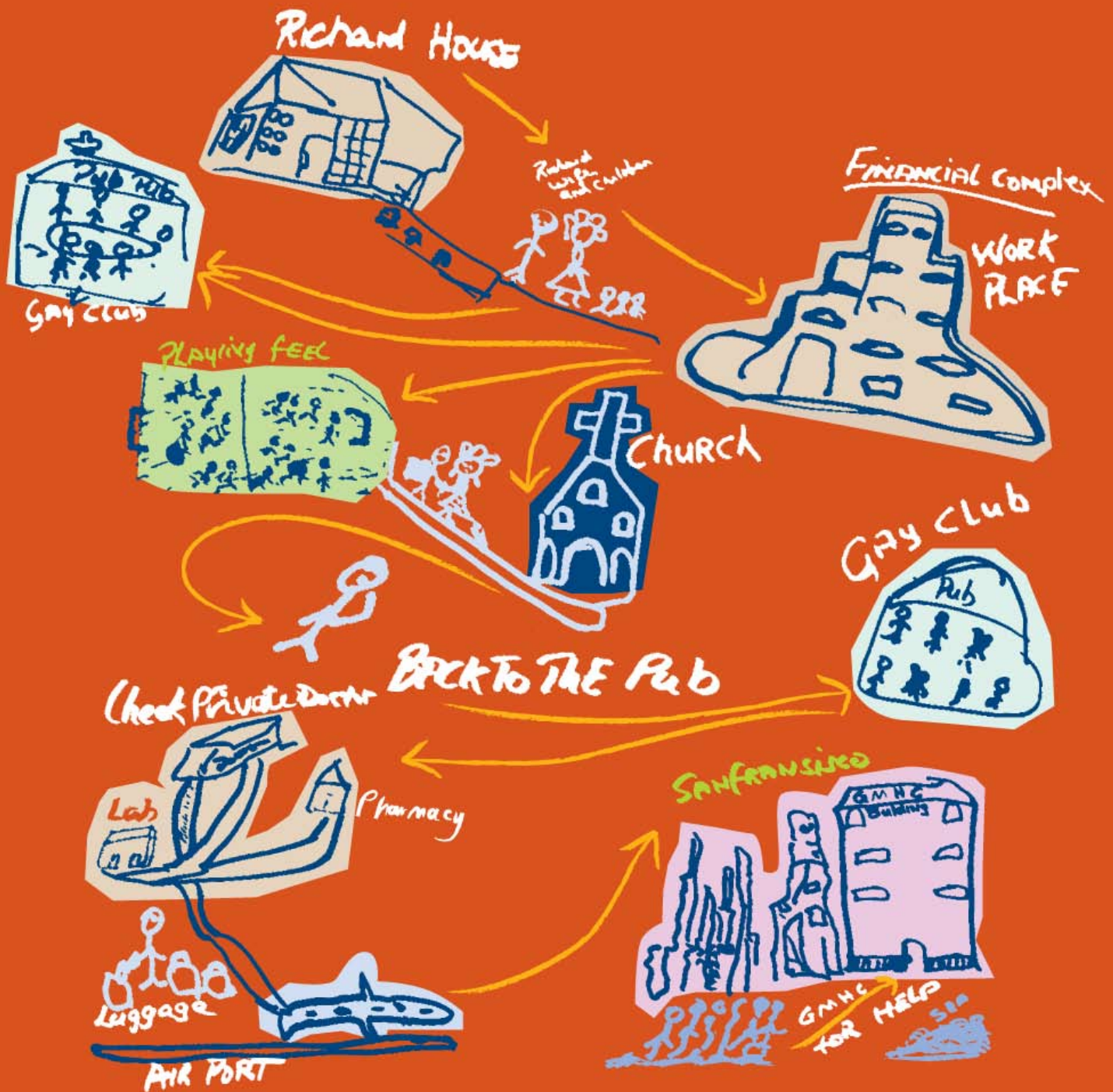


# The health journey

Understanding the dimensions of care and treatment for people with HIV  
A community-centred methodology



## International HIV/AIDS Alliance

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally-based organisations working to support community action on HIV and AIDS. Our shared vision is to reduce the spread of HIV and meet the challenges of AIDS. To date over \$140million has been channelled to more than 40 developing countries in support of over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

The Alliance Caribbean Regional Programme works with partners in nine small countries in the East Caribbean, including community-based organisations formed by female sex workers, gay men and other men who have sex with men, and people with HIV. We share learning with local non-governmental organisations, and support the Caribbean Regional Network of People with HIV/AIDS and other groups working with people with HIV. Activities have included training workshops on issues such as basic AIDS prevention, national-level HIV prevention, and advocacy work with regional bodies to promote the rights and needs of members of key populations.



A participant at a workshop in the Caribbean depicts his health journey. His completed drawing appears on the cover of this publication.

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This resource was compiled and written by Carolyn Green of the Care and Impact Mitigation team at the Alliance secretariat. The following Alliance staff contributed to the development, field testing and adaptation of the methodology:

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## What is it?

- An innovative method for putting a person with a health problem at the centre of the picture and mapping their real-life experiences, highlighting what actually happens, rather than simply what ought to happen.
- A way to focus discussions on a real situation, using participants' own experience as a key input.
- A springboard for analysing local challenges, highlighting existing stakeholders and services and examining possibilities for change.
- A flexible tool that supports, for example, focusing on major issues faced by people with health problems, tackling practical problems in service delivery and clarifying policy issues.

## How can it be applied?

- It is designed for situations related to HIV treatment, care, prevention and support, but can easily be adapted to address other health issues.
- It can be used with groups, for example:
  - peer groups of people with HIV, to share their experiences
  - multi-disciplinary groups of, for example, people with HIV, health workers, NGO staff, to encourage fresh thinking, exchange of ideas and collaborative planning.
- It can be used with individuals, for example as a treatment support tool.

## How does it work?

- The activity is based on defined objectives – why is the health journey being used in this situation, what do we hope to gain from it?
- Using brief scenarios about typical individuals in a particular setting, participants discuss and depict the journeys that these individuals might follow in their search for support and care.
- Feedback highlights important features, and discusses challenges and possible solutions that emerge in each person's journey.
- Subsequent discussions flow from the feedback, guided by the objectives and aimed at achieving outcomes, for example defining an action plan.

## What is in this document?

- Clear instructions for using the methodology.
- Suggestions on how to use the outcomes of the journey activity.
- Five examples of how the health journey has been used in different settings, including the scenarios, photographs, and descriptions of how the outcomes were used.
- A list of other useful Alliance participatory toolkits and guides.

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# Introduction

Community organisations in HIV-affected countries often work with people who are not easily reached by public health systems. Providing support to people with HIV, their families and communities gives them unique insight into the challenges of living with HIV. They know from experience that the majority of care and support is provided away from clinics and hospitals. Often spoken of as 'informal' care, it is nevertheless a major component for meeting the needs of people with HIV.

At the same time, clinical service providers face increasing demands for treatment and medical care, which can be difficult to provide from existing resources. Even when formal health resources are adequate, barriers such as discrimination, poverty, low literacy and lack of community education can make those services difficult to access and under-utilised.

The Alliance is committed to the UN goal of universal access to prevention, treatment, care and support services for people with HIV by 2010. We support work in many countries, aiming to build the capacity of people with HIV, community organisations and front-line health care workers and to support and increase uptake and use of vital services.

The Alliance has developed innovative approaches, called 'community engagement', to facilitate coordinated community and health service interventions. The key starting point for this is that everyone involved should have a clear understanding of the many challenges faced by people with HIV and be enabled to work together to resolve some of those challenges.

“ The health journey has really opened people's eyes. ”

*Participant, treatment support skills-building workshop, Uganda*

The aim is to improve support for people with HIV on such important issues such as uptake of services, treatment adherence, reducing stigma and HIV prevention. It also supports health workers, strengthening their links with communities and providing greater job satisfaction when their patients are actively supported and followed up in the community.

The health journey is a simple and highly useful tool that provides a starting point for community engagement and community-centred health service planning. Outcomes from using the tool have already contributed to improved coordination of community support and health care for people with HIV in a variety of settings, within the Caribbean, Zambia, Uganda, Myanmar and China.

Originally called a treatment journey, the tool was developed during the early days of public health scale-up of antiretroviral treatment (ART). Clearly, ART involves far more than taking pills and there are many other challenges faced by a person with HIV, so the tool is now named the health journey. This reflects the fact that maintaining or re-gaining health is the underlying goal of the search for treatment, care, support and prevention.

**Part 1** of this publication explains what a health journey is, who can make use of the methodology and why it is a useful tool for understanding the experiences of people with HIV.

**Part 2** explains how to set up and use the methodology. **Part 3** provides five different examples of health journey workshops and what impacts resulted from them.

At the end of the publication is a list of useful resources.

“ The interactive approach of the workshop has enabled me to better understand the issues around treatment and care, especially through the experiences shared. 'Big up' for the methodology! ”

*Person living with HIV, treatment preparedness workshop, Trinidad*

We hope that the simplicity of the concept and the flexibility of the methodology will encourage users to adapt it to their own needs and local situations. Although developed for individuals, groups and organisations working in HIV care and support, it can easily be adapted to other issues, particularly where needs are complex, situations are user-unfriendly or resources are limited.

In this section we describe what a health journey is and who can make use of the methodology. We explain why we think it is a useful tool for understanding the experiences of people with HIV who are trying to do something about their health problems and to live positively. The health journey is based on the common human experience of journeys. It uses participatory methods to share and understand them.

## What is a health journey?

When someone experiences a health problem, he or she has some questions to ask and decisions to make about what to do. This is the starting point of a journey, the health journey – an individual's attempts to find solutions to a health problem and to work out how to deal with any consequences.

For example, imagine a person who decides to go an HIV testing service. She not only needs the actual service – she also needs information on where it is and how to use it, and counselling before and after the test. She may also need both community support and referrals for clinical and social services. But she may also want or need other things – care for her children, confidentiality about her diagnosis, money for transport or fees, protection from discrimination and so on. Before the journey starts, a person's first thoughts might be something like this:

I have a health problem that is worrying me. Maybe it will go away if I decide to ignore it, or maybe I can just keep my fears to myself and hope that it will get better.



If I decide to do something about it, what should I do? Who should I speak to? Where should I go?



How can I find out what to do? How can I make sure that I get the help I need?

The journey might start with talking to a family member, a friend or a neighbour. They might advise her to see a healer or go to a doctor or local clinic. She might decide to go to a drug seller or to the market to buy herbs. A clinic or help centre might suggest a referral, for example to a VCT centre for an HIV test. This might lead to a trip to a laboratory for more tests and maybe a referral to a hospital. At the same time, she might also decide to visit an NGO working in the neighbourhood, or a pastor or

other community leader for further advice or counselling. At some stage she will return home and will be faced with decisions – for example, who to tell about what has happened, who to ask for support, how to deal with fears about disclosure.

Health journeys can sometimes be brief and easy. But for a lot of people the journey is a long one with many stages. There are often difficulties or obstacles on the way, especially if the journey relates to matters that are not easy to disclose or explain to others, such as HIV or sexual health. A person might have to deal with many different people and may get the wrong advice or take some wrong turns. The ease of the journey depends on many factors – people's attitudes, costs, transport, availability and opening times of services, the clarity and accuracy of the information that you receive and so on. Within the health journey methodology, the key activity is to map a person's journey on paper, using simple drawings, based on participatory discussion about the person with a health problem and the people and environments among which that person's journey takes place.

The journey is usually a fictional one, based on a story about a typical person from a community. But it takes place within a real situation – the community must be one that participants are familiar with and can talk about from personal experience. The journey may alternatively be based on a real person, if someone is willing to allow their experiences to be used in this way, but this poses some challenges related to confidentiality and stigma – fictional people are easier to talk about.

Discussion and analysis of the outcomes of the drawing activity will provide a springboard for further analysis and planning for action on specific issues. The aim is to make health journeys more user-friendly and more likely to result in beneficial outcomes for individuals with HIV.

See Part 3 for examples of how the health journey outcomes have been used in different settings.

## Who can make use of the health journey methodology?

The methodology has been designed be of use to:

- Groups of people living with HIV
- Trainers and programme planners in NGOs
- Leaders of community organisations
- Front-line health workers and managers

However, the simplicity of the tool invites people to use it very flexibly and to adapt it, both to the local situation and to the specific issues that need to be addressed. The primary aim is to enable participants to talk openly together about the realities of trying to access and make the best use of prevention, care, treatment and support services within the context of HIV. It can therefore be used in a number of ways and with a variety of participants.

It is often used as a group activity. For example, it has proved to be an excellent way to get mixed groups of people with HIV, health workers and NGO partners to look together at issues that are of common interest, leading to improvements in access, uptake and continuing use of care and support services. It has also been used effectively with HIV positive individuals, as a starting point for developing positive living plans or providing ARV treatment adherence support.

Since this is a highly participatory methodology, it is essential that facilitators should be people who have a basic understanding of how participatory methods can help participants to focus on their own experiences and to use the results of the activity as a starting point for developing new approaches and innovative thinking. Facilitators should also have sufficient skill to follow and adapt the activity template provided in Part 2, and an open and non-judgemental attitude that encourages and supports participation.

## Why is the health journey so useful?

The health journey is closely related to well-established participatory development tools such as community mapping, life lines, narratives and histories. The Alliance and its partners make regular use of such tools in their work, enabling democratic and needs-based solutions to emerge from the complex challenges that face people and communities living with and affected by HIV.

The drawing activity provides important detail on local situations, based on real-life experiences. It highlights connections between the key people, services and environments in the communities concerned. It also enables participants to focus on challenges and obstacles that face a person with HIV. Its main strength is that **a person with HIV is at the centre of the picture**. It focuses on what **actually** happens to that person, rather than on what **ought** to happen.

Through analysis of discussions, during and after the drawing activity, it becomes clearer what people's real needs and concerns are, and highlights what is helpful to them and what is not. Because of the person-centred approach, the results highlight the very wide range of other people and relationships that have influence on a person with HIV in a particular community as well as the formal services and professional help that are available. How this information is used will depend on the aims and context of the activity, illustrated with the examples in Part 3.

Especially if the group is a mixed one, including service users, providers and other stakeholders, experience shows that doing the health journey together will encourage greater sharing of knowledge about how people try to do something about their health problems. It is a highly useful first step towards resolving challenges, providing both focus and impetus for analysis, planning and implementation of services and policies that will be more effective and better utilised.

This section contains advice about using the health journey activity within a workshop setting and making use of the results. It is essential that you read through this section carefully and act on the advice in order to get the best from the activity. The actual steps and timings for organising the health journey are given on pages 10 to 12.

## First things first – getting started

The two most important things to concentrate on right from the beginning are:

- Participation of people who are familiar with the local situation and contexts where you are working, both as participants and if possible as facilitators.
- Preparation, preparation, preparation! Always give yourself enough time for this and never assume that facilitators and participants will just know automatically what to do. Follow the suggestions below and make sure that you plan carefully and fully understand what the activity will require, so that you can guide the process and support participation.

The methodology requires two facilitators or more if the group is large – facilitators will need to circulate round small discussion groups as well as facilitating full group discussions. At least one facilitator should have some experience in participatory group work.

In addition to group facilitation, there should be one person to time-keep and one person to take care of housekeeping e.g. registration of participants, address lists, checking that refreshments are ready, dealing with money and other practical issues.

Participants will need to be chosen, and informed about what to expect, ahead of the purpose of the workshop. They will also need to know how to get to the venue and have sufficient resources to allow them to attend.

### Who should participate?

The success of this type of workshop depends on participants being willing to enter into discussions and to share their understanding and experiences. The methodology is intended to improve participants' understanding of what it is like for a person with HIV to try to access care and support. People with HIV must therefore be included as participants and, if at all possible, as facilitators (see right).

In some situations, it might be advantageous to have a group consisting only of people with HIV. This is most likely to be when people with HIV have previously had little chance to share experiences with their peers, and might feel inhibited by talking in front of those who are not going through the same experience.

In other situations, it may be much better to have a mixed group. When planning new services or seeing how to improve existing ones, different viewpoints and knowledge need to be heard and shared solutions need to be worked out. Working on a task together is a very good way to break down barriers and enable people who don't usually talk to each other to develop new relationships. This depends on the context and the intended purpose of the activity.

Limited writing and reading skills are required for the activity and discussions. At least some participants should be able to make simple drawings on paper and write down relevant information – for example names or places. The drawings are only there to illustrate a situation and to stimulate discussion. They are not meant to be a work of art. If participants need support with language (translations, accents) or have speech or hearing disabilities, make sure that they are supported by others in the group and that facilitators take care to fully include them in discussions.

### Who can facilitate the health journey?

Facilitators should first of all be people with the necessary human qualities of openness and ability to relate to people in a friendly and straightforward manner. Facilitators need to be experienced in working with small and large groups and able to manage plenary discussions. They should be able to multi-task, monitoring the needs and interactions in the groups as well as providing guidance and support. Also, it is inevitable during discussions about personal experience that some very personal reflections and feelings will surface for individual participants. Facilitators need to allow for this to happen and to contain the group if difficult feelings arise, assisting individuals to take time out if needed.



During the activities, it is very likely that participants will ask for information and raise issues about HIV, prevention, stigma, treatment and support. Facilitators will need to have good basic knowledge about HIV and be able to provide information to participants in an easy-to-understand way, avoiding very technical or medical language. They should also be open about what they **don't** know and be able to suggest where participants can get further information if needed.

Facilitators will need to have at least secondary-level literacy and numeracy skills, for reading background materials, recording results of discussions, writing reports and managing expenses.

## How many people can participate?

As few as two people can do the health journey together. But to get a wider understanding of a situation, anything from 10 to 25 people is best. Larger groups than this will become difficult to manage and more time will be needed. So you need to check the following before finalising the numbers:

- What are the minimum and maximum numbers of people that you **must** invite?
- What accommodation is available within the funds allocated?
- If the numbers are large, must they all attend the workshop together, can you split the numbers to make two workshops, or can you limit the numbers in some way?
- How many people will the room comfortably accommodate for a plenary group?
- How many small groups can be accommodated? Small groups should be limited to four to seven people, to allow each person a chance to contribute.
- Is there room for each small group to discuss together and to make drawings on large sheets of paper?

## Preparation for the workshop

First, work out how much time you need for preparation. Based on experience, preparation usually requires at least twice the amount of time that is allocated for the workshop. When facilitators have sufficient experience of using the methodology, preparation may become a bit quicker – but the process of organising venue, participants, budget and transport may take just as long.

- **Facilitators:** One person should be agreed as the lead facilitator, who should manage the process and ensure that all preparations are organised and completed in good time. The lead facilitator should support all facilitators to go through the timetable of the workshop together, step by step, in order to:

- clarify the goals of the workshop and the steps required to reach those goals
- clarify facilitation ground rules to ensure the workshop runs smoothly
- assign various tasks to different facilitators so that the preparation work is shared
- decide who will take the lead on each part of the process,
- decide how much time to allow for each part of the preparation process (timings for the actual activity are given in the next section)
- decide what participants need to know beforehand and how to communicate this – by invitation letter or phone call, for example
- note what resources are needed
- discuss how to co-facilitate the activity, including how to handle difficult or unexpected situations and how to ensure confidentiality of personal information shared by participants, especially during the activity and discussions.

- **Participants** will need to know:

- the date, time and location of the workshop
- the objectives of the workshop
- arrangements for transport, refreshments, etc.
- who to reply to about attendance at the workshop.

## What resources do you need?

### Environment

- A room with sufficient space for the full group and for small group activities (if the large room is not big enough, check if there are other spaces for small groups).
- However, participants will be sharing their own experiences, so make sure that any space you use will provide privacy (watch out for staff or others standing around and listening while you are working).
- Ensure that adequate refreshments will be available at appropriate times, including some food and clean water (necessary for people with HIV to take their tablets).

### Funding

Work out before you invite people what needs to be paid for and make a written budget. This can include:

- transport for participants to and from the venue
- refreshments
- hire of venue
- cost of materials
- any incentives or pay for participants and facilitators (depending on local custom).



## Materials checklist

- ✓ Felt pens (medium tips) in several colours for drawing
- ✓ Flipcharts (A1 size) sufficient to allow for:
  - a list of the workshop objectives
  - a timetable for the workshop
  - participants' expectations and fears for the workshop
  - participants' ground rules for the workshop
  - 2-3 sheets for each small group to draw their health journey (allowing for mistakes and re-drawing)
  - enough sheets for summarising discussions and developing action plans, depending on the context and aims of the workshop and the numbers of participants and small groups
- ✓ Masking tape and/or adhesive rubber (blue-tack, sticky stuff, etc.) to attach charts to walls
- ✓ Writing paper or notebooks and pens for participants to write their own notes
- ✓ Notebooks or a computer to record key aspects of the workshop and to write a report afterwards
- ✓ Adhesive notes (stickies, post-its) for the activity
- ✓ Copies of the health journey (this document) for participants who want to make further use of the methodology



## Time-keeping

This is always a challenge for facilitators of this activity! The methodology enables people to open up and share experiences very readily. Lively debate usually starts up as soon as real issues and challenges come up in discussions, especially if there has not been much chance to do this before. Therefore:

- a large clock that everyone can see is a great advantage
- if there is no clock, at least one facilitator should have a watch, and
- one facilitator should have the main responsibility for time-keeping
- all facilitators should be responsible for ending small group discussions and bringing people back together for plenary feed-back and discussions.

## Scenarios (brief stories) about fictional people

- These are essential for the health journey. They provide a very short 'script' that participants can work with to illustrate a person's journey in their community.
- Participants will be asked to describe the journey all the way from when the person first recognises the need for help or support, through the different people and places he or she goes to, until the needs are met (or not) and the person returns home.
- Using fictional scenarios, based on their own communities, allows people to talk from experience without disclosing any of their own personal information unless they want to. This makes discussions easier and more lively from an early stage.
- It is sometimes possible to use a real person's details for the journey, but there are risks involved – for example, embarrassment, difficult memories for the person involved or lack of respect for confidentiality. No-one should be put under any pressure to reveal anything they do not want to share. Informed consent and confidentiality are highly important throughout and must be respected.
- One scenario will be needed for each small group, each describing a person who is more or less typical of the community that is under discussion. If there will be five small groups doing the activity, you will need to develop five different stories.
- Ask local facilitators or people who are familiar with HIV and who know the local situation to help you to develop the scenarios. Examples of fictional scenarios are given in Part 3, pages 21 to 22.
- The scenarios should be brief, with not more than four or five sentences – they should provide the name and age of the person, plus some brief family, social and health details. Vary the stories, describing different types of people, and ensure appropriate gender and age balance.
- There should be just enough in the scenario to support participants to use their imagination to describe the person's journey – too much information will limit their creativity but too little information will make it difficult to get started.
- If possible, arrange a meeting with one or two participants ahead of the workshop, to check the stories for authenticity and allow facilitators to learn more about the local situation.

## Things to watch out for during the workshop

Facilitators are required to manage the tasks of the workshop and to monitor the way in which participants interact and contribute. This must be done in a positive and encouraging manner, but it will also be necessary

to take some control at certain stages. Based on experience, the following important issues can come up during the health journey activity at some stage or other.

## Confidentiality

Mutual respect is essential between participants, and this includes accepting that when a person shares some private information in a confidential setting, the information still belongs to that person. No-one else has the right to disclose that information to others without the person's permission. Facilitators will need to establish consensus about this at the beginning of the workshop – never take it for granted. It will also be necessary to check who is able to overhear what is going on in the workshop, for example staff of the organisation or meeting place where it is held; if necessary, take time to speak to managers or supervisors to ensure that this does not happen.

## Expressing difficult feelings such as anger, frustration, blame or grief

The health journey is a participatory 'space' and is an excellent way to help people to open up and talk about their experiences. However, the reason for doing the journey is usually that some of those experiences have been very difficult and improvements need to be made to people's journeys.

If a person has not had sufficient space to talk about them before, negative feelings can come to the surface and prevent the person from talking calmly about what has happened and what needs to change. The person might need a chance to express the feelings or might need to take some quiet time out as a result. Facilitators will need to look out for this and ensure that the person is treated with respect, but it will also be necessary sometimes to take action to prevent the workshop being diverted or dominated by one person's feelings.

For example, in one workshop, a person talking about his own experience broke down in front of the group. The facilitators therefore asked the whole group to take a break, and provided individual support to him and anyone else who wanted it. Then the discussions

continued only after the whole group gave their permission – a participant said, "We have all been through such difficulties, we can continue now because we share those feelings."

## People who take over and people who don't speak up or join in

Establish ground rules at the beginning and ensure that they are respected. The rules must include: only one person speaking at a time; no interruption when someone is speaking; do not contradict when someone is describing their own experience; and do not take up so much time that others do not have time to contribute. Facilitators should watch out for people who are not speaking, and make sure that they have a chance to do so if they wish.

## People 'topping' each other's stories

This is when a person tries to describe something more extreme or difficult than the previous person's story. This is sometimes a risk when people start to share their stories. As one person talks, other people start to think about themselves and remember their own stories, which they might want to share with the others. This can be good, but sometimes a group will start to 'trade' stories and offer more and more anecdotes. Depending on time, it will be necessary to pull the group back together and remind them of the goals of their work together. Story-sharing can continue during breaks.

## Facilitators joining in and sharing

The facilitators might also feel that they themselves want to join in and share their experiences. However, the primary job of a facilitator is to be at the service of the group and to ensure that participants have maximum room to share their experiences and develop priorities and solutions. Therefore, facilitators must not talk so much about their own experiences that they limit the chance for participants to share, or make participants feel that their contributions are irrelevant or less important. Facilitators must limit themselves to only using personal experiences to briefly illustrate very specific points. This is a key ground rule for facilitators.

## Organising the health journey – a step-by-step guide

Step	What to do	Timing (approximate)
1	<p><b>Introduce the workshop</b></p> <p>First, introduce the aims and objectives of the activity. Provide a timetable on a flipchart on the wall, and briefly outline what each stage will involve.</p>	10 minutes
2	<p><b>Personal introductions</b></p> <p>Get each person in the room to introduce themselves briefly, including all participants, facilitators and anyone else who is there. (Depending on your experience, the size of the group and the time available, you may decide to use alternative introduction methods here.)</p>	10-15 minutes
3	<p><b>Expectations and fears</b></p> <p>Ask participants to write one expectation and one fear on separate post-it notes and to put them under the appropriate heading on a flipchart. Check what is coming up and summarise it for the group. Explain which expectations the workshop can meet and which, if any, it cannot. Allow brief discussion if needed.</p>	5-10 minutes
4	<p><b>Ground rules</b></p> <p>Then ask participants to establish ground rules for the workshop – either ask for suggestions and note them on a flipchart, or put up a ready-prepared flipchart with suggestions and ask people if they wish to change them or add anything.</p>	10 minutes
5	<p><b>Introduction to the activity</b></p> <p>Introduce the general idea of the health journey, based on the explanation on page 1. Try to make it personal to participants by talking about situations that they are familiar with. You will know quite quickly when participants ‘get’ the idea. If they don’t, allow them time to ask questions and clarify what they have to do.</p> <p>You can use different methods to help you explain. For example: sketch the idea on a large piece of paper to help them understand; act it out yourself, using different individuals as stopping points on your way; help a small group of participants to act something out.</p> <p>It can be helpful to show examples of previous health journeys – for example the photos in this publication – but only show them briefly, and then encourage participants to make their own versions and not to copy other people’s ideas.</p>	5 minutes (10-15 minutes if further explanation is needed)
6	<p><b>Drawing the journey – small groups</b></p> <p>Divide participants into small groups (five to six people) and give each person a paper with the scenario (story) of a person from their community. Provide some flipchart paper and some coloured marker pens. Ask each group to think about the health journey that their assigned community member may follow and draw this on a flipchart, showing where the person goes to, the people they will encounter and significant events and experiences along the way.</p>	5 minutes in full group, then 20-30 minutes in small groups

Step	What to do	Timing (approximate)
6(a)	<p><b>Optional: Preparing the journey role plays</b></p> <p>Depending on how much time you can allocate and how many small groups you have. When the drawings are complete, you can ask each small group to choose one particular point on the journey they have drawn. Ask them to prepare a short (five minutes) role play to show the rest of the participants what happened and how the person dealt with it.</p>	10-15 minutes
7	<p><b>Presenting the journeys – plenary</b></p> <p>Ask the first group to present the drawing of their health journey to the rest of the participants and to describe what happens during the journey. Note any important points regarding helpful and unhelpful aspects of the journey on a flipchart. Allow the large group to ask for clarification, but avoid detailed discussion until all have presented. Then ask each of the remaining groups in turn to present their journeys, each time followed by questions for clarification. Stick each drawing to the wall of the room after it has been described, so that there is a gallery for all to see.</p>	5-10 minutes for each small group
7(a)	<p><b>Optional : Acting out the journey role plays</b></p> <p>If you have chosen to include stage 6(a) in the activity, ask one or more groups to act out their role plays now, depending on the time available.</p>	5-10 minutes for each small group
8	<p><b>Discussion of the journeys</b></p> <p>Then, facilitate discussion based on the points noted during the presentations of the group work. Ask how these health journeys could have been made better, quicker or easier.</p>	20 minutes
8(a)	<p><b>Optional: Key issues role play</b></p> <p>If steps 6(a) and 7(a) were <b>not</b> used, you could now ask a group to develop a ten-fifteen minute role play focused on one or more of the key issues that emerged from the journeys and to act it in front of the whole group before discussions start. This is often an excellent way to energise a group and get them talking freely, and it will help the group to focus directly onto the discussion issues. Preparation could be done during a lunch break, for instance, with the role play as the first activity in the afternoon.</p>	15-20 minutes preparation 10-15 minutes role play
9	<p><b>Focused discussions and action planning</b></p> <p>Use the results of the journeys (and the role plays, if used) as the basis for further discussion, depending on the chosen aims and objectives of the workshop or meeting. Different examples are given on the following pages to demonstrate how this can be done. For example, if the aim is to make an action plan for improving experiences of care:</p> <ul style="list-style-type: none"> <li>• first focus discussion on difficulties and obstacles in the journey</li> <li>• then discuss what improvements people need to make for themselves and what should be done by others</li> <li>• develop a timeline to clarify what needs to be done immediately and what are medium or long-term goals for change</li> <li>• develop a work plan based on basic planning principles, showing who will carry out actions, what resources are needed, etc.</li> </ul>	To be determined when planning the workshop

## Using the methodology

Step	What to do	Timing (approximate)
10	<b>Ownership of workshop outputs</b> Before the workshop ends, facilitators and participants should decide together what will happen to the journey pictures and any list or action plans they have developed. Participants sometimes want to keep them for further reference – if so, facilitators can keep a record by taking photographs of each or, if there is no camera, recording them by hand.	5 minutes
11	<b>Evaluation</b> Carry out a brief evaluation of the workshop. <b>Either:</b> put six pieces of paper up on the wall, each one with a different heading – for example: “Logistics”, “Venue”, “Facilitation”, “Methodology”, “What I liked most”, “What I didn’t like” and ask participants to write any comments under each heading, either directly on the paper or using stickers. <b>Or:</b> stick four pieces of flip chart together to form a square, then draw a big circle on the square; divide the square into six ‘slices’ and write one heading on each; then ask participants to write comments under each heading or use stickers. Facilitators can then summarise the comments and address any unresolved issues.	10 minutes
12	<b>Conclusion and next steps</b> <ul style="list-style-type: none"><li>• Thank all participants for their work.</li><li>• Summarise the major outcomes, and check if people’s expectations have been met or not.</li><li>• Outline the next steps based on the outcomes of the workshop.</li><li>• Ask participants if they want to make any final comments.</li><li>• Bring the workshop to a close.</li></ul>	10-20 minutes

## Making use of the outcomes

As already stated, the health journey is a starting point for understanding local situations. The use that will be made of the drawings and discussions depends to a large extent on the objectives of doing the activity. This emphasises the importance of having a clear reason for bringing people together to do the health journey.

However, it is also important to respond to what comes up during the activities. If something unexpected comes up that is clearly very important to participants, it might be necessary to re-plan the rest of the workshop to allow the issue to be addressed in a satisfactory way. For example, the issue of stigma in health care settings was a major concern for people with HIV in a workshop in Trinidad. Facilitators rearranged the timetable after the journeys were drawn – first, a role play was organised to demonstrate why stigma was so important and then a wide-ranging discussion allowed all participants to express what they thought. This led to some concrete plans for making a difference to the levels of stigma in hospitals and clinics through working with providers and people with HIV.

The first outcomes from the health journey will be the journey drawings and some lists of the issues that are important for participants. Typically, the lists will focus first on difficulties and barriers for people with HIV. Positive aspects are also highlighted sometimes, though often only after people have first described negative aspects of their experiences. Facilitators should not ‘push’ participants into being positive – with adequate discussion, any positives eventually tend to emerge naturally.

Using the discussion outcomes as a springboard for action will require a few further steps (see box on right and example from the Caribbean on page 14).

### Steps for further action

- 1 Get participants to identify the most important issues among all the points that have been made. A useful way of rating the issues is to ask each participant to indicate the three or four issues they would most like to address. You can ask them either to put a sticker next to each issue on the feedback flip chart, or to draw a tick next to it. When all participants have done this, it should be easy to count the stickers or ticks and identify the issues that most people consider to be of major importance.
- 2 Ask participants to discuss who should take action on each of these issues – including themselves and any other group or stakeholder who should be involved. This can be done in plenary, or in small groups – ask each group to work on just one issue.
- 3 Then ask them to develop the list into a workplan, indicating:
  - who should do what
  - in partnership with who
  - who should be the target for each action
  - when the action should happen
  - what funding or other resources will be needed
  - how the work will be monitored
  - how the impact would be measured.A personal action plan for each participant is also helpful if time allows, so that they can remind themselves after the workshop about their roles and responsibilities for any action or change.
- 4 Alternatively, if the workshop is related to designing a new programme, it might be necessary first to develop a detailed map of the community involved, and to clarify who the important stakeholders are, how they are linked with each other, what services are available and what gaps exist. Then further discussion can take place to plan what changes are needed in that community and what can be done to address the gaps.

## Example of identifying further action

A workshop of people with HIV in Grenada, St. Vincent and Grenadines came up with the following about ARV treatment:

### Key issues

- Access to ARVs on a long term basis
- Knowing what the ARVs can do and what the side effects are
- Follow-up of patients' situations

### Highest priorities

- Ensuring people with HIV have good and balanced diet
- Treatment literacy and adherence
- Cheaper costs of drugs for opportunistic infections
- Ensuring that people with HIV take full advantage of ARVs

### Who can address them?

- People with HIV
- NGOs
- Government/politicians
- Churches/faith-based organisations
- CBOs
- Media

### What can we do?

- Enhance public awareness/advocate
- Educate people with HIV about importance of drugs and getting access to them
- Provide peer support to other people with HIV

### What can others do?

- Become volunteer care givers
- Be advocates
- Become partners in sourcing ARVs (financial)
- Educate other people with HIV about the use of ARVs
- Encourage families to be more supportive



Examples of health journeys from Uganda



This section provides five different examples of how the health journey (or treatment journey) has been used by the Alliance. Each example includes a description of the context, the setting in which it was used, the outcomes of the activity and how plans were developed for further action as a result.

There is no 'one size fits all' in developing community engagement for universal access and support for people with HIV. Through illustrating a variety of examples, we hope that readers and users of the activity will be able to think of developments and adaptations of the health journey methodology to fit their own situation. We would be happy to hear any reports of how people have used it and how it has helped people with HIV, communities and the health workers involved.

## Example 1 Understanding the effects of stigma on the uptake of HIV services

The health journey was a starting point for a workshop on ARV treatment literacy organised by the Alliance for representatives of HIV-related community organisations in the Caribbean in August 2005, in support of the Caribbean HIV/AIDS Regional Training (CHART) Network.

The aim of the workshop was to enable participants to understand the concept of treatment literacy and to develop community approaches for improving the quality of HIV and AIDS services from the service user perspective. Participants from eight countries met to discuss their experiences of care, treatment and support services and to strategise on how they could play a greater role in increasing demand for, access to, and the quality of services for people with HIV.

At a pre-workshop meeting, the main facilitator met with local facilitators chosen from among potential workshop participants. Together, they developed the agenda for the meeting and selected different methods to facilitate each stage. The health journey was chosen as an early activity for the workshop and facilitators developed brief scenarios about four different people – see pages 17 to 18 for scenarios and journey drawings.

### How was the health journey used?

After introductions, the three-day workshop began with a brainstorm to highlight and clarify what participants understood about care and treatment. This focused the participants' attention on the key issues of the workshop and enabled them to get used to working with each other before starting the health journey. Facilitators were also able to assess how individuals in the group might work most effectively with each other.

The health journey activity followed the template "Organising the health journey – a step-by-step guide" (see pages 10-12) but did not use steps 6(a) and 7(a). Powerful experiences of stigma within health systems emerged as a major feature of all the four health journeys that participants prepared. We used step 8(a) and asked four participants to produce a role play that showed their experience of the relationships between stigma, care, treatment and prevention.

We then facilitated an extended discussion, realising that it was important to allow sufficient time for participants to talk about their experiences in some depth. This led all of us to a much clearer understanding of how stigma affects uptake and use of HIV services in the Caribbean, and produced some suggestions of ways in which it might be reduced.

Over the following two days, further workshop activities looked at treatment literacy and treatment adherence, focusing on personal, cultural, social and medical challenges and how people with HIV could help to resolve them. The conclusion was that most of the challenges were experienced throughout the Caribbean and that there is a need to engage people with HIV in analysing situations and finding solutions.

Recommendations for specific actions by people with HIV included:

- Lobbying and advocacy for better care, treatment and support
- Capacity building for government, civil society, faith-based organisations and the private sector
- Sharing experiences of what works and doesn't work and encouraging national and regional synergies
- Greater engagement between government and civil society.

# The health journey in different settings Example 1

The workshop concluded with practical action-planning activities for improving the quality of care and treatment by working with a range of service providers and policy makers, both regionally and in participants' own home countries.

The following pages detail two scenarios with photos of the health journeys and participants' responses on overcoming barriers and improve the person's experiences.

## What were the outcomes and how were they used?

Immediately following the workshop, the health journey was successfully used in a meeting with service providers at a regional hospital in Trinidad. The hospital staff were keen to improve services, but a local HIV NGO felt that they first needed a better understanding of the challenges facing people with HIV.

Groups of doctors, nurses, health visitors, nutritionists and volunteers of a local HIV NGO were involved in a real case scenario of a young woman with HIV and pregnancy-related problems. She had undergone a long and complicated course of events in trying to get access to the right services but had eventually died. The

story was described by her sister, inevitably bringing up difficult emotions both for herself and the participants, but also making the story very 'real'. While the story was being told, an Alliance staff member helped to draw the journey on flipcharts on the wall

The health workers then divided into small groups, based on their work roles. They discussed what actions they should take, what support they would need for these actions, and what others should do to support their efforts and bring about change. They finished by preparing priority action plans with timescales for each of the components needed to achieve the priorities.

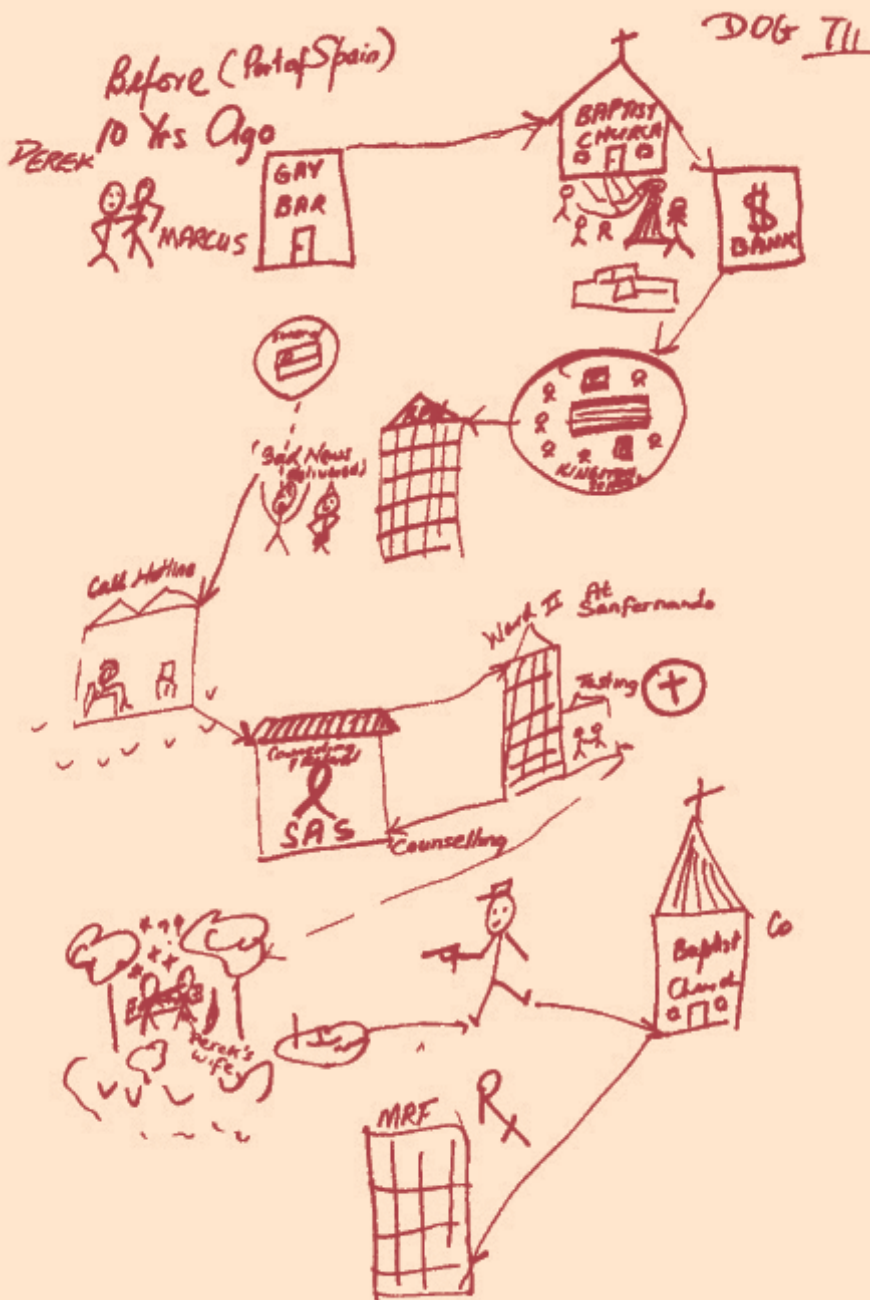
For instance, the doctors highlighted the need to "remove the inequalities in our medical services – we are not adhering to the basic principles of public health". They resolved to provide ongoing training on HIV and AIDS treatment and care for all health care workers at their facilities. The nursing staff focused on accessibility, availability and affordability of services and on acceptance of the HIV diagnosis by patients, saying that they should "ensure the person has accepted a positive test result and continue to equip her or him with coping skills for daily living; after acceptance, disclosure should be less difficult to those who are part of his or her support system".



Example of health journey from the Caribbean

# The health journey in different settings Example 1

## Scenario 1 – Derek



Derek is a 30 year old man. He is married to Sandra. He works at a bank. He has one child, aged 10 years. He has just found out (from one of the nurses at the clinic) that an old sexual partner, Marcus, has tested positive for HIV. Derek has never had an HIV test. He is scared to go for a test because some of the nurses know him.

### Barriers

Fear that HIV means death  
How to disclose to his wife?  
Underground sexual practice – having sex with men  
Popular person – know in community

### How were barriers overcome?

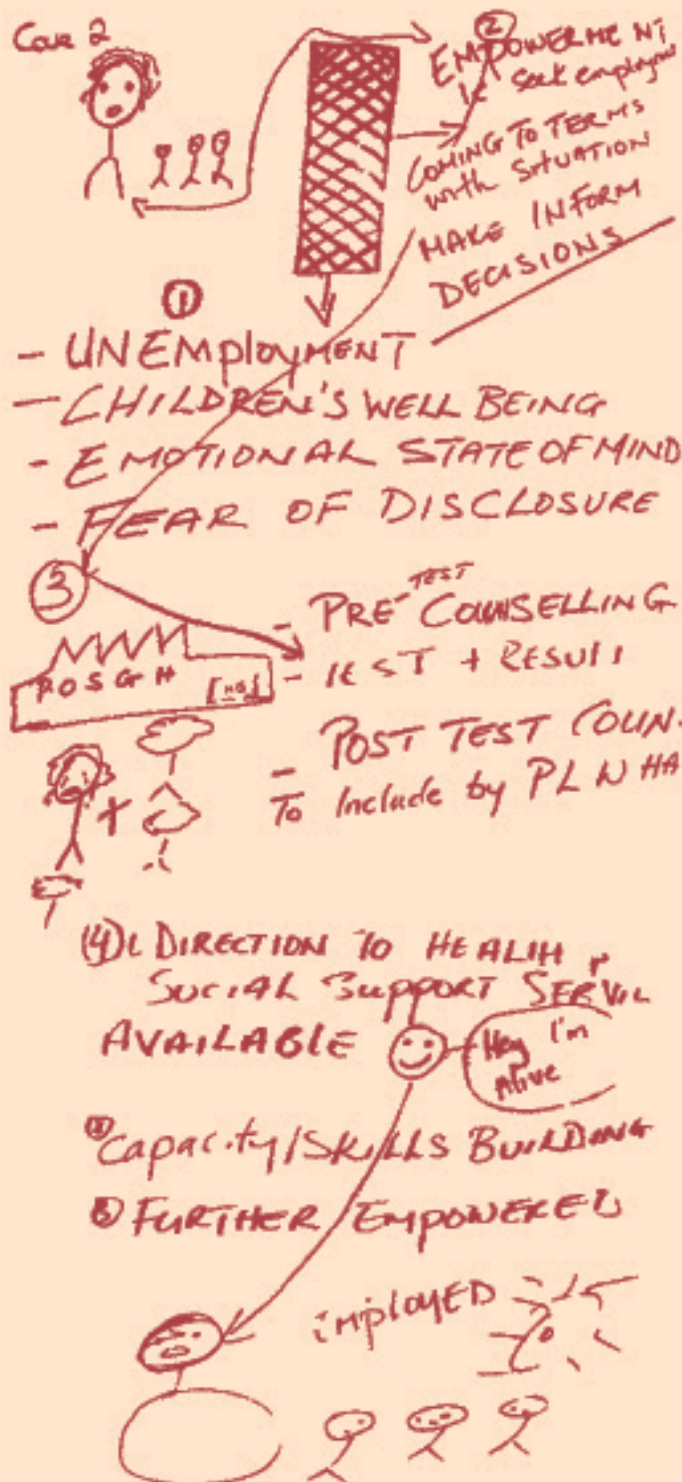
Called a hotline (anonymity)  
Referred to a support group  
Went for testing far from where people know him  
Post-test counselling for dealing with status, and how to disclose  
Go to the Baptist Church for counselling  
Go to the Medical Research Foundation for treatment

### What can the community do?

Support and encourage the use of the hotline  
Support individuals to seek testing  
Encourage and support with post-test counselling to deal with status and disclosure

# The health journey in different settings Example 1

## Scenario 2 – Gloria



Gloria is a 28 year old woman with three children, ages 8 years, 3 years and 6 months. She is not working and depends on her current partner, John, the last child's father who visits and lives with her sometimes. Her friend Brenda told her he has another girlfriend in the next town, he sometimes sleeps by hers and she is having his baby. He used crack cocaine but told Gloria he stopped months ago. Brenda came two days ago and told Gloria he was seen coming from the clinic in town that treats sexually transmitted infections and HIV. Gloria is scared. She noticed some swollen glands in her neck a few months ago, and has a rash on parts of her body. She refused the HIV test at the antenatal clinic when she was having her baby, but she wants to have one now. She knows if she asks John any questions he may beat her up and might leave.

### Barriers

- Unemployed with three children
- At risk of becoming pregnant again
- Fears for the well being of her children if she tests HIV positive
- Fears people are thinking she is HIV positive

### How were barriers overcome?

- Seeks empowerment to help her come to grips with her situation (that she might be positive) and make informed decisions
- Goes for pre-test counselling at hospital and gets post-test counselling
- Gets information about how she should lead her life
- Counselling includes talking to people with HIV who help her with how to deal with her situation

## Example 2

### User experiences of HIV-related health care

This version of the health journey was developed specifically for use with groups of HIV service users and providers in individual countries in the Caribbean region. It followed the regional workshop described in example 1.

Focusing on individual countries was a first step towards developing a user-friendly and constructive feedback mechanism for the benefit of both users and providers. Understanding the experiences and needs of people with HIV with regard to HIV treatment and care services in their own country was aimed at complementing provider-led assessments of services and contributing to development of in-country, user-led criteria (indicators) of service quality. One-day health journey workshops were held in St. Vincent, Grenada and Barbados in April and May in 2006 to collect data and to field-test the tool with people with HIV in the Caribbean setting.

#### How was the health journey used?

The health journey activity followed the steps in the section “Organising the health journey – a step-by-step guide” (see pages 10-12). Generally, we took the option not to use steps 6(a) and 7(a) in these workshops, but we sometimes used step 8(a) instead at the beginning of a later session in which participants highlighted the barriers they encountered in their country relating to stigma, care and treatment.

As well as using fictional scenarios for treatment journeys, we invited a few participants to talk about their own real-life journeys, if they were willing to share them with the whole group. This helped to bring out aspects that had not emerged in the fictional journeys and to add important details. The sharing of personal journeys was usually done verbally, without making pictures.

After the health journey activity, participants were able to develop a list of priorities for action to improve service users’ experiences, categorised according to a timeline – immediate, short-term, medium-term, long-term and ongoing or training. On the right is an example from Barbados.

#### Timeline of priorities for action, Barbados

##### Short term

- Provide information on medication to clients
- Provide information when medication is changed
- Provide information when new drugs are prescribed
- Provide more open air testing but manage the waiting time
- Provide information about the availability of care and treatment services
- Clients to communicate their changes, concerns and updates to the providers

##### Medium to long term

- Reduce waiting time at hospital – one way to do this would be to extend the service hours at poly-clinics to handle minor accidents, prescriptions, etc. and take some of the workload off the hospital
- Provide updated information on HIV, AIDS, ARVs, STIs, etc by producing booklets, pamphlets, posters, etc.
- Do regular quarterly inventories to manage the supply of medication and testing kits
- People with HIV community to undertake group advocacy efforts to lobby for an improvement of the food supply from the food bank
- Promote customer service rights within the health sector

##### For training (ongoing)

- Provide more sensitisation training for health care providers and other health care workers
- Do aptitude testing for health care workers
- Provide training for counsellors and educators from people with HIV community so that they can become an integrated (and paid) part of care and treatment delivery
- A specific recommendation was made to health care providers to keep an open mind and to be open to other experiences in order to learn more

### What were the outcomes and how were they used?

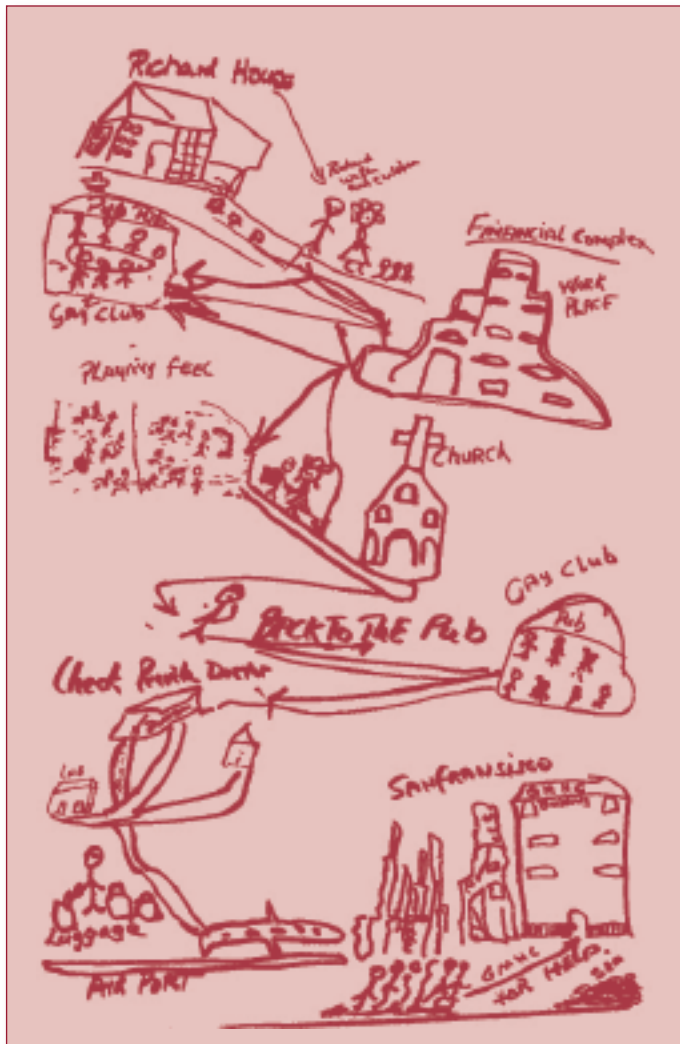
The outputs of the treatment journey workshops were later presented to health providers in each country by people with HIV who had been at the health journey workshops, with support from Alliance staff to facilitate them to meet successfully with health providers in small-scale focus group discussions.

This approach led, for example, to changes in the location and format of an ART clinic and the layout of the pharmacy in one hospital, which helped to remove stigmatising practices and ensure greater privacy and confidentiality. In a different country, people with HIV are now involved in providing input to trainee doctors at the hospital, and health workers receive support and information from the Alliance to update their understanding of caring for patients and caregivers.

In preparation for the client-provider discussion workshops, the Alliance recognised that previous efforts to bring clients and providers together had sometimes been confrontational. The Alliance sought to overcome this by focusing on rights and responsibilities, partnerships, and positive communication approaches. It was emphasised that change was necessary from both sides in order to improve care and treatment. A list of steps for management of the process was developed, summarised as follows:

- 1 Reports from health journey workshops were circulated to participants, and feedback was incorporated into the reports.
- 2 People with HIV who participated in the health journey workshops were informed that the outcomes would be shared with health care providers to improve care and treatment.
- 3 People with HIV were selected to make the presentations to health care providers, and were supported to ensure that all the key points were highlighted.
- 4 People with HIV, as representatives of health care clients, were trained in basic communication and advocacy skills and advised on handling potential conflicts, responding to criticism, listening skills and strategies for effective collaboration with providers.
- 5 “Ground rules” were shared with clients and providers, for example on respecting each other’s opinions, listening to each other and taking the opportunity for sharing and dialogue, not for criticising or blaming.
- 6 Presentations were given without interruption, reserving questions and discussion for small group work, thereby reducing the potential for conflict and encouraging constructive sharing of experiences by both clients and providers. Alliance staff monitored the process and acted to defuse tensions, re-phrase questions and clarify points of information.
- 7 Before the group sessions, Alliance staff observed individual and group interactions and ensured that small groups contained providers and clients who were able to work together constructively and without confrontation.
- 8 After the client presentations, small group work was guided by a request to identify four key issues in care and treatment that clients and providers could work on together in order to take action. Facilitators coordinated the responses and summarised the main issues and recommendations from the workshop.
- 9 The session was held in the morning and ended with an informal lunch, enabling further discussions and strengthening of relationships between providers and clients
- 10 The Alliance e-mailed copies of the draft workshop report to all participants as the first follow-up after the workshop. The report included the workshop methodology, aiming to enable further workshops to follow the same process without further Alliance facilitation.

## Scenarios for Caribbean health journeys



Richard is 35 years old and is married. He is a civil servant with a good job in the government service. He lives with his wife and they have three children. Although Richard has a wife, he sometimes has sex with men. Richard likes to socialise – to go out for drinks, play football and to go to church with his wife sometimes. In recent times, Richard often feels sick, and is coughing a lot.

Marcia is a 14-year-old girl who lives with her mother at home. Marcia was involved with a 19-year-old boyfriend who was also having sex with another girl in the same area. The boy became sick, went to the doctor, was asked to take an HIV test and found out he was HIV positive. He has told Marcia of his status and has advised her that the nurse wants Marcia to visit the clinic as well.



### Scenarios for Caribbean health journeys

Lisa is 19 years old and is pregnant from an older, married man. She has a one-year-old child being looked after by her mother. Lisa also has a boyfriend who is her age and doesn't know about her pregnancy or the older man. She did not finish school – only went to third form – and is not working. She found out she is HIV positive at the antenatal clinic.

Yvette is married with two children. She is very dedicated to her church, always sits in the front pew, never misses a Sunday service and takes part in all church activities. Yvette goes to the doctor because she has not been feeling very well lately. After examining her, asking her questions and discussing an infection that has not gone away the doctor recommends that Yvette has a test for HIV.

Tike is a 24-year-old 'boy on the block'. He has been having sex with and without condoms for three or four years. He just found out that one of his frequent partners died, and the gossip is that it might be of AIDS.

Michael is 26 years old and is a taxi driver. He is very popular and works hard to try to make a good living. Michael lives with his present girlfriend but he had quite a few girlfriends before her. He now plans to move to the US to join his mother and family who are living there. Michael had an HIV test for his visa and discovered he is HIV positive.

Nicholas is 20 years old. He has sex with both women and men. He has just found out that he is HIV positive after taking a test with a private doctor. He is worried about going to the government clinic for treatment (where he might be recognised), but he can't afford to go for treatment in a private clinic.

Vashti is a 15-year-old girl who has just heard from a friend at school that her previous boyfriend Matthew, who drove a maxi taxi in town, is in hospital. The talk on the street is that he has AIDS. They broke up six months ago, and she has not seen him in the last three months. She is worried and wants to have an HIV test. She cannot talk to her parents about the situation. They did not know she was missing school to be with Matthew. She wants to ask her best friend, Jane, but she knows that Jane likes to talk about everyone's business.

Mark is a 17-year-old youth. He lives with his mother. He has been having sex with male tourists who he meets at the beach, to earn some money. He is sure his mother would throw him out if she found out. Some of the men do not use a condom because they do not like the way it feels. He has been having a burning sensation around his bottom, and has no idea why, but is worried he might have some kind of infection.



## Example 3

### A starting point for a community referral system

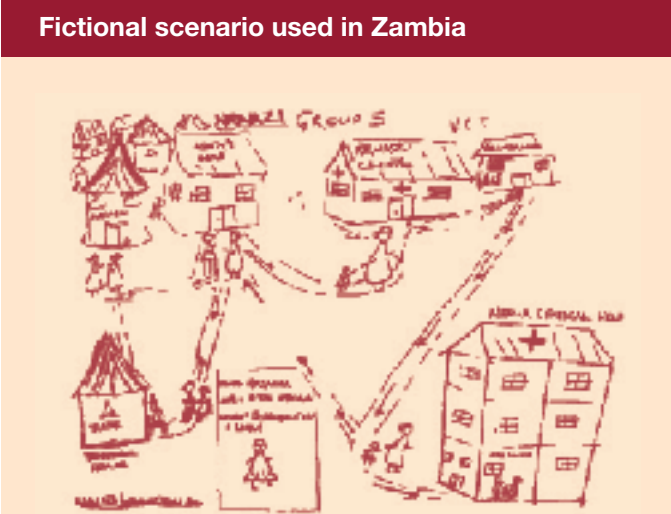
In Zambia, the Alliance has been running an integrated community education, referral and ARV treatment support programme, the ACER Project, since 2004. It is a comprehensive approach, including several partners, each having different functions – a home-based care programme, the traditional healers association, an HIV positive people’s network, the local clinics and the ART referral clinic staff. The health journey was an important step in the early planning of this project.

#### How was the health journey used?

First, we asked partners to draw a map of their community and the health and support services that were available. Then they were asked to locate themselves on the map and to clarify what skills and support each of them might contribute to the ACER project. The drawing below shows one of the maps

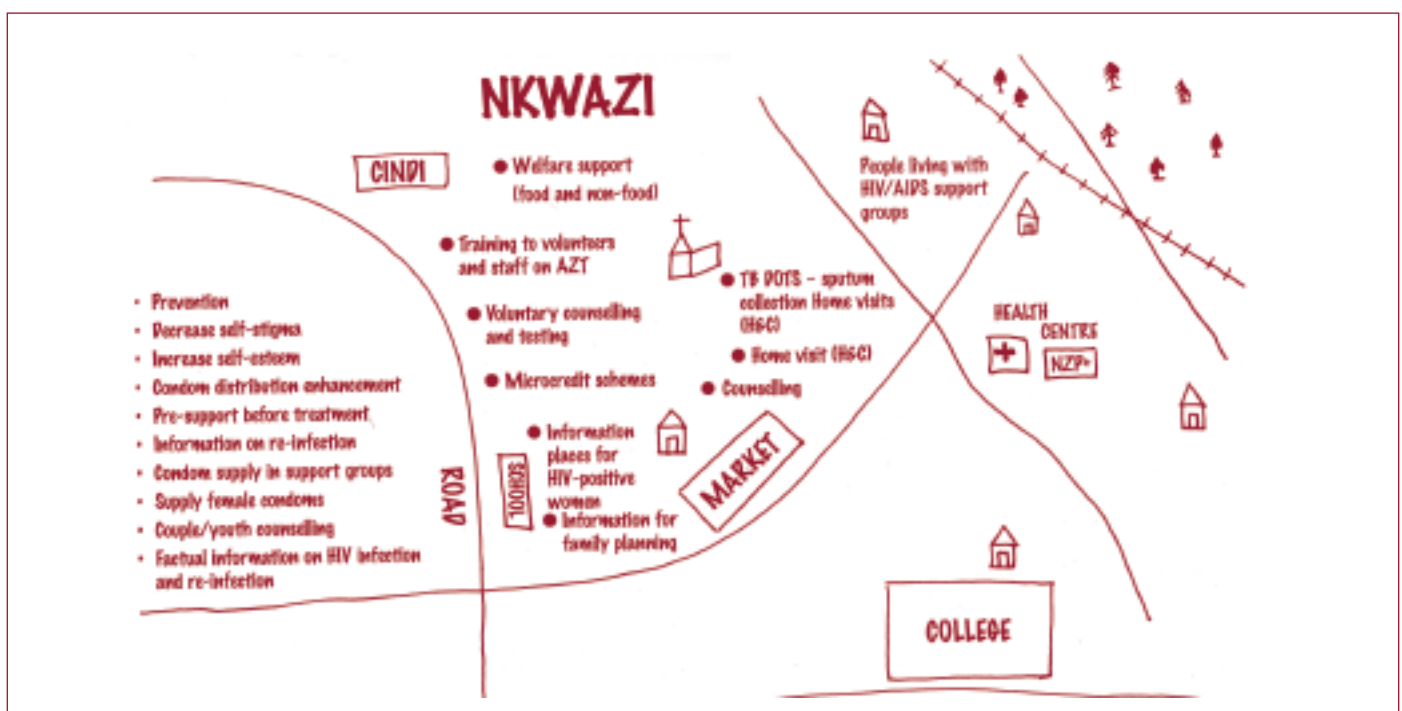
ACER partners were next introduced to the health journey, based on fictional scenarios about five different adults and children who were typical of people in these communities. The activity followed the steps outlined on pages 10 to 12. The role plays suggested in steps 6(a) and 7(a) of the template were included in the activity, and partners were asked to highlight what would be

**Fictional scenario used in Zambia**



Natasha, a 6-year-old girl, is an orphan and lives with an aunt and uncle. They often shout at her and treat her differently from their own children, although they do not beat her. She does not play with the other children and sometimes sits behind the house crying. A neighbour notices that she is frequently ill and unhappy and suggests to the aunt that she be taken to a traditional healer. The healer correctly realises that Natasha might be HIV positive and he refers her for medical attention.

needed at each stage of the journey to make sure that the person was referred to the right person or place for the next stage of the journey.



## What were the outcomes and how were they used?

When discussing and summarising what emerged from the journeys and the role plays, the facilitators made notes on separate flip charts on what was helpful and what was not.

This information became the basis from which the ACER partners developed a check list of what is necessary for a 'good' referral from the point of view of the client, the person to whom the referral is made and any community organisation that provides support to the client. This check list was used to develop a **two-way community referral system** that has been instrumental in ensuring that people gain access to the health system and other forms of support when they need it, and that they are followed up when they return to the community.

A person in need of care is given a referral form by the partner organisation and takes it to the place they have been referred to – usually the local clinic or the government ART clinic. When clinic staff have seen the client, they hand the tear-off portion of the form back to the client to take back to the organisation that made the referral, for ongoing support and follow-up. Depending on circumstances, the treatment support worker might also accompany the person back to the community and ensure that the referrer is aware of what has happened.

Partners – community and health system – hold regular referral coordination meetings to track performance of the system and to discuss the issues and needs of individual clients. As a result, the system runs smoothly and all partners have ownership of the system and are committed to using it efficiently.

## Using the outcomes, Zambia

ACER partners identified the following as being important for an effective referral.

### For the client

- Clear instructions on where to go, who to see, and what times or days a service is available
- Formal 'introduction' e.g. a referral form that explains why the person needs to access the service
- Information from the referrer and the provider on why the referral is necessary, what actions the provider proposes and why

### For the service provider

- Information about why the person is being referred
- Name and address of the person being referred and the person making the referral

### For the person/organisation making the referral

- Feedback from the service provider on what has happened and suggestions for further support to the client

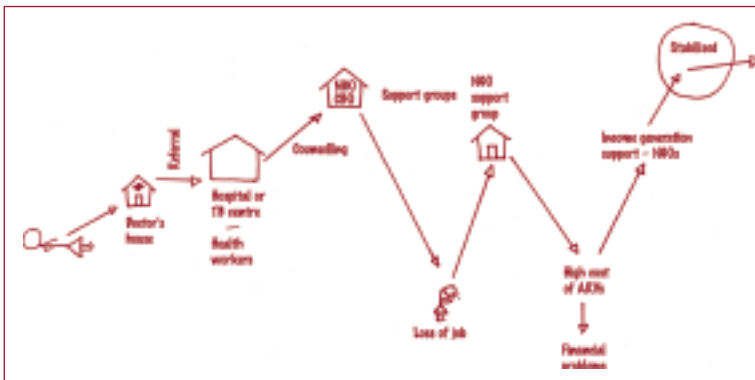
The image shows a sample of a referral form from Alliance. The form is titled 'Alliance Supporting Community Action on AIDS in Developing Countries' and 'REFERRAL FORM'. It includes fields for 'To:', 'From:', 'State:', 'Name:', 'Residential Address:', and 'Reason for Referral:'. There is also a section for 'Name:', 'Designation:', and 'Signature:'. The form is numbered 'No. 1301' and has a date field 'App/Year: / /'. Below the referral form is a 'FEEDBACK' section with fields for 'Name:', 'Date:', 'Comments:', and 'Signature:'. The form is shown at an angle, suggesting it is a physical document.

## Example 4 Treatment support for people with HIV

This version of the tool takes a slightly different approach from the previous examples. It is taken from another Alliance toolkit, "Tools Together Now". It involves drawing the story of one person's health over a period of time – a personal health journey – and marking in the person's health "ups" and "downs", identifying the treatment and support that they need at each stage and where they might get it.

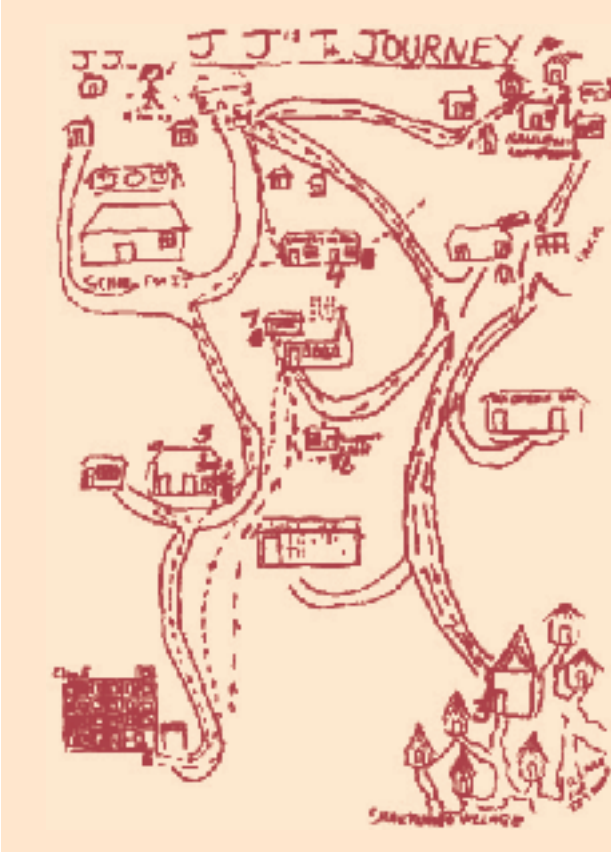
Instead of working with 'fictional' examples of people from their community, each participant looks at their own individual treatment or care journey. They are asked to highlight important issues and work out ways to make the journey better and more effective.

Using the journey in this way can be very effective. It helps individuals to look at their own role and to ensure that they get the help they need to use services successfully, to adhere to their treatment and to manage their own health.



*The journey of a person who decided to go for voluntary counselling and testing. Adapted from an Alliance care and treatment workshop, Nigeria. Tools together now, International HIV/AIDS Alliance, 2006*

### JJ's Journey – treatment planning



JJ is a young man of 17. He likes to go to bars and hang around with several girlfriends. He still goes to school, sometimes. When he started to get sick, he went back to his home village to stay with his grandparents. Eventually he decided he should get tested for HIV and get his sexually transmitted infections treated. At the clinic, he was also told to start ARV treatment and was referred to hospital.

Drawing the journey with JJ showed that he would have many challenges in adhering to treatment or in changing his behaviour in order to prevent transmission of HIV to other people.

JJ's treatment support worker helped him to work out how he could remember to take his treatment regularly, whatever activities he was engaged in each day. She also helped him to think about his behaviour and to start using condoms regularly for sex. Eventually, he realised he should be more responsible in his relationships and he cut down on the number of people he was having sex with.

## The health journey helps to

- provide a non-threatening way to discuss sensitive issues about one's own physical or mental health and HIV.
- identify one's knowledge and beliefs about HIV
- identify common health problems faced by people living with HIV
- identify the treatment and support needed for one's health problems
- identify what treatment and support is available to people with HIV
- discuss who can and who cannot access existing treatment and support services
- identify barriers to treatment and support and discuss how they might be overcome.

## How to use this version of the health journey

- 1** Health journeys are best done with individuals or in pairs. Explain to participants the purpose of the tool.
- 2** Ask the participants to think about the different health issues experienced by people with HIV or their own health issues.
- 3** Ask the participants to choose a specific period of time, e.g. a person's health journey in the last month or "my health journey since being diagnosed HIV positive."
- 4** Encourage the participants to draw their personal health journey. As the journey progresses the line goes up when things get better and down when things get worse (see diagram on page 25). Indicate on the line what made things better or worse at each point.
- 5** Discuss the health issues that the person may experience during the chosen period of time. These may be physical or mental health issues – show them on the health journey line.
- 6** Encourage the participants to identify gaps in available treatment and support.
- 7** Ask participants to present their health journeys to other participants (but respect any decision by a participant to keep their journey private). Ask them to explain what has helped them, what has not, and how the health journey could be made easier.

## Facilitator's notes

- A person might not want to draw their own health journey, for example if there is something they do not want to disclose or because the journey has been too difficult to talk about. You should offer all participants the alternative of making up a 'fictional' story by thinking of the health journey of different people they are familiar with or have heard about.
- Participants could draw health journeys for different people – for example, a young man, a young woman, a child – this helps to explore the differences in health and treatment issues faced by different people.
- Encourage participants to think about informal treatment and support as well as 'modern' medicines, for example traditional medicine or psycho-social support from friends and family.
- When the activity has been completed, ask participants to brainstorm examples of other ways to use the health journey. This can help them to think about using it with other people they are supporting, or of ways it could be used by service providers.

## Example 5 Human resources for health – a new approach

At a 2004 Alliance policy workshop on ARV treatment for its NGO partners, human resources for health was a key topic for discussion. After input about health systems and professional health care workers, we used a new tool, the treatment journey, to help participants think more creatively about the many other people who also act as 'human resources' for HIV prevention, testing, treatment and care.

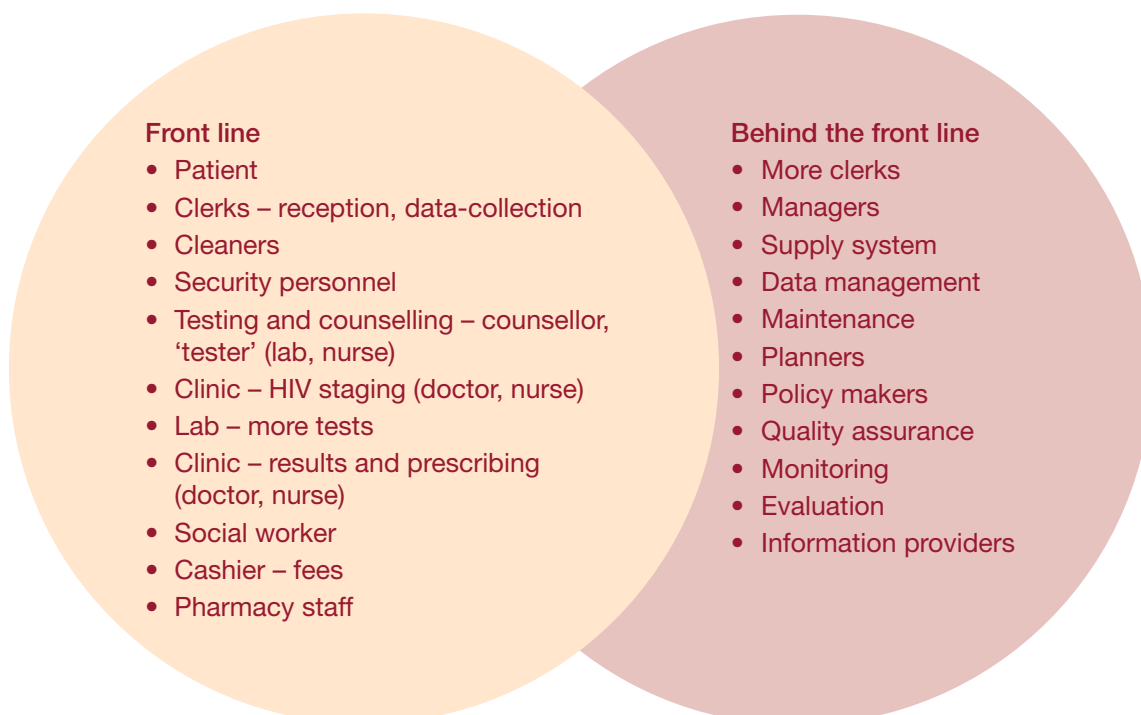
After explaining what we meant by the treatment journey, we asked participants to brainstorm their responses to some questions in small groups, asking:

- Where and with whom does the treatment journey start?
- How does the journey continue when a person reaches a health facility?
- Who provides support to a person with ongoing treatment and health needs?

Participants responded that the journey starts with:

- Oneself – the individual with the problem
- Family or friends who can offer advice and support, or suggest some simple remedy
- Local drug or remedy provider – pharmacy, herbalist, traditional healer, market trader
- Local HIV 'contact point' – a helpline, an NGO or community organisation, etc.
- A trusted local adviser such as a teacher, religious leader, etc.
- A local clinic – doctor, nurse or others
- A more remote clinic (especially if nothing else is available closer to home, or if the individual wants to keep the problem secret) – doctor, nurse and others.

In response to the question about what happens when a person reaches a health facility, participants highlighted that a person meets with the 'front line' workers in a health facility – not only the medical workers, but several other types of people who might interact directly with the individual. Behind this 'front line' are those who make it possible for front line workers to do their jobs. These people might not interact directly with patients, but they are responsible for services and support that affect what can be done for patients and the quality of what is offered.



# The health journey in different settings Example 5

On the question of who provides support to a person with ongoing treatment and health needs, participants agreed that the journey is not just a “one-way street” to see a medical worker. It continues after the person leaves the health facility and moves on – to home, to another source of help, or elsewhere. So we also need to understand which are the human resources for this part of the journey.

## Participants gave these examples

### Within a health facility:

- Relative/friend
- People with HIV supporter or advocate
- Other patients in the queue
- Nurses, cleaners, clerks, etc.

### Within the community:

- Other people with HIV
- Close family or friends
- Extended family
- Community
- Employer
- Church
- People with HIV groups, NGOs
- Information media

This initial use of the journey concept was based purely on discussion, without using the drawing process that was later developed into the health journey methodology. Nevertheless, it successfully highlighted the great importance of the many non-medical people who can influence access to and use of services such as HIV testing, ARV or other treatments and care for someone living with the difficulties presented by being HIV positive.

These people can greatly facilitate the journey if they are well-informed and do not discriminate against people with HIV. On the other hand, they can be a serious source of misinformation and stigma, thereby discouraging or even blocking effective access to and use of services.

Such ‘non-professional’ human resources are often not included in planning for health services. Yet they have much influence on the individual and on the uptake of health provision. They therefore need to be able to give accurate information, be aware of what can be done to improve health, and be supportive of people with HIV. Then they can contribute greatly to the success of a health service and can actively influence design, delivery and management of services. This is what is meant by community engagement and having client-centred health services.

**TREATMENT**

- FINANCE - PERSONAL/FAMILY/WORKING FINANCE - BARRIERS TO TREATMENT
- FINANCE TO TAKE HOME } STAFF OF DISCOUNT A LINK OF TRANSPARENT & HONEST
- QUALIFIED PERSONNEL FOR TREATMENT
- PROMOTION OF MEDICAL SERVICES
- PROMOTION TO RECEIVE ART OF MEDICINE
- EFFECTIVE ANTIRETROVIRAL
- CONTINUOUS MONITORING TO CONSERVATION OF DRUGS (As MONITORING OF THE PROJECT)
- AVAILABILITY
- EMPOWERED DECISION MAKING (CARE)
- CD4 & VIREAL LOAD TESTS
- SUBSTITUTES COSTS (TABLETS/CLAY/INJECTION/ART)
- TREATMENT IS PART OF HEALTH CARE SYSTEM (As PARTIAL TREATMENT - STAFF/DISCOUNT APPROACH TO NEEDS OVERCOMING BARRIERS - CONSULTANTS)
- KNOWLEDGE OF DIFFERENTIALS OF TREATMENT & HEALTH SYSTEMS
- SIDE EFFECTS

**CARE & SUPPORT**

- Lack of 'genuineness' by family towards the care & support for family members who are positive
- PLWHA are concerned about "how we are going to get the help that we really need" in the presence of limited support
- Family & community have a pivotal role to play in providing care & support
- Support helps PLWHA to build & move forward - "we have to be caring in a supportive way"
- PLWHA must demand respect, care & support "we must be bold"
- We have to be honest, esp to our family, as they are important in providing care & support "if family is to look for us, they must be aware of the situation, & only PLWHA can clarify the special needs"
- Persons often times ignore the psychological needs of PLWHA in terms of care & support

**CARE**

- 1) THE PERSONS TOTAL WELLBEING (NOT JUST MEDICAL)
- 2) CARING FOR THE CAREWORKER
- 3) ATTENTION TO SMALL BUT IMPORTANT DETAILS NORMALLY OVERLOOKED IS HYGIENE
- 4) LISTENING, BODY LANGUAGE
- 5) CONTINUOUS CARE FOR CAREWORKER
- 6) INDIVIDUAL CARE (EVERYONE DIFFERS)

C COMFORT / CONSIDERATION  
A ASSIST/ALSOSS  
R REACHOUT / RESPECT  
E EDUCATE & EMPOWER / ENGAGE

Output from discussions by people with HIV on their understanding of care, support and treatment, which followed the health journey activity at an Alliance treatment preparedness workshop in Trinidad held in 2005

## Useful resources and tools

These publications are useful resources for community mobilisation and action for HIV-related treatment, care and prevention. All Alliance publications can be downloaded or ordered from the website at [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications) or by e-mail to [publications@aidalliance.org](mailto:publications@aidalliance.org)

### Community Engagement for Antiretroviral Treatment – Trainers' Manual

Participatory tools, information and activities for civil society organisations working with people with HIV on treatment, care and prevention. 2006 (English and French): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### Let's Talk About Counselling and Testing – Facilitators Guide

This guide is designed to help NGOs, CBOs and others to increase their knowledge and improve the quality of their work on HIV counselling and testing. 2006 (English and Spanish): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### Understanding and Challenging HIV Stigma: Toolkit for Action

This toolkit was designed for NGOs, community groups and HIV educators to raise awareness and promote actions to challenge HIV stigma and discrimination. Based on research in Ethiopia, Tanzania and Zambia, the toolkit contains more than 125 exercises. 2007 (English, French, Portuguese and some modules in Kiswahili): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### Tools Together Now! 100 participatory tools to mobilise communities for HIV/AIDS

This publication provides a selection of effective tools for community mobilisation. It is designed to help put All Together Now! into practice to become actively and influentially involved in addressing the causes and effects of HIV and AIDS. 2006 (English): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### All Together Now! Community Mobilisation for HIV/AIDS

This accompanies Tools Together Now! and provides comprehensive guidance on mobilising communities to respond effectively to HIV and AIDS. 2006 (English): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### A Facilitators Guide to Participatory Workshops with NGOs/CBOs Responding to HIV/AIDS

This provides guidance on how to organise participatory training workshops. 2001 (English, French and Spanish): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### 100 Ways to Energise Groups: Games to Use in Workshops, Meetings and the Community

A series of 100 simple exercises to help energise participatory sessions and workshops. 2002 (English, French and Spanish): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### Peer Education Training Manual

Describes ways in which NGOs may design, deliver and manage training programmes for peer educators. Its purpose is to assist NGOs to design and implement strategies and work-plans for peer education, as part of comprehensive sexual health interventions. 2006 (English): [www.aidsalliance.org/publications](http://www.aidsalliance.org/publications)

### NGO Support Toolkit

This searchable online toolkit provides downloadable information on HIV and AIDS prevention, care, support, treatment, impact mitigation and NGO/CBO capacity building. Of particular interest, it provides information on participatory assessments with injecting drug users, populations key to the epidemic and children affected by HIV and AIDS. 2005. (English but contains some documents in French, Portuguese, Spanish and Russian): [www.ngosupport.net](http://www.ngosupport.net)

### OVC Toolkit

This searchable online toolkit provides a series of useful resources for NGOs wishing to respond to children affected by HIV and AIDS. 2006. (English but contains some documents in French, Portuguese, Spanish and Russian): [www.ovcsupport.net](http://www.ovcsupport.net)



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