

What do we do about...MICROBICIDES?

Report on the 'Microbicides Information Day' organised by the UK African Microbicides Working Group and held on 20 March 2006 at Wesley Chapel, London

Foreword

The Microbicides Information Day was organised by the UK African Microbicides Working Group. The working group is part of the UK Campaign on Microbicides and the Global Campaign for Microbicides. The Working Group aims to ensure that the public interest of African communities are protected and the rights and interests of trial participants, users and communities are fully represented and respected.

The aim of the Information Day was to bring together key workers within African community organisations to discuss the issue of microbicides and its implications for African communities in the UK. More specifically, we sought:

- To raise awareness of microbicides amongst members of African community organisations;
- To gain information from members of African community organisations about their experiences and what they already know about microbicides;
- To identify members of African community organisations who may be interested in joining the UK African Microbicides Working Group;
- To initiate discussions about the kinds of messages we could begin sending out to African communities in the UK.

Thirty-six people representing twenty-seven organisations attended the seminar to learn more about microbicides. Many participants mentioned the amount of new information they learnt and commented that they were enthusiastic about taking information back to their organisations for further discussion.

There were four speakers, including Angelina Namiba from Positively Women and Lydia Zigomo from Interact Worldwide, both of whom are members of the UK African Microbicides Working Group. We also had the opportunity to hear from Saul Walker from the International Partnership for Microbicides (IPM) and Arwa Meijer from the Global Campaign for Microbicides (GCM).

The Microbicides Information day was the first community activity of the UK African Microbicides Group. Discussions and feedback from the seminar will inform future debates and activities.

The UK African Microbicides Working Group would like to thank everyone who attended the seminar and contributed to important and stimulating discussions.

Speakers

Angelina Namiba, Positively Women

Angelina presented the film 'In Women's Hands' and introduced the topic of microbicides. She focused on what microbicides are, how they would work, what they would look like, how they would benefit HIV positive people, their effectiveness and the potential public health impact.

Saul Walker, International Partnership for Microbicides

Saul discussed microbicides as a comprehensive approach to tackling HIV/AIDS. He highlighted the timeline, the progress in manufacturing the different products, the trials that are going on and the focus of IPM. He mentioned that IPM also works on access and delivery/manufacturing, but it is important to have community involvement in at an early stage for best results. He also talked about regulatory hurdles.

Lydia Zigomo, Interact Worldwide

Lydia focussed on microbicides trials in terms of ethical considerations and community preparedness. She started off with an exercise asking people why they might or might not participate in clinical trials in London. Reasons FOR NOT enrolling included fear of side-effects, especially the long-term aspects, the risk is not outweighed by benefits, lack of interest in the trial, lack of trust in science, the criteria for enrolment (HIV positive, women etc), being guinea pigs, taking into account people in your environment, and family concerns.

Reasons FOR enrolling included medication and the need for treatment for health problems, and incentives such as payments and reimbursements. Lydia also discussed issues of informed consent, standard of care, and key questions that communities have to think about in terms of ethics, since there are not yet solutions for these questions.

Arwa Meijer, Global Campaign on Microbicides

Arwa spoke about the GCM goals. She explained why the GCM exists, how they work in the Global North and Global South, and their aim of bringing their goals forward through partners in the different parts of the world. Arwa also demonstrated how individuals and organisations can be involved in the advocacy for microbicides through the UK African Microbicides Working Group, UK Campaign on Microbicides and Global Campaign for Microbicides.

All four presentations are available at

http://www.ahpn.org/activities/index.php?meeting_id=26

Questions & Answers

When would a microbicide be available?

There are currently 5 phase III trials and it will probably be around 2008 - 2010 if a product is shown to be effective. However, at that point regulatory issues need to be faced which can take up to 12 - 18 months and the manufacturing and delivery also have to be taken into account. So therefore it is crucial to already work on these issues at an early stage of development to make the process faster.

Where can we find further information about microbicides?

GCM has factsheets available and some of them are in the packs distributed. Both GCM and IPM have websites where you can find the information available (www.global-campaign.org and www.ipm-microbicides.org).

Would you have to go to a gynaecologist to put the product in your vagina or can you do it yourself?

It depends, we hope it will be easy to use and that people can put it in themselves, but it depends on the approval by either the European Agency for the Evaluation of Medicinal Products (EMA), Food and Drugs Administration (FDA) or national approval systems and whether it will be a product that can be sold over the counter or in pharmacies.

Why are Phase III trials only being done in the Sub-Saharan Africa?

Phase III trials are effectiveness trials which enroll thousands of people in several sites, and measure whether or not the microbicide actually works to prevent HIV and STDs. There are legitimate scientific reasons explaining why most large-scale trials of microbicides are taking place in Africa. It is neither cheaper nor easier to conduct prevention trials in developing countries. Effectiveness trials have to be conducted where the risk of HIV transmission is high and where the primary route of infection is through heterosexual sex. Such communities exist largely in Africa and Asia.

If a condom gives irritation, gynaecologists often refer them to non-latex condoms, would there be different microbicides in case irritations comes up?

There will be different forms (like a gel, ring, sponge, etc.) of microbicides and we hope that if one causes irritation to a person, they can use another form.

If a vaccine comes into the picture, where would microbicides be? Would they be out of the picture?

Microbicides are intended to be one option among a whole range of options. A vaccine will take about 15-20 years to develop and we know there is a need to have other prevention options in the meantime. The vaccine will probably not be 100% effective when it first comes onto the market, so microbicides would still be a very good option.

Are African Governments committed to microbicides research?

Government approval is needed to get microbicides to communities, so it is important to raise awareness with the African governments and the African Union. There is a network called the African Microbicides Advocacy Group (AMAG) that is working closely with trial sites and creating dialogue with decision-makers.

What is the African Microbicides Advocacy Group (AMAG)?

It is a group of researchers, women rights advocates, local HIV/AIDS organisations and other stakeholders which come together in communities where trials are happening. They monitor, get health professionals involved, check the information that is given to trial participants, and articulate concerns. GCM provides funding and staff support to AMAG.

We just heard that trials went wrong here in the UK. How do you still advocate positively for trials within this context?

First of all, the trials which went wrong were a totally different product. Of course, there is always a risk that it can go wrong, but any new product must go through rigorous safety testing before becoming available to consumers. Women's health activists and researchers are working closely together to ensure that the clinical testing of microbicides is thorough and ethical. Fortunately, many of the substances and mechanisms of action under investigation are already commonly used in over the counter products. It will not be possible to say what side-effects each microbicide may have until the completion of trials which test the product in thousands of women and men. Even if a microbicide does have minor side-effects, like many other modern medicines, advocates argue that people should be able to make up their own minds between the side effect and the risk of contracting HIV.

Group Work

Participants broke out into four working groups to discuss the following questions:

What are your views on microbicides?

- Empowers women and widens choice
- About marrying research and advocacy agenda
- Community engagement in research may indicate a new way of working
- About security and control
- Need for more community involvement in advocacy (by traditional healers, young people, parents)
- Need to strengthen support and infrastructure for advocating for the use of microbicides
- Issues of consent need to be explained fully to participants
- Disclosure for HIV-positive people may be a problem in enrolling
- Concern that microbicides won't get into the hands of African people who most need them
- Adverse effect on behaviour change because people may stop using condoms or have more sex
- Need for more clarity about why African countries are not fully involved
- Many questions and expectations unanswered by research organisations
- Issue of consent needs to be explained fully
- Creates some hope that interventions are being organised for women
- Hope of empowering and protecting women
- Resource of multiple benefits
- Addresses gender inequality
- What will it do around disclosure?
- How microbicides would impact on African social, sexual and cultural norms?
- What is the chemical content?
- What are the side effects for male/females?
- Need for dispelling myths of different barriers to HIV
- Need to have realistic expectations about availability
- Frustration in terms of length of time before we have a microbicide
- I want to feel it and put my hands on it!

What role can your organisation play in the microbicides campaign?

- Awareness-raising and education
- Ensuring updated information is circulated to network of members
- Resource development
- Join the UK African Microbicides Working Group
- Find out more about microbicides
- Participate in more dialogues and engage in advocacy
- Organise trainings, events, seminars
- Continue ethical debate
- Lobbying at policy level
- Advertising
- Sending out information to mailing list
- Capacity to mobilise people
- Continue to challenge ethical and cultural aspects to using it
- Engaging men to be advocates
- Lobbying United Nations and governments
- Unsure with current level of information

How do we get the message across?

- Outreach activities, such as disseminating information at family planning clinics
- Workshops and seminars
- Funding: getting Department of Health interested, local MPS, research findings, fundraising targeted at individuals and organisations
- Leaflets and posters to hang up in the organisations to raise awareness
- Make use of national days to raise awareness on microbicides
- Tagging onto events such as Africa Day and Refugee Week
- University fairs
- User-friendly community brief or leaflet
- Use DVD at events
- Through PCTs
- Local media, such as radio for information dissemination
- Microbicides could be generally incorporated in current health promotion work
- Get pharmaceuticals engaged
- Get people who are in an influential or 'powerful' position engaged in microbicides, such as traditional healers and celebrities
- Involve organisations such as Africans in Diaspora
- Take the exhibition to Scotland
- Engage men
- Enhance networking at all levels
- Using accurate, culturally appropriate and simple language
- Educate established members of communities, including peer educators, Church leaders, elders, political leaders
- Better links between people living in developed countries and developing countries through organisations such as the Centre for African Policy & Peace Strategy
- Commitment of support from African governments

What support would you need to enable you to do this?

- User friendly leaflets and posters
- Regular updates from UK African Microbicides Working Group and GC News
- Access to resources (funding and information) for events and seminars
- Training of trainers
- International meetings
- Continuity and follow-up of meetings
- Organise meetings outside London
- Information from international meetings to be fed back at local meetings
- Educate our communities to ask the right questions
- Funding from organisations such as IPM and GCM for activities
- Factsheet on men and microbicides
- Funding from government and pharmaceutical companies
- Skill-building sessions
- Training (doctors, family planning, HIV specialists)
- A UK conference about microbicides bringing together HIV positive people, government officials and health care professionals
- Support of media - newspapers, radio, MTV, OBE, the Voice
- Support of Black and Asian MPs and Black celebrities
- Incorporate it into current organisational activities such as health events, WAD events, training, staff meetings, leaflets, videos, DVDs (in different languages)

Feedback

Some of your comments on the seminar included:

“Very well organised and very nice to see that there is so much interest from the African community”

“Presentations were clear, simple to understand, very good slides”

“Please could we have more details about results of Phase I and Phase II trials and answers to some of the ethical questions?”

“More tutoring is needed about microbicides”

“Could have had more time for questions”

“Excellent work, inspiring and encouraging”

“It [the seminar] managed to raise awareness and was provoke thinking”

“The atmosphere was very friendly, food was delicious, a lot of refreshments”

“I think the area of African governments and traditional healers has been left unexplored”

“Would like to have more of these days with more focus on the situation in African communities”

“These are some very seriously burning issues, we need more time to discuss it further. Trials and research are very sensitive topics. Therefore we need certain approaches to addressing them”

“The organisation was fantastic, food, hospitality”

“Could we please have some follow-up about the seminar?”

“Very enjoyable and educating”

“I would like to learn more about the side effects of microbicides”

“I think the message is there, but it is about how to effectively get it across and I think this is an area that needs some extra time and focus”

“Presentations were succinct, to the point, informative and in layman and woman’s terms”

“I found it interesting and informative, liked the venue- warm, light and easy to get to. Relaxed atmosphere”

“Enjoyed the workshop very much. Hope to attend another one”

“Fabulous engagement from participants, lots of motivation”

For further information about the UK African Microbicides Working Group, please contact:

Georgina Caswell
African HIV Policy Network
New City Cloisters
196 Old Street
London EC1V 9FR
Tel 020 7017 8917
Email georgina.caswell@ahpn.org

Members of the working group include:

Angelina Namiba	Positively Women	anamiba@positivelywomen.org.uk
Beatrice Nabulya	RestorEgo	beatrice@restorego.com
Clement Musonda	Rain Trust	clement_musonda@yahoo.co.uk
Georgina Caswell	African HIV Policy Network	georgina.caswell@ahpn.org
Lydia Zigomo	Interact Worldwide	zigomol@interactworldwide.org
Sarah Pulle	Newham Social Services	sarah.pulle@newham.gov.uk
Syson Namaganda	Black Health Agency	syson@blackhealthagency.org.uk
Rhon Reynolds	African HIV Policy Network	rhon.reynolds@ahpn.org
Yvonne Feare	Zimbabwe Women's Network UK	Yvonne2001@aol.com

Other useful contacts:

UK Campaign on Microbicides
Interact Worldwide
325 Highgate Studios
Highgate Road
London NW5 1TL
Tel 0870 770 2476 / 020 7241 8511
Email Microbicides@interactworldwide.org

Arwa Meijer
Global Campaign for Microbicides
Rue du Trône 98, 7th Floor
1050 Brussels
Belgium
Tel +32 (0)2 507 1229
Email ameijer@path.org