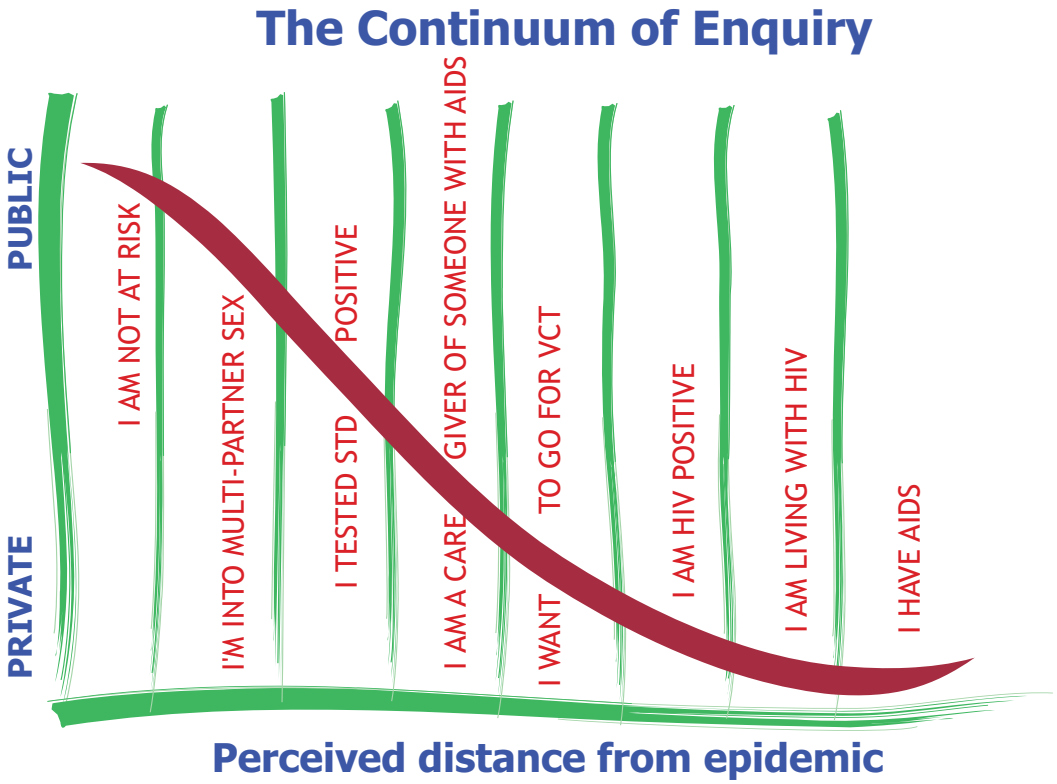
The Continuum of ENQUIRY

How do a person's questions change as his or her self-risk perception changes?

As the distance individuals perceive between themselves and HIV decreases, their questions begin to change and deepen — they grow more personal, more urgent, more technical, more emotional, and more confidential. How can the quality of enquiry be used to gauge progress towards new behavior?

Where do people's questions about HIV and AIDS come from? Why does one want to discuss only whether the origin was an African Green Monkey, while another seems to be fixated on whether condoms have holes, while a third is urgently enquiring whether she is better off with ARTs or just improved nutrition?

Many who work with community members in peer education programs have noticed that questions form a mosaic that vary from person to person. With the same person, they may vary from time to time. They als notice those who seem to have no questions at all, but seem intensely engaged in the discussion going on. At another extreme seem to be those individuals who have numerous penetrating questions, but will only ask them when no-one else is listening. There are individuals who usually bubble over with questions but suddenly fall quiet, and usually silent spec-



Analysis by **C Y Gopinath,** Creative Director
PATH, ACS Plaza, Lenana Road, P O Box 76634, Nairobi, Kenya.
email: cygopi@path-kenya.or.ke

path

The Continuum of ENQUIRY

How do a person's questions change as his or her self-risk perception changes?

tators who seem to grow urgent questions.

What accounts for these ebbs and tides and changes of flavour in people's questions? The Continuum of Enquiry is an artificial construct, based on insights gleaned from working with communities in dialogue-oriented processes, that seeks patterns in the way that people's questions emerge and change and grow. The Continuum of Enquiry suggests that changing patterns of enquiry may be linked to changing patterns of self-risk perception. As a person perceives a closing of the perceived distance between himself or herself and HIV, their questions change and grow.

Since behaviour change is most often connected with imminence of perceived risk, there is possibly a correlation between changing patterns of questions and imminent behaviour change. Such a link, though it would be extremely useful for practitioners of behaviour change interventions, needs to be established through rigorous research. This document attempts to lay out an intuitively and experientially cogent construct that has already helped in a better understanding of individuals' progress towards deeper risk perception.

Consider these two characters, both representative of real-life stereotypes:

- **John is 21,** and believes that he will never get infected by HIV . He is healthy, happy, full of energy, a champion of the football team, and really popular with the girls. He believes HIV infects people who visit commercial sex workers. Since his partners are all healthy looking and beautiful young girls, he believes condoms are unnecessary. John's questions about HIV and AIDS are usually superficial and theoretical — Where did AIDS come from? Do mosquitoes spread HIV? Is HIV part of a global conspiracy to wipe out Africa? Is it true that condoms are laced with HIV? In fact, John believes that safe sex is not for him, and will tell you that condoms don't work, have holes that let HIV through, or burst during sex.

- **Mary, 28,** recently learned that she was HIV positive. After a period of shock, guilt, anger, and depression, she began to deal positively with her infection. There is much Mary wants to know about HIV and AIDS, and she cannot wait. Every new fact she learns is helping her understand how she can live better withis virus in her blood — How long does HIV take before it causes AIDS? What kind of foods should I eat in order to survive longer with HIV? Can anti-AIDS drugs help me stay alive longer? Can an HIV positive person marry and have children? If I become pregnant, what are the chances of my baby being HIV positive? What kind of opportunistic infections will a person with HIV get? What are the chances of a vaccine or cure for HIV?

Mary's questions are urgent, technical, and specific, unlike John's, but her problem is that she will never dare ask these questions in public, for fear that the very act of asking them may make others wonder if she is HIV positive.

John perceives a huge distance between himself and HIV, while Mary knows that the virus is in her blood and will kill her one day. John is hardly interested in HIV and his questions express his superficial and detached interest, while Mary's questions show that she is deeply involved in knowing as much as she can about the virus and AIDS.

The Continuum of Enquiry

As a person perceives growing personal risk from HIV, his or her questions change to reflect new information needs and perceived gaps. This intuitive observation is easily borne out by a little reflection: we ask questions for a purpose, usually to acquire information that we feel we need. If I feel in danger, I seek information that will help me escape, overcome, or surivive the danger. If the danger is immediate and imminent, my need too is immediate and urgent. If I perceive the danger to be far, then my question will reflect the lack of urgency.

Facilitators dealing with the questions of community members are aware that as a person feels nearer and nearer to the risk of HIV infection, his or her questions evolve to reflect new areas of interest and emerging concerns. This is called the Continuum of Enquiry. Behavior change is most likely when a person feels that HIV is close enough to do harm to him or her. The purpose of facilitated discussions is to improve the quality of a person's questions. As their understanding deepens, they are more likely to personalize the epidemic, and move towards behavior and attitude change.

The Stages of Enquiry

The Continuum of Enquiry proposes eight identifiable stages of increasing or changing self-risk perception (see diagram). These stages do not represent risk

The Continuum of ENQUIRY

How do a person's questions change as his or her self-risk perception changes?

from HIV alone. For example, until a person is confirmed HIV positive (stage 6), the main risk he or she may perceive is of HIV infection itself. But once a person is confirmed seropositive, the perceived risk is of re-infection by HIV, opportunistic infections, and of course, death through AIDS.

It is also worth noting that the risk perception and accompanying concerns of a person who has just learnt of a positive rest result tend to be significantly different from those of a person who has begun coming to terms with being HIV positive, and is finding ways to prolong life. On the other hand, the individual who has just learned that he or she is HIV positive will pass through complex emotions and may behave in unpredictable and sometimes destructive ways. To create space for these differences, the Continuum of Enquiry includes stage 6 for I am HIV Positive and stage 7 for I am living with HIV.

A casual overview of the Continuum of Enquiry reveals certain groupings:

1. The Prevention stages: Stages 1 through 5 represent a period when infection may be feared or suspected but is not confirmed. In these stages, prevention is an important focus, including pre-emption, early treatment for STIs, and VCT. Questions during these stages typically tend to be about transmission, the prevention and treatment of STIs and HIV infection, condoms, and VCT related issues such as confidentiality.

2. The Care and Support stages: Once HIV infection is confirmed, there is a dramatic shift in self-risk perception. In stages 6 through 8, which are post-infection, typical concerns tend to be about survival, life extension, re-infection, opportunistic infections, nutrition, stigma, and care. Questions in these stages tend to be very private, and will sometimes not even be asked unless it is a confidential setting with a trusted individual such as a counselor or close friend.

An appreciation of differences in the quality and content of enquiry through the stages of the continuum yields certain insights.

1. More technical: As a person's self-risk perception increases or changes, their questions become increasingly more specific and technical.

2. More urgent: Questions tend to get more urgent as a person's moves left to right along the Continuum of Enquiry.

3. More emotional: The language used to frame questions becomes more personal or emotional as one moves along the Continuum of Enquiry. For instance, an individual in Stage 1 (I am not at risk) may ask, "Do mosquitoes transmit HIV?" The same question asked by a caregiver of someone with AIDS (Stage 4), may be phrased, "Can I get HIV infection when a mosquito bites me?"

4. Need for confidentiality: The greater the perceived risk, the more confidential the questions. Typically, growing reticence manifests itself from Stage 5 (I want to go for VCT). This growing need for confidentiality, driven by fears of stigma, discrimination, and guilt, leads to a paradoxical situations: those with the greatest need for answers may be least likely to ask their questions unless the setting is right and the person a trusted confidante or friend.

5. Not a linear progression: Movement along the continuum is not linear and unidirectional. Rather it is dictated by the currently foremost concern in the person's mind. For example, in the immediate aftermath of particularly involving discussion on mother to child transmission of HIV, a person may display a temporary spike in their detailed questions about MTCT.

Using the Continuum of Enquiry

What sort of attitudes and experiences should we expect at different stages from individuals along the Continuum of Enquiry? What sort of questions should we expect? There are no firm rules, but certainly we can attempt some interpretations from experience. The table at the end of this document tries to lay out our current understanding of the attitudes and questions that may be expected at different stages of the Continuum of Enquiry.

The Continuum of Enquiry is yet to be validated through field-level research, but has demonstrated great practical applicability within dialogue-based interventions that promote critical thinking, reflection, and informed choices. It has added a formal process of Harvesting Questions within peer education sessions in the IMPACT program in Kenya. In addition, it has created renewed interest in tracking individual progress towards new behaviour using questions asked as indicators of movement along the Continuum of Enquiry.

The Continuum of ENQUIRY

How do a person's questions change as his or her self-risk perception changes?

It has created interest also in whether similar continuums of enquiry might exist in related areas of reproductive health such as the decision to adopt family planning methods.

Bingwa's Continuum

The real-life case history from Mumias, in Kenya's Western province, matches a Kenyan youth's changing pattern of enquiry with his progress towards new behaviour

At 24, Bingwa represents the typical Kenyan out-of-school youth: unemployed, hot-blooded, ignorant but generally hopeful and lively. He had been a regular attendee of community theatre sessions of the Rojo-Rojo troupe in Mumias, in Kenya's Western province.

Between January and September 2002, Bingwa's life evolved dramatically. This very average young man— married, father of a 15-month son, sexually active outside his marriage but insulated by a sense that he is not at risk of any infection — became the first youth who was stimulated by Magnet Theatre to navigate a course to new personal behavior that has made him a community role model. He volunteered to go for VCT, learnt for himself that he was not infected, and took serious steps to introduce fidelity into his sexual life.

Standing as landmarks to Bingwa's progress towards new behavior are his slowly deepening questions over a period of several weeks. As his understanding grew, his questions diversified, became more intense, more personal, and more confidential. Bingwa's story demonstrates the Continuum of Enquiry at work.

Bingwa makes a living by taking care of his uncle's four rental houses, and ekes out his income by selling odds and ends from a kiosk. In his spare time, Bingwa hangs out with his buddies, all of whom have turned Bingwa's kiosk into a hanging out joint. When they are together, the friends generally talk about politics, football, job opportunities, college work and inevitably, girls. Bingwa is the de facto group leader, if only from the fact that he has a house and is economically better off than the rest. There was a time when his house used to be known as The Butchery in recognition of the fact that the young men in the estate would bring girls over for sex there. Bingwa would be happy to oblige by making his house available and disappearing for a while.

First contact

Bingwa's first questions came on a Friday in January 2002, at the end of a session of community theatre by the Rojo-Rojo Magnet Theatre in Mumias. The Theatre Coordinator, Madiang, was looking forward to the weekend, and hurriedly fastening the bag containing the tools of his trade — gun microphone, banners, referral and speedback forms, P-model, and a half full packet of condoms — on the carrier of his Yamaha 125 DT motorcycle.

Bingwa approached Madiang, and after a few moments of small talk, he asked in a more serious tone, **"Say, is an STD the same as AIDS?"**

It is a question that comes often from youth. Madiang nonchalantly answered in the negative. But Bingwa became pensive and launched a second question: **"Okay then, if they are not the same, does the one turn into the other? I mean, does an STI later become AIDS if it is not treated?"**

Alert now, Madiang explained to Bingwa the difference in terms between STI and HIV, and that HIV is just one of various STIs. After citing some examples of other STIs, he offered an explanation on how some STIs can pave the way infection with HIV.

Bingwa now asked, rather hesitantly, **"So which STDs are treatable?"**

As they spoke, Madiang was trying to place Bingwa on the Continuum of Enquiry. He seemed uninformed but also genuinely concerned. He had chosen a private moment to raise his concerns, thus adding weight to his concern.

Madiang came to several tentative assumptions: Bingwa could be infected with an STI;

He could be seeking treatment for that STI;

He could be concerned about his HIV status. He possibly engaged in multi-partner or unprotected sex.

Bingwa's first questions, Madiang thought, placed him in the second or third stages on the Continuum of Enquiry (I have sex with many partners' or I am infected with an STI).

Later interviews revealed that Bingwa's concerns at the time he asked those questions were about his

The Continuum of ENQUIRY

How do a person's questions change as his or her self-risk perception changes?

cousin, who had had unprotected sex with a prostitute and was infected with an STI. Bingwa was pressing him to go for treatment, but the cousin was afraid that he would have to disclose the source of the infection. Bingwa's questions were apparently on his cousin's behalf.

Ironically, Bingwa believed that he was at no risk of HIV at that time, even though he was regularly having unprotected sex at that time with multiple partners out his marriage. His complacency came from the fact that, unlike his cousin, he was not having sex with commercial sex workers. Thus, Bingwa was actually in the first position on the Continuum of Enquiry at the initial meeting.

Three weeks later

Time passed. Three weeks later, Bingwa had more questions, which he asked in the presence of his friends during a discussion following a community theatre session. They seemed to be general questions stemming from that day's enactment of a person who had been advised to go for VCT before entering into a relationship with a new girl. The protagonist was depicted as a person who enjoyed unprotected sex frequently with many partners, and did not care about the risks. Bingwa's questions this time were:

What was this VCT that was being referred to in the play?

Does the test also check for the other STDs?

Must someone undergo the counseling in order to be tested?

Bingwa's questions indicated that he was still in the second or third positions in the Continuum of Enquiry. His question about whether the test checked for other STIs too strengthened the supposition that Bingwa might himself be infected with an STI. But his keen interest in the HIV test made Madiang wonder if he might have moved to the fifth position in the Continuum ('I want to go for VCT.').

In reality, as later interviews revealed, by the time Bingwa was asking that question, he had already heard about VCT, but did not understand it well. He confessed that it was at the discussion he'd attended in community theatre sessions that he had begun thinking of himself as a candidate for VCT. The enactments had led him to start reflecting on his former life. He had become convinced that he was probably infected with an STI, and that it was only a matter of time before things came out into the light. VCT seemed to him an opportunity to check his STI status.

However, he was not sure that he was ready for the HIV test. Reason? "I assumed that I was already infected with HIV. I would take the tests for other STIs, but not go for VCT only to learn that I was HIV positive."

These questions also seem to have been a turning point in Bingwa's life. It was after asking these questions that "I sat back alone in the kiosk and really looked at my life". According to Bingwa, every answer he got to his questions only confirmed his fear that he was already infected. It was around this point that he decided, in his words, to "stop engaging in sex, even with my wife. I was afraid!" Bingwa had never met anyone who had gone for VCT and even doubted whether anyone actually did.

The final push

It was not very long before Bingwa took the decision to go for VCT. He spoke to Madiang in private for nearly one-and-a-half hours, and asked him more questions than he ever had before. He would listen to the answers keenly, be quiet for a while, and then launch another question. This was also the first time that Bingwa began using the first person in his questions — "How long will it take before I get my results? How long will it take before I get my results?" By the end of the session, Bingwa had firmly placed himself in the fifth position on the Continuum of Enquiry (I want to go for VCT).

Two days later, Bingwa became the first young man to go for VCT out of his exposure to the Magnet Theatre process.

Some of the questions that Bingwa asked in his final session were:

Where do you offer these services?

What is the cost of taking the test?

How long will it take before I get my results?

Will I be issued with a card showing whether I am positive or negative?

You are saying they will not take my name; how then will they know that the results are

indeed mine?

What does that window period mean?

So if I am found to be positive, I don't have to go for a confirmatory test?

Have you (referring to Madiang) gone for the test? How many times?

How much blood will they draw?

How long does the counseling take?

By this time, Bingwa had acknowledged his proximity to the HIV. He was taking the test so as to "know my status and how I will live thereafter". Not wanting to use the VCT facility in his town, where he might be recognized, he chose to go to a different town. Though he did not tell his wife he was going for the test, he managed to persuade her to be tested too shortly after his experience.

A new life

Bingwa's life has not been the same since he went for VCT. He has already spoken out on IMPACT's radio serial drama, Kati Yetu, strongly urging others to go for VCT and reflect on their sexual lives and behaviours. Standing in front of his peers in a community theatre session, Bingwa pledged that he would no longer engage in multi-partner sex. As of that year's end, Bingwa affirmed that he had had neither extramarital nor unprotected sex. That made for six months since he took up a new behavior.

Bingwa's questions show how he moved gradually from the first position on the Continuum of Enquiry, when he perceived himself at no risk at all, to the fifth, when he was seeking VCT. The nearer Bingwa perceived the HIV virus to be to his life, the more specific his questions became, and the more private. By the time his questions moved to the first person, he was indeed looking at his life and health in relation to his behavior choices.

Today Bingwa has become a role model in his community and has helped innumerable numbers of his peers also go for VCT. He is often asked to share his experience and the benefits of VCT, information he is always willing to give out.

And his house is no longer called 'The Butchery'.

	I am not at risk	I have sex with many partners.	I have an STI.	I am a caregiver for someone with AIDS.	I would like to go for VCT.	I am HIV positive.	I am living with HIV.	I have AIDS.
Who would say this?	Those who do not understand HIV transmission. Those who believe that HIV is a problem of homosexuals or those who go to CSWs. Also, well-informed people who use condoms consistently during sexual intercourse, or are in a mutually faithful long-term relationship with one partner, or have been practicing total abstinence.	Those who have begun exploring sexual relationships. Commercial sex workers; Older men in relationships with younger girls, Those who have extramarital relationships. Those with multiple sexual partners.	Those who have had unprotected sex with a person with an STI. There is likely to be a personal awareness of being at risk for HIV.	Those who are part of a household that is caring for someone with AIDS. Within families, such people tend to be mothers or grandparents. In some cases, it may be the uninfected spouse of an infected person. Clinical workers and health care providers, or those who routinely deal with the bodies of those who have died of AIDS.	Those who have acknowledged that their behavior may have put them at risk of HIV infection, and want to decide if they should go for a test. May have had unprotected casual sex with different partners, or have been exposed to other risky situations. Partners of high-risk people, such as a faithful woman whose partner is promiscuous, or a victim of rape.	Those who have just learnt that he or she is HIV positive and are coping with complex emotions such information evokes. Such people may feel that now that they are infected, there is no need for condoms. There may be ignorance about issues of re-infection.	Persons living with HIV and learning to accept the infection. They may even have realized that it is possible to live a full life even with the infection.	Those who have begun developing the early opportunistic infections that come as the body's immune system begins to collapse. Some may be in the stage of full-blown AIDS. Couples who have both tested positive, and have children who will become orphaned when they die.
Typical concerns	Theoretical, general and sometimes trivial questions about origin of AIDS, political issues, and gossip about HIV or AIDS. Sometimes a person may ask a question for the sake of appearing interested.	Transmission, the efficacy of condoms, and symptoms of STI infection, including how one can make out if a person is HIV positive. Those who have multiple sex partners may be concerned about transmission and protection The word 'I' may occur in the question.	Treatment for the STI, facilities available, confidentiality, disclosure, cost, chances of HIV infection. May also be questions about HIV transmission, and efficacy of condoms.	Transmission, precautions, nutrition, treatment and drugs. If the caregiver is the spouse of the person with HIV or AIDS, then there may also be questions about condoms, risk of sexual transmission, and mother-to-child transmission.	VCT, confidentiality, reliability of test results, cure and treatment of HIV, and vaccines against HIV. Prevent HIV infection. Policy towards HIV positive workers. Questions tend to be personal and private, asked in confidential settings.	Possible cures, the transition from HIV to AIDS, protection, nutrition, stigma, re-infection. Likely to be asked in one-on-one conversations with trusted friends, relatives or counselors.	Nutrition, ART treatment, vaccine trials, spirituality, protection, re-infection, the transition from HIV to AIDS, stigma, legal issues and policy issues around HIV and AIDS.	Treatment, nutrition, care, spirituality, the future of the family, funeral arrangements, and so on. However, they may only be voiced to a close and trusted individual.
Sample questions	Where did AIDS come from? Do mosquitoes transmit HIV? Is AIDS a western conspiracy to wipe out poor countries? What is HIV?	If two people have gentle sex, and one is HIV positive, is there a chance that the other person will not get infected? If a person wears more than one condom, is there less risk of infection? How can I convince my partner to wear condoms?	Are all STIs curable? If I have an STI like gonorrhea, will I get HIV? If I go for an STI check-up, will my results be confidential? Will I also have to take my partner for an STI check-up? Are condoms effective against all STIs?	If I come into contact with the phlegm or vomit of a person with HIV, can I get infected? Can HIV spread through one act of sexual intercourse between an infected person and the spouse? Will a baby born to an infected mother will be positive?	Is it true that those who find out their HIV status will die earlier? Is a counselor obliged to inform the family and sexual partners of an HIV+ person? Is my employer entitled to know my HIV status? Are there any medicines that can get rid of HIV infection if I take immediately?	Can a person get rid of HIV infection through sex with a virgin? Is it safe to have unprotected sex with another infected person? Are there any drugs that cure HIV infection in early stages? What are the opportunistic infections that could affect me?	What are the best foods for prolonging my life? How effective are traditional therapies for dealing with HIV? How long will it take before I develop AIDS? Will I be at any risk if I have sex with another infected person? When could we have a vaccine against HIV?	What will happen if I start a course of anti-AIDS drugs but cannot afford the next dose? Are there special foods that can help a person who has AIDS? If I have a complete change of blood, can I get rid of AIDS? Do alternative therapies have fewer side effects than anti retroviral therapy?