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THE COUNTRY'S NEW DNA LAW RAISES PRIVACY CONCERNS

Context:

▶ The DNA Technology (Use and Application) Regulation Bill, 2019 was recently introduced in Lok Sabha by Mr. Harsh Vardhan, Minister for Science and Technology.

Introduction:

- ▶ The utility of DNA based technologies for solving various issues is well recognized across the world.
- **▶** DNA technology is used to help enforcement agencies identify both perpetrators and victims in criminal cases.
- ▶ In medicine, DNA is used to identify the susceptibility of a person to diseases such as cancer and Alzheimer's.
- >> In civilian life, DNA can be used to establish parentage of children or sibling relationships.
- Therefore, worldwide various countries have felt the need of strict regulation in the use of DNA data. Thus, with the proposal for a new law, there are hopes that the new law would fill a major regulatory gap, as the use of DNA technology in India has been left unregulated for a long time.
- ▶ Unfortunately, there are major lacunae in the way the new law addresses core issues such as privacy and fundamental rights.

Key provisions of the Bill:

- **▶ Data Banks:** As per the Bill, national and regional DNA data banks will be set up for maintaining a national database for identification of victims, suspects in cases, undertrials, missing persons and unidentified human remains.
- ▶ **Punishment:** According to it, those leaking the DNA profile information to people or entities who are not entitled to have it, will be punished with a jail term of up to three years and a fine of up to Rs. 1 lakh. Similar, punishment has also been provided for those who seek the information on DNA profiles illegally.
- **Wage:** As per the bill, all DNA data, including DNA profiles, DNA samples and records, will only be used for identification of the person and not for "any other purpose".
- **▶ Consent:** Authorities are required to obtain consent for collection of DNA data in certain situations.

- 1. For arrested persons, authorities are required to obtain written consent if the offence carries a punishment of up to seven years. If the offence carries more than seven years of imprisonment or death, consent is not required.
- 2. Further, if the person is a victim, or relative of a missing person, or a minor or disabled person, the authorities are required to obtain the written consent of such victim, or relative, or parent or guardian of the minor or disabled person.
- **▶ Regulation:** The Bill establishes a DNA Regulatory Board to accredit the DNA laboratories that analyse DNA samples to establish the identity of an individual.
- **▶ Identification:** The bill's provisions will enable the cross-matching between persons who have been reported missing on the one hand and unidentified dead bodies found in various parts of the country on the other, and also for establishing the identity of victims in mass disasters.

Major issues regarding the bill

1. Lack of consent provision in civil cases:

- The law does not require the consent of an individual while giving DNA samples in civil matters such as a paternity suit.
- The ethic behind the need for consent is that a person's bodily substances include DNA, which not only identifies the person, but also reveals her genetic information such as physical and medical traits.
- Such information may affect her privacy, and so consent offers a safeguard against DNA misuse.

2. Storage of data regarding civil cases:

- ➤ Consider the provision related to the national DNA database that is being created under the law. As the name suggests, the database is a central repository of DNA information of individuals covered by the law.
- ▶ While the database will have information related to criminal offences, the law is unclear on whether DNA collected for civil cases will be stored in this database.
- This is because the law requires all DNA laboratories to share DNA test results with the data bank. Therefore, were a DNA laboratory to analyse a DNA sample in the course of a private dispute between parties (say, an in vitro fertilization clinic and a pregnant woman), would it share this information with the data bank?
- ➤ The Bill does not state that DNA information related to civil matters will not be stored in it. Note that the Combined DNA Index System (CODIS) in the US and the National Criminal Intelligence DNA Database in the UK are national DNA data banks with information related only to criminal investigations.

3. DNA data (vs) Right to Privacy:

- ▶ If DNA information related to civil matters is stored in the data bank, it may violate the fundamental right to privacy as laid down by the Supreme Court.
- ➤ The Court has stated that the right to privacy may be infringed only through the enactment of a law, and that law must achieve a public purpose that's proportionate to the infringement of privacy. Since the storage of DNA profiles for civil matters (such as paternity suits and medical diagnoses) may not serve a public purpose, it may violate the right to privacy.

4. DNA data regarding Medical and diagnostic settings:

- ▶ A more fundamental issue is ambiguity on whether the law intends to regulate DNA tests conducted in medical and diagnostic settings.
- ➤ For instance, many laboratories across the country offer such tests to determine a person's predisposition to cancer, diabetes and other diseases
- ➤ Such testing can also be used to identify an individual. For example, breast cancer can be diagnosed by analysing mutations in the BRCA1 gene, which involve analysis of large parts of an individual's DNA, which could provide enough information to identify an individual.
- The law does not address how this DNA data will be stored, for how long, whom it will be shared with (such as a person's health insurer), and when it will be deleted.

Conclusion:

- The gaps in the new DNA law dovetail into the larger issue of the lack of a data privacy law, which was raised by several Members of Parliament opposed to the law.
- While introducing it, Union minister stated that the law intends to regulate DNA testing for identifying criminals, victims, missing, and deceased persons. Clearly, the law goes beyond this objective.
- **▶** So, the bill needs to undergo rigorous scrutiny by a cross-section of experts and wider consultations.
- This can be achieved if the Bill is referred to a parliamentary committee. Otherwise, it could be a missed opportunity to effectively regulate the use of DNA technology.