

ENGAGING EDITORS

Notes from a dialogue on reporting a pandemic

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Contextualising the Editors' Forum

DURING OUR three-year partnership with the Nelson Mandela Foundation we have hosted five discussion forums with the aim of stimulating discussion on media coverage of HIV/AIDS amongst a wide range of stakeholders – journalists, doctors, scientists, activists, academics and others.

Although we have engaged over 350 stakeholders during these discussions, only a handful of editors have attended. It was clear that there was a need to engage them more directly.

This, and another need – for health journalists to share more with one another – were identified at a forum on 12 July 2005 entitled, "Covering Sex and the Epidemic: a comparative look at HIV/AIDS reportage in the US and South Africa". Here I briefly give a sense of how these issues were raised at the forum.

The importance of health reporters sharing

Tamar Kahn responded to a comment about synergy between media institutions by saying:

"In the real world of daily newspapers, the idea of health reporters from different newspapers working together does not fly. We are competing with each other; we try to scoop each other all the time.

We very rarely collaborate and we very rarely even talk about the constraints we battle with. [But we are] all battling with exactly the same issues: censorship within the

newsrooms, battling to get our stories out, threats from people like AIDS dissidents ..."

Jillian Green added:

"I work for Independent Newspapers, one of the biggest groups in the country. We have newspapers in Durban, Cape Town, Johannesburg and Pretoria, yet within our group we cannot synergise. We have health reporters in each centre but to actually get talking is a mission and we haven't got it right."

The importance of engaging editors

Professor Doug Foster, of the Medill School of Journalism at Northwestern University, raised the issue of engaging editors in his keynote speech:

"I do not see any editors here but maybe the messages need to be taken to them. A commitment from the top level down is needed in newsrooms by editors and owners to provide consistent, balanced and dynamic as well as well-researched coverage of the disease."

Anton Harber, Caxton Professor of Journalism at the University of the Witwatersrand, said:

"I was at a panel discussion recently where the editor of the *Sowetan* said clearly that he is fighting a life-and-death circulation battle, and he had two front pages that were disastrous. One was the Stilfontein mine disaster and the circulation dropped 15 000 in a day, and the other was an AIDS story. His conclusion was simple: he was reluctant to put AIDS anywhere near the front page because he would lose the [circulation] war."

John Perlman responded:

"Is it naïve to believe Sanef [the South African National Editors' Forum] should have a forum to table a set of fundamental things about AIDS that everyone needs to know... and should get editors to commit to delivering [these]? ... Maybe that's where the NGOs should come in and [work with] the newspaper editors."

We immediately noticed a gap, and relying on our long-standing partnership, sought to fill it by hosting two round-table discussion forums. The first was held in February 2006 at the Nelson Mandela Foundation, with a group of 25 health reporters from national and regional print and broadcast media.

The key issues raised in this forum are presented on pages 1 and 2, and the rest of the booklet is dedicated to recording the second forum, held in February 2007, for the editors. – *Natalie Ridgard, HIV/AIDS and the Media Project, University of the Witwatersrand*

The Challenge for Health Journalists

In 2006, the HIV/AIDS and the Media Project in partnership with the Nelson Mandela Foundation (NMF) organised a forum at the NMF in Houghton, Johannesburg, for health reporters to discuss the challenges they face in covering the pandemic. Some of the issues raised included editors' reluctance in publishing stories on HIV/AIDS and the difficulties in getting sources to speak openly. A selection of quotes from this forum highlights some of these challenges.

What Makes a Good Story?

WELL RESEARCHED, accurate and high-quality stories are needed in order for HIV reporting to gain the attention it craves. Several suggestions about how to achieve this were made.

Philippa Garson
Freelance journalist

BECAUSE IT'S such an ongoing thing, there isn't the high drama found with crime stories. The challenge for journalists is to educate themselves, so

much so that one can get the nuanced story.

Christina Stucky
HIV/AIDS and the Media Fellow,
University of the Witwatersrand

JUST BECAUSE it's a worthy story and important, doesn't make it a good story. It still has to be well written and well resourced. I think there's still more need for training around the issue. A good story is based on thorough research; you've got to know your stuff.



CHRISTINA STUCKY: HIV/AIDS and the Media Fellow, University of the Witwatersrand.

AIDS Fatigue

IT IS an ongoing challenge for reporters to keep their stories fresh. The need to find new angles in order to overcome public, and perhaps even editor, fatigue is crucial.

Anton Harber
Wits Journalism Programme

ON THE notion of reader fatigue, I'm convinced there is editor fatigue. You may be challenged [by your editor] on the way you wrote the story, the angle you have taken, but there is no question that people would be interested in something

that affects them and their lives so much.

Helen Struthers
Perinatal HIV Research Unit

EVERYONE THINKS HIV/AIDS is a boring story and in a way it may well be, but it goes further than that, people don't understand a whole lot of issues.

We hear about reader fatigue because we are not getting to the issues that readers want to read about.



AMALIA CHRISTOFF: Carte Blanche

Amalia Christoff
Carte Blanche

PEOPLE HAVE fatigue when it comes to issues regarding HIV and AIDS. How do you keep thinking of new angles to keep people interested?

Editors' AIDS Fatigue



JILLIAN GREEN: *The Star*

THE BATTLE between journalists and editors over the newsworthiness of HIV/AIDS stories has become a constant challenge for health reporters. But the battle is one worth fighting.

Jillian Green *The Star*

FOR EACH and every story you have to motivate strongly why the story needs to be done, it's not a given that simply because it's an HIV story it's going to be used and used well. It's very exhausting, because you constantly have to motivate the same points.

Anton Harber

HEALTH REPORTERS in a newsroom sometimes feel they are fighting for every story. Hopefully, through health reporters talking to one another, they won't feel quite as alone in newsrooms as they might.

Christina Stucky

YOU NEED to network out of the health range. HIV/AIDS still seems to be located so much in the health beat and it's not. I think there should be much more brainstorming in newsrooms.

The Position of the Journalist

HEALTH REPORTERS are concerned about their position within the HIV debate. Their engagement in emotional situations and advocacy issues causes confusion about what role the journalist should play.

Nazli Jugbaran

Centre for AIDS Development,
Research Evaluation

IF A journalist has to speak to a family, interview them. If someone has an emotional breakdown, how are they equipped to deal with that, seeing as they are not really qualified counsellors?

Ursula Beatty *Femina*

IT'S HUMAN empathy. If your friend was to break down you would hold

her and comfort her, it's the same thing, even if you want to or not, you just become empathetic.

If you walk into a situation you are not expecting, personally, I'd take it as my responsibility to make sure I don't cause more harm. The second thing I'd do is phone a person who is more relevant to deal with this than I am.

Jillian Green

ONE OF the things we grapple with as journalists is exactly what our role is in HIV/AIDS.

Are we taking an activist role, are we a lobby group, what lines do we draw, how far do we go with lobbying for certain things? Am I being less objective in this story because of certain issues?

Stereotyping and Stigma

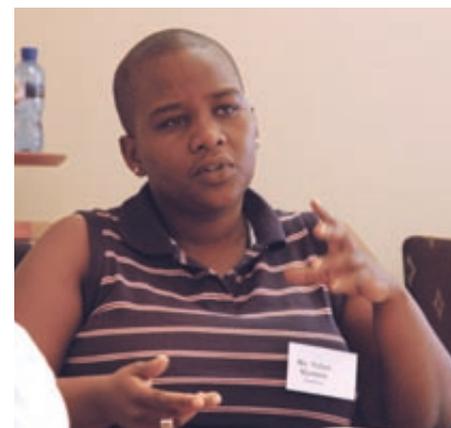
THE STIGMA around HIV/AIDS within South African society is a challenge for reporters. If people are afraid to speak out, breaking the stigma is difficult.

Mariska Noble SABC

I STRUGGLE to find HIV-positive white people and Indian people to speak out. Even if you say you will disguise their identity, they don't want to talk about it. That makes it really difficult to break down stereotypes.

Yolisa Njamela *Health-e*

THERE IS a lack of trust that you won't really hide identity. When it comes to kids, they are very secretive, because in their communities they see how most people who come out as HIV positive are being treated. When



YOLISA NJAMELA: *Health-e*

you grow up in that environment, there is no way you are going to just consent.

Christina Stucky

THE STORIES are still "over there, out there, not happening in my neighbourhood".

Introduction to the Editors' Forum

I SPENT FIVE years in the field of AIDS trying to grapple with the issue of advocacy and communication around AIDS and what it means. I think wherever I've worked I've discovered that not only in South Africa but around the world people still do not absorb the fact that AIDS will be with us for many years. We cannot think of the response to AIDS in terms of years, we have to think in terms of decades. That is very often difficult for people, governments, communities, activists and scientists, as well as journalists, to absorb.

What does it mean to convey to your community that however well we do, we will be living with this disease for a long time to come? It has implications for the way we plan, not only at government level but at community level as well. And more importantly it has implications for the dialogue that we enter into and the way the dialogue is phrased.

AIDS is a very complex disease and I am not saying that we should make it even more complex. But oversimplifying the issues is as dangerous as trying to make them more complex than they are. I think there is a tendency to assume that once you get the funding in place, once you get the resources in place, AIDS is going to disappear – it is not.

I hope that the journalists will help promote a dialogue in this country about AIDS as something that is not going to go away very quickly. Perhaps the most appropriate place to start is a dialogue between journalists and scientists; a genuine dialogue about what science does and can do and how that is communicated.

There are many scientists who have complained about the way their work is being portrayed. Similarly, I think scientists have a duty to communicate with journalists about what this means and in a sense break down the separate walls that we live in.

Now let me welcome our Deputy Minister of Health, Nozizwe Madlala-Routledge. She has been an activist, a technician, a Member of Parliament and now, as a deputy minister, she is certainly making a mark on our country.

– Achmat Dangor, CEO, Nelson Mandela Foundation



NELSON MANDELA
FOUNDATION

Living the Legacy

The Role of the Media in HIV/AIDS Reporting

GOOD AFTERNOON everybody, and thank you so much, Comrade Achmat Dangor, for welcoming me so warmly to the Nelson Mandela Foundation (NMF). I feel I'm part of the family now. I must start by confessing my nervousness at appearing before such a powerhouse of people. I was warned that the media can make or break you.

I think that we've reached a point in the history of the pandemic where we should all be sitting like this together around a table. So thank you very much for inviting me to participate in this forum, which looks at the role of the media in reporting on HIV and AIDS.

The debate, as you all know, has been so polarised and painful. I know that reporting on the pandemic must have been like walking in a minefield. Fortunately that painful path is receding into the distance and our focus is on uniting all our people in a single campaign to overcome HIV.

The NMF, the South African National Editors' Forum (SANEF) and the Wits Perinatal HIV Research

Unit are important strategic partners of government and this round table provides the much-needed space for South Africans to dialogue and deliberate, a space for moving towards national consensus on one of the most pressing issues of our time, the HIV and AIDS pandemic.

I just want to remind you what President Mbeki said at the close of the debate on the State of the Nation Address in February 2007 – he called on all South Africans to unite behind a common agenda, and in terms of HIV and AIDS specifically, he called on all of us to strengthen all the components of the campaign and in particular to strengthen partnerships. This message is giving a boost to the

process being led by the South African National AIDS Council (SANAC), under Deputy President Phumzile Mlambo-Ngcuka.

The process of developing a new HIV and AIDS National Strategic Plan (NSP) for 2007-2011 which has been a collaborative one, has brought together AIDS activists, people living with AIDS, HIV clinicians, researchers, civil society organisations, organised labour and business, the faith-based sector, non-governmental organisations and the media.

The NSP is a product of consultation that began when government acknowledged the importance of dialogue around the pandemic as well as the importance of effective, clear communication on the issue of HIV and AIDS. The strategic plan will need to be taken to all our cities and towns, villages, communities and homes. Our people must own the strategic plan because its implementation depends

ABOUT THE SPEAKER

NOZIZWE MADLALA-ROUTLEDGE was born in KwaZulu-Natal. She completed high school at Inanda Seminary in Durban, and went on to study at Natal University and Fort Hare. She obtained a degree in social science, majoring in philosophy and sociology. She also completed a postgraduate diploma in adult education and a diploma in medical technology.

Madlala-Routledge served as deputy minister of defence from 1999 to April 2004, following which she became deputy minister of health. She is a Member of Parliament for the African National Congress (ANC) and an activist for women's rights and peace.

Madlala-Routledge worked as a laboratory technologist for six years and at the peak of the apartheid struggle resigned to work full-time for the Natal Organisation of Women (NOW) for three years. She has served on the National Executive Committee of the Women's National Coalition and also worked as the managing secretary for the Transitional Executive Council (TEC) before the 1994 elections.

Madlala-Routledge has been at the forefront of the fight against HIV/AIDS, embracing organisations like the Treatment Action Campaign (TAC) and mediating between the government and civil society on HIV/AIDS.





on each and every one of us.

It's important to look at other experiences and the media play such a critical role in this. We need to look at what Malawi, Zambia and Uganda are doing and learn from that, because there is no need for us to reinvent the wheel.

We are going to need to look within our resources in the region to see how we can improve and in this regard I think we all know about the Botswana experience. I think that one of the things that is often

said about Botswana and Uganda is the issue of the importance of political leadership.

So it's very important for us to look at those examples. With regards to Zambia, for example, there the process was taken up at a very high level of mobilising the whole government,

so that it was not left solely to the Health Department, but it was put in the presidency so that the whole public service took the responsibility of leading and getting everybody else to deliver. Where is the best place to locate the leadership of the campaign and the programme to combat HIV?

“There is definitely a role for newspapers and for radio, to educate and inform.”

Some of you are involved in the task team that has been appointed to assist in fine-tuning the NSP, and are working very hard. You know what's so powerful about what's happening in our country, is how this pandemic is releasing the energy of our people.

People are prepared to put everything aside and work as hard as they can so that we can be proud of a product that is effective and that's going to achieve results. And what for

me is so particularly important about that process, is that researchers from outside the Department of Health are sitting at one table with researchers from inside the department and talking from the same page, even on the issue of statistics. Statistics has been one of the battle zones in this campaign and fortunately in that regard, as I was assured this morning by our person in the department responsible for epidemiology, all the agencies are now talking to one another and talking from basically very similar statistics.

So the process, as it is unfolding, is bringing us together and even those components of our society that were at loggerheads are now sitting around the same table to try achieve the results.

I have two sons, Mandela and Simon; Mandela is 25, Simon is 17. I was asked recently if I believed my two sons and their peers would live to see an HIV-free generation. My answer was: it is possible. I said in

the same way that my two sons are growing up as part of an apartheid-free generation, and in the same way that Oliver Tambo inspired us, when he declared "Freedom in our Lifetime", I think it is possible for my sons and for us to inspire our youth to say "Freedom from HIV in our Lifetime."

But to realise this dream we need to join forces and mount a campaign similar or greater in scale as the fight against apartheid.

Now we have entered the 21st century, I think we should wage a new struggle to free ourselves from the grip of disease and poverty.

I think one of the reasons why there are problems reporting HIV and AIDS is because it means reporting bad news most of the time. People don't like to hear that there's this enemy among us and that we are not able to defeat it. But I think there are some good news stories that are coming out, especially from the communities,

and it is important for us to find these good news stories.

What is so important about this round table is that we are now talking and listening to one another. The media is a key institution for deliberation, consensus building and information dissemination.

Government recognises this role

and regards the media as a strategic partner, even though we sometimes want to shoot the messenger.

We must not allow these ideological differences to come in the way of helping the

nation find one another and to find solutions to our common challenges. In the face of such a serious threat as HIV, we need to dialogue, deliberate, find consensus and act together. This is a threat that affects all of us and we are all affected or infected.

It may be useful for the media to look at the two roles in reporting on HIV and AIDS. The one role is the normal one, in a politicised society, reporting the news that sells and

offering critical editorial comment. But the other role is the spatial one in the face of a pandemic, where there is a special educative, consensus building, deliberative and mobilising role, and I would add advocacy as well. This role is being played by the media in different ways.

For example, the *Sunday Times* has a campaign for everybody in this country to test, and we believe that it is possible within one year for everybody to test. Also, the *Sunday Times'* "Everyone Knows Someone" campaign has become very popular because it is telling the stories of ordinary South Africans.

But there are other examples. I've been fascinated when I pick up *The Star* and see the red ribbon, and you just want to read the story, but also the highlighting of stories and following people's lives is absolutely crucial.

I think those people that are often neglected, who are dying, have stories to tell us from which we can learn.

I commend the *Sowetan* and Lucky Mazibuko's column, which normalises the issue and tells the story from one who is living with the virus. The

"Many editors do not always believe the HIV/AIDS issue to be print-worthy."



Mail&Guardian's AIDS barometer is a very useful educative tool, which is doing more than just counting the number of cases, but is also telling stories, for example, about the state of our hospitals. They conducted a series highlighting the impact of the pandemic not only in terms of people dying but also in terms of how it is affecting the delivery of health care, as well as health professionals themselves.

But radio, and this something that is growing in our country, is also playing a key role. With the phone-in programmes, I think we could develop a campaign in the country where people can dialogue and talk about the various issues around testing and the disease. In television, *Siyaqoba – Beat It* – those programmes on treatment literacy have also been extremely popular.

Now having identified these two roles, the question is how do we prevent the second educative role from being swamped by the more sensational and personalised first role?

How do we expand the second consensus-building, deliberative and mobilising role? I've argued that in the case of a pandemic as big as the one we have, that this role needs to be emphasised and developed. And in that regard I think I want to commend SANEF, because I believe that the World Editors' Forum in June is going to be having a special session looking at reporting on HIV.

In the health budget vote debate last year I called for a national consensus on health issues because I believe, that in the face of the pandemic, health should be above party political differences as well as above individual personalities. HIV and AIDS should not be politicised and the media can



“I believe that in the face of the pandemic, health should be above party political differences as well as above individual personalities.”

and must play a critical role in helping to find consensus and keeping us focused on the delivery of essential services.

Do not allow us to be consumed with petty politics and do not allow yourselves to be similarly distracted. Apart from this round-table deliberation on reporting on HIV and AIDS it would be useful if this same topic were deliberated on by others in other arenas. It would be useful if we consider how best to report on this and these other deliberations, so that they generate light and not heat. In addition there is value in deliberating other aspects of HIV and AIDS and I've flagged some of these.

I just want to say something about deliberative democracy which involves getting the citizenry active in between elections, so you don't just have a situation where people go

and vote, and between elections they are not active in shaping their lives. With deliberative democracy you identify an issue of social concern, you bring it into the public arena, it is debated and you influence public opinion. But the key thing is that from there you should then be able to influence the legislative and administrative powers. And I give the example of what happened with the campaign for treatment in this country.

It started off with a civil society organisation which identified the issue, the media gave it prominence. It was debated in the country and then the government was brought to see the importance of this issue, which contributed to the decision in 2003 to provide comprehensive health care and treatment for people with HIV. So this is I think a very key way in a constitutional democracy to

get everybody involved in shaping their lives.

Now the areas which I've identified which I think the media could throw light on in reporting are the following:

□ The use of statistics to report the extent and progress of the pandemic, because we know that depending on which statistics you use, you will get different results.

The different agencies that deal with statistics needed to be brought together. We had a situation where the Department of Health would issue a set of figures, and for example Stats SA would issue a different set of figures.

We want to thank UNAIDS for facilitating, bringing all of these people into one room and saying 'OK, let's look at the different methods and let's find a method with which we

“I was asked recently if I believed my two sons and their peers would live to see an HIV-free generation. My answer was: it is possible.”
– Nozizwe Madlala-Routledge

can all at least work, with similar or close to similar figures.’

❑ Then of course the issue of the role of evidence-based research and anecdotal or walking evidence in reporting and promoting untested cures.

❑ The issue of voluntary or compulsory testing – right now there is the issue of whether we should be going for the opt-out route for testing, which means testing becomes routine.

❑ The issue of the role of medical science, complimentary medicine and traditional healing in combating the disease; how can they compliment each other rather than compete?

❑ The issue of the economics of HIV and AIDS: the cost to the nation both directly as well as the cost of the loss of people in the prime of their lives; and the additional cost of bringing up orphans and the lost opportunities of not investing in other productive areas.

❑ The issue of intellectual property rights – and this is quite an important issue facing us right now, with the Novartis challenge to the Indian government.

❑ The issue of the production of generic medicines, parallel importing and the cost of medicines in the face of the pandemic.

❑ Reporting on the different responses to the pandemic in the region, which I’ve indicated earlier, from which we can learn. There are other examples of issues which I think we could deliberate on.

❑ What is the correct balance in expenditure between prevention, treatment, the search for a cure and care?

❑ The issue of the role of nutrition in treatment has been deliberated on, and I think we have reached

consensus on that issue. We know that nutrition has a role but it doesn’t replace treatment and this is the message of government.

❑ Finally how do we report on HIV and AIDS so that we inspire hope?

I believe that there is hope, as we understand enough about the disease to be able to overcome it. It is possible to halt the spread of the disease if we change our behaviour. This is a task of monumental proportions, but it is possible, and the media have a leading role in communicating this.

There are positive indications that a vaccine could be developed within a few years. We already know that it is possible to extend the lives of people living with HIV, so that it can be regarded as another chronic disease.

The media are constantly reporting on the transforming ways in which people are caring for those infected and the ways in which those living with HIV and AIDS are leading the way and inspiring others.

Just to conclude, I want to remind you that during the days of apartheid many media institutions played

a pivotal role. In our fledgling democracy it is as vital as it was then. Many editors do not always believe the HIV and AIDS issue to be print-worthy as it may not sell newspapers, but on the other hand we must consider that HIV is the greatest health and social challenge our country has ever faced.

“It is possible to halt the spread of the disease if we change our behaviour.”

Now, in closing, I want to emphasise the role of the media in providing checks and balances on government, but over

and above that I want to mention this, that as members of the executive, sometimes the information we get from officials has been filtered.

You know the officials are concerned about their careers and will sometimes sacrifice the truth to tell us what they think we want to hear. So it helps a lot for us to know that if you open a newspaper you may find a completely different report on the issue that you were informed about by your officials in a filtered way.

I thank you for this opportunity to share my thoughts and concerns with you, and I’m looking forward to hearing yours on the issue of reporting on HIV and AIDS.

I hope it will help you as media find the particular roles you can play in ensuring that we achieve the best National Strategic Plan on HIV and AIDS and that we can actually see a difference this time around with our strategic plan, the measurables, what are we going to be measuring and how are we going to see that we are making a difference in people’s lives. I thank you.

Response to Madlala-Routledge's Speech

The deputy minister's speech was followed with questions from the participants.



Cyril Madlala *UmAfrika*

I WONDER if the minister is of the view that the kind of journalism we see on a national level matches that on a regional level. For instance, you are talking about walking evidence. I don't see much coverage of that on a national scale in terms of our national media. Is there much you can do to bring that up and make that as serious an issue as I think it ought to be?



Nozizwe Madlala-Routledge *Deputy Minister of Health*

FIRST I just want to acknowledge the importance of regionally based media. I think we should make much greater use of the media at regional level in its different forms. Now the issue of walking evidence, as apposed to scientific, I think especially with traditional medicine, what you often find is that people say it works because "I used it and got better".

This then encourages somebody else to try it without any evidence, apart from this person who says it works. Unfortunately the traditional healers themselves also use this method. Similarly, if the newspaper sounds as if it supports this particular so-called cure, readers will want to go and get that cure because they are desperate. As the health department, we definitely need to play our role to protect people.

I heard in the news, about long queues in West Street in Durban outside a traditional healer's practice. He comes from Malawi, and there is this myth that the further away the healer comes from, the more effective that cure will be. Now what is happening is a lot of people are coming from neighbouring countries and exploiting this space.

I think we must work with them because if indeed they do have something that can be put to the test and it works, we should put this through the normal research mechanisms.

The Department of Health is trying to protect people and that is why there is a definition for a medicine. You cannot take a foodstuff and say it is a medicine when you have not actually done the necessary tests.

So there is definitely a role for regional newspapers, for national newspapers and for radio, to educate and inform. But this must be based on scientific evidence.



ENGAGING IN DIALOGUE: The forum was well attended by editors and health professionals from across the country. Pictured are (left to right) John Conyngham (*The Witness*), Tyrone August (*Cape Times*), and Nonhlanhla Khumalo (*South African Medical Research Journal*).



Glenda Gray Perinatal HIV Research Unit

DO YOU know what the national rates of HIV testing are? We conducted a household survey in Soweto where we found about 65% of people we surveyed actually had had an HIV test already. So two-thirds of Sowetans surveyed actually had an HIV test. Is Soweto something special or do we have any access to national figures of HIV testing? It would be interesting to see what is unique or different about Soweto.



Nozizwe Madlala-Routledge Deputy Minister of Health

IT WOULD be interesting to see when people who are testing in Soweto are actually testing. Are they testing when they think they might have the virus? Are they testing because their insurance requires them to test? In terms of national figures we are very concerned, as the Department of Health, as the uptake for testing is very low. We have increased the sites for Voluntary Counselling and Testing (VCT). But what we are hearing is that the numbers of people who are testing are low. In fact I think the department last year issued figures saying about 1,5 to 2-million people had tested in the whole country.

If you look at the total population and the prevalence of the disease we need to really step up testing. But what is also a bit different with the *Sunday Times'* campaign is that the five other people with whom you test then become your support base. You support one another because testing once is not enough. But also once you've tested and you know your status, you need to be supported. If others know your status they will support you if you are HIV negative in the ways that you can to stay negative. If you are HIV positive they will support you to monitor your CD4 count, to maybe even modify your lifestyle and to get treatment at the time that you need it.



Natalie Ridgard HIV/AIDS and the Media Project

I JUST wanted to hear about your impressions about denial. I mean psycho-social denial of HIV/AIDS. For me, when I think of the longer term implications of HIV/AIDS in the country, the scientists are there to a certain extent, the treatment is there, but it seems that a lot of people seem to be dying of denial as opposed to an AIDS-related illness. This seems to be something that we aren't tackling with everything we've got and I would just like to hear your impressions on this.



Nozizwe Madlala-Routledge Deputy Minister of Health

WITH ANY life-threatening disease the normal response is initially denial. If and when you discover that you're positive, they say that there is a partner of anger: "why me"? Then of course there is acceptance. This denial is extremely important for us to address, at a personal level, but also at a community level. I think there is also the other factor, and I think this affects us a lot as politicians, where we are supposed to be strong and never fall ill and always know the answers. Even when you know you are sick it is very difficult for you to accept this.



Helen Rees Reproductive Health & HIV Research Unit

I THINK that it is interesting that there are so many figures for what the prevalence of testing is. The one figure that is often quoted is that 2% of the adult population has been tested. With the National Strategic Plan that is currently being looked at, one of the issues that we are looking at around testing is that you can go to one antenatal centre and get 85% uptake of testing and you can go 3km down the road and get 10% uptake of testing. So there is a lot that we don't understand about testing and denial. The problem is there is this issue of media fatigue, how do you keep this in the public eye? I think this is one of the most difficult things for the media to tackle.



Nozizwe Madlala-Routledge Deputy Minister of Health

THIS IS a very crucial area to understand and it helps to look at other examples. For example, apartheid started to get boring in terms of the international media and even in our own country. The media had to take a special stand. Basically human tragedies can never be stale and I think we should not allow them to go stale. Often I have to remind myself that it is people who are dying in Iraq, you need to remind yourself all the time that this is a human tragedy. It's similar with AIDS. But with HIV and AIDS, it takes such a long

time to start to show in a person's body. We've got to be quite creative about how we tell the story of this pandemic that is affecting people at a very personal level.



Saul Johnson *Health and Development Africa*

HAS THERE been discussion about how to get consistency of messaging coming from government? I think that has been an issue in the past, not only with the national government but going all the way down to provincial and local level, and from private health to education and even outside of the social sector.



Nozizwe Madlala-Routledge *Deputy Minister of Health*

THE EMBARRASSMENT last year in Toronto galvanised government to take the issue of communication and make sure it is streamlined. The International Marketing Council was established, which has been given the responsibility with the deputy president to ensure that we are all communicating the same message.

The Government Communication and Information Service, GCIS, meets with all the communicators from the different departments. I don't know if they meet with provincial communicators but it would make a lot of sense to do that and consistently give correct, or as correct as possible, messages.



Nonhlanhla Khumalo *South African Medical Journal*

I WANTED to ask you as a mother who is also a minister, do you think the messages that the media are putting across are actually reaching our children? There is a large amount of money that is spent on trying to reach the youth and I think we are talking right past them. I'd like to know what we can do to improve this?



Nozizwe Madlala-Routledge *Deputy Minister of Health*

THERE HAS been a lot of money spent on reaching the youth, especially from NGOs, but also from government. We've had media campaigns with huge billboards and we've not really been able to achieve the results that we are looking for. But I think some of it has to begin with us as parents communicating to our children about a subject that parents and even children don't normally feel comfortable talking about. I really think we need to find ways to communicate openly. We need to find creative ways, targeted ways.



Benita Levin *Highveld Stereo*

WHEN YOU took your test, I think it was such a powerful message that you sent out to South Africans. I know getting other ministers to do the same ended up being quite a sensitive issue, but with all these campaigns happening now, is that a chapter that can be reopened?



Nozizwe Madlala-Routledge *Deputy Minister of Health*

I CANNOT speak on behalf of my colleagues in Cabinet but I think it is very good to lead by example. People tend to talk about this in this way; they say it's a personal matter. Unfortunately that is not consistent with other messages that we are sending out; that it is important to test.



Sue Valentine *Facilitator*

I THINK as we all know the media can report events quite easily. A process that lasts not just years but decades and is going to last for a generation and more is another challenge all together.

HIV and AIDS falls within that category which has a very particular set of challenges. How do we sustain that with intelligent, analytical media coverage that actually does inform our citizens of the choices before us or the choices that need to be made by those who are allocating our budget?

The HIV/AIDS Pandemic: How Best to Cover it?

The challenges of covering HIV and AIDS are varied and complex. Journalists need to understand the sometimes difficult science behind, for example, vaccine and microbicide trials, in order to report them well. They need to sell stories to their editors, who may be reticent to run them, in sometimes well-founded fear that they are not what their readers are after, and sales may drop. The forum participants explored these and many related issues, in a dialogue characterised by openness and a common desire to improve coverage of the disease and its impact on South Africa.

Sue Valentine Facilitator

I WOULD LIKE to open the discussion to hear from the media and editors about some of the challenges they are facing in consistently pursuing stories relating to HIV and AIDS.

There are serious human rights debates that go with this issue which citizens need to engage with. I know that the media is often hugely challenged in terms of resources and perhaps even ideas. I think that through the dialogue we can gain insight and ideas that the media can then take forward.



Nathan Geffen Treatment Action Campaign

I THINK the media has, generally, taken a very moral and commendable stance on the HIV epidemic and holding government and pharmaceutical companies to account. But there is one challenge which I would like some of the editors to respond to with some ideas.

This is that the vast majority of articles that one reads on HIV in newspapers, sees on television and hears on the radio, have glaring

scientific errors in them. I imagine it goes beyond HIV. Most people rely on the media for their understanding of science and clearly there are deep structural problems which cause this. Most journalists haven't had training in science and most media organisations can't afford to train their journalists in science. So do editors have any ideas for addressing the problem of a lack of scientific knowledge of journalists and opinion



editors who sometimes run the biggest junk on these pages?

Sue Goldstein Soul City

AN ISSUE for me is about voice; whose voice are we hearing within the media and do we hear all the time? There've been a number of studies which have been done which show that it's largely white men whose voice we are hearing.

I think the assumption comes across that the people we are speaking to are HIV-negative while we know very well that 5-million South Africans are HIV-positive. Finally, I would argue that the youth are being reached.

Youth behaviour is far better than their elders'; they've learnt a lot, they know a lot. They're not supported by their elders and, the kind of media that we're talking about, including loveLife, Soul City and Khomanani, is like a tadpole swimming against a tsunami.

If you ever watch television late at



night, you'll see pornography. There is so much stuff that is giving exactly the opposite messaging.

I think that people really need to look at the whole society; nobody's going to be able to make changes through one campaign unless everybody supports those campaigns.

**“I think the assumption comes across that the people we are speaking to are HIV-negative while we know very well that 5-million South Africans are HIV-positive”
– Sue Goldstein**





Neil Martinson

Perinatal HIV Research Unit



ESSENTIALLY, THE ABC approach has failed in this country and probably in other countries, too. Recently there was confirmation of this through the Orange Farm circumcision study, which was reported by the South African press.

One of the notable features of the reporting of two trials that were done in Uganda and Kenya was that no-one really tried to get government comment on this incredible finding that by circumcising young men, you can reduce their risk of HIV.

I think it would be dreadfully sad if we missed that opportunity, first of all for the media to interrogate this in a wider manner and to find out what are government's plans.

Secondly, for government to respond in a manner which takes control and says this is something that is unheard of, unprecedented, and we're going to be responding to it.

Brett Anderson Lifelab

I'VE TALKED quite extensively at school level about living with this disease and it is apparent as day that young women are getting infected due to cultural beliefs.

What can we do differently for South Africans to realise that no culture can survive a pandemic like this? The truth of the matter is if we hold on to our culture, we're not going to be celebrating certain cultures in the near future.

How can we further this discussion on what is culture? One school I went to had 29 students that the principal knew of that were HIV-positive, out of 1500 kids.



Einstein said, "If you continue doing what you've been doing forever, don't expect a different result." It is time for all of us in this country to actually realise that if we continue what we've been doing, we are going to fail.

Marius Louw *Die Burger*

WE NEED to be careful about how we tell stories. If you lead with an AIDS story on page one and you lost 30 000 readers that day, people didn't get your message. What we do at *Die Burger* is we make sure that we put people into our stories.

On the website you can actually go and see how many of those stories get read, as opposed to long stories with a lot of science in it that people just don't read. The lay press just hasn't got space for it. Always remember, news competes.

If anything more exciting happens, that highly scientific story is going



to get pushed off the page. We're making a point of writing an AIDS story each and every day, we try and find one and we blackmail or beat or beg the editors to make sure those go in, if we have to. You can never write too much about AIDS.



Ferial Haffajee *Mail&Guardian*

WE'RE READY to do a new battle now. It is going to require that we have many deputy ministers to infuse the entire state. We got chased from numerous hospitals in the course of our hospital project. So we're going to need access and we're going to need information if we are to be partners.

Every time my colleague Thabo Leshilo from the *Sowetan* puts a story on AIDS on the front page, he sees a circulation dip of 30 000 to 35 000. This is about a nation that's turning its face away. We need to be doing better journalism that makes people look again.

Susan Smuts *Sunday Times*

I THINK when we report on the research that scientists have done it's because it's interesting, it's relevant, we know that our readers want to know about this and we really do want to get it right. When we do get it wrong, it is important to use the space that newspapers provide and demand to have a right of reply and to fix what we've got wrong.

In terms of training journalists, the idea of having workshops is a good one, because even if a lot of people have done it, newspapers have quite a high turnover of staff and there are always people who need to be brought up to speed.

Ideally people who report on science, actually ought to have some kind of science training, but that's quite a long-term project.

I suggest that where it's possible, if there is stuff that's highly technical, to ask to see the story, or to hear it, because sometimes we can sort out mistakes at that level.



Tyrone August *Cape Times*

I WILL be the first to concede that there is ignorance amongst journalists, for various reasons.

But I think there's also an obligation on the scientific community to get more proactive.

What we've done at the *Cape Times* is to draw on people who are experts on HIV/AIDS or other scientific matters.

It's true that we are inadequate in certain respects, but I think there is a need for the scientific and medical community to engage a bit more.

Helen Rees *Reproductive Health & HIV Research Unit*

WE DID a national youth survey a couple of years ago, where we looked at the behaviour and the HIV status of about 11 000 young people. What we've done is compared it to a similar survey from the US.

What's interesting is the fact that most of the parameters are better here. The age of first sexual debut is higher, the number of partners is lower, the condom use is better. So there has been an impact, but we're dealing with an epidemic that is very different and much more aggressive. So we have to be aware of that.

I want to raise the recent coverage of microbicide research. There was one microbicide trial with one product which had an unexpected outcome. It

was a trial that by every other measure had been conducted properly, but it had an unexpected and a very unfortunate outcome. The impact is that it gets very confused in the community's mind that, in fact, all trials are now bad. We started, coincidentally, another observational study that week with pregnant women and women said, "We don't want to join your study because we're frightened now." The impact is profound.

There is no doubt that something like the cellulose sulphate trial, which has now come out, has to be covered honestly and that the communities of course have to be informed. The question is how do we get the right balance and the honest facts?



Mbulawa Mugabe *UNAIDS*

THERE ARE times when it's refreshing to pick up a newspaper and see how, for instance, one province is surging ahead of everybody else, trying to put people on treatment. I was particularly thrilled to read about the state of the province address by the premier of Gauteng, saying that their target for March 2008 is 70 000 people on treatment for this province alone. I think it's some of those stories that show the different responses that we need to highlight. It's also important that we go beyond just the figure, the prevalence, the 5.5-million every day, but also to bring out things that are actually working.



Achmat Dangor
Nelson Mandela Foundation

THE CHALLENGE that the newspaper people face is how do you take the complexities of reporting on HIV/AIDS into account and still sell your papers? Because if you don't sell the papers the news is not being carried to anyone, so it's self-defeating.

John Conyngham *The Witness*



THE KINDS of stories that editors want to publish in their papers are invariably stories refracted through the experience of

a particular individual rather than planned generalisations.

One can never be entirely wise and have the time to research things, so if one gets it wrong, please challenge us. There's sometimes a deafening silence of informed opinion out there, which

is quite intimidating for people who are professing to be that themselves.

So the onus is to some extent on you, those who really know what you're talking about, to deal with us who think we know what we're talking about.

Nozizwe Madlala-Routledge Deputy Minister of Health

REGARDING MANDATORY testing, I'm reminded about issues of human rights, I think those would need to be taken into account. I think the dialogue that we are having also needs to take those issues into account.

If you take somebody who has extreme drug-resistant TB, who does not want to admit themselves for hospitalisation, then the issue is, whose rights are more important? And we know that our constitution does limit individual rights, when those rights threaten the wider public's rights.

I think personally it's very important for couples to know each other's status, because we've had cases of people getting infected by their partners, whether male or female. I've been following the Indian example where they are bringing new legislation to get people to test and those who are getting married to test. These are things that we should be open about in South Africa and talk about.

Regarding the issue of the Department of Health opening its doors: I think it's an open secret that the director-general did instruct provinces not to open their doors. So I think this is something for us to deal with, with regards to our own administration. Is

the administration saying the same thing as the government and the leadership? Sometimes provinces actually tend to not even like us coming into their territory, whereas surprise visits are an important thing.

Perhaps, very briefly on the issue of the role of culture, I really think we do need a dialogue around this. We need to explore, for example, why some African men think that it is right for them to have as many partners as possible.

Is this an issue, for example, that we shouldn't skirt around, that we should go directly to and address, because this perhaps might be encouraging the spread of the virus?

I think some things that are called traditional are actually not at all traditional. Some of these so-called cultural practices are killing us and we need to not skirt around that.

I was personally distressed also in terms of the reporting on the microbicide trial because it really was reinforcing these ideas about blacks being used as guinea pigs. Indeed, I was very pleased when the researchers wanted to brief me about the trial and what exactly the issues were.

I was proud of the Medical Research Council in how they defended the ethical standards that they were using



in that trial. I think in our country people are following the strictest of standards when it comes to these trials.

So it is all of our responsibility to communicate a message that, if we are to find a solution, we really do need volunteers and to appreciate those volunteers who are coming forward for the vaccine trial.



Saul Johnson Health and Development Africa

I'M NOT as interested in the "AIDS stories" as in all the other parts of your media because HIV needs to come into every bit of what we do.

Where's the debate about that in the media, where do we start to engage with those issues? It's in your sports pages, in your fashion pages, in your back pages of the *Sunday Times*.

You know, you could be running a great programme, but what's going on everywhere else in the newspaper?

Where's the thinking? Where is the HIV context, where 300 000 to 400 000 people are dying every year? We need to just take it up a level and that's all of our responsibility, not only journalists' or editors', but everybody's.

Natalie Ridgard HIV/AIDS and the Media Project, Wits

IT'S ALSO the journalists' responsibility themselves to be knowledgeable and educated on how to report on the science of HIV/AIDS. It sounds simple but is a difficult thing.

But if a health journalist knows the fundamentals of how a clinical trial works, then they are able to understand that the trial didn't set out to make 20 women HIV-positive or whatever the case may be.

How we address this is really difficult because journalists aren't going to come to training sessions

on how to report the science of HIV/AIDS. So the responsibility, obviously, lies on many different levels.

We had a roundtable last year for health reporters, specifically to get together and to discuss some of the challenges that they felt in their reporting on HIV/AIDS.

One of the things that came out of that meeting was a lot of them said that, "We are committed, we do actually want to write the meaningful, interesting, exciting stories, that aren't reported enough, that are



under-reported, but we often get blocked at an editorial level." If there are old and boring stories coming in from your newsrooms, what kinds of stories would you like to see your journalists generating around HIV/AIDS? What gets editors going, in terms of reporting on HIV?

Sicelo Fayo
Johnnic Communications

WE HAVE a tendency, generally, to skirt around issues. It's a challenge that we also face in newsrooms. For example in the Eastern Cape, you get subtle messages filtering through which if taken, if not handled in a careful way, would send out the wrong message.

In the Eastern Cape there's a certain way, there is predominant culture there which is practised by those people and which impacts on their social behaviour. How do we construct a story in such a way that they will understand what is being said without feeling that there is a degree of infringement? Maybe we need to also be sensitive to relay the correct message.

One can never be entirely wise and have the time to research things, so if one gets it wrong, please challenge us. There's sometimes a deafening silence of informed opinion out there, which is quite intimidating for people who are professing to be that themselves. So the onus is to some extent on you, those who really know what you're talking about, to deal with us who think we know what we're talking about.

Refilwe Africa loveLife

JUST IN terms of youth and HIV/AIDS, I'm actually not that despondent in terms of the progress that we can make: behavioural changes *are* possible, youth *do* listen.

They want something better, they want something different, they aspire to achieve. So, in fact, if you ask a typical teenager about their biggest problems, on a typical day, HIV is somewhere right at the bottom.

Yes, it is important for parents to communicate with their children. So those control factors, the broadcasting responsibilities, how do you make it easier for a young person to actually digest everything that

has been thrown at them?

And then the second thing that I'm grappling with, we were trying to get interviews with young people who are HIV positive, but from all races.

It's amazing how you come up with a black person easily, but you do not get a young person who is HIV positive from other races. How can we, as media, play that role where we challenge every race to come on board?

We keep on saying that it affects everybody, yet it's black people who come to the fore. There are so many races in South Africa, yet you get the same old people, telling the same old stories.

Anton Harber Wits Journalism Programme

I'M VERY struck with what's being said about the microbicide story and the way it appeared and the potential damage in that.

The question I wanted to ask is, whose function is it to try and correct that message? Whose job is it to get hold of journalists as quickly as possible and say, "Be careful what you say" or "Do you know this?" Or when they see something wrong in print or

hear it on the radio to say, "There's a problem here." Is there a body whose job it is to try and give out a counter message?





Mark Stirling UNAIDS

I'M JUST wondering whether there's not need for more discussion about control and censorship around media and information.

If you look at most of the movie channels and the pornography on TV, there are mixed messages. If we want to have responsible communications around more responsible sexual behaviour and social norms, that probably needs to be stopped.

There's a great sensitivity, as there must be, around human rights. But that seems to be also running in the face of the need to stigmatise certain behaviour and to build cultures of zero-tolerance within communities. If

we look at countries like Uganda, they deliberately stigmatise irresponsible sexual behaviour. Another example with control again goes back to Uganda, where there were certain pacts made there around consistency in messaging, agreements on who says what, how many times a day.

You can't have the luxury of fulfilling everybody's individual rights but at the same time addressing the needs of those particularly vulnerable communities, which also require some protection.

I'm not saying exactly where I stand on it but I think there needs to be much more discussion about this issue.



Ernest Darkoh BroadReach

THE MOST interesting thing for me would be the extent to which the media is really a strategic thought-partner in how we approach the epidemic. I believe we, one way or another, have failed in a lot of our messaging.

I don't believe science people are the best people to be leading any kind of communication campaign. We really do need the strategic thought-partnership of the media and ideas on how we can begin to approach this. How do we actually get these messages to where they need to get to?

Paddy Nhlapo Ochre Media

I'D LIKE to emphasise the issue of correct and accurate reporting and messaging and, maybe, suggest that different media houses or journalists need to have some kind of a pool of strategic advisors or experts that they can readily use when developing their articles.

The advantage with people like us in agencies is that most of the time we dictate what the timeline should be, unfortunately, with others, there are stricter deadlines. Also, there was an idea about government opening doors for people to get stories, but equally,



as communicators, we also would like editors to open doors.

**Marilyn Keegan
The Council for Health Services
Accreditation of Southern Africa**



WOULD THE Department of Health be brave enough to open the doors so that journalists will be able to give accurate, current and timely information about what is happening in terms of the roll-out of antiretrovirals, and also to be honest about what the problems and obstacles are?

Those can be tackled and instead of having a government-bashing session, which I know has gone on for a very long time, in fact there would be the consensus that you are looking for.

Anton Harber Wits Journalism Programme

I EXPECT you're as struck as I am by how useful it is for doctors, scientists, media people, journalists and politicians to be able to exchange views in this manner and how valuable, necessary and important it is and how we need to think about making it happen again.

It's clear to me that journalists can see a need to find more and better ways to report on what is a difficult story to keep going.

It seems to be clear that doctors and scientists are aware of the need to communicate better and more efficiently.

And I think we owe a special thanks to our key guest, the deputy minister,

for the openness with which she has approached this dialogue.

She introduced a period in which we can have a serious discussion about how politicians, doctors and the media can sync together about the best ways in which they can contribute to tackling this, as opposed to just attacking each other, criticising each other, snarling at each other. So thank you very much.

A big thank you to the Nelson Mandela Foundation for hosting us today, to Sue Valentine for chairing, to Natalie Ridgard for the hard work she's done to bring us all together and to people who came from quite far away to participate.



“There are serious human rights debates that go with this issue which citizens need to become engaged with. Through this dialogue we can actually gain insight and ideas that the media can then take forward.”
– Sue Valentine

Mothomang Diaho
Nelson Mandela Foundation

THANK YOU very much everyone for coming and making time. I called people at the last minute and thank you for always responding.

But specifically to the deputy minister, Nozizwe Madlala-Routledge, I'd like to say that I'm ending this at a personal level, on a very high note, because the mood today is very special. I see this as a beginning, because listening to the conversation here, a lot of topics were put on the table.

Personally, I'd really like to explore the interface between science and socio-cultural aspects and how that drives the epidemic, and to create a safe-enough space for people to come out and share their stories. I think that it's important for that conversation to happen.

But I think it's also important to create a dialogue space, so that our partners and our colleagues have a space where they feel they can actually come out and support this process. Because ultimately, it's an individual choice to change behaviour.



Reflections on the Forum



Sue Valentine Facilitator

"I think it was a crucial kind of discussion that should happen. I worked for Health-e News Service from 1999 to the end of 2004 and it was a terrible time [in terms of relations between journalists and the health authorities]. Finally, we're beginning to deal with the impact, the issues, how we should respond, which we should have been doing 10 years ago."



Nozizwe Madlala-Routledge Deputy Minister of Health

"Somehow, I felt part of history here today. We were South Africans coming from different walks of life – in this case the media coming together with politicians and scientists – on an issue we share. This is so important to deepen our democracy. Everyone in the room was passionate about stopping this epidemic. People were being open about their reality, their concerns and issues. This is the kind of openness we really need. The virus thrives on conflict, on ignorance and inertia."



Anton Harber Wits Journalism Programme

"It is so rare to see three levels of people talking in this way. There was a whole range of absolutely critical issues which emerged and should be thrashed out. I sense for the first time, the eagerness of all three parties to grapple seriously with issues around communication and around the pandemic."



Achmat Dangor Nelson Mandela Foundation

"Well, I think from the foundation's side we're going to pursue this with our partners, widen it and even bring the UN as well. They can help with resources required to carry on with the fight against the pandemic. The deputy minister is a breath of fresh air; we need to encourage this kind of interaction. This kind of dialogue would not have been possible a year ago."



Johan du Plessis Diamond Fields Advertiser

"There is sometimes a misconception that editors are demi-gods sitting in their offices making big decisions, this is totally wrong. There is the idea that editors chuck out stories but actually editors use their journalists as sources of information. We base our decisions on feedback from our journalists – they are the people on the ground."



Mothomang Diaho Nelson Mandela Foundation

"I think for me, a space was created for scientists and the media and activists and everyone in the room to begin a conversation that needs to continue long into the future."



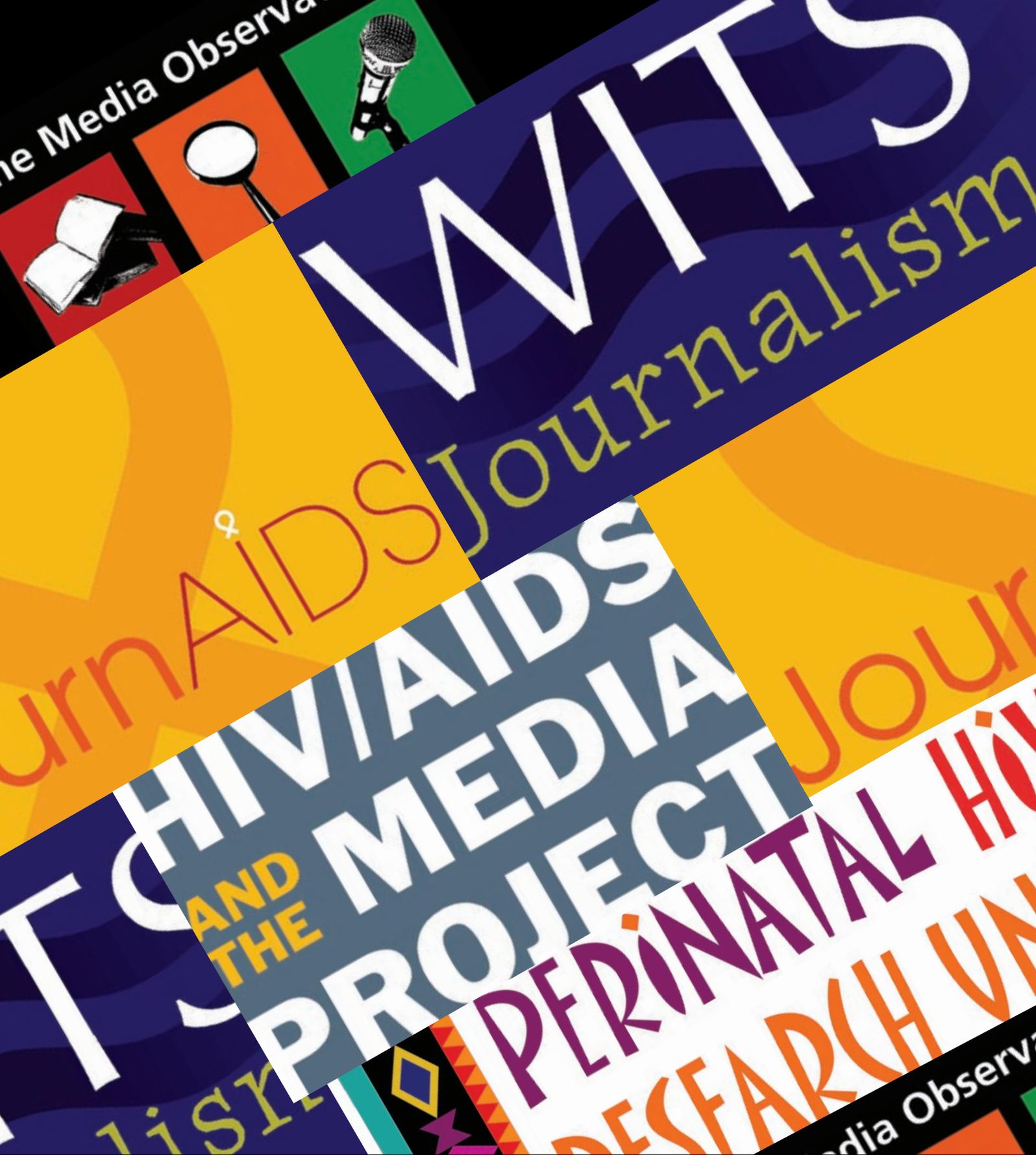
Mpadi Makgabo Johns Hopkins Health Education South Africa

"The science and culture debate is still ongoing but it was not really the place to expand on this. But it is good that it is taking place."



Brett Anderson Lifelab

"I'm just astounded by [Nozizwe Madlala-Routledge's] openness. This is what we've been waiting for; this is leadership."



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