Speaking freely, being strong
HIV social movements, communication and inclusive social change – a case study in South Africa and Namibia
Acknowledgements

Panos London would like to thank the interviewers involved in the oral testimony project for their time and commitment: Phumzile Nywagi (local coordinator), Mteto Dyanti and Vuyisa Dumile from Khululeka; Martha C J Shindi from ICW Namibia, and Vathiswa KamKam, Sylvia Jacobs, Georgina Boeysen, Ali Sesanga, Bulelwa Zono, and Thembelani Nkunkuma from TAC. We would also like to thank the narrators and interviewees for their time and participation in the project.

This report was written by Lucy Stackpool-Moore, policy and programme officer, London AIDS Programme. Comments on the draft were gratefully received from Bec Shaw Crompton, Robin Vincent, Helena Lindborg, Fiona Roberts, Siobhan Warrington, Keren Ghitis, Olivia Bennett and Teresa Hanley.

Khululeka means ‘Be free’. The support group aims to bring men together (most members are living with HIV), help them to improve their own lives and then make a difference to the lives of other people in their community.

PHOTO: KHULULEKA MEN’S SUPPORT GROUP

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For further information contact:

London AIDS Programme
Panos London
9 White Lion Street
London N1 9PD

Tel: +44 (0)20 7278 1111
Fax: +44 (0)20 7278 0345
hivaids@panos.org.uk
www.panos.org.uk/aids

ISBN 1 870670 73 6
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Executive summary

‘One thing I have learnt is that when we meet it brings peace into my life. When I am at home, sometimes I think of many things which are not good for me, but when we come for a support group meeting it relaxes my mind. We talk about our daily problems and it really brings peace to me. Even when I go back home I feel good.’

Female, member of ICW, Namibia

Social movements have brought energy, vitality and self-defined change to local, national and international responses to HIV and AIDS. By bringing people together and advocating effectively, social movements have amplified voices of people most affected by HIV and AIDS and created opportunities for their voices to influence governments and other decision makers. How can communication more effectively support social movements to debate, act and bring about change in favour of those most affected by HIV and AIDS?

‘It’s really the informal networks that work. Not these big guys, you know. You know that saying, “Nothing about us without us”... that kind of civil society is just another informal tier of government.’

Freelance radio journalist, South Africa

This document outlines some of the main findings of a pilot case study in South Africa, conducted in 2006 as the first phase of the Panos HIV social movements project. It will form the basis for a roundtable dialogue in Cape Town in November 2006, bringing together key stakeholders (members of social movements, media professionals, civil society and local policy makers) to discuss the findings and critique the recommendations.

Panos launched the project to learn from HIV social movements about the role of communication in social mobilisation. We published a discussion paper in March 2006, *We are one but we are many*,¹ and have since developed the ideas in two pilot case study projects – in Cape Town, South Africa, and Recife, Brazil – both countries having a history of strong and effective social mobilisation, as well as a high prevalence of HIV.

The project seeks to address some key questions. How, for example, do social movements ignite passion and commitment to action? How do social movements bridge individual vision for change with collective action? What is the role of communication in connecting people, creating social movements and supporting people living with HIV and AIDS? How can the relationship between social movements and the media be enhanced to open up and diversify public debate around policy and other key decisions relating to HIV and AIDS?

These and other questions were addressed in the South African pilot study through a number of research methodologies. The main methodology was oral testimony, which aims to let individuals share their personal stories. In Cape Town, in collaboration with the Centre for Popular Memory at the University of Cape Town (UCT),² Panos facilitated an oral testimony workshop with representatives from three different social movements – the Treatment Action Campaign (TAC), Khululeka Men’s Support Group and the International Community of Women Living With HIV/AIDS (ICW).³ The participating members from these three movements then carried out open-ended, in-depth interviews with their peers. Key themes in the testimonies include identity, motivation for being involved in a movement or support group, representation and voice. There was also some discussion around the external communication of the movement or group, and its relationship with the media. Other research consisted of interviews with media professionals and focus group discussions. Quotes from these are also included in this report.

¹ [www.panos.org.uk/PDF/reports/socialmovements.pdf](http://www.panos.org.uk/PDF/reports/socialmovements.pdf)
² [www.popularmemory.org](http://www.popularmemory.org)
³ There were 10 participants in total – five women (four from TAC and one from ICW) and five men (two from TAC and three from Khululeka)
Approximately one third of this report consists of extracts from the testimonies. The aim has been, as far as possible, to let the narrators speak for themselves through quotes and longer extracts.

A number of key issues emerged, which require us to look at communication at various levels.

First, coming to terms with HIV and talking about it is extremely challenging at an individual or personal level. Talking with others is also one of the mechanisms by which individuals reflect on their situation and become impassioned and motivated to start a social movement.

At the interpersonal level, connecting with other people plays a critical role in providing support for people affected by HIV and AIDS. Sharing a place or talking with another HIV-positive person can make a world of difference to someone attempting to come to terms and cope with a positive diagnosis. Communication between people also enables the sharing of enthusiasm, potentially sparking even greater commitment to a common cause, and is vital for sustaining networks of people.

At the public level, communication is crucial in amplifying – to policy and other decision makers – the voices and concerns of those most affected by HIV and AIDS. It is the process whereby social movements can raise awareness and mobilise support for their campaigns; it is also the process by which the media frame stories around HIV and AIDS and other related issues.

From a synthesis of the main findings of the project, several key issues emerge, some unique to the South African context. These include the following:

- In social movements, communication connects people at a deeper level than the merely rational: it supports, inspires and helps people living positively with HIV. Because social movements usually emerge from informal networks of people, communication is arguably more important in sustaining momentum in this context than in organisations that can rely on institutionalised structures and processes to keep them going.
- Communication has a vital role in connecting and supporting people living with HIV and AIDS at both individual and collective levels.
- Small, informal community-based groups have an important role to play in responding to the immediate needs and concerns of their members, whereas big, national social movements may lose some direct relevance to the practical needs of the broadening base of their membership.
- Social movements enhance the visibility of people living with HIV and AIDS and provide a platform for challenging the government and other decision makers.
- Social movements create, claim and shape spaces for public debate. In South Africa particularly, drawing from the history of struggle and social mobilisation against the apartheid regime, social movements have played an important part in shaping spaces for democratic debate.
- Strong movements can dominate public debate and contribute to a polarisation between civil society and the government. Although the strength of the civil society response concerning access to treatment and advocating for improved national policies has put HIV in the public spotlight, it has not necessarily strengthened the vibrancy and diversity of public debate around these issues.
- People living with HIV and AIDS need additional communication skills and exposure to the media to enable ethical, accurate and comprehensive coverage of HIV and AIDS in the media.
Media professionals need additional support and incentives to engage critically and proactively with social movements in their coverage of HIV and AIDS. Key obstacles needing addressing were identified:

‘HIV is a difficult thing to report on, in terms of the personal attitudes that go with it. It’s around sex, so its unbelievably intimate, loaded with whatever the taboos are.’

Freelance print journalist, South Africa

Although Panos is still in the early stages of this project, a few recommendations are emerging. They include the following:

- Support capacity development with members of HIV social movements and people most affected by HIV and AIDS to help them to communicate clearly, represent themselves effectively, and be represented legitimately, accurately and ethically in the media.

- Support places for debate that guarantee diverse participation and enable the voices of people most affected by HIV and AIDS to be heard. These can be spaces generated by social movements, or others that enable people most affected by HIV to represent themselves and their priorities meaningfully.

- Promote communication and advocacy environments that encourage diverse voices, and promote multidirectional accountability (for governments, civil society, social movements and other key public actors).

- Promote proactive rather than reactive journalism. Around issues of HIV and social movements, this would include providing incentives and allowing time for journalists to undertake investigative research around key issues, focusing particularly on accessing and amplifying the voices of people most affected.

- Foster and support greater linkages between media professionals and members of HIV social movements.

- Media professionals – including freelance and staff reporters – should be guided in their coverage of HIV and AIDS by ethical guidelines that encourage non-stigmatising, accurate and informative coverage of the key issues.

- Support and promote creative, innovative and multimedia approaches that are participatory and can enable a plurality of voices to be heard in debates about key HIV and AIDS policy decisions.

‘If I could say it directly the way I want to say it, then I would be heard the way I want to be heard.’

Male, member of Khululeka, South Africa
People most affected by HIV and AIDS are still under-represented in government and other key decision-making processes that directly affect their lives. Social movements have brought energy, vitality and self-defined change to local, national and international responses to HIV and AIDS. They start outside institutionalised spaces by igniting passions and connecting individuals. By bringing people together and advocating effectively, social movements have amplified voices of people most affected by HIV and AIDS and created opportunities for their voices to influence governments and other decision makers. How can communication more effectively support social movements, strengthening their capacity to debate, act and bring about change to the advantage of those most affected by HIV and AIDS?

Communication has often been understood to be the technical means of providing information and ‘messages’ to people. However, it is more than that: it consists of the processes of dialogue, exchange of information and resources, negotiation, advocacy and capacity building that shape self-knowledge and bring about understanding, participation in public and political processes, and the realisation of rights. This expanded definition steers the work of Panos and others, and is loosely known as communication for social change. Communication for social change puts people at the centre of their own change, setting their own priorities, and finding their own ways of communicating and organising. Communication for social change is a framework for understanding how dialogue between people can support them in making informed and relevant decisions about how to live their lives.

Panos launched the HIV social movements project in 2006 to learn from HIV social movements about how communication can support social mobilisation leading to personal and social change. Social movements challenge us to link the individual with the collective, and to think more deeply about how interpersonal dialogue and debate contribute to individual change (eg, behaviour change, realisation of rights, coping with a positive diagnosis) as well as social change (eg, collective action, policy change, addressing stigmatising and discriminatory attitudes and practices). Panos published a discussion paper on the subject in March 2006, *We are one but we are many,* and has since developed the ideas in two pilot case study projects: in Cape Town, South Africa, and Recife, Brazil.

Overall, the project aims to increase understanding of how social movements contribute to social change and support spaces for debate that amplify the voices of people most affected by HIV and AIDS and hold decision makers to account. Communication is central to processes of social mobilisation. It allows links to be made between likeminded people, groups and organisations, as well as supporting advocacy with external audiences. The project seeks to address some key questions:

- How are social movements different from other civil society groups?
- How do social movements ignite passion and commitment to action?
- What is the role of communication in connecting people, creating social movements and supporting people living with HIV and AIDS?
- How can the relationship between social movements and the media be enhanced so as to open up and diversify public debate around policy and other key decisions relating to HIV and AIDS?
- How do social movements engage with institutional spaces for debate and processes of accountability?
- How can communication more effectively support social movements and strengthen their capacity to debate, act and bring about change to the advantage of people most affected by HIV and AIDS?
Each of the groups we worked with in the pilot case study project in South Africa shines a new and slightly differently angled light on these issues. At the local level, the Khululeka Men's Support Group relies on word of mouth, informal networks and regular Sunday meetings to attract new members. One way that Khululeka shows its support for HIV-positive men is by attending (and sometimes arranging) funerals for men who have been discriminated against or stigmatised because of their status. At the international level, the International Community of Women Living With HIV/AIDS (ICW) is run by – and for – HIV-positive women. It has strong networks at the local, regional and international level. Much of ICW's work is less visible but no less powerful behind-the-scenes activism through lobbying, so that change can happen without confrontation. The Treatment Action Campaign (TAC) has worked consistently to engage the media and include the voices of people living with HIV in public debates about national policies on HIV and AIDS. In a different way from ICW, TAC has also been instrumental in connecting global activists on issues to do with access to treatment and drug pricing and working with international alliances to support its national advocacy work. These examples touch on only a small aspect of how communication supports each group in working towards its objectives. The examples begin to illuminate the intricate dynamics of communication at work in supporting and sustaining social movements.

In addition, one of the reasons that social movements can be so dynamic and vibrant is because they unite people's passions as well as engaging people's minds. Communication enables people to connect with each other, to identify with and become part of a group, and to engage at an emotional as well as a rational level. Certainly for HIV social movements, one of the main reasons that an individual might initially join a movement or group is to access information about living positively and to experience mutual support and acceptance within a group, which can be an oasis in an environment that is often stigmatising and judgemental.

Social movements therefore challenge us to think about communication and its role in processes of social mobilisation at many different levels, including:

- formal processes and structures that link people together (meetings, recruitment)
- advocacy structures that support the movements' work with an external audience (newsletters, press releases)
- media coverage on social movements and other civil society actors (TV, print, radio)
- interpersonal connections and relationships
- self-development
- support and emotional engagement.
The findings outlined in this report address these questions and others emerging from a process of exploring the intersection of communication, social mobilisation and social change. This is a new area of work for Panos, and a new approach for understanding communication for development. As such, the report forms part of ongoing conversations and analysis about key concepts, ideas for further research and projects, and ethical ways of working with social movements.

This report seeks to outline some of the main findings from the pilot case study project in South Africa. It will form the basis for a dialogue event in Cape Town in November 2006, bringing together key stakeholders (members of social movements, media professionals, civil society and local policy makers) to debate the findings, critique the recommendations and talk through the implications.
We launched the project in South Africa for a combination of strategic as well as practical reasons, including the unique history of social mobilisation in the country (in general, the anti-apartheid movement, as well as specifically, in response to HIV), the prevalence of HIV, and connections between Panos and local civil society actors to advise on the project. The oral testimony (OT) project also included one participant from Namibia, but the majority of participants involved in the OT project and respondents were from South Africa. As such, the bulk of the report focuses on key findings in the South African context.

The pilot case study had four key components:

1. An oral testimony workshop and testimony collection with members of HIV social movements to look at communication within a social movement. The specific focus was on individual experiences of HIV, what it’s like to be part of a support group/movement, and how the group/movement can amplify the voices of people most affected by HIV and AIDS and contribute towards inclusive social change.

The workshop focused on life stories and interviewing skills. There were 10 participants – six from the Treatment Action Campaign (four women and two men, all either community media practitioners or contributors to TAC’s Equal Treatment magazine); three from Khululeka Men’s Support Group in Guguguletu; and one woman from the Namibian chapter of the International Community of Women living positively. The workshop was co-facilitated by Panos and representatives from the Centre for Popular Memory at the University of Cape Town.

The interview collection took place over six months, and each of the interviewers interviewed their peers within their social movements. The interviewers were free to choose the narrators themselves, based on the simple criterion that the narrators were also involved in an HIV social movement or support group. Many of the interviewers chose to interview along gender lines (i.e., a female interviewer interviewing a female narrator), but some chose to interview both men and women. At the time of writing, the oral testimony collection includes 34 interviews.

2. Semi-structured interviews with media professionals (freelance and staff reporters), organisers of social movements and other civil society organisations about the relationship between movements/civil society and the media. The interviews were designed to be informative and illuminating, but not comprehensive. We interviewed seven people in total – five media professionals (electronic, print and radio) and two civil society representatives (Médecins sans Frontières and Workers World Media Productions) – a handful of perspectives among many in South Africa. As with the oral testimonies, the semi-structured interviews were designed to add depth and diverse individual perspectives to the main research topics.

The overall questions focused on the relationship between media and social movements, the role of the media in response to HIV and AIDS in South Africa, and the role of the media in supporting inclusive social change and holding government and other key decision makers to account.
Focus group discussion with members of social movements on the final day of the OT workshop. This discussion explored the relationship between social movements and the media, and issues of accountability in relation to government health policy.

Meetings with members of the advisory group to review and deepen the conceptual ideas outlined in the discussion paper. The advisory group is drawn from academics (in South Africa and in the UK), civil society, including NGOs and social movements, and networks of people living with HIV (South Africa and the UK).

**The story of HIV in South Africa and Namibia**

South Africa is a highly politicised environment, balancing tense historical legacies with new hopes and groundbreaking democratic structures. The HIV and AIDS environment is no exception, embroiled in politics that both foster and impede the processes of change.

After India, which has a much larger population (and lower prevalence rate), South Africa has the second-largest number of people living with HIV and AIDS. However, while recent actions on the part of the South African government have reflected progressive thinking and openmindedness, the early years were marred by ‘AIDS denialism’ and the traumatic legacy of apartheid. TAC, established in 1998, has contributed to putting HIV and AIDS, and health care, on the political agenda. Although TAC initially targeted big pharmaceutical companies for restricting access to much needed antiretroviral drugs (ARVs) through high pricing, the movement extended its focus to government health policy and the national policy response to HIV and AIDS treatment. A National AIDS Council was established in 1999 and the National Treatment Plan to make access to treatment available to all was passed in 2003. Despite the limitations of the roll-out of ARVs under this policy, TAC is seen as one of the most successful post-apartheid social movements for its role in influencing the government to develop the Plan in the first place.

Several provisions in the Namibian constitution have been invoked in the response to HIV and AIDS. After a relatively slow start, the government developed a coordinated plan in 1990, a second National Strategic Plan for 1999–2004 and a comprehensive Third Medium Term Plan in 2004. The Third Medium Term Plan on HIV and AIDS urges more involvement for those directly affected by the disease, but, as yet, it appears that little actual change has taken place.

The latest UNAIDS figures estimate that 5.5 million people in South Africa and 230,000 in Namibia are living with HIV. The data suggest that prevalence continues to increase in South Africa, and to show no clear signs of declining in Namibia. The adult (15–49 years) prevalence rates are estimated as 18.8 per cent and 19.6 per cent respectively. Of the adults aged 15 and over living with HIV, 58 per cent in South Africa and 62 per cent in Namibia are women. While the number of people receiving ARV treatment in South Africa increased dramatically during 2004–2005 and the country accounts for a quarter of all those receiving ARVs in sub-Saharan Africa, therapy coverage has only reached 20 per cent. Namibia is one of only three countries in sub-Saharan Africa where ARV therapy coverage reaches or exceeds 50 per cent.

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**Notes:**


Media and HIV

The South African media are classified as free, and are among the most developed and well resourced in Africa. There is vibrant advocacy for freedom of the press and there are strong organisations of journalists. The media do seem relatively free and independent from the government, although the South African Broadcasting Corporation (SABC) has been criticised for displaying a pro-African National Congress (ANC) bias and for practising self-censorship. Particularly relevant for this case study, research conducted by the Perinatal HIV and AIDS Research Unit and the Witwatersrand University Journalism Programme suggests that conflict around HIV and AIDS policy determines the extent of HIV and AIDS content in the commercial press generally. The study found that over 50 per cent of the key messages during the monitored periods (March–May 2002; and again in 2003) related to the conflict between government and HIV and AIDS activists. This ties in with the politicisation of HIV and AIDS in South Africa, with reporting on conflict around government policy marginalising other key issues relating to the epidemic. Although there are notable exceptions, media coverage of HIV and AIDS in South Africa has often been found to derive from single sources, to be dominated by a particular interest group and to perpetuate inaccuracies.

Namibia has been heralded as one of the more ‘media friendly’ countries in Africa, and has a constitution that explicitly enshrines the freedom of the press and is supported by government. Overall, most news reports on HIV and AIDS are usually limited in scope to administrative details and government announcements. An overall content study of the Namibian media found that, out of 42 topics receiving coverage, HIV and AIDS represented only approximately 3 per cent of the total. The study also highlighted that most stories rely on authority figures, particularly government officers, as sources of information. Meanwhile, there is little news about the personal aspects of dealing with HIV and AIDS or its emotional impact on people’s lives. As in South Africa, there appears to be a high turnover of journalists, and both new and existing staff need to be trained on how to report on HIV and AIDS.

History of political struggle and civil protest and HIV

South Africa is a relatively new constitutional democracy. The first democratic elections in 1994 marked the end of the apartheid era and the new political leadership of the African National Congress. A new constitution was passed in 1996 and is progressive in many ways. Significantly for this research, it is the only constitution in the world (to date) that recognises the rights of lesbian and gay people. It also safeguards the independence of the broadcasting regulator against state interference.

Several authors have looked at the evolution of AIDS activism in the context of the history of struggle in South Africa – in particular the history of the anti-apartheid movement, gay rights movement – and the rights-based discourse that has underpinned social activism in South Africa throughout these processes. TAC originates from within the newly formed constitutional democracy. This is significant because the new constitutional environment enabled the emergence of new democratic spaces; and also because it enabled activists who had previously been engaged in other social struggles to focus their energies on AIDS treatment and public health. In founding TAC and launching the campaigns for rights for people affected by HIV and AIDS, the leaders were putting old skills to use in a new environment.
There are three main ways that TAC has been able to mobilise South Africans and engage with the new democratic spaces for debate: working with international and national media, working with the legal system and the Constitutional Court, and promoting a culture of 'mass-openness' among members. The openness that TAC cultivates has contributed towards promoting diverse voices within the membership inviting criticism of the TAC leadership, and encouraging a greater openness within South African society to talking about HIV and AIDS. Drawing on the experiences of the gay and anti-apartheid movements, TAC's activism has strengthened rights-based approaches to social policy and the realisation of citizenship in the new democratic environment in South Africa. TAC and other social movements have helped convert rights on paper into reality.

Beyond the realisation of rights at the collective level, social movements in South Africa and in general have also been criticised for being undemocratic internally. The leaders of social movements are often charismatic and visionary, but can be prone to manipulating diverse perspectives within the movements into simple positions aimed at unified and more effective campaign messages. As such, movements are often astride a tension between the process of social mobilisation and the outcomes they are striving to achieve. This tension makes it difficult for movements to challenge, rather than perpetuate, the political cultures that maintain existing power inequalities.

As mentioned above, some of the oral testimonies collected for this case study are from Namibia – a different but not unrelated social and political context. However, the majority of the research focused on South Africa, which is reflected in this report. The history of struggle and recent transformative social and political change in South Africa, combined with the interest of members as well as leaders of three social movements in the region, provided a unique and interesting opportunity to pilot the Panos social movements project.

19 See footnote 9
20 S Friedman and S Mottiar (2004), see footnote 17
21 See footnote 9
Oral testimonies are vivid, personal and direct, and provide different perspectives from other types of research as their primary focus is on letting individuals share their personal stories. The testimonies are the result of open-ended, in-depth interviews, usually carried out on a one-to-one basis. A fundamental aspect of Panos’s approach is that the interviews are often carried out by the narrators’ peers. The interviews usually last 1–2 hours and are recorded and then transcribed word for word.

Panos used oral testimonies in this project to illuminate individual stories about participating in social movements, experiences of HIV, and visions for change. The key themes include identity, motivation for being involved in a movement or support group, representation and voice. There was also some discussion around the external communication of the movement or group, and its relationship with the media.

The life stories include aspects of the individuals’ background and identity that are related to and also go beyond their HIV status or experience. In focusing on the individual within social movements, the testimonies aim to provide insights into individual reasons for participating in such movements and personal visions for social change.

The oral testimony project had five key components:

1. Participatory training workshop: five days (including practice interviews) where the participants developed their interviewing skills, discussed interview relationships and ethics, and helped devise the topic guidelines for the interviews.

2. Testimony collection: after the workshop, the participants each interviewed four or five of their peers.

3. Mid-project review meeting: participants re-convened after recording and transcribing at least one completed interview to share their experiences and refine their interviewing technique.

4. End-of-collection meeting: to celebrate the hard work of the interviewers and discuss some of the cross-cutting themes emerging from the collection.

5. International and local use and dissemination of the testimonies: at the international level this is done through the Panos publications and website; at the local level small grants support the participants, and their groups use the testimonies in launch events such as community discussions, exhibitions and readings, and in publications such as pamphlets or - in edited form - for existing formats such as newsletters or websites.
The participants and their social movements

In Cape Town, in collaboration with the Centre for Popular Memory at the University of Cape Town (UCT), Panos facilitated the HIV social movements oral testimony workshop with representatives from three different social movements – the Treatment Action Campaign (TAC), Khululeka Mens’ Support Group and the International Community of Women living positively (ICW). There is a strong emphasis within the OT project on listening to and communicating the voices of people who may not previously have been particularly vocal. Likewise, the workshop aimed to develop the interviewing and listening skills of the participants. For this reason we worked mostly with the members of the movements in the oral testimony project, who were then encouraged to interview their peers (rather than the leaders) in the interviews.

The Treatment Action Campaign (TAC – www.tac.org.za) in South Africa has used a variety of different media technologies (web, photo, video and written narratives) to document personal testimonies from the diverse members of the network as well as from the leadership. One key aspect of the success of TAC in advocating for access for all to treatment and care in South Africa (which resulted in a national policy change in 2003) is the breadth and diversity of its membership and its highly visible and effective public image. Recent research has looked at the role of new media and TAC, and argues that alternative media can complement as well as supplement ‘traditional’ media. For example, TAC uses text messages as well as word of mouth to mobilise crowds at their demonstrations, and publishes alternative news bulletins as well as press releases about its activities.

The International Community of Women (ICW – www.icw.org) is an international movement bringing together women affected by HIV and AIDS around the world. It is the only international network run for and by HIV-positive women, and was formed by a group of HIV-positive women from many different countries who stormed the platform of the Eighth International Conference on AIDS held in Amsterdam in July 1992. Nowadays, much of ICW’s work is less visible but no less powerful behind-the-scenes activism through lobbying, so that change can happen without confrontation. This approach reflects the reality that many women still can’t be open about their status, that not every woman can afford the time to go to demonstrations – or risk being photographed by the press, arrested or injured at them – or to write to email groups, since women often have many other commitments as carers of family and friends.

23 www.popularmemory.org
24 There were 10 participants in total – five women (four from TAC and one from ICW) and five men (two from TAC and three from Khululeka)
Khululeka was formed in September 2004. It is a locally based group mainly comprising males who are living with HIV/AIDS. It came to my mind that there was a need for it. By the year 2001 I was diagnosed with HIV and had TB as well. I started attending a support group of people living with AIDS. This was when I developed self-esteem and confidence; but at first it was really difficult to attend.

As time went on I noticed that most of the time I was the only male. I had unanswered questions about the partners of these women. I set myself a target of challenging all guys out there to make a difference to our lives as well.

Attending a support group – really that makes life easier for you to cope with stigma, discrimination and to live a better life. The name Khululeka means ‘Be free’. Our logo says ‘Together we rise’, and as time goes on we will bring both genders together so that we can rise from worse to better lives.

Our aim is to reach the unreachable people and to make a difference to our lives first, and thereafter to the rest of our communities. We aim to empower ourselves with lots of skills; to uplift our morals and to change our behaviour. We aim to educate, build our skills, get jobs and live healthy positive lives.

Our space is very small at the moment (a shipping container in my back garden), but we aim to have a centre or a hall whereby both genders can meet together. We’re doing home visits, hospital visits, open-air education, work with schools, work with individuals, family education and supporting each other, social clubs, open funerals, treatment literacy counselling and outreach. Most of the time we educate ourselves. We also accept invitations from other social movements. We network with other support groups as well, mobilising our communities about HIV/AIDS.

Phumzile Nywagi
Key issues emerging – voices from the oral testimony project

This section includes some of the voices of interviewers and narrators involved in the oral testimony project. It is not comprehensive or representative, as each voice is unique and each testimony only a snapshot of a complex and personal life story. By being flexible and open, the oral testimony process aims to look at a particular issue, in this case, HIV social movements and communication, within the larger and more complicated context of an individual’s life. Each of the testimonies in the HIV social movements collection covers a wide range of topics, including childhood, relationships, education, hopes and dreams, death, survival, growing up in South Africa or Namibia, living with HIV, participating in a social movement, as well as wider social and political issues.

In the pages that follow, we have drawn out the principal cross-cutting themes that have emerged from the collection and have identified some key quotes under each. As far as possible, we have let the narrators speak for themselves through quotes and longer extracts.

Identity, culture and context

The short amount of space available in this report cannot do justice to the rich and intricate details of identity, culture and context that the narrators shared in their testimonies. Below are some short extracts that highlight some of the main issues, such as men and masculinity, fertility, gender relations, positive relationships, religion, childhood, abuse, politics, resistance, coping and support. Many of the narrators described moments of intense despair and hardship relating to their early experiences of diagnosis living with HIV. Many (but not all) then described a journey of survival and hope supported by friends, family and others living with HIV, as well as access to essential services and treatments.

The diversity of the individual stories within the collection highlights the complex and holistic nature of the HIV epidemic, touching on many dimensions of an individual’s life as well as the social and cultural context that it permeates.

Culture is something dynamic

‘To me culture is something dynamic. We must start to see the dynamics. There is no culture which says women must be undermined, women must be beaten. There is no culture like that. My culture, the African culture, the Xhosa culture, respects women. Women are seen as co-partners all the time but unfortunately along the line it has been destroyed by some men to advance their interests as men. It has come time to unwind the truth of culture itself. You must have listened to a programme yesterday about lobola [bride price]; people are complaining lobola was part of our tradition. It is a dowry, I paid lobola; I was not paying money to buy my wife but I was expressing to her family a thank-you for moulding and shaping a woman like this one. The amount I paid is not her worth, but it was my human endeavour to say thank you to the families.’

Male, member of TAC, South Africa
Handshake of a lifetime

‘Sometimes people treat me differently and in the beginning my family was very overprotective of me. Once I was walking with a Muslim man in Cape Town. I started talking to him about HIV and asked him how he feels about people who are HIV positive. He said according to their beliefs someone is HIV positive when they have committed a ‘sin’, and that they stone such people to death. I said to him that it is not a sin to be HIV positive. He said he will never touch a person who is HIV positive. As we walked on, I thanked him for the conversation and took his hand for a handshake. I said ‘Sir, you have just touched someone who is HIV positive.’ He went to pull his hand out of mine. I said “No sir, nothing will happen to you – you can greet me.” And you know what? He gave me a hug and said thank you.’

Female, member of TAC, South Africa

We need more men

‘The men in our community are too scared to talk about their HIV status. I only know of, say, three. Three in our community that are open about their status. And we need more men – we really need more men.’

Male, member of TAC, South Africa

Unemployment

‘I have been unemployed. I felt bad because I couldn’t provide, as a man with a family, for my girlfriend and my child. I had to provide for them at the same time as looking after my mother, I had to make ends meet.’

Male, member of Khululeka, South Africa

A hard time getting food

‘I have never been employed in my life up to this stage. Not even as a maid. The only job I did was self-employed, selling my meat... I am really having a hard time when it comes to food. With those drugs you need to have food. That is why you always see me coming to a support group, to meetings, hoping to get meal maize. But no, I am really having a hard time with food.’

Female, member of ICW, Namibia

Individual spirituality

‘I started seeking the churches that offer spiritual healing, because I knew that for me to overcome this I needed to have God or Jesus within me. I needed to pray. I can’t tell you how many churches I went to that year – you would not believe it. I went to so many churches and the messages I was hearing put me off, because they were saying if you read in Revelations this disease is going to come and all those people have this disease, it is God punishing them. It made it even worse, because I started to believe that God was punishing me. I went there to seek spiritual healing, but before I could even interact with anybody – the pastor or priest or whoever – the negative message meant I said to myself I am not even going to talk to anybody because they are going to point a finger at me – maybe chase me out of the church because they see me as sinner [laughs]... Why should they judge me? Why should they judge me instead of supporting me, embracing me? I said it’s not worth going to a church when I know I am going to hear a negative message. I would rather pray by myself and seek a personal relationship with God and I have found that for me it works.’

Female, member of ICW, Namibia
The church fights stigma and discrimination
‘The church has brought a change into my life and the church is trying to fight against stigma and discrimination. It also encourages you that you are still a human being. Jesus Christ loves you, and also God loves you.’
Female, member of ICW, Namibia

Talking about sex
‘I tell my children to really protect themselves, especially when it comes to sex. I am not telling them not to have sexual intercourse; I tell them to use condoms. They listen to me. One of them did come, one of the boys, to ask advice. I felt proud. I felt good because he does not want to make mistakes. I know that he wants to have sex but first he wants to get information.’
Female, member of ICW, Namibia

Sex
‘If we were [HIV] negative, we would do it every day [claps hands and laughs] but we are limited. We use condoms, male condoms, but every time I get a sore because it’s rubber. So we tried female condoms, which were OK, but at the end we saw that it fell off and it has gone inside the vagina! So I don’t know how safe that is. That is why I am looking forward to the microbicide development. If it comes and it works really well, I think it will be a life-saver for us, both male and female.’
Female, member of ICW, Namibia

Living with HIV
All of the narrators were affected by HIV in some way. Most are HIV positive and living openly with their status. Some have experienced opportunistic infections such as TB or pneumonia. Each of the testimonies tells a unique story of how the narrator heard about HIV, what prompted them to go for testing, how they responded to the diagnosis and how they have been able to cope. Many of the narrators described initial feelings of sadness, fear and despair. Through access to more information, ARVs as and when needed, and identifying support networks, the stories move on to inspiring glimmers of hope and survival.

Life is tough
‘Life is tough – it is like you see a thorn there and you go and step on it by yourself. When I got infected it’s difficult to live with it, because the people who were supposed to help you in difficult times don’t want you, there’s no one who wants to help you. Even you yourself don’t feel well in your heart. Life is real tough. You see, there’s no hope. You only think that this is it, I am already dead, there’s nothing I can do, I am already dead. I am only waiting to die, there’s no hope… The first group that I attended was at Lironga Eparu. It is where I met people who are like me, who are also positive. It was my first time and I never saw something like this before and it encouraged me to know that I am not the only one – we are many.’
Female, member of ICW, Namibia
HIV positive?
‘I’m HIV positive. I was tested on 14 November 2002. I did a rapid test and I immediately tested positive after I had an infection in my kidneys. I was aware of HIV/AIDS because I was working at the local hospital at that stage. And I saw a lot of people dying. The first person I saw who died was actually five days after my diagnosis. And that gave me a real fright because I didn’t want to die like that. That was when I attempted my second suicide. It was a very hectic time for me. I ended up in hospital four times [because of] trying to take my own life and in psychiatric institutions four times because I wasn’t myself. I was shocked – I don’t know, I can’t describe myself at that stage.’
Male, member of TAC, South Africa

I was seeing my funeral in front of me
‘That my son and I, we are HIV positive, now what? At that moment I said to my son – you know my son was about one year and six months – I said to him “Forgive me”, and I told him over and over “Forgive me”. I was so emotional and in my mind I was like, we are going to die – because I know nothing about HIV. But when will I die, when will it happen? There were times when I was just sitting – I didn’t want anything to do with my husband. I was sometimes seeing my funeral in front of me. My son’s funeral was there too sometimes. I asked the Lord why he did this to me, why not to someone else? And it was just like I had to go on, you see, it is not something that happens today and goes away tomorrow. It stays with you. I realised that I was very cross but that I am not going to die today. I can still go on, you see, I can still move on.’
Female member, TAC, South Africa

I have to educate myself
‘I take things the way they are. I learn to live with what I have; and what I don’t have, I don’t. A ‘life’ of living positively. A life where I have to educate myself about these issues of HIV and AIDS.’
Female, member of ICW, Namibia

Disclosing to God
‘The first, the very first person I tell is the Lord. That’s the very first person I share [my status] with.’
Female, member of ICW, Namibia

Living very very positively
‘First of all I want to tell you that my name is Jennifer Gatsi Mallet and I am a 48 year old who looks 16 years old and I am living with HIV for 15 years now and I am living very very positively with it.’
Female, member of ICW, Namibia
Finding strength from a support group

‘When I came to Cape Town I heard a lot about HIV/AIDS, but it felt that HIV is far from me. I didn’t even think that I can have it. I decided to go for a test because my boyfriend had a lot of girlfriends. I went to the clinic and asked the nurse if I could have an HIV test and [said] that I also want to know about AIDS. They laughed at me. They said that they don’t do the test here and advised me to go to the private sector or go to the big hospital and get the test. They also wanted to know why I want to do the test and I told them that I wanted to know. After I went to the clinic I felt very discouraged and decided not to go anywhere for the test.

‘I had a lot of boyfriends because if I didn’t have a boyfriend I didn’t have money and I was suffering financially. I met a boyfriend in church and he wanted a baby so I decided “Why not?” I gave birth to my baby and started breastfeeding and I didn’t know about HIV/AIDS. When my child was about a year I had some problems with my boyfriend and left him.

‘I met my husband when my child was two years old. I fell pregnant again because we wanted a child of our own. I went to the clinic to go and book and that’s how I found out that I am HIV positive.

‘The counsellor wasn’t so good. She asked me what would I do if I test HIV positive. I said that I will accept it. I thought to myself that I’m coming from other relationships, my husband is older and that my child is well, these were all the things that were going on inside me. I thought, if I have HIV, my child will also have HIV. The counsellor came back to give me my result and I just smiled after she told me I’m HIV positive, because I thought the counsellor was making a joke. The counsellor told me that she wouldn’t joke about something so serious. She wanted to know what I was going to do. I said I don’t know and took my bag and went outside.

‘As I walked outside I was looking at the people sitting in the passage. What they think when they see you coming out of that office – they will see in your eyes if something is wrong, so I decided not to cry. My sister had come with me and when we left I told my sister at the gate of the clinic that I tested HIV positive. I started to cry. I told my sister that I felt much better now that I had cried. I couldn’t wait for my husband to come home so I can tell him the results. I told myself that I will fight this thing, it will not do anything to me.

‘My husband went for the test and the counsellor called us in to give his result and he said “No, you are HIV negative.” I started to cry again and asked how can it be? How can my husband be negative and I’m positive? I cried till I got home. At home my husband told me not to cry and that everything will work out and he loves me. I wanted to know, where did I get this thing? My husband told me not to worry about where this comes from and where I got it and I should concentrate on helping myself. At that time I was very angry but now I am fine. I always asked myself: why? Why? Why? I think at one stage I wanted him to be positive as well but all of that is in the past and I am glad that he is HIV negative.

‘My aunt told me that we must make an appointment so we can talk. I went with my husband to my aunt one Sunday and she and her husband talked and counselled us and she referred me to a counsellor. My husband also told me about a lady that I can talk to. I told myself if I can go to this lady and talk to her, maybe I’ll feel better. I went and she advised me to go to this support group. After I went to the support group I started to feel better and I told myself, this thing – I’m going to fight it and conquer it.’

Female, member of TAC, South Africa
Why join a social movement?

The collection shows a host of different reasons why people became involved or interested in a social movement. Often it was for support. Social movements were identified as one source of support alongside other support groups, religion and counselling services.

The testimonies reveal that different experiences within the movement subsequently motivated people to become more or less involved as their experience with the movement matured. Some of the most common reasons people gave for joining a movement included finding support, referral from friends or counsellors, and an individual passion to fight HIV at a community level. Some narrators ascribe the decision to difficult experiences in coming to terms with the diagnosis and to the stigma and discrimination they were experiencing. Other reasons include access to information, finding a sense of belonging, looking for hope and stories of survival, and connecting with other women or men living with HIV.

I met with friends who were open

‘I was shocked to hear that I am positive. I kept silent, without telling anyone at home. I had that denial, but the other day I told my sister that I have this thing. She was not shocked. She told my mother, and my mother took it for granted because there are a lot of people who live with it. Then I was free, but the denial was always with me. I didn’t want to go with people living with HIV/AIDS. The guys know in the community – there were a lot of gossips. Then I met with friends who were open about their HIV status. I have been free since then.’

Male, member of Khululeka, South Africa

Accessing information

‘I have a lot of experience with HIV/AIDS. I found out that I am infected in 2002. I did not know what was going on in my life. I was very sick. I was encouraged to do an HIV test after I got sick. I did not know my status and then I got tested. At that time my life changed. I was very sick, but now I know, because of TAC, I had developed opportunistic infections: it was TB and pneumonia.’

Male, member of TAC, South Africa

Strong leaders

‘I was looking for TAC because I have heard about this man Zackie Achmat, who I would like to see. He is very famous. He is trying to help people get ARVs. I was very interested. I was positive at the time, but I had been looking for TAC when I was HIV negative because I heard of this man and I wanted to see him very, very much. I even went to the library looking for the Treatment Action Campaign. Where is it? Where can I go? There was a lady who, when I disclosed my status, said you cannot sleep in bed: we must go; you must come join TAC. If you reach there, we will meet people who are HIV positive and negative – so you will be free. That’s how I joined TAC. When I saw Zackie Achmat, I was very, very, very glad. I remember when I met him, when I went to the office for the first time, he was there. I did not know he was Zackie Achmat. I saw only this man who said “Hello, welcome to TAC”. When I went out of the office they said that was Zackie Achmat! My day – that day – was very, very, very interesting.’

Male, member of TAC, South Africa
You can speak freely

‘I am involved in the men-only support group called Khululeka. We socialise and learn things about living with the disease called HIV. I’m glad I’m involved because it has uplifted my spirit, and I can express myself about knowing my status. The uniqueness about Khululeka is that it is a male-only support group. You can speak freely about anything under the sun pertaining to men and you don’t have to look over your shoulder to wonder if there are any women.’

Male, member of Khululeka, South Africa

Overcoming discrimination

‘There were situations where people call you names. They treat you very bad. They call you names like lesbian or gay or what-what. But now people are no longer like that. For example, most of my friends are ‘non-HIV’ people. I think the issue of discrimination against another person is because of a lack of information.’

Female, member of ICW, Namibia

Visibility

‘We move around a lot, people see us as and we have T-Shirts with the Khululeka name. People who are interested approach us and ask what we are all about and what we stand for. Then we explain and that’s how people come to join us.’

Male, member of Khululeka, South Africa

Or start your own...?

A passion to help women living with HIV

‘I came to know about ICW as a person living positively. And I should tell you I also started a psycho-social support group in Katutura Windhoek, because I was working for the women’s organisation and I could see the frustration which women were going through. They didn’t have anybody to talk to. I could see it because I underwent the same situation – I did not have anyone to talk to, any friend, any other relative beside my sister and my mother. I am living with HIV and I can see a lot of frustration among people with HIV by just looking at them. So that is how I started the support group here... My passion is to help women who are living with HIV and AIDS.’

Female, member of ICW, Namibia

Mothers to mothers

‘When I was in the clinic, I joined the support group and there were TAC members who used to come to the group. They talked to me about TAC, HIV treatment and people’s rights and the nearest clinics. Most of those people were living with HIV and were encouraging us to join TAC. I joined TAC in 2003. In the support group, I was the first mentor in the organisation encouraging other HIV positive pregnant women. We combined, with other mothers, to form the mothers to mothers group. The difference is that the group is only HIV positive pregnant women. In TAC there are different people, not only HIV-positive people. That’s the difference.’

Female, member of TAC, South Africa
How can communication support people living with HIV and AIDS?

All of the testimonies touched on aspects of communication in relation to living with HIV and participating in a social movement or support group. In describing their experience of learning about their diagnosis, counselling, coping and disclosure, every narrator described a process of talking to someone, listening to someone, and the emotional responses involved.

Specifically in terms of social movements, communication was described as both a means to an end (a way of bringing people together, sharing information, etc) and an end in itself (the formation of the group or movement being perceived as a communication process in itself). The key processes identified include referral and sharing of information about access to services between people; talking and being together as a way of addressing stigma and discrimination (internally as well as in the community); solidarity and a sense of belonging as a source of hope; collective problem-solving and suggestions about living with HIV (such as practical solutions about how to treat opportunistic infections); working together to support other people who are affected by HIV; and working together to prevent the spread of HIV and supporting people who are HIV negative to stay that way.

Just by bringing people together

‘ICW helps people to be able to speak about their status openly, to be able to live their lives positively, with no fear – just by bringing people together. And with ICW, knowing that it’s not only Namibian women, has given me the voice to speak up. It’s given me reason to move on and reach out to other people.’

Female, member of ICW, Namibia

Recruit more people

‘I do a lot of awareness-raising and I encourage people to speak out. I encourage people to speak out because you can get very sick if you carry this burden alone. I do talks at local schools and at functions, youth days and stuff like that, where I tell my life story to people to do the ABCs of HIV/AIDS. I do a lot of work in the community. From a few years ago up until now things have drastically changed. And we need more people like me to make this thing work. Because if you don’t recruit more people and if people are not going to speak up, the virus is going to kill us, and we are not going to get a cure for the virus.’

Male, member of TAC, South Africa

We can’t be open that much when there’s men around

‘Even though we are open to each other in the group, we can’t really be that open, especially when there’s men around. Sometimes, as a woman, maybe I have a problem with my reproductive health, but I can’t really talk about that in a support group. When there are men, it’s a bit embarrassing.’

Female, member of ICW, Namibia
Coming to terms with a positive diagnosis

‘Good! Joining TAC did make a big change in my life. You know, before, I was – like – I am not good enough to do anything because I am HIV positive. But after I went for my first training, there was one lady who really motivated me a lot, always saying to me: “Sylvia, I know you can do that.” And I said to myself, if she says that I can do that, then I can overcome a lot of this. Since then, I am more focused in life and I am more open about my status. I can talk in front of a whole group of people and in that way I think I can help people who are HIV positive, especially married couples.’

Female, member of TAC, South Africa

Talking brings peace

‘I do not know a lot about this movement. All I know is that I am still a member. We haven’t seen the good things yet, but we are hoping that in the near future good things will come. One thing I have learnt is that when we meet it brings peace into my life. When I am at home, sometimes I think of many things which are not good for me, but when we come for support group meetings it relaxes my mind. We talk about our daily problems and it really brings peace to me. Even when I go back home I feel good.’

Female, member of ICW, Namibia

Working with the media

Not all of the testimonies touched on the relationship between social movements and the media. The ones that did focused on the role of media in response to the HIV epidemic generally, as well as specifically on how the media can support social movements. Some of the main issues to emerge included voice and representation, with several of the narrators suggesting that people living with HIV and AIDS should have more opportunities to speak and be heard in the media, particularly through radio. This subject came up in a number of the Khululeka testimonies, as some members of the group were undergoing training with a community radio station (Bush Radio) in preparation for hosting their own one-hour slot.

Narrators indicated that the media has a key role to play in disseminating information and promoting HIV prevention among the general public. In addition, the media (and particularly radio) was seen as a way to connect people and encourage people who may not yet be living positively with their diagnosis to come forward and seek out a local support group. Indeed, as shown above, some of the narrators indicated that it was through information they had heard on the radio or read in leaflets or on posters that they had been able to identify and find a local support group.

Hearing you are not alone

‘Maybe there’s someone who is hiding because of fear. When this person hears someone speaking on the radio this will help the other person to come out and also know that he or she is not alone.’

Female, member of ICW, Namibia
**Speaking freely, being strong**

*Oral testimony*

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**Finding support**

‘You see, in the north there was no support group, there was nothing. You keep your status within yourself. You will not find a person with whom you can share information or ideas about HIV and AIDS. I came here and started staying with one of my friends. We were trying to find the Catholic AIDS Action Support Group, and we went to many different places... I had heard that there’s one near Katutura, and I was just standing and looking around to see whether I could find a pamphlet. I could see no such thing. Then one day I heard on the radio that the office is near the Red Cross Society. The group has brought a lot into my life. It has helped me to accept my situation and also to know that I am a person like other people. I can survive with the virus for a long time, you know.’

Female, member of ICW, Namibia

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**Informing the nation**

‘The media are really trying their best to give information about HIV and AIDS to the nation. But the people themselves, they don’t want to change their lifestyle and the media is trying the best they can.’

Female, member of ICW, Namibia

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**Reaching out to men who aren’t yet free to talk**

‘We had an open-air education [event] once at Nyanga Junction where we were speaking about HIV and AIDS. As an individual, you have to speak your mind about what you feel and what you know; that’s how I came to speak about what was happening within my life. We will have a slot on Bush Radio and have discussions about topics pertaining to HIV and let people know that a men’s support group is here. Through the slot we want to reach out to more men out there who are living with the disease, but who aren’t free yet to talk about it.’

Male, member of Khululeka, South Africa

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**Missing voices**

‘I think at the moment the media is getting stories from other and different sources on HIV and AIDS, but they are missing people living with HIV. They should not go to an NGO and hear what the director is talking about, what they are doing. They should invite people living with HIV. Please come, come to us... The media should take our stories, like what TAC is doing. I think members of TAC are talking to the media, but in Namibia we haven’t got that. There’s information, but a lot of it is in print form, which most people don’t get – they are not readers. There are messages on the radio, but they are being given by people who are not positive, they are negative. So how can you attract a woman who is positive to listen to someone who does not know exactly what it means to live with HIV? They should put on people who are living with HIV – to come and talk on a one-hour slot there, talk about their experience. I think this will also reduce stigma and violence because I am sure if men start hearing women on the radio, talking about their experiences, they will start to understand why they need not be violent against women.’

Female, member of ICW, Namibia
They only cover TAC when they’ve got a march

‘In most cases when TAC is working with the media it would be with an independent TV or radio station. Since there’s a perception that TAC is fighting against government, government media aren’t actually covering TAC that much. They only cover TAC when they’ve got a march, but they do not state the reasons why that march is there. They give out this negative attitude about TAC to our communities. The media could give a more broad explanation about TAC, about its campaigns; explain to civil society actually what TAC is about. When TAC has a campaign, they should not put it that TAC is fighting the government, but put it that TAC is – because we are actually – the people’s voices. Civil society is demanding this – and from government – because it is our right as citizens.’

Female, member of TAC, South Africa

Challenging the government

Many of the testimonies touched on government policies that affect people living with HIV – particularly the South African and Namibian governments’ policies on access to ARVs. Some of the testimonies were more politicised than others, with the narrators emphasising the influence that social movements and groups of people living with HIV and AIDS can have on government policies and practices. There was a sense that the advocacy and visibility of social movements and support groups could also keep government policies ‘real’ – that is, connected to and responding to the realities of people living with HIV and AIDS.

We challenge the government

‘We challenge the government a lot, but many times we don’t get what we really want from the government. It’s like the government are putting us [up against] a brick wall. We really want the government to bring change so that all people can go on, can rely on the government and not just on TAC. I just hope that in the future we can work with the government and the government can provide us with what we really need.’

Female, member of TAC, South Africa

Connecting MPs and communities

‘I am working with a member of parliament in a project called Parliamentarians for Women’s Health that has been funded by the Bill Gates Foundation. This is a consortium of five international organisations in which ICW is a partner. So I am working with the MP on women’s health with a particular focus on my HIV women. We need to educate MPs because when we had our first meeting we could see that they don’t have the knowledge, and we need to educate them about why [they should] focus on positive women. After that, we need to take them to the communities because most of the time they sit in their office, they don’t know the real situation in the communities. We have started already, we had a workshop training for them – and this was [in answer to] a request from them. They know that HIV/AIDS is here but they don’t know the deeper issues.’

Female, member of ICW, Namibia
How are we going to eat treatment when we have no food in our houses?

‘I want [TAC] to demand more jobs and treatment. Some of them ask us: how are we going to eat treatment when we don’t have food in our houses? Because the government is saying if your CD4 count is more than 200 they won’t give us disability grant. The government must stop that. The government must not wait for you until you are below 200 because you might die – and the government knows that.’

Female, member of TAC, South Africa

Linking government policies with clinical practice

‘I know HIV cannot stop at this moment, but it would help if the government gave all people ARVs in the hospitals. I would ask TAC to try to go to the clinics and talk to those in charge. They must support the prevention of mother-to-child transmission. I love to talk to people who are HIV positive. I am on their side. There must be a PMTCT [prevention of mother-to-child transmission] programme at the clinic. The person who is sick must not wait for a long time. There must be a superior clinic for HIV-positive people because there are still people who are denialists. I will be glad if TAC will try to do that, because still people are refusing to go to the clinic for treatment.’

Female, member of TAC, South Africa

Fighting for treatment

‘The minister of health must stop playing with people’s lives. We are all human beings and I want her to do what is right for health. My question is: why do people who are diabetic not have to fight for their treatment? Why do people who have cancer not have to fight for treatment? But people who are HIV positive must fight so hard, and in this process people are dying. Why? I want the president, Thabo Mbeki, to look after his people and see that Manto [the minister of health] is doing a wrong thing.’

Female, member of TAC, South Africa

Leadership and role models

‘We need our leaders to lead in the eradication of stigma and violence and come up with positive messages about HIV and AIDS, not negative messages. They should go to the communities and hold meetings, not rely on the radio only, [but] go into the communities, whatever language is being spoken, and use that language. This is not happening at the moment. And if some of the leaders know that they are living with the virus, they must also come out and say: “I am living with the virus and I am living positively.” People will listen to their leaders and [be open] when they hear their leader say that, because their leader is their role model. Because no leader has come out so they think that none is affected by HIV, but they are affected and they are also living in silence.’

Female, member of ICW, Namibia
Hopes and visions

As the final question in the interviews, the narrators were often asked about their hopes for the future or visions for change. The answers were pragmatic as well as inspiring. They ranged from finding a cure for AIDS, to prevention of HIV transmission, to access to essential treatments and support for all. Some also called for greater inclusion of and respect for people affected by HIV and AIDS, and the end to cultures of silence, stigma and discrimination.

Let us stand up and use what we have

‘I advise everyone to talk about HIV/AIDS, and go for the test in order to know their status. HIV is there. People should wake up and seek help. It doesn’t help to stay indoors because you are HIV positive. TAC has fought for us – now we are having treatment in some of our areas. People, let us stand up and use what we have.’

Female, member of TAC, South Africa

Remaining HIV negative

‘I do encourage those who are still negative to remain negative. The positive must speak out. I told them to be free or else they are going to die. I used to tell them to look at me – how many years now, and I am still living and doing everything like the other people.’

Male, member of Khululeka, South Africa

HIV is here in our community

‘I want the community to know, and to realise, that HIV is not there outside, overseas or in another town but it’s here in our community. I can work through you with the media, and with other organisations to make that message clearer – for the community to get the message and to get the facts.’

Male, member of TAC, South Africa

Helping others

‘I want to work for my community, helping other people so that they do not get sick like me.’

Male, member of TAC, South Africa
To complement the oral testimony collection, Panos also conducted semi-structured interviews with media professionals, organised a focus group discussion with members of the social movements (the participants in the OT workshop) and held meetings with members of the project’s advisory group to review and discuss key concepts and ideas.

Some of the key themes include the relationship between social movements/civil society and the media, accountability, and gaps and needs in the current media response to the HIV epidemic in South Africa. As indicated above, the interviews were designed to add depth and perspective to the main research topics and to illuminate more of the complexities around media, communication, social change, social mobilisation and HIV and AIDS in South Africa.

The findings have been grouped into key thematic areas, including:

- HIV and AIDS as a holistic issue for national development
- Social mobilisation and advocacy on HIV and AIDS in South Africa
- The relationship between the media and social movements in response to HIV in South Africa;
- The role of the media in challenging/supporting social movements.

These findings, combined with the other ideas outlined in this report, will be discussed with all participants, interviewees and other key stakeholders at the roundtable discussion in November 2006.

HIV and AIDS as a holistic issue for national development

One of the key issues that emerged in the interviews as well as in the oral testimonies was that HIV and AIDS are linked with fundamental dimensions of identity and livelihoods – race, gender, ethnicity, culture and employment. HIV is a complex epidemic that highlights the complexity of social relations and individual identities within a fluid and rapidly changing society. South Africa is a unique and striking example of this.

‘One last thought: the multidimensional aspect of people’s lives. I remember interviewing some young TAC members, in January 2001 or 2002 – I was putting together one of these AIDS programmes I had to do every Thursday. I asked them: the New Year’s started, what are your hopes? Had we put behind us some of the questioning of the president? We’ve made some progress...? They answered: yes, things are going to be better this year. I wanted to know why and was ready to head down the route of waiting to hear them affirm my assumptions that this was around treatment becoming available and that the MSF (Médecins sans Frontières) project was working well, and they had access to PMTCT and drugs. And one woman said: “Things are much better for me because I’ve got a job, and last year I didn’t.” It’s about realising what things impact on people’s lives: it’s about unemployment and poverty and we can’t escape that stuff.’

Freelance print journalist, South Africa
HIV and AIDS was also identified as underpinning many of the main bread-and-butter issues affecting people living in South Africa. Some respondents suggested that HIV and AIDS are in fact hampering the social and economic development of individuals and the new democracy in South Africa.

‘The trade union movement is also stretched, there are the bread-and-butter issues, but my view is that you can’t separate the bread-and-butter issues from HIV and AIDS. There is a slogan in the manual which said, “What is the point of fighting and winning the living wage if you will die of AIDS?” That’s really the point. You can fight for wages and save people’s jobs, but if all is going to be undermined by the pandemic then what is the point?’

Trade unionist and People’s World Radio presenter, South Africa

On the other side, some argued that HIV and AIDS are being given too much attention and indeed too many resources, resulting in the neglect of other important areas for local and national development. The amount of government funds spent on HIV and AIDS in comparison with other issues – housing or sanitation, for example – was criticised for inhibiting a more comprehensive response to pressing social inequalities.

‘AIDS is a symptom; it’s not the fundamental problem. So I think resources are being squandered by trying to put out the fires rather than trying to catch the people who start the fire.’

Print journalist, South Africa

Overall, taking into account these differing perspectives, HIV and AIDS were linked by most of the respondents to individual livelihoods and national development more holistically. As indicated in the extracts above, HIV and AIDS were linked to questions of poverty, race, culture, employment and other issues – all of which cover intensely personal as well as public dimensions.

Social mobilisation and advocacy on HIV and AIDS in South Africa

Resoundingly, one of the key areas identified in all interviews concerned the polarised nature of public debate about HIV and AIDS in South Africa. Several reasons were given for this – primarily, the history of struggle in South Africa against apartheid, the strength of civil society and particularly TAC, and the nature of citizenship in the evolving democracy. So strong was the perception of TAC as a force taking issue with the government that it was even referred to by one respondent as the opposition party, with Zackie Achmat (the current leader of TAC) as a backbencher in parliament.

‘TAC is a political organisation against government health policies.’

Male, member of Khululeka, South Africa

The general sense was that this was a bittersweet situation for democracy in South Africa. On the one hand, there was no question that TAC and its effective advocacy had been critical in influencing the government’s policy to roll out ARVs for all in 2003. On the other hand, TAC was also criticised for dominating spaces of public debate on HIV and AIDS issues and potentially overshadowing the views of other civil society organisations and social movements.
All the respondents struggled to identify other HIV social movements in South Africa and kept referring back to TAC in the examples they gave during the interviews. Some respondents suggested that that the strength of TAC may have contributed to the polarisation of the HIV debate in South Africa and had an adverse effect on the diversity of public debate.

‘In this country we have the TAC as the spokesperson for all kinds of AIDS issues and personally I think that’s quite problematic ’cos what you have is this dominant civil society group with a particular agenda and point of view on HIV/AIDS. And I find it doesn’t stimulate any kind of debate that steers away from what their mandate is.’
Freelance radio journalist, South Africa

Polarisation has two sides, and the government emerged as equally responsible for the perceived binary opposition concerning AIDS policies in South Africa. Several respondents questioned the government’s relationship with TAC and other legitimate groups and criticised a lack of government willingness to engage constructively with civil society.

‘There is a perception that the health department chooses to work with the more dodgy civil society organisations. We have a national association of people living with AIDS which is an organisation, a kind of support group organisation for PWAs (people with AIDS) which has a really dodgy background: they have been audited several times and found that they can’t account for money – it’s all government money; it’s taxpayers’ money. But these are the kind of people that governments support for their own political mileage to serve as an opposition force to the TAC.’
Online journalist, South Africa

The result seems to be a semi-paralysis of public debate for three key reasons: the dominance of one civil society actor, persistent opposition between that actor and the government, and a government reluctant to engage with a diversity of activists.

‘But look at the unique situation you have here? We’ve got government and civil society locking horns, knocking heads constantly. There’s not space for them to actually come together.’
Freelance radio journalist, South Africa

**Media and social movements in response to HIV in South Africa**

Several key points emerged from the interviews about the role of the media in response to HIV and AIDS in South Africa in general, and more specifically about the relationship between media and social movements. Beyond disseminating information about HIV, the main role of the media (linked to engagement with social movements) was identified as promoting accountability (of both government and civil society) and amplifying the voices of people most affected by HIV and AIDS. Several respondents discussed the importance for achieving these objectives of new and alternative media (particularly produced by the groups themselves) as well as the mass media.
It was generally felt that the media in South Africa have been effective at disseminating information about HIV and AIDS. People spoke of the mass media as well as alternative media such as community radio as having a critical role in providing information about testing, treatment, health rights and access to health services. Examples given included leaflets and posters produced by civil society such as MSF posters on testing and treatment literacy information published by TAC. Soap operas and the success of 'edutainment' initiatives were also cited as good examples of creative dissemination of information through the media.

‘Soaps are very popular and they do capture the imagination of the South African public, especially the locally produced soaps... HIV and AIDS have to be woven into the drama, and we should seek increasingly to make it become part of everyday African life, what people talk about – and they do talk about the soaps.’
Trade unionist and radio presenter, South Africa

Beyond information-sharing, it also emerged that the media have a key role to play in promoting accountability – of the government as well as other key actors in the HIV and AIDS debate. Several of the media professionals interviewed stressed that civil society organisations and social movements have their own agenda, just like private companies or politicians, and need to be held accountable as well.

This was seen as something that the media are not doing as effectively as they could at the moment, but is a vital element of their role in promoting public debate. For example, while the news stories are written by journalists many of the ‘op-ed’ (opinion and editorial) pieces written about HIV and AIDS are in fact written by NGO staff. ‘Civil society is doing most of the writing,’ observed one of the respondents.

‘One would need to critique what TAC said as much as one would critique government. I think we tended to fall much closer on the side of assisting the activists. I think that at first it was just so obvious to do that because the evidence was very clear, and there wasn’t the same caution and scrutiny of what stories we pursued.’
Freelance print journalist, South Africa

Participants felt that in the lead up to 2003, and the shift in government policy towards providing universal access to treatment, the mass media had taken an advocacy role. The distinction was blurred between reflecting society back to society and trying to change it. Another reason cited for TAC’s effective use of the media in the campaign for access to treatment was that in the battle between the two opponents one side had an obvious ethical advantage.

‘The media was instrumental... in shaming the government on these issues. How much the media did [this] is an area to explore much more. How much was the media reflecting what was said by the activists, and how much was the media advocating? And that’s another study.’
Freelance print journalist, South Africa
Much has been written about TAC being particularly media savvy, and the Panos research supports this. Many of the other studies have focused on the innovative and strategic approach of TAC.\(^\text{26}\) One additional dimension that emerged from our research is how TAC was able to capitalise on specific gaps and needs in the media itself. It was pointed out that TAC uses engaging spokespersons, connects members with journalists, and publishes well researched and accessible information on access to treatment, testimonies for people living with HIV and AIDS, and concise summaries of research on HIV and AIDS. Some respondents suggested that the effectiveness of TAC’s media efforts was due to a combination of strategic and timely initiatives on the part of TAC that were able to fill the gaps and needs experienced by health journalists.

‘TAC was incredibly effective at using the media. The issues were hugely valid, there was no question of that, but I think that the media did swallow the TAC line, and partly because TAC was doing the stuff that the journalists should’ve been doing in terms of the research, understanding the medical journals, getting on top of the science, being able to track things as they developed, understanding the science, international trade rules around pharmaceutical pricing and those sorts of things. Journalists very much took the research that TAC did as gospel, and reproduced it.’

Freelance print journalist, South Africa

The media were also cited as crucial in supporting movements and civil society organisations in their campaigns – both in terms of garnering support from their members and the public, and in terms of broadcasting their campaign objectives to policy and other decision makers. For campaigns as well as for information dissemination, several respondents also identified the need to look to new and alternative media as well as the mass media.

‘Media is an indispensable part of the campaign, but it has to be multimedia, not simply publications.’

Trade unionist and radio presenter, South Africa

‘We need to find novel ways for what we call media... and not only look at the traditional ways of newspapers and magazines or radio.’

Online journalist, South Africa

A key role for the media identified by all participants in supporting social movements was increasing the visibility and amplifying the voices of people living with HIV and AIDS. One of the difficulties expressed by members of the social movements interviewed was that the media tend to distort their words and/or not consult them sufficiently on coverage of policies that affect their lives.

‘If I could say it directly the way I want to say it, then I would be heard the way I want to be heard.’

Male, member of Khululeka, South Africa

\(^{26}\) For example, H Wasserman (2005) ‘Renaissance and Resistance: Using ICTs for Social Change in Africa, African Studies 64:2; S Friedman and S Mottiar (2006), as in footnote 8
TAC and ICW have both been innovative with the use of alternative media. TAC has a quarterly magazine, *Equal Treatment*, which has a distribution of over 40,000 print copies and thousands more online. To produce *Equal Treatment*, TAC has worked with and trained some of its members to become ‘community media practitioners’ who interview people, write stories and contribute to the production of the magazine. The magazine seems to be prepared with the assistance of experienced journalists as well, and several editions have been guest-edited by prominent print journalists. ICW has a bi-monthly newsletter, *ICW News*, with a distribution of over 5,000 and thousands more readers online. Both publications have the dual purpose of providing information and news to their members, as well as collecting and publishing members’ stories, and amplifying the concerns of people living with HIV and AIDS to national and international audiences.

In addition, one respondent also suggested that the media have not adequately explored the topic of social movements in the national response to HIV and AIDS in South Africa.

‘I think the work TAC has done at the level of supporting people, and how it has transformed the lives of individuals who’ve joined TAC, is an area that the media hasn’t really looked at. I think it’s very interesting...as you become involved you become empowered, you have a voice.’

Freelance print journalist, South Africa

**Summary of key findings**

Overall, it seems that much could be done to strengthen the relationship between the media and social movements to support the South African response to HIV and AIDS. In summary, the findings highlighted key gaps and needs in the current relationship that could be addressed to amplify more effectively the voices of people affected by HIV and AIDS and facilitate multi-dimensional accountability. These include the following:

- The media seem to be perpetuating rather than challenging the polarisation of the HIV and AIDS debate between the Department of Health and TAC.

‘I think there is still a very strong sense, if you’re doing health – it’s still that you are either in the TAC camp or in the government camp. There is no sense of, yes, you are just an independent person with a mind of your own, that you are going to form opinions and you are going to report on your beat; that one day you’re going to see the government’s side of the story and tomorrow you’re going to see the TAC perspective, the next day you’re going to see the traditional healer’s perspective... You know you have to pick a side, and I’m not prepared to do that. You walk a tightrope.’

Freelance online journalist, South Africa

- Social movements, politicians and other public actors have capitalised on identified weaknesses within the media in covering HIV and AIDS.

‘The media has fallen short and good luck to any social movement that can exploit that. That’s not to invalidate what they’re saying but to say that the media has abdicated one of its roles, because social movements are making use of the organs that are available.’

Freelance print journalist, South Africa
The media have abdicated their role as a watchdog in promoting multidirectional accountability and acting as a watchdog of civil society as well as of the government.

‘I think it has been the wrong way round, that the media have followed what social movements are saying and have reproduced that to create their stories, and there is nothing wrong about that as the media does reflect what is going on in society. If social movements are creating a stink about something then of course the media should cover that. But the media should cover it and interrogate it; it shouldn’t cover it and take it as is.’
Freelance print journalist, South Africa

Reporting on HIV and AIDS and health is complicated, emotionally draining and not as highly respected as other news beats. This is to do with deadlines, lack of incentives, pressures and hierarchies in the newsrooms that are related with the capacity of health media professionals more generally.

‘I’ve got four different stories to push out in a day and actually I wouldn’t have time to go out and do the kind of stories where I’ve heard this, so I can go and speak to people and find out more. I just really don’t have the capacity and I don’t think journalism in this country does have that kind of capacity... You need guidance, you need direction. Here we just don’t have that.’
Freelance radio journalist, South Africa

‘AIDS fatigue’ is found among readers and audiences (and consumers) as well as among journalists themselves. There seems to be a lack of support and diminishing motivation on the part of individual journalists to cover HIV and AIDS issues – which is especially significant, given the difficult and personal nature of HIV as a subject.

‘There is as much AIDS fatigue within the newsroom as there is within the public.’
Freelance print journalist, South Africa

‘HIV is a difficult thing to report on, in terms of the personal attitudes that go with it. It’s around sex, so it’s unbelievably intimate, loaded with whatever the taboos are.’
Freelance print journalist, South Africa
Bringing the oral testimonies and other research methodologies together, it is clear that HIV social movements force us to consider the role of communication on many different levels.

Coming to terms with HIV and talking about it is extremely challenging at an individual, personal level. This was true for the narrators in the oral testimony project as members of social movements as well as for respondents in the interviews as media professionals or civil society activists. It is also one of the mechanisms by which individuals reflect on their situation and become impassioned and motivated to become involved in a social movement.

At the interpersonal level, talking about HIV and AIDS and connecting with other people play a critical role in the formation of social movements, in providing support for people affected by HIV and AIDS, referring people to appropriate services and addressing stigma, culture, gender relations and other contextual dynamics that are at the core of the epidemic. Talking is also the process whereby one committed and passionate activist shares their enthusiasm with another and potentially sparks the other person's own commitment to a cause.

At the public level, communication is central to the amplification of the voices and concerns of people most affected by HIV and AIDS to policy and other decision makers; it is the process through which social movements and other civil society actors can raise awareness and gain support for their campaigns; it is the mechanism that support spaces for debate; it is the process whereby citizens engage in those spaces for debate (in an individual and collective way); it is the process by which the media frame stories about HIV and AIDS, issues related to these; and it the process of social mobilisation.

These dimensions of communication are fundamental in general to supporting local and national responses to the HIV epidemic. What is particularly unique about social movements is the strength and importance of communication in connecting people in a way that is much deeper than at a rational level – in supporting people, inspiring people, and helping people transform their understanding of a positive diagnosis from a ‘near death to a new life’ experience. Because social movements are usually formed from informal networks of people, communication is arguably more important in sustaining the momentum than in other organisations that can also rely on structures or institutionalised processes to keep the group together.

In synthesising the key findings from the project, several key issues emerge as unique to the South African context. Spanning politics, media environments and the dynamics of civil society, the issues highlight barriers as well as opportunities shaping how communication supports social change in the national response to HIV and AIDS. These include the following:

- **Communication has a vital role in connecting and supporting people living with HIV and AIDS at both the individual and collective levels** Communication connects people diagnosed HIV positive with local support groups and friendly faces; helps individuals become literate and expert in managing their own care and treatment; facilitates the sharing of new ideas and knowledge; and enables people to identify suitable sources of support.

- **Learning about, realising and claiming rights** Although not necessarily linked to the motivation for joining, participation in an HIV social movement seems to raise the awareness of people living with and affected by HIV about their rights. This includes accessing information, participating in democratic spaces for debate about HIV issues (such as marches or invited discussions with members of parliament) and realising rights to access treatment and healthcare.
Small, informal community-based groups have a strong role to play in responding to the immediate needs and concerns of their members. In becoming organised and big, national social movements may lose some direct relevance to the practical needs of the broadening base of their membership. What they gain in national attention and advocacy strength, they may lose in connection with people most affected by HIV and AIDS in different communities.

Advocacy and the increased visibility of people living with HIV and AIDS

By drawing on individual passions and commitment, and then gaining strength through numbers, social movements can stimulate public debate; strengthen the visibility of people living with HIV and AIDS in those public debates; and help to enable people directly affected by HIV to hold their government to account and influence social change in their favour.

Spaces for debate

In South Africa particularly, drawing from the history of struggle and social mobilisation against the apartheid regime, social movements have played an important part in shaping spaces for democratic debate. This has contributed to new spaces and the democratisation of public debate (for example, through public demonstrations or fora where social movements are invited to the same table as members of parliament) but also, paradoxically, to the polarisation of debate or the positioning of civil society in opposition to the government.

Polarisation of the debate

The strength of the civil society response to HIV in South Africa, led by TAC, has contributed to the polarisation of much of the policy debate. Although the strength of the civil society response concerning access to treatment and advocating for improved national policies has put HIV in the public spotlight, it seems that this has not necessarily strengthened the vibrancy and diversity of public debate around these issues.

While South Africa hosts an active and free media environment, several concerns were raised in the research about the role of the media in reporting on HIV and AIDS. The media are not sufficiently fulfilling their role as a watchdog of the government and of civil society. Because of limited capacity, the media have abdicated responsibilities in promoting accountability in the national response to HIV and AIDS. Social movements and the government alike have been able to capitalise on these weaknesses.

Key obstacles for media professionals in the research include: the increasing youth and inexperience of media professionals; a lack of incentives for journalists to cover health issues; hierarchies in the newsroom that do not prioritise health; tight deadlines and pressures to produce; AIDS fatigue in society and in the newsroom; the complex and personal nature of HIV as a subject to report on.

Communication skills and exposure to the media for people living with HIV and AIDS

Often people most affected by HIV and AIDS are underrepresented or misrepresented in the media. The media can be an effective tool in amplifying their voices to policy and other decision makers. Capacity development activities should therefore work with social movements, their members and other people affected by HIV and AIDS to build their confidence and communication skills, and enable them to directly participate in and/or be represented in policy debates on their own terms.

Social change is a complicated process that is vulnerable to manipulation. There are risks involved when particular actors are not held accountable for their actions or opinions – this includes the media, social movements and government alike.
Recommendations

Although Panos is still in the early stages of this research, and South Africa is the first case study project, a few recommendations are emerging. The thinking on these will be contested and deepened through the other phases of the research, and will be debated at the roundtable event in November. Some initial recommendations include:

- Support capacity development with members of HIV social movements and people most affected by HIV and AIDS to help them to communicate clearly, represent themselves effectively, and be represented legitimately, accurately and ethically in the media. This involves gaining skills as interviewees as well as developing interviewing skills so that people most affected by HIV and AIDS can become media professionals at the local and national level.

- Support places for debate that guarantee diverse participation and enable the voices of people most affected by HIV and AIDS to be heard. These can be spaces generated and created by social movements, or others that enable people most affected by HIV to represent themselves and their priorities meaningfully.

- Promote communication and advocacy environments that enable debate, encourage diverse voices and promote multidirectional accountability (for governments, civil society, social movements and other key public actors).

- Promote proactive rather than reactive journalism. Around issues of HIV and social movements, this would include providing incentives and allowing time for journalists to undertake investigative research around key issues, focusing particularly on accessing and amplifying the voices of people most affected.

- Foster and support greater linkages between media professionals and members of HIV social movements.

- Media professionals – including freelance and staff reporters – should be guided in their coverage of HIV and AIDS by ethical guidelines that encourage non-stigmatising, accurate and informative coverage of the key issues.

- Support and promote creative, innovative and multimedia approaches that are participatory and can enable a plurality of voices to be heard in debates about key HIV and AIDS policy decisions.

Ideas for further research and follow-up activities

Learning from the findings of this pilot case study in South Africa, Panos aims to further strengthen the relationship between social movements and the media in their efforts to bring about inclusive social change. Ideas include the following:

- **Generate public debate about these research findings** by facilitating a roundtable discussion about this report. This event could also be used as a catalyst to connect members of social movements with media professionals, and vice versa.

- **Support and strengthen existing spaces for democratic public debate** and create new ones – spaces where diverse voices from all sectors of society (policy makers, government officials, members of different social movements, spokespeople of different social movements, media professionals, people living with HIV and AIDS, etc) can come together to discuss important issues in the national response to HIV and AIDS. This could include the use of physical spaces (for workshops, conferences, regional and world social fora) and virtual spaces (community radio, online sites, email discussion groups).
Facilitate and support learning between social movements at the local, national and international level. At the local level, this could include partnering with different social movements in the workshops and research for the case study projects. At the national and international level, it could involve co-facilitating sessions and sponsoring participation at regional and world social fora.

Facilitate and support learning between health media professionals (journalists and editors) through local, national and regional fora such as the Southern African Editors Forum.

Promote further research into the relationship between media, journalists and democratic spaces for public debate in response to HIV and AIDS.