# **Countdown to Challenging orthodoxies** related to SRH and HIV











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## Countdown to 2015: Challenging Orthodoxies related to Sexual & Reproductive Health and HIV

"Countdown to 2015" was an exciting conference which examined and critiqued many orthodoxies. It provided a chance to survey the fields of sexual and reproductive health and HIV from a very broad perspective, looking at issues from the clinical to the socio-economic. Foremost – befitting a review of DFID funded work – it looked at these agendas from a policy perspective; most important it looked at them in relation to policy learning.

DFID set up the Research Programme Consortia (RPCs) to produce "useful knowledge" – translatable knowledge, knowledge derived from rigorous research that can inform action on the ground. Over two days, we heard about five thematic areas in relation to a range of national and regional settings. The thematic areas impinge intimately and bulk very large in people's lives – a theme underlined by an excellent and original photographic display about sexuality and development.

- Bridging treatment and prevention in HIV starts at the most personal. After almost 30 years, we still don't have any one answer to the conundrum of prevention of transmission. Treatment is effective, but how to provide it effectively and without creating public health risks through development of viral resistance remains problematic in poor countries.
- Addressing social, structural and economic "drivers" of HIV and SRH: HIV/AIDS has made us even more aware of the links between sexual intimacy and broad social, economic and cultural forces. How these drivers operate remains unclear but we are learning that all drivers are not homogeneous and their strength varies from place to place.

- Contextualising and implementing SRH rights: despite a well developed international human rights language, rights based frameworks are often controversial and poorly understood in the field of SRH. Their focus on the individual can be in tension with public health approaches to the general good and to more social understandings of the individual
- Building health systems for the future of HIV and SRH: Well functioning health systems are essential for good HIV and SRH services. The focus here is on building effective policy and implementation.
- Getting research into policy and practice and the use of evidence by policymakers.

The significance of the conference was underlined in his opening remarks by

DFID's Chief Scientist, Professor Chris Whitty. The meeting attracted UK and international delegates and speakers. Around 150 people attended, including international policy advocates, DFID, NGOs, media, researchers, parliamentarians and editors of SRH, HIV and other healthrelated journals. All of them came away with more insight and understanding of the links between research and policy, and between personal sexual behaviour and the possibilities for effective interventions. As one DFID staffer said: "This conference really shows the effectiveness of DFID's investment in academic knowledge production – I have gained a new perspective and can take these lessons straight back into the policy arena."

Very useful content and many interesting perspectives for our work.

### Sessions 1 and 2 Building health systems for the future of HIV and sexual and reproductive health

This two-part session aimed to illustrate some of the challenges to building strong health systems that would help to deliver MDGs related to SRH and HIV. For example, is integration of SRH and HIV services the best way to provide those much needed and



Panellists: Malcolm McNeil, Dr Francis Ndowa, Dr Therese Delvaux

region, underpinning the lack of government planning even in apparently well-funded programmes, the shortage of skilled health care workers, and the impact of migration (internal or international) on overburdened services.

#### Prof Helen Rees

inter-related services? Does the increased focus on provision of HIV treatment services lead to stronger health systems? And how do we assess, or create, the need for such integrated services?

Dr Susannah Mayhew presented the outline and baseline results of a large study conducted by IPPF and LSHTM in Kenya, Malawi and Swaziland looking at the effectiveness, benefits and costs of various models of integration of SRH and HIV services. The project also sought to determine the impact of integration on changes in HIV risk behaviour, HIV related stigma and various SRH outcomes. The models studied included the integration of HIV care with VCT and family planning services, prenatal care, or youth services versus stand alone services. Preliminary findings suggest that actual demand for integration from the public appears low, and that integrated services do not always appear better at serving the needs of HIV-positive populations. The research highlighted the difficulty (by any service provision model) of reaching young people who are most at risk and vulnerable to HIV and adverse SRH outcomes.

**Prof Alan Whiteside** discussed the impact of crises, predictable or not, whether man-made (e.g. strikes in the public sector service in South Africa, violence and economic crisis in Zimbabwe leading to influx of migrants in South Africa) or natural catastrophes (e.g. floods in Mozambique), on the provision of antiretroviral services in Southern Africa. He argued that

strategies to manage such crises are poor in the

Dr Philippe Mayaud (LSHTM) discussed lessons learnt from the introduction of new SRH technologies "From Tampons to Condoms" over 50 years, and what health services should embrace as a more positive pro-market approach to 'selling' their services. These include: patience (it takes 5-6 years for products to typically 'take-off' and 10-20 years to reach maturity), not raising expectations (upper bounds of coverage typically are around 70%) and work on increasing the desirability of the products through judicious introduction and proper marketing. One of the major challenges, discussed with the audience, is the lack of predictability of marketing trajectories.

**Dr Sam Phiri** presented the experience of the Lighthouse Centre, the primary HIV treatment and training centre in Malawi, which, nearly from its inception in 2004, has offered integrated internal referral services for PMTCT to pregnant women, STI treatment, and more recently Tuberculosis screening for its HIV-infected patients. He recounted how the efforts to scale up ART provision and the training and strengthening of the systems put in place to counsel and trace patients, actually had some positive knock on effects on detection and tracing of TB patients, improving rates of PMTCT and family planning uptake, etc.



Everyone I spoke to really valued the opportunity to exchange information and spot new opportunities for further exchange.



**Panellists:** Dr Francis Ndowa; Dr Therese Delvaux; Marge Berer; Malcolm McNeil.

#### **Panel perspectives**

Integrations of services: This is still seen as complex, and actually is, but the shameful situation is the lack of interest from donors and funders who seem to shy away from it. They do not pro-actively fund programs that are trying to link the MDGs 4, 5 and 6, but tend to focus on their own funding silos, or navigate on 'trends' (for example, current interest to link family planning and HIV, but maternal health is neglected). An important facet (not discussed enough in the presentations) for building health systems is the current human resource crisis in many health systems of developing countries, which few are trying to address, and the often poor quality of supervision of health workers to help motivate them and get the 'extra 10%' that would make such a difference.

**Neglected technologies:** It was remarked that, in their quest, but still failure, to get new effective prevention methods, it appears that both researchers and policy makers have forgotten that condom use is increasing in Africa and yet considered a forgotten or even 'failed' technology. Panellists also lamented the way female condoms had not taken off despite being an efficacious and female controlled form of protection. Where did the marketing go wrong?

**Marketing of services:** More work needs to be done on the demand side from possible service/ product users and communities. In particular the desirability of new (or existing) products and services, and their availability – where communities would best like to find them.



### Session 3 Sexual and reproductive health rights in everyday experience

**Sessions 3 and 4** focused on rights discourses and debates in the field of SRH and HIV and AIDS. Both sessions aimed to raise questions that may challenge orthodox ways of presenting and "doing" rights. These included:

- The potential for disconnection between the international language of universal legal human rights which derives from western jurisprudence, and locally grounded social constructs of rights which can represent very different understandings of SRH related entitlements.
- The ways in which some rights can be ignored because they are 'uncomfortable' rights – they are linked to sex and sexuality or bring together different domains where links are not made, for instance the relationship between poverty and sexuality.
- The question of what "doing rights" means in practice? If rights are about claims through popular and political struggle, what is the role of external agencies? Can rights be forwarded through the bureaucratic means of tools and frameworks?

This session addressed rights from a grounded perspective of what rights mean for specific populations. Sabina Faiz Rashid spoke about her research on young, poor women living in urban slums of Bangladesh. Drawing lessons from their experience in insecure urban environments with very unequal gender relations, she argued that poor women have to mediate their life choices and decisions within larger structural inequalities. The political economy of urban slums with high levels of poverty and routinised violence leads to early marriage and childbearing which offer "protection" while closing off other reproductive choices. Public health needs to incorporate concepts and aims of social justice. Susie Jolly presented thinking on the relationship between sexual rights and economic justice and argued that this is an intimate but poorly acknowledged relationship. She argued that poverty is not just material but also comes from social exclusion, ill-being and restrictions on capacities and freedoms. Many categories of people are socially excluded on the grounds of their sexuality or because they do not "fit" prevailing social norms about sexual behaviour. This has economic as well as social impacts - both creating and exacerbating poverty and social exclusion.

Interventions need to create links between these separate domains, recognising the economic as well as the social justice value of sexual rights. Rose Oronje examined the experiences of civil society organisations in working to expand the policy space for SRH rights in Kenya, Botswana and Nigeria. SRH rights have low priority and there is no political leadership and limited funding – much of the financing comes from donors. She reflected that SRH rights discussion is limited to abortion, same sex relationships and access to services for adolescents. Some SRH issues have been integrated into HIV programmes but progress is slow. Noting that rights language is often controversial and that reforming legislation on SRH rights issues has made limited progress, she described how CSOs are taking leadership in expanding rights based services and advocating for reform, moving away from adversarial tactics while trying to retain a focus on rights.

Nana Oye Lithur, the discussant for the session and a practising human rights lawyer, drew attention to policy makers and enforcers' reluctance to fulfil the state's obligations to protect, promote and fulfil rights. These are often unpopular issues which do not attract votes or political support. She commented "We can talk about negotiating safe sex, HIV disclosure, condom use but all of this is affected by gender inequality. If we don't address this we will fail. In Ghana women need to ask for permission before going to the hospital. Many rights violations are not recognised as crimes." She noted the importance of starting practically with minimum obligations of states and other duty bears and with implementation of good quality SRH programmes.



Good opportunities for networking and very strong content from the RPCs and invited speakers.

### Session 4 How does a rights perspective aid researchers, policy makers and programme implementers?

In the first presentation, Sarah Hawkes and Martine Collumbien described the challenges faced in conducting research on sex work, drug use, HIV and rights in Pakistan. The study combined quantitative methods with in-depth qualitative approaches working with marginalised population groups. Recommendations included targeted interventions with different kinds of sex workers and training of police. Given the conservative setting in Pakistan, policy shifts are difficult and slow to effect. Despite being a signatory to international treaties related to SRH and rights, the public position is that sex outside marriage, sex work and "sodomy" are illegal. Policy makers were receptive to the idea of human rights training for police, believing this would be socially acceptable, but opposed to any public funding going to services for groups such as men who have sex with men. They concluded that to create a more favourable climate for sexual minority rights, it is necessary to identify and give support to drivers of change within civil society.

In the second presentation, Tim Quinlan spoke on the need to re-think field work protocols for socio-economic HIV/AIDS research in sub-Saharan Africa in the context of the ethical challenges in doing HIV research. These include extreme poverty and high levels of violence and crime. In these contexts the guidance from ethics boards is insufficient to the real life situations researchers face. Research designs have to accommodate sample attrition due to HIV illness and death. The research can be very intrusive in focusing on sexuality and sexual behaviour. But research designs presume normality, equilibrium in terms of sample, and truth and self-reporting despite the stigma related to HIV. This raises potent issues of rights where the poor, illiterate and most abused groups carry the burden of research but are unlikely to benefit unless there is a much clearer common understanding on the part of both researchers and subjects built into the research from the outset.

In the third presentation, **Kelly Hallman** spoke and showed a film about a programme developed by the Population Council, Isihlangu Health and Development Agency and the Health Economics & HIV/AIDS Research Division (HEARD) working with socially vulnerable adolescents in South Africa. This recognises the linkages between adolescent HIV risk and family/household demographics (survival of parents/presence in the household), economic status, gender role attitudes, social connections and isolation due to class or geographical location. The programme goes beyond the ABC mantra to work with their real life circumstances and how these can change. Using a randomised design, recent matriculates were trained as facilitators and advisors to secondary school students. The programme has been evaluated as successful in educating people on rights and providing skills to access entitlements and knowledge that nonreceipt of rights is a violation.

Panel discussants Petra Boynton (UCL), Malcolm McNeil (DFID) and Nana **Oye Lithur** (Commonwealth Human Rights Commission) raised many pertinent issues, including the question of agency – how can we convey vulnerability without turning people into victims; the need to pay much more attention to what is being discussed on social media and blogs – people are bypassing the old routes and discussing these issues we need to listen more to them; the importance of using the kind of methodologies employed in the Pakistan study to tease out hard to reach information; and the need to interrogate the extent to which cultural traditions increase the risk of HIV infection or rights abuses.

The conference promoted the exchange of lessons and experiences extensively.

Prof. Tim Quinlan (University of KwaZulu-Natal) Ireen Namakhoma, Prof. Richard Hayes, Dr Deborah Watson-Jones, Dr Reuben Granich

### Session 5 Bridging treatment and prevention

This session focused on the highly topical issue of HIV treatment as prevention and also looked at the missed opportunities for HIV treatment care and prevention in current ARV treatment programmes. **Dr Reuben Granich** summarised the current status of the mathematical modelling which explores the possibility of reducing incident infections and eventual elimination of the epidemic by implementing regular universal HIV testing followed by immediate treatment of HIV positives. **Professor Richard Hayes** then presented the key research questions which need to be answered in relation to ascertaining the acceptability, feasibility and effectiveness of the UTT approach. **Professor Francois Venter** 

gave a perspective from the field on the possible pros and cons to exploring and implementing such an approach looking at the situation in South Africa. The final two presentations highlighted research on missed opportunities to provide HIV treatment and care. Ireen Namakhoma presented a study from **REACH in Malawi looking** at factors which delay ART initiation and **Dr** Deborah Watsonlones looked at missed

opportunities to link prevention to care in prevention of mother to child transmission services.

Since the initial publication of the WHO model of using HIV testing and immediate treatment to reduce and possibly eradicate the HIV epidemic, WHO has continued to co-ordinate the dialogue around this contentious area. Reuben Granich's presentation rehearsed the evidence for ART as prevention citing the several studies showing the reduction in HIV transmissions associated with lowering HIV viral load. Increasing access to HIV testing has many benefits and universal access to HIV treatment and care will not be achieved unless far more people learn their HIV status. It is estimated that in Sub-Saharan Africa 60% of people living with HIV do not know their status. In the modelling there are key differences in impact when starting ARV treatment at differing CD4 counts. Starting ARV with CD4 < 350, as in current guidelines, will save 2.41 million lives but employing the UTT approach nearly triples that number to 7.35. Dr Granich presented the more recent work done looking at the reduction in TB incidence associated with initiation of ART and detailed the

RT and detailed the work to cost a human rights framework to support the provision of human rights interventions.

Dr Reuben Granich

Dr Ade Fakoya (International HIV/AIDS Alliance)



This conference has shown the importance of documenting and sharing the work around rights that our African partners are already doing. We need to share research findings with small implementing partners so that they can use it to influence their work.

#### Key messages from Professor Richard Hayes

- The acceptability, feasibility, effectiveness, costs and adverse effects of UTT have not been established. UTT interventions should only be implemented after careful evaluation of these parameters.
- Several research methodologies are required to provide evidence for the above. These include observational studies, operational research, modelling, pilot studies.
- It is important that more limited research approaches to ART as prevention are explored as preliminary studies may find that the UTT strategy is not feasible or acceptable. These will include looking at early ART in serodiscordant couples, and the effects of ARV provision at higher CD4 counts.

Ireen Namakhoma presented a study from Lilongwe, Malawi in which preliminary findings show that most people went for HIV testing because they were ill. Generally patients made multiple visits to health providers before initiating ART with seven median visits before starting. Patients from rural areas and the poor were more likely to both travel further and have more visits before initiation.

Finally, there are many opportunities for HIV prevention and treatment interventions during pregnancy, at time of delivery and in the early post-natal period, but there are multiple missed opportunities including, the testing and retesting at time of delivery and post-partum, the failure of mothers to receive ARV for PMTCT and their own health as well as missed opportunities for family planning. Better linkages and clearer communication is needed between different healthcare providers for care of HIV+ pregnant women and infants.

### Session 6 Addressing social, structural and economic drivers of HIV and SRH

Dr Julia Kim reviewed the wider lessons from her own research on structural interventions. Her broad message to the conference was that structural interventions mean working with communities, that microfinance is a way of addressing people's basic needs and thus making them less vulnerable, and that such approaches provide entry points for sustained contact with gender/HIV interventions. Above all, these approaches require sustained interdisciplinary research and analysis. They are not solely about women, they are in the most fundamental sense, about gender as a set of complex economic, political and symbolic – as well as biological - relationships. In conclusion, Dr Kim noted that while governments and policy makers take a relatively short term view, structural changes take time. This raised the questions of: (a) Whether and where there is the commitment to see structural change through? (b) What if, after 2015, development is no longer the sexy issue will these issues fall out of sight? We should not forget that HIV/AIDS is a long term wave.

Latifat Ibisomi talked about conceptualisation and contextualisation of sex among adolescents in two African countries. She emphasised the importance of understanding the social context of the lives of adolescent males, suggesting that this is key to addressing their vulnerability to sexual risks. She pointed out that their findings indicated that in the sexual arena, traditional masculine gender scripts dictate sexual exploration, activity and assertiveness as something synonymous to manliness. Adolescent males possess knowledge, interest, concerns and ideas about sex based on their interpretation, assimilation and adaptation of cultural values and norms from early age. It is these which are important drivers of SRH infections and it is at these points, but not only in relation to individual behaviour, where interventions must be targeted.

**Eva Roca** and **Kelly Hallman** addressed the question of whether financial education and social support enhance the effectiveness of an adolescent HIV prevention program in South Africa. The research findings of this project suggested that the following factors are important in protecting adolescents from infection: (a) education, (b) hope for the future, (c) access to financial services and social grants, (d) social support. This research adopted a rigorous method to examine how improvement in adolescent functional capabilities influenced behaviours. The results were that the intervention group, compared with the control, showed higher awareness of social grants, felt more powerful, were more confident about condom use and reduced use of alcohol and drugs. Perhaps most notably, the intervention group felt more confident about making plans for the future – in other words, greater hope. Hope appears to be a good proxy for improved relationship between the states of structural drivers as they are experienced by the individual.

Also concerning themselves with hope, Daniel Wight and Pieter Remes reported on a community-based parenting programme in Mwanza, Tanzania. This intervention used the idea of recruiting formal and informal opinion leaders so as to propagate innovation and changes in gender and community power. Once again, the same sort of drivers were attacked as in the other RPC interventions but at a more proximate level to the individual, in particular (a) getting to know each other, (b) positive parenting strategies, (c) sexual information and influences, (d) how parents transmit values about sexuality, (e) practical ways of communicating with children. The conclusions from early analysis of the data from this research indicate that: (a) support from local leaders is essential, (b) ppinion leaders require some payment and proper training, (c) well trained and incentivised opinion leaders go on to deliver satisfactory and effective sessions to young people. Parents participate in and facilitate sessions. This lends support to the intended outcome of the project which is that adolescent and adult sexual risk behaviours will be reduced and collective efficacy will increase. Further analysis is in progress to ascertain how robust these early findings are.

Justin Parkhurst summarised and discussed the papers in this session. He began by challenging the idea of a generalised social-structural approach, noting that such interventions are (a) context specific, (b) time specific, (c) "risk" varies from setting to setting and that (d) there is no one structural intervention, each context has to be treated in its own terms. Above all it is hard to arrive at clear cause-effect findings in relation to such complex terrains. It may be that we have to be satisfied with "sociological plausibility". But the strongest lesson of these projects is that participation and empowerment are important, but only in a social and political context of hope and material security. These were the two greatest findings of this approach: at the highest level, these are the two main areas where structural driver interventions have to be made.



Prof. Tony Barnett (LSE)



Dr Latifat Ibisomi (APHRC)

Follow up would be useful on how to draw synergies between research, implementation, policy and the politics behind all these.

### Session 7 Getting research into policy and practice and the use of evidence by policy makers

This session aimed to showcase the diversity of techniques employed by the four RPCs to feed their work into policy and practice. Led by Dr Sally Theobald the session incorporated ten 'lightening presentations' and a panel discussion. The 'lightening presentations' highlighted the roles and experiences of researchers, communications specialists, policy analysts and consortia advisory group members in policy engagement. Shared messages and dilemmas include:

#### **Messages:**

- Build a common agenda and partnerships: involve policy makers from the start
- Ensure results speak to the policy makers' plans; establish institutional linkages; involve NGOs and identify advocates
- Knowledge and communications intermediaries increase impact; communications strategies should be dynamic
- Be aware from the start that communicating research takes considerable time, skill and resources
- Bring the voice of people to health policy through sharing SRH and HIV needs and priorities
- It is possible to create a public space and dialogue on SRH and rights in a conservative and challenging environment

#### Dilemmas:

- Policy makers don't always act according to results
- What is the best way to track policy influence?
- How much can you challenge policy without being over critical?
- How can results be tailored towards different stakeholders?
- Individuals or donors may have influence and can by-pass formal systems, but this means the use of research will be influenced by those with the most influence.

**Panellists:** Dr Ann Phoya, (Ministry of Health, Malawi); Abigail Mulhall, DFID; Dr. Robin Vincent, PANOS; Dr. Eliya Zulu, African Institute of Development Policy.

#### Panel perspectives

*Time:* Policy makers do use evidence from researchers, but there is often a time lag as to when evidence gets used. It is therefore useful to think that although policy at national level

is difficult to change quickly, *operations* can be changed more frequently and easily.

**Priorities:** Health policy makers and researchers should discuss priorities together and develop research questions from the knowledge gaps identified at an early stage and using appropriate language for policy makers. For example, in Malawi some programs have an in-built mechanism for operational research in SRH and HIV.

**Stakeholders:** Don't talk to the minister, they don't make the policy; go to the technocrats and the committees who draft policy documents.

**DFID's 10% communications' budget:** is very positive and has supported building communications capacity in the north and south. Communications is coming of age in research and is reflected by the DFID investment in it.

**Communications:** Much communications work is about making partnerships and trust which can be intangible and therefore difficult to evaluate.

**Power:** Elite policy networks dominate policy making, so building relationships is very important.

**Disconnect:** Policy makers lament on the publication orientation of

researchers, yet researchers complain policy makers don't use research findings.

Synthesis: There is a role for synthesis of evidence on specific issues so that policy makers can absorb evidence; incentives for researchers are publicationbased rather than on synthesising evidence for policy. What a grand end to the RPCs. Long live the partnership.

> Dr Ann Phoya (Ministry of Health, Malawi)

### Programme

### Monday 17th May 2010

Time	Торіс	Speaker
9.00am	Registration	
9.30am	Opening	Professor Chris Whitty, DFID
10am	Session 1: Building health systems for the future of	Facilitator: Philippe Mayaud, Director, SRH &HIV RPC
TUAITI	HIV and sexual and reproductive health	
	Assessing integrated SRH and HIV services in Kenya, Swaziland and Malawi: preliminary findings and emerging questions	Susannah Mayhew, LSHTM, UK (SRH&HIV) and the Integra Team (IPPF, LSHTM, Population Council-Nairobi)
	Weak health systems and crises in Southern Africa: the impact on access and adherence to ARVs	Alan Whiteside (ABBA)
11.00am	Break	
11.20am	Session 2: Building health systems for the future of HIV and sexual and reproductive health (continued)	Facilitator: Ade Fakoya, Acting Director, Evidence for Action
	Tampons to Condoms: what have we learnt about introducing new technologies?	Helen Rees (SRH & HIV)
	Integration of HIV and other services: lessons learnt from The Lighthouse Experience in Lilongwe – Malawi	Sam Phiri (Evidence for Action)
	Discussion	Discussants: Dr Francis Ndowa, Dr Therese Delvaux,
	Audience questions and answers	Marge Berer, Malcolm McNeil
1pm	Lunch	
2pm	Session 3: Sexual and Reproductive Health Rights in everyday experience	Facilitator: Hilary Standing, Director, Realising Rights RPC
	Contextualising sexual and reproductive health and rights: what does it mean for young, poor women living in slums settlements in Bangladesh?	Sabina Faiz Rashid (Realising Rights)
	Sexual rights and economic justice: An intimate relationship	Susie Jolly (Realising Rights)
	Expanding policy space for SRH rights discourse: some experiences of CSOs in sub-Saharan Africa	Rose Ndakala Oronje (Realising Rights)
	Session reflection: Audience questions and discussion	Guest speaker: Nana Oye Lithur
3.20pm	Break	
3.40pm	Session 4: How does a rights perspective aid researchers, policy makers and programme implementers?	
	Whose rights? Ethics in the conduct of policy driven research	
	Protecting the unprotected: ethical challenges in conducting research on drug use, sex work, HIV and rights in Pakistan	Sarah Hawkes and Martine Collumbien (SRH & HIV + Realising Rights)
	Re-thinking fieldwork protocols for socio-economic HIV/AIDS research in South Africa – improving a 'rights perspective' for better research	Tim Quinlan (ABBA)
	Policy applications	
	Applying a human rights framework to a health, economic and social capabilities-building program for young people in KwaZulu-Natal, South Africa	Hallman K, Roca E, Govender K, Mbatha E and Rogan M (ABBA)
	Discussion and responses from speakers	Discussants : Petra Boynton, Malcolm McNeil, Nana Oye Lithur
5pm	Close	

### Tuesday 18th May 2010

Time	Торіс	Speaker
9.30am	Session 5: Bridging treatment and prevention	Chair: Ade Fakoya, Acting Director, Evidence for Action RPC
	Keynote: Bridging treatment and prevention	Reuben Granich (World Health Organization)
	Universal testing and treatment for HIV infection: Key research questions	Richard Hayes (SRH & HIV / Evidence for Action)
	Universal treatment for HIV prevention: views from the field	Francois Venter (SRH & HIV)
	Factors contributing to delayed antiretroviral therapy initiation among patients in Lilongwe, Malawi	Ireen Namakhoma (ABBA)
	Missed opportunities in linking prevention and care: the case of prevention of mother to child transmission services	Deborah Watson-Jones (Evidence for Action)
11.10am	Break	
11.30am	Session 6: Addressing social, structural and economic drivers of HIV and SRH	Chair: Tony Barnett (ABBA)
	<b>Overview</b> – Challenges and opportunities for a social/ structural approach to SRH/HIV	Julia Kim (UNDP)
	The conceptualisation and contextualisation of sex among adolescents in three African countries	Latifat Ibisomi (Realising Rights)
	Building capabilities of highly vulnerable youth for HIV prevention in South Africa	Kelly Hallman (ABBA)
	Addressing parenting in HIV prevention – lessons from Mema Kwa Jamii	Daniel Wight and Pieter Remes (SRH & HIV)
	Discussant and reflection on conceptualising social-structural research and prevention	Justin Parkhurst (Evidence for Action)
	<b>Open Discussion</b> – How does the shift to addressing social, structural and economic drivers affect our work? Do we need new methods or conceptualisations? What are the issues in scaling up structural approaches, particularly if they are meant to be context specific or tailored to local contexts?	
1pm	Lunch	
2pm	Session 7: Getting research into policy and practice (GRIPP) and the use of evidence by policymakers	Chair: Sally Theobald (Realising Rights)
	<i>Short</i> presentations highlighting researchers, communication specialists and CAG members' GRIPP experiences and dilemmas	Discussants: Dr. Ann Phoya (Ministry of Health Malawi) Dr. Abigail Mulhall (DFID) Dr. Robin Vincent (PANOS) Dr. Eliya Zulu (AFIDEP)
4 pm	Break	
4.20 – 5.00pm	Summary and close	

### **Participants**

Samah Abbasi UNICEF

Petra Abdulsalam-Saghir Natural Resources Institute, University of Greenwich

**Yaw Adu-Sarkodie** Kwame Nkrumah University of Science & Technology

**Kwadwo Anakwah** Research Development Unit, Ghana Health Service

**Parijat Baijal** Global Fund to Fight AIDS, Tuberculosis and Malaria

**Rebecca Balira** National Institute for Medical Research, Mwanza, Tanzania / London School of Hygiene & Tropical Medicine (LSHTM)

Tony Barnett London School of Economics

**Emmanuel Baron** MSF/Epicentre, France

Stephanie Bartlett MSF, UK

Anne Barusi Regional AIDS Training Network (RATN)

Mags Beksinska Reproductive Health & HIV Research Unit (RHRU), South Africa

Marge Berer Reproductive Health Matters

Charlotte Blackmore LSHTM

Petra Boynton University College London

Gavin Bryce Pamoja Consulting

Michelle Burns Department for International Development (DFID)

**Joanna Busza** LSHTM

Fabian Cataldo International HIV/AIDS Alliance

Katie Chapman DFID

Aoife Nic Charthaigh Interact Worldwide

Nathaniel Chishinga ZAMBART (Zambia AIDS Related Tuberculosis Project) **Kathryn Church** LSHTM

Kimberly Clarke Independent consultant

Martine Collumbien LSHTM Ros Davies

Women & Children First

**Cornelius Debpuur** Navrongo Health Research Centre, Ghana

Sinead Delany-Moretlwe Reproductive Health & HIV Research Unit (RHRU), South Africa

Therese Delvaux Institute of Tropical Medicine, Belgium

Benson Droti MRC Uganda Virus Research Institute (UVRI)

Nel Druce DFID

**Ruth Duebbert** Women & Children First

John Dusabe Liverpool School of Tropical Medicine

Jerker Edstrom Institute of Development Studies

Gary Edwards Institute of Development Studies

Ade Fakoya International HIV/AIDS Alliance

Alice Fay Save the Children

**Jo Feather** Save the Children

**Di Gibbs** MRC Clinical Trials Unit

Rutti Goldberger Interact Worldwide

Gabriela Gomez Imperial College

Reuben Granich WHO

**Alison Grant** LSHTM

Caroline Grundy Imperial College London

John Gyapong Ghana Health Service

Kelly Hallman Population Council Caroline Halmshaw Interact Worldwide

Sarah Hawkes University College London

Kate Hawkins Institute of Development Studies

Richard Hayes LSHTM

Lori Heise LSHTM

Sarah Hepworth Options Consultancy Services

Susan Hoskins MRC Clinical Trials Unit

Eleanor Hutchinson LSHTM

Latifat Dasola Ibisomi African Population and Health Research Center (APHRC)

Teresa Jackson Independent for Population Council/ABBA

Nina Jahn University College London

Ilona Johnston International HIV/AIDS Alliance

Susie Jolly Institute of Development Studies

**Elizabeth Kahurani** African Population and Health Research Center (APHRC)

Tamsin Kelk LSHTM

**Julia Kim** UNDP

Sue Kinn DFID

Ann Mette Kjaerby All Party Parliamentary Group (APPG) on Population, Development and Reproductive Health

Wendy Knerr The Pleasure Project

Anne Koerber LSHTM

Carole Leach-Lemens NAM – the HIV/AIDS information charity

Frankie Liew LSHTM

Nana Oye Lithur Human Rights Advocacy Centre, Ghana Kathy Lowndes Health Protection Agency, UK

Bruce Mackay HLSP

Nyovani Madise Southampton University

Barbara Magalhaes International HIV/AIDS Alliance

Jen Marshall DFID

Tessa Mattholie DFID

**Kari Mawhood** APPG on Population, Development and Reproductive Health

Philippe Mayaud LSHTM

Susannah Mayhew LSHTM

Christine McLanachan HLSP

Malcolm McNeil DFID

Helen Merati HLSP

**Tom Merrick** World Bank

Kevin Miles Options Consultancy Services

Anne Mills LSHTM

Abigail Mulhall DFID

Elaine Murphy Population Reference Bureau

Maurice Musheke ZAMBART

Beryl Mutonono-Watkiss Healthlink

Petra Nahmias DFID

Ireen Namakhoma Research for Equity and Community Health Trust (REACH)

Shampa Nath Healthlink

Francis Ndowa WHO

Sarah Nelson Institute of Development Studies

Veronica Oakeshott APPG on AIDS

Angela Obasi Liverpool School of Tropical Medicine

**Baafuor Kofi Opoku** Kwame Nkrumah University of Science & Technology, Ghana Rose Oronje Institute of Development Studies

Ramesh Paranjape National AIDS Research Institute, India

**Justin Parkhurst** LSHTM

Trevor Pearcy International HIV/AIDS Alliance

**Sam Phiri** Lighthouse Trust, Malawi

**Ann Phoya** Ministry of Health, Malawi

Kholoud Porter MRC Clinical Trials Unit

Tim Quinlan Health Economics and HIV/AIDS Research Division (HEARD), South Africa

Patrice Rabathaly LSHTM

Sabina Faiz Rashid BRAC, Bangladesh

Samantha Reddin Institute of Development Studies

Helen Rees Reproductive Health & HIV Research Unit (RHRU), South Africa

**Pieter Remes** MRC Mwanza, Tanzania

Nurshen Reshat LSHTM

**Eva Roca** Consultant to Population Council

Marsha Rosengarten Goldsmith, University of London

Rebecka Rosenquist Interact Worldwide

David Ross LSHTM

Julia Ross International HIV/AIDS Alliance

Fiona Samuels Overseas Development Institute

**Silke Seco** DFID

Tim Shand International Planned Parenthood Federation (IPPF)

Charlotte Smith International HIV/AIDS Alliance

Martin Smith DFID

Annabelle South LSHTM

Hilary Standing Institute of Development Studies

Christine Stegling International HIV/AIDS Alliance Suzanne Taunton Save the Children Liz Tayler

DFID

Fern Terris-Prestholt LSHTM

Sally Theobald Institute of Development Studies / Liverpool School of Tropical Medicine

Rachel Tolhurst Liverpool School of Tropical Medicine

Sam Toroei Regional AIDS Training Network (RATN)

Myriam Toure LSHTM

Alejandra Trossero International Planned Parenthood Federation (IPPF)

Olivia Tulloch Liverpool School of Tropical Medicine

Mark Urassa National Institute for Medical Research, Mwanza, Tanzania

Jas Vaghadia Institute of Development Studies

**Francois Venter** Reproductive Health & HIV Research Unit (RHRU), South Africa

Robin Vincent Panos

Isabelle Wachsmuth-Huguet WHO EVIPNET

Deborah Watson-Jones LSHTM

Charlotte Watts LSHTM

Ralf Weigel Lighthouse Trust, Malawi

Ian Weller University College London

Amy Whalley UNICEF

Alan Whiteside Health Economics and HIV/AIDS Research Division (HEARD), South Africa

Chris Whitty DFID

Danny Wight MRC Social & Public Health Sciences Unit

Felicia Wong International HIV/AIDS Alliance

Basia Zaba LSHTM

**Eliya Zulu** African Population and Health Research Center (APHRC)

### Abstracts

### Sessions 1 and 2

#### Assessing integrated SRH and HIV services in Kenya, Swaziland and Malawi: preliminary findings and emerging questions

Susannah Mayhew, London School of Hygiene & Tropical Medicine, UK (SRH&HIV) and the Integra Team (IPPF, LSHTM, Population Council-Nairobi)

**Background:** This ambitious five-year Gates Foundation funded project aimed to assess the benefits, costs and challenges to integrating a range of SRH and HIV services in Kenya (midprevalence HIV), Swaziland (one of highest HIV rates) and Malawi (high HIV). In both countries governments have expressed commitments to integration, but there are still few robust data on the costs and benefits of different types of integration to the health system or to individuals. The project is a collaboration involving IPPF, LSHTM and Population Council-Nairobi.

**Methods by integration model and country:** Four models of care (VCT/ART into FP; VCT/ART into PNC; youth services; HIV-specialist services) were analysed using multiple methods: community surveys (2600 adults), clinic facility assessments (36 clinics), economic analyses (36 clinics), cohort (4800 clients), qualitative interviews (providers, clients, community).

Preliminary findings and emerging questions

Is there demand for integrated services and what are patterns of use? Community survey data from 1800 men and women in Kenya show apparent lack of demand for integrated services and low levels of multiple-service use. Explanatory factors are being analysed.

Are integrated clinics better than specialist clinics at meeting SRH needs of HIV+ people? Qualitative data from 16 providers and 22 clients at four HIV clinics found: HIV providers ill prepared to deal with other SRH needs; high levels of unmet SRH needs; high client-satisfaction with specialist services; integrated services may be less supportive of HIV+ clients.

How do we reach youth with integrated services? Expansion of mobile clinics in Malawi resulted in increased uptake of all SRH services by youth and particularly of VCT. Cost analyses showed economies of scale resulted in unit costs per service declining from \$24 to \$6 per person. It is not clear whether these gains can be made in all settings, where base levels of utilisation of resources and services may be higher.

Challenges to measuring 'integration' & its cost-effectiveness: Despite assumptions being made about the potential costeffectiveness of integration, high quality assessments are rare. Integration in 'real situations' is highly complex and in constant flux. This presents multiple challenges for research into its effects. A 'continuum of integration' is being developed to aid analysis, and a framework for cost-effectiveness analysis is evolving.

#### Weak health systems and crises in southern Africa: the impact on access and adherence to antiretrovirals

Alan Whiteside<sup>1</sup>, Nina Veenstra<sup>1</sup>, Andrew Gibbs<sup>1</sup>, David Lalloo<sup>2</sup> <sup>1</sup>Health Economics & HIV/AIDS Research Division (HEARD), University of KwaZulu Natal, South Africa; <sup>2</sup> Liverpool School of Tropical Medicine, UK

**Background:** As ARV treatment is scaled up across southern Africa, the role of weak health systems in undermining access and adherence to ARVs is increasingly considered a major concern. Treatment interruptions lead to poor outcomes for individuals and to the development of drug resistance at the population level. While research has focused on many aspects of weak health systems in shaping access and adherence to ARVs, little research has understood how crises may affect this. We look at three crises in southern Africa: the 2008 floods in Mozambique, the current economic and political crisis in Zimbabwe and the 2007 public sector strike in South Africa. Understanding the effect of these crises and how they were handled might help us strengthen health systems that can keep patients on treatment under difficult circumstances.

**Methods:** We conducted an extensive published and grey literature review and used snowball sampling to identify three key informants in each country. Semi-structured interviews focused on the impact of each crisis on patients' access to ARVs and strategies used to limit the impact.

**Results:** In all three crises patients had reduced access to ARVs. While there were attempts to actively manage the impact of crises by health managers and partnerships between government, NGOs and donors, these were typically less effective than hoped for. Specific barriers included limited patient information and tracking, poor management of crises by governments, the migration of patients and limited numbers of health workers.

**Conclusions:** Based on our findings we suggest that the impact of crises on health systems is a function of already weak health systems and ARV delivery processes. Crises serve to amplify long-term, underlying health system flaws. We suggest that to ensure access and adherence to ARVs during crises there is a need to:

- 1. Strengthen health systems generally. Through general health systems strengthening in the region, health systems will be better able cope with and manage crises when they occur;
- 2. Identify and support existing approaches to managing crises. Where these do not exist, work to support innovative ways of ensuring crises are adequately responded to, enabling continued access and adherence to ARVs.

### Tampons to condoms: what have we learnt about introducing new technologies?

Helen Rees, Executive Director, Reproductive Health & HIV Research Unit (RHRU), University of the Witwatersrand, Johannesburg, South Africa

**Background:** History has taught us a lot of lessons about the introduction of new reproductive health technologies, going back to the Victorian days of douches to the more recent attempts to introduce the tampon. The art of how you brand, place and market a product is one well known to the corporate sector and an approach which is increasingly being considered by the public health sector when it introduces new technologies. For the public sector the driver for introduction of technologies is not for profit but is for public health benefit. The immunisation field taught us a hard lesson through our faltering approach to the introduction of the Hepatitis B vaccine. This vaccine is life saving to many adults and children in the developing world, yet it took twenty years between its introduction into rich countries and its final introduction into poorer countries where the public health need was the greatest.

**Lessons learnt:** This presentation will review the history of introduction of reproductive health and HIV technologies and consider the rights and wrongs of how this has been done. It will look at lessons learnt from the private sector and the theoretical model of product introduction. It will then use examples of product introduction including a review of female condom introduction in different settings, and see how these lessons can inform the modeling of technology introduction and give us further guidance on how to do this better. The final message from this presentation will consolidate recommendations on how we can streamline and accelerate future technology introductions.

#### Integration of HIV and other services: lessons learnt from the Lighthouse experience in Lilongwe – Malawi

Sam Phiri, Executive Director, Lighthouse Trust, Kamuzu Central Hospital, Lilongwe, Malawi

**Background:** Service integration and linkage can improve treatment, care and support programs as well as reduce missed opportunities for key interventions such as provision of antiretroviral drugs (ART). Although there has been a rapid ART scale up in Malawi, integration of HIV with other services has been slow. The Martin Preuss Centre (MPC) at Bwaila hospital was purposefully designed to integrate tuberculosis (TB), prevention of mother-to-child transmission (PMTCT) and HIV care and treatment. This abstract describes our experience integrating HIV services with TB, PMTCT and STI services.

**Description:** Bwaila Hospital has the largest PMTCT programme in Malawi with more than 12,000 deliveries per year. HIV prevalence among ANC attendees is 12%. Eligible women are referred to MPC for ART initiation. Of these women, 76% reach MPC and 95% start ART within a week of registration. MPC also has the largest TB registry in Malawi registering 4,000 TB patients annually. MPC provides routine HIV testing and counseling (HTC) to both chronic coughers and TB patients: 95% of TB patients and 60% of chronic coughers know their HIV status when they leave the centre For those who are HIV+, both ART initiation and follow up are provided within the TB unit. Of TB patients, 66% are co-infected with HIV and 65% of them eventually start ART. Currently, 45% of STI patients are HIV positive, reaching as high as 61% among genital ulcer disease patients. However, there is low uptake of HTC among STI clients. To address this service gap, Lighthouse initiated a program to improve HIV testing through integrated HIV/STI management in June 2009 according to National STI treatment guidelines.

**Lessons learnt:** Patients frequently need care for multiple critical health problems simultaneously. Integrated care enables timely, holistic service provision while lowering the burden on the patient by providing comprehensive services in one location. Integration of care is also an important strategy to improve patient retention in long-term HIV care and treatment by meeting diverse patient needs through a linked team of service providers. Efficiency is also positively affected in several ways by extending the continuum of care: 1) clients may access treatment and adherence support for various conditions in one location; 2) defaulter tracing could be simplified through a single team for patient follow-up; and 3) monitoring and evaluation could improve through streamlined data linkages and improved communication.

### Sessions 3 and 4

#### Contextualising sexual and reproductive health and rights: what does it mean for young, poor women living in slums settlements in Bangladesh?

Sabina Faiz Rashid, Associate Professor, James P Grant School of Public Health, BRAC University, Bangladesh

This presentation will draw upon ethnographic case histories of poor young women living in urban slums settlements in Dhaka, Bangladesh to challenge and critically reflect on notions of sexual and reproductive health and rights (SRHR). Given the reality of poor women's lives, many go along with decisions not of their own making, which may violate their sense of sexual and reproductive bodily integrity and well-being. Structural and social inequalities, a harsh political economy and indifference on the part of the state have made the urban poor in Bangladesh a socially excluded population, with young women extremely vulnerable. The reproductive and sexual lives of young women in an urban slum are grounded in the social, political and economic structures of their everyday lives. Slum settlements remain rife with violence, crime, gang warfare, and added to this are job insecurities, with tense and fragile relationships with family members and with community members. For young adolescent women, their lives are fraught with tensions, dilemmas and opportunities, which place their reproductive bodies at risk. Financial constraints within families compel many young women to work in garment factories to earn a living, resulting in greater interaction with men and opportunity of forming relationships. While these young women face greater mobility and freedom to fall in love, the community leaders/gang members also act as moral guardians by enforcing fines, punishment and forced marriages on young couples. Marital instability is common, with city life allowing men anonymity to relocate and leave their spouses,

with little fear of punishment. Young women spoke of coerced sexual relations, the need for early child-bearing to cement marriages, pregnancy terminations due to poverty/marital instability/abandonment. In the face of these insecurities, females often rely on their sexuality as an economic resource, to hold on to spouses and to attract potential suitors, placing them at risk of adverse reproductive experiences and violence. So what do reproductive and sexual rights mean for married adolescent women living in urban slums in Dhaka city? They mean something quite different than normally implied in SRHR discussions: they mean something to forfeit in exchange for tenuous rights to security; they mean a short-lived power – usually mediated by men. But they very rarely mean having control over one's experiences or being able to act responsibly in the interests of one's reproductive and sexual health.

#### Sexual rights and economic justice: an intimate relationship

Susie Jolly, Sexuality and Development Programme Convenor, Institute of Development Studies, University of Sussex, Brighton, UK

Many sexual rights organisations in the south work on poverty reduction. This is because for many people with nonconforming sexual and gender identities, people living with HIV/AIDS, sex workers, and others facing marginalisation on the basis of sexuality, economic disadvantage intersects with this marginalisation. Sexual rights and economic justice are understood to be interrelated. A number of studies show that people who diverge from sexuality norms are economically marginalised, and that people who do conform can be 'adversely included' in unequal relationships and structures. In turn, poverty can make people more vulnerable to sexual rights violations. Poverty reduction efforts need to learn from the practices of southern organisations on the intersectionality between sexual rights and economic justice, and to take these into account in their programming. Otherwise they risk exacerbating marginalisation based on sexuality, and failing to effectively reduce poverty.

### Expanding policy space for SRH rights discourse: some experiences of CSOs in sub-Saharan Africa

Rose Ndaka Oronje, Doctoral candidate, IDS and formerly communications officer, APHRC, Nairobi, Kenya

Even though it is more than 15 years since the rights perspective to SRH emerged on the international RH scene at the ICPD '94, the approach still faces resistance in many poor countries. The rights approach to SRH is resisted mainly by the church and politicians, among others, on moralistic grounds as it is seen to allow the provision of abortion services, and contraception to young people, practices perceived as 'killing' and/or promoting 'irresponsible' sexual behaviour. The approach is also resisted because it recognises same-sex relationships, which, according to the moralistic rhetoric community, are 'unnatural'. This presentation aims to share experiences of CSOs and groups in some sub-Saharan African countries working to expand policy space for the rights approach to addressing SRH issues, and start a discussion on lessons and way forward.

### Protecting the unprotected: ethical challenges in conducting research on drug use, sex work, HIV and rights in Pakistan

Sarah Hawkes<sup>1</sup>, Martine Collumbien<sup>2</sup>, Susannah Mayhew<sup>2</sup>, Hasan Abbas Zaheer<sup>3</sup>

<sup>1</sup> University College London, UK, <sup>2</sup> London School of Hygiene and Tropical Medicine, UK, <sup>3</sup> National AIDS Control Programme, Pakistan

The presentation will draw on experiences of doing research in Pakistan among vulnerable and marginalised people (male, female and transgender sex workers and injecting drug users) and the methodological and ethical issues this research raised. One aim of the research was to measure the extent of human rights abuses among marginalised people, and to determine whether these abuses were linked to vulnerability to sexual ill-health (including HIV risk). Conducting such research in Pakistan was challenging from a number of perspectives.

The first challenge was how to conduct research in a manner that was locally acceptable and gives a voice to these vulnerable populations that are very hard to reach. The second was how to translate the findings into policy-relevant recommendations that would serve to protect human rights in the future.

We addressed these challenges in two ways. Firstly, we explored and eventually used participatory methods (a peer ethnographic approach) to engage high-risk group members in a relationship of responsibility and self-affirming dignity through the research process itself. The presentation will describe this approach, its benefits and challenges. The participatory process itself resulted in a different quality 'rapport' being built between the project researchers and the peer researchers who reported how much they valued being given the responsibility of doing interviews with their peers and the value with which their information was treated. In other words, the process of the research allowed them to be treated as 'equals' not as a passive group of 'researched'. The development of this rapport in turn facilitated the collection of 'truer' data on sexual risk behaviour and experiences of discrimination and abuse than would have been possible using conventional methods. This then allowed us to inform development of a structured questionnaire in a way that enabled us to ask sensitive questions in a more acceptable and meaningful way to the groups involved. This guestionnaire was then used in bio-behavioural measurement surveys. Illustrative examples will be given in the presentation.

Secondly, we used theories from policy analysis to guide our relationship and subsequent collaborative research programme with key stakeholders, including the National AIDS Control Programme (NACP). Our evidence-based recommendations were derived from the study's findings and included a recommendation to protect the human rights of vulnerable populations through training programmes directed at state actors (including police and prison officers). These recommendations were then subjected to a prospective policy analysis which assessed their feasibility and 'palatability' among the policy elite in Pakistan. Revisions to the recommendations were made based on the findings of the policy analysis. Our close relationship with the NACP led to joint dissemination and communication activities and may have increased the potential policy impact of the study's findings.

#### Re-thinking field work protocols for socio-economic HIV/AIDS research in South Africa – improving a 'rights perspective' for better research

Tim Quinlan, Research Director, Health Economics & HIV/AIDS Research Division (HEARD), University of KwaZulu Natal, South Africa

During the last year and half, experiences of HEARD researchers in the field as well as data from a range of projects have highlighted the very high levels of domestic violence, sexual abuse and crime in rural and urban areas of South Africa. Reports from fieldworkers on general experiences conveyed by informants in passing and on formal responses in surveys (that often include, in some form, questions relating to sexual and reproductive health [SRH] and sexual behaviour) have led me ask whether our ethics protocols are adequate. This is in the face of a range of issues raised by fieldworkers such as stress when faced with reports of rape and/or visible evidence of abuse and, also, doubts by project leaders about adequacy of training and practice by fieldworkers despite regular updates to 'field manuals', to training and ethical practices such as inclusion of trained counsellors.

This presentation puts forward for debate a position that I am considering as a basis for revising HEARD research protocols. The position, baldly stated, is that our current ethical standards and procedures, like those of the University of KwaZulu-Natal and, probably, other universities in and beyond SA, are inadequate because our socio-economic/psycho-social studies are 'abnormal' investigations in 'abnormal' situations. On the one hand, HEARD's research designs usually have to accommodate high rates (probable and actual) of 'sample attrition' due to HIV illness and AIDS-related deaths, are very intrusive (questions on SRH. sexual behaviour, social stresses) and they are conducted in contexts of extremely high levels of conflict and violence (e.g. SA has highest femicide rate in the world). On the other hand, our survey designs tacitly presume 'normality' in the use of concepts such as households and community, 'equilibrium' or controllable variables in experimental and quantitative study designs, and 'truth' in self-reporting in questionnaires (despite evidence of considerable denial, stigma and discrimination on the subject of HIV/AIDS); plus they assume validity of protocols founded on bio-physical research standards and conventions. However, I will seek discussion on measured steps to address the challenge.

#### Applying a human rights framework to a health, economic and social capabilities-building program for young people in KwaZulu-Natal, South Africa

#### Kelly Hallman, *Director ABBA RPC, Population Council, New* York, USA

Many young people in KwaZulu-Natal reside in a setting characterised by extremely high rates of HIV prevalence, unintended adolescent pregnancy, poverty and inequality, residential segregation, unequal access to resources and opportunities, traditional and pop culture values that compete with health messages, as well as social exclusion that is played out along race, class and gender dimensions.

How was the need for, design, targeting, implementation and assessment of a program to enhance the sexual health,

economic and social capabilities of such young people in KwaZulu-Natal informed by the human rights approach?

The four key principles for human rights programming are universality; accountability; indivisibility; and participation:

*Universality:* Those who are marginalised, remote or excluded are as equally important for the goals and objectives of programs as those who are less excluded, easier to reach, or already included.

Accountability: Young people are social actors and must be regarded as subjects of rights to whom others have shared responsibilities for ensuring.

*Indivisibility*: All rights – social, cultural, economic, civil and political – are interrelated and multi-sectoral approaches are needed.

*Participation:* Community-led design, implementation and assessment may increase chances for positive impact and sustainability.

Practical application of human rights principles as they relate to the Siyakha Nentsha program in KwaZulu-Natal will be illustrated using an audiovisual slideshow. Young program participants' experiences conceiving of and utilising a human rights framework in their daily lives will be highlighted.

### Session 5

#### Bridging treatment and prevention

Reuben Granich, HIV/AIDS Department, World Health Organization, Geneva, Switzerland

After over 27 years it is important to pause and consider the devastating extent of the HIV pandemic. Over 25 million people have died and an estimated 33 million people are living with HIV. In 2008, about 79% of people living with HIV were in sub-Saharan Africa with around 35% in eight countries alone. HIV is the strongest risk factor for tuberculosis (TB) and an estimated 1.4 million people living with HIV developed TB causing 520,000 (26%) of total HIV-related deaths. In 2005 and 2009 the G8 met in Scotland and Italy and committed to achieving Universal Access to HIV prevention, care and treatment by 2010. By end 2008, over 4 million people were on treatment and over a million people were started on ART. However, despite this remarkable achievement, over 5 million needed treatment and in 2008 there were 2.7 million new infections. Around 23 million people were waiting, mostly unknowingly, to become treatment-eligible, sicken or die. The estimated coverage of antiretroviral therapy reached 42% in low and middle-income countries using the lower 200 CD4 count eligibility criteria. Universal Access remains a dream for millions of people and faces serious technical, economic and political challenges on a number of fronts.

Although there has been unprecedented investment in confronting HIV/AIDS – the Joint United Nations Programme on HIV/AIDS estimates \$13.8 billion was spent in 2008 – a key challenge is how to address the HIV/AIDS epidemic given limited and potentially shrinking resources. Economic disparities may further exacerbate human rights issues and widen the increasingly divergent approaches to HIV

prevention, care and treatment. HIV transmission only occurs from people with HIV, and viral load is the single greatest risk factor for all modes of transmission. HAART can lower viral load to nearly undetectable levels. Prevention of mother to child transmission offers proof of the concept of HAART interrupting transmission, and observational studies and previous modelling work support using HAART for prevention. Although knowing one's HIV status is key for prevention efforts, it is not known with certainty when to start HAART.

Building on previous modelling work, we used an HIV/AIDS epidemic of South African intensity to explore the impact of expanding access to ART and combination prevention including to those with <350 CD4 cells (Universal Access) and everyone with HIV irrespective of CD4 count. Increasing access to ART and combination prevention for those <350 and above would dramatically reduce annual HIV incidence and mortality. The model also highlighted a number of key programmatic issues that would need to be addressed for ART expansion to have maximal impact. To explore HAART as a prevention strategy, we recommend further discussions to explore human rights and ethical considerations, clarify modelling assumptions, economic costs and benefits, research priorities and review feasibility and acceptability issues.

### Universal testing and treatment for HIV infection: key research questions

Richard Hayes , Professor, London School of Hygiene & Tropical Medicine, London, UK

Based on the results of mathematical modelling, it has been proposed that the promotion of universal voluntary counselling and testing for HIV infection followed by the provision of immediate antiretroviral therapy for all those found HIVpositive (the UTT strategy) may be an effective HIV prevention strategy, leading to substantial reductions in HIV incidence at population level. The acceptability, feasibility, effectiveness, costs and adverse effects of UTT have not yet been established, and UTT interventions should only be implemented after careful evaluation of these parameters.

This talk briefly reviews the research questions that need to be addressed before UTT could be recommended for widescale implementation. We consider questions concerning HIV testing strategies, HIV treatment strategies, health service issues, effects of UTT on HIV transmission and other research questions. We briefly outline the rationale and design of a cluster randomised trial to measure the impact of UTT on HIV incidence, should preliminary studies show the intervention to be feasible and acceptable.

### Universal treatment for HIV prevention: views from the field

Francois Venter, Cluster Leader, Reproductive Health & HIV Research Unit (RHRU), University of the Witwatersrand, Johannesburg, South Africa

HIV prevention interventions have yielded disappointing results at a public health level. Even where country-level incidence and prevalence has decreased, there is little agreement as to exactly what to attribute this success. Proven interventions that work at an individual level, such as PMTCT and male circumcision, have not yet been shown to affect population level transmission dynamics.

Recent mathematical models, built on strong evidence of the highly protective effect of ART in stopping HIV transmission, by decreasing the viral load in HIV-infected people, suggest that a population level effect can be rapidly and effectively attained if sufficient HIV testing and treatment is provided to people with HIV, irrespective of immunity level.

These models have yielded much controversy, ranging from whether the mathematical model assumptions are right, to affordability, to resistance, to practical application in countries with some of the weakest health systems in the world. However, these concerns have to be weighed against an epidemic that is increasingly looking uncontainable through traditional means, with no other intervention promising more than a slight impact on the existing epidemic.

### Factors contributing to delayed antiretroviral therapy initiation among patients in Lilongwe, Malawi

Ireen Namakhoma<sup>1</sup>, Sally Theobald<sup>2</sup> Brian Faragher<sup>2</sup> Gillian Mann<sup>2</sup> David Lalloo<sup>2</sup>

<sup>1</sup> Research for Equity and Community Health (REACH) Trust, Lilongwe, Malawi; <sup>2</sup> Liverpool School of Tropical Medicine, UK

**Background:** Malawi has been greatly affected by the HIV pandemic with a prevalence rate of 12% among the 15-49 age groups. It is estimated that 85,000 people die each year due to HIV related diseases. Amongst those who die while on antiretroviral therapy, it is estimated that about 70% die in the first three months of treatment which is mainly attributed to late treatment initiation.

This study therefore aimed to understand the patient health care seeking pathway to HIV and AIDS care and treatment and to understand the associated social and economic costs of health care seeking for patients at household level.

**Results:** A total of 453 patients were recruited from seven health facilities in urban and rural Lilongwe. Over 70% of the patients sought care from formal health providers. There was low suspicion of HIV among patients who mainly perceived to be suffering from malaria, Tuberculosis and diarrhea and few suspected to be infected with HIV and AIDS. The health care seeking pathway to Antiretroviral initiation was characterised by multiple and repeated visits to different health providers. Only about 50% of the patients were initiated on treatment by their sixth visit to a provider. The choice of provider was mainly influenced by distance to a health facility, low cost or free treatment, perceived effectiveness of treatment provided. Care seeking has also been described by high care seeking costs, especially for the rural poor who also take longer to travel to a health facility.

**Conclusions:** Health services need to be more equitable and more efforts are required to influence the care seeking patterns both among communities and within the health system in order to promote early HIV testing and ART initiation.

#### Missed opportunities in linking prevention and care: the case of prevention of mother to child transmission services

Deborah Watson-Jones, Senior Lecturer, London School of Hygiene & Tropical Medicine, London, UK

Background: Prevention of mother to child transmission (PMTCT) programmes present an opportunity to improve mother and infant care beyond prevention of maternal transmission of HIV. However the programmes face challenges in implementation, as HIV positive women must negotiate a cascade of intervention steps with significant fall-off at each step. Three EFA-supported studies are investigating missed opportunities in PMTCT programmes in sub-Saharan Africa. Studies in Tanzania and Kenya are examining the operational performance of the PMTCT programme and its links to the longer-term HIV treatment and care for both the mother and infant, and the barriers to successful completion of each step of the programme. A study in Uganda is determining acceptability and adherence to standard ART regimens for PMTCT and use of family planning methods in women screened for HIV. Preliminary findings will be presented.

**Results:** Uptake of HIV testing in antenatal clinics has improved in recent years, but failure to re-screen women who deliver in health facilities and losses to follow-up post-partum remain a challenge. A high proportion of pregnancies in HIV positive women may be unwanted, revealing an unmet need for family planning services. Timely referral of women to adult HIV care and treatment clinics for assessment of their need for HAART is rare, with many women failing to attend or only attending after delivery. Linkages between the different programmes remain weak.

**Discussion**: Missed opportunities for women's care and treatment could be provided through provision of HIV care in ANC/MCH services, efficient referral to adult HIV treatment clinics, a shorter time to assess eligibility for HAART and improved tracking of mother-infant pairs post-partum. Immediate initiation of HAART may also merit evaluation. Focus should be given to improving access to family planning services and to measuring adherence to ARVs for PMTCT.

### **Session 6**

#### The conceptualisation and contextualisation of sex among adolescents in three African countries

Latifat Ibisomi, African Population and Health Research Center (APHRC), Kenya

**Key point:** The study improves our understanding of how the youth perceive sex and how this in turn influences their sexual attitude and behaviours.

Drawing from four studies (three qualitative and one quantitative), the presentation tells a multi-country story of (1) how adolescents males conceptualise and contextualise sex and sexual activities (2) how male and female youths described attitudes, behaviours and motivations to reduce unplanned pregnancies and spread of HIV/AIDS (3) adolescents' males beliefs in relation to voluntary counselling and HIV testing and (4) the correlates of HIV testing among adolescents. The papers were drawn from the "Protecting the Next Generation" study conducted among males and females aged 12-19 years in Malawi, Uganda and Burkina Faso.

Results show that adolescents see sex as a natural and routine activity of which pleasure and passion are essential components. A critical driver of adolescent males' vulnerability is their sexual scripts, which constitute masculinity as very fragile and in need of constant protection – making boys wary both of female partners who refuse them sex and of sexual practices, which offer little or no control and power over women, raising suspicions about their manliness.

Further, male youth framed going for HIV testing in terms of danger – a sign of lack of self confidence and an acknowledgement of vulnerability. Results also show that adolescents who perceived themselves to be at great or moderate risk for HIV were more likely to have ever been tested; those who held stigmatising attitudes towards people living with HIV/AIDS were less likely to have been tested; adolescents who reported history of pregnancy were more likely to have ever been tested; and those from poorer households or out of school were significantly less likely to have been tested.

We contend that these attitudes, beliefs, behaviours and identified risk factors portend potential dangers to these young people ultimately realising their full sexual and reproductive health and rights. The programmatic implications of the results are also discussed.

### Enhancing the health, social and economic capabilities of highly vulnerable youths

Siyakha Nentsha Study Team: Kelly Hallman, Eva Roca, Kasthuri Govender, Emmanuel Mbatha, Mike Rogan and Hannah Taboada

Population Council, New York, USA

**Background:** This paper presents longitudinal findings from a randomised control study, the Siyakha Nentsha program, in KwaZulu Natal Province, South Africa. It seeks to build the health, social, and economic capabilities of highly vulnerable young women and young men in a severely HIV and AIDSaffected environment. Many programs aim to improve the lives of young people, but few target those who are most vulnerable with specific and applicable skills tailored to their circumstances.

**Methods:** The program was randomised to 1,000 youths. One arm received financial and HIV education with social support, a second got HIV education with social support, while a third got only HIV education without social support. The program has been tracked for 18 months. Pre- and post-intervention measures were collected on young people's gender attitudes, knowledge and practice of HIV preventive behaviors, knowledge and confidence in financial matters and practice of financial skills, such as saving money and budgeting.

**Preliminary findings:** So far we have only been able to investigate a few key findings related to sexual and

reproductive health. Preliminary findings show that both versions of the intervention are more effective than the control program for several key outcomes. Some of these outcomes differed by gender, but specifically program participants reported feeling more powerful, having greater awareness of social grants, greater confidence in correct condom use, more responsible sexual decisionmaking, and fewer sexual partners than learners in the control group. These early results are promising and indicate that carefully contextualised programs can be effective in changing the environment in which vulnerable young people make decisions about their futures.

### Addressing parenting in HIV prevention: lessons from Mema Kwa Jamii

Daniel Wight<sup>1</sup> and Pieter Remes<sup>2</sup>

<sup>1</sup> Leader of Sexual Health and Families Programme, <sup>2</sup>Investigator Scientist, Sexual Health and Families Programme, MRC Social and Public Health Sciences Unit, Glasgow, UK

This paper will present the rationale for interventions with parents to reduce their children's sexual risk behaviours. It will describe one such programme in northern Tanzania, *Mema kwa Jamii* (Good Things for Communities), and will present preliminary findings from initial piloting.

The limited effectiveness of behavioural interventions targeted at young people suggests the need for additional communitylevel interventions that: (a) include powerful sections of the population; (b) tackle underlying cultural features that perpetuate young people's vulnerability; (c) involve most people in the community so that revised norms can be continually reinforced through everyday social interaction; and (d) tap into the target group's pre-existing motivations. Interventions with parents of adolescents can, potentially, meet all these requirements and offer a means to tackle cultural factors that drive the epidemic.

The potential value of parenting interventions has been recognised in several countries in sub-Saharan Africa, by NGOs, researchers and some governments. In high income countries there have been several attempts to reduce adolescents' sexual risks through parenting interventions, and a systematic review identifies promising evidence of effectiveness.

A needs assessment in rural northern Tanzania found that parents were concerned about their children's sexual risks but felt inadequate to protect them, due to: lack of sexual health knowledge; believing their own experiences no longer relevant; and not knowing how to engage with their children about sex.

Since nearly all adults are also parents, a parenting intervention can potentially reach across a community, it can harness parents' existing motivation to protect their children, and can raise parents' awareness of their own sexual risks. It can address gender norms that perpetuate vulnerability, and provides a rare opportunity to get men to address masculinity. Working with parents fits with the Tanzanian government policy on HIV/AIDS (National Multi-Sectoral Framework on HIV and AIDS, 2008-2012).

Mema kwa Jamii is designed for parents of 10-14 year olds

and aims to promote positive sexual norms and behaviors at a community level. It is derived from theories of diffusion of innovation, collective efficacy, the role of gender and power in relationships, and "learning-by-teaching" (reinforcing and internalising learning through active dissemination). The presentation will describe the programme content and its mode of delivery: a cascade of peer-facilitated training starting with opinion leaders and continuing to successive waves of peer groups. Each parent is meant to both actively participate in training and subsequently deliver the course to others.

We will present early findings from piloting in three contrasting villages, focusing on: the strategy of using opinion leaders; factors affecting the reach of the programme; fidelity; gendered participation; the suitability of the content, and remaining challenges.

A new mother at Kojja-Mukono Health Centre, Uganda, which has a PMTCT programme led by one nurse and several NSAs © Nell Freeman/Alliance

### **Further information**



#### ABBA

Addressing the Balance of Burden in AIDS Research Programme Consortium (ABBA RPC) is a multi-country research project in sub-Saharan Africa that explores the context around prevention, treatment, care, and mitigation of the effects of HIV and AIDS in vulnerable populations. Its goal is to improve the effectiveness of poverty-reduction efforts and to contribute towards the achievement of the MDGs.

#### Further information: www.abbarpc.org

Population Council at One Dag Hammarskjold Plaza, New York, New York 10017 USA **Tel:** +1 212 339 0602 Hannah Taboada, ABBA Coordinator or Teresa Jackson, Communications Project Manager **Email: abbarpc@popcouncil.org** 



#### **Realising Rights**

Realising Rights works in the context of the recent MDG target on Universal Access to Reproductive Health by 2015. It focuses on areas that are often neglected or controversial but are essential to meeting the MDGs, such as unmet need for contraception, unsafe abortion, non-HIV STIs and sexual rights; and on poor and marginalised people. Realising Rights works to raise the profile of these issues on the policy agenda through improving the evidence base, undertaking intervention based research and engaging policy and advocacy actors at national, regional and international levels.

Further information: www.realising-rights.org

Jas Vaghadia, Programme Coordinator. Realising Rights Consortium, Institute of Development Studies, at the University of Sussex, Brighton, BN1 9RE **Tel:** +44 (0)1273 915683 **Email: J.Vaghadia@ids.ac.uk** 



#### Evidence for Action on HIV Treatment and Care Systems

Evidence for Action is an international research consortium carrying out policy-relevant research on issues relating to HIV treatment and care. Through increasing knowledge, and informing and influencing policy and practice in this area, we are working to reduce HIV-related morbidity and mortality.

Further information: www.evidence4action.org

Annabelle South, Programme Administration & Communications Manager, Evidence for Action, LSHTM, Keppel Street, London, WC1E 7HT **Tel:** +44 (0)20 7927 2703 **Email: info@evidence4action.org** 



#### Programme for Research & Capacity Building in Sexual & Reproductive Health & HIV in Developing Countries

Reversal of the spread of HIV/AIDS is one of the eight MDGs. Success in achieving this goal will depend critically on improving access to effective interventions for those who are particularly vulnerable to infection (e.g. the poor). Since 2005, the Programme has been working to strengthen the evidence base to enable policy makers to identify and prioritise interventions that will improve reproductive and sexual health and reduce HIV incidence among the poor in Africa and Asia.

#### Further information: www.srh-hiv.org

Tamsin Kelk, Communications Officer Programme for Research & Capacity Building in Sexual & Reproductive Health & HIV, LSHTM, Keppel Street, London, WC1E 7HT, UK **Tel:** +44 (0)20 7927 2404 **Email: Tamsin.Kelk@lshtm.ac.uk**