

Submission to the UN Working Group on Discrimination Against Women Consultation on women and girls' sexual and reproductive health and rights in times of crisis

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## Privacy International's submission on women's and girls' sexual and reproductive health and rights in situations of crisis

Privacy International (PI)<sup>1</sup> welcomes the call of the UN Working Group on discrimination against women and girls regarding the "women's and girls' sexual and reproductive health and rights in situations of crisis" to inform the Working Group's thematic report to the 47th session of the UN Human Rights Council in June 2021.<sup>2</sup>

The issues highlighted in the call for submissions are ones that PI with its global network of partners<sup>3</sup> has been investigating, reporting and monitoring on forms of data exploitation strategies targeted at women<sup>4</sup> in the reproductive health sphere<sup>5</sup>, the intersection between gender and privacy, as well as gendered impacts of emerging forms of technology, and the importance of privacy in the healthcare context. This submission is intended to serve as a global overview of the challenges PI has identified in terms of accessing sexual and reproductive health services.

In particular the following submission provides information on:

- the obstacles faced by women in accessing non-biased and scientifically accurate information about sexual and reproductive health topics and services;
- the specific challenges posed by menstruation apps in light of their popularity and the intimate nature of information involved;
- the different issues concerning safe abortion care;
- the challenges arising from the digitalisation of public health services; and finally,
- the disproportionate impact of obstacles previously identified in groups of women.

The issues highlighted in the following paragraphs are concerning at the best of times. However, all of them are exacerbated in times of crisis.

<sup>&</sup>lt;sup>1</sup> Privacy International (PI) is a London based registered charity that works globally at the intersection of modern technologies and rights. We challenge overreaching state and corporate surveillance, so that people everywhere can have greater security and freedom through greater personal privacy. We are fighting for a world where technology will empower and enable us, not exploit our data for profit and power. <sup>2</sup>https://www.ohchr.org/EN/Issues/Women/WGWomen/Pages/SexualReproductiveHealthRights.aspx.

<sup>&</sup>lt;sup>3</sup> PI, *Our Global Reach*, available at: <u>https://privacyinternational.org/where-we-work</u>

<sup>&</sup>lt;sup>4</sup> Throughout this submission, the concept of "women" is intended to encapsulate women in all their diversity, including transgender, gender-diverse people, lesbians, bisexual people, sex workers, women and girls with disabilities, women living with HIV, women who use drugs, refugees, migrants, women and girls in conflict zones, detention and humanitarian settings, indigenous women and those from other racial and ethnic minorities. <sup>5</sup> PI, *Reproductive Rights and Privacy Project*, available at:

https://privacyinternational.org/campaigns/reproductive-rights-and-privacy-project.

## Recommendations

PI suggests the following main recommendations to be included in the recommendations by the UN Working Group:

Guaranteeing equal access to sexual and reproductive rights

- Recognise that sexual and reproductive rights are protected online, as well as offline, including in times of crisis.
- Stress that all women are guaranteed equal access to sexual and reproductive services and information. Any measures taken in response to a crisis must properly take into account the experiences of all women, in particular those who are disproportionately discriminated, excluded or otherwise victimised on account of their gender identity, race, and socioeconomic background.
- Explicitly recognise that states should ensure that all legal and practical obstacles to women accessing healthcare on equal footing are removed.

Availability of adequate healthcare services

- Highlight that appropriate legal frameworks are needed to ensure women can have safe access to healthcare services including to abortion at all times.
- Note that the conceptualisation, implementation and monitoring of RMNCH initiatives must be underpinned by health, gender equality and privacy considerations, with clear responsibilities being assigned to each of the actors involved.

Educational and training-related measures

• Recognise that obstacles in accessing non-biased and scientifically accurate information on sexual and reproductive matters and services constitute an undue interference with sexual and reproductive rights.

Data exploitation

- Call on states to draft, implement and enforce legislation penalising establishments and professionals falsely presenting as possessing medical accreditation.
- Note that companies should respect human rights online, as well as offline.
- Recommend that states should ensure that the appropriate independent authority is empowered to make investigations pursuant to complaints or by its own initiative, and to impose fines and sanctions if it determines that a violation/breach has occurred.
- Recommend that national criminal legislation is amended to reflect new forms of gender-based violence involving the use of technology.

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#### Introduction

Governments around the world have embraced digital innovations to help progressively realize social, economic and cultural rights, including for sexual and reproductive healthcare. Yet women continue not to enjoy these health rights equally, including health, and sexual and reproductive rights, where they experience numerous violations, as evidenced by unacceptably high maternal mortality and morbidity rates around the world.<sup>6</sup> There is no question that technology can help governments to ensure effective access and delivery of reproductive, maternal, newborn and child health (RMNCH) services, but adequate safeguards are needed to mitigate risks and to ensure the roles and obligations of different stakeholders are complied with.

Digital initiatives create some key concerns in relation to the protection, respect and promotion of the right to privacy as provided for by international and national declarations, as well as in relation to the effective exercise of reproductive and sexual rights. As the systems being deployed interfere with individuals' privacy, they need to meet overarching principles of legality, necessity and proportionality, and additional implications on non-discrimination and equality.

The issues highlighted in the following paragraphs are concerning at the best of times. However, all of them are exacerbated in times of crisis. For example:

- The pandemic has resulted in increased reliance on online services and resources, as traditional avenues for accessing sexual and reproductive healthcare were significantly cut back due to health-related concerns.
- The state of lockdown has brought about a staggering increase in forms of genderbased violence,<sup>7</sup> and resulted in the victimisation of some of the women venturing outdoors.
- Beyond the pandemic context, crisis periods can be protracted in some countries, which imports particular challenges in the conception, implementation and delivery of digitised sexual and reproductive healthcare initiatives.
- Furthermore in period of crisis, it becomes much more challenging to enforce laws and regulations, and in many instances in these situations governments declare 'a state of emergency', which provides the rationale for suspending rights and freedoms guaranteed under a country's constitution or basic law, which is sometimes done through martial law or revoking habeas corpus depending on the country.
- As far as rural, trans, status-less women and sexual and domestic violence survivors are concerned, crisis can be a prolonged state of being in light of their continuing experiences of exclusion, discrimination, and trauma.

# I) Obstacles in the access to non-biased and scientifically accurate information about sexual and reproductive health matters and services

PI has identified a series of obstacles in the access to non-biased and scientifically accurate information about sexual and reproductive health topics and services. While some of these obstacles are relatively new, others have long troubled comprehensive access to healthcare services. These obstacles are heightened in situations of crisis when it becomes harder to regulate and oversee information being shared.

<sup>&</sup>lt;sup>6</sup> UN OHCHR, *Women's economic, social and cultural rights*, available at: <u>https://www.ohchr.org/EN/Issues/Women/Pages/WomenESCR.aspx</u>

<sup>&</sup>lt;sup>7</sup> The Guardian, "Lockdowns around the world bring rise in domestic violence", 28 March 2020, available at" <u>https://www.theguardian.com/society/2020/mar/28/lockdowns-world-rise-domestic-violence</u>

## A) Traditional obstacles

## Public health shortcomings

*Widespread lack of information.* In many countries where legal abortion is available only in limited set of circumstances, people seeking sexual and reproductive health information or services face additional hurdles, including lack of access to information and social stigma. In Brazil, for instance, despite the few avenues to legal abortion, access to information and safe procedures is limited. Research, conducted by Article 19 in Brazil, found that the "quantity and quality of information offered by public health institutions about sexual and reproductive rights, particularly on legal abortion, is below what is expected".<sup>8</sup>

There is not enough information about the hospitals providing safe legal abortions and the websites of health departments across different Brazilian states do not address abortion care or sexual and reproductive health rights. Moreover, the Penal Offenses Act (Lei das Contravenções Penais) imposes a fine to those "advertising the process, substance or object intended to cause abortion."<sup>9</sup> This provision has been interpreted as imposing a penalty for the dissemination of information relating to abortion generally – even in those instances where abortion is lawful under Brazilian law – with the effect of limiting access to information about legal avenues to abortion. This approach has been institutionally validated. In 2019, the Minister for Women, Family and Human Rights requested the Public Attorney to sue a news outlet after it published an article explaining the three circumstances in which abortion is legal and providing more information on safe abortion care.<sup>10</sup> The Minister also tweeted that the article was an "apology of crime".<sup>11</sup>

*Deficient sexual education.* In countries researched by PI, several shortcomings persist in the provision of non-biased, accurate and comprehensive sexual education. In Indonesia, though the Ministry of Education and Culture includes reproductive health rights education in the curriculum for school counsellors, the program omits important topics, such as abortion care or contraception for unmarried people.<sup>12</sup> In Argentina, a comprehensive sexual education program was introduced by law. However, thirteen years on, the Ministry of National Education has found that 75% of adolescents in the last 2 years of high school reported not learning enough on the subject.<sup>13</sup> In Peru, only 8% of teachers teach comprehensive sex education and only 21% of school children received information on these topics at school. Contraception and unplanned pregnancy remain among the least covered areas in sex education classes, with 85%

<sup>&</sup>lt;sup>8</sup> Article 19, *Breve Panorama sobre aborto legal e transparencia no Brasil*, 2018, available at: <u>https://mapaabortolegal.org/wp-content/uploads/2019/03/AbortoLegaleTransparencia.pdf</u>

<sup>&</sup>lt;sup>9</sup> PI, *Country case-study: sexual and reproductive rights in Brazil*, available at: <u>https://privacyinternational.org/long-read/3895/country-case-study-sexual-and-reproductive-rights-</u> <u>brazil</u>

<sup>&</sup>lt;sup>10</sup> Human Rights Watch, "A falsa preocupacao da ministra dos Direitos Humanos com as mulheres", 4 October 2019, available at: <u>https://www.hrw.org/pt/news/2019/10/04/334411</u>

<sup>&</sup>lt;sup>11</sup> UOL Noticias, "Damares denuncia site por reportagem sobre aborto: "apologia ao crime", 20 September 2019, available at: <u>https://noticias.uol.com.br/saude/ultimas-noticias/redacao/2019/09/20/damaresdenuncia-site-por-reportagem-sobre-aborto-apologia-ao-crime.htm</u>
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<sup>&</sup>lt;sup>12</sup> PI, *Country case-study: sexual and reproductive rights in Indonesia*, available at: <u>https://privacyinternational.org/long-read/3853/country-case-study-sexual-and-reproductive-rights-indonesia</u>

<sup>&</sup>lt;sup>13</sup> Diario Digital Femenino, "¿Cuál es el estado de implementación de la ESI a casi 13 años de la sanción de la ley 26.150?", 27 September 2019, available at: <u>https://diariofemenino.com.ar/cual-es-el-estado-de-implementacion-de-la-esi/</u>

of school children reporting that they are learning about sexuality online.<sup>14</sup> Also, Chile does not have a comprehensive sexual education policy, and its indicators are proof of the consequences. Between 2008 and 2015, Chile was the country that made the least progress in the prevention of unwanted pregnancies through sex education compared to the other 16 countries that also underwent the study by the International Family Planning Federation.<sup>15</sup>

## Stigma and prejudice among healthcare professionals

In Indonesia, it is apparently common for doctors to ask patients about their marital status before providing medical information about contraceptives. There have been instances where women have been told they needed to be married before accessing contraception. This causes some women to avoid seeking medical help and go online where misinformation abounds.<sup>16</sup>

## B) Modern obstacles

Opposition groups to reproductive rights<sup>17</sup> and governments have become adept at using data exploitative tactics to restrict access to reproductive healthcare, including the ones described below.

## Misleading online advertising

Opposition groups have made use of a series of online tools in order to attract women seeking reproductive health information. These tools have the effect of curtailing access to accurate information about sexual and reproductive health matters. As such, they are able to reach and communicate with people seeking reproductive health information without being transparent about the limitations and biased nature of the services they provide.

*Targeted advertising.* Inaccurate and biased information on sexual and reproductive health often reaches online users through targeted ads. Ads are "targeted" when they are aimed at an audience with a specific profile based on the product or service that is being advertised. Ad targeting options are commercially available in most online platforms, and enable the advertiser to target users on the basis of age, interests, behaviour, and more. For example, in France, anti-abortion ads on Facebook were found to be targeting young women under 30 years old.<sup>18</sup>

*Geo-fencing*. Geo-fencing is the creation of a virtual boundary around an area that allows software to trigger a response or alert when a mobile phone enter or leaves an

<sup>&</sup>lt;sup>14</sup> Peru21, "El 85% de escolares aprende sobre sexualidad por medio de Internet", 10 February 2018, available at: <u>https://peru21.pe/peru/educacion-sexual-peru-85-escolares-aprende-sexualidad-medio-internet-395319-noticia/</u>

<sup>&</sup>lt;sup>15</sup> Universidad Católica, "Educación sexual en Chile: ¿desafío eterno?", available at: <u>http://comunicaciones.ucsh.cl/opiniones/educacion-sexual-en-chile-desafio-eterno/</u>

<sup>&</sup>lt;sup>16</sup> PI, *Country case-study: sexual and reproductive rights in Indonesia*, available at: <u>https://privacyinternational.org/long-read/3853/country-case-study-sexual-and-reproductive-rights-</u>indonesia

<sup>&</sup>lt;sup>17</sup> Throughout this consultation response, PI refers to groups opposing abortion or the exercise of any other sexual and reproductive rights as "the opposition".

<sup>&</sup>lt;sup>18</sup> Le Monde, « Les anti-IVG ciblent les jeunes femmes grâce aux publicités sur Facebook », 11 July 2018, available at : <u>https://www.lemonde.fr/les-decodeurs/article/2018/07/11/les-anti-ivg-ciblent-les-jeunes-femmes-grace-aux-publicites-sur-facebook\_5329906\_4355770.html</u>

area. A 2016 investigation by Rewire News found that anti-abortion groups used geofencing technology in the United States to send targeted ads to the phones of women visiting sexual and reproductive health clinics.<sup>19</sup> The ads are usually for crisis pregnancy centres or other anti-abortion ads and are meant to steer women towards biased websites.

*Poor enforcement of fact-checking policies.* In the absence of fact-checking policies, opposition groups use targeted ads on social media to spread misleading health information. Ads accessed by PI on the Facebook Ad Library – which records some of the ads published on Facebook – promoted the abortion pill reversal, despite the procedure's dubious effectiveness or safety.<sup>20</sup> Fact-checking procedures can mitigate the harmful impact of inaccurate targeted ads; however, they are not infallible, and biased or misleading ads may fall through the cracks. Depending on the amount spent and targeting options chosen by the advertiser, misleading ads on reproductive health may reach millions before they are taken down.

#### Proliferation of misleading and inaccurate healthcare websites

Web design solutions. Heartbeat International, an opposition organisation, runs Extend Web Services, a web design company that develops websites for crisis pregnancy centres (CPCs). Extend Web Service templates are globally available, and are promoted as user-friendly solutions, which attract "abortion-minded" users and are designed to make them "feel comfortable".<sup>21</sup> Extend Web Services restricts the ability for their clients to change the language used on 5 "medical pages", thereby restricting the ability of CPCs to edit the language used on the following pages: "abortion information/education", "abortion recovery", "sexual health", "pregnancy", and "emergency contraception".<sup>22</sup> An Extend Web Services representative told PI that these 5 medical pages could either be completely removed, or be replaced in their entirety by the client – but not edited.<sup>23</sup> The content of those pages is misleading and biased. For instance, one "abortion information/education" page reads: "[e]ven though pregnancy tests are generally accurate, it can also be a good idea to get an ultrasound. This can tell you if your pregnancy is viable". The language used not only conflates pregnancy viability with getting an ultrasound, it also may sway women seeking abortions to get an ultrasound.

*Honey pot websites.* Research carried out in Brazil shows there is evidence that the opposition organisation Associação Mulher, associated with the website Gravidez Indesejada, uses Extend Web Services.<sup>24</sup> The website itself contains incorrect information about abortion pills and abortion consequences to convince women not to get an abortion. In 2018, when an undercover journalist attended an appointment obtained through Gravidez Indesejada as part of an Agência Pública investigation, she was not only provided with incorrect information about abortion and its

<sup>&</sup>lt;sup>19</sup> Rewire News, "Anti-Choice groups user smartphone surveillance to target 'abortion-minded women' during clinic visits", 25 May 2016, available at: <u>https://rewire.news/article/2016/05/25/anti-choice-groups-deploy-smartphone-surveillance-target-abortion-minded-women-clinic-visits/</u>

<sup>&</sup>lt;sup>20</sup> PI, *A documentation of data exploitation in sexual and reproductive rights*, available at: <u>https://privacyinternational.org/long-read/3669/documentation-data-exploitation-sexual-and-reproductive-rights</u>

<sup>&</sup>lt;sup>21</sup> Extend Web Services, Home page, available at: <u>https://extendwebservices.com/services/websites</u>

<sup>&</sup>lt;sup>22</sup> PI, How anti-abortion activism is exploiting data, available at: <u>https://privacyinternational.org/long-read/3096/how-anti-abortion-activism-exploiting-data</u>
<sup>23</sup> Id.

<sup>&</sup>lt;sup>24</sup> PI, *Country case-study: sexual and reproductive rights in Brazil,* available at: <u>https://privacyinternational.org/long-read/3895/country-case-study-sexual-and-reproductive-rights-brazil</u>

consequences, but she was also forced to see images of unsafe abortions and hold a plastic fetus.<sup>25</sup> This is only one example of what is a widespread trend in Latin America. An investigation by OpenDemocracy spanning four Latin American countries found that a network of CPCs specifically targeted women looking for abortion information and services online, with many presenting themselves as pro-choice groups.<sup>26</sup> These networks of CPCs in these countries are funded by Heartbeat International, which has formed a presence in the region through funding a Latin American Network of Women's Aid Centres (Centros de Ayuda para la Mujer).<sup>27</sup>

*Copycat websites.* Some opposition groups go as far as creating copycat websites pretending to offer official, government-sanctioned information about pregnancy options. In Ireland, a man set up a fake Irish Health Services website confusingly similar to the official Health Services crisis pregnancy service. The fake website offered pregnancy scans and discouraged women from getting abortions.<sup>28</sup>

*Online censorship policies.* Misinformation on sexual and reproductive health can thrive in the absence of non-biased websites providing scientifically accurate information. PI research has found that, in at least two countries, online censorship practices have targeted and effectively blocked access to reliable and accurate reproductive health information. In Indonesia, specifically, the government's blocking and filtering policy – known as the "Healthy Internet" programme – enables it to "block" websites on the basis of a keyword-filtering method. The method is over-inclusive and as a result, websites such as breastfeeding education websites and sexual and reproductive health websites are blocked. The website of NGO Women on Web, known to promote sexual and reproductive healthcare services worldwide, was blocked by the filtering policy after posting an article on abortion.<sup>29</sup> In Brazil, research found that the pro-choice website Women on Waves – a sister initiative to Women on Web – was blocked on several networks, with no explanation from the telecommunications companies concerned.<sup>30</sup>

#### Misleading Apps

Opposition groups covertly fund smartphone apps requesting a lot of information about people's reproductive health while disseminating doubt about the safety of birth control. The newspaper, The Guardian, reported that the popular FEMM app purporting to "[teach] women to understand their bodies" and "[provide] accurate medical testing and treatment based on new research and medical protocol" is funded by anti-abortion and catholic campaigners.<sup>31</sup> FEMM worked with the

<sup>&</sup>lt;sup>25</sup> Agência Pública, "Armadilha para mulheres", 22 January 2018, available at: <u>https://apublica.org/2018/01/armadilha-para-mulheres/</u>

<sup>&</sup>lt;sup>26</sup> OpenDemocracy, "Revealed: US-linked anti-abortion centres 'lie' and 'scare women' across Latin America", 12 February 2020, available at: <u>https://www.opendemocracy.net/en/5050/revealed-us-linked-anti-abortion-centres-lie-and-scare-women-across-latin-america/</u>

<sup>&</sup>lt;sup>27</sup> ld.

<sup>&</sup>lt;sup>28</sup> The Irish Times, "HSE takes action over allegedly misleading pregnancy options website", 13 February 2019, available at: <u>https://www.irishtimes.com/news/crime-and-law/courts/high-court/hse-takes-action-over-allegedly-misleading-pregnancy-options-website-1.3792806</u>

<sup>&</sup>lt;sup>29</sup> PI, *Country case-study: sexual and reproductive rights in Indonesia*, available at: <u>https://privacyinternational.org/long-read/3853/country-case-study-sexual-and-reproductive-rights-indonesia</u>

<sup>&</sup>lt;sup>30</sup> PI, *Country case-study: sexual and reproductive rights in Brazil,* available at: <u>https://privacyinternational.org/long-read/3895/country-case-study-sexual-and-reproductive-rights-brazil</u>

<sup>&</sup>lt;sup>31</sup> The Guardian, "Revealed: women's fertility app is funded by anti-abortion campaigners", 30 May 2019, available at: <u>https://www.theguardian.com/world/2019/may/30/revealed-womens-fertility-app-is-funded-by-anti-abortion-campaigners</u>

Reproductive Health Research Institute in the development of medical research and training. However, according to the Guardian, medical advisors who work with the Institute are not licensed to practice medicine in the United States.

#### Social media

Research by PI and some of its global partners has found that social media platforms, such as Instagram, play an increasingly important role in spreading misinformation on reproductive health and potentially curtailing access to sexual and reproductive rights.

*Social media profiles of opposition groups.* In Brazil, for instance, opposition website Gravidez Indesejada uses an Instagram account to attract women to its website.<sup>32</sup> Despite the fact that Gravidez Indesejada seeks to dissuade women from seeking abortion, the posts available on their Instagram account state that they promote "Girl Power", and that they can help women "defend their rights" and assist them to "make their choices".

Standalone influencers. Also in Brazil, there is growing evidence that influencers are obstructing the exercise of reproductive rights.<sup>33</sup> At least one influencer profile has been found to operate anti-abortion initiatives. Screenshots collected by Brazil-based NGO Coding Rights show influencers reportedly having Whatsapp conversations with users having contacted them to seek help in dissuading pregnant women from seeking abortion care. These screenshots show that opposition figures with a strong social media following are able to disseminate their views through informal and unmonitored channels, with real consequences for the women "referred" to them.

## International campaigns and educational programs

There are numerous examples of the use of international campaigns and educational programs by opposition groups to promote an anti-reproductive rights agenda. Heartbeat International, for example, runs an "Academy" offering online talks and courses promoted through the organisation's large international network of crisis pregnancy centres. The courses contain misleading and inaccurate information such as the scientifically unproven claim that abortion can lead to cancer and mental illnesses. In India, opposition group Life Matters Worldwide partnered with at least one rural hospital to provide them with ultrasound equipment raising concerns about their intention to actively restrict abortion for rural women. TeenStar, an educational programme used in 36 countries, actively discourages the use of contraceptives – and yet the Croatian government sponsored the programme for a decade despite the fact that it is not backed by science. The World Youth Alliance, a global alliance aiming at curtailing access to sex education, contraception and abortion care, has similarly promoted and run training sessions around the world.<sup>34</sup>

PI is concerned that the abovementioned multiple strategies used by opposition groups restrict access to non-biased and scientifically accurate information about sexual and reproductive health care in many countries.

<sup>&</sup>lt;sup>32</sup> PI, Country case-study: sexual and reproductive rights in Brazil.

<sup>&</sup>lt;sup>33</sup> PI, Country case-study: sexual and reproductive rights in Brazil.

<sup>&</sup>lt;sup>34</sup> PI, *A documentation of data exploitation in sexual and reproductive rights*, available at: <u>https://privacyinternational.org/long-read/3669/documentation-data-exploitation-sexual-and-reproductive-rights</u>

## Recommendations

- The Working Group should highlight the obstacles in accessing non-biased and scientifically accurate information on sexual and reproductive matters and services and stress that such obstacles constitute an undue interference with women's sexual and reproductive rights.
- It should further recommend to states to produce, promote and disseminate, in a comprehensive and accessible manner, non-biased and scientifically accurate sexual and reproductive health materials and information.
- Also, it should recommend that comprehensive, gender-inclusive, objective and accurate sexual education is provided in all schools.
- The Working Group could recommend that states should refrain from taking policy or regulatory measures which have the effect of curtailing access to nonbiased and scientifically accurate sexual and reproductive health materials and information.
- Also, the report should recommend that healthcare professionals be trained to provide women with sexual and reproductive health treatments in a non-discriminatory manner.
- The Working Group should recommend the introduction of robust data protection frameworks protecting women's privacy, which should at a minimum include the following:
  - A requirement for organisations and companies to provide users with a privacy notice that is concise, transparent, intelligible, and easily accessible.
  - A definition of consent which requires such consent to be freely given, specific, informed, and unambiguous;
  - A set of principles applicable to all data processing activities without exception, including lawfulness, fairness, transparency, purpose limitation, data minimisation, accuracy, storage limitation, integrity and confidentiality, and accountability;
  - The fullest possible array of data subject rights, including the right to information, access, rectification, erasure, restriction of processing, data portability, and to object.

## II) Menstrual hygiene apps and challenges to privacy

Period-tracking apps, informally referred to as menstruation apps, have seen an exponential growth in use, with over 100 million women worldwide relying on them to monitor their menstruation cycle. PI's research revealed in 2019 that period-tracking apps MIA Fem and Maya sent information on the user's use of contraception, the timings of their monthly periods, symptoms like swelling and cramps, and more, directly to Facebook through the use of analytics.<sup>35</sup>

*Collection of sensitive data.* As a starting point, any data entered on a period-tracking app for the purposes of describing one's menstrual cycle constitutes health-related information, and therefore amounts to especially sensitive data.<sup>36</sup> In addition, period-tracking apps allow the user to enter intimate data unrelated to the menstrual cycle, such as sexual activity, type of contraception used, and mood. While users may be under the impression that this data is kept confidential and not shared with third

<sup>&</sup>lt;sup>35</sup> PI, *No Body's Business But Mine: How Menstruation Apps Are Sharing Your Data*, available at: <u>https://www.privacyinternational.org/long-read/3196/no-bodys-business-mine-how-menstruations-apps-are-sharing-your-data</u>

parties, there were at least two instances documented by PI where this was the case. The nature of data to be shared with a third-party, and the basis on which it would be shared, was unclear from the Privacy Policy.

*Data-sharing.* The disclosure of health-related information or other personal data to third parties on the basis of uninformed consent is a harm to privacy in and of itself. But the consequences of such disclosure can be even more far-reaching. Information as to a woman's mood, when shared with advertisers, can be used in order to target that woman with content known to elicit specific responses by women in that specific mood. On this front, research by PI on French health website Doctissimo disclosed the results of depression tests taken online with advertisers.<sup>37</sup> Similar data-sharing practices could be occurring on period-tracking apps.

## Recommendations

- The Working Group should highlight that companies providing sexual and reproductive rights services should respect human rights, including the right to privacy, at all times.
- In that respect, the Working Group should recommend the introduction of robust data protection frameworks protecting women's privacy, which should at a minimum include the following:
  - A requirement for organisations and companies to provide users with a privacy notice that is concise, transparent, intelligible, and easily accessible.
  - A definition of consent which requires such consent to be freely given, specific, informed, and unambiguous;
  - A set of principles applicable to all data processing activities without exception, including lawfulness, fairness, transparency, purpose limitation, data minimisation, accuracy, storage limitation, integrity and confidentiality, and accountability;
  - The fullest possible array of data subject rights, including the right to information, access, rectification, erasure, restriction of processing, data portability, and to object.

## III) Obstacles to the access to abortion care

Research by PI and its global partners documented limited access to safe legal abortion care across all the countries surveyed<sup>38</sup>. In some countries where access to legal abortion is limited, women often resort to unsafe abortion procedures. In 2017, over 200 thousand women were hospitalised in Brazil due to medical complications after undergoing clandestine procedures.<sup>39</sup>

## Obstacles in accessing abortion services

*Limited availability of abortion medication.* In some countries, legislation may place restrictions on the procurement of medication used to induce abortion in addition to the traditional legal prohibitions on abortion. In Brazil, the Penal Code forbids the sale of medication not registered with the National Health Agency, which is the case for

<sup>&</sup>lt;sup>37</sup> PI, *Complaint against Doctissimo*, available at: <u>https://privacyinternational.org/legal-action/complaint-against-doctissimo</u>

<sup>&</sup>lt;sup>38</sup> PI, *Country case-studies Reproductive rights*, available at: <u>https://privacyinternational.org/learning-resources/country-case-studies-reproductive-rights</u>

<sup>&</sup>lt;sup>39</sup> PI, *Country case-study: sexual and reproductive rights in Brazil*, available at: <u>https://privacyinternational.org/long-read/3895/country-case-study-sexual-and-reproductive-rights-</u> <u>brazil</u>

abortion pills. Substances are also strictly regulated: Misoprostol, the active substance of abortive medicines, is restricted to a select few hospitals registered with the Ministry of Health.  $^{\rm 40}$ 

*Extensive and prohibitive requirements to satisfy the legal basis for abortion.* In Indonesia, a woman is only allowed to get an abortion in case of a medical emergency with her husband or family's approval, or in case of rape with a letter from a doctor and from the investigator, psychologist, and/or another expert on the rape. Concerning the latter case, the abortion must be done within six weeks. This is an issue because many rape survivors do not realise that they are pregnant until it is too late, and procuring the relevant documents to obtain an abortion can be a time-consuming task.

*Burdensome approval systems.* In India, private clinics require government approval to provide abortion services. Approval is a central government faculty which is delegated to state governments. Depending on the party in power, private clinics face different approval processes based on their state. Approval applications must be sent to District Level Committees (DLCs) consisting of 3-5 members, and the DLC must return a certificate of approval in order for a private clinic to legally practice abortions. The certification system is inherently contradictory: professionals can only undergo training if they are certified, however, to be certified, at least one trained professional must already be employed. As a consequence, if these facilities do choose to perform abortion services without seeking approval, they are automatically considered to be doing so illegally.<sup>41</sup>

*Delaying and blocking tactics.* Opposition groups tactics include misleading women seeking abortion with false information in order to delay their abortion and ultimately discourage them from seeking it. For instance, in Kenya, anti-abortion groups campaign in 2018 led to the temporary suspension of some of Marie Stopes International's reproductive health services thereby limiting women's access to abortion.<sup>42</sup> In Brazil, opposition groups have been known to target especially vulnerable populations. Once such group, "40 days for life", targeted a referral center for female survivors of sexual violence which was responsible for half the legal abortions made in the State of São Paulo from 2015 until 2019.<sup>43</sup>

## Surveillance and data exploitation: a safety issue

A key dimension of safety is being able to access sexual and reproductive rights freely and without negative repercussions. However, in many cases, women are prevented access to safe abortion services on account of being unnecessarily subjected to data exploitation and surveillance by governments or/and opposition groups. Privacy often becomes a hidden cost to the access of legitimate, or illegitimate, abortion care. If women find themselves having to sacrifice their privacy to access abortion care, or

<sup>&</sup>lt;sup>40</sup> PI, *Country case-study: sexual and reproductive rights in Brazil*, available at: <u>https://privacyinternational.org/long-read/3895/country-case-study-sexual-and-reproductive-rights-brazil</u>

<sup>&</sup>lt;sup>41</sup> PI, *Country case-study: sexual and reproductive rights in India*, available at: <u>https://privacyinternational.org/long-read/3863/country-case-study-sexual-and-reproductive-rights-</u> <u>india</u>

<sup>&</sup>lt;sup>42</sup> PI, *Country case-study: sexual and reproductive rights in Kenya*, available at: <u>https://privacyinternational.org/long-read/3859/country-case-study-sexual-and-reproductive-rights-kenya</u>

<sup>&</sup>lt;sup>43</sup> PI, *Country case-study: sexual and reproductive rights in Brazil,* available at: <u>https://privacyinternational.org/long-read/3895/country-case-study-sexual-and-reproductive-rights-</u> <u>brazil</u>

any other sexual and reproductive health service, the access to these services is not safe.  $^{\rm 44}$ 

*Identity verification systems.* In India, research by the Center for Internet and Society found that many public hospitals are demanding Aadhaar cards - the national ID before allowing women to access reproductive health procedures.<sup>45</sup> This has resulted in a denial of essential services to people who have not been able to register to the Aadhaar database.<sup>46</sup> For those people who are able to access reproductive health care services, their data is collected, centralised and accessible to parties who have their individual's Aadhaar number. Those parties include most government bodies, banks and telecommunications companies. Moreover, the Aadhaar system is susceptible to data leaks; for instance, the data breach of a government agency in April 2019 made health records of 12.5 million pregnant women available online. In 2016, the Minister for Women and Child Development proposed linking information on the Health Management Information System and the above-mentioned Mother and Child Tracking System, which includes data on maternal health in the ante-natal and postnatal periods, to the Aadhaar system. This further endangers the safe access to reproductive health services, especially for vulnerable groups such as young, unmarried or migrant women.

*Data-sharing practices.* In the United States, health information of migrant pregnant girls is potentially shared between crisis pregnancy centres they are referred to by the Office of Refugee Resettlement (ORR). Moreover, it was found that the Director of the Missouri Department of Health and Senior Services created a spreadsheet tracking the menstrual cycles of patients of the state only abortion clinic supposedly to identify women who had failed abortions. The spreadsheet was shared amongst health department employees.<sup>47</sup> Data sharing between anti-abortion groups has a chilling effect on safe abortion services. In Malta, opposition groups shared data of people seeking abortion care with an opposition group in Ireland. As a result, women seeking abortions were contacted by an Irish person pretending to be an abortion provider in the United Kingdom. Some women received abusive text messages or were visited at their home addresses.<sup>48</sup>

*Data-intensive technologies.* Opposition organisations also use data to target people seeking reproductive health information online and develop data intensive technologies for the management of CPCs. Heartbeat International offers a management system called Next Level which "harnesses the power of big data" for anti-choice centres.<sup>49</sup> It appears that Next Level system standardises the type of questions people are asked when they seek a centre's help and visit a centre. The data collected includes name, address, email address, ethnicity, marital status, living

<sup>&</sup>lt;sup>44</sup> PI, "Privacy matters because...it protects our bodily autonomy", available at: <u>https://privacyinternational.org/case-study/3388/it-protects-our-bodily-autonomy</u>

<sup>&</sup>lt;sup>45</sup> PI, *Country case-study: sexual and reproductive rights in India*, available at: <u>https://privacyinternational.org/long-read/3863/country-case-study-sexual-and-reproductive-rights-india</u>

<sup>&</sup>lt;sup>46</sup> ld.

<sup>&</sup>lt;sup>47</sup> PI, *A documentation of data exploitation in sexual and reproductive rights*, available at: <u>https://privacyinternational.org/long-read/3669/documentation-data-exploitation-sexual-and-reproductive-rights</u>

<sup>&</sup>lt;sup>48</sup> Abortion Support Network, "Charities warn that anti-choice groups in Malta are targeting women with "lies and misinformation" to prevent them accessing legal abortion care overseas", 5 June 2019, available at: <u>https://www.asn.org.uk/news-and-events/press-release-charities-warn-that-anti-choice-groups-in-</u> <u>malta-are-targeting-women-with-lies-and-misinformation-to-prevent-them-accessing-legal-abortion-</u> <u>care-overseas/</u>

<sup>&</sup>lt;sup>49</sup> PI, How anti-abortion activism is exploiting data, available at: <u>https://privacyinternational.org/long-</u> read/3096/how-anti-abortion-activism-exploiting-data

arrangement, education, income source, alcohol, cigarette, and drug intake, medications and medical history, sexual transmitted disease history, name of the referring person/organisation, pregnancy symptoms, pregnancy history, medical testing information, and eventually even ultrasound photos.<sup>50</sup>

*Online chat services.* Opposition websites often feature an online chat service. While appearing user-friendly, the way in which information entered by the user into the chatbox is used is often unclear. For instance, Heartbeat International has developed Option Line, a website, chat service and call line for opposition websites.<sup>51</sup> Before users are able to engage with the chat service, they are required to enter their name, demographic information, location and whether they are considering an abortion. It is unclear what happens with the information submitted before and during the chat and who has access to it. This issue is compounded by the lack of privacy policies on these websites. Research carried out in Peru by Hiperderecho found that none of the opposition websites surveyed had a privacy policy.<sup>52</sup> This makes it difficult for users to make an informed decision as to how their data will be used, and ultimately obstructs the exercise of their data rights in relation to the information they entered into an online chatbox.

## Recommendations

- The Working Group should recommend that states should ensure that women seeking abortion treatment through legal avenues are provided with timely, affordable and adequate treatment, even in times of crisis.
- It should highlight that any healthcare referrals by government entities are made to properly accredited centres and/or professionals that provide services on an objective and non-discriminatory basis.
- The Working Group should highlight that companies should respect their data protection obligations.
- It should recommend that states should ensure that data protection law and penalties are promptly enforced against companies found to be in breach.

## IV) Privacy violations as modern instances of gender-based violence

Numerous sexist, misogynistic and abusive practices are flourishing online, in ways that are harder for national authorities to stop than when abuse takes place offline. These forms of gender-based violence rely on using women's private information against them. Among these instances of gender-based violence, PI has identified data exploitative practices, revenge pornography and stalkerware as increasingly concerning examples of gendered violations of privacy. Situations of crisis, such as the pandemic, have made it possible for the harm resulting from such instances of genderbased violence to be exponentially magnified.

## Data exploitative practices

In previous paragraphs, PI has showcased a range of data exploitative practices covertly obstructing access to sexual and reproductive health services. The use of these practices constitutes a form of gender-based violence given its

<sup>&</sup>lt;sup>50</sup> See PI, A documentation of data exploitation in sexual and reproductive rights, available at: <u>https://privacyinternational.org/long-read/3669/documentation-data-exploitation-sexual-and-reproductive-rights</u> <sup>51</sup> Id.

<sup>&</sup>lt;sup>52</sup> PI, *Country case-study: sexual and reproductive rights in Peru*, available a: <u>https://privacyinternational.org/long-read/3791/country-case-study-sexual-and-reproductive-rights-peru</u>

disproportionate targeting of, and impact on, women seeking to exercise their rights. The harms stemming from this gender-based violence can be particularly severe.

Only this year, in Brazil, a 10-year old girl who became pregnant as a result of being raped by a family member was significantly victimised and harassed after deciding to undertake an abortion. Despite the fact that rape is a lawful basis for abortion in Brazil, the hospital where she was initially admitted refused to carry out the abortion. After a judge gave permission for the abortion to take place, an anti-abortion activist unlawfully published the name of the minor and the name of the hospital where she would have the procedure on several social media platforms, including Google, Facebook and Twitter.<sup>53</sup> Although the posts were subsequently removed, the damage had been done. Anti-abortion protesters blocked access to the hospital where the girl would have the abortion and harassed and insulted its personnel. As a result, she had to enter the facility hidden in the trunk of a minivan, a turn of events which unnecessarily compounded her ordeal and rendered the experience even more traumatic. This is only one example of the ways in which social media platforms have been used to criminalise and harass women and girls seeking to exercise their reproductive and sexual rights.

#### Revenge pornography

One of these practices is 'revenge pornography', which involves online distribution of private sexual images without the consent of the person depicted. Revenge pornography' and other forms of image-based sexual abuse are a threat to individual autonomy and sexual agency.<sup>54</sup> This practice can silence victims and contribute to them withdrawing from the public sphere, becoming depressed and in some cases even committing suicide. Victims of 'revenge porn' are often identified online and receive numerous malicious and violent threats. Considering that majority of victims are women, this sends a message to all women that they should not be comfortable online.<sup>55</sup>

Heightened impact during the pandemic. Considering the current COVID-19 crisis, when numerous people have been confined to their homes during the lockdown, the mental health and psychological impacts for victims of 'revenge porn' are magnified. Not only are they prevented from seeing their family and being active in the 'real world', but also, they do not feel safe in the 'virtual world' due to the abuse they may experience online. Further, considering the coronavirus lockdown, it may be harder for victims of 'revenge porn' to obtain psychological support. The difficulty in removing the private sexual images from the internet, once they are uploaded online, often means that any harms stemming from this practice are significant and long-lasting.

Absence of appropriate police investigations. Due to the unwillingness of the police to be involved in investigations of 'revenge porn', victims are often having to spend days, weeks, months policing the internet themselves and searching for their images once they have gone viral. This has a monumental impact on their mental and physical health.

 <sup>&</sup>lt;sup>53</sup> Human Rights Watch, A 10-Year-Old Girl's Ordeal to Have a Legal Abortion in Brazil, 20 August 2020, available at: <u>https://www.hrw.org/news/2020/08/20/10-year-old-girls-ordeal-have-legal-abortion-brazil</u>
 <sup>54</sup> PI, "Privacy matters because...it protects our development", available at: <u>https://privacyinternational.org/case-study/4113/it-protects-our-development</u>

<sup>&</sup>lt;sup>55</sup> SWGfL, "Research reveals gendered trends in revenge porn crimes", available at: <u>https://swgfl.org.uk/magazine/revenge-porn-research-2019/</u>

#### Stalkerware

Pl is investigating the new forms of gender-based violence that are being perpetrated with the use of digital technologies. We are concerned about the prevalent use of stalkerware, a software often used by abusers to spy on their partners.<sup>56</sup> It is a commercially available programme which the abuser purchases and installs on the victim's phone. This can be done without their knowledge if the perpetrator knows the passwords on the victim's device or by tricking them into installing it themselves. Once stalkerware is installed, the abuser can gain access to victim's communications, emails, contacts, location and photos. Essentially perpetrators have access to their victim's mind.

*Extensive surveillance capabilities.* Once the programme is installed, the abuser pays the stalkerware company for access to a portal, which transfers the information from that device on their dashboard. These capabilities can afford dramatic powers and control over an individual's everyday life. Stalkerware can operate as a predator in a person's pocket, magnifying the pervasive surveillance of the spyware operator. Especially since intimate partner violence, abuse, and harassment is routinely linked with efforts to monitor and control a targeted person. This software gives abusers and stalkers a robust tool to perpetrate harassment, monitoring, stalking, and abuse. This type of abuse can be terrifying, traumatizing, and raises significant safety risks.

Absence of privacy safeguards. PI is also concerned about the potential lack of measures to prevent data exploitation being implemented by these companies. Since the operation of stalkerware is premised on its covert nature, companies providing this software neither seek nor obtain consent from the victims to process and collect their personal data. Similarly, companies do not facilitate the exercise of data rights by victims. Companies fail to make clear how the victims of stalkerware can have their data deleted, when they haven't meaningfully consented to the collection in the first place.<sup>57</sup> Stalkerware application companies do not fully account for the personal data that can be captured when operating the software. Also, they do not notify victims targeted by their stalkerware applications in the case of data breaches.

#### Recommendations

- The UN Working Group should recommend that criminal legislation is amended to reflect new forms of gender-based violence involving the use of technology.
- It should further call states to ensure that any legislation making the use of revenge porn, stalkerware or the unauthorised use of personal data an offence is properly enforced at all times.
- Also, it should note that police and prosecutors should receive adequate training in order to properly investigate and prosecute complaints on the use of stalkerware and revenge porn.
- V) Pregnancy-related health services, including pre- and post-natal care, assistance during child-birth, and emergency obstetric care

<sup>&</sup>lt;sup>56</sup> Women's Aid and PI, "Women's Aid and Privacy International launch digital information cards to help women stay safe on Valentine's Day", available at: <u>https://privacyinternational.org/long-read/3366/womens-aid-and-privacy-international-launch-digital-information-cards-help-women</u>; PI, "Privacy matters because...it protects marriage equality", available at: <u>https://privacyinternational.org/case-study/3538/it-protects-marriage-equality</u>

<sup>&</sup>lt;sup>57</sup> CitizenLab, *The Predator in Your Pocket*, June 2019, available at: <u>https://citizenlab.ca/docs/stalkerware-holistic.pdf</u>

As part of wider developments in the health sector around the use of data and technology, there has been a notable increase in digital health initiatives focusing strengthening delivery of reproductive, maternal, newborn and child health (RMNCH) services in many low- and middle-income countries (LMICs), including in fragile settings characterised by ongoing crises.<sup>58</sup> An assessment published by the World Health Organisation in 2018 indicated that 69 percent of the 62 countries surveyed were monitoring reproductive health indicators through health information systems, a majority of which were at least partially digital.<sup>59</sup>

Driven by the promises of new technologies data revolution to tackle global socioeconomic challenges and as a key to meeting the Sustainable Development Goals, digital health initiatives have evolved from mHealth and eHealth to more innovative techniques and tools, from big data and data analytics to now artificial intelligence, machine learning and automation.

RMNCH digital initiatives range from facilitating scheduling through SMS, remote access to care and counselling,<sup>60</sup> to health workers using a mobile phone to track an individual pregnant mother over the cycle of pregnancy, or a child over his/her cycle of immunization, and the use of mobile applications, sensors, wearable devices and others.<sup>61</sup> Working with partners around the world, we have observed the following areas of concern which must be addressed.

Absence of human rights and privacy considerations in the implementation of RMNCH services

Lack of data governance and human rights approach. Often the deployment of digital health initiatives is not accompanied at both the policy and operational levels with adequate legal and regulatory protections for data governance that impact human rights and gender equality. As with many misguided and ill-prepared digital solutions, the failure to consider these elements makes beneficiaries of RMNCH services vulnerable to exploitation and exclusion, while rendering the potential benefits from these digital initiatives to improve services delivery sub-optimal in terms of reach, coverage, scale and sustainability.

*Poor impact assessments.* Some of the shortcomings observed in the deployment of digital RMNCH initiatives have included not foreseeing and assessing the new concerns emerging with the digitization of RMNCH services: i) risks associated with visibility and tracking of patients especially when combined with identification systems where access is managed through registration into a large-scale complex identification system, and in its absence are denied access to services as well as others sources of data being brought together and the risks associated with the vast intelligence which can be gathered as a result, and ii) the failure to understand and respond to the complex infrastructural requirements of such initiative including access to secure, reliable internet.

<sup>&</sup>lt;sup>58</sup> Donna Mavley & Donna Slovensky, *mHealth*, Springer, 2014.

<sup>&</sup>lt;sup>59</sup> WHO, *eHealth and innovation in women's and children's health: a base line review*, March 2014, available at: <u>https://www.who.int/goe/publications/baseline\_fullreport/en/</u>

<sup>&</sup>lt;sup>60</sup> Sunday Oluwafemi Oyeyemi, Rolf Wynn, "Giving cell phones to pregnant women and improving services may increase primary health facility utilization: a case-control study of a Nigerian project", 11(1) *Reprod Health*, available at: <u>https://pubmed.ncbi.nlm.nih.gov/24438150/</u>

<sup>&</sup>lt;sup>61</sup> Smisha Agarwal, Alain Labrique, "Newborn health on the line: the potential mHealth applications", 312(3) *JAMA*, available at: <u>https://pubmed.ncbi.nlm.nih.gov/24953141/</u>

#### Risks stemming from regulatory gaps

*Mission creep: tools for surveillance*. Often the driving logic of these systems is around strengthening centralized surveillance and control rather than for improving local care processes. The processing of personal data in a legal and policy void raises concerns of mission creep, i.e. used for other purposes, and data being misused for surveillance purposes and made accessible to different entities for unintended purposes without prior consent of the individual, and they are also concerns about industry led initiatives raising concerns about accountability of such actors, and risks of corporate exploitation of personal data processed for the purpose RMNCH digital initiatives.

*Poorly regulated complex ecosystem.* In many low- and middle-income countries (LMICs) and in particular fragile settings, there is a complex ecosystem where public, private and donors all play a role. The roles and responsibilities of each of these actors are often not defined in law and policy, where such frameworks exist, and in settings where no such frameworks are in place these actors operate in a legal and regulatory void. This leads to no accountability and obligations being shifted from one party to another without any taking ownership. These concerns are heightened by the proliferation of private sector corporations in public health systems. The engagement of private sector vendors to build technical solutions further the inequality between the technical and the health needs and can amplify pre-existing shortcomings and injustice including gender inequality and discrimination.

#### Challenges specific to fragile environments

Contexts of fragility are multi-faceted and vary with historical legacy, population sizes, economic and political structures, adoption of technology, but they often characterised by weak governance and policy environments making engagement a long-term challenge. Furthermore, fragility is relevant to consider in RMNCH services, as a high percentage of population living in these settings are women and children, making them vulnerable to challenges related to unwanted pregnancies, sexual violence, and unmet contraception needs.<sup>62</sup> Choices of digital technologies and models of implementation are shaped by context, such as the infrastructure conditions favouring the use of mobile instead of fixed networks. Initial research findings of research being conducted by the Institute of Community and Public Health, Birzeit University (BZU) in the West Bank, the Jordan University for Science and Technology (JUST) in Amman, the Institute for Informatics, University of Oslo (UiO) and PI on the governance of digital personal data to strengthen reproductive, maternal, newborn and child health services in Palestine indicates that there is an array of digital RMNCH initiatives being deployed in Palestine and Jordan, and it is unclear so far what governance framework is being applied to ensure respect with human rights including right to health, gender equality and privacy.

Below are references to a few case studies of digital RMNCH initiatives including in fragile settings:

AviCenna Health Information Medical, e-registries and other digital RMNCH initiatives, Palestine. A decade ago the Palestinian Ministry of Health in the West Bank started to implement an e-health system AviCenna Health Information Medical System, which

<sup>&</sup>lt;sup>62</sup> Maternal Health Task Force, *Closing the Gaps of Maternal Health in Conflict and Crises,* available at: <u>https://www.mhtf.org/projects/woodrow-wilson-international-center-advancing-dialogue-on-maternal-health-series/closing-the-gaps-of-maternal-health-in-conflict-and-crises/</u>

includes provision of some RMNCH services.<sup>63</sup> There is also a collaborative project between the Palestinian Health Authorities and the Norwegian Institute of Public Health (NIPH) on a 5-year NORAD funded e-registries project aimed at strengthening RMNCH preparedness capacities.<sup>64</sup> This is in addition to an array of digital RMNCH initiatives being deployed by public, private and international institutions such as development and humanitarian organisations.

Perinatal and Neonatal Mortality Surveillance and Auditing System (J-SANDS), Hakeem Program and other digital RMNCH initiatives, Jordan. The J-SANDS system seeks to strengthen perinatal and neonatal (PNN) registration and reporting system and is currently deployed in 4 main hospitals in Jordan.<sup>65</sup> In October 2009, the Electronic Health Solutions (EHS) launched its flagship program, Hakeem, the first national Electronic Health Record (HER).<sup>66</sup> Based on a patient's national ID number, the system aims to provide clinicians with access to patient's historical information, including of comprehensive medical and surgical history, physical examinations, procedural and surgical reports, current medications, allergies as well as in-patient and out-patient clinic visit notes.

Mother and Child Tracking System, India. India's health programme instituted an information system in 2009, the Mother and Child Tracking System (MCTS), which is aimed at collecting data on maternal and child health. Between 2011 and 2018, 120 million pregnant women and 111 million children have been registered on the MCTS. The central database collects data on each visit of the woman from conception to 42 days postpartum, including details of direct benefit transfer of maternity benefit schemes, by tracking a move and children through a 16 digital identification number. The MCTS does not operate in a silo, and has an infrastructure in place facilitating access to cash assistance for deliveries and post-natal care for the mother. Similarly, there are plans to link MCTS to Aadhar, the Indian ID database – one of the biggest biometric databases on the planet - which remains an ongoing concern due to its intrusiveness.<sup>67</sup> Not unlike Aadhaar, the MCTS was deployed in the absence of robust data protection measures. Research by the Centre for Internet and Society explored the MCTS as part of an assessment of the use of big in reproductive health in India, finding that the MCTS failed to take into account local realities including personal ownership of a mobile phone by users, and flagging lack of training of staff using the system, and flaws in the system design.<sup>68</sup>

## Recommendations

The Working Group should highlight that the conceptualisation, • implementation and monitoring of RMNCH initiatives must be underpinned by health, gender equality and privacy considerations, with clear responsibilities being assigned to each of the actors involved.

<sup>67</sup> PI, "Initial analysis of Indian Supreme Court decision on Aadhaar", available at: https://privacyinternational.org/long-read/2299/initial-analysis-indian-supreme-court-decision-aadhaar

<sup>&</sup>lt;sup>63</sup> Avicenna Medical Systems, Chronic Care Management Overview, available at: <u>https://www.avicenna-</u> medical.com/chronic-care-management-software-benefits-avitracks-cm

<sup>&</sup>lt;sup>64</sup> NIPH, Global Health Preparedness Project in Palestine, 22 September 2017, available at: https://www.fhi.no/en/gk/global-healt-collaboration/global-health-preparedness-programme/ourpartner-countries/palestine/ <sup>65</sup> JSANDS, *About J-SANDS*, available at: <u>www.jsands.jo</u>

<sup>&</sup>lt;sup>66</sup> Electronic Health Solutions, *About EHS*, available at: <u>https://ehs.com.jo/</u>

<sup>&</sup>lt;sup>68</sup> Centre for Internet and Society, *Big Data and Reproductive Health: A case study of the Mother and Child* Tracking System, October 2019, available at: <u>https://cis-india.org/raw/big-data-reproductive-health-india-</u> <u>mcts</u>

- It should further recommend that states should ensure that risks to privacy are incorporated into risk assessments applied to RMNCH initiatives.
- VI) Legal and policy safeguards against abuses and delays in the provision of SRH services

Several challenges to women's full and free exercise of their sexual and reproductive rights exist in relation to confidentiality, referrals, informed consent, conscientious objection, and third party consent requirements. These obstacles are often enshrined in primary legislation and have the effect of pushing women towards clandestine and ultimately unsafe abortions.

## Challenges to patient confidentiality

*Compulsory reporting requirements.* Some countries require healthcare professionals to report women who they believe have undergone an illegal abortion to government authorities. In Peru, doctors are legally compelled to report women who seek treatment after suffering complications from an abortion to the police if they suspect that an illegal abortion has taken place. This legal requirement overrides doctors' right to professional secrecy in a doctor-patient relationship, and has continued to be enforced despite regional human rights jurisprudence to the contrary.<sup>69</sup> This continued practice forces a difficult – and unnecessary – choice onto women: seek medical help and risk prosecution, or leave potentially serious complications unattended.

*Poor working conditions.* In Chile, women seeking to undergo an abortion under one of the specified legal avenues are entitled by law to access an accompaniment program. However, two years after the introduction the program, serious issues were raised by supporting staff, who reported that their precarious conditions of work meant that they were not in a position to guarantee the confidentiality of the patients they worked with.<sup>70</sup> Among the difficulties they noted was the hostility they faced from other healthcare professionals, including doctors, midwives and nurses, when asserting the patient's right to receiving adequate support.

## Abuse of the conscientious objection

Conscientious objection was raised multiple times in research commissioned by PI as one of the obstacles to women exercising their sexual and reproductive rights. Despite its emphasis on individual beliefs, there is evidence to show that conscientious objection is institutionally applied.

*Institutional reliance on conscientious objection.* In Argentina, objection is frequently practised in health institutions and can occur across the entire department or establishment, resulting in one of the main institutional barriers to legal abortion services. It also contributes to the abortion stigma and fuels the idea that abortion is illegal.<sup>71</sup> In Chile, the picture is bleaker. Research by Human Rights Watch found that

<sup>&</sup>lt;sup>69</sup> PI, Country case-study: sexual and reproductive rights in Peru, available at: <u>https://privacyinternational.org/long-read/3791/country-case-study-sexual-and-reproductive-rights-peru</u>
<sup>70</sup> CIPER, "Acompañamiento a las mujeres que abortan: un programa abandonado a su suerte", 9 October 2019, available at: <u>https://ciperchile.cl/2019/10/09/acompanamiento-a-las-mujeres-que-abortan-un-programa-abandonado-a-su-suerte/</u>

<sup>&</sup>lt;sup>71</sup> PI, Country case-study: sexual and reproductive rights in Argentina, available at: <u>https://privacyinternational.org/long-read/3856/country-case-study-sexual-and-reproductive-rights-argentina</u>

nearly 50% of all medical providers objected to providing abortions after rape, and some public hospitals lacked a single provider willing to perform an abortion in those circumstances.<sup>72</sup> Importantly, conscientious objection is often not an individual choice, but an institutional one: where the head of the hospital objects to abortion, they are able to pressure individual doctors who are not conscientious objectors to object.<sup>73</sup>

Absence of justification requirements. Conscientious objection in Chile is facilitated to the fullest possible extent by the Ministry of Health, which merely requires the completion of a form and refrains from requesting any details or background information as to the reasons behind the objection.

#### Informed consent

The notion of informed consent lies at the heart of ethical medical practice and data protection. However, there is growing evidence that opposition tactics, both online and in-person, erode the notion of informed consent for women seeking access to sexual and reproductive health services.

Absence of accreditation. As stated in the paragraphs above, multiple opposition-led websites and centres purport to give sexual and reproductive health advice without offering any form of medical accreditation or qualification. An Open Democracy investigation spanning 18 countries found that these centres presented themselves, whether through advertising or in person, as medically qualified institutions.<sup>74</sup> Pl research later confirmed that these misleading practices extended to the online sphere.<sup>75</sup> Strong penalties should exist for individuals or institutions holding themselves out as medically qualified, and they should be properly enforced.

*The impact on privacy.* Whether in online interactions or in person, women are more likely to disclose personal information if they believe they are speaking to a healthcare professional, not least because of the widespread notion of patient-doctor confidentiality. In the same way women would not so readily accept treatment from unqualified professionals, they may also have reservations about sharing their personal data with an unqualified third-party.

## Recommendations

- The Working Group should recommend for doctor-patient confidentiality to be unequivocally protected and enforced at all times.
- It should recommend that states should ensure that any legislation interfering with doctor-patient confidentiality is made compatible with women's rights or, alternatively, repealed.
- It should note that any support services made available to women accessing sexual and reproductive healthcare must be in a position to be able to respect the patient's privacy even in times of crisis.

<sup>&</sup>lt;sup>72</sup> Human Rights Watch, *Chile Events of 2018*, available at: <u>https://www.hrw.org/world-report/2019/country-chapters/chile#085afa</u>

<sup>&</sup>lt;sup>73</sup> CIPER, "Todos los obstáculos y presiones que impiden a las mujeres acceder al aborto por tres causales", 4 September 2018, available at: <u>https://ciperchile.cl/2018/09/04/todos-los-obstaculos-y-presiones-que-impiden-a-las-mujeres-acceder-al-aborto-por-tres-causales/</u>

impiden-a-las-mujeres-acceder-al-aborto-por-tres-causales/
 <sup>74</sup> Open Democracy, "Exclusive: Trump-linked religious 'extremists' target women with disinformation worldwide", 10 February 2020. Available at: <a href="https://www.opendemocracy.net/en/5050/trump-linked-religious-extremists-global-disinformation-pregnant-women/">https://www.opendemocracy.net/en/5050/trump-linked-religious-extremists-global-disinformation-pregnant-women/</a>

<sup>&</sup>lt;sup>75</sup> PI, A documentation of data exploitation in sexual and reproductive rights, available at: <u>https://privacyinternational.org/long-read/3669/documentation-data-exploitation-sexual-and-reproductive-rights</u>

#### VII) Groups of women disproportionately affected by restrictions on the exercise of reproductive rights

Some obstacles to the exercise of sexual and reproductive rights have a disproportionate effect on particular categories of women. PI has found that women without legal status, those living in rural setting, and those having survived domestic violence are among those who are adversely affected.

#### Migrant women

PI has been working with partners around the world to expose how welfare systems and healthcare systems are turning into systems of surveillance through the requirement for ID systems. Though our research on this front is preliminary, PI has found a trend in several countries, such as the Philippines, Kenya, Panama, Colombia, where people are required to provide ID to access health and welfare programmes. Such requirements prevent women without legal status to access sexual and reproductive health services. In the Philippines this problem is compounded by the requirement to show a birth certificate in order to obtain a valid ID. If the birth certificate is lost, damaged or otherwise not available, ID will not be issued.

#### Rural women

Difficulties in obtaining ID. As previously stated, in India, many public hospitals are demanding Aadhaar cards - the national ID - before allowing women to access reproductive health procedures. This has resulted in a denial of essential services to people who have not been able to register to the Aadhaar database.<sup>76</sup> Of course, access to ID is predicated on access to government infrastructure, which is usually located in urban centres. However, considering that 70% of the Indian population is rural, it is likely the number of ID-holding population is limited.<sup>77</sup>

Digital literacy and inclusion. Internet has become a key gateway to access to information, including accurate and reliable information on sexual and reproductive rights. However, the digital gap often means that women in rural areas may not benefit from the vast knowledge trove that is the Internet. In Peru, for example, only 12.5% of women in rural areas use Internet. In a joint submission to the Committee on the Elimination of All Forms of Discrimination Against Women, PI and Hiperderecho highlighted the digital gap as a factor exacerbating the country's social inequalities. requesting the Committee to support the development of gender-specific objectives in policies relating to technology, broadband, infrastructure and privacy.<sup>78</sup>

## Trans women

Trans women face obstacles in virtually every aspect of their lives. The fact that trans women's experience of discrimination is exacerbated by being constrained to use an ID with their birth name and gender, as opposed to the name and gender they self-

<sup>76</sup> PI, Country case-study: sexual and reproductive rights in India, available at: https://privacyinternational.org/long-read/3863/country-case-study-sexual-and-reproductive-rightsindia

Country case-study: sexual and reproductive rights India, available PI in at: https://privacyinternational.org/long-read/3863/country-case-study-sexual-and-reproductive-rightsindia

<sup>&</sup>lt;sup>78</sup> PI and Hiperderecho, Submission to the UN CEDAW Committee for the Examination of the Republic of Peru, available https://privacyinternational.org/sites/default/files/2020at:

identify with, has been exhaustively researched and documented. As PI has documented in interviews with trans activists, the repercussions of the mismatch between ID and self-identity extend to trans women's access to sexual and reproductive health services, with many trans people being discouraged from accessing healthcare services.<sup>79</sup>

Access to healthcare during the pandemic. In countries which applied genderedmeasures in response to the pandemic, for example by assigning different circulation days to women and men, instances of discrimination of transgender women were widely documented. This was the case in Peru, Panama and Colombia. In all of these countries, the implementation of gendered-measures resulted in trans women whose ID did not match the gender they self-identified with having their identity challenged and being accused of breaching lockdown rules.<sup>80</sup> This meant that trans women's circulation was obstructed on the days when they could rightfully leave their home, and that their access to healthcare was curtailed both when they were unfairly stopped by authorities, or when they were deterred from seeking help on account of fear of reprisals.

## Domestic and sexual violence survivors

Domestic and sexual violence survivors deserve timely and adequate support. However, practical, social and cultural restrictions on the right to abortion may result in the double victimisation of survivors, even when support mechanisms are implemented by law. In 2005, India passed legislation addressing and outlining the rights of survivors of domestic and sexual violence, introducing amendments to the criminal code which made the failure by public and private actors to immediately treat victims of sexual violence a crime.<sup>81</sup>Despite this, research by the Centre for Enquiry into Health and Allied Themes (CEHAT) found that private and public facilities frequently refuse to provide abortions to women, either when it is the woman's first pregnancy, or if the pregnancy goes beyond the 20-week mark. Both grounds for refusal openly defy the domestic violence legislation.<sup>82</sup>

## Recommendations

- The Working Group should recognise that all women must be guaranteed equal access to sexual and reproductive services and information at all times.
- It should recommend that all legal and practical obstacles to women accessing healthcare on equal footing are removed.
- It should recommend for states to ensure that any measures taken in response to a crisis properly take into account the experiences of all women, in particular those who are disproportionately discriminated, excluded or otherwise victimised on account of their gender identity, race, and socioeconomic background.

<sup>&</sup>lt;sup>79</sup> PI, From Oppression to Liberation: Reclaiming the Right to Privacy, p. 22, available at: https://privacyinternational.org/sites/default/files/2018-11/From%20oppression%20to%20liberationreclaiming%20the%20right%20to%20privacy.pdf

<sup>&</sup>lt;sup>80</sup> Reuters, "Las personas trans, expuestas a discriminación y violencia en las cuarentenas de América Latina", 6 May 2020, available at: <u>https://es.reuters.com/article/entertainmentNews/idESKBN22I0D4</u>

<sup>&</sup>lt;sup>81</sup> PI, *Country case-study: sexual and reproductive rights in India*, available at: <u>https://privacyinternational.org/long-read/3863/country-case-study-sexual-and-reproductive-rights-india</u>

<sup>&</sup>lt;sup>82</sup> Padma Bhate-Deosthali, & Sangeeta Rege, "Denial of safe abortion to survivors of rape in India", (2019) *Health and human rights, 21*(2), p. 189.