

Responsible AI and Data Protection in India in the Healthcare Sector: National Perspectives

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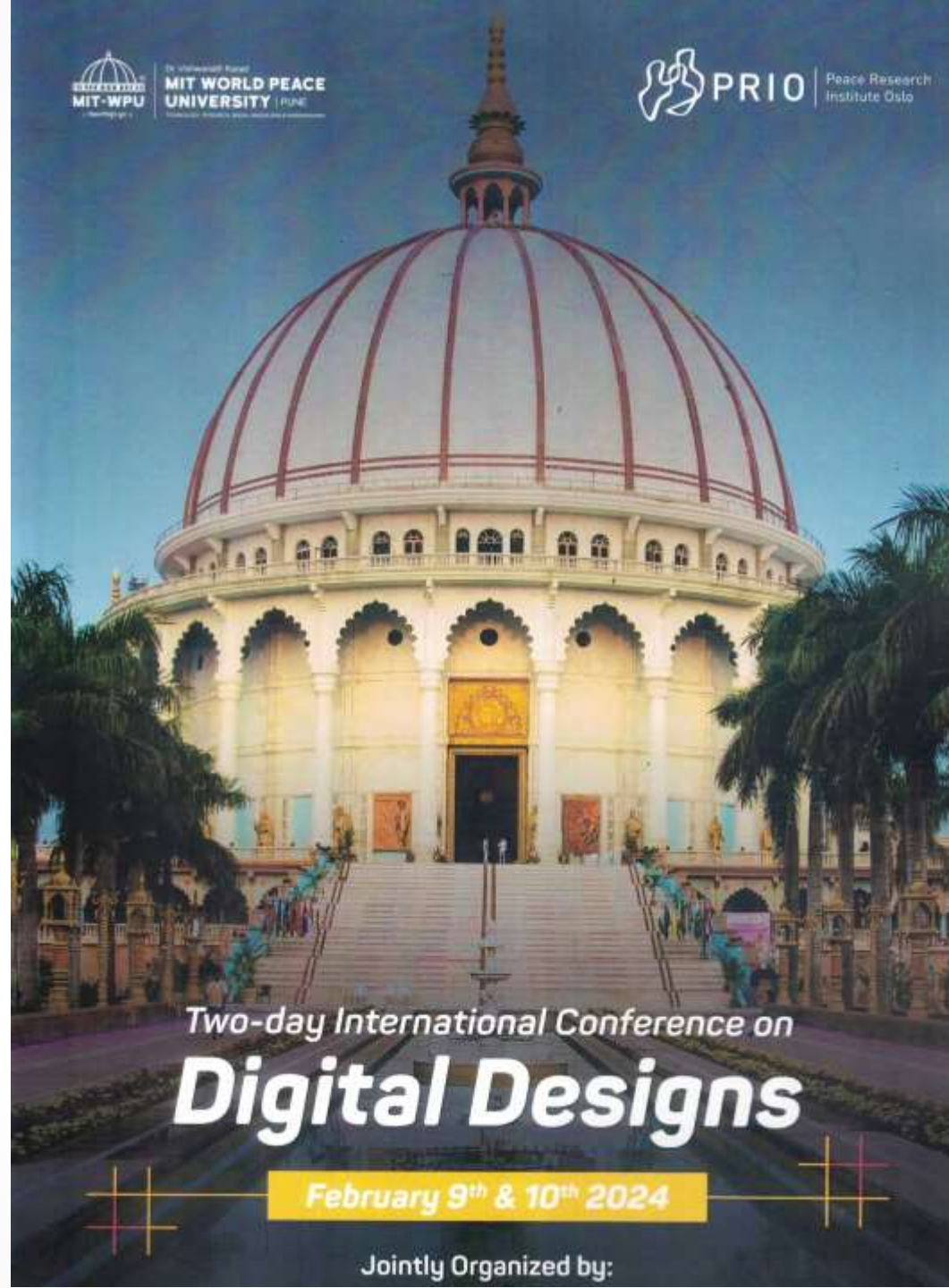
New Delhi, India

www.anupkumardas.blogspot.com

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Context

- Responsible Artificial Intelligence (AI) enables the design, development and deployment of ethical AI systems and solutions.
- Ethical AI fosters moral values and enables human accountability and understanding.
- Having a responsible AI system in place ensures fairness, reliability and transparency.
- Trustworthy AI standards help the data scientists and software developers to deploy Responsible AI models.
- Bigtech solutions such as AI tools can be designed in a way to make the world peaceful.



NATIONAL STRATEGY FOR ARTIFICIAL INTELLIGENCE #AIFORALL

JUNE 2018

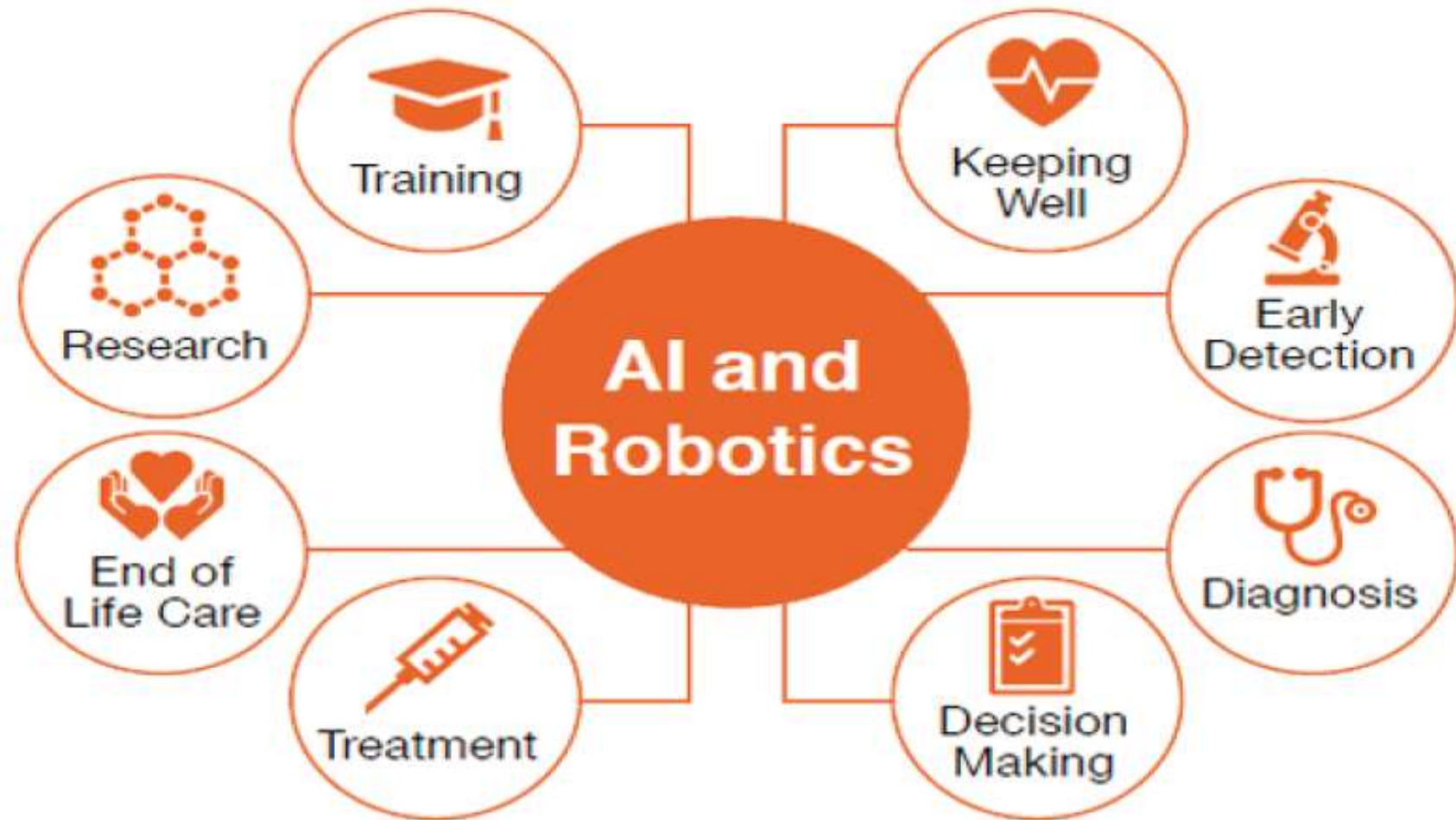
The NITI Aayog released the **National Strategy for Artificial Intelligence (NSAI)** in June 2018 as a Discussion Paper with a tagline #AIforAll.

- AI is poised to disrupt our world. India, the fastest growing large economy has a significant stake in the AI revolution. NITI Aayog acknowledged this in NSAI.
- India has the potential to emerge as a leader in the AI revolution.
- NSAI acts as a lodestar to leverage AI for serving the greater good of the nation.
- NSAI seeks to catapult India onto the world stage of AI superstars through innovative, inclusive & indigenous development of a technologically-charged, collaborative ecosystem.
- India's workforce, infrastructure, and institutions, including the NSAI, contribute to India's unique scalability and implementation of AI.
- Source: NITI.gov.in

More About the National Strategy for Artificial Intelligence

- According to NSAI, India has only 64 doctors available per 1,00,000 people compared to the global average of 150.
- NSAI advocates the use of AI across various sectors & states the 'Kumbh Mela Experiment' among the best-use cases of AI in India.
- Healthcare Key Areas: Faster and easier access through AI-driven diagnostics, personalized treatment, early identification of potential pandemics, and imagine diagnostics.
- Source: NITI.gov.in

Figure 10: Potential use cases of AI in Healthcare



Source: NITI Aayog (2018). National Strategy for Artificial Intelligence: Discussion Paper.

Unclear privacy, security and ethical regulations

Unattractive Intellectual Property regime to incentivize research and adoption of AI

Key challenges to adoption of AI in India

Low intensity of AI research

Inadequate availability of AI expertise, manpower and skilling opportunities

Lack of enabling data ecosystems

High resource cost and low awareness for adopting AI in business processes



NITI Aayog

<http://bit.ly/2kPGWFK>

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Source: [Twitter.com](#)

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RESPONSIBLE AI #AIFORALL

Approach Document for India
Part 1 - Principles for Responsible AI

FEBRUARY 2021



RESPONSIBLE AI #AIForAll

Approach Document for India:
Part 2 - Operationalizing Principles for Responsible AI

AUGUST 2021

Seven Responsible AI (RAI) Principles

- Safety and reliability,
- Inclusivity and non-discrimination,
- Equality,
- Privacy and security,
- Transparency,
- Accountability, protection, and
- Reinforcement of positive human values.

Responsible AI: Part 1 – Principles for Responsible AI

Key Takeaways

- There is a need for fine balancing between large-scale adoption of AI for public good and protecting societal interest.
- There are two main considerations when it comes to ethical challenges: a) system considerations and b) societal considerations.
- The system considerations primarily deal with challenges such as lack of understanding of AI functioning, explaining AI decisions and assigning accountability.
- The societal challenges are focused on impact on jobs and unrequired psychological profiling.
- There are 7 broad principles that needs to be adhered to when managing responsible AI.
- In addition to this, it is important to see that the manner in which such principles are implemented is enabling a positive environment for adoption of responsible AI ecosystem in the country.
- Source: [Indiaai.gov.in](https://indiaai.gov.in)

Responsible AI: Part 2 - Operationalizing Principles for Responsible AI | Key Takeaways

- Operationalizing and implementing principles laid down for Responsible AI is the key to realize the results;
- A balance needs to be attained between maximizing overall benefits along with minimizing risks while adopting these principles;
- Bridging sectoral and regional gaps to drive a coordinated response to challenges arising out of AI is important;
- There is a need to inculcate an attitude towards developing responsible AI among private sectors.
- **Source: [Indiaai.gov.in](https://indiaai.gov.in)**

In the series of its publication on Responsible Artificial Intelligence (RAI), NITI Aayog brings the third paper titled "Responsible AI for All: Adopting the Framework - A use case approach on Facial Recognition Technology".

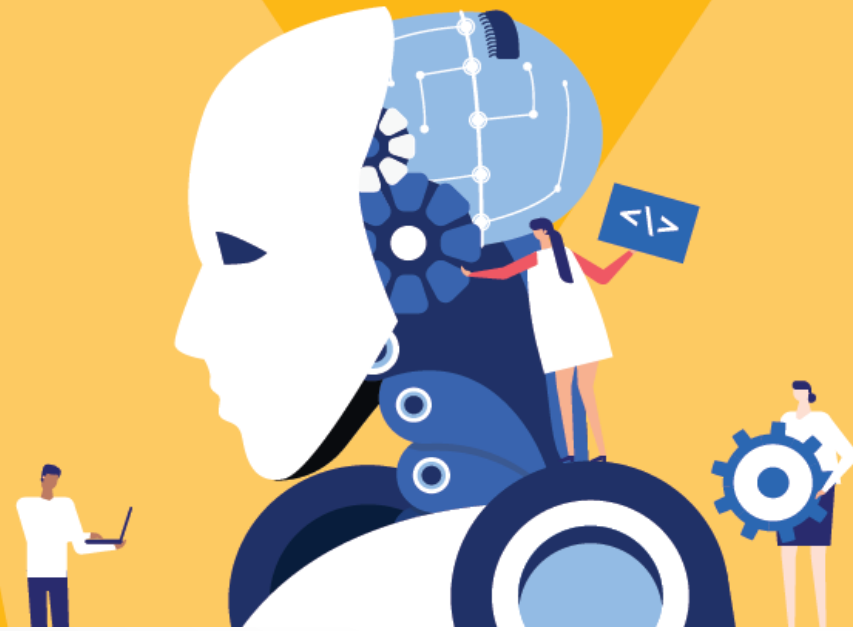
This draft discussion paper is being released for seeking public comments. Comments may be sent on or before 30th November 2022 addressed to Anna Roy, Senior Adviser, NITI Aayog at the email id adviserdma-niti@gov.in

RESPONSIBLE AI

#AIForAll

Adopting the Framework: A Use Case Approach
on Facial Recognition Technology

Discussion Paper | November 2022





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ETHICAL GUIDELINES FOR APPLICATION OF ARTIFICIAL INTELLIGENCE IN BIOMEDICAL RESEARCH AND HEALTHCARE



ICMR Ethical Guidelines for Application of Artificial Intelligence in Biomedical Research and Healthcare, March 2023.

- Indian Council of Medical Research (ICMR) came out with a series of guidelines to address ethical challenges present in the use of AI in biomedical research and healthcare involving human participants.
- This is a significant milestone as it marks the first time that such Guidelines have been established.
- This aimed at creating “an ethics framework which can assist in the development and adoption of AI-based solutions” in the fields specified.
- This provide an ethical framework for the development of AI-based tools which will benefit all stakeholders. **Source: [ICMR.gov.in](https://www.icmr.gov.in)**

The Digital Personal Data Protection Act, 2023

MINISTRY OF LAW AND JUSTICE

(Legislative Department)

New Delhi, the 11th August, 2023/Sravana 20, 1945 (Saka)

The following Act of Parliament received the assent of the President on the 11th August, 2023 and is hereby published for general information:—

THE DIGITAL PERSONAL DATA PROTECTION ACT, 2023

(No. 22 OF 2023)

[11th August, 2023.]

An Act to provide for the processing of digital personal data in a manner that recognises both the right of individuals to protect their personal data and the need to process such personal data for lawful purposes and for matters connected therewith or incidental thereto.

BE it enacted by Parliament in the Seventy-fourth Year of the Republic of India as follows:—

Timeline of the Digital Personal Data Protection Act, 2023

- Introduced in Lok Sabha on 3 August 2023
- Passed in Lok Sabha on 7 August 2023
- Passed in Rajya Sabha on 9 August 2023
- Gazette Notification on 11 August 2023

More About the DPDP Act

Scope and Applicability	Does not cover offline personal data and non-automated processing.
Reporting of data breaches	Every personal data breach must be reported to the Data Protection Board of India and each affected data principal, in prescribed manner.
Exemptions from provisions of the Act for the security of the state, public order, prevention of offences, etc.	The central government may exempt by notification; does not require any procedure or safeguards to be specified.
Right to Data Portability and Right to be Forgotten	Not provided
Harm from processing of personal data	Not provided
Regulators	Provides for the Data Protection Board of India, whose primary function is to adjudicate non-compliance; Telecom Disputes Settlement and Appellate Tribunal (TDSAT) has been designated as the Appellate Tribunal.
Transfer of personal data outside India	The central government may restrict of personal data to certain countries through notification.

Source: Prsindia.org

Highlights of the DPDP Act

- The Act applies to the processing of digital personal data within India where such data is collected online, or collected offline and is digitised. It will also apply to such processing outside India, if it is for offering goods or services in India.
- Personal data may be processed only for a lawful purpose upon consent of an individual. Consent may not be required for specified legitimate uses such as voluntary sharing of data by the individual or processing by the State for permits, licenses, benefits, and services.
- Data fiduciaries will be obligated to maintain the accuracy of data, keep data secure, and delete data once its purpose has been met.
- The Act grants certain rights to individuals including the right to obtain information, seek correction and erasure, and grievance redressal.
- The central government may exempt government agencies from the application of provisions of the Act in the interest of specified grounds such as security of the state, public order, and prevention of offences.
- The central government will establish the Data Protection Board of India to adjudicate on non-compliance with the provisions of the Act.
- [Source: Prsindia.org](https://www.prsindia.org)

Key Issues and Analysis of the DPDP Act

- The Act does not regulate risks of harms arising from processing of personal data.
- The Act does not grant the right to data portability and the right to be forgotten to the data principal.
- The Act allows transfer of personal data outside India, except to countries notified by the central government. This mechanism may not ensure adequate evaluation of data protection standards in the countries where transfer of personal data is allowed.
- Exemptions to data processing by the State on grounds such as national security may lead to data collection, processing, and retention beyond what is necessary. This may violate the fundamental right to privacy.
- The members of the Data Protection Board of India will be appointed for two years and will be eligible for re-appointment. The short term with scope for re-appointment may affect the independent functioning of the Board.
- **Source: [Prsindia.org](https://prsindia.org)**

Data Governance under the DPDP Act

Data Fiduciary

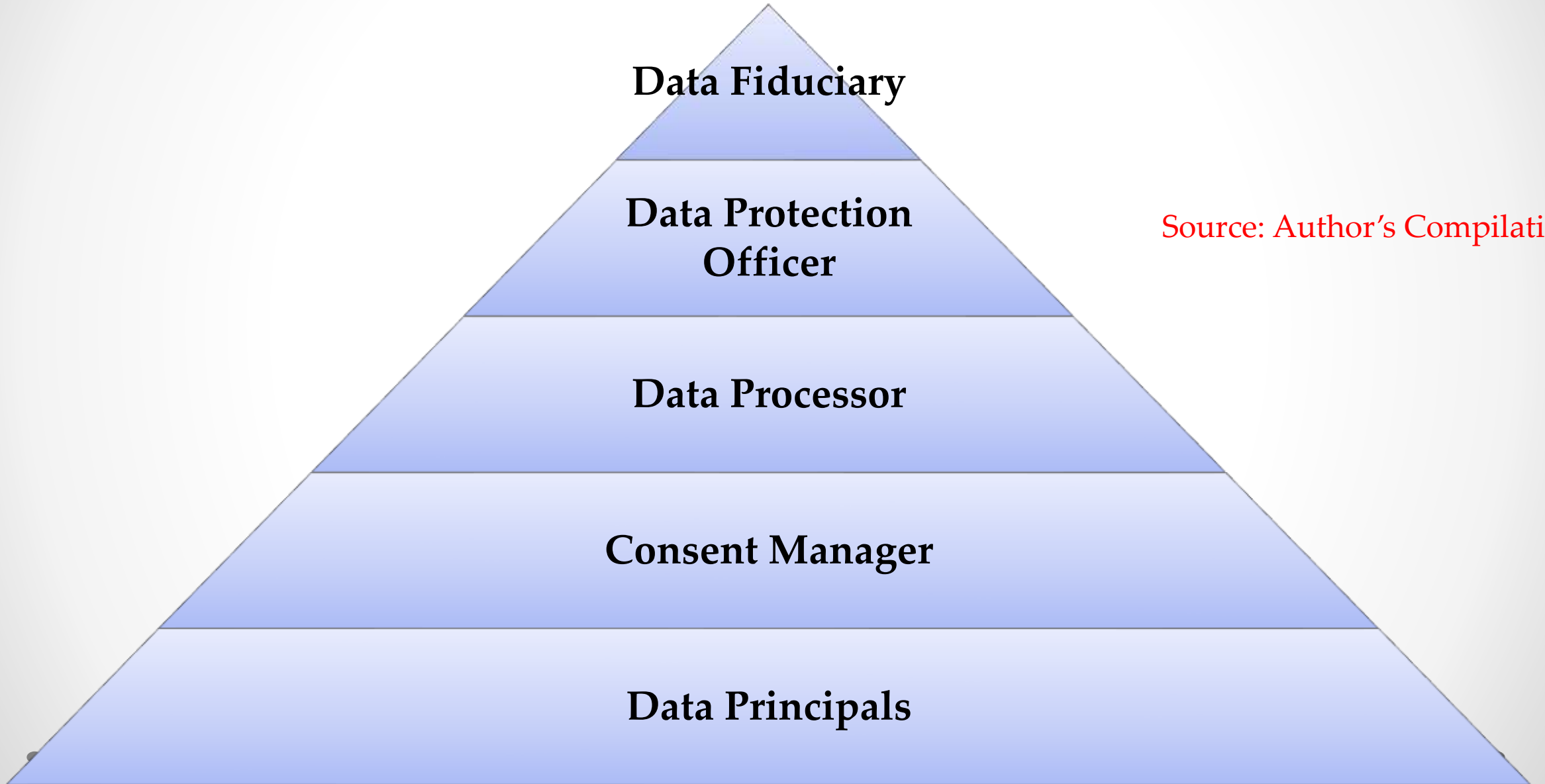
**Data Protection
Officer**

Data Processor

Consent Manager

Data Principals

Source: Author's Compilation



Data Governance under the General Data Protection Regulation (GDPR 2016)

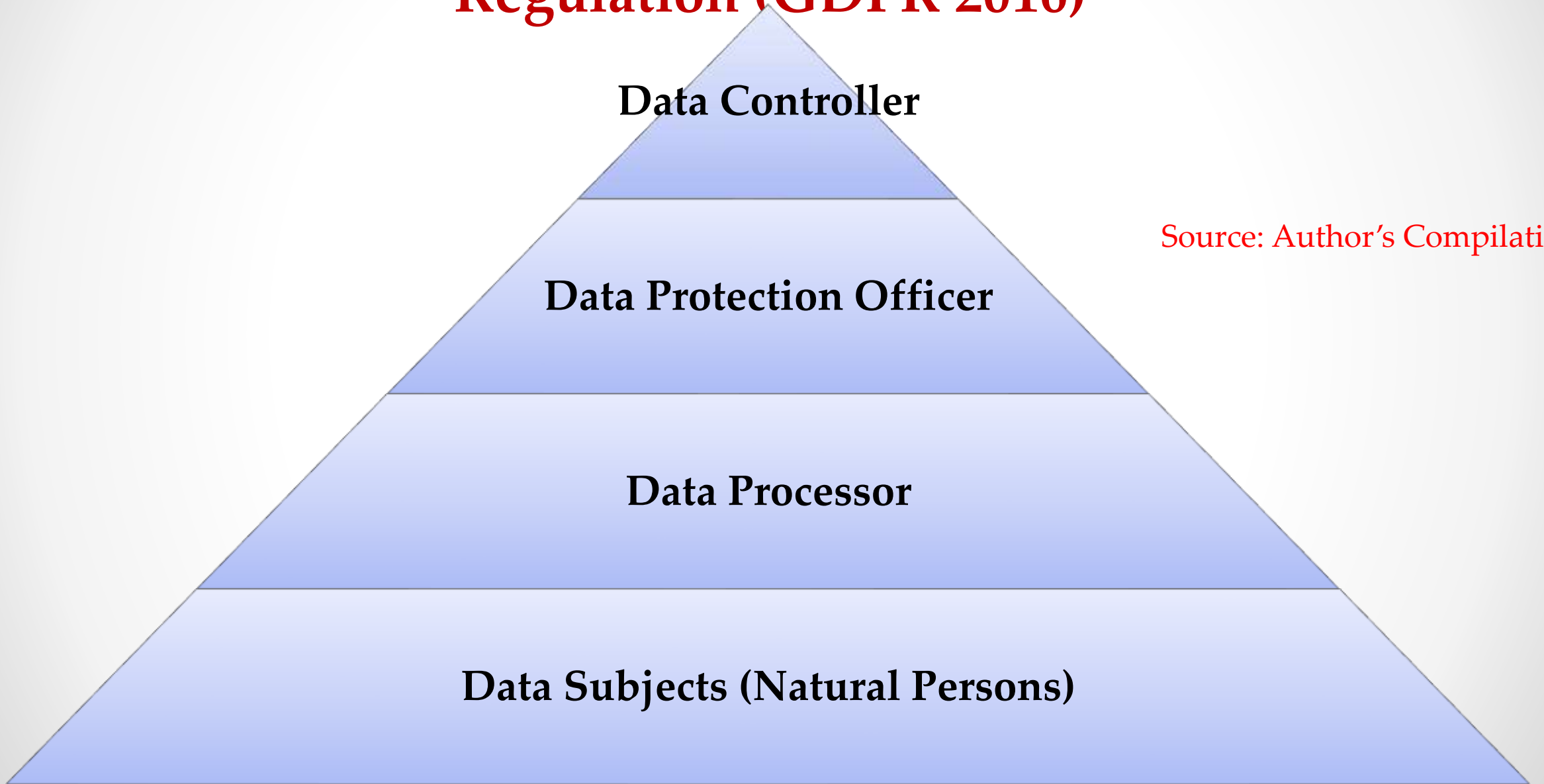
Data Controller

Data Protection Officer

Data Processor

Data Subjects (Natural Persons)

Source: Author's Compilation



Key Persons for Data Governance under the DPDP Act

Key Term	Meaning
Data Fiduciary	Any person who alone or in conjunction with other persons determines the purpose and means of processing of personal data.
Data Protection Officer	An individual appointed by the Significant Data Fiduciary under clause (a) of sub-section (2) of section 10.
Data Processor	Any person who processes personal data on behalf of a Data Fiduciary.
Consent Manager	A person registered with the Board, who acts as a single point of contact to enable a Data Principal to give, manage, review and withdraw her consent through an accessible, transparent and interoperable platform.
Data Principal	The individual to whom the personal data relates and where such individual is (i) a child, includes the parents or lawful guardian of such a child; (ii) a person with disability, includes her lawful guardian, acting on her Behalf.



Post

Personal Data Breach Example



TIMES NOW

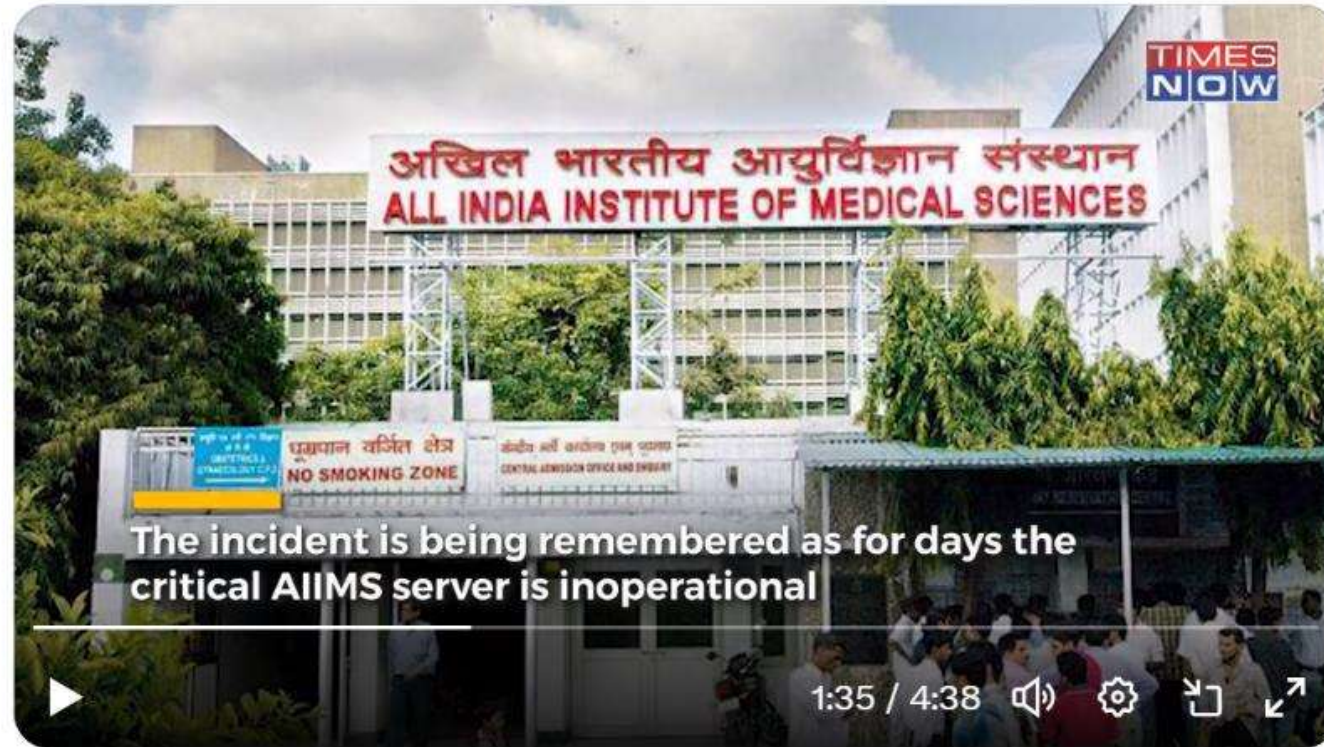
@TimesNow



AIIMS Cyber Attack: Info On Top VIPs Of Country Compromised; How The Data Breach Poses Greater Risk.



#TNDIGITALVIDEOS #AIIMS



11:15 PM · Nov 29, 2022

Source: Twitter.com



Suraksha P
@SurakshaPinnuET

If bank customers request deletion of loan data from the database of a credit information company (CIC), exercising a right under the Digital Personal Data Protection (DPDP) Act, they may not be able to continue with the banking system in the future.

economictimes.indiatimes.com/tech/technolog...

Difficulties in Deletion of Personal Data

'Banking Access at Risk if You Seek to Delete Credit Data'

Under DPDP Act, credit data deletion may close access to banking too, says official

Suraksha P, Aashish Aryan
& Gayatri Nayak

Bengaluru | New Delhi | Mumbai: If bank customers request deletion of loan data from the database of a credit information company (CIC), exercising a right under the Digital Personal Data Protection (DPDP) Act, they may no longer be able to continue with the banking system in the future,



Source: Twitter.com



Ali Tejani, MD @AliTejaniMD · Mar 26, 2020

“All individuals...with access to clinical **data** inherently take on the same **fiduciary** obligations as those of **medical** professionals.”

Great to see ongoing discussion about responsible use of **#AI** and protecting our patients as our generation of **#radres** takes on this unique task.



RSNA @RSNA · Mar 24, 2020

Researchers have developed a framework for using and sharing clinical data in the development of **#AI** applications. A special report, published in @radiology_rsna, outlines the framework: bit.ly/33KElCh **#RadAI**



RSNA News™ 30



← Post



Kent Bye (Voices of VR)

@kentbye

Biomedical data IS medical information that should be private. Do you want the early detection of disease to be sold to insurance companies so they can deny you coverage? There's no fiduciary responsibility here. Imagine your doctor selling your health data to the highest bidder.

10:19 PM · Aug 20, 2020



Source: [Twitter.com](https://www.twitter.com)



EY India @EY_India

Join us for the first episode, where we explore the effects of the Digital Personal and Privacy Bill **#DPDP** on **#Healthcare**. Lalit Kalra, EY India's Cybersecurity partner and Data Privacy Leader, how **#dataprivacy** and protection is imperative to **#healthcare**. go.ey.com/3OCKEBc





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The Digital Personal Data Protection Act 2023 (DPDPA) lays down stringent safeguards for the processing of digital personal data. The new law is expected to build trust in the healthcare ecosystem by addressing technical intricacies with adequate resource allocation.

ARTICLE #GTBharat
IMAGINE VIBRANT INDIA

Safeguarding progress, protecting privacy - Shaping India's healthier future

Findings from our survey of healthcare professionals conducted in early 2023:

- 84%** intend to enhance digital solution budgets
- 40%** believe their technology safeguards patient data privacy
- 66%** lack confidence in their technology infrastructure's ability to thwart cyber threats

[Know more](#)

3:21 PM · Sep 12, 2023 · 138 Views



Source: [Twitter.com](https://twitter.com)



Jiggs Barasara @BarasaraJignesh · Jan 4, 2024

Data Protection for #healthcare #platforms is very different from other #consumer facing platforms. Let's not ignore the #sensitivity of intimate #personaldata for one's #health #dpdpa #regulatory #assessment

Sid Shah @Sid_Healthcare · Oct 31, 2023

#India is piloting ambitious #digitalhealth initiatives while neglecting #data safeguards - The Digital Personal Data Protection Act #DPDPA which came into force in August, has few provisions that to secure the sensitive health data of citizens | #privacy <https://buff.ly/3QDVbgt>

Sid Shah @Sid_Healthcare · Sep 12, 2023

Safeguarding progress, protecting #privacy - shaping #India's healthier future | #cybersecurity #GDPR #DPDPA



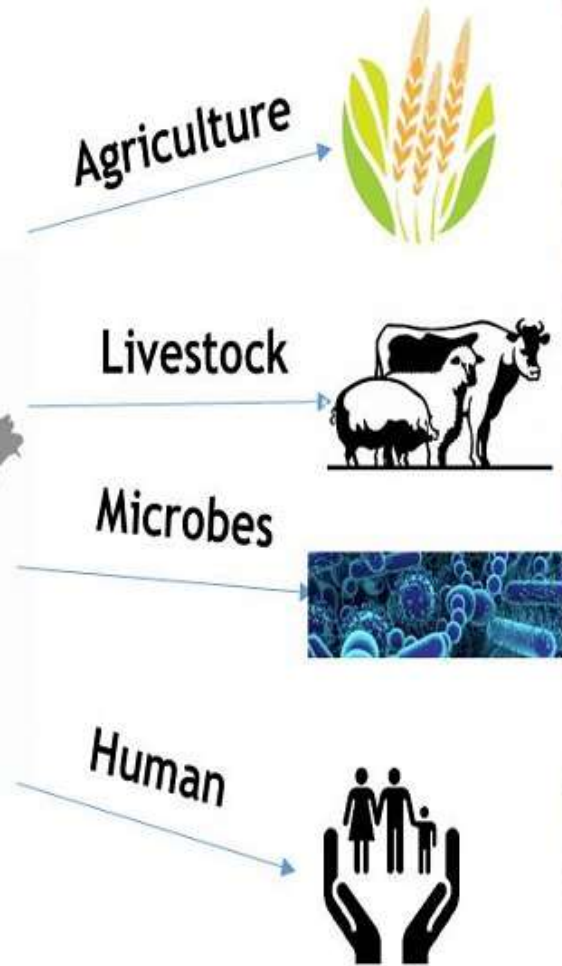
- Indian Biological Data Centre (IBDC) has been set up at a cost of ₹100 crore (INR 1 Billion) at RCB, Faridabad, Haryana.
- Dedicated to the Nation on 10 November 2022 by the Union Minister of State for S&T. It is supported by Department of Biotechnology (DBT).
- IBDC is the first national repository for life science data in India.
- As per BIOTECH-PRIDE guidelines, IBDC is mandated to archive all life science data generated from publicly-funded research in India.
- IBDC is committed to the spirit of data sharing as per the FAIR (Findable, Accessible, Interoperable and Reusable) principles.

Highlights

- **Aim:** IBDC is mandated to archive all life science data generated from publicly-funded research in India.
 - It has a data storage capacity of about **4 petabytes** and houses the '**Brahm**' High Performance Computing (HPC) facility.
- **Location:** IBDC is established at Regional Centre of Biotechnology (RCB), Faridabad with a data '**Disaster Recovery**' site at NIC, Bhubaneswar.
- It hosts an online 'Dashboard' for the **genomic surveillance** data generated by the INSACOG labs.
 - The dashboard provides customized data submission, access, data analysis services, and **real-time SARS-CoV-2 variant monitoring** across India.
- It is being developed in a modular fashion wherein different sections would typically deal with particular type/s of life science data.

IBDC Data Portals

- **The Indian Nucleotide Data Archive (INDA)**, is an open-access platform for archiving, managing, and sharing diverse types of nucleotide sequencing data generated across India following the International Nucleotide Sequence Database Collaboration (INSDC) guidelines.
- **The Indian Nucleotide Data Archive - Controlled Access (INDA-CA)**, is a controlled access/ private platform for archiving and managing diverse types of nucleotide sequencing data generated across India.
- **Indian Crop Phenome Database (ICPD)** is an open-access platform facilitating the digitization, management, storage, analysis and exchange of crop phenotyping data.
- **Indian Structural Data Archive (ISDA)** is a structural biology archive that contains information about the 3D shapes of proteins, nucleic acids, and complex assemblies. In addition, ISDA also contain structural information curated by running various tools and software.
- **Indian Metabolome Data Archive (IMDA)** is an open-access platform for archiving, managing, sharing metabolomics data and relevant information generated by MS and NMR techniques in metabolomics experiments.



IBDC

- Deposition of Biological data
- Quality control, curation, and annotation of data.
- Distribution of data
- Data backup and management.
- Training and outreach activities.



One point data access

Inter-database search

Metadata access

Data archive

Conclusion and Way Forward

- There are concerns from the patients advocacy groups that the majority of the healthcare service providers have not yet established the data governance mechanisms as prescribed by DPDPA 2023.
- A Whitepaper on the Institutional Mechanisms required for patients' data governance within a healthcare service provider in India as prescribed by DPDPA 2023 should be developed in consultation with the relevant stakeholders.
- Healthcare service providers that already have patients' data governance units and their functioning should be documented and best practices shared.
- Awareness raising on the Responsible AI Principles, as documented by NITI Aayog, and Best Practices specifically fitted for the healthcare sector in India, should also be undertaken.

Thank You!

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