIV. Voluntary HIV counselling and testing may, therefore, be of benefit to pregnant women who have access to antiretroviral therapy, when this is part of a package of care and support available to women with HIV. New, cheaper therapies are currently being researched which may make mother-to-child transmission easier to prevent.

The package of care and support should include:
- reducing the risk of HIV infection in babies and, as a result, the number of babies born with HIV
- enabling women and their partners to make informed decisions about feeding their babies, sexual behaviour and future pregnancies.

However, testing and counselling pregnant women can have disadvantages as well as benefits. These must be considered carefully before introducing testing for pregnant women, even where antiretroviral therapy is available. The fact that antiretroviral therapy is available to a small number of women may lead to situations where confidentiality, informed consent and counselling are not adequate. For example:
- clinics introducing routine or mandatory HIV testing for pregnant women
- pregnant women being pressured to take an HIV test by counsellors and health workers for the sake of their unborn babies, and feeling unable to refuse testing

- health workers or counsellors not giving pregnant women balanced information about the risks as well as the benefits of HIV testing, so that women are unable to make a fully informed decision.

Other potential disadvantages of testing pregnant women include:
- reluctance by women to seek antenatal care for fear of compulsory testing
- negative attitudes of health workers and denial of routine antenatal care or support during birth
- pressure on women to have an abortion if they are found to be HIV positive
- increased stress and anxiety, especially if there is no access to antiretroviral therapy and it is not feasible to use alternative infant feeding methods
- difficulty in keeping HIV status confidential, especially if HIV-positive women choose not to breastfeed in cultures where breastfeeding is the norm
- discrimination, abuse, rejection and violence if the woman’s HIV status is revealed, either directly or indirectly – for example, if she decides not to breastfeed or brings up the subject of safer sex with her partner
- blaming women for bringing HIV into the family and for giving the baby HIV.
Targeting testing at pregnant women where there is no access to antiretroviral therapy and where alternatives to breastfeeding are not feasible has few, if any, benefits.

Where antiretroviral therapy is available, voluntary counselling and testing services for pregnant women need to offer specific pre-test and post-test counselling, in addition to the usual counselling. The following issues need to be discussed with the woman:

- information about HIV, pregnancy and the risks of transmission to the unborn baby
- information about the possible benefits for the woman of knowing her HIV status, including support and care if the test result is positive
- implications of a positive result for the baby, future children and decisions about feeding the baby
- implications of a positive result for the woman’s relationship with the baby’s father and whether she would feel able to share the result with him – it may be easier for the woman if her partner comes for counselling and testing at the same time
- an explanation that testing is not mandatory, and that the woman will not be denied access to antenatal care if she chooses not to be tested.

Post-test counselling for pregnant women who are HIV positive should include, in addition to usual post-test counselling, information about:

- antiretroviral therapy
- feeding options for the baby, and the benefits and risks of breastfeeding, to help the woman make an informed decision about how to feed her baby
- safe alternatives to breastfeeding, if the woman decides not to breastfeed, and family planning, because of the increased possibility of becoming pregnant again soon as a result of not breastfeeding
- care of the baby
- the importance of good nutrition and seeking early treatment for illness for the woman
- information about child spacing and contraceptives
- referral to treatment, care and support services.

Discussion with the pregnant woman should include:

- the potential benefits and risks of sharing information about the woman’s HIV status with partners, families and friends
- family counselling, if possible, to avoid HIV-positive women being blamed and rejected
- planning for the future, including referral to spiritual and legal support.

**Babies and children**

HIV testing of babies and children should be considered very carefully. Diagnosis is difficult in children aged less than 18 months and there are implications for the mother and the rest of the family.

All children born to mothers with HIV have the mother’s HIV antibodies in their blood at birth, unless the mother is in the window period (see page 9). This means that an HIV antibody test will give a positive result, but does not necessarily mean that the baby is infected.

The mother’s antibodies only start to disappear from the baby after about 12–15 months of age, and the baby only begins to produce its own antibodies by about 18 months of age. Antibody testing cannot tell whether a baby has HIV until after the age of 18 months. To diagnose HIV infection in children under 18 months of age, expensive tests, such as PCR or viral culture, which test for the virus rather than the antibody, must be used.

A positive test result in an infant aged over 18 months suggests that the mother has HIV. A mother must receive counselling and give her consent before a baby or child is tested. Otherwise she will be unprepared to cope with the fact that her child has HIV that she herself may have HIV, her partner may have HIV, and any future children may also be infected.

**People with tuberculosis**

Tuberculosis is caused by a bacteria *Mycobacterium tuberculosis*. Most people who are infected by the bacteria never become sick with active tuberculosis illness. Before HIV, only one in ten people infected with the tuberculosis bacteria developed tuberculosis infection (active tuberculosis or TB) and the remaining nine out of ten people stayed healthy. Now it is estimated that as many as one third to one half of people who have both HIV and the tuberculosis bacteria will develop TB.

HIV testing is often proposed for people who are suspected of having TB. One reason is because people with tuberculosis infection and HIV may experience serious side effects to thiacetazone, an anti-tuberculosis drug. Another reason is that people with TB are more likely to have HIV than the rest of the population, and therefore are sometimes seen as a group that may benefit from voluntary HIV testing and counselling.

A health worker may suspect that someone with tuberculosis symptoms has HIV infection, if the tuberculosis is difficult to diagnose, or if the person has other HIV-associated illnesses. The person should be offered counselling and testing, if available. However, they should not be pressured into taking an HIV test.

- It is not necessary to test tuberculosis patients for HIV to decide on the anti-tuberculosis treatment.

**Providing care and support**

The Kara Counselling Centre in Zambia offers a range of care and support services for people diagnosed with HIV. People with HIV are screened for active tuberculosis (TB) and, if clear, are offered tuberculosis preventive therapy. If they have active TB they receive anti-tuberculosis treatment. In addition, HIV-positive people are offered access to skills training, a post-test club, a clinic for basic medical problems and a referral service for those with more complicated medical problems.
Collecting sputum samples for tuberculosis tests.

Regimen. In areas where many people have HIV, it is recommended that another anti-tuberculosis drug is used instead of thiacetazone. Treating all tuberculosis patients with alternatives to thiacetazone is less expensive than HIV testing for all patients diagnosed with tuberculosis.

- Compulsory testing of tuberculosis patients for HIV could deter patients from seeking care, reduce the credibility of health services and increase stigmatisation of people with tuberculosis. In many places, people are already aware of the association between tuberculosis and HIV, and if a young adult has tuberculosis it may be incorrectly assumed that they also have HIV.
- Tuberculosis disease can be effectively treated in people with HIV. Treatment is the same regardless of HIV status, (as long as this is not being used where HIV status is not known) so HIV testing is not necessary to decide about anti-tuberculosis treatment.
- People with HIV who are infected with the tuberculosis bacteria but do not yet have active tuberculosis disease can benefit from prophylaxis with an anti-tuberculosis drug, most often isoniazid. However, the availability of isoniazid preventive therapy (IPT) is not a reason for testing tuberculosis patients for HIV. IPT is only useful for people with HIV who are not yet showing symptoms of tuberculosis.

A more effective approach than HIV testing for TB patients is to ensure that pre-test counselling for people seeking voluntary HIV testing includes information about tuberculosis signs and symptoms and the importance of early diagnosis and treatment. Everyone being tested should be asked whether they have a cough. If possible, those that do should be screened for tuberculosis. Anyone who has tuberculosis should be registered and treated by the tuberculosis programme.

Screening for TB and offering isoniazid preventive therapy for people with tuberculosis infection, but not active TB, should be part of a package of care for people who have been diagnosed as HIV positive after voluntary counselling and HIV testing.

**Health workers, HIV and TB**

Health workers who deal with tuberculosis patients sometimes consider having an HIV test. This is because health workers with HIV may be at high risk of contracting tuberculosis infection. However, like anyone else, health workers should make their own decisions about whether to seek counselling and HIV testing. Health workers who are HIV positive could be offered preventive therapy and given duties that minimise contact with tuberculosis patients.