Data Privacy in Healthcare Industry: Indian Perspective

(By Prof. Prathamesh Churi)

According to the one of the renowned and Oscar award-winning American actor and film director Marlon Brando who once said -

"Privacy is not something that I'm merely entitled to, it's an absolute prerequisite."

According to the definition from the Cambridge dictionary, "Someone's right to keep their matters and relationships secret". Privacy is the fundamental right of the human being and the same has been repeated a number of times by many of the juridical systems of various countries. Privacy threatening and Data breach are happening every day in this world and countries are mitigating the consequences happening due to privacy and data breaches.

More than 200 million surveillance cameras are installed around china's country with the help of improved facial recognition and artificial intelligence technology. The purpose of installing this technology is to identify malpractices happening around cities. Through it is on pedestrian, luxury retail stores, inside classrooms to identify students' malpractices- the privacy of identifying an individual is always compromised.

The healthcare industry is one of the largest and rapidly developing industry in recent years. According to IBM Global Business Services, Executive Report-2012, the overall healthcare management is changing **from disease centric to patient-centric**. While on one side, the analysis of healthcare data plays an important role in healthcare management, on the other side, the privacy of patient's records must be of equal concern.

Preserving the privacy of medical data is not only an ethical but also a legal requirement, posed by several data-sharing regulations and policies worldwide, such as the Privacy Rule of the Health Insurance Portability and Accountability Act in the USA, and the Data Protection Act in the UK. Besides, we are witnessing a wealth of approaches for preserving privacy in many phases of the healthcare information lifecycle, including data collection, communication, and sharing, as well as the knowledge management of healthcare information. To achieve privacy goals, these approaches employ various techniques, such as cryptography, access control, and data anonymization, generalization, and perturbation.

Privacy issues in healthcare-specific to India are due to prevalent complacency, culture, politics, budget limitations, huge population and the infrastructure present. Due to these factors, data security takes a backseat allowing for easy access to confidential information. The culture prevalent also affects healthcare disclosure in India. In many cultures, the disclosure of sensitive personal healthcare data is looked down upon. This leads to discrepancies in the healthcare data recorded as well as a decrease in the level of treatment meted out. Research and statistics of treatment given then don't match the records due to inaccurate reporting of data.

India is a country of large democracy and large populations. Maintaining standard infrastructure is another issue of implementing privacy. The cost required to implement a privacy model is substantial and requires funding from the government and individuals. To make the privacy model a success, it involves the work of specialists in the field of privacy and the field of healthcare. Budget constraints may lead to an ineffective model getting implemented which won't be secure and safe from attacks.

Context to this- Privacy issues to Indian Healthcare System must be addressed first. Surprisingly, there were hardly any research documents who were speaking on the privacy issues of the Indian healthcare system. Very few researchers had a keen interest in solving the privacy threats and data breaching issue on Indian healthcare data. This motivation forced us to consolidate the privacy and data breaching issues in India and make it available as an open-access manuscript. According to the limited available research, the Indian healthcare data which is already published on public platforms - does not have any procedure to de-identify the individual patient's record.

Data Publishing is one of the states of the art technique of publishing healthcare data in tabular format on either public platform such as blogs/websites/public columns OR publishing selective data to selective people which can be only accessed based upon authentication. Since Indian healthcare data contains sensitive information of an individual, the privacy concern of the user must treat equally important.

According to the recent news, India's health ministry has proposed a law to govern data security in the healthcare sector that would give individuals complete ownership of their health data. Individuals can access, share and deny the healthcare records. The draft Digital Information Security in Healthcare Act was proposed by the health ministry on March 11, 2018. The committee suggested the following key-points and developed privacy framework:

1. The law must be flexible and must be adhered to changing technologies.
2. Law must be applied to public and Private sector entities.
3. Entities controlling the data should be accountable for any data processing.
4. Consent must be Structured and Genuine.
5. Processing and analysis of healthcare data must be minimal.
6. Enforcement of the hdata protection framework should be by a high-powered statutory authority.

One of the fruitful observation that can be drawn from above perspective is that - Indian published health data is very diverse and collected from different heterogeneous sources, there are nor do regulations over the authorship of the health data, due to which any third party can take access among the sensitive data and can misuse the data. The re-identification attack is the most common attack of health data wherein with the help of a group of some identifiable entities (Called as quasi-identifiers), an identity of an individual can be easily determined. The proposed law mentioned in the above paragraph has guidelines and technological aspects of preserving the privacy of healthcare data.

According to our research, the proposed solution may include the awareness of understanding the procedure of how healthcare data is stored and processed. The backup of healthcare data, distribution of data among data publishers, working of consent, etc. must be clearly understood by every Indian who has healthcare records. Assurance of an individual's healthcare data is a fundamental right of every Indian citizen. The surety can be only be increased if the technology can be implemented in publicly available Indian healthcare data. Another aspect of awareness that we must bring is to have proper authentication for accessing healthcare data. The trust of Indian individuals to any organization is very vacillating as far as healthcare data sharing is concerned. Every client should be properly verified before granting access to the information and should be immediately taken back if there is some suspicious activity from the user side. Verification can be done from UID/AADHAR authentication. Strong anonymization technique is still needed in heterogeneous, diverse healthcare data which guarantees the fact that - Indian healthcare data is not only privatized but equally can be used for utility analysis for further research in Indian healthcare for the betterment of the society.

Another angle of the story is the cultural and sociological view of the said problem. Literacy and awareness should be spread about the need to disclose healthcare information accurately and promptly. Healthcare privacy models can only be successful when the Indian citizens change their mindset and are willing to share their information correctly. Trust must be from both the side. Indians should be

emphasized that disclosing medical data is not a weakness and shouldn't be looked down upon. Education and awareness camps should be held to inform citizens about the privacy model and the need to disclose healthcare information in a secure data environment

The sociological view is to combat slackness and laxness prevalent in India, promotion to levels of authority should be based on merit. Corruption should be eliminated and bureaucrats should be held responsible for their failures. A strict work ethic should be established and deadlines should be met. This can be done only if the mindset of bureaucrats changes from doing something only for themselves to a mindset of doing something for the citizens and the country

The research article is concluded by saying- "Privacy is not a product, It is a process " The product can be 100% Secure, Process cannot be!

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