



Report on Beyond Consultation Dialogue Day

On 30 November 2010 Naz Project London and Panos London held a dialogue day for the Beyond Consultation project. This report provides some background on the project to date and an overview of the dialogue day. We would like to thank everyone who participated in the dialogue day and/or has contributed to the project so far.

About Beyond Consultation

Beyond Consultation aims to involve young Africans in shaping Sexual Health and HIV/AIDS services in the boroughs of Lambeth, Southwark and Lewisham in order to help develop more effective services that respond to the needs of the community. The project aims to help improve services which in turn should help to improve the health and wellbeing of young Africans.

The project is providing an opportunity for young Africans to communicate their own priorities rather than simply being consulted about what service providers think are their needs.

A group of 10 African women of various ages and a group of 9 young African men who have sex with men have been reflecting on their experience of sexual health and HIV services and about wider issues affecting their sexual health.

We have used a range of participatory and creative methods, including; drawing, drama, photography, video, group discussion, and analysis of issues and problems from participants' experiences, to identify potential avenues for improving sexual health. Out of this process the participants have been producing materials to share with service providers.

The project has also been working with NHS staff to get a picture of what are key sexual health and HIV issues for providers of services for young Africans. Recently we have been meeting individual staff and teams at clinics to make them aware of the project and explore their interest in being involved further.

Beyond Consultation is managed by Naz Project London in partnership with Panos London and is funded by the Department of Health Innovation Fund.

Why a dialogue day?

Having worked with African men, African women, and with NHS staff separately the Beyond Consultation Dialogue Day was an opportunity for different stakeholders in Sexual health and HIV services in London to come together to explore further some of the emerging challenges around HIV and sexual health from both the service provider and user perspectives.

This was intended as a step towards working together to improve HIV and sexual health services and related support. The next phase of Beyond Consultation aims to build on the experiences and insights of participants and the issues and opportunities identified during the dialogue day to support a process of collaborative design where staff and users can identify ways of improving services together.

What happened at the dialogue day?

African women living with HIV, service providers from sexual health and HIV services in London and representatives from community and voluntary organisations met to discuss key issues they face.

There was a commitment to confidentiality for this event and to strict anonymity when reporting on the event.

The day was facilitated by Professor Danny Burns from the Institute of Development Studies, University of Sussex. The approach which drew on Whole Systems Action Research was to support participants in thinking about the issues they face as being situated within a complex system rather than looking at issues in isolation. Often we look at the problem without looking at the system but to address problems we need to look at the whole system within which they are situated.

“The way to bring out complex systemic issues depends on getting details about people’s lives and experiences.”

Danny Burns

We started the day by listening to and viewing the materials that have been produced by Beyond Consultation participants. These included interviews, digital stories and posters which represented a range of views and experiences from the detail of a clinical encounter to the wider social issues of housing, and employment and stigma.

Service providers were then asked to share their responses to these materials. What was significant for them in what they had seen or heard? The relationship between the clinical and the social came out strongly in this discussion and NHS staff found it valuable to hear service users’ experiences in their own voices.

After lunch Danny facilitated a session to build a map of the systemic issues, stakeholders, facts and assumptions which operate in regard to how clinicians deal with social issues that impact on African women living with HIV. Initially the service providers contributed their views and experiences then the African women present joined in. A number of lines of inquiry developed through the systemic mapping which can serve as a starting point for the next phase of the project.

Emerging themes and lines of inquiry

As can be seen from the photograph of the system map above, the issues explored on the day and emerging themes or lines of inquiry are inextricably linked. In this brief summary, points are listed under different headings and sub-headings; many points are relevant in multiple categories.

The emerging themes can be summarised as follows:

- 1. Social realities of living with HIV**
- 2. Relationships between clinicians and patients**
- 3. Trust**

We have included a summary and some quotes relating to each theme to give a sense of the discussion around the lines of inquiry that were mapped.

1. Social realities of living with HIV

People go on a journey to get to the clinic. *“They are not airlifted there.”* This can be a life journey, an actual journey or a clinical journey.

What are the social issues that affect people living with HIV in South London?

- Immigration

“As soon as you ask a patient about immigration, they shut down. They think you are trying to catch them out.”

- Money/Finance
- Family
- School for children
- Place to take medicines
- Housing
- Transport

“People may have no money on their oyster card or credit on the phone. You may have to walk. Or you can’t get through the phone system with only 10p credit.”

- Not having information, not having a choice, not having a support system, not wanting to be seen as HIV positive.

We considered some aspects of the role of clinicians in dealing with the social realities which impact on the health of African women living with HIV

Referrals

Referrals for social services via support organisations are an important means of improving the quality of people’s lives and therefore their health and their ability to access health services.

“In terms of support around housing, benefits, immigration and a range of other services, we have had [an HIV support organisation] person based with us for some months. We have been able to refer to her as opposed to directly addressing some of these issues. I don’t have the expertise, I have some understanding.” Health advisor (HA)

“I used to see a consultant at [hospital in S.London]. I don’t go out much. I’ve never been to a group before. We started talking and I told him everything I’d been through. He rang up M from [an HIV support organisation] and she gave me an appointment for the next Tuesday. Since I met that lady, things changed. She gave me a support worker and he took me to college, to the library, showed me the computer. Before I didn’t know the computer, I didn’t know the email. Now I can type bits and pieces. If it wasn’t for my consultant, I wouldn’t have known about [support organisation for people living with HIV] You have to talk to your consultant, otherwise they can’t help you.” African Woman (AW)

“You have to get to know other families who have HIV. I got to know [family support organisation] from my clinic. Clinicians should know all these organisations.” African Woman

However, there are concerns for the future from health professionals:

“People say if the patient has a problem with immigration, benefits, etc, go over there. But as the cuts come in, we haven’t got the data to say right you need to go over there.” Health advisor

Making the right referrals is also an issue of trust. When it goes wrong, trust can be broken. See section on „Trust“.

Understanding and awareness of social issues by clinicians

Both health services staff and service users thought that clinicians need an awareness of the social issues that impact on each service user’s life and health.

“We are very HIV focused and tunnel vision, when we are seeing a service user who is late, we don’t ask what their problems are, why they are late. We have users who walk miles to get to the centre, in the cold, without a coat, we don’t ask that. We need to ask what the very practical blocks and issues are?” Health advisor

“Clinicians should see the person as whole. They don’t need to know about the details of housing etc but being conscious of other things, they should be taught and trained how to manage a patient holistically.” African Woman

“What is at stake in a real tangible sense both generally for service users but particularly for this group [gay African men]? What are the stakes involved in coming to Europe for a chance of a better life? We have a meeting with someone who has a whole experience, and that affects how they see the services.” Health Advisor

“Sometimes I see people and I am conscious that I only get half the picture. But a lot of work is more social work than nursing because if I don’t address the social issues, then the nursing won’t work.” Community Matron.

Under-the-radar work and risk taking for health professionals

Health professionals with greater awareness of the social context are faced by the limits of their remit. They can sometimes take action which is „under-the-radar“ to support service users.

“My role as a health adviser, there are some risks that I do take in my work, in order to get things done or else they won’t get done. Other clinicians won’t do that.” Health Advisor

“Personally and professionally I am going to have some challenges ahead of me if I carry on doing things the way I am doing.” Health Advisor

“We put our own value judgement on who is deserving of the under-the-radar stuff. If people are late, if they get on your nerves etc, you might not do as much as you can for them.” Health Service Provider

“Often you feel like you can’t do anything to help. When you can, it is under-the-radar and risky.” Health Service Provider

2. Relationships between clinicians and patients

The power relationship between the clinician and the patient was raised as was how appropriate it may or may not be to have open discussion of sexuality and sexual practices.

What are the impacts of a patient turning up late or not at all to appointments? The patient is seen as „lazy“. If they are seen like this, the way they are subsequently treated doesn’t encourage them to come back. It is a parent – child relationship between the clinician and the patient.

Other issues related to approaches to questioning. One health advisor said:

“We might think that being open in our questioning is helpful to someone, but if you come from somewhere where being open is not acceptable, then is it right for us to ask these questions?”

Responses about this from the African women varied:

“For me, I am fine with talking openly. To be frank, I want to ask about my medicines.”AW

Others were not so comfortable with being that open, the building of a relationship of trust and continuity are important.

“For me, it would take time. You have to have a relationship with your doctor. It takes time.” AW

“I don’t give away my information until I am strong enough. The first time engagement is difficult.” AW

“There is a bond with you and the doctor.” AW

“It changes over time, the relationship. It is important to have the same doctor. You reach a point where you are comfortable and open up.” AW

There is an attitude of deference towards doctors

“We expect the doctor to find out, we don’t tell.” AW

“Even if you think the doctor is wrong, you don’t say. You just go away thinking: it is not right. If you have been here, [in the UK] for a long time you are more confident. If you are new, it is different.” AW

Doctors hold power for service users. One example being the letters that they write which can have a significant impact on people's lives.

"Doctors understand the emotional link which makes our medication work. The doctor wrote to social services and asked them to house me. He wrote a letter to a solicitor. We need doctors to be a voice and a bridge to a lot of issues for us." AW

"The clinician is everything to us." AW

"Some are supportive, others are not. The consultant I have is not powerful enough. What they write is not strong enough to convey that I'm going through this situation." AW

"You see another GP and he is the one you ask to write a letter, but he is not the one who understands what you are going through." AW

"When you write letters you have to be careful not to lie, you have to be factual." HSP

This links to the question of the clinician's responsibility to understand the social realities that underpin people's lives.

How do you create a more equal relationship between the clinician and the patient?

"In twenty years of HIV, I've only had one doctor acknowledge the imbalance of power between the doctor and the patient." Person Living with HIV

"There is a culture of the doctor always being right." AW

"It is patronising, intimidating. You don't want to be seen as a fool, as stupid." AW

The culture of medicine can impact on treatment and well-being

"It seems that we are still stuck with medicine being delivered in a western clinical model, which is fine for people who are culturally western. But it doesn't fit for others who may see illness and health very differently." Person Living with HIV

"It seems like the consultants and the GPs don't communicate. They don't talk." AW

"I tell my patients, I have knowledge but I don't have experience. You need to talk to other people in your own language. Our health system is built on knowledge, not on experience. I have knowledge about it in relation to other people's lives, but not your life." Health Advisor

3. Trust

How do you create trust? How do you stop trust being broken? What is the role of the community in the trust process? How do you create trust once it is broken? Some key issues for patients emerged.

There were a number of experiences of receiving poor advice

"I went to see a counsellor, she wasn't really there. She gave me bad advice. She treated me badly, I spent my last penny, £3000, on a solicitor that she told me to go to, and they did nothing. I went back to my room and I thought let them come and collect the debt here. I went back to her, and she said if I complained, she would tell them to deport me." AW

"The consultant, he sent me to the [HIV support organisation], there was a solicitor there who could help me with immigration. But he didn't help me at all." AW

"When you have a social worker – when you got to get your £30, the social worker is bad, says to me, what you got no permit to stay? They'll send you back." AW

Perceptions

"There are also some things about people's perceptions of how they are treated differently, but how are they being treated differently? Is this their perception or are they actually being treated differently?" Community Matron

Disclosing to different people

If we see the social as important, the continuity of the relationship is critical. How do you ensure the continuity of the relationship? Health providers again showed concern over the future, that the model of HIV care was moving away from continuity rather than towards it.

"Meeting different doctors at the GPs. I see a different one every time and I have to start all over again with each one. It breaks me down." AW

"This person, the clinician, might be the only person that the patient has disclosed to." AW

Stigma and discrimination

"One thing I don't like, when you got the hospital, the receptionist, some behave badly. You sit where there is a lot of people, the way they look at your paper, and say "sit there. Step this way", it is discrimination." AW

Positive images of people living with HIV can help to overcome this.

"We employ people with HIV to do all the front line work. Someone recently diagnosed was too frightened to come to the group. The case worker reached out to her and the woman said, "I thought this woman was lying because she had a good job, was well-dressed, a family, a relationship and I could not think she had all these things and be HIV positive." Representative from a voluntary organisation

"I have newly diagnosed clients who go to the clinic and see everyone there and they say they "they can't be here for HIV, they are so well!" And I say, "this is how HIV is these days, you can treat it." HSP

The positive face is not to be taken for granted. I get frustrated at not being made enough use of in this role. A doctor ran up to me yesterday morning, and said to me that a patient has a huge concern about the number of pills, and side effects etc. I was able to go down and have a chat with the person and a doctor together, and talk about my combination and how I take it, and how I overcame my reluctance to take it. They haven't agreed immediately, but they have gone away with something useful. So please make more use of me!" A Person Living with HIV

There are tensions between messages about prevention and the messages you receive once you have a positive diagnosis.

"An epidemiologist said our treatment is about HIV, but our prevention messages are about AIDS. AIDS messaging is very negative, very dangerous, but when you are diagnosed with HIV, people say "oh, it's ok, you'll be ok". If you only see prevention messages, you won't think it is ok to have a positive diagnosis."HSP

What will we be doing next?

At the end of the day participants were asked for their feedback on the event and what they would take away from it. This was very positive with people finding the discussion interesting and feeling that they had learned from it and that there were things that could be taken forward. There was some disappointment at the low numbers of clinical staff and the absence of any doctors at the event (although a number had been invited and some had expressed an interest in attending). A Person Living with HIV called for more solidarity.

I'd like to see more solidarity among people living with HIV. We used to be together. I'd like to come back again. Together, we can do things."

Beyond Consultation has funding until March 2012. In the next stage of the project we intend to use this systems map, the themes raised in the discussion and the materials produced by African men and women prior to this event, as a basis to explore possible solutions and recommendations to improve service provision and uptake. To do this we hope to form inquiry groups made up of the participants from the African women's and men's groups, the people who attended the stakeholder event and any other stakeholders who would be interested in being involved. We hope to have more clinical involvement. These groups will be supported to identify an area of concern, to research it further where needed and then to go through a co-design process to find ways of making changes to ensure that Sexual health and HIV services better serve the needs of African service users.

By the end of the project we will have developed a guide based on the methods and materials developed during the project.

Attendance

The event was attended by a range of NHS staff working with sexual health and HIV services across London, including co-ordinators, health advisors, and nursing staff as well as representatives from community and voluntary organisations offering support to African migrants living with HIV. Women participants from the Beyond Consultation project and staff from Panos London and Naz Project London also attended.

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