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Privacy, Surveillance and HIV/AIDS in the Workplace. A South African Case Study“
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Interview Leighton MCDONALD, Qualsa Executive Manager, 30.11.07

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Date: 30.11.2007
Time: 15.00– 16.00

Questions:

1. The reasons for collecting data on workers HIV status in the workplace
   - Should the value of reporting (monitoring the disease) overweigh the value of confidentiality or the opposite?
2. Concerns about confidentiality of HIV related data
   - What are disciplinary actions for unauthorised disclosure in the workplace?
3. Does confidentiality play a major role in low VCT and ARV uptake or they are other important factors?
4. The way HIV/AIDS data is stored
   - Do companies report this data outside?
   - How companies monitor who is infected in the workplace – through VCT or there are other means of gathering this information?
   - Possibilities of collecting HIV information by using other methods of workplace surveillance

Big employers did quite a lot in South Africa in terms of reacting to the HIV/AIDS epidemic. They have been providing testing and treatment, mostly to workers, but some companies (eg. Shell) provide treatment also to workers‘ dependants.

In order to evaluate the efficiency of workplace HIV/AIDS policies employers are interested in HIV/AIDS data. However, almost without exceptions, employers are not interested in information that allows identification of HIV-positive workers. It can be said that Qualsa is not asked for this kind of information. Anyway, even if asked, Qualsa has developed safeguards that enable to protect confidentiality of identifiable HIV/AIDS information. For instance, if we provide with profiled information on a small branch of a company we customise our reports in order not to allow identification of particular HIV-positive workers – eg. if there will be 9 HIV-positive men and 1 woman in the branch Qualsa does not provide information on gender etc. Employers are rather interested in

trends, not identification. We do not give identifiable HIV information and it can be said we are not asked for it.

In my opinion a company does not need identifiable HIV/AIDS information in order to assess costs and efficiency of workplace HIV/AIDS policies.
Subsequently, I also think that drug resistance will not create significant problems for cost benefit analysis. It will rather not create long term increase in costs. For that reason, I do not think there will be a threat to privacy rights from the side of employers anxious about rising costs and therefor willing to investigate cost benefit analysis of their HIV/AIDS policies more closely. There will be rather exceptions from the rule.

Although I do not think that there is currently the problem of employers interested in employees‘ identifiable HIV/AIDS data, the workplace itself it is not the place to process this kind of information. Certainly, the reality is that the employer is mainly interested in the employees‘ performance. Sometimes, information about HIV status may influence the employer’s decision to dismiss an employee, unwelcome for other reasons - like personal attitude. In such cases, it is difficult to say whether discrimination on grounds of HIV/AIDS status did not take place. That is why monitoring of the epidemic in the workplace as well as gathering and processing of employees‘ HIV/AIDS data should rather be done by an outside entity, which is interested only in managing health risks and keeping people healthy and therefore the possilility of discrimination in the workplace is limited.

It can be said that confidentiality itself is a good reason for outsourcing HIV/AIDS management in the workplace. The third party independent process allows for both providing the employers‘ with control over the HIV/AIDS risks in their companies as well as ensuring employees‘ privacy and confidentiality of HIV/AIDS status. It is true that weak perception of confidentiality is the main reason for low uptake of HIV testing and treatment in the workplace. If we want everyone to be tested there is a need to implement measures that will enhance perceptions of confidentiality in the workplace.

I am of the opinion that achieving as higher rates of tesing as possible is crucial in fighting HIV/AIDS epidemic. We need to find the way to make people tested. Human rights concerns should be focused on securing freedom to disclose the HIV/AIDS status, while testing should be subject to the opt-out rule. The VCT uptake is still much too low. Even in Qualsa, where we encourage our staff to get tested and where we provide with all possibilities to get tested, the uptake is around 10-20%. People tend to believe that they are not the part of the risk group and therefore do not need to test or they are afraid to learn their status and prefer not to know. For me testing people should be made a priority, even to the extend where for any public action (like eg. getting driving licence etc.) there should be a requirement to present a valid HIV/AIDS test. Of course, only the proof of the last testing would be required, with no information of the outcome of the test.

Although I am in favour of strong action (even coercive methods) in favour of testing I do not think that individual rights to confidentiality of HIV/AIDS status should be overruled by the needs of public health to control the epidemic. Instead, a sensible

balance should be sought. However, once more, as long as people who should test, do not test, we are not winning. It was obvious for me during my work for Anglo American that without achieving better testing rates we are not able to manage HIV/AIDS in the workplace.[1] The key issue is to „close the loop“, first test people, than make them go for treatment.

Definately, from the point of view of confidentiality, HIV/AIDS management in the workplace should be done by an independent, outsourced company. In case of Anglo American, this management is done by Aurum, a medical research company, owned by Anglo, yet independent. In my view in this case confidentiality of data is guaranteed and, provided that the insourced company is sufficiently indiependent, there is no threat for security of HIV/AIDS data.

I am not aware of any case of internal unauthorised data leak. However, it is more or less obvious that such cases may take place. It is not a big problem as enterprises are insured and therefore the insurance will cover the costs of liability for an unauthorised data disclosure. In case of external leak – enterprises like Qualsa are liable. However, I would say that the practice is careful.

In Qualsa all units that deal with HIV/AIDS related information are separated, with a strictly controlled access for the staff only. Also, HIV/AIDS information in placed in separate databases to which access is restricted as well.

We use identification numbers which are added to the file of every employee we have in our information system. This system is organized in a data warehouse, central for the whole company. When the data is pulled out from the database identifiable information is delinked. It is possible to access linked information (e.g. the profile and medical data on treatment of an individual worker) only working on the database. Accordingly, when reporting the data back to the company (e.g. data on HIV/AIDS prevelence) we only used delinked, unidentifiable data.

When it comes to corporate response to HIV/AIDS in South Africa, it is obvious that the attitude of enterprises was evolving. At the beginning it seemed that HIV/AIDS is a terminal illness. Noone knew how to respond. That is why perhaps employers were so rigid and discriminating, demanding pre-employment testing. There a lot of unnecessary hysteria, related to the lack of information and lack of possibilities of treatment.

Then the treatment became available but very expensive. The cost of treating one worker was equal to R48000 per year in 2002 in comparison to R3000 today. Accordingly, the corporate attitude towards HIV/AIDS in the workplace evolved from a terminal

[1] Leighton McDonald completed an intership at Anglo American’s Ernest Oppenheimer Hospital in Welkom and afterwards he managed the delivery of a comprehensive helathcare service to 30 000 mine employers and their dependants for Anglo American. www.qualsa.co.za/page.asp?page=people [22.11.2007].

unmanageable disease to manageable but not cost-effective and, fionally to the cost-effective and manageable disease.

At the same time, the global debate on HIV/AIDS in the workplace was evolving. There were more and more lobby groups that advocated that treating HIV/AIDS is a moral obligation, not a question that should be subject to cost-effect analysis. There were also global actions against multinational corportations like Coca-Cola, that were refusing to provide treatment for AIDS. There were less and less arguments not to treat HIV/AIDS in the workplace. In this way the policy of risk avoidance evolved into risk management. The risk management means prevention (key aspect), testing and treatment of HIV/AIDS in the workplace.

In relation to trade unions position on HIV/AIDS in South Africa, I would say that the main pressure to provide treatment in the workplace was coming from activist organizations, not trade unions. In case of illegal actions undertaken by an employer (like drastic cases of HIV/AIDS based discrimination) there used to be a trade union reaction but even now I would not say that HIV/AIDS is among their priority issues and I was surprised that their position has not been stronger on this. To some extend political complications played the role. COSATU was forming the part of the ruling alliance and in the times of the Government’s conflict with activist organiations on providing ARV treatment through public healthcare it was difficult for trade unions to take the position. Currently, trade unions are efficient in reacting to illegal practices of employers, pre-employment HIV testing etc. but their concern is still more with traditional industrial issues like remuneration.