

# HATIP

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# HIV and TB in Practice: Progress on IPT roll-out in South Africa

By Theo Smart

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## Implementing isoniazid prophylaxis treatment (IPT) in South Africa

A majority of randomly surveyed South Africa health facilities have started implementing the recent National TB screening and IPT Guidelines according to a cross-sectional study by the US Centers for Disease Control (CDC) and the SA Department of Health presented as a poster at the 5<sup>th</sup> South African AIDS Conference in Durban 7-10 June, 2010.<sup>1</sup>

If the study is indeed representative of the country as a whole, it suggests there's been a dramatic increase in the number of people living with HIV receiving IPT compared to the past. However, policy implementation was markedly uneven – with little to no action at all in some provinces, and concerns about the quality of the service at some sites.

Two other reports at the conference, however focusing on IPT implementation in specific districts or subdistricts, may provide models for the Health Department in how to do IPT right.

### Background

The current guidelines, updated in June last year, recommended TB screening in all people living with HIV. All those with TB symptoms should be referred for TB diagnosis, while everyone else should be given IPT. The guidelines no longer require mandatory chest X-rays or a tuberculin skin test (TST) before starting HIV-positive patients on IPT, and its coadministration with antiretrovirals is longer discouraged.

“There is no excuse for health workers to withhold this inexpensive and effective intervention to prevent TB,” said Minister of Health Aaron Motsoaledi – and the department of health set ambitious targets for the first year of its roll-out (around 450,000 people).

But there has been a longstanding reluctance to scale up IPT among many in the healthcare establishment and some concerns that the health department was rushing to roll out the policy, without adequate preparation – with local authorities left to translate the policy into practice, develop training and operating procedures for staff based upon the guidance. Given these issues, what progress has been made in South Africa since the guidelines change?

To assess how the policy was being put into effect in the country, researchers from the US Centers for Disease Control (CDC) and the SA Department of Health performed a cross-sectional study in 49 randomly selected clinics in South Africa's nine provinces. These included one clinic drawn from the district with the highest antenatal HIV prevalence in each province (except for KZN where two were chosen), public health clinics, community health centre and district hospitals. Teams were trained to interview supervisors of TB and HIV services using standardised questionnaires to assess

clinic policy, service delivery, supply, recording and reporting and barriers to implementation.

As of February 2011, 71.4% of the clinics were implementing IPT – with about 56% of the eligible patients in the sample receiving IPT. Among the clinics not providing IPT, the most commonly offered excuses were that they hadn't had clear guidance or commitment from local authorities on the policy (29%), while about a fifth said they were concerned it would lead to resistance (though a number of studies have shown this is unlikely to occur). There was a high rate of implementation at PHC and district hospitals, but community health centres didn't do as well.

Among the 35 clinics providing IPT, coverage varied markedly by province. Sampled clinics in some provinces reported that they had put more clients on IPT than the total number eligible (all those who had screened negative for active TB). So something was not quite right with these figures. There was little implementation at the sampled clinics in Limpopo or the Eastern Cape, and oddly, no implementation at all in the Western Cape. Likewise, although most clinics had at least some staff who had been trained in HIV/TB, this also varied significantly across the provinces.

Some form of IPT counselling was also being provided by all of the clinics providing IPT in each of the provinces except Limpopo, where only half of them were. However, the quality of the counselling was uneven. The researchers had identified four essential components for IPT counselling including adherence, reporting symptoms, reporting side effects and reducing alcohol intake – but only 17.3% of the IPT dispensing facilities got all these messages into their counselling.

All the facilities providing IPT were recording and reporting IPT data – all but one facility that counselled on IPT also recorded IPT data in their registers.

The researchers recommended continuing efforts to make IPT a priority intervention, especially in the Western Cape, the Eastern Cape and Limpopo, and called on PEPFAR to support the Department of Health's efforts to increase monitoring of IPT. They added that the quality of IPT counselling should also be improved by mentorship at the facility level.

Regardless, these findings suggest that IPT is being scaled up at a much greater pace than before the recent guidelines were released – and although uneven – it represents a good start.

However, as the study's author's noted “while counselling of IPT is common, quality and comprehensive counselling is rare.” This raises the spectre that nurses and patients might not understand the intervention well enough for it to be given safely.

Another issue is that the study said nothing about intensified case finding itself – how widely and routinely TB screening was being performed, and how many active cases were being identified.

Finding and treating active TB cases in people living with HIV is a crucial part of the ICF/IPT strategy to prevent TB spread and acquisition, especially in health facilities. A focus just on the performance of IPT is not only incomplete, but potentially dangerous – continued screening of patients put on IPT is recommended to make certain that cases weren't missed the previous time, and to quickly detect breakthrough cases.

The study also left some other very important questions unasked – most notably, how many of the people being given IPT are adhering to treatment, being retained in care, and completing their course of treatment? Does the programme know? As the example of the IPT programme in Botswana has shown, it's easy enough to start handing out IPT to patients – it is another matter entirely to keep track of what happens to them. Given this well-known experience in

a neighbouring country, why was this assessment mum on the topic?

It would also be useful to have more information on the ways in which performances at health facilities differed – and what factors were associated with success or failure to implement.

While the lack of clear guidance from local authorities might be business as usual for the clinics that aren't scaling up IPT – the CDC study gave little insight on how IPT was being operationalised at the other clinics.

Why are some clinics and districts scaling up so much better than others, and how are they doing it? Is it due to the kinds of support that they are receiving?

As already noted, quality improvement, mentoring, community-based outreach teams and peer-based adherence support were recurring themes at the 5<sup>th</sup> South African AIDS Conference. Along with training and technical support provided by NGOs these measures have improved the quality and reach of health services in a number of now model districts, contributing to the improvement of PPTCT services and helping support nurses to initiate ART.

These methods are now also being employed in the scale up of IPT (as well as the other Three Is for HIV/TB, intensified case finding and TB infection control) – while some districts have benefited considerably from technical expertise of some of the smartest NGOs.

## The staged implementation of IPT in Ugu District Health services

Dr Pria Pundit of Broadreach Healthcare reported on the rapid implementation of IPT and TB infection control across an entire Ugu health district in KwaZulu Natal in a poster presentation.<sup>2</sup>

The Ugu District, on the coast at the southern edge of KZN comprises 78 health facilities, including five hospitals (one of which is a specialised TB hospital), one community health centre, five mobile clinics, and 57 primary health clinics (PHCs) It serves a population of around 757,000 – with an antenatal HIV prevalence of 40.6%. Broadreach Healthcare has been working with district health teams there for the past four years.

When changes to the IPT policy were announced, the NGO and its district health team considered how best to roll out IPT, along with infection control, quickly across the entire district.

After defining the key team responsible for project planning and coordination, implementation, monitoring and reporting, they set a target to put over 15,000 people on IPT in the district by June 2011.

The first step was to develop the IPT implementation tools, resources and training materials, all of which would need to conform to the DOH policies, including the updated IPT policy. These would include:

- Training Package: a training curriculum on IPT implementation, and infection control (IC) measures;
- IEC Materials: Infection Control poster focusing on 5 IC measures (Is there an infection control practitioner at the facility? Good cross ventilation? Is there a cough monitor? Are coughing patients triaged? Is cough etiquette taught?);
- Clinical Management Tools: IPT clinical guidelines, IPT initiation algorithm, IPT screening and decision support tools for nurses and counsellors;
- Data Management – IPT Register;
- Supportive supervision tools: tools for use by healthcare workers providing supportive supervision to health facilities

They chose to roll the programme out in phases – piloting in twelve better performing clinics first, in April 2010. Clinics were chosen that had low patient volumes, low TB defaulter rates and high TB treatment/cure rates. The clinic manager from each of these facilities was trained on IPT implementation, guidelines, tools and resources were distributed to the facilities. They would report and give feedback to the District TB Coordinator on a monthly basis.

Once that experience was under their belt, phase II was launched in October 10, with the roll-out of IPT to 66 health facilities. Two professional nurses from each facility were trained on IPT, materials and tools distributed to the facility, with monthly reporting and feedback.

Phase III, which began in January of this year, consisted of monitoring and supportive supervision, again with monthly reporting and feedback.

### Results

Overall 162 professional nurses were trained on IPT and IC, and three sets of guidelines were distributed to each facility, together with IEC materials.

Between launch in January 2010 and the end of the first quarter of 2011, there had been a steady and marked increase in the numbers of new patients put onto IPT each quarter – with over 2300 enrolled in the last quarter and a total of 5151 patients by the end of March 2011. The district target is expected to be reached in the fourth quarter of this year.

Most of the health facilities (49 as of January this year) were also successfully implementing all five basic IC measures. (That's one approach. Note, during an oral presentation Dr Adams Tongman described how Aurum Institutes is supporting implementation of TBIC at 11 health facilities in South Africa.<sup>3</sup> Aurum developed guidelines, training manuals, a training course on TBIC, and a TBIC assessment tool (TBICAT) that was used for spontaneous audits of the facility. After conducting these audits, which would highlight gaps that needed to be addressed, Aurum provided further training and mentorship leading to marked improvements in the implementation of simple administrative control measures, which are the most important and can be improved without going to great expense.)

Having a multidisciplinary team was helpful in project implementation, concluded the authors, and the District TB Champion (district TB co-ordination) played a core role in co-ordinating activities of the project on the ground. (It is interesting that their project works relies so heavily on the district TB coordinator – in many settings TB officials are not always eager to see IPT scaled up. Also, it is important for HIV programmes to begin to take more responsibility for reducing the burden of TB in people living with HIV.)

Additionally, Pundit and colleagues noted that the training of facility level healthcare workers to implement and monitor the project helped to develop ownership of the programme.

As the project goes forward, there will need to be continuing supportive supervision to make sure that the programme continues to be implemented, that patient outcomes are monitored, and IPT data recording and reporting is strengthened. But Pundit and colleagues suggest that their approach could serve as a model to other districts – and could be adapted across different departments of health programmes.

## Mentors, community linkages and use of data for management to increase implementation of IPT

But their model may have some friendly competition from the TB/HIV Care Association, which reported their remarkable progress in mobilising healthcare providers in Sisonke District, KwaZulu Natal to scale up IPT to people who screen negative for TB, through mentorship and other technical support.<sup>4</sup> Sisonke District is also in the extreme southwest corner of KwaZulu Natal—and another hot spot for HIV and TB.

As described by a poster at the conference, the TB/HIV Care Association's Project Integrate is engaged in supporting the health system there, as well as in the Cape Metro and West Coast districts of the Western Cape. This includes a number of interventions to increase access to HIV, sexually transmitted infections (STI) and TB diagnosis, treatment and care.<sup>5</sup>

These interventions involve community-based HIV counselling and testing (HCT) teams (each with one professional nurse and three lay people) that also offer STI and TB screening and refer people testing positive for HIV or STIs, and TB suspects, to the nearest health facility and track them to make sure they are linked to care. In addition, the project included nurse mentors who strive to improve the quality of care provided by DOH clinic staff, and paid DOTS supporters and community care givers to provide adherence support.

In the years that TB/HIV Care has been there, the districts it supports have reported a substantial increase in the numbers being tested for HIV (in both provinces) and entering into care in KZN, and over the last year, with the Western Cape as well. For instance, between October 2009 and September 2010, the community-based HCT team tested over 40,000 people for HIV and screened them for TB, identifying nearly 2,000 cases of HIV, and 161 TB suspects.

One of the consequences of such testing and screening campaigns is that many of the people who test HIV-positive, screen negative for TB. According to the national guidelines, they should be given IPT to reduce the risk that they might develop active and potentially fatal TB.

But Jennifer McLoughlin, HIV Coordinator at Grey's Hospital, who reported on the project in Sisonke District, said that there have been problems getting people to prescribe IPT because of misconceptions about the risk of it leading to drug resistance or the likelihood of serious toxicity. This is despite the fact that the new policy comes with targets, including a provincial target for KZN to implement IPT and to initiate 120,000 HIV-infected people on IPT. The target in Sisonke district, KwaZulu-Natal — from April 2010 to March 2011 was 12,000 people, which means 3,000 clients need to be initiated each quarter.

Something had to be done in order for the district to get anywhere near reaching these targets.

"The Mentorship Programme was introduced to improve the integration of TB/HIV services — including increasing the implementation of IPT, by identifying and removing the barriers to implementation," said McLoughlin. Each PHC supervisor/mentor was given four to six facilities to supervise.

The programme included formal didactic training on IPT and screening for active TB to ensure that IPT was part of the package of care, for HIV-positive clients. Lay counsellors and professional nurses were mentored to ensure high quality counseling and testing, and staff were trained on how to screen for TB.

"We had to change the mindset that screening of TB wasn't taking a sputum, it was asking a symptomatic screen," said McLoughlin. And of course, at this point, if they screened negative for active TB, they were to be given IPT.

They used an IPT register, that the TB/HIV Care Association had developed, for all clients who were initiated on IPT, who were entered into that register to ensure that clients were followed up to monitor weight, treatment adherence, and address side-effects with TB screening to be conducted monthly. The register was designed to run for 24 months, to see how many of the clients that were initiated onto IPT developed TB after completing 6 months of treatment.

They engaged national, provincial and district programme managers to audit progress. Each clinic was told about its targets and the need to use data for management. They would hold quarterly district meetings where the data was analysed and progress assessed.

"Our focus was to ensure that all HIV-positive clients that were tested in the HCT Campaign, were entered into care," said McLoughlin. "Really, it's an ethical right of a client who is eligible for IPT to be offered IPT at the service."

### Symptom screens to exclude active TB

**The following symptom screen is recommended in WHO's recently released Guidelines on Intensified TB Case Finding and the Provision of Isoniazid Preventive Therapy (available in pdf form [here](#)), and based on an exhaustive review of the available clinical data.**

**Adults and adolescents living with HIV should be screened for TB with a clinical algorithm and those who do not report any one of the symptoms of: current cough, fever, weight loss or night sweats are unlikely to have active TB and should be offered IPT.**

**Those who do have symptoms should receive or be effectively linked to further diagnostic services. No screen is 100% full proof because TB just starting to become active may have yet to produce noticeable symptoms so individuals placed on IPT should be screened for active TB at each monthly visit.**

**Contraindications for IPT include: active hepatitis (acute or chronic), regular and heavy alcohol consumption, and symptoms of peripheral neuropathy. Past history of TB and current pregnancy should not be contraindications for starting IPT.**

Only a year after the mentorship programme had begun, there had already been a turnaround in the provision of IPT.

The initial target was to get at least 25% of those testing HIV-positive onto IPT (~3000 per quarter for Sisonke District). Only 19% of the target had been met before the intervention (April to June 2010) — this increased steadily to 81% of the target by Jan-March 2011.

The data on treatment completion are among the best ever reported in a programmatic setting: ~98% of people on IPT completed six months of treatment, with only two per cent interrupting treatment. About 1 per cent developed TB despite IPT.

However, McLoughlin said stock-outs had delayed the completion of treatment for some individuals.

With the exception of supply issues, these outcomes compare quite favourably to other settings where IPT programmes have been plagued by drop outs and losses to follow-up.

McCloughlin attributes the good outcomes to several lessons the programme had learned

- Each nurse mentor became the champion for the implementation of IPT in the sub-districts of Sisonke.
- We established the Wellness Clinics to initiate pre-ART clients on IPT, and then monthly monitoring for weight, encouraging adherence, addressing side-effects and screening for active TB
- Adherence was monitored using a diary system and clients were recalled if they did not show up to appointments.
- The community health facilitators are the link between the facility and the community, and they played a vital role in ensuring that when a client was put onto IPT they were linked with a community caregiver. This played a huge role in promoting adherence.
- A strong collaboration between HIV and TB programmes is necessary.
- Use the IPT register to summarise 1) clients started, 2) completion of six months of IPT and 3) clients developed TB on or after IPT.
- Use of data to forecast drug supplies –we really did use data to try and ensure we had a sustainable drug supply and
- Use of the data for management, with data analysed every quarter.

There are a number of ongoing challenges to the successful scale-up of IPT, including making sure they can keep an adequate and sustainable drug supply, according to McLoughlin. One issue is confusion around the strength of the tablets, which she said seems to change from 100 mg to 300 mg tablets. Keeping on top of changes in the policy, addressing the persistent fears about risk of resistance to isoniazid and alleviating fears about toxicities all continue to be challenges.

Finally, it will probably always be “difficult to motivate clients to come monthly when they feel well,” she said.

Planning ahead, she said that the Department of Health would need to standardise an IPT register for all districts and to ensure sustainable drug supply of isoniazid 300 mg tablets.

“We have to hold clinicians and facility managers accountable for reaching targets. We have to be accountable – is it ethical when you’ve got an intervention that works, not to be offering it to patients?”

#### **Preparation, training and support are essential for successful IPT implementation**

That being said, healthcare staff also clearly need to be given adequate support to provide these interventions well. It isn’t enough to say ‘just do it’ and then leave local programmes to their own devices. Some just won’t do it or won’t do it well, while the others will invest valuable time and resources setting up a programme, but in doing so, be reinventing the wheel and duplicating efforts to develop training, tools, registers and educational materials.

The Department of Health needs to do more than simply standardise IPT registers – it needs to determine out who is doing the best job of implementing the intervention – and then take the best model or put together one based on the best bits of the best models and promote it country-wide, provided that model can be scaled up affordably. One issue that was not addressed in these studies was how much was spent on developing and implementing these model programmes, which may be another reason some of

the local authorities have yet to provide clinics with clear guidance about what to do – they simply don’t have adequate resources at hand to develop and support the programme.

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## What will it take to put millions more South Africans onto antiretroviral therapy?

By Theo Smart

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“The rapid expansion of antiretroviral therapy (ART) programmes within a limited budget will require innovative and cost-effective approaches to service delivery,” Professor Yunus Moosa of the University of KwaZulu Natal said during his plenary presentation on the last day of the 5<sup>th</sup> South African AIDS Conference. Some of the innovations that could help South Africa meet its massive need for treatment that were discussed over the course of the conference included making better use of the private sector, task shifting, decentralisation of services to primary health clinics, improving service quality (and efficiency), and making health services more user-friendly for the patient on life-long chronic care.

After a slow start, South Africa has within a fairly short time launched the largest ART programme in the world, putting over 1.4 million people onto treatment, 400,000 of whom initiated within the

last year. This is remarkable but the programme must continue to grow. It has not yet reached its targets for getting all of those who currently qualify for ART onto treatment – and will need to almost double that number by the end of 2012. If the country follows WHO's 2010 ART guidelines and increased the CD4 cell count threshold for initiating ART to 350, the number qualifying for treatment would immediately jump significantly. One can expect most of those people to thrive and continue on care, while most of the remaining South Africans currently infected will also eventually be in line for treatment.

How can the system manage, when there are already some indications there may be a decrease in quality of care and retention in care as patient volume on ART in some facilities has increased. How will South Africa deliver ART to so many in need?

To come up with potential solutions, it may help to identify and better understand the obstacles that limit the successful delivery and scale-up of ART services. Prof. Moosa described a number of patient-related, programmatic and provider-related challenges to expanding care.

### Patient-related barriers to the delivery of care

A number of patient-related factors can serve as obstacles to HIV testing and counselling, such as making referrals, ensuring strict adherence to medication and retention in care. For instance, delivery of care for HIV may be complicated simply by the age at which the disease affects most people – during the prime of their lives. Good health seeking behaviour is less likely during a stage of life when people may still be emotionally immature, with a “reckless, indomitable attitude to life leading to an immortality complex. Death is not something they want to discuss or think about,” said Prof. Moosa.

Likewise, he noted that poor social and financial support complicates the lives of many HIV-positive people. When dealing with basic survival issues, such as the need to keep a roof over one's head or to feed one's children, the need to deal with one's HIV may seem quite remote. When managing so many competing priorities and other crises, making clinic appointments and staying on treatment can get put on the back burner.

It doesn't help matters when clinical services are not easily accessible or user-friendly for the people who need them. Patients often risk losing their jobs because they time wasted sitting in queues at clinics waiting for medication.

“The stuff we want as healthcare workers is not what the patient wants,” said Professor Francois Venter. “They want appointments and they want clinic hours when they don't have to be at work. It's good to say we have this patient-centered approach but we'll only do it from 8 am to 4 pm during the weekday - it's not patient-centred! That's healthcare worker centred.”

The topic of *how* patients want their healthcare delivered was addressed by a number of speakers as well as a dedicated session at the conference. Prof. Moosa stressed that the programme has to design services “for the lifelong delivery of care [which means it has to] seamlessly integrate into the routine of life. It's critical to ensure each visit is a positive experience,” he said.

Much was made of evidence several years ago showing treatment adherence was better in Africa than in industrialised countries. Indeed this was important because it soundly refuted the racist constructs of those who said that ART would never work in Africa. Nevertheless, there is evidence showing that adherence declines over time in a resource-limited setting, so programmes

need to consider ways to make adherence simpler, such as the use of aids like pill-boxes.

Without adequate support, adherence may be complicated by the not-uncommon changes in the packaging, strength or appearance of tablets as the programme switches to drugs supplied by different generic pharmaceutical companies. Packaging can also enhance adherence (co-packaging) and delivery. The switch to using fixed dose combinations (especially once a day) should also make adherence somewhat easier.

But stigma topped Prof. Moosa's list of patient-level barriers to care. Social stigma against HIV has a number of sources, and affects access at all levels. People living with HIV are stigmatised due to often irrational fears about how they might spread the infection. They are also stigmatised because HIV is associated with already stigmatised at-risk populations, including men who have sex with men, people who use drugs and sex workers, and linked with sexual promiscuity. Prejudice and moral judgements about how HIV is acquired dehumanise people as less deserving of compassion or care, and it is important to note that stigma is also usually internalised, leading to, or worsening, already existing feelings of depression and low self-worth.

Regardless of the source, stigma seriously affects health-seeking behaviour and particularly obstructs the main entry point into care – HIV counselling and testing (HCT). It may also be part of why many people do not achieve an effective referral after testing positive.

Social stigma often seriously impacts on the support structure available to someone who tests positive. It also causes the person with HIV to fear loss of their existing social support structures.

These fears are not entirely unfounded, as there are people who act out on social stigma with violence. Women are particularly threatened by violence. Given such fear, it is easy to see how stigma could lead to poor adherence to ART and to medication for prevention of parent to child transmission, when people fear that pill taking will arouse suspicion.

To help reduce HIV-related stigma, Prof. Moosa said that HIV needs to be demystified “to be as matter of fact as possible. Health care workers need to be part of the solution and not part of the problem when it comes to stigma. Education is the only way to deal with stigma.”

That may be part of the solution to addressing stigma due to ignorance about the risk of transmission. But it won't address the moral judgments, stigma, prejudice and violence directed against the vulnerable or marginalised populations in Africa.

“Between 2001 and 2011, the political environment in South Africa has vastly improved leading to the availability of ART, PMTCT and children on treatment. But the social environment, with stigma and violence among young people, has remained the same ... or has it worsened?” said Mark Heywood of Section 27, giving the second part of the Nkosi Johnson Memorial Lecture. He cited the case of Noxolo Nogwaza, a young lesbian who was murdered on April 24, 2011, “one of many,” he said.

Heywood believes the cycle of violence and vulnerability can only be broken by demanding that everyone be given his or her basic human right to a decent education, including adult education. But it will take time to implement and years to produce those outcomes.

In the meantime, the effects of stigma and discrimination can still be tackled – for instance through laws protecting people living with HIV, together with practical means for reporting and human rights violations.

In addition, alternatives to the family and community support that may be lost for people who test positive are needed. Consequently, a number of NGOs and programmes are recognising

the need to foster the development of peer supporters and caregivers to reduce the vulnerability of people living with HIV, help them make effective linkages to care and navigate the health system, bolster adherence, and eventually contribute more to their own management for life-long ART.

### Programmatic factors affecting ART delivery

The dramatic increase in uptake in HCT is a major step forward, but it matters little if those people never make it onto ART. Programmatic barriers appear to contribute to substantial losses to follow up in the linkage between HCT and ART programmes – resulting in a failure to initiate timely ART. Prof. Moosa cited a paper last year in AIDS that examined factors related to commencement of ART within the first year of a new diagnosis of HIV in an outpatient setting among ART-eligible patients.<sup>1</sup> Out of 1474 people who tested positive, 462 (31%) never made the linkage to the ART programme to get their CD4 cell counts measured. At least 583 (53%) of those who did complete the referral had CD4 cell counts below 200. Of these, 62% did not initiate ART within twelve months although they qualified for it. Among ART-eligible subjects, there were 108 known deaths; 82% occurred before ART initiation or with unknown ART initiation status.

Males or anyone without an HIV-positive friend or family member were significantly less likely to initiate ART within the year (knowing someone living with HIV facilitates disclosure and increases social support).<sup>2</sup>

The same team looked at factors associated with pre-treatment losses to care and loss to follow-up, which they defined as failure to get a CD4 cell test within 8 weeks of diagnosis, which occurred with nearly half the subjects testing HIV-positive and referred to care at the sites in Durban. The study found that people were significantly more likely to be lost to care if they lived ten or more kilometres from the testing centre, had a history of tuberculosis treatment or were referred for testing by a health care provider rather than self-referred. Of course, given the high cost of transportation to the clinic, financial constraints could be part of the reason the distance from the clinic mattered. Likewise, clinic hours may lead to greater losses among working men, who can't afford the time off work.

The need for peer-based tracking systems to ensure that people complete their follow-up to the ART site, get timely CD4 cell counts and commence treatment, was emphasised by several speakers. Clinic services also need to become more user-friendly.

Another programmatic challenge that will clearly have an impact on patient load and other factors is the question of when to start treatment. Virtually everyone agrees that it would be better for a person living with HIV to start before their CD4 cell count falls to 200. Increasing the CD4 threshold for initiating treatment to 350 would reduce the risk of opportunistic diseases, death, serious non-AIDS events, immune reconstitution inflammatory syndrome (IRIS), the chances of achieving a normal CD4 count, drug related toxicities.

Furthermore the recent results of the HPTN 052 study have confirmed that antiretroviral therapy clearly reduces the risk of HIV transmission in couples where the HIV-positive partner is receiving treatment.

But regardless of the guidelines, people in South Africa have only been coming in for care when their CD4 cells are below 100, according to Moosa. However, this is likely to change with more people getting tested for HIV before they start falling ill.

"Current data is compelling enough to revisit the debate on when to start treatment in South Africa," said Prof. Moosa, "though the

sickest must be prioritised." At the same time, it is logical that the one way to reduce the pool of the ill (who consume far more health system resources) is to prevent the well from becoming sick. It may be in the national interest to target particular groups intensively, such as nurses and teachers, for early commencement of ART.

But even without increasing the CD4 cell threshold, the number of patients in need of treatment will increase – and the current doctor-based model will not be able to meet the increasing demand for care.

An alternative in resource-limited settings, Prof. Moosa noted, is the public health approach. This strategy to scaling up access was promoted by WHO's 3x5 initiative, and has even allowed the poorest of countries, such as Malawi, to rapidly scale up ART. The approach relies on the use of simple standardised regimens, decentralised service delivery and the delivery of care by non-specialist healthcare workers, including medical officers, nurses (the most practical and widely implemented in resource-constrained countries) and community workers.

Nurse-led models of care have been shown to be effective in the management of other chronic diseases, such as hypertension.<sup>3</sup> Prof. Moosa also cited the CIPRA-SA study, concued by Ian Sanne and colleagues. CIPRA-SA was a prospective, non-blinded, non-inferiority randomised controlled study comparing doctor-managed versus nurse-managed ART.<sup>4</sup> Care was either provided by two experienced primary health-care nurses vs. two doctors. Both groups had little or no experience with ART at the beginning of the study, but each group received similar structured didactic and clinical training.

"The study found that nurses are as effective and efficient at providing ART, with regards to early virologic failure; late virologic failure, toxicity management, and loss to follow up," said Prof. Moosa. (Similar findings were presented from the STRETCH study this year at the conference and are described in a separate article in this edition). "Note however, that both doctors and nurses received protocol-specific training, lectures on clinical management and ongoing telephonic clinical support. To duplicate these results you need to duplicate [the level of ] training and clinical support."

With larger facilities at capacity, there is a need to decentralise care, and shift more of the workload to primary healthcare clinics, and step-down facilities.

A recent retrospective cohort analysis study from the team at Kheth'Impilo, compared routine adult ART in three tiers of health care sites, primary, district and regional hospitals in four provinces from 2004-2007, with seven per cent of the subjects on ART. Analysis of baseline characteristics showed that primary health care facilities were seeing patients that are sicker than at higher levels of care. Despite seeing a sicker population the primary healthcare sites consistently out-performed higher levels of care, with regards to better retention in care, and fewer losses to follow-up. Mortality was similar to that seen in regional hospitals but better than district hospitals, with comparable rates of virological suppression.<sup>5</sup>

Since it was not a prospective randomised study, differences in outcome could have been specific to these facilities. Nevertheless, the data seem reassuring that "ART can be *adequately* provided at PHC level," according to Prof. Moosa.

### Improving diagnostics and monitoring

Also required for the continued expansion of ART programmes is the maintenance of an uninterrupted chain of drug supply as well as good laboratory service delivery (between the clinic and the reference laboratory and visa versa). Notably there are a number of



point of care (POC) tests becoming available to some facilities that might reduce turn around time, including the CD4 cell tests, the GeneXpert TB test, and tests for haemoglobin, ALT, creatinine, and lactate.

Point of care testing could have the potential to speed up the interval between presentation at the health facility and diagnosis, reducing the risk that patients will be lost to follow-up, suffer delayed treatment or treated inappropriately.

Dr Lesley Scott, of the National Laboratory Service (NLS) described some potential challenges introducing on site, nurse-operated venepuncture for POC testing.<sup>6</sup> The NLS developed standard operating procedures, quick reference charts, provided training and monitored outcomes. On the positive side, the nurses did a good job, with lab results that were consistent with the NLS on the same specimens. The big problem is that there's no easy way to link all these devices with the central database (the Laboratory Information System). They all use non-standard protocol communications; each device requires different proprietary software and data management systems to interface with the LIS systems, and some of the devices don't support bi-directional communications. To list but a few of the problems. The net effect is that this creates much more work than it should.

So NLS has initiated a collaborative effort to investigate options, ideally trying to find something that could operate as a universal interface program, and data management system for all the POCs. Dr Scott said they still need to perform a randomized controlled study to make certain this will work in more remote settings, whether it improves patient outcomes, is safe and cost-effective.

It isn't absolutely clear that it will be. For instance, the introduction of a BD FACScount, which produces a CD4 cell count result in about 40 minutes, did not turn out to have quite the impact desired according to when it was first piloted at the Themba Lethu Clinic in Johannesburg, according to a retrospective analysis presented at the conference by Buyiswa Ndidongo, a health economics researcher at the Wits Health Consortium.<sup>7</sup> She evaluated whether people newly diagnosed with HIV who were known to have been offered a POC CD4 cell test that provided results while they waited, started ART any sooner than either an historic control and a control group of other patients who were not offered the test.

They did, but not profoundly. The group offered POC initiated ART 32.2 days after HCT, 9.8 days sooner on average than the historical control ( $p = 0.003$  (95% CI 3.49, 16.11) (and no differences between historical and concurrent controls). 54% of those offered POC who were initiated onto ART within 16 weeks, 8-16% higher compared to comparison groups,  $p < 0.05$ . "This reached statistical significance," said Ndidongo, "but the effect was only modest."

Notably, "a large proportion of walk-in HCT patients have low CD4 counts, below 250, on the day they completed HIV testing," she added, 63-71% of those who had their CD4 cell counts measured (depending on group).

One theoretical benefit of POC testing is that it could reduce the number of clinic visits required. But the expectation had been that offering POC CD4 would lead to a lot of participants starting treatment almost right away, and that people wouldn't be lost between the time they had blood drawn for CD4 cell counts and the next clinic visit. What no one had counted on was that a lot of people simply didn't seem to be ready for this step — 39% rejected the offer of POC CD4 — which is perhaps not so dissimilar to the number of people who wouldn't come back for their CD4 cell results. These people clearly need a different type of intervention.

Another potential challenge to optimising the programme is "the flow of information from the coal face to the centre," said Prof. Moosa. "Data is a powerful tool to rapidly improve care. It allows staff to measure their performance against national benchmarks and nearby clinics." Data analysis can reveal the reasons for poor practice, and lead to the detection and dissemination of best practices.

Some of the quality improvement efforts in the country have initially been stymied by the lack of good quality data. According to Dr Wendy Dhlomo-Mphatswe of the 20,000plus Partnership, a quality improvement process was targeted at each step of the PPTCT cascade, in order to reduce PPTCT in KwaZulu Natal to below 5%.<sup>8</sup> "This would require data for each step to map the processes of PMTCT care and track progress with data," she said. The data feedback loop would be complete when the local staff began to put their local data to use in monitoring their own progress. But an initial data audit found problems. "We needed targeted data improvement initiatives first!" she said.

### Care provider factors

A number of care provider factors such as knowledge and its application are obstacles to the successful delivery of ART. Prof. Moosa said that HIV should be seen as the silent killer. "Every patient is infected with HIV until proven otherwise, just like every patient has hypertension until he has his blood pressure checked," he said.

People are going to be living with HIV into old age, added Prof. Moosa, with risk factors of non-AIDS conditions in multiple organ systems. He said that it will be critical not to create a health system within a health system to manage these conditions but to rather integrate the HIV programme with mainstream medical care where these conditions are routinely managed.

However, all the specialists and other healthcare workers will need to have adequate knowledge about HIV. "No practicing healthcare workers (phlebotomist to psychiatrist) should be allowed to practice without some basic knowledge of HIV," said Prof. Moosa. It is important to put processes into place to ensure that health care workers have adequate knowledge, and that they know how to apply that knowledge. Prof. Moosa cited a study which reported that although 95% of doctors were aware of the recommendations for managing their patients with cardiac disease, only 50% of their patients were at treatment goals for those risks. Quality of care must be monitored. Prof. Moosa added that care providers should have current maps and contact details of all up and down-referral centres.

Ultimately, as suggested earlier, ART will need to be provided for life using a chronic care delivery model. Ideally, the patient should be an active participant in their own care, adequately trained to manage their illness, with the assistance of family/peer/community support systems, while the healthcare providers need to be prepared and adequately supported by protocols, data, and the appropriately designed clinic system.

### Conclusion

Prof. Moosa reiterated that the key obstacles to moving millions more South Africans living with HIV onto ART in the coming years will be the burgeoning patient load that will become unmanageable for doctor-based services, as long as primary health clinics are underutilised. Rapid scale-up can only be achieved if treatment is initiated at the primary health care level using less specialised but well-trained staff.

“The ongoing challenges faced in the struggle to scale up high-quality ART are formidable,” said Prof. Moosa. “This is a fight we have to fight. Failure is not an option. If we fail, it should not be from lack of trying. It will be a delicately balanced burden but if everyone pulls their weight we will overcome.”

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# Access to HIV services can be increased by task shifting — but only with support and encouragement

By Theo Smart

Several studies presented at the 5th South African AIDS Conference provided reassuring evidence that many health services, including the initiation and management of antiretroviral therapy (ART), can be safely provided by well-trained nurses, while other tasks such as HIV counselling and testing (HCT), patient tracking and adherence support can be shifted to adequately prepared lay staff — all without a loss in quality of care.

However, these and other presentations also reported that task shifting is not the quick and easy solution to sub-Saharan Africa's human resources for health crisis that many had hoped. Poorly executed and supported task shifting could put stress on both non-physician healthcare workers and the health system, while lack of confidence, poor integration into the local health services and other obstacles can keep newly tasked health staff from realising their full potential.

This doesn't mean that task shifting won't work — but effective task shifting could require careful planning, training with appropriate guidelines for referral of difficult cases and, above all, support. However, with close monitoring and evaluation — possibly linked with a quality improvement process to identify and address barriers that keep staff from practising their new skills — as well as ongoing supervision, coaching or mentoring, task shifting could

result in a truly significant expansion of the delivery and coverage of high-quality HIV services.

## STRETCH-ing to support the nurse-initiation and management of antiretroviral therapy (NIMART)

People living with HIV at sites where nurses initiated and managed ART do just as well as those who start treatment at clinics where only doctors can prescribe ART, according to presentations of the STRETCH (Streamlining Tasks and Roles to Expand Treatment and Care for HIV) study, which evaluated the effect of task shifting ART prescribing to nurse-led clinics in the Free State.

In fact, “viral load responses were equivalent, and there were some indications of more benefit at nurse-led clinics, including better weight gain, and higher rates of TB case detection,” according to Lara Fairall of the Knowledge Translation Unit, University of Cape Town Lung Institute, who gave an oral presentation of the STRETCH study results.<sup>1</sup> However, she also reported that uptake of ART was not significantly better at the nurse-led clinics, contrary to expectations, though it should be pointed out that access to ART improved across the board in the Free State by the end of the study period.

## Background on shifting ART management to non-physicians

There is clear evidence of what happens whenever the number of HIV-positive people who need ART outstrips the health system's will or capacity to deliver it. Fairall began her talk by describing some of the previous experiences in the Free State's ART programme in 2004 to 2005.<sup>2</sup> Over a period of 18 months 14,627 people enrolled in the programme, 48% of whom were eligible for ART. Unfortunately, only 25% received it. Follow-up data were available for 4570 of the programme participants for more than one year. More than half of these individuals (53%) died, 87% before ART could be initiated. Among those with CD4 counts below 200, who did not receive ART, the hazard ratio (HR) for survival was only 0.14 (95% confidence interval [CI] 0.11-0.18).

One of the factors limiting access to ART was that only doctors could initiate patients on ART. However, in 2008, task shifting was recommended to expand access to ART by both WHO (see WHO document [Task Shifting: Global Recommendations and Guidelines](#)), and the South African National AIDS Council (SANAC). (See Technical Task Team (TTT) on Treatment, Care and Support document *Building the Capacity of the Primary Health Care System for HIV/AIDS care and treatment in South Africa: Task Shifting Recommendations Document*. September 2008).

Fairall reviewed the published literature describing the increasing evidence that task shifting may help expand access to ART. For instance, task shifting ART care to nurses has been increasingly used and described in Botswana<sup>3</sup>, Lesotho<sup>4</sup>, Rwanda, South Africa (Lusikisiki)<sup>5</sup>, Zambia<sup>6</sup>, and Uganda<sup>7</sup>.

But there have only been a few comparative studies. One from Mozambique, was presented by Dr Kenneth Gimbel-Sherr of the University of Washington and Health Alliance International at AIDS 2008 in Mexico City and [previously described in HATIP](#). This non-randomised study reported similar outcomes whether ART was initiated by non-physician clinicians at international NGO-supported clinics or at clinics where doctors initiated patients on ART.<sup>8,9</sup> Dr Gimbel-Sherr concluded that the care provided by the non-physician clinicians seemed “equivalent to or slightly better than that provided by MDs,” but he added that “results from large centralised sites

with more supervision may not apply to smaller remote sites with less supervision.”

A similar study reported that clinic attendance and patient experience were better with nurse-led antiretroviral treatment based in primary healthcare facilities than with hospital care – with similar health-related outcomes at 15 nurse-led clinics compared to 14 hospitals in Swaziland.<sup>10</sup>

Only a few of the reports on task shifting of ART management have come from randomised controlled trials. One was the study from Jinja, Uganda that reported similar rates of virological failure whether follow-up was provided by community-based health workers (home-based carers) or clinics.<sup>11</sup> The second reported similar outcomes in South African patients whether follow-up was provided at two nurse-led clinics or clinics where doctors managed ART (see description in *What will it take to put millions more on ART?*).<sup>12</sup>

Neither of these studies looked at non-physician *initiation* of ART (NIMART). The STRETCH study is really the first rigorous evaluation of NIMART – and one that evaluated its introduction within the constraints of routine public sector health care.

## Learning to STRETCH

Fairall and her colleagues have long been working to increase the ability of nurses in the Free State to manage serious conditions, such as tuberculosis, through the Practical Approach to Lung Health and HIV/AIDS in South Africa (PALSA PLUS) model. Indeed, the nurses at the primary healthcare level were already managing people living with HIV including many who had already been initiated on ART by doctors – however, whenever someone qualified for ART, or needed to have prescriptions renewed, they had to be referred by the nurses to doctors at ART treatment sites. The case for introducing NIMART seemed obvious: if nurses could re-prescribe and prescribe ART, it ought to reduce the number of clinic visits the patient has to make, reduce the likelihood of loss to follow-up during the referral process and thus increase access to ART.

So the PALSA PLUS model was adapted to introduce nurse initiation of ART – with guidelines, materials (the STRETCH toolkit) and training tailored specifically to the nurses, with clear clinical criteria for referral of complex cases to doctors. A ‘change facilitator’ – the STRETCH provincial co-ordinator – would oversee the training and mentoring programme, which involved trainers, experienced fellow nurses, doctors and district ART co-ordinators – as well as a participatory action approach with local facility management teams for the reorganisation of care to enable nurses to prescribe ART at the primary care facility. STRETCH was implemented in three phases, first with training on the guidelines, then scaling up nurse re-prescription, and finally, nurse initiation of ART.

## The STRETCH trial and evaluations

STRETCH was evaluated through a pragmatic randomised controlled trial of 31 clinics, sixteen where STRETCH would be introduced, fifteen controls where it would not be. Several evaluations were performed using the data from these sites. One would look at the effects of NIMART on ART access and on quality of ART care, and on “waiting list mortality”. Two poster presentations also described an evaluation to see whether the integration of elements of ART care into primary care had an effect on mortality, and a qualitative process evaluation of those participating in STRETCH over the course of the study.<sup>13,14</sup>

The effects of NIMART were evaluated in two cohorts.

- Cohort 1 was a superiority study assessing whether task shifting would reduce the time to death, in other words, could it achieve superior reductions in ‘waiting list’ mortality by improving access to ART among patients with CD4 cell counts below 350 (9252 patients at 31 clinics).

- Cohort 2 was an equivalence study to see whether a nurse-led service could provide equivalent ART care (as measured by viral load suppression) in the medium to long term for those patients already on ART  $\geq 6$  months (6321 patients at the 31 clinics).

Fairall reiterated that this was a pragmatic trial, run in the real world, and within all the usual constraints of the public health system. First, nurse re-prescription of ART took about three months to be introduced into the sixteen clinics, but one year into the study, nurse initiation of ART was only taking place at fourteen out of sixteen of the clinics randomised to the intervention. The training effort was frequently confounded by high staff turnover.

There were major problems with drug distribution to the sites, including the much-publicised difficulties with maintaining ART supplies in the Free State during late 2008 and 2009 – including when a moratorium on new prescriptions was temporarily put in place.

In addition, Fairall pointed out that the fidelity of the control arm of the study was compromised as doctor-supported sites also dramatically increased ART prescribing over the course of the study.

As a result, “contrary to our expectations, STRETCH was not superior in improving access to ART in the study context,” said Fairall. Nor did it appear to cause a profound reduction in ‘waiting list’ mortality.

In cohort 1 (the number of those with CD4 cell counts below or equal to 350), there was no significantly improved survival among those patients at the NIMART clinics followed out to 18 months (with a HR of death of 0.92 [95% CI 0.76-1.15; p 0.532]).

The effect was primarily powered among the patients with CD4 cell counts below 200 (CD4 count  $\leq 200$  HR 1.00 [95% CI 0.52-1.00; p 0.020]).

However, survival did look somewhat better for the NIMART cohorts among those with baseline CD4 cell counts between 201 and 350, with HR 0.73 (95% CI 0.54-1.00; p = 0.052) interaction term p = 0.050.

Even though the study failed to demonstrate the superiority of nurse-initiated management of ART, it should be pointed out that the intervention hadn’t really fully come online – only about 26% of patients who started ART in the STRETCH group were initiated by a nurse.

It proved relatively easy to demonstrate that nurses provided equivalent management of stable patients on ART for more than six months, however.

Of note, part of STRETCH involved the integration of new ART-related activities into clinic settings, so another evaluation looked at correlations between the integration of HIV care and mortality rates (in Cohort 1) using a semi-quantitative questionnaire including 4 assessments of integration at each clinic during the trial, with questions on:

- 1 **pre-ART care** (VCT, CD4 counts, routine HIV care) and
- 2 **ART care** (baseline bloods, drug readiness training and monthly ART supply) at *two levels* of primary care services: integration of above elements of HIV care into primary care services *within* the ART site (**internal integration**) and provision of above elements of HIV care by primary care clinics, not designated as ART sites, and referring patients to the trial ART site (**mainstreaming HIV care**).<sup>15</sup>
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**Cohort 1: ART Provision to people with CD4  $\leq$  350 not yet on ART**

Outcome	STRETCH group		Control group		Effect estimate			
	n/N	%	n/N	%	Type	Point	95% CI	P value
Received ART	3712/5390	68.9	2418/3862	62.6	RR	1.06	0.97, 1.17	0.210
Time to ART					HR	1.14	0.92, 1.43	0.232
New TB diagnosis	1057/5390	19.6	510/3862	13.2	RR	1.46	1.18, 1.81	0.001
Lost to care at 12 months	2017/5390	37.4	1608/3862	41.6	RR	0.91	0.86, 0.96	<0.001
Mean change in weight (kg)	3.1 (n=2557)	9.1	3.4 (n=1503)	9.0	$\Delta$ in means	-0.05	-1.12, 1.03	0.932
CD4 count at follow-up	161.3 (n=2345)	175.2	141.7 (n=1544)	161.6	$\Delta$ in means	22.3	3.6, 40.9	0.021

**Cohort 2: On ART  $\geq$  6 months**

Outcome	STRETCH group		Control group		Effect estimate			
	n/N	%	n/N	%	Type	Point	95% CI	P value
Suppressed viral load	2156/3029	71.2	2230/3202	69.6	Risk difference	1.1%	-2.3, 4.6	0.534
New TB diagnosis	119/3029	3.9	113/3202	3.5	Risk difference	0.21%	-0.40, 0.84	0.487
Change in ART Drugs	161/3029	5.0	57/3202	1.78	Risk difference	1.25	0.65, 1.86	<0.001
Time to Death					HR	1.05	0.84, 1.31	0.684
Mean change in weight (kg)	1.3 (n=2136)	7.4	0.47 (n=2288)	7.1	$\Delta$ in means	0.77	0.20, 1.34	0.010
CD4 count at follow-up	433.8 (n=1735)	219.5	418.4 (n=1691)	201.8	$\Delta$ in means	24.2	7.2, 41.3	0.007

Integration scores improved significantly by the third assessment, which the preliminary analysis suggested was associated with a significant overall improvement in survival at *all* the clinics. This was probably driven by the integration of pre-ART care, which correlated with improved survival again at *all* of the clinics (intervention and non-intervention), while the integration of ART care and mainstreaming of HIV care was significantly correlated with improved survival at the intervention clinics.

This suggests that as integration (and implementation) of these ART-related activities improves over time, survival also improves – and also that the integration clinics are not the only clinics which are improving their performance.

“It should be remembered that this was a pragmatic trial and that provision of doctor support increased disproportionately during the trial with the result that we compared nurse-led doctor-poor clinics to clinics with substantially more doctor support,” said Fairall.

She noted one factor that proved to be a particular barrier to better performance: “We did not address the complex logistics of drug distribution which our qualitative evaluation highlighted as a key barrier to scaling up services.”

**Qualitative evaluations**

Fairall said that the “nurses took on ART prescribing without complaint, and didn't even ask for more money.”

The qualitative evaluation, which involved in-depth interviews (n=26) and focus group discussions (n=16) with patients, nurses, doctors and health service managers across the Free State, quoted several of the nurses participating in the programme.

“I think we are very much busier now,” said one.

“And I'm working very much harder, yes,” said another.

“Now, with one patient, you have to exclude a lot of things...But we are enjoying it, because we understand whatever we've been taught from the STRETCH. So there is more information, so we are able to explain to our patients better than before,” said another nurse.

But while the evaluation concluded NIMART was generally acceptable to the nurses, patients (who were after all happy for the reduced transport costs and time costs due to decentralised care), doctors and managers, it was not all smooth sailing:

- Nurse confidence grew slowly – and some nurses expressed “hesitation regarding their management of the sickest patients and the lack of clinical support at times.”
- Although doctors were in favour of NIMART, and senior management and political support was strong, the clinical support offered by doctors and local management support varied widely by clinic.
- STRETCH took place against “the background of an already struggling health system” with pressures such as clinic buildings that were too small to accommodate ever-increasing patient numbers. STRETCH increased some of these pressures.
- While decreasing the burden on doctors, STRETCH increased the workload, not only of nurses, but of pharmacists, and, notably, other staff such as lay counsellors or data capturers, who were sometimes called upon to perform basic nursing duties in an improvised manner when the nurses were not available.
- “The pace of rollout varied greatly across clinics, with some clinics unable to easily implement the full task shifting envisaged within STRETCH,” wrote the poster's authors.

In other words, while NIMART appears feasible, “it results in significant increases in training and clinical support needs,

workload and capacity constraints, as well as shifts in the working and referral relationships between health staff,” the authors concluded.

Quite plainly, NIMART can only be scaled up incrementally, requires a great deal of training and support, and “a significant reorganisation of health services to accommodate these shifts in practice.”

Perhaps this is why, in her conclusion, Fairall emphasised “We found no evidence of harm whatsoever, and the nurse-led service delivered equivalent viral suppression rates and a substantial improvement in survival among the patients nurses felt qualified and confident to assist.” She added, “it is important to note that this improvement is not attributable to the provision of ART alone, but rather to better overall care, for which there was robust evidence of multiple improvements — both in processes of care [TB case detection and programme retention] and in actual patient outcomes,” such as CD4 cell count and weight.

Perhaps the take home message is that NIMART in the Free State is a work in progress that has yet to reach its full capacity.

### Optimising NIMART services

On the basis of the recommendations and data on task shifting, including the preliminary data from STRETCH, the South African government has moved forward with NIMART in order to meet the demands to scale up ART across the country. But several other presentations also suggested more work is needed to develop confidence and capacity among nursing staff trained to initiate ART.

“After announcing ART expansion, the National Department of Health set a target to train 6000 nurses and initiate 500,000 new patients onto ART by March 2011,” said Elizabeth Mokoka, a nurse with a PhD working for the International Training and Education Centre for Health (I-TECH). (I-TECH is a PEPFAR-supported international NGO working in health capacity development — primarily the development of a skilled health workforce and well-organised national health delivery systems.)<sup>16</sup>

The initial results of this training programme were not as successful as hoped.

Province	Number of Nurses Trained	Number of Nurses Initiating
Eastern Cape	862	375 (43.5%)
Free State	410	94 (23.4%)
Gauteng	1082	453 (42%)
KwaZulu Natal	2805	182 (6.5%)
Limpopo	901	249 (28%)
Mpumalanga	698	221 (32%)
Northern Cape	202	89 (44%)
Northwest Province	532	80 (15%)

Source: NDOH, 2011

According to Mokoka, this slow uptake of NIMART was due to delays “in setting up effective mentoring systems for trained nurses; there was a backlog of facilities to be assessed and delays resolving facility infrastructure issues (space, etc.),” she said. Also, there was initially poor co-ordination between the nurses trained in NIMART and facilities being made ready as ART service points.

South Africa doesn’t just need NIMART, it needs nurses who are efficient, competent and confident to prescribe ART safely in practice, who are capable of implementing national policies and guidelines.

### Scaling up clinical mentoring

To develop this capacity, the National Department of Health needs to accelerate clinical mentoring of NIMART-trained nurses, according to Mokoka, and develop a standard national curriculum on clinical mentoring. Some of this is already underway, including the development of a clinical mentoring manual, and the beginnings of a standardised curriculum with pilot training.

The training process begins with didactic training, followed by clinical practice with ongoing continuous assessment and support from a clinical mentor. This should lead to competence, and then proficiency as the nurse learns to independently make clinical decisions, developing clinical expertise.

“Clinical mentoring bridges the gap between theory and practice, and supports nurses after NIMART training, supporting the decentralisation of healthcare delivery with high quality of care,” said Mokoka. “It should strengthen problem-solving and decision-making skills and build the capacity of providers to manage or refer unfamiliar or complicated cases... The use of algorithms and guidelines should not replace critical thinking and application of problem-solving skills.”

Clinical mentors should clearly have clinical experience and current practice in the field but they should also be trained as mentors, according to Mokoka, and need key skills, such as the ability to teach, facilitate case discussions and assess clinical skills. In fact, the training process for mentors is not too dissimilar to the training process for nurse prescribers, although it focuses on developing mentoring skills (e.g., how to build relationships, effectively communicate, assess and identify systems issues and provide feedback to the nurse and task teams).

In the past eight months, I-TECH has trained 204 mentors: 107 of the public sector clinical mentors trained in Mpumalanga and Limpopo and 97 mentors from five partner organisations. These will support 235 public facilities where trained nurse providers will practise. Mentoring of the mentors is ongoing, with an average 3 to 4 on-site follow-up visits conducted with each clinical mentor, and support provided by phone, SMS or email.

Although a partial solution to helping NIMART reach its potential, Mokoka pointed out that developing mentors also takes time and funding — and requires a dedicated budget. It can be a challenge to select appropriate trainees (who are willing and committed), and they will need to receive some form of recognition (including a formal position within the DHS). Mentoring also directly consumes resources, such as transportation expenses, and time from the mentor’s usual clinical duties must be allocated for mentoring. Collaboration is essential, so that district trainers and clinical mentors co-ordinate activities — so all the stakeholders need to be oriented on their role in the process.

### Expansion of NIMART at the Nkwenkwezi Primary Health Clinic

The scale up of NIMART at one primary health clinic was fraught with challenges and opportunities, according to Dr Sundesh Maharaj, who presented the experience at the Nkwenkwezi Primary Health Clinic in the Eastern Cape, which was assisted by Africare, another US-based NGO supporting health system capacity and other development needs in Africa.<sup>17</sup>

Africare's Injongo Yethu project uses roving clinical support teams to support comprehensive HIV/AIDS programmes in the Eastern Cape, including 24 sites in Makana District, 24 sites in Nkonkobe District and 31 sites in Lukhanji District. It employs a clinical systems mentorship model approach targeted at the provider, team and site level.

The Nkwenkwezi Clinic is a primary health clinic with a catchment area of 4600 in Nkwenkwezi township near Port Alfred. The ANC prevalence in the Eastern Cape is around 23%. Onsite HIV counselling and testing conducted at the Nkwenkwezi Clinic, from October 2010 to March 2011 found a HIV prevalence of 9.3% amongst all tested clients, and a 20% prevalence amongst ANC attendees.

Clinic staff includes a clinic manager, five full-time professional nurses (three of whom have been trained on NIMART, one sessional doctor who visits the clinic once a month (3 hour sessions per visit), one pharmacy assistant, one auxiliary pharmacist, one data capturer, and one cleaner. Clearly, there was limited doctor support for NIMART at the clinic, limited infrastructure and space constraints.

Nevertheless, the clinic was approved as a NIMART site as of 1 April 2010, with two feeder sites: PAL2 and Station Hill Clinics; while the Port Alfred Hospital serves as the referral centre and facilitates the supply of ARVs. Lab services are provided by the NHLS Service via a courier who comes twice daily to collect specimens and deliver results. Support for people living with HIV includes a support group that meets onsite weekly, a dietitian available at the referral hospital who also visits the clinic weekly, and a social worker, available via hospital referral.

Consultations and planning meetings were held with the site management staff, including the district HIV Programme Manager, Site Clinic Manager/Supervisor, the Site Multidisciplinary Team and key staff from the referral hospital to discuss how to support NIMART.

The plan was to hold fortnightly onsite multidisciplinary team meetings on the initiation of new clients on ART. A client initiation checklist was provided to ensure comprehensive preparation for ART initiation — including clinical and social parameters (such as adherence support). There would be a doctor review of patients conducted at months 6 and 12, with complicated cases reviewed as they arose, including participation of staff from the two feeder clinics.

There would also be monthly HIV stakeholder meetings including the PHC's and key referral hospital staff and support services (the social worker, dietitian, and pharmacy staff) to discuss referrals, drug supply, support services, revisions to guidelines, and case reviews.

As a result, there was an increase in provider-initiated counselling and testing from 50% of patients in October to 90% in March, an increase in cases discussed, roughly 77% of whom have since been initiated on ART. So far, a total of 96 patients have been started on ART including twelve who were pregnant, six children and nine TB-coinfected patients. Four individuals started on ART have since passed away.

Dr Maharaj highlighted the CD4 cell counts at which patients are now being initiated on ART. At the start of the programme, there was a sudden drop in the CD4 cell count at initiation, as the most ill patients who were waiting were initiated on treatment, but since September last year the CD4 cell count at initiation has been a median of 134.6, which is substantially higher than the norm in South Africa (~100).

"The Antiretroviral Treatment in Lower-Income Countries (ART-LINC) collaborative has shown that the most important predictor of a patient's CD4 response on ART is the baseline CD4 count at the time treatment is initiated," he said.

Even so, the infrastructure and shortage of human resources continue to challenge the clinic, which now has added stress due to the high influx of patients from the hospitals to the 'new' more convenient NIMART sites, according to Dr Maharaj.

"All the nurses need to be trained in NIMART with certification," he said. In addition, there continues to be limited doctor support, and the number of patients who must be reviewed every six months is simply getting unwieldy for just one doctor to manage. Another issue is there are poor community links to support and follow-up on patients — who are very mobile between clinics.

More mentorship and supervision will be needed to make NIMART sustainable at this and similar clinics, Dr Maharaj believes. He said that clinic supervisors will need capacity development to act as mentors, with more nurse mentor support from the Department of Health. Finally, they will need to arrange more outreach support visits with hospital doctors.

### Quality improvement to empower nurses at PHC facilities to deliver ART

A final presentation, touched on briefly in the last HATIP, described how the quality improvement process could be used to improve the delivery of nurse-initiated ART to pregnant women at clinics in Ugu District in KwaZulu Natal.<sup>18</sup>

The district has an antenatal HIV prevalence of 40.2%, one of the highest rates in the country. In 2009, 51% of the maternal deaths in the district were HIV-related. Sixty-one per cent of pregnant women who were eligible for ARV therapy in the Ugu district were referred for treatment initiation, and only 44% of those referred for treatment were successfully initiated.

ART initiation was dependent on doctors. Nurses have been trained but lacked confidence to prescribe, according to Mpume Shibe, PMTCT Co-ordinator for the district who presented the report.

So the district multidisciplinary team set a goal to increase the proportion of primary health clinics in districts where nurses initiate ART from 32% to 75% over a six-month period (July 2010 to January 2011), building on an existing quality initiative *The Masibavikele Campaign*.

A data-driven 'dashboard' was created to track monthly progress and test changes — small non-threatening tests of change that were introduced to build confidence in the nurses who had been trained on NIMART, according to Shibe. Again, teams of doctors helped capacitate, motivate and mentor the PHC nurses to start initiating ART.

There were three other key interventions worth noting — the pre-packaging of drugs, the development and scale-up of a 'change package' and the engagement of community health workers.

"The hospital pharmacy, from the Mother Hospital, began pre-packing of the antiretrovirals that the women needed to be initiated with. They pre-packed the drug for the clinic so that it became easier for them to initiate it," said Shibe.

"We were also able to work with the team to develop and scale up a 'change package' — a collection of ideas that are developed by the frontline staff in order to facilitate the implementation of the intervention of the programme," she said.

Finally, community health workers were assigned to each pregnant woman, and made responsible for arranging

collection/follow-up of CD4 cell counts, and tracking of women lost to follow-up.

## Results

“By November 2010, we already reached our target of 75% of the clinics where nurses now initiated pregnant women on ART,” said Shibe. The numbers of pregnant women initiated on ART also jumped sharply (though Shibe did not show what percentage of pregnant women with CD4 cell counts below 350 were starting ART). By December 2010, all of the clinics in Ugu district were initiating ART for pregnant women. Over this same period, there were also sharp drops in the perinatal transmission rate at six weeks (although this was due to multiple factors and interventions). There also appears to have been a recent drop in maternal mortality, although these rates were not being monitored prior to 2009.

Shibe believes that the quality improvement process was critical to build nurse confidence in NIMART.

“A quality improvement approach empowers nurses because it recognises nurses as local leaders. It promotes the use of data-driven decision making; it encourages nurses to creatively design local solutions to their challenges and nurtures a sense of teamwork among facility staff,” she said.

There’s also a better chance that the approach will lead to sustained improvement, because the “team work creates a culture of improvement... and ensures that improvement discussions are ‘hard-wired’ into the system,” she concluded.

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## Task shifting to lay personnel

By Theo Smart, Lance Sherriff

As suggested by the STRETCH study, and the experience in Ugu district, to allow nurses to take on other duties, it will also be necessary to shift some of the nurse’s routine duties to lay personnel and community-based caregivers. At least one presentation at this conference demonstrated that some activities can be successfully transferred to HIV counsellors with careful training and support – and help the HIV programme meet its targets.

However another qualitative study found that while there is much to be gained by engaging peer-health workers in the delivery of services, there are some pitfalls as well, especially when there is a lack of capacity to manage these staff and a lack of interest in making them an integral part of the health team.

### Training counsellors to perform HIV counselling and testing (HCT) services and correctly interpret results

“Trained lay counsellors can safely conduct high quality rapid HIV tests, in the home setting, and correctly interpret the results,” said Dr Tanya Doherty, of South Africa’s Medical Research Council, who presented the results of a quality assessment of community delivered home-based testing services in the Umzimkhulu subdistrict of Sisonke District in KwaZulu Natal.<sup>1</sup>

In many other countries, lay counsellors routinely do thumb pricks and perform rapid HIV tests as part of HIV counselling and testing programmes. But, until recently most HIV testing in South Africa has been performed in health care facilities and by nurses—as only nurses were permitted to ‘draw’ blood.

“There are several barriers to this model - especially in rural areas without transport, the cost of getting to the facilities, stigma issues,” said Dr Doherty. There is a clear need to dramatically expand HIV testing services to non-clinical settings with lay counsellors, particularly to support the country’s HCT campaign.

“Also the primary health care revitalisation strategy is drawing heavily on community-based health workers,” said Dr Doherty. “So it is important to assess the ability of these workers to do certain tasks, including HIV testing.”

She presented data drawn from the quality assessment stage of an ongoing cluster randomised trial comparing testing rates

between facility-based testing, and home based testing. The intervention group included 11 lay counsellors conducting door-to-door visits in eight rural communities in the sub-district. She noted that this is a poor rural area, where most households don't have electricity or any running water to the house; rivers are usually used as a source of water; and the antenatal HIV prevalence is 35% with an infant mortality of 99 per 1000.

The lay counsellors were all recruited from the communities in which they work.

"We stuck with the same salary level that lay counsellors are earning within clinics – I think around four thousand rands," said Dr Doherty.

Training to perform the rapid tests consisted of a two-week training course, with six weeks in-service training in clinics before counsellors were sent out to provide home based testing. A registered nurse supervises the team.

Counselling and rapid HIV testing is offered to all members of each household who are willing and consent to test.

To assess the quality of rapid testing, the lay counsellors were also instructed to take a dried blood spot sample from each individual tested, which was sent to an independent laboratory for quality control testing in Durban. Cell phones were used for data collection and uploading results (though Doherty noted this was just for study purposes and may not be necessary in the field).

#### High testing accuracy and uptake

Over the past year to eighteen months, 5,086 people have been tested. After a while, researchers concluded that they didn't have to confirm negative test results. Out of the 3981 remaining blood samples, there were only fourteen cases where the results reported by the counsellors didn't match the results from the lab.

In ten of these cases, the lay counsellor reported to the lab that the result was indeterminate – but did not give the results to the individual until it was confirmed positive by the lab.

"So that is showing good insight on the part of the lay counsellors," said Dr Doherty.

Overall, the lay counsellors result achieved a specificity (true negative) of 99.9% (95% CI: 99.7 – 99.9%), and a sensitivity (true positive) of 98.0% (95% CI: 96.3 – 98.9%).

"Both measures of sensitivity and specificity are very high – in fact our lower bound of the confidence interval for specificity of 99% is actually higher than the NIH standard of 98% for assessing the quality of rapid HIV tests," she said.

"This evidence supports the recent change in policy of the South African Government allowing lay counsellors to do finger pricks for certain blood tests. And it has important implications for the expansion of HCT services in South Africa and in other countries, especially in community-based settings," she said.

How much this affects access compared to clinic-based testing has yet to be determined. However, during the question and answer session, Dr Doherty said that the testing uptake throughout the intervention has been around 75% in this very rural area.

"Prior to the intervention only 33% of individuals knew their HIV status – so the acceptance has been huge! Mostly due to the involvement of the chiefs [and other leaders] in the area who were the first to test, and who then promoted these lay counsellors within their meetings."

#### Implications

While training and sending out teams of lay counsellors who can provide and correctly interpret rapid HIV tests in the home would be a needed step towards providing greater access to HCT – described as "a fundamental human right" by Jonathan Berger of Section 27

during the rapporteur session – there are some also concerns about how such testing would be implemented.

"Implementation of these services may raise further human rights issues: including privacy, autonomy, confidentiality, equality and unfair discrimination," said Berger. While it clearly can be important to get support from community leaders for home-based testing in communities, programmes should make certain that the support does not constitute coercion – such as an order from the chief to be tested.

There is also a clear need to make sure that when HCT is rolled out to more remote communities, that it comes with adequate support services, particularly for women who test positive in front of their husbands and who may be at risk of domestic violence.

Furthermore, testing and the delivery of results needs to be backed up by effective linkage to HIV care and treatment programmes. This will enable newly diagnosed people to quickly receive critical diagnostic tests (TB screening, CD4 cell testing) and treatment services (IPT and ART if eligible). (See the HIV and TB in Practice article.)

Task shifting of HCT to community-health workers is necessary because the formal health sector doesn't always reach people where they need services in the community and at home. Other tasks, such as support services to help people adjust to being HIV-positive, assistance completing referrals, preparing for ART, adherence support, follow-up and lost-to-follow-up (LTFU) tracing, need to be shifted to caregivers in the community as well.

WHO recommends task-shifting "less technical tasks to lessen the burden on overworked health care workers. Involving community members in the clinic helps enable community outreach. In addition, it could provide employment, training and a small financial income for unemployed people living with HIV/AIDS."

### Community care providers strengthen linkage to and retention in ART programme

Several programmes reported that community health workers are indeed essential in helping people who test positive make it to the ART site, and once there, stay in care.

For instance, in Tanzania, Africare's KAYA community care initiative, a CDC-PEPFAR funded home based care project has introduced a 'provider linkage and referral strategy (PLRS)'.<sup>2</sup> The strategy entails linking each *volunteer* community home based care provider to an HIV care and treatment centre, making sure they are stationed with the facilities catchment area and engaged in patient tracking, to strengthen linkages between the health facility and the clinical services.

The strategy was used in 31 facilities to monitor LTFU tracking and return rates between July and December 2010. The community home based care providers tracked LTFUs with a CTC registry book, provided home-based counselling to the patients and encouraged them to return to care. Facility-based supervisors provided ongoing supervision. The intervention was highly effective. By the end of the study period, 220 out of 285 (77%) of the LTFU patients referred to the home-based care providers were returned to care.

Another study in rural South Africa reported similar findings. "Community health workers are key for referring, encouraging and maintaining clients in the formal health system," said Dr Ahmad Haeri Mazanderani of the Good Start Foundation, but he questioned whether such systems are sustainable, noting HBC organisations may or may not be registered for providing such services, and consequently may or may not be subsidised and regulated."<sup>3</sup>



“A successful and sustainable CHW programme depends on the existence of an enabling environment,” he said. The following are indispensable: a supportive regulatory framework, functioning referral systems, robust quality assurance mechanisms, adequate remuneration of health workers, and sufficient resources for health service delivery.

There has been little evidence documenting the experiences of community health workers in linking clients to the formal health sector in rural South Africa — or to what extent this potential resource is being utilised in order to improve the level of health care to underserved populations.

So he and his colleagues decided to conduct the Care in the Home Study in Bushbuckridge, a rural municipality in Mpumalanga province, designated as one of the 22 most poverty stricken areas of South Africa. It is comprised of 235 dispersed villages and rural settlements, with a population greater than 500,000 people. The health system is overstretched, and community care groups have sprung up to meet the need for services.

The qualitative study investigated the relationship between community health workers, primary care givers and clients, sampling nine out of 37 home-based care organisations, 18 out of 246 volunteer community health workers and 32 of their clients.

The study found that the community health workers were crucial for case-finding. (The majority of clients (23 of 32) were found going door-to-door within the communities) and in linking clients to the formal health care system — but there were not fully integrated in the health system (the clinics rarely referred patients to community health workers for support services).

“The current lack of standardised referral practices represent a health system in which CHWs are not fully integrated..,” said Dr Mazanderani.

“It was good in the beginning but not in the end. One of the reasons that made me leave was that there was a lot of critics where I used to work. I started thinking to myself why I even bothered to work with them because I wasn’t even getting paid. It was as if I was taking their job away. They made me feel as if I was wrong when I asked them questions. Sometimes when I asked for something they would tell me they were too busy. They wouldn’t take my presence into consideration,” said one community health worker in the study.

Furthermore, the majority of community health workers made explicit reference during the interviews to the need to use their own money (for client transport to the clinic) or their own food, to ensure the client’s treatment adherence.

*“When I find a patient who isn’t working I sometimes have to sacrifice myself and use my own money to transport him to the hospital or the clinic. And the organisation doesn’t reimburse us for it nor give us a travelling allowance. Another sacrifice we make is that when we find that the patient doesn’t have any food we take our own maize meal to cook for him so he can eat before taking his pills because most pills nowadays require a person to eat before taking them,”* said another community health worker.

“As the CHWs belong to the same impoverished communities they serve, this raises questions of whether they are not putting themselves at risk by their continued volunteering work?” asked Dr Mazanderani.

“Community health workers offer an essential resource for patient mobilisation into care. However, risk-protection strategies for community health workers are urgently needed,” concluded Dr Mazanderani. “However, risk-protection strategies for CHWs are urgently needed to ensure the sustainability of the community

health worker programme and prevent a downward spiral of impoverishment and destitution for communities.”

## Expert patients

Similarly, employing expert patients in the health services “can achieve better adherence patterns, reductions in stigma, provide positive role models for clients, and lead to a reduction in lost-to-follow-up (LFTU) cases and other improved health outcomes,” said Taru Jaroszynski who presented findings on the strengths and weakness of the Expert Patient Programme, run by Paediatric AIDS Treatment for Africa (PATA).<sup>4</sup> “But we have a *long way to go* before treatment teams learn to fully engage expert patients and maximise their contributions to a multidisciplinary team.”

The Paediatric and Adolescent AIDS Treatment for Africa (PATA) is a network of treatment teams at more than 130 paediatric clinics in 23 countries scattered across Sub-Saharan Africa. PATA hosts forums with teams of doctors and nurses and counsellors and pharmacists, meeting in a collaborative learning environment to discuss their successes and challenges in paediatric treatment, care and prevention and to set quality improvement tasks for the year ahead.

“At the PATA forum in 2007, a common challenge articulated by many teams was the lack of human resources within clinics, which was leading to long patient waiting times and limited psychosocial support services, and ultimately resulting in compromised quality of care,” said Jaroszynski. In response, PATA launched the Expert Patient Programme, funded by One to One Children’s Fund. This programme was modelled on the Partners in Health accompagnateur programme. The goal has been to include people living with HIV in the multidisciplinary treatment teams, and provide employment, training and an income for people living with HIV/AIDS.

They were called *expert patients* in acknowledgement of their expertise in ART adherence, and their knowledge of the clinic, based on their own experience of living with HIV or caring for a child affected by HIV.

### How PATA teams began incorporating expert patients

The PATA Treatment Team typically consists of a doctor, nurse, pharmacist and counsellor working together in a facility. Jaroszynski says that they have usually first been exposed to the expert patient programme at PATA Forums.

“The team may identify a need for task shifting in their clinic. The team must then examine their own process and identify the tasks that need to be shifted and the other services that can be provided by an Expert Patient/s. They need to consult local labour laws and policies and develop a plan on how to use the (US) \$216 per month provided by the programme,” she said.

The team is responsible for appealing to clinic management for permission to run the programme and then they have to recruit, train, supervise and mentor the expert patients in their role.

“The ultimate goal is to have the Expert Patients fully integrated in the Treatment Team, as a key member who brings new knowledge, skills and a deeper community understanding to the team and helps in the continuous quality improvement project,” said Jaroszynski. This approach to task shifting can be adaptable to address the needs of the specific clinic and is driven by a team of frontline health care workers. But that also means there is a lack of standardisation and in some cases no overarching national endorsement of task shifting.

PATA’s Expert Patient Programme has been running for five years with 182 Expert Patients working in 49 clinics in 14 countries. Each clinic employs about three to four expert patients who work

about 25 hours per week. Monthly wages for the Expert Patients vary widely from \$7 dollars to \$250. The majority of Expert Patients are women, most of whom were previously unemployed.

#### Evaluating how Expert Patients work in practice

But to better characterise how and what expert patients were doing, and how well the programme was doing, Jaroszynski and colleagues performed interviews and combed reports over a two year period, analysing the data by using a thematic content analysis.

They found that expert patients are being employed to perform a wide variety of tasks within clinics. This has enabled clinics to expand their repertoire of services. For instance, at one clinic in Transmara, Kenya, Expert Patients conduct home visits and act as treatment buddies - a service that would not exist otherwise. Teams at the clinic report they benefit from having more time to spend with patients, as a result of expert patients freeing up their time, according to Jaroszynski.

Clinics are more child-friendly. For instance, at Groote Schuur Hospital in Cape Town, caregivers are able to enjoy private consultations with doctors or nurses because children are looked after by the Expert Patients. Clinics are also more adolescent-friendly. In Zimbabwe, older adolescents are employed to act as peer educators and support group facilitators.

Now employed, many expert patients report improvements in the quality of life for themselves and their families.

"There are better links between health care teams and communities as a result of the under-acknowledged community liaison role that expert patients fill. Expert patients often fill a 'cultural broker' role helping patients navigate to and around the clinic," said Jaroszynski.

So on the plus side, "people living with HIV/AIDS have great energy and passion and are an incredible resource for busy clinics and thus must be fairly remunerated to ensure that their value is acknowledged," said Jaroszynski. "Clinic qualitative data has linked the programme to better adherence patterns, reductions in stigma, positive role models for clients, a reduction in lost to follow up cases and other improved health outcomes."

#### Dropping the other shoe

However the Expert Patient programme also needs to consider how the programme is working for the Expert Patients themselves. A recently created Expert Patient Review Committee is grappling with difficult issues regarding how the programme is working on the level of the expert patient as an individual, the clinic and the overall management. Jaroszynski highlighted a few of the programme's challenges.

"At an individual level Expert Patients have poor job security and limited career advancement," said Jaroszynski, and even when they are doing their best, the clinics are failing to fully engage them. At the clinic level, clinic staff need to be trained on how to mentor and supervise expert patients so they are included in the team and basic good employment standards are met.

"Policies need to be developed to safeguard expert patients – and this includes more stringent guidelines for clinics on employing expert patients. However, the greatest challenge at a management level is the poor integration of programmes such as the Expert Patient Programme within an overall district plan and the limited cooperation of NGOs at a local level," she said.

In some clinics, expert patients form part of a larger body of community health care workers funded by different organisations.

But the different funding streams and NGO approaches "results in inequality in pay and benefits; confusion over lines of reporting; different names and titles for community health workers doing the same tasks; professional jealousy as some community health care workers have access to more job security, career advancement and training opportunities; and pettiness and competition between different NGOs is a huge difficulty," said Jaroszynski.

These are not minor problems, but she believes that the PATA network may provide the ideal platform for bringing together stakeholders working with community health care workers in local contexts, to strategically plan how such programmes can become more integrated within an overall health plan.

"We are hoping to start this conversation now!" she said. "Until such a time as the Health Departments are able to provide clinics with funds to task-shift to improve the quality of care in clinics and include community members in health care treatment teams, there is a need for NGO-run programmes such as the Expert Patient Programme."

However, she also pointed out that this presented something of a catch 22, since NGO engagement in filling this need may contribute to health department inaction.

"Our challenge is to channel energy into advocating for the widespread adoption of these programmes so that they are recognised as an integral part of the health care system," she concluded. "After all, our children and their families deserve the highest quality care."

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