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Privacy and Reproductive Health: Curtailing Rights and Choices

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PRIVACY AND REPRODUCTIVE HEALTH: CURTAILING RIGHTS AND CHOICES

—Ambika Tandon*

Digital identification (ID) and data-driven systems have become central to the delivery of welfare and health services in the global South. These policies are designed to monitor and control developmental indicators, with some negative repercussions for women. They also impact the exercise of reproductive rights and access to health and welfare, in addition to informational privacy. This paper aims to understand the various axes along which digitalisation and data collection systems impact the exercise of the right to privacy, including reproductive rights. It focuses on two specific services that have been a target of digital and analog monitoring over the past decade – conditional cash transfers tied to maternal health, and abortion services. Through interviews with women patients, their families, and health providers in New Delhi, it found that monitoring systems can restrict women’s access to critical services. Extensive procedural requirements introduced for better targeting of welfare schemes, such as Aadhaar linked bank accounts and income and caste certifications acted as significant barriers to access. These requirements particularly impacted women who carry stigma when accessing abortion services, including poor and unmarried women, and adolescents. Health providers were forced to prioritise data collection over inclusive delivery of services. Data collection for Aadhaar-linked databases without informed consent was rampant, with repercussions for women’s informational privacy. Reproductive rights and various dimensions of privacy, including informational

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privacy and decisional autonomy are thus intrinsically linked. Future research on digital health needs to further probe these interlinkages and broaden the definition of the right to privacy.

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I. INTRODUCTION

Over the past decade, digitisation and data-driven initiatives have increasingly been introduced in the delivery of reproductive health services in India. Extending to health services more broadly, such initiatives range from the collection of centralised real-time data from local health workers¹ to the mandatory use of digital identity to access services and welfare benefits.

Welfare delivery in general, and maternal health in particular, has been a key area of focus for digitisation efforts. In particular, the Aadhaar project was mainstreamed across welfare programmes with the stated objective of making targeting more efficient and reducing corruption.² Conditional cash transfer programmes, such as the Janani Suraksha Yojana launched in 2005,³ have more recently pivoted from cash disbursement to direct benefit transfers through digital payments. The privacy risks of digital identity programmes for social protection systems have been documented in India⁴ and elsewhere.⁵ The digitisation of maternal health delivery has included the implementation of digital information systems to collect granular data about maternity services in public health institutions, including the Mother and Child Tracking System ('the MCTS') and the Integrated Child Development System ('the ICDS'). Such

¹ Ambika Tandon, *Big Data and Reproductive Health in India: A Case Study of the Mother and Child Tracking System* (The Centre for Internet and Society 2019) <<https://cis-india.org/raw/big-data-reproductive-health-india-mcts>> accessed 9 December 2020.

² Surabhi Agarwal, 'Aadhaar Will Reduce Corruption in the System: PM' (*Livemint*, 20 October 2012) <<https://www.livemint.com/Politics/NX7HMkUfwKUJjT5jWMpsM/Aadhaar-will-reduce-corruption-in-the-system-PM.html>> accessed 9 December 2020.

³ Lim SS and others, 'India's Janani Suraksha Yojana, a Conditional Cash Transfer Programme to Increase Births in Health Facilities: An Impact Evaluation' (2010) 375 *The Lancet* 2009.

⁴ Reetika Khera, *Dissent on Aadhaar: Big Data Meets Big Brother* (Orient BlackSwan 2019).

⁵ Alston P, 'Report of the Special Rapporteur on Extreme Poverty and Human Rights' (*United Nations*, 2019) Agenda item 70 (b), Seventy fourth session United Nations General Assembly A/74/493 <<https://undocs.org/pdf?symbol=en/A/74/493>> accessed 9 December 2020.

health information systems can be useful in measuring policy outcomes, but can expose citizens to informational privacy risks as these databases are centralised and linked with the Aadhaar.⁶⁷

The right to privacy is intimately connected with reproductive rights along several interlinked dimensions. It encompasses other dimensions in addition to informational privacy, including bodily autonomy and the right to exercise control over decisions about one's body.⁸ In *KS Puttaswamy v Union of India*⁹ (*'Puttaswamy I'*), the Supreme Court recognised the right to privacy as an inalienable right vested in individuals, which is grounded in personal liberty as enshrined in Article 21 of the Indian Constitution. Reproductive rights are a key part of this conception of privacy, since these rights are tied to decisional autonomy and bodily integrity. These rights encompass the freedom from the interference of the state in decisions regarding 'private affairs',¹⁰ particularly those regarding the body, including the self-governance of sexuality and reproduction, among other aspects.

This paper will assess the extent to which women's right to privacy is protected by institutional actors as the former access reproductive health services in private and public medical institutions. It will particularly focus on the impact of digitisation and digital systems on the exercise of the various dimensions of privacy, as well as the interlinkages between informational privacy and decisional autonomy. Various components of reproductive health services will be interrogated, including abortion and maternity benefits. Within maternity benefits, I will focus on conditional cash transfer schemes. Through such schemes, funds are transferred to the bank accounts of beneficiaries if they are able to meet certain goalposts in their pregnancy cycle, such as registration and delivery at a public health centre. Abortion services have been an area of focus for data collection and state surveillance, as is evident from the special

⁶ Ramya Chandrashekar, 'Here Are the Consequences of Linking Women's Medical Records to Their Aadhaar' (*The Indian Express*, 24 April 2018) <<https://indianexpress.com/article/gender/here-are-the-consequences-of-linking-womens-medical-records-to-their-aadhaar-5139360/>> accessed 11 December 2020.

⁷ These two objectives of health information systems are not mutually exclusive, but there is evidence that the absence of health workers in designing these systems hurts their interests and leads to challenges in adoption. See Joyojeet Pal and others, *Changing Data Practices for Community Health Workers: Introducing Digital Data Collection in West Bengal, India* (Association for Computing Machinery 2017).

⁸ Sama Resource Group for Women and Health and Partners in Law and Development, 'State of Human rights in the context of Sexual Health and Reproductive Health Rights in India: Country assessment Undertaken for National Human Rights Commission' (*NHRC*, 2018) <https://nhrc.nic.in/sites/default/files/sexual_health_reproductive_health_rights_SAMA_PLD_2018_01012019_1.pdf> accessed 9 December 2020.

⁹ (2017) 10 SCC 1.

¹⁰ A Ghosh and N Khaitan, 'A Womb of One's Own: Privacy and Reproductive Rights' (*Vidhi*, 02 November 2017) <<https://vidhilegalpolicy.in/blog/2017-11-2-a-womb-of-ones-own-privacy-and-reproductive-rights/>> accessed 9 December 2020.

processes for collecting abortion data. Pre-natal ultrasounds have a specific data collection process posited in the Pre-Conception and Pre-Natal Diagnostic Techniques Act, 1994 ('the PCPNDT'),¹¹ separately from other reproductive health data. The PCPNDT aims to regulate the facilities providing ultrasound services for pregnant women, with the aim to reduce sex-selective abortions. More recently, there has also been discussion at the national level to link abortion delivery mandatorily with the Aadhaar, to track and reduce the abortions of female fetuses.¹²

The analysis in this paper is based on interviews conducted at public and private institutions in New Delhi in early 2020. The paper argues that the governing policy frameworks and the everyday practices of the delivery of reproductive services constrain the exercise of the right to privacy.

The paper is structured as follows. The next section discusses the methodology of the interviews conducted. This is followed by a background discussion of privacy and reproductive rights, the regulation of abortion, and the history of conditional cash transfers in India. The findings section discusses the implications of the ground-level practices with respect to reproductive health services at medical institutions for the privacy and bodily autonomy of patients.

II. METHODOLOGY

The essay draws on fieldwork conducted across one and a half months, between January to February 2020, in New Delhi. Twenty-four in-depth semi-structured interviews were undertaken across 3 major public hospitals, 1 public-private hospital, 1 private hospital and 2 private clinics. These sites were selected with a view to diversifying the types of institutions being assessed, with a focus on public institutions. Of the interviews, 4 were conducted with healthcare providers (doctors and nurses), and seventeen with women patients between the ages of twenty to forty-five. Additionally, in 3 cases, the women concerned could not be interviewed, since they were unavailable and family members were instead interviewed. Instead of focussing on the experiences of the respondents, the interviews with family members were only used to discuss the process of registration if the patient had availed of a maternity scheme. This posed a limitation as women's experiences are not fully represented by their families – male members of the family have been found to misrepresent women's health concerns, which could impact the findings of this

¹¹ Pre-Conception and Pre-Natal Diagnostic Techniques Act 1994, ch 3 s 4(3).

¹² Chandrashekhar (n 6).

study.¹³ This limitation has been mitigated by clearly noting the findings that have been drawn from these interviews.

The participants were selected randomly at the sites of study, with a focus on eligible beneficiaries for maternity benefits programmes.

Aligning with feminist principles of research methods, I was reflexive of the impact of my identity as a savarna woman from a high-income family interviewing women from low-income families, some of whom were also Dalit or Bahun. I tried to address this power hierarchy by posing dynamic open-ended questions to respondents that opened the space for them to express their lived experiences, while also conducting interviews in respondents' homes since that was a space familiar to them when possible. Further, I did not remain an objective 'observer', and actively tried to resolve the challenges faced by my respondents in accessing maternity benefits by providing them with information about government procedures.

In accordance with an ethical framework for undertaking field research for the collection of sensitive data, informed consent was taken from all respondents in an audio or written format. All respondents were informed of (i) the objectives of the study, (ii) that no harm would come to them as a result of the study, (iii) that all personal information would be kept anonymous and no respondents would be identifiable, and (iv) that respondents can refuse to participate at any point during the research.

Given the qualitative approach, the focus of this paper is to document and analyse the experiences of the respondents in the context of the policy frameworks and the legislation governing reproductive and privacy rights. The study does not claim to be representative of larger communities. The paper also relies on secondary analysis of law and policy frameworks to discuss possible implications for patients.

The study is limited in its geographical scope, given its location in a metropolitan city in some of the highly-funded public hospitals in the country. Although the findings would broadly be applicable in other contexts with similar processes of consent and quality of care, future research could assess the scale and scope of the applicability of the findings of this study in different geographies, especially in more remote and resource-poor locations.

¹³ Ambika Tandon, *Feminist Methodology in Technology Research: A Literature Review* (The Centre for Internet and Society 2019) <<https://cis-india.org/internet-governance/feminist-methodology-in-technology-research.pdf>> accessed 9 December 2020.

III. BACKGROUND

A. Privacy and reproductive rights

Several legal scholars have argued that the right to privacy encompasses reproductive rights and abortion within its ambit, which stem from the conception of privacy as promoting individual private choice, labelled ‘decisional privacy’.¹⁴ Anita Allen offers a typology of privacy, which also forms part of the feminist critique cited in *Puttaswamy I*. Allen understands the right to privacy as encompassing:

- (a) informational privacy, or the ability to exercise control over flows of individual data;
- (b) physical/spatial privacy, or protections against the invasion of the physical space of individuals; and
- (c) decisional autonomy and privacy, which protects the right of individuals to take decisions that impact self-determination without coercion or intrusion by the state or other actors.¹⁵

These aspects of privacy are characterised as interdependent, with each impacting the exercise of the other.

Reproductive rights have also been considered as part of liberty, privacy, and autonomy in other jurisprudence in India.¹⁶ In *Puttaswamy I*, the court noted that reproductive rights are within the ambit of personal liberty and the derivative right to privacy.¹⁷ The plurality opinion interpreted liberty as having a zone of privacy that is protected from state intrusion.¹⁸ The court in *Puttaswamy I* also referred to *Suchitra Srivastava v Chandigarh Admn.*,¹⁹ in which the court held that reproductive rights fall within the ambit of personal liberty and bodily integrity, and *Devika Biswas v Union of India*,²⁰ which also included them within the ambit of the right to life and liberty.

The conception of privacy and reproductive rights as vested in an individual and enhancing individual choices is not without criticism. Nivedita Menon has

¹⁴ Anita Allen, ‘Taking Liberties: Privacy, Private Choice, and Social Contract Theory’ (1987) 56 *University of Cincinnati Law Review* 461.

¹⁵ *ibid.*

¹⁶ Dipika Jain, ‘Time to Rethink Criminalisation of Abortion? Towards a Gender Justice Approach’ (2019) 12(1) *NUJS Law Review* 21.

¹⁷ *Puttaswamy* (n 9).

¹⁸ Severyna Magill, ‘The Right to Privacy and Access to Abortion in a Post-Puttaswamy World’ (2020) 3(2) *University of Oxford Human Rights Hub Journal* 160.

¹⁹ (2009) 9 SCC 1.

²⁰ (2016) 10 SCC 726.

argued that this conception is not applicable in contexts where there are structural barriers to the exercise of individual choice, such as restrictive familial or societal structures where decisions about women's reproductive health are often made by their partners or families.²¹ Further, poor health infrastructure and low levels of access to critical health information implies that women are often unable to exercise choice in a meaningful manner.²² The right to privacy, at its core, is a negative right against unwanted intervention by the state and other actors in an individual's personal space and body; it may not guarantee the creation of conditions that facilitate its exercise.²³

Nevertheless, Allen and several others argue that privacy can be a useful lens to examine institutions and structures, including the family and the state.²⁴ This is because privacy and related rights offer a lens to critique state intervention in fundamental aspects of individual life and identity without denying the diversity of experience that may shape such identities. While it becomes difficult to actualise the right to privacy in the context of reproductive rights without addressing socio-economic and cultural barriers, the right offers a useful tool to preserve women's personal liberty, particularly from state intervention.²⁵

B. Regulating abortions

India's historical focus on population control has led to a strong focus on reproductive health in its health agenda. Some key aspects of the national reproductive health programme include decreasing maternal and neo-natal mortality, and expanding the reach of birth control methods.²⁶ In line with these aims, India legalised abortion partially through the Medical Termination of Pregnancy Act, 1971 ('the MTP Act').²⁷ However, Section 312 of the Indian Penal Code²⁸ continues to criminalise abortions, except as permitted by the MTP Act under specific conditions. These conditions include negative impact on the physical and mental health of mothers. The MTP Act and subsequent amendments place decision-making in the hands of medical practitioners as opposed to women seeking abortions, which severely undermines the exercise of the reproductive and privacy rights of the latter.²⁹ The Medical Termination

²¹ Nivedita Menon, 'The Impossibility of "Justice": Female Foeticide and Feminist Discourse on Abortion' (1995) 29 Contributions to Indian Sociology 369.

²² Magill (n 19).

²³ T Sarkar, 'Privacy and Medical Termination of Pregnancy' The Centre for Internet and Society (forthcoming).

²⁴ Allen (n 15).

²⁵ Dipika Jain and Payal Shah, 'Reimagining Reproductive Rights Jurisprudence in India: Reflections on the Recent Decisions on Privacy and Gender Equality from the Supreme Court of India' (2020) 39(2) Columbia Journal of Gender and Law 1.

²⁶ Mohan Rao, *From Population Control To Reproductive Health* (SAGE Publishing 2004).

²⁷ Medical Termination of Pregnancy Act 1971.

²⁸ The Indian Penal Code 1860, s 312.

²⁹ Jain (n 17).

of Pregnancy (Amendment) Bill, 2020 reduces the requirement for approval for abortion to that of 1 medical practitioner upto twenty weeks of pregnancy, and that of 2 practitioners till twenty-four weeks.³⁰ While an improvement over the original MTP Act, which required approval from 1 practitioner for abortions up to twelve weeks of pregnancy and from 2 practitioners for those between twelve and twenty-four weeks,³¹ the MTP Act in its current version continues to vest the ability to refuse abortions in the medical practitioner.

Although the Indian state has retained its goal of stabilising population growth numbers, since the 1990s, the discourse of policy-making has shifted towards enhancing women's empowerment.³² Many grassroots organisations have argued that this political discourse of empowerment has not translated into practice. This history of prioritising the state's policy imperatives over women's autonomy continues to shape programmes today, and is also reflected in the design and implementation of data-driven initiatives.^{33,34} The PCPNDT regulates the provision of pre-natal sonography in India, and directs facilities providing ultrasounds to "keep complete record thereof in the clinic in such manner, as may be prescribed".³⁵ Although the PCPNDT is aimed at curbing sex-selective abortions, bottlenecks in its implementation can also restrict the provision of this essential service by causing long delays in the licensing of ultrasound technology.³⁶ Recently, several states including Delhi,³⁷ Haryana,³⁸ and Odisha³⁹ have issued guidelines directing providers to mandate identity proof with address proof. Critically, the collection of personal sensitive data of patients rather than providers is meant to regulate the persons availing these

³⁰ Medical Termination of Pregnancy (Amendment) Bill 2020, s 3.

³¹ The Medical Termination of Pregnancy Act 1971, s 3(2).

³² Rachel Simon-Kumar, *Marketing Reproduction: Political Rhetoric and Gender Policy in India* (Zubaan 2006).

³³ Aayush Rathi and Ambika Tandon, 'Data Infrastructures and Inequities: Why Does Reproductive Health Surveillance in India Need Our Urgent Attention?' (2019) 54(6) *Economic and Political Weekly* <<https://www.epw.in/engage/article/data-infrastructures-inequities-why-does-reproductive-health-surveillance-india-need-urgent-attention>>.

³⁴ Potdar P and others, "'If a Woman Has Even One Daughter, I Refuse to Perform the Abortion': Sex Determination and Safe Abortion in India' (2015) 23 *Reproductive Health Matters* 114 <<https://doi.org/10.1016/j.rhm.2015.06.003>>

³⁵ Pre-conception and Pre-natal Diagnostic Techniques Act 1994, ch 3 s 4(3).

³⁶ Pritam Potdar and others, "'If a Woman Has Even One Daughter, I Refuse to Perform the Abortion': Sex Determination and Safe Abortion in India' (2015) 23 *Reproductive Health Matters* 114.

³⁷ Directorate of Family Welfare, Government of NCT of Delhi, 'Identity Proof with Address Mandatory for Ultrasonography & Prenatal Diagnostic Tests & Procedures in Antenatal Cases (Pregnancy) under PC & PNDT Act' (2015) <<https://cdn.s3waas.gov.in/s3c06d-06da9666a219db15cf575aff2824/uploads/2019/05/2019050747.pdf>>.

³⁸ Savita Thakur, 'New Rule in Haryana: Women to Submit their Photographs to Get an Ultrasound' (*Medical Dialogues*, 3 June 2017) <<https://medicaldialogues.in/new-rule-in-haryana-women-to-submit-their-photographs-to-get-an-ultrasound>> accessed 9 December 2020.

³⁹ PTI, 'ID Proof Must for Ultrasound of Pregnant Women' (*The Hindu BusinessLine*, 22 February 2013) <<https://www.thehindubusinessline.com/news/national/id-proof-must-for-ultrasound-of-pregnant-women/article23090824.ece>> accessed 9 December 2020.

services rather than placing institutions under scrutiny, thereby attempting to control and surveil women's bodies.

C. Maternity benefits and conditional cash transfers in India

Conditional cash transfer schemes place certain obligations on beneficiaries in exchange for monetary incentives. In the recent years, these schemes have shifted to direct benefit transfer ('DBT') systems, which transfer funds directly to the bank accounts of beneficiaries, with greater documentary requirements than cash support. To track all digital payments, DBTs are linked with the Aadhaar database and Jan Dhan bank accounts.

The reproductive health programme has been an early adopter of cash transfer schemes in India, with the offering of cash incentives targeting women beneficiaries through the Janani Suraksha Yojana ('the JSY').⁴⁰ Conditional cash transfer schemes aim to achieve modifications in behaviour by placing certain obligations on beneficiaries to be fulfilled to receive benefits.⁴¹ In the case of maternal health, these schemes are largely focused on increasing institutional deliveries with the eventual outcome of reducing maternal and infant mortality, which continue to be very high in India despite progress over the last 2 decades.⁴² Cash transfers are undertaken on the basis of beneficiaries' completing certain goalposts in their pregnancy cycle, such as registering with public health care centres, making a requisite number of visits etc. They work in tandem with other schemes offering free treatment and medication. There are separate incentive structures for Accredited Social Health Activist ('ASHA') workers as well, who are responsible for implementing these schemes and guiding women through their requirements.⁴³

The National Maternity Benefit Scheme was launched in 2001 to provide nutrition support to pregnant women.⁴⁴ It was replaced by the JSY in 2013. This scheme was launched under the National Health Mission, in accordance with the provisions of the National Food Security Act 2013 ('the NFSA').⁴⁵

⁴⁰ Lim and others (n 3).

⁴¹ Jishnu Das and others, 'Reassessing Conditional Cash Transfer Programs' (2005) 20(1) The World Bank Research Observer 57.

⁴² 'Special Bulletin on Maternal Mortality in India 2016-18' (*CensusIndia*, July 2020) <https://censusindia.gov.in/vital_statistics/SRS_Bulletins/MMR%20Bulletin%202016-18.pdf> accessed 9 December 2020.

⁴³ 'Janani Suraksha Yojana: Guidelines for Implementation' (*ILO*) <<https://www.ilo.org/dyn/travail/docs/683/JananiSurakshaYojanaGuidelines/MinistryofHealthandFamilyWelfare.pdf>> accessed 9 December 2020.

⁴⁴ Chandrakant Lahariya, 'Cash Incentives for Institutional Delivery: Linking with Antenatal and Post Natal Care May Ensure 'Continuum of Care' in India' (2009) 34(1) *Indian Journal of Community Medicine* 15.

⁴⁵ National Food Security Act 2013, s 4(b).

The JSY is the largest cash transfer scheme of its kind in the world.⁴⁶ As of 2019-20, there are over 1 crore beneficiaries enrolled in this scheme.⁴⁷ The JSY has a higher allocation for low-performing states, due to their low performance in maternal and neo-natal developmental goals.⁴⁸ This study was undertaken in a high-performing state, where only beneficiaries from below the poverty line and belonging to a Scheduled Caste or Tribe are eligible. On the contrary, in low-performing states, all women who deliver at public institutions are eligible, in addition to women in empanelled private hospitals in both categories. The restricted eligibility criteria in high performing states places a higher burden of proof on beneficiaries, with the expectation of proving eligibility through the proof of caste or income status. This increases the scope for surveillance measures to target welfare beneficiaries in the high-performing states.

The Pradhan Mantri Matru Vandana Yojana ('the PMMVY') was launched in 2016 to compensate for wage loss during maternity, in combination with the JSY.⁴⁹ The PMMVY, although touted as a 'flagship' scheme, rebrands the Indira Gandhi Matritva Sahyog Yojana ('the IGMSY') launched in 2010. The IGMSY had offered an incentive of Rs. 6000 in 3 instalments to pregnant and post-partum women for the first 2 deliveries, on the basis of meeting conditions such as institutional delivery, vaccination of the infant etc.⁵⁰ The PMMVY reduced the entitlements to Rs. 5000 per woman, while also limiting the same to the first birth. These are transferred in 3 instalments: at registration, after 6 months of pregnancy upon receiving 1 ante-natal check-up, and upon the registration of the child and the administration of vaccines.⁵¹

Conditional cash transfers facilitated through digital payments pose privacy concerns, since sensitive data has to be collected to track the goalposts tied to registration, delivery, and post-natal care. The linkage of this database with the Aadhaar database also brings to the fore concerns relating to the centralisation

⁴⁶ Lim and others (n 3).

⁴⁷ 'Janani Suraksha Yojana: National Health Mission' (*National Health Mission*) <<https://nhm.gov.in/index1.php?lang=1&level=3&sublinkid=841&lid=309>> accessed 9 December 2020.

⁴⁸ Uttar Pradesh, Uttaranchal, Bihar, Jharkhand, Madhya Pradesh, Chhattisgarh, Assam, Rajasthan, Orissa and Jammu and Kashmir have been designated as low performing states due to the low rates of institutional delivery in these states. The incentive structure for these states is higher – women and ASHA workers in rural areas receive Rs 1200 and Rs 600, while those in urban areas receive Rs 1000 and Rs 400 respectively. Benefits in high performing states are Rs 700 and Rs 600 for women and ASHA workers in rural areas, and Rs 600 and Rs 400 for those in urban areas respectively.

⁴⁹ 'Pradhan Mantri Matru Vandana Yojana Scheme Implementation Guidelines' (Ministry of Women and Child Development, 2017) <https://wcd.nic.in/sites/default/files/PMMVY%20Scheme%20Implementation%20Guidelines%20-%20MWCD%20%281%29_0.pdf> accessed 9 December 2020.

⁵⁰ Development Monitoring and Evaluation Office (DMEO), 'Quick Evaluation Study On Indira Gandhi Matritva Sahyog Yojana (IGMSY)' (NITI Aayog) <https://niti.gov.in/writereaddata/files/document_publication/IGMSY_FinalReport.pdf> accessed 9 December 2020.

⁵¹ PMMVY Implementation Guidelines (n 50).

of data and linkage with other individual data, in addition to concerns regarding exclusion as a result of biometric authentication. The following section discusses the implications of these policy frameworks on the reproductive and privacy rights of women.⁵²

IV. FINDINGS

A. Access to information

The interviews with respondents pointed to a gap in access to information across various aspects of reproductive health service delivery and the relevant welfare provisions, with evidence of several layers of information asymmetry between beneficiaries and institutions. Eligible beneficiaries were often unaware of schemes, or of their eligibility and procedural requirements. Lack of information about welfare schemes and eligibility criteria directly leads to exclusion of beneficiaries. In addition, absence of clarity around procedural requirements can also render grievance redressal systems ineffective, as beneficiaries may not be aware of how to tailor their application to make a stronger claim for benefits.

Ten respondents were not aware of maternal health schemes as they had not been given any information by the facility they were visiting. This included patients at various stages of their pregnancy, as well as those seeking post-natal care. 3 eligible patients refused to participate in the study, citing the lack of awareness of benefits, and pointed towards health providers as sources of information. None of these patients had applied for either scheme, given their lack of awareness. This gap exists despite explicit guidelines to publicise schemes at every public hospital, possibly as a result of the lack of institutional will.⁵³

All respondents except 2 had at least some level of awareness about the Mother-Child Protection (MCP)/tika card. The term connotes a physical card given to every mother delivering at the hospital, containing her details as well as listing upcoming services and dates on which she needs to make institutional visits. These details were handwritten in Hindi. 2 women respondents, both of whom were illiterate and belonged to families with low education, lacked adequate information about this card. Both had received the first JSY

⁵² In Delhi, primary healthcare centres under the current Aam Aadmi Party government in Delhi, referred to as Aam Aadmi Mohalla Clinics (local clinics), were set up after their election to office in 2015. The Delhi government has also set up specialty centres that bring in doctors with different specialties for free consultation and provide free medication. See more at Sadhika Tiwari, 'Aam Aadmi Mohalla Clinics: What Worked, What Hasn't' (*IndiaSpend*, 7 February 2020) <<https://www.indiaspend.com/aam-aadmi-mohalla-clinics-what-has-worked-what-hasnt/>> accessed 9 December 2020.

⁵³ PMMVY Implementation Guidelines (n 50).

payment, but were at risk of losing out on the subsequent ones as they were unaware of when they would have to come for their next visit.

When the respondents were asked about whether or not the facilities they were visiting store their personal health information and share it with the government, all seventeen respondents indicated that they did not have any information about this. There are 3 health information systems which store data about maternal health – the MCTS, the Reproductive and Child Health portal ('the RCH'), and the ICDS,⁵⁴ all linked with the centralised Aadhaar database. Although these systems were developed by the Ministry of Health and Family Welfare and the Ministry of Women and Child Development respectively, their linkage with the Aadhaar database leads to the centralisation of data contained in these information systems. The mandatory linkage of reproductive databases with the centralised Aadhaar database without informing patients or providing them with the right to opt out violates their right to privacy as imagined under *Puttaswamy*. It also makes grievance redressal impossible in case of data leakage or misuse, since patients have no information about such linkage in the first place.⁵⁵ None of the respondents I spoke to had any information about reproductive data systems, or their linkage with the Aadhaar. They also did not have any information about how their data would be stored or processed, or if there is a procedure to change their data.

At public hospitals, the beneficiaries of welfare schemes were expected to share their data willingly in exchange for the delivery of services, with no obligation on the authorities of seeking informed consent or dispensing information about data processing. There were no processes for verbally disclosing the terms of data collection.. This significantly undermines the data rights of patients, and demonstrates the lacunae in the consent architecture in the public healthcare system. Interviews with healthcare professionals and the review of data collection forms indicates the presence of standard consent mechanisms with a clause confirming consent to store and share data through health information systems. However, without verbal explanation of the terms and conditions, particularly with respect to storage and linkage with the Aadhaar, these consent mechanisms remain ineffective and are present only on paper. Further,

⁵⁴ The MCTS and RCH are health information systems specifically designed to collect data about reproductive health in India. They store and process individual data on each pregnancy treated at public institutions to measure metrics of maternal health, such as institutional deliveries, maternal and neonatal mortality. See Tandon (n 1).

⁵⁵ The MCTS, the ICDS, and the RCH portals are health information systems designed by the ministries of Health and Family Welfare and Women and Child Development specifically designed to collect data about reproductive health in India. They store and process individual data on each pregnant woman treated at public institutions to measure metrics of maternal health, such as institutional deliveries, maternal and neo-natal mortality. See *ibid*.

consent mechanisms have been critiqued for placing the onus on individuals to protect their data rights while giving impunity to data fiduciaries.⁵⁶

Given the overarching affordances made in the Personal Data Protection Bill ('the PDP Bill') 2019⁵⁷ for data processing by the government, particularly the exemption from seeking consent from data subjects,⁵⁸ the practices of public institutions are expected to remain unchanged if the Bill becomes law. The Bill allows the state to be exempted from taking informed consent if it is providing any service or benefit to the data principal.⁵⁹ However, there are examples of other jurisdictions holding the government to higher standards when processing sensitive data, including health data. One such example is the direction given to member-states by Article 9 of the General Data Protection Regulation.⁶⁰ It specifies that member-states must authorise their own processing of health data by law or collective agreements which provide for safeguards for the fundamental rights and interests of data subjects. Contrast that with the PDP Bill, as per which only public-private and private institutions would be obligated to uphold rights such as taking informed consent.

In *KS Puttaswamy v Union of India* ('*Puttaswamy II*'), the Supreme Court held that the processing of Aadhaar data by the state is legal for provision of welfare benefits. It hence upheld the Aadhaar (Targeted Delivery of Financial and Other Subsidies, Benefits, and Services) Act, 2016 ('the Aadhaar Act').⁶¹ Clauses 3(2) and 8(3) require enrolling and authentication agencies to ensure that the nature of information and the uses to which the same is being put is shared with individuals. Clause 8(2) requires the authenticating agency to obtain consent from individuals with some exceptions, while 8(3)(c) requires agencies to ensure that individuals are provided with alternatives for identity verification documents. As discussed in this and the following sections, none of these protections were provided to the respondents, in violation of their right to privacy as imagined under *Puttaswamy I*.

B. Identification documents and data systems

Recognising the instances of exclusion resulting from errors in Aadhaar enrolment, updation, or authentication, the Supreme Court in *Puttaswamy II* directed the executive to ensure that eligible beneficiaries are not excluded

⁵⁶ Anja Kovacs and Tripti Jain, *Informed Consent – Said Who? A Feminist Perspective on Principles of Consent in the Age of Embodied Data Working Paper 13* (Data Governance Network 2020).

⁵⁷ Personal Data Protection Bill 2019, ch III 12 (a).

⁵⁸ *ibid.*

⁵⁹ *ibid.*

⁶⁰ General Data Protection Regulation [2016] OJ L 119, 4-5-2016; cor. OJ L 127, 23-5-2018, art 9.

⁶¹ (2019) 1 SCC 1.

on these grounds alone.⁶² Clause 7 of the Aadhaar Act requires authenticating agencies to provide “alternate and viable means of identification” for service delivery to individuals who are not enrolled, but not to those who are facing issues in authentication or updation. Across the hospitals and clinics surveyed for this study, submitting the Aadhaar card was mandatory to enrol for maternity benefits as well as to receive subsidised or free-of-cost treatment in government empanelled private hospitals, public hospitals, Mohalla clinics, and other primary health care centres. The beneficiaries were not informed of any alternatives.

To register at Anganwadis and health centres, all respondents needed to give the following personal details: name, husband’s name, address, phone number, and Aadhaar number. They also needed to produce a copy of their Aadhaar card. Details such as caste and income were not recorded at the stage of registration, even though these were required to determine eligibility for benefits in subsequent visits. These smaller facilities then referred patients to larger public hospitals, which required further details such as the health history (number of pregnancies, abortions, and deliveries), medical history, and personal details including income, and in some cases, religion and caste status, to determine eligibility for various schemes. A photocopy of the Aadhaar card was to be submitted once again.

Healthcare professionals indicated that to register themselves in the JSY, women needed to procure a certificate from the District Collector indicating their BPL/SC/ST status (or any other certification of this status), the account details of an Aadhaar-seeded bank account, the proof of institutional delivery from the hospital, and a photocopy of the Aadhaar card. This was the standard practice across the institutions surveyed for the study, despite a ruling by the Delhi High Court directing the Delhi government to not insist on such documents (including the Aadhaar and bank passbooks) for providing JSY benefits to eligible candidates, on the basis that the JSY policy framework does not explicitly state such requirements.⁶³ This does not apply to the PMMVY, since its guidelines explicitly demand the submission of the Aadhaar cards of the pregnant woman and her husband, in addition to the details of an Aadhaar-seeded bank account/post office account.⁶⁴ The payment of the third instalment of the PMMVY is dependent on submitting the Aadhaar details of the husband only.⁶⁵ Activists have pointed out the difficulty women face in acquiring Aadhaar cards and getting their address changed post-marriage, often leading to exclusions.⁶⁶

⁶² *ibid.*

⁶³ *Nisha v Govt of NCT of Delhi* 2018 SCC OnLine Del 10438.

⁶⁴ PMMVY Implementation Guidelines (n 50).

⁶⁵ *ibid.*

⁶⁶ See Press Trust of India, ‘Denied Entry Over Aadhaar, Woman Delivers Baby Outside Gurgaon Hospital’ (*NDTV.com*, 10 February 2018) <<https://www.ndtv.com/gurgaon-news/>

Further, single, divorced, and widowed women are simply excluded as the scheme does not perceive them as eligible beneficiaries at all. The explicit exclusion indicates that the ‘ideal beneficiary’ of reproductive health programmes is a mother in a heteronormative familial structure with childcare obligations, as has been argued in other contexts as well.⁶⁷ Restricting the targeting of family planning and reproductive health programmes to this subset of ‘ideal’ mothers is an instance of moral policing which then excludes all other categories of women from maternity benefits. Such restrictions violate not only the right to privacy of single and divorced mothers but also their right to food security, as a result of the JSY and other maternity benefits being included in the ambit of schemes made available under the NFSA.⁶⁸

The Aadhaar was also the *de facto* identification (‘ID’) document demanded from patients that wanted to receive a pregnancy-related ultrasound. Across the public and private institutions included in the study, the requirement for any ID document morphed into a demand for the Aadhaar, which has in effect become mandatory to receive an abortion. There have been reported instances of the denial of abortions⁶⁹ because of the inability to submit the Aadhaar, in violation of both the MTP Act and the right to privacy as per *Puttaswamy*.⁷⁰ These practices continued despite protections against exclusion in the Aadhaar Act, and multiple notifications by the Unique Identification Authority of India (the nodal body responsible for the distribution and authorisation of Aadhaar cards), which clarified that the lack of an Aadhaar should not be a reason for the denial of essential services⁷¹.

A doctor at a private clinic said that the provision in the PCPNDT that mandates patients to submit ID documents is aimed at controlling sex-selective abortions through regulating health providers, but often ends up harming

with-no-aadhaar-gurgaon-hospital-turns-woman-away-she-delivers-outside-1810911> accessed 9 December 2020; Correspondent DNA, ‘Uttar Pradesh Shocker: Pregnant Woman Denied Admission for Not Producing Aadhaar Card; Delivers Child at Gate’ (*DNA India*, 30 January 2018) <<https://www.dnaindia.com/india/report-uttar-pradesh-shocker-pregnant-woman-denied-admission-for-not-producing-aadhaar-card-delivers-child-at-gate-2579791>> accessed 9 December 2020.; and ANI, ‘MP: Pregnant Woman without Aadhaar Denied Help at Hospital in Jaunpur’ (*The Free Press Journal*, 30 January 2018) <<https://www.freepressjournal.in/cmcm/mp-pregnant-woman-without-aadhaar-denied-help-at-hospital-in-jaunpur>> accessed 9 December 2020.

⁶⁷ Tara Patricia Cookson, ‘Working for Inclusion? Conditional Cash Transfers, Rural Women, and the Reproduction of Inequality’ (2016) 48 *Antipode* 1187.

⁶⁸ National Food Security Act 2013, s 4 (b).

⁶⁹ ‘Activists Slam Mandatory Linking of Aadhaar to Health Services After Woman Denied Abortion’ (*The Wire*, 1 November 2017) <<https://thewire.in/government/activists-slam-mandatory-linking-aadhaar-health-services-woman-denied-abortion>> accessed 9 December 2020.

⁷⁰ Sama and PLD (n 8).

⁷¹ Unique Identification Authority of India (UIDAI), ‘As Per Aadhaar Act, No Denial for Want of Aadhaar: UIDAI’ (*UIDAI*, 10 February 2018) <https://uidai.gov.in/images/news/press_note_on_no_denials_100218.pdf>.

patients. They have “put the onus on doctors and tied our hands. They have stopped us from providing a safe and open environment to patients where they can get abortions without fear. Lawmakers have made people afraid.” She described how patients often have the fear of the breach of informational privacy, especially if they are unmarried or are hiding the abortion from members of their family. There are protections around data storage and sharing: The patients’ information is stored with each provider individually unless on the order of a District Magistrate, which is only issued under special circumstances, and is not collected by the state on a regular basis. Even so, the doctor indicated that patients are afraid that medical providers will reveal their information to their family, which is further exacerbated by making the submission of an ID document mandatory to receive abortions. These fears relate to socio-cultural norms that stigmatise abortion, particularly among unmarried women. It is also pertinent to note that at public facilities, information about abortion is stored in the MCTS/RCH database, along with personally identifiable information such as the name, age, address, and phone numbers of patients. Given the absence of data protection laws in India and poor cybersecurity practices, this can also expose patients to data breaches without their consent to the data collection or the knowledge of breach.⁷² If implemented in its current form, Section 25 of the PDP Bill would mandate the notification of such data breaches to data subjects. Nevertheless, linking the sexual and reproductive health data of patients with centralised biometric identification leaves their data vulnerable.

All the patients I spoke to had already enrolled in the Aadhaar programme, and had either already received the card or were in the process of receiving it. There were some common issues that came up in trying to enrol. Several respondents spoke of having to pay a bribe to enrol, ranging from Rs. 500 to 2000. This includes both those who had enrolled in Delhi and those who had enrolled in other states and migrated to Delhi. 5 respondents who had additionally procured or were in the process of procuring additional documents such as income and caste certificates also had to pay hefty bribes to local officials.

Another common complaint with the Aadhaar was the difficulty of registration and updation, compounded by the virtual absence of a grievance redressal system. Two pregnant women spoke about having to start waiting in line at 7 A.M. to get tokens for an appointment, and then having to wait for 4-5 hours before they could get a token. They had high burdens of care at home, and complained about not having the time to update their Aadhaar while managing care duties. They had not been able to update their Aadhaar despite having visited the updation centre multiple times, and were reliant on their husbands’ documentation for registering themselves for delivery at the hospital.

⁷² Tandon (n 1).

Migrants from other states were able to get registered in programmes and receive services in Delhi, but faced difficulties in address verification. One respondent spoke about not getting benefits after specially opening up an Aadhaar-seeded bank account for enrolling in the JSY, because of the discrepancy in the address noted by the local health centre and their address in the Aadhaar. As the discussion so far has demonstrated, such small errors in registration or updation of the Aadhaar can exclude women from various reproductive health services, thereby limiting their exercise of informational and decisional privacy.

The integration of biometric identification and authentication systems into maternity and abortion services was forced through under the rubric of better targeting and increased access for vulnerable populations. For the respondents of this study, these benefits were not realised. Rather, digital identification systems created another layer of compliances for beneficiaries, while also making them vulnerable on account of centralised data streams that have been created without their consent. The following section discusses additional forms of compliances faced by patients accessing abortions, which further limit their decisional autonomy when accessing these services.

C. Violation of bodily autonomy and decisional privacy

The vesting of decision-making power in the hands of the medical practitioner through the MTP Act implies that local practices, including stigma and negative beliefs around abortion, can impact its provision by each provider.

This can particularly have an adverse impact on groups who face increased stigma while seeking abortions, such as single or divorced women. The major public hospitals I visited in Delhi did not have streamlined policies for the provision of abortion to unmarried women. The procedures were locally determined, and varied across hospitals.

At one public hospital, the healthcare provider I spoke to indicated that all unmarried women seeking abortion have to report to the police, who would be called in to verify that the sexual intercourse was consensual. Only after giving a written declaration of the consensual nature of the sexual intercourse could unmarried woman proceed with the abortion. If the patient did not comply with this requirement, they would be denied the abortion. At another public hospital in North Delhi, a doctor stated that they perform abortions for unmarried women, but first ask them if they want to file a medico-legal case. The doctor described that each healthcare provider at the hospital takes their own decisions on whether they want to proceed with the abortion, based on whether they think the woman “looks like she has an understanding what she is doing” or is “working”. This practice can be blatantly discriminatory against young

women or those with lower levels of education while seeking abortions, as they may not appear to meet this criteria. The doctor described that in such cases, the hospital first calls the police, who will be asked to verify the consensual nature of intercourse by asking for a written declaration. However, this too “depends on the consultant if they want to go forward with the risk” of proceeding with an abortion for an unmarried woman. The member of staff that I interviewed said that doctors might be afraid to undertake abortions, since “If it turns into a medico-legal case, the police will take over the case. Then it takes a long time.” Abortions are not granted till the legal case is resolved, which can result in significantly delay in conducting the abortion. The framing of “risk” was contingent on legal compliances – granting abortions to women without partners was considered risky, because providers at the hospital were wary of cases by patients’ families or partners being filed in the future. This dismisses the capacities and autonomy of women in making decisions about their own bodies, and delays or denies their access to abortion, thereby violating their bodily autonomy.

This arbitrary determination of whether or not to provide abortions is not in line with the MTP Act, which provides specific grounds based on which abortions should be conducted,⁷³ even though it leaves the ultimate decision-making power in the hands of medical practitioners. A healthcare provider at a public hospital indicated that because of the necessity of such compliances, unmarried women prefer to seek abortions at private facilities, which can either be expensive (costing up to Rs. 10,000 at the facilities I visited) or unsafe, depending on the provider. Existing research has also showcased the exclusionary impact of third-party authorisation for abortions.⁷⁴ Exercising their discretionary powers, medical providers often refer women to courts to approve abortions beyond 24 weeks of pregnancy, and sometimes even before this period has expired, due to the stringency of section 312 of the Indian Penal Code.⁷⁵ This is not the case in other countries that allow abortions on request, or that treat it as any other medical procedure with no governing legislations.⁷⁶

The bodily autonomy of adolescents is even more constrained. Under the Protection of Children from Sexual Offences Act, 2012 (‘the POCSO Act’) and subsequent amendments, all sexual activity performed by a minor under the age of 18 has been criminalised.⁷⁷ The Act does not make any distinctions between consensual and non-consensual sex. A doctor at a public clinic said that girls under the age of 18 are not likely to come to public hospitals because of fear of compliances around medico-legal cases, as well as privacy concerns.

⁷³ Medical Termination of Pregnancy Act 1971, s 3.

⁷⁴ Jain (n 17).

⁷⁵ *ibid.*

⁷⁶ *ibid.*

⁷⁷ Protection of Children from Sexual Offences Act 2012, s 2(1)(d).

This includes concerns around decisional and informational privacy, as the police and parents of the patient are mandated to be informed. Unmarried adolescents are then more likely to seek abortions at unsafe providers rather than at public facilities.

The MTP (Amendment) Act, 2021 requires providers to maintain confidentiality regarding the “name and other particulars except to a person authorised by law”.⁷⁸ This is aimed at protecting the informational privacy of women seeking abortions. However, since the MTP Act mandates the consent of parents or guardians for granting abortions to minors below 18, and the sexual activity by minors has been criminalised under the POCSO Act, any abortion involving a minor would become a medico-legal case. It hence becomes impossible to protect the informational privacy or bodily autonomy of mature minors above the age of 16 regardless of the context in which they are seeking the abortion. Previous research has demonstrated the detrimental impact of mandatory disclosure on access to abortion for adolescents.⁷⁹ Several other jurisdictions have either waived the requirement of mandatory consent for mature minors,⁸⁰ or created alternate mechanisms if minors are not able to procure parental consent, including judicial bypass.⁸¹ The absence of such alternatives in India points to a failure of the state to provide access to abortion to mature minors without violating their right to privacy and bodily autonomy.

V. CONCLUSION

This paper dealt with the intersection of privacy and reproductive rights. It discussed the impact of informational requirements and databasing on women’s access to maternal health schemes and abortion services.

Across reproductive health programmes, including cash transfer schemes and abortion services, women’s right to privacy and right to choice is undermined by state incentives to control their bodies. This often takes place through data collection and ID systems which systematically exclude even those women from its purview that have been deemed ‘worthy’ by the state’s own metrics. This is evident by the insistence on the Aadhaar and other ID documents despite lower access to these documents for women, particularly

⁷⁸ Medical Termination of Pregnancy (Amendment) Act 2021, s 4.

⁷⁹ Cynthia Dailard and Chinue Turner Richardson, ‘Teenagers’ Access to Confidential Reproductive Health Services’ (2005) 8 *Guttmacher Institute* 6.

⁸⁰ ‘The Injustice and Harms of Parental Consent Laws for Abortion Position Paper #58’ (*Abortion Rights Coalition of Canada*, October 2017) <<https://www.arcc-cdac.ca/wp-content/uploads/2020/06/58-Parental-Consent.pdf>> 9 December 2020.

⁸¹ ‘Parental Involvement in Minors’ Abortions’ (*Guttmacher Institute*, 1 January 2021) <<https://www.guttmacher.org/state-policy/explore/parental-involvement-minors-abortions>> accessed 9 December 2020.

for women from low-income groups. Several instances of the exclusion of women from access to maternity services and benefits have been recorded across India. Mandatory requirements continued to be enforced despite explicit protections in Supreme Court judgements relating to the right to privacy, *Puttaswamy I and II*, and the Aadhaar Act. The patients and families I spoke to were completely unaware of the ways in which their data was being stored and used by healthcare institutions, despite provisions relating to obtaining informed consent in existing frameworks. The integration of digital systems of extracting data also reinforce the paternalism of public institutions, designed explicitly to monitor and curtail women's access rather than ensuring universal coverage.

The detrimental impact of state surveillance is also evident in the approach of curtailing sex-selective abortions through the mandatory submission of ID documents. The perceived violation of privacy at public institutions has turned many women away from public abortion providers if they can afford private services. Healthcare providers indicated that privacy was a key concern among women accessing abortions, particularly among those who carry additional stigmas regarding seeking abortions, such as single women or adolescents. The state's approach towards abortion services remains paternalistic and contingent on the comfort of individual medical providers, rather than empowering women to exercise their bodily autonomy.

Women have to go through excessive legal verification to prove several things to the state – among other things, their own identity and that of their family, their consent to sexual intercourse, and their income and caste status. In each of these cases, officials of the state have the last word in determining whether women are stating the truth about their bodies.