



**Jamaica AIDS Support for Life**  
**Submission to the Joint Select Committee reviewing the Bill entitled: An Act to**  
**protect the privacy of certain data and concerned matters**

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**Prepared By: Jamaica AIDS Support for Life**

**Contact:** Kandas Levermore

Executive Director

[klevermorejasl@gmail.com](mailto:klevermorejasl@gmail.com) | 969-0282 / 875-2737

SUBMISSION TO THE JOINT SELECT COMMITTEE OF PARLIAMENT APPOINTED TO REVIEW THE DATA PROTECTION BILL - An ACT to protect the privacy of certain data and for connected matters.

### **BACKGROUND OF CONTRIBUTING ORGANIZATION**

Jamaica AIDS Support for Life hereinafter referred to as JASL is the oldest and largest AIDS-focused, human rights, non-governmental organisation in the region. It is dedicated to preserving the dignity and rights of persons living with HIV and AIDS, and those vulnerable to HIV infection. Importantly, a key component of the organization's work is to create an enabling environment for those infected and affected by HIV through bio-medical and social support services. In its fight against the spread of the epidemic in Jamaica, the organization has a comprehensive public health approach through prevention efforts such as public education around HIV, as well as efforts to protect those who are most vulnerable to contracting the virus.

JASL as a service provider is classified as a "data controller" and more specifically will be one in possession of an "accessible record" as we are in the business of providing health care. Stigma and discrimination has been the leading barrier to people accessing health services (**MOH 2014**). More specifically stigma and discrimination on the basis of HIV status and sexual orientation has deterred persons in need of health care from accessing, has caused persons to be dismissed from their jobs and driven out of their homes and communities. (**UNAIDS 2016**).

It is the position of JASL that while this piece of legislation is commendable and of vital importance we cannot purport to enact legislation to protect the information of all citizens and at the same time put a significant percentage of our people at a disadvantage by virtue of said legislation.

This submission is made primarily to ensure that while the legislation around securing citizens data is enacted same is not done at the peril of the ordinary man who in the process of making a living manages peoples data and that sensitive information around people's health is not subject to whoever may wish to see but continues to be protected by virtue of the confidentiality arrangements we have with our clients..

Our recommendations are in keeping with the Government of Jamaica's commitment, as per vision 2030, to ensure that all Jamaicans know their rights and responsibilities and stand equal before the law.

Specific recommendations include:

1. Expressed prohibition for Insurance companies to require HIV test to provide coverage
2. A more deliberate effort in the wording of the act to protect people's health information.
3. Revisiting the definition of a minor.
4. A more equitable system of obligations placed on 'data controllers'

5. The inclusion of an oversight body for the Commissioner
6. The broadening of the definition of consent to include informed consent and coerced consent.

### **Recommendation # 1**

#### ***Express prohibitions for insurance companies to require HIV test to provide coverage.***

The practice of requiring persons to provide health records specific to their HIV status as a pre-condition for insurance coverage has been a common practise in Jamaica. There are insurance companies who will not provide coverage to a person infected with HIV and there are those who will provide conditional coverage under the circumstance.

As the lead civil society organization working in HIV for over 25 years we find this practice discriminatory and see this piece of legislation as the opportunity to expressly prohibit same. Section 65 (1) reads:

*“A person concerned with the provision of goods, facilities or services to the public or a section of the public , whether for payment or not shall not as a condition of providing or offering to provide any goods, facilities or services to an individual, require that individual supply or produce a ‘relevant record’”*

The section continues to explain that this would not apply to a person that showed that this imposition was required by law, by a court order or justified as being in the public interest. It can be inferred that by interpretation this section would speak to the issue at hand. We however believe that seeing the practice is so widespread an expressed provision to address same is necessary as opposed to leaving it up to interpretations that can go one way or the other.

### **Recommendation # 2**

#### ***A more deliberate effort in the wording of the act to protect people’s health information, sexual orientation and HIV status.***

The bill in section 2(1)(a) defines a ‘accessible record’ as a ‘health record’ and goes further to describe a ‘health record’ as any record in the custody or control of a health professional.

In listing what is considered sensitive personal data the bills name “sex life” It is our position that the act should clearly define what sex life means and we propose that it should cover a person’s activity and sexual attractions as a whole to include their sexual orientation and sexual behaviour. The Data Protection Act of Trinidad and Tobago 2011 can be instructive in this regard as it explicitly list under sensitive data Sexual orientation or sex life.

While the bill recognizes doctor patient confidentiality and contractual obligation that may require that certain data be kept confidential it provides for the commissioner to examine the grounds on which the data controller refuses to provide the data and make a determination whether the grounds for refusal is sufficient.

The organization proposes that HIV related information must be included within the definitions of personal or medical data and subjected to the same level of privacy that is afforded to medical data in general. The challenges related to HIV are well known and as such, this submission is to ensure that an individual's HIV status is expressly protected in law and is not left up to judicial interpretation when implied in the legislation. HIV status should not be shared except and only for medical purposes required for proper diagnoses and to administer necessary treatment. It must be so protected that for it to be revealed the consent required will have to be explicit or any processing of such data must be necessary for medical purposes such as sharing the data with another medical professional who has the same duty to confidentiality.

We propose that Health records be totally exempt from any provisions under this act and can only be made to be disclosed by an order from a legally constituted court of law or other existing legislation that contains provisions for same.

### **Recommendation # 3**

#### ***Revisiting the definition of a minor***

The bill in the preliminary section defines a minor as “*an individual under the age of eighteen*”. We are recommending that this provision be revisited and the age 16 be substituted.

It is common practice in Jamaican law that a minor is defined as a person under the age of 18 in some pieces of legislation, 16 in others and both 16 & 18 in different sections of the same piece of legislation. **The Sexual offences Act** is one such example where the definition of a minor varies according to section. The Law Reform Age of Majority Act allows a child who has attained the age of 16 to consent to medical treatment. Defining a minor as a person under the age of 18 in this piece of legislation will prove problematic as it would mean that the parents of a seventeen year old who access services at our facility could demand that we produce that persons health records without the consent of that person.

### **Recommendation # 4**

#### ***A more equitable system of obligations place on data controllers***

On the matter of ‘Data Controllers’ the bill outlines as follows:

*“Any person or public authority who either alone or jointly or in common with other persons determines the purposes for which and the manner in which any personal data are , or are to be processed, and where personal data are processed only for purposes where they are required under any enactment to be processed, the person on whom the obligation to process the data is imposed by or under that enactment is for the purposes of this act a data controller”*

This definition captures a wide cross section of persons from the sole trader to large corporations. It is inequitable to place the same obligations on persons from such a wide category as it will be almost impossible in some instances for one party to meet obligations as outlined under the act as opposed to another. The obligations that the bill seeks to place on data controllers should be categorized according to size, age, sensitivity of data handled and financial position.

We believe that this is important as while the bill seeks to implement well needed measures if obligations are the same for all categories of persons we are basically setting them up to be in contravention and ultimately may be closing the doors of operations that provides a living for a family or a few families.

We are not asking for the law to be too simple because as Benjamin Franklyn reminds us “Laws too gentle are seldom obeyed” but in the same breath opines that “Laws too severe are seldom executed”.

## **Recommendation # 5**

### ***The inclusion of an oversight body for the commissioner***

Section 4 of the proposed legislation creates the post of an Information commissioner that shall be appointed by the Governor General after consultation with the Prime Minister and the Leader of the opposition. This office is given far reaching uncensored powers under the proposed legislation except for the requirements that some of its actions be sanctioned by both houses of parliament.

The Commission Acts as he see fit albeit in accordance with “good practice”. While it is good practice in a democracy to have independence or persons in such positions such independence cannot go unchecked or not thoroughly checked. This oversight body while not interfering with the Commissioners independence will provide for better checks and balances in the system. We propose that this body should comprise of members of the government, the opposition, civil society , the private sector and the church.

American Physician Dean Ornish said “I strongly believe that the founding fathers of our country got it right; power corrupts and anytime you have too much power in one place it tends to get abused so checks and balances are always needed”.

## **Recommendation # 6**

### ***The broadening of the definition of consent to include “informed consent” and “coerced consent”***

The term “consent” is used numerous times in the bill and it is defined in section 2 as follows:

*“Consent , in reference to any consent required to be given by data subject to the processing of data mean expressed consent given orally or in writing and includes any such expression of consent given by-*

- a. Legal personal representative of the data subject;*
- b. Any individual to whom the data subject delegates the right to give or withhold consent to the processing; or*
- c. In the case of a minor a parent or legal guardian of the minor*

We submit that the terms ‘informed consent’ and ‘coerced consent’ be inserted into the bill so it provides wider protections for the most vulnerable among us. As it stands consent given orally is enough to satisfy obligations under the proposed legislation and may put individuals who do not quite understand at a disadvantage. The obligation therefore must be placed on the ‘data controller’ to ensure that the ‘data subject’ clearly understands what he or she is consenting to and the implications of said consent.

We submit that the law must state that consent has to be *freely given* (not coerced) and *informed* where there is an understanding of the scope of consequences.

A request for consent must therefore be:

- Presented in clear and accessible forms
- In clear, plain language
- Prior to consent being given, data subjects must be informed that consent may be withdrawn at any time, even after consent have been given.
- The burden of proof that valid consent has been given by a data subject lies with the controller. Consequently, it is essential that controllers document all consents obtained from data subjects.
- For consent to be valid and relied upon it must respond to clear imbalance between the data subject and controller, if the controller is a public authority or an employer asking for consent from employees.
- Based on the foregoing, consent should not be legally valid if the fulfilment of a contract or promotion is dependent on that consent, when consent is not necessary for such fulfilment.

## **Conclusion**

Confidentiality is incorporated as one of the key guiding principles of the National HIV/AIDS policy in accordance with ILO principles on HIV/AIDS and the world of work. National policy also stipulates that employers and workers should be informed about these principles and their right to privacy. It would therefore be counterproductive to these already established standards for new legislation to be enacted that goes against these established principles or does not expressly reinforce them. It is the duty of our legislators to ensure that legislation is as comprehensive as possible and is so drafted to reflect the realities of the day. We anticipate the committee's careful consideration of our submission and ultimately including the proposed in the final draft of The Data Protection Bill.