



IMPACT & INNOVATION SERIES



# Prevention of Mother-to-Child Transmission of HIV (PMTCT) Through a Health Literacy Lens

A Collection of Thoughtful Voices

## Featured Voices

**Kulsoom Ally**, Corporate Social Investment Manager for Africa & the Middle East, Nokia

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**Mitch Besser**, Founder & Medical Director, mothers2mothers

**Brian Brink**, Chief Medical Officer, Anglo American PLC

**Ashraf Coovadia**, Director, Empilweni Clinic Enhancing Childhood HIV Outcomes (ECHO); Head of Paediatric HIV Services, Rahima Moosa Mother and Child Hospital

**Glenda Gray**, Executive Director, Perinatal HIV Research Unit, Chris Hani Baragwanath Hospital, University of the Witwatersrand

**Alice Kang'ethe**, Executive Vice President, Maternal & Child Health, Clinton Health Access Initiative

**Hellen Kotlolo**, Midwife & Nurse, Ashoka Young Champion

**Nyovani Madise**, Professor of Demography & Social Statistics and Associate Dean of Research, Faculty of Social and Human Sciences, University of Southampton

**Elizabeth Mason**, Director, Department of Child and Adolescent Health and Development, World Health Organization

**Peter McDermott**, Managing Director, The Children's Investment Fund Foundation

**Babatunde Osotimehin**, Minister of Health, Nigeria (former) and Executive Director, United Nations Population Fund (UNFPA)

**Jeff Richardson**, Vice President, Abbott Fund

**Tina Sharkey**, Chairman & Global President, BabyCenter

**Joanne Stevens**, Program Manager, Google.org

**Paul Stoffels**, Worldwide Chairman, Pharmaceuticals, Johnson & Johnson

**Yu Wang**, Director, Chinese Center for Disease Control and Prevention

*Compiled and edited by Karuna Luthra, Carolyn Roper, and Claire Topal*

## INTRODUCTION

**A 2010** Pacific Health Summit workshop, "Prevention of Mother-to-Child Transmission of HIV (PMTCT) through a Health Literacy Lens" focused on looking at health literacy challenges to PMTCT and ways to overcome these obstacles. The session examined the challenges from a wide variety of perspectives from a diverse group of high-level stakeholders. Participants hailed from science, industry, policy, academia, and medicine who do not often come together around this theme.

Health literacy was defined as the ability to obtain, understand, and use health information to improve health. The health literacy lens was applied to mothers, practitioners, and policymakers. Participants addressed many questions, including: What are the information needs? What interventions enhance access and uptake of preventive care and treatment? What makes a system health literacy-friendly with regard to PMTCT? What actions can policymakers take to enhance health literacy? How can the private sector help address challenges?

Participants, who have considerable 'on-the-ground' experience in some of the world's most challenging settings, grappled with these questions and identified numerous current and potential innovative partnership opportunities for action to improve health literacy as it pertains to PMTCT.

The Question & Answer format on the following pages presents excerpts from this workshop.

**–Franklin Apfel, Workshop Moderator**

## KEY HEALTH LITERACY CHALLENGES FOR PMTCT

**Q** What are the key challenges and obstacles related to PMTCT? What are the consequences of low health literacy—among the general population and healthcare providers—in this arena?

### Quality of Care, Counseling, and Access to Information

#### Nyovani Madise

Data from UNICEF and the Demographic and Health Service, gathered with help from USAID, indicate that globally only about 50% of men and women are actually aware of ways to prevent mother-to-child transmission of HIV. When pregnant women go to health facilities for antenatal care, few of them are actually counseled about PMTCT. Without counsel, a very small percentage of them then get tested for HIV and AIDS. For example, in Africa, we're looking at an average of 18% of pregnant women who are tested, and if they are not tested, then they clearly do not have access to drugs to prevent mother-to-child transmission.

#### Glenda Gray

In South Africa, the stigma levels are much lower. For most women, if they are offered HIV testing, they take it up. This is especially the case in urban settings, and it has become routine to test for HIV in healthcare clinics. However, the system breaks down when healthcare workers provide tenuous access to AZT (azidothymidine), and do not refer patients to treatment access centers. I think it has a lot to do with educating nurses and health facilities, and holding them responsible for breaking the chain of care.

*“Only if women are treated with respect and support will they be likely to come back for delivery, which is the critical time for preventing HIV transmission.”*

**Brian Brink**, Chief Medical Officer, Anglo American PLC

### Overcoming Stigma

#### Brian Brink

The reason women don't seek PMTCT is not a lack of information or communication—it is fear of stigma and discrimination. The fear of violence at home if their status becomes known and in the community. These are things that have to be tackled.

If we're going to improve uptake at the level of primary healthcare services, women need to be treated with respect and on a timely basis. When I say women, bear in mind that a lot of the people are actually girls—teenagers. They need to be assured that testing and counseling is voluntary and confidential. That if they need treatment, they will get it. That if they decide to disclose their HIV status, they will be supported in doing that. And for those women who test HIV-positive, they have to be given certain things. They need early and supportive information with regard to choices on breast feeding. They need full information about the consequences of the pregnancy on their own health status, and in countries where it's legal, that they will have access to a safe abortion, if that's their wish. Only if women are treated with respect and support will they be likely to come back for delivery, which is the critical time for preventing HIV transmission.

### Personnel Capacity

#### Paul Stoffels

If you look at the data on preventative therapy for mothers and children during pregnancy and breast feeding, it's clear it can be done, but it is not getting done. The first challenge is determining if it's the drugs and products which are failing the people, or are the people failing the drugs? Even where drugs and products are available, people in many settings are not getting treatment.

**Mitch Besser**

When we look at districts in South Africa, 30% of nursing and doctor slots are vacant. Through task shifting, as more roles are passed from doctors to nurses, you find that nurses are being asked to do more, in ways that just aren't sustainable. When you ask a nurse to do one or two tasks, she's going to do them well; but when you ask her to do nine or ten things, she'll eventually do none of them well. It's about giving nurses jobs that they may not understand or can't deliver on because they simply don't have the time.

When you take this to the patient level, patients don't understand what they're being asked to do and ultimately don't do things that contribute to the best health outcomes. The challenge is to try and find ways to get patients to change their behaviors and to do it not just by educating them in facilities, but to also reach into communities and connect with their partners and families. We need to find ways to change perspectives on the HIV infection; to try to reduce stigma and to really bring communities along as a whole. This is part of a holistic approach to PMTCT.



Franklin Apfel, Yu Wang, Nyovani Madise, Peter McDermott (left to right)

**Q How have limited access to PMTCT services acted as barriers between practitioners and rural populations? What challenges do PMTCT services face in rural areas?**

**Increasing Education**

**Yu Wang**

In China we have nearly 70,000 patients who are being treated for HIV; 2.2% of them have contracted HIV through mother-to-child transmission. We can give away anti-virus treatments during a woman's pregnancy, and following the delivery of the child, we can provide the mother and the family with replacement formula and other foods for the newborn. The technology is already clear and efficient, but

we don't know how to make people in rural areas understand the need to go to the hospital to take the tests and find out if they're HIV-positive. I think this is the number one challenge in China.

**Increasing Access**

**Nyovani Madise**

There are clearly rural and urban differentials, with more and more women in rural areas not having access to treatment and drugs, and let us not forget that the poorer populations already have lower levels of access to services...I think that things can be done, like getting women to go to antenatal care clinics earlier, which would give health providers the opportunity to actually counsel and provide HIV testing.

## INTERVENTIONS AND STRATEGIES FOR SUCCESS

**Q** How are challenges specific to resource-poor settings best addressed? What are some interventions that could be made in systems and settings to align individuals' knowledge, skills, and capacities with the complexities and demands of successfully reducing rates of mother-to-child transmission of HIV?

### Leveraging Best Practices

#### Peter McDermott

Ten years ago, Botswana had pediatric infection rates of 40-50%, and by 2009 there were no reported deaths from HIV/AIDS for children in Botswana, and an estimated mother-to-child transmission rate of under 4%. If someone had told us this would be the reality ten years

ago, I don't think anyone would have ever believed it. The very fact that a resource-poor country, no matter how small, is demonstrating what can be done—keeping women alive and improving health services at the antenatal level—shows what is possible. Whether it's the community work that mothers provide to other mothers, the primary prevention of women in women's groups, or whether it is the quality of care, the virtual elimination of transmission is possible.

#### Glenda Gray

I'm with the Perinatal HIV Research Unit in South Africa, and we have been responsible for the rollout of PMTCT in Soweto. By adding more complicated regimens, we've managed to get transmission rates down to about 4% for the 6,000 or so babies we bring back for early testing. We still see one or two cases of HIV infection per week, and we're trying to implement a strategy in Soweto to investigate each outbreak of HIV infection in children.



*“PMTCT is actually about maternal and child survival and I think we probably need to think more broadly about our strategy, how we brand it, and how PMTCT is given the communication message that it deserves... PMTCT is a gateway for opportunities. It doesn't need to create anything new. Many answers already exist, they just need better implementation.”*

**Ashraf Coovadia**, Director, Empilweni Clinic Enhancing Childhood HIV Outcomes (ECHO); Head of Paediatric HIV Services, Rahima Moosa Mother and Child Hospital

**Q** What are some examples of successful community interventions that have increased health literacy among pregnant woman, healthcare providers, and the general population? What are the outcomes of these interventions?

### ICT Solutions

#### Babatunde Osotimehin

One of the interventions we've done recently in Nigeria relates to trying to meet the human resources needs for maternity care. If you look at the geography of Nigeria, you'll find that there are some areas that have dire needs. So we went out and centrally recruited midwives and retired midwives, retraining them to go back out to the rural areas. These places don't have any skilled manpower, so we equipped the midwives with cell phones. We have an IT solution to communicate with them and build their capacity, which allows us to collect and pass on information. This has worked considerably well, and importantly, they feel that they are a part of a community. We've been able to mobilize close to about 2,500 midwives this way.

#### Jeff Richardson

Indiana University and the Ministry of Health in Kenya began a program in Eldoret called "AMPATH," which utilizes community mobilizers and equips them with handheld technologies such as GPS systems, PDAs, and OpenMRS, to go door-to-door in western Kenya. They can reach 2 million people this way, and they're connected with Eldoret's Moi Hospital. They have a 97% welcoming rate into homes, where they educate people about the need for testing. They have a remarkable 91% acceptance rate for HIV testing.

I think part of AMPATH's success is that they're testing for both TB and HIV. They're also handing out malaria bed nets, de-worming medication, and doing nutrition assessments. So they are part of a whole package of services.

### Community Mobilization

#### Mitch Besser

The mothers2mothers program was designed to take HIV-positive mothers who have gone through PMTCT programs and bring them back into health facilities as professional care providers. We've chosen to train these women and then pay them as part of the healthcare team. They fill staffing gaps and work to connect communities with the healthcare facili-

*"Whether it's the community work that mothers provide to other mothers, the primary prevention of women in women's groups, or whether it is the quality of care, the virtual elimination of transmission is possible."*

Peter McDermott, Managing Director, The Children's Investment Fund Foundation

ties. These are women who come from the communities, who have received care in the facilities in which they are working, and then turn around and become care providers. Essentially, former patients educating and caring for current patients.

#### Nyovani Madise

In Malawi, where I come from, there are community interventions that are trying to increase the proportion of women who get counseled and tested. One successful initiative is to counsel both the man and the woman because that actually gives support to the woman to take on services when they are offered, without fear of reprisals in the home.

**Q** How can PMTCT services be integrated with HIV and other healthcare services to improve and strengthen overall healthcare delivery to populations? Could integration improve uptake of PMTCT and reduce transmission rates?

### Integrating Health Services

#### Brian Brink

One overriding message—if we want to improve uptake of PMTCT—is that we're going to have to make health services women-friendly. And if you take nothing else away from what I say, that's probably the most important. A strong reproductive health service foundation is essential for PMTCT to work. The aim should really be to raise the priority of reproductive and child health in the national health plan as a basis for strengthening the health system so that budget and money is specifically allocated to these services. The supply chain and information systems should also contribute to

these kinds of vertical programs that we're talking about, and they will only work well if we get the system strengthened.

**Mitch Besser**

PMTCT is really a gateway to maternal healthcare and, in fact, healthcare more broadly; with the realization that when women come through the door, pregnant and living with HIV, we have an opportunity to engage them in family planning services, get CD4 counts, and make sure eligible mothers start treatment.



**Maternal and Child Survival**

**Hellen Kotlolo**

We need to include OB-GYNs in the conversation and programs. It's not just about the babies or PMTCT—it's about the mother and the baby. Every mother needs to have a healthy baby, and every HIV-negative or healthy baby needs to have a mum that will raise them.

**Simon Wright**

One important issue is minimizing the impact that donors have on government decisions. This is about more than just the advice that donors give, it is about the very principle that donors circumvent governments by actually delivering services outside of the government system. This is the kind of factor that will undermine a government's accountability to its people. In countries where a society knows and is able to assert its entitlements, governments are more likely to come up with systems and schemes that will deliver that entitlement. For example, Sierra Leone has gone through a lot of trouble to communicate to citizens about the new free healthcare policy, and to put in place mechanisms such as free telephone hotlines for reporting health facilities still charging fees. We'll probably see less progress in countries where people are less empowered.

**Ashraf Coovadia**

PMTCT doesn't start and end in the antenatal clinic or in the delivery room. It's much wider than that, and it has the potential for much more. I think that we need to do a lot of communication within the health system as much as we do with the public. The term 'prevention of mother-to-child transmission' could even be a misnomer. It's about child survival as much as it is about maternal survival. So when we talk about PMTCT, we automatically put a lot of people off because they think,

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**Nyovani Madise**, Professor of Demography & Social Statistics and Associate Dean of Research, Faculty of Social and Human Sciences, University of Southampton

‘well, that’s the HIV folks’ job and that’s the HIV specialist’s job.’ But PMTCT is actually about maternal and child survival, and I think we probably need to think more broadly about our strategy, how we brand it, and how PMTCT is given the communication message that it deserves.

## THE ROLE OF INDUSTRY AND PARTNERSHIPS

**Q** How can the business sector apply its marketing and communication expertise to help make critical PMTCT services and information more accessible, understandable, and actionable? How can we use innovative communication approaches, such as mobile phones and other technologies, to enhance PMTCT? In what ways can partners from across different sectors work collaboratively for further reach and impact?

### Utilizing Private Sector Expertise

#### Brian Brink

I am inspired from listening to industry—how they deal with their consumers, how they assess the needs of their target audience, and how they deliver on the needs expressed by those people. And I think a lot of that is missing from our health services.

#### Ashraf Coovadia

One key message for industry and those outside the health system is that PMTCT is a gateway for opportunities. It doesn’t need to create anything new. Many answers already exist, they just need better implementation.

*“What do we, as corporations, do to really engage with the very important public sector and civil society organizations that we will rely upon to be able to deliver the kind of change that we are being asked to create?”*

**Kulsoom Ally**, Corporate Social Investment Manager for Africa & the Middle East, Nokia



#### Tina Sharkey

The engagement has to be broken down to a level where you’re with a woman throughout the journey of her pregnancy and where you ultimately help her educate herself and her family. You have to figure out how you can relate to this person, this woman, and find that moment that matters and motivates her so that she’s engaged in her journey and she knows what’s happening in her body. Then she can come into the clinic and talk to her healthcare worker. She can ask intelligent questions of her doctor or her midwife. We’re looking at this model across the world and trying to personalize it in every single market.

### Information Sharing

#### Kulsoom Ally

Mobile technologies can play a very significant role in the area of health literacy. The problem that we face as a mobile phone company and as a corporation, is in taking action in an area where we do not have subject matter expertise. And this is where we rely upon civil society and the public sector. Unfortunately, our experience in engaging with civil society and the public sector in this area has been quite negative in that we have approached NGOs and public sector bodies and found that there is a sense of not wanting to be seen sharing information through a corporation. We are often told by organizations that they don’t want to act in a way that offers a potential benefit to a corporation, even if this would help people. Understandably, perhaps, there is also some disagreement on the standards of care, or what

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**Elizabeth Mason**, Director, Department of Child and Adolescent Health and Development, World Health Organization

information is authoritative. So the question is: what do we, as corporations, do to really engage with the very important public sector and civil society organizations that we will rely upon to be able to deliver the kind of change that we are being asked to create?

**Joanne Stevens**

Google.org builds technology platforms to provide information to consumers, but we rely on those of you in the room to actually create that information and to make it available with the right licensing so that we can use it for the greater good. I



second the challenge to please take this effort on and to work with us. We'd like to make this content available to people, and we have the technology platforms to do so.

**Jorge Bermudez**

We need more information from the ground—for us it's very important what we have heard today because UNITAID does not operate directly in countries, but through implementing partners. We are funding PMTCT projects in 17 countries through UNICEF and WHO—13 countries in Africa, plus India, China, Haiti, and Myanmar so it's very important for us to receive information and feedback from people close to the action. We have ten partners working with us, implementing in the field on our behalf. We also work with country representatives and ministries of health, as well as coordinators of national programs for malaria, HIV/AIDS, and TB. It's very important for us to really listen to the problems encountered so that we can improve work, while respecting our business model of a small secretariat, low overheads, and rapid disbursement of funds.

**Tina Sharkey**

BabyCenter is the largest global network of new and expecting moms around the world, reaching over 20 million moms a month in 22 countries and in 12 languages. And we do it through very small, very specific, very focused personalized messages. We start by telling an expectant mother that this week her baby can still fit in her hand. Once they smile, then you can tell them they have to get a blood test. You have to find the incentives to motivate people and to engage them. If mobile is the installed base, then you have to use it to find the incentives.

## *The Game-Changing Potential of Partnerships*

### **Elizabeth Mason**

What is it that we can jointly do with industry, with health services, and the public and private sectors to make a quantum change in the way we think? I think Botswana made a quantum change to a situation where women could demand testing because they knew it was their right. The message needs to come out to reduce the levels of stigma.

One approach is to use the media to convey that HIV doesn't have to be a death sentence. That HIV is affecting one-in-three or one-in-four people in many of the most heavily affected countries. How can we, together, make this message known to reduce the level of stigma? And how can we rapidly get the message out to families, mothers, children, nurses, and doctors? How can we get everybody to work together to make a change over the next two years? The resources are actually available, but I think it needs to be a joint effort because one group alone isn't going to be able to meet this challenge.

### **Alice Kang'ethe**

We need to use traditional birth attendants, to mirror the example given earlier about looking at mortality as a business opportunity, as an opportunity to engage women. We have a partner in our program in Lesotho (PIH) that has been very successful in this. Instead of ignoring the traditional birth attendant, they are incentivizing her to bring women to the clinic. It's not necessarily something that is applicable across the board, but recognizing their respected status in



Young women and feeding baby, South Africa

the community and using birth attendants as the entry point to pregnant women in a catchment area is one way forward.

### **Paul Stoffels**

We have to get together in industry—all the partners, and together with government—to do what we can do today, at this moment, with the tools we have. Companies will have to work hard and with each other, as well as together with governments, scientists, and academia, in order to get to products and services to patients worldwide, not just to the West. It's not enough for people to be able to prevent their own kids from getting HIV; those kids need to survive to see their kids grow up. I think until we achieve that, we'll continue to have those discussions on stigma. There has to be a commitment from all of us, and we can't give up before we are at the point of resolution, and I am convinced we'll get there.

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**Paul Stoffels**, Worldwide Chairman, Pharmaceuticals, Johnson & Johnson