

**Workshop:  
Globalisation and New Epidemics:  
Ethics, Security and Policy Making**

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**Epidemics, Privacy Rights and  
Public Concerns: The Hong Kong  
SARS Experience**

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**Mr Chairman, Distinguished Guests, Ladies and  
Gentlemen,**

I would like in the limited time available to offer you some thoughts on the impact of the SARS epidemic in 2003, specifically in Hong Kong. I do not know how typical our experience was but it is from that standpoint that I speak. I will restrict myself to the SARS epidemic because our handling of it provides rich learning in terms of the way in which we might deal with the threat of Avian Flu, which we also had some experienced of in 1997, along with dengue fever and Japanese encephalitis.

What I would like to do is refresh people's memory of what happened when SARS struck Hong Kong, the impact that it had on virtually every aspect of our society, and some of the issues it

raised. I will then look at how personal privacy rights can be accommodated in a time of crisis, without totally nullifying their value and conclude by taking a look at some of the public concerns that emerged during the 6 months of the SARS epidemic which in many ways dictated public policy, disclosure of information, medical surveillance procedures etc. Let me commence though by setting privacy in the context of Hong Kong.

## **The Privacy Context**

To begin with, as the Privacy Commissioner for Personal Data, and I emphasize **personal data** because we are not directly involved in privacy in its more generic sense, let me very briefly overview the scene in Hong Kong. My office was established in August 1996 and opened its doors for business in December 1996. Primarily we exist to uphold the provisions of the **Personal Data (Privacy) Ordinance** which is a complex and comprehensive piece of legislation running to 70 sections. We act in the capacity of a statutory regulatory body and exist to serve **two** main purposes.

- 1 **First**, to uphold the personal data privacy rights of the individual. Those rights pertain to the collection, use, accuracy and security of personal data and are comparable with the privacy rights you enjoy in Europe.
- 2 **Second**, we exist to ensure that what we call data users, which means any person or organisation that collects personal data, discharge their obligations in accordance with the provisions of the Ordinance. The Ordinance applies to all data users irrespective of the size of organisation or sector.

The fact that we have fielded 154,000 enquiries and over 6,700 complaints over the 10 year period we have been in existence gives you some measure of the job.

In Hong Kong privacy rights are enshrined not only in the Ordinance we administer but in the **International Covenant on**

**Civil and Political Rights**, to which Hong Kong is a signatory, and our **Bill of Rights** which is, in effect, a mini Constitution. I think therefore that we take our human rights, and privacy rights more specifically, very seriously and this is a distinguishing feature of our society. Hong Kong took on a pioneering role in Asia in terms of getting privacy on the statute book and setting up the institutions to protect it. However, I must at this point, temper what I have said by saying that we do not subscribe to the view that personal data privacy rights are some superordinate set of rights that are either immutable or omnipotent. Indeed, our Ordinance contains no fewer than 12 categories of exemptions and one of them relates to health. If I were to summarise our position it would be to say that we have adopted a pragmatic approach to dealing with personal data privacy issues as distinct from taking a hard line purist stance. That pragmatism is perhaps best characterised by the accommodation of other rights in seeking to strike a tenable balance between different sets of public and private interests which in certain cases conflict with one another, e.g. freedom of information. I don't know how well pragmatic privacy as a position sits with my audience but it is an approach that works for Hong Kong and to that extent I don't, at this stage, see the need to change it.

So, accommodation of the interests and needs of others is important in our thinking of how to respond to the privacy dimension of any public policy issue or contemporary problem. I might add that I think this approach has been instrumental in gaining respect for the work of the Commissioner's Office and that makes life a little easier for us.

Let me turn to the events of 2003 that, more than any other recent issue Hong Kong has had to confront, made a massive impact upon the collective psyche and is indelibly imprinted upon the memory of all of us.

## The SARS Epidemic in Hong Kong

The SARS epidemic in Hong Kong commenced in February 2003 with the first infection confirmed in March. The last infection was in June. By the last week in March the infection rate was at its worst with 80 cases being confirmed in a single week. Rapidly escalating statistics such as these alarmed the government, the entire healthcare sector and the general public. There was a sense of apoplexy and helplessness which fuelled the media frenzy to the point that words like, horrific, catastrophic and dire assumed everyday use, if not over use. Of course the epidemic was, in the early stages of the outbreak, something of a medical conundrum and this accentuated the sense of vulnerability among citizens. Inevitably, the focus very rapidly shifted to the Government to provide solutions which it did, but these were frequently criticised as being too little too late with adverse comparisons being made with how the epidemic was being handled elsewhere in Asia, notably in Singapore. There the government took prompt action in terms of isolation and quarantine protocols and made use of electronic bracelets to monitor the 608 patients under the confinement programme.

I won't dwell on the medical chronology of what transpired over the 6 or 7 months that the epidemic was **THE** issue but I will say that, as a long time resident of the city, the sight of the population going about its daily business in surgical masks was an image that is impossible to forget. I suspect for many there were much more tragic images. The pervasiveness of SARS made it impossible to detach oneself from it and the spectre that it raised.

Before looking at some of the privacy issues that emerged during the course of the epidemic I would like to convey a few facts that illustrate the magnitude and consequences of the disease in terms human life and other costs. Let me offer you some reminder of the suffering.

- 1 1755 cases of SARS were identified of which 300 resulted in deaths. In mainland China 5,327 infections officially reported

with 349 deaths. The global total was of 8,400 infections and 916 deaths, of which two thirds occurred in Hong Kong and China. Various reasons for this high toll have been put forward. For example:

- ~ poor personal and public hygiene practices;
- ~ the healthcare sector being initially overwhelmed by the proportions of the epidemic;
- ~ an overly departmentalised response from various Government agencies that created command, co-ordination and communication problems
- ~ the close proximity within which people in Hong Kong live i.e. high rise apartment blocks; and
- ~ large two way traffic and human flows across the Hong Kong and Mainland China border.

2 The economic fallout from SARS was also very severe. Many businesses, especially in the restaurant and entertainment sector, closed down for good and drove unemployment to a high of 7.8% by the end of April. For example, the wholesale and retail trades sector contracted by 9.3% for the second quarter of 2003 and the restaurants and hotel sector by 31.7%. Some premium hotels recorded single figure residency rates and airlines cut up to half of their flights in any one week.

In the midst of all this rumours grew exponentially - SARS was the both the cause and effect of everything - although, as we were to establish there were powerful intervening variables in that causality. While citizens were constantly asked to take precautionary measures rumours, pet theories and disinformation abounded. Powerful phobias existed within the population, between Hong Kong and mainland China and between the rest of the world and Hong Kong and China. For example, boycotts of Chinese restaurants in Toronto and London. In one bizarre sighting in Hong Kong a man was seen out walking his dog. Both the man and the dog were wearing surgical masks!

Let me move to a consideration of the communications aspects of the epidemic and the response from various quarters for more information which, at times, clearly implied compromising privacy rights. I'll call this war of words the **The Public Right to Know**. And I mean to know **everything**.

## **The Public Right to Know**

Saturation media coverage and a jittery populace left the way open for calls for "the right to know." The leader of one of Hong Kong's political parties was quoted as saying:

**"The public's interest should override individual privacy interest at the moment." [James Tien].**

I hasten to add that not everyone agreed. A more circumspect view taken by other politicians reinforces what I said earlier about Hong Kong taking its human rights and privacy rights seriously.

Cognisant of the fears that SARS was causing in the community, the Hong Kong Government sought to protect the privacy of those infected with SARS, or those under surveillance, on the grounds that to do so upheld their human rights and because it did not want to stigmatise those suffering or their families. In March this led to one political party demanding that all infected patients in Hong Kong be named. The then Privacy Commissioner took the view that consent of the individual had to be sought before names could be named. Of course he was criticised for so doing because those holding opposing views wanted a radical approach to be taken. That radical approach, had it been implemented, would have meant casting privacy considerations aside. Furthermore, he advised that any disclosure of patients names by the Government should only be undertaken if it was felt that the measure equated with the test of what constitutes public interest. The government's view was endorsed by the chairman of the Hong Kong Medical Association who maintained that the identity of patients ought to be protected no matter what the circumstances. Other members of the Legislative Council felt that

naming would lead quickly to shaming and only add to the psychological distress that the infected and their families were experiencing.

The Department of Health and other agencies also withheld the names of patients on the grounds that not to do so would be a breach of confidentiality. From a very early stage therefore the Government was very protective of the privacy of individuals. However, a serious outbreak in one residential block in Kowloon led to fresh demands by the Legislative Council for the Department of Health to disclose the residential addresses of patients. Let me spend a little time depicting what happened because I think it marked a pivotal point in the entire saga of the epidemic. The outbreak in question took place in Kowloon in residential estate called Amoy Gardens.

### **The Amoy Gardens Incident**

The index case in Amoy Gardens was identified on the 14<sup>th</sup> March 2003 and for six days there were no further reports of infections among persons residing in the block. However, in the space of the four subsequent days infections rose to a peak of in excess of 70 cases on the day. By the time that SARS had run its full course no fewer than 329 residents were infected of whom 42 died. Of course this triggered many questions, the most significant of which was that the mode of transmission might not exclusively be by airborne droplets of body secretions. After an extensive onsite investigation this turned out to be the case.

Tragic as the Amoy Gardens incident was, it did ultimately provide evidence to suggest that transmission was not restricted to close contact between people but that there was something else in the environment that was the source of transmission. This was later verified and was an important piece of information in curbing the ravages of the epidemic. In Amoy Gardens it was established that both the sewerage and drainage systems were causes of the vertical spread of the SARS in one block in particular. As if to rub salt into the wound it was ascertained that a simple dilution of household

bleach poured down the drains and U traps would address the problem. As a result, preventative public health measures went into overdrive and public education programmes intensified.

Let me return to the public right to know. The concentration of infections in Amoy Gardens left the media and public asking for full disclosure of **all** facts on the grounds that this was the only course of action if the Government were to be regarded as responsible and credible force that was sympathetic to the needs of the community. This was an understandable demand but a rather selfish one. While people were dying around us, causing great distress in many locales in Hong Kong, the call for unlimited disclosure smacked of self-interest.

However, such demands were resisted by the Secretary for Health on the grounds that it would only heighten fears and result in discrimination if not acrimonious relations between residents occupying the same apartment block. Pressure mounted and in early April seven political parties jointly urged the Department of Health to identify infected persons place of residence. Of course, this demand immediately sparked further demands for the disclosure of their place of work, the hospitals treating patients the numbers of medical staff infected etc.

As you can see the insistence for more information escalated. As far as that commodity was concerned you could forget the concept of less is more: more information was never enough information to assuage the demands of the media and some politicians alike. However, the Government held the line and it was not until mid-April that the Department of Health agreed to informing the management companies of residential buildings in which infected persons had been living. However, it still refused to publish the names of the buildings in which they resided. With pressure mounting, on 11 April the Department of Health agreed to disclosing the building list where the infected had lived **prior** to hospitalisation, but it still withheld detailed addresses and the identity of patients. This was a very courageous decision on the part of the Government which was under tremendous pressure to



disclose. The critics response was to maintain that a less than totally transparent system fell short of satisfying the public interest and may, I say may, have accelerated the infection rate. However, that is speculative and a matter for epidemiologists to address. What is clear though is that the panel of experts that were convened to review the SARS epidemic made no official reference to this possibility in their final report.

Living through those times one is struck by the way in which less than responsible elements self-attributed SARS expertise and in so doing rationalised their demand for complete freedom of information.

Let me now turn to a consideration of the medical management information system used by the healthcare authorities during the earlier stages of the epidemic.

## **Communicable Disease Information Management**

Communicable disease information management was a cause for concern because the systems in place prior to the outbreak relied very much on family doctors, clinics and hospitals assuming responsibility for informing the appropriate authorities. However, in the earlier stages of the SARS epidemic they were unaware of the nature of the beast they were wrestling with. Once informed public health case workers would then undertake interviews and field visits to document individual cases. This system proved woefully inadequate given the rate at which the epidemic was spreading. It was claimed at one point that the website set up by an enterprising citizen depicting SARS infected areas was more complete and accurate than the official page on the Department of Health's website. What this may indicate is that the three organisations most directly concerned with mapping the incidence and spread of SARS – the Department of Health the policy bureau and the Hospital Authority were working at cross purposes and this was dysfunctional.

Nonetheless, as knowledge enhanced understanding, efforts were made to rectify the situation. The sharing of information and communications improved such that healthcare providers, hospitals, virologists and visiting experts were able to obtain raw data much more quickly. Three major steps were taken.

- 1 First, the Department of Health and the Hospital Authority collaborated to establish an e-SARS web-based system to generate real-time information exchange on newly infected cases thereby permitting caseworkers to trace and track contacts.
- 2 Second, a SARS-case Contact Information System – a data management system - was developed with a cluster analysis function for field epidemiologists to construct cluster trees and extract cases of identified clusters for rigorous analysis.
- 3 Third, the Major Incident Investigation and Disaster Support System, a crime investigation programme used by the Hong Kong Police Force, was deployed. This led to much improved early identification of the linkages between new infections, contact tracing and high risk locations of SARS thereby facilitating rapid implementation of public health measures.

These systems provided a much needed boost to the thousands of people working directly or indirectly on tackling SARS in terms of the quality and timeliness of the information received. Interestingly, it was acknowledged during the building of these inter-departmental systems that any interpretation of information should always strike an appropriate balance between the privacy rights of the individual and the broader-based rights of those suspected of having had contact with an infected person to know of this.

In seeking to effect that balance the Department of Health formulated a policy on privacy and the disclosure of information in order to instil a sense of personal responsibility and foster

community confidence in the rapidly evolving counter-measures being taken.

This leads me to review the line taken by the then Privacy Commissioner towards privacy interests and SARS

## **Personal Data Privacy and SARS**

I want to make it clear that the various agencies of government, and we are **not** one of them, were at pains to consult the Commissioner's Office regarding personal data and its public disclosure. What is indisputable is that the authorities could have used the law to disclose more information than they chose to do. Without question they were very conscious of the need to disclose the **minimum** amount of personal data on newly infected persons, patients and their contacts thereby upholding the ethics that govern patient/doctor confidentiality. They were also demonstrating what in the Commissioners' Office we would regard as being good personal data privacy practices.

The response could have been very different because the authorities could have invoked an exemption under the Health provisions of the Personal Data Privacy Ordinance. This provision states:

**“ Personal data relating to the physical or mental health of the data subject are exempt from DPP3 – use of personal data and change of use only with consent – in any case in which the application of the data would be likely to cause serious harm to the physical or mental health of the data subjects or any other individual.”**

They chose not to succumb to mounting demands to disclose and although I have a vested interest in saying so, I think they made the right call. From what I have been able to discern there is no evidence to support the view that this position in any way obstructed attempts to bring SARS under control.

In point of fact the SARS outbreak generated just **two** complaints to the Commissioner's Office. In one instance there was no prima facie case and in the other the case was withdrawn.

SARS is a highly contagious disease and the Hong Kong Government eventually realised the role of communications in trying to check the spread of the epidemic. The withholding of personal data by the authorities was something that divided opinion. On the one hand there was massive pressure to submit to demands for complete transparency. On the other, that approach seemed excessive and would have been interpreted as the Government capitulating to popular demand. If the social stigma argument is accepted then the full disclosure of personal data may have been tantamount to putting out the flames with gasoline. The Government resisted the temptation to cave in even though the stakes could not have been higher. I think they felt that their position was vindicated once appropriate surveillance information gathering and tracking measures had been put in place as those measures proved to be generally effective. Looking back there seems to have been no compelling need to divulge personal data of infected persons or the people they had had contact with to anyone other than healthcare providers.

At the Commissioner's Office we took the view that the disclosure of patients information should serve a purpose that was in the public interest but that it should be restricted to that personal data essential to serving that purpose. We also held the line with the Government that the identity of individuals should not be disclosed. We felt that was an appropriate application of the law at the time and we still do. Not only did it protect people's privacy but it also protected their human dignity.

So, what happened once the SARS epidemic subsided in Hong Kong?

## **The Aftermath of SARS**

In the aftermath of SARS the Chief Secretary appointed 11 distinguished epidemiologists, doctors and medical scientists to the SARS Expert Committee. With the exception of two academics nobody in the public sector in Hong Kong was appointed to the Committee. The terms of reference were:

- 1 to review the work of the Government, including the Hospital Authority, in the management and control of the SARS outbreak;
- 2 secondly, to examine and review the capabilities of the structure of the health care system in Hong Kong in terms of the prevention and management of infectious diseases such as SARS: and
- 3 to identify the lessons to be learned and make recommendations.

In its conclusions the Expert Committee stated, “... overall, the epidemic in Hong Kong was handled well, although there were clearly significant shortcomings of system performance during the early phase when little was known about the disease or its cause.” Eight conclusions were drawn covering topics such as preparedness for future epidemics, surveillance and reporting systems, formulating clear command and control structures and ensuring transparency and effective communication. On the latter point the Committee dwelt on the fear that can rapidly be spread in a community trying to get to grips with a poorly understood communicable disease and consequences such as unwarranted discrimination. Although communications, command and coordination aspects of the epidemic would, with hindsight, have been handled very differently the World Health Organisation was moved to comment that Hong Kong had been, “exemplary in its transparency of reporting, even when the economic consequences of doing so were known to be significant.” No suggestion was made that the Government got its values wrong and that the privacy rights of individuals should have been sacrificed in service of the public good.

Subsequent to the Expert Committee report being published the Government launched a raft of measures to try and enhance public hygiene with a view to better managing the conditions in which transmission of a disease might be facilitated. One such initiative was the **Team Clean** programme. This was a plan to locate CCTV cameras in certain locations in Hong Kong that public health, welfare and environment officers had identified as black spots. The intention was for the cameras to have a deterrent effect and to record any activities that may create the conditions in which disease might be spread. In addition, the Government took action to compel landlords and tenants to repair pipework and other fixtures that were both an eyesore and a public health risk.

The Commissioner's Office advised the Government on the precautions that should be taken when locating cameras in public places e.g. specific suggestions on notification and retention of records and the duration of the programme. Understandably there was widespread support for the scheme even though everyone may not have fully realised its privacy-intrusive nature. That said, our research indicates quite clearly that there is a tolerance for CCTV cameras in public places in Hong Kong. The Commissioner's Office raised no objections in principle to the scheme which was implemented. As I mentioned earlier, we take a pragmatic rather than a purist stance on personal data privacy.

## **Conclusion**

It has been said that at one point the rumours and fear surrounding the spread of SARS travelled more rapidly than the disease itself and it is in that context that one must address the information issues and their privacy ramifications. I will not comment on the matter of communications because that has been dealt with comprehensively by the Expert Committee. On the matter of privacy I think that the Government was correct in taking a conservative approach to disclosure and resolute stand in protecting the privacy of patients. That approach clearly indicated a respect for their dignity and human rights. I cannot speak for

the Government as to whether they would do things differently in the event of an outbreak of something like Avian Flu but my office would certainly advise them, as we did with SARS, that the onset of such an intimidating epidemic should not in any way signal that the denial of human rights is something that is acceptable. It is not. As I said at the beginning, we have worked hard to establish them and I am pleased to report, as the SARS epidemic demonstrates, that even under the most testing of circumstances privacy rights were not sacrificed as they could so easily have been.

Without a doubt there was a great deal painful but valuable learning during the entire episode of SARS and the measures the government has subsequently taken are evidence of the fact that the lessons have been learned and applied. Whether that learning will stand up to the demands of a full blown Avian Flu epidemic is not something I am knowledgeable enough to comment upon. But, I do rest easily with the advice the Commissioner's Office provided during the epidemic and I would commit to a similar approach were the worst to happen at some point in the future.

**Roderick B. Woo**

**Privacy Commissioner for Personal Data, Hong Kong SAR  
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