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TITLE:- "THE DATA PROTECTION IMPLICATIONS FOR OUR DNA BILL"

PRESENTED BY DRUDEISHA CAULLYCHURN-MADHUB,DATA PROTECTION COMMISSIONER,
DEFENCE AND HOME AFFAIRS DEPARTMENT, PRIME MINISTER'S OFFICE

TEL :- 201 36 04

PMO-DPO@MAIL.GOV.MU

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- The Data Protection Act 2004 (DPA) gives individuals the right to know what information is held about them. It provides the legal framework to ensure that personal information is handled properly.
- Forensic DNA analysis joins a very exclusive club of physical intrusions that society tolerates from the state.
- Therefore it is essential that the intrusions inherent in forensic DNA analysis be restricted to those circumstances that are truly necessary and reasonably justifiable in a democratic society.

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- Envisioning the appropriate level of privacy protection for the use of DNA database has been a complex endeavor for many countries.
- The question is whether privacy invasion is outweighed by a stronger societal interest in using DNA?
- Any regulatory framework enabling the setup of a DNA database has to address the privacy issue and make a compelling case for using such a database.
- Any storage and use of personal information is an invasion of the individual's privacy. DNA information is personal data and the FSL, a data controller falling within the purview of the Data Protection Act (DPA).

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✓**What does processing, legally speaking, mean?**

- "processing" means any operation or set of operations which is performed on the data and includes -
- collecting, organising or altering the data;
- retrieving, consulting, using, storing or adapting the data;
- disclosing the data by transmitting, disseminating or otherwise making it available; or
- aligning, combining, blocking, erasing or destroying the data.

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- "personal data" is defined under the DPA as-
- data which relate to an individual who can be identified from those data; or

- data or other information, including an opinion forming part of a database, whether or not recorded in a material form, about an individual whose identity is apparent or can reasonably be ascertained from the data, information or opinion.

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➢ Personal data is defined under the DPA as data, whether recorded electronically or otherwise, which relates to an identified or identifiable living individual, i.e, whose identity is apparent or can reasonably be ascertained from the data.

➢ **What does sensitive personal data mean?**

It means personal information of a data subject which consists of information as to his/her -

- racial or ethnic origin;
- political opinion or adherence;

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- religious belief or other belief of a similar nature;
- membership to a trade union;
- physical or mental health;
- sexual preferences or practices;
- the commission of an offence; or
- any proceedings for an offence committed or alleged to have been committed by him, the disposal of such proceedings or the sentence of any court in such proceeding.

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- **Can sensitive data be processed by a data controller ?**
  - No sensitive data can be processed without the consent of the data subject or where the latter has made the data public, subject to certain further exceptions as provided in the Act.
  - However, as provided in section 25(2) of the DPA no consent is required where the data controller is performing any obligation imposed by law to which he is a subject.

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Who is a data controller?

- He is a natural or legal person person who, either alone or jointly with any other person, makes a decision with regard to the purposes for which and in the manner in which any personal data are, or are to be, processed.

- In short, he is the person who processes personal information of individuals.

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- A data controller is under the obligation to register with the DPO. Otherwise, it is an offence. Registration forms are available at the DPO or on the website as from this week.
- A medical practitioner would usually be the controller of the data processed on his clients; a company would be the controller of the data processed on its clients and employees; a sports club would control the data processed on its members and a public library controls the data processed on its users.

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- The DPA has been fully proclaimed on the 16th of February 2009(except for section 17 relating to powers of entry and search).
- Additional Amendments have been made to the DPA through the Additional Stimulus Package(Miscellaneous Provisions) Act 2009 as regards the prospective registration of data processors and to give more independence to the Commissioner in the exercise of her functions.

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- As per section 46 of the DPA, the processing of personal data for the purpose of the prevention or detection of crime is exempt from some of the principles of data protection and certain sections of the Act.

Section 46 provides:-The processing of personal data for the purposes of -

the prevention or detection of crime;

the apprehension or prosecution of offenders; or

(...)shall be exempt from -

the Second, Third, Fourth and Eighth data protection principles;

sections 23 to 26; and

Part VI of this Act in respect of blocking personal data,

to the extent to which the application of such provisions would be likely to prejudice any of the matters specified in paragraphs (a) to (c).

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- The eight principles elaborated in the First Schedule of the Data Protection Act provide some pragmatic framework to address, answer and reason a number of vexing policy issues on the privacy regulation of DNA databases.
- The principles of privacy-sensitive processing of personal data are as follows:-
  - The "collection limitation principle" provides that the collection of personal information must not be limitless;

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that personal information should be lawfully and fairly obtained, and where appropriate with the consent of the individual concerned.

- The "data quality principle" focuses on the need of information to be relevant to the purpose for which it is collected and used, and should be kept up-to-date.
- The "purpose specification principle" sets out the requirement that personal information collected for one purpose can not subsequently be used for a different, incompatible purpose.

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- The "use limitation principle" specifies that personal information may not be disclosed or used for other purposes except with the individual's consent or by the authority of law.

- The "security safeguard principle" requires security measures to prevent loss or unauthorized access, modification or disclosure.
- The "openness principle" demands that the use of personal information be transparent to the user.

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- The "individual participation principle" permits the individual to have access to the personal information stored about him or her as well as giving him or her a right to have inaccurate information modified.

- Finally, the "accountability principle" stipulates that the processor of personal information must be held liable for violations of his duties.

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- The data protection principles place an emphasis on the purpose of the use of personal information and the need to narrowly tailor the means of collection to the purpose.

- This is where the collection limitation principle, the data quality principle, the purpose specification principle and the use limitation principle come together. The more invasive the means, the better the fit with the purpose has to be.

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➢What is data-matching under the DPA?

The "data matching procedure" means any procedure, whether manually or by means of any electronic or other device, whereby personal data collected for one or more purposes in respect of 10 or more data subjects are compared with personal data collected for any other purpose in respect of those data subjects where the comparison –

- is for the purpose of producing or verifying data that; or

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- produces or verifies data in respect of which it is reasonable to believe that it is practicable that the data,
- may be used, whether immediately or at any subsequent time, for the purpose of taking any adverse action against any of those data subjects;

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The data-matching procedure may be carried out subject to four conditions being fulfilled:-

1. the data subject whose personal data is the subject to that procedure has given his consent to the procedure being carried out;
2. the Commissioner has consented to the procedure being carried out; and
3. the procedure is carried out in accordance with such conditions as the Commissioner may impose; or
4. it is required or permitted under any other enactment.

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A DATA CONTROLLER SHALL NOT TAKE ANY ADVERSE ACTION AGAINST ANY DATA SUBJECT AS A CONSEQUENCE OF THE CARRYING OUT OF A DATA MATCHING PROCEDURE–

UNLESS THE DATA CONTROLLER HAS SERVED A NOTICE IN WRITING ON THE DATA SUBJECT –

SPECIFYING THE ADVERSE ACTION IT PROPOSES TO TAKE AND THE REASONS THEREFOR;

STATING THAT THE DATA SUBJECT HAS 7 DAYS AFTER THE RECEIPT OF THE NOTICE TO SHOW CAUSE WHY THE ADVERSE ACTION SHOULD NOT BE TAKEN;

SUBSECTION (2) SHALL NOT PRECLUDE A DATA CONTROLLER FROM TAKING ANY ADVERSE ACTION AGAINST ANY DATA SUBJECT IF COMPLIANCE WITH THE REQUIREMENTS OF THAT SUBSECTION SHALL PREJUDICE ANY INVESTIGATION INTO THE COMMISSION OF ANY OFFENCE WHICH HAS BEEN, IS BEING OR IS LIKELY, TO BE COMMITTED.

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- "Adverse action", in relation to a data subject, means any action that may adversely affect the person's rights, benefits, privileges, obligations or interests" as defined in section 2 of the DPA.

The FSI is further not exempt from the requirements imposed under section 32 of the DPA which relates to the data matching procedure defined under section 2 of the act wherein the FSL should also obtain apart from the consent of the data subject, the data protection commissioner's consent before this procedure is carried out which may also be subject to such conditions as may be imposed by the commissioner, or where the law provides otherwise.

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- The objectives of the Bill should be clearly defined so as to restrict the powers of enquiry of the police **to serious offences who** will be able to make use of DNA samples for the purpose of helping to elucidate the involvement of a person in connection to serious **offences**.
- I suggest that the use of DNA samples be restricted to serious offenders as is the current trend in the world namely, Australia, Canada and Germany unlike the UK whose legislation has been heavily criticized for accepting any "recordable offence".

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- Section 2 of the Bill should thus include a definition of “serious offence”.
- Committing a severe crime permits the state to intrude further into one's privacy than committing a lesser crime. This sliding scale facilitates assessing the "weight" of the privacy right.
- Crimes against persons, like murder or rape, are particularly unacceptable in our society.

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- This is why individuals committing such crimes face the strongest forms of punishment and may have to accept a reduced right to privacy.
- Similarly the "weight" of the government benefit is related to why the government wants to solve a particular crime.
- Here, too, searching for (and finding) a murderer provides a greater "benefit" than searching for the proverbial "chicken thief". The required balancing combines these two factors. The government's case is strongest when searching for a murderer amongst convicted murderers, and much weaker when trying to find a "chicken thief" among convicted "chicken thieves".

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- The regulatory challenge is to create a DNA database statute that takes this kind of balancing into account. DNA evidence should *not* be collected from suspects as a matter of routine nor should it be a fishing expedition or a weapon of mass surveillance.
- Consent of the data subject is vital. Section 2 of the Bill should define consent which must contain the following elements: it must be voluntary, informed, specific and in writing.

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- The Bill should include the court's authorization for the carrying out of a forensic procedure on a child or an incapable person in the event the parent is unable to do so as is the case in Germany.
- Further, a restriction should be provided in the Bill with regard to the minimal age of a person to be subject to the carrying out of forensic procedures. In Australia, a person who is under 10 is not subject to the carrying out of forensic procedures.

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- Before determining whether to make a request for a DNA sample, a police officer must have regard to :-

(a) the nature of the offence **and the circumstances in which it was committed**;

(b) The degree of the person's involvement in the offence;

(c) The existence of a lesser intrusive way of obtaining evidence; and

(d) the age and the physical and mental health of the person.

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- Subsection (d) takes into account the concept of minimal risk which has been defined in section 102 (h) (i) of the US Code of Federal Regulations as:-

"the probability and magnitude of harm or discomfort anticipated … are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests."

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- An application to the Judge in Chambers where made in case of refusal by the person for the collection of his DNA should be subject to stringent criteria to be satisfied by the Police, i.e , it must be able to satisfy the test of reasonableness in making the application,i.e, the police must be reasonable satisfied that the person may be connected with a serious offence.
- A DNA Population Statistical Database should be set up **but subject to such procedures and guidelines as may be laid down by the FSL.**

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- Thus the FSL may develop a research protocol for the DNA population statistical database, the overriding principle of which would be confidentiality, privacy and appropriate security safeguards. It must specify the mode of storage of the DNA information, i.e., it should be in de-identified or coded form.
- The assistance of the Data Protection Office may be envisaged by the FSL for the creation of such a protocol.

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- The DPO may also develop a Code of Practice for the FSL, for that matter, should this be required .
- Forensic procedure must be carried out in circumstances affording reasonable privacy to the suspect. This includes not carrying out the procedure in the presence or view of a person of the opposite sex to the suspect, not removing more clothing than is necessary, nor involving more visual inspection than is necessary.

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Questioning of the suspect should also be prohibited during the carrying out of the procedure.

The protocol must further provide that, in seeking informed consent from a *volunteer*, the following information must be provided:

an explanation of the purpose of the research and the expected duration of the participant's participation,

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a description of the procedures to be followed, and identification of any procedures which are experimental;

a description of any reasonably foreseeable risks or discomforts to the subject;

a description of any potential benefits to the subjects or to others;

a disclosure of appropriate alternative procedures;

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- a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained;
- for research involving more than minimal risk, an explanation as to whether any compensation or medical treatments are available if injury occurs;
- an explanation of whom the subject should contact regarding queries related to the research;
- a statement that participation is voluntary, and that refusal to participate, or withdrawal from the research at any time, will involve no penalty or loss of benefits to which the subject is otherwise entitled.

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- *Thank You*
- *Any Questions or Comments?*