Digital health data and gendered disembodiment in India

kcl.ac.uk/digital-health-data-and-gendered-disembodiment-in-india

In India, the extent to which digital health data is generated, surveyed and monitored through health records collection and analysis is largely ignored. This article interrogates the persistent disembodied constructions of data and seemingly innocuous measures to surveil women using health records in India. This is done by exploring the implications and consequences of collecting and using of personal health data. The article explores recent arrests made in Assam for child marriages where digital health records were exploitatively used to further marginalise women from lower castes, and from minority religious groups.

Early in February 2023, in the north-eastern state of Assam more than 3000 people were arrested under the allegation of being involved in child marriages. These arrests were made under the Prohibition of Child Marriage Act (PCMA), 2006, under which a court can sentence an offender to two years imprisonment and impose up to Rs 1 lakh (1220.7 USD) in fine. The National Family Health Survey (NFHS-5) 2019-2021 data state 32 per cent of women in Assam in the 20-24 age bracket were underage at the time of marriage and that 12 per cent of them were either pregnant or had already become mothers.

The issue received a lot of political and media attention, where the government officers and political ministers had to step in to show some action was being taken, such as awareness drives, stakeholder workshops and focus on preventive actions. Legal and feminist activists highlighted different aspects of the issue of child marriages, and existing laws to prevent child marriages from happening, and analysed gaps in these laws. The Protection of Children from Sexual Offences (POCSO) Act, 2012 is one such law, which seeks to provide a robust legal framework for the protection of children from offences of sexual assault and sexual harassment. The Government of Assam enforced this law to take action against those who married minors under the age of 14 in the state. The state's decision criminalises all sexual acts between adults and children below the age of 18 years. However, the Gauhati High Court observed that the state's crackdown on child marriages created havoc in the lives of the people, and instead of making arrests they

should focus on creating awareness and file chargesheets to act as deterrents. Women in the districts of Dhubri, Morigaon, South-Salamara Mancachar who protested at the police stations against the state government's action suffered teargas and baton attacks by the police.

Most of these individuals were reportedly married for several years, and these arrests have disrupted family lives, affecting livelihoods and causing distress to family members. A holistic understanding that looks beyond the age of marriage and tackles the issues related to poverty, their lack of nutrition, poor quality of health services, or quality of schooling is necessary. Besides the social, legal and political aspects of this issue, what is currently being overlooked is how the state accessed the information about these families. It is believed the state was able to identify and target individuals to be arrested after a health survey was carried out identifying underage pregnant girls. This is leading to a distrust of healthcare service providers in the state, and necessitates an understanding of how personal health data and private information was used by the state for surveillance.

There has been a recent push towards digitalisation of health services in India leading to the recent launch of Ayushman Bharat Digital Mission (ABDM) that aims:

> To create a national digital health ecosystem that supports universal health coverage in an efficient, accessible, inclusive, affordable, timely and safe manner, that provides a wide-range of data, information and infrastructure services, duly leveraging open, interoperable, standards-based digital systems, and ensures the security, confidentiality and privacy of health-related personal information.–
> *Ayushman Bharat Digital Mission (ABDM)*

The Digital Mission aims to develop and maintain three key registries: Health ID, Health Professional Registry (HPR), Health Facility Registry (HFR) and digital infrastructure for data exchange. The digitalisation of health records is part of the agenda under National Health Mission: the Integrated Child Development Services-Common Application Software (ICDS-CAS) was launched in 2018 as an IT-based nutrition monitoring system to track and follow the needs of pregnant women, mothers of young children and their children who need health and nutrition services. The female frontline health workers – ASHAs (Accredited Social Health Activists) and Anganwadi workers (AWWs)– are tasked with uploading data on mothers, children and pregnant women, including photo evidence of the opening of Anganwadis; attendance of children; details of food, weight, and height and updating daily activities so that officials at the district, state, and even at the national levels can monitor this data for improvement in the quality of delivery of targeted health services.

The onus of providing primary health care, particularly to women and children has now shifted towards digitising women's records and tracking their 'progress' from marriages, to pregnancy to child birth and immunisation online. The data is tracked on an online portal

called the Reproductive and Child Health portal set up by the Ministry of Health and Family Welfare in India which tracks and targets women's bodies by linking their electronic health records with biometric identity set up by Aadhar. The portal enhances the delivery of reproductive, maternal, newborn and child health (RMNCH) schemes and programmes. It is intended to facilitate early identification and tracking of women's reproductive health. It targets health services appropriate to women's bodies by characterising their age, marital and social status. This data can be entered on the ground, by ASHAs and AWWs alone. Without uploading this information both the mother and the frontline worker cannot benefit from the financial incentives that encourage hospital deliveries under the Janani Suraksha Yojana (maternal safety scheme). Those belonging to wealthier families tend can afford private healthcare and are not enforced to register their births and deaths with the neighbourhood health clinic too avail financial incentives. In terms of privacy and data protection, as well as access to high-quality healthcare treatments, this results in a class split. The relatively wealthy people are sheltered from such inspection, whereas the poor and marginalised women who depend on public health care are subjected to rigorous surveillance and monitoring. Professor Rajiv Mishra of Jawaharlal Nehru University is critical of the extensive use of digital infrastructures and the biometrics-based appropriation of the body for ensuring accessibility and delivery of welfare entitlements. He argues that the use of biometrics identification, with its genesis in colonial India, has been in a social and political context of mistrust, policing, suspect identities and surveillance, as a result of which the body becomes an object of appropriation, both for record keeping and generating data, information, and knowledge on the body for further development of medicine and healthcare. Evidently in this case the state has relied on personal health records to ascertain the age of the mother at childbirth and retrospectively arrest their husband, in-laws and subject them to imprisonment, in all cases these women belong to Muslim families.

As digital interventions proliferate, there is a need for multi-scalar and embodied examinations of their gendered power dynamics across different social groups. Shoshana Zuboff argues the concept of surveillance capitalism is useful to understand private companies, governments and business corporations commodify and make huge profits from this data, usually without the knowledge of the consumers. It is not surprising that surveillant technologies have gendered outcomes, however, what this practice obscures is that this digitalisation is fragmenting women's bodies into a series of discrete stages from which information flows. The resultant 'surveillant assemblage', a term coined by Kevin D. Haggerty and Richard V. Ericson, is reassembled in different locations as discrete and virtual 'data doubles'. That is, a female body is now reconstituted as an additional self, whose primary purpose is to serve the objectives of a state and its diktats. If the state clamps down on the datafied bodies of underage girls who are being married off, these data records serve them with personal information such as village-level data, the birthdates and marriage information of the couple, their phone numbers, religion, caste, and Aadhar numbers, Below Poverty Level (BPL) or Above Poverty Level (APL) status, medical records related to previous pregnancies, immunisation records during antenatal check-ups and post-delivery information about mother and infant.

Routine collection of such detailed personal information and the dangers of data misuse is addressed through data protection frameworks. However, when we consider that a female body is reconstituted as their data, and what happens to this information, how it is used, how it will affect them and who has access to this information, for what purposes and how much control do we retain in not only our data, but also our body, has far reaching implications for women physically. These implications fall in the grey lines within policy frameworks that separately govern data and bodies. For instance, in the Indian Parliament the law-making body is going to discuss the Digital Personal Data Protection Bill, 2022 in the monsoon session of the Parliament in 2023. The bill sets out the obligations of data fiduciary – any person who alone or in conjunction with other persons determines the purpose and means of processing of personal data - grounds for processing digital personal data, consent, deemed consent, with very limited scope to prevent leakages, and it is more concerned with prescriptive and compliance aspects. The Bill also gives the power to the government to offer exemption from its provisions, "in the interests of sovereignty and integrity of India" and to maintain public order. Such a policy framework aims to protect personal data and not bodies that generate this data. The data protection concerns of an individual cannot override the national security concerns. As witnessed in Assam, the root of the problem is that women's data were used post-hoc to specifically target families from a religious minority. Hence it is important to question the narrative presented by the government which frames it as a women's rights issue to serve a political interest.

In 2020, the Government of India passed the Citizenship Amendment Act, 2019. Women, particularly in Muslim minority groups across the country, actively rejected the provision of citizenship based on religious identity. Particularly in Assam, the state has implemented the National Registry of Citizens threatening indigenous identities of the multi-ethnic and diverse tribal and linguistic groups. The current National Register of Citizenship (NRC), an illegal migrant identification exercise that took place in Assam between 2015–2019, rendered 1.9 million people stateless, with the burden of proving citizenship placed on the individual. These people are reduced to non-citizen and non-human status, conflating issues of identity and citizenship, where women's bodily data is weaponised to target Muslim families.

To reconcile this difference, van der Ploeg in her edited book 'Digitizing Identities: Doing Identity in a Networked World' suggests that when data emerges as an extension of our bodies, the harms of data misuse should be reconceptualised as violations of bodily integrity rather than data protection violations so that more stringent criteria may apply to them. This reframing of data protection and bodily protection and integrity is an important policy consideration to avoid the continual reduction of women's bodies into commodities to instil fear, to impose punishments and to penalise marginalised families. The larger threat of underlying political intentions in using women's health data for surveillance cannot be ignored and needs to be stopped before it is beyond our control.

Footnotes

Image captions:

- Hero image: 'Anganwadi meeting in a district in Haryana', Image taken by Dayawanti Poonia, May 2023.
- Thumbnail image: 'Village health and nutrition day held in Maharashtra', Image by Sneha Krishnan, 2019.

About the author

Dr Sneha Krishnan (b.1987) trained to be a researcher in the interstices of development, health and disasters. After years of humanitarian practice and studies, one day she grew tired of the world of research that converted people's life stories into data and evidence, and instead dived deep into the world of telling stories with prose, poetry and photographs.

She is Associate Professor, Public Health and Human Development at OP Jindal Global University, India and Founder-Director of a Global South-based, women-led start-up ETCH Consultancy Services.

To get in touch, follow her on Twitter: @snek87 or @etchcs, Instagram: @etchconsultancy, or LinkedIn: Sneha Krishnan