A FEMINIST ONTOLOGY TO DATA COMMERCIALISATION: EVALUATING WOMEN'S ACCESS TO INFORMATION AND PRIVACY WITHIN THE MEDICO-LEGAL SPHERE IN SOUTH AFRICA

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DECLARATION

I declare that this Research Report is my own unaided work. It is submitted in partial fulfilment of the requirements for the degree of Master of Laws (by Coursework and Research Report) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in this or any other university.

I have submitted my final Research Report through Turn-It-In and have attached the report to my submission to the University of the Witwatersrand, Johannesburg.

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ABSTRACT

With the dawn of the Fourth Industrial Revolution, rapid exchanges of data have intensified. Technologies like biometric monitoring, female-oriented technologies, and artificial intelligence bring with them a host of legal issues related to consent, access, privacy, and liability. Vulnerable populations or groups must be given particular attention as standard data practices serve to reinforce existing inequalities. For this reason, female-directed and female-generated health data is specifically considered herein. By employing a data feminism lens, it becomes apparent that the current South African regulatory framework has been legislatively misapproached with regards to the medico-legal sphere in South Africa. The methodology herein draws on critical review methods, thematic analysis, and legal discourse analysis, ultimately utilising the general principles of research inherent in the socio-legal sciences. A responsive and flexible health data law that incorporates intersectional narratives is advanced. This holistic response must account for the two-faced coin of female access to information and privacy in order to address historical structures of power inequity.

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I. INTRODUCTION

As the Third Industrial Revolution (the 'Digital Age') draws to a close, and the Fourth Industrial Revolution dawns, the lines between digital, biological, and physical spheres are blurred through a fusion of technologies.[2] With these technological developments, exchanges and transfers of data have rapidly gained ground.[3] Billions of individuals' daily lives are affected by the flow of data which, in turn, necessitates a thorough consideration of transparency and privacy particularly in areas vulnerable to abuse like healthcare.[4]

At first consideration, the right of access to information and the right to protection of personal privacy may appear contradictory.[5] Put simply, access to information is the fundamental right of any person to access information held by public or private bodies, while privacy safeguards the individual's fundamental right to control public or private bodies' access, use, and collection of their personal data.[6]

These rights are complementary and serve to promote the individual's right to protect themselves and ensure accountability of powerful institutions.[7] The interrelatedness of these rights is not a novel concept. In their 1986 recommendation, the Council of Europe stated that these rights were not separate but formed part of society's landscape of information policy.[8]

[1] BA Law (Distinction), LLB (Distinction), PGDip in Attorneys' Practice (Top WET), LLM in Commercial and Business Law (Candidate), and Legal Analyst.
[2] Bianca Rodrigues Teixeira, Daniel Schwabe, & Fernanda A Baião et al 'Privacy and transparency within the 4IR: Two faces of the same coin' 2019 *Companion Proceedings of The 2019 World Wide Web Conference* 581–93 at 582.
[3] Olayinka Adeniyi 'Engendering women data use, privacy, and protection in Africa: Focus on data laws in South Africa and Kenya' 2022 *QMLJ* 52–66 at 52.
[4] Op cit note 2.
[5] David Banisar 'The right to information and privacy: Balancing rights and managing conflicts' 2011 *World Bank Institute Governance Working Paper Series* 3.
[6] Ibid.
[7] Ibid at 9.
[8] Ibid.

Having been described as two faces of the same coin, neither right takes precedence over the other.[9]

This dissertation specifically considers women's access to information and privacy within the medico-legal sphere in South Africa by employing data feminism. 'Data feminism' considers the limits and use of data as informed through considerations of direct experiences, the commitment to action by agents of change, and intersectional feminist thought.[10] I consider this approach particularly necessary in policy and law-making, as power is not equally distributed in the world.[11] Nor is technology created in a vacuum, but rather designed and employed in contexts that are already structured with exclusionary practices or inequalities.[12]

At a fundamental level, male and female data differs because of biological, societal, cultural, and other factors. While not all individuals can and/or should be easily classified into male and female categories,[13] data science employs standard practices. For example, imputing medical knowledge premised on male data to the female body without consideration of sex differences.[14] These harmful standard practices play out in different spheres – herein, the focus is the health-related setting – through the abovementioned fusion of technologies.[15] Without committed interventions, these standard data science practices ultimately reinforce pre-existing inequalities.[16]

As a practical illustration, I refer to coronary heart disease. This disease is a leading cause of death for women in most industrialised countries, yet only in the recent vicennial has emphasis been placed on validating the investigation of sex differences to improve health outcomes for women.[17] The underrepresentation of women and/or lack of gender- or sex-specific reporting in clinical trials limits our available knowledge as well as our evidence-based medicines, like the failure to account for menopausal hormone therapy.[18]

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[9] Ibid at 3.
[10] Catherine D'Ignazio & Lauren F Klein *Data Feminism* 2020 at 8.
[11] Ibid.
[12] Javiera Atenas, Helen Beetham, & Frances Bell et al 'Feminisms, technologies and learning: continuities and contestations' (2022) 47(1) *Learning, Media and Technology* 1–10 at 1.
[13] For example, classification of persons associated with intersex variations, or differences in sex development, or congenital variations in sex characteristics all remain pathologized by the World Health Organization. In fact, the ICD-11 (the 11th revision of the International Classification of Diseases) by the World Health Organization describes these variations as sex development disorders.
See: Morgan Carpenter 'Intersex variations, human rights, and the international classification of diseases' (2018) 20(2) *Health Hum Rights* 205–14 at 205.
[14] Caroline Criado Pérez *Invisible Women: Exposing Data Bias in a World Designed for Men* (2019) at 147.
[15] Op cit note 2.
[16] Op cit note 10.
[17] Nanette K Wenger 'Coronary heart disease: The female heart is vulnerable' (2003) 46(3) *Progress in Cardiovascular Diseases* 199–229 at 199–200.
[18] Ibid.

While South Africa's legal framework does safeguard confidentiality of personal information and privacy alongside providing access to information, this is to a limited extent only. For example, women may voluntarily or inadvertently share their data without specific informed consent through compelled authorisations, loan and employment applications, peer-to-peer file sharing, and direct-to-consumer genetic testing.[19] This may result in their data being commercialised with the potential for abuse, including the materialisation of data security risks or discrimination.[20]

This dissertation seeks to evidence women's right of access to information and privacy as having been legislatively misapproached, thereby necessitating a holistic response. The aims of this dissertation fit squarely within the topic as they provide strong legal queries in which to examine our current legislative framework through a modern feminist and data commercialisation lens. The feminist lens employs data feminism as described above, while the data commercialisation lens acknowledges the value and commercialisation potential of data, particularly regarding the process of exploiting an existing body of data to create a new revenue stream.[21] In addressing this topic, various domestic, foreign, and/or international legislative devices are considered herein.

These include *inter alia* domestic acts like the Protection of Personal Information Act 4 of 2013 ("POPIA"), the National Health Act 61 of 2003 ("NHA"), the Electronic Communications and Transactions Act 25 of 2002 ("ECT"), and the Promotion of Access to Information Act 2 of 2000 ("PAIA"). Furthermore, assorted guidelines including the Department of Health's quasi-legal guidelines,[22] and relevant agreements like the Material Transfer Agreement for Human Biological Materials.[23] Additionally, foreign legislation like the General Data Protection Regulation or principles like the Organisation for Economic Co-operation and Development Privacy Guidelines.[24]

This topic is worthy of academic research to highlight the inappropriateness of our current domestic legislation and to underscore the potential and realised harm to women's health or personhood due to abuse or misuse of health data. Even newly-effected legislation

[19] M Botes, A Olckers & M Labuschaigne 'Data commercialisation in the South African health care context' 2021 (24) *PER/PELJ* 1–35 at 5.
[20] Ibid at 6.
[21] Ibid at 1.
[22] Department of Health 'Ethics in Health Research: Principles, processes, and structures' (2015) 2 available at *https://www.ru.ac.za/media/rhodesuniversity/content/ethics/documents/nationalguidelines/DOH_(2015)_Ethics_in_health_research_Principles,_processes_and_structures.pdf*, accessed on 14 July 2023 at 1–94 at 43.
[23] GN R719 in GG 4178 of 20 July 2018 (Material Transfer Agreement for Human Biological Materials).
[24] Adéle da Veiga 'A study on information privacy concerns and expectations of demographic groups in South Africa' (2022) 47 *Computer Law & Security Review* 1–38 at 5.

like POPIA must be framed as inadequate in terms of the data feminism and commercialisation lens, especially in the context of gender justice. Overall, a responsive health data law incorporating the regulation of female-oriented technologies is proposed, thusly attending to the two faces of the metaphorical coin of access to information and privacy.

II. METHODOLOGY AND LIMITATIONS

By drawing on the principles (if not the formal structure) of research inherent in the socio-legal sciences, this dissertation makes use of critical review methods,[25] concomitant with thematic analysis and legal discourse analysis.[26]

While thematic analysis is commonly utilised in psychology, Braun and Clarke advocate for its broader application due to its theoretical flexibility and accessibility of approach in analysing qualitative data.[27] By using this foundational method, I identify, analyse, and report themes or patterns within the data,[28] including within the legal discourse.

Beyond extensive research or literature analysis, I then consider the quality of the literature presented in accordance with the aims of critical review.[29] The focus herein is on the international and, more particularly, the domestic statutory and regulatory framework related to women's health data and/or femtech. This is set against the background of access to information and privacy in the medico-legal sphere.

At the outset, I clarify that I refer to sex as a dichotomy classification of biological sex – male or female – with the corresponding differences in hormonal, chromosomal, or immunological characteristics.[30] As the scope of this dissertation pertains to female data or biometric technology, much – if not all – of the discussion will be directed towards female persons, interchangeably with the term "women".

For this reason, I contemplate sex-specific data and not necessarily gender-sensitive data. I fully acknowledge, however, that sex may differ from gender and that some non-female persons may identify with issues herein. Indeed, this dissertation is limited by the available research insofar as numerous authors did not specify whether the term 'women' referred to sex,

[25] Werner de Klerk & Jené Pretorius 'Guideline for conducting critical reviews in psychology research' (2019) *Journal of Psychology in Africa* 645–9 at 646, 648.
[26] Virginia Braun & Victoria Clarke 'Using thematic analysis in psychology' (2006) 3(77) *Qualitative Research in Psychology* at 77.
[27] Ibid.
[28] Ibid at 79.
[29] Op cit note 25 at 645.
[30] Sabra L Klein & Katie L Flanagan 'Sex differences in immune responses' (2016) 16(10) *Nature Reviews Immunology* 626–38 at 626.

gender, or both. Moreso, insofar as legal scholars by and large did not adhere to rigorous research methodologies.

III. SEX-DISAGGREGATED DATA

Throughout history, law and medicine have been interrelated, with jurist, physician, and priest once united in a single person.[31] In fact, the Law Code of Hammurabi was the first (documented) Code of Laws in human civilisation, and it concerned the skills of Mesopotamian physicians.[32] This is partly the reason why I consider the field of medicine to be inextricable from the development of policy and law. Part of the influence of medicine is, of course, sex-disaggregated data.

The World Health Organisation's Annual World Health Statistics Report acknowledges that disaggregated data may be used to address inequalities.[33] This was evident during the COVID-19 pandemic, where sex-difference impacted health responses.[34] For example, in the past vicennial, significant gains have been made in maternal health, with the global maternal mortality ratio falling by nearly 40% since 2000.[35] However, the COVID-19 pandemic predictably negatively affected life expectancy and/or healthy life expectancy by either reversing or slowing progress made in some parts of population health.[36] This included anaemia among women, violence against women, or other risks awaiting the collection and analysis of further data.[37]

But despite the significance of gender and sex in health outcomes and the purported commitment to disaggregation of data in health policies and programmes, continuously (and conspicuously) lower-income countries (like South Africa) remain absent of such data.[38] This is problematic as the right of access to information cannot be given full effect to unless data is

[31] Smith Ely Jelliffe 'Medicine, the law and juvenile delinquency' 1936 (27)4 *Journal of Criminal Law & Criminology* 503–14 at 505.
[32] Magdaleen Swanepoel 'The development of the interface between law, medicine and psychiatry: Medico-legal perspectives in history' (2009) (12)4 *PER* at 124–71 at 125–6.
[33] World Health Organisation 'World health statistics 2022: monitoring health for the SDGs, sustainable development goals' *WHO* available at *https://cdn.who.int/media/docs/default-source/gho-documents/world-health-statistic-reports/worldhealthstatistics_2022.pdf?sfvrsn=6fbb4d17_3*, accessed on 23 May 2022 at 14.
[34] Ibid.
[35] Ibid at vii-viii.
[36] Ibid at viii.
[37] Ibid at viii.
[38] Sarah Hawkes, Athena Pantazis & Anna Purdie et al 'Sex-disaggregated data matters: Tracking the impact of COVID-19 on the health of women and men' (2022) 39 *Economia Politica* 55–73 at 55.

indeed disaggregated. Access to information is essential for the exercise of basic political and socioeconomic rights.[39]

Further compounding this matter is that although there are growing concerns related to the threat of governmental or technological interference in the individual's privacy,[40] half of the world still remains offline, with the majority constituting women in developing countries.[41]

Put simply, disaggregated data at the national and/or subnational levels is necessary to investigate for inequity; identify inequality; and design and implement responsive, committed interventions.[42] To provide a practical historical example, I refer to the National Strategic Plans for HIV/AIDS ("NSP"), which describe priorities for services and/or programmes, like targets quantifying progress towards international and national goals.[43] The NSP are critical, country-planning documents directed towards the HIV epidemic, influencing donor-funding priorities, and guiding data collection for international and/or domestic monitoring and evaluation.[44]

The inclusion of sex-disaggregated targets is significant because the disease burden among young women and/or adolescent girls is high in sub-Saharan Africa due to a blend of factors, including predisposing social risk factors such as harmful norms, education income inequality, or violence, as well as biological vulnerability.[45] Despite this, only around one-third of countries in sub-Saharan Africa include sex-disaggregation in their NSP targets, at the time of study.[46] Common targets include improving women's access to human and legal rights, family planning, or decision-making power.[47] In national planning, the inclusion of sex-disaggregated targets is paramount to ensure programmes result in progress for *all* population groups.[48]

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[39] The Carter Centre 'Women and the right of access to information' *TCC* available at *https://www.cartercenter.org/peace/ati/women.html,* accessed on 23 May 2022.
[40] Hanno N Olinger, Johannes J Britz, & Martin S Olivier 'Western privacy and/or Ubuntu? Some critical comments on the influences in the forthcoming data privacy bill in South Africa' (2007) 39(1) *The International Information & Library Review* 31–43 at 32.
[41] Carlos Iglesias 'The gender gap in internet access: Using a women-centred method' *World Wide Web Foundation* 10 March 2020 available at *https://webfoundation.org/2020/03/the-gender-gap-in-internet-access-using-a-women-centred-method/,* accessed on 22 May 2022.
[42] Daniel A Cohn, Maureen P Kellya, & Kalpana Bhandaria et al 'Gender equity in mass drug administration for neglected tropical diseases: Data from 16 countries' (2019) 11 *Int Health* 370–78 at 371.
[43] Jennifer Sherwood, Alana Sharp, & Bergen Cooper et al 'HIV/AIDS National Strategic Plans of Sub-Saharan African countries: An analysis for gender equality and sex-disaggregated HIV targets' (2017) 32(10) *Health Policy and Planning* 1361–7 at 1361.
[44] Ibid at 1362.
[45] Ibid.
[46] Ibid at 1361.
[47] Ibid.
[48] Ibid at 1362.

Both preclinical and clinical research has established that male and female bodies can differ to a significant degree, in terms of response to treatment, common disease, efficacy, or adverse effects.[49] Spanning health domains, and consistently throughout history, male-generated data has been collected and then generalised to female bodies.[50] The disaggregation of data by sex permits the identification of difference between female and male bodies, facilitating an understanding of sociocultural and biological factors in health matters like disease presentation,[51] or pregnancy and childbirth.[52]

I submit that by including sex-disaggregated data for any-and-all health-related matters, the individual (male or female) may be empowered through the information obtained. For example, economic opportunities or access to resources by (and for) young women is beneficially associated with their sexual health outcomes.[53] Without such disaggregation, information can neither be appropriately accessed by national planning schemes nor by the individual themselves.

Problematically, a cursory reading of the existing body of literature does not appear to describe women's rate of access to their own health data compared to men in any meaningful way. I propose this may well be because of medical bias towards male bodies. There is an identifiable need for sex-disaggregated data, particularly in the healthcare setting. In fact, only in 2019 alone did the World Health Organization sex-disaggregate their 'Global Health Statistics' for the first time, despite the fact that breaking down data by sex assists health systems in identifying and responding to gender inequalities in health.[54]

On the flip side of this two-faced coin (of access to information and privacy law) is that data is highly commercialised with the potential for abuse looming high, which is contrary to rights such as privacy.[55] In other words, women-generated data and/or women-focused data is not necessarily accessed by women at the rate it should be, alongside that data then being underrepresented or abused.

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[49] N Krieger, & R Genders 'Sex and gender in health research: Updating policy to reflect evidence' (2018) 108(S3) *The American Journal of Public Health* 293–5.
[50] Ibid.
[51] Ibid.
[52] World Health Organization 'Women and health: today's evidence tomorrow's agenda' 2009 available at *https://apps.who.int/iris/bitstream/handle/10665/44168/9789241563857_eng.pdf?sequence=1&isAllowed=y*, accessed on 10 September 2023 at xi.
[53] Op cit note 4 at 1364.
[54] World Health Organization 'Closing data gaps in gender' available at *https://www.who.int/activities/closing-data-gaps-in-gender*, accessed on 10 September 2023.
[55] Op cit note 19 at 10.

IV. ACCESS AND PERSONAL HEALTH RECORDS

That said, the general rate of access to patient's medical notes has been increasing globally in the developed world due to a primary tenet of medical ethics, namely patient autonomy.[56] In support of this, an England-based study established that the policy of women holding and maintaining constant access to their own full obstetric records assists them in feeling greater control over their antenatal care.[57]

Moreover, it improved the lines of communication between patient and health practitioner with the additional benefit of reduced clerical time.[58] I note that neither did these women report feeling greater levels of anxiety.[59]

I contrast this to the state of policy of medical records in South Africa. A South African-based study in Limpopo canvassing forty hospitals revealed that 73% of respondents – namely, staff within the records management or information management units – consider the state of records management in their institution 'very poor' or 'poor'.[60]

This is a sobering statistic, particularly when considering that missing files negatively contribute to the timely, effective delivery of healthcare services.[61] Resultantly, medical professionals are either unable to treat patients immediately or, alternatively, elect to administer treatment without records, thereby compromising the patient's health.[62]

This is an identifiable problem in South Africa's history, affecting our urban and rural areas. In an archival survey, a mere 39% of requested records were located in connection with four district hospitals within the rural community – this, I note, less than two years after treatment.[63] Problems stemmed from absent or incorrect documentation, different folder numbers, incomplete folders, and poor methods of filing.[64] Healthcare practitioners often

[56] Stephanie N D'Costa, Isla L Kuhn, & Zoë Fritz 'A systematic review of patient access to medical records in the acute setting: practicalities, perspectives and ethical consequences' (2020) 21(18) *BMC Med Ethics* 1–19 at 1.
[57] D Elbourne, M Richardson, & I Chalmers et al 'The Newbury Maternity Care Study: a randomized controlled trial to assess a policy of women holding their own obstetric records' (1987) 94(7) *British Journal of Obstetrics and Gynaecology* 612–19 at 612.
[58] Ibid.
[59] Ibid.
[60] Ngoako S Marutha & Mpho Ngoepe 'The role of medical records in the provision of public healthcare services in the Limpopo province of South Africa' (2017) 19(1) *South African Journal of Information Management* 1–8 at 4.
[61] Ibid at 1.
[62] Ibid.
[63] Wegner L & Rhoda A 'Missing medical records: an obstacle to archival survey-research in a rural community in South Africa' (2013) 69(2) *South African Journal of Physiotherapy* 15–19 at 18.
[64] Ibid at 17.

neglect the recordkeeping part of their workload.[65] In my opinion, some of the fault of this particular attitude lies at the feet of our existing policies and the implementation thereof.

Under sections 7, 14, and 15–16 of the NHA, the written informed consent requirements are outlined, alongside the need for confidentiality, personal information protection, and protection of (and access to) medical records. Particularly, section 13 requires that the person in charge of a health establishment ensures a health record is created, and maintained, for every user of the health services. Under section 8.1 of the revised Health Professions Council of South Africa's Guidelines on the Keeping of Patient Health Records ("HPCSA Guidelines"), the patient's health record is 'owned' by the health practitioner or entity generating the record.[66]

Section 9.2.1 of the Guidelines states that the health practitioner will provide any person (age 12 or older) with a copy or abstract or direct access to their own records related to medical treatment on request,[67] but problematically the term 'abstract access' does not appear to be defined. In any event, the patient may still be charged a fee for copies of the record or images, in the case of state institutions or private hospitals.[68]

This seems a somewhat flawed approach. Already, the quality of recordkeeping, financial barriers, lack of appropriate education, or problematic data systems have all served in some way to limit access or prejudice privacy. The express removal of ownership seems dissociated from the idea of data belonging to the data subject, in a space that ought to be purely about their health. 'Ownership' of health records may be a pedantic point – but law is often about the question of wording.

Given the above, an appropriate mechanism may be the implementation and use of personal health records and/or electronic health records. As tools, these may provide more immediate relief and the conferment of ownership to patients over their own health. These records assist patients in becoming active participants invested in their own health.[69]

I submit that South Africa is already lagging behind the global trend for personal health records. For instance, in Australia, paper-based health records are not a novel concept, and

[65] Ibid at 15.
[66] Health Professions Council of South Africa 'Guidelines for Good Practice in the Healthcare Profession: Guidelines on the Keeping of Patient Health Records' (Revised September 2022) Booklet 9 available at *https://www.hpcsa-blogs.co.za/wp-content/uploads/2022/11/Booklet-9-Keeping-of-Patient-Records_Review-Draft_-FINAL_Sept-2022.pdf*, accessed on 1 August 2023 at section 8.1.
[67] Ibid at section 9.2.1.
[68] Ibid at sections 8.3–8.4.
[69] Paul C Tang, Joan S Ash, & David W Bates et al 'Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption' (2006) 13(2) *J Am Med Inform Assoc.* 121–6 at 121.

have been utilised for years.[70] Recently, electronic medical records (held on secure patient platforms) have also been favourably received by patients. An Australian cross-sectional study established that 86.2% of maternity patients would use their electronic medical record again for their future pregnancies.[71]

In effect, this study demonstrated the favourable reception of one of the first 'web-based' patient portals deployed in Australia.[72] I consider this persuasive in the overall argument for women holding and maintaining constant access to their obstetric records. Overall, electronic health records also point to the growing trend for the spread of 'e-health', termed a 'key component' of modern-day healthcare delivery.[73]

V. PRIVACY AND BIOMETRIC MONITORING

(a) Analysis of female-oriented technologies

Under this umbrella topic of 'e-health', I note the presence of biometric technology in the consumer market has not only grown, but become increasingly normalised.[74] Biometric technology is concerned with automatically authenticating individuals based on their unique physiological and/or physical characteristics (e.g., fingerprints) such that the data is recorded, measured, quantified, and stored in digital form.[75] The reliance on physical or bodily data means that this technology is amongst the most intrusive on the market.[76]

As a form of biometric technology, female-oriented technology ("femtech") consists of an ever-expanding range of wearables and/or mobile apps.[77] Femtech ranges from the Internet of Things devices (meaning physical objects with sensors and software), apps, or services and goods directed towards managing female health.[78] Female health may refer to biological processes like menstruation, pregnancy, menopause, specific health conditions like

[70] Megan Forster, Kerrie Dennison, & Joanne Callen et al 'Maternity patients' access to their electronic medical records: Use and perspectives of a patient portal' (2015) 44(1) *Health Inf Manag* 4–11 at 4.
[71] Ibid.
[72] Ibid.
[73] Ibid.
[74] Sejin Paik, Kate K Mays, & James E Katz 'Invasive yet inevitable? Privacy normalization trends in biometric technology' (2022) 1(16) *Social Media + Society* 1–16 at 1.
[75] Ibid.
[76] Ibid at 2.
[77] Elizabeth A Brown 'The femtech paradox: How workplace monitoring threatens women's equity' (2021) 61 *Jurimetrics* 289–329 at 290.
[78] Maryam Mehrnezhad, Laura Shipp, & Teresa Almeida et al 'Vision: Too little too late? Do the risks of femtech already outweigh the benefits?' 2022 *Proceedings of the 2022 European Symposium on Usable Security* 145–50 at 145.

endometriosis, breast cancer, migraines, or to general wellbeing including longevity, healthy living, and mental health.[79]

The femtech market arguably arose due to the need to address the technological and medical neglect of women's health considering that education, medical practice, and research are all afflicted with bias.[80] I submit this echoes the same sentiments of the interest in personal health records.

Racial and gender bias in clinical practice continuously results in clinical disparities.[81] For instance, a previous experimental study has demonstrated that clinicians medically reviewing video accounts of patients presenting with chest pain disproportionately refer white patients over black patients and, further, male patients over female patients for the most appropriate treatment (according to guidelines and high standards of care).[82] These biases clearly have practical ramifications for women's health outcomes and treatments.[83] The study further demonstrated that peer-reviewed communication networks reduced the clinician's bias perceptions, suggesting that clinical decision-making relates to a social and behavioural lens.[84] This presents an opportunity for digital technologies: either for clinicians in information-sharing networks,[85] and/or arguably equipping the patient herself to take control of her health with femtech.[86]

The advantages of femtech are numerous. They may increase women's agency by encouraging them to take control of their bodies and health while reducing unnecessary dependency on gynaecologists, primary care doctors, and obstetricians.[87] It additionally may enable women to overcome existing challenges in research and healthcare.[88] For example, the harmful standard data practices that reinforce existing inequalities.[89] That said, femtech products generally work by amassing user-entered data or sensors to record environmental or body measurements like basal body temperature or ovulation detection.[90] Sensors may include

[79] Ibid.
[80] Ibid.
[81] Damon Centola, Douglas Guilbeault, & Urmimala Sarkar et al 'The reduction of race and gender bias in clinical treatment recommendations using clinician peer networks in an experimental setting' 2021 (12) *Nature Communications* 1–10 at 2.
[82] Ibid.
[83] Op cit note 78 at 145.
[84] Op cit note 81.
[85] Ibid.
[86] Tereza Hendl & Bianca Jansky 'Tales of self-empowerment through digital health technologies: A closer look at 'femtech'' 2021 *The Association for Social Economics* 1–31 at 2.
[87] Op cit note 77.
[88] Op cit note 78.
[89] Op cit note 15 at 147.
[90] Op cit note 78.

biometric, motion, communicational, ambient, medical, or other individual or combined factors.[91]

As such, femtech devices collect data related to sexual activities, reproductive choices, or personal details, and process the data through complex algorithms, creating large data sets around sensitive information not necessarily collected by other technology.[92]

With the rise in popularity of biometric technology,[93] specifically of femtech Internet of Things devices,[94] and facially-neutral biometric monitoring,[95] new risks are introduced. Biometric monitoring may include inherent design biases and algorithms which interpret the health data collected and reflect inherent sex or gender biases. In turn, this may result in monitoring losing efficacy.

Despite this rise and the potential for risk, there is a lack of clarity in industry practice and the law regarding specific informed consent or the potential harm attached to algorithmic bias and third-party sharing.[96] As opposed to empowering women, these technological tools increase data that may be used to further sexual discrimination and harassment, including in the workplace.[97] The workplace is but one area of potential harm, but I consider it a major consideration that is worth discussing due to the potential ramifications.

(b) Workplace health monitoring – a new frontier of discrimination

The collection of health data like fertility, abortion, pregnancy, or menopausal status is increasing within the work environment because of the rise of workplace health monitoring and/or wellness programmes (seen with the COVID-19 pandemic alone).[98]

I couple this with the fact that women (particularly black women) already suffer intersectional, ongoing prejudices in the workplace.[99] To date, the implementation and monitoring of employment equity in the South African private sector is an ongoing critical challenge.[100] Employment equity may be defined as individuals' employment in an unbiased,

[91] Ibid at 146.
[92] Op cit note 78.
[93] Op cit note 74.
[94] Op cit note 78.
[95] Op cit note 77.
[96] Op cit note 78.
[97] Op cit note 77.
[98] Ibid.
[99] Motlhatlego Dennis Matotoka & Kolawole Olusola Odeku 'Untangling discrimination in the private sector workplace in South Africa: Paving the way for Black African women progression to managerial positions' (2021) 21(1) *International Journal of Discrimination and the Law* 47–71 at 49.
[100] Ibid at 50.

fair manner to promote equal opportunity by eliminating discrimination in employment practices or policies.[101] Ultimately, the Employment Equity Act 55 of 1998 has not been successful in tackling gender, race, and class parity, with private sector companies able to endure employment equity noncompliance fines by smart 'budgeting'.[102]

Despite the advent of democracy, South Africa is still deeply segregated.[103] The concern with femtech in the workplace, or workplace health monitoring overall, is that it will be used to amplify gender discrimination by providing health data clearinghouses and employers with detailed data about female bodies compared to male bodies.[104] Women are more likely than men to suffer harmful effects from this increased monitoring of employee bodies because there are significant sex-based differences in the kinds of data recorded, the way in which this data is collected, the accuracy of algorithms processing the data, and the consequences that ultimately result.[105]

Femtech may feed into harmful existing stereotypes, strengthen stereotypes with intimate details, or reduce women's reasonable expectations of privacy, including in the workplace.[106] In encouraging a community of sharing of health data, femtech companies may make it increasingly difficult for women to succeed with privacy infringement claims.[107] For instance, a woman using a femtech app may share her experiences regarding her fertility struggles on the community forum space provided due to the cultivated 'sharing culture'.[108] If such a woman litigates for invasion of privacy by the employer, she will need to establish her reasonable expectations of privacy.[109] This, however, may be difficult to do because it necessitates arguing that she intended her fertility struggles to remain private despite her posting in the femtech community forum spaces.[110] Resultantly, women may face difficulty establishing a legal wrong or adverse action as the unlawful discrimination is allegedly dissolved through the reliance on objective-appearing data.[111]

Another example is dismissal for pregnancy. Under sections 9(3) to (4) of the Constitution, a person cannot be dismissed or discriminated against due to pregnancy. This

[101] Rudolf M Oosthuizen, Louise Tonelli, & Claude-Hélène Mayer 'Subjective experiences of employment equity in South African organisations' (2019) 17(1) *SA Journal of Human Resource Management* 1–12 at 1-2.
[102] Op cit note 99 at 50.
[103] Ibid at 47.
[104] Op cit note 77.
[105] Ibid.
[106] Ibid.
[107] Ibid at 291.
[108] Ibid at 317.
[109] Ibid.
[110] Ibid.
[111] Ibid at 292.

prohibition is reiterated under section 6 of the Employment Equity Act. Further, under section 187(1)(e) of the Labour Relations Act 65 of 1995, a dismissal is automatically unfair if it is premised on the employee's intended pregnancy, actual pregnancy, or any other pregnancy-related reason.[112]

In determining automatically unfair dismissals under section 187(1)(a), being strike or protest action, the court in *SACWU* considered the 'most probable inference' drawn from established facts.[113] In *Heath*, the court imputed this principle to determinations under section 187(1)(e) of the LRA, that is, pregnancy-related dismissals.[114] I submit that with the advent of workplace health monitoring, determining the 'most probable inference' may become extremely difficult due to the subversive nature of the monitoring.

Despite the clear potential for harm, femtech receives little attention from legal scholars.[115] Femtech, particularly when utilised in vulnerable spaces like the workplace, requires specific legal recognition because of the sex-specific consequences it presents compared to the broader umbrella of biometric monitoring.[116] This is, in part, due to the focus on biological difference and the technological focus on female bodies.[117]

Neither of these are, in my view, necessarily problematic unless weaponised, exploited, or recklessly advanced. For instance, recent femtech is often descriptive as well as prescriptive, acting as an advisor to women based on their biometric data.[118] With the growth of Artificial Intelligence ("AI") in healthcare and medicine, numerous concerns are cropping up, related to ethics, data privacy, and legal liability.[119] I submit these AI systems act in a prescriptive manner, given that they may guide diagnoses,[120] health tracking applications, dispense drugs, or even carry out robotic surgeries.[121]

(c) Artificial intelligence

[112] Labour Relations Act 65 of 1995, section 187(1)(e).
[113] *SACWU and Others v Afrox Ltd* (1999) 20 ILJ 1718 (LAC) para 32.
[114] *Heath v A & N Paneelkloppers* (JS932/2012) [2014] ZALCJHB 343 para 42.
[115] Op cit note 77 at 292.
[116] Ibid.
[117] Ibid.
[118] Ibid.
[119] Abdullah Shuaib, Husain Arian, & Ali Shuaib 'The increasing role of artificial intelligence in health care: Will robots replace doctors in the future?' (2020) 13 *International Journal of General Medicine* 891–896 at 891.
[120] Op cit note 15.
[121] Op cit note 119.

The introduction of AI in the medical sphere appears to have been accompanied with little or no acknowledgement of the chronic, well-documented gaps in medical data regarding women.[122] This could result in disaster or fatality, given machine-learning's ability to amplify pre-existing biases.[123] With the body of medical knowledge biased in favour of male bodies, the advent of AI may result in diagnoses for women drastically worsening as opposed to improving.[124]

The effect of AI will be felt in many fields, including delictual law, labour law, privacy law, or data protection law, and women may bear the brunt of the harm due to the aforementioned biases. Currently, there is a clear precedence in establishing causation through human conduct in medical negligence cases. However, the legal waters are muddied with the advent of AI.

The medical negligence precedence is observable in our jurisprudence. For instance, in *N.P v MEC*, the point of adjudication was whether the clinic staff had been negligent in their dealings or management of the Plaintiff's pregnancy, and whether this negligence was causally connected to the infant child's injuries.[125] I consider this case relevant insofar as it clearly relies on causation through *human* conduct – what, then, is the precedence for AI? Comparatively, any potential harm associated with these seemingly intelligent, autonomous technologies may not be adequately mitigated by our current regulatory delictual frameworks.[126] This is because the very nature of AI systems implicates notions of control or foreseeability that may render these existing delictual frameworks ineffective.[127]

Problematically, South Africa neither has an overall AI strategy nor any specific legislation directed towards AI.[128] Domestic and statutory regulators like the National Health Research Ethics Council, the HPCSA, the South African Pharmacy Council in terms of the Pharmacy Act 5 of 1974, the Nursing Council, or the National Department of Health have developed ethical guidelines corresponding with their core mandates but none that pertain to AI healthcare in South Africa (never-mind to the sex-specific implications of biased data).[129]

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[122] Op cit note 15.
[123] Ibid.
[124] Ibid.
[125] *N.P v MEC for Health, Eastern Cape* (1196/2012) [2014] ZAECMHC 28 (24 July 2014) para 2.
[126] Anisha Amarat Jogi *Artificial intelligence and healthcare in South Africa: Ethical and legal challenges* (Doctor of Laws Dissertation, UNISA, 2021) 14.
[127] Ibid.
[128] Dusty-Lee Donnelly 'First do no harm: Legal principles regulating the future of artificial intelligence in health care in South Africa' (2022) 25 *PER / PELJ* 1–43 at 27.
[129] Op cit note 126 at 17.

International instruments that have developed guidelines on AI include the Organisation for Economic Co-operation and Development ("OECD"),[130] the G20 Ministerial Statement on Trade and Digital Economy, and the United Nations Educational, Scientific and Cultural Organisation ("UNESCO").[131] None of these AI guidelines deal specifically with approaches for the healthcare sector.[132] I submit that, on a global level, there is a disconnect between the current data-related legislative narratives and the Fourth Industrial Revolution.

As AI itself has not been afforded legal personhood, we are not yet at the stage where it is legally acceptable to assign any AI system corresponding rights and responsibilities.[133] It is therefore increasingly important to establish which of the human actors (if any) in the chain should be held accountable for harm suffered as a consequence of the use of AI systems in the interim of the AI regulatory vacuum.[134]

As systems, AI presents great opportunity but equal risk. I submit AI may assist with accessing female-related data and likewise attract data feminism critiques related to standard data practices and privacy concerns. The recent release of ChatGPT, for example, has stirred debate on interactive learning environments.[135]

In brief summation, the biometric monitoring of female bodies takes multiple forms. It may be a watch on a wrist, a health program at work, or even a smart chat with AI. I note that AI may – or may not – be integrated into biometric technology. These technologies may assist women in gaining or maintaining access to their health data in an efficient and effective manner. But with these exciting new technologies come valid privacy concerns which must also be considered.

VI. THE RIGHT TO HIDE AND THE RIGHT TO DECIDE

(a) Domestic framework

Generally, privacy can be broken down into separate definitions e.g., informational, physical, decisional, or mental privacies.[136] The problem with distinguishing different kinds of privacies

[130] OECD 'AI Guidelines' available at *http://www.oecd.org/going-digital/ai/principles/*, accessed on 5 July 2023.
[131] Op cit note 126 at 16.
[132] Ibid at 17.
[133] Ibid at 275.
[134] Ibid at 275.
[135] Pericles 'Asher' Rospigliosi 'Artificial intelligence in teaching and learning: what questions should we ask of ChatGPT?' (2023) 31(1) *Routledge* 1–3 at 3.
[136] Jeroen Seynhaeve *Ethics of data privacy* (MPhil thesis, Stellenbosch University, 2022) 1–84 at 14.

from one another, however, is that it may overlook the interrelatedness of the concept itself.[137] That is, privacy as a right to nondisclosure and to non-interference i.e., the right to hide and to decide.[138] This, I submit, reflects the inextricable link between 'privacy' and 'access' – the two-faced coin.

(i) Constitution

The discussion of access to information and privacy law in the context of gender justice and data processing and regulation speaks to various sources of law, including our constitutional rights and values.

The Constitution expressly provides for the justiciable right to privacy in section 14, with subsection (d) specifically providing that every person has the right not to have the privacy of their communications infringed.

Section 10 of the Constitution provides for the right to human dignity, a fundamental value. Our common law defines privacy as inextricably linked to our personhood, with the non-consensual act of sharing data classed as a wrongful act.[139]

Section 32(1) of the Constitution provides that everyone has the right of access to information and/or records held by the State or information held by another person which is required to protect or exercise other rights. In harmony with the Constitution, there are various corresponding statutes.

(ii) POPIA

1. Pre-POPIA legislative landscape

In South Africa, privacy is largely regulated through POPIA which commenced in 2021.[140] POPIA served to inform the pre-existing medico-legal framework by developing our understanding of health data processing.[141]

[137] Ibid at 14–15.
[138] Ibid.
[139] Op cit note 19 at 11.
[140] Op cit note 24 at 2.
[141] L Swales 'The Protection of Personal Information Act 4 of 2013 in the context of health research: Enabler of privacy rights or roadblock?' (2022) 25(1) *PER* 1–32 at 10.

Various legislative devices were already in effect, complimentary to the supreme law and common law. For example, acts like the Health Professions Act 56 of 1974, the South African Medical Research Council Act 58 of 1991 ("SAMRC"), and the NHA.[142] Additionally, councils like the Health Professions Council of South Africa, alongside guidelines like the Ethics in Health Research guideline.[143]

Prior to 2013, however, South Africa did not have comprehensive 'data protection' legislation.[144] Resultantly, where personal information was compromised, or privacy infringed, delictual and common law remedies were applied.[145] For example, these remedies included the interdict, the *actio legis aquiliae*, and the *actio iniuriarum*.[146] Certain legislative provisions – predominantly within the Consumer Protection Act 68 of 2008, the Electronic Communications and Transactions Act 36 of 2005, and the Promotion of Access to Information Act 2 of 2000 – covered mere 'aspects' of the protection of personal information or informational privacy.[147] Even the much-lauded African Convention on Cyber Security and Personal Data Protection ("Malabo Convention") is exceptionally broad in scope, and lacks specificity to data processing of healthcare-related information and/or electronic health services.[148]

Ultimately, any separate definitions of 'privacy' (like informational or physical) may result in a fundamental disconnect regarding data privacy.[149] Our mental processes, personal identities, autonomous decisions, and bodily interactions are increasingly being defined by digital data and the technologies processing such data.[150]

This means that data privacy refers not only to digitalised informational privacy – in reality, it incorporates all notions of privacy directed to protecting essential aspects of freedom, autonomy, identity, and integrity of persons in a data-driven society.[151]

2. Post-POPIA legislative landscape

[142] Ibid at 8–10.
[143] Ibid.
[144] Andi William Lee *An analysis of the Protection of Personal Information Act (POPIA) and the European data protection framework: Suggestions for South Africa* (LLM Dissertation, University of KZN, 2021) 1–87 at 8. See also: J Neethling, PJ Visser & JM Potgieter Neethling *Law of Personality* (2005) 2 at 51.
[145] Ibid.
[146] Ibid.
[147] Ibid.
[148] Beverley Alice Townsend *Privacy and data protection in eHealth in Africa: An assessment of the regulatory frameworks that govern privacy and data protection in the effective implementation of electronic health care in Africa: Is there a need for reform and greater regional collaboration in regulatory policymaking?* (PhD Dissertation, UCT, 2017) 1–246 at 236.
[149] Op cit note 136 at 14–15.
[150] Ibid.
[151] Ibid.

Broadly speaking, POPIA was given effect so as to strengthen the processing of information (including health data) by introducing strict rules on the sharing of any personal information.[152] POPIA aims to align the regulation of personal information with the Constitution and international standards.[153]

In its preamble, POPIA provides that, among other things, it serves to promote the protection and the regulation of personal information that is processed by public and/or private bodies. Personal information is defined as information related to any identifiable, living, and natural person.[154] These public or private bodies must process personal information per the provisions of POPIA, which account for collection, protection, and use of personal information.[155]

When considering POPIA's provisions, I submit it is important to acknowledge that different demographical groups hold varying privacy expectations and confidence levels.[156] These levels are informative insofar as they reflect population perceptions. As is often the case, law requires an understanding of the sociological background which it ultimately seeks to address. Compared to their male counterparts, South African females hold significantly higher expectations for respecting privacy principles; and interestingly, females also hold significantly lower confidence rates in their knowledge of privacy rights and in these rights being met in practice.[157]

Despite holding significantly lower expectations of privacy than their white counterparts, black participants are concerned with protecting their personal information (specifically their health information).[158] Comparatively, black participants also suffered from greater loss resulting from data misuse (like data breaches) than white participants.[159] This aligns with notions of intersectional thought, and highlights the need for a healthy level of paranoia for data security in vulnerable areas, as in healthcare.

Under POPIA, there are eight conditions for lawful data processing: accountability, under section 8; process limitation, under sections 9—12; purpose specification, under sections

[152] Ciara Staunton, Kathrina Tschigg, & Gayle Sherman 'Data protection, data management, and data sharing: Stakeholder perspectives on the protection of personal health information in South Africa' (2021) 16(12) *PLoS ONE* 1–19 at 1.
[153] POPIA, preamble.
[154] POPIA, section 1.
[155] Op cit note 24 at 2.
[156] Ibid at 28.
[157] Ibid at 22.
[158] Ibid.
[159] Ibid at 19, 22.

13—14; further processing limitation, including consent, under section 15; information quality, under section 16; openness, under sections 17—18; security safeguards, under sections 19—22; and data subject participation, including awareness and accessibility, under sections 23—25. Overall, the principle of the data subject's consent operates in tandem with the principle of explainability (i.e., transparency).[160]

Moreso to these conditions, female health data may be classed as special personal information under section 26 of POPIA. This is because it is data related to biometric information, health, or sex life.[161] The general prohibition under section 26 necessitates additional requirements for processing.

For instance, under section 27(1)(a), the prohibition falls away where the data subject provides their consent to processing. Further, under section 27(1)(e), where the data subject has deliberately made public their data. This ties in with the discussion earlier herein regarding women uninformedly consenting to either terms and conditions or community health data sharing, as in femtech apps.

I say 'uninformedly' because there is a lack of specific consent: women may be aware of – and have consented to – some uses initially but be totally ignorant of certain sensors or tracking.[162] Additionally, scholars Mehrnezhad and Almeida recently conducted an empirical study of thirty top fertility apps and concluded that many do not comply with guidelines of the Information Commissioner's Office and/or GDPR.[163] In fact, around half of the apps did not present privacy-related information at first usage while others continued to track user data or process personal information in contravention of the GDPR.[164] Overall, the standard practices were described as 'easily violating the law'.[165] In any event, as consent may be withdrawn at any time, it is arguably a poor way of lawfully processing women's health data.[166] With withdrawal or objection, the data processor must stop processing.[167]

Further, the prohibition falls away under section 27(1)(d) where the processing is for historical, research, or statistical purposes, given either a public interest requirement or merely

[160] Emmanuel Matambo and Edmund Terem Ugar 'South Africa's data sovereignty regulations: merits and possible limitations' 2022 *CACS* 1–8 at 5.
[161] POPIA, section 26(1)(a).
[162] Catriona McMillan 'Monitoring female fertility through 'femtech': The need for a whole-system approach to regulation' (2022) 30(3) *Medical Law Review* 410–30 at 426–7.
[163] Ibid at 425.
[164] Ibid at 426.
[165] Ibid.
[166] Brea Jones 'Is POPIA bad business for South Africa? Comparing the GDPR to POPIA and analyzing POPIA's impact on businesses in South Africa' (2021) 10(1) *Penn State Journal of Law and International Affairs* 217–48 at 230.
[167] Ibid.

that obtaining consent is disproportionately difficult. I submit this creates opportunity for the misuse and/or abuse of female health data, particularly when concomitant with other insufficient provisions.

For instance, section 32(1)(b)(ii) of POPIA provides that special personal information as defined in section 32(5) (that is, health or sex life under section 26) permits insurance companies to process such data in the performance of a medical and/or insurance scheme agreement as well as the enforcement of contractual obligations or rights. This evidences that our current framework, while admirable, is still insufficient as health insurance companies may create 'spin-off' companies that commercialise genetic information and establish intellectual property rights in genomic data sets, for instance.[168]

Coupled with the fact that women's data is mined from downloadable femtech like menstrual health trackers,[169] it may result in infringement of various constitutional rights. Women are uninformedly consenting to this type of mining because they are not necessarily aware of how our current legal definitions of consent play out, the consequences of usage, or the potential for harm.[170]

3. Transborder information flow

Where female health data is on-sold and/or transferred outside of South Africa, the conditions for transborder information flow must be complied with. Per section 72(1)(e)(i)-(ii) of POPIA, a responsible party may only internationally transfer the data subject's personal information if they satisfy an exception.[171]

For example, where the data subject consents to the transfer or, alternatively, where the transfer is for the data subject's benefit, and their consent is impractical to obtain, but this consent would likely have been given in any event.[172]

Beyond the issue of consent as previously discussed, South Africa lacks a uniform Data Transfer Agreement and the current Mutual Transfer Agreement is considered insufficient as it does not meet the threshold and/or standards of POPIA.[173]

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[168] Op cit note 55 at 13–14.
[169] Michele Estrin Gilman 'Periods for profit and the rise of menstrual surveillance' (2021) 41(1) *Columbia Journal of Gender & Law* 100–13 at 101–2.
[170] Ibid at 100.
[171] POPIA, section 72(1)(e)(i)-(ii).
[172] POPIA, section 72(1)(e).
[173] S Mahomed, G Loots & C Staunton 'The role of Data Transfer Agreements in ethically managing data sharing for research in South Africa' (2022) 15(1) *SAJBL* 26–30 at 26–7.

In my view, this is symptomatic of the shortfall between POPIA's theoretical application and the actual practical effect. Relevant stakeholders like governmental departments, health researchers, and ideally data subjects should collaborate to develop a national Data Transfer Agreement, both satisfying POPIA's provisions, and supporting an integrated bioethics approach.[174] It does not stop here – POPIA has a multitude of shortcomings, particularly when compared to its veritable role model, the GDPR.

4. Limitations compared to the GDPR

Contemporary data protection law is comparable to environmental regulation, in that it aims to protect the cultural, moral, and democratic environment, collectively termed the 'commons'.[175] Both the EU GDPR and South African POPIA seek to protect the fundamental foundations of democratic society and promote an ethical management culture for personal data in an uncertain period of technological expansion.[176] But POPIA falls short, lacking many of the collaborative governance mechanisms found in the GDPR.[177]

For instance, in some cases the GDPR requires a Data Protection Impact Assessment on risks regarding data protection, whereas no such mechanism exists under POPIA.[178] Also, unlike the GDPR, the individual does not enjoy the right to data portability under POPIA i.e., to receive her health data in a common, machine-readable, structured format, permitting her to securely transfer data across different applications, platforms, programs, or IT environments.[179] The effect of this is that the right of access is strangled before it evolves into a wider right allowing users to securely transmit their data to the next data controller.[180] For instance, from femtech app to gynaecologist.

Additionally, POPIA fails to adequately delineate the boundaries of de-identified data, allowing a breeding ground of 'data masking' to flourish. This is because it does not contemplate 'pseudo-anonymisation' of data, merely de-identification through the deletion of data that may (directly or through some reasonably foreseeable method) identify the data

[174] Ibid at 26, 29.
[175] Victoria Bronstein 'Prioritising command-and-control over collaborative governance: The role of the Information Regulator under the Protection of Personal Information Act' 2022 (25) *PER/ PELJ* 1—41 at 2.
[176] Ibid at 3.
[177] Ibid at 4.
[178] Ibid.
[179] GDPR, Article 20.
[180] Sarah Turner, July Galindo Quintero, & Simon Turner et al 'The exercisability of the right to data portability in the emerging Internet of Things (IoT) environment' (2021) 23(10) *New Media & Society* 2861–81 at 2862–4.

subject in a data set.[181] Contrastingly, the GDPR refers to pseudo-anonymisation where there is potential for re-identification of the data subject.[182] True anonymisation is only obtained if the data is irreversibly deleted, which is virtually impossible.[183]

As a final brief note, some scholars argue that a purposive interpretation of POPIA demonstrates that broad consent is permissible.[184] These proponents cite the limitation clause, the section 12(2) exceptions, and POPIA's preamble in support of their argument. In the context of health data, I submit only narrow or tiered consent as considered in the Department of Health's quasi-legal guidelines may be appropriate, given the nature of health data as discussed herein.[185]

(b) Foreign legislative framework

Notwithstanding POPIA's shortcomings, it contains many of the common information privacy principles that are found in most regulatory frameworks. For instance, the Fair Information Practice Principles, incorporated into the US Privacy Act of 1974; the Organisation for Economic Co-operation and Development (OECD) Privacy Guidelines, considered in Europe; and the Asia-Pacific Economic Cooperation (APEC) Privacy Framework, applicable to member states.[186]

Overall, data protection in the European Union appears to be at its peak, with data protection recognised as a fundamental right, as with the right to privacy.[187] Primary and secondary data protection law benefits from guidelines, reports, soft law, and recommendations of specialised independent bodies or authorities at national and European Union level.[188] For instance, Data Protection Authorities, or the European Data Protection Board. The recent introduction of the European GDPR alone has modernised data protection, having been intended to confront the challenges of the Fourth Industrial Revolution.[189]

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[181] Rachel Adams, Fola Adeleke, & Dominique Anderson et al 'POPIA code of conduct for research' (2021) 117(5/6) *S Afr J Sci* 1–12 at 2–3.
[182] GDPR, Article 3.
[183] Emily M Weitzenboeck, Pierre Lison, & Malgorzata Cyndecka et al 'The GDPR and unstructured data: Is anonymization possible?' (2022) 12(3) *International Data Privacy Law* 184-206 at 184.
[184] C Staunton & E D Stadler 'Protection of Personal Information Act No. 4 of 2013: Implications for biobanks' (2019) 109(4) *SAMJ* 232–4 at 233.
[185] Op cit note 22.
[186] Op cit note 24.
[187] Maria Tzanou 'The future of EU data privacy law: Towards a more egalitarian data privacy' 2020 *Journal of International and Comparative Law* 1–29 at 2.
[188] Ibid.
[189] Ibid.

Generally, are these current information privacy principles of sufficient standard? I submit not. Much like South Africa, the EU data protection narrative has missed out on fundamental questions about the gender, socio-economic, and intersectional exceptions under EU data protection law.[190] For EU data protection narratives to maintain relevancy, they must include the mostly-ignored data privacy problems afflicting marginalised or vulnerable groups.[191]

Currently, the EU data protection narrative is technology- and court-focused.[192] I submit the same may be said of South Africa, particularly considering POPIA is modelled after the GDPR in some ways. The issue with this approach is that technology is rapidly innovating. It may not be practical or wise for data protection laws to attempt to keep up with each advancement – not, I submit, in isolation. Attempting to do so has resulted in the Court of Justice of the European Union being accused of going 'beyond the limits of interpretation' and manipulating texts to create some 'super' fundamental right to privacy.[193]

What, then, is the way forward? Data protection law – be it European or South African – must consider whom data protection is directed towards.[194] Historically, women have had their rights diminished.[195] With modern technology, the surveillance has continued and expanded. Wearable devices or mobile apps track periods, provide alleged fertility solutions, measure sexual performance or activity, and contribute to reproductive healthcare among other things.[196] Our communications, relationships, cycles, bodies, and activities have become constructions, that is, 'monitored subjects'.[197]

Set against the ever-pretty notion of control and access to our health data, biometric monitoring and femtech are rife with multi-faceted, institutionalised assaults on female autonomy over our wellbeing and health.[198] For instance, the many stigmas around menstruation and (in)fertility; alleged, perhaps dangerous 'optimal' decisions around pregnancy; or the politicisation and criminalisation of female reproductive choices. There is a constant tug-of-war between 'access' and 'privacy' instead of the requisite balancing of rights.

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[190] Ibid at 3.
[191] Ibid.
[192] Ibid at 6.
[193] Ibid at 7.
See also: *Google Spain SL, EU: C:* 2014: 317, [81].
[194] Op cit note 187 at 8.
[195] Ibid at 15.
[196] Ibid.
[197] Ibid at 16.
[198] Op cit note 162 at 411–12.

Accordingly, intersectional considerations of race, sexual orientation, class, gender, age, disability, and ethnicity must inform our understanding of the complex harms related to surveillance.[199]

(c) Litigation and legal disputes over the monitoring of female bodies

As this is a new frontier, legal cases and disputes are still emerging. However, we have already seen the crossover of misuse of female health data through biometric technology in the global arena.

Recently, the period tracking app termed Flo Health Inc. finalised an out-of-court settlement with the (U.S.) Federal Trade Commission ("FTC"), after concluding the app had shared the sensitive health data of millions of users with analytics and marketing firms, including Google and Facebook.[200]

The FTC also instituted litigation against data-broker, Kochava, for selling the geo-location of millions of mobile devices which could be used to identify the physical location of consumers, including in sensitive areas like reproductive health clinics.[201]

Globally, these legal disputes are on the rise and require prescriptive legal attention. The current South African framework is insufficient, even with the advent of POPIA. The two-sided coin of access and privacy has not been sufficiently addressed.

It becomes clear that this dissertation does not contemplate claiming domestic, international, or foreign legislation on this matter does not exist. The issue, rather, is that our legislative response thus far does not appear to appropriately consider access to information and privacy law as an inclusive concept, nor implement appropriate control mechanisms, nor consider data feminism. Somewhat, the tides are turning: the Carter Centre, for instance, has implemented a program titled the Access to Information Project which advances the effective exercise of the right of access to information for women in Sub-Saharan Africa.[202]

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[199] Op cit note 187 at 19.

[200] Federal Trade Commission 'FTC finalizes order with Flo Health, a fertility-tracking app that shared sensitive health data with Facebook, Google, and others' available at *https://www.ftc.gov/news-events/news/press-releases/2021/06/ftc-finalizes-order-flo-health-fertility-tracking-app-shared-sensitive-health-data-facebook-google*, accessed on 26 September 2023.
See also: *Erica Frasco v Flo Health Inc*. Case No. 3:21-cv-00757-JD United States District Court, N.D. California, June 6, 2022.

[201] Federal Trade Commission 'FTC sues Kochava for selling data that tracks people at reproductive health clinics, places of worship, and other sensitive locations' available at *https://www.ftc.gov/news-events/news/press-releases/2022/08/ftc-sues-kochava-selling-data-tracks-people-reproductive-health-clinics-places-worship-other*, accessed on 26 September 2023.

[202] Op cit note 39.

VII. RECOMMENDATIONS AND CONCLUSION

'Power' – the law itself may be considered a system of allocation of power. This is because legal discourse reflects and constitutes the consequences of power in our society.[203] As women, we have historically been constructed as 'different', and as both subjects and objects of law.[204] The dissembling of unfair power structures becomes a matter of finding pragmatic methods of working *with* the law, recognising its gendered nature, and identifying contexts informed by considerations of difference.[205]

In 1992, Columbian Law Professor Martha Albertson wrote that, at any point, there may be multiple legal feminist projects as either the law, perceptions, or circumstances change.[206] I submit that with the dawn of the Fourth Industrial Revolution, a new feminist project surfaces, muddy still, but becoming clearer.[207] I submit this project challenges our very definitions of what constitutes access, privacy, consent, or even health data. It necessitates a thorough re-consideration of our existing legislative framework.

With the advent of new technologies like biometric monitoring, femtech, and artificial intelligence, the institutionalised assaults on female autonomy have become increasingly abstract within the medico-legal sphere.[208] Using the data feminism and data commercialisation lenses, we understand that the standard practices employed in data science reinforce existing inequalities and,[209] to compound that, existing bodies of data are exploited.[210]

What, then, is the way forward, given the inextricable link between privacy and access, or the right to hide and the right to decide?[211] To start, we must recognise the various systemic regulatory failures, and consider a holistic approach.[212]

Currently, and as described herein, the approach with these contemporary health technologies is piecemeal at best.[213] Law necessitates a level of certainty and specificity, yet there is a corrosive lack of awareness of the fundamental interests and rights that are at stake

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[203] Martha Albertson Fineman 'Feminist theory in law: The difference it makes' (1992) 2(1) *Columbia Journal of Gender and Law* 1–24 at 5.
[204] Ibid at 1.
[205] Ibid at 23.
[206] Ibid at 5.
[207] Op cit note 2.
[208] Op cit note 162 at 411–412.
[209] Op cit note 10.
[210] Op cit note 19 at 1.
[211] Op cit note 136 at 14–15.
[212] Op cit note 162 at 431.
[213] Ibid at 432.

for women – especially those subject to intersectional marginalisation – as a class of consumer and as a social group in this new medico-legal frontier.[214]

It is beyond the scope of this dissertation to describe the precise appearance of this legal reform. I submit the multiple layers to this intricate issue requires a thorough appreciation of the cross-coupling of various elements. Doing so would require a hundredfold this word-count. However, any proposed system must be responsive and flexible to changing circumstances.[215] It is also likely that any potential reform will be captured within a 'web of conflicting constraints'.[216]

It is clear that women's right of access to information and privacy has been legislatively misapproached. South Africa requires a regulatory framework for the use of personal health records, biometric technology, femtech, AI software as a medical device, and other technologies still to emerge.[217] This framework must account for both faces of the two-sided coin. The reform, then, must advance personal health records to confer patients with ownership and autonomy over their bodies.[218]

There are various sources of inspiration. Australia, for instance, has already utilised paper-based personal health records for years.[219] Additionally, the WHO framework, titled Generating Evidence for Artificial Intelligence-based Medical Devices, may assist by informing the accommodation of AI software.[220] Further, the HPCSA guidelines for healthcare practitioners should be amended to provide guidance on the requisite specific informed consent.[221] Moreover, we must work towards developing a statutory scheme for strict liability, mandatory insurance, or product liability, as the current common law principles of fault-based liability in medical negligence cases are inadequate.[222]

In my view, the ideal structure of this reform includes the crafting of a single, holistic health data law that both confirms and adopts the various helpful elements already found in our piecemeal legislation.[223] This statute must accommodate for a fusion of technologies and,[224] importantly, it must appreciate the confluence of sex, gender, class, disability, age, ethnicity,

[214] Ibid at 433.
[215] Op cit note 148 at 203.
[216] Stuart A Kauffman *The Origins of Order: Self-organization and Selection in Evolutio*n 1993 173–206.
[217] Op cit note 128 at 28.
[218] Op cit note 70.
[219] Ibid.
[220] Op cit note 128 at 28.
[221] Ibid.
[222] Ibid.
[223] Op cit note 148 at 244.
[224] Op cit note 2.

or the like.[225] It must emphasise sex-disaggregated targets because appropriate consideration of sex differences can improve outcomes for women.[226]

Surely, if jurist, physician, and priest were once combined in a single person, then we in our allegedly advanced world can once again account for the true melding of law, medicine, and the unknown.[227]

[225] Op cit note 187 at 19.
[226] Op cit note 17.
[227] Op cit note 31.

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