

ePrivacy, Surveillance and HIV/AIDS in the Workplace. A South African Case Study“  
Z. Muskat-Gorska

**Interview with dr Salome Charalambous, HIV/AIDS Programme Director, Aurum  
Institute, 05.12.07**

Aurum Institute  
47 Main Street, Johannesburg  
PO Box 61587, Marshalltown 2107, South Africa  
Tel: +27 11 638 26 07  
Cell: 082 856 11 46  
e-mail: [scharalambous@auruminstitute.org](mailto:scharalambous@auruminstitute.org)

Place: Wits University  
Wits University Campus  
Braamfontein...  
Johannesburg  
Date: 05.12.2007  
Time: 14.00 – 15.00

1. Is it possible to quantify the effects and impacts of HIV program without individual information on HIV/AIDS status? How it is possible to trace the impact of treatment of individual employees on productivity?
2. How data on individual HIV/AIDS status is stored in Aurum?
  - What is the code of confidentiality?
  - Is data stored centrally (for how many countries?)
  - How data is transported?
  - Is data digitalized (2006 Financial Times – testing a pen that electronically reads medical forms for HIV patients filled by hand)
3. Insourcing-Outsourcing – consequences for confidentiality
  - Why Lifeworks has been hired for VCT in 2007 for the Anglo American head office in Johannesburg
4. What is the regulation for disciplinary action for unauthorised disclosure?
  - What are security measures for data leak?
5. Do you have to report HIV/AIDS data outside?
6. Did you hear about the examples that companies asked for more identifiable data in Aurum?
7. Does perceptions of confidentiality cause low uptake of VCT?

There is definitely a natural clash between the requirements of monitoring of the disease and its management in the workplace and encouraging trust among workers to get tested and treated. Companies try to overcome this clash in different ways: by contracting an

independent VCT provider, by conducting anonymous testing, by providing workers with vouchers to get tested elsewhere.

At the same time, trade unions in South Africa are strong and militant and they are rather reluctant to grant the employer their trust. They also usually see prevalence surveys or VCT as the ways in which the employers try to identify HIV-positive workers.

In this context, companies do not want to lose trust of employees. They rather decide not to have the exact data and not to run surveys of HIV/AIDS programs than to discourage workers from taking part in these programs by compromising confidentiality.

Aurum position allows to some extent to overcome these problems. The institute is independent from Anglo American and supported by the international group of research institutions (like the London School of Health). Therefore, companies that contract Aurum's services may trust its scientific expertise and objectivity. In the field of assessing HIV/AIDS prevalence in the workplace there are, however, various practices. Some of the companies decide to begin HIV/AIDS workplace program without earlier prevalence survey. Some companies decide to treat results of workplace VCT as close to prevalence (however, it is possible only in cases when uptake is very high and even then the remaining untested group creates the risk of changing the assumed rates). Other companies decide to assume prevalence from modeling studies (e.g. age structure in the company – whether it indicates high risk groups, relying on migrant workers etc.)

The argument about the need for individualized data to assess effectiveness of HIV/AIDS program or individual employee's productivity after beginning ART treatment does not seem right. In my experience I had once access to complete data of individual workers which included personal data as well as HIV/AIDS and TB status. The aim of the project I worked on, which was run in one of the Anglo American mines, was to assess the impact of ART treatment on TB. Although we noted a massive reduction in TB rates it was not clear whether it was caused by ART. The issue was too complex to draw strong conclusions. For instance, at the time of introduction of ART the company also got rid of hostels for migrant workers in which TB was easily transmitted. Also, simultaneously, the company run a downsizing program and some of sick workers might have been dismissed, with the effect on TB prevalence rates. The same problem is with assessing productivity. The issue is too complex to draw one-way conclusions (like: putting a worker on ARTs enhances or does not enhance his/her productivity). There are numerous factors which may play role, especially in the mining sector, where productivity often has to be measured by group. Therefore, the argument about the need for identifiable data to assess productivity is not very strong. Even when in possession of such information, assessing productivity is tricky and complex.

The correlation that we did find was that the impact of HIV/AIDS or ART treatment on productivity was related to how labour-intensive the work is. Productivity depends on physicality of the job. The more physically demanding work, the bigger impact of HIV/AIDS on worker's productivity. For instance, HIV/AIDS will not affect productivity of the office worker in the way it might sometimes influence productivity of a miner etc.

Also, HIV/AIDS may interact with occupational diseases, such as silicosis, and then the impact of HIV/AIDS will be more significant.

However, it should be underlined that, according to the research, arguments about negative influence of HIV/AIDS on productivity are not supported. HIV-positive workers, especially if tested, for decades work with no difference to HIV-negative ones. Some time ago there were concerns expressed that HIV/AIDS might affect concentration and therefore cause an increase in occupational accidents rates. These concerns were not confirmed by research results.

In relation to data treatment I would say that health providers in the companies (occupational clinics) realize how sensitive data on workers HIV/AIDS status is. They do have identifiable information in their disposal but their medical staff is under Hippocratic oath and should be aware how important it is to keep this data confidential, especially in relation with the employer. In our units we have additional security arrangements for this part of our database where information on HIV/AIDS status is stored. To work on this database (e.g. entering data) there is a separate, digitalized password required. Access to offices with computers connected to this database is controlled. This password has to be changed regularly and there are restrictions on reusing the same passwords (30 different passwords before the system allows reusing). Also, not all people who work on the database and enter data can access this data. There might be 15 persons working on the database and 2-3 persons that can actually access information stored there.

We also have a protocol for the room with a fax machine that receives information from site clinics on HIV/AIDS in the workplace. The last person that leaves the office, locks the room. It is true that in Aurum we tested a device to digitalize patients' records kept in paper form. Among other reasons, we would like to reduce faxing as well as store all information in one database.

In relation to transport of HIV/AIDS data from the site to Aurum headquarters, we do not have particular procedures as we outsource transport.

However, I would say that the concern about sensitivity of HIV/AIDS data, or medical data in general, is recent. For instance, in one hospital I worked members of medical staff used e.g. to look in other nurses patients' files to check HIV/AIDS status of a patient for gossiping. After some time access to patients' files has been restricted.

Even now, sometimes people that work with HIV/AIDS data forget how sensitive HIV/AIDS individual data is, as they work with it for long and get adjusted to it, (*the need for regulation!*)

To the employer we report in cumulative number grouped data back to the companies. Of course, we adjust reports in order not to give identifiable data. It is possible that Aurum, being a research unit, not a commercial provider, is more free in deciding what kind of data will be delivered to the employer, as it is not that focused on customer care and are perhaps more assertive in contacts with them. Not that we were ever asked for more

identifiable data on workers' HIV/AIDS status. But, if we are for instance asked to draw conclusions from data and the time of data gathering is too short to draw conclusions – we will refuse. It might be difficult in terms of relations with the customers as their managers are usually target-driven business people who want clear answers, because they got used to think in black and white categories. They sometimes do not understand that science is more grey than black and white. Customer-care oriented companies in such situation might be more eager to compromise the need to analyze data in a long term in order to get more reliable results.

As far as insourcing/outsourcing of HIV/AIDS testing or treatment is concerned, Aurum is not a good example of insourcing research or management of HIV/AIDS in the workplace. We are independent and we work more as watchdogs to company-driven programs. It is not always true that outsourcing makes the uptake better. Insourcing means that workers can get testing and/or treatment on the site. In case of providing it by an independent provider outside the workplace workers have to travel to e.g. get a test. In some cases convenience issues may be decisive in not going for a test. I was once told by a worker how difficult it is to organize a trip to the centre of Cape Town where VCT was provided for workers of this company, especially for workers with family obligations.

Providing VCT in Anglo American headquarters by Lifeworks as an external provider instead of Aurum was not caused by privacy concerns and the belief for better confidentiality safeguards in when VCT is outsourced. Although it is easier to keep data anonymous in the mine with 7000 workers than in the significantly smaller office but the main reasons for outsourcing in this case were practical. Aurum does not provide VCT and their occupational clinic did not have extra capacity to organize it. That is why testing was outsourced to a different company.